

WEBVTT

NOTE duration:"01:09:33"

NOTE recognizability:0.877

NOTE language:en-us

NOTE Confidence: 0.65117991

00:00:00.000 --> 00:00:01.640 Get the game going.

NOTE Confidence: 0.745273842857143

00:00:04.800 --> 00:00:06.557 All right. We're going to get started.

NOTE Confidence: 0.745273842857143

00:00:06.560 --> 00:00:08.520 Thank you so much for coming tonight.

NOTE Confidence: 0.862012862

00:00:10.560 --> 00:00:11.760 My name is Mark Mercurio.

NOTE Confidence: 0.862012862

00:00:11.760 --> 00:00:13.769 I'm the director of the Program for

NOTE Confidence: 0.862012862

00:00:13.769 --> 00:00:15.080 Biomedical Ethics here at Yale.

NOTE Confidence: 0.862012862

00:00:15.080 --> 00:00:16.810 This is our last session

NOTE Confidence: 0.862012862

00:00:16.810 --> 00:00:18.194 of the academic year.

NOTE Confidence: 0.862012862

00:00:18.200 --> 00:00:19.440 We're going to finish up with a bang,

NOTE Confidence: 0.862012862

00:00:19.440 --> 00:00:21.360 but we'll be back in September,

NOTE Confidence: 0.862012862

00:00:21.360 --> 00:00:23.040 and hopefully you're all on our mailing list,

NOTE Confidence: 0.862012862

00:00:23.040 --> 00:00:24.198 and we'll hear about that later.

NOTE Confidence: 0.862012862

00:00:24.200 --> 00:00:25.691 But for tonight,

NOTE Confidence: 0.862012862

00:00:25.691 --> 00:00:28.673 let me tell you about tonight.
NOTE Confidence: 0.862012862

00:00:28.680 --> 00:00:30.960 Tonight's guest is Yaram Unguru,
NOTE Confidence: 0.862012862

00:00:30.960 --> 00:00:33.648 who is both a very well known
NOTE Confidence: 0.862012862

00:00:33.648 --> 00:00:36.434 pediatric bioethicist as well as a
NOTE Confidence: 0.862012862

00:00:36.434 --> 00:00:37.997 pediatric hematologist oncologist.
NOTE Confidence: 0.862012862

00:00:38.000 --> 00:00:38.332 Educationally,
NOTE Confidence: 0.862012862

00:00:38.332 --> 00:00:40.988 he's a product of the University of Maryland
NOTE Confidence: 0.862012862

00:00:40.988 --> 00:00:43.118 for a bachelor's and master's degree,
NOTE Confidence: 0.862012862

00:00:43.120 --> 00:00:44.919 as well as Toro for another master's,
NOTE Confidence: 0.862012862

00:00:44.920 --> 00:00:46.720 as well as Technion, Israel,
NOTE Confidence: 0.862012862

00:00:46.720 --> 00:00:47.880 where I just learned tonight,
NOTE Confidence: 0.862012862

00:00:47.880 --> 00:00:51.534 'cause my friend never told me that he was
NOTE Confidence: 0.862012862

00:00:51.534 --> 00:00:53.808 valedictorian when he got his MD. And no,
NOTE Confidence: 0.862012862

00:00:53.808 --> 00:00:55.760 there weren't just like 5 kids in the class,
NOTE Confidence: 0.862012862

00:00:55.760 --> 00:00:57.702 it was a big class. Come on.
NOTE Confidence: 0.862012862

00:00:57.702 --> 00:01:00.157 And he was the valedictorian.

NOTE Confidence: 0.862012862

00:01:00.160 --> 00:01:02.368 He is the leader of the bioethics group

NOTE Confidence: 0.862012862

00:01:02.368 --> 00:01:04.518 for the Children's Oncology Group.

NOTE Confidence: 0.862012862

00:01:04.520 --> 00:01:07.096 He's very well known in in in

NOTE Confidence: 0.862012862

00:01:07.096 --> 00:01:08.200 pediatric oncology circles,

NOTE Confidence: 0.862012862

00:01:08.200 --> 00:01:09.868 Also in pediatric bioethics.

NOTE Confidence: 0.862012862

00:01:09.868 --> 00:01:11.953 He's been an ethics advisor,

NOTE Confidence: 0.862012862

00:01:11.960 --> 00:01:12.704 if he will,

NOTE Confidence: 0.862012862

00:01:12.704 --> 00:01:14.192 to the American Academy of Pediatrics,

NOTE Confidence: 0.862012862

00:01:14.200 --> 00:01:16.644 the American Medical Association,

NOTE Confidence: 0.862012862

00:01:16.644 --> 00:01:18.477 to the FDA,

NOTE Confidence: 0.862012862

00:01:18.480 --> 00:01:19.992 and I even think to the Homeland

NOTE Confidence: 0.862012862

00:01:19.992 --> 00:01:21.159 Security Group at some point.

NOTE Confidence: 0.915576332

00:01:23.280 --> 00:01:26.208 He is chairman of the Ethics

NOTE Confidence: 0.915576332

00:01:26.208 --> 00:01:28.160 Committee at Sinai Baltimore.

NOTE Confidence: 0.915576332

00:01:28.160 --> 00:01:30.281 He's also on the faculty at Johns

NOTE Confidence: 0.915576332

00:01:30.281 --> 00:01:32.366 Hopkins and and core faculty at

NOTE Confidence: 0.915576332

00:01:32.366 --> 00:01:33.982 the Berman Institute and the

NOTE Confidence: 0.915576332

00:01:33.982 --> 00:01:35.237 Berman Institute at Johns Hopkins.

NOTE Confidence: 0.915576332

00:01:35.240 --> 00:01:36.479 For those of you who don't know,

NOTE Confidence: 0.915576332

00:01:36.480 --> 00:01:38.874 is a lot like the Program for

NOTE Confidence: 0.915576332

00:01:38.874 --> 00:01:40.320 Biomedical Ethics at Yale,

NOTE Confidence: 0.915576332

00:01:40.320 --> 00:01:44.176 kind of like LeBron James is a

NOTE Confidence: 0.915576332

00:01:44.176 --> 00:01:45.940 lot like your little brother in

NOTE Confidence: 0.915576332

00:01:46.000 --> 00:01:47.680 terms of playing basketball.

NOTE Confidence: 0.915576332

00:01:47.680 --> 00:01:49.374 I mean the the the the Berman

NOTE Confidence: 0.915576332

00:01:49.374 --> 00:01:51.237 Institute is is where it's going on.

NOTE Confidence: 0.915576332

00:01:51.240 --> 00:01:52.566 And Yaram's been an important part

NOTE Confidence: 0.915576332

00:01:52.566 --> 00:01:54.328 of that for a long time since

NOTE Confidence: 0.915576332

00:01:54.328 --> 00:01:55.156 his fellowship days.

NOTE Confidence: 0.915576332

00:01:55.160 --> 00:01:56.585 He actually did his fellowship

NOTE Confidence: 0.915576332

00:01:56.585 --> 00:01:58.414 I think at Children's National.

NOTE Confidence: 0.915576332

00:01:58.414 --> 00:01:58.832 Yes.

NOTE Confidence: 0.915576332

00:01:58.832 --> 00:02:01.340 And did residency work at the

NOTE Confidence: 0.915576332

00:02:01.414 --> 00:02:04.536 University of at Sinai where he's back now.

NOTE Confidence: 0.915576332

00:02:04.536 --> 00:02:06.840 So chair of an Ethics Committee,

NOTE Confidence: 0.915576332

00:02:06.840 --> 00:02:09.444 a well known clinician and a

NOTE Confidence: 0.915576332

00:02:09.444 --> 00:02:11.835 national I'll go to person on

NOTE Confidence: 0.915576332

00:02:11.835 --> 00:02:13.790 various important issues related to

NOTE Confidence: 0.915576332

00:02:13.864 --> 00:02:16.240 pediatric oncology and hematology.

NOTE Confidence: 0.915576332

00:02:16.240 --> 00:02:18.560 So and I've known you wrong for years,

NOTE Confidence: 0.915576332

00:02:18.560 --> 00:02:19.560 he's been here once before,

NOTE Confidence: 0.915576332

00:02:19.560 --> 00:02:20.848 did a marvelous job.

NOTE Confidence: 0.915576332

00:02:20.848 --> 00:02:23.165 So I was so grateful when he

NOTE Confidence: 0.915576332

00:02:23.165 --> 00:02:24.720 agreed to come back tonight.

NOTE Confidence: 0.915576332

00:02:24.720 --> 00:02:26.000 What's going to happen,

NOTE Confidence: 0.915576332

00:02:26.000 --> 00:02:28.464 as is our usual, is Doctor Roguru

NOTE Confidence: 0.915576332

00:02:28.464 --> 00:02:30.838 will speak for about 45 minutes,
NOTE Confidence: 0.915576332

00:02:30.840 --> 00:02:32.040 give or take,
NOTE Confidence: 0.915576332

00:02:32.040 --> 00:02:34.440 and then we'll have a conversation.
NOTE Confidence: 0.915576332

00:02:34.440 --> 00:02:35.920 And when the conversation happens,
NOTE Confidence: 0.915576332

00:02:35.920 --> 00:02:38.800 just to remind you on if you're here on Zoom,
NOTE Confidence: 0.915576332

00:02:38.800 --> 00:02:40.396 please send your questions via the
NOTE Confidence: 0.915576332

00:02:40.396 --> 00:02:41.726 Q&A function and hopefully I'll
NOTE Confidence: 0.915576332

00:02:41.726 --> 00:02:43.010 get to some of those questions
NOTE Confidence: 0.915576332

00:02:43.010 --> 00:02:44.400 for the folks who are on Zoom.
NOTE Confidence: 0.915576332

00:02:44.400 --> 00:02:45.276 For the folks in the room,
NOTE Confidence: 0.915576332

00:02:45.280 --> 00:02:45.960 if you have a question,
NOTE Confidence: 0.915576332

00:02:45.960 --> 00:02:47.824 wait'll I call on ya and and Karen
NOTE Confidence: 0.915576332

00:02:47.824 --> 00:02:49.789 or Amir bring a microphone to you
NOTE Confidence: 0.915576332

00:02:49.789 --> 00:02:51.825 so that everybody can hear you cause
NOTE Confidence: 0.915576332

00:02:51.825 --> 00:02:53.687 'cause I can't hear much and cause
NOTE Confidence: 0.915576332

00:02:53.687 --> 00:02:54.956 the folks who are on Zoom can't

NOTE Confidence: 0.915576332

00:02:54.956 --> 00:02:56.598 hear you at all unless you have the mic.

NOTE Confidence: 0.915576332

00:02:56.600 --> 00:02:59.127 So we'll have that conversation and there'll

NOTE Confidence: 0.915576332

00:02:59.127 --> 00:03:01.959 be a hard stop at 6:30 and at 6:20,

NOTE Confidence: 0.915576332

00:03:01.960 --> 00:03:02.249 eight.

NOTE Confidence: 0.915576332

00:03:02.249 --> 00:03:03.983 I'm pretty sure it's going to

NOTE Confidence: 0.915576332

00:03:03.983 --> 00:03:05.627 stop raining for about 15 minutes

NOTE Confidence: 0.915576332

00:03:05.627 --> 00:03:07.690 just to allow you to get to your

NOTE Confidence: 0.915576332

00:03:07.690 --> 00:03:08.998 cars without getting wet.

NOTE Confidence: 0.915576332

00:03:09.000 --> 00:03:12.234 So this should work out just right.

NOTE Confidence: 0.915576332

00:03:12.240 --> 00:03:14.358 That's the plan for the evening.

NOTE Confidence: 0.915576332

00:03:14.360 --> 00:03:15.872 Hope, hype, and cure.

NOTE Confidence: 0.915576332

00:03:15.872 --> 00:03:17.762 Four letter words and novel

NOTE Confidence: 0.915576332

00:03:17.762 --> 00:03:19.678 therapies for sickle cell anemia.

NOTE Confidence: 0.915576332

00:03:19.680 --> 00:03:21.190 Please join me in welcoming

NOTE Confidence: 0.915576332

00:03:21.190 --> 00:03:22.398 a Doctor Yiramun guru.

NOTE Confidence: 0.915576332

00:03:22.400 --> 00:03:22.560 Thank
NOTE Confidence: 0.90570823

00:03:27.000 --> 00:03:27.480 you, Mark.
NOTE Confidence: 0.937309648947368

00:03:29.920 --> 00:03:32.678 I am always hot and the best
NOTE Confidence: 0.937309648947368

00:03:32.678 --> 00:03:35.351 thing about the weather was that
NOTE Confidence: 0.937309648947368

00:03:35.351 --> 00:03:38.153 my damn blazer got really wet.
NOTE Confidence: 0.937309648947368

00:03:38.160 --> 00:03:40.683 And it would be a shame if I went home to
NOTE Confidence: 0.937309648947368

00:03:40.683 --> 00:03:43.077 my wife and my adult daughters with a cold.
NOTE Confidence: 0.937309648947368

00:03:43.080 --> 00:03:44.520 Wouldn't it mark?
NOTE Confidence: 0.937309648947368

00:03:44.520 --> 00:03:47.080 Because I wore this God forsaken thing.
NOTE Confidence: 0.937309648947368

00:03:47.080 --> 00:03:50.638 Now my mother, who's almost 90,
NOTE Confidence: 0.937309648947368

00:03:50.640 --> 00:03:52.846 is going to find one of you and say,
NOTE Confidence: 0.937309648947368

00:03:52.846 --> 00:03:55.276 did you're on, look presentable?
NOTE Confidence: 0.937309648947368

00:03:55.280 --> 00:03:59.560 Didn't wear a blazer and a top.
NOTE Confidence: 0.937309648947368

00:03:59.560 --> 00:04:03.052 Now you can tell my mom. Yeah. See.
NOTE Confidence: 0.937309648947368

00:04:03.052 --> 00:04:05.432 Absolutely the best, best dressed figure.
NOTE Confidence: 0.937309648947368

00:04:05.432 --> 00:04:07.544 I mean, come on now.

NOTE Confidence: 0.937309648947368

00:04:07.544 --> 00:04:10.786 So I'm gonna try this, but it's wet

NOTE Confidence: 0.937309648947368

00:04:10.786 --> 00:04:13.998 and I get hot and I may take it off.

NOTE Confidence: 0.937309648947368

00:04:14.000 --> 00:04:17.318 And then my sister, who's a designer,

NOTE Confidence: 0.937309648947368

00:04:17.320 --> 00:04:19.759 is cringing at the short sleeves and the tie.

NOTE Confidence: 0.937309648947368

00:04:19.760 --> 00:04:21.356 Oh my God, you did it again.

NOTE Confidence: 0.937309648947368

00:04:21.360 --> 00:04:23.556 I told you it's so unfashionable.

NOTE Confidence: 0.937309648947368

00:04:23.560 --> 00:04:26.240 You look like a nerd with my sister.

NOTE Confidence: 0.937309648947368

00:04:26.240 --> 00:04:26.748 Contact you.

NOTE Confidence: 0.937309648947368

00:04:26.748 --> 00:04:29.120 You can say that all you saw was this,

NOTE Confidence: 0.937309648947368

00:04:29.120 --> 00:04:30.968 and you can imagine that there were

NOTE Confidence: 0.937309648947368

00:04:30.968 --> 00:04:32.440 some sleeves poking through here.

NOTE Confidence: 0.937309648947368

00:04:32.440 --> 00:04:35.040 OK. But I'm very happy to be here.

NOTE Confidence: 0.937309648947368

00:04:35.040 --> 00:04:37.616 I want to thank Mark for that

NOTE Confidence: 0.937309648947368

00:04:37.616 --> 00:04:38.352 lovely introduction.

NOTE Confidence: 0.937309648947368

00:04:38.360 --> 00:04:40.796 And Mark is humble and Mark

NOTE Confidence: 0.937309648947368

00:04:40.796 --> 00:04:43.239 is smart and Mark is kind.
NOTE Confidence: 0.937309648947368

00:04:43.240 --> 00:04:46.680 And my career has blossomed,
NOTE Confidence: 0.937309648947368

00:04:46.680 --> 00:04:49.770 in part due to Mark's collegiality
NOTE Confidence: 0.937309648947368

00:04:49.770 --> 00:04:51.315 and his mentorship.
NOTE Confidence: 0.937309648947368

00:04:51.320 --> 00:04:52.880 And I truly am grateful.
NOTE Confidence: 0.937309648947368

00:04:52.880 --> 00:04:55.960 And today is the first time that Mark and I,
NOTE Confidence: 0.937309648947368

00:04:55.960 --> 00:04:58.480 they've seen one another in a little bit.
NOTE Confidence: 0.937309648947368

00:04:58.480 --> 00:05:01.400 And so I thought this would be a good start.
NOTE Confidence: 0.937309648947368

00:05:01.400 --> 00:05:01.891 Mark,
NOTE Confidence: 0.937309648947368

00:05:01.891 --> 00:05:06.320 we're putting the band back together again.
NOTE Confidence: 0.937309648947368

00:05:06.320 --> 00:05:08.558 We're on a mission from God.
NOTE Confidence: 0.937309648947368

00:05:08.560 --> 00:05:10.142 So I'll leave it to you to
NOTE Confidence: 0.937309648947368

00:05:10.142 --> 00:05:11.636 decide which one of us is Jake
NOTE Confidence: 0.937309648947368

00:05:11.636 --> 00:05:13.200 and which one of us is Elwood.
NOTE Confidence: 0.89698558

00:05:16.720 --> 00:05:18.228 So unlike The Supremes,
NOTE Confidence: 0.89698558

00:05:18.228 --> 00:05:20.113 Thomas and Gorsuch and Dr.

NOTE Confidence: 0.89698558

00:05:20.120 --> 00:05:21.880 Balsaga from Sloan Kettering and

NOTE Confidence: 0.89698558

00:05:21.880 --> 00:05:24.120 George Santos and the Trump family,

NOTE Confidence: 0.89698558

00:05:24.120 --> 00:05:26.717 I'm APT Monk guy who does bioethics

NOTE Confidence: 0.89698558

00:05:26.717 --> 00:05:29.120 and I have no disclosures.

NOTE Confidence: 0.89698558

00:05:29.120 --> 00:05:30.148 So this evening we're

NOTE Confidence: 0.89698558

00:05:30.148 --> 00:05:31.433 going to talk about hope,

NOTE Confidence: 0.89698558

00:05:31.440 --> 00:05:34.114 hype and cure and in clinical medicine

NOTE Confidence: 0.89698558

00:05:34.114 --> 00:05:36.799 and in pediatric hemonk in particular.

NOTE Confidence: 0.89698558

00:05:36.800 --> 00:05:38.348 And we're also going to look

NOTE Confidence: 0.89698558

00:05:38.348 --> 00:05:40.308 at the impact of language and

NOTE Confidence: 0.89698558

00:05:40.308 --> 00:05:42.032 communication and how these

NOTE Confidence: 0.89698558

00:05:42.032 --> 00:05:43.756 influence medical decision making.

NOTE Confidence: 0.89698558

00:05:43.760 --> 00:05:46.034 And we could easily focus on

NOTE Confidence: 0.89698558

00:05:46.034 --> 00:05:48.280 cancer to examine these concepts.

NOTE Confidence: 0.89698558

00:05:48.280 --> 00:05:50.044 But I actually prefer to view

NOTE Confidence: 0.89698558

00:05:50.044 --> 00:05:51.585 these four letter words through
NOTE Confidence: 0.89698558

00:05:51.585 --> 00:05:53.439 the lens of sickle cell anemia.
NOTE Confidence: 0.89698558

00:05:53.440 --> 00:05:54.798 And yes, the focus of my talk
NOTE Confidence: 0.89698558

00:05:54.798 --> 00:05:56.280 is going to be on sickle cell.
NOTE Confidence: 0.89698558

00:05:56.280 --> 00:05:58.176 But throughout I will share some
NOTE Confidence: 0.89698558

00:05:58.176 --> 00:06:00.400 examples of four letter words in cancer.
NOTE Confidence: 0.89698558

00:06:00.400 --> 00:06:02.584 And this 1913 article from the New
NOTE Confidence: 0.89698558

00:06:02.584 --> 00:06:04.833 York Times is an early example of
NOTE Confidence: 0.89698558

00:06:04.833 --> 00:06:07.160 how cure is portrayed in the media.
NOTE Confidence: 0.89698558

00:06:07.160 --> 00:06:09.072 So what I'd ask you to do throughout
NOTE Confidence: 0.89698558

00:06:09.072 --> 00:06:10.720 the time that we have together
NOTE Confidence: 0.89698558

00:06:10.720 --> 00:06:14.360 think about our patients and how we
NOTE Confidence: 0.89698558

00:06:14.360 --> 00:06:17.000 also internalize these statements.
NOTE Confidence: 0.89698558

00:06:17.000 --> 00:06:18.566 Now I realize that not everybody
NOTE Confidence: 0.89698558

00:06:18.566 --> 00:06:20.233 here has made the brought wise
NOTE Confidence: 0.89698558

00:06:20.233 --> 00:06:21.925 decision to devote your career to

NOTE Confidence: 0.89698558

00:06:21.925 --> 00:06:23.957 he Monk and I'm sorry to hear that.

NOTE Confidence: 0.89698558

00:06:23.960 --> 00:06:26.214 So maybe a little bit of background

NOTE Confidence: 0.89698558

00:06:26.214 --> 00:06:28.278 about sickle cell would be helpful.

NOTE Confidence: 0.89698558

00:06:28.280 --> 00:06:29.659 What you see on the left here

NOTE Confidence: 0.89698558

00:06:29.659 --> 00:06:30.858 is a cartoon representation of

NOTE Confidence: 0.89698558

00:06:30.858 --> 00:06:32.514 the inside of a blood vessel,

NOTE Confidence: 0.89698558

00:06:32.520 --> 00:06:34.664 and you can see sickle shaped red blood

NOTE Confidence: 0.89698558

00:06:34.664 --> 00:06:36.520 cells and normal red blood cells.

NOTE Confidence: 0.89698558

00:06:36.520 --> 00:06:38.578 And on the right the arrows are

NOTE Confidence: 0.89698558

00:06:38.578 --> 00:06:40.631 showing you what an actual sickle

NOTE Confidence: 0.89698558

00:06:40.631 --> 00:06:42.839 cell looks like under the microscope.

NOTE Confidence: 0.89698558

00:06:42.840 --> 00:06:44.460 And some of the consequences of

NOTE Confidence: 0.89698558

00:06:44.460 --> 00:06:46.109 sickle cell were captured in a

NOTE Confidence: 0.89698558

00:06:46.109 --> 00:06:47.394 recent New England Journal piece,

NOTE Confidence: 0.89698558

00:06:47.400 --> 00:06:48.840 and the authors observed that.

NOTE Confidence: 0.89698558

00:06:48.840 --> 00:06:49.980 As you can see,
NOTE Confidence: 0.89698558
00:06:49.980 --> 00:06:51.690 a diagnosis of sickle cell disease
NOTE Confidence: 0.89698558
00:06:51.749 --> 00:06:53.554 portends a lifetime of crises
NOTE Confidence: 0.89698558
00:06:53.554 --> 00:06:54.998 marked by substantial pain,
NOTE Confidence: 0.89698558
00:06:55.000 --> 00:06:55.491 infections,
NOTE Confidence: 0.89698558
00:06:55.491 --> 00:06:58.437 anemia and increased risk of stroke.
NOTE Confidence: 0.89698558
00:06:58.440 --> 00:07:01.236 And that's only half of it.
NOTE Confidence: 0.89698558
00:07:01.240 --> 00:07:03.683 Too often we think of our disease
NOTE Confidence: 0.89698558
00:07:03.683 --> 00:07:05.878 burden through our US centric lens,
NOTE Confidence: 0.89698558
00:07:05.880 --> 00:07:07.890 and broadening this perspective beyond our
NOTE Confidence: 0.89698558
00:07:07.890 --> 00:07:10.280 own borders is important for lots of reasons.
NOTE Confidence: 0.89698558
00:07:10.280 --> 00:07:12.320 As we'll talk about shortly,
NOTE Confidence: 0.89698558
00:07:12.320 --> 00:07:14.600 how common is sickle cell vary.
NOTE Confidence: 0.89698558
00:07:14.600 --> 00:07:16.490 About 300,000 infants are born each
NOTE Confidence: 0.89698558
00:07:16.490 --> 00:07:18.277 year worldwide who have sickle cell
NOTE Confidence: 0.89698558
00:07:18.277 --> 00:07:20.480 and as you can see from these he maps,

NOTE Confidence: 0.89698558
00:07:20.480 --> 00:07:22.475 most of them are in sub-Saharan Africa,
NOTE Confidence: 0.89698558
00:07:22.480 --> 00:07:23.740 India, the Mediterranean,
NOTE Confidence: 0.89698558
00:07:23.740 --> 00:07:26.260 the Middle East and in some
NOTE Confidence: 0.89698558
00:07:26.260 --> 00:07:27.440 African countries.
NOTE Confidence: 0.89698558
00:07:27.440 --> 00:07:30.086 As many as 40% of people have
NOTE Confidence: 0.89698558
00:07:30.086 --> 00:07:32.757 sickle cell trait so kind of common.
NOTE Confidence: 0.89698558
00:07:32.760 --> 00:07:34.320 Circling back to the US,
NOTE Confidence: 0.89698558
00:07:34.320 --> 00:07:36.693 there's about 100,000 people who have sickle
NOTE Confidence: 0.89698558
00:07:36.693 --> 00:07:39.599 cell and as you can see from the map here,
NOTE Confidence: 0.89698558
00:07:39.600 --> 00:07:41.920 most of them live in these 10 states.
NOTE Confidence: 0.89698558
00:07:41.920 --> 00:07:44.537 You can also see that one in 365
NOTE Confidence: 0.89698558
00:07:44.537 --> 00:07:47.279 African American kids has sickle cell.
NOTE Confidence: 0.89698558
00:07:47.280 --> 00:07:48.726 Sickle cell is more than three
NOTE Confidence: 0.89698558
00:07:48.726 --> 00:07:50.272 times as common as some other
NOTE Confidence: 0.89698558
00:07:50.272 --> 00:07:51.862 genetic diseases that happen in the
NOTE Confidence: 0.89698558

00:07:51.862 --> 00:07:53.679 US that you may be familiar with,
NOTE Confidence: 0.89698558

00:07:53.680 --> 00:07:56.400 things like CF and hemophilia.
NOTE Confidence: 0.89698558

00:07:56.400 --> 00:07:57.116 Excuse me,
NOTE Confidence: 0.89698558

00:07:57.116 --> 00:07:59.264 and I'll come back to this
NOTE Confidence: 0.89698558

00:07:59.264 --> 00:08:00.839 a little bit later.
NOTE Confidence: 0.89698558

00:08:00.840 --> 00:08:03.800 So given how common sickle cell is in the US,
NOTE Confidence: 0.967516998947368

00:08:03.800 --> 00:08:06.530 you might be surprised to know that
NOTE Confidence: 0.967516998947368

00:08:06.530 --> 00:08:08.389 universal newborn screening has only
NOTE Confidence: 0.967516998947368

00:08:08.389 --> 00:08:10.559 been around for fewer than 20 years.
NOTE Confidence: 0.967516998947368

00:08:10.560 --> 00:08:12.779 But the impact of that screening really
NOTE Confidence: 0.967516998947368

00:08:12.779 --> 00:08:14.919 has been nothing short of remarkable.
NOTE Confidence: 0.967516998947368

00:08:14.920 --> 00:08:17.746 Since its implementation among kids ages
NOTE Confidence: 0.967516998947368

00:08:17.746 --> 00:08:22.440 1 to 4, mortality has decreased by 50%
NOTE Confidence: 0.967516998947368

00:08:22.440 --> 00:08:25.092 and overall life expectancy has increased
NOTE Confidence: 0.967516998947368

00:08:25.092 --> 00:08:28.440 from around a median of 14 to close to 50.
NOTE Confidence: 0.967516998947368

