

WEBVTT

NOTE duration:"01:28:42"

NOTE recognizability:0.984

NOTE language:en-us

NOTE Confidence: 0.965131177241379

00:00:00.000 --> 00:00:00.936 Good evening friends.

NOTE Confidence: 0.965131177241379

00:00:00.936 --> 00:00:03.578 This is a this is the kickoff evening

NOTE Confidence: 0.965131177241379

00:00:03.578 --> 00:00:05.930 ethics seminar for the program for

NOTE Confidence: 0.965131177241379

00:00:05.930 --> 00:00:08.332 Biomedical Ethics and the Yale Pediatric

NOTE Confidence: 0.965131177241379

00:00:08.332 --> 00:00:10.660 Ethics program for this academic year.

NOTE Confidence: 0.965131177241379

00:00:10.660 --> 00:00:12.683 Hung those of you who have looked

NOTE Confidence: 0.965131177241379

00:00:12.683 --> 00:00:14.441 at the schedule online know that

NOTE Confidence: 0.965131177241379

00:00:14.441 --> 00:00:16.380 this was not the talk that was

NOTE Confidence: 0.965131177241379

00:00:16.442 --> 00:00:18.325 scheduled as of a few weeks ago.

NOTE Confidence: 0.965131177241379

00:00:18.330 --> 00:00:20.305 We've had a couple of

NOTE Confidence: 0.965131177241379

00:00:20.305 --> 00:00:21.885 cancellations in in September,

NOTE Confidence: 0.965131177241379

00:00:21.890 --> 00:00:22.676 some COVID related,

NOTE Confidence: 0.965131177241379

00:00:22.676 --> 00:00:24.248 and we're doing the best we

NOTE Confidence: 0.965131177241379

00:00:24.248 --> 00:00:25.547 can to respond to this.
NOTE Confidence: 0.965131177241379

00:00:25.550 --> 00:00:27.134 What we decided to do tonight was to
NOTE Confidence: 0.965131177241379

00:00:27.134 --> 00:00:28.895 address a very specific problem that's come
NOTE Confidence: 0.965131177241379

00:00:28.895 --> 00:00:30.690 up in the newborn intensive care unit.
NOTE Confidence: 0.965131177241379

00:00:30.690 --> 00:00:33.035 Here at Yale, and I think other
NOTE Confidence: 0.965131177241379

00:00:33.035 --> 00:00:34.970 places all over the country.
NOTE Confidence: 0.965131177241379

00:00:34.970 --> 00:00:37.553 And and and then we were able
NOTE Confidence: 0.965131177241379

00:00:37.553 --> 00:00:40.119 to assemble a wonderful panel.
NOTE Confidence: 0.965131177241379

00:00:40.120 --> 00:00:42.025 Dr Zespri loyal doctor Naomi
NOTE Confidence: 0.965131177241379

00:00:42.025 --> 00:00:43.930 Laventhol and attorney Jay Sicklick.
NOTE Confidence: 0.965131177241379

00:00:43.930 --> 00:00:45.938 And you'll hear briefly from each of them
NOTE Confidence: 0.965131177241379

00:00:45.938 --> 00:00:47.967 before we open this up for conversation.
NOTE Confidence: 0.965131177241379

00:00:47.970 --> 00:00:50.114 So I just want to let you know
NOTE Confidence: 0.965131177241379

00:00:50.114 --> 00:00:52.036 that our evening ethics seminars
NOTE Confidence: 0.965131177241379

00:00:52.036 --> 00:00:54.226 happen about twice a month.
NOTE Confidence: 0.965131177241379

00:00:54.230 --> 00:00:57.219 And this the schedule can be found

NOTE Confidence: 0.965131177241379
00:00:57.219 --> 00:00:59.015 at biomedical ethics at yale.edu.
NOTE Confidence: 0.965131177241379
00:00:59.015 --> 00:00:59.840 On our website,
NOTE Confidence: 0.965131177241379
00:00:59.840 --> 00:01:01.956 you can always reach out to me or
NOTE Confidence: 0.965131177241379
00:01:01.956 --> 00:01:03.804 to Karen Kolb, our program manager,
NOTE Confidence: 0.965131177241379
00:01:03.804 --> 00:01:05.028 with any questions.
NOTE Confidence: 0.965131177241379
00:01:05.030 --> 00:01:05.762 About these things,
NOTE Confidence: 0.965131177241379
00:01:05.762 --> 00:01:07.470 I'm delighted you're here with us tonight,
NOTE Confidence: 0.965131177241379
00:01:07.470 --> 00:01:10.430 and I think it's time for me to get started.
NOTE Confidence: 0.965131177241379
00:01:10.430 --> 00:01:12.187 So if I can share the screen,
NOTE Confidence: 0.965131177241379
00:01:12.190 --> 00:01:13.254 I'll begin the presentation.
NOTE Confidence: 0.965131177241379
00:01:13.254 --> 00:01:15.111 I'm going to talk for about 1/2
NOTE Confidence: 0.965131177241379
00:01:15.111 --> 00:01:16.743 hour or so and then we're going to
NOTE Confidence: 0.965131177241379
00:01:16.743 --> 00:01:18.516 hear for a few minutes from each
NOTE Confidence: 0.965131177241379
00:01:18.516 --> 00:01:19.864 of our esteemed panelists before
NOTE Confidence: 0.965131177241379
00:01:19.864 --> 00:01:21.868 we open it up for conversation.
NOTE Confidence: 0.965131177241379

00:01:21.870 --> 00:01:25.197 We will have a hard stop at 6:30.
NOTE Confidence: 0.965131177241379

00:01:25.197 --> 00:01:26.118 So, as always,
NOTE Confidence: 0.965131177241379

00:01:26.118 --> 00:01:28.295 I apologize to whoever was had a
NOTE Confidence: 0.965131177241379

00:01:28.295 --> 00:01:30.213 really good thing to say or question
NOTE Confidence: 0.965131177241379

00:01:30.213 --> 00:01:31.967 at 6:29 'cause we may not get to.
NOTE Confidence: 0.965131177241379

00:01:31.970 --> 00:01:34.168 Everybody will see how the conversation goes,
NOTE Confidence: 0.965131177241379

00:01:34.170 --> 00:01:35.180 but I know that the.
NOTE Confidence: 0.965131177241379

00:01:35.180 --> 00:01:36.388 Your time is valuable,
NOTE Confidence: 0.965131177241379

00:01:36.388 --> 00:01:38.550 and we're not going to keep you
NOTE Confidence: 0.965131177241379

00:01:38.550 --> 00:01:40.018 any later than 6:30. Alright.
NOTE Confidence: 0.965131177241379

00:01:40.018 --> 00:01:41.250 With that in mind,
NOTE Confidence: 0.965131177241379

00:01:41.250 --> 00:01:44.754 let's see if I can get this going.
NOTE Confidence: 0.965131177241379

00:01:44.760 --> 00:01:46.416 All right, are we looking at my slides here,
NOTE Confidence: 0.965131177241379

00:01:46.420 --> 00:01:49.020 uh? Sam, that's good, looks great.
NOTE Confidence: 0.968619277142857

00:01:51.940 --> 00:01:54.838 Here we go I already I'm a.
NOTE Confidence: 0.968619277142857

00:01:54.840 --> 00:01:56.536 There we go, getting calls from the ICU.

NOTE Confidence: 0.968619277142857
00:01:56.540 --> 00:01:58.395 OK, so tonight's presentation is
NOTE Confidence: 0.968619277142857
00:01:58.395 --> 00:02:00.250 on parental refusal of screening
NOTE Confidence: 0.968619277142857
00:02:00.315 --> 00:02:02.259 tests and preventative treatments.
NOTE Confidence: 0.968619277142857
00:02:02.260 --> 00:02:05.235 The search for a fair and coherent
NOTE Confidence: 0.968619277142857
00:02:05.235 --> 00:02:07.510 approach and where this comes from
NOTE Confidence: 0.968619277142857
00:02:07.510 --> 00:02:10.151 is we faced problems like this for
NOTE Confidence: 0.968619277142857
00:02:10.151 --> 00:02:12.643 many years in the world of Pediatrics
NOTE Confidence: 0.968619277142857
00:02:12.643 --> 00:02:14.889 in the world of neonatology.
NOTE Confidence: 0.968619277142857
00:02:14.890 --> 00:02:17.179 But recently we had a child who
NOTE Confidence: 0.968619277142857
00:02:17.179 --> 00:02:19.489 was expected to be born overnight,
NOTE Confidence: 0.968619277142857
00:02:19.490 --> 00:02:20.822 and it was anticipated for reasons
NOTE Confidence: 0.968619277142857
00:02:20.822 --> 00:02:22.159 I don't need to get into,
NOTE Confidence: 0.968619277142857
00:02:22.160 --> 00:02:25.324 that the child's mother was going to
NOTE Confidence: 0.968619277142857
00:02:25.324 --> 00:02:27.365 decline some treatments that we felt
NOTE Confidence: 0.968619277142857
00:02:27.365 --> 00:02:29.520 were indicated based on our protocols
NOTE Confidence: 0.968619277142857

00:02:29.520 --> 00:02:33.540 for prevention of early onset sepsis,
NOTE Confidence: 0.968619277142857

00:02:33.540 --> 00:02:34.548 and I'll get into that a
NOTE Confidence: 0.968619277142857

00:02:34.548 --> 00:02:35.220 little bit more detail.
NOTE Confidence: 0.968619277142857

00:02:35.220 --> 00:02:36.300 So the question was, well,
NOTE Confidence: 0.968619277142857

00:02:36.300 --> 00:02:38.295 what do we do if she refuses?
NOTE Confidence: 0.968619277142857

00:02:38.300 --> 00:02:40.262 Now we've had we've dealt with
NOTE Confidence: 0.968619277142857

00:02:40.262 --> 00:02:41.570 parent refusal and parenting
NOTE Confidence: 0.968619277142857

00:02:41.626 --> 00:02:42.810 assistance for many years,
NOTE Confidence: 0.968619277142857

00:02:42.810 --> 00:02:45.160 and I want to talk about an overall approach.
NOTE Confidence: 0.968619277142857

00:02:45.160 --> 00:02:46.852 To that and then suddenly apply
NOTE Confidence: 0.968619277142857

00:02:46.852 --> 00:02:48.433 that approach to this specific
NOTE Confidence: 0.968619277142857

00:02:48.433 --> 00:02:50.388 question about the screening tests.
NOTE Confidence: 0.989050581111111

00:02:53.880 --> 00:02:54.308 That's interesting,
NOTE Confidence: 0.989050581111111

00:02:54.308 --> 00:02:55.806 let's see how we can do here.
NOTE Confidence: 0.987530657142857

00:02:58.610 --> 00:03:00.577 There we go. OK, nothing to disclose,
NOTE Confidence: 0.987530657142857

00:03:00.580 --> 00:03:03.639 except that I steal pictures from Google.

NOTE Confidence: 0.987530657142857
00:03:03.640 --> 00:03:05.215 So let me begin with the story of Mr.
NOTE Confidence: 0.987530657142857
00:03:05.220 --> 00:03:06.108 Smith. Mrs.
NOTE Confidence: 0.987530657142857
00:03:06.108 --> 00:03:09.216 Smith teaches at the local middle school.
NOTE Confidence: 0.987530657142857
00:03:09.220 --> 00:03:10.030 Everybody knows Mr.
NOTE Confidence: 0.987530657142857
00:03:10.030 --> 00:03:11.380 Smith, she's a smart woman.
NOTE Confidence: 0.987530657142857
00:03:11.380 --> 00:03:14.134 She's a nice woman and she's 28 years old,
NOTE Confidence: 0.987530657142857
00:03:14.140 --> 00:03:15.939 middle school teacher and one day she
NOTE Confidence: 0.987530657142857
00:03:15.939 --> 00:03:17.976 gets uh, brought into the emergency
NOTE Confidence: 0.987530657142857
00:03:17.976 --> 00:03:19.492 department by ambulance because
NOTE Confidence: 0.987530657142857
00:03:19.492 --> 00:03:21.810 she was in an automobile accident.
NOTE Confidence: 0.987530657142857
00:03:21.810 --> 00:03:25.780 And the physicians in the ambulance say,
NOTE Confidence: 0.987530657142857
00:03:25.780 --> 00:03:26.962 should be the physicians in the
NOTE Confidence: 0.987530657142857
00:03:26.962 --> 00:03:27.790 emergency department. Say. Mr.
NOTE Confidence: 0.987530657142857
00:03:27.790 --> 00:03:29.510 Smith, you know you're in a car accident,
NOTE Confidence: 0.987530657142857
00:03:29.510 --> 00:03:30.300 she said, yes, I know,
NOTE Confidence: 0.987530657142857

00:03:30.300 --> 00:03:31.660 and they say we have to take it
NOTE Confidence: 0.987530657142857

00:03:31.660 --> 00:03:33.057 to the operating room right away
NOTE Confidence: 0.987530657142857

00:03:33.057 --> 00:03:34.563 to take care of your injuries.
NOTE Confidence: 0.987530657142857

00:03:34.570 --> 00:03:36.972 She says, OK, let's go, and they say,
NOTE Confidence: 0.987530657142857

00:03:36.972 --> 00:03:39.300 well, also, we have to transfuse you.
NOTE Confidence: 0.987530657142857

00:03:39.300 --> 00:03:40.798 We have to give you some blood.
NOTE Confidence: 0.987530657142857

00:03:40.800 --> 00:03:42.500 And she says, absolutely not,
NOTE Confidence: 0.987530657142857

00:03:42.500 --> 00:03:43.310 and they say, but Mr.
NOTE Confidence: 0.987530657142857

00:03:43.310 --> 00:03:44.518 Smith, if we don't give you the blood,
NOTE Confidence: 0.987530657142857

00:03:44.520 --> 00:03:45.048 you could die.
NOTE Confidence: 0.987530657142857

00:03:45.048 --> 00:03:46.510 In fact, we think you probably will
NOTE Confidence: 0.987530657142857

00:03:46.510 --> 00:03:48.150 die if you don't get the blood.
NOTE Confidence: 0.987530657142857

00:03:48.150 --> 00:03:49.698 And she says, I understand that,
NOTE Confidence: 0.987530657142857

00:03:49.700 --> 00:03:51.293 but I would rather die than get the blood,
NOTE Confidence: 0.987530657142857

00:03:51.300 --> 00:03:52.144 because I think it's.
NOTE Confidence: 0.987530657142857

00:03:52.144 --> 00:03:52.777 Offensive to God.

NOTE Confidence: 0.987530657142857

00:03:52.780 --> 00:03:54.100 It's against my religion.

NOTE Confidence: 0.987530657142857

00:03:54.100 --> 00:03:55.750 I don't want the blood.

NOTE Confidence: 0.987530657142857

00:03:55.750 --> 00:03:57.220 Now, assuming for the sake

NOTE Confidence: 0.987530657142857

00:03:57.220 --> 00:03:58.690 of this discussion that Mrs.

NOTE Confidence: 0.987530657142857

00:03:58.690 --> 00:04:02.418 Smith is felt to be of sound mind.

NOTE Confidence: 0.987530657142857

00:04:02.420 --> 00:04:03.539 That that Mrs.

NOTE Confidence: 0.987530657142857

00:04:03.539 --> 00:04:05.777 Smith's refusal as I think pretty

NOTE Confidence: 0.987530657142857

00:04:05.777 --> 00:04:07.762 much every American physician

NOTE Confidence: 0.987530657142857

00:04:07.762 --> 00:04:10.317 knows Mrs Smith's refusal stands.

NOTE Confidence: 0.987530657142857

00:04:10.320 --> 00:04:11.944 She has a right to refuse treatment,

NOTE Confidence: 0.987530657142857

00:04:11.950 --> 00:04:14.800 even lifesaving treatment.

NOTE Confidence: 0.987530657142857

00:04:14.800 --> 00:04:17.400 And you know the old story was that

NOTE Confidence: 0.987530657142857

00:04:17.400 --> 00:04:19.678 if Jehovah's Witnesses didn't exist,

NOTE Confidence: 0.987530657142857

00:04:19.680 --> 00:04:21.515 then by witnesses probably would

NOTE Confidence: 0.987530657142857

00:04:21.515 --> 00:04:23.825 have invented them for the purpose

NOTE Confidence: 0.987530657142857

00:04:23.825 --> 00:04:25.040 of their lectures.
NOTE Confidence: 0.987530657142857

00:04:25.040 --> 00:04:27.822 So that may well be the point being,
NOTE Confidence: 0.987530657142857

00:04:27.822 --> 00:04:30.126 it's an exercise in recognizing that
NOTE Confidence: 0.987530657142857

00:04:30.126 --> 00:04:32.059 patient autonomy of patients right
NOTE Confidence: 0.987530657142857

00:04:32.059 --> 00:04:34.794 to bodily integrity is such that the
NOTE Confidence: 0.987530657142857

00:04:34.794 --> 00:04:37.434 patient can refuse even lifesaving treatment,
NOTE Confidence: 0.987530657142857

00:04:37.440 --> 00:04:38.720 and this, by the way,
NOTE Confidence: 0.987530657142857

00:04:38.720 --> 00:04:41.324 is why pediatric ethics is harder
NOTE Confidence: 0.987530657142857

00:04:41.324 --> 00:04:43.434 than adult ethics, because of course,
NOTE Confidence: 0.987530657142857

00:04:43.434 --> 00:04:44.774 just a few minutes later,
NOTE Confidence: 0.987530657142857

00:04:44.780 --> 00:04:46.200 another ambulance pulled up
NOTE Confidence: 0.987530657142857

00:04:46.200 --> 00:04:47.975 and the stretcher comes out.
NOTE Confidence: 0.987530657142857

00:04:47.980 --> 00:04:48.960 And who's on the ambulance?
NOTE Confidence: 0.987530657142857

00:04:48.960 --> 00:04:50.460 02 year old Boy, it's Jr.
NOTE Confidence: 0.987530657142857

00:04:50.460 --> 00:04:52.170 Smith and they say to Mrs.
NOTE Confidence: 0.987530657142857

00:04:52.170 --> 00:04:53.714 Smith look. It's Jr. Smith, your son.

NOTE Confidence: 0.987530657142857
00:04:53.714 --> 00:04:55.360 She says, I know he was in the car.
NOTE Confidence: 0.987530657142857
00:04:55.360 --> 00:04:56.946 With me and they said well, Mr.
NOTE Confidence: 0.987530657142857
00:04:56.946 --> 00:04:58.376 Smith. He's had internal injuries.
NOTE Confidence: 0.987530657142857
00:04:58.380 --> 00:05:00.260 He needs to go to the operating room
NOTE Confidence: 0.987530657142857
00:05:00.260 --> 00:05:03.298 right away and she says OK, go miss and Mrs.
NOTE Confidence: 0.987530657142857
00:05:03.300 --> 00:05:03.489 Smith.
NOTE Confidence: 0.987530657142857
00:05:03.489 --> 00:05:04.623 We have to transfuse him were
NOTE Confidence: 0.987530657142857
00:05:04.623 --> 00:05:06.000 afraid if we don't transfuse him,
NOTE Confidence: 0.987530657142857
00:05:06.000 --> 00:05:07.372 he's going to die.
NOTE Confidence: 0.987530657142857
00:05:07.372 --> 00:05:10.340 And she says absolutely not no transfusion.
NOTE Confidence: 0.987530657142857
00:05:10.340 --> 00:05:13.116 Now I think every pediatrician on the call,
NOTE Confidence: 0.987530657142857
00:05:13.120 --> 00:05:14.338 and I suspect a lot of other
NOTE Confidence: 0.987530657142857
00:05:14.338 --> 00:05:15.110 people on the call,
NOTE Confidence: 0.987530657142857
00:05:15.110 --> 00:05:16.726 also recognize that this
NOTE Confidence: 0.987530657142857
00:05:16.726 --> 00:05:17.938 is somehow different.
NOTE Confidence: 0.987530657142857

00:05:17.940 --> 00:05:18.268 Mrs.
NOTE Confidence: 0.987530657142857

00:05:18.268 --> 00:05:20.236 Smith could refuse her own transfusion,
NOTE Confidence: 0.987530657142857

00:05:20.240 --> 00:05:21.712 even if it's lifesaving,
NOTE Confidence: 0.987530657142857

00:05:21.712 --> 00:05:23.184 but she couldn't necessarily
NOTE Confidence: 0.987530657142857

00:05:23.184 --> 00:05:25.367 refuse the transfusion for her son.
NOTE Confidence: 0.987530657142857

00:05:25.370 --> 00:05:26.560 And it's a fascinating question
NOTE Confidence: 0.987530657142857

00:05:26.560 --> 00:05:27.930 as to why that should be.
NOTE Confidence: 0.987530657142857

00:05:27.930 --> 00:05:29.715 So we say that she can refuse
NOTE Confidence: 0.987530657142857

00:05:29.715 --> 00:05:30.480 based on our
NOTE Confidence: 0.9897391353333333

00:05:30.543 --> 00:05:32.668 obligation to respect her autonomy.
NOTE Confidence: 0.9897391353333333

00:05:32.670 --> 00:05:34.110 The patient autonomy,
NOTE Confidence: 0.9897391353333333

00:05:34.110 --> 00:05:36.510 which literally means self rule.
NOTE Confidence: 0.9897391353333333

00:05:36.510 --> 00:05:39.128 Now some folks refer to parental autonomy,
NOTE Confidence: 0.9897391353333333

00:05:39.130 --> 00:05:41.236 but I would suggest it's parental
NOTE Confidence: 0.9897391353333333

00:05:41.236 --> 00:05:43.020 autonomy is a nonsense term.
NOTE Confidence: 0.9897391353333333

00:05:43.020 --> 00:05:44.376 Autonomy means self rule.

NOTE Confidence: 0.989739135333333
00:05:44.376 --> 00:05:46.071 You can't really have self
NOTE Confidence: 0.989739135333333
00:05:46.071 --> 00:05:47.548 rule over someone else.
NOTE Confidence: 0.989739135333333
00:05:47.550 --> 00:05:50.238 I don't think there's such a thing as
NOTE Confidence: 0.989739135333333
00:05:50.238 --> 00:05:52.392 parental autonomy so much as parental
NOTE Confidence: 0.989739135333333
00:05:52.392 --> 00:05:53.802 authority and the parental authority,
NOTE Confidence: 0.989739135333333
00:05:53.802 --> 00:05:55.428 of course, is very strong.
NOTE Confidence: 0.989739135333333
00:05:55.428 --> 00:05:57.258 But perhaps not as strong.
NOTE Confidence: 0.989739135333333
00:05:57.260 --> 00:06:00.067 Definitely not as strong as patient autonomy,
NOTE Confidence: 0.989739135333333
00:06:00.070 --> 00:06:01.126 as illustrated by the
NOTE Confidence: 0.989739135333333
00:06:01.126 --> 00:06:02.446 very extreme case of Mrs.
NOTE Confidence: 0.989739135333333
00:06:02.450 --> 00:06:03.550 Smith and Jr. Smith.
NOTE Confidence: 0.989739135333333
00:06:03.550 --> 00:06:05.980 She has a right to refuse for herself,
NOTE Confidence: 0.989739135333333
00:06:05.980 --> 00:06:08.269 but we would say that she doesn't
NOTE Confidence: 0.989739135333333
00:06:08.269 --> 00:06:10.889 have a right to refuse for her son.
NOTE Confidence: 0.989739135333333
00:06:10.890 --> 00:06:12.154 She is, of course,
NOTE Confidence: 0.989739135333333

00:06:12.154 --> 00:06:13.418 the surrogate decision maker
NOTE Confidence: 0.9897391353333333

00:06:13.418 --> 00:06:14.690 in this situation,
NOTE Confidence: 0.9897391353333333

00:06:14.690 --> 00:06:16.472 and whenever someone is not capable
NOTE Confidence: 0.9897391353333333

00:06:16.472 --> 00:06:17.660 of deciding for themselves,
NOTE Confidence: 0.9897391353333333

00:06:17.660 --> 00:06:19.330 we seek a surrogate decision
NOTE Confidence: 0.9897391353333333

00:06:19.330 --> 00:06:21.000 maker who decides for them.
NOTE Confidence: 0.9897391353333333

00:06:21.000 --> 00:06:23.296 This is commonly a member of the family,
NOTE Confidence: 0.9897391353333333

00:06:23.300 --> 00:06:25.799 a spouse and adult son or daughter.
NOTE Confidence: 0.9897391353333333

00:06:25.800 --> 00:06:27.200 In the case of adults,
NOTE Confidence: 0.9897391353333333

00:06:27.200 --> 00:06:28.340 and in the case of children,
NOTE Confidence: 0.9897391353333333

00:06:28.340 --> 00:06:30.452 it's usually the parents or one
NOTE Confidence: 0.9897391353333333

00:06:30.452 --> 00:06:32.850 of the parents are both parents.
NOTE Confidence: 0.9897391353333333

00:06:32.850 --> 00:06:34.698 And of course with all small children
NOTE Confidence: 0.9897391353333333

00:06:34.698 --> 00:06:36.580 like Jr Smith and all the newborns
NOTE Confidence: 0.9897391353333333

00:06:36.580 --> 00:06:38.600 that we're here to talk about tonight.
NOTE Confidence: 0.9897391353333333

00:06:38.600 --> 00:06:40.865 These people these kids can't

NOTE Confidence: 0.989739135333333
00:06:40.865 --> 00:06:42.224 speak for themselves.
NOTE Confidence: 0.989739135333333
00:06:42.230 --> 00:06:43.742 So in medical ethics,
NOTE Confidence: 0.989739135333333
00:06:43.742 --> 00:06:45.254 when a surrogate decision
NOTE Confidence: 0.989739135333333
00:06:45.254 --> 00:06:46.749 maker has to decide,
NOTE Confidence: 0.989739135333333
00:06:46.750 --> 00:06:48.920 we suggest that the surrogate decision maker
NOTE Confidence: 0.989739135333333
00:06:48.920 --> 00:06:51.314 I brought you a little bit of New Haven
NOTE Confidence: 0.989739135333333
00:06:51.314 --> 00:06:53.540 music here just to add to the flair of it,
NOTE Confidence: 0.989739135333333
00:06:53.540 --> 00:06:56.258 we suggest that.
NOTE Confidence: 0.989739135333333
00:06:56.260 --> 00:06:56.920 The surge,
NOTE Confidence: 0.989739135333333
00:06:56.920 --> 00:06:58.900 its surrogate decision maker should decide,
NOTE Confidence: 0.989739135333333
00:06:58.900 --> 00:07:00.398 not because what they think is best,
NOTE Confidence: 0.989739135333333
00:07:00.400 --> 00:07:01.840 what they want for themselves,
NOTE Confidence: 0.989739135333333
00:07:01.840 --> 00:07:03.732 but by substituted judgment,
NOTE Confidence: 0.989739135333333
00:07:03.732 --> 00:07:04.678 which is,
NOTE Confidence: 0.989739135333333
00:07:04.680 --> 00:07:06.726 if I'm deciding for my father,
NOTE Confidence: 0.989739135333333

00:07:06.730 --> 00:07:08.917 what would dad have wanted to do in this
NOTE Confidence: 0.9897391353333333

00:07:08.917 --> 00:07:10.717 situation based on my best understanding.
NOTE Confidence: 0.9897391353333333

00:07:10.720 --> 00:07:12.580 Maybe even left me written instructions,
NOTE Confidence: 0.9897391353333333

00:07:12.580 --> 00:07:13.996 but based on my best understanding,
NOTE Confidence: 0.9897391353333333

00:07:14.000 --> 00:07:17.018 what would dad want me to do here now in the
NOTE Confidence: 0.9897391353333333

00:07:17.018 --> 00:07:18.719 case of little kids in the case of babies,
NOTE Confidence: 0.9897391353333333

00:07:18.720 --> 00:07:20.380 we can't use substituted judgment.
NOTE Confidence: 0.9897391353333333

00:07:20.380 --> 00:07:21.406 They've never formed
NOTE Confidence: 0.9897391353333333

00:07:21.406 --> 00:07:22.774 opinions on these matters.
NOTE Confidence: 0.9897391353333333

00:07:22.780 --> 00:07:23.194 Consequently,
NOTE Confidence: 0.9897391353333333

00:07:23.194 --> 00:07:25.678 we fall to a different standard,
NOTE Confidence: 0.9897391353333333

00:07:25.680 --> 00:07:26.776 which is the patients.
NOTE Confidence: 0.9897391353333333

00:07:26.776 --> 00:07:27.598 Best interest standard,
NOTE Confidence: 0.9897391353333333

00:07:27.600 --> 00:07:29.330 which is what is commonly
NOTE Confidence: 0.9897391353333333

00:07:29.330 --> 00:07:30.368 invoked in Pediatrics,
NOTE Confidence: 0.9897391353333333

00:07:30.370 --> 00:07:31.602 and this specifically refers

NOTE Confidence: 0.989739135333333
00:07:31.602 --> 00:07:33.142 to our obligation to choose
NOTE Confidence: 0.989739135333333
00:07:33.142 --> 00:07:34.869 or the surrogates obligation.
NOTE Confidence: 0.989739135333333
00:07:34.870 --> 00:07:37.878 I should say to choose based on the
NOTE Confidence: 0.989739135333333
00:07:37.880 --> 00:07:39.785 patient's best interest simply to
NOTE Confidence: 0.989739135333333
00:07:39.785 --> 00:07:42.338 weigh the benefits of the proposed
NOTE Confidence: 0.989739135333333
00:07:42.338 --> 00:07:44.340 treatment against the burdens or
NOTE Confidence: 0.989739135333333
00:07:44.340 --> 00:07:46.115 risk of the proposed treatment,
NOTE Confidence: 0.989739135333333
00:07:46.120 --> 00:07:47.492 and then choose based on that whether
NOTE Confidence: 0.989739135333333
00:07:47.492 --> 00:07:49.109 or not it's in the patient's best
NOTE Confidence: 0.989739135333333
00:07:49.109 --> 00:07:50.579 interest to get the proposed treatment.
NOTE Confidence: 0.989739135333333
00:07:50.580 --> 00:07:52.806 And that's how we like the
NOTE Confidence: 0.989739135333333
00:07:52.806 --> 00:07:54.850 surrogate decision maker to decide.
NOTE Confidence: 0.989739135333333
00:07:54.850 --> 00:07:55.684 But in truth,
NOTE Confidence: 0.989739135333333
00:07:55.684 --> 00:07:57.352 that's not exactly how it works.
NOTE Confidence: 0.989739135333333
00:07:57.360 --> 00:08:00.207 In Pediatrics and it was now almost two
NOTE Confidence: 0.989739135333333

00:08:00.207 --> 00:08:02.300 decades ago that my friend Doug Diekema,
NOTE Confidence: 0.9897391353333333

00:08:02.300 --> 00:08:05.168 well known voice in pediatric ethics,
NOTE Confidence: 0.9897391353333333

00:08:05.170 --> 00:08:06.031 articulated something he
NOTE Confidence: 0.9897391353333333

00:08:06.031 --> 00:08:07.179 called the harm principle,
NOTE Confidence: 0.9897391353333333

00:08:07.180 --> 00:08:08.796 and for those of you who studied philosophy,
NOTE Confidence: 0.9897391353333333

00:08:08.800 --> 00:08:09.750 this is something a little
NOTE Confidence: 0.9897391353333333

00:08:09.750 --> 00:08:10.700 bit different than the harm
NOTE Confidence: 0.9897391353333333

00:08:10.735 --> 00:08:11.578 principle in philosophy.
NOTE Confidence: 0.9897391353333333

00:08:11.580 --> 00:08:13.518 But what what he said was
NOTE Confidence: 0.9897391353333333

00:08:13.518 --> 00:08:14.810 that actually we don't
NOTE Confidence: 0.9868345255

00:08:14.884 --> 00:08:17.712 require parents to choose what's in a
NOTE Confidence: 0.9868345255

00:08:17.712 --> 00:08:20.446 child's best interest, as long as they
NOTE Confidence: 0.9868345255

00:08:20.446 --> 00:08:22.720 stay above some threshold of harm.
NOTE Confidence: 0.9868345255

00:08:22.720 --> 00:08:25.120 So, for example, let's say that a family
NOTE Confidence: 0.9868345255

00:08:25.120 --> 00:08:27.568 lives in a town that has a really bad.
NOTE Confidence: 0.9868345255

00:08:27.570 --> 00:08:29.045 Public school and a really

NOTE Confidence: 0.9868345255

00:08:29.045 --> 00:08:29.930 good private school.

NOTE Confidence: 0.9868345255

00:08:29.930 --> 00:08:30.617 Bye everybody's measure.

NOTE Confidence: 0.9868345255

00:08:30.617 --> 00:08:32.220 The public school is bad enough for

NOTE Confidence: 0.9868345255

00:08:32.264 --> 00:08:33.446 all the reasons you can decide.

NOTE Confidence: 0.9868345255

00:08:33.450 --> 00:08:35.058 And the private school is really

NOTE Confidence: 0.9868345255

00:08:35.058 --> 00:08:37.152 good and no one would argue that

NOTE Confidence: 0.9868345255

00:08:37.152 --> 00:08:38.757 it that everyone would agree.

NOTE Confidence: 0.9868345255

00:08:38.760 --> 00:08:39.999 It's in the child's best interest to

NOTE Confidence: 0.9868345255

00:08:39.999 --> 00:08:41.764 go to that private school, for example.

NOTE Confidence: 0.9868345255

00:08:41.764 --> 00:08:44.510 But and the parents have the money for it.

NOTE Confidence: 0.9868345255

00:08:44.510 --> 00:08:44.828 Nevertheless,

NOTE Confidence: 0.9868345255

00:08:44.828 --> 00:08:47.054 we don't require the parents to send

NOTE Confidence: 0.9868345255

00:08:47.054 --> 00:08:48.928 their child to that private school,

NOTE Confidence: 0.9868345255

00:08:48.930 --> 00:08:51.189 even if by their lights and by our lights.

NOTE Confidence: 0.9868345255

00:08:51.190 --> 00:08:52.989 That's what's in the child's best interest.

NOTE Confidence: 0.9868345255

00:08:52.990 --> 00:08:53.890 We say, no, you can.
NOTE Confidence: 0.9868345255

00:08:53.890 --> 00:08:56.104 You can send the child to the public school.
NOTE Confidence: 0.9868345255

00:08:56.110 --> 00:08:57.838 You can send the child to another school.
NOTE Confidence: 0.9868345255

00:08:57.840 --> 00:09:00.000 You could even homeschool this child.
NOTE Confidence: 0.9868345255

00:09:00.000 --> 00:09:00.960 And then if the parents say,
NOTE Confidence: 0.9868345255

00:09:00.960 --> 00:09:01.975 well, we're going to do is just
NOTE Confidence: 0.9868345255

00:09:01.975 --> 00:09:02.570 not schooling at all.
NOTE Confidence: 0.9868345255

00:09:02.570 --> 00:09:04.310 We're gonna let him watch television,
NOTE Confidence: 0.9868345255

00:09:04.310 --> 00:09:06.421 and then we'd say, well, hang on now,
NOTE Confidence: 0.9868345255

00:09:06.421 --> 00:09:08.570 you've fallen below some threshold to farm.
NOTE Confidence: 0.9868345255

00:09:08.570 --> 00:09:09.380 So now indeed,
NOTE Confidence: 0.9868345255

00:09:09.380 --> 00:09:11.540 if this child is getting no education now,
NOTE Confidence: 0.9868345255

00:09:11.540 --> 00:09:13.310 the state will step in.
NOTE Confidence: 0.9868345255

00:09:13.310 --> 00:09:15.116 So it's not exactly about the
NOTE Confidence: 0.9868345255

00:09:15.116 --> 00:09:16.398 patients best interest, really,
NOTE Confidence: 0.9868345255

00:09:16.398 --> 00:09:18.288 but it's about staying above

NOTE Confidence: 0.9868345255

00:09:18.288 --> 00:09:19.800 that threshold of harm.

NOTE Confidence: 0.9868345255

00:09:19.800 --> 00:09:21.739 As long as the service decide above

NOTE Confidence: 0.9868345255

00:09:21.739 --> 00:09:22.920 the threshold, the farm, and of course,

NOTE Confidence: 0.9868345255

00:09:22.920 --> 00:09:25.200 that's a very subjective judgment,

NOTE Confidence: 0.9868345255

00:09:25.200 --> 00:09:25.370 right?

NOTE Confidence: 0.9868345255

00:09:25.370 --> 00:09:26.730 But if it's a little bit like this,

NOTE Confidence: 0.9868345255

00:09:26.730 --> 00:09:28.500 and the parents choose something that's

NOTE Confidence: 0.9868345255

00:09:28.500 --> 00:09:30.260 not quite what's best in general.

NOTE Confidence: 0.9868345255

00:09:30.260 --> 00:09:32.180 We tend to respect that.

NOTE Confidence: 0.9868345255

00:09:32.180 --> 00:09:34.756 Until we get to that threshold of harm.

NOTE Confidence: 0.9868345255

00:09:34.760 --> 00:09:36.884 So what's our role in all this as clinicians?

NOTE Confidence: 0.9868345255

00:09:36.890 --> 00:09:37.128 Well,

NOTE Confidence: 0.9868345255

00:09:37.128 --> 00:09:38.556 the first thing I would suggest

NOTE Confidence: 0.9868345255

00:09:38.556 --> 00:09:39.970 is that we're moral agents was

NOTE Confidence: 0.9868345255

00:09:39.970 --> 00:09:41.782 just to say that we should be able

NOTE Confidence: 0.9868345255

00:09:41.782 --> 00:09:43.067 to discern right from wrong,
NOTE Confidence: 0.9868345255

00:09:43.070 --> 00:09:44.520 and that's not so easy.
NOTE Confidence: 0.9868345255

00:09:44.520 --> 00:09:46.218 But that's part of our job,
NOTE Confidence: 0.9868345255

00:09:46.220 --> 00:09:48.956 and we're responsible for our actions.
NOTE Confidence: 0.9868345255

00:09:48.960 --> 00:09:50.640 So what happens in that hospital?
NOTE Confidence: 0.9868345255

00:09:50.640 --> 00:09:52.090 What happens in that nursery?
NOTE Confidence: 0.9868345255

00:09:52.090 --> 00:09:54.070 What happens in that newborn
NOTE Confidence: 0.9868345255

00:09:54.070 --> 00:09:55.654 ICU under our direction?
NOTE Confidence: 0.9868345255

00:09:55.660 --> 00:09:57.750 And we're responsible for that.
NOTE Confidence: 0.9868345255

00:09:57.750 --> 00:10:00.081 And if we say that parental authority
NOTE Confidence: 0.9868345255

00:10:00.081 --> 00:10:02.550 is not quite as strong as patient.
NOTE Confidence: 0.9868345255

00:10:02.550 --> 00:10:05.616 Autonomy that it does have limits.
NOTE Confidence: 0.9868345255

00:10:05.620 --> 00:10:07.414 Then the rule of the clinician
NOTE Confidence: 0.9868345255

00:10:07.414 --> 00:10:10.008 to a great extent is to find the
NOTE Confidence: 0.9868345255

00:10:10.008 --> 00:10:11.344 limit of parental authority.
NOTE Confidence: 0.9868345255

00:10:11.350 --> 00:10:13.170 Where exactly does it?

NOTE Confidence: 0.9868345255

00:10:13.170 --> 00:10:15.445 Does the parents reach that

NOTE Confidence: 0.9868345255

00:10:15.445 --> 00:10:16.590 threshold of harm?

NOTE Confidence: 0.9868345255

00:10:16.590 --> 00:10:17.326 Where we say no,

NOTE Confidence: 0.9868345255

00:10:17.326 --> 00:10:18.864 we're not just going to do what you

NOTE Confidence: 0.9868345255

00:10:18.864 --> 00:10:20.229 want us to do in this situation.

