

WEBVTT

NOTE duration:"00:45:51.0800000"

NOTE recognizability:0.834

NOTE language:en-us

NOTE Confidence: 0.903832825714286

00:00:00.000 --> 00:00:02.310 I have the pleasure of introducing Dr.

NOTE Confidence: 0.903832825714286

00:00:02.310 --> 00:00:03.627 Ignacio Tapia today.

NOTE Confidence: 0.903832825714286

00:00:03.627 --> 00:00:06.261 Doctor Tapia received his medical degree

NOTE Confidence: 0.903832825714286

00:00:06.261 --> 00:00:08.774 from University of Concepcion, Chile.

NOTE Confidence: 0.903832825714286

00:00:08.774 --> 00:00:10.838 He did his residency in Pediatrics

NOTE Confidence: 0.903832825714286

00:00:10.838 --> 00:00:12.385 and fellowship in pediatric

NOTE Confidence: 0.903832825714286

00:00:12.385 --> 00:00:14.665 pulmonology from University of Chile.

NOTE Confidence: 0.903832825714286

00:00:14.670 --> 00:00:17.046 He then moved to US and again completed

NOTE Confidence: 0.903832825714286

00:00:17.046 --> 00:00:19.345 his residency in Pediatrics and Fellowship

NOTE Confidence: 0.903832825714286

00:00:19.345 --> 00:00:21.395 in pediatric pulmonology from the

NOTE Confidence: 0.903832825714286

00:00:21.395 --> 00:00:23.269 Children's Hospital of Philadelphia.

NOTE Confidence: 0.903832825714286

00:00:23.270 --> 00:00:25.251 And then he got his masters of

NOTE Confidence: 0.903832825714286

00:00:25.251 --> 00:00:27.165 Science degree from University of

NOTE Confidence: 0.903832825714286

00:00:27.165 --> 00:00:29.169 Pennsylvania in Translational Research.
NOTE Confidence: 0.903832825714286

00:00:29.170 --> 00:00:31.335 He's currently an associate professor
NOTE Confidence: 0.903832825714286

00:00:31.335 --> 00:00:33.880 of Pediatrics at the Children's Hour.
NOTE Confidence: 0.903832825714286

00:00:33.880 --> 00:00:35.925 University of Pennsylvania School of
NOTE Confidence: 0.903832825714286

00:00:35.925 --> 00:00:38.407 Medicine is also the Distinguished Endowed
NOTE Confidence: 0.903832825714286

00:00:38.407 --> 00:00:40.675 Chair in the Department of Pediatrics.
NOTE Confidence: 0.903832825714286

00:00:40.680 --> 00:00:42.738 He also serves as a director of
NOTE Confidence: 0.903832825714286

00:00:42.738 --> 00:00:44.006 the Pulmonary Medicine Fellowship
NOTE Confidence: 0.903832825714286

00:00:44.006 --> 00:00:45.968 program and the director of the
NOTE Confidence: 0.903832825714286

00:00:45.968 --> 00:00:48.530 Sleep Research at the Sleep Center at
NOTE Confidence: 0.903832825714286

00:00:48.530 --> 00:00:50.054 Children's Hospital of Philadelphia.
NOTE Confidence: 0.903832825714286

00:00:50.060 --> 00:00:51.980 Is received many awards as a
NOTE Confidence: 0.903832825714286

00:00:51.980 --> 00:00:53.260 recipient of several grants,
NOTE Confidence: 0.903832825714286

00:00:53.260 --> 00:00:54.724 including from the NIH,
NOTE Confidence: 0.903832825714286

00:00:54.724 --> 00:00:56.920 and has authored over 70 publications.
NOTE Confidence: 0.903832825714286

00:00:56.920 --> 00:01:00.008 He has lectured in courses in pediatric sleep

NOTE Confidence: 0.903832825714286

00:01:00.008 --> 00:01:02.020 disorders nationally and internationally.

NOTE Confidence: 0.903832825714286

00:01:02.020 --> 00:01:02.754 Doctor tapia.

NOTE Confidence: 0.903832825714286

00:01:02.754 --> 00:01:04.589 Has also had leadership position

NOTE Confidence: 0.903832825714286

00:01:04.589 --> 00:01:06.823 in many national societies and is

NOTE Confidence: 0.903832825714286

00:01:06.823 --> 00:01:08.608 a strong advocate for diversity.

NOTE Confidence: 0.903832825714286

00:01:08.610 --> 00:01:11.298 He has held editorial positions in many

NOTE Confidence: 0.903832825714286

00:01:11.298 --> 00:01:12.990 publications including the editorial

NOTE Confidence: 0.903832825714286

00:01:12.990 --> 00:01:15.370 Board of Pediatric Respiratory Reviews.

NOTE Confidence: 0.903832825714286

00:01:15.370 --> 00:01:17.420 His research focuses mostly on

NOTE Confidence: 0.903832825714286

00:01:17.420 --> 00:01:18.650 pathophysiology of obstructive

NOTE Confidence: 0.903832825714286

00:01:18.650 --> 00:01:20.741 sleep apnea syndrome in Pediatrics

NOTE Confidence: 0.903832825714286

00:01:20.741 --> 00:01:22.349 and Down syndrome patients.

NOTE Confidence: 0.903832825714286

00:01:22.350 --> 00:01:23.806 Thank you so much for being with us,

NOTE Confidence: 0.903832825714286

00:01:23.810 --> 00:01:24.506 Doctor Tapian.

NOTE Confidence: 0.903832825714286

00:01:24.506 --> 00:01:25.550 Without further delay,

NOTE Confidence: 0.903832825714286

00:01:25.550 --> 00:01:27.368 I would like to hand it over to you
NOTE Confidence: 0.903832825714286

00:01:27.368 --> 00:01:29.417 to share your expertise on sleeping
NOTE Confidence: 0.903832825714286

00:01:29.417 --> 00:01:31.202 in individuals with Down syndrome.
NOTE Confidence: 0.903832825714286

00:01:31.210 --> 00:01:31.830 Thank you.
NOTE Confidence: 0.82801099826087

00:01:32.070 --> 00:01:33.262 Thank you very much.
NOTE Confidence: 0.82801099826087

00:01:33.262 --> 00:01:35.431 The invitation is a pleasure to to
NOTE Confidence: 0.82801099826087

00:01:35.431 --> 00:01:37.678 share with me about the sleeping kids
NOTE Confidence: 0.82801099826087

00:01:37.678 --> 00:01:39.469 and individuals with Down syndrome.
NOTE Confidence: 0.74043532375

00:01:43.220 --> 00:01:44.780 Well, let me try you on this slide.
NOTE Confidence: 0.9654253

00:01:50.630 --> 00:01:54.920 OK. This is your my disclosure
NOTE Confidence: 0.9654253

00:01:54.920 --> 00:01:57.349 and the number that you need for
NOTE Confidence: 0.9654253

00:01:57.349 --> 00:01:59.967 the your to get your CE credit.
NOTE Confidence: 0.9654253

00:01:59.970 --> 00:02:02.130 These are my current grant funding
NOTE Confidence: 0.9654253

00:02:02.130 --> 00:02:03.570 and have significant funding
NOTE Confidence: 0.9654253

00:02:03.636 --> 00:02:05.730 from the NIH about studies in
NOTE Confidence: 0.9654253

00:02:05.730 --> 00:02:07.126 individuals with Down syndrome,

NOTE Confidence: 0.9654253

00:02:07.130 --> 00:02:09.365 such as acceptability and performance

NOTE Confidence: 0.9654253

00:02:09.365 --> 00:02:10.706 of income polysomnography.

NOTE Confidence: 0.9654253

00:02:10.710 --> 00:02:12.870 We have another one about positive

NOTE Confidence: 0.9654253

00:02:12.870 --> 00:02:14.651 airway pressure for treatment of

NOTE Confidence: 0.9654253

00:02:14.651 --> 00:02:16.618 OSA and also have another grant and

NOTE Confidence: 0.9654253

00:02:16.618 --> 00:02:18.387 where we're comparing home sleep

NOTE Confidence: 0.9654253

00:02:18.387 --> 00:02:20.679 apnea testing compared to a lab

NOTE Confidence: 0.9654253

00:02:20.679 --> 00:02:22.222 polysomnography in children with

NOTE Confidence: 0.9654253

00:02:22.222 --> 00:02:24.526 and without them syndrome and have

NOTE Confidence: 0.9654253

00:02:24.526 --> 00:02:26.808 another grant in health disparities.

NOTE Confidence: 0.9654253

00:02:26.810 --> 00:02:28.889 So the learning objectives of of this

NOTE Confidence: 0.9654253

00:02:28.889 --> 00:02:30.620 presentation are to identify sleep

NOTE Confidence: 0.9654253

00:02:30.620 --> 00:02:32.966 disorders in individuals with down syndromes,

NOTE Confidence: 0.9654253

00:02:32.970 --> 00:02:34.805 to recognize the challenges of

NOTE Confidence: 0.9654253

00:02:34.805 --> 00:02:36.640 sleep in individual with down

NOTE Confidence: 0.9654253

00:02:36.709 --> 00:02:38.609 syndromes and provide highlights
NOTE Confidence: 0.9654253

00:02:38.609 --> 00:02:40.509 of ongoing research projects.
NOTE Confidence: 0.9654253

00:02:40.510 --> 00:02:42.603 So this is what we really know
NOTE Confidence: 0.9654253

00:02:42.603 --> 00:02:44.230 about sleeping individual with down
NOTE Confidence: 0.9654253

00:02:44.230 --> 00:02:45.910 syndromes like basically not much.
NOTE Confidence: 0.9654253

00:02:45.910 --> 00:02:49.060 It's a population that had been largely
NOTE Confidence: 0.9654253

00:02:49.060 --> 00:02:50.988 understudied or actually neglected
NOTE Confidence: 0.9654253

00:02:50.988 --> 00:02:53.508 from research or clinical trials.
NOTE Confidence: 0.9654253

00:02:53.510 --> 00:02:55.856 So recently the NIH launched the
NOTE Confidence: 0.9654253

00:02:55.856 --> 00:02:57.967 include initiative which is geared
NOTE Confidence: 0.9654253

00:02:57.967 --> 00:02:59.895 towards including individuals with
NOTE Confidence: 0.9654253

00:02:59.895 --> 00:03:02.996 Down syndrome in existing trials or in
NOTE Confidence: 0.9654253

00:03:02.996 --> 00:03:05.180 trials specific for them or to boost
NOTE Confidence: 0.9654253

00:03:05.180 --> 00:03:07.372 their research for individuals with
NOTE Confidence: 0.9654253

00:03:07.372 --> 00:03:10.180 Down syndrome across the lifespan from
NOTE Confidence: 0.9654253

00:03:10.257 --> 00:03:12.667 basic science to clinical research.

NOTE Confidence: 0.9654253

00:03:12.670 --> 00:03:14.590 And going back to OSA,

NOTE Confidence: 0.9654253

00:03:14.590 --> 00:03:16.315 the OSA prevalence in individuals

NOTE Confidence: 0.9654253

00:03:16.315 --> 00:03:18.390 with Down syndrome is very high.

NOTE Confidence: 0.9654253

00:03:18.390 --> 00:03:21.446 It's estimated to be 45 to 55%

NOTE Confidence: 0.9654253

00:03:21.446 --> 00:03:23.510 according to different publications.

NOTE Confidence: 0.9654253

00:03:23.510 --> 00:03:25.575 And actually when you perform a sleep

NOTE Confidence: 0.9654253

00:03:25.575 --> 00:03:27.490 study in individuals with Down syndrome,

NOTE Confidence: 0.9654253

00:03:27.490 --> 00:03:29.290 most likely it would be abnormal,

NOTE Confidence: 0.9654253

00:03:29.290 --> 00:03:30.818 maybe not severely abnormal,

NOTE Confidence: 0.9654253

00:03:30.818 --> 00:03:33.110 but it would be abnormal per

NOTE Confidence: 0.9654253

00:03:33.185 --> 00:03:35.670 pediatric criteria or adult criteria.

NOTE Confidence: 0.9654253

00:03:35.670 --> 00:03:37.626 So based on these high prevalence,

NOTE Confidence: 0.9654253

00:03:37.630 --> 00:03:39.935 the American Academy of Pediatrics

NOTE Confidence: 0.9654253

00:03:39.935 --> 00:03:41.774 recommended in 2011 that.

NOTE Confidence: 0.9654253

00:03:41.774 --> 00:03:44.059 It's children with Down syndrome

NOTE Confidence: 0.9654253

00:03:44.059 --> 00:03:46.638 had an evaluation at age 6 month.
NOTE Confidence: 0.9654253

00:03:46.640 --> 00:03:47.005 However,
NOTE Confidence: 0.9654253

00:03:47.005 --> 00:03:49.560 the details of this evaluation are a
NOTE Confidence: 0.9654253

00:03:49.560 --> 00:03:52.185 little bit laxed and they recommend also
NOTE Confidence: 0.9654253

00:03:52.185 --> 00:03:55.057 that they have sleep study by age 4 years.
NOTE Confidence: 0.9654253

00:03:55.060 --> 00:03:56.908 However, this is a little bit difficult
NOTE Confidence: 0.9654253

00:03:56.908 --> 00:03:58.400 to accomplish because there are many,
NOTE Confidence: 0.9654253

00:03:58.400 --> 00:04:00.450 there are not many dedicated
NOTE Confidence: 0.9654253

00:04:00.450 --> 00:04:01.680 pediatric sleep lab,
NOTE Confidence: 0.9654253

00:04:01.680 --> 00:04:03.665 let alone with expertise in
NOTE Confidence: 0.9654253

00:04:03.665 --> 00:04:05.253 individuals with Down syndrome.
NOTE Confidence: 0.9654253

00:04:05.260 --> 00:04:07.460 As part of research we have been contacted,
NOTE Confidence: 0.9654253

00:04:07.460 --> 00:04:08.058 for example,
NOTE Confidence: 0.9654253

00:04:08.058 --> 00:04:09.553 from families far away from
NOTE Confidence: 0.9654253

00:04:09.553 --> 00:04:11.240 my center in Philadelphia.
NOTE Confidence: 0.9654253

00:04:11.240 --> 00:04:12.696 I remember one family.

NOTE Confidence: 0.9654253

00:04:12.696 --> 00:04:14.880 From North Dakota wanted to participate

NOTE Confidence: 0.9654253

00:04:14.940 --> 00:04:17.284 in the study and in talking to them

NOTE Confidence: 0.9654253

00:04:17.284 --> 00:04:19.073 they mentioned that the child was

NOTE Confidence: 0.9654253

00:04:19.073 --> 00:04:20.277 diagnosed with obstructive sleep

NOTE Confidence: 0.9654253

00:04:20.277 --> 00:04:22.596 apnea and they were not all for any

NOTE Confidence: 0.9654253

00:04:22.596 --> 00:04:23.956 particular treatment and were told

NOTE Confidence: 0.9654253

00:04:24.006 --> 00:04:25.862 that there it was just part of the

NOTE Confidence: 0.9654253

00:04:25.862 --> 00:04:28.826 syndrome and they have to live with it.

NOTE Confidence: 0.9654253

00:04:28.830 --> 00:04:31.063 And and so it's our duty as

NOTE Confidence: 0.9654253

00:04:31.063 --> 00:04:32.975 providers to educate the community

NOTE Confidence: 0.9654253

00:04:32.975 --> 00:04:34.747 about children in general,

NOTE Confidence: 0.9654253

00:04:34.750 --> 00:04:35.899 children with developmental

NOTE Confidence: 0.9654253

00:04:35.899 --> 00:04:37.048 disabilities and specifically

NOTE Confidence: 0.9654253

00:04:37.048 --> 00:04:38.580 children with Down syndrome.

NOTE Confidence: 0.9654253

00:04:38.580 --> 00:04:40.902 There are many treatment that the

NOTE Confidence: 0.9654253

00:04:40.902 --> 00:04:43.068 treatments that are available to them
NOTE Confidence: 0.9654253

00:04:43.068 --> 00:04:45.675 and I will show you that they're able to
NOTE Confidence: 0.9654253

00:04:45.675 --> 00:04:47.985 be adherent to some of those treatments.
NOTE Confidence: 0.9654253

00:04:47.990 --> 00:04:48.391 Importantly,
NOTE Confidence: 0.9654253

00:04:48.391 --> 00:04:50.396 this high prevalence of obstructive
NOTE Confidence: 0.9654253

00:04:50.396 --> 00:04:52.413 sleep apnea is also associated
NOTE Confidence: 0.9654253

00:04:52.413 --> 00:04:54.489 with a low rate of resolution.
NOTE Confidence: 0.9654253

00:04:54.490 --> 00:04:57.088 Many children with Down syndrome do
NOTE Confidence: 0.9654253

00:04:57.088 --> 00:04:58.820 not resolve after adenotonsillectomy
NOTE Confidence: 0.817372078181818

00:04:58.888 --> 00:05:02.100 requiring. Other treatments?
NOTE Confidence: 0.817372078181818

00:05:02.100 --> 00:05:04.963 In terms of the increased incidence or
NOTE Confidence: 0.817372078181818

00:05:04.963 --> 00:05:07.865 risk of obstructive sleep apnea in this
NOTE Confidence: 0.817372078181818

00:05:07.865 --> 00:05:10.271 population is due to several factors.
NOTE Confidence: 0.817372078181818

00:05:10.280 --> 00:05:11.940 One of those are anatomical,
NOTE Confidence: 0.817372078181818

00:05:11.940 --> 00:05:15.378 such as midface hypoplasia or glossoptosis.
NOTE Confidence: 0.817372078181818

00:05:15.380 --> 00:05:18.372 And also they do have some factors affecting

NOTE Confidence: 0.817372078181818
00:05:18.372 --> 00:05:20.898 their neuromotor control of the upper airway,
NOTE Confidence: 0.817372078181818
00:05:20.900 --> 00:05:22.820 such as hypotonia for example.
NOTE Confidence: 0.817372078181818
00:05:22.820 --> 00:05:24.500 If they are really hypotonic,
NOTE Confidence: 0.817372078181818
00:05:24.500 --> 00:05:26.092 they're upper Airways hypotonic.
NOTE Confidence: 0.817372078181818
00:05:26.092 --> 00:05:28.856 Many of them have swallowing dysfunction and
NOTE Confidence: 0.817372078181818
00:05:28.856 --> 00:05:31.096 many of the infants have silent swallowing,
NOTE Confidence: 0.817372078181818
00:05:31.100 --> 00:05:31.868 swallowing. Function.
NOTE Confidence: 0.817372078181818
00:05:31.868 --> 00:05:35.704 We have to think that to have to be able
NOTE Confidence: 0.817372078181818
00:05:35.704 --> 00:05:38.440 to choke or to protect your upper airway
NOTE Confidence: 0.817372078181818
00:05:38.513 --> 00:05:41.717 or to or to have cough related to aspiration,
NOTE Confidence: 0.817372078181818
00:05:41.720 --> 00:05:43.490 you need to have certain
NOTE Confidence: 0.817372078181818
00:05:43.490 --> 00:05:45.260 coordination of your upper airway.
NOTE Confidence: 0.817372078181818
00:05:45.260 --> 00:05:47.493 The upper airway is a very complex
NOTE Confidence: 0.817372078181818
00:05:47.493 --> 00:05:49.467 system from a neuromuscular perspective
NOTE Confidence: 0.817372078181818
00:05:49.467 --> 00:05:52.771 and we are as adults and typically
NOTE Confidence: 0.817372078181818

00:05:52.771 --> 00:05:54.650 developing adults were able to.
NOTE Confidence: 0.817372078181818

00:05:54.650 --> 00:05:56.960 Talk to breathe and to swallow
NOTE Confidence: 0.817372078181818

