WEBVTT

NOTE duration:"01:26:30"

NOTE recognizability:0.826

NOTE language:en-us

NOTE Confidence: 0.90342785125

00:00:00.000 --> 00:00:03.216 Well, I think we're going to get started.

NOTE Confidence: 0.90342785125

00:00:03.220 --> 00:00:05.320 Welcome. My name is Mark Mercurio.

NOTE Confidence: 0.90342785125

00:00:05.320 --> 00:00:06.922 I'm the director of the program

NOTE Confidence: 0.90342785125

00:00:06.922 --> 00:00:08.362 for Biomedical Ethics and the

NOTE Confidence: 0.90342785125

00:00:08.362 --> 00:00:09.638 Yale Pediatric Ethics program.

NOTE Confidence: 0.90342785125

00:00:09.640 --> 00:00:12.956 And tonight's evening ethics seminar is

NOTE Confidence: 0.90342785125

00:00:12.956 --> 00:00:15.440 hosted by the Yale PDF Ethics program.

NOTE Confidence: 0.90342785125

00:00:15.440 --> 00:00:18.104 And I'm delighted to have three

NOTE Confidence: 0.90342785125

00:00:18.104 --> 00:00:20.460 colleagues from from Canada from

NOTE Confidence: 0.90342785125

00:00:20.460 --> 00:00:22.448 Montreal joining us tonight.

NOTE Confidence: 0.90342785125

00:00:22.450 --> 00:00:24.274 We're going to talk about neonatal

NOTE Confidence: 0.90342785125

00:00:24.274 --> 00:00:26.925 follow up and some of the things that we

NOTE Confidence: 0.90342785125

00:00:26.925 --> 00:00:28.946 follow closely and some of the things

NOTE Confidence: 0.90342785125

00:00:28.946 --> 00:00:30.990 that we value and and there's some

NOTE Confidence: 0.90342785125

00:00:30.990 --> 00:00:32.890 great insights coming our way tonight.

NOTE Confidence: 0.90342785125

00:00:32.890 --> 00:00:34.948 I look forward to the presentation

NOTE Confidence: 0.90342785125

00:00:34.948 --> 00:00:37.510 and then and then the conversation.

NOTE Confidence: 0.90342785125

00:00:37.510 --> 00:00:40.918 We will have about 50 or 60 minutes

NOTE Confidence: 0.90342785125

00:00:40.918 --> 00:00:44.269 of of a presentation by our guest

NOTE Confidence: 0.90342785125

00:00:44.269 --> 00:00:45.834 speakers and then followed by

NOTE Confidence: 0.90342785125

00:00:45.834 --> 00:00:47.648 a question and answer session.

NOTE Confidence: 0.90342785125

00:00:47.650 --> 00:00:48.670 So I asked you this,

NOTE Confidence: 0.90342785125

00:00:48.670 --> 00:00:50.368 save your questions if you would

NOTE Confidence: 0.90342785125

00:00:50.368 --> 00:00:52.449 and then send them through the Q&amp;A.

NOTE Confidence: 0.90342785125

00:00:52.450 --> 00:00:54.170 Function on zoom and I'll take a look

NOTE Confidence: 0.90342785125

00:00:54.170 --> 00:00:55.895 at those and then I'll moderate a

NOTE Confidence: 0.90342785125

00:00:55.895 --> 00:00:57.666 session and be reading those to our

NOTE Confidence: 0.90342785125

00:00:57.666 --> 00:00:59.100 guests tonight and we'll go through

NOTE Confidence: 0.90342785125

00:00:59.100 --> 00:01:01.196 that and then we'll have a hard stop at 6:30.

NOTE Confidence: 0.90342785125

00:01:01.200 --> 00:01:03.752 So my apologies to whoever has a really

NOTE Confidence: 0.90342785125

00:01:03.752 --> 00:01:05.315 good question at 6:29 because I'm

NOTE Confidence: 0.90342785125

00:01:05.315 --> 00:01:07.499 afraid we might not get to all of them.

NOTE Confidence: 0.90342785125

00:01:07.500 --> 00:01:09.649 But let me go ahead and introduce

NOTE Confidence: 0.90342785125

00:01:09.649 --> 00:01:11.581 the three speakers for tonight as

NOTE Confidence: 0.90342785125

00:01:11.581 --> 00:01:13.492 we get into the conversation and

NOTE Confidence: 0.90342785125

00:01:13.492 --> 00:01:14.780 in no particular order,

NOTE Confidence: 0.90342785125

00:01:14.780 --> 00:01:16.280 and this might be the order

NOTE Confidence: 0.90342785125

00:01:16.280 --> 00:01:17.280 that they're speaking in,

NOTE Confidence: 0.90342785125

00:01:17.280 --> 00:01:18.354 but there's going to be kind

NOTE Confidence: 0.90342785125

00:01:18.354 --> 00:01:19.839 of A tag team approach tonight.

NOTE Confidence: 0.90342785125

00:01:19.840 --> 00:01:21.470 So I'm going to introduce

NOTE Confidence: 0.90342785125

00:01:21.470 --> 00:01:22.774 all three speakers now.

NOTE Confidence: 0.90342785125

00:01:22.780 --> 00:01:24.250 1st is Doctor Annie John V,

NOTE Confidence: 0.90342785125

00:01:24.250 --> 00:01:25.830 Who's a neonatologist and

NOTE Confidence: 0.90342785125

00:01:25.830 --> 00:01:27.410 clinical ethicist in Montreal.

NOTE Confidence: 0.90342785125

00:01:27.410 --> 00:01:29.909 There she is.

NOTE Confidence: 0.90342785125

00:01:29.910 --> 00:01:30.347 Any,

NOTE Confidence: 0.90342785125

00:01:30.347 --> 00:01:30.784 as,

NOTE Confidence: 0.90342785125

00:01:30.784 --> 00:01:31.221 any,

NOTE Confidence: 0.90342785125

00:01:31.221 --> 00:01:34.406 as many of you know Annie is on

NOTE Confidence: 0.90342785125

00:01:34.406 --> 00:01:36.066 everybody's very short list of

NOTE Confidence: 0.90342785125

00:01:36.066 --> 00:01:38.741 the of the neonatal and pediatric

NOTE Confidence: 0.90342785125

00:01:38.741 --> 00:01:41.049 ethicist in North America.

NOTE Confidence: 0.90342785125

00:01:41.050 --> 00:01:42.870 She's written a great deal.

NOTE Confidence: 0.90342785125

00:01:42.870 --> 00:01:44.335 She's spoken all over including

NOTE Confidence: 0.90342785125

00:01:44.335 --> 00:01:46.749 here at Yale before as many of you

NOTE Confidence: 0.90342785125

00:01:46.749 --> 00:01:48.835 remember and she's a very valued colleague.

NOTE Confidence: 0.90342785125

00:01:48.840 --> 00:01:50.358 And I'm grateful that Annie that

NOTE Confidence: 0.90342785125

00:01:50.358 --> 00:01:52.248 you made time to join us tonight.

NOTE Confidence: 0.90342785125

00:01:52.250 --> 00:01:54.296 Any Co directs the Masters and

00:01:54.296 --> 00:01:56.081 PhD programs in clinical ethics

00:01:56.081 --> 00:01:58.235 at the University Of Montreal and

00:01:58.235 --> 00:02:00.000 her main research interests.

00:02:00.000 --> 00:02:00.758 In bioethics,

00:02:00.758 --> 00:02:03.032 our decision making for fragile patients

00:02:03.032 --> 00:02:05.659 and family integrated care and Pediatrics.

00:02:05.660 --> 00:02:07.532 She investigates parent patient,

00:02:07.532 --> 00:02:09.404 family important outcomes after

00:02:09.404 --> 00:02:10.720 an accused stay.

00:02:10.720 --> 00:02:12.532 She has a Bachelor of Science

00:02:12.532 --> 00:02:13.438 from McGill University,

00:02:13.440 --> 00:02:15.522 a Doctor of medicine at University

00:02:15.522 --> 00:02:17.868 Of Montreal as well as it did

00:02:17.868 --> 00:02:19.242 her residency and fellowship,

00:02:19.242 --> 00:02:20.024 Excuse Me,

00:02:20.024 --> 00:02:21.979 residency at Montreal and her

NOTE Confidence: 0.90342785125

00:02:21.979 --> 00:02:23.019 fellowship at McGill.

NOTE Confidence: 0.90342785125

00:02:23.020 --> 00:02:25.060 And she also has a PhD in bioethics,

NOTE Confidence: 0.90342785125

00:02:25.060 --> 00:02:26.945 medical ethics on from the

NOTE Confidence: 0.90342785125

00:02:26.945 --> 00:02:28.076 University Of Montreal.

NOTE Confidence: 0.90342785125

00:02:28.080 --> 00:02:31.360 So we say thank you very much and welcome to.

NOTE Confidence: 0.90342785125

00:02:31.360 --> 00:02:33.170 Next I would introduce please

NOTE Confidence: 0.90342785125

00:02:33.170 --> 00:02:34.980 uh Dr Tweed may Lou,

NOTE Confidence: 0.90342785125

00:02:34.980 --> 00:02:36.828 who's a pediatrician and a medical

NOTE Confidence: 0.90342785125

00:02:36.828 --> 00:02:38.837 director of the CSU San Justin

NOTE Confidence: 0.90342785125

00:02:38.837 --> 00:02:40.979 Neonatal follow up program in Montreal,

NOTE Confidence: 0.90342785125

00:02:40.980 --> 00:02:41.406 QC.

NOTE Confidence: 0.90342785125

00:02:41.406 --> 00:02:43.962 He's also director of the Canadian

NOTE Confidence: 0.90342785125

00:02:43.962 --> 00:02:45.240 Neonatal Follow-up Network,

NOTE Confidence: 0.90342785125

00:02:45.240 --> 00:02:47.510 a research network consisting of

NOTE Confidence: 0.90342785125

00:02:47.510 --> 00:02:49.780 26 neonatal programs across Canada.

NOTE Confidence: 0.90342785125

00:02:49.780 --> 00:02:51.712 She received her MD from McGill

NOTE Confidence: 0.90342785125

00:02:51.712 --> 00:02:53.000 and her pediatrician Reef

NOTE Confidence: 0.686098891428572

00:02:53.058 --> 00:02:54.638 from University Of Montreal.

NOTE Confidence: 0.686098891428572

00:02:54.640 --> 00:02:57.040 She then pursued further training at

NOTE Confidence: 0.686098891428572

00:02:57.040 --> 00:02:59.469 Brown with our friend Betty Gore.

NOTE Confidence: 0.686098891428572

00:02:59.470 --> 00:03:01.894 He completed a Masters degree in

NOTE Confidence: 0.686098891428572

00:03:01.894 --> 00:03:03.947 epidemiology and Biostatistics at McGill

NOTE Confidence: 0.686098891428572

00:03:03.947 --> 00:03:06.558 and is currently a senior research scholar

NOTE Confidence: 0.686098891428572

00:03:06.558 --> 00:03:08.719 from Quebec Health research funds.

NOTE Confidence: 0.686098891428572

00:03:08.720 --> 00:03:11.222 Her research focuses on long term

NOTE Confidence: 0.686098891428572

00:03:11.222 --> 00:03:12.473 neurodevelopmental and physical

NOTE Confidence: 0.686098891428572

00:03:12.473 --> 00:03:14.240 health outcomes following preterm

NOTE Confidence: 0.686098891428572

00:03:14.240 --> 00:03:16.380 birth from infancy to adulthood,

NOTE Confidence: 0.686098891428572

00:03:16.380 --> 00:03:18.462 is looking at risk and resiliency

NOTE Confidence: 0.686098891428572

00:03:18.462 --> 00:03:20.437 factors along with best screening

NOTE Confidence: 0.686098891428572

00:03:20.437 --> 00:03:23.027 strategies to enhance clinical follow-up.

NOTE Confidence: 0.686098891428572

00:03:23.030 --> 00:03:25.215 And the third speaker tonight

NOTE Confidence: 0.686098891428572

00:03:25.215 --> 00:03:26.526 is Rebecca Pierce,

NOTE Confidence: 0.686098891428572

00:03:26.530 --> 00:03:30.607 who who's who is the mother of Amarin Bargas,

NOTE Confidence: 0.686098891428572

00:03:30.610 --> 00:03:33.430 who was born at 25 weeks back in 2009,

NOTE Confidence: 0.686098891428572

00:03:33.430 --> 00:03:35.830 and Lily Barsness, Martins twin,

NOTE Confidence: 0.686098891428572

00:03:35.830 --> 00:03:37.867 who died one week after her birth.

NOTE Confidence: 0.686098891428572

00:03:37.870 --> 00:03:39.585 She's also the mother of Eleanor Barses,

NOTE Confidence: 0.686098891428572

00:03:39.590 --> 00:03:42.410 born at term in 2012.

NOTE Confidence: 0.686098891428572

00:03:42.410 --> 00:03:44.042 Rebecca has been a part of

NOTE Confidence: 0.686098891428572

00:03:44.042 --> 00:03:45.130 the Parents Voice project,

NOTE Confidence: 0.686098891428572

00:03:45.130 --> 00:03:47.244 which seeks to engage parents and Co,

NOTE Confidence: 0.686098891428572

00:03:47.250 --> 00:03:48.578 creating definitions of important

NOTE Confidence: 0.686098891428572

00:03:48.578 --> 00:03:50.570 outcomes of prematurity that may be

NOTE Confidence: 0.686098891428572

00:03:50.628 --> 00:03:52.362 different than outcomes that may be

NOTE Confidence: 0.686098891428572

00:03:52.362 --> 00:03:54.150 valued by clinicians and researchers.

00:03:54.150 --> 00:03:55.082 And this, of course,

00:03:55.082 --> 00:03:57.210 is the focus of our talk this evening.

00:03:57.210 --> 00:03:59.373 She's also the Co chair of the

00:03:59.373 --> 00:04:00.867 Canadian Premature Babies Foundation

00:04:00.867 --> 00:04:02.397 Family Advisory committee.

00:04:02.400 --> 00:04:03.762 Rebecca is the vice principal at

00:04:03.762 --> 00:04:05.199 Villa Maria High School in Montreal,

00:04:05.200 --> 00:04:06.784 and she holds a Bachelors degree

00:04:06.784 --> 00:04:08.420 in biology from Queens University,

00:04:08.420 --> 00:04:10.778 a Masters in biology from McMaster,

00:04:10.780 --> 00:04:13.090 and B Ed from Brock University.

00:04:13.090 --> 00:04:15.218 Rebecca is a PhD candidate in the

00:04:15.218 --> 00:04:16.552 Department of Integrative Studies

00:04:16.552 --> 00:04:18.397 and Education at McGill University,

00:04:18.400 --> 00:04:20.992 where she is studying the mathematical

00:04:20.992 --> 00:04:21.424 identities.

NOTE Confidence: 0.686098891428572

00:04:21.430 --> 00:04:24.510 Of extremely preterm children welcome

NOTE Confidence: 0.686098891428572

00:04:24.510 --> 00:04:26.588 Rebecca. Welcome to all three of you.

NOTE Confidence: 0.686098891428572

00:04:26.590 --> 00:04:29.152 And I believe that Annie is our

NOTE Confidence: 0.686098891428572

00:04:29.152 --> 00:04:31.060 first speaker tonight Doctor Jean

NOTE Confidence: 0.686098891428572

00:04:31.060 --> 00:04:34.010 view and am I correct in that?

NOTE Confidence: 0.686098891428572

00:04:34.010 --> 00:04:36.809 Actually no it's.

NOTE Confidence: 0.686098891428572

00:04:36.810 --> 00:04:39.230 It's it's going to be my OK well,

NOTE Confidence: 0.686098891428572

00:04:39.230 --> 00:04:41.150 thank you very much and we'll

NOTE Confidence: 0.686098891428572

00:04:41.150 --> 00:04:42.520 start take it away, Doctor Liu.

NOTE Confidence: 0.869225307142857

00:04:46.320 --> 00:04:49.057 Great. Thank you for this nice introduction.

NOTE Confidence: 0.869225307142857

00:04:49.060 --> 00:04:51.755 So I will now share the screen.

NOTE Confidence: 0.655280643333333

00:04:58.080 --> 00:05:02.910 Need a screen? Yeah, spiritually, OK. So

NOTE Confidence: 0.85444383375

00:05:03.580 --> 00:05:04.489 we have, well,

NOTE Confidence: 0.85444383375

00:05:04.489 --> 00:05:06.004 maybe we are conflicted people,

NOTE Confidence: 0.85444383375

00:05:06.010 --> 00:05:09.550 but we have no conflicts to disclose.

NOTE Confidence: 0.85444383375

00:05:09.550 --> 00:05:11.384 So today what we're going to do

NOTE Confidence: 0.85444383375

00:05:11.384 --> 00:05:13.779 is I'm first going to discuss why

NOTE Confidence: 0.85444383375

00:05:13.779 --> 00:05:15.327 neonatal outcomes are measured.

NOTE Confidence: 0.85444383375

00:05:15.330 --> 00:05:17.122 Rebecca is then going to tell her story

NOTE Confidence: 0.85444383375

00:05:17.122 --> 00:05:19.106 and we will then discuss results from

NOTE Confidence: 0.85444383375

00:05:19.106 --> 00:05:20.928 the Parents Voice project that we've

NOTE Confidence: 0.85444383375

00:05:20.928 --> 00:05:24.370 been conducting over the past few years.

NOTE Confidence: 0.85444383375

00:05:24.370 --> 00:05:25.470 So as you all know,

NOTE Confidence: 0.85444383375

00:05:25.470 --> 00:05:28.179 worldwide 10% of babies are born preterm,

NOTE Confidence: 0.85444383375

00:05:28.180 --> 00:05:30.304 which means below 37 weeks of

NOTE Confidence: 0.85444383375

00:05:30.304 --> 00:05:32.756 gestational age and about 1% are born

NOTE Confidence: 0.85444383375

00:05:32.756 --> 00:05:35.440 extremely preterm before 28 weeks.

NOTE Confidence: 0.85444383375

00:05:35.440 --> 00:05:38.203 And if we look at survival rate based on

NOTE Confidence: 0.85444383375

00:05:38.203 --> 00:05:41.369 the Canadian neonatal Network annual report,

NOTE Confidence: 0.85444383375

00:05:41.370 --> 00:05:43.794 it's quite high at 23 to 24 weeks,

NOTE Confidence: 0.85444383375

00:05:43.800 --> 00:05:47.704 survival is 63%, at 25 to 26 weeks,

NOTE Confidence: 0.85444383375

00:05:47.710 --> 00:05:50.175 it's 87% and survival rate

NOTE Confidence: 0.85444383375

00:05:50.175 --> 00:05:53.370 is 94% at 27 to 28 weeks.

NOTE Confidence: 0.85444383375

00:05:53.370 --> 00:05:54.642 So what's really important?

NOTE Confidence: 0.85444383375

00:05:54.642 --> 00:05:56.940 Now is really to monitor how these

NOTE Confidence: 0.85444383375

00:05:56.940 --> 00:05:58.884 preterm infants will grow and develop

NOTE Confidence: 0.85444383375

00:05:58.884 --> 00:06:01.113 and these are some of the lovely kids

NOTE Confidence: 0.85444383375

00:06:01.113 --> 00:06:03.399 I get to follow in that my neonatal

NOTE Confidence: 0.85444383375

00:06:03.399 --> 00:06:05.214 follow-up clinic here in Montreal.

NOTE Confidence: 0.863813854444444

00:06:07.480 --> 00:06:08.920 So what do we do in

NOTE Confidence: 0.863813854444444

00:06:08.920 --> 00:06:09.640 neonatal follow-up program?

NOTE Confidence: 0.863813854444444

00:06:09.640 --> 00:06:11.978 So most often there are two mandates,

NOTE Confidence: 0.863813854444444

00:06:11.980 --> 00:06:14.110 a clinical one and an

NOTE Confidence: 0.863813854444444

00:06:14.110 --> 00:06:15.814 academic slash research one.

NOTE Confidence: 0.863813854444444

00:06:15.820 --> 00:06:17.932 So as a pediatrician working in

NOTE Confidence: 0.863813854444444

00:06:17.932 --> 00:06:19.340 the neonatal follow-up clinic,

00:06:19.340 --> 00:06:21.092 I will see my preterm babies

00:06:21.092 --> 00:06:22.260 to monitor their growth,

00:06:22.260 --> 00:06:24.156 their health and their own development.

00:06:24.160 --> 00:06:26.603 And the goal is to identify early

00:06:26.603 --> 00:06:29.220 cues or early signs that could be.

00:06:29.220 --> 00:06:31.200 The first manifestation of a problem.

00:06:31.200 --> 00:06:33.573 So I can refer this child for

00:06:33.573 --> 00:06:35.433 a further assessment or early

00:06:35.433 --> 00:06:37.749 intervention which is proven to improve

00:06:37.749 --> 00:06:40.088 over the long term functioning.

00:06:40.090 --> 00:06:42.484 I will also inform and help

00:06:42.484 --> 00:06:44.550 parents to their journey after

00:06:44.550 --> 00:06:47.203 their after neonatology and really

00:06:47.203 --> 00:06:49.398 guide them on what to expect in

00:06:49.398 --> 00:06:51.800 the future with their child.

00:06:51.800 --> 00:06:53.292 But as a researcher,

NOTE Confidence: 0.863813854444444

00:06:53.292 --> 00:06:55.157 I also collect outcome data.

NOTE Confidence: 0.863813854444444

00:06:55.160 --> 00:06:55.836 For example,

NOTE Confidence: 0.863813854444444

00:06:55.836 --> 00:06:57.864 outcome data is really important for

NOTE Confidence: 0.863813854444444

00:06:57.864 --> 00:07:00.106 benchmarking so we can identify targets

NOTE Confidence: 0.863813854444444

00:07:00.106 --> 00:07:01.614 for quality improvement endeavors,

NOTE Confidence: 0.863813854444444

00:07:01.620 --> 00:07:03.912 and it's also useful for many

NOTE Confidence: 0.863813854444444

00:07:03.912 --> 00:07:05.058 observational cohort studies

NOTE Confidence: 0.863813854444444

00:07:05.058 --> 00:07:07.018 that we do in clinical trials.

NOTE Confidence: 0.863813854444444

00:07:07.020 --> 00:07:09.444 But I also feed this outcome data to

NOTE Confidence: 0.863813854444444

00:07:09.444 --> 00:07:11.667 my colleagues in neonatology that will

NOTE Confidence: 0.863813854444444

00:07:11.667 --> 00:07:13.995 use this information to inform parents,

NOTE Confidence: 0.863813854444444

00:07:14.000 --> 00:07:16.128 and maybe we'll use it to make

NOTE Confidence: 0.863813854444444

00:07:16.128 --> 00:07:17.941 life and death decisions and

NOTE Confidence: 0.863813854444444

00:07:17.941 --> 00:07:19.605 prepare for the future.

NOTE Confidence: 0.863813854444444

00:07:19.610 --> 00:07:21.830 But what are you outcome data?

NOTE Confidence: 0.863813854444444

00:07:21.830 --> 00:07:23.270 What do we need exactly?

NOTE Confidence: 0.863813854444444

00:07:23.270 --> 00:07:24.692 So I'm showing here what we're

NOTE Confidence: 0.863813854444444

00:07:24.692 --> 00:07:26.598 doing as part of the Canadian unit.

NOTE Confidence: 0.863813854444444

00:07:26.600 --> 00:07:27.952 All follow up network,

NOTE Confidence: 0.863813854444444

00:07:27.952 --> 00:07:29.980 but this is pretty similar to

NOTE Confidence: 0.863813854444444

00:07:30.052 --> 00:07:31.712 what many large networks are

NOTE Confidence: 0.863813854444444

00:07:31.712 --> 00:07:34.391 doing in the states in the UK or

NOTE Confidence: 0.863813854444444

00:07:34.391 --> 00:07:35.976 in Australia and New Zealand.

NOTE Confidence: 0.863813854444444

00:07:35.980 --> 00:07:37.564 So we have a standardized follow-up

NOTE Confidence: 0.863813854444444

00:07:37.564 --> 00:07:39.518 visit at 18 to 24 months corrected

NOTE Confidence: 0.863813854444444

00:07:39.518 --> 00:07:41.198 age where all infants will have

NOTE Confidence: 0.863813854444444

00:07:41.198 --> 00:07:42.597 a neurological examination to

NOTE Confidence: 0.863813854444444

00:07:42.597 --> 00:07:44.721 identify signs of cerebral palsy and

NOTE Confidence: 0.863813854444444

00:07:44.721 --> 00:07:46.640 if the child has cerebral palsy,

NOTE Confidence: 0.863813854444444

00:07:46.640 --> 00:07:49.538 we then classify their level of

NOTE Confidence: 0.863813854444444

00:07:49.538 --> 00:07:52.050 motor functioning using the GMFCS.

NOTE Confidence: 0.863813854444444

00:07:52.050 --> 00:07:53.904 We also do a developmental assessment

NOTE Confidence: 0.863813854444444

00:07:53.904 --> 00:07:55.779 and many networks will be using

NOTE Confidence: 0.863813854444444

00:07:55.779 --> 00:07:57.830 the baby scales which will yield a

NOTE Confidence: 0.863813854444444

00:07:57.830 --> 00:07:59.159 developmental score for language,

NOTE Confidence: 0.863813854444444

00:07:59.160 --> 00:08:00.504 cognition and motor skills.

NOTE Confidence: 0.863813854444444

00:08:00.504 --> 00:08:03.416 And we also look at hearing based on

NOTE Confidence: 0.863813854444444

00:08:03.416 --> 00:08:05.491 audiology report and visual function

NOTE Confidence: 0.863813854444444

00:08:05.491 --> 00:08:08.028 based on ophthalmology or optometry report.

NOTE Confidence: 0.863813854444444

00:08:08.030 --> 00:08:10.949 And then what many people will do

NOTE Confidence: 0.863813854444444

00:08:10.949 --> 00:08:13.725 is determine whether this child has

NOTE Confidence: 0.863813854444444

00:08:13.725 --> 00:08:15.609 neurodevelopmental impairment or not

NOTE Confidence: 0.863813854444444

00:08:15.609 --> 00:08:18.030 based on presence of cerebral palsy,

NOTE Confidence: 0.863813854444444

00:08:18.030 --> 00:08:19.114 developmental delay,

NOTE Confidence: 0.863813854444444

00:08:19.114 --> 00:08:21.824 hearing impairment or visual impairment.

NOTE Confidence: 0.863813854444444

00:08:21.830 --> 00:08:24.246 So the child can either have no NDI,

NOTE Confidence: 0.863813854444444

00:08:24.250 --> 00:08:27.298 which means obviously none of these.

NOTE Confidence: 0.863813854444444

00:08:27.300 --> 00:08:29.099 If we then we could talk about

NOTE Confidence: 0.863813854444444

00:08:29.099 --> 00:08:31.111 mild and moderate and I and the

NOTE Confidence: 0.863813854444444

00:08:31.111 --> 00:08:32.596 definition might change by networks,

NOTE Confidence: 0.863813854444444

00:08:32.600 --> 00:08:34.640 but for us it's a child with several

NOTE Confidence: 0.863813854444444

00:08:34.640 --> 00:08:36.491 palsy with a gross motor function

NOTE Confidence: 0.863813854444444

00:08:36.491 --> 00:08:38.411 classification system of one or two,

NOTE Confidence: 0.863813854444444

00:08:38.420 --> 00:08:41.374 which means that later on this child.

NOTE Confidence: 0.863813854444444

00:08:41.380 --> 00:08:43.466 Might have some limping when he or

NOTE Confidence: 0.863813854444444

00:08:43.466 --> 00:08:45.758 she is walking or climbing up stairs.

NOTE Confidence: 0.863813854444444

00:08:45.760 --> 00:08:47.161 Might need braces,

NOTE Confidence: 0.863813854444444

00:08:47.161 --> 00:08:49.826 but is usually quite functional actually,

NOTE Confidence: 0.863813854444444

00:08:49.826 --> 00:08:51.456 like maybe for the GMFCS.

NOTE Confidence: 0.863813854444444

00:08:51.460 --> 00:08:53.290 Some people might not even notice

NOTE Confidence: 0.863813854444444

00:08:53.290 --> 00:08:55.379 that this child has several palsy.

NOTE Confidence: 0.863813854444444

00:08:55.380 --> 00:08:56.304 For developmental delay,

NOTE Confidence: 0.863813854444444

00:08:56.304 --> 00:08:58.460 that is based on a Bailey scale

NOTE Confidence: 0.863813854444444

00:08:58.521 --> 00:09:00.336 score below 1 standard deviation,

NOTE Confidence: 0.863813854444444

00:09:00.340 --> 00:09:02.265 below the mean, which means below 85.

NOTE Confidence: 0.863813854444444

00:09:02.270 --> 00:09:03.794 But some networks will be more

NOTE Confidence: 0.863813854444444

00:09:03.794 --> 00:09:04.810 severe and will use

NOTE Confidence: 0.856476743125

00:09:04.865 --> 00:09:06.335 a definition of less than 70,

NOTE Confidence: 0.856476743125

00:09:06.340 --> 00:09:07.920 which means below 2 standard

NOTE Confidence: 0.856476743125

00:09:07.920 --> 00:09:09.459 deviation below the.

NOTE Confidence: 0.856476743125

00:09:09.460 --> 00:09:12.084 And then a child with some degree of

NOTE Confidence: 0.856476743125

00:09:12.084 --> 00:09:14.006 hearing impairment or visual impairment

NOTE Confidence: 0.856476743125

00:09:14.006 --> 00:09:16.016 will usually enter this category.

NOTE Confidence: 0.856476743125

00:09:16.020 --> 00:09:17.994 And then we have the severe ENVI,

NOTE Confidence: 0.856476743125

00:09:18.000 --> 00:09:20.285 which are children with cerebral

NOTE Confidence: 0.856476743125

00:09:20.285 --> 00:09:22.113 palsy that requires some,

NOTE Confidence: 0.856476743125

00:09:22.120 --> 00:09:24.640 that will require help to emulate,

NOTE Confidence: 0.856476743125

00:09:24.640 --> 00:09:27.335 most likely like they will need a

NOTE Confidence: 0.856476743125

00:09:27.335 --> 00:09:29.387 wheelchair and depending on networks for

NOTE Confidence: 0.856476743125

00:09:29.387 --> 00:09:32.510 us we use 345 as something as severe.

NOTE Confidence: 0.856476743125

00:09:32.510 --> 00:09:34.323 But I know for example in Australia

NOTE Confidence: 0.856476743125

00:09:34.323 --> 00:09:36.169 it's only children with a level four

NOTE Confidence: 0.856476743125

00:09:36.169 --> 00:09:37.693 and five who are considered severe,

NOTE Confidence: 0.856476743125

00:09:37.700 --> 00:09:39.548 which means that they do need

NOTE Confidence: 0.856476743125

00:09:39.548 --> 00:09:41.589 someone to help them move around.

NOTE Confidence: 0.856476743125

00:09:41.590 --> 00:09:42.550 For developmental delay,

NOTE Confidence: 0.856476743125

00:09:42.550 --> 00:09:44.470 it's going to be 2 standard

NOTE Confidence: 0.856476743125

00:09:44.470 --> 00:09:45.609 deviations below the mean,

NOTE Confidence: 0.856476743125

00:09:45.610 --> 00:09:47.420 although like some networks will

NOTE Confidence: 0.856476743125

00:09:47.420 --> 00:09:49.230 will use 3 standard deviations

NOTE Confidence: 0.856476743125

00:09:49.294 --> 00:09:50.789 below the mean and severe,

NOTE Confidence: 0.856476743125

00:09:50.790 --> 00:09:52.638 and the eye will also encompass

NOTE Confidence: 0.856476743125

19

00:09:52.638 --> 00:09:53.562 severe hearing impairment,

NOTE Confidence: 0.856476743125

00:09:53.570 --> 00:09:55.342 which means requiring hearing

NOTE Confidence: 0.856476743125

00:09:55.342 --> 00:09:57.114 aids and bilateral blindness.

NOTE Confidence: 0.61206347

00:09:59.160 --> 00:10:01.534 So if we look at outcomes of

NOTE Confidence: 0.61206347

00:10:01.534 --> 00:10:03.360 babies born below 28 weeks,

NOTE Confidence: 0.61206347

00:10:03.360 --> 00:10:05.656 we have a survival rate overall of

NOTE Confidence: 0.61206347

00:10:05.660 --> 00:10:07.645 81% and majority actually don't

NOTE Confidence: 0.61206347

00:10:07.645 --> 00:10:10.360 have any NI with 55% with no MDI.

NOTE Confidence: 0.61206347

00:10:10.360 --> 00:10:13.012 Modern moderate is going to be about 29% and

NOTE Confidence: 0.61206347

00:10:13.012 --> 00:10:15.405 significant and there is going to be 17%.

NOTE Confidence: 0.61206347

00:10:15.405 --> 00:10:18.432 And if we look later on at 6 to 7 years

NOTE Confidence: 0.61206347

00:10:18.432 --> 00:10:20.682 that those are numbers from actually

NOTE Confidence: 0.61206347

00:10:20.682 --> 00:10:23.000 the United States by Susan Hintz,

NOTE Confidence: 0.61206347

00:10:23.000 --> 00:10:25.415 62% don't have any neurodevelopmental

NOTE Confidence: 0.61206347

00:10:25.415 --> 00:10:27.040 impairment, whereas moderate to

NOTE Confidence: 0.61206347

00:10:27.040 --> 00:10:32.130 severe ND I is found in about 15%.

NOTE Confidence: 0.61206347

00:10:32.130 --> 00:10:34.825 But what about the quality of life?

NOTE Confidence: 0.61206347

00:10:34.830 --> 00:10:36.966 If we look at studies from Sarah Segal,

NOTE Confidence: 0.61206347

00:10:36.970 --> 00:10:40.475 who is our, I would say our up program

NOTE Confidence: 0.61206347

00:10:40.475 --> 00:10:42.774 free of neonatal follow up here in

NOTE Confidence: 0.61206347

00:10:42.774 --> 00:10:44.310 Canada using objective measures,

NOTE Confidence: 0.61206347

00:10:44.310 --> 00:10:46.164 health related quality of life will

NOTE Confidence: 0.61206347

00:10:46.164 --> 00:10:48.582 be rated as worst in individuals born

NOTE Confidence: 0.61206347

00:10:48.582 --> 00:10:51.193 preterm when compared to full term controls.

NOTE Confidence: 0.61206347

00:10:51.200 --> 00:10:54.224 But if you actually ask preterm

NOTE Confidence: 0.61206347

00:10:54.224 --> 00:10:55.736 more more subjectively,

NOTE Confidence: 0.61206347

00:10:55.740 --> 00:10:59.980 it is similar to control born full term.