NOTE Confidence: 0.9868345255

00:10:20.230 --> 00:10:22.550 There's a couple of nice

NOTE Confidence: 0.9868345255

00:10:22.550 --> 00:10:23.874 important landmarks on this.

NOTE Confidence: 0.9868345255

00:10:23.874 --> 00:10:25.529 There was a Supreme Court

NOTE Confidence: 0.9868345255

00:10:25.529 --> 00:10:27.056 case in 1947 or 1948.

NOTE Confidence: 0.9868345255

00:10:27.056 --> 00:10:29.108 It wasn't actually about health care,

NOTE Confidence: 0.9868345255

00:10:29.110 --> 00:10:31.158 but that comments from it and Prince V.

NOTE Confidence: 0.9868345255

00:10:31.160 --> 00:10:32.006 Commonwealth of Massachusetts.

NOTE Confidence: 0.9868345255

00:10:32.006 --> 00:10:33.698 Related to the fact that parents

NOTE Confidence: 0.9868345255

00:10:33.698 --> 00:10:35.019 have a right to make martyrs,

NOTE Confidence: 0.9868345255

00:10:35.020 --> 00:10:35.821 martyrs of themselves,

NOTE Confidence: 0.9868345255

00:10:35.821 --> 00:10:37.423 but that doesn't mean they have
NOTE Confidence: 0.9868345255

00:10:37.423 --> 00:10:39.568 a right to make martyrs of their
NOTE Confidence: 0.9868345255

00:10:39.568 --> 00:10:40.788 children in similar circumstances
NOTE Confidence: 0.985800735666667

00:10:40.838 --> 00:10:42.854 until such time as a child reaches an age
NOTE Confidence: 0.985800735666667

00:10:42.854 --> 00:10:45.754 where he or she can decide for themselves.
NOTE Confidence: 0.985800735666667

00:10:45.760 --> 00:10:47.904 And that's of course related to the Jr.
NOTE Confidence: 0.985800735666667

00:10:47.910 --> 00:10:50.398 Smith case. If you'd like the American
NOTE Confidence: 0.985800735666667

00:10:50.398 --> 00:10:52.393 Academy of Pediatrics Committee on
NOTE Confidence: 0.985800735666667

00:10:52.393 --> 00:10:54.747 Bioethics now more than 20 years ago,
NOTE Confidence: 0.985800735666667

00:10:54.750 --> 00:10:56.046 had a lovely policy which has
NOTE Confidence: 0.985800735666667

00:10:56.046 --> 00:10:57.460 since been updated in the wording,
NOTE Confidence: 0.985800735666667

00:10:57.460 --> 00:11:00.386 got lost, but the AP policy stated
NOTE Confidence: 0.985800735666667

00:11:00.386 --> 00:11:02.809 that we believe all children.
NOTE Confidence: 0.985800735666667

00:11:02.810 --> 00:11:05.010 Are entitled to treatment likely
NOTE Confidence: 0.985800735666667

00:11:05.010 --> 00:11:06.770 to prevent significant harm,
NOTE Confidence: 0.985800735666667

00:11:06.770 --> 00:11:07.823 suffering or death,

NOTE Confidence: 0.985800735666667
00:11:07.823 --> 00:11:10.719 and I think every word in that in
NOTE Confidence: 0.985800735666667
00:11:10.719 --> 00:11:12.885 that in that phrase is important,
NOTE Confidence: 0.985800735666667
00:11:12.890 --> 00:11:15.070 likely to prevent significant harm,
NOTE Confidence: 0.985800735666667
00:11:15.070 --> 00:11:16.174 suffering, or death.
NOTE Confidence: 0.985800735666667
00:11:16.174 --> 00:11:18.382 These may be ways that particular
NOTE Confidence: 0.985800735666667
00:11:18.382 --> 00:11:19.775 term from the AP, especially,
NOTE Confidence: 0.985800735666667
00:11:19.775 --> 00:11:21.620 may be a way for us to help get
NOTE Confidence: 0.985800735666667
00:11:21.677 --> 00:11:23.553 a handle on what the limits of
NOTE Confidence: 0.985800735666667
00:11:23.553 --> 00:11:24.550 parental authority should be.
NOTE Confidence: 0.985800735666667
00:11:24.550 --> 00:11:25.756 Now we believe,
NOTE Confidence: 0.985800735666667
00:11:25.756 --> 00:11:28.168 as pediatricians and shared decision making.
NOTE Confidence: 0.985800735666667
00:11:28.170 --> 00:11:29.330 This is how we like to do it.
NOTE Confidence: 0.985800735666667
00:11:29.330 --> 00:11:30.919 We like to work with the parents
NOTE Confidence: 0.985800735666667
00:11:30.919 --> 00:11:32.589 and reach a decision together.
NOTE Confidence: 0.985800735666667
00:11:32.590 --> 00:11:33.346 That's our approach.
NOTE Confidence: 0.985800735666667

00:11:33.346 --> 00:11:35.500 I wanna make that clear from the outset,
NOTE Confidence: 0.985800735666667

00:11:35.500 --> 00:11:37.090 but there are some things that
NOTE Confidence: 0.985800735666667

00:11:37.090 --> 00:11:38.947 we're going to feel we have to do.
NOTE Confidence: 0.985800735666667

00:11:38.950 --> 00:11:40.756 Even if the parents don't want
NOTE Confidence: 0.985800735666667

00:11:40.756 --> 00:11:42.210 to or we shouldn't do,
NOTE Confidence: 0.985800735666667

00:11:42.210 --> 00:11:44.009 we will not do even if the
NOTE Confidence: 0.985800735666667

00:11:44.009 --> 00:11:45.547 parents will want us to do it.
NOTE Confidence: 0.985800735666667

00:11:45.550 --> 00:11:47.350 So we have to decide when that is.
NOTE Confidence: 0.985800735666667

00:11:47.350 --> 00:11:49.080 How do we decide that?
NOTE Confidence: 0.985800735666667

00:11:49.080 --> 00:11:50.832 And often how we decide anything
NOTE Confidence: 0.985800735666667

00:11:50.832 --> 00:11:52.674 in medicine is the standard of
NOTE Confidence: 0.985800735666667

00:11:52.674 --> 00:11:54.210 care and the standard of care can
NOTE Confidence: 0.985800735666667

00:11:54.210 --> 00:11:55.770 be defined a few different ways.
NOTE Confidence: 0.985800735666667

00:11:55.770 --> 00:11:57.485 It can just be with most reasonable
NOTE Confidence: 0.985800735666667

00:11:57.485 --> 00:11:59.208 physicians would do in this circumstance.
NOTE Confidence: 0.985800735666667

00:11:59.210 --> 00:12:00.503 With professional organizations,

NOTE Confidence: 0.985800735666667
00:12:00.503 --> 00:12:02.227 recommend what's commonly done
NOTE Confidence: 0.985800735666667
00:12:02.227 --> 00:12:03.520 in your community.
NOTE Confidence: 0.985800735666667
00:12:03.520 --> 00:12:04.940 There are different standards.
NOTE Confidence: 0.985800735666667
00:12:04.940 --> 00:12:06.906 Of care but and I don't want to get into
NOTE Confidence: 0.985800735666667
00:12:06.906 --> 00:12:08.276 the legal aspect of standard of care.
NOTE Confidence: 0.985800735666667
00:12:08.280 --> 00:12:11.920 All except to say this that with
NOTE Confidence: 0.985800735666667
00:12:11.920 --> 00:12:14.400 regard to standard of care.
NOTE Confidence: 0.985800735666667
00:12:14.400 --> 00:12:16.563 I think that our obligation to adhere
NOTE Confidence: 0.985800735666667
00:12:16.563 --> 00:12:19.140 to a standard of care on a scientific
NOTE Confidence: 0.985800735666667
00:12:19.140 --> 00:12:21.509 question and this analogy is not perfect,
NOTE Confidence: 0.985800735666667
00:12:21.510 --> 00:12:23.632 but I think it's helpful on a
NOTE Confidence: 0.985800735666667
00:12:23.632 --> 00:12:25.056 scientific question which antibiotic
NOTE Confidence: 0.985800735666667
00:12:25.056 --> 00:12:27.749 is should be used for which infection.
NOTE Confidence: 0.985800735666667
00:12:27.750 --> 00:12:29.885 I think if there's a standard of
NOTE Confidence: 0.985800735666667
00:12:29.885 --> 00:12:31.782 care based on large randomized
NOTE Confidence: 0.985800735666667

00:12:31.782 --> 00:12:34.057 trials and years of experience,
NOTE Confidence: 0.985800735666667

00:12:34.060 --> 00:12:36.588 that in fact our obligation to adhere to
NOTE Confidence: 0.985800735666667

00:12:36.588 --> 00:12:38.749 that standard of care is pretty strong.
NOTE Confidence: 0.985800735666667

00:12:38.750 --> 00:12:40.646 If in fact it stands on something less
NOTE Confidence: 0.985800735666667

00:12:40.646 --> 00:12:42.859 if it stands on maybe smaller trials,
NOTE Confidence: 0.985800735666667

00:12:42.860 --> 00:12:44.468 just one or two smaller trials,
NOTE Confidence: 0.985800735666667

00:12:44.470 --> 00:12:46.185 then our obligation maybe a bit less.
NOTE Confidence: 0.985800735666667

00:12:46.190 --> 00:12:47.744 If there is no actual evidence
NOTE Confidence: 0.985800735666667

00:12:47.744 --> 00:12:48.780 that this is best,
NOTE Confidence: 0.985800735666667

00:12:48.780 --> 00:12:50.690 but it makes sense physiologically,
NOTE Confidence: 0.985800735666667

00:12:50.690 --> 00:12:51.902 our obligations would hear
NOTE Confidence: 0.985800735666667

00:12:51.902 --> 00:12:53.114 that standard is less,
NOTE Confidence: 0.985800735666667

00:12:53.120 --> 00:12:54.936 and if it's based on what's often based
NOTE Confidence: 0.985800735666667

00:12:54.936 --> 00:12:56.943 on just this is kind of what we all do.
NOTE Confidence: 0.985800735666667

00:12:56.950 --> 00:12:58.726 This is, you know how I was taught.
NOTE Confidence: 0.985800735666667

00:12:58.730 --> 00:13:00.050 This is what we all do.

NOTE Confidence: 0.985800735666667
00:13:00.050 --> 00:13:01.940 I think our obligations would here to
NOTE Confidence: 0.985800735666667
00:13:01.940 --> 00:13:03.570 a standard that's just standing on
NOTE Confidence: 0.985800735666667
00:13:03.570 --> 00:13:05.924 that is less similarly with an ethics
NOTE Confidence: 0.985800735666667
00:13:05.924 --> 00:13:07.940 question with an ethical question,
NOTE Confidence: 0.985800735666667
00:13:07.940 --> 00:13:08.490 for example,
NOTE Confidence: 0.985800735666667
00:13:08.490 --> 00:13:09.865 when to overrule the parents.
NOTE Confidence: 0.985800735666667
00:13:09.870 --> 00:13:11.920 Refusal.
NOTE Confidence: 0.985800735666667
00:13:11.920 --> 00:13:14.420 I think that if our standard of care that we
NOTE Confidence: 0.986688703
00:13:14.480 --> 00:13:16.460 come about comes from a careful
NOTE Confidence: 0.986688703
00:13:16.460 --> 00:13:17.780 consideration of the data,
NOTE Confidence: 0.986688703
00:13:17.780 --> 00:13:19.862 a careful consideration of all the
NOTE Confidence: 0.986688703
00:13:19.862 --> 00:13:21.600 rights and obligations at play,
NOTE Confidence: 0.986688703
00:13:21.600 --> 00:13:23.800 and then an exchange of ideas and then
NOTE Confidence: 0.986688703
00:13:23.800 --> 00:13:25.900 a consensus among professional leaders,
NOTE Confidence: 0.986688703
00:13:25.900 --> 00:13:27.818 then I think our obligation to adhere
NOTE Confidence: 0.986688703

00:13:27.818 --> 00:13:29.658 to that standard may be significant.
NOTE Confidence: 0.986688703

00:13:29.660 --> 00:13:31.016 It's certainly higher than if it
NOTE Confidence: 0.986688703

00:13:31.016 --> 00:13:32.770 would just be all just kind of took
NOTE Confidence: 0.986688703

00:13:32.770 --> 00:13:34.513 a vote and decided this is what we're
NOTE Confidence: 0.986688703

00:13:34.513 --> 00:13:36.007 going to do without any consideration
NOTE Confidence: 0.986688703

00:13:36.007 --> 00:13:37.875 of all the different aspects,
NOTE Confidence: 0.986688703

00:13:37.875 --> 00:13:39.695 including the ethical arguments.
NOTE Confidence: 0.986688703

00:13:39.700 --> 00:13:41.518 And so I put the Yale seal up there.
NOTE Confidence: 0.986688703

00:13:41.520 --> 00:13:42.488 Looks at Vera tos.
NOTE Confidence: 0.986688703

00:13:42.488 --> 00:13:44.675 Right, which the Latin scholars know
NOTE Confidence: 0.986688703

00:13:44.675 --> 00:13:47.190 means it means because we say so.
NOTE Confidence: 0.986688703

00:13:47.190 --> 00:13:48.846 That's not actually what it means,
NOTE Confidence: 0.986688703

00:13:48.850 --> 00:13:50.290 but sometimes that's what the
NOTE Confidence: 0.986688703

00:13:50.290 --> 00:13:51.730 standard care comes down to.
NOTE Confidence: 0.986688703

00:13:51.730 --> 00:13:52.948 Why is that? The standard of care?
NOTE Confidence: 0.986688703

00:13:52.950 --> 00:13:53.895 Well, we all got in the room,

NOTE Confidence: 0.986688703

00:13:53.900 --> 00:13:55.238 and we decided this is what

NOTE Confidence: 0.986688703

00:13:55.238 --> 00:13:56.130 we're going to do.

NOTE Confidence: 0.986688703

00:13:56.130 --> 00:13:58.068 So that's the standard of care.

NOTE Confidence: 0.986688703

00:13:58.070 --> 00:13:59.290 I don't think really,

NOTE Confidence: 0.986688703

00:13:59.290 --> 00:14:01.572 that's the best way for us to

NOTE Confidence: 0.986688703

00:14:01.572 --> 00:14:03.100 answer an ethical question.

NOTE Confidence: 0.986688703

00:14:03.100 --> 00:14:04.420 So how should we answer it?

NOTE Confidence: 0.986688703

00:14:04.420 --> 00:14:05.744 This is my suggestion.

NOTE Confidence: 0.986688703

00:14:05.744 --> 00:14:08.160 This is something called the IPO scale,

NOTE Confidence: 0.986688703

00:14:08.160 --> 00:14:11.449 and for any treatment or or test or

NOTE Confidence: 0.986688703

00:14:11.449 --> 00:14:13.567 screening tests we want to determine

NOTE Confidence: 0.986688703

00:14:13.567 --> 00:14:16.118 if it is ethically impermissible,

NOTE Confidence: 0.986688703

00:14:16.120 --> 00:14:17.620 permissible or obligatory.

NOTE Confidence: 0.986688703

00:14:17.620 --> 00:14:20.120 Any treatment can be defined,

NOTE Confidence: 0.986688703

00:14:20.120 --> 00:14:23.018 described as one of those three things,

NOTE Confidence: 0.986688703

00:14:23.020 --> 00:14:24.040 and within permissible.
NOTE Confidence: 0.986688703

00:14:24.040 --> 00:14:26.420 There are some things that are inadvisable.
NOTE Confidence: 0.986688703

00:14:26.420 --> 00:14:27.760 We don't really recommend it,
NOTE Confidence: 0.986688703

00:14:27.760 --> 00:14:29.608 but it's not to the point where it's
NOTE Confidence: 0.986688703

00:14:29.608 --> 00:14:31.077 actually ethically impermissible to do it.
NOTE Confidence: 0.986688703

00:14:31.080 --> 00:14:32.720 There are some things that
NOTE Confidence: 0.986688703

00:14:32.720 --> 00:14:33.704 are ethically advisable.
NOTE Confidence: 0.986688703

00:14:33.710 --> 00:14:33.892 Well,
NOTE Confidence: 0.986688703

00:14:33.892 --> 00:14:35.530 we think this is really what you should do,
NOTE Confidence: 0.986688703

00:14:35.530 --> 00:14:37.147 but it hasn't really reached the threshold.
NOTE Confidence: 0.986688703

00:14:37.150 --> 00:14:39.020 Those red vertical lines hasn't
NOTE Confidence: 0.986688703

00:14:39.020 --> 00:14:40.890 really reached the threshold where
NOTE Confidence: 0.986688703

00:14:40.956 --> 00:14:42.826 we think is ethically obligatory.
NOTE Confidence: 0.986688703

00:14:42.830 --> 00:14:44.998 I mean a classic example of his visible
NOTE Confidence: 0.986688703

00:14:44.998 --> 00:14:47.040 right now is childhood vaccinations,
NOTE Confidence: 0.986688703

00:14:47.040 --> 00:14:47.754 right we?

NOTE Confidence: 0.986688703

00:14:47.754 --> 00:14:49.539 I think any pediatrician worth

NOTE Confidence: 0.986688703

00:14:49.539 --> 00:14:52.498 his or her salt strongly advises

NOTE Confidence: 0.986688703

00:14:52.498 --> 00:14:54.316 recommends those vaccinations,

NOTE Confidence: 0.986688703

00:14:54.320 --> 00:14:57.494 but we don't take away custody

NOTE Confidence: 0.986688703

00:14:57.494 --> 00:14:58.658 and forced vaccinations.

NOTE Confidence: 0.986688703

00:14:58.660 --> 00:15:00.048 If the parents refused,

NOTE Confidence: 0.986688703

00:15:00.048 --> 00:15:02.430 there's issues later on with school etc.

NOTE Confidence: 0.986688703

00:15:02.430 --> 00:15:03.770 But this is something we

NOTE Confidence: 0.986688703

00:15:03.770 --> 00:15:04.842 feel as strongly advisable.

NOTE Confidence: 0.986688703

00:15:04.850 --> 00:15:06.618 But not necessarily obligatory.

NOTE Confidence: 0.986688703

00:15:06.618 --> 00:15:08.674 And like fashion, there are some things

NOTE Confidence: 0.986688703

00:15:08.674 --> 00:15:10.160 that we think it's not really advisable,

NOTE Confidence: 0.986688703

00:15:10.160 --> 00:15:11.546 but if the parents really want to do it,

NOTE Confidence: 0.986688703

00:15:11.550 --> 00:15:13.430 OK, you know we.

NOTE Confidence: 0.986688703

00:15:13.430 --> 00:15:15.310 We can do that.

NOTE Confidence: 0.986688703

00:15:15.310 --> 00:15:16.546 So how do we do this?
NOTE Confidence: 0.986688703

00:15:16.550 --> 00:15:16.806 Well,
NOTE Confidence: 0.986688703

00:15:16.806 --> 00:15:17.830 if it's ethically impermissible,
NOTE Confidence: 0.986688703

00:15:17.830 --> 00:15:20.078 we shouldn't do it and we shouldn't offer
NOTE Confidence: 0.986688703

00:15:20.078 --> 00:15:22.012 to do it if it's ethically permissible.
NOTE Confidence: 0.986688703

00:15:22.012 --> 00:15:22.906 We should offer,
NOTE Confidence: 0.986688703

00:15:22.910 --> 00:15:24.235 even if the parents aren't
NOTE Confidence: 0.986688703

00:15:24.235 --> 00:15:25.295 smart enough to ask,
NOTE Confidence: 0.986688703

00:15:25.300 --> 00:15:26.878 or savvy enough is a better
NOTE Confidence: 0.986688703

00:15:26.878 --> 00:15:28.210 word savvy enough to ask.
NOTE Confidence: 0.986688703

00:15:28.210 --> 00:15:29.590 And if it's ethically obligatory,
NOTE Confidence: 0.986688703

00:15:29.590 --> 00:15:31.414 we the clinicians should do it
NOTE Confidence: 0.986688703

00:15:31.414 --> 00:15:33.470 now we should insist if necessary,
NOTE Confidence: 0.986688703

00:15:33.470 --> 00:15:35.426 and rarely it comes to this,
NOTE Confidence: 0.986688703

00:15:35.430 --> 00:15:36.630 but we may get legal help,
NOTE Confidence: 0.986688703

00:15:36.630 --> 00:15:37.944 and we may even have to go to court

NOTE Confidence: 0.986688703

00:15:37.944 --> 00:15:39.357 in the rarest of circumstances when I

NOTE Confidence: 0.986688703

00:15:39.357 --> 00:15:40.907 think of the times I've done this as

NOTE Confidence: 0.986688703

00:15:40.907 --> 00:15:42.846 maybe two or three times in my career.

NOTE Confidence: 0.986688703

00:15:42.846 --> 00:15:45.534 It in fact was about transfusion.

NOTE Confidence: 0.98746688

00:15:45.540 --> 00:15:48.400 So that remains an option,

NOTE Confidence: 0.98746688

00:15:48.400 --> 00:15:49.930 but this is basically, uh,

NOTE Confidence: 0.98746688

00:15:49.930 --> 00:15:52.160 this is what we do, so we could stop now.

NOTE Confidence: 0.98746688

00:15:52.160 --> 00:15:53.576 But we have some more time.

NOTE Confidence: 0.98746688

00:15:53.580 --> 00:15:54.732 So the real question,

NOTE Confidence: 0.98746688

00:15:54.732 --> 00:15:57.336 the real ethical work here is how do we

NOTE Confidence: 0.98746688

00:15:57.336 --> 00:15:59.233 locate a given treatment on that line?

NOTE Confidence: 0.98746688

00:15:59.240 --> 00:16:01.820 If there's a treatment in question,

NOTE Confidence: 0.98746688

00:16:01.820 --> 00:16:03.242 how do we decide if it's

NOTE Confidence: 0.98746688

00:16:03.242 --> 00:16:03.716 ethically impermissible?

NOTE Confidence: 0.98746688

00:16:03.720 --> 00:16:05.128 We're not doing it.

NOTE Confidence: 0.98746688

00:16:05.128 --> 00:16:06.536 If it's ethically permissible,
NOTE Confidence: 0.98746688

00:16:06.540 --> 00:16:07.920 we're willing to do it,
NOTE Confidence: 0.98746688

00:16:07.920 --> 00:16:09.390 or if it's ethically obligatory,
NOTE Confidence: 0.98746688

00:16:09.390 --> 00:16:11.735 we insist ethically that whole range of
NOTE Confidence: 0.98746688

00:16:11.735 --> 00:16:13.406 ethical permissible is something that's
NOTE Confidence: 0.98746688

00:16:13.406 --> 00:16:15.548 also been referred to as the zone.
NOTE Confidence: 0.98746688

00:16:15.550 --> 00:16:16.474 Of parental discretion.
NOTE Confidence: 0.98746688

00:16:16.474 --> 00:16:18.630 That's where we give parents a lot
NOTE Confidence: 0.98746688

00:16:18.693 --> 00:16:20.604 of latitude in terms of what's done.
NOTE Confidence: 0.98746688

00:16:20.610 --> 00:16:22.024 I think we located on the line
NOTE Confidence: 0.98746688

00:16:22.024 --> 00:16:23.684 based on the prognosis with and
NOTE Confidence: 0.98746688

00:16:23.684 --> 00:16:25.024 without the proposed treatment.
NOTE Confidence: 0.98746688

00:16:25.030 --> 00:16:26.380 We weigh the benefits and burdens
NOTE Confidence: 0.98746688

00:16:26.380 --> 00:16:27.932 of the treatment in question or
NOTE Confidence: 0.98746688

00:16:27.932 --> 00:16:29.148 the screening testing question,
NOTE Confidence: 0.98746688

00:16:29.150 --> 00:16:30.725 and we consider the likelihood

NOTE Confidence: 0.98746688

00:16:30.725 --> 00:16:31.985 of those possible outcomes.

NOTE Confidence: 0.98746688

00:16:31.990 --> 00:16:33.760 So examples might be antibiotics

NOTE Confidence: 0.98746688

00:16:33.760 --> 00:16:36.477 in a ventilator for a full term

NOTE Confidence: 0.98746688

00:16:36.477 --> 00:16:38.225 baby with bacterial pneumonia.

NOTE Confidence: 0.98746688

00:16:38.230 --> 00:16:39.330 I think mostly on it.

NOTE Confidence: 0.98746688

00:16:39.330 --> 00:16:41.004 Ologists, myself included,

NOTE Confidence: 0.98746688

00:16:41.004 --> 00:16:43.464 would say that this is obligatory.

NOTE Confidence: 0.98746688

00:16:43.464 --> 00:16:44.808 This is ethically obligatory,

NOTE Confidence: 0.98746688

00:16:44.810 --> 00:16:46.010 because frankly this there's a.

NOTE Confidence: 0.98746688

00:16:46.010 --> 00:16:47.840 There's a significant chance this channel

NOTE Confidence: 0.98746688

00:16:47.840 --> 00:16:49.670 could die without those antibiotics,

NOTE Confidence: 0.98746688

00:16:49.670 --> 00:16:50.525 and there's a.

NOTE Confidence: 0.98746688

00:16:50.525 --> 00:16:52.235 Tremendous chance the child going to

NOTE Confidence: 0.98746688

00:16:52.235 --> 00:16:54.255 survive and do fine with those antibiotics,

NOTE Confidence: 0.98746688

00:16:54.260 --> 00:16:56.378 and so those differences in prognosis.

NOTE Confidence: 0.98746688

00:16:56.380 --> 00:16:58.730 How about Jenna Meissen as
NOTE Confidence: 0.98746688

00:16:58.730 --> 00:17:00.140 treatment for cytomegalovirus?
NOTE Confidence: 0.98746688

00:17:00.140 --> 00:17:01.952 Now for those in the room
NOTE Confidence: 0.98746688

00:17:01.952 --> 00:17:03.160 who aren't clinical US,
NOTE Confidence: 0.98746688

00:17:03.160 --> 00:17:04.882 gentamicin doesn't work
NOTE Confidence: 0.98746688

00:17:04.882 --> 00:17:06.030 against cytomegalovirus.
NOTE Confidence: 0.98746688

00:17:06.030 --> 00:17:07.270 It will not help,
NOTE Confidence: 0.98746688

00:17:07.270 --> 00:17:09.830 and in fact it carries some toxicity,
NOTE Confidence: 0.98746688

00:17:09.830 --> 00:17:11.321 in which case I would say that
NOTE Confidence: 0.98746688

00:17:11.321 --> 00:17:12.439 gentamicin is treatment for settle.
NOTE Confidence: 0.98746688

00:17:12.440 --> 00:17:14.720 Megalo virus is ethically impermissible.
NOTE Confidence: 0.98746688

00:17:14.720 --> 00:17:16.768 There's clear risks and burdens to the child,
NOTE Confidence: 0.98746688

00:17:16.770 --> 00:17:18.085 and there's no perceived benefits
NOTE Confidence: 0.98746688

00:17:18.085 --> 00:17:19.766 of some parents that I read
NOTE Confidence: 0.98746688

00:17:19.766 --> 00:17:21.010 an article about gentamicin.
NOTE Confidence: 0.98746688

00:17:21.010 --> 00:17:22.306 I want you to give it to my child.

NOTE Confidence: 0.98746688

00:17:22.310 --> 00:17:23.918 With CMV I think mostly only

NOTE Confidence: 0.98746688

00:17:23.918 --> 00:17:25.682 challenges would see that as ethically

NOTE Confidence: 0.98746688

00:17:25.682 --> 00:17:27.272 impermissible even if they didn't

NOTE Confidence: 0.98746688

00:17:27.272 --> 00:17:29.103 use that language and say no.

NOTE Confidence: 0.98746688

00:17:29.103 --> 00:17:29.394 Well,

NOTE Confidence: 0.98746688

00:17:29.394 --> 00:17:31.489 one thing to remember about this line

NOTE Confidence: 0.98746688

00:17:31.489 --> 00:17:33.526 to recognize is that location on the

NOTE Confidence: 0.98746688

00:17:33.526 --> 00:17:35.677 line for any therapy is not static.

NOTE Confidence: 0.98746688

00:17:35.680 --> 00:17:38.340 It moves based on changing the prognosis.

NOTE Confidence: 0.98746688

00:17:38.340 --> 00:17:40.062 So think about a few examples for

NOTE Confidence: 0.98746688

00:17:40.062 --> 00:17:41.777 transposition of the great vessels for

NOTE Confidence: 0.98746688

00:17:41.777 --> 00:17:43.317 transposition of the great arteries.

NOTE Confidence: 0.98746688

00:17:43.320 --> 00:17:44.880 There is a surgical procedure

NOTE Confidence: 0.98746688

00:17:44.880 --> 00:17:45.816 called arterial switch.

NOTE Confidence: 0.98746688

00:17:45.820 --> 00:17:47.206 Very high effectiveness,

NOTE Confidence: 0.98746688

00:17:47.206 --> 00:17:48.130 very effective,
NOTE Confidence: 0.98746688

00:17:48.130 --> 00:17:49.691 and at this point the outcomes mean
NOTE Confidence: 0.98746688

00:17:49.691 --> 00:17:51.415 more than 90% of those kids are going
NOTE Confidence: 0.98746688

00:17:51.415 --> 00:17:53.424 to survive and do well and without it.
NOTE Confidence: 0.98746688

00:17:53.424 --> 00:17:55.014 These kids could could die.
NOTE Confidence: 0.98746688

00:17:55.020 --> 00:17:55.491 Consequently,
NOTE Confidence: 0.98746688

00:17:55.491 --> 00:17:58.317 we would consider that ethically obligatory,
NOTE Confidence: 0.98746688

00:17:58.320 --> 00:18:00.480 but I remember a time when that procedure.
NOTE Confidence: 0.98746688

00:18:00.480 --> 00:18:02.656 Brand new and when it first came out,
NOTE Confidence: 0.98746688

00:18:02.660 --> 00:18:03.677 if you will.
NOTE Confidence: 0.98746688

00:18:03.677 --> 00:18:05.033 It wasn't immediately considered
NOTE Confidence: 0.98746688

00:18:05.033 --> 00:18:06.338 ethically obligatory as we
NOTE Confidence: 0.98746688

00:18:06.338 --> 00:18:07.724 gathered more data and saw with
NOTE Confidence: 0.98746688

00:18:07.724 --> 00:18:09.159 how good the outcomes were.
NOTE Confidence: 0.98746688

00:18:09.160 --> 00:18:11.255 Eventually it replaced the previous
NOTE Confidence: 0.98746688

00:18:11.255 --> 00:18:13.730 procedure that was more commonly used,

NOTE Confidence: 0.98746688
00:18:13.730 --> 00:18:16.313 so it moved from left to right
NOTE Confidence: 0.98746688
00:18:16.313 --> 00:18:17.998 from permissible to obligatory
NOTE Confidence: 0.98746688
00:18:17.998 --> 00:18:20.518 as more data became available.
NOTE Confidence: 0.98746688
00:18:20.520 --> 00:18:22.620 Right now for hypoplastic left
NOTE Confidence: 0.98746688
00:18:22.620 --> 00:18:23.460 Heart syndrome,
NOTE Confidence: 0.986211588333333
00:18:23.460 --> 00:18:25.860 there's a stage surgical repair done,
NOTE Confidence: 0.986211588333333
00:18:25.860 --> 00:18:28.101 and this is a disease where the child will
NOTE Confidence: 0.986211588333333
00:18:28.101 --> 00:18:30.300 die without this stage surgical repair,
NOTE Confidence: 0.986211588333333
00:18:30.300 --> 00:18:32.538 unless there's a rare transplant done.
NOTE Confidence: 0.986211588333333
00:18:32.540 --> 00:18:35.095 Come and so some folks say that
NOTE Confidence: 0.986211588333333
00:18:35.095 --> 00:18:37.374 the outcome is is poor enough still
NOTE Confidence: 0.986211588333333
00:18:37.374 --> 00:18:39.150 that the parents should have the
NOTE Confidence: 0.986211588333333
00:18:39.210 --> 00:18:41.000 option of comfort measures only.
NOTE Confidence: 0.986211588333333
00:18:41.000 --> 00:18:42.617 We don't have to do the surgery.
NOTE Confidence: 0.986211588333333
00:18:42.620 --> 00:18:43.740 It's the stage sorted.
NOTE Confidence: 0.986211588333333

00:18:43.740 --> 00:18:45.334 It's a long, difficult treatment
NOTE Confidence: 0.986211588333333

00:18:45.334 --> 00:18:47.596 and many children don't survive it.
NOTE Confidence: 0.986211588333333

00:18:47.600 --> 00:18:49.160 Others would say that the outcomes
NOTE Confidence: 0.986211588333333

00:18:49.160 --> 00:18:50.570 have gotten better and better,
NOTE Confidence: 0.986211588333333

00:18:50.570 --> 00:18:52.454 so it's crossed that line like
NOTE Confidence: 0.986211588333333

00:18:52.454 --> 00:18:53.710 the arterial switch procedure.
NOTE Confidence: 0.986211588333333

00:18:53.710 --> 00:18:56.062 It's crossed that red line between
NOTE Confidence: 0.986211588333333

00:18:56.062 --> 00:18:57.238 permissible and obligatory.
NOTE Confidence: 0.986211588333333

00:18:57.240 --> 00:18:59.616 It's gone from advisable to obligatory.
NOTE Confidence: 0.986211588333333

00:18:59.620 --> 00:19:02.596 And therein lies a significant dispute.
NOTE Confidence: 0.986211588333333

00:19:02.600 --> 00:19:02.970 Right now,
NOTE Confidence: 0.986211588333333

00:19:02.970 --> 00:19:04.265 and the only tells you and you'll
NOTE Confidence: 0.986211588333333

00:19:04.265 --> 00:19:05.532 hear different things from
NOTE Confidence: 0.986211588333333

00:19:05.532 --> 00:19:06.226 different cardiologists,
NOTE Confidence: 0.986211588333333

00:19:06.230 --> 00:19:07.730 neonatologists and CT surgeons,
NOTE Confidence: 0.986211588333333

00:19:07.730 --> 00:19:09.980 whether parents should still have the

NOTE Confidence: 0.986211588333333
00:19:10.035 --> 00:19:12.198 option of comfort measures only if we
NOTE Confidence: 0.986211588333333
00:19:12.198 --> 00:19:14.328 think that surgical repair is obligatory.
NOTE Confidence: 0.986211588333333
00:19:14.330 --> 00:19:16.085 We would then not offer
NOTE Confidence: 0.986211588333333
00:19:16.085 --> 00:19:17.489 them comfort measures only.
NOTE Confidence: 0.986211588333333
00:19:17.490 --> 00:19:18.915 Apnea prematurity is another interesting
NOTE Confidence: 0.986211588333333
00:19:18.915 --> 00:19:20.922 example where years ago it was treated
NOTE Confidence: 0.986211588333333
00:19:20.922 --> 00:19:22.805 with supplemental oxygen and it worked there.
NOTE Confidence: 0.986211588333333
00:19:22.810 --> 00:19:24.614 Apnea of prematurity where
NOTE Confidence: 0.986211588333333
00:19:24.614 --> 00:19:25.967 they stopped breathing,
NOTE Confidence: 0.986211588333333
00:19:25.970 --> 00:19:26.440 actually decreases.
NOTE Confidence: 0.986211588333333
00:19:26.440 --> 00:19:29.338 If you could put him in 100% oxygen so that
NOTE Confidence: 0.986211588333333
00:19:29.338 --> 00:19:31.418 was an ethically permissible treatment.
NOTE Confidence: 0.986211588333333
00:19:31.420 --> 00:19:32.700 Eventually more data became
NOTE Confidence: 0.986211588333333
00:19:32.700 --> 00:19:34.300 available and it became through
NOTE Confidence: 0.986211588333333
00:19:34.300 --> 00:19:36.445 that this run the risk of causing
NOTE Confidence: 0.986211588333333

00:19:36.445 --> 00:19:37.625 blindness in premature babies.
NOTE Confidence: 0.986211588333333

00:19:37.630 --> 00:19:38.080 Consequently,
NOTE Confidence: 0.986211588333333

00:19:38.080 --> 00:19:40.330 this moved from permissible to
NOTE Confidence: 0.986211588333333

00:19:40.330 --> 00:19:42.464 impermissible as the burdens and
NOTE Confidence: 0.986211588333333

00:19:42.464 --> 00:19:43.862 risks of the child increased,
NOTE Confidence: 0.986211588333333

00:19:43.862 --> 00:19:45.110 or I should say,
NOTE Confidence: 0.986211588333333

00:19:45.110 --> 00:19:47.480 our awareness of them increased.
NOTE Confidence: 0.986211588333333

00:19:47.480 --> 00:19:48.341 And of course,
NOTE Confidence: 0.986211588333333

00:19:48.341 --> 00:19:49.776 with regard to extreme prematurity.
NOTE Confidence: 0.986211588333333

00:19:49.780 --> 00:19:50.304 Here again,
NOTE Confidence: 0.986211588333333

00:19:50.304 --> 00:19:52.400 we've got a we have a case where,
NOTE Confidence: 0.986211588333333

00:19:52.400 --> 00:19:54.146 at what gestational age at what
NOTE Confidence: 0.986211588333333

00:19:54.146 --> 00:19:55.596 prognosis do we resuscitate and
NOTE Confidence: 0.986211588333333

00:19:55.596 --> 00:19:57.220 we've all seen that move those of
NOTE Confidence: 0.986211588333333

00:19:57.220 --> 00:19:58.965 us who've been at this for a while,
NOTE Confidence: 0.986211588333333

00:19:58.970 --> 00:20:01.119 that as the outcomes get better and

NOTE Confidence: 0.986211588333333
00:20:01.119 --> 00:20:03.520 better for a given gestational age.
NOTE Confidence: 0.986211588333333
00:20:03.520 --> 00:20:05.970 Resuscitation at that just inhalation
NOTE Confidence: 0.986211588333333
00:20:05.970 --> 00:20:08.862 gestational age moves left to right
NOTE Confidence: 0.986211588333333
00:20:08.862 --> 00:20:10.893 on this scale, and for example,
NOTE Confidence: 0.986211588333333
00:20:10.893 --> 00:20:12.137 when I was training,
NOTE Confidence: 0.986211588333333
00:20:12.140 --> 00:20:13.908 I think most people would say that a
NOTE Confidence: 0.986211588333333
00:20:13.908 --> 00:20:15.628 child born at 25 weeks or many would,
NOTE Confidence: 0.986211588333333
00:20:15.630 --> 00:20:16.950 that that's something that we want to do.
NOTE Confidence: 0.986211588333333
00:20:16.950 --> 00:20:18.294 But if the parents say absolutely not.
NOTE Confidence: 0.986211588333333
00:20:18.300 --> 00:20:18.868 He won't do it.
NOTE Confidence: 0.986211588333333
00:20:18.868 --> 00:20:20.120 I think a lot on the Internet.
NOTE Confidence: 0.986211588333333
00:20:20.120 --> 00:20:21.696 Ologist would said no.
NOTE Confidence: 0.986211588333333
00:20:21.696 --> 00:20:24.090 At this point on the outcomes are so
NOTE Confidence: 0.986211588333333
00:20:24.090 --> 00:20:26.108 good that I think that, for example,
NOTE Confidence: 0.986211588333333
00:20:26.108 --> 00:20:28.936 the AAP says and the and the.
NOTE Confidence: 0.986211588333333

00:20:28.940 --> 00:20:31.088 And and the British organization says
NOTE Confidence: 0.986211588333333

00:20:31.088 --> 00:20:32.983 in the Canadian Associ Academy of
NOTE Confidence: 0.986211588333333

00:20:32.983 --> 00:20:34.609 Pediatrics and others have said no.
NOTE Confidence: 0.986211588333333

00:20:34.610 --> 00:20:36.668 At that point, it's obligatory now,
NOTE Confidence: 0.986211588333333

00:20:36.670 --> 00:20:39.855 because the prognosis has moved with time.
NOTE Confidence: 0.986211588333333

00:20:39.860 --> 00:20:41.500 So one important aspect of this is we
NOTE Confidence: 0.986211588333333

00:20:41.500 --> 00:20:43.280 can't make a decision about any treatment.
NOTE Confidence: 0.986211588333333

00:20:43.280 --> 00:20:44.448 And then five years from now and say,
NOTE Confidence: 0.986211588333333

00:20:44.450 --> 00:20:45.590 well, we already talked about that.
NOTE Confidence: 0.986211588333333

00:20:45.590 --> 00:20:48.002 We decided it may have moved on the line.
NOTE Confidence: 0.986211588333333

00:20:48.010 --> 00:20:49.168 We have to take another look,
NOTE Confidence: 0.986211588333333

00:20:49.170 --> 00:20:52.180 see what other data have become apparent.
NOTE Confidence: 0.986211588333333

00:20:52.180 --> 00:20:52.413 Now,
NOTE Confidence: 0.986211588333333

00:20:52.413 --> 00:20:53.578 it's not just prognosis that's
NOTE Confidence: 0.986211588333333

00:20:53.578 --> 00:20:54.510 going to determine that.
NOTE Confidence: 0.986211588333333

00:20:54.510 --> 00:20:56.478 It's also feasibility, right?