00:05:56.960 --> 00:05:59.429 or drink at the same time.
NOTE Confidence: 0.817372078181818

00:05:59.430 --> 00:05:59.740 However,
NOTE Confidence: 0.817372078181818

00:05:59.740 --> 00:06:01.910 this requires a lot of coordination that
NOTE Confidence: 0.817372078181818

00:06:01.910 --> 00:06:04.698 is not there in children and specifically
NOTE Confidence: 0.817372078181818

00:06:04.698 --> 00:06:06.803 in those with developmental disabilities.
NOTE Confidence: 0.817372078181818

00:06:06.810 --> 00:06:08.742 Many of the patient with Down syndrome
NOTE Confidence: 0.817372078181818

00:06:08.742 --> 00:06:11.117 who present to clinic and they do not
NOTE Confidence: 0.817372078181818

00:06:11.117 --> 00:06:12.602 have other symptoms of aspiration.
NOTE Confidence: 0.817372078181818

00:06:12.610 --> 00:06:15.770 When you request the videos from one study,
NOTE Confidence: 0.817372078181818

00:06:15.770 --> 00:06:18.220 you find out actually from mild aspiration
NOTE Confidence: 0.817372078181818

00:06:18.220 --> 00:06:20.670 to severe aspiration that has been unnoticed.
NOTE Confidence: 0.817372078181818

00:06:20.670 --> 00:06:22.330 This can have effects obviously,
NOTE Confidence: 0.817372078181818

00:06:22.330 --> 00:06:24.826 because then you have alterations in.
NOTE Confidence: 0.817372078181818

00:06:24.830 --> 00:06:27.525 You mismatch due to the chronic aspiration

NOTE Confidence: 0.817372078181818
00:06:27.525 --> 00:06:30.548 and you can have profound desaturations
NOTE Confidence: 0.817372078181818
00:06:30.548 --> 00:06:33.533 with the associated obstructive events.
NOTE Confidence: 0.817372078181818
00:06:33.540 --> 00:06:33.886 Also,
NOTE Confidence: 0.817372078181818
00:06:33.886 --> 00:06:36.654 we have to think that many of the
NOTE Confidence: 0.817372078181818
00:06:36.654 --> 00:06:39.522 children may develop obesity and have
NOTE Confidence: 0.817372078181818
00:06:39.522 --> 00:06:41.972 also hypothyroidism that may contribute
NOTE Confidence: 0.817372078181818
00:06:42.047 --> 00:06:44.567 further to obstructive sleep apnea.
NOTE Confidence: 0.817372078181818
00:06:44.570 --> 00:06:48.077 We know that obstructive sleep apnea in.
NOTE Confidence: 0.817372078181818
00:06:48.080 --> 00:06:50.130 Children without them syndrome is
NOTE Confidence: 0.817372078181818
00:06:50.130 --> 00:06:51.770 also associated to neurobehavioral
NOTE Confidence: 0.817372078181818
00:06:51.770 --> 00:06:53.680 deficits such as executive function,
NOTE Confidence: 0.817372078181818
00:06:53.680 --> 00:06:55.896 for example systemic hypertension.
NOTE Confidence: 0.817372078181818
00:06:55.896 --> 00:06:58.112 They have possibly elevated
NOTE Confidence: 0.817372078181818
00:06:58.112 --> 00:06:59.220 cardiometabolic risk.
NOTE Confidence: 0.817372078181818
00:06:59.220 --> 00:07:01.500 My colleague here in the endocrinology,
NOTE Confidence: 0.817372078181818

00:07:01.500 --> 00:07:02.280 Andrea Kelly,
NOTE Confidence: 0.817372078181818

00:07:02.280 --> 00:07:04.230 has authored several papers about
NOTE Confidence: 0.817372078181818

00:07:04.230 --> 00:07:06.778 that and there's a possible link of
NOTE Confidence: 0.817372078181818

00:07:06.778 --> 00:07:08.752 on treating OSA with early dementia
NOTE Confidence: 0.817372078181818

00:07:08.815 --> 00:07:10.399 in the general population.
NOTE Confidence: 0.817372078181818

00:07:10.400 --> 00:07:13.214 This has to be further studied in
NOTE Confidence: 0.817372078181818

00:07:13.214 --> 00:07:15.160 individuals with Down syndrome.
NOTE Confidence: 0.817372078181818

00:07:15.160 --> 00:07:16.552 This slide that was linked to
NOTE Confidence: 0.817372078181818

00:07:16.552 --> 00:07:18.310 me by one of my colleagues.
NOTE Confidence: 0.817372078181818

00:07:18.310 --> 00:07:19.152 And UCLA.
NOTE Confidence: 0.817372078181818

00:07:19.152 --> 00:07:22.099 And they do analysis of the EEG,
NOTE Confidence: 0.817372078181818

00:07:22.100 --> 00:07:24.356 like big data analysis of EEG.
NOTE Confidence: 0.817372078181818

00:07:24.360 --> 00:07:27.279 This is our adults without an syndrome
NOTE Confidence: 0.817372078181818

00:07:27.279 --> 00:07:30.578 who have OSA and who do not have OSA.
NOTE Confidence: 0.817372078181818

00:07:30.580 --> 00:07:32.356 You have there the numbers how
NOTE Confidence: 0.817372078181818

00:07:32.356 --> 00:07:34.663 they were pair and they came up

NOTE Confidence: 0.817372078181818

00:07:34.663 --> 00:07:36.433 investigators with an aging index,

NOTE Confidence: 0.817372078181818

00:07:36.440 --> 00:07:36.872 right?

NOTE Confidence: 0.817372078181818

00:07:36.872 --> 00:07:39.056 An aging index that as

NOTE Confidence: 0.817372078181818

00:07:39.056 --> 00:07:41.336 as the the person ages.

NOTE Confidence: 0.817372078181818

00:07:41.340 --> 00:07:43.524 There's certain signals in the in

NOTE Confidence: 0.817372078181818

00:07:43.524 --> 00:07:45.772 the EEG that allow investigators to

NOTE Confidence: 0.817372078181818

00:07:45.772 --> 00:07:48.628 come up with an index and they see

NOTE Confidence: 0.817372078181818

00:07:48.705 --> 00:07:51.020 that chronological age they have.

NOTE Confidence: 0.817372078181818

00:07:51.020 --> 00:07:53.220 If you see here in the Gray axis in the

NOTE Confidence: 0.817372078181818

00:07:53.285 --> 00:07:55.547 Gray color with the confidence interval,

NOTE Confidence: 0.817372078181818

00:07:55.550 --> 00:07:57.692 there you have how this brain index

NOTE Confidence: 0.817372078181818

00:07:57.692 --> 00:07:59.939 is that it increases with age,

NOTE Confidence: 0.817372078181818

00:07:59.940 --> 00:08:02.040 but it's not super, super significant.

NOTE Confidence: 0.817372078181818

00:08:02.040 --> 00:08:02.440 However,

NOTE Confidence: 0.817372078181818

00:08:02.440 --> 00:08:04.834 in those who always say start

NOTE Confidence: 0.817372078181818

00:08:04.834 --> 00:08:07.198 to increase a lot with age.
NOTE Confidence: 0.817372078181818

00:08:07.200 --> 00:08:08.004 So that means,
NOTE Confidence: 0.817372078181818

00:08:08.004 --> 00:08:08.540 for example,
NOTE Confidence: 0.817372078181818

00:08:08.540 --> 00:08:10.255 an individual who is 50
NOTE Confidence: 0.817372078181818

00:08:10.255 --> 00:08:11.970 years old and has untreated
NOTE Confidence: 0.853614664857143

00:08:12.044 --> 00:08:14.634 obstructive sleep apnea has a brain index
NOTE Confidence: 0.853614664857143

00:08:14.634 --> 00:08:17.739 that is older than the same individual
NOTE Confidence: 0.853614664857143

00:08:17.739 --> 00:08:19.659 without obstructive sleep apnea.
NOTE Confidence: 0.853614664857143

00:08:19.660 --> 00:08:24.097 So this is a theory that may link on
NOTE Confidence: 0.853614664857143

00:08:24.097 --> 00:08:25.982 treating obstructive sleep apnea with
NOTE Confidence: 0.853614664857143

00:08:25.982 --> 00:08:28.303 the appearance of early dementia or
NOTE Confidence: 0.853614664857143

00:08:28.303 --> 00:08:30.188 Alzheimer likes in individuals with
NOTE Confidence: 0.853614664857143

00:08:30.188 --> 00:08:32.318 Down syndrome as early as age 30.
NOTE Confidence: 0.853614664857143

00:08:32.320 --> 00:08:35.498 And this is what we're further investigating.
NOTE Confidence: 0.853614664857143

00:08:35.500 --> 00:08:37.990 So we know that in specifically
NOTE Confidence: 0.853614664857143

00:08:37.990 --> 00:08:39.631 in Down syndrome police,

NOTE Confidence: 0.853614664857143
00:08:39.631 --> 00:08:41.977 hypnotherapy improves in only a portion
NOTE Confidence: 0.853614664857143
00:08:41.977 --> 00:08:44.360 of children after adenotonsillectomy.
NOTE Confidence: 0.853614664857143
00:08:44.360 --> 00:08:46.288 So it may well be that police have
NOTE Confidence: 0.853614664857143
00:08:46.288 --> 00:08:47.880 monography is not the best outcome,
NOTE Confidence: 0.853614664857143
00:08:47.880 --> 00:08:49.890 it's the outcome that interest
NOTE Confidence: 0.853614664857143
00:08:49.890 --> 00:08:51.498 US physicians or scientists.
NOTE Confidence: 0.853614664857143
00:08:51.500 --> 00:08:53.849 But it may may not be the outcome that
NOTE Confidence: 0.853614664857143
00:08:53.849 --> 00:08:56.853 is interesting for the family or for the
NOTE Confidence: 0.853614664857143
00:08:56.853 --> 00:08:58.899 daytime functioning of the children.
NOTE Confidence: 0.853614664857143
00:08:58.900 --> 00:09:01.120 We need to investigate more about
NOTE Confidence: 0.853614664857143
00:09:01.120 --> 00:09:03.819 what is their data and functioning,
NOTE Confidence: 0.853614664857143
00:09:03.820 --> 00:09:06.324 what is the importance of quality of life.
NOTE Confidence: 0.853614664857143
00:09:06.330 --> 00:09:08.675 What are the car you metabolic outcomes
NOTE Confidence: 0.853614664857143
00:09:08.675 --> 00:09:11.488 and what are the family center outcomes?
NOTE Confidence: 0.853614664857143
00:09:11.490 --> 00:09:12.838 So based on this,
NOTE Confidence: 0.853614664857143

00:09:12.838 --> 00:09:14.523 because they don't resolve some
NOTE Confidence: 0.853614664857143

00:09:14.523 --> 00:09:18.050 individuals are referred for initiation.
NOTE Confidence: 0.853614664857143

00:09:18.050 --> 00:09:20.794 So what next with with that information,
NOTE Confidence: 0.853614664857143

00:09:20.800 --> 00:09:22.893 we have a lot of unknowns in
NOTE Confidence: 0.853614664857143

00:09:22.893 --> 00:09:24.120 Down syndrome and OSA.
NOTE Confidence: 0.853614664857143

00:09:24.120 --> 00:09:24.896 For example,
NOTE Confidence: 0.853614664857143

00:09:24.896 --> 00:09:27.224 in terms of diagnostic diagnosis and
NOTE Confidence: 0.853614664857143

00:09:27.224 --> 00:09:29.638 treatment of sleep disorder breathing,
NOTE Confidence: 0.853614664857143

00:09:29.640 --> 00:09:31.962 we have the possibility of Indianapolis
NOTE Confidence: 0.853614664857143

00:09:31.962 --> 00:09:34.488 of Monography that I was referring
NOTE Confidence: 0.853614664857143

00:09:34.488 --> 00:09:36.296 to there also unfortunately
NOTE Confidence: 0.853614664857143

00:09:36.296 --> 00:09:38.104 for obstructive sleep apnea.
NOTE Confidence: 0.853614664857143

00:09:38.110 --> 00:09:40.007 And there's no like like a point
NOTE Confidence: 0.853614664857143

00:09:40.007 --> 00:09:41.414 of care tool, for example,
NOTE Confidence: 0.853614664857143

00:09:41.414 --> 00:09:43.493 a hemoglobin A1C that we can say,
NOTE Confidence: 0.853614664857143

00:09:43.500 --> 00:09:43.796 OK,

NOTE Confidence: 0.853614664857143
00:09:43.796 --> 00:09:45.572 this is your risk or cholesterol
NOTE Confidence: 0.853614664857143
00:09:45.572 --> 00:09:47.221 or whatever thing that you can
NOTE Confidence: 0.853614664857143
00:09:47.221 --> 00:09:48.386 do in blood or urine.
NOTE Confidence: 0.853614664857143
00:09:48.390 --> 00:09:50.739 They have to go to the left PSG to
NOTE Confidence: 0.853614664857143
00:09:50.739 --> 00:09:53.210 know whether they have uh OSI or not.
NOTE Confidence: 0.853614664857143
00:09:53.210 --> 00:09:55.170 Also it is unknown what is the role
NOTE Confidence: 0.853614664857143
00:09:55.170 --> 00:09:57.563 for in home screening or diagnosis or
NOTE Confidence: 0.853614664857143
00:09:57.563 --> 00:09:59.930 homeless sleep apnea testing for example.
NOTE Confidence: 0.853614664857143
00:09:59.930 --> 00:10:01.988 It is also known whether Athena
NOTE Confidence: 0.853614664857143
00:10:01.988 --> 00:10:03.984 tonsillectomy is the first line of
NOTE Confidence: 0.853614664857143
00:10:03.984 --> 00:10:05.930 treatment or whether it is the the
NOTE Confidence: 0.853614664857143
00:10:05.930 --> 00:10:08.290 best indicated treatment for everybody.
NOTE Confidence: 0.853614664857143
00:10:08.290 --> 00:10:10.630 Maybe some kids would improve with
NOTE Confidence: 0.853614664857143
00:10:10.630 --> 00:10:13.009 advance electronic but some others need,
NOTE Confidence: 0.853614664857143
00:10:13.010 --> 00:10:15.558 some others need to go to CPAP
NOTE Confidence: 0.853614664857143

00:10:15.558 --> 00:10:17.256 or other other therapeutic.
NOTE Confidence: 0.853614664857143

00:10:17.256 --> 00:10:20.154 Weapons such As for example inspire
NOTE Confidence: 0.853614664857143

00:10:20.154 --> 00:10:22.955 and they're also lack of randomized
NOTE Confidence: 0.853614664857143

00:10:22.955 --> 00:10:25.150 control trials in children with
NOTE Confidence: 0.853614664857143

00:10:25.150 --> 00:10:27.280 Down syndrome specifically.
NOTE Confidence: 0.853614664857143

00:10:27.280 --> 00:10:29.062 Also a patient centered outcomes is
NOTE Confidence: 0.853614664857143

00:10:29.062 --> 00:10:31.241 something that we don't know what is
NOTE Confidence: 0.853614664857143

00:10:31.241 --> 00:10:32.801 the most appropriate nerve behavioral
NOTE Confidence: 0.853614664857143

00:10:32.801 --> 00:10:34.869 testing and the lack of harmonization
NOTE Confidence: 0.853614664857143

00:10:34.869 --> 00:10:36.604 between the different groups for
NOTE Confidence: 0.853614664857143

00:10:36.604 --> 00:10:38.480 conducting research in the population.
NOTE Confidence: 0.853614664857143

00:10:38.480 --> 00:10:40.380 Also as I explained before,
NOTE Confidence: 0.853614664857143

00:10:40.380 --> 00:10:40.902 for example,
NOTE Confidence: 0.853614664857143

00:10:40.902 --> 00:10:42.468 police of knowledge is something that
NOTE Confidence: 0.853614664857143

00:10:42.468 --> 00:10:44.260 we love is sort of an easy outcome.
NOTE Confidence: 0.853614664857143

00:10:44.260 --> 00:10:44.648 However,

NOTE Confidence: 0.853614664857143
00:10:44.648 --> 00:10:46.588 if families may experience different
NOTE Confidence: 0.853614664857143
00:10:46.588 --> 00:10:49.260 challenges that are more important for them.
NOTE Confidence: 0.853614664857143
00:10:49.260 --> 00:10:51.105 Then those of typically developing
NOTE Confidence: 0.853614664857143
00:10:51.105 --> 00:10:53.313 children and also families may be
NOTE Confidence: 0.853614664857143
00:10:53.313 --> 00:10:54.843 interested in smaller strides is
NOTE Confidence: 0.853614664857143
00:10:54.843 --> 00:10:57.173 something that I I see a lot of
NOTE Confidence: 0.853614664857143
00:10:57.173 --> 00:10:58.739 families with Down syndrome and I
NOTE Confidence: 0.853614664857143
00:10:58.740 --> 00:11:00.896 have learned so much from from them.
NOTE Confidence: 0.853614664857143
00:11:00.900 --> 00:11:03.315 One family I remember we were talking
NOTE Confidence: 0.853614664857143
00:11:03.315 --> 00:11:05.888 about starting CPAP and I was explaining
NOTE Confidence: 0.853614664857143
00:11:05.888 --> 00:11:07.364 the desensitization process and
NOTE Confidence: 0.853614664857143
00:11:07.364 --> 00:11:09.678 how it's progressive and etcetera,
NOTE Confidence: 0.853614664857143
00:11:09.680 --> 00:11:09.995 etcetera.
NOTE Confidence: 0.853614664857143
00:11:09.995 --> 00:11:12.830 And I remember mom told me we we we
NOTE Confidence: 0.850755390714286
00:11:12.900 --> 00:11:14.621 go for the 1%, she said it's
NOTE Confidence: 0.850755390714286

00:11:14.621 --> 00:11:15.856 something that we have learned.
NOTE Confidence: 0.850755390714286

00:11:15.860 --> 00:11:19.433 So whatever we do, we do PT or OT.
NOTE Confidence: 0.850755390714286

00:11:19.440 --> 00:11:21.365 Any milestone that we need to reach,
NOTE Confidence: 0.850755390714286

00:11:21.370 --> 00:11:24.235 I go for the 1% and won't give it to that 1%,
NOTE Confidence: 0.850755390714286

00:11:24.240 --> 00:11:27.258 we move to the next 1% and things like that.
NOTE Confidence: 0.850755390714286

00:11:27.258 --> 00:11:29.664 So we have to consider that maybe the
NOTE Confidence: 0.850755390714286

00:11:29.664 --> 00:11:32.040 time that it takes for them to arbitrate
NOTE Confidence: 0.850755390714286

00:11:32.109 --> 00:11:34.349 to any therapy that we may want to
NOTE Confidence: 0.850755390714286

00:11:34.349 --> 00:11:37.698 institute is a little bit longer.
NOTE Confidence: 0.850755390714286

00:11:37.700 --> 00:11:39.509 So what are the challenges, right?
NOTE Confidence: 0.850755390714286

00:11:39.509 --> 00:11:41.603 We have testing that is required
NOTE Confidence: 0.850755390714286

00:11:41.603 --> 00:11:44.247 for diagnosis and that is a major
NOTE Confidence: 0.850755390714286

00:11:44.247 --> 00:11:45.779 challenge because of availability.
NOTE Confidence: 0.850755390714286

00:11:45.780 --> 00:11:47.900 Also because it's the rest for the family,
NOTE Confidence: 0.850755390714286

00:11:47.900 --> 00:11:49.839 they have to come with other siblings
NOTE Confidence: 0.850755390714286

00:11:49.839 --> 00:11:52.114 or pay for someone to take care of

NOTE Confidence: 0.850755390714286

00:11:52.114 --> 00:11:54.217 the other kids while the family is

NOTE Confidence: 0.850755390714286

00:11:54.217 --> 00:11:56.191 overnight and sleep lab also this

NOTE Confidence: 0.850755390714286

00:11:56.191 --> 00:11:58.215 expensive and you have to come from

NOTE Confidence: 0.850755390714286

00:11:58.215 --> 00:12:00.253 from far away for example for the

NOTE Confidence: 0.850755390714286

00:12:00.253 --> 00:12:02.374 lab there are many costs that are

NOTE Confidence: 0.850755390714286

00:12:02.374 --> 00:12:04.214 associated with that also the tolerance

NOTE Confidence: 0.850755390714286

00:12:04.214 --> 00:12:06.122 is something that has been discussed

NOTE Confidence: 0.850755390714286

00:12:06.122 --> 00:12:08.477 at length by several publications that.

