

WEBVTT

NOTE duration: "01:26:01.800"

NOTE Confidence: 0.9726509

00:00:08.559 --> 00:00:10.080 Good evening, everybody, and welcome.

NOTE Confidence: 0.9726509

00:00:10.080 --> 00:00:11.380 Thanks so much for coming.

NOTE Confidence: 0.92163485

00:00:11.759 --> 00:00:13.005 I know most of you.

NOTE Confidence: 0.92163485

00:00:13.164 --> 00:00:14.525 My name is Mark Mercurio.

NOTE Confidence: 0.92163485

00:00:14.525 --> 00:00:15.485 I'm the director of the

NOTE Confidence: 0.92163485

00:00:15.485 --> 00:00:17.185 Yale Pediatric Ethics Program,

NOTE Confidence: 0.9737137

00:00:17.485 --> 00:00:18.925 and I'm, very pleased to

NOTE Confidence: 0.9737137

00:00:18.925 --> 00:00:20.845 introduce tonight's speaker in just

NOTE Confidence: 0.9737137

00:00:20.845 --> 00:00:22.045 a minute to let you

NOTE Confidence: 0.9737137

00:00:22.045 --> 00:00:24.045 know there's CME information up

NOTE Confidence: 0.9737137

00:00:24.045 --> 00:00:24.925 on the screen if you

NOTE Confidence: 0.9737137

00:00:24.925 --> 00:00:26.704 wanna submit for CME credit.

NOTE Confidence: 0.96541506

00:00:27.920 --> 00:00:29.040 And the way this works,

NOTE Confidence: 0.96541506

00:00:29.040 --> 00:00:29.920 most of you know, but

NOTE Confidence: 0.96541506

00:00:29.920 --> 00:00:31.220 for those who might not,
NOTE Confidence: 0.96541506

00:00:31.520 --> 00:00:32.740 the way this will work
NOTE Confidence: 0.96541506

00:00:32.800 --> 00:00:34.400 is, doctor Kassev is gonna
NOTE Confidence: 0.96541506

00:00:34.400 --> 00:00:35.760 speak for about forty five
NOTE Confidence: 0.96541506

00:00:35.760 --> 00:00:36.260 minutes,
NOTE Confidence: 0.9790697

00:00:36.800 --> 00:00:37.680 give or take a little
NOTE Confidence: 0.9790697

00:00:37.680 --> 00:00:39.540 bit, and then we will,
NOTE Confidence: 0.9392374

00:00:39.920 --> 00:00:41.040 have a question and answer
NOTE Confidence: 0.9392374

00:00:41.040 --> 00:00:41.860 in a conversation
NOTE Confidence: 0.9758603

00:00:42.415 --> 00:00:44.095 about this really fascinating subject.
NOTE Confidence: 0.9758603

00:00:44.095 --> 00:00:45.534 And to some of you
NOTE Confidence: 0.9758603

00:00:45.534 --> 00:00:46.735 who are not medical, this
NOTE Confidence: 0.9758603

00:00:46.735 --> 00:00:47.615 subject may be a little
NOTE Confidence: 0.9758603

00:00:47.615 --> 00:00:49.295 bit foreign, but you'll learn
NOTE Confidence: 0.9758603

00:00:49.295 --> 00:00:50.495 pretty quickly how important this
NOTE Confidence: 0.9758603

00:00:50.495 --> 00:00:51.534 is and how interesting this

NOTE Confidence: 0.9758603
00:00:51.534 --> 00:00:52.895 is both from a clinical
NOTE Confidence: 0.9758603
00:00:52.895 --> 00:00:54.675 standpoint and from an ethics
NOTE Confidence: 0.9758603
00:00:54.735 --> 00:00:56.095 standpoint. So when we get
NOTE Confidence: 0.9758603
00:00:56.095 --> 00:00:56.910 to the q and a,
NOTE Confidence: 0.98897344
00:00:58.030 --> 00:00:59.250 Amir and Karen
NOTE Confidence: 0.9467607
00:00:59.630 --> 00:01:01.470 are going to, are gonna
NOTE Confidence: 0.9467607
00:01:01.470 --> 00:01:02.750 have some microphones, and I'm
NOTE Confidence: 0.9467607
00:01:02.750 --> 00:01:03.710 gonna I'm gonna call and
NOTE Confidence: 0.9467607
00:01:03.710 --> 00:01:04.910 I'll moderate and Katya will
NOTE Confidence: 0.9467607
00:01:04.910 --> 00:01:06.110 answer the questions. But I'm
NOTE Confidence: 0.9467607
00:01:06.110 --> 00:01:07.069 gonna point and call on
NOTE Confidence: 0.9467607
00:01:07.069 --> 00:01:07.569 you,
NOTE Confidence: 0.99967206
00:01:08.270 --> 00:01:08.955 so that
NOTE Confidence: 0.9806315
00:01:09.435 --> 00:01:10.315 they can bring a mic
NOTE Confidence: 0.9806315
00:01:10.315 --> 00:01:11.834 to you, because it's important
NOTE Confidence: 0.9806315

00:01:11.834 --> 00:01:12.715 that you speak into the
NOTE Confidence: 0.9806315

00:01:12.715 --> 00:01:14.315 microphone, one, so I can
NOTE Confidence: 0.9806315

00:01:14.315 --> 00:01:15.435 hear you. But the other
NOTE Confidence: 0.9806315

00:01:15.435 --> 00:01:16.315 is that the folks on
NOTE Confidence: 0.9806315

00:01:16.315 --> 00:01:17.035 Zoom can hear you as
NOTE Confidence: 0.9806315

00:01:17.035 --> 00:01:17.675 well, so we can all
NOTE Confidence: 0.9806315

00:01:17.675 --> 00:01:18.635 hear each other. So please
NOTE Confidence: 0.9806315

00:01:18.635 --> 00:01:19.515 wait until they give you
NOTE Confidence: 0.9806315

00:01:19.515 --> 00:01:20.635 a mic, to ask your
NOTE Confidence: 0.9806315

00:01:20.635 --> 00:01:21.595 question. But we'll get to
NOTE Confidence: 0.9806315

00:01:21.595 --> 00:01:22.795 that in about forty five
NOTE Confidence: 0.9806315

00:01:22.795 --> 00:01:24.360 minutes. But before that, Amir,
NOTE Confidence: 0.9806315

00:01:24.360 --> 00:01:24.920 would you give me a
NOTE Confidence: 0.9806315

00:01:24.920 --> 00:01:25.880 hand with something up here
NOTE Confidence: 0.9806315

00:01:25.880 --> 00:01:26.539 real quick?
NOTE Confidence: 0.99201053

00:01:28.119 --> 00:01:29.319 So you might know that

NOTE Confidence: 0.99201053
00:01:29.319 --> 00:01:30.439 that running a meeting like
NOTE Confidence: 0.99201053
00:01:30.439 --> 00:01:31.240 this can always be a
NOTE Confidence: 0.99201053
00:01:31.240 --> 00:01:32.380 little bit nerve wracking.
NOTE Confidence: 0.9693756
00:01:33.720 --> 00:01:35.079 And one of the really
NOTE Confidence: 0.9693756
00:01:35.079 --> 00:01:35.579 calming,
NOTE Confidence: 0.9988189
00:01:36.134 --> 00:01:37.094 things is if you have
NOTE Confidence: 0.9988189
00:01:37.094 --> 00:01:38.075 someone from IT
NOTE Confidence: 0.97290367
00:01:38.534 --> 00:01:39.515 who is actually
NOTE Confidence: 0.9826898
00:01:40.134 --> 00:01:41.414 really knows what they're doing
NOTE Confidence: 0.9826898
00:01:41.414 --> 00:01:42.854 and always stays calm and
NOTE Confidence: 0.9826898
00:01:42.854 --> 00:01:44.054 always make sure everything is
NOTE Confidence: 0.9826898
00:01:44.054 --> 00:01:46.314 under control. Mister Amir Glenn
NOTE Confidence: 0.9826898
00:01:46.454 --> 00:01:47.414 has been doing this for
NOTE Confidence: 0.9826898
00:01:47.414 --> 00:01:48.375 a year for us, and
NOTE Confidence: 0.9826898
00:01:48.375 --> 00:01:49.895 tonight is his last night.
NOTE Confidence: 0.9826898

00:01:49.895 --> 00:01:50.854 If we could have a
NOTE Confidence: 0.9826898

00:01:50.854 --> 00:01:51.755 round of applause
NOTE Confidence: 0.7155335

00:01:52.430 --> 00:01:53.170 for Amir.
NOTE Confidence: 0.88968027

00:01:54.430 --> 00:01:56.050 Now I have something
NOTE Confidence: 0.8082233

00:01:56.590 --> 00:01:57.950 tied up here. Maybe it's
NOTE Confidence: 0.8082233

00:01:57.950 --> 00:01:58.690 my view.
NOTE Confidence: 0.88844794

00:02:01.310 --> 00:02:03.250 This is important business list.
NOTE Confidence: 0.8990108

00:02:09.535 --> 00:02:10.975 The one right? Yeah. This
NOTE Confidence: 0.8990108

00:02:10.975 --> 00:02:12.735 is correct. Now, Amir, just
NOTE Confidence: 0.8990108

00:02:12.975 --> 00:02:13.775 we got a few things
NOTE Confidence: 0.8990108

00:02:13.775 --> 00:02:14.495 in here, but hold this
NOTE Confidence: 0.8990108

00:02:14.495 --> 00:02:15.294 thing up here because this
NOTE Confidence: 0.8990108

00:02:15.294 --> 00:02:16.655 is important. These babies are
NOTE Confidence: 0.8990108

00:02:16.655 --> 00:02:18.014 like gold. Alright. You can't
NOTE Confidence: 0.8990108

00:02:18.495 --> 00:02:19.935 not available in any store.
NOTE Confidence: 0.8990108

00:02:19.935 --> 00:02:21.450 A program for biomedical ethics

NOTE Confidence: 0.8990108

00:02:21.450 --> 00:02:21.950 sweatshirt.

NOTE Confidence: 0.6874844

00:02:22.650 --> 00:02:23.150 And,

NOTE Confidence: 0.6634516

00:02:23.610 --> 00:02:24.889 and a few other ones.

NOTE Confidence: 0.6634516

00:02:24.889 --> 00:02:25.389 Because

NOTE Confidence: 0.7385961

00:02:26.810 --> 00:02:28.590 you're so trimmily these days.

NOTE Confidence: 0.6995873

00:02:30.330 --> 00:02:30.830 Alright.

NOTE Confidence: 0.66890657

00:02:35.530 --> 00:02:36.410 Even if it's too small.

NOTE Confidence: 0.66890657

00:02:36.569 --> 00:02:37.825 To be comfortable. Oh, okay.

NOTE Confidence: 0.66890657

00:02:38.065 --> 00:02:39.025 To be comfortable. Thank you

NOTE Confidence: 0.66890657

00:02:39.025 --> 00:02:39.525 for

NOTE Confidence: 0.9506106

00:02:39.985 --> 00:02:41.185 everything, Amir. Thank you. Thank

NOTE Confidence: 0.9506106

00:02:41.185 --> 00:02:41.685 you.

NOTE Confidence: 0.99607545

00:02:43.505 --> 00:02:44.405 You'll be missed.

NOTE Confidence: 0.9823863

00:02:44.945 --> 00:02:45.985 He's going over the main

NOTE Confidence: 0.9823863

00:02:45.985 --> 00:02:47.505 campus to manage the financial

NOTE Confidence: 0.9823863

00:02:47.505 --> 00:02:48.544 stuff. So now that you
NOTE Confidence: 0.9823863

00:02:48.544 --> 00:02:49.665 know his name and his
NOTE Confidence: 0.9823863

00:02:49.665 --> 00:02:50.940 face, if anything ever goes
NOTE Confidence: 0.9823863

00:02:50.940 --> 00:02:52.139 wrong with your with your
NOTE Confidence: 0.9823863

00:02:52.139 --> 00:02:53.580 paychecks, Amir says to reach
NOTE Confidence: 0.9823863

00:02:53.580 --> 00:02:54.940 out to him directly. We'll
NOTE Confidence: 0.9823863

00:02:54.940 --> 00:02:56.139 have his we'll have his
NOTE Confidence: 0.9823863

00:02:56.139 --> 00:02:57.020 cell phone and his home
NOTE Confidence: 0.9823863

00:02:57.020 --> 00:02:57.820 phone up on the screen
NOTE Confidence: 0.9823863

00:02:57.820 --> 00:02:58.639 later on.
NOTE Confidence: 0.99336684

00:02:59.420 --> 00:03:01.180 So here is the situation
NOTE Confidence: 0.99336684

00:03:01.180 --> 00:03:02.460 we find ourselves in right
NOTE Confidence: 0.99336684

00:03:02.460 --> 00:03:03.895 now is that,
NOTE Confidence: 0.9994198

00:03:04.355 --> 00:03:05.655 my friend and colleague,
NOTE Confidence: 0.8771131

00:03:05.955 --> 00:03:07.334 doctor Katya Kasiv,
NOTE Confidence: 0.99644387

00:03:08.035 --> 00:03:09.155 is here to speak about

NOTE Confidence: 0.99644387

00:03:09.155 --> 00:03:11.014 trisomy thirteen and eighteen

NOTE Confidence: 0.9664945

00:03:11.555 --> 00:03:13.315 and congenital heart disease in

NOTE Confidence: 0.9664945

00:03:13.315 --> 00:03:14.595 that setting, which as I

NOTE Confidence: 0.9664945

00:03:14.595 --> 00:03:15.394 said, you'll find is a

NOTE Confidence: 0.9664945

00:03:15.394 --> 00:03:16.595 fascinating issue from both a

NOTE Confidence: 0.9664945

00:03:16.595 --> 00:03:18.455 clinical and an ethical standpoint.

NOTE Confidence: 0.92093366

00:03:18.860 --> 00:03:20.620 Doctor Kossev is a graduate

NOTE Confidence: 0.92093366

00:03:20.620 --> 00:03:21.760 of Vanderbilt University,

NOTE Confidence: 0.99128526

00:03:22.060 --> 00:03:23.579 of Ross University School of

NOTE Confidence: 0.99128526

00:03:23.579 --> 00:03:24.079 Medicine.

NOTE Confidence: 0.98327404

00:03:24.379 --> 00:03:25.439 She did residency,

NOTE Confidence: 0.91463155

00:03:26.139 --> 00:03:27.819 I believe at Arkansas Children's.

NOTE Confidence: 0.91463155

00:03:27.819 --> 00:03:29.919 Yes? Fellowship. Fellowship at Arkansas.

NOTE Confidence: 0.99947405

00:03:30.379 --> 00:03:30.879 Residency

NOTE Confidence: 0.9929905

00:03:31.180 --> 00:03:33.735 at Peoria, Illinois. Mhmm. Peoria,

NOTE Confidence: 0.9929905

00:03:33.735 --> 00:03:36.135 Illinois. Peoria, Illinois, baby. Southern

NOTE Confidence: 0.9929905

00:03:36.135 --> 00:03:37.035 Illinois University.

NOTE Confidence: 0.9900152

00:03:38.535 --> 00:03:39.895 University of Illinois. You shouldn't

NOTE Confidence: 0.9900152

00:03:39.895 --> 00:03:40.694 have to think about that

NOTE Confidence: 0.9900152

00:03:40.694 --> 00:03:42.375 for a while. University of

NOTE Confidence: 0.9900152

00:03:42.375 --> 00:03:44.395 Illinois. And then from there,

NOTE Confidence: 0.96355957

00:03:44.799 --> 00:03:46.640 to Arkansas Children's. Yes. And

NOTE Confidence: 0.96355957

00:03:46.640 --> 00:03:48.319 from there to UCSF, so

NOTE Confidence: 0.96355957

00:03:48.319 --> 00:03:49.599 a fellowship and then further

NOTE Confidence: 0.96355957

00:03:49.599 --> 00:03:51.280 advanced training in imaging. So

NOTE Confidence: 0.96355957

00:03:51.280 --> 00:03:52.079 she comes to us with

NOTE Confidence: 0.96355957

00:03:52.079 --> 00:03:53.060 all kinds of training.

NOTE Confidence: 0.9878809

00:03:53.360 --> 00:03:54.400 She's on the faculty for

NOTE Confidence: 0.9878809

00:03:54.400 --> 00:03:55.599 a few years now. Over

NOTE Confidence: 0.9878809

00:03:55.599 --> 00:03:56.799 the course of her training,

NOTE Confidence: 0.9878809

00:03:56.799 --> 00:03:58.159 she actually did some research

NOTE Confidence: 0.9878809

00:03:58.159 --> 00:04:00.165 in trisomy thirteen and eighteen

NOTE Confidence: 0.9878809

00:04:00.165 --> 00:04:01.525 and congenital heart disease in

NOTE Confidence: 0.9878809

00:04:01.525 --> 00:04:02.265 that setting.

NOTE Confidence: 0.9904723

00:04:03.765 --> 00:04:05.045 And she has since published

NOTE Confidence: 0.9904723

00:04:05.045 --> 00:04:06.965 some important work. She's involved

NOTE Confidence: 0.9904723

00:04:06.965 --> 00:04:08.165 in an important group right

NOTE Confidence: 0.9904723

00:04:08.165 --> 00:04:09.705 now called the trisomy collaborative.

NOTE Confidence: 0.9779803

00:04:10.405 --> 00:04:11.605 So she's got a national

NOTE Confidence: 0.9779803

00:04:11.605 --> 00:04:13.470 presence in this particular area

NOTE Confidence: 0.9779803

00:04:13.470 --> 00:04:15.090 and with this particular question.

NOTE Confidence: 0.9779803

00:04:15.150 --> 00:04:16.589 So I'm delighted that she

NOTE Confidence: 0.9779803

00:04:16.589 --> 00:04:17.630 made some time to talk

NOTE Confidence: 0.9779803

00:04:17.630 --> 00:04:18.670 to us tonight about this

NOTE Confidence: 0.9779803

00:04:18.670 --> 00:04:20.270 subject. Please welcome doctor Katya

NOTE Confidence: 0.9779803

00:04:20.270 --> 00:04:20.770 Casa.

NOTE Confidence: 0.68127906

00:04:21.470 --> 00:04:22.210 Thank you.
NOTE Confidence: 0.88732743

00:04:22.910 --> 00:04:23.410 Thanks.
NOTE Confidence: 0.9195585

00:04:25.645 --> 00:04:27.085 All right. Well, thank you
NOTE Confidence: 0.9195585

00:04:27.085 --> 00:04:28.784 everybody. Thank you for coming.
NOTE Confidence: 0.95245075

00:04:29.164 --> 00:04:30.305 Thank you for the invitation,
NOTE Confidence: 0.95245075

00:04:30.604 --> 00:04:32.284 Mark, and to the Yale
NOTE Confidence: 0.95245075

00:04:32.284 --> 00:04:33.824 Pediatric Ethics Program.
NOTE Confidence: 0.9494877

00:04:34.205 --> 00:04:35.964 I'm really excited to share
NOTE Confidence: 0.9494877

00:04:35.964 --> 00:04:37.664 this topic with you.
NOTE Confidence: 0.885754

00:04:38.444 --> 00:04:39.025 Let's see.
NOTE Confidence: 0.9709187

00:04:41.950 --> 00:04:43.710 Alright. So, you know, so
NOTE Confidence: 0.9709187

00:04:43.710 --> 00:04:44.510 the title of my talk
NOTE Confidence: 0.9709187

00:04:44.510 --> 00:04:46.510 is perinatal decision making in
NOTE Confidence: 0.9709187

00:04:46.510 --> 00:04:48.510 trisomy thirteen eighteen with congenital
NOTE Confidence: 0.9709187

00:04:48.510 --> 00:04:49.250 heart c's.
NOTE Confidence: 0.9859476

00:04:50.910 --> 00:04:51.730 Why perinatal?

NOTE Confidence: 0.9962953
00:04:52.110 --> 00:04:53.550 Well, this is this is
NOTE Confidence: 0.9962953
00:04:53.550 --> 00:04:54.430 something that,
NOTE Confidence: 0.98785204
00:04:54.830 --> 00:04:55.330 spans,
NOTE Confidence: 0.97465223
00:04:56.224 --> 00:04:57.345 I guess, kind of two
NOTE Confidence: 0.97465223
00:04:57.345 --> 00:04:59.504 patients. One being the the
NOTE Confidence: 0.97465223
00:04:59.504 --> 00:05:00.964 parent that you're gonna meet.
NOTE Confidence: 0.98368466
00:05:01.585 --> 00:05:03.205 Oftentimes, this is a diagnosis
NOTE Confidence: 0.98368466
00:05:03.264 --> 00:05:04.784 that is made before a
NOTE Confidence: 0.98368466
00:05:04.784 --> 00:05:06.485 child is born, and then
NOTE Confidence: 0.98368466
00:05:06.544 --> 00:05:08.705 that decision making extends right
NOTE Confidence: 0.98368466
00:05:08.705 --> 00:05:09.205 through,
NOTE Confidence: 0.98748386
00:05:10.380 --> 00:05:11.120 right through,
NOTE Confidence: 0.99083877
00:05:11.820 --> 00:05:12.320 infancy.
NOTE Confidence: 0.9760007
00:05:13.100 --> 00:05:13.600 So,
NOTE Confidence: 0.98649454
00:05:14.460 --> 00:05:15.920 this is a topic that,
NOTE Confidence: 0.97036946

00:05:17.180 --> 00:05:19.100 I've been particularly interested in

NOTE Confidence: 0.97036946

00:05:19.100 --> 00:05:20.560 since I was a fellow,

NOTE Confidence: 0.986553

00:05:21.340 --> 00:05:22.960 studying pediatric cardiology.

NOTE Confidence: 0.9878433

00:05:24.784 --> 00:05:26.145 You'll see over the course

NOTE Confidence: 0.9878433

00:05:26.145 --> 00:05:26.865 of you know, when I

NOTE Confidence: 0.9878433

00:05:26.865 --> 00:05:28.784 talk about background, but, things

NOTE Confidence: 0.9878433

00:05:28.784 --> 00:05:30.145 have really changed in terms

NOTE Confidence: 0.9878433

00:05:30.145 --> 00:05:31.345 of our thinking about,

NOTE Confidence: 0.9935961

00:05:31.985 --> 00:05:33.044 these two conditions.

NOTE Confidence: 0.97689134

00:05:34.064 --> 00:05:35.125 So I'm excited,

NOTE Confidence: 0.97813046

00:05:35.504 --> 00:05:36.784 to be here to share

NOTE Confidence: 0.97813046

00:05:36.784 --> 00:05:38.544 some of my work, some

NOTE Confidence: 0.97813046

00:05:38.544 --> 00:05:39.604 other people's work,

NOTE Confidence: 0.99077636

00:05:39.960 --> 00:05:41.419 and I'm gonna use cases

NOTE Confidence: 0.96431303

00:05:41.880 --> 00:05:42.860 and some,

NOTE Confidence: 0.97794056

00:05:44.759 --> 00:05:46.199 some new research that I've

NOTE Confidence: 0.97794056
00:05:46.199 --> 00:05:46.680 just,
NOTE Confidence: 0.999915
00:05:47.560 --> 00:05:48.060 submitted
NOTE Confidence: 0.9841032
00:05:48.440 --> 00:05:50.539 to kind of, provide some,
NOTE Confidence: 0.99521255
00:05:52.714 --> 00:05:53.595 like, a way to think
NOTE Confidence: 0.99521255
00:05:53.595 --> 00:05:54.654 about this. Okay?
NOTE Confidence: 0.9988216
00:05:55.275 --> 00:05:56.575 So let's get started.
NOTE Confidence: 0.9753909
00:05:57.195 --> 00:05:59.214 First, in terms of disclosures,
NOTE Confidence: 0.94993466
00:06:00.714 --> 00:06:02.154 I have two disclosures. One
NOTE Confidence: 0.94993466
00:06:02.154 --> 00:06:03.755 is I'm a, I'm a
NOTE Confidence: 0.94993466
00:06:03.755 --> 00:06:05.214 medical adviser for
NOTE Confidence: 0.8981743
00:06:06.139 --> 00:06:07.660 a a support organization for
NOTE Confidence: 0.8981743
00:06:07.660 --> 00:06:08.160 parents
NOTE Confidence: 0.93939704
00:06:08.620 --> 00:06:10.300 who have children with trisomy
NOTE Confidence: 0.93939704
00:06:10.300 --> 00:06:12.000 thirteen eighteen. It's called Soft.
NOTE Confidence: 0.955187
00:06:12.540 --> 00:06:14.620 And then second, as, Mark
NOTE Confidence: 0.955187

00:06:14.620 --> 00:06:15.120 mentioned,
NOTE Confidence: 0.9247389

00:06:15.500 --> 00:06:17.100 on a steering committee for,
NOTE Confidence: 0.9247389

00:06:17.260 --> 00:06:18.000 the trisomy
NOTE Confidence: 0.99469924

00:06:18.460 --> 00:06:19.760 thirteen eighteen collaborative.
NOTE Confidence: 0.99892026

00:06:23.275 --> 00:06:25.835 Alright. So my objectives for
NOTE Confidence: 0.99892026

00:06:25.835 --> 00:06:26.335 tonight
NOTE Confidence: 0.9992734

00:06:26.875 --> 00:06:28.794 are to talk about some
NOTE Confidence: 0.9992734

00:06:28.794 --> 00:06:30.475 of the changes with respect
NOTE Confidence: 0.9992734

00:06:30.475 --> 00:06:32.014 to survival outcomes,
NOTE Confidence: 0.9330432

00:06:32.714 --> 00:06:34.555 in Trisomy thirteen eighteen. And,
NOTE Confidence: 0.9330432

00:06:34.555 --> 00:06:35.055 specifically,
NOTE Confidence: 0.99464244

00:06:35.580 --> 00:06:37.360 I'm gonna be focusing on,
NOTE Confidence: 0.9939428

00:06:38.300 --> 00:06:39.439 procedural interventions,
NOTE Confidence: 0.96451473

00:06:40.860 --> 00:06:41.339 and,
NOTE Confidence: 0.9966801

00:06:41.740 --> 00:06:42.720 cardiac surgery.
NOTE Confidence: 0.9921163

00:06:43.500 --> 00:06:44.939 And then I'm also gonna

NOTE Confidence: 0.9921163
00:06:44.939 --> 00:06:47.199 talk about what makes prenatal
NOTE Confidence: 0.98070484
00:06:47.500 --> 00:06:49.659 counseling and perinatal decision making
NOTE Confidence: 0.98070484
00:06:49.659 --> 00:06:50.400 so challenging,
NOTE Confidence: 0.99930316
00:06:51.325 --> 00:06:53.585 and and focus on how
NOTE Confidence: 0.99930316
00:06:53.645 --> 00:06:54.145 perspectives
NOTE Confidence: 0.981514
00:06:55.005 --> 00:06:56.044 on quality of life and
NOTE Confidence: 0.981514
00:06:56.044 --> 00:06:57.505 also some very objective,
NOTE Confidence: 0.99571866
00:06:58.525 --> 00:06:59.025 considerations
NOTE Confidence: 0.9883095
00:06:59.565 --> 00:07:01.264 make decision making challenging.
NOTE Confidence: 0.9543252
00:07:02.125 --> 00:07:03.264 And then finally,
NOTE Confidence: 0.9989084
00:07:03.645 --> 00:07:04.865 I want us to move
NOTE Confidence: 0.91271466
00:07:05.165 --> 00:07:06.065 kind of toward,
NOTE Confidence: 0.99689394
00:07:08.020 --> 00:07:09.620 a plan of action or
NOTE Confidence: 0.99689394
00:07:09.620 --> 00:07:10.580 to have some sort of
NOTE Confidence: 0.99689394
00:07:10.580 --> 00:07:11.240 a framework
NOTE Confidence: 0.98644555

00:07:11.620 --> 00:07:12.660 for how we're gonna make
NOTE Confidence: 0.98644555

00:07:12.660 --> 00:07:14.580 decisions. And that's gonna be
NOTE Confidence: 0.98644555

00:07:14.580 --> 00:07:16.520 guided by ethical principles
NOTE Confidence: 0.9811021

00:07:17.300 --> 00:07:18.660 that, I think will kind
NOTE Confidence: 0.9811021

00:07:18.660 --> 00:07:19.880 of help to give us,
NOTE Confidence: 0.9826087

00:07:20.675 --> 00:07:22.275 some kind of clarity about,
NOTE Confidence: 0.9826087

00:07:22.275 --> 00:07:24.195 again, decision making. And so
NOTE Confidence: 0.9826087

00:07:24.195 --> 00:07:25.315 I'm gonna, again, I'm gonna
NOTE Confidence: 0.9826087

00:07:25.315 --> 00:07:27.175 use some patient cases to,
NOTE Confidence: 0.9670368

00:07:28.115 --> 00:07:30.035 illustrate points and then also
NOTE Confidence: 0.9670368

00:07:30.035 --> 00:07:32.055 some physician comments that,
NOTE Confidence: 0.9997233

00:07:32.595 --> 00:07:33.895 that I recently collected
NOTE Confidence: 0.99672836

00:07:35.440 --> 00:07:36.260 in some research
NOTE Confidence: 0.99900675

00:07:37.640 --> 00:07:38.140 I've
NOTE Confidence: 0.9969773

00:07:39.520 --> 00:07:41.300 done. Alright. So
NOTE Confidence: 0.96661866

00:07:41.680 --> 00:07:42.720 I think first we need

NOTE Confidence: 0.96661866
00:07:42.720 --> 00:07:44.080 some background for those of
NOTE Confidence: 0.96661866
00:07:44.080 --> 00:07:45.040 you who might not be
NOTE Confidence: 0.96661866
00:07:45.040 --> 00:07:46.720 familiar with this, these two
NOTE Confidence: 0.96661866
00:07:46.720 --> 00:07:47.220 conditions.
NOTE Confidence: 0.9946327
00:07:47.840 --> 00:07:49.780 So trisomy eighteen and thirteen
NOTE Confidence: 0.9946327
00:07:50.000 --> 00:07:51.625 are the the second and
NOTE Confidence: 0.9946327
00:07:51.625 --> 00:07:53.085 third most common trisomy
NOTE Confidence: 0.96185344
00:07:53.385 --> 00:07:55.544 chromosomal trisomy after trisomy twenty
NOTE Confidence: 0.96185344
00:07:55.544 --> 00:07:56.905 one. So we're talking about
NOTE Confidence: 0.96185344
00:07:56.905 --> 00:07:57.565 an extra
NOTE Confidence: 0.9924135
00:07:57.945 --> 00:07:59.805 copy of the of chromosome
NOTE Confidence: 0.9924135
00:08:00.104 --> 00:08:01.405 eighteen or thirteen.
NOTE Confidence: 0.9913101
00:08:02.585 --> 00:08:03.705 And then based on the
NOTE Confidence: 0.9913101
00:08:03.705 --> 00:08:04.845 most up to date,
NOTE Confidence: 0.9472542
00:08:08.180 --> 00:08:09.540 excuse me, based on the
NOTE Confidence: 0.9472542

00:08:09.540 --> 00:08:10.840 most up to date prevalence
NOTE Confidence: 0.9472542

00:08:10.900 --> 00:08:11.400 statistics,
NOTE Confidence: 0.9719365

00:08:11.860 --> 00:08:13.140 for major birth defects in
NOTE Confidence: 0.9719365

00:08:13.140 --> 00:08:15.480 the United States, trisomy thirteen
NOTE Confidence: 0.9719365

00:08:15.540 --> 00:08:16.820 occurs at about one point
NOTE Confidence: 0.9719365

00:08:16.820 --> 00:08:18.660 six for ten thousand live
NOTE Confidence: 0.9719365

00:08:18.660 --> 00:08:19.780 births. So that's about six
NOTE Confidence: 0.9719365

00:08:19.780 --> 00:08:21.000 hundred cases annually.
NOTE Confidence: 0.9864715

00:08:21.380 --> 00:08:23.185 And then for trisomy eighteen,
NOTE Confidence: 0.9887019

00:08:23.645 --> 00:08:25.085 a bit more common at
NOTE Confidence: 0.9887019

00:08:25.085 --> 00:08:26.444 three point four per ten
NOTE Confidence: 0.9887019

00:08:26.444 --> 00:08:26.944 thousand,
NOTE Confidence: 0.9995719

00:08:27.324 --> 00:08:28.845 which is about one thousand
NOTE Confidence: 0.9995719

00:08:28.845 --> 00:08:30.544 three hundred cases annually.
NOTE Confidence: 0.9364567

00:08:32.125 --> 00:08:33.964 So perinatal mortality in this
NOTE Confidence: 0.9364567

00:08:33.964 --> 00:08:35.565 condition is is is very

NOTE Confidence: 0.9364567
00:08:35.565 --> 00:08:36.065 high,
NOTE Confidence: 0.95711297
00:08:37.190 --> 00:08:38.790 and that's that's gonna be
NOTE Confidence: 0.95711297
00:08:38.790 --> 00:08:39.290 important.
NOTE Confidence: 0.98069924
00:08:40.550 --> 00:08:42.470 Some estimates are as high
NOTE Confidence: 0.98069924
00:08:42.470 --> 00:08:43.510 as fifty percent,
NOTE Confidence: 0.98039037
00:08:43.910 --> 00:08:45.050 perinatal loss.
NOTE Confidence: 0.798191
00:08:46.870 --> 00:08:47.769 So, basically,
NOTE Confidence: 0.9987802
00:08:48.790 --> 00:08:50.010 a baby not surviving
NOTE Confidence: 0.9986554
00:08:50.390 --> 00:08:51.450 to to delivery.
NOTE Confidence: 0.96205574
00:08:52.535 --> 00:08:53.894 There was a study recently
NOTE Confidence: 0.96205574
00:08:53.894 --> 00:08:55.175 out of Cincinnati that put
NOTE Confidence: 0.96205574
00:08:55.175 --> 00:08:56.454 that number at twenty percent.
NOTE Confidence: 0.96205574
00:08:56.454 --> 00:08:56.954 So,
NOTE Confidence: 0.90763134
00:08:57.415 --> 00:08:58.454 just include kind of a
NOTE Confidence: 0.90763134
00:08:58.454 --> 00:08:59.815 broad estimate there of twenty
NOTE Confidence: 0.90763134

00:08:59.815 --> 00:09:00.875 to fifty percent.

NOTE Confidence: 0.9915361

00:09:05.510 --> 00:09:07.690 Children with trisomy thirteen eighteen

NOTE Confidence: 0.9915361

00:09:07.750 --> 00:09:08.250 have,

NOTE Confidence: 0.9194457

00:09:08.870 --> 00:09:10.330 multiple medical issues.

NOTE Confidence: 0.98848724

00:09:10.870 --> 00:09:12.150 And some of those issues

NOTE Confidence: 0.98848724

00:09:12.150 --> 00:09:13.510 can be pretty pretty,

NOTE Confidence: 0.98057026

00:09:14.070 --> 00:09:15.270 pretty significant. So,

NOTE Confidence: 0.9114677

00:09:16.194 --> 00:09:17.574 that includes some phalliceal,

NOTE Confidence: 0.96517074

00:09:19.235 --> 00:09:20.115 where, you know, some of

NOTE Confidence: 0.96517074

00:09:20.115 --> 00:09:21.795 the abdominal contents are outside

NOTE Confidence: 0.96517074

00:09:21.795 --> 00:09:23.574 of the body, congenital diaphragmatic

NOTE Confidence: 0.96517074

00:09:23.795 --> 00:09:25.315 hernia, where a portion of

NOTE Confidence: 0.96517074

00:09:25.315 --> 00:09:26.834 the diaphragm is not formed

NOTE Confidence: 0.96517074

00:09:26.834 --> 00:09:27.975 correctly, and so,

NOTE Confidence: 0.8982242

00:09:28.834 --> 00:09:30.295 the organs in the abdomen

NOTE Confidence: 0.8982242

00:09:30.355 --> 00:09:31.579 kind of come into the

NOTE Confidence: 0.9281981

00:09:31.959 --> 00:09:32.860 chest. Tracheoesophageal

NOTE Confidence: 0.9355551

00:09:33.319 --> 00:09:34.679 fistula, so a connection between

NOTE Confidence: 0.9355551

00:09:34.679 --> 00:09:36.360 the trachea and esophagus or

NOTE Confidence: 0.9355551

00:09:36.360 --> 00:09:38.300 esophageal atresia where there's actually

NOTE Confidence: 0.9355551

00:09:38.519 --> 00:09:39.259 no continuation.

NOTE Confidence: 0.95843714

00:09:41.240 --> 00:09:42.600 They can also have structural

NOTE Confidence: 0.95843714

00:09:42.600 --> 00:09:43.420 brain anomalies,

NOTE Confidence: 0.96467364

00:09:43.880 --> 00:09:44.839 and some of these will

NOTE Confidence: 0.96467364

00:09:44.839 --> 00:09:45.740 lead to seizures.

NOTE Confidence: 0.9771305

00:09:46.385 --> 00:09:47.585 There's also a big question

NOTE Confidence: 0.9771305

00:09:47.585 --> 00:09:49.265 about central apnea, whether or

NOTE Confidence: 0.9771305

00:09:49.265 --> 00:09:50.465 not the brain is is

NOTE Confidence: 0.9771305

00:09:50.465 --> 00:09:50.965 telling,

NOTE Confidence: 0.99712807

00:09:51.905 --> 00:09:53.205 telling them to breathe.

NOTE Confidence: 0.9816501

00:09:53.985 --> 00:09:55.665 There are also some ear,

NOTE Confidence: 0.9816501

00:09:55.665 --> 00:09:57.525 nose, and throat concerns, specifically

NOTE Confidence: 0.9816501

00:09:57.665 --> 00:09:59.200 airway concerns. Some of these

NOTE Confidence: 0.9816501

00:09:59.200 --> 00:10:00.800 children have cleft lip. They

NOTE Confidence: 0.9816501

00:10:00.800 --> 00:10:02.340 can have upper airway obstruction,

NOTE Confidence: 0.9816501

00:10:02.400 --> 00:10:03.920 which can also contribute to

NOTE Confidence: 0.9816501

00:10:03.920 --> 00:10:04.420 apnea,

NOTE Confidence: 0.99247473

00:10:05.440 --> 00:10:06.880 and apnea being just not

NOTE Confidence: 0.99247473

00:10:06.880 --> 00:10:07.380 breathing.

NOTE Confidence: 0.9960017

00:10:08.800 --> 00:10:10.660 Some children require technological

NOTE Confidence: 0.989563

00:10:10.960 --> 00:10:13.115 assistance in order to,

NOTE Confidence: 0.9959174

00:10:14.134 --> 00:10:14.934 in order to be able

NOTE Confidence: 0.9959174

00:10:14.934 --> 00:10:15.595 to breathe,

NOTE Confidence: 0.9900248

00:10:16.134 --> 00:10:16.634 to,

NOTE Confidence: 0.95619446

00:10:17.654 --> 00:10:18.475 to grow.

NOTE Confidence: 0.96682435

00:10:18.934 --> 00:10:20.554 So that might include mechanical

NOTE Confidence: 0.96682435

00:10:20.615 --> 00:10:21.115 ventilation.

NOTE Confidence: 0.9981961

00:10:21.894 --> 00:10:23.274 That might include a tracheostomy,

NOTE Confidence: 0.9761051

00:10:23.894 --> 00:10:24.634 a gastrostomy

NOTE Confidence: 0.80407387

00:10:25.095 --> 00:10:25.595 tube.

NOTE Confidence: 0.9934102

00:10:26.130 --> 00:10:27.730 And then they are often

NOTE Confidence: 0.9934102

00:10:27.809 --> 00:10:29.830 they often have profound neurodevelopmental

NOTE Confidence: 0.98157436

00:10:30.290 --> 00:10:30.790 impairment.

NOTE Confidence: 0.9941863

00:10:32.290 --> 00:10:32.790 And

NOTE Confidence: 0.98502505

00:10:33.650 --> 00:10:35.330 I think the older thinking

NOTE Confidence: 0.98502505

00:10:35.330 --> 00:10:37.030 was that these children didn't

NOTE Confidence: 0.98502505

00:10:37.330 --> 00:10:38.175 achieve any milestones,

NOTE Confidence: 0.986736

00:10:44.415 --> 00:10:46.035 examples are self feeding,

NOTE Confidence: 0.9983674

00:10:46.654 --> 00:10:47.154 smiling,

NOTE Confidence: 0.8724779

00:10:49.375 --> 00:10:50.355 simple commands.