NOTE Confidence: 0.61206347

00:10:59.980 --> 00:11:01.360 And that actually leads me,

NOTE Confidence: 0.61206347

00:11:01.360 --> 00:11:03.634 if you look at this kid, you know,

NOTE Confidence: 0.61206347

00:11:03.634 --> 00:11:05.119 this kid has cerebral palsy,

NOTE Confidence: 0.61206347

00:11:05.120 --> 00:11:07.479 he needs a Walker to walk around.

NOTE Confidence: 0.61206347

00:11:07.480 --> 00:11:09.846 So he's actually with a gross motor

NOTE Confidence: 0.61206347

00:11:09.846 --> 00:11:11.766 function classification system of three.

NOTE Confidence: 0.61206347

00:11:11.766 --> 00:11:15.376 So in many networks that would be

NOTE Confidence: 0.61206347

00:11:15.376 --> 00:11:16.954 considered severe neurodevelopmental

NOTE Confidence: 0.61206347

00:11:16.954 --> 00:11:18.829 impairment and actually based.

NOTE Confidence: 0.61206347

00:11:18.830 --> 00:11:21.590 On this kid who will feed many statistics,

NOTE Confidence: 0.61206347

00:11:21.590 --> 00:11:23.270 maybe some, you know,

NOTE Confidence: 0.61206347

00:11:23.270 --> 00:11:26.310 maybe some kids in the NICU will.

NOTE Confidence: 0.61206347

00:11:26.310 --> 00:11:28.452 Will be faced with the decision of

NOTE Confidence: 0.61206347

00:11:28.452 --> 00:11:30.336 maybe withdrawing care or even not

NOTE Confidence: 0.61206347

00:11:30.336 --> 00:11:31.726 starting care because, you know,

NOTE Confidence: 0.61206347

00:11:31.726 --> 00:11:33.630 maybe they're at risk of severe and die.

NOTE Confidence: 0.61206347

00:11:33.630 --> 00:11:35.578 But I would argue that, you know,

NOTE Confidence: 0.61206347

00:11:35.578 --> 00:11:38.052 when I look at this kid and I see

NOTE Confidence: 0.61206347

00:11:38.052 --> 00:11:40.818 several of them, he looks pretty happy.

NOTE Confidence: 0.61206347

00:11:40.818 --> 00:11:42.586 He's actually having fun,

NOTE Confidence: 0.61206347

00:11:42.590 --> 00:11:45.248 he's having friends and he's able,

NOTE Confidence: 0.61206347

00:11:45.250 --> 00:11:47.490 even though he has some motor limitation,

NOTE Confidence: 0.61206347

00:11:47.490 --> 00:11:50.145 he's actually able to move

NOTE Confidence: 0.61206347

00:11:50.145 --> 00:11:51.207 independently around.

NOTE Confidence: 0.61206347

00:11:51.210 --> 00:11:51.534 So,

NOTE Confidence: 0.61206347

00:11:51.534 --> 00:11:52.182 you know,

NOTE Confidence: 0.61206347

00:11:52.182 --> 00:11:54.831 is that really severe and should we be

NOTE Confidence: 0.61206347

00:11:54.831 --> 00:11:57.029 making a decision based on a child?

NOTE Confidence: 0.61206347

00:11:57.030 --> 00:12:00.410 Has some difficulty walking.

NOTE Confidence: 0.61206347

00:12:00.410 --> 00:12:02.496 This is really like somewhere where I

NOTE Confidence: 0.61206347

00:12:02.496 --> 00:12:04.448 got a little bit uncomfortable with

NOTE Confidence: 0.61206347

00:12:04.448 --> 00:12:07.110 this whole notion of severe and I as

NOTE Confidence: 0.61206347

00:12:07.110 --> 00:12:08.958 a pediatrician and I will now turn

NOTE Confidence: 0.61206347

00:12:08.958 --> 00:12:11.440 to let Rebecca talk about her story.

NOTE Confidence: 0.90158437

00:12:15.210 --> 00:12:16.610 Thank you so much, Mike.

NOTE Confidence: 0.8343542375

00:12:16.890 --> 00:12:18.098 So on Monday, September

NOTE Confidence: 0.821311906

00:12:19.330 --> 00:12:21.416 21st, 2009, my children Mary and Irene

NOTE Confidence: 0.821311906

00:12:21.416 --> 00:12:24.157 and Lily Ruth were born at 25 weeks and

NOTE Confidence: 0.821311906

00:12:24.157 --> 00:12:25.927 five days gestational age, weighing

NOTE Confidence: 0.821311906

00:12:25.927 --> 00:12:29.389 760 grams and 840 grams respectively.

NOTE Confidence: 0.821311906

00:12:29.390 --> 00:12:30.710 It was my first pregnancy,

NOTE Confidence: 0.821311906

00:12:30.710 --> 00:12:32.310 and they were born after a week spent

NOTE Confidence: 0.821311906

00:12:32.310 --> 00:12:34.027 at Saint Justine Hospital in Montreal,

NOTE Confidence: 0.821311906

00:12:34.030 --> 00:12:36.631 where doctors had tried to stop my labor that

NOTE Confidence: 0.821311906

00:12:36.631 --> 00:12:39.230 had unexpectedly started three days prior.

NOTE Confidence: 0.821311906

00:12:39.230 --> 00:12:41.022 My husband Jason and I at that time

NOTE Confidence: 0.821311906

00:12:41.022 --> 00:12:43.007 had no idea what it meant to give

NOTE Confidence: 0.821311906

00:12:43.007 --> 00:12:45.010 birth to babies who were so premature.

NOTE Confidence: 0.821311906

00:12:45.010 --> 00:12:46.677 And the next months would prove to be the

NOTE Confidence: 0.821311906

00:12:46.677 --> 00:12:48.966 most traumatic and difficult of our lives.

NOTE Confidence: 0.821311906

00:12:48.970 --> 00:12:51.350 The following Sunday week after their birth,

NOTE Confidence: 0.821311906

00:12:51.350 --> 00:12:53.686 will we developed an infection that led to

NOTE Confidence: 0.821311906

00:12:53.686 --> 00:12:55.447 intestinal damage and a brain hemorrhage.

NOTE Confidence: 0.821311906

00:12:55.450 --> 00:12:56.800 And she died that afternoon.

NOTE Confidence: 0.821311906

00:12:56.800 --> 00:12:58.564 And in fact, yesterday was the

NOTE Confidence: 0.821311906

00:12:58.564 --> 00:13:00.130 13th anniversary of her death.

NOTE Confidence: 0.821311906

00:13:00.130 --> 00:13:02.048 It turned out that Marin had the

NOTE Confidence: 0.821311906

00:13:02.048 --> 00:13:03.696 same bacterial infection and she was

NOTE Confidence: 0.821311906

00:13:03.696 --> 00:13:05.250 started on a course of antibiotics

NOTE Confidence: 0.821311906

00:13:05.250 --> 00:13:06.428 several weeks after birth.

NOTE Confidence: 0.821311906

00:13:06.430 --> 00:13:08.670 She required a PDA allegation that was risky.

NOTE Confidence: 0.821311906

00:13:08.670 --> 00:13:10.050 Because of her instability.

NOTE Confidence: 0.821311906

00:13:10.050 --> 00:13:11.775 She caught a fungal infection

NOTE Confidence: 0.821311906

00:13:11.775 --> 00:13:13.130 that needed treatment.

NOTE Confidence: 0.821311906

00:13:13.130 --> 00:13:14.530 She developed severe BPD.

NOTE Confidence: 0.821311906

00:13:14.530 --> 00:13:17.271 And spent lots of time on 100% oxygen

NOTE Confidence: 0.821311906

00:13:17.271 --> 00:13:19.308 or in a high frequency ventilator and

NOTE Confidence: 0.821311906

00:13:19.308 --> 00:13:21.639 had a number of respiratory crises.

NOTE Confidence: 0.821311906

00:13:21.640 --> 00:13:23.576 She was on a ventilator for a total

NOTE Confidence: 0.821311906

00:13:23.576 --> 00:13:25.261 of seven weeks and she required

NOTE Confidence: 0.821311906

00:13:25.261 --> 00:13:26.977 steroids to wean her from it.

NOTE Confidence: 0.821311906

00:13:26.980 --> 00:13:29.420 Finally, about two months into her NICU stay,

NOTE Confidence: 0.821311906

00:13:29.420 --> 00:13:31.124 things started to stabilize.

NOTE Confidence: 0.821311906

00:13:31.124 --> 00:13:33.680 Maren kept slowly growing and progressing,

NOTE Confidence: 0.821311906

00:13:33.680 --> 00:13:35.591 and after about three months she was

NOTE Confidence: 0.821311906

00:13:35.591 --> 00:13:37.393 finally moved to the intermediate facility

NOTE Confidence: 0.821311906

00:13:37.393 --> 00:13:39.870 where we could prepare to take her home.

NOTE Confidence: 0.821311906

00:13:39.870 --> 00:13:41.223 A few weeks before we thought

NOTE Confidence: 0.821311906

00:13:41.223 --> 00:13:42.888 Marion might finally be discharged,

NOTE Confidence: 0.821311906

00:13:42.890 --> 00:13:44.576 we were approached by a doctor

NOTE Confidence: 0.821311906

00:13:44.576 --> 00:13:46.330 about performing a head MRI on her.

NOTE Confidence: 0.821311906

00:13:46.330 --> 00:13:48.242 At the time, back in 2009,

NOTE Confidence: 0.821311906

00:13:48.242 --> 00:13:50.356 this was standard for babies born below

NOTE Confidence: 0.821311906

00:13:50.356 --> 00:13:52.866 26 weeks gestational age at Saint Justine,

NOTE Confidence: 0.821311906

00:13:52.870 --> 00:13:54.355 and we agreed without really

NOTE Confidence: 0.821311906

00:13:54.355 --> 00:13:55.246 thinking about it.

NOTE Confidence: 0.821311906

00:13:55.250 --> 00:13:55.616 Shockingly,

NOTE Confidence: 0.821311906

00:13:55.616 --> 00:13:57.446 the MRI results indicated that

NOTE Confidence: 0.821311906

00:13:57.446 --> 00:13:59.684 there was moderate damage to marine

NOTE Confidence: 0.821311906

00:13:59.684 --> 00:14:01.484 cerebellum caused by a previously

NOTE Confidence: 0.821311906

00:14:01.484 --> 00:14:02.564 undetected brain bleed.

NOTE Confidence: 0.821311906

00:14:02.570 --> 00:14:04.150 This news was completely unexpected

NOTE Confidence: 0.821311906

00:14:04.150 --> 00:14:06.880 to us and nobody could really tell us

NOTE Confidence: 0.821311906

00:14:06.880 --> 00:14:08.690 what this devastating diagnosis meant.

NOTE Confidence: 0.821311906

00:14:08.690 --> 00:14:10.050 So with this knowledge, Marin.

NOTE Confidence: 0.821311906

00:14:10.050 --> 00:14:11.600 Discharge from the hospital at

NOTE Confidence: 0.821311906

00:14:11.600 --> 00:14:13.150 the end of January 2010,

NOTE Confidence: 0.821311906

00:14:13.150 --> 00:14:15.830 four months and one week after her birth.

NOTE Confidence: 0.821311906

00:14:15.830 --> 00:14:18.374 Most people like me have no idea about

NOTE Confidence: 0.821311906

00:14:18.374 --> 00:14:21.296 the impacts of preterm birth on long term

NOTE Confidence: 0.821311906

00:14:21.296 --> 00:14:23.609 outcomes and the development of children.

NOTE Confidence: 0.821311906

00:14:23.610 --> 00:14:25.304 I did know my way around things

NOTE Confidence: 0.821311906

00:14:25.304 --> 00:14:26.650 like Google Scholar and PUB Med,

NOTE Confidence: 0.821311906

00:14:26.650 --> 00:14:28.421 so I turned to the medical research

NOTE Confidence: 0.821311906

00:14:28.421 --> 00:14:29.949 literature to try to get an idea,

NOTE Confidence: 0.821311906

00:14:29.950 --> 00:14:31.454 like a crystal ball,

NOTE Confidence: 0.821311906

00:14:31.454 --> 00:14:33.334 of what marini's medical history

NOTE Confidence: 0.821311906

00:14:33.334 --> 00:14:35.748 might mean for her future and for us.

NOTE Confidence: 0.821311906

00:14:35.750 --> 00:14:38.060 Now remember that Marian was born at

NOTE Confidence: 0.821311906

00:14:38.060 --> 00:14:41.058 under 26 weeks gestational age weighing 760.

NOTE Confidence: 0.821311906

00:14:41.058 --> 00:14:42.998 Grams she had PDA surgery,

NOTE Confidence: 0.821311906

00:14:43.000 --> 00:14:44.160 a number of infections,

NOTE Confidence: 0.821311906

00:14:44.160 --> 00:14:45.900 was on a ventilator for seven

NOTE Confidence: 0.821311906

00:14:45.957 --> 00:14:47.377 weeks and needed steroids.

NOTE Confidence: 0.821311906

00:14:47.380 --> 00:14:49.020 She came home on oxygen.

NOTE Confidence: 0.821311906

00:14:49.020 --> 00:14:50.604 She couldn't be held for weeks

NOTE Confidence: 0.821311906

00:14:50.604 --> 00:14:51.396 after her birth,

NOTE Confidence: 0.821311906

00:14:51.400 --> 00:14:53.340 and she had cerebellar damage.

NOTE Confidence: 0.821311906

00:14:53.340 --> 00:14:55.302 So what do you think the

NOTE Confidence: 0.821311906

00:14:55.302 --> 00:14:56.610 research told me about

NOTE Confidence: 0.903663835294118

00:14:56.688 --> 00:14:59.054 the outcomes of a child like this?

NOTE Confidence: 0.903663835294118

00:14:59.060 --> 00:15:00.234 So as my discussed,

NOTE Confidence: 0.903663835294118

00:15:00.234 --> 00:15:02.019 there's a substantial focus in

NOTE Confidence: 0.903663835294118

00:15:02.019 --> 00:15:04.270 pre term birth outcome research

NOTE Confidence: 0.903663835294118

00:15:04.270 --> 00:15:06.502 with neurocognitive outcomes or

NOTE Confidence: 0.903663835294118

00:15:06.502 --> 00:15:08.176 MDI neurodevelopmental impairment,

NOTE Confidence: 0.903663835294118

00:15:08.180 --> 00:15:09.988 for example blindness, deafness,

NOTE Confidence: 0.903663835294118

00:15:09.988 --> 00:15:13.360 cerebral palsy and IQ of less than 85,

NOTE Confidence: 0.903663835294118

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00:15:13.360 --> 00:15:15.190 but also things like learning

NOTE Confidence: 0.903663835294118

00:15:15.190 --> 00:15:16.654 disability and vision problems.

NOTE Confidence: 0.903663835294118

00:15:16.660 --> 00:15:18.348 The problem with these measures that

NOTE Confidence: 0.903663835294118

00:15:18.348 --> 00:15:20.238 they are reported as dichotomous,

NOTE Confidence: 0.903663835294118

00:15:20.240 --> 00:15:22.060 so either a child has them or

NOTE Confidence: 0.903663835294118

00:15:22.060 --> 00:15:23.254 they don't without acknowledging

NOTE Confidence: 0.903663835294118

00:15:23.254 --> 00:15:25.372 that most of these outcomes are

NOTE Confidence: 0.903663835294118

00:15:25.372 --> 00:15:27.298 continuous and fall within a range.

NOTE Confidence: 0.903663835294118

00:15:27.300 --> 00:15:27.724 For example,

NOTE Confidence: 0.903663835294118

00:15:27.724 --> 00:15:29.590 we know that children can have a variety of.

NOTE Confidence: 0.903663835294118

00:15:29.590 --> 00:15:32.116 Vision problems or a diversity of

NOTE Confidence: 0.903663835294118

00:15:32.116 --> 00:15:33.800 learning differences or disabilities.

NOTE Confidence: 0.903663835294118

00:15:33.800 --> 00:15:35.588 There's also very little research that

NOTE Confidence: 0.903663835294118

00:15:35.588 --> 00:15:37.140 looks at what these neurocognitive

NOTE Confidence: 0.903663835294118

00:15:37.140 --> 00:15:39.296 outcomes mean for the quality of life

NOTE Confidence: 0.903663835294118

00:15:39.296 --> 00:15:41.472 and for the day-to-day functioning of

NOTE Confidence: 0.903663835294118

00:15:41.472 --> 00:15:43.352 preterm children and their families.

NOTE Confidence: 0.903663835294118

00:15:43.360 --> 00:15:45.061 Darren had lots of visits to seeing

NOTE Confidence: 0.903663835294118

00:15:45.061 --> 00:15:46.634 Justine to the follow-up clinic where

NOTE Confidence: 0.903663835294118

00:15:46.634 --> 00:15:48.475 she was given tests such as the

NOTE Confidence: 0.903663835294118

00:15:48.526 --> 00:15:50.276 Bayley scales of infant development.

NOTE Confidence: 0.903663835294118

00:15:50.280 --> 00:15:52.038 And we know that welby's tests

NOTE Confidence: 0.903663835294118

00:15:52.038 --> 00:15:53.565 can identify children that may

NOTE Confidence: 0.903663835294118

00:15:53.565 --> 00:15:54.757 need more follow-up care.

NOTE Confidence: 0.903663835294118

00:15:54.760 --> 00:15:56.896 They actually have limited predictive value,

NOTE Confidence: 0.903663835294118

00:15:56.900 --> 00:15:58.675 so they might actually be

NOTE Confidence: 0.903663835294118

00:15:58.675 --> 00:16:00.450 unhelpful or relevant for parents.

NOTE Confidence: 0.903663835294118

00:16:00.450 --> 00:16:01.878 Most of the outcome measures that

NOTE Confidence: 0.903663835294118

00:16:01.878 --> 00:16:03.531 have been chosen for research have

NOTE Confidence: 0.903663835294118

00:16:03.531 --> 00:16:04.827 been chosen by neonatologists,

NOTE Confidence: 0.903663835294118

00:16:04.830 --> 00:16:05.804 developmental psychologists,

NOTE Confidence: 0.903663835294118

31

00:16:05.804 --> 00:16:07.752 or clinicians without considering

NOTE Confidence: 0.903663835294118

00:16:07.752 --> 00:16:10.116 what parents or families feel

NOTE Confidence: 0.903663835294118

00:16:10.116 --> 00:16:11.548 are important or impactful.

NOTE Confidence: 0.903663835294118

00:16:11.550 --> 00:16:12.495 As an example,

NOTE Confidence: 0.903663835294118

00:16:12.495 --> 00:16:14.700 Marin had to be hospitalized with pneumonia

NOTE Confidence: 0.903663835294118

00:16:14.760 --> 00:16:16.986 numerous times before her third birthday,

NOTE Confidence: 0.903663835294118

00:16:16.990 --> 00:16:19.350 which was very difficult for all of us.

NOTE Confidence: 0.903663835294118

00:16:19.350 --> 00:16:20.710 There's very little, if any,

NOTE Confidence: 0.903663835294118

00:16:20.710 --> 00:16:22.790 research that considers rehospitalization

NOTE Confidence: 0.903663835294118

00:16:22.790 --> 00:16:24.870 as an impactful outcome.

NOTE Confidence: 0.903663835294118

00:16:24.870 --> 00:16:26.370 I really wanted to know how

NOTE Confidence: 0.903663835294118

00:16:26.370 --> 00:16:27.770 families cope with the stress,

NOTE Confidence: 0.903663835294118

00:16:27.770 --> 00:16:28.330 the uncertainty,

NOTE Confidence: 0.903663835294118

00:16:28.330 --> 00:16:30.290 and the potential difficulties of having a.

NOTE Confidence: 0.903663835294118

00:16:30.290 --> 00:16:31.950 Preterm child but information about

NOTE Confidence: 0.903663835294118

00:16:31.950 --> 00:16:34.440 this is very hard to find as well.

00:16:34.440 --> 00:16:36.722 What was very easy to find was

00:16:36.722 --> 00:16:38.133 medicalized deficit based research

00:16:38.133 --> 00:16:40.335 that focused on all the problems

00:16:40.335 --> 00:16:42.356 that preterm children as a group

00:16:42.356 --> 00:16:44.066 have without any sort of discussion

00:16:44.066 --> 00:16:45.844 or examination of their positive

00:16:45.844 --> 00:16:48.560 attributes and what they can do and be.

00:16:48.560 --> 00:16:50.639 I was recently reading a study that

00:16:50.639 --> 00:16:52.237 asked about parents perceptions of

00:16:52.237 --> 00:16:54.181 the health related quality of life

00:16:54.181 --> 00:16:56.240 of preterm children with severe BPD.

00:16:56.240 --> 00:16:58.456 The authors of the paper noted that the

00:16:58.456 --> 00:17:00.298 normal emotional health of these children.

00:17:00.300 --> 00:17:02.260 Maybe an area of resilience

00:17:02.260 --> 00:17:03.044 that's unrecognized.

00:17:03.050 --> 00:17:04.863 And I thought that was really funny

NOTE Confidence: 0.903663835294118

00:17:04.863 --> 00:17:06.015 because parents clearly recognize

NOTE Confidence: 0.903663835294118

00:17:06.015 --> 00:17:07.630 that their children are resilient,

NOTE Confidence: 0.903663835294118

00:17:07.630 --> 00:17:09.877 but it's the research community that doesn't

NOTE Confidence: 0.903663835294118

00:17:09.877 --> 00:17:12.087 really value this as an outcome to study.

NOTE Confidence: 0.903663835294118

00:17:12.090 --> 00:17:13.938 I find it very strange that as a

NOTE Confidence: 0.903663835294118

00:17:13.938 --> 00:17:15.907 society we spend huge amounts of time,

NOTE Confidence: 0.903663835294118

00:17:15.910 --> 00:17:17.780 money and effort to medically

NOTE Confidence: 0.903663835294118

00:17:17.780 --> 00:17:19.650 intervene to save preterm children,

NOTE Confidence: 0.903663835294118

00:17:19.650 --> 00:17:21.546 only to turn around and spend more time,

NOTE Confidence: 0.903663835294118

00:17:21.550 --> 00:17:23.890 money and brainpower to conduct research

NOTE Confidence: 0.903663835294118

00:17:23.890 --> 00:17:26.426 that suggests how atypical they are and

NOTE Confidence: 0.903663835294118

00:17:26.426 --> 00:17:28.547 how in most measures they are inferior.

NOTE Confidence: 0.903663835294118

00:17:28.550 --> 00:17:29.832 As you will see from some of the

NOTE Confidence: 0.903663835294118

00:17:29.832 --> 00:17:31.666 data that we'll present in this talk,

NOTE Confidence: 0.903663835294118

00:17:31.670 --> 00:17:33.335 parents are pretty realistic about

NOTE Confidence: 0.903663835294118

00:17:33.335 --> 00:17:35.000 the concerns for their children,

NOTE Confidence: 0.903663835294118

00:17:35.000 --> 00:17:36.560 which do include developmental

NOTE Confidence: 0.903663835294118

00:17:36.560 --> 00:17:38.510 delays and difficulties in school.

NOTE Confidence: 0.903663835294118

00:17:38.510 --> 00:17:39.490 However, for many parents,

NOTE Confidence: 0.903663835294118

00:17:39.490 --> 00:17:40.960 this is just part of who

NOTE Confidence: 0.858086593846154

00:17:41.009 --> 00:17:41.729 their child is,

NOTE Confidence: 0.858086593846154

00:17:41.730 --> 00:17:43.650 and it doesn't necessarily have a

NOTE Confidence: 0.858086593846154

00:17:43.650 --> 00:17:45.356 massive impact on their day-to-day

NOTE Confidence: 0.858086593846154

00:17:45.356 --> 00:17:47.570 quality of life or their happiness.

NOTE Confidence: 0.858086593846154

00:17:47.570 --> 00:17:49.705 The voices of parents and children are

NOTE Confidence: 0.858086593846154

00:17:49.705 --> 00:17:51.610 largely absent in outcome research,

NOTE Confidence: 0.858086593846154

00:17:51.610 --> 00:17:53.885 although this is slowly starting to change.

NOTE Confidence: 0.858086593846154

00:17:53.890 --> 00:17:55.465 These voices are really important

NOTE Confidence: 0.858086593846154

00:17:55.465 --> 00:17:57.040 because they provide a critical

NOTE Confidence: 0.858086593846154

00:17:57.094 --> 00:17:58.550 counterpoint to deficit based.

NOTE Confidence: 0.858086593846154

00:17:58.550 --> 00:17:59.765 Research. For example,

NOTE Confidence: 0.858086593846154

00:17:59.765 --> 00:18:01.385 as my just mentioned,

NOTE Confidence: 0.858086593846154

00:18:01.390 --> 00:18:02.680 studies that examine the quality

NOTE Confidence: 0.858086593846154

00:18:02.680 --> 00:18:04.294 of life and function of extremely

NOTE Confidence: 0.858086593846154

00:18:04.294 --> 00:18:05.950 preterm children as they get older

NOTE Confidence: 0.858086593846154

00:18:05.950 --> 00:18:07.420 have shown that these individuals

NOTE Confidence: 0.858086593846154

00:18:07.420 --> 00:18:08.895 generally rate their quality of

NOTE Confidence: 0.858086593846154

00:18:08.895 --> 00:18:10.854 life and their happiness as equal

NOTE Confidence: 0.858086593846154

00:18:10.854 --> 00:18:13.360 to that of their term born peers.

NOTE Confidence: 0.858086593846154

00:18:13.360 --> 00:18:14.955 The majority of extremely preterm

NOTE Confidence: 0.858086593846154

00:18:14.955 --> 00:18:17.480 children end up as adults who are content,

NOTE Confidence: 0.858086593846154

00:18:17.480 --> 00:18:18.893 employed, living independently,

NOTE Confidence: 0.858086593846154

00:18:18.893 --> 00:18:21.719 and are contributing members of society.

NOTE Confidence: 0.858086593846154

00:18:21.720 --> 00:18:23.385 But this pretty important information

NOTE Confidence: 0.858086593846154

00:18:23.385 --> 00:18:25.748 gets drowned out by research that focuses

NOTE Confidence: 0.858086593846154

00:18:25.748 --> 00:18:27.680 on what's wrong with preterm children,

NOTE Confidence: 0.858086593846154

00:18:27.680 --> 00:18:28.790 one of the reasons why.

NOTE Confidence: 0.858086593846154

00:18:28.790 --> 00:18:30.255 This parent centered research is

NOTE Confidence: 0.858086593846154

00:18:30.255 --> 00:18:32.338 of great interest to me is because

NOTE Confidence: 0.858086593846154

00:18:32.338 --> 00:18:34.284 I was curious to learn about other

NOTE Confidence: 0.858086593846154

00:18:34.284 --> 00:18:35.832 parents responses to their preterm

NOTE Confidence: 0.858086593846154

00:18:35.832 --> 00:18:37.656 birth and how they regarded the

NOTE Confidence: 0.858086593846154

00:18:37.660 --> 00:18:39.820 impact of prematurity on their lives.

NOTE Confidence: 0.858086593846154

00:18:39.820 --> 00:18:40.920 This is information,

NOTE Confidence: 0.858086593846154

00:18:40.920 --> 00:18:42.548 information that's really missing

NOTE Confidence: 0.858086593846154

00:18:42.548 --> 00:18:44.990 from research and that could be

NOTE Confidence: 0.858086593846154

00:18:45.061 --> 00:18:46.876 of great benefit to everyone.

NOTE Confidence: 0.858086593846154

00:18:46.880 --> 00:18:48.320 So today, Marin is a happy,

NOTE Confidence: 0.858086593846154

00:18:48.320 --> 00:18:49.464 healthy 13 year old.

NOTE Confidence: 0.858086593846154

00:18:49.464 --> 00:18:51.180 She started Grade 8 this year,

NOTE Confidence: 0.858086593846154

00:18:51.180 --> 00:18:53.196 her second year of high school in Quebec,

NOTE Confidence: 0.858086593846154

00:18:53.200 --> 00:18:54.496 and despite being one of the

NOTE Confidence: 0.858086593846154

00:18:54.496 --> 00:18:55.650 youngest children in her class,

NOTE Confidence: 0.858086593846154

00:18:55.650 --> 00:18:57.390 because the grade cutoff is the

NOTE Confidence: 0.858086593846154

00:18:57.390 --> 00:18:59.287 end of September here and being

NOTE Confidence: 0.858086593846154

00:18:59.287 --> 00:19:00.639 born four months premature,

NOTE Confidence: 0.858086593846154

00:19:00.640 --> 00:19:01.980 things are going pretty well.

NOTE Confidence: 0.858086593846154

00:19:01.980 --> 00:19:03.480 She takes the metro to school

NOTE Confidence: 0.858086593846154

00:19:03.480 --> 00:19:04.480 by herself each morning.

NOTE Confidence: 0.858086593846154

00:19:04.480 --> 00:19:05.704 She's made good friends.

NOTE Confidence: 0.858086593846154

00:19:05.704 --> 00:19:06.316 She's bilingual,

NOTE Confidence: 0.858086593846154

00:19:06.320 --> 00:19:08.200 she loves to read and ride her bike.

NOTE Confidence: 0.858086593846154

00:19:08.200 --> 00:19:09.760 She plays the piano and is

NOTE Confidence: 0.858086593846154

00:19:09.760 --> 00:19:10.540 learning the flute.

NOTE Confidence: 0.858086593846154

00:19:10.540 --> 00:19:13.076 She swims and figure skates and does karate.

NOTE Confidence: 0.858086593846154

00:19:13.080 --> 00:19:14.898 She also has a slower processing

NOTE Confidence: 0.858086593846154

00:19:14.898 --> 00:19:17.100 speed and a weak working memory.

00:19:17.100 --> 00:19:18.710 And was diagnosed with a

00:19:18.710 --> 00:19:19.676 math learning disability.

00:19:19.680 --> 00:19:21.085 These are all hallmarks of

00:19:21.085 --> 00:19:22.310 extreme prematurity that we can

00:19:22.310 --> 00:19:23.860 read about in the literature,

00:19:23.860 --> 00:19:25.125 and they would certainly make

00:19:25.125 --> 00:19:26.671 her less than perfect in the

00:19:26.671 --> 00:19:28.039 eyes of a follow up physician.

00:19:28.040 --> 00:19:30.020 But they don't define humaran is,

00:19:30.020 --> 00:19:31.706 and they really matter less in

00:19:31.706 --> 00:19:33.500 day-to-day life than one might think.

00:19:33.500 --> 00:19:35.714 Marin also, as I said, has friends.

00:19:35.714 --> 00:19:38.299 She's kind, she's exceptionally hardworking,

00:19:38.300 --> 00:19:39.688 happy and again resilient,

00:19:39.688 --> 00:19:41.770 which are traits that many other

00:19:41.828 --> 00:19:44.084 preterm children possess but that have

00:19:44.084 --> 00:19:46.180 been neglected in outcome research.

00:19:46.180 --> 00:19:48.121 So are we asking the right questions?

00:19:48.121 --> 00:19:50.023 The outcome research what is the

00:19:50.023 --> 00:19:51.726 purpose to some of the research

00:19:51.726 --> 00:19:52.790 that can is conducted?

00:19:52.790 --> 00:19:54.190 How is it actually contributing

00:19:54.190 --> 00:19:56.032 to improving the lives of preterm

00:19:56.032 --> 00:19:57.568 individuals and their families?

00:19:57.570 --> 00:19:59.369 Remember that a lot of outcome research,

00:19:59.370 --> 00:20:00.108 or at least some of it,

00:20:00.110 --> 00:20:02.566 is picked up and reported by popular media,

00:20:02.570 --> 00:20:04.190 and this unfortunately shapes

00:20:04.190 --> 00:20:06.236 people's perception of preterm

00:20:06.236 --> 00:20:08.088 individuals as somehow damaged.

00:20:08.090 --> 00:20:09.410 Outcome research is very important

NOTE Confidence: 0.858086593846154

00:20:09.410 --> 00:20:10.730 for a number of reasons,

NOTE Confidence: 0.858086593846154

00:20:10.730 --> 00:20:12.410 but it needs to be balanced.

NOTE Confidence: 0.858086593846154

00:20:12.410 --> 00:20:13.650 We all know that's extreme.

NOTE Confidence: 0.858086593846154

00:20:13.650 --> 00:20:14.733 Prematurity is devastating.

NOTE Confidence: 0.858086593846154

00:20:14.733 --> 00:20:17.260 There's nothing good about being born four

NOTE Confidence: 0.861284454166667

00:20:17.321 --> 00:20:18.594 months premature. However,

NOTE Confidence: 0.861284454166667

00:20:18.594 --> 00:20:20.958 most preterm children are regular kids,

NOTE Confidence: 0.861284454166667

00:20:20.960 --> 00:20:22.720 and they're prematurity doesn't negatively

NOTE Confidence: 0.861284454166667

00:20:22.720 --> 00:20:24.840 impact them on a day-to-day basis.

NOTE Confidence: 0.861284454166667

00:20:24.840 --> 00:20:26.410 Most preterm children do OK

NOTE Confidence: 0.861284454166667

00:20:26.410 --> 00:20:27.860 in school and have friends.

NOTE Confidence: 0.861284454166667

00:20:27.860 --> 00:20:30.020 Most preterm children are hay.

NOTE Confidence: 0.861284454166667

00:20:30.020 --> 00:20:31.910 Most preterm children do not have

NOTE Confidence: 0.861284454166667

00:20:31.910 --> 00:20:33.720 serious long term health problems.

NOTE Confidence: 0.861284454166667

00:20:33.720 --> 00:20:35.805 Most preterm children are independent

NOTE Confidence: 0.861284454166667

00:20:35.805 --> 00:20:37.795 and functional members of society's.

NOTE Confidence: 0.861284454166667

00:20:37.795 --> 00:20:38.740 Most preterm children

NOTE Confidence: 0.861284454166667

00:20:38.740 --> 00:20:40.000 are strong and resilient,

NOTE Confidence: 0.861284454166667

00:20:40.000 --> 00:20:41.902 and the parents of these children

NOTE Confidence: 0.861284454166667

00:20:41.902 --> 00:20:44.092 love and value them no matter

NOTE Confidence: 0.861284454166667

00:20:44.092 --> 00:20:45.808 what their neurocognitive status.

NOTE Confidence: 0.861284454166667

00:20:45.810 --> 00:20:47.854 So again, I'm only one person and

NOTE Confidence: 0.861284454166667

00:20:47.854 --> 00:20:49.569 I've clearly explained my perspective.

NOTE Confidence: 0.861284454166667

00:20:49.570 --> 00:20:51.586 But the bigger question is how can

NOTE Confidence: 0.861284454166667

00:20:51.586 --> 00:20:52.895 we integrate parental perspectives

NOTE Confidence: 0.861284454166667

00:20:52.895 --> 00:20:55.080 into the larger research picture O.

