WEBVTT

NOTE duration: "00:18:22.6230000"

NOTE language:en-us

NOTE Confidence: 0.8450877

 $00:00:00.000 \longrightarrow 00:00:02.155$ My name is Sam Powell.

NOTE Confidence: 0.8450877

 $00:00:02.155 \longrightarrow 00:00:05.090$ I'm an MD, PhD student and currently

NOTE Confidence: 0.8450877

 $00:00:05.090 \longrightarrow 00:00:08.711$ in my final year of the PhD in the

NOTE Confidence: 0.8450877

 $00{:}00{:}08.711 \dashrightarrow 00{:}00{:}11.224$ lab of Kristen Byrne and it's my

NOTE Confidence: 0.8450877

 $00:00:11.316 \longrightarrow 00:00:14.226$ great pleasure to introduce our next

NOTE Confidence: 0.8450877

00:00:14.226 --> 00:00:16.930 speaker who is Doctor Mike Murray.

NOTE Confidence: 0.8450877

 $00{:}00{:}16.930 \dashrightarrow 00{:}00{:}18.830$ Doctor Murray joined Yale in

NOTE Confidence: 0.8450877

 $00:00:18.830 \longrightarrow 00:00:21.394$ 2018 as the Director of Clinical

NOTE Confidence: 0.8450877

 $00{:}00{:}21.394 \dashrightarrow 00{:}00{:}23.649$ Operations in the newly formed

NOTE Confidence: 0.8450877

 $00:00:23.649 \longrightarrow 00:00:25.920$ Yale Center of Genomic Health.

NOTE Confidence: 0.8450877

00:00:25.920 --> 00:00:28.040 Prior to coming to Yale,

NOTE Confidence: 0.8450877

 $00:00:28.040 \longrightarrow 00:00:31.190$ he was the Director of Genomic Medicine.

NOTE Confidence: 0.8450877

00:00:31.190 --> 00:00:32.658 At Geisinger Health System,

NOTE Confidence: 0.8450877

 $00{:}00{:}32.658 \dashrightarrow 00{:}00{:}35.358$ where he led the design and implementation

00:00:35.358 --> 00:00:38.340 of the Genome First Program in 2015,

NOTE Confidence: 0.8450877

 $00:00:38.340 \longrightarrow 00:00:41.140$ he is a physician and his board certified

NOTE Confidence: 0.8450877

00:00:41.140 --> 00:00:43.888 in internal medicine and medical genetics,

NOTE Confidence: 0.8450877

 $00:00:43.890 \longrightarrow 00:00:45.875$ and is the principle investigator

NOTE Confidence: 0.8450877

 $00:00:45.875 \dashrightarrow 00:00:47.860$ on the Yale Generations Project.

NOTE Confidence: 0.8450877

 $00:00:47.860 \longrightarrow 00:00:50.844$ So with that I will turn over the

NOTE Confidence: 0.8450877

00:00:50.844 --> 00:00:53.028 virtual floor to Doctor Murray.

NOTE Confidence: 0.80774873

00:00:59.030 --> 00:01:00.400 I think you're still muted,

NOTE Confidence: 0.80774873

 $00:01:00.400 \longrightarrow 00:01:01.210$ muted Doctor Mary.

NOTE Confidence: 0.883763

 $00:01:03.040 \longrightarrow 00:01:04.966$ Thank you, thanks Sam and thanks

NOTE Confidence: 0.883763

 $00:01:04.966 \longrightarrow 00:01:07.010$ to all the organizers and everyone

NOTE Confidence: 0.883763

 $00:01:07.010 \longrightarrow 00:01:10.518$ that's worked on this. I have the.

NOTE Confidence: 0.883763

 $00:01:10.520 \longrightarrow 00:01:13.448$ The honor and the opportunity to tell you

NOTE Confidence: 0.883763

 $00:01:13.448 \longrightarrow 00:01:16.121$ about the Generations project and it is

NOTE Confidence: 0.883763

00:01:16.121 --> 00:01:19.291 the work of dozens and dozens of people

 $00:01:19.291 \longrightarrow 00:01:22.154$ around the health system and the school.

NOTE Confidence: 0.883763

 $00{:}01{:}22.160 \dashrightarrow 00{:}01{:}25.580$ So I will tell you about it in 15 minutes

NOTE Confidence: 0.883763

 $00{:}01{:}25.672 \dashrightarrow 00{:}01{:}28.423$ and hopefully have a little bit of

NOTE Confidence: 0.883763

 $00:01:28.423 \longrightarrow 00:01:31.856$ time for for some questions at the end.