00:08:28.440 --> 00:08:30.198 And there's various reasons for this,

NOTE Confidence: 0.967516998947368
00:08:30.200 --> 00:08:32.979 as likely as a result of early
NOTE Confidence: 0.967516998947368
00:08:32.979 --> 00:08:35.120 initiation of penicillin prophylaxis,
NOTE Confidence: 0.967516998947368
00:08:35.120 --> 00:08:37.640 early treatment of infectious complications,
NOTE Confidence: 0.967516998947368
00:08:37.640 --> 00:08:40.100 just education and awareness both
NOTE Confidence: 0.967516998947368
00:08:40.100 --> 00:08:43.320 by clinical people and by parents.
NOTE Confidence: 0.967516998947368
00:08:43.320 --> 00:08:44.132 Newborn screening,
NOTE Confidence: 0.967516998947368
00:08:44.132 --> 00:08:46.568 though it also allows for early
NOTE Confidence: 0.967516998947368
00:08:46.568 --> 00:08:48.398 identification of at risk couples,
NOTE Confidence: 0.967516998947368
00:08:48.400 --> 00:08:50.725 that allows for genetic counseling
NOTE Confidence: 0.967516998947368
00:08:50.725 --> 00:08:52.120 regarding future pregnancies.
NOTE Confidence: 0.967516998947368
00:08:52.120 --> 00:08:54.340 Now arguably, early identification and
NOTE Confidence: 0.967516998947368
00:08:54.340 --> 00:08:56.560 genetic counseling are good things.
NOTE Confidence: 0.967516998947368
00:08:56.560 --> 00:08:57.600 And in his excellent book
NOTE Confidence: 0.967516998947368
00:08:57.600 --> 00:08:58.960 Dying in the City of Blues,
NOTE Confidence: 0.967516998947368
00:08:58.960 --> 00:09:00.960 Keith Whalu makes the argument
NOTE Confidence: 0.967516998947368

00:09:00.960 --> 00:09:02.560 that genetic screening amounted
NOTE Confidence: 0.967516998947368

00:09:02.560 --> 00:09:04.928 to veiled eugenics in an attempt
NOTE Confidence: 0.967516998947368

00:09:04.928 --> 00:09:06.833 to control the black population.
NOTE Confidence: 0.967516998947368

00:09:06.840 --> 00:09:09.115 And in this quotation from Keith's book,
NOTE Confidence: 0.967516998947368

00:09:09.120 --> 00:09:11.320 what we see is that what makes sense
NOTE Confidence: 0.967516998947368

00:09:11.320 --> 00:09:13.951 from a public health perspective may be
NOTE Confidence: 0.967516998947368

00:09:13.951 --> 00:09:16.800 viewed by individual groups as problematic.
NOTE Confidence: 0.967516998947368

00:09:16.800 --> 00:09:19.360 And you can hear see what Keith has to say.
NOTE Confidence: 0.967516998947368

00:09:19.360 --> 00:09:20.880 And sometimes if you hear it out loud,
NOTE Confidence: 0.967516998947368

00:09:20.880 --> 00:09:22.720 it really drives it home.
NOTE Confidence: 0.967516998947368

00:09:22.720 --> 00:09:24.742 Looking back at the controversy geneticists
NOTE Confidence: 0.967516998947368

00:09:24.742 --> 00:09:27.040 and health policy makers frequently recall,
NOTE Confidence: 0.967516998947368

00:09:27.040 --> 00:09:29.192 the backlash is a warning sign that the
NOTE Confidence: 0.967516998947368

00:09:29.192 --> 00:09:31.714 use of hereditary knowledge can pose
NOTE Confidence: 0.967516998947368

00:09:31.714 --> 00:09:34.114 unforeseen dangers to individual self
NOTE Confidence: 0.967516998947368

00:09:34.114 --> 00:09:35.424 determination, promote discrimination,

NOTE Confidence: 0.967516998947368
00:09:35.424 --> 00:09:35.836 and,
NOTE Confidence: 0.967516998947368
00:09:35.836 --> 00:09:38.720 when directed at a single minority group,
NOTE Confidence: 0.967516998947368
00:09:38.720 --> 00:09:41.072 feed legitimate fears of a return
NOTE Confidence: 0.967516998947368
00:09:41.072 --> 00:09:42.640 to eugenics and genocide.
NOTE Confidence: 0.967516998947368
00:09:42.640 --> 00:09:44.600 Huh.
NOTE Confidence: 0.967516998947368
00:09:44.600 --> 00:09:45.844 Although the complications of
NOTE Confidence: 0.967516998947368
00:09:45.844 --> 00:09:47.399 sickle cell accumulate with age,
NOTE Confidence: 0.967516998947368
00:09:47.400 --> 00:09:48.850 there's no question that infants
NOTE Confidence: 0.967516998947368
00:09:48.850 --> 00:09:51.242 and kids are at risk for many
NOTE Confidence: 0.967516998947368
00:09:51.242 --> 00:09:52.559 life threatening complications.
NOTE Confidence: 0.967516998947368
00:09:52.560 --> 00:09:52.982 In fact,
NOTE Confidence: 0.967516998947368
00:09:52.982 --> 00:09:54.459 by the time a kid with sickle
NOTE Confidence: 0.967516998947368
00:09:54.459 --> 00:09:55.558 cell becomes an adult,
NOTE Confidence: 0.967516998947368
00:09:55.560 --> 00:09:58.955 they've probably had more than one scare.
NOTE Confidence: 0.967516998947368
00:09:58.960 --> 00:09:59.384 Also,
NOTE Confidence: 0.967516998947368

00:09:59.384 --> 00:10:01.080 these complications they can
NOTE Confidence: 0.967516998947368

00:10:01.080 --> 00:10:02.776 result result in irreversible
NOTE Confidence: 0.967516998947368

00:10:02.776 --> 00:10:04.958 organ damage and even early death.
NOTE Confidence: 0.967516998947368

00:10:04.960 --> 00:10:07.718 And I want you to remember this
NOTE Confidence: 0.967516998947368

00:10:07.718 --> 00:10:09.753 notion of irreversible organ damage
NOTE Confidence: 0.967516998947368

00:10:09.753 --> 00:10:12.075 when we talk about gene therapy
NOTE Confidence: 0.967516998947368

00:10:12.075 --> 00:10:14.239 and bone marrow transplant.
NOTE Confidence: 0.967516998947368

00:10:14.240 --> 00:10:15.232 In the US though,
NOTE Confidence: 0.967516998947368

00:10:15.232 --> 00:10:16.472 most kids with sickle cell
NOTE Confidence: 0.967516998947368

00:10:16.472 --> 00:10:17.638 live to become adults.
NOTE Confidence: 0.967516998947368

00:10:17.640 --> 00:10:18.920 But as you can see,
NOTE Confidence: 0.967516998947368

00:10:18.920 --> 00:10:20.798 life expectancy is still 20 years
NOTE Confidence: 0.967516998947368

00:10:20.798 --> 00:10:23.580 lower than what it is for the general
NOTE Confidence: 0.967516998947368

00:10:23.580 --> 00:10:25.415 population and mortality is highest
NOTE Confidence: 0.967516998947368

00:10:25.415 --> 00:10:27.319 during that period of transition
NOTE Confidence: 0.967516998947368

00:10:27.319 --> 00:10:29.159 from pediatric to adult care.

NOTE Confidence: 0.967516998947368
00:10:29.160 --> 00:10:31.600 But as we see also in developing countries,
NOTE Confidence: 0.967516998947368
00:10:31.600 --> 00:10:33.200 it's a very different story.
NOTE Confidence: 0.967516998947368
00:10:33.200 --> 00:10:35.120 Life expectancy is much lower.
NOTE Confidence: 0.967516998947368
00:10:35.120 --> 00:10:37.328 You can see that in sub-Saharan
NOTE Confidence: 0.967516998947368
00:10:37.328 --> 00:10:39.498 Africa many kids with sickle cell
NOTE Confidence: 0.967516998947368
00:10:39.498 --> 00:10:41.682 die before age 5 and in India
NOTE Confidence: 0.967516998947368
00:10:41.682 --> 00:10:43.878 one in five dies before age 2.
NOTE Confidence: 0.967516998947368
00:10:43.880 --> 00:10:46.043 And here you can see just graphically
NOTE Confidence: 0.967516998947368
00:10:46.043 --> 00:10:47.958 the progress that's been made in places
NOTE Confidence: 0.967516998947368
00:10:47.958 --> 00:10:50.280 like the US in terms of life expectancy.
NOTE Confidence: 0.967516998947368
00:10:50.280 --> 00:10:52.680 But this really drives home the
NOTE Confidence: 0.967516998947368
00:10:52.680 --> 00:10:53.703 significant difference depending
NOTE Confidence: 0.967516998947368
00:10:53.703 --> 00:10:56.090 on one where happens to be born
NOTE Confidence: 0.967516998947368
00:10:56.147 --> 00:10:57.637 and lived and their disease.
NOTE Confidence: 0.827764386
00:11:00.480 --> 00:11:01.560 These are red blood cells.
NOTE Confidence: 0.827764386

00:11:01.560 --> 00:11:03.324 For those of you who are wondering
NOTE Confidence: 0.827764386

00:11:03.324 --> 00:11:05.541 best thing you know in the world better
NOTE Confidence: 0.827764386

00:11:05.541 --> 00:11:07.329 than neonatology and vents and numbers
NOTE Confidence: 0.827764386

00:11:07.329 --> 00:11:09.237 and better than psychiatry and couches
NOTE Confidence: 0.827764386

00:11:09.237 --> 00:11:11.300 and better than all you know, blood.
NOTE Confidence: 0.827764386

00:11:11.300 --> 00:11:12.675 It's all about the blood.
NOTE Confidence: 0.827764386

00:11:12.680 --> 00:11:14.896 OK, so here you can see normal red
NOTE Confidence: 0.827764386

00:11:14.896 --> 00:11:16.918 blood cells and you can see sickle
NOTE Confidence: 0.827764386

00:11:16.918 --> 00:11:18.772 cells and current therapies for
NOTE Confidence: 0.827764386

00:11:18.772 --> 00:11:21.130 sickle cell are divided into what
NOTE Confidence: 0.827764386

00:11:21.200 --> 00:11:24.266 we call disease modifying agents and
NOTE Confidence: 0.827764386

00:11:24.266 --> 00:11:25.799 potentially curative treatments.
NOTE Confidence: 0.827764386

00:11:25.800 --> 00:11:27.767 And it wasn't until 1995 that was
NOTE Confidence: 0.827764386

00:11:27.767 --> 00:11:29.745 in most of our lifespans that
NOTE Confidence: 0.827764386

00:11:29.745 --> 00:11:31.875 the first drug for sickle cell,
NOTE Confidence: 0.827764386

00:11:31.880 --> 00:11:34.520 hydroxyurea was approved for adults

NOTE Confidence: 0.827764386

00:11:34.520 --> 00:11:37.688 and it took 22 years until 2017 the

NOTE Confidence: 0.827764386

00:11:37.688 --> 00:11:40.198 hydroxyurea was approved in children.

NOTE Confidence: 0.827764386

00:11:40.200 --> 00:11:43.160 So that was definitely not that long ago.

NOTE Confidence: 0.827764386

00:11:43.160 --> 00:11:45.880 And after hydroxyurea was approved,

NOTE Confidence: 0.827764386

00:11:45.880 --> 00:11:48.680 23 years went by until the next drug,

NOTE Confidence: 0.827764386

00:11:48.680 --> 00:11:51.200 L glutamine, was approved for sickle cell.

NOTE Confidence: 0.827764386

00:11:51.200 --> 00:11:51.839 And since then,

NOTE Confidence: 0.827764386

00:11:51.839 --> 00:11:53.117 there have been two other drugs

NOTE Confidence: 0.827764386

00:11:53.117 --> 00:11:54.159 that have been approved,

NOTE Confidence: 0.827764386

00:11:54.160 --> 00:11:55.507 prisnalizumab and voxelator.

NOTE Confidence: 0.827764386

00:11:55.507 --> 00:11:57.303 And prisnalizumab actually was

NOTE Confidence: 0.827764386

00:11:57.303 --> 00:11:59.619 shown recently in phase three trials

NOTE Confidence: 0.827764386

00:11:59.619 --> 00:12:01.437 to be no better than placebo.

NOTE Confidence: 0.827764386

00:12:01.440 --> 00:12:03.320 So yes, there's been a lot of movement,

NOTE Confidence: 0.827764386

00:12:03.320 --> 00:12:05.354 but we still have a long way to go.

NOTE Confidence: 0.827764386

00:12:05.360 --> 00:12:06.880 And then there's these potentially
NOTE Confidence: 0.827764386

00:12:06.880 --> 00:12:08.096 curative treatments that we're
NOTE Confidence: 0.827764386

00:12:08.096 --> 00:12:09.437 gonna talk about in a moment,
NOTE Confidence: 0.827764386

00:12:09.440 --> 00:12:11.780 bone marrow transplant and
NOTE Confidence: 0.827764386

00:12:11.780 --> 00:12:14.120 in particular gene therapy.
NOTE Confidence: 0.827764386

00:12:14.120 --> 00:12:16.586 What I want to show for you in this
NOTE Confidence: 0.827764386

00:12:16.586 --> 00:12:19.371 slide is that really there is no organ
NOTE Confidence: 0.827764386

00:12:19.371 --> 00:12:21.559 that's not involved in sickle cells.
NOTE Confidence: 0.827764386

00:12:21.560 --> 00:12:22.958 If you just think about it,
NOTE Confidence: 0.827764386

00:12:22.960 --> 00:12:24.568 I showed you those slides jokingly
NOTE Confidence: 0.827764386

00:12:24.568 --> 00:12:25.640 of the blood cells.
NOTE Confidence: 0.827764386

00:12:25.640 --> 00:12:28.040 But blood really is everywhere in our body,
NOTE Confidence: 0.827764386

00:12:28.040 --> 00:12:30.280 truly from head to toe.
NOTE Confidence: 0.827764386

00:12:30.280 --> 00:12:32.156 And so patients with sickle cell are
NOTE Confidence: 0.827764386

00:12:32.156 --> 00:12:34.207 at risk for stroke and retinopathy
NOTE Confidence: 0.827764386

00:12:34.207 --> 00:12:36.187 and heart failure and pulmonary

NOTE Confidence: 0.827764386

00:12:36.187 --> 00:12:38.439 hypertension and liver and kidney failure.

NOTE Confidence: 0.827764386

00:12:38.440 --> 00:12:39.960 Their spleen doesn't work well,

NOTE Confidence: 0.827764386

00:12:39.960 --> 00:12:41.240 so they're going to compromise.

NOTE Confidence: 0.827764386

00:12:41.240 --> 00:12:43.879 They get Bony pain and Bony disease,

NOTE Confidence: 0.827764386

00:12:43.880 --> 00:12:44.838 skin ulcers,

NOTE Confidence: 0.827764386

00:12:44.838 --> 00:12:45.796 fertility issues.

NOTE Confidence: 0.827764386

00:12:45.796 --> 00:12:49.747 So it really can be a disease that

NOTE Confidence: 0.827764386

00:12:49.747 --> 00:12:53.800 can cover the gamut of complications.

NOTE Confidence: 0.827764386

00:12:53.800 --> 00:12:55.320 And to appreciate the frequent

NOTE Confidence: 0.827764386

00:12:55.320 --> 00:12:56.840 interactions that patients with sickle

NOTE Confidence: 0.827764386

00:12:56.888 --> 00:12:58.520 cell have with the healthcare system,

NOTE Confidence: 0.827764386

00:12:58.520 --> 00:13:00.434 I think there's no better way

NOTE Confidence: 0.827764386

00:13:00.434 --> 00:13:02.160 to capture this than fever.

NOTE Confidence: 0.827764386

00:13:02.160 --> 00:13:03.665 I just mentioned to you a second

NOTE Confidence: 0.827764386

00:13:03.665 --> 00:13:05.158 ago that kids with sickle cell,

NOTE Confidence: 0.827764386

00:13:05.160 --> 00:13:06.012 adults with sickle cell,
NOTE Confidence: 0.827764386

00:13:06.012 --> 00:13:07.077 their spleen doesn't work well,
NOTE Confidence: 0.827764386

00:13:07.080 --> 00:13:08.200 so they're in a compromise.
NOTE Confidence: 0.827764386

00:13:08.200 --> 00:13:10.600 What this translates to is that
NOTE Confidence: 0.827764386

00:13:10.600 --> 00:13:12.200 patients with sickle cell,
NOTE Confidence: 0.827764386

00:13:12.200 --> 00:13:13.520 when they have a fever,
NOTE Confidence: 0.827764386

00:13:13.520 --> 00:13:14.560 it's a medical emergency.
NOTE Confidence: 0.827764386

00:13:14.560 --> 00:13:16.120 They have to drop what they're
NOTE Confidence: 0.827764386

00:13:16.168 --> 00:13:17.834 doing and they have to be evaluated.
NOTE Confidence: 0.827764386

00:13:17.840 --> 00:13:20.080 Now I imagine some of you have children.
NOTE Confidence: 0.827764386

00:13:20.080 --> 00:13:22.278 Think about how often your own child,
NOTE Confidence: 0.827764386

00:13:22.280 --> 00:13:25.115 who probably has an intact immune system,
NOTE Confidence: 0.827764386

00:13:25.120 --> 00:13:26.425 gets a fever,
NOTE Confidence: 0.827764386

00:13:26.425 --> 00:13:29.035 and imagine middle of the night,
NOTE Confidence: 0.827764386

00:13:29.040 --> 00:13:30.062 weekend holiday,
NOTE Confidence: 0.827764386

00:13:30.062 --> 00:13:32.617 dropping everything and coming to

NOTE Confidence: 0.827764386

00:13:32.617 --> 00:13:33.639 the hospital.

NOTE Confidence: 0.827764386

00:13:33.640 --> 00:13:36.020 And imagine how those frequent

NOTE Confidence: 0.827764386

00:13:36.020 --> 00:13:38.400 interactions will color both your

NOTE Confidence: 0.827764386

00:13:38.476 --> 00:13:40.558 attitude as the parent and the

NOTE Confidence: 0.827764386

00:13:40.558 --> 00:13:42.576 kid and the clinician's attitude.

NOTE Confidence: 0.827764386

00:13:42.576 --> 00:13:45.504 So something just to keep in

NOTE Confidence: 0.827764386

00:13:45.504 --> 00:13:47.680 mind as some of you likely know,

NOTE Confidence: 0.827764386

00:13:47.680 --> 00:13:49.425 vase occlusive or painful crises

NOTE Confidence: 0.827764386

00:13:49.425 --> 00:13:51.540 over the hallmark of sickle cell

NOTE Confidence: 0.827764386

00:13:51.540 --> 00:13:53.080 and vase occlusive crises can

NOTE Confidence: 0.827764386

00:13:53.080 --> 00:13:54.312 affect any part of

NOTE Confidence: 0.800832513666666

00:13:54.376 --> 00:13:56.376 the body and what you see in the

NOTE Confidence: 0.800832513666666

00:13:56.376 --> 00:13:58.068 upper left hand corner here is

NOTE Confidence: 0.800832513666666

00:13:58.068 --> 00:13:59.553 something that we call dactylitis.

NOTE Confidence: 0.800832513666666

00:13:59.560 --> 00:14:01.176 And dactylitis is something

NOTE Confidence: 0.800832513666666

00:14:01.176 --> 00:14:03.196 that affects infants with sickle
NOTE Confidence: 0.800832513666666

00:14:03.196 --> 00:14:05.347 cell and often is the first
NOTE Confidence: 0.800832513666666

00:14:05.347 --> 00:14:07.400 manifestation of disease if you will.
NOTE Confidence: 0.800832513666666

00:14:07.400 --> 00:14:08.732 And it's painful swelling
NOTE Confidence: 0.800832513666666

00:14:08.732 --> 00:14:10.397 of the hands and feet.
NOTE Confidence: 0.800832513666666

00:14:10.400 --> 00:14:12.155 Well, dactylitis is actually one
NOTE Confidence: 0.800832513666666

00:14:12.155 --> 00:14:14.621 of the only types of this sickle
NOTE Confidence: 0.800832513666666

00:14:14.621 --> 00:14:16.553 cell pain that can be seen.
NOTE Confidence: 0.800832513666666

00:14:16.560 --> 00:14:18.522 I mean, we can all appreciate
NOTE Confidence: 0.800832513666666

00:14:18.522 --> 00:14:20.679 that this kids hands are swollen.
NOTE Confidence: 0.800832513666666

00:14:20.680 --> 00:14:23.290 That, as well as the fact that it affects
NOTE Confidence: 0.800832513666666

00:14:23.290 --> 00:14:25.210 infants means that many clinicians
NOTE Confidence: 0.800832513666666

00:14:25.210 --> 00:14:27.556 actually want to treat dactylitis pain.
NOTE Confidence: 0.800832513666666

00:14:27.560 --> 00:14:27.882 Unfortunately,
NOTE Confidence: 0.800832513666666

00:14:27.882 --> 00:14:29.814 that doesn't always happen in older
NOTE Confidence: 0.800832513666666

00:14:29.814 --> 00:14:31.520 kids and adults who have pain.

NOTE Confidence: 0.800832513666666
00:14:31.520 --> 00:14:33.832 And we'll come back to this when we
NOTE Confidence: 0.800832513666666
00:14:33.832 --> 00:14:35.918 talk about some of the inequities.
NOTE Confidence: 0.800832513666666
00:14:35.920 --> 00:14:37.164 This is Carlton Haywood.
NOTE Confidence: 0.800832513666666
00:14:37.164 --> 00:14:39.397 Carlton was a dear colleague of mine
NOTE Confidence: 0.800832513666666
00:14:39.397 --> 00:14:41.263 at the Bioethics Institute and Carlton
NOTE Confidence: 0.800832513666666
00:14:41.263 --> 00:14:43.380 was a sickle cell researcher and
NOTE Confidence: 0.800832513666666
00:14:43.380 --> 00:14:45.636 educator and a champion for HealthEquity.
NOTE Confidence: 0.800832513666666
00:14:45.640 --> 00:14:47.894 And Carlton died at age 46 on
NOTE Confidence: 0.800832513666666
00:14:47.894 --> 00:14:50.586 New Year's Eve of 2021 due to
NOTE Confidence: 0.800832513666666
00:14:50.586 --> 00:14:52.594 complications of sickle cell.
NOTE Confidence: 0.800832513666666
00:14:52.600 --> 00:14:54.440 And among Carlton's many
NOTE Confidence: 0.800832513666666
00:14:54.440 --> 00:14:56.280 contributions to the field,
NOTE Confidence: 0.800832513666666
00:14:56.280 --> 00:14:58.272 he developed and validated a tool
NOTE Confidence: 0.800832513666666
00:14:58.272 --> 00:14:59.600 to assess clinicians attitudes
NOTE Confidence: 0.800832513666666
00:14:59.657 --> 00:15:01.317 towards people with sickle cell.
NOTE Confidence: 0.800832513666666

00:15:01.320 --> 00:15:03.624 And what Carlton showed was that

NOTE Confidence: 0.800832513666666

00:15:03.624 --> 00:15:05.502 by showing clinicians something as

NOTE Confidence: 0.800832513666666

00:15:05.502 --> 00:15:07.476 simple as a video of people with

NOTE Confidence: 0.800832513666666

00:15:07.476 --> 00:15:09.111 sickle cell outside the clinical

NOTE Confidence: 0.800832513666666

00:15:09.111 --> 00:15:10.796 world in the real world,

NOTE Confidence: 0.800832513666666

00:15:10.800 --> 00:15:13.080 it changed many clinicians attitudes

NOTE Confidence: 0.800832513666666

00:15:13.080 --> 00:15:15.360 and judgments about sickle cell.

NOTE Confidence: 0.800832513666666

00:15:15.360 --> 00:15:16.880 And in describing the sensation

NOTE Confidence: 0.800832513666666

00:15:16.880 --> 00:15:18.400 of a sickle cell crisis,

NOTE Confidence: 0.800832513666666

00:15:18.400 --> 00:15:19.840 Carlton was always eloquent,

NOTE Confidence: 0.800832513666666

00:15:19.840 --> 00:15:21.640 as you can see here.

NOTE Confidence: 0.800832513666666

00:15:21.640 --> 00:15:23.166 And I remember talking to him once

NOTE Confidence: 0.800832513666666

00:15:23.166 --> 00:15:24.557 because his office was next to mine.

NOTE Confidence: 0.800832513666666

00:15:24.560 --> 00:15:26.280 And he also described it

NOTE Confidence: 0.800832513666666

00:15:26.280 --> 00:15:28.000 as a rainstorm of daggers.

NOTE Confidence: 0.800832513666666

00:15:28.000 --> 00:15:31.204 I mean he had a way with words and

NOTE Confidence: 0.800832513666666
00:15:31.204 --> 00:15:33.280 this is a fact that we know that
NOTE Confidence: 0.800832513666666
00:15:33.280 --> 00:15:34.873 over half of adults with sickle
NOTE Confidence: 0.800832513666666
00:15:34.873 --> 00:15:36.318 cell experience pain on more
NOTE Confidence: 0.800832513666666
00:15:36.318 --> 00:15:37.840 than half of their days.
NOTE Confidence: 0.800832513666666
00:15:37.840 --> 00:15:39.400 So again this is pathognomonic
NOTE Confidence: 0.800832513666666
00:15:39.400 --> 00:15:41.320 for the disease if you will.
NOTE Confidence: 0.92717245
00:15:43.520 --> 00:15:44.960 Patients with sickle cell
NOTE Confidence: 0.92717245
00:15:44.960 --> 00:15:46.760 repeatedly face stigma and bias,
NOTE Confidence: 0.92717245
00:15:46.760 --> 00:15:48.968 often from the very people who
NOTE Confidence: 0.92717245
00:15:48.968 --> 00:15:50.840 are responsible for their care.
NOTE Confidence: 0.92717245
00:15:50.840 --> 00:15:52.660 Patients with sickle cell are more likely
NOTE Confidence: 0.92717245
00:15:52.660 --> 00:15:54.718 to be labeled as so-called drug seekers.
NOTE Confidence: 0.92717245
00:15:54.720 --> 00:15:56.395 And there's numerous well designed
NOTE Confidence: 0.92717245
00:15:56.395 --> 00:15:58.070 studies that show that patients
NOTE Confidence: 0.92717245
00:15:58.124 --> 00:15:59.825 with sickle cell get lower doses of
NOTE Confidence: 0.92717245

00:15:59.825 --> 00:16:01.678 pain meds in patients with cancer,
NOTE Confidence: 0.92717245

00:16:01.680 --> 00:16:03.204 patients with arthritis,
NOTE Confidence: 0.92717245

00:16:03.204 --> 00:16:05.645 patients with muscular dystrophy and
NOTE Confidence: 0.92717245

00:16:05.645 --> 00:16:08.075 patients with sickle cell are often
NOTE Confidence: 0.92717245

00:16:08.075 --> 00:16:09.920 times pejoratively called sicklers.
NOTE Confidence: 0.92717245

00:16:09.920 --> 00:16:12.839 And when clinicians call somebody a sickler,
NOTE Confidence: 0.92717245

00:16:12.840 --> 00:16:14.296 they're defining the patient
NOTE Confidence: 0.92717245

00:16:14.296 --> 00:16:16.480 based upon his or her disease,
NOTE Confidence: 0.92717245

00:16:16.480 --> 00:16:18.760 and it's dehumanizing rather than
NOTE Confidence: 0.92717245

00:16:18.760 --> 00:16:21.040 calling them as an individual.
NOTE Confidence: 0.92717245

00:16:21.040 --> 00:16:22.170 When patients with sickle cell
NOTE Confidence: 0.92717245

00:16:22.170 --> 00:16:23.800 go to the ER to get care,
NOTE Confidence: 0.92717245

00:16:23.800 --> 00:16:25.960 when they go to infusion centers,
NOTE Confidence: 0.92717245

00:16:25.960 --> 00:16:27.540 many clinicians doubt that
NOTE Confidence: 0.92717245

00:16:27.540 --> 00:16:29.515 they actually need pain meds.
NOTE Confidence: 0.92717245

00:16:29.520 --> 00:16:30.801 And here too,

NOTE Confidence: 0.92717245

00:16:30.801 --> 00:16:32.509 studies have shown repeatedly

NOTE Confidence: 0.92717245

00:16:32.509 --> 00:16:34.611 the clinicians opinions and our

NOTE Confidence: 0.92717245

00:16:34.611 --> 00:16:36.491 judgments are based upon cultural

NOTE Confidence: 0.92717245

00:16:36.491 --> 00:16:38.416 accounts that are linking sickle

NOTE Confidence: 0.92717245

00:16:38.416 --> 00:16:40.236 cell to the drug problem.

