

WEBVTT

NOTE duration: "01:15:22.960"

NOTE Confidence: 0.9656398

00:00:00.160 --> 00:00:01.920 I would like to, address

NOTE Confidence: 0.9656398

00:00:01.920 --> 00:00:03.439 our wonderful speaker tonight, doctor

NOTE Confidence: 0.9656398

00:00:03.439 --> 00:00:03.939 Cortezzo.

NOTE Confidence: 0.99364704

00:00:04.559 --> 00:00:06.399 So, Donna Maria Cortezzo is

NOTE Confidence: 0.99364704

00:00:06.399 --> 00:00:06.980 a neonatologist

NOTE Confidence: 0.97835016

00:00:07.919 --> 00:00:09.380 and hospice and palliative,

NOTE Confidence: 0.95511085

00:00:10.000 --> 00:00:12.099 medicine physician and the neonatal

NOTE Confidence: 0.95511085

00:00:12.160 --> 00:00:13.519 lead for fetal care at

NOTE Confidence: 0.95511085

00:00:13.519 --> 00:00:14.580 Connecticut Children's,

NOTE Confidence: 0.94120216

00:00:14.975 --> 00:00:15.935 who has an appointment as

NOTE Confidence: 0.94120216

00:00:15.935 --> 00:00:17.635 an associate professor of pediatrics

NOTE Confidence: 0.9884196

00:00:18.015 --> 00:00:19.375 at the University of Connecticut

NOTE Confidence: 0.9884196

00:00:19.375 --> 00:00:20.275 School of Medicine.

NOTE Confidence: 0.9795661

00:00:20.735 --> 00:00:22.095 She works primarily in the

NOTE Confidence: 0.9795661

00:00:22.095 --> 00:00:23.615 level four NICU and fetal
NOTE Confidence: 0.9795661

00:00:23.615 --> 00:00:25.375 care center with her clinical
NOTE Confidence: 0.9795661

00:00:25.375 --> 00:00:27.535 interests spanning fetuses and neonates
NOTE Confidence: 0.9795661

00:00:27.535 --> 00:00:29.075 with multiple congenital anomalies,
NOTE Confidence: 0.9495056

00:00:29.560 --> 00:00:30.380 complex diagnoses,
NOTE Confidence: 0.99908334

00:00:31.000 --> 00:00:33.979 congenital diaphragmatic hernias, complex air-
ways,
NOTE Confidence: 0.99862325

00:00:34.440 --> 00:00:36.380 neonates requiring surgical intervention,
NOTE Confidence: 0.9822905

00:00:37.000 --> 00:00:38.920 ECMO, neonatal pain management, and
NOTE Confidence: 0.9822905

00:00:38.920 --> 00:00:41.720 neonatal perinatal palliative care. So
NOTE Confidence: 0.9822905

00:00:41.720 --> 00:00:43.500 quite intense and quite expansive.
NOTE Confidence: 0.97959435

00:00:44.625 --> 00:00:46.225 She counsels families with various
NOTE Confidence: 0.97959435

00:00:46.225 --> 00:00:48.225 complex prenatal diagnoses and partners
NOTE Confidence: 0.97959435

00:00:48.225 --> 00:00:49.745 with them to create personalized
NOTE Confidence: 0.97959435

00:00:49.745 --> 00:00:51.284 birth plans and care strategies.
NOTE Confidence: 0.9877067

00:00:51.745 --> 00:00:53.344 Her research focuses on improving
NOTE Confidence: 0.9877067

00:00:53.344 --> 00:00:54.785 outcomes for neonates with complex
NOTE Confidence: 0.9877067

00:00:54.785 --> 00:00:55.285 diagnoses,
NOTE Confidence: 0.99838114

00:00:55.745 --> 00:00:57.824 neonatal and perinatal palliative care,
NOTE Confidence: 0.99838114

00:00:57.824 --> 00:00:59.125 neonatal pain management,
NOTE Confidence: 0.978399

00:00:59.500 --> 00:01:01.840 bereaved parent experiences, and communication
NOTE Confidence: 0.978399

00:01:01.900 --> 00:01:02.940 and counseling as well as
NOTE Confidence: 0.978399

00:01:02.940 --> 00:01:04.620 shared decision making. And tonight,
NOTE Confidence: 0.978399

00:01:04.620 --> 00:01:05.660 she's going to be talking
NOTE Confidence: 0.978399

00:01:05.660 --> 00:01:06.459 to us about some of
NOTE Confidence: 0.978399

00:01:06.459 --> 00:01:07.979 the evolving clinical and ethical
NOTE Confidence: 0.978399

00:01:07.979 --> 00:01:08.479 considerations
NOTE Confidence: 0.9760365

00:01:08.940 --> 00:01:10.479 in complex fetal diagnosis
NOTE Confidence: 0.9747559

00:01:11.020 --> 00:01:12.459 diagnoses. So thank you so
NOTE Confidence: 0.9747559

00:01:12.459 --> 00:01:13.979 much, doctor Corteza. We really
NOTE Confidence: 0.9747559

00:01:13.979 --> 00:01:15.315 appreciate your coming here, and
NOTE Confidence: 0.9747559

00:01:15.315 --> 00:01:16.755 and we're looking forward very

NOTE Confidence: 0.9747559

00:01:16.755 --> 00:01:17.975 much to hearing your talk.

NOTE Confidence: 0.98715836

00:01:22.995 --> 00:01:24.035 Thank you, Sarah, for that

NOTE Confidence: 0.98715836

00:01:24.035 --> 00:01:25.095 wonderful introduction.

NOTE Confidence: 0.9979634

00:01:25.555 --> 00:01:26.595 This evening, I will be

NOTE Confidence: 0.9979634

00:01:26.595 --> 00:01:27.875 using the example of fetal

NOTE Confidence: 0.9979634

00:01:27.875 --> 00:01:29.470 kidney failure to highlight the

NOTE Confidence: 0.9979634

00:01:29.470 --> 00:01:31.569 ethical considerations and the complexity

NOTE Confidence: 0.9979634

00:01:31.630 --> 00:01:33.150 of care options and counseling

NOTE Confidence: 0.9979634

00:01:33.150 --> 00:01:34.690 after a serious fetal diagnosis

NOTE Confidence: 0.9979634

00:01:34.830 --> 00:01:35.490 is made.

NOTE Confidence: 0.9996929

00:01:36.190 --> 00:01:37.569 I have nothing to disclose.

NOTE Confidence: 0.98055077

00:01:38.830 --> 00:01:39.950 I will only begin to

NOTE Confidence: 0.98055077

00:01:39.950 --> 00:01:41.970 highlight the ethical considerations surrounding

NOTE Confidence: 0.98055077

00:01:42.030 --> 00:01:43.150 the treatment options and care

NOTE Confidence: 0.98055077

00:01:43.150 --> 00:01:44.430 of fetuses and neonates with

NOTE Confidence: 0.98055077

00:01:44.430 --> 00:01:45.465 complex diagnoses.
NOTE Confidence: 0.9544781

00:01:46.005 --> 00:01:47.785 With innovative fetal and neonatal
NOTE Confidence: 0.9544781

00:01:47.845 --> 00:01:49.125 interventions, we have the ability
NOTE Confidence: 0.9544781

00:01:49.125 --> 00:01:50.485 to potentially alter what ones
NOTE Confidence: 0.9544781

00:01:50.485 --> 00:01:52.405 were considered lethal diagnoses to
NOTE Confidence: 0.9544781

00:01:52.405 --> 00:01:53.865 complex chronic diseases.
NOTE Confidence: 0.98337847

00:01:54.565 --> 00:01:55.845 With this, though, it's important
NOTE Confidence: 0.98337847

00:01:55.845 --> 00:01:57.305 to consider the ethical implications
NOTE Confidence: 0.98337847

00:01:57.365 --> 00:01:58.185 for the fetus,
NOTE Confidence: 0.8456513

00:01:58.485 --> 00:02:00.960 neonate, pregnant individual family, and
NOTE Confidence: 0.8456513

00:02:00.960 --> 00:02:01.460 society.
NOTE Confidence: 0.9994419

00:02:02.000 --> 00:02:03.619 It's also important to recognize
NOTE Confidence: 0.9994419

00:02:03.680 --> 00:02:05.220 the constraints on the availability
NOTE Confidence: 0.9994419

00:02:05.280 --> 00:02:06.159 of some of the certain
NOTE Confidence: 0.9994419

00:02:06.159 --> 00:02:06.900 care options.
NOTE Confidence: 0.99457324

00:02:07.759 --> 00:02:10.080 Counseling involves complex discussions and

NOTE Confidence: 0.99457324

00:02:10.080 --> 00:02:11.840 a shared decision making approach

NOTE Confidence: 0.99457324

00:02:11.840 --> 00:02:13.280 to really help determine the

NOTE Confidence: 0.99457324

00:02:13.280 --> 00:02:15.174 most appropriate treatment path and

NOTE Confidence: 0.99457324

00:02:15.174 --> 00:02:16.954 medical care for the family.

NOTE Confidence: 0.9944063

00:02:17.334 --> 00:02:18.694 In this context, I'll also

NOTE Confidence: 0.9944063

00:02:18.694 --> 00:02:20.135 explain the importance of palliative

NOTE Confidence: 0.9944063

00:02:20.135 --> 00:02:21.495 care for families facing a

NOTE Confidence: 0.9944063

00:02:21.495 --> 00:02:22.875 complex fetal diagnosis.

NOTE Confidence: 0.9985835

00:02:23.575 --> 00:02:24.454 That's a lot to touch

NOTE Confidence: 0.9985835

00:02:24.454 --> 00:02:25.495 upon in a short period

NOTE Confidence: 0.9985835

00:02:25.495 --> 00:02:26.215 of time, but I hope

NOTE Confidence: 0.9985835

00:02:26.215 --> 00:02:27.415 it'll lead to a fruitful

NOTE Confidence: 0.9985835

00:02:27.415 --> 00:02:27.915 discussion.

NOTE Confidence: 0.9584157

00:02:29.569 --> 00:02:30.530 While I can talk for

NOTE Confidence: 0.9584157

00:02:30.530 --> 00:02:31.669 hours about the pathophysiology

NOTE Confidence: 0.9898071

00:02:32.209 --> 00:02:33.650 and management of fetal kidney

NOTE Confidence: 0.9898071

00:02:33.650 --> 00:02:34.790 failure, I won't.

NOTE Confidence: 0.96118605

00:02:35.090 --> 00:02:36.610 The details of the specific

NOTE Confidence: 0.96118605

00:02:36.610 --> 00:02:37.970 diagnosis is not the focus

NOTE Confidence: 0.96118605

00:02:37.970 --> 00:02:39.090 of the talk. I will

NOTE Confidence: 0.96118605

00:02:39.090 --> 00:02:40.610 give some of the basics

NOTE Confidence: 0.96118605

00:02:40.610 --> 00:02:42.290 so to give some context

NOTE Confidence: 0.96118605

00:02:42.290 --> 00:02:43.590 for this evening's discussion.

NOTE Confidence: 0.99162334

00:02:45.405 --> 00:02:47.405 Fetal kidney failure can result

NOTE Confidence: 0.99162334

00:02:47.405 --> 00:02:49.165 from several diagnoses that ultimately

NOTE Confidence: 0.99162334

00:02:49.165 --> 00:02:50.925 lead to nonfunctioning kidneys and

NOTE Confidence: 0.99162334

00:02:50.925 --> 00:02:52.845 an absence of amniotic fluid

NOTE Confidence: 0.99162334

00:02:52.845 --> 00:02:53.665 or anhydramnios

NOTE Confidence: 0.99760896

00:02:54.445 --> 00:02:55.565 prior to twenty two weeks

NOTE Confidence: 0.99760896

00:02:55.565 --> 00:02:56.065 gestation.

NOTE Confidence: 0.9538377

00:02:56.605 --> 00:02:57.965 The most common diagnoses are

NOTE Confidence: 0.9538377

00:02:57.965 --> 00:03:00.030 bilateral renal agenesis or complete

NOTE Confidence: 0.9538377

00:03:00.110 --> 00:03:01.010 absence of kidneys,

NOTE Confidence: 0.9666928

00:03:01.310 --> 00:03:03.950 bilateral multicystic dysplastic kidneys, and

NOTE Confidence: 0.9666928

00:03:03.950 --> 00:03:05.970 severe lower urinary tract obstructions.

NOTE Confidence: 0.99777025

00:03:06.990 --> 00:03:08.930 After sixteen to eighteen weeks,

NOTE Confidence: 0.99777025

00:03:09.069 --> 00:03:10.590 the fetal kidneys are really

NOTE Confidence: 0.99777025

00:03:10.590 --> 00:03:12.770 responsible for making amniotic fluid.

NOTE Confidence: 0.8788996

00:03:13.315 --> 00:03:13.815 Anhydramnios

NOTE Confidence: 0.9719844

00:03:14.355 --> 00:03:15.555 after that point can be

NOTE Confidence: 0.9719844

00:03:15.555 --> 00:03:17.475 indicative of fetal kidney failure,

NOTE Confidence: 0.9719844

00:03:17.475 --> 00:03:18.435 something we don't have a

NOTE Confidence: 0.9719844

00:03:18.435 --> 00:03:19.575 cure for.

NOTE Confidence: 0.9816846

00:03:20.035 --> 00:03:21.735 Also, amniotic fluid

NOTE Confidence: 0.9374718

00:03:22.355 --> 00:03:23.175 is critical

NOTE Confidence: 0.9659053

00:03:23.555 --> 00:03:24.915 from sixteen through at least

NOTE Confidence: 0.9659053

00:03:24.915 --> 00:03:26.435 twenty six weeks for a
NOTE Confidence: 0.9659053

00:03:26.435 --> 00:03:27.575 lung growth and development.
NOTE Confidence: 0.9580235

00:03:28.035 --> 00:03:29.430 With out it, the lungs
NOTE Confidence: 0.9580235

00:03:29.430 --> 00:03:31.450 may not develop enough to
NOTE Confidence: 0.9580235

00:03:31.590 --> 00:03:33.270 function or effectively breathe after
NOTE Confidence: 0.9580235

00:03:33.270 --> 00:03:33.770 delivery.
NOTE Confidence: 0.9921649

00:03:34.710 --> 00:03:36.870 These diagnoses have historically been
NOTE Confidence: 0.9921649

00:03:36.870 --> 00:03:37.850 considered lethal.
NOTE Confidence: 0.9849303

00:03:38.550 --> 00:03:39.990 In the seventies, there was
NOTE Confidence: 0.9849303

00:03:39.990 --> 00:03:41.210 report of a monozygotic
NOTE Confidence: 0.94183236

00:03:41.565 --> 00:03:43.485 twin with no kidneys who
NOTE Confidence: 0.94183236

00:03:43.485 --> 00:03:45.025 had normal lungs but died
NOTE Confidence: 0.94183236

00:03:45.085 --> 00:03:46.365 at several days due to
NOTE Confidence: 0.94183236

00:03:46.365 --> 00:03:47.185 kidney failure.
NOTE Confidence: 0.9978588

00:03:48.045 --> 00:03:48.545 Monozygotic
NOTE Confidence: 0.99011844

00:03:48.845 --> 00:03:49.885 twins are a unique type

NOTE Confidence: 0.99011844
00:03:49.885 --> 00:03:51.665 of twins that share amniotic
NOTE Confidence: 0.99011844
00:03:51.725 --> 00:03:53.345 sac and amniotic fluid.
NOTE Confidence: 0.98859125
00:03:54.150 --> 00:03:55.590 Presumably, the effects of fluid
NOTE Confidence: 0.98859125
00:03:55.590 --> 00:03:56.630 from the twin who had
NOTE Confidence: 0.98859125
00:03:56.630 --> 00:03:58.870 functioning kidneys surrounding the twin
NOTE Confidence: 0.98859125
00:03:58.870 --> 00:04:00.470 with no kidneys promoted lung
NOTE Confidence: 0.98859125
00:04:00.470 --> 00:04:01.850 development in that child.
NOTE Confidence: 0.9992158
00:04:02.790 --> 00:04:04.890 Subsequent reports of other monozygotic
NOTE Confidence: 0.9961616
00:04:05.190 --> 00:04:06.630 twins with fetal kidney failure
NOTE Confidence: 0.9961616
00:04:06.630 --> 00:04:07.770 surviving the neonatal
NOTE Confidence: 0.9680279
00:04:08.225 --> 00:04:09.765 period really challenged the designation
NOTE Confidence: 0.9680279
00:04:09.905 --> 00:04:10.885 of these diagnoses
NOTE Confidence: 0.9897095
00:04:11.185 --> 00:04:12.545 as lethal and led to
NOTE Confidence: 0.9897095
00:04:12.545 --> 00:04:13.205 in utero
NOTE Confidence: 0.97311115
00:04:13.745 --> 00:04:15.505 interventions with subsequent attempts at
NOTE Confidence: 0.97311115

00:04:15.505 --> 00:04:17.445 neonatal treatment, including dialysis.

NOTE Confidence: 0.9977006

00:04:20.160 --> 00:04:21.600 Some centers are offering in

NOTE Confidence: 0.9977006

00:04:21.600 --> 00:04:23.600 utero interventions to restore fluid

NOTE Confidence: 0.9977006

00:04:23.600 --> 00:04:24.740 around the fetus.

NOTE Confidence: 0.99144554

00:04:25.279 --> 00:04:26.980 This picture shows a subcutaneous

NOTE Confidence: 0.99144554

00:04:27.200 --> 00:04:28.560 port in a pregnant individual

NOTE Confidence: 0.99144554

00:04:28.560 --> 00:04:29.680 used to instill fluid around

NOTE Confidence: 0.99144554

00:04:29.680 --> 00:04:31.040 the fetus multiple times throughout

NOTE Confidence: 0.99144554

00:04:31.040 --> 00:04:31.700 the pregnancy.

NOTE Confidence: 0.9991952

00:04:32.855 --> 00:04:34.375 This does not impact the

NOTE Confidence: 0.9991952

00:04:34.375 --> 00:04:35.275 kidney function.

NOTE Confidence: 0.98258036

00:04:35.654 --> 00:04:36.695 The hope, though, is to

NOTE Confidence: 0.98258036

00:04:36.695 --> 00:04:38.315 promote lung growth and development.

NOTE Confidence: 0.9896496

00:04:39.175 --> 00:04:41.255 Without in utero interventions, a

NOTE Confidence: 0.9896496

00:04:41.255 --> 00:04:42.775 neonate will live hours at

NOTE Confidence: 0.9896496

00:04:42.775 --> 00:04:44.955 most. With in utero interventions

NOTE Confidence: 0.9896496
00:04:45.015 --> 00:04:46.215 and a comfort measures approach
NOTE Confidence: 0.9896496
00:04:46.215 --> 00:04:47.654 after delivery, a neonate will
NOTE Confidence: 0.9896496
00:04:47.654 --> 00:04:48.770 live weeks at most.
NOTE Confidence: 0.98657835
00:04:49.310 --> 00:04:50.830 And with invasive in utero
NOTE Confidence: 0.98657835
00:04:50.830 --> 00:04:52.750 and neonatal interventions, if the
NOTE Confidence: 0.98657835
00:04:52.750 --> 00:04:54.370 neonate is a pulmonary survivor,
NOTE Confidence: 0.98657835
00:04:54.589 --> 00:04:56.350 they are expected to have
NOTE Confidence: 0.98657835
00:04:56.350 --> 00:04:58.690 neonatal kidney failure and require
NOTE Confidence: 0.98657835
00:04:58.750 --> 00:04:59.970 dialysis and, ultimately,
NOTE Confidence: 0.99717504
00:05:00.270 --> 00:05:01.790 kidney transplant for long term
NOTE Confidence: 0.99717504
00:05:01.790 --> 00:05:02.290 survival.
NOTE Confidence: 0.9953694
00:05:03.555 --> 00:05:04.755 In one study of a
NOTE Confidence: 0.9953694
00:05:04.755 --> 00:05:06.055 hundred and four pregnancies
NOTE Confidence: 0.9285373
00:05:06.355 --> 00:05:08.135 of the hundred live born,
NOTE Confidence: 0.9285373
00:05:08.275 --> 00:05:09.955 ninety three survived the delivery
NOTE Confidence: 0.9285373

00:05:09.955 --> 00:05:10.455 room,
NOTE Confidence: 0.9560205

00:05:10.835 --> 00:05:12.435 and fifty three per of
NOTE Confidence: 0.9560205

00:05:12.435 --> 00:05:13.895 those were pulmonary survivors.
NOTE Confidence: 0.9471781

00:05:14.675 --> 00:05:16.355 Forty percent survived a hospital
NOTE Confidence: 0.9471781

00:05:16.355 --> 00:05:16.855 discharge,
NOTE Confidence: 0.99857235

00:05:17.210 --> 00:05:18.570 and fifty seven percent of
NOTE Confidence: 0.99857235

00:05:18.570 --> 00:05:19.870 those neonates were ultimately
NOTE Confidence: 0.9998048

00:05:20.250 --> 00:05:20.750 transplanted.
NOTE Confidence: 0.99674565

00:05:21.450 --> 00:05:23.610 For survivors, the care is
NOTE Confidence: 0.99674565

00:05:23.610 --> 00:05:25.710 incredibly complex and lifelong.
NOTE Confidence: 0.9834099

00:05:26.570 --> 00:05:29.130 Twenty percent have developmental delays,
NOTE Confidence: 0.9834099

00:05:29.130 --> 00:05:30.810 and seventy three percent have
NOTE Confidence: 0.9834099

00:05:30.810 --> 00:05:31.710 serious comorbidities.
NOTE Confidence: 0.97599727

00:05:33.055 --> 00:05:34.895 A significant number die prior
NOTE Confidence: 0.97599727

00:05:34.895 --> 00:05:36.895 to transplants, and transplants do
NOTE Confidence: 0.97599727

00:05:36.895 --> 00:05:38.035 not last a lifetime.

NOTE Confidence: 0.99815226

00:05:38.735 --> 00:05:39.795 So while interventions

NOTE Confidence: 0.9983118

00:05:40.335 --> 00:05:41.955 can be effective at prolonging

NOTE Confidence: 0.9983118

00:05:42.014 --> 00:05:44.654 life, morbidity and mortality remains

NOTE Confidence: 0.9983118

00:05:44.654 --> 00:05:45.154 high.

NOTE Confidence: 0.99689525

00:05:45.750 --> 00:05:47.430 Survivors will have prolonged hospital

NOTE Confidence: 0.99689525

00:05:47.430 --> 00:05:50.010 stays, multiple complications, and lifelong

NOTE Confidence: 0.99689525

00:05:50.070 --> 00:05:51.050 complex care.

NOTE Confidence: 0.9994837

00:05:53.270 --> 00:05:55.190 This slide highlights perspectives of

NOTE Confidence: 0.9994837

00:05:55.190 --> 00:05:56.550 twenty seven parents on the

NOTE Confidence: 0.9994837

00:05:56.550 --> 00:05:58.070 impact of caring for children

NOTE Confidence: 0.9994837

00:05:58.070 --> 00:05:59.610 with chronic kidney disease.

NOTE Confidence: 0.9905704

00:06:00.185 --> 00:06:01.865 Themes identified in the study

NOTE Confidence: 0.9905704

00:06:01.865 --> 00:06:03.305 included loss of freedom and

NOTE Confidence: 0.9905704

00:06:03.305 --> 00:06:05.085 control, really having to prioritize

NOTE Confidence: 0.9905704

00:06:05.225 --> 00:06:06.685 the care of their child,

NOTE Confidence: 0.99432796

00:06:06.985 --> 00:06:08.525 the burden of sole responsibility
NOTE Confidence: 0.99432796

00:06:08.745 --> 00:06:10.345 with the inability to rely
NOTE Confidence: 0.99432796

00:06:10.345 --> 00:06:11.085 on others,
NOTE Confidence: 0.9878006

00:06:11.625 --> 00:06:13.600 adapting for survival, having to
NOTE Confidence: 0.9878006

00:06:13.600 --> 00:06:15.040 rechannel resources to meet the
NOTE Confidence: 0.9878006

00:06:15.040 --> 00:06:16.660 basic needs of the family,
NOTE Confidence: 0.99937785

00:06:17.360 --> 00:06:17.860 instability
NOTE Confidence: 0.99925566

00:06:18.320 --> 00:06:19.060 of circumstances,
NOTE Confidence: 0.9991943

00:06:19.440 --> 00:06:21.940 depleted capacity to work, unpredictability
NOTE Confidence: 0.96954495

00:06:22.320 --> 00:06:24.000 of the child's health, burden
NOTE Confidence: 0.96954495

00:06:24.000 --> 00:06:26.100 of travel related costs, imposition
NOTE Confidence: 0.96954495

00:06:26.160 --> 00:06:28.105 of debt, and domestic upheaval,
NOTE Confidence: 0.97898346

00:06:28.645 --> 00:06:30.325 and struggle in really seeking
NOTE Confidence: 0.97898346

00:06:30.325 --> 00:06:30.825 support
NOTE Confidence: 0.95038956

00:06:31.205 --> 00:06:32.325 falling through the cracks with
NOTE Confidence: 0.95038956

00:06:32.325 --> 00:06:34.505 unmet medical and informational needs.

NOTE Confidence: 0.98260856

00:06:35.045 --> 00:06:37.305 When making prenatal decisions about

NOTE Confidence: 0.98260856

00:06:37.365 --> 00:06:39.225 interventions, families try to begin

NOTE Confidence: 0.98260856

00:06:39.285 --> 00:06:40.725 if that baby survives, what

NOTE Confidence: 0.98260856

00:06:40.725 --> 00:06:42.165 survival means for that child

NOTE Confidence: 0.98260856

00:06:42.165 --> 00:06:43.065 and that family.

NOTE Confidence: 0.9799414

00:06:44.990 --> 00:06:46.270 Taking a step back, each

NOTE Confidence: 0.9799414

00:06:46.270 --> 00:06:47.470 year in the United States,

NOTE Confidence: 0.9799414

00:06:47.470 --> 00:06:49.310 over a hundred thousand individuals

NOTE Confidence: 0.9799414

00:06:49.310 --> 00:06:50.750 have a pregnancy complicated by

NOTE Confidence: 0.9799414

00:06:50.750 --> 00:06:52.290 a fetus with severe abnormalities,

NOTE Confidence: 0.9971273

00:06:52.670 --> 00:06:53.870 and greater than five hundred

NOTE Confidence: 0.9971273

00:06:53.870 --> 00:06:55.410 thousand neonates are born prematurely

NOTE Confidence: 0.9971273

00:06:55.470 --> 00:06:57.089 or with severe congenital malformations.

NOTE Confidence: 0.9958146

00:06:58.365 --> 00:06:59.805 Twenty to forty percent of

NOTE Confidence: 0.9958146

00:06:59.805 --> 00:07:00.625 pregnant individuals

NOTE Confidence: 0.9572482

00:07:01.085 --> 00:07:02.145 continue a pregnancy
NOTE Confidence: 0.9965269

00:07:02.525 --> 00:07:03.725 with a life limiting or
NOTE Confidence: 0.9965269

00:07:03.725 --> 00:07:05.105 complex fetal diagnosis.
NOTE Confidence: 0.99234015

00:07:05.805 --> 00:07:07.665 With any complex fetal diagnosis,
NOTE Confidence: 0.99234015

00:07:07.725 --> 00:07:09.565 including fetal kidney failure, it
NOTE Confidence: 0.99234015

00:07:09.565 --> 00:07:11.345 truly is a care journey.
NOTE Confidence: 0.98815405

00:07:12.120 --> 00:07:13.880 Multiple points along this journey
NOTE Confidence: 0.98815405

00:07:13.880 --> 00:07:16.140 involve decisions about care options.
NOTE Confidence: 0.99883294

00:07:16.840 --> 00:07:18.600 Immediately after diagnosis during the
NOTE Confidence: 0.99883294

00:07:18.600 --> 00:07:20.360 pregnancy, appropriate care options may
NOTE Confidence: 0.99883294

00:07:20.360 --> 00:07:21.260 include abortion,
NOTE Confidence: 0.9997565

00:07:21.640 --> 00:07:22.540 fetal interventions,
NOTE Confidence: 0.9795233

00:07:23.080 --> 00:07:25.104 hospice and palliative care, and
NOTE Confidence: 0.9795233

00:07:25.104 --> 00:07:26.544 neonatal interventions with a goal
NOTE Confidence: 0.9795233

00:07:26.544 --> 00:07:27.585 of a survivor who will
NOTE Confidence: 0.9795233

00:07:27.585 --> 00:07:29.205 require complex chronic care.

NOTE Confidence: 0.95486116
00:07:31.264 --> 00:07:32.625 When thinking about the treatment
NOTE Confidence: 0.95486116
00:07:32.625 --> 00:07:34.465 options, outcomes, and care at
NOTE Confidence: 0.95486116
00:07:34.465 --> 00:07:35.585 each phase in the journey,
NOTE Confidence: 0.95486116
00:07:35.585 --> 00:07:36.720 it's really important to flex
NOTE Confidence: 0.95486116
00:07:36.800 --> 00:07:38.000 down the implications for the
NOTE Confidence: 0.95486116
00:07:38.000 --> 00:07:40.320 fetus, neonate, pregnant individual, family,
NOTE Confidence: 0.95486116
00:07:40.320 --> 00:07:41.140 and society.
NOTE Confidence: 0.99936056
00:07:42.960 --> 00:07:44.340 With fetal interventions,
NOTE Confidence: 0.999155
00:07:44.640 --> 00:07:46.400 the neonate will may have
NOTE Confidence: 0.999155
00:07:46.400 --> 00:07:47.380 reduced mortality.
NOTE Confidence: 0.9736429
00:07:47.920 --> 00:07:48.880 This, though, can be at
NOTE Confidence: 0.9736429
00:07:48.880 --> 00:07:50.800 the expense of prematurity where
NOTE Confidence: 0.9736429
00:07:50.800 --> 00:07:52.020 there's additional morbidities
NOTE Confidence: 0.9989131
00:07:52.474 --> 00:07:53.835 and limits to the interventions
NOTE Confidence: 0.9989131
00:07:53.835 --> 00:07:55.275 that can be offered. In
NOTE Confidence: 0.9989131

00:07:55.275 --> 00:07:56.634 other words, we may create
NOTE Confidence: 0.9989131

00:07:56.634 --> 00:07:58.395 a pulmonary survivor who will
NOTE Confidence: 0.9989131

00:07:58.395 --> 00:07:59.435 die of kidney failure if
NOTE Confidence: 0.9989131

00:07:59.435 --> 00:08:00.315 they are too small for
NOTE Confidence: 0.9989131

00:08:00.315 --> 00:08:00.815 dialysis.
NOTE Confidence: 0.99903846

00:08:01.675 --> 00:08:03.275 To survive, the neonate will
NOTE Confidence: 0.99903846

00:08:03.275 --> 00:08:04.655 require multiple hospitalizations,
NOTE Confidence: 0.9992344

00:08:05.514 --> 00:08:06.895 require multiple surgeries,
NOTE Confidence: 0.9923421

00:08:07.210 --> 00:08:08.970 organ transplant, and experience life
NOTE Confidence: 0.9923421

00:08:08.970 --> 00:08:10.669 with a complex chronic illness.
NOTE Confidence: 0.9613945

00:08:11.289 --> 00:08:12.169 At times, they will be
NOTE Confidence: 0.9613945

00:08:12.169 --> 00:08:13.690 in pain and treatments may
NOTE Confidence: 0.9613945

00:08:13.690 --> 00:08:14.190 fail.
NOTE Confidence: 0.9996411

00:08:14.889 --> 00:08:16.669 The relative risks and benefits
NOTE Confidence: 0.99635273

00:08:17.050 --> 00:08:18.830 are really uncertain as morbidity,
NOTE Confidence: 0.99635273

00:08:19.129 --> 00:08:19.629 infection,

NOTE Confidence: 0.9802946

00:08:20.185 --> 00:08:22.425 wound healing, feeding intolerance, failure

NOTE Confidence: 0.9802946

00:08:22.425 --> 00:08:24.824 of treatments, stroke related to

NOTE Confidence: 0.9802946

00:08:24.824 --> 00:08:26.505 neonatal dialysis, and the multiple

NOTE Confidence: 0.9802946

00:08:26.505 --> 00:08:28.685 interventions necessary remains high.

NOTE Confidence: 0.96715003

00:08:29.465 --> 00:08:31.625 Limited studies suggest that they

NOTE Confidence: 0.96715003

00:08:31.625 --> 00:08:33.005 may have some degree

NOTE Confidence: 0.9989537

00:08:33.385 --> 00:08:35.085 of impaired quality of life.

NOTE Confidence: 0.9929002

00:08:35.510 --> 00:08:36.550 On the other hand, with

NOTE Confidence: 0.9929002

00:08:36.550 --> 00:08:38.070 abortion or comfort measures, there

NOTE Confidence: 0.9929002

00:08:38.070 --> 00:08:39.510 is no expected chance of

NOTE Confidence: 0.9929002

00:08:39.510 --> 00:08:41.110 survival. This, though, may mean

NOTE Confidence: 0.9929002

00:08:41.110 --> 00:08:42.309 they're not going to experience

NOTE Confidence: 0.9929002

00:08:42.309 --> 00:08:44.070 suffering or an unacceptable quality

NOTE Confidence: 0.9929002

00:08:44.070 --> 00:08:44.649 of life.

