WEBVTT

NOTE duration:"00:59:40"

NOTE recognizability:0.849

NOTE language:en-us

NOTE Confidence: 0.937374225

00:00:00.000 --> 00:00:02.759 OK, so good afternoon everyone

NOTE Confidence: 0.937374225

00:00:02.759 --> 00:00:04.624 and welcome to sleep seminar.

NOTE Confidence: 0.924347438333333

00:00:04.630 --> 00:00:06.926 So I just before we get started

NOTE Confidence: 0.924347438333333

00:00:06.926 --> 00:00:09.462 I do want to introduce just a

NOTE Confidence: 0.924347438333333

00:00:09.462 --> 00:00:11.219 couple of just a couple of points.

NOTE Confidence: 0.924347438333333

00:00:11.220 --> 00:00:13.831 First that we do have these lectures

NOTE Confidence: 0.924347438333333

00:00:13.831 --> 00:00:15.924 available for credit and that the

NOTE Confidence: 0.924347438333333

00:00:15.924 --> 00:00:17.730 code for the lecture does need

NOTE Confidence: 0.924347438333333

00:00:17.730 --> 00:00:19.865 to be tested by 3:15 PM today.

NOTE Confidence: 0.924347438333333

00:00:19.870 --> 00:00:22.156 And if you don't if you missed the code,

NOTE Confidence: 0.924347438333333

00:00:22.160 --> 00:00:23.915 don't worry, it will show up in the chat.

NOTE Confidence: 0.924347438333333

00:00:23.920 --> 00:00:26.153 OK if you have questions during the

NOTE Confidence: 0.924347438333333

00:00:26.153 --> 00:00:28.320 talk please use the chat feature and

NOTE Confidence: 0.924347438333333

00:00:28.320 --> 00:00:30.913 then we'll get to them at the end so.

NOTE Confidence: 0.924347438333333

00:00:30.913 --> 00:00:33.454 Now it's my great pleasure to introduce

NOTE Confidence: 0.924347438333333

00:00:33.454 --> 00:00:35.418 Doctor Marie Lynn Marie Trotti.

NOTE Confidence: 0.924347438333333

00:00:35.420 --> 00:00:37.442 Dr Trotty is an associate professor

NOTE Confidence: 0.924347438333333

00:00:37.442 --> 00:00:39.282 of neurology and also associate

NOTE Confidence: 0.924347438333333

00:00:39.282 --> 00:00:41.437 professor of Pediatrics at Emory

NOTE Confidence: 0.924347438333333

00:00:41.437 --> 00:00:43.161 University School of Medicine.

NOTE Confidence: 0.924347438333333

00:00:43.170 --> 00:00:44.880 She serves as the associate Sleep

NOTE Confidence: 0.924347438333333

00:00:44.880 --> 00:00:46.380 Medicine Fellowship director at

NOTE Confidence: 0.924347438333333

00:00:46.380 --> 00:00:48.630 Emory and directs the Sleep Medicine

NOTE Confidence: 0.924347438333333

00:00:48.691 --> 00:00:50.852 rotations there and she is the

NOTE Confidence: 0.924347438333333

00:00:50.852 --> 00:00:52.850 director of the Restless Leg Syndrome

NOTE Confidence: 0.924347438333333

00:00:52.921 --> 00:00:54.909 Foundation Quality Care Center.

NOTE Confidence: 0.924347438333333

00:00:54.910 --> 00:00:56.465 Doctor Trotti received her medical

NOTE Confidence: 0.924347438333333

00:00:56.465 --> 00:00:58.020 degree from Baylor College of

NOTE Confidence: 0.924347438333333

00:00:58.072 --> 00:00:59.773 Medicine and then she moved to Emory

NOTE Confidence: 0.924347438333333

00:00:59.773 --> 00:01:01.378 where she was a medical intern.

NOTE Confidence: 0.924347438333333

00:01:01.380 --> 00:01:02.331 A neurology resident,

NOTE Confidence: 0.924347438333333

00:01:02.331 --> 00:01:03.916 a chief resident and then

NOTE Confidence: 0.924347438333333

00:01:03.916 --> 00:01:05.630 a fellow in Sleep Medicine.

NOTE Confidence: 0.924347438333333

00:01:05.630 --> 00:01:07.196 She joined the faculty at Emory,

NOTE Confidence: 0.924347438333333

00:01:07.200 --> 00:01:09.167 where she received a Masters in Clinical

NOTE Confidence: 0.924347438333333

00:01:09.167 --> 00:01:11.247 Research and where she's an active educator,

NOTE Confidence: 0.924347438333333

00:01:11.250 --> 00:01:12.699 clinician, and researcher.

NOTE Confidence: 0.924347438333333

00:01:12.699 --> 00:01:15.570 She has served on multiple local,

NOTE Confidence: 0.924347438333333

00:01:15.570 --> 00:01:15.951 national,

NOTE Confidence: 0.924347438333333

00:01:15.951 --> 00:01:17.094 and international committees

NOTE Confidence: 0.924347438333333

00:01:17.094 --> 00:01:18.237 and working groups,

NOTE Confidence: 0.924347438333333

00:01:18.240 --> 00:01:20.150 and notably for this presentation,

NOTE Confidence: 0.924347438333333

00:01:20.150 --> 00:01:21.550 she served on the American

NOTE Confidence: 0.924347438333333

00:01:21.550 --> 00:01:22.670 Academy of Sleep Medicine,

NOTE Confidence: 0.924347438333333

00:01:22.670 --> 00:01:24.002 Central Disorders of Hypersomnolence

NOTE Confidence: 0.924347438333333

00:01:24.002 --> 00:01:26.601 Task Force that led to the updated

NOTE Confidence: 0.924347438333333

00:01:26.601 --> 00:01:28.227 hypersomnia treatment guidelines,

NOTE Confidence: 0.924347438333333

00:01:28.230 --> 00:01:30.148 which were just published in the Journal

NOTE Confidence: 0.924347438333333

00:01:30.148 --> 00:01:32.058 of Clinical Sleep Medicine in September.

NOTE Confidence: 0.924347438333333

00:01:32.060 --> 00:01:33.730 She has received numerous awards,

NOTE Confidence: 0.924347438333333

00:01:33.730 --> 00:01:35.742 including the Hypersomnia Foundation.

NOTE Confidence: 0.924347438333333

00:01:35.742 --> 00:01:37.754 Impact award in 2020.

NOTE Confidence: 0.924347438333333

00:01:37.760 --> 00:01:39.410 She serves on several editorial

NOTE Confidence: 0.924347438333333

00:01:39.410 --> 00:01:41.060 boards including the Journal of

NOTE Confidence: 0.924347438333333

00:01:41.120 --> 00:01:42.800 Clinical Sleep Medicine and she's

NOTE Confidence: 0.924347438333333

00:01:42.800 --> 00:01:44.480 an associate editor for Sleep.

NOTE Confidence: 0.924347438333333

00:01:44.480 --> 00:01:46.505 She's published widely in areas

NOTE Confidence: 0.924347438333333

00:01:46.505 --> 00:01:47.315 of hypersomnia,

NOTE Confidence: 0.924347438333333

00:01:47.320 --> 00:01:49.380 restless leg syndrome and movement

NOTE Confidence: 0.924347438333333

00:01:49.380 --> 00:01:51.240 disorders and the overlap of

NOTE Confidence: 0.924347438333333

00:01:51.240 --> 00:01:52.500 sleep and neurologic disorders

NOTE Confidence: 0.924347438333333

00:01:52.500 --> 00:01:54.300 such as Parkinson's disease.

NOTE Confidence: 0.924347438333333

00:01:54.300 --> 00:01:54.675 However,

NOTE Confidence: 0.924347438333333

00:01:54.675 --> 00:01:56.925 her primary research focus is the

NOTE Confidence: 0.924347438333333

00:01:56.925 --> 00:01:58.591 pathophysiology and treatment of

NOTE Confidence: 0.924347438333333

00:01:58.591 --> 00:02:00.037 central hypersomnolence disorders,

NOTE Confidence: 0.924347438333333

00:02:00.040 --> 00:02:02.084 so we feel really excited and fortunate

NOTE Confidence: 0.924347438333333

00:02:02.084 --> 00:02:04.499 to have doctor Trotty join us today

NOTE Confidence: 0.924347438333333

00:02:04.499 --> 00:02:05.983 to discuss idiopathic hypersomnia.

NOTE Confidence: 0.924347438333333

00:02:05.990 --> 00:02:07.559 Clinical update welcome.

NOTE Confidence: 0.904870811818182

00:02:08.560 --> 00:02:09.700 Thank you so much.

NOTE Confidence: 0.904870811818182

00:02:09.700 --> 00:02:11.820 I am very excited to be here.

NOTE Confidence: 0.904870811818182

00:02:11.820 --> 00:02:13.510 I see some familiar faces

NOTE Confidence: 0.904870811818182

00:02:13.510 --> 00:02:15.200 and names on the zoom.

NOTE Confidence: 0.904870811818182

00:02:15.200 --> 00:02:17.522 I wish we could be in person,

NOTE Confidence: 0.904870811818182

00:02:17.522 --> 00:02:19.868 but I'm excited to be here

NOTE Confidence: 0.904870811818182

00:02:19.868 --> 00:02:22.398 to talk with you all today.

NOTE Confidence: 0.904870811818182

00:02:22.400 --> 00:02:26.306 So without further ado up my CME

NOTE Confidence: 0.904870811818182

00:02:26.306 --> 00:02:30.496 disclosure is that I am a speaker for

NOTE Confidence: 0.904870811818182

00:02:30.496 --> 00:02:34.329 Medscape on some of their CME content.

NOTE Confidence: 0.904870811818182

00:02:34.330 --> 00:02:36.535 This has been mitigated by

NOTE Confidence: 0.904870811818182

00:02:36.535 --> 00:02:37.858 the appropriate offices.

NOTE Confidence: 0.904870811818182

00:02:37.860 --> 00:02:38.790 My non financial.

NOTE Confidence: 0.904870811818182

00:02:38.790 --> 00:02:40.340 Disclosures are these I will

NOTE Confidence: 0.904870811818182

00:02:40.340 --> 00:02:42.256 be discussing off label use of

NOTE Confidence: 0.904870811818182

00:02:42.256 --> 00:02:43.496 approved medications and depending

NOTE Confidence: 0.904870811818182

00:02:43.496 --> 00:02:45.309 on where the conversation goes,

NOTE Confidence: 0.904870811818182

00:02:45.310 --> 00:02:47.030 might discuss unapproved medications.

NOTE Confidence: 0.904870811818182

00:02:47.030 --> 00:02:49.610 Also important to know that although

NOTE Confidence: 0.904870811818182

00:02:49.677 --> 00:02:51.771 I do not have any intellectual

NOTE Confidence: 0.904870811818182

00:02:51.771 --> 00:02:53.167 property related to anything,

NOTE Confidence: 0.904870811818182

00:02:53.170 --> 00:02:54.550 I will be talking about today.

NOTE Confidence: 0.904870811818182

00:02:54.550 --> 00:02:56.902 Several of my collaborators here at

NOTE Confidence: 0.904870811818182

00:02:56.902 --> 00:02:59.266 Emory and Emory themselves have some

NOTE Confidence: 0.904870811818182

00:02:59.266 --> 00:03:01.096 intellectual property related to the

NOTE Confidence: 0.904870811818182

00:03:01.096 --> 00:03:04.065 use of GABA agents for the treatment

NOTE Confidence: 0.904870811818182

00:03:04.065 --> 00:03:05.865 of excessive daytime sleepiness.

NOTE Confidence: 0.904870811818182

00:03:05.870 --> 00:03:06.534 And finally,

NOTE Confidence: 0.904870811818182

00:03:06.534 --> 00:03:09.560 I'm a member of the Board of the ASM.

NOTE Confidence: 0.904870811818182

00:03:09.560 --> 00:03:10.643 I'm very opinionated,

NOTE Confidence: 0.904870811818182

00:03:10.643 --> 00:03:13.936 but all of those opinions are my own and

NOTE Confidence: 0.904870811818182

00:03:13.936 --> 00:03:16.720 do not necessarily reflect those of the ASM.

NOTE Confidence: 0.904870811818182

00:03:16.720 --> 00:03:20.132 So here we go.

NOTE Confidence: 0.904870811818182

00:03:20.132 --> 00:03:21.838 Idiopathic hypersomnia.

NOTE Confidence: 0.904870811818182

00:03:21.840 --> 00:03:24.160 Just to get us all on the page,

NOTE Confidence: 0.904870811818182

00:03:24.160 --> 00:03:26.645 same page to start here or the

NOTE Confidence: 0.904870811818182

00:03:26.645 --> 00:03:30.190 diagnostic criteria in the ICS D3.

NOTE Confidence: 0.904870811818182

00:03:30.190 --> 00:03:32.452 It is required that there be

NOTE Confidence: 0.904870811818182

00:03:32.452 --> 00:03:33.960 excessive daytime sleepiness for

NOTE Confidence: 0.904870811818182

00:03:34.030 --> 00:03:36.193 at least three months and then it

NOTE Confidence: 0.904870811818182

00:03:36.193 --> 00:03:38.748 is required that a number of things

NOTE Confidence: 0.904870811818182

00:03:38.748 --> 00:03:40.698 get ruled out because idiopathic

NOTE Confidence: 0.904870811818182

00:03:40.698 --> 00:03:42.494 hypersomnia implies that there is

NOTE Confidence: 0.904870811818182

00:03:42.494 --> 00:03:44.600 not another cause for the symptoms,

NOTE Confidence: 0.904870811818182

00:03:44.600 --> 00:03:46.833 and so there cannot be cataplexy because

NOTE Confidence: 0.904870811818182

00:03:46.833 --> 00:03:49.308 then you would have narcolepsy type one.

NOTE Confidence: 0.904870811818182

00:03:49.310 --> 00:03:51.460 There cannot be multiple sleep

NOTE Confidence: 0.904870811818182

00:03:51.460 --> 00:03:54.110 on sat REM periods between the

NOTE Confidence: 0.904870811818182

00:03:54.110 --> 00:03:56.185 overnight study and the MSLT,

NOTE Confidence: 0.904870811818182

00:03:56.190 --> 00:03:59.665 because then you would have narcolepsy and.

NOTE Confidence: 0.904870811818182

00:03:59.665 --> 00:04:00.150 Finally,

NOTE Confidence: 0.904870811818182

00:04:00.150 --> 00:04:02.575 you have to exclude some

NOTE Confidence: 0.904870811818182

00:04:02.575 --> 00:04:04.750 number of other things,

NOTE Confidence: 0.904870811818182

00:04:04.750 --> 00:04:06.674 specifically institution sleep durations,

NOTE Confidence: 0.904870811818182

00:04:06.674 --> 00:04:09.079 but any other disorder that

NOTE Confidence: 0.904870811818182

00:04:09.079 --> 00:04:11.393 might explain the symptoms should

NOTE Confidence: 0.904870811818182

00:04:11.393 --> 00:04:13.157 theoretically be ruled out.

NOTE Confidence: 0.904870811818182

00:04:13.160 --> 00:04:16.160 It is not only a disorder of exclusion,

NOTE Confidence: 0.904870811818182

00:04:16.160 --> 00:04:20.024 however you do need at least one objective

NOTE Confidence: 0.904870811818182

00:04:20.024 --> 00:04:22.740 confirmation of the hypersomnolence,

NOTE Confidence: 0.904870811818182

00:04:22.740 --> 00:04:25.422 and so there's three ways you can do that.

NOTE Confidence: 0.904870811818182

00:04:25.430 --> 00:04:27.229 Typically what we do is the multiple

NOTE Confidence: 0.904870811818182

00:04:27.229 --> 00:04:29.103 sleep latency test showing a mean sleep

NOTE Confidence: 0.904870811818182

00:04:29.103 --> 00:04:30.675 latency of less than eight minutes,

NOTE Confidence: 0.904870811818182

00:04:30.680 --> 00:04:33.368 and I say typically we do that because

NOTE Confidence: 0.904870811818182

00:04:33.368 --> 00:04:34.995 the differential includes narcolepsy

NOTE Confidence: 0.904870811818182

00:04:34.995 --> 00:04:37.653 and that's how we diagnose narcolepsy.

NOTE Confidence: 0.904870811818182

00:04:37.660 --> 00:04:38.940 But as we'll talk about in a minute,

NOTE Confidence: 0.904870811818182

00:04:38.940 --> 00:04:41.600 that's probably not a great way to

NOTE Confidence: 0.904870811818182

00:04:41.600 --> 00:04:42.740 diagnose idiopathic hypersomnia,

NOTE Confidence: 0.904870811818182

00:04:42.740 --> 00:04:44.948 and so you can also for those people

NOTE Confidence: 0.904870811818182

00:04:44.948 --> 00:04:46.859 who have long sleep durations,

NOTE Confidence: 0.904870811818182

00:04:46.860 --> 00:04:49.240 make the diagnosis either through

NOTE Confidence: 0.904870811818182

00:04:49.240 --> 00:04:50.878 24 hour PSG showing at least 11

NOTE Confidence: 0.904870811818182

00:04:50.878 --> 00:04:52.422 hours of measured sleep time should

NOTE Confidence: 0.904870811818182

00:04:52.422 --> 00:04:54.000 you happen to practice with the

NOTE Confidence: 0.904870811818182

00:04:54.000 --> 00:04:55.574 place where that is a thing you

NOTE Confidence: 0.904870811818182

00:04:55.574 --> 00:04:57.132 can obtain and get reimbursed for,

NOTE Confidence: 0.904870811818182

00:04:57.132 --> 00:04:59.980 or you can do at least seven days

NOTE Confidence: 0.904870811818182

00:05:00.055 --> 00:05:02.305 of actigraphy showing an average

NOTE Confidence: 0.904870811818182

00:05:02.305 --> 00:05:04.984 estimated total sleep time of that

NOTE Confidence: 0.904870811818182

00:05:04.984 --> 00:05:07.964 same 11 hour cutoff for 24 hour period.

NOTE Confidence: 0.904870811818182

00:05:07.964 --> 00:05:09.944 So that's in a nutshell.

NOTE Confidence: 0.904870811818182

00:05:09.950 --> 00:05:10.406 UM,

NOTE Confidence: 0.904870811818182

00:05:10.406 --> 00:05:12.686 those are the working criteria

NOTE Confidence: 0.904870811818182

00:05:12.686 --> 00:05:14.054 for the diagnosis.

NOTE Confidence: 0.904870811818182

00:05:14.060 --> 00:05:15.806 They are imperfect,

NOTE Confidence: 0.904870811818182

00:05:15.806 --> 00:05:19.880 like all diagnostic criteria and and I

NOTE Confidence: 0.904870811818182

00:05:19.986 --> 00:05:22.590 anticipate maybe these will continue.

NOTE Confidence: 0.904870811818182

00:05:22.590 --> 00:05:24.990 Hopefully this will continue to be

NOTE Confidence: 0.9148805956

00:05:25.061 --> 00:05:27.448 refined as we continue to collect more

NOTE Confidence: 0.9148805956

00:05:27.448 --> 00:05:30.376 and more data about what this disorder is.

NOTE Confidence: 0.9148805956

00:05:30.380 --> 00:05:32.697 But I think it's important to know

NOTE Confidence: 0.9148805956

00:05:32.697 --> 00:05:34.958 where our starting point is up with

NOTE Confidence: 0.9148805956

00:05:34.958 --> 00:05:36.758 the criteria that we have right

NOTE Confidence: 0.9148805956

00:05:36.823 --> 00:05:39.119 now and and the first is that the

NOTE Confidence: 0.9148805956

00:05:39.119 --> 00:05:41.962 MSLT doesn't seem to do a good job

NOTE Confidence: 0.9148805956

00:05:41.962 --> 00:05:44.292 of distinguishing people we think

NOTE Confidence: 0.9148805956

00:05:44.292 --> 00:05:46.388 clinically have idiopathic hypersomnia.

NOTE Confidence: 0.9198542068

00:05:48.850 --> 00:05:51.478 And by that I mean that if you take

NOTE Confidence: 0.9198542068

00:05:51.478 --> 00:05:54.130 clinical populations and these are three

NOTE Confidence: 0.9198542068

00:05:54.130 --> 00:05:56.420 different series from three different

NOTE Confidence: 0.9198542068

00:05:56.492 --> 00:05:59.147 expert groups for hypersomnia disorders.

NOTE Confidence: 0.9198542068

00:05:59.150 --> 00:06:01.061 And you take people who are suspected

NOTE Confidence: 0.9198542068

00:06:01.061 --> 00:06:02.698 to have idiopathic hypersomnia or

NOTE Confidence: 0.9198542068

00:06:02.698 --> 00:06:04.226 who have problematic sleepiness.

NOTE Confidence: 0.9198542068

00:06:04.230 --> 00:06:05.880 That is not better explained

NOTE Confidence: 0.9198542068

00:06:05.880 --> 00:06:06.870 by something else.

NOTE Confidence: 0.9198542068

00:06:06.870 --> 00:06:11.760 And you do the MSLT on them less than half.

NOTE Confidence: 0.9198542068

00:06:11.760 --> 00:06:12.950 I haven't been sleep latency

NOTE Confidence: 0.9198542068

00:06:12.950 --> 00:06:14.140 of less than 8 minutes,

NOTE Confidence: 0.9198542068

00:06:14.140 --> 00:06:16.625 so we know the MSLT is really

NOTE Confidence: 0.9198542068

00:06:16.625 --> 00:06:18.419 good for narcolepsy type one.

NOTE Confidence: 0.9198542068

00:06:18.420 --> 00:06:20.424 There's something maybe about

NOTE Confidence: 0.9198542068

00:06:20.424 --> 00:06:22.428 the sleepiness of idiopathic

NOTE Confidence: 0.9198542068

00:06:22.428 --> 00:06:24.595 hypersomnia that is not being

NOTE Confidence: 0.9198542068

00:06:24.595 --> 00:06:26.779 captured reliably with the MSL team,

NOTE Confidence: 0.9198542068

00:06:26.780 --> 00:06:28.100 and so I point this out not to

NOTE Confidence: 0.9198542068

00:06:28.100 --> 00:06:29.520 pick on the diagnostic criteria,

NOTE Confidence: 0.9198542068

00:06:29.520 --> 00:06:31.711 but just to say if you think

NOTE Confidence: 0.9198542068

00:06:31.711 --> 00:06:33.087 someone has idiopathic hypersomnia

NOTE Confidence: 0.9198542068

00:06:33.087 --> 00:06:35.331 and their MSLT shows immune sleep

NOTE Confidence: 0.9198542068

00:06:35.331 --> 00:06:37.440 latency of more than 8 minutes.

NOTE Confidence: 0.9198542068

00:06:37.440 --> 00:06:38.940 That's probably not surprised.

NOTE Confidence: 0.828604076153846

00:06:40.980 --> 00:06:44.580 The other issue with the MSLT for making

NOTE Confidence: 0.828604076153846

00:06:44.580 --> 00:06:47.382 this diagnosis is that the the MSLT

NOTE Confidence: 0.828604076153846

00:06:47.382 --> 00:06:50.118 based diagnosis is not stable overtime,

NOTE Confidence: 0.828604076153846

00:06:50.120 --> 00:06:52.591 so again in narcolepsy type one that

NOTE Confidence: 0.828604076153846

00:06:52.591 --> 00:06:55.197 disorder for which the MSLT was optimized.

NOTE Confidence: 0.828604076153846

00:06:55.200 --> 00:06:58.126 If you repeat the MSLT you generally

NOTE Confidence: 0.828604076153846

00:06:58.126 --> 00:07:01.260 get the same narcolepsy diagnosis,

NOTE Confidence: 0.828604076153846

00:07:01.260 --> 00:07:03.402 but for the central disorders of

NOTE Confidence: 0.828604076153846

00:07:03.402 --> 00:07:05.123 hypersomnia other than narcolepsy type

NOTE Confidence: 0.828604076153846

00:07:05.123 --> 00:07:07.220 one that turns out not to be the case,

NOTE Confidence: 0.828604076153846

00:07:07.220 --> 00:07:09.220 so they figure that you're looking at our

NOTE Confidence: 0.828604076153846

00:07:09.220 --> 00:07:11.575 old data now that we did with Omar Neurology.