NOTE Confidence: 0.986211588333333
00:20:56.478 --> 00:20:57.954 Medical and economic.
NOTE Confidence: 0.986211588333333
00:20:57.960 --> 00:20:58.650 Interestingly enough,
NOTE Confidence: 0.986211588333333
00:20:58.650 --> 00:21:01.410 if something can't be done that it can't
NOTE Confidence: 0.988840224615385
00:21:01.470 --> 00:21:03.030 become ethically obligatory,
NOTE Confidence: 0.988840224615385
00:21:03.030 --> 00:21:05.016 there's an adage ought implies can,
NOTE Confidence: 0.988840224615385
00:21:05.020 --> 00:21:05.580 which applies.
NOTE Confidence: 0.988840224615385
00:21:05.580 --> 00:21:07.540 We can't say you're obligated to do
NOTE Confidence: 0.988840224615385
00:21:07.540 --> 00:21:09.280 something if you absolutely can't do it,
NOTE Confidence: 0.988840224615385
00:21:09.280 --> 00:21:10.953 either because you don't have the medical
NOTE Confidence: 0.988840224615385
00:21:10.953 --> 00:21:12.500 resources or the economic resources.
NOTE Confidence: 0.988840224615385
00:21:12.500 --> 00:21:15.470 So what's ethically obligatory in
NOTE Confidence: 0.988840224615385
00:21:15.470 --> 00:21:17.280 some countries may be considered
NOTE Confidence: 0.988840224615385
00:21:17.280 --> 00:21:18.728 a not ethically obligatory,
NOTE Confidence: 0.988840224615385
00:21:18.730 --> 00:21:20.770 and others depending on the availability
NOTE Confidence: 0.988840224615385
00:21:20.770 --> 00:21:23.166 of resources, including personnel and.
NOTE Confidence: 0.988840224615385

00:21:23.166 --> 00:21:24.310 Facilities etc.
NOTE Confidence: 0.988840224615385

00:21:24.310 --> 00:21:25.591 Prognosis and feasibility.
NOTE Confidence: 0.988840224615385

00:21:25.591 --> 00:21:28.580 And the third thing that locates things
NOTE Confidence: 0.988840224615385

00:21:28.649 --> 00:21:30.980 on that line of the relevant rights.
NOTE Confidence: 0.988840224615385

00:21:30.980 --> 00:21:32.330 So let's think about this.
NOTE Confidence: 0.988840224615385

00:21:32.330 --> 00:21:34.549 The parents have a right to decide.
NOTE Confidence: 0.988840224615385

00:21:34.550 --> 00:21:35.815 We recognize that I think
NOTE Confidence: 0.988840224615385

00:21:35.815 --> 00:21:36.827 we should recognize that.
NOTE Confidence: 0.988840224615385

00:21:36.830 --> 00:21:39.098 Hence our goal of shared decision
NOTE Confidence: 0.988840224615385

00:21:39.098 --> 00:21:41.089 making our acknowledgment of parental
NOTE Confidence: 0.988840224615385

00:21:41.089 --> 00:21:43.549 authority needs to be very respectful.
NOTE Confidence: 0.988840224615385

00:21:43.550 --> 00:21:45.713 Parents have a right to decide almost
NOTE Confidence: 0.988840224615385

00:21:45.713 --> 00:21:47.908 always what should happen to their child.
NOTE Confidence: 0.988840224615385

00:21:47.910 --> 00:21:50.318 Our role as clinicians is to find
NOTE Confidence: 0.988840224615385

00:21:50.318 --> 00:21:52.184 that threshold where we should
NOTE Confidence: 0.988840224615385

00:21:52.184 --> 00:21:54.094 seek to overrule their decision.

NOTE Confidence: 0.988840224615385
00:21:54.100 --> 00:21:55.780 So what right may Trump the
NOTE Confidence: 0.988840224615385
00:21:55.780 --> 00:21:56.900 parents right to decide?
NOTE Confidence: 0.988840224615385
00:21:56.900 --> 00:21:58.700 I think two come to mind for me and there
NOTE Confidence: 0.988840224615385
00:21:58.748 --> 00:22:00.414 may be others that you would consider.
NOTE Confidence: 0.988840224615385
00:22:00.420 --> 00:22:02.180 One is the child's right to treatment if
NOTE Confidence: 0.988840224615385
00:22:02.180 --> 00:22:03.986 the parents are refusing a treatment that
NOTE Confidence: 0.988840224615385
00:22:03.986 --> 00:22:05.560 is likely to prevent significant harm,
NOTE Confidence: 0.988840224615385
00:22:05.560 --> 00:22:07.568 suffering or death that I think that in
NOTE Confidence: 0.988840224615385
00:22:07.568 --> 00:22:10.098 fact as a clinician I would seek to overrule.
NOTE Confidence: 0.988840224615385
00:22:10.100 --> 00:22:11.684 In that case our rights based
NOTE Confidence: 0.988840224615385
00:22:11.684 --> 00:22:13.509 analysis tells me this is something
NOTE Confidence: 0.988840224615385
00:22:13.509 --> 00:22:15.289 that should be ethically obligatory.
NOTE Confidence: 0.988840224615385
00:22:15.290 --> 00:22:16.450 The other thing is something
NOTE Confidence: 0.988840224615385
00:22:16.450 --> 00:22:17.910 called the child's right to mercy.
NOTE Confidence: 0.988840224615385
00:22:17.910 --> 00:22:19.614 Which you know we wrote about from here,
NOTE Confidence: 0.988840224615385

00:22:19.620 --> 00:22:21.222 but in fact this is not a new concept,

NOTE Confidence: 0.988840224615385

00:22:21.230 --> 00:22:22.310 just new wording for it.

NOTE Confidence: 0.988840224615385

00:22:22.310 --> 00:22:24.221 Perhaps in the idea that the child

NOTE Confidence: 0.988840224615385

00:22:24.221 --> 00:22:26.081 should not be made to undergo

NOTE Confidence: 0.988840224615385

00:22:26.081 --> 00:22:27.706 treatment that is painful or

NOTE Confidence: 0.988840224615385

00:22:27.706 --> 00:22:29.372 difficult or invasive that offers

NOTE Confidence: 0.988840224615385

00:22:29.372 --> 00:22:31.605 no chance of benefit to that child.

NOTE Confidence: 0.988840224615385

00:22:31.610 --> 00:22:33.170 No significant benefit.

NOTE Confidence: 0.988840224615385

00:22:33.170 --> 00:22:34.210 So sometimes,

NOTE Confidence: 0.988840224615385

00:22:34.210 --> 00:22:35.752 as we've seen in the world

NOTE Confidence: 0.988840224615385

00:22:35.752 --> 00:22:36.780 of newborn intensive care,

NOTE Confidence: 0.988840224615385

00:22:36.780 --> 00:22:38.892 parents ask us to do things that we

NOTE Confidence: 0.988840224615385

00:22:38.892 --> 00:22:41.165 think are just going to hurt the child

NOTE Confidence: 0.988840224615385

00:22:41.165 --> 00:22:43.410 and offer no chance to help the child.

NOTE Confidence: 0.988840224615385

00:22:43.410 --> 00:22:45.447 I would say in that setting some

NOTE Confidence: 0.988840224615385

00:22:45.447 --> 00:22:46.708 things become ethically obligatory

NOTE Confidence: 0.988840224615385
00:22:46.708 --> 00:22:48.040 based upon the child.
NOTE Confidence: 0.988840224615385
00:22:48.040 --> 00:22:49.450 Right to mercy,
NOTE Confidence: 0.988840224615385
00:22:49.450 --> 00:22:53.410 and sometimes clinicians should say no.
NOTE Confidence: 0.988840224615385
00:22:53.410 --> 00:22:54.508 And there may be other rights
NOTE Confidence: 0.988840224615385
00:22:54.508 --> 00:22:55.329 involved here too, right?
NOTE Confidence: 0.988840224615385
00:22:55.329 --> 00:22:56.674 The families best interest and
NOTE Confidence: 0.988840224615385
00:22:56.674 --> 00:22:58.314 the other members of the family
NOTE Confidence: 0.988840224615385
00:22:58.314 --> 00:22:59.844 are affected by decisions we make
NOTE Confidence: 0.988840224615385
00:22:59.850 --> 00:23:01.210 other members of society society
NOTE Confidence: 0.988840224615385
00:23:01.210 --> 00:23:03.295 as a whole because of how we
NOTE Confidence: 0.988840224615385
00:23:03.295 --> 00:23:04.639 distribute our limited resources,
NOTE Confidence: 0.988840224615385
00:23:04.640 --> 00:23:05.262 distributive justice,
NOTE Confidence: 0.988840224615385
00:23:05.262 --> 00:23:05.884 of course,
NOTE Confidence: 0.988840224615385
00:23:05.884 --> 00:23:08.125 refers to a fair allocation of limited
NOTE Confidence: 0.988840224615385
00:23:08.125 --> 00:23:10.051 resources and the healthcare dollar is
NOTE Confidence: 0.988840224615385

00:23:10.051 --> 00:23:12.015 a limited resource that we don't really
NOTE Confidence: 0.988840224615385

00:23:12.015 --> 00:23:13.756 live that way often in this country,
NOTE Confidence: 0.988840224615385

00:23:13.756 --> 00:23:16.600 but more and more we're going to need to.
NOTE Confidence: 0.988840224615385

00:23:16.600 --> 00:23:18.456 Other rights may come into play as well.
NOTE Confidence: 0.988840224615385

00:23:18.460 --> 00:23:20.362 I'm not sure for this discussion
NOTE Confidence: 0.988840224615385

00:23:20.362 --> 00:23:22.102 about parents refusing a screening
NOTE Confidence: 0.988840224615385

00:23:22.102 --> 00:23:23.750 test that it's necessarily.
NOTE Confidence: 0.988840224615385

00:23:23.750 --> 00:23:25.110 On relevant to the discussion,
NOTE Confidence: 0.988840224615385

00:23:25.110 --> 00:23:26.466 but something to be thought of.
NOTE Confidence: 0.988840224615385

00:23:26.470 --> 00:23:29.186 This is all part of a rights
NOTE Confidence: 0.988840224615385

00:23:29.186 --> 00:23:31.310 based analysis which is going
NOTE Confidence: 0.988840224615385

00:23:31.310 --> 00:23:33.926 to help locate any treatment or
NOTE Confidence: 0.988840224615385

00:23:33.926 --> 00:23:36.310 screening test on that IPO scale.
NOTE Confidence: 0.988840224615385

00:23:36.310 --> 00:23:40.930 Prognosis, feasibility and relevant rights.
NOTE Confidence: 0.989685066666667

00:23:40.930 --> 00:23:41.908 And something else,
NOTE Confidence: 0.989685066666667

00:23:41.908 --> 00:23:43.864 and so get to something else.

NOTE Confidence: 0.989685066666667
00:23:43.870 --> 00:23:46.094 I want to tell you a brief story.
NOTE Confidence: 0.989685066666667
00:23:46.100 --> 00:23:49.924 If I could please some years back when
NOTE Confidence: 0.989685066666667
00:23:49.924 --> 00:23:52.220 extra corporeal membrane oxygenation
NOTE Confidence: 0.989685066666667
00:23:52.220 --> 00:23:54.516 essentially heart lung bypass,
NOTE Confidence: 0.989685066666667
00:23:54.520 --> 00:23:56.650 became a treatment more often used
NOTE Confidence: 0.989685066666667
00:23:56.650 --> 00:23:59.190 in newborns who had a problem
NOTE Confidence: 0.989685066666667
00:23:59.190 --> 00:24:00.768 called pulmonary hypertension.
NOTE Confidence: 0.989685066666667
00:24:00.770 --> 00:24:02.190 Basically we could not get
NOTE Confidence: 0.989685066666667
00:24:02.190 --> 00:24:03.326 enough auction their blood,
NOTE Confidence: 0.989685066666667
00:24:03.330 --> 00:24:05.190 even if you used a ventilator
NOTE Confidence: 0.989685066666667
00:24:05.190 --> 00:24:06.054 at 100% auction,
NOTE Confidence: 0.989685066666667
00:24:06.054 --> 00:24:07.518 we still were not getting enough
NOTE Confidence: 0.989685066666667
00:24:07.518 --> 00:24:09.007 oxygen in their blood and constantly
NOTE Confidence: 0.989685066666667
00:24:09.007 --> 00:24:10.423 they risk death or brain damage
NOTE Confidence: 0.989685066666667
00:24:10.423 --> 00:24:11.687 or other end organ damage.
NOTE Confidence: 0.989685066666667

00:24:11.690 --> 00:24:14.794 If they survive and so these kids would

NOTE Confidence: 0.989685066666667

00:24:14.794 --> 00:24:18.185 be put on bypass if you will on ECMO.

NOTE Confidence: 0.989685066666667

00:24:18.190 --> 00:24:20.682 One thing I recall for when ECMO

NOTE Confidence: 0.989685066666667

00:24:20.682 --> 00:24:22.272 first became available for newborns

NOTE Confidence: 0.989685066666667

00:24:22.272 --> 00:24:24.390 it was more and more commonly used

NOTE Confidence: 0.989685066666667

00:24:24.390 --> 00:24:26.056 is that it was considered that we

NOTE Confidence: 0.989685066666667

00:24:26.056 --> 00:24:28.860 wouldn't do it in cases of trisomy 21,

NOTE Confidence: 0.989685066666667

00:24:28.860 --> 00:24:31.020 also known as Down syndrome.

NOTE Confidence: 0.989685066666667

00:24:31.020 --> 00:24:32.348 They weren't considered candidates,

NOTE Confidence: 0.989685066666667

00:24:32.348 --> 00:24:34.008 and you'll hear that phrase

NOTE Confidence: 0.989685066666667

00:24:34.008 --> 00:24:35.208 a lot in medicine,

NOTE Confidence: 0.989685066666667

00:24:35.210 --> 00:24:36.954 and we have to be careful about the

NOTE Confidence: 0.989685066666667

00:24:36.954 --> 00:24:38.198 circular arguments are not candidates

NOTE Confidence: 0.989685066666667

00:24:38.198 --> 00:24:39.722 'cause it's not indicated it's not

NOTE Confidence: 0.989685066666667

00:24:39.722 --> 00:24:41.278 indicated because they're not candidates,

NOTE Confidence: 0.989685066666667

00:24:41.280 --> 00:24:42.368 and the candidates 'cause

NOTE Confidence: 0.989685066666667
00:24:42.368 --> 00:24:44.000 it's not the standard of care,
NOTE Confidence: 0.989685066666667
00:24:44.000 --> 00:24:45.456 and it's not the standard of care
NOTE Confidence: 0.989685066666667
00:24:45.456 --> 00:24:46.343 because they're not candidates
NOTE Confidence: 0.989685066666667
00:24:46.343 --> 00:24:47.855 in and around and around it goes.
NOTE Confidence: 0.989685066666667
00:24:47.860 --> 00:24:48.980 The fact of the matter is in the.
NOTE Confidence: 0.989685066666667
00:24:48.980 --> 00:24:52.236 Early days of ECMO kids with trisomy 21.
NOTE Confidence: 0.989685066666667
00:24:52.240 --> 00:24:55.340 It was I saw were were rarely put on ECMO,
NOTE Confidence: 0.989685066666667
00:24:55.340 --> 00:24:56.480 even if they otherwise met.
NOTE Confidence: 0.989685066666667
00:24:56.480 --> 00:24:58.350 The indications in the early
NOTE Confidence: 0.989685066666667
00:24:58.350 --> 00:25:00.220 part of the 21st century.
NOTE Confidence: 0.989685066666667
00:25:00.220 --> 00:25:02.116 In the first years it became,
NOTE Confidence: 0.989685066666667
00:25:02.120 --> 00:25:04.613 I thought I noticed and I spoke to my
NOTE Confidence: 0.989685066666667
00:25:04.613 --> 00:25:06.516 colleagues here on the ECMO team that
NOTE Confidence: 0.989685066666667
00:25:06.516 --> 00:25:08.223 there was more and more willingness
NOTE Confidence: 0.989685066666667
00:25:08.223 --> 00:25:10.337 to now put these kids on ECMO.
NOTE Confidence: 0.989685066666667

00:25:10.340 --> 00:25:12.428 So we did a survey of ECMO centers
NOTE Confidence: 0.989685066666667

00:25:12.428 --> 00:25:14.538 all over the country and overseas.
NOTE Confidence: 0.989685066666667

00:25:14.540 --> 00:25:15.308 Rachel Chapman, you see,
NOTE Confidence: 0.989685066666667

00:25:15.308 --> 00:25:16.800 is the first author of our service.
NOTE Confidence: 0.989685066666667

00:25:16.800 --> 00:25:19.292 She was the head of our ecmel
NOTE Confidence: 0.989685066666667

00:25:19.292 --> 00:25:20.360 program here then.
NOTE Confidence: 0.989685066666667

00:25:20.360 --> 00:25:21.344 And we asked,
NOTE Confidence: 0.989685066666667

00:25:21.344 --> 00:25:22.984 assuming the patient meets the
NOTE Confidence: 0.989685066666667

00:25:22.984 --> 00:25:24.379 respiratory criteria and there
NOTE Confidence: 0.989685066666667

00:25:24.379 --> 00:25:25.755 are no other contraindications.
NOTE Confidence: 0.989685066666667

00:25:25.760 --> 00:25:28.976 Would you offer ECMO in the presence of
NOTE Confidence: 0.989685066666667

00:25:28.976 --> 00:25:31.558 trisomy 21 and the choices were never?
NOTE Confidence: 0.989685066666667

00:25:31.560 --> 00:25:34.100 Rarely, sometimes, usually or always.
NOTE Confidence: 0.989685066666667

00:25:34.100 --> 00:25:35.956 And to say we would offer it as
NOTE Confidence: 0.989685066666667

00:25:35.956 --> 00:25:37.418 opposed to insist or refuse,
NOTE Confidence: 0.989685066666667

00:25:37.420 --> 00:25:39.850 suggests that we see it as

NOTE Confidence: 0.989685066666667
00:25:39.850 --> 00:25:40.660 ethically permissible.
NOTE Confidence: 0.989685066666667
00:25:40.660 --> 00:25:41.328 Now again,
NOTE Confidence: 0.989685066666667
00:25:41.328 --> 00:25:44.000 I think if we've done this much earlier,
NOTE Confidence: 0.989685066666667
00:25:44.000 --> 00:25:45.380 we would have seen that that
NOTE Confidence: 0.989685066666667
00:25:45.380 --> 00:25:46.560 relatively few centers do this.
NOTE Confidence: 0.989685066666667
00:25:46.560 --> 00:25:47.944 That was my experience,
NOTE Confidence: 0.989685066666667
00:25:47.944 --> 00:25:51.421 but when we did this in 2008 and 2009,
NOTE Confidence: 0.989685066666667
00:25:51.421 --> 00:25:53.289 we saw that most.
NOTE Confidence: 0.989685066666667
00:25:53.290 --> 00:25:56.236 At most centers usually are always.
NOTE Confidence: 0.989685066666667
00:25:56.240 --> 00:25:59.957 Offer FMO in children with trisomy 21.
NOTE Confidence: 0.989685066666667
00:25:59.960 --> 00:26:01.016 And that fascinated me.
NOTE Confidence: 0.989685066666667
00:26:01.016 --> 00:26:02.318 Why did that change?
NOTE Confidence: 0.989685066666667
00:26:02.320 --> 00:26:04.093 Why did it seem to move on that line?
NOTE Confidence: 0.989685066666667
00:26:04.100 --> 00:26:05.276 And no one spoke in terms of
NOTE Confidence: 0.989685066666667
00:26:05.276 --> 00:26:06.270 that scale in those days?
NOTE Confidence: 0.989685066666667

00:26:06.270 --> 00:26:08.419 But why did our approach to that
NOTE Confidence: 0.989685066666667

00:26:08.419 --> 00:26:10.450 change to the prognosis change?
NOTE Confidence: 0.989685066666667

00:26:10.450 --> 00:26:10.880 Now?
NOTE Confidence: 0.989685066666667

00:26:10.880 --> 00:26:11.792 It really didn't.
NOTE Confidence: 0.989685066666667

00:26:11.792 --> 00:26:13.616 That were the things about trisomy
NOTE Confidence: 0.989685066666667

00:26:13.616 --> 00:26:14.700 21 that changed.
NOTE Confidence: 0.989685066666667

00:26:14.700 --> 00:26:15.294 Not really,
NOTE Confidence: 0.989685066666667

00:26:15.294 --> 00:26:17.373 so we have to ask ourselves what
NOTE Confidence: 0.989685066666667

00:26:17.373 --> 00:26:19.499 changed and if it wasn't the prognosis.
NOTE Confidence: 0.989685066666667

00:26:19.500 --> 00:26:21.072 Maybe it had to do with
NOTE Confidence: 0.989685066666667

00:26:21.072 --> 00:26:22.120 our attitudes or values
NOTE Confidence: 0.980288926153846

00:26:22.182 --> 00:26:23.298 about the procedure,
NOTE Confidence: 0.980288926153846

00:26:23.300 --> 00:26:25.850 perhaps was it seen as something
NOTE Confidence: 0.980288926153846

00:26:25.850 --> 00:26:28.098 that was really experimental or
NOTE Confidence: 0.980288926153846

00:26:28.098 --> 00:26:30.478 extremely novel or extraordinary care?
NOTE Confidence: 0.980288926153846

00:26:30.480 --> 00:26:32.200 A term that many ethicists,

NOTE Confidence: 0.980288926153846
00:26:32.200 --> 00:26:34.650 myself included, try very hard to avoid,
NOTE Confidence: 0.980288926153846
00:26:34.650 --> 00:26:36.510 but that our attitude about ECMO
NOTE Confidence: 0.980288926153846
00:26:36.510 --> 00:26:38.949 changed as I become more commonly used.
NOTE Confidence: 0.980288926153846
00:26:38.950 --> 00:26:41.127 Or wasn't our attitudes about the patients?
NOTE Confidence: 0.980288926153846
00:26:41.130 --> 00:26:43.377 Do we see newborns as perhaps having
NOTE Confidence: 0.980288926153846
00:26:43.377 --> 00:26:45.559 fewer rights or lesser rights than
NOTE Confidence: 0.980288926153846
00:26:45.559 --> 00:26:47.863 older children or adults or newborns?
NOTE Confidence: 0.980288926153846
00:26:47.870 --> 00:26:49.422 Specifically with trisomy 21?
NOTE Confidence: 0.980288926153846
00:26:49.422 --> 00:26:51.750 Was it our attitudes or values
NOTE Confidence: 0.980288926153846
00:26:51.822 --> 00:26:53.830 about people with disabilities?
NOTE Confidence: 0.980288926153846
00:26:53.830 --> 00:26:55.891 We all know that all children with trisomy 21
NOTE Confidence: 0.980288926153846
00:26:55.891 --> 00:26:58.035 are going to have some cognitive disability.
NOTE Confidence: 0.980288926153846
00:26:58.040 --> 00:27:00.504 Is that why it was felt they shouldn't
NOTE Confidence: 0.980288926153846
00:27:00.504 --> 00:27:02.716 be candidates in the early days of ECMO,
NOTE Confidence: 0.980288926153846
00:27:02.720 --> 00:27:04.169 there was no evidence to show that
NOTE Confidence: 0.980288926153846

00:27:04.169 --> 00:27:05.808 they were less likely to survive ECMO.
NOTE Confidence: 0.980288926153846

00:27:05.810 --> 00:27:08.169 All the information we had was just
NOTE Confidence: 0.980288926153846

00:27:08.169 --> 00:27:11.050 as likely to help them as a child
NOTE Confidence: 0.980288926153846

00:27:11.050 --> 00:27:12.486 who was otherwise normal.
NOTE Confidence: 0.980288926153846

00:27:12.490 --> 00:27:13.870 Our attitudes about disability
NOTE Confidence: 0.980288926153846

00:27:13.870 --> 00:27:14.905 was our attitude,
NOTE Confidence: 0.980288926153846

00:27:14.910 --> 00:27:16.390 perhaps about the parental
NOTE Confidence: 0.980288926153846

00:27:16.390 --> 00:27:17.870 rights at his side.
NOTE Confidence: 0.980288926153846

00:27:17.870 --> 00:27:18.755 I don't know,
NOTE Confidence: 0.980288926153846

00:27:18.755 --> 00:27:20.230 but I think our attitudes
NOTE Confidence: 0.980288926153846

00:27:20.230 --> 00:27:21.908 and values influence where we
NOTE Confidence: 0.980288926153846

00:27:21.908 --> 00:27:23.608 locate things on that line,
NOTE Confidence: 0.980288926153846

00:27:23.610 --> 00:27:25.507 and that should come with a caution.
NOTE Confidence: 0.980288926153846

00:27:25.510 --> 00:27:27.838 And it should come with a caution because
NOTE Confidence: 0.980288926153846

00:27:27.838 --> 00:27:29.793 sometimes our attitudes and values are
NOTE Confidence: 0.980288926153846

00:27:29.793 --> 00:27:31.761 also really our biases or prejudices,

NOTE Confidence: 0.980288926153846
00:27:31.770 --> 00:27:33.522 and some of them are enlightened
NOTE Confidence: 0.980288926153846
00:27:33.522 --> 00:27:35.229 and some of them are not.
NOTE Confidence: 0.980288926153846
00:27:35.230 --> 00:27:36.040 So we have to be.
NOTE Confidence: 0.980288926153846
00:27:36.040 --> 00:27:37.881 We have to really stop and ask
NOTE Confidence: 0.980288926153846
00:27:37.881 --> 00:27:39.865 ourselves if I don't consider this
NOTE Confidence: 0.980288926153846
00:27:39.865 --> 00:27:42.127 person a candidate for this treatment,
NOTE Confidence: 0.980288926153846
00:27:42.130 --> 00:27:42.387 but.
NOTE Confidence: 0.980288926153846
00:27:42.387 --> 00:27:43.929 This other person is what's the
NOTE Confidence: 0.980288926153846
00:27:43.929 --> 00:27:45.981 difference and is it a morally relevant
NOTE Confidence: 0.980288926153846
00:27:45.981 --> 00:27:47.516 difference between these two people?
NOTE Confidence: 0.980288926153846
00:27:47.520 --> 00:27:48.420 And I think in general,
NOTE Confidence: 0.980288926153846
00:27:48.420 --> 00:27:50.820 if we're trying to find the
NOTE Confidence: 0.980288926153846
00:27:50.820 --> 00:27:52.420 difference largely it should
NOTE Confidence: 0.980288926153846
00:27:52.496 --> 00:27:54.566 be a difference in prognosis.
NOTE Confidence: 0.980288926153846
00:27:54.570 --> 00:27:55.746 OK, prognosis,
NOTE Confidence: 0.980288926153846

00:27:55.746 --> 00:27:56.334 feasibility,
NOTE Confidence: 0.980288926153846

00:27:56.334 --> 00:27:58.900 relevant rights and also with a caution.
NOTE Confidence: 0.980288926153846

00:27:58.900 --> 00:28:01.492 Our attitudes and values will locate
NOTE Confidence: 0.980288926153846

00:28:01.492 --> 00:28:03.664 where a proposed treatment or
NOTE Confidence: 0.980288926153846

00:28:03.664 --> 00:28:05.896 screening test falls on that scale.
NOTE Confidence: 0.980288926153846

00:28:05.900 --> 00:28:07.250 How might we get it wrong?
NOTE Confidence: 0.980288926153846

00:28:07.250 --> 00:28:08.797 We might get it wrong when we're
NOTE Confidence: 0.980288926153846

00:28:08.797 --> 00:28:09.970 not honest with ourselves.
NOTE Confidence: 0.980288926153846

00:28:09.970 --> 00:28:11.770 This is, of course, William Shakespeare,
NOTE Confidence: 0.980288926153846

00:28:11.770 --> 00:28:13.525 who in one of his plays when the old
NOTE Confidence: 0.980288926153846

00:28:13.525 --> 00:28:15.380 man sends his son out into the world.
NOTE Confidence: 0.980288926153846

00:28:15.380 --> 00:28:16.910 He says this above all else
NOTE Confidence: 0.980288926153846

00:28:16.910 --> 00:28:18.449 to thine own self be true.
NOTE Confidence: 0.980288926153846

00:28:18.450 --> 00:28:20.256 The one Shakespeare play or read in
NOTE Confidence: 0.980288926153846

00:28:20.256 --> 00:28:22.268 high school to the known self be true.
NOTE Confidence: 0.980288926153846

00:28:22.270 --> 00:28:23.516 Then it must follow as the night.

NOTE Confidence: 0.980288926153846
00:28:23.520 --> 00:28:24.990 Today though cannot be false
NOTE Confidence: 0.980288926153846
00:28:24.990 --> 00:28:26.166 to any other man.
NOTE Confidence: 0.980288926153846
00:28:26.170 --> 00:28:27.801 So we've got to be honest about
NOTE Confidence: 0.980288926153846
00:28:27.801 --> 00:28:29.268 what the data show and what
NOTE Confidence: 0.980288926153846
00:28:29.268 --> 00:28:30.684 the limits of the data are.
NOTE Confidence: 0.980288926153846
00:28:30.690 --> 00:28:32.260 First, we're honest with ourselves.
NOTE Confidence: 0.980288926153846
00:28:32.260 --> 00:28:33.556 Do we really know what would
NOTE Confidence: 0.980288926153846
00:28:33.556 --> 00:28:35.042 happen if we gave this treatment
NOTE Confidence: 0.980288926153846
00:28:35.042 --> 00:28:36.740 if we didn't give this treatment,
NOTE Confidence: 0.980288926153846
00:28:36.740 --> 00:28:38.696 do we really know the likelihood
NOTE Confidence: 0.980288926153846
00:28:38.696 --> 00:28:39.348 of catastrophe?
NOTE Confidence: 0.980288926153846
00:28:39.350 --> 00:28:40.660 If we don't do this,
NOTE Confidence: 0.980288926153846
00:28:40.660 --> 00:28:43.140 we gotta be honest with ourselves about this.
NOTE Confidence: 0.980288926153846
00:28:43.140 --> 00:28:44.904 We also have to think about a
NOTE Confidence: 0.980288926153846
00:28:44.904 --> 00:28:46.614 risk for injustice that could come
NOTE Confidence: 0.980288926153846

00:28:46.614 --> 00:28:48.109 from the savviness requirement and
NOTE Confidence: 0.980288926153846

00:28:48.109 --> 00:28:49.820 by the sadness requirement.
NOTE Confidence: 0.980288926153846

00:28:49.820 --> 00:28:52.016 What I mean is that if we say well,
NOTE Confidence: 0.980288926153846

00:28:52.020 --> 00:28:53.360 I'm willing to offer something
NOTE Confidence: 0.980288926153846

00:28:53.360 --> 00:28:55.109 to someone if they ask for it,
NOTE Confidence: 0.9876692

00:28:55.110 --> 00:28:57.024 but I would never offered to
NOTE Confidence: 0.9876692

00:28:57.024 --> 00:28:59.119 them if they don't ask for it.
NOTE Confidence: 0.9876692

00:28:59.120 --> 00:29:00.772 That means that the people who are
NOTE Confidence: 0.9876692

00:29:00.772 --> 00:29:02.378 savvy enough to know as an option,
NOTE Confidence: 0.9876692

00:29:02.380 --> 00:29:03.820 perhaps they have a relative
NOTE Confidence: 0.9876692

00:29:03.820 --> 00:29:05.260 in the health care business.
NOTE Confidence: 0.9876692

00:29:05.260 --> 00:29:06.700 Perhaps they're very skilled
NOTE Confidence: 0.9876692

00:29:06.700 --> 00:29:07.780 with the Internet.
NOTE Confidence: 0.9876692

00:29:07.780 --> 00:29:09.412 They're given more options than people
NOTE Confidence: 0.9876692

00:29:09.412 --> 00:29:11.326 who don't have friends or family in
NOTE Confidence: 0.9876692

00:29:11.326 --> 00:29:13.139 healthcare and aren't good with the Internet,

NOTE Confidence: 0.9876692

00:29:13.140 --> 00:29:14.498 and that seems an injustice to me.

NOTE Confidence: 0.9876692

00:29:14.500 --> 00:29:15.570 To treat these people differently,

NOTE Confidence: 0.9876692

00:29:15.570 --> 00:29:17.290 to give them different options

NOTE Confidence: 0.9876692

00:29:17.290 --> 00:29:19.700 based on their degree of savviness.

NOTE Confidence: 0.9876692

00:29:19.700 --> 00:29:21.884 This is a couple of ways we could

NOTE Confidence: 0.9876692

00:29:21.884 --> 00:29:24.058 get this ethical reasoning wrong.

NOTE Confidence: 0.9876692

00:29:24.060 --> 00:29:25.684 But how we do this and how we

NOTE Confidence: 0.9876692

00:29:25.684 --> 00:29:27.027 create these sorts of things is

NOTE Confidence: 0.9876692

00:29:27.027 --> 00:29:28.653 that we need to function as a

NOTE Confidence: 0.9876692

00:29:28.653 --> 00:29:30.099 team and think ahead when we're

NOTE Confidence: 0.9876692

00:29:30.099 --> 00:29:31.386 deciding about a specific treatment,

NOTE Confidence: 0.9876692

00:29:31.386 --> 00:29:33.332 and so I would say we need

NOTE Confidence: 0.9876692

00:29:33.332 --> 00:29:34.810 to understand the data,

NOTE Confidence: 0.9876692

00:29:34.810 --> 00:29:36.868 including all the failures of the data,

NOTE Confidence: 0.9876692

00:29:36.870 --> 00:29:38.179 and we've done this in our division

NOTE Confidence: 0.9876692

00:29:38.179 --> 00:29:39.577 on a couple different issues and it
NOTE Confidence: 0.9876692

00:29:39.577 --> 00:29:41.210 takes a long time and it's hard work.
NOTE Confidence: 0.9876692

00:29:41.210 --> 00:29:42.464 We need to get together and
NOTE Confidence: 0.9876692

00:29:42.464 --> 00:29:43.490 we don't just say OK.
NOTE Confidence: 0.9876692

00:29:43.490 --> 00:29:44.764 So what do we want to do
NOTE Confidence: 0.9876692

00:29:44.764 --> 00:29:45.749 about children at 22 weeks?
NOTE Confidence: 0.9876692

00:29:45.750 --> 00:29:47.397 What do we want to do about trisomy 13?
NOTE Confidence: 0.9876692

00:29:47.400 --> 00:29:48.569 Let me see you show a hands.
NOTE Confidence: 0.9876692

00:29:48.570 --> 00:29:50.730 OK, this is what we're going to do now.
NOTE Confidence: 0.9876692

00:29:50.730 --> 00:29:52.210 I don't think that's adequate.
NOTE Confidence: 0.9876692

00:29:52.210 --> 00:29:53.398 I think we need to really
NOTE Confidence: 0.9876692

00:29:53.398 --> 00:29:54.190 work through the data.
NOTE Confidence: 0.9876692

00:29:54.190 --> 00:29:56.272 Strengths and weaknesses we need to
NOTE Confidence: 0.9876692

00:29:56.272 --> 00:29:58.055 consider the relevant rights and
NOTE Confidence: 0.9876692

00:29:58.055 --> 00:29:59.730 obligations and the relevant laws
NOTE Confidence: 0.9876692

00:29:59.730 --> 00:30:01.770 we need to make a fair and feasible

NOTE Confidence: 0.9876692

00:30:01.770 --> 00:30:03.789 plan prior to the crisis or conflict.

NOTE Confidence: 0.9876692

00:30:03.790 --> 00:30:04.369 We don't know.

NOTE Confidence: 0.9876692

00:30:04.369 --> 00:30:05.527 Wait till it's midnight and a

NOTE Confidence: 0.9876692

00:30:05.527 --> 00:30:06.589 mother is refusing something.

NOTE Confidence: 0.9876692

00:30:06.590 --> 00:30:09.037 We need to make a plan ahead of time.

NOTE Confidence: 0.9876692

00:30:09.037 --> 00:30:11.480 And we need to recognize the need

NOTE Confidence: 0.9876692

00:30:11.560 --> 00:30:13.664 for consensus, which is to say,

NOTE Confidence: 0.9876692

00:30:13.664 --> 00:30:14.748 we can't say that.

NOTE Confidence: 0.9876692

00:30:14.750 --> 00:30:16.970 Well, you know on Tuesday night,

NOTE Confidence: 0.9876692

00:30:16.970 --> 00:30:18.834 Steve would say he has to get it.

NOTE Confidence: 0.9876692

00:30:18.840 --> 00:30:19.704 But on Wednesday night,

NOTE Confidence: 0.9876692

00:30:19.704 --> 00:30:21.000 Mark would say the kid doesn't

NOTE Confidence: 0.9876692

00:30:21.040 --> 00:30:21.640 have to get it.

NOTE Confidence: 0.9876692

00:30:21.640 --> 00:30:23.120 And then on Thursday morning,

NOTE Confidence: 0.9876692

00:30:23.120 --> 00:30:23.384 uh,

NOTE Confidence: 0.9876692

00:30:23.384 --> 00:30:25.232 now Naomi comes in and she says
NOTE Confidence: 0.9876692

00:30:25.232 --> 00:30:26.928 now the kid should get it.
NOTE Confidence: 0.9876692

00:30:26.930 --> 00:30:28.962 Should we can't function like that as a
NOTE Confidence: 0.9876692

00:30:28.962 --> 00:30:31.468 team if we're all sharing the same patients?
NOTE Confidence: 0.9876692

00:30:31.470 --> 00:30:32.716 We've got to get ourselves on the
NOTE Confidence: 0.9876692

00:30:32.716 --> 00:30:34.084 same page and we've got to agree
NOTE Confidence: 0.9876692

00:30:34.084 --> 00:30:35.266 that we're going to work together
NOTE Confidence: 0.9876692

00:30:35.312 --> 00:30:36.494 to come to some consensus about
NOTE Confidence: 0.9876692

00:30:36.494 --> 00:30:38.343 what our approach is going to be,
NOTE Confidence: 0.9876692

00:30:38.343 --> 00:30:40.098 whether it's vitamin K administration.
NOTE Confidence: 0.9876692

00:30:40.100 --> 00:30:42.315 Or resuscitation at 22 weeks
NOTE Confidence: 0.9876692

00:30:42.315 --> 00:30:44.530 or whatever the question is.
NOTE Confidence: 0.9876692

00:30:44.530 --> 00:30:46.266 We also have to see that there's
NOTE Confidence: 0.9876692

00:30:46.266 --> 00:30:47.496 occasionally a need to deviate
NOTE Confidence: 0.9876692

00:30:47.496 --> 00:30:49.216 from the plan once we make a plan.
NOTE Confidence: 0.9876692

00:30:49.220 --> 00:30:51.380 Sometimes we may want to deviate from it,

NOTE Confidence: 0.9876692

00:30:51.380 --> 00:30:53.984 but again, there's a risk for injustice.