NOTE Confidence: 0.850755390714286

00:12:08.480 --> 00:12:10.255 Children with Down syndrome may

NOTE Confidence: 0.850755390714286

00:12:10.255 --> 00:12:11.646 not tolerate the setup.

NOTE Confidence: 0.850755390714286

00:12:11.646 --> 00:12:13.674 In my personal experience that our

NOTE Confidence: 0.850755390714286

00:12:13.674 --> 00:12:15.688 center the checks are fantastic.

NOTE Confidence: 0.850755390714286

00:12:15.690 --> 00:12:18.308 They have a great expertise in kids

NOTE Confidence: 0.850755390714286

00:12:18.308 --> 00:12:19.749 with developmental disabilities and

NOTE Confidence: 0.850755390714286

00:12:19.749 --> 00:12:21.845 most of them get to tolerate the entire

NOTE Confidence: 0.850755390714286

00:12:21.845 --> 00:12:24.008 set up as a workshop show show later.

NOTE Confidence: 0.850755390714286

00:12:24.010 --> 00:12:27.330 But that may not be the case everywhere.

NOTE Confidence: 0.850755390714286

00:12:27.330 --> 00:12:30.114 So also it is important to note that

NOTE Confidence: 0.850755390714286

00:12:30.114 --> 00:12:32.359 research has shown that for example

NOTE Confidence: 0.850755390714286

00:12:32.359 --> 00:12:34.115 90% of children with Down syndrome

NOTE Confidence: 0.850755390714286

00:12:34.115 --> 00:12:35.943 that would that they of children

NOTE Confidence: 0.850755390714286

00:12:35.943 --> 00:12:37.098 without the syndrome,

NOTE Confidence: 0.850755390714286

00:12:37.100 --> 00:12:38.558 sorry that were treated with that.

NOTE Confidence: 0.850755390714286

00:12:38.560 --> 00:12:40.044 They're just selectively for

NOTE Confidence: 0.850755390714286

00:12:40.044 --> 00:12:41.528 presume obstructive sleep apnea,

NOTE Confidence: 0.850755390714286

00:12:41.530 --> 00:12:44.188 never really had a sleep study.

NOTE Confidence: 0.850755390714286

00:12:44.190 --> 00:12:46.031 So the question is did they really

NOTE Confidence: 0.850755390714286

00:12:46.031 --> 00:12:47.150 have obstructive sleep apnea,

NOTE Confidence: 0.850755390714286

00:12:47.150 --> 00:12:48.574 did they really have,

NOTE Confidence: 0.850755390714286

00:12:48.574 --> 00:12:50.710 did we really require the surgery?

NOTE Confidence: 0.850755390714286

00:12:50.710 --> 00:12:52.450 And then tonsillectomy is one of

NOTE Confidence: 0.850755390714286
00:12:52.450 --> 00:12:53.970 the most common surgeries performed
NOTE Confidence: 0.850755390714286
00:12:53.970 --> 00:12:55.210 in the United States,
NOTE Confidence: 0.850755390714286
00:12:55.210 --> 00:12:57.238 but it still has some complications.
NOTE Confidence: 0.850755390714286
00:12:57.240 --> 00:12:58.444 That are not frequent,
NOTE Confidence: 0.850755390714286
00:12:58.444 --> 00:13:00.250 but when they occur they're very
NOTE Confidence: 0.850755390714286
00:13:00.309 --> 00:13:02.059 upsetting such for example hemorrhage
NOTE Confidence: 0.850755390714286
00:13:02.059 --> 00:13:04.503 pains and families need to be readmitted
NOTE Confidence: 0.850755390714286
00:13:04.503 --> 00:13:06.715 to the hospital due to the hemorrhage.
NOTE Confidence: 0.850755390714286
00:13:06.720 --> 00:13:09.438 So the risk benefit of it has to be
NOTE Confidence: 0.850755390714286
00:13:09.438 --> 00:13:11.719 further studied in this population.
NOTE Confidence: 0.850755390714286
00:13:11.720 --> 00:13:13.645 Based on this we they actually one
NOTE Confidence: 0.850755390714286
00:13:13.645 --> 00:13:16.532 that I have that I'm copying with my
NOTE Confidence: 0.850755390714286
00:13:16.532 --> 00:13:18.532 colleague Andrew Kelly from endocrinology.
NOTE Confidence: 0.850755390714286
00:13:18.540 --> 00:13:20.916 We decided to study the tolerability,
NOTE Confidence: 0.850755390714286
00:13:20.920 --> 00:13:22.950 the family reported perception and
NOTE Confidence: 0.850755390714286

00:13:22.950 --> 00:13:25.437 experience of feasibility and also the
NOTE Confidence: 0.850755390714286

00:13:25.437 --> 00:13:27.407 accuracy for diagnosis for moderate
NOTE Confidence: 0.850755390714286

00:13:27.407 --> 00:13:29.711 to severe obstructive sleep apnea or
NOTE Confidence: 0.850755390714286

00:13:29.711 --> 00:13:31.697 type 2 homeless sleep apnea testing.
NOTE Confidence: 0.850755390714286

00:13:31.700 --> 00:13:33.863 So for that we selected a device
NOTE Confidence: 0.850755390714286

00:13:33.863 --> 00:13:36.080 that could give us the same signals
NOTE Confidence: 0.850755390714286

00:13:36.080 --> 00:13:38.072 like 90% of the signals that we have
NOTE Confidence: 0.850755390714286

00:13:38.072 --> 00:13:39.998 in lab and polysomnography but at
NOTE Confidence: 0.850755390714286

00:13:39.998 --> 00:13:42.050 home and we're working with the.
NOTE Confidence: 0.850755390714286

00:13:42.050 --> 00:13:43.502 Device that the picture is there
NOTE Confidence: 0.850755390714286

00:13:43.502 --> 00:13:44.470 is there is more.
NOTE Confidence: 0.850755390714286

00:13:44.470 --> 00:13:46.238 You will see it in the next picture
NOTE Confidence: 0.850755390714286

00:13:46.238 --> 00:13:48.032 how it it is there with the kid
NOTE Confidence: 0.850755390714286

00:13:48.032 --> 00:13:49.520 and you see here the technician
NOTE Confidence: 0.850755390714286

00:13:49.520 --> 00:13:51.522 is holding the device in the kids.
NOTE Confidence: 0.850755390714286

00:13:51.530 --> 00:13:53.637 This is a kid with Down syndrome

NOTE Confidence: 0.850755390714286
00:13:53.637 --> 00:13:54.540 who is having
NOTE Confidence: 0.893107832666667
00:13:54.609 --> 00:13:56.967 the setup that we do in the lab and
NOTE Confidence: 0.893107832666667
00:13:56.967 --> 00:13:58.930 then they go overnight to their
NOTE Confidence: 0.893107832666667
00:13:58.930 --> 00:14:01.300 house and they have the home sleep
NOTE Confidence: 0.893107832666667
00:14:01.300 --> 00:14:03.490 apnea testing in a different night.
NOTE Confidence: 0.893107832666667
00:14:03.490 --> 00:14:05.778 They have an in lab police of no
NOTE Confidence: 0.893107832666667
00:14:05.778 --> 00:14:08.147 graphy and we compare that we recruited
NOTE Confidence: 0.893107832666667
00:14:08.147 --> 00:14:10.984 children 10 to 20 years and we also
NOTE Confidence: 0.893107832666667
00:14:10.984 --> 00:14:13.066 we did a questionnaires about that.
NOTE Confidence: 0.893107832666667
00:14:13.070 --> 00:14:15.617 These are the videos that I want to share
NOTE Confidence: 0.893107832666667
00:14:15.617 --> 00:14:17.840 with you that we did specifically about
NOTE Confidence: 0.893107832666667
00:14:17.840 --> 00:14:20.912 the setup in the hospital of a in lab
NOTE Confidence: 0.893107832666667
00:14:20.912 --> 00:14:22.662 polysomnography about what to expect
NOTE Confidence: 0.893107832666667
00:14:22.670 --> 00:14:25.208 and the one for the setup setup at home.
NOTE Confidence: 0.893107832666667
00:14:25.210 --> 00:14:26.908 The videos have been very informative.
NOTE Confidence: 0.893107832666667

00:14:26.910 --> 00:14:29.070 Families have been like very thankful
NOTE Confidence: 0.893107832666667

00:14:29.070 --> 00:14:31.729 for us to provide the videos to them
NOTE Confidence: 0.893107832666667

00:14:31.729 --> 00:14:34.308 so they can work with the children and
NOTE Confidence: 0.893107832666667

00:14:34.308 --> 00:14:37.052 explain to them what to expect overnight.
NOTE Confidence: 0.893107832666667

00:14:37.060 --> 00:14:39.733 So the 34 kids were tested when I was
NOTE Confidence: 0.893107832666667

00:14:39.733 --> 00:14:41.698 doing these slides and the median
NOTE Confidence: 0.893107832666667

00:14:41.698 --> 00:14:43.780 age is there is 16 years.
NOTE Confidence: 0.893107832666667

00:14:43.780 --> 00:14:45.400 In addition to the homeless sleep
NOTE Confidence: 0.893107832666667

00:14:45.400 --> 00:14:46.767 apnea testing the little device
NOTE Confidence: 0.893107832666667

00:14:46.767 --> 00:14:48.433 that you that I showed you before,
NOTE Confidence: 0.893107832666667

00:14:48.440 --> 00:14:50.740 they were this response socks
NOTE Confidence: 0.893107832666667

00:14:50.740 --> 00:14:53.040 that is connected via Bluetooth.
NOTE Confidence: 0.893107832666667

00:14:53.040 --> 00:14:56.802 And we had a median or a child that was 14.2.
NOTE Confidence: 0.893107832666667

00:14:56.802 --> 00:14:59.472 We had a full range of 4.8 to
NOTE Confidence: 0.893107832666667

00:14:59.472 --> 00:15:00.936 22.8 events per hour.
NOTE Confidence: 0.893107832666667

00:15:00.940 --> 00:15:03.245 Of the kids, what you see, many of them,

NOTE Confidence: 0.893107832666667
00:15:03.245 --> 00:15:05.680 I mean of most of them were not,
NOTE Confidence: 0.893107832666667
00:15:05.680 --> 00:15:07.816 did not have normal sleep studies.
NOTE Confidence: 0.893107832666667
00:15:07.820 --> 00:15:09.972 And the total sleep time that we have
NOTE Confidence: 0.893107832666667
00:15:09.972 --> 00:15:12.414 in the lab was about 6 point at home,
NOTE Confidence: 0.893107832666667
00:15:12.420 --> 00:15:14.958 sorry, 6.3 hours.
NOTE Confidence: 0.893107832666667
00:15:14.960 --> 00:15:16.240 In terms of the questionnaire
NOTE Confidence: 0.893107832666667
00:15:16.240 --> 00:15:17.860 that we ask the families about,
NOTE Confidence: 0.893107832666667
00:15:17.860 --> 00:15:19.528 how did it go,
NOTE Confidence: 0.893107832666667
00:15:19.528 --> 00:15:22.424 they said that 94% reported that it took less
NOTE Confidence: 0.893107832666667
00:15:22.424 --> 00:15:24.838 than 15 minutes for them to set up at home.
NOTE Confidence: 0.893107832666667
00:15:24.840 --> 00:15:25.980 What we do in the lab,
NOTE Confidence: 0.893107832666667
00:15:25.980 --> 00:15:27.870 we put the EEG leads,
NOTE Confidence: 0.893107832666667
00:15:27.870 --> 00:15:28.830 the the eyelids,
NOTE Confidence: 0.893107832666667
00:15:28.830 --> 00:15:31.540 we put the belts and then we send
NOTE Confidence: 0.893107832666667
00:15:31.540 --> 00:15:33.500 them home with the cannulas.
NOTE Confidence: 0.893107832666667

00:15:33.500 --> 00:15:34.860 They demonstrate to the family
NOTE Confidence: 0.893107832666667

00:15:34.860 --> 00:15:36.700 how to put the candle at home,
NOTE Confidence: 0.893107832666667

00:15:36.700 --> 00:15:38.764 and the family has only to put the
NOTE Confidence: 0.893107832666667

00:15:38.764 --> 00:15:40.610 candle and to put the ball socks.
NOTE Confidence: 0.893107832666667

00:15:40.610 --> 00:15:42.833 The system that we sent at home because it
NOTE Confidence: 0.893107832666667

00:15:42.833 --> 00:15:45.230 was geared toward sleep disorder breathing,
NOTE Confidence: 0.893107832666667

00:15:45.230 --> 00:15:46.742 we did not send the families
NOTE Confidence: 0.893107832666667

00:15:46.742 --> 00:15:47.750 home with leg leads.
NOTE Confidence: 0.893107832666667

00:15:47.750 --> 00:15:49.479 However, it's something that we could do.
NOTE Confidence: 0.893107832666667

00:15:49.480 --> 00:15:49.895 Also,
NOTE Confidence: 0.893107832666667

00:15:49.895 --> 00:15:51.970 the home sleep apnea testing
NOTE Confidence: 0.893107832666667

00:15:51.970 --> 00:15:53.581 right out-of-the-box does not
NOTE Confidence: 0.893107832666667

00:15:53.581 --> 00:15:55.566 have the availability of measure
NOTE Confidence: 0.893107832666667

00:15:55.566 --> 00:15:57.689 entitled CO2 or transcutaneous CO2,
NOTE Confidence: 0.893107832666667

00:15:57.690 --> 00:15:57.973 however,
NOTE Confidence: 0.893107832666667

00:15:57.973 --> 00:16:00.866 is something that you can do with a with a

NOTE Confidence: 0.893107832666667
00:16:00.866 --> 00:16:03.122 device that you adapt and connect to that.
NOTE Confidence: 0.893107832666667
00:16:03.130 --> 00:16:04.369 But we didn't want to do that.
NOTE Confidence: 0.893107832666667
00:16:04.370 --> 00:16:06.494 We didn't want it to be as simple as
NOTE Confidence: 0.893107832666667
00:16:06.494 --> 00:16:08.258 possible so it could be reproducible.
NOTE Confidence: 0.893107832666667
00:16:08.260 --> 00:16:09.886 Also you can see there that
NOTE Confidence: 0.893107832666667
00:16:09.886 --> 00:16:10.970 the ratings that families.
NOTE Confidence: 0.893107832666667
00:16:10.970 --> 00:16:13.025 Provided in terms of placing
NOTE Confidence: 0.893107832666667
00:16:13.025 --> 00:16:14.258 the hands oximeter,
NOTE Confidence: 0.893107832666667
00:16:14.260 --> 00:16:15.892 the cannula or anything
NOTE Confidence: 0.893107832666667
00:16:15.892 --> 00:16:17.932 come off overnight are high.
NOTE Confidence: 0.893107832666667
00:16:17.940 --> 00:16:19.240 Things may come off overnight
NOTE Confidence: 0.893107832666667
00:16:19.240 --> 00:16:20.990 like the ball sacks for example.
NOTE Confidence: 0.893107832666667
00:16:20.990 --> 00:16:23.814 However families were able to to replace it.
NOTE Confidence: 0.893107832666667
00:16:23.820 --> 00:16:25.608 They think that the test was
NOTE Confidence: 0.893107832666667
00:16:25.608 --> 00:16:27.554 usable for them and overall the
NOTE Confidence: 0.893107832666667

00:16:27.554 --> 00:16:29.606 experience was already as good or
NOTE Confidence: 0.893107832666667

00:16:29.606 --> 00:16:33.428 very good by 87% of the families.
NOTE Confidence: 0.893107832666667

00:16:33.430 --> 00:16:35.726 Then we finally analyze all the data.
NOTE Confidence: 0.868392037586207

00:16:35.730 --> 00:16:37.944 We submitted this paper for publication
NOTE Confidence: 0.868392037586207

00:16:37.944 --> 00:16:40.712 and we're waiting for to hear from the
NOTE Confidence: 0.868392037586207

00:16:40.712 --> 00:16:43.309 journals and we ended up recording 63 youth
NOTE Confidence: 0.868392037586207

00:16:43.309 --> 00:16:45.703 for participation of of them some decline.
NOTE Confidence: 0.868392037586207

00:16:45.710 --> 00:16:48.377 We consented 43 to participate and of
NOTE Confidence: 0.868392037586207

00:16:48.377 --> 00:16:51.029 those 40 completed the study procedures.
NOTE Confidence: 0.868392037586207

00:16:51.030 --> 00:16:53.094 So when I hear our children with Down
NOTE Confidence: 0.868392037586207

00:16:53.094 --> 00:16:54.930 syndrome they cannot do PSG and say no,
NOTE Confidence: 0.868392037586207

00:16:54.930 --> 00:16:56.736 we do have data they can only
NOTE Confidence: 0.868392037586207

00:16:56.736 --> 00:16:58.645 three were unable to complete the
NOTE Confidence: 0.868392037586207

00:16:58.645 --> 00:17:00.085 complete the study procedures.
NOTE Confidence: 0.868392037586207

00:17:00.090 --> 00:17:01.460 One was unable to complete
NOTE Confidence: 0.868392037586207

00:17:01.460 --> 00:17:03.050 the eight set and meaning by.

NOTE Confidence: 0.868392037586207
00:17:03.050 --> 00:17:04.550 Enable means that sometimes the
NOTE Confidence: 0.868392037586207
00:17:04.550 --> 00:17:06.658 family didn't want to you know when
NOTE Confidence: 0.868392037586207
00:17:06.658 --> 00:17:08.576 you all provide research and you are
NOTE Confidence: 0.868392037586207
00:17:08.576 --> 00:17:10.565 gonna be paying for that we we have
NOTE Confidence: 0.868392037586207
00:17:10.565 --> 00:17:12.280 one family that really wanted to do
NOTE Confidence: 0.868392037586207
00:17:12.280 --> 00:17:13.530 only the anlap polysomnography and
NOTE Confidence: 0.868392037586207
00:17:13.530 --> 00:17:14.943 the research slow down so earlier
NOTE Confidence: 0.868392037586207
00:17:14.943 --> 00:17:16.556 and then you know went to anything
NOTE Confidence: 0.868392037586207
00:17:16.556 --> 00:17:18.124 with that and the other just didn't
NOTE Confidence: 0.868392037586207
00:17:18.124 --> 00:17:20.254 want to proceed with the PSG and one
NOTE Confidence: 0.868392037586207
00:17:20.254 --> 00:17:22.247 family consent in that ended up not
NOTE Confidence: 0.868392037586207
00:17:22.247 --> 00:17:23.915 doing any any of the procedures.
NOTE Confidence: 0.868392037586207
00:17:23.920 --> 00:17:25.726 So in terms of which test was
NOTE Confidence: 0.868392037586207
00:17:25.726 --> 00:17:27.998 easiest for you as you can see there
NOTE Confidence: 0.868392037586207
00:17:27.998 --> 00:17:29.798 most people consider that the home
NOTE Confidence: 0.868392037586207

00:17:29.798 --> 00:17:31.622 sleep apnea testing was easier for
NOTE Confidence: 0.868392037586207

00:17:31.622 --> 00:17:33.425 them and this is very important.
NOTE Confidence: 0.868392037586207

00:17:33.425 --> 00:17:35.820 It's not that we want to necessarily say
NOTE Confidence: 0.868392037586207

00:17:35.820 --> 00:17:37.731 that every kid with Down syndrome needs
NOTE Confidence: 0.868392037586207

00:17:37.731 --> 00:17:39.790 to have a home sleep apnea testing,
NOTE Confidence: 0.868392037586207

00:17:39.790 --> 00:17:42.541 but we are working hard to prove
NOTE Confidence: 0.868392037586207

00:17:42.541 --> 00:17:44.949 is that options are necessary,
NOTE Confidence: 0.868392037586207

00:17:44.950 --> 00:17:46.720 the choice of families to decide
NOTE Confidence: 0.868392037586207

00:17:46.720 --> 00:17:48.809 what test is the best for them.
NOTE Confidence: 0.868392037586207

00:17:48.810 --> 00:17:49.374 For example,
NOTE Confidence: 0.868392037586207

00:17:49.374 --> 00:17:51.066 some families may prefer for whatever
NOTE Confidence: 0.868392037586207

00:17:51.066 --> 00:17:52.743 reason they in lab tests are not
NOTE Confidence: 0.868392037586207

00:17:52.743 --> 00:17:54.090 willing to put anything at home,
NOTE Confidence: 0.868392037586207

00:17:54.090 --> 00:17:56.448 or they don't have the the right setup at
NOTE Confidence: 0.868392037586207

00:17:56.448 --> 00:17:58.826 home to contact the study perfectly fine,
NOTE Confidence: 0.868392037586207

00:17:58.830 --> 00:18:00.546 they can go to the lab.