NOTE Confidence: 0.99819684

00:08:46.550 --> 00:08:48.550 With fetal interventions, the pregnant

NOTE Confidence: 0.99819684

00:08:48.550 --> 00:08:50.325 individual will expose themselves to
NOTE Confidence: 0.99819684

00:08:50.325 --> 00:08:52.005 invasive procedures with no medical
NOTE Confidence: 0.99819684

00:08:52.005 --> 00:08:52.985 benefit to themselves,
NOTE Confidence: 0.996782

00:08:53.445 --> 00:08:55.205 will have lost reproductive potential
NOTE Confidence: 0.996782

00:08:55.205 --> 00:08:56.165 for a fetus that may
NOTE Confidence: 0.996782

00:08:56.165 --> 00:08:57.225 or may not survive,
NOTE Confidence: 0.99924916

00:08:58.005 --> 00:08:59.605 and the interventions could lead
NOTE Confidence: 0.99924916

00:08:59.605 --> 00:09:00.265 to complications.
NOTE Confidence: 0.94019544

00:09:01.365 --> 00:09:02.885 The entire family must be
NOTE Confidence: 0.94019544

00:09:02.885 --> 00:09:04.565 considered as a pregnant individual
NOTE Confidence: 0.94019544

00:09:04.565 --> 00:09:06.020 and neonate will be hospitalized
NOTE Confidence: 0.94019544

00:09:06.020 --> 00:09:07.559 for prolonged periods of time.
NOTE Confidence: 0.9947556

00:09:08.179 --> 00:09:08.679 Afterwards,
NOTE Confidence: 0.9870557

00:09:09.140 --> 00:09:10.740 parents often become full time
NOTE Confidence: 0.9870557

00:09:10.740 --> 00:09:13.300 caregivers. There's increased expenses, and
NOTE Confidence: 0.9870557

00:09:13.300 --> 00:09:14.420 the families may need to

NOTE Confidence: 0.9870557
00:09:14.420 --> 00:09:14.920 relocate.
NOTE Confidence: 0.9811525
00:09:15.860 --> 00:09:17.380 Parents may rule view their
NOTE Confidence: 0.9811525
00:09:17.380 --> 00:09:18.855 roles as parents and spouses
NOTE Confidence: 0.9811525
00:09:18.915 --> 00:09:19.415 differently,
NOTE Confidence: 0.9297259
00:09:19.795 --> 00:09:21.475 and children and siblings will
NOTE Confidence: 0.9297259
00:09:21.475 --> 00:09:23.095 have altered childhood experiences.
NOTE Confidence: 0.9783979
00:09:24.355 --> 00:09:25.795 Some studies show the positive
NOTE Confidence: 0.9783979
00:09:25.795 --> 00:09:27.795 impact, such as redefining values
NOTE Confidence: 0.9783979
00:09:27.795 --> 00:09:29.175 and learning about compassion,
NOTE Confidence: 0.9608263
00:09:29.555 --> 00:09:31.075 while others show a negative
NOTE Confidence: 0.9608263
00:09:31.075 --> 00:09:32.675 impact such as siblings feeling
NOTE Confidence: 0.9608263
00:09:32.675 --> 00:09:33.175 neglected.
NOTE Confidence: 0.989435
00:09:34.490 --> 00:09:36.010 Parents, while thankful for their
NOTE Confidence: 0.989435
00:09:36.010 --> 00:09:37.450 child, may feel guilt when
NOTE Confidence: 0.989435
00:09:37.450 --> 00:09:38.650 their child is in pain
NOTE Confidence: 0.989435

00:09:38.650 --> 00:09:39.850 or has a complication and
NOTE Confidence: 0.989435

00:09:39.850 --> 00:09:41.470 that they cannot focus equally
NOTE Confidence: 0.989435

00:09:41.530 --> 00:09:42.750 on family members.
NOTE Confidence: 0.99921644

00:09:43.290 --> 00:09:44.830 There can be strained relationships
NOTE Confidence: 0.99921644

00:09:45.050 --> 00:09:46.890 with varying opinions on quality
NOTE Confidence: 0.99921644

00:09:46.890 --> 00:09:47.929 of life or the best
NOTE Confidence: 0.99921644

00:09:47.929 --> 00:09:49.309 care path for that child.
NOTE Confidence: 0.9673115

00:09:50.304 --> 00:09:51.824 Without interventions, though, the family
NOTE Confidence: 0.9673115

00:09:51.824 --> 00:09:52.945 will be left with incorporating
NOTE Confidence: 0.9673115

00:09:52.945 --> 00:09:54.225 the memory of as opposed
NOTE Confidence: 0.9673115

00:09:54.225 --> 00:09:55.584 to the physical child into
NOTE Confidence: 0.9673115

00:09:55.584 --> 00:09:57.264 their family unit. They may
NOTE Confidence: 0.9673115

00:09:57.264 --> 00:09:59.125 feel comfort in having control,
NOTE Confidence: 0.99461544

00:09:59.505 --> 00:10:00.945 peace in protecting their child
NOTE Confidence: 0.99461544

00:10:00.945 --> 00:10:01.684 from suffering,
NOTE Confidence: 0.9718058

00:10:02.144 --> 00:10:04.545 pressure to attempt interventions with

NOTE Confidence: 0.9718058
00:10:04.545 --> 00:10:05.720 uncertain benefits at a a
NOTE Confidence: 0.9718058
00:10:05.720 --> 00:10:07.240 high cost to the family
NOTE Confidence: 0.9718058
00:10:07.240 --> 00:10:08.840 or guilt for not exhausting
NOTE Confidence: 0.9718058
00:10:08.840 --> 00:10:10.280 all options to try and
NOTE Confidence: 0.9718058
00:10:10.280 --> 00:10:11.559 save their baby despite those
NOTE Confidence: 0.9718058
00:10:11.559 --> 00:10:12.380 global costs.
NOTE Confidence: 0.98911476
00:10:14.520 --> 00:10:16.140 There are also societal implications
NOTE Confidence: 0.98911476
00:10:16.360 --> 00:10:17.020 to consider.
NOTE Confidence: 0.9974128
00:10:17.480 --> 00:10:18.300 While variable,
NOTE Confidence: 0.9999435
00:10:18.920 --> 00:10:19.420 pediatric
NOTE Confidence: 0.9939751
00:10:19.800 --> 00:10:22.175 outpatient dialysis and home care
NOTE Confidence: 0.9939751
00:10:22.175 --> 00:10:23.455 can cost upwards of two
NOTE Confidence: 0.9939751
00:10:23.455 --> 00:10:24.735 hundred thousand dollars a year
NOTE Confidence: 0.9939751
00:10:24.735 --> 00:10:26.495 once home, three hundred thousand
NOTE Confidence: 0.9939751
00:10:26.495 --> 00:10:27.375 dollars for the year of
NOTE Confidence: 0.9939751

00:10:27.375 --> 00:10:29.054 kidney transplant, and seventy five
NOTE Confidence: 0.9939751

00:10:29.054 --> 00:10:30.095 thousand dollars a year for
NOTE Confidence: 0.9939751

00:10:30.095 --> 00:10:30.595 follow-up.
NOTE Confidence: 0.98238254

00:10:31.214 --> 00:10:32.334 That does not include the
NOTE Confidence: 0.98238254

00:10:32.334 --> 00:10:34.575 fetal or neonatal interventions, lost
NOTE Confidence: 0.98238254

00:10:34.575 --> 00:10:37.075 parental wages, or ancillary costs.
NOTE Confidence: 0.9836808

00:10:37.670 --> 00:10:39.750 The global economic costs are
NOTE Confidence: 0.9836808

00:10:39.750 --> 00:10:41.030 high and shared by the
NOTE Confidence: 0.9836808

00:10:41.030 --> 00:10:43.210 family, institution, and society.
NOTE Confidence: 0.9978382

00:10:44.550 --> 00:10:45.910 In addition, in times of
NOTE Confidence: 0.9978382

00:10:45.910 --> 00:10:46.410 unprecedented
NOTE Confidence: 0.9808926

00:10:46.790 --> 00:10:48.650 shortages of medical resources,
NOTE Confidence: 0.99771905

00:10:49.190 --> 00:10:49.690 space,
NOTE Confidence: 0.98251003

00:10:50.125 --> 00:10:52.144 medications, organs, subspecialists,
NOTE Confidence: 0.9677791

00:10:52.684 --> 00:10:55.324 health, home health, staff. These
NOTE Confidence: 0.9677791

00:10:55.324 --> 00:10:56.925 interventions may burden an already

NOTE Confidence: 0.9677791

00:10:56.925 --> 00:10:58.225 strained medical system.

NOTE Confidence: 0.994283

00:10:59.485 --> 00:11:01.005 At times, the individual but

NOTE Confidence: 0.994283

00:11:01.005 --> 00:11:01.804 at the same time, the

NOTE Confidence: 0.994283

00:11:01.804 --> 00:11:03.884 hospitals and the individual providers

NOTE Confidence: 0.994283

00:11:03.884 --> 00:11:05.505 may gain notoriety from innovation.

NOTE Confidence: 0.9990886

00:11:06.190 --> 00:11:08.350 Without interventions, the medical community

NOTE Confidence: 0.9990886

00:11:08.350 --> 00:11:09.870 will really lose opportunities to

NOTE Confidence: 0.9990886

00:11:09.870 --> 00:11:11.709 change disease trajectories and gain

NOTE Confidence: 0.9990886

00:11:11.709 --> 00:11:13.570 experience with innovative therapies.

NOTE Confidence: 0.9960862

00:11:14.510 --> 00:11:16.190 With either path, providers can

NOTE Confidence: 0.9960862

00:11:16.190 --> 00:11:17.550 have moral distress if they

NOTE Confidence: 0.9960862

00:11:17.550 --> 00:11:18.510 feel they're being asked to

NOTE Confidence: 0.9960862

00:11:18.510 --> 00:11:20.155 provide care that they feel

NOTE Confidence: 0.9960862

00:11:20.155 --> 00:11:21.355 is causing more harm than

NOTE Confidence: 0.9960862

00:11:21.355 --> 00:11:22.315 good for that child or

NOTE Confidence: 0.9960862

00:11:22.315 --> 00:11:22.815 family.
NOTE Confidence: 0.99886745

00:11:25.195 --> 00:11:26.315 Now that we've considered the
NOTE Confidence: 0.99886745

00:11:26.315 --> 00:11:27.135 various implications
NOTE Confidence: 0.9129384

00:11:28.155 --> 00:11:29.855 for the options in general,
NOTE Confidence: 0.9129384

00:11:30.075 --> 00:11:32.235 ethical criteria for fetal interventions
NOTE Confidence: 0.9129384

00:11:32.235 --> 00:11:33.649 include that that the intervention
NOTE Confidence: 0.9129384

00:11:33.649 --> 00:11:34.690 should be expected to be
NOTE Confidence: 0.9129384

00:11:34.690 --> 00:11:35.190 lifesaving
NOTE Confidence: 0.9826046

00:11:35.569 --> 00:11:37.110 or prevent serious disease.
NOTE Confidence: 0.99407756

00:11:37.490 --> 00:11:38.529 They should be carried out
NOTE Confidence: 0.99407756

00:11:38.529 --> 00:11:39.670 in a way that minimizes
NOTE Confidence: 0.99407756

00:11:39.730 --> 00:11:40.850 risk of fetal death or
NOTE Confidence: 0.99407756

00:11:40.850 --> 00:11:41.350 morbidity,
NOTE Confidence: 0.9673275

00:11:41.809 --> 00:11:42.610 and the risk to the
NOTE Confidence: 0.9673275

00:11:42.610 --> 00:11:44.790 present individual should be low.
NOTE Confidence: 0.95923513

00:11:45.545 --> 00:11:47.245 With novel fetal and neonatal

NOTE Confidence: 0.95923513

00:11:47.304 --> 00:11:49.384 interventions, the lines between research,

NOTE Confidence: 0.95923513

00:11:49.384 --> 00:11:51.304 innovation, and ultimately routine care

NOTE Confidence: 0.95923513

00:11:51.304 --> 00:11:52.524 are not always distinct.

NOTE Confidence: 0.9987074

00:11:53.304 --> 00:11:54.985 Fetal kidney failure is a

NOTE Confidence: 0.9987074

00:11:54.985 --> 00:11:56.345 rare condition that no center

NOTE Confidence: 0.9987074

00:11:56.345 --> 00:11:57.804 sees in large volumes.

NOTE Confidence: 0.999704

00:11:58.690 --> 00:12:00.870 Invasive interventions are not routine

NOTE Confidence: 0.95770836

00:12:01.730 --> 00:12:02.850 care and the standard of

NOTE Confidence: 0.95770836

00:12:02.850 --> 00:12:03.809 care. So the role of

NOTE Confidence: 0.95770836

00:12:03.809 --> 00:12:05.490 serial amnion fusions in terms

NOTE Confidence: 0.95770836

00:12:05.490 --> 00:12:07.329 of long term survival remains

NOTE Confidence: 0.95770836

00:12:07.329 --> 00:12:08.470 at best unclear.

NOTE Confidence: 0.9985845

00:12:09.170 --> 00:12:10.529 More importantly, it does not

NOTE Confidence: 0.9985845

00:12:10.529 --> 00:12:11.029 preclude

NOTE Confidence: 0.9478992

00:12:11.365 --> 00:12:12.885 the need for kidney replacement

NOTE Confidence: 0.9478992

00:12:12.885 --> 00:12:15.065 therapy and ultimately kidney transplant.

NOTE Confidence: 0.99495745

00:12:15.925 --> 00:12:17.285 Most centers do not offer

NOTE Confidence: 0.99495745

00:12:17.285 --> 00:12:17.785 interventions.

NOTE Confidence: 0.9882314

00:12:18.565 --> 00:12:20.965 Some offer interventions routinely, some

NOTE Confidence: 0.9882314

00:12:20.965 --> 00:12:22.485 only when savvy families request

NOTE Confidence: 0.9882314

00:12:22.485 --> 00:12:23.765 it, and some as parts

NOTE Confidence: 0.9882314

00:12:23.765 --> 00:12:24.985 of research protocols.

NOTE Confidence: 0.98995095

00:12:26.059 --> 00:12:27.740 This can lead to variable

NOTE Confidence: 0.98995095

00:12:27.740 --> 00:12:29.740 oversight from ethics committees and

NOTE Confidence: 0.98995095

00:12:29.740 --> 00:12:31.820 IRBs and asymmetric collection and

NOTE Confidence: 0.98995095

00:12:31.820 --> 00:12:33.600 publications of outcomes data.

NOTE Confidence: 0.98516446

00:12:34.459 --> 00:12:35.899 Some families are willing to

NOTE Confidence: 0.98516446

00:12:35.899 --> 00:12:37.020 take on this risk and

NOTE Confidence: 0.98516446

00:12:37.020 --> 00:12:38.300 are accepting of those blurred

NOTE Confidence: 0.98516446

00:12:38.300 --> 00:12:39.839 lines between research innovation

NOTE Confidence: 0.98056656

00:12:40.524 --> 00:12:41.565 and routine care, though, because

NOTE Confidence: 0.98056656

00:12:41.565 --> 00:12:43.105 the alternative is death.

NOTE Confidence: 0.9656596

00:12:45.725 --> 00:12:47.565 Specific to fetal interventions, is

NOTE Confidence: 0.9656596

00:12:47.565 --> 00:12:49.105 the patient the pregnant individual,

NOTE Confidence: 0.9656596

00:12:49.325 --> 00:12:50.865 the fetus, or both?

NOTE Confidence: 0.99846214

00:12:51.485 --> 00:12:52.925 Who takes priority when there's

NOTE Confidence: 0.99846214

00:12:52.925 --> 00:12:53.904 competing interests?

NOTE Confidence: 0.98387086

00:12:54.365 --> 00:12:55.904 While the interests of each

NOTE Confidence: 0.98387086

00:12:56.030 --> 00:12:57.550 are interdependent, they may not

NOTE Confidence: 0.98387086

00:12:57.550 --> 00:12:58.690 always be aligned.

NOTE Confidence: 0.9949613

00:12:59.470 --> 00:13:00.750 Historically, there has been one

NOTE Confidence: 0.9949613

00:13:00.750 --> 00:13:02.690 patient, the pregnant patient.

NOTE Confidence: 0.9670094

00:13:03.390 --> 00:13:04.929 Recently, though, when individuals

NOTE Confidence: 0.9918861

00:13:05.390 --> 00:13:07.230 seek invasive fetal therapies, some

NOTE Confidence: 0.9918861

00:13:07.230 --> 00:13:08.590 have moved beyond the absolute

NOTE Confidence: 0.9918861

00:13:08.590 --> 00:13:10.050 risk to the pregnant individual

NOTE Confidence: 0.9993421

00:13:10.385 --> 00:13:11.825 to consider the overall risk
NOTE Confidence: 0.9993421

00:13:11.825 --> 00:13:12.804 benefit analysis.
NOTE Confidence: 0.9738273

00:13:13.665 --> 00:13:15.184 Each component of the dyad
NOTE Confidence: 0.9738273

00:13:15.184 --> 00:13:16.804 has different risks and benefits
NOTE Confidence: 0.9738273

00:13:16.865 --> 00:13:18.145 to consider not only in
NOTE Confidence: 0.9738273

00:13:18.145 --> 00:13:19.665 isolation, but also for the
NOTE Confidence: 0.9738273

00:13:19.665 --> 00:13:20.804 family and society.
NOTE Confidence: 0.9924882

00:13:21.505 --> 00:13:23.524 Beneficence, autonomy, and nonmaleficence
NOTE Confidence: 0.9864154

00:13:24.330 --> 00:13:25.290 are determined on a case
NOTE Confidence: 0.9864154

00:13:25.290 --> 00:13:26.410 by case basis from the
NOTE Confidence: 0.9864154

00:13:26.410 --> 00:13:28.170 collective information available and that
NOTE Confidence: 0.9864154

00:13:28.170 --> 00:13:29.870 overall risk benefit ratio.
NOTE Confidence: 0.99023557

00:13:33.130 --> 00:13:34.250 After birth, when we think
NOTE Confidence: 0.99023557

00:13:34.250 --> 00:13:35.850 about critical decision making for
NOTE Confidence: 0.99023557

00:13:35.850 --> 00:13:37.690 the neonate, the IPO framework
NOTE Confidence: 0.99023557

00:13:37.690 --> 00:13:39.290 best described by Mark can

NOTE Confidence: 0.99023557
00:13:39.290 --> 00:13:39.975 be utilized.
NOTE Confidence: 0.97546697
00:13:40.535 --> 00:13:42.134 Based on the anticipated harm
NOTE Confidence: 0.97546697
00:13:42.134 --> 00:13:43.654 and benefit, a treatment can
NOTE Confidence: 0.97546697
00:13:43.654 --> 00:13:45.355 be classified as ethically impermissible,
NOTE Confidence: 0.97546697
00:13:45.574 --> 00:13:46.954 permissible, or obligatory.
NOTE Confidence: 0.9916761
00:13:48.214 --> 00:13:49.654 The challenging part for providers,
NOTE Confidence: 0.9916761
00:13:49.654 --> 00:13:50.615 though, is deciding where a
NOTE Confidence: 0.9916761
00:13:50.615 --> 00:13:51.975 treatment should be located on
NOTE Confidence: 0.9916761
00:13:51.975 --> 00:13:52.714 that spectrum.
NOTE Confidence: 0.9936071
00:13:53.280 --> 00:13:54.480 This is determined by the
NOTE Confidence: 0.9936071
00:13:54.480 --> 00:13:56.340 prognosis with and without treatment,
NOTE Confidence: 0.9936071
00:13:56.560 --> 00:13:58.400 the feasibility of providing the
NOTE Confidence: 0.9936071
00:13:58.400 --> 00:14:00.240 treatment, and the consideration of
NOTE Confidence: 0.9936071
00:14:00.240 --> 00:14:01.780 all relevant rights and obligations.
NOTE Confidence: 0.99757534
00:14:03.040 --> 00:14:04.880 Given the potential for neonatal
NOTE Confidence: 0.99757534

00:14:04.880 --> 00:14:06.580 dialysis to increase survival,
NOTE Confidence: 0.9956516

00:14:07.045 --> 00:14:08.725 if survival is the desired
NOTE Confidence: 0.9956516

00:14:08.725 --> 00:14:10.985 outcome, it is ethically permissible.
NOTE Confidence: 0.98730105

00:14:11.925 --> 00:14:13.684 Ethically permissible treatment should be
NOTE Confidence: 0.98730105

00:14:13.684 --> 00:14:15.285 explained so that parents can
NOTE Confidence: 0.98730105

00:14:15.285 --> 00:14:16.425 choose from the options.
NOTE Confidence: 0.974485

00:14:17.125 --> 00:14:18.585 Within that zone, a treatment
NOTE Confidence: 0.974485

00:14:18.804 --> 00:14:20.745 may be inadvisable or advisable,
NOTE Confidence: 0.974485

00:14:20.965 --> 00:14:22.165 but parents can accept or
NOTE Confidence: 0.974485

00:14:22.165 --> 00:14:23.440 forego that recommendation.
NOTE Confidence: 0.99603534

00:14:24.540 --> 00:14:25.820 Some, for example, may feel
NOTE Confidence: 0.99603534

00:14:25.820 --> 00:14:27.420 outcomes related to dialysis are
NOTE Confidence: 0.99603534

00:14:27.420 --> 00:14:28.079 good enough,
NOTE Confidence: 0.9339054

00:14:28.380 --> 00:14:29.980 especially if the alternative is
NOTE Confidence: 0.9339054

00:14:29.980 --> 00:14:32.079 death to strongly recommend it.
NOTE Confidence: 0.9742536

00:14:32.540 --> 00:14:33.899 At the same time, the

NOTE Confidence: 0.9742536

00:14:33.899 --> 00:14:35.339 burdens of therapy or chance

NOTE Confidence: 0.9742536

00:14:35.339 --> 00:14:36.675 of a poor outcome are

NOTE Confidence: 0.9742536

00:14:36.675 --> 00:14:37.795 high enough that treatments are

NOTE Confidence: 0.9742536

00:14:37.795 --> 00:14:39.154 not obligatory of the standard

NOTE Confidence: 0.9742536

00:14:39.154 --> 00:14:40.435 of care, and some providers

NOTE Confidence: 0.9742536

00:14:40.435 --> 00:14:41.654 recommend against it.

NOTE Confidence: 0.97577226

00:14:42.195 --> 00:14:43.635 Families should not feel obligated

NOTE Confidence: 0.97577226

00:14:43.635 --> 00:14:45.415 to pursue or forego recommendations.

NOTE Confidence: 0.9927324

00:14:48.115 --> 00:14:49.815 When fetal or neonatal interventions

NOTE Confidence: 0.9927324

00:14:50.035 --> 00:14:51.410 are offered, there are many

NOTE Confidence: 0.9927324

00:14:51.410 --> 00:14:53.089 factors that drive decision makings

NOTE Confidence: 0.9927324

00:14:53.089 --> 00:14:54.710 for families and providers.

NOTE Confidence: 0.9943338

00:14:55.250 --> 00:14:56.690 Each pose their own ethical

NOTE Confidence: 0.9943338

00:14:56.690 --> 00:14:58.210 challenges. There are those blurred

NOTE Confidence: 0.9943338

00:14:58.210 --> 00:14:59.730 lines between the pregnant individual

NOTE Confidence: 0.9943338

00:14:59.730 --> 00:15:01.570 fetal and neonatal decision making
NOTE Confidence: 0.9943338

00:15:01.570 --> 00:15:03.190 with often competing interests.
NOTE Confidence: 0.98678035

00:15:03.954 --> 00:15:05.954 After delivery, we as providers
NOTE Confidence: 0.98678035

00:15:05.954 --> 00:15:07.075 must balance the goals of
NOTE Confidence: 0.98678035

00:15:07.075 --> 00:15:08.035 the parents with the best
NOTE Confidence: 0.98678035

00:15:08.035 --> 00:15:09.575 interest of the neonate.
NOTE Confidence: 0.99928224

00:15:09.954 --> 00:15:10.834 We also have to think
NOTE Confidence: 0.99928224

00:15:10.834 --> 00:15:12.055 about resource allocations,
NOTE Confidence: 0.99505305

00:15:12.435 --> 00:15:14.035 access to interventions, and the
NOTE Confidence: 0.99505305

00:15:14.035 --> 00:15:16.514 support necessary for lifelong complex
NOTE Confidence: 0.99505305

00:15:16.514 --> 00:15:16.980 care.
NOTE Confidence: 0.9919546

00:15:17.620 --> 00:15:18.760 This is in the context
NOTE Confidence: 0.9919546

00:15:18.820 --> 00:15:20.660 of variable views about the
NOTE Confidence: 0.9919546

00:15:20.660 --> 00:15:22.100 treatment paths and data on
NOTE Confidence: 0.9919546

00:15:22.100 --> 00:15:22.600 survival,
NOTE Confidence: 0.9981445

00:15:23.060 --> 00:15:25.160 morbidity, and quality of life.

NOTE Confidence: 0.989057
00:15:25.860 --> 00:15:27.139 The downstream effects of the
NOTE Confidence: 0.989057
00:15:27.139 --> 00:15:29.060 decision to pursue abortion, comfort
NOTE Confidence: 0.989057
00:15:29.060 --> 00:15:31.399 measures, or interventions really transcends
NOTE Confidence: 0.989057
00:15:31.699 --> 00:15:32.600 beyond the pregnancy
NOTE Confidence: 0.97870535
00:15:33.285 --> 00:15:34.964 dyad to the fetus, neonate,
NOTE Confidence: 0.97870535
00:15:34.964 --> 00:15:36.885 pregnant individual, family, and society
NOTE Confidence: 0.97870535
00:15:36.885 --> 00:15:37.705 as a whole.
NOTE Confidence: 0.99968976
00:15:39.285 --> 00:15:40.665 We also have to consider
NOTE Confidence: 0.9981967
00:15:41.045 --> 00:15:42.505 if all pregnant individuals,
NOTE Confidence: 0.9586249
00:15:42.885 --> 00:15:44.645 neonates, and children have access
NOTE Confidence: 0.9586249
00:15:44.645 --> 00:15:46.745 to comparable and equal treatment
NOTE Confidence: 0.9586249
00:15:46.964 --> 00:15:48.024 if there's justice.
NOTE Confidence: 0.9704244
00:15:49.180 --> 00:15:51.260 Ideally, families or individuals and
NOTE Confidence: 0.9704244
00:15:51.260 --> 00:15:52.620 providers use the shared decision
NOTE Confidence: 0.9704244
00:15:52.620 --> 00:15:53.980 making approach to really help
NOTE Confidence: 0.9704244

00:15:53.980 --> 00:15:55.900 determine the most appropriate treatment
NOTE Confidence: 0.9704244

00:15:55.900 --> 00:15:58.000 path. There are times, though,
NOTE Confidence: 0.9704244

00:15:58.140 --> 00:15:59.660 when external factors such as
NOTE Confidence: 0.9704244

00:15:59.660 --> 00:16:02.060 regional resources, institutional policies, and
NOTE Confidence: 0.9704244

00:16:02.060 --> 00:16:02.560 legislation
NOTE Confidence: 0.97728014

00:16:03.180 --> 00:16:04.815 may limit the options available
NOTE Confidence: 0.97728014

00:16:04.815 --> 00:16:06.334 for individuals or families so
NOTE Confidence: 0.97728014

00:16:06.334 --> 00:16:07.535 that they aren't no longer
NOTE Confidence: 0.97728014

00:16:07.535 --> 00:16:08.654 feasible or for all intents
NOTE Confidence: 0.97728014

00:16:08.654 --> 00:16:10.274 and purposes aren't really options.
NOTE Confidence: 0.99080354

00:16:12.255 --> 00:16:14.035 One external factor is geographic
NOTE Confidence: 0.99080354

00:16:14.175 --> 00:16:16.175 location. It's important for providers
NOTE Confidence: 0.99080354

00:16:16.175 --> 00:16:17.214 to know where the various
NOTE Confidence: 0.99080354

00:16:17.214 --> 00:16:18.709 types of care and interventions
NOTE Confidence: 0.99080354

00:16:18.769 --> 00:16:20.290 available are located in relation
NOTE Confidence: 0.99080354

00:16:20.290 --> 00:16:21.730 to where an individual lives

NOTE Confidence: 0.99080354

00:16:21.730 --> 00:16:22.930 as that may impact whether

NOTE Confidence: 0.99080354

00:16:22.930 --> 00:16:23.810 certain types of care are

NOTE Confidence: 0.99080354

00:16:23.810 --> 00:16:25.510 realistically an option for them.

NOTE Confidence: 0.9982424

00:16:27.170 --> 00:16:28.850 In twenty twenty three, over

NOTE Confidence: 0.9982424

00:16:28.850 --> 00:16:29.889 a hundred and sixty three

NOTE Confidence: 0.9982424

00:16:29.889 --> 00:16:31.410 thousand abortions were provided to

NOTE Confidence: 0.9982424

00:16:31.410 --> 00:16:32.895 patients traveling out of state

NOTE Confidence: 0.9982424

00:16:33.295 --> 00:16:34.675 largely due to bans.

NOTE Confidence: 0.9993109

00:16:35.455 --> 00:16:37.455 This slide demonstrates the percentage

NOTE Confidence: 0.9993109

00:16:37.455 --> 00:16:38.895 of abortions provided to out

NOTE Confidence: 0.9993109

00:16:38.895 --> 00:16:40.415 of state patients in each

NOTE Confidence: 0.9993109

00:16:40.415 --> 00:16:40.915 state.

NOTE Confidence: 0.9987643

00:16:41.455 --> 00:16:43.295 In New Mexico, for example,

NOTE Confidence: 0.9987643

00:16:43.295 --> 00:16:44.655 over sixty percent of abortions

NOTE Confidence: 0.9987643

00:16:44.655 --> 00:16:45.615 were provided to out of

NOTE Confidence: 0.9987643

00:16:45.615 --> 00:16:46.355 state patients.
NOTE Confidence: 0.9437363

00:16:47.170 --> 00:16:48.690 This percentage was much lower
NOTE Confidence: 0.9437363

00:16:48.690 --> 00:16:50.690 in Connecticut presumably because the
NOTE Confidence: 0.9437363

00:16:50.690 --> 00:16:52.150 surrounding states don't have restrictive
NOTE Confidence: 0.9437363

00:16:52.210 --> 00:16:52.710 bans.
NOTE Confidence: 0.9859392

00:16:53.410 --> 00:16:55.490 The average distance overall for
NOTE Confidence: 0.9859392

00:16:55.570 --> 00:16:57.090 to travel for abortion related
NOTE Confidence: 0.9859392

00:16:57.090 --> 00:16:59.350 health care has increased approximately
NOTE Confidence: 0.9859392

00:16:59.410 --> 00:17:00.450 a hundred miles since the
NOTE Confidence: 0.9859392

00:17:00.450 --> 00:17:01.270 Dobbs ruling.
NOTE Confidence: 0.94788563

00:17:01.725 --> 00:17:02.685 Abortion may only be an
NOTE Confidence: 0.94788563

00:17:02.685 --> 00:17:03.885 option for individuals who are
NOTE Confidence: 0.94788563

00:17:03.885 --> 00:17:05.565 able to travel significant distance,
NOTE Confidence: 0.94788563

00:17:05.565 --> 00:17:07.184 including crossing several states.
NOTE Confidence: 0.97975105

00:17:09.725 --> 00:17:11.424 For those seeking further comprehensive
NOTE Confidence: 0.97975105

00:17:11.565 --> 00:17:13.645 counseling evaluation and interventions after

NOTE Confidence: 0.97975105

00:17:13.645 --> 00:17:15.240 a fetal diagnosis, we have

NOTE Confidence: 0.97975105

00:17:15.240 --> 00:17:16.520 seen the development of more

NOTE Confidence: 0.97975105

00:17:16.520 --> 00:17:17.880 fetal care centers throughout the

NOTE Confidence: 0.97975105

00:17:17.880 --> 00:17:18.380 country.

NOTE Confidence: 0.9854797

00:17:19.000 --> 00:17:20.200 Based on the NAFT NET

NOTE Confidence: 0.9854797

00:17:20.200 --> 00:17:21.640 website, there are forty six

NOTE Confidence: 0.9854797

00:17:21.640 --> 00:17:23.080 medical centers in the United

NOTE Confidence: 0.9854797

00:17:23.080 --> 00:17:25.080 States that offer advanced fetal

NOTE Confidence: 0.9854797

00:17:25.080 --> 00:17:27.260 therapeutic procedures with their locations

NOTE Confidence: 0.9854797

00:17:27.320 --> 00:17:28.460 displayed on the slide.

NOTE Confidence: 0.9989263

00:17:29.325 --> 00:17:30.445 The centers tend to be

NOTE Confidence: 0.9989263

00:17:30.445 --> 00:17:32.044 concentrated in certain areas of

NOTE Confidence: 0.9989263

00:17:32.044 --> 00:17:33.484 the country with no centers

NOTE Confidence: 0.9989263

00:17:33.484 --> 00:17:36.065 designated within large geographic areas.

NOTE Confidence: 0.9586927

00:17:36.845 --> 00:17:37.965 They are located in just

NOTE Confidence: 0.9586927

00:17:37.965 --> 00:17:39.645 twenty two states and thirty
NOTE Confidence: 0.9586927

00:17:39.645 --> 00:17:40.465 seven cities.
NOTE Confidence: 0.9985747

00:17:41.325 --> 00:17:42.284 Only a few of these
NOTE Confidence: 0.9985747

00:17:42.284 --> 00:17:43.885 offer interventions for fetal kidney
NOTE Confidence: 0.9985747

00:17:43.885 --> 00:17:44.385 failure.
NOTE Confidence: 0.9890636

00:17:45.059 --> 00:17:46.419 Individuals may have to travel
NOTE Confidence: 0.9890636

00:17:46.419 --> 00:17:48.100 significant distance in order to
NOTE Confidence: 0.9890636

00:17:48.100 --> 00:17:50.019 receive an initial evaluation and
NOTE Confidence: 0.9890636

00:17:50.019 --> 00:17:51.380 then potentially have the ability
NOTE Confidence: 0.9890636

00:17:51.380 --> 00:17:52.039 to relocate
NOTE Confidence: 0.9959263

00:17:52.419 --> 00:17:53.299 for the remainder of the
NOTE Confidence: 0.9959263

00:17:53.299 --> 00:17:54.820 pregnancy and afterwards to receive
NOTE Confidence: 0.9959263

00:17:54.820 --> 00:17:55.559 these interventions.
NOTE Confidence: 0.99521273

00:17:58.025 --> 00:17:59.385 What about patients who wish
NOTE Confidence: 0.99521273

00:17:59.385 --> 00:18:01.005 to continue the pregnancy with
NOTE Confidence: 0.99521273

00:18:01.065 --> 00:18:02.684 palliative and hospice care?

NOTE Confidence: 0.94004685

00:18:03.145 --> 00:18:05.304 Variations in accesses services offered

NOTE Confidence: 0.94004685

00:18:05.304 --> 00:18:07.065 and financial sustainability have been

NOTE Confidence: 0.94004685

00:18:07.065 --> 00:18:07.885 well described.

NOTE Confidence: 0.9597533

00:18:08.664 --> 00:18:10.265 This slide, while not reflective

NOTE Confidence: 0.9597533

00:18:10.265 --> 00:18:11.145 of all of the programs

NOTE Confidence: 0.9597533

00:18:11.145 --> 00:18:12.265 in the country, shows data

NOTE Confidence: 0.9597533

00:18:12.265 --> 00:18:13.460 from the twenty eighteen eighteen

NOTE Confidence: 0.9597533

00:18:13.460 --> 00:18:14.920 National Palliative Care Registry.

NOTE Confidence: 0.9128688

00:18:15.700 --> 00:18:17.480 There were no participating pediatric

NOTE Confidence: 0.9992278

00:18:17.780 --> 00:18:19.300 palliative care programs in twenty

NOTE Confidence: 0.9992278

00:18:19.300 --> 00:18:19.960 two states.

NOTE Confidence: 0.98142725

00:18:21.380 --> 00:18:23.700 Perinatal hospice dot org currently

NOTE Confidence: 0.98142725

00:18:23.700 --> 00:18:24.740 lists over two hundred and

NOTE Confidence: 0.98142725

00:18:24.740 --> 00:18:26.420 seventy programs in forty eight

NOTE Confidence: 0.98142725

00:18:26.420 --> 00:18:26.920 states.

NOTE Confidence: 0.98447293

00:18:27.325 --> 00:18:28.785 However, the types of diagnoses

NOTE Confidence: 0.98447293

00:18:28.845 --> 00:18:30.525 seen, care models, training of

NOTE Confidence: 0.98447293

00:18:30.525 --> 00:18:31.965 team members, and continuity of

NOTE Confidence: 0.98447293

00:18:31.965 --> 00:18:33.725 care is really variable between

NOTE Confidence: 0.98447293

00:18:33.725 --> 00:18:34.225 programs.

NOTE Confidence: 0.99691427

00:18:35.325 --> 00:18:36.765 Throughout Connecticut, we have a

NOTE Confidence: 0.99691427

00:18:36.765 --> 00:18:38.605 couple of perinatal palliative care

NOTE Confidence: 0.99691427

00:18:38.605 --> 00:18:39.105 programs,

NOTE Confidence: 0.99362594

00:18:39.660 --> 00:18:41.600 varying degrees of inpatient pediatric

NOTE Confidence: 0.99362594

00:18:41.660 --> 00:18:43.900 palliative care services, and limited

NOTE Confidence: 0.99362594

00:18:43.900 --> 00:18:45.600 outpatient and home services.

NOTE Confidence: 0.99251455

00:18:46.300 --> 00:18:47.580 This impacts not only the

NOTE Confidence: 0.99251455

00:18:47.580 --> 00:18:49.340 availability of hospice and palliative

NOTE Confidence: 0.99251455

00:18:49.340 --> 00:18:50.540 care, but also the services

NOTE Confidence: 0.99251455

00:18:50.540 --> 00:18:52.060 provided and the experiences that

NOTE Confidence: 0.99251455

00:18:52.060 --> 00:18:53.040 families have.

NOTE Confidence: 0.9995011

00:18:55.055 --> 00:18:57.155 Those who seek invasive interventions

NOTE Confidence: 0.9995011

00:18:57.295 --> 00:18:59.055 will require subspecialty care to

NOTE Confidence: 0.9995011

00:18:59.055 --> 00:19:00.655 meet their child's complex medical

NOTE Confidence: 0.9995011

00:19:00.655 --> 00:19:01.155 needs.

NOTE Confidence: 0.99167466

00:19:02.095 --> 00:19:03.775 Thirty nine million children reside

NOTE Confidence: 0.99167466

00:19:03.775 --> 00:19:04.975 more than eighty miles from

NOTE Confidence: 0.99167466

00:19:04.975 --> 00:19:05.475 subspecialists

NOTE Confidence: 0.99645746

00:19:05.855 --> 00:19:07.135 at ratios as low as

NOTE Confidence: 0.99645746

00:19:07.135 --> 00:19:08.734 one physician per hundred thousand

NOTE Confidence: 0.99645746

00:19:08.734 --> 00:19:09.234 children.

NOTE Confidence: 0.97349226

00:19:10.279 --> 00:19:11.480 To better understand what that

NOTE Confidence: 0.97349226

00:19:11.480 --> 00:19:12.279 mean mean, I went to

NOTE Confidence: 0.97349226

00:19:12.279 --> 00:19:13.960 the ABP website and looked

NOTE Confidence: 0.97349226

00:19:13.960 --> 00:19:15.899 up information for pediatric nephrologist.

NOTE Confidence: 0.99860114

00:19:17.159 --> 00:19:18.520 The mean driving distance to

NOTE Confidence: 0.99860114

00:19:18.520 --> 00:19:20.200 a pediatric nephrologist is twenty
NOTE Confidence: 0.99860114

00:19:20.200 --> 00:19:21.419 nine point four miles.
NOTE Confidence: 0.981969

00:19:21.799 --> 00:19:24.200 There's great geographic variability. Again,
NOTE Confidence: 0.981969

00:19:24.200 --> 00:19:25.640 meaning large regions do not
NOTE Confidence: 0.981969

00:19:25.640 --> 00:19:27.405 have coverage within driving distance.
NOTE Confidence: 0.99919444

00:19:28.265 --> 00:19:29.545 Over twenty percent of children
NOTE Confidence: 0.99919444

00:19:29.545 --> 00:19:30.825 live greater than forty miles
NOTE Confidence: 0.99919444

00:19:30.825 --> 00:19:31.645 from a nephrologist.
NOTE Confidence: 0.9855067

00:19:32.585 --> 00:19:34.205 While these numbers are worrisome
NOTE Confidence: 0.9855067

00:19:34.265 --> 00:19:35.785 and may limit the options
NOTE Confidence: 0.9855067

00:19:35.785 --> 00:19:36.825 available, it may be even
NOTE Confidence: 0.9855067

00:19:36.825 --> 00:19:38.105 worse than the map suggests
NOTE Confidence: 0.9855067

00:19:38.105 --> 00:19:39.565 because neonatal dialysis
NOTE Confidence: 0.96866065

00:19:39.919 --> 00:19:41.200 is very specialized, and not
NOTE Confidence: 0.96866065

00:19:41.200 --> 00:19:42.500 every center with a pediatric
NOTE Confidence: 0.96866065

00:19:42.559 --> 00:19:44.320 nephrologist is really equipped to

NOTE Confidence: 0.96866065

00:19:44.320 --> 00:19:45.440 provide the complex pre and

NOTE Confidence: 0.96866065

00:19:45.440 --> 00:19:47.059 postnatal care or offer dialysis.