NOTE Confidence: 0.828604076153846

00:07:11.580 --> 00:07:13.812 Residents looking at people who had

NOTE Confidence: 0.828604076153846

00:07:13.812 --> 00:07:16.269 had two multiple sleep latency tests,

NOTE Confidence: 0.828604076153846

00:07:16.270 --> 00:07:19.042 the first of which either showing narcolepsy

NOTE Confidence: 0.828604076153846

00:07:19.042 --> 00:07:21.699 type 2 idiopathic hypersomnia or normal.

NOTE Confidence: 0.828604076153846

00:07:21.700 --> 00:07:23.344 Despite clinically problematic sleepiness,

NOTE Confidence: 0.828604076153846

00:07:23.344 --> 00:07:26.659 and then you can see the arrows tell

NOTE Confidence: 0.828604076153846

00:07:26.659 --> 00:07:29.011 you all the directions that people

NOTE Confidence: 0.828604076153846

00:07:29.011 --> 00:07:30.969 diagnosis changed on repeat testing,

NOTE Confidence: 0.828604076153846

00:07:30.970 --> 00:07:32.350 despite the fact that they were

NOTE Confidence: 0.828604076153846

00:07:32.350 --> 00:07:32.810 still symptomatic,

NOTE Confidence: 0.828604076153846

00:07:32.810 --> 00:07:35.620 and so this turned out to be just over half

NOTE Confidence: 0.828604076153846

00:07:35.692 --> 00:07:38.639 of people's diagnosis changed on repeat MSLT.

NOTE Confidence: 0.828604076153846

00:07:38.640 --> 00:07:39.915 A number of groups have

NOTE Confidence: 0.828604076153846

00:07:39.915 --> 00:07:40.935 looked at this subsequently,

NOTE Confidence: 0.828604076153846

00:07:40.940 --> 00:07:42.740 and the story tends to be the same,

NOTE Confidence: 0.828604076153846

00:07:42.740 --> 00:07:45.050 which is for narcolepsy type one.

NOTE Confidence: 0.828604076153846

00:07:45.050 --> 00:07:46.978 It is generally repeatable

NOTE Confidence: 0.828604076153846

00:07:46.978 --> 00:07:49.513 upwards of 90% of the time.

NOTE Confidence: 0.828604076153846

00:07:49.513 --> 00:07:51.318 You get the same diagnosis,

NOTE Confidence: 0.828604076153846

00:07:51.320 --> 00:07:53.564 but for narcolepsy type 2 idiopathic

NOTE Confidence: 0.828604076153846

00:07:53.564 --> 00:07:55.060 hypersomnia and people whose

NOTE Confidence: 0.828604076153846

00:07:55.118 --> 00:07:57.050 first MSLT is normal even though

NOTE Confidence: 0.828604076153846

00:07:57.050 --> 00:07:58.800 they themselves are not normal,

NOTE Confidence: 0.828604076153846

00:07:58.800 --> 00:08:01.380 they have problematic sleepiness.

NOTE Confidence: 0.828604076153846

00:08:01.380 --> 00:08:04.605 The repeatability is much poorer.

NOTE Confidence: 0.828604076153846

00:08:04.610 --> 00:08:06.806 And that is because of changes

NOTE Confidence: 0.828604076153846

00:08:06.806 --> 00:08:08.803 across the eight minute threshold

NOTE Confidence: 0.828604076153846

00:08:08.803 --> 00:08:11.118 changes across the two minutes.

NOTE Confidence: 0.828604076153846

00:08:11.120 --> 00:08:15.775 The bonds at rent threshold for both.

NOTE Confidence: 0.828604076153846

00:08:15.780 --> 00:08:18.447 So this is really why the ISD

NOTE Confidence: 0.828604076153846

00:08:18.447 --> 00:08:20.504 three incorporated this other way

NOTE Confidence: 0.828604076153846

00:08:20.504 --> 00:08:22.609 of confirming the IH diagnosis.

NOTE Confidence: 0.828604076153846

00:08:22.610 --> 00:08:25.010 By measuring long sleep durations because

NOTE Confidence: 0.828604076153846

00:08:25.010 --> 00:08:27.818 they knew that the MSLT was missing.

NOTE Confidence: 0.828604076153846

00:08:27.820 --> 00:08:29.787 Some of these patients and we needed

NOTE Confidence: 0.828604076153846

00:08:29.787 --> 00:08:32.730 to be able to capture them. And so.

NOTE Confidence: 0.828604076153846

00:08:32.730 --> 00:08:36.510 This can be done with extended PSG.

NOTE Confidence: 0.828604076153846

00:08:36.510 --> 00:08:39.470 These this is how it is done often in Europe,

NOTE Confidence: 0.828604076153846

00:08:39.470 --> 00:08:40.966 particularly in research settings,

NOTE Confidence: 0.828604076153846

00:08:40.966 --> 00:08:43.550 but often in clinical settings as well.

NOTE Confidence: 0.828604076153846

00:08:43.550 --> 00:08:45.425 And there are several different

NOTE Confidence: 0.828604076153846

00:08:45.425 --> 00:08:46.925 protocols for doing this.

NOTE Confidence: 0.828604076153846

00:08:46.930 --> 00:08:50.668 I'm showing you two different protocols here.

NOTE Confidence: 0.828604076153846

00:08:50.670 --> 00:08:53.226 Both from different groups in France.

NOTE Confidence: 0.828604076153846

00:08:53.230 --> 00:08:55.197 The first was really just ad Lib

NOTE Confidence: 0.828604076153846

00:08:55.197 --> 00:08:56.815 sleep overnight and then a long

NOTE Confidence: 0.828604076153846

00:08:56.815 --> 00:08:58.481 as you want morning nap and long

NOTE Confidence: 0.828604076153846

00:08:58.538 --> 00:09:00.281 as you want afternoon nap and so

NOTE Confidence: 0.828604076153846

00:09:00.281 --> 00:09:02.420 a little less than 24 hours to see

NOTE Confidence: 0.828604076153846

00:09:02.420 --> 00:09:03.810 how much people would sleep.

NOTE Confidence: 0.828604076153846

00:09:03.810 --> 00:09:06.582 This is where the 11 hour cutoff in the

NOTE Confidence: 0.828604076153846

00:09:06.582 --> 00:09:09.336 ICS D3 comes from is from this study.

NOTE Confidence: 0.828604076153846

00:09:09.340 --> 00:09:09.755 Subsequently,

NOTE Confidence: 0.828604076153846

00:09:09.755 --> 00:09:12.245 another French group has proposed that

NOTE Confidence: 0.828604076153846

00:09:12.245 --> 00:09:15.014 what we should do instead is 32 hours

NOTE Confidence: 0.828604076153846

00:09:15.014 --> 00:09:16.976 of bed rest monitoring during which

NOTE Confidence: 0.828604076153846

00:09:16.976 --> 00:09:19.401 you see how much sleep people obtain

NOTE Confidence: 0.828604076153846

00:09:19.401 --> 00:09:21.845 and when they looked over just the

NOTE Confidence: 0.828604076153846

00:09:21.845 --> 00:09:23.873 first 24 hours of that monitoring,

NOTE Confidence: 0.828604076153846

00:09:23.880 --> 00:09:26.820 they thought a 12 hour cutoff was

NOTE Confidence: 0.828604076153846

00:09:26.820 --> 00:09:29.684 better for differentiating people with

NOTE Confidence: 0.828604076153846

00:09:29.684 --> 00:09:32.128 idiopathic hypersomnia from controls.

NOTE Confidence: 0.828604076153846

00:09:32.130 --> 00:09:34.062 This is obviously logistically

NOTE Confidence: 0.828604076153846

00:09:34.062 --> 00:09:35.994 challenging up before sleep.

NOTE Confidence: 0.828604076153846

00:09:36.000 --> 00:09:39.520 Labs for payers and and and so on,

NOTE Confidence: 0.828604076153846

00:09:39.520 --> 00:09:41.920 but when available this is a nice way

NOTE Confidence: 0.828604076153846

00:09:41.920 --> 00:09:43.800 of documenting long sleep durations.

NOTE Confidence: 0.828604076153846

00:09:43.800 --> 00:09:44.460 Of course,

NOTE Confidence: 0.828604076153846

00:09:44.460 --> 00:09:46.110 not all patients with idiopathic

NOTE Confidence: 0.828604076153846

00:09:46.110 --> 00:09:47.919 hypersomnia have long sleep duration,

NOTE Confidence: 0.828604076153846

00:09:47.920 --> 00:09:50.713 so this is only going to identify

NOTE Confidence: 0.828604076153846

00:09:50.713 --> 00:09:51.910 and diagnose this

NOTE Confidence: 0.923012093636364

00:09:51.992 --> 00:09:53.844 subset. Over here I would

NOTE Confidence: 0.923012093636364

00:09:53.844 --> 00:09:55.474 say we usually do actigraphy.

NOTE Confidence: 0.923012093636364

00:09:55.480 --> 00:09:57.315 More commonly activities also not

NOTE Confidence: 0.923012093636364

00:09:57.315 --> 00:09:59.580 reimbursed all that well by pairs,

NOTE Confidence: 0.923012093636364

00:09:59.580 --> 00:10:02.442 but at least it is less of a money

NOTE Confidence: 0.923012093636364

00:10:02.442 --> 00:10:05.465 loser than an unreimbursed 24 hour PSG,

NOTE Confidence: 0.923012093636364

00:10:05.470 --> 00:10:07.996 and so we pretty routinely do

NOTE Confidence: 0.923012093636364

00:10:07.996 --> 00:10:09.680 actigraphy before PSG MSLT,

NOTE Confidence: 0.923012093636364

00:10:09.680 --> 00:10:11.857 and otherwise if we want to confirm

NOTE Confidence: 0.923012093636364

00:10:11.857 --> 00:10:14.148 the diagnosis and people who have a

NOTE Confidence: 0.923012093636364

00:10:14.148 --> 00:10:16.086 phenotype of long superacion with IH,

NOTE Confidence: 0.923012093636364

00:10:16.090 --> 00:10:19.366 and this is example of one of my patients

NOTE Confidence: 0.923012093636364

00:10:19.366 --> 00:10:22.727 who had a PSG normal having MSLT normal.

NOTE Confidence: 0.923012093636364

00:10:22.730 --> 00:10:24.718 Despite the fact that I was convinced

NOTE Confidence: 0.923012093636364

00:10:24.718 --> 00:10:26.230 she had idiopathic hypersomnia,

NOTE Confidence: 0.923012093636364

00:10:26.230 --> 00:10:29.070 so then she took a week off work

NOTE Confidence: 0.923012093636364

00:10:29.070 --> 00:10:31.038 so she could do this actigraphy

NOTE Confidence: 0.923012093636364

00:10:31.038 --> 00:10:33.099 and indeed it showed an average

NOTE Confidence: 0.923012093636364

00:10:33.099 --> 00:10:35.145 estimated total sleep time of over

NOTE Confidence: 0.923012093636364

00:10:35.145 --> 00:10:37.090 12 hours per 24 hour period,

NOTE Confidence: 0.923012093636364

00:10:37.090 --> 00:10:38.740 so we could confirm her diagnosis.

NOTE Confidence: 0.867987238333333

00:10:41.270 --> 00:10:42.971 I took her fee is not as good as

NOTE Confidence: 0.867987238333333

00:10:42.971 --> 00:10:45.315 we might like, but the I do think

NOTE Confidence: 0.867987238333333

00:10:45.315 --> 00:10:47.270 an important caveat is that it

NOTE Confidence: 0.867987238333333

00:10:47.270 --> 00:10:49.180 is not actually measuring sleep.

NOTE Confidence: 0.867987238333333

00:10:49.180 --> 00:10:52.264 It is measuring movement as a

NOTE Confidence: 0.867987238333333

00:10:52.264 --> 00:10:54.873 surrogate for wakefulness and lack

NOTE Confidence: 0.867987238333333

00:10:54.873 --> 00:10:58.079 of movement is a surrogate for sleep.

NOTE Confidence: 0.867987238333333

00:10:58.080 --> 00:11:01.010 And So what we like to do is have these

NOTE Confidence: 0.867987238333333

00:11:01.088 --> 00:11:03.570 patients not just wear their actigraphy

NOTE Confidence: 0.867987238333333

00:11:03.570 --> 00:11:06.129 for the week before their PSG MSLT,

NOTE Confidence: 0.867987238333333

00:11:06.130 --> 00:11:07.970 but also where they're active.

NOTE Confidence: 0.867987238333333

00:11:07.970 --> 00:11:10.410 Your fee for the night of their PSG,

NOTE Confidence: 0.867987238333333

00:11:10.410 --> 00:11:11.808 so we can at least see.

NOTE Confidence: 0.867987238333333

00:11:11.810 --> 00:11:13.430 In an individual person,

NOTE Confidence: 0.867987238333333

00:11:13.430 --> 00:11:15.860 how well did the actigraphy capture

NOTE Confidence: 0.867987238333333

00:11:15.931 --> 00:11:17.887 their sleep in the sleep lab?

NOTE Confidence: 0.867987238333333

00:11:17.890 --> 00:11:20.306 That may not be the same as the

NOTE Confidence: 0.867987238333333

00:11:20.306 --> 00:11:22.396 accuracy that it has in their home,

NOTE Confidence: 0.867987238333333

00:11:22.400 --> 00:11:24.587 but at least gives us some benchmark for was.

NOTE Confidence: 0.867987238333333

00:11:24.590 --> 00:11:25.910 The actor could be good,

NOTE Confidence: 0.867987238333333

00:11:25.910 --> 00:11:27.266 pretty good or terrible.

NOTE Confidence: 0.867987238333333

00:11:27.266 --> 00:11:29.993 This is my cautionary tale of a patient

NOTE Confidence: 0.867987238333333

00:11:29.993 --> 00:11:32.505 who came to see me for excessive daytime

NOTE Confidence: 0.867987238333333

00:11:32.569 --> 00:11:34.717 sleepiness and her first seven days

NOTE Confidence: 0.867987238333333

00:11:34.717 --> 00:11:37.416 of actigraphy are the first seven bars,

NOTE Confidence: 0.867987238333333

00:11:37.416 --> 00:11:39.948 and that's what this table is

NOTE Confidence: 0.867987238333333

00:11:39.948 --> 00:11:42.210 summarizing over her first seven days.

NOTE Confidence: 0.867987238333333

00:11:42.210 --> 00:11:46.112 For average total sleep time estimated

NOTE Confidence: 0.867987238333333

00:11:46.112 --> 00:11:48.878 by her actigraphy was 11 hours and

NOTE Confidence: 0.867987238333333

00:11:48.878 --> 00:11:50.888 44 minutes for 24 hour period.

NOTE Confidence: 0.867987238333333

00:11:50.890 --> 00:11:52.348 This last night is the night

NOTE Confidence: 0.867987238333333

00:11:52.348 --> 00:11:54.150 that she was in the Sleep lab,

NOTE Confidence: 0.867987238333333

00:11:54.150 --> 00:11:57.066 and so we just took the ACT to watch,

NOTE Confidence: 0.867987238333333

00:11:57.070 --> 00:11:59.356 and we adjusted the window to

NOTE Confidence: 0.867987238333333

00:11:59.356 --> 00:12:02.069 the PSG lights out and lights on,

NOTE Confidence: 0.867987238333333

00:12:02.070 --> 00:12:04.653 and did the audit scoring city actor

NOTE Confidence: 0.867987238333333

00:12:04.653 --> 00:12:07.025 watch and the human expert scoring

NOTE Confidence: 0.867987238333333

00:12:07.025 --> 00:12:09.014 for the PSG and the actigraphy

NOTE Confidence: 0.867987238333333

00:12:09.014 --> 00:12:10.890 that night is you would kind of

NOTE Confidence: 0.867987238333333

00:12:10.945 --> 00:12:12.499 guess looking at the bar was.

NOTE Confidence: 0.867987238333333

00:12:12.500 --> 00:12:15.832 7 hours, 4 hours,

NOTE Confidence: 0.867987238333333

00:12:15.832 --> 00:12:17.498 420 minutes.

NOTE Confidence: 0.867987238333333

00:12:17.500 --> 00:12:20.680 Or PSG actually showed a measured

NOTE Confidence: 0.867987238333333

00:12:20.680 --> 00:12:24.079 sleep duration of 26 minutes now.

NOTE Confidence: 0.867987238333333

00:12:24.080 --> 00:12:25.704 There were a lot of weird things

NOTE Confidence: 0.867987238333333

00:12:25.704 --> 00:12:26.400 about this case.

NOTE Confidence: 0.867987238333333

00:12:26.400 --> 00:12:28.128 I assume she normally sleeps more

NOTE Confidence: 0.867987238333333

00:12:28.128 --> 00:12:29.620 than 26 minutes at home,

NOTE Confidence: 0.867987238333333

00:12:29.620 --> 00:12:33.092 but this is my record for the most

NOTE Confidence: 0.867987238333333

00:12:33.092 --> 00:12:34.565 discrepancy between actigraphy

NOTE Confidence: 0.867987238333333

00:12:34.565 --> 00:12:37.667 and simultaneous PSG in a patient.

NOTE Confidence: 0.867987238333333

00:12:37.670 --> 00:12:39.918 I do think the authors of the ICS

NOTE Confidence: 0.867987238333333

00:12:39.918 --> 00:12:42.574 D3 did a really nice job of saying

NOTE Confidence: 0.867987238333333

00:12:42.574 --> 00:12:45.050 when the science was not sufficient,

NOTE Confidence: 0.867987238333333

00:12:45.050 --> 00:12:47.078 but they had to make recommendations

NOTE Confidence: 0.867987238333333

00:12:47.078 --> 00:12:49.363 anyway because we need to be able

NOTE Confidence: 0.867987238333333

00:12:49.363 --> 00:12:51.115 to diagnose disease and so they

NOTE Confidence: 0.867987238333333

00:12:51.115 --> 00:12:52.564 straight up say actigraphy has

NOTE Confidence: 0.867987238333333

00:12:52.564 --> 00:12:54.826 not been validated for this use.

NOTE Confidence: 0.867987238333333

00:12:54.830 --> 00:12:57.254 There's a lot that needs to be validated.

NOTE Confidence: 0.867987238333333

00:12:57.260 --> 00:12:59.270 One is whether the accuracy of

NOTE Confidence: 0.867987238333333

00:12:59.270 --> 00:13:00.610 Actigraphy is the same,

NOTE Confidence: 0.867987238333333

00:13:00.610 --> 00:13:02.698 and NIH population as indeed many

NOTE Confidence: 0.867987238333333

00:13:02.698 --> 00:13:04.465 other populations in which it's

NOTE Confidence: 0.867987238333333

00:13:04.465 --> 00:13:05.717 been studied it might.

NOTE Confidence: 0.867987238333333

00:13:05.720 --> 00:13:06.051 Plus,

NOTE Confidence: 0.867987238333333

00:13:06.051 --> 00:13:08.699 if we even be better because I accuracy

NOTE Confidence: 0.867987238333333

00:13:08.699 --> 00:13:11.037 is related to sleep efficiency,

NOTE Confidence: 0.867987238333333

00:13:11.040 --> 00:13:13.808 the cutoff of 11 hours was just pulled

NOTE Confidence: 0.867987238333333

00:13:13.808 --> 00:13:16.202 from PSG data for convenience and so

NOTE Confidence: 0.867987238333333

00:13:16.202 --> 00:13:19.423 it may be a very different cutoff to

NOTE Confidence: 0.867987238333333

00:13:19.423 --> 00:13:21.958 make the distinction by actigraphy,

NOTE Confidence: 0.867987238333333

00:13:21.960 --> 00:13:25.506 and then I think it also is less important

NOTE Confidence: 0.867987238333333

00:13:25.506 --> 00:13:28.540 to distinguish IH from controls,

NOTE Confidence: 0.867987238333333

00:13:28.540 --> 00:13:29.452 although that's important.

NOTE Confidence: 0.867987238333333

00:13:29.452 --> 00:13:32.025 We also want to be able to distinguish

NOTE Confidence: 0.867987238333333

00:13:32.025 --> 00:13:34.299 I ate from other hypersomnia disorders

NOTE Confidence: 0.867987238333333

00:13:34.299 --> 00:13:36.420 for our medical decision making.

NOTE Confidence: 0.867987238333333

00:13:36.420 --> 00:13:38.694 And then each device has accuracy

NOTE Confidence: 0.867987238333333

00:13:38.694 --> 00:13:41.629 issues that need to be validated and

NOTE Confidence: 0.867987238333333

00:13:41.629 --> 00:13:43.864 then settings within that device.

NOTE Confidence: 0.90817184375

00:13:43.870 --> 00:13:47.190 So to that end, I highlight this study

NOTE Confidence: 0.90817184375

00:13:47.190 --> 00:13:49.878 by by Jesse Cook from David Plants

NOTE Confidence: 0.90817184375

00:13:49.878 --> 00:13:52.593 Group looking at just one device

NOTE Confidence: 0.90817184375

00:13:52.593 --> 00:13:55.073 in people with clinical idiopathic

NOTE Confidence: 0.90817184375

00:13:55.073 --> 00:13:58.145 hypersomnia and then this is the actor

NOTE Confidence: 0.90817184375

00:13:58.145 --> 00:14:00.512 watch there's two settings you can

NOTE Confidence: 0.90817184375

00:14:00.512 --> 00:14:02.744 adjust standard Lee in the device,

NOTE Confidence: 0.90817184375

00:14:02.750 --> 00:14:04.250 the sensitivity and how long

NOTE Confidence: 0.90817184375

00:14:04.250 --> 00:14:06.250 someone has to be a mobile.

NOTE Confidence: 0.90817184375

00:14:06.250 --> 00:14:07.700 Before you decide that they

NOTE Confidence: 0.90817184375

00:14:07.700 --> 00:14:09.233 are asleep or not, IMO,

NOTE Confidence: 0.90817184375

00:14:09.233 --> 00:14:12.217 before you decide they are awake and you

NOTE Confidence: 0.90817184375

00:14:12.217 --> 00:14:15.570 can see just by varying those two factors,

NOTE Confidence: 0.90817184375

00:14:15.570 --> 00:14:18.910 you get a really broad.

NOTE Confidence: 0.90817184375

00:14:18.910 --> 00:14:22.739 Do friends in how well the sleep

NOTE Confidence: 0.90817184375

00:14:22.739 --> 00:14:24.380 time measured simultaneously

NOTE Confidence: 0.90817184375

00:14:24.477 --> 00:14:27.165 with PSG and the active watch?

NOTE Confidence: 0.90817184375

00:14:27.170 --> 00:14:29.276 How how that agreement was the

NOTE Confidence: 0.90817184375

00:14:29.276 --> 00:14:31.587 default setting for the active watch

NOTE Confidence: 0.90817184375

00:14:31.587 --> 00:14:33.677 are here in blue overestimating,

NOTE Confidence: 0.90817184375

00:14:33.680 --> 00:14:37.250 with almost every combination of settings so.

NOTE Confidence: 0.90817184375

00:14:37.250 --> 00:14:40.154 Validating actigraphy for this purpose is

NOTE Confidence: 0.90817184375

00:14:40.154 --> 00:14:43.867 going to involve a lot of detailed work.

NOTE Confidence: 0.90817184375

00:14:43.870 --> 00:14:46.300 It also raises the question of,

NOTE Confidence: 0.90817184375

00:14:46.300 --> 00:14:47.020 you know,

NOTE Confidence: 0.90817184375

00:14:47.020 --> 00:14:49.540 in the ICSE 2 there was idiopathic

NOTE Confidence: 0.90817184375

00:14:49.540 --> 00:14:51.281 hypersomnia without long sleep time

NOTE Confidence: 0.90817184375

00:14:51.281 --> 00:14:53.638 less than 10 hours and with long

NOTE Confidence: 0.90817184375

00:14:53.638 --> 00:14:55.564 sleep time more than 10 hours.