NOTE Confidence: 0.861284454166667

00:20:55.080 --> 00:20:56.265 This includes using different

NOTE Confidence: 0.861284454166667

00:20:56.265 --> 00:20:58.005 methodologies to rigorously investigate

NOTE Confidence: 0.861284454166667

00:20:58.005 --> 00:21:00.619 what matters to families and what

NOTE Confidence: 0.861284454166667

00:21:00.619 --> 00:21:02.869 parents consider to be important outcomes,

NOTE Confidence: 0.861284454166667

00:21:02.870 --> 00:21:04.790 with the aim of improving research

NOTE Confidence: 0.861284454166667

00:21:04.790 --> 00:21:06.070 into what's meaningful to,

NOTE Confidence: 0.861284454166667

00:21:06.070 --> 00:21:08.678 again, parents and families.

NOTE Confidence: 0.861284454166667

00:21:08.680 --> 00:21:10.658 So in 2018 Megaville,

NOTE Confidence: 0.861284454166667

00:21:10.658 --> 00:21:12.728 Jaworski and Montreal and her

NOTE Confidence: 0.861284454166667

00:21:12.728 --> 00:21:14.517 co-authors published a paper

NOTE Confidence: 0.861284454166667

00:21:14.517 --> 00:21:15.960 entitled Parental Perspectives

NOTE Confidence: 0.861284454166667

00:21:15.960 --> 00:21:18.365 regarding outcomes of very preterm

NOTE Confidence: 0.861284454166667

00:21:18.365 --> 00:21:20.617 infants towards a balanced approach.

NOTE Confidence: 0.861284454166667

00:21:20.620 --> 00:21:22.246 190 parents of infants born at

NOTE Confidence: 0.861284454166667

00:21:22.246 --> 00:21:24.191 less than 29 weeks gestational age

NOTE Confidence: 0.861284454166667

00:21:24.191 --> 00:21:26.186 were asked to open-ended questions

NOTE Confidence: 0.861284454166667

00:21:26.186 --> 00:21:28.390 that their children's 18 to 22

NOTE Confidence: 0.861284454166667

00:21:28.390 --> 00:21:29.654 month neonatal follow-up visit.

NOTE Confidence: 0.861284454166667

00:21:29.660 --> 00:21:31.205 These questions were what are

NOTE Confidence: 0.861284454166667

00:21:31.205 --> 00:21:32.750 your concerns or what concerns

NOTE Confidence: 0.861284454166667

00:21:32.801 --> 00:21:34.136 you most about your child?

NOTE Confidence: 0.861284454166667

00:21:34.140 --> 00:21:35.525 And please describe the best

NOTE Confidence: 0.861284454166667

00:21:35.525 --> 00:21:37.255 thing about your child or what

NOTE Confidence: 0.861284454166667

00:21:37.255 --> 00:21:38.710 is positive about your child.

NOTE Confidence: 0.861284454166667

00:21:38.710 --> 00:21:40.534 Data were analyzed thematically

NOTE Confidence: 0.861284454166667

00:21:40.534 --> 00:21:43.270 and there were 180 again parent

NOTE Confidence: 0.861284454166667

00:21:43.343 --> 00:21:46.091 responses plus the corresponding

NOTE Confidence: 0.861284454166667

00:21:46.091 --> 00:21:47.465 neurodevelopmental data.

NOTE Confidence: 0.861284454166667

00:21:47.470 --> 00:21:50.158 So the results show that 73% of

NOTE Confidence: 0.861284454166667

00:21:50.158 --> 00:21:52.228 parents had both positive and

NOTE Confidence: 0.861284454166667

00:21:52.228 --> 00:21:54.190 negative comments and concerns,

NOTE Confidence: 0.861284454166667

00:21:54.190 --> 00:21:56.398 and 27% of parents,

NOTE Confidence: 0.861284454166667

00:21:56.398 --> 00:21:56.950 interestingly,

NOTE Confidence: 0.861284454166667

00:21:56.950 --> 00:21:58.720 had only positive comments to

NOTE Confidence: 0.861284454166667

00:21:58.720 --> 00:22:00.490 say about their preterm children.

NOTE Confidence: 0.861284454166667

00:22:00.490 --> 00:22:03.040 There was also a minimal association

NOTE Confidence: 0.861284454166667

00:22:03.040 --> 00:22:05.553 between parental answers and the presence

NOTE Confidence: 0.861284454166667

00:22:05.553 --> 00:22:08.150 or level of disability of their child.

NOTE Confidence: 0.861284454166667

00:22:08.150 --> 00:22:10.243 There were many positive themes that emerged

NOTE Confidence: 0.861284454166667

00:22:10.243 --> 00:22:12.230 from the answers to the two questions,

NOTE Confidence: 0.861284454166667

00:22:12.230 --> 00:22:13.960 themes that are not currently

NOTE Confidence: 0.861284454166667

00:22:13.960 --> 00:22:15.344 measured in outcome research.

NOTE Confidence: 0.861284454166667

00:22:15.350 --> 00:22:17.888 These themes related to the personality,

NOTE Confidence: 0.861284454166667

00:22:17.890 --> 00:22:18.442 Happiness,

NOTE Confidence: 0.861284454166667

00:22:18.442 --> 00:22:18.994 health,

NOTE Confidence: 0.861284454166667

00:22:18.994 --> 00:22:20.650 and developmental outcomes

NOTE Confidence: 0.861284454166667

00:22:20.650 --> 00:22:22.306 that exceeded expectations,

NOTE Confidence: 0.861284454166667

00:22:22.310 --> 00:22:23.980 and all parents had positive

NOTE Confidence: 0.861284454166667

00:22:23.980 --> 00:22:26.086 outcomes to say or positive comments

NOTE Confidence: 0.861284454166667

00:22:26.086 --> 00:22:27.926 to say about their children.

NOTE Confidence: 0.861284454166667

00:22:27.930 --> 00:22:29.755 There were also parental concerns

NOTE Confidence: 0.861284454166667

00:22:29.755 --> 00:22:30.850 or negative themes,

NOTE Confidence: 0.861284454166667

00:22:30.850 --> 00:22:32.275 including developmental concerns,

NOTE Confidence: 0.861284454166667

00:22:32.275 --> 00:22:34.650 physical health concerns and parental

NOTE Confidence: 0.861284454166667

00:22:34.650 --> 00:22:36.650 concerns about children's future,

NOTE Confidence: 0.861284454166667

00:22:36.650 --> 00:22:38.522 again many of which are not

NOTE Confidence: 0.861284454166667

00:22:38.522 --> 00:22:39.770 measured in outcome research.

NOTE Confidence: 0.861284454166667

00:22:39.770 --> 00:22:42.185 And some parents also explicitly said that

NOTE Confidence: 0.861284454166667

00:22:42.185 --> 00:22:45.009 they had no concerns about their child.

NOTE Confidence: 0.861284454166667

00:22:45.010 --> 00:22:45.226 So,

NOTE Confidence: 0.861284454166667

00:22:45.226 --> 00:22:46.306 as Annie said to me,

NOTE Confidence: 0.861284454166667

00:22:46.310 --> 00:22:48.425 this paper was really a kick in the ****.

NOTE Confidence: 0.861284454166667

00:22:48.430 --> 00:22:50.334 That led to the idea of asking

NOTE Confidence: 0.861284454166667

00:22:50.334 --> 00:22:51.540 more parents similar questions

NOTE Confidence: 0.861284454166667

00:22:51.540 --> 00:22:53.185 in a more rigorous fashion.

NOTE Confidence: 0.861284454166667

00:22:53.190 --> 00:22:55.212 There was also an editorial published

NOTE Confidence: 0.861284454166667

00:22:55.212 --> 00:22:57.200 in 2018 called What Parents Want

NOTE Confidence: 0.861284454166667

00:22:57.200 --> 00:22:58.850 to know after preterm birth.

NOTE Confidence: 0.861284454166667

00:22:58.850 --> 00:23:00.735 That included some very relevant

NOTE Confidence: 0.861284454166667

00:23:00.735 --> 00:23:01.866 questions and conclusions.

NOTE Confidence: 0.861284454166667

00:23:01.870 --> 00:23:02.582 Most notably,

NOTE Confidence: 0.861284454166667

00:23:02.582 --> 00:23:03.650 why has neurodevelopmental

NOTE Confidence: 0.861284454166667

00:23:03.650 --> 00:23:05.715 impairment been chosen as a measure

NOTE Confidence: 0.861284454166667

00:23:05.715 --> 00:23:07.430 of an accused success?

NOTE Confidence: 0.861284454166667

00:23:07.430 --> 00:23:09.439 Why has it become central to the

NOTE Confidence: 0.861284454166667

00:23:09.439 --> 00:23:11.179 way that doctors counsel patients

NOTE Confidence: 0.861284454166667

00:23:11.179 --> 00:23:13.229 and discuss prognosis with them?

NOTE Confidence: 0.861284454166667

00:23:13.230 --> 00:23:15.150 And to doctor's answers all address

NOTE Confidence: 0.861284454166667

00:23:15.150 --> 00:23:16.750 the real concerns and needs of

NOTE Confidence: 0.861284454166667

00:23:16.750 --> 00:23:18.388 parents of infants form pre term.

NOTE Confidence: 0.861284454166667

00:23:18.388 --> 00:23:20.530 And the authors also noted that it's

NOTE Confidence: 0.7985370305

00:23:20.590 --> 00:23:22.894 imperative to redefine the way that

NOTE Confidence: 0.7985370305

00:23:22.894 --> 00:23:25.690 outcomes are described after preterm birth.

NOTE Confidence: 0.7985370305

00:23:25.690 --> 00:23:27.769 So thank you for listening and I will now

NOTE Confidence: 0.7985370305

00:23:27.769 --> 00:23:29.704 turn turn things over to my pardon me,

NOTE Confidence: 0.7985370305

00:23:29.710 --> 00:23:31.257 who will start to discuss the parents.

NOTE Confidence: 0.7985370305

00:23:31.260 --> 00:23:32.210 Voice project.

NOTE Confidence: 0.84382847

00:23:37.180 --> 00:23:38.960 So following this first work,

NOTE Confidence: 0.84382847

00:23:38.960 --> 00:23:41.050 we launched the Parents Voice

NOTE Confidence: 0.84382847

00:23:41.050 --> 00:23:43.555 project with the support from the

NOTE Confidence: 0.84382847

00:23:43.555 --> 00:23:45.595 Child Bride network and this was

NOTE Confidence: 0.84382847

00:23:45.595 --> 00:23:48.277 this is the work from an amazing

NOTE Confidence: 0.84382847

00:23:48.277 --> 00:23:50.659 group of ladies from across Canada.

NOTE Confidence: 0.84382847

00:23:50.660 --> 00:23:52.570 Happens that there's no man,

NOTE Confidence: 0.84382847

00:23:52.570 --> 00:23:54.118 but this is how it is.

NOTE Confidence: 0.847075254333334

00:23:56.170 --> 00:23:58.039 So the goal of the parents Voice

NOTE Confidence: 0.847075254333334

00:23:58.039 --> 00:23:59.682 project was really to engage

NOTE Confidence: 0.847075254333334

00:23:59.682 --> 00:24:02.040 parents to Co create definitions of

NOTE Confidence: 0.847075254333334

00:24:02.040 --> 00:24:03.179 neurodevelopmental impairment and

NOTE Confidence: 0.847075254333334

00:24:03.179 --> 00:24:04.967 also to determine what were outcomes

NOTE Confidence: 0.847075254333334

00:24:04.967 --> 00:24:06.662 that they valued as important.

NOTE Confidence: 0.847075254333334

00:24:06.662 --> 00:24:08.642 So there were several projects

NOTE Confidence: 0.847075254333334

00:24:08.642 --> 00:24:11.089 that will be presenting today.

NOTE Confidence: 0.847075254333334

00:24:11.090 --> 00:24:14.162 The first project was to compare

NOTE Confidence: 0.847075254333334

00:24:14.162 --> 00:24:15.186 neurodevelopmental impairment

NOTE Confidence: 0.847075254333334

00:24:15.186 --> 00:24:17.046 classification as per parental

NOTE Confidence: 0.847075254333334

00:24:17.046 --> 00:24:18.966 view compared to the medical

NOTE Confidence: 0.847075254333334

00:24:18.966 --> 00:24:21.209 definition that is used by CNN Fun.

NOTE Confidence: 0.847075254333334

00:24:21.210 --> 00:24:23.325 So what we did was over a year period

NOTE Confidence: 0.847075254333334

00:24:23.325 --> 00:24:25.396 all parents are very preterm infants

NOTE Confidence: 0.847075254333334

00:24:25.396 --> 00:24:27.518 who were attending a neonatal follow-up

NOTE Confidence: 0.847075254333334

00:24:27.518 --> 00:24:29.766 clinic through in the as part of the

NOTE Confidence: 0.847075254333334

00:24:29.766 --> 00:24:32.570 CN Fund 18 to 21 month visit were

NOTE Confidence: 0.847075254333334

00:24:32.570 --> 00:24:34.924 eligible to participate and they were

NOTE Confidence: 0.847075254333334

00:24:34.924 --> 00:24:37.210 asked this specific question that was

NOTE Confidence: 0.847075254333334

00:24:37.210 --> 00:24:39.250 done prior to the standardized health

NOTE Confidence: 0.847075254333334

00:24:39.250 --> 00:24:40.530 and neurodevelopmental assessment.

NOTE Confidence: 0.847075254333334

00:24:40.530 --> 00:24:41.630 So we asked them.

NOTE Confidence: 0.847075254333334

00:24:41.630 --> 00:24:43.280 Please tell us how you would

NOTE Confidence: 0.847075254333334

00:24:43.344 --> 00:24:45.140 rate your child's development.

NOTE Confidence: 0.847075254333334

00:24:45.140 --> 00:24:46.088 Parents could choose.

NOTE Confidence: 0.847075254333334

00:24:46.088 --> 00:24:48.860 I think that my child is developing normally.

NOTE Confidence: 0.847075254333334

00:24:48.860 --> 00:24:50.890 I think that my child has a

NOTE Confidence: 0.847075254333334

00:24:50.890 --> 00:24:51.760 mild developmental impairment,

NOTE Confidence: 0.847075254333334

00:24:51.760 --> 00:24:54.076 a moderate impairment or a severe

NOTE Confidence: 0.847075254333334

00:24:54.076 --> 00:24:56.318 impairment and what would what we

NOTE Confidence: 0.847075254333334

00:24:56.318 --> 00:24:58.202 did was to compare their response

NOTE Confidence: 0.847075254333334

00:24:58.202 --> 00:25:00.339 to CNN fund classification of

NOTE Confidence: 0.847075254333334

00:25:00.340 --> 00:25:03.740 neurodevelopmental impairment.

NOTE Confidence: 0.847075254333334

00:25:03.740 --> 00:25:06.900 So overall we had over 1000 responses and

NOTE Confidence: 0.847075254333334

00:25:06.900 --> 00:25:10.396 you can see that agreement of parental

NOTE Confidence: 0.847075254333334

00:25:10.396 --> 00:25:13.016 classification versus the CNT fund

NOTE Confidence: 0.847075254333334

00:25:13.104 --> 00:25:16.008 classification is not so great with.

NOTE Confidence: 0.847075254333334

00:25:16.010 --> 00:25:19.042 A cup of 0.29 so if we look

NOTE Confidence: 0.847075254333334

00:25:19.042 --> 00:25:22.187 at CNN classification of 54%

NOTE Confidence: 0.847075254333334

00:25:22.187 --> 00:25:24.449 of children had no ND I,

NOTE Confidence: 0.847075254333334

00:25:24.450 --> 00:25:26.832 but when we look at parents

NOTE Confidence: 0.847075254333334

00:25:26.832 --> 00:25:29.201 classification that was higher at 68%.

NOTE Confidence: 0.847075254333334

00:25:29.201 --> 00:25:29.772 Interestingly,

NOTE Confidence: 0.847075254333334

00:25:29.772 --> 00:25:32.627 when we compare CNN fan

NOTE Confidence: 0.847075254333334

00:25:32.627 --> 00:25:34.340 and parents Classification,

NOTE Confidence: 0.847075254333334

00:25:34.340 --> 00:25:37.766 80 to 83% agree regarding children

NOTE Confidence: 0.847075254333334

00:25:37.766 --> 00:25:40.050 with no ND I.

NOTE Confidence: 0.847075254333334

00:25:40.050 --> 00:25:40.372 However,

NOTE Confidence: 0.847075254333334

00:25:40.372 --> 00:25:42.948 if a child was classified as having mild

NOTE Confidence: 0.847075254333334

00:25:42.948 --> 00:25:45.749 to moderate neurodevelopmental impairment,

NOTE Confidence: 0.847075254333334

00:25:45.750 --> 00:25:49.400 only 40% of parents agreed.

NOTE Confidence: 0.847075254333334

00:25:49.400 --> 00:25:52.340 And if we look at significant

NOTE Confidence: 0.847075254333334

00:25:52.340 --> 00:25:53.320 neurodevelopmental impairment,

NOTE Confidence: 0.847075254333334

00:25:53.320 --> 00:25:55.660 only 12% of parents agree.

NOTE Confidence: 0.847075254333334

00:25:55.660 --> 00:25:58.054 And as you can see most of the time

NOTE Confidence: 0.847075254333334

00:25:58.054 --> 00:26:00.186 they would classify their child or

NOTE Confidence: 0.847075254333334

00:26:00.186 --> 00:26:02.641 rate them as less severe as what

NOTE Confidence: 0.847075254333334

00:26:02.641 --> 00:26:04.640 CNN found with with determined.

NOTE Confidence: 0.847075254333334

00:26:04.640 --> 00:26:07.262 And when we looked more granularly

NOTE Confidence: 0.847075254333334

00:26:07.262 --> 00:26:08.573 at the data,

NOTE Confidence: 0.847075254333334

00:26:08.580 --> 00:26:10.350 things like mild or moderate

NOTE Confidence: 0.847075254333334

00:26:10.350 --> 00:26:12.120 language delay was not something

NOTE Confidence: 0.847075254333334

00:26:12.180 --> 00:26:13.890 very significant for parents and

NOTE Confidence: 0.847075254333334

00:26:13.890 --> 00:26:15.970 also hearing like having a hearing

NOTE Confidence: 0.847075254333334

00:26:15.970 --> 00:26:17.812 aid but being able to function

NOTE Confidence: 0.847075254333334

00:26:17.812 --> 00:26:19.513 was not really considered.

NOTE Confidence: 0.847075254333334

00:26:19.513 --> 00:26:21.810 Significantly as a significant

NOTE Confidence: 0.847075254333334

00:26:21.810 --> 00:26:24.920 role developmental impairment.

NOTE Confidence: 0.847075254333334

00:26:24.920 --> 00:26:26.147 So in summary,

NOTE Confidence: 0.847075254333334

00:26:26.147 --> 00:26:28.192 results only showed only fair

NOTE Confidence: 0.847075254333334

00:26:28.192 --> 00:26:29.915 agreement between parents perspective

NOTE Confidence: 0.847075254333334

00:26:29.915 --> 00:26:32.411 and healthcare provider as per the

NOTE Confidence: 0.847075254333334

00:26:32.411 --> 00:26:35.092 in terms of NOI and children born

NOTE Confidence: 0.847075254333334

00:26:35.092 --> 00:26:37.166 very preterm and parents were more

NOTE Confidence: 0.847075254333334

00:26:37.166 --> 00:26:38.596 likely to describe their child

NOTE Confidence: 0.847075254333334

00:26:38.596 --> 00:26:40.500 development as not or less impaired.

NOTE Confidence: 0.85519625

00:26:47.280 --> 00:26:49.370 So the second project

NOTE Confidence: 0.67223157

00:26:49.800 --> 00:26:52.350 in the Parents Voice project was to

NOTE Confidence: 0.67223157

00:26:52.350 --> 00:26:55.002 use vignettes to evaluate parental

NOTE Confidence: 0.67223157

00:26:55.002 --> 00:26:59.094 perceptions of the severity of visibility.

NOTE Confidence: 0.67223157

00:26:59.100 --> 00:27:02.460 So we created vignettes based on CNN fund

NOTE Confidence: 0.67223157

00:27:02.460 --> 00:27:05.666 definitions of a severe that we now use

NOTE Confidence: 0.67223157

00:27:05.666 --> 00:27:07.542 significant disability because parents

NOTE Confidence: 0.67223157

00:27:07.542 --> 00:27:11.138 don't want us to use severe disability.

NOTE Confidence: 0.67223157

00:27:11.140 --> 00:27:14.224 And after creating all these vignettes,

NOTE Confidence: 0.67223157

00:27:14.224 --> 00:27:16.600 the survey was distributed to parents

NOTE Confidence: 0.67223157

00:27:16.661 --> 00:27:18.932 of very preterm children and parent

NOTE Confidence: 0.67223157

00:27:18.932 --> 00:27:21.062 foundation that made this survey

NOTE Confidence: 0.67223157

00:27:21.062 --> 00:27:23.550 available to parents and stakeholders.

NOTE Confidence: 0.67223157

00:27:23.550 --> 00:27:26.090 So this was really Internet

NOTE Confidence: 0.67223157

00:27:26.090 --> 00:27:28.122 based and widely distributed.

NOTE Confidence: 0.865084516153846

00:27:30.160 --> 00:27:33.590 So I'll give you an example of one of the

NOTE Confidence: 0.865084516153846

00:27:33.681 --> 00:27:36.558 vignette of Jamie, who's 18 months old,

NOTE Confidence: 0.865084516153846

00:27:36.558 --> 00:27:39.239 who can sit with support and roll in,

NOTE Confidence: 0.865084516153846

00:27:39.240 --> 00:27:40.232 creep on his stomach.

00:27:40.232 --> 00:27:43.150 He has stiff legs and will very likely use

00:27:43.150 --> 00:27:45.720 a weak wheelchair for longer distances.

00:27:45.720 --> 00:27:49.290 Then we describe that all the rest is normal.

00:27:49.290 --> 00:27:53.875 So Jamie is a child with significant

00:27:53.880 --> 00:27:57.380 ND I and who has cerebral palsy,

00:27:57.380 --> 00:27:58.676 isolated cerebral palsy.

00:27:58.676 --> 00:28:00.836 So we ask Questions 2.

00:28:00.840 --> 00:28:03.232 Questions after each vignette.

00:28:03.232 --> 00:28:05.701 If zero is the worst possible health,

00:28:05.701 --> 00:28:08.047 intent is the best possible health.

00:28:08.050 --> 00:28:10.276 Where do you think Jamie is

00:28:10.276 --> 00:28:12.730 on this scale from zero to 10?

00:28:12.730 --> 00:28:15.230 And does Jamie's case describe

00:28:15.230 --> 00:28:16.864 a severe health condition?

00:28:16.864 --> 00:28:20.190 And they could say yes, no, or they did.

00:28:20.190 --> 00:28:21.120 They didn't know.

NOTE Confidence: 0.782384898

00:28:23.560 --> 00:28:26.660 So we had 800 participants,

NOTE Confidence: 0.782384898

00:28:26.660 --> 00:28:29.306 827 participants from all over the world,

NOTE Confidence: 0.782384898

00:28:29.310 --> 00:28:31.896 mainly parents of extreme preterm infants,

NOTE Confidence: 0.782384898

00:28:31.900 --> 00:28:34.847 but some preterm infants who were older

NOTE Confidence: 0.782384898

00:28:34.847 --> 00:28:37.260 and some clinicians in neonatology.

NOTE Confidence: 0.782384898

00:28:37.260 --> 00:28:40.220 And you can see that the child with

NOTE Confidence: 0.782384898

00:28:40.220 --> 00:28:42.440 no impairment received immediate

NOTE Confidence: 0.782384898

00:28:42.440 --> 00:28:46.940 evaluation of 10 and that actually

NOTE Confidence: 0.782384898

00:28:46.940 --> 00:28:48.825 the child getting the worse

NOTE Confidence: 0.782384898

00:28:48.825 --> 00:28:51.198 evaluation or the vignette with the

NOTE Confidence: 0.782384898

00:28:51.198 --> 00:28:53.278 worst evaluation were the children.

NOTE Confidence: 0.782384898

00:28:53.280 --> 00:28:54.690 With visual impairment,

NOTE Confidence: 0.782384898

00:28:54.690 --> 00:28:57.040 language and cognitive delays or

NOTE Confidence: 0.782384898

00:28:57.040 --> 00:28:59.308 cerebral palsy and language delay,

NOTE Confidence: 0.782384898

00:28:59.310 --> 00:29:01.364 but they were not at 2110,

NOTE Confidence: 0.782384898

00:29:01.364 --> 00:29:04.262 they were on the median of six

NOTE Confidence: 0.782384898

00:29:04.262 --> 00:29:07.500 on 10 with all the other severe

NOTE Confidence: 0.782384898

00:29:07.500 --> 00:29:10.601 disabilities that we call severe rated

NOTE Confidence: 0.782384898

00:29:10.601 --> 00:29:14.358 at 7 on 10 or higher by parents,

NOTE Confidence: 0.782384898

00:29:14.358 --> 00:29:15.930 mainly by parents.

NOTE Confidence: 0.782384898

00:29:15.930 --> 00:29:18.884 So you see that not all severe

NOTE Confidence: 0.782384898

00:29:18.884 --> 00:29:20.890 disabilities are evaluated the same.

NOTE Confidence: 0.923426533333333

00:29:23.010 --> 00:29:24.756 When we asked participant

NOTE Confidence: 0.923426533333333

00:29:24.756 --> 00:29:27.086 is this vignette does it,

NOTE Confidence: 0.923426533333333

00:29:27.090 --> 00:29:30.550 is it a severe health condition?

NOTE Confidence: 0.923426533333333

00:29:30.550 --> 00:29:32.954 You can see that only cerebral

NOTE Confidence: 0.923426533333333

00:29:32.954 --> 00:29:36.458 palsy and language delay only there

NOTE Confidence: 0.923426533333333

00:29:36.458 --> 00:29:39.238 did participant 55% of them judge

NOTE Confidence: 0.923426533333333

00:29:39.238 --> 00:29:41.650 it was a severe health condition.

NOTE Confidence: 0.923426533333333

00:29:41.650 --> 00:29:44.290 All the other severe conditions that

NOTE Confidence: 0.923426533333333

00:29:44.290 --> 00:29:46.624 we call severe as neonatologists

NOTE Confidence: 0.923426533333333

00:29:46.624 --> 00:29:49.894 and clinicians and researchers were

NOTE Confidence: 0.923426533333333

00:29:49.894 --> 00:29:52.434 considered severe by less than half.

NOTE Confidence: 0.923426533333333

00:29:52.434 --> 00:29:53.338 Of participant.

NOTE Confidence: 0.895339574375

00:29:56.300 --> 00:29:59.352 So the summary of the vignette study

NOTE Confidence: 0.895339574375

00:29:59.352 --> 00:30:01.959 shows that clinical vignettes are

NOTE Confidence: 0.895339574375

00:30:01.959 --> 00:30:04.399 ranked differently by individuals

NOTE Confidence: 0.895339574375

00:30:04.400 --> 00:30:07.030 that are not researchers or

NOTE Confidence: 0.895339574375

00:30:07.030 --> 00:30:08.608 clinicians and neonatology.

NOTE Confidence: 0.895339574375

00:30:08.610 --> 00:30:11.754 They're not ranked the way disabilities

NOTE Confidence: 0.895339574375

00:30:11.754 --> 00:30:13.850 are classified in neonatology.

NOTE Confidence: 0.895339574375

00:30:13.850 --> 00:30:15.558 The percentage of respondents

NOTE Confidence: 0.895339574375

00:30:15.558 --> 00:30:18.120 who perceive the vignette to be

NOTE Confidence: 0.895339574375

00:30:18.197 --> 00:30:20.228 severe differs significantly.

NOTE Confidence: 0.895339574375

00:30:20.230 --> 00:30:21.766 Even within participants.

NOTE Confidence: 0.895339574375

00:30:21.766 --> 00:30:24.326 The combination of cerebral palsy

NOTE Confidence: 0.895339574375

00:30:24.326 --> 00:30:26.581 and language delay was perceived

NOTE Confidence: 0.895339574375

00:30:26.581 --> 00:30:29.269 to be the most severe vignette and

NOTE Confidence: 0.895339574375

00:30:29.346 --> 00:30:31.908 cognitive delay as the least severe,

NOTE Confidence: 0.895339574375

00:30:31.910 --> 00:30:34.085 and many delays described as

NOTE Confidence: 0.895339574375

00:30:34.085 --> 00:30:36.890 severe are not perceived as severe

NOTE Confidence: 0.895339574375

00:30:36.890 --> 00:30:39.066 by parents and stakeholders.

NOTE Confidence: 0.878780485

00:30:44.980 --> 00:30:46.168 So I'll be presenting

NOTE Confidence: 0.87322448125

00:30:46.180 --> 00:30:48.340 the third part or the third study here,

NOTE Confidence: 0.87322448125

00:30:48.340 --> 00:30:50.854 which was looking at parental perspectives

NOTE Confidence: 0.87322448125

00:30:50.854 --> 00:30:53.680 in relation to four different areas.

NOTE Confidence: 0.87322448125

00:30:53.680 --> 00:30:55.040 So the health of parents,

NOTE Confidence: 0.87322448125

00:30:55.040 --> 00:30:56.875 premature baby, the impact of

NOTE Confidence: 0.87322448125

00:30:56.875 --> 00:30:59.300 prematurity on the lives of parents,

NOTE Confidence: 0.87322448125

00:30:59.300 --> 00:31:01.295 parents need for information about

NOTE Confidence: 0.87322448125

00:31:01.295 --> 00:31:03.290 prematurity and any decision or

NOTE Confidence: 0.87322448125

00:31:03.359 --> 00:31:05.537 regrets that parents might have had.

NOTE Confidence: 0.87322448125

00:31:05.540 --> 00:31:10.732 So between 2018, July 2018 and July 2019.

NOTE Confidence: 0.87322448125

00:31:10.732 --> 00:31:13.228 All of the parents of children who were

NOTE Confidence: 0.87322448125

00:31:13.228 --> 00:31:15.743 seen at the Saint Justine unital follow-up

NOTE Confidence: 0.87322448125

00:31:15.743 --> 00:31:18.667 clinic for their 18 month to 7 year visits,

NOTE Confidence: 0.87322448125

00:31:18.670 --> 00:31:20.651 who were born at less than 29

NOTE Confidence: 0.87322448125

00:31:20.651 --> 00:31:22.224 weeks gestational age were invited

NOTE Confidence: 0.87322448125

00:31:22.224 --> 00:31:23.889 to participate in this study.

NOTE Confidence: 0.87322448125

00:31:23.890 --> 00:31:25.135 Parental perspectives were

NOTE Confidence: 0.87322448125

00:31:25.135 --> 00:31:26.795 measured through a questionnaire,

NOTE Confidence: 0.87322448125

00:31:26.800 --> 00:31:28.520 and this questionnaire was administered

NOTE Confidence: 0.87322448125

00:31:28.520 --> 00:31:30.854 in a variety of different ways in

NOTE Confidence: 0.87322448125

00:31:30.854 --> 00:31:32.534 order to get as many participants

NOTE Confidence: 0.87322448125

00:31:32.534 --> 00:31:34.367 as possible so it was given online.

NOTE Confidence: 0.87322448125

00:31:34.370 --> 00:31:35.646 Parents could answer verbally,

NOTE Confidence: 0.87322448125

00:31:35.646 --> 00:31:38.329 over the phone or in person by interview,

NOTE Confidence: 0.87322448125

00:31:38.330 --> 00:31:41.378 or they could write their answers on paper.

NOTE Confidence: 0.87322448125

00:31:41.380 --> 00:31:43.205 The data were analyzed thematically

NOTE Confidence: 0.87322448125

00:31:43.205 --> 00:31:45.030 by a multidisciplinary research team,

NOTE Confidence: 0.87322448125

00:31:45.030 --> 00:31:46.764 including a neonatologist,

NOTE Confidence: 0.87322448125

00:31:46.764 --> 00:31:47.920 developmental pediatrician,

NOTE Confidence: 0.87322448125

00:31:47.920 --> 00:31:48.564 sociologist,

NOTE Confidence: 0.87322448125

00:31:48.564 --> 00:31:51.140 parents and medical students,

NOTE Confidence: 0.87322448125

00:31:51.140 --> 00:31:53.428 and coding of the data was done by

NOTE Confidence: 0.87322448125

00:31:53.428 --> 00:31:55.800 teams of two independent reviewers.

NOTE Confidence: 0.87322448125

00:31:55.800 --> 00:31:58.062 So this just shows the participants

NOTE Confidence: 0.87322448125

00:31:58.062 --> 00:31:59.193 in the study.

NOTE Confidence: 0.87322448125

00:31:59.200 --> 00:32:02.651 So 83% of parents who are eligible

NOTE Confidence: 0.87322448125

00:32:02.651 --> 00:32:05.439 for follow-up were contacted and

NOTE Confidence: 0.87322448125

00:32:05.440 --> 00:32:07.760 98% of parents who came to follow up

NOTE Confidence: 0.87322448125

00:32:07.760 --> 00:32:09.100 actually participated in this study.

NOTE Confidence: 0.87322448125

00:32:09.100 --> 00:32:12.324 So for a total of 248 parents of

NOTE Confidence: 0.87322448125

00:32:12.324 --> 00:32:14.200 213 children, so in a very, very,

NOTE Confidence: 0.87322448125

00:32:14.200 --> 00:32:16.780 very high participation rate.

NOTE Confidence: 0.87322448125

00:32:16.780 --> 00:32:18.772 These are the characteristics of the

NOTE Confidence: 0.87322448125

00:32:18.772 --> 00:32:20.959 children who are part of this study.

NOTE Confidence: 0.87322448125

00:32:20.960 --> 00:32:23.158 So the mean gestational age was 26,

NOTE Confidence: 0.87322448125

00:32:23.160 --> 00:32:24.516 just under 27 weeks.

NOTE Confidence: 0.87322448125

00:32:24.516 --> 00:32:27.620 And you can see here that the other

NOTE Confidence: 0.87322448125

00:32:27.620 --> 00:32:29.596 statistics are fairly characteristic

NOTE Confidence: 0.87322448125

00:32:29.596 --> 00:32:32.910 of children who were born at 26 weeks.

NOTE Confidence: 0.87322448125

00:32:32.910 --> 00:32:34.382 So the first question that parents

NOTE Confidence: 0.87322448125

00:32:34.382 --> 00:32:36.356 were asked was to rate your child's

NOTE Confidence: 0.87322448125

00:32:36.356 --> 00:32:38.049 health from the point of view or

NOTE Confidence: 0.87322448125

00:32:38.049 --> 00:32:39.739 your point of view on a scale of

NOTE Confidence: 0.87322448125

00:32:39.739 --> 00:32:41.042 0 very poor to 10, excellent.