NOTE Confidence: 0.9948736

00:10:53.520 --> 00:10:56.080 So where where I became

NOTE Confidence: 0.9948736

00:10:56.080 --> 00:10:57.440 very curious about this is

NOTE Confidence: 0.9948736

00:10:57.440 --> 00:10:58.559 that a lot of these
NOTE Confidence: 0.9948736

00:10:58.559 --> 00:11:00.400 kids also have congenital heart
NOTE Confidence: 0.9948736

00:11:00.400 --> 00:11:01.840 disease. About eighty to ninety
NOTE Confidence: 0.9948736

00:11:01.840 --> 00:11:02.340 percent
NOTE Confidence: 0.9985393

00:11:02.720 --> 00:11:04.660 also have congenital heart disease.
NOTE Confidence: 0.9997539

00:11:05.375 --> 00:11:06.975 The most common defects that
NOTE Confidence: 0.9997539

00:11:06.975 --> 00:11:08.274 we're seeing are
NOTE Confidence: 0.9723598

00:11:08.975 --> 00:11:10.495 are the simpler, I guess,
NOTE Confidence: 0.9723598

00:11:10.495 --> 00:11:11.394 defects. So,
NOTE Confidence: 0.99922776

00:11:11.934 --> 00:11:13.394 atrial septal defects
NOTE Confidence: 0.9685676

00:11:13.934 --> 00:11:15.954 or ventricular septal defects,
NOTE Confidence: 0.9202911

00:11:16.255 --> 00:11:17.535 another one called the patent
NOTE Confidence: 0.9202911

00:11:17.535 --> 00:11:18.514 ductus arteriosus.
NOTE Confidence: 0.9994394

00:11:19.569 --> 00:11:21.509 But we also see very
NOTE Confidence: 0.9994394

00:11:21.569 --> 00:11:22.069 complex
NOTE Confidence: 0.981441

00:11:22.370 --> 00:11:23.110 heart lesions.

NOTE Confidence: 0.9704487

00:11:24.129 --> 00:11:25.170 And one of those I

NOTE Confidence: 0.9704487

00:11:25.170 --> 00:11:26.610 have up in this, the

NOTE Confidence: 0.9704487

00:11:26.610 --> 00:11:27.889 picture all the way to

NOTE Confidence: 0.9704487

00:11:27.889 --> 00:11:30.050 the left, that's hypoplastic left

NOTE Confidence: 0.9704487

00:11:30.050 --> 00:11:30.790 heart syndrome

NOTE Confidence: 0.9675486

00:11:31.329 --> 00:11:32.370 where the left side of

NOTE Confidence: 0.9675486

00:11:32.370 --> 00:11:33.889 the heart is underdeveloped and

NOTE Confidence: 0.9675486

00:11:33.889 --> 00:11:34.389 really

NOTE Confidence: 0.93780655

00:11:34.934 --> 00:11:35.434 nonfunctional.

NOTE Confidence: 0.9670948

00:11:36.295 --> 00:11:37.035 And so,

NOTE Confidence: 0.9511199

00:11:38.695 --> 00:11:40.395 these these type of defects,

NOTE Confidence: 0.95756036

00:11:40.934 --> 00:11:42.715 will require, you know, different,

NOTE Confidence: 0.9673131

00:11:43.895 --> 00:11:45.815 usually require different ways to

NOTE Confidence: 0.9673131

00:11:45.815 --> 00:11:47.355 to address them. Some being

NOTE Confidence: 0.9537351

00:11:48.160 --> 00:11:49.600 more kind of straightforward, some

NOTE Confidence: 0.9537351

00:11:49.600 --> 00:11:51.040 being much more complex like
NOTE Confidence: 0.9537351

00:11:51.040 --> 00:11:52.960 the example all the way
NOTE Confidence: 0.9537351

00:11:52.960 --> 00:11:53.860 on the left.
NOTE Confidence: 0.98119897

00:11:58.880 --> 00:12:00.559 So when we think about
NOTE Confidence: 0.98119897

00:12:00.559 --> 00:12:02.515 survival, as I mentioned, perinatal,
NOTE Confidence: 0.9844263

00:12:04.255 --> 00:12:06.595 perinatal mortality is quite high.
NOTE Confidence: 0.9844263

00:12:06.735 --> 00:12:08.115 When we think about survival
NOTE Confidence: 0.9844263

00:12:08.335 --> 00:12:10.195 after birth, it's also,
NOTE Confidence: 0.9436832

00:12:11.375 --> 00:12:13.535 significant. So this was a,
NOTE Confidence: 0.9436832

00:12:13.855 --> 00:12:15.155 probably the most recent
NOTE Confidence: 0.9168857

00:12:16.840 --> 00:12:19.080 estimate of postnatal survival. This
NOTE Confidence: 0.9168857

00:12:19.080 --> 00:12:20.280 was published by Goll et
NOTE Confidence: 0.9168857

00:12:20.280 --> 00:12:21.420 al in twenty nineteen.
NOTE Confidence: 0.97594225

00:12:21.880 --> 00:12:22.360 And,
NOTE Confidence: 0.9366795

00:12:22.920 --> 00:12:24.220 this was looking at,
NOTE Confidence: 0.9727895

00:12:26.120 --> 00:12:27.400 at children all all over

NOTE Confidence: 0.9727895

00:12:27.400 --> 00:12:28.440 the world. So these are

NOTE Confidence: 0.9727895

00:12:28.440 --> 00:12:29.580 international estimates.

NOTE Confidence: 0.99811053

00:12:30.280 --> 00:12:30.780 So

NOTE Confidence: 0.9626176

00:12:32.214 --> 00:12:33.335 a review of about twenty

NOTE Confidence: 0.9626176

00:12:33.335 --> 00:12:35.595 registries revealed median survival

NOTE Confidence: 0.98931515

00:12:35.895 --> 00:12:37.495 of fifty two percent within

NOTE Confidence: 0.98931515

00:12:37.495 --> 00:12:38.535 the first week of life

NOTE Confidence: 0.98931515

00:12:38.535 --> 00:12:40.615 for trisomy thirteen and fifty

NOTE Confidence: 0.98931515

00:12:40.615 --> 00:12:42.455 eight percent for trisomy eighteen

NOTE Confidence: 0.98931515

00:12:42.455 --> 00:12:43.735 with nearly half of all

NOTE Confidence: 0.98931515

00:12:43.735 --> 00:12:45.575 deaths occurring on the first

NOTE Confidence: 0.98931515

00:12:45.575 --> 00:12:46.475 day of life.

NOTE Confidence: 0.9860397

00:12:47.890 --> 00:12:49.970 Sixteen registries recorded data out

NOTE Confidence: 0.9860397

00:12:49.970 --> 00:12:51.890 to one year with estimates

NOTE Confidence: 0.9860397

00:12:51.890 --> 00:12:53.730 of survival of thirteen percent

NOTE Confidence: 0.9860397

00:12:53.730 --> 00:12:55.410 for trisomy thirteen and twelve

NOTE Confidence: 0.9860397

00:12:55.410 --> 00:12:57.650 percent for trisomy eighteen. And

NOTE Confidence: 0.9860397

00:12:57.650 --> 00:12:58.929 then it gets you know,

NOTE Confidence: 0.9860397

00:12:58.929 --> 00:13:00.690 there's so eleven registries out

NOTE Confidence: 0.9860397

00:13:00.690 --> 00:13:02.415 to five years with about

NOTE Confidence: 0.9860397

00:13:02.415 --> 00:13:03.695 seven percent and eight percent

NOTE Confidence: 0.9860397

00:13:03.695 --> 00:13:04.195 respectively.

NOTE Confidence: 0.9849013

00:13:05.135 --> 00:13:07.075 But what's what's not reflected

NOTE Confidence: 0.9849013

00:13:07.215 --> 00:13:08.755 here in these statistics

NOTE Confidence: 0.9962135

00:13:09.215 --> 00:13:09.715 is

NOTE Confidence: 0.99108773

00:13:10.095 --> 00:13:11.635 the impact that,

NOTE Confidence: 0.9856856

00:13:12.495 --> 00:13:13.855 intervention kind of has on

NOTE Confidence: 0.9856856

00:13:13.855 --> 00:13:15.215 survival. So these are all

NOTE Confidence: 0.9856856

00:13:15.215 --> 00:13:15.615 comers,

NOTE Confidence: 0.9650279

00:13:16.910 --> 00:13:18.290 and I'm gonna show you,

NOTE Confidence: 0.9706475

00:13:19.230 --> 00:13:20.530 what where the,

NOTE Confidence: 0.9949555

00:13:21.470 --> 00:13:22.910 I guess, where the the

NOTE Confidence: 0.9949555

00:13:22.910 --> 00:13:24.750 issue lies in terms of

NOTE Confidence: 0.9949555

00:13:24.750 --> 00:13:25.970 survival and intervention.

NOTE Confidence: 0.8932991

00:13:29.415 --> 00:13:30.395 So, historically,

NOTE Confidence: 0.9942679

00:13:31.015 --> 00:13:33.434 trisomy thirteen eighteen have been

NOTE Confidence: 0.9942679

00:13:33.495 --> 00:13:35.654 viewed as lethal conditions that

NOTE Confidence: 0.9942679

00:13:35.654 --> 00:13:37.355 are incompatible with life.

NOTE Confidence: 0.9942681

00:13:38.135 --> 00:13:39.675 So because of that,

NOTE Confidence: 0.9960555

00:13:40.135 --> 00:13:42.395 medical treatment and procedural intervention

NOTE Confidence: 0.9960555

00:13:42.535 --> 00:13:43.675 were typically denied.

NOTE Confidence: 0.9736812

00:13:44.054 --> 00:13:45.389 This was this is how

NOTE Confidence: 0.9736812

00:13:45.389 --> 00:13:46.750 I how I learned about

NOTE Confidence: 0.9736812

00:13:46.750 --> 00:13:47.410 the condition,

NOTE Confidence: 0.997051

00:13:48.350 --> 00:13:49.709 when I was a medical

NOTE Confidence: 0.997051

00:13:49.709 --> 00:13:51.089 student or in training.

NOTE Confidence: 0.97330636

00:13:52.110 --> 00:13:53.309 So treatment was felt to
NOTE Confidence: 0.97330636

00:13:53.309 --> 00:13:53.970 be futile.
NOTE Confidence: 0.9836042

00:13:54.750 --> 00:13:56.509 But, unfortunately, this also creates
NOTE Confidence: 0.9836042

00:13:56.509 --> 00:13:57.804 a, like, a self fulfilling
NOTE Confidence: 0.9836042

00:13:57.804 --> 00:13:59.964 prophecy. Right? So if you
NOTE Confidence: 0.9836042

00:13:59.964 --> 00:14:02.285 don't resuscitate after a child
NOTE Confidence: 0.9836042

00:14:02.285 --> 00:14:03.804 is born, you don't provide
NOTE Confidence: 0.9836042

00:14:03.804 --> 00:14:04.304 nutrition,
NOTE Confidence: 0.9989993

00:14:04.684 --> 00:14:06.705 hydration, respiratory support,
NOTE Confidence: 0.99439585

00:14:07.165 --> 00:14:08.285 any kind of medical or
NOTE Confidence: 0.99439585

00:14:08.285 --> 00:14:09.265 surgical intervention
NOTE Confidence: 0.97322303

00:14:10.329 --> 00:14:11.529 or, you know, for any
NOTE Confidence: 0.97322303

00:14:11.529 --> 00:14:12.029 condition,
NOTE Confidence: 0.9511983

00:14:12.490 --> 00:14:14.429 then those patients will die,
NOTE Confidence: 0.9805758

00:14:14.970 --> 00:14:17.050 and then their death will
NOTE Confidence: 0.9805758

00:14:17.050 --> 00:14:17.550 justify

NOTE Confidence: 0.95544696

00:14:17.929 --> 00:14:18.429 nonintervention.

NOTE Confidence: 0.99786437

00:14:24.825 --> 00:14:25.805 One of the most,

NOTE Confidence: 0.99565816

00:14:27.065 --> 00:14:27.725 I guess,

NOTE Confidence: 0.92647445

00:14:29.385 --> 00:14:31.485 most recognizable genetics textbooks

NOTE Confidence: 0.99647284

00:14:31.945 --> 00:14:32.985 had this to say in

NOTE Confidence: 0.99647284

00:14:32.985 --> 00:14:34.765 nineteen eighty eight about trisomy

NOTE Confidence: 0.99647284

00:14:34.825 --> 00:14:35.725 thirteen eighteen.

NOTE Confidence: 0.9709847

00:14:36.720 --> 00:14:38.399 So babies with trisomy eighteen

NOTE Confidence: 0.9709847

00:14:38.399 --> 00:14:40.240 syndrome are usually feeble and

NOTE Confidence: 0.9709847

00:14:40.240 --> 00:14:42.000 have a limited capacity for

NOTE Confidence: 0.9709847

00:14:42.000 --> 00:14:42.500 survival.

NOTE Confidence: 0.99797374

00:14:43.279 --> 00:14:44.720 Once the diagnosis has been

NOTE Confidence: 0.99797374

00:14:44.720 --> 00:14:45.220 established,

NOTE Confidence: 0.99410087

00:14:45.760 --> 00:14:47.600 the author recommends limitation of

NOTE Confidence: 0.99410087

00:14:47.600 --> 00:14:49.459 all medical means for prolongation

NOTE Confidence: 0.99410087

00:14:49.600 --> 00:14:50.260 of life.
NOTE Confidence: 0.9305551

00:14:50.855 --> 00:14:52.555 Similarly, for trisomy thirteen,
NOTE Confidence: 0.99815243

00:14:53.654 --> 00:14:54.694 it is the opinion of
NOTE Confidence: 0.99815243

00:14:54.694 --> 00:14:55.274 the author
NOTE Confidence: 0.9383433

00:14:55.654 --> 00:14:57.095 that no medical means should
NOTE Confidence: 0.9383433

00:14:57.095 --> 00:14:58.875 be utilized to prolong prolong
NOTE Confidence: 0.9383433

00:14:59.095 --> 00:15:00.535 the life of individuals with
NOTE Confidence: 0.9383433

00:15:00.535 --> 00:15:01.194 the syndrome.
NOTE Confidence: 0.9951508

00:15:05.500 --> 00:15:06.000 Alright.
NOTE Confidence: 0.98850995

00:15:07.020 --> 00:15:07.520 So
NOTE Confidence: 0.99658406

00:15:09.180 --> 00:15:09.680 so
NOTE Confidence: 0.85917085

00:15:10.940 --> 00:15:11.900 here I am as this
NOTE Confidence: 0.85917085

00:15:12.060 --> 00:15:13.040 one of our sonographers.
NOTE Confidence: 0.9888482

00:15:15.675 --> 00:15:16.335 Our role
NOTE Confidence: 0.9527593

00:15:16.955 --> 00:15:18.315 as as a as a
NOTE Confidence: 0.9527593

00:15:18.315 --> 00:15:20.075 pediatric cardiology team is to

NOTE Confidence: 0.9527593
00:15:20.075 --> 00:15:21.855 diagnose congenital heart disease
NOTE Confidence: 0.9962599
00:15:22.155 --> 00:15:23.055 in the fetus.
NOTE Confidence: 0.99913424
00:15:23.675 --> 00:15:24.175 So
NOTE Confidence: 0.99923915
00:15:24.795 --> 00:15:26.255 we are meeting families
NOTE Confidence: 0.95743465
00:15:27.115 --> 00:15:28.395 in around, you know, eighteen
NOTE Confidence: 0.95743465
00:15:28.395 --> 00:15:29.535 to twenty two weeks
NOTE Confidence: 0.95546705
00:15:29.949 --> 00:15:31.149 when they are both learning
NOTE Confidence: 0.95546705
00:15:31.149 --> 00:15:31.649 about
NOTE Confidence: 0.98643136
00:15:32.029 --> 00:15:33.149 the fact that their child
NOTE Confidence: 0.98643136
00:15:33.149 --> 00:15:34.610 has congenital heart disease,
NOTE Confidence: 0.9974283
00:15:35.070 --> 00:15:36.750 and they're also learning about
NOTE Confidence: 0.9974283
00:15:36.750 --> 00:15:37.790 the fact that their child
NOTE Confidence: 0.9974283
00:15:37.790 --> 00:15:39.649 has trisomy thirteen eighteen.
NOTE Confidence: 0.99456453
00:15:40.990 --> 00:15:41.730 And so
NOTE Confidence: 0.96524864
00:15:42.185 --> 00:15:43.005 we're kinda tasked
NOTE Confidence: 0.9999425

00:15:43.865 --> 00:15:44.685 with providing
NOTE Confidence: 0.96431756

00:15:45.305 --> 00:15:45.805 counseling,
NOTE Confidence: 0.99873155

00:15:47.464 --> 00:15:50.045 making decisions very early on
NOTE Confidence: 0.99873155

00:15:50.345 --> 00:15:50.845 about,
NOTE Confidence: 0.99484587

00:15:51.464 --> 00:15:52.925 you know, what's gonna happen.
NOTE Confidence: 0.9970669

00:15:53.464 --> 00:15:54.285 And so
NOTE Confidence: 0.99826527

00:15:55.210 --> 00:15:56.590 I'm gonna use a case
NOTE Confidence: 0.99826527

00:15:56.650 --> 00:15:57.630 to kind of elaborate
NOTE Confidence: 0.9987155

00:15:58.010 --> 00:15:59.470 some of the the difficulty
NOTE Confidence: 0.9987155

00:15:59.529 --> 00:16:00.430 here. Okay?
NOTE Confidence: 0.998347

00:16:01.210 --> 00:16:02.570 So this is a couple
NOTE Confidence: 0.998347

00:16:02.570 --> 00:16:03.610 that was referred for a
NOTE Confidence: 0.998347

00:16:03.610 --> 00:16:05.370 level two ultrasound, and that's
NOTE Confidence: 0.998347

00:16:05.370 --> 00:16:06.410 basically just kind of a
NOTE Confidence: 0.998347

00:16:06.410 --> 00:16:07.630 higher level ultrasound
NOTE Confidence: 0.96396655

00:16:08.170 --> 00:16:09.785 after genetic testing,

NOTE Confidence: 0.99154073

00:16:10.485 --> 00:16:12.185 confirmed trisomy eighteen.

NOTE Confidence: 0.9993267

00:16:12.964 --> 00:16:14.024 The fetal echocardiogram

NOTE Confidence: 0.9937515

00:16:15.204 --> 00:16:16.964 showed a large VSD, so

NOTE Confidence: 0.9937515

00:16:16.964 --> 00:16:18.005 a large hole in the

NOTE Confidence: 0.9937515

00:16:18.005 --> 00:16:19.225 bottom part of the heart.

NOTE Confidence: 0.9003591

00:16:19.685 --> 00:16:20.404 They have met with the

NOTE Confidence: 0.9003591

00:16:20.404 --> 00:16:22.084 genetics team and learned about

NOTE Confidence: 0.9003591

00:16:22.084 --> 00:16:22.280 the medical and neurodevelopmental issues

NOTE Confidence: 0.9003591

00:16:22.280 --> 00:16:22.325 associated with trisomy eighteen. They've

NOTE Confidence: 0.9003591

00:16:22.325 --> 00:16:23.075 also been

NOTE Confidence: 0.99801886

00:16:23.670 --> 00:16:26.010 issues associated with trisomy eighteen.

NOTE Confidence: 0.97450554

00:16:26.630 --> 00:16:28.149 They've also been counseled about

NOTE Confidence: 0.97450554

00:16:28.149 --> 00:16:30.089 the elevated perinatal mortality.

NOTE Confidence: 0.9856357

00:16:30.790 --> 00:16:32.070 They do not wanna pursue

NOTE Confidence: 0.9856357

00:16:32.070 --> 00:16:34.390 postnatal interventions that increase pain

NOTE Confidence: 0.9856357

00:16:34.390 --> 00:16:35.050 and suffering,
NOTE Confidence: 0.98797923

00:16:35.585 --> 00:16:37.185 but would reconsider if those
NOTE Confidence: 0.98797923

00:16:37.185 --> 00:16:39.505 interventions improve quality of life
NOTE Confidence: 0.98797923

00:16:39.505 --> 00:16:40.245 and survival.
NOTE Confidence: 0.9961928

00:16:42.785 --> 00:16:43.285 So
NOTE Confidence: 0.97637624

00:16:47.425 --> 00:16:48.305 if I you know, if
NOTE Confidence: 0.97637624

00:16:48.305 --> 00:16:49.445 we use the data,
NOTE Confidence: 0.974191

00:16:50.170 --> 00:16:50.970 if we look at the
NOTE Confidence: 0.974191

00:16:50.970 --> 00:16:51.470 data,
NOTE Confidence: 0.975866

00:16:52.010 --> 00:16:53.210 you would you would wanna
NOTE Confidence: 0.975866

00:16:53.210 --> 00:16:54.430 communicate. Well,
NOTE Confidence: 0.9674887

00:16:55.050 --> 00:16:56.330 you know, the the mortality
NOTE Confidence: 0.9674887

00:16:56.330 --> 00:16:57.210 is really high. You know,
NOTE Confidence: 0.9674887

00:16:57.210 --> 00:16:58.650 perinatal mortality is up to
NOTE Confidence: 0.9674887

00:16:58.650 --> 00:16:59.470 fifty percent,
NOTE Confidence: 0.99856734

00:16:59.930 --> 00:17:01.210 and, you know, half of

NOTE Confidence: 0.99856734

00:17:01.210 --> 00:17:02.410 all babies will die within

NOTE Confidence: 0.99856734

00:17:02.410 --> 00:17:03.630 the first week of life.

NOTE Confidence: 0.9998093

00:17:04.315 --> 00:17:06.494 There wasn't much data on

NOTE Confidence: 0.9998093

00:17:06.715 --> 00:17:07.375 the impact

NOTE Confidence: 0.9983105

00:17:07.835 --> 00:17:09.675 of congenital heart disease in

NOTE Confidence: 0.9983105

00:17:09.675 --> 00:17:10.415 terms of,

NOTE Confidence: 0.9949765

00:17:10.795 --> 00:17:12.234 you know, thinking about outcomes

NOTE Confidence: 0.9949765

00:17:12.234 --> 00:17:13.755 in these babies when I

NOTE Confidence: 0.9949765

00:17:13.755 --> 00:17:15.595 first started to to wonder

NOTE Confidence: 0.9949765

00:17:15.595 --> 00:17:16.335 about this.

NOTE Confidence: 0.9919204

00:17:16.955 --> 00:17:18.315 And so in twenty but

NOTE Confidence: 0.9919204

00:17:18.315 --> 00:17:19.679 in twenty sixteen, there was

NOTE Confidence: 0.9919204

00:17:19.679 --> 00:17:20.419 this paper

NOTE Confidence: 0.98502207

00:17:21.520 --> 00:17:22.399 that was published out of

NOTE Confidence: 0.98502207

00:17:22.399 --> 00:17:22.899 Canada

NOTE Confidence: 0.99570864

00:17:23.279 --> 00:17:24.980 by Nelson and colleagues,
NOTE Confidence: 0.99944055

00:17:26.080 --> 00:17:27.380 that looked at the prevalence
NOTE Confidence: 0.99944055

00:17:27.440 --> 00:17:29.220 of medical and surgical interventions
NOTE Confidence: 0.97403145

00:17:29.520 --> 00:17:30.820 in Ontario, Canada.
NOTE Confidence: 0.9823312

00:17:31.185 --> 00:17:32.145 And, you know, the the
NOTE Confidence: 0.9823312

00:17:32.145 --> 00:17:33.265 great thing about Canada is
NOTE Confidence: 0.9823312

00:17:33.265 --> 00:17:34.225 that, you know, it's so
NOTE Confidence: 0.9823312

00:17:34.225 --> 00:17:36.065 nice to everything is organized,
NOTE Confidence: 0.9823312

00:17:36.065 --> 00:17:37.425 and it's it's really easy
NOTE Confidence: 0.9823312

00:17:37.425 --> 00:17:38.725 to do some some research.
NOTE Confidence: 0.9823312

00:17:38.785 --> 00:17:40.465 So but, anyways, this is
NOTE Confidence: 0.9823312

00:17:40.465 --> 00:17:41.845 a Kaplan Meier curve,
NOTE Confidence: 0.98611796

00:17:42.705 --> 00:17:44.625 that looks at survival over
NOTE Confidence: 0.98611796

00:17:44.625 --> 00:17:45.890 time. So on the x
NOTE Confidence: 0.98611796

00:17:45.890 --> 00:17:47.270 axis, you have years,
NOTE Confidence: 0.9958447

00:17:47.730 --> 00:17:48.929 and on the y axis,

NOTE Confidence: 0.9958447

00:17:48.929 --> 00:17:50.230 you have percent survival.

NOTE Confidence: 0.9834101

00:17:51.010 --> 00:17:53.190 So first, you'll see that

NOTE Confidence: 0.9834101

00:17:53.330 --> 00:17:54.789 survival wasn't zero.

NOTE Confidence: 0.99645346

00:17:55.169 --> 00:17:56.210 It wasn't that it was

NOTE Confidence: 0.99645346

00:17:56.210 --> 00:17:57.890 lethal. It wasn't that all

NOTE Confidence: 0.99645346

00:17:57.890 --> 00:17:58.950 children died.

NOTE Confidence: 0.97983176

00:18:00.644 --> 00:18:01.845 So that was, you know,

NOTE Confidence: 0.97983176

00:18:01.845 --> 00:18:02.644 that I think that was

NOTE Confidence: 0.97983176

00:18:02.644 --> 00:18:03.304 the first

NOTE Confidence: 0.98148257

00:18:04.725 --> 00:18:06.164 kind of jarring moment for

NOTE Confidence: 0.98148257

00:18:06.164 --> 00:18:07.764 me in terms of what

NOTE Confidence: 0.98148257

00:18:07.764 --> 00:18:08.744 I had learned.

NOTE Confidence: 0.9945544

00:18:09.605 --> 00:18:10.184 And then

NOTE Confidence: 0.9442468

00:18:10.965 --> 00:18:12.570 bucking, you know, the recommendations

NOTE Confidence: 0.9442468

00:18:12.869 --> 00:18:14.330 that were in Smith's,

NOTE Confidence: 0.97215044

00:18:15.350 --> 00:18:16.250 genetics textbook,
NOTE Confidence: 0.9538041

00:18:16.630 --> 00:18:18.710 interventions were being offered, and
NOTE Confidence: 0.9538041

00:18:18.710 --> 00:18:20.070 they resulting and they were
NOTE Confidence: 0.9538041

00:18:20.070 --> 00:18:20.570 resulting
NOTE Confidence: 0.98997426

00:18:21.030 --> 00:18:22.730 in long term survival.
NOTE Confidence: 0.96843255

00:18:23.190 --> 00:18:24.230 I mean, you can see
NOTE Confidence: 0.96843255

00:18:24.230 --> 00:18:25.450 out to eleven years.
NOTE Confidence: 0.9666496

00:18:25.955 --> 00:18:26.455 So,
NOTE Confidence: 0.9742549

00:18:26.994 --> 00:18:28.595 so this this study showed
NOTE Confidence: 0.9742549

00:18:28.595 --> 00:18:29.095 that,
NOTE Confidence: 0.9549817

00:18:29.795 --> 00:18:32.055 about seventy percent of patients
NOTE Confidence: 0.9549817

00:18:32.115 --> 00:18:33.975 with trisomy thirteen and eighteen
NOTE Confidence: 0.9892378

00:18:34.355 --> 00:18:35.095 were surviving,
NOTE Confidence: 0.95213795

00:18:36.195 --> 00:18:37.715 were surviving their the first
NOTE Confidence: 0.95213795

00:18:37.715 --> 00:18:39.255 year after having surgery,
NOTE Confidence: 0.9995796

00:18:40.330 --> 00:18:41.609 and many of those were

NOTE Confidence: 0.9995796

00:18:41.609 --> 00:18:42.990 surviving beyond that.

NOTE Confidence: 0.99384576

00:18:48.889 --> 00:18:50.330 A second question comes up

NOTE Confidence: 0.99384576

00:18:50.330 --> 00:18:52.010 about, you know, why do

NOTE Confidence: 0.99384576

00:18:52.010 --> 00:18:53.789 so many children die

NOTE Confidence: 0.96643376

00:18:54.195 --> 00:18:55.875 in that first on that

NOTE Confidence: 0.96643376

00:18:55.875 --> 00:18:57.635 first day of life? So

NOTE Confidence: 0.96643376

00:18:57.635 --> 00:18:58.994 what what is what's behind

NOTE Confidence: 0.96643376

00:18:58.994 --> 00:18:59.815 all of that?

NOTE Confidence: 0.9962125

00:19:00.914 --> 00:19:02.135 And so this was

NOTE Confidence: 0.9672847

00:19:02.515 --> 00:19:03.475 a this was a,

NOTE Confidence: 0.98796034

00:19:04.195 --> 00:19:04.855 a recent,

NOTE Confidence: 0.982716

00:19:05.475 --> 00:19:06.674 analysis that was done out

NOTE Confidence: 0.982716

00:19:06.674 --> 00:19:07.414 of Cincinnati,

NOTE Confidence: 0.99286103

00:19:08.450 --> 00:19:09.730 and they were looking at

NOTE Confidence: 0.99286103

00:19:09.730 --> 00:19:11.570 neonatal and one year survival

NOTE Confidence: 0.99286103

00:19:11.570 --> 00:19:13.570 among neonates with trisomy thirteen

NOTE Confidence: 0.99286103

00:19:13.570 --> 00:19:14.310 and eighteen.

NOTE Confidence: 0.99477077

00:19:15.570 --> 00:19:17.730 And they were looking at

NOTE Confidence: 0.99477077

00:19:17.730 --> 00:19:18.950 their sort of region

NOTE Confidence: 0.95726204

00:19:19.490 --> 00:19:21.645 trying to limit ascertainment bias.

NOTE Confidence: 0.95726204

00:19:21.645 --> 00:19:22.785 So they also included

NOTE Confidence: 0.9858886

00:19:23.244 --> 00:19:24.385 their level four NICU.

NOTE Confidence: 0.9958302

00:19:24.845 --> 00:19:26.305 They had four level three,

NOTE Confidence: 0.9438572

00:19:27.485 --> 00:19:29.665 you know, NICUs and then

NOTE Confidence: 0.9438572

00:19:29.725 --> 00:19:30.465 some nurseries.

NOTE Confidence: 0.95596933

00:19:31.325 --> 00:19:32.765 And what they what they

NOTE Confidence: 0.95596933

00:19:33.085 --> 00:19:34.765 obviously, the number of children

NOTE Confidence: 0.95596933

00:19:34.765 --> 00:19:36.210 that serve, you know, survived

NOTE Confidence: 0.95596933

00:19:36.270 --> 00:19:37.550 to be born was was

NOTE Confidence: 0.95596933

00:19:37.550 --> 00:19:38.850 low. It was twenty five.

NOTE Confidence: 0.95596933

00:19:38.910 --> 00:19:39.870 But about half of the

NOTE Confidence: 0.95596933
00:19:39.870 --> 00:19:40.850 patients chose
NOTE Confidence: 0.9984183
00:19:41.390 --> 00:19:42.590 comfort care. So what is
NOTE Confidence: 0.9984183
00:19:42.590 --> 00:19:44.130 comfort care? Comfort care
NOTE Confidence: 0.99207723
00:19:44.510 --> 00:19:46.210 is basically any intervention
NOTE Confidence: 0.99566406
00:19:46.670 --> 00:19:48.350 that the goal is not
NOTE Confidence: 0.99566406
00:19:48.350 --> 00:19:49.170 to sustain
NOTE Confidence: 0.9978803
00:19:49.710 --> 00:19:51.515 life. Okay? So this would
NOTE Confidence: 0.9978803
00:19:51.515 --> 00:19:53.135 be defined as hospice care
NOTE Confidence: 0.9368252
00:19:53.595 --> 00:19:55.674 or any interventions that were
NOTE Confidence: 0.9368252
00:19:55.674 --> 00:19:57.355 provide relief for symptoms such
NOTE Confidence: 0.9368252
00:19:57.355 --> 00:19:59.195 as pain, agitation, air hunger,
NOTE Confidence: 0.9368252
00:19:59.195 --> 00:20:00.174 but not to prolong
NOTE Confidence: 0.9771136
00:20:00.554 --> 00:20:01.054 life.
NOTE Confidence: 0.9413274
00:20:01.515 --> 00:20:03.355 And the others chose some
NOTE Confidence: 0.9413274
00:20:03.355 --> 00:20:04.965 combination of either non,
NOTE Confidence: 0.88008404

00:20:07.169 --> 00:20:08.149 sorry, noninvasive
NOTE Confidence: 0.9949549

00:20:08.450 --> 00:20:10.390 or invasive life extending treatment.
NOTE Confidence: 0.97048664

00:20:10.770 --> 00:20:11.730 So if you look on
NOTE Confidence: 0.97048664

00:20:11.730 --> 00:20:12.470 this graph,
NOTE Confidence: 0.97732323

00:20:13.730 --> 00:20:14.529 oh, good. I have my
NOTE Confidence: 0.97732323

00:20:14.529 --> 00:20:16.230 pointer. So the green
NOTE Confidence: 0.93416965

00:20:16.609 --> 00:20:17.510 green represents,
NOTE Confidence: 0.9426223

00:20:18.625 --> 00:20:20.544 invasive intensive interventions or invasive
NOTE Confidence: 0.9426223

00:20:20.544 --> 00:20:21.424 interventions. So that would be,
NOTE Confidence: 0.9426223

00:20:21.424 --> 00:20:22.885 like, endotracheal intubation.
NOTE Confidence: 0.98798305

00:20:24.784 --> 00:20:25.984 And then the the the
NOTE Confidence: 0.98798305

00:20:25.984 --> 00:20:26.484 blue
NOTE Confidence: 0.95887375

00:20:26.945 --> 00:20:27.765 are noninvasive
NOTE Confidence: 0.9431688

00:20:28.225 --> 00:20:29.744 interventions that would be, like,
NOTE Confidence: 0.9431688

00:20:29.744 --> 00:20:31.205 providing nasal cannula.
NOTE Confidence: 0.97861356

00:20:32.600 --> 00:20:33.720 And then the red is

NOTE Confidence: 0.97861356
00:20:33.720 --> 00:20:34.220 really,
NOTE Confidence: 0.97370785
00:20:35.000 --> 00:20:35.740 not providing,
NOTE Confidence: 0.9613275
00:20:36.600 --> 00:20:37.880 those at all. So that
NOTE Confidence: 0.9613275
00:20:37.880 --> 00:20:39.080 would be, you know, like
NOTE Confidence: 0.9613275
00:20:39.080 --> 00:20:41.180 I said, medications for pain.
NOTE Confidence: 0.9613275
00:20:41.400 --> 00:20:42.840 And so what was what
NOTE Confidence: 0.9613275
00:20:42.840 --> 00:20:44.760 was notable is that the
NOTE Confidence: 0.9613275
00:20:44.760 --> 00:20:46.460 the babies that were resuscitated,
NOTE Confidence: 0.9677386
00:20:48.315 --> 00:20:50.255 had a much higher survival,
NOTE Confidence: 0.9980643
00:20:50.955 --> 00:20:52.635 and the the babies that
NOTE Confidence: 0.9980643
00:20:52.635 --> 00:20:53.135 weren't
NOTE Confidence: 0.92272884
00:20:53.515 --> 00:20:54.015 didn't.
NOTE Confidence: 0.9617925
00:20:55.195 --> 00:20:57.035 So and and, obviously, the
NOTE Confidence: 0.9617925
00:20:57.035 --> 00:20:58.395 red is the comfort care
NOTE Confidence: 0.9617925
00:20:58.395 --> 00:20:59.755 line. That was associated with
NOTE Confidence: 0.9617925

00:20:59.755 --> 00:21:00.895 the lowest survival.
NOTE Confidence: 0.94930637

00:21:02.980 --> 00:21:04.180 And the first curve, you
NOTE Confidence: 0.94930637

00:21:04.180 --> 00:21:05.700 know, initially looks out only
NOTE Confidence: 0.94930637

00:21:05.700 --> 00:21:07.060 to thirty day to thirty
NOTE Confidence: 0.94930637

00:21:07.060 --> 00:21:07.560 days,
NOTE Confidence: 0.9805729

00:21:07.940 --> 00:21:09.380 but the second curve looks
NOTE Confidence: 0.9805729

00:21:09.380 --> 00:21:09.859 out,
NOTE Confidence: 0.9822087

00:21:10.980 --> 00:21:12.420 out to one year. And
NOTE Confidence: 0.9822087

00:21:12.420 --> 00:21:13.800 you can see that those
NOTE Confidence: 0.93147075

00:21:14.565 --> 00:21:14.885 those,
NOTE Confidence: 0.99850416

00:21:16.484 --> 00:21:18.885 survival percentages kind of extend
NOTE Confidence: 0.99850416

00:21:18.885 --> 00:21:19.385 out.
NOTE Confidence: 0.9943115

00:21:19.924 --> 00:21:22.345 So it's not simply that,
NOTE Confidence: 0.97354686

00:21:22.725 --> 00:21:23.544 like, their
NOTE Confidence: 0.99265546

00:21:24.005 --> 00:21:25.445 children will just die when
NOTE Confidence: 0.99265546

00:21:25.445 --> 00:21:26.184 they're born,

NOTE Confidence: 0.9963053
00:21:26.644 --> 00:21:28.164 but it's that we're we're
NOTE Confidence: 0.9963053
00:21:28.164 --> 00:21:28.664 not
NOTE Confidence: 0.991271
00:21:29.240 --> 00:21:31.020 doing anything to kind of
NOTE Confidence: 0.991271
00:21:31.080 --> 00:21:33.000 keep them from dying. And
NOTE Confidence: 0.991271
00:21:33.000 --> 00:21:34.280 so, again, it's this kind
NOTE Confidence: 0.991271
00:21:34.280 --> 00:21:35.880 of futility argument. You know?
NOTE Confidence: 0.991271
00:21:35.880 --> 00:21:36.840 So if you if you
NOTE Confidence: 0.991271
00:21:36.840 --> 00:21:37.820 don't do anything,
NOTE Confidence: 0.99887276
00:21:38.359 --> 00:21:39.820 you know, then they probably
NOTE Confidence: 0.99887276
00:21:39.880 --> 00:21:41.100 will pass away.
NOTE Confidence: 0.91741973
00:21:43.365 --> 00:21:44.244 So this is gonna lead
NOTE Confidence: 0.91741973
00:21:44.244 --> 00:21:45.205 me to my my third
NOTE Confidence: 0.91741973
00:21:45.205 --> 00:21:46.645 Kaplan Meier curve and hopefully
NOTE Confidence: 0.91741973
00:21:46.645 --> 00:21:47.445 my last. But,
NOTE Confidence: 0.9281708
00:21:48.405 --> 00:21:49.605 but hopefully, it'll drive home
NOTE Confidence: 0.9281708

00:21:49.605 --> 00:21:51.205 the point. So this is,
NOTE Confidence: 0.99376476

00:21:52.165 --> 00:21:53.205 this is a study that
NOTE Confidence: 0.99376476

00:21:53.205 --> 00:21:54.585 I did in twenty seventeen,
NOTE Confidence: 0.96855515

00:21:55.045 --> 00:21:56.905 with colleagues from Arkansas Children's,
NOTE Confidence: 0.9735846

00:21:57.205 --> 00:21:58.790 and we looked, at the
NOTE Confidence: 0.9735846

00:21:58.790 --> 00:22:00.230 FIS database. So the FIS
NOTE Confidence: 0.9735846

00:22:00.230 --> 00:22:01.030 is a is a big
NOTE Confidence: 0.9735846

00:22:01.030 --> 00:22:02.710 billing database, and it includes
NOTE Confidence: 0.9735846

00:22:02.710 --> 00:22:04.170 a lot of children's hospitals.
NOTE Confidence: 0.9962244

00:22:05.190 --> 00:22:06.230 And we looked at data
NOTE Confidence: 0.9962244

00:22:06.230 --> 00:22:07.350 from two thousand four to
NOTE Confidence: 0.9962244

00:22:07.350 --> 00:22:08.170 twenty fifteen.
NOTE Confidence: 0.9435227

00:22:08.790 --> 00:22:09.910 We looked at children with
NOTE Confidence: 0.9435227

00:22:09.910 --> 00:22:11.270 trisomy thirteen and eighteen. We
NOTE Confidence: 0.9435227

00:22:11.270 --> 00:22:12.650 compared those that,
NOTE Confidence: 0.98334676

00:22:13.994 --> 00:22:15.595 had cardiac surgery and those

NOTE Confidence: 0.98334676
00:22:15.595 --> 00:22:17.695 that didn't. And it's similar,
NOTE Confidence: 0.98334676
00:22:17.835 --> 00:22:18.875 you know, it's a similar
NOTE Confidence: 0.98334676
00:22:18.875 --> 00:22:19.835 curve where you have,
NOTE Confidence: 0.98278403
00:22:20.475 --> 00:22:21.994 the you have survival on
NOTE Confidence: 0.98278403
00:22:21.994 --> 00:22:23.595 the y axis, and then
NOTE Confidence: 0.98278403
00:22:23.595 --> 00:22:24.335 you have,
NOTE Confidence: 0.9977743
00:22:25.035 --> 00:22:26.575 time on the x axis.
NOTE Confidence: 0.9851066
00:22:26.880 --> 00:22:27.920 And this is a little
NOTE Confidence: 0.9851066
00:22:27.920 --> 00:22:29.200 bit different. It's called freedom
NOTE Confidence: 0.9851066
00:22:29.200 --> 00:22:30.880 from in hospital mortality. And
NOTE Confidence: 0.9851066
00:22:30.880 --> 00:22:32.320 the reason that we can't
NOTE Confidence: 0.9851066
00:22:32.320 --> 00:22:34.000 say survival is because since
NOTE Confidence: 0.9851066
00:22:34.000 --> 00:22:35.440 it's a billing database, it
NOTE Confidence: 0.9851066
00:22:35.440 --> 00:22:37.040 only reflects what's happening in
NOTE Confidence: 0.9851066
00:22:37.040 --> 00:22:37.780 the hospital.
NOTE Confidence: 0.9959614