NOTE Confidence: 0.92717245

00:16:40.240 --> 00:16:40.785 Also,

NOTE Confidence: 0.92717245

00:16:40.785 --> 00:16:44.600 there's no real objective measure of pain.

NOTE Confidence: 0.92717245

00:16:44.600 --> 00:16:46.770 I can tell you right now that

NOTE Confidence: 0.92717245

00:16:46.770 --> 00:16:49.239 I have horrible pain and I may

NOTE Confidence: 0.92717245

00:16:49.239 --> 00:16:51.074 look really cool and comfortable.

NOTE Confidence: 0.92717245

00:16:51.080 --> 00:16:53.102 This is another reason why patients

NOTE Confidence: 0.92717245

00:16:53.102 --> 00:16:55.202 with sickle cell often time don't

NOTE Confidence: 0.92717245

00:16:55.202 --> 00:16:57.260 get the meds they need because

NOTE Confidence: 0.92717245

00:16:57.260 --> 00:16:59.000 clinicians simply don't believe it.

NOTE Confidence: 0.92717245

00:16:59.000 --> 00:17:00.000 Your vitals look good.

NOTE Confidence: 0.92717245

00:17:00.000 --> 00:17:01.000 You're on your phone.
NOTE Confidence: 0.92717245

00:17:01.000 --> 00:17:02.236 You're texting away.
NOTE Confidence: 0.92717245

00:17:02.236 --> 00:17:05.120 Patients of mine have told me that
NOTE Confidence: 0.92717245

00:17:05.120 --> 00:17:07.148 sometimes when they have a horrible
NOTE Confidence: 0.92717245

00:17:07.148 --> 00:17:09.160 crisis before they go to the ER,
NOTE Confidence: 0.92717245

00:17:09.160 --> 00:17:10.408 they feel as though they have
NOTE Confidence: 0.92717245

00:17:10.408 --> 00:17:11.640 to put their best face on.
NOTE Confidence: 0.92717245

00:17:11.640 --> 00:17:12.680 And what does that mean?
NOTE Confidence: 0.92717245

00:17:12.680 --> 00:17:14.456 That means they did do something
NOTE Confidence: 0.92717245

00:17:14.456 --> 00:17:15.640 that's anathema to me.
NOTE Confidence: 0.92717245

00:17:15.640 --> 00:17:17.520 Dress up, wear a suit.
NOTE Confidence: 0.92717245

00:17:17.520 --> 00:17:21.015 Or some of my young adolescent female
NOTE Confidence: 0.92717245

00:17:21.015 --> 00:17:22.520 patients tell me they actually put on,
NOTE Confidence: 0.92717245

00:17:22.520 --> 00:17:24.221 make up and put on a nice
NOTE Confidence: 0.92717245

00:17:24.221 --> 00:17:25.320 blouse to look good.
NOTE Confidence: 0.92717245

00:17:25.320 --> 00:17:26.220 So imagine that.

NOTE Confidence: 0.92717245

00:17:26.220 --> 00:17:27.920 You've got horrible, Bony pain.

NOTE Confidence: 0.92717245

00:17:27.920 --> 00:17:29.520 It's been equated to,

NOTE Confidence: 0.92717245

00:17:29.520 --> 00:17:30.320 you know,

NOTE Confidence: 0.92717245

00:17:30.320 --> 00:17:31.920 a dagger of rainstorms.

NOTE Confidence: 0.92717245

00:17:31.920 --> 00:17:34.362 But first you got to spend

NOTE Confidence: 0.92717245

00:17:34.362 --> 00:17:35.990 time beautifying yourself so

NOTE Confidence: 0.92717245

00:17:36.072 --> 00:17:38.000 you'll be taken seriously.

NOTE Confidence: 0.92717245

00:17:38.000 --> 00:17:39.626 Earlier I mentioned that sickle cell's

NOTE Confidence: 0.92717245

00:17:39.626 --> 00:17:41.452 more than three times as common as

NOTE Confidence: 0.92717245

00:17:41.452 --> 00:17:42.838 other genetic diseases in the US,

NOTE Confidence: 0.92717245

00:17:42.840 --> 00:17:44.256 like CF and hemophilia.

NOTE Confidence: 0.92717245

00:17:44.256 --> 00:17:46.380 Yet funding for sickle cell has

NOTE Confidence: 0.92717245

00:17:46.445 --> 00:17:48.989 lagged far behind these less common

NOTE Confidence: 0.92717245

00:17:48.989 --> 00:17:51.121 diseases that primarily affect white

NOTE Confidence: 0.92717245

00:17:51.121 --> 00:17:54.033 populations and this has been known for many,

NOTE Confidence: 0.92717245

00:17:54.040 --> 00:17:55.146 many decades.
NOTE Confidence: 0.92717245

00:17:55.146 --> 00:17:58.051 As far back as 1968,
NOTE Confidence: 0.92717245

00:17:58.051 --> 00:17:59.433 voluntary organizations
NOTE Confidence: 0.92717245

00:17:59.433 --> 00:18:02.197 raised \$2,000,000 for CF,
NOTE Confidence: 0.92717245

00:18:02.200 --> 00:18:04.640 \$8 million for muscular dystrophy,
NOTE Confidence: 0.92717245

00:18:04.640 --> 00:18:06.664 50,000 for sickle cell.
NOTE Confidence: 0.92717245

00:18:06.664 --> 00:18:09.120 President Nixon, some of you may recall,
NOTE Confidence: 0.92717245

00:18:09.120 --> 00:18:10.919 coined the term a war on cancer.
NOTE Confidence: 0.92717245

00:18:10.920 --> 00:18:13.422 Well that allowed for really important
NOTE Confidence: 0.92717245

00:18:13.422 --> 00:18:15.920 funding for cancer and at the time
NOTE Confidence: 0.92717245

00:18:15.920 --> 00:18:19.478 \$2.6 billion was allocated for cancer.
NOTE Confidence: 0.92717245

00:18:19.480 --> 00:18:20.988 At the same time,
NOTE Confidence: 0.92717245

00:18:20.988 --> 00:18:22.496 the government allocated \$5
NOTE Confidence: 0.92717245

00:18:22.496 --> 00:18:24.293 million for sickle cell.
NOTE Confidence: 0.92717245

00:18:24.293 --> 00:18:27.119 That was an extremely common disease
NOTE Confidence: 0.92717245

00:18:27.120 --> 00:18:30.840 and hemophilia is another example.

NOTE Confidence: 0.92717245

00:18:30.840 --> 00:18:33.648 It's cared for through 340 B

NOTE Confidence: 0.92717245

00:18:33.648 --> 00:18:35.520 national drug pricing programs.

NOTE Confidence: 0.92717245

00:18:35.520 --> 00:18:37.205 But unfortunately there's no similar

NOTE Confidence: 0.92717245

00:18:37.205 --> 00:18:39.160 government sponsored program for sickle cell.

NOTE Confidence: 0.92717245

00:18:39.160 --> 00:18:40.882 So what that means is that

NOTE Confidence: 0.92717245

00:18:40.882 --> 00:18:42.934 defining a standard of care falls

NOTE Confidence: 0.92717245

00:18:42.934 --> 00:18:44.200 to individual clinicians.

NOTE Confidence: 0.92717245

00:18:44.200 --> 00:18:46.096 And because of our own biases

NOTE Confidence: 0.92717245

00:18:46.096 --> 00:18:47.931 and because of centers differing

NOTE Confidence: 0.92717245

00:18:47.931 --> 00:18:49.437 priorities and budgets,

NOTE Confidence: 0.933662170909091

00:18:49.440 --> 00:18:50.484 these inequities happen.

NOTE Confidence: 0.933662170909091

00:18:50.484 --> 00:18:53.320 And then take a look at this data.

NOTE Confidence: 0.933662170909091

00:18:53.320 --> 00:18:55.080 This is current data CF.

NOTE Confidence: 0.933662170909091

00:18:55.080 --> 00:18:56.440 It's three times less common,

NOTE Confidence: 0.933662170909091

00:18:56.440 --> 00:18:58.060 but it gets three times

NOTE Confidence: 0.933662170909091

00:18:58.060 --> 00:18:59.356 as much Federal funding.
NOTE Confidence: 0.933662170909091

00:18:59.360 --> 00:19:01.400 Foundation expenditure still far outpace
NOTE Confidence: 0.933662170909091

00:19:01.400 --> 00:19:04.600 for CF than they do for sickle cell.
NOTE Confidence: 0.933662170909091

00:19:04.600 --> 00:19:05.984 There's more research articles
NOTE Confidence: 0.933662170909091

00:19:05.984 --> 00:19:08.060 and more drugs approved for CF
NOTE Confidence: 0.933662170909091

00:19:08.120 --> 00:19:09.878 than there are for sickle cell,
NOTE Confidence: 0.945738091428572

00:19:12.320 --> 00:19:14.196 so as we strive to make inroads,
NOTE Confidence: 0.945738091428572

00:19:14.200 --> 00:19:15.920 we can learn a lot by looking back.
NOTE Confidence: 0.945738091428572

00:19:15.920 --> 00:19:18.272 And a few slides ago I referenced
NOTE Confidence: 0.945738091428572

00:19:18.272 --> 00:19:20.065 Keith Whalu's excellent book on
NOTE Confidence: 0.945738091428572

00:19:20.065 --> 00:19:21.517 the intersection of politics,
NOTE Confidence: 0.945738091428572

00:19:21.520 --> 00:19:22.580 Race, and health as viewed
NOTE Confidence: 0.945738091428572

00:19:22.580 --> 00:19:23.880 through the lens of sickle cell.
NOTE Confidence: 0.945738091428572

00:19:23.880 --> 00:19:26.358 And if you've not read Keith's book,
NOTE Confidence: 0.945738091428572

00:19:26.360 --> 00:19:29.874 I really encourage you to 1972 saw
NOTE Confidence: 0.945738091428572

00:19:29.874 --> 00:19:31.673 passage of the Sickle Cell Control Act,

NOTE Confidence: 0.945738091428572
00:19:31.680 --> 00:19:33.756 and this provided funding for research,
NOTE Confidence: 0.945738091428572
00:19:33.760 --> 00:19:35.556 patient care, reproductive counseling.
NOTE Confidence: 0.945738091428572
00:19:35.556 --> 00:19:38.680 And as Keith notes in his book,
NOTE Confidence: 0.945738091428572
00:19:38.680 --> 00:19:39.880 and this is a quote,
NOTE Confidence: 0.945738091428572
00:19:39.880 --> 00:19:41.232 for many black Americans,
NOTE Confidence: 0.945738091428572
00:19:41.232 --> 00:19:43.740 the term Control Act was an ominous
NOTE Confidence: 0.945738091428572
00:19:43.740 --> 00:19:46.194 indicator that the real goals of
NOTE Confidence: 0.945738091428572
00:19:46.194 --> 00:19:48.195 genetic counseling were eugenic in
NOTE Confidence: 0.945738091428572
00:19:48.195 --> 00:19:50.680 nature in a form of population control.
NOTE Confidence: 0.945738091428572
00:19:50.680 --> 00:19:52.816 And these fears were well founded
NOTE Confidence: 0.945738091428572
00:19:52.816 --> 00:19:54.240 beyond the historical experience.
NOTE Confidence: 0.945738091428572
00:19:54.240 --> 00:19:56.108 Think Tuskegee, Linus Pauling,
NOTE Confidence: 0.945738091428572
00:19:56.108 --> 00:19:57.976 credited with discovering the
NOTE Confidence: 0.945738091428572
00:19:57.976 --> 00:19:59.960 molecular basis for sickle cell,
NOTE Confidence: 0.945738091428572
00:19:59.960 --> 00:20:01.464 actually said and published.
NOTE Confidence: 0.945738091428572

00:20:01.464 --> 00:20:03.720 That every person with sickle cell
NOTE Confidence: 0.945738091428572

00:20:03.784 --> 00:20:05.644 trait and disease have a tattoo
NOTE Confidence: 0.945738091428572

00:20:05.644 --> 00:20:07.755 on their forehead as a warning to
NOTE Confidence: 0.945738091428572

00:20:07.755 --> 00:20:09.631 the other person so that the two
NOTE Confidence: 0.945738091428572

00:20:09.640 --> 00:20:11.300 wouldn't procreate and you have
NOTE Confidence: 0.945738091428572

00:20:11.300 --> 00:20:12.960 more people with sickle cell.
NOTE Confidence: 0.945738091428572

00:20:12.960 --> 00:20:15.000 And here's what what Pauling had to say.
NOTE Confidence: 0.945738091428572

00:20:15.000 --> 00:20:15.600 And again,
NOTE Confidence: 0.945738091428572

00:20:15.600 --> 00:20:17.700 sometimes it it helps drive the point
NOTE Confidence: 0.945738091428572

00:20:17.700 --> 00:20:20.274 home when somebody says it out loud for you.
NOTE Confidence: 0.945738091428572

00:20:20.280 --> 00:20:21.920 I've suggested that there should
NOTE Confidence: 0.945738091428572

00:20:21.920 --> 00:20:23.930 be tattooed on the forehead of
NOTE Confidence: 0.945738091428572

00:20:23.930 --> 00:20:25.766 every young person a symbol showing
NOTE Confidence: 0.945738091428572

00:20:25.766 --> 00:20:27.678 possession of the sickle cell gene.
NOTE Confidence: 0.945738091428572

00:20:27.680 --> 00:20:28.656 If this were done,
NOTE Confidence: 0.945738091428572

00:20:28.656 --> 00:20:29.876 two young people carrying the

NOTE Confidence: 0.945738091428572
00:20:29.876 --> 00:20:31.033 same seriously defective gene
NOTE Confidence: 0.945738091428572
00:20:31.033 --> 00:20:32.749 would refrain from falling in love
NOTE Confidence: 0.945738091428572
00:20:32.749 --> 00:20:34.240 as though it were that easy.
NOTE Confidence: 0.945738091428572
00:20:34.240 --> 00:20:35.944 Legislation along this line,
NOTE Confidence: 0.945738091428572
00:20:35.944 --> 00:20:37.648 compulsory testing before marriage
NOTE Confidence: 0.945738091428572
00:20:37.648 --> 00:20:40.547 and some form of public or semi public
NOTE Confidence: 0.945738091428572
00:20:40.547 --> 00:20:43.000 display of this possession should be adopted.
NOTE Confidence: 0.945738091428572
00:20:43.000 --> 00:20:45.148 Pauling then double S down informing
NOTE Confidence: 0.945738091428572
00:20:45.148 --> 00:20:47.000 the opinion I presented above.
NOTE Confidence: 0.945738091428572
00:20:47.000 --> 00:20:48.456 I made application of what I consider
NOTE Confidence: 0.945738091428572
00:20:48.456 --> 00:20:50.239 to be a basic ethical principle,
NOTE Confidence: 0.945738091428572
00:20:50.240 --> 00:20:51.840 the principle of minimization
NOTE Confidence: 0.945738091428572
00:20:51.840 --> 00:20:53.040 of human suffering.
NOTE Confidence: 0.945738091428572
00:20:53.040 --> 00:20:54.876 It's our duty to take these
NOTE Confidence: 0.945738091428572
00:20:54.876 --> 00:20:56.648 actions the consequence of rational
NOTE Confidence: 0.945738091428572

00:20:56.648 --> 00:20:58.600 consideration of ethical problems.
NOTE Confidence: 0.945738091428572

00:20:58.600 --> 00:21:00.850 I believe that almost all ethical
NOTE Confidence: 0.945738091428572

00:21:00.850 --> 00:21:03.279 problems and legal problems can be solved,
NOTE Confidence: 0.945738091428572

00:21:03.280 --> 00:21:05.650 although often not without effort
NOTE Confidence: 0.945738091428572

00:21:05.650 --> 00:21:06.598 and difficulty,
NOTE Confidence: 0.945738091428572

00:21:06.600 --> 00:21:10.760 by application of this principle.
NOTE Confidence: 0.945738091428572

00:21:10.760 --> 00:21:12.182 This is a review article from
NOTE Confidence: 0.945738091428572

00:21:12.182 --> 00:21:13.679 JAMA from a couple years ago,
NOTE Confidence: 0.945738091428572

00:21:13.680 --> 00:21:15.415 and seeing statements like these
NOTE Confidence: 0.945738091428572

00:21:15.415 --> 00:21:17.150 in our leading medical journal
NOTE Confidence: 0.945738091428572

00:21:17.211 --> 00:21:19.098 shouldn't be surprising that an
NOTE Confidence: 0.945738091428572

00:21:19.098 --> 00:21:20.643 integral component of someone living
NOTE Confidence: 0.945738091428572

00:21:20.643 --> 00:21:22.710 with sickle cell is the perceived
NOTE Confidence: 0.945738091428572

00:21:22.710 --> 00:21:24.158 inadequacy of healthcare systems,
NOTE Confidence: 0.945738091428572

00:21:24.160 --> 00:21:25.720 stigma, bias, mistrust,
NOTE Confidence: 0.945738091428572

00:21:25.720 --> 00:21:28.320 lack of evidence based treatments,

NOTE Confidence: 0.945738091428572
00:21:28.320 --> 00:21:30.576 paucity of therapeutic options,
NOTE Confidence: 0.945738091428572
00:21:30.576 --> 00:21:33.396 and poor access to trials.
NOTE Confidence: 0.945738091428572
00:21:33.400 --> 00:21:35.444 So Fast forward from Pauling in 68
NOTE Confidence: 0.945738091428572
00:21:35.444 --> 00:21:37.295 to current times and take a look
NOTE Confidence: 0.945738091428572
00:21:37.295 --> 00:21:39.044 at what I bolded in this passage
NOTE Confidence: 0.945738091428572
00:21:39.044 --> 00:21:40.934 and the emphasis on building trust
NOTE Confidence: 0.945738091428572
00:21:40.934 --> 00:21:43.113 and not only listening to patients,
NOTE Confidence: 0.945738091428572
00:21:43.113 --> 00:21:45.168 but hearing and believing what
NOTE Confidence: 0.945738091428572
00:21:45.168 --> 00:21:46.519 they have to say.
NOTE Confidence: 0.945738091428572
00:21:46.520 --> 00:21:48.220 If we expect patients to
NOTE Confidence: 0.945738091428572
00:21:48.220 --> 00:21:49.240 abide our recommendations,
NOTE Confidence: 0.945738091428572
00:21:49.240 --> 00:21:51.440 we should be willing to hear them out.
NOTE Confidence: 0.945738091428572
00:21:51.440 --> 00:21:54.646 And this is central to culturally where
NOTE Confidence: 0.945738091428572
00:21:54.646 --> 00:21:57.119 communication and ethically sensitive care.
NOTE Confidence: 0.945738091428572
00:21:57.120 --> 00:21:59.262 There's many ways that we can listen
NOTE Confidence: 0.945738091428572

00:21:59.262 --> 00:22:01.400 to and believe patients listening can
NOTE Confidence: 0.945738091428572

00:22:01.400 --> 00:22:03.440 happen by hearing the spoken word.
NOTE Confidence: 0.945738091428572

00:22:03.440 --> 00:22:06.075 It can also happen by seeing Hertz.
NOTE Confidence: 0.945738091428572

00:22:06.075 --> 00:22:09.555 Nazir was a artist and a sickle cell
NOTE Confidence: 0.920151268333333

00:22:09.560 --> 00:22:13.180 advocate, and he died also in 2021 at
NOTE Confidence: 0.920151268333333

00:22:13.180 --> 00:22:15.400 age 48 from sickle cell complications.
NOTE Confidence: 0.920151268333333

00:22:15.400 --> 00:22:17.171 And he used his art to raise
NOTE Confidence: 0.920151268333333

00:22:17.171 --> 00:22:18.440 awareness and to educate.
NOTE Confidence: 0.920151268333333

00:22:18.440 --> 00:22:20.648 And these three of his paintings
NOTE Confidence: 0.920151268333333

00:22:20.648 --> 00:22:22.120 are entitled 10 Redefined,
NOTE Confidence: 0.920151268333333

00:22:22.120 --> 00:22:26.116 Hope and Need Not Suffer Alone.
NOTE Confidence: 0.920151268333333

00:22:26.120 --> 00:22:27.758 All right, what you been waiting for?
NOTE Confidence: 0.920151268333333

00:22:27.760 --> 00:22:28.657 Four letter words.
NOTE Confidence: 0.920151268333333

00:22:28.657 --> 00:22:31.160 So let me let me juice up here.
NOTE Confidence: 0.805944856666667

00:22:35.600 --> 00:22:37.336 So hope and hype are both four letter
NOTE Confidence: 0.805944856666667

00:22:37.336 --> 00:22:39.118 words and we're gonna talk about this.

NOTE Confidence: 0.805944856666667
00:22:39.120 --> 00:22:40.805 And when talking about sickle
NOTE Confidence: 0.805944856666667
00:22:40.805 --> 00:22:42.153 cell treatment and research,
NOTE Confidence: 0.805944856666667
00:22:42.160 --> 00:22:43.546 one can't underestimate
NOTE Confidence: 0.805944856666667
00:22:43.546 --> 00:22:45.394 the importance of hope.
NOTE Confidence: 0.805944856666667
00:22:45.400 --> 00:22:47.044 But distinguishing were novel
NOTE Confidence: 0.805944856666667
00:22:47.044 --> 00:22:48.688 technologies and treatments like
NOTE Confidence: 0.805944856666667
00:22:48.688 --> 00:22:50.759 CRISPR and gene therapy live on.
NOTE Confidence: 0.805944856666667
00:22:50.760 --> 00:22:53.274 This hope hype spectrum isn't always
NOTE Confidence: 0.805944856666667
00:22:53.274 --> 00:22:56.072 easy because both the media and
NOTE Confidence: 0.805944856666667
00:22:56.072 --> 00:22:58.065 scientists struggle in describing CRISPR.
NOTE Confidence: 0.805944856666667
00:22:58.065 --> 00:23:00.270 The MIT Technology Review went so far
NOTE Confidence: 0.805944856666667
00:23:00.328 --> 00:23:02.200 as calling it a miracle of our age,
NOTE Confidence: 0.805944856666667
00:23:02.200 --> 00:23:04.396 and in his book Editing Humanity,
NOTE Confidence: 0.805944856666667
00:23:04.400 --> 00:23:06.392 Kevin Davies equated it to the
NOTE Confidence: 0.805944856666667
00:23:06.392 --> 00:23:07.720 Holy Grail of science.
NOTE Confidence: 0.961242922222222

00:23:10.000 --> 00:23:12.860 Many of us in this room likely have a sense

NOTE Confidence: 0.961242922222222

00:23:12.933 --> 00:23:15.397 of what hope in the medical world is.

NOTE Confidence: 0.961242922222222

00:23:15.400 --> 00:23:16.885 How Hope is portrayed in

NOTE Confidence: 0.961242922222222

00:23:16.885 --> 00:23:18.073 other areas is important.

NOTE Confidence: 0.961242922222222

00:23:18.080 --> 00:23:19.800 And So what I'd like to do is take a

NOTE Confidence: 0.961242922222222

00:23:19.850 --> 00:23:21.544 bit of a tour, if you'll indulge me.

NOTE Confidence: 0.961242922222222

00:23:21.544 --> 00:23:24.168 And I want to look and see how hope

NOTE Confidence: 0.961242922222222

00:23:24.168 --> 00:23:25.878 is represented in popular culture,

NOTE Confidence: 0.961242922222222

00:23:25.880 --> 00:23:28.155 including things like the books we read,

NOTE Confidence: 0.961242922222222

00:23:28.160 --> 00:23:30.218 the movies we watch, the news outlets

NOTE Confidence: 0.961242922222222

00:23:30.218 --> 00:23:32.399 where we get our information from,

NOTE Confidence: 0.961242922222222

00:23:32.400 --> 00:23:33.417 and in advertisements.

NOTE Confidence: 0.961242922222222

00:23:33.417 --> 00:23:35.790 So one view of hope from contemporary

NOTE Confidence: 0.961242922222222

00:23:35.847 --> 00:23:37.542 literature comes from Ann Patchett

NOTE Confidence: 0.961242922222222

00:23:37.542 --> 00:23:40.600 in this book, State of Wonder.

NOTE Confidence: 0.961242922222222

00:23:40.600 --> 00:23:41.800 Hope's a horrible Thing.

NOTE Confidence: 0.9612429222222222
00:23:41.800 --> 00:23:43.385 You know, I don't know who decided
NOTE Confidence: 0.9612429222222222
00:23:43.385 --> 00:23:44.720 to package hope as a virtue,
NOTE Confidence: 0.9612429222222222
00:23:44.720 --> 00:23:46.916 because it's not. It's a plague.
NOTE Confidence: 0.9612429222222222
00:23:46.920 --> 00:23:48.390 Hope is like walking around with a
NOTE Confidence: 0.9612429222222222
00:23:48.390 --> 00:23:50.089 fish hook in your mouth and somebody
NOTE Confidence: 0.9612429222222222
00:23:50.089 --> 00:23:51.800 just keeps pulling it and pulling it.
NOTE Confidence: 0.82892685125
00:23:53.840 --> 00:23:55.715 From the recent HBO series
NOTE Confidence: 0.82892685125
00:23:55.715 --> 00:23:56.840 Time Traveler's Wife,
NOTE Confidence: 0.82892685125
00:23:56.840 --> 00:24:00.035 which is based on a movie and a book,
NOTE Confidence: 0.82892685125
00:24:00.040 --> 00:24:04.056 anyone can stand any kind of torture except
NOTE Confidence: 0.82892685125
00:24:04.056 --> 00:24:06.920 hope from Stephen King's Billy Summers.
NOTE Confidence: 0.82892685125
00:24:06.920 --> 00:24:08.760 It's more than a glimmer of hope now,
NOTE Confidence: 0.82892685125
00:24:08.760 --> 00:24:10.720 and hope may be the thing with feathers,
NOTE Confidence: 0.82892685125
00:24:10.720 --> 00:24:13.920 but it's also the thing that hurts you.
NOTE Confidence: 0.82892685125
00:24:13.920 --> 00:24:15.450 From Kazuishiguru's excellent
NOTE Confidence: 0.82892685125

00:24:15.450 --> 00:24:18.000 book Clara and the Sun,
NOTE Confidence: 0.82892685125

00:24:18.000 --> 00:24:20.835 Hope damn Thing never leaves you alone.
NOTE Confidence: 0.82892685125

00:24:20.840 --> 00:24:24.248 And this next quotation is a
NOTE Confidence: 0.82892685125

00:24:24.248 --> 00:24:26.840 discussion between the AI thing.
NOTE Confidence: 0.82892685125

00:24:26.840 --> 00:24:29.080 I don't know what to call it.
NOTE Confidence: 0.82892685125

00:24:29.080 --> 00:24:32.400 And and and a human in the that
NOTE Confidence: 0.82892685125

00:24:32.400 --> 00:24:34.080 I'm going to share with you.
NOTE Confidence: 0.82892685125

00:24:34.080 --> 00:24:35.680 Josie's condition is very concerning.
NOTE Confidence: 0.82892685125

00:24:35.680 --> 00:24:38.560 Even so, I'm hoping soon she'll get better.
NOTE Confidence: 0.82892685125

00:24:38.560 --> 00:24:39.680 Is that merely hoping,
NOTE Confidence: 0.82892685125

00:24:39.680 --> 00:24:41.360 or is it something more solid?
NOTE Confidence: 0.82892685125

00:24:41.360 --> 00:24:42.398 You're expecting something
NOTE Confidence: 0.82892685125

00:24:42.398 --> 00:24:44.474 the rest of us haven't seen?
NOTE Confidence: 0.82892685125

00:24:44.480 --> 00:24:47.424 I suppose it's merely hope, but a real one.
NOTE Confidence: 0.82892685125

00:24:47.424 --> 00:24:50.160 I believe Josie will soon become better.
NOTE Confidence: 0.82892685125

00:24:50.160 --> 00:24:51.240 Maybe you can see things

NOTE Confidence: 0.82892685125

00:24:51.240 --> 00:24:52.320 the rest of us can't.

NOTE Confidence: 0.82892685125

00:24:52.320 --> 00:24:53.880 Maybe you're right to be hopeful.