NOTE Confidence: 0.868392037586207

00:18:00.550 --> 00:18:03.799 Most of the people may be able to do

NOTE Confidence: 0.868392037586207

00:18:03.799 --> 00:18:06.360 it at home. Which states do you prefer?

NOTE Confidence: 0.868392037586207

00:18:06.360 --> 00:18:08.410 Most families also prefer home

NOTE Confidence: 0.868392037586207

00:18:08.410 --> 00:18:09.640 sleep apnea testing.

NOTE Confidence: 0.868392037586207

00:18:09.640 --> 00:18:11.518 Which test was easier for you?

NOTE Confidence: 0.868392037586207

00:18:11.520 --> 00:18:13.242 You know, most families also mentioned

NOTE Confidence: 0.868392037586207

00:18:13.242 --> 00:18:14.800 that homeless sleep apnea testing,

NOTE Confidence: 0.868392037586207

00:18:14.800 --> 00:18:16.487 I'm sorry, was easier for the child.

NOTE Confidence: 0.868392037586207

00:18:16.490 --> 00:18:18.296 So it appears that home sleep

NOTE Confidence: 0.868392037586207

00:18:18.296 --> 00:18:20.222 apnea testing is feasible and well

NOTE Confidence: 0.868392037586207

00:18:20.222 --> 00:18:21.538 accepted by their families.

NOTE Confidence: 0.868392037586207

00:18:21.540 --> 00:18:22.554 And importantly,

NOTE Confidence: 0.868392037586207

00:18:22.554 --> 00:18:25.596 regarding the correlation with the inlab

NOTE Confidence: 0.868392037586207

00:18:25.596 --> 00:18:28.099 apnea obstructive apnea hypopnea index,

NOTE Confidence: 0.868392037586207

00:18:28.100 --> 00:18:30.757 we have there the 95% confidence

NOTE Confidence: 0.868392037586207

00:18:30.757 --> 00:18:33.079 intervals in Gray and the fitted
NOTE Confidence: 0.868392037586207

00:18:33.079 --> 00:18:35.189 values in the line in blue.
NOTE Confidence: 0.868392037586207

00:18:35.190 --> 00:18:36.798 On the X axis,
NOTE Confidence: 0.868392037586207

00:18:36.798 --> 00:18:39.210 we had them in lab polysomnography
NOTE Confidence: 0.868392037586207

00:18:39.299 --> 00:18:41.007 obstructive apnea hypopnea index
NOTE Confidence: 0.868392037586207

00:18:41.007 --> 00:18:44.230 on the Y axis on in orange,
NOTE Confidence: 0.868392037586207

00:18:44.230 --> 00:18:46.141 we have the home sleep apnea testing
NOTE Confidence: 0.868392037586207

00:18:46.141 --> 00:18:48.215 and we can see that the correlation
NOTE Confidence: 0.868392037586207

00:18:48.215 --> 00:18:50.498 is very high with the high sensitivity
NOTE Confidence: 0.868392037586207

00:18:50.498 --> 00:18:52.266 and very high specificity,
NOTE Confidence: 0.868392037586207

00:18:52.270 --> 00:18:53.930 something that is very important
NOTE Confidence: 0.868392037586207

00:18:53.930 --> 00:18:54.926 to point out.
NOTE Confidence: 0.868392037586207

00:18:54.930 --> 00:18:57.378 When you do a test and you are
NOTE Confidence: 0.868392037586207

00:18:57.378 --> 00:19:00.028 going to decide if you're a pedic,
NOTE Confidence: 0.868392037586207

00:19:00.030 --> 00:19:02.634 if therapeutic you're going to have
NOTE Confidence: 0.868392037586207

00:19:02.634 --> 00:19:04.770 therapeutic decision with that test.

NOTE Confidence: 0.868392037586207

00:19:04.770 --> 00:19:06.714 You know what matters is in the case

NOTE Confidence: 0.868392037586207

00:19:06.714 --> 00:19:08.453 of will say it's not necessarily

NOTE Confidence: 0.868392037586207

00:19:08.453 --> 00:19:10.241 that they compare one to one,

NOTE Confidence: 0.868392037586207

00:19:10.250 --> 00:19:12.970 that for example if I do have 30

NOTE Confidence: 0.868392037586207

00:19:12.970 --> 00:19:15.608 here or HIV in the inland PSG,

NOTE Confidence: 0.7276868825

00:19:15.610 --> 00:19:17.746 I have the same 30 into 8 set.

NOTE Confidence: 0.7276868825

00:19:17.750 --> 00:19:18.990 That's not what really matters.

NOTE Confidence: 0.7276868825

00:19:18.990 --> 00:19:21.862 What matter is that with 30 for example

NOTE Confidence: 0.7276868825

00:19:21.862 --> 00:19:24.609 in the inland PSG I will say OK,

NOTE Confidence: 0.7276868825

00:19:24.610 --> 00:19:26.626 your kid needs treatment and if they

NOTE Confidence: 0.7276868825

00:19:26.626 --> 00:19:28.912 have 20 in the homeless lipner testing

NOTE Confidence: 0.7276868825

00:19:28.912 --> 00:19:31.310 most likely I would say the same.

NOTE Confidence: 0.7276868825

00:19:31.310 --> 00:19:33.172 So that will really matters is that

NOTE Confidence: 0.7276868825

00:19:33.172 --> 00:19:34.850 we provide families that opportunity.

NOTE Confidence: 0.7276868825

00:19:34.850 --> 00:19:36.285 Integrated home and eventually you

NOTE Confidence: 0.7276868825

00:19:36.285 --> 00:19:38.220 know our dream would talk about all
NOTE Confidence: 0.7276868825

00:19:38.220 --> 00:19:39.795 all the time about this would be
NOTE Confidence: 0.7276868825

00:19:39.795 --> 00:19:41.532 that when we had these families from
NOTE Confidence: 0.7276868825

00:19:41.532 --> 00:19:43.326 North Dakota or the coming far away,
NOTE Confidence: 0.7276868825

00:19:43.326 --> 00:19:44.414 they want to participate,
NOTE Confidence: 0.7276868825

00:19:44.420 --> 00:19:46.380 we should be able to ship them the
NOTE Confidence: 0.7276868825

00:19:46.380 --> 00:19:48.188 device and to partner with the Sleep
NOTE Confidence: 0.7276868825

00:19:48.188 --> 00:19:50.416 lab there who can do the setup or
NOTE Confidence: 0.7276868825

00:19:50.416 --> 00:19:52.246 neurology office or something like that
NOTE Confidence: 0.7276868825

00:19:52.246 --> 00:19:54.716 and then we can read the study remote.
NOTE Confidence: 0.7276868825

00:19:54.720 --> 00:19:55.972 We're not there yet.
NOTE Confidence: 0.7276868825

00:19:55.972 --> 00:19:58.231 Another point that is is very important
NOTE Confidence: 0.7276868825

00:19:58.231 --> 00:20:00.422 is that the total sleep time at
NOTE Confidence: 0.7276868825

00:20:00.422 --> 00:20:02.619 home was significantly different,
NOTE Confidence: 0.7276868825

00:20:02.620 --> 00:20:05.760 like an hour longer than the PSG in the lab.
NOTE Confidence: 0.7276868825

00:20:05.760 --> 00:20:07.524 And this is very important because

NOTE Confidence: 0.7276868825

00:20:07.524 --> 00:20:08.700 if you have awakenings,

NOTE Confidence: 0.7276868825

00:20:08.700 --> 00:20:10.849 the more sleep you capture the better.

NOTE Confidence: 0.7276868825

00:20:10.850 --> 00:20:13.274 And in the lab as you know them,

NOTE Confidence: 0.7276868825

00:20:13.280 --> 00:20:15.584 at least here around 6:00 or 6:30 AM

NOTE Confidence: 0.7276868825

00:20:15.584 --> 00:20:17.620 they start waking up everybody because

NOTE Confidence: 0.7276868825

00:20:17.620 --> 00:20:20.162 the the the shift ends, people leave.

NOTE Confidence: 0.7276868825

00:20:20.162 --> 00:20:22.568 However at home they can start

NOTE Confidence: 0.7276868825

00:20:22.568 --> 00:20:25.070 the the sleep when they want.

NOTE Confidence: 0.7276868825

00:20:25.070 --> 00:20:27.518 The usual time and they can wake up at

NOTE Confidence: 0.7276868825

00:20:27.518 --> 00:20:30.072 the usual time and that's why we had

NOTE Confidence: 0.7276868825

00:20:30.072 --> 00:20:32.500 longer sleep time and that provided

NOTE Confidence: 0.7276868825

00:20:32.500 --> 00:20:36.478 us more data, more RAM mostly too.

NOTE Confidence: 0.7276868825

00:20:36.480 --> 00:20:39.028 And this is a child with Down

NOTE Confidence: 0.7276868825

00:20:39.028 --> 00:20:40.120 syndrome and CPAP.

NOTE Confidence: 0.7276868825

00:20:40.120 --> 00:20:41.758 You know, typically parents say no,

NOTE Confidence: 0.7276868825

00:20:41.760 --> 00:20:43.016 they will not be able to use it.

NOTE Confidence: 0.7276868825

00:20:43.020 --> 00:20:44.118 And then we have, you know,

NOTE Confidence: 0.7276868825

00:20:44.120 --> 00:20:46.096 if you have a child of three years

NOTE Confidence: 0.7276868825

00:20:46.096 --> 00:20:48.379 or so or two like this little one,

NOTE Confidence: 0.7276868825

00:20:48.380 --> 00:20:50.340 you know that there's no coercion in

NOTE Confidence: 0.7276868825

00:20:50.340 --> 00:20:52.340 the world that would make her look,

NOTE Confidence: 0.7276868825

00:20:52.340 --> 00:20:53.556 smile with the mask,

NOTE Confidence: 0.7276868825

00:20:53.556 --> 00:20:53.860 anything.

NOTE Confidence: 0.7276868825

00:20:53.860 --> 00:20:56.320 It's just not really having a

NOTE Confidence: 0.7276868825

00:20:56.320 --> 00:20:58.490 good time at that time.

NOTE Confidence: 0.7276868825

00:20:58.490 --> 00:21:00.026 So with that I will change gears and

NOTE Confidence: 0.7276868825

00:21:00.026 --> 00:21:01.721 I will talk a little bit about the

NOTE Confidence: 0.7276868825

00:21:01.721 --> 00:21:03.355 other brand that we have which is

NOTE Confidence: 0.7276868825

00:21:03.355 --> 00:21:04.843 part in children with Down syndrome.

NOTE Confidence: 0.7276868825

00:21:04.850 --> 00:21:07.755 So this is a an initiative called

NOTE Confidence: 0.7276868825

00:21:07.755 --> 00:21:10.144 an R6133 and the R61 is preliminary

NOTE Confidence: 0.7276868825

00:21:10.144 --> 00:21:12.386 work to launch a clinical trial

NOTE Confidence: 0.7276868825

00:21:12.386 --> 00:21:14.760 that happens during the R33 phase.

NOTE Confidence: 0.7276868825

00:21:14.760 --> 00:21:17.540 So what we do for the R61 study,

NOTE Confidence: 0.7276868825

00:21:17.540 --> 00:21:20.235 we do the qualitative study where we

NOTE Confidence: 0.7276868825

00:21:20.235 --> 00:21:22.451 interview 20 families in Philadelphia

NOTE Confidence: 0.7276868825

00:21:22.451 --> 00:21:24.646 and 20 families in Cincinnati

NOTE Confidence: 0.7276868825

00:21:24.646 --> 00:21:26.646 because it's a two side study,

NOTE Confidence: 0.7276868825

00:21:26.650 --> 00:21:29.100 the parents of children with Down syndrome.

NOTE Confidence: 0.7276868825

00:21:29.100 --> 00:21:29.864 Unattractively Batnaya,

NOTE Confidence: 0.7276868825

00:21:29.864 --> 00:21:32.538 who had been treated with CPAP or

NOTE Confidence: 0.7276868825

00:21:32.538 --> 00:21:34.690 Bipap for greater than six months

NOTE Confidence: 0.7276868825

00:21:34.690 --> 00:21:36.807 to see what their experience was

NOTE Confidence: 0.7276868825

00:21:36.807 --> 00:21:38.919 to to inform the development of

NOTE Confidence: 0.7276868825

00:21:38.919 --> 00:21:40.436 the randomized control trial that

NOTE Confidence: 0.7276868825

00:21:40.436 --> 00:21:41.120 we're doing now.

NOTE Confidence: 0.823943624615385

00:21:43.150 --> 00:21:44.926 So the strategies that we have
NOTE Confidence: 0.823943624615385

00:21:44.926 --> 00:21:46.949 to increase Bob use in any child,
NOTE Confidence: 0.823943624615385

00:21:46.950 --> 00:21:49.296 but specifically in those with developmental
NOTE Confidence: 0.823943624615385

00:21:49.296 --> 00:21:51.169 disabilities and Down syndrome is
NOTE Confidence: 0.823943624615385

00:21:51.169 --> 00:21:52.947 to meet the families where they are.
NOTE Confidence: 0.823943624615385

00:21:52.950 --> 00:21:54.210 We cannot tell them, OK,
NOTE Confidence: 0.823943624615385

00:21:54.210 --> 00:21:56.130 you need to start using this every night.
NOTE Confidence: 0.823943624615385

00:21:56.130 --> 00:21:58.086 Now we know that some families
NOTE Confidence: 0.823943624615385

00:21:58.086 --> 00:22:00.608 might be able to, most will not.
NOTE Confidence: 0.823943624615385

00:22:00.608 --> 00:22:02.638 So we'll start with the
NOTE Confidence: 0.823943624615385

00:22:02.638 --> 00:22:03.450 desensitization process.
NOTE Confidence: 0.823943624615385

00:22:03.450 --> 00:22:05.070 We work closely with
NOTE Confidence: 0.823943624615385

00:22:05.070 --> 00:22:05.880 behavioral psychologists.
NOTE Confidence: 0.823943624615385

00:22:05.880 --> 00:22:08.238 We have great partners in behavioral
NOTE Confidence: 0.823943624615385

00:22:08.238 --> 00:22:10.190 psychology embedded in our team.
NOTE Confidence: 0.823943624615385

00:22:10.190 --> 00:22:12.470 They streamlined the bedtime routine.

NOTE Confidence: 0.823943624615385
00:22:12.470 --> 00:22:14.210 So it's important that the family.
NOTE Confidence: 0.823943624615385
00:22:14.210 --> 00:22:15.386 Have established bedtime
NOTE Confidence: 0.823943624615385
00:22:15.386 --> 00:22:17.738 routine that can work for them.
NOTE Confidence: 0.823943624615385
00:22:17.740 --> 00:22:19.666 It cannot be something prescribed that
NOTE Confidence: 0.823943624615385
00:22:19.666 --> 00:22:22.652 it can be and to use the mask initially
NOTE Confidence: 0.823943624615385
00:22:22.652 --> 00:22:25.160 during an activity that the child enjoys.
NOTE Confidence: 0.823943624615385
00:22:25.160 --> 00:22:26.942 Sometimes they like to call with
NOTE Confidence: 0.823943624615385
00:22:26.942 --> 00:22:29.100 the parents or they like to watch
NOTE Confidence: 0.823943624615385
00:22:29.100 --> 00:22:30.918 specific cartoon for example to do
NOTE Confidence: 0.823943624615385
00:22:30.918 --> 00:22:32.875 that and to do the role modeling.
NOTE Confidence: 0.823943624615385
00:22:32.880 --> 00:22:33.976 So something that's positive
NOTE Confidence: 0.823943624615385
00:22:33.976 --> 00:22:35.917 every time that the word the mask
NOTE Confidence: 0.823943624615385
00:22:35.917 --> 00:22:37.157 and the world falls apart,
NOTE Confidence: 0.823943624615385
00:22:37.160 --> 00:22:38.240 it's like if you're doing
NOTE Confidence: 0.823943624615385
00:22:38.240 --> 00:22:39.320 potty training with your kids,
NOTE Confidence: 0.823943624615385

00:22:39.320 --> 00:22:41.290 like yeah, this is amazing,
NOTE Confidence: 0.823943624615385

00:22:41.290 --> 00:22:41.734 etcetera,
NOTE Confidence: 0.823943624615385

00:22:41.734 --> 00:22:44.398 something that you receive positive feedback.
NOTE Confidence: 0.823943624615385

00:22:44.400 --> 00:22:46.086 Most likely you will continue to
NOTE Confidence: 0.823943624615385

00:22:46.086 --> 00:22:48.374 do and that's what we have to work
NOTE Confidence: 0.823943624615385

00:22:48.374 --> 00:22:50.030 with the families and the parents.
NOTE Confidence: 0.823943624615385

00:22:50.030 --> 00:22:51.590 When the parents buy in,
NOTE Confidence: 0.823943624615385

00:22:51.590 --> 00:22:53.470 everything runs very smoothly and
NOTE Confidence: 0.823943624615385

00:22:53.470 --> 00:22:55.969 many times our job or the job.
NOTE Confidence: 0.823943624615385

00:22:55.970 --> 00:22:58.034 This psychologist is like to convince
NOTE Confidence: 0.823943624615385

00:22:58.034 --> 00:23:00.058 the parents that they can do it,
NOTE Confidence: 0.823943624615385

00:23:00.060 --> 00:23:03.096 that they're able to do this.
NOTE Confidence: 0.823943624615385

00:23:03.100 --> 00:23:04.920 So we have different sessions per day.
NOTE Confidence: 0.823943624615385

00:23:04.920 --> 00:23:06.864 What we do for them to start using path,
NOTE Confidence: 0.823943624615385