NOTE Confidence: 0.90817184375

00:14:55.570 --> 00:14:57.901 Now we have this 11 hour cutoff as as

NOTE Confidence: 0.90817184375

00:14:57.901 --> 00:15:00.497 a as one of the diagnostic criteria,

NOTE Confidence: 0.90817184375

00:15:00.500 --> 00:15:03.628 but many people with IH don't have long

NOTE Confidence: 0.90817184375

00:15:03.628 --> 00:15:05.850 sleep durations and so it's really

NOTE Confidence: 0.90817184375

00:15:05.850 --> 00:15:08.401 not clear whether IH with and without

NOTE Confidence: 0.90817184375

00:15:08.401 --> 00:15:11.390 long sleep durations are the same thing.

NOTE Confidence: 0.90817184375

00:15:11.390 --> 00:15:14.926 Or are they just severity on a spectrum?

NOTE Confidence: 0.90817184375

00:15:14.930 --> 00:15:16.334 They really different disorders

NOTE Confidence: 0.90817184375

00:15:16.334 --> 00:15:18.909 and so this was a cluster analysis

NOTE Confidence: 0.90817184375

00:15:18.909 --> 00:15:21.425 that looked at MSLT variables and

NOTE Confidence: 0.90817184375

00:15:21.425 --> 00:15:23.540 then characteristics of the daytime

NOTE Confidence: 0.90817184375

00:15:23.613 --> 00:15:25.881 naps that people took and then just

NOTE Confidence: 0.90817184375

00:15:25.881 --> 00:15:28.094 did a cluster analysis and then

NOTE Confidence: 0.90817184375

00:15:28.094 --> 00:15:30.434 subsequently looked at how the MSLT

NOTE Confidence: 0.90817184375

00:15:30.434 --> 00:15:33.510 based diagnosis aligned with the

NOTE Confidence: 0.90817184375

00:15:33.510 --> 00:15:36.860 clusters that the computer created

NOTE Confidence: 0.90817184375

00:15:36.860 --> 00:15:39.530 and what you see is unsurprisingly,

NOTE Confidence: 0.90817184375

00:15:39.530 --> 00:15:41.966 I think in cluster 3 narcolepsy

NOTE Confidence: 0.90817184375

00:15:41.966 --> 00:15:43.184 with cataplexy cluster.

NOTE Confidence: 0.90817184375

00:15:43.190 --> 00:15:45.024 By itself, it is a pretty distinct.

NOTE Confidence: 0.90817184375

00:15:45.030 --> 00:15:45.427 Phenotype,

NOTE Confidence: 0.90817184375

00:15:45.427 --> 00:15:47.809 but then these other two clusters

NOTE Confidence: 0.90817184375

00:15:47.809 --> 00:15:50.464 in cluster two was primarily people

NOTE Confidence: 0.90817184375

00:15:50.464 --> 00:15:52.784 with idiopathic hypersomnia with long

NOTE Confidence: 0.90817184375

00:15:52.784 --> 00:15:55.268 sleep time defined by the ICS D2.

NOTE Confidence: 0.90817184375

00:15:55.270 --> 00:15:58.390 The other cluster was this mix of narcolepsy,

NOTE Confidence: 0.90817184375

00:15:58.390 --> 00:16:00.930 without cataplexy and idiopathic hypersomnia,

NOTE Confidence: 0.90817184375

00:16:00.930 --> 00:16:02.502 without long superacion,

NOTE Confidence: 0.90817184375

00:16:02.502 --> 00:16:05.122 and so suggesting there's something

NOTE Confidence: 0.90817184375

00:16:05.122 --> 00:16:07.258 meaningfully different in the phenotype

NOTE Confidence: 0.90817184375

00:16:07.258 --> 00:16:09.645 that the width and without long sleep

NOTE Confidence: 0.90817184375

00:16:09.708 --> 00:16:12.546 time that segregated into different clusters.

NOTE Confidence: 0.90817184375

00:16:12.550 --> 00:16:14.678 I'm trying to get at that same question.

NOTE Confidence: 0.90817184375

00:16:14.680 --> 00:16:18.778 These are clinical data looking at

NOTE Confidence: 0.90817184375

00:16:18.780 --> 00:16:21.468 IH patients and separating them out

NOTE Confidence: 0.90817184375

00:16:21.468 --> 00:16:24.848 based on long sleep duration and look

NOTE Confidence: 0.90817184375

00:16:24.848 --> 00:16:27.602 then looking at them clinically and

NOTE Confidence: 0.90817184375

00:16:27.602 --> 00:16:29.366 looking at it this way that people

NOTE Confidence: 0.90817184375

00:16:29.366 --> 00:16:31.194 with long sleep durations are more

NOTE Confidence: 0.90817184375

00:16:31.194 --> 00:16:33.432 likely to have difficulty waking up in

NOTE Confidence: 0.90817184375

00:16:33.432 --> 00:16:35.455 the morning with with more sleep inertia.

NOTE Confidence: 0.90817184375

00:16:35.460 --> 00:16:38.115 They are less likely to be refreshed by naps,

NOTE Confidence: 0.90817184375

00:16:38.120 --> 00:16:40.350 they are.

NOTE Confidence: 0.90817184375

00:16:40.350 --> 00:16:42.840 More likely to have fatigue,

NOTE Confidence: 0.90817184375

00:16:42.840 --> 00:16:45.738 they are less likely to have

NOTE Confidence: 0.90817184375

00:16:45.738 --> 00:16:47.187 an abnormal MSLT.

NOTE Confidence: 0.90817184375

00:16:47.190 --> 00:16:49.644 And so suggesting there is some

NOTE Confidence: 0.90817184375

00:16:49.644 --> 00:16:52.050 important difference in the phenotype.

NOTE Confidence: 0.90817184375

00:16:52.050 --> 00:16:54.360 We looked at this in hypersomnia

NOTE Confidence: 0.90817184375

00:16:54.360 --> 00:16:55.130 foundation registry,

NOTE Confidence: 0.90817184375

00:16:55.130 --> 00:16:57.506 so this was a this is an ongoing

NOTE Confidence: 0.90817184375

00:16:57.506 --> 00:16:59.488 registry of people with hypersomnia

NOTE Confidence: 0.90817184375

00:16:59.488 --> 00:17:02.122 disorders who self input data about

NOTE Confidence: 0.90817184375

00:17:02.122 --> 00:17:04.590 their diagnosis and their symptoms,

NOTE Confidence: 0.90817184375

00:17:04.590 --> 00:17:05.874 and so it doesn't have the

NOTE Confidence: 0.90817184375

00:17:05.874 --> 00:17:06.730 precision of the clinic

NOTE Confidence: 0.915105784375

00:17:06.781 --> 00:17:08.065 based study I just showed you,

NOTE Confidence: 0.915105784375

00:17:08.070 --> 00:17:10.560 but much bigger sample because

NOTE Confidence: 0.915105784375

00:17:10.560 --> 00:17:13.050 it is an international registry,

NOTE Confidence: 0.915105784375

00:17:13.050 --> 00:17:15.435 but we found essentially the

NOTE Confidence: 0.915105784375

00:17:15.435 --> 00:17:17.578 same thing, which is the people.

NOTE Confidence: 0.915105784375

00:17:17.578 --> 00:17:18.469 With long sleep,

NOTE Confidence: 0.915105784375

00:17:18.470 --> 00:17:21.008 durations tend to have more sleep.

NOTE Confidence: 0.915105784375

00:17:21.010 --> 00:17:23.330 In our show they have more brain fog.

NOTE Confidence: 0.915105784375

00:17:23.330 --> 00:17:25.390 They have more cognitive

NOTE Confidence: 0.915105784375

00:17:25.390 --> 00:17:26.935 complaints they have.

NOTE Confidence: 0.878853204782608

00:17:29.280 --> 00:17:30.728 Just a different phenotype.

NOTE Confidence: 0.878853204782608

00:17:30.728 --> 00:17:32.900 It seems like the difficulty in

NOTE Confidence: 0.878853204782608

00:17:32.969 --> 00:17:34.565 wakening the unrefreshing sleep

NOTE Confidence: 0.878853204782608

00:17:34.565 --> 00:17:36.560 and the long sleep durations

NOTE Confidence: 0.878853204782608

00:17:36.560 --> 00:17:38.380 tend to segregate together,

NOTE Confidence: 0.878853204782608

00:17:38.380 --> 00:17:40.840 so that may be a meaningful

NOTE Confidence: 0.878853204782608

00:17:40.840 --> 00:17:44.160 difference diagnostically.

NOTE Confidence: 0.878853204782608

00:17:44.160 --> 00:17:45.908 Another important question is,

NOTE Confidence: 0.878853204782608

00:17:45.908 --> 00:17:48.093 given that our current diagnostic

NOTE Confidence: 0.878853204782608

00:17:48.093 --> 00:17:50.474 tools are imperfect and we don't

NOTE Confidence: 0.878853204782608

00:17:50.474 --> 00:17:52.349 yet understand the biology enough

NOTE Confidence: 0.878853204782608

00:17:52.414 --> 00:17:53.974 to develop a biomarker that

NOTE Confidence: 0.878853204782608

00:17:53.974 --> 00:17:55.911 would let us make this diagnosis,

NOTE Confidence: 0.878853204782608

00:17:55.911 --> 00:17:58.137 what else can we mine about

NOTE Confidence: 0.878853204782608

00:17:58.137 --> 00:18:00.672 this disease to help us improve

NOTE Confidence: 0.878853204782608

00:18:00.672 --> 00:18:02.476 diagnosis and so specifically,

NOTE Confidence: 0.878853204782608

00:18:02.480 --> 00:18:04.958 can we take the clinical features

NOTE Confidence: 0.878853204782608

00:18:04.958 --> 00:18:07.674 of IH and translate any of

NOTE Confidence: 0.878853204782608

00:18:07.674 --> 00:18:09.646 those into diagnostic measures?

NOTE Confidence: 0.878853204782608

00:18:09.650 --> 00:18:11.314 So keep in mind, in the ICS D3,

NOTE Confidence: 0.878853204782608

00:18:11.320 --> 00:18:12.964 the supportive features are

NOTE Confidence: 0.878853204782608

00:18:12.964 --> 00:18:14.197 unrefreshing naps lasting.

NOTE Confidence: 0.878853204782608

00:18:14.200 --> 00:18:15.688 At least an hour.

NOTE Confidence: 0.878853204782608

00:18:15.688 --> 00:18:17.920 A PSG sleep efficiency of at

NOTE Confidence: 0.878853204782608

00:18:18.010 --> 00:18:20.138 least 90% and then severe.

NOTE Confidence: 0.878853204782608

00:18:20.138 --> 00:18:21.536 Prolonged sleep inertia.

NOTE Confidence: 0.878853204782608

00:18:21.540 --> 00:18:23.640 Great difficulty waking up in the morning,

NOTE Confidence: 0.878853204782608

00:18:23.640 --> 00:18:25.152 sometimes called sleep inertia.

NOTE Confidence: 0.878853204782608

00:18:25.152 --> 00:18:26.664 Sleep drunkenness because it

NOTE Confidence: 0.878853204782608

00:18:26.664 --> 00:18:28.954 is so pronounced and then the

NOTE Confidence: 0.878853204782608

00:18:28.954 --> 00:18:30.799 ancillary symptoms of iih fatigue,

NOTE Confidence: 0.878853204782608

00:18:30.800 --> 00:18:32.570 autonomic symptoms.

NOTE Confidence: 0.878853204782608

00:18:32.570 --> 00:18:34.340 Cognitive dysfunction.

NOTE Confidence: 0.878853204782608

00:18:34.340 --> 00:18:36.108 So long unrefreshing naps,

NOTE Confidence: 0.878853204782608

00:18:36.108 --> 00:18:38.318 I believe firmly are part

NOTE Confidence: 0.878853204782608

00:18:38.318 --> 00:18:40.537 of the experience of IH,

NOTE Confidence: 0.878853204782608

00:18:40.540 --> 00:18:43.207 but they have all the same measurement

NOTE Confidence: 0.878853204782608

00:18:43.207 --> 00:18:45.526 issues that the nocturnal sleep does

NOTE Confidence: 0.878853204782608

00:18:45.526 --> 00:18:48.280 that the MSLT does that is potentially

NOTE Confidence: 0.878853204782608

00:18:48.280 --> 00:18:52.060 going to be a challenging thing to

NOTE Confidence: 0.878853204782608

00:18:52.060 --> 00:18:55.080 operationalize as part of the diagnosis.

NOTE Confidence: 0.878853204782608

00:18:55.080 --> 00:18:57.201 I also tend to think that high

NOTE Confidence: 0.878853204782608

00:18:57.201 --> 00:18:58.454 sleep efficiency should be

NOTE Confidence: 0.878853204782608

00:18:58.454 --> 00:18:59.859 a supportive feature of IH.

NOTE Confidence: 0.878853204782608

00:18:59.860 --> 00:19:01.690 I am a little skeptical when

NOTE Confidence: 0.878853204782608

00:19:01.690 --> 00:19:03.947 someone comes in with a lower sleep

NOTE Confidence: 0.878853204782608

00:19:03.947 --> 00:19:05.897 efficiency and a diagnosis of iih,

NOTE Confidence: 0.878853204782608

00:19:05.900 --> 00:19:07.980 but it is worth saying this is a

NOTE Confidence: 0.878853204782608

00:19:07.980 --> 00:19:09.498 meta analysis from David plant

NOTE Confidence: 0.878853204782608

00:19:09.498 --> 00:19:10.754 and several years ago.

NOTE Confidence: 0.878853204782608

00:19:10.760 --> 00:19:12.998 If you look at what's published

NOTE Confidence: 0.878853204782608

00:19:13.000 --> 00:19:15.046 about sleep efficiency and I ate,

NOTE Confidence: 0.878853204782608

00:19:15.050 --> 00:19:17.938 it is actually that it is not different

NOTE Confidence: 0.878853204782608

00:19:17.938 --> 00:19:20.099 from controls in in meta analysis,

NOTE Confidence: 0.878853204782608

00:19:20.100 --> 00:19:22.564 and so I think that's an important

NOTE Confidence: 0.878853204782608

00:19:22.564 --> 00:19:24.762 question to some work that's being

NOTE Confidence: 0.878853204782608

00:19:24.762 --> 00:19:27.000 done now looking at spectral analysis.

NOTE Confidence: 0.878853204782608

00:19:27.000 --> 00:19:29.926 And other more sophisticated ways of looking

NOTE Confidence: 0.878853204782608

00:19:29.926 --> 00:19:33.545 at the PSC might shed some light on that.

NOTE Confidence: 0.878853204782608

00:19:33.550 --> 00:19:35.458 But I think really where there's a lot of

NOTE Confidence: 0.878853204782608

00:19:35.458 --> 00:19:37.079 interest now is what can we do with this?

NOTE Confidence: 0.878853204782608

00:19:37.080 --> 00:19:39.204 Sleep, drunkeness, right?

NOTE Confidence: 0.878853204782608

00:19:39.204 --> 00:19:40.620 So normal,

NOTE Confidence: 0.878853204782608

00:19:40.620 --> 00:19:41.236 sleep, inertia,

NOTE Confidence: 0.878853204782608

00:19:41.236 --> 00:19:41.852 physiologic state,

NOTE Confidence: 0.878853204782608

00:19:41.852 --> 00:19:43.700 we all go through it when

NOTE Confidence: 0.878853204782608

00:19:43.761 --> 00:19:45.125 we're transitioning from being

NOTE Confidence: 0.878853204782608

00:19:45.125 --> 00:19:46.489 asleep to being awake.

NOTE Confidence: 0.878853204782608

00:19:46.490 --> 00:19:47.906 But it is usually really short,

NOTE Confidence: 0.878853204782608

00:19:47.910 --> 00:19:49.245 especially if we're not sleep

NOTE Confidence: 0.878853204782608

00:19:49.245 --> 00:19:50.935 deprived or waking up during the

NOTE Confidence: 0.878853204782608

00:19:50.935 --> 00:19:52.934 biological right or from N 3.

NOTE Confidence: 0.878853204782608

00:19:52.934 --> 00:19:55.010 But in people with idiopathic hypersomnia,

NOTE Confidence: 0.878853204782608

00:19:55.010 --> 00:19:56.946 not all of them, but many of them,

NOTE Confidence: 0.878853204782608

00:19:56.950 --> 00:19:58.730 it is often very pronounced.

NOTE Confidence: 0.878853204782608

00:19:58.730 --> 00:20:00.794 It is sometimes the worst feature

NOTE Confidence: 0.878853204782608

00:20:00.794 --> 00:20:01.826 of the disease,

NOTE Confidence: 0.878853204782608

00:20:01.830 --> 00:20:03.408 and so this is a historical.

NOTE Confidence: 0.878853204782608

00:20:03.410 --> 00:20:06.025 Note from Bed Rick Ross describing

NOTE Confidence: 0.878853204782608

00:20:06.025 --> 00:20:08.200 this disorder which he called

NOTE Confidence: 0.878853204782608

00:20:08.200 --> 00:20:09.940 hypersomnia with sleep drunkenness,

NOTE Confidence: 0.878853204782608

00:20:09.940 --> 00:20:11.880 in which the sleep drunkenness

NOTE Confidence: 0.878853204782608

00:20:11.880 --> 00:20:13.820 was sometimes worse than daytime

NOTE Confidence: 0.878853204782608

00:20:13.889 --> 00:20:15.893 sleepiness or even sometimes

NOTE Confidence: 0.878853204782608

00:20:15.893 --> 00:20:17.897 happened without daytime sleepiness.

NOTE Confidence: 0.878853204782608

00:20:17.900 --> 00:20:20.385 He subsequently would decide that

NOTE Confidence: 0.878853204782608

00:20:20.385 --> 00:20:22.870 these folks had idiopathic hypersomnia,

NOTE Confidence: 0.878853204782608

00:20:22.870 --> 00:20:25.318 but I think it tells you how fundamental

NOTE Confidence: 0.878853204782608

00:20:25.318 --> 00:20:28.229 it is to the phenotype that it was

NOTE Confidence: 0.878853204782608

00:20:28.229 --> 00:20:30.719 initially identified as its food disorder.

NOTE Confidence: 0.878853204782608

00:20:30.720 --> 00:20:33.240 It does seem pretty tightly

NOTE Confidence: 0.878853204782608

00:20:33.240 --> 00:20:35.256 related to idiopathic hypersomnia.

NOTE Confidence: 0.878853204782608

00:20:35.260 --> 00:20:37.073 These were all the data I could

NOTE Confidence: 0.878853204782608

00:20:37.073 --> 00:20:39.516 find a few years ago looking at

NOTE Confidence: 0.878853204782608

00:20:39.516 --> 00:20:41.120 sleep drunkenness by diagnosis.

NOTE Confidence: 0.834000750833333

00:20:41.120 --> 00:20:43.745 About half of people with

NOTE Confidence: 0.834000750833333

00:20:43.745 --> 00:20:45.320 idiopathic hypersomnia have

NOTE Confidence: 0.834000750833333

00:20:45.320 --> 00:20:47.489 really pronounced sleep inertia.

NOTE Confidence: 0.834000750833333

00:20:47.490 --> 00:20:49.476 Come and it's pretty rare in

NOTE Confidence: 0.834000750833333

00:20:49.476 --> 00:20:51.256 narcolepsy type one, it's about 8%.

NOTE Confidence: 0.834000750833333

00:20:51.256 --> 00:20:52.828 They'll be at the numbers there.

NOTE Confidence: 0.834000750833333

00:20:52.830 --> 00:20:53.890 Get a little bit small.

NOTE Confidence: 0.834000750833333

00:20:53.890 --> 00:20:57.338 I really could not find a good estimate

NOTE Confidence: 0.834000750833333

00:20:57.338 --> 00:20:59.829 in narcolepsy Type 2 numerically.

NOTE Confidence: 0.834000750833333

00:20:59.830 --> 00:21:01.170 It's very similar to age,

NOTE Confidence: 0.834000750833333

00:21:01.170 --> 00:21:03.250 but with a very very small sample size.

NOTE Confidence: 0.834000750833333

00:21:03.250 --> 00:21:05.095 I think it will turn out to be like

NOTE Confidence: 0.834000750833333

00:21:05.095 --> 00:21:06.799 many things in narcolepsy Type 2,

NOTE Confidence: 0.834000750833333

00:21:06.800 --> 00:21:08.494 which is some people have a phenotype

NOTE Confidence: 0.834000750833333

00:21:08.494 --> 00:21:10.408 that's a little bit more like narcolepsy.

NOTE Confidence: 0.834000750833333

00:21:10.410 --> 00:21:12.670 Type one may be undiagnosed.

NOTE Confidence: 0.834000750833333

00:21:12.670 --> 00:21:13.910 Type of creating efficiency and

NOTE Confidence: 0.834000750833333

00:21:13.910 --> 00:21:15.150 some people haven't seen it.

NOTE Confidence: 0.834000750833333

00:21:15.150 --> 00:21:18.186 Typed it as much more like

NOTE Confidence: 0.834000750833333

00:21:18.186 --> 00:21:19.704 the pathic hypersomnia.

NOTE Confidence: 0.834000750833333

00:21:19.710 --> 00:21:22.832 We looked at sleep inertia in the

NOTE Confidence: 0.834000750833333

00:21:22.832 --> 00:21:24.170 hypersomnia foundation registry

NOTE Confidence: 0.834000750833333

00:21:24.170 --> 00:21:25.940 with a variety of questions

NOTE Confidence: 0.834000750833333

00:21:25.940 --> 00:21:27.356 to measure sleep inertia,

NOTE Confidence: 0.834000750833333

00:21:27.360 --> 00:21:29.010 and that's basically what we found,

NOTE Confidence: 0.834000750833333

00:21:29.010 --> 00:21:30.888 which is it is most common

NOTE Confidence: 0.834000750833333

00:21:30.888 --> 00:21:31.827 in idiopathic hypersomnia.

NOTE Confidence: 0.834000750833333

00:21:31.830 --> 00:21:33.458 It's relatively uncommon in

NOTE Confidence: 0.834000750833333

00:21:33.458 --> 00:21:35.086 that narcolepsy type one,

NOTE Confidence: 0.834000750833333

00:21:35.090 --> 00:21:36.818 although depending on how

NOTE Confidence: 0.834000750833333

00:21:36.818 --> 00:21:38.546 you ask the question,

NOTE Confidence: 0.834000750833333

00:21:38.550 --> 00:21:40.573 you may see some of it in

NOTE Confidence: 0.834000750833333

00:21:40.573 --> 00:21:42.639 narcolepsy type one and then sort

NOTE Confidence: 0.834000750833333

00:21:42.639 --> 00:21:44.524 of intermediate in in narcolepsy,

NOTE Confidence: 0.834000750833333

00:21:44.530 --> 00:21:45.012 type 2,

NOTE Confidence: 0.834000750833333

00:21:45.012 --> 00:21:46.458 but all measures of sleep inertia

NOTE Confidence: 0.834000750833333

00:21:46.458 --> 00:21:48.225 with all the ways that we thought

NOTE Confidence: 0.834000750833333

00:21:48.225 --> 00:21:49.455 to ask it and hypersomnia.

NOTE Confidence: 0.834000750833333

00:21:49.460 --> 00:21:52.170 Foundation were endorsed most often

NOTE Confidence: 0.834000750833333

00:21:52.170 --> 00:21:56.600 by the idiopathic hypersomnia group.

NOTE Confidence: 0.834000750833333

00:21:56.600 --> 00:21:59.274 It would be nice to have questionnaires

NOTE Confidence: 0.834000750833333

00:21:59.274 --> 00:22:01.697 that value were validated and asked

NOTE Confidence: 0.834000750833333

00:22:01.697 --> 00:22:04.511 about sleep inertia in a standard way.

NOTE Confidence: 0.834000750833333

00:22:04.520 --> 00:22:06.872 We have borrowed the sleep Inertia

NOTE Confidence: 0.834000750833333

00:22:06.872 --> 00:22:09.140 questionnaire from the psychiatry literature.

NOTE Confidence: 0.834000750833333

00:22:09.140 --> 00:22:11.114 This is a scale that was developed

NOTE Confidence: 0.834000750833333

00:22:11.114 --> 00:22:12.791 to capture these sleep inertia

NOTE Confidence: 0.834000750833333

00:22:12.791 --> 00:22:14.339 that people with depression.