NOTE Confidence: 0.82892685125

00:24:53.880 --> 00:24:56.760 Maybe you're right.

NOTE Confidence: 0.82892685125

00:24:56.760 --> 00:24:59.433 This is a book who's the protagonist's

NOTE Confidence: 0.82892685125

00:24:59.433 --> 00:25:01.791 daughter is diagnosed with pediatric ALL

NOTE Confidence: 0.82892685125

00:25:01.791 --> 00:25:04.717 and he's having this discussion in his head

NOTE Confidence: 0.82892685125

00:25:04.717 --> 00:25:07.080 and thinking about the pediatric oncologist.

NOTE Confidence: 0.82892685125

00:25:07.080 --> 00:25:09.156 Sometimes 4 letters mean the world.

NOTE Confidence: 0.82892685125

00:25:09.160 --> 00:25:11.440 People fear being someone else's hope.

NOTE Confidence: 0.82892685125

00:25:11.440 --> 00:25:12.226 I understand her,

NOTE Confidence: 0.82892685125

00:25:12.226 --> 00:25:13.274 but I wanted her,

NOTE Confidence: 0.82892685125

00:25:13.280 --> 00:25:15.560 the oncologist to be our hope.

NOTE Confidence: 0.8269563

00:25:17.640 --> 00:25:19.188 What about for movies?

NOTE Confidence: 0.8269563

00:25:19.188 --> 00:25:22.719 Hope is a monster and I'm its plaything.

NOTE Confidence: 0.8269563

00:25:22.720 --> 00:25:24.094 I've been waiting to give a

NOTE Confidence: 0.8269563

00:25:24.094 --> 00:25:25.406 grand rounds like thing where I
NOTE Confidence: 0.8269563

00:25:25.406 --> 00:25:27.720 get to give talk about Batman.
NOTE Confidence: 0.8269563

00:25:27.720 --> 00:25:30.412 So from Batman, there's a reason why
NOTE Confidence: 0.8269563

00:25:30.412 --> 00:25:32.200 this prison is the worst hell on earth.
NOTE Confidence: 0.8269563

00:25:32.200 --> 00:25:34.811 Hope. I learned here that there can
NOTE Confidence: 0.8269563

00:25:34.811 --> 00:25:37.719 be no true despair without hope.
NOTE Confidence: 0.8269563

00:25:37.720 --> 00:25:38.908 So if contemporary fiction
NOTE Confidence: 0.8269563

00:25:38.908 --> 00:25:40.393 and movies aren't your thing,
NOTE Confidence: 0.8269563

00:25:40.400 --> 00:25:42.754 we can turn to Omar Khayyam's 12th
NOTE Confidence: 0.8269563

00:25:42.754 --> 00:25:45.239 century Persian epic The Rubiad.
NOTE Confidence: 0.8269563

00:25:45.240 --> 00:25:48.024 The worldly hope men set their hearts upon
NOTE Confidence: 0.8269563

00:25:48.024 --> 00:25:50.918 turns ashes or it prospers in Anon like snow.
NOTE Confidence: 0.8269563

00:25:50.920 --> 00:25:53.398 Upon the desert's dusty face lighting.
NOTE Confidence: 0.8269563

00:25:53.400 --> 00:25:55.836 A little hour or two is gone,
NOTE Confidence: 0.8269563

00:25:55.840 --> 00:25:57.620 and then from Shakespeare,
NOTE Confidence: 0.8269563

00:25:57.620 --> 00:25:58.955 measure for measure.

NOTE Confidence: 0.8269563

00:25:58.960 --> 00:26:00.585 The miserable have no other

NOTE Confidence: 0.8269563

00:26:00.585 --> 00:26:01.560 medicine than hope.

NOTE Confidence: 0.8269563

00:26:01.560 --> 00:26:03.079 I have hope that I will live,

NOTE Confidence: 0.8269563

00:26:03.080 --> 00:26:04.560 but I'm prepared to die.

NOTE Confidence: 0.930212042727273

00:26:06.680 --> 00:26:08.948 This recent New Yorker piece adds

NOTE Confidence: 0.930212042727273

00:26:08.948 --> 00:26:10.874 additional perspective and I draw

NOTE Confidence: 0.930212042727273

00:26:10.874 --> 00:26:12.614 your attention in particular to

NOTE Confidence: 0.930212042727273

00:26:12.614 --> 00:26:14.799 the second and third blurbs here,

NOTE Confidence: 0.930212042727273

00:26:14.800 --> 00:26:16.051 the 2nd quotation.

NOTE Confidence: 0.930212042727273

00:26:16.051 --> 00:26:18.136 Especially this part about selling

NOTE Confidence: 0.930212042727273

00:26:18.136 --> 00:26:20.012 something makes me wonder about

NOTE Confidence: 0.930212042727273

00:26:20.012 --> 00:26:21.637 another 4 letter word hype.

NOTE Confidence: 0.930212042727273

00:26:21.640 --> 00:26:24.106 And then this third quotation is

NOTE Confidence: 0.930212042727273

00:26:24.106 --> 00:26:26.528 especially Apartment because it draws the

NOTE Confidence: 0.930212042727273

00:26:26.528 --> 00:26:29.352 unique link that science and hope also share.

NOTE Confidence: 0.930212042727273

00:26:29.360 --> 00:26:31.292 And so that's what I want to
NOTE Confidence: 0.930212042727273

00:26:31.292 --> 00:26:33.280 talk about for a couple minutes.
NOTE Confidence: 0.930212042727273

00:26:33.280 --> 00:26:35.490 So there may be truth to the view of hope
NOTE Confidence: 0.930212042727273

00:26:35.552 --> 00:26:37.752 that I've just shared with you from all
NOTE Confidence: 0.930212042727273

00:26:37.752 --> 00:26:39.880 these books and movies and other things,
NOTE Confidence: 0.930212042727273

00:26:39.880 --> 00:26:41.278 but hope is a good thing.
NOTE Confidence: 0.930212042727273

00:26:41.280 --> 00:26:43.488 I mean, it drives so much of what
NOTE Confidence: 0.930212042727273

00:26:43.488 --> 00:26:45.000 everybody in this room does.
NOTE Confidence: 0.930212042727273

00:26:45.000 --> 00:26:46.918 And so let's take a deeper dive
NOTE Confidence: 0.930212042727273

00:26:46.918 --> 00:26:48.802 and examine what hope in the
NOTE Confidence: 0.930212042727273

00:26:48.802 --> 00:26:50.477 clinical research world looks like.
NOTE Confidence: 0.930212042727273

00:26:50.480 --> 00:26:53.333 And here you can see how HOPE and clinical
NOTE Confidence: 0.930212042727273

00:26:53.333 --> 00:26:55.398 medicine is leveraged and portrayed.
NOTE Confidence: 0.930212042727273

00:26:55.400 --> 00:26:57.276 In the case of Duchesne muscular dystrophy,
NOTE Confidence: 0.930212042727273

00:26:57.280 --> 00:26:58.930 the name of the trial incorporates
NOTE Confidence: 0.930212042727273

00:26:58.930 --> 00:27:00.085 the word hope. St.

NOTE Confidence: 0.930212042727273
00:27:00.085 --> 00:27:02.360 Jude has an entire foundation called St.
NOTE Confidence: 0.930212042727273
00:27:02.360 --> 00:27:04.225 Hope and Hope Clinical Research
NOTE Confidence: 0.930212042727273
00:27:04.225 --> 00:27:06.800 is the name of a company.
NOTE Confidence: 0.930212042727273
00:27:06.800 --> 00:27:08.040 And then in sickle cell,
NOTE Confidence: 0.930212042727273
00:27:08.040 --> 00:27:09.734 I showed you one of the medications
NOTE Confidence: 0.930212042727273
00:27:09.734 --> 00:27:10.920 that was recently approved,
NOTE Confidence: 0.930212042727273
00:27:10.920 --> 00:27:11.205 Oxalatory.
NOTE Confidence: 0.930212042727273
00:27:11.205 --> 00:27:13.200 The name of the trial was called
NOTE Confidence: 0.930212042727273
00:27:13.200 --> 00:27:14.160 the HOPE trial.
NOTE Confidence: 0.972077412857143
00:27:16.600 --> 00:27:17.815 Here's another example
NOTE Confidence: 0.972077412857143
00:27:17.815 --> 00:27:19.435 from the oncology side.
NOTE Confidence: 0.972077412857143
00:27:19.440 --> 00:27:21.426 Hope has been and continues to
NOTE Confidence: 0.972077412857143
00:27:21.426 --> 00:27:23.181 be integral to participation in
NOTE Confidence: 0.972077412857143
00:27:23.181 --> 00:27:24.661 cooperative group clinical trials
NOTE Confidence: 0.972077412857143
00:27:24.661 --> 00:27:26.511 and the prospect for improved
NOTE Confidence: 0.972077412857143

00:27:26.520 --> 00:27:28.585 survival's a powerful tool that's
NOTE Confidence: 0.972077412857143

00:27:28.585 --> 00:27:31.160 not lost on clinicians or physicians
NOTE Confidence: 0.972077412857143

00:27:31.160 --> 00:27:33.800 or nurses or parents or industry.
NOTE Confidence: 0.972077412857143

00:27:33.800 --> 00:27:35.585 And I think we can all appreciate
NOTE Confidence: 0.972077412857143

00:27:35.585 --> 00:27:37.194 that faced with a deadly disease
NOTE Confidence: 0.972077412857143

00:27:37.194 --> 00:27:38.760 and no guarantee for a cure,
NOTE Confidence: 0.972077412857143

00:27:38.760 --> 00:27:40.878 a parent's willingness to offer and
NOTE Confidence: 0.972077412857143

00:27:40.878 --> 00:27:43.153 and take any chance that'll prolong
NOTE Confidence: 0.972077412857143

00:27:43.153 --> 00:27:45.541 their their kids life even when
NOTE Confidence: 0.972077412857143

00:27:45.541 --> 00:27:47.559 that treatment has unknown risks.
NOTE Confidence: 0.972077412857143

00:27:47.560 --> 00:27:49.792 And this is especially true for
NOTE Confidence: 0.972077412857143

00:27:49.792 --> 00:27:51.746 novel or cutting edge therapies
NOTE Confidence: 0.972077412857143

00:27:51.746 --> 00:27:54.076 that are grounded in science.
NOTE Confidence: 0.972077412857143

00:27:54.080 --> 00:27:56.229 And in fact studies have shown that
NOTE Confidence: 0.972077412857143

00:27:56.229 --> 00:27:58.282 for many parents the sicker their kid
NOTE Confidence: 0.972077412857143

00:27:58.282 --> 00:28:00.946 the more they feel as if they have no

NOTE Confidence: 0.972077412857143

00:28:00.946 --> 00:28:02.956 choice but to participate in research.

NOTE Confidence: 0.972077412857143

00:28:02.960 --> 00:28:05.636 And ethically this is a concern

NOTE Confidence: 0.972077412857143

00:28:05.636 --> 00:28:07.420 because parents vulnerability and

NOTE Confidence: 0.972077412857143

00:28:07.493 --> 00:28:09.755 their perceived lack of a choice.

NOTE Confidence: 0.972077412857143

00:28:09.760 --> 00:28:12.147 It has implications for those of us

NOTE Confidence: 0.972077412857143

00:28:12.147 --> 00:28:13.759 who recommend research for kids,

NOTE Confidence: 0.972077412857143

00:28:13.760 --> 00:28:16.320 be that the clinician, investigator,

NOTE Confidence: 0.972077412857143

00:28:16.320 --> 00:28:18.760 the IRB and etcetera.

NOTE Confidence: 0.968310405625

00:28:21.360 --> 00:28:23.331 Hope is integral to those who live with and

NOTE Confidence: 0.968310405625

00:28:23.331 --> 00:28:25.235 care for kids with life limiting illness,

NOTE Confidence: 0.968310405625

00:28:25.240 --> 00:28:27.075 including parents and clinicians and

NOTE Confidence: 0.968310405625

00:28:27.075 --> 00:28:29.719 viewed through the prism of medical care.

NOTE Confidence: 0.968310405625

00:28:29.720 --> 00:28:32.357 One definition of hope is what you see here,

NOTE Confidence: 0.968310405625

00:28:32.360 --> 00:28:34.335 an inner resource that allows

NOTE Confidence: 0.968310405625

00:28:34.335 --> 00:28:35.915 individuals to transcend the

NOTE Confidence: 0.968310405625

00:28:35.915 --> 00:28:37.439 constraints imposed by illness,
NOTE Confidence: 0.968310405625

00:28:37.440 --> 00:28:39.108 hopes of positive orientation
NOTE Confidence: 0.968310405625

00:28:39.108 --> 00:28:41.193 to to towards the future,
NOTE Confidence: 0.968310405625

00:28:41.200 --> 00:28:43.840 and the anticipation of an improvement.
NOTE Confidence: 0.968310405625

00:28:43.840 --> 00:28:45.877 For parents of a critically ill child,
NOTE Confidence: 0.968310405625

00:28:45.880 --> 00:28:47.440 hope serves as a buoy.
NOTE Confidence: 0.968310405625

00:28:47.440 --> 00:28:49.560 It allows them to endure,
NOTE Confidence: 0.968310405625

00:28:49.560 --> 00:28:52.040 and understandably Hope assumes different
NOTE Confidence: 0.968310405625

00:28:52.040 --> 00:28:54.520 forms for parents and clinicians,
NOTE Confidence: 0.968310405625

00:28:54.520 --> 00:28:56.475 and it oftentimes evolves based
NOTE Confidence: 0.968310405625

00:28:56.475 --> 00:28:58.039 on the illness trajectory.
NOTE Confidence: 0.968310405625

00:28:58.040 --> 00:28:59.800 And both parents and clinicians
NOTE Confidence: 0.968310405625

00:28:59.800 --> 00:29:02.120 hope for the best medical outcome,
NOTE Confidence: 0.968310405625

00:29:02.120 --> 00:29:04.322 but they may perceive that outcome
NOTE Confidence: 0.968310405625

00:29:04.322 --> 00:29:07.038 is more or less likely to occur.
NOTE Confidence: 0.968310405625

00:29:07.040 --> 00:29:09.592 In a study by my colleague Brian Sisk

NOTE Confidence: 0.968310405625

00:29:09.592 --> 00:29:12.439 and and his colleagues looked at parents

NOTE Confidence: 0.968310405625

00:29:12.439 --> 00:29:15.100 sources of hope and for parents of kids

NOTE Confidence: 0.968310405625

00:29:15.100 --> 00:29:17.519 with cancer who were the study population,

NOTE Confidence: 0.968310405625

00:29:17.520 --> 00:29:18.995 Brian and his colleagues found

NOTE Confidence: 0.968310405625

00:29:18.995 --> 00:29:20.960 that they had many forms of hope,

NOTE Confidence: 0.968310405625

00:29:20.960 --> 00:29:22.520 four of which were child focus.

NOTE Confidence: 0.968310405625

00:29:22.520 --> 00:29:23.182 And yes,

NOTE Confidence: 0.968310405625

00:29:23.182 --> 00:29:24.837 cure was the most obvious.

NOTE Confidence: 0.968310405625

00:29:24.840 --> 00:29:26.688 But it was only one type of hope

NOTE Confidence: 0.968310405625

00:29:26.688 --> 00:29:28.923 and I think it would be really

NOTE Confidence: 0.968310405625

00:29:28.923 --> 00:29:30.628 cool to replicate Brian's study

NOTE Confidence: 0.968310405625

00:29:30.693 --> 00:29:32.786 in the sickle cell community now,

NOTE Confidence: 0.968310405625

00:29:32.786 --> 00:29:34.716 irrespective of a child's condition.

NOTE Confidence: 0.968310405625

00:29:34.720 --> 00:29:37.144 Cancer, sickle cell CF.

NOTE Confidence: 0.968310405625

00:29:37.144 --> 00:29:38.356 Muscular dystrophy.

NOTE Confidence: 0.968310405625

00:29:38.360 --> 00:29:40.649 I would suggest that parental hope for

NOTE Confidence: 0.968310405625

00:29:40.649 --> 00:29:42.389 improved survival and ultimately cure

NOTE Confidence: 0.968310405625

00:29:42.389 --> 00:29:44.477 is a powerful and motivating force.

NOTE Confidence: 0.968310405625

00:29:44.480 --> 00:29:45.402 And understandably,

NOTE Confidence: 0.968310405625

00:29:45.402 --> 00:29:48.168 many parents look to clinical research

NOTE Confidence: 0.968310405625

00:29:48.168 --> 00:29:51.437 as a means to get to that cure goal.

NOTE Confidence: 0.968310405625

00:29:51.440 --> 00:29:53.222 Sampson and colleagues found that for

NOTE Confidence: 0.968310405625

00:29:53.222 --> 00:29:55.440 parents of kids with muscular dystrophy,

NOTE Confidence: 0.968310405625

00:29:55.440 --> 00:29:57.666 they viewed medical research as a means

NOTE Confidence: 0.968310405625

00:29:57.666 --> 00:30:00.154 to a miracle cure through things like

NOTE Confidence: 0.968310405625

00:30:00.154 --> 00:30:02.356 gene therapy and stem cell therapy.

NOTE Confidence: 0.968310405625

00:30:02.360 --> 00:30:04.850 And our colleague Rick Kodish observed

NOTE Confidence: 0.968310405625

00:30:04.850 --> 00:30:07.328 that really any therapy that has

NOTE Confidence: 0.968310405625

00:30:07.328 --> 00:30:09.578 the veneer of cutting edge science

NOTE Confidence: 0.968310405625

00:30:09.578 --> 00:30:11.598 instills and fosters more hope.

NOTE Confidence: 0.968310405625

00:30:11.600 --> 00:30:12.976 What does this mean?

NOTE Confidence: 0.968310405625

00:30:12.976 --> 00:30:14.020 Well, to me,

NOTE Confidence: 0.968310405625

00:30:14.020 --> 00:30:16.120 it means that as physician investigators,

NOTE Confidence: 0.968310405625

00:30:16.120 --> 00:30:18.776 we have a duty to recognize just how

NOTE Confidence: 0.968310405625

00:30:18.776 --> 00:30:20.797 instrumental hope is and not dispel it.

NOTE Confidence: 0.968310405625

00:30:20.800 --> 00:30:22.900 Data shows that even when parents know

NOTE Confidence: 0.968310405625

00:30:22.900 --> 00:30:24.670 their kids dying, they're still hopeful.

NOTE Confidence: 0.968310405625

00:30:24.670 --> 00:30:26.120 Remember, hope is a buoy.

NOTE Confidence: 0.968310405625

00:30:26.120 --> 00:30:28.319 It's a salve.

NOTE Confidence: 0.968310405625

00:30:28.320 --> 00:30:29.940 And so rather than view patient

NOTE Confidence: 0.968310405625

00:30:29.940 --> 00:30:31.598 and parental hope as a failure

NOTE Confidence: 0.968310405625

00:30:31.598 --> 00:30:33.158 to accept facts on the ground,

NOTE Confidence: 0.968310405625

00:30:33.160 --> 00:30:36.177 I think we may be better suited

NOTE Confidence: 0.968310405625

00:30:36.177 --> 00:30:38.435 to recognize hope as fundamental.

NOTE Confidence: 0.968310405625

00:30:38.435 --> 00:30:41.690 And while we support and foster what

NOTE Confidence: 0.968310405625

00:30:41.779 --> 00:30:44.719 I call reasonable and reshaped hope,

NOTE Confidence: 0.968310405625

00:30:44.720 --> 00:30:47.400 exactly how far patients, families,
NOTE Confidence: 0.968310405625

00:30:47.400 --> 00:30:49.518 clinicians, and oversight bodies like IR,
NOTE Confidence: 0.968310405625

00:30:49.520 --> 00:30:49.811 BS,
NOTE Confidence: 0.968310405625

00:30:49.811 --> 00:30:51.848 and FDA are willing to tip this
NOTE Confidence: 0.968310405625

00:30:51.848 --> 00:30:54.454 hope scale in the effort to have
NOTE Confidence: 0.968310405625

00:30:54.454 --> 00:30:56.022 important advances and important
NOTE Confidence: 0.968310405625

00:30:56.022 --> 00:30:57.999 ethical and practical questions.
NOTE Confidence: 0.968310405625

00:30:58.000 --> 00:31:00.340 And these next examples really
NOTE Confidence: 0.968310405625

00:31:00.340 --> 00:31:02.680 drive home the balancing act
NOTE Confidence: 0.968310405625

00:31:02.760 --> 00:31:04.872 between protecting kids involved
NOTE Confidence: 0.968310405625

00:31:04.872 --> 00:31:07.512 in risky research and hope.
NOTE Confidence: 0.968310405625

00:31:07.520 --> 00:31:09.220 In their Seminole 1991 New
NOTE Confidence: 0.968310405625

00:31:09.220 --> 00:31:10.240 England Journal paper,
NOTE Confidence: 0.968310405625

00:31:10.240 --> 00:31:11.804 Kodish and colleagues shared
NOTE Confidence: 0.968310405625

00:31:11.804 --> 00:31:13.759 the results of their study.
NOTE Confidence: 0.968310405625

00:31:13.760 --> 00:31:16.448 And they asked parents of kids with

NOTE Confidence: 0.968310405625

00:31:16.448 --> 00:31:19.072 sickle cell what would you be willing

NOTE Confidence: 0.968310405625

00:31:19.072 --> 00:31:21.630 to trade off in support of a potentially

NOTE Confidence: 0.968310405625

00:31:21.630 --> 00:31:22.838 curative bone marrow transplant?

NOTE Confidence: 0.968310405625

00:31:22.840 --> 00:31:24.255 And what they found was

NOTE Confidence: 0.968310405625

00:31:24.255 --> 00:31:25.670 that over 1/3 of parents

NOTE Confidence: 0.8944242832

00:31:25.733 --> 00:31:27.678 would proceed with the potentially

NOTE Confidence: 0.8944242832

00:31:27.678 --> 00:31:29.623 curative transplant even if the

NOTE Confidence: 0.8944242832

00:31:29.688 --> 00:31:31.398 risk of short term mortality,

NOTE Confidence: 0.8944242832

00:31:31.400 --> 00:31:34.160 meaning death, was more than 15%.

NOTE Confidence: 0.8944242832

00:31:34.160 --> 00:31:36.456 And more than 10% of those parents

NOTE Confidence: 0.8944242832

00:31:36.456 --> 00:31:38.469 would proceed if the risk of

NOTE Confidence: 0.8944242832

00:31:38.469 --> 00:31:40.074 mortality was more than 50%.

NOTE Confidence: 0.8944242832

00:31:40.080 --> 00:31:42.117 Nearly 25 years later in the era,

NOTE Confidence: 0.8944242832

00:31:42.120 --> 00:31:44.560 more widespread knowledge about transplant,

NOTE Confidence: 0.8944242832

00:31:44.560 --> 00:31:46.568 Emily Myers and colleagues

NOTE Confidence: 0.8944242832

00:31:46.568 --> 00:31:48.074 replicated Codish's study,
NOTE Confidence: 0.8944242832

00:31:48.080 --> 00:31:50.006 and they found that nearly three
NOTE Confidence: 0.8944242832

00:31:50.006 --> 00:31:52.072 out of four parents would proceed
NOTE Confidence: 0.8944242832

00:31:52.072 --> 00:31:54.220 with a transplant even if the
NOTE Confidence: 0.8944242832

00:31:54.220 --> 00:31:56.240 mortality risk was greater than 5%.
NOTE Confidence: 0.8944242832

00:31:56.240 --> 00:31:58.176 And more half of the parents would proceed
NOTE Confidence: 0.8944242832

00:31:58.176 --> 00:32:00.396 if the risk of graft versus host disease.
NOTE Confidence: 0.8944242832

00:32:00.400 --> 00:32:03.513 A very bad transplant complication was
NOTE Confidence: 0.8944242832

00:32:03.513 --> 00:32:06.093 gonna happen more than 10% of the time.
NOTE Confidence: 0.8944242832

00:32:06.093 --> 00:32:07.719 And then when adults with sickle
NOTE Confidence: 0.8944242832

00:32:07.719 --> 00:32:09.384 cell were asked what would you
NOTE Confidence: 0.8944242832

00:32:09.384 --> 00:32:11.599 be willing to trade off for a
NOTE Confidence: 0.8944242832

00:32:11.599 --> 00:32:12.838 potentially curative transplant,
NOTE Confidence: 0.8944242832

00:32:12.840 --> 00:32:14.991 nearly two out of three would do so if
NOTE Confidence: 0.8944242832

00:32:14.991 --> 00:32:17.276 the risk of mortality was more than 5%.
NOTE Confidence: 0.8944242832

00:32:17.280 --> 00:32:19.296 And more than 10% of the adults

NOTE Confidence: 0.8944242832
00:32:19.296 --> 00:32:21.246 with sickle cell would proceed with
NOTE Confidence: 0.8944242832
00:32:21.246 --> 00:32:23.298 a curative transplant even if the
NOTE Confidence: 0.8944242832
00:32:23.298 --> 00:32:25.320 risk of dying was more than 40%.
NOTE Confidence: 0.8944242832
00:32:25.320 --> 00:32:26.916 So when I see this data,
NOTE Confidence: 0.8944242832
00:32:26.920 --> 00:32:29.167 the first thing that comes to mind
NOTE Confidence: 0.8944242832
00:32:29.167 --> 00:32:31.320 is sickle cell is a bad disease.
NOTE Confidence: 0.8944242832
00:32:31.320 --> 00:32:33.308 But the other thing that I think
NOTE Confidence: 0.8944242832
00:32:33.308 --> 00:32:35.704 about is what are patients and
NOTE Confidence: 0.8944242832
00:32:35.704 --> 00:32:37.528 families hearing about these
NOTE Confidence: 0.8944242832
00:32:37.528 --> 00:32:39.350 potentially curative therapies that
NOTE Confidence: 0.8944242832
00:32:39.350 --> 00:32:41.858 may explain their reasons and their
NOTE Confidence: 0.8944242832
00:32:41.858 --> 00:32:43.920 willingness to accept such risks.
NOTE Confidence: 0.8944242832
00:32:43.920 --> 00:32:46.152 And this is a just published
NOTE Confidence: 0.8944242832
00:32:46.152 --> 00:32:48.600 study from December of 2023 that
NOTE Confidence: 0.8944242832
00:32:48.600 --> 00:32:51.000 asked the exact same question,
NOTE Confidence: 0.8944242832

00:32:51.000 --> 00:32:53.597 not about transplant but about gene therapy.

NOTE Confidence: 0.8944242832

00:32:53.600 --> 00:32:55.350 The researcher asked adults with

NOTE Confidence: 0.8944242832

00:32:55.350 --> 00:32:57.752 sickle cell and parents of kids with

NOTE Confidence: 0.8944242832

00:32:57.752 --> 00:32:59.824 sickle cell what would you be willing

NOTE Confidence: 0.8944242832

00:32:59.824 --> 00:33:03.185 to trade off in in exchange for a

NOTE Confidence: 0.8944242832

00:33:03.185 --> 00:33:05.157 potentially curative gene therapy,

NOTE Confidence: 0.8944242832

00:33:05.160 --> 00:33:07.254 and the authors concluded that both

NOTE Confidence: 0.8944242832

00:33:07.254 --> 00:33:09.403 of those groups view gene therapy

NOTE Confidence: 0.8944242832

00:33:09.403 --> 00:33:11.118 as acceptable and they thought

NOTE Confidence: 0.8944242832

00:33:11.118 --> 00:33:12.959 there was a good option.

NOTE Confidence: 0.8944242832

00:33:12.960 --> 00:33:15.040 They also found that patients

NOTE Confidence: 0.8944242832

00:33:15.040 --> 00:33:17.120 with more severe disease were

NOTE Confidence: 0.8944242832

00:33:17.193 --> 00:33:19.168 actually more accepting and were

NOTE Confidence: 0.8944242832

00:33:19.168 --> 00:33:21.920 willing to have less of a benefit.