NOTE Confidence: 0.87322448125

00:32:41.042 --> 00:32:44.018 So the median rating for all parents was

NOTE Confidence: 0.87322448125

00:32:44.018 --> 00:32:47.401 a nine with a range of ratings from 3 to 10.

NOTE Confidence: 0.87322448125

00:32:47.410 --> 00:32:49.170 There was a relationship between

NOTE Confidence: 0.87322448125

00:32:49.170 --> 00:32:51.355 diagnosed and DI and parents rating

NOTE Confidence: 0.87322448125

00:32:51.355 --> 00:32:53.503 of their child's health and that

NOTE Confidence: 0.87322448125

00:32:53.503 --> 00:32:55.345 parents whose children have been

NOTE Confidence: 0.87322448125

00:32:55.345 --> 00:32:57.457 diagnosed with significant ND I rated

NOTE Confidence: 0.87322448125

00:32:57.457 --> 00:32:59.163 their child's health is significantly

NOTE Confidence: 0.87322448125

00:32:59.163 --> 00:33:01.480 worse than parents with mild or whose

NOTE Confidence: 0.87322448125

00:33:01.538 --> 00:33:03.435 children had mild to moderate ND I.

NOTE Confidence: 0.87322448125

00:33:03.440 --> 00:33:04.337 Or no NDI.

NOTE Confidence: 0.87322448125

00:33:04.337 --> 00:33:04.636 However,

NOTE Confidence: 0.87322448125

00:33:04.636 --> 00:33:06.916 you can still see that even the

NOTE Confidence: 0.87322448125

00:33:06.916 --> 00:33:09.016 parents of children diagnosed with

NOTE Confidence: 0.87322448125

00:33:09.016 --> 00:33:11.270 significant NDI rated their children

NOTE Confidence: 0.87322448125

00:33:11.270 --> 00:33:13.446 with the median rating of just over 7,

NOTE Confidence: 0.87322448125

00:33:13.450 --> 00:33:16.825 which is we could argue is is fairly high.

NOTE Confidence: 0.87322448125

00:33:16.830 --> 00:33:18.084 Parents were then asked if you

NOTE Confidence: 0.87322448125

00:33:18.084 --> 00:33:19.780 could improve up to two things about

NOTE Confidence: 0.87322448125

00:33:19.780 --> 00:33:21.140 your child's health or development.

NOTE Confidence: 0.87322448125

00:33:21.140 --> 00:33:22.924 What would they be?

NOTE Confidence: 0.87322448125

00:33:22.924 --> 00:33:24.775 So 55% of parents identify development

NOTE Confidence: 0.87322448125

00:33:24.775 --> 00:33:26.482 is something that they would like

NOTE Confidence: 0.87322448125

00:33:26.482 --> 00:33:27.727 to improve about their child,

NOTE Confidence: 0.87322448125

00:33:27.730 --> 00:33:29.401 including language, communication,

NOTE Confidence: 0.87322448125

00:33:29.401 --> 00:33:31.629 behavior and emotional health,

NOTE Confidence: 0.87322448125

00:33:31.630 --> 00:33:32.390 motor development,

NOTE Confidence: 0.87322448125

00:33:32.390 --> 00:33:34.290 and cognitive and learning skills.

NOTE Confidence: 0.87322448125

00:33:34.290 --> 00:33:36.061 This is followed by 1/4 of parents

NOTE Confidence: 0.87322448125

00:33:36.061 --> 00:33:36.567 who responded,

NOTE Confidence: 0.87322448125

00:33:36.570 --> 00:33:38.462 respiratory health and the

NOTE Confidence: 0.87322448125

00:33:38.462 --> 00:33:39.408 respiratory fragility.

NOTE Confidence: 0.87322448125

00:33:39.410 --> 00:33:40.324 And finally,

NOTE Confidence: 0.87322448125

00:33:40.324 --> 00:33:42.609 14% of parents identified nutrition,

NOTE Confidence: 0.87322448125

00:33:42.610 --> 00:33:44.134 feeding and growth.

NOTE Confidence: 0.87322448125

00:33:44.134 --> 00:33:45.150 And interestingly,

NOTE Confidence: 0.886030165555555

00:33:45.150 --> 00:33:46.910 19% of parents explicitly said

NOTE Confidence: 0.886030165555555

00:33:46.910 --> 00:33:48.318 that they wouldn't improve.

NOTE Confidence: 0.886030165555555

00:33:48.320 --> 00:33:50.328 Anything about their child's

NOTE Confidence: 0.886030165555555

00:33:50.328 --> 00:33:51.834 health or development.

NOTE Confidence: 0.886030165555555

00:33:51.840 --> 00:33:53.658 Parents were asked to choose the

NOTE Confidence: 0.886030165555555

00:33:53.658 --> 00:33:55.739 statement that best fit their situation

NOTE Confidence: 0.886030165555555

00:33:55.740 --> 00:33:57.980 3/4 almost 3/4 of the parents said

NOTE Confidence: 0.886030165555555

00:33:57.980 --> 00:34:00.099 that their child's prematurity had or

NOTE Confidence: 0.886030165555555

00:34:00.099 --> 00:34:02.277 has both positive and negative impacts

NOTE Confidence: 0.886030165555555

00:34:02.277 --> 00:34:04.456 on my life and my family's life.

NOTE Confidence: 0.886030165555555

00:34:04.460 --> 00:34:06.782 And again, only 7% of parents

NOTE Confidence: 0.886030165555555

00:34:06.782 --> 00:34:08.330 that their child's prematurity

NOTE Confidence: 0.886030165555555

00:34:08.394 --> 00:34:10.368 had only negative impacts on their

NOTE Confidence: 0.886030165555555

00:34:10.368 --> 00:34:12.780 life or the life of their family.

NOTE Confidence: 0.886030165555555

00:34:12.780 --> 00:34:14.788 Parents were then asked to tell or to

NOTE Confidence: 0.886030165555555

00:34:14.788 --> 00:34:16.496 explain one or two positive impacts

NOTE Confidence: 0.886030165555555

00:34:16.496 --> 00:34:18.218 of their child's birth that they

NOTE Confidence: 0.886030165555555

00:34:18.275 --> 00:34:20.249 consider to be the most important or

NOTE Confidence: 0.886030165555555

00:34:20.249 --> 00:34:22.276 impactful for them or their family.

NOTE Confidence: 0.886030165555555

00:34:22.276 --> 00:34:24.236 48% of parents identified that

NOTE Confidence: 0.886030165555555

00:34:24.236 --> 00:34:26.089 their child's birth had given

NOTE Confidence: 0.886030165555555

00:34:26.089 --> 00:34:28.093 them a different outlook on life

NOTE Confidence: 0.886030165555555

00:34:28.093 --> 00:34:30.360 and a greater gratitude for life,

NOTE Confidence: 0.886030165555555

00:34:30.360 --> 00:34:32.472 33% identified with their child's birth

NOTE Confidence: 0.886030165555555

00:34:32.472 --> 00:34:34.979 had resulted in stronger family connections,

NOTE Confidence: 0.886030165555555

00:34:34.980 --> 00:34:37.360 and 28% of parents view

NOTE Confidence: 0.886030165555555

00:34:37.360 --> 00:34:39.740 their child as a gift.

NOTE Confidence: 0.886030165555555

00:34:39.740 --> 00:34:41.204 These are some of the quotes

NOTE Confidence: 0.886030165555555

00:34:41.204 --> 00:34:42.540 of parents from the study.

NOTE Confidence: 0.886030165555555

00:34:42.540 --> 00:34:43.624 So one parent said,

NOTE Confidence: 0.886030165555555

00:34:43.624 --> 00:34:44.979 my baby has brought together

NOTE Confidence: 0.886030165555555

00:34:44.979 --> 00:34:46.298 our family and friends.

NOTE Confidence: 0.886030165555555

00:34:46.300 --> 00:34:47.536 We see life differently,

NOTE Confidence: 0.886030165555555

00:34:47.536 --> 00:34:49.081 including the importance of the

NOTE Confidence: 0.886030165555555

00:34:49.081 --> 00:34:50.498 present moment and letting go.

NOTE Confidence: 0.886030165555555

00:34:50.500 --> 00:34:52.140 My child is a miracle in our lives

NOTE Confidence: 0.886030165555555

00:34:52.140 --> 00:34:53.628 and his strength and resilience

NOTE Confidence: 0.886030165555555

00:34:53.628 --> 00:34:55.338 give me strength and resilience,

NOTE Confidence: 0.886030165555555

00:34:55.340 --> 00:34:56.786 and my daughter's birth has helped

NOTE Confidence: 0.886030165555555

00:34:56.786 --> 00:34:58.499 me learn to focus on the present.

NOTE Confidence: 0.886030165555555

00:34:58.500 --> 00:34:59.700 Along with learning that

NOTE Confidence: 0.886030165555555

00:34:59.700 --> 00:35:00.600 nothing is impossible.

NOTE Confidence: 0.886030165555555

00:35:00.600 --> 00:35:01.626 Seeing her walk,

NOTE Confidence: 0.886030165555555

00:35:01.626 --> 00:35:03.678 talk and doing something as simple

NOTE Confidence: 0.886030165555555

00:35:03.678 --> 00:35:05.930 as breathing is just so amazing.

NOTE Confidence: 0.886030165555555

00:35:05.930 --> 00:35:08.009 Parents were then asked to explain or

NOTE Confidence: 0.886030165555555

00:35:08.009 --> 00:35:10.311 to discuss one or two negative impacts

NOTE Confidence: 0.886030165555555

00:35:10.311 --> 00:35:12.333 of their child's preterm birth that

NOTE Confidence: 0.886030165555555

00:35:12.396 --> 00:35:14.566 they consider to be important to them.

NOTE Confidence: 0.886030165555555

00:35:14.570 --> 00:35:16.754 42% of parents said that parental

NOTE Confidence: 0.886030165555555

00:35:16.754 --> 00:35:19.058 stress and anxiety resulting from their

NOTE Confidence: 0.886030165555555

00:35:19.058 --> 00:35:21.028 child's birth were very significant,

NOTE Confidence: 0.886030165555555

00:35:21.030 --> 00:35:23.487 36% identified that they had a loss

NOTE Confidence: 0.886030165555555

00:35:23.487 --> 00:35:25.669 of family balance and equilibrium,

NOTE Confidence: 0.886030165555555

00:35:25.670 --> 00:35:27.550 21% identified their child's development

NOTE Confidence: 0.886030165555555

00:35:27.550 --> 00:35:30.268 as having a negative impact on their life,

NOTE Confidence: 0.886030165555555

00:35:30.270 --> 00:35:32.910 and 19% of parents still view

NOTE Confidence: 0.886030165555555

00:35:32.910 --> 00:35:34.670 their children as vulnerable.

NOTE Confidence: 0.886030165555555

00:35:34.670 --> 00:35:36.756 So one parent or one mother identified

NOTE Confidence: 0.886030165555555

00:35:36.756 --> 00:35:38.802 the fact that she had constant

NOTE Confidence: 0.886030165555555

00:35:38.802 --> 00:35:40.627 fears during her second pregnancy.

NOTE Confidence: 0.886030165555555

00:35:40.630 --> 00:35:42.022 My career dreams extinguished,

NOTE Confidence: 0.886030165555555

00:35:42.022 --> 00:35:44.110 this was a mother as well,

NOTE Confidence: 0.886030165555555

00:35:44.110 --> 00:35:44.911 another parent said.

NOTE Confidence: 0.886030165555555

00:35:44.911 --> 00:35:46.513 Although he is doing amazingly well,

NOTE Confidence: 0.886030165555555

00:35:46.520 --> 00:35:48.116 there's still a lot of anxiety

NOTE Confidence: 0.886030165555555

00:35:48.116 --> 00:35:49.749 about what the future will hold,

NOTE Confidence: 0.886030165555555

00:35:49.750 --> 00:35:52.158 feelings of experiencing motherhood

NOTE Confidence: 0.886030165555555

00:35:52.158 --> 00:35:53.964 abnormally and loneliness.

NOTE Confidence: 0.886030165555555

00:35:53.970 --> 00:35:55.727 And another set of parents or mother

NOTE Confidence: 0.886030165555555

00:35:55.727 --> 00:35:57.590 said the fear of losing our babies,

NOTE Confidence: 0.886030165555555

00:35:57.590 --> 00:35:59.030 the hypervigilance that's persisted

NOTE Confidence: 0.886030165555555

00:35:59.030 --> 00:36:00.830 since we left the hospital.

NOTE Confidence: 0.886030165555555

00:36:00.830 --> 00:36:01.486 And interestingly,

NOTE Confidence: 0.886030165555555

00:36:01.486 --> 00:36:02.798 those parents were parents

NOTE Confidence: 0.886030165555555

00:36:02.798 --> 00:36:04.630 of twins and their children.

NOTE Confidence: 0.886030165555555

00:36:04.630 --> 00:36:05.880 Are not 18 months old.

NOTE Confidence: 0.886030165555555

00:36:05.880 --> 00:36:08.240 I think they were five years old at the time,

NOTE Confidence: 0.886030165555555

00:36:08.240 --> 00:36:09.864 or a lot older than babies still,

NOTE Confidence: 0.886030165555555

00:36:09.870 --> 00:36:11.795 and they're still worried about

NOTE Confidence: 0.886030165555555

00:36:11.795 --> 00:36:12.565 their children.

NOTE Confidence: 0.886030165555555

00:36:12.570 --> 00:36:13.224 Parents were asked,

NOTE Confidence: 0.886030165555555

00:36:13.224 --> 00:36:14.314 knowing what you know now,

NOTE Confidence: 0.886030165555555

00:36:14.320 --> 00:36:16.144 what you wish doctors would have

NOTE Confidence: 0.886030165555555

00:36:16.144 --> 00:36:17.722 told you about prematurity before

NOTE Confidence: 0.886030165555555

00:36:17.722 --> 00:36:19.227 or after your child's birth.

NOTE Confidence: 0.886030165555555

00:36:19.230 --> 00:36:21.407 So the good news is that 50%

NOTE Confidence: 0.886030165555555

00:36:21.410 --> 00:36:22.780 of the parents were explicitly

NOTE Confidence: 0.886030165555555

00:36:22.780 --> 00:36:24.150 satisfied with the information that

NOTE Confidence: 0.886030165555555

00:36:24.199 --> 00:36:25.489 they received from the doctors.

NOTE Confidence: 0.886030165555555

00:36:25.490 --> 00:36:27.848 At Saint Justine,

NOTE Confidence: 0.886030165555555

00:36:27.850 --> 00:36:29.440 21% of parents would have liked

NOTE Confidence: 0.886030165555555

00:36:29.440 --> 00:36:30.500 more information for their

NOTE Confidence: 0.851081014

00:36:30.549 --> 00:36:31.829 return home with their baby.

NOTE Confidence: 0.851081014

00:36:31.830 --> 00:36:33.175 So this included things about

NOTE Confidence: 0.851081014

00:36:33.175 --> 00:36:34.957 what to expect for the baby's

NOTE Confidence: 0.851081014

00:36:34.957 --> 00:36:36.489 future health and development,

NOTE Confidence: 0.851081014

00:36:36.490 --> 00:36:37.804 the types of follow up that

NOTE Confidence: 0.851081014

00:36:37.804 --> 00:36:39.110 they would need to undergo,

NOTE Confidence: 0.851081014

00:36:39.110 --> 00:36:40.825 and the you know the frequency of

NOTE Confidence: 0.851081014

00:36:40.825 --> 00:36:42.590 this follow up and also practical.

NOTE Confidence: 0.851081014

00:36:42.590 --> 00:36:43.679 Considerations like daily

NOTE Confidence: 0.851081014

00:36:43.679 --> 00:36:45.857 life with a a preterm baby,

NOTE Confidence: 0.851081014

00:36:45.860 --> 00:36:47.036 how to care for their baby,

NOTE Confidence: 0.851081014

00:36:47.040 --> 00:36:49.130 and what supports were out

NOTE Confidence: 0.851081014

00:36:49.130 --> 00:36:51.220 there for them as parents.

NOTE Confidence: 0.851081014

00:36:51.220 --> 00:36:52.380 Then parents were asked,

NOTE Confidence: 0.851081014

00:36:52.380 --> 00:36:53.830 knowing what you know now,

NOTE Confidence: 0.851081014

00:36:53.830 --> 00:36:55.510 which you wish that doctors would have told

NOTE Confidence: 0.851081014

00:36:55.510 --> 00:36:57.129 you about prematurity before and after.

NOTE Confidence: 0.851081014

00:36:57.130 --> 00:36:59.278 Sorry, this is the same question.

NOTE Confidence: 0.851081014

00:36:59.280 --> 00:37:01.422 16% of parents wanted more practical

NOTE Confidence: 0.851081014

00:37:01.422 --> 00:37:03.200 information on their NICU stay,

NOTE Confidence: 0.851081014

00:37:03.200 --> 00:37:04.915 so they wanted to know what role

NOTE Confidence: 0.851081014

00:37:04.915 --> 00:37:06.317 they would have undertaken as

NOTE Confidence: 0.851081014

00:37:06.317 --> 00:37:07.847 parents earlier and get involved

NOTE Confidence: 0.851081014

00:37:07.847 --> 00:37:09.538 with the care of their baby.

NOTE Confidence: 0.851081014

00:37:09.540 --> 00:37:11.661 They would have liked to know more

NOTE Confidence: 0.851081014

00:37:11.661 --> 00:37:13.172 information about the trajectory of

NOTE Confidence: 0.851081014

00:37:13.172 --> 00:37:15.792 their baby in the NICU and also ways to

NOTE Confidence: 0.851081014

00:37:15.792 --> 00:37:17.777 prevent the complications of prematurity.

NOTE Confidence: 0.851081014

00:37:17.780 --> 00:37:18.410 And finally,

NOTE Confidence: 0.851081014

00:37:18.410 --> 00:37:20.300 maybe most importantly to me anyway,

NOTE Confidence: 0.851081014

00:37:20.300 --> 00:37:21.182 as a parent.

NOTE Confidence: 0.851081014

00:37:21.182 --> 00:37:23.834 14% of parents wanted a better style of

NOTE Confidence: 0.851081014

00:37:23.834 --> 00:37:25.950 communication with medical professionals,

NOTE Confidence: 0.851081014

00:37:25.950 --> 00:37:28.488 so they wanted more optimism from

NOTE Confidence: 0.851081014

00:37:28.488 --> 00:37:30.180 doctors specifically and better

NOTE Confidence: 0.851081014

00:37:30.252 --> 00:37:32.237 parent medical team interactions in

NOTE Confidence: 0.851081014

00:37:32.237 --> 00:37:35.009 order to engage them more as parents.

NOTE Confidence: 0.851081014

00:37:35.010 --> 00:37:37.224 So these are some of the quotes from parents,

NOTE Confidence: 0.851081014

00:37:37.230 --> 00:37:39.406 so speak to us about positive stories too.

NOTE Confidence: 0.851081014

00:37:39.410 --> 00:37:40.540 Not only the negative and

NOTE Confidence: 0.851081014

00:37:40.540 --> 00:37:41.670 the bad that can happen.

NOTE Confidence: 0.851081014

00:37:41.670 --> 00:37:42.974 It's impossible to live

NOTE Confidence: 0.851081014

00:37:42.974 --> 00:37:44.604 in fear after the birth.

NOTE Confidence: 0.851081014

00:37:44.610 --> 00:37:46.770 We want to have ideas of what we can expect.

NOTE Confidence: 0.851081014

00:37:46.770 --> 00:37:48.395 And even if each child's

NOTE Confidence: 0.851081014

00:37:48.395 --> 00:37:49.370 journey is different,

NOTE Confidence: 0.851081014

00:37:49.370 --> 00:37:50.882 I would have liked to have been better

NOTE Confidence: 0.851081014

00:37:50.882 --> 00:37:52.489 equipped for going out with all the bacteria.

NOTE Confidence: 0.851081014

00:37:52.490 --> 00:37:55.150 How to manage this, what to do and not to do?

NOTE Confidence: 0.851081014

00:37:55.150 --> 00:37:57.222 How to protect him the most without

NOTE Confidence: 0.851081014

00:37:57.222 --> 00:37:58.970 having him hospitalized every two weeks.

NOTE Confidence: 0.851081014

00:37:58.970 --> 00:38:00.362 In any case, give parents the

NOTE Confidence: 0.851081014

00:38:00.362 --> 00:38:01.870 tools so this does not happen.

NOTE Confidence: 0.851081014

00:38:01.870 --> 00:38:03.280 And you can tell this parent

NOTE Confidence: 0.851081014

00:38:03.280 --> 00:38:03.985 wrote this themselves.

NOTE Confidence: 0.851081014

00:38:03.990 --> 00:38:05.390 All the exclamation marks.

NOTE Confidence: 0.851081014

00:38:05.390 --> 00:38:06.790 Written by the parents.

NOTE Confidence: 0.851081014

00:38:06.790 --> 00:38:07.410 And finally,

00:38:07.410 --> 00:38:09.270 don't just speak about cerebral palsy,

00:38:09.270 --> 00:38:10.635 but what we can do in a

00:38:10.635 --> 00:38:11.689 practical sense is a family.

00:38:11.690 --> 00:38:12.665 How many appointments?

00:38:12.665 --> 00:38:13.640 Where? For what?

00:38:13.640 --> 00:38:14.708 What does it mean for others?

00:38:14.710 --> 00:38:15.930 The good and the bad.

00:38:15.930 --> 00:38:17.720 A diagnosis doesn't help much.

00:38:17.720 --> 00:38:20.808 What we can do about it actually helps.

00:38:20.810 --> 00:38:22.620 And finally, parents were asked,

00:38:22.620 --> 00:38:23.920 knowing what you know now,

00:38:23.920 --> 00:38:26.818 what would you have done differently?

00:38:26.820 --> 00:38:28.900 54% of parents explicitly again so that they

00:38:28.900 --> 00:38:30.629 wouldn't have done anything differently.

00:38:30.630 --> 00:38:32.846 They felt that they did what they could

00:38:32.846 --> 00:38:35.259 and what they were told to do in the NICU.

NOTE Confidence: 0.851081014

00:38:35.259 --> 00:38:36.404 22% of parents would have

NOTE Confidence: 0.851081014

00:38:36.404 --> 00:38:37.590 made changes in the NICU,

NOTE Confidence: 0.851081014

00:38:37.590 --> 00:38:39.958 including self-care and better

NOTE Confidence: 0.851081014

00:38:39.958 --> 00:38:42.326 communication with medical professionals.

NOTE Confidence: 0.851081014

00:38:42.330 --> 00:38:43.185 16% of parents,

NOTE Confidence: 0.851081014

00:38:43.185 --> 00:38:44.895 which again I think is this

NOTE Confidence: 0.851081014

00:38:44.895 --> 00:38:46.728 is a significant statistic.

NOTE Confidence: 0.851081014

00:38:46.730 --> 00:38:48.225 Mostly mothers still feel guilt

NOTE Confidence: 0.851081014

00:38:48.225 --> 00:38:49.720 about preterm birth prevention and

NOTE Confidence: 0.851081014

00:38:49.771 --> 00:38:51.319 they really feel like there was

NOTE Confidence: 0.851081014

00:38:51.319 --> 00:38:52.630 something that they could have.

NOTE Confidence: 0.851081014

00:38:52.630 --> 00:38:54.262 For sure should have done in

NOTE Confidence: 0.851081014

00:38:54.262 --> 00:38:55.759 order to prevent the premature

NOTE Confidence: 0.851081014

00:38:55.759 --> 00:38:57.139 birth of their child.

NOTE Confidence: 0.851081014

00:38:57.140 --> 00:38:57.984 And finally,

NOTE Confidence: 0.851081014

00:38:57.984 --> 00:39:00.094 9% of parent have regrets

NOTE Confidence: 0.851081014

00:39:00.094 --> 00:39:01.360 considering parental roles,

NOTE Confidence: 0.743169274117647

00:39:01.360 --> 00:39:02.364 their parental role, me,

NOTE Confidence: 0.743169274117647

00:39:02.364 --> 00:39:04.167 NICU and felt that they should have

NOTE Confidence: 0.743169274117647

00:39:04.167 --> 00:39:05.619 spent more time in the hospital.

NOTE Confidence: 0.743169274117647

00:39:05.620 --> 00:39:06.458 And interestingly,

NOTE Confidence: 0.743169274117647

00:39:06.458 --> 00:39:08.553 no parents reported regretting life

NOTE Confidence: 0.743169274117647

00:39:08.553 --> 00:39:10.779 and death decisions for their child.

NOTE Confidence: 0.743169274117647

00:39:10.780 --> 00:39:12.663 So some of the things that parents

NOTE Confidence: 0.743169274117647

00:39:12.663 --> 00:39:14.420 said in response to this question,

NOTE Confidence: 0.743169274117647

00:39:14.420 --> 00:39:15.995 I would have listened to the nurses

NOTE Confidence: 0.743169274117647

00:39:15.995 --> 00:39:17.769 and gone to sleep because we spent 18

NOTE Confidence: 0.743169274117647

00:39:17.769 --> 00:39:19.878 hours a day in the NICU near our babies.

NOTE Confidence: 0.743169274117647

00:39:19.880 --> 00:39:21.410 I would have consulted the

NOTE Confidence: 0.743169274117647

00:39:21.410 --> 00:39:23.011 psychologist of the unit. Immediately,

NOTE Confidence: 0.743169274117647

00:39:23.011 --> 00:39:25.608 instead of consulting five years after birth,

NOTE Confidence: 0.743169274117647

00:39:25.610 --> 00:39:27.418 I would have liked to know what parents

NOTE Confidence: 0.743169274117647

00:39:27.418 --> 00:39:29.107 can do earlier to get involved.

NOTE Confidence: 0.743169274117647

00:39:29.110 --> 00:39:29.582 And finally,

NOTE Confidence: 0.743169274117647

00:39:29.582 --> 00:39:31.234 I would have pushed for better care

NOTE Confidence: 0.743169274117647

00:39:31.234 --> 00:39:32.790 and monitoring during pregnancy.

NOTE Confidence: 0.743169274117647

00:39:32.790 --> 00:39:34.666 And when I thought something was wrong,

NOTE Confidence: 0.743169274117647

00:39:34.670 --> 00:39:35.930 I felt as though I wasn't listening

NOTE Confidence: 0.743169274117647

00:39:35.930 --> 00:39:37.433 to you and I thought I was in

NOTE Confidence: 0.743169274117647

00:39:37.433 --> 00:39:38.950 labor when sure enough, I was.

NOTE Confidence: 0.83800679

00:39:43.910 --> 00:39:44.318 So I have

NOTE Confidence: 0.775915662857143

00:39:44.330 --> 00:39:47.795 the closing slides, the voice of parent

NOTE Confidence: 0.785908795

00:39:47.810 --> 00:39:50.018 project and many other

NOTE Confidence: 0.785908795

00:39:50.030 --> 00:39:52.890 parent perspective projects

NOTE Confidence: 0.76733915

00:39:52.890 --> 00:39:56.378 demonstrate humility and curiosity

NOTE Confidence: 0.76733915

00:39:56.378 --> 00:39:59.690 and that we should have a lot more in

NOTE Confidence: 0.76733915

00:39:59.690 --> 00:40:02.064 neonatology to do research with families,

NOTE Confidence: 0.76733915

00:40:02.064 --> 00:40:05.543 not just research about families or children.

NOTE Confidence: 0.76733915

00:40:05.550 --> 00:40:07.811 And we have to remember that we're

NOTE Confidence: 0.76733915

00:40:07.811 --> 00:40:10.170 the experts of patients healthcare.

NOTE Confidence: 0.76733915

00:40:10.170 --> 00:40:12.680 But parents and families are the expert of

NOTE Confidence: 0.76733915

00:40:12.680 --> 00:40:16.218 their children and their couple, their life,

NOTE Confidence: 0.76733915

00:40:16.220 --> 00:40:19.610 their family and their loved ones.

NOTE Confidence: 0.76733915

00:40:19.610 --> 00:40:22.552 So measuring the all the

NOTE Confidence: 0.76733915

00:40:22.552 --> 00:40:24.268 patient important outcomes,

NOTE Confidence: 0.76733915

00:40:24.270 --> 00:40:27.458 it's getting done more and more,

NOTE Confidence: 0.76733915

00:40:27.458 --> 00:40:29.768 but it's complex and there's

NOTE Confidence: 0.76733915

00:40:29.770 --> 00:40:32.890 this is a our vision.

NOTE Confidence: 0.76733915

00:40:32.890 --> 00:40:35.302 So it's not a new universal vision,

NOTE Confidence: 0.76733915

00:40:35.302 --> 00:40:38.039 but the mistake number one that is

NOTE Confidence: 0.76733915

00:40:38.039 --> 00:40:40.762 done quite a bit in patient oriented

NOTE Confidence: 0.76733915

00:40:40.762 --> 00:40:42.959 research is to validate medical

NOTE Confidence: 0.76733915

00:40:42.959 --> 00:40:45.427 important outcomes with stakeholders.

NOTE Confidence: 0.76733915

00:40:45.430 --> 00:40:47.896 So for example to take all

NOTE Confidence: 0.76733915

00:40:47.896 --> 00:40:49.540 the three letter words.

NOTE Confidence: 0.76733915

00:40:49.540 --> 00:40:51.150 Acronyms that we don't in

NOTE Confidence: 0.76733915

00:40:51.150 --> 00:40:52.760 unitology for a bad outcome,

NOTE Confidence: 0.76733915

00:40:52.760 --> 00:40:56.960 for example BPD and US stakeholders parents,

NOTE Confidence: 0.76733915

00:40:56.960 --> 00:40:58.792 is BPD important to you?

NOTE Confidence: 0.76733915

00:40:58.792 --> 00:41:00.796 Is a Grade 3 bleed important

NOTE Confidence: 0.76733915

00:41:00.800 --> 00:41:03.511 to you without actually asking

NOTE Confidence: 0.76733915

00:41:03.511 --> 00:41:06.253 parents what is important to them?

NOTE Confidence: 0.76733915

00:41:06.260 --> 00:41:08.864 So trying to again put the parent

NOTE Confidence: 0.76733915

00:41:08.864 --> 00:41:11.758 in the mold and say look at our

NOTE Confidence: 0.76733915

00:41:11.758 --> 00:41:14.609 mold and look at what is important.

NOTE Confidence: 0.76733915

00:41:14.610 --> 00:41:18.130 The other mistake is to seek a consensus.

NOTE Confidence: 0.76733915

00:41:18.130 --> 00:41:20.332 Parents are all different and this

NOTE Confidence: 0.76733915

00:41:20.332 --> 00:41:22.797 is very important even for prenatal

NOTE Confidence: 0.76733915

00:41:22.797 --> 00:41:25.408 counseling or speaking, speaking to families.

NOTE Confidence: 0.76733915

00:41:25.410 --> 00:41:27.883 And you can see that even when we

NOTE Confidence: 0.76733915

00:41:27.883 --> 00:41:30.038 presented what we call doctors,

NOTE Confidence: 0.76733915

00:41:30.040 --> 00:41:31.542 severe disabilities,

NOTE Confidence: 0.76733915

00:41:31.542 --> 00:41:34.546 parents didn't all agree.

NOTE Confidence: 0.76733915

00:41:34.550 --> 00:41:37.238 Most often it was 50% or less

NOTE Confidence: 0.76733915

00:41:37.238 --> 00:41:38.270 that agreed together.

NOTE Confidence: 0.76733915

00:41:38.270 --> 00:41:39.632 And for example,

NOTE Confidence: 0.76733915

00:41:39.632 --> 00:41:41.448 parents who are musicians

NOTE Confidence: 0.806518746

00:41:41.510 --> 00:41:45.680 being deaf may be way more significant. Then

NOTE Confidence: 0.897192982

00:41:45.690 --> 00:41:49.560 for parents who are deaf themselves.

NOTE Confidence: 0.897192982

00:41:49.560 --> 00:41:51.912 And the third mistake is to

NOTE Confidence: 0.897192982

00:41:51.912 --> 00:41:53.480 do research about parents.

NOTE Confidence: 0.897192982

00:41:53.480 --> 00:41:56.392 I'm not with parents and not engage

NOTE Confidence: 0.897192982

00:41:56.392 --> 00:41:58.827 parents in Co construction of

NOTE Confidence: 0.897192982

00:41:58.827 --> 00:42:02.133 protocols or of even analyzing text.

NOTE Confidence: 0.897192982

00:42:02.140 --> 00:42:04.988 So it was very interesting when we were

NOTE Confidence: 0.897192982

00:42:04.988 --> 00:42:07.740 reading the stories of the parents to

NOTE Confidence: 0.897192982

00:42:07.740 --> 00:42:10.084 see different views for for example,

NOTE Confidence: 0.897192982

00:42:10.084 --> 00:42:12.698 a child who was he runs everywhere,

NOTE Confidence: 0.897192982

00:42:12.700 --> 00:42:14.518 he's so happy, he laughs all

NOTE Confidence: 0.897192982

00:42:14.518 --> 00:42:16.640 the time and sings all the time.

NOTE Confidence: 0.897192982

00:42:16.640 --> 00:42:19.623 But Rebecca saw a happy child.

NOTE Confidence: 0.897192982

00:42:19.623 --> 00:42:21.578 I saw a happy child,

NOTE Confidence: 0.897192982

00:42:21.580 --> 00:42:23.830 but those in rehab and follow up were like,

NOTE Confidence: 0.897192982

00:42:23.830 --> 00:42:26.150 Oh no, hyperactive child.

NOTE Confidence: 0.897192982

00:42:26.150 --> 00:42:29.363 So you can see that even subjectively

NOTE Confidence: 0.897192982

00:42:29.363 --> 00:42:31.522 interpreting what parents were saying

NOTE Confidence: 0.897192982

00:42:31.522 --> 00:42:34.322 had to be done by groups to decrease

NOTE Confidence: 0.897192982

00:42:34.400 --> 00:42:37.320 the bias of how we read parents stories.

00:42:39.720 --> 00:42:43.140 So there's two slides with recommendations.

00:42:43.140 --> 00:42:45.696 In our opinion, it's essential to

00:42:45.696 --> 00:42:47.400 redefine outcomes and classification

00:42:47.462 --> 00:42:49.407 of outcomes after preterm birth.

00:42:49.410 --> 00:42:52.730 This is how we describe how preterms do

00:42:52.730 --> 00:42:56.497 and this is not how parents describe them.

00:42:56.500 --> 00:42:58.348 Function should be measured

00:42:58.348 --> 00:43:00.196 as opposed to diagnosis.

00:43:00.200 --> 00:43:03.098 We know that too from the literature

00:43:03.098 --> 00:43:06.098 of children who live with trisomy 21.

00:43:06.100 --> 00:43:07.580 Resilience and adaptation

00:43:07.580 --> 00:43:09.840 should be mentioned to families.