NOTE Confidence: 0.883763

 $00:01:31.860 \longrightarrow 00:01:34.332$ So when we describe the generations

NOTE Confidence: 0.883763

 $00:01:34.332 \longrightarrow 00:01:37.125$ project we talked about it as a

NOTE Confidence: 0.883763

 $00:01:37.125 \longrightarrow 00:01:38.905$ large sequence cohort project aiming

NOTE Confidence: 0.883763

 $00:01:38.905 \longrightarrow 00:01:41.369$ to get at least 100,000 volunteers

NOTE Confidence: 0.883763

 $00{:}01{:}41.369 \dashrightarrow 00{:}01{:}43.883$ over the first five year period.

NOTE Confidence: 0.883763

00:01:43.890 --> 00:01:47.112 And to be an engine for both 21st century

NOTE Confidence: 0.883763

 $00{:}01{:}47.112 \dashrightarrow 00{:}01{:}49.128$ Health care and Discovery Research,

NOTE Confidence: 0.883763

00:01:49.130 --> 00:01:52.226 I have no see any conflicts of interest

NOTE Confidence: 0.883763

 $00:01:52.226 \longrightarrow 00:01:56.087$ for this event when we talk about the

NOTE Confidence: 0.883763

 $00:01:56.087 \longrightarrow 00:01:58.820$ deliverables from the Generations project.

NOTE Confidence: 0.883763

 $00:01:58.820 \longrightarrow 00:02:00.552$ There's four main areas.

NOTE Confidence: 0.883763

 $00:02:00.552 \longrightarrow 00:02:02.717$ First is data for research,

 $00:02:02.720 \dashrightarrow 00:02:05.429$ so DNA datasets linked to HR phenotypes

NOTE Confidence: 0.883763

 $00:02:05.429 \longrightarrow 00:02:07.480$ are available for researchers.

NOTE Confidence: 0.883763

 $00:02:07.480 \longrightarrow 00:02:10.006$ They can be either identified or

NOTE Confidence: 0.883763

 $00:02:10.006 \longrightarrow 00:02:12.201$ deidentified depending on the IRB

NOTE Confidence: 0.883763

 $00:02:12.201 \longrightarrow 00:02:14.406$ approval that the researchers have.

NOTE Confidence: 0.883763

 $00:02:14.410 \longrightarrow 00:02:16.142$ We have banked biospecimens.

NOTE Confidence: 0.883763

00:02:16.142 --> 00:02:18.718 Right now, it's just germline DNA,

NOTE Confidence: 0.883763

00:02:18.718 --> 00:02:21.280 but over time we anticipate adding

NOTE Confidence: 0.883763

 $00:02:21.361 \longrightarrow 00:02:23.496$ other types of bio specimens.

NOTE Confidence: 0.883763

 $00:02:23.500 \longrightarrow 00:02:24.799$ There are participants.

NOTE Confidence: 0.883763

 $00:02:24.799 \longrightarrow 00:02:26.964$ All the volunteers are consented

NOTE Confidence: 0.883763

 $00:02:26.964 \longrightarrow 00:02:27.830$ for Recontact,

NOTE Confidence: 0.883763

 $00:02:27.830 \longrightarrow 00:02:29.222$ so there potentially.

NOTE Confidence: 0.883763

00:02:29.222 --> 00:02:31.078 Participants for new studies,

NOTE Confidence: 0.883763

 $00:02:31.080 \longrightarrow 00:02:32.559$ including clinical trials,

 $00:02:32.559 \longrightarrow 00:02:35.517$ surveys the callbacks for deep phenotyping

NOTE Confidence: 0.883763

 $00{:}02{:}35.517 \dashrightarrow 00{:}02{:}37.724$ biospecimens another and the last

NOTE Confidence: 0.883763

 $00:02:37.724 \longrightarrow 00:02:39.376$ deliverable is precision medicine,

NOTE Confidence: 0.883763

 $00:02:39.380 \longrightarrow 00:02:42.026$ so everyone that volunteers into the

NOTE Confidence: 0.883763

 $00:02:42.026 \longrightarrow 00:02:44.344$ project receives back clinical results

NOTE Confidence: 0.883763

 $00:02:44.344 \longrightarrow 00:02:46.759$ into their electronic health record.

NOTE Confidence: 0.883763

 $00:02:46.760 \longrightarrow 00:02:50.012$ And I'll describe how that works

NOTE Confidence: 0.883763

 $00:02:50.012 \longrightarrow 00:02:53.840$ to you in the slides ahead.

NOTE Confidence: 0.883763

 $00{:}02{:}53.840 \dashrightarrow 00{:}02{:}56.414$ So we spent about a year and a half

NOTE Confidence: 0.883763

 $00:02:56.414 \longrightarrow 00:02:58.636$ setting up the workflows and building

NOTE Confidence: 0.883763

 $00{:}02{:}58.636 \dashrightarrow 00{:}03{:}01.099$ this and and this workshop as well.