NOTE Confidence: 0.9811632

00:19:50.159 --> 00:19:52.000 These geographic constraints lead to

NOTE Confidence: 0.9811632

00:19:52.000 --> 00:19:53.764 injustice when distance to care

NOTE Confidence: 0.9811632

00:19:53.764 --> 00:19:56.105 means inadequate or nonexistent care.

NOTE Confidence: 0.97668445

00:19:56.484 --> 00:19:57.845 Autonomy can be challenged if

NOTE Confidence: 0.97668445

00:19:57.845 --> 00:19:58.804 a patient cannot get the

NOTE Confidence: 0.97668445

00:19:58.804 --> 00:19:59.924 care that they desire, and,

NOTE Confidence: 0.97668445

00:19:59.924 --> 00:20:00.424 resultantly,

NOTE Confidence: 0.65699315

00:20:00.884 --> 00:20:01.384 nonmalevolence

NOTE Confidence: 0.99835587

00:20:01.684 --> 00:20:02.884 comes into play because the

NOTE Confidence: 0.99835587

00:20:02.884 --> 00:20:04.664 system fails to prevent harm.

NOTE Confidence: 0.9904284

00:20:06.680 --> 00:20:08.859 Irrespective of the geographic proximity

NOTE Confidence: 0.9904284

00:20:08.920 --> 00:20:10.359 to care options, providers should

NOTE Confidence: 0.9904284

00:20:10.359 --> 00:20:11.580 be aware of the economic

NOTE Confidence: 0.9904284

00:20:11.640 --> 00:20:13.000 implications and how that may
NOTE Confidence: 0.9904284

00:20:13.000 --> 00:20:14.840 impact the feasibility of certain
NOTE Confidence: 0.9904284

00:20:14.840 --> 00:20:16.300 care paths for patients.
NOTE Confidence: 0.98306406

00:20:18.455 --> 00:20:19.734 If they have physical access
NOTE Confidence: 0.98306406

00:20:19.734 --> 00:20:20.935 to care, there still may
NOTE Confidence: 0.98306406

00:20:20.935 --> 00:20:22.155 be financial barriers.
NOTE Confidence: 0.9985134

00:20:22.695 --> 00:20:24.055 These barriers are true for
NOTE Confidence: 0.9985134

00:20:24.055 --> 00:20:25.195 all of the care options.
NOTE Confidence: 0.9617069

00:20:25.815 --> 00:20:27.835 With increased distance to abortion
NOTE Confidence: 0.9617069

00:20:27.975 --> 00:20:29.915 services and variable insurance coverage,
NOTE Confidence: 0.9617069

00:20:30.135 --> 00:20:31.415 individuals may not be able
NOTE Confidence: 0.9617069

00:20:31.415 --> 00:20:32.695 to afford taking time off
NOTE Confidence: 0.9617069

00:20:32.695 --> 00:20:34.500 work, travel expenses, or the
NOTE Confidence: 0.9617069

00:20:34.500 --> 00:20:35.560 procedures themselves.
NOTE Confidence: 0.9993498

00:20:36.820 --> 00:20:38.040 With fetal interventions,
NOTE Confidence: 0.9996791

00:20:38.420 --> 00:20:40.340 those same financial considerations are

NOTE Confidence: 0.9996791

00:20:40.340 --> 00:20:40.840 applicable.

NOTE Confidence: 0.99687445

00:20:41.620 --> 00:20:43.140 In addition, individuals may need

NOTE Confidence: 0.99687445

00:20:43.140 --> 00:20:43.860 to factor in if they

NOTE Confidence: 0.99687445

00:20:43.860 --> 00:20:44.820 can relocate and what that

NOTE Confidence: 0.99687445

00:20:44.820 --> 00:20:45.860 means for their job or

NOTE Confidence: 0.99687445

00:20:45.860 --> 00:20:46.840 their other children.

NOTE Confidence: 0.99982816

00:20:47.955 --> 00:20:49.234 With hospice, they have to

NOTE Confidence: 0.99982816

00:20:49.234 --> 00:20:49.734 consider

NOTE Confidence: 0.992312

00:20:50.195 --> 00:20:51.794 the financial resources to hire

NOTE Confidence: 0.992312

00:20:51.794 --> 00:20:53.075 private help with a scarcity

NOTE Confidence: 0.992312

00:20:53.075 --> 00:20:54.275 of home health resources and

NOTE Confidence: 0.992312

00:20:54.275 --> 00:20:55.554 whether insurance will cover all

NOTE Confidence: 0.992312

00:20:55.554 --> 00:20:56.855 of the necessary care.

NOTE Confidence: 0.99713886

00:20:57.875 --> 00:20:59.715 With invasive interventions and complex

NOTE Confidence: 0.99713886

00:20:59.715 --> 00:21:01.715 chronic care, financial constraints really

NOTE Confidence: 0.99713886

00:21:01.715 --> 00:21:02.940 come into play most often.
NOTE Confidence: 0.99713886

00:21:03.179 --> 00:21:03.919 The anticipated
NOTE Confidence: 0.9606798

00:21:04.220 --> 00:21:05.500 hospital stays long and the
NOTE Confidence: 0.9606798

00:21:05.500 --> 00:21:06.779 care needs are high and
NOTE Confidence: 0.9606798

00:21:06.779 --> 00:21:07.759 often lifelong.
NOTE Confidence: 0.99958694

00:21:09.820 --> 00:21:10.859 We can expand a bit
NOTE Confidence: 0.99958694

00:21:10.859 --> 00:21:12.320 more on the financial implications
NOTE Confidence: 0.99958694

00:21:12.460 --> 00:21:13.519 of home dialysis.
NOTE Confidence: 0.9978131

00:21:14.700 --> 00:21:16.779 A group interviewed primary caregivers
NOTE Confidence: 0.9978131

00:21:16.779 --> 00:21:18.225 of children receiving dialysis at
NOTE Confidence: 0.9978131

00:21:18.225 --> 00:21:19.345 three centers in the United
NOTE Confidence: 0.9978131

00:21:19.345 --> 00:21:19.845 States.
NOTE Confidence: 0.98502266

00:21:20.785 --> 00:21:22.145 This slide has themes from
NOTE Confidence: 0.98502266

00:21:22.145 --> 00:21:23.924 quotes of the financial impact.
NOTE Confidence: 0.996277

00:21:24.304 --> 00:21:25.744 Parents note the impact of
NOTE Confidence: 0.996277

00:21:25.744 --> 00:21:26.565 lost wages,

NOTE Confidence: 0.9855759
00:21:26.865 --> 00:21:28.625 having difficulty paying for other
NOTE Confidence: 0.9855759
00:21:28.625 --> 00:21:29.905 necessities, such as the special
NOTE Confidence: 0.9855759
00:21:29.905 --> 00:21:31.684 groceries for their child's dietary
NOTE Confidence: 0.9855759
00:21:31.744 --> 00:21:34.170 needs, sibling care, car insurance,
NOTE Confidence: 0.9855759
00:21:34.310 --> 00:21:35.510 and the impact of visits
NOTE Confidence: 0.9855759
00:21:35.510 --> 00:21:36.869 on their job and monthly
NOTE Confidence: 0.9855759
00:21:36.869 --> 00:21:37.369 budget.
NOTE Confidence: 0.9828472
00:21:37.990 --> 00:21:39.609 There are many outpatient visits,
NOTE Confidence: 0.9828472
00:21:39.670 --> 00:21:40.790 and every time the child
NOTE Confidence: 0.9828472
00:21:40.790 --> 00:21:41.750 has a fever, they have
NOTE Confidence: 0.9828472
00:21:41.750 --> 00:21:43.270 to be seen urgently, which
NOTE Confidence: 0.9828472
00:21:43.270 --> 00:21:44.470 means time off of work
NOTE Confidence: 0.9828472
00:21:44.470 --> 00:21:45.450 and co pay.
NOTE Confidence: 0.9901669
00:21:46.184 --> 00:21:47.544 Parking can be twenty dollars
NOTE Confidence: 0.9901669
00:21:47.544 --> 00:21:48.664 a visit, more if they
NOTE Confidence: 0.9901669

00:21:48.664 --> 00:21:49.465 have to leave to go
NOTE Confidence: 0.9901669

00:21:49.465 --> 00:21:50.825 to work and return afterwards
NOTE Confidence: 0.9901669

00:21:50.825 --> 00:21:51.965 to pick up their child.
NOTE Confidence: 0.9902294

00:21:52.904 --> 00:21:54.265 One parent even noted having
NOTE Confidence: 0.9902294

00:21:54.265 --> 00:21:55.385 to choose between paying the
NOTE Confidence: 0.9902294

00:21:55.385 --> 00:21:56.984 medical bills or their mortgage,
NOTE Confidence: 0.9902294

00:21:56.984 --> 00:21:58.684 electricity, and gas for transportation
NOTE Confidence: 0.9902294

00:21:58.744 --> 00:21:59.804 to and from appointments.
NOTE Confidence: 0.9987167

00:22:00.830 --> 00:22:02.050 Those who had insurance,
NOTE Confidence: 0.99438095

00:22:02.750 --> 00:22:04.830 especially private insurance, noted that
NOTE Confidence: 0.99438095

00:22:04.830 --> 00:22:06.030 there are huge gaps in
NOTE Confidence: 0.99438095

00:22:06.030 --> 00:22:06.530 coverage.
NOTE Confidence: 0.9679655

00:22:07.070 --> 00:22:08.109 While we don't like to
NOTE Confidence: 0.9679655

00:22:08.109 --> 00:22:09.630 think of costs, families have
NOTE Confidence: 0.9679655

00:22:09.630 --> 00:22:11.330 to consider the financial burden
NOTE Confidence: 0.9679655

00:22:11.470 --> 00:22:12.590 for their entire family. And

NOTE Confidence: 0.9679655

00:22:12.590 --> 00:22:14.270 if the ancillary costs associated

NOTE Confidence: 0.9679655

00:22:14.270 --> 00:22:16.105 with any care path, especially

NOTE Confidence: 0.9679655

00:22:16.105 --> 00:22:17.165 invasive interventions,

NOTE Confidence: 0.99871695

00:22:17.545 --> 00:22:19.165 is sustainable for many years.

NOTE Confidence: 0.9942096

00:22:21.625 --> 00:22:23.305 Economic constraints can lead to

NOTE Confidence: 0.9942096

00:22:23.305 --> 00:22:25.145 injustice if patients with fewer

NOTE Confidence: 0.9942096

00:22:25.145 --> 00:22:26.345 resources do not have the

NOTE Confidence: 0.9942096

00:22:26.345 --> 00:22:27.809 same care options as those

NOTE Confidence: 0.9942096

00:22:27.809 --> 00:22:29.669 with greater resources, really perpetuating

NOTE Confidence: 0.90750885

00:22:29.970 --> 00:22:31.730 the resultant social determinants of

NOTE Confidence: 0.90750885

00:22:31.730 --> 00:22:32.230 health.

NOTE Confidence: 0.961119

00:22:32.769 --> 00:22:33.669 If a family

NOTE Confidence: 0.99808174

00:22:34.130 --> 00:22:35.490 of a neonate with kidney

NOTE Confidence: 0.99808174

00:22:35.490 --> 00:22:36.529 failure does not have the

NOTE Confidence: 0.99808174

00:22:36.529 --> 00:22:38.230 resources to afford home dialysis,

NOTE Confidence: 0.99808174

00:22:38.529 --> 00:22:40.289 the injustice challenges the family's
NOTE Confidence: 0.99808174

00:22:40.289 --> 00:22:41.809 autonomy and can cause moral
NOTE Confidence: 0.99808174

00:22:41.809 --> 00:22:42.869 distress and harm.
NOTE Confidence: 0.9969545

00:22:45.265 --> 00:22:47.025 Even if geographic and financial
NOTE Confidence: 0.9969545

00:22:47.025 --> 00:22:49.125 constraints didn't exist, there's variation
NOTE Confidence: 0.9969545

00:22:49.185 --> 00:22:50.465 in the ways patients are
NOTE Confidence: 0.9969545

00:22:50.465 --> 00:22:51.665 counseled that can limit the
NOTE Confidence: 0.9969545

00:22:51.665 --> 00:22:53.345 options they're made aware of,
NOTE Confidence: 0.9969545

00:22:53.345 --> 00:22:54.565 offered, or choose.
NOTE Confidence: 0.99696165

00:22:55.600 --> 00:22:57.440 Multiple factors impact how providers
NOTE Confidence: 0.99696165

00:22:57.440 --> 00:22:58.880 counsel patients and the treatments
NOTE Confidence: 0.99696165

00:22:58.880 --> 00:22:59.700 that they offer.
NOTE Confidence: 0.98679507

00:23:00.240 --> 00:23:01.119 At times, it can be
NOTE Confidence: 0.98679507

00:23:01.119 --> 00:23:01.919 because of a lack of
NOTE Confidence: 0.98679507

00:23:01.919 --> 00:23:03.440 knowledge of treatments or interventions,
NOTE Confidence: 0.98679507

00:23:03.440 --> 00:23:04.559 and at times, it's because

NOTE Confidence: 0.98679507

00:23:04.559 --> 00:23:05.220 of bias.

NOTE Confidence: 0.9974794

00:23:05.840 --> 00:23:07.519 Irrespective of the reason, the

NOTE Confidence: 0.9974794

00:23:07.519 --> 00:23:08.820 manner in which we counsel

NOTE Confidence: 0.9974794

00:23:08.880 --> 00:23:09.380 families

NOTE Confidence: 0.9965516

00:23:09.984 --> 00:23:11.345 impacts the options available to

NOTE Confidence: 0.9965516

00:23:11.345 --> 00:23:12.304 them and the choices they

NOTE Confidence: 0.9965516

00:23:12.304 --> 00:23:13.924 make about those available options.

NOTE Confidence: 0.97694755

00:23:16.385 --> 00:23:18.644 Twelve hundred pediatric surgeons, neonatologists,

NOTE Confidence: 0.97694755

00:23:18.865 --> 00:23:20.465 and maternal fetal medicine specialists

NOTE Confidence: 0.97694755

00:23:20.465 --> 00:23:21.424 were asked if they would

NOTE Confidence: 0.97694755

00:23:21.424 --> 00:23:23.320 recommend fetal surgery to save

NOTE Confidence: 0.97694755

00:23:23.320 --> 00:23:24.279 the life of a fetus

NOTE Confidence: 0.97694755

00:23:24.279 --> 00:23:25.960 who would otherwise die if

NOTE Confidence: 0.97694755

00:23:25.960 --> 00:23:27.000 survival would result in a

NOTE Confidence: 0.97694755

00:23:27.000 --> 00:23:28.039 child living with what they

NOTE Confidence: 0.97694755

00:23:28.039 --> 00:23:29.259 term severe disabilities.

NOTE Confidence: 0.96541965

00:23:30.119 --> 00:23:31.419 This slide has the responses

NOTE Confidence: 0.96541965

00:23:31.480 --> 00:23:32.700 broken down by subspecialists.

NOTE Confidence: 0.9755511

00:23:33.480 --> 00:23:35.259 On the first graph, overall,

NOTE Confidence: 0.9911285

00:23:36.415 --> 00:23:38.734 nineteen percent strongly agreed, fifty

NOTE Confidence: 0.9911285

00:23:38.734 --> 00:23:39.875 nine percent disagreed,

NOTE Confidence: 0.9987498

00:23:40.415 --> 00:23:42.255 twenty one percent agreed, and

NOTE Confidence: 0.9987498

00:23:42.255 --> 00:23:44.255 one percent strongly agreed that

NOTE Confidence: 0.9987498

00:23:44.255 --> 00:23:46.095 they would recommend surgery under

NOTE Confidence: 0.9987498

00:23:46.095 --> 00:23:46.835 these circumstances.

NOTE Confidence: 0.9952314

00:23:48.270 --> 00:23:50.030 Between seventeen to thirty percent

NOTE Confidence: 0.9952314

00:23:50.030 --> 00:23:51.470 displayed by subspecialty on the

NOTE Confidence: 0.9952314

00:23:51.470 --> 00:23:53.150 second graph felt that abortion

NOTE Confidence: 0.9952314

00:23:53.150 --> 00:23:54.350 is morally wrong and would

NOTE Confidence: 0.9952314

00:23:54.350 --> 00:23:55.410 not offer it.

NOTE Confidence: 0.9997044

00:23:55.710 --> 00:23:56.609 This is consistent
NOTE Confidence: 0.99971145

00:23:56.910 --> 00:23:58.190 with other studies that show
NOTE Confidence: 0.99971145

00:23:58.190 --> 00:23:58.690 variability
NOTE Confidence: 0.9922968

00:23:59.070 --> 00:24:01.010 in discussing the various options,
NOTE Confidence: 0.9804765

00:24:01.345 --> 00:24:03.265 abortion, invasive interventions, and comfort
NOTE Confidence: 0.9804765

00:24:03.265 --> 00:24:05.445 measures with varying fetal diagnoses.
NOTE Confidence: 0.9691508

00:24:08.465 --> 00:24:10.245 A study of pediatric nephrologist
NOTE Confidence: 0.9691508

00:24:10.385 --> 00:24:10.885 intensivists
NOTE Confidence: 0.97321796

00:24:11.265 --> 00:24:11.925 and neonatologists
NOTE Confidence: 0.9326701

00:24:12.385 --> 00:24:14.225 explore decision making for neonates
NOTE Confidence: 0.9326701

00:24:14.225 --> 00:24:15.765 with end stage kidney disease.
NOTE Confidence: 0.9991031

00:24:16.420 --> 00:24:18.180 With isolated end stage kidney
NOTE Confidence: 0.9991031

00:24:18.180 --> 00:24:19.640 disease, the first graph,
NOTE Confidence: 0.992145

00:24:19.940 --> 00:24:21.060 thirty eight to fifty two
NOTE Confidence: 0.992145

00:24:21.060 --> 00:24:23.000 percent would offer kidney replacement
NOTE Confidence: 0.992145

00:24:23.060 --> 00:24:23.560 therapy,

NOTE Confidence: 0.996534

00:24:24.100 --> 00:24:25.700 and forty eight to sixty

NOTE Confidence: 0.996534

00:24:25.700 --> 00:24:27.060 two percent would propose what

NOTE Confidence: 0.996534

00:24:27.060 --> 00:24:28.340 they termed palliative care, a

NOTE Confidence: 0.996534

00:24:28.340 --> 00:24:29.780 comfort measures only approach to

NOTE Confidence: 0.996534

00:24:29.780 --> 00:24:30.280 care.

NOTE Confidence: 0.96467555

00:24:31.024 --> 00:24:32.304 In the setting of pulmonary

NOTE Confidence: 0.96467555

00:24:32.304 --> 00:24:33.984 hypoplasia to any degree, the

NOTE Confidence: 0.96467555

00:24:33.984 --> 00:24:35.904 second graph, far fewer would

NOTE Confidence: 0.96467555

00:24:35.904 --> 00:24:37.825 offer kidney replacement therapy, and

NOTE Confidence: 0.96467555

00:24:37.825 --> 00:24:38.865 the majority, but not all,

NOTE Confidence: 0.96467555

00:24:38.865 --> 00:24:40.144 would propose a comfort measures

NOTE Confidence: 0.96467555

00:24:40.144 --> 00:24:41.445 only approach to care.

NOTE Confidence: 0.91637886

00:24:44.120 --> 00:24:46.280 Similarly, two international surveys showed

NOTE Confidence: 0.91637886

00:24:46.280 --> 00:24:47.420 that not all nephrologists,

NOTE Confidence: 0.97175336

00:24:47.800 --> 00:24:49.160 forty one and thirty percent

NOTE Confidence: 0.97175336

00:24:49.160 --> 00:24:49.660 respectively,
NOTE Confidence: 0.9956325

00:24:50.040 --> 00:24:52.120 would offer kidney replacement therapy
NOTE Confidence: 0.9956325

00:24:52.120 --> 00:24:53.400 to all neonates less than
NOTE Confidence: 0.9956325

00:24:53.400 --> 00:24:54.760 one month of age. And
NOTE Confidence: 0.9956325

00:24:54.760 --> 00:24:56.385 at the same time, roughly
NOTE Confidence: 0.9956325

00:24:56.385 --> 00:24:57.744 a quarter felt it's never
NOTE Confidence: 0.9956325

00:24:57.744 --> 00:24:59.605 acceptable for parents to refuse
NOTE Confidence: 0.9956325

00:24:59.744 --> 00:25:01.665 kidney replacement therapies for neonates
NOTE Confidence: 0.9956325

00:25:01.665 --> 00:25:02.465 less than one month of
NOTE Confidence: 0.9956325

00:25:02.465 --> 00:25:04.725 age. That dialysis is obligatory.
NOTE Confidence: 0.96339315

00:25:05.905 --> 00:25:07.505 In the study where nineteen
NOTE Confidence: 0.96339315

00:25:07.505 --> 00:25:09.025 percent felt it's never acceptable
NOTE Confidence: 0.96339315

00:25:09.025 --> 00:25:10.385 for parents to refuse kidney
NOTE Confidence: 0.96339315

00:25:10.385 --> 00:25:11.445 replacement therapy,
NOTE Confidence: 0.9946346

00:25:11.960 --> 00:25:13.080 Fifty percent said that it's
NOTE Confidence: 0.9946346

00:25:13.080 --> 00:25:14.440 usually acceptable for them to

NOTE Confidence: 0.9946346

00:25:14.440 --> 00:25:15.560 refuse it, that it's not

NOTE Confidence: 0.9946346

00:25:15.560 --> 00:25:16.060 obligatory.

NOTE Confidence: 0.9976714

00:25:17.560 --> 00:25:19.480 Collectively, these studies suggest that

NOTE Confidence: 0.9976714

00:25:19.480 --> 00:25:20.760 depending on the views of

NOTE Confidence: 0.9976714

00:25:20.760 --> 00:25:22.460 the individual providing the counseling,

NOTE Confidence: 0.9857468

00:25:22.920 --> 00:25:24.200 not all families are made

NOTE Confidence: 0.9857468

00:25:24.200 --> 00:25:26.125 aware of all acceptable treatment

NOTE Confidence: 0.9857468

00:25:26.125 --> 00:25:27.085 options, or at the very

NOTE Confidence: 0.9857468

00:25:27.085 --> 00:25:28.605 least, the information is presented

NOTE Confidence: 0.9857468

00:25:28.605 --> 00:25:29.805 differently based on the views

NOTE Confidence: 0.9857468

00:25:29.805 --> 00:25:30.625 of the providers.

NOTE Confidence: 0.99535346

00:25:32.845 --> 00:25:33.825 When an individual

NOTE Confidence: 0.8945803

00:25:34.285 --> 00:25:35.805 providers apply their own beliefs,

NOTE Confidence: 0.8945803

00:25:35.805 --> 00:25:37.505 views, and values and preferences

NOTE Confidence: 0.8945803

00:25:37.565 --> 00:25:38.625 to the bias in

NOTE Confidence: 0.95528626

00:25:39.300 --> 00:25:40.420 counseling and care that they
NOTE Confidence: 0.95528626

00:25:40.420 --> 00:25:42.180 provide, they interfere with autonomy
NOTE Confidence: 0.95528626

00:25:42.180 --> 00:25:43.860 and ultimately the patient provider
NOTE Confidence: 0.95528626

00:25:43.860 --> 00:25:44.360 relationship.
NOTE Confidence: 0.99942356

00:25:47.060 --> 00:25:49.140 Beyond individual provider factors, there
NOTE Confidence: 0.99942356

00:25:49.140 --> 00:25:50.680 may be institutional constraints
NOTE Confidence: 0.9991917

00:25:50.980 --> 00:25:52.520 on the prenatal and postnatal
NOTE Confidence: 0.9991917

00:25:52.740 --> 00:25:53.560 options available.
NOTE Confidence: 0.9996394

00:25:55.765 --> 00:25:56.725 This may be due to
NOTE Confidence: 0.9996394

00:25:56.725 --> 00:25:57.385 the capability
NOTE Confidence: 0.91436356

00:25:57.685 --> 00:25:59.125 of or resources at certain
NOTE Confidence: 0.91436356

00:25:59.125 --> 00:26:00.725 hospitals, level of care they
NOTE Confidence: 0.91436356

00:26:00.725 --> 00:26:02.725 provide, or institutional policies really
NOTE Confidence: 0.91436356

00:26:02.725 --> 00:26:04.905 related into intra institutional variability.
NOTE Confidence: 0.9722416

00:26:06.085 --> 00:26:07.605 Abortion when within the statutory
NOTE Confidence: 0.9722416

00:26:07.605 --> 00:26:08.645 limit of a state may

NOTE Confidence: 0.9722416

00:26:08.645 --> 00:26:09.685 not be offered at all

NOTE Confidence: 0.9722416

00:26:09.685 --> 00:26:11.230 centers, may only be offered

NOTE Confidence: 0.9722416

00:26:11.230 --> 00:26:12.910 under certain circumstances, or after

NOTE Confidence: 0.9722416

00:26:12.910 --> 00:26:14.350 the involvement of ethics and

NOTE Confidence: 0.9722416

00:26:14.350 --> 00:26:15.170 risk management.

NOTE Confidence: 0.992721

00:26:16.190 --> 00:26:17.410 With comfort care,

NOTE Confidence: 0.99081826

00:26:17.869 --> 00:26:19.390 some institutions no longer feel

NOTE Confidence: 0.99081826

00:26:19.390 --> 00:26:20.350 that this is an appropriate

NOTE Confidence: 0.99081826

00:26:20.350 --> 00:26:21.710 option to offer, that families

NOTE Confidence: 0.99081826

00:26:21.710 --> 00:26:22.750 have the right to refuse

NOTE Confidence: 0.99081826

00:26:22.750 --> 00:26:24.290 dialysis or other interventions.

NOTE Confidence: 0.9688499

00:26:25.365 --> 00:26:26.965 Some centers only offer comfort

NOTE Confidence: 0.9688499

00:26:26.965 --> 00:26:27.465 measures.

NOTE Confidence: 0.9692285

00:26:27.845 --> 00:26:28.885 Some offer a degree of

NOTE Confidence: 0.9692285

00:26:28.885 --> 00:26:30.805 invasive medical support, and some

NOTE Confidence: 0.9692285

00:26:30.805 --> 00:26:32.885 offer all medical interventions including
NOTE Confidence: 0.9692285

00:26:32.885 --> 00:26:33.385 tracheostomy,
NOTE Confidence: 0.9985574

00:26:33.765 --> 00:26:35.065 ECMO, and dialysis.
NOTE Confidence: 0.99981594

00:26:36.005 --> 00:26:37.225 This means that individuals
NOTE Confidence: 0.98241013

00:26:37.540 --> 00:26:38.820 in the same region may
NOTE Confidence: 0.98241013

00:26:38.820 --> 00:26:40.500 be counseled differently and offer
NOTE Confidence: 0.98241013

00:26:40.500 --> 00:26:41.400 different interventions
NOTE Confidence: 0.97058284

00:26:41.780 --> 00:26:42.920 to based on the capabilities
NOTE Confidence: 0.97058284

00:26:42.980 --> 00:26:44.180 or views of the institution
NOTE Confidence: 0.97058284

00:26:44.180 --> 00:26:45.800 where they ultimately seek care.
NOTE Confidence: 0.9993939

00:26:48.180 --> 00:26:50.100 This table has practice patterns
NOTE Confidence: 0.9993939

00:26:50.100 --> 00:26:52.359 regarding prenatal counseling and dialysis
NOTE Confidence: 0.9993939

00:26:52.500 --> 00:26:53.000 initiation
NOTE Confidence: 0.9915356

00:26:53.484 --> 00:26:54.924 from thirty eight centers who
NOTE Confidence: 0.9915356

00:26:54.924 --> 00:26:56.225 offer neonatal dialysis.
NOTE Confidence: 0.9895956

00:26:57.005 --> 00:26:58.684 There was variability amongst the

NOTE Confidence: 0.9895956

00:26:58.684 --> 00:27:00.065 centers in contraindications

NOTE Confidence: 0.99849916

00:27:00.445 --> 00:27:01.105 to dialysis.

NOTE Confidence: 0.9890162

00:27:01.885 --> 00:27:03.484 About half reported having formal

NOTE Confidence: 0.9890162

00:27:03.484 --> 00:27:05.345 guidelines outlining what their criteria

NOTE Confidence: 0.9890162

00:27:05.404 --> 00:27:05.904 were.

NOTE Confidence: 0.98795915

00:27:06.369 --> 00:27:07.490 Over half had a minimum

NOTE Confidence: 0.98795915

00:27:07.490 --> 00:27:08.770 birth weight, and some had

NOTE Confidence: 0.98795915

00:27:08.770 --> 00:27:10.630 criteria based on genetic testing,

NOTE Confidence: 0.9759083

00:27:11.090 --> 00:27:11.590 pulmonary,

NOTE Confidence: 0.99933004

00:27:11.890 --> 00:27:13.270 or neurologic status.

NOTE Confidence: 0.94894505

00:27:15.490 --> 00:27:17.010 In many contexts, it's not

NOTE Confidence: 0.94894505

00:27:17.010 --> 00:27:18.929 uncommon for rules, rituals, attitudes,

NOTE Confidence: 0.94894505

00:27:18.929 --> 00:27:20.929 and beliefs to differentiate societal

NOTE Confidence: 0.94894505

00:27:20.929 --> 00:27:21.429 institutions.

NOTE Confidence: 0.99556565

00:27:22.145 --> 00:27:23.424 The top picture on the

NOTE Confidence: 0.99556565

00:27:23.424 --> 00:27:25.365 slide show three religious institutions,
NOTE Confidence: 0.99556565

00:27:25.585 --> 00:27:27.105 a synagogue, a mosque, and
NOTE Confidence: 0.99556565

00:27:27.105 --> 00:27:27.765 a church.
NOTE Confidence: 0.998555

00:27:28.304 --> 00:27:30.544 People expect differences between religious
NOTE Confidence: 0.998555

00:27:30.544 --> 00:27:32.145 institutions based on their professed
NOTE Confidence: 0.998555

00:27:32.145 --> 00:27:32.645 doctrine.
NOTE Confidence: 0.9912725

00:27:33.760 --> 00:27:35.460 However, patients expect hospitals,
NOTE Confidence: 0.99443597

00:27:35.840 --> 00:27:37.359 one shown below, to provide
NOTE Confidence: 0.99443597

00:27:37.359 --> 00:27:38.880 similar care and may not
NOTE Confidence: 0.99443597

00:27:38.880 --> 00:27:39.840 be able to predict the
NOTE Confidence: 0.99443597

00:27:39.840 --> 00:27:42.080 available care options, determine hospital
NOTE Confidence: 0.99443597

00:27:42.080 --> 00:27:43.520 policies, or realize that other
NOTE Confidence: 0.99443597

00:27:43.520 --> 00:27:45.520 hospitals would offer different options
NOTE Confidence: 0.99443597

00:27:45.520 --> 00:27:46.820 when they choose an institution.
NOTE Confidence: 0.9952104

00:27:47.545 --> 00:27:49.465 This can challenge autonomy, justice,
NOTE Confidence: 0.9952104

00:27:49.465 --> 00:27:51.005 and potentially cause harm.

NOTE Confidence: 0.99958336
00:27:53.305 --> 00:27:53.805 Irrespective
NOTE Confidence: 0.97339875
00:27:54.185 --> 00:27:55.625 of the other constraints, we
NOTE Confidence: 0.97339875
00:27:55.625 --> 00:27:57.065 cannot ignore the current medical
NOTE Confidence: 0.97339875
00:27:57.065 --> 00:27:58.265 legal climate and its impact
NOTE Confidence: 0.97339875
00:27:58.265 --> 00:27:59.225 on the counseling and care
NOTE Confidence: 0.97339875
00:27:59.225 --> 00:27:59.885 we provide.
NOTE Confidence: 0.9997177
00:28:00.260 --> 00:28:01.619 This factor is affecting more
NOTE Confidence: 0.9997177
00:28:01.619 --> 00:28:02.840 and more of our patients.
NOTE Confidence: 0.99519527
00:28:05.140 --> 00:28:06.580 Many fetal anomalies are not
NOTE Confidence: 0.99519527
00:28:06.580 --> 00:28:07.940 identified until the eighteen to
NOTE Confidence: 0.99519527
00:28:07.940 --> 00:28:09.300 twenty two week anatomy scan,
NOTE Confidence: 0.99519527
00:28:09.300 --> 00:28:10.420 and about twenty five percent
NOTE Confidence: 0.99519527
00:28:10.420 --> 00:28:11.540 are not identified until the
NOTE Confidence: 0.99519527
00:28:11.540 --> 00:28:12.360 third trimester.
NOTE Confidence: 0.99729604
00:28:13.585 --> 00:28:15.045 Even before the Dobbs ruling,
NOTE Confidence: 0.99729604

00:28:15.185 --> 00:28:16.645 a fair number of individuals
NOTE Confidence: 0.99729604

00:28:16.705 --> 00:28:18.325 received a severe fetal diagnosis
NOTE Confidence: 0.99729604

00:28:18.465 --> 00:28:20.245 after their state's abortion limit.
NOTE Confidence: 0.9982697

00:28:20.945 --> 00:28:22.385 The June twenty twenty two
NOTE Confidence: 0.9982697

00:28:22.385 --> 00:28:23.425 ruling that there is no
NOTE Confidence: 0.9982697

00:28:23.425 --> 00:28:25.185 constitutional right to abortion has
NOTE Confidence: 0.9982697

00:28:25.185 --> 00:28:26.225 led to trigger laws at
NOTE Confidence: 0.9982697

00:28:26.225 --> 00:28:27.925 the state level with increasing
NOTE Confidence: 0.9982697

00:28:28.065 --> 00:28:28.565 restrictions.
NOTE Confidence: 0.9894171

00:28:29.690 --> 00:28:31.770 While it's continually changing, at
NOTE Confidence: 0.9894171

00:28:31.770 --> 00:28:33.130 the time this slide was
NOTE Confidence: 0.9894171

00:28:33.130 --> 00:28:34.570 created, forty one states prohibit
NOTE Confidence: 0.9894171

00:28:34.570 --> 00:28:35.850 abortion at a certain point
NOTE Confidence: 0.9894171

00:28:35.850 --> 00:28:36.590 in pregnancy.
NOTE Confidence: 0.95374155

00:28:37.210 --> 00:28:38.830 Fourteen ban abortion completely.
NOTE Confidence: 0.97442514

00:28:39.130 --> 00:28:40.410 Four ban abortion at six

NOTE Confidence: 0.97442514
00:28:40.410 --> 00:28:42.270 weeks. Two at twelve weeks.
NOTE Confidence: 0.9996451
00:28:42.664 --> 00:28:43.485 One at fifteen weeks,
NOTE Confidence: 0.9991327
00:28:44.105 --> 00:28:45.705 one at eighteen weeks, three
NOTE Confidence: 0.9991327
00:28:45.705 --> 00:28:46.765 at twenty two weeks,
NOTE Confidence: 0.9715274
00:28:47.225 --> 00:28:48.605 five at twenty four weeks,
NOTE Confidence: 0.9715274
00:28:48.745 --> 00:28:49.945 ten impose a ban at
NOTE Confidence: 0.9715274
00:28:49.945 --> 00:28:51.865 viability with varying interpretations on
NOTE Confidence: 0.9715274
00:28:51.865 --> 00:28:53.544 the gestational age that's considered
NOTE Confidence: 0.9715274
00:28:53.544 --> 00:28:54.845 viable for this purpose,
NOTE Confidence: 0.9982796
00:28:55.145 --> 00:28:56.345 and one state imposes a
NOTE Confidence: 0.9982796
00:28:56.345 --> 00:28:57.725 ban at twenty five weeks.
NOTE Confidence: 0.99804556
00:28:58.500 --> 00:29:00.280 Several states make rare exceptions
NOTE Confidence: 0.98854387
00:29:00.660 --> 00:29:02.740 for some fetal anomalies slightly
NOTE Confidence: 0.98854387
00:29:02.740 --> 00:29:04.340 beyond the gestational age statutory
NOTE Confidence: 0.98854387
00:29:04.340 --> 00:29:05.380 limit in their state. And
NOTE Confidence: 0.98854387

00:29:05.380 --> 00:29:06.020 on the other end of
NOTE Confidence: 0.98854387

00:29:06.020 --> 00:29:06.680 the spectrum,
NOTE Confidence: 0.9936248

00:29:07.140 --> 00:29:09.060 some prohibit abortion when within
NOTE Confidence: 0.9936248

00:29:09.060 --> 00:29:10.360 the statutory gestational
NOTE Confidence: 0.99865675

00:29:10.660 --> 00:29:11.865 age limit for their state
NOTE Confidence: 0.99865675

00:29:11.945 --> 00:29:12.825 in the context of a
NOTE Confidence: 0.99865675

00:29:12.825 --> 00:29:14.445 genetic diagnosis or anomaly.
NOTE Confidence: 0.9919015

00:29:15.145 --> 00:29:16.585 Collectively, this means that many
NOTE Confidence: 0.9919015

00:29:16.585 --> 00:29:18.265 states prohibit abortion before an
NOTE Confidence: 0.9919015

00:29:18.265 --> 00:29:19.545 individual even knows there's a
NOTE Confidence: 0.9919015

00:29:19.545 --> 00:29:20.765 severe fetal abnormality.
NOTE Confidence: 0.9918669

00:29:21.625 --> 00:29:23.225 More so, there's confusion amongst
NOTE Confidence: 0.9918669

00:29:23.225 --> 00:29:23.725 providers
NOTE Confidence: 0.9749495

00:29:24.105 --> 00:29:25.560 if abortion can be discussed
NOTE Confidence: 0.9749495

00:29:25.720 --> 00:29:26.700 as part of the counseling
NOTE Confidence: 0.9749495

00:29:26.760 --> 00:29:27.960 process in states where there

NOTE Confidence: 0.9749495
00:29:27.960 --> 00:29:29.000 are total bans or if
NOTE Confidence: 0.9749495
00:29:29.000 --> 00:29:30.200 the individual is beyond the
NOTE Confidence: 0.9749495
00:29:30.200 --> 00:29:31.560 gestational age limit in their
NOTE Confidence: 0.9749495
00:29:31.560 --> 00:29:32.060 state.
NOTE Confidence: 0.9887895
00:29:34.360 --> 00:29:35.320 While we don't know the
NOTE Confidence: 0.9887895
00:29:35.320 --> 00:29:36.680 full impact of the Dobbs
NOTE Confidence: 0.9887895
00:29:36.680 --> 00:29:38.380 ruling, a recent study evaluated
NOTE Confidence: 0.9887895
00:29:38.600 --> 00:29:41.455 neonatal and infant deaths after
NOTE Confidence: 0.9887895
00:29:41.455 --> 00:29:43.535 Texas senate bill eight, which
NOTE Confidence: 0.9887895
00:29:43.535 --> 00:29:46.015 banned abortion after embryonic cardiac
NOTE Confidence: 0.9887895
00:29:46.015 --> 00:29:47.855 activity without exemptions for congenital
NOTE Confidence: 0.9887895
00:29:47.855 --> 00:29:49.295 anomalies was enacted in twenty
NOTE Confidence: 0.9887895
00:29:49.295 --> 00:29:50.115 twenty one.
NOTE Confidence: 0.9998277
00:29:50.495 --> 00:29:51.554 Prior to this,
NOTE Confidence: 0.99610794
00:29:52.290 --> 00:29:53.810 the neonatal and infant deaths
NOTE Confidence: 0.99610794

00:29:53.810 --> 00:29:55.650 in Texas were comparable pretty

NOTE Confidence: 0.99610794

00:29:55.650 --> 00:29:56.770 much to the rest of

NOTE Confidence: 0.99610794

00:29:56.770 --> 00:29:57.750 the United States.