00:22:38.400 --> 00:22:38.900 Okay?
NOTE Confidence: 0.9983556

00:22:39.359 --> 00:22:40.240 But what was so
NOTE Confidence: 0.98915124

00:22:40.955 --> 00:22:42.234 again, what was so kind
NOTE Confidence: 0.98915124

00:22:42.234 --> 00:22:42.734 of,
NOTE Confidence: 0.97187763

00:22:43.275 --> 00:22:44.715 dramatic was there was a
NOTE Confidence: 0.97187763

00:22:44.715 --> 00:22:45.855 there was a difference
NOTE Confidence: 0.9652972

00:22:46.155 --> 00:22:47.055 when you compared,
NOTE Confidence: 0.9997862

00:22:48.315 --> 00:22:48.815 those
NOTE Confidence: 0.9994427

00:22:49.275 --> 00:22:50.815 children that had surgery
NOTE Confidence: 0.9982215

00:22:51.115 --> 00:22:52.815 versus those that had not.
NOTE Confidence: 0.999701

00:22:53.340 --> 00:22:53.840 So
NOTE Confidence: 0.9972362

00:22:54.299 --> 00:22:56.619 the mortality reduction following heart
NOTE Confidence: 0.9972362

00:22:56.619 --> 00:22:57.119 surgery,
NOTE Confidence: 0.9881846

00:22:58.220 --> 00:23:00.539 in trisomy thirteen was,
NOTE Confidence: 0.99764794

00:23:01.020 --> 00:23:02.960 thirty versus fifty five percent
NOTE Confidence: 0.95642436

00:23:03.500 --> 00:23:05.580 and then sixteen versus forty

NOTE Confidence: 0.95642436
00:23:05.580 --> 00:23:07.575 four percent in trisomy eighteen.
NOTE Confidence: 0.8438218
00:23:08.135 --> 00:23:09.914 So those are pretty stark,
NOTE Confidence: 0.97255564
00:23:10.375 --> 00:23:11.274 you know, differences.
NOTE Confidence: 0.9547404
00:23:12.294 --> 00:23:13.975 And so this this has
NOTE Confidence: 0.9547404
00:23:13.975 --> 00:23:14.715 kind of
NOTE Confidence: 0.9735465
00:23:15.174 --> 00:23:16.715 been this has actually
NOTE Confidence: 0.7886523
00:23:17.255 --> 00:23:17.755 been,
NOTE Confidence: 0.98366326
00:23:18.855 --> 00:23:19.994 repeated recently.
NOTE Confidence: 0.88424075
00:23:20.375 --> 00:23:21.174 So this was a,
NOTE Confidence: 0.9775518
00:23:23.059 --> 00:23:24.440 a paper that was published
NOTE Confidence: 0.9775518
00:23:24.660 --> 00:23:25.619 only, like, I think, a
NOTE Confidence: 0.9775518
00:23:25.619 --> 00:23:26.679 month or two ago,
NOTE Confidence: 0.82091624
00:23:26.980 --> 00:23:28.200 but basically just
NOTE Confidence: 0.988229
00:23:28.580 --> 00:23:29.960 looked further out,
NOTE Confidence: 0.9226674
00:23:31.140 --> 00:23:32.280 at the FIS database
NOTE Confidence: 0.78947467

00:23:33.220 --> 00:23:33.720 and
NOTE Confidence: 0.9962845

00:23:35.155 --> 00:23:35.975 kind of replicated
NOTE Confidence: 0.9995016

00:23:36.275 --> 00:23:36.934 the same
NOTE Confidence: 0.9901449

00:23:37.234 --> 00:23:38.675 the same information that we
NOTE Confidence: 0.9901449

00:23:38.675 --> 00:23:40.375 showed before, which was that,
NOTE Confidence: 0.98637605

00:23:41.155 --> 00:23:43.795 that survival was improved. But
NOTE Confidence: 0.98637605

00:23:43.795 --> 00:23:44.835 one of the, I think,
NOTE Confidence: 0.98637605

00:23:44.835 --> 00:23:46.275 the key points from from
NOTE Confidence: 0.98637605

00:23:46.275 --> 00:23:47.415 that paper
NOTE Confidence: 0.99960935

00:23:48.119 --> 00:23:48.859 was that
NOTE Confidence: 0.96299046

00:23:49.240 --> 00:23:50.200 you can if you look
NOTE Confidence: 0.96299046

00:23:50.200 --> 00:23:51.740 at especially for trisomy
NOTE Confidence: 0.99768835

00:23:52.040 --> 00:23:54.220 eighteen, the number of operations
NOTE Confidence: 0.99768835

00:23:54.440 --> 00:23:56.040 that are being performed is
NOTE Confidence: 0.99768835

00:23:56.040 --> 00:23:56.859 going up.
NOTE Confidence: 0.9985172

00:23:57.560 --> 00:23:59.500 So there was a change

NOTE Confidence: 0.9985172
00:23:59.720 --> 00:24:00.940 in terms of
NOTE Confidence: 0.94111884
00:24:02.015 --> 00:24:02.515 referrals,
NOTE Confidence: 0.9862264
00:24:02.894 --> 00:24:04.335 the number of referrals, the
NOTE Confidence: 0.9862264
00:24:04.335 --> 00:24:06.195 number of patients that were
NOTE Confidence: 0.9862264
00:24:06.255 --> 00:24:07.955 being put forward for surgery.
NOTE Confidence: 0.9924208
00:24:08.494 --> 00:24:10.015 Not such a big difference
NOTE Confidence: 0.9924208
00:24:10.015 --> 00:24:11.855 with trisomy thirteen, but it's
NOTE Confidence: 0.9924208
00:24:11.855 --> 00:24:13.315 still significant. So,
NOTE Confidence: 0.99153227
00:24:14.340 --> 00:24:16.100 in in twenty seventeen, the
NOTE Confidence: 0.99153227
00:24:16.100 --> 00:24:17.460 rate of surgical repair for
NOTE Confidence: 0.99153227
00:24:17.460 --> 00:24:19.220 both conditions was around seven
NOTE Confidence: 0.99153227
00:24:19.220 --> 00:24:19.720 percent.
NOTE Confidence: 0.9993781
00:24:20.419 --> 00:24:21.160 And then
NOTE Confidence: 0.9947334
00:24:21.539 --> 00:24:23.000 with this new data
NOTE Confidence: 0.8621936
00:24:23.380 --> 00:24:23.880 that,
NOTE Confidence: 0.9997428

00:24:25.299 --> 00:24:27.080 those percentages went up
NOTE Confidence: 0.98991066

00:24:27.705 --> 00:24:29.145 from seven percent to twelve
NOTE Confidence: 0.98991066

00:24:29.145 --> 00:24:30.684 percent in trisomy thirteen
NOTE Confidence: 0.9695084

00:24:31.225 --> 00:24:33.244 and seventeen percent in trisomy
NOTE Confidence: 0.9695084

00:24:33.385 --> 00:24:33.885 eighteen.
NOTE Confidence: 0.9940151

00:24:34.345 --> 00:24:34.825 And,
NOTE Confidence: 0.96191895

00:24:35.225 --> 00:24:36.365 for those of you,
NOTE Confidence: 0.9989369

00:24:37.304 --> 00:24:38.025 who are
NOTE Confidence: 0.9209252

00:24:41.279 --> 00:24:42.260 well, anyways, basically,
NOTE Confidence: 0.99843776

00:24:43.200 --> 00:24:44.019 there's a
NOTE Confidence: 0.9744978

00:24:44.320 --> 00:24:45.460 collection of,
NOTE Confidence: 0.9628681

00:24:46.240 --> 00:24:47.220 children's hospitals,
NOTE Confidence: 0.99981815

00:24:47.760 --> 00:24:48.260 that
NOTE Confidence: 0.98375934

00:24:49.119 --> 00:24:50.559 kind of give their data
NOTE Confidence: 0.98375934

00:24:50.559 --> 00:24:52.240 to a database called the
NOTE Confidence: 0.98375934

00:24:52.240 --> 00:24:54.019 Society for Thoracic Surgery.

NOTE Confidence: 0.99614656
00:24:54.320 --> 00:24:55.779 And so in that database,
NOTE Confidence: 0.9978675
00:24:56.975 --> 00:24:58.415 we know that seventy percent
NOTE Confidence: 0.9978675
00:24:58.415 --> 00:25:00.115 of hospitals in that database
NOTE Confidence: 0.9978675
00:25:00.255 --> 00:25:01.315 have performed surgery,
NOTE Confidence: 0.9970348
00:25:02.015 --> 00:25:03.475 for trisomy eighteen.
NOTE Confidence: 0.9913467
00:25:03.855 --> 00:25:05.875 So there's really this shift,
NOTE Confidence: 0.9888053
00:25:06.655 --> 00:25:08.675 that happened in the last,
NOTE Confidence: 0.83644944
00:25:09.230 --> 00:25:10.690 I would say, twenty years
NOTE Confidence: 0.9106661
00:25:11.230 --> 00:25:12.210 where survival
NOTE Confidence: 0.8980291
00:25:12.830 --> 00:25:13.330 depends.
NOTE Confidence: 0.9628266
00:25:15.150 --> 00:25:15.890 It is,
NOTE Confidence: 0.99544203
00:25:16.910 --> 00:25:18.350 it depends on, you know,
NOTE Confidence: 0.99544203
00:25:18.350 --> 00:25:20.050 the interventions that are provided.
NOTE Confidence: 0.99559736
00:25:20.830 --> 00:25:21.330 So,
NOTE Confidence: 0.9541855
00:25:22.109 --> 00:25:23.630 Mark said good ethics begins
NOTE Confidence: 0.9541855

00:25:23.630 --> 00:25:24.609 with good data.
NOTE Confidence: 0.98770714

00:25:25.184 --> 00:25:26.144 So, you know, this is,
NOTE Confidence: 0.98770714

00:25:26.144 --> 00:25:27.264 I think, the data to
NOTE Confidence: 0.98770714

00:25:27.264 --> 00:25:27.764 support,
NOTE Confidence: 0.95098644

00:25:29.184 --> 00:25:30.865 these, new out these new
NOTE Confidence: 0.95098644

00:25:30.865 --> 00:25:31.924 survival estimates.
NOTE Confidence: 0.9799508

00:25:33.345 --> 00:25:33.845 And
NOTE Confidence: 0.8977655

00:25:34.705 --> 00:25:35.205 so,
NOTE Confidence: 0.97899246

00:25:36.304 --> 00:25:37.264 there have been some other
NOTE Confidence: 0.97899246

00:25:37.264 --> 00:25:38.384 studies that I think are
NOTE Confidence: 0.97899246

00:25:38.384 --> 00:25:40.350 helpful too, when thinking about
NOTE Confidence: 0.97899246

00:25:40.350 --> 00:25:41.410 this. So this is,
NOTE Confidence: 0.97897005

00:25:42.109 --> 00:25:43.490 a study that was,
NOTE Confidence: 0.98717856

00:25:44.270 --> 00:25:45.950 published from the Society for
NOTE Confidence: 0.98717856

00:25:45.950 --> 00:25:48.130 Thoracic Surgery, which found that
NOTE Confidence: 0.98717856

00:25:48.270 --> 00:25:50.190 survival after cardiac surgery was

NOTE Confidence: 0.98717856

00:25:50.190 --> 00:25:51.310 about eighty five to eighty

NOTE Confidence: 0.98717856

00:25:51.310 --> 00:25:52.050 nine percent

NOTE Confidence: 0.9941858

00:25:52.575 --> 00:25:54.174 versus ninety seven percent in

NOTE Confidence: 0.9941858

00:25:54.174 --> 00:25:55.695 children that did not have

NOTE Confidence: 0.9941858

00:25:55.695 --> 00:25:56.674 a genetic syndrome.

NOTE Confidence: 0.9951296

00:25:57.215 --> 00:25:58.575 And then up the street,

NOTE Confidence: 0.9951296

00:25:58.575 --> 00:26:00.274 we have Boston Children's Hospital,

NOTE Confidence: 0.98130614

00:26:01.215 --> 00:26:02.654 that reported a ninety four

NOTE Confidence: 0.98130614

00:26:02.654 --> 00:26:04.095 percent thirty day post op

NOTE Confidence: 0.98130614

00:26:04.095 --> 00:26:04.595 survival

NOTE Confidence: 0.9579308

00:26:05.040 --> 00:26:06.320 and a seventy nine percent

NOTE Confidence: 0.9579308

00:26:06.320 --> 00:26:06.640 one,

NOTE Confidence: 0.9592274

00:26:07.280 --> 00:26:08.800 seventy nine percent survival up

NOTE Confidence: 0.9592274

00:26:08.800 --> 00:26:10.100 to one year in operated

NOTE Confidence: 0.9592274

00:26:10.240 --> 00:26:12.000 versus fifty two percent in

NOTE Confidence: 0.9592274

00:26:12.000 --> 00:26:12.500 nonoperated
NOTE Confidence: 0.9989305

00:26:12.880 --> 00:26:13.380 patients.
NOTE Confidence: 0.97686136

00:26:14.000 --> 00:26:14.500 So,
NOTE Confidence: 0.9671438

00:26:16.320 --> 00:26:17.360 all of these things, you
NOTE Confidence: 0.9671438

00:26:17.360 --> 00:26:18.400 know, have been coming out
NOTE Confidence: 0.9671438

00:26:18.400 --> 00:26:19.760 and it and it I
NOTE Confidence: 0.9671438

00:26:19.760 --> 00:26:20.500 think it
NOTE Confidence: 0.9447178

00:26:21.005 --> 00:26:21.505 behooved
NOTE Confidence: 0.9997337

00:26:22.365 --> 00:26:23.265 our community
NOTE Confidence: 0.9987878

00:26:23.885 --> 00:26:25.425 to respond to,
NOTE Confidence: 0.97299

00:26:26.205 --> 00:26:28.205 to these these changing survival
NOTE Confidence: 0.97299

00:26:28.205 --> 00:26:29.805 outcomes and also to provide
NOTE Confidence: 0.97299

00:26:29.805 --> 00:26:31.345 some guidance to physicians
NOTE Confidence: 0.98127514

00:26:31.965 --> 00:26:32.465 who
NOTE Confidence: 0.99880666

00:26:33.320 --> 00:26:34.859 weren't sure about
NOTE Confidence: 0.99969816

00:26:35.320 --> 00:26:35.820 how

NOTE Confidence: 0.97338456
00:26:36.760 --> 00:26:38.380 to maybe counsel a family
NOTE Confidence: 0.9871672
00:26:38.760 --> 00:26:40.119 or, you know, what was
NOTE Confidence: 0.9871672
00:26:40.119 --> 00:26:41.420 gonna be their guiding principles.
NOTE Confidence: 0.9871672
00:26:41.640 --> 00:26:42.380 And so,
NOTE Confidence: 0.93967843
00:26:42.920 --> 00:26:43.420 earlier,
NOTE Confidence: 0.9992547
00:26:44.760 --> 00:26:45.580 this year,
NOTE Confidence: 0.99494195
00:26:46.784 --> 00:26:49.125 the American Academy of Thoracic
NOTE Confidence: 0.99494195
00:26:49.184 --> 00:26:49.684 Surgery,
NOTE Confidence: 0.97433436
00:26:50.384 --> 00:26:52.244 published this consensus guideline,
NOTE Confidence: 0.99946445
00:26:52.865 --> 00:26:54.644 which provided recommendations
NOTE Confidence: 0.9588724
00:26:55.105 --> 00:26:57.105 for the care of children
NOTE Confidence: 0.9588724
00:26:57.105 --> 00:26:58.625 with trisomy thirteen eighteen and
NOTE Confidence: 0.9588724
00:26:58.625 --> 00:27:00.625 congenital heart disease. And the
NOTE Confidence: 0.9588724
00:27:00.625 --> 00:27:01.125 first
NOTE Confidence: 0.983496
00:27:01.609 --> 00:27:03.210 the first recommendation was that
NOTE Confidence: 0.983496

00:27:03.210 --> 00:27:04.910 cardiac surgery is reasonable,

NOTE Confidence: 0.98767555

00:27:06.170 --> 00:27:07.070 if the,

NOTE Confidence: 0.98483807

00:27:07.690 --> 00:27:09.369 consequences of that heart disease

NOTE Confidence: 0.98483807

00:27:09.369 --> 00:27:11.130 prohibit discharge from the hospital

NOTE Confidence: 0.98483807

00:27:11.130 --> 00:27:11.869 or NICU.

NOTE Confidence: 0.9669911

00:27:12.490 --> 00:27:13.869 And second, that

NOTE Confidence: 0.99963284

00:27:14.175 --> 00:27:15.955 timely surgery is reasonable

NOTE Confidence: 0.9560135

00:27:16.495 --> 00:27:18.415 in infants and children who,

NOTE Confidence: 0.9503403

00:27:18.735 --> 00:27:19.935 were at home or need

NOTE Confidence: 0.9503403

00:27:19.935 --> 00:27:22.015 recurrent hospitalization. So this was

NOTE Confidence: 0.9503403

00:27:22.015 --> 00:27:23.055 the first time we were

NOTE Confidence: 0.9503403

00:27:23.055 --> 00:27:23.555 actually

NOTE Confidence: 0.98862094

00:27:24.575 --> 00:27:26.415 saying something very different from

NOTE Confidence: 0.98862094

00:27:26.415 --> 00:27:26.915 what,

NOTE Confidence: 0.9830779

00:27:27.950 --> 00:27:28.910 Smith's what, you know, what

NOTE Confidence: 0.9830779

00:27:28.910 --> 00:27:30.030 was published in Smith's or

NOTE Confidence: 0.9830779

00:27:30.030 --> 00:27:31.070 what had been sort of

NOTE Confidence: 0.9830779

00:27:31.070 --> 00:27:31.570 the

NOTE Confidence: 0.99165446

00:27:32.350 --> 00:27:34.270 the go to wisdom, which

NOTE Confidence: 0.99165446

00:27:34.270 --> 00:27:35.390 was that, you know, we're

NOTE Confidence: 0.99165446

00:27:35.390 --> 00:27:36.530 not gonna do anything,

NOTE Confidence: 0.99589777

00:27:37.230 --> 00:27:38.369 and that sort

NOTE Confidence: 0.95117784

00:27:39.550 --> 00:27:40.750 of further that sort of

NOTE Confidence: 0.95117784

00:27:40.750 --> 00:27:42.050 self fulfilling prophecy.

NOTE Confidence: 0.99212736

00:27:44.615 --> 00:27:46.774 So when families ask me

NOTE Confidence: 0.99212736

00:27:46.774 --> 00:27:47.595 about survival,

NOTE Confidence: 0.9995529

00:27:48.774 --> 00:27:50.375 I tell them about these

NOTE Confidence: 0.9995529

00:27:50.375 --> 00:27:50.875 changes

NOTE Confidence: 0.9970064

00:27:51.654 --> 00:27:53.515 and about possible outcomes.

NOTE Confidence: 0.9411402

00:27:55.510 --> 00:27:57.289 I don't make sweeping recommendations

NOTE Confidence: 0.9411402

00:27:57.429 --> 00:27:58.869 that all children should have

NOTE Confidence: 0.9411402

00:27:58.869 --> 00:28:00.410 surgery, but I at least
NOTE Confidence: 0.9411402

00:28:00.590 --> 00:28:01.770 am transparent
NOTE Confidence: 0.99982893

00:28:02.230 --> 00:28:02.730 about
NOTE Confidence: 0.9998319

00:28:03.030 --> 00:28:03.850 what has
NOTE Confidence: 0.9996678

00:28:04.390 --> 00:28:06.150 changed over the past twenty
NOTE Confidence: 0.9996678

00:28:06.150 --> 00:28:06.650 years.
NOTE Confidence: 0.9345256

00:28:08.355 --> 00:28:09.635 Now I know that not
NOTE Confidence: 0.9345256

00:28:09.635 --> 00:28:11.475 everybody agrees with me, and,
NOTE Confidence: 0.99208254

00:28:12.115 --> 00:28:13.795 and some people have, you
NOTE Confidence: 0.99208254

00:28:13.795 --> 00:28:15.795 know, some questions about quality
NOTE Confidence: 0.99208254

00:28:15.795 --> 00:28:16.455 of life.
NOTE Confidence: 0.99633026

00:28:16.994 --> 00:28:18.195 And so that's gonna that's
NOTE Confidence: 0.99633026

00:28:18.195 --> 00:28:19.315 gonna get to my next
NOTE Confidence: 0.99633026

00:28:19.315 --> 00:28:19.815 case.
NOTE Confidence: 0.99840236

00:28:20.970 --> 00:28:22.350 So case number two
NOTE Confidence: 0.97562367

00:28:22.970 --> 00:28:24.490 is here's another couple who

NOTE Confidence: 0.97562367

00:28:24.490 --> 00:28:25.530 has a baby who's been

NOTE Confidence: 0.97562367

00:28:25.530 --> 00:28:26.890 diagnosed with a VSD, but

NOTE Confidence: 0.97562367

00:28:26.890 --> 00:28:28.010 this time, they also have

NOTE Confidence: 0.97562367

00:28:28.010 --> 00:28:29.450 something called coarctation of the

NOTE Confidence: 0.97562367

00:28:29.450 --> 00:28:31.530 aorta. And so coarctation of

NOTE Confidence: 0.97562367

00:28:31.530 --> 00:28:33.050 the aorta is when the

NOTE Confidence: 0.97562367

00:28:33.050 --> 00:28:34.350 main artery,

NOTE Confidence: 0.9888147

00:28:35.130 --> 00:28:36.875 that takes blood to your

NOTE Confidence: 0.9888147

00:28:36.875 --> 00:28:38.315 body from your heart is

NOTE Confidence: 0.9888147

00:28:38.315 --> 00:28:39.535 narrow or obstructed,

NOTE Confidence: 0.9983171

00:28:40.235 --> 00:28:41.375 and it's a surgical,

NOTE Confidence: 0.9996708

00:28:41.835 --> 00:28:43.215 it's a surgical problem.

NOTE Confidence: 0.9627595

00:28:44.235 --> 00:28:45.515 The VSD is large and

NOTE Confidence: 0.9627595

00:28:45.515 --> 00:28:46.635 the aortic arch is small

NOTE Confidence: 0.9627595

00:28:46.635 --> 00:28:48.655 and likely will require surgical

NOTE Confidence: 0.9627595

00:28:48.715 --> 00:28:49.215 repair.
NOTE Confidence: 0.99960333

00:28:49.620 --> 00:28:50.420 So they would like to
NOTE Confidence: 0.99960333

00:28:50.420 --> 00:28:52.260 know the options available after
NOTE Confidence: 0.99960333

00:28:52.260 --> 00:28:52.760 birth.
NOTE Confidence: 0.98618025

00:28:54.580 --> 00:28:56.100 So right now, we don't
NOTE Confidence: 0.98618025

00:28:56.100 --> 00:28:57.160 really understand
NOTE Confidence: 0.9781363

00:28:57.860 --> 00:28:59.800 the practice patterns of pediatric
NOTE Confidence: 0.9781363

00:28:59.940 --> 00:29:00.440 cardiologists
NOTE Confidence: 0.9556133

00:29:01.300 --> 00:29:03.160 when they're providing prenatal counseling,
NOTE Confidence: 0.96469474

00:29:03.864 --> 00:29:04.324 in,
NOTE Confidence: 0.9202591

00:29:04.784 --> 00:29:07.083 trisomy thirteen eighteen in congenital
NOTE Confidence: 0.9202591

00:29:07.083 --> 00:29:08.463 heart disease. So,
NOTE Confidence: 0.8222242

00:29:08.923 --> 00:29:10.302 I I mean
NOTE Confidence: 0.9929581

00:29:10.762 --> 00:29:13.061 and I was curious about
NOTE Confidence: 0.9929581

00:29:13.061 --> 00:29:13.981 it. So,
NOTE Confidence: 0.98881686

00:29:14.440 --> 00:29:16.280 so I worked with,

NOTE Confidence: 0.98274523

00:29:16.740 --> 00:29:17.860 I was I worked with

NOTE Confidence: 0.98274523

00:29:17.860 --> 00:29:19.300 a group in Utah, and

NOTE Confidence: 0.98274523

00:29:19.300 --> 00:29:20.340 then I was also supported

NOTE Confidence: 0.98274523

00:29:20.340 --> 00:29:21.640 by the fetal heart society

NOTE Confidence: 0.98274523

00:29:21.700 --> 00:29:22.760 to do a survey

NOTE Confidence: 0.9987597

00:29:23.460 --> 00:29:25.400 that would try to investigate

NOTE Confidence: 0.9987597

00:29:25.700 --> 00:29:27.080 these practice patterns.

NOTE Confidence: 0.9844387

00:29:27.860 --> 00:29:29.140 And so what we did

NOTE Confidence: 0.9844387

00:29:29.140 --> 00:29:30.760 was we we surveyed pediatric

NOTE Confidence: 0.9844387

00:29:30.900 --> 00:29:31.400 cardiologists,

NOTE Confidence: 0.97094506

00:29:32.135 --> 00:29:33.255 and we asked them how

NOTE Confidence: 0.97094506

00:29:33.255 --> 00:29:34.235 would they counsel,

NOTE Confidence: 0.9422086

00:29:36.055 --> 00:29:37.115 how would they counsel,

NOTE Confidence: 0.91390574

00:29:37.975 --> 00:29:39.995 a family whose baby had

NOTE Confidence: 0.91390574

00:29:40.055 --> 00:29:41.675 a large VST and coarctation,

NOTE Confidence: 0.95599234

00:29:42.375 --> 00:29:44.455 but then we we presented
NOTE Confidence: 0.95599234

00:29:44.455 --> 00:29:46.350 them with the scenario but
NOTE Confidence: 0.95599234

00:29:46.350 --> 00:29:48.450 changed the genetic diagnosis. So,
NOTE Confidence: 0.94908834

00:29:48.990 --> 00:29:50.270 they were presented with two
NOTE Confidence: 0.94908834

00:29:50.270 --> 00:29:52.190 scenarios, the same congenital heart
NOTE Confidence: 0.94908834

00:29:52.190 --> 00:29:53.870 disease, but the first one
NOTE Confidence: 0.94908834

00:29:53.870 --> 00:29:55.470 would have trisomy eighteen and
NOTE Confidence: 0.94908834

00:29:55.470 --> 00:29:56.350 the second one would have
NOTE Confidence: 0.94908834

00:29:56.350 --> 00:29:58.345 trisomy twenty one. And we
NOTE Confidence: 0.94908834

00:29:58.345 --> 00:29:59.325 basically hypothesized
NOTE Confidence: 0.99671954

00:29:59.625 --> 00:30:00.845 that, you know,
NOTE Confidence: 0.9505688

00:30:01.225 --> 00:30:03.005 they would provide variable counseling,
NOTE Confidence: 0.98955584

00:30:03.544 --> 00:30:05.404 and they would that variability
NOTE Confidence: 0.99914336

00:30:05.705 --> 00:30:07.085 would be driven by,
NOTE Confidence: 0.9559107

00:30:08.025 --> 00:30:09.784 you know, various factors, genetic
NOTE Confidence: 0.9559107

00:30:09.784 --> 00:30:11.485 diagnosis being the most important.

NOTE Confidence: 0.9764447

00:30:12.360 --> 00:30:14.280 And then other factors would

NOTE Confidence: 0.9764447

00:30:14.280 --> 00:30:15.640 be survival and then the

NOTE Confidence: 0.9764447

00:30:15.640 --> 00:30:16.760 presence of the type of

NOTE Confidence: 0.9764447

00:30:16.760 --> 00:30:18.360 heart lesion and the presence

NOTE Confidence: 0.9764447

00:30:18.360 --> 00:30:19.340 of other noncardiac

NOTE Confidence: 0.9977778

00:30:19.640 --> 00:30:20.140 lesions.

NOTE Confidence: 0.9870291

00:30:21.720 --> 00:30:22.840 So about a hundred and

NOTE Confidence: 0.9870291

00:30:22.840 --> 00:30:24.760 forty two pediatric cardiologists responded,

NOTE Confidence: 0.9870291

00:30:24.760 --> 00:30:26.140 which I think is actually

NOTE Confidence: 0.99437296

00:30:26.785 --> 00:30:27.525 pretty amazing.

NOTE Confidence: 0.9867433

00:30:28.465 --> 00:30:29.685 Most of them were representing

NOTE Confidence: 0.9867433

00:30:29.825 --> 00:30:30.805 academic centers.

NOTE Confidence: 0.9894394

00:30:31.505 --> 00:30:32.705 So on the y axis,

NOTE Confidence: 0.9894394

00:30:32.705 --> 00:30:33.765 you have the percentages,

NOTE Confidence: 0.96543187

00:30:34.545 --> 00:30:35.585 of of folks,

NOTE Confidence: 0.9612605

00:30:36.145 --> 00:30:37.445 in terms of their response.
NOTE Confidence: 0.9984874

00:30:37.905 --> 00:30:39.205 And then on the
NOTE Confidence: 0.9962872

00:30:39.505 --> 00:30:40.065 on the
NOTE Confidence: 0.9939159

00:30:40.625 --> 00:30:41.925 so the the tables,
NOTE Confidence: 0.93584025

00:30:43.640 --> 00:30:44.600 or not the table. Excuse
NOTE Confidence: 0.93584025

00:30:44.600 --> 00:30:46.140 me. These bar graph represent
NOTE Confidence: 0.93584025

00:30:46.200 --> 00:30:47.559 the answer to the question,
NOTE Confidence: 0.93584025

00:30:47.559 --> 00:30:48.220 which is,
NOTE Confidence: 0.9985845

00:30:49.240 --> 00:30:50.460 would you discuss
NOTE Confidence: 0.99758476

00:30:51.240 --> 00:30:52.940 postnatal cardiac surgery
NOTE Confidence: 0.9952399

00:30:53.240 --> 00:30:54.600 with the family during your
NOTE Confidence: 0.9952399

00:30:54.600 --> 00:30:55.740 prenatal consultation?
NOTE Confidence: 0.99911684

00:30:57.075 --> 00:30:57.235 So
NOTE Confidence: 0.93995816

00:30:57.875 --> 00:31:00.135 and the blue represents trisomy
NOTE Confidence: 0.93995816

00:31:00.274 --> 00:31:02.054 eighteen, and the orange represents
NOTE Confidence: 0.93995816

00:31:02.115 --> 00:31:03.875 trisomy twenty one. So the

NOTE Confidence: 0.93995816
00:31:03.875 --> 00:31:05.315 first column is those patients
NOTE Confidence: 0.93995816
00:31:05.315 --> 00:31:06.755 who said yes or sorry,
NOTE Confidence: 0.93995816
00:31:06.755 --> 00:31:08.115 not the patient. Sorry. Those
NOTE Confidence: 0.93995816
00:31:08.115 --> 00:31:09.715 physicians who said yes, I
NOTE Confidence: 0.93995816
00:31:09.715 --> 00:31:11.575 would discuss postnatal surgery.
NOTE Confidence: 0.89025766
00:31:12.990 --> 00:31:14.210 The second column,
NOTE Confidence: 0.9823863
00:31:14.830 --> 00:31:16.450 represents those that would not.
NOTE Confidence: 0.9631886
00:31:16.830 --> 00:31:18.350 And so that's about sixteen
NOTE Confidence: 0.9631886
00:31:18.350 --> 00:31:19.490 percent of all respondents,
NOTE Confidence: 0.9929473
00:31:19.950 --> 00:31:21.470 and about twenty percent were
NOTE Confidence: 0.9929473
00:31:21.470 --> 00:31:21.970 unsure.
NOTE Confidence: 0.9963246
00:31:23.150 --> 00:31:23.650 And
NOTE Confidence: 0.98528975
00:31:23.950 --> 00:31:26.130 compared to trisomy twenty one,
NOTE Confidence: 0.98545086
00:31:26.684 --> 00:31:27.565 you can see there's a
NOTE Confidence: 0.98545086
00:31:27.565 --> 00:31:29.245 difference. So for trisomy twenty
NOTE Confidence: 0.98545086

00:31:29.245 --> 00:31:30.865 one, it's nearly unanimously
NOTE Confidence: 0.9856813

00:31:31.485 --> 00:31:32.924 recommended, and I don't think
NOTE Confidence: 0.9856813

00:31:32.924 --> 00:31:34.385 there would be any cardiologist
NOTE Confidence: 0.9856813

00:31:34.605 --> 00:31:35.965 who wouldn't, though we did
NOTE Confidence: 0.9856813

00:31:35.965 --> 00:31:37.085 have one. So I'm not
NOTE Confidence: 0.9856813

00:31:37.085 --> 00:31:38.065 exactly sure
NOTE Confidence: 0.9753695

00:31:38.684 --> 00:31:39.885 how that all shakes out.
NOTE Confidence: 0.9753695

00:31:39.885 --> 00:31:40.125 But,
NOTE Confidence: 0.997206

00:31:41.570 --> 00:31:42.210 you know, you can see
NOTE Confidence: 0.997206

00:31:42.210 --> 00:31:43.170 there's a big there's a
NOTE Confidence: 0.997206

00:31:43.170 --> 00:31:43.910 big difference.
NOTE Confidence: 0.75735

00:31:45.063 --> 00:31:45.563 At
NOTE Confidence: 0.9978409

00:31:46.130 --> 00:31:47.270 in twenty thirteen,
NOTE Confidence: 0.9807212

00:31:47.730 --> 00:31:49.410 the same kind of question
NOTE Confidence: 0.9807212

00:31:49.410 --> 00:31:51.110 was posed to pediatric cardiologists,
NOTE Confidence: 0.9868588

00:31:51.890 --> 00:31:53.650 and the number was about

NOTE Confidence: 0.9868588

00:31:53.650 --> 00:31:55.325 a third who would discuss.

NOTE Confidence: 0.9868588

00:31:55.325 --> 00:31:56.285 So you can see that

NOTE Confidence: 0.9868588

00:31:56.285 --> 00:31:57.245 there is there is a

NOTE Confidence: 0.9868588

00:31:57.245 --> 00:31:58.445 change, but there's still quite

NOTE Confidence: 0.9868588

00:31:58.445 --> 00:31:59.345 a bit of variability.

NOTE Confidence: 0.98221713

00:32:00.685 --> 00:32:01.965 Now I don't want to

NOTE Confidence: 0.98221713

00:32:01.965 --> 00:32:03.725 equivocate trisomy twenty one and

NOTE Confidence: 0.98221713

00:32:03.725 --> 00:32:05.565 trisomy thirteen eighteen. They're very

NOTE Confidence: 0.98221713

00:32:05.565 --> 00:32:07.025 different conditions, but

NOTE Confidence: 0.9888763

00:32:07.325 --> 00:32:08.970 there are parallels that you

NOTE Confidence: 0.9888763

00:32:08.970 --> 00:32:10.350 can draw between the two.

NOTE Confidence: 0.9888763

00:32:10.490 --> 00:32:11.690 So and I think the

NOTE Confidence: 0.9888763

00:32:11.690 --> 00:32:13.370 the one that, to me

NOTE Confidence: 0.9888763

00:32:13.370 --> 00:32:14.750 is the most, I guess,

NOTE Confidence: 0.9893101

00:32:15.610 --> 00:32:17.130 the similar sort of narrative

NOTE Confidence: 0.9893101

00:32:17.130 --> 00:32:18.010 is that there was a
NOTE Confidence: 0.9893101

00:32:18.010 --> 00:32:19.450 time where we'd never operated
NOTE Confidence: 0.9893101

00:32:19.450 --> 00:32:20.670 on babies with trisomy,
NOTE Confidence: 0.9824926

00:32:21.690 --> 00:32:23.274 twenty one. And,
NOTE Confidence: 0.96087694

00:32:23.654 --> 00:32:25.015 and I think, you know
NOTE Confidence: 0.96087694

00:32:25.095 --> 00:32:25.595 and
NOTE Confidence: 0.981844

00:32:26.135 --> 00:32:27.495 and when we when we
NOTE Confidence: 0.981844

00:32:27.495 --> 00:32:28.934 started to operate on them
NOTE Confidence: 0.981844

00:32:28.934 --> 00:32:30.635 and we saw the improvement
NOTE Confidence: 0.981844

00:32:30.695 --> 00:32:31.735 in terms of, you know,
NOTE Confidence: 0.981844

00:32:31.735 --> 00:32:33.894 pulmonary hypertension or specific outcomes
NOTE Confidence: 0.981844

00:32:33.894 --> 00:32:35.750 related to control heart surgery,
NOTE Confidence: 0.981844

00:32:35.750 --> 00:32:36.789 you know, it became very
NOTE Confidence: 0.981844

00:32:36.789 --> 00:32:38.390 obvious that it was,
NOTE Confidence: 0.9988126

00:32:40.309 --> 00:32:41.429 it was it was what
NOTE Confidence: 0.9988126

00:32:41.429 --> 00:32:42.630 we should be doing. In

NOTE Confidence: 0.9988126
00:32:42.630 --> 00:32:43.130 fact,
NOTE Confidence: 0.98480594
00:32:43.830 --> 00:32:45.929 with trisomy twenty one, outcomes
NOTE Confidence: 0.9739977
00:32:46.390 --> 00:32:48.470 with respect to complete AV
NOTE Confidence: 0.9739977
00:32:48.470 --> 00:32:49.429 canal repair, which is a
NOTE Confidence: 0.9739977
00:32:49.429 --> 00:32:50.955 very common lesion that these
NOTE Confidence: 0.9739977
00:32:50.955 --> 00:32:53.055 babies have, was actually superior,
NOTE Confidence: 0.95853794
00:32:54.315 --> 00:32:54.815 than,
NOTE Confidence: 0.98155844
00:32:55.434 --> 00:32:57.195 children with complete AV canal
NOTE Confidence: 0.98155844
00:32:57.195 --> 00:32:58.395 repair who did not have
NOTE Confidence: 0.98155844
00:32:58.395 --> 00:32:59.515 trisomy twenty one. So their
NOTE Confidence: 0.98155844
00:32:59.515 --> 00:33:01.135 surgical outcomes were actually better,
NOTE Confidence: 0.99157655
00:33:01.515 --> 00:33:02.555 but we would have never
NOTE Confidence: 0.99157655
00:33:02.555 --> 00:33:04.155 known that had we, you
NOTE Confidence: 0.99157655
00:33:04.155 --> 00:33:05.295 know, not tried.
NOTE Confidence: 0.93977195
00:33:07.130 --> 00:33:08.890 So why the differing opinions
NOTE Confidence: 0.93977195

00:33:08.890 --> 00:33:10.030 in variable counseling?
NOTE Confidence: 0.984157

00:33:10.890 --> 00:33:12.090 So I'm gonna use the
NOTE Confidence: 0.984157

00:33:12.090 --> 00:33:13.789 next two cases to,
NOTE Confidence: 0.9974439

00:33:14.410 --> 00:33:14.910 highlight,
NOTE Confidence: 0.9979748

00:33:16.410 --> 00:33:16.990 you know,
NOTE Confidence: 0.9825756

00:33:17.850 --> 00:33:19.470 what what the objective
NOTE Confidence: 0.98098403

00:33:19.770 --> 00:33:22.355 criteria and also some subjective
NOTE Confidence: 0.98098403

00:33:22.355 --> 00:33:23.495 criteria about
NOTE Confidence: 0.97776073

00:33:23.875 --> 00:33:25.955 why the why why there's
NOTE Confidence: 0.97776073

00:33:25.955 --> 00:33:26.775 variable counseling.
NOTE Confidence: 0.9965279

00:33:27.555 --> 00:33:28.435 So this is case number
NOTE Confidence: 0.9965279

00:33:28.435 --> 00:33:29.635 three. A mother carrying a
NOTE Confidence: 0.9965279

00:33:29.635 --> 00:33:31.795 fetus with suspected trisomy thirteen
NOTE Confidence: 0.9965279

00:33:31.795 --> 00:33:32.855 has declined amniocentesis
NOTE Confidence: 0.9841617

00:33:33.235 --> 00:33:34.275 and is committed to the
NOTE Confidence: 0.9841617

00:33:34.275 --> 00:33:34.775 pregnancy.