NOTE Confidence: 0.9876692

00:30:53.990 --> 00:30:54.890 Here's what we're going to do,

NOTE Confidence: 0.9876692

00:30:54.890 --> 00:30:55.638 but you know what?

NOTE Confidence: 0.9876692

00:30:55.638 --> 00:30:56.199 In this case,

NOTE Confidence: 0.9876692

00:30:56.200 --> 00:30:57.982 I'm going to give these parents

NOTE Confidence: 0.9876692

00:30:57.982 --> 00:30:59.424 more latitude. Well, why is that?

NOTE Confidence: 0.9876692

00:30:59.424 --> 00:31:00.971 Is it because they look more like

NOTE Confidence: 0.9876692

00:31:00.971 --> 00:31:02.357 my family than someone else is?

NOTE Confidence: 0.9876692

00:31:02.360 --> 00:31:02.591 Family?

NOTE Confidence: 0.9876692

00:31:02.591 --> 00:31:03.977 Is it because these parents seem

NOTE Confidence: 0.9876692

00:31:03.977 --> 00:31:05.340 to me to be very kind,

NOTE Confidence: 0.988557396

00:31:05.340 --> 00:31:06.770 whereas other parents were rude?

NOTE Confidence: 0.988557396

00:31:06.770 --> 00:31:09.218 So that doesn't mean that the parents who I

NOTE Confidence: 0.988557396

00:31:09.218 --> 00:31:11.277 perceive as rude should have fewer options

NOTE Confidence: 0.988557396

00:31:11.280 --> 00:31:13.485 so we can call an audible if you will.

NOTE Confidence: 0.988557396

00:31:13.490 --> 00:31:14.780 But we have to be careful.
NOTE Confidence: 0.988557396

00:31:14.780 --> 00:31:16.372 Because there's a real
NOTE Confidence: 0.988557396

00:31:16.372 --> 00:31:17.964 risk for injustice there.
NOTE Confidence: 0.988557396

00:31:17.970 --> 00:31:19.275 Well, this is the fundamental
NOTE Confidence: 0.988557396

00:31:19.275 --> 00:31:21.229 question I want to talk about today.
NOTE Confidence: 0.988557396

00:31:21.230 --> 00:31:22.718 This is where this is where we're going.
NOTE Confidence: 0.988557396

00:31:22.720 --> 00:31:24.360 What about newborn screening?
NOTE Confidence: 0.988557396

00:31:24.360 --> 00:31:26.410 We screen these children for
NOTE Confidence: 0.988557396

00:31:26.410 --> 00:31:28.622 rare but potentially serious
NOTE Confidence: 0.988557396

00:31:28.622 --> 00:31:30.350 potentially lethal disorders.
NOTE Confidence: 0.988557396

00:31:30.350 --> 00:31:32.450 What about vitamin K administration?
NOTE Confidence: 0.988557396

00:31:32.450 --> 00:31:35.294 We give vitamin K to every baby to prevent
NOTE Confidence: 0.988557396

00:31:35.294 --> 00:31:37.020 hemorrhagic disease of the newborn.
NOTE Confidence: 0.988557396

00:31:37.020 --> 00:31:38.780 Sometimes parents refuse it.
NOTE Confidence: 0.988557396

00:31:38.780 --> 00:31:40.980 Jasprit may comment on that.
NOTE Confidence: 0.988557396

00:31:40.980 --> 00:31:42.560 Others may comment on it.

NOTE Confidence: 0.988557396

00:31:42.560 --> 00:31:44.260 What about a sepsis evaluation

NOTE Confidence: 0.988557396

00:31:44.260 --> 00:31:45.280 for risk factors?

NOTE Confidence: 0.988557396

00:31:45.280 --> 00:31:47.530 This is really interesting because.

NOTE Confidence: 0.988557396

00:31:47.530 --> 00:31:49.060 This is what provoked this

NOTE Confidence: 0.988557396

00:31:49.060 --> 00:31:50.284 conversation to begin with,

NOTE Confidence: 0.988557396

00:31:50.290 --> 00:31:51.766 where we have a child who,

NOTE Confidence: 0.988557396

00:31:51.770 --> 00:31:52.796 by our calculations,

NOTE Confidence: 0.988557396

00:31:52.796 --> 00:31:55.601 the risk of early onset sepsis is high

NOTE Confidence: 0.988557396

00:31:55.601 --> 00:31:58.155 enough that we want to draw blood culture.

NOTE Confidence: 0.988557396

00:31:58.160 --> 00:31:58.281 Well,

NOTE Confidence: 0.988557396

00:31:58.281 --> 00:31:59.007 what does it have to be?

NOTE Confidence: 0.988557396

00:31:59.010 --> 00:32:01.458 It has to be better by our protocol and

NOTE Confidence: 0.988557396

00:32:01.458 --> 00:32:03.716 commonly accepted protocols in the country.

NOTE Confidence: 0.988557396

00:32:03.720 --> 00:32:06.483 If the chance of sepsis is greater than 1000,

NOTE Confidence: 0.988557396

00:32:06.490 --> 00:32:07.606 we're going to draw blood culture.

NOTE Confidence: 0.988557396

00:32:07.610 --> 00:32:09.068 If it's greater than three and
NOTE Confidence: 0.988557396

00:32:09.068 --> 00:32:10.532 1000 and someone correct me if
NOTE Confidence: 0.988557396

00:32:10.532 --> 00:32:11.637 I've got these numbers wrong,
NOTE Confidence: 0.988557396

00:32:11.640 --> 00:32:12.750 we're going to give antibiotics.
NOTE Confidence: 0.988557396

00:32:12.750 --> 00:32:14.286 We get the blood culture and
NOTE Confidence: 0.988557396

00:32:14.286 --> 00:32:15.647 give antibiotics for a couple
NOTE Confidence: 0.988557396

00:32:15.647 --> 00:32:17.327 days and watch this kid closely.
NOTE Confidence: 0.988557396

00:32:17.330 --> 00:32:18.400 Now it's an interesting question.
NOTE Confidence: 0.988557396

00:32:18.400 --> 00:32:20.066 If there's a three and 1000 chance,
NOTE Confidence: 0.988557396

00:32:20.070 --> 00:32:21.210 what if the parents say no?
NOTE Confidence: 0.988557396

00:32:21.210 --> 00:32:23.466 I don't want those antibiotics for my child,
NOTE Confidence: 0.988557396

00:32:23.470 --> 00:32:24.590 and we say, well,
NOTE Confidence: 0.988557396

00:32:24.590 --> 00:32:26.578 this is serious business right there as
NOTE Confidence: 0.988557396

00:32:26.578 --> 00:32:28.349 early onset sepsis can kill a child.
NOTE Confidence: 0.988557396

00:32:28.350 --> 00:32:29.565 We've seen it.
NOTE Confidence: 0.988557396

00:32:29.565 --> 00:32:30.780 We know this.

NOTE Confidence: 0.988557396

00:32:30.780 --> 00:32:32.328 This is a very high degree

NOTE Confidence: 0.988557396

00:32:32.328 --> 00:32:33.880 of harm if it occurs,

NOTE Confidence: 0.988557396

00:32:33.880 --> 00:32:36.706 but there's a low risk of the adverse event,

NOTE Confidence: 0.988557396

00:32:36.710 --> 00:32:37.970 and that's what makes it tricky.

NOTE Confidence: 0.988557396

00:32:37.970 --> 00:32:40.784 When we were questioning people about the

NOTE Confidence: 0.988557396

00:32:40.784 --> 00:32:42.300 antibiotics, I mean the thing we got.

NOTE Confidence: 0.988557396

00:32:42.300 --> 00:32:42.543 Well,

NOTE Confidence: 0.988557396

00:32:42.543 --> 00:32:44.244 you're trying to prevent a very serious,

NOTE Confidence: 0.988557396

00:32:44.250 --> 00:32:45.282 potentially fatal illness.

NOTE Confidence: 0.988557396

00:32:45.282 --> 00:32:45.626 Yeah,

NOTE Confidence: 0.988557396

00:32:45.626 --> 00:32:48.339 but at some point at some point does

NOTE Confidence: 0.988557396

00:32:48.339 --> 00:32:50.376 the low risk of that adverse event

NOTE Confidence: 0.988557396

00:32:50.376 --> 00:32:52.510 way into our decision about whether

NOTE Confidence: 0.988557396

00:32:52.510 --> 00:32:54.518 it should be advisable or obligatory.

NOTE Confidence: 0.988557396

00:32:54.518 --> 00:32:55.963 We're trying to find that

NOTE Confidence: 0.988557396

00:32:55.963 --> 00:32:57.230 now highlighted in yellow,
NOTE Confidence: 0.988557396

00:32:57.230 --> 00:32:58.930 that threshold between advisable
NOTE Confidence: 0.988557396

00:32:58.930 --> 00:32:59.780 and obligatory.
NOTE Confidence: 0.988557396

00:32:59.780 --> 00:33:01.556 Certainly we all advise vitamin K.
NOTE Confidence: 0.988557396

00:33:01.560 --> 00:33:02.784 Prophylaxis for hemorrhagic
NOTE Confidence: 0.988557396

00:33:02.784 --> 00:33:04.416 disease of the newborn.
NOTE Confidence: 0.988557396

00:33:04.420 --> 00:33:04.972 I mean,
NOTE Confidence: 0.988557396

00:33:04.972 --> 00:33:06.684 fewer than 1% of those kids are
NOTE Confidence: 0.988557396

00:33:06.684 --> 00:33:08.010 going to get hemorrhagic disease of
NOTE Confidence: 0.988557396

00:33:08.060 --> 00:33:10.040 the newborn if they don't get it,
NOTE Confidence: 0.988557396

00:33:10.040 --> 00:33:11.240 but we feel that that risk,
NOTE Confidence: 0.988557396

00:33:11.240 --> 00:33:12.768 you know, should we.
NOTE Confidence: 0.988557396

00:33:12.768 --> 00:33:14.296 Should it be obligatory,
NOTE Confidence: 0.988557396

00:33:14.300 --> 00:33:16.988 we've got to try and define what that
NOTE Confidence: 0.988557396

00:33:16.988 --> 00:33:18.871 threshold should be for these things
NOTE Confidence: 0.988557396

00:33:18.871 --> 00:33:21.339 and for any other tests we want to do.

NOTE Confidence: 0.988557396

00:33:21.340 --> 00:33:23.600 So that's the simple man.

NOTE Confidence: 0.988557396

00:33:23.600 --> 00:33:24.371 A simple question,

NOTE Confidence: 0.988557396

00:33:24.371 --> 00:33:26.198 and here's what I think I think,

NOTE Confidence: 0.988557396

00:33:26.198 --> 00:33:28.350 as we as we move across that line

NOTE Confidence: 0.988557396

00:33:28.419 --> 00:33:30.279 from advisable to obligatory,

NOTE Confidence: 0.988557396

00:33:30.280 --> 00:33:32.464 that's going to be determined by the risk

NOTE Confidence: 0.988557396

00:33:32.464 --> 00:33:34.516 or burden of the screen or treatment.

NOTE Confidence: 0.988557396

00:33:34.520 --> 00:33:34.858 OK,

NOTE Confidence: 0.988557396

00:33:34.858 --> 00:33:37.900 if it's a newborn screen or a sepsis screen,

NOTE Confidence: 0.985690532307692

00:33:37.900 --> 00:33:39.192 or giving vitamin K.

NOTE Confidence: 0.985690532307692

00:33:39.192 --> 00:33:42.350 If there's a risk or burden to the treatment,

NOTE Confidence: 0.985690532307692

00:33:42.350 --> 00:33:44.250 the more the risk gets, the less likely

NOTE Confidence: 0.985690532307692

00:33:44.250 --> 00:33:46.410 it is that it's going to be obligatory.

NOTE Confidence: 0.985690532307692

00:33:46.410 --> 00:33:47.940 The severity of harm if we

NOTE Confidence: 0.985690532307692

00:33:47.940 --> 00:33:49.839 don't do it as that goes up,

NOTE Confidence: 0.985690532307692

00:33:49.840 --> 00:33:51.720 that's going to move things to the right.
NOTE Confidence: 0.985690532307692

00:33:51.720 --> 00:33:52.648 OK, and of course,
NOTE Confidence: 0.985690532307692

00:33:52.648 --> 00:33:54.340 as the severity of harm gets work,
NOTE Confidence: 0.985690532307692

00:33:54.340 --> 00:33:56.367 it goes to the right and X&Y.
NOTE Confidence: 0.985690532307692

00:33:56.367 --> 00:33:57.849 I mean, you could just say
NOTE Confidence: 0.985690532307692

00:33:57.849 --> 00:33:59.498 if we looked at this simply,
NOTE Confidence: 0.985690532307692

00:33:59.500 --> 00:34:02.034 we'd say well, how obligatory is it?
NOTE Confidence: 0.985690532307692

00:34:02.040 --> 00:34:04.850 Well, that comes with an answer of y -- X.
NOTE Confidence: 0.985690532307692

00:34:04.850 --> 00:34:07.460 If this is really bad harm that could come,
NOTE Confidence: 0.985690532307692

00:34:07.460 --> 00:34:09.630 then it becomes more obligatory if
NOTE Confidence: 0.985690532307692

00:34:09.630 --> 00:34:11.520 the risk or burden of the screen
NOTE Confidence: 0.985690532307692

00:34:11.520 --> 00:34:12.959 or treatment is really high.
NOTE Confidence: 0.985690532307692

00:34:12.960 --> 00:34:14.380 It becomes less obligatory,
NOTE Confidence: 0.985690532307692

00:34:14.380 --> 00:34:16.510 but importantly in the thing that
NOTE Confidence: 0.985690532307692

00:34:16.576 --> 00:34:18.496 gets lost in these conversations.
NOTE Confidence: 0.985690532307692

00:34:18.500 --> 00:34:19.976 Is there something else,

NOTE Confidence: 0.985690532307692
00:34:19.976 --> 00:34:21.821 and that's the likelihood of
NOTE Confidence: 0.985690532307692
00:34:21.821 --> 00:34:23.407 harm if we don't do it?
NOTE Confidence: 0.985690532307692
00:34:23.410 --> 00:34:26.245 Consider if I have a screening test for a
NOTE Confidence: 0.985690532307692
00:34:26.245 --> 00:34:28.774 disorder and if I find it I can prevent it,
NOTE Confidence: 0.985690532307692
00:34:28.780 --> 00:34:30.420 and if I told you that if I
NOTE Confidence: 0.985690532307692
00:34:30.420 --> 00:34:31.687 could prevent it if I find it.
NOTE Confidence: 0.985690532307692
00:34:31.690 --> 00:34:33.930 If I do the screen test one out of 10 kids,
NOTE Confidence: 0.985690532307692
00:34:33.930 --> 00:34:35.690 I'm going to find a fatal problem and
NOTE Confidence: 0.985690532307692
00:34:35.690 --> 00:34:37.355 I'm going to be able to prevent it.
NOTE Confidence: 0.985690532307692
00:34:37.360 --> 00:34:38.809 I think you would say to me,
NOTE Confidence: 0.985690532307692
00:34:38.810 --> 00:34:40.256 wow, you should have to do.
NOTE Confidence: 0.985690532307692
00:34:40.260 --> 00:34:41.360 Even if parents refuse it.
NOTE Confidence: 0.985690532307692
00:34:41.360 --> 00:34:43.005 One of the ten chance you could
NOTE Confidence: 0.985690532307692
00:34:43.005 --> 00:34:44.692 save this kid's life by doing this
NOTE Confidence: 0.985690532307692
00:34:44.692 --> 00:34:46.548 screen you should do it one at a 10.
NOTE Confidence: 0.985690532307692

00:34:46.548 --> 00:34:46.720 OK,
NOTE Confidence: 0.985690532307692

00:34:46.720 --> 00:34:48.480 so now if I say as a one out of
NOTE Confidence: 0.985690532307692

00:34:48.543 --> 00:34:50.217 10 million chance that I could
NOTE Confidence: 0.985690532307692

00:34:50.217 --> 00:34:52.283 save this child by doing this now,
NOTE Confidence: 0.985690532307692

00:34:52.283 --> 00:34:53.252 does that affect?
NOTE Confidence: 0.985690532307692

00:34:53.252 --> 00:34:55.190 I think that affects where we
NOTE Confidence: 0.985690532307692

00:34:55.257 --> 00:34:56.747 locate this on the line.
NOTE Confidence: 0.985690532307692

00:34:56.750 --> 00:34:58.654 We're going to try and find some kind
NOTE Confidence: 0.985690532307692

00:34:58.654 --> 00:35:01.058 of a threshold now as a case in point,
NOTE Confidence: 0.985690532307692

00:35:01.060 --> 00:35:03.376 we went through this analysis here.
NOTE Confidence: 0.985690532307692

00:35:03.380 --> 00:35:05.170 A few of us here not long ago and we
NOTE Confidence: 0.985690532307692

00:35:05.225 --> 00:35:07.019 published it just earlier this year.
NOTE Confidence: 0.985690532307692

00:35:07.020 --> 00:35:08.464 The Journal of Pediatrics.
NOTE Confidence: 0.985690532307692

00:35:08.464 --> 00:35:11.590 Babies who are at risk for hypoglycemia,
NOTE Confidence: 0.985690532307692

00:35:11.590 --> 00:35:12.331 low blood sugar,
NOTE Confidence: 0.985690532307692

00:35:12.331 --> 00:35:14.424 and they can be at risk because the

NOTE Confidence: 0.985690532307692
00:35:14.424 --> 00:35:15.944 mother had gestational diabetes or
NOTE Confidence: 0.985690532307692
00:35:15.944 --> 00:35:17.993 because the kids are very small or
NOTE Confidence: 0.985690532307692
00:35:17.993 --> 00:35:19.406 very large, or some other things.
NOTE Confidence: 0.985690532307692
00:35:19.406 --> 00:35:21.629 Kids who are at risk but are asymptomatic,
NOTE Confidence: 0.985690532307692
00:35:21.630 --> 00:35:22.407 they look beautiful,
NOTE Confidence: 0.985690532307692
00:35:22.407 --> 00:35:23.961 but we know they're at higher
NOTE Confidence: 0.985690532307692
00:35:23.961 --> 00:35:25.069 risk for hypoglycemia.
NOTE Confidence: 0.985690532307692
00:35:25.070 --> 00:35:28.045 We advise we advise a specific screening.
NOTE Confidence: 0.985690532307692
00:35:28.050 --> 00:35:29.676 We check their blood sugar hourly
NOTE Confidence: 0.985690532307692
00:35:29.676 --> 00:35:31.350 or periodically as we go along
NOTE Confidence: 0.985690532307692
00:35:31.350 --> 00:35:32.690 we monitor their blood sugar.
NOTE Confidence: 0.985690532307692
00:35:32.690 --> 00:35:33.908 We poke their heal a little bit,
NOTE Confidence: 0.985690532307692
00:35:33.910 --> 00:35:35.734 we sample some blood and we
NOTE Confidence: 0.985690532307692
00:35:35.734 --> 00:35:36.950 check their blood sugar.
NOTE Confidence: 0.985690532307692
00:35:36.950 --> 00:35:39.274 The question was raised now last year.
NOTE Confidence: 0.985690532307692

00:35:39.280 --> 00:35:39.657 Well,
NOTE Confidence: 0.985690532307692

00:35:39.657 --> 00:35:41.542 what happens when parents refuse
NOTE Confidence: 0.985690532307692

00:35:41.542 --> 00:35:43.272 that screen and so we did?
NOTE Confidence: 0.985690532307692

00:35:43.272 --> 00:35:43.758 An analysis.
NOTE Confidence: 0.985690532307692

00:35:43.760 --> 00:35:45.416 Let's really take a look at the data.
NOTE Confidence: 0.985690532307692

00:35:45.420 --> 00:35:47.002 How likely is it that we're going
NOTE Confidence: 0.985690532307692

00:35:47.002 --> 00:35:47.680 to prevent harm?
NOTE Confidence: 0.985690532307692

00:35:47.680 --> 00:35:49.726 We all know that severe hypoglycemia
NOTE Confidence: 0.985690532307692

00:35:49.726 --> 00:35:51.600 can lead to brain damage,
NOTE Confidence: 0.985690532307692

00:35:51.600 --> 00:35:52.952 seizures, and brain damage.
NOTE Confidence: 0.985690532307692

00:35:52.952 --> 00:35:53.966 That's serious business.
NOTE Confidence: 0.985690532307692

00:35:53.970 --> 00:35:54.143 Well,
NOTE Confidence: 0.985690532307692

00:35:54.143 --> 00:35:55.700 how likely is it going to be if we
NOTE Confidence: 0.984230612272727

00:35:55.745 --> 00:35:57.065 have an asymptomatic newborn that
NOTE Confidence: 0.984230612272727

00:35:57.065 --> 00:35:58.820 we're going to prevent that you know?
NOTE Confidence: 0.984230612272727

00:35:58.820 --> 00:36:00.710 How good is our screen?

NOTE Confidence: 0.984230612272727
00:36:00.710 --> 00:36:02.200 How good is our treatment?
NOTE Confidence: 0.984230612272727
00:36:02.200 --> 00:36:04.279 We went through all these data and
NOTE Confidence: 0.984230612272727
00:36:04.279 --> 00:36:05.800 essentially what we determined in the
NOTE Confidence: 0.984230612272727
00:36:05.800 --> 00:36:07.240 analysis and it's published in JPS.
NOTE Confidence: 0.984230612272727
00:36:07.240 --> 00:36:10.050 If you'd like to read it was you know what?
NOTE Confidence: 0.984230612272727
00:36:10.050 --> 00:36:12.250 Then the screening for hypoglycemia.
NOTE Confidence: 0.984230612272727
00:36:12.250 --> 00:36:13.738 This reaches what we
NOTE Confidence: 0.984230612272727
00:36:13.738 --> 00:36:15.226 consider to be advisable.
NOTE Confidence: 0.984230612272727
00:36:15.230 --> 00:36:16.546 Yeah, we think it's a good idea.
NOTE Confidence: 0.984230612272727
00:36:16.550 --> 00:36:17.366 We recommend it.
NOTE Confidence: 0.984230612272727
00:36:17.366 --> 00:36:19.610 This is our standard care in our unit,
NOTE Confidence: 0.984230612272727
00:36:19.610 --> 00:36:21.360 and I think pretty much throughout the
NOTE Confidence: 0.984230612272727
00:36:21.360 --> 00:36:23.297 country for kids at risk for hypoglycemia.
NOTE Confidence: 0.984230612272727
00:36:23.300 --> 00:36:23.975 But in fact,
NOTE Confidence: 0.984230612272727
00:36:23.975 --> 00:36:25.550 if you really look at the data
NOTE Confidence: 0.984230612272727

00:36:25.603 --> 00:36:27.328 and consider the relevant rights,
NOTE Confidence: 0.984230612272727

00:36:27.330 --> 00:36:28.930 which is to say at some point the
NOTE Confidence: 0.984230612272727

00:36:28.930 --> 00:36:30.283 parents have a right to control
NOTE Confidence: 0.984230612272727

00:36:30.283 --> 00:36:31.418 what happens to their child.
NOTE Confidence: 0.984230612272727

00:36:31.420 --> 00:36:31.946 In fact,
NOTE Confidence: 0.984230612272727

00:36:31.946 --> 00:36:33.787 there's not enough data to say that
NOTE Confidence: 0.984230612272727

00:36:33.787 --> 00:36:35.568 this should be able to get or so
NOTE Confidence: 0.984230612272727

00:36:35.568 --> 00:36:37.411 in the case of neonatal screening
NOTE Confidence: 0.984230612272727

00:36:37.411 --> 00:36:39.341 for neonatal hypoglycemia in an
NOTE Confidence: 0.984230612272727

00:36:39.341 --> 00:36:41.128 asymptomatic baby, I want to emphasize.
NOTE Confidence: 0.984230612272727

00:36:41.128 --> 00:36:43.201 This isn't a child who's jittery or or
NOTE Confidence: 0.984230612272727

00:36:43.201 --> 00:36:44.979 is having seizures or something like that.
NOTE Confidence: 0.984230612272727

00:36:44.980 --> 00:36:46.500 This account is perfectly looks,
NOTE Confidence: 0.984230612272727

00:36:46.500 --> 00:36:47.202 looks perfect.
NOTE Confidence: 0.984230612272727

00:36:47.202 --> 00:36:50.008 We would say that yes, it's advisable,
NOTE Confidence: 0.984230612272727

00:36:50.008 --> 00:36:51.580 but not obligatory.

NOTE Confidence: 0.984230612272727
00:36:51.580 --> 00:36:52.760 That's one case in point.
NOTE Confidence: 0.984230612272727
00:36:52.760 --> 00:36:54.176 Now you could look at the same data
NOTE Confidence: 0.984230612272727
00:36:54.176 --> 00:36:55.627 and come to a different conclusion.
NOTE Confidence: 0.984230612272727
00:36:55.630 --> 00:36:56.306 Of course,
NOTE Confidence: 0.984230612272727
00:36:56.306 --> 00:36:58.334 it's invariably has to be subjective
NOTE Confidence: 0.984230612272727
00:36:58.334 --> 00:37:00.554 'cause we have to figure out what
NOTE Confidence: 0.984230612272727
00:37:00.554 --> 00:37:02.835 that threshold is going to be or
NOTE Confidence: 0.984230612272727
00:37:02.835 --> 00:37:04.299 advisable and obligatory cross.
NOTE Confidence: 0.984230612272727
00:37:04.300 --> 00:37:05.872 And I think that should be
NOTE Confidence: 0.984230612272727
00:37:05.872 --> 00:37:07.564 determined by the risk or burden
NOTE Confidence: 0.984230612272727
00:37:07.564 --> 00:37:09.019 of the Screener treatment X.
NOTE Confidence: 0.984230612272727
00:37:09.020 --> 00:37:11.856 The severity of harm if not done, why?
NOTE Confidence: 0.984230612272727
00:37:11.856 --> 00:37:15.600 And the likelihood of harm if not done so.
NOTE Confidence: 0.984230612272727
00:37:15.600 --> 00:37:17.136 It's not just how bad is
NOTE Confidence: 0.984230612272727
00:37:17.136 --> 00:37:18.620 hemorrhagic disease of the newborn,
NOTE Confidence: 0.984230612272727

00:37:18.620 --> 00:37:20.668 but how likely is it if we don't
NOTE Confidence: 0.984230612272727

00:37:20.668 --> 00:37:22.578 give vitamin K are or how not just a
NOTE Confidence: 0.984230612272727

00:37:22.578 --> 00:37:24.629 question of how bad is early onset sepsis?
NOTE Confidence: 0.984230612272727

00:37:24.630 --> 00:37:25.932 But how likely is it if we
NOTE Confidence: 0.984230612272727

00:37:25.932 --> 00:37:27.169 don't give the blood culture?
NOTE Confidence: 0.984230612272727

00:37:27.170 --> 00:37:29.122 If we don't do the blood culture and
NOTE Confidence: 0.984230612272727

00:37:29.122 --> 00:37:31.228 give the antibiotics and a final point
NOTE Confidence: 0.984230612272727

00:37:31.228 --> 00:37:34.660 about this is the importance of coherence.
NOTE Confidence: 0.984230612272727

00:37:34.660 --> 00:37:36.130 And as we think about this,
NOTE Confidence: 0.984230612272727

00:37:36.130 --> 00:37:38.340 rather than think about each
NOTE Confidence: 0.984230612272727

00:37:38.340 --> 00:37:39.666 specific screen independently,
NOTE Confidence: 0.984230612272727

00:37:39.670 --> 00:37:41.462 I think we should start by having
NOTE Confidence: 0.984230612272727

00:37:41.462 --> 00:37:43.000 a more global conversation.
NOTE Confidence: 0.984230612272727

00:37:43.000 --> 00:37:45.241 And and what I mean by coherence is if
NOTE Confidence: 0.984230612272727

00:37:45.241 --> 00:37:47.544 we say if we have one thing that's got
NOTE Confidence: 0.984230612272727

00:37:47.544 --> 00:37:50.074 a 100 chance of preventing disaster and

NOTE Confidence: 0.984230612272727
00:37:50.074 --> 00:37:53.316 we and we allow the parents to opt out.
NOTE Confidence: 0.984230612272727
00:37:53.320 --> 00:37:54.520 But we have something else
NOTE Confidence: 0.984230612272727
00:37:54.520 --> 00:37:56.113 that's got a one in 1000%,
NOTE Confidence: 0.984230612272727
00:37:56.113 --> 00:37:58.078 one in a thousand chance
NOTE Confidence: 0.984230612272727
00:37:58.078 --> 00:37:59.257 of preventing disaster.
NOTE Confidence: 0.984230612272727
00:37:59.260 --> 00:38:00.725 And we don't allow parents
NOTE Confidence: 0.984230612272727
00:38:00.725 --> 00:38:02.190 to opt out of that.
NOTE Confidence: 0.984230612272727
00:38:02.190 --> 00:38:03.910 That does not seem coherent.
NOTE Confidence: 0.984230612272727
00:38:03.910 --> 00:38:05.464 I think we've got to kind of
NOTE Confidence: 0.984230612272727
00:38:05.464 --> 00:38:07.165 get a handle roughly on where
NOTE Confidence: 0.984230612272727
00:38:07.165 --> 00:38:08.465 that threshold should be,
NOTE Confidence: 0.984230612272727
00:38:08.470 --> 00:38:10.120 and then apply that thinking
NOTE Confidence: 0.984230612272727
00:38:10.120 --> 00:38:11.770 to each screen in turn.
NOTE Confidence: 0.984230612272727
00:38:11.770 --> 00:38:13.560 Because it seems unfair to
NOTE Confidence: 0.984230612272727
00:38:13.560 --> 00:38:15.350 say to one parent listen,
NOTE Confidence: 0.984230612272727

00:38:15.350 --> 00:38:16.582 we have to do this because there's
NOTE Confidence: 0.984230612272727

00:38:16.582 --> 00:38:18.096 a one in 1000 chance it's going to
NOTE Confidence: 0.984230612272727

00:38:18.096 --> 00:38:19.613 help your kid and to say to the
NOTE Confidence: 0.984230612272727

00:38:19.613 --> 00:38:20.845 parent in the next room while we
NOTE Confidence: 0.987056658571429

00:38:20.850 --> 00:38:22.872 recommend we do this 'cause there's
NOTE Confidence: 0.987056658571429

00:38:22.872 --> 00:38:24.750 a 100% chance it could save your kid,
NOTE Confidence: 0.987056658571429

00:38:24.750 --> 00:38:26.450 but we're not going to do it if you insist,
NOTE Confidence: 0.987056658571429

00:38:26.450 --> 00:38:29.404 if you refuse, will respect that refusal.
NOTE Confidence: 0.987056658571429

00:38:29.410 --> 00:38:32.170 We need coherence in our approach.
NOTE Confidence: 0.987056658571429

00:38:32.170 --> 00:38:33.380 So what do you think?
NOTE Confidence: 0.987056658571429

00:38:33.380 --> 00:38:35.830 What other factors have I not considered?
NOTE Confidence: 0.987056658571429

00:38:35.830 --> 00:38:37.460 Who should participate in the
NOTE Confidence: 0.987056658571429

00:38:37.460 --> 00:38:39.090 discussion in the decision tonight?
NOTE Confidence: 0.987056658571429

00:38:39.090 --> 00:38:40.674 I want all of you to participate in
NOTE Confidence: 0.987056658571429

00:38:40.674 --> 00:38:42.124 the discussion because this is a real
NOTE Confidence: 0.987056658571429

00:38:42.124 --> 00:38:43.404 problem that we're trying to sort

NOTE Confidence: 0.987056658571429

00:38:43.404 --> 00:38:44.760 through the the clinical leadership of

NOTE Confidence: 0.987056658571429

00:38:44.760 --> 00:38:46.675 our NICU here at Yale and Casey guys

NOTE Confidence: 0.987056658571429

00:38:46.675 --> 00:38:48.925 on Steve Peterich are the ones who are

NOTE Confidence: 0.987056658571429

00:38:48.925 --> 00:38:50.520 who have instigated this conversation

NOTE Confidence: 0.987056658571429

00:38:50.520 --> 00:38:52.424 largely and and we want to be able

NOTE Confidence: 0.987056658571429

00:38:52.424 --> 00:38:54.733 to at some point give some guidance

NOTE Confidence: 0.987056658571429

00:38:54.733 --> 00:38:57.238 to the whole neonatology division.

NOTE Confidence: 0.987056658571429

00:38:57.240 --> 00:38:57.996 And what else?

NOTE Confidence: 0.987056658571429

00:38:57.996 --> 00:38:59.508 What else should go into this?

NOTE Confidence: 0.987056658571429

00:38:59.510 --> 00:39:01.568 UM, who should be making this decision,

NOTE Confidence: 0.987056658571429

00:39:01.570 --> 00:39:04.906 and what else should we be thinking about?

NOTE Confidence: 0.987056658571429

00:39:04.910 --> 00:39:06.524 Aside from just thinking that we

NOTE Confidence: 0.987056658571429

00:39:06.524 --> 00:39:08.539 all wish we were on Block Island,

NOTE Confidence: 0.987056658571429

00:39:08.540 --> 00:39:12.108 I guess that a final point I would

NOTE Confidence: 0.987056658571429

00:39:12.108 --> 00:39:15.656 make is that we are moral agents.

NOTE Confidence: 0.987056658571429

00:39:15.660 --> 00:39:18.558 We are responsible for what happens
NOTE Confidence: 0.987056658571429

00:39:18.558 --> 00:39:20.007 in our hospital.
NOTE Confidence: 0.987056658571429

00:39:20.010 --> 00:39:23.130 And sometimes we have to insist.
NOTE Confidence: 0.987056658571429

00:39:23.130 --> 00:39:24.726 And sometimes we have to refuse,
NOTE Confidence: 0.987056658571429

00:39:24.730 --> 00:39:25.630 which is to say,
NOTE Confidence: 0.987056658571429

00:39:25.630 --> 00:39:26.980 sometimes we have to seek to
NOTE Confidence: 0.987056658571429

00:39:27.030 --> 00:39:28.580 overrule what the parents want.
NOTE Confidence: 0.987056658571429

00:39:28.580 --> 00:39:30.400 And I think that sometimes
NOTE Confidence: 0.987056658571429

00:39:30.400 --> 00:39:31.128 that's appropriate.
NOTE Confidence: 0.987056658571429

00:39:31.130 --> 00:39:33.354 But it needs to be based on something
NOTE Confidence: 0.987056658571429

00:39:33.354 --> 00:39:35.154 more than because we say so.
NOTE Confidence: 0.987056658571429

00:39:35.154 --> 00:39:37.450 We need to do better than that.
NOTE Confidence: 0.987056658571429

00:39:37.450 --> 00:39:39.536 So with that I want to introduce
NOTE Confidence: 0.987056658571429

00:39:39.536 --> 00:39:40.430 this wonderful panel.
NOTE Confidence: 0.987056658571429

00:39:40.430 --> 00:39:43.050 We've managed to assemble here,
NOTE Confidence: 0.987056658571429

00:39:43.050 --> 00:39:45.570 so I'm going to stop sharing this.

NOTE Confidence: 0.987056658571429

00:39:45.570 --> 00:39:48.384 And introduce you to my friend

NOTE Confidence: 0.987056658571429

00:39:48.384 --> 00:39:51.077 and colleague Dr Jaspreet loyal a

NOTE Confidence: 0.987056658571429

00:39:51.077 --> 00:39:53.226 jaspreet is a pediatric hospital is an

NOTE Confidence: 0.987056658571429

00:39:53.226 --> 00:39:54.802 associate professor in the Department

NOTE Confidence: 0.987056658571429

00:39:54.802 --> 00:39:56.916 of Pediatrics at Yale School of Medicine.

NOTE Confidence: 0.987056658571429

00:39:56.920 --> 00:39:58.776 She has served in the past as medical

NOTE Confidence: 0.987056658571429

00:39:58.776 --> 00:40:00.319 director for our well newborn unit

NOTE Confidence: 0.987056658571429

00:40:00.319 --> 00:40:02.134 here at the L Children's Hospital and

NOTE Confidence: 0.987056658571429

00:40:02.134 --> 00:40:03.990 for the past four years she's been the

NOTE Confidence: 0.987056658571429

00:40:03.990 --> 00:40:06.650 medical director of the inpatient unit.

NOTE Confidence: 0.987056658571429

00:40:06.650 --> 00:40:08.685 She's currently the chief of

NOTE Confidence: 0.987056658571429

00:40:08.685 --> 00:40:10.313 our Hospital Medicine division.

NOTE Confidence: 0.987056658571429

00:40:10.320 --> 00:40:12.605 She's a graduate of Saint

NOTE Confidence: 0.987056658571429

00:40:12.605 --> 00:40:14.433 Catherine University in Minnesota.

NOTE Confidence: 0.987056658571429

00:40:14.440 --> 00:40:16.095 Received a degree in epidemiology

NOTE Confidence: 0.987056658571429

00:40:16.095 --> 00:40:16.757 at Stanford.
NOTE Confidence: 0.987056658571429

00:40:16.760 --> 00:40:18.932 She graduated the Medical College of
NOTE Confidence: 0.987056658571429

00:40:18.932 --> 00:40:21.295 Wisconsin and did her residency at
NOTE Confidence: 0.987056658571429

00:40:21.295 --> 00:40:23.196 Weill Cornell, New York Presbyterian.
NOTE Confidence: 0.987056658571429

00:40:23.196 --> 00:40:25.660 Jasprit knows a thing or two about
NOTE Confidence: 0.987056658571429

00:40:25.725 --> 00:40:27.579 many things to do with babies,
NOTE Confidence: 0.987056658571429

00:40:27.580 --> 00:40:29.212 and so I really appreciate her
NOTE Confidence: 0.987056658571429

00:40:29.212 --> 00:40:30.876 thoughts on what I just said
NOTE Confidence: 0.987056658571429

00:40:30.876 --> 00:40:32.418 and on the problem at hand.
NOTE Confidence: 0.987056658571429

00:40:32.420 --> 00:40:35.170 So with that jaspreet, I turn it over to you.
NOTE Confidence: 0.984875364

00:40:37.510 --> 00:40:40.318 Thanks, Mark, thank you so much
NOTE Confidence: 0.984875364

00:40:40.318 --> 00:40:43.158 for the invitation and it's very
NOTE Confidence: 0.984875364

00:40:43.158 --> 00:40:45.780 difficult to follow you and I.
NOTE Confidence: 0.984875364

00:40:45.780 --> 00:40:48.120 I really appreciate you setting up
NOTE Confidence: 0.984875364

00:40:48.120 --> 00:40:50.736 the framework I I think what I have to
NOTE Confidence: 0.984875364

00:40:50.736 --> 00:40:52.569 offer here is a different perspective.