NOTE Confidence: 0.883763

 $00:03:01.100 \longrightarrow 00:03:03.389$ Time because we're now really at the

NOTE Confidence: 0.883763

00:03:03.389 --> 00:03:06.048 point where we can open this up broadly,

NOTE Confidence: 0.883763

 $00:03:06.050 \longrightarrow 00:03:08.426$ an invite health care providers and

NOTE Confidence: 0.883763

 $00{:}03{:}08.426 \dashrightarrow 00{:}03{:}10.808$ researchers around Yale to think about

NOTE Confidence: 0.883763

 $00:03:10.808 \longrightarrow 00:03:12.992$ this unique infrastructure to build on

 $00{:}03{:}12.992 \dashrightarrow 00{:}03{:}15.899$ it and to collaborate with this project.

NOTE Confidence: 0.883763

 $00:03:15.900 \longrightarrow 00:03:18.044$ So what are we talking about when we

NOTE Confidence: 0.883763

00:03:18.044 --> 00:03:20.008 talk about 21st century healthcare?

NOTE Confidence: 0.883763

00:03:20.010 --> 00:03:21.760 We describe it like this.

NOTE Confidence: 0.883763

 $00:03:21.760 \longrightarrow 00:03:23.500$ A patient who volunteers has

NOTE Confidence: 0.883763

 $00:03:23.500 \longrightarrow 00:03:24.892$ a comprehensive data set,

NOTE Confidence: 0.883763

 $00:03:24.900 \longrightarrow 00:03:26.705$ genomic data set that's created

NOTE Confidence: 0.883763

 $00{:}03{:}26.705 \dashrightarrow 00{:}03{:}28.898$ and then held securely within the

NOTE Confidence: 0.883763

 $00{:}03{:}28.898 \dashrightarrow 00{:}03{:}30.824$ health system and over a lifetime.

NOTE Confidence: 0.883763

 $00{:}03{:}30.830 \dashrightarrow 00{:}03{:}32.958$ We anticipate that that data set can

NOTE Confidence: 0.883763

 $00:03:32.958 \longrightarrow 00:03:35.368$ be used to generate test results.

NOTE Confidence: 0.883763

 $00:03:35.370 \longrightarrow 00:03:37.799$ There's two types of test results that

NOTE Confidence: 0.883763

 $00{:}03{:}37.799 \dashrightarrow 00{:}03{:}39.900$ we anticipate and are planning on.

NOTE Confidence: 0.883763

 $00:03:39.900 \longrightarrow 00:03:41.650$ The first are screening results,

NOTE Confidence: 0.883763

00:03:41.650 --> 00:03:43.822 so looking at an individual's data

 $00:03:43.822 \longrightarrow 00:03:45.699$ and looking for otherwise invisible

NOTE Confidence: 0.883763

 $00{:}03{:}45.699 \dashrightarrow 00{:}03{:}48.275$ risks for heart disease or cancer or

NOTE Confidence: 0.883763

 $00:03:48.275 \longrightarrow 00:03:50.457$ other diseases that are there and are.

NOTE Confidence: 0.883763

 $00:03:50.460 \longrightarrow 00:03:50.792$ Present,

NOTE Confidence: 0.883763

 $00:03:50.792 \longrightarrow 00:03:52.784$ but they and their health care

NOTE Confidence: 0.883763

00:03:52.784 --> 00:03:55.505 provider may not know about the second

NOTE Confidence: 0.883763

 $00:03:55.505 \longrightarrow 00:03:57.165$ category are clinically indicated.

NOTE Confidence: 0.883763

00:03:57.170 --> 00:03:58.232 Diagnostic test results.

NOTE Confidence: 0.883763

 $00{:}03{:}58.232 \dashrightarrow 00{:}04{:}01.164$ So when a patient presents with a medical

NOTE Confidence: 0.883763

00:04:01.164 --> 00:04:03.516 problem and it's part of generations,

NOTE Confidence: 0.883763

 $00:04:03.520 \longrightarrow 00:04:04.666$ we anticipated overtime,

NOTE Confidence: 0.883763

 $00:04:04.666 \longrightarrow 00:04:06.576$ more and more opportunities will

NOTE Confidence: 0.883763

 $00{:}04{:}06.576 \dashrightarrow 00{:}04{:}08.805$ be available to order a clinical

NOTE Confidence: 0.883763

 $00:04:08.805 \longrightarrow 00:04:09.858$ test through generations.