NOTE Confidence: 0.99940467

00:33:35.429 --> 00:33:36.570 At twenty one weeks,

NOTE Confidence: 0.98598456

00:33:37.190 --> 00:33:39.110 fetal echo reveals a complex

NOTE Confidence: 0.98598456

00:33:39.110 --> 00:33:41.669 cardiac lesion, including single ventricle

NOTE Confidence: 0.98598456

00:33:41.669 --> 00:33:43.370 with an interrupted aortic arch.

NOTE Confidence: 0.9980028

00:33:43.830 --> 00:33:45.850 During counseling, the pediatric cardiologist

NOTE Confidence: 0.9980028

00:33:45.990 --> 00:33:47.924 informs her that cardiac surgery

NOTE Confidence: 0.9980028

00:33:47.924 --> 00:33:48.745 slash palliation

NOTE Confidence: 0.98783773

00:33:49.125 --> 00:33:50.565 is not recommended for infants

NOTE Confidence: 0.98783773

00:33:50.565 --> 00:33:52.424 with trisomy thirteen and eighteen

NOTE Confidence: 0.98783773

00:33:52.485 --> 00:33:54.505 with complex congenital heart disease.

NOTE Confidence: 0.98783773

00:33:54.725 --> 00:33:56.424 Family opted for comfort care

NOTE Confidence: 0.98783773

00:33:56.485 --> 00:33:57.865 with the exception of prostaglandin

NOTE Confidence: 0.98783773

00:33:58.164 --> 00:33:59.784 and certain neonatal interventions,

NOTE Confidence: 0.9997601

00:34:00.085 --> 00:34:01.445 which would allow for additional

NOTE Confidence: 0.9997601

00:34:01.445 --> 00:34:02.985 time together after birth.

NOTE Confidence: 0.9749954

00:34:04.940 --> 00:34:06.060 So in the same survey,
NOTE Confidence: 0.9749954

00:34:06.060 --> 00:34:07.820 we asked pediatric cardiologists if
NOTE Confidence: 0.9749954

00:34:07.820 --> 00:34:09.739 there were certain cardiac lesions
NOTE Confidence: 0.9749954

00:34:09.739 --> 00:34:11.020 they would not recommend for
NOTE Confidence: 0.9749954

00:34:11.020 --> 00:34:12.000 surgical repair.
NOTE Confidence: 0.9948127

00:34:12.300 --> 00:34:13.200 And most,
NOTE Confidence: 0.99451447

00:34:13.739 --> 00:34:15.420 you know, over ninety percent
NOTE Confidence: 0.99451447

00:34:15.420 --> 00:34:16.380 said that they would not
NOTE Confidence: 0.99451447

00:34:16.380 --> 00:34:18.460 recommend repair for hypoplastic left
NOTE Confidence: 0.99451447

00:34:18.460 --> 00:34:20.114 heart syndrome or other single
NOTE Confidence: 0.99451447

00:34:20.114 --> 00:34:21.015 ventricle lesions.
NOTE Confidence: 0.9878243

00:34:21.955 --> 00:34:23.415 Eighteen to twenty eight percent
NOTE Confidence: 0.9878243

00:34:23.555 --> 00:34:25.335 of respondents reported hesitation
NOTE Confidence: 0.87674314

00:34:25.635 --> 00:34:27.895 in recommending surgical repair, incomplete
NOTE Confidence: 0.87674314

00:34:28.035 --> 00:34:29.875 AV canal, tetralogy of flow,
NOTE Confidence: 0.87674314

00:34:29.875 --> 00:34:30.375 coarctation,

NOTE Confidence: 0.9469694

00:34:30.995 --> 00:34:32.455 and then ASD and VSD.

NOTE Confidence: 0.9988103

00:34:33.315 --> 00:34:35.239 So why why the difference?

NOTE Confidence: 0.9988103

00:34:35.239 --> 00:34:36.619 Well, surgical complexity

NOTE Confidence: 0.9909207

00:34:36.920 --> 00:34:38.440 is very different when we

NOTE Confidence: 0.9909207

00:34:38.440 --> 00:34:40.460 talk about single ventricle lesions,

NOTE Confidence: 0.9487674

00:34:41.719 --> 00:34:42.119 and,

NOTE Confidence: 0.82619846

00:34:43.400 --> 00:34:45.239 a simple septal defect. Not

NOTE Confidence: 0.82619846

00:34:45.239 --> 00:34:46.460 just surgical complexity,

NOTE Confidence: 0.97779477

00:34:46.920 --> 00:34:47.660 but also

NOTE Confidence: 0.9304314

00:34:47.960 --> 00:34:49.695 survival outcomes, and that is

NOTE Confidence: 0.9304314

00:34:49.775 --> 00:34:50.675 in all comers.

NOTE Confidence: 0.99190533

00:34:51.135 --> 00:34:52.515 So, you know, a hypoplastic

NOTE Confidence: 0.9953497

00:34:53.055 --> 00:34:54.114 left heart syndrome

NOTE Confidence: 0.9458129

00:34:54.575 --> 00:34:56.175 palliation, and we say palliation

NOTE Confidence: 0.9458129

00:34:56.175 --> 00:34:57.614 because we really can't repair

NOTE Confidence: 0.9458129

00:34:57.614 --> 00:34:59.395 the defect, you know, includes
NOTE Confidence: 0.9988286

00:35:00.415 --> 00:35:00.915 three
NOTE Confidence: 0.9886146

00:35:01.295 --> 00:35:03.250 three different operations at three
NOTE Confidence: 0.9886146

00:35:03.250 --> 00:35:04.390 different time points.
NOTE Confidence: 0.95583755

00:35:05.410 --> 00:35:06.370 They are the one of
NOTE Confidence: 0.95583755

00:35:06.370 --> 00:35:08.050 the more complicated operations we
NOTE Confidence: 0.95583755

00:35:08.050 --> 00:35:10.370 do versus a atrial septal
NOTE Confidence: 0.95583755

00:35:10.370 --> 00:35:11.890 defect or a ventricular septal
NOTE Confidence: 0.95583755

00:35:11.890 --> 00:35:12.930 defect, which would be a
NOTE Confidence: 0.95583755

00:35:12.930 --> 00:35:13.750 patch closure.
NOTE Confidence: 0.9703456

00:35:15.605 --> 00:35:16.805 So now I'm gonna talk
NOTE Confidence: 0.9703456

00:35:16.805 --> 00:35:18.565 about case number four. So
NOTE Confidence: 0.9703456

00:35:18.565 --> 00:35:19.645 a couple was referred for
NOTE Confidence: 0.9703456

00:35:19.645 --> 00:35:21.305 a fetal echo after noninvasive
NOTE Confidence: 0.9703456

00:35:21.525 --> 00:35:23.285 prenatal testing was positive for
NOTE Confidence: 0.9703456

00:35:23.285 --> 00:35:25.385 trisomy eighteen, and an ultrasound

NOTE Confidence: 0.9703456

00:35:25.444 --> 00:35:27.684 revealed a congenital diaphragmatic hernia

NOTE Confidence: 0.9703456

00:35:27.684 --> 00:35:29.545 with suspected congenital heart disease.

NOTE Confidence: 0.9757109

00:35:30.000 --> 00:35:31.200 Fetal echo shows that the

NOTE Confidence: 0.9757109

00:35:31.200 --> 00:35:32.480 heart is displaced into the

NOTE Confidence: 0.9757109

00:35:32.480 --> 00:35:33.760 right chest with compression of

NOTE Confidence: 0.9757109

00:35:33.760 --> 00:35:34.900 the left sided chambers.

NOTE Confidence: 0.9892546

00:35:35.200 --> 00:35:36.960 A small muscular VSD is

NOTE Confidence: 0.9892546

00:35:36.960 --> 00:35:38.560 possibly seen, but apart from

NOTE Confidence: 0.9892546

00:35:38.560 --> 00:35:40.560 compression, there's no evidence of

NOTE Confidence: 0.9892546

00:35:40.560 --> 00:35:41.940 left sided outlet obstruction.

NOTE Confidence: 0.9690687

00:35:42.605 --> 00:35:43.805 The risk of high drops

NOTE Confidence: 0.9690687

00:35:43.805 --> 00:35:45.805 or heart failure, not secondary

NOTE Confidence: 0.9690687

00:35:45.805 --> 00:35:46.765 to the heart disease, but

NOTE Confidence: 0.9690687

00:35:46.765 --> 00:35:49.085 secondary to congenital diaphragmatic hernia

NOTE Confidence: 0.9690687

00:35:49.085 --> 00:35:49.744 is discussed.

NOTE Confidence: 0.9361868

00:35:50.045 --> 00:35:51.244 Family is counseled on a
NOTE Confidence: 0.9361868

00:35:51.244 --> 00:35:52.065 guarded prognosis
NOTE Confidence: 0.9624699

00:35:52.444 --> 00:35:54.364 and given the concomitant findings
NOTE Confidence: 0.9624699

00:35:54.364 --> 00:35:56.170 of both of the congenital
NOTE Confidence: 0.98457605

00:35:56.630 --> 00:35:59.050 diaphragmatic hernia and trisomy eighteen.
NOTE Confidence: 0.97663295

00:36:00.150 --> 00:36:01.930 So that that previous scenario
NOTE Confidence: 0.97663295

00:36:02.070 --> 00:36:03.850 is is not uncommon.
NOTE Confidence: 0.9937112

00:36:04.230 --> 00:36:05.350 So I can recall many
NOTE Confidence: 0.9937112

00:36:05.350 --> 00:36:06.810 cases where there was,
NOTE Confidence: 0.9962325

00:36:07.190 --> 00:36:08.730 a congenital heart defect.
NOTE Confidence: 0.9616222

00:36:09.435 --> 00:36:10.635 In this case, there wasn't
NOTE Confidence: 0.9616222

00:36:10.635 --> 00:36:12.235 even a significant congenital heart
NOTE Confidence: 0.9616222

00:36:12.235 --> 00:36:12.735 defect,
NOTE Confidence: 0.98816943

00:36:13.275 --> 00:36:15.035 and then another significant medical
NOTE Confidence: 0.98816943

00:36:15.035 --> 00:36:15.535 problem,
NOTE Confidence: 0.9843369

00:36:16.555 --> 00:36:19.275 from congenital diaphragmatic hernia to

NOTE Confidence: 0.9843369

00:36:19.275 --> 00:36:20.715 spina bifida to a major

NOTE Confidence: 0.9843369

00:36:20.715 --> 00:36:21.535 brain anomaly.

NOTE Confidence: 0.99943674

00:36:22.089 --> 00:36:23.390 So in that same survey,

NOTE Confidence: 0.99943674

00:36:23.450 --> 00:36:24.569 greater than ninety percent of

NOTE Confidence: 0.99943674

00:36:24.569 --> 00:36:25.069 respondents

NOTE Confidence: 0.96406305

00:36:25.369 --> 00:36:27.230 stated that a noncardiac anomaly,

NOTE Confidence: 0.999366

00:36:27.770 --> 00:36:29.230 including congenital diaphragmatic

NOTE Confidence: 0.89961547

00:36:30.329 --> 00:36:32.589 congenital diaphragmatic hernia and emphyseal

NOTE Confidence: 0.92914295

00:36:32.890 --> 00:36:33.950 impact their counseling.

NOTE Confidence: 0.99817085

00:36:34.730 --> 00:36:35.550 And so

NOTE Confidence: 0.9876265

00:36:36.344 --> 00:36:37.705 in our survey, we also

NOTE Confidence: 0.9876265

00:36:37.705 --> 00:36:39.225 asked folks to write in

NOTE Confidence: 0.9876265

00:36:39.225 --> 00:36:39.725 comments,

NOTE Confidence: 0.9910384

00:36:40.505 --> 00:36:41.465 you know, because we we

NOTE Confidence: 0.9910384

00:36:41.465 --> 00:36:42.744 felt like maybe people had

NOTE Confidence: 0.9910384

00:36:42.744 --> 00:36:44.105 something that they wanted to
NOTE Confidence: 0.9910384

00:36:44.105 --> 00:36:44.844 to say.
NOTE Confidence: 0.98590684

00:36:45.145 --> 00:36:46.665 And I received fifty four
NOTE Confidence: 0.98590684

00:36:46.665 --> 00:36:48.185 additional comments, which I feel
NOTE Confidence: 0.98590684

00:36:48.185 --> 00:36:49.305 like is a lot to
NOTE Confidence: 0.98590684

00:36:49.305 --> 00:36:50.660 type in on your phone.
NOTE Confidence: 0.98590684

00:36:50.800 --> 00:36:51.839 So I feel like people
NOTE Confidence: 0.98590684

00:36:51.839 --> 00:36:52.800 have a lot that they
NOTE Confidence: 0.98590684

00:36:52.800 --> 00:36:53.540 wanna say.
NOTE Confidence: 0.9984913

00:36:54.239 --> 00:36:56.239 And the prevailing concern with
NOTE Confidence: 0.9984913

00:36:56.239 --> 00:36:57.219 prenatal counseling
NOTE Confidence: 0.9561516

00:36:57.760 --> 00:36:58.719 was and when they were
NOTE Confidence: 0.9561516

00:36:58.719 --> 00:36:59.599 answering this, what they were
NOTE Confidence: 0.9561516

00:36:59.599 --> 00:37:00.719 saying, like, each case is
NOTE Confidence: 0.9561516

00:37:00.719 --> 00:37:01.219 unique.
NOTE Confidence: 0.9561402

00:37:01.520 --> 00:37:02.800 Everything is medical you know,

NOTE Confidence: 0.9561402

00:37:02.800 --> 00:37:04.160 each case is medically complex.

NOTE Confidence: 0.9561402

00:37:04.160 --> 00:37:05.219 We need an individualized

NOTE Confidence: 0.959036

00:37:05.525 --> 00:37:06.185 care plan.

NOTE Confidence: 0.9475059

00:37:06.645 --> 00:37:08.005 Then they've voiced concerns about,

NOTE Confidence: 0.9475059

00:37:08.005 --> 00:37:08.965 you know, the type of

NOTE Confidence: 0.9475059

00:37:08.965 --> 00:37:09.945 cardiac lesion,

NOTE Confidence: 0.95260704

00:37:10.245 --> 00:37:11.685 the presence of non cardiac

NOTE Confidence: 0.95260704

00:37:11.685 --> 00:37:13.305 disease. What are the respiratory

NOTE Confidence: 0.95260704

00:37:13.364 --> 00:37:14.485 needs of the baby gonna

NOTE Confidence: 0.95260704

00:37:14.485 --> 00:37:16.005 be after, you know, after

NOTE Confidence: 0.95260704

00:37:16.005 --> 00:37:17.205 the baby is born? Will

NOTE Confidence: 0.95260704

00:37:17.205 --> 00:37:19.020 they require will they require

NOTE Confidence: 0.95260704

00:37:19.020 --> 00:37:20.540 a ventilator? Will they require

NOTE Confidence: 0.95260704

00:37:20.540 --> 00:37:21.120 a tracheostomy?

NOTE Confidence: 0.97823626

00:37:22.380 --> 00:37:23.260 You know, what about the

NOTE Confidence: 0.97823626

00:37:23.260 --> 00:37:24.380 fact that these babies you
NOTE Confidence: 0.97823626

00:37:24.380 --> 00:37:25.100 know, one of the things
NOTE Confidence: 0.97823626

00:37:25.100 --> 00:37:26.060 I didn't talk about is
NOTE Confidence: 0.97823626

00:37:26.060 --> 00:37:27.260 that babies are often born
NOTE Confidence: 0.97823626

00:37:27.260 --> 00:37:29.180 premature, low birth weight. These
NOTE Confidence: 0.97823626

00:37:29.180 --> 00:37:29.920 are additional
NOTE Confidence: 0.999569

00:37:30.380 --> 00:37:30.880 complexities
NOTE Confidence: 0.8914563

00:37:31.580 --> 00:37:33.120 that get added to, you
NOTE Confidence: 0.97260123

00:37:34.085 --> 00:37:35.204 you know, the already difficult
NOTE Confidence: 0.97260123

00:37:35.204 --> 00:37:37.204 medical decision making. What about
NOTE Confidence: 0.97260123

00:37:37.204 --> 00:37:38.484 pulmonary hypertension? A lot of
NOTE Confidence: 0.97260123

00:37:38.484 --> 00:37:40.184 these babies have pulmonary hypertension.
NOTE Confidence: 0.99102104

00:37:40.565 --> 00:37:42.005 What about the anesthesia risk?
NOTE Confidence: 0.99102104

00:37:42.005 --> 00:37:43.045 What's gonna happen when we
NOTE Confidence: 0.99102104

00:37:43.045 --> 00:37:44.904 put these babies under anesthesia?
NOTE Confidence: 0.9897404

00:37:45.204 --> 00:37:46.404 You know? Will we ever

NOTE Confidence: 0.9897404

00:37:46.404 --> 00:37:47.944 be able to extubate them?

NOTE Confidence: 0.9920316

00:37:48.570 --> 00:37:49.230 And so,

NOTE Confidence: 0.99091804

00:37:49.690 --> 00:37:50.650 one of the quotes,

NOTE Confidence: 0.9735284

00:37:51.290 --> 00:37:52.010 that was,

NOTE Confidence: 0.9809466

00:37:52.570 --> 00:37:53.690 that one of the quotes

NOTE Confidence: 0.9809466

00:37:53.690 --> 00:37:54.650 from the from one of

NOTE Confidence: 0.9809466

00:37:54.650 --> 00:37:56.750 the physicians was fetal conversations

NOTE Confidence: 0.9809466

00:37:56.890 --> 00:37:58.010 always include a lot of

NOTE Confidence: 0.9809466

00:37:58.010 --> 00:37:59.850 discussion about these factors, which

NOTE Confidence: 0.9809466

00:37:59.850 --> 00:38:00.830 could disqualify

NOTE Confidence: 0.99930567

00:38:01.130 --> 00:38:02.830 a baby from surgical candidacy

NOTE Confidence: 0.99930567

00:38:02.969 --> 00:38:03.614 for their heart.

NOTE Confidence: 0.9963171

00:38:04.175 --> 00:38:04.895 And so I think this

NOTE Confidence: 0.9963171

00:38:04.895 --> 00:38:06.335 is where you get a

NOTE Confidence: 0.9963171

00:38:06.335 --> 00:38:07.535 lot of physicians who are

NOTE Confidence: 0.9963171

00:38:07.535 --> 00:38:08.975 just not sure. They're not
NOTE Confidence: 0.9963171

00:38:08.975 --> 00:38:10.114 sure what to say.
NOTE Confidence: 0.94861954

00:38:10.895 --> 00:38:12.175 And so I think these
NOTE Confidence: 0.94861954

00:38:12.175 --> 00:38:14.415 are very real objective and
NOTE Confidence: 0.94861954

00:38:14.415 --> 00:38:15.315 valid concerns.
NOTE Confidence: 0.95950633

00:38:15.940 --> 00:38:17.140 But sometimes it's like it
NOTE Confidence: 0.95950633

00:38:17.140 --> 00:38:18.760 seems like this huge checklist
NOTE Confidence: 0.97280115

00:38:19.060 --> 00:38:19.860 that you have to go
NOTE Confidence: 0.97280115

00:38:19.860 --> 00:38:21.560 through in order for anybody
NOTE Confidence: 0.97280115

00:38:21.780 --> 00:38:23.060 to be, you know, to
NOTE Confidence: 0.97280115

00:38:23.060 --> 00:38:24.500 move forward with surgery. So
NOTE Confidence: 0.97280115

00:38:24.500 --> 00:38:25.700 it's it's I don't think
NOTE Confidence: 0.97280115

00:38:25.700 --> 00:38:27.400 that they're a perfect candidate
NOTE Confidence: 0.97280115

00:38:27.540 --> 00:38:28.040 exists.
NOTE Confidence: 0.9926833

00:38:30.174 --> 00:38:31.855 So, again, the guidelines committee
NOTE Confidence: 0.9926833

00:38:31.855 --> 00:38:33.474 tried to address this concern,

NOTE Confidence: 0.9926833

00:38:33.535 --> 00:38:34.335 and I think they did

NOTE Confidence: 0.9926833

00:38:34.335 --> 00:38:35.454 a pretty good job, but

NOTE Confidence: 0.9926833

00:38:35.454 --> 00:38:36.415 I think there's a lot

NOTE Confidence: 0.9926833

00:38:36.415 --> 00:38:37.454 more research that needs to

NOTE Confidence: 0.9926833

00:38:37.454 --> 00:38:38.575 be done here to understand

NOTE Confidence: 0.9926833

00:38:38.575 --> 00:38:40.255 this. So they they said

NOTE Confidence: 0.9926833

00:38:40.255 --> 00:38:41.694 that cardiac surgery may not

NOTE Confidence: 0.9926833

00:38:41.694 --> 00:38:43.295 be reasonable for very complex

NOTE Confidence: 0.9926833

00:38:43.295 --> 00:38:44.655 congenital heart disease or single

NOTE Confidence: 0.9926833

00:38:44.655 --> 00:38:45.155 ventricle.

NOTE Confidence: 0.96798337

00:38:46.440 --> 00:38:48.360 Cardiac surgery can be considered

NOTE Confidence: 0.96798337

00:38:48.360 --> 00:38:50.140 after other defects are addressed.

NOTE Confidence: 0.99428195

00:38:51.160 --> 00:38:53.180 Early cardiac surgery is reasonable,

NOTE Confidence: 0.9365811

00:38:53.719 --> 00:38:55.260 to prevent pulmonary hypertension,

NOTE Confidence: 0.9642411

00:38:56.280 --> 00:38:58.440 and surgical repair of congenital

NOTE Confidence: 0.9642411

00:38:58.440 --> 00:38:59.640 heart disease of mild to
NOTE Confidence: 0.9642411

00:38:59.640 --> 00:39:00.460 moderate complexity
NOTE Confidence: 0.9999242

00:39:00.875 --> 00:39:01.694 can be considered
NOTE Confidence: 0.99211335

00:39:01.994 --> 00:39:03.355 in children who are ventilator
NOTE Confidence: 0.99211335

00:39:03.355 --> 00:39:03.855 dependent,
NOTE Confidence: 0.9944097

00:39:04.395 --> 00:39:05.434 if the severity of the
NOTE Confidence: 0.9944097

00:39:05.434 --> 00:39:07.214 respiratory disease is not prohibitive.
NOTE Confidence: 0.95511943

00:39:07.674 --> 00:39:08.875 So, again, it's a little
NOTE Confidence: 0.95511943

00:39:08.875 --> 00:39:10.234 bit of a kind of
NOTE Confidence: 0.95511943

00:39:10.234 --> 00:39:10.895 a disqualifier
NOTE Confidence: 0.9990012

00:39:11.434 --> 00:39:12.415 there at the end.
NOTE Confidence: 0.9863634

00:39:15.140 --> 00:39:16.820 So, so, you know, those
NOTE Confidence: 0.9863634

00:39:16.820 --> 00:39:18.420 are a lot of very
NOTE Confidence: 0.9863634

00:39:18.420 --> 00:39:20.840 valid concerns with respect to,
NOTE Confidence: 0.96736795

00:39:21.700 --> 00:39:23.060 whether or not, you know,
NOTE Confidence: 0.96736795

00:39:23.060 --> 00:39:23.940 a a patient will be

NOTE Confidence: 0.96736795

00:39:23.940 --> 00:39:24.600 a candidate.

NOTE Confidence: 0.96566075

00:39:25.940 --> 00:39:27.540 But there are there's another

NOTE Confidence: 0.96566075

00:39:27.540 --> 00:39:29.555 component too that, I'm gonna

NOTE Confidence: 0.96566075

00:39:29.555 --> 00:39:30.934 use this case to highlight.

NOTE Confidence: 0.99469733

00:39:31.315 --> 00:39:32.194 So this is about a

NOTE Confidence: 0.99469733

00:39:32.194 --> 00:39:33.315 forty four year old woman

NOTE Confidence: 0.99469733

00:39:33.315 --> 00:39:35.395 with abnormal ultrasound findings. So

NOTE Confidence: 0.99469733

00:39:35.395 --> 00:39:36.275 I think one thing you'll

NOTE Confidence: 0.99469733

00:39:36.275 --> 00:39:37.474 notice is that, you know,

NOTE Confidence: 0.99469733

00:39:37.474 --> 00:39:39.015 the risk for having,

NOTE Confidence: 0.9395913

00:39:39.635 --> 00:39:41.395 a fetus that's affected by

NOTE Confidence: 0.9395913

00:39:41.395 --> 00:39:43.174 a trisomy goes up with,

NOTE Confidence: 0.9707099

00:39:43.890 --> 00:39:45.910 increased maternal age. So,

NOTE Confidence: 0.96557575

00:39:46.450 --> 00:39:47.410 just to kind of if

NOTE Confidence: 0.96557575

00:39:47.410 --> 00:39:48.690 you're if anybody was curious

NOTE Confidence: 0.96557575

00:39:48.690 --> 00:39:49.430 about that.
NOTE Confidence: 0.92602

00:39:50.609 --> 00:39:52.150 So she she has undergone,
NOTE Confidence: 0.9718512

00:39:52.530 --> 00:39:53.190 an amniocentesis,
NOTE Confidence: 0.92517126

00:39:53.730 --> 00:39:55.750 which reveals mosaicism in trisomy,
NOTE Confidence: 0.9862567

00:39:56.555 --> 00:39:58.315 Mosaic, excuse me, trisomy eighteen.
NOTE Confidence: 0.9862567

00:39:58.315 --> 00:40:00.395 So mosaicism is when you
NOTE Confidence: 0.9862567

00:40:00.395 --> 00:40:01.835 sample the cells, but not
NOTE Confidence: 0.9862567

00:40:01.835 --> 00:40:02.815 all the cells
NOTE Confidence: 0.9216041

00:40:03.435 --> 00:40:05.275 have this extra chromosome. Only,
NOTE Confidence: 0.9216041

00:40:05.275 --> 00:40:06.075 you know, a few, and
NOTE Confidence: 0.9216041

00:40:06.075 --> 00:40:07.435 they they usually tell you
NOTE Confidence: 0.9216041

00:40:07.435 --> 00:40:08.130 how many.
NOTE Confidence: 0.97359776

00:40:08.529 --> 00:40:10.130 She has counseled about variable
NOTE Confidence: 0.97359776

00:40:10.130 --> 00:40:11.650 perinatal outcomes related to the
NOTE Confidence: 0.97359776

00:40:11.650 --> 00:40:12.150 mosaicism.
NOTE Confidence: 0.94186604

00:40:12.849 --> 00:40:13.969 So, you know, because you

NOTE Confidence: 0.94186604

00:40:13.969 --> 00:40:15.489 don't know exactly is it

NOTE Confidence: 0.94186604

00:40:15.489 --> 00:40:17.329 gonna be very affected or

NOTE Confidence: 0.94186604

00:40:17.329 --> 00:40:18.390 minimally affected.

NOTE Confidence: 0.94585514

00:40:18.849 --> 00:40:20.049 So the fetal echo twenty

NOTE Confidence: 0.94585514

00:40:20.049 --> 00:40:21.645 one twenty one weeks, excuse

NOTE Confidence: 0.94585514

00:40:21.645 --> 00:40:23.325 me, reveals a ventricular septal

NOTE Confidence: 0.94585514

00:40:23.325 --> 00:40:25.025 defect and mild aortic stenosis.

NOTE Confidence: 0.99903685

00:40:25.405 --> 00:40:27.265 She ultimately decides to continue

NOTE Confidence: 0.99903685

00:40:27.325 --> 00:40:28.065 the pregnancy

NOTE Confidence: 0.9249148

00:40:28.525 --> 00:40:30.125 but is unsure about goals

NOTE Confidence: 0.9249148

00:40:30.125 --> 00:40:30.785 of care.

NOTE Confidence: 0.9913307

00:40:31.165 --> 00:40:32.605 She relays sadness about the

NOTE Confidence: 0.9913307

00:40:32.605 --> 00:40:34.445 diagnosis and reports feeling pressure

NOTE Confidence: 0.9913307

00:40:34.445 --> 00:40:35.665 to terminate the pregnancy.

NOTE Confidence: 0.99874717

00:40:36.270 --> 00:40:37.310 She also reports that her

NOTE Confidence: 0.99874717

00:40:37.310 --> 00:40:39.250 husband has distanced himself from
NOTE Confidence: 0.9972161

00:40:39.630 --> 00:40:40.850 her. In her third trimester,
NOTE Confidence: 0.9967772

00:40:41.870 --> 00:40:43.489 she meets with palliative care
NOTE Confidence: 0.94344914

00:40:43.790 --> 00:40:45.489 and voices her goals regarding
NOTE Confidence: 0.94344914

00:40:45.550 --> 00:40:47.790 delivery, seeking some interventions, including
NOTE Confidence: 0.94344914

00:40:47.790 --> 00:40:49.469 intubation, but not others such
NOTE Confidence: 0.94344914

00:40:49.469 --> 00:40:51.010 as cold medications or compressions.
NOTE Confidence: 0.99226415

00:40:51.765 --> 00:40:52.885 Her care is transferred to
NOTE Confidence: 0.99226415

00:40:52.885 --> 00:40:54.405 deliver at Yale, and the
NOTE Confidence: 0.99226415

00:40:54.405 --> 00:40:55.684 infant is delivered at thirty
NOTE Confidence: 0.99226415

00:40:55.684 --> 00:40:57.204 seven weeks via scheduled c
NOTE Confidence: 0.99226415

00:40:57.204 --> 00:40:58.885 section and is resuscitated and
NOTE Confidence: 0.99226415

00:40:58.885 --> 00:41:00.344 intubated in the NICU.
NOTE Confidence: 0.98945427

00:41:00.805 --> 00:41:01.844 After a few days in
NOTE Confidence: 0.98945427

00:41:01.844 --> 00:41:02.805 the NICU, she and her
NOTE Confidence: 0.98945427

00:41:02.805 --> 00:41:04.664 husband elect to discontinue mechanical

NOTE Confidence: 0.98945427

00:41:04.724 --> 00:41:06.325 ventilation, and the infant passes

NOTE Confidence: 0.98945427

00:41:06.325 --> 00:41:06.825 away.

NOTE Confidence: 0.8793386

00:41:09.180 --> 00:41:10.700 So, you know, I bring

NOTE Confidence: 0.8793386

00:41:10.700 --> 00:41:11.520 up this story,

NOTE Confidence: 0.8708535

00:41:12.060 --> 00:41:13.440 one to talk about,

NOTE Confidence: 0.9709851

00:41:14.540 --> 00:41:15.680 a lot of the other

NOTE Confidence: 0.9709851

00:41:15.820 --> 00:41:18.060 people that are involved in

NOTE Confidence: 0.9709851

00:41:18.060 --> 00:41:19.900 in the in counseling. So,

NOTE Confidence: 0.9709851

00:41:19.900 --> 00:41:21.135 you know, caring for a

NOTE Confidence: 0.9709851

00:41:21.135 --> 00:41:22.255 child caring for, excuse me,

NOTE Confidence: 0.9709851

00:41:22.255 --> 00:41:23.395 a complicated pregnancy,

NOTE Confidence: 0.9733457

00:41:23.695 --> 00:41:24.735 which may result in a

NOTE Confidence: 0.9733457

00:41:24.735 --> 00:41:26.335 child with complex medical needs,

NOTE Confidence: 0.9733457

00:41:26.335 --> 00:41:27.795 involves a lot of players.

NOTE Confidence: 0.89447814

00:41:28.975 --> 00:41:30.255 You have a patient. You

NOTE Confidence: 0.89447814

00:41:30.255 --> 00:41:31.215 have the patient and her
NOTE Confidence: 0.89447814

00:41:31.215 --> 00:41:32.575 family. You know? So we
NOTE Confidence: 0.89447814

00:41:32.575 --> 00:41:33.375 can see in the last
NOTE Confidence: 0.89447814

00:41:33.375 --> 00:41:34.575 case, there was, you know,
NOTE Confidence: 0.89447814

00:41:34.575 --> 00:41:34.655 some,
NOTE Confidence: 0.9782418

00:41:35.940 --> 00:41:38.260 some discordance between the both
NOTE Confidence: 0.9782418

00:41:38.260 --> 00:41:39.960 parents. We also have,
NOTE Confidence: 0.98003376

00:41:40.260 --> 00:41:41.619 you know, your your the
NOTE Confidence: 0.98003376

00:41:41.619 --> 00:41:43.300 cardiologist, then you have the
NOTE Confidence: 0.98003376

00:41:43.300 --> 00:41:45.219 obstetrician, the maternal fetal medicine
NOTE Confidence: 0.98003376

00:41:45.219 --> 00:41:46.839 doctor, genetic counselors,
NOTE Confidence: 0.9394068

00:41:47.380 --> 00:41:47.880 neonatologists,
NOTE Confidence: 0.9878685

00:41:48.660 --> 00:41:49.560 other cardiologists,
NOTE Confidence: 0.9143604

00:41:50.344 --> 00:41:51.244 palliative care.
NOTE Confidence: 0.9101534

00:41:52.105 --> 00:41:53.964 You may have general surgery.
NOTE Confidence: 0.9627253

00:41:54.825 --> 00:41:55.944 You can have, you know,

NOTE Confidence: 0.9627253

00:41:55.944 --> 00:41:56.904 ear, nose, and throat. You

NOTE Confidence: 0.9627253

00:41:56.904 --> 00:41:58.605 may have religious representation.

NOTE Confidence: 0.995057

00:41:59.464 --> 00:42:01.144 So and each of these

NOTE Confidence: 0.995057

00:42:01.144 --> 00:42:03.065 each of these stakeholders may

NOTE Confidence: 0.995057

00:42:03.065 --> 00:42:05.144 have different ideas about quality

NOTE Confidence: 0.995057

00:42:05.144 --> 00:42:06.719 of life, And all of

NOTE Confidence: 0.995057

00:42:06.719 --> 00:42:08.500 those may impact their counseling.

NOTE Confidence: 0.9763057

00:42:09.040 --> 00:42:10.580 So the pressure to terminate

NOTE Confidence: 0.9763057

00:42:10.719 --> 00:42:12.340 is is a pretty commonly

NOTE Confidence: 0.9763057

00:42:12.640 --> 00:42:13.140 encountered,

NOTE Confidence: 0.9153308

00:42:13.840 --> 00:42:14.340 issue.

NOTE Confidence: 0.96362656

00:42:15.280 --> 00:42:16.400 And I think that,

NOTE Confidence: 0.9938487

00:42:17.680 --> 00:42:19.040 this may come from some

NOTE Confidence: 0.9938487

00:42:19.040 --> 00:42:20.260 of the, you know,

NOTE Confidence: 0.9987761

00:42:21.165 --> 00:42:22.945 views regarding quality of life.

NOTE Confidence: 0.9814227

00:42:23.645 --> 00:42:25.245 So one physician had this
NOTE Confidence: 0.9814227

00:42:25.245 --> 00:42:26.205 to say, there has been
NOTE Confidence: 0.9814227

00:42:26.205 --> 00:42:27.885 significant evolution in the attitudes
NOTE Confidence: 0.9814227

00:42:27.885 --> 00:42:29.985 of caretakers of these patients,
NOTE Confidence: 0.9939257

00:42:30.285 --> 00:42:31.965 and not all subspecialties are
NOTE Confidence: 0.9939257

00:42:31.965 --> 00:42:33.344 always on the same page.
NOTE Confidence: 0.96288115

00:42:35.099 --> 00:42:36.940 So the difficulty thing the
NOTE Confidence: 0.96288115

00:42:36.940 --> 00:42:38.700 difficult thing about quality of
NOTE Confidence: 0.96288115

00:42:38.700 --> 00:42:40.460 life is it's kind of
NOTE Confidence: 0.96288115

00:42:40.460 --> 00:42:41.579 dependent on the eyes of
NOTE Confidence: 0.96288115

00:42:41.579 --> 00:42:42.160 the beholder.
NOTE Confidence: 0.97836185

00:42:43.339 --> 00:42:45.099 So it it differs from
NOTE Confidence: 0.97836185

00:42:45.099 --> 00:42:47.019 physician to physician, it differs
NOTE Confidence: 0.97836185

00:42:47.019 --> 00:42:48.619 from physician to parent, and
NOTE Confidence: 0.97836185

00:42:48.619 --> 00:42:50.295 it differs from parent to
NOTE Confidence: 0.97836185

00:42:50.295 --> 00:42:50.795 parent.

NOTE Confidence: 0.9972436

00:42:51.255 --> 00:42:52.135 So, you know, if you

NOTE Confidence: 0.9972436

00:42:52.135 --> 00:42:53.035 look at this picture,

NOTE Confidence: 0.9922899

00:42:53.415 --> 00:42:54.614 some of you see, you

NOTE Confidence: 0.9922899

00:42:54.614 --> 00:42:55.734 know, a young lady, you

NOTE Confidence: 0.9922899

00:42:55.734 --> 00:42:56.855 know, looking off in the

NOTE Confidence: 0.9922899

00:42:56.855 --> 00:42:57.355 distance.

NOTE Confidence: 0.99404776

00:42:57.734 --> 00:42:58.935 Some of you see an

NOTE Confidence: 0.99404776

00:42:58.935 --> 00:42:59.755 older lady.

NOTE Confidence: 0.9941268

00:43:00.135 --> 00:43:01.255 Some of you see both,

NOTE Confidence: 0.9941268

00:43:01.255 --> 00:43:02.075 like, interchangeably.

NOTE Confidence: 0.96657926

00:43:02.790 --> 00:43:03.750 So I don't think there's

NOTE Confidence: 0.96657926

00:43:03.750 --> 00:43:05.350 one right or right or

NOTE Confidence: 0.96657926

00:43:05.350 --> 00:43:06.950 wrong answer, and I think

NOTE Confidence: 0.96657926

00:43:06.950 --> 00:43:08.650 that that's kind of like,

NOTE Confidence: 0.96657926

00:43:08.790 --> 00:43:10.170 you know, quality of life.

NOTE Confidence: 0.99886465

00:43:10.870 --> 00:43:11.370 So
NOTE Confidence: 0.9735828

00:43:12.070 --> 00:43:13.190 I'm gonna talk about a
NOTE Confidence: 0.9735828

00:43:13.190 --> 00:43:14.310 little bit about sort of
NOTE Confidence: 0.9735828

00:43:14.310 --> 00:43:16.785 the discordance between health care
NOTE Confidence: 0.9735828

00:43:16.785 --> 00:43:18.305 providers and parents when it
NOTE Confidence: 0.9735828

00:43:18.305 --> 00:43:19.185 comes to the issue of
NOTE Confidence: 0.9735828

00:43:19.185 --> 00:43:20.085 quality of life.
NOTE Confidence: 0.9967926

00:43:20.705 --> 00:43:22.945 And, I think these these
NOTE Confidence: 0.9967926

00:43:22.945 --> 00:43:24.785 disagreements are driven by different
NOTE Confidence: 0.9967926

00:43:24.785 --> 00:43:27.364 values, different perspectives, different subjective
NOTE Confidence: 0.9967926

00:43:27.585 --> 00:43:28.085 experiences.
NOTE Confidence: 0.85898733

00:43:28.864 --> 00:43:29.105 So,
NOTE Confidence: 0.99918157

00:43:30.890 --> 00:43:31.390 parents
NOTE Confidence: 0.9521624

00:43:31.770 --> 00:43:33.290 value their child's place in
NOTE Confidence: 0.9521624

00:43:33.290 --> 00:43:34.570 their family and the social
NOTE Confidence: 0.9521624

00:43:34.570 --> 00:43:36.570 interactions they they share. In

NOTE Confidence: 0.9521624

00:43:36.570 --> 00:43:37.690 a survey of parents of

NOTE Confidence: 0.9521624

00:43:37.690 --> 00:43:39.130 children with trisomy thirteen and

NOTE Confidence: 0.9521624

00:43:39.130 --> 00:43:40.910 eighteen, Jean Vie et al.

NOTE Confidence: 0.9521624

00:43:41.130 --> 00:43:42.650 Found that eighty nine percent

NOTE Confidence: 0.9521624

00:43:42.650 --> 00:43:44.590 of parents report overall positive

NOTE Confidence: 0.9521624

00:43:44.730 --> 00:43:45.230 experiences,

NOTE Confidence: 0.9977447

00:43:45.915 --> 00:43:47.195 and ninety seven state that

NOTE Confidence: 0.9977447

00:43:47.195 --> 00:43:49.055 their child enriches their lives.

NOTE Confidence: 0.9905486

00:43:49.515 --> 00:43:50.815 This has been my experience

NOTE Confidence: 0.9905486

00:43:50.875 --> 00:43:52.655 when I've attended soft meetings.