00:43:09.840 --> 00:43:11.340 This is what families tell us.

00:43:11.340 --> 00:43:12.708 It's really difficult,

00:43:12.708 --> 00:43:15.900 but the majority of them of them

00:43:15.984 --> 00:43:18.966 told us that and give them examples.

NOTE Confidence: 0.902478725

00:43:18.970 --> 00:43:21.590 We have to avoid conflating

NOTE Confidence: 0.902478725

00:43:21.590 --> 00:43:24.210 outcomes into a severe category.

NOTE Confidence: 0.902478725

00:43:24.210 --> 00:43:25.206 And even worse,

NOTE Confidence: 0.902478725

00:43:25.206 --> 00:43:27.530 we often we didn't speak about this,

NOTE Confidence: 0.902478725

00:43:27.530 --> 00:43:29.506 say death or BPD.

NOTE Confidence: 0.902478725

00:43:29.506 --> 00:43:32.470 We should say which kids survived

NOTE Confidence: 0.902478725

00:43:32.574 --> 00:43:35.286 and then which kid have BPD.

NOTE Confidence: 0.902478725

00:43:35.290 --> 00:43:38.188 And we shouldn't consider severe categories,

NOTE Confidence: 0.902478725

00:43:38.190 --> 00:43:39.670 we should describe them.

NOTE Confidence: 0.902478725

00:43:39.670 --> 00:43:42.831 And there is no other place in medicine

NOTE Confidence: 0.902478725

00:43:42.831 --> 00:43:45.001 where outcomes are conflated this

NOTE Confidence: 0.902478725

00:43:45.001 --> 00:43:47.912 way of outcomes that don't mean the

NOTE Confidence: 0.902478725

00:43:47.912 --> 00:43:50.216 same thing into a severe category.

NOTE Confidence: 0.902478725

00:43:50.220 --> 00:43:53.230 So we don't have death or colostomy

NOTE Confidence: 0.902478725

00:43:53.230 --> 00:43:57.096 described to a patient who has colon cancer,

NOTE Confidence: 0.902478725

00:43:57.100 --> 00:43:58.700 nor a severe outcome.

NOTE Confidence: 0.902478725

00:43:58.700 --> 00:44:00.700 They will describe each outcome

NOTE Confidence: 0.902478725

00:44:00.700 --> 00:44:02.557 individually in a functional manner.

NOTE Confidence: 0.902478725

00:44:02.560 --> 00:44:03.630 They won't see a colostomy,

NOTE Confidence: 0.902478725

00:44:03.630 --> 00:44:04.726 they'll say a stool,

NOTE Confidence: 0.902478725

00:44:04.726 --> 00:44:06.924 a bag that collects tool and speak about

NOTE Confidence: 0.902478725

00:44:06.924 --> 00:44:09.740 if it's reversible or not, for example.

NOTE Confidence: 0.902478725

00:44:09.740 --> 00:44:12.660 So the leader function.

NOTE Confidence: 0.902478725

00:44:12.660 --> 00:44:13.492 To families,

NOTE Confidence: 0.902478725

00:44:13.492 --> 00:44:15.156 we should describe functional

NOTE Confidence: 0.902478725

00:44:15.156 --> 00:44:17.400 outcomes in a balanced fashion,

NOTE Confidence: 0.902478725

00:44:17.400 --> 00:44:19.512 not severe disability which

NOTE Confidence: 0.902478725

00:44:19.512 --> 00:44:21.096 is unfortunately done.

NOTE Confidence: 0.902478725

00:44:21.100 --> 00:44:24.474 For example after a great for bleed.

NOTE Confidence: 0.902478725

00:44:24.480 --> 00:44:26.400 Acceptable would be to say

NOTE Confidence: 0.902478725

00:44:26.400 --> 00:44:28.320 your child may be deaf,

NOTE Confidence: 0.902478725

00:44:28.320 --> 00:44:31.224 but preferable and optimal would say

NOTE Confidence: 0.902478725

00:44:31.224 --> 00:44:34.664 your child may need to use hearing

NOTE Confidence: 0.902478725

00:44:34.664 --> 00:44:37.490 aids or cochlear implants to hear.

NOTE Confidence: 0.902478725

00:44:37.490 --> 00:44:39.709 To tell parents their kid has a

NOTE Confidence: 0.902478725

00:44:39.709 --> 00:44:42.368 risk of BPD is should not be done.

NOTE Confidence: 0.902478725

00:44:42.370 --> 00:44:44.786 We can see the risk of going home

NOTE Confidence: 0.902478725

00:44:44.786 --> 00:44:47.580 on oxygen and what that means or

NOTE Confidence: 0.902478725

00:44:47.580 --> 00:44:50.190 rehospitalization or what it actually means.

NOTE Confidence: 0.902478725

00:44:50.190 --> 00:44:51.426 That pulmonary important outcomes.

NOTE Confidence: 0.902478725

00:44:51.426 --> 00:44:53.280 And we're working on this to

NOTE Confidence: 0.902478725

00:44:53.338 --> 00:44:54.663 actually speak to parents what

NOTE Confidence: 0.902478725

00:44:54.663 --> 00:44:56.290 it means in their daily life.

NOTE Confidence: 0.902478725

00:44:56.290 --> 00:44:58.108 It's not the three letter word,

NOTE Confidence: 0.902478725

00:44:58.110 --> 00:44:59.890 it's where they're more stuff

NOTE Confidence: 0.882168414

00:44:59.900 --> 00:45:01.030 that it means for them.

NOTE Confidence: 0.884109966

00:45:03.100 --> 00:45:05.260 So the key messages are that

NOTE Confidence: 0.884109966

00:45:05.260 --> 00:45:07.246 parents generally have a positive

NOTE Confidence: 0.884109966

00:45:07.246 --> 00:45:09.146 perception of their child,

NOTE Confidence: 0.884109966

00:45:09.150 --> 00:45:12.640 and this confirms prior research.

NOTE Confidence: 0.884109966

00:45:12.640 --> 00:45:14.495 Developmental issues are still a

NOTE Confidence: 0.884109966

00:45:14.495 --> 00:45:17.525 main concern, but we even signed the

NOTE Confidence: 0.884109966

00:45:17.525 --> 00:45:19.810 developmental issues that behavior and

NOTE Confidence: 0.884109966

00:45:19.886 --> 00:45:21.952 emotional outcomes were more important

NOTE Confidence: 0.884109966

00:45:21.952 --> 00:45:24.290 to parents than they were to us,

NOTE Confidence: 0.884109966

00:45:24.290 --> 00:45:26.874 and other outcomes that were important to us,

NOTE Confidence: 0.884109966

00:45:26.880 --> 00:45:28.480 such as their cerebral palsy,

NOTE Confidence: 0.884109966

00:45:28.480 --> 00:45:33.410 were considered less severe, significant.

NOTE Confidence: 0.884109966

00:45:33.410 --> 00:45:35.178 Some parental concerns are

NOTE Confidence: 0.884109966

00:45:35.178 --> 00:45:37.388 forgotten in our outcome measures,

NOTE Confidence: 0.884109966

00:45:37.390 --> 00:45:39.614 such as respiratory health,

NOTE Confidence: 0.884109966

00:45:39.614 --> 00:45:40.982 rehospitalization, fragility,

NOTE Confidence: 0.884109966

00:45:40.982 --> 00:45:44.230 eating, nutrition and sleeping.

NOTE Confidence: 0.884109966

00:45:44.230 --> 00:45:46.222 For some parents, when they considered

NOTE Confidence: 0.884109966

00:45:46.222 --> 00:45:48.330 their child to be significant,

NOTE Confidence: 0.884109966

00:45:48.330 --> 00:45:50.870 to have a significant impairment,

NOTE Confidence: 0.884109966

00:45:50.870 --> 00:45:53.048 it was often in those spheres

NOTE Confidence: 0.884109966

00:45:53.048 --> 00:45:55.050 when we considered them normal,

NOTE Confidence: 0.884109966

00:45:55.050 --> 00:45:57.480 quote UN quote.

NOTE Confidence: 0.884109966

00:45:57.480 --> 00:46:00.410 Parents describe both positive and

NOTE Confidence: 0.884109966

00:46:00.410 --> 00:46:02.754 negative impacts of prematurity,

NOTE Confidence: 0.884109966

00:46:02.760 --> 00:46:04.592 although scientific literature tends

NOTE Confidence: 0.884109966

00:46:04.592 --> 00:46:07.340 to emphasize or not even emphasize,

NOTE Confidence: 0.884109966

00:46:07.340 --> 00:46:10.320 only look at the negative.

NOTE Confidence: 0.884109966

00:46:10.320 --> 00:46:12.644 The themes of resilience and positive

NOTE Confidence: 0.884109966

00:46:12.644 --> 00:46:15.380 transformations are clear in our research,

NOTE Confidence: 0.884109966

00:46:15.380 --> 00:46:18.820 but they are not in usual outcome research,

NOTE Confidence: 0.884109966

00:46:18.820 --> 00:46:20.930 and parents would really benefit

NOTE Confidence: 0.884109966

00:46:20.930 --> 00:46:23.547 from hearing that it is not

NOTE Confidence: 0.884109966

00:46:23.547 --> 00:46:26.121 always like this and that most

NOTE Confidence: 0.884109966

00:46:26.121 --> 00:46:28.170 parents find something positive.

NOTE Confidence: 0.884109966

00:46:28.170 --> 00:46:30.155 Parents who don't want more

NOTE Confidence: 0.884109966

00:46:30.155 --> 00:46:31.386 practical guidance, again,

NOTE Confidence: 0.884109966

00:46:31.386 --> 00:46:33.566 a function, not a diagnosis.

NOTE Confidence: 0.884109966

00:46:33.570 --> 00:46:35.700 What that means for the family?

NOTE Confidence: 0.884109966

00:46:35.700 --> 00:46:37.805 More optimism and more fluid

NOTE Confidence: 0.884109966

00:46:37.805 --> 00:46:39.489 communication with the medical

NOTE Confidence: 0.884109966

00:46:39.489 --> 00:46:42.458 team of how they can team up with

NOTE Confidence: 0.884109966

00:46:42.458 --> 00:46:44.938 clinicians to help their baby.

NOTE Confidence: 0.884109966

00:46:44.940 --> 00:46:45.726 So finally,

NOTE Confidence: 0.884109966

00:46:45.726 --> 00:46:48.084 the classification we use in unitology

NOTE Confidence: 0.884109966

00:46:48.084 --> 00:46:50.123 is suboptimal and doesn't correspond

NOTE Confidence: 0.884109966

00:46:50.123 --> 00:46:52.499 to the lived experience of parents.

NOTE Confidence: 0.884109966

00:46:52.500 --> 00:46:55.440 It's more optimistic and

NOTE Confidence: 0.884109966

00:46:55.440 --> 00:46:58.380 generally misses the point.

NOTE Confidence: 0.884109966

00:46:58.380 --> 00:47:01.070 So I'll actually stop sharing

NOTE Confidence: 0.884109966

00:47:01.070 --> 00:47:03.430 our presentation or slides,

NOTE Confidence: 0.884109966

00:47:03.430 --> 00:47:06.826 so you can ask US questions.

NOTE Confidence: 0.884109966

00:47:06.830 --> 00:47:11.070 And we will all gather together.

NOTE Confidence: 0.884109966

00:47:11.070 --> 00:47:14.570 I thought we will pass through top plus.

NOTE Confidence: 0.884109966

00:47:14.570 --> 00:47:14.910 This

NOTE Confidence: 0.923888952

00:47:14.920 --> 00:47:17.810 was an absolutely marvelous presentation.

NOTE Confidence: 0.923888952

00:47:17.810 --> 00:47:19.310 Thank you. Thank you both.

NOTE Confidence: 0.923888952

00:47:19.310 --> 00:47:20.836 Thank you all three of you so

NOTE Confidence: 0.923888952

00:47:20.836 --> 00:47:22.250 much for this terrific talk.

NOTE Confidence: 0.923888952

00:47:22.250 --> 00:47:23.965 There's there's a lot to lot to

NOTE Confidence: 0.923888952

00:47:23.965 --> 00:47:27.530 unpack here and this is where the

NOTE Confidence: 0.923888952

00:47:27.530 --> 00:47:29.770 neonatology fellows are on the line.

NOTE Confidence: 0.923888952

00:47:29.770 --> 00:47:32.180 This is, this is really

NOTE Confidence: 0.923888952

00:47:32.180 --> 00:47:34.108 serious and important stuff.

NOTE Confidence: 0.923888952

00:47:34.110 --> 00:47:35.982 And let me first just say let you

NOTE Confidence: 0.923888952

00:47:35.982 --> 00:47:37.840 folks know that that's the way the

NOTE Confidence: 0.923888952

00:47:37.840 --> 00:47:39.806 questions will be asked is if you

NOTE Confidence: 0.923888952

00:47:39.806 --> 00:47:41.534 would please send your questions in

NOTE Confidence: 0.923888952

00:47:41.534 --> 00:47:43.570 through the Q&amp;A function on zoom and

NOTE Confidence: 0.923888952

00:47:43.570 --> 00:47:45.621 then I'll read them to the speakers

NOTE Confidence: 0.923888952

00:47:45.621 --> 00:47:48.150 and we can and we can go from there.

NOTE Confidence: 0.923888952

00:47:48.150 --> 00:47:50.214 But let me take the privilege

NOTE Confidence: 0.923888952

00:47:50.214 --> 00:47:51.590 of of doing the,

NOTE Confidence: 0.923888952

00:47:51.590 --> 00:47:53.564 the the first question and it's I

NOTE Confidence: 0.923888952

00:47:53.564 --> 00:47:56.027 mean I I was jotting down stuff.

NOTE Confidence: 0.923888952

00:47:56.030 --> 00:47:56.783 This is really,

NOTE Confidence: 0.923888952

00:47:56.783 --> 00:47:58.540 this is really important and it it

NOTE Confidence: 0.923888952

00:47:58.590 --> 00:48:00.216 strikes me essentially which I think

NOTE Confidence: 0.923888952

00:48:00.216 --> 00:48:02.404 is your point and it's so beautifully

NOTE Confidence: 0.923888952

00:48:02.404 --> 00:48:03.808 presented in this particular.

NOTE Confidence: 0.923888952

00:48:03.810 --> 00:48:04.980 Presentation the way you did it,

NOTE Confidence: 0.923888952

00:48:04.980 --> 00:48:06.220 but also in these data,

NOTE Confidence: 0.923888952

00:48:06.220 --> 00:48:06.985 which I'm very,

NOTE Confidence: 0.923888952

00:48:06.985 --> 00:48:08.770 very anxious to see published and I

NOTE Confidence: 0.923888952

00:48:08.826 --> 00:48:10.874 really look forward to having it so that,

NOTE Confidence: 0.923888952

00:48:10.880 --> 00:48:11.639 you know, we'll,

NOTE Confidence: 0.923888952

00:48:11.639 --> 00:48:14.040 we'll be able to share this talk with folks,

NOTE Confidence: 0.923888952

00:48:14.040 --> 00:48:15.920 but also to share here's the paper here.

NOTE Confidence: 0.923888952

00:48:15.920 --> 00:48:20.002 Here are the data which suggests in

NOTE Confidence: 0.923888952

00:48:20.002 --> 00:48:22.654 essence that we're doing it wrong,

NOTE Confidence: 0.923888952

00:48:22.660 --> 00:48:24.660 that we're doing it wrong.

NOTE Confidence: 0.923888952

00:48:24.660 --> 00:48:27.012 And so a question I have for for

NOTE Confidence: 0.923888952

00:48:27.012 --> 00:48:29.484 any and all three of you is why

NOTE Confidence: 0.923888952

00:48:29.484 --> 00:48:31.798 do you suppose we do this wrong?

NOTE Confidence: 0.923888952

00:48:31.800 --> 00:48:34.056 Why do you suppose we do this differently?

NOTE Confidence: 0.923888952

00:48:34.060 --> 00:48:36.538 Than the way we do for adults

NOTE Confidence: 0.923888952

00:48:36.538 --> 00:48:38.590 with colon cancer for example.

NOTE Confidence: 0.923888952

00:48:38.590 --> 00:48:41.110 I'm convinced and and and and I've had

NOTE Confidence: 0.923888952

00:48:41.110 --> 00:48:42.608 these conversations over the years.

NOTE Confidence: 0.923888952

00:48:42.610 --> 00:48:44.385 I'm convinced that we've got

NOTE Confidence: 0.923888952

00:48:44.385 --> 00:48:45.805 the wrong framework here.

NOTE Confidence: 0.923888952

00:48:45.810 --> 00:48:47.818 But I'm interested to know what what you

NOTE Confidence: 0.923888952

00:48:47.818 --> 00:48:50.108 3 think why why are we doing it this way?

NOTE Confidence: 0.923888952

00:48:50.110 --> 00:48:51.406 Why are we getting it wrong.

NOTE Confidence: 0.923888952

00:48:51.410 --> 00:48:52.520 I think I'm convinced about

NOTE Confidence: 0.923888952

00:48:52.520 --> 00:48:53.733 how we're getting it wrong.

NOTE Confidence: 0.923888952

00:48:53.733 --> 00:48:54.920 I'm curious to know what you

NOTE Confidence: 0.923888952

00:48:54.920 --> 00:48:55.325 think about why

NOTE Confidence: 0.762457115

00:48:55.340 --> 00:48:56.700 we're getting it wrong. I think we'll have

NOTE Confidence: 0.859996433333333

00:48:56.710 --> 00:48:57.838 different versions of

NOTE Confidence: 0.5975400175

00:48:57.850 --> 00:48:58.818 why. But I'll have

NOTE Confidence: 0.742052568571429

00:48:58.830 --> 00:49:00.615 to follow up visit eager follow up

NOTE Confidence: 0.5757310175

00:49:00.630 --> 00:49:01.958 physician speak. So are

NOTE Confidence: 0.63347455

00:49:01.970 --> 00:49:03.200 the parents. I thought. I

NOTE Confidence: 0.86664198

00:49:03.210 --> 00:49:06.898 thought about this a lot and I think not to

NOTE Confidence: 0.601214176

00:49:06.940 --> 00:49:08.772 stoke everybody's ego necessarily.

NOTE Confidence: 0.601214176

00:49:08.772 --> 00:49:10.514 Fair. But I feel like the people

NOTE Confidence: 0.601214176

00:49:10.514 --> 00:49:12.074 that are doing the follow-up or

NOTE Confidence: 0.601214176

00:49:12.074 --> 00:49:13.704 that are deciding what's important,

NOTE Confidence: 0.601214176

00:49:13.710 --> 00:49:16.050 you're not, you're looking at outcomes

NOTE Confidence: 0.601214176

00:49:16.050 --> 00:49:18.589 through your own lens of experience.

NOTE Confidence: 0.601214176

00:49:18.590 --> 00:49:21.902 So if you're a PhD or you're a doctor,

NOTE Confidence: 0.601214176

00:49:21.910 --> 00:49:24.526 you, no offense, but you don't

NOTE Confidence: 0.601214176

00:49:24.526 --> 00:49:26.870 really represent the general public.

NOTE Confidence: 0.601214176

00:49:26.870 --> 00:49:28.050 So you're more, you know,

NOTE Confidence: 0.601214176

00:49:28.050 --> 00:49:29.458 you're intelligent, you're educated,

NOTE Confidence: 0.601214176

00:49:29.458 --> 00:49:31.570 you make a lot of money,

NOTE Confidence: 0.601214176

00:49:31.570 --> 00:49:34.549 you know you're you have a lot of resources.

NOTE Confidence: 0.601214176

00:49:34.550 --> 00:49:36.095 You've potentially different

NOTE Confidence: 0.601214176

00:49:36.095 --> 00:49:39.185 expectations I would say then perhaps.

NOTE Confidence: 0.601214176

00:49:39.190 --> 00:49:42.244 Everybody else does and I want to. So again,

NOTE Confidence: 0.601214176

00:49:42.244 --> 00:49:45.810 like the idea of having a child that has.

NOTE Confidence: 0.601214176

00:49:45.810 --> 00:49:47.735 You know, a low IQ or something,

NOTE Confidence: 0.601214176

00:49:47.740 --> 00:49:48.619 I'm guessing again.

NOTE Confidence: 0.601214176

00:49:48.619 --> 00:49:50.084 Or those types of things.

NOTE Confidence: 0.601214176

00:49:50.090 --> 00:49:51.550 Or that is less mobile.

NOTE Confidence: 0.601214176

00:49:51.550 --> 00:49:54.049 I don't know, I feel like because.

NOTE Confidence: 0.601214176

00:49:54.050 --> 00:49:55.814 I I sort of feel it's a little bit

NOTE Confidence: 0.601214176

00:49:55.814 --> 00:49:57.732 bad that the people that are making

NOTE Confidence: 0.601214176

00:49:57.732 --> 00:49:59.945 these decisions might not have the same

NOTE Confidence: 0.601214176

00:49:59.945 --> 00:50:02.326 desires or or or wants for kids or

NOTE Confidence: 0.601214176

00:50:02.326 --> 00:50:04.255 more might be more critical potentially

NOTE Confidence: 0.601214176

00:50:04.255 --> 00:50:07.170 about what they want those outcomes to be.

NOTE Confidence: 0.601214176

00:50:07.170 --> 00:50:09.116 And I think that that's part of

NOTE Confidence: 0.601214176

00:50:09.116 --> 00:50:10.780 it because again when you talk

NOTE Confidence: 0.601214176

00:50:10.780 --> 00:50:12.565 to sort of a range of parents.

NOTE Confidence: 0.601214176

00:50:12.570 --> 00:50:15.405 Things like again and DI are not,

NOTE Confidence: 0.601214176

00:50:15.410 --> 00:50:16.790 you know, they're not that important.

NOTE Confidence: 0.601214176

00:50:16.790 --> 00:50:19.340 Things like they are important,

NOTE Confidence: 0.601214176

00:50:19.340 --> 00:50:20.545 but they're not as important

NOTE Confidence: 0.601214176

00:50:20.545 --> 00:50:21.509 as one might think.

NOTE Confidence: 0.601214176

00:50:21.510 --> 00:50:23.967 So again, I find it really interesting

NOTE Confidence: 0.601214176

00:50:23.967 --> 00:50:25.970 that there's this real focus on,

NOTE Confidence: 0.601214176

00:50:25.970 --> 00:50:27.710 again, development IQ.

NOTE Confidence: 0.601214176

00:50:27.710 --> 00:50:28.870 And again,

NOTE Confidence: 0.601214176

00:50:28.870 --> 00:50:30.634 from my just from the reading that I've done,

NOTE Confidence: 0.601214176

00:50:30.640 --> 00:50:33.986 there's a huge amount of research into

NOTE Confidence: 0.601214176

00:50:33.986 --> 00:50:36.138 school outcomes, neuro, you know,

NOTE Confidence: 0.601214176

00:50:36.138 --> 00:50:38.710 like I said, how kids do in school,

NOTE Confidence: 0.601214176

00:50:38.710 --> 00:50:41.114 how kids do in math, things like that.

NOTE Confidence: 0.601214176

00:50:41.114 --> 00:50:42.602 And we know that that's important.

NOTE Confidence: 0.601214176

00:50:42.610 --> 00:50:43.334 But I think again,

NOTE Confidence: 0.601214176

00:50:43.334 --> 00:50:44.058 if you ask parents,

NOTE Confidence: 0.601214176

00:50:44.060 --> 00:50:45.296 it's probably at the bottom of

NOTE Confidence: 0.601214176

00:50:45.296 --> 00:50:46.681 their list of what they consider

NOTE Confidence: 0.601214176

00:50:46.681 --> 00:50:47.717 to be really important.

NOTE Confidence: 0.601214176

00:50:47.720 --> 00:50:49.916 They want to know that their kids are happy.

NOTE Confidence: 0.601214176

00:50:49.920 --> 00:50:51.467 They want their kids again to be

NOTE Confidence: 0.601214176

00:50:51.467 --> 00:50:52.500 functional members of society.

NOTE Confidence: 0.601214176

00:50:52.500 --> 00:50:54.957 They want them to just go to regular school.

NOTE Confidence: 0.601214176

00:50:54.960 --> 00:50:56.480 They want them to be able to have a job.

NOTE Confidence: 0.601214176

00:50:56.480 --> 00:50:58.080 It doesn't necessarily matter to

NOTE Confidence: 0.601214176

00:50:58.080 --> 00:51:00.176 a lot of parents if you know,

NOTE Confidence: 0.601214176

00:51:00.176 --> 00:51:01.808 their kids end up being doctors.

NOTE Confidence: 0.601214176

00:51:01.810 --> 00:51:03.298 Does that kind of make sense?

NOTE Confidence: 0.601214176

00:51:03.300 --> 00:51:04.399 So I think that's part of it.

NOTE Confidence: 0.601214176

00:51:04.400 --> 00:51:06.155 I think it's just like I said that the

NOTE Confidence: 0.601214176

00:51:06.155 --> 00:51:07.707 people that are choosing these are

NOTE Confidence: 0.601214176

00:51:07.707 --> 00:51:09.254 are choosing these outcomes sort of

NOTE Confidence: 0.601214176

00:51:09.254 --> 00:51:10.838 based on their own lens and not again,

NOTE Confidence: 0.601214176

00:51:10.840 --> 00:51:13.270 what most, you know, if you took 100 parents,

NOTE Confidence: 0.601214176

00:51:13.270 --> 00:51:14.674 what they would necessarily.

NOTE Confidence: 0.601214176

00:51:14.674 --> 00:51:17.130 Considered to be as important to them.

NOTE Confidence: 0.601214176

00:51:17.130 --> 00:51:17.394 So.

NOTE Confidence: 0.601214176

00:51:17.394 --> 00:51:19.242 And I also feel like there's a

NOTE Confidence: 0.601214176

00:51:19.242 --> 00:51:20.506 difference because children are

NOTE Confidence: 0.601214176

00:51:20.506 --> 00:51:22.247 sort of unfinished canvases, right?

NOTE Confidence: 0.601214176

00:51:22.247 --> 00:51:24.509 Like with adults and colon cancer,

NOTE Confidence: 0.601214176

00:51:24.510 --> 00:51:24.924 you know,

NOTE Confidence: 0.601214176

00:51:24.924 --> 00:51:26.580 we know that person has had a chance

NOTE Confidence: 0.601214176

00:51:26.634 --> 00:51:28.170 to grow and develop a personality.

NOTE Confidence: 0.601214176

00:51:28.170 --> 00:51:30.246 And with kids, there's more pressure,

NOTE Confidence: 0.601214176

00:51:30.250 --> 00:51:30.778 I guess,

NOTE Confidence: 0.601214176

00:51:30.778 --> 00:51:32.626 again on what these kids are going

NOTE Confidence: 0.601214176

00:51:32.626 --> 00:51:33.928 to be and to become.

NOTE Confidence: 0.601214176

00:51:33.930 --> 00:51:35.858 And so I feel like there's, you know,

NOTE Confidence: 0.601214176

00:51:35.858 --> 00:51:37.496 adults or adults and kids or kids.

NOTE Confidence: 0.79343801

00:51:37.500 --> 00:51:38.692 So there's there's more.

NOTE Confidence: 0.79343801

00:51:38.692 --> 00:51:39.914 Yeah. It's just a different,

NOTE Confidence: 0.79343801

00:51:39.914 --> 00:51:42.498 a different outlook. I think so, yeah.

NOTE Confidence: 0.57859536

00:51:43.750 --> 00:51:46.391 And your second point, Rebecca,

NOTE Confidence: 0.57859536

99

00:51:46.391 --> 00:51:48.639 I think was was really important the fact

NOTE Confidence: 0.57859536

00:51:48.639 --> 00:51:50.964 that the that the newborns in particularly

NOTE Confidence: 0.57859536

00:51:50.964 --> 00:51:53.057 are the unfinished cannabis as you put it,

NOTE Confidence: 0.57859536

00:51:53.060 --> 00:51:54.593 compared to adults and even to some

NOTE Confidence: 0.57859536

00:51:54.593 --> 00:51:55.909 extent compared to older children,

NOTE Confidence: 0.57859536

00:51:55.910 --> 00:51:57.722 because this is not an Annie

NOTE Confidence: 0.57859536

00:51:57.722 --> 00:51:59.789 and I have worked on together.

NOTE Confidence: 0.57859536

00:51:59.790 --> 00:52:01.379 Far exceeded my own in this area.

NOTE Confidence: 0.57859536

00:52:01.380 --> 00:52:03.732 But but the whole our attitudes toward

NOTE Confidence: 0.57859536

00:52:03.732 --> 00:52:05.821 premature babies in particular and full

NOTE Confidence: 0.57859536

00:52:05.821 --> 00:52:07.867 term babies also is different even

NOTE Confidence: 0.57859536

00:52:07.867 --> 00:52:10.359 than our attitudes toward other children.

NOTE Confidence: 0.57859536

00:52:10.360 --> 00:52:12.691 And so the idea that that the

NOTE Confidence: 0.57859536

00:52:12.691 --> 00:52:14.762 physician has a different perspective

NOTE Confidence: 0.57859536

00:52:14.762 --> 00:52:17.756 than the parents or the patient,

NOTE Confidence: 0.57859536

00:52:17.760 --> 00:52:19.000 I think that makes sense.

NOTE Confidence: 0.57859536

00:52:19.000 --> 00:52:20.908 Which is why it's so valuable

NOTE Confidence: 0.57859536

00:52:20.908 --> 00:52:22.904 to hear from you, Miss Pierce,

NOTE Confidence: 0.57859536

00:52:22.904 --> 00:52:25.438 and to hear from you Doctor Javier,

NOTE Confidence: 0.57859536

00:52:25.440 --> 00:52:27.807 who I know that that it's not a secret

NOTE Confidence: 0.57859536

00:52:27.807 --> 00:52:30.207 that Annie has been in both situations.

NOTE Confidence: 0.57859536

00:52:30.210 --> 00:52:33.770 And you, you showed very briefly your book.

NOTE Confidence: 0.57859536

00:52:33.770 --> 00:52:34.661 Breathe, baby, breathe,

NOTE Confidence: 0.57859536

00:52:34.661 --> 00:52:36.656 which is a wonderful look from the

NOTE Confidence: 0.57859536

00:52:36.656 --> 00:52:38.042 inside by a physician who is also

NOTE Confidence: 0.57859536

00:52:38.042 --> 00:52:39.576 the mother of a very preterm baby.

NOTE Confidence: 0.57859536

00:52:39.580 --> 00:52:41.080 And so we're

NOTE Confidence: 0.8592251

00:52:41.080 --> 00:52:44.680 moving furniture around to be able to answer

NOTE Confidence: 0.764077366666667

00:52:44.680 --> 00:52:48.170 the question. I think there's also that we've

NOTE Confidence: 0.840178346666667

00:52:48.180 --> 00:52:49.726 discussed this and wrote about

NOTE Confidence: 0.840178346666667

00:52:49.726 --> 00:52:52.108 it like saving versus creating.

NOTE Confidence: 0.840178346666667

00:52:52.108 --> 00:52:54.116 I think as neonatologist,

NOTE Confidence: 0.840178346666667

00:52:54.120 --> 00:52:56.320 we feel we create disability,

NOTE Confidence: 0.840178346666667

00:52:56.320 --> 00:52:59.160 whereas others feel they save patients

NOTE Confidence: 0.840178346666667

00:52:59.160 --> 00:53:02.512 and many of these very fragile babies,

NOTE Confidence: 0.840178346666667

00:53:02.512 --> 00:53:04.384 we can take life and death.

NOTE Confidence: 0.840178346666667

00:53:04.390 --> 00:53:05.810 Decisions and stop the

NOTE Confidence: 0.818813081428571

00:53:05.820 --> 00:53:08.165 respirator, for example after a great 4

NOTE Confidence: 0.941132793333333

00:53:08.180 --> 00:53:10.555 hemorrhage. So we feel we

NOTE Confidence: 0.941132793333333

00:53:10.555 --> 00:53:12.455 need to prepare parents.

NOTE Confidence: 0.941132793333333

00:53:12.460 --> 00:53:14.300 For the future, in a grim way,

NOTE Confidence: 0.941132793333333

00:53:14.300 --> 00:53:15.692 we don't do elsewhere.

NOTE Confidence: 0.941132793333333

00:53:15.692 --> 00:53:18.430 So if you speak to any critical

NOTE Confidence: 0.941132793333333

00:53:18.430 --> 00:53:20.718 care physician who describes

NOTE Confidence: 0.941132793333333

00:53:20.720 --> 00:53:22.212 2 parents for example,

NOTE Confidence: 0.941132793333333

00:53:22.212 --> 00:53:24.636 if something horrendous a burnt victim,

NOTE Confidence: 0.941132793333333

00:53:24.640 --> 00:53:26.203 70% burns, what?

NOTE Confidence: 0.941132793333333

00:53:26.203 --> 00:53:28.808 What the future will look

NOTE Confidence: 0.941132793333333

00:53:28.808 --> 00:53:30.619 like or the PICC state,

NOTE Confidence: 0.941132793333333

00:53:30.619 --> 00:53:32.113 they really don't do what we

NOTE Confidence: 0.941132793333333

00:53:32.113 --> 00:53:33.968 try to do with decision aids,

NOTE Confidence: 0.941132793333333

00:53:33.970 --> 00:53:36.328 showing how much pain they have

NOTE Confidence: 0.941132793333333

00:53:36.328 --> 00:53:38.432 and then how much withdrawal

NOTE Confidence: 0.941132793333333

00:53:38.432 --> 00:53:41.350 and then how much depression.

NOTE Confidence: 0.941132793333333

00:53:41.350 --> 00:53:43.210 And they they don't do that.

NOTE Confidence: 0.941132793333333

00:53:43.210 --> 00:53:45.118 They they try to be encouraging

NOTE Confidence: 0.941132793333333

00:53:45.118 --> 00:53:47.405 the same thing in cancer and we

NOTE Confidence: 0.941132793333333

00:53:47.405 --> 00:53:49.420 arrive with our list of all the

NOTE Confidence: 0.941132793333333

00:53:49.420 --> 00:53:51.452 bad things that can happen to kids

NOTE Confidence: 0.941132793333333

00:53:51.452 --> 00:53:53.642 in a very structured manner as

NOTE Confidence: 0.941132793333333

00:53:53.642 --> 00:53:55.928 recommended by the AAP to approach

NOTE Confidence: 0.941132793333333

00:53:55.928 --> 00:53:57.988 parent with the disaster tree.

NOTE Confidence: 0.941132793333333

00:53:57.990 --> 00:53:58.643 So it's.

NOTE Confidence: 0.941132793333333

00:53:58.643 --> 00:54:02.790 I think there's a lot about newborns,

NOTE Confidence: 0.941132793333333

00:54:02.790 --> 00:54:03.628 optional newborns,

NOTE Confidence: 0.941132793333333

00:54:03.628 --> 00:54:05.723 replaceable newborns for some that

NOTE Confidence: 0.941132793333333

00:54:05.723 --> 00:54:08.129 you can just make another one.