NOTE Confidence: 0.8944242832

00:33:21.920 --> 00:33:22.880 They also found,

NOTE Confidence: 0.8944242832

00:33:22.880 --> 00:33:24.160 which was really interesting,

NOTE Confidence: 0.8944242832

00:33:24.160 --> 00:33:27.135 that parents more than adults with sickle

NOTE Confidence: 0.8944242832

00:33:27.135 --> 00:33:29.744 cell had a much higher level of risk

NOTE Confidence: 0.8944242832

00:33:29.744 --> 00:33:31.757 tolerance and that they were willing

NOTE Confidence: 0.8944242832

00:33:31.757 --> 00:33:34.116 to accept less than the adults were.

NOTE Confidence: 0.8944242832

00:33:34.120 --> 00:33:36.436 And the author surmised that one

NOTE Confidence: 0.8944242832

00:33:36.436 --> 00:33:38.403 of the contributing factors for

NOTE Confidence: 0.8944242832

00:33:38.403 --> 00:33:40.527 this maybe for this high risk

NOTE Confidence: 0.8944242832

00:33:40.527 --> 00:33:42.451 tolerance maybe media attention that

NOTE Confidence: 0.8944242832

00:33:42.451 --> 00:33:44.742 triggered some form of of hope.

NOTE Confidence: 0.8944242832

00:33:44.742 --> 00:33:47.550 And I'm gonna come back to this study

NOTE Confidence: 0.8944242832

00:33:47.626 --> 00:33:49.604 a little bit later because there's

NOTE Confidence: 0.8944242832

00:33:49.604 --> 00:33:51.114 some concerns with its design,

NOTE Confidence: 0.8944242832

00:33:51.120 --> 00:33:54.756 I think, and and its findings.

NOTE Confidence: 0.8944242832

00:33:54.760 --> 00:33:56.536 A few slides back I mentioned that hope

NOTE Confidence: 0.8944242832

00:33:56.536 --> 00:33:58.279 and hype are both four letter words.

NOTE Confidence: 0.8944242832

00:33:58.280 --> 00:34:00.093 And here are a few examples of
NOTE Confidence: 0.8944242832

00:34:00.093 --> 00:34:02.526 how the two are portrayed in lay
NOTE Confidence: 0.8944242832

00:34:02.526 --> 00:34:03.717 in academic communities.
NOTE Confidence: 0.8944242832

00:34:03.720 --> 00:34:05.064 In 2016, Eric Lander,
NOTE Confidence: 0.8944242832

00:34:05.064 --> 00:34:06.744 founding director of the Broad
NOTE Confidence: 0.8944242832

00:34:06.744 --> 00:34:08.498 Institute of MIT and Harvard penned
NOTE Confidence: 0.8944242832

00:34:08.498 --> 00:34:10.240 this op-ed in the Boston Globe.
NOTE Confidence: 0.8944242832

00:34:10.240 --> 00:34:12.718 And what did Lander have to say?
NOTE Confidence: 0.8944242832

00:34:12.720 --> 00:34:13.360 The Hope,
NOTE Confidence: 0.8944242832

00:34:13.360 --> 00:34:14.960 hype contradiction highlights a thorny
NOTE Confidence: 0.8944242832

00:34:14.960 --> 00:34:16.745 challenge in the ongoing conversation
NOTE Confidence: 0.8944242832

00:34:16.745 --> 00:34:18.680 between scientists and the public.
NOTE Confidence: 0.9464047444444444

00:34:20.760 --> 00:34:21.666 What about hype?
NOTE Confidence: 0.9464047444444444

00:34:21.666 --> 00:34:23.478 Well, here's one definition of hype,
NOTE Confidence: 0.9464047444444444

00:34:23.480 --> 00:34:25.124 and for our purpose,
NOTE Confidence: 0.9464047444444444

00:34:25.124 --> 00:34:27.590 I'll qualify this as public exaggeration

NOTE Confidence: 0.946404744444444

00:34:27.662 --> 00:34:30.356 about the expected benefits of research.

NOTE Confidence: 0.946404744444444

00:34:30.360 --> 00:34:32.558 And because hype can impair decision making,

NOTE Confidence: 0.946404744444444

00:34:32.560 --> 00:34:34.336 it's worth, I think,

NOTE Confidence: 0.946404744444444

00:34:34.336 --> 00:34:38.160 talking a little bit about excuse me.

NOTE Confidence: 0.946404744444444

00:34:38.160 --> 00:34:40.599 So what I'd like to do is show you

NOTE Confidence: 0.946404744444444

00:34:40.599 --> 00:34:43.475 some examples now about how medical

NOTE Confidence: 0.946404744444444

00:34:43.475 --> 00:34:45.503 breakthroughs in research that's

NOTE Confidence: 0.946404744444444

00:34:45.503 --> 00:34:47.958 promising are portrayed in the media.

NOTE Confidence: 0.946404744444444

00:34:47.960 --> 00:34:48.880 From the New York Times,

NOTE Confidence: 0.946404744444444

00:34:48.880 --> 00:34:50.960 Hype springs eternal in medicine,

NOTE Confidence: 0.946404744444444

00:34:50.960 --> 00:34:53.564 and you can't imagine what you're

NOTE Confidence: 0.946404744444444

00:34:53.564 --> 00:34:56.560 gonna see over the next 30 years.

NOTE Confidence: 0.946404744444444

00:34:56.560 --> 00:34:57.673 Confronted with devastating

NOTE Confidence: 0.946404744444444

00:34:57.673 --> 00:34:59.157 diseases like sickle cell,

NOTE Confidence: 0.946404744444444

00:34:59.160 --> 00:35:01.180 it's not hard to see why so many of us

NOTE Confidence: 0.946404744444444

00:35:01.240 --> 00:35:03.320 really want to believe in a better way.
NOTE Confidence: 0.9464047444444444

00:35:03.320 --> 00:35:05.370 And this following example really
NOTE Confidence: 0.9464047444444444

00:35:05.370 --> 00:35:08.040 illustrates the line between hope and hype.
NOTE Confidence: 0.9464047444444444

00:35:08.040 --> 00:35:09.440 When this story aired,
NOTE Confidence: 0.9464047444444444

00:35:09.440 --> 00:35:11.540 some patients with sickle cell feared
NOTE Confidence: 0.9464047444444444

00:35:11.606 --> 00:35:13.692 that they were trading their sickle cell
NOTE Confidence: 0.9464047444444444

00:35:13.692 --> 00:35:16.398 for HIV in order to get the gene therapy.
NOTE Confidence: 0.9464047444444444

00:35:16.400 --> 00:35:18.440 So what does this say about
NOTE Confidence: 0.9464047444444444

00:35:18.440 --> 00:35:19.800 how information is presented,
NOTE Confidence: 0.9464047444444444

00:35:19.800 --> 00:35:20.720 Explained, perceived?
NOTE Confidence: 0.9464047444444444

00:35:20.720 --> 00:35:23.020 Being thoughtful and being careful
NOTE Confidence: 0.9464047444444444

00:35:23.020 --> 00:35:25.009 with words applies equally to
NOTE Confidence: 0.9464047444444444

00:35:25.009 --> 00:35:26.913 every one of us in this room,
NOTE Confidence: 0.9464047444444444

00:35:26.920 --> 00:35:30.035 but also to our health journalist colleagues.
NOTE Confidence: 0.9464047444444444

00:35:30.040 --> 00:35:32.700 We all have to communicate responsibly and
NOTE Confidence: 0.9464047444444444

00:35:32.700 --> 00:35:34.640 clearly about treatments without bias,

NOTE Confidence: 0.9464047444444444
00:35:34.640 --> 00:35:37.920 even if it risks a less sexy headline.
NOTE Confidence: 0.9464047444444444
00:35:37.920 --> 00:35:40.068 And this is a really interesting
NOTE Confidence: 0.9464047444444444
00:35:40.068 --> 00:35:42.340 article by Mandy Young and Craig
NOTE Confidence: 0.9464047444444444
00:35:42.340 --> 00:35:44.644 Stewart that from a social science
NOTE Confidence: 0.9464047444444444
00:35:44.644 --> 00:35:46.761 perspective is looking at that whole
NOTE Confidence: 0.9464047444444444
00:35:46.761 --> 00:35:49.143 60 minute story and how the mental
NOTE Confidence: 0.9464047444444444
00:35:49.143 --> 00:35:52.384 models of patients with sickle cell were
NOTE Confidence: 0.9464047444444444
00:35:52.384 --> 00:35:54.996 influenced by what they saw compared
NOTE Confidence: 0.9464047444444444
00:35:54.996 --> 00:35:58.399 to those people who don't have sickle cell.
NOTE Confidence: 0.9464047444444444
00:35:58.400 --> 00:36:00.632 This is a screenshot taken from a talk
NOTE Confidence: 0.9464047444444444
00:36:00.632 --> 00:36:02.897 given by Melissa Creary back in 2021.
NOTE Confidence: 0.9464047444444444
00:36:02.897 --> 00:36:05.256 Melissa is a sickle cell researcher at
NOTE Confidence: 0.9464047444444444
00:36:05.256 --> 00:36:07.422 University of Michigan and you can see
NOTE Confidence: 0.9464047444444444
00:36:07.422 --> 00:36:09.800 what this doctor said at the time of
NOTE Confidence: 0.9464047444444444
00:36:09.800 --> 00:36:11.879 the gene therapy trials in sickle cell.
NOTE Confidence: 0.9464047444444444

00:36:11.880 --> 00:36:14.704 It would just open the door of hope
NOTE Confidence: 0.9464047444444444

00:36:14.704 --> 00:36:17.560 for these patients in November of 2021.
NOTE Confidence: 0.9464047444444444

00:36:17.560 --> 00:36:19.000 Again from the Times,
NOTE Confidence: 0.9464047444444444

00:36:19.000 --> 00:36:21.639 sickle cell is cure at a hand.
NOTE Confidence: 0.9464047444444444

00:36:21.640 --> 00:36:23.615 The same time November 2021
NOTE Confidence: 0.9464047444444444

00:36:23.615 --> 00:36:24.800 in Scientific American,
NOTE Confidence: 0.9464047444444444

00:36:24.800 --> 00:36:27.998 4 success stories in gene therapy.
NOTE Confidence: 0.9464047444444444

00:36:28.000 --> 00:36:30.254 March of 2022 in The New Yorker
NOTE Confidence: 0.9464047444444444

00:36:30.254 --> 00:36:32.759 Are we about to cure sickle cell?
NOTE Confidence: 0.9464047444444444

00:36:32.760 --> 00:36:34.616 And then just so you don't think that
NOTE Confidence: 0.9464047444444444

00:36:34.616 --> 00:36:36.678 this is isolated to the popular media,
NOTE Confidence: 0.9464047444444444

00:36:36.680 --> 00:36:38.720 take a look at some of our journals.
NOTE Confidence: 0.9464047444444444

00:36:38.720 --> 00:36:39.514 Gene therapy,
NOTE Confidence: 0.9464047444444444

00:36:39.514 --> 00:36:41.499 the Ultimate Cure for Hereditary
NOTE Confidence: 0.9464047444444444

00:36:41.499 --> 00:36:44.000 Diseases and From Catastrophe to cure.
NOTE Confidence: 0.9464047444444444

00:36:44.000 --> 00:36:45.080 In 20 years,

NOTE Confidence: 0.813758086

00:36:47.200 --> 00:36:49.200 as positive trial data emerged,

NOTE Confidence: 0.813758086

00:36:49.200 --> 00:36:51.363 we saw even greater use of four

NOTE Confidence: 0.813758086

00:36:51.363 --> 00:36:53.158 letter words including hope and cure.

NOTE Confidence: 0.813758086

00:36:53.160 --> 00:36:54.900 Take a look at what Doctor

NOTE Confidence: 0.813758086

00:36:54.900 --> 00:36:58.400 Tisdale from NHLBI had to say.

NOTE Confidence: 0.813758086

00:36:58.400 --> 00:36:59.800 And then as many of us know,

NOTE Confidence: 0.813758086

00:36:59.800 --> 00:37:01.516 on December 8th of last year,

NOTE Confidence: 0.813758086

00:37:01.520 --> 00:37:03.776 the FDA approved these two gene

NOTE Confidence: 0.813758086

00:37:03.776 --> 00:37:05.280 therapies for sickle cell.

NOTE Confidence: 0.813758086

00:37:05.280 --> 00:37:07.314 And this quotation from Gina Colada

NOTE Confidence: 0.813758086

00:37:07.314 --> 00:37:09.280 and the Times really captures,

NOTE Confidence: 0.813758086

00:37:09.280 --> 00:37:11.206 I think the challenges that are

NOTE Confidence: 0.813758086

00:37:11.206 --> 00:37:12.934 associated with these new promising

NOTE Confidence: 0.813758086

00:37:12.934 --> 00:37:14.849 treatments and hopeful parents and

NOTE Confidence: 0.813758086

00:37:14.849 --> 00:37:17.072 clinicians are going to be constrained

NOTE Confidence: 0.813758086

00:37:17.072 --> 00:37:18.962 by the limited number of centers
NOTE Confidence: 0.813758086

00:37:18.962 --> 00:37:21.178 that can offer this treatment.
NOTE Confidence: 0.813758086

00:37:21.178 --> 00:37:24.165 Experts estimate that no more than 10 a
NOTE Confidence: 0.813758086

00:37:24.165 --> 00:37:26.837 year are going to be able to be done.
NOTE Confidence: 0.813758086

00:37:26.840 --> 00:37:28.688 And so with not enough product
NOTE Confidence: 0.813758086

00:37:28.688 --> 00:37:29.920 to serve all patients,
NOTE Confidence: 0.813758086

00:37:29.920 --> 00:37:32.356 the needed expertise and the high cost,
NOTE Confidence: 0.813758086

00:37:32.360 --> 00:37:34.280 how centers allocate this scarce
NOTE Confidence: 0.813758086

00:37:34.280 --> 00:37:36.200 resource is a real dilemma.
NOTE Confidence: 0.813758086

00:37:36.200 --> 00:37:37.964 And right now there is no uniform
NOTE Confidence: 0.813758086

00:37:37.964 --> 00:37:39.237 approach and centers are making
NOTE Confidence: 0.813758086

00:37:39.237 --> 00:37:40.635 it up as they're going along.
NOTE Confidence: 0.813758086

00:37:40.640 --> 00:37:41.561 So for example,
NOTE Confidence: 0.813758086

00:37:41.561 --> 00:37:43.710 CHOP has said they plan on doing
NOTE Confidence: 0.813758086

00:37:43.781 --> 00:37:45.635 gene therapy on a first come,
NOTE Confidence: 0.813758086

00:37:45.640 --> 00:37:46.462 first serve basis.

NOTE Confidence: 0.813758086

00:37:46.462 --> 00:37:47.832 And Children's National has said

NOTE Confidence: 0.813758086

00:37:47.832 --> 00:37:49.437 they're going to do the sickest first.

NOTE Confidence: 0.813758086

00:37:49.440 --> 00:37:51.066 And some folks in Boston say

NOTE Confidence: 0.813758086

00:37:51.066 --> 00:37:52.950 you know what we're going to do

NOTE Confidence: 0.813758086

00:37:52.950 --> 00:37:54.686 this piece meal one patient at a

NOTE Confidence: 0.813758086

00:37:54.746 --> 00:37:56.438 time to work out the wrinkles.

NOTE Confidence: 0.813758086

00:37:56.440 --> 00:37:58.420 And so it seems like national

NOTE Confidence: 0.813758086

00:37:58.420 --> 00:38:01.006 guidance or at least some kind of

NOTE Confidence: 0.813758086

00:38:01.006 --> 00:38:02.931 clinical criteria are needed for

NOTE Confidence: 0.813758086

00:38:02.931 --> 00:38:05.570 figuring out how to proceed with gene

NOTE Confidence: 0.813758086

00:38:05.651 --> 00:38:07.438 therapy and then hot off the presses.

NOTE Confidence: 0.813758086

00:38:07.440 --> 00:38:09.996 Some of you may have seen the story just

NOTE Confidence: 0.813758086

00:38:09.996 --> 00:38:12.556 last week and this was the first patient,

NOTE Confidence: 0.813758086

00:38:12.560 --> 00:38:14.492 a 12 year old boy at Children's

NOTE Confidence: 0.813758086

00:38:14.492 --> 00:38:16.684 National in DC who is getting the

NOTE Confidence: 0.813758086

00:38:16.684 --> 00:38:18.304 approved now no longer research
NOTE Confidence: 0.813758086

00:38:18.304 --> 00:38:20.756 but approved gene therapy and the
NOTE Confidence: 0.813758086

00:38:20.756 --> 00:38:22.746 challenges of allocation of this
NOTE Confidence: 0.813758086

00:38:22.746 --> 00:38:24.769 expensive and sought after treatment
NOTE Confidence: 0.813758086

00:38:24.769 --> 00:38:27.083 were covered in the story Children's
NOTE Confidence: 0.813758086

00:38:27.083 --> 00:38:29.098 National David Jacobson who heads
NOTE Confidence: 0.813758086

00:38:29.098 --> 00:38:31.285 up BMT and cellular Therapeutics
NOTE Confidence: 0.813758086

00:38:31.285 --> 00:38:33.283 stated exactly what the expert said.
NOTE Confidence: 0.813758086

00:38:33.283 --> 00:38:34.589 We're not going to be able to do
NOTE Confidence: 0.813758086

00:38:34.589 --> 00:38:35.597 more than ten of these a year,
NOTE Confidence: 0.813758086

00:38:35.600 --> 00:38:37.888 but there's a long list of people who
NOTE Confidence: 0.813758086

00:38:37.888 --> 00:38:39.699 are waiting to for these treatments.
NOTE Confidence: 0.813758086

00:38:39.699 --> 00:38:42.626 And David also noted that our MO is
NOTE Confidence: 0.813758086

00:38:42.626 --> 00:38:45.314 we're going to prioritize the sickest first,
NOTE Confidence: 0.813758086

00:38:45.320 --> 00:38:47.085 but insurance payment comes into
NOTE Confidence: 0.813758086

00:38:47.085 --> 00:38:49.642 this and so we have the situation

NOTE Confidence: 0.813758086

00:38:49.642 --> 00:38:51.437 of have and have not.

NOTE Confidence: 0.813758086

00:38:51.440 --> 00:38:53.757 There can be a very sick kid

NOTE Confidence: 0.813758086

00:38:53.760 --> 00:38:55.200 but his insurance company is not

NOTE Confidence: 0.813758086

00:38:55.200 --> 00:38:56.440 willing to foot the bill.

NOTE Confidence: 0.813758086

00:38:56.440 --> 00:38:59.040 And so that kid may get pushed to

NOTE Confidence: 0.813758086

00:38:59.040 --> 00:39:01.820 somebody who may not be as sick but whose

NOTE Confidence: 0.813758086

00:39:01.820 --> 00:39:04.160 insurance company is willing to pay.

NOTE Confidence: 0.813758086

00:39:04.160 --> 00:39:06.392 And in this story there's a

NOTE Confidence: 0.813758086

00:39:06.392 --> 00:39:08.280 subheading called chances and hope.

NOTE Confidence: 0.813758086

00:39:08.280 --> 00:39:09.920 And these are the parents of this young

NOTE Confidence: 0.813758086

00:39:09.920 --> 00:39:11.555 boy and you can see what they said.

NOTE Confidence: 0.813758086

00:39:11.560 --> 00:39:13.835 They were very hopeful for gene therapy,

NOTE Confidence: 0.813758086

00:39:13.840 --> 00:39:15.716 but when they found out the cost,

NOTE Confidence: 0.813758086

00:39:15.720 --> 00:39:17.676 they lost some of their hope.

NOTE Confidence: 0.813758086

00:39:17.680 --> 00:39:18.248 And this,

NOTE Confidence: 0.813758086

00:39:18.248 --> 00:39:19.952 I think is a really telling
NOTE Confidence: 0.813758086

00:39:19.952 --> 00:39:21.239 statement from the parents.
NOTE Confidence: 0.813758086

00:39:21.240 --> 00:39:22.860 We're nervous reading through the consents
NOTE Confidence: 0.813758086

00:39:22.860 --> 00:39:24.598 and what he'll have to go through.
NOTE Confidence: 0.813758086

00:39:24.600 --> 00:39:25.620 And for obvious reasons,
NOTE Confidence: 0.813758086

00:39:25.620 --> 00:39:27.150 which wasn't the focus of the
NOTE Confidence: 0.971455130909091

00:39:27.197 --> 00:39:28.320 story, they didn't go into that.
NOTE Confidence: 0.971455130909091

00:39:28.320 --> 00:39:30.198 But you have to get chemotherapy
NOTE Confidence: 0.971455130909091

00:39:30.198 --> 00:39:32.000 before you get gene therapy.
NOTE Confidence: 0.971455130909091

00:39:32.000 --> 00:39:33.448 And so it would be nice to know
NOTE Confidence: 0.971455130909091

00:39:33.448 --> 00:39:34.759 a little bit more about this.
NOTE Confidence: 0.971455130909091

00:39:34.760 --> 00:39:36.800 And then four letter words again,
NOTE Confidence: 0.971455130909091

00:39:36.800 --> 00:39:38.198 this is from the boy himself.
NOTE Confidence: 0.971455130909091

00:39:38.200 --> 00:39:39.640 He wants to be cured,
NOTE Confidence: 0.971455130909091

00:39:39.640 --> 00:39:41.158 wants to play basketball, he said.
NOTE Confidence: 0.971455130909091

00:39:41.160 --> 00:39:42.080 Understandable.

NOTE Confidence: 0.693563905625

00:39:44.120 --> 00:39:45.760 This is to remind me to drink all the

NOTE Confidence: 0.6508648825

00:39:48.600 --> 00:39:50.040 all right. Doing all right with the jacket,

NOTE Confidence: 0.6508648825

00:39:50.040 --> 00:39:51.510 huh? Looks really good.

NOTE Confidence: 0.6508648825

00:39:51.510 --> 00:39:53.986 Just remember when my mom finds you.

NOTE Confidence: 0.6508648825

00:39:53.986 --> 00:39:57.320 All right? So with all the focus and

NOTE Confidence: 0.6508648825

00:39:57.320 --> 00:39:59.528 talk about cure, maybe it would be

NOTE Confidence: 0.6508648825

00:39:59.528 --> 00:40:01.040 helpful if we actually define it.

NOTE Confidence: 0.6508648825

00:40:01.040 --> 00:40:02.560 And as you can see,

NOTE Confidence: 0.6508648825

00:40:02.560 --> 00:40:05.598 there's more than one definition of cure.

NOTE Confidence: 0.6508648825

00:40:05.600 --> 00:40:07.484 And I would tell you that

NOTE Confidence: 0.6508648825

00:40:07.484 --> 00:40:09.120 really when talking about cure,

NOTE Confidence: 0.6508648825

00:40:09.120 --> 00:40:10.155 perspective is important.

NOTE Confidence: 0.6508648825

00:40:10.155 --> 00:40:13.040 For a person who's stranded on an island,

NOTE Confidence: 0.6508648825

00:40:13.040 --> 00:40:15.154 that boat on the horizon is salvation.

NOTE Confidence: 0.6508648825

00:40:15.160 --> 00:40:17.080 But for that person who's on the boat,

NOTE Confidence: 0.6508648825

00:40:17.080 --> 00:40:18.496 that island is salvation.
NOTE Confidence: 0.6508648825

00:40:18.496 --> 00:40:21.136 And so the BMT or cellular physician
NOTE Confidence: 0.6508648825

00:40:21.136 --> 00:40:23.351 would probably define cure as
NOTE Confidence: 0.6508648825

00:40:23.351 --> 00:40:25.570 persistence of that novel hemoglobin
NOTE Confidence: 0.6508648825

00:40:25.570 --> 00:40:28.594 and a lack of Graf versus host disease.
NOTE Confidence: 0.6508648825

00:40:28.600 --> 00:40:29.998 The hematologist, on the other hand,
NOTE Confidence: 0.6508648825

00:40:30.000 --> 00:40:30.800 would say no, no, no,
NOTE Confidence: 0.6508648825

00:40:30.800 --> 00:40:32.360 that's not how we define cure.
NOTE Confidence: 0.6508648825

00:40:32.360 --> 00:40:35.192 We define cure based on no need for
NOTE Confidence: 0.6508648825

00:40:35.192 --> 00:40:37.004 disease modifying treatments like
NOTE Confidence: 0.6508648825

00:40:37.004 --> 00:40:39.248 hydroxyurea and packed red blood cell
NOTE Confidence: 0.6508648825

00:40:39.248 --> 00:40:40.758 transfusions and patients and families
NOTE Confidence: 0.6508648825

00:40:40.758 --> 00:40:42.758 are probably saying you guys are crazy.
NOTE Confidence: 0.6508648825

00:40:42.760 --> 00:40:44.680 That's not how we define cure.
NOTE Confidence: 0.6508648825

00:40:44.680 --> 00:40:47.214 We probably would think that patients and
NOTE Confidence: 0.6508648825

00:40:47.214 --> 00:40:49.454 families define cure as resolution of

NOTE Confidence: 0.6508648825

00:40:49.454 --> 00:40:51.632 pain and restoration of organ function.

NOTE Confidence: 0.6508648825

00:40:51.640 --> 00:40:53.355 And so before we talk about cure,

NOTE Confidence: 0.6508648825

00:40:53.360 --> 00:40:55.000 maybe like this cartoon suggests,

NOTE Confidence: 0.6508648825

00:40:55.000 --> 00:40:57.408 we need to put ourselves in each other's

NOTE Confidence: 0.6508648825

00:40:57.408 --> 00:40:59.398 shoes and agree on a definition.

NOTE Confidence: 0.6508648825

00:40:59.400 --> 00:41:00.876 And just so you think that,

NOTE Confidence: 0.6508648825

00:41:00.880 --> 00:41:02.638 and I am biased towards hematology,

NOTE Confidence: 0.6508648825

00:41:02.640 --> 00:41:03.940 oncology 'cause it's the coolest

NOTE Confidence: 0.6508648825

00:41:03.940 --> 00:41:04.720 thing out there,

NOTE Confidence: 0.6508648825

00:41:04.720 --> 00:41:07.198 but this isn't just impedes HEMONT.

NOTE Confidence: 0.6508648825

00:41:07.200 --> 00:41:08.880 This is an article that was

NOTE Confidence: 0.6508648825

00:41:08.880 --> 00:41:10.280 just released two days ago.

NOTE Confidence: 0.6508648825

00:41:10.280 --> 00:41:13.584 And these are all the various FDA and

NOTE Confidence: 0.6508648825

00:41:13.584 --> 00:41:15.489 European Medical Association approved

NOTE Confidence: 0.6508648825

00:41:15.489 --> 00:41:19.299 gene therapies for kids as of December 2023.

NOTE Confidence: 0.6508648825

00:41:19.299 --> 00:41:21.392 And you can see this is across
NOTE Confidence: 0.6508648825

00:41:21.392 --> 00:41:22.800 disciplines and and diseases.
NOTE Confidence: 0.6508648825

00:41:22.800 --> 00:41:23.948 And in this article,
NOTE Confidence: 0.6508648825

00:41:23.948 --> 00:41:25.670 the authors note that right now
NOTE Confidence: 0.6508648825

00:41:25.734 --> 00:41:27.594 there's more than 40 gene therapy
NOTE Confidence: 0.6508648825

00:41:27.594 --> 00:41:29.538 products on the market and dozens
NOTE Confidence: 0.6508648825

00:41:29.538 --> 00:41:31.158 and dozens in clinical trials.
NOTE Confidence: 0.6508648825

00:41:31.160 --> 00:41:34.456 And so gene therapy is very sexy.
NOTE Confidence: 0.6508648825

00:41:34.456 --> 00:41:35.996 It's also a big business.
NOTE Confidence: 0.6508648825

00:41:36.000 --> 00:41:38.600 And this certainly is true for sickle cell.
NOTE Confidence: 0.6508648825

00:41:38.600 --> 00:41:40.602 And I want to thank my colleague
NOTE Confidence: 0.6508648825

00:41:40.602 --> 00:41:42.136 Akshay Sharma at Saint Jude
NOTE Confidence: 0.6508648825

00:41:42.136 --> 00:41:43.676 for lending me this slide.
NOTE Confidence: 0.6508648825

00:41:43.680 --> 00:41:46.520 And what Akshay is showing in this slide
NOTE Confidence: 0.6508648825

00:41:46.520 --> 00:41:48.760 is what some of the current efforts
NOTE Confidence: 0.6508648825

00:41:48.760 --> 00:41:51.357 are to find a cure for sickle cell.