NOTE Confidence: 0.9918671

00:43:53.035 --> 00:43:53.995 You know, I I get

NOTE Confidence: 0.9918671

00:43:53.995 --> 00:43:55.435 to see parents and their

NOTE Confidence: 0.9918671

00:43:55.435 --> 00:43:55.935 children

NOTE Confidence: 0.81094384

00:43:56.315 --> 00:43:56.815 happy,

NOTE Confidence: 0.99045795

00:43:57.114 --> 00:43:58.895 engaging in activities and events

NOTE Confidence: 0.99045795

00:43:59.035 --> 00:44:00.575 like other families do.
NOTE Confidence: 0.9954356

00:44:01.230 --> 00:44:02.750 Now I acknowledge that it
NOTE Confidence: 0.9954356

00:44:02.750 --> 00:44:04.370 might be hard to
NOTE Confidence: 0.9996456

00:44:05.070 --> 00:44:06.850 ascertain the views of parents
NOTE Confidence: 0.99191314

00:44:07.230 --> 00:44:08.670 who maybe don't feel that
NOTE Confidence: 0.99191314

00:44:08.670 --> 00:44:09.410 their child,
NOTE Confidence: 0.9914195

00:44:09.950 --> 00:44:10.910 has a good quality of
NOTE Confidence: 0.9914195

00:44:10.910 --> 00:44:11.410 life.
NOTE Confidence: 0.98353696

00:44:11.710 --> 00:44:12.670 And I think that some
NOTE Confidence: 0.98353696

00:44:12.670 --> 00:44:14.050 physicians may be influenced
NOTE Confidence: 0.95389575

00:44:14.430 --> 00:44:16.445 when they see family struggling
NOTE Confidence: 0.95389575

00:44:16.505 --> 00:44:18.185 or harboring, or they themselves
NOTE Confidence: 0.95389575

00:44:18.185 --> 00:44:19.385 may harbor some negative,
NOTE Confidence: 0.8982248

00:44:21.065 --> 00:44:22.825 negative added or not negative,
NOTE Confidence: 0.8982248

00:44:22.825 --> 00:44:23.945 but maybe they've had some
NOTE Confidence: 0.8982248

00:44:23.945 --> 00:44:25.005 negative experiences

NOTE Confidence: 0.99875224

00:44:25.305 --> 00:44:26.425 from taking care of children

NOTE Confidence: 0.99875224

00:44:26.425 --> 00:44:27.245 in the hospital.

NOTE Confidence: 0.976746

00:44:27.785 --> 00:44:29.040 And so and I think

NOTE Confidence: 0.976746

00:44:29.200 --> 00:44:30.719 that physicians may also place

NOTE Confidence: 0.976746

00:44:30.719 --> 00:44:32.660 emphasis on cognitive and functional

NOTE Confidence: 0.976746

00:44:32.719 --> 00:44:33.940 ability, and therefore,

NOTE Confidence: 0.912567

00:44:34.239 --> 00:44:35.120 you know, they feel that

NOTE Confidence: 0.912567

00:44:35.120 --> 00:44:36.800 medical intervention is unwarranted in

NOTE Confidence: 0.912567

00:44:36.800 --> 00:44:38.500 the face of significant disability.

NOTE Confidence: 0.912567

00:44:38.560 --> 00:44:39.780 So this is about disability

NOTE Confidence: 0.912567

00:44:39.840 --> 00:44:40.340 bias.

NOTE Confidence: 0.958219

00:44:41.945 --> 00:44:43.065 So these are the next

NOTE Confidence: 0.958219

00:44:43.065 --> 00:44:44.665 two studies looked at, they

NOTE Confidence: 0.958219

00:44:44.665 --> 00:44:46.505 were also surveys of of

NOTE Confidence: 0.958219

00:44:46.505 --> 00:44:47.005 physicians.

NOTE Confidence: 0.78561825

00:44:49.385 --> 00:44:51.465 The Jacobs et al, surveyed
NOTE Confidence: 0.78561825

00:44:51.465 --> 00:44:51.965 neonatologists
NOTE Confidence: 0.9793404

00:44:53.545 --> 00:44:54.985 and asked them questions about,
NOTE Confidence: 0.9793404

00:44:54.985 --> 00:44:56.185 you know, to what extent
NOTE Confidence: 0.9793404

00:44:56.185 --> 00:44:57.300 they was like a Likert
NOTE Confidence: 0.9793404

00:44:57.300 --> 00:44:58.440 scale. They could either
NOTE Confidence: 0.97237134

00:44:58.900 --> 00:45:00.820 strongly, you know, disagree or
NOTE Confidence: 0.97237134

00:45:00.820 --> 00:45:02.180 strongly agree and then, you
NOTE Confidence: 0.97237134

00:45:02.180 --> 00:45:03.239 know, kind of,
NOTE Confidence: 0.94008803

00:45:04.260 --> 00:45:04.980 we had a, like, a
NOTE Confidence: 0.94008803

00:45:04.980 --> 00:45:06.820 five point, Likert scale. Excuse
NOTE Confidence: 0.94008803

00:45:06.820 --> 00:45:07.940 me. So the the first
NOTE Confidence: 0.94008803

00:45:07.940 --> 00:45:09.540 question was trisomy eighteen. Is
NOTE Confidence: 0.94008803

00:45:09.540 --> 00:45:10.900 it a lethal condition? Eighty
NOTE Confidence: 0.94008803

00:45:10.900 --> 00:45:11.505 three percent
NOTE Confidence: 0.9969194

00:45:12.464 --> 00:45:12.964 agreed.

NOTE Confidence: 0.97642916

00:45:13.505 --> 00:45:14.864 Active treatment of a fetus

NOTE Confidence: 0.97642916

00:45:14.864 --> 00:45:16.464 or newborn with trisomy eighteen

NOTE Confidence: 0.97642916

00:45:16.464 --> 00:45:17.285 is futile.

NOTE Confidence: 0.99802226

00:45:17.585 --> 00:45:18.805 Sixty percent agreed.

NOTE Confidence: 0.9886414

00:45:19.664 --> 00:45:21.664 Trisomy eighteen is compatible with

NOTE Confidence: 0.9886414

00:45:21.664 --> 00:45:23.045 a child having a meaningful

NOTE Confidence: 0.9886414

00:45:23.105 --> 00:45:25.525 life. Sixty six percent disagreed.

NOTE Confidence: 0.9904397

00:45:26.464 --> 00:45:26.964 So,

NOTE Confidence: 0.9995599

00:45:27.640 --> 00:45:29.239 you know, these are these

NOTE Confidence: 0.9995599

00:45:29.239 --> 00:45:30.460 are the attitudes

NOTE Confidence: 0.99995136

00:45:30.840 --> 00:45:31.340 that

NOTE Confidence: 0.98416346

00:45:32.040 --> 00:45:33.800 might be behind some of

NOTE Confidence: 0.98416346

00:45:33.800 --> 00:45:36.060 the counseling that families are,

NOTE Confidence: 0.9925767

00:45:36.760 --> 00:45:37.260 receiving.

NOTE Confidence: 0.9064739

00:45:37.880 --> 00:45:38.380 When,

NOTE Confidence: 0.93330806

00:45:40.215 --> 00:45:41.655 Fruman et al, did a
NOTE Confidence: 0.93330806

00:45:41.655 --> 00:45:42.715 survey of obstetricians,
NOTE Confidence: 0.9964455

00:45:43.095 --> 00:45:44.455 and seventy five percent of
NOTE Confidence: 0.9964455

00:45:44.455 --> 00:45:45.995 those obstetricians considered
NOTE Confidence: 0.9995875

00:45:46.295 --> 00:45:47.675 cardiac surgery unethical
NOTE Confidence: 0.9661503

00:45:48.535 --> 00:45:50.215 in trisomy thirteen eighteen. So
NOTE Confidence: 0.9661503

00:45:50.215 --> 00:45:50.955 not just
NOTE Confidence: 0.98475784

00:45:51.335 --> 00:45:53.095 but literally, like, it's not
NOTE Confidence: 0.98475784

00:45:53.095 --> 00:45:54.695 ethical to be to be
NOTE Confidence: 0.98475784

00:45:54.695 --> 00:45:55.820 doing cardiac
NOTE Confidence: 0.9711349

00:45:57.719 --> 00:45:58.460 surgery. So
NOTE Confidence: 0.97374

00:45:58.840 --> 00:46:00.520 when different views regarding quality
NOTE Confidence: 0.97374

00:46:00.520 --> 00:46:02.360 of life impact counseling, then
NOTE Confidence: 0.97374

00:46:02.360 --> 00:46:04.440 these biases may translate into
NOTE Confidence: 0.97374

00:46:04.440 --> 00:46:06.520 limiting possible available medical and
NOTE Confidence: 0.97374

00:46:06.520 --> 00:46:07.500 procedural options.

NOTE Confidence: 0.9788613
00:46:07.800 --> 00:46:08.760 And I think that this
NOTE Confidence: 0.9788613
00:46:08.760 --> 00:46:09.500 was best,
NOTE Confidence: 0.9753318
00:46:10.325 --> 00:46:11.765 was kind of first expressed
NOTE Confidence: 0.9753318
00:46:11.765 --> 00:46:13.365 by Duff and Campbell in
NOTE Confidence: 0.9753318
00:46:13.365 --> 00:46:15.045 nineteen seventy three when they
NOTE Confidence: 0.9753318
00:46:15.045 --> 00:46:15.545 reported,
NOTE Confidence: 0.98291373
00:46:16.165 --> 00:46:17.605 that fourteen percent of the
NOTE Confidence: 0.98291373
00:46:17.605 --> 00:46:19.205 deaths that happened in Yale
NOTE Confidence: 0.98291373
00:46:19.205 --> 00:46:20.265 Special Care Nursery
NOTE Confidence: 0.99693567
00:46:20.565 --> 00:46:22.260 were due to withholding treatment
NOTE Confidence: 0.9988322
00:46:23.060 --> 00:46:24.200 for defective infants
NOTE Confidence: 0.99390423
00:46:24.500 --> 00:46:25.780 who had little or no
NOTE Confidence: 0.99390423
00:46:25.780 --> 00:46:27.640 hope of achieving meaningful
NOTE Confidence: 0.99131536
00:46:28.180 --> 00:46:28.680 humanhood.
NOTE Confidence: 0.9712702
00:46:29.460 --> 00:46:30.500 Well, there's a lot of
NOTE Confidence: 0.9712702

00:46:30.500 --> 00:46:32.280 heavy language in there about,
NOTE Confidence: 0.9985116

00:46:33.140 --> 00:46:33.960 sort of
NOTE Confidence: 0.99664557

00:46:35.075 --> 00:46:35.734 the determination,
NOTE Confidence: 0.9842594

00:46:36.114 --> 00:46:37.494 I guess, of those children.
NOTE Confidence: 0.9082588

00:46:39.075 --> 00:46:40.275 And so and I and
NOTE Confidence: 0.9082588

00:46:40.275 --> 00:46:41.875 that's reflected in the language
NOTE Confidence: 0.9082588

00:46:41.875 --> 00:46:43.315 that's used to counsel families.
NOTE Confidence: 0.9082588

00:46:43.315 --> 00:46:44.674 So Sean Vietle on that
NOTE Confidence: 0.9082588

00:46:44.674 --> 00:46:45.414 same survey,
NOTE Confidence: 0.98131174

00:46:45.875 --> 00:46:47.075 she characterized some of the
NOTE Confidence: 0.98131174

00:46:47.075 --> 00:46:48.420 language that's used in counseling.
NOTE Confidence: 0.98131174

00:46:48.420 --> 00:46:50.200 So eighty seven percent incompatible
NOTE Confidence: 0.98131174

00:46:50.260 --> 00:46:51.800 with life, fifty seven percent
NOTE Confidence: 0.98131174

00:46:51.940 --> 00:46:53.079 live a life of suffering,
NOTE Confidence: 0.98131174

00:46:53.140 --> 00:46:54.180 fifty percent would be a
NOTE Confidence: 0.98131174

00:46:54.180 --> 00:46:54.680 vegetable,

NOTE Confidence: 0.9998386
00:46:55.140 --> 00:46:55.880 fifty percent
NOTE Confidence: 0.97173667
00:46:56.180 --> 00:46:57.540 meaningless life. So these are
NOTE Confidence: 0.97173667
00:46:57.540 --> 00:46:58.660 the you know, how often
NOTE Confidence: 0.97173667
00:46:58.660 --> 00:46:59.540 these come out. Twenty three
NOTE Confidence: 0.97173667
00:46:59.540 --> 00:47:00.820 percent ruin a marriage, twenty
NOTE Confidence: 0.97173667
00:47:00.820 --> 00:47:02.200 three percent ruin a family.
NOTE Confidence: 0.96366805
00:47:04.395 --> 00:47:06.335 This sort of language
NOTE Confidence: 0.86292386
00:47:09.995 --> 00:47:10.895 is is problematic
NOTE Confidence: 0.93565434
00:47:11.195 --> 00:47:11.695 because,
NOTE Confidence: 0.9992768
00:47:12.235 --> 00:47:13.375 again, it is
NOTE Confidence: 0.99843484
00:47:13.675 --> 00:47:14.335 it is
NOTE Confidence: 0.9958034
00:47:15.290 --> 00:47:16.830 influencing the kind of,
NOTE Confidence: 0.91915846
00:47:17.770 --> 00:47:18.910 I guess, unbiased
NOTE Confidence: 0.9988008
00:47:19.210 --> 00:47:20.489 recommendations that we should be
NOTE Confidence: 0.9988008
00:47:20.489 --> 00:47:20.989 providing.
NOTE Confidence: 0.93608606

00:47:21.770 --> 00:47:24.270 So Kugler, Wilfond, and Ross,
NOTE Confidence: 0.83596736

00:47:24.730 --> 00:47:26.010 in the in the Hastings
NOTE Confidence: 0.83596736

00:47:26.010 --> 00:47:27.705 Center report called lethal language,
NOTE Confidence: 0.83596736

00:47:27.705 --> 00:47:28.605 lethal decisions,
NOTE Confidence: 0.96620876

00:47:28.985 --> 00:47:30.925 wrote, quality of life judgments
NOTE Confidence: 0.96620876

00:47:30.985 --> 00:47:32.425 are embedded in the decision
NOTE Confidence: 0.96620876

00:47:32.425 --> 00:47:34.125 to withhold treatment and thereby
NOTE Confidence: 0.96620876

00:47:34.185 --> 00:47:35.805 interfere with the parent's authority
NOTE Confidence: 0.999246

00:47:36.265 --> 00:47:37.625 to define what is best
NOTE Confidence: 0.999246

00:47:37.625 --> 00:47:38.525 for their child.
NOTE Confidence: 0.9739496

00:47:42.680 --> 00:47:43.960 So I'm gonna return back
NOTE Confidence: 0.9739496

00:47:43.960 --> 00:47:45.160 to my survey. I think
NOTE Confidence: 0.9739496

00:47:45.160 --> 00:47:46.120 this is gonna be the
NOTE Confidence: 0.9739496

00:47:46.120 --> 00:47:46.620 last,
NOTE Confidence: 0.9851928

00:47:47.240 --> 00:47:48.600 the last kind of table
NOTE Confidence: 0.9851928

00:47:48.600 --> 00:47:49.960 that I'll bring up. But

NOTE Confidence: 0.9851928

00:47:49.960 --> 00:47:52.060 we wanted to understand, again,

NOTE Confidence: 0.9851928

00:47:52.120 --> 00:47:53.420 what were some of the

NOTE Confidence: 0.9413491

00:47:53.880 --> 00:47:55.720 factors that maybe influenced folks

NOTE Confidence: 0.9413491

00:47:55.720 --> 00:47:57.180 when they were providing prenatal

NOTE Confidence: 0.9413491

00:47:57.240 --> 00:47:57.740 counseling?

NOTE Confidence: 0.942535

00:47:58.805 --> 00:48:00.724 And so, specifically, whether or

NOTE Confidence: 0.942535

00:48:00.724 --> 00:48:01.684 not they would talk about

NOTE Confidence: 0.942535

00:48:01.684 --> 00:48:02.664 surgery. So

NOTE Confidence: 0.9281848

00:48:02.964 --> 00:48:04.085 it's a little confusing here,

NOTE Confidence: 0.9281848

00:48:04.085 --> 00:48:05.204 but you got least important

NOTE Confidence: 0.9281848

00:48:05.204 --> 00:48:06.085 on the top and most

NOTE Confidence: 0.9281848

00:48:06.085 --> 00:48:07.204 important on the bottom. That

NOTE Confidence: 0.9281848

00:48:07.204 --> 00:48:08.565 was simply because most important,

NOTE Confidence: 0.9281848

00:48:08.565 --> 00:48:09.969 we said, was one. At

NOTE Confidence: 0.9281848

00:48:09.969 --> 00:48:11.010 least important is five. So,

NOTE Confidence: 0.9281848

00:48:11.010 --> 00:48:11.730 again, that looks sort of
NOTE Confidence: 0.9281848

00:48:11.730 --> 00:48:12.630 Likert scale.
NOTE Confidence: 0.9795503

00:48:13.410 --> 00:48:14.690 And we asked them, you
NOTE Confidence: 0.9795503

00:48:14.690 --> 00:48:16.050 know, how do these factors
NOTE Confidence: 0.9795503

00:48:16.050 --> 00:48:17.430 measure up in terms of,
NOTE Confidence: 0.9795503

00:48:17.730 --> 00:48:18.930 their impact when you provide
NOTE Confidence: 0.9795503

00:48:18.930 --> 00:48:19.830 prenatal counseling?
NOTE Confidence: 0.976991

00:48:20.290 --> 00:48:21.570 And you can see here
NOTE Confidence: 0.976991

00:48:21.570 --> 00:48:22.530 that one of those was
NOTE Confidence: 0.976991

00:48:22.530 --> 00:48:24.344 quality of life. It actually
NOTE Confidence: 0.976991

00:48:24.405 --> 00:48:25.525 was one of the most
NOTE Confidence: 0.976991

00:48:25.525 --> 00:48:27.605 important factors when counseling for
NOTE Confidence: 0.976991

00:48:27.605 --> 00:48:29.205 trisomy twenty one, but one
NOTE Confidence: 0.976991

00:48:29.205 --> 00:48:30.325 of the least important for
NOTE Confidence: 0.976991

00:48:30.325 --> 00:48:32.245 trisomy eighteen. Well, that doesn't
NOTE Confidence: 0.976991

00:48:32.245 --> 00:48:33.445 make sense. I feel like

NOTE Confidence: 0.976991

00:48:33.445 --> 00:48:34.805 we've kind of been you

NOTE Confidence: 0.976991

00:48:34.805 --> 00:48:35.305 know,

NOTE Confidence: 0.9799222

00:48:36.260 --> 00:48:37.780 I've been emphasizing that I

NOTE Confidence: 0.9799222

00:48:37.780 --> 00:48:38.980 think quality of life,

NOTE Confidence: 0.9748165

00:48:39.380 --> 00:48:40.820 you know, calculations on quality

NOTE Confidence: 0.9748165

00:48:40.820 --> 00:48:42.200 of life are impacting counseling.

NOTE Confidence: 0.9814911

00:48:43.460 --> 00:48:44.579 However, when you look at

NOTE Confidence: 0.9814911

00:48:44.579 --> 00:48:46.420 genetic diagnosis, so simply the

NOTE Confidence: 0.9814911

00:48:46.420 --> 00:48:48.339 genetic diagnosis of having trisomy

NOTE Confidence: 0.9814911

00:48:48.339 --> 00:48:49.859 eighteen versus having trisomy twenty

NOTE Confidence: 0.9814911

00:48:49.859 --> 00:48:50.359 one,

NOTE Confidence: 0.99035656

00:48:50.864 --> 00:48:52.065 that was one of the

NOTE Confidence: 0.99035656

00:48:52.065 --> 00:48:54.145 most impactful things for trisomy

NOTE Confidence: 0.99035656

00:48:54.145 --> 00:48:55.985 eighteen and trisomy twenty one.

NOTE Confidence: 0.99035656

00:48:55.985 --> 00:48:57.825 So perhaps, you know, what

NOTE Confidence: 0.99035656

00:48:57.825 --> 00:48:58.225 this,
NOTE Confidence: 0.9979961

00:48:58.625 --> 00:49:00.385 what this this graph is
NOTE Confidence: 0.9979961

00:49:00.385 --> 00:49:00.885 inferring
NOTE Confidence: 0.9945398

00:49:01.425 --> 00:49:02.165 is that,
NOTE Confidence: 0.98681265

00:49:02.989 --> 00:49:04.510 you know, the cardiologists are
NOTE Confidence: 0.98681265

00:49:04.510 --> 00:49:05.469 trying to stay away from
NOTE Confidence: 0.98681265

00:49:05.469 --> 00:49:06.849 the quality of life bias,
NOTE Confidence: 0.92567396

00:49:07.309 --> 00:49:08.190 but I think that there
NOTE Confidence: 0.92567396

00:49:08.270 --> 00:49:09.869 it's just masked in sort
NOTE Confidence: 0.92567396

00:49:09.869 --> 00:49:11.150 of an inherent bias that
NOTE Confidence: 0.92567396

00:49:11.150 --> 00:49:12.670 is nested within a genetic
NOTE Confidence: 0.92567396

00:49:12.670 --> 00:49:13.170 diagnosis.
NOTE Confidence: 0.99694705

00:49:14.030 --> 00:49:15.789 And one respondent had this
NOTE Confidence: 0.99694705

00:49:15.789 --> 00:49:16.989 to say, which I thought
NOTE Confidence: 0.99694705

00:49:16.989 --> 00:49:17.890 was very telling.
NOTE Confidence: 0.9174768

00:49:18.435 --> 00:49:18.915 So,

NOTE Confidence: 0.9766439

00:49:19.235 --> 00:49:20.835 this person wrote, I personally

NOTE Confidence: 0.9766439

00:49:20.835 --> 00:49:22.855 am agnostic about repairing trisomy

NOTE Confidence: 0.9766439

00:49:22.995 --> 00:49:24.675 eighteen. I have had patients

NOTE Confidence: 0.9766439

00:49:24.675 --> 00:49:26.195 do well after surgery, but

NOTE Confidence: 0.9766439

00:49:26.195 --> 00:49:27.235 the quality of life is

NOTE Confidence: 0.9766439

00:49:27.235 --> 00:49:28.355 horrible for the child and

NOTE Confidence: 0.9766439

00:49:28.355 --> 00:49:30.035 the family. Regardless of the

NOTE Confidence: 0.9766439

00:49:30.035 --> 00:49:31.955 surgical alpha excuse me. Regardless

NOTE Confidence: 0.9766439

00:49:31.955 --> 00:49:33.175 of the surgical outcome,

NOTE Confidence: 0.9974971

00:49:33.475 --> 00:49:34.770 I think quality of life

NOTE Confidence: 0.9974971

00:49:34.770 --> 00:49:36.370 should matter more than whether

NOTE Confidence: 0.9974971

00:49:36.370 --> 00:49:37.330 or not we can close

NOTE Confidence: 0.9974971

00:49:37.330 --> 00:49:37.910 a hole.

NOTE Confidence: 0.9927684

00:49:39.250 --> 00:49:39.750 So,

NOTE Confidence: 0.97832495

00:49:41.410 --> 00:49:42.610 how do we communicate with

NOTE Confidence: 0.97832495

00:49:42.610 --> 00:49:43.330 each other? I don't know

NOTE Confidence: 0.97832495

00:49:43.330 --> 00:49:44.050 if any of you are

NOTE Confidence: 0.97832495

00:49:44.050 --> 00:49:45.410 familiar with this painting, this

NOTE Confidence: 0.97832495

00:49:45.410 --> 00:49:46.610 fresco, I should say. This

NOTE Confidence: 0.97832495

00:49:46.610 --> 00:49:47.270 is Raphael's

NOTE Confidence: 0.8991509

00:49:47.890 --> 00:49:48.930 fresco of,

NOTE Confidence: 0.8958035

00:49:49.704 --> 00:49:50.825 School of Athens. And so

NOTE Confidence: 0.8958035

00:49:50.825 --> 00:49:52.105 you got all these famous

NOTE Confidence: 0.8958035

00:49:52.105 --> 00:49:54.364 thinkers and got Plato and,

NOTE Confidence: 0.8883358

00:49:55.305 --> 00:49:57.244 Socrates and or sorry, Aristotle

NOTE Confidence: 0.9305265

00:49:57.545 --> 00:49:58.424 and you know, so all

NOTE Confidence: 0.9305265

00:49:58.424 --> 00:49:59.944 these smart people. Everybody's got

NOTE Confidence: 0.9305265

00:49:59.944 --> 00:50:01.545 an idea about how things

NOTE Confidence: 0.9305265

00:50:01.545 --> 00:50:02.960 should be. And yet the

NOTE Confidence: 0.9305265

00:50:02.960 --> 00:50:04.579 painting, everything so, like, beautifully

NOTE Confidence: 0.9305265

00:50:04.640 --> 00:50:05.140 coexists.

NOTE Confidence: 0.8853386

00:50:06.319 --> 00:50:08.020 You got Raphael over here,

NOTE Confidence: 0.98403937

00:50:08.400 --> 00:50:09.359 you know, just kind of

NOTE Confidence: 0.98403937

00:50:09.359 --> 00:50:10.400 looking off into the distance.

NOTE Confidence: 0.98403937

00:50:10.400 --> 00:50:11.200 I feel like maybe this

NOTE Confidence: 0.98403937

00:50:11.200 --> 00:50:12.160 is, like, the parent in

NOTE Confidence: 0.98403937

00:50:12.160 --> 00:50:12.900 our situation.

NOTE Confidence: 0.96670735

00:50:13.680 --> 00:50:14.980 So I'm gonna suggest,

NOTE Confidence: 0.98437846

00:50:15.815 --> 00:50:16.935 that we can work with

NOTE Confidence: 0.98437846

00:50:16.935 --> 00:50:18.935 our patients, employing shared decision

NOTE Confidence: 0.98437846

00:50:18.935 --> 00:50:20.055 making to arrive at goals

NOTE Confidence: 0.98437846

00:50:20.055 --> 00:50:21.735 of care that both respect

NOTE Confidence: 0.98437846

00:50:21.735 --> 00:50:23.575 parental values and also can

NOTE Confidence: 0.98437846

00:50:23.575 --> 00:50:25.355 address medically feasible options.

NOTE Confidence: 0.99884903

00:50:26.215 --> 00:50:26.715 So

NOTE Confidence: 0.96537817

00:50:27.015 --> 00:50:27.815 how do we do this?

NOTE Confidence: 0.96537817

00:50:27.815 --> 00:50:28.695 I think first, we need
NOTE Confidence: 0.96537817

00:50:28.695 --> 00:50:30.570 to acknowledge that parents and
NOTE Confidence: 0.96537817

00:50:30.570 --> 00:50:32.410 family excuse me. Parents and
NOTE Confidence: 0.96537817

00:50:32.410 --> 00:50:34.890 families make variable decisions when
NOTE Confidence: 0.96537817

00:50:34.890 --> 00:50:36.750 they're confronted with this situation.
NOTE Confidence: 0.9630898

00:50:37.130 --> 00:50:39.050 But not everybody is it's
NOTE Confidence: 0.9630898

00:50:39.050 --> 00:50:40.650 not that everybody is seeking
NOTE Confidence: 0.9630898

00:50:40.650 --> 00:50:42.330 intervention or that nobody's seeking
NOTE Confidence: 0.9630898

00:50:42.330 --> 00:50:43.755 intervention. Parents make
NOTE Confidence: 0.95538545

00:50:44.154 --> 00:50:45.295 a variety of choices,
NOTE Confidence: 0.9980421

00:50:46.075 --> 00:50:47.194 and I think that's best
NOTE Confidence: 0.9980421

00:50:47.194 --> 00:50:49.055 exemplified by this article.
NOTE Confidence: 0.9625743

00:50:49.755 --> 00:50:50.714 So this is an article
NOTE Confidence: 0.9625743

00:50:50.714 --> 00:50:52.714 that was published, in response
NOTE Confidence: 0.9625743

00:50:52.714 --> 00:50:54.954 to the highly publicized case
NOTE Confidence: 0.9625743

00:50:54.954 --> 00:50:55.800 of Kate Cox

NOTE Confidence: 0.9839848

00:50:56.280 --> 00:50:57.420 who filed a lawsuit,

NOTE Confidence: 0.9736048

00:50:57.880 --> 00:50:59.100 against the state of Texas

NOTE Confidence: 0.9717823

00:50:59.400 --> 00:51:00.680 where she was prevented from

NOTE Confidence: 0.9717823

00:51:00.680 --> 00:51:02.360 terminating her pregnancy after she

NOTE Confidence: 0.9717823

00:51:02.360 --> 00:51:03.560 learned that her fetus had

NOTE Confidence: 0.9717823

00:51:03.560 --> 00:51:04.540 trisomy eighteen.

NOTE Confidence: 0.88492006

00:51:05.239 --> 00:51:06.140 And the article,

NOTE Confidence: 0.9968509

00:51:06.600 --> 00:51:08.200 tells the story of two

NOTE Confidence: 0.9968509

00:51:08.200 --> 00:51:08.700 families.

NOTE Confidence: 0.9053017

00:51:09.080 --> 00:51:11.020 The first family pictured here,

NOTE Confidence: 0.9769848

00:51:11.565 --> 00:51:13.025 is a family that chose,

NOTE Confidence: 0.9544653

00:51:13.325 --> 00:51:15.005 you know, all the all

NOTE Confidence: 0.9544653

00:51:15.005 --> 00:51:16.145 the possible interventions.

NOTE Confidence: 0.978919

00:51:17.724 --> 00:51:19.185 And the second family,

NOTE Confidence: 0.91414165

00:51:19.724 --> 00:51:20.925 did not, and they chose

NOTE Confidence: 0.91414165

00:51:20.925 --> 00:51:22.364 comfort care. And their child
NOTE Confidence: 0.91414165

00:51:22.364 --> 00:51:23.580 lived for twenty nine days.
NOTE Confidence: 0.99153936

00:51:24.460 --> 00:51:25.900 Days. And both families were
NOTE Confidence: 0.99153936

00:51:25.900 --> 00:51:27.420 aware of the various options
NOTE Confidence: 0.99153936

00:51:27.420 --> 00:51:28.780 available to them, and they
NOTE Confidence: 0.99153936

00:51:28.780 --> 00:51:29.900 made the choice that was
NOTE Confidence: 0.99153936

00:51:29.900 --> 00:51:30.800 right for them.
NOTE Confidence: 0.98161125

00:51:31.500 --> 00:51:33.020 So the fact that,
NOTE Confidence: 0.9924623

00:51:34.380 --> 00:51:35.500 the fact that parents make
NOTE Confidence: 0.9924623

00:51:35.500 --> 00:51:37.255 variable decisions means that they
NOTE Confidence: 0.9924623

00:51:37.255 --> 00:51:38.935 also have variable feelings about
NOTE Confidence: 0.9924623

00:51:38.935 --> 00:51:40.395 trisomy eighteen and thirteen.
NOTE Confidence: 0.9758519

00:51:41.015 --> 00:51:43.255 In that same, report by,
NOTE Confidence: 0.95121443

00:51:44.135 --> 00:51:45.735 Coogler, Wilfon, and Ross, the
NOTE Confidence: 0.95121443

00:51:45.735 --> 00:51:47.815 Hastings Center report, they argue
NOTE Confidence: 0.95121443

00:51:47.815 --> 00:51:49.175 that in cases of severe

NOTE Confidence: 0.95121443

00:51:49.175 --> 00:51:49.675 neurological

NOTE Confidence: 0.92790574

00:51:49.975 --> 00:51:51.950 impairment, there's an ambiguity,

NOTE Confidence: 0.86089146

00:51:53.210 --> 00:51:53.690 about,

NOTE Confidence: 0.98653275

00:51:54.170 --> 00:51:55.790 whether treatment should be required

NOTE Confidence: 0.98653275

00:51:56.010 --> 00:51:57.850 or prohibited. And so parental

NOTE Confidence: 0.98653275

00:51:57.850 --> 00:51:58.350 decisions

NOTE Confidence: 0.99910915

00:51:58.810 --> 00:52:00.010 should be based on their

NOTE Confidence: 0.99910915

00:52:00.010 --> 00:52:02.670 calculation of benefit versus burden.

NOTE Confidence: 0.8705969

00:52:03.935 --> 00:52:05.155 So in these cases,

NOTE Confidence: 0.9993868

00:52:05.614 --> 00:52:07.395 parental preference should be honored

NOTE Confidence: 0.9760309

00:52:07.695 --> 00:52:08.735 as they have, like, the

NOTE Confidence: 0.9760309

00:52:08.735 --> 00:52:09.635 moral authority

NOTE Confidence: 0.99808496

00:52:09.935 --> 00:52:11.295 to either request or deny

NOTE Confidence: 0.99808496

00:52:11.295 --> 00:52:12.195 medical intervention.

NOTE Confidence: 0.9805806

00:52:12.895 --> 00:52:13.935 And as this New York

NOTE Confidence: 0.9805806

00:52:13.935 --> 00:52:16.094 Times story highlights, parents make

NOTE Confidence: 0.9805806

00:52:16.094 --> 00:52:17.695 different decisions, which are all

NOTE Confidence: 0.9805806

00:52:17.695 --> 00:52:18.195 morally

NOTE Confidence: 0.9952716

00:52:21.370 --> 00:52:23.310 permissible. Shared decision making

NOTE Confidence: 0.9995497

00:52:23.850 --> 00:52:24.750 can be facilitated

NOTE Confidence: 0.9831473

00:52:25.050 --> 00:52:26.810 by seeking out parental values

NOTE Confidence: 0.9831473

00:52:26.810 --> 00:52:28.650 and goals and aligning those

NOTE Confidence: 0.9831473

00:52:28.650 --> 00:52:30.330 goals with medical feasible with

NOTE Confidence: 0.9831473

00:52:30.330 --> 00:52:32.110 medically feasible options.

NOTE Confidence: 0.97129875

00:52:33.025 --> 00:52:34.065 So in a review of

NOTE Confidence: 0.97129875

00:52:34.065 --> 00:52:35.744 patient centered care, Hogg et

NOTE Confidence: 0.97129875

00:52:35.744 --> 00:52:37.525 al. Highlighted four key principles.

NOTE Confidence: 0.97129875

00:52:37.744 --> 00:52:38.785 I'm gonna focus on the

NOTE Confidence: 0.97129875

00:52:38.785 --> 00:52:40.565 first one, dignity and respect.

NOTE Confidence: 0.96263444

00:52:41.105 --> 00:52:42.864 The principles of dignity and

NOTE Confidence: 0.96263444

00:52:42.864 --> 00:52:45.105 respect remind us that value

NOTE Confidence: 0.96263444

00:52:45.105 --> 00:52:47.105 judgments regarding disability and quality

NOTE Confidence: 0.96263444

00:52:47.105 --> 00:52:48.660 of life are best made

NOTE Confidence: 0.96263444

00:52:48.660 --> 00:52:49.400 by parents.

NOTE Confidence: 0.99643975

00:52:50.099 --> 00:52:50.599 And

NOTE Confidence: 0.9996355

00:52:51.460 --> 00:52:53.540 we can only learn about

NOTE Confidence: 0.9996355

00:52:53.540 --> 00:52:54.359 what their

NOTE Confidence: 0.9915982

00:52:54.660 --> 00:52:56.260 goals and values are by

NOTE Confidence: 0.9915982

00:52:56.260 --> 00:52:57.719 talking with them, by communicating

NOTE Confidence: 0.9915982

00:52:57.859 --> 00:52:59.460 with them. So here's where

NOTE Confidence: 0.9915982

00:52:59.460 --> 00:53:01.540 I find my perinatal palliative

NOTE Confidence: 0.9915982

00:53:01.540 --> 00:53:03.015 care colleagues to be incredibly

NOTE Confidence: 0.9915982

00:53:03.015 --> 00:53:03.515 helpful,

NOTE Confidence: 0.99236554

00:53:04.694 --> 00:53:05.974 because they sit and they

NOTE Confidence: 0.99236554

00:53:05.974 --> 00:53:07.335 spend the time with families

NOTE Confidence: 0.99236554

00:53:07.335 --> 00:53:08.795 to kind of suss out,

NOTE Confidence: 0.99236554

00:53:08.934 --> 00:53:10.155 you know, what
NOTE Confidence: 0.9996511

00:53:10.694 --> 00:53:12.315 suffering looks like to them
NOTE Confidence: 0.92216194

00:53:12.694 --> 00:53:13.734 and and to kind of
NOTE Confidence: 0.92216194

00:53:13.734 --> 00:53:14.635 help align
NOTE Confidence: 0.9992933

00:53:15.015 --> 00:53:16.820 what is what is possible
NOTE Confidence: 0.99422294

00:53:17.440 --> 00:53:18.900 with what they may want.
NOTE Confidence: 0.9790544

00:53:23.040 --> 00:53:25.040 So and and I think
NOTE Confidence: 0.9790544

00:53:25.040 --> 00:53:26.560 that, you know, in this
NOTE Confidence: 0.9790544

00:53:26.560 --> 00:53:27.920 sort of shared decision making
NOTE Confidence: 0.9790544

00:53:27.920 --> 00:53:29.360 model, we have to work
NOTE Confidence: 0.9790544

00:53:29.360 --> 00:53:29.860 with,
NOTE Confidence: 0.99902546

00:53:30.185 --> 00:53:31.725 you know, multiple colleagues.
NOTE Confidence: 0.9944254

00:53:32.585 --> 00:53:34.505 So one of two more,
NOTE Confidence: 0.9992287

00:53:34.905 --> 00:53:35.405 guidelines
NOTE Confidence: 0.9810609

00:53:35.705 --> 00:53:37.005 that or two more recommendations
NOTE Confidence: 0.9810609

00:53:37.225 --> 00:53:38.285 that this guideline,

NOTE Confidence: 0.9947752

00:53:38.665 --> 00:53:40.445 paper recommended was that

NOTE Confidence: 0.98916286

00:53:40.825 --> 00:53:42.344 management of children with trisomy

NOTE Confidence: 0.98916286

00:53:42.344 --> 00:53:44.190 thirteen eighteen requires multidisciplinary

NOTE Confidence: 0.91014975

00:53:44.810 --> 00:53:46.989 teams, including palliative care,

NOTE Confidence: 0.9956543

00:53:47.690 --> 00:53:49.050 are recommended as a component

NOTE Confidence: 0.9956543

00:53:49.050 --> 00:53:50.650 of an overall comprehensive care

NOTE Confidence: 0.9956543

00:53:50.650 --> 00:53:52.430 plan to enhance decision making.

NOTE Confidence: 0.99277675

00:53:53.290 --> 00:53:53.770 And,

NOTE Confidence: 0.9741945

00:53:54.090 --> 00:53:55.930 and finally, the parents who

NOTE Confidence: 0.9741945

00:53:55.930 --> 00:53:57.210 are carrying a child with

NOTE Confidence: 0.9741945

00:53:57.210 --> 00:53:58.670 trisomy thirteen eighteen,

NOTE Confidence: 0.9486898

00:53:59.735 --> 00:54:01.655 should be referred to a,

NOTE Confidence: 0.94241536

00:54:02.055 --> 00:54:03.735 center that that can help

NOTE Confidence: 0.94241536

00:54:03.735 --> 00:54:04.935 them to develop this plan.

NOTE Confidence: 0.94241536

00:54:04.935 --> 00:54:06.135 So that has access to

NOTE Confidence: 0.94241536

00:54:06.135 --> 00:54:07.594 maternal fetal medicine, neonatology,

NOTE Confidence: 0.99649954

00:54:07.895 --> 00:54:08.395 genetics,

NOTE Confidence: 0.9678601

00:54:09.175 --> 00:54:10.855 etcetera. So here at Yale,

NOTE Confidence: 0.9678601

00:54:10.855 --> 00:54:11.895 we have the fetal care

NOTE Confidence: 0.9678601

00:54:11.895 --> 00:54:13.495 center. We have a model

NOTE Confidence: 0.9678601

00:54:13.495 --> 00:54:15.230 for this where, you know,

NOTE Confidence: 0.9678601

00:54:15.230 --> 00:54:17.270 you know, parents can meet

NOTE Confidence: 0.9678601

00:54:17.270 --> 00:54:18.330 with various subspecialties

NOTE Confidence: 0.96825516

00:54:18.630 --> 00:54:20.410 and sort of start to,

NOTE Confidence: 0.9915227

00:54:21.430 --> 00:54:22.950 identify what are their values

NOTE Confidence: 0.9915227

00:54:22.950 --> 00:54:23.910 and goals and how to

NOTE Confidence: 0.9915227

00:54:23.910 --> 00:54:25.210 best represent them.

NOTE Confidence: 0.9196717

00:54:26.870 --> 00:54:28.035 One respond and wrote, it

NOTE Confidence: 0.9196717

00:54:28.035 --> 00:54:29.155 has been beneficial to have

NOTE Confidence: 0.9196717

00:54:29.155 --> 00:54:29.815 a multidisciplinary

NOTE Confidence: 0.9943494

00:54:30.194 --> 00:54:31.635 team involved with these patients

NOTE Confidence: 0.9943494

00:54:31.635 --> 00:54:32.994 and give families the space

NOTE Confidence: 0.9943494

00:54:32.994 --> 00:54:34.355 to explore options for their

NOTE Confidence: 0.9943494

00:54:34.355 --> 00:54:36.194 child, whether it be comfort

NOTE Confidence: 0.9943494

00:54:36.194 --> 00:54:37.494 care or medical intervention.