NOTE Confidence: 0.941132793333333

00:54:08.130 --> 00:54:13.170 I'm I'm being challenging on purpose.

NOTE Confidence: 0.941132793333333

00:54:13.170 --> 00:54:13.960 And this

NOTE Confidence: 0.897115195

00:54:13.970 --> 00:54:17.156 window of opportunity, as well as

NOTE Confidence: 0.876812802941176

00:54:17.230 --> 00:54:18.600 the feeling that we create

NOTE Confidence: 0.876812802941176

00:54:18.600 --> 00:54:20.279 disabled kids and we don't want

NOTE Confidence: 0.876812802941176

00:54:20.279 --> 00:54:22.223 parents to come back and say, oh,

NOTE Confidence: 0.876812802941176

00:54:22.223 --> 00:54:25.254 I regret that you saved my child.

NOTE Confidence: 0.876812802941176

00:54:25.260 --> 00:54:27.836 And I don't know if my has

NOTE Confidence: 0.876812802941176

00:54:27.836 --> 00:54:28.940 some epidemiology comments.

NOTE Confidence: 0.876812802941176

00:54:28.940 --> 00:54:31.495 I think it's very practical to lump

NOTE Confidence: 0.876812802941176

00:54:31.495 --> 00:54:33.680 things together to find a P value.

NOTE Confidence: 0.876812802941176

00:54:33.680 --> 00:54:35.976 So if you lump death or whatever and

NOTE Confidence: 0.876812802941176

00:54:35.980 --> 00:54:38.451 then a whole lot of adverse outcomes,

NOTE Confidence: 0.876812802941176

00:54:38.451 --> 00:54:42.520 then you may find a P value somewhere.

NOTE Confidence: 0.876812802941176

00:54:42.520 --> 00:54:44.326 But that's not the way they

NOTE Confidence: 0.876812802941176

00:54:44.326 --> 00:54:46.170 do it in cancer outcome.

NOTE Confidence: 0.841740347

00:54:48.760 --> 00:54:51.250 And I also think like one of the problem is.

NOTE Confidence: 0.681016143142857

00:54:53.510 --> 00:54:54.518 Well, I'm a pediatrician.

NOTE Confidence: 0.681016143142857

00:54:54.518 --> 00:54:56.030 I don't work in the neonatal

NOTE Confidence: 0.681016143142857

00:54:56.081 --> 00:54:57.109 in the neonatal units.

NOTE Confidence: 0.681016143142857

00:54:57.110 --> 00:54:58.958 I guess like I don't have to make

NOTE Confidence: 0.681016143142857

00:54:58.958 --> 00:55:00.468 those life and death decision.

NOTE Confidence: 0.681016143142857

00:55:00.470 --> 00:55:02.396 And I think it's probably important

NOTE Confidence: 0.681016143142857

00:55:02.396 --> 00:55:04.737 to say well you know you're the

NOTE Confidence: 0.681016143142857

00:55:04.737 --> 00:55:07.086 child may have Sir Bob Palsy but

NOTE Confidence: 0.681016143142857

00:55:07.086 --> 00:55:08.821 then for parents serval palsy

NOTE Confidence: 0.681016143142857

00:55:08.821 --> 00:55:11.075 is a very vague term and we'll

NOTE Confidence: 0.681016143142857

00:55:11.075 --> 00:55:13.433 we'll think about the child who's

NOTE Confidence: 0.681016143142857

00:55:13.433 --> 00:55:15.483 wheelchair bound and cannot talk.

NOTE Confidence: 0.681016143142857

00:55:15.490 --> 00:55:16.998 It cannot do anything.

NOTE Confidence: 0.681016143142857

00:55:16.998 --> 00:55:18.782 Whereas actually I, you know,

NOTE Confidence: 0.681016143142857

00:55:18.782 --> 00:55:20.738 like majority of kids will end

NOTE Confidence: 0.681016143142857

00:55:20.738 --> 00:55:22.610 up walking and they can have.

NOTE Confidence: 0.681016143142857

00:55:22.610 --> 00:55:26.276 A normal life despite their disability.

NOTE Confidence: 0.681016143142857

00:55:26.280 --> 00:55:29.079 So for example let's say a child has cancer.

NOTE Confidence: 0.681016143142857

00:55:29.080 --> 00:55:31.176 You know I I see the hematologist he

NOTE Confidence: 0.681016143142857

00:55:31.176 --> 00:55:33.294 will say well you know the child may

NOTE Confidence: 0.681016143142857

00:55:33.294 --> 00:55:35.658 have you know is at higher risk of

NOTE Confidence: 0.681016143142857

00:55:35.658 --> 00:55:37.854 infection but we have antibiotics you know,

NOTE Confidence: 0.681016143142857

00:55:37.854 --> 00:55:39.498 to get to treat your child.

NOTE Confidence: 0.681016143142857

00:55:39.500 --> 00:55:41.264 So you know like and you're intelligent.

NOTE Confidence: 0.681016143142857

00:55:41.270 --> 00:55:43.493 You say well your child is at risk of

NOTE Confidence: 0.681016143142857

00:55:43.493 --> 00:55:45.321 several palsy but you know this sounds

NOTE Confidence: 0.681016143142857

00:55:45.321 --> 00:55:47.599 like the end of the world but you

NOTE Confidence: 0.681016143142857

00:55:47.599 --> 00:55:49.411 know the talking have cerebral palsy.

NOTE Confidence: 0.681016143142857

00:55:49.420 --> 00:55:51.121 But we will make sure that we

NOTE Confidence: 0.681016143142857

00:55:51.121 --> 00:55:52.797 identify this early so we can provide.

NOTE Confidence: 0.681016143142857

00:55:52.800 --> 00:55:53.620 Early intervention.

NOTE Confidence: 0.681016143142857

00:55:53.620 --> 00:55:55.670 So despite the cerebral palsy,

NOTE Confidence: 0.681016143142857

00:55:55.670 --> 00:55:57.973 your child can be functional as other

NOTE Confidence: 0.681016143142857

00:55:57.973 --> 00:56:00.809 kids or we'll do our best to make your

NOTE Confidence: 0.681016143142857

00:56:00.809 --> 00:56:03.028 child function and be happy and play.

NOTE Confidence: 0.681016143142857

00:56:03.030 --> 00:56:03.377 So,

NOTE Confidence: 0.681016143142857

00:56:03.377 --> 00:56:05.459 and maybe this is also because

NOTE Confidence: 0.681016143142857

00:56:05.459 --> 00:56:07.989 there's a lack of knowledge of what

NOTE Confidence: 0.681016143142857

00:56:07.990 --> 00:56:09.926 neurodevelopmental impairment actually means,

NOTE Confidence: 0.681016143142857

00:56:09.926 --> 00:56:12.830 even like from the people who

NOTE Confidence: 0.681016143142857

00:56:12.897 --> 00:56:14.767 are doing the the counseling.

NOTE Confidence: 0.681016143142857

00:56:14.770 --> 00:56:17.146 So I guess I, I think it's still,

NOTE Confidence: 0.681016143142857

00:56:17.150 --> 00:56:18.648 you know, don't don't get us wrong.

NOTE Confidence: 0.681016143142857

00:56:18.650 --> 00:56:20.205 I mean development was still

NOTE Confidence: 0.681016143142857

00:56:20.205 --> 00:56:21.760 something that parents felt was

NOTE Confidence: 0.681016143142857

00:56:21.818 --> 00:56:23.480 important but what they said is,

NOTE Confidence: 0.681016143142857

00:56:23.480 --> 00:56:24.668 you know, you should.

NOTE Confidence: 0.681016143142857

00:56:24.668 --> 00:56:25.856 Also emphasize what the

NOTE Confidence: 0.681016143142857

00:56:25.856 --> 00:56:27.247 child will be able to do,

NOTE Confidence: 0.681016143142857

00:56:27.250 --> 00:56:29.350 not just the negative aspects.

NOTE Confidence: 0.829723406

00:56:31.490 --> 00:56:32.690 Thank you. Thank you, Maya.

NOTE Confidence: 0.829723406

00:56:32.690 --> 00:56:34.454 I'm going to get to some of

NOTE Confidence: 0.829723406

00:56:34.454 --> 00:56:35.770 the questions and comments.

NOTE Confidence: 0.829723406

00:56:35.770 --> 00:56:38.086 First things first we heard from

NOTE Confidence: 0.829723406

00:56:38.090 --> 00:56:41.390 Doctor Thomas Duffy, who is.

NOTE Confidence: 0.829723406

00:56:41.390 --> 00:56:42.662 Of one of the.

NOTE Confidence: 0.829723406

00:56:42.662 --> 00:56:45.017 One of the looming very large figures

NOTE Confidence: 0.829723406

00:56:45.017 --> 00:56:47.642 in medicine here at Yale and far

NOTE Confidence: 0.829723406

00:56:47.642 --> 00:56:49.978 beyond Yale as well, Doctor Duffy,

NOTE Confidence: 0.829723406

00:56:49.978 --> 00:56:52.074 is the the professor's professor,

NOTE Confidence: 0.829723406

00:56:52.074 --> 00:56:54.186 and he says an excellent session,

NOTE Confidence: 0.829723406

00:56:54.190 --> 00:56:56.770 remarkably well articulated and structured.

NOTE Confidence: 0.829723406

00:56:56.770 --> 00:56:59.990 A pleasure to hear and learn from.

NOTE Confidence: 0.829723406

00:56:59.990 --> 00:57:02.714 Next, was there any analysis of

NOTE Confidence: 0.829723406

00:57:02.714 --> 00:57:04.530 themes across different socioeconomic

NOTE Confidence: 0.829723406

00:57:04.597 --> 00:57:06.895 strata and or racial ethnic groups?

NOTE Confidence: 0.897691948

00:57:08.510 --> 00:57:11.546 Yes, we actually did some, uh, analysis.

NOTE Confidence: 0.897691948

00:57:11.546 --> 00:57:15.136 Um. There were some differences,

NOTE Confidence: 0.897691948

00:57:15.140 --> 00:57:19.810 with actually parents of lower

NOTE Confidence: 0.897691948

00:57:19.810 --> 00:57:24.480 socioeconomic status being less concerned.

NOTE Confidence: 0.897691948

00:57:24.480 --> 00:57:27.100 They were more optimistic in

NOTE Confidence: 0.897691948

00:57:27.100 --> 00:57:29.720 how they perceive their child,

NOTE Confidence: 0.897691948

00:57:29.720 --> 00:57:32.130 and they had less regrets to less regrets.

NOTE Confidence: 0.79498336

00:57:33.460 --> 00:57:34.668 But nothing for racial,

NOTE Confidence: 0.671920883333333

00:57:34.940 --> 00:57:36.359 nothing for racial.

NOTE Confidence: 0.784722828

00:57:38.470 --> 00:57:43.168 Thank you. The next from one of our NICU

NOTE Confidence: 0.784722828

00:57:43.168 --> 00:57:44.809 nurses, an outstanding presentation.

NOTE Confidence: 0.784722828

00:57:44.809 --> 00:57:47.735 Your marine is just stunning and I and

NOTE Confidence: 0.784722828

00:57:47.735 --> 00:57:49.767 I second that what a beautiful kid I

NOTE Confidence: 0.784722828

00:57:49.767 --> 00:57:52.359 am a NICU nurse for 34 years and just

NOTE Confidence: 0.784722828

00:57:52.359 --> 00:57:54.380 have recently begun to spend a portion

NOTE Confidence: 0.784722828

00:57:54.380 --> 00:57:56.618 of my discharge prep to be blatantly

NOTE Confidence: 0.784722828

00:57:56.618 --> 00:57:59.152 describing the impact of all the post

NOTE Confidence: 0.784722828

00:57:59.152 --> 00:58:01.152 discharge appointments, Brad Clinic,

NOTE Confidence: 0.784722828

00:58:01.152 --> 00:58:03.107 pulmonary cardiology, birth to three,

NOTE Confidence: 0.784722828

00:58:03.110 --> 00:58:04.430 healthy beauty appointments,

NOTE Confidence: 0.784722828

00:58:04.430 --> 00:58:06.510 sick appointments, but also how the

NOTE Confidence: 0.784722828

00:58:06.510 --> 00:58:08.690 parents can plan and make those days.

NOTE Confidence: 0.784722828

00:58:08.690 --> 00:58:10.294 Easier on their family,

NOTE Confidence: 0.784722828

00:58:10.294 --> 00:58:12.299 like planning takeout dinners or

NOTE Confidence: 0.784722828

00:58:12.299 --> 00:58:14.240 having leftovers those nights,

NOTE Confidence: 0.784722828

00:58:14.240 --> 00:58:16.024 packing a lunch, etcetera.

NOTE Confidence: 0.784722828

00:58:16.024 --> 00:58:18.700 Packing a lunch for the trip.

NOTE Confidence: 0.784722828

00:58:18.700 --> 00:58:20.704 So some some practical advice and

NOTE Confidence: 0.784722828

00:58:20.704 --> 00:58:22.680 suggestions. It comes with time.

NOTE Confidence: 0.784722828

00:58:22.680 --> 00:58:23.500 And experience.

NOTE Confidence: 0.8404760725

00:58:25.600 --> 00:58:27.808 And this is from a colleague out to

NOTE Confidence: 0.775794538571429

00:58:28.670 --> 00:58:30.749 one of the when we asked parents,

NOTE Confidence: 0.775794538571429

00:58:30.750 --> 00:58:32.470 we didn't put all of the quotes on,

NOTE Confidence: 0.775794538571429

00:58:32.470 --> 00:58:34.334 they actually gave recommendations

NOTE Confidence: 0.775794538571429

00:58:34.334 --> 00:58:37.976 to new families such as that.

NOTE Confidence: 0.775794538571429

00:58:37.980 --> 00:58:39.140 To take, you know,

NOTE Confidence: 0.775794538571429

00:58:39.390 --> 00:58:41.682 some very very practical recommendations.

00:58:41.682 --> 00:58:44.818 So this will be in the articles too

00:58:44.818 --> 00:58:47.030 like what can you actually tell

00:58:47.030 --> 00:58:49.503 families in the NICU and and using

00:58:49.503 --> 00:58:52.087 our data to speak to families for the

00:58:52.090 --> 00:58:54.346 nurses out there is very interesting.

00:58:54.350 --> 00:58:57.143 Such as I now use instead of

00:58:57.143 --> 00:58:59.129 saying you should go rest.

00:58:59.130 --> 00:59:02.106 I tell parents we've asked parents like you,

00:59:02.110 --> 00:59:04.405 all the parents that came back during a year,

00:59:04.410 --> 00:59:06.552 what they regret the most and it's

00:59:06.552 --> 00:59:08.399 not taking care of themselves.

00:59:08.400 --> 00:59:10.276 And they told us if we'd known

00:59:10.276 --> 00:59:11.879 we would have rested more,

00:59:11.880 --> 00:59:13.616 we would have taken time for a couple,

00:59:13.620 --> 00:59:16.202 we would have done this, this and that.

00:59:16.202 --> 00:59:17.984 So parents don't feel, oh,

00:59:17.984 --> 00:59:19.120 they're kicking me out,

00:59:19.120 --> 00:59:19.996 I'm bothering them.

00:59:19.996 --> 00:59:22.040 They don't think I'm a good parent.

00:59:22.040 --> 00:59:23.360 They actually say, oh,

00:59:23.360 --> 00:59:25.340 this is advice from other parents.

00:59:25.340 --> 00:59:27.174 All the other parents who came through

00:59:27.174 --> 00:59:29.424 the same unit say this is their tough

00:59:29.424 --> 00:59:30.834 regret that they were exhausted.

00:59:30.840 --> 00:59:33.642 So even speaking to families now,

00:59:33.642 --> 00:59:36.246 I use that like many parents

00:59:36.246 --> 00:59:38.587 tell us that many parents.

00:59:38.590 --> 00:59:40.424 It has a lot more impact than

00:59:40.424 --> 00:59:42.496 Annie tells you to go rest at

00:59:42.496 --> 00:59:43.720 home because it's important.

00:59:43.720 --> 00:59:44.270 So,

NOTE Confidence: 0.775794538571429

00:59:44.270 --> 00:59:46.496 and I'm sure the nurse who was

NOTE Confidence: 0.775794538571429

00:59:46.496 --> 00:59:48.907 there for 34 years knows a lot

NOTE Confidence: 0.775794538571429

00:59:48.907 --> 00:59:50.884 more about what is useful for

NOTE Confidence: 0.775794538571429

00:59:50.884 --> 00:59:53.679 parents in the long run in the NICU

NOTE Confidence: 0.775794538571429

00:59:53.679 --> 00:59:55.664 then than us as neonatologist.

NOTE Confidence: 0.907231724

00:59:57.100 --> 00:59:59.796 But I think it's helpful for us because you

NOTE Confidence: 0.907231724

00:59:59.796 --> 01:00:01.819 did mention in the talk a bit about guilt.

NOTE Confidence: 0.907231724

01:00:01.820 --> 01:00:04.060 And so I think that what might come

NOTE Confidence: 0.907231724

01:00:04.060 --> 01:00:06.302 along with that sense of that misplaced

NOTE Confidence: 0.907231724

01:00:06.302 --> 01:00:08.470 sense of guilt that some parents,

NOTE Confidence: 0.907231724

01:00:08.470 --> 01:00:09.379 particularly some mothers,

NOTE Confidence: 0.907231724

01:00:09.379 --> 01:00:11.500 might feel through all this stuff is

NOTE Confidence: 0.907231724

01:00:11.557 --> 01:00:13.562 therefore a sense of a need to continually

NOTE Confidence: 0.907231724

01:00:13.562 --> 01:00:16.019 self sacrifice and when in the long

NOTE Confidence: 0.907231724

01:00:16.019 --> 01:00:18.586 run that really doesn't help anybody.

NOTE Confidence: 0.907231724

01:00:18.590 --> 01:00:20.615 And I I think that that that we do

NOTE Confidence: 0.907231724

01:00:20.615 --> 01:00:22.539 well to remember to tell them that

NOTE Confidence: 0.907231724

01:00:22.539 --> 01:00:24.439 I I've often told parents that,

NOTE Confidence: 0.907231724

01:00:24.440 --> 01:00:25.616 you know, next to her own health,

NOTE Confidence: 0.907231724

01:00:25.620 --> 01:00:27.708 your child's greatest asset in life.

NOTE Confidence: 0.907231724

01:00:27.710 --> 01:00:30.104 Is your health and your marriage so,

NOTE Confidence: 0.907231724

01:00:30.110 --> 01:00:32.054 so make sure you're paying attention

NOTE Confidence: 0.907231724

01:00:32.054 --> 01:00:33.634 to those things because it's

NOTE Confidence: 0.907231724

01:00:33.634 --> 01:00:35.458 going to mean a lot to your kids.

NOTE Confidence: 0.907231724

01:00:35.460 --> 01:00:37.224 But so I think that so many,

NOTE Confidence: 0.907231724

01:00:37.230 --> 01:00:39.126 so many parents feel that at

NOTE Confidence: 0.907231724

01:00:39.126 --> 01:00:40.390 this point there's almost,

NOTE Confidence: 0.907231724

01:00:40.390 --> 01:00:43.390 it's almost sacramental that I I don't sleep

NOTE Confidence: 0.907231724

01:00:43.390 --> 01:00:46.410 and that I don't do anything for myself.

NOTE Confidence: 0.907231724

01:00:46.410 --> 01:00:47.290 And of course we can't.

NOTE Confidence: 0.907231724

115

01:00:47.290 --> 01:00:48.830 We would never possibly consider

NOTE Confidence: 0.907231724

01:00:48.830 --> 01:00:50.370 going out for dinner while

NOTE Confidence: 0.907231724

01:00:50.425 --> 01:00:51.937 our child in the newborn ICU.

NOTE Confidence: 0.907231724

01:00:51.940 --> 01:00:52.576 Well, I get it.

NOTE Confidence: 0.907231724

01:00:52.576 --> 01:00:54.626 If you had a kid in the ICU for three days,

NOTE Confidence: 0.907231724

01:00:54.630 --> 01:00:56.690 you know, if your kid was in a car accident,

NOTE Confidence: 0.907231724

01:00:56.690 --> 01:00:57.662 that would be a little surprising

NOTE Confidence: 0.907231724

01:00:57.662 --> 01:00:58.899 if you wanted to go out to dinner.

NOTE Confidence: 0.907231724

01:00:58.900 --> 01:00:59.166 But.

NOTE Confidence: 0.907231724

01:00:59.166 --> 01:01:00.496 You're talking about months and

NOTE Confidence: 0.907231724

01:01:00.496 --> 01:01:02.366 months of a long distance run here

NOTE Confidence: 0.907231724

01:01:02.366 --> 01:01:04.123 so you know taking some time for

NOTE Confidence: 0.907231724

01:01:04.176 --> 01:01:06.108 yourselves and and giving the and Annie

NOTE Confidence: 0.907231724

01:01:06.108 --> 01:01:07.724 that's a really that's a really nice

NOTE Confidence: 0.907231724

01:01:07.724 --> 01:01:09.135 insight that for us to tell parents

NOTE Confidence: 0.907231724

01:01:09.135 --> 01:01:10.639 by the way it's not my opinion this

NOTE Confidence: 0.907231724

01:01:10.639 --> 01:01:12.073 is what we hear from parents that

NOTE Confidence: 0.907231724

01:01:12.073 --> 01:01:13.930 they wish they had done that they

NOTE Confidence: 0.907231724

01:01:13.930 --> 01:01:15.680 would value that's very helpful.

NOTE Confidence: 0.907231724

01:01:15.680 --> 01:01:18.288 This from a colleague in the Midwest and

NOTE Confidence: 0.907231724

01:01:18.288 --> 01:01:20.104 says comparatively few neonatologists do

NOTE Confidence: 0.907231724

01:01:20.104 --> 01:01:22.312 long term follow-up of NICU graduates.

NOTE Confidence: 0.907231724

01:01:22.320 --> 01:01:22.600 True,

NOTE Confidence: 0.907231724

01:01:22.600 --> 01:01:24.840 most of us aren't directly involved in NICU.

NOTE Confidence: 0.907231724

01:01:24.840 --> 01:01:25.960 Excuse me and Nick,

NOTE Confidence: 0.907231724

01:01:25.960 --> 01:01:26.800 you follow up.

NOTE Confidence: 0.907231724

01:01:26.800 --> 01:01:28.300 If this is playing a significant

NOTE Confidence: 0.907231724

01:01:28.300 --> 01:01:30.239 role in the way they view things,

NOTE Confidence: 0.907231724

01:01:30.240 --> 01:01:32.368 why is this so undervalued by the

NOTE Confidence: 0.907231724

01:01:32.368 --> 01:01:34.674 specialty and what does this mean for

NOTE Confidence: 0.907231724

01:01:34.674 --> 01:01:36.339 the way neonatologists are trained

NOTE Confidence: 0.907231724

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01:01:36.339 --> 01:01:38.636 and what might be required changes

NOTE Confidence: 0.907231724

01:01:38.636 --> 01:01:40.536 for those choosing this specialty?

NOTE Confidence: 0.899498465

01:01:42.210 --> 01:01:47.188 Well, we all agree. So I think like

NOTE Confidence: 0.899498465

01:01:47.188 --> 01:01:48.998 when you were a neonatologist,

NOTE Confidence: 0.899498465

01:01:49.000 --> 01:01:51.940 I guess you feed with adrenaline and

NOTE Confidence: 0.899498465

01:01:51.940 --> 01:01:54.970 acute stuff that goes very quickly and

NOTE Confidence: 0.899498465

01:01:54.970 --> 01:01:57.420 you know in a neonatal follow clinic

NOTE Confidence: 0.899498465

01:01:57.420 --> 01:02:00.219 we see one patient per 45 minutes.

NOTE Confidence: 0.899498465

01:02:00.220 --> 01:02:01.600 It's very slow pace.

NOTE Confidence: 0.899498465

01:02:01.600 --> 01:02:04.220 It's you know there's not much action.

NOTE Confidence: 0.899498465

01:02:04.220 --> 01:02:06.040 It's a lot of well,

NOTE Confidence: 0.899498465

01:02:06.040 --> 01:02:07.900 it's important when we do,

NOTE Confidence: 0.899498465

01:02:07.900 --> 01:02:10.404 but maybe this is what why people are

NOTE Confidence: 0.899498465

01:02:10.404 --> 01:02:12.946 not so interested because it's it's a

NOTE Confidence: 0.899498465

01:02:12.946 --> 01:02:16.080 slow pace and I think people feel like.

NOTE Confidence: 0.899498465

01:02:16.080 --> 01:02:18.348 Ohh, I'm going to give a diagnosis of autism.

01:02:18.350 --> 01:02:19.589 This is the end of the world.

01:02:19.590 --> 01:02:21.360 But actually there is something

01:02:21.360 --> 01:02:24.121 that can be done and maybe this is

01:02:24.121 --> 01:02:26.263 a part of training is you know.

01:02:26.270 --> 01:02:28.975 Maybe like developmental problems are

01:02:28.975 --> 01:02:32.260 seen like something which is awful.

01:02:32.260 --> 01:02:33.548 But actually it's not.

01:02:33.548 --> 01:02:34.836 It's just being different.

01:02:34.840 --> 01:02:36.346 And I guess like once you're

01:02:36.346 --> 01:02:37.350 trained to see that,

01:02:37.350 --> 01:02:38.086 you know,

01:02:38.086 --> 01:02:40.294 difference doesn't mean a bad thing.

01:02:40.300 --> 01:02:40.976 And this,

01:02:40.976 --> 01:02:43.342 the way we accompany families and children

01:02:43.342 --> 01:02:46.199 is really meaningful and makes you know it.

01:02:46.200 --> 01:02:47.880 It just makes you more humble.

NOTE Confidence: 0.899498465

01:02:47.880 --> 01:02:49.077 But there is something to be done.

NOTE Confidence: 0.899498465

01:02:49.080 --> 01:02:50.829 There are interventions,

NOTE Confidence: 0.899498465

01:02:50.829 --> 01:02:53.620 but maybe I just don't know about it.

NOTE Confidence: 0.899498465

01:02:53.620 --> 01:02:56.248 So they feel a little bit

NOTE Confidence: 0.899498465

01:02:56.248 --> 01:02:58.000 uncomfortable announcing a diagnosis,

NOTE Confidence: 0.899498465

01:02:58.000 --> 01:02:59.836 thinking that this is the end of the world,

NOTE Confidence: 0.899498465

01:02:59.840 --> 01:03:01.248 but it's actually not.

NOTE Confidence: 0.899498465

01:03:01.248 --> 01:03:03.008 It's part of the journey.

NOTE Confidence: 0.899498465

01:03:03.010 --> 01:03:03.240 And

NOTE Confidence: 0.89847421

01:03:03.250 --> 01:03:04.390 I think to be honest,

NOTE Confidence: 0.89847421

01:03:04.390 --> 01:03:06.952 there should be a a proportion of

NOTE Confidence: 0.89847421

01:03:06.952 --> 01:03:09.190 neonatologists doing the follow-up clinic.

NOTE Confidence: 0.89847421

01:03:09.190 --> 01:03:11.310 In fact, I was never encouraged to do

NOTE Confidence: 0.89847421

01:03:11.310 --> 01:03:13.680 the follow up clinic and I thought as a

NOTE Confidence: 0.89847421

01:03:13.680 --> 01:03:15.610 resident I didn't even have rotations.

NOTE Confidence: 0.89847421

01:03:15.610 --> 01:03:16.630 It's changed now.

NOTE Confidence: 0.89847421

01:03:16.630 --> 01:03:19.010 I didn't have rotations and I didn't

NOTE Confidence: 0.89847421

01:03:19.073 --> 01:03:21.229 even know I could do follow up

NOTE Confidence: 0.89847421

01:03:21.229 --> 01:03:22.937 as a neonatologist because those

NOTE Confidence: 0.89847421

01:03:22.937 --> 01:03:25.085 who were supervising me didn't do

NOTE Confidence: 0.89847421

01:03:25.085 --> 01:03:27.795 follow up and I didn't have access

NOTE Confidence: 0.89847421

01:03:27.795 --> 01:03:29.383 to the follow-up clinic.

NOTE Confidence: 0.89847421

01:03:29.390 --> 01:03:31.412 But perhaps the health unit is

NOTE Confidence: 0.89847421

01:03:31.412 --> 01:03:33.420 1 where a third or half?

NOTE Confidence: 0.89847421

01:03:33.420 --> 01:03:35.804 And we need to know of neonatologists

NOTE Confidence: 0.89847421

01:03:35.804 --> 01:03:38.540 actually do the follow-up clinic to

NOTE Confidence: 0.89847421

01:03:38.621 --> 01:03:41.412 feedback and and you know integrate

NOTE Confidence: 0.89847421

01:03:41.412 --> 01:03:43.480 how outcomes are viewed.

NOTE Confidence: 0.89847421

01:03:43.480 --> 01:03:44.160 And I think it's

NOTE Confidence: 0.911474244

01:03:44.170 --> 01:03:46.800 important as well for students,

NOTE Confidence: 0.911474244

01:03:46.800 --> 01:03:48.991 as Annie said, to have to do this.

NOTE Confidence: 0.911474244

01:03:48.991 --> 01:03:50.513 It's sort of links them looking at

NOTE Confidence: 0.911474244

01:03:50.513 --> 01:03:52.617 the the one of the last questions or

NOTE Confidence: 0.911474244

01:03:52.617 --> 01:03:54.499 the next questions, if it's important.

NOTE Confidence: 0.911474244

01:03:54.499 --> 01:03:55.990 I think for doctors who see their

NOTE Confidence: 0.911474244

01:03:56.038 --> 01:03:57.568 babies when they're at their sickest

NOTE Confidence: 0.911474244

01:03:57.568 --> 01:03:59.220 and their smallest, I mean you see,

NOTE Confidence: 0.911474244

01:03:59.220 --> 01:04:01.316 you see our kids when they're at their worst,

NOTE Confidence: 0.911474244

01:04:01.320 --> 01:04:02.640 basically in the NICU.

NOTE Confidence: 0.911474244

01:04:02.640 --> 01:04:03.960 It's important I think,

NOTE Confidence: 0.911474244

01:04:03.960 --> 01:04:06.496 to see them years later and to recognize

NOTE Confidence: 0.911474244

01:04:06.496 --> 01:04:08.470 that even children who aren't perfect,

NOTE Confidence: 0.911474244

01:04:08.470 --> 01:04:10.683 you might have you know, developmental

NOTE Confidence: 0.911474244

01:04:10.683 --> 01:04:13.498 disabilities or whatever that they're.

NOTE Confidence: 0.911474244

01:04:13.500 --> 01:04:14.955 Their family's lives aren't tragic

NOTE Confidence: 0.911474244

01:04:14.955 --> 01:04:16.810 like their lives are not tragic.

NOTE Confidence: 0.911474244

01:04:16.810 --> 01:04:17.878 Their families lives aren't

NOTE Confidence: 0.911474244

01:04:17.880 --> 01:04:19.780 tragic and people adjust.

NOTE Confidence: 0.911474244

01:04:19.780 --> 01:04:21.900 And again, it's not saying that these are

NOTE Confidence: 0.911474244

01:04:21.953 --> 01:04:23.849 necessarily outcomes that we strive for,

NOTE Confidence: 0.911474244

01:04:23.850 --> 01:04:25.470 obviously not.

NOTE Confidence: 0.911474244

01:04:25.470 --> 01:04:27.080 But even again an outcome that

NOTE Confidence: 0.911474244

01:04:27.080 --> 01:04:28.714 would be considered, you know,

NOTE Confidence: 0.911474244

01:04:28.714 --> 01:04:31.246 very negative outcome in outcome research

NOTE Confidence: 0.911474244

01:04:31.250 --> 01:04:33.614 is not viewed the necessarily that way

NOTE Confidence: 0.911474244

01:04:33.614 --> 01:04:36.510 by families or by the kids themselves.

NOTE Confidence: 0.911474244

01:04:36.510 --> 01:04:37.640 So I think it's really important

NOTE Confidence: 0.911474244

01:04:37.640 --> 01:04:39.110 to see that that you know,

NOTE Confidence: 0.911474244

01:04:39.110 --> 01:04:41.021 even a kid again is my said that

NOTE Confidence: 0.911474244

01:04:41.021 --> 01:04:42.571 has diagnosed with severe cerebral

NOTE Confidence: 0.911474244

01:04:42.571 --> 01:04:44.130 palsy many of these kids.

NOTE Confidence: 0.911474244

01:04:44.130 --> 01:04:46.510 Live relatively normal lives.

NOTE Confidence: 0.911474244

01:04:46.510 --> 01:04:49.530 You know, kids that might have blindness or,

NOTE Confidence: 0.911474244

01:04:49.530 --> 01:04:50.982 you know, developmental delays,

NOTE Confidence: 0.911474244

01:04:50.982 --> 01:04:52.434 they live happy lives.

NOTE Confidence: 0.911474244

01:04:52.440 --> 01:04:53.420 Their parents are happy.

NOTE Confidence: 0.911474244

01:04:53.420 --> 01:04:55.527 This isn't something that becomes a tragedy

NOTE Confidence: 0.911474244

01:04:55.527 --> 01:04:57.409 for those children and their families.

NOTE Confidence: 0.911474244

01:04:57.410 --> 01:04:58.775 And I think that that's something very,

NOTE Confidence: 0.911474244

01:04:58.780 --> 01:04:59.416 very important.

NOTE Confidence: 0.911474244

01:04:59.416 --> 01:05:00.370 They're living normal

NOTE Confidence: 0.911474244

01:05:00.370 --> 01:05:01.642 lives like everybody else.

NOTE Confidence: 0.911474244

01:05:01.650 --> 01:05:03.138 It's just these are their kids.

NOTE Confidence: 0.911474244

01:05:03.140 --> 01:05:04.846 And I think it's really important to

NOTE Confidence: 0.911474244

01:05:04.846 --> 01:05:07.612 see that for neonatologists and people

NOTE Confidence: 0.911474244

01:05:07.612 --> 01:05:10.180 training to be neonatologists as well.