NOTE Confidence: 0.6508648825

00:41:51.360 --> 00:41:54.036 And since Akshay produced this slide,

NOTE Confidence: 0.6508648825

00:41:54.040 --> 00:41:56.875 a number of companies have dropped out,

NOTE Confidence: 0.6508648825

00:41:56.880 --> 00:41:58.020 as you can see.

NOTE Confidence: 0.6508648825

00:41:58.020 --> 00:42:00.240 And they've dropped out for various reasons.

NOTE Confidence: 0.6508648825

00:42:00.240 --> 00:42:00.520 A.

NOTE Confidence: 0.6508648825

00:42:00.520 --> 00:42:01.360 This is hard.

NOTE Confidence: 0.6508648825

00:42:01.360 --> 00:42:03.040 Finding a cure is really hard,

NOTE Confidence: 0.6508648825

00:42:03.040 --> 00:42:05.360 but also it may not be in the

NOTE Confidence: 0.6508648825

00:42:05.360 --> 00:42:07.115 business interest of the company

NOTE Confidence: 0.6508648825

00:42:07.115 --> 00:42:08.595 to pursue these treatments.

NOTE Confidence: 0.8766580075

00:42:11.040 --> 00:42:13.070 Earlier I mentioned that some of the

NOTE Confidence: 0.8766580075

00:42:13.070 --> 00:42:14.600 equity concerns about sickle cell,

NOTE Confidence: 0.8766580075

00:42:14.600 --> 00:42:16.847 especially in the US compared to other

NOTE Confidence: 0.8766580075

00:42:16.847 --> 00:42:19.255 diseases like CF and multiple dystrophy

NOTE Confidence: 0.8766580075

00:42:19.255 --> 00:42:21.555 that primarily affect white populations,

NOTE Confidence: 0.8766580075

00:42:21.560 --> 00:42:24.480 gene therapies are really expensive.
NOTE Confidence: 0.8766580075

00:42:24.480 --> 00:42:27.080 CRISPR and Vertex's gene therapy
NOTE Confidence: 0.8766580075

00:42:27.080 --> 00:42:29.320 \$2.2 million for one treatment,
NOTE Confidence: 0.8766580075

00:42:29.320 --> 00:42:33.280 Bluebirds \$3.1 million for one treatment.
NOTE Confidence: 0.8766580075

00:42:33.280 --> 00:42:36.164 These make them among the most costly
NOTE Confidence: 0.8766580075

00:42:36.164 --> 00:42:38.050 drugs out there, or treatments,
NOTE Confidence: 0.8766580075

00:42:38.050 --> 00:42:40.000 how everyone wants to call it.
NOTE Confidence: 0.8766580075

00:42:40.000 --> 00:42:43.848 So in high income countries paying for these
NOTE Confidence: 0.8766580075

00:42:43.848 --> 00:42:47.125 therapies is really challenging and it
NOTE Confidence: 0.8766580075

00:42:47.125 --> 00:42:49.315 raises all sorts of policy considerations.
NOTE Confidence: 0.8766580075

00:42:49.320 --> 00:42:52.855 But in middle and low income countries
NOTE Confidence: 0.8766580075

00:42:52.855 --> 00:42:55.824 where 60% of the world's 120 million people
NOTE Confidence: 0.8766580075

00:42:55.824 --> 00:42:59.960 with sickle cell live, it's impossible.
NOTE Confidence: 0.8766580075

00:42:59.960 --> 00:43:04.396 And we have to also think what happens if
NOTE Confidence: 0.8766580075

00:43:04.396 --> 00:43:07.000 this treatment of the gene therapy works,
NOTE Confidence: 0.8766580075

00:43:07.000 --> 00:43:09.280 but you need a second treatment

NOTE Confidence: 0.8766580075

00:43:09.280 --> 00:43:10.280 10 years down the road?

NOTE Confidence: 0.8766580075

00:43:10.280 --> 00:43:11.280 15 years down the road?

NOTE Confidence: 0.8766580075

00:43:11.280 --> 00:43:13.520 Are insurance companies going to cover it?

NOTE Confidence: 0.8766580075

00:43:13.520 --> 00:43:15.992 Keep in mind that the average cost over

NOTE Confidence: 0.8766580075

00:43:15.992 --> 00:43:17.976 the lifespan of a person with sickle

NOTE Confidence: 0.8766580075

00:43:17.976 --> 00:43:22.039 cell in the US \$1.7 million and that the

NOTE Confidence: 0.8766580075

00:43:22.039 --> 00:43:24.277 US healthcare system spends \$3 billion

NOTE Confidence: 0.8766580075

00:43:24.280 --> 00:43:27.360 a year on sickle cell related costs.

NOTE Confidence: 0.8766580075

00:43:27.360 --> 00:43:29.194 And so now maybe if you're the

NOTE Confidence: 0.8766580075

00:43:29.200 --> 00:43:30.600 drug company that's making these,

NOTE Confidence: 0.8766580075

00:43:30.600 --> 00:43:31.092 you're you're,

NOTE Confidence: 0.8766580075

00:43:31.092 --> 00:43:33.060 you know not so far off in in

NOTE Confidence: 0.8766580075

00:43:33.125 --> 00:43:34.637 charging these high prices.

NOTE Confidence: 0.8766580075

00:43:34.640 --> 00:43:36.936 So a lot of questions here about

NOTE Confidence: 0.8766580075

00:43:36.936 --> 00:43:39.292 access and equity when we're thinking

NOTE Confidence: 0.8766580075

00:43:39.292 --> 00:43:41.457 about these these costly treatments
NOTE Confidence: 0.8766580075

00:43:41.457 --> 00:43:44.238 and here's one example that CMS is
NOTE Confidence: 0.8766580075

00:43:44.238 --> 00:43:46.078 trying to implement for patients
NOTE Confidence: 0.8766580075

00:43:46.080 --> 00:43:47.872 with sickle silhouette Medicaid.
NOTE Confidence: 0.8766580075

00:43:47.872 --> 00:43:50.560 And essentially what CMS is trying
NOTE Confidence: 0.8766580075

00:43:50.627 --> 00:43:53.139 to do is saying on a voluntary basis
NOTE Confidence: 0.8766580075

00:43:53.139 --> 00:43:55.212 states can partner with us and
NOTE Confidence: 0.8766580075

00:43:55.212 --> 00:43:57.072 based on outcomes associated with
NOTE Confidence: 0.8766580075

00:43:57.072 --> 00:43:59.399 the gene therapy for sickle cell,
NOTE Confidence: 0.8766580075

00:43:59.400 --> 00:44:01.955 we will offset some of the cost.
NOTE Confidence: 0.8766580075

00:44:01.960 --> 00:44:04.440 But these are voluntary and it's early days,
NOTE Confidence: 0.8766580075

00:44:04.440 --> 00:44:07.248 but this is some of the thinking that's
NOTE Confidence: 0.8766580075

00:44:07.248 --> 00:44:09.440 happening because again 2.2 million,
NOTE Confidence: 0.8766580075

00:44:09.440 --> 00:44:10.560 three-point 1,000,000,
NOTE Confidence: 0.8766580075

00:44:10.560 --> 00:44:13.920 I mean these are astronomical costs.
NOTE Confidence: 0.8766580075

00:44:13.920 --> 00:44:14.860 So hopefully I've been able

NOTE Confidence: 0.8766580075

00:44:14.860 --> 00:44:15.800 to convince you that hope,

NOTE Confidence: 0.8766580075

00:44:15.800 --> 00:44:16.137 hype,

NOTE Confidence: 0.8766580075

00:44:16.137 --> 00:44:18.972 and cure exist on a continuum and the

NOTE Confidence: 0.8766580075

00:44:18.972 --> 00:44:21.408 three really influence one another and

NOTE Confidence: 0.8766580075

00:44:21.408 --> 00:44:23.557 our understanding of what these means.

NOTE Confidence: 0.8766580075

00:44:23.560 --> 00:44:26.836 And the world uses hope as a marketing tool.

NOTE Confidence: 0.8766580075

00:44:26.840 --> 00:44:29.840 And I am not singling out these excellent,

NOTE Confidence: 0.8766580075

00:44:29.840 --> 00:44:30.718 excellent centers.

NOTE Confidence: 0.8766580075

00:44:30.718 --> 00:44:34.230 I just want to show you how all

NOTE Confidence: 0.8766580075

00:44:34.321 --> 00:44:36.555 of us use these words and what

NOTE Confidence: 0.8766580075

00:44:36.555 --> 00:44:38.795 we're saying to ourselves and what

NOTE Confidence: 0.8766580075

00:44:38.795 --> 00:44:40.680 we're saying to our patients.

NOTE Confidence: 0.8766580075

00:44:40.680 --> 00:44:41.680 At the same time though,

NOTE Confidence: 0.8766580075

00:44:41.680 --> 00:44:43.388 I think we need to be careful

NOTE Confidence: 0.8766580075

00:44:43.388 --> 00:44:44.560 about the words we use,

NOTE Confidence: 0.8766580075

00:44:44.560 --> 00:44:47.000 especially around words like science.
NOTE Confidence: 0.8766580075

00:44:47.000 --> 00:44:48.080 We need to be about clear,
NOTE Confidence: 0.8766580075

00:44:48.080 --> 00:44:49.448 about risks and benefits,
NOTE Confidence: 0.8766580075

00:44:49.448 --> 00:44:52.758 and we need to speak about them in lay terms.
NOTE Confidence: 0.8766580075

00:44:52.760 --> 00:44:54.839 We need to address the emotional risk,
NOTE Confidence: 0.8766580075

00:44:54.840 --> 00:44:56.120 and that doesn't happen enough.
NOTE Confidence: 0.8766580075

00:44:56.120 --> 00:44:59.870 And hope includes real things and
NOTE Confidence: 0.8766580075

00:44:59.870 --> 00:45:02.203 emotional things like Rick Kodish.
NOTE Confidence: 0.8766580075

00:45:02.203 --> 00:45:04.730 My colleague GAIL Geller at the Bioethics
NOTE Confidence: 0.8766580075

00:45:04.793 --> 00:45:07.208 Institute has appreciated that medical
NOTE Confidence: 0.8766580075

00:45:07.208 --> 00:45:09.140 and scientific breakthroughs often
NOTE Confidence: 0.8766580075

00:45:09.140 --> 00:45:11.059 times are understood and translated
NOTE Confidence: 0.8766580075

00:45:11.059 --> 00:45:13.948 and marketed as a hope for a cure.
NOTE Confidence: 0.8766580075

00:45:13.948 --> 00:45:14.776 And understandably,
NOTE Confidence: 0.8766580075

00:45:14.776 --> 00:45:16.846 many patients and families hold
NOTE Confidence: 0.8766580075

00:45:16.846 --> 00:45:18.198 on to this hope,

NOTE Confidence: 0.8766580075

00:45:18.200 --> 00:45:20.636 even when the data suggests otherwise.

NOTE Confidence: 0.8845197675

00:45:20.640 --> 00:45:23.240 And, GAIL says, as you can see here,

NOTE Confidence: 0.8845197675

00:45:23.240 --> 00:45:25.226 the promise of advances in biomedical

NOTE Confidence: 0.8845197675

00:45:25.226 --> 00:45:27.719 research can have a paradoxical effect.

NOTE Confidence: 0.8845197675

00:45:27.720 --> 00:45:29.456 Rather than reducing suffering,

NOTE Confidence: 0.8845197675

00:45:29.456 --> 00:45:32.760 the expectation of cure can be a burden.

NOTE Confidence: 0.8845197675

00:45:32.760 --> 00:45:34.440 And as many of us know

NOTE Confidence: 0.8845197675

00:45:34.440 --> 00:45:35.560 from our clinical lives,

NOTE Confidence: 0.8845197675

00:45:35.560 --> 00:45:38.955 if cure is even remotely a possibility,

NOTE Confidence: 0.8845197675

00:45:38.960 --> 00:45:41.200 some, many, certainly not all.

NOTE Confidence: 0.8845197675

00:45:41.200 --> 00:45:43.330 But at least some patients and

NOTE Confidence: 0.8845197675

00:45:43.330 --> 00:45:45.206 families will push forward despite

NOTE Confidence: 0.8845197675

00:45:45.206 --> 00:45:47.558 the cost on physical and emotional

NOTE Confidence: 0.8845197675

00:45:47.558 --> 00:45:49.799 well-being and their quality of life.

NOTE Confidence: 0.8845197675

00:45:49.800 --> 00:45:52.397 Hope can also be accompanied by anxiety.

NOTE Confidence: 0.8845197675

00:45:52.400 --> 00:45:52.726 Absolutely.
NOTE Confidence: 0.8845197675

00:45:52.726 --> 00:45:54.030 Patients are hopeful that
NOTE Confidence: 0.8845197675

00:45:54.030 --> 00:45:55.660 they're gonna benefit from the
NOTE Confidence: 0.8845197675

00:45:55.712 --> 00:45:57.197 next latest and greatest thing,
NOTE Confidence: 0.8845197675

00:45:57.200 --> 00:45:58.558 but at the same time they're worried.
NOTE Confidence: 0.8845197675

00:45:58.560 --> 00:46:00.006 Am I gonna live long enough
NOTE Confidence: 0.8845197675

00:46:00.006 --> 00:46:01.400 until it comes to market?
NOTE Confidence: 0.8845197675

00:46:01.400 --> 00:46:03.758 Am I gonna be eligible for the clinical trial
NOTE Confidence: 0.8845197675

00:46:03.758 --> 00:46:06.153 if it's still on a in a research setting?
NOTE Confidence: 0.8845197675

00:46:06.160 --> 00:46:08.320 How am I gonna deal with the side effects?
NOTE Confidence: 0.8845197675

00:46:08.320 --> 00:46:09.904 And when it comes to sickle
NOTE Confidence: 0.8845197675

00:46:09.904 --> 00:46:10.960 cell and gene therapy,
NOTE Confidence: 0.8845197675

00:46:10.960 --> 00:46:13.072 one wonders do patients and families
NOTE Confidence: 0.8845197675

00:46:13.072 --> 00:46:15.599 understand that when we use the word cure,
NOTE Confidence: 0.8845197675

00:46:15.600 --> 00:46:18.558 this is a potentially curative treatment.
NOTE Confidence: 0.8845197675

00:46:18.560 --> 00:46:21.840 We are not going to reverse organ damage.

NOTE Confidence: 0.8845197675

00:46:21.840 --> 00:46:24.794 We are not gonna restore organ function.

NOTE Confidence: 0.8845197675

00:46:24.800 --> 00:46:26.998 And cure really comes at a cost.

NOTE Confidence: 0.8845197675

00:46:27.000 --> 00:46:28.840 And that cost itself sometimes

NOTE Confidence: 0.8845197675

00:46:28.840 --> 00:46:30.312 can cause more suffering.

NOTE Confidence: 0.8845197675

00:46:30.320 --> 00:46:31.880 In order to get a bone marrow transplant,

NOTE Confidence: 0.8845197675

00:46:31.880 --> 00:46:33.637 in order to get a gene therapy,

NOTE Confidence: 0.8845197675

00:46:33.640 --> 00:46:36.160 you have to get chemotherapy.

NOTE Confidence: 0.8845197675

00:46:36.160 --> 00:46:37.996 And then there's also some larger,

NOTE Confidence: 0.8845197675

00:46:38.000 --> 00:46:41.600 I would argue, policy considerations.

NOTE Confidence: 0.8845197675

00:46:41.600 --> 00:46:43.128 We're talking about cure.

NOTE Confidence: 0.8845197675

00:46:43.128 --> 00:46:44.274 We're marketing cure.

NOTE Confidence: 0.8845197675

00:46:44.280 --> 00:46:45.462 Like I said,

NOTE Confidence: 0.8845197675

00:46:45.462 --> 00:46:47.782 we see it everywhere when promised

NOTE Confidence: 0.8845197675

00:46:47.782 --> 00:46:49.637 for a cure isn't realized.

NOTE Confidence: 0.8845197675

00:46:49.640 --> 00:46:51.254 This can undermine public trust in

NOTE Confidence: 0.8845197675

00:46:51.254 --> 00:46:53.400 science and in the research enterprise.

NOTE Confidence: 0.8845197675

00:46:53.400 --> 00:46:56.389 And so one more thing for us

NOTE Confidence: 0.8845197675

00:46:56.389 --> 00:46:58.280 to potentially think about.

NOTE Confidence: 0.8845197675

00:46:58.280 --> 00:47:00.480 So in the time that I have left,

NOTE Confidence: 0.8845197675

00:47:00.480 --> 00:47:02.657 I wanna share with you some data

NOTE Confidence: 0.8845197675

00:47:02.657 --> 00:47:04.784 about a multi center study that

NOTE Confidence: 0.8845197675

00:47:04.784 --> 00:47:07.034 colleagues and I are working on.

NOTE Confidence: 0.8845197675

00:47:07.040 --> 00:47:09.284 And what we're interested in learning

NOTE Confidence: 0.8845197675

00:47:09.284 --> 00:47:11.520 from patients with sickle cell and

NOTE Confidence: 0.8845197675

00:47:11.520 --> 00:47:13.210 caregivers of patients with sickle

NOTE Confidence: 0.8845197675

00:47:13.210 --> 00:47:15.479 cell are what are their attitudes,

NOTE Confidence: 0.8845197675

00:47:15.480 --> 00:47:16.855 what are their preferences about

NOTE Confidence: 0.8845197675

00:47:16.855 --> 00:47:17.955 these so-called high risk,

NOTE Confidence: 0.8845197675

00:47:17.960 --> 00:47:20.360 high reward treatments like gene therapy?

NOTE Confidence: 0.8845197675

00:47:20.360 --> 00:47:23.120 And we call ourselves SCD Gene.

NOTE Confidence: 0.8845197675

00:47:23.120 --> 00:47:24.160 Not a four letter word,

NOTE Confidence: 0.8845197675

00:47:24.160 --> 00:47:26.918 but gene is a four letter word.

NOTE Confidence: 0.8845197675

00:47:26.920 --> 00:47:28.600 And what we found is really interesting.

NOTE Confidence: 0.8845197675

00:47:28.600 --> 00:47:31.274 What we found is that fewer than

NOTE Confidence: 0.8845197675

00:47:31.280 --> 00:47:33.744 5% of the respondents in our group

NOTE Confidence: 0.8845197675

00:47:33.744 --> 00:47:35.808 said that they felt extremely

NOTE Confidence: 0.8845197675

00:47:35.808 --> 00:47:37.676 knowledgeable about gene therapy

NOTE Confidence: 0.8845197675

00:47:37.676 --> 00:47:40.839 and 2/3 said they had no knowledge.

NOTE Confidence: 0.8845197675

00:47:40.840 --> 00:47:42.192 And maybe not surprisingly,

NOTE Confidence: 0.8845197675

00:47:42.192 --> 00:47:44.220 the more people said that they

NOTE Confidence: 0.8845197675

00:47:44.280 --> 00:47:45.680 knew about gene therapy,

NOTE Confidence: 0.8845197675

00:47:45.680 --> 00:47:47.773 the more comfortable they were that gene

NOTE Confidence: 0.8845197675

00:47:47.773 --> 00:47:50.196 therapy is a safe and a good treatment.

NOTE Confidence: 0.8845197675

00:47:50.200 --> 00:47:52.522 And a question that I have is how and

NOTE Confidence: 0.8845197675

00:47:52.522 --> 00:47:54.823 why does being more knowledgeable about

NOTE Confidence: 0.8845197675

00:47:54.823 --> 00:47:57.227 gene therapy translate to a greater

NOTE Confidence: 0.8845197675

00:47:57.227 --> 00:48:00.075 willingness to accept it as a safe therapy?

NOTE Confidence: 0.8845197675

00:48:00.080 --> 00:48:01.040 Is that cause of hope?

NOTE Confidence: 0.8845197675

00:48:01.040 --> 00:48:02.600 Is that because of hype?

NOTE Confidence: 0.8845197675

00:48:02.600 --> 00:48:05.996 Is it because of something else?

NOTE Confidence: 0.8845197675

00:48:06.000 --> 00:48:07.896 Families are absolutely aware of the

NOTE Confidence: 0.8845197675

00:48:07.896 --> 00:48:09.760 toll of these curative therapies.

NOTE Confidence: 0.8845197675

00:48:09.760 --> 00:48:10.699 And in fact,

NOTE Confidence: 0.8845197675

00:48:10.699 --> 00:48:12.264 our findings directly oppose those

NOTE Confidence: 0.8845197675

00:48:12.264 --> 00:48:13.990 findings of that study I shared

NOTE Confidence: 0.8845197675

00:48:13.990 --> 00:48:15.550 with you on gene therapy that

NOTE Confidence: 0.945605941666667

00:48:15.609 --> 00:48:17.331 found that adults and parents of

NOTE Confidence: 0.945605941666667

00:48:17.331 --> 00:48:19.168 kids with sickle cell were accepting

NOTE Confidence: 0.945605941666667

00:48:19.168 --> 00:48:21.232 of gene therapy and willing to

NOTE Confidence: 0.945605941666667

00:48:21.232 --> 00:48:23.638 have a very high risk threshold.

NOTE Confidence: 0.945605941666667

00:48:23.640 --> 00:48:24.880 So far we've, you know,

NOTE Confidence: 0.945605941666667

00:48:24.880 --> 00:48:27.032 qualitatively coded 45 parent

NOTE Confidence: 0.945605941666667
00:48:27.032 --> 00:48:30.260 interviews and only five parents out
NOTE Confidence: 0.945605941666667
00:48:30.350 --> 00:48:33.006 of the 4511% said they think the gene
NOTE Confidence: 0.945605941666667
00:48:33.006 --> 00:48:35.479 therapy would be right for their kid.
NOTE Confidence: 0.945605941666667
00:48:35.480 --> 00:48:37.430 Of 14 patients who've already
NOTE Confidence: 0.945605941666667
00:48:37.430 --> 00:48:38.600 undergone gene therapy,
NOTE Confidence: 0.945605941666667
00:48:38.600 --> 00:48:40.644 two of them told us they would
NOTE Confidence: 0.945605941666667
00:48:40.644 --> 00:48:42.040 not do it again.
NOTE Confidence: 0.945605941666667
00:48:42.040 --> 00:48:44.020 And nearly 60% of patients who
NOTE Confidence: 0.945605941666667
00:48:44.020 --> 00:48:45.766 we interviewed said they didn't
NOTE Confidence: 0.945605941666667
00:48:45.766 --> 00:48:47.962 think that the benefits of gene
NOTE Confidence: 0.945605941666667
00:48:47.962 --> 00:48:49.480 therapy outweighed the risks.
NOTE Confidence: 0.945605941666667
00:48:49.480 --> 00:48:50.132 In fact,
NOTE Confidence: 0.945605941666667
00:48:50.132 --> 00:48:52.088 most of the respondents in our
NOTE Confidence: 0.945605941666667
00:48:52.088 --> 00:48:54.087 research said they don't think that
NOTE Confidence: 0.945605941666667
00:48:54.087 --> 00:48:56.405 their own sickle cell or their kids
NOTE Confidence: 0.945605941666667

00:48:56.405 --> 00:48:58.729 sickle cell is severe enough to warrant
NOTE Confidence: 0.945605941666667

00:48:58.729 --> 00:49:00.612 the risks associated with gene therapy.
NOTE Confidence: 0.945605941666667

00:49:00.612 --> 00:49:03.080 And those risks are things like infertility,
NOTE Confidence: 0.945605941666667

00:49:03.080 --> 00:49:04.946 organ damage from the myelo ablative
NOTE Confidence: 0.945605941666667

00:49:04.946 --> 00:49:06.639 chemo that you have to get.
NOTE Confidence: 0.945605941666667

00:49:06.640 --> 00:49:10.140 And from a just overall kind of
NOTE Confidence: 0.945605941666667

00:49:10.140 --> 00:49:11.640 research enterprise perspective,
NOTE Confidence: 0.945605941666667

00:49:11.640 --> 00:49:13.776 they also told us that they have an
NOTE Confidence: 0.945605941666667

00:49:13.776 --> 00:49:15.374 uneasiness with medical research and
NOTE Confidence: 0.945605941666667

00:49:15.374 --> 00:49:17.396 they have concerns about the novelty,
NOTE Confidence: 0.945605941666667

00:49:17.400 --> 00:49:19.884 the newness of gene therapy and
NOTE Confidence: 0.945605941666667

00:49:19.884 --> 00:49:22.520 this notion of changing one's genes.
NOTE Confidence: 0.945605941666667

00:49:22.520 --> 00:49:24.840 From a pediatric bioethics perspective,
NOTE Confidence: 0.945605941666667

00:49:24.840 --> 00:49:27.640 what parents told us was super interesting.
NOTE Confidence: 0.945605941666667

00:49:27.640 --> 00:49:29.440 The majority of parents said,
NOTE Confidence: 0.945605941666667

00:49:29.440 --> 00:49:30.289 you know what,

NOTE Confidence: 0.945605941666667
00:49:30.289 --> 00:49:31.987 this is not our decision to
NOTE Confidence: 0.945605941666667
00:49:31.987 --> 00:49:33.119 make for our kids.
NOTE Confidence: 0.945605941666667
00:49:33.120 --> 00:49:34.800 This is a decision that
NOTE Confidence: 0.945605941666667
00:49:34.800 --> 00:49:36.480 our kids need to make.
NOTE Confidence: 0.945605941666667
00:49:36.480 --> 00:49:39.280 And the clinicians in the room will
NOTE Confidence: 0.945605941666667
00:49:39.280 --> 00:49:41.800 understand that the longer one waits,
NOTE Confidence: 0.945605941666667
00:49:41.800 --> 00:49:44.778 the outcomes of gene therapy and bone
NOTE Confidence: 0.945605941666667
00:49:44.778 --> 00:49:46.512 marrow transplant as well can change
NOTE Confidence: 0.945605941666667
00:49:46.512 --> 00:49:48.200 because you've had more organ damage,
NOTE Confidence: 0.945605941666667
00:49:48.200 --> 00:49:50.064 you've gotten more treatment
NOTE Confidence: 0.945605941666667
00:49:50.064 --> 00:49:50.996 related toxicity.
NOTE Confidence: 0.945605941666667
00:49:51.000 --> 00:49:52.620 So it makes sense that
NOTE Confidence: 0.945605941666667
00:49:52.620 --> 00:49:53.916 parents say that perhaps,
NOTE Confidence: 0.945605941666667
00:49:53.920 --> 00:49:56.400 but of course there's always the other side.
NOTE Confidence: 0.959833969166667
00:49:58.480 --> 00:50:01.343 Take a look at these observations from
NOTE Confidence: 0.959833969166667

00:50:01.343 --> 00:50:03.560 patients and caregivers and especially
NOTE Confidence: 0.959833969166667

00:50:03.560 --> 00:50:06.640 know the need to equally highlight the
NOTE Confidence: 0.959833969166667

00:50:06.640 --> 00:50:08.844 downside and the side effects of gene
NOTE Confidence: 0.959833969166667

00:50:08.844 --> 00:50:11.040 therapy and not just sell the upside.
NOTE Confidence: 0.959833969166667

00:50:11.040 --> 00:50:13.224 And you can see how from these quotations
NOTE Confidence: 0.959833969166667

00:50:13.224 --> 00:50:15.359 how hope comes into this whole issue.
NOTE Confidence: 0.958730425

00:50:17.400 --> 00:50:19.278 Maybe not surprising to this group,
NOTE Confidence: 0.958730425

00:50:19.280 --> 00:50:23.438 but what we learned was that trust is really
NOTE Confidence: 0.958730425

00:50:23.438 --> 00:50:26.556 important in how people get information.
NOTE Confidence: 0.958730425

00:50:26.560 --> 00:50:29.720 People also said honest communication,
NOTE Confidence: 0.958730425

00:50:29.720 --> 00:50:32.208 transparent communication is important,
NOTE Confidence: 0.958730425

00:50:32.208 --> 00:50:34.074 relatability is important.
NOTE Confidence: 0.958730425

00:50:34.080 --> 00:50:36.908 And what I what I interpret relatability
NOTE Confidence: 0.958730425

00:50:36.908 --> 00:50:39.405 to mean is we've talked about the fact
NOTE Confidence: 0.958730425

00:50:39.405 --> 00:50:40.996 that there's very few centers that
NOTE Confidence: 0.958730425

00:50:40.996 --> 00:50:42.514 have the expertise and the ability

NOTE Confidence: 0.958730425

00:50:42.514 --> 00:50:44.000 to provide these new treatments.