NOTE Confidence: 0.984875364

00:40:52.570 --> 00:40:56.626 As someone who's not an expert in bioethics,

NOTE Confidence: 0.984875364

00:40:56.630 --> 00:41:00.388 nor is a neonatologist my I've been.

NOTE Confidence: 0.984875364

00:41:00.388 --> 00:41:02.390 I've been at Yale for 10 years,

NOTE Confidence: 0.984875364

00:41:02.390 --> 00:41:05.506 and my first five years I was

NOTE Confidence: 0.984875364

00:41:05.506 --> 00:41:07.396 the medical director of the.

NOTE Confidence: 0.984875364

00:41:07.400 --> 00:41:09.572 Newborn nursery and which is now

NOTE Confidence: 0.984875364

00:41:09.572 --> 00:41:11.928 in the very capable hands of my.

NOTE Confidence: 0.984875364

00:41:11.930 --> 00:41:16.690 My UM. Colleague Dr Arizona.

NOTE Confidence: 0.984875364

00:41:16.690 --> 00:41:20.047 And what I wanted to share with you was

NOTE Confidence: 0.984875364

00:41:20.050 --> 00:41:22.822 my my personal journey through dealing

NOTE Confidence: 0.984875364

00:41:22.822 --> 00:41:25.890 with some of these refusal issues

NOTE Confidence: 0.984875364

00:41:25.890 --> 00:41:29.466 that in part began with my role here

NOTE Confidence: 0.984875364

00:41:29.466 --> 00:41:33.477 as the the nursery Medical director.

NOTE Confidence: 0.984875364

00:41:33.480 --> 00:41:35.252 So as Mark said,

NOTE Confidence: 0.984875364

00:41:35.252 --> 00:41:37.024 I did my training.

NOTE Confidence: 0.984875364

00:41:37.030 --> 00:41:38.920 In Pediatrics in New York,
NOTE Confidence: 0.984875364

00:41:38.920 --> 00:41:41.986 and that will become relevant momentarily,
NOTE Confidence: 0.984875364

00:41:41.990 --> 00:41:44.816 and I first encountered vitamin K
NOTE Confidence: 0.984875364

00:41:44.816 --> 00:41:48.128 refusal in the newborn nursery at Yale.
NOTE Confidence: 0.984875364

00:41:48.130 --> 00:41:52.225 And I had many mentors in the
NOTE Confidence: 0.984875364

00:41:52.225 --> 00:41:55.450 section of general Pediatrics.
NOTE Confidence: 0.984875364

00:41:55.450 --> 00:41:58.714 A couple of them were sort of instrumental
NOTE Confidence: 0.984875364

00:41:58.714 --> 00:42:02.350 in pushing me to investigate this.
NOTE Confidence: 0.984875364

00:42:02.350 --> 00:42:05.490 Observation one was Brian Forsythe,
NOTE Confidence: 0.984875364

00:42:05.490 --> 00:42:09.482 who told me to be curious and investigate
NOTE Confidence: 0.984875364

00:42:09.482 --> 00:42:12.620 what bothered me and eat Colson who
NOTE Confidence: 0.984875364

00:42:12.620 --> 00:42:16.220 told me that the nursery is my lab.
NOTE Confidence: 0.984875364

00:42:16.220 --> 00:42:18.988 So that's where I started and you know,
NOTE Confidence: 0.984875364

00:42:18.990 --> 00:42:21.118 I know that there's there's a number of
NOTE Confidence: 0.984875364

00:42:21.118 --> 00:42:23.706 folks in the audience who are neonatologists,
NOTE Confidence: 0.984875364

00:42:23.710 --> 00:42:26.086 but the bulk of newborns are in the well,

NOTE Confidence: 0.984875364

00:42:26.090 --> 00:42:30.696 newborn nursery and across our health system.

NOTE Confidence: 0.984875364

00:42:30.700 --> 00:42:32.998 In four of our main sites.

NOTE Confidence: 0.984875364

00:42:33.000 --> 00:42:35.920 In a year, there's approximately

NOTE Confidence: 0.984875364

00:42:35.920 --> 00:42:38.840 10,000 newborns that are delivered.

NOTE Confidence: 0.984875364

00:42:38.840 --> 00:42:41.780 So when I started it at in my role at Yale,

NOTE Confidence: 0.984875364

00:42:41.780 --> 00:42:44.428 I saw Vitamin K refusal here and there

NOTE Confidence: 0.984875364

00:42:44.428 --> 00:42:46.701 and it was extremely stressful for

NOTE Confidence: 0.984875364

00:42:46.701 --> 00:42:50.067 me as well as the nurses and took a

NOTE Confidence: 0.984875364

00:42:50.067 --> 00:42:52.384 lot of time sometimes over an hour

NOTE Confidence: 0.984875364

00:42:52.390 --> 00:42:54.730 and I felt inadequately prepared.

NOTE Confidence: 0.984875364

00:42:54.730 --> 00:42:55.510 Part of this,

NOTE Confidence: 0.984875364

00:42:55.510 --> 00:42:57.070 and I'm hoping that we'll talk

NOTE Confidence: 0.984875364

00:42:57.070 --> 00:42:58.630 about this with the panelists,

NOTE Confidence: 0.984875364

00:42:58.630 --> 00:43:00.574 is that in the state of New York,

NOTE Confidence: 0.984875364

00:43:00.580 --> 00:43:03.088 there is a state mandate that

NOTE Confidence: 0.984875364

00:43:03.088 --> 00:43:04.990 you cannot refuse vitamin K,
NOTE Confidence: 0.984875364

00:43:04.990 --> 00:43:07.006 and that is not the case in Connecticut.
NOTE Confidence: 0.984875364

00:43:07.010 --> 00:43:10.370 And maybe that's why I saw more of it here.
NOTE Confidence: 0.984875364

00:43:10.370 --> 00:43:13.370 So my first call of action was to
NOTE Confidence: 0.984875364

00:43:13.370 --> 00:43:15.995 determine how big of a problem is this
NOTE Confidence: 0.984875364

00:43:15.995 --> 00:43:18.810 and so just like any other researcher.
NOTE Confidence: 0.984875364

00:43:18.810 --> 00:43:20.994 Did a chart review of our newborns
NOTE Confidence: 0.984875364

00:43:20.994 --> 00:43:23.160 to determine the extent of refusals,
NOTE Confidence: 0.984875364

00:43:23.160 --> 00:43:25.920 because everyone felt like a lot.
NOTE Confidence: 0.984875364

00:43:25.920 --> 00:43:28.405 But when you actually looked at the
NOTE Confidence: 0.984875364

00:43:28.405 --> 00:43:32.205 data at Yale of all of our deliveries
NOTE Confidence: 0.984875364

00:43:32.205 --> 00:43:35.881 about point path .5% of parents
NOTE Confidence: 0.984875364

00:43:35.881 --> 00:43:38.589 refused intramuscular vitamin K.
NOTE Confidence: 0.984875364

00:43:38.590 --> 00:43:40.526 So I thought this is a problem just
NOTE Confidence: 0.984875364

00:43:40.526 --> 00:43:43.270 at Yale or it's just more pervasive.
NOTE Confidence: 0.984875364

00:43:43.270 --> 00:43:43.914 And again,

NOTE Confidence: 0.984875364

00:43:43.914 --> 00:43:45.524 with the tremendous mentor ship

NOTE Confidence: 0.984875364

00:43:45.524 --> 00:43:46.920 in the Department of Gen.

NOTE Confidence: 0.984875364

00:43:46.920 --> 00:43:48.732 Peeves and some nudging from my

NOTE Confidence: 0.984875364

00:43:48.732 --> 00:43:51.088 friend out of Fenwick by out did the

NOTE Confidence: 0.984875364

00:43:51.088 --> 00:43:53.413 same study in a network of newborn

NOTE Confidence: 0.984875364

00:43:53.413 --> 00:43:55.517 nurseries through the Academic

NOTE Confidence: 0.984875364

00:43:55.517 --> 00:43:57.621 Pediatric Association and found

NOTE Confidence: 0.984875364

00:43:57.621 --> 00:43:59.944 that their refusal rate was not that

NOTE Confidence: 0.984875364

00:43:59.944 --> 00:44:02.412 different than what I found at Yale.

NOTE Confidence: 0.984875364

00:44:02.412 --> 00:44:03.810 It was around

NOTE Confidence: 0.986320825555556

00:44:03.810 --> 00:44:07.959 .6%, but in some places as high as 2%.

NOTE Confidence: 0.986320825555556

00:44:07.960 --> 00:44:11.356 So. Again, going back to Ventureship,

NOTE Confidence: 0.986320825555556

00:44:11.360 --> 00:44:13.894 which is so critical in in everything

NOTE Confidence: 0.986320825555556

00:44:13.894 --> 00:44:16.573 that we do, EVE suggested that

NOTE Confidence: 0.986320825555556

00:44:16.573 --> 00:44:19.228 I do some qualitative research,

NOTE Confidence: 0.986320825555556

00:44:19.230 --> 00:44:23.100 so one of my first one of my first studies.

NOTE Confidence: 0.986320825555556

00:44:23.100 --> 00:44:24.312 In qualitative research,

NOTE Confidence: 0.986320825555556

00:44:24.312 --> 00:44:27.140 was in the newborn nursery where I

NOTE Confidence: 0.986320825555556

00:44:27.212 --> 00:44:29.626 interviewed mothers of infants who did

NOTE Confidence: 0.986320825555556

00:44:29.626 --> 00:44:32.430 not get vitamin K and to ask them why.

NOTE Confidence: 0.986320825555556

00:44:32.430 --> 00:44:34.590 And I partnered with a colleague at UC

NOTE Confidence: 0.986320825555556

00:44:34.590 --> 00:44:36.709 Davis who did the same in California.

NOTE Confidence: 0.986320825555556

00:44:36.710 --> 00:44:39.447 Together we found four main themes when

NOTE Confidence: 0.986320825555556

00:44:39.447 --> 00:44:42.950 speaking with these families first.

NOTE Confidence: 0.986320825555556

00:44:42.950 --> 00:44:46.046 The this idea of the risk benefit ratio,

NOTE Confidence: 0.986320825555556

00:44:46.050 --> 00:44:48.264 where the perceived risk to their

NOTE Confidence: 0.986320825555556

00:44:48.264 --> 00:44:50.614 newborn in many cases was greater

NOTE Confidence: 0.986320825555556

00:44:50.614 --> 00:44:53.428 than the benefit and the risk from

NOTE Confidence: 0.986320825555556

00:44:53.428 --> 00:44:55.353 preservatives from the dose being

NOTE Confidence: 0.986320825555556

00:44:55.353 --> 00:44:57.525 high to some parents thinking that

NOTE Confidence: 0.986320825555556

00:44:57.530 --> 00:44:59.906 pain from the injection would cause

NOTE Confidence: 0.986320825555556
00:44:59.906 --> 00:45:01.995 their child to develop depression
NOTE Confidence: 0.986320825555556
00:45:01.995 --> 00:45:04.155 or anxiety as young adults.
NOTE Confidence: 0.986320825555556
00:45:04.160 --> 00:45:07.552 The second was this idea of having a
NOTE Confidence: 0.986320825555556
00:45:07.552 --> 00:45:10.144 naturalistic approach and if the mother
NOTE Confidence: 0.986320825555556
00:45:10.144 --> 00:45:13.250 has eight more alfalfa then the baby
NOTE Confidence: 0.986320825555556
00:45:13.250 --> 00:45:16.890 would get vitamin K through the breast milk.
NOTE Confidence: 0.986320825555556
00:45:16.890 --> 00:45:19.710 Uhm, or taking oral vitamin K,
NOTE Confidence: 0.986320825555556
00:45:19.710 --> 00:45:20.998 which is something that's
NOTE Confidence: 0.986320825555556
00:45:20.998 --> 00:45:22.930 done in Europe all the time.
NOTE Confidence: 0.986320825555556
00:45:22.930 --> 00:45:25.458 So what was what made the standard of
NOTE Confidence: 0.986320825555556
00:45:25.458 --> 00:45:27.429 care different in the United States?
NOTE Confidence: 0.986320825555556
00:45:27.430 --> 00:45:29.586 Where in Europe oral Vitamin K was
NOTE Confidence: 0.986320825555556
00:45:29.586 --> 00:45:31.990 was part of the standard of care,
NOTE Confidence: 0.986320825555556
00:45:31.990 --> 00:45:34.650 and babies did fine.
NOTE Confidence: 0.986320825555556
00:45:34.650 --> 00:45:37.093 The third was this idea of placement
NOTE Confidence: 0.986320825555556

00:45:37.093 --> 00:45:38.860 of trust and mistrust,
NOTE Confidence: 0.986320825555556

00:45:38.860 --> 00:45:41.150 where there was mistrust of
NOTE Confidence: 0.986320825555556

00:45:41.150 --> 00:45:42.206 medical establishments.
NOTE Confidence: 0.986320825555556

00:45:42.206 --> 00:45:43.262 Pharmaceutical companies,
NOTE Confidence: 0.986320825555556

00:45:43.262 --> 00:45:46.430 trust of self and like minded
NOTE Confidence: 0.986320825555556

00:45:46.498 --> 00:45:48.568 people and the complexity here.
NOTE Confidence: 0.986320825555556

00:45:48.570 --> 00:45:50.762 Sometimes those like minded
NOTE Confidence: 0.986320825555556

00:45:50.762 --> 00:45:53.502 people were pediatricians who also
NOTE Confidence: 0.986320825555556

00:45:53.502 --> 00:45:55.786 felt that the parents autonomy,
NOTE Confidence: 0.986320825555556

00:45:55.786 --> 00:45:58.438 in this case should be respected.
NOTE Confidence: 0.986320825555556

00:45:58.440 --> 00:46:00.798 And then the last one was
NOTE Confidence: 0.986320825555556

00:46:00.798 --> 00:46:02.370 being informed by experiences.
NOTE Confidence: 0.986320825555556

00:46:02.370 --> 00:46:04.840 So are our process here.
NOTE Confidence: 0.986320825555556

00:46:04.840 --> 00:46:05.223 Yeah,
NOTE Confidence: 0.986320825555556

00:46:05.223 --> 00:46:07.138 when I when intramuscular vitamin
NOTE Confidence: 0.986320825555556

00:46:07.138 --> 00:46:08.670 K is is administered,

NOTE Confidence: 0.986320825555556
00:46:08.670 --> 00:46:10.707 is no one really asks the parent,
NOTE Confidence: 0.986320825555556
00:46:10.710 --> 00:46:12.660 it's more of an opt out if you if you
NOTE Confidence: 0.986320825555556
00:46:12.716 --> 00:46:14.750 come in with a birth plan and you know
NOTE Confidence: 0.986320825555556
00:46:14.750 --> 00:46:16.774 that you don't want it for your child,
NOTE Confidence: 0.986320825555556
00:46:16.780 --> 00:46:17.704 you'll tell somebody.
NOTE Confidence: 0.986320825555556
00:46:17.704 --> 00:46:19.860 But otherwise the baby is born and
NOTE Confidence: 0.986320825555556
00:46:19.915 --> 00:46:21.619 they get their eyes and thighs,
NOTE Confidence: 0.986320825555556
00:46:21.620 --> 00:46:23.708 which is the.
NOTE Confidence: 0.986320825555556
00:46:23.710 --> 00:46:25.214 Iris Formation ointment in
NOTE Confidence: 0.986320825555556
00:46:25.214 --> 00:46:27.094 the eye and the injection.
NOTE Confidence: 0.986320825555556
00:46:27.100 --> 00:46:29.782 Hepatitis B is a different conversation
NOTE Confidence: 0.986320825555556
00:46:29.782 --> 00:46:32.581 where verbal consent is obtained and is
NOTE Confidence: 0.986320825555556
00:46:32.581 --> 00:46:35.550 a little bit more of more of a process.
NOTE Confidence: 0.986320825555556
00:46:35.550 --> 00:46:37.406 The next thing I did was ask clinicians,
NOTE Confidence: 0.986320825555556
00:46:37.410 --> 00:46:41.362 so would you give oral vitamin K knowing
NOTE Confidence: 0.986320825555556

00:46:41.362 --> 00:46:43.610 that intramuscular is work better
NOTE Confidence: 0.986320825555556

00:46:43.610 --> 00:46:46.081 and so we surveyed our own hospital
NOTE Confidence: 0.986320825555556

00:46:46.081 --> 00:46:48.896 is here and and neonatologist as well
NOTE Confidence: 0.986320825555556

00:46:48.896 --> 00:46:51.420 as at a couple of other institutions.
NOTE Confidence: 0.986320825555556

00:46:51.420 --> 00:46:54.806 And we found that over 50% felt
NOTE Confidence: 0.986320825555556

00:46:54.806 --> 00:46:57.946 comfortable prescribing oral vitamin K.
NOTE Confidence: 0.986320825555556

00:46:57.950 --> 00:47:00.610 The pediatric community is divided.
NOTE Confidence: 0.986320825555556

00:47:00.610 --> 00:47:03.045 Some folks feel that intramuscular
NOTE Confidence: 0.986320825555556

00:47:03.045 --> 00:47:06.299 vitamin K or nothing and others feel
NOTE Confidence: 0.986320825555556

00:47:06.299 --> 00:47:08.897 that something is better than nothing.
NOTE Confidence: 0.986320825555556

00:47:08.900 --> 00:47:12.512 And across all this is maintaining the
NOTE Confidence: 0.986320825555556

00:47:12.512 --> 00:47:14.980 therapeutic relationship with the family.
NOTE Confidence: 0.986320825555556

00:47:14.980 --> 00:47:16.877 I was also interested in so I'm
NOTE Confidence: 0.986320825555556

00:47:16.877 --> 00:47:18.373 meeting families for the first
NOTE Confidence: 0.986320825555556

00:47:18.373 --> 00:47:19.938 time as a pediatric hospitalist,
NOTE Confidence: 0.986320825555556

00:47:19.940 --> 00:47:21.908 but who gets who meets with

NOTE Confidence: 0.98632082555556
00:47:21.908 --> 00:47:23.220 them way before I
NOTE Confidence: 0.984885249230769
00:47:23.299 --> 00:47:25.302 do the obstetrician, gynecologist,
NOTE Confidence: 0.984885249230769
00:47:25.302 --> 00:47:29.096 midwives, and so there is an association
NOTE Confidence: 0.984885249230769
00:47:29.096 --> 00:47:31.770 between going to a midwife and
NOTE Confidence: 0.984885249230769
00:47:31.770 --> 00:47:34.585 increased refusal rates of standard
NOTE Confidence: 0.984885249230769
00:47:34.585 --> 00:47:36.837 of common newborn interventions.
NOTE Confidence: 0.984885249230769
00:47:36.840 --> 00:47:40.886 So my colleagues in Iowa and Michigan,
NOTE Confidence: 0.984885249230769
00:47:40.890 --> 00:47:42.775 and I interviewed midwives in
NOTE Confidence: 0.984885249230769
00:47:42.775 --> 00:47:45.310 our States and ask them what he?
NOTE Confidence: 0.984885249230769
00:47:45.310 --> 00:47:46.780 What do you think? How do you?
NOTE Confidence: 0.984885249230769
00:47:46.780 --> 00:47:49.040 How do you handle parents
NOTE Confidence: 0.984885249230769
00:47:49.040 --> 00:47:51.300 who don't want to come?
NOTE Confidence: 0.984885249230769
00:47:51.300 --> 00:47:53.772 Do the routine standard of care and so
NOTE Confidence: 0.984885249230769
00:47:53.772 --> 00:47:56.390 it was really interesting and what we
NOTE Confidence: 0.984885249230769
00:47:56.390 --> 00:47:59.051 found and this is sitting in the with
NOTE Confidence: 0.984885249230769

00:47:59.051 --> 00:48:00.557 the Journal of Maternal Child Health.
NOTE Confidence: 0.984885249230769

00:48:00.560 --> 00:48:02.674 For six months we'll see what happens,
NOTE Confidence: 0.984885249230769

00:48:02.680 --> 00:48:04.412 but they, the midwives,
NOTE Confidence: 0.984885249230769

00:48:04.412 --> 00:48:07.010 told us that for them supporting
NOTE Confidence: 0.984885249230769

00:48:07.094 --> 00:48:09.959 parent decision making authority was.
NOTE Confidence: 0.984885249230769

00:48:09.960 --> 00:48:11.570 Prime.
NOTE Confidence: 0.984885249230769

00:48:11.570 --> 00:48:14.186 They felt that their low intervention
NOTE Confidence: 0.984885249230769

00:48:14.186 --> 00:48:15.930 philosophy attracted certain parents,
NOTE Confidence: 0.984885249230769

00:48:15.930 --> 00:48:17.922 so it wasn't that the midwives
NOTE Confidence: 0.984885249230769

00:48:17.922 --> 00:48:19.250 were promoting non adherence.
NOTE Confidence: 0.984885249230769

00:48:19.250 --> 00:48:20.770 They were attracting parents
NOTE Confidence: 0.984885249230769

00:48:20.770 --> 00:48:22.670 who wanted to do less.
NOTE Confidence: 0.984885249230769

00:48:22.670 --> 00:48:24.650 Another important theme was was
NOTE Confidence: 0.984885249230769

00:48:24.650 --> 00:48:26.234 lack of positive relationships
NOTE Confidence: 0.984885249230769

00:48:26.234 --> 00:48:28.218 between midwives and pediatricians,
NOTE Confidence: 0.984885249230769

00:48:28.220 --> 00:48:29.740 where the midwives felt that

NOTE Confidence: 0.984885249230769
00:48:29.740 --> 00:48:31.260 pediatricians were all or nothing.
NOTE Confidence: 0.984885249230769
00:48:31.260 --> 00:48:32.636 If you don't want to vaccinate your child,
NOTE Confidence: 0.984885249230769
00:48:32.640 --> 00:48:34.048 don't come to us.
NOTE Confidence: 0.984885249230769
00:48:34.048 --> 00:48:36.160 We're not going to meet you
NOTE Confidence: 0.984885249230769
00:48:36.238 --> 00:48:38.348 in that that halfway point.
NOTE Confidence: 0.984885249230769
00:48:38.350 --> 00:48:39.510 And then to Mark's point,
NOTE Confidence: 0.984885249230769
00:48:39.510 --> 00:48:41.550 refusals don't stop at vitamin
NOTE Confidence: 0.984885249230769
00:48:41.550 --> 00:48:43.489 K1 of auto repair. My sin does.
NOTE Confidence: 0.984885249230769
00:48:43.490 --> 00:48:46.353 Does it make it less problematic that
NOTE Confidence: 0.984885249230769
00:48:46.353 --> 00:48:49.546 that that is refused for most of us?
NOTE Confidence: 0.984885249230769
00:48:49.550 --> 00:48:50.182 I don't.
NOTE Confidence: 0.984885249230769
00:48:50.182 --> 00:48:52.394 I don't die on that sword because
NOTE Confidence: 0.984885249230769
00:48:52.394 --> 00:48:54.928 most moms are screened for gonorrhoea,
NOTE Confidence: 0.984885249230769
00:48:54.930 --> 00:48:55.790 not all.
NOTE Confidence: 0.984885249230769
00:48:55.790 --> 00:48:58.370 And that's really important to be
NOTE Confidence: 0.984885249230769

00:48:58.370 --> 00:49:01.236 mindful of as gonorrhea rates are
NOTE Confidence: 0.984885249230769

00:49:01.236 --> 00:49:04.110 increasing and moms are screened are
NOTE Confidence: 0.984885249230769

00:49:04.197 --> 00:49:07.529 based on risk behavior in some instances.
NOTE Confidence: 0.984885249230769

00:49:07.530 --> 00:49:09.650 Hepatitis B vaccine is interesting,
NOTE Confidence: 0.984885249230769

00:49:09.650 --> 00:49:12.009 and my approach with trainees is there
NOTE Confidence: 0.984885249230769

00:49:12.009 --> 00:49:14.289 are three buckets of approach to this.
NOTE Confidence: 0.984885249230769

00:49:14.290 --> 00:49:16.666 One that the family doesn't know
NOTE Confidence: 0.984885249230769

00:49:16.666 --> 00:49:18.530 what hepatitis B vaccine is,
NOTE Confidence: 0.984885249230769

00:49:18.530 --> 00:49:20.020 and it's an opportunity for
NOTE Confidence: 0.984885249230769

00:49:20.020 --> 00:49:22.212 us to counsel them to their.
NOTE Confidence: 0.984885249230769

00:49:22.212 --> 00:49:25.188 They want the hepatitis B vaccine.
NOTE Confidence: 0.984885249230769

00:49:25.190 --> 00:49:26.947 They just don't want it in the
NOTE Confidence: 0.984885249230769

00:49:26.947 --> 00:49:28.675 newborn nursery and they want it
NOTE Confidence: 0.984885249230769

00:49:28.675 --> 00:49:29.907 at their pediatricians office.
NOTE Confidence: 0.984885249230769

00:49:29.910 --> 00:49:31.740 Some folks in my group feels
NOTE Confidence: 0.984885249230769

00:49:31.740 --> 00:49:33.669 strongly one way or the other,

NOTE Confidence: 0.984885249230769
00:49:33.670 --> 00:49:35.278 but that's one that I don't
NOTE Confidence: 0.984885249230769
00:49:35.278 --> 00:49:37.071 feel as strongly about the third
NOTE Confidence: 0.984885249230769
00:49:37.071 --> 00:49:38.067 and more problematic.
NOTE Confidence: 0.984885249230769
00:49:38.070 --> 00:49:40.430 Bucket is I don't want hepatitis B vaccine.
NOTE Confidence: 0.984885249230769
00:49:40.430 --> 00:49:42.663 I don't want any vaccine and I
NOTE Confidence: 0.984885249230769
00:49:42.663 --> 00:49:44.377 have a pediatrician that aligns
NOTE Confidence: 0.984885249230769
00:49:44.377 --> 00:49:46.107 with me and that's harder.
NOTE Confidence: 0.984885249230769
00:49:46.110 --> 00:49:47.738 In addition to hypoglycemia
NOTE Confidence: 0.984885249230769
00:49:47.738 --> 00:49:49.773 refusal that Mark mentioned there's
NOTE Confidence: 0.984885249230769
00:49:49.773 --> 00:49:51.758 others that are more problematic,
NOTE Confidence: 0.984885249230769
00:49:51.760 --> 00:49:53.284 so critical congenital
NOTE Confidence: 0.984885249230769
00:49:53.284 --> 00:49:54.808 heart screening refusal,
NOTE Confidence: 0.984885249230769
00:49:54.810 --> 00:49:57.026 so this is a pre and post ductal
NOTE Confidence: 0.984885249230769
00:49:57.026 --> 00:49:59.044 pulse ox pulse oximeter that
NOTE Confidence: 0.984885249230769
00:49:59.044 --> 00:50:00.900 we place that's noninvasive,
NOTE Confidence: 0.984885249230769

00:50:00.900 --> 00:50:03.366 a little sticker on the baby's hand and foot,

NOTE Confidence: 0.984885249230769

00:50:03.370 --> 00:50:05.890 and parents will refuse that

NOTE Confidence: 0.984885249230769

00:50:05.890 --> 00:50:08.356 transcutaneous bilirubin measurements.

NOTE Confidence: 0.984885249230769

00:50:08.356 --> 00:50:10.000 Hearing screams,

NOTE Confidence: 0.984885249230769

00:50:10.000 --> 00:50:11.842 I have a colleague at Dartmouth

NOTE Confidence: 0.984885249230769

00:50:11.842 --> 00:50:13.875 who tells me that parents refused

NOTE Confidence: 0.984885249230769

00:50:13.875 --> 00:50:16.095 the hearing test because they feel

NOTE Confidence: 0.984885249230769

00:50:16.095 --> 00:50:18.049 that the government is putting

NOTE Confidence: 0.984885249230769

00:50:18.049 --> 00:50:19.969 things in the baby's brain.

NOTE Confidence: 0.984885249230769

00:50:19.970 --> 00:50:22.270 The one particularly challenging one

NOTE Confidence: 0.984885249230769

00:50:22.270 --> 00:50:24.570 that my colleague Electrosurgery Kez,

NOTE Confidence: 0.984885249230769

00:50:24.570 --> 00:50:26.098 has to deal with when she was the

NOTE Confidence: 0.984885249230769

00:50:26.098 --> 00:50:27.208 medical director at Saint Rayfield,

NOTE Confidence: 0.984885249230769

00:50:27.210 --> 00:50:30.180 was refusal of the birth certificate.

NOTE Confidence: 0.984885249230769

00:50:30.180 --> 00:50:31.500 In that scenario,

NOTE Confidence: 0.984885249230769

00:50:31.500 --> 00:50:34.580 we involved our social worker DCF team.

NOTE Confidence: 0.99107075

00:50:34.580 --> 00:50:37.638 And. We let the family go home,

NOTE Confidence: 0.99107075

00:50:37.640 --> 00:50:39.803 but it was a very very challenging

NOTE Confidence: 0.99107075

00:50:39.803 --> 00:50:41.160 situation that I don't.

NOTE Confidence: 0.99107075

00:50:41.160 --> 00:50:43.015 I still don't feel very

NOTE Confidence: 0.99107075

00:50:43.015 --> 00:50:45.660 great about what happened.

NOTE Confidence: 0.99107075

00:50:45.660 --> 00:50:47.358 And then finally,

NOTE Confidence: 0.99107075

00:50:47.358 --> 00:50:50.194 my colleague at UCSD Michelle lesson.

NOTE Confidence: 0.99107075

00:50:50.194 --> 00:50:52.750 I just published her a review

NOTE Confidence: 0.99107075

00:50:52.830 --> 00:50:55.222 on refusals in the clinics with

NOTE Confidence: 0.99107075

00:50:55.222 --> 00:50:57.166 parents perinatology and talk

NOTE Confidence: 0.99107075

00:50:57.166 --> 00:50:59.110 about therapeutic hesitancy and

NOTE Confidence: 0.99107075

00:50:59.184 --> 00:51:01.578 what we proposed is there is a

NOTE Confidence: 0.99107075

00:51:01.578 --> 00:51:03.459 spectrum of hesitancy and refusal,

NOTE Confidence: 0.99107075

00:51:03.460 --> 00:51:05.060 and it takes a skill set on this.

NOTE Confidence: 0.99107075

00:51:05.060 --> 00:51:07.972 Decide on the side of the provider that

NOTE Confidence: 0.99107075

00:51:07.972 --> 00:51:10.350 includes high emotional intelligence,
NOTE Confidence: 0.99107075

00:51:10.350 --> 00:51:13.698 listening and a lot of patients.
NOTE Confidence: 0.99107075

00:51:13.700 --> 00:51:16.787 So a couple of strategies that we.
NOTE Confidence: 0.99107075

00:51:16.790 --> 00:51:20.507 We propose one is MRQ alluded to.
NOTE Confidence: 0.99107075

00:51:20.510 --> 00:51:22.687 This was the the the critical piece
NOTE Confidence: 0.99107075

00:51:22.687 --> 00:51:24.658 of building alliance and how do you
NOTE Confidence: 0.99107075

00:51:24.658 --> 00:51:26.486 do this as a hospitalist when you're
NOTE Confidence: 0.99107075

00:51:26.486 --> 00:51:28.579 meeting a family for the first time?
NOTE Confidence: 0.99107075

00:51:28.580 --> 00:51:31.960 Thinking about standard scripting and.
NOTE Confidence: 0.99107075

00:51:31.960 --> 00:51:33.685 There's a lot of evidence
NOTE Confidence: 0.99107075

00:51:33.685 --> 00:51:35.065 in the vaccine literature.
NOTE Confidence: 0.99107075

00:51:35.070 --> 00:51:36.243 Hesitancy literature around
NOTE Confidence: 0.99107075

00:51:36.243 --> 00:51:38.198 higher success with opt in,
NOTE Confidence: 0.99107075

00:51:38.200 --> 00:51:39.880 which is what we do with vitamin K.
NOTE Confidence: 0.99107075

00:51:39.880 --> 00:51:42.544 It's time for your child's vitamin
NOTE Confidence: 0.99107075

00:51:42.544 --> 00:51:45.358 K injection versus do you want it?

NOTE Confidence: 0.99107075

00:51:45.360 --> 00:51:48.480 Also important is displaying curiosity.

NOTE Confidence: 0.99107075

00:51:48.480 --> 00:51:51.210 Tell me why?

NOTE Confidence: 0.99107075

00:51:51.210 --> 00:51:53.870 And determining who is the decision maker?

NOTE Confidence: 0.99107075

00:51:53.870 --> 00:51:54.918 Sometimes it's some other,

NOTE Confidence: 0.99107075

00:51:54.918 --> 00:51:56.490 and sometimes there are other people,

NOTE Confidence: 0.99107075

00:51:56.490 --> 00:51:59.970 so you have to determine.

NOTE Confidence: 0.99107075

00:51:59.970 --> 00:52:03.438 Who's going to make that decision?

NOTE Confidence: 0.99107075

00:52:03.440 --> 00:52:04.754 Make the recommendation.

NOTE Confidence: 0.99107075

00:52:04.754 --> 00:52:07.382 Meet the family where they are,

NOTE Confidence: 0.99107075

00:52:07.390 --> 00:52:09.760 but the other important thing is

NOTE Confidence: 0.99107075

00:52:09.760 --> 00:52:12.298 persistence and the value of the nudge.

NOTE Confidence: 0.99107075

00:52:12.300 --> 00:52:14.748 I felt like at the beginning,

NOTE Confidence: 0.99107075

00:52:14.750 --> 00:52:16.900 almost distraught and defeated when

NOTE Confidence: 0.99107075

00:52:16.900 --> 00:52:20.034 a family refused Vitamin K and I I

NOTE Confidence: 0.99107075

00:52:20.034 --> 00:52:22.498 felt like I failed the the child.

NOTE Confidence: 0.99107075

00:52:22.500 --> 00:52:25.092 But what I felt what I know now
NOTE Confidence: 0.99107075

00:52:25.092 --> 00:52:27.696 after years is by planting that seed.
NOTE Confidence: 0.99107075

00:52:27.700 --> 00:52:28.900 And going in the next day,
NOTE Confidence: 0.99107075

00:52:28.900 --> 00:52:31.028 I may have opened the door a little
NOTE Confidence: 0.99107075

00:52:31.028 --> 00:52:32.715 bit for the next person that
NOTE Confidence: 0.99107075

00:52:32.715 --> 00:52:34.850 comes in to talk to the family.
NOTE Confidence: 0.99107075

00:52:34.850 --> 00:52:37.550 When does refusal cause harm?
NOTE Confidence: 0.99107075

00:52:37.550 --> 00:52:40.196 And parents have the right to
NOTE Confidence: 0.99107075

00:52:40.196 --> 00:52:41.960 decline many medical interventions
NOTE Confidence: 0.99107075

00:52:42.032 --> 00:52:43.477 and and we love them.
NOTE Confidence: 0.99107075

00:52:43.480 --> 00:52:46.420 The challenge and the challenge around
NOTE Confidence: 0.99107075

00:52:46.420 --> 00:52:50.215 laws and and that and mandates in states
NOTE Confidence: 0.99107075

00:52:50.215 --> 00:52:53.980 is tricky because as I said in New York.
NOTE Confidence: 0.99107075

00:52:53.980 --> 00:52:55.364 Vitamin K is mandated,
NOTE Confidence: 0.99107075

00:52:55.364 --> 00:52:57.909 but I have colleagues there who deal
NOTE Confidence: 0.99107075

00:52:57.909 --> 00:52:59.889 with this problem still because.

NOTE Confidence: 0.99107075

00:52:59.890 --> 00:53:01.978 Do you report to DCF and is DCF going

NOTE Confidence: 0.99107075

00:53:01.978 --> 00:53:04.196 to remove the child just because the

NOTE Confidence: 0.99107075

00:53:04.196 --> 00:53:06.700 family didn't get the vitamin K injection?

NOTE Confidence: 0.99107075

00:53:06.700 --> 00:53:07.540 And then the last point,

NOTE Confidence: 0.99107075

00:53:07.540 --> 00:53:10.102 I'll say two quick points why we

NOTE Confidence: 0.99107075

00:53:10.102 --> 00:53:12.958 did develop a refusal form at Yale.

NOTE Confidence: 0.99107075

00:53:12.960 --> 00:53:15.408 Does that actually change parents mind?

NOTE Confidence: 0.99107075

00:53:15.410 --> 00:53:16.184 In my opinion,

NOTE Confidence: 0.99107075

00:53:16.184 --> 00:53:16.442 no.

NOTE Confidence: 0.99107075

00:53:16.442 --> 00:53:19.574 I think we do it more to document that we've

NOTE Confidence: 0.99107075

00:53:19.574 --> 00:53:22.440 done the education and there's value in that.

NOTE Confidence: 0.99107075

00:53:22.440 --> 00:53:24.246 But the other important piece is that

NOTE Confidence: 0.99107075

00:53:24.246 --> 00:53:25.809 we're training the next generation.

NOTE Confidence: 0.99107075

00:53:25.810 --> 00:53:28.000 So thinking about how we handle

NOTE Confidence: 0.99107075

00:53:28.000 --> 00:53:29.970 refusals and how we teach,

NOTE Confidence: 0.99107075

00:53:29.970 --> 00:53:31.986 how we teach our trainees to
NOTE Confidence: 0.99107075

00:53:31.986 --> 00:53:34.384 talk to families, develop trust.
NOTE Confidence: 0.99107075

00:53:34.384 --> 00:53:36.460 This is key,
NOTE Confidence: 0.99107075

00:53:36.460 --> 00:53:38.086 so I'll stop there and and
NOTE Confidence: 0.99107075

00:53:38.086 --> 00:53:39.590 just one last point again,
NOTE Confidence: 0.99107075

00:53:39.590 --> 00:53:40.340 my my colleagues.
NOTE Confidence: 0.99107075

00:53:40.340 --> 00:53:41.090 Like I mentioned,
NOTE Confidence: 0.99107075

00:53:41.090 --> 00:53:43.620 Elena Eragon and Alexis Rodriguez
NOTE Confidence: 0.99107075

00:53:43.620 --> 00:53:46.764 developed a really nice tool kit
NOTE Confidence: 0.99107075

00:53:46.764 --> 00:53:50.106 that they disseminated at a workshop
NOTE Confidence: 0.988653350769231

00:53:50.110 --> 00:53:53.274 this year and that is available which
NOTE Confidence: 0.988653350769231

00:53:53.274 --> 00:53:56.590 mark we will share with you. Thank you.
NOTE Confidence: 0.97383136

00:53:59.200 --> 00:54:00.440 Thank you so much,
NOTE Confidence: 0.97383136

00:54:00.440 --> 00:54:01.719 jaspreet, that was great.
NOTE Confidence: 0.97383136

00:54:01.719 --> 00:54:03.334 I want to introduce now.
NOTE Confidence: 0.97383136

00:54:03.340 --> 00:54:05.152 Please doctor Naomi Laventhol

NOTE Confidence: 0.97383136

00:54:05.152 --> 00:54:07.417 from the University of Michigan.

NOTE Confidence: 0.97383136

00:54:07.420 --> 00:54:09.060 She's a clinical associate professor

NOTE Confidence: 0.97383136

00:54:09.060 --> 00:54:10.700 in the Department of Pediatrics

NOTE Confidence: 0.97383136

00:54:10.754 --> 00:54:12.008 and Communicable diseases,

NOTE Confidence: 0.97383136

00:54:12.010 --> 00:54:13.977 and she's a member of the Division

NOTE Confidence: 0.97383136

00:54:13.977 --> 00:54:15.330 of Neonatal Perinatal Medicine.