00:23:06.870 --> 00:23:07.482 for example,
NOTE Confidence: 0.823943624615385

00:23:07.482 --> 00:23:09.318 to begin with an activity that

NOTE Confidence: 0.823943624615385
00:23:09.318 --> 00:23:10.789 is calming and enjoyable.
NOTE Confidence: 0.823943624615385
00:23:10.790 --> 00:23:12.338 Anything that they like to do,
NOTE Confidence: 0.823943624615385
00:23:12.340 --> 00:23:14.756 like the tablets, help a lot with that.
NOTE Confidence: 0.823943624615385
00:23:14.760 --> 00:23:17.020 For example,
NOTE Confidence: 0.823943624615385
00:23:17.020 --> 00:23:19.295 praise the kid a lot with clapping
NOTE Confidence: 0.823943624615385
00:23:19.295 --> 00:23:20.536 or positive reinforcements and
NOTE Confidence: 0.823943624615385
00:23:20.536 --> 00:23:21.556 with and as I said,
NOTE Confidence: 0.823943624615385
00:23:21.560 --> 00:23:23.422 and also remind them that the adult
NOTE Confidence: 0.823943624615385
00:23:23.422 --> 00:23:25.775 would be the one taking the mask off of.
NOTE Confidence: 0.823943624615385
00:23:25.780 --> 00:23:27.979 Let's put the mask on, it doesn't matter.
NOTE Confidence: 0.823943624615385
00:23:27.979 --> 00:23:28.858 It's 5 seconds.
NOTE Confidence: 0.823943624615385
00:23:28.860 --> 00:23:30.740 We're going to build up on that time,
NOTE Confidence: 0.823943624615385
00:23:30.740 --> 00:23:32.468 little by little until they get.
NOTE Confidence: 0.823943624615385
00:23:32.470 --> 00:23:33.208 Used to it.
NOTE Confidence: 0.823943624615385
00:23:33.208 --> 00:23:35.283 Basically all kids and all of us who
NOTE Confidence: 0.823943624615385

00:23:35.283 --> 00:23:37.320 were children we were looking at for
NOTE Confidence: 0.823943624615385

00:23:37.320 --> 00:23:39.698 our parents and looking for their approval.
NOTE Confidence: 0.823943624615385

00:23:39.700 --> 00:23:41.268 So that's where we have to work
NOTE Confidence: 0.823943624615385

00:23:41.268 --> 00:23:42.839 with the bond of the caregiver.
NOTE Confidence: 0.857112731111111

00:23:45.550 --> 00:23:47.335 So we also said that they need
NOTE Confidence: 0.857112731111111

00:23:47.335 --> 00:23:49.489 to try to ignore the negative
NOTE Confidence: 0.857112731111111

00:23:49.489 --> 00:23:51.684 behavior similar as potty training.
NOTE Confidence: 0.857112731111111

00:23:51.690 --> 00:23:54.250 For example, try to stay calm and positive
NOTE Confidence: 0.857112731111111

00:23:54.250 --> 00:23:56.432 gently got the the the hands out if
NOTE Confidence: 0.857112731111111

00:23:56.432 --> 00:23:59.054 the kid wants to remove the mask during
NOTE Confidence: 0.857112731111111

00:23:59.054 --> 00:24:01.014 the desensitization process and repeat
NOTE Confidence: 0.857112731111111

00:24:01.014 --> 00:24:04.007 the same task until the child is cooperative.
NOTE Confidence: 0.857112731111111

00:24:04.010 --> 00:24:06.458 Typically we do not recommend that they put
NOTE Confidence: 0.857112731111111

00:24:06.458 --> 00:24:09.186 the mask on once the child is in deep sleep.
NOTE Confidence: 0.857112731111111

00:24:09.190 --> 00:24:11.108 It would work for the treatment but
NOTE Confidence: 0.857112731111111

00:24:11.108 --> 00:24:13.670 for one hour or two, but then we all

NOTE Confidence: 0.8571127311111111
00:24:13.670 --> 00:24:15.270 have awakenings during the night.
NOTE Confidence: 0.8571127311111111
00:24:15.270 --> 00:24:16.595 And if you have something
NOTE Confidence: 0.8571127311111111
00:24:16.595 --> 00:24:17.655 that you didn't have,
NOTE Confidence: 0.8571127311111111
00:24:17.660 --> 00:24:19.404 when you fall asleep you don't have that
NOTE Confidence: 0.8571127311111111
00:24:19.404 --> 00:24:20.927 association and you will remove everything,
NOTE Confidence: 0.8571127311111111
00:24:20.930 --> 00:24:21.980 which is worse.
NOTE Confidence: 0.8571127311111111
00:24:21.980 --> 00:24:24.080 So it's better to create the
NOTE Confidence: 0.8571127311111111
00:24:24.080 --> 00:24:25.994 association during sleep time with
NOTE Confidence: 0.8571127311111111
00:24:25.994 --> 00:24:27.869 the interface and the headgear,
NOTE Confidence: 0.8571127311111111
00:24:27.870 --> 00:24:31.128 and then things will roll good.
NOTE Confidence: 0.8571127311111111
00:24:31.130 --> 00:24:33.418 And these are some of the quotes that
NOTE Confidence: 0.8571127311111111
00:24:33.418 --> 00:24:35.890 I have there of the families that
NOTE Confidence: 0.8571127311111111
00:24:35.890 --> 00:24:38.550 participate in the R61 phase of our study.
NOTE Confidence: 0.8571127311111111
00:24:38.550 --> 00:24:41.062 We divided them in those who are higher
NOTE Confidence: 0.8571127311111111
00:24:41.062 --> 00:24:43.568 rent or low adherence and you know,
NOTE Confidence: 0.8571127311111111

00:24:43.570 --> 00:24:46.146 they they provide great input for us.
NOTE Confidence: 0.8571127311111111

00:24:46.150 --> 00:24:47.083 Like for example,
NOTE Confidence: 0.8571127311111111

00:24:47.083 --> 00:24:48.949 let the child dictate the timeline
NOTE Confidence: 0.8571127311111111

00:24:48.949 --> 00:24:50.741 gives some ownership filled with
NOTE Confidence: 0.8571127311111111

00:24:50.741 --> 00:24:52.526 the personalizing of the machine.
NOTE Confidence: 0.8571127311111111

00:24:52.530 --> 00:24:53.909 In their case, they bought a ribbon.
NOTE Confidence: 0.8571127311111111

00:24:53.910 --> 00:24:55.569 We all the time say with the
NOTE Confidence: 0.8571127311111111

00:24:55.569 --> 00:24:56.854 families to the kids, OK,
NOTE Confidence: 0.8571127311111111

00:24:56.854 --> 00:24:57.830 this is your machine,
NOTE Confidence: 0.8571127311111111

00:24:57.830 --> 00:24:59.612 this is you or you're going to give it
NOTE Confidence: 0.8571127311111111

00:24:59.612 --> 00:25:01.739 a name and people come up with the most.
NOTE Confidence: 0.8571127311111111

00:25:01.740 --> 00:25:02.262 Surprising name.
NOTE Confidence: 0.8571127311111111

00:25:02.262 --> 00:25:04.089 You know I learned so much and
NOTE Confidence: 0.8571127311111111

00:25:04.089 --> 00:25:05.796 that's what I like working with kids
NOTE Confidence: 0.8571127311111111

00:25:05.800 --> 00:25:07.613 and also families say they need to
NOTE Confidence: 0.8571127311111111

00:25:07.613 --> 00:25:09.477 figure it out how to make it fun.

NOTE Confidence: 0.8571127311111111
00:25:09.480 --> 00:25:11.100 Families have said that their
NOTE Confidence: 0.8571127311111111
00:25:11.100 --> 00:25:13.069 children are more visual and they
NOTE Confidence: 0.8571127311111111
00:25:13.069 --> 00:25:14.809 that's why we developed the videos
NOTE Confidence: 0.8571127311111111
00:25:14.809 --> 00:25:16.858 so they have something with that.
NOTE Confidence: 0.8571127311111111
00:25:16.860 --> 00:25:18.505 We also develop social stories
NOTE Confidence: 0.8571127311111111
00:25:18.505 --> 00:25:20.480 with the name of the kid.
NOTE Confidence: 0.8571127311111111
00:25:20.480 --> 00:25:20.712 OK,
NOTE Confidence: 0.8571127311111111
00:25:20.712 --> 00:25:21.408 this is Johnny.
NOTE Confidence: 0.8571127311111111
00:25:21.408 --> 00:25:23.684 I'm going to work his CPAP and this is
NOTE Confidence: 0.8571127311111111
00:25:23.684 --> 00:25:25.334 for Johnny doing his bedtime routine.
NOTE Confidence: 0.8571127311111111
00:25:25.340 --> 00:25:27.868 He's sort of like that that we materials
NOTE Confidence: 0.8571127311111111
00:25:27.868 --> 00:25:30.089 that we provide for the family.
NOTE Confidence: 0.8571127311111111
00:25:30.090 --> 00:25:30.604 You know,
NOTE Confidence: 0.8571127311111111
00:25:30.604 --> 00:25:32.146 some parents have reported that the
NOTE Confidence: 0.8571127311111111
00:25:32.146 --> 00:25:34.085 idea that would be good to write a
NOTE Confidence: 0.8571127311111111

00:25:34.085 --> 00:25:35.556 book about children with sleep apnea
NOTE Confidence: 0.8571127311111111

00:25:35.556 --> 00:25:37.320 always say so other families can help
NOTE Confidence: 0.8571127311111111

00:25:37.320 --> 00:25:39.290 with that and also the importance of
NOTE Confidence: 0.8571127311111111

00:25:39.290 --> 00:25:40.995 role modeling of having someone who
NOTE Confidence: 0.8571127311111111

00:25:40.995 --> 00:25:43.027 looks like them to come up with that.
NOTE Confidence: 0.8571127311111111

00:25:43.030 --> 00:25:44.738 So it's something that I ask of
NOTE Confidence: 0.8571127311111111

00:25:44.738 --> 00:25:46.628 my patients who are of age or
NOTE Confidence: 0.8571127311111111

00:25:46.628 --> 00:25:47.728 participating in social media
NOTE Confidence: 0.8571127311111111

00:25:47.728 --> 00:25:49.429 with Down syndrome who are bad.
NOTE Confidence: 0.8571127311111111

00:25:49.430 --> 00:25:50.048 And, you know,
NOTE Confidence: 0.8571127311111111

00:25:50.048 --> 00:25:51.078 you will be surprised because
NOTE Confidence: 0.8571127311111111

00:25:51.078 --> 00:25:52.852 many do and say OK, do you TikTok,
NOTE Confidence: 0.8571127311111111

00:25:52.852 --> 00:25:54.894 do you have Instagram? Ohh yeah, I do.
NOTE Confidence: 0.8571127311111111

00:25:54.894 --> 00:25:55.110 OK.
NOTE Confidence: 0.8571127311111111

00:25:55.110 --> 00:25:56.356 So why don't you do one when
NOTE Confidence: 0.8571127311111111

00:25:56.356 --> 00:25:57.120 you're wearing your mask,

NOTE Confidence: 0.8571127311111111
00:25:57.120 --> 00:25:59.206 you will be helping so many children,
NOTE Confidence: 0.8571127311111111
00:25:59.210 --> 00:26:00.706 you know, social media.
NOTE Confidence: 0.8571127311111111
00:26:00.706 --> 00:26:02.576 There's so many tentacles that
NOTE Confidence: 0.8571127311111111
00:26:02.576 --> 00:26:03.938 we don't know of.
NOTE Confidence: 0.8571127311111111
00:26:03.940 --> 00:26:06.236 It would be way more empowering for kids
NOTE Confidence: 0.8571127311111111
00:26:06.236 --> 00:26:08.360 with Down syndrome than seeing them.
NOTE Confidence: 0.8571127311111111
00:26:08.360 --> 00:26:09.945 They're seeing a kid without
NOTE Confidence: 0.8571127311111111
00:26:09.945 --> 00:26:11.213 developmental disability of the
NOTE Confidence: 0.8571127311111111
00:26:11.213 --> 00:26:12.757 doctor playing with the machine.
NOTE Confidence: 0.89459415
00:26:12.760 --> 00:26:14.580 If I do it, nobody will. I won't.
NOTE Confidence: 0.89459415
00:26:14.580 --> 00:26:16.416 I won't get any hits, you know,
NOTE Confidence: 0.89459415
00:26:16.416 --> 00:26:18.160 Tick Tock will most likely will fire me,
NOTE Confidence: 0.89459415
00:26:18.160 --> 00:26:20.575 but with the kids will be better.
NOTE Confidence: 0.89459415
00:26:20.580 --> 00:26:22.736 It's also to do the positive reinforcement,
NOTE Confidence: 0.89459415
00:26:22.740 --> 00:26:24.574 as it will, as we said there,
NOTE Confidence: 0.89459415

00:26:24.580 --> 00:26:25.680 to make it fun,
NOTE Confidence: 0.89459415

00:26:25.680 --> 00:26:28.780 to get them to make it play with the mask,
NOTE Confidence: 0.89459415

00:26:28.780 --> 00:26:30.920 to make it, make it them, be familiar,
NOTE Confidence: 0.89459415

00:26:30.920 --> 00:26:32.950 that is part of them and also
NOTE Confidence: 0.89459415

00:26:32.950 --> 00:26:34.477 something that is so important.
NOTE Confidence: 0.89459415

00:26:34.480 --> 00:26:37.120 Every family, but even more so with those
NOTE Confidence: 0.89459415

00:26:37.120 --> 00:26:38.884 with developmental disabilities is the
NOTE Confidence: 0.89459415

00:26:38.884 --> 00:26:40.972 importance of social support in both.
NOTE Confidence: 0.89459415

00:26:40.980 --> 00:26:42.492 In kids who were adherent or and
NOTE Confidence: 0.89459415

00:26:42.492 --> 00:26:43.840 those who were not adherents,
NOTE Confidence: 0.89459415

00:26:43.840 --> 00:26:45.288 families reported that the
NOTE Confidence: 0.89459415

00:26:45.288 --> 00:26:47.460 family has to work as as,
NOTE Confidence: 0.89459415

00:26:47.460 --> 00:26:48.666 as a group that many times
NOTE Confidence: 0.89459415

00:26:48.666 --> 00:26:50.060 is too much on the parent,
NOTE Confidence: 0.89459415

00:26:50.060 --> 00:26:51.680 that parents is typically the
NOTE Confidence: 0.89459415

00:26:51.680 --> 00:26:54.020 man and they have to to work

NOTE Confidence: 0.89459415

00:26:54.020 --> 00:26:56.136 with some other person you know.

NOTE Confidence: 0.89459415

00:26:56.136 --> 00:26:58.992 So they can take a night off.

NOTE Confidence: 0.89459415

00:26:59.000 --> 00:27:01.696 Both parents have to be in the same

NOTE Confidence: 0.89459415

00:27:01.696 --> 00:27:05.000 in in the same page on the same page.

NOTE Confidence: 0.89459415

00:27:05.000 --> 00:27:06.100 And this is data,

NOTE Confidence: 0.89459415

00:27:06.100 --> 00:27:08.100 a retrospective data from our lab over

NOTE Confidence: 0.89459415

00:27:08.100 --> 00:27:09.876 cohort of children with Down syndrome

NOTE Confidence: 0.89459415

00:27:09.876 --> 00:27:11.900 that we have followed for two years

NOTE Confidence: 0.89459415

00:27:11.900 --> 00:27:13.922 and we are analyzing how is their

NOTE Confidence: 0.89459415

00:27:13.922 --> 00:27:16.334 path trajectory of adherence over time.

NOTE Confidence: 0.89459415

00:27:16.340 --> 00:27:18.734 And you can see there in we have the

NOTE Confidence: 0.89459415

00:27:18.734 --> 00:27:20.945 different groups in blue from zero to

NOTE Confidence: 0.89459415

00:27:20.945 --> 00:27:23.109 six months from initiation to six months

NOTE Confidence: 0.89459415

00:27:23.109 --> 00:27:25.782 after that then you read six months to 12,

NOTE Confidence: 0.89459415

00:27:25.782 --> 00:27:27.828 green 12 to 18 month and

NOTE Confidence: 0.89459415

00:27:27.828 --> 00:27:29.680 orange 18 to 24 months,
NOTE Confidence: 0.89459415

00:27:29.680 --> 00:27:32.109 how the percentage of nights use differ
NOTE Confidence: 0.89459415

00:27:32.109 --> 00:27:34.930 and then we can see that actually we.
NOTE Confidence: 0.89459415

00:27:34.930 --> 00:27:37.191 Of a very good experience that in
NOTE Confidence: 0.89459415

00:27:37.191 --> 00:27:39.188 between zero to six months the
NOTE Confidence: 0.89459415

00:27:39.188 --> 00:27:41.148 median is about 40% that increases
NOTE Confidence: 0.89459415

00:27:41.148 --> 00:27:43.521 to two years then tend to decrease
NOTE Confidence: 0.89459415

00:27:43.521 --> 00:27:46.443 a little bit in in 12 to 18 and then
NOTE Confidence: 0.89459415

00:27:46.443 --> 00:27:48.790 finally sort of becomes the median
NOTE Confidence: 0.89459415

00:27:48.790 --> 00:27:50.736 around 60 something percent which
NOTE Confidence: 0.89459415

00:27:50.736 --> 00:27:52.812 is pretty good actually I could
NOTE Confidence: 0.89459415

00:27:52.812 --> 00:27:55.210 say it's very comparable of kids,
NOTE Confidence: 0.89459415

00:27:55.210 --> 00:27:57.210 two kids with developmental disabilities.
NOTE Confidence: 0.89459415

00:27:57.210 --> 00:27:57.536 However,
NOTE Confidence: 0.89459415

00:27:57.536 --> 00:28:00.144 we also have to look at there are
NOTE Confidence: 0.89459415

00:28:00.144 --> 00:28:02.131 certain outliers you have have here

NOTE Confidence: 0.89459415

00:28:02.131 --> 00:28:04.969 that you can see here that the whiskers.

NOTE Confidence: 0.89459415

00:28:04.970 --> 00:28:07.160 There are people who still have

NOTE Confidence: 0.89459415

00:28:07.160 --> 00:28:09.269 0 adherence 2 years into it.

NOTE Confidence: 0.89459415

00:28:09.270 --> 00:28:11.746 So those kids in my opinion, after year.

NOTE Confidence: 0.89459415

00:28:11.746 --> 00:28:14.290 So they may need to consider something else,

NOTE Confidence: 0.89459415

00:28:14.290 --> 00:28:16.870 inspire or any other therapy.

NOTE Confidence: 0.89459415

00:28:16.870 --> 00:28:19.299 And also there are people who are

NOTE Confidence: 0.89459415

00:28:19.299 --> 00:28:21.050 overachievers and they're almost 100%

NOTE Confidence: 0.89459415

00:28:21.050 --> 00:28:22.733 at the very beginning and they keep that way.

NOTE Confidence: 0.674415647

00:28:25.020 --> 00:28:26.450 This is presents the minute

NOTE Confidence: 0.674415647

00:28:26.450 --> 00:28:27.880 use on the Knights use.

NOTE Confidence: 0.674415647

00:28:27.880 --> 00:28:29.404 It's the same color and you

NOTE Confidence: 0.674415647

00:28:29.404 --> 00:28:31.209 can see that also is something

NOTE Confidence: 0.674415647

00:28:31.209 --> 00:28:33.019 that improves overnight that we

NOTE Confidence: 0.674415647

00:28:33.019 --> 00:28:34.884 started with around 150 minutes

NOTE Confidence: 0.674415647

00:28:34.884 --> 00:28:37.108 and then we stabilize around 240
NOTE Confidence: 0.674415647

00:28:37.108 --> 00:28:38.836 or so minutes in the median.
NOTE Confidence: 0.674415647

00:28:38.840 --> 00:28:40.505 The interquartile range is is
NOTE Confidence: 0.674415647

00:28:40.505 --> 00:28:42.739 very variable but it goes up to
NOTE Confidence: 0.674415647

00:28:42.739 --> 00:28:44.517 400 minutes or so and also there
NOTE Confidence: 0.674415647

00:28:44.517 --> 00:28:46.467 was no difference between them.
NOTE Confidence: 0.674415647

00:28:46.470 --> 00:28:48.478 The the time intervals.
NOTE Confidence: 0.83484555875

00:28:50.780 --> 00:28:51.833 So in conclusion,
NOTE Confidence: 0.83484555875

00:28:51.833 --> 00:28:53.939 we have that sleeping individuals with
NOTE Confidence: 0.83484555875

00:28:53.939 --> 00:28:56.369 Down syndrome has not been well studied.
NOTE Confidence: 0.83484555875

00:28:56.370 --> 00:28:58.918 OSA is very prevalent and more trials
NOTE Confidence: 0.83484555875

00:28:58.918 --> 00:29:01.090 for treatment of OSA are needed.
NOTE Confidence: 0.83484555875

00:29:01.090 --> 00:29:03.098 Also of our data from home sleep apnea
NOTE Confidence: 0.83484555875

00:29:03.098 --> 00:29:04.912 testing is that I do really think that
NOTE Confidence: 0.83484555875

00:29:04.912 --> 00:29:06.880 it has a role well in all children.
NOTE Confidence: 0.83484555875

00:29:06.880 --> 00:29:08.889 That's another study that we're doing now.