NOTE Confidence: 0.834000750833333

00:22:14.340 --> 00:22:16.950 How and breaks down questions really,

NOTE Confidence: 0.834000750833333

00:22:16.950 --> 00:22:18.420 in four domains,

NOTE Confidence: 0.834000750833333

00:22:18.420 --> 00:22:20.123 cognitive difficulties, behavioral,

NOTE Confidence: 0.834000750833333

00:22:20.123 --> 00:22:21.569 different difficulties,

NOTE Confidence: 0.834000750833333

00:22:21.569 --> 00:22:24.461 physiologic things like balance

NOTE Confidence: 0.834000750833333

00:22:24.461 --> 00:22:26.630 and then emotional.

NOTE Confidence: 0.834000750833333

00:22:26.630 --> 00:22:29.290 Pinky and I age you see the

NOTE Confidence: 0.834000750833333

00:22:29.290 --> 00:22:30.518 first three a lot.

NOTE Confidence: 0.834000750833333

00:22:30.518 --> 00:22:32.156 You are less likely to see things

NOTE Confidence: 0.834000750833333

00:22:32.156 --> 00:22:33.849 like dread about starting today.

NOTE Confidence: 0.834000750833333

00:22:33.850 --> 00:22:34.620 I don't think people would.

NOTE Confidence: 0.834000750833333

00:22:34.620 --> 00:22:36.069 I age don't want to wake up.

NOTE Confidence: 0.834000750833333

00:22:36.070 --> 00:22:39.052 I think they can't wake up up,

NOTE Confidence: 0.834000750833333

00:22:39.052 --> 00:22:41.948 but when we have looked at this in

NOTE Confidence: 0.834000750833333

00:22:41.948 --> 00:22:45.169 our folks with sleepiness disorders,

NOTE Confidence: 0.834000750833333

00:22:45.170 --> 00:22:47.426 we see what you would expect,

NOTE Confidence: 0.834000750833333

00:22:47.430 --> 00:22:48.582 sort of based on what we've

NOTE Confidence: 0.834000750833333

00:22:48.582 --> 00:22:49.350 talked about so far,

NOTE Confidence: 0.834000750833333

00:22:49.350 --> 00:22:51.961 which is that people who sleep the

NOTE Confidence: 0.834000750833333

00:22:51.961 --> 00:22:54.476 longest also tend to have the highest

NOTE Confidence: 0.834000750833333

00:22:54.476 --> 00:22:56.873 sleep inertia as sort of a construct.

NOTE Confidence: 0.834000750833333

00:22:56.873 --> 00:22:58.938 Validity it also correlates with

NOTE Confidence: 0.834000750833333

00:22:58.938 --> 00:23:01.320 the number of alarm rings people

NOTE Confidence: 0.834000750833333

00:23:01.320 --> 00:23:03.616 report takes to to wake them up,

NOTE Confidence: 0.834000750833333

00:23:03.620 --> 00:23:05.040 but not particularly related

NOTE Confidence: 0.834000750833333

00:23:05.040 --> 00:23:06.460 with mean sleep latency,

NOTE Confidence: 0.834000750833333

00:23:06.460 --> 00:23:09.628 number of sewer, and so on.

NOTE Confidence: 0.834000750833333

00:23:09.630 --> 00:23:11.373 I'm I do think we could not

NOTE Confidence: 0.834000750833333

00:23:11.373 --> 00:23:13.019 just ask about sleep inertia.

NOTE Confidence: 0.834000750833333

00:23:13.020 --> 00:23:14.400 We can measure sleeping here,

NOTE Confidence: 0.834000750833333

00:23:14.400 --> 00:23:15.940 so this is done in healthy control.

NOTE Confidence: 0.834000750833333

00:23:15.940 --> 00:23:18.495 Studies of sleep inertia all the time,

NOTE Confidence: 0.834000750833333

00:23:18.500 --> 00:23:21.479 and so we could do this as a measurement

NOTE Confidence: 0.834000750833333

00:23:21.479 --> 00:23:23.410 potentially even in the sleep lab as

NOTE Confidence: 0.834000750833333

00:23:23.410 --> 00:23:25.770 part of the PSG or part of the MSLT,

NOTE Confidence: 0.834000750833333

00:23:25.770 --> 00:23:27.835 maybe for the ambulatory setting as well,

NOTE Confidence: 0.834000750833333

00:23:27.840 --> 00:23:29.800 especially with things like smartphones.

NOTE Confidence: 0.834000750833333

00:23:29.800 --> 00:23:32.306 We already know the measures that capture

NOTE Confidence: 0.834000750833333

00:23:32.306 --> 00:23:34.699 sleep inertia well and healthy controls.

NOTE Confidence: 0.834000750833333

00:23:34.700 --> 00:23:35.920 The only downsides are of

NOTE Confidence: 0.834000750833333

00:23:35.920 --> 00:23:37.140 course not everybody with IH

NOTE Confidence: 0.834000750833333

00:23:37.188 --> 00:23:38.500 has pronounced sleep inertia,

NOTE Confidence: 0.834000750833333

00:23:38.500 --> 00:23:39.808 so you won't capture.

NOTE Confidence: 0.834000750833333

00:23:39.808 --> 00:23:41.770 Everybody with this it's also not

NOTE Confidence: 0.814818997666666

00:23:41.832 --> 00:23:43.672 specific to video pathic hypersomnia

NOTE Confidence: 0.814818997666666

00:23:43.672 --> 00:23:46.269 you will catch people who have a

NOTE Confidence: 0.814818997666666

00:23:46.269 --> 00:23:47.994 delayed sleep phase syndrome with

NOTE Confidence: 0.814818997666666

00:23:47.994 --> 00:23:49.930 measures of sleep inertia and also

NOTE Confidence: 0.814818997666666

00:23:49.930 --> 00:23:51.430 people who are sleep deprived.

NOTE Confidence: 0.814818997666666

00:23:51.430 --> 00:23:54.082 So important things on the differential

NOTE Confidence: 0.814818997666666

00:23:54.082 --> 00:23:55.408 for idiopathic hypersomnia,

NOTE Confidence: 0.814818997666666

00:23:55.410 --> 00:23:58.112 but I think there's enough promise there

NOTE Confidence: 0.814818997666666

00:23:58.112 --> 00:24:01.099 that that we do need some data these.

NOTE Confidence: 0.814818997666666

00:24:01.100 --> 00:24:02.717 This was one group that looked at

NOTE Confidence: 0.814818997666666

00:24:02.717 --> 00:24:04.397 this question a number of years ago.

NOTE Confidence: 0.814818997666666

00:24:04.400 --> 00:24:09.136 Now to say, could we just add vote

NOTE Confidence: 0.814818997666666

00:24:09.136 --> 00:24:12.600 potentials to what we're already doing

NOTE Confidence: 0.814818997666666

00:24:12.600 --> 00:24:15.470 instrumentation wise and in the.

NOTE Confidence: 0.814818997666666

00:24:15.470 --> 00:24:16.655 In these patients,

NOTE Confidence: 0.814818997666666

00:24:16.655 --> 00:24:20.490 as they are waking up and see if we

NOTE Confidence: 0.814818997666666

00:24:20.490 --> 00:24:22.815 can capture sleep inertia through

NOTE Confidence: 0.814818997666666

00:24:22.815 --> 00:24:25.507 either a behavioral measure or

NOTE Confidence: 0.814818997666666

00:24:25.507 --> 00:24:28.182 changes in the evoked potential,

NOTE Confidence: 0.814818997666666

00:24:28.190 --> 00:24:30.015 and they in fact demonstrated

NOTE Confidence: 0.814818997666666

00:24:30.015 --> 00:24:31.840 sleep inertia in their behavioral

NOTE Confidence: 0.814818997666666

00:24:31.906 --> 00:24:33.880 measures for the number of errors,

NOTE Confidence: 0.814818997666666

00:24:33.880 --> 00:24:36.736 but also with a revoked potential saw.

NOTE Confidence: 0.814818997666666

00:24:36.740 --> 00:24:39.728 This lengthening of the P300 latency,

NOTE Confidence: 0.814818997666666

00:24:39.730 --> 00:24:42.778 which is one of the measures and evoked

NOTE Confidence: 0.814818997666666

00:24:42.778 --> 00:24:45.460 potential across a variety of sleepiness.

NOTE Confidence: 0.814818997666666

00:24:45.460 --> 00:24:47.540 Disorders.

NOTE Confidence: 0.814818997666666

00:24:47.540 --> 00:24:49.275 So potentially it does require

NOTE Confidence: 0.814818997666666

00:24:49.275 --> 00:24:52.331 sort of extra add on to what we are

NOTE Confidence: 0.814818997666666

00:24:52.331 --> 00:24:54.209 already doing in the sleep lab.

NOTE Confidence: 0.814818997666666

00:24:54.210 --> 00:24:55.930 So what we decided to do was borrow

NOTE Confidence: 0.814818997666666

00:24:55.930 --> 00:24:57.708 a tool from the sleep deprivation

NOTE Confidence: 0.814818997666666

00:24:57.708 --> 00:24:59.323 literature which is the psycho

NOTE Confidence: 0.814818997666666

00:24:59.323 --> 00:25:00.470 Motor vigilance task.

NOTE Confidence: 0.814818997666666

00:25:00.470 --> 00:25:03.098 It is a 10 minute simple reaction time task

NOTE Confidence: 0.814818997666666

00:25:03.098 --> 00:25:05.830 and we just added it to our MSLT protocol.

NOTE Confidence: 0.814818997666666

00:25:05.830 --> 00:25:08.658 So anybody who comes in for an

NOTE Confidence: 0.814818997666666

00:25:08.658 --> 00:25:11.758 MSLT has this 10 minute PDT before

NOTE Confidence: 0.814818997666666

00:25:11.758 --> 00:25:14.897 and after nap two and before and

NOTE Confidence: 0.814818997666666

00:25:14.897 --> 00:25:16.958 after NAP 4 because we were hoping

NOTE Confidence: 0.814818997666666

00:25:16.958 --> 00:25:19.000 that we would be able to capture.

NOTE Confidence: 0.814818997666666

00:25:19.000 --> 00:25:20.725 This sleep owners are patients

NOTE Confidence: 0.814818997666666

00:25:20.725 --> 00:25:22.816 were reporting by looking at the

NOTE Confidence: 0.814818997666666

00:25:22.816 --> 00:25:24.326 change during the MSLT nap.

NOTE Confidence: 0.814818997666666

00:25:24.330 --> 00:25:25.158 And then, uhm,

NOTE Confidence: 0.814818997666666

00:25:25.158 --> 00:25:27.493 we also looked at it in some non

NOTE Confidence: 0.814818997666666

00:25:27.493 --> 00:25:29.497 sleepy can not sleep it controls

NOTE Confidence: 0.814818997666666

00:25:29.497 --> 00:25:31.474 and what you're looking at here

NOTE Confidence: 0.814818997666666

00:25:31.474 --> 00:25:33.588 on the left is actually just at

NOTE Confidence: 0.814818997666666

00:25:33.590 --> 00:25:37.098 baseline before nap too.

NOTE Confidence: 0.814818997666666

00:25:37.100 --> 00:25:38.875 The distribution of lapses when

NOTE Confidence: 0.814818997666666

00:25:38.875 --> 00:25:41.730 it takes at least a half a second

NOTE Confidence: 0.814818997666666

00:25:41.730 --> 00:25:43.734 to press the button in response

NOTE Confidence: 0.814818997666666

00:25:43.734 --> 00:25:46.240 to a stimulus and what we saw was

NOTE Confidence: 0.814818997666666

00:25:46.240 --> 00:25:49.166 people who are sleepy are much worse

NOTE Confidence: 0.814818997666666

00:25:49.166 --> 00:25:51.760 at the Pvt then controls,

NOTE Confidence: 0.814818997666666

00:25:51.760 --> 00:25:54.358 but actually not different by sleepiness,

NOTE Confidence: 0.814818997666666

00:25:54.360 --> 00:25:57.937 diagnosis and then on the right here.

NOTE Confidence: 0.814818997666666

00:25:57.940 --> 00:26:00.262 When we looked at the difference

NOTE Confidence: 0.814818997666666

00:26:00.262 --> 00:26:02.180 before and after the nap,

NOTE Confidence: 0.814818997666666

00:26:02.180 --> 00:26:05.474 how much people got worse with a short nap?

NOTE Confidence: 0.814818997666666

00:26:05.480 --> 00:26:06.260 Again controls.

NOTE Confidence: 0.814818997666666

00:26:06.260 --> 00:26:08.990 We don't see an effect here that

NOTE Confidence: 0.814818997666666

00:26:08.990 --> 00:26:10.715 controls don't really get worse

NOTE Confidence: 0.814818997666666

00:26:10.715 --> 00:26:12.950 on the PPT with a short nap.

NOTE Confidence: 0.814818997666666

00:26:12.950 --> 00:26:15.134 If they're not sleep deprived which

NOTE Confidence: 0.814818997666666

00:26:15.134 --> 00:26:17.049 are controlled by definition or not.

NOTE Confidence: 0.814818997666666

00:26:17.050 --> 00:26:21.610 But all of this sleepy people get worse,

NOTE Confidence: 0.814818997666666

00:26:21.610 --> 00:26:23.374 or at least all those sleeping groups

NOTE Confidence: 0.814818997666666

00:26:23.374 --> 00:26:25.570 have an average worsening of Pvt performance.

NOTE Confidence: 0.814818997666666

00:26:25.570 --> 00:26:28.930 So we are capturing sleep inertia in the

NOTE Confidence: 0.814818997666666

00:26:28.930 --> 00:26:31.030 sleep lab in a way that differentiates

NOTE Confidence: 0.814818997666666

00:26:31.030 --> 00:26:32.948 sleepy participants from controls,

NOTE Confidence: 0.814818997666666

00:26:32.950 --> 00:26:37.409 but is not unique to idiopathic hypersomnia.

NOTE Confidence: 0.814818997666666

00:26:37.410 --> 00:26:38.739 Then this is,

NOTE Confidence: 0.814818997666666

00:26:38.739 --> 00:26:39.182 uhm,

NOTE Confidence: 0.814818997666666

00:26:39.182 --> 00:26:41.840 another Group One of the French

NOTE Confidence: 0.814818997666666

00:26:41.934 --> 00:26:44.856 groups looking at the Pvt before

NOTE Confidence: 0.814818997666666

00:26:44.856 --> 00:26:47.752 nighttime sleep on the PSG and

NOTE Confidence: 0.814818997666666

00:26:47.752 --> 00:26:50.302 then in the morning after waking

NOTE Confidence: 0.814818997666666

00:26:50.302 --> 00:26:53.370 up from the PSG 30 minutes later

NOTE Confidence: 0.814818997666666

00:26:53.370 --> 00:26:55.580 and then several hours later,

NOTE Confidence: 0.814818997666666

00:26:55.580 --> 00:26:57.449 and their question was not so much.

NOTE Confidence: 0.941623793333333

00:26:57.450 --> 00:26:59.640 How was it different by diagnosis?

NOTE Confidence: 0.941623793333333

00:26:59.640 --> 00:27:01.250 But how did it relate

NOTE Confidence: 0.941623793333333

00:27:01.250 --> 00:27:02.538 with self reported sleep?

NOTE Confidence: 0.941623793333333

00:27:02.540 --> 00:27:05.468 Inertia or sleep drunkenness using their

NOTE Confidence: 0.941623793333333

00:27:05.468 --> 00:27:07.860 idiopathic hypersomnia severity scale which.

NOTE Confidence: 0.941623793333333

00:27:07.860 --> 00:27:10.639 Looks at a variety of symptoms of

NOTE Confidence: 0.941623793333333

00:27:10.639 --> 00:27:11.876 idiopathic hypersomnia, including

NOTE Confidence: 0.941623793333333

00:27:11.876 --> 00:27:14.056 sleep inertia and sleep drunkenness,

NOTE Confidence: 0.941623793333333

00:27:14.060 --> 00:27:17.204 and they found that there's a very strong

NOTE Confidence: 0.941623793333333

00:27:17.204 --> 00:27:18.969 relationship between self reported

NOTE Confidence: 0.941623793333333

00:27:18.969 --> 00:27:21.234 sleep inertia and sleep drunkenness,

NOTE Confidence: 0.941623793333333

00:27:21.240 --> 00:27:22.536 and Pvt worsening.

NOTE Confidence: 0.941623793333333

00:27:22.536 --> 00:27:24.696 After a night of sleep.

NOTE Confidence: 0.941623793333333

00:27:24.700 --> 00:27:26.156 So the red and black were the

NOTE Confidence: 0.941623793333333

00:27:26.156 --> 00:27:27.439 people with severe sleep inertia.

NOTE Confidence: 0.941623793333333

00:27:27.440 --> 00:27:29.096 The green was mild sleep inertia,

NOTE Confidence: 0.941623793333333

00:27:29.100 --> 00:27:31.018 and the blue was no sleep inertia,

NOTE Confidence: 0.941623793333333

00:27:31.020 --> 00:27:32.539 and you can really see this worsening.

NOTE Confidence: 0.941623793333333

00:27:32.540 --> 00:27:34.460 People know, I think, unsurprisingly,

NOTE Confidence: 0.941623793333333

00:27:34.460 --> 00:27:38.280 when they have sleep inertia.

NOTE Confidence: 0.941623793333333

00:27:38.280 --> 00:27:41.208 Well, the ancillary symptoms help us.

NOTE Confidence: 0.941623793333333

00:27:41.210 --> 00:27:42.314 That's harder.

NOTE Confidence: 0.941623793333333

00:27:42.314 --> 00:27:45.626 I think fatigue is very nonspecific,

NOTE Confidence: 0.941623793333333

00:27:45.630 --> 00:27:47.350 and certainly is not easier

NOTE Confidence: 0.941623793333333

00:27:47.350 --> 00:27:48.726 to measure than sleepiness.

NOTE Confidence: 0.941623793333333

00:27:48.730 --> 00:27:50.030 It's probably harder to

NOTE Confidence: 0.941623793333333

00:27:50.030 --> 00:27:51.005 measure than sleepiness,

NOTE Confidence: 0.941623793333333

00:27:51.010 --> 00:27:53.994 and so I don't think the fatigue of

NOTE Confidence: 0.941623793333333

00:27:53.994 --> 00:27:57.556 IH is particularly going to help us.

NOTE Confidence: 0.941623793333333

00:27:57.560 --> 00:28:00.310 There are commonly autonomic symptoms,

NOTE Confidence: 0.941623793333333

00:28:00.310 --> 00:28:03.064 and people with IH as well as the other

NOTE Confidence: 0.941623793333333

00:28:03.064 --> 00:28:05.520 central disorders of Hypersomnolence UM,

NOTE Confidence: 0.941623793333333

00:28:05.520 --> 00:28:06.840 which theoretically can

NOTE Confidence: 0.941623793333333

00:28:06.840 --> 00:28:08.160 be objectively tested.

NOTE Confidence: 0.941623793333333

00:28:08.160 --> 00:28:10.197 I think the issues we run into

NOTE Confidence: 0.941623793333333

00:28:10.197 --> 00:28:12.258 there is it's still a subgroup,

NOTE Confidence: 0.941623793333333

00:28:12.260 --> 00:28:13.325 or some people.

NOTE Confidence: 0.941623793333333

00:28:13.325 --> 00:28:15.455 It might be a medication effect,

NOTE Confidence: 0.941623793333333

00:28:15.460 --> 00:28:16.810 even in the unmedicated group

NOTE Confidence: 0.941623793333333

00:28:16.810 --> 00:28:18.160 you can still see it,

NOTE Confidence: 0.941623793333333

00:28:18.160 --> 00:28:20.435 but it also doesn't really answer what's

NOTE Confidence: 0.941623793333333

00:28:20.435 --> 00:28:22.798 the cause and and what's the effect.

NOTE Confidence: 0.941623793333333

00:28:22.800 --> 00:28:25.632 I do think that cognitive symptoms

NOTE Confidence: 0.941623793333333

00:28:25.632 --> 00:28:28.119 add to disease burden a lot.

NOTE Confidence: 0.941623793333333

00:28:28.120 --> 00:28:30.092 Similarly nonspecific but measurable,

NOTE Confidence: 0.941623793333333

00:28:30.092 --> 00:28:34.308 it might be a subgroup of people with IH,

NOTE Confidence: 0.941623793333333

00:28:34.310 --> 00:28:36.410 but it might be something David plant

NOTE Confidence: 0.941623793333333

00:28:36.410 --> 00:28:38.463 has advocated that for IH instead of

NOTE Confidence: 0.941623793333333

00:28:38.463 --> 00:28:40.101 looking for the one perfect test,

NOTE Confidence: 0.941623793333333

00:28:40.110 --> 00:28:42.710 we need to just think of a multimodal

NOTE Confidence: 0.941623793333333

00:28:42.710 --> 00:28:44.340 diagnosis where you you know

NOTE Confidence: 0.941623793333333

00:28:44.340 --> 00:28:46.176 if you maybe have six different

NOTE Confidence: 0.941623793333333

00:28:46.176 --> 00:28:47.468 tests to choose from.

NOTE Confidence: 0.941623793333333

00:28:47.470 --> 00:28:49.030 If you need at least three of them,

NOTE Confidence: 0.941623793333333

00:28:49.030 --> 00:28:50.670 you get the diagnosis,

NOTE Confidence: 0.941623793333333

00:28:50.670 --> 00:28:52.310 so cognitive dysfunction might

NOTE Confidence: 0.941623793333333

00:28:52.310 --> 00:28:54.785 fit well in that sort of a model.

NOTE Confidence: 0.941623793333333

00:28:54.790 --> 00:28:57.006 I showed you, our Pvt data at baseline,

NOTE Confidence: 0.941623793333333

00:28:57.010 --> 00:28:57.451 which.

NOTE Confidence: 0.941623793333333

00:28:57.451 --> 00:28:58.774 Differentiated all sleepy

NOTE Confidence: 0.941623793333333

00:28:58.774 --> 00:29:00.097 people from controls,

NOTE Confidence: 0.941623793333333

00:29:00.100 --> 00:29:03.076 but did not differentiate by diagnosis.

NOTE Confidence: 0.941623793333333

00:29:03.080 --> 00:29:04.988 Another group has reported on the

NOTE Confidence: 0.941623793333333

00:29:04.988 --> 00:29:06.560 sustained attention to response task.

NOTE Confidence: 0.941623793333333

00:29:06.560 --> 00:29:09.524 A different test of attention,

NOTE Confidence: 0.941623793333333

00:29:09.524 --> 00:29:11.792 but found a very similar thing,

NOTE Confidence: 0.941623793333333

00:29:11.800 --> 00:29:13.256 which is that regardless

NOTE Confidence: 0.941623793333333

00:29:13.256 --> 00:29:15.076 of why you are sleepy,

NOTE Confidence: 0.941623793333333

00:29:15.080 --> 00:29:16.336 people who are sleepy

NOTE Confidence: 0.941623793333333

00:29:16.336 --> 00:29:17.278 have impaired attention.

NOTE Confidence: 0.941623793333333

00:29:17.280 --> 00:29:18.776 It's worse than controls,

NOTE Confidence: 0.941623793333333

00:29:18.776 --> 00:29:21.578 but doesn't add to the diagnosis between

NOTE Confidence: 0.941623793333333

00:29:21.578 --> 00:29:24.048 the central supporters of hypersomnia.

NOTE Confidence: 0.897961695384616

00:29:26.920 --> 00:29:29.216 I was told to give a clinical focused

NOTE Confidence: 0.897961695384616

00:29:29.216 --> 00:29:31.480 update and so I am not going to say

NOTE Confidence: 0.897961695384616

00:29:31.480 --> 00:29:33.257 much about the pathophysiology of

NOTE Confidence: 0.897961695384616

00:29:33.257 --> 00:29:35.289 idiopathic hypersomnia it helps,

NOTE Confidence: 0.897961695384616

00:29:35.290 --> 00:29:37.956 so we don't really know anything about the

NOTE Confidence: 0.897961695384616

00:29:37.956 --> 00:29:39.724 pathophysiology of idiopathic hypersomnia,

NOTE Confidence: 0.897961695384616

00:29:39.730 --> 00:29:41.290 so there'd be a limited amount.