NOTE Confidence: 0.883763

 $00{:}04{:}09.860 \dashrightarrow 00{:}04{:}12.044$ So the test results that are ordered

NOTE Confidence: 0.883763

 $00:04:12.044 \longrightarrow 00:04:14.080$ in this way will get delivered

 $00:04:14.080 \longrightarrow 00:04:16.488$ into the EHR without a new patient

NOTE Confidence: 0.883763

 $00:04:16.561 \longrightarrow 00:04:19.249$ sample without a repeat blood drawn

NOTE Confidence: 0.883763

00:04:19.249 --> 00:04:21.041 without any additional sequencing

NOTE Confidence: 0.8756842

 $00:04:21.050 \longrightarrow 00:04:24.077$ or genotyping. And then the

NOTE Confidence: 0.8756842

 $00:04:24.077 \longrightarrow 00:04:25.972$ results are managed by clinical

NOTE Confidence: 0.8756842

 $00:04:25.972 \longrightarrow 00:04:27.960$ experts within the health system.

NOTE Confidence: 0.8756842

 $00:04:27.960 \longrightarrow 00:04:29.670$ Highlighted in red are the

NOTE Confidence: 0.8756842

 $00:04:29.670 \longrightarrow 00:04:31.907$ two areas that really are new

NOTE Confidence: 0.8756842

00:04:31.907 --> 00:04:33.747 within the generations project,

NOTE Confidence: 0.8756842

 $00:04:33.750 \longrightarrow 00:04:36.702$ and as far as I know are not being

NOTE Confidence: 0.8756842

 $00:04:36.702 \longrightarrow 00:04:38.704$ offered or anticipated anytime

NOTE Confidence: 0.8756842

 $00{:}04{:}38.704 \dashrightarrow 00{:}04{:}40.828$ soon within similar sequence

NOTE Confidence: 0.8756842

 $00{:}04{:}40.828 \dashrightarrow 00{:}04{:}43.520$ cohorts at other institutions.

NOTE Confidence: 0.8756842

00:04:43.520 --> 00:04:45.930 So more broadly, about generations,

NOTE Confidence: 0.8756842

 $00:04:45.930 \longrightarrow 00:04:47.430$ as mentioned earlier,

 $00:04:47.430 \longrightarrow 00:04:49.930$ this is a collaboration between

NOTE Confidence: 0.8756842

 $00:04:49.930 \longrightarrow 00:04:52.657$ the health system in the school,

NOTE Confidence: 0.8756842

 $00:04:52.660 \longrightarrow 00:04:54.584$ anticipating at least 100,000

NOTE Confidence: 0.8756842

 $00:04:54.584 \longrightarrow 00:04:57.470$ volunteers over a five year period.

NOTE Confidence: 0.8756842

 $00:04:57.470 \longrightarrow 00:05:00.837$ The DNA samples undergo both zoman sniper,

NOTE Confidence: 0.8756842

 $00:05:00.840 \longrightarrow 00:05:02.280$ a data generation.

NOTE Confidence: 0.8756842

 $00:05:02.280 \longrightarrow 00:05:04.680$ There are no exclusion criteria,

NOTE Confidence: 0.8756842

00:05:04.680 --> 00:05:07.566 any age, any health status can

NOTE Confidence: 0.8756842

 $00{:}05{:}07.566 \dashrightarrow 00{:}05{:}09.490$ volunteer into this project,

NOTE Confidence: 0.8756842

 $00:05:09.490 \longrightarrow 00:05:13.000$ and the data gets linked to.

NOTE Confidence: 0.8756842

 $00:05:13.000 \longrightarrow 00:05:16.510$ To the individuals electronic health record.

NOTE Confidence: 0.8756842

 $00:05:16.510 \longrightarrow 00:05:18.350$ So the consenting is.

NOTE Confidence: 0.8620367

 $00:05:20.390 \longrightarrow 00:05:21.754$ Is a little complicated

NOTE Confidence: 0.8620367

 $00:05:21.754 \longrightarrow 00:05:23.118$ because of that integration,

NOTE Confidence: 0.8620367

 $00:05:23.120 \longrightarrow 00:05:25.661$ so it's different than maybe some other

NOTE Confidence: 0.8620367

 $00:05:25.661 \longrightarrow 00:05:27.714$ consenting that you're familiar with and

00:05:27.714 --> 00:05:30.280 the IT Group has really made this happen,

NOTE Confidence: 0.8620367

 $00{:}05{:}30.280 \to 00{:}05{:}32.380$ and we're grateful when someone wants

NOTE Confidence: 0.8620367

 $00:05:32.380 \longrightarrow 00:05:34.467$ to volunteer for four generations if

NOTE Confidence: 0.8620367

00:05:34.467 --> 00:05:36.939 they have never been seen at the Yale

NOTE Confidence: 0.8620367

 $00{:}05{:}37.001 \dashrightarrow 00{:}05{:}39.451$ New Haven health System and don't have

NOTE Confidence: 0.8620367

 $00:05:39.451 \longrightarrow 00:05:41.790$ an electronic health record or consent team,

NOTE Confidence: 0.8620367

 $00:05:41.790 \longrightarrow 00:05:43.710$ is able to generate an electronic

NOTE Confidence: 0.8620367

 $00{:}05{:}43.767 \dashrightarrow 00{:}05{:}45.617$ health record during the process.