NOTE Confidence: 0.83484555875

00:29:08.890 --> 00:29:10.894 But in children with Down syndrome

NOTE Confidence: 0.83484555875

00:29:10.894 --> 00:29:12.721 specifically because families are so happy

NOTE Confidence: 0.83484555875

00:29:12.721 --> 00:29:14.489 that this study can be done at home.

NOTE Confidence: 0.83484555875

00:29:14.490 --> 00:29:17.028 Some of the things that we notice is that

NOTE Confidence: 0.83484555875

00:29:17.028 --> 00:29:19.629 the the setup of the device that we use,

NOTE Confidence: 0.83484555875

00:29:19.630 --> 00:29:21.415 the Type 2 device that we use.

NOTE Confidence: 0.83484555875

00:29:21.420 --> 00:29:23.418 Is that the the whole process

NOTE Confidence: 0.83484555875

00:29:23.418 --> 00:29:25.420 imagery was being removed overnight.

NOTE Confidence: 0.83484555875

00:29:25.420 --> 00:29:27.100 The thumb shape of children with

NOTE Confidence: 0.83484555875

00:29:27.100 --> 00:29:28.864 Down syndrome is a little bit

NOTE Confidence: 0.83484555875

00:29:28.864 --> 00:29:30.901 different that the that the sort of

NOTE Confidence: 0.83484555875

00:29:30.901 --> 00:29:32.739 gloves setup that the device have.

NOTE Confidence: 0.83484555875

00:29:32.740 --> 00:29:34.414 So sometimes we have to recommend

NOTE Confidence: 0.83484555875

00:29:34.414 --> 00:29:35.995 to families that they can tape

NOTE Confidence: 0.83484555875

00:29:35.995 --> 00:29:37.619 it and also they can use like a

NOTE Confidence: 0.83484555875

00:29:37.674 --> 00:29:39.198 Band-Aid on the net before so.
NOTE Confidence: 0.83484555875

00:29:39.200 --> 00:29:42.568 So to get used the kid that they
NOTE Confidence: 0.83484555875

00:29:42.568 --> 00:29:44.939 have something in their finger.
NOTE Confidence: 0.83484555875

00:29:44.940 --> 00:29:46.760 In terms of future research,
NOTE Confidence: 0.83484555875

00:29:46.760 --> 00:29:48.860 what is the best home screening
NOTE Confidence: 0.83484555875

00:29:48.860 --> 00:29:50.846 tool instead of device? Is it?
NOTE Confidence: 0.83484555875

00:29:50.846 --> 00:29:52.897 What is something that we can do?
NOTE Confidence: 0.83484555875

00:29:52.900 --> 00:29:55.015 So someone, a family, comes to me and say,
NOTE Confidence: 0.83484555875

00:29:55.020 --> 00:29:56.340 you know, I want to scream.
NOTE Confidence: 0.83484555875

00:29:56.340 --> 00:29:58.800 If my child needs to come to the sleep lab,
NOTE Confidence: 0.83484555875

00:29:58.800 --> 00:30:00.096 maybe they don't need to come.
NOTE Confidence: 0.83484555875

00:30:00.100 --> 00:30:02.359 And it's something that we can do every year.
NOTE Confidence: 0.83484555875

00:30:02.360 --> 00:30:03.760 Like I was mentioning,
NOTE Confidence: 0.83484555875

00:30:03.760 --> 00:30:05.160 like a cholesterol level
NOTE Confidence: 0.83484555875

00:30:05.160 --> 00:30:06.900 HBA 1C that we don't have.
NOTE Confidence: 0.83484555875

00:30:06.900 --> 00:30:08.800 Is something coming from omics,

NOTE Confidence: 0.83484555875
00:30:08.800 --> 00:30:10.660 is something coming from a device.
NOTE Confidence: 0.83484555875
00:30:10.660 --> 00:30:12.220 It's the combination of both.
NOTE Confidence: 0.83484555875
00:30:12.220 --> 00:30:13.624 Is it a questionnaire?
NOTE Confidence: 0.83484555875
00:30:13.624 --> 00:30:15.379 We don't know for sure.
NOTE Confidence: 0.83484555875
00:30:15.380 --> 00:30:16.865 Also we need randomized control
NOTE Confidence: 0.83484555875
00:30:16.865 --> 00:30:18.350 trial of eight side individuals
NOTE Confidence: 0.83484555875
00:30:18.401 --> 00:30:20.099 with Down syndrome we're doing that.
NOTE Confidence: 0.83484555875
00:30:20.100 --> 00:30:21.492 Our trial is comprehensive,
NOTE Confidence: 0.83484555875
00:30:21.492 --> 00:30:23.232 the one that we're starting.
NOTE Confidence: 0.83484555875
00:30:23.240 --> 00:30:25.080 Also we need data-driven screening
NOTE Confidence: 0.83484555875
00:30:25.080 --> 00:30:27.260 algorithm that is something so important
NOTE Confidence: 0.83484555875
00:30:27.260 --> 00:30:29.524 and we need all to work together and
NOTE Confidence: 0.83484555875
00:30:29.524 --> 00:30:31.250 use data this harmonized for example
NOTE Confidence: 0.83484555875
00:30:31.250 --> 00:30:34.024 and I uh came up with nahh toolbox so
NOTE Confidence: 0.83484555875
00:30:34.024 --> 00:30:35.754 people can measure their behavioral
NOTE Confidence: 0.83484555875

00:30:35.754 --> 00:30:37.748 in kids without them syndrome.

NOTE Confidence: 0.83484555875

00:30:37.750 --> 00:30:39.150 We have used it also in kids

NOTE Confidence: 0.83484555875

00:30:39.150 --> 00:30:39.750 with Down syndrome,

NOTE Confidence: 0.83484555875

00:30:39.750 --> 00:30:40.865 but it's mostly for kids

NOTE Confidence: 0.83484555875

00:30:40.865 --> 00:30:41.534 without Down syndrome.

NOTE Confidence: 0.83484555875

00:30:41.540 --> 00:30:42.620 So if you have a,

NOTE Confidence: 0.83484555875

00:30:42.620 --> 00:30:42.840 a,

NOTE Confidence: 0.83484555875

00:30:42.840 --> 00:30:44.160 a research and you're using that

NOTE Confidence: 0.83484555875

00:30:44.160 --> 00:30:45.479 tool and using the same tool.

NOTE Confidence: 0.83484555875

00:30:45.480 --> 00:30:47.124 Eventually you know there's a big

NOTE Confidence: 0.83484555875

00:30:47.124 --> 00:30:48.750 thing about data sharing right now.

NOTE Confidence: 0.83484555875

00:30:48.750 --> 00:30:50.802 We can harmonize the data and

NOTE Confidence: 0.83484555875

00:30:50.802 --> 00:30:52.750 and and analyze it better.

NOTE Confidence: 0.83484555875

00:30:52.750 --> 00:30:54.638 And something that to me is very puzzling

NOTE Confidence: 0.83484555875

00:30:54.638 --> 00:30:56.702 and I want to continue working in the

NOTE Confidence: 0.83484555875

00:30:56.702 --> 00:30:58.488 future with that is the relationship

NOTE Confidence: 0.83484555875

00:30:58.488 --> 00:31:00.248 between untreated OSA and aging,

NOTE Confidence: 0.83484555875

00:31:00.250 --> 00:31:02.150 premature aging or Alzheimer's

NOTE Confidence: 0.83484555875

00:31:02.150 --> 00:31:04.525 in individual with Down syndrome.

NOTE Confidence: 0.83484555875

00:31:04.530 --> 00:31:07.338 This is my linked into our code if you

NOTE Confidence: 0.83484555875

00:31:07.338 --> 00:31:10.081 want to be my friend in LinkedIn since

NOTE Confidence: 0.83484555875

00:31:10.081 --> 00:31:13.209 you know I'm not a tick tock star.

NOTE Confidence: 0.83484555875

00:31:13.210 --> 00:31:14.236 And thank you.

NOTE Confidence: 0.83484555875

00:31:14.236 --> 00:31:16.288 And these are all my collaborators

NOTE Confidence: 0.83484555875

00:31:16.288 --> 00:31:18.650 and I'm happy to answer any questions.

NOTE Confidence: 0.685539748888889

00:31:21.540 --> 00:31:24.095 Thank you Doctor Tapia for

NOTE Confidence: 0.685539748888889

00:31:24.095 --> 00:31:26.139 that very interesting talk.

NOTE Confidence: 0.685539748888889

00:31:26.140 --> 00:31:28.180 If anybody has any questions,

NOTE Confidence: 0.685539748888889

00:31:28.180 --> 00:31:30.469 please feel free to ask Doctor Krieger.

NOTE Confidence: 0.915905565

00:31:32.380 --> 00:31:36.708 So over the years I've seen children and

NOTE Confidence: 0.915905565

00:31:36.708 --> 00:31:40.026 adults with Down syndrome who also have

NOTE Confidence: 0.915905565

00:31:40.026 --> 00:31:44.080 right to left cardiovascular shunts.
NOTE Confidence: 0.915905565

00:31:44.080 --> 00:31:46.117 What has been your experience with them?
NOTE Confidence: 0.915905565

00:31:46.120 --> 00:31:50.050 Because they're hypoxic from their shunt.
NOTE Confidence: 0.915905565

00:31:50.050 --> 00:31:52.080 I wonder if you can just tell us about that.
NOTE Confidence: 0.923260244

00:31:52.130 --> 00:31:54.841 Yeah, we do have some, but I would
NOTE Confidence: 0.923260244

00:31:54.841 --> 00:31:57.130 say that mostly now the youngest kids
NOTE Confidence: 0.923260244

00:31:57.199 --> 00:31:59.670 have been all repaired very early on.
NOTE Confidence: 0.923260244

00:31:59.670 --> 00:32:01.983 So it's not something that we see that often.
NOTE Confidence: 0.923260244

00:32:01.990 --> 00:32:04.430 The older kids is something that we would
NOTE Confidence: 0.923260244

00:32:04.430 --> 00:32:06.986 see and in that case many times we have
NOTE Confidence: 0.923260244

00:32:06.986 --> 00:32:09.466 to use some oxygen with PAP or something
NOTE Confidence: 0.923260244

00:32:09.466 --> 00:32:13.115 to to to have some some values that
NOTE Confidence: 0.923260244

00:32:13.115 --> 00:32:15.730 they would that would be like suitable.
NOTE Confidence: 0.923260244

00:32:15.730 --> 00:32:17.249 But what is more important is to
NOTE Confidence: 0.923260244

00:32:17.249 --> 00:32:19.007 know what is the baseline saturation
NOTE Confidence: 0.923260244

00:32:19.007 --> 00:32:20.411 from the cardiology. Visits.

NOTE Confidence: 0.923260244

00:32:20.411 --> 00:32:23.139 So we based on that for example a

NOTE Confidence: 0.923260244

00:32:23.139 --> 00:32:25.328 kid with right Shawn comes to the

NOTE Confidence: 0.923260244

00:32:25.328 --> 00:32:27.179 lab and we tell the technicians we

NOTE Confidence: 0.923260244

00:32:27.179 --> 00:32:29.153 put there in the note for example

NOTE Confidence: 0.923260244

00:32:29.153 --> 00:32:30.079 baseline saturation is 85.

NOTE Confidence: 0.923260244

00:32:30.080 --> 00:32:32.056 So we know that they don't mark every

NOTE Confidence: 0.923260244

00:32:32.056 --> 00:32:33.837 event because also we have like some

NOTE Confidence: 0.923260244

00:32:33.837 --> 00:32:35.270 guidelines that need to call us.

NOTE Confidence: 0.923260244

00:32:35.270 --> 00:32:35.897 They would be,

NOTE Confidence: 0.923260244

00:32:35.897 --> 00:32:37.360 they would be calling me every night.

NOTE Confidence: 0.923260244

00:32:37.360 --> 00:32:39.358 You're not saying they'll be saturating

NOTE Confidence: 0.923260244

00:32:39.358 --> 00:32:42.183 so you know they they have to go with the

NOTE Confidence: 0.923260244

00:32:42.183 --> 00:32:44.370 three or 4% but according to their baseline.

NOTE Confidence: 0.923260244

00:32:45.320 --> 00:32:47.140 Thank you.

NOTE Confidence: 0.923260244

00:32:47.140 --> 00:32:48.380 Great talk.

NOTE Confidence: 0.923260244

00:32:48.380 --> 00:32:48.870 Thank you.
NOTE Confidence: 0.895825646

00:32:52.430 --> 00:32:54.130 Hi, I have a question.
NOTE Confidence: 0.895825646

00:32:54.130 --> 00:32:57.110 Hi Doctor Tapia, great talk.
NOTE Confidence: 0.895825646

00:32:57.110 --> 00:32:58.822 I have a lot of kids with Down
NOTE Confidence: 0.895825646

00:32:58.822 --> 00:33:00.386 syndrome in my practice with sleep
NOTE Confidence: 0.895825646

00:33:00.386 --> 00:33:02.006 apnea that we manage with CPAP
NOTE Confidence: 0.895825646

00:33:02.065 --> 00:33:03.885 and in my experience it seems like
NOTE Confidence: 0.895825646

00:33:03.885 --> 00:33:05.180 there's almost 2 populations.
NOTE Confidence: 0.895825646

00:33:05.180 --> 00:33:07.220 There's a population that
NOTE Confidence: 0.895825646

00:33:07.220 --> 00:33:08.750 is wonderfully adherent,
NOTE Confidence: 0.895825646

00:33:08.750 --> 00:33:11.718 like the most adherent patients you can get,
NOTE Confidence: 0.895825646

00:33:11.720 --> 00:33:13.603 and then there's kids that really have
NOTE Confidence: 0.895825646

00:33:13.603 --> 00:33:15.909 a lot of difficulty tolerating it.
NOTE Confidence: 0.895825646

00:33:15.910 --> 00:33:18.205 Whatsoever, do you think it's
NOTE Confidence: 0.895825646

00:33:18.205 --> 00:33:20.500 more patient factors or parent
NOTE Confidence: 0.895825646

00:33:20.580 --> 00:33:23.058 factors that are kind of driving

NOTE Confidence: 0.895825646

00:33:23.058 --> 00:33:25.480 success or failure in patients?

NOTE Confidence: 0.747045306

00:33:25.890 --> 00:33:28.166 I think it's a mixed, you know in

NOTE Confidence: 0.747045306

00:33:28.166 --> 00:33:29.950 the research I show part of the data,

NOTE Confidence: 0.747045306

00:33:29.950 --> 00:33:31.158 but unfortunately something that

NOTE Confidence: 0.747045306

00:33:31.158 --> 00:33:33.316 we see all the time in anything

NOTE Confidence: 0.747045306

00:33:33.316 --> 00:33:35.032 that is sleep related and wearing

NOTE Confidence: 0.747045306

00:33:35.032 --> 00:33:36.989 my hat of health disparities,

NOTE Confidence: 0.747045306

00:33:36.990 --> 00:33:38.840 there's a huge disparities within

NOTE Confidence: 0.747045306

00:33:38.840 --> 00:33:41.122 the education of the family and

NOTE Confidence: 0.747045306

00:33:41.122 --> 00:33:42.578 that unfortunately somewhat linked

NOTE Confidence: 0.747045306

00:33:42.578 --> 00:33:44.890 to race in the United States.

NOTE Confidence: 0.747045306

00:33:44.890 --> 00:33:46.642 We do see that.

NOTE Confidence: 0.747045306

00:33:46.642 --> 00:33:49.270 Any parents who are more educated

NOTE Confidence: 0.747045306

00:33:49.360 --> 00:33:50.878 or more affluent?

NOTE Confidence: 0.747045306

00:33:50.880 --> 00:33:52.228 It goes better everything.

NOTE Confidence: 0.747045306

00:33:52.228 --> 00:33:53.913 I think it's a combination
NOTE Confidence: 0.747045306

00:33:53.913 --> 00:33:55.580 because they have more support.
NOTE Confidence: 0.747045306

00:33:55.580 --> 00:33:57.099 They're able to have a job that
NOTE Confidence: 0.747045306

00:33:57.099 --> 00:33:58.966 maybe 5:00 or 6:00 PM there at home
NOTE Confidence: 0.747045306

00:33:58.966 --> 00:34:00.420 and they can dedicate this time.
NOTE Confidence: 0.747045306

00:34:00.420 --> 00:34:02.180 If I were working two jobs and from
NOTE Confidence: 0.747045306

00:34:02.180 --> 00:34:04.000 here I had to go to another place
NOTE Confidence: 0.747045306

00:34:04.000 --> 00:34:05.779 and do this and that I get home,
NOTE Confidence: 0.747045306

00:34:05.780 --> 00:34:07.817 do I really want to deal with
NOTE Confidence: 0.747045306

00:34:07.820 --> 00:34:09.698 all the stuff most likely now?
NOTE Confidence: 0.747045306

00:34:09.700 --> 00:34:12.340 So I think it's it's it's a combination.
NOTE Confidence: 0.747045306

00:34:12.340 --> 00:34:14.204 You know I see a lot of Hispanic
NOTE Confidence: 0.747045306

00:34:14.204 --> 00:34:15.862 families that they do not speak English
NOTE Confidence: 0.747045306

00:34:15.862 --> 00:34:17.599 they came to see me specifically for
NOTE Confidence: 0.747045306

00:34:17.599 --> 00:34:19.783 and I do remember saying that mom and
NOTE Confidence: 0.747045306

00:34:19.790 --> 00:34:21.606 the mom told me it will never happen.

NOTE Confidence: 0.747045306

00:34:21.610 --> 00:34:23.164 I don't know how to do it.

NOTE Confidence: 0.747045306

00:34:23.170 --> 00:34:25.630 The the kid is difficult, have the

NOTE Confidence: 0.747045306

00:34:25.630 --> 00:34:27.230 developmental disabilities and whatever.

NOTE Confidence: 0.747045306

00:34:27.230 --> 00:34:28.994 And we had to work with that

NOTE Confidence: 0.747045306

00:34:28.994 --> 00:34:30.850 man to put that confidence.

NOTE Confidence: 0.747045306

00:34:30.850 --> 00:34:31.830 And when she did it,

NOTE Confidence: 0.747045306

00:34:31.830 --> 00:34:32.808 like it took like a year.

NOTE Confidence: 0.747045306

00:34:32.810 --> 00:34:34.148 And that hearing was super good,

NOTE Confidence: 0.747045306

00:34:34.150 --> 00:34:36.230 not perfect, but super good.