NOTE Confidence: 0.665734306

01:05:11.340 --> 01:05:14.745 And we see that but seeing is believing

NOTE Confidence: 0.665734306

01:05:14.745 --> 01:05:18.286 and and perhaps nurses too should or we

NOTE Confidence: 0.665734306

01:05:18.286 --> 01:05:21.180 tell parents now at follow-up to come

NOTE Confidence: 0.665734306

01:05:21.180 --> 01:05:23.788 like they tell go upstairs to say hi

NOTE Confidence: 0.665734306

01:05:23.788 --> 01:05:26.565 and when you actually see the kids and

NOTE Confidence: 0.665734306

01:05:26.565 --> 01:05:29.423 I think it's like the 22 weekers when

NOTE Confidence: 0.665734306

01:05:29.423 --> 01:05:32.248 you see a 22 weaker surviving a baby

NOTE Confidence: 0.665734306

01:05:32.248 --> 01:05:34.312 born at 22 weeks gestation surviving

NOTE Confidence: 0.665734306

01:05:34.312 --> 01:05:36.903 you believe they can survive as a nurse

NOTE Confidence: 0.665734306

01:05:36.903 --> 01:05:39.063 but you don't believe it if you've

NOTE Confidence: 0.665734306

01:05:39.063 --> 01:05:41.365 seen 3 deaths so there there's if you.

NOTE Confidence: 0.665734306

01:05:41.365 --> 01:05:43.930 You see the smiles and you see the happiness.

NOTE Confidence: 0.665734306

01:05:43.930 --> 01:05:44.749 You believe it.

NOTE Confidence: 0.665734306

01:05:44.749 --> 01:05:46.387 It's very hard to just read

NOTE Confidence: 0.665734306

01:05:46.387 --> 01:05:47.608 it and believe it.

NOTE Confidence: 0.665734306

01:05:47.610 --> 01:05:49.360 I think there's an emotional

NOTE Confidence: 0.665734306

01:05:49.360 --> 01:05:50.800 component that's important.

NOTE Confidence: 0.832859472

01:05:51.790 --> 01:05:52.810 Yeah, that makes sense. Yeah.

NOTE Confidence: 0.832859472

01:05:52.810 --> 01:05:54.628 And I wonder if, you know,

NOTE Confidence: 0.832859472

01:05:54.630 --> 01:05:56.870 I mean I recently got a text

NOTE Confidence: 0.832859472

01:05:56.870 --> 01:05:58.650 from a nursing colleague,

NOTE Confidence: 0.832859472

01:05:58.650 --> 01:06:00.302 a picture of a kid running in

NOTE Confidence: 0.832859472

01:06:00.302 --> 01:06:01.749 his first cross country race.

NOTE Confidence: 0.832859472

01:06:01.750 --> 01:06:02.746 And it started with,

NOTE Confidence: 0.832859472

01:06:02.746 --> 01:06:04.240 you might remember there was this

NOTE Confidence: 0.832859472

01:06:04.290 --> 01:06:06.242 child born at 25 weeks who had a

NOTE Confidence: 0.832859472

01:06:06.242 --> 01:06:07.569 pulmonary hemorrhage and and you know,

NOTE Confidence: 0.832859472

01:06:07.570 --> 01:06:08.594 and it was a,

NOTE Confidence: 0.832859472

01:06:08.594 --> 01:06:10.850 it was a lovely Texan picture to receive,

NOTE Confidence: 0.832859472

01:06:10.850 --> 01:06:11.890 but I otherwise would not

NOTE Confidence: 0.832859472

01:06:11.890 --> 01:06:12.722 have encountered that kid.

NOTE Confidence: 0.832859472

01:06:12.730 --> 01:06:13.558 I think the pediatricians,

126

NOTE Confidence: 0.832859472

01:06:13.558 --> 01:06:14.593 I noticed on the call,

NOTE Confidence: 0.832859472

01:06:14.600 --> 01:06:15.350 we have some of that,

NOTE Confidence: 0.832859472

01:06:15.350 --> 01:06:17.470 some of some wonderful general

NOTE Confidence: 0.832859472

01:06:17.470 --> 01:06:19.590 pediatricians on the call tonight,

NOTE Confidence: 0.832859472

01:06:19.590 --> 01:06:22.730 Owen and others who who.

NOTE Confidence: 0.832859472

01:06:22.730 --> 01:06:24.100 Who saw these kids longitudinally

NOTE Confidence: 0.832859472

01:06:24.100 --> 01:06:25.196 and they would often,

NOTE Confidence: 0.832859472

01:06:25.200 --> 01:06:26.792 you know when when when I was spend

NOTE Confidence: 0.832859472

01:06:26.792 --> 01:06:28.577 time in a smaller Community Hospital,

NOTE Confidence: 0.832859472

01:06:28.580 --> 01:06:29.966 I would see the general pediatricians

NOTE Confidence: 0.832859472

01:06:29.966 --> 01:06:31.387 more often I would say you know

NOTE Confidence: 0.832859472

01:06:31.387 --> 01:06:32.712 I saw this kid or I saw that

NOTE Confidence: 0.832859472

01:06:32.712 --> 01:06:33.917 kidder here's what's going on.

NOTE Confidence: 0.832859472

01:06:33.920 --> 01:06:35.888 We missed that perspective.

NOTE Confidence: 0.832859472

01:06:35.888 --> 01:06:38.126 But I wonder if there isn't some

NOTE Confidence: 0.832859472

01:06:38.126 --> 01:06:39.656 some happy compromise which is

NOTE Confidence: 0.832859472

01:06:39.656 --> 01:06:41.216 if every name theologist can't

NOTE Confidence: 0.832859472

01:06:41.216 --> 01:06:42.793 spend a substantial amount of

NOTE Confidence: 0.832859472

01:06:42.793 --> 01:06:44.178 time in the follow-up clinic.

NOTE Confidence: 0.832859472

01:06:44.180 --> 01:06:44.928 And by the way,

NOTE Confidence: 0.832859472

01:06:44.928 --> 01:06:46.300 I know this is our speakers know

NOTE Confidence: 0.832859472

01:06:46.300 --> 01:06:47.500 this but for the audience that

NOTE Confidence: 0.832859472

01:06:47.500 --> 01:06:48.829 all of our units ologists who

NOTE Confidence: 0.832859472

01:06:48.829 --> 01:06:50.411 are training now do in fact spend

NOTE Confidence: 0.832859472

01:06:50.420 --> 01:06:51.790 time in the follow-up clinic.

NOTE Confidence: 0.832859472

01:06:51.790 --> 01:06:53.572 But I didn't and I guess Andy didn't either.

NOTE Confidence: 0.832859472

01:06:53.580 --> 01:06:54.630 And so, so there was,

NOTE Confidence: 0.832859472

01:06:54.630 --> 01:06:55.364 you know,

NOTE Confidence: 0.832859472

01:06:55.364 --> 01:06:56.832 until relatively recently that

NOTE Confidence: 0.832859472

01:06:56.832 --> 01:06:58.300 wasn't a standard consistent

NOTE Confidence: 0.832859472

01:06:58.359 --> 01:07:00.009 part of the anthology training,

NOTE Confidence: 0.832859472

01:07:00.010 --> 01:07:02.422 but it is now thanks to

NOTE Confidence: 0.832859472

01:07:02.422 --> 01:07:03.628 our educational leaders.

NOTE Confidence: 0.832859472

01:07:03.630 --> 01:07:06.514 But I wonder if there isn't something

NOTE Confidence: 0.832859472

01:07:06.514 --> 01:07:08.274 for those of us who aren't doing that,

NOTE Confidence: 0.832859472

01:07:08.280 --> 01:07:10.128 who aren't working a lot in the

NOTE Confidence: 0.832859472

01:07:10.128 --> 01:07:11.259 clinic to nevertheless periodically

NOTE Confidence: 0.832859472

01:07:11.259 --> 01:07:12.987 get some exposure to this to

NOTE Confidence: 0.832859472

01:07:12.987 --> 01:07:14.700 take advantage of what and what

NOTE Confidence: 0.832859472

01:07:14.700 --> 01:07:16.284 you described as the seeing is

NOTE Confidence: 0.832859472

01:07:16.284 --> 01:07:17.489 believing phenomena to actually

NOTE Confidence: 0.832859472

01:07:17.489 --> 01:07:19.930 see some of these kids we used to,

NOTE Confidence: 0.832859472

01:07:19.930 --> 01:07:20.890 we have it in some time.

NOTE Confidence: 0.832859472

01:07:20.890 --> 01:07:22.540 We have both in New Haven.

NOTE Confidence: 0.832859472

01:07:22.540 --> 01:07:24.472 And in London had the wonderful uh

NOTE Confidence: 0.832859472

01:07:24.472 --> 01:07:25.930 reunions where these kids would

NOTE Confidence: 0.832859472

129

01:07:25.930 --> 01:07:27.646 come back with their families would

NOTE Confidence: 0.832859472

01:07:27.646 --> 01:07:29.356 be outside with a big fair with

NOTE Confidence: 0.832859472

01:07:29.356 --> 01:07:30.848 games and and food and such and

NOTE Confidence: 0.832859472

01:07:30.848 --> 01:07:32.276 and and the staff would come and

NOTE Confidence: 0.832859472

01:07:32.276 --> 01:07:33.684 the families and kids would come

NOTE Confidence: 0.832859472

01:07:33.684 --> 01:07:35.390 and you see these kids afterwards.

NOTE Confidence: 0.832859472

01:07:35.390 --> 01:07:37.148 And well yeah these are these

NOTE Confidence: 0.832859472

01:07:37.148 --> 01:07:38.027 are little kids,

NOTE Confidence: 0.832859472

01:07:38.030 --> 01:07:40.376 you know not just tiny babies.

NOTE Confidence: 0.832859472

01:07:40.380 --> 01:07:42.046 And then as time goes on of

NOTE Confidence: 0.832859472

01:07:42.046 --> 01:07:43.581 course those little kids are are

NOTE Confidence: 0.832859472

01:07:43.581 --> 01:07:45.105 bigger kids than adults so that

NOTE Confidence: 0.832859472

01:07:45.105 --> 01:07:46.679 we're missing that perspective.

NOTE Confidence: 0.832859472

01:07:46.680 --> 01:07:49.155 You're quite right this from

NOTE Confidence: 0.832859472

01:07:49.155 --> 01:07:50.640 an obstetrics colleague.

NOTE Confidence: 0.832859472

01:07:50.640 --> 01:07:52.122 I think that as clinicians we

NOTE Confidence: 0.832859472

01:07:52.122 --> 01:07:53.110 worry about giving patients.

NOTE Confidence: 0.832859472

01:07:53.110 --> 01:07:55.000 False and unrealistic hopes and try

NOTE Confidence: 0.832859472

01:07:55.000 --> 01:07:57.344 to be as objective as possible in

NOTE Confidence: 0.832859472

01:07:57.344 --> 01:07:59.054 presenting the data to families.

NOTE Confidence: 0.832859472

01:07:59.060 --> 01:08:01.223 We worry about doing too much in

NOTE Confidence: 0.832859472

01:08:01.223 --> 01:08:02.512 situations where the outcomes

NOTE Confidence: 0.832859472

01:08:02.512 --> 01:08:04.017 are likely to be poor.

NOTE Confidence: 0.832859472

01:08:04.020 --> 01:08:05.189 But let me just add something to

NOTE Confidence: 0.832859472

01:08:05.189 --> 01:08:06.311 that to that important question and

NOTE Confidence: 0.832859472

01:08:06.311 --> 01:08:08.039 see what you guys have to say about it.

NOTE Confidence: 0.832859472

01:08:08.040 --> 01:08:10.400 But and you made the point at the very end,

NOTE Confidence: 0.862978628666667

01:08:10.400 --> 01:08:11.975 Danny, and and it's clear

NOTE Confidence: 0.862978628666667

01:08:11.975 --> 01:08:13.550 from your information that in

NOTE Confidence: 0.862978628666667

01:08:13.612 --> 01:08:15.157 our effort to be objective,

NOTE Confidence: 0.862978628666667

01:08:15.160 --> 01:08:17.260 we're kind of measuring the wrong stuff.

NOTE Confidence: 0.862978628666667

01:08:17.260 --> 01:08:19.060 And in fact we are,

NOTE Confidence: 0.862978628666667

01:08:19.060 --> 01:08:20.596 I think it's reasonable to say,

NOTE Confidence: 0.862978628666667

01:08:20.600 --> 01:08:24.046 overly pessimistic. For example,

NOTE Confidence: 0.862978628666667

01:08:24.046 --> 01:08:26.482 we often quote the follow-up data at

NOTE Confidence: 0.862978628666667

01:08:26.482 --> 01:08:29.048 18 to 26 months or 18 to 22 months,

NOTE Confidence: 0.862978628666667

01:08:29.050 --> 01:08:31.227 when repeatedly it's been shown that those

NOTE Confidence: 0.862978628666667

01:08:31.227 --> 01:08:33.169 data themselves are overly pessimistic.

NOTE Confidence: 0.862978628666667

01:08:33.170 --> 01:08:34.409 When you look at those same kids

NOTE Confidence: 0.862978628666667

01:08:34.409 --> 01:08:35.670 when they're six or eight years old,

NOTE Confidence: 0.862978628666667

01:08:35.670 --> 01:08:37.115 they're actually many of them

NOTE Confidence: 0.862978628666667

01:08:37.115 --> 01:08:38.560 doing better than would have

NOTE Confidence: 0.862978628666667

01:08:38.613 --> 01:08:40.008 been predicted at 20 months.

NOTE Confidence: 0.862978628666667

01:08:40.010 --> 01:08:41.408 So we're trying to be objective,

NOTE Confidence: 0.862978628666667

01:08:41.410 --> 01:08:42.050 Francis, right?

NOTE Confidence: 0.862978628666667

01:08:42.050 --> 01:08:43.970 And that might be the explanation.

NOTE Confidence: 0.862978628666667

01:08:43.970 --> 01:08:45.545 But in fact, it seems to me,

NOTE Confidence: 0.862978628666667

01:08:45.550 --> 01:08:47.713 from what you've said that your work

NOTE Confidence: 0.862978628666667

01:08:47.713 --> 01:08:50.050 confirms that we are overly pessimistic.

NOTE Confidence: 0.862978628666667

01:08:50.050 --> 01:08:51.594 Is that a fair assessment of your work?

NOTE Confidence: 0.69588838

01:08:53.240 --> 01:08:56.978 Ohh yeah. No, but we were shown to

NOTE Confidence: 0.88452812

01:08:56.990 --> 01:08:58.592 be overly pessimistic.

NOTE Confidence: 0.88452812

01:08:58.592 --> 01:09:00.728 But for the obstetrician,

NOTE Confidence: 0.88452812

01:09:00.730 --> 01:09:02.984 they were shown to be even more

NOTE Confidence: 0.88452812

01:09:02.984 --> 01:09:04.949 pessimistic than bad in ICU doctors.

NOTE Confidence: 0.88452812

01:09:04.950 --> 01:09:07.499 So that it's I think.

NOTE Confidence: 0.88452812

01:09:07.500 --> 01:09:09.450 To be honest, they also the

NOTE Confidence: 0.88452812

01:09:09.450 --> 01:09:11.759 obstetrician has to care for the mother,

NOTE Confidence: 0.88452812

01:09:11.760 --> 01:09:12.800 for the sick mother,

NOTE Confidence: 0.88452812

01:09:12.800 --> 01:09:15.140 for the mom who has severe preeclampsia,

NOTE Confidence: 0.88452812

01:09:15.140 --> 01:09:16.770 her health is at risk.

NOTE Confidence: 0.88452812

01:09:16.770 --> 01:09:20.410 How much can you prolong pregnancy,

NOTE Confidence: 0.88452812

01:09:20.410 --> 01:09:22.130 cesarean section,

NOTE Confidence: 0.88452812

01:09:22.130 --> 01:09:24.710 decisions and thinking?

NOTE Confidence: 0.88452812

01:09:24.710 --> 01:09:26.838 There's also we didn't speak about mortality,

NOTE Confidence: 0.88452812

01:09:26.840 --> 01:09:29.240 but Caesarean section decisions when,

NOTE Confidence: 0.88452812

01:09:29.240 --> 01:09:29.910 for example,

NOTE Confidence: 0.88452812

01:09:29.910 --> 01:09:33.072 have the kids die afterwards and how do you

NOTE Confidence: 0.88452812

01:09:33.072 --> 01:09:35.556 feel about doing interventions like this?

NOTE Confidence: 0.88452812

01:09:35.560 --> 01:09:37.436 So it gets, I think, even more.

NOTE Confidence: 0.88452812

01:09:37.436 --> 01:09:39.584 Complicated where in ethics we call

NOTE Confidence: 0.88452812

01:09:39.584 --> 01:09:41.988 it the fetal maternal conflict.

NOTE Confidence: 0.88452812

01:09:41.990 --> 01:09:43.376 I don't think it's a conflict

NOTE Confidence: 0.88452812

01:09:43.376 --> 01:09:44.069 because one does.

NOTE Confidence: 0.88452812

01:09:44.070 --> 01:09:46.188 You know the fetus can't be

NOTE Confidence: 0.88452812

01:09:46.188 --> 01:09:48.430 there if their moms not there.

NOTE Confidence: 0.88452812

01:09:48.430 --> 01:09:52.520 But I I think obstetrician has have more

NOTE Confidence: 0.88452812

01:09:52.520 --> 01:09:55.850 burden in in the decisions they have to take.

NOTE Confidence: 0.88452812

01:09:55.850 --> 01:09:57.628 We also have some burden after that.

NOTE Confidence: 0.88452812

01:09:57.630 --> 01:09:59.370 We don't want parents to come

NOTE Confidence: 0.88452812

01:09:59.370 --> 01:10:01.204 back and have regrets of saying

NOTE Confidence: 0.88452812

01:10:01.204 --> 01:10:02.744 we shouldn't have done this.

NOTE Confidence: 0.88452812

01:10:02.750 --> 01:10:06.404 And we hear like sometimes doctors saying,

NOTE Confidence: 0.88452812

01:10:06.410 --> 01:10:06.666 oh,

NOTE Confidence: 0.88452812

01:10:06.666 --> 01:10:08.714 a parent came back and told us that.

NOTE Confidence: 0.88452812

01:10:08.720 --> 01:10:09.244 Interestingly,

NOTE Confidence: 0.88452812

01:10:09.244 --> 01:10:12.636 in a year with 98% of parents who

NOTE Confidence: 0.88452812

01:10:12.636 --> 01:10:14.580 came to follow up who answered,

NOTE Confidence: 0.88452812

01:10:14.580 --> 01:10:16.914 none of them had regrets about

NOTE Confidence: 0.88452812

01:10:16.914 --> 01:10:18.470 life and death decisions.

NOTE Confidence: 0.88452812

01:10:18.470 --> 01:10:20.050 So I think,

NOTE Confidence: 0.88452812

01:10:20.050 --> 01:10:22.180 I think it's really mainly describing

NOTE Confidence: 0.88452812

01:10:22.180 --> 01:10:24.288 function and perhaps the the best way

NOTE Confidence: 0.88452812

01:10:24.288 --> 01:10:26.481 to do a parallel in the obstetrics

NOTE Confidence: 0.88452812

01:10:26.481 --> 01:10:29.577 literature is speaking about Down syndrome.

NOTE Confidence: 0.88452812

01:10:29.580 --> 01:10:33.138 And there's very good Kathy sheets,

NOTE Confidence: 0.88452812

01:10:33.140 --> 01:10:33.699 very,

NOTE Confidence: 0.88452812

01:10:33.699 --> 01:10:35.935 very good research done

NOTE Confidence: 0.88452812

01:10:35.935 --> 01:10:38.730 also by Doctor Scott Co.

NOTE Confidence: 0.88452812

01:10:38.730 --> 01:10:41.018 How to speak and they actually 10

NOTE Confidence: 0.88452812

01:10:41.018 --> 01:10:43.156 years ago we're saying give balanced

NOTE Confidence: 0.88452812

01:10:43.156 --> 01:10:45.430 information what the child can do,

NOTE Confidence: 0.88452812

01:10:45.430 --> 01:10:47.488 but where the child is limited,

NOTE Confidence: 0.88452812

01:10:47.490 --> 01:10:49.450 give information about the family,

NOTE Confidence: 0.88452812

01:10:49.450 --> 01:10:50.346 give information.

NOTE Confidence: 0.88452812

01:10:50.346 --> 01:10:53.482 And there there is this data and

NOTE Confidence: 0.88452812

01:10:53.482 --> 01:10:56.079 perhaps we'll start giving information

NOTE Confidence: 0.88452812

01:10:56.079 --> 01:10:59.181 about function and what the families

NOTE Confidence: 0.88452812

01:10:59.190 --> 01:11:01.020 look like and the positive and

NOTE Confidence: 0.88452812

01:11:01.020 --> 01:11:02.905 negative in a balanced fashion as

NOTE Confidence: 0.88452812

01:11:02.905 --> 01:11:04.717 opposed to a list of diagnosis.

NOTE Confidence: 0.863235928571429

01:11:06.300 --> 01:11:07.906 Oh, I was just going to say that I

NOTE Confidence: 0.863235928571429

01:11:07.906 --> 01:11:09.689 just want to point out as well the,

NOTE Confidence: 0.863235928571429

01:11:09.690 --> 01:11:10.980 the sort of the statement the

NOTE Confidence: 0.863235928571429

01:11:10.980 --> 01:11:12.220 outcomes are likely to be poor.

NOTE Confidence: 0.863235928571429

01:11:12.220 --> 01:11:14.138 I think that this, the research we

NOTE Confidence: 0.863235928571429

01:11:14.138 --> 01:11:15.760 presented shows that these outcomes,

NOTE Confidence: 0.863235928571429

01:11:15.760 --> 01:11:18.520 poor outcomes are subjective, right.

NOTE Confidence: 0.863235928571429

01:11:18.520 --> 01:11:19.888 So again, what a clinician might

NOTE Confidence: 0.863235928571429

01:11:19.888 --> 01:11:21.720 consider to be a poor outcome or

NOTE Confidence: 0.863235928571429

01:11:21.720 --> 01:11:23.165 is not necessarily what parents

NOTE Confidence: 0.863235928571429

01:11:23.165 --> 01:11:24.832 would consider to be a poor outcome.

NOTE Confidence: 0.863235928571429

01:11:24.832 --> 01:11:26.468 So I think it's important again to

NOTE Confidence: 0.863235928571429

01:11:26.468 --> 01:11:27.939 remember that that that you're looking,

NOTE Confidence: 0.863235928571429

01:11:27.940 --> 01:11:29.000 you know, as an obstetrician,

NOTE Confidence: 0.863235928571429

01:11:29.000 --> 01:11:30.164 I guess you're looking at outcomes

NOTE Confidence: 0.863235928571429

01:11:30.164 --> 01:11:32.090 through your own lens or through

NOTE Confidence: 0.863235928571429

01:11:32.090 --> 01:11:33.140 the lens of the research.

NOTE Confidence: 0.863235928571429

01:11:33.140 --> 01:11:35.195 But again, this doesn't necessarily

NOTE Confidence: 0.863235928571429

01:11:35.195 --> 01:11:36.428 reflect what parents.

NOTE Confidence: 0.863235928571429

01:11:36.430 --> 01:11:37.878 Fuel or poor outcomes.

NOTE Confidence: 0.863235928571429

01:11:37.878 --> 01:11:39.688 So that's an important consideration.

NOTE Confidence: 0.758460130666667

01:11:41.250 --> 01:11:43.133 Thank you Rebecca that that that is

NOTE Confidence: 0.758460130666667

01:11:43.133 --> 01:11:44.852 a really important point and so and

NOTE Confidence: 0.758460130666667

01:11:44.852 --> 01:11:46.641 I I think I've looked this from your

NOTE Confidence: 0.758460130666667

01:11:46.641 --> 01:11:48.433 talk as well that that that this is

NOTE Confidence: 0.758460130666667

01:11:48.440 --> 01:11:50.168 language that I may have used and I

NOTE Confidence: 0.758460130666667

01:11:50.168 --> 01:11:52.099 think we all use which to say that

NOTE Confidence: 0.758460130666667

01:11:52.099 --> 01:11:53.862 that here's the chances of a severe

NOTE Confidence: 0.758460130666667

01:11:53.862 --> 01:11:55.612 disability and just that framing of it,

NOTE Confidence: 0.758460130666667

01:11:55.620 --> 01:11:57.937 of that phrasing of it is not

NOTE Confidence: 0.758460130666667

01:11:57.937 --> 01:11:59.158 particularly helpful because what I

NOTE Confidence: 0.758460130666667

01:11:59.158 --> 01:12:00.460 think is severe may be different than

NOTE Confidence: 0.758460130666667

01:12:00.498 --> 01:12:01.680 what the mother thinks is severe.

NOTE Confidence: 0.758460130666667

01:12:01.680 --> 01:12:03.840 And so rather than that say here is

NOTE Confidence: 0.758460130666667

01:12:03.840 --> 01:12:05.874 some likely outcomes of this and here's

NOTE Confidence: 0.758460130666667

01:12:05.874 --> 01:12:08.552 what can be done about them rather than

NOTE Confidence: 0.758460130666667

01:12:08.552 --> 01:12:11.100 just kind of conflating all these different.

NOTE Confidence: 0.758460130666667

01:12:11.100 --> 01:12:12.220 Comes under the category

NOTE Confidence: 0.758460130666667

01:12:12.220 --> 01:12:13.300 of severe disability.

NOTE Confidence: 0.73245752375

01:12:14.810 --> 01:12:17.746 Yeah. Just to be assured that a person,

NOTE Confidence: 0.73245752375

01:12:17.750 --> 01:12:20.280 and it's been more than, you know,

NOTE Confidence: 0.73245752375

01:12:20.280 --> 01:12:21.680 it's almost 15 years I've

NOTE Confidence: 0.73245752375

01:12:21.680 --> 01:12:23.300 been doing unit of follow-up.

NOTE Confidence: 0.73245752375

01:12:23.300 --> 01:12:25.226 I often hear the new Unitologist

NOTE Confidence: 0.73245752375

01:12:25.226 --> 01:12:27.690 said that my child could not do this

NOTE Confidence: 0.73245752375

01:12:27.690 --> 01:12:29.799 and look at what he's able to do.

NOTE Confidence: 0.73245752375

01:12:29.800 --> 01:12:31.624 My, the neonatologist said that he

NOTE Confidence: 0.73245752375

01:12:31.624 --> 01:12:34.063 was going to be like a vegetable but

NOTE Confidence: 0.73245752375

01:12:34.063 --> 01:12:36.498 look like he can sing, he can dance.

NOTE Confidence: 0.73245752375

01:12:36.498 --> 01:12:38.780 But I've never heard a neonatologist never

NOTE Confidence: 0.73245752375

01:12:38.844 --> 01:12:41.060 told me that my child would have this.

NOTE Confidence: 0.73245752375

01:12:41.060 --> 01:12:43.428 I've never heard that in 15 years, so.

NOTE Confidence: 0.73245752375

01:12:43.428 --> 01:12:46.386 It's very, you know, it's experience.

NOTE Confidence: 0.73245752375

01:12:46.386 --> 01:12:47.998 It's not evidence based,

NOTE Confidence: 0.73245752375

01:12:48.000 --> 01:12:51.350 but it's anecdotal, but it's anecdotal.

NOTE Confidence: 0.7240695665

01:12:52.400 --> 01:12:53.954 And it's it's the anecdotal experience

NOTE Confidence: 0.7240695665

01:12:53.954 --> 01:12:55.925 of of of a very experienced 15

NOTE Confidence: 0.7240695665

01:12:55.925 --> 01:12:57.962 years of as a problem of physician.

NOTE Confidence: 0.7240695665

01:12:57.970 --> 01:13:02.182 So it's not nothing my and I appreciate

NOTE Confidence: 0.7240695665

01:13:02.182 --> 01:13:04.590 the the observation because it is true.

NOTE Confidence: 0.7240695665

01:13:04.590 --> 01:13:06.939 We live in we we on the intensive care

NOTE Confidence: 0.7240695665

01:13:06.939 --> 01:13:09.180 side live in fear that we are going

NOTE Confidence: 0.7240695665

01:13:09.180 --> 01:13:11.213 to have misled parents and send them

NOTE Confidence: 0.7240695665

01:13:11.213 --> 01:13:13.298 home with a child who was profoundly

NOTE Confidence: 0.7240695665

01:13:13.298 --> 01:13:15.506 disabled and we never warned them.

NOTE Confidence: 0.7240695665

01:13:15.510 --> 01:13:17.460 But it it seems to me from not just what

NOTE Confidence: 0.7240695665

01:13:17.516 --> 01:13:19.508 I'm hearing you say but from the data

NOTE Confidence: 0.7240695665

01:13:19.508 --> 01:13:21.410 you presented that while that may be a

NOTE Confidence: 0.7240695665

01:13:21.410 --> 01:13:23.141 concern in fact we're far more likely.

NOTE Confidence: 0.7240695665

01:13:23.141 --> 01:13:24.803 To be overly pessimistic and to

NOTE Confidence: 0.7240695665

01:13:24.803 --> 01:13:26.258 mislead them about what capabilities

NOTE Confidence: 0.7240695665

01:13:26.258 --> 01:13:27.950 our child is likely to have.

NOTE Confidence: 0.81308095

01:13:30.580 --> 01:13:34.090 Next question, comment one slide showed.

NOTE Confidence: 0.81308095

01:13:34.090 --> 01:13:35.791 100 parents who rated their child as

NOTE Confidence: 0.81308095

01:13:35.791 --> 01:13:37.530 having mild to moderate disability,

NOTE Confidence: 0.81308095

141

01:13:37.530 --> 01:13:40.210 but testing showed no disability.

NOTE Confidence: 0.81308095

01:13:40.210 --> 01:13:41.981 Is there a different subset of parents

NOTE Confidence: 0.81308095

01:13:41.981 --> 01:13:43.910 who see their child as more affected,

NOTE Confidence: 0.81308095

01:13:43.910 --> 01:13:45.400 perhaps in grand sense of

NOTE Confidence: 0.81308095

01:13:45.400 --> 01:13:46.592 vulnerability in their child?

NOTE Confidence: 0.8316725

01:13:47.670 --> 01:13:50.160 And we had there's quotes that

NOTE Confidence: 0.9087261

01:13:50.170 --> 01:13:54.855 go with that and examples are my

NOTE Confidence: 0.9087261

01:13:54.855 --> 01:13:57.980 child is hospitalized every month.

NOTE Confidence: 0.9087261

01:13:57.980 --> 01:14:01.400 It's held to feed him.

NOTE Confidence: 0.9087261

01:14:01.400 --> 01:14:04.067 Or suppers are no longer nice family

NOTE Confidence: 0.9087261

01:14:04.067 --> 01:14:06.489 suppers because there's no more feeding it.

NOTE Confidence: 0.9087261

01:14:06.490 --> 01:14:08.458 It's just trying to bring nutrition.

NOTE Confidence: 0.9087261

01:14:08.460 --> 01:14:10.028 He's not gaining weight.

NOTE Confidence: 0.9087261

01:14:10.028 --> 01:14:11.988 We're constantly at the hospital.

NOTE Confidence: 0.9087261

01:14:11.990 --> 01:14:14.630 But yet because my child is not disabled,

NOTE Confidence: 0.9087261

01:14:14.630 --> 01:14:17.670 I don't have services I not

01:14:17.670 --> 01:14:19.070 judged as being disabled.

01:14:19.070 --> 01:14:20.918 So there's a lot of things

01:14:20.918 --> 01:14:22.610 that we see as mild,

01:14:22.610 --> 01:14:24.585 like behavior is probably the

01:14:24.585 --> 01:14:27.040 worst that we see as mild.

01:14:27.040 --> 01:14:29.266 That is not mild for families,

01:14:29.270 --> 01:14:31.460 a child who's violent to others.

01:14:31.460 --> 01:14:34.058 Who goes whole to school always has

01:14:34.058 --> 01:14:36.530 problems with other it's violent to others,

01:14:36.530 --> 01:14:39.308 is kicked out of school repeatedly,

01:14:39.310 --> 01:14:42.523 is seen also be seen as the bad parents.

01:14:42.530 --> 01:14:44.658 There's a quote I remember from a dad

01:14:44.658 --> 01:14:47.273 is that nobody's nice to us because our

01:14:47.273 --> 01:14:49.510 child kicks everybody and it's not nice,

01:14:49.510 --> 01:14:53.052 but he was actually classified as normal.

01:14:53.052 --> 01:14:55.607 But this dad was devastated.

NOTE Confidence: 0.9087261

01:14:55.610 --> 01:14:58.034 So I think there's a lot of spheres

NOTE Confidence: 0.9087261

01:14:58.034 --> 01:14:59.988 like this where we're really,

NOTE Confidence: 0.9087261

01:14:59.990 --> 01:15:01.775 we can't see that at the MRI.

NOTE Confidence: 0.9087261

01:15:01.780 --> 01:15:03.590 We can't see it on the ultrasound.

NOTE Confidence: 0.9087261

01:15:03.590 --> 01:15:05.904 We can only hear about it at follow-up.

NOTE Confidence: 0.9087261

01:15:05.910 --> 01:15:08.490 We can't predict it,

NOTE Confidence: 0.9087261

01:15:08.490 --> 01:15:10.572 but we don't investigate this and

NOTE Confidence: 0.9087261

01:15:10.572 --> 01:15:12.879 it seems these parents don't have

NOTE Confidence: 0.9087261

01:15:12.879 --> 01:15:15.014 enough help because severe feeding

NOTE Confidence: 0.9087261

01:15:15.014 --> 01:15:17.370 difficulties are not put in,

NOTE Confidence: 0.9087261

01:15:17.370 --> 01:15:19.254 in significant disability.

NOTE Confidence: 0.9087261

01:15:19.254 --> 01:15:21.766 So some parents also,

NOTE Confidence: 0.9087261

01:15:21.770 --> 01:15:22.534 you're right,

NOTE Confidence: 0.9087261

01:15:22.534 --> 01:15:23.298 a minority,

NOTE Confidence: 0.9087261

01:15:23.298 --> 01:15:26.250 speak about like their child has problems,

NOTE Confidence: 0.9087261

01:15:26.250 --> 01:15:27.702 but we don't see them because

NOTE Confidence: 0.9087261

01:15:27.702 --> 01:15:29.673 we look at the Bailey and the

NOTE Confidence: 0.9087261

01:15:29.673 --> 01:15:30.986 deafness and the severe things

NOTE Confidence: 0.9087261

01:15:30.986 --> 01:15:32.266 that we think are severe.

NOTE Confidence: 0.970052375

01:15:35.260 --> 01:15:35.740 Thank you.

NOTE Confidence: 0.852377783333333

01:15:37.780 --> 01:15:39.036 One of my practitioner,

NOTE Confidence: 0.852377783333333

01:15:39.036 --> 01:15:40.920 friends of many years and colleagues

NOTE Confidence: 0.852377783333333

01:15:40.974 --> 01:15:42.619 says that we need to realize the

NOTE Confidence: 0.852377783333333

01:15:42.619 --> 01:15:44.427 value of the child to the family.

NOTE Confidence: 0.852377783333333

01:15:44.430 --> 01:15:46.719 We will care for them no matter

NOTE Confidence: 0.852377783333333

01:15:46.719 --> 01:15:48.750 what when we realize that,

NOTE Confidence: 0.852377783333333

01:15:48.750 --> 01:15:50.295 when we realize the value

NOTE Confidence: 0.852377783333333

01:15:50.295 --> 01:15:52.390 of the child to the family.