NOTE Confidence: 0.9665774

00:29:58.770 --> 00:30:00.050 Between twenty twenty one and

NOTE Confidence: 0.9665774

00:30:00.050 --> 00:30:01.330 twenty twenty two in the

NOTE Confidence: 0.9665774

00:30:01.330 --> 00:30:03.190 black box over here,

NOTE Confidence: 0.9867469

00:30:03.730 --> 00:30:05.410 neonatal deaths in Texas increased

NOTE Confidence: 0.9867469

00:30:05.410 --> 00:30:06.610 by ten point four percent

NOTE Confidence: 0.9867469

00:30:06.610 --> 00:30:07.650 in the green bar, whereas

NOTE Confidence: 0.9867469

00:30:07.650 --> 00:30:08.845 the rest of the country

NOTE Confidence: 0.9727364

00:30:09.225 --> 00:30:10.425 represented by the blue bar

NOTE Confidence: 0.9727364

00:30:10.425 --> 00:30:11.625 experienced a one point six

NOTE Confidence: 0.9727364

00:30:11.625 --> 00:30:12.445 percent increase.

NOTE Confidence: 0.9487663

00:30:13.065 --> 00:30:14.185 There was also a greater

NOTE Confidence: 0.9487663

00:30:14.185 --> 00:30:15.625 than expected number of infant

NOTE Confidence: 0.9487663

00:30:15.625 --> 00:30:17.065 deaths with a twelve point

NOTE Confidence: 0.9487663

00:30:17.065 --> 00:30:18.525 nine percent increase in Texas,

NOTE Confidence: 0.9487663

00:30:18.745 --> 00:30:19.945 the purple bar compared to

NOTE Confidence: 0.9487663

00:30:19.945 --> 00:30:21.225 one point eight percent, the

NOTE Confidence: 0.9487663

00:30:21.225 --> 00:30:22.345 rest bar in the rest

NOTE Confidence: 0.9487663

00:30:22.345 --> 00:30:23.085 of the country.

NOTE Confidence: 0.9832775

00:30:24.080 --> 00:30:25.620 Cause of death, the second

NOTE Confidence: 0.9832775

00:30:25.760 --> 00:30:27.440 graph on this slide shows

NOTE Confidence: 0.9832775

00:30:27.440 --> 00:30:28.880 that infant deaths attributed to

NOTE Confidence: 0.9832775

00:30:28.880 --> 00:30:31.360 congenital anomalies increased by twenty

NOTE Confidence: 0.9832775

00:30:31.360 --> 00:30:32.400 two point nine percent in

NOTE Confidence: 0.9832775

00:30:32.400 --> 00:30:33.920 Texas compared to a two

NOTE Confidence: 0.9832775

00:30:33.920 --> 00:30:35.280 point nine percent decrease in

NOTE Confidence: 0.9832775

00:30:35.280 --> 00:30:36.340 the rest of the country.

NOTE Confidence: 0.9952073

00:30:37.485 --> 00:30:39.565 These results suggest that restrictive

NOTE Confidence: 0.9952073

00:30:39.565 --> 00:30:40.845 abortion policies may lead to

NOTE Confidence: 0.9952073

00:30:40.845 --> 00:30:42.205 an increase in neonatal and
NOTE Confidence: 0.9952073

00:30:42.205 --> 00:30:43.025 infant mortality,
NOTE Confidence: 0.99930525

00:30:43.405 --> 00:30:44.765 especially in the context of
NOTE Confidence: 0.99930525

00:30:44.765 --> 00:30:45.905 congenital anomalies.
NOTE Confidence: 0.99638975

00:30:48.365 --> 00:30:49.725 To be clear, the Dobbs
NOTE Confidence: 0.99638975

00:30:49.725 --> 00:30:51.325 ruling and other legislation related
NOTE Confidence: 0.99638975

00:30:51.325 --> 00:30:52.845 to abortion is strictly about
NOTE Confidence: 0.99638975

00:30:52.845 --> 00:30:54.020 abortion and not the type
NOTE Confidence: 0.99638975

00:30:54.020 --> 00:30:55.539 of care provided after a
NOTE Confidence: 0.99638975

00:30:55.539 --> 00:30:56.740 live birth or other care
NOTE Confidence: 0.99638975

00:30:56.740 --> 00:30:58.039 provided during the pregnancy.
NOTE Confidence: 0.9755203

00:30:59.140 --> 00:31:00.179 At the same time, the
NOTE Confidence: 0.9755203

00:31:00.179 --> 00:31:01.539 ruling has led to proposed
NOTE Confidence: 0.9755203

00:31:01.539 --> 00:31:03.240 legislation related to personhood.
NOTE Confidence: 0.9329147

00:31:04.500 --> 00:31:06.020 Eighteen states have born alive
NOTE Confidence: 0.9329147

00:31:06.020 --> 00:31:06.520 protections,

NOTE Confidence: 0.98914593
00:31:06.900 --> 00:31:08.500 and others have proposed similar
NOTE Confidence: 0.98914593
00:31:08.500 --> 00:31:09.995 bills, most based on the
NOTE Confidence: 0.98914593
00:31:09.995 --> 00:31:11.534 concept of fetal personhood,
NOTE Confidence: 0.98295295
00:31:11.914 --> 00:31:13.274 which is incongruent with the
NOTE Confidence: 0.98295295
00:31:13.274 --> 00:31:14.635 US codes of law that
NOTE Confidence: 0.98295295
00:31:14.635 --> 00:31:16.654 establish personhood after birth.
NOTE Confidence: 0.97304857
00:31:17.274 --> 00:31:18.475 It's important to note, though,
NOTE Confidence: 0.97304857
00:31:18.475 --> 00:31:19.934 that the existence of personhood,
NOTE Confidence: 0.97304857
00:31:19.995 --> 00:31:21.755 whenever it's decided that exist,
NOTE Confidence: 0.97304857
00:31:21.755 --> 00:31:23.195 does not determine the standard
NOTE Confidence: 0.97304857
00:31:23.195 --> 00:31:24.335 of medical care.
NOTE Confidence: 0.9790559
00:31:25.210 --> 00:31:27.130 Recent language, though, such as
NOTE Confidence: 0.9790559
00:31:27.130 --> 00:31:28.730 unborn human being or child
NOTE Confidence: 0.9790559
00:31:28.730 --> 00:31:29.630 creates ambiguity.
NOTE Confidence: 0.95221454
00:31:30.330 --> 00:31:31.450 If there is forced birth
NOTE Confidence: 0.95221454

00:31:31.450 --> 00:31:32.649 of an unborn person, does
NOTE Confidence: 0.95221454

00:31:32.649 --> 00:31:34.350 that necessitate forced resuscitation?
NOTE Confidence: 0.9979949

00:31:35.370 --> 00:31:36.490 If a fetus can be
NOTE Confidence: 0.9979949

00:31:36.490 --> 00:31:37.769 claimed as a dependent on
NOTE Confidence: 0.9979949

00:31:37.769 --> 00:31:39.235 taxes, what does that mean
NOTE Confidence: 0.9979949

00:31:39.235 --> 00:31:40.135 for decisions
NOTE Confidence: 0.9990833

00:31:40.595 --> 00:31:41.095 about
NOTE Confidence: 0.96544653

00:31:42.515 --> 00:31:43.955 interventions in utero or after
NOTE Confidence: 0.96544653

00:31:43.955 --> 00:31:44.455 delivery?
NOTE Confidence: 0.9973037

00:31:45.475 --> 00:31:46.934 The ambiguity of the legislation
NOTE Confidence: 0.9973037

00:31:46.995 --> 00:31:48.215 has also led to questions
NOTE Confidence: 0.9973037

00:31:48.434 --> 00:31:49.794 about the ability to offer
NOTE Confidence: 0.9973037

00:31:49.794 --> 00:31:51.395 invasive in utero or fetal
NOTE Confidence: 0.9973037

00:31:51.395 --> 00:31:52.960 interventions given the risks of
NOTE Confidence: 0.9973037

00:31:52.960 --> 00:31:54.880 fetal demise, nuances of multiple
NOTE Confidence: 0.9973037

00:31:54.880 --> 00:31:55.940 gestational pregnancies,

NOTE Confidence: 0.9892442

00:31:56.399 --> 00:31:57.940 and the potential for overuse

NOTE Confidence: 0.9892442

00:31:58.000 --> 00:31:59.600 of therapies if the laws

NOTE Confidence: 0.9892442

00:31:59.600 --> 00:32:01.039 are interpreted that to mean

NOTE Confidence: 0.9892442

00:32:01.039 --> 00:32:02.240 that fetal life must be

NOTE Confidence: 0.9892442

00:32:02.240 --> 00:32:03.539 preserved at all cost.

NOTE Confidence: 0.95086527

00:32:04.255 --> 00:32:06.174 Some proposed legislations, like, just

NOTE Confidence: 0.95086527

00:32:06.174 --> 00:32:07.955 that any neonate displaying movement,

NOTE Confidence: 0.95086527

00:32:08.015 --> 00:32:10.275 sound, heartbeat, or pulsating umbilical

NOTE Confidence: 0.95086527

00:32:10.335 --> 00:32:12.995 cord receives life sustaining interventions.

NOTE Confidence: 0.98320854

00:32:13.855 --> 00:32:15.455 This could mean providing potentially

NOTE Confidence: 0.98320854

00:32:15.455 --> 00:32:16.434 medically inappropriate

NOTE Confidence: 0.95862603

00:32:16.735 --> 00:32:18.495 treatments to previable neonates and

NOTE Confidence: 0.95862603

00:32:18.495 --> 00:32:19.955 neonates with life limiting

NOTE Confidence: 0.9254175

00:32:20.309 --> 00:32:21.830 anomalies such as fetal kidney

NOTE Confidence: 0.9254175

00:32:21.830 --> 00:32:22.330 failure

NOTE Confidence: 0.97206473

00:32:22.710 --> 00:32:23.590 when they would not be
NOTE Confidence: 0.97206473

00:32:23.590 --> 00:32:25.830 beneficial or if the parents
NOTE Confidence: 0.97206473

00:32:25.830 --> 00:32:27.190 and families perceive them as
NOTE Confidence: 0.97206473

00:32:27.190 --> 00:32:28.009 causing suffering.
NOTE Confidence: 0.9977582

00:32:28.950 --> 00:32:30.389 In this context, it would
NOTE Confidence: 0.9977582

00:32:30.389 --> 00:32:32.230 contradict recommendations from the AAP
NOTE Confidence: 0.9977582

00:32:32.230 --> 00:32:33.690 and other medical organizations,
NOTE Confidence: 0.9848439

00:32:34.605 --> 00:32:36.125 undermine patient autonomy, and really
NOTE Confidence: 0.9848439

00:32:36.125 --> 00:32:38.225 undervalue that patient physician relationship
NOTE Confidence: 0.91232985

00:32:38.845 --> 00:32:40.205 because all of these complex
NOTE Confidence: 0.91232985

00:32:40.205 --> 00:32:40.705 decisions
NOTE Confidence: 0.98473006

00:32:41.165 --> 00:32:42.285 really should be made by
NOTE Confidence: 0.98473006

00:32:42.285 --> 00:32:43.965 individuals or families and providers
NOTE Confidence: 0.98473006

00:32:43.965 --> 00:32:45.325 who really have the training
NOTE Confidence: 0.98473006

00:32:45.325 --> 00:32:46.365 and knowledge to understand the
NOTE Confidence: 0.98473006

00:32:46.365 --> 00:32:49.005 limits of interventions, explore family

NOTE Confidence: 0.98473006

00:32:49.005 --> 00:32:50.500 values, and navigate goals of

NOTE Confidence: 0.98473006

00:32:50.500 --> 00:32:51.000 care.

NOTE Confidence: 0.9986609

00:32:53.539 --> 00:32:55.539 One ethical concern with recent

NOTE Confidence: 0.9986609

00:32:55.539 --> 00:32:57.880 abortion legislation is lethality labeling.

NOTE Confidence: 0.9995558

00:32:58.659 --> 00:32:59.559 In Louisiana,

NOTE Confidence: 0.9878456

00:32:59.860 --> 00:33:01.299 abortion is banned with rare

NOTE Confidence: 0.9878456

00:33:01.299 --> 00:33:02.900 exceptions for a profound and

NOTE Confidence: 0.9878456

00:33:02.900 --> 00:33:05.559 irremediable congenital or chromosomal anomaly

NOTE Confidence: 0.9878456

00:33:05.595 --> 00:33:07.434 that is incompatible with sustaining

NOTE Confidence: 0.9878456

00:33:07.434 --> 00:33:08.655 life after birth.

NOTE Confidence: 0.9607368

00:33:09.275 --> 00:33:10.875 The list they created includes

NOTE Confidence: 0.9607368

00:33:10.875 --> 00:33:12.255 diagnosis such as holoprosencephaly

NOTE Confidence: 0.9741632

00:33:13.034 --> 00:33:15.195 and bilateral renal agenesis that

NOTE Confidence: 0.9741632

00:33:15.195 --> 00:33:16.975 can be compatible with life.

NOTE Confidence: 0.9955722

00:33:17.515 --> 00:33:19.275 Presumably, the creators of the

NOTE Confidence: 0.9955722

00:33:19.275 --> 00:33:21.070 list either didn't have appropriate
NOTE Confidence: 0.9955722

00:33:21.070 --> 00:33:23.010 medical knowledge or made assumptions
NOTE Confidence: 0.9595953

00:33:23.390 --> 00:33:25.070 about children with profound impairments
NOTE Confidence: 0.9595953

00:33:25.070 --> 00:33:26.350 in a shortened lifespan or
NOTE Confidence: 0.9595953

00:33:26.350 --> 00:33:27.890 individuals with medical complexity.
NOTE Confidence: 0.99902534

00:33:28.750 --> 00:33:30.370 This could perpetuate misunderstandings
NOTE Confidence: 0.99491626

00:33:30.909 --> 00:33:32.590 about disability or living with
NOTE Confidence: 0.99491626

00:33:32.590 --> 00:33:34.610 medical complexity and promote ableism.
NOTE Confidence: 0.9997721

00:33:35.505 --> 00:33:37.445 Some feel that disability discrimination
NOTE Confidence: 0.99844074

00:33:37.905 --> 00:33:39.105 is a concern if the
NOTE Confidence: 0.99844074

00:33:39.105 --> 00:33:40.805 reason for abortion is disability
NOTE Confidence: 0.99844074

00:33:40.865 --> 00:33:41.605 or disease.
NOTE Confidence: 0.99909335

00:33:42.625 --> 00:33:43.665 On the other hand, if
NOTE Confidence: 0.99909335

00:33:43.665 --> 00:33:44.725 a pregnant individual's
NOTE Confidence: 0.9981483

00:33:45.025 --> 00:33:46.945 decision is not respected, their
NOTE Confidence: 0.9981483

00:33:46.945 --> 00:33:48.325 autonomy is challenged.

NOTE Confidence: 0.98209906

00:33:48.705 --> 00:33:49.710 They may feel that their

NOTE Confidence: 0.98209906

00:33:49.710 --> 00:33:50.750 child will suffer for the

NOTE Confidence: 0.98209906

00:33:50.750 --> 00:33:51.789 duration of his or her

NOTE Confidence: 0.98209906

00:33:51.789 --> 00:33:53.309 life. There can be long

NOTE Confidence: 0.98209906

00:33:53.309 --> 00:33:55.649 lasting detrimental physical and psychological

NOTE Confidence: 0.98209906

00:33:55.870 --> 00:33:57.390 effects for that individual and

NOTE Confidence: 0.98209906

00:33:57.390 --> 00:33:58.850 the entire family unit.

NOTE Confidence: 0.9977113

00:34:01.230 --> 00:34:03.070 Some have inappropriately assumed that

NOTE Confidence: 0.9977113

00:34:03.070 --> 00:34:04.929 the existence of personhood dictates

NOTE Confidence: 0.9993038

00:34:05.235 --> 00:34:06.054 neonatal care.

NOTE Confidence: 0.9922829

00:34:06.434 --> 00:34:08.055 In other words, when personhood

NOTE Confidence: 0.9922829

00:34:08.195 --> 00:34:10.355 exists, invasive interventions must be

NOTE Confidence: 0.9922829

00:34:10.355 --> 00:34:11.955 pursued even when it's against

NOTE Confidence: 0.9922829

00:34:11.955 --> 00:34:13.155 the standard of care or

NOTE Confidence: 0.9922829

00:34:13.155 --> 00:34:14.215 parental wishes.

NOTE Confidence: 0.9902011

00:34:14.675 --> 00:34:16.114 This has resulted in not
NOTE Confidence: 0.9902011

00:34:16.114 --> 00:34:17.795 being able to redirect care,
NOTE Confidence: 0.9902011

00:34:17.795 --> 00:34:19.494 provide comfort care for neonate
NOTE Confidence: 0.9789257

00:34:19.860 --> 00:34:21.620 when families felt interventions would
NOTE Confidence: 0.9789257

00:34:21.620 --> 00:34:22.700 cause their baby to suffer
NOTE Confidence: 0.9789257

00:34:22.700 --> 00:34:23.940 or only prolong the dying
NOTE Confidence: 0.9789257

00:34:23.940 --> 00:34:24.440 process.
NOTE Confidence: 0.9852552

00:34:25.060 --> 00:34:26.900 Some examples include that some
NOTE Confidence: 0.9852552

00:34:26.900 --> 00:34:28.680 were not able to redirect
NOTE Confidence: 0.9852552

00:34:28.740 --> 00:34:29.700 care for a twenty two
NOTE Confidence: 0.9852552

00:34:29.700 --> 00:34:31.620 weaker despite parental wishes and
NOTE Confidence: 0.9852552

00:34:31.620 --> 00:34:32.840 were told by their institution
NOTE Confidence: 0.9852552

00:34:33.125 --> 00:34:34.244 that they had to continue
NOTE Confidence: 0.9852552

00:34:34.244 --> 00:34:35.924 invasive interventions until the baby
NOTE Confidence: 0.9852552

00:34:35.924 --> 00:34:37.125 was actively dying on the
NOTE Confidence: 0.9852552

00:34:37.125 --> 00:34:37.625 ventilator.

NOTE Confidence: 0.9863173

00:34:38.405 --> 00:34:39.924 Others have resuscitated babies that

NOTE Confidence: 0.9863173

00:34:39.924 --> 00:34:41.385 they were felt were periviable

NOTE Confidence: 0.9863173

00:34:41.525 --> 00:34:43.125 without discussing comfort measures with

NOTE Confidence: 0.9863173

00:34:43.125 --> 00:34:44.344 the family when they previously

NOTE Confidence: 0.9863173

00:34:44.405 --> 00:34:45.145 would have.

NOTE Confidence: 0.98816437

00:34:45.750 --> 00:34:46.630 Some were not able to

NOTE Confidence: 0.98816437

00:34:46.630 --> 00:34:48.150 offer comfort measures for neonates

NOTE Confidence: 0.98816437

00:34:48.150 --> 00:34:49.930 with various life limiting diagnoses.

NOTE Confidence: 0.99934596

00:34:51.110 --> 00:34:52.630 Several have shared situations where

NOTE Confidence: 0.99934596

00:34:52.630 --> 00:34:53.989 they were asked to provide

NOTE Confidence: 0.99934596

00:34:53.989 --> 00:34:55.050 invasive interventions

NOTE Confidence: 0.9360271

00:34:55.590 --> 00:34:57.270 to pre viable neonates because

NOTE Confidence: 0.9360271

00:34:57.270 --> 00:34:58.390 they had a heartbeat or

NOTE Confidence: 0.9360271

00:34:58.390 --> 00:34:59.770 breathing after birth.

NOTE Confidence: 0.9994723

00:35:00.405 --> 00:35:02.405 Collectively, many have expressed situations

NOTE Confidence: 0.9994723

00:35:02.405 --> 00:35:03.445 where they were forced to
NOTE Confidence: 0.9994723

00:35:03.445 --> 00:35:04.485 provide care that they felt
NOTE Confidence: 0.9994723

00:35:04.485 --> 00:35:05.705 was medically inappropriate
NOTE Confidence: 0.983964

00:35:06.005 --> 00:35:07.225 or against the parental
NOTE Confidence: 0.9991393

00:35:07.525 --> 00:35:08.025 wishes.
NOTE Confidence: 0.9980069

00:35:09.285 --> 00:35:10.725 With the concept of fetal
NOTE Confidence: 0.9980069

00:35:10.725 --> 00:35:11.225 personhood,
NOTE Confidence: 0.99171317

00:35:11.525 --> 00:35:13.305 it also transcends to decisions
NOTE Confidence: 0.9996109

00:35:13.685 --> 00:35:14.585 during the pregnancy.
NOTE Confidence: 0.99882954

00:35:15.670 --> 00:35:17.050 Some have felt pressure
NOTE Confidence: 0.99529386

00:35:17.510 --> 00:35:19.430 to promote fetal interventions to
NOTE Confidence: 0.99529386

00:35:19.510 --> 00:35:20.390 in an attempt to save
NOTE Confidence: 0.99529386

00:35:20.390 --> 00:35:21.510 a fetus as opposed to
NOTE Confidence: 0.99529386

00:35:21.510 --> 00:35:23.050 using a shared decision making
NOTE Confidence: 0.99529386

00:35:23.110 --> 00:35:24.810 approach with the pregnant individual.
NOTE Confidence: 0.99511373

00:35:25.670 --> 00:35:26.710 Some have expressed that they

NOTE Confidence: 0.99511373
00:35:26.710 --> 00:35:27.830 were unsure whether they could
NOTE Confidence: 0.99511373
00:35:27.830 --> 00:35:30.075 offer selective fetal reduction or,
NOTE Confidence: 0.9693341
00:35:30.474 --> 00:35:31.454 laser photocoagulation
NOTE Confidence: 0.9681402
00:35:31.835 --> 00:35:33.195 in the attempt to save
NOTE Confidence: 0.9681402
00:35:33.195 --> 00:35:35.195 a healthy twin and unsure
NOTE Confidence: 0.9681402
00:35:35.195 --> 00:35:36.234 that if they offer fetal
NOTE Confidence: 0.9681402
00:35:36.234 --> 00:35:37.775 surgery and the fetus demises,
NOTE Confidence: 0.9681402
00:35:37.994 --> 00:35:39.775 what those implications will be.
NOTE Confidence: 0.9869359
00:35:40.395 --> 00:35:41.915 One even described a woman
NOTE Confidence: 0.9869359
00:35:41.915 --> 00:35:43.594 undergoing a c section against
NOTE Confidence: 0.9869359
00:35:43.594 --> 00:35:45.110 her wishes in an attempt
NOTE Confidence: 0.9869359
00:35:45.110 --> 00:35:45.989 to save a fetus with
NOTE Confidence: 0.9869359
00:35:45.989 --> 00:35:47.130 a complex diagnosis.
NOTE Confidence: 0.97445756
00:35:48.150 --> 00:35:49.670 These situations are happening more
NOTE Confidence: 0.97445756
00:35:49.670 --> 00:35:51.510 and more frequently, really rule
NOTE Confidence: 0.97445756

00:35:51.590 --> 00:35:53.430 overruling those ethical principles of
NOTE Confidence: 0.97445756

00:35:53.430 --> 00:35:55.290 autonomy, beneficence, and nonmaleficence.
NOTE Confidence: 0.9823844

00:35:58.265 --> 00:35:59.385 The reality is even with
NOTE Confidence: 0.9823844

00:35:59.385 --> 00:36:01.145 the multiple ethical considerations and
NOTE Confidence: 0.9823844

00:36:01.145 --> 00:36:02.585 the constraints on the availability
NOTE Confidence: 0.9823844

00:36:02.585 --> 00:36:04.765 of care paths, innovative therapies
NOTE Confidence: 0.9823844

00:36:04.825 --> 00:36:06.585 have shifted the paradigm from
NOTE Confidence: 0.9823844

00:36:06.585 --> 00:36:08.025 fetal kidney failure and other
NOTE Confidence: 0.9823844

00:36:08.025 --> 00:36:10.345 complex fetal diagnoses being lethal
NOTE Confidence: 0.9823844

00:36:10.345 --> 00:36:11.840 or life limiting diagnoses to
NOTE Confidence: 0.9823844

00:36:11.840 --> 00:36:13.200 ones in which intensive care,
NOTE Confidence: 0.9823844

00:36:13.200 --> 00:36:15.300 surgeries, and kidney replacement therapies
NOTE Confidence: 0.9823844

00:36:15.520 --> 00:36:16.640 may lead to long term
NOTE Confidence: 0.9823844

00:36:16.640 --> 00:36:17.140 survival.
NOTE Confidence: 0.99638367

00:36:17.840 --> 00:36:19.360 However, we are not able
NOTE Confidence: 0.99638367

00:36:19.360 --> 00:36:20.960 to predict which fetuses will

NOTE Confidence: 0.99638367
00:36:20.960 --> 00:36:22.420 respond to in utero interventions
NOTE Confidence: 0.99638367
00:36:22.480 --> 00:36:23.860 and be pulmonary survivors.
NOTE Confidence: 0.97974885
00:36:24.855 --> 00:36:26.055 Likewise, we do not have
NOTE Confidence: 0.97974885
00:36:26.055 --> 00:36:27.895 models to predict which patients
NOTE Confidence: 0.97974885
00:36:27.895 --> 00:36:29.355 will survive to kidney transplant
NOTE Confidence: 0.97974885
00:36:29.494 --> 00:36:30.695 or which neonates will have
NOTE Confidence: 0.97974885
00:36:30.695 --> 00:36:33.035 detrimental complications related to interventions.
NOTE Confidence: 0.97817785
00:36:33.895 --> 00:36:35.035 The disease trajectory,
NOTE Confidence: 0.99844414
00:36:35.415 --> 00:36:36.795 irrespective of institutional
NOTE Confidence: 0.9477505
00:36:37.094 --> 00:36:38.920 experience, is uncertain and the
NOTE Confidence: 0.9477505
00:36:38.920 --> 00:36:40.440 clinical picture is still being
NOTE Confidence: 0.9477505
00:36:40.440 --> 00:36:40.940 understood.
NOTE Confidence: 0.9989436
00:36:41.560 --> 00:36:42.760 This really adds to the
NOTE Confidence: 0.9989436
00:36:42.760 --> 00:36:44.860 complexity involved in counseling individuals
NOTE Confidence: 0.9989436
00:36:44.920 --> 00:36:45.580 and families.
NOTE Confidence: 0.99853563

00:36:47.719 --> 00:36:49.480 Advances in prenatal screening and
NOTE Confidence: 0.99853563

00:36:49.480 --> 00:36:49.980 diagnostic
NOTE Confidence: 0.9703616

00:36:50.424 --> 00:36:51.464 technologies have allowed for the
NOTE Confidence: 0.9703616

00:36:51.464 --> 00:36:53.005 earlier and more frequent identification
NOTE Confidence: 0.9703616

00:36:53.224 --> 00:36:54.684 of complex fetal diagnoses.
NOTE Confidence: 0.98897773

00:36:55.545 --> 00:36:56.984 With the multiple potential care
NOTE Confidence: 0.98897773

00:36:56.984 --> 00:36:58.344 options, an increased number of
NOTE Confidence: 0.98897773

00:36:58.344 --> 00:37:00.684 families are seeking support, anticipatory
NOTE Confidence: 0.98897773

00:37:00.904 --> 00:37:02.045 guidance, and counseling.
NOTE Confidence: 0.97542775

00:37:02.950 --> 00:37:04.630 While learning the diagnosis earlier
NOTE Confidence: 0.97542775

00:37:04.630 --> 00:37:06.330 allows families time to grieve,
NOTE Confidence: 0.97542775

00:37:06.469 --> 00:37:08.070 make informed decisions, and plan
NOTE Confidence: 0.97542775

00:37:08.070 --> 00:37:09.450 for the remainder of pregnancy
NOTE Confidence: 0.97542775

00:37:09.510 --> 00:37:10.950 and when appropriate birth and
NOTE Confidence: 0.97542775

00:37:10.950 --> 00:37:12.790 neonatal care, it can also
NOTE Confidence: 0.97542775

00:37:12.790 --> 00:37:14.150 lead to more options and

NOTE Confidence: 0.97542775

00:37:14.150 --> 00:37:15.610 uncertainty as to the prognosis

NOTE Confidence: 0.9992137

00:37:15.910 --> 00:37:17.930 and most appropriate care plan.

NOTE Confidence: 0.9997306

00:37:18.485 --> 00:37:19.385 In this context,

NOTE Confidence: 0.9859791

00:37:20.085 --> 00:37:22.105 maternal fetal medicine specialists, neonatologists,

NOTE Confidence: 0.9872569

00:37:22.565 --> 00:37:24.885 nephrologists, palliative care providers, other

NOTE Confidence: 0.9872569

00:37:24.885 --> 00:37:26.825 subspecialists are tasked with providing

NOTE Confidence: 0.9872569

00:37:26.885 --> 00:37:28.585 comprehensive prognostic counseling

NOTE Confidence: 0.99663824

00:37:28.885 --> 00:37:30.165 and offering therapies in an

NOTE Confidence: 0.99663824

00:37:30.165 --> 00:37:31.285 ethical way where the burdens

NOTE Confidence: 0.99663824

00:37:31.285 --> 00:37:32.505 do not outweigh the benefits.

NOTE Confidence: 0.9975024

00:37:34.619 --> 00:37:36.380 Despite the importance of this

NOTE Confidence: 0.9975024

00:37:36.380 --> 00:37:37.819 comprehensive counseling care, we do

NOTE Confidence: 0.9975024

00:37:37.819 --> 00:37:38.960 have room for improvement.

NOTE Confidence: 0.9909591

00:37:39.500 --> 00:37:40.779 A recent survey showed that

NOTE Confidence: 0.9909591

00:37:40.779 --> 00:37:41.920 nephrologists and neonatologists

NOTE Confidence: 0.9984676

00:37:42.299 --> 00:37:43.900 do not consistently participate in
NOTE Confidence: 0.9984676

00:37:43.900 --> 00:37:45.259 counseling when there's a diagnosis
NOTE Confidence: 0.9984676

00:37:45.259 --> 00:37:46.640 of fetal kidney failure.
NOTE Confidence: 0.9765483

00:37:47.545 --> 00:37:49.305 Additionally, palliative care providers are
NOTE Confidence: 0.9765483

00:37:49.305 --> 00:37:50.745 never involved thirty five percent
NOTE Confidence: 0.9765483

00:37:50.745 --> 00:37:51.945 of the time and sometimes
NOTE Confidence: 0.9765483

00:37:51.945 --> 00:37:53.225 involved sixty percent of the
NOTE Confidence: 0.9765483

00:37:53.225 --> 00:37:53.725 time.
NOTE Confidence: 0.9935299

00:37:54.344 --> 00:37:56.025 This suggests that many families
NOTE Confidence: 0.9935299

00:37:56.025 --> 00:37:58.025 are making decisions without complete
NOTE Confidence: 0.9935299

00:37:58.025 --> 00:37:59.645 counseling care and support.
NOTE Confidence: 0.99705416

00:38:00.549 --> 00:38:02.309 Given the complex chronic nature
NOTE Confidence: 0.99705416

00:38:02.309 --> 00:38:03.670 of the diagnosis, the benefits
NOTE Confidence: 0.99705416

00:38:03.670 --> 00:38:04.869 and burdens to both the
NOTE Confidence: 0.99705416

00:38:04.869 --> 00:38:06.150 child and the family need
NOTE Confidence: 0.99705416

00:38:06.150 --> 00:38:06.969 to be understood.

NOTE Confidence: 0.999758
00:38:07.910 --> 00:38:09.049 While it is reasonable
NOTE Confidence: 0.99944234
00:38:09.430 --> 00:38:10.710 for parents to assume some
NOTE Confidence: 0.99944234
00:38:10.710 --> 00:38:11.989 burdens in order to improve
NOTE Confidence: 0.99944234
00:38:11.989 --> 00:38:12.650 the outcome
NOTE Confidence: 0.9987751
00:38:13.109 --> 00:38:14.955 of their child's health,
NOTE Confidence: 0.9941251
00:38:15.435 --> 00:38:16.635 forcing them to provide a
NOTE Confidence: 0.9941251
00:38:16.635 --> 00:38:18.235 therapy that may unduly burden
NOTE Confidence: 0.9941251
00:38:18.235 --> 00:38:19.435 their child may not benefit
NOTE Confidence: 0.9941251
00:38:19.435 --> 00:38:20.175 that child.
NOTE Confidence: 0.99525917
00:38:20.795 --> 00:38:22.875 Parental refusal of in utero
NOTE Confidence: 0.99525917
00:38:22.875 --> 00:38:24.875 interventions and neonatal dialysis may
NOTE Confidence: 0.99525917
00:38:24.875 --> 00:38:25.995 be a thoughtful and loving
NOTE Confidence: 0.99525917
00:38:25.995 --> 00:38:26.495 decision
NOTE Confidence: 0.982135
00:38:26.875 --> 00:38:28.555 or stem from misinformation and
NOTE Confidence: 0.982135
00:38:28.555 --> 00:38:30.255 a lack of comprehensive counseling.
NOTE Confidence: 0.9855591

00:38:31.050 --> 00:38:32.489 Views and decisions really tend
NOTE Confidence: 0.9855591

00:38:32.489 --> 00:38:34.090 to evolve over time as
NOTE Confidence: 0.9855591

00:38:34.090 --> 00:38:35.130 families with the help of
NOTE Confidence: 0.9855591

00:38:35.130 --> 00:38:36.250 their care team really begin
NOTE Confidence: 0.9855591

00:38:36.250 --> 00:38:37.530 to understand what life with
NOTE Confidence: 0.9855591

00:38:37.530 --> 00:38:38.810 end stage kidney disease or
NOTE Confidence: 0.9855591

00:38:38.810 --> 00:38:40.750 foregoing interventions looks like.
NOTE Confidence: 0.9929399

00:38:43.025 --> 00:38:44.465 It's important to remember that
NOTE Confidence: 0.9929399

00:38:44.465 --> 00:38:45.825 many fetal anomalies are not
NOTE Confidence: 0.9929399

00:38:45.825 --> 00:38:47.105 identified until that eighteen to
NOTE Confidence: 0.9929399

00:38:47.105 --> 00:38:48.625 twenty two week anatomy scan,
NOTE Confidence: 0.9929399

00:38:48.625 --> 00:38:49.905 and some are not identified
NOTE Confidence: 0.9929399

00:38:49.905 --> 00:38:51.125 till long after that.
NOTE Confidence: 0.99919355

00:38:51.825 --> 00:38:53.425 While grieving, the family often
NOTE Confidence: 0.99919355

00:38:53.425 --> 00:38:54.545 has a limited window to
NOTE Confidence: 0.99919355

00:38:54.545 --> 00:38:56.305 gather more information about what

NOTE Confidence: 0.99919355

00:38:56.305 --> 00:38:57.505 those anomalies mean for their

NOTE Confidence: 0.99919355

00:38:57.505 --> 00:38:59.690 pregnancy and make decisions about

NOTE Confidence: 0.99919355

00:38:59.910 --> 00:39:00.410 abortion,

NOTE Confidence: 0.9911261

00:39:00.710 --> 00:39:02.469 fetal interventions when appropriate, or

NOTE Confidence: 0.9911261

00:39:02.469 --> 00:39:03.510 the care path that best

NOTE Confidence: 0.9911261

00:39:03.510 --> 00:39:04.810 aligns with their views.