NOTE Confidence: 0.97383136

00:54:15.330 --> 00:54:17.970 They only is an accomplished

NOTE Confidence: 0.97383136

00:54:17.970 --> 00:54:19.920 neonatologist a product of the

NOTE Confidence: 0.97383136

00:54:19.920 --> 00:54:21.340 University of Chicago system,

NOTE Confidence: 0.97383136

00:54:21.340 --> 00:54:22.695 who was an important figure

NOTE Confidence: 0.97383136

00:54:22.695 --> 00:54:24.050 in the world of neonatology,

NOTE Confidence: 0.97383136

00:54:24.050 --> 00:54:26.500 but also in the world of pediatric

NOTE Confidence: 0.97383136

00:54:26.500 --> 00:54:28.180 ethics on their helmets.

NOTE Confidence: 0.97383136

00:54:28.180 --> 00:54:30.460 Got research interests in neonatal bioethics.

NOTE Confidence: 0.97383136

00:54:30.460 --> 00:54:31.846 She's one of the leaders nationally.

NOTE Confidence: 0.97383136

00:54:31.850 --> 00:54:32.486 In fact,
NOTE Confidence: 0.97383136

00:54:32.486 --> 00:54:34.394 she's currently the chair of the
NOTE Confidence: 0.97383136

00:54:34.394 --> 00:54:35.901 American Academy of Pediatrics
NOTE Confidence: 0.97383136

00:54:35.901 --> 00:54:37.119 Committee on Bioethics,
NOTE Confidence: 0.97383136

00:54:37.120 --> 00:54:41.285 which is the policy writing arm of
NOTE Confidence: 0.97383136

00:54:41.285 --> 00:54:44.239 the bioethics efforts at the AP.
NOTE Confidence: 0.97383136

00:54:44.240 --> 00:54:46.337 And so I reached out to Naomi to think,
NOTE Confidence: 0.97383136

00:54:46.340 --> 00:54:47.438 what can we do about this,
NOTE Confidence: 0.97383136

00:54:47.440 --> 00:54:48.868 and what can we sort out,
NOTE Confidence: 0.97383136

00:54:48.870 --> 00:54:49.930 and I'm very interested in
NOTE Confidence: 0.97383136

00:54:49.930 --> 00:54:50.778 Naomi's thoughts on this,
NOTE Confidence: 0.97383136

00:54:50.780 --> 00:54:52.766 as both an accomplished neonatologist and
NOTE Confidence: 0.97383136

00:54:52.766 --> 00:54:55.528 a leader of the world of neonatal ethics.
NOTE Confidence: 0.97383136

00:54:55.528 --> 00:54:55.916 So,
NOTE Confidence: 0.97383136

00:54:55.916 --> 00:54:56.692 with that,
NOTE Confidence: 0.97383136

00:54:56.692 --> 00:54:58.244 Naomi take it away.

NOTE Confidence: 0.975333091428572
00:54:58.900 --> 00:55:01.406 Well, Mark, that was a really generous.
NOTE Confidence: 0.975333091428572
00:55:01.410 --> 00:55:02.522 Introduction thank you and
NOTE Confidence: 0.975333091428572
00:55:02.522 --> 00:55:04.190 thank you for having me here.
NOTE Confidence: 0.975333091428572
00:55:04.190 --> 00:55:05.990 It's really. It's really a pleasure
NOTE Confidence: 0.975333091428572
00:55:05.990 --> 00:55:08.130 to get to do this and this.
NOTE Confidence: 0.975333091428572
00:55:08.130 --> 00:55:10.706 I think for a neonatologist it's for someone
NOTE Confidence: 0.975333091428572
00:55:10.706 --> 00:55:12.846 whose primary job really is in the nick.
NOTE Confidence: 0.975333091428572
00:55:12.850 --> 00:55:14.310 You taking care of babies.
NOTE Confidence: 0.975333091428572
00:55:14.310 --> 00:55:15.634 This is so close.
NOTE Confidence: 0.975333091428572
00:55:15.634 --> 00:55:18.947 This is so kind of personal for us and
NOTE Confidence: 0.975333091428572
00:55:18.947 --> 00:55:21.449 and that distress that Zespri describes.
NOTE Confidence: 0.975333091428572
00:55:21.450 --> 00:55:23.234 I think we've all felt that of sort
NOTE Confidence: 0.975333091428572
00:55:23.234 --> 00:55:24.958 of what are my obligations to this
NOTE Confidence: 0.975333091428572
00:55:24.958 --> 00:55:26.910 child in the face of this refusal,
NOTE Confidence: 0.975333091428572
00:55:26.910 --> 00:55:28.149 and this takes a lot of time.
NOTE Confidence: 0.975333091428572

00:55:28.150 --> 00:55:28.888 It takes a lot of sweat,
NOTE Confidence: 0.975333091428572

00:55:28.890 --> 00:55:30.726 equity and so so this is,
NOTE Confidence: 0.975333091428572

00:55:30.730 --> 00:55:32.140 I think this is personal for.
NOTE Confidence: 0.975333091428572

00:55:32.140 --> 00:55:34.596 For for people who care for these infants,
NOTE Confidence: 0.975333091428572

00:55:34.600 --> 00:55:36.262 I'm I'm going to confess upfront
NOTE Confidence: 0.975333091428572

00:55:36.262 --> 00:55:37.742 that my remarks, I think,
NOTE Confidence: 0.975333091428572

00:55:37.742 --> 00:55:39.668 are going to be less beautifully
NOTE Confidence: 0.975333091428572

00:55:39.668 --> 00:55:41.464 structured and follow less of
NOTE Confidence: 0.975333091428572

00:55:41.464 --> 00:55:42.916 a really admirably productive
NOTE Confidence: 0.975333091428572

00:55:42.916 --> 00:55:44.556 research arc compared to jaspreet.
NOTE Confidence: 0.975333091428572

00:55:44.556 --> 00:55:46.066 And one thing for those
NOTE Confidence: 0.975333091428572

00:55:46.066 --> 00:55:47.440 who don't realize this,
NOTE Confidence: 0.975333091428572

00:55:47.440 --> 00:55:49.336 having dabbled in research in this
NOTE Confidence: 0.975333091428572

00:55:49.336 --> 00:55:51.918 area is what a leader does pre Disney
NOTE Confidence: 0.975333091428572

00:55:51.918 --> 00:55:54.180 in this and how few people are really
NOTE Confidence: 0.975333091428572

00:55:54.180 --> 00:55:55.780 getting into the evidence about this.

NOTE Confidence: 0.975333091428572
00:55:55.780 --> 00:55:57.820 There's not a lot written about
NOTE Confidence: 0.975333091428572
00:55:57.820 --> 00:56:00.100 refusal of these newborn interventions,
NOTE Confidence: 0.975333091428572
00:56:00.100 --> 00:56:02.244 and I think that in and of itself.
NOTE Confidence: 0.975333091428572
00:56:02.250 --> 00:56:03.912 Is really telling and I'm really
NOTE Confidence: 0.975333091428572
00:56:03.912 --> 00:56:05.350 grateful that she's built this
NOTE Confidence: 0.975333091428572
00:56:05.350 --> 00:56:07.012 community of folks who are committed
NOTE Confidence: 0.975333091428572
00:56:07.012 --> 00:56:08.900 to advancing our knowledge about that.
NOTE Confidence: 0.975333091428572
00:56:08.900 --> 00:56:11.024 'cause 'cause you know in the later in the,
NOTE Confidence: 0.975333091428572
00:56:11.030 --> 00:56:11.325 UM,
NOTE Confidence: 0.975333091428572
00:56:11.325 --> 00:56:13.980 as my my late mentor Bill Meadow would say,
NOTE Confidence: 0.975333091428572
00:56:13.980 --> 00:56:15.660 good ethics start with good facts
NOTE Confidence: 0.975333091428572
00:56:15.660 --> 00:56:17.830 and so I think that information to
NOTE Confidence: 0.975333091428572
00:56:17.830 --> 00:56:19.838 inform this is is so important.
NOTE Confidence: 0.975333091428572
00:56:19.840 --> 00:56:22.228 So thank you for that work.
NOTE Confidence: 0.975333091428572
00:56:22.230 --> 00:56:23.826 My remarks are going to be,
NOTE Confidence: 0.975333091428572

00:56:23.830 --> 00:56:25.468 I think a bit more structured around

NOTE Confidence: 0.975333091428572

00:56:25.468 --> 00:56:26.805 responding to some of the things

NOTE Confidence: 0.975333091428572

00:56:26.805 --> 00:56:28.177 that marks that and a little bit

NOTE Confidence: 0.975333091428572

00:56:28.221 --> 00:56:29.571 around some of the things that

NOTE Confidence: 0.975333091428572

00:56:29.571 --> 00:56:30.926 Jaspreet said and I've sort of

NOTE Confidence: 0.975333091428572

00:56:30.926 --> 00:56:32.264 frantically taking notes to try to.

NOTE Confidence: 0.975333091428572

00:56:32.270 --> 00:56:34.070 Put some structure to this,

NOTE Confidence: 0.975333091428572

00:56:34.070 --> 00:56:35.950 but the first thing I want to set

NOTE Confidence: 0.975333091428572

00:56:35.950 --> 00:56:38.408 up is that I do think there are

NOTE Confidence: 0.975333091428572

00:56:38.408 --> 00:56:40.010 dramatic differences in the way

NOTE Confidence: 0.975333091428572

00:56:40.010 --> 00:56:41.823 this plays out for a baby who's

NOTE Confidence: 0.975333091428572

00:56:41.823 --> 00:56:44.285 sort of been sort of like reached

NOTE Confidence: 0.975333091428572

00:56:44.285 --> 00:56:46.581 the clutches of a neonatologist as

NOTE Confidence: 0.975333091428572

00:56:46.581 --> 00:56:48.625 opposed to a child is being cared

NOTE Confidence: 0.975333091428572

00:56:48.625 --> 00:56:51.109 for in the normal newborn nursery.

NOTE Confidence: 0.975333091428572

00:56:51.110 --> 00:56:52.374 And there's some really

NOTE Confidence: 0.975333091428572
00:56:52.374 --> 00:56:53.006 philosophical differences,
NOTE Confidence: 0.975333091428572
00:56:53.010 --> 00:56:54.975 I think that come into play and
NOTE Confidence: 0.975333091428572
00:56:54.975 --> 00:56:57.250 some of that has to do with,
NOTE Confidence: 0.975333091428572
00:56:57.250 --> 00:57:00.280 I think a appropriate response to
NOTE Confidence: 0.975333091428572
00:57:00.280 --> 00:57:02.720 the resurgence and interest and.
NOTE Confidence: 0.975333091428572
00:57:02.720 --> 00:57:04.215 A naturalistic and holistic birth
NOTE Confidence: 0.975333091428572
00:57:04.215 --> 00:57:06.048 experience and when you think about
NOTE Confidence: 0.975333091428572
00:57:06.048 --> 00:57:07.758 infants in a normal newborn nursery,
NOTE Confidence: 0.975333091428572
00:57:07.760 --> 00:57:10.288 your infants were born at home with midwives.
NOTE Confidence: 0.975333091428572
00:57:10.290 --> 00:57:12.120 Is the assumption that most babies,
NOTE Confidence: 0.975333091428572
00:57:12.120 --> 00:57:13.026 when they're born,
NOTE Confidence: 0.975333091428572
00:57:13.026 --> 00:57:14.838 are healthy and you know millennia
NOTE Confidence: 0.975333091428572
00:57:14.838 --> 00:57:15.680 of humanity.
NOTE Confidence: 0.975333091428572
00:57:15.680 --> 00:57:17.432 Support the fact that most babies
NOTE Confidence: 0.975333091428572
00:57:17.432 --> 00:57:18.910 are healthy when they're born.
NOTE Confidence: 0.975333091428572

00:57:18.910 --> 00:57:21.031 And so I think that that sort
NOTE Confidence: 0.975333091428572

00:57:21.031 --> 00:57:22.980 of setting of really emphasizing
NOTE Confidence: 0.975333091428572

00:57:22.980 --> 00:57:25.395 the maternal infant dyad and,
NOTE Confidence: 0.975333091428572

00:57:25.400 --> 00:57:26.132 you know, I realized,
NOTE Confidence: 0.975333091428572

00:57:26.132 --> 00:57:26.864 that's actually kinda dated
NOTE Confidence: 0.975333091428572

00:57:26.864 --> 00:57:27.788 way to talk about this.
NOTE Confidence: 0.975333091428572

00:57:27.790 --> 00:57:28.280 You know,
NOTE Confidence: 0.975333091428572

00:57:28.280 --> 00:57:29.750 we talk about pregnant people now,
NOTE Confidence: 0.988704291111111

00:57:29.750 --> 00:57:30.665 not pregnant woman in the
NOTE Confidence: 0.988704291111111

00:57:30.665 --> 00:57:31.397 world that has changed.
NOTE Confidence: 0.988704291111111

00:57:31.400 --> 00:57:33.440 When you think about this family
NOTE Confidence: 0.988704291111111

00:57:33.440 --> 00:57:35.673 structure and the sanctity of this
NOTE Confidence: 0.988704291111111

00:57:35.673 --> 00:57:37.693 family structure that the contemporary
NOTE Confidence: 0.988704291111111

00:57:37.693 --> 00:57:40.003 hospital normal newborn nursery has where
NOTE Confidence: 0.988704291111111

00:57:40.003 --> 00:57:42.079 we kind of prioritize non intervention
NOTE Confidence: 0.988704291111111

00:57:42.079 --> 00:57:43.621 and prioritize non separation.

NOTE Confidence: 0.9887042911111111
00:57:43.621 --> 00:57:46.840 The minute if babies sort of in the
NOTE Confidence: 0.9887042911111111
00:57:46.840 --> 00:57:49.066 ICU we've upended that whole thing
NOTE Confidence: 0.9887042911111111
00:57:49.070 --> 00:57:51.620 and suddenly this strong strong.
NOTE Confidence: 0.9887042911111111
00:57:51.620 --> 00:57:54.000 Emphasis on this very kind of holistic
NOTE Confidence: 0.9887042911111111
00:57:54.000 --> 00:57:56.247 and family unit centered care goes
NOTE Confidence: 0.9887042911111111
00:57:56.247 --> 00:57:58.177 away and the baby's condition.
NOTE Confidence: 0.9887042911111111
00:57:58.180 --> 00:57:59.090 There's some reason that the
NOTE Confidence: 0.9887042911111111
00:57:59.090 --> 00:58:00.352 baby is in the NICU, right?
NOTE Confidence: 0.9887042911111111
00:58:00.352 --> 00:58:01.760 So in my world,
NOTE Confidence: 0.9887042911111111
00:58:01.760 --> 00:58:03.264 most babies aren't healthy
NOTE Confidence: 0.9887042911111111
00:58:03.264 --> 00:58:05.520 because healthy babies are in my.
NOTE Confidence: 0.9887042911111111
00:58:05.520 --> 00:58:07.350 And so I think that
NOTE Confidence: 0.9887042911111111
00:58:07.350 --> 00:58:08.862 appreciating that difference,
NOTE Confidence: 0.9887042911111111
00:58:08.862 --> 00:58:12.390 and that that that that jarring mindset
NOTE Confidence: 0.9887042911111111
00:58:12.463 --> 00:58:14.695 that that puts families through even
NOTE Confidence: 0.9887042911111111

00:58:14.695 --> 00:58:17.648 if the baby is not fully admitted,
NOTE Confidence: 0.9887042911111111

00:58:17.650 --> 00:58:18.780 but someone called the neonatologist
NOTE Confidence: 0.9887042911111111

00:58:18.780 --> 00:58:20.160 to come and see the baby.
NOTE Confidence: 0.9887042911111111

00:58:20.160 --> 00:58:20.545 Suddenly,
NOTE Confidence: 0.9887042911111111

00:58:20.545 --> 00:58:23.240 we've challenged this idea that this baby
NOTE Confidence: 0.9887042911111111

00:58:23.240 --> 00:58:25.684 is healthy and I think that that's a
NOTE Confidence: 0.9887042911111111

00:58:25.684 --> 00:58:28.080 whole new stressor and pressure on families,
NOTE Confidence: 0.9887042911111111

00:58:28.080 --> 00:58:30.060 particularly families who seek to avoid
NOTE Confidence: 0.9887042911111111

00:58:30.060 --> 00:58:32.140 a lot of intervention around birth.
NOTE Confidence: 0.9887042911111111

00:58:32.140 --> 00:58:32.752 And suddenly,
NOTE Confidence: 0.9887042911111111

00:58:32.752 --> 00:58:33.364 you know,
NOTE Confidence: 0.9887042911111111

00:58:33.364 --> 00:58:35.200 it's beyond just the birth plan.
NOTE Confidence: 0.9887042911111111

00:58:35.200 --> 00:58:35.920 And sort of being,
NOTE Confidence: 0.9887042911111111

00:58:35.920 --> 00:58:37.250 you know asked what do you want?
NOTE Confidence: 0.9887042911111111

00:58:37.250 --> 00:58:38.202 And giving an answer,
NOTE Confidence: 0.9887042911111111

00:58:38.202 --> 00:58:39.154 but there's I think,

NOTE Confidence: 0.9887042911111111
00:58:39.160 --> 00:58:41.008 and among a lot of families a lot
NOTE Confidence: 0.9887042911111111
00:58:41.008 --> 00:58:42.002 more apprehension about you're
NOTE Confidence: 0.9887042911111111
00:58:42.002 --> 00:58:43.442 already trying to take away from
NOTE Confidence: 0.9887042911111111
00:58:43.442 --> 00:58:45.020 me what I wanted for my person.
NOTE Confidence: 0.9887042911111111
00:58:45.020 --> 00:58:46.934 And so I think that that
NOTE Confidence: 0.9887042911111111
00:58:46.934 --> 00:58:48.210 contrast is really important.
NOTE Confidence: 0.9887042911111111
00:58:48.210 --> 00:58:51.202 The other thing I want to contrast is
NOTE Confidence: 0.9887042911111111
00:58:51.202 --> 00:58:53.461 interventions that we the preventative
NOTE Confidence: 0.9887042911111111
00:58:53.461 --> 00:58:55.385 or screening interventions that
NOTE Confidence: 0.9887042911111111
00:58:55.385 --> 00:58:57.430 uniformly offered to everyone
NOTE Confidence: 0.9887042911111111
00:58:57.430 --> 00:58:58.594 versus risk based strategies,
NOTE Confidence: 0.9887042911111111
00:58:58.594 --> 00:59:00.980 because I think there are some differences,
NOTE Confidence: 0.9887042911111111
00:59:00.980 --> 00:59:02.460 they're not entirely different,
NOTE Confidence: 0.9887042911111111
00:59:02.460 --> 00:59:04.680 but if you think about vitamin
NOTE Confidence: 0.9887042911111111
00:59:04.744 --> 00:59:05.820 K for everyone uh,
NOTE Confidence: 0.9887042911111111

00:59:05.820 --> 00:59:07.830 erythromycin eye ointment for everyone,
NOTE Confidence: 0.9887042911111111

00:59:07.830 --> 00:59:09.916 as opposed to a risk based this
NOTE Confidence: 0.9887042911111111

00:59:09.916 --> 00:59:11.869 baby had this well appearing.
NOTE Confidence: 0.9887042911111111

00:59:11.870 --> 00:59:14.978 Baby has identified risk factors for
NOTE Confidence: 0.9887042911111111

00:59:14.978 --> 00:59:17.210 sepsis and I think there's a sort
NOTE Confidence: 0.9887042911111111

00:59:17.210 --> 00:59:19.321 of important symbolic act when you
NOTE Confidence: 0.9887042911111111

00:59:19.321 --> 00:59:21.596 move out of universal recommendations
NOTE Confidence: 0.9887042911111111

00:59:21.596 --> 00:59:22.961 versus personalized recommendations,
NOTE Confidence: 0.9887042911111111

00:59:22.970 --> 00:59:24.926 and that might not be rational,
NOTE Confidence: 0.9887042911111111

00:59:24.930 --> 00:59:26.778 but I think that it's there.
NOTE Confidence: 0.9887042911111111

00:59:26.780 --> 00:59:29.125 And so by the time we're being
NOTE Confidence: 0.9887042911111111

00:59:29.125 --> 00:59:31.618 asked to consider early onset sepsis
NOTE Confidence: 0.9887042911111111

00:59:31.618 --> 00:59:33.973 evaluation for well appearing baby,
NOTE Confidence: 0.9887042911111111

00:59:33.980 --> 00:59:35.804 I think to many of us that feels
NOTE Confidence: 0.9887042911111111

00:59:35.804 --> 00:59:37.307 different than the refusal of vitamin
NOTE Confidence: 0.9887042911111111

00:59:37.307 --> 00:59:39.078 K that we recommend to every infant

NOTE Confidence: 0.9887042911111111
00:59:39.078 --> 00:59:41.175 who I want to say walks through the door.
NOTE Confidence: 0.9887042911111111
00:59:41.180 --> 00:59:43.268 But that analogy is called fun.
NOTE Confidence: 0.9887042911111111
00:59:43.270 --> 00:59:45.587 So I think that that that contrast
NOTE Confidence: 0.9887042911111111
00:59:45.587 --> 00:59:47.601 is really important to the way
NOTE Confidence: 0.9887042911111111
00:59:47.601 --> 00:59:49.196 different groups think about this
NOTE Confidence: 0.9887042911111111
00:59:49.196 --> 00:59:51.439 and has contributed to the difficulty
NOTE Confidence: 0.9887042911111111
00:59:51.439 --> 00:59:53.755 in finding a coherent and uniform
NOTE Confidence: 0.9887042911111111
00:59:53.760 --> 00:59:55.495 strategy in that the philosophy
NOTE Confidence: 0.9887042911111111
00:59:55.495 --> 00:59:56.883 of care for infants.
NOTE Confidence: 0.9887042911111111
00:59:56.890 --> 00:59:58.048 So different when you think about
NOTE Confidence: 0.9887042911111111
00:59:58.048 --> 00:59:59.588 them in the in the normal newborn
NOTE Confidence: 0.982381775
00:59:59.600 --> 01:00:00.720 nursery versus the Nikki.
NOTE Confidence: 0.984042791666667
01:00:02.200 --> 01:00:03.304 There are a few other things
NOTE Confidence: 0.984042791666667
01:00:03.304 --> 01:00:04.599 that I really want to highlight.
NOTE Confidence: 0.984042791666667
01:00:04.600 --> 01:00:06.840 One is, I think, to be really clear.
NOTE Confidence: 0.984042791666667

01:00:06.840 --> 01:00:08.370 One of the things that I work on a lot
NOTE Confidence: 0.984042791666667

01:00:08.417 --> 01:00:09.937 when I teach ethics is to be really
NOTE Confidence: 0.984042791666667

01:00:09.937 --> 01:00:11.367 clear about what we're talking about,
NOTE Confidence: 0.984042791666667

01:00:11.370 --> 01:00:13.434 and I think in this situation a lot
NOTE Confidence: 0.984042791666667

01:00:13.434 --> 01:00:15.459 of the time we're talking about
NOTE Confidence: 0.984042791666667

01:00:15.459 --> 01:00:17.631 the bundle of preferences that has
NOTE Confidence: 0.984042791666667

01:00:17.696 --> 01:00:20.230 become kind of an architect and the
NOTE Confidence: 0.984042791666667

01:00:20.230 --> 01:00:21.678 non interventional list family,
NOTE Confidence: 0.984042791666667

01:00:21.678 --> 01:00:22.752 particularly around birth,
NOTE Confidence: 0.984042791666667

01:00:22.752 --> 01:00:26.038 and we think of when I think about this,
NOTE Confidence: 0.984042791666667

01:00:26.040 --> 01:00:27.576 as in unitologist,
NOTE Confidence: 0.984042791666667

01:00:27.576 --> 01:00:30.028 and this reveals my own bias.
NOTE Confidence: 0.984042791666667

01:00:30.028 --> 01:00:32.590 But these are people who don't want.
NOTE Confidence: 0.984042791666667

01:00:32.590 --> 01:00:34.283 Any of what I'm selling, right?
NOTE Confidence: 0.984042791666667

01:00:34.283 --> 01:00:36.307 I have a bundle of stuff and and
NOTE Confidence: 0.984042791666667

01:00:36.307 --> 01:00:37.890 regardless of what their plans were,

NOTE Confidence: 0.984042791666667
01:00:37.890 --> 01:00:40.172 they didn't involve me and it didn't
NOTE Confidence: 0.984042791666667
01:00:40.172 --> 01:00:41.650 involve my artificial chemical
NOTE Confidence: 0.984042791666667
01:00:41.650 --> 01:00:42.958 plastic wrapped stuff.
NOTE Confidence: 0.984042791666667
01:00:42.960 --> 01:00:43.881 My disposable diapers,
NOTE Confidence: 0.984042791666667
01:00:43.881 --> 01:00:45.716 my bottles with rubber ***** like
NOTE Confidence: 0.984042791666667
01:00:45.716 --> 01:00:47.788 none of that is what they wanted.
NOTE Confidence: 0.984042791666667
01:00:47.790 --> 01:00:51.734 And I think that that group has dominated.
NOTE Confidence: 0.984042791666667
01:00:51.740 --> 01:00:53.708 I think our modern discussion about
NOTE Confidence: 0.984042791666667
01:00:53.708 --> 01:00:56.068 this and our anguish about this has
NOTE Confidence: 0.984042791666667
01:00:56.068 --> 01:00:58.364 been what my colleague tree begins order.
NOTE Confidence: 0.984042791666667
01:00:58.370 --> 01:00:59.980 Who writes really eloquently about
NOTE Confidence: 0.984042791666667
01:00:59.980 --> 01:01:02.199 this in the lay press talks at
NOTE Confidence: 0.984042791666667
01:01:02.199 --> 01:01:03.554 the cult of the natural?
NOTE Confidence: 0.984042791666667
01:01:03.560 --> 01:01:07.536 Right, but not every parent who refuses.
NOTE Confidence: 0.984042791666667
01:01:07.540 --> 01:01:10.108 One or more of these interventions
NOTE Confidence: 0.984042791666667

01:01:10.108 --> 01:01:12.648 is is of that philosophy,
NOTE Confidence: 0.984042791666667

01:01:12.648 --> 01:01:15.081 and sometimes parents say, listen,
NOTE Confidence: 0.984042791666667

01:01:15.081 --> 01:01:16.686 I'll take anything you recommend
NOTE Confidence: 0.984042791666667

01:01:16.686 --> 01:01:18.360 if it makes sense to me,
NOTE Confidence: 0.984042791666667

01:01:18.360 --> 01:01:20.691 but a one in a thousand chance
NOTE Confidence: 0.984042791666667

01:01:20.691 --> 01:01:22.459 of substance just like that.
NOTE Confidence: 0.984042791666667

01:01:22.460 --> 01:01:23.364 You know, you know,
NOTE Confidence: 0.984042791666667

01:01:23.364 --> 01:01:23.816 for me,
NOTE Confidence: 0.984042791666667

01:01:23.820 --> 01:01:25.920 the example of that would be the
NOTE Confidence: 0.984042791666667

01:01:25.920 --> 01:01:27.480 mark talked about savviness,
NOTE Confidence: 0.984042791666667

01:01:27.480 --> 01:01:29.412 but the student physician who says
NOTE Confidence: 0.984042791666667

01:01:29.412 --> 01:01:31.067 everything I've ever learned says
NOTE Confidence: 0.984042791666667

01:01:31.067 --> 01:01:32.627 that exposure to broader spectrum
NOTE Confidence: 0.984042791666667

01:01:32.627 --> 01:01:34.490 antibiotics is bad for microbiome,
NOTE Confidence: 0.984042791666667

01:01:34.490 --> 01:01:36.158 and this risk seems very low,
NOTE Confidence: 0.984042791666667

01:01:36.160 --> 01:01:38.430 and I'll accept rational recommendations.

NOTE Confidence: 0.984042791666667
01:01:38.430 --> 01:01:41.070 But I don't think this one is rational,
NOTE Confidence: 0.984042791666667
01:01:41.070 --> 01:01:43.324 and so I think being really precise
NOTE Confidence: 0.984042791666667
01:01:43.324 --> 01:01:46.152 in what we talk about and not UN
NOTE Confidence: 0.984042791666667
01:01:46.152 --> 01:01:47.718 inappropriately reducing this
NOTE Confidence: 0.984042791666667
01:01:47.718 --> 01:01:52.076 to a sort of war with the with
NOTE Confidence: 0.984042791666667
01:01:52.076 --> 01:01:54.881 the naturalist family is really
NOTE Confidence: 0.984042791666667
01:01:54.881 --> 01:01:57.440 important so that our our.
NOTE Confidence: 0.984042791666667
01:01:57.440 --> 01:01:57.812 R.
NOTE Confidence: 0.984042791666667
01:01:57.812 --> 01:02:00.044 Rubric that we develop policies and
NOTE Confidence: 0.984042791666667
01:02:00.044 --> 01:02:02.308 guidelines and I agree with Mark,
NOTE Confidence: 0.984042791666667
01:02:02.310 --> 01:02:03.948 I think at least within institutions,
NOTE Confidence: 0.984042791666667
01:02:03.950 --> 01:02:05.220 we need to be specific.
NOTE Confidence: 0.984042791666667
01:02:05.220 --> 01:02:07.800 But what that is isn't a sort of war with
NOTE Confidence: 0.984042791666667
01:02:07.868 --> 01:02:10.388 a type and that we're really staying in,
NOTE Confidence: 0.984042791666667
01:02:10.390 --> 01:02:12.166 like what is reasonable that for
NOTE Confidence: 0.984042791666667

01:02:12.166 --> 01:02:13.889 parents while we're on on marks.
NOTE Confidence: 0.984042791666667

01:02:13.890 --> 01:02:16.730 Beautiful spectrum of impermissible,
NOTE Confidence: 0.984042791666667

01:02:16.730 --> 01:02:18.860 permissible and obligatory.
NOTE Confidence: 0.984042791666667

01:02:18.860 --> 01:02:21.149 Does this fit that should be about
NOTE Confidence: 0.984042791666667

01:02:21.149 --> 01:02:23.296 what's right for the baby and not
NOTE Confidence: 0.984042791666667

01:02:23.296 --> 01:02:25.675 what we feel about a group of parents
NOTE Confidence: 0.984042791666667

01:02:25.675 --> 01:02:28.095 who parent in a particular way that
NOTE Confidence: 0.984042791666667

01:02:28.095 --> 01:02:30.765 has become kind of an archetype.
NOTE Confidence: 0.984042791666667

01:02:30.770 --> 01:02:32.624 There's a few more things I want to mention.
NOTE Confidence: 0.984042791666667

01:02:32.630 --> 01:02:35.541 If Mark will indulge me and one he
NOTE Confidence: 0.984042791666667

01:02:35.541 --> 01:02:37.683 alluded to and Jaspreet alluded to,
NOTE Confidence: 0.984042791666667

01:02:37.690 --> 01:02:39.540 but I really like to call this out by name,
NOTE Confidence: 0.984042791666667

01:02:39.540 --> 01:02:41.304 because this is such a source of
NOTE Confidence: 0.984042791666667

01:02:41.304 --> 01:02:42.649 misconception and a lot of the
NOTE Confidence: 0.984042791666667

01:02:42.649 --> 01:02:43.369 work that I do,
NOTE Confidence: 0.984042791666667

01:02:43.370 --> 01:02:44.862 particularly with house officers,

NOTE Confidence: 0.984042791666667
01:02:44.862 --> 01:02:47.767 and that has to do with who owns
NOTE Confidence: 0.984042791666667
01:02:47.767 --> 01:02:49.890 the outcome of refusal.
NOTE Confidence: 0.984042791666667
01:02:49.890 --> 01:02:51.515 And Mark talked really nicely
NOTE Confidence: 0.984042791666667
01:02:51.515 --> 01:02:53.140 about us being moral agents,
NOTE Confidence: 0.987627848
01:02:53.140 --> 01:02:55.128 and I think one of the distinct
NOTE Confidence: 0.987627848
01:02:55.128 --> 01:02:55.980 features of Pediatrics.
NOTE Confidence: 0.987627848
01:02:55.980 --> 01:02:57.390 If you think about marks,
NOTE Confidence: 0.987627848
01:02:57.390 --> 01:03:01.037 example of the woman who is anemic.
NOTE Confidence: 0.987627848
01:03:01.040 --> 01:03:03.308 After a car accident and would make
NOTE Confidence: 0.987627848
01:03:03.308 --> 01:03:05.677 an informed choice to risk death as
NOTE Confidence: 0.987627848
01:03:05.677 --> 01:03:07.342 opposed to getting a transfusion,
NOTE Confidence: 0.987627848
01:03:07.350 --> 01:03:09.958 we have both legal and I think moral
NOTE Confidence: 0.987627848
01:03:09.958 --> 01:03:12.151 mechanisms by which we don't have
NOTE Confidence: 0.987627848
01:03:12.151 --> 01:03:13.996 moral culpability in her death.
NOTE Confidence: 0.987627848
01:03:14.000 --> 01:03:15.696 Now, that doesn't mean we don't feel it,
NOTE Confidence: 0.987627848

01:03:15.700 --> 01:03:17.364 and that we don't feel bad about it,
NOTE Confidence: 0.987627848

01:03:17.370 --> 01:03:20.598 but we're well set up to
NOTE Confidence: 0.987627848

01:03:20.598 --> 01:03:22.212 make competent adults.
NOTE Confidence: 0.987627848

01:03:22.220 --> 01:03:23.832 Morally responsible for the
NOTE Confidence: 0.987627848

01:03:23.832 --> 01:03:25.444 outcomes of their choices,
NOTE Confidence: 0.987627848

01:03:25.450 --> 01:03:27.637 and that is not a luxury in Pediatrics that's
NOTE Confidence: 0.987627848

01:03:27.637 --> 01:03:29.718 not in doubt that we have in Pediatrics,
NOTE Confidence: 0.987627848

01:03:29.720 --> 01:03:31.232 particularly for infants.
NOTE Confidence: 0.987627848

01:03:31.232 --> 01:03:35.754 And so if I abide apparent not refusing
NOTE Confidence: 0.987627848

01:03:35.754 --> 01:03:39.346 any form of vitamin K for an infant,
NOTE Confidence: 0.987627848

01:03:39.350 --> 01:03:41.075 and that baby has hemorrhagic
NOTE Confidence: 0.987627848

01:03:41.075 --> 01:03:42.455 disease of the newborn,
NOTE Confidence: 0.987627848

01:03:42.460 --> 01:03:44.080 I'm neither morally nor legally
NOTE Confidence: 0.987627848

01:03:44.080 --> 01:03:46.057 absolved by the fact that they
NOTE Confidence: 0.987627848

01:03:46.057 --> 01:03:47.857 were willing to own that choice.
NOTE Confidence: 0.987627848

01:03:47.860 --> 01:03:48.712 The parent might say,

NOTE Confidence: 0.987627848

01:03:48.712 --> 01:03:49.777 I'm really knowing that choice,

NOTE Confidence: 0.987627848

01:03:49.780 --> 01:03:51.319 but that's not.

NOTE Confidence: 0.987627848

01:03:51.319 --> 01:03:52.858 That's not OK.

NOTE Confidence: 0.987627848

01:03:52.860 --> 01:03:54.708 Relevant mechanism for us and the way

NOTE Confidence: 0.987627848

01:03:54.708 --> 01:03:56.796 I boil this down to trainees all the

NOTE Confidence: 0.987627848

01:03:56.796 --> 01:03:58.970 time is AMA or against medical advice.

NOTE Confidence: 0.987627848

01:03:58.970 --> 01:04:01.930 There's no AMA for kits and a mechanism

NOTE Confidence: 0.987627848

01:04:01.930 --> 01:04:03.965 of absolving ourselves of that

NOTE Confidence: 0.987627848

01:04:03.965 --> 01:04:06.807 culpability by virtue of sort of thing.

NOTE Confidence: 0.987627848

01:04:06.810 --> 01:04:08.330 I am willing to take on the risks

NOTE Confidence: 0.987627848

01:04:08.330 --> 01:04:10.019 of this that's not available to us,

NOTE Confidence: 0.987627848

01:04:10.020 --> 01:04:12.984 and I'm I'm alarmed at how

NOTE Confidence: 0.987627848

01:04:12.984 --> 01:04:15.890 many people are fuzzy on that.

NOTE Confidence: 0.987627848

01:04:15.890 --> 01:04:17.650 And I think that really does come to

NOTE Confidence: 0.987627848

01:04:17.650 --> 01:04:19.577 play with some of what the mechanisms

NOTE Confidence: 0.987627848

01:04:19.577 --> 01:04:21.012 that would jaspreet talked about
NOTE Confidence: 0.987627848

01:04:21.065 --> 01:04:22.547 with the sort of refusal forms.
NOTE Confidence: 0.987627848

01:04:22.550 --> 01:04:24.162 And stuff.
NOTE Confidence: 0.987627848

01:04:24.162 --> 01:04:24.968 I.
NOTE Confidence: 0.987627848

01:04:24.970 --> 01:04:26.924 My interpretation of things like
NOTE Confidence: 0.987627848

01:04:26.924 --> 01:04:29.240 these informed refusal forms is what
NOTE Confidence: 0.987627848

01:04:29.307 --> 01:04:31.297 those are our choice architecture.
NOTE Confidence: 0.987627848

01:04:31.300 --> 01:04:32.251 Those are nudges.
NOTE Confidence: 0.987627848

01:04:32.251 --> 01:04:34.831 Those are to sort of use anything we
NOTE Confidence: 0.987627848

01:04:34.831 --> 01:04:37.215 have to get what people to make the
NOTE Confidence: 0.987627848

01:04:37.215 --> 01:04:39.010 decisions that we think are good,
NOTE Confidence: 0.987627848

01:04:39.010 --> 01:04:41.146 but those are not releases of either moral,
NOTE Confidence: 0.987627848

01:04:41.150 --> 01:04:42.350 moral or legal culpability,
NOTE Confidence: 0.987627848

01:04:42.350 --> 01:04:43.850 and they won't protect you.
NOTE Confidence: 0.987627848

01:04:43.850 --> 01:04:45.154 And I don't want to get in trouble
NOTE Confidence: 0.987627848

01:04:45.154 --> 01:04:46.411 'cause we have a lawyer following me

NOTE Confidence: 0.987627848

01:04:46.411 --> 01:04:47.859 so I won't speak more about the law,

NOTE Confidence: 0.987627848

01:04:47.860 --> 01:04:49.708 but I just want to be really clear

NOTE Confidence: 0.987627848

01:04:49.708 --> 01:04:51.381 about what those refusal forms

NOTE Confidence: 0.987627848

01:04:51.381 --> 01:04:53.123 should mean symbolically, does.

NOTE Confidence: 0.987627848

01:04:53.123 --> 01:04:53.706 Uhm,

NOTE Confidence: 0.987627848

01:04:53.706 --> 01:04:57.204 two other comments and I think

NOTE Confidence: 0.987627848

01:04:57.204 --> 01:05:00.180 I'll probably stop after that.

NOTE Confidence: 0.987627848

01:05:00.180 --> 01:05:03.596 Had to do with the scope of parental

NOTE Confidence: 0.987627848

01:05:03.596 --> 01:05:05.740 authority and also fairness.

NOTE Confidence: 0.987627848

01:05:05.740 --> 01:05:08.309 So one thing that Mark mentioned that

NOTE Confidence: 0.987627848

01:05:08.309 --> 01:05:10.295 I've always found really interesting

NOTE Confidence: 0.987627848

01:05:10.295 --> 01:05:13.144 is this idea that people should have

NOTE Confidence: 0.987627848

01:05:13.144 --> 01:05:15.758 equal or fair access to bad decisions.

NOTE Confidence: 0.987627848

01:05:15.760 --> 01:05:18.014 And that's a hard that for me.