NOTE Confidence: 0.852377783333333

01:15:52.390 --> 01:15:53.461 Another comment question.

NOTE Confidence: 0.852377783333333

01:15:53.461 --> 01:15:54.889 I applaud your work.

NOTE Confidence: 0.852377783333333

01:15:54.890 --> 01:15:56.549 I think a balanced and hopeful approach

NOTE Confidence: 0.852377783333333

01:15:56.549 --> 01:15:58.061 is missing in medicine, however.

NOTE Confidence: 0.852377783333333

01:15:58.061 --> 01:16:00.167 I feel that providing hope or

NOTE Confidence: 0.852377783333333

01:16:00.167 --> 01:16:02.380 presenting a balanced view can be

NOTE Confidence: 0.852377783333333

01:16:02.380 --> 01:16:04.210 viewed negatively by other physicians,

NOTE Confidence: 0.852377783333333

01:16:04.210 --> 01:16:04.968 nurses, etcetera.

NOTE Confidence: 0.852377783333333

01:16:04.968 --> 01:16:07.242 Do you think there's a connection

NOTE Confidence: 0.852377783333333

01:16:07.242 --> 01:16:08.640 with physician counseling

NOTE Confidence: 0.852377783333333

01:16:08.640 --> 01:16:09.714 and physician burnout?

NOTE Confidence: 0.852377783333333

01:16:09.714 --> 01:16:11.146 Are we too jaded?

NOTE Confidence: 0.8167539875

01:16:12.860 --> 01:16:14.951 Many questions. Well,

NOTE Confidence: 0.8167539875

01:16:14.951 --> 01:16:18.760 there's the moral distress literature that

NOTE Confidence: 0.8167539875

01:16:18.760 --> 01:16:21.616 shows us who is more morally distressed.

NOTE Confidence: 0.8167539875

01:16:21.620 --> 01:16:25.224 So the least experience you have the in

NOTE Confidence: 0.8167539875

01:16:25.224 --> 01:16:27.134 neonatology if you look longitudinally

NOTE Confidence: 0.8167539875

01:16:27.134 --> 01:16:29.730 over a moral distress and burnout.

NOTE Confidence: 0.8167539875

01:16:29.730 --> 01:16:32.516 And this is my she's not a

NOTE Confidence: 0.8167539875

01:16:32.516 --> 01:16:33.710 PhD student anymore.

NOTE Confidence: 0.8167539875

01:16:33.710 --> 01:16:36.356 Trisha Apprentice, who was my PhD student,

NOTE Confidence: 0.8167539875

01:16:36.360 --> 01:16:38.959 was a wonderful clinician in Australia,

NOTE Confidence: 0.8167539875

01:16:38.960 --> 01:16:41.403 has looked at how people are morally

NOTE Confidence: 0.8167539875

01:16:41.403 --> 01:16:43.039 distressed clinician in the NICU.

NOTE Confidence: 0.8167539875

01:16:43.040 --> 01:16:44.432 Over a year,

NOTE Confidence: 0.8167539875

01:16:44.432 --> 01:16:47.680 and they are nurses are often distressed

NOTE Confidence: 0.8167539875

01:16:47.768 --> 01:16:50.568 when doctors are not distressed,

NOTE Confidence: 0.8167539875

01:16:50.570 --> 01:16:52.782 there is more distress when not all

NOTE Confidence: 0.8167539875

01:16:52.782 --> 01:16:55.149 the team is distressed together.

NOTE Confidence: 0.8167539875

01:16:55.150 --> 01:16:57.075 There's more distress when we

NOTE Confidence: 0.8167539875

01:16:57.075 --> 01:16:59.793 think the child will die and the

NOTE Confidence: 0.8167539875

01:16:59.793 --> 01:17:02.052 parents don't want to reorient care.

NOTE Confidence: 0.8167539875

01:17:02.052 --> 01:17:04.616 And usually everybody agrees

NOTE Confidence: 0.8167539875

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01:17:04.616 --> 01:17:07.180 together in these conditions.

NOTE Confidence: 0.8167539875

01:17:07.180 --> 01:17:08.325 And the least experience you

NOTE Confidence: 0.8167539875

01:17:08.325 --> 01:17:09.680 have the more distressed you are.

NOTE Confidence: 0.8167539875

01:17:09.680 --> 01:17:12.776 I said that and interestingly the

NOTE Confidence: 0.8167539875

01:17:12.776 --> 01:17:14.840 distressed actually disappears when

NOTE Confidence: 0.8167539875

01:17:14.923 --> 01:17:17.317 the kid is no longer ventilated.

NOTE Confidence: 0.8167539875

01:17:17.320 --> 01:17:20.236 So why don't we can't stop

NOTE Confidence: 0.8167539875

01:17:20.236 --> 01:17:21.694 life sustaining interventions.

NOTE Confidence: 0.8167539875

01:17:21.700 --> 01:17:23.458 The distress seems to go away.

NOTE Confidence: 0.8167539875

01:17:23.460 --> 01:17:25.296 So when a child has bilateral

NOTE Confidence: 0.8167539875

01:17:25.296 --> 01:17:26.214 Grade 4 seizing,

NOTE Confidence: 0.8167539875

01:17:26.220 --> 01:17:28.103 not doing well at all and has

NOTE Confidence: 0.8167539875

01:17:28.103 --> 01:17:30.418 neck and short gut and let's put a

NOTE Confidence: 0.8167539875

01:17:30.418 --> 01:17:32.208 very bad scenario and we're trying

NOTE Confidence: 0.8167539875

01:17:32.208 --> 01:17:34.224 to engage with parents to see do

NOTE Confidence: 0.8167539875

01:17:34.224 --> 01:17:35.688 we want to reorient care,

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NOTE Confidence: 0.8167539875

01:17:35.688 --> 01:17:37.453 he'll stay long, a long time.

NOTE Confidence: 0.8167539875

01:17:37.453 --> 01:17:39.912 May be lifelong TPN and parents

NOTE Confidence: 0.8167539875

01:17:39.912 --> 01:17:42.236 refuse and the care continues.

NOTE Confidence: 0.8167539875

01:17:42.236 --> 01:17:45.580 When this child is now only on low

NOTE Confidence: 0.8167539875

01:17:45.580 --> 01:17:48.198 flow oxygen and TPN and goes home,

NOTE Confidence: 0.8167539875

01:17:48.200 --> 01:17:49.400 actually very,

NOTE Confidence: 0.8167539875

01:17:49.400 --> 01:17:53.000 very few people are morally distressed.

NOTE Confidence: 0.8167539875

01:17:53.000 --> 01:17:57.184 So I'm not sure it's how we paint

NOTE Confidence: 0.8167539875

01:17:57.184 --> 01:18:00.039 the outcomes that that would make

NOTE Confidence: 0.8167539875

01:18:00.040 --> 01:18:01.659 everybody morally distressed.

NOTE Confidence: 0.8167539875

01:18:01.659 --> 01:18:03.895 Certainly other physicians don't

NOTE Confidence: 0.8167539875

01:18:03.895 --> 01:18:06.131 necessarily look at preemies

NOTE Confidence: 0.8167539875

01:18:06.131 --> 01:18:07.939 in a very kind way.

NOTE Confidence: 0.8167539875

01:18:07.940 --> 01:18:10.250 So in because the same thing,

NOTE Confidence: 0.8167539875

01:18:10.250 --> 01:18:12.147 they don't go to neonatal follow up,

NOTE Confidence: 0.8167539875

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01:18:12.150 --> 01:18:14.130 they don't see our kids when

NOTE Confidence: 0.8167539875

01:18:14.130 --> 01:18:16.130 they're just eating lunch at school.

NOTE Confidence: 0.8167539875

01:18:16.130 --> 01:18:19.133 When they see our kids is because

NOTE Confidence: 0.8167539875

01:18:19.133 --> 01:18:20.712 they're hospitalized with RSV

NOTE Confidence: 0.8167539875

01:18:20.712 --> 01:18:22.980 or they see their kids with

NOTE Confidence: 0.8167539875

01:18:22.980 --> 01:18:25.030 quadriparesis or the residents too.

NOTE Confidence: 0.8167539875

01:18:25.030 --> 01:18:27.517 They only see the the, the, you know,

NOTE Confidence: 0.8167539875

01:18:27.517 --> 01:18:29.680 the kids who need to be rehospitalized

NOTE Confidence: 0.8167539875

01:18:29.744 --> 01:18:31.725 who at that point are not smiling.

NOTE Confidence: 0.8167539875

01:18:31.730 --> 01:18:33.179 So they think our kids don't smile

NOTE Confidence: 0.8167539875

01:18:33.179 --> 01:18:34.410 because when they're rehospitalized.

NOTE Confidence: 0.8167539875

01:18:34.410 --> 01:18:36.192 But I don't smile when I

NOTE Confidence: 0.8167539875

01:18:36.192 --> 01:18:37.565 read I'm rehospitalized, so.

NOTE Confidence: 0.8167539875

01:18:37.565 --> 01:18:39.706 It's also the people,

NOTE Confidence: 0.8167539875

01:18:39.706 --> 01:18:42.330 and it's an NICU graduate and they're like,

NOTE Confidence: 0.8167539875

01:18:42.330 --> 01:18:42.627 yeah,

NOTE Confidence: 0.8167539875

01:18:42.627 --> 01:18:44.678 there's an NICU graduate and RPI.

NOTE Confidence: 0.8167539875

01:18:44.680 --> 01:18:46.857 They don't say there's a hemon graduate,

NOTE Confidence: 0.8167539875

01:18:46.860 --> 01:18:49.668 like dying on the wards and the the kind

NOTE Confidence: 0.8167539875

01:18:49.668 --> 01:18:52.593 of bad Rep we get in the hospital too.

NOTE Confidence: 0.8167539875

01:18:52.600 --> 01:18:54.478 So you're right that maybe if

NOTE Confidence: 0.8167539875

01:18:54.478 --> 01:18:56.586 we start being more balanced and

NOTE Confidence: 0.8167539875

01:18:56.586 --> 01:18:58.938 positive that some doctors will say,

NOTE Confidence: 0.8167539875

01:18:58.940 --> 01:18:59.480 Oh my God,

NOTE Confidence: 0.8167539875

01:18:59.480 --> 01:18:59.840 you know,

NOTE Confidence: 0.8167539875

01:18:59.840 --> 01:19:02.180 these neonatologists are totally delusional.

NOTE Confidence: 0.8167539875

01:19:02.180 --> 01:19:04.148 But then maybe we can send us the

NOTE Confidence: 0.8167539875

01:19:04.148 --> 01:19:05.768 papers and they can read them.

NOTE Confidence: 0.742290114

01:19:06.640 --> 01:19:09.290 Yeah, yeah. Your. Your. Your.

NOTE Confidence: 0.73811504

01:19:11.850 --> 01:19:14.048 Uh, there was a sailor at sea,

NOTE Confidence: 0.73811504

01:19:14.050 --> 01:19:16.458 captain from a couple 100 years ago who

NOTE Confidence: 0.73811504

01:19:16.458 --> 01:19:18.709 famously said my cannon will speak for me.

NOTE Confidence: 0.73811504

01:19:18.710 --> 01:19:20.432 So perhaps the team from Montreal

NOTE Confidence: 0.73811504

01:19:20.432 --> 01:19:22.471 says our data will speak for us

NOTE Confidence: 0.73811504

01:19:22.471 --> 01:19:24.127 because you you don't present us

NOTE Confidence: 0.73811504

01:19:24.127 --> 01:19:26.180 just with your opinions or outlooks.

NOTE Confidence: 0.73811504

01:19:26.180 --> 01:19:28.168 You also present us with some compelling

NOTE Confidence: 0.73811504

01:19:28.168 --> 01:19:30.362 data on which I think we need to share

NOTE Confidence: 0.73811504

01:19:30.362 --> 01:19:32.279 with our non Una Township colleague.

NOTE Confidence: 0.73811504

01:19:32.280 --> 01:19:34.218 A comment, more of a comment,

NOTE Confidence: 0.73811504

01:19:34.220 --> 01:19:37.088 I think the real follow-up clinic.

NOTE Confidence: 0.73811504

01:19:37.090 --> 01:19:40.149 Is the medical home where us general

NOTE Confidence: 0.73811504

01:19:40.149 --> 01:19:42.307 peace follow those NICU graduates

NOTE Confidence: 0.73811504

01:19:42.307 --> 01:19:45.355 for 20 years and see them on that

NOTE Confidence: 0.73811504

01:19:45.443 --> 01:19:47.828 sometimes tumultuous journeys.

NOTE Confidence: 0.73811504

01:19:47.830 --> 01:19:51.088 That's the follow up clinic is the is the.

NOTE Confidence: 0.73811504

01:19:51.090 --> 01:19:52.698 Is the general pediatric uh the

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NOTE Confidence: 0.73811504

01:19:52.698 --> 01:19:54.070 general of the medical home?

NOTE Confidence: 0.73811504

01:19:54.070 --> 01:19:56.740 It's an interesting observation from Cliff.

NOTE Confidence: 0.73811504

01:19:56.740 --> 01:20:00.817 Um. And uh, this from one of the associates,

NOTE Confidence: 0.73811504

01:20:00.820 --> 01:20:01.944 directors of our program.

NOTE Confidence: 0.73811504

01:20:01.944 --> 01:20:02.506 We asked,

NOTE Confidence: 0.73811504

01:20:02.510 --> 01:20:04.502 I wonder if some of physicians

NOTE Confidence: 0.73811504

01:20:04.502 --> 01:20:06.504 pessimism about the outcomes of very

NOTE Confidence: 0.73811504

01:20:06.504 --> 01:20:08.358 premature children has to do with

NOTE Confidence: 0.73811504

01:20:08.358 --> 01:20:10.048 their concern about the burdens,

NOTE Confidence: 0.73811504

01:20:10.050 --> 01:20:11.229 economic and otherwise,

NOTE Confidence: 0.73811504

01:20:11.229 --> 01:20:13.587 they might be imposing on society

NOTE Confidence: 0.73811504

01:20:13.587 --> 01:20:15.630 by keeping the child alive,

NOTE Confidence: 0.73811504

01:20:15.630 --> 01:20:18.948 creating a burden rather than saving a life.

NOTE Confidence: 0.73811504

01:20:18.948 --> 01:20:20.497 I don't know if my friend Jack had

NOTE Confidence: 0.73811504

01:20:20.497 --> 01:20:21.691 actually read the paper that you

NOTE Confidence: 0.73811504

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01:20:21.691 --> 01:20:23.153 and I wrote together many years

NOTE Confidence: 0.73811504

01:20:23.153 --> 01:20:24.523 ago about saving versus creating,

NOTE Confidence: 0.73811504

01:20:24.530 --> 01:20:27.482 but you also alluded to it in your talk.

NOTE Confidence: 0.73811504

01:20:27.490 --> 01:20:28.757 Do you think that it's possible that?

NOTE Confidence: 0.73811504

01:20:28.760 --> 01:20:30.280 Some of the positions pessimism

NOTE Confidence: 0.73811504

01:20:30.280 --> 01:20:32.122 is related to their concern about

NOTE Confidence: 0.73811504

01:20:32.122 --> 01:20:33.730 the the burdens that they might

NOTE Confidence: 0.73811504

01:20:33.730 --> 01:20:35.000 be imposing on society.

NOTE Confidence: 0.810755261904762

01:20:36.540 --> 01:20:39.452 But I don't think this is evidence

NOTE Confidence: 0.810755261904762

01:20:39.452 --> 01:20:42.585 based because the work from from Doctor

NOTE Confidence: 0.810755261904762

01:20:42.585 --> 01:20:45.279 Spencer has shown that actually it

NOTE Confidence: 0.810755261904762

01:20:45.360 --> 01:20:48.768 is a very good for society to spend

NOTE Confidence: 0.810755261904762

01:20:48.768 --> 01:20:51.516 money in neonatal care just because

NOTE Confidence: 0.810755261904762

01:20:51.516 --> 01:20:55.014 of you know all the the the long

NOTE Confidence: 0.810755261904762

01:20:55.014 --> 01:20:58.346 life that those babies can have and.

NOTE Confidence: 0.810755261904762

01:20:58.350 --> 01:21:01.829 Once again, like we have this impression

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01:21:01.829 --> 01:21:04.417 that significant disability is something

01:21:04.417 --> 01:21:07.483 very prevalent among very premature babies,

01:21:07.490 --> 01:21:09.788 but it's actually not so high.

01:21:09.790 --> 01:21:11.206 It doesn't mean that you have

01:21:11.206 --> 01:21:12.455 several palsy that you cannot

01:21:12.455 --> 01:21:14.205 contribute to society and have a job.

01:21:14.210 --> 01:21:16.583 It doesn't mean because you have autism

01:21:16.583 --> 01:21:19.019 that you're not able to have a job so.

01:21:19.020 --> 01:21:21.988 So actually I think it's a misconception

01:21:21.988 --> 01:21:24.880 that children or even individual with

01:21:24.880 --> 01:21:27.958 disabilities are not valuable to society.

01:21:27.960 --> 01:21:30.010 So I think that the,

01:21:30.010 --> 01:21:31.697 the big mistake here is to invest

01:21:31.697 --> 01:21:34.068 a lot in neonatology and not in

01:21:34.068 --> 01:21:36.048 follow-up care and rehabilitation care.

01:21:36.050 --> 01:21:38.264 Because what I see a lot is that families,

NOTE Confidence: 0.810755261904762

01:21:38.270 --> 01:21:39.596 they want to help their children,

NOTE Confidence: 0.810755261904762

01:21:39.600 --> 01:21:41.305 but there's no speech and

NOTE Confidence: 0.810755261904762

01:21:41.305 --> 01:21:41.987 language pathologist,

NOTE Confidence: 0.810755261904762

01:21:41.990 --> 01:21:43.462 there's no physical therapist.

NOTE Confidence: 0.810755261904762

01:21:43.462 --> 01:21:45.670 Maybe this is a Canadian problem,

NOTE Confidence: 0.810755261904762

01:21:45.670 --> 01:21:48.070 problem with our universal healthcare.

NOTE Confidence: 0.810755261904762

01:21:48.070 --> 01:21:50.290 But I think that, you know,

NOTE Confidence: 0.810755261904762

01:21:50.290 --> 01:21:51.490 following this family,

NOTE Confidence: 0.810755261904762

01:21:51.490 --> 01:21:53.090 helping out them through

NOTE Confidence: 0.810755261904762

01:21:53.090 --> 01:21:54.710 their journey being there,

NOTE Confidence: 0.810755261904762

01:21:54.710 --> 01:21:56.390 this is such an important piece to

NOTE Confidence: 0.810755261904762

01:21:56.390 --> 01:21:58.039 make sure that you know the kids.

NOTE Confidence: 0.810755261904762

01:21:58.040 --> 01:21:59.936 Can do whatever they want in their life

NOTE Confidence: 0.810755261904762

01:21:59.936 --> 01:22:02.096 and they can really contribute to society.

NOTE Confidence: 0.810755261904762

01:22:02.100 --> 01:22:04.700 I think it's a misconception that we think

NOTE Confidence: 0.810755261904762

01:22:04.700 --> 01:22:06.639 that disability equals being a burden.

NOTE Confidence: 0.672114431

01:22:07.500 --> 01:22:09.276 And I'm sorry go ahead the

NOTE Confidence: 0.672114431

01:22:09.276 --> 01:22:10.460 and the economy there.

NOTE Confidence: 0.672114431

01:22:10.460 --> 01:22:12.890 There are there are economic analysis.

NOTE Confidence: 0.672114431

01:22:12.890 --> 01:22:14.186 There is zupancic.

NOTE Confidence: 0.672114431

01:22:14.186 --> 01:22:17.660 There's Bill Meadow did some and Edward Bell.

NOTE Confidence: 0.672114431

01:22:17.660 --> 01:22:20.044 And in fact it's the cheapest one of

NOTE Confidence: 0.672114431

01:22:20.044 --> 01:22:21.659 the cheapest endeavor in medicine

NOTE Confidence: 0.672114431

01:22:21.659 --> 01:22:23.878 is if you look at qualities you

NOTE Confidence: 0.672114431

01:22:23.939 --> 01:22:26.035 look at how long then the kids can

NOTE Confidence: 0.672114431

01:22:26.035 --> 01:22:28.170 work and support us when we're old

NOTE Confidence: 0.781767395

01:22:28.850 --> 01:22:31.044 and pay the taxes for my health care.

NOTE Confidence: 0.781767395

01:22:31.044 --> 01:22:32.950 So no but it's it is for

NOTE Confidence: 0.858433807777778

01:22:32.960 --> 01:22:36.002 real if you really do an

NOTE Confidence: 0.858433807777778

01:22:36.002 --> 01:22:37.523 economic analysis mammograms.

NOTE Confidence: 0.858433807777778

01:22:37.530 --> 01:22:40.526 Are really not very good compared to

NOTE Confidence: 0.858433807777778

01:22:40.526 --> 01:22:42.490 treating extremely extreme preemies.

NOTE Confidence: 0.858433807777778

01:22:42.490 --> 01:22:44.362 Automatic defibrillator devices

NOTE Confidence: 0.858433807777778

01:22:44.362 --> 01:22:47.204 that we have everywhere and we keep

NOTE Confidence: 0.858433807777778

01:22:47.204 --> 01:22:49.022 functioning are an apocalypse because

NOTE Confidence: 0.858433807777778

01:22:49.022 --> 01:22:51.038 most of them then are disabled.

NOTE Confidence: 0.858433807777778

01:22:51.040 --> 01:22:53.784 They send the hospital or they die and

NOTE Confidence: 0.858433807777778

01:22:53.784 --> 01:22:56.052 they don't have very good outcomes

NOTE Confidence: 0.858433807777778

01:22:56.052 --> 01:22:58.275 and and then they're disabled and

NOTE Confidence: 0.858433807777778

01:22:58.275 --> 01:23:00.225 do not make money because it's

NOTE Confidence: 0.858433807777778

01:23:00.225 --> 01:23:02.227 more likely to be an older people.

NOTE Confidence: 0.858433807777778

01:23:02.227 --> 01:23:05.089 So all these economic analysis use

NOTE Confidence: 0.858433807777778

01:23:05.089 --> 01:23:07.550 real economic analysis of the worth.

NOTE Confidence: 0.858433807777778

01:23:07.550 --> 01:23:09.938 Of the person that's bringing back

NOTE Confidence: 0.858433807777778

01:23:09.938 --> 01:23:12.049 money later and they all point

NOTE Confidence: 0.858433807777778

01:23:12.049 --> 01:23:13.605 towards actually neonatology being

NOTE Confidence: 0.858433807777778

01:23:13.605 --> 01:23:16.068 a bargain in terms of economic

NOTE Confidence: 0.858433807777778

01:23:16.068 --> 01:23:18.318 analysis compared to other things.

NOTE Confidence: 0.858433807777778

01:23:18.320 --> 01:23:21.119 Not you know not compared to you know

NOTE Confidence: 0.858433807777778

01:23:21.119 --> 01:23:23.857 minor minor aesthetic surgery but

NOTE Confidence: 0.858433807777778

01:23:23.857 --> 01:23:25.999 I mean compared to other endeavors

NOTE Confidence: 0.858433807777778

01:23:25.999 --> 01:23:28.550 in in the Quaternary Care center.

NOTE Confidence: 0.502099941

01:23:28.600 --> 01:23:29.720 I'm just reading Doctor.

NOTE Confidence: 0.502099941

01:23:29.720 --> 01:23:30.690 Doctor Katz. Dr Hughes.

NOTE Confidence: 0.502099941

01:23:30.690 --> 01:23:31.715 Sorry we're not we're not

NOTE Confidence: 0.502099941

01:23:31.715 --> 01:23:32.900 trying to jump on you. I know

NOTE Confidence: 0.837223538

01:23:32.910 --> 01:23:34.530 he's he said I did

NOTE Confidence: 0.945740526666667

01:23:34.540 --> 01:23:35.809 read your paper.

NOTE Confidence: 0.85476293

01:23:35.860 --> 01:23:36.970 I'm just trying to but

NOTE Confidence: 0.8686253

01:23:36.980 --> 01:23:37.990 I think this. I think

NOTE Confidence: 0.870257386153846

01:23:38.000 --> 01:23:39.208 that I think you make a good point

NOTE Confidence: 0.870257386153846

01:23:39.208 --> 01:23:40.642 and I think that this brings up

NOTE Confidence: 0.870257386153846

01:23:40.642 --> 01:23:42.762 again the fact that the difference,

NOTE Confidence: 0.870257386153846

01:23:42.762 --> 01:23:44.954 the difference that that clinicians

NOTE Confidence: 0.870257386153846

01:23:44.954 --> 01:23:47.008 have in viewing babies versus adults

NOTE Confidence: 0.870257386153846

01:23:47.008 --> 01:23:49.552 like again it's very hard to imagine a

NOTE Confidence: 0.870257386153846

01:23:49.552 --> 01:23:51.728 premature baby as a functioning you know,

NOTE Confidence: 0.870257386153846

01:23:51.730 --> 01:23:54.448 teenager or a 25 year old.

NOTE Confidence: 0.870257386153846

01:23:54.450 --> 01:23:56.506 And I think there's a lot of statistics,

NOTE Confidence: 0.870257386153846

01:23:56.510 --> 01:23:57.728 I don't know exactly what they are,

NOTE Confidence: 0.870257386153846

01:23:57.730 --> 01:23:59.057 but about how, you know the last

NOTE Confidence: 0.870257386153846

01:23:59.057 --> 01:24:01.148 year of people's lives is the is

NOTE Confidence: 0.870257386153846

01:24:01.148 --> 01:24:03.484 that when we spend the most money

NOTE Confidence: 0.870257386153846

01:24:03.484 --> 01:24:05.559 on healthcare for those people

NOTE Confidence: 0.870257386153846

01:24:05.559 --> 01:24:08.079 even though it's kind of useless.

NOTE Confidence: 0.870257386153846

01:24:08.080 --> 01:24:09.208 And so because they're

NOTE Confidence: 0.845154373333333

01:24:09.760 --> 01:24:11.296 and so I find it interesting

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NOTE Confidence: 0.782315684285714

01:24:11.310 --> 01:24:12.286 that we're, you know,

NOTE Confidence: 0.782315684285714

01:24:12.286 --> 01:24:13.018 we're questioning spirit,

NOTE Confidence: 0.782315684285714

01:24:13.020 --> 01:24:14.298 you know, and sorry Doctor Who,

NOTE Confidence: 0.782315684285714

01:24:14.300 --> 01:24:15.308 I know you're not saying this,

NOTE Confidence: 0.782315684285714

01:24:15.310 --> 01:24:16.900 but I know you know that some people

NOTE Confidence: 0.782315684285714

01:24:16.900 --> 01:24:17.968 might question the expenditure

NOTE Confidence: 0.782315684285714

01:24:17.968 --> 01:24:19.552 for these babies that as Annie

NOTE Confidence: 0.782315684285714

01:24:19.552 --> 01:24:21.097 said are going to become like

NOTE Confidence: 0.782315684285714

01:24:21.100 --> 01:24:23.120 most of the vast majority of them

NOTE Confidence: 0.782315684285714

01:24:23.120 --> 01:24:24.520 functioning members of society.

NOTE Confidence: 0.782315684285714

01:24:24.520 --> 01:24:25.890 But we don't necessarily question

NOTE Confidence: 0.782315684285714

01:24:25.890 --> 01:24:27.646 again spending you know tons of

NOTE Confidence: 0.782315684285714

01:24:27.646 --> 01:24:29.380 money on medical treatment for

NOTE Confidence: 0.782315684285714

01:24:29.380 --> 01:24:31.400 like a 94 year old for example.

NOTE Confidence: 0.782315684285714

01:24:31.400 --> 01:24:32.870 So again it's this difference I

NOTE Confidence: 0.782315684285714

01:24:32.870 --> 01:24:34.568 think in how we view babies versus

NOTE Confidence: 0.782315684285714

01:24:34.568 --> 01:24:36.536 how we view full grown adults.

NOTE Confidence: 0.699848113333333

01:24:36.850 --> 01:24:38.710 So anyway. Yeah,

NOTE Confidence: 0.819584911481481

01:24:38.930 --> 01:24:39.858 yeah. No, good point.

NOTE Confidence: 0.819584911481481

01:24:39.858 --> 01:24:41.714 And Jack and by the way he puts

NOTE Confidence: 0.819584911481481

01:24:41.714 --> 01:24:43.362 here and I was going to say that

NOTE Confidence: 0.819584911481481

01:24:43.417 --> 01:24:45.167 Jack if you didn't that was clear,

NOTE Confidence: 0.819584911481481

01:24:45.170 --> 01:24:46.838 he was trying to think about

NOTE Confidence: 0.819584911481481

01:24:46.838 --> 01:24:47.950 the explanation for physicians

NOTE Confidence: 0.819584911481481

01:24:48.001 --> 01:24:49.570 view not to justify the belief

NOTE Confidence: 0.489692805

01:24:50.080 --> 01:24:51.260 that shooting the messenger here.

NOTE Confidence: 0.8186011

01:24:52.780 --> 01:24:54.649 He has a far more knowledgeable and

NOTE Confidence: 0.8186011

01:24:54.649 --> 01:24:55.998 sophisticated view of the economics

NOTE Confidence: 0.8186011

01:24:55.998 --> 01:24:57.474 of medicine than most of us.

NOTE Confidence: 0.8186011

01:24:57.480 --> 01:24:59.056 This is one of the things that Jack

NOTE Confidence: 0.8186011

01:24:59.056 --> 01:25:00.940 teaches here at Yale, and he gets it.

NOTE Confidence: 0.8186011

01:25:00.940 --> 01:25:02.620 But trying to understand why people

NOTE Confidence: 0.8186011

01:25:02.680 --> 01:25:04.566 feel that way, whatever that way is,

NOTE Confidence: 0.8186011

01:25:04.566 --> 01:25:05.961 is really helpful in trying

NOTE Confidence: 0.8186011

01:25:05.961 --> 01:25:07.480 to change people's minds,

NOTE Confidence: 0.8186011

01:25:07.480 --> 01:25:10.686 trying to understand why people feel that.

NOTE Confidence: 0.8186011

01:25:10.690 --> 01:25:11.530 Good morning, ladies.

NOTE Confidence: 0.8186011

01:25:11.530 --> 01:25:13.210 Are more optional or that that

NOTE Confidence: 0.8186011

01:25:13.210 --> 01:25:14.759 there's some in some way inferior.

NOTE Confidence: 0.8186011

01:25:14.760 --> 01:25:16.378 I notice that at one point, Rebecca,

NOTE Confidence: 0.8186011

01:25:16.378 --> 01:25:18.602 you used the word inferior and I jot

NOTE Confidence: 0.8186011

01:25:18.602 --> 01:25:20.495 down not that this was your view,

NOTE Confidence: 0.8186011

01:25:20.500 --> 01:25:22.921 but that this may be a view taken by

NOTE Confidence: 0.8186011

01:25:22.921 --> 01:25:25.615 some of the in the medical establishment.

NOTE Confidence: 0.8186011

01:25:25.620 --> 01:25:26.908 Anyway, as I said,

NOTE Confidence: 0.8186011

01:25:26.908 --> 01:25:28.518 we're not completely done here,

NOTE Confidence: 0.8186011

01:25:28.520 --> 01:25:31.344 but we are done because the hour is

NOTE Confidence: 0.8186011

01:25:31.344 --> 01:25:33.860 about the hour and a half is up.

NOTE Confidence: 0.8186011

01:25:33.860 --> 01:25:35.740 Wanna let you guys think for 10 seconds

NOTE Confidence: 0.8186011

01:25:35.740 --> 01:25:37.885 about any final comments you'd like to make.

NOTE Confidence: 0.8186011

01:25:37.890 --> 01:25:41.334 While I say that this has been

NOTE Confidence: 0.8186011

01:25:41.334 --> 01:25:42.810 an outstanding presentation,

NOTE Confidence: 0.8186011

01:25:42.810 --> 01:25:45.218 this I think your work as well as

NOTE Confidence: 0.8186011

01:25:45.218 --> 01:25:46.925 a presentation of this quality

NOTE Confidence: 0.8186011

01:25:46.925 --> 01:25:48.650 clearly has great potential to

NOTE Confidence: 0.8186011

01:25:48.650 --> 01:25:50.821 move the needle and to change the

NOTE Confidence: 0.8186011

01:25:50.821 --> 01:25:52.870 way we do things for the better.

NOTE Confidence: 0.8186011

01:25:52.870 --> 01:25:54.445 And I really appreciate that.

NOTE Confidence: 0.8186011

01:25:54.450 --> 01:25:56.155 I had actually expected something

NOTE Confidence: 0.8186011

01:25:56.155 --> 01:25:57.860 really good because I've I'm

NOTE Confidence: 0.8186011

01:25:57.922 --> 01:25:59.410 familiar with Annie's work,

NOTE Confidence: 0.8186011

01:25:59.410 --> 01:26:01.186 but this even exceeded my expectations.

NOTE Confidence: 0.8186011

01:26:01.190 --> 01:26:02.611 I thank you so much for taking

NOTE Confidence: 0.8186011

01:26:02.611 --> 01:26:03.950 the time to speak with us.

NOTE Confidence: 0.8186011

01:26:03.950 --> 01:26:04.188 Tonight,

NOTE Confidence: 0.8186011

01:26:04.188 --> 01:26:06.330 and I want to just let you have any

NOTE Confidence: 0.8186011

01:26:06.384 --> 01:26:08.085 last words you might like to say

NOTE Confidence: 0.8186011

01:26:08.085 --> 01:26:09.898 to this crew who's listening in.

NOTE Confidence: 0.897878783333333

01:26:11.940 --> 01:26:14.058 Well, thank you for inviting us.

NOTE Confidence: 0.897878783333333

01:26:14.060 --> 01:26:15.320 My kids were really impressed.

NOTE Confidence: 0.897878783333333

01:26:15.320 --> 01:26:16.630 I was speaking at Yale

NOTE Confidence: 0.636056766666667

01:26:16.700 --> 01:26:17.669 from the kitchen.

NOTE Confidence: 0.685393

01:26:19.850 --> 01:26:24.200 Yeah, well. Doctor Liu and Miss

NOTE Confidence: 0.685393

01:26:24.200 --> 01:26:25.700 Pierce and Doctor Janvier,

NOTE Confidence: 0.881701798

01:26:25.700 --> 01:26:27.130 this was a wonderful evening.

NOTE Confidence: 0.881701798

01:26:27.130 --> 01:26:28.438 Thank you very much.

NOTE Confidence: 0.881701798

01:26:28.438 --> 01:26:30.000 We wish you all well. Take care.