NOTE Confidence: 0.9782494

00:54:38.035 --> 00:54:39.734 Each family has a dedicated

NOTE Confidence: 0.9782494

00:54:39.875 --> 00:54:41.700 team member that provides support

NOTE Confidence: 0.9782494

00:54:41.700 --> 00:54:43.320 for the family both prenatally

NOTE Confidence: 0.99184066

00:54:43.700 --> 00:54:45.320 and then during their hospital

NOTE Confidence: 0.99184066

00:54:45.380 --> 00:54:45.880 stay.

NOTE Confidence: 0.9654881

00:54:49.460 --> 00:54:51.400 The other the other principles

NOTE Confidence: 0.9654881

00:54:51.460 --> 00:54:52.739 that Hogg et al talked

NOTE Confidence: 0.9654881

00:54:52.739 --> 00:54:53.940 about was the the one

NOTE Confidence: 0.9654881

00:54:53.940 --> 00:54:55.300 of the principles was about

NOTE Confidence: 0.9654881

00:54:55.300 --> 00:54:55.800 basically

NOTE Confidence: 0.9968928

00:54:56.775 --> 00:54:57.674 sharing information.

NOTE Confidence: 0.99887556

00:54:58.055 --> 00:54:58.555 So
NOTE Confidence: 0.9984178

00:54:59.255 --> 00:55:00.934 the principle of justice implies
NOTE Confidence: 0.9984178

00:55:00.934 --> 00:55:02.694 that parents should be informed
NOTE Confidence: 0.9984178

00:55:02.694 --> 00:55:04.234 of all permissible options.
NOTE Confidence: 0.99654675

00:55:04.694 --> 00:55:07.035 It's unfair if cardiac surgery
NOTE Confidence: 0.99654675

00:55:07.174 --> 00:55:08.535 is only offered to those
NOTE Confidence: 0.99654675

00:55:08.535 --> 00:55:10.055 parents who are medically savvy
NOTE Confidence: 0.99654675

00:55:10.055 --> 00:55:11.494 enough to request or advocate
NOTE Confidence: 0.99654675

00:55:11.494 --> 00:55:12.155 for it.
NOTE Confidence: 0.9526118

00:55:13.710 --> 00:55:15.469 I'm gonna quote, Mark here,
NOTE Confidence: 0.9526118

00:55:15.469 --> 00:55:16.770 but he wrote, a willingness
NOTE Confidence: 0.9526118

00:55:16.830 --> 00:55:18.610 to perform surgery if requested,
NOTE Confidence: 0.9633853

00:55:19.230 --> 00:55:20.830 coupled with a reluctance to
NOTE Confidence: 0.9633853

00:55:20.830 --> 00:55:22.350 inform parents of the option
NOTE Confidence: 0.9633853

00:55:22.350 --> 00:55:24.190 is not ethically justifiable. So
NOTE Confidence: 0.9633853

00:55:24.190 --> 00:55:25.090 we can't just

NOTE Confidence: 0.98886657

00:55:25.550 --> 00:55:26.510 only offer it if the

NOTE Confidence: 0.98886657

00:55:26.510 --> 00:55:27.975 parent requests it, but then

NOTE Confidence: 0.98886657

00:55:28.135 --> 00:55:29.495 hide it from another family

NOTE Confidence: 0.98886657

00:55:29.495 --> 00:55:30.455 just because they don't know

NOTE Confidence: 0.98886657

00:55:30.455 --> 00:55:31.114 about it.

NOTE Confidence: 0.98902875

00:55:32.055 --> 00:55:33.255 And, you know, how is

NOTE Confidence: 0.98902875

00:55:33.255 --> 00:55:33.735 this kind of

NOTE Confidence: 0.9788442

00:55:34.855 --> 00:55:36.215 how is this sort of

NOTE Confidence: 0.9788442

00:55:36.215 --> 00:55:37.415 represented, I think, in the

NOTE Confidence: 0.9788442

00:55:37.415 --> 00:55:39.495 literature? So here's a study

NOTE Confidence: 0.9788442

00:55:39.495 --> 00:55:40.535 that looked at a Texas

NOTE Confidence: 0.9788442

00:55:40.535 --> 00:55:42.295 billing database that found Hispanic

NOTE Confidence: 0.9788442

00:55:42.295 --> 00:55:43.915 ethnicity and Medicaid insurance

NOTE Confidence: 0.91901225

00:55:48.910 --> 00:55:48.932 are less likely to have

NOTE Confidence: 0.91901225

00:55:48.932 --> 00:55:48.958 surgery. That same Phys database

NOTE Confidence: 0.91901225

00:55:48.958 --> 00:55:48.981 found a higher percentage of
NOTE Confidence: 0.91901225

00:55:48.981 --> 00:55:49.890 patients with private insurance.
NOTE Confidence: 0.9430681

00:55:50.270 --> 00:55:51.650 And then another survey,
NOTE Confidence: 0.81582034

00:55:52.190 --> 00:55:53.170 where again,
NOTE Confidence: 0.9108327

00:55:53.630 --> 00:55:55.969 various subspecialists were asked about
NOTE Confidence: 0.9108327

00:55:56.109 --> 00:55:57.890 a hypothetical cardiac intervention,
NOTE Confidence: 0.9184581

00:55:58.344 --> 00:55:59.965 cardiac intervention, excuse me,
NOTE Confidence: 0.9912751

00:56:00.505 --> 00:56:02.364 there was a threefold increase
NOTE Confidence: 0.9912751

00:56:02.585 --> 00:56:04.665 of recommending the surgery if
NOTE Confidence: 0.9912751

00:56:04.665 --> 00:56:06.125 the parents asked for it.
NOTE Confidence: 0.99794096

00:56:07.625 --> 00:56:08.125 So
NOTE Confidence: 0.9811675

00:56:08.825 --> 00:56:10.025 what how can we kind
NOTE Confidence: 0.9811675

00:56:10.025 --> 00:56:11.380 of think about, you know,
NOTE Confidence: 0.9811675

00:56:11.380 --> 00:56:13.880 this difficult question? Obviously, I've,
NOTE Confidence: 0.9811675

00:56:13.940 --> 00:56:15.540 you know, we've we've talked
NOTE Confidence: 0.9811675

00:56:15.540 --> 00:56:16.739 about how how tough it

NOTE Confidence: 0.9811675
00:56:16.739 --> 00:56:18.739 is. So this is a
NOTE Confidence: 0.9811675
00:56:18.739 --> 00:56:19.239 framework,
NOTE Confidence: 0.9390389
00:56:19.780 --> 00:56:20.280 that,
NOTE Confidence: 0.9627424
00:56:21.700 --> 00:56:22.980 Mark has talked about, and
NOTE Confidence: 0.9627424
00:56:22.980 --> 00:56:23.719 I I'm
NOTE Confidence: 0.94753504
00:56:24.455 --> 00:56:25.815 shamelessly borrowing it, but I
NOTE Confidence: 0.94753504
00:56:25.815 --> 00:56:27.335 think it's really important and
NOTE Confidence: 0.94753504
00:56:27.335 --> 00:56:28.455 really helpful in this situation.
NOTE Confidence: 0.94753504
00:56:28.455 --> 00:56:29.815 It's called the IPO decision
NOTE Confidence: 0.94753504
00:56:29.815 --> 00:56:30.315 framework.
NOTE Confidence: 0.90851504
00:56:30.695 --> 00:56:32.295 And IPO stands for I
NOTE Confidence: 0.90851504
00:56:32.295 --> 00:56:33.275 stands for impermissible,
NOTE Confidence: 0.9982035
00:56:33.735 --> 00:56:35.255 p stands for permissible, and
NOTE Confidence: 0.9982035
00:56:35.255 --> 00:56:36.475 o stands for obligatory.
NOTE Confidence: 0.9792468
00:56:37.015 --> 00:56:39.015 So ethically impermissible means it
NOTE Confidence: 0.9792468

00:56:39.015 --> 00:56:40.320 should never be done even
NOTE Confidence: 0.9792468

00:56:40.320 --> 00:56:40.980 if it's requested.
NOTE Confidence: 0.9917034

00:56:42.320 --> 00:56:42.820 Obligatory,
NOTE Confidence: 0.93387556

00:56:43.920 --> 00:56:45.200 means it should always be
NOTE Confidence: 0.93387556

00:56:45.200 --> 00:56:46.480 done even if there are
NOTE Confidence: 0.93387556

00:56:46.480 --> 00:56:48.340 objections. So for example, obligatory
NOTE Confidence: 0.93387556

00:56:48.400 --> 00:56:49.360 would be like if a
NOTE Confidence: 0.93387556

00:56:49.360 --> 00:56:50.580 child had an infection
NOTE Confidence: 0.94502515

00:56:50.880 --> 00:56:52.080 and the parents refused the
NOTE Confidence: 0.94502515

00:56:52.080 --> 00:56:53.280 antibiotics, but we know the
NOTE Confidence: 0.94502515

00:56:53.280 --> 00:56:54.480 antibiotics are gonna make the
NOTE Confidence: 0.94502515

00:56:54.480 --> 00:56:55.219 child better.
NOTE Confidence: 0.94307244

00:56:55.695 --> 00:56:56.735 We have to give the
NOTE Confidence: 0.94307244

00:56:56.735 --> 00:56:57.875 kid the antibiotics.
NOTE Confidence: 0.99097246

00:56:59.535 --> 00:57:00.735 And then there's this gray
NOTE Confidence: 0.99097246

00:57:00.735 --> 00:57:02.094 zone in the middle called

NOTE Confidence: 0.99097246

00:57:02.094 --> 00:57:02.594 permissible

NOTE Confidence: 0.5793406

00:57:03.135 --> 00:57:03.635 where

NOTE Confidence: 0.9757721

00:57:04.015 --> 00:57:05.855 it's not necessarily that we

NOTE Confidence: 0.9757721

00:57:05.855 --> 00:57:07.455 are recommending or saying that's

NOTE Confidence: 0.9757721

00:57:07.455 --> 00:57:07.955 advisable

NOTE Confidence: 0.9410403

00:57:08.495 --> 00:57:09.535 or we or we, you

NOTE Confidence: 0.9410403

00:57:09.535 --> 00:57:10.755 know, we don't recommend.

NOTE Confidence: 0.97326726

00:57:12.119 --> 00:57:14.280 There's some this area in

NOTE Confidence: 0.97326726

00:57:14.280 --> 00:57:14.859 the middle,

NOTE Confidence: 0.9735537

00:57:15.799 --> 00:57:17.559 allows for some judgment in

NOTE Confidence: 0.9735537

00:57:17.559 --> 00:57:19.260 recommendation, but not a limitation

NOTE Confidence: 0.9735537

00:57:19.319 --> 00:57:20.760 in choice. So, for example,

NOTE Confidence: 0.9735537

00:57:20.760 --> 00:57:21.799 when it comes to the

NOTE Confidence: 0.9735537

00:57:21.799 --> 00:57:23.720 question about cardiac surgery, if

NOTE Confidence: 0.9735537

00:57:23.720 --> 00:57:24.280 we go back to the

NOTE Confidence: 0.9735537

00:57:24.280 --> 00:57:25.020 first scenario,
NOTE Confidence: 0.97672117

00:57:26.555 --> 00:57:27.595 we we should ask them
NOTE Confidence: 0.97672117

00:57:27.595 --> 00:57:28.795 about their goals of care
NOTE Confidence: 0.97672117

00:57:28.795 --> 00:57:30.075 treatment and find out sort
NOTE Confidence: 0.97672117

00:57:30.075 --> 00:57:31.115 of, like, what is the
NOTE Confidence: 0.97672117

00:57:31.115 --> 00:57:32.655 goal? What is the outcome?
NOTE Confidence: 0.9991965

00:57:33.035 --> 00:57:33.775 And then
NOTE Confidence: 0.9409281

00:57:34.395 --> 00:57:35.515 if it's so, for example,
NOTE Confidence: 0.9409281

00:57:35.515 --> 00:57:36.415 if it's survival,
NOTE Confidence: 0.9962942

00:57:37.115 --> 00:57:38.795 well, you know, what are
NOTE Confidence: 0.9962942

00:57:38.795 --> 00:57:39.295 the
NOTE Confidence: 0.99409467

00:57:39.910 --> 00:57:41.530 what are the the choices
NOTE Confidence: 0.9729187

00:57:42.310 --> 00:57:43.930 that could achieve that goal?
NOTE Confidence: 0.9729187

00:57:43.990 --> 00:57:45.590 So, for example, with is
NOTE Confidence: 0.9729187

00:57:45.590 --> 00:57:47.430 cardiac surgery able to achieve
NOTE Confidence: 0.9729187

00:57:47.430 --> 00:57:48.870 that goal? Well, if it

NOTE Confidence: 0.9729187

00:57:48.870 --> 00:57:50.390 is, and that's the that's

NOTE Confidence: 0.9729187

00:57:50.390 --> 00:57:51.670 the outcome that we're looking

NOTE Confidence: 0.9729187

00:57:51.670 --> 00:57:53.690 for, then it's ethically permissible

NOTE Confidence: 0.9729187

00:57:53.750 --> 00:57:55.035 to offer cardiac surgery.

NOTE Confidence: 0.96152586

00:57:56.395 --> 00:57:57.755 And this is obviously gonna

NOTE Confidence: 0.96152586

00:57:57.755 --> 00:57:58.954 be dependent on a benefit

NOTE Confidence: 0.96152586

00:57:58.954 --> 00:58:00.635 and burn ratio relative to

NOTE Confidence: 0.96152586

00:58:00.635 --> 00:58:01.835 some of the valid concerns

NOTE Confidence: 0.96152586

00:58:01.835 --> 00:58:02.895 we brought up before.

NOTE Confidence: 0.9914142

00:58:03.674 --> 00:58:04.795 But parents should have a

NOTE Confidence: 0.9914142

00:58:04.795 --> 00:58:06.974 say in terms of deciding

NOTE Confidence: 0.9858742

00:58:07.515 --> 00:58:09.275 about burdensome options with respect

NOTE Confidence: 0.9858742

00:58:09.275 --> 00:58:10.255 to, like, tracheostomy

NOTE Confidence: 0.9642435

00:58:11.100 --> 00:58:12.160 or home ventilator.

NOTE Confidence: 0.9997969

00:58:13.100 --> 00:58:13.900 I don't think it should

NOTE Confidence: 0.9997969

00:58:13.900 --> 00:58:14.400 be
NOTE Confidence: 0.98449695

00:58:14.860 --> 00:58:15.360 the
NOTE Confidence: 0.99234253

00:58:15.980 --> 00:58:18.060 physician's decision necessarily to sort
NOTE Confidence: 0.99234253

00:58:18.060 --> 00:58:19.260 of put that off take
NOTE Confidence: 0.99234253

00:58:19.260 --> 00:58:20.240 that off the table.
NOTE Confidence: 0.9537389

00:58:20.700 --> 00:58:21.900 And so if, again, if
NOTE Confidence: 0.9537389

00:58:21.900 --> 00:58:23.100 the if the option if
NOTE Confidence: 0.9537389

00:58:23.100 --> 00:58:24.855 the goal is achievable, say,
NOTE Confidence: 0.9537389

00:58:24.855 --> 00:58:26.295 survival, then the option should
NOTE Confidence: 0.9537389

00:58:26.295 --> 00:58:27.435 be ethically permissible,
NOTE Confidence: 0.9944689

00:58:27.815 --> 00:58:29.575 and it's basically within their
NOTE Confidence: 0.9944689

00:58:29.575 --> 00:58:30.615 right to request it or
NOTE Confidence: 0.9944689

00:58:30.615 --> 00:58:31.515 to choose it.
NOTE Confidence: 0.9924078

00:58:35.575 --> 00:58:36.075 So
NOTE Confidence: 0.95938694

00:58:37.320 --> 00:58:38.040 I've come to the end
NOTE Confidence: 0.95938694

00:58:38.040 --> 00:58:39.240 of my my,

NOTE Confidence: 0.974198

00:58:39.720 --> 00:58:41.320 presentation today, and I'm just

NOTE Confidence: 0.974198

00:58:41.320 --> 00:58:42.060 gonna summarize,

NOTE Confidence: 0.9702546

00:58:43.080 --> 00:58:44.440 with those cases and kinda

NOTE Confidence: 0.9702546

00:58:44.440 --> 00:58:45.420 come back to them,

NOTE Confidence: 0.9614109

00:58:46.360 --> 00:58:47.480 kind of tying in the

NOTE Confidence: 0.9614109

00:58:47.480 --> 00:58:48.760 things we talked about. So

NOTE Confidence: 0.9614109

00:58:48.760 --> 00:58:50.245 for example, for case one,

NOTE Confidence: 0.9614109

00:58:50.385 --> 00:58:52.145 when families ask about survival

NOTE Confidence: 0.9614109

00:58:52.145 --> 00:58:54.565 outcomes, provide recent survival outcomes

NOTE Confidence: 0.9614109

00:58:54.785 --> 00:58:55.765 and be forthcoming

NOTE Confidence: 0.9913787

00:58:56.225 --> 00:58:57.825 regarding how decision making about

NOTE Confidence: 0.9913787

00:58:57.825 --> 00:58:58.325 resuscitation,

NOTE Confidence: 0.94909865

00:58:58.705 --> 00:59:00.705 medical and procedure intervention will

NOTE Confidence: 0.94909865

00:59:00.705 --> 00:59:01.605 impact survival.

NOTE Confidence: 0.9990525

00:59:02.720 --> 00:59:03.859 For case two,

NOTE Confidence: 0.99924105

00:59:04.240 --> 00:59:06.160 when parents inquire about surgical

NOTE Confidence: 0.99924105

00:59:06.160 --> 00:59:06.660 intervention,

NOTE Confidence: 0.9601329

00:59:06.960 --> 00:59:09.140 be honest about valid objective

NOTE Confidence: 0.9601329

00:59:09.200 --> 00:59:09.700 considerations,

NOTE Confidence: 0.999887

00:59:10.079 --> 00:59:10.579 including

NOTE Confidence: 0.9933492

00:59:10.880 --> 00:59:12.240 cardiac you know, the presence

NOTE Confidence: 0.9933492

00:59:12.240 --> 00:59:13.619 of noncardiac lesions,

NOTE Confidence: 0.9850151

00:59:14.160 --> 00:59:15.815 the impact of complex congenital

NOTE Confidence: 0.9850151

00:59:15.815 --> 00:59:16.475 heart disease,

NOTE Confidence: 0.99973434

00:59:16.775 --> 00:59:17.675 and the possibility

NOTE Confidence: 0.99798506

00:59:18.215 --> 00:59:19.675 for technological dependence

NOTE Confidence: 0.99675727

00:59:20.055 --> 00:59:21.275 to support these outcomes.

NOTE Confidence: 0.9993445

00:59:22.295 --> 00:59:23.275 Use the opportunity

NOTE Confidence: 0.99852854

00:59:23.655 --> 00:59:25.255 to try and learn parental

NOTE Confidence: 0.99852854

00:59:25.255 --> 00:59:26.375 hopes and goals for the

NOTE Confidence: 0.99852854

00:59:26.375 --> 00:59:27.835 pregnancy and for the child.

NOTE Confidence: 0.9980074
00:59:28.760 --> 00:59:30.119 For cases three and four,
NOTE Confidence: 0.9980074
00:59:30.119 --> 00:59:32.119 again, highlight the issues related
NOTE Confidence: 0.9980074
00:59:32.119 --> 00:59:33.180 to medical complexity
NOTE Confidence: 0.9902796
00:59:33.560 --> 00:59:34.920 that parents and physicians face
NOTE Confidence: 0.9902796
00:59:34.920 --> 00:59:35.640 when they have to make
NOTE Confidence: 0.9902796
00:59:35.640 --> 00:59:36.460 these decisions.
NOTE Confidence: 0.9989878
00:59:37.400 --> 00:59:38.680 Hopefully, we'll have some more
NOTE Confidence: 0.9989878
00:59:38.680 --> 00:59:40.460 research, you know, that will
NOTE Confidence: 0.9931739
00:59:40.994 --> 00:59:42.775 clarify some of of the,
NOTE Confidence: 0.9972086
00:59:43.875 --> 00:59:45.015 the objective considerations
NOTE Confidence: 0.98065
00:59:45.315 --> 00:59:46.994 with respect to, you know,
NOTE Confidence: 0.98065
00:59:46.994 --> 00:59:47.494 performing,
NOTE Confidence: 0.9654317
00:59:48.755 --> 00:59:50.134 interventions in these children.
NOTE Confidence: 0.9874024
00:59:50.674 --> 00:59:51.555 And then I would say
NOTE Confidence: 0.9874024
00:59:51.555 --> 00:59:53.474 use that IPO approach and
NOTE Confidence: 0.9874024

00:59:53.474 --> 00:59:54.615 work with your teammates
NOTE Confidence: 0.9990389

00:59:55.200 --> 00:59:56.960 to develop an individualized care
NOTE Confidence: 0.9990389

00:59:56.960 --> 00:59:57.460 plan.
NOTE Confidence: 0.95005214

00:59:58.000 --> 00:59:59.280 And then lastly, kind of
NOTE Confidence: 0.95005214

00:59:59.280 --> 01:00:00.820 returning to that fifth case,
NOTE Confidence: 0.999354

01:00:01.440 --> 01:00:03.060 remember that parents are making
NOTE Confidence: 0.999354

01:00:03.200 --> 01:00:04.180 difficult decisions
NOTE Confidence: 0.8396624

01:00:05.040 --> 01:00:06.339 and kind of
NOTE Confidence: 0.96061105

01:00:06.880 --> 01:00:08.080 make sure that we're honoring,
NOTE Confidence: 0.96061105

01:00:08.080 --> 01:00:10.339 respecting, you know, that
NOTE Confidence: 0.9932723

01:00:11.634 --> 01:00:13.075 that that those choices that
NOTE Confidence: 0.9932723

01:00:13.075 --> 01:00:13.815 they're making.
NOTE Confidence: 0.9847048

01:00:14.835 --> 01:00:16.434 Sometimes they're making these decisions
NOTE Confidence: 0.9847048

01:00:16.434 --> 01:00:18.355 alone. Sometimes it takes time
NOTE Confidence: 0.9847048

01:00:18.355 --> 01:00:19.555 for both parents to agree
NOTE Confidence: 0.9847048

01:00:19.555 --> 01:00:20.615 on goals of care.

NOTE Confidence: 0.9909997
01:00:20.994 --> 01:00:22.375 However, I think returning
NOTE Confidence: 0.9824988
01:00:22.755 --> 01:00:24.355 again, returning to the question
NOTE Confidence: 0.9824988
01:00:24.355 --> 01:00:25.490 about, you know, what are
NOTE Confidence: 0.9824988
01:00:25.490 --> 01:00:26.730 their values, what are their
NOTE Confidence: 0.9824988
01:00:26.730 --> 01:00:27.230 goals,
NOTE Confidence: 0.95659435
01:00:27.530 --> 01:00:28.890 I think will help us
NOTE Confidence: 0.95659435
01:00:28.890 --> 01:00:30.030 to kinda make headway
NOTE Confidence: 0.99496657
01:00:30.410 --> 01:00:31.370 in terms of coming to
NOTE Confidence: 0.99496657
01:00:31.370 --> 01:00:32.510 a decision. So,
NOTE Confidence: 0.9944995
01:00:32.810 --> 01:00:34.330 you know, I think families
NOTE Confidence: 0.9944995
01:00:34.330 --> 01:00:35.610 take different paths, and I
NOTE Confidence: 0.9944995
01:00:35.610 --> 01:00:37.150 think one of our jobs
NOTE Confidence: 0.9944995
01:00:37.290 --> 01:00:39.130 is to help them follow
NOTE Confidence: 0.9944995
01:00:39.130 --> 01:00:40.430 the path they choose.
NOTE Confidence: 0.93975997
01:00:43.424 --> 01:00:44.565 Alright. I don't
NOTE Confidence: 0.97726715

01:00:47.664 --> 01:00:48.545 do I have enough time
NOTE Confidence: 0.97726715

01:00:48.545 --> 01:00:49.365 to show this?
NOTE Confidence: 0.99340236

01:00:50.145 --> 01:00:51.845 Okay. So this is
NOTE Confidence: 0.9665231

01:00:53.760 --> 01:00:55.680 this is, Annie Genvier. She's
NOTE Confidence: 0.9665231

01:00:55.680 --> 01:00:57.040 one of those, one of
NOTE Confidence: 0.9665231

01:00:57.040 --> 01:00:57.360 the,
NOTE Confidence: 0.92492884

01:00:57.840 --> 01:00:59.060 researchers that,
NOTE Confidence: 0.90017676

01:01:00.320 --> 01:01:01.520 I discussed, and she's a
NOTE Confidence: 0.90017676

01:01:01.520 --> 01:01:02.020 pneumatologist
NOTE Confidence: 0.98492885

01:01:02.400 --> 01:01:03.220 and an ethicist.
NOTE Confidence: 0.99334323

01:01:03.840 --> 01:01:04.340 And
NOTE Confidence: 0.9233833

01:01:06.974 --> 01:01:08.575 she recently gave this TED
NOTE Confidence: 0.9233833

01:01:08.575 --> 01:01:09.075 talk,
NOTE Confidence: 0.975996

01:01:09.615 --> 01:01:10.734 and I think it the
NOTE Confidence: 0.975996

01:01:10.734 --> 01:01:11.775 the end at the end
NOTE Confidence: 0.975996

01:01:11.775 --> 01:01:13.135 of the TED talk, I

NOTE Confidence: 0.975996
01:01:13.135 --> 01:01:14.174 think she gives us some
NOTE Confidence: 0.975996
01:01:14.174 --> 01:01:14.994 sort of
NOTE Confidence: 0.9519339
01:01:16.654 --> 01:01:18.015 way to look forward into
NOTE Confidence: 0.9519339
01:01:18.015 --> 01:01:19.135 the future. So
NOTE Confidence: 0.74555844
01:01:58.540 --> 01:01:59.040 Alright.
NOTE Confidence: 0.96859306
01:01:59.660 --> 01:02:01.260 And just something I just
NOTE Confidence: 0.96859306
01:02:01.260 --> 01:02:02.720 recently learned about this,
NOTE Confidence: 0.9990858
01:02:03.555 --> 01:02:04.615 this woman
NOTE Confidence: 0.9463753
01:02:04.994 --> 01:02:06.595 was that she herself is
NOTE Confidence: 0.9463753
01:02:06.595 --> 01:02:07.255 a neonatologist,
NOTE Confidence: 0.9785151
01:02:07.875 --> 01:02:09.474 but she had a baby
NOTE Confidence: 0.9785151
01:02:09.474 --> 01:02:11.075 at twenty three, twenty four
NOTE Confidence: 0.9785151
01:02:11.075 --> 01:02:11.575 weeks.
NOTE Confidence: 0.9772228
01:02:11.954 --> 01:02:12.994 And her child was in
NOTE Confidence: 0.9772228
01:02:12.994 --> 01:02:14.835 the NICU for for four
NOTE Confidence: 0.9772228

01:02:14.835 --> 01:02:15.335 months,
NOTE Confidence: 0.9981835

01:02:15.875 --> 01:02:17.289 and she had made her
NOTE Confidence: 0.9981835

01:02:17.289 --> 01:02:19.069 career as a researcher studying
NOTE Confidence: 0.9981835

01:02:19.289 --> 01:02:19.789 outcomes
NOTE Confidence: 0.9888073

01:02:20.250 --> 01:02:20.990 in neonatology.
NOTE Confidence: 0.9994804

01:02:21.930 --> 01:02:23.230 And her experience
NOTE Confidence: 0.9908637

01:02:23.530 --> 01:02:24.970 going through, I think, with
NOTE Confidence: 0.9908637

01:02:24.970 --> 01:02:26.190 her with her daughter
NOTE Confidence: 0.9771737

01:02:26.569 --> 01:02:27.930 kind of upended all of
NOTE Confidence: 0.9771737

01:02:27.930 --> 01:02:29.375 that. And so,
NOTE Confidence: 0.9819115

01:02:29.835 --> 01:02:31.115 anyways, I think that I
NOTE Confidence: 0.9819115

01:02:31.115 --> 01:02:32.395 think it just reminds us
NOTE Confidence: 0.9819115

01:02:32.395 --> 01:02:33.915 that to kind of have
NOTE Confidence: 0.9819115

01:02:33.915 --> 01:02:35.995 humility again with respect to,
NOTE Confidence: 0.9819115

01:02:35.995 --> 01:02:36.955 you know, how we care
NOTE Confidence: 0.9819115

01:02:36.955 --> 01:02:38.255 for families, how we're counseling

NOTE Confidence: 0.9819115

01:02:38.315 --> 01:02:40.015 families. So with that,

NOTE Confidence: 0.80171424

01:02:40.790 --> 01:02:42.869 this will end, and hopefully

NOTE Confidence: 0.80171424

01:02:42.869 --> 01:02:43.770 you'll take some questions.

NOTE Confidence: 0.5887717

01:02:47.589 --> 01:02:48.089 Wait.

NOTE Confidence: 0.8832316

01:02:51.030 --> 01:02:52.150 You can stand here. You

NOTE Confidence: 0.8832316

01:02:52.150 --> 01:02:53.030 know what some people do

NOTE Confidence: 0.8832316

01:02:53.030 --> 01:02:53.830 is just kinda go in

NOTE Confidence: 0.8832316

01:02:53.830 --> 01:02:54.550 front and sit on the

NOTE Confidence: 0.8832316

01:02:54.550 --> 01:02:55.830 table, lean on the table,

NOTE Confidence: 0.8832316

01:02:55.830 --> 01:02:56.490 stand there.

NOTE Confidence: 0.9917355

01:02:56.845 --> 01:02:57.725 You can stand here with

NOTE Confidence: 0.9917355

01:02:57.725 --> 01:02:58.365 me, but I'm gonna be

NOTE Confidence: 0.9917355

01:02:58.365 --> 01:02:59.965 sometimes reading some Zoom questions

NOTE Confidence: 0.9917355

01:02:59.965 --> 01:03:00.465 too.

NOTE Confidence: 0.96320033

01:03:01.805 --> 01:03:03.565 So wherever you're comfortable, my

NOTE Confidence: 0.96320033

01:03:03.565 --> 01:03:05.005 friend. Okay. Alright. She's a

NOTE Confidence: 0.96320033

01:03:05.005 --> 01:03:06.445 glass of water there. Alright.

NOTE Confidence: 0.96320033

01:03:06.445 --> 01:03:08.045 So I know you you

NOTE Confidence: 0.96320033

01:03:08.045 --> 01:03:09.245 guys are wondering just what

NOTE Confidence: 0.96320033

01:03:09.245 --> 01:03:10.205 is it that makes these

NOTE Confidence: 0.96320033

01:03:10.205 --> 01:03:11.425 seminars so cool?

NOTE Confidence: 0.9490958

01:03:11.900 --> 01:03:13.260 And and, of course, the

NOTE Confidence: 0.9490958

01:03:13.260 --> 01:03:14.380 obvious answer is because we

NOTE Confidence: 0.9490958

01:03:14.380 --> 01:03:15.820 get such terrific speakers like

NOTE Confidence: 0.9490958

01:03:15.820 --> 01:03:16.640 Katya Kasuf.

NOTE Confidence: 0.9677125

01:03:16.940 --> 01:03:17.820 But but the other half

NOTE Confidence: 0.9677125

01:03:17.820 --> 01:03:18.700 of the equation, of course,

NOTE Confidence: 0.9677125

01:03:18.700 --> 01:03:19.580 is the people who come

NOTE Confidence: 0.9677125

01:03:19.580 --> 01:03:20.540 to these things. So I'm

NOTE Confidence: 0.9677125

01:03:20.540 --> 01:03:21.740 looking out, and I'm hearing

NOTE Confidence: 0.9677125

01:03:21.740 --> 01:03:22.700 this great talk, and I'm

NOTE Confidence: 0.9677125
01:03:22.700 --> 01:03:24.300 seeing leaders in here at
NOTE Confidence: 0.9677125
01:03:24.300 --> 01:03:25.280 Yale in neonatology
NOTE Confidence: 0.8672991
01:03:25.580 --> 01:03:26.240 and cardiology.
NOTE Confidence: 0.9833945
01:03:26.615 --> 01:03:28.234 I'm seeing a long accomplished
NOTE Confidence: 0.9833945
01:03:28.295 --> 01:03:29.355 cardiac surgeon.
NOTE Confidence: 0.95332223
01:03:29.734 --> 01:03:31.174 I'm seeing a a master
NOTE Confidence: 0.95332223
01:03:31.174 --> 01:03:33.335 of patient counseling from, the
NOTE Confidence: 0.95332223
01:03:33.335 --> 01:03:34.795 child psych world, the palliative
NOTE Confidence: 0.95332223
01:03:34.855 --> 01:03:35.895 care team, and, of course,
NOTE Confidence: 0.95332223
01:03:35.895 --> 01:03:36.934 the cream of the Yale
NOTE Confidence: 0.95332223
01:03:36.934 --> 01:03:39.015 School of Medicine. So we've
NOTE Confidence: 0.95332223
01:03:39.015 --> 01:03:40.775 we've got this tremendous collection
NOTE Confidence: 0.95332223
01:03:40.775 --> 01:03:41.640 of people here,
NOTE Confidence: 0.9993815
01:03:42.039 --> 01:03:43.240 and and I'm looking forward
NOTE Confidence: 0.9993815
01:03:43.240 --> 01:03:44.380 to a rich conversation.
NOTE Confidence: 0.90599394

01:03:44.760 --> 01:03:45.260 So,
NOTE Confidence: 0.9932023

01:03:46.200 --> 01:03:47.240 if you have a question
NOTE Confidence: 0.9932023

01:03:47.240 --> 01:03:48.519 or a comment, please raise
NOTE Confidence: 0.9932023

01:03:48.519 --> 01:03:49.240 your hand up. We will
NOTE Confidence: 0.9932023

01:03:49.240 --> 01:03:50.039 have a hard stop at
NOTE Confidence: 0.9932023

01:03:50.039 --> 01:03:51.240 six thirty, but we've got
NOTE Confidence: 0.9932023

01:03:51.240 --> 01:03:52.920 over twenty minutes to chat
NOTE Confidence: 0.9932023

01:03:52.920 --> 01:03:53.720 for a bit. One of
NOTE Confidence: 0.9932023

01:03:53.720 --> 01:03:55.000 the while while we're waiting
NOTE Confidence: 0.9932023

01:03:55.000 --> 01:03:55.960 for someone to speak up,
NOTE Confidence: 0.9932023

01:03:55.960 --> 01:03:57.079 I'll I'll take the first
NOTE Confidence: 0.9932023

01:03:57.079 --> 01:03:58.164 one. One of the things
NOTE Confidence: 0.9932023

01:03:58.164 --> 01:03:59.365 that struck me, Katya, when
NOTE Confidence: 0.9932023

01:03:59.365 --> 01:04:00.105 you went over
NOTE Confidence: 0.97512174

01:04:00.885 --> 01:04:01.845 some of the stuff about
NOTE Confidence: 0.97512174

01:04:01.845 --> 01:04:02.005 the,

NOTE Confidence: 0.9385311
01:04:03.125 --> 01:04:03.525 the,
NOTE Confidence: 0.9428113
01:04:04.404 --> 01:04:06.404 coexisting anomalies. For example, you
NOTE Confidence: 0.9428113
01:04:06.404 --> 01:04:07.464 know, diaphragmatic
NOTE Confidence: 0.8833901
01:04:07.765 --> 01:04:09.285 hernia and a congenital heart
NOTE Confidence: 0.8833901
01:04:09.285 --> 01:04:10.404 disease in the presence and
NOTE Confidence: 0.8833901
01:04:10.404 --> 01:04:11.924 and and what what is
NOTE Confidence: 0.8833901
01:04:11.924 --> 01:04:12.984 this? And I and
NOTE Confidence: 0.9750243
01:04:13.460 --> 01:04:14.500 some of these things that
NOTE Confidence: 0.9750243
01:04:14.500 --> 01:04:16.260 occurs to me, it's it's
NOTE Confidence: 0.9750243
01:04:16.260 --> 01:04:17.539 likely that the honest answer
NOTE Confidence: 0.9750243
01:04:17.539 --> 01:04:18.740 to, well, what's the chance
NOTE Confidence: 0.9750243
01:04:18.740 --> 01:04:20.500 of survival when these two
NOTE Confidence: 0.9750243
01:04:20.500 --> 01:04:21.559 anomalies coexist
NOTE Confidence: 0.96297866
01:04:22.180 --> 01:04:23.299 that some of these the
NOTE Confidence: 0.96297866
01:04:23.299 --> 01:04:24.339 the the honest answer will
NOTE Confidence: 0.96297866

01:04:24.339 --> 01:04:25.299 be, well, we're not really

NOTE Confidence: 0.96297866

01:04:25.299 --> 01:04:26.420 sure. We don't know. Mhmm.

NOTE Confidence: 0.96297866

01:04:26.420 --> 01:04:27.059 For a lot of these,

NOTE Confidence: 0.96297866

01:04:27.059 --> 01:04:28.180 I I suspect we don't

NOTE Confidence: 0.96297866

01:04:28.180 --> 01:04:28.515 have,

NOTE Confidence: 0.89381164

01:04:29.154 --> 01:04:30.755 really good data. And and

NOTE Confidence: 0.89381164

01:04:30.755 --> 01:04:31.414 I and

NOTE Confidence: 0.97566795

01:04:31.875 --> 01:04:32.994 I I I fear that

NOTE Confidence: 0.97566795

01:04:32.994 --> 01:04:34.515 sometimes in those situations, we

NOTE Confidence: 0.97566795

01:04:34.515 --> 01:04:35.954 don't just say, well, we're

NOTE Confidence: 0.97566795

01:04:35.954 --> 01:04:37.555 not really sure. But there's

NOTE Confidence: 0.97566795

01:04:37.555 --> 01:04:38.595 so much stuff that we

NOTE Confidence: 0.97566795

01:04:38.674 --> 01:04:39.815 that everybody knows.

NOTE Confidence: 0.9201652

01:04:40.515 --> 01:04:41.714 Like, everybody knows kids with

NOTE Confidence: 0.9201652

01:04:41.714 --> 01:04:44.010 trisomy thirteen, for example, cannot

NOTE Confidence: 0.9201652

01:04:44.010 --> 01:04:45.310 tolerate general anesthesia.