NOTE Confidence: 0.987627848

01:05:18.020 --> 01:05:19.640 That's kind of an interesting contradiction,

NOTE Confidence: 0.987627848

01:05:19.640 --> 01:05:21.271 but it does come up in terms
NOTE Confidence: 0.987627848

01:05:21.271 --> 01:05:22.640 of that savviness requirement.
NOTE Confidence: 0.987627848

01:05:22.640 --> 01:05:23.900 And when we think historically about,
NOTE Confidence: 0.987627848

01:05:23.900 --> 01:05:25.060 for example,
NOTE Confidence: 0.987627848

01:05:25.060 --> 01:05:27.380 who has refused vaccination?
NOTE Confidence: 0.987627848

01:05:27.380 --> 01:05:27.696 Uhm,
NOTE Confidence: 0.987627848

01:05:27.696 --> 01:05:30.224 so this idea that if we're going to
NOTE Confidence: 0.987627848

01:05:30.224 --> 01:05:32.712 allow a certain kind of savvy user
NOTE Confidence: 0.987627848

01:05:32.712 --> 01:05:35.043 to demand something or that demand
NOTE Confidence: 0.987627848

01:05:35.043 --> 01:05:38.032 something that we don't recommend or refuse,
NOTE Confidence: 0.987627848

01:05:38.040 --> 01:05:39.615 something that we do recommend
NOTE Confidence: 0.987627848

01:05:39.615 --> 01:05:41.577 that we maybe then should make
NOTE Confidence: 0.987627848

01:05:41.577 --> 01:05:43.182 those same bad choices available
NOTE Confidence: 0.987627848

01:05:43.182 --> 01:05:44.466 to people who don't
NOTE Confidence: 0.988051750740741

01:05:44.528 --> 01:05:46.390 have the savviness to ask for it.
NOTE Confidence: 0.988051750740741

01:05:46.390 --> 01:05:47.930 There's a purity of that argument that

NOTE Confidence: 0.988051750740741

01:05:47.930 --> 01:05:49.960 I can't that I can't deny. It's there.

NOTE Confidence: 0.988051750740741

01:05:49.960 --> 01:05:52.128 And and you know, this comes up.

NOTE Confidence: 0.988051750740741

01:05:52.128 --> 01:05:54.325 For example, in our world about offering

NOTE Confidence: 0.988051750740741

01:05:54.325 --> 01:05:57.050 comfort care at 24 weeks of gestation.

NOTE Confidence: 0.988051750740741

01:05:57.050 --> 01:05:59.342 Where at my institution the well

NOTE Confidence: 0.988051750740741

01:05:59.342 --> 01:06:01.441 counseled family that has repeatedly

NOTE Confidence: 0.988051750740741

01:06:01.441 --> 01:06:03.946 incoherently said that understanding the

NOTE Confidence: 0.988051750740741

01:06:03.946 --> 01:06:06.939 outcome statistics as we provided them,

NOTE Confidence: 0.988051750740741

01:06:06.940 --> 01:06:08.410 they would like to pursue comfort care

NOTE Confidence: 0.988051750740741

01:06:08.410 --> 01:06:10.204 for the 24 week baby in some situations

NOTE Confidence: 0.988051750740741

01:06:10.204 --> 01:06:11.839 will have a heavy heart about that,

NOTE Confidence: 0.988051750740741

01:06:11.840 --> 01:06:12.972 but will allow it.

NOTE Confidence: 0.988051750740741

01:06:12.972 --> 01:06:14.670 And then that begs the question,

NOTE Confidence: 0.988051750740741

01:06:14.670 --> 01:06:16.385 if I'll allow it in one family.

NOTE Confidence: 0.988051750740741

01:06:16.390 --> 01:06:19.678 Join my obligated to offer it to every.

NOTE Confidence: 0.988051750740741

01:06:19.680 --> 01:06:22.464 And so I think that this idea of
NOTE Confidence: 0.988051750740741

01:06:22.464 --> 01:06:24.869 equal access to inferior medical
NOTE Confidence: 0.988051750740741

01:06:24.869 --> 01:06:27.579 choices is compelling and important.
NOTE Confidence: 0.988051750740741

01:06:27.580 --> 01:06:27.978 Important,
NOTE Confidence: 0.988051750740741

01:06:27.978 --> 01:06:30.366 but to me also deeply troubling.
NOTE Confidence: 0.988051750740741

01:06:30.370 --> 01:06:31.812 And the flip side of that is
NOTE Confidence: 0.988051750740741

01:06:31.812 --> 01:06:32.780 when we think again,
NOTE Confidence: 0.988051750740741

01:06:32.780 --> 01:06:35.180 for examples of examples like
NOTE Confidence: 0.988051750740741

01:06:35.180 --> 01:06:38.234 vaccine refusal and not just the
NOTE Confidence: 0.988051750740741

01:06:38.234 --> 01:06:40.486 savviness requirement but the.
NOTE Confidence: 0.988051750740741

01:06:40.490 --> 01:06:42.800 The privilege to be able to refuse
NOTE Confidence: 0.988051750740741

01:06:42.800 --> 01:06:45.366 some of these interventions and the
NOTE Confidence: 0.988051750740741

01:06:45.366 --> 01:06:47.876 relative safety of refusing those
NOTE Confidence: 0.988051750740741

01:06:47.876 --> 01:06:50.599 interventions for well resourced families.
NOTE Confidence: 0.988051750740741

01:06:50.600 --> 01:06:52.721 If you have access to a pediatrician
NOTE Confidence: 0.988051750740741

01:06:52.721 --> 01:06:54.444 who answers your calls 24 hours

NOTE Confidence: 0.988051750740741
01:06:54.444 --> 01:06:55.694 a day and a vehicle,
NOTE Confidence: 0.988051750740741
01:06:55.700 --> 01:06:57.188 and the ability to park and the ability
NOTE Confidence: 0.988051750740741
01:06:57.188 --> 01:06:58.838 to have child care to bring your child,
NOTE Confidence: 0.988051750740741
01:06:58.840 --> 01:07:00.940 and you can respond to illness differently,
NOTE Confidence: 0.988051750740741
01:07:00.940 --> 01:07:03.754 and so as refusal of these interventions
NOTE Confidence: 0.988051750740741
01:07:03.754 --> 01:07:06.080 sort of disseminates and becomes more
NOTE Confidence: 0.988051750740741
01:07:06.080 --> 01:07:08.523 broad in a society where people with
NOTE Confidence: 0.988051750740741
01:07:08.597 --> 01:07:11.369 really little advantage and few resources.
NOTE Confidence: 0.988051750740741
01:07:11.370 --> 01:07:13.350 I think the potential for the
NOTE Confidence: 0.988051750740741
01:07:13.350 --> 01:07:14.622 consequences of that, UM,
NOTE Confidence: 0.988051750740741
01:07:14.622 --> 01:07:15.186 are different,
NOTE Confidence: 0.988051750740741
01:07:15.186 --> 01:07:16.878 and I just think that's something
NOTE Confidence: 0.988051750740741
01:07:16.878 --> 01:07:17.690 really important.
NOTE Confidence: 0.988051750740741
01:07:17.690 --> 01:07:19.965 Think about you know what will be
NOTE Confidence: 0.988051750740741
01:07:19.965 --> 01:07:22.141 the consequences on the children of
NOTE Confidence: 0.988051750740741

01:07:22.141 --> 01:07:24.421 the most disadvantaged families as as
NOTE Confidence: 0.988051750740741

01:07:24.421 --> 01:07:26.479 refusing these things becomes more popular.
NOTE Confidence: 0.986445229

01:07:29.010 --> 01:07:30.666 Briefly, and you could,
NOTE Confidence: 0.986445229

01:07:30.666 --> 01:07:33.150 we could fill hours on this.
NOTE Confidence: 0.986445229

01:07:33.150 --> 01:07:36.454 Mark and I have talked offline about.
NOTE Confidence: 0.986445229

01:07:36.460 --> 01:07:38.756 Whether and how this is different for
NOTE Confidence: 0.986445229

01:07:38.756 --> 01:07:40.669 infants compared to older children,
NOTE Confidence: 0.986445229

01:07:40.670 --> 01:07:42.560 and whether that's right or wrong,
NOTE Confidence: 0.986445229

01:07:42.560 --> 01:07:44.720 and I think he and I both Lynn on the on.
NOTE Confidence: 0.986445229

01:07:44.720 --> 01:07:46.827 The decision that it's probably not right,
NOTE Confidence: 0.986445229

01:07:46.830 --> 01:07:48.470 but I think it's there.
NOTE Confidence: 0.986445229

01:07:48.470 --> 01:07:50.180 And when you know if you
NOTE Confidence: 0.986445229

01:07:50.180 --> 01:07:51.320 think about it visually,
NOTE Confidence: 0.986445229

01:07:51.320 --> 01:07:54.758 the marks visual is so helpful of of what
NOTE Confidence: 0.986445229

01:07:54.758 --> 01:07:57.747 falls in the spectrum of permissible,
NOTE Confidence: 0.986445229

01:07:57.750 --> 01:07:59.310 I think implicitly,

NOTE Confidence: 0.986445229
01:07:59.310 --> 01:08:02.950 as a society that range is wider
NOTE Confidence: 0.986445229
01:08:03.059 --> 01:08:05.480 for for a parental infant dyad,
NOTE Confidence: 0.986445229
01:08:05.480 --> 01:08:06.550 for newborns, and it is.
NOTE Confidence: 0.986445229
01:08:06.550 --> 01:08:08.125 For older children,
NOTE Confidence: 0.986445229
01:08:08.125 --> 01:08:11.275 and I think that we afford.
NOTE Confidence: 0.986445229
01:08:11.280 --> 01:08:13.025 It's a extended parental authority
NOTE Confidence: 0.986445229
01:08:13.025 --> 01:08:14.421 or extended parental rights
NOTE Confidence: 0.986445229
01:08:14.421 --> 01:08:16.459 in the newborn period that we
NOTE Confidence: 0.986445229
01:08:16.459 --> 01:08:18.094 wouldn't afford to older children,
NOTE Confidence: 0.986445229
01:08:18.100 --> 01:08:19.066 and I think that's been shown in
NOTE Confidence: 0.986445229
01:08:19.066 --> 01:08:20.299 a lot of really elegant studies.
NOTE Confidence: 0.986445229
01:08:20.300 --> 01:08:22.556 I think Andy Johnny is the hero of
NOTE Confidence: 0.986445229
01:08:22.556 --> 01:08:25.390 that of talking about about how
NOTE Confidence: 0.986445229
01:08:25.390 --> 01:08:29.350 somehow or another we don't afford.
NOTE Confidence: 0.986445229
01:08:29.350 --> 01:08:31.280 Infants the same moral status
NOTE Confidence: 0.981586966

01:08:31.290 --> 01:08:32.400 as we do. Older children,
NOTE Confidence: 0.986918862857143

01:08:33.300 --> 01:08:35.276 and I think that that implicitly has a
NOTE Confidence: 0.986918862857143

01:08:35.276 --> 01:08:37.710 lot to do with why we have historically
NOTE Confidence: 0.986918862857143

01:08:37.710 --> 01:08:39.300 allowed people to refuse fund.
NOTE Confidence: 0.986918862857143

01:08:39.300 --> 01:08:41.676 Some of these things when in a comparable
NOTE Confidence: 0.986918862857143

01:08:41.676 --> 01:08:43.707 situation an older child we might not,
NOTE Confidence: 0.986918862857143

01:08:43.710 --> 01:08:46.572 and I think this this now in a sort
NOTE Confidence: 0.986918862857143

01:08:46.572 --> 01:08:49.000 of cultural way, has a lot to do
NOTE Confidence: 0.986918862857143

01:08:49.000 --> 01:08:50.369 with this right to have a birth.
NOTE Confidence: 0.986918862857143

01:08:50.370 --> 01:08:51.350 How you want it.
NOTE Confidence: 0.986918862857143

01:08:51.350 --> 01:08:53.233 And this the birth that a family
NOTE Confidence: 0.986918862857143

01:08:53.233 --> 01:08:55.008 and visions for themselves and
NOTE Confidence: 0.986918862857143

01:08:55.008 --> 01:08:56.855 their infant takes some moral
NOTE Confidence: 0.986918862857143

01:08:56.855 --> 01:08:58.660 priority over the absolute medical
NOTE Confidence: 0.986918862857143

01:08:58.660 --> 01:09:00.382 best interest of that nature.
NOTE Confidence: 0.986918862857143

01:09:00.382 --> 01:09:01.742 And I think that contradiction

NOTE Confidence: 0.986918862857143
01:09:01.742 --> 01:09:03.025 is really hard, for,
NOTE Confidence: 0.986918862857143
01:09:03.025 --> 01:09:04.420 for for obstetricians,
NOTE Confidence: 0.986918862857143
01:09:04.420 --> 01:09:06.280 infinite ologist and family,
NOTE Confidence: 0.986918862857143
01:09:06.280 --> 01:09:07.080 family medicine,
NOTE Confidence: 0.986918862857143
01:09:07.080 --> 01:09:09.480 docs and and normal newborn attendings
NOTE Confidence: 0.986918862857143
01:09:09.480 --> 01:09:11.970 is this idea that somehow or
NOTE Confidence: 0.986918862857143
01:09:11.970 --> 01:09:14.000 another that parental authority the
NOTE Confidence: 0.986918862857143
01:09:14.000 --> 01:09:16.187 purview of that parental authority?
NOTE Confidence: 0.986918862857143
01:09:16.190 --> 01:09:17.930 Contracts as that child nears the
NOTE Confidence: 0.986918862857143
01:09:17.930 --> 01:09:19.760 door and then gets discharged.
NOTE Confidence: 0.986918862857143
01:09:19.760 --> 01:09:22.550 But in the newborn period we
NOTE Confidence: 0.986918862857143
01:09:22.550 --> 01:09:24.410 somehow haven't quite granted
NOTE Confidence: 0.986918862857143
01:09:24.494 --> 01:09:26.418 personhood to that info.
NOTE Confidence: 0.986918862857143
01:09:26.420 --> 01:09:26.672 Uhm,
NOTE Confidence: 0.986918862857143
01:09:26.672 --> 01:09:28.688 the final thing I want to say gets
NOTE Confidence: 0.986918862857143

01:09:28.688 --> 01:09:30.561 just gets back to a little bit of
NOTE Confidence: 0.986918862857143

01:09:30.561 --> 01:09:32.670 what I was talking about with this,
NOTE Confidence: 0.986918862857143

01:09:32.670 --> 01:09:33.654 the culpability issue.
NOTE Confidence: 0.986918862857143

01:09:33.654 --> 01:09:35.294 And who owns the outcome?
NOTE Confidence: 0.986918862857143

01:09:35.300 --> 01:09:36.848 Because this is another thing I
NOTE Confidence: 0.986918862857143

01:09:36.848 --> 01:09:38.236 think where people get derailed
NOTE Confidence: 0.986918862857143

01:09:38.236 --> 01:09:40.078 sometimes and it's important not to.
NOTE Confidence: 0.986918862857143

01:09:40.080 --> 01:09:41.724 Whoever his feet were going to
NOTE Confidence: 0.986918862857143

01:09:41.724 --> 01:09:44.285 hold to the fire for the burden of
NOTE Confidence: 0.986918862857143

01:09:44.285 --> 01:09:46.035 refusing one of these interventions,
NOTE Confidence: 0.986918862857143

01:09:46.040 --> 01:09:47.724 whether it's the clinician,
NOTE Confidence: 0.986918862857143

01:09:47.724 --> 01:09:50.250 whether it's the parent that culpability
NOTE Confidence: 0.986918862857143

01:09:50.321 --> 01:09:52.116 doesn't hinge on the outcome.
NOTE Confidence: 0.986918862857143

01:09:52.120 --> 01:09:53.528 So what and what I mean by that
NOTE Confidence: 0.986918862857143

01:09:53.528 --> 01:09:55.057 is that I sometimes get question,
NOTE Confidence: 0.986918862857143

01:09:55.060 --> 01:09:55.910 you know,

NOTE Confidence: 0.986918862857143
01:09:55.910 --> 01:09:58.885 if a parent refuses an MMR vaccine
NOTE Confidence: 0.986918862857143
01:09:58.885 --> 01:10:01.789 and the child gets the measles.
NOTE Confidence: 0.986918862857143
01:10:01.790 --> 01:10:03.836 Or is that parents somehow more
NOTE Confidence: 0.986918862857143
01:10:03.836 --> 01:10:05.589 culpable than when they they
NOTE Confidence: 0.986918862857143
01:10:05.589 --> 01:10:07.521 refused the memory and the child
NOTE Confidence: 0.986918862857143
01:10:07.521 --> 01:10:09.470 didn't get the results and the
NOTE Confidence: 0.986918862857143
01:10:09.470 --> 01:10:11.598 the the thing that the refuser or
NOTE Confidence: 0.986918862857143
01:10:11.600 --> 01:10:13.526 the abider of the Refuser owns
NOTE Confidence: 0.986918862857143
01:10:13.526 --> 01:10:15.460 is the decision not to do it,
NOTE Confidence: 0.986918862857143
01:10:15.460 --> 01:10:17.032 not the outcome?
NOTE Confidence: 0.986918862857143
01:10:17.032 --> 01:10:20.047 And so I I think that we should be
NOTE Confidence: 0.986918862857143
01:10:20.047 --> 01:10:21.714 careful about getting into the logic
NOTE Confidence: 0.986918862857143
01:10:21.714 --> 01:10:23.846 or we say that whether or not you
NOTE Confidence: 0.986918862857143
01:10:23.846 --> 01:10:25.670 have moral or legal culpability for
NOTE Confidence: 0.986918862857143
01:10:25.670 --> 01:10:28.474 a bad outcome doesn't depend on on
NOTE Confidence: 0.986918862857143

01:10:28.474 --> 01:10:31.300 whether how it comes to fruition.
NOTE Confidence: 0.986918862857143

01:10:31.300 --> 01:10:33.930 So the. This sort of.
NOTE Confidence: 0.986918862857143

01:10:33.930 --> 01:10:36.555 The moral wrong innocence is not doing
NOTE Confidence: 0.986918862857143

01:10:36.555 --> 01:10:38.509 what's best interest in the baby,
NOTE Confidence: 0.986918862857143

01:10:38.510 --> 01:10:40.204 not whether or not the one in
NOTE Confidence: 0.986918862857143

01:10:40.204 --> 01:10:41.390 1000 steps section happens.
NOTE Confidence: 0.986918862857143

01:10:41.390 --> 01:10:41.666 I don't.
NOTE Confidence: 0.986918862857143

01:10:41.666 --> 01:10:42.494 I don't know that I've explained
NOTE Confidence: 0.986918862857143

01:10:42.494 --> 01:10:43.369 that as well as I wanted to,
NOTE Confidence: 0.986918862857143

01:10:43.370 --> 01:10:44.540 but I think that people get
NOTE Confidence: 0.986918862857143

01:10:44.540 --> 01:10:45.809 derailed with that a little bit.
NOTE Confidence: 0.986918862857143

01:10:45.810 --> 01:10:49.540 So I just I just wanted to make that point.
NOTE Confidence: 0.986918862857143

01:10:49.540 --> 01:10:51.234 I think that's about what I have
NOTE Confidence: 0.986918862857143

01:10:51.234 --> 01:10:53.296 to say and I'm really curious to
NOTE Confidence: 0.986918862857143

01:10:53.296 --> 01:10:55.158 to hear our third panelist and and
NOTE Confidence: 0.986918862857143

01:10:55.158 --> 01:10:56.880 what this audience has to say.

NOTE Confidence: 0.9796848

01:10:57.960 --> 01:10:59.950 Thank you so much, Naomi.

NOTE Confidence: 0.9796848

01:10:59.950 --> 01:11:02.926 I now want to return to Jay Sicklick.

NOTE Confidence: 0.9796848

01:11:02.930 --> 01:11:05.177 Attorney cyclic began as a staff attorney

NOTE Confidence: 0.9796848

01:11:05.177 --> 01:11:07.905 in the Center for children's Advocacy and

NOTE Confidence: 0.9796848

01:11:07.905 --> 01:11:10.461 founded the first collaborative medical legal

NOTE Confidence: 0.9796848

01:11:10.524 --> 01:11:12.855 partnership in the country back in 2000.

NOTE Confidence: 0.9796848

01:11:12.860 --> 01:11:15.070 Uhm, and prior to that he was on the faculty

NOTE Confidence: 0.9796848

01:11:15.120 --> 01:11:17.276 at University of Connecticut School of Law.

NOTE Confidence: 0.9796848

01:11:17.280 --> 01:11:19.121 He served as a senior staff attorney

NOTE Confidence: 0.9796848

01:11:19.121 --> 01:11:21.307 at the Legal Aid Society in the Bronx.

NOTE Confidence: 0.9796848

01:11:21.310 --> 01:11:23.500 He's currently an adjunct professor of

NOTE Confidence: 0.9796848

01:11:23.500 --> 01:11:25.940 law at the University of Connecticut.

NOTE Confidence: 0.9796848

01:11:25.940 --> 01:11:27.602 He's a clinical instructor in the

NOTE Confidence: 0.9796848

01:11:27.602 --> 01:11:29.389 Department of Pediatrics at the University

NOTE Confidence: 0.9796848

01:11:29.389 --> 01:11:30.974 of Connecticut School of Medicine.

NOTE Confidence: 0.9796848

01:11:30.980 --> 01:11:33.479 Mr. Cyclic is a graduate of Colgate
NOTE Confidence: 0.9796848

01:11:33.479 --> 01:11:35.829 University in Boston College Law School.
NOTE Confidence: 0.9796848

01:11:35.830 --> 01:11:38.308 He's the author of several publications,
NOTE Confidence: 0.9796848

01:11:38.310 --> 01:11:40.788 and he's spoken at numerous conferences
NOTE Confidence: 0.9796848

01:11:40.790 --> 01:11:44.380 on hospital, hospital related issues,
NOTE Confidence: 0.9796848

01:11:44.380 --> 01:11:46.424 legal health related topics,
NOTE Confidence: 0.9796848

01:11:46.424 --> 01:11:49.554 and so he's a wonderful person to come
NOTE Confidence: 0.9796848

01:11:49.554 --> 01:11:51.720 and speak to us about this question.
NOTE Confidence: 0.9796848

01:11:51.720 --> 01:11:53.385 So Jay, I want to thank you so much
NOTE Confidence: 0.9796848

01:11:53.385 --> 01:11:54.844 for doing this with us and I'll
NOTE Confidence: 0.9796848

01:11:54.844 --> 01:11:55.900 turn it over to you.
NOTE Confidence: 0.984826715333333

01:11:57.740 --> 01:12:00.588 Thanks Mark, I appreciate it and it's it's
NOTE Confidence: 0.984826715333333

01:12:00.588 --> 01:12:03.866 hard to back clean up in this line up.
NOTE Confidence: 0.984826715333333

01:12:03.866 --> 01:12:06.970 There are some impressive heaters before me.
NOTE Confidence: 0.984826715333333

01:12:06.970 --> 01:12:09.090 I hope I'm not like the Yankees and
NOTE Confidence: 0.984826715333333

01:12:09.149 --> 01:12:11.368 perpetually strike out every game at the

NOTE Confidence: 0.984826715333333
01:12:11.368 --> 01:12:14.080 number 4 slot, but we'll do our best.
NOTE Confidence: 0.984826715333333
01:12:14.080 --> 01:12:15.320 I'm going to be brief,
NOTE Confidence: 0.984826715333333
01:12:15.320 --> 01:12:17.480 I promise 'cause I know there are probably
NOTE Confidence: 0.984826715333333
01:12:17.480 --> 01:12:20.093 a lot of questions and a lot of thoughtful
NOTE Confidence: 0.984826715333333
01:12:20.093 --> 01:12:23.310 folks who have opinions on the clinical side.
NOTE Confidence: 0.984826715333333
01:12:23.310 --> 01:12:25.692 I'm going to be really brief
NOTE Confidence: 0.984826715333333
01:12:25.692 --> 01:12:27.710 about the legal perspective here.
NOTE Confidence: 0.984826715333333
01:12:27.710 --> 01:12:29.229 One of my favorite quotes in the
NOTE Confidence: 0.984826715333333
01:12:29.229 --> 01:12:30.729 law not being novel about this,
NOTE Confidence: 0.984826715333333
01:12:30.730 --> 01:12:32.620 but most folks probably have heard it
NOTE Confidence: 0.984826715333333
01:12:32.620 --> 01:12:34.758 is from Oliver Wendell Holmes, right,
NOTE Confidence: 0.984826715333333
01:12:34.758 --> 01:12:38.532 life of the law has not been logic.
NOTE Confidence: 0.984826715333333
01:12:38.532 --> 01:12:40.432 It has been experience, right?
NOTE Confidence: 0.984826715333333
01:12:40.432 --> 01:12:42.340 The life of the law has not been logic.
NOTE Confidence: 0.984826715333333
01:12:42.340 --> 01:12:44.148 It has been experience.
NOTE Confidence: 0.984826715333333

01:12:44.150 --> 01:12:47.642 Blog doesn't use logic as a
NOTE Confidence: 0.984826715333333

01:12:47.642 --> 01:12:50.707 fundamental paradigm like the wonderful
NOTE Confidence: 0.984826715333333

01:12:50.707 --> 01:12:52.490 paradigm you set up,
NOTE Confidence: 0.984826715333333

01:12:52.490 --> 01:12:54.835 mark and the different issues that your
NOTE Confidence: 0.984826715333333

01:12:54.835 --> 01:12:56.629 colleagues here have talked about.
NOTE Confidence: 0.984826715333333

01:12:56.630 --> 01:12:58.930 That is why mandates exist.
NOTE Confidence: 0.984826715333333

01:12:58.930 --> 01:13:00.311 But they exist from a
NOTE Confidence: 0.984826715333333

01:13:00.311 --> 01:13:01.193 legislative perspective.
NOTE Confidence: 0.984826715333333

01:13:01.193 --> 01:13:03.398 If you break this down
NOTE Confidence: 0.984826715333333

01:13:03.398 --> 01:13:05.630 into kind of three pockets,
NOTE Confidence: 0.984826715333333

01:13:05.630 --> 01:13:07.386 there are legislative mandates.
NOTE Confidence: 0.984826715333333

01:13:07.386 --> 01:13:10.536 What are the consequences of not following
NOTE Confidence: 0.984826715333333

01:13:10.536 --> 01:13:12.731 those mandates that require certain
NOTE Confidence: 0.984826715333333

01:13:12.731 --> 01:13:15.869 type of testing or care and treatment?
NOTE Confidence: 0.984826715333333

01:13:15.870 --> 01:13:17.985 We don't have a lot of those in Connecticut.
NOTE Confidence: 0.984826715333333

01:13:17.990 --> 01:13:20.450 There aren't a lot nationwide,

NOTE Confidence: 0.984826715333333
01:13:20.450 --> 01:13:23.378 I think that you know doctor loyal talked
NOTE Confidence: 0.984826715333333
01:13:23.378 --> 01:13:26.629 about the vitamin K requirement in New York,
NOTE Confidence: 0.984826715333333
01:13:26.630 --> 01:13:28.315 but she also implied what
NOTE Confidence: 0.984826715333333
01:13:28.315 --> 01:13:29.326 are the consequences?
NOTE Confidence: 0.984826715333333
01:13:29.330 --> 01:13:32.348 Of not adhering to that mandate,
NOTE Confidence: 0.984826715333333
01:13:32.350 --> 01:13:35.974 the second category is has the refusal to
NOTE Confidence: 0.984826715333333
01:13:35.974 --> 01:13:39.996 a pink care reached a level of neglect,
NOTE Confidence: 0.984826715333333
01:13:40.000 --> 01:13:41.353 specifically medical neglect?
NOTE Confidence: 0.984826715333333
01:13:41.353 --> 01:13:43.608 What does that mean though?
NOTE Confidence: 0.984826715333333
01:13:43.610 --> 01:13:45.596 Does it mean there's going to
NOTE Confidence: 0.984826715333333
01:13:45.596 --> 01:13:46.920 be some further consequences,
NOTE Confidence: 0.984826715333333
01:13:46.920 --> 01:13:48.831 or does it mean that there's just
NOTE Confidence: 0.984826715333333
01:13:48.831 --> 01:13:50.658 an issue of medical neglect and
NOTE Confidence: 0.984826715333333
01:13:50.658 --> 01:13:52.863 we're going to let it live there
NOTE Confidence: 0.984826715333333
01:13:52.931 --> 01:13:54.567 without any further action?
NOTE Confidence: 0.984826715333333

01:13:54.570 --> 01:13:55.330 In #3,
NOTE Confidence: 0.9848267153333333

01:13:55.330 --> 01:13:56.510 there's the idea.
NOTE Confidence: 0.9848267153333333

01:13:56.510 --> 01:13:58.510 Have you crossed the threshold
NOTE Confidence: 0.9848267153333333

01:13:58.510 --> 01:13:59.710 into what constitutes?
NOTE Confidence: 0.9848267153333333

01:13:59.710 --> 01:14:01.924 Obligatory care as Mark talked about
NOTE Confidence: 0.9848267153333333

01:14:01.924 --> 01:14:03.889 talked about that the consequences
NOTE Confidence: 0.9848267153333333

01:14:03.889 --> 01:14:06.409 of failure to treat could result
NOTE Confidence: 0.9848267153333333

01:14:06.409 --> 01:14:08.120 in some catastrophic event,
NOTE Confidence: 0.9848267153333333

01:14:08.120 --> 01:14:10.608 and he crossed over into what I think
NOTE Confidence: 0.9848267153333333

01:14:10.608 --> 01:14:13.328 we would call the idea that there is
NOTE Confidence: 0.9848267153333333

01:14:13.328 --> 01:14:15.191 a requirement of state intervention
NOTE Confidence: 0.9848267153333333

01:14:15.191 --> 01:14:17.825 into this particular issue or into
NOTE Confidence: 0.9848267153333333

01:14:17.825 --> 01:14:20.430 the greater issue or the larger issue
NOTE Confidence: 0.9848267153333333

01:14:20.430 --> 01:14:22.350 of should we be requiring mandates
NOTE Confidence: 0.9848267153333333

01:14:22.417 --> 01:14:24.301 for these types of screenings or
NOTE Confidence: 0.9848267153333333

01:14:24.301 --> 01:14:25.980 these types of blood tests,

NOTE Confidence: 0.984826715333333
01:14:25.980 --> 01:14:27.730 or these types of treatments,
NOTE Confidence: 0.984826715333333
01:14:27.730 --> 01:14:29.410 and that is the ultimate question here,
NOTE Confidence: 0.984826715333333
01:14:29.410 --> 01:14:29.767 right?
NOTE Confidence: 0.984826715333333
01:14:29.767 --> 01:14:32.266 What is the ultimate end game in
NOTE Confidence: 0.984826715333333
01:14:32.266 --> 01:14:35.150 terms of the law and how does that
NOTE Confidence: 0.984826715333333
01:14:35.150 --> 01:14:37.669 work from a practical point of view?
NOTE Confidence: 0.984826715333333
01:14:37.670 --> 01:14:40.057 In terms of what constitutes the legal
NOTE Confidence: 0.984826715333333
01:14:40.057 --> 01:14:42.890 right of a parent to make decisions,
NOTE Confidence: 0.984826715333333
01:14:42.890 --> 01:14:44.930 the last always extraordinarily
NOTE Confidence: 0.984826715333333
01:14:44.930 --> 01:14:47.990 on the backs of the parent.
NOTE Confidence: 0.984826715333333
01:14:47.990 --> 01:14:49.530 The presumption is that parents
NOTE Confidence: 0.984826715333333
01:14:49.530 --> 01:14:51.539 get to make health care decisions
NOTE Confidence: 0.984826715333333
01:14:51.539 --> 01:14:52.757 for their children.
NOTE Confidence: 0.984826715333333
01:14:52.760 --> 01:14:54.769 It is rooted in the 14th amendment,
NOTE Confidence: 0.984826715333333
01:14:54.770 --> 01:14:57.598 is rooted in the due process clause.
NOTE Confidence: 0.984826715333333

01:14:57.600 --> 01:14:59.928 If the parents overstep their bounds,
NOTE Confidence: 0.984826715333333

01:14:59.930 --> 01:15:01.886 like in that famous Prince case,
NOTE Confidence: 0.984826715333333

01:15:01.890 --> 01:15:04.050 which ironically is Mark brought
NOTE Confidence: 0.984826715333333

01:15:04.050 --> 01:15:06.210 up involved the Jehovah's Witnesses
NOTE Confidence: 0.988124054166667

01:15:06.280 --> 01:15:08.544 family who? Or attempting to require
NOTE Confidence: 0.988124054166667

01:15:08.544 --> 01:15:10.890 their child to sell religious literature
NOTE Confidence: 0.988124054166667

01:15:10.954 --> 01:15:12.758 in violation of Massachusetts.
NOTE Confidence: 0.988124054166667

01:15:12.760 --> 01:15:14.664 Log this back in the mid 40s,
NOTE Confidence: 0.988124054166667

01:15:14.670 --> 01:15:16.546 the Supreme Court waited and said no,
NOTE Confidence: 0.988124054166667

01:15:16.550 --> 01:15:19.273 the parents can't require their child to
NOTE Confidence: 0.988124054166667

01:15:19.273 --> 01:15:21.929 violate child labor laws under the auspices
NOTE Confidence: 0.988124054166667

01:15:21.929 --> 01:15:24.720 of the First Amendment right of religion.
NOTE Confidence: 0.988124054166667

01:15:24.720 --> 01:15:27.300 Even the auspices of the parents
NOTE Confidence: 0.988124054166667

01:15:27.300 --> 01:15:29.772 right to care for their children
NOTE Confidence: 0.988124054166667

01:15:29.772 --> 01:15:31.384 under the 14th amendment.
NOTE Confidence: 0.988124054166667

01:15:31.390 --> 01:15:34.141 But we have made these decisions along

NOTE Confidence: 0.988124054166667
01:15:34.141 --> 01:15:37.140 the way under this notion of parents.
NOTE Confidence: 0.988124054166667
01:15:37.140 --> 01:15:39.939 Patri I that the law does get to intervene.
NOTE Confidence: 0.988124054166667
01:15:39.940 --> 01:15:41.740 The state gets to intervene.
NOTE Confidence: 0.988124054166667
01:15:41.740 --> 01:15:43.125 The state entity gets to
NOTE Confidence: 0.988124054166667
01:15:43.125 --> 01:15:45.046 intervene if that line is crossed,
NOTE Confidence: 0.988124054166667
01:15:45.046 --> 01:15:47.065 and that's what I think we're
NOTE Confidence: 0.988124054166667
01:15:47.065 --> 01:15:48.034 talking about here.
NOTE Confidence: 0.988124054166667
01:15:48.040 --> 01:15:50.060 We've made mandates for vaccines,
NOTE Confidence: 0.988124054166667
01:15:50.060 --> 01:15:51.957 but the penalty is that your child
NOTE Confidence: 0.988124054166667
01:15:51.957 --> 01:15:54.419 can't go to school or can't go to camp,
NOTE Confidence: 0.988124054166667
01:15:54.420 --> 01:15:56.240 or can't go to preschool,
NOTE Confidence: 0.988124054166667
01:15:56.240 --> 01:15:58.627 but we haven't taken away the parents
NOTE Confidence: 0.988124054166667
01:15:58.627 --> 01:16:00.819 right to refuse that vaccination.
NOTE Confidence: 0.988124054166667
01:16:00.820 --> 01:16:03.316 To the extent that it requires
NOTE Confidence: 0.988124054166667
01:16:03.316 --> 01:16:05.465 state intervention in terms of
NOTE Confidence: 0.988124054166667

01:16:05.465 --> 01:16:07.500 removing a child and requiring.
NOTE Confidence: 0.988124054166667

01:16:07.500 --> 01:16:09.348 That vaccine we look at it along
NOTE Confidence: 0.988124054166667

01:16:09.348 --> 01:16:11.303 the lines of the threshold that
NOTE Confidence: 0.988124054166667

01:16:11.303 --> 01:16:12.775 Mark talked about before.
NOTE Confidence: 0.988124054166667

01:16:12.780 --> 01:16:15.114 If withholding care is in fact
NOTE Confidence: 0.988124054166667

01:16:15.114 --> 01:16:17.442 going to create some catastrophic
NOTE Confidence: 0.988124054166667

01:16:17.442 --> 01:16:19.670 event if it is lifesaving care,
NOTE Confidence: 0.988124054166667

01:16:19.670 --> 01:16:20.570 which is necessary,
NOTE Confidence: 0.988124054166667

01:16:20.570 --> 01:16:23.078 then the state has the right to intervene
NOTE Confidence: 0.988124054166667

01:16:23.078 --> 01:16:25.472 and we're all familiar with the Cassandra
NOTE Confidence: 0.988124054166667

01:16:25.472 --> 01:16:28.219 C case that occurred about 5-6 years ago,
NOTE Confidence: 0.988124054166667

01:16:28.220 --> 01:16:30.764 which resulted in state intervention and
NOTE Confidence: 0.988124054166667

01:16:30.764 --> 01:16:33.200 forced medical treatment for a teenager.
NOTE Confidence: 0.988124054166667

01:16:33.200 --> 01:16:35.569 So we know there is a line
NOTE Confidence: 0.988124054166667

01:16:35.569 --> 01:16:36.884 that needs to be crossed,
NOTE Confidence: 0.988124054166667

01:16:36.890 --> 01:16:37.649 but the law.

NOTE Confidence: 0.988124054166667
01:16:37.649 --> 01:16:38.408 As I said,
NOTE Confidence: 0.988124054166667
01:16:38.410 --> 01:16:40.601 does not work with the same precision
NOTE Confidence: 0.988124054166667
01:16:40.601 --> 01:16:42.890 and this is one of these paradigms
NOTE Confidence: 0.988124054166667
01:16:42.890 --> 01:16:44.810 that would allow us to say,
NOTE Confidence: 0.988124054166667
01:16:44.810 --> 01:16:45.133 well,
NOTE Confidence: 0.988124054166667
01:16:45.133 --> 01:16:47.717 we're going to make a line in the
NOTE Confidence: 0.988124054166667
01:16:47.717 --> 01:16:50.490 sand rule that will in fact require
NOTE Confidence: 0.988124054166667
01:16:50.490 --> 01:16:53.180 state intervention at a certain point,
NOTE Confidence: 0.988124054166667
01:16:53.180 --> 01:16:55.514 which would then take those rights
NOTE Confidence: 0.988124054166667
01:16:55.514 --> 01:16:58.303 away from the parent as a as important
NOTE Confidence: 0.988124054166667
01:16:58.303 --> 01:17:01.057 as they may be to allow refusal of
NOTE Confidence: 0.988124054166667
01:17:01.057 --> 01:17:03.894 treatment or denial of particular care.
NOTE Confidence: 0.988124054166667
01:17:03.894 --> 01:17:05.534 But there is a line.
NOTE Confidence: 0.988124054166667
01:17:05.540 --> 01:17:06.910 It is a moving line.
NOTE Confidence: 0.988124054166667
01:17:06.910 --> 01:17:07.922 It's not a static.
NOTE Confidence: 0.988124054166667

01:17:07.922 --> 01:17:10.170 Long as technology improves
NOTE Confidence: 0.988124054166667

01:17:10.170 --> 01:17:11.362 and that's the decision,
NOTE Confidence: 0.988124054166667

01:17:11.362 --> 01:17:13.805 I think that has to be brought to
NOTE Confidence: 0.988124054166667

01:17:13.805 --> 01:17:16.141 bear on the folks who make the laws
NOTE Confidence: 0.988124054166667

01:17:16.209 --> 01:17:18.369 in each jurisdiction to determine.
NOTE Confidence: 0.988124054166667

01:17:18.370 --> 01:17:21.094 Has this line reached the point
NOTE Confidence: 0.988124054166667

01:17:21.094 --> 01:17:22.910 where state intervention probably
NOTE Confidence: 0.988124054166667

01:17:22.983 --> 01:17:25.288 should be necessary and required?
NOTE Confidence: 0.988124054166667

01:17:25.290 --> 01:17:27.156 If that line has been met,
NOTE Confidence: 0.988124054166667

01:17:27.160 --> 01:17:28.402 I'm going to stop there because
NOTE Confidence: 0.988124054166667

01:17:28.402 --> 01:17:29.769 I know we're up against it.
NOTE Confidence: 0.988124054166667

01:17:29.770 --> 01:17:31.260 Mark and I'm going to,
NOTE Confidence: 0.988124054166667

01:17:31.260 --> 01:17:31.854 you know,
NOTE Confidence: 0.988124054166667

01:17:31.854 --> 01:17:34.230 keep the lines open for questions on this.
NOTE Confidence: 0.988124054166667

01:17:34.230 --> 01:17:35.590 I could probably talk for a lot longer,
NOTE Confidence: 0.988124054166667

01:17:35.590 --> 01:17:38.020 but I do want to give folks in the audience.