NOTE Confidence: 0.8620367

 $00:05:45.620 \longrightarrow 00:05:46.984$ So in many registration,

NOTE Confidence: 0.8620367

 $00{:}05{:}46.984 \dashrightarrow 00{:}05{:}49.030$ all volunteers then sign a consent.

NOTE Confidence: 0.8620367

00:05:49.030 --> 00:05:50.800 It gets direct, directly linked.

NOTE Confidence: 0.8620367

 $00:05:50.800 \longrightarrow 00:05:53.704$ Into their epic record and that

NOTE Confidence: 0.8620367

 $00{:}05{:}53.704 \dashrightarrow 00{:}05{:}55.640$ consenting triggers a physician

NOTE Confidence: 0.8620367

 $00:05:55.725 \longrightarrow 00:05:58.107$ order for DNA test within Epic.

NOTE Confidence: 0.8620367

 $00:05:58.110 \longrightarrow 00:06:00.400$ This is a clinical order.

 $00:06:00.400 \longrightarrow 00:06:03.200$ This is not a research request and

NOTE Confidence: 0.8620367

 $00{:}06{:}03.200 \dashrightarrow 00{:}06{:}06.196$ that DNA sample goes through the

NOTE Confidence: 0.8620367

 $00:06:06.196 \longrightarrow 00:06:08.472$ normal clinical workflows through

NOTE Confidence: 0.8620367

00:06:08.472 --> 00:06:11.798 the laboratories and off to the DNA

NOTE Confidence: 0.8620367

 $00:06:11.798 \longrightarrow 00:06:14.566$ diagnostic lab in the West Campus for

NOTE Confidence: 0.8620367

00:06:14.566 --> 00:06:16.846 for genomic sequencing and genotyping.

NOTE Confidence: 0.8620367

 $00{:}06{:}16.850 \dashrightarrow 00{:}06{:}20.654$ The DNA can be acquired from

NOTE Confidence: 0.8620367

 $00:06:20.654 \longrightarrow 00:06:23.190$ either blood or saliva.

NOTE Confidence: 0.8620367

 $00:06:23.190 \longrightarrow 00:06:25.776$ The deliverables we talk about it

NOTE Confidence: 0.8620367

 $00:06:25.776 \longrightarrow 00:06:29.468$ as all the results that we plan on

NOTE Confidence: 0.8620367

 $00{:}06{:}29.468 \dashrightarrow 00{:}06{:}31.818$ giving back are actionable results.

NOTE Confidence: 0.8620367

 $00:06:31.820 \longrightarrow 00:06:33.528$ They have clinical utility,

NOTE Confidence: 0.8620367

 $00:06:33.528 \longrightarrow 00:06:36.090$ meaning that of provider and the

NOTE Confidence: 0.8620367

 $00:06:36.164 \longrightarrow 00:06:39.006$ volunteer can use that to make clinical

NOTE Confidence: 0.8620367

 $00:06:39.006 \longrightarrow 00:06:41.912$ decisions and the examples of broad

NOTE Confidence: 0.8620367

 $00{:}06{:}41.912 \dashrightarrow 00{:}06{:}44.068$ categories are monogenic screening,

00:06:44.070 --> 00:06:44.672 pharmaco,

NOTE Confidence: 0.8620367

 $00{:}06{:}44.672 \dashrightarrow 00{:}06{:}47.080$ genomics and diagnostic testing.

NOTE Confidence: 0.8620367

00:06:47.080 --> 00:06:48.274 Following the screening,

NOTE Confidence: 0.8620367

 $00:06:48.274 \longrightarrow 00:06:50.662$ we give back the positive results

NOTE Confidence: 0.8620367

 $00:06:50.662 \longrightarrow 00:06:52.570$ through the genomic health team,

NOTE Confidence: 0.8620367

 $00:06:52.570 \longrightarrow 00:06:54.430$ and there's three steps that

NOTE Confidence: 0.8620367

 $00:06:54.430 \longrightarrow 00:06:56.880$ go with each return of result.

NOTE Confidence: 0.8620367

 $00:06:56.880 \longrightarrow 00:06:57.664$ That is,

NOTE Confidence: 0.8620367

 $00:06:57.664 \longrightarrow 00:07:00.408$ the first step is education and counseling,

NOTE Confidence: 0.8620367

00:07:00.410 --> 00:07:01.192 essentially genetic

NOTE Confidence: 0.8620367

 $00:07:01.192 \longrightarrow 00:07:02.756$ counseling about the result,

NOTE Confidence: 0.8620367

 $00:07:02.760 \longrightarrow 00:07:05.896$ what it means and what it doesn't mean,