NOTE Confidence: 0.96296746
01:04:45.610 --> 01:04:46.330 But like a lot of
NOTE Confidence: 0.96296746
01:04:46.330 --> 01:04:48.090 things that everybody knows, turns
NOTE Confidence: 0.96296746
01:04:48.090 --> 01:04:49.210 out not to be true.
NOTE Confidence: 0.96296746
01:04:49.210 --> 01:04:49.690 Mhmm.
NOTE Confidence: 0.9766965
01:04:50.410 --> 01:04:51.610 And there's there's so much
NOTE Confidence: 0.9766965
01:04:51.610 --> 01:04:53.050 of that. There's so much
NOTE Confidence: 0.9766965
01:04:53.050 --> 01:04:54.250 of that in in this.
NOTE Confidence: 0.9766965
01:04:54.250 --> 01:04:55.850 And so we really appreciate
NOTE Confidence: 0.9766965
01:04:55.850 --> 01:04:56.970 this talk to kinda take
NOTE Confidence: 0.9766965
01:04:56.970 --> 01:04:57.710 us through
NOTE Confidence: 0.9544293
01:04:58.175 --> 01:04:59.295 how things were, how these
NOTE Confidence: 0.9544293
01:04:59.295 --> 01:05:00.575 situations evolving. And and, of
NOTE Confidence: 0.9544293
01:05:00.575 --> 01:05:02.095 course, it's fascinating because you
NOTE Confidence: 0.9544293
01:05:02.095 --> 01:05:03.135 pointed out there's still an
NOTE Confidence: 0.9544293
01:05:03.135 --> 01:05:04.015 awful lot of folks out
NOTE Confidence: 0.9544293

01:05:04.015 --> 01:05:05.474 there who say,
NOTE Confidence: 0.95079935

01:05:05.935 --> 01:05:06.895 yes. You know, I'm gonna
NOTE Confidence: 0.95079935

01:05:06.895 --> 01:05:08.095 tell the parents about surgical
NOTE Confidence: 0.95079935

01:05:08.095 --> 01:05:09.295 options and an awful lot
NOTE Confidence: 0.95079935

01:05:09.295 --> 01:05:10.175 who say, no. I'm not
NOTE Confidence: 0.95079935

01:05:10.175 --> 01:05:11.375 gonna tell them about surgical
NOTE Confidence: 0.95079935

01:05:11.375 --> 01:05:12.420 options. And then there are
NOTE Confidence: 0.95079935

01:05:12.420 --> 01:05:13.220 others who say, and you
NOTE Confidence: 0.95079935

01:05:13.220 --> 01:05:14.020 pointed this out about this
NOTE Confidence: 0.95079935

01:05:14.020 --> 01:05:14.980 avenue, so, well, I'll talk
NOTE Confidence: 0.95079935

01:05:14.980 --> 01:05:15.940 about it if they ask.
NOTE Confidence: 0.95079935

01:05:15.940 --> 01:05:17.140 Yeah. So people who are
NOTE Confidence: 0.95079935

01:05:17.140 --> 01:05:18.420 good with the Internet get
NOTE Confidence: 0.95079935

01:05:18.420 --> 01:05:19.160 the information,
NOTE Confidence: 0.9795805

01:05:20.660 --> 01:05:21.780 but the people who aren't
NOTE Confidence: 0.9795805

01:05:21.780 --> 01:05:22.579 are are left in the

NOTE Confidence: 0.9795805
01:05:22.579 --> 01:05:23.079 dark.
NOTE Confidence: 0.97124946
01:05:23.940 --> 01:05:25.644 Ben, please wait one second,
NOTE Confidence: 0.97124946
01:05:25.644 --> 01:05:26.525 though, because you're gonna get
NOTE Confidence: 0.97124946
01:05:26.525 --> 01:05:28.045 a microphone so that everybody
NOTE Confidence: 0.97124946
01:05:28.045 --> 01:05:28.865 can hear you.
NOTE Confidence: 0.9952954
01:05:29.565 --> 01:05:30.305 So so
NOTE Confidence: 0.94227135
01:05:31.005 --> 01:05:31.884 you you spoke a lot
NOTE Confidence: 0.94227135
01:05:31.884 --> 01:05:33.984 about the, cardiac prognosis.
NOTE Confidence: 0.8901892
01:05:34.845 --> 01:05:35.805 I would think in in
NOTE Confidence: 0.8901892
01:05:35.805 --> 01:05:36.305 counseling,
NOTE Confidence: 0.9825281
01:05:36.684 --> 01:05:38.070 parents would be very important
NOTE Confidence: 0.9825281
01:05:38.070 --> 01:05:38.950 to speak also to the
NOTE Confidence: 0.9825281
01:05:38.950 --> 01:05:40.790 neurologic prognosis, and I imagine
NOTE Confidence: 0.9825281
01:05:40.790 --> 01:05:42.150 you probably have a lot
NOTE Confidence: 0.9825281
01:05:42.150 --> 01:05:43.830 more information about that than
NOTE Confidence: 0.9825281

01:05:43.830 --> 01:05:45.270 than most folks. Could you
NOTE Confidence: 0.9825281

01:05:45.270 --> 01:05:46.310 speak a little bit to
NOTE Confidence: 0.9825281

01:05:46.310 --> 01:05:48.010 the neurologic prognosis
NOTE Confidence: 0.95701754

01:05:48.310 --> 01:05:49.430 in in the long term
NOTE Confidence: 0.95701754

01:05:49.430 --> 01:05:50.550 survivors that you you sort
NOTE Confidence: 0.95701754

01:05:50.550 --> 01:05:51.510 of show? There's, like, about
NOTE Confidence: 0.95701754

01:05:51.510 --> 01:05:52.330 fifty percent
NOTE Confidence: 0.9997034

01:05:53.475 --> 01:05:54.215 with surgery
NOTE Confidence: 0.993714

01:05:54.915 --> 01:05:55.735 will survive
NOTE Confidence: 0.8796423

01:05:56.275 --> 01:05:57.015 long term.
NOTE Confidence: 0.9837522

01:05:57.875 --> 01:05:59.335 What's the range of neurologic
NOTE Confidence: 0.9837522

01:05:59.395 --> 01:06:00.515 prognosis and sort of what
NOTE Confidence: 0.9837522

01:06:00.595 --> 01:06:02.035 what's best, worst, and most
NOTE Confidence: 0.9837522

01:06:02.035 --> 01:06:03.315 likely outcome that you've seen
NOTE Confidence: 0.9837522

01:06:03.315 --> 01:06:04.135 in that population?
NOTE Confidence: 0.96820676

01:06:04.595 --> 01:06:06.370 You mean, just to clarify.

NOTE Confidence: 0.96820676
01:06:06.370 --> 01:06:07.090 So do you mean in
NOTE Confidence: 0.96820676
01:06:07.090 --> 01:06:09.030 terms of, like, among the
NOTE Confidence: 0.9873337
01:06:10.370 --> 01:06:11.970 the if the neurological outcome
NOTE Confidence: 0.9873337
01:06:11.970 --> 01:06:13.250 would be, let's say, different
NOTE Confidence: 0.9873337
01:06:13.250 --> 01:06:14.530 if the child had heart
NOTE Confidence: 0.9873337
01:06:14.530 --> 01:06:16.290 surgery versus not? Or So
NOTE Confidence: 0.9873337
01:06:16.290 --> 01:06:17.350 so among the
NOTE Confidence: 0.99492157
01:06:17.795 --> 01:06:19.555 patients who do get cardiac
NOTE Confidence: 0.99492157
01:06:19.555 --> 01:06:20.595 surgery, it looks like about
NOTE Confidence: 0.99492157
01:06:20.595 --> 01:06:22.615 fifty percent survive out to
NOTE Confidence: 0.9988289
01:06:23.075 --> 01:06:25.175 Right. Three to eleven years
NOTE Confidence: 0.84490496
01:06:26.275 --> 01:06:27.415 in that population.
NOTE Confidence: 0.9444908
01:06:28.595 --> 01:06:29.395 So if you if you're,
NOTE Confidence: 0.9444908
01:06:29.395 --> 01:06:30.595 like, counseling a family and
NOTE Confidence: 0.9444908
01:06:30.595 --> 01:06:31.975 you're just trying to describe
NOTE Confidence: 0.9444908

01:06:32.035 --> 01:06:33.570 what the child's life might
NOTE Confidence: 0.9444908

01:06:33.570 --> 01:06:34.610 look like if they do
NOTE Confidence: 0.9444908

01:06:34.610 --> 01:06:35.910 survive in the fifty percent
NOTE Confidence: 0.9310187

01:06:36.370 --> 01:06:37.670 case that they would survive,
NOTE Confidence: 0.9973293

01:06:38.050 --> 01:06:39.490 can can you describe that
NOTE Confidence: 0.9973293

01:06:39.490 --> 01:06:39.990 that
NOTE Confidence: 0.9975131

01:06:40.450 --> 01:06:42.370 the range of neurologic functioning
NOTE Confidence: 0.9975131

01:06:42.370 --> 01:06:43.410 that you see in in
NOTE Confidence: 0.9975131

01:06:43.410 --> 01:06:44.310 those survivors?
NOTE Confidence: 0.99485725

01:06:45.010 --> 01:06:46.370 Yeah. I think that's that's
NOTE Confidence: 0.99485725

01:06:46.370 --> 01:06:47.750 a great question. I
NOTE Confidence: 0.95016927

01:06:49.305 --> 01:06:50.585 I I I think that
NOTE Confidence: 0.95016927

01:06:50.585 --> 01:06:51.085 in
NOTE Confidence: 0.95253634

01:06:51.465 --> 01:06:52.585 the way I'm gonna answer
NOTE Confidence: 0.95253634

01:06:52.585 --> 01:06:53.625 it as best I can
NOTE Confidence: 0.95253634

01:06:53.625 --> 01:06:55.065 is that these children in

NOTE Confidence: 0.95253634
01:06:55.065 --> 01:06:56.765 general have pretty
NOTE Confidence: 0.9990899
01:06:57.065 --> 01:06:59.005 profound neurologic disability
NOTE Confidence: 0.96093255
01:06:59.465 --> 01:07:00.985 sort of regardless of whether
NOTE Confidence: 0.96093255
01:07:00.985 --> 01:07:02.190 or not they would have
NOTE Confidence: 0.96093255
01:07:02.270 --> 01:07:03.490 surgery or not have surgery.
NOTE Confidence: 0.9860065
01:07:04.030 --> 01:07:05.470 And so I don't think
NOTE Confidence: 0.9860065
01:07:05.470 --> 01:07:05.970 that,
NOTE Confidence: 0.9836865
01:07:07.550 --> 01:07:08.589 I think that you kind
NOTE Confidence: 0.9836865
01:07:08.589 --> 01:07:10.750 of being upfront about just
NOTE Confidence: 0.9836865
01:07:10.750 --> 01:07:12.369 the the the general
NOTE Confidence: 0.9002912
01:07:13.310 --> 01:07:14.609 neurological disability,
NOTE Confidence: 0.9778805
01:07:16.194 --> 01:07:17.474 like, people have to accept
NOTE Confidence: 0.9778805
01:07:17.474 --> 01:07:17.974 that
NOTE Confidence: 0.9378805
01:07:18.435 --> 01:07:20.035 first, I think, to be
NOTE Confidence: 0.9378805
01:07:20.035 --> 01:07:21.734 able to kinda move forward.
NOTE Confidence: 0.97468734

01:07:22.194 --> 01:07:24.275 Because I don't necessarily think
NOTE Confidence: 0.97468734

01:07:24.275 --> 01:07:24.775 that,
NOTE Confidence: 0.99562705

01:07:25.954 --> 01:07:28.375 that performing heart surgery changes
NOTE Confidence: 0.98778814

01:07:28.994 --> 01:07:29.474 the
NOTE Confidence: 0.9771271

01:07:30.730 --> 01:07:31.930 Yeah. So I'm I'm not
NOTE Confidence: 0.9771271

01:07:31.930 --> 01:07:33.290 asking about the effect of
NOTE Confidence: 0.9771271

01:07:33.290 --> 01:07:35.130 heart surgery Yeah. On neurologic
NOTE Confidence: 0.9771271

01:07:35.130 --> 01:07:36.330 prognosis. I'm asking, like, what
NOTE Confidence: 0.9771271

01:07:36.330 --> 01:07:37.770 what is the neurologic prognosis
NOTE Confidence: 0.9771271

01:07:37.770 --> 01:07:38.830 of a kid with trisomy
NOTE Confidence: 0.9771271

01:07:38.890 --> 01:07:40.270 thirteen Yeah. Or eighteen?
NOTE Confidence: 0.9552812

01:07:40.650 --> 01:07:41.850 Can can you expect that
NOTE Confidence: 0.9552812

01:07:41.850 --> 01:07:43.210 they're gonna be a hundred
NOTE Confidence: 0.9552812

01:07:43.210 --> 01:07:44.190 percent nonverbal
NOTE Confidence: 0.88508856

01:07:44.650 --> 01:07:46.484 Yeah. Bed bound? Okay. Yeah.
NOTE Confidence: 0.88508856

01:07:46.484 --> 01:07:47.125 I see I see what

NOTE Confidence: 0.88508856
01:07:47.125 --> 01:07:48.244 you're saying. So,
NOTE Confidence: 0.96365666
01:07:49.605 --> 01:07:50.724 and and, again, this is
NOTE Confidence: 0.96365666
01:07:50.724 --> 01:07:52.345 just my experience. But,
NOTE Confidence: 0.9995918
01:07:53.285 --> 01:07:54.505 most most kids
NOTE Confidence: 0.99063593
01:07:55.285 --> 01:07:56.585 may are are nonverbal.
NOTE Confidence: 0.99866754
01:07:57.980 --> 01:08:00.079 Most children cannot walk independently.
NOTE Confidence: 0.99754393
01:08:00.700 --> 01:08:01.900 A lot of them require
NOTE Confidence: 0.99754393
01:08:01.900 --> 01:08:03.020 assistance with you know, they
NOTE Confidence: 0.99754393
01:08:03.020 --> 01:08:03.920 have a wheelchair
NOTE Confidence: 0.9751811
01:08:04.300 --> 01:08:04.800 or,
NOTE Confidence: 0.94415414
01:08:05.500 --> 01:08:06.960 like, a motorized wheelchair.
NOTE Confidence: 0.9911925
01:08:09.339 --> 01:08:10.880 They they do
NOTE Confidence: 0.9982498
01:08:11.685 --> 01:08:13.545 have interactions with their family.
NOTE Confidence: 0.96034896
01:08:14.005 --> 01:08:14.905 They smile.
NOTE Confidence: 0.96296185
01:08:15.685 --> 01:08:17.205 You know, they're you know,
NOTE Confidence: 0.96296185

01:08:17.205 --> 01:08:18.245 so I saw pictures of
NOTE Confidence: 0.96296185

01:08:18.245 --> 01:08:19.765 one woman with her child
NOTE Confidence: 0.96296185

01:08:19.765 --> 01:08:20.425 at a,
NOTE Confidence: 0.9612524

01:08:20.965 --> 01:08:22.245 at a wedding. You know,
NOTE Confidence: 0.9612524

01:08:22.245 --> 01:08:23.064 they're dancing,
NOTE Confidence: 0.99926126

01:08:24.020 --> 01:08:24.713 you know,
NOTE Confidence: 0.9954109

01:08:25.166 --> 01:08:26.526 at the wedding.
NOTE Confidence: 0.97033805

01:08:26.979 --> 01:08:28.600 It isn't the kind of,
NOTE Confidence: 0.97033805

01:08:28.820 --> 01:08:31.060 I think, interactions that we
NOTE Confidence: 0.97033805

01:08:31.060 --> 01:08:32.979 feel most comfortable with, like,
NOTE Confidence: 0.97033805

01:08:32.979 --> 01:08:34.420 where we're talking or, you
NOTE Confidence: 0.97033805

01:08:34.420 --> 01:08:35.640 know, we're having a conversation.
NOTE Confidence: 0.9993102

01:08:36.260 --> 01:08:37.960 But there there are connections
NOTE Confidence: 0.9993102

01:08:38.180 --> 01:08:38.680 there
NOTE Confidence: 0.8028711

01:08:39.140 --> 01:08:39.640 that,
NOTE Confidence: 0.98136187

01:08:40.215 --> 01:08:42.395 exist between the family members

NOTE Confidence: 0.98136187

01:08:42.534 --> 01:08:44.455 that that seem to, I

NOTE Confidence: 0.98136187

01:08:44.455 --> 01:08:46.455 think, suffice for them having

NOTE Confidence: 0.98136187

01:08:46.455 --> 01:08:48.475 a connection with their child.

NOTE Confidence: 0.862092

01:08:51.655 --> 01:08:52.955 There, you know, there's

NOTE Confidence: 0.99824905

01:08:53.415 --> 01:08:53.915 some

NOTE Confidence: 0.9721656

01:08:54.220 --> 01:08:55.500 ability to kind of feed

NOTE Confidence: 0.9721656

01:08:55.500 --> 01:08:56.000 themselves,

NOTE Confidence: 0.94407165

01:08:56.460 --> 01:08:57.900 but often they do require

NOTE Confidence: 0.94407165

01:08:57.900 --> 01:08:59.600 assistance, you know, with feeding.

NOTE Confidence: 0.95011616

01:09:01.180 --> 01:09:02.140 Is it safe to say,

NOTE Confidence: 0.95011616

01:09:02.140 --> 01:09:03.820 Katja, that so the they're

NOTE Confidence: 0.95011616

01:09:03.820 --> 01:09:05.760 profoundly they're all profoundly neurologically

NOTE Confidence: 0.95011616

01:09:05.979 --> 01:09:07.224 disabled. So is it safe

NOTE Confidence: 0.95011616

01:09:07.224 --> 01:09:08.545 to say that that's in

NOTE Confidence: 0.95011616

01:09:08.545 --> 01:09:09.585 large part why,

NOTE Confidence: 0.9365253

01:09:11.344 --> 01:09:12.465 no one sees this as
NOTE Confidence: 0.9365253

01:09:12.465 --> 01:09:13.985 obligatory, but rather as, you
NOTE Confidence: 0.9365253

01:09:13.985 --> 01:09:15.025 know, I guess, as Coogler
NOTE Confidence: 0.9365253

01:09:15.025 --> 01:09:15.985 said in two thousand three
NOTE Confidence: 0.9365253

01:09:15.985 --> 01:09:17.505 in many sense that that
NOTE Confidence: 0.9365253

01:09:17.505 --> 01:09:19.104 that families should judge whether
NOTE Confidence: 0.9365253

01:09:19.104 --> 01:09:20.945 that's something that that should
NOTE Confidence: 0.92268956

01:09:21.860 --> 01:09:23.060 whether that severe outcome is
NOTE Confidence: 0.92268956

01:09:23.060 --> 01:09:24.200 something that should dictate,
NOTE Confidence: 0.98299366

01:09:24.660 --> 01:09:25.620 whether or not the child
NOTE Confidence: 0.98299366

01:09:25.620 --> 01:09:26.600 gets gets treatment.
NOTE Confidence: 0.769504

01:09:27.140 --> 01:09:28.500 Yeah. Because they're the
NOTE Confidence: 0.9509805

01:09:29.300 --> 01:09:30.660 there are still I take
NOTE Confidence: 0.9509805

01:09:30.660 --> 01:09:32.500 it many pediatricians and many
NOTE Confidence: 0.9509805

01:09:32.500 --> 01:09:34.180 families who feel that that
NOTE Confidence: 0.9509805

01:09:34.180 --> 01:09:35.700 level of severe disability is

NOTE Confidence: 0.9509805
01:09:35.700 --> 01:09:36.825 such that the surgery should
NOTE Confidence: 0.9509805
01:09:36.825 --> 01:09:37.865 not be done. Is that
NOTE Confidence: 0.9509805
01:09:37.865 --> 01:09:38.365 right?
NOTE Confidence: 0.95651394
01:09:38.745 --> 01:09:40.585 Correct. Yeah. I think that
NOTE Confidence: 0.95651394
01:09:40.585 --> 01:09:41.945 that's I think that's sort
NOTE Confidence: 0.95651394
01:09:41.945 --> 01:09:42.905 of the upfront,
NOTE Confidence: 0.98094237
01:09:47.305 --> 01:09:48.045 you know,
NOTE Confidence: 0.96895057
01:09:48.780 --> 01:09:50.160 that's sort of the upfront
NOTE Confidence: 0.96895057
01:09:50.220 --> 01:09:51.740 conversation that kinda needs to
NOTE Confidence: 0.96895057
01:09:51.740 --> 01:09:53.200 be had in terms of,
NOTE Confidence: 0.9649593
01:09:53.900 --> 01:09:55.340 you know, we're we're maybe
NOTE Confidence: 0.9649593
01:09:55.340 --> 01:09:56.479 changing survival,
NOTE Confidence: 0.9875085
01:09:56.780 --> 01:09:58.060 like, meaning a child will
NOTE Confidence: 0.9875085
01:09:58.060 --> 01:09:59.740 actually survive to the point
NOTE Confidence: 0.9875085
01:09:59.740 --> 01:10:01.520 of being nine or ten.
NOTE Confidence: 0.9986362

01:10:02.415 --> 01:10:04.195 But in terms of
NOTE Confidence: 0.999702

01:10:05.534 --> 01:10:06.114 the outcome
NOTE Confidence: 0.9399433

01:10:06.814 --> 01:10:07.934 of an of the of
NOTE Confidence: 0.9399433

01:10:07.934 --> 01:10:09.135 them, how how they'll be
NOTE Confidence: 0.9399433

01:10:09.135 --> 01:10:11.054 neurologically, like, that, I don't
NOTE Confidence: 0.9399433

01:10:11.054 --> 01:10:11.554 think
NOTE Confidence: 0.9802497

01:10:11.854 --> 01:10:12.835 we can shift.
NOTE Confidence: 0.8925212

01:10:16.659 --> 01:10:17.300 But I might I might
NOTE Confidence: 0.8925212

01:10:17.300 --> 01:10:18.579 be wrong. I mean No.
NOTE Confidence: 0.8925212

01:10:18.579 --> 01:10:19.420 I think that's that that
NOTE Confidence: 0.8925212

01:10:19.460 --> 01:10:20.340 I mean, that sounds right
NOTE Confidence: 0.8925212

01:10:20.340 --> 01:10:21.139 to me. Now there's there's
NOTE Confidence: 0.8925212

01:10:21.139 --> 01:10:21.939 people who know,
NOTE Confidence: 0.99955547

01:10:22.500 --> 01:10:23.159 these things
NOTE Confidence: 0.9846153

01:10:23.619 --> 01:10:24.420 as as well or better
NOTE Confidence: 0.9846153

01:10:24.420 --> 01:10:25.219 than I do. Yeah. But

NOTE Confidence: 0.9846153

01:10:25.219 --> 01:10:26.260 but I think that's right.

NOTE Confidence: 0.9846153

01:10:26.260 --> 01:10:27.219 I think that and, of

NOTE Confidence: 0.9846153

01:10:27.219 --> 01:10:27.719 course,

NOTE Confidence: 0.9964075

01:10:28.114 --> 01:10:29.574 that severe neurologic

NOTE Confidence: 0.81508577

01:10:29.875 --> 01:10:30.375 impairment,

NOTE Confidence: 0.94573414

01:10:30.915 --> 01:10:31.955 there there's I'm not aware

NOTE Confidence: 0.94573414

01:10:31.955 --> 01:10:32.915 of any physicians who are

NOTE Confidence: 0.94573414

01:10:32.915 --> 01:10:34.114 saying to families you must

NOTE Confidence: 0.94573414

01:10:34.114 --> 01:10:35.795 elect surgery Yeah. On that

NOTE Confidence: 0.94573414

01:10:35.795 --> 01:10:37.074 there are now more who

NOTE Confidence: 0.94573414

01:10:37.074 --> 01:10:38.835 say you may, but there

NOTE Confidence: 0.94573414

01:10:38.835 --> 01:10:40.290 are none who say you

NOTE Confidence: 0.94573414

01:10:40.290 --> 01:10:41.410 must. Right? I mean, I'm

NOTE Confidence: 0.94573414

01:10:41.410 --> 01:10:42.210 not aware of any that

NOTE Confidence: 0.94573414

01:10:42.210 --> 01:10:43.010 that say this is something

NOTE Confidence: 0.94573414

01:10:43.010 --> 01:10:43.810 that that has to be
NOTE Confidence: 0.94573414

01:10:43.810 --> 01:10:45.410 done. These these children should
NOTE Confidence: 0.94573414

01:10:45.410 --> 01:10:46.610 have surgery, but rather that
NOTE Confidence: 0.94573414

01:10:46.610 --> 01:10:48.050 that the that some folks
NOTE Confidence: 0.94573414

01:10:48.050 --> 01:10:49.410 say they should be given
NOTE Confidence: 0.94573414

01:10:49.410 --> 01:10:50.450 the option, not that they
NOTE Confidence: 0.94573414

01:10:50.610 --> 01:10:51.350 that the families
NOTE Confidence: 0.9876148

01:10:51.970 --> 01:10:53.395 must choose surgery for this
NOTE Confidence: 0.9876148

01:10:53.395 --> 01:10:54.675 kid. I think that's correct.
NOTE Confidence: 0.9876148

01:10:54.675 --> 01:10:55.875 Yeah. I don't I I
NOTE Confidence: 0.9876148

01:10:55.875 --> 01:10:57.494 think if anything, it's
NOTE Confidence: 0.9934687

01:10:57.795 --> 01:10:58.835 you know, we only saw
NOTE Confidence: 0.9934687

01:10:58.835 --> 01:11:00.195 seventeen percent. Right? So these
NOTE Confidence: 0.9934687

01:11:00.195 --> 01:11:01.574 are people who are actively
NOTE Confidence: 0.9934687

01:11:01.795 --> 01:11:03.814 seeking out, you know, programs
NOTE Confidence: 0.9934687

01:11:04.034 --> 01:11:05.235 where, you know, that might

NOTE Confidence: 0.9934687
01:11:05.235 --> 01:11:06.375 be offered to them.
NOTE Confidence: 0.9601739
01:11:07.310 --> 01:11:08.510 This lady right here, please.
NOTE Confidence: 0.9601739
01:11:08.510 --> 01:11:09.650 Hi. I'm a pediatric
NOTE Confidence: 0.998542
01:11:09.950 --> 01:11:10.450 chaplain.
NOTE Confidence: 0.99986416
01:11:11.150 --> 01:11:12.350 Part of my job is
NOTE Confidence: 0.99986416
01:11:12.350 --> 01:11:14.210 to listen to a child's
NOTE Confidence: 0.99986416
01:11:14.270 --> 01:11:15.570 voice and spirit
NOTE Confidence: 0.9498564
01:11:16.350 --> 01:11:17.890 no matter what their age.
NOTE Confidence: 0.9417364
01:11:20.405 --> 01:11:21.625 With your patience,
NOTE Confidence: 0.9977769
01:11:23.045 --> 01:11:24.485 have you seen children like
NOTE Confidence: 0.9977769
01:11:24.485 --> 01:11:24.985 these
NOTE Confidence: 0.9959806
01:11:26.165 --> 01:11:26.665 fighting
NOTE Confidence: 0.99926865
01:11:27.285 --> 01:11:28.564 and wanting to be with
NOTE Confidence: 0.99926865
01:11:28.564 --> 01:11:29.305 their family
NOTE Confidence: 0.5532725
01:11:31.364 --> 01:11:31.864 versus
NOTE Confidence: 0.9971468

01:11:32.564 --> 01:11:33.925 the other way around of
NOTE Confidence: 0.9971468

01:11:33.925 --> 01:11:34.425 parents
NOTE Confidence: 0.97714037

01:11:35.510 --> 01:11:36.870 wanting to fight for their
NOTE Confidence: 0.97714037

01:11:36.870 --> 01:11:38.469 child. Do you see the
NOTE Confidence: 0.97714037

01:11:38.469 --> 01:11:38.969 child
NOTE Confidence: 0.9003933

01:11:39.830 --> 01:11:41.770 somehow in this small body
NOTE Confidence: 0.98081267

01:11:43.270 --> 01:11:44.630 show others on the team
NOTE Confidence: 0.98081267

01:11:44.630 --> 01:11:45.530 or the family
NOTE Confidence: 0.97980917

01:11:46.229 --> 01:11:47.050 their desire
NOTE Confidence: 0.99661195

01:11:47.830 --> 01:11:49.370 to fight or live?
NOTE Confidence: 0.96898365

01:11:55.195 --> 01:11:56.314 You know, I I,
NOTE Confidence: 0.9915582

01:11:56.955 --> 01:11:57.695 I've often
NOTE Confidence: 0.9254819

01:11:58.635 --> 01:12:00.075 I've heard people say, like,
NOTE Confidence: 0.9254819

01:12:00.075 --> 01:12:01.195 parents would say, like, well,
NOTE Confidence: 0.9254819

01:12:01.195 --> 01:12:02.495 my kid is a fighter.
NOTE Confidence: 0.9254819

01:12:02.795 --> 01:12:03.354 You know, that's

NOTE Confidence: 0.9975092
01:12:08.240 --> 01:12:09.780 it's it's it's
NOTE Confidence: 0.9656803
01:12:11.360 --> 01:12:12.400 the way that I would
NOTE Confidence: 0.9656803
01:12:12.400 --> 01:12:13.380 be able to
NOTE Confidence: 0.96415675
01:12:14.240 --> 01:12:15.600 see that, you know, typically,
NOTE Confidence: 0.96415675
01:12:15.600 --> 01:12:16.880 like, where somebody can express
NOTE Confidence: 0.96415675
01:12:16.880 --> 01:12:18.000 it. You know, obviously, in
NOTE Confidence: 0.96415675
01:12:18.000 --> 01:12:18.660 this situation,
NOTE Confidence: 0.97930634
01:12:19.040 --> 01:12:20.340 that's not gonna happen.
NOTE Confidence: 0.7759007
01:12:23.564 --> 01:12:24.385 And I
NOTE Confidence: 0.9918037
01:12:24.685 --> 01:12:25.985 I think in this situation
NOTE Confidence: 0.9918037
01:12:26.205 --> 01:12:26.705 where,
NOTE Confidence: 0.9903749
01:12:27.085 --> 01:12:29.104 you know, those children,
NOTE Confidence: 0.9885127
01:12:30.925 --> 01:12:32.285 it's hard to hear their
NOTE Confidence: 0.9885127
01:12:32.285 --> 01:12:34.205 voice or or hard to
NOTE Confidence: 0.9885127
01:12:34.205 --> 01:12:35.805 hear what they would express
NOTE Confidence: 0.9885127

01:12:35.805 --> 01:12:36.545 for themselves
NOTE Confidence: 0.7731597

01:12:37.085 --> 01:12:37.985 because they can't
NOTE Confidence: 0.99968445

01:12:38.500 --> 01:12:39.000 necessarily
NOTE Confidence: 0.9952504

01:12:39.300 --> 01:12:40.920 advocate on their behalf.
NOTE Confidence: 0.9851534

01:12:41.620 --> 01:12:42.660 You know, we're sort of
NOTE Confidence: 0.9851534

01:12:42.660 --> 01:12:43.160 relying
NOTE Confidence: 0.98296607

01:12:44.180 --> 01:12:45.700 on on the parents and,
NOTE Confidence: 0.98296607

01:12:45.700 --> 01:12:46.600 you know, we
NOTE Confidence: 0.9872995

01:12:47.460 --> 01:12:49.479 we defer to their parental
NOTE Confidence: 0.9872995

01:12:49.620 --> 01:12:50.120 authority.
NOTE Confidence: 0.95486903

01:12:51.540 --> 01:12:52.020 Have I
NOTE Confidence: 0.9911619

01:12:53.074 --> 01:12:54.354 I I think, you know,
NOTE Confidence: 0.9911619

01:12:54.354 --> 01:12:55.955 I probably I have had
NOTE Confidence: 0.9911619

01:12:55.955 --> 01:12:56.455 experiences
NOTE Confidence: 0.9309361

01:12:56.915 --> 01:12:57.415 where,
NOTE Confidence: 0.97997534

01:12:58.835 --> 01:13:00.514 and many of them have

NOTE Confidence: 0.97997534

01:13:00.514 --> 01:13:02.054 sort of, in some ways,

NOTE Confidence: 0.9746492

01:13:03.715 --> 01:13:05.814 inspired this work, but where,

NOTE Confidence: 0.9746492

01:13:05.875 --> 01:13:06.514 you know, I was like,

NOTE Confidence: 0.9746492

01:13:06.514 --> 01:13:08.600 wow. This this child is

NOTE Confidence: 0.9746492

01:13:08.600 --> 01:13:10.520 is still alive despite, like,

NOTE Confidence: 0.9746492

01:13:10.520 --> 01:13:12.600 everything that's been done or

NOTE Confidence: 0.9746492

01:13:12.600 --> 01:13:13.960 not been done. And so

NOTE Confidence: 0.9746492

01:13:14.600 --> 01:13:15.800 and and you almost it

NOTE Confidence: 0.9746492

01:13:15.800 --> 01:13:16.920 almost came to a point

NOTE Confidence: 0.9746492

01:13:16.920 --> 01:13:17.420 where

NOTE Confidence: 0.9981965

01:13:17.800 --> 01:13:18.200 it felt

NOTE Confidence: 0.92617327

01:13:19.320 --> 01:13:20.600 it it really questioned why

NOTE Confidence: 0.92617327

01:13:20.600 --> 01:13:21.800 why hadn't we done something

NOTE Confidence: 0.92617327

01:13:21.800 --> 01:13:22.939 a long time ago.

NOTE Confidence: 0.9933773

01:13:24.485 --> 01:13:26.104 So but that's you know,

NOTE Confidence: 0.9933773

01:13:26.165 --> 01:13:27.284 the problem with that is
NOTE Confidence: 0.9933773

01:13:27.284 --> 01:13:28.505 that's not a scientific
NOTE Confidence: 0.91961074

01:13:29.604 --> 01:13:30.104 explanation,
NOTE Confidence: 0.98423547

01:13:30.485 --> 01:13:32.085 but that's I think that's
NOTE Confidence: 0.98423547

01:13:32.085 --> 01:13:32.585 where,
NOTE Confidence: 0.98364186

01:13:33.445 --> 01:13:34.905 you know, it is important
NOTE Confidence: 0.98364186

01:13:35.045 --> 01:13:36.485 to kind of question or
NOTE Confidence: 0.98364186

01:13:36.485 --> 01:13:37.685 at least wonder, hey. You
NOTE Confidence: 0.98364186

01:13:37.685 --> 01:13:39.120 know, why do we make
NOTE Confidence: 0.98364186

01:13:39.120 --> 01:13:40.739 the decisions that we make?
NOTE Confidence: 0.98364186

01:13:40.960 --> 01:13:43.300 What's the background behind them?
NOTE Confidence: 0.9751527

01:13:45.439 --> 01:13:46.320 I don't I don't know
NOTE Confidence: 0.9751527

01:13:46.320 --> 01:13:47.540 if that that's probably
NOTE Confidence: 0.9463595

01:13:48.239 --> 01:13:50.000 the one the the the
NOTE Confidence: 0.9463595

01:13:50.159 --> 01:13:51.199 I I know a specific
NOTE Confidence: 0.9463595

01:13:51.360 --> 01:13:52.640 there's a specific person I

NOTE Confidence: 0.9463595
01:13:52.640 --> 01:13:53.780 have in mind where,
NOTE Confidence: 0.95221454
01:13:54.155 --> 01:13:55.515 you know, the child who's
NOTE Confidence: 0.95221454
01:13:55.515 --> 01:13:57.675 still alive, you know, had,
NOTE Confidence: 0.95221454
01:13:57.675 --> 01:13:59.615 like, really bad had tetralogy
NOTE Confidence: 0.95221454
01:13:59.755 --> 01:14:00.415 of flow,
NOTE Confidence: 0.9224438
01:14:01.115 --> 01:14:02.395 was like one of these
NOTE Confidence: 0.9224438
01:14:02.395 --> 01:14:02.895 tetralogy
NOTE Confidence: 0.9381879
01:14:03.595 --> 01:14:04.795 of flow is a condition
NOTE Confidence: 0.9381879
01:14:04.795 --> 01:14:05.755 where you have a hole
NOTE Confidence: 0.9381879
01:14:05.755 --> 01:14:06.875 in their in your heart
NOTE Confidence: 0.9381879
01:14:06.875 --> 01:14:08.520 and you have trouble getting
NOTE Confidence: 0.9381879
01:14:08.520 --> 01:14:09.560 blood flow to your lungs,
NOTE Confidence: 0.9381879
01:14:09.560 --> 01:14:11.080 and so those babies can
NOTE Confidence: 0.9381879
01:14:11.080 --> 01:14:12.280 have what's called tet spells
NOTE Confidence: 0.9381879
01:14:12.280 --> 01:14:13.340 and be very blue.
NOTE Confidence: 0.99409205

01:14:13.640 --> 01:14:14.840 And so this baby was
NOTE Confidence: 0.99409205

01:14:14.840 --> 01:14:15.900 having these, like,
NOTE Confidence: 0.91384697

01:14:16.680 --> 01:14:18.840 really intense tet spells or,
NOTE Confidence: 0.91384697

01:14:18.840 --> 01:14:19.720 at this point, sort of
NOTE Confidence: 0.91384697

01:14:19.720 --> 01:14:20.695 like toddler.
NOTE Confidence: 0.9961425

01:14:21.955 --> 01:14:22.995 And, you know, we were
NOTE Confidence: 0.9961425

01:14:22.995 --> 01:14:23.815 trying to,
NOTE Confidence: 0.99553555

01:14:24.675 --> 01:14:25.875 you know, keep
NOTE Confidence: 0.9356186

01:14:26.435 --> 01:14:27.555 my point is I think,
NOTE Confidence: 0.9356186

01:14:27.555 --> 01:14:28.755 like, you know, I was
NOTE Confidence: 0.9356186

01:14:28.755 --> 01:14:29.715 thinking that, you know, could
NOTE Confidence: 0.9356186

01:14:29.715 --> 01:14:30.915 that child have been repaired
NOTE Confidence: 0.9356186

01:14:30.915 --> 01:14:31.875 and then we we wouldn't
NOTE Confidence: 0.9356186

01:14:31.875 --> 01:14:33.015 have been in this situation
NOTE Confidence: 0.9356186

01:14:33.075 --> 01:14:33.815 at all?
NOTE Confidence: 0.99554086

01:14:35.040 --> 01:14:35.540 So,

NOTE Confidence: 0.7397124

01:14:36.240 --> 01:14:36.740 anyways.

NOTE Confidence: 0.938021

01:14:38.000 --> 01:14:38.900 Doctor Rasmus.

NOTE Confidence: 0.917905

01:14:41.280 --> 01:14:42.240 Oh, I'm sorry. Wait. Wait.

NOTE Confidence: 0.917905

01:14:42.240 --> 01:14:43.200 Wait. One second, Jeremy. I

NOTE Confidence: 0.917905

01:14:43.200 --> 01:14:44.000 I didn't realize you had

NOTE Confidence: 0.917905

01:14:44.000 --> 01:14:44.800 to no. No. No. Please.

NOTE Confidence: 0.917905

01:14:44.800 --> 01:14:46.320 Eric, I apologize. There was

NOTE Confidence: 0.917905

01:14:46.320 --> 01:14:47.200 someone in the line ahead

NOTE Confidence: 0.917905

01:14:47.200 --> 01:14:47.939 of you, Jeremy.

NOTE Confidence: 0.953497

01:14:49.344 --> 01:14:50.705 Alright. And then doctor Thompson

NOTE Confidence: 0.953497

01:14:50.705 --> 01:14:51.604 right after, please.

NOTE Confidence: 0.9716598

01:14:52.224 --> 01:14:54.485 Thanks, Katya. So I have,

NOTE Confidence: 0.9892406

01:14:55.104 --> 01:14:57.025 two questions. One is sort

NOTE Confidence: 0.9892406

01:14:57.025 --> 01:14:57.685 of similar.

NOTE Confidence: 0.97280955

01:14:59.185 --> 01:15:00.304 I I think that there's

NOTE Confidence: 0.97280955

01:15:00.304 --> 01:15:02.304 a problem of focusing on
NOTE Confidence: 0.97280955

01:15:02.304 --> 01:15:04.389 the parent's voice, and there
NOTE Confidence: 0.97280955

01:15:04.389 --> 01:15:06.150 is no child's voice. Right?
NOTE Confidence: 0.97280955

01:15:06.150 --> 01:15:06.969 Mhmm. So,
NOTE Confidence: 0.9985843

01:15:07.510 --> 01:15:08.889 and these decisions are being
NOTE Confidence: 0.96977234

01:15:09.269 --> 01:15:09.769 made,
NOTE Confidence: 0.9674143

01:15:10.550 --> 01:15:11.670 at a time when no
NOTE Confidence: 0.9674143

01:15:11.670 --> 01:15:13.050 child has a voice because
NOTE Confidence: 0.9674143

01:15:13.349 --> 01:15:15.030 these are babies for the
NOTE Confidence: 0.9674143

01:15:15.030 --> 01:15:17.045 most part, where these decisions
NOTE Confidence: 0.9674143

01:15:17.045 --> 01:15:18.324 are getting made. But I'm
NOTE Confidence: 0.9674143

01:15:18.324 --> 01:15:20.085 curious about the data. Survival
NOTE Confidence: 0.9674143

01:15:20.085 --> 01:15:22.005 data is interesting, but to
NOTE Confidence: 0.9674143

01:15:22.005 --> 01:15:22.745 me, irrelevant
NOTE Confidence: 0.92615104

01:15:23.364 --> 01:15:25.045 because we can make many,
NOTE Confidence: 0.92615104

01:15:25.045 --> 01:15:25.545 many

NOTE Confidence: 0.96612436

01:15:26.165 --> 01:15:28.745 infants and babies survive. Mhmm.

NOTE Confidence: 0.96612436

01:15:29.045 --> 01:15:30.005 But that means they have

NOTE Confidence: 0.96612436

01:15:30.005 --> 01:15:31.439 a heartbeat and a blood

NOTE Confidence: 0.96612436

01:15:31.520 --> 01:15:32.880 pressure, and that's kind of

NOTE Confidence: 0.96612436

01:15:32.880 --> 01:15:34.260 about it for survival.

NOTE Confidence: 0.9661006

01:15:34.880 --> 01:15:36.560 But what so you you

NOTE Confidence: 0.9661006

01:15:36.560 --> 01:15:38.560 talked about technological dependence. Yeah.

NOTE Confidence: 0.9661006

01:15:38.560 --> 01:15:39.840 Do we have data to

NOTE Confidence: 0.9661006

01:15:39.840 --> 01:15:41.680 talk about to that shows

NOTE Confidence: 0.9661006

01:15:41.680 --> 01:15:43.199 us what the level of

NOTE Confidence: 0.9661006

01:15:43.199 --> 01:15:44.960 technological dependence is and what

NOTE Confidence: 0.9661006

01:15:44.960 --> 01:15:46.765 the level of independence is

NOTE Confidence: 0.9661006

01:15:47.005 --> 01:15:48.945 Mhmm. For for this cohort?