NOTE Confidence: 0.97211456

00:39:05.510 --> 00:39:06.469 Mapped out on the slide,

NOTE Confidence: 0.97211456

00:39:06.469 --> 00:39:08.090 they're meeting with multiple subspecialists

NOTE Confidence: 0.9803228

00:39:08.550 --> 00:39:09.290 in green

NOTE Confidence: 0.9618972

00:39:09.670 --> 00:39:11.109 to discuss the prognosis and

NOTE Confidence: 0.9618972

00:39:11.109 --> 00:39:12.710 care paths in blue at

NOTE Confidence: 0.9618972

00:39:12.710 --> 00:39:13.590 a time when they really

NOTE Confidence: 0.9618972

00:39:13.590 --> 00:39:14.655 need trust with their care

NOTE Confidence: 0.9618972

00:39:14.655 --> 00:39:15.155 team.

NOTE Confidence: 0.99962866

00:39:15.614 --> 00:39:16.355 The obstetrician

NOTE Confidence: 0.97090715

00:39:16.735 --> 00:39:17.775 who they developed a very
NOTE Confidence: 0.97090715

00:39:17.775 --> 00:39:19.295 strong relationship with may or
NOTE Confidence: 0.97090715

00:39:19.295 --> 00:39:20.575 may not continue to follow
NOTE Confidence: 0.97090715

00:39:20.575 --> 00:39:21.075 them.
NOTE Confidence: 0.9524983

00:39:21.695 --> 00:39:23.055 When a family continues the
NOTE Confidence: 0.9524983

00:39:23.055 --> 00:39:24.655 pregnancy, there will be multiple
NOTE Confidence: 0.9524983

00:39:24.655 --> 00:39:26.815 visits, oftentimes with providers in
NOTE Confidence: 0.9524983

00:39:26.815 --> 00:39:28.114 different hospital systems.
NOTE Confidence: 0.99898416

00:39:28.730 --> 00:39:29.849 If they elect for comfort
NOTE Confidence: 0.99898416

00:39:29.849 --> 00:39:31.529 measures, it'll be important that
NOTE Confidence: 0.99898416

00:39:31.529 --> 00:39:32.650 everyone is aware of their
NOTE Confidence: 0.99898416

00:39:32.650 --> 00:39:33.150 goals
NOTE Confidence: 0.99703735

00:39:33.609 --> 00:39:34.730 and what that care will
NOTE Confidence: 0.99703735

00:39:34.730 --> 00:39:35.390 look like.
NOTE Confidence: 0.9983422

00:39:35.770 --> 00:39:37.289 When families elect for invasive
NOTE Confidence: 0.9983422

00:39:37.289 --> 00:39:37.789 interventions,

NOTE Confidence: 0.9997727

00:39:38.329 --> 00:39:39.130 we are going to be

NOTE Confidence: 0.9997727

00:39:39.130 --> 00:39:39.630 providing

NOTE Confidence: 0.99741924

00:39:40.089 --> 00:39:42.029 care for medically complex patients.

NOTE Confidence: 0.99178934

00:39:42.455 --> 00:39:44.475 We engage in ongoing conversations

NOTE Confidence: 0.99527735

00:39:45.015 --> 00:39:46.055 about the goals of care

NOTE Confidence: 0.99527735

00:39:46.055 --> 00:39:47.975 in purple and treatment paths

NOTE Confidence: 0.99527735

00:39:47.975 --> 00:39:49.094 as they may shift over

NOTE Confidence: 0.99527735

00:39:49.094 --> 00:39:49.594 time.

NOTE Confidence: 0.9984815

00:39:50.295 --> 00:39:51.594 With the multiple complications,

NOTE Confidence: 0.9975708

00:39:51.895 --> 00:39:54.215 challenges, and invasive procedures, there

NOTE Confidence: 0.9975708

00:39:54.215 --> 00:39:55.755 will be many decision points.

NOTE Confidence: 0.9515389

00:39:56.400 --> 00:39:57.839 Having a consistent care team,

NOTE Confidence: 0.9515389

00:39:57.839 --> 00:39:59.119 the palliative care team, who

NOTE Confidence: 0.9515389

00:39:59.119 --> 00:40:00.640 over time knows the family

NOTE Confidence: 0.9515389

00:40:00.640 --> 00:40:02.420 and their journey facilitates trust,

NOTE Confidence: 0.9940168

00:40:02.799 --> 00:40:04.579 open conversations, and a mutual
NOTE Confidence: 0.9940168

00:40:04.640 --> 00:40:06.480 understanding as they're navigating these
NOTE Confidence: 0.9940168

00:40:06.480 --> 00:40:07.460 complex decisions.
NOTE Confidence: 0.99876773

00:40:09.315 --> 00:40:10.594 When counseling a family, the
NOTE Confidence: 0.99876773

00:40:10.594 --> 00:40:11.955 goal is not simply to
NOTE Confidence: 0.99876773

00:40:11.955 --> 00:40:13.655 deliver information or direct
NOTE Confidence: 0.9464224

00:40:13.955 --> 00:40:15.474 care decisions and care. The
NOTE Confidence: 0.9464224

00:40:15.474 --> 00:40:16.594 intent is to engage in
NOTE Confidence: 0.9464224

00:40:16.594 --> 00:40:18.275 on dialogue that promotes autonomy
NOTE Confidence: 0.9464224

00:40:18.275 --> 00:40:19.815 and informed decision making.
NOTE Confidence: 0.9761467

00:40:20.275 --> 00:40:21.555 The focus should be on
NOTE Confidence: 0.9761467

00:40:21.555 --> 00:40:22.110 the patient,
NOTE Confidence: 0.9982514

00:40:22.670 --> 00:40:24.590 their values, their goals, their
NOTE Confidence: 0.9982514

00:40:24.590 --> 00:40:25.489 unique journey.
NOTE Confidence: 0.9607794

00:40:25.950 --> 00:40:26.910 Knowing this will make it
NOTE Confidence: 0.9607794

00:40:26.910 --> 00:40:28.750 easier to provide information the

NOTE Confidence: 0.9607794
00:40:28.750 --> 00:40:30.030 patient can drive meaning from
NOTE Confidence: 0.9607794
00:40:30.030 --> 00:40:31.310 it, make truly formed in
NOTE Confidence: 0.9607794
00:40:31.310 --> 00:40:32.290 decisions with.
NOTE Confidence: 0.9956373
00:40:32.670 --> 00:40:33.790 What we're really talking about
NOTE Confidence: 0.9956373
00:40:33.790 --> 00:40:34.989 is a shared decision making
NOTE Confidence: 0.9956373
00:40:34.989 --> 00:40:36.050 approach to care.
NOTE Confidence: 0.9996545
00:40:36.474 --> 00:40:37.755 When weighing the risks and
NOTE Confidence: 0.9996545
00:40:37.755 --> 00:40:38.255 benefits
NOTE Confidence: 0.97837144
00:40:38.875 --> 00:40:39.994 of a treatment path for
NOTE Confidence: 0.97837144
00:40:39.994 --> 00:40:41.594 pregnancy with a complex fetal
NOTE Confidence: 0.97837144
00:40:41.594 --> 00:40:44.015 diagnosis, parents consider that diagnostic
NOTE Confidence: 0.97837144
00:40:44.155 --> 00:40:44.815 and prognostic
NOTE Confidence: 0.8963407
00:40:45.114 --> 00:40:45.614 certainty,
NOTE Confidence: 0.98578185
00:40:46.315 --> 00:40:47.675 the likelihood of a good
NOTE Confidence: 0.98578185
00:40:47.675 --> 00:40:49.614 outcome, and avoidance of suffering
NOTE Confidence: 0.98578185

00:40:49.755 --> 00:40:50.494 and regret.
NOTE Confidence: 0.9752939

00:40:51.320 --> 00:40:52.200 It is our job to
NOTE Confidence: 0.9752939

00:40:52.200 --> 00:40:53.640 really engage in a partnership
NOTE Confidence: 0.9752939

00:40:53.640 --> 00:40:55.160 to better understand how in
NOTE Confidence: 0.9752939

00:40:55.160 --> 00:40:57.020 the context of their specific
NOTE Confidence: 0.9752939

00:40:57.080 --> 00:40:58.520 situation and goals or values
NOTE Confidence: 0.9752939

00:40:58.520 --> 00:41:00.380 the medical information becomes important.
NOTE Confidence: 0.9990543

00:41:01.320 --> 00:41:02.520 Based on that, we can
NOTE Confidence: 0.9990543

00:41:02.520 --> 00:41:04.335 arrive at a decision about
NOTE Confidence: 0.9990543

00:41:04.335 --> 00:41:05.535 the most appropriate plan of
NOTE Confidence: 0.9990543

00:41:05.535 --> 00:41:06.895 care that really builds trust,
NOTE Confidence: 0.9990543

00:41:06.895 --> 00:41:08.495 minimizes burden, and promotes the
NOTE Confidence: 0.9990543

00:41:08.495 --> 00:41:09.635 best patient outcomes.
NOTE Confidence: 0.9984196

00:41:10.335 --> 00:41:11.614 Parents rely on us to
NOTE Confidence: 0.9984196

00:41:11.614 --> 00:41:12.815 encourage them to express their
NOTE Confidence: 0.9984196

00:41:12.815 --> 00:41:14.195 hopes, fears, and goals.

NOTE Confidence: 0.9769788

00:41:14.735 --> 00:41:16.175 Only then can providers and

NOTE Confidence: 0.9769788

00:41:16.175 --> 00:41:17.900 parents collaborate to make decisions

NOTE Confidence: 0.9769788

00:41:17.900 --> 00:41:19.660 and plans really balancing autonomy

NOTE Confidence: 0.9769788

00:41:19.660 --> 00:41:21.420 and parental authority with medical

NOTE Confidence: 0.9769788

00:41:21.420 --> 00:41:22.800 recommendations and prognosis.

NOTE Confidence: 0.95736384

00:41:25.260 --> 00:41:26.620 When navigating goals of care,

NOTE Confidence: 0.95736384

00:41:26.620 --> 00:41:28.300 many factors influence the decisions

NOTE Confidence: 0.95736384

00:41:28.300 --> 00:41:29.180 that are made and how

NOTE Confidence: 0.95736384

00:41:29.180 --> 00:41:30.860 an individual determines what a

NOTE Confidence: 0.95736384

00:41:30.860 --> 00:41:31.245 good outcome

NOTE Confidence: 0.8937129

00:41:32.445 --> 00:41:35.045 is. These factors include personal

NOTE Confidence: 0.8937129

00:41:35.045 --> 00:41:36.285 attributes, such as age, medical

NOTE Confidence: 0.8937129

00:41:36.285 --> 00:41:38.065 history, gestation at diagnosis,

NOTE Confidence: 0.9478248

00:41:38.445 --> 00:41:39.805 the context of the pregnancy,

NOTE Confidence: 0.9478248

00:41:39.805 --> 00:41:40.605 if it was planned or

NOTE Confidence: 0.9478248

00:41:40.605 --> 00:41:41.485 they had a long journey
NOTE Confidence: 0.9478248

00:41:41.485 --> 00:41:42.465 to become pregnant,
NOTE Confidence: 0.98784655

00:41:42.765 --> 00:41:44.205 past experiences with the medical
NOTE Confidence: 0.98784655

00:41:44.205 --> 00:41:45.105 field, and socioeconomic
NOTE Confidence: 0.99879277

00:41:45.565 --> 00:41:46.065 status.
NOTE Confidence: 0.9468304

00:41:46.969 --> 00:41:48.989 Personal views including religious beliefs,
NOTE Confidence: 0.9468304

00:41:49.289 --> 00:41:51.549 cultural values, tolerance of uncertainty,
NOTE Confidence: 0.9583598

00:41:51.849 --> 00:41:53.049 views of quality of life,
NOTE Confidence: 0.9583598

00:41:53.049 --> 00:41:54.730 and beliefs about those various
NOTE Confidence: 0.9583598

00:41:54.730 --> 00:41:56.829 treatment options play a significant
NOTE Confidence: 0.9583598

00:41:56.890 --> 00:41:57.390 role.
NOTE Confidence: 0.9779472

00:41:58.010 --> 00:41:59.609 There's also the information itself
NOTE Confidence: 0.9779472

00:41:59.609 --> 00:42:00.730 and how it's conveyed to
NOTE Confidence: 0.9779472

00:42:00.730 --> 00:42:01.230 families,
NOTE Confidence: 0.9997001

00:42:01.625 --> 00:42:02.984 the severity of the anomalies,
NOTE Confidence: 0.9997001

00:42:02.984 --> 00:42:04.204 the expected prognosis,

NOTE Confidence: 0.9947387

00:42:04.585 --> 00:42:06.665 treatment options available, bias we

NOTE Confidence: 0.9947387

00:42:06.665 --> 00:42:08.025 portray in counseling, and the

NOTE Confidence: 0.9947387

00:42:08.025 --> 00:42:09.545 influences of families and friends

NOTE Confidence: 0.9947387

00:42:09.545 --> 00:42:10.045 matter.

NOTE Confidence: 0.9864607

00:42:10.744 --> 00:42:11.704 And then there are those

NOTE Confidence: 0.9864607

00:42:11.704 --> 00:42:13.545 structural influences, including whether an

NOTE Confidence: 0.9864607

00:42:13.545 --> 00:42:14.045 individual

NOTE Confidence: 0.9873524

00:42:14.420 --> 00:42:15.620 has access to all the

NOTE Confidence: 0.9873524

00:42:15.620 --> 00:42:17.000 options for various reasons.

NOTE Confidence: 0.9660557

00:42:17.300 --> 00:42:18.100 All this is to say

NOTE Confidence: 0.9660557

00:42:18.100 --> 00:42:19.460 that decisions are made based

NOTE Confidence: 0.9660557

00:42:19.460 --> 00:42:21.060 on multiple important factors beyond

NOTE Confidence: 0.9660557

00:42:21.060 --> 00:42:21.640 the medical

NOTE Confidence: 0.99900925

00:42:21.940 --> 00:42:23.300 facts or information conveyed to

NOTE Confidence: 0.99900925

00:42:23.300 --> 00:42:23.880 the family.

NOTE Confidence: 0.9973843

00:42:25.620 --> 00:42:26.660 When we take a step
NOTE Confidence: 0.9973843

00:42:26.660 --> 00:42:27.780 back and review the care
NOTE Confidence: 0.9973843

00:42:27.780 --> 00:42:29.080 journey, we can really appreciate
NOTE Confidence: 0.9973843

00:42:29.140 --> 00:42:30.965 how complex it is. Many
NOTE Confidence: 0.9973843

00:42:30.965 --> 00:42:32.825 pursue abortion or comfort measures.
NOTE Confidence: 0.9997919

00:42:33.205 --> 00:42:34.665 For those who pursue interventions,
NOTE Confidence: 0.99948674

00:42:35.125 --> 00:42:36.585 survival may be possible.
NOTE Confidence: 0.9857736

00:42:37.125 --> 00:42:38.325 With survival, though, there are
NOTE Confidence: 0.9857736

00:42:38.325 --> 00:42:40.005 unique challenges and long term
NOTE Confidence: 0.9857736

00:42:40.005 --> 00:42:40.745 care needs.
NOTE Confidence: 0.9904344

00:42:41.205 --> 00:42:42.085 I've given you a lot
NOTE Confidence: 0.9904344

00:42:42.085 --> 00:42:43.605 of information to digest in
NOTE Confidence: 0.9904344

00:42:43.605 --> 00:42:44.820 less than an hour, but
NOTE Confidence: 0.9904344

00:42:44.820 --> 00:42:46.020 think about the patients and
NOTE Confidence: 0.9904344

00:42:46.020 --> 00:42:47.219 families who are expected to
NOTE Confidence: 0.9904344

00:42:47.219 --> 00:42:48.980 digest this information and more

NOTE Confidence: 0.9904344

00:42:48.980 --> 00:42:50.500 sometimes over the course of

NOTE Confidence: 0.9904344

00:42:50.500 --> 00:42:51.400 a day or so.

NOTE Confidence: 0.9989665

00:42:51.860 --> 00:42:53.060 How can we provide total

NOTE Confidence: 0.9989665

00:42:53.060 --> 00:42:54.120 care to these patients?

NOTE Confidence: 0.9973215

00:42:54.660 --> 00:42:55.160 Irrespective

NOTE Confidence: 0.9689639

00:42:55.700 --> 00:42:56.739 of the goals of care

NOTE Confidence: 0.9689639

00:42:56.739 --> 00:42:58.660 treatment options chosen, palliative care

NOTE Confidence: 0.9689639

00:42:58.660 --> 00:43:00.344 is an important component to

NOTE Confidence: 0.9689639

00:43:00.344 --> 00:43:01.244 providing that total

NOTE Confidence: 0.9977794

00:43:01.705 --> 00:43:02.765 comprehensive care.

NOTE Confidence: 0.97574395

00:43:04.505 --> 00:43:06.185 Neonatal perinatal palliative care has

NOTE Confidence: 0.97574395

00:43:06.185 --> 00:43:06.905 really grown out of the

NOTE Confidence: 0.97574395

00:43:06.905 --> 00:43:08.265 field of hospice and palliative

NOTE Confidence: 0.97574395

00:43:08.265 --> 00:43:09.465 medicine with the goal of

NOTE Confidence: 0.97574395

00:43:09.465 --> 00:43:10.825 caring for and supporting families

NOTE Confidence: 0.97574395

00:43:10.825 --> 00:43:12.605 with a concerning life limiting,
NOTE Confidence: 0.97574395

00:43:12.665 --> 00:43:14.364 life threatening fetal or neonatal
NOTE Confidence: 0.97574395

00:43:14.505 --> 00:43:15.005 diagnosis.
NOTE Confidence: 0.9996094

00:43:15.780 --> 00:43:17.300 When such a diagnosis is
NOTE Confidence: 0.9996094

00:43:17.300 --> 00:43:18.900 made, the pregnancy and birth
NOTE Confidence: 0.9996094

00:43:18.900 --> 00:43:20.340 narrative has really been broken
NOTE Confidence: 0.9996094

00:43:20.340 --> 00:43:21.160 for that family.
NOTE Confidence: 0.9965524

00:43:21.700 --> 00:43:23.060 The goal is to offer
NOTE Confidence: 0.9965524

00:43:23.060 --> 00:43:24.200 comprehensive interdisciplinary
NOTE Confidence: 0.9947462

00:43:24.500 --> 00:43:25.620 care during the remainder of
NOTE Confidence: 0.9947462

00:43:25.620 --> 00:43:26.840 the pregnancy and afterwards,
NOTE Confidence: 0.9990015

00:43:27.380 --> 00:43:29.160 help parents process the information,
NOTE Confidence: 0.95867664

00:43:29.540 --> 00:43:31.305 consider the potential care pass,
NOTE Confidence: 0.95867664

00:43:31.305 --> 00:43:32.765 and parent their baby.
NOTE Confidence: 0.9848705

00:43:33.224 --> 00:43:34.585 For each family, this care
NOTE Confidence: 0.9848705

00:43:34.585 --> 00:43:35.625 is unique, and it is

NOTE Confidence: 0.9848705

00:43:35.625 --> 00:43:37.464 continued irrespective of the disease

NOTE Confidence: 0.9848705

00:43:37.464 --> 00:43:37.964 trajectory,

NOTE Confidence: 0.9956097

00:43:38.265 --> 00:43:40.364 treatment options chosen, or transitions

NOTE Confidence: 0.9956097

00:43:40.425 --> 00:43:41.484 in care settings.

NOTE Confidence: 0.99872434

00:43:42.105 --> 00:43:43.944 Many only associate palliative care

NOTE Confidence: 0.99872434

00:43:43.944 --> 00:43:44.685 with hospice.

NOTE Confidence: 0.9966542

00:43:45.290 --> 00:43:46.730 While an important component, it

NOTE Confidence: 0.9966542

00:43:46.730 --> 00:43:48.010 is a small portion of

NOTE Confidence: 0.9966542

00:43:48.010 --> 00:43:50.089 the comprehensive care provided. My

NOTE Confidence: 0.9966542

00:43:50.089 --> 00:43:50.890 goal is not to get

NOTE Confidence: 0.9966542

00:43:50.890 --> 00:43:52.089 the DNR or convince a

NOTE Confidence: 0.9966542

00:43:52.089 --> 00:43:53.290 family to pursue a comfort

NOTE Confidence: 0.9966542

00:43:53.290 --> 00:43:54.910 measures only approach to care.

NOTE Confidence: 0.9776402

00:43:55.290 --> 00:43:56.570 I'm an intensivist at heart,

NOTE Confidence: 0.9776402

00:43:56.570 --> 00:43:57.609 and anyone who knows me

NOTE Confidence: 0.9776402

00:43:57.609 --> 00:43:58.489 knows I like to take
NOTE Confidence: 0.9776402

00:43:58.489 --> 00:43:59.530 care of the most complex
NOTE Confidence: 0.9776402

00:43:59.530 --> 00:44:01.005 and critically ill babies in
NOTE Confidence: 0.9776402

00:44:01.005 --> 00:44:01.825 the NICU.
NOTE Confidence: 0.98874587

00:44:02.605 --> 00:44:03.724 My goal is in the
NOTE Confidence: 0.98874587

00:44:03.724 --> 00:44:05.005 midst of an intensive care
NOTE Confidence: 0.98874587

00:44:05.005 --> 00:44:07.005 mindset to provide value driven
NOTE Confidence: 0.98874587

00:44:07.005 --> 00:44:07.904 medical care
NOTE Confidence: 0.9878861

00:44:08.204 --> 00:44:09.805 and to provide total support
NOTE Confidence: 0.9878861

00:44:09.805 --> 00:44:10.924 and care to the entire
NOTE Confidence: 0.9878861

00:44:10.924 --> 00:44:11.424 family.
NOTE Confidence: 0.98351115

00:44:13.109 --> 00:44:14.309 The team can assist in
NOTE Confidence: 0.98351115

00:44:14.309 --> 00:44:14.809 communication,
NOTE Confidence: 0.93687975

00:44:15.269 --> 00:44:16.950 support families in complex medical
NOTE Confidence: 0.93687975

00:44:16.950 --> 00:44:18.549 decision making, and ensure that
NOTE Confidence: 0.93687975

00:44:18.549 --> 00:44:20.329 there is continuity in care.

NOTE Confidence: 0.99877125

00:44:20.789 --> 00:44:22.390 Recognizing that the family is

NOTE Confidence: 0.99877125

00:44:22.390 --> 00:44:23.829 experiencing loss at the time

NOTE Confidence: 0.99877125

00:44:23.829 --> 00:44:24.489 of diagnosis,

NOTE Confidence: 0.9980216

00:44:25.045 --> 00:44:26.645 bereavement and grief support are

NOTE Confidence: 0.9980216

00:44:26.645 --> 00:44:28.245 offered from the beginning through

NOTE Confidence: 0.9980216

00:44:28.245 --> 00:44:29.765 that entire illness course and

NOTE Confidence: 0.9980216

00:44:29.765 --> 00:44:30.265 beyond.

NOTE Confidence: 0.9977678

00:44:30.805 --> 00:44:31.844 At any one point in

NOTE Confidence: 0.9977678

00:44:31.844 --> 00:44:33.364 time, there really is a

NOTE Confidence: 0.9977678

00:44:33.364 --> 00:44:35.285 balance between curing, healing, and

NOTE Confidence: 0.9977678

00:44:35.285 --> 00:44:35.785 bereavement.

NOTE Confidence: 0.9754253

00:44:37.110 --> 00:44:38.310 The focus is always on

NOTE Confidence: 0.9754253

00:44:38.310 --> 00:44:39.590 quality of life and comfort

NOTE Confidence: 0.9754253

00:44:39.590 --> 00:44:41.850 irrespective of those medical management

NOTE Confidence: 0.9754253

00:44:41.910 --> 00:44:42.410 goals.

NOTE Confidence: 0.99944144

00:44:42.790 --> 00:44:44.150 In addition to helping families
NOTE Confidence: 0.99944144

00:44:44.150 --> 00:44:45.750 understand the diagnosis and medical
NOTE Confidence: 0.99944144

00:44:45.750 --> 00:44:47.830 management, we provide opportunities for
NOTE Confidence: 0.99944144

00:44:47.830 --> 00:44:49.690 birth planning and memory making.
NOTE Confidence: 0.9997391

00:44:50.395 --> 00:44:51.435 Again, end of life care
NOTE Confidence: 0.9997391

00:44:51.435 --> 00:44:53.035 is one component for some
NOTE Confidence: 0.9997391

00:44:53.035 --> 00:44:53.535 patients.
NOTE Confidence: 0.9496444

00:44:55.595 --> 00:44:56.975 Mapped out on this slide,
NOTE Confidence: 0.9496444

00:44:57.195 --> 00:44:58.955 there should be continual support,
NOTE Confidence: 0.9496444

00:44:58.955 --> 00:45:00.875 consistency, and counseling through all
NOTE Confidence: 0.9496444

00:45:00.875 --> 00:45:01.935 phases in care.
NOTE Confidence: 0.9628552

00:45:02.330 --> 00:45:04.489 This continuity really facilitates seamless
NOTE Confidence: 0.9628552

00:45:04.489 --> 00:45:05.610 transitions in care and a
NOTE Confidence: 0.9628552

00:45:05.610 --> 00:45:07.370 unique journey opportunity to walk
NOTE Confidence: 0.9628552

00:45:07.370 --> 00:45:08.510 the journey with the family.
NOTE Confidence: 0.906418

00:45:09.050 --> 00:45:10.969 Immediately after diagnosis, after as

NOTE Confidence: 0.906418

00:45:10.969 --> 00:45:12.830 I mentioned, families are grieving.

NOTE Confidence: 0.9985387

00:45:13.210 --> 00:45:14.505 They often need time to

NOTE Confidence: 0.9985387

00:45:14.505 --> 00:45:16.105 process the information, and they

NOTE Confidence: 0.9985387

00:45:16.105 --> 00:45:17.805 may need more information before

NOTE Confidence: 0.9985387

00:45:17.864 --> 00:45:18.844 making a decision.

NOTE Confidence: 0.9953175

00:45:19.625 --> 00:45:21.385 As the pregnancy continues, they're

NOTE Confidence: 0.9953175

00:45:21.385 --> 00:45:22.744 really beginning to incorporate the

NOTE Confidence: 0.9953175

00:45:22.744 --> 00:45:23.644 medical information

NOTE Confidence: 0.9995724

00:45:24.344 --> 00:45:26.204 into their decision making framework.

NOTE Confidence: 0.994978

00:45:26.950 --> 00:45:28.469 Our job is to ensure

NOTE Confidence: 0.994978

00:45:28.469 --> 00:45:29.590 that all providers are aware

NOTE Confidence: 0.994978

00:45:29.590 --> 00:45:30.330 of the information,

NOTE Confidence: 0.9892404

00:45:30.790 --> 00:45:31.830 where they are in their

NOTE Confidence: 0.9892404

00:45:31.830 --> 00:45:32.330 journey,

NOTE Confidence: 0.99070114

00:45:32.870 --> 00:45:34.230 and their goals so that

NOTE Confidence: 0.99070114

00:45:34.230 --> 00:45:35.770 unified care is provided.
NOTE Confidence: 0.99950826

00:45:36.550 --> 00:45:37.670 It's important that we help
NOTE Confidence: 0.99950826

00:45:37.670 --> 00:45:39.350 families understand what the medical
NOTE Confidence: 0.99950826

00:45:39.350 --> 00:45:40.870 information means in the context
NOTE Confidence: 0.99950826

00:45:40.870 --> 00:45:42.410 of their views and values.
NOTE Confidence: 0.98894644

00:45:43.155 --> 00:45:44.195 I find it helpful to
NOTE Confidence: 0.98894644

00:45:44.195 --> 00:45:44.995 remember that when it comes
NOTE Confidence: 0.98894644

00:45:44.995 --> 00:45:46.295 to a fetus or neonate,
NOTE Confidence: 0.98894644

00:45:46.515 --> 00:45:47.395 the parents may not have
NOTE Confidence: 0.98894644

00:45:47.395 --> 00:45:48.355 thought about quality of life
NOTE Confidence: 0.98894644

00:45:48.355 --> 00:45:49.555 or advanced care planning for
NOTE Confidence: 0.98894644

00:45:49.555 --> 00:45:51.415 themselves, let alone their baby.
NOTE Confidence: 0.985346

00:45:58.440 --> 00:45:59.640 It's also important that we
NOTE Confidence: 0.985346

00:45:59.640 --> 00:46:01.160 help families celebrate moments during
NOTE Confidence: 0.985346

00:46:01.160 --> 00:46:02.680 the pregnancy and make beautiful
NOTE Confidence: 0.985346

00:46:02.680 --> 00:46:03.180 memories.

NOTE Confidence: 0.96980476
00:46:03.560 --> 00:46:05.020 When the pregnancy continues,
NOTE Confidence: 0.99974096
00:46:05.960 --> 00:46:07.640 even after delivery, families may
NOTE Confidence: 0.99974096
00:46:07.640 --> 00:46:09.500 need more information or time
NOTE Confidence: 0.99974096
00:46:09.560 --> 00:46:10.060 to
NOTE Confidence: 0.9996485
00:46:10.594 --> 00:46:12.035 determine the most appropriate care
NOTE Confidence: 0.9996485
00:46:12.035 --> 00:46:13.075 plan for their baby and
NOTE Confidence: 0.9996485
00:46:13.075 --> 00:46:13.734 their family.
NOTE Confidence: 0.99769807
00:46:14.275 --> 00:46:15.315 We should provide them with
NOTE Confidence: 0.99769807
00:46:15.315 --> 00:46:16.914 clear information and support a
NOTE Confidence: 0.99769807
00:46:16.914 --> 00:46:18.434 shared decision making approach to
NOTE Confidence: 0.99769807
00:46:18.434 --> 00:46:20.614 care. This includes really facilitating
NOTE Confidence: 0.99769807
00:46:20.755 --> 00:46:21.974 comprehensive conversations,
NOTE Confidence: 0.99743325
00:46:22.515 --> 00:46:24.355 understanding how they're making medical
NOTE Confidence: 0.99743325
00:46:24.355 --> 00:46:24.810 decisions,
NOTE Confidence: 0.9844067
00:46:25.290 --> 00:46:26.969 navigating how the medical information
NOTE Confidence: 0.9844067

00:46:26.969 --> 00:46:28.170 is important in the context
NOTE Confidence: 0.9844067

00:46:28.170 --> 00:46:29.930 of these decisions, and at
NOTE Confidence: 0.9844067

00:46:29.930 --> 00:46:31.770 times reshaping their expectations for
NOTE Confidence: 0.9844067

00:46:31.770 --> 00:46:32.430 the future.
NOTE Confidence: 0.9984746

00:46:33.290 --> 00:46:34.890 The palliative care team is
NOTE Confidence: 0.9984746

00:46:34.890 --> 00:46:36.330 a consistent presence and can
NOTE Confidence: 0.9984746

00:46:36.330 --> 00:46:38.344 help anticipate the decision points,
NOTE Confidence: 0.9984746

00:46:38.565 --> 00:46:39.844 ensure the family has all
NOTE Confidence: 0.9984746

00:46:39.844 --> 00:46:41.205 the information they need, and
NOTE Confidence: 0.9984746

00:46:41.205 --> 00:46:42.485 really help team members and
NOTE Confidence: 0.9984746

00:46:42.485 --> 00:46:44.085 families realize that goals may
NOTE Confidence: 0.9984746

00:46:44.085 --> 00:46:45.525 evolve and change over time.
NOTE Confidence: 0.9984746

00:46:45.525 --> 00:46:46.645 We support families from the
NOTE Confidence: 0.9984746

00:46:46.645 --> 00:46:47.545 time of diagnosis
NOTE Confidence: 0.97812605

00:46:47.844 --> 00:46:48.725 through the remainder of the
NOTE Confidence: 0.97812605

00:46:48.725 --> 00:46:50.905 pregnancy neonatal course and beyond.

NOTE Confidence: 0.9937451
00:46:52.760 --> 00:46:54.200 When an individual or family
NOTE Confidence: 0.9937451
00:46:54.200 --> 00:46:55.160 is faced with a severe
NOTE Confidence: 0.9937451
00:46:55.160 --> 00:46:57.000 fetal diagnosis, the care paths
NOTE Confidence: 0.9937451
00:46:57.000 --> 00:46:58.619 and treatment options are incredibly
NOTE Confidence: 0.9937451
00:46:58.680 --> 00:46:59.180 complex.
NOTE Confidence: 0.95923805
00:46:59.640 --> 00:47:00.839 As we continue to learn
NOTE Confidence: 0.95923805
00:47:00.839 --> 00:47:01.900 more about the diagnoses
NOTE Confidence: 0.9677957
00:47:02.200 --> 00:47:04.380 and how innovative the interventions
NOTE Confidence: 0.9968811
00:47:04.905 --> 00:47:06.425 can change outcomes, there are
NOTE Confidence: 0.9968811
00:47:06.425 --> 00:47:08.505 multiple ethical considerations the medical
NOTE Confidence: 0.9968811
00:47:08.505 --> 00:47:10.364 community is continuing to navigate.
NOTE Confidence: 0.9976139
00:47:11.145 --> 00:47:12.665 There may be external factors
NOTE Confidence: 0.9976139
00:47:12.665 --> 00:47:13.785 that limit the reality of
NOTE Confidence: 0.9976139
00:47:13.785 --> 00:47:14.825 some of these paths for
NOTE Confidence: 0.9976139
00:47:14.825 --> 00:47:15.325 individuals.
NOTE Confidence: 0.99926376

00:47:16.025 --> 00:47:17.065 In the midst of this,
NOTE Confidence: 0.99926376

00:47:17.065 --> 00:47:18.344 we are tasked with supporting
NOTE Confidence: 0.99926376

00:47:18.344 --> 00:47:18.844 families,
NOTE Confidence: 0.99676436

00:47:19.219 --> 00:47:20.579 counseling them, and helping them
NOTE Confidence: 0.99676436

00:47:20.579 --> 00:47:21.940 navigate goals of care often
NOTE Confidence: 0.99676436

00:47:21.940 --> 00:47:23.079 in the face of uncertainty.
NOTE Confidence: 0.9993334

00:47:23.779 --> 00:47:25.319 This can be incredibly challenging,
NOTE Confidence: 0.9960613

00:47:25.779 --> 00:47:27.559 fraught with emotions, and incredibly
NOTE Confidence: 0.9960613

00:47:27.700 --> 00:47:28.200 rewarding.
NOTE Confidence: 0.9943362

00:47:28.739 --> 00:47:30.260 By taking the time to
NOTE Confidence: 0.9943362

00:47:30.260 --> 00:47:31.460 learn about the family, how
NOTE Confidence: 0.9943362

00:47:31.460 --> 00:47:32.819 they're making decisions, and what's
NOTE Confidence: 0.9943362

00:47:32.819 --> 00:47:34.180 important to them, the team
NOTE Confidence: 0.9943362

00:47:34.180 --> 00:47:35.114 will be prepared to help
NOTE Confidence: 0.9943362

00:47:35.195 --> 00:47:36.735 them navigate the medical decisions.
NOTE Confidence: 0.98906004

00:47:37.355 --> 00:47:38.715 The difficult decisions that are

NOTE Confidence: 0.98906004
00:47:38.715 --> 00:47:40.395 being made, the care that's
NOTE Confidence: 0.98906004
00:47:40.395 --> 00:47:41.755 being provided, and the experience
NOTE Confidence: 0.98906004
00:47:41.755 --> 00:47:43.355 the family has impacts not
NOTE Confidence: 0.98906004
00:47:43.355 --> 00:47:44.235 only the time with their
NOTE Confidence: 0.98906004
00:47:44.235 --> 00:47:45.614 baby, but the time afterwards.
NOTE Confidence: 0.9602871
00:47:46.635 --> 00:47:48.395 The palliative care team can
NOTE Confidence: 0.9602871
00:47:48.395 --> 00:47:49.915 be a consistent presence across
NOTE Confidence: 0.9602871
00:47:49.915 --> 00:47:51.339 all phases and care to
NOTE Confidence: 0.9602871
00:47:51.339 --> 00:47:52.460 support the family and team
NOTE Confidence: 0.9602871
00:47:52.460 --> 00:47:53.500 ensuring that they have all
NOTE Confidence: 0.9602871
00:47:53.500 --> 00:47:54.859 the information they need and
NOTE Confidence: 0.9602871
00:47:54.859 --> 00:47:56.300 help the family navigate, evolve,
NOTE Confidence: 0.9602871
00:47:56.300 --> 00:47:57.660 and goals of care and
NOTE Confidence: 0.9602871
00:47:57.660 --> 00:47:59.520 multiple complex medical decisions.
NOTE Confidence: 0.9994746
00:48:00.700 --> 00:48:02.140 And to finish things off,
NOTE Confidence: 0.9994746

00:48:02.140 --> 00:48:03.180 these are three of my
NOTE Confidence: 0.9994746
00:48:03.180 --> 00:48:03.680 babies.
NOTE Confidence: 0.93017405
00:48:04.185 --> 00:48:05.145 The first is a girl
NOTE Confidence: 0.93017405
00:48:05.145 --> 00:48:06.425 who had a complex course
NOTE Confidence: 0.93017405
00:48:06.425 --> 00:48:08.105 including in utero interventions for
NOTE Confidence: 0.93017405
00:48:08.105 --> 00:48:09.785 key to kidney failure, an
NOTE Confidence: 0.93017405
00:48:09.785 --> 00:48:11.065 ostomy placed in her first
NOTE Confidence: 0.93017405
00:48:11.065 --> 00:48:12.445 days of life and neonatal,
NOTE Confidence: 0.998942
00:48:13.145 --> 00:48:14.285 peritoneal dialysis.
NOTE Confidence: 0.99473715
00:48:14.665 --> 00:48:16.205 She received her first kidney
NOTE Confidence: 0.99473715
00:48:16.344 --> 00:48:18.025 shortly after she turned two
NOTE Confidence: 0.99473715
00:48:18.025 --> 00:48:19.325 and is doing well.
NOTE Confidence: 0.95097715
00:48:20.079 --> 00:48:21.680 The second is a beautiful
NOTE Confidence: 0.95097715
00:48:21.680 --> 00:48:23.520 girl whose parents took her
NOTE Confidence: 0.95097715
00:48:23.520 --> 00:48:24.799 home with a comfort measure's
NOTE Confidence: 0.95097715
00:48:24.799 --> 00:48:25.920 only approach to care where

NOTE Confidence: 0.95097715

00:48:25.920 --> 00:48:26.960 she was surrounded by love

NOTE Confidence: 0.95097715

00:48:26.960 --> 00:48:28.020 her entire life.