NOTE Confidence: 0.8620367

 $00:07:05.900 \longrightarrow 00:07:07.845$ and then family cascade testing

NOTE Confidence: 0.8620367

 $00:07:07.845 \longrightarrow 00:07:10.636$ is offered so that if someone has

NOTE Confidence: 0.8620367

 $00:07:10.636 \longrightarrow 00:07:12.946$ a risk result that we uncover,

 $00:07:12.950 \longrightarrow 00:07:14.423$ then their siblings,

NOTE Confidence: 0.8620367

 $00{:}07{:}14.423 \dashrightarrow 00{:}07{:}16.878$ children and parents are offered

NOTE Confidence: 0.8620367

 $00:07:16.878 \longrightarrow 00:07:18.886$ participation so that they can

NOTE Confidence: 0.8620367

 $00:07:18.886 \longrightarrow 00:07:21.098$ find out if they have the same.

NOTE Confidence: 0.8620367

 $00:07:21.100 \longrightarrow 00:07:25.306$ Same risk and then referral to

NOTE Confidence: 0.8620367

 $00{:}07{:}25.306 \dashrightarrow 00{:}07{:}28.110$ clinical experts for management

NOTE Confidence: 0.8620367

 $00:07:28.226 \longrightarrow 00:07:30.938$ and evaluation overtime.

NOTE Confidence: 0.8620367

 $00:07:30.940 \longrightarrow 00:07:32.540$ There's no cost for participation

NOTE Confidence: 0.8620367

 $00:07:32.540 \longrightarrow 00:07:34.140$ to the to the volunteer,

NOTE Confidence: 0.8620367

 $00:07:34.140 \longrightarrow 00:07:35.505$ the DNA analysis,

NOTE Confidence: 0.8620367

 $00:07:35.505 \longrightarrow 00:07:38.235$ and the Genomic health visit are

NOTE Confidence: 0.8620367

 $00:07:38.235 \longrightarrow 00:07:40.759$ part of being in the project.

NOTE Confidence: 0.8620367

 $00:07:40.760 \longrightarrow 00:07:42.866$ This is data that we pulled

NOTE Confidence: 0.8620367

 $00:07:42.866 \longrightarrow 00:07:44.270$ recently on the approximately

NOTE Confidence: 0.8620367

 $00:07:44.340 \longrightarrow 00:07:46.470$ 3500 patients that are currently

NOTE Confidence: 0.8620367

 $00:07:46.470 \longrightarrow 00:07:48.600$ enrolled in the Generations project.

 $00:07:48.600 \longrightarrow 00:07:51.416$ On the top panel you can see that

NOTE Confidence: 0.8620367

00:07:51.416 --> 00:07:53.896 the cohort currently is made up

NOTE Confidence: 0.8620367

 $00:07:53.896 \longrightarrow 00:07:56.440$ of primarily of adults age 2280.

NOTE Confidence: 0.8620367

 $00:07:56.440 \longrightarrow 00:07:56.833$ However,

NOTE Confidence: 0.8620367

 $00:07:56.833 \longrightarrow 00:07:58.798$ there are children and there

NOTE Confidence: 0.8620367

 $00:07:58.798 \longrightarrow 00:08:00.815$ are older individuals that have

NOTE Confidence: 0.8620367

00:08:00.815 --> 00:08:02.710 been consented into the project,

NOTE Confidence: 0.8620367

 $00:08:02.710 \longrightarrow 00:08:04.590$ including an individual over the

NOTE Confidence: 0.8620367

 $00:08:04.590 \longrightarrow 00:08:07.780$ age of 100 in the middle and lower

NOTE Confidence: 0.8620367

 $00:08:07.780 \longrightarrow 00:08:10.240$ panel or pie charts showing the.

NOTE Confidence: 0.8620367

00:08:10.240 --> 00:08:12.886 Race and ethnicity of the participants.

NOTE Confidence: 0.8620367

 $00{:}08{:}12.890 \dashrightarrow 00{:}08{:}15.230$ It's important to note that this

NOTE Confidence: 0.8620367

00:08:15.230 --> 00:08:17.879 race and ethnicity is drawn directly

NOTE Confidence: 0.8620367

00:08:17.879 --> 00:08:20.409 from the electronic health record,

NOTE Confidence: 0.8620367

 $00:08:20.410 \longrightarrow 00:08:23.362$ and so both both of those pie charts

 $00:08:23.362 \longrightarrow 00:08:26.056$ have relatively large slices that are

NOTE Confidence: 0.8620367

 $00{:}08{:}26.056 \dashrightarrow 00{:}08{:}28.401$ unknown because the electronic health

NOTE Confidence: 0.8620367

 $00:08:28.401 \longrightarrow 00:08:31.007$ record doesn't doesn't require this.