NOTE Confidence: 0.897961695384616

00:29:41.290 --> 00:29:43.570 I could say, even if I wanted to.

NOTE Confidence: 0.897961695384616

00:29:43.570 --> 00:29:45.929 But but let me just pause and

NOTE Confidence: 0.897961695384616

00:29:45.929 --> 00:29:48.534 say there are a number of sort

NOTE Confidence: 0.897961695384616

00:29:48.534 --> 00:29:50.796 of threads out there about what

NOTE Confidence: 0.897961695384616

00:29:50.875 --> 00:29:54.210 idiopathic hypersomnia might be up.

NOTE Confidence: 0.897961695384616

00:29:54.210 --> 00:29:56.922 There is known as I talked

NOTE Confidence: 0.897961695384616

00:29:56.922 --> 00:29:57.854 about a minute ago.

NOTE Confidence: 0.897961695384616

00:29:57.860 --> 00:29:59.860 There's known to commonly

NOTE Confidence: 0.897961695384616

00:29:59.860 --> 00:30:01.360 be autonomic symptoms,

NOTE Confidence: 0.897961695384616

00:30:01.360 --> 00:30:05.539 more commonly in IH than in controls.

NOTE Confidence: 0.897961695384616

00:30:05.540 --> 00:30:07.948 There's been very little

NOTE Confidence: 0.897961695384616

00:30:07.948 --> 00:30:09.754 beyond symptoms done.

NOTE Confidence: 0.897961695384616

00:30:09.760 --> 00:30:11.428 There is one small study looking

NOTE Confidence: 0.897961695384616

00:30:11.428 --> 00:30:12.540 at heart rate variability,

NOTE Confidence: 0.897961695384616

00:30:12.540 --> 00:30:14.001 showing differences between

NOTE Confidence: 0.897961695384616

00:30:14.001 --> 00:30:16.436 people with IH and controls,

NOTE Confidence: 0.897961695384616

00:30:16.440 --> 00:30:18.519 basically at rest,

NOTE Confidence: 0.897961695384616

00:30:18.519 --> 00:30:20.598 higher parasympathetic activity.

NOTE Confidence: 0.897961695384616

00:30:20.600 --> 00:30:22.320 But after arousal from sleep,

NOTE Confidence: 0.897961695384616

00:30:22.320 --> 00:30:24.844 higher sympathetic activity in

NOTE Confidence: 0.897961695384616

00:30:24.844 --> 00:30:27.999 the IH patients versus controls.

NOTE Confidence: 0.897961695384616

00:30:28.000 --> 00:30:30.280 The one theory is that because

NOTE Confidence: 0.897961695384616

00:30:30.280 --> 00:30:32.305 people they've had a hypersomnia

NOTE Confidence: 0.897961695384616

00:30:32.305 --> 00:30:34.420 tend to be night owls.

NOTE Confidence: 0.897961695384616

00:30:34.420 --> 00:30:37.630 This may be a circadian problem.

NOTE Confidence: 0.897961695384616

00:30:37.630 --> 00:30:39.947 They can't meet criteria for delayed sleep,

NOTE Confidence: 0.897961695384616

00:30:39.950 --> 00:30:41.039 wake phase disorder,

NOTE Confidence: 0.897961695384616

00:30:41.039 --> 00:30:43.580 but maybe there is a more subtle

NOTE Confidence: 0.897961695384616

00:30:43.652 --> 00:30:46.117 dysfunction of the circadian system.

NOTE Confidence: 0.897961695384616

00:30:46.120 --> 00:30:48.868 Some preliminary work looking

NOTE Confidence: 0.897961695384616

00:30:48.868 --> 00:30:50.929 at circadian clock.

NOTE Confidence: 0.848537069

00:30:53.440 --> 00:30:55.428 Mechanics within peripheral skin

NOTE Confidence: 0.848537069

00:30:55.428 --> 00:30:57.913 fibroblasts have suggested that the

NOTE Confidence: 0.848537069

00:30:57.913 --> 00:31:00.951 period length may be too long and

NOTE Confidence: 0.848537069

00:31:00.951 --> 00:31:02.595 people with idiopathic hypersomnia,

NOTE Confidence: 0.848537069

00:31:02.600 --> 00:31:04.616 which might explain some of these

NOTE Confidence: 0.848537069

00:31:04.616 --> 00:31:05.960 long nocturnal sleep periods,

NOTE Confidence: 0.848537069

00:31:05.960 --> 00:31:09.856 but also that the amplitude may be reduced,

NOTE Confidence: 0.848537069

00:31:09.860 --> 00:31:11.955 which could possibly contribute to

NOTE Confidence: 0.848537069

00:31:11.955 --> 00:31:14.997 this sort of feeling of like I'm

NOTE Confidence: 0.848537069

00:31:14.997 --> 00:31:17.167 never reached full wakefulness that

NOTE Confidence: 0.848537069

00:31:17.167 --> 00:31:19.700 are people with my age describe.

NOTE Confidence: 0.848537069

00:31:19.700 --> 00:31:21.797 And then work by my colleagues here at Emory,

NOTE Confidence: 0.848537069

00:31:21.800 --> 00:31:24.070 suggesting that maybe people with

NOTE Confidence: 0.848537069

00:31:24.070 --> 00:31:25.886 idiopathic hypersomnia are producing

NOTE Confidence: 0.848537069

00:31:25.886 --> 00:31:28.169 a substance that abnormally activates

NOTE Confidence: 0.848537069

00:31:28.169 --> 00:31:31.280 GABA a receptors and then triggers a

NOTE Confidence: 0.848537069

00:31:31.280 --> 00:31:33.656 soporific pathway through the GABA system.

NOTE Confidence: 0.848537069

00:31:33.660 --> 00:31:37.244 I don't think these theories are multiple

NOTE Confidence: 0.848537069

00:31:37.244 --> 00:31:39.820 are mutually exclusive necessarily,

NOTE Confidence: 0.848537069

00:31:39.820 --> 00:31:43.924 but but neither are any of them really

NOTE Confidence: 0.848537069

00:31:43.924 --> 00:31:46.348 fully conclusive at this point in time,

NOTE Confidence: 0.848537069

00:31:46.350 --> 00:31:48.566 so it's still a lot of work to

NOTE Confidence: 0.848537069

00:31:48.566 --> 00:31:50.288 be done in that regard.

NOTE Confidence: 0.848537069

00:31:50.290 --> 00:31:51.326 So for the rest of my time,

NOTE Confidence: 0.848537069

00:31:51.330 --> 00:31:56.314 I'm going to turn and talk more

NOTE Confidence: 0.848537069

00:31:56.314 --> 00:31:58.450 about treatment strategies.

NOTE Confidence: 0.848537069

00:31:58.450 --> 00:32:00.490 I think by the time people

NOTE Confidence: 0.848537069

00:32:00.490 --> 00:32:01.850 come to clinical attention,

NOTE Confidence: 0.848537069

00:32:01.850 --> 00:32:03.496 nonpharmacologic strategies

NOTE Confidence: 0.848537069

00:32:03.496 --> 00:32:06.788 or not usually enough.

NOTE Confidence: 0.848537069

00:32:06.790 --> 00:32:08.770 I think people generally need

NOTE Confidence: 0.848537069

00:32:08.770 --> 00:32:11.233 pharmacology by the time it gets

NOTE Confidence: 0.848537069

00:32:11.233 --> 00:32:13.687 severe enough for them to seek

NOTE Confidence: 0.848537069

00:32:13.687 --> 00:32:15.440 medical treatment in my experience.

NOTE Confidence: 0.848537069

00:32:15.440 --> 00:32:17.610 But I do think there's potentially a

NOTE Confidence: 0.848537069

00:32:17.673 --> 00:32:19.598 role for non pharmacologic strategies

NOTE Confidence: 0.848537069

00:32:19.598 --> 00:32:22.032 as adjunctive treatment and I certainly

NOTE Confidence: 0.848537069

00:32:22.032 --> 00:32:24.720 believe that patients are looking for

NOTE Confidence: 0.848537069

00:32:24.720 --> 00:32:27.016 nonpharmacologic strategies to add to

NOTE Confidence: 0.848537069

00:32:27.016 --> 00:32:29.854 or to lower their their medication.

NOTE Confidence: 0.848537069

00:32:29.860 --> 00:32:31.700 Burden.

NOTE Confidence: 0.848537069

00:32:31.700 --> 00:32:33.709 One thing that I think is really

NOTE Confidence: 0.848537069

00:32:33.709 --> 00:32:35.918 important is that this is not Mark Alexi

NOTE Confidence: 0.848537069

00:32:35.918 --> 00:32:38.357 in the sense that it's very common for us.

NOTE Confidence: 0.848537069

00:32:38.360 --> 00:32:40.000 With our narcolepsy type one

NOTE Confidence: 0.848537069

00:32:40.000 --> 00:32:42.043 patients to recommend napping as a

NOTE Confidence: 0.848537069

00:32:42.043 --> 00:32:43.788 treatment strategy right to write

NOTE Confidence: 0.848537069

00:32:43.788 --> 00:32:45.481 accommodation letters so they can

NOTE Confidence: 0.848537069

00:32:45.481 --> 00:32:46.909 take naps at school or not.

NOTE Confidence: 0.848537069

00:32:46.910 --> 00:32:48.956 So at work because people with

NOTE Confidence: 0.848537069

00:32:48.956 --> 00:32:51.114 narcolepsy type one often can take a

NOTE Confidence: 0.848537069

00:32:51.114 --> 00:32:53.210 15 minute nap and wake up and feel

NOTE Confidence: 0.848537069

00:32:53.210 --> 00:32:55.508 much better in people with idiopathic

NOTE Confidence: 0.848537069

00:32:55.508 --> 00:32:57.980 hypersomnia not generally are not refreshing,

NOTE Confidence: 0.848537069

00:32:57.980 --> 00:33:00.086 they tend to have sleep inertia

NOTE Confidence: 0.848537069

00:33:00.086 --> 00:33:02.079 for a prolonged period of time.

NOTE Confidence: 0.848537069

00:33:02.080 --> 00:33:03.214 When they wake up from naps

NOTE Confidence: 0.848537069

00:33:03.214 --> 00:33:04.419 and then that's are not short.

NOTE Confidence: 0.848537069

00:33:04.420 --> 00:33:06.620 They are very long and so it is

NOTE Confidence: 0.848537069

00:33:06.620 --> 00:33:08.494 actually I would say more common

NOTE Confidence: 0.848537069

00:33:08.494 --> 00:33:11.040 for my patients with IH to try very,

NOTE Confidence: 0.848537069

00:33:11.040 --> 00:33:13.567 very hard to avoid maps because they

NOTE Confidence: 0.848537069

00:33:13.567 --> 00:33:16.602 make them feel so bad and so I don't

NOTE Confidence: 0.848537069

00:33:16.602 --> 00:33:18.500 generally recommend maps as a strategy

NOTE Confidence: 0.848537069

00:33:18.500 --> 00:33:20.910 for people with high age unless they

NOTE Confidence: 0.848537069

00:33:20.910 --> 00:33:22.825 have a pretty atypical phenotype.

NOTE Confidence: 0.848537069

00:33:22.830 --> 00:33:23.829 But Despite that,

NOTE Confidence: 0.848537069

00:33:23.829 --> 00:33:25.827 I do think accommodations for school

NOTE Confidence: 0.848537069

00:33:25.827 --> 00:33:28.147 or work can still be really helpful,

NOTE Confidence: 0.848537069

00:33:28.150 --> 00:33:30.508 because there does tend to be a phase delay,

NOTE Confidence: 0.848537069

00:33:30.510 --> 00:33:32.869 and because it can take people several

NOTE Confidence: 0.848537069

00:33:32.869 --> 00:33:35.536 hours to wake up in a way that it

NOTE Confidence: 0.848537069

00:33:35.536 --> 00:33:38.069 doesn't take the rest of us later start

NOTE Confidence: 0.848537069

00:33:38.069 --> 00:33:40.169 times or unexpectedly showing up for

NOTE Confidence: 0.848537069

00:33:40.170 --> 00:33:43.920 work can be a helpful accommodation.

NOTE Confidence: 0.848537069

00:33:43.920 --> 00:33:44.810 And then,

NOTE Confidence: 0.848537069

00:33:44.810 --> 00:33:47.035 although the literature is pretty

NOTE Confidence: 0.848537069

00:33:47.035 --> 00:33:50.038 limited on the objective testing of

NOTE Confidence: 0.848537069

00:33:50.038 --> 00:33:52.678 cognitive function in IH patients.

NOTE Confidence: 0.848537069

00:33:52.680 --> 00:33:54.080 What data are there?

NOTE Confidence: 0.848537069

00:33:54.080 --> 00:33:56.180 Do suggest similar cognitive profile to

NOTE Confidence: 0.848537069

00:33:56.243 --> 00:33:58.578 other disorders of excessive sleepiness,

NOTE Confidence: 0.848537069

00:33:58.580 --> 00:34:01.703 and certainly accommodations

NOTE Confidence: 0.848537069

00:34:01.703 --> 00:34:06.908 that target that extra time.

NOTE Confidence: 0.848537069

00:34:06.910 --> 00:34:11.438 Brakes and so on can can be helpful.

NOTE Confidence: 0.950573446428571

00:34:11.440 --> 00:34:13.832 And then of course, there is a counseling

NOTE Confidence: 0.950573446428571

00:34:13.832 --> 00:34:15.618 and support aspect here as well.

NOTE Confidence: 0.950573446428571

00:34:15.620 --> 00:34:17.464 There are safety issues

NOTE Confidence: 0.950573446428571

00:34:17.464 --> 00:34:19.308 in terms of sleepiness.

NOTE Confidence: 0.950573446428571

00:34:19.310 --> 00:34:22.208 While driving, we know people with

NOTE Confidence: 0.950573446428571

00:34:22.208 --> 00:34:24.140 hypersomnia disorders including IH,

NOTE Confidence: 0.950573446428571

00:34:24.140 --> 00:34:26.380 are more likely to have car accidents.

NOTE Confidence: 0.950573446428571

00:34:26.380 --> 00:34:28.276 We know that if you give them Modafinil,

NOTE Confidence: 0.950573446428571

00:34:28.280 --> 00:34:29.936 you improve their on road driving,

NOTE Confidence: 0.950573446428571

00:34:29.940 --> 00:34:32.159 but do not normalize it compared

NOTE Confidence: 0.950573446428571

00:34:32.159 --> 00:34:34.054 to controls and so important

NOTE Confidence: 0.950573446428571

00:34:34.054 --> 00:34:36.300 counseling there and then counseling.

NOTE Confidence: 0.950573446428571

00:34:36.300 --> 00:34:38.316 Of course, about medication side effects.

NOTE Confidence: 0.950573446428571

00:34:38.320 --> 00:34:41.505 I'm a big believer in patient groups.

NOTE Confidence: 0.950573446428571

00:34:41.510 --> 00:34:43.526 I think it's hard to get a diagnosis

NOTE Confidence: 0.950573446428571

00:34:43.526 --> 00:34:45.171 of something you've never heard of

NOTE Confidence: 0.950573446428571

00:34:45.171 --> 00:34:47.086 and don't know anybody else has ever

NOTE Confidence: 0.950573446428571

00:34:47.086 --> 00:34:48.870 had it and it has a terrible name.

NOTE Confidence: 0.950573446428571

00:34:48.870 --> 00:34:50.870 Like idiopathic hypersomnia is like,

NOTE Confidence: 0.950573446428571

00:34:50.870 --> 00:34:53.446 well, we don't know what it is.

NOTE Confidence: 0.950573446428571

00:34:53.450 --> 00:34:55.938 And so I think it can be really

NOTE Confidence: 0.950573446428571

00:34:55.938 --> 00:34:57.284 profoundly meaningful for people

NOTE Confidence: 0.950573446428571

00:34:57.284 --> 00:34:58.929 with this diagnosis to meet

NOTE Confidence: 0.950573446428571

00:34:58.929 --> 00:35:00.860 other people with this diagnosis.

NOTE Confidence: 0.950573446428571

00:35:00.860 --> 00:35:01.928 I do warn people,

NOTE Confidence: 0.950573446428571

00:35:01.928 --> 00:35:02.996 the people who gravitate,

NOTE Confidence: 0.950573446428571

00:35:03.000 --> 00:35:05.359 I think to Facebook groups and so

NOTE Confidence: 0.950573446428571

00:35:05.359 --> 00:35:08.218 on May not be the typical patient.

NOTE Confidence: 0.950573446428571

00:35:08.220 --> 00:35:09.732 I think you tend to see the

NOTE Confidence: 0.950573446428571

00:35:09.732 --> 00:35:10.380 more severe patients,

NOTE Confidence: 0.950573446428571

00:35:10.380 --> 00:35:11.460 and so I think it needs to be taken

NOTE Confidence: 0.950573446428571

00:35:11.460 --> 00:35:12.648 a little bit with a grain of salt.

NOTE Confidence: 0.950573446428571

00:35:12.650 --> 00:35:15.199 But in general I'm a big believer in

NOTE Confidence: 0.950573446428571

00:35:15.199 --> 00:35:17.353 in resources for patients so they

NOTE Confidence: 0.950573446428571

00:35:17.353 --> 00:35:20.527 can get to know other people with the

NOTE Confidence: 0.950573446428571

00:35:20.527 --> 00:35:23.930 disorder and and form pure support that way.

NOTE Confidence: 0.950573446428571

00:35:23.930 --> 00:35:27.906 Uh Jason Ong has done some really nice

NOTE Confidence: 0.950573446428571

00:35:27.906 --> 00:35:31.329 preliminary work on the development of CBTH.

NOTE Confidence: 0.950573446428571

00:35:31.329 --> 00:35:35.280 So unlike CBT I where the idea is you

NOTE Confidence: 0.950573446428571

00:35:35.385 --> 00:35:39.489 can actually fix the insomnia with

NOTE Confidence: 0.950573446428571

00:35:39.489 --> 00:35:43.250 cognitive behavioral therapy for insomnia.

NOTE Confidence: 0.950573446428571

00:35:43.250 --> 00:35:46.010 The idea was CBT H is not that.

NOTE Confidence: 0.950573446428571

00:35:46.010 --> 00:35:48.074 I don't think anyone,

NOTE Confidence: 0.950573446428571

00:35:48.074 --> 00:35:49.106 especially Jason,

NOTE Confidence: 0.950573446428571

00:35:49.110 --> 00:35:52.146 thinks that you will cure hypersomnia,

NOTE Confidence: 0.950573446428571

00:35:52.150 --> 00:35:55.950 narcolepsy, IH whatever with CBT.

NOTE Confidence: 0.950573446428571

00:35:55.950 --> 00:35:58.785 But there's plenty of symptoms

NOTE Confidence: 0.950573446428571

00:35:58.785 --> 00:36:01.620 in the hypersomnia disorders that

NOTE Confidence: 0.950573446428571

00:36:01.715 --> 00:36:04.637 could benefit from a structured CBT

NOTE Confidence: 0.950573446428571

00:36:04.637 --> 00:36:07.480 sort of support and training,

NOTE Confidence: 0.950573446428571

00:36:07.480 --> 00:36:10.153 and so this was a pilot study that they

NOTE Confidence: 0.950573446428571

00:36:10.153 --> 00:36:12.052 did in published across narcolepsy

NOTE Confidence: 0.950573446428571

00:36:12.052 --> 00:36:15.509 type 1/2 and IH who also had at least

NOTE Confidence: 0.950573446428571

00:36:15.509 --> 00:36:17.711 mild depression and did a combination

NOTE Confidence: 0.950573446428571

00:36:17.711 --> 00:36:20.420 of individual or group CBT eight.

NOTE Confidence: 0.950573446428571

00:36:20.420 --> 00:36:22.335 So it was basically designed

NOTE Confidence: 0.950573446428571

00:36:22.335 --> 00:36:23.867 based on stakeholder intervention.

NOTE Confidence: 0.950573446428571

00:36:23.870 --> 00:36:26.208 What was known about CBT for other?

NOTE Confidence: 0.950573446428571

00:36:26.210 --> 00:36:27.234 Chronic diseases,

NOTE Confidence: 0.950573446428571

00:36:27.234 --> 00:36:30.818 and then what is known specifically about.

NOTE Confidence: 0.950573446428571

00:36:30.820 --> 00:36:32.830 These disorders and and although

NOTE Confidence: 0.950573446428571

00:36:32.830 --> 00:36:35.836 it was a small pilot study mostly

NOTE Confidence: 0.950573446428571

00:36:35.836 --> 00:36:37.660 to look at feasibility,

NOTE Confidence: 0.950573446428571

00:36:37.660 --> 00:36:39.835 they did find significant improvement

NOTE Confidence: 0.950573446428571

00:36:39.835 --> 00:36:42.756 in depression severity as well as a

NOTE Confidence: 0.950573446428571

00:36:42.756 --> 00:36:44.806 measure of global self efficacy, right?

NOTE Confidence: 0.950573446428571

00:36:44.806 --> 00:36:46.942 These are chronic diseases that are

NOTE Confidence: 0.950573446428571

00:36:46.942 --> 00:36:49.244 hard to manage and so increasing

NOTE Confidence: 0.950573446428571

00:36:49.244 --> 00:36:51.535 self efficacy is potentially going

NOTE Confidence: 0.950573446428571

00:36:51.535 --> 00:36:53.555 to be really helpful.

NOTE Confidence: 0.950573446428571

00:36:53.560 --> 00:36:54.656 But as I said,

NOTE Confidence: 0.950573446428571

00:36:54.656 --> 00:36:57.379 the mainstay of what we do is medications,

NOTE Confidence: 0.950573446428571

00:36:57.380 --> 00:37:00.166 so these are the new clinical practice

NOTE Confidence: 0.950573446428571

00:37:00.166 --> 00:37:02.762 guidelines from the ASM for the

NOTE Confidence: 0.950573446428571

00:37:02.762 --> 00:37:04.530 central disorders of hypersomnia.

NOTE Confidence: 0.950573446428571

00:37:04.530 --> 00:37:07.386 I'm actually only showing you on this slide.

NOTE Confidence: 0.950573446428571

00:37:07.390 --> 00:37:09.586 Three of the disorders that are

NOTE Confidence: 0.950573446428571

00:37:09.586 --> 00:37:11.050 covered in that guideline.

NOTE Confidence: 0.950573446428571

00:37:11.050 --> 00:37:13.054 We do know that narcolepsy type

NOTE Confidence: 0.950573446428571

00:37:13.054 --> 00:37:14.890 one in our club today.

NOTE Confidence: 0.950573446428571

00:37:14.890 --> 00:37:15.850 Two are different,

NOTE Confidence: 0.950573446428571

00:37:15.850 --> 00:37:17.450 but this guideline has continued

NOTE Confidence: 0.950573446428571

00:37:17.450 --> 00:37:19.142 to lump the narcolepsy together

NOTE Confidence: 0.950573446428571

00:37:19.142 --> 00:37:21.128 because most of the studies lumped

NOTE Confidence: 0.950573446428571

00:37:21.128 --> 00:37:23.116 in narcolepsy together and these

NOTE Confidence: 0.950573446428571

00:37:23.116 --> 00:37:24.716 are evidence based pipelines.

NOTE Confidence: 0.618426005

00:37:24.720 --> 00:37:28.056 Uhm, the ASM gives things strong.

NOTE Confidence: 0.618426005

00:37:28.060 --> 00:37:30.037 Recommendations for conditional

NOTE Confidence: 0.618426005

00:37:30.037 --> 00:37:32.014 recommendations for conditional

NOTE Confidence: 0.618426005

00:37:32.014 --> 00:37:33.991 recommendations against or

NOTE Confidence: 0.618426005

00:37:33.991 --> 00:37:35.651 strong recommendations against

NOTE Confidence: 0.618426005

00:37:35.651 --> 00:37:38.423 depending on the strength of the

NOTE Confidence: 0.618426005

00:37:38.423 --> 00:37:40.944 evidence in the context of patient

NOTE Confidence: 0.618426005

00:37:40.944 --> 00:37:43.230 preferences and values and so on.