NOTE Confidence: 0.98656

01:15:49.885 --> 01:15:51.905 There there is some, Jeremy.

NOTE Confidence: 0.98656

01:15:51.965 --> 01:15:54.305 It's not as robust as,

NOTE Confidence: 0.984463

01:15:55.725 --> 01:15:56.765 where you could, you know,
NOTE Confidence: 0.984463

01:15:56.765 --> 01:15:57.965 quote it to a family,
NOTE Confidence: 0.984463

01:15:57.965 --> 01:15:58.705 let's say.
NOTE Confidence: 0.9818427

01:16:01.400 --> 01:16:03.099 We're hoping to change that.
NOTE Confidence: 0.9929855

01:16:03.880 --> 01:16:05.159 You know, we're hoping to
NOTE Confidence: 0.9929855

01:16:05.159 --> 01:16:06.380 to to change that.
NOTE Confidence: 0.96909606

01:16:07.400 --> 01:16:08.920 One thing that I think
NOTE Confidence: 0.96909606

01:16:08.920 --> 01:16:10.520 kinda changed my perspective on
NOTE Confidence: 0.96909606

01:16:10.520 --> 01:16:12.860 this is seeing children who
NOTE Confidence: 0.96909606

01:16:12.920 --> 01:16:14.380 were trach dependent
NOTE Confidence: 0.99271905

01:16:14.915 --> 01:16:15.795 kind of move out of
NOTE Confidence: 0.99271905

01:16:15.795 --> 01:16:17.635 that phase and and be
NOTE Confidence: 0.99271905

01:16:17.635 --> 01:16:18.135 decannulated
NOTE Confidence: 0.96324813

01:16:19.155 --> 01:16:20.995 and then not require mechanical
NOTE Confidence: 0.96324813

01:16:20.995 --> 01:16:22.215 ventilation further.
NOTE Confidence: 0.9271725

01:16:24.835 --> 01:16:25.335 And

NOTE Confidence: 0.9971428

01:16:25.715 --> 01:16:26.835 when I've gone to these

NOTE Confidence: 0.9971428

01:16:26.835 --> 01:16:28.035 events where, you know, you're

NOTE Confidence: 0.9971428

01:16:28.035 --> 01:16:29.575 meeting kids who are older,

NOTE Confidence: 0.9996786

01:16:30.690 --> 01:16:31.430 Very few

NOTE Confidence: 0.9030821

01:16:32.290 --> 01:16:33.190 are trach dependent.

NOTE Confidence: 0.994317

01:16:33.890 --> 01:16:35.170 So I feel like the

NOTE Confidence: 0.994317

01:16:35.170 --> 01:16:35.670 overwhelming

NOTE Confidence: 0.99950695

01:16:36.370 --> 01:16:37.670 perspective in the hospital

NOTE Confidence: 0.9927496

01:16:38.050 --> 01:16:38.930 is that they can't come

NOTE Confidence: 0.9927496

01:16:38.930 --> 01:16:39.750 off the ventilator.

NOTE Confidence: 0.9899941

01:16:40.770 --> 01:16:41.729 But I but I I

NOTE Confidence: 0.9899941

01:16:41.729 --> 01:16:43.750 think that many children do

NOTE Confidence: 0.9899941

01:16:43.810 --> 01:16:45.514 once they're home. Yeah. I

NOTE Confidence: 0.9899941

01:16:45.514 --> 01:16:46.554 I worry a bit that

NOTE Confidence: 0.9899941

01:16:46.554 --> 01:16:48.715 the support group population is

NOTE Confidence: 0.9899941

01:16:48.715 --> 01:16:50.635 a very biased population. Right?

NOTE Confidence: 0.9899941

01:16:50.635 --> 01:16:51.675 I mean, you're looking at

NOTE Confidence: 0.9899941

01:16:51.675 --> 01:16:53.195 the kids who are and

NOTE Confidence: 0.9899941

01:16:53.195 --> 01:16:54.335 families who are

NOTE Confidence: 0.9464877

01:16:55.034 --> 01:16:56.395 bringing their kids to these

NOTE Confidence: 0.9464877

01:16:56.395 --> 01:16:58.494 events. And clearly, they're attached

NOTE Confidence: 0.9743288

01:16:58.920 --> 01:16:59.920 to their children, and that

NOTE Confidence: 0.9743288

01:17:00.040 --> 01:17:01.479 that's what why they're there.

NOTE Confidence: 0.9743288

01:17:01.479 --> 01:17:02.679 Yeah. But, I mean and

NOTE Confidence: 0.9743288

01:17:02.679 --> 01:17:03.719 you mentioned sort of use

NOTE Confidence: 0.9743288

01:17:03.719 --> 01:17:04.920 of a wheelchair before. I

NOTE Confidence: 0.9743288

01:17:04.920 --> 01:17:05.960 I would assume that these

NOTE Confidence: 0.9743288

01:17:05.960 --> 01:17:07.560 are kids who are in

NOTE Confidence: 0.9743288

01:17:07.560 --> 01:17:09.160 a wheelchair that somebody else

NOTE Confidence: 0.9743288

01:17:09.160 --> 01:17:11.580 is actually using. Yes. Absolutely.

NOTE Confidence: 0.9743288

01:17:11.640 --> 01:17:12.655 So Yeah. So they have

NOTE Confidence: 0.9743288
01:17:12.655 --> 01:17:14.175 a mobile chair. But I
NOTE Confidence: 0.9743288
01:17:14.175 --> 01:17:15.795 I think it's important information
NOTE Confidence: 0.9728546
01:17:16.175 --> 01:17:17.455 to be able to counsel
NOTE Confidence: 0.9728546
01:17:17.455 --> 01:17:18.735 families about because I think
NOTE Confidence: 0.9728546
01:17:18.735 --> 01:17:19.235 families
NOTE Confidence: 0.96457505
01:17:19.614 --> 01:17:21.295 like our field in general
NOTE Confidence: 0.96457505
01:17:21.295 --> 01:17:23.054 for many, many decades has
NOTE Confidence: 0.96457505
01:17:23.054 --> 01:17:25.054 focused purely on survival without
NOTE Confidence: 0.96457505
01:17:25.054 --> 01:17:26.195 really thinking about
NOTE Confidence: 0.94499886
01:17:26.495 --> 01:17:27.469 what is what does it
NOTE Confidence: 0.94499886
01:17:27.469 --> 01:17:28.130 mean to be alive.
NOTE Confidence: 0.95035857
01:17:29.070 --> 01:17:30.590 Yeah. And so I think
NOTE Confidence: 0.95035857
01:17:30.590 --> 01:17:31.790 that's gotta be the next
NOTE Confidence: 0.95035857
01:17:31.790 --> 01:17:33.150 shift. Is a shift away
NOTE Confidence: 0.95035857
01:17:33.150 --> 01:17:34.770 from just the survival discussion,
NOTE Confidence: 0.9992105

01:17:35.150 --> 01:17:36.850 but more to one of
NOTE Confidence: 0.9697972

01:17:37.630 --> 01:17:38.830 when we talk about quality
NOTE Confidence: 0.9697972

01:17:38.830 --> 01:17:40.185 of life, what what does
NOTE Confidence: 0.9697972

01:17:40.185 --> 01:17:42.185 it actually mean and have
NOTE Confidence: 0.9697972

01:17:42.185 --> 01:17:43.784 families make decisions based on
NOTE Confidence: 0.9697972

01:17:43.784 --> 01:17:45.145 that, not based on whether
NOTE Confidence: 0.9697972

01:17:45.145 --> 01:17:45.864 or not we can get
NOTE Confidence: 0.9697972

01:17:45.864 --> 01:17:47.405 you through. Right?
NOTE Confidence: 0.99665856

01:17:49.465 --> 01:17:50.205 Thank you.
NOTE Confidence: 0.974527

01:17:50.985 --> 01:17:51.885 Eric, please.
NOTE Confidence: 0.8981846

01:17:52.969 --> 01:17:54.250 Use both microphones, Eric, so
NOTE Confidence: 0.8981846

01:17:54.250 --> 01:17:55.449 people will really hear you.
NOTE Confidence: 0.8981846

01:17:55.449 --> 01:17:56.350 Yeah. I
NOTE Confidence: 0.9657806

01:17:57.050 --> 01:17:58.330 agree with what you just
NOTE Confidence: 0.9657806

01:17:58.330 --> 01:17:59.849 said about survival. Open up
NOTE Confidence: 0.9657806

01:17:59.849 --> 01:18:01.290 a little closer, please. I'm,

NOTE Confidence: 0.9657806
01:18:01.689 --> 01:18:03.370 I'm Eric Thompson, and my
NOTE Confidence: 0.9657806
01:18:03.370 --> 01:18:04.489 wife will say my main
NOTE Confidence: 0.9657806
01:18:04.489 --> 01:18:05.689 claim to fame in life
NOTE Confidence: 0.9657806
01:18:05.689 --> 01:18:07.005 is that Mark and I
NOTE Confidence: 0.9657806
01:18:07.005 --> 01:18:07.825 were classmates
NOTE Confidence: 0.9756748
01:18:08.285 --> 01:18:10.064 going back to fifth grade.
NOTE Confidence: 0.9950959
01:18:10.365 --> 01:18:11.185 But the second
NOTE Confidence: 0.9612763
01:18:11.805 --> 01:18:13.645 is I I'm retired cardiac
NOTE Confidence: 0.9612763
01:18:13.645 --> 01:18:15.085 surgeon. And the third is
NOTE Confidence: 0.9612763
01:18:15.085 --> 01:18:15.585 I
NOTE Confidence: 0.9854635
01:18:15.885 --> 01:18:17.165 when my third son was
NOTE Confidence: 0.9854635
01:18:17.165 --> 01:18:19.185 born, he had trisomy eighteen.
NOTE Confidence: 0.99129176
01:18:20.110 --> 01:18:20.610 And,
NOTE Confidence: 0.96423906
01:18:21.283 --> 01:18:23.070 it and the decision making
NOTE Confidence: 0.96423906
01:18:23.070 --> 01:18:23.890 that went on
NOTE Confidence: 0.9894519

01:18:24.270 --> 01:18:25.250 right then was
NOTE Confidence: 0.91913337

01:18:26.030 --> 01:18:27.229 about the hardest thing I've
NOTE Confidence: 0.91913337

01:18:27.229 --> 01:18:27.970 ever done.
NOTE Confidence: 0.9344035

01:18:28.670 --> 01:18:30.030 And I can speak for
NOTE Confidence: 0.9344035

01:18:30.030 --> 01:18:31.229 my my wife at the
NOTE Confidence: 0.9344035

01:18:31.229 --> 01:18:32.350 time too. It was a
NOTE Confidence: 0.9344035

01:18:32.865 --> 01:18:33.825 was a she worked in
NOTE Confidence: 0.9344035

01:18:33.825 --> 01:18:34.485 the pediatric
NOTE Confidence: 0.97823554

01:18:34.865 --> 01:18:36.545 cardiac surgery unit. So she
NOTE Confidence: 0.97823554

01:18:36.545 --> 01:18:37.985 had she had a ton
NOTE Confidence: 0.97823554

01:18:37.985 --> 01:18:38.725 of experience
NOTE Confidence: 0.92611253

01:18:39.104 --> 01:18:40.465 Yeah. Taking care of kids
NOTE Confidence: 0.92611253

01:18:40.465 --> 01:18:42.225 with very complicated problems, so
NOTE Confidence: 0.92611253

01:18:42.225 --> 01:18:43.205 it was hard. And,
NOTE Confidence: 0.9944173

01:18:46.064 --> 01:18:47.685 if you focus on survival,
NOTE Confidence: 0.97592145

01:18:48.680 --> 01:18:49.720 all of a sudden people

NOTE Confidence: 0.97592145

01:18:49.720 --> 01:18:50.760 think and you see the

NOTE Confidence: 0.97592145

01:18:50.760 --> 01:18:52.280 survival numbers. All of a

NOTE Confidence: 0.97592145

01:18:52.280 --> 01:18:53.720 sudden people think that, you

NOTE Confidence: 0.97592145

01:18:53.720 --> 01:18:54.680 know, maybe this is a

NOTE Confidence: 0.97592145

01:18:54.680 --> 01:18:55.800 good idea because you can

NOTE Confidence: 0.97592145

01:18:55.800 --> 01:18:56.920 get somebody through because you

NOTE Confidence: 0.97592145

01:18:56.920 --> 01:18:57.660 can survive.

NOTE Confidence: 0.9972296

01:18:58.040 --> 01:18:59.260 And I'm gonna argue

NOTE Confidence: 0.9894109

01:18:59.960 --> 01:19:01.740 I'm gonna argue based on

NOTE Confidence: 0.9624703

01:19:02.675 --> 01:19:04.354 what happens, not not in

NOTE Confidence: 0.9624703

01:19:04.354 --> 01:19:05.314 infancy, but at the end

NOTE Confidence: 0.9624703

01:19:05.314 --> 01:19:06.055 of life.

NOTE Confidence: 0.97691345

01:19:07.075 --> 01:19:08.515 If you you mentioned the

NOTE Confidence: 0.97691345

01:19:08.515 --> 01:19:10.354 Society of Thoracic Surgeons database.

NOTE Confidence: 0.97691345

01:19:10.354 --> 01:19:11.575 So for, like, ten years,

NOTE Confidence: 0.98908705

01:19:12.195 --> 01:19:13.635 standard of care doing heart

NOTE Confidence: 0.98908705

01:19:13.635 --> 01:19:15.235 surgery is you're you are

NOTE Confidence: 0.98908705

01:19:15.235 --> 01:19:16.035 supposed to talk to the

NOTE Confidence: 0.98908705

01:19:16.035 --> 01:19:17.335 patient and their family

NOTE Confidence: 0.978051

01:19:17.940 --> 01:19:18.100 about,

NOTE Confidence: 0.9983802

01:19:19.060 --> 01:19:19.880 their predicted

NOTE Confidence: 0.78757346

01:19:20.860 --> 01:19:21.360 outcomes.

NOTE Confidence: 0.998533

01:19:22.340 --> 01:19:22.840 And

NOTE Confidence: 0.9476227

01:19:23.620 --> 01:19:25.380 not one person is ever

NOTE Confidence: 0.9476227

01:19:25.380 --> 01:19:27.080 ever persuaded by

NOTE Confidence: 0.9866302

01:19:27.460 --> 01:19:29.460 the operative mortality. If you

NOTE Confidence: 0.9866302

01:19:29.460 --> 01:19:30.580 if you tell somebody you

NOTE Confidence: 0.9866302

01:19:30.580 --> 01:19:31.780 have a one percent chance

NOTE Confidence: 0.9866302

01:19:31.780 --> 01:19:33.034 of dying or or you

NOTE Confidence: 0.9866302

01:19:33.034 --> 01:19:33.915 tell somebody else you have

NOTE Confidence: 0.9866302

01:19:33.915 --> 01:19:34.955 a twenty percent chance of

NOTE Confidence: 0.9866302

01:19:34.955 --> 01:19:36.715 dying, that will never ever

NOTE Confidence: 0.9866302

01:19:36.715 --> 01:19:38.235 affect their decision about whether

NOTE Confidence: 0.9866302

01:19:38.235 --> 01:19:39.054 to go ahead.

NOTE Confidence: 0.9987178

01:19:39.435 --> 01:19:41.195 But there's another metric in

NOTE Confidence: 0.9987178

01:19:41.195 --> 01:19:42.415 the STS data

NOTE Confidence: 0.99173087

01:19:42.955 --> 01:19:44.175 that's that says

NOTE Confidence: 0.94684637

01:19:44.729 --> 01:19:45.850 it it's a, you know,

NOTE Confidence: 0.94684637

01:19:45.850 --> 01:19:46.989 it's a it's a euphemism,

NOTE Confidence: 0.99541503

01:19:47.610 --> 01:19:48.430 and it says,

NOTE Confidence: 0.87380904

01:19:49.770 --> 01:19:52.010 prolonged care, thirty percent thirty

NOTE Confidence: 0.87380904

01:19:52.010 --> 01:19:53.550 percent chance of prolonged care.

NOTE Confidence: 0.98390186

01:19:53.850 --> 01:19:54.970 And they'll say, you know,

NOTE Confidence: 0.98390186

01:19:54.970 --> 01:19:56.090 what does that mean? Well,

NOTE Confidence: 0.98390186

01:19:56.090 --> 01:19:57.290 that means that you're gonna

NOTE Confidence: 0.98390186

01:19:57.290 --> 01:19:58.425 you're go to a nursing

NOTE Confidence: 0.98390186

01:19:58.425 --> 01:19:59.304 home for a little while
NOTE Confidence: 0.98390186

01:19:59.304 --> 01:20:00.824 after this with a thirty
NOTE Confidence: 0.98390186

01:20:00.824 --> 01:20:02.264 percent chance of that. Well,
NOTE Confidence: 0.98390186

01:20:02.264 --> 01:20:03.064 I'm not if that's the
NOTE Confidence: 0.98390186

01:20:03.064 --> 01:20:04.445 case, I'm not having surgery.
NOTE Confidence: 0.98390186

01:20:04.665 --> 01:20:05.625 Right. And so it's all
NOTE Confidence: 0.98390186

01:20:05.625 --> 01:20:06.985 about quality of life. And
NOTE Confidence: 0.98390186

01:20:06.985 --> 01:20:08.104 I think if you talk
NOTE Confidence: 0.98390186

01:20:08.264 --> 01:20:10.104 if the if if if
NOTE Confidence: 0.98390186

01:20:10.104 --> 01:20:12.604 your discussion is not about
NOTE Confidence: 0.99582213

01:20:13.070 --> 01:20:14.270 just take the survival out
NOTE Confidence: 0.99582213

01:20:14.270 --> 01:20:15.950 of it and and talk
NOTE Confidence: 0.99582213

01:20:15.950 --> 01:20:17.150 about the quality of life
NOTE Confidence: 0.99582213

01:20:17.150 --> 01:20:18.590 of these kids, I I
NOTE Confidence: 0.99582213

01:20:18.590 --> 01:20:20.430 think it would it's you're
NOTE Confidence: 0.99582213

01:20:20.430 --> 01:20:21.250 gonna get

NOTE Confidence: 0.9288437
01:20:21.710 --> 01:20:22.690 a different opinion.
NOTE Confidence: 0.9985468
01:20:23.710 --> 01:20:24.530 And and
NOTE Confidence: 0.99852306
01:20:24.910 --> 01:20:25.710 I'll tell you one more
NOTE Confidence: 0.99852306
01:20:25.710 --> 01:20:26.690 thing that happened
NOTE Confidence: 0.9824419
01:20:27.095 --> 01:20:28.135 at the time was, you
NOTE Confidence: 0.9824419
01:20:28.135 --> 01:20:29.814 know, we we had we
NOTE Confidence: 0.9824419
01:20:29.814 --> 01:20:31.675 had really, you know, really
NOTE Confidence: 0.9824419
01:20:31.814 --> 01:20:34.055 expert advice about this, and
NOTE Confidence: 0.9824419
01:20:34.055 --> 01:20:35.735 we decided we were gonna
NOTE Confidence: 0.9824419
01:20:35.735 --> 01:20:37.735 provide comfort care. We're totally
NOTE Confidence: 0.9824419
01:20:37.735 --> 01:20:38.875 comfortable with that.
NOTE Confidence: 0.9516072
01:20:39.210 --> 01:20:40.170 But there was a nurse
NOTE Confidence: 0.9516072
01:20:40.170 --> 01:20:41.450 in the neo in the
NOTE Confidence: 0.9516072
01:20:41.450 --> 01:20:42.590 neonatal ICU
NOTE Confidence: 0.99705744
01:20:43.050 --> 01:20:43.710 that was
NOTE Confidence: 0.9437086

01:20:44.489 --> 01:20:45.790 had a different opinion,
NOTE Confidence: 0.9553702

01:20:46.250 --> 01:20:48.090 and that made and felt
NOTE Confidence: 0.9553702

01:20:48.410 --> 01:20:49.130 you know, she made a
NOTE Confidence: 0.9553702

01:20:49.130 --> 01:20:50.250 big stink about it, said,
NOTE Confidence: 0.9553702

01:20:50.250 --> 01:20:51.370 you know, this this baby
NOTE Confidence: 0.9553702

01:20:51.370 --> 01:20:52.570 needs to have feeding tube
NOTE Confidence: 0.9553702

01:20:52.570 --> 01:20:53.370 and this and that and
NOTE Confidence: 0.9553702

01:20:53.370 --> 01:20:54.189 the other thing.
NOTE Confidence: 0.991409

01:20:54.655 --> 01:20:55.854 Same thing could happen if
NOTE Confidence: 0.991409

01:20:55.854 --> 01:20:57.375 you the same thing could
NOTE Confidence: 0.991409

01:20:57.375 --> 01:20:59.055 happen about cardiac surgery. If
NOTE Confidence: 0.991409

01:20:59.055 --> 01:21:00.895 you if you have you
NOTE Confidence: 0.991409

01:21:00.895 --> 01:21:02.175 know, if there's survival with
NOTE Confidence: 0.991409

01:21:02.175 --> 01:21:03.615 cardiac surgery, people are gonna
NOTE Confidence: 0.991409

01:21:03.615 --> 01:21:04.575 say, well, you have to
NOTE Confidence: 0.991409

01:21:04.575 --> 01:21:06.354 offer this kid cardiac surgery.

NOTE Confidence: 0.9732391
01:21:10.630 --> 01:21:11.130 So
NOTE Confidence: 0.94180185
01:21:11.510 --> 01:21:12.150 I don't know if you
NOTE Confidence: 0.94180185
01:21:12.150 --> 01:21:13.429 wanna if I appreciate that
NOTE Confidence: 0.94180185
01:21:13.590 --> 01:21:14.869 Yeah. That comment very much,
NOTE Confidence: 0.94180185
01:21:14.869 --> 01:21:15.989 Erica. I don't know if
NOTE Confidence: 0.94180185
01:21:15.989 --> 01:21:17.110 you if you I have
NOTE Confidence: 0.94180185
01:21:17.110 --> 01:21:18.229 one question I wanna go
NOTE Confidence: 0.94180185
01:21:18.229 --> 01:21:20.150 to here on Zoom next,
NOTE Confidence: 0.94180185
01:21:20.469 --> 01:21:21.429 just in case he's having
NOTE Confidence: 0.94180185
01:21:21.429 --> 01:21:22.710 a difficult enough. Yeah. Because
NOTE Confidence: 0.94180185
01:21:22.710 --> 01:21:23.985 she's living on my phone.
NOTE Confidence: 0.94180185
01:21:23.985 --> 01:21:24.945 Just No. No. No. No.
NOTE Confidence: 0.94180185
01:21:24.945 --> 01:21:25.824 I just wanna make sure
NOTE Confidence: 0.94180185
01:21:25.824 --> 01:21:27.425 that, that if I responded
NOTE Confidence: 0.94180185
01:21:27.425 --> 01:21:28.625 to the comment, I wouldn't
NOTE Confidence: 0.94180185

01:21:28.625 --> 01:21:30.225 go over time. So,
NOTE Confidence: 0.96456194

01:21:31.104 --> 01:21:32.545 I I think I I
NOTE Confidence: 0.96456194

01:21:32.545 --> 01:21:33.824 think the point that that
NOTE Confidence: 0.96456194

01:21:33.824 --> 01:21:35.025 you're both making is a
NOTE Confidence: 0.96456194

01:21:35.025 --> 01:21:36.705 very, very important point. And
NOTE Confidence: 0.96456194

01:21:36.705 --> 01:21:37.925 I I hope
NOTE Confidence: 0.9508606

01:21:40.309 --> 01:21:42.090 it's it's hard to represent.
NOTE Confidence: 0.9942943

01:21:43.030 --> 01:21:43.670 I think one of the
NOTE Confidence: 0.9942943

01:21:43.670 --> 01:21:45.510 hardest things to represent are
NOTE Confidence: 0.9942943

01:21:45.510 --> 01:21:46.729 maybe the individuals
NOTE Confidence: 0.99219257

01:21:47.429 --> 01:21:48.409 who, you know,
NOTE Confidence: 0.9502525

01:21:48.949 --> 01:21:50.309 don't think that the quality
NOTE Confidence: 0.9502525

01:21:50.309 --> 01:21:51.590 of life is gonna and
NOTE Confidence: 0.9502525

01:21:51.590 --> 01:21:52.945 like what you were saying
NOTE Confidence: 0.9502525

01:21:52.945 --> 01:21:53.445 about,
NOTE Confidence: 0.9659739

01:21:54.225 --> 01:21:55.185 you know, it's a biased

NOTE Confidence: 0.9659739
01:21:55.185 --> 01:21:56.225 sample. Like, if you go
NOTE Confidence: 0.9659739
01:21:56.225 --> 01:21:57.525 to these support,
NOTE Confidence: 0.74167764
01:21:58.545 --> 01:21:59.365 these support,
NOTE Confidence: 0.7380105
01:22:00.225 --> 01:22:00.725 events,
NOTE Confidence: 0.95813906
01:22:01.905 --> 01:22:03.345 you're right. I mean, right,
NOTE Confidence: 0.95813906
01:22:03.345 --> 01:22:04.705 you're just meeting the people
NOTE Confidence: 0.95813906
01:22:04.705 --> 01:22:05.205 who
NOTE Confidence: 0.9785562
01:22:05.640 --> 01:22:07.320 opted for that, and they're
NOTE Confidence: 0.9785562
01:22:07.320 --> 01:22:08.540 kind of all in.
NOTE Confidence: 0.99873984
01:22:09.000 --> 01:22:10.760 Like, they're all in for
NOTE Confidence: 0.99873984
01:22:10.760 --> 01:22:11.420 the whole
NOTE Confidence: 0.9960946
01:22:12.439 --> 01:22:13.960 the gamut, you know, from
NOTE Confidence: 0.9960946
01:22:13.960 --> 01:22:16.060 the wheelchair to the possibility
NOTE Confidence: 0.9960946
01:22:16.199 --> 01:22:17.320 of, you know, doing the
NOTE Confidence: 0.97605413
01:22:17.960 --> 01:22:19.400 and I and I think
NOTE Confidence: 0.97605413

01:22:19.400 --> 01:22:19.900 that,
NOTE Confidence: 0.9535785

01:22:21.135 --> 01:22:22.175 I think, I guess, the
NOTE Confidence: 0.9535785

01:22:22.175 --> 01:22:23.314 important thing is
NOTE Confidence: 0.99388516

01:22:23.695 --> 01:22:24.574 to sort of be
NOTE Confidence: 0.9995875

01:22:25.934 --> 01:22:27.074 to have some transparency,
NOTE Confidence: 0.99115044

01:22:27.775 --> 01:22:29.715 I guess, about various outcomes,
NOTE Confidence: 0.99115044

01:22:29.775 --> 01:22:30.814 but not to sort of
NOTE Confidence: 0.99115044

01:22:30.814 --> 01:22:31.314 impose
NOTE Confidence: 0.9996252

01:22:32.175 --> 01:22:33.554 your own objective
NOTE Confidence: 0.9837294

01:22:34.630 --> 01:22:36.150 or your own subjective idea
NOTE Confidence: 0.9837294

01:22:36.150 --> 01:22:37.030 of whether or not, like,
NOTE Confidence: 0.9837294

01:22:37.030 --> 01:22:37.530 that's,
NOTE Confidence: 0.9751593

01:22:38.550 --> 01:22:39.750 a quality of life that
NOTE Confidence: 0.9751593

01:22:39.750 --> 01:22:41.130 I'm comfortable with.
NOTE Confidence: 0.99338084

01:22:41.510 --> 01:22:42.470 And I and I think
NOTE Confidence: 0.99338084

01:22:42.470 --> 01:22:43.290 that that's

NOTE Confidence: 0.9623256
01:22:43.590 --> 01:22:44.950 that's, I think, really hard
NOTE Confidence: 0.9623256
01:22:44.950 --> 01:22:46.890 for us as physicians where
NOTE Confidence: 0.9623256
01:22:47.064 --> 01:22:48.025 there should be a right
NOTE Confidence: 0.9623256
01:22:48.025 --> 01:22:49.304 and the wrong way, and
NOTE Confidence: 0.9623256
01:22:49.304 --> 01:22:50.344 I just don't think that
NOTE Confidence: 0.9623256
01:22:50.344 --> 01:22:51.704 that exists here. I think
NOTE Confidence: 0.9623256
01:22:51.704 --> 01:22:52.445 that there's
NOTE Confidence: 0.9724109
01:22:52.985 --> 01:22:54.744 a there's a variety of
NOTE Confidence: 0.9724109
01:22:54.744 --> 01:22:55.244 different,
NOTE Confidence: 0.99983025
01:22:56.824 --> 01:22:57.324 responses.
NOTE Confidence: 0.97849095
01:22:57.945 --> 01:22:59.064 Now I think one of
NOTE Confidence: 0.97849095
01:22:59.064 --> 01:23:00.640 the questions is, like, is
NOTE Confidence: 0.97849095
01:23:00.640 --> 01:23:02.160 the pendulum gonna sway now,
NOTE Confidence: 0.97849095
01:23:02.160 --> 01:23:03.600 like, in this other direction
NOTE Confidence: 0.97849095
01:23:03.600 --> 01:23:04.720 where we're gonna say, like,
NOTE Confidence: 0.97849095

01:23:04.720 --> 01:23:05.840 all these kids should have
NOTE Confidence: 0.97849095

01:23:05.840 --> 01:23:07.280 heart surgery? And I don't
NOTE Confidence: 0.97849095

01:23:07.280 --> 01:23:09.280 think that's the correct answer
NOTE Confidence: 0.97849095

01:23:09.280 --> 01:23:10.020 at all.
NOTE Confidence: 0.974139

01:23:12.000 --> 01:23:12.500 But,
NOTE Confidence: 0.99958766

01:23:13.555 --> 01:23:14.295 you know,
NOTE Confidence: 0.9160379

01:23:14.835 --> 01:23:16.595 understanding better what does it
NOTE Confidence: 0.9160379

01:23:16.595 --> 01:23:17.795 mean to have a child
NOTE Confidence: 0.9160379

01:23:17.795 --> 01:23:19.314 that has tri twenty thirteen
NOTE Confidence: 0.9160379

01:23:19.314 --> 01:23:21.175 eighteen who's gonna then live
NOTE Confidence: 0.9924412

01:23:21.475 --> 01:23:22.615 beyond, you know,
NOTE Confidence: 0.9121993

01:23:23.635 --> 01:23:25.635 whatever those mortality statistics were
NOTE Confidence: 0.9121993

01:23:25.635 --> 01:23:27.095 one year, two years.
NOTE Confidence: 0.9746866

01:23:28.780 --> 01:23:29.820 We have to I think
NOTE Confidence: 0.9746866

01:23:29.820 --> 01:23:30.780 we need a better idea
NOTE Confidence: 0.9746866

01:23:30.780 --> 01:23:31.660 of what that looks like.

NOTE Confidence: 0.9746866

01:23:31.660 --> 01:23:32.479 And I'm hoping

NOTE Confidence: 0.99146193

01:23:32.939 --> 01:23:34.060 with, you know, some of

NOTE Confidence: 0.99146193

01:23:34.060 --> 01:23:35.100 the work that we'll be

NOTE Confidence: 0.99146193

01:23:35.100 --> 01:23:37.340 doing is we'll we'll have

NOTE Confidence: 0.99146193

01:23:37.340 --> 01:23:38.300 a better idea of what

NOTE Confidence: 0.99146193

01:23:38.300 --> 01:23:39.580 that looks like. We'll organize

NOTE Confidence: 0.99146193

01:23:39.580 --> 01:23:41.340 that information so that, you

NOTE Confidence: 0.99146193

01:23:41.340 --> 01:23:42.960 know, families can see that.

NOTE Confidence: 0.98628855

01:23:44.344 --> 01:23:45.785 Thank you. I have one

NOTE Confidence: 0.98628855

01:23:45.785 --> 01:23:47.705 one last question here from,

NOTE Confidence: 0.98628855

01:23:47.945 --> 01:23:49.245 from an OB colleague.

NOTE Confidence: 0.9943012

01:23:50.344 --> 01:23:52.025 And and she writes, thanks

NOTE Confidence: 0.9943012

01:23:52.025 --> 01:23:53.324 for a great talk, Katie.

NOTE Confidence: 0.9943012

01:23:53.545 --> 01:23:55.225 I'm almost uncomfortable asking this

NOTE Confidence: 0.9943012

01:23:55.225 --> 01:23:56.685 question, but here it is.

NOTE Confidence: 0.99055445

01:23:57.040 --> 01:23:58.159 In a world of limited
NOTE Confidence: 0.99055445

01:23:58.159 --> 01:23:59.600 health care resources, how do
NOTE Confidence: 0.99055445

01:23:59.600 --> 01:24:00.719 we factor in the cost
NOTE Confidence: 0.99055445

01:24:00.719 --> 01:24:01.380 of interventions
NOTE Confidence: 0.99977237

01:24:01.840 --> 01:24:03.520 for babies with severe medical
NOTE Confidence: 0.99977237

01:24:03.520 --> 01:24:04.020 conditions
NOTE Confidence: 0.9859569

01:24:04.400 --> 01:24:06.260 and limited expected lifespan?
NOTE Confidence: 0.9973655

01:24:08.159 --> 01:24:08.659 Alright.
NOTE Confidence: 0.96555704

01:24:11.040 --> 01:24:12.715 In one minute. Yeah. I
NOTE Confidence: 0.96555704

01:24:12.715 --> 01:24:13.215 mean,
NOTE Confidence: 0.98064274

01:24:14.635 --> 01:24:15.995 the the cost of care
NOTE Confidence: 0.98064274

01:24:15.995 --> 01:24:16.875 when you have, you know,
NOTE Confidence: 0.98064274

01:24:16.875 --> 01:24:17.755 when you have a child
NOTE Confidence: 0.98064274

01:24:17.755 --> 01:24:18.635 who's gonna be in an
NOTE Confidence: 0.98064274

01:24:18.635 --> 01:24:20.255 ICU, who's gonna require,
NOTE Confidence: 0.96302456

01:24:21.195 --> 01:24:22.555 you know, additional assistance is

NOTE Confidence: 0.96302456
01:24:22.555 --> 01:24:23.935 definitely gonna be higher.
NOTE Confidence: 0.9864703
01:24:24.875 --> 01:24:26.075 And I don't I think
NOTE Confidence: 0.9864703
01:24:26.075 --> 01:24:27.450 in, you know, where we
NOTE Confidence: 0.9864703
01:24:27.450 --> 01:24:28.410 are in the United States,
NOTE Confidence: 0.9864703
01:24:28.410 --> 01:24:29.950 we don't have to necessarily
NOTE Confidence: 0.9864703
01:24:30.250 --> 01:24:31.930 be making those decisions quite
NOTE Confidence: 0.9864703
01:24:31.930 --> 01:24:32.430 yet.
NOTE Confidence: 0.92366725
01:24:32.810 --> 01:24:34.410 I don't know, like, what
NOTE Confidence: 0.92366725
01:24:34.410 --> 01:24:35.530 the next couple of years
NOTE Confidence: 0.92366725
01:24:35.530 --> 01:24:36.510 looks like. But,
NOTE Confidence: 0.96843916
01:24:37.850 --> 01:24:38.890 but I I don't think
NOTE Confidence: 0.96843916
01:24:38.890 --> 01:24:40.170 that's a that's a decision
NOTE Confidence: 0.96843916
01:24:40.170 --> 01:24:41.450 that or that's a kind
NOTE Confidence: 0.96843916
01:24:41.450 --> 01:24:43.085 of calculus that we have
NOTE Confidence: 0.96843916
01:24:43.085 --> 01:24:43.925 to make right now, but
NOTE Confidence: 0.96843916

01:24:43.925 --> 01:24:44.804 it but it is a
NOTE Confidence: 0.96843916

01:24:44.804 --> 01:24:46.405 valid a valid one to
NOTE Confidence: 0.96843916

01:24:46.405 --> 01:24:47.145 think about.
NOTE Confidence: 0.9996737

01:24:49.204 --> 01:24:49.864 I guess
NOTE Confidence: 0.9115081

01:24:51.684 --> 01:24:53.045 when I think about the
NOTE Confidence: 0.9115081

01:24:53.045 --> 01:24:53.545 the
NOTE Confidence: 0.96005744

01:24:54.450 --> 01:24:56.530 the number of people who
NOTE Confidence: 0.96005744

01:24:56.530 --> 01:24:58.210 choose who are gonna gotta
NOTE Confidence: 0.96005744

01:24:58.210 --> 01:24:59.330 go down this road and
NOTE Confidence: 0.96005744

01:24:59.330 --> 01:25:00.770 who might, you know, choose
NOTE Confidence: 0.96005744

01:25:00.770 --> 01:25:02.229 this option, it's so
NOTE Confidence: 0.97037256

01:25:02.610 --> 01:25:04.210 it's such a, like, a
NOTE Confidence: 0.97037256

01:25:04.290 --> 01:25:05.170 not a it's not a
NOTE Confidence: 0.97037256

01:25:05.170 --> 01:25:07.875 significant amount that I don't
NOTE Confidence: 0.97037256

01:25:07.875 --> 01:25:09.555 necessarily think it's, like, this
NOTE Confidence: 0.97037256

01:25:09.555 --> 01:25:10.455 huge imposition

NOTE Confidence: 0.98388803

01:25:11.635 --> 01:25:12.775 on our,

NOTE Confidence: 0.88893706

01:25:13.635 --> 01:25:14.775 health care dollars,

NOTE Confidence: 0.9626358

01:25:15.955 --> 01:25:16.995 but that's my point of

NOTE Confidence: 0.9626358

01:25:16.995 --> 01:25:18.915 view. We appreciate it very

NOTE Confidence: 0.9626358

01:25:18.915 --> 01:25:20.195 much. Thank you so much,

NOTE Confidence: 0.9626358

01:25:20.195 --> 01:25:21.095 Patrick. Patrick.

NOTE Confidence: 0.7713704

01:25:23.510 --> 01:25:24.010 Okay.

NOTE Confidence: 0.71889585

01:25:26.229 --> 01:25:27.750 I do a wondering. Yeah.

NOTE Confidence: 0.71889585

01:25:27.750 --> 01:25:28.550 I'm here to get the

NOTE Confidence: 0.71889585

01:25:28.550 --> 01:25:29.369 last existing

NOTE Confidence: 0.55218214

01:25:30.070 --> 01:25:30.949 program for a bottom of

NOTE Confidence: 0.55218214

01:25:30.949 --> 01:25:31.449 that.

NOTE Confidence: 0.9317816

01:25:31.989 --> 01:25:33.289 And the answer is no.

NOTE Confidence: 0.8528817

01:25:33.829 --> 01:25:34.619 I have this you get

NOTE Confidence: 0.8528817

01:25:34.619 --> 01:25:35.795 a Panera bag bag for

NOTE Confidence: 0.8528817

01:25:35.795 --> 01:25:36.755 free because this bag is
NOTE Confidence: 0.8528817

01:25:36.755 --> 01:25:38.195 coming apart. We've got a
NOTE Confidence: 0.8528817

01:25:38.195 --> 01:25:38.695 sweatshirt.
NOTE Confidence: 0.92746705

01:25:39.715 --> 01:25:40.835 Lots of good stuff here
NOTE Confidence: 0.92746705

01:25:40.835 --> 01:25:42.515 because all our visiting speakers
NOTE Confidence: 0.92746705

01:25:42.515 --> 01:25:43.715 get a little honorarium, but
NOTE Confidence: 0.92746705

01:25:43.715 --> 01:25:44.995 our Yale faculty were kind
NOTE Confidence: 0.92746705

01:25:44.995 --> 01:25:46.035 enough to work to prepare
NOTE Confidence: 0.92746705

01:25:46.035 --> 01:25:46.630 a talk and come here
NOTE Confidence: 0.92746705

01:25:46.630 --> 01:25:48.640 in the evenings, get stuff
NOTE Confidence: 0.92746705

01:25:48.640 --> 01:25:49.140 instead.
NOTE Confidence: 0.9658791

01:25:49.440 --> 01:25:51.200 So thank you so much.
NOTE Confidence: 0.9658791

01:25:51.200 --> 01:25:52.080 That was a great job.
NOTE Confidence: 0.9658791

01:25:52.080 --> 01:25:53.040 We really appreciate it. Thank
NOTE Confidence: 0.9658791

01:25:53.040 --> 01:25:54.160 you. Alright. That's it for
NOTE Confidence: 0.9658791

01:25:54.160 --> 01:25:55.440 two thousand twenty four. We'll

NOTE Confidence: 0.9658791

01:25:55.440 --> 01:25:56.660 see you guys in January.

NOTE Confidence: 0.9591655

01:25:58.240 --> 01:25:59.220 I'm so sorry.

NOTE Confidence: 0.56517

01:26:00.640 --> 01:26:01.800 Yeah. Those things.