NOTE Confidence: 0.8620367

 $00:08:31.010 \longrightarrow 00:08:33.220$ This category of information currently,

NOTE Confidence: 0.8620367

00:08:33.220 --> 00:08:35.430 so we're working on strategies

NOTE Confidence: 0.8620367

 $00:08:35.430 \longrightarrow 00:08:37.640$ to fill those gaps overtime.

NOTE Confidence: 0.88035905

00:08:39.700 --> 00:08:44.070 Her two other pie charts, the one on the top,

NOTE Confidence: 0.88035905

 $00:08:44.070 \longrightarrow 00:08:47.129$ talks about those that had an electronic

NOTE Confidence: 0.88035905

 $00{:}08{:}47.129 \to 00{:}08{:}50.185$ health record versus those that had one

NOTE Confidence: 0.88035905

 $00:08:50.185 \longrightarrow 00:08:52.681$ generated in order to become volunteers

NOTE Confidence: 0.88035905

 $00{:}08{:}52.756 \dashrightarrow 00{:}08{:}55.476$ and generations 17% in the dark blue.

NOTE Confidence: 0.88035905

 $00:08:55.476 \longrightarrow 00:08:59.239$ There are those that had a new epic record

NOTE Confidence: 0.88035905

 $00:08:59.239 \longrightarrow 00:09:01.984$ created for participation in generations,

NOTE Confidence: 0.88035905

 $00:09:01.990 \longrightarrow 00:09:04.612$ and then the bottom pie chart

NOTE Confidence: 0.88035905

 $00:09:04.612 \longrightarrow 00:09:06.815$ shows the approximately 75% of

NOTE Confidence: 0.88035905

 $00:09:06.815 \longrightarrow 00:09:09.090$ individuals who were new registrants.

 $00:09:09.090 \longrightarrow 00:09:10.314$ Via the process,

NOTE Confidence: 0.88035905

 $00:09:10.314 \longrightarrow 00:09:12.762$ who then later had a clinical

NOTE Confidence: 0.88035905

 $00:09:12.762 \longrightarrow 00:09:15.140$ encounter of some sort following it.

NOTE Confidence: 0.88035905

00:09:15.140 --> 00:09:17.504 So though we haven't been specifically

NOTE Confidence: 0.88035905

 $00:09:17.504 \longrightarrow 00:09:19.553$ targeting individuals who are not

NOTE Confidence: 0.88035905

00:09:19.553 --> 00:09:21.177 Yellow Haven hospital patients,

NOTE Confidence: 0.88035905

 $00:09:21.180 \longrightarrow 00:09:23.908$ they are coming to us and they are

NOTE Confidence: 0.88035905

 $00{:}09{:}23.908 \dashrightarrow 00{:}09{:}26.819$ not only signing up for generations,

NOTE Confidence: 0.88035905

 $00:09:26.820 \longrightarrow 00:09:29.196$ but they're then getting some elements

NOTE Confidence: 0.88035905

 $00:09:29.196 \dashrightarrow 00:09:32.060$ of their care within the health system.

NOTE Confidence: 0.8184872

 $00:09:34.460 \longrightarrow 00:09:36.938$ Shown here on the left is our

NOTE Confidence: 0.8184872

 $00{:}09{:}36.938 \dashrightarrow 00{:}09{:}38.460$ monogenic risk screening table.

NOTE Confidence: 0.8184872

 $00{:}09{:}38.460 \dashrightarrow 00{:}09{:}40.644$ There are 10 genes associated with

NOTE Confidence: 0.8184872

00:09:40.644 --> 00:09:43.199 monogenic risk for cancer or heart disease,

NOTE Confidence: 0.8184872

 $00:09:43.200 \longrightarrow 00:09:46.840$ 10 out of the 20,000 that each of us have.

 $00:09:46.840 \longrightarrow 00:09:49.059$ So I jokingly say that this version

NOTE Confidence: 0.8184872

00:09:49.059 --> 00:09:51.568 one will go through many versions,

NOTE Confidence: 0.8184872

 $00:09:51.570 \longrightarrow 00:09:54.250$ be before we eventually get to the 20,000

NOTE Confidence: 0.8184872

00:09:54.250 --> 00:09:56.657 total that will ultimately give back,

NOTE Confidence: 0.8184872

 $00:09:56.660 \longrightarrow 00:09:59.428$ and then on the right is the Pharmaco

NOTE Confidence: 0.8184872

 $00:09:59.428 \dashrightarrow 00:10:02.119$ genomics panel that we currently offer back.

NOTE Confidence: 0.8184872

 $00{:}10{:}02.120 \dashrightarrow 00{:}10{:}04.180$ There are six genes associated

NOTE Confidence: 0.8184872

 $00:10:04.180 \longrightarrow 00:10:06.240$ with the medications that you

NOTE Confidence: 0.8184872

 $00{:}10{:}06.312 \dashrightarrow 00{:}10{:}08.028$ can see on the far right.