NOTE Confidence: 0.958730425

00:50:44.000 --> 00:50:45.799 And so my center certainly does not.

NOTE Confidence: 0.958730425

00:50:45.800 --> 00:50:47.528 So I'm gonna be sending my

NOTE Confidence: 0.958730425

00:50:47.528 --> 00:50:49.680 patients to you guys, for example.

NOTE Confidence: 0.958730425

00:50:49.680 --> 00:50:52.680 Well, my patients don't know you,

NOTE Confidence: 0.958730425

00:50:52.680 --> 00:50:54.541 you're you're you're, you know, strangers.

NOTE Confidence: 0.958730425

00:50:54.541 --> 00:50:57.909 And if we know that trust is important

NOTE Confidence: 0.958730425

00:50:57.909 --> 00:51:00.480 and relatability is important,

NOTE Confidence: 0.958730425

00:51:00.480 --> 00:51:01.800 we need to earn that trust.

NOTE Confidence: 0.958730425

00:51:01.800 --> 00:51:03.648 But also I think that suggests that

NOTE Confidence: 0.958730425

00:51:03.648 --> 00:51:06.001 there's got to be a role for the

NOTE Confidence: 0.958730425

00:51:06.001 --> 00:51:07.205 primary hematology team throughout

NOTE Confidence: 0.958730425

00:51:07.205 --> 00:51:09.196 this entire process to stay engaged.

NOTE Confidence: 0.958730425

00:51:09.200 --> 00:51:11.432 And it's not where we send our patient off.

NOTE Confidence: 0.958730425

00:51:11.440 --> 00:51:12.684 And six months later,

NOTE Confidence: 0.958730425

00:51:12.684 --> 00:51:15.641 they come back and there was no contact or

NOTE Confidence: 0.958730425

00:51:15.641 --> 00:51:18.035 there was only contact between the teams.

NOTE Confidence: 0.958730425

00:51:18.040 --> 00:51:19.960 What did we take away?

NOTE Confidence: 0.958730425

00:51:19.960 --> 00:51:22.680 Avoid jargon, check for understanding,

NOTE Confidence: 0.958730425

00:51:22.680 --> 00:51:24.120 Allow time for questions.

NOTE Confidence: 0.958730425

00:51:24.120 --> 00:51:25.560 Don't gloss over things.

NOTE Confidence: 0.958730425

00:51:25.560 --> 00:51:28.518 Don't rush things.

NOTE Confidence: 0.958730425

00:51:28.520 --> 00:51:30.599 What you see here in descending order.

NOTE Confidence: 0.958730425

00:51:30.600 --> 00:51:31.560 And I'm dating myself because

NOTE Confidence: 0.958730425

00:51:31.560 --> 00:51:32.520 for those you don't know,

NOTE Confidence: 0.958730425

00:51:32.520 --> 00:51:33.144 that's Dave Letterman.

NOTE Confidence: 0.958730425

00:51:33.144 --> 00:51:34.600 And he used to do every night

NOTE Confidence: 0.958730425

00:51:34.640 --> 00:51:35.400 this top ten thing.

NOTE Confidence: 0.958730425

00:51:35.400 --> 00:51:36.228 That was awesome.

NOTE Confidence: 0.958730425

00:51:36.228 --> 00:51:38.160 But what you see here is not

NOTE Confidence: 0.958730425

00:51:38.220 --> 00:51:39.720 Letterman's top ten list.

NOTE Confidence: 0.958730425

00:51:39.720 --> 00:51:41.952 This is what the people in our study

NOTE Confidence: 0.958730425

00:51:41.952 --> 00:51:44.798 told us were the top 10 things that were

NOTE Confidence: 0.958730425

00:51:44.798 --> 00:51:47.280 important to them about novel treatments,

NOTE Confidence: 0.958730425

00:51:47.280 --> 00:51:50.376 and they may not be the same top ten

NOTE Confidence: 0.958730425

00:51:50.376 --> 00:51:52.598 important things that we consider.

NOTE Confidence: 0.958730425

00:51:52.600 --> 00:51:55.360 So as I'm wrapping up,

NOTE Confidence: 0.958730425

00:51:55.360 --> 00:51:57.160 I'll leave you with these ideas.

NOTE Confidence: 0.958730425

00:51:57.160 --> 00:52:00.008 I would say that physicians with others shape

NOTE Confidence: 0.958730425

00:52:00.008 --> 00:52:02.800 and alter both patient and parental hope,

NOTE Confidence: 0.958730425

00:52:02.800 --> 00:52:04.540 especially when we're talking

NOTE Confidence: 0.958730425

00:52:04.540 --> 00:52:06.280 about a poor prognosis.

NOTE Confidence: 0.958730425

00:52:06.280 --> 00:52:08.136 We have to be intentional in our interactions

NOTE Confidence: 0.958730425

00:52:08.136 --> 00:52:10.079 and we need to recognize our influence.

NOTE Confidence: 0.958730425

00:52:10.080 --> 00:52:11.588 That's clear and subtle.

NOTE Confidence: 0.958730425

00:52:11.588 --> 00:52:13.850 Changes in how hope is understood

NOTE Confidence: 0.958730425

00:52:13.918 --> 00:52:16.000 not only can contribute to hype,
NOTE Confidence: 0.958730425

00:52:16.000 --> 00:52:19.240 but also to perspectives on cure.
NOTE Confidence: 0.958730425

00:52:19.240 --> 00:52:21.480 And rather than dissuade hope,
NOTE Confidence: 0.958730425

00:52:21.480 --> 00:52:24.472 we need to respect the ranges of hope
NOTE Confidence: 0.958730425

00:52:24.472 --> 00:52:26.840 that patients and families express.
NOTE Confidence: 0.958730425

00:52:26.840 --> 00:52:29.206 And we have to give patients an
NOTE Confidence: 0.958730425

00:52:29.206 --> 00:52:31.279 opportunity and the chance to hope.
NOTE Confidence: 0.958730425

00:52:31.280 --> 00:52:33.210 Through listening and by engaging
NOTE Confidence: 0.958730425

00:52:33.210 --> 00:52:34.754 with patients and families,
NOTE Confidence: 0.958730425

00:52:34.760 --> 00:52:38.554 we can better understand what hope means.
NOTE Confidence: 0.958730425

00:52:38.560 --> 00:52:40.760 This slide is also from my colleague Akshay,
NOTE Confidence: 0.958730425

00:52:40.760 --> 00:52:42.678 and I've adapted it a little bit.
NOTE Confidence: 0.958730425

00:52:42.680 --> 00:52:44.630 So we're hopeful that soon
NOTE Confidence: 0.958730425

00:52:44.630 --> 00:52:45.800 we'll have treatments.
NOTE Confidence: 0.958730425

00:52:45.800 --> 00:52:48.474 And for a lot of genetic diseases,
NOTE Confidence: 0.958730425

00:52:48.480 --> 00:52:50.265 communication is important.

NOTE Confidence: 0.958730425

00:52:50.265 --> 00:52:53.240 Noam Chomsky said words matter.

NOTE Confidence: 0.958730425

00:52:53.240 --> 00:52:55.508 And so yes, we can qualify by

NOTE Confidence: 0.958730425

00:52:55.508 --> 00:52:56.480 saying potentially curative,

NOTE Confidence: 0.958730425

00:52:56.480 --> 00:52:58.920 but maybe we need to get rid of the word

NOTE Confidence: 0.958730425

00:52:58.986 --> 00:53:01.177 cure altogether and corrective, right?

NOTE Confidence: 0.958730425

00:53:01.177 --> 00:53:02.959 We're not gonna restore organ damage.

NOTE Confidence: 0.958730425

00:53:02.960 --> 00:53:05.012 We're not gonna reverse things that

NOTE Confidence: 0.958730425

00:53:05.012 --> 00:53:06.491 have already happened. Absolutely.

NOTE Confidence: 0.958730425

00:53:06.491 --> 00:53:09.197 We need more long term data.

NOTE Confidence: 0.958730425

00:53:09.200 --> 00:53:11.036 And then when we do use words like cure,

NOTE Confidence: 0.958730425

00:53:11.040 --> 00:53:12.618 we need to remember that cure

NOTE Confidence: 0.958730425

00:53:12.618 --> 00:53:14.599 for me is not cure for Mark.

NOTE Confidence: 0.958730425

00:53:14.600 --> 00:53:16.800 You know it's not cure for the rest of you.

NOTE Confidence: 0.949979775

00:53:16.800 --> 00:53:18.640 Each one of us has our own idea.

NOTE Confidence: 0.949979775

00:53:18.640 --> 00:53:21.754 If I can't play tennis every chance I can,

NOTE Confidence: 0.949979775

00:53:21.760 --> 00:53:24.560 then you know that's what's important to me.
NOTE Confidence: 0.949979775

00:53:24.560 --> 00:53:26.416 For Mark, it's being on his boat with
NOTE Confidence: 0.949979775

00:53:26.416 --> 00:53:28.398 his family, maybe etcetera, etcetera.
NOTE Confidence: 0.847669707142857

00:53:30.800 --> 00:53:32.555 Melissa Crary showed this slide
NOTE Confidence: 0.847669707142857

00:53:32.555 --> 00:53:34.310 at the inaugural Carlton Haywood
NOTE Confidence: 0.847669707142857

00:53:34.371 --> 00:53:36.151 Memorial Symposium back in 2022,
NOTE Confidence: 0.847669707142857

00:53:36.151 --> 00:53:38.959 and it's called the Burden of Sickle Cell.
NOTE Confidence: 0.847669707142857

00:53:38.960 --> 00:53:40.832 And so we've got the burden of sickle cell.
NOTE Confidence: 0.847669707142857

00:53:40.840 --> 00:53:43.680 And then we have a lovely beach in
NOTE Confidence: 0.847669707142857

00:53:43.680 --> 00:53:46.572 near my hometown. And I think, Mark,
NOTE Confidence: 0.847669707142857

00:53:46.572 --> 00:53:49.314 we've got time for some Q&A. Yeah,
OK.
NOTE Confidence: 0.847669707142857

00:53:49.314 --> 00:53:52.269 And I want to thank you guys and
NOTE Confidence: 0.847669707142857

00:53:52.269 --> 00:53:55.157 I'm very proud that I left this on.
NOTE Confidence: 0.847669707142857

00:53:55.160 --> 00:53:55.718 But thank you.
NOTE Confidence: 0.685545438

00:54:00.160 --> 00:54:01.000 You want me over here. You
NOTE Confidence: 0.585604268

00:54:01.200 --> 00:54:02.800 know that was so. Yeah.
NOTE Confidence: 0.585604268

00:54:02.800 --> 00:54:06.480 So you someplace comfortable?
NOTE Confidence: 0.585604268

00:54:06.480 --> 00:54:08.884 I'm right here. You can you can sit
NOTE Confidence: 0.585604268

00:54:08.884 --> 00:54:11.028 up here if you'd like and if that
NOTE Confidence: 0.585604268

00:54:11.028 --> 00:54:13.646 works have this and and and I'll
NOTE Confidence: 0.585604268

00:54:13.646 --> 00:54:16.038 look at this and and how we doing.
NOTE Confidence: 0.585604268

00:54:16.038 --> 00:54:16.716 We're doing good.
NOTE Confidence: 0.585604268

00:54:16.720 --> 00:54:18.200 I'm just gonna put the last slide up.
NOTE Confidence: 0.585604268

00:54:18.200 --> 00:54:20.120 Sure. So
NOTE Confidence: 0.965635631666667

00:54:22.520 --> 00:54:24.816 first of all, as far as when you
NOTE Confidence: 0.965635631666667

00:54:24.816 --> 00:54:27.120 invite a guy who named his dog Elwood,
NOTE Confidence: 0.965635631666667

00:54:27.120 --> 00:54:29.834 you gotta. And you know, I just,
NOTE Confidence: 0.965635631666667

00:54:29.834 --> 00:54:31.919 I I never carry sunglasses.
NOTE Confidence: 0.965635631666667

00:54:31.920 --> 00:54:34.048 But I just happened to have come from
NOTE Confidence: 0.965635631666667

00:54:34.048 --> 00:54:35.475 vacation and so I had my you know,
NOTE Confidence: 0.965635631666667

00:54:35.480 --> 00:54:38.880 I can, I can I can I can play the

NOTE Confidence: 0.7422071225

00:54:39.880 --> 00:54:40.920 part I can sure

NOTE Confidence: 0.8542304

00:54:40.920 --> 00:54:44.480 I can be Jake. I could be Jake.

NOTE Confidence: 0.8542304

00:54:44.480 --> 00:54:47.455 Blues. You know the the chance the

NOTE Confidence: 0.8542304

00:54:47.455 --> 00:54:49.548 chance of hearing about Batman and the

NOTE Confidence: 0.8542304

00:54:49.548 --> 00:54:51.399 Blues Brothers in the same lecture,

NOTE Confidence: 0.8542304

00:54:51.400 --> 00:54:52.560 it's pretty it's pretty low.

NOTE Confidence: 0.8542304

00:54:52.560 --> 00:54:53.688 So I'm going to give you

NOTE Confidence: 0.8542304

00:54:53.688 --> 00:54:54.919 a lot of credit for that.

NOTE Confidence: 0.8542304

00:54:54.920 --> 00:54:55.640 But I have to tell you,

NOTE Confidence: 0.8542304

00:54:55.640 --> 00:55:00.500 this was for me a Tour de force,

NOTE Confidence: 0.8542304

00:55:00.500 --> 00:55:03.244 a very powerful lecture and very sobering.

NOTE Confidence: 0.8542304

00:55:03.244 --> 00:55:05.584 And sometimes it's interesting to

NOTE Confidence: 0.8542304

00:55:05.584 --> 00:55:07.777 check ourselves and ask ourselves how

NOTE Confidence: 0.8542304

00:55:07.777 --> 00:55:10.518 do we feel at the end of a lecture.

NOTE Confidence: 0.8542304

00:55:10.520 --> 00:55:15.800 And I'll tell you just personally,

NOTE Confidence: 0.8542304

00:55:15.800 --> 00:55:16.958 I feel sad
NOTE Confidence: 0.92027974625

00:55:19.040 --> 00:55:21.385 this didn't leave, that I worry that
NOTE Confidence: 0.92027974625

00:55:21.385 --> 00:55:24.678 we do a lot of harm with these words.
NOTE Confidence: 0.92027974625

00:55:24.680 --> 00:55:26.648 And I know that this was your message
NOTE Confidence: 0.92027974625

00:55:26.648 --> 00:55:28.997 and it was and it was taught very well.
NOTE Confidence: 0.92027974625

00:55:29.000 --> 00:55:29.920 I think there's, you know,
NOTE Confidence: 0.92027974625

00:55:29.920 --> 00:55:32.440 our responsibility about how we use words.
NOTE Confidence: 0.92027974625

00:55:32.440 --> 00:55:34.862 I remember years ago with a surgeon
NOTE Confidence: 0.92027974625

00:55:34.862 --> 00:55:37.320 whose name doesn't need to be mentioned.
NOTE Confidence: 0.92027974625

00:55:37.320 --> 00:55:40.511 Voldemort. No, I would be in the operating
NOTE Confidence: 0.92027974625

00:55:40.511 --> 00:55:42.420 room with him and as a as an intern
NOTE Confidence: 0.92027974625

00:55:42.420 --> 00:55:44.280 and he'd say to the medical student,
NOTE Confidence: 0.92027974625

00:55:44.280 --> 00:55:46.812 he'd always say, he said to her,
NOTE Confidence: 0.92027974625

00:55:46.812 --> 00:55:47.877 this is like a ritual.
NOTE Confidence: 0.92027974625

00:55:47.880 --> 00:55:49.878 What's the definition of false hope?
NOTE Confidence: 0.92027974625

00:55:49.880 --> 00:55:51.994 And she was always supposed to say

NOTE Confidence: 0.92027974625

00:55:52.000 --> 00:55:54.436 there's no such thing as false hope.

NOTE Confidence: 0.92027974625

00:55:54.440 --> 00:55:56.274 And I think, well, I didn't exactly.

NOTE Confidence: 0.92027974625

00:55:56.280 --> 00:55:57.448 Right, because sometimes there

NOTE Confidence: 0.92027974625

00:55:57.448 --> 00:55:59.520 is such a thing as false hope.

NOTE Confidence: 0.92027974625

00:55:59.520 --> 00:56:04.348 But but I worry a lot about the

NOTE Confidence: 0.92027974625

00:56:04.348 --> 00:56:06.916 damage we do with these words.

NOTE Confidence: 0.92027974625

00:56:06.920 --> 00:56:08.400 And it it, I mean,

NOTE Confidence: 0.92027974625

00:56:08.400 --> 00:56:10.248 your heart can be broken in many

NOTE Confidence: 0.92027974625

00:56:10.248 --> 00:56:11.600 different places in this talk,

NOTE Confidence: 0.92027974625

00:56:11.600 --> 00:56:13.440 from what was the word,

NOTE Confidence: 0.92027974625

00:56:13.440 --> 00:56:17.072 a rainstorm of daggers to the idea that

NOTE Confidence: 0.92027974625

00:56:17.072 --> 00:56:18.880 we can potentially stop a child suffering,

NOTE Confidence: 0.92027974625

00:56:18.880 --> 00:56:20.052 but it'll cost \$3,000,000.

NOTE Confidence: 0.92027974625

00:56:20.052 --> 00:56:22.213 And then the question is how many

NOTE Confidence: 0.92027974625

00:56:22.213 --> 00:56:23.920 children can we help like that?

NOTE Confidence: 0.969741345

00:56:26.200 --> 00:56:26.920 I guess
NOTE Confidence: 0.680596664

00:56:30.080 --> 00:56:31.800 in my I, I, I
NOTE Confidence: 0.898783909

00:56:31.920 --> 00:56:33.400 I'm having trouble putting my
NOTE Confidence: 0.898783909

00:56:33.400 --> 00:56:34.880 thoughts into words on this,
NOTE Confidence: 0.898783909

00:56:34.880 --> 00:56:37.289 'cause I was a very much moved by your talk
NOTE Confidence: 0.898783909

00:56:37.289 --> 00:56:39.999 and about hope and I and words do matter,
NOTE Confidence: 0.898783909

00:56:40.000 --> 00:56:42.331 and this made me worry about our
NOTE Confidence: 0.898783909

00:56:42.331 --> 00:56:44.198 responsibility in the words we use,
NOTE Confidence: 0.898783909

00:56:44.200 --> 00:56:46.960 that we can actually hurt people.
NOTE Confidence: 0.898783909

00:56:46.960 --> 00:56:49.074 If I saw the glasses half full,
NOTE Confidence: 0.898783909

00:56:49.080 --> 00:56:49.840 I would say, well, wow,
NOTE Confidence: 0.898783909

00:56:49.840 --> 00:56:51.870 there's an awful lot of suffering that
NOTE Confidence: 0.898783909

00:56:51.870 --> 00:56:53.913 likely in the years to come is going
NOTE Confidence: 0.898783909

00:56:53.913 --> 00:56:56.916 to be addressed in a very helpful way.
NOTE Confidence: 0.898783909

00:56:56.920 --> 00:56:58.996 So. So that part is good.
NOTE Confidence: 0.898783909

00:56:59.000 --> 00:57:00.640 Anyway, that's my reflections on

NOTE Confidence: 0.898783909

00:57:00.640 --> 00:57:02.952 what I thought was an extremely

NOTE Confidence: 0.898783909

00:57:02.952 --> 00:57:04.760 insightful and powerful talk and

NOTE Confidence: 0.898783909

00:57:04.760 --> 00:57:06.560 I and I truly appreciate it.

NOTE Confidence: 0.898783909

00:57:06.560 --> 00:57:08.744 We have some time and what I would

NOTE Confidence: 0.898783909

00:57:08.744 --> 00:57:11.040 like to do is OfferUp the chance here,

NOTE Confidence: 0.898783909

00:57:11.040 --> 00:57:12.400 starting with Doctor Cardone,

NOTE Confidence: 0.898783909

00:57:12.400 --> 00:57:13.600 if you wait just till someone

NOTE Confidence: 0.898783909

00:57:13.600 --> 00:57:14.500 brings your microphone, please.

NOTE Confidence: 0.898783909

00:57:14.500 --> 00:57:14.800 Lori.

NOTE Confidence: 0.91219777

00:57:22.460 --> 00:57:24.900 Hi, I'm Lori Cardone, I'm pediatric

NOTE Confidence: 0.91219777

00:57:24.900 --> 00:57:26.820 psychologist and I worked for

NOTE Confidence: 0.721462351875

00:57:26.886 --> 00:57:29.280 many years in hematology and oncology.

NOTE Confidence: 0.721462351875

00:57:29.280 --> 00:57:32.654 I'm wondering if you might have

NOTE Confidence: 0.721462351875

00:57:32.654 --> 00:57:34.989 some thoughts about the Ascent

NOTE Confidence: 0.721462351875

00:57:34.989 --> 00:57:38.000 process with the patient themselves.

NOTE Confidence: 0.721462351875

00:57:38.000 --> 00:57:43.412 And how do we balance providing
NOTE Confidence: 0.721462351875

00:57:43.412 --> 00:57:45.508 psychoeducation in a way that
NOTE Confidence: 0.721462351875

00:57:45.508 --> 00:57:46.399 is developmentally appropriate,
NOTE Confidence: 0.721462351875

00:57:46.400 --> 00:57:48.488 much like our wonderful child life
NOTE Confidence: 0.721462351875

00:57:48.488 --> 00:57:50.804 colleagues do who create wonderful coloring
NOTE Confidence: 0.721462351875

00:57:50.804 --> 00:57:54.038 books and stories to explain a procedure.
NOTE Confidence: 0.721462351875

00:57:54.040 --> 00:57:55.680 But this is not that.
NOTE Confidence: 0.721462351875

00:57:55.680 --> 00:57:58.758 And so how do we think about a scent?
NOTE Confidence: 0.721462351875

00:57:58.760 --> 00:58:00.972 I I was listening for you to
NOTE Confidence: 0.721462351875

00:58:00.972 --> 00:58:02.320 say something about that.
NOTE Confidence: 0.721462351875

00:58:02.320 --> 00:58:04.600 You talked a lot about informed
NOTE Confidence: 0.721462351875

00:58:04.600 --> 00:58:06.120 consent from the parents,
NOTE Confidence: 0.721462351875

00:58:06.120 --> 00:58:07.440 but what about the child?
NOTE Confidence: 0.943764813333333

00:58:09.480 --> 00:58:11.620 Is this on? Can you hear me?
NOTE Confidence: 0.943764813333333

00:58:11.620 --> 00:58:15.208 Yes. So I got. I cut my teeth in
NOTE Confidence: 0.943764813333333

00:58:15.208 --> 00:58:16.908 pediatric ethics and a scent and

NOTE Confidence: 0.943764813333333

00:58:16.908 --> 00:58:18.504 I've been trying to escape from it

NOTE Confidence: 0.943764813333333

00:58:18.504 --> 00:58:20.439 for 25 years and I'm never able to.

NOTE Confidence: 0.943764813333333

00:58:20.440 --> 00:58:21.640 I'm always drawn back to it,

NOTE Confidence: 0.943764813333333

00:58:21.640 --> 00:58:23.410 which is totally fine and thank

NOTE Confidence: 0.943764813333333

00:58:23.410 --> 00:58:25.490 you for the question because it's

NOTE Confidence: 0.943764813333333

00:58:25.490 --> 00:58:27.158 a totally appropriate question.

NOTE Confidence: 0.943764813333333

00:58:27.160 --> 00:58:29.274 What I didn't tell you about this

NOTE Confidence: 0.943764813333333

00:58:29.274 --> 00:58:31.500 study that we're working on is that the

NOTE Confidence: 0.943764813333333

00:58:31.500 --> 00:58:34.078 second part of the intervention if you will,

NOTE Confidence: 0.943764813333333

00:58:34.080 --> 00:58:39.240 is coming up with really well designed

NOTE Confidence: 0.943764813333333

00:58:39.240 --> 00:58:42.660 validated decisional aids that help patients,

NOTE Confidence: 0.943764813333333

00:58:42.660 --> 00:58:44.960 kids as well as adults,

NOTE Confidence: 0.943764813333333

00:58:44.960 --> 00:58:48.380 but also families reconcile the very

NOTE Confidence: 0.943764813333333

00:58:48.380 --> 00:58:51.200 difficult choices that they face.

NOTE Confidence: 0.943764813333333

00:58:51.200 --> 00:58:53.720 And part of the whole idea there is,

NOTE Confidence: 0.943764813333333

00:58:53.720 --> 00:58:56.079 as you know as a pediatric psychologist,
NOTE Confidence: 0.943764813333333

00:58:56.080 --> 00:58:58.397 you know, Ascent is not diet consent,
NOTE Confidence: 0.943764813333333

00:58:58.400 --> 00:59:01.076 it's not, you know, consent light,
NOTE Confidence: 0.943764813333333

00:59:01.080 --> 00:59:03.960 it's developmental, it's maturational,
NOTE Confidence: 0.943764813333333

00:59:03.960 --> 00:59:06.656 it's frontal lobe, it's,
NOTE Confidence: 0.943764813333333

00:59:06.656 --> 00:59:08.800 it is neurocognitive functioning.
NOTE Confidence: 0.943764813333333

00:59:08.800 --> 00:59:10.180 It's a very,
NOTE Confidence: 0.943764813333333

00:59:10.180 --> 00:59:13.519 very complicated process and we owe
NOTE Confidence: 0.943764813333333

00:59:13.519 --> 00:59:17.000 our patients the ability to be able
NOTE Confidence: 0.943764813333333

00:59:17.000 --> 00:59:20.110 to a be part of these discussions
NOTE Confidence: 0.943764813333333

00:59:20.110 --> 00:59:21.520 as developmentally appropriate.
NOTE Confidence: 0.943764813333333

00:59:21.520 --> 00:59:24.679 As Laney Ross, who some of you may know,
NOTE Confidence: 0.943764813333333

00:59:24.680 --> 00:59:27.055 who's a pediatrician and pediatric
NOTE Confidence: 0.943764813333333

00:59:27.055 --> 00:59:28.480 ethicist has said,
NOTE Confidence: 0.943764813333333

00:59:28.480 --> 00:59:30.594 we shouldn't involve kids and allow them
NOTE Confidence: 0.943764813333333

00:59:30.594 --> 00:59:33.240 a decision if we don't plan to listen to it.