NOTE Confidence: 0.988124054166667

01:17:38.020 --> 01:17:40.099 And your colleagues at a chance to.

NOTE Confidence: 0.988124054166667

01:17:40.100 --> 01:17:42.284 If further the discussion along the

NOTE Confidence: 0.988124054166667

01:17:42.284 --> 01:17:44.909 the premise that you that you provided

NOTE Confidence: 0.97415496

01:17:45.370 --> 01:17:47.260 thank you. Thank you so much Jake.

NOTE Confidence: 0.97415496

01:17:47.260 --> 01:17:49.528 Now just very quickly 'cause we have a few

NOTE Confidence: 0.97415496

01:17:49.528 --> 01:17:51.396 minutes left for a for a few questions.

NOTE Confidence: 0.97415496

01:17:51.400 --> 01:17:53.456 I want to introduce Sarah Hall who is

NOTE Confidence: 0.97415496

01:17:53.456 --> 01:17:55.531 the associate director of the Program for

NOTE Confidence: 0.97415496

01:17:55.531 --> 01:17:57.699 Biomedical Ethics here to School of Medicine.

NOTE Confidence: 0.97415496

01:17:57.700 --> 01:17:59.482 Given that some of the questions may be to

NOTE Confidence: 0.97415496

01:17:59.482 --> 01:18:01.492 me and the well known fact that I can't

NOTE Confidence: 0.97415496

01:18:01.492 --> 01:18:03.308 actually walk and chew gum at the same time,

NOTE Confidence: 0.97415496

01:18:03.310 --> 01:18:05.284 I will not be moderating this discussion.

NOTE Confidence: 0.97415496

01:18:05.290 --> 01:18:06.740 But Doctor Hall will Sarah.

NOTE Confidence: 0.97415496

01:18:06.740 --> 01:18:08.028 I thank you so much for this.

NOTE Confidence: 0.97415496

01:18:08.030 --> 01:18:08.996 And I turn it over to you.
NOTE Confidence: 0.98139468375

01:18:10.090 --> 01:18:11.630 Thank you so much, Mark and thank
NOTE Confidence: 0.98139468375

01:18:11.630 --> 01:18:13.568 you to all of our panelists for
NOTE Confidence: 0.98139468375

01:18:13.568 --> 01:18:15.560 this really fascinating discussion.
NOTE Confidence: 0.97355721

01:18:15.910 --> 01:18:18.210 And it is true. And, you know,
NOTE Confidence: 0.97355721

01:18:18.210 --> 01:18:20.630 I can say this as as an adult
NOTE Confidence: 0.97355721

01:18:20.630 --> 01:18:23.100 cardiologist that that that as
NOTE Confidence: 0.978654028

01:18:23.100 --> 01:18:25.050 as ethically fraught as a lot of
NOTE Confidence: 0.978654028

01:18:25.050 --> 01:18:27.054 adult medicine can be, pediatric
NOTE Confidence: 0.978654028

01:18:27.054 --> 01:18:29.090 medicine has so many more wrinkles,
NOTE Confidence: 0.978654028

01:18:29.090 --> 01:18:32.160 and these are some really tough decisions.
NOTE Confidence: 0.978654028

01:18:32.160 --> 01:18:34.088 So without further ado,
NOTE Confidence: 0.978654028

01:18:34.088 --> 01:18:35.680 since we don't have a ton of time,
NOTE Confidence: 0.989263845

01:18:36.370 --> 01:18:38.440 let me just start out question
NOTE Confidence: 0.98724116625

01:18:38.450 --> 01:18:41.114 one. In addition to the role of prognosis.
NOTE Confidence: 0.98724116625

01:18:41.120 --> 01:18:42.470 Feasibility and rights.

NOTE Confidence: 0.98724116625
01:18:42.470 --> 01:18:44.060 Does the caregiving burden on
NOTE Confidence: 0.98724116625
01:18:44.060 --> 01:18:45.400 the child's family or parents
NOTE Confidence: 0.98724116625
01:18:45.400 --> 01:18:46.600 affect the analysis at all?
NOTE Confidence: 0.98724116625
01:18:46.600 --> 01:18:48.107 This was this question was asked
NOTE Confidence: 0.98724116625
01:18:48.107 --> 01:18:50.549 during marks portion of the talk
NOTE Confidence: 0.98724116625
01:18:50.550 --> 01:18:52.742 or is this something that gets
NOTE Confidence: 0.98724116625
01:18:52.742 --> 01:18:53.980 factored into the question of
NOTE Confidence: 0.98724116625
01:18:53.980 --> 01:18:55.730 feasibility and again that was a lot
NOTE Confidence: 0.98724116625
01:18:55.730 --> 01:18:57.450 so I'm just going to repeat that in
NOTE Confidence: 0.98724116625
01:18:57.450 --> 01:18:59.280 addition to the role of prognosis,
NOTE Confidence: 0.98724116625
01:18:59.280 --> 01:19:01.130 feasibility and rights,
NOTE Confidence: 0.98724116625
01:19:01.130 --> 01:19:02.872 does the caregiving burden on
NOTE Confidence: 0.98724116625
01:19:02.872 --> 01:19:04.387 the child's family or parents
NOTE Confidence: 0.98724116625
01:19:04.387 --> 01:19:06.072 affect the analysis at all or
NOTE Confidence: 0.98724116625
01:19:06.072 --> 01:19:07.564 is that just something that is
NOTE Confidence: 0.98724116625

01:19:07.564 --> 01:19:08.568 factored into the feasibility?
NOTE Confidence: 0.984160326

01:19:09.330 --> 01:19:11.690 So I would say I think it's a great question.
NOTE Confidence: 0.984160326

01:19:11.690 --> 01:19:13.335 And I would say remember I talked
NOTE Confidence: 0.984160326

01:19:13.335 --> 01:19:14.814 about relevant rights and the other
NOTE Confidence: 0.984160326

01:19:14.814 --> 01:19:16.029 rights that they possibly consider
NOTE Confidence: 0.984160326

01:19:16.029 --> 01:19:17.420 would be the families rights.
NOTE Confidence: 0.984160326

01:19:17.420 --> 01:19:18.948 So this is where I would consider it.
NOTE Confidence: 0.984160326

01:19:18.950 --> 01:19:21.713 So at some point should the burden to the
NOTE Confidence: 0.984160326

01:19:21.713 --> 01:19:23.906 family be considered in this equation
NOTE Confidence: 0.984160326

01:19:23.906 --> 01:19:26.013 and and and the short simple answer is
NOTE Confidence: 0.984160326

01:19:26.013 --> 01:19:28.191 that this is supposed to be about the
NOTE Confidence: 0.984160326

01:19:28.191 --> 01:19:30.528 benefits and burdens to the child in reality.
NOTE Confidence: 0.984160326

01:19:30.530 --> 01:19:33.010 At some level we do allow some consideration,
NOTE Confidence: 0.984160326

01:19:33.010 --> 01:19:34.490 I mean different different ethicists.
NOTE Confidence: 0.984160326

01:19:34.490 --> 01:19:36.338 Don't different level that at some point
NOTE Confidence: 0.984160326

01:19:36.338 --> 01:19:38.118 the parents burden should be considered,

NOTE Confidence: 0.984160326

01:19:38.120 --> 01:19:39.845 but for the things we're

NOTE Confidence: 0.984160326

01:19:39.845 --> 01:19:41.225 talking about and this,

NOTE Confidence: 0.984160326

01:19:41.230 --> 01:19:42.938 this gets in a different direction about.

NOTE Confidence: 0.984160326

01:19:42.940 --> 01:19:45.065 For example, care of children

NOTE Confidence: 0.984160326

01:19:45.065 --> 01:19:46.765 who have significant disability,

NOTE Confidence: 0.984160326

01:19:46.770 --> 01:19:49.562 but for this when it comes to these

NOTE Confidence: 0.984160326

01:19:49.562 --> 01:19:51.953 screening procedures that we wish to do that,

NOTE Confidence: 0.984160326

01:19:51.953 --> 01:19:54.971 the burden to the family is

NOTE Confidence: 0.984160326

01:19:54.971 --> 01:19:55.977 actually negligible.

NOTE Confidence: 0.984160326

01:19:55.980 --> 01:19:57.404 There may be some burden of the child,

NOTE Confidence: 0.984160326

01:19:57.410 --> 01:19:57.998 for example,

NOTE Confidence: 0.984160326

01:19:57.998 --> 01:19:59.468 exposure to the antibiotics or

NOTE Confidence: 0.984160326

01:19:59.468 --> 01:20:00.999 the pain of the needle,

NOTE Confidence: 0.984160326

01:20:01.000 --> 01:20:02.380 but the burdens others for this

NOTE Confidence: 0.984160326

01:20:02.380 --> 01:20:03.620 question is went out there.

NOTE Confidence: 0.984160326

01:20:03.620 --> 01:20:05.036 But for other questions we face.

NOTE Confidence: 0.984160326

01:20:05.040 --> 01:20:06.150 Yeah, that's a fair point.

NOTE Confidence: 0.984160326

01:20:06.150 --> 01:20:07.110 And that's something that has to

NOTE Confidence: 0.984160326

01:20:07.110 --> 01:20:07.430 be considered.

NOTE Confidence: 0.99194

01:20:08.600 --> 01:20:13.037 Mark can I take a slightly opposing view,

NOTE Confidence: 0.99194

01:20:13.040 --> 01:20:16.312 please? So I think I I can't argue

NOTE Confidence: 0.99194

01:20:16.312 --> 01:20:18.987 with the fact that it is considered,

NOTE Confidence: 0.99194

01:20:18.990 --> 01:20:21.006 and when parents are taking on,

NOTE Confidence: 0.99194

01:20:21.010 --> 01:20:24.636 I'd say sort of permissible but not

NOTE Confidence: 0.99194

01:20:24.636 --> 01:20:26.190 obligatory intervention decisions.

NOTE Confidence: 0.99194

01:20:26.190 --> 01:20:27.708 How this will affect their lives,

NOTE Confidence: 0.99194

01:20:27.710 --> 01:20:29.390 their jobs, their home life,

NOTE Confidence: 0.99194

01:20:29.390 --> 01:20:30.490 the health and well being

NOTE Confidence: 0.99194

01:20:30.490 --> 01:20:31.370 of their other children.

NOTE Confidence: 0.99194

01:20:31.370 --> 01:20:33.226 I think parents think about all of that,

NOTE Confidence: 0.99194

01:20:33.230 --> 01:20:35.228 and that's what good parents do.

NOTE Confidence: 0.99194

01:20:35.230 --> 01:20:37.195 However, remember that that our

NOTE Confidence: 0.99194

01:20:37.195 --> 01:20:39.160 framework of ethics that we

NOTE Confidence: 0.99194

01:20:39.228 --> 01:20:41.559 practice in is that above all else,

NOTE Confidence: 0.99194

01:20:41.560 --> 01:20:44.343 we don't use people as a means to enact and.

NOTE Confidence: 0.99194

01:20:44.343 --> 01:20:49.090 That we should be at the end of the day,

NOTE Confidence: 0.99194

01:20:49.090 --> 01:20:50.575 really thinking about what's right

NOTE Confidence: 0.99194

01:20:50.575 --> 01:20:52.419 for that child and not whether

NOTE Confidence: 0.99194

01:20:52.419 --> 01:20:54.261 what's right for that child is

NOTE Confidence: 0.99194

01:20:54.261 --> 01:20:56.166 convenient for other people and one,

NOTE Confidence: 0.99194

01:20:56.166 --> 01:20:58.014 and I understand I'm saying convenient

NOTE Confidence: 0.99194

01:20:58.014 --> 01:20:59.910 to be a little provocative,

NOTE Confidence: 0.99194

01:20:59.910 --> 01:21:01.238 but I think again,

NOTE Confidence: 0.99194

01:21:01.238 --> 01:21:03.230 going back to that personhood thing,

NOTE Confidence: 0.99194

01:21:03.230 --> 01:21:05.386 I think we're more willing to talk

NOTE Confidence: 0.99194

01:21:05.386 --> 01:21:07.130 about caregiver burden Fernand fence.

NOTE Confidence: 0.99194

01:21:07.130 --> 01:21:08.614 Then we are for an older child,
NOTE Confidence: 0.99194

01:21:08.620 --> 01:21:10.988 and I think this idea that that that
NOTE Confidence: 0.99194

01:21:10.988 --> 01:21:13.029 that child the infants still somehow
NOTE Confidence: 0.99194

01:21:13.029 --> 01:21:16.119 morally are viewed more as an appendage then?
NOTE Confidence: 0.99194

01:21:16.120 --> 01:21:17.432 As a free standing.
NOTE Confidence: 0.99194

01:21:17.432 --> 01:21:19.072 Individual human with sort of
NOTE Confidence: 0.99194

01:21:19.072 --> 01:21:20.676 ethical standing and the right not
NOTE Confidence: 0.99194

01:21:20.676 --> 01:21:22.867 to be used as a means to an end.
NOTE Confidence: 0.982561448333333

01:21:23.740 --> 01:21:25.320 You and I are on the same page on that
NOTE Confidence: 0.982561448333333

01:21:25.361 --> 01:21:26.726 they only accepted very well is that
NOTE Confidence: 0.982561448333333

01:21:26.726 --> 01:21:28.457 I think it comes down to moral status
NOTE Confidence: 0.982561448333333

01:21:28.457 --> 01:21:29.844 and moral standing that we afford.
NOTE Confidence: 0.982561448333333

01:21:29.844 --> 01:21:32.116 We accord a lower moral status to newborns
NOTE Confidence: 0.982561448333333

01:21:32.116 --> 01:21:34.484 at some in our minds that older children,
NOTE Confidence: 0.982561448333333

01:21:34.490 --> 01:21:36.848 and so I don't see that as a morally
NOTE Confidence: 0.982561448333333

01:21:36.848 --> 01:21:38.750 relevant difference that kids two days

NOTE Confidence: 0.982561448333333
01:21:38.750 --> 01:21:41.318 old versus two years old or 12 years old.
NOTE Confidence: 0.982561448333333
01:21:41.320 --> 01:21:42.464 So I'm with you.
NOTE Confidence: 0.982561448333333
01:21:42.464 --> 01:21:44.180 I think those things get considered,
NOTE Confidence: 0.982561448333333
01:21:44.180 --> 01:21:45.890 but ultimately it has to be
NOTE Confidence: 0.982561448333333
01:21:45.890 --> 01:21:47.460 what's best for the child.
NOTE Confidence: 0.982561448333333
01:21:47.460 --> 01:21:47.992 Yes, please.
NOTE Confidence: 0.982561448333333
01:21:47.992 --> 01:21:48.790 Sarah, I'm sorry,
NOTE Confidence: 0.988813723333333
01:21:49.520 --> 01:21:51.908 don't be sorry that was excellent.
NOTE Confidence: 0.988813723333333
01:21:51.910 --> 01:21:53.950 Is the factual basis for
NOTE Confidence: 0.988813723333333
01:21:53.950 --> 01:21:56.180 parents refusal ever relevant?
NOTE Confidence: 0.988813723333333
01:21:56.180 --> 01:21:58.105 If the refusal is based on a
NOTE Confidence: 0.988813723333333
01:21:58.105 --> 01:21:59.180 demonstrably false belief such
NOTE Confidence: 0.988813723333333
01:21:59.180 --> 01:22:00.584 as the vaccine autism link
NOTE Confidence: 0.988813723333333
01:22:00.584 --> 01:22:02.360 that's been debunked, perhaps,
NOTE Confidence: 0.988813723333333
01:22:02.360 --> 01:22:04.226 does that alter its moral standing
NOTE Confidence: 0.990191553333333

01:22:04.260 --> 01:22:05.970 or our obligations
NOTE Confidence: 0.986983213333333
01:22:05.980 --> 01:22:06.550 to respect it?
NOTE Confidence: 0.988208645
01:22:12.670 --> 01:22:13.950 Anyone wanna take that?
NOTE Confidence: 0.988208645
01:22:13.950 --> 01:22:15.870 You want me to take it?
NOTE Confidence: 0.988208645
01:22:15.870 --> 01:22:18.560 I think it's a great question.
NOTE Confidence: 0.988208645
01:22:18.560 --> 01:22:19.268 Go ahead Jeffrey.
NOTE Confidence: 0.986798593125
01:22:20.470 --> 01:22:22.514 Well I I think it's it's very
NOTE Confidence: 0.986798593125
01:22:22.514 --> 01:22:24.392 difficult because we can't force the
NOTE Confidence: 0.986798593125
01:22:24.392 --> 01:22:26.560 vaccine on them, even if they're
NOTE Confidence: 0.986798593125
01:22:26.560 --> 01:22:29.212 if their beliefs are are wrong.
NOTE Confidence: 0.986798593125
01:22:29.212 --> 01:22:32.754 So what we attempt to correct those
NOTE Confidence: 0.986798593125
01:22:32.754 --> 01:22:35.088 beliefs, guide them and nudge.
NOTE Confidence: 0.984626898333333
01:22:37.290 --> 01:22:40.030 But it's it's a great question. Yeah,
NOTE Confidence: 0.983094098571429
01:22:41.040 --> 01:22:42.188 I I was doing please I I
NOTE Confidence: 0.983094098571429
01:22:42.188 --> 01:22:43.279 would say that for me it is.
NOTE Confidence: 0.983094098571429
01:22:43.280 --> 01:22:44.912 It would be based on the

NOTE Confidence: 0.983094098571429
01:22:44.912 --> 01:22:45.728 things these refusals,
NOTE Confidence: 0.983094098571429
01:22:45.730 --> 01:22:47.605 whether or not something is
NOTE Confidence: 0.983094098571429
01:22:47.605 --> 01:22:48.730 obligatory versus advisable.
NOTE Confidence: 0.983094098571429
01:22:48.730 --> 01:22:51.142 For me it's got to do with the prognosis
NOTE Confidence: 0.983094098571429
01:22:51.142 --> 01:22:53.590 with and without the treatment and the
NOTE Confidence: 0.983094098571429
01:22:53.590 --> 01:22:55.165 consideration of relevant rights etc.
NOTE Confidence: 0.983094098571429
01:22:55.170 --> 01:22:56.730 So that's what you're determined,
NOTE Confidence: 0.983094098571429
01:22:56.730 --> 01:22:57.730 not what the parents are.
NOTE Confidence: 0.983094098571429
01:22:57.730 --> 01:22:58.762 Reasoning is if this.
NOTE Confidence: 0.983094098571429
01:22:58.762 --> 01:23:00.595 If the data suggests that this is
NOTE Confidence: 0.983094098571429
01:23:00.595 --> 01:23:02.419 going to do enough to prevent the harm
NOTE Confidence: 0.983094098571429
01:23:02.419 --> 01:23:04.553 that it's that we are justified and
NOTE Confidence: 0.983094098571429
01:23:04.553 --> 01:23:06.040 overriding the parents decision whether
NOTE Confidence: 0.983094098571429
01:23:06.040 --> 01:23:07.540 that decision was based on religious.
NOTE Confidence: 0.983094098571429
01:23:07.540 --> 01:23:09.192 Police philosophical beliefs of
NOTE Confidence: 0.983094098571429

01:23:09.192 --> 01:23:11.257 false understanding of the science.
NOTE Confidence: 0.983094098571429

01:23:11.260 --> 01:23:12.166 In any case,
NOTE Confidence: 0.983094098571429

01:23:12.166 --> 01:23:14.280 if I think if the data suggests
NOTE Confidence: 0.983094098571429

01:23:14.280 --> 01:23:15.816 that the benefits outweigh the risks
NOTE Confidence: 0.983094098571429

01:23:15.816 --> 01:23:17.708 for the child to such a significant
NOTE Confidence: 0.983094098571429

01:23:17.708 --> 01:23:19.605 extent that we would do it regardless
NOTE Confidence: 0.983094098571429

01:23:19.656 --> 01:23:21.060 of the source of the parents,
NOTE Confidence: 0.983094098571429

01:23:21.060 --> 01:23:23.316 I think regards to the source of the
NOTE Confidence: 0.983094098571429

01:23:23.316 --> 01:23:24.950 parents opinion or judgment on it.
NOTE Confidence: 0.985152458571429

01:23:25.740 --> 01:23:27.747 And connect it if you don't mind me jumping
NOTE Confidence: 0.985152458571429

01:23:27.747 --> 01:23:29.633 in for one second mark, I would leave.
NOTE Confidence: 0.985152458571429

01:23:29.633 --> 01:23:33.636 I would say that the you know parents,
NOTE Confidence: 0.985152458571429

01:23:33.640 --> 01:23:36.790 incorrect assumptions or their factual
NOTE Confidence: 0.985152458571429

01:23:36.790 --> 01:23:39.429 miss apprehension of the of the data
NOTE Confidence: 0.985152458571429

01:23:39.429 --> 01:23:41.761 would be directly relevant to whether
NOTE Confidence: 0.985152458571429

01:23:41.761 --> 01:23:44.750 or not a judge might intervene and say,

NOTE Confidence: 0.985152458571429
01:23:44.750 --> 01:23:46.374 you know the facts of this case
NOTE Confidence: 0.985152458571429
01:23:46.374 --> 01:23:47.820 are based on the evidence,
NOTE Confidence: 0.985152458571429
01:23:47.820 --> 01:23:49.656 not what your perceptions are not,
NOTE Confidence: 0.985152458571429
01:23:49.660 --> 01:23:51.394 whether you believe you have moral
NOTE Confidence: 0.985152458571429
01:23:51.394 --> 01:23:53.180 standing which can be considered.
NOTE Confidence: 0.985152458571429
01:23:53.180 --> 01:23:54.979 If there's some kind of religious objection,
NOTE Confidence: 0.985152458571429
01:23:54.980 --> 01:23:56.356 but not for the.
NOTE Confidence: 0.985152458571429
01:23:56.356 --> 01:23:59.142 Idea that there is imminent harm to a
NOTE Confidence: 0.985152458571429
01:23:59.142 --> 01:24:01.403 child and there has to be intervention
NOTE Confidence: 0.985152458571429
01:24:01.403 --> 01:24:03.980 in order to invoke immediate care,
NOTE Confidence: 0.985152458571429
01:24:03.980 --> 01:24:09.510 so that may have some more kind of looser.
NOTE Confidence: 0.985152458571429
01:24:09.510 --> 01:24:11.736 Interpretation in terms of moral relevance,
NOTE Confidence: 0.985152458571429
01:24:11.740 --> 01:24:13.558 but in terms of legal relevance,
NOTE Confidence: 0.985152458571429
01:24:13.560 --> 01:24:15.912 it would be it wouldn't be considered
NOTE Confidence: 0.985152458571429
01:24:15.912 --> 01:24:18.458 as in as nearly as important,
NOTE Confidence: 0.985152458571429

01:24:18.460 --> 01:24:19.100 for example,
NOTE Confidence: 0.985152458571429

01:24:19.100 --> 01:24:21.340 as the evidence and the factual data
NOTE Confidence: 0.985152458571429

01:24:21.340 --> 01:24:23.466 that supports the decision to intervene
NOTE Confidence: 0.985152458571429

01:24:23.466 --> 01:24:26.478 or to make a declaration of neglect that
NOTE Confidence: 0.985152458571429

01:24:26.478 --> 01:24:28.478 would then require state intervention.
NOTE Confidence: 0.9872471

01:24:30.770 --> 01:24:33.112 Well, and the converse is just if
NOTE Confidence: 0.9872471

01:24:33.112 --> 01:24:35.010 reasonable people can really disagree.
NOTE Confidence: 0.982136748571429

01:24:35.010 --> 01:24:36.258 We probably shouldn't do
NOTE Confidence: 0.982136748571429

01:24:36.258 --> 01:24:37.502 it as obligatory, right?
NOTE Confidence: 0.982136748571429

01:24:37.502 --> 01:24:38.710 If there are strong,
NOTE Confidence: 0.982136748571429

01:24:38.710 --> 01:24:40.534 well founded, rational reasons,
NOTE Confidence: 0.982136748571429

01:24:40.534 --> 01:24:42.814 why an informed parent would
NOTE Confidence: 0.982136748571429

01:24:42.814 --> 01:24:44.979 not want that intervention,
NOTE Confidence: 0.982136748571429

01:24:44.980 --> 01:24:47.266 it's a weaker case for saying
NOTE Confidence: 0.982136748571429

01:24:47.266 --> 01:24:49.390 they shouldn't have a choice.
NOTE Confidence: 0.982136748571429

01:24:49.390 --> 01:24:50.080 That's actually

NOTE Confidence: 0.9695885375

01:24:50.090 --> 01:24:51.138 a great segue into

NOTE Confidence: 0.990060733333333

01:24:51.150 --> 01:24:53.474 the next question. If we if you don't

NOTE Confidence: 0.990060733333333

01:24:53.474 --> 01:24:57.140 mind if I squeak it in an which is,

NOTE Confidence: 0.98921115625

01:24:57.390 --> 01:25:00.130 how do we reconcile the

NOTE Confidence: 0.98921115625

01:25:00.130 --> 01:25:01.774 treatments and interventions

NOTE Confidence: 0.958147585

01:25:00.110 --> 01:25:00.638 to a mother and

NOTE Confidence: 0.9856700125

01:25:00.650 --> 01:25:01.770 labor may violate her

NOTE Confidence: 0.980492045454546

01:25:01.780 --> 01:25:03.718 autonomy and in fact be subject

NOTE Confidence: 0.980492045454546

01:25:03.718 --> 01:25:05.290 to practice patterns which vary

NOTE Confidence: 0.980492045454546

01:25:05.290 --> 01:25:07.360 widely across obstetricians.

NOTE Confidence: 0.980492045454546

01:25:07.360 --> 01:25:09.058 A single obstetrician can always say

NOTE Confidence: 0.980492045454546

01:25:09.058 --> 01:25:10.374 that he or she thinks the caesarean

NOTE Confidence: 0.980492045454546

01:25:10.380 --> 01:25:11.616 is in the baby's best interest,

NOTE Confidence: 0.9919439325

01:25:11.800 --> 01:25:14.220 but nine other obstetricians may disagree.

NOTE Confidence: 0.990093645

01:25:14.220 --> 01:25:15.883 In addition, much of what we have

NOTE Confidence: 0.990093645

01:25:15.883 --> 01:25:16.546 introduced, his interventions
NOTE Confidence: 0.98933823125

01:25:16.560 --> 01:25:17.748 in labor units over the decades
NOTE Confidence: 0.98933823125

01:25:17.748 --> 01:25:19.698 has not improved neonatal outcomes.
NOTE Confidence: 0.98933823125

01:25:19.700 --> 01:25:21.807 So perhaps we have lost parental trust.
NOTE Confidence: 0.952776863888889

01:25:26.980 --> 01:25:29.508 Uhm? Well, I I think given the time
NOTE Confidence: 0.952776863888889

01:25:29.508 --> 01:25:32.274 that that I would just point out that
NOTE Confidence: 0.952776863888889

01:25:32.274 --> 01:25:34.300 what's done during pregnancy is very,
NOTE Confidence: 0.952776863888889

01:25:34.300 --> 01:25:35.640 very different than what's
NOTE Confidence: 0.952776863888889

01:25:35.640 --> 01:25:37.319 done after the child is born.
NOTE Confidence: 0.952776863888889

01:25:37.320 --> 01:25:39.228 From an ethical point of view,
NOTE Confidence: 0.952776863888889

01:25:39.230 --> 01:25:40.890 which is to say that that when that baby is
NOTE Confidence: 0.952776863888889

01:25:40.932 --> 01:25:42.480 born and they only look at this as well.
NOTE Confidence: 0.952776863888889

01:25:42.480 --> 01:25:44.237 But now we have a separate human
NOTE Confidence: 0.952776863888889

01:25:44.237 --> 01:25:46.013 being who I believe has rights
NOTE Confidence: 0.952776863888889

01:25:46.013 --> 01:25:47.618 as a human being separate,
NOTE Confidence: 0.952776863888889

01:25:47.620 --> 01:25:49.879 and that we can do things to this human

NOTE Confidence: 0.952776863888889
01:25:49.879 --> 01:25:52.190 being to this child without having to
NOTE Confidence: 0.952776863888889
01:25:52.190 --> 01:25:54.479 violate the bodily integrity of anybody else.
NOTE Confidence: 0.952776863888889
01:25:54.480 --> 01:25:55.330 But we may have to.
NOTE Confidence: 0.952776863888889
01:25:55.330 --> 01:25:56.996 We may have to go against some
NOTE Confidence: 0.952776863888889
01:25:56.996 --> 01:25:58.570 parents opinion but during pregnancy.
NOTE Confidence: 0.952776863888889
01:25:58.570 --> 01:25:59.446 I don't think I may have.
NOTE Confidence: 0.952776863888889
01:25:59.450 --> 01:26:01.530 I I didn't know if I caught the
NOTE Confidence: 0.952776863888889
01:26:01.530 --> 01:26:03.435 whole question but but during
NOTE Confidence: 0.952776863888889
01:26:03.435 --> 01:26:04.317 pregnancy obstetricians,
NOTE Confidence: 0.952776863888889
01:26:04.320 --> 01:26:04.972 I believe,
NOTE Confidence: 0.952776863888889
01:26:04.972 --> 01:26:06.646 and I think most bioethicists
NOTE Confidence: 0.952776863888889
01:26:06.646 --> 01:26:07.744 and most obstetricians.
NOTE Confidence: 0.952776863888889
01:26:07.744 --> 01:26:10.492 Now we believe that options are not in
NOTE Confidence: 0.952776863888889
01:26:10.492 --> 01:26:12.468 a position to do anything to a pregnant
NOTE Confidence: 0.952776863888889
01:26:12.531 --> 01:26:14.736 woman of soundmine that she doesn't want.
NOTE Confidence: 0.952776863888889

01:26:14.740 --> 01:26:17.043 So she has a right to refuse
NOTE Confidence: 0.952776863888889

01:26:17.043 --> 01:26:18.706 anything and everything even even
NOTE Confidence: 0.952776863888889

01:26:18.706 --> 01:26:20.530 if there is something that even
NOTE Confidence: 0.952776863888889

01:26:20.530 --> 01:26:22.847 if the fetus is at risk of death,
NOTE Confidence: 0.952776863888889

01:26:22.850 --> 01:26:24.838 that I think if if someone thinks
NOTE Confidence: 0.952776863888889

01:26:24.838 --> 01:26:26.395 that C-section needs to be done
NOTE Confidence: 0.952776863888889

01:26:26.395 --> 01:26:27.480 to save a baby's life,
NOTE Confidence: 0.952776863888889

01:26:27.480 --> 01:26:28.720 to save a fetus's life.
NOTE Confidence: 0.952776863888889

01:26:28.720 --> 01:26:31.160 Future baby's life and the mother says no,
NOTE Confidence: 0.952776863888889

01:26:31.160 --> 01:26:33.524 the C-section shouldn't happen that her
NOTE Confidence: 0.952776863888889

01:26:33.524 --> 01:26:36.319 right to bodily integrity ultimately Trump's.
NOTE Confidence: 0.952776863888889

01:26:36.320 --> 01:26:38.072 That wasn't always that way and
NOTE Confidence: 0.952776863888889

01:26:38.072 --> 01:26:39.240 obstetrics in United States,
NOTE Confidence: 0.952776863888889

01:26:39.240 --> 01:26:40.812 but certainly in in the last
NOTE Confidence: 0.952776863888889

01:26:40.812 --> 01:26:41.598 couple of decades.
NOTE Confidence: 0.952776863888889

01:26:41.600 --> 01:26:43.355 I think we see more and more that that.

NOTE Confidence: 0.952776863888889

01:26:43.360 --> 01:26:44.815 That holds sway and I

NOTE Confidence: 0.952776863888889

01:26:44.815 --> 01:26:45.979 think appropriately so so.

NOTE Confidence: 0.952776863888889

01:26:45.980 --> 01:26:47.600 The obstetricians aren't in a

NOTE Confidence: 0.952776863888889

01:26:47.600 --> 01:26:49.220 position to say something so

NOTE Confidence: 0.952776863888889

01:26:49.284 --> 01:26:51.019 obligatory to a pregnant woman.

NOTE Confidence: 0.952776863888889

01:26:51.020 --> 01:26:51.698 In my opinion.

NOTE Confidence: 0.983622177142857

01:26:53.900 --> 01:26:55.209 I think if I if I may,

NOTE Confidence: 0.983622177142857

01:26:55.210 --> 01:26:56.981 one piece of Jessica brings up in

NOTE Confidence: 0.983622177142857

01:26:56.981 --> 01:26:58.608 that question is is around trust,

NOTE Confidence: 0.983622177142857

01:26:58.610 --> 01:27:01.350 which I do think is is a theme and at

NOTE Confidence: 0.983622177142857

01:27:01.428 --> 01:27:04.460 least my experience is a lot of these

NOTE Confidence: 0.983622177142857

01:27:04.460 --> 01:27:06.950 refusals are based on his perception

NOTE Confidence: 0.983622177142857

01:27:06.950 --> 01:27:09.970 or an experience that caused a family

NOTE Confidence: 0.983622177142857

01:27:09.970 --> 01:27:12.460 to not trust the medical community.

NOTE Confidence: 0.991616415

01:27:18.500 --> 01:27:21.844 Well, perhaps. Sarah is editor,

NOTE Confidence: 0.991616415

01:27:21.844 --> 01:27:23.980 we are. We at the hour we
NOTE Confidence: 0.988245839

01:27:23.990 --> 01:27:24.862 are at the hour.
NOTE Confidence: 0.988245839

01:27:24.862 --> 01:27:26.170 We do have some more questions
NOTE Confidence: 0.966197802222222

01:27:26.180 --> 01:27:28.250 but we I know we have a hard rule
NOTE Confidence: 0.950935754

01:27:28.260 --> 01:27:30.731 of a of a hard stop at 6:30.
NOTE Confidence: 0.950935754

01:27:30.731 --> 01:27:32.440 So I wanted to give you a chance to
NOTE Confidence: 0.950935754

01:27:32.440 --> 01:27:34.290 provide a few concluding remarks.
NOTE Confidence: 0.979093420833333

01:27:35.690 --> 01:27:36.682 Thank you so much,
NOTE Confidence: 0.979093420833333

01:27:36.682 --> 01:27:38.790 Doctor Hall and thank you all for coming,
NOTE Confidence: 0.979093420833333

01:27:38.790 --> 01:27:40.594 especially to our panelists.
NOTE Confidence: 0.979093420833333

01:27:40.594 --> 01:27:42.154 A doctor, loyal Doctor,
NOTE Confidence: 0.979093420833333

01:27:42.154 --> 01:27:43.462 Leventhal, and attorney cyclic
NOTE Confidence: 0.979093420833333

01:27:43.462 --> 01:27:45.499 and all of you who came up.
NOTE Confidence: 0.979093420833333

01:27:45.500 --> 01:27:46.949 You can find that we're doing this
NOTE Confidence: 0.979093420833333

01:27:46.949 --> 01:27:48.269 twice a month in the evening.
NOTE Confidence: 0.979093420833333

01:27:48.270 --> 01:27:50.321 We have some some seminars that I

NOTE Confidence: 0.979093420833333
01:27:50.321 --> 01:27:52.198 hope are interest to you biomedical
NOTE Confidence: 0.979093420833333
01:27:52.198 --> 01:27:54.155 ethics at yale.edu and if you reach
NOTE Confidence: 0.979093420833333
01:27:54.155 --> 01:27:56.318 out to us through there will get you
NOTE Confidence: 0.979093420833333
01:27:56.318 --> 01:27:58.110 on the mailing list so that you'll
NOTE Confidence: 0.979093420833333
01:27:58.170 --> 01:28:00.186 get notified of each of these things.
NOTE Confidence: 0.979093420833333
01:28:00.190 --> 01:28:01.948 Many people than Medical Center are.
NOTE Confidence: 0.979093420833333
01:28:01.950 --> 01:28:03.231 I also saw the names of some
NOTE Confidence: 0.979093420833333
01:28:03.231 --> 01:28:04.050 of the folks here.
NOTE Confidence: 0.979093420833333
01:28:04.050 --> 01:28:05.947 Some pediatricians I've known over the years.
NOTE Confidence: 0.979093420833333
01:28:05.950 --> 01:28:08.070 You are absolutely gold standard.
NOTE Confidence: 0.979093420833333
01:28:08.070 --> 01:28:09.295 The kind of people that I would
NOTE Confidence: 0.979093420833333
01:28:09.295 --> 01:28:10.529 go to with these questions.
NOTE Confidence: 0.979093420833333
01:28:10.530 --> 01:28:12.406 So if you have advice on this,
NOTE Confidence: 0.979093420833333
01:28:12.410 --> 01:28:13.346 if you have thoughts on this,
NOTE Confidence: 0.979093420833333
01:28:13.350 --> 01:28:15.468 you didn't get to bring here.
NOTE Confidence: 0.979093420833333

01:28:15.470 --> 01:28:17.094 My I can be reached and I'd be
NOTE Confidence: 0.979093420833333

01:28:17.094 --> 01:28:18.149 interested in your opinion.
NOTE Confidence: 0.979093420833333

01:28:18.150 --> 01:28:18.400 I'm at
NOTE Confidence: 0.921526778

01:28:21.020 --> 01:28:22.464 mark.mercurio@yale.edu and you can
NOTE Confidence: 0.921526778

01:28:22.464 --> 01:28:24.630 find me also through that website,
NOTE Confidence: 0.921526778

01:28:24.630 --> 01:28:27.033 so I'm this is a real issue we're facing
NOTE Confidence: 0.921526778

01:28:27.033 --> 01:28:29.547 and I'm happy to have anybody's opinion,
NOTE Confidence: 0.921526778

01:28:29.550 --> 01:28:30.642 particularly pediatricians that I
NOTE Confidence: 0.921526778

01:28:30.642 --> 01:28:32.544 have known and respected for so long
NOTE Confidence: 0.921526778

01:28:32.544 --> 01:28:34.084 who were kind enough to come tonight.
NOTE Confidence: 0.921526778

01:28:34.090 --> 01:28:36.066 Sarah, thank you so much for doing this.
NOTE Confidence: 0.921526778

01:28:36.070 --> 01:28:38.334 And come with that, I will say goodnight.
NOTE Confidence: 0.921526778

01:28:38.340 --> 01:28:38.940 Thank you all.
NOTE Confidence: 0.98513945

01:28:39.600 --> 01:28:42.000 Thank you everyone.