NOTE Confidence: 0.747045306

00:34:36.230 --> 00:34:37.448 And we told her, you know,

NOTE Confidence: 0.747045306

00:34:37.450 --> 00:34:39.362 you did it and we believed in you

NOTE Confidence: 0.747045306

00:34:39.362 --> 00:34:41.539 and you believe in yourself and and,

NOTE Confidence: 0.747045306

00:34:41.540 --> 00:34:42.270 you know,

NOTE Confidence: 0.747045306

00:34:42.270 --> 00:34:44.498 she started to cry and we didn't know

NOTE Confidence: 0.747045306

00:34:44.498 --> 00:34:45.969 what to do because she started to cry.

NOTE Confidence: 0.747045306

00:34:45.970 --> 00:34:46.792 Oh my God.
NOTE Confidence: 0.747045306

00:34:46.792 --> 00:34:48.162 The first time that someone
NOTE Confidence: 0.747045306

00:34:48.162 --> 00:34:49.890 had said that to me, you know,
NOTE Confidence: 0.747045306

00:34:49.890 --> 00:34:51.570 there are so many things the way.
NOTE Confidence: 0.747045306

00:34:51.570 --> 00:34:54.074 I went to Med school because I like
NOTE Confidence: 0.747045306

00:34:54.074 --> 00:34:56.657 science I didn't know anything about.
NOTE Confidence: 0.747045306

00:34:56.660 --> 00:34:58.244 You know, I also grew up in Chile,
NOTE Confidence: 0.747045306

00:34:58.250 --> 00:35:00.262 so I didn't know any relation,
NOTE Confidence: 0.747045306

00:35:00.262 --> 00:35:01.790 was pretty homogeneous were
NOTE Confidence: 0.747045306

00:35:01.790 --> 00:35:03.318 all Latinos and everything.
NOTE Confidence: 0.747045306

00:35:03.320 --> 00:35:04.928 So I didn't know anything about
NOTE Confidence: 0.747045306

00:35:04.928 --> 00:35:06.500 all this difference or anything.
NOTE Confidence: 0.747045306

00:35:06.500 --> 00:35:08.020 I was super pretty naive.
NOTE Confidence: 0.747045306

00:35:08.020 --> 00:35:10.117 So but now I see all the importance of
NOTE Confidence: 0.747045306

00:35:10.117 --> 00:35:12.577 the social determinants of health are huge.
NOTE Confidence: 0.809489430333334

00:35:14.810 --> 00:35:16.698 And I would ask, I want to sort

NOTE Confidence: 0.809489430333334

00:35:16.698 --> 00:35:18.371 of correlate question to you is

NOTE Confidence: 0.809489430333334

00:35:18.371 --> 00:35:20.081 how successful clearly some of our

NOTE Confidence: 0.809489430333334

00:35:20.135 --> 00:35:21.875 children just need more time than

NOTE Confidence: 0.809489430333334

00:35:21.875 --> 00:35:23.986 three months to work on adherence.

NOTE Confidence: 0.809489430333334

00:35:23.986 --> 00:35:26.824 How successful have you been doing

NOTE Confidence: 0.809489430333334

00:35:26.824 --> 00:35:29.739 with home care companies because?

NOTE Confidence: 0.809489430333334

00:35:29.740 --> 00:35:32.444 We've had, we've had a fair amount of

NOTE Confidence: 0.809489430333334

00:35:32.444 --> 00:35:33.731 inflexibility sometimes and having

NOTE Confidence: 0.809489430333334

00:35:33.731 --> 00:35:35.938 to do extra studies simply to re

NOTE Confidence: 0.809489430333334

00:35:35.938 --> 00:35:37.133 demonstrate the children have sleep

NOTE Confidence: 0.809489430333334

00:35:37.133 --> 00:35:38.697 apnea and we know that they do.

NOTE Confidence: 0.809489430333334

00:35:38.700 --> 00:35:40.626 It just seems like a big waste of time.

NOTE Confidence: 0.813806793333333

00:35:40.680 --> 00:35:42.060 It's a huge waste of time.

NOTE Confidence: 0.813806793333333

00:35:42.060 --> 00:35:43.650 Typically we some comical companies

NOTE Confidence: 0.813806793333333

00:35:43.650 --> 00:35:45.790 you know they require like a recent

NOTE Confidence: 0.813806793333333

00:35:45.790 --> 00:35:47.512 within six months or so sleep study
NOTE Confidence: 0.8138067933333333

00:35:47.512 --> 00:35:48.996 and it happens that Johnny had
NOTE Confidence: 0.8138067933333333

00:35:48.996 --> 00:35:51.065 a six month and one day ago and
NOTE Confidence: 0.8138067933333333

00:35:51.065 --> 00:35:52.835 then you have to reorder right.
NOTE Confidence: 0.8138067933333333

00:35:52.840 --> 00:35:53.617 It's it's ridiculous.
NOTE Confidence: 0.8138067933333333

00:35:53.617 --> 00:35:55.752 So yes and also the other thing that
NOTE Confidence: 0.8138067933333333

00:35:55.752 --> 00:35:57.635 we have with home care companies and
NOTE Confidence: 0.8138067933333333

00:35:57.635 --> 00:35:59.300 this happened just yesterday seeing.
NOTE Confidence: 0.8138067933333333

00:35:59.300 --> 00:36:01.280 Finally that that was all convinced,
NOTE Confidence: 0.8138067933333333

00:36:01.280 --> 00:36:03.866 starting CPAP now with the pandemic.
NOTE Confidence: 0.8138067933333333

00:36:03.870 --> 00:36:04.894 Before we could start,
NOTE Confidence: 0.8138067933333333

00:36:04.894 --> 00:36:07.073 we would bring the home care company here
NOTE Confidence: 0.8138067933333333

00:36:07.073 --> 00:36:09.409 and we would start here doing the initiation.
NOTE Confidence: 0.8138067933333333

00:36:09.410 --> 00:36:11.506 Turn off the Machine was a full day
NOTE Confidence: 0.8138067933333333

00:36:11.506 --> 00:36:13.290 visit whatever, not with me all the time,
NOTE Confidence: 0.8138067933333333

00:36:13.290 --> 00:36:15.810 but with the team and with the pandemic.

NOTE Confidence: 0.8138067933333333
00:36:15.810 --> 00:36:17.914 Now what happens is that the home Care
NOTE Confidence: 0.8138067933333333
00:36:17.914 --> 00:36:19.399 company delivers the device at home.
NOTE Confidence: 0.8138067933333333
00:36:19.400 --> 00:36:20.610 That's the teaching at home.
NOTE Confidence: 0.8138067933333333
00:36:20.610 --> 00:36:22.140 And then when that happened,
NOTE Confidence: 0.8138067933333333
00:36:22.140 --> 00:36:23.680 we do the initiation here because we're
NOTE Confidence: 0.8138067933333333
00:36:23.680 --> 00:36:25.278 not allowed to turn it on the device.
NOTE Confidence: 0.8138067933333333
00:36:25.280 --> 00:36:26.610 And then we have to close the
NOTE Confidence: 0.8138067933333333
00:36:26.610 --> 00:36:27.470 room or whatever thing.
NOTE Confidence: 0.8138067933333333
00:36:27.470 --> 00:36:28.807 And then that came and he said,
NOTE Confidence: 0.8138067933333333
00:36:28.810 --> 00:36:30.130 you know, everything was super good.
NOTE Confidence: 0.8138067933333333
00:36:30.130 --> 00:36:31.551 You guys provided me with a mask
NOTE Confidence: 0.8138067933333333
00:36:31.551 --> 00:36:32.619 or we're playing with that.
NOTE Confidence: 0.8138067933333333
00:36:32.620 --> 00:36:34.078 The home care company came up.
NOTE Confidence: 0.8138067933333333
00:36:34.080 --> 00:36:35.600 They deliver a box home.
NOTE Confidence: 0.8138067933333333
00:36:35.600 --> 00:36:36.910 This is your staff home.
NOTE Confidence: 0.8138067933333333

00:36:36.910 --> 00:36:38.254 This is your Mac. Where is the kid?
NOTE Confidence: 0.8138067933333333

00:36:38.260 --> 00:36:39.090 Bam.
NOTE Confidence: 0.8138067933333333

00:36:39.090 --> 00:36:41.580 On your face.
NOTE Confidence: 0.755592496

00:36:39.820 --> 00:36:41.568 Ohh, I don't like it. You have to wear
NOTE Confidence: 0.8593447383333333

00:36:41.580 --> 00:36:42.690 it. If you don't wear it,
NOTE Confidence: 0.8593447383333333

00:36:42.690 --> 00:36:44.246 like in 90 days.
NOTE Confidence: 0.8593447383333333

00:36:44.246 --> 00:36:46.191 We build the family with
NOTE Confidence: 0.8593447383333333

00:36:46.191 --> 00:36:47.699 whatever thing you know,
NOTE Confidence: 0.8593447383333333

00:36:47.700 --> 00:36:51.684 how long it takes to undo the wrong.
NOTE Confidence: 0.8593447383333333

00:36:51.690 --> 00:36:53.290 It's it's like in impressive.
NOTE Confidence: 0.8593447383333333

00:36:53.290 --> 00:36:54.641 So now actually we just had a
NOTE Confidence: 0.8593447383333333

00:36:54.641 --> 00:36:55.697 meeting that we're talking about
NOTE Confidence: 0.8593447383333333

00:36:55.697 --> 00:36:56.999 that here like an admin meeting
NOTE Confidence: 0.8593447383333333

00:36:56.999 --> 00:36:58.731 and said we need to talk to the
NOTE Confidence: 0.8593447383333333

00:36:58.731 --> 00:36:59.905 leadership of those companies to
NOTE Confidence: 0.8593447383333333

00:36:59.905 --> 00:37:02.250 like smooth them or like be friends

NOTE Confidence: 0.859344738333333
00:37:02.250 --> 00:37:04.447 with them so they can understand
NOTE Confidence: 0.859344738333333
00:37:04.447 --> 00:37:07.050 what it is because they don't know,
NOTE Confidence: 0.859344738333333
00:37:07.050 --> 00:37:08.886 they have zero idea you know.
NOTE Confidence: 0.80328462
00:37:09.910 --> 00:37:12.438 Yeah, it's, it's like all the home care
NOTE Confidence: 0.80328462
00:37:12.438 --> 00:37:14.448 companies are so strapped right now.
NOTE Confidence: 0.80328462
00:37:14.450 --> 00:37:17.314 We've seen a lot of consolidation and lately
NOTE Confidence: 0.80328462
00:37:17.314 --> 00:37:19.699 actually just don't mean to hijack this.
NOTE Confidence: 0.80328462
00:37:19.700 --> 00:37:22.087 We've had a couple of kids giving
NOTE Confidence: 0.80328462
00:37:22.087 --> 00:37:24.029 older machines with without online
NOTE Confidence: 0.80328462
00:37:24.029 --> 00:37:26.154 monitoring because there's such a
NOTE Confidence: 0.80328462
00:37:26.154 --> 00:37:28.589 backlog of people needing machines.
NOTE Confidence: 0.80328462
00:37:28.590 --> 00:37:29.836 So then some, my mom came in
NOTE Confidence: 0.80328462
00:37:29.836 --> 00:37:31.238 with an SD card and I'm like,
NOTE Confidence: 0.80328462
00:37:31.240 --> 00:37:32.728 I I haven't had an SD card reader
NOTE Confidence: 0.80328462
00:37:32.728 --> 00:37:35.540 in 10 years, you know? It's crazy.
NOTE Confidence: 0.783800789

00:37:35.870 --> 00:37:37.473 We had this semester, it's the same
NOTE Confidence: 0.783800789

00:37:37.473 --> 00:37:39.283 stuff and you know we're doing and this
NOTE Confidence: 0.783800789

00:37:39.283 --> 00:37:41.246 is an NIH drive that we were doing and
NOTE Confidence: 0.783800789

00:37:41.246 --> 00:37:42.814 by now we're supposed to be finished.
NOTE Confidence: 0.783800789

00:37:42.814 --> 00:37:44.334 And luckily while they understood
NOTE Confidence: 0.783800789

00:37:44.334 --> 00:37:45.550 it's not our business,
NOTE Confidence: 0.783800789

00:37:45.550 --> 00:37:47.910 but with the CPAP recall,
NOTE Confidence: 0.783800789

00:37:47.910 --> 00:37:50.070 we were like super delayed,
NOTE Confidence: 0.783800789

00:37:50.070 --> 00:37:52.317 like enrolling like one every quarter and
NOTE Confidence: 0.783800789

00:37:52.317 --> 00:37:55.415 we had to be like 8 or something like that.
NOTE Confidence: 0.783800789

00:37:55.420 --> 00:37:56.860 But we are there continuing
NOTE Confidence: 0.783800789

00:37:56.860 --> 00:37:58.012 with with the study.
NOTE Confidence: 0.84681912

00:37:58.770 --> 00:38:00.540 Thank you. This is great work. Appreciate
NOTE Confidence: 0.694465529

00:38:00.550 --> 00:38:02.646 it. I see someone asking can you speak
NOTE Confidence: 0.694465529

00:38:02.646 --> 00:38:04.648 about the physiological traits of OCD
NOTE Confidence: 0.694465529

00:38:04.648 --> 00:38:06.612 about patient with that. OK yeah.

NOTE Confidence: 0.694465529

00:38:06.612 --> 00:38:08.238 So you know that the physiopathology

NOTE Confidence: 0.694465529

00:38:08.238 --> 00:38:10.339 was says a combination of the muscular

NOTE Confidence: 0.694465529

00:38:10.339 --> 00:38:11.844 factor with an atomic factors.

NOTE Confidence: 0.694465529

00:38:11.850 --> 00:38:13.730 I will talk about the studies done in,

NOTE Confidence: 0.694465529

00:38:13.730 --> 00:38:15.830 in, in, in typically developing kids

NOTE Confidence: 0.694465529

00:38:15.830 --> 00:38:18.327 because the same study have not been

NOTE Confidence: 0.694465529

00:38:18.327 --> 00:38:20.385 reproduced in kids with Down syndrome.

NOTE Confidence: 0.694465529

00:38:20.390 --> 00:38:22.326 When I talked to one of the Down

NOTE Confidence: 0.694465529

00:38:22.326 --> 00:38:23.574 syndrome foundations about that I

NOTE Confidence: 0.694465529

00:38:23.574 --> 00:38:25.002 would be interested in doing that.

NOTE Confidence: 0.694465529

00:38:25.010 --> 00:38:26.249 They almost have like a heart attack.

NOTE Confidence: 0.694465529

00:38:26.250 --> 00:38:28.728 So I'm not bringing up the idea.

NOTE Confidence: 0.694465529

00:38:28.730 --> 00:38:30.102 That soon, but I will tell you

NOTE Confidence: 0.694465529

00:38:30.102 --> 00:38:30.900 what the studies are.

NOTE Confidence: 0.694465529

00:38:30.900 --> 00:38:33.012 So to study the neuromotor function

NOTE Confidence: 0.694465529

00:38:33.012 --> 00:38:35.335 during sleep, we do have to do
NOTE Confidence: 0.694465529

00:38:35.335 --> 00:38:36.627 negative pressure during sleep.
NOTE Confidence: 0.694465529

00:38:36.630 --> 00:38:37.938 So you have a CPAP machine.
NOTE Confidence: 0.694465529

00:38:37.940 --> 00:38:40.019 This is adapted to provide negative pressure.
NOTE Confidence: 0.694465529

00:38:40.020 --> 00:38:41.440 And basically what you're doing,
NOTE Confidence: 0.694465529

00:38:41.440 --> 00:38:43.638 you're sucking air out up to some
NOTE Confidence: 0.694465529

00:38:43.638 --> 00:38:46.220 point that you don't have flow anymore.
NOTE Confidence: 0.694465529

00:38:46.220 --> 00:38:47.876 Yeah, since this is sleep group,
NOTE Confidence: 0.694465529

00:38:47.880 --> 00:38:49.752 I can tell you there's a way of
NOTE Confidence: 0.694465529

00:38:49.752 --> 00:38:51.595 doing it very fast that will show
NOTE Confidence: 0.694465529

00:38:51.595 --> 00:38:53.500 us what is an active response,
NOTE Confidence: 0.694465529

00:38:53.500 --> 00:38:55.936 a fast response to the negative pressure
NOTE Confidence: 0.694465529

00:38:55.936 --> 00:38:59.375 apply or a low way or or a stepwise way that.
NOTE Confidence: 0.694465529

00:38:59.380 --> 00:39:01.540 Will elicit like the slow response
NOTE Confidence: 0.694465529

00:39:01.540 --> 00:39:04.349 of the this the flow volume curve.
NOTE Confidence: 0.694465529

00:39:04.350 --> 00:39:06.338 So eventually you apply so much negative

NOTE Confidence: 0.694465529

00:39:06.338 --> 00:39:08.228 pressure that you don't have any flow.

NOTE Confidence: 0.694465529

00:39:08.230 --> 00:39:10.477 And when you have zero flow that

NOTE Confidence: 0.694465529

00:39:10.477 --> 00:39:12.338 is the critical closing pressure

NOTE Confidence: 0.694465529

00:39:12.338 --> 00:39:13.990 of the upper airway.

NOTE Confidence: 0.694465529

00:39:13.990 --> 00:39:15.920 The studies in typically developing

NOTE Confidence: 0.694465529

00:39:15.920 --> 00:39:17.464 children without obstructive sleep

NOTE Confidence: 0.694465529

00:39:17.464 --> 00:39:19.895 apnea have shown that you need to apply

NOTE Confidence: 0.694465529

00:39:19.895 --> 00:39:21.569 negative pressure that are super high.

NOTE Confidence: 0.694465529

00:39:21.570 --> 00:39:23.530 Extrapolated to like minus 100

NOTE Confidence: 0.694465529

00:39:23.530 --> 00:39:25.490 to close the upper airway,

NOTE Confidence: 0.694465529

00:39:25.490 --> 00:39:27.884 the device goes up down to minus

NOTE Confidence: 0.694465529

00:39:27.884 --> 00:39:29.390 25 centimeters of water.

NOTE Confidence: 0.694465529

00:39:29.390 --> 00:39:29.701 However,

NOTE Confidence: 0.694465529

00:39:29.701 --> 00:39:31.878 in those who have obstructive sleep apnea,

NOTE Confidence: 0.694465529

00:39:31.880 --> 00:39:34.048 you can you can elicit the peak

NOTE Confidence: 0.694465529

00:39:34.048 --> 00:39:36.435 rate and minus 15 or things like that.
NOTE Confidence: 0.694465529

00:39:36.440 --> 00:39:38.546 My impression if I were to do that in
NOTE Confidence: 0.694465529

00:39:38.546 --> 00:39:40.804 kids with Down syndrome is that they
NOTE Confidence: 0.694465529

00:39:40.804 --> 00:39:42.463 would have critical closing pressure
NOTE Confidence: 0.694465529

00:39:42.463 --> 00:39:44.735 of the upper airway close to 0 or
NOTE Confidence: 0.694465529

00:39:44.735 --> 00:39:46.404 positive values close to adults.
NOTE Confidence: 0.694465529

00:39:46.404 --> 00:39:48.860 But those studies have not been done.
NOTE Confidence: 0.694465529

00:39:48.860 --> 00:39:51.247 Now in terms of the responsive to
NOTE Confidence: 0.694465529

00:39:51.247 --> 00:39:53.140 inspire your inspires is fantastic.
NOTE Confidence: 0.694465529

00:39:53.140 --> 00:39:55.636 However, it is not for everybody.
NOTE Confidence: 0.694465529

00:39:55.640 --> 00:39:57.880 You need to have a certain anatomic
NOTE Confidence: 0.694465529

00:39:57.880 --> 00:39:59.840 obstruction that is showing in dice.
NOTE Confidence: 0.694465529

00:39:59.840 --> 00:40:01.480 To be candidate for inspire.
NOTE Confidence: 0.694465529

00:40:01.480 --> 00:40:03.426 And the other thing is that the
NOTE Confidence: 0.694465529

00:40:03.426 --> 00:40:04.849 large trials inspire in adults.
NOTE Confidence: 0.694465529

00:40:04.850 --> 00:40:06.218 They show a reduction,

NOTE Confidence: 0.694465529

00:40:06.218 --> 00:40:08.466 immediate reduction in the OHI of 50%.