NOTE Confidence: 0.943764813333333
00:59:33.240 --> 00:59:33.990 It's disingenuous,
NOTE Confidence: 0.943764813333333
00:59:33.990 --> 00:59:34.365 right.
NOTE Confidence: 0.943764813333333
00:59:34.365 --> 00:59:36.240 If if I say Mark,
NOTE Confidence: 0.943764813333333
00:59:36.240 --> 00:59:36.640 you know,
NOTE Confidence: 0.833215544285714
00:59:38.800 --> 00:59:40.452 give me your opinion and then I
NOTE Confidence: 0.833215544285714
00:59:40.452 --> 00:59:42.037 I never intend to listen to it,
NOTE Confidence: 0.833215544285714
00:59:42.040 --> 00:59:43.552 that that's not cool.
NOTE Confidence: 0.833215544285714
00:59:43.552 --> 00:59:46.585 And so part of the idea here is
NOTE Confidence: 0.833215544285714
00:59:46.585 --> 00:59:49.273 that we need to do a better job.
NOTE Confidence: 0.833215544285714
00:59:49.280 --> 00:59:50.726 And I would, I would suggest
NOTE Confidence: 0.833215544285714
00:59:50.726 --> 00:59:52.160 that it's not just dissent.
NOTE Confidence: 0.833215544285714
00:59:52.160 --> 00:59:54.356 Dissent is probably harder, of course,
NOTE Confidence: 0.833215544285714
00:59:54.360 --> 00:59:56.598 but also with the consent process.
NOTE Confidence: 0.833215544285714
00:59:56.600 --> 00:59:59.680 Because what we know from reams of studies,
NOTE Confidence: 0.833215544285714
00:59:59.680 --> 01:00:03.238 decades of research is that patients,
NOTE Confidence: 0.833215544285714

01:00:03.240 --> 01:00:05.200 parents and often clinicians
NOTE Confidence: 0.833215544285714

01:00:05.200 --> 01:00:08.140 don't do a good job understanding
NOTE Confidence: 0.833215544285714

01:00:08.227 --> 01:00:10.757 and working through these steps.
NOTE Confidence: 0.833215544285714

01:00:10.760 --> 01:00:13.560 And so the group that we're working
NOTE Confidence: 0.833215544285714

01:00:13.560 --> 01:00:16.598 with to create these decisional aids.
NOTE Confidence: 0.833215544285714

01:00:16.600 --> 01:00:19.640 Is a multimedia company where
NOTE Confidence: 0.833215544285714

01:00:19.640 --> 01:00:20.960 both of them are docs,
NOTE Confidence: 0.833215544285714

01:00:20.960 --> 01:00:23.900 but one of them's a an artist
NOTE Confidence: 0.833215544285714

01:00:23.900 --> 01:00:26.026 and the other I don't know,
NOTE Confidence: 0.833215544285714

01:00:26.026 --> 01:00:27.358 he's he's just remarkable.
NOTE Confidence: 0.833215544285714

01:00:27.360 --> 01:00:29.474 I can't remember what his background is
NOTE Confidence: 0.833215544285714

01:00:29.480 --> 01:00:33.239 but using audio visuals to create these.
NOTE Confidence: 0.833215544285714

01:00:33.240 --> 01:00:36.005 Now, people have done quality of ascent
NOTE Confidence: 0.833215544285714

01:00:36.005 --> 01:00:38.880 and quality of consent tools forever,
NOTE Confidence: 0.833215544285714

01:00:38.880 --> 01:00:39.860 and there's probably more
NOTE Confidence: 0.833215544285714

01:00:39.860 --> 01:00:41.640 than one good way to do this.

NOTE Confidence: 0.833215544285714
01:00:41.640 --> 01:00:44.792 But that is the way that we have
NOTE Confidence: 0.833215544285714
01:00:44.792 --> 01:00:46.862 decided that we need to try
NOTE Confidence: 0.833215544285714
01:00:46.862 --> 01:00:48.438 to slim the gap a little bit,
NOTE Confidence: 0.833215544285714
01:00:48.440 --> 01:00:48.878 if you will,
NOTE Confidence: 0.69453777
01:00:50.680 --> 01:00:51.592 Krish, please.
NOTE Confidence: 0.69453777
01:00:51.592 --> 01:00:53.660 Hi, I'm Lakshman Krishnamurthy.
NOTE Confidence: 0.69453777
01:00:53.660 --> 01:00:55.400 And when I. And I have to tell you,
NOTE Confidence: 0.69453777
01:00:55.400 --> 01:00:56.816 I forgot to mention before these
NOTE Confidence: 0.69453777
01:00:56.816 --> 01:00:57.760 microphones that you've got,
NOTE Confidence: 0.69453777
01:00:57.760 --> 01:00:59.280 some of you guys have heard me talk about it.
NOTE Confidence: 0.69453777
01:00:59.280 --> 01:01:01.429 It's a, it's a function of these
NOTE Confidence: 0.69453777
01:01:01.429 --> 01:01:03.479 microphones that if you can't talk to,
NOTE Confidence: 0.69453777
01:01:03.480 --> 01:01:05.073 you've got to actually hold it up like that,
NOTE Confidence: 0.69453777
01:01:05.080 --> 01:01:06.304 like you're got it.
NOTE Confidence: 0.69453777
01:01:06.304 --> 01:01:07.784 Rock star, Krish, which you are.
NOTE Confidence: 0.69453777

01:01:07.784 --> 01:01:09.120 So, OK, there you go
NOTE Confidence: 0.7348748133333333

01:01:09.840 --> 01:01:11.528 in. In Full disclosure,
NOTE Confidence: 0.7348748133333333

01:01:11.528 --> 01:01:14.060 I'm both a pediatric hematologist and
NOTE Confidence: 0.7348748133333333

01:01:14.135 --> 01:01:16.560 a transplanter actively involved in
NOTE Confidence: 0.7348748133333333

01:01:16.560 --> 01:01:18.560 consenting patients for gene therapy.
NOTE Confidence: 0.7348748133333333

01:01:18.560 --> 01:01:21.680 Every week, a wonderful talk,
NOTE Confidence: 0.7348748133333333

01:01:21.680 --> 01:01:23.896 I got to hear a part of some
NOTE Confidence: 0.7348748133333333

01:01:23.896 --> 01:01:25.758 of this content at ASFO.
NOTE Confidence: 0.7348748133333333

01:01:25.760 --> 01:01:28.160 I have two comments to make.
NOTE Confidence: 0.7348748133333333

01:01:28.160 --> 01:01:31.400 One, cost, because I think we've
NOTE Confidence: 0.7348748133333333

01:01:31.400 --> 01:01:33.596 all talked so much about cost,
NOTE Confidence: 0.7348748133333333

01:01:33.600 --> 01:01:36.512 but we fail to recognize how the federal
NOTE Confidence: 0.7348748133333333

01:01:36.512 --> 01:01:39.040 government has taken a huge step forward.
NOTE Confidence: 0.7348748133333333

01:01:39.040 --> 01:01:40.798 And you briefly alluded to it,
NOTE Confidence: 0.7348748133333333

01:01:40.800 --> 01:01:42.744 but the whole story is that
NOTE Confidence: 0.7348748133333333

01:01:42.744 --> 01:01:43.716 the federal government,

NOTE Confidence: 0.734874813333333
01:01:43.720 --> 01:01:47.608 CMS will negotiate on behalf of 50 states
NOTE Confidence: 0.734874813333333
01:01:47.608 --> 01:01:50.696 for the cost and the companies are
NOTE Confidence: 0.734874813333333
01:01:50.696 --> 01:01:53.640 coming to the table starting this month.
NOTE Confidence: 0.734874813333333
01:01:53.640 --> 01:01:55.816 So I think that we might may may
NOTE Confidence: 0.734874813333333
01:01:55.816 --> 01:01:58.312 solve the OR alleviate the cost
NOTE Confidence: 0.734874813333333
01:01:58.312 --> 01:02:00.752 problem sooner than we think.
NOTE Confidence: 0.734874813333333
01:02:00.760 --> 01:02:02.452 You know India is already making
NOTE Confidence: 0.734874813333333
01:02:02.452 --> 01:02:03.929 big investments in gene therapy
NOTE Confidence: 0.734874813333333
01:02:03.929 --> 01:02:05.399 and they're just this year,
NOTE Confidence: 0.734874813333333
01:02:05.400 --> 01:02:08.202 this week published you know in
NOTE Confidence: 0.734874813333333
01:02:08.202 --> 01:02:11.199 vitro gene editing for sickle cell.
NOTE Confidence: 0.734874813333333
01:02:11.200 --> 01:02:14.500 I think the global gene therapy
NOTE Confidence: 0.734874813333333
01:02:14.500 --> 01:02:17.200 initiative is taking the NIH,
NOTE Confidence: 0.734874813333333
01:02:17.200 --> 01:02:19.800 you know non commercial IP and want to
NOTE Confidence: 0.734874813333333
01:02:19.800 --> 01:02:22.639 take it to Africa and India and stuff.
NOTE Confidence: 0.734874813333333

01:02:22.640 --> 01:02:23.146 So.
NOTE Confidence: 0.7348748133333333

01:02:23.146 --> 01:02:26.419 So you know really cost is great
NOTE Confidence: 0.7348748133333333

01:02:26.419 --> 01:02:28.777 but it's not hopefully I mean
NOTE Confidence: 0.7348748133333333

01:02:28.777 --> 01:02:32.078 we all saw how quickly the cost
NOTE Confidence: 0.7348748133333333

01:02:32.078 --> 01:02:34.366 of whole genome sequencing you
NOTE Confidence: 0.7348748133333333

01:02:34.366 --> 01:02:36.396 know went from being impossible.
NOTE Confidence: 0.7348748133333333

01:02:36.400 --> 01:02:39.680 I don't need to say this to to this group.
NOTE Confidence: 0.7348748133333333

01:02:39.680 --> 01:02:44.200 The second comment I want to make is the,
NOTE Confidence: 0.7348748133333333

01:02:44.200 --> 01:02:48.900 you know, understanding. Is there hype?
NOTE Confidence: 0.7348748133333333

01:02:48.900 --> 01:02:51.075 Is there misrepresentation?
NOTE Confidence: 0.7348748133333333

01:02:51.080 --> 01:02:53.880 I honestly believe the largest
NOTE Confidence: 0.7348748133333333

01:02:53.880 --> 01:02:56.665 problem is that people's lives are
NOTE Confidence: 0.7348748133333333

01:02:56.665 --> 01:02:59.937 so wrapped up in sickle cell disease
NOTE Confidence: 0.7348748133333333

01:02:59.937 --> 01:03:03.172 in the narrative of I am suffering.
NOTE Confidence: 0.7348748133333333

01:03:03.172 --> 01:03:07.600 So it probably was meant to be and I can't.
NOTE Confidence: 0.7348748133333333

01:03:07.600 --> 01:03:10.438 I don't have a Doctor Who knows

NOTE Confidence: 0.734874813333333
01:03:10.438 --> 01:03:12.671 anything about gene therapy to send me
NOTE Confidence: 0.734874813333333
01:03:12.671 --> 01:03:15.157 to somebody who knows something about
NOTE Confidence: 0.734874813333333
01:03:15.157 --> 01:03:18.598 gene therapy and and I can't believe anybody.
NOTE Confidence: 0.734874813333333
01:03:18.600 --> 01:03:20.868 So the larger problem is how are
NOTE Confidence: 0.734874813333333
01:03:20.868 --> 01:03:23.389 we going to reach all of these
NOTE Confidence: 0.734874813333333
01:03:23.389 --> 01:03:25.972 people who could actually benefit,
NOTE Confidence: 0.734874813333333
01:03:25.972 --> 01:03:27.078 you know,
NOTE Confidence: 0.734874813333333
01:03:27.080 --> 01:03:29.368 if they only were able to wrap their
NOTE Confidence: 0.734874813333333
01:03:29.368 --> 01:03:30.600 head around this whole problem.
NOTE Confidence: 0.734874813333333
01:03:30.600 --> 01:03:32.900 And I see this from a perspective of
NOTE Confidence: 0.734874813333333
01:03:32.900 --> 01:03:35.270 a deeply held belief that ordinary
NOTE Confidence: 0.734874813333333
01:03:35.345 --> 01:03:38.073 people can comprehend extraordinarily
NOTE Confidence: 0.734874813333333
01:03:38.073 --> 01:03:40.360 complex information, you know,
NOTE Confidence: 0.734874813333333
01:03:40.360 --> 01:03:42.200 in in informed self-interest.
NOTE Confidence: 0.734874813333333
01:03:42.200 --> 01:03:44.000 So I think those are probably
NOTE Confidence: 0.734874813333333

01:03:44.000 --> 01:03:46.358 too big and so but lovely talk.
NOTE Confidence: 0.7348748133333333

01:03:46.360 --> 01:03:48.440 I'm so glad I showed up to hear you again.
NOTE Confidence: 0.94582171125

01:03:49.120 --> 01:03:51.170 Thank you for those amazing
NOTE Confidence: 0.94582171125

01:03:51.170 --> 01:03:52.400 observations and comments.
NOTE Confidence: 0.94582171125

01:03:52.400 --> 01:03:56.558 And I think your patients are probably
NOTE Confidence: 0.94582171125

01:03:56.558 --> 01:03:59.202 among the lucky few who have you
NOTE Confidence: 0.94582171125

01:03:59.202 --> 01:04:01.720 who are is able to walk through
NOTE Confidence: 0.94582171125

01:04:01.720 --> 01:04:05.120 this difficult process with them
NOTE Confidence: 0.94582171125

01:04:05.120 --> 01:04:06.884 because if you're both serving as
NOTE Confidence: 0.94582171125

01:04:06.884 --> 01:04:09.270 a hematologist and a you guys call
NOTE Confidence: 0.94582171125

01:04:09.270 --> 01:04:10.798 yourselves now cellular physicians,
NOTE Confidence: 0.94582171125

01:04:10.800 --> 01:04:12.436 right, not just transplanters
NOTE Confidence: 0.94582171125

01:04:12.436 --> 01:04:14.890 but whatever you want to call
NOTE Confidence: 0.94582171125

01:04:14.965 --> 01:04:16.208 yourself they're lucky.
NOTE Confidence: 0.94582171125

01:04:16.208 --> 01:04:17.240 So thank you.
NOTE Confidence: 0.87219165625

01:04:20.400 --> 01:04:23.320 You know I I what what potentially may

NOTE Confidence: 0.87219165625

01:04:23.320 --> 01:04:26.037 happen in the US with CMS is great.

NOTE Confidence: 0.87219165625

01:04:26.040 --> 01:04:27.804 I still struggle with what's going

NOTE Confidence: 0.87219165625

01:04:27.804 --> 01:04:30.077 to happen in the rest of the world.

NOTE Confidence: 0.87219165625

01:04:30.080 --> 01:04:32.789 But I also to your second point

NOTE Confidence: 0.87219165625

01:04:32.789 --> 01:04:34.919 about getting to the masses.

NOTE Confidence: 0.87219165625

01:04:34.920 --> 01:04:36.957 I've made a point since gene therapy.

NOTE Confidence: 0.87219165625

01:04:36.960 --> 01:04:39.400 The preliminary data seem to

NOTE Confidence: 0.87219165625

01:04:39.400 --> 01:04:41.840 suggest that it's probably positive.

NOTE Confidence: 0.87219165625

01:04:41.840 --> 01:04:44.080 I made a point of and there are days where

NOTE Confidence: 0.87219165625

01:04:44.140 --> 01:04:46.120 in my clinic and I I do heme and ARC.

NOTE Confidence: 0.87219165625

01:04:46.120 --> 01:04:48.384 So there's days where I see kids with

NOTE Confidence: 0.87219165625

01:04:48.384 --> 01:04:50.114 heavy menstrual bleeding and sickle cell

NOTE Confidence: 0.87219165625

01:04:50.114 --> 01:04:52.478 and anemia and days where I see ARC and.

NOTE Confidence: 0.87219165625

01:04:52.480 --> 01:04:53.999 But there's some days where most of

NOTE Confidence: 0.87219165625

01:04:53.999 --> 01:04:55.699 the kids I'm seeing happen to have

NOTE Confidence: 0.87219165625

01:04:55.699 --> 01:04:57.436 sickle cell and I made a point of
NOTE Confidence: 0.87219165625

01:04:57.436 --> 01:04:58.880 of talking to patients and parents.
NOTE Confidence: 0.87219165625

01:04:58.880 --> 01:05:01.036 You heard of this thing called gene
NOTE Confidence: 0.87219165625

01:05:01.036 --> 01:05:03.154 therapy and it's amazing to me which
NOTE Confidence: 0.87219165625

01:05:03.154 --> 01:05:05.632 patients and parents say yes and which
NOTE Confidence: 0.87219165625

01:05:05.632 --> 01:05:08.195 ones kind of look at me Gene what and
NOTE Confidence: 0.87219165625

01:05:08.195 --> 01:05:10.395 and I think we failed in that regard.
NOTE Confidence: 0.87219165625

01:05:10.400 --> 01:05:16.004 We with a royal you know W and and that
NOTE Confidence: 0.87219165625

01:05:16.004 --> 01:05:18.769 to me is is a Clarion call and we need
NOTE Confidence: 0.87219165625

01:05:18.769 --> 01:05:20.920 to do a better job getting out to the masses.
NOTE Confidence: 0.87219165625

01:05:20.920 --> 01:05:23.964 And then equally important is our
NOTE Confidence: 0.87219165625

01:05:23.964 --> 01:05:26.040 message and how do we convey that.
NOTE Confidence: 0.87219165625

01:05:26.040 --> 01:05:28.640 But I I think you are spot on spot on.
NOTE Confidence: 0.9494854775

01:05:30.000 --> 01:05:31.240 Thank you. Yes, Howard,
NOTE Confidence: 0.815253796

01:05:34.360 --> 01:05:36.080 thanks. It was very interesting.
NOTE Confidence: 0.815253796

01:05:36.080 --> 01:05:38.444 I was very taken with your

NOTE Confidence: 0.815253796

01:05:38.444 --> 01:05:40.720 numbers and you said that 40%,

NOTE Confidence: 0.815253796

01:05:40.720 --> 01:05:43.415 if I heard you right of the

NOTE Confidence: 0.815253796

01:05:43.415 --> 01:05:45.466 parents that had gotten it

NOTE Confidence: 0.815253796

01:05:45.466 --> 01:05:47.600 said they wouldn't do it again.

NOTE Confidence: 0.6813488

01:05:48.720 --> 01:05:50.865 And I there were 14 patients

NOTE Confidence: 0.6813488

01:05:50.865 --> 01:05:52.610 in our group who had

NOTE Confidence: 0.858997927857143

01:05:52.696 --> 01:05:55.280 already had gene therapy, 22411 percent

NOTE Confidence: 0.858997927857143

01:05:55.280 --> 01:05:58.132 said they would not do it again. I see.

NOTE Confidence: 0.858997927857143

01:05:58.132 --> 01:05:59.840 Just two small numbers. Very small

NOTE Confidence: 0.678565436

01:05:59.880 --> 01:06:02.920 numbers. Well, what were the reasons?

NOTE Confidence: 0.790713856666667

01:06:04.320 --> 01:06:05.598 I don't have the I honestly,

NOTE Confidence: 0.790713856666667

01:06:05.600 --> 01:06:08.396 I don't have that data yet.

NOTE Confidence: 0.790713856666667

01:06:08.400 --> 01:06:10.362 Our colleagues who are doing the

NOTE Confidence: 0.790713856666667

01:06:10.362 --> 01:06:11.960 coding hadn't gotten that far.

NOTE Confidence: 0.790713856666667

01:06:11.960 --> 01:06:14.160 But of course that's the that's

NOTE Confidence: 0.790713856666667

01:06:14.160 --> 01:06:17.440 the that's the the money, right?
NOTE Confidence: 0.790713856666667

01:06:17.440 --> 01:06:18.574 Yeah. Stay tuned.
NOTE Confidence: 0.790713856666667

01:06:18.574 --> 01:06:21.220 When Mark invites me back when it's
NOTE Confidence: 0.790713856666667

01:06:21.299 --> 01:06:23.400 not raining I'll I'll part due.
NOTE Confidence: 0.790713856666667

01:06:23.400 --> 01:06:25.200 I'll I'll I'll share that Hold.
NOTE Confidence: 0.747552181

01:06:25.280 --> 01:06:26.888 I say the blame. The rain
NOTE Confidence: 0.747552181

01:06:26.888 --> 01:06:27.960 is primarily your fault.
NOTE Confidence: 0.576579041428571

01:06:28.400 --> 01:06:29.748 Definitely my fault. You've
NOTE Confidence: 0.576579041428571

01:06:29.748 --> 01:06:31.360 talked about girls. It's always my
NOTE Confidence: 0.742637420666667

01:06:33.720 --> 01:06:35.232 girls, you know, and and and Chris made
NOTE Confidence: 0.742637420666667

01:06:35.232 --> 01:06:36.679 a really good point about the cost,
NOTE Confidence: 0.742637420666667

01:06:36.680 --> 01:06:38.078 of course, for everything we've seen.
NOTE Confidence: 0.742637420666667

01:06:38.080 --> 01:06:40.123 We and I gave a lecture on this myself
NOTE Confidence: 0.742637420666667

01:06:40.123 --> 01:06:42.196 not long ago on various technologies,
NOTE Confidence: 0.742637420666667

01:06:42.200 --> 01:06:45.244 how the cost of these things tend to
NOTE Confidence: 0.742637420666667

01:06:45.244 --> 01:06:47.154 go down sometimes quite dramatically.

NOTE Confidence: 0.742637420666667
01:06:47.160 --> 01:06:49.211 And so I feel maybe more hopeful
NOTE Confidence: 0.742637420666667
01:06:49.211 --> 01:06:52.002 than I did 10 minutes ago that maybe
NOTE Confidence: 0.742637420666667
01:06:52.002 --> 01:06:54.474 more kids are actually gonna get some
NOTE Confidence: 0.742637420666667
01:06:54.474 --> 01:06:56.598 relief of suffering kids and adults.
NOTE Confidence: 0.742637420666667
01:06:56.600 --> 01:06:58.360 Other thoughts, comments, questions.
NOTE Confidence: 0.743714282
01:07:04.400 --> 01:07:06.600 If not, then you're wrong.
NOTE Confidence: 0.743714282
01:07:06.600 --> 01:07:07.500 If you don't, I don't want
NOTE Confidence: 0.743714282
01:07:07.500 --> 01:07:08.480 to put you on the spot.
NOTE Confidence: 0.743714282
01:07:08.480 --> 01:07:09.761 So I'm going to ask you if
NOTE Confidence: 0.743714282
01:07:09.761 --> 01:07:10.919 you have any final words.
NOTE Confidence: 0.743714282
01:07:10.920 --> 01:07:13.548 So maybe before you do I'll just take a
NOTE Confidence: 0.743714282
01:07:13.548 --> 01:07:16.040 a minute or two to thank you so much.
NOTE Confidence: 0.743714282
01:07:16.040 --> 01:07:20.758 This was for want of a better word
NOTE Confidence: 0.743714282
01:07:20.758 --> 01:07:22.668 of powerful talk and it and it
NOTE Confidence: 0.743714282
01:07:22.668 --> 01:07:24.146 it for those who are involved in
NOTE Confidence: 0.743714282

01:07:24.146 --> 01:07:25.634 caring for people with sickle cell.

NOTE Confidence: 0.743714282

01:07:25.640 --> 01:07:27.424 I think there was much to be learned

NOTE Confidence: 0.743714282

01:07:27.424 --> 01:07:29.548 for those of us who care for a

NOTE Confidence: 0.743714282

01:07:29.548 --> 01:07:30.632 very different patient populations.

NOTE Confidence: 0.743714282

01:07:30.640 --> 01:07:30.977 Nevertheless,

NOTE Confidence: 0.743714282

01:07:30.977 --> 01:07:33.336 there was a lot to be learned

NOTE Confidence: 0.743714282

01:07:33.336 --> 01:07:35.480 about the responsibility we have

NOTE Confidence: 0.743714282

01:07:35.480 --> 01:07:38.864 in the words that we use it.

NOTE Confidence: 0.743714282

01:07:38.864 --> 01:07:40.928 It leaves us very thoughtful And

NOTE Confidence: 0.743714282

01:07:40.928 --> 01:07:43.784 and I and I and I will amend my

NOTE Confidence: 0.743714282

01:07:43.784 --> 01:07:46.232 initial comments and say that that

NOTE Confidence: 0.743714282

01:07:46.232 --> 01:07:48.833 not a bit as a sad that so many

NOTE Confidence: 0.743714282

01:07:48.840 --> 01:07:50.445 are suffering and will continue

NOTE Confidence: 0.743714282

01:07:50.445 --> 01:07:52.725 to suffer for some time but with

NOTE Confidence: 0.743714282

01:07:52.725 --> 01:07:54.853 some hope that there will be less

NOTE Confidence: 0.743714282

01:07:54.853 --> 01:07:56.560 suffering thanks to the work above.

NOTE Confidence: 0.743714282

01:07:56.560 --> 01:07:58.345 So many folks in the audience who

NOTE Confidence: 0.743714282

01:07:58.345 --> 01:07:59.720 haven't spoken up here today,

NOTE Confidence: 0.743714282

01:07:59.720 --> 01:08:01.926 but a lot of people who have spent

NOTE Confidence: 0.743714282

01:08:01.926 --> 01:08:03.141 their lives making life better

NOTE Confidence: 0.743714282

01:08:03.141 --> 01:08:04.399 for these kids and adults.

NOTE Confidence: 0.76816826

01:08:04.520 --> 01:08:06.396 And and if I may, if you'll indulge me,

NOTE Confidence: 0.76816826

01:08:06.396 --> 01:08:08.951 first of all I want to thank you for I mean

NOTE Confidence: 0.76816826

01:08:08.951 --> 01:08:11.278 being the the clean up hitter for the season.

NOTE Confidence: 0.76816826

01:08:11.280 --> 01:08:12.558 I mean that's a huge honor.

NOTE Confidence: 0.76816826

01:08:12.560 --> 01:08:14.956 Thank you for letting me, you know close

NOTE Confidence: 0.76816826

01:08:14.956 --> 01:08:17.000 up the shop for the academic season.

NOTE Confidence: 0.76816826

01:08:17.000 --> 01:08:18.610 But I don't want you guys to

NOTE Confidence: 0.76816826

01:08:18.610 --> 01:08:20.198 think that I am not hopeful.

NOTE Confidence: 0.76816826

01:08:20.200 --> 01:08:22.314 I mean I'm a pediatric chemonk doc.

NOTE Confidence: 0.76816826

01:08:22.320 --> 01:08:25.088 I mean it's in my DNA to be

NOTE Confidence: 0.76816826

01:08:25.088 --> 01:08:27.044 hopeful and to be positive.

NOTE Confidence: 0.76816826

01:08:27.044 --> 01:08:30.862 And and I think that there's these, you know,

NOTE Confidence: 0.76816826

01:08:30.862 --> 01:08:33.560 euphemisms that we use and you know,

NOTE Confidence: 0.76816826

01:08:33.560 --> 01:08:35.256 I'm, I'm always qualifying

NOTE Confidence: 0.76816826

01:08:35.256 --> 01:08:38.200 by putting potential before,

NOTE Confidence: 0.76816826

01:08:38.200 --> 01:08:40.120 but I am absolutely hopeful.

NOTE Confidence: 0.76816826

01:08:40.120 --> 01:08:41.680 And in my young career and

NOTE Confidence: 0.76816826

01:08:41.680 --> 01:08:43.639 it has been a young career.

NOTE Confidence: 0.76816826

01:08:43.640 --> 01:08:46.320 I'm not that you know that that old.

NOTE Confidence: 0.76816826

01:08:46.320 --> 01:08:46.400 I'm

NOTE Confidence: 0.773276378571429

01:08:46.520 --> 01:08:47.272 not that young either.

NOTE Confidence: 0.773276378571429

01:08:47.272 --> 01:08:48.800 But go ahead, but keep going. Yeah,

NOTE Confidence: 0.938411681666667

01:08:50.360 --> 01:08:53.516 but it's been remarkable to see

NOTE Confidence: 0.938411681666667

01:08:53.520 --> 01:08:56.019 you know the the, the advances that

NOTE Confidence: 0.938411681666667

01:08:56.019 --> 01:08:58.039 that obviously we we have made.

NOTE Confidence: 0.938411681666667

01:08:58.040 --> 01:09:00.588 But I think that the lessons that

NOTE Confidence: 0.938411681666667
01:09:00.588 --> 01:09:04.066 maybe we see from the sickle cell
NOTE Confidence: 0.938411681666667
01:09:04.066 --> 01:09:06.280 community absolutely translate to
NOTE Confidence: 0.938411681666667
01:09:06.280 --> 01:09:09.160 every single area of clinical medicine,
NOTE Confidence: 0.938411681666667
01:09:09.160 --> 01:09:11.335 in particular those that involve
NOTE Confidence: 0.938411681666667
01:09:11.335 --> 01:09:12.640 life limiting illnesses.
NOTE Confidence: 0.938411681666667
01:09:12.640 --> 01:09:15.280 And to be present to me,
NOTE Confidence: 0.938411681666667
01:09:15.280 --> 01:09:18.088 it's been very humbling to learn
NOTE Confidence: 0.938411681666667
01:09:18.088 --> 01:09:20.920 and to hear from patients,
NOTE Confidence: 0.938411681666667
01:09:20.920 --> 01:09:23.920 but to be present and to hear and
NOTE Confidence: 0.938411681666667
01:09:23.920 --> 01:09:26.151 to try to simply understand what
NOTE Confidence: 0.938411681666667
01:09:26.151 --> 01:09:28.136 patients are going through in
NOTE Confidence: 0.938411681666667
01:09:28.136 --> 01:09:29.879 their perspectives is so important.
NOTE Confidence: 0.938411681666667
01:09:29.880 --> 01:09:33.000 So thank you. Thank you.