NOTE Confidence: 0.97648114

00:48:28.799 --> 00:48:30.640 The third delivered prematurely after

NOTE Confidence: 0.97648114

00:48:30.640 --> 00:48:32.420 receiving serial amnio infusions.

NOTE Confidence: 0.9712276

00:48:32.985 --> 00:48:34.364 He was initially intubated.

NOTE Confidence: 0.99360794

00:48:35.065 --> 00:48:36.585 Then care was redirected when

NOTE Confidence: 0.99360794

00:48:36.585 --> 00:48:37.945 it became clear that medical

NOTE Confidence: 0.99360794

00:48:37.945 --> 00:48:39.725 interventions were no longer helping.

NOTE Confidence: 0.99966127

00:48:40.185 --> 00:48:41.225 He died at six hours

NOTE Confidence: 0.99966127

00:48:41.225 --> 00:48:42.845 of life from pulmonary hypoplasia.

NOTE Confidence: 0.9659991

00:48:43.785 --> 00:48:45.145 The family was appreciative that

NOTE Confidence: 0.9659991

00:48:45.145 --> 00:48:46.185 we were willing to attempt

NOTE Confidence: 0.9659991

00:48:46.185 --> 00:48:47.460 to save their son's life,

NOTE Confidence: 0.9659991

00:48:47.700 --> 00:48:48.580 thankful for the time that

NOTE Confidence: 0.9659991

00:48:48.580 --> 00:48:49.460 they had with him, and

NOTE Confidence: 0.9659991

00:48:49.460 --> 00:48:50.660 ultimately the beautiful end of

NOTE Confidence: 0.9659991

00:48:50.660 --> 00:48:51.859 life experience they gave him

NOTE Confidence: 0.9659991

00:48:51.859 --> 00:48:53.060 when it became clear that

NOTE Confidence: 0.9659991

00:48:53.060 --> 00:48:54.339 the medical interventions were no

NOTE Confidence: 0.9659991

00:48:54.339 --> 00:48:55.080 longer helping.

NOTE Confidence: 0.9971702

00:48:55.780 --> 00:48:57.060 When we invest ourselves in

NOTE Confidence: 0.9971702

00:48:57.060 --> 00:48:58.099 the journey with the families,

NOTE Confidence: 0.9971702

00:48:58.099 --> 00:48:59.140 we can support them through

NOTE Confidence: 0.9971702

00:48:59.140 --> 00:49:00.280 some of the most difficult

NOTE Confidence: 0.9971702

00:49:00.339 --> 00:49:01.540 times and allow parents to

NOTE Confidence: 0.9971702

00:49:01.540 --> 00:49:03.165 parent and make beautiful memories.

NOTE Confidence: 0.97294325

00:49:03.805 --> 00:49:04.925 It's really an honor and

NOTE Confidence: 0.97294325

00:49:04.925 --> 00:49:05.805 a privilege that they let

NOTE Confidence: 0.97294325

00:49:05.805 --> 00:49:06.925 us endure in such sacred

NOTE Confidence: 0.97294325

00:49:06.925 --> 00:49:08.125 and intimate moments and to

NOTE Confidence: 0.97294325

00:49:08.125 --> 00:49:09.265 be part of their journey.

NOTE Confidence: 0.98135847
00:49:09.885 --> 00:49:11.085 And with that, I will
NOTE Confidence: 0.98135847
00:49:11.085 --> 00:49:12.125 open it up to discussion
NOTE Confidence: 0.98135847
00:49:12.125 --> 00:49:13.245 and let you sort through
NOTE Confidence: 0.98135847
00:49:13.245 --> 00:49:14.864 and unravel all of this.
NOTE Confidence: 0.98135847
00:49:14.925 --> 00:49:16.045 Hopefully, you can come up
NOTE Confidence: 0.98135847
00:49:16.045 --> 00:49:17.489 with some solutions to ensure
NOTE Confidence: 0.98135847
00:49:17.489 --> 00:49:18.690 that we continue to provide
NOTE Confidence: 0.98135847
00:49:18.690 --> 00:49:19.969 complete counseling and care for
NOTE Confidence: 0.98135847
00:49:19.969 --> 00:49:21.810 these complex fetal and neonatal
NOTE Confidence: 0.98135847
00:49:21.810 --> 00:49:22.310 diagnoses.
NOTE Confidence: 0.9822916
00:49:28.370 --> 00:49:29.570 Thank you so much, doctor
NOTE Confidence: 0.9822916
00:49:29.570 --> 00:49:31.445 Poteza. That was an incredible
NOTE Confidence: 0.9822916
00:49:31.665 --> 00:49:32.864 overview of some of the
NOTE Confidence: 0.9822916
00:49:32.864 --> 00:49:33.364 really
NOTE Confidence: 0.97068554
00:49:33.825 --> 00:49:35.425 complex situations that that you
NOTE Confidence: 0.97068554

00:49:35.425 --> 00:49:36.864 encounter that, you know, as
NOTE Confidence: 0.97068554

00:49:36.864 --> 00:49:38.705 an adult physician, I it's
NOTE Confidence: 0.97068554

00:49:38.705 --> 00:49:39.585 hard for me to even
NOTE Confidence: 0.97068554

00:49:39.585 --> 00:49:40.465 wrap my head around how
NOTE Confidence: 0.97068554

00:49:40.465 --> 00:49:41.745 how difficult that must be.
NOTE Confidence: 0.97068554

00:49:41.745 --> 00:49:43.265 So really appreciate you're taking
NOTE Confidence: 0.97068554

00:49:43.265 --> 00:49:44.500 the time, and let's open
NOTE Confidence: 0.97068554

00:49:44.500 --> 00:49:45.560 up to questions.
NOTE Confidence: 0.9972169

00:49:47.220 --> 00:49:48.500 Who wants to start us
NOTE Confidence: 0.9972169

00:49:48.500 --> 00:49:49.000 out?
NOTE Confidence: 0.99900603

00:49:52.100 --> 00:49:53.400 We have no questions.
NOTE Confidence: 0.9011426

00:49:53.700 --> 00:49:54.980 I'm relying on you guys
NOTE Confidence: 0.9011426

00:49:54.980 --> 00:49:56.120 to sort through all this.
NOTE Confidence: 0.967045

00:49:56.580 --> 00:49:57.460 I will start then. I'll
NOTE Confidence: 0.967045

00:49:57.460 --> 00:49:59.065 take the moderator's prerogative. You
NOTE Confidence: 0.967045

00:49:59.065 --> 00:50:00.025 know, I was struck when

NOTE Confidence: 0.967045
00:50:00.025 --> 00:50:01.145 you were talking about some
NOTE Confidence: 0.967045
00:50:01.145 --> 00:50:03.145 of the bans on,
NOTE Confidence: 0.95781046
00:50:04.105 --> 00:50:05.385 obviously, I'm I'm well aware
NOTE Confidence: 0.95781046
00:50:05.385 --> 00:50:06.585 of the implications of the
NOTE Confidence: 0.95781046
00:50:06.585 --> 00:50:08.025 Dobbs decision and and abortion
NOTE Confidence: 0.95781046
00:50:08.025 --> 00:50:09.245 bans in some states.
NOTE Confidence: 0.99877155
00:50:09.705 --> 00:50:11.245 But what I was less,
NOTE Confidence: 0.99226654
00:50:11.705 --> 00:50:13.340 aware of was that there
NOTE Confidence: 0.99226654
00:50:13.340 --> 00:50:14.380 there are also is it
NOTE Confidence: 0.99226654
00:50:14.380 --> 00:50:15.660 that there are actually laws
NOTE Confidence: 0.99226654
00:50:15.660 --> 00:50:17.340 or just interpretations of laws
NOTE Confidence: 0.99226654
00:50:17.340 --> 00:50:19.520 that also seem to impose
NOTE Confidence: 0.99226654
00:50:19.580 --> 00:50:20.400 or mandate
NOTE Confidence: 0.99916625
00:50:21.020 --> 00:50:22.080 aggressive interventions
NOTE Confidence: 0.9993605
00:50:22.540 --> 00:50:23.040 after
NOTE Confidence: 0.9706007

00:50:23.580 --> 00:50:25.260 birth, which seems to me
NOTE Confidence: 0.9706007

00:50:25.260 --> 00:50:27.224 like that is is fundamentally
NOTE Confidence: 0.9706007

00:50:27.364 --> 00:50:28.984 a step even farther because
NOTE Confidence: 0.9706007

00:50:29.205 --> 00:50:30.185 I'm not sure there's
NOTE Confidence: 0.99301416

00:50:30.565 --> 00:50:32.344 equal precedent even for,
NOTE Confidence: 0.9703867

00:50:32.645 --> 00:50:34.565 you know, non neonatal children
NOTE Confidence: 0.9703867

00:50:34.565 --> 00:50:36.484 that parents don't have discretion,
NOTE Confidence: 0.9703867

00:50:36.484 --> 00:50:37.445 you know, except at those
NOTE Confidence: 0.9703867

00:50:37.445 --> 00:50:38.484 very ends of the IPO
NOTE Confidence: 0.9703867

00:50:38.484 --> 00:50:40.130 framework where things are obviously
NOTE Confidence: 0.9703867

00:50:40.269 --> 00:50:41.150 going to cause harm and
NOTE Confidence: 0.9703867

00:50:41.150 --> 00:50:41.809 are impermissible,
NOTE Confidence: 0.98090154

00:50:42.349 --> 00:50:43.309 or it would be so
NOTE Confidence: 0.98090154

00:50:43.309 --> 00:50:44.989 harmful to withhold something that
NOTE Confidence: 0.98090154

00:50:44.989 --> 00:50:46.190 it would be obligatory to
NOTE Confidence: 0.98090154

00:50:46.190 --> 00:50:47.469 give it, that there's a

NOTE Confidence: 0.98090154
00:50:47.469 --> 00:50:48.829 lot of parental discretion. And
NOTE Confidence: 0.98090154
00:50:48.829 --> 00:50:50.430 and so I'm wondering, like,
NOTE Confidence: 0.98090154
00:50:50.430 --> 00:50:51.630 at can you talk a
NOTE Confidence: 0.98090154
00:50:51.630 --> 00:50:52.750 little bit more about that?
NOTE Confidence: 0.98090154
00:50:52.750 --> 00:50:54.344 Like, where does that end?
NOTE Confidence: 0.98090154
00:50:54.344 --> 00:50:55.385 Like, how do we define
NOTE Confidence: 0.98090154
00:50:55.385 --> 00:50:56.364 the end of the neonatal
NOTE Confidence: 0.98090154
00:50:56.425 --> 00:50:58.364 period? Are these these explicitly
NOTE Confidence: 0.98090154
00:50:58.425 --> 00:50:59.885 neonatal, or is it just
NOTE Confidence: 0.98090154
00:50:59.945 --> 00:51:01.065 interpretation because there's a lot
NOTE Confidence: 0.98090154
00:51:01.065 --> 00:51:02.105 of confusion about the law?
NOTE Confidence: 0.98090154
00:51:02.105 --> 00:51:02.985 Because I I I found
NOTE Confidence: 0.98090154
00:51:02.985 --> 00:51:05.005 that very striking and and
NOTE Confidence: 0.98090154
00:51:05.145 --> 00:51:05.945 with a lot of potential
NOTE Confidence: 0.98090154
00:51:05.945 --> 00:51:07.545 for slippery slope. Intentionally put
NOTE Confidence: 0.98090154

00:51:07.545 --> 00:51:08.985 up the language from that
NOTE Confidence: 0.98090154
00:51:08.985 --> 00:51:09.485 bill.
NOTE Confidence: 0.9636402
00:51:09.840 --> 00:51:10.800 As far as I'm aware,
NOTE Confidence: 0.9636402
00:51:10.800 --> 00:51:11.680 none of those bills have
NOTE Confidence: 0.9636402
00:51:11.680 --> 00:51:12.800 been passed yet, but there
NOTE Confidence: 0.9636402
00:51:12.800 --> 00:51:14.080 are several states, I think,
NOTE Confidence: 0.9636402
00:51:14.080 --> 00:51:15.140 eight who have,
NOTE Confidence: 0.9890814
00:51:16.000 --> 00:51:17.380 bills that have been proposed
NOTE Confidence: 0.8591566
00:51:18.400 --> 00:51:19.219 to that would
NOTE Confidence: 0.97697085
00:51:19.520 --> 00:51:20.020 essentially
NOTE Confidence: 0.9979873
00:51:20.560 --> 00:51:21.060 obligate
NOTE Confidence: 0.98791534
00:51:21.520 --> 00:51:22.955 life sustaining interventions.
NOTE Confidence: 0.9992661
00:51:23.335 --> 00:51:24.375 The one the language from
NOTE Confidence: 0.9992661
00:51:24.375 --> 00:51:25.015 the one that I put
NOTE Confidence: 0.9992661
00:51:25.015 --> 00:51:26.215 up was from a bill
NOTE Confidence: 0.9992661
00:51:26.215 --> 00:51:27.515 that is in the

NOTE Confidence: 0.9551349
00:51:27.815 --> 00:51:29.114 house in Ohio.
NOTE Confidence: 0.9731895
00:51:29.655 --> 00:51:30.395 But but
NOTE Confidence: 0.94984186
00:51:30.695 --> 00:51:32.135 But only haven't passed to
NOTE Confidence: 0.94984186
00:51:32.135 --> 00:51:33.415 date. But what are what's
NOTE Confidence: 0.94984186
00:51:33.415 --> 00:51:35.095 proposed is is just for
NOTE Confidence: 0.94984186
00:51:35.095 --> 00:51:36.555 neonates or for all children?
NOTE Confidence: 0.94984186
00:51:36.680 --> 00:51:38.200 For neonates. Okay. So in
NOTE Confidence: 0.94984186
00:51:38.200 --> 00:51:39.400 that situation and the one
NOTE Confidence: 0.94984186
00:51:39.400 --> 00:51:40.200 that I put up there,
NOTE Confidence: 0.94984186
00:51:40.200 --> 00:51:41.260 it was for,
NOTE Confidence: 0.99573386
00:51:42.200 --> 00:51:43.000 I can go back to
NOTE Confidence: 0.99573386
00:51:43.000 --> 00:51:44.140 the slide.
NOTE Confidence: 0.97663546
00:51:47.880 --> 00:51:48.620 Oh, so
NOTE Confidence: 0.9979798
00:51:49.035 --> 00:51:49.535 exhibits
NOTE Confidence: 0.9457356
00:51:49.994 --> 00:51:52.234 any movement, sound, pulsating, umbilical
NOTE Confidence: 0.9457356

00:51:52.234 --> 00:51:53.594 cord, or heartbeat, the hospital
NOTE Confidence: 0.9457356

00:51:53.594 --> 00:51:55.035 shall ensure the infant is
NOTE Confidence: 0.9457356

00:51:55.035 --> 00:51:57.214 provided aggressive life sustaining interventions,
NOTE Confidence: 0.95586586

00:51:57.594 --> 00:51:59.515 and they specifically designated twenty
NOTE Confidence: 0.95586586

00:51:59.515 --> 00:52:00.714 two to twenty six weeks
NOTE Confidence: 0.95586586

00:52:00.714 --> 00:52:01.214 gestation,
NOTE Confidence: 0.9719058

00:52:01.594 --> 00:52:02.795 less than twenty one weeks,
NOTE Confidence: 0.9719058

00:52:02.795 --> 00:52:03.535 but demonstrated
NOTE Confidence: 0.54501927

00:52:03.835 --> 00:52:04.670 survival or
NOTE Confidence: 0.8530912

00:52:06.010 --> 00:52:07.450 an infant with disability regardless
NOTE Confidence: 0.8530912

00:52:07.450 --> 00:52:08.850 of the gestational age. Got
NOTE Confidence: 0.8530912

00:52:08.850 --> 00:52:10.030 it. Okay. Sorry.
NOTE Confidence: 0.93115675

00:52:10.410 --> 00:52:11.210 I I I missed that
NOTE Confidence: 0.93115675

00:52:11.210 --> 00:52:12.010 because I think I was
NOTE Confidence: 0.93115675

00:52:12.010 --> 00:52:13.309 just Yeah. So
NOTE Confidence: 0.93392885

00:52:13.770 --> 00:52:15.369 flabbergasted and was trying to

NOTE Confidence: 0.93392885

00:52:15.369 --> 00:52:16.250 wrap my head around it.

NOTE Confidence: 0.93392885

00:52:16.250 --> 00:52:18.255 So after twenty six weeks,

NOTE Confidence: 0.93392885

00:52:18.255 --> 00:52:19.454 then it kind of reverts

NOTE Confidence: 0.93392885

00:52:19.454 --> 00:52:20.494 to the standard, at least

NOTE Confidence: 0.93392885

00:52:20.494 --> 00:52:21.934 per these proposed bills that

NOTE Confidence: 0.93392885

00:52:21.934 --> 00:52:23.055 you can withhold this. After

NOTE Confidence: 0.93392885

00:52:23.055 --> 00:52:24.414 twenty six weeks, the standard

NOTE Confidence: 0.93392885

00:52:24.414 --> 00:52:25.454 would be to provide life

NOTE Confidence: 0.93392885

00:52:25.454 --> 00:52:27.315 sustaining interventions unless there's

NOTE Confidence: 0.97296256

00:52:27.614 --> 00:52:28.994 other significant morbidity.

NOTE Confidence: 0.93527734

00:52:29.454 --> 00:52:30.789 Okay. Great. Thank you for

NOTE Confidence: 0.93527734

00:52:30.789 --> 00:52:32.309 clarifying that. Absolutely. And sorry,

NOTE Confidence: 0.93527734

00:52:32.309 --> 00:52:33.430 I I I didn't get

NOTE Confidence: 0.93527734

00:52:33.430 --> 00:52:34.569 that the first time.

NOTE Confidence: 0.9887747

00:52:36.150 --> 00:52:37.829 Any other questions that we

NOTE Confidence: 0.9887747

00:52:37.829 --> 00:52:38.650 have? Yes.
NOTE Confidence: 0.9668308
00:52:41.670 --> 00:52:43.109 Oh, someone else hasn't got
NOTE Confidence: 0.9668308
00:52:43.109 --> 00:52:43.910 a mic, and we've got
NOTE Confidence: 0.9668308
00:52:43.910 --> 00:52:44.969 a question on Zoom.
NOTE Confidence: 0.9980032
00:52:45.755 --> 00:52:47.435 Hi. Thank you so much.
NOTE Confidence: 0.9980032
00:52:47.435 --> 00:52:48.175 That was
NOTE Confidence: 0.99490166
00:52:48.795 --> 00:52:50.175 that was a lot to
NOTE Confidence: 0.9802035
00:52:51.195 --> 00:52:52.155 to to get in there,
NOTE Confidence: 0.9802035
00:52:52.155 --> 00:52:54.155 and it's, it's remarkable the
NOTE Confidence: 0.9802035
00:52:54.155 --> 00:52:55.355 way that you presented it
NOTE Confidence: 0.9802035
00:52:55.355 --> 00:52:55.855 all.
NOTE Confidence: 0.9814136
00:52:56.795 --> 00:52:57.915 Katia, I'm one of the
NOTE Confidence: 0.9814136
00:52:57.915 --> 00:52:59.515 pediatric cardiologists. By the way,
NOTE Confidence: 0.9814136
00:52:59.515 --> 00:53:00.555 nice to meet you. Nice
NOTE Confidence: 0.9814136
00:53:00.555 --> 00:53:01.580 to meet you. You.
NOTE Confidence: 0.9854017
00:53:02.413 --> 00:53:04.460 So my question is about

NOTE Confidence: 0.9854017
00:53:04.600 --> 00:53:05.660 when when,
NOTE Confidence: 0.9450716
00:53:06.440 --> 00:53:08.060 when the experts disagree,
NOTE Confidence: 0.76735306
00:53:09.320 --> 00:53:09.820 and,
NOTE Confidence: 0.9943281
00:53:10.280 --> 00:53:11.719 you know, what what have
NOTE Confidence: 0.9943281
00:53:11.719 --> 00:53:12.219 you
NOTE Confidence: 0.9383071
00:53:13.480 --> 00:53:14.360 or what is,
NOTE Confidence: 0.98395187
00:53:15.915 --> 00:53:17.035 what have you found to
NOTE Confidence: 0.98395187
00:53:17.035 --> 00:53:17.535 be,
NOTE Confidence: 0.999212
00:53:17.995 --> 00:53:18.495 effective
NOTE Confidence: 0.9979795
00:53:19.195 --> 00:53:19.935 in terms
NOTE Confidence: 0.99239355
00:53:20.475 --> 00:53:21.915 of kind of maintaining that
NOTE Confidence: 0.99239355
00:53:21.915 --> 00:53:23.435 sort of shared decision making
NOTE Confidence: 0.99239355
00:53:23.435 --> 00:53:23.935 model
NOTE Confidence: 0.99091715
00:53:24.555 --> 00:53:25.855 when experts disagree?
NOTE Confidence: 0.9960232
00:53:26.315 --> 00:53:27.435 And I think the reality
NOTE Confidence: 0.9960232

00:53:27.435 --> 00:53:28.415 is that's happening
NOTE Confidence: 0.972353

00:53:29.040 --> 00:53:30.560 more and more commonly as
NOTE Confidence: 0.972353

00:53:30.560 --> 00:53:32.400 we're seeing children with more
NOTE Confidence: 0.972353

00:53:32.400 --> 00:53:35.060 complex medical interventions surviving longer,
NOTE Confidence: 0.972353

00:53:35.280 --> 00:53:37.219 more therapies to offer with,
NOTE Confidence: 0.9989711

00:53:38.239 --> 00:53:39.380 variable outcomes.
NOTE Confidence: 0.99915326

00:53:39.840 --> 00:53:41.120 I think one thing that's
NOTE Confidence: 0.99915326

00:53:41.120 --> 00:53:42.500 important is that providers
NOTE Confidence: 0.99888915

00:53:43.040 --> 00:53:44.340 talk amongst themselves
NOTE Confidence: 0.9995022

00:53:44.875 --> 00:53:45.935 and really understand
NOTE Confidence: 0.9772634

00:53:46.635 --> 00:53:48.315 why individuals are coming from
NOTE Confidence: 0.9772634

00:53:48.315 --> 00:53:49.835 either the perspective of we
NOTE Confidence: 0.9772634

00:53:49.835 --> 00:53:51.515 think this intervention is futile,
NOTE Confidence: 0.9772634

00:53:51.515 --> 00:53:52.955 which in my mind is
NOTE Confidence: 0.9772634

00:53:52.955 --> 00:53:54.635 very hard to argue the
NOTE Confidence: 0.9772634

00:53:54.635 --> 00:53:56.975 legal definition of futility regardless

NOTE Confidence: 0.9772634
00:53:57.035 --> 00:53:58.495 of how we feel personally
NOTE Confidence: 0.9772634
00:53:58.555 --> 00:54:00.140 about it, from a legal
NOTE Confidence: 0.9772634
00:54:00.140 --> 00:54:00.640 standpoint
NOTE Confidence: 0.97919273
00:54:00.940 --> 00:54:02.700 versus why individuals think if
NOTE Confidence: 0.97919273
00:54:02.700 --> 00:54:04.720 a family is appropriately counseled
NOTE Confidence: 0.7729829
00:54:05.180 --> 00:54:05.680 that
NOTE Confidence: 0.9978754
00:54:06.460 --> 00:54:08.480 medical interventions may be reasonable
NOTE Confidence: 0.9978754
00:54:08.620 --> 00:54:09.280 to offer.
NOTE Confidence: 0.9992262
00:54:09.580 --> 00:54:10.160 I think
NOTE Confidence: 0.985147
00:54:10.540 --> 00:54:12.160 because of my multiple hats,
NOTE Confidence: 0.9701355
00:54:12.540 --> 00:54:14.239 I have a unique perspective,
NOTE Confidence: 0.98721933
00:54:14.964 --> 00:54:16.085 which gives me far less
NOTE Confidence: 0.98721933
00:54:16.085 --> 00:54:18.165 moral distress than others. I
NOTE Confidence: 0.98721933
00:54:18.165 --> 00:54:19.605 get the benefit of meeting
NOTE Confidence: 0.98721933
00:54:19.605 --> 00:54:21.605 with families prenatally to see
NOTE Confidence: 0.98721933

00:54:21.605 --> 00:54:22.484 with a lot of these
NOTE Confidence: 0.98721933

00:54:22.484 --> 00:54:23.704 very serious diagnoses
NOTE Confidence: 0.95531386

00:54:24.165 --> 00:54:26.244 that many families select abortion
NOTE Confidence: 0.95531386

00:54:26.244 --> 00:54:28.340 or comfort measures. It's only
NOTE Confidence: 0.95531386

00:54:28.340 --> 00:54:30.020 a small subset that make
NOTE Confidence: 0.95531386

00:54:30.020 --> 00:54:31.140 their way to the NICU
NOTE Confidence: 0.95531386

00:54:31.140 --> 00:54:32.600 asking for invasive interventions,
NOTE Confidence: 0.9955685

00:54:33.060 --> 00:54:33.860 and I get to see
NOTE Confidence: 0.9955685

00:54:33.860 --> 00:54:35.700 the extensive counseling they've received
NOTE Confidence: 0.9955685

00:54:35.700 --> 00:54:36.900 about really what that course
NOTE Confidence: 0.9955685

00:54:36.900 --> 00:54:37.800 could look like.
NOTE Confidence: 0.94837105

00:54:38.100 --> 00:54:38.980 I also then, in my
NOTE Confidence: 0.94837105

00:54:38.980 --> 00:54:40.020 other hat, get to see
NOTE Confidence: 0.94837105

00:54:40.020 --> 00:54:41.300 the benefit of going into
NOTE Confidence: 0.94837105

00:54:41.300 --> 00:54:43.565 the homes after words to
NOTE Confidence: 0.9863833

00:54:43.864 --> 00:54:45.145 see not just three months

NOTE Confidence: 0.9863833
00:54:45.145 --> 00:54:46.205 while they're in the NICU,
NOTE Confidence: 0.9863833
00:54:46.265 --> 00:54:47.945 six months, two years, six
NOTE Confidence: 0.9863833
00:54:47.945 --> 00:54:49.224 years, what life looks like
NOTE Confidence: 0.9863833
00:54:49.224 --> 00:54:50.185 for that family. And it's
NOTE Confidence: 0.9863833
00:54:50.185 --> 00:54:51.625 given me a far more
NOTE Confidence: 0.9863833
00:54:51.625 --> 00:54:52.605 balanced perspective
NOTE Confidence: 0.98666763
00:54:52.984 --> 00:54:54.665 about the varying views of
NOTE Confidence: 0.98666763
00:54:54.665 --> 00:54:56.285 quality of life that individuals
NOTE Confidence: 0.98666763
00:54:56.344 --> 00:54:57.085 may have.
NOTE Confidence: 0.99956375
00:55:00.130 --> 00:55:01.570 Any other questions that we
NOTE Confidence: 0.99956375
00:55:01.570 --> 00:55:02.550 have in the audience?
NOTE Confidence: 0.87134093
00:55:04.930 --> 00:55:06.150 Oh, over at the grave.
NOTE Confidence: 0.998022
00:55:09.489 --> 00:55:10.530 Hi. Thank you so much
NOTE Confidence: 0.998022
00:55:10.530 --> 00:55:11.190 for that
NOTE Confidence: 0.98076814
00:55:11.489 --> 00:55:11.989 very
NOTE Confidence: 0.9767046

00:55:12.705 --> 00:55:14.145 wonderful overview that I'm I'm

NOTE Confidence: 0.9767046

00:55:14.145 --> 00:55:15.905 working on on digesting. I'm

NOTE Confidence: 0.9767046

00:55:15.905 --> 00:55:16.645 I'm curious,

NOTE Confidence: 0.99763906

00:55:18.385 --> 00:55:19.425 when you were talking about

NOTE Confidence: 0.99763906

00:55:19.425 --> 00:55:21.125 sort of the financial burdens,

NOTE Confidence: 0.9803273

00:55:21.505 --> 00:55:22.465 seems like there's a lot

NOTE Confidence: 0.9803273

00:55:22.465 --> 00:55:23.745 of injustice there, and it

NOTE Confidence: 0.9803273

00:55:23.745 --> 00:55:25.105 it feels very unjust that

NOTE Confidence: 0.9803273

00:55:25.105 --> 00:55:25.825 that would be part of

NOTE Confidence: 0.9803273

00:55:25.825 --> 00:55:27.905 the decision making process for

NOTE Confidence: 0.9803273

00:55:27.905 --> 00:55:28.350 families.

NOTE Confidence: 0.6283467

00:55:29.710 --> 00:55:30.210 But

NOTE Confidence: 0.9879889

00:55:30.910 --> 00:55:32.210 that being said, I'm wondering

NOTE Confidence: 0.9879889

00:55:32.510 --> 00:55:33.790 what role there is in

NOTE Confidence: 0.9879889

00:55:33.790 --> 00:55:34.690 terms of, like,

NOTE Confidence: 0.93919545

00:55:35.310 --> 00:55:37.230 are families prepared as they're

NOTE Confidence: 0.93919545
00:55:37.230 --> 00:55:38.750 making these decisions? Or do
NOTE Confidence: 0.93919545
00:55:38.750 --> 00:55:40.050 they know what the financial
NOTE Confidence: 0.93919545
00:55:40.110 --> 00:55:41.390 burdens will be, or or
NOTE Confidence: 0.93919545
00:55:41.390 --> 00:55:42.510 what role does that or
NOTE Confidence: 0.93919545
00:55:42.510 --> 00:55:43.825 should that play in in
NOTE Confidence: 0.93919545
00:55:43.825 --> 00:55:44.325 counseling?
NOTE Confidence: 0.97783244
00:55:46.145 --> 00:55:47.505 It's a tough one because
NOTE Confidence: 0.97783244
00:55:47.505 --> 00:55:49.025 we all like to think
NOTE Confidence: 0.97783244
00:55:49.025 --> 00:55:50.225 that we live in an
NOTE Confidence: 0.97783244
00:55:50.225 --> 00:55:51.825 ideal world where that shouldn't
NOTE Confidence: 0.97783244
00:55:51.825 --> 00:55:53.265 impact. Because in all reality,
NOTE Confidence: 0.97783244
00:55:53.265 --> 00:55:54.785 it should not impact whether
NOTE Confidence: 0.97783244
00:55:54.785 --> 00:55:55.525 an individual
NOTE Confidence: 0.9760236
00:55:56.065 --> 00:55:57.585 is able to choose whether
NOTE Confidence: 0.9760236
00:55:57.585 --> 00:55:59.205 it's a heart transplant, dialysis
NOTE Confidence: 0.9760236

00:55:59.480 --> 00:56:01.160 for any diagnosis for their
NOTE Confidence: 0.9760236
00:56:01.160 --> 00:56:01.660 child.
NOTE Confidence: 0.9811486
00:56:02.599 --> 00:56:04.200 But there have been multiple
NOTE Confidence: 0.9811486
00:56:04.200 --> 00:56:06.039 families who weren't prepared and
NOTE Confidence: 0.9811486
00:56:06.039 --> 00:56:07.480 didn't know and then weren't
NOTE Confidence: 0.9811486
00:56:07.480 --> 00:56:08.779 able to sustain
NOTE Confidence: 0.99451023
00:56:09.079 --> 00:56:10.839 that commitment long term. I
NOTE Confidence: 0.99451023
00:56:10.839 --> 00:56:12.460 think it is appropriate to
NOTE Confidence: 0.99451023
00:56:12.599 --> 00:56:14.685 counsel families about what that
NOTE Confidence: 0.99451023
00:56:14.765 --> 00:56:15.885 path will look like. I've
NOTE Confidence: 0.99451023
00:56:15.885 --> 00:56:17.645 had I had one family
NOTE Confidence: 0.99451023
00:56:17.645 --> 00:56:18.145 recently.
NOTE Confidence: 0.9891043
00:56:18.685 --> 00:56:20.205 They had a postnatal diagnosis,
NOTE Confidence: 0.9891043
00:56:20.205 --> 00:56:21.745 a complex genetic diagnosis,
NOTE Confidence: 0.99908173
00:56:22.285 --> 00:56:23.805 and had always been very
NOTE Confidence: 0.99908173
00:56:23.805 --> 00:56:24.545 well off.