NOTE Confidence: 0.694465529

00:40:08.466 --> 00:40:11.199 So it doesn't mean that it will be cured.

NOTE Confidence: 0.694465529

00:40:11.200 --> 00:40:13.693 So let's say if I had a child with

NOTE Confidence: 0.694465529

00:40:13.693 --> 00:40:16.396 Down syndrome who had an OH, IO50I.

NOTE Confidence: 0.694465529

00:40:16.396 --> 00:40:19.384 Wouldn't be OK with my child

NOTE Confidence: 0.694465529

00:40:19.384 --> 00:40:21.309 having another child 25.

NOTE Confidence: 0.694465529

00:40:21.310 --> 00:40:23.326 I wouldn't my child to have

NOTE Confidence: 0.694465529

00:40:23.326 --> 00:40:25.950 closer to 0 or less than five.

NOTE Confidence: 0.694465529

00:40:25.950 --> 00:40:29.388 Cpap does that, but it has to be adherent.

NOTE Confidence: 0.694465529

00:40:29.390 --> 00:40:31.586 So for me, the first line,

NOTE Confidence: 0.694465529

00:40:31.590 --> 00:40:31.870 yeah,

NOTE Confidence: 0.694465529

00:40:31.870 --> 00:40:34.110 I mean we still do an option selection

NOTE Confidence: 0.694465529

00:40:34.110 --> 00:40:36.525 until we prove that it's not for everybody.

NOTE Confidence: 0.694465529

00:40:36.530 --> 00:40:37.808 But it would be like after

NOTE Confidence: 0.694465529

00:40:37.808 --> 00:40:38.660 that would be like

NOTE Confidence: 0.857049216470588

00:40:38.712 --> 00:40:40.420 CPAP with all the bells and whistle,
NOTE Confidence: 0.857049216470588

00:40:40.420 --> 00:40:41.344 the psychologist, whatever,
NOTE Confidence: 0.857049216470588

00:40:41.344 --> 00:40:42.884 if that doesn't work out
NOTE Confidence: 0.857049216470588

00:40:42.884 --> 00:40:43.960 that eventually inspired.
NOTE Confidence: 0.857049216470588

00:40:43.960 --> 00:40:47.408 But with the cabinet that inspire may not.
NOTE Confidence: 0.857049216470588

00:40:47.410 --> 00:40:49.354 Cure you and also many of the kids
NOTE Confidence: 0.857049216470588

00:40:49.354 --> 00:40:51.375 were now are part of this trial
NOTE Confidence: 0.857049216470588

00:40:51.375 --> 00:40:53.171 inspired trial here they wake up
NOTE Confidence: 0.857049216470588

00:40:53.171 --> 00:40:54.991 during the titration and so we are
NOTE Confidence: 0.857049216470588

00:40:54.991 --> 00:40:57.788 not able to get to the to the output
NOTE Confidence: 0.857049216470588

00:40:57.788 --> 00:40:59.867 in millivolts that we want because
NOTE Confidence: 0.857049216470588

00:40:59.867 --> 00:41:02.282 the kid wakes up with the inspire
NOTE Confidence: 0.857049216470588

00:41:02.356 --> 00:41:04.712 other complication that it has now
NOTE Confidence: 0.857049216470588

00:41:04.712 --> 00:41:06.406 the important thing is not not use
NOTE Confidence: 0.857049216470588

00:41:06.406 --> 00:41:08.384 this and don't use that or don't
NOTE Confidence: 0.857049216470588

00:41:08.384 --> 00:41:09.824 use public use inspire whatever.

NOTE Confidence: 0.857049216470588
00:41:09.830 --> 00:41:11.622 The thing is that we need to
NOTE Confidence: 0.857049216470588
00:41:11.622 --> 00:41:12.760 continue developing more alternatives
NOTE Confidence: 0.857049216470588
00:41:12.760 --> 00:41:14.370 so people can have options.
NOTE Confidence: 0.857049216470588
00:41:14.370 --> 00:41:15.938 Right now for example I have a headache
NOTE Confidence: 0.857049216470588
00:41:15.938 --> 00:41:17.426 I can take Tylenol I can take.
NOTE Confidence: 0.857049216470588
00:41:17.430 --> 00:41:18.660 Military, I can do this,
NOTE Confidence: 0.857049216470588
00:41:18.660 --> 00:41:19.652 I can do whatever,
NOTE Confidence: 0.857049216470588
00:41:19.652 --> 00:41:21.140 but you have always saying you
NOTE Confidence: 0.857049216470588
00:41:21.193 --> 00:41:22.429 have a developmental disability
NOTE Confidence: 0.857049216470588
00:41:22.429 --> 00:41:23.974 and your son was stuck.
NOTE Confidence: 0.857049216470588
00:41:23.980 --> 00:41:27.556 So that's our role to advocate.
NOTE Confidence: 0.857049216470588
00:41:27.560 --> 00:41:29.876 Make noise and make people visible,
NOTE Confidence: 0.857049216470588
00:41:29.880 --> 00:41:32.568 you know, if they're not visible.
NOTE Confidence: 0.857049216470588
00:41:32.570 --> 00:41:33.340 Nobody cares.
NOTE Confidence: 0.894269741428571
00:41:34.740 --> 00:41:35.248 Thank you.
NOTE Confidence: 0.894269741428571

00:41:35.248 --> 00:41:36.518 We have some more questions.
NOTE Confidence: 0.894269741428571

00:41:36.520 --> 00:41:37.798 And Doctor Tapia,
NOTE Confidence: 0.894269741428571

00:41:37.798 --> 00:41:40.354 this is from Doctor David Angel.
NOTE Confidence: 0.894269741428571

00:41:40.360 --> 00:41:42.040 Do you have a preferred interface
NOTE Confidence: 0.894269741428571

00:41:42.040 --> 00:41:43.638 you use with this population
NOTE Confidence: 0.894269741428571

00:41:43.638 --> 00:41:45.310 given their facial anatomy?
NOTE Confidence: 0.85247899

00:41:45.840 --> 00:41:48.260 It depends so much on the size of the kids.
NOTE Confidence: 0.85247899

00:41:48.260 --> 00:41:51.300 So many times the WISP works well like
NOTE Confidence: 0.85247899

00:41:51.300 --> 00:41:53.916 like only nasal typically then we prefer
NOTE Confidence: 0.85247899

00:41:53.916 --> 00:41:55.980 to start with the nasal interfaces.
NOTE Confidence: 0.85247899

00:41:55.980 --> 00:41:57.300 Now when we have proved that
NOTE Confidence: 0.85247899

00:41:57.300 --> 00:41:58.610 the kids have for example,
NOTE Confidence: 0.85247899

00:41:58.610 --> 00:42:00.326 like a strong mouth breathing and
NOTE Confidence: 0.85247899

00:42:00.326 --> 00:42:02.065 despite the high pressures they they're
NOTE Confidence: 0.85247899

00:42:02.065 --> 00:42:03.709 not able to have nasal breathing,
NOTE Confidence: 0.85247899

00:42:03.710 --> 00:42:05.600 then we will go to oronasal.

NOTE Confidence: 0.85247899

00:42:05.600 --> 00:42:07.581 But with Oronasal we we need to

NOTE Confidence: 0.85247899

00:42:07.581 --> 00:42:09.057 have some assurance that someone

NOTE Confidence: 0.85247899

00:42:09.057 --> 00:42:11.038 is with the kid overnight just in

NOTE Confidence: 0.85247899

00:42:11.038 --> 00:42:12.912 case they have vomiting and they may

NOTE Confidence: 0.85247899

00:42:12.912 --> 00:42:15.668 not be able to remove the the mask.

NOTE Confidence: 0.886149

00:42:16.860 --> 00:42:19.548 OK. There is a comment,

NOTE Confidence: 0.886149

00:42:19.548 --> 00:42:20.970 thank you for a great talk

NOTE Confidence: 0.886149

00:42:21.031 --> 00:42:22.216 and a question by Sony.

NOTE Confidence: 0.886149

00:42:22.220 --> 00:42:24.308 Vejar any collaboration with

NOTE Confidence: 0.886149

00:42:24.308 --> 00:42:26.396 dental medicine like mandibular

NOTE Confidence: 0.886149

00:42:26.396 --> 00:42:28.669 advancement, appliances, we we

NOTE Confidence: 0.798564580833333

00:42:28.680 --> 00:42:30.504 have not actually collaborated with them

NOTE Confidence: 0.798564580833333

00:42:30.504 --> 00:42:32.499 officially like on the research realm.

NOTE Confidence: 0.798564580833333

00:42:32.500 --> 00:42:34.408 We have collaborated with them clinically

NOTE Confidence: 0.798564580833333

00:42:34.408 --> 00:42:36.759 and eventually we do send patients there,

NOTE Confidence: 0.798564580833333

00:42:36.760 --> 00:42:40.316 but it's the minority of our patients.
NOTE Confidence: 0.798564580833333

00:42:40.320 --> 00:42:42.248 Something that we didn't touch up on because
NOTE Confidence: 0.798564580833333

00:42:42.248 --> 00:42:44.257 it sort of discredited his tracheostomy,
NOTE Confidence: 0.798564580833333

00:42:44.260 --> 00:42:46.150 something that I typically do not
NOTE Confidence: 0.798564580833333

00:42:46.150 --> 00:42:48.205 indicate for OSA, but I had a patient
NOTE Confidence: 0.798564580833333

00:42:48.205 --> 00:42:49.540 referred to me already years ago,
NOTE Confidence: 0.798564580833333

00:42:49.540 --> 00:42:51.673 like four or five years ago that was had
NOTE Confidence: 0.798564580833333

00:42:51.673 --> 00:42:54.174 a tracheostomy 4 was saying that different
NOTE Confidence: 0.798564580833333

00:42:54.174 --> 00:42:56.316 institution and mom came here because
NOTE Confidence: 0.798564580833333

00:42:56.316 --> 00:42:58.451 she wanted to decannulation her and go
NOTE Confidence: 0.798564580833333

00:42:58.451 --> 00:43:01.400 to now parental situation or whatever.
NOTE Confidence: 0.798564580833333

00:43:01.400 --> 00:43:05.396 The kid was never able really to use PAP.
NOTE Confidence: 0.798564580833333

00:43:05.400 --> 00:43:07.704 However, all the studies with the
NOTE Confidence: 0.798564580833333

00:43:07.704 --> 00:43:09.240 tracheostomy open are amazing.
NOTE Confidence: 0.798564580833333

00:43:09.240 --> 00:43:10.696 So you know then you have to.
NOTE Confidence: 0.798564580833333

00:43:10.700 --> 00:43:12.212 Have the conversation that I have with

NOTE Confidence: 0.798564580833333

00:43:12.212 --> 00:43:14.390 this family, you know the kid is treated,

NOTE Confidence: 0.798564580833333

00:43:14.390 --> 00:43:17.386 we are safe track is not pretty.

NOTE Confidence: 0.798564580833333

00:43:17.390 --> 00:43:19.148 It has some complications and a

NOTE Confidence: 0.798564580833333

00:43:19.148 --> 00:43:21.233 lot of things, but it's treated.

NOTE Confidence: 0.798564580833333

00:43:21.233 --> 00:43:24.770 So we have to evaluate when that happens,

NOTE Confidence: 0.798564580833333

00:43:24.770 --> 00:43:27.402 you know whether it's worth to the

NOTE Confidence: 0.798564580833333

00:43:27.402 --> 00:43:29.619 candidating everybody or not some people.

NOTE Confidence: 0.798564580833333

00:43:29.620 --> 00:43:30.580 Might not be able to.

NOTE Confidence: 0.798564580833333

00:43:30.580 --> 00:43:31.460 It's something to consider,

NOTE Confidence: 0.798564580833333

00:43:31.460 --> 00:43:31.900 you know,

NOTE Confidence: 0.798564580833333

00:43:31.900 --> 00:43:34.508 I think there's a treatment or of there's

NOTE Confidence: 0.798564580833333

00:43:34.508 --> 00:43:37.259 room for every treatment in these cases.

NOTE Confidence: 0.819814411666667

00:43:41.340 --> 00:43:43.638 I have a question for you.

NOTE Confidence: 0.819814411666667

00:43:43.640 --> 00:43:45.560 You shared some excellent strategies

NOTE Confidence: 0.819814411666667

00:43:45.560 --> 00:43:48.181 to use with patients with kids with

NOTE Confidence: 0.819814411666667

00:43:48.181 --> 00:43:50.400 Down syndrome and the usage of CPAP.
NOTE Confidence: 0.819814411666667

00:43:50.400 --> 00:43:52.731 Do you have any such recommendations once
NOTE Confidence: 0.819814411666667

00:43:52.731 --> 00:43:54.884 they transition to adulthood? You know,
NOTE Confidence: 0.819814411666667

00:43:54.884 --> 00:43:56.788 in terms of compliance using the app,
NOTE Confidence: 0.777459922307692

00:43:57.220 --> 00:43:59.509 yes, well typically we try to transition
NOTE Confidence: 0.777459922307692

00:43:59.509 --> 00:44:01.799 them when they are already adherent.
NOTE Confidence: 0.777459922307692

00:44:01.800 --> 00:44:03.036 It doesn't happen all the time.
NOTE Confidence: 0.777459922307692

00:44:03.040 --> 00:44:04.774 So continue doing what they what
NOTE Confidence: 0.777459922307692

00:44:04.774 --> 00:44:06.560 they are doing and for adult,
NOTE Confidence: 0.777459922307692

00:44:06.560 --> 00:44:08.228 I think they have less allotted
NOTE Confidence: 0.777459922307692

00:44:08.228 --> 00:44:10.139 time maybe to see the patients,
NOTE Confidence: 0.777459922307692

00:44:10.140 --> 00:44:10.900 but it would be to.
NOTE Confidence: 0.777459922307692

00:44:10.900 --> 00:44:12.364 Continue with the positive
NOTE Confidence: 0.777459922307692

00:44:12.364 --> 00:44:13.828 reinforcement depending on the
NOTE Confidence: 0.777459922307692

00:44:13.828 --> 00:44:15.129 developmental stage of the kid.
NOTE Confidence: 0.777459922307692

00:44:15.130 --> 00:44:17.160 Now with the apps are super friendly

NOTE Confidence: 0.777459922307692
00:44:17.160 --> 00:44:19.190 and they all played some sort of
NOTE Confidence: 0.777459922307692
00:44:19.190 --> 00:44:21.225 video game is to show them look
NOTE Confidence: 0.777459922307692
00:44:21.225 --> 00:44:23.253 when the app shows green amazing
NOTE Confidence: 0.777459922307692
00:44:23.253 --> 00:44:25.143 like something that they like to
NOTE Confidence: 0.777459922307692
00:44:25.143 --> 00:44:27.180 do for example like a small token
NOTE Confidence: 0.777459922307692
00:44:27.245 --> 00:44:29.459 economy you want works really well.
NOTE Confidence: 0.958440095
00:44:31.430 --> 00:44:33.840 Thank you. Any
NOTE Confidence: 0.75331073
00:44:33.850 --> 00:44:34.482 other something?
NOTE Confidence: 0.75331073
00:44:34.482 --> 00:44:37.412 Yeah, my my last point of words of wisdom
NOTE Confidence: 0.75331073
00:44:37.412 --> 00:44:39.743 that I learned from my own patients.
NOTE Confidence: 0.75331073
00:44:39.750 --> 00:44:42.596 You know what we were doing the R61 study,
NOTE Confidence: 0.75331073
00:44:42.596 --> 00:44:44.744 the qualitative interviews is for caregivers.
NOTE Confidence: 0.75331073
00:44:44.750 --> 00:44:46.507 And then parents start to just say,
NOTE Confidence: 0.75331073
00:44:46.510 --> 00:44:47.406 oh, you want to talk to me,
NOTE Confidence: 0.75331073
00:44:47.410 --> 00:44:48.946 you don't want to talk to the child.
NOTE Confidence: 0.75331073

00:44:48.950 --> 00:44:50.570 And between us we were talking,
NOTE Confidence: 0.75331073

00:44:50.570 --> 00:44:51.788 can we talk to the child?
NOTE Confidence: 0.75331073

00:44:51.790 --> 00:44:53.644 And then we decided why are we so stupid?
NOTE Confidence: 0.75331073

00:44:53.650 --> 00:44:55.714 I mean we should talk to the children
NOTE Confidence: 0.75331073

00:44:55.714 --> 00:44:57.667 and let's see what we come up with.
NOTE Confidence: 0.75331073

00:44:57.670 --> 00:44:59.482 So now in the continuation and
NOTE Confidence: 0.75331073

00:44:59.482 --> 00:45:00.690 the randomized control trial,
NOTE Confidence: 0.75331073

00:45:00.690 --> 00:45:01.894 we put some qualitative
NOTE Confidence: 0.75331073

00:45:01.894 --> 00:45:03.700 interviews and the end of the.
NOTE Confidence: 0.75331073

00:45:03.700 --> 00:45:04.726 Of the sessions,
NOTE Confidence: 0.75331073

00:45:04.726 --> 00:45:06.778 and we're talking to the parents
NOTE Confidence: 0.75331073

00:45:06.778 --> 00:45:08.810 about the trial and to the kids.
NOTE Confidence: 0.75331073

00:45:08.810 --> 00:45:10.094 We know that maybe not every
NOTE Confidence: 0.75331073

00:45:10.094 --> 00:45:11.720 kid will be able to participate.
NOTE Confidence: 0.75331073

00:45:11.720 --> 00:45:13.519 Sometimes the the parent will sort of
NOTE Confidence: 0.75331073

00:45:13.519 --> 00:45:15.068 translate what the kids want to do,

NOTE Confidence: 0.75331073

00:45:15.070 --> 00:45:16.904 but we don't go to the source.

NOTE Confidence: 0.75331073

00:45:16.910 --> 00:45:18.584 I don't feel that we can advance the field.

NOTE Confidence: 0.75331073

00:45:18.590 --> 00:45:19.778 So it's something that we have

NOTE Confidence: 0.75331073

00:45:19.778 --> 00:45:21.249 to get rid of this story of,

NOTE Confidence: 0.75331073

00:45:21.250 --> 00:45:22.660 of by proxy of thinking that

NOTE Confidence: 0.75331073

00:45:22.660 --> 00:45:23.923 we're smarter than the next

NOTE Confidence: 0.75331073

00:45:23.923 --> 00:45:25.027 person because it's just,

NOTE Confidence: 0.75331073

00:45:25.030 --> 00:45:25.760 I don't think it's true.

NOTE Confidence: 0.6451105

00:45:28.710 --> 00:45:29.240 Great.

NOTE Confidence: 0.9186527333333333

00:45:30.820 --> 00:45:32.329 Any other questions?

NOTE Confidence: 0.7188337

00:45:36.020 --> 00:45:39.002 Well. Thank you so much for sharing

NOTE Confidence: 0.7188337

00:45:39.002 --> 00:45:40.930 your work and this wonderful talk.

NOTE Confidence: 0.7188337

00:45:40.930 --> 00:45:42.760 Doctor Tapia, thank you so much.

NOTE Confidence: 0.830926752

00:45:42.930 --> 00:45:44.490 Thank you for the invitation.

NOTE Confidence: 0.830926752

00:45:44.490 --> 00:45:46.166 Have you a good day, you guys

NOTE Confidence: 0.830926752

00:45:46.166 --> 00:45:51.080 enjoy the snow. Thank you. Bye.