NOTE Confidence: 0.618426005

00:37:43.230 --> 00:37:46.884 You can see here for idiopathic hypersomnia,

NOTE Confidence: 0.618426005

00:37:46.890 --> 00:37:49.410 we made one strong for recommendation,

NOTE Confidence: 0.618426005

00:37:49.410 --> 00:37:50.982 which is for Modafinil,

NOTE Confidence: 0.618426005

00:37:50.982 --> 00:37:53.340 and then we make 4 conditional

NOTE Confidence: 0.618426005

00:37:53.416 --> 00:37:55.972 recommendations or methylphenidate sodium

NOTE Confidence: 0.618426005

00:37:55.972 --> 00:37:59.167 oxybate to listen and clarithromycin.

NOTE Confidence: 0.618426005

00:37:59.170 --> 00:38:01.648 So a couple of comments about this.

NOTE Confidence: 0.618426005

00:38:01.650 --> 00:38:03.250 I will not talk further

NOTE Confidence: 0.618426005

00:38:03.250 --> 00:38:03.890 about methylphenidate.

NOTE Confidence: 0.618426005

00:38:03.890 --> 00:38:06.375 This is based on clinical data that's

NOTE Confidence: 0.618426005

00:38:06.375 --> 00:38:08.390 published showing that methylphenidate

NOTE Confidence: 0.618426005

00:38:08.390 --> 00:38:10.650 helps people with idiopathic hypersomnia.

NOTE Confidence: 0.618426005

00:38:10.650 --> 00:38:12.840 There's not a randomized controlled trial.

NOTE Confidence: 0.618426005

00:38:12.840 --> 00:38:15.264 I think we believe it probably does help.

NOTE Confidence: 0.618426005

00:38:15.270 --> 00:38:17.130 It helps for lots of other

NOTE Confidence: 0.618426005

00:38:17.130 --> 00:38:18.060 kinds of sleepiness.

NOTE Confidence: 0.746546604666667

00:38:20.250 --> 00:38:21.870 Patrol assignment there's data out

NOTE Confidence: 0.746546604666667

00:38:21.870 --> 00:38:23.974 of France showing that that Oleson

NOTE Confidence: 0.746546604666667

00:38:23.974 --> 00:38:25.690 helps with idiopathic hypersomnia.

NOTE Confidence: 0.746546604666667

00:38:25.690 --> 00:38:27.160 Again, in a clinical series,

NOTE Confidence: 0.746546604666667

00:38:27.160 --> 00:38:29.130 not a randomized controlled trial.

NOTE Confidence: 0.746546604666667

00:38:29.130 --> 00:38:30.478 Realistically, here in EU.

NOTE Confidence: 0.746546604666667

00:38:30.478 --> 00:38:32.880 S that is really hard to get

NOTE Confidence: 0.746546604666667

00:38:32.880 --> 00:38:34.740 cover for people with high age

NOTE Confidence: 0.746546604666667

00:38:34.740 --> 00:38:36.869 'cause it is really expensive,

NOTE Confidence: 0.746546604666667

00:38:36.870 --> 00:38:38.766 so it does have a conditional

NOTE Confidence: 0.746546604666667

00:38:38.766 --> 00:38:39.398 for recommendation,

NOTE Confidence: 0.746546604666667

00:38:39.400 --> 00:38:40.966 but I don't generally use it.

NOTE Confidence: 0.746546604666667

00:38:40.970 --> 00:38:42.382 In my age patients.

NOTE Confidence: 0.746546604666667

00:38:42.382 --> 00:38:44.500 And we'll talk more about sort

NOTE Confidence: 0.746546604666667

00:38:44.578 --> 00:38:46.698 of for my son in a little bit,

NOTE Confidence: 0.746546604666667

00:38:46.700 --> 00:38:48.320 but I definitely want to talk

NOTE Confidence: 0.746546604666667

00:38:48.320 --> 00:38:49.400 more about sodium oxybate.

NOTE Confidence: 0.746546604666667

00:38:49.400 --> 00:38:52.526 So these guidelines were finished before

NOTE Confidence: 0.746546604666667

00:38:52.526 --> 00:38:55.900 the lower sodium oxybate clinical trial,

NOTE Confidence: 0.746546604666667

00:38:55.900 --> 00:38:57.180 and idiopathic hypersomnia released

NOTE Confidence: 0.746546604666667

00:38:57.180 --> 00:38:59.544 any data so we could not incorporate

NOTE Confidence: 0.746546604666667

00:38:59.544 --> 00:39:01.459 those data into this guideline.

NOTE Confidence: 0.746546604666667

00:39:01.460 --> 00:39:03.470 That's why there's not any comments

NOTE Confidence: 0.746546604666667

00:39:03.470 --> 00:39:05.626 on lower sodium oxybate the sodium

NOTE Confidence: 0.746546604666667

00:39:05.626 --> 00:39:07.876 oxybate data that led to the

NOTE Confidence: 0.746546604666667

00:39:07.876 --> 00:39:08.982 conditional recommendation was

NOTE Confidence: 0.746546604666667

00:39:08.982 --> 00:39:10.734 a clinical series out of France,

NOTE Confidence: 0.746546604666667

00:39:10.740 --> 00:39:13.880 not a clinical trial.

NOTE Confidence: 0.746546604666667

00:39:13.880 --> 00:39:15.870 So.

NOTE Confidence: 0.746546604666667

00:39:15.870 --> 00:39:16.316 Briefly,

NOTE Confidence: 0.746546604666667

00:39:16.316 --> 00:39:19.438 UM Modafinil I think has been for

NOTE Confidence: 0.746546604666667

00:39:19.438 --> 00:39:22.570 a long time and should continue to

NOTE Confidence: 0.746546604666667

00:39:22.570 --> 00:39:26.376 be one of the first line treatments

NOTE Confidence: 0.746546604666667

00:39:26.376 --> 00:39:28.728 for idiopathic hypersomnia.

NOTE Confidence: 0.746546604666667

00:39:28.730 --> 00:39:31.142 It is worth knowing because occasionally

NOTE Confidence: 0.746546604666667

00:39:31.142 --> 00:39:33.203 sways insurance companies that there

NOTE Confidence: 0.746546604666667

00:39:33.203 --> 00:39:35.183 are now two published randomized

NOTE Confidence: 0.746546604666667

00:39:35.183 --> 00:39:36.767 controlled trials of Modafinil.

NOTE Confidence: 0.746546604666667

00:39:36.770 --> 00:39:38.372 They both used a dose of

NOTE Confidence: 0.746546604666667

00:39:38.372 --> 00:39:39.730 200 milligrams once a day,

NOTE Confidence: 0.746546604666667

00:39:39.730 --> 00:39:41.032 which is a lower dose than

NOTE Confidence: 0.746546604666667

00:39:41.032 --> 00:39:42.809 most of my age patients are on.

NOTE Confidence: 0.746546604666667

00:39:42.810 --> 00:39:44.915 I generally need to titrate

NOTE Confidence: 0.746546604666667

00:39:44.915 --> 00:39:46.599 up to 400 milligrams.

NOTE Confidence: 0.746546604666667

00:39:46.600 --> 00:39:47.910 But between the two studies,

NOTE Confidence: 0.746546604666667

00:39:47.910 --> 00:39:49.670 there were about 100 participants,

NOTE Confidence: 0.746546604666667

00:39:49.670 --> 00:39:51.830 so pretty good size in combination,

NOTE Confidence: 0.746546604666667

00:39:51.830 --> 00:39:54.035 almost all of whom met them without

NOTE Confidence: 0.746546604666667

00:39:54.035 --> 00:39:56.023 long flight sleep time criteria from

NOTE Confidence: 0.746546604666667

00:39:56.023 --> 00:39:58.779 the ICS D2 and what you're looking at

NOTE Confidence: 0.746546604666667

00:39:58.779 --> 00:40:01.857 here is just a meta analysis of the

NOTE Confidence: 0.746546604666667

00:40:01.857 --> 00:40:04.350 on treatment Epworth at three weeks.

NOTE Confidence: 0.746546604666667

00:40:04.350 --> 00:40:06.653 A reduction in the word Apple Group

NOTE Confidence: 0.746546604666667

00:40:06.653 --> 00:40:08.977 versus the placebo group of five points.

NOTE Confidence: 0.746546604666667

00:40:08.980 --> 00:40:11.164 So similar to what we would see and

NOTE Confidence: 0.746546604666667

00:40:11.164 --> 00:40:12.869 with Modafinil and other disorders,

NOTE Confidence: 0.746546604666667

00:40:12.870 --> 00:40:15.234 and similarly on the MWT used

NOTE Confidence: 0.746546604666667

00:40:15.234 --> 00:40:16.416 in both studies.

NOTE Confidence: 0.746546604666667

00:40:16.420 --> 00:40:18.430 And improvements in 4.7 minutes and

NOTE Confidence: 0.746546604666667

00:40:18.430 --> 00:40:20.510 the ability to maintain wakefulness.

NOTE Confidence: 0.746546604666667

00:40:20.510 --> 00:40:21.262 So unsurprising,

NOTE Confidence: 0.746546604666667

00:40:21.262 --> 00:40:23.518 I think because I think we

NOTE Confidence: 0.746546604666667

00:40:23.518 --> 00:40:25.140 all know clinically,

NOTE Confidence: 0.746546604666667

00:40:25.140 --> 00:40:26.880 the Modafinil helps plenty of

NOTE Confidence: 0.746546604666667

00:40:26.880 --> 00:40:28.272 people with idiopathic hypersomnia.

NOTE Confidence: 0.746546604666667

00:40:28.280 --> 00:40:30.020 Not all of them, but plenty.

NOTE Confidence: 0.746546604666667

00:40:30.020 --> 00:40:32.692 But now objective randomized

NOTE Confidence: 0.746546604666667

00:40:32.692 --> 00:40:34.696 controlled trial data,

NOTE Confidence: 0.746546604666667

00:40:34.700 --> 00:40:36.764 particularly with most of the sample

NOTE Confidence: 0.746546604666667

00:40:36.764 --> 00:40:40.610 added in this 2021 publication.

NOTE Confidence: 0.746546604666667

00:40:40.610 --> 00:40:42.926 Really, what I wanna talk about

NOTE Confidence: 0.746546604666667

00:40:42.930 --> 00:40:45.250 is lower sodium oxybate,

NOTE Confidence: 0.746546604666667

00:40:45.250 --> 00:40:46.948 so calcium, magnesium,

NOTE Confidence: 0.746546604666667

00:40:46.948 --> 00:40:47.486 potassium,

NOTE Confidence: 0.746546604666667

00:40:47.486 --> 00:40:48.562 sodium, oxybate.

NOTE Confidence: 0.746546604666667

00:40:48.562 --> 00:40:52.184 So recall that sodium oxybate has at

NOTE Confidence: 0.746546604666667

00:40:52.184 --> 00:40:54.704 least if you were on the 4.5 grams,

NOTE Confidence: 0.746546604666667

00:40:54.710 --> 00:40:57.094 twice a night dose,

NOTE Confidence: 0.746546604666667

00:40:57.094 --> 00:40:59.478 almost your daily maximum

NOTE Confidence: 0.746546604666667

00:40:59.478 --> 00:41:02.257 recommended amount of sodium in it.

NOTE Confidence: 0.746546604666667

00:41:02.260 --> 00:41:07.057 And so now there is this mixed salt oxybate,

NOTE Confidence: 0.746546604666667

00:41:07.060 --> 00:41:09.594 often referred to as lower sodium oxybate,

NOTE Confidence: 0.746546604666667

00:41:09.600 --> 00:41:14.520 which is 92% less sodium than sodium oxybate.

NOTE Confidence: 0.746546604666667

00:41:14.520 --> 00:41:17.388 The approval for the treatment of

NOTE Confidence: 0.746546604666667

00:41:17.388 --> 00:41:19.560 narcolepsy for kids older than seven

NOTE Confidence: 0.746546604666667

00:41:19.560 --> 00:41:22.278 and an adult back in July of 2020.

NOTE Confidence: 0.746546604666667

00:41:22.280 --> 00:41:24.260 But the reason we're talking about

NOTE Confidence: 0.746546604666667

00:41:24.260 --> 00:41:27.090 it today is of course last month or

NOTE Confidence: 0.746546604666667

00:41:27.090 --> 00:41:29.120 we talked over now two months ago.

NOTE Confidence: 0.746546604666667

00:41:29.120 --> 00:41:31.394 It got approval for the treatment

NOTE Confidence: 0.746546604666667

00:41:31.394 --> 00:41:32.910 of IH in adults,

NOTE Confidence: 0.746546604666667

00:41:32.910 --> 00:41:35.406 which made it the very first

NOTE Confidence: 0.746546604666667

00:41:35.406 --> 00:41:37.070 medication FDA approved for

NOTE Confidence: 0.746546604666667

00:41:37.149 --> 00:41:38.859 idiopathic hypersomnia,

NOTE Confidence: 0.810538875

00:41:38.860 --> 00:41:40.150 which is a really big deal.

NOTE Confidence: 0.852518689615385

00:41:43.290 --> 00:41:44.762 It is still oxybate,

NOTE Confidence: 0.852518689615385

00:41:44.762 --> 00:41:47.314 which means it is still covered by

NOTE Confidence: 0.852518689615385

00:41:47.314 --> 00:41:49.735 a REMS program by the FDA to try to

NOTE Confidence: 0.852518689615385

00:41:49.808 --> 00:41:52.430 mitigate the risk of this medication.

NOTE Confidence: 0.852518689615385

00:41:52.430 --> 00:41:54.188 It is a schedule three drug.

NOTE Confidence: 0.852518689615385

00:41:54.190 --> 00:41:56.602 It is a one to one dose Ng with

NOTE Confidence: 0.852518689615385

00:41:56.602 --> 00:41:58.675 sodium oxybate because it is

NOTE Confidence: 0.852518689615385

00:41:58.675 --> 00:42:00.403 the same active ingredient.

NOTE Confidence: 0.852518689615385

00:42:00.410 --> 00:42:02.167 I'm gonna dig a little bit into

NOTE Confidence: 0.852518689615385

00:42:02.167 --> 00:42:04.112 the data and support this for

NOTE Confidence: 0.852518689615385

00:42:04.112 --> 00:42:05.620 idiopathic hypersomnia as of

NOTE Confidence: 0.852518689615385

00:42:05.620 --> 00:42:07.610 Friday these weren't published yet.

NOTE Confidence: 0.852518689615385

00:42:07.610 --> 00:42:08.695 I don't think they've been

NOTE Confidence: 0.852518689615385

00:42:08.695 --> 00:42:09.346 published since then,

NOTE Confidence: 0.852518689615385

00:42:09.350 --> 00:42:11.840 but these are data from their

NOTE Confidence: 0.852518689615385

00:42:11.840 --> 00:42:13.045 abstracts from clinicaltrials.gov

NOTE Confidence: 0.852518689615385

00:42:13.045 --> 00:42:14.920 and from the package insert.

NOTE Confidence: 0.67715895

00:42:17.860 --> 00:42:21.836 Be a they did an interesting study design.

NOTE Confidence: 0.67715895

00:42:21.840 --> 00:42:23.994 So further narcolepsy trials where they

NOTE Confidence: 0.67715895

00:42:23.994 --> 00:42:25.860 already knew sodium oxybate worked.

NOTE Confidence: 0.67715895

00:42:25.860 --> 00:42:27.900 They said well, for lower sodium

NOTE Confidence: 0.67715895

00:42:27.900 --> 00:42:29.260 oxybate same active ingredient.

NOTE Confidence: 0.67715895

00:42:29.260 --> 00:42:31.366 Let's do a double blind withdrawal

NOTE Confidence: 0.67715895

00:42:31.366 --> 00:42:33.521 study where you type train people

NOTE Confidence: 0.67715895

00:42:33.521 --> 00:42:35.579 up on the medicine open label.

NOTE Confidence: 0.67715895

00:42:35.580 --> 00:42:37.878 Keep people on their stable dose

NOTE Confidence: 0.67715895

00:42:37.878 --> 00:42:40.255 of the medication open label and

NOTE Confidence: 0.67715895

00:42:40.255 --> 00:42:42.553 then do a double blind withdrawal.

NOTE Confidence: 0.67715895

00:42:42.560 --> 00:42:44.020 Some people stay on medicine,

NOTE Confidence: 0.67715895

00:42:44.020 --> 00:42:47.230 some people go to placebo.

NOTE Confidence: 0.67715895

00:42:47.230 --> 00:42:50.422 And see how much worse the placebo

NOTE Confidence: 0.67715895

00:42:50.422 --> 00:42:52.542 group group guests for narcolepsy,

NOTE Confidence: 0.67715895

00:42:52.542 --> 00:42:54.798 where they already knew oxybate worked.

NOTE Confidence: 0.67715895

00:42:54.800 --> 00:42:56.935 This is a pretty reasonable study design.

NOTE Confidence: 0.67715895

00:42:56.940 --> 00:42:59.922 It keeps people on placebo for the

NOTE Confidence: 0.67715895

00:42:59.922 --> 00:43:01.850 shortest possible amount of time.

NOTE Confidence: 0.67715895

00:43:01.850 --> 00:43:03.090 It is interesting to me.

NOTE Confidence: 0.67715895

00:43:03.090 --> 00:43:05.202 They decided to do the same thing for

NOTE Confidence: 0.67715895

00:43:05.202 --> 00:43:07.519 IH when they didn't have any data

NOTE Confidence: 0.67715895

00:43:07.519 --> 00:43:09.249 showing that oxybate was helpful,

NOTE Confidence: 0.67715895

00:43:09.250 --> 00:43:11.525 but nevertheless that is what they did

NOTE Confidence: 0.67715895

00:43:11.525 --> 00:43:14.028 and so there was a screening period.

NOTE Confidence: 0.67715895

00:43:14.030 --> 00:43:16.364 People could be on other wake

NOTE Confidence: 0.67715895

00:43:16.364 --> 00:43:17.920 promoting medications or die.

NOTE Confidence: 0.67715895

00:43:17.920 --> 00:43:20.160 Rams excuse me sodium oxybate.

NOTE Confidence: 0.67715895

00:43:20.160 --> 00:43:23.334 And then there were changed to lower

NOTE Confidence: 0.67715895

00:43:23.334 --> 00:43:25.218 sodium oxybate or lower sodium oxybate

NOTE Confidence: 0.67715895

00:43:25.218 --> 00:43:27.825 was added if they were on another way

NOTE Confidence: 0.67715895

00:43:27.825 --> 00:43:29.862 promoting medication for a stable dose

NOTE Confidence: 0.67715895

00:43:29.862 --> 00:43:31.747 in period before this randomization.

NOTE Confidence: 0.67715895

00:43:31.750 --> 00:43:35.246 So who were the IH patients up there?

NOTE Confidence: 0.67715895

00:43:35.250 --> 00:43:37.782 154 adults meeting ICS D Two

NOTE Confidence: 0.67715895

00:43:37.782 --> 00:43:39.470 or three IH criteria?

NOTE Confidence: 0.67715895

00:43:39.470 --> 00:43:42.698 Median age of 3971% women.

NOTE Confidence: 0.67715895

00:43:42.698 --> 00:43:45.530 Their efforts had to be at least 11.

NOTE Confidence: 0.67715895

00:43:45.530 --> 00:43:48.410 He's fit well with our clinical

NOTE Confidence: 0.67715895

00:43:48.410 --> 00:43:51.329 picture of who has IH 41% had

NOTE Confidence: 0.67715895

00:43:51.329 --> 00:43:53.327 not ever been treated for IH,

NOTE Confidence: 0.67715895

00:43:53.330 --> 00:43:55.892 but the majority had been treated before

NOTE Confidence: 0.67715895

00:43:55.892 --> 00:43:59.686 in fact and 58% of them stayed on a wake

NOTE Confidence: 0.67715895

00:43:59.686 --> 00:44:01.819 promoting medication during this study.

NOTE Confidence: 0.67715895

00:44:01.820 --> 00:44:04.244 A handful had been on sodium oxybate and

NOTE Confidence: 0.67715895

00:44:04.244 --> 00:44:06.180 were transitions to lower sodium oxybate.

NOTE Confidence: 0.67715895

00:44:06.180 --> 00:44:08.505 They couldn't have other causes

NOTE Confidence: 0.67715895

00:44:08.505 --> 00:44:10.830 of hypersomnia or untreated OSA.

NOTE Confidence: 0.67715895

00:44:10.830 --> 00:44:12.678 They could not have had a major

NOTE Confidence: 0.67715895

00:44:12.678 --> 00:44:14.059 depression episode within the last

NOTE Confidence: 0.67715895

00:44:14.059 --> 00:44:15.673 year or any current suicidal ideations

NOTE Confidence: 0.67715895

00:44:15.673 --> 00:44:17.140 or history of suicide attempt.

NOTE Confidence: 0.67715895

00:44:17.140 --> 00:44:18.460 Couldn't, of course,

NOTE Confidence: 0.67715895

00:44:18.460 --> 00:44:19.780 beyond sedating medications,

NOTE Confidence: 0.67715895

00:44:19.780 --> 00:44:20.218 alcohol,

NOTE Confidence: 0.67715895

00:44:20.218 --> 00:44:22.408 cannabinoids that would be dangerous

NOTE Confidence: 0.67715895

00:44:22.408 --> 00:44:25.024 with lower sodium oxybate couldn't have

NOTE Confidence: 0.67715895

00:44:25.024 --> 00:44:27.430 a history of substance abuse disorder.

NOTE Confidence: 0.67715895

00:44:27.430 --> 00:44:29.803 What they did that was different than

NOTE Confidence: 0.67715895

00:44:29.803 --> 00:44:31.762 the narcolepsy studies was to allow

NOTE Confidence: 0.67715895

00:44:31.762 --> 00:44:33.820 people to either take the twice nightly

NOTE Confidence: 0.67715895

00:44:33.878 --> 00:44:36.308 dosing that we are used to for oxidates or,

NOTE Confidence: 0.67715895

00:44:36.310 --> 00:44:37.561 once nightly dosing,

NOTE Confidence: 0.67715895

00:44:37.561 --> 00:44:39.229 the rationale being that

NOTE Confidence: 0.67715895

00:44:39.229 --> 00:44:41.020 case series from France,

NOTE Confidence: 0.67715895

00:44:41.020 --> 00:44:42.854 then so the people with IH because

NOTE Confidence: 0.67715895

00:44:42.854 --> 00:44:44.699 they're bad at waking up have a

NOTE Confidence: 0.67715895

00:44:44.699 --> 00:44:46.205 really hard time waking up to,

NOTE Confidence: 0.67715895

00:44:46.210 --> 00:44:46.453 say,

NOTE Confidence: 0.67715895

00:44:46.453 --> 00:44:48.397 take a second dose in sodium oxidate after

NOTE Confidence: 0.67715895

00:44:48.397 --> 00:44:50.108 they've only been asleep for four hours.

NOTE Confidence: 0.67715895

00:44:50.110 --> 00:44:52.810 So here they actually let the

NOTE Confidence: 0.67715895

00:44:52.810 --> 00:44:54.610 the treating investigator decide

NOTE Confidence: 0.67715895

00:44:54.684 --> 00:44:56.789 once or twice nightly dosing,

NOTE Confidence: 0.67715895

00:44:56.790 --> 00:44:58.082 and so the total.

NOTE Confidence: 0.67715895

00:44:58.082 --> 00:45:00.020 Nightly dose varied depending on whether

NOTE Confidence: 0.67715895

00:45:00.083 --> 00:45:01.980 they were taking it once or twice.

NOTE Confidence: 0.67715895

00:45:01.980 --> 00:45:04.297 Actually they ended up with most people.

NOTE Confidence: 0.67715895

00:45:04.300 --> 00:45:06.408 3/4 taking two doses.

NOTE Confidence: 0.67715895

00:45:06.408 --> 00:45:08.516 Of lower setting oxybate,

NOTE Confidence: 0.67715895

00:45:08.520 --> 00:45:10.914 so their primary outcome was the

NOTE Confidence: 0.67715895

00:45:10.914 --> 00:45:13.357 Epworth UM and during the time

NOTE Confidence: 0.67715895

00:45:13.357 --> 00:45:15.661 they were open label on oxybate

NOTE Confidence: 0.67715895

00:45:15.661 --> 00:45:17.620 the Epworth were quite low.