NOTE Confidence: 0.95707536
00:56:25.005 --> 00:56:26.125 She was a lawyer, had
NOTE Confidence: 0.95707536
00:56:26.125 --> 00:56:27.185 her own law practice,
NOTE Confidence: 0.9753693
00:56:27.965 --> 00:56:29.185 and they ultimately,
NOTE Confidence: 0.97959775
00:56:29.810 --> 00:56:31.250 for quality of life reasons,
NOTE Confidence: 0.97959775
00:56:31.250 --> 00:56:32.690 chose comfort measures, and their
NOTE Confidence: 0.97959775
00:56:32.690 --> 00:56:33.969 child died at six months.
NOTE Confidence: 0.97959775
00:56:33.969 --> 00:56:34.469 But
NOTE Confidence: 0.999291
00:56:34.770 --> 00:56:35.969 when we talked about this
NOTE Confidence: 0.999291
00:56:35.969 --> 00:56:37.430 and the importance of
NOTE Confidence: 0.9739944
00:56:37.969 --> 00:56:40.070 highlighting to families the financial
NOTE Confidence: 0.9739944
00:56:40.130 --> 00:56:41.489 implications, she said told me
NOTE Confidence: 0.9739944
00:56:41.489 --> 00:56:43.010 she's felt validated for first
NOTE Confidence: 0.9739944
00:56:43.010 --> 00:56:44.915 time. The reality is her
NOTE Confidence: 0.9739944
00:56:44.915 --> 00:56:46.995 child living six months with
NOTE Confidence: 0.9739944
00:56:46.995 --> 00:56:48.435 home hospice and palliative care,
NOTE Confidence: 0.9739944

00:56:48.435 --> 00:56:49.235 she had to close down
NOTE Confidence: 0.9739944

00:56:49.235 --> 00:56:50.675 her law practice. And she
NOTE Confidence: 0.9739944

00:56:50.675 --> 00:56:52.275 said she's lucky enough where
NOTE Confidence: 0.9739944

00:56:52.275 --> 00:56:53.235 in a couple of years,
NOTE Confidence: 0.9739944

00:56:53.235 --> 00:56:54.035 she will be able to
NOTE Confidence: 0.9739944

00:56:54.035 --> 00:56:55.895 financially recover, but most families
NOTE Confidence: 0.9739944

00:56:56.035 --> 00:56:56.535 aren't.
NOTE Confidence: 0.9998649

00:56:57.119 --> 00:56:58.160 It's nice for us to
NOTE Confidence: 0.9998649

00:56:58.160 --> 00:56:58.660 think
NOTE Confidence: 0.9673384

00:56:59.599 --> 00:57:00.900 we can offer dialysis.
NOTE Confidence: 0.9768798

00:57:01.359 --> 00:57:02.559 Does a family really have
NOTE Confidence: 0.9768798

00:57:02.559 --> 00:57:04.019 the capability to relocate,
NOTE Confidence: 0.99015456

00:57:05.039 --> 00:57:06.719 come to the hospital several
NOTE Confidence: 0.99015456

00:57:06.719 --> 00:57:07.519 days a week if they're
NOTE Confidence: 0.99015456

00:57:07.519 --> 00:57:08.420 receiving hemodialysis,
NOTE Confidence: 0.95492905

00:57:08.960 --> 00:57:10.035 have the support to do

NOTE Confidence: 0.95492905
00:57:10.434 --> 00:57:11.875 home dialysis, and then all
NOTE Confidence: 0.95492905
00:57:11.875 --> 00:57:13.395 the ancillary costs that insurance
NOTE Confidence: 0.95492905
00:57:13.395 --> 00:57:14.454 isn't gonna cover.
NOTE Confidence: 0.9711925
00:57:15.395 --> 00:57:16.615 It is a huge injustice,
NOTE Confidence: 0.9711925
00:57:16.674 --> 00:57:17.954 and I wish we had
NOTE Confidence: 0.9711925
00:57:17.954 --> 00:57:20.194 better solutions for it. But
NOTE Confidence: 0.9711925
00:57:20.194 --> 00:57:21.234 it's the reality that many
NOTE Confidence: 0.9711925
00:57:21.234 --> 00:57:22.615 of our faith patients face.
NOTE Confidence: 0.9978726
00:57:24.194 --> 00:57:24.934 Thank you.
NOTE Confidence: 0.8956309
00:57:27.480 --> 00:57:28.460 Oh, oh, go ahead.
NOTE Confidence: 0.9806029
00:57:30.120 --> 00:57:31.000 Hi. Thank you so much.
NOTE Confidence: 0.9806029
00:57:31.000 --> 00:57:31.800 I'm Sarah Cross. I'm one
NOTE Confidence: 0.9806029
00:57:31.800 --> 00:57:33.080 of the MFMs, and I
NOTE Confidence: 0.9806029
00:57:33.080 --> 00:57:33.720 I think I have a
NOTE Confidence: 0.9806029
00:57:33.720 --> 00:57:34.600 question, but it might be
NOTE Confidence: 0.9806029

00:57:34.600 --> 00:57:35.580 more of a commiseration.
NOTE Confidence: 0.9935149

00:57:35.880 --> 00:57:37.160 I I think a lot
NOTE Confidence: 0.9935149

00:57:37.160 --> 00:57:38.280 about the language that we
NOTE Confidence: 0.9935149

00:57:38.280 --> 00:57:39.480 use. And over the course
NOTE Confidence: 0.9935149

00:57:39.480 --> 00:57:40.140 of my
NOTE Confidence: 0.9959589

00:57:40.505 --> 00:57:41.625 career now, a lot of
NOTE Confidence: 0.9959589

00:57:41.625 --> 00:57:43.005 what used to be considered
NOTE Confidence: 0.9959589

00:57:43.145 --> 00:57:44.445 lethal is now
NOTE Confidence: 0.99503076

00:57:44.745 --> 00:57:46.425 life limiting because of, you
NOTE Confidence: 0.99503076

00:57:46.425 --> 00:57:47.165 know, amazing
NOTE Confidence: 0.96515393

00:57:47.625 --> 00:57:48.765 advances in medicine.
NOTE Confidence: 0.9958315

00:57:49.625 --> 00:57:50.585 And we've just really moved
NOTE Confidence: 0.9958315

00:57:50.585 --> 00:57:52.025 away from using that term
NOTE Confidence: 0.9958315

00:57:52.025 --> 00:57:53.005 for most,
NOTE Confidence: 0.9918772

00:57:53.740 --> 00:57:54.540 like, fetal,
NOTE Confidence: 0.975992

00:57:55.180 --> 00:57:56.700 diagnoses. And, you know, here

NOTE Confidence: 0.975992
00:57:56.700 --> 00:57:57.980 I am in Connecticut, and
NOTE Confidence: 0.975992
00:57:57.980 --> 00:57:59.340 that's doesn't really come up
NOTE Confidence: 0.975992
00:57:59.340 --> 00:58:00.380 as as an issue for
NOTE Confidence: 0.975992
00:58:00.380 --> 00:58:01.580 us, but I I worry
NOTE Confidence: 0.975992
00:58:01.580 --> 00:58:02.780 a lot about the law,
NOTE Confidence: 0.975992
00:58:02.780 --> 00:58:04.060 which is very black and
NOTE Confidence: 0.975992
00:58:04.060 --> 00:58:05.660 white and doesn't see things
NOTE Confidence: 0.975992
00:58:05.660 --> 00:58:06.780 in in the gray that
NOTE Confidence: 0.975992
00:58:06.780 --> 00:58:08.320 we know is true.
NOTE Confidence: 0.964873
00:58:08.755 --> 00:58:09.875 And the loss of, like,
NOTE Confidence: 0.964873
00:58:09.875 --> 00:58:11.234 that term that, you know,
NOTE Confidence: 0.964873
00:58:11.234 --> 00:58:12.355 most things are not called
NOTE Confidence: 0.964873
00:58:12.355 --> 00:58:14.035 lethal anymore and really what
NOTE Confidence: 0.964873
00:58:14.035 --> 00:58:15.315 that means for choice for
NOTE Confidence: 0.964873
00:58:15.315 --> 00:58:16.435 patients in a lot of
NOTE Confidence: 0.964873

00:58:16.435 --> 00:58:17.155 the US.
NOTE Confidence: 0.96751744

00:58:18.275 --> 00:58:19.635 And I guess it's not
NOTE Confidence: 0.96751744

00:58:19.635 --> 00:58:20.435 a question, but more of
NOTE Confidence: 0.96751744

00:58:20.435 --> 00:58:21.234 a comment. Or or if
NOTE Confidence: 0.96751744

00:58:21.234 --> 00:58:22.435 you have thoughts about kind
NOTE Confidence: 0.96751744

00:58:22.435 --> 00:58:23.700 of, you know, and it's
NOTE Confidence: 0.96751744

00:58:23.859 --> 00:58:24.740 a lot of things that's
NOTE Confidence: 0.96751744

00:58:24.740 --> 00:58:26.020 not accurate to call them
NOTE Confidence: 0.96751744

00:58:26.020 --> 00:58:27.380 lethal, but that really has
NOTE Confidence: 0.96751744

00:58:27.380 --> 00:58:28.660 limited, I think, a lot
NOTE Confidence: 0.96751744

00:58:28.660 --> 00:58:29.320 of patients,
NOTE Confidence: 0.9993874

00:58:29.859 --> 00:58:30.359 given
NOTE Confidence: 0.77929974

00:58:30.980 --> 00:58:31.720 their coexistence
NOTE Confidence: 0.99661416

00:58:32.180 --> 00:58:34.520 of medical advances with the
NOTE Confidence: 0.99661416

00:58:34.579 --> 00:58:35.079 legislation.
NOTE Confidence: 0.99983895

00:58:36.905 --> 00:58:38.525 It's really hard to argue

NOTE Confidence: 0.965387
00:58:38.825 --> 00:58:40.744 now that what lethal is.
NOTE Confidence: 0.965387
00:58:40.744 --> 00:58:41.785 And the interesting part is
NOTE Confidence: 0.965387
00:58:41.785 --> 00:58:42.825 if you really look at
NOTE Confidence: 0.965387
00:58:42.825 --> 00:58:43.945 some of the language in
NOTE Confidence: 0.965387
00:58:43.945 --> 00:58:45.065 some of the laws, bills,
NOTE Confidence: 0.965387
00:58:45.065 --> 00:58:46.605 especially states that have chosen
NOTE Confidence: 0.9267333
00:58:47.705 --> 00:58:48.925 in addition to
NOTE Confidence: 0.962619
00:58:50.190 --> 00:58:52.030 allowing exemptions for lethal or
NOTE Confidence: 0.962619
00:58:52.030 --> 00:58:53.170 life limiting conditions,
NOTE Confidence: 0.9827216
00:58:53.630 --> 00:58:55.310 make list of conditions, many
NOTE Confidence: 0.9827216
00:58:55.310 --> 00:58:56.670 of us would argue that
NOTE Confidence: 0.9827216
00:58:56.670 --> 00:58:58.530 those conditions aren't lethal.
NOTE Confidence: 0.71797115
00:59:06.275 --> 00:59:08.275 Yes. Okay. Oh, oh, actually,
NOTE Confidence: 0.71797115
00:59:08.275 --> 00:59:08.835 before you ask,
NOTE Confidence: 0.98031646
00:59:09.395 --> 00:59:10.435 just to remind you on
NOTE Confidence: 0.98031646

00:59:10.435 --> 00:59:11.715 the Zoom, please don't raise

NOTE Confidence: 0.98031646

00:59:11.715 --> 00:59:12.355 your hand if you have

NOTE Confidence: 0.98031646

00:59:12.355 --> 00:59:13.474 a question. Please enter your

NOTE Confidence: 0.98031646

00:59:13.474 --> 00:59:14.595 question into the q and

NOTE Confidence: 0.98031646

00:59:14.595 --> 00:59:15.555 a so that we can

NOTE Confidence: 0.98031646

00:59:15.555 --> 00:59:16.435 we can read it. Thank

NOTE Confidence: 0.98031646

00:59:16.435 --> 00:59:16.935 you.

NOTE Confidence: 0.94580466

00:59:19.020 --> 00:59:20.140 I'm I'm interested in in

NOTE Confidence: 0.94580466

00:59:20.140 --> 00:59:20.640 the,

NOTE Confidence: 0.97511214

00:59:21.580 --> 00:59:22.080 how,

NOTE Confidence: 0.9982001

00:59:22.620 --> 00:59:23.120 ethically

NOTE Confidence: 0.97820246

00:59:23.740 --> 00:59:25.500 obligatory it is to to

NOTE Confidence: 0.97820246

00:59:25.500 --> 00:59:26.800 present all of the options

NOTE Confidence: 0.97820246

00:59:27.020 --> 00:59:28.800 for for families. And,

NOTE Confidence: 0.89118236

00:59:29.580 --> 00:59:31.575 so any any patient with

NOTE Confidence: 0.89118236

00:59:31.575 --> 00:59:32.635 a a a lethal

NOTE Confidence: 0.8477645
00:59:32.935 --> 00:59:34.075 diagnosis, what we
NOTE Confidence: 0.91187745
00:59:34.375 --> 00:59:35.335 don't you'd like to use
NOTE Confidence: 0.91187745
00:59:35.335 --> 00:59:36.715 that phrase, but lethal diagnosis
NOTE Confidence: 0.91187745
00:59:36.775 --> 00:59:38.395 for renal disorders in utero,
NOTE Confidence: 0.92558724
00:59:39.415 --> 00:59:41.175 are we obligated to let
NOTE Confidence: 0.92558724
00:59:41.175 --> 00:59:42.695 them know about all these
NOTE Confidence: 0.92558724
00:59:42.695 --> 00:59:43.195 options,
NOTE Confidence: 0.87827206
00:59:44.109 --> 00:59:45.950 of, the infusions and and
NOTE Confidence: 0.87827206
00:59:45.950 --> 00:59:47.410 taking out this long course.
NOTE Confidence: 0.94675356
00:59:47.869 --> 00:59:49.470 And it seems like perhaps
NOTE Confidence: 0.94675356
00:59:49.470 --> 00:59:50.829 we are. And then I
NOTE Confidence: 0.94675356
00:59:50.829 --> 00:59:51.869 think a lot about,
NOTE Confidence: 0.87318623
00:59:52.190 --> 00:59:53.630 how we handle patients who
NOTE Confidence: 0.87318623
00:59:53.630 --> 00:59:54.609 have Nek Totalis
NOTE Confidence: 0.9709282
00:59:54.910 --> 00:59:56.030 and come back from the
NOTE Confidence: 0.9709282

00:59:56.030 --> 00:59:57.810 OR, and we universally
NOTE Confidence: 0.99857104

00:59:58.190 --> 00:59:59.730 say, you know, your baby
NOTE Confidence: 0.9288079

01:00:00.105 --> 01:00:01.545 cannot survive and we need
NOTE Confidence: 0.9288079

01:00:01.545 --> 01:00:02.665 to transition to comfort care
NOTE Confidence: 0.9288079

01:00:02.665 --> 01:00:04.365 when there is that option
NOTE Confidence: 0.9288079

01:00:04.425 --> 01:00:05.165 of continuing,
NOTE Confidence: 0.9723586

01:00:06.825 --> 01:00:09.545 care with prolonged TPN and
NOTE Confidence: 0.9723586

01:00:09.545 --> 01:00:11.305 eventual, you know, bowel and,
NOTE Confidence: 0.92451775

01:00:11.990 --> 01:00:13.670 possibly liver transplant. I think
NOTE Confidence: 0.92451775

01:00:13.670 --> 01:00:14.650 it's sort of analogous
NOTE Confidence: 0.98009145

01:00:15.109 --> 01:00:16.470 to what you're dealing with.
NOTE Confidence: 0.98009145

01:00:16.470 --> 01:00:17.369 Maybe maybe,
NOTE Confidence: 0.9906658

01:00:18.230 --> 01:00:19.270 there's a lot of differences,
NOTE Confidence: 0.9906658

01:00:19.270 --> 01:00:20.230 of course, the outcome from
NOTE Confidence: 0.9906658

01:00:20.230 --> 01:00:21.750 bowel transplant compared to kidney
NOTE Confidence: 0.9906658

01:00:21.750 --> 01:00:23.510 transplant and the suffering that

NOTE Confidence: 0.9906658
01:00:23.510 --> 01:00:25.450 goes on with dialysis versus
NOTE Confidence: 0.94378275
01:00:25.750 --> 01:00:27.190 prolonged TPN and infections and
NOTE Confidence: 0.94378275
01:00:27.190 --> 01:00:28.734 so forth. But we sort
NOTE Confidence: 0.94378275
01:00:28.734 --> 01:00:30.335 of treat them very different
NOTE Confidence: 0.94378275
01:00:30.415 --> 01:00:31.695 differently, and I I I
NOTE Confidence: 0.94378275
01:00:31.695 --> 01:00:32.675 wonder why
NOTE Confidence: 0.95649326
01:00:33.055 --> 01:00:33.775 and if you have any
NOTE Confidence: 0.95649326
01:00:33.775 --> 01:00:34.815 thoughts about how we should
NOTE Confidence: 0.95649326
01:00:34.815 --> 01:00:35.775 handle that situation
NOTE Confidence: 0.95660573
01:00:36.175 --> 01:00:36.975 Yeah. It is for both
NOTE Confidence: 0.95660573
01:00:36.975 --> 01:00:38.675 of them. Interesting. I think
NOTE Confidence: 0.9811278
01:00:39.695 --> 01:00:41.455 for a neonate who's already
NOTE Confidence: 0.9811278
01:00:41.455 --> 01:00:42.630 there, been to the OR,
NOTE Confidence: 0.9811278
01:00:42.789 --> 01:00:43.769 a lot of us
NOTE Confidence: 0.99884796
01:00:44.309 --> 01:00:45.690 interpret their suffering
NOTE Confidence: 0.9952067

01:00:46.069 --> 01:00:47.450 and use that as justification
NOTE Confidence: 0.99960285

01:00:47.829 --> 01:00:48.329 for
NOTE Confidence: 0.97198325

01:00:48.710 --> 01:00:51.049 the decisions we're either presenting
NOTE Confidence: 0.97198325

01:00:51.269 --> 01:00:52.710 or options we're presenting, I
NOTE Confidence: 0.97198325

01:00:52.710 --> 01:00:54.410 should say, to a family.
NOTE Confidence: 0.98225844

01:00:54.865 --> 01:00:55.985 You know, and the reality
NOTE Confidence: 0.98225844

01:00:55.985 --> 01:00:57.265 is you're right. Very few
NOTE Confidence: 0.98225844

01:00:57.265 --> 01:00:58.645 centers have a pathway
NOTE Confidence: 0.9998356

01:00:58.945 --> 01:00:59.445 to
NOTE Confidence: 0.88745564

01:00:59.985 --> 01:01:01.525 small bowel transplant,
NOTE Confidence: 0.95258886

01:01:03.425 --> 01:01:04.385 and it might not be
NOTE Confidence: 0.95258886

01:01:04.385 --> 01:01:06.005 appropriate. A lot of those
NOTE Confidence: 0.95258886

01:01:06.065 --> 01:01:07.985 children are in DIC are
NOTE Confidence: 0.95258886

01:01:07.985 --> 01:01:08.485 actively
NOTE Confidence: 0.93106294

01:01:09.025 --> 01:01:10.325 dying. Some aren't.
NOTE Confidence: 0.9156036

01:01:10.910 --> 01:01:11.410 Certainly,

NOTE Confidence: 0.9965739
01:01:11.710 --> 01:01:13.070 when I was, you know,
NOTE Confidence: 0.9965739
01:01:13.070 --> 01:01:14.590 at my prior institution, we
NOTE Confidence: 0.9965739
01:01:14.590 --> 01:01:15.490 would get
NOTE Confidence: 0.82827425
01:01:15.790 --> 01:01:16.830 every once while once or
NOTE Confidence: 0.82827425
01:01:16.830 --> 01:01:18.290 twice a year the referral
NOTE Confidence: 0.82827425
01:01:18.350 --> 01:01:19.710 of the neck totalis baby
NOTE Confidence: 0.82827425
01:01:19.710 --> 01:01:20.530 whose family
NOTE Confidence: 0.96683174
01:01:20.910 --> 01:01:21.870 knew enough to ask the
NOTE Confidence: 0.96683174
01:01:21.870 --> 01:01:23.150 questions and really push to
NOTE Confidence: 0.96683174
01:01:23.150 --> 01:01:23.810 be transferred.
NOTE Confidence: 0.9971649
01:01:24.350 --> 01:01:24.850 And
NOTE Confidence: 0.9935663
01:01:25.325 --> 01:01:26.605 did many of them pass
NOTE Confidence: 0.9935663
01:01:26.605 --> 01:01:28.125 away during their hospital journey?
NOTE Confidence: 0.9935663
01:01:28.125 --> 01:01:29.325 Yes. But every once in
NOTE Confidence: 0.9935663
01:01:29.325 --> 01:01:30.045 a while, you got a
NOTE Confidence: 0.9935663

01:01:30.045 --> 01:01:31.965 baby who survived and is
NOTE Confidence: 0.9935663

01:01:31.965 --> 01:01:33.645 now several years old, and
NOTE Confidence: 0.9935663

01:01:33.645 --> 01:01:35.185 their family thinks that
NOTE Confidence: 0.9814814

01:01:35.645 --> 01:01:37.645 their child has significant quality
NOTE Confidence: 0.9814814

01:01:37.645 --> 01:01:39.405 of life. And more importantly,
NOTE Confidence: 0.9814814

01:01:39.405 --> 01:01:40.545 I think even the
NOTE Confidence: 0.99745905

01:01:41.190 --> 01:01:43.270 babies who passed away, the
NOTE Confidence: 0.99745905

01:01:43.270 --> 01:01:45.270 families were appreciative to hear
NOTE Confidence: 0.99745905

01:01:45.270 --> 01:01:47.030 that there were options and
NOTE Confidence: 0.99745905

01:01:47.030 --> 01:01:48.070 felt like they were trying
NOTE Confidence: 0.99745905

01:01:48.070 --> 01:01:49.690 and advocating for their child.
NOTE Confidence: 0.97687525

01:01:54.674 --> 01:01:55.875 Great. We have a we
NOTE Confidence: 0.97687525

01:01:55.875 --> 01:01:56.755 have a question from the
NOTE Confidence: 0.97687525

01:01:56.755 --> 01:01:57.255 Zoom.
NOTE Confidence: 0.9890343

01:01:58.515 --> 01:01:59.015 And,
NOTE Confidence: 0.9867068

01:01:59.315 --> 01:02:01.075 it's the request is, you

NOTE Confidence: 0.9867068
01:02:01.075 --> 01:02:02.355 know, if you could speak
NOTE Confidence: 0.9867068
01:02:02.355 --> 01:02:03.474 just for a few minutes
NOTE Confidence: 0.9867068
01:02:03.474 --> 01:02:05.154 on fetal diagnoses that aren't
NOTE Confidence: 0.9867068
01:02:05.154 --> 01:02:06.214 necessarily considered
NOTE Confidence: 0.925556
01:02:06.780 --> 01:02:08.300 terminal or even life limiting,
NOTE Confidence: 0.925556
01:02:08.540 --> 01:02:09.420 because I know, again, as
NOTE Confidence: 0.925556
01:02:09.420 --> 01:02:10.880 we discussed the the terminology
NOTE Confidence: 0.925556
01:02:10.940 --> 01:02:12.460 like terminal lethal, life limiting
NOTE Confidence: 0.925556
01:02:12.460 --> 01:02:14.220 can be fraud. But but
NOTE Confidence: 0.925556
01:02:14.220 --> 01:02:16.160 nonetheless are accompanied by significant
NOTE Confidence: 0.925556
01:02:16.300 --> 01:02:16.800 lifelong,
NOTE Confidence: 0.7571785
01:02:17.420 --> 01:02:18.540 this person must in quotes
NOTE Confidence: 0.7571785
01:02:18.540 --> 01:02:19.040 disability,
NOTE Confidence: 0.97216696
01:02:19.445 --> 01:02:20.565 the degree to it of
NOTE Confidence: 0.97216696
01:02:20.565 --> 01:02:21.445 which may be hard to
NOTE Confidence: 0.97216696

01:02:21.445 --> 01:02:23.045 estimate until postnatal and early

NOTE Confidence: 0.97216696

01:02:23.045 --> 01:02:24.025 childhood development,

NOTE Confidence: 0.96905833

01:02:24.965 --> 01:02:27.205 such as, Chiari malformations and

NOTE Confidence: 0.96905833

01:02:27.205 --> 01:02:27.705 myelomeningocele.

NOTE Confidence: 0.88293284

01:02:28.885 --> 01:02:30.265 And actually, myelomeningocele

NOTE Confidence: 0.9598478

01:02:30.885 --> 01:02:32.400 is what popped into

NOTE Confidence: 0.9411098

01:02:32.940 --> 01:02:34.300 my head and is the

NOTE Confidence: 0.9411098

01:02:34.300 --> 01:02:35.680 question to speak to

NOTE Confidence: 0.95999557

01:02:35.980 --> 01:02:37.900 the different options or how

NOTE Confidence: 0.95999557

01:02:37.900 --> 01:02:38.880 we counsel?

NOTE Confidence: 0.9823178

01:02:39.980 --> 01:02:41.340 I I it's it's not

NOTE Confidence: 0.9823178

01:02:41.340 --> 01:02:42.380 clear from but I but

NOTE Confidence: 0.9823178

01:02:42.380 --> 01:02:43.820 I think my sense is

NOTE Confidence: 0.9823178

01:02:43.820 --> 01:02:44.619 just if you could sort

NOTE Confidence: 0.9823178

01:02:44.619 --> 01:02:46.460 of review sort of maybe

NOTE Confidence: 0.9823178

01:02:46.460 --> 01:02:47.360 some of the

NOTE Confidence: 0.9881724

01:02:47.694 --> 01:02:49.454 ethical considerations that are, you

NOTE Confidence: 0.9881724

01:02:49.454 --> 01:02:50.494 know, sort of comparing and

NOTE Confidence: 0.9881724

01:02:50.494 --> 01:02:51.615 contrasting some of the ethical

NOTE Confidence: 0.9881724

01:02:51.615 --> 01:02:53.214 considerations in those cases versus

NOTE Confidence: 0.9881724

01:02:53.214 --> 01:02:54.994 others. But that's I'm intuiting

NOTE Confidence: 0.9881724

01:02:55.055 --> 01:02:56.335 based on And part of

NOTE Confidence: 0.9881724

01:02:56.335 --> 01:02:57.855 it depends on if there's

NOTE Confidence: 0.9881724

01:02:57.855 --> 01:02:58.355 potential

NOTE Confidence: 0.9924862

01:02:58.815 --> 01:03:00.835 in utero or fetal interventions

NOTE Confidence: 0.9942834

01:03:01.135 --> 01:03:02.910 to offer. For example, in

NOTE Confidence: 0.9942834

01:03:02.910 --> 01:03:03.890 the case of myelomeningocele,

NOTE Confidence: 0.99933064

01:03:04.510 --> 01:03:05.010 there

NOTE Confidence: 0.99790174

01:03:05.549 --> 01:03:06.910 is fetal surgery that we

NOTE Confidence: 0.99790174

01:03:06.910 --> 01:03:08.210 could offer that

NOTE Confidence: 0.9854844

01:03:08.510 --> 01:03:10.609 potentially could improve motor outcomes.

NOTE Confidence: 0.9854844

01:03:10.829 --> 01:03:12.270 There are risks associated with
NOTE Confidence: 0.9854844

01:03:12.270 --> 01:03:13.069 that, which is a whole
NOTE Confidence: 0.9854844

01:03:13.069 --> 01:03:14.290 talk in and of itself
NOTE Confidence: 0.9604329

01:03:14.829 --> 01:03:16.910 because you're potentially putting that
NOTE Confidence: 0.9604329

01:03:16.910 --> 01:03:18.445 fetus at risk of prematurity,
NOTE Confidence: 0.9994306

01:03:18.825 --> 01:03:20.205 which also has significant
NOTE Confidence: 0.9998242

01:03:20.585 --> 01:03:21.085 morbidity
NOTE Confidence: 0.9606131

01:03:21.465 --> 01:03:23.305 associated with it when you're
NOTE Confidence: 0.9606131

01:03:23.465 --> 01:03:24.345 and it really comes down
NOTE Confidence: 0.9606131

01:03:24.345 --> 01:03:25.705 to the counseling process and
NOTE Confidence: 0.9606131

01:03:25.705 --> 01:03:27.145 talking to those families about
NOTE Confidence: 0.9606131

01:03:27.145 --> 01:03:28.185 the risk and benefit to
NOTE Confidence: 0.9606131

01:03:28.185 --> 01:03:29.405 both to the pregnant individual
NOTE Confidence: 0.9853483

01:03:29.865 --> 01:03:31.305 and the fetus with either
NOTE Confidence: 0.9853483

01:03:31.305 --> 01:03:32.125 care path.
NOTE Confidence: 0.9780293

01:03:33.420 --> 01:03:34.319 As far as

NOTE Confidence: 0.99714816
01:03:35.099 --> 01:03:36.460 comfort measures, that would not
NOTE Confidence: 0.99714816
01:03:36.460 --> 01:03:38.640 be an acceptable option for,
NOTE Confidence: 0.9338063
01:03:39.339 --> 01:03:40.540 most people to offer with
NOTE Confidence: 0.9338063
01:03:40.540 --> 01:03:41.920 diagnoses such as myelomeningocele
NOTE Confidence: 0.92090964
01:03:42.460 --> 01:03:43.900 because we feel that that
NOTE Confidence: 0.92090964
01:03:43.900 --> 01:03:44.780 is out of the zone
NOTE Confidence: 0.92090964
01:03:44.780 --> 01:03:47.099 of parental discretion. But thinking
NOTE Confidence: 0.92090964
01:03:47.099 --> 01:03:47.128 back to the fetus, if
NOTE Confidence: 0.92090964
01:03:47.128 --> 01:03:47.157 it's within the gestational age
NOTE Confidence: 0.92090964
01:03:47.157 --> 01:03:47.430 and statutory limit of the
NOTE Confidence: 0.92090964
01:03:47.430 --> 01:03:47.930 state,
NOTE Confidence: 0.71924806
01:03:51.365 --> 01:03:52.585 termination is
NOTE Confidence: 0.9154442
01:03:52.885 --> 01:03:54.005 an option. If a family
NOTE Confidence: 0.9154442
01:03:54.005 --> 01:03:54.665 does not choose
NOTE Confidence: 0.9209317
01:03:54.965 --> 01:03:56.725 termination, then, really, their pathway
NOTE Confidence: 0.9209317

01:03:56.725 --> 01:03:58.345 is either in utero interventions
NOTE Confidence: 0.9209317

01:03:58.565 --> 01:03:59.865 or invasive interventions
NOTE Confidence: 0.96071345

01:04:00.165 --> 01:04:01.290 knowing that their child will
NOTE Confidence: 0.96071345

01:04:01.770 --> 01:04:03.690 have complex medical needs for
NOTE Confidence: 0.96071345

01:04:03.690 --> 01:04:05.530 their entire life. Okay. And
NOTE Confidence: 0.96071345

01:04:05.530 --> 01:04:07.050 and the this question actually
NOTE Confidence: 0.96071345

01:04:07.050 --> 01:04:07.550 clarified,
NOTE Confidence: 0.9829171

01:04:08.010 --> 01:04:08.650 sort of how do you
NOTE Confidence: 0.9829171

01:04:08.650 --> 01:04:09.770 address the gray area in
NOTE Confidence: 0.9829171

01:04:09.770 --> 01:04:10.810 counseling when it's hard to
NOTE Confidence: 0.9829171

01:04:10.810 --> 01:04:13.070 estimate or prognosticate about neurological
NOTE Confidence: 0.9829171

01:04:13.210 --> 01:04:13.710 function?
NOTE Confidence: 0.999094

01:04:16.155 --> 01:04:17.055 I think it's
NOTE Confidence: 0.9592557

01:04:17.915 --> 01:04:19.135 honesty and transparency.
NOTE Confidence: 0.9839542

01:04:19.755 --> 01:04:20.795 And there have been times
NOTE Confidence: 0.9839542

01:04:20.795 --> 01:04:21.855 what I've seen

NOTE Confidence: 0.99415207
01:04:22.155 --> 01:04:23.615 more recently is
NOTE Confidence: 0.9912442
01:04:24.155 --> 01:04:24.655 certain
NOTE Confidence: 0.9865191
01:04:24.955 --> 01:04:27.835 subtle CNS anomalies on fetal
NOTE Confidence: 0.9865191
01:04:27.835 --> 01:04:29.375 imaging. We're better at ultrasound
NOTE Confidence: 0.9865191
01:04:29.435 --> 01:04:30.815 now. We have fetal MRI.
NOTE Confidence: 0.9575247
01:04:31.130 --> 01:04:32.250 And the reality is that
NOTE Confidence: 0.9575247
01:04:32.250 --> 01:04:32.830 the early
NOTE Confidence: 0.9637662
01:04:33.210 --> 01:04:33.710 gestation,
NOTE Confidence: 0.9897701
01:04:34.650 --> 01:04:37.310 you cannot see migrational disorders
NOTE Confidence: 0.9897701
01:04:37.370 --> 01:04:38.970 or other more severe findings,
NOTE Confidence: 0.9897701
01:04:38.970 --> 01:04:39.790 but families
NOTE Confidence: 0.98371774
01:04:40.090 --> 01:04:41.450 sometimes are coming for counseling
NOTE Confidence: 0.98371774
01:04:41.450 --> 01:04:43.050 because they're making decisions potentially
NOTE Confidence: 0.98371774
01:04:43.050 --> 01:04:44.430 about continuing the pregnancy.
NOTE Confidence: 0.9957198
01:04:44.735 --> 01:04:45.375 And we have to be
NOTE Confidence: 0.9957198

01:04:45.375 --> 01:04:46.415 honest with them that we
NOTE Confidence: 0.9957198

01:04:46.415 --> 01:04:47.695 don't think that their child
NOTE Confidence: 0.9957198

01:04:47.695 --> 01:04:49.295 will have what we would
NOTE Confidence: 0.9957198

01:04:49.295 --> 01:04:51.615 consider a normal neurologic outcome,
NOTE Confidence: 0.9957198

01:04:51.615 --> 01:04:52.755 but there is a spectrum
NOTE Confidence: 0.9957198

01:04:52.815 --> 01:04:55.155 from mild to severe delays.
NOTE Confidence: 0.9978739

01:04:55.695 --> 01:04:56.195 Unfortunately,
NOTE Confidence: 0.9781255

01:04:57.055 --> 01:04:58.590 many times, we don't know
NOTE Confidence: 0.9781255

01:04:58.830 --> 01:05:00.030 whether they're more likely to
NOTE Confidence: 0.9781255

01:05:00.030 --> 01:05:02.270 be in the mild versus
NOTE Confidence: 0.9781255

01:05:02.270 --> 01:05:03.310 severe at least early in
NOTE Confidence: 0.9781255

01:05:03.310 --> 01:05:04.370 pregnancy. Sometimes
NOTE Confidence: 0.8518417

01:05:04.830 --> 01:05:06.030 later in pregnancy, when you
NOTE Confidence: 0.8518417

01:05:06.030 --> 01:05:07.410 see a migrational disorder,
NOTE Confidence: 0.97783136

01:05:08.270 --> 01:05:08.770 schizencephaly,
NOTE Confidence: 0.8968612

01:05:09.230 --> 01:05:10.830 certain CNS diagnosis, you can

NOTE Confidence: 0.8968612
01:05:10.830 --> 01:05:12.830 say you would expect severe
NOTE Confidence: 0.8968612
01:05:12.830 --> 01:05:13.635 or profound impairments.
NOTE Confidence: 0.9722352
01:05:14.115 --> 01:05:15.395 Impairments. But the reality is
NOTE Confidence: 0.9722352
01:05:15.395 --> 01:05:16.695 early on before the gestational
NOTE Confidence: 0.9722352
01:05:16.755 --> 01:05:17.635 age limit, if they're making
NOTE Confidence: 0.9722352
01:05:17.635 --> 01:05:18.915 decisions whether to continue the
NOTE Confidence: 0.9722352
01:05:18.915 --> 01:05:20.515 pregnancy, we don't have those
NOTE Confidence: 0.9722352
01:05:20.515 --> 01:05:22.035 answers. And those are probably
NOTE Confidence: 0.9722352
01:05:22.035 --> 01:05:23.415 some of the hardest counseling
NOTE Confidence: 0.9835262
01:05:24.035 --> 01:05:25.235 sessions for me and the
NOTE Confidence: 0.9835262
01:05:25.235 --> 01:05:26.295 ones that really
NOTE Confidence: 0.9322834
01:05:27.940 --> 01:05:29.560 you leave there not feeling
NOTE Confidence: 0.9322834
01:05:29.700 --> 01:05:30.980 great because you're the family
NOTE Confidence: 0.9322834
01:05:30.980 --> 01:05:31.780 is coming to you for
NOTE Confidence: 0.9322834
01:05:31.780 --> 01:05:32.900 help, and you're just telling
NOTE Confidence: 0.9322834

01:05:32.900 --> 01:05:33.400 them,
NOTE Confidence: 0.99937886
01:05:34.180 --> 01:05:35.380 I know the outcome is
NOTE Confidence: 0.99937886
01:05:35.380 --> 01:05:36.680 going to be some impairments.
NOTE Confidence: 0.99937886
01:05:36.820 --> 01:05:37.640 It could be
NOTE Confidence: 0.99780494
01:05:38.020 --> 01:05:39.880 mild speech delays to
NOTE Confidence: 0.9617422
01:05:40.275 --> 01:05:41.474 requiring help with all their
NOTE Confidence: 0.9617422
01:05:41.474 --> 01:05:42.674 activities of daily living. And
NOTE Confidence: 0.9617422
01:05:42.674 --> 01:05:43.555 the reality is at this
NOTE Confidence: 0.9617422
01:05:43.555 --> 01:05:44.914 age, in gestation, I cannot
NOTE Confidence: 0.9617422
01:05:44.914 --> 01:05:45.494 tell you
NOTE Confidence: 0.9985763
01:05:45.954 --> 01:05:47.234 where that child is going
NOTE Confidence: 0.9985763
01:05:47.234 --> 01:05:47.815 to lie.
NOTE Confidence: 0.98713505
01:05:48.194 --> 01:05:49.315 Yeah. Thank you. I I
NOTE Confidence: 0.98713505
01:05:49.315 --> 01:05:51.155 think that that's a common
NOTE Confidence: 0.98713505
01:05:51.155 --> 01:05:52.674 theme that that we experience
NOTE Confidence: 0.98713505
01:05:52.674 --> 01:05:54.035 in multiple domains of medicine,

NOTE Confidence: 0.98713505
01:05:54.035 --> 01:05:56.069 the uncertainty and the discomfort
NOTE Confidence: 0.98713505
01:05:56.130 --> 01:05:57.030 that not only
NOTE Confidence: 0.96312386
01:05:57.490 --> 01:05:59.650 patients and their families have
NOTE Confidence: 0.96312386
01:05:59.650 --> 01:06:00.530 with it, but also that
NOTE Confidence: 0.96312386
01:06:00.530 --> 01:06:01.910 we, I think, as clinicians
NOTE Confidence: 0.96312386
01:06:01.970 --> 01:06:03.010 have with it, it's very
NOTE Confidence: 0.96312386
01:06:03.010 --> 01:06:03.510 uncomfortable.
NOTE Confidence: 0.93161714
01:06:04.210 --> 01:06:04.530 And,
NOTE Confidence: 0.97885096
01:06:05.490 --> 01:06:06.869 I agree. Honesty and transparency
NOTE Confidence: 0.97885096
01:06:06.930 --> 01:06:08.690 and humility with respect to
NOTE Confidence: 0.97885096
01:06:08.690 --> 01:06:10.015 the lack of our ability
NOTE Confidence: 0.97885096
01:06:10.015 --> 01:06:10.595 to prognosticate
NOTE Confidence: 0.98811644
01:06:10.895 --> 01:06:11.555 so often
NOTE Confidence: 0.9724479
01:06:11.935 --> 01:06:13.295 is really key. So thank
NOTE Confidence: 0.9724479
01:06:13.295 --> 01:06:14.755 you. Other questions
NOTE Confidence: 0.97015095

01:06:15.615 --> 01:06:16.595 in the audience
NOTE Confidence: 0.9332308

01:06:17.935 --> 01:06:18.994 or on Zoom?
NOTE Confidence: 0.9821623

01:06:25.960 --> 01:06:27.800 Any other questions? Well, then
NOTE Confidence: 0.9821623

01:06:27.800 --> 01:06:28.920 I'll I will ask another
NOTE Confidence: 0.9821623

01:06:28.920 --> 01:06:30.040 question while while we're waiting
NOTE Confidence: 0.9821623

01:06:30.040 --> 01:06:31.100 for more to come in.
NOTE Confidence: 0.9821623

01:06:31.160 --> 01:06:32.280 You, you know, you you
NOTE Confidence: 0.9821623

01:06:32.280 --> 01:06:33.400 really kind of gave us
NOTE Confidence: 0.9821623

01:06:33.400 --> 01:06:35.240 a quite a a sweeping
NOTE Confidence: 0.9821623

01:06:35.240 --> 01:06:36.360 view of the landscape of
NOTE Confidence: 0.9821623

01:06:36.360 --> 01:06:37.820 all of the potential barriers
NOTE Confidence: 0.9821623

01:06:37.880 --> 01:06:39.785 to, you know, really
NOTE Confidence: 0.9812129

01:06:40.085 --> 01:06:42.165 inform shared decision making and
NOTE Confidence: 0.9812129

01:06:42.165 --> 01:06:44.165 providing care that's, you know,
NOTE Confidence: 0.9812129

01:06:44.165 --> 01:06:45.445 going to support the goals
NOTE Confidence: 0.9812129

01:06:45.445 --> 01:06:47.385 and values of the the

NOTE Confidence: 0.9812129

01:06:47.525 --> 01:06:49.605 whole family unit, not just

NOTE Confidence: 0.9812129

01:06:49.605 --> 01:06:50.345 one individual.

NOTE Confidence: 0.984862

01:06:50.940 --> 01:06:52.380 What in your experience do

NOTE Confidence: 0.984862

01:06:52.380 --> 01:06:53.500 you think is you know,

NOTE Confidence: 0.984862

01:06:53.500 --> 01:06:55.020 it can you identify one

NOTE Confidence: 0.984862

01:06:55.020 --> 01:06:57.020 barrier that seems particularly salient

NOTE Confidence: 0.984862

01:06:57.020 --> 01:06:58.700 either in your personal practice

NOTE Confidence: 0.984862

01:06:58.700 --> 01:06:59.500 or, you know, in the

NOTE Confidence: 0.984862

01:06:59.500 --> 01:07:01.020 current landscape that that you

NOTE Confidence: 0.984862

01:07:01.020 --> 01:07:02.220 feel is maybe the most

NOTE Confidence: 0.984862

01:07:02.220 --> 01:07:03.900 daunting? Is it the financial

NOTE Confidence: 0.984862

01:07:03.900 --> 01:07:05.260 limitations that others have brought

NOTE Confidence: 0.984862

01:07:05.260 --> 01:07:06.275 up? Is it, you know,

NOTE Confidence: 0.984862

01:07:06.275 --> 01:07:08.035 the evolving legal landscape? Is

NOTE Confidence: 0.984862

01:07:08.035 --> 01:07:09.095 it just the simple

NOTE Confidence: 0.9762016

01:07:09.475 --> 01:07:10.915 uncertainty that that like, is
NOTE Confidence: 0.9762016

01:07:10.915 --> 01:07:12.035 is there one that that
NOTE Confidence: 0.9762016

01:07:12.035 --> 01:07:13.475 seems to sort of outweigh
NOTE Confidence: 0.9762016

01:07:13.475 --> 01:07:14.355 some of the others in
NOTE Confidence: 0.9762016

01:07:14.355 --> 01:07:15.015 your experience,
NOTE Confidence: 0.982447

01:07:15.635 --> 01:07:16.675 or is it kind of
NOTE Confidence: 0.982447

01:07:16.675 --> 01:07:18.275 very much context dependent? I
NOTE Confidence: 0.982447

01:07:18.275 --> 01:07:19.875 think the medical legal landscape
NOTE Confidence: 0.982447

01:07:19.875 --> 01:07:22.740 is continually changing, which doesn't
NOTE Confidence: 0.9853835

01:07:23.119 --> 01:07:24.960 help things. The financial barriers,
NOTE Confidence: 0.9853835

01:07:24.960 --> 01:07:25.460 geographic
NOTE Confidence: 0.9158917

01:07:25.760 --> 01:07:27.839 barriers are really hard and
NOTE Confidence: 0.9158917

01:07:27.839 --> 01:07:29.299 certainly on a
NOTE Confidence: 0.9781296

01:07:29.680 --> 01:07:31.200 state level, on a national
NOTE Confidence: 0.9781296

01:07:31.200 --> 01:07:32.640 level, there are ways we
NOTE Confidence: 0.9781296

01:07:32.640 --> 01:07:33.839 can partner with our medical

NOTE Confidence: 0.9781296
01:07:33.839 --> 01:07:34.339 organizations
NOTE Confidence: 0.97897863
01:07:34.720 --> 01:07:36.944 to help provide more appropriate
NOTE Confidence: 0.97897863
01:07:36.944 --> 01:07:38.625 counseling or aid to families.
NOTE Confidence: 0.97897863
01:07:38.625 --> 01:07:40.785 But on an individual provider
NOTE Confidence: 0.97897863
01:07:40.785 --> 01:07:42.144 level, something that we can
NOTE Confidence: 0.97897863
01:07:42.144 --> 01:07:43.505 all do is recognize our
NOTE Confidence: 0.97897863
01:07:43.505 --> 01:07:44.884 own bias and
NOTE Confidence: 0.995384
01:07:45.184 --> 01:07:46.384 the way we counsel and
NOTE Confidence: 0.995384
01:07:46.384 --> 01:07:47.664 be very intentional about the
NOTE Confidence: 0.995384
01:07:47.664 --> 01:07:48.884 words we use.
NOTE Confidence: 0.97698843
01:07:49.560 --> 01:07:50.440 Yeah. And I think that's
NOTE Confidence: 0.97698843
01:07:50.440 --> 01:07:51.240 a really good point too.
NOTE Confidence: 0.97698843
01:07:51.240 --> 01:07:52.460 The the idea of recognizing
NOTE Confidence: 0.97698843
01:07:52.520 --> 01:07:53.640 our own bias as opposed
NOTE Confidence: 0.97698843
01:07:53.640 --> 01:07:55.000 to just kind of trying
NOTE Confidence: 0.97698843

01:07:55.000 --> 01:07:56.120 not to have bias because
NOTE Confidence: 0.97698843

01:07:56.120 --> 01:07:57.359 the the fact is we
NOTE Confidence: 0.97698843

01:07:57.359 --> 01:07:58.200 we all have bias. That
NOTE Confidence: 0.97698843

01:07:58.200 --> 01:07:59.400 is the human condition. That's
NOTE Confidence: 0.97698843

01:07:59.400 --> 01:08:00.680 how our brains make shortcuts
NOTE Confidence: 0.97698843

01:08:00.680 --> 01:08:01.880 and, you know, being aware
NOTE Confidence: 0.97698843

01:08:01.880 --> 01:08:02.600 of that and trying to
NOTE Confidence: 0.97698843

01:08:02.600 --> 01:08:03.880 mitigate it rather than trying
NOTE Confidence: 0.97698843

01:08:03.880 --> 01:08:04.845 to get to some
NOTE Confidence: 0.95924485

01:08:05.805 --> 01:08:07.565 point of con convincing yourself
NOTE Confidence: 0.95924485

01:08:07.565 --> 01:08:08.605 you don't have bias because
NOTE Confidence: 0.95924485

01:08:08.605 --> 01:08:10.045 sometimes I think that's actually
NOTE Confidence: 0.95924485

01:08:10.045 --> 01:08:10.925 the space in which we
NOTE Confidence: 0.95924485

01:08:10.925 --> 01:08:11.724 can make some of the
NOTE Confidence: 0.95924485

01:08:11.724 --> 01:08:13.724 most harmful decisions unknowingly when
NOTE Confidence: 0.95924485

01:08:13.885 --> 01:08:15.085 whereas if we can acknowledge

NOTE Confidence: 0.95924485

01:08:15.085 --> 01:08:16.685 our bias and recognize when

NOTE Confidence: 0.95924485

01:08:16.685 --> 01:08:18.300 we may be overly inclined

NOTE Confidence: 0.95924485

01:08:18.300 --> 01:08:19.420 toward one path that might

NOTE Confidence: 0.95924485

01:08:19.420 --> 01:08:20.380 be right for us, but

NOTE Confidence: 0.95924485

01:08:20.380 --> 01:08:21.920 not for for our patients.

NOTE Confidence: 0.9736724

01:08:22.300 --> 01:08:22.800 Great.

NOTE Confidence: 0.95999336

01:08:23.500 --> 01:08:24.719 Other oh,

NOTE Confidence: 0.8828667

01:08:25.099 --> 01:08:26.619 yes. You oh, hang on

NOTE Confidence: 0.8828667

01:08:26.619 --> 01:08:27.280 one sec.

NOTE Confidence: 0.9823732

01:08:30.965 --> 01:08:32.005 I was just wondering if

NOTE Confidence: 0.9823732

01:08:32.005 --> 01:08:34.324 you've seen technology increase access

NOTE Confidence: 0.9823732

01:08:34.324 --> 01:08:35.465 to care and,

NOTE Confidence: 0.9852283

01:08:36.085 --> 01:08:38.005 autonomy and decision making. Are

NOTE Confidence: 0.9852283

01:08:38.005 --> 01:08:39.625 people reaching out to get

NOTE Confidence: 0.9852283

01:08:39.764 --> 01:08:40.264 counseling

NOTE Confidence: 0.99876344

01:08:40.724 --> 01:08:41.604 when they live in an
NOTE Confidence: 0.99876344

01:08:41.604 --> 01:08:42.564 area where it may not
NOTE Confidence: 0.99876344

01:08:42.564 --> 01:08:44.184 be readily available?
NOTE Confidence: 0.96504337

01:08:45.030 --> 01:08:46.810 If the families have resources,
NOTE Confidence: 0.98898935

01:08:48.470 --> 01:08:49.510 at least what I'm seeing
NOTE Confidence: 0.98898935

01:08:49.510 --> 01:08:50.330 is referrals
NOTE Confidence: 0.9989126

01:08:50.710 --> 01:08:51.210 from
NOTE Confidence: 0.9780755

01:08:51.510 --> 01:08:52.810 families from,
NOTE Confidence: 0.9973954

01:08:53.189 --> 01:08:55.130 you know, Oklahoma, Oregon,
NOTE Confidence: 0.9699046

01:08:55.430 --> 01:08:56.950 various places coming out, but
NOTE Confidence: 0.9699046

01:08:56.950 --> 01:08:58.604 that's relying on them having
NOTE Confidence: 0.9699046

01:08:58.604 --> 01:08:59.645 the ability to be able
NOTE Confidence: 0.9699046

01:08:59.645 --> 01:09:00.865 to take time off work,
NOTE Confidence: 0.9699046

01:09:01.005 --> 01:09:02.525 come out for counseling process,
NOTE Confidence: 0.9699046

01:09:02.525 --> 01:09:04.945 potentially relocating depending on the
NOTE Confidence: 0.9699046

01:09:05.085 --> 01:09:07.085 results of, you know, the

NOTE Confidence: 0.9699046
01:09:07.085 --> 01:09:08.845 diagnosis and what's potential care
NOTE Confidence: 0.9699046
01:09:08.845 --> 01:09:10.305 options we have to offer.
NOTE Confidence: 0.99969625
01:09:14.390 --> 01:09:15.610 Any other questions
NOTE Confidence: 0.9348169
01:09:16.070 --> 01:09:17.910 from either the audience here?
NOTE Confidence: 0.9348169
01:09:17.910 --> 01:09:18.489 Oh, great.
NOTE Confidence: 0.9979213
01:09:22.070 --> 01:09:23.450 Getting my steps in.
NOTE Confidence: 0.9907681
01:09:25.344 --> 01:09:26.545 This this might be kind
NOTE Confidence: 0.9907681
01:09:26.545 --> 01:09:27.665 of a I I don't
NOTE Confidence: 0.9907681
01:09:27.665 --> 01:09:28.165 think
NOTE Confidence: 0.7289181
01:09:28.784 --> 01:09:29.284 anyways,
NOTE Confidence: 0.9593385
01:09:29.824 --> 01:09:30.625 but it's a it's a
NOTE Confidence: 0.9593385
01:09:30.625 --> 01:09:31.824 question that I I I
NOTE Confidence: 0.9593385
01:09:31.824 --> 01:09:33.025 face. But when I I
NOTE Confidence: 0.9593385
01:09:33.025 --> 01:09:34.465 think, like, palliative care is
NOTE Confidence: 0.9593385
01:09:34.465 --> 01:09:36.244 awesome. And I think, like,
NOTE Confidence: 0.9593385

01:09:36.304 --> 01:09:38.064 so many patients would benefit

NOTE Confidence: 0.9593385

01:09:38.064 --> 01:09:40.030 from it, but it has

NOTE Confidence: 0.9593385

01:09:40.030 --> 01:09:41.390 this stigma, which I think

NOTE Confidence: 0.9593385

01:09:41.390 --> 01:09:42.429 you mentioned that, like, you

NOTE Confidence: 0.9593385

01:09:42.429 --> 01:09:43.870 know, end of life care

NOTE Confidence: 0.9593385

01:09:43.870 --> 01:09:45.790 or life, whatever, limiting or

NOTE Confidence: 0.9593385

01:09:45.790 --> 01:09:46.989 what you know, is this

NOTE Confidence: 0.9593385

01:09:46.989 --> 01:09:48.110 certain it's just like a

NOTE Confidence: 0.9593385

01:09:48.110 --> 01:09:48.610 fraction.

NOTE Confidence: 0.9995278

01:09:49.469 --> 01:09:50.850 What do you propose

NOTE Confidence: 0.99913126

01:09:51.229 --> 01:09:51.729 as

NOTE Confidence: 0.9998143

01:09:52.225 --> 01:09:53.285 a vehicle

NOTE Confidence: 0.9753281

01:09:53.745 --> 01:09:54.565 or a,

NOTE Confidence: 0.9723589

01:09:55.265 --> 01:09:56.465 or a step to move

NOTE Confidence: 0.9723589

01:09:56.465 --> 01:09:57.905 away from that? Do you

NOTE Confidence: 0.9723589

01:09:57.905 --> 01:09:58.645 think there,

NOTE Confidence: 0.99549055
01:09:59.505 --> 01:10:00.305 do you think that it's
NOTE Confidence: 0.99549055
01:10:00.305 --> 01:10:01.205 something that
NOTE Confidence: 0.95521617
01:10:01.505 --> 01:10:02.005 is,
NOTE Confidence: 0.80613464
01:10:03.505 --> 01:10:04.005 like
NOTE Confidence: 0.96939266
01:10:04.545 --> 01:10:05.045 yeah.
NOTE Confidence: 0.99873275
01:10:05.970 --> 01:10:07.729 I think it comes back
NOTE Confidence: 0.99873275
01:10:07.729 --> 01:10:08.390 to recognizing
NOTE Confidence: 0.9943531
01:10:09.250 --> 01:10:10.550 our bias and,
NOTE Confidence: 0.9412084
01:10:11.410 --> 01:10:13.090 patient's bias. The reality is,
NOTE Confidence: 0.9412084
01:10:13.090 --> 01:10:14.689 especially in the context of
NOTE Confidence: 0.9412084
01:10:14.689 --> 01:10:15.890 a fetus or an NA,
NOTE Confidence: 0.9412084
01:10:15.890 --> 01:10:17.890 if the pregnant individual or
NOTE Confidence: 0.9412084
01:10:17.890 --> 01:10:19.275 their family has heard
NOTE Confidence: 0.99765027
01:10:19.755 --> 01:10:21.114 of palliative care before, it's
NOTE Confidence: 0.99765027
01:10:21.114 --> 01:10:22.875 usually in the context of,
NOTE Confidence: 0.99765027

01:10:22.875 --> 01:10:24.574 you know, an adult grandparent

NOTE Confidence: 0.99917656

01:10:24.875 --> 01:10:26.635 who had that type of

NOTE Confidence: 0.99917656

01:10:26.635 --> 01:10:27.835 support and care involved in

NOTE Confidence: 0.99917656

01:10:27.835 --> 01:10:29.114 their final hours and days

NOTE Confidence: 0.99917656

01:10:29.114 --> 01:10:29.775 of life.

NOTE Confidence: 0.99647665

01:10:30.795 --> 01:10:32.554 Some centers have suggested naming

NOTE Confidence: 0.99647665

01:10:32.554 --> 01:10:34.175 the team something other than

NOTE Confidence: 0.9980014

01:10:34.550 --> 01:10:36.229 the palliative care team. I

NOTE Confidence: 0.9980014

01:10:36.229 --> 01:10:36.729 always

NOTE Confidence: 0.9760201

01:10:37.110 --> 01:10:38.630 laugh because at my previous

NOTE Confidence: 0.9760201

01:10:38.630 --> 01:10:39.989 institution, I said, you have

NOTE Confidence: 0.9760201

01:10:39.989 --> 01:10:40.950 a team named the heart

NOTE Confidence: 0.9760201

01:10:40.950 --> 01:10:42.390 failure team unless you take

NOTE Confidence: 0.9760201

01:10:42.390 --> 01:10:43.610 failure out of it.

NOTE Confidence: 0.98922557

01:10:44.150 --> 01:10:45.590 I'm a board certified in

NOTE Confidence: 0.98922557

01:10:45.590 --> 01:10:47.094 palliative care, but it's really

NOTE Confidence: 0.98922557
01:10:47.094 --> 01:10:48.954 about taking the time to
NOTE Confidence: 0.99977
01:10:49.255 --> 01:10:49.755 recognize
NOTE Confidence: 0.99081814
01:10:50.375 --> 01:10:52.054 what people assume palliative care
NOTE Confidence: 0.99081814
01:10:52.054 --> 01:10:53.814 is and then explaining that
NOTE Confidence: 0.99081814
01:10:53.814 --> 01:10:55.814 it's an additional layer of
NOTE Confidence: 0.99081814
01:10:55.814 --> 01:10:56.314 support
NOTE Confidence: 0.90769494
01:10:57.014 --> 01:10:57.514 irrespective
NOTE Confidence: 0.99951565
01:10:58.135 --> 01:10:59.895 of the goals or treatment
NOTE Confidence: 0.99951565
01:10:59.895 --> 01:11:00.875 options chosen.
NOTE Confidence: 0.98296493
01:11:01.880 --> 01:11:02.920 Most people have told me
NOTE Confidence: 0.98296493
01:11:02.920 --> 01:11:03.479 that or a lot of
NOTE Confidence: 0.98296493
01:11:03.479 --> 01:11:04.199 people told me I have
NOTE Confidence: 0.98296493
01:11:04.199 --> 01:11:05.260 a bipolar career
NOTE Confidence: 0.9781348
01:11:05.719 --> 01:11:07.820 because I am the intensivist
NOTE Confidence: 0.9781348
01:11:08.040 --> 01:11:09.159 at heart who signs up
NOTE Confidence: 0.9781348

01:11:09.159 --> 01:11:10.520 for the most critically ill
NOTE Confidence: 0.9781348

01:11:10.520 --> 01:11:11.500 patients, and
NOTE Confidence: 0.9893265

01:11:11.880 --> 01:11:13.560 I'm a palliative care provider.
NOTE Confidence: 0.9893265

01:11:13.560 --> 01:11:14.679 To me, it makes the
NOTE Confidence: 0.9893265

01:11:14.679 --> 01:11:15.979 most sense because
NOTE Confidence: 0.9948319

01:11:16.455 --> 01:11:18.375 when I'm putting a child
NOTE Confidence: 0.9948319

01:11:18.375 --> 01:11:20.235 on ECMO, when we're navigating
NOTE Confidence: 0.9948319

01:11:20.295 --> 01:11:21.755 complex surgical decisions,
NOTE Confidence: 0.9742715

01:11:22.455 --> 01:11:24.554 the family benefits from really
NOTE Confidence: 0.9834879

01:11:25.255 --> 01:11:26.695 total care and support and
NOTE Confidence: 0.9834879

01:11:26.695 --> 01:11:28.215 value driven medical care, taking
NOTE Confidence: 0.9834879

01:11:28.215 --> 01:11:29.415 the time to understand what
NOTE Confidence: 0.9834879

01:11:29.415 --> 01:11:30.375 their values and goals are
NOTE Confidence: 0.9834879

01:11:30.375 --> 01:11:31.494 and making sure we're supporting
NOTE Confidence: 0.9834879

01:11:31.494 --> 01:11:32.189 that every step
NOTE Confidence: 0.9910414

01:11:34.110 --> 01:11:35.887 of the way. Great. We

NOTE Confidence: 0.9910414
01:11:35.887 --> 01:11:37.710 have another, question on Zoom.
NOTE Confidence: 0.9910414
01:11:37.710 --> 01:11:39.090 Actually, this person has has
NOTE Confidence: 0.9910414
01:11:39.150 --> 01:11:39.630 two,
NOTE Confidence: 0.99967253
01:11:40.030 --> 01:11:40.530 questions.
NOTE Confidence: 0.97791445
01:11:41.229 --> 01:11:41.729 One,
NOTE Confidence: 0.9589935
01:11:42.830 --> 01:11:43.790 the question is, are state
NOTE Confidence: 0.9589935
01:11:43.790 --> 01:11:44.830 payers more or less likely
NOTE Confidence: 0.9589935
01:11:44.830 --> 01:11:46.110 to cover these care options?
NOTE Confidence: 0.9589935
01:11:46.110 --> 01:11:47.310 So I I'm interpreting that
NOTE Confidence: 0.9589935
01:11:47.310 --> 01:11:48.030 as is there a lot
NOTE Confidence: 0.9589935
01:11:48.030 --> 01:11:49.145 of state to state variability?
NOTE Confidence: 0.9165633
01:11:51.285 --> 01:11:51.785 And,
NOTE Confidence: 0.9578762
01:11:52.165 --> 01:11:52.965 you know, in terms of
NOTE Confidence: 0.9578762
01:11:52.965 --> 01:11:54.485 coverage, perhaps if people are
NOTE Confidence: 0.9578762
01:11:54.485 --> 01:11:56.325 dependent on, like, Medicaid, for
NOTE Confidence: 0.9578762

01:11:56.325 --> 01:11:56.825 example.
NOTE Confidence: 0.97294384

01:11:58.005 --> 01:11:59.365 Or alter and and the
NOTE Confidence: 0.97294384

01:11:59.365 --> 01:12:00.564 second question from this person
NOTE Confidence: 0.97294384

01:12:00.564 --> 01:12:01.625 is how do you handle
NOTE Confidence: 0.97294384

01:12:01.760 --> 01:12:03.200 these kinds of discussions if
NOTE Confidence: 0.97294384

01:12:03.200 --> 01:12:04.560 the family has lower health
NOTE Confidence: 0.97294384

01:12:04.560 --> 01:12:05.060 literacy?
NOTE Confidence: 0.9966437

01:12:07.439 --> 01:12:10.180 The funding and paying is
NOTE Confidence: 0.9966437

01:12:10.320 --> 01:12:11.140 very challenging.
NOTE Confidence: 0.9996484

01:12:11.520 --> 01:12:13.140 Honestly, when it comes to
NOTE Confidence: 0.9919279

01:12:14.014 --> 01:12:15.875 dialysis, things of that nature,
NOTE Confidence: 0.97069013

01:12:16.255 --> 01:12:18.255 private insurance actually has larger
NOTE Confidence: 0.97069013

01:12:18.255 --> 01:12:19.715 gaps in coverage,
NOTE Confidence: 0.9667822

01:12:20.415 --> 01:12:22.094 but there still are unmet
NOTE Confidence: 0.9667822

01:12:22.094 --> 01:12:23.215 needs all of the other
NOTE Confidence: 0.9667822

01:12:23.215 --> 01:12:25.054 ancillary costs. Even if insurance

NOTE Confidence: 0.9667822
01:12:25.054 --> 01:12:26.175 is paying for the hospital
NOTE Confidence: 0.9667822
01:12:26.175 --> 01:12:27.189 stay or dialysis,
NOTE Confidence: 0.9920166
01:12:27.650 --> 01:12:29.090 they're not able to pay
NOTE Confidence: 0.9920166
01:12:29.090 --> 01:12:30.530 for all of the home
NOTE Confidence: 0.9920166
01:12:30.530 --> 01:12:31.889 health care needs, the time
NOTE Confidence: 0.9920166
01:12:31.889 --> 01:12:33.810 off work. The reality is
NOTE Confidence: 0.9920166
01:12:33.810 --> 01:12:35.250 it's usually if it's a
NOTE Confidence: 0.9920166
01:12:35.250 --> 01:12:37.409 two parent household, one parent
NOTE Confidence: 0.9920166
01:12:37.409 --> 01:12:38.530 has to quit their job
NOTE Confidence: 0.9920166
01:12:38.530 --> 01:12:40.229 to provide total care for
NOTE Confidence: 0.9264674
01:12:40.795 --> 01:12:42.494 meet their child's needs.
NOTE Confidence: 0.9920504
01:12:43.434 --> 01:12:44.554 So it is variable state
NOTE Confidence: 0.9920504
01:12:44.554 --> 01:12:45.835 to state and then insurance
NOTE Confidence: 0.9920504
01:12:45.835 --> 01:12:46.574 to insurance.
NOTE Confidence: 0.9906598
01:12:47.114 --> 01:12:48.394 And then the second question
NOTE Confidence: 0.9906598

01:12:48.394 --> 01:12:50.014 was related to health literacy.
NOTE Confidence: 0.9906598

01:12:50.074 --> 01:12:51.195 Right. How you know, do
NOTE Confidence: 0.9906598

01:12:51.195 --> 01:12:52.795 you have a particular approach
NOTE Confidence: 0.9906598

01:12:52.795 --> 01:12:54.314 to these discussions when health
NOTE Confidence: 0.9906598

01:12:54.314 --> 01:12:55.375 literacy is limited?
NOTE Confidence: 0.9948025

01:12:57.010 --> 01:12:57.510 Honestly,
NOTE Confidence: 0.970885

01:12:58.530 --> 01:13:00.389 irrespective of that, before I
NOTE Confidence: 0.98904634

01:13:01.969 --> 01:13:03.489 start talking and counseling, I
NOTE Confidence: 0.98904634

01:13:03.489 --> 01:13:04.449 try and spend a fair
NOTE Confidence: 0.98904634

01:13:04.449 --> 01:13:05.969 amount of time just learning
NOTE Confidence: 0.98904634

01:13:05.969 --> 01:13:07.409 about the family. Are they
NOTE Confidence: 0.98904634

01:13:07.409 --> 01:13:09.270 visual learners? Are they
NOTE Confidence: 0.96799386

01:13:09.735 --> 01:13:11.255 auditory learners? How do they
NOTE Confidence: 0.96799386

01:13:11.255 --> 01:13:13.655 process informations? Are they the
NOTE Confidence: 0.96799386

01:13:13.735 --> 01:13:14.695 in the weeds, and I
NOTE Confidence: 0.96799386

01:13:14.695 --> 01:13:15.975 want to know the data

NOTE Confidence: 0.96799386
01:13:15.975 --> 01:13:17.175 from every study or big
NOTE Confidence: 0.96799386
01:13:17.175 --> 01:13:18.215 picture, just what does this
NOTE Confidence: 0.96799386
01:13:18.215 --> 01:13:19.175 mean for my child and
NOTE Confidence: 0.96799386
01:13:19.175 --> 01:13:19.995 family globally?
NOTE Confidence: 0.96655697
01:13:20.455 --> 01:13:21.655 And then I tailor my
NOTE Confidence: 0.96655697
01:13:21.655 --> 01:13:23.655 counseling approach based on all
NOTE Confidence: 0.96655697
01:13:23.655 --> 01:13:25.790 the collective information I have.
NOTE Confidence: 0.9990535
01:13:27.530 --> 01:13:28.830 That sounds very wise.
NOTE Confidence: 0.99802095
01:13:30.090 --> 01:13:31.390 Any other questions
NOTE Confidence: 0.9989147
01:13:32.170 --> 01:13:33.229 from our audience?
NOTE Confidence: 0.99719274
01:13:35.689 --> 01:13:36.189 Alright.
NOTE Confidence: 0.9753867
01:13:37.290 --> 01:13:38.490 Well, I think we're gonna
NOTE Confidence: 0.9753867
01:13:38.490 --> 01:13:39.210 wrap up in a few
NOTE Confidence: 0.9753867
01:13:39.210 --> 01:13:40.824 minutes. Oh, oh, we got
NOTE Confidence: 0.9753867
01:13:40.824 --> 01:13:41.324 one
NOTE Confidence: 0.9656453

01:13:41.625 --> 01:13:43.804 more. Going once, going twice.

NOTE Confidence: 0.76519036

01:13:44.425 --> 01:13:45.864 Sorry. Thanks for having me

NOTE Confidence: 0.76519036

01:13:45.864 --> 01:13:46.364 on.

NOTE Confidence: 0.9495889

01:13:46.824 --> 01:13:48.025 I'm curious if you could

NOTE Confidence: 0.9495889

01:13:48.025 --> 01:13:49.704 speak on the nurses role

NOTE Confidence: 0.9495889

01:13:49.704 --> 01:13:50.585 at all in all of

NOTE Confidence: 0.9495889

01:13:50.585 --> 01:13:51.324 these conversations,

NOTE Confidence: 0.9075577

01:13:52.104 --> 01:13:53.784 not as provider, but as

NOTE Confidence: 0.9075577

01:13:53.784 --> 01:13:55.304 people in primary care clinics

NOTE Confidence: 0.9075577

01:13:55.304 --> 01:13:56.045 as in

NOTE Confidence: 0.97680426

01:13:56.560 --> 01:13:57.760 OB offices and in the

NOTE Confidence: 0.97680426

01:13:57.760 --> 01:13:58.260 NICU,

NOTE Confidence: 0.9939823

01:13:58.640 --> 01:14:00.400 how we can support families

NOTE Confidence: 0.9939823

01:14:00.400 --> 01:14:01.860 in these in these processes.

NOTE Confidence: 0.98084784

01:14:02.400 --> 01:14:04.160 I always say, especially in

NOTE Confidence: 0.98084784

01:14:04.160 --> 01:14:06.080 fetal care, that our nurse

NOTE Confidence: 0.98084784

01:14:06.080 --> 01:14:07.220 coordinators become

NOTE Confidence: 0.9560771

01:14:07.680 --> 01:14:09.360 the first line and the

NOTE Confidence: 0.9560771

01:14:09.360 --> 01:14:10.979 best friends of the families

NOTE Confidence: 0.9560771

01:14:11.040 --> 01:14:12.985 because while maybe one, two,

NOTE Confidence: 0.9560771

01:14:12.985 --> 01:14:14.105 three time points during the

NOTE Confidence: 0.9560771

01:14:14.105 --> 01:14:15.305 pregnancy, we're sitting down and

NOTE Confidence: 0.9560771

01:14:15.305 --> 01:14:16.825 meeting with them. They're fielding

NOTE Confidence: 0.9560771

01:14:16.825 --> 01:14:18.025 calls every time the family

NOTE Confidence: 0.9560771

01:14:18.025 --> 01:14:18.905 has a question or every

NOTE Confidence: 0.9560771

01:14:18.905 --> 01:14:20.505 couple weeks calling them, checking

NOTE Confidence: 0.9560771

01:14:20.505 --> 01:14:21.405 in on them.

NOTE Confidence: 0.9932622

01:14:21.785 --> 01:14:23.805 Same thing in the unit.

NOTE Confidence: 0.9932622

01:14:24.050 --> 01:14:25.170 We may stop by the

NOTE Confidence: 0.9932622

01:14:25.170 --> 01:14:26.450 bedside a couple of times

NOTE Confidence: 0.9932622

01:14:26.450 --> 01:14:28.210 a day. The nurses are

NOTE Confidence: 0.9932622

01:14:28.210 --> 01:14:29.650 there for twelve hours at
NOTE Confidence: 0.9932622

01:14:29.650 --> 01:14:30.690 a time and really get
NOTE Confidence: 0.9932622

01:14:30.690 --> 01:14:31.490 to know the family on
NOTE Confidence: 0.9932622

01:14:31.490 --> 01:14:33.810 a much deeper level. So
NOTE Confidence: 0.9932622

01:14:33.810 --> 01:14:34.790 I think empowering,
NOTE Confidence: 0.93936294

01:14:35.810 --> 01:14:37.330 our nurses too to feel
NOTE Confidence: 0.93936294

01:14:37.330 --> 01:14:38.710 comfortable to navigate
NOTE Confidence: 0.98170644

01:14:39.225 --> 01:14:40.365 the values,
NOTE Confidence: 0.9800445

01:14:40.825 --> 01:14:42.425 goals, start some of these
NOTE Confidence: 0.9800445

01:14:42.425 --> 01:14:44.525 discussions with families is invaluable.
NOTE Confidence: 0.9800445

01:14:44.665 --> 01:14:46.585 And then I always ask
NOTE Confidence: 0.9800445

01:14:46.585 --> 01:14:48.685 them before a care conference
NOTE Confidence: 0.9608794

01:14:49.225 --> 01:14:50.585 anything that they've learned about
NOTE Confidence: 0.9608794

01:14:50.585 --> 01:14:51.785 the family or always make
NOTE Confidence: 0.9608794

01:14:51.785 --> 01:14:53.064 sure if at all possible
NOTE Confidence: 0.9608794

01:14:53.064 --> 01:14:54.240 the primary nurse can be

NOTE Confidence: 0.9608794
01:14:54.240 --> 01:14:55.280 present because they're seen as
NOTE Confidence: 0.9608794
01:14:55.280 --> 01:14:56.560 such a support system for
NOTE Confidence: 0.9608794
01:14:56.560 --> 01:14:57.300 that family.
NOTE Confidence: 0.99970555
01:15:01.360 --> 01:15:01.860 Great.
NOTE Confidence: 0.99962354
01:15:02.880 --> 01:15:03.780 Anyone else?
NOTE Confidence: 0.98447776
01:15:06.574 --> 01:15:07.074 Alright.
NOTE Confidence: 0.98615247
01:15:08.175 --> 01:15:09.534 Well, thank you again so
NOTE Confidence: 0.98615247
01:15:09.534 --> 01:15:10.034 much,
NOTE Confidence: 0.95760083
01:15:10.895 --> 01:15:12.655 doctor Cortez. This was just
NOTE Confidence: 0.95760083
01:15:12.655 --> 01:15:14.094 a wonderful talk, and and
NOTE Confidence: 0.95760083
01:15:14.094 --> 01:15:15.215 we really appreciate your sharing
NOTE Confidence: 0.95760083
01:15:15.215 --> 01:15:16.814 your experiences and your ethical
NOTE Confidence: 0.95760083
01:15:16.814 --> 01:15:17.795 reflections. And
NOTE Confidence: 0.9925687
01:15:18.095 --> 01:15:19.055 it's been it's been great
NOTE Confidence: 0.9925687
01:15:19.055 --> 01:15:19.854 to have you, and we
NOTE Confidence: 0.9925687

01:15:19.854 --> 01:15:20.975 really appreciate it. Thank you

NOTE Confidence: 0.9925687

01:15:20.975 --> 01:15:21.935 so much. Oh, and we

NOTE Confidence: 0.9925687

01:15:21.935 --> 01:15:22.735 have a swag bag for

NOTE Confidence: 0.9925687

01:15:22.735 --> 01:15:22.960 you.