NOTE Confidence: 0.67715895

00:45:17.620 --> 00:45:19.699 When they put people from lower sodium

NOTE Confidence: 0.67715895

00:45:19.699 --> 00:45:21.173 oxybate 2 placebo there Equifax

NOTE Confidence: 0.67715895

00:45:21.173 --> 00:45:23.293 quite a lot worse and the people who

NOTE Confidence: 0.8459028508

00:45:23.349 --> 00:45:24.939 stayed on treatment it didn't.

NOTE Confidence: 0.8459028508

00:45:24.940 --> 00:45:28.349 So a seven point difference in the Epworth.

NOTE Confidence: 0.8459028508

00:45:28.349 --> 00:45:30.470 It's not really an apples to apples

NOTE Confidence: 0.8459028508

00:45:30.538 --> 00:45:32.623 comparison with a traditional parallel

NOTE Confidence: 0.8459028508

00:45:32.623 --> 00:45:34.708 group design like the Modafinil

NOTE Confidence: 0.8459028508

00:45:34.769 --> 00:45:36.922 studies I showed you, but certainly.

NOTE Confidence: 0.8459028508

00:45:36.922 --> 00:45:39.177 People taken off of lower

NOTE Confidence: 0.8459028508

00:45:39.177 --> 00:45:41.070 sodium oxybate got worse.

NOTE Confidence: 0.8459028508

00:45:41.070 --> 00:45:43.020 They also looked at the global

NOTE Confidence: 0.8459028508

00:45:43.020 --> 00:45:45.031 impression of change and people felt

NOTE Confidence: 0.8459028508

00:45:45.031 --> 00:45:47.306 worse when they came off the medication

NOTE Confidence: 0.8459028508

00:45:47.306 --> 00:45:49.229 and then the idiopathic paper.

NOTE Confidence: 0.8459028508

00:45:49.230 --> 00:45:52.130 Samia severity scales force

NOTE Confidence: 0.8459028508

00:45:52.130 --> 00:45:54.988 again worsening when people

NOTE Confidence: 0.8459028508

00:45:54.988 --> 00:45:58.508 were were randomized to SIBO.

NOTE Confidence: 0.8459028508

00:45:58.510 --> 00:46:01.471 11% of people withdrew due to adverse

NOTE Confidence: 0.8459028508

00:46:01.471 --> 00:46:04.590 events at some point and another 154

NOTE Confidence: 0.8459028508

00:46:04.590 --> 00:46:07.302 who started the study only about 110.

NOTE Confidence: 0.8459028508

00:46:07.302 --> 00:46:09.030 Actually ended up randomized,

NOTE Confidence: 0.8459028508

00:46:09.030 --> 00:46:11.030 not necessarily because of AES,

NOTE Confidence: 0.8459028508

00:46:11.030 --> 00:46:13.166 but there was a decent amount of attrition.

NOTE Confidence: 0.863913511666667

00:46:16.180 --> 00:46:18.742 The other people who withdrew anxiety

NOTE Confidence: 0.863913511666667

00:46:18.742 --> 00:46:21.590 was most common reason for withdrawal,

NOTE Confidence: 0.863913511666667

00:46:21.590 --> 00:46:23.662 but you can see a handful of reasons

NOTE Confidence: 0.863913511666667

00:46:23.662 --> 00:46:25.364 why people with through and then

NOTE Confidence: 0.863913511666667

00:46:25.364 --> 00:46:27.773 during the open label dose in the most

NOTE Confidence: 0.863913511666667

00:46:27.773 --> 00:46:29.428 common adverse events for nausea,

NOTE Confidence: 0.863913511666667

00:46:29.430 --> 00:46:30.822 headache, dizziness,

NOTE Confidence: 0.863913511666667

00:46:30.822 --> 00:46:33.606 insomnia and again anxiety.

NOTE Confidence: 0.863913511666667

00:46:33.610 --> 00:46:35.745 And so I think not surprising given

NOTE Confidence: 0.863913511666667

00:46:35.745 --> 00:46:37.831 what we know about sodium oxybate

NOTE Confidence: 0.863913511666667

00:46:37.831 --> 00:46:40.033 and how it works in narcolepsy,

NOTE Confidence: 0.863913511666667

00:46:40.040 --> 00:46:41.904 but know that that is now an option.

NOTE Confidence: 0.863913511666667

00:46:41.910 --> 00:46:43.710 Lower sodium oxybate for idiopathic

NOTE Confidence: 0.863913511666667

00:46:43.710 --> 00:46:44.790 hypersomnia I think.

NOTE Confidence: 0.863913511666667

00:46:44.790 --> 00:46:46.393 We still have work to do in

NOTE Confidence: 0.863913511666667

00:46:46.393 --> 00:46:48.074 figuring out where in the treatment

NOTE Confidence: 0.863913511666667

00:46:48.074 --> 00:46:49.326 algorithm that should fall,

NOTE Confidence: 0.863913511666667

00:46:49.330 --> 00:46:51.530 especially given the exclusion

NOTE Confidence: 0.863913511666667

00:46:51.530 --> 00:46:54.280 criteria for the clinical trial.

NOTE Confidence: 0.863913511666667

00:46:54.280 --> 00:46:55.726 A couple of other points about

NOTE Confidence: 0.863913511666667

00:46:55.726 --> 00:46:56.690 the treatment of idiopathic

NOTE Confidence: 0.863913511666667

00:46:56.732 --> 00:46:58.268 hypersomnia for some people to sleep,

NOTE Confidence: 0.863913511666667

00:46:58.270 --> 00:47:00.048 inertia is really a problem and so

NOTE Confidence: 0.863913511666667

00:47:00.048 --> 00:47:02.080 needs to be addressed separately in

NOTE Confidence: 0.863913511666667

00:47:02.080 --> 00:47:04.510 addition to the wake promoting medication,

NOTE Confidence: 0.863913511666667

00:47:04.510 --> 00:47:06.120 lower sodium oxybate seems like

NOTE Confidence: 0.863913511666667

00:47:06.120 --> 00:47:08.050 a good idea for that now.

NOTE Confidence: 0.863913511666667

00:47:08.050 --> 00:47:09.610 If people otherwise qualify and

NOTE Confidence: 0.863913511666667

00:47:09.610 --> 00:47:10.858 it's otherwise appropriate to

NOTE Confidence: 0.863913511666667

00:47:10.858 --> 00:47:12.608 put them on lower sodium oxybate,

NOTE Confidence: 0.863913511666667

00:47:12.610 --> 00:47:14.854 it does seem to have helped

NOTE Confidence: 0.863913511666667

00:47:14.854 --> 00:47:17.000 with that piece of things.

NOTE Confidence: 0.863913511666667

00:47:17.000 --> 00:47:21.840 What many people do is set two alarms,

NOTE Confidence: 0.863913511666667

00:47:21.840 --> 00:47:23.248 one for when they need to wake up,

NOTE Confidence: 0.863913511666667

00:47:23.250 --> 00:47:25.100 and one an hour earlier.

NOTE Confidence: 0.863913511666667

00:47:25.100 --> 00:47:27.436 Wake up just enough to swallow their wake

NOTE Confidence: 0.863913511666667

00:47:27.436 --> 00:47:29.019 promoting medication angle back to sleep,

NOTE Confidence: 0.863913511666667

00:47:29.020 --> 00:47:30.060 and then when the second

NOTE Confidence: 0.863913511666667

00:47:30.060 --> 00:47:31.420 alarm goes off an hour later,

NOTE Confidence: 0.863913511666667

00:47:31.420 --> 00:47:33.412 they actually have a level of

NOTE Confidence: 0.863913511666667

00:47:33.412 --> 00:47:35.075 medication in their system that

NOTE Confidence: 0.863913511666667

00:47:35.075 --> 00:47:37.235 makes it easier for them to wake up.

NOTE Confidence: 0.863913511666667

00:47:37.240 --> 00:47:37.586 Sometimes.

NOTE Confidence: 0.863913511666667

00:47:37.586 --> 00:47:40.354 If they really can't even wake up enough

NOTE Confidence: 0.863913511666667

00:47:40.354 --> 00:47:42.818 to take medication an hour earlier,

NOTE Confidence: 0.863913511666667

00:47:42.820 --> 00:47:44.540 we those things at bedtime.

NOTE Confidence: 0.863913511666667

00:47:44.540 --> 00:47:47.760 There's a nice key series Carlos Shank

NOTE Confidence: 0.863913511666667

00:47:47.760 --> 00:47:51.489 looking at using boubyan bupropion for that.

NOTE Confidence: 0.863913511666667

00:47:51.490 --> 00:47:54.311 Who knew there is a delayed release

NOTE Confidence: 0.863913511666667

00:47:54.311 --> 00:47:55.520 methylphenidate at bedtime?

NOTE Confidence: 0.863913511666667

00:47:55.520 --> 00:47:57.383 480 HD that when I can get up for

NOTE Confidence: 0.863913511666667

00:47:57.383 --> 00:47:59.457 my age patients II quite like and

NOTE Confidence: 0.863913511666667

00:47:59.457 --> 00:48:01.421 sometimes we just use Lotus wake

NOTE Confidence: 0.863913511666667

00:48:01.421 --> 00:48:03.533 promoting medications for the people in

NOTE Confidence: 0.863913511666667

00:48:03.533 --> 00:48:05.296 whom there is a circadian component.

NOTE Confidence: 0.863913511666667

00:48:05.296 --> 00:48:07.760 There seems to be a phase delay component.

NOTE Confidence: 0.863913511666667

00:48:07.760 --> 00:48:10.208 Melatonin light ways to shift the

NOTE Confidence: 0.863913511666667

00:48:10.208 --> 00:48:12.530 phase earlier may be helpful.

NOTE Confidence: 0.863913511666667

00:48:12.530 --> 00:48:14.470 And then in treatment refractory

NOTE Confidence: 0.863913511666667

00:48:14.470 --> 00:48:16.022 cases reassess the diagnosis.

NOTE Confidence: 0.863913511666667

00:48:16.030 --> 00:48:18.268 Make sure it's right combination therapy.

NOTE Confidence: 0.863913511666667

00:48:18.270 --> 00:48:20.069 And then here's what I'm going to

NOTE Confidence: 0.863913511666667

00:48:20.069 --> 00:48:21.416 talk very briefly about service

NOTE Confidence: 0.863913511666667

00:48:21.416 --> 00:48:23.372 for maintenance and as an L we did

NOTE Confidence: 0.863913511666667

00:48:23.372 --> 00:48:24.980 a study of floor three mice in a

NOTE Confidence: 0.863913511666667

00:48:25.033 --> 00:48:26.888 couple of phone number of years ago.

NOTE Confidence: 0.863913511666667

00:48:26.890 --> 00:48:29.067 Now it was a twenty person just

NOTE Confidence: 0.863913511666667

00:48:29.067 --> 00:48:30.430 pilot randomized controlled trials.

NOTE Confidence: 0.863913511666667

00:48:30.430 --> 00:48:31.062 They crossover.

NOTE Confidence: 0.863913511666667

00:48:31.062 --> 00:48:32.958 We did not see an improvement

NOTE Confidence: 0.863913511666667

00:48:32.958 --> 00:48:33.980 in reaction times,

NOTE Confidence: 0.863913511666667

00:48:33.980 --> 00:48:36.524 but we did see significant improvements

NOTE Confidence: 0.863913511666667

00:48:36.524 --> 00:48:38.640 in our subjective self reported

NOTE Confidence: 0.863913511666667

00:48:38.640 --> 00:48:41.432 outcomes and so we use it when people

NOTE Confidence: 0.863913511666667

00:48:41.432 --> 00:48:43.557 have failed many other things.

NOTE Confidence: 0.863913511666667

00:48:43.560 --> 00:48:45.000 We at least try it.

NOTE Confidence: 0.863913511666667

00:48:45.000 --> 00:48:47.219 It is very important to know this

NOTE Confidence: 0.863913511666667

00:48:47.219 --> 00:48:48.659 safety communication from the FDA,

NOTE Confidence: 0.863913511666667

00:48:48.660 --> 00:48:49.676 which is that clarifies,

NOTE Confidence: 0.863913511666667

00:48:49.676 --> 00:48:50.946 may increase mortality in people

NOTE Confidence: 0.863913511666667

00:48:50.946 --> 00:48:51.819 with heart disease.

NOTE Confidence: 0.863913511666667

00:48:51.820 --> 00:48:53.780 This comes from the cleric or study,

NOTE Confidence: 0.863913511666667

00:48:53.780 --> 00:48:55.240 which is a very large,

NOTE Confidence: 0.863913511666667

00:48:55.240 --> 00:48:55.996 randomized controlled trial

NOTE Confidence: 0.863913511666667

00:48:55.996 --> 00:48:57.256 that thought it would show.

NOTE Confidence: 0.863913511666667

00:48:57.260 --> 00:48:58.855 Clarithromycin helped people with MI

NOTE Confidence: 0.863913511666667

00:48:58.855 --> 00:49:01.560 or angina and in fact found the opposite,

NOTE Confidence: 0.863913511666667

00:49:01.560 --> 00:49:03.912 which that is that it increased

NOTE Confidence: 0.863913511666667

00:49:03.912 --> 00:49:05.480 mortality in people with

NOTE Confidence: 0.84887176

00:49:05.550 --> 00:49:07.368 a history of MI or angina.

NOTE Confidence: 0.84887176

00:49:07.370 --> 00:49:09.230 In their post hoc analysis,

NOTE Confidence: 0.84887176

00:49:09.230 --> 00:49:11.732 this was only people who are not on saturns,

NOTE Confidence: 0.84887176

00:49:11.740 --> 00:49:14.036 but the only randomized

NOTE Confidence: 0.84887176

00:49:14.036 --> 00:49:15.758 component was clarithromycin.

NOTE Confidence: 0.84887176

00:49:15.760 --> 00:49:17.641 So now I know it was not covered in

NOTE Confidence: 0.84887176

00:49:17.641 --> 00:49:19.410 the clinical practice guideline,

NOTE Confidence: 0.84887176

00:49:19.410 --> 00:49:20.498 'cause there wasn't enough

NOTE Confidence: 0.84887176

00:49:20.498 --> 00:49:21.858 data to make a recommendation,

NOTE Confidence: 0.84887176

00:49:21.860 --> 00:49:24.857 but we do sometimes use a flumazenil as well.

NOTE Confidence: 0.84887176

00:49:24.860 --> 00:49:27.360 It has to be compounded,

NOTE Confidence: 0.84887176

00:49:27.360 --> 00:49:29.194 it cannot be taken orally because of

NOTE Confidence: 0.84887176

00:49:29.194 --> 00:49:31.220 a very large first pass metabolism.

NOTE Confidence: 0.84887176

00:49:31.220 --> 00:49:34.232 So we compound it into either a

NOTE Confidence: 0.84887176

00:49:34.232 --> 00:49:36.087 transdermal cream at that goes

NOTE Confidence: 0.84887176

00:49:36.087 --> 00:49:38.540 on the venous plexus right here,

NOTE Confidence: 0.84887176

00:49:38.540 --> 00:49:40.724 or these little lozenges that go

NOTE Confidence: 0.84887176

00:49:40.724 --> 00:49:43.160 under the tongue to be dissolved.

NOTE Confidence: 0.84887176

00:49:43.160 --> 00:49:45.904 We just looked at our clinical data.

NOTE Confidence: 0.84887176

00:49:45.910 --> 00:49:48.600 In in our first 153 people on film as well,

NOTE Confidence: 0.84887176

00:49:48.600 --> 00:49:49.976 about 60% say yes.

NOTE Confidence: 0.84887176

00:49:49.976 --> 00:49:51.696 This helps with my sleepiness.

NOTE Confidence: 0.84887176

00:49:51.700 --> 00:49:53.836 Only about 40% of people stay

NOTE Confidence: 0.84887176

00:49:53.836 --> 00:49:57.009 on it for a variety of reasons.

NOTE Confidence: 0.84887176

00:49:57.010 --> 00:49:59.626 We do Council people that in

NOTE Confidence: 0.84887176

00:49:59.626 --> 00:50:01.222 that first 153 people,

NOTE Confidence: 0.84887176

00:50:01.222 --> 00:50:03.749 two people had a stroke equivalent to

NOTE Confidence: 0.84887176

00:50:03.749 --> 00:50:06.705 180 and one of radio graphic vasculopathy

NOTE Confidence: 0.84887176

00:50:06.710 --> 00:50:08.425 both had pre-existing risk factors

NOTE Confidence: 0.84887176

00:50:08.425 --> 00:50:10.480 that potentially there is a risk.

NOTE Confidence: 0.84887176

00:50:10.480 --> 00:50:10.965 There.

NOTE Confidence: 0.84887176

00:50:10.965 --> 00:50:13.390 More commonly dizziness and anxiety,

NOTE Confidence: 0.84887176

00:50:13.390 --> 00:50:15.298 or what we saw.

NOTE Confidence: 0.84887176

00:50:15.300 --> 00:50:15.780 Finally,

NOTE Confidence: 0.84887176

00:50:15.780 --> 00:50:18.039 I think when we now we start to have

NOTE Confidence: 0.84887176

00:50:18.039 --> 00:50:20.258 more treatment options for patients,

NOTE Confidence: 0.84887176

00:50:20.260 --> 00:50:21.940 we get to start thinking about

NOTE Confidence: 0.84887176

00:50:21.940 --> 00:50:23.560 which treatment for which patients.

NOTE Confidence: 0.84887176

00:50:23.560 --> 00:50:25.426 So what are the key symptoms

NOTE Confidence: 0.84887176

00:50:25.426 --> 00:50:26.048 beyond sleepiness?

NOTE Confidence: 0.84887176

00:50:26.050 --> 00:50:27.298 We need to manage?

NOTE Confidence: 0.84887176

00:50:27.298 --> 00:50:28.858 What are the important comorbidities

NOTE Confidence: 0.84887176

00:50:28.858 --> 00:50:30.661 that might lead you away from

NOTE Confidence: 0.84887176

00:50:30.661 --> 00:50:32.091 a treatment like lower sodium,

NOTE Confidence: 0.84887176

00:50:32.100 --> 00:50:34.876 oxybate or substance abuse

NOTE Confidence: 0.84887176

00:50:34.876 --> 00:50:36.958 or cardiac comorbidities?

NOTE Confidence: 0.84887176

00:50:36.960 --> 00:50:38.664 And then of course for people

NOTE Confidence: 0.84887176

00:50:38.664 --> 00:50:39.516 of childbearing potential,

NOTE Confidence: 0.84887176

00:50:39.520 --> 00:50:42.022 what are their plans for childbearing

NOTE Confidence: 0.84887176

00:50:42.022 --> 00:50:44.880 and not just Modafinil and armodafinil,

NOTE Confidence: 0.84887176

00:50:44.880 --> 00:50:46.332 but control is on?

NOTE Confidence: 0.84887176

00:50:46.332 --> 00:50:48.147 Now two interferes with hormonal

NOTE Confidence: 0.84887176

00:50:48.147 --> 00:50:50.398 birth control to decrease its

NOTE Confidence: 0.84887176

00:50:50.398 --> 00:50:52.214 efficacy at preventing pregnancy.

NOTE Confidence: 0.84887176

00:50:52.220 --> 00:50:53.780 Important to use a different

NOTE Confidence: 0.84887176

00:50:53.780 --> 00:50:55.028 form of birth control.

NOTE Confidence: 0.84887176

00:50:55.030 --> 00:50:56.750 Comorbid mood disorders are tough.

NOTE Confidence: 0.84887176

00:50:56.750 --> 00:50:58.985 I don't think idiopathic hypersomnia

NOTE Confidence: 0.84887176

00:50:58.985 --> 00:51:01.220 is protective against those up,

NOTE Confidence: 0.84887176

00:51:01.220 --> 00:51:03.506 but there are cautions for many

NOTE Confidence: 0.84887176

00:51:03.506 --> 00:51:05.993 mood disorders with with all of

NOTE Confidence: 0.84887176

00:51:05.993 --> 00:51:08.208 these treatments and then comorbid

NOTE Confidence: 0.84887176

00:51:08.208 --> 00:51:10.044 medical disorders often will

NOTE Confidence: 0.84887176

00:51:10.044 --> 00:51:11.788 guide our treatment option,

NOTE Confidence: 0.84887176

00:51:11.790 --> 00:51:14.175 particularly with cardiac

NOTE Confidence: 0.84887176

00:51:14.175 --> 00:51:16.560 related comorbidities limiting.

NOTE Confidence: 0.84887176

00:51:16.560 --> 00:51:19.050 Some of our instead of being

NOTE Confidence: 0.84887176

00:51:19.050 --> 00:51:20.422 uses and and so on.

NOTE Confidence: 0.84887176

00:51:20.422 --> 00:51:22.240 And with that I thank you all

NOTE Confidence: 0.84887176

00:51:22.240 --> 00:51:23.875 very much for your attention.

NOTE Confidence: 0.84887176

00:51:23.880 --> 00:51:24.264 We do,

NOTE Confidence: 0.84887176

00:51:24.264 --> 00:51:25.800 I think have a few minutes for questions.

NOTE Confidence: 0.84887176

00:51:25.800 --> 00:51:29.265 I would love to answer any questions.

NOTE Confidence: 0.84887176

00:51:29.270 --> 00:51:29.510 Well,

NOTE Confidence: 0.962356775714286

00:51:29.520 --> 00:51:31.900 thank you so much. That was fabulous.

NOTE Confidence: 0.962356775714286

00:51:31.900 --> 00:51:32.892 Fabulous Overview,

NOTE Confidence: 0.962356775714286

00:51:32.892 --> 00:51:34.380 really concentrating on.

NOTE Confidence: 0.962356775714286

00:51:34.380 --> 00:51:36.158 I think all of our clinical experience,

NOTE Confidence: 0.962356775714286

00:51:36.160 --> 00:51:37.686 how difficult it is to really make

NOTE Confidence: 0.962356775714286

00:51:37.686 --> 00:51:39.059 a diagnosis in these patients.

NOTE Confidence: 0.962356775714286

00:51:39.060 --> 00:51:40.815 Be confident in the diagnosis

NOTE Confidence: 0.962356775714286

00:51:40.815 --> 00:51:42.960 and then of course treat them.

NOTE Confidence: 0.962356775714286

00:51:42.960 --> 00:51:45.235 And I'm gonna ask people to either

NOTE Confidence: 0.962356775714286

00:51:45.235 --> 00:51:46.999 put their questions in the chat.

NOTE Confidence: 0.962356775714286

00:51:47.000 --> 00:51:49.416 I'll be happy to read them or unmute.

NOTE Confidence: 0.962356775714286

00:51:49.420 --> 00:51:51.740 But one question I had about the oxidates.

NOTE Confidence: 0.962356775714286

00:51:51.740 --> 00:51:52.640 You know what?

NOTE Confidence: 0.962356775714286

00:51:52.640 --> 00:51:54.440 And I know we weren't really

NOTE Confidence: 0.962356775714286

00:51:54.440 --> 00:51:56.100 talking about pathophysiology,

NOTE Confidence: 0.962356775714286

00:51:56.100 --> 00:51:57.546 but what do you think the mechanism

NOTE Confidence: 0.962356775714286

00:51:57.546 --> 00:51:59.490 of action might be?

NOTE Confidence: 0.962356775714286

00:51:59.490 --> 00:52:01.400 In idiopathic hypersomnia, you know,

NOTE Confidence: 0.962356775714286

00:52:01.400 --> 00:52:03.206 in narcolepsy you know we understand

NOTE Confidence: 0.962356775714286

00:52:03.206 --> 00:52:04.697 there's these patients have fragmented

NOTE Confidence: 0.962356775714286

00:52:04.697 --> 00:52:06.812 sleep and a lot of you know sleep state

NOTE Confidence: 0.962356775714286

00:52:06.864 --> 00:52:08.886 dysregulation and it's sort of intuitively.

NOTE Confidence: 0.962356775714286

00:52:08.890 --> 00:52:10.150 Oh, we consolidate their sleep.

NOTE Confidence: 0.962356775714286

00:52:10.150 --> 00:52:11.974 They're better, but these people have

NOTE Confidence: 0.962356775714286

00:52:11.974 --> 00:52:13.810 long sleeve with high efficiency.

NOTE Confidence: 0.962356775714286

00:52:13.810 --> 00:52:14.228 Why?

NOTE Confidence: 0.962356775714286

00:52:14.228 --> 00:52:16.318 Why should this work right

NOTE Confidence: 0.877030912631579

00:52:16.350 --> 00:52:17.838 right? No, I agree.

NOTE Confidence: 0.877030912631579

00:52:17.838 --> 00:52:20.475 And actually mean before that case series

NOTE Confidence: 0.877030912631579

00:52:20.475 --> 00:52:23.163 from France came out a few years ago.

NOTE Confidence: 0.877030912631579

00:52:23.170 --> 00:52:25.172 I didn't ever use oxidative my age

NOTE Confidence: 0.877030912631579

00:52:25.172 --> 00:52:26.709 patients for exactly that reason.

NOTE Confidence: 0.877030912631579

00:52:26.710 --> 00:52:28.838 It didn't make sense to me, right?

NOTE Confidence: 0.877030912631579

00:52:28.838 --> 00:52:31.274 I I think there's a few possibilities.

NOTE Confidence: 0.877030912631579

00:52:31.280 --> 00:52:33.920 One is that there may be something wrong

NOTE Confidence: 0.877030912631579

00:52:33.920 --> 00:52:36.860 with the sleep that people with IH get that

NOTE Confidence: 0.877030912631579

00:52:36.860 --> 00:52:39.697 we don't see with our traditional tools.

NOTE Confidence: 0.877030912631579

00:52:39.700 --> 00:52:41.617 I like e.g as much as the next person,

NOTE Confidence: 0.877030912631579

00:52:41.620 --> 00:52:43.030 but you're still measuring the scalp

NOTE Confidence: 0.877030912631579

00:52:43.030 --> 00:52:44.710 and trying to get it the thalamus.

NOTE Confidence: 0.877030912631579

00:52:44.710 --> 00:52:45.391 There's a lot,

NOTE Confidence: 0.877030912631579

00:52:45.391 --> 00:52:46.753 you know that happens in there,

NOTE Confidence: 0.877030912631579

00:52:46.760 --> 00:52:48.706 so it it may be that oxybate

NOTE Confidence: 0.877030912631579

00:52:48.706 --> 00:52:50.228 is fixing something with the

NOTE Confidence: 0.877030912631579

00:52:50.228 --> 00:52:52.100 nocturnal sleep that we can't see.

NOTE Confidence: 0.877030912631579

00:52:52.100 --> 00:52:54.298 Maybe people need a lot of sleep.

NOTE Confidence: 0.877030912631579

00:52:54.300 --> 00:52:55.824 Because there's something

NOTE Confidence: 0.877030912631579

00:52:55.824 --> 00:52:57.348 missing that's possible.

NOTE Confidence: 0.877030912631579

00:52:57.350 --> 00:52:59.006 It's also possible that some of

NOTE Confidence: 0.877030912631579

00:52:59.006 --> 00:53:00.520 the effects of oxybate or not.

NOTE Confidence: 0.877030912631579

00:53:00.520 --> 00:53:02.140 It's not just that it changes

NOTE Confidence: 0.877030912631579

00:53:02.140 --> 00:53:04.110 nighttime sleep and said it suppresses

NOTE Confidence: 0.877030912631579

00:53:04.110 --> 00:53:05.370 dopamine and norepinephrine,

NOTE Confidence: 0.877030912631579

00:53:05.370 --> 00:53:07.647 and so you get this rebound in the morning,

NOTE Confidence: 0.877030912631579

00:53:07.650 --> 00:53:09.096 and so it might actually have

NOTE Confidence: 0.877030912631579

00:53:09.096 --> 00:53:10.770 some of its mechanism through the

NOTE Confidence: 0.877030912631579

00:53:10.770 --> 00:53:12.405 traditional ways that we think

NOTE Confidence: 0.877030912631579

00:53:12.405 --> 00:53:13.910 Modafinil and amphetamines are right.

NOTE Confidence: 0.877030912631579

00:53:13.910 --> 00:53:16.638 Promoting through increasing dopaminergic

NOTE Confidence: 0.877030912631579

00:53:16.638 --> 00:53:18.684 and noradrenergic neurotransmission.

NOTE Confidence: 0.877030912631579

00:53:18.690 --> 00:53:19.980 So I don't think we know.

NOTE Confidence: 0.847294096

00:53:21.370 --> 00:53:23.730 Great thank you. Alright,

NOTE Confidence: 0.847294096

00:53:23.730 --> 00:53:25.830 anybody questions from the audience.

NOTE Confidence: 0.847294096

00:53:25.830 --> 00:53:27.838 I want to give you a chance, I see.

NOTE Confidence: 0.847294096

00:53:27.838 --> 00:53:30.480 I see a few faces. Who undone I Brian?

NOTE Confidence: 0.847294096

00:53:30.480 --> 00:53:32.929 I didn't know if you had a question,

NOTE Confidence: 0.847294096

00:53:32.930 --> 00:53:35.040 you may be able to unmute yourself if you do.

NOTE Confidence: 0.847294096

00:53:35.040 --> 00:53:38.220 If not, just feel free to put it in the chat.

NOTE Confidence: 0.896239649047619

00:53:41.900 --> 00:53:44.028 I guess while we're waiting for people

NOTE Confidence: 0.896239649047619

00:53:44.028 --> 00:53:46.488 to question it so it sounded to me

NOTE Confidence: 0.896239649047619

00:53:46.488 --> 00:53:48.210 like your approach for diagnosis is,

NOTE Confidence: 0.896239649047619

00:53:48.210 --> 00:53:50.714 you still rely on the PSG with MSLT,

NOTE Confidence: 0.896239649047619

00:53:50.720 --> 00:53:53.520 but everybody gets the seven

NOTE Confidence: 0.896239649047619

00:53:53.520 --> 00:53:55.760 days of Actigraphy beforehand.

NOTE Confidence: 0.896239649047619

00:53:55.760 --> 00:53:57.740 Yeah, and are you using the actor?

NOTE Confidence: 0.896239649047619

00:53:57.740 --> 00:53:59.987 Watch what? What do you use we

NOTE Confidence: 0.733905978

00:54:00.000 --> 00:54:01.250 doing is the actor watch

NOTE Confidence: 0.89976562625

00:54:02.080 --> 00:54:03.030 and which setting do you

NOTE Confidence: 0.89976562625

00:54:03.030 --> 00:54:04.128 keep it on, 'cause you may?

NOTE Confidence: 0.79229656

00:54:05.780 --> 00:54:08.244 We haven't even just like Jesse's paper.

NOTE Confidence: 0.79229656

00:54:08.250 --> 00:54:10.338 We did not. We have not changed that.

NOTE Confidence: 0.79229656

00:54:10.340 --> 00:54:12.972 We still stay on the on the

NOTE Confidence: 0.79229656

00:54:12.972 --> 00:54:16.226 default settings up the UM.

NOTE Confidence: 0.79229656

00:54:16.226 --> 00:54:19.282 You know, I think the problem with actigraphy

NOTE Confidence: 0.79229656

00:54:19.282 --> 00:54:21.088 is that really to make the diagnosis,

NOTE Confidence: 0.79229656

00:54:21.090 --> 00:54:23.435 people need to be able to sleep

NOTE Confidence: 0.79229656

00:54:23.435 --> 00:54:25.918 adlib and it is really hard to

NOTE Confidence: 0.79229656

00:54:25.918 --> 00:54:28.406 sleep 11 hours every night and still

NOTE Confidence: 0.79229656

00:54:28.406 --> 00:54:31.533 have a job and so many people with

NOTE Confidence: 0.79229656

00:54:31.533 --> 00:54:33.957 IH or curtailing or sleep time.

NOTE Confidence: 0.79229656

00:54:33.960 --> 00:54:35.056 Nine hours, you know,

NOTE Confidence: 0.79229656

00:54:35.056 --> 00:54:36.700 we're just still plenty of sleep,

NOTE Confidence: 0.79229656

00:54:36.700 --> 00:54:39.924 but you may not catch it on actigraphy.

NOTE Confidence: 0.79229656

00:54:39.930 --> 00:54:41.914 It looks like we're starting to see any

NOTE Confidence: 0.79229656

00:54:41.914 --> 00:54:44.233 change in insurance coverage for any of

NOTE Confidence: 0.79229656

00:54:44.233 --> 00:54:46.003 the medicine for idiopathic hypersomnia.

NOTE Confidence: 0.79229656

00:54:46.010 --> 00:54:50.530 Hi Karen, I'm not yet it just happened,

NOTE Confidence: 0.79229656

00:54:50.530 --> 00:54:52.005 but absolutely in every appeal

NOTE Confidence: 0.79229656

00:54:52.005 --> 00:54:53.185 letter I right now,

NOTE Confidence: 0.79229656

00:54:53.190 --> 00:54:54.846 and medicines are denied for IH.

NOTE Confidence: 0.79229656

00:54:54.850 --> 00:54:57.562 I say the only FDA approved medication with

NOTE Confidence: 0.79229656

00:54:57.562 --> 00:55:00.025 indication is the way it is very expensive.

NOTE Confidence: 0.79229656

00:55:00.030 --> 00:55:02.910 This is a cheaper alternative.

NOTE Confidence: 0.79229656

00:55:02.910 --> 00:55:04.510 Trusted insurance companies will

NOTE Confidence: 0.79229656

00:55:04.510 --> 00:55:06.510 act in their self interest.

NOTE Confidence: 0.79229656

00:55:06.510 --> 00:55:09.132 Uh, I'm hoping that'll be that'll

NOTE Confidence: 0.79229656

00:55:09.132 --> 00:55:11.260 cause pressure and moved out

NOTE Confidence: 0.79229656

00:55:11.260 --> 00:55:13.066 and it will be paid for.

NOTE Confidence: 0.79229656

00:55:13.070 --> 00:55:15.490 Brian, hi, Brian says, uh,

NOTE Confidence: 0.79229656

00:55:15.490 --> 00:55:17.912 do you think the sleep of my

NOTE Confidence: 0.79229656

00:55:17.912 --> 00:55:19.443 age is qualitative differently

NOTE Confidence: 0.79229656

00:55:19.443 --> 00:55:21.909 and can capture it with EG.

NOTE Confidence: 0.79229656

00:55:21.910 --> 00:55:22.762 You know I,

NOTE Confidence: 0.79229656

00:55:22.762 --> 00:55:24.182 I think our traditional measures

NOTE Confidence: 0.79229656

00:55:24.182 --> 00:55:25.790 are not capturing it well,

NOTE Confidence: 0.79229656

00:55:25.790 --> 00:55:29.374 but I think that some of the data

NOTE Confidence: 0.79229656

00:55:29.374 --> 00:55:32.048 that's coming out now looking

NOTE Confidence: 0.79229656

00:55:32.048 --> 00:55:34.848 at either spectral analysis or.

NOTE Confidence: 0.79229656

00:55:34.850 --> 00:55:36.510 How often people are shifting

NOTE Confidence: 0.79229656

00:55:36.510 --> 00:55:38.170 between states may capture some

NOTE Confidence: 0.79229656

00:55:38.224 --> 00:55:40.016 of the stuff that we are missing,

NOTE Confidence: 0.79229656

00:55:40.020 --> 00:55:41.870 so I think we don't.

NOTE Confidence: 0.79229656

00:55:41.870 --> 00:55:44.118 Have as much we haven't got as much

NOTE Confidence: 0.79229656

00:55:44.118 --> 00:55:46.350 data out of the E as we as we can,

NOTE Confidence: 0.79229656

00:55:46.350 --> 00:55:48.366 and so I'm hoping that will be

NOTE Confidence: 0.79229656

00:55:48.366 --> 00:55:49.440 helpful diagnostically as we.

NOTE Confidence: 0.886992092941177

00:55:51.680 --> 00:55:53.132 You know, as we learn more

NOTE Confidence: 0.886992092941177

00:55:53.132 --> 00:55:54.801 about that and then a related

NOTE Confidence: 0.886992092941177

00:55:54.801 --> 00:55:56.416 question about percent slow wave,

NOTE Confidence: 0.886992092941177

00:55:56.420 --> 00:55:58.445 percent RAM, it's not grossly

NOTE Confidence: 0.886992092941177

00:55:58.445 --> 00:56:01.020 different NIH than than other people.

NOTE Confidence: 0.886992092941177

00:56:01.020 --> 00:56:03.848 And so those those sort of traditional

NOTE Confidence: 0.886992092941177

00:56:03.848 --> 00:56:06.128 measures don't get us a long way.

NOTE Confidence: 0.886992092941177

00:56:06.130 --> 00:56:07.570 Potential mechanism for

NOTE Confidence: 0.886992092941177

00:56:07.570 --> 00:56:09.010 clarithromycin or flumazenil.

NOTE Confidence: 0.886992092941177

00:56:09.010 --> 00:56:10.996 We started using those because they

NOTE Confidence: 0.886992092941177

00:56:10.996 --> 00:56:13.615 act at GABA a receptors to decrease

NOTE Confidence: 0.886992092941177

00:56:13.615 --> 00:56:16.051 this increased activity that we see

NOTE Confidence: 0.886992092941177

00:56:16.051 --> 00:56:18.560 in sleepy patients so flumazenil.

NOTE Confidence: 0.800629981111111

00:56:20.570 --> 00:56:22.894 Is a negative allosteric modulator of GABA

NOTE Confidence: 0.800629981111111

00:56:22.894 --> 00:56:25.775 a receptors for information may have some

NOTE Confidence: 0.800629981111111

00:56:25.775 --> 00:56:27.603 more directly antagonistic properties.

NOTE Confidence: 0.800629981111111

00:56:27.610 --> 00:56:29.194 Were saying they didn't actually know

NOTE Confidence: 0.800629981111111

00:56:29.194 --> 00:56:30.547 what the mechanism of clarithromycin

NOTE Confidence: 0.800629981111111

00:56:30.547 --> 00:56:32.304 is because it is a dirty drug.

NOTE Confidence: 0.800629981111111

00:56:32.310 --> 00:56:33.230 It does lots of things.

NOTE Confidence: 0.800629981111111

00:56:33.230 --> 00:56:34.258 It's an anti inflammatory.

NOTE Confidence: 0.800629981111111

00:56:34.258 --> 00:56:36.511 It's an antibiotic and so my current funding

NOTE Confidence: 0.800629981111111

00:56:36.511 --> 00:56:38.503 is a mechanistic study of clarithromycin.

NOTE Confidence: 0.800629981111111

00:56:38.510 --> 00:56:41.206 They try to figure out why it's working,

NOTE Confidence: 0.800629981111111

00:56:41.210 --> 00:56:43.282 but we started it because we think

NOTE Confidence: 0.800629981111111

00:56:43.282 --> 00:56:44.920 there's a problem of increased

NOTE Confidence: 0.800629981111111

00:56:44.920 --> 00:56:47.314 activation of the sedating GABA a system.

NOTE Confidence: 0.64297075

00:56:52.550 --> 00:56:54.587 If a patient fails, Modafinil and oxidate,

NOTE Confidence: 0.64297075

00:56:54.590 --> 00:56:55.690 would you give sinoussi a

NOTE Confidence: 0.64297075

00:56:55.690 --> 00:56:56.790 try or go to clarithromycin?

NOTE Confidence: 0.64297075

00:56:56.790 --> 00:56:57.910 Are from as you know.

NOTE Confidence: 0.64297075

00:56:57.910 --> 00:57:00.328 I think Susie is so rampant.

NOTE Confidence: 0.64297075

00:57:00.330 --> 00:57:03.706 All sorry Jimmy RCMP office I think so

NOTE Confidence: 0.64297075

00:57:03.706 --> 00:57:07.570 ramped all is a surprisingly good medication.

NOTE Confidence: 0.64297075

00:57:07.570 --> 00:57:08.802 I it's mechanistically similar

NOTE Confidence: 0.64297075

00:57:08.802 --> 00:57:10.960 to a lot of what we use,

NOTE Confidence: 0.64297075

00:57:10.960 --> 00:57:13.123 and so I was not super optimistic

NOTE Confidence: 0.64297075

00:57:13.123 --> 00:57:14.766 when it was being developed,

NOTE Confidence: 0.64297075

00:57:14.766 --> 00:57:17.630 but the clinical trials was a pretty robust

NOTE Confidence: 0.64297075

00:57:17.698 --> 00:57:20.090 benefit on the MWT especially and I had.

NOTE Confidence: 0.64297075

00:57:20.090 --> 00:57:22.310 Had some very nice responders

NOTE Confidence: 0.64297075

00:57:22.310 --> 00:57:24.266 of people who didn't do well

NOTE Confidence: 0.64297075

00:57:24.266 --> 00:57:25.570 with armor standard medications.

NOTE Confidence: 0.64297075

00:57:25.570 --> 00:57:27.458 It's fair to get paid for in IH,

NOTE Confidence: 0.64297075

00:57:27.460 --> 00:57:30.310 so I treat a lot of like PRD eyes of

NOTE Confidence: 0.64297075

00:57:30.310 --> 00:57:33.332 5.1 when I watch cats as sleep apnea

NOTE Confidence: 0.64297075

00:57:33.332 --> 00:57:35.216 with positional therapy and then I

NOTE Confidence: 0.64297075

00:57:35.216 --> 00:57:37.260 can get so rampant all so absolutely.

NOTE Confidence: 0.64297075

00:57:37.260 --> 00:57:39.660 I like I like so ramp at all

NOTE Confidence: 0.64297075

00:57:39.734 --> 00:57:41.617 when I can get it paid for.

NOTE Confidence: 0.64297075

00:57:41.620 --> 00:57:44.546 I use a lot of traditional stimulants.

NOTE Confidence: 0.64297075

00:57:44.550 --> 00:57:45.837 I use methylphenidate.

NOTE Confidence: 0.64297075

00:57:45.837 --> 00:57:47.982 I use the amphetamines and

NOTE Confidence: 0.64297075

00:57:47.982 --> 00:57:50.440 so I generally do those.

NOTE Confidence: 0.64297075

00:57:50.440 --> 00:57:50.720 Also,

NOTE Confidence: 0.64297075

00:57:50.720 --> 00:57:52.400 before I would go to clarithromycin

NOTE Confidence: 0.64297075

00:57:52.400 --> 00:57:54.103 are for now and I'll come.

NOTE Confidence: 0.64297075

00:57:54.103 --> 00:57:56.401 I would generally whether I would

NOTE Confidence: 0.64297075

00:57:56.401 --> 00:57:58.832 do oxybate or clarithromycin or

NOTE Confidence: 0.64297075

00:57:58.832 --> 00:58:01.236 flumazenil first really depends

NOTE Confidence: 0.64297075

00:58:01.236 --> 00:58:03.640 on the psychiatric comorbidities.

NOTE Confidence: 0.64297075

00:58:03.640 --> 00:58:05.019 For somebody with a lot of depression,

NOTE Confidence: 0.64297075

00:58:05.020 --> 00:58:06.160 I worry about oxidate,

NOTE Confidence: 0.64297075

00:58:06.160 --> 00:58:07.970 but otherwise I would generally

NOTE Confidence: 0.64297075

00:58:07.970 --> 00:58:10.068 probably try Oxidate first.

NOTE Confidence: 0.857934964285714

00:58:13.680 --> 00:58:14.555 Do you have time for one more?

NOTE Confidence: 0.857934964285714

00:58:14.560 --> 00:58:15.454 Do we need to stop because

NOTE Confidence: 0.857934964285714

00:58:15.454 --> 00:58:16.220 of the other right now?

NOTE Confidence: 0.857934964285714

00:58:16.220 --> 00:58:17.110 I think there's just the

NOTE Confidence: 0.811976809090909

00:58:17.120 --> 00:58:18.020 one more from Christine,

NOTE Confidence: 0.811976809090909

00:58:18.020 --> 00:58:19.640 one who says it's a great talk.

NOTE Confidence: 0.811976809090909

00:58:19.640 --> 00:58:21.168 But do you think the residual

NOTE Confidence: 0.811976809090909

00:58:21.170 --> 00:58:22.241 sleepiness was treated?

NOTE Confidence: 0.811976809090909

00:58:22.241 --> 00:58:24.383 OSA has an overlap with IH

NOTE Confidence: 0.867693486666667

00:58:25.210 --> 00:58:28.171 I do. I mean, I think that there's probably

NOTE Confidence: 0.867693486666667

00:58:28.171 --> 00:58:30.810 two reasons why people have residual

NOTE Confidence: 0.867693486666667

00:58:30.810 --> 00:58:33.540 sleepiness after OSA is treated right.

NOTE Confidence: 0.867693486666667

00:58:33.540 --> 00:58:35.269 One is that probably for the people

NOTE Confidence: 0.867693486666667

00:58:35.269 --> 00:58:37.325 with a lot of hypoxemia for a lot

NOTE Confidence: 0.867693486666667

00:58:37.325 --> 00:58:39.180 of years before they get diagnosed.

NOTE Confidence: 0.867693486666667

00:58:39.180 --> 00:58:41.180 They have chronic damage

NOTE Confidence: 0.867693486666667

00:58:41.180 --> 00:58:43.180 to wake promoting regions.

NOTE Confidence: 0.867693486666667

00:58:43.180 --> 00:58:45.460 Or it's just irreversible, right?

NOTE Confidence: 0.867693486666667

00:58:45.460 --> 00:58:47.764 There's animal data that that suggests

NOTE Confidence: 0.867693486666667

00:58:47.764 --> 00:58:50.218 that's a plausible mechanism for Sleeping S,

NOTE Confidence: 0.867693486666667

00:58:50.220 --> 00:58:51.912 but for lots of people with

NOTE Confidence: 0.867693486666667

00:58:51.912 --> 00:58:53.040 sleep apnea and sleepiness,

NOTE Confidence: 0.867693486666667

00:58:53.040 --> 00:58:54.700 I think they probably just

NOTE Confidence: 0.867693486666667

00:58:54.700 --> 00:58:55.696 have two diagnosis,

NOTE Confidence: 0.867693486666667

00:58:55.700 --> 00:58:57.856 especially the people with pretty mild sleep

NOTE Confidence: 0.867693486666667

00:58:57.856 --> 00:59:00.000 apnea and pretty substantial sleepiness.

NOTE Confidence: 0.867693486666667

00:59:00.000 --> 00:59:02.340 It may be that the battery is just common

NOTE Confidence: 0.867693486666667

00:59:02.340 --> 00:59:04.712 enough that you can have sleep apnea and

NOTE Confidence: 0.867693486666667

00:59:04.712 --> 00:59:07.449 narcolepsy even have sleep apnea, and I ate.

NOTE Confidence: 0.867693486666667

00:59:07.449 --> 00:59:10.130 And so absolutely I think there's a

NOTE Confidence: 0.867693486666667

00:59:10.213 --> 00:59:13.453 group of people who we treat their OSA.

NOTE Confidence: 0.867693486666667

00:59:13.460 --> 00:59:14.736 And they're still sleepy.

NOTE Confidence: 0.867693486666667

00:59:14.736 --> 00:59:16.650 The reason they're still sleepy is

NOTE Confidence: 0.867693486666667

00:59:16.711 --> 00:59:18.790 because they probably had IH all along.

NOTE Confidence: 0.861214244444445

00:59:20.280 --> 00:59:22.107 Well, thank you. This is we are at time.

NOTE Confidence: 0.861214244444445

00:59:22.110 --> 00:59:23.556 I think the questions would keep

NOTE Confidence: 0.861214244444445

00:59:23.556 --> 00:59:25.476 going on and on but we really

NOTE Confidence: 0.861214244444445

00:59:25.476 --> 00:59:26.981 really appreciate your time and

NOTE Confidence: 0.861214244444445

00:59:26.981 --> 00:59:28.188 your expertise today thanks.

NOTE Confidence: 0.861214244444445

00:59:28.188 --> 00:59:29.678 Thank you for coming and

NOTE Confidence: 0.861214244444445

00:59:29.678 --> 00:59:30.870 thanks everybody for joining.

NOTE Confidence: 0.861214244444445

00:59:30.870 --> 00:59:31.830 Have a great afternoon.

NOTE Confidence: 0.772177563333333

00:59:32.750 --> 00:59:33.878 Bye bye bye.