NOTE Confidence: 0.8184872

 $00:10:08.030 \longrightarrow 00:10:09.562$ Column that are given

NOTE Confidence: 0.8184872

 $00{:}10{:}09.562 \dashrightarrow 00{:}10{:}11.477$ back into the epic record,

NOTE Confidence: 0.8184872

 $00:10:11.480 \longrightarrow 00:10:13.740$ and then there's clinical decision

NOTE Confidence: 0.8184872

 $00:10:13.740 \longrightarrow 00:10:16.000$ support driven off of that.

NOTE Confidence: 0.8184872

 $00:10:16.000 \longrightarrow 00:10:18.352$ A lot of folks ask what's the

NOTE Confidence: 0.8184872

00:10:18.352 --> 00:10:20.119 percentage of people that get

NOTE Confidence: 0.8184872

 $00:10:20.119 \longrightarrow 00:10:21.844$ back results based on this?

00:10:21.850 --> 00:10:23.580 We're currently giving back about

NOTE Confidence: 0.8184872

 $00{:}10{:}23.580 {\:{\circ}{\circ}{\circ}}>00{:}10{:}25.960$ as you can see there 1.4% of

NOTE Confidence: 0.8184872

00:10:25.960 --> 00:10:27.610 volunteers are getting a result

NOTE Confidence: 0.8184872

 $00:10:27.610 \longrightarrow 00:10:30.405$ back on this short list of 10 genes

NOTE Confidence: 0.8184872

00:10:30.405 --> 00:10:32.170 and conditions for monogenic risk,

NOTE Confidence: 0.8184872

 $00:10:32.170 \longrightarrow 00:10:34.578$ that number will go up later this

NOTE Confidence: 0.8184872

 $00:10:34.578 \longrightarrow 00:10:37.330$ year when we go to our version two,

NOTE Confidence: 0.8184872

 $00:10:37.330 \longrightarrow 00:10:39.507$ which will have 44 genes in the

NOTE Confidence: 0.8184872

00:10:39.507 --> 00:10:41.526 panel and this is consistent with

NOTE Confidence: 0.8184872

00:10:41.526 --> 00:10:43.892 with other groups as far as the

NOTE Confidence: 0.8184872

 $00{:}10{:}43.965 {\:\dashrightarrow\:} 00{:}10{:}46.470$ percentage is receiving back results.

NOTE Confidence: 0.8184872

00:10:46.470 --> 00:10:47.529 On the pharmacogenomics,

NOTE Confidence: 0.8184872

 $00:10:47.529 \longrightarrow 00:10:49.647$ there are now over 2000 individuals

NOTE Confidence: 0.8184872

00:10:49.647 --> 00:10:51.104 that have pharmaco genomic

NOTE Confidence: 0.8184872

00:10:51.104 --> 00:10:52.839 results in their epic record.

 $00:10:52.840 \longrightarrow 00:10:55.318$ As a result of participation in generations.

NOTE Confidence: 0.84937644

00:10:57.470 --> 00:10:59.666 Some of you will be familiar

NOTE Confidence: 0.84937644

 $00:10:59.666 \longrightarrow 00:11:01.130$ with this published data.

NOTE Confidence: 0.84937644

00:11:01.130 --> 00:11:04.790 This came out of work that I was involved in,

NOTE Confidence: 0.84937644

 $00:11:04.790 \longrightarrow 00:11:06.420$ and Geisinger Health System in

NOTE Confidence: 0.84937644

 $00:11:06.420 \longrightarrow 00:11:08.050$ Pennsylvania where we did a

NOTE Confidence: 0.84937644

 $00:11:08.110 \longrightarrow 00:11:09.910$ similar sequence cohort project.

NOTE Confidence: 0.84937644

 $00:11:09.910 \longrightarrow 00:11:12.381$ This was on the 1st 50,000 individuals

NOTE Confidence: 0.84937644

00:11:12.381 --> 00:11:14.310 who participate in that project.

NOTE Confidence: 0.84937644

 $00:11:14.310 \longrightarrow 00:11:16.466$ We went back and we looked at

NOTE Confidence: 0.84937644

 $00{:}11{:}16.466 \dashrightarrow 00{:}11{:}18.316$ their data for those individuals

NOTE Confidence: 0.84937644

00:11:18.316 --> 00:11:20.884 that had changes in their BRCA,

NOTE Confidence: 0.84937644

 $00:11:20.890 \longrightarrow 00:11:23.347$ one or two gene that would be

NOTE Confidence: 0.84937644

00:11:23.347 --> 00:11:25.648 expected to confer risk for cancer.

NOTE Confidence: 0.84937644

 $00:11:25.650 \longrightarrow 00:11:28.072$ We found that about one in 190

NOTE Confidence: 0.84937644

 $00:11:28.072 \longrightarrow 00:11:29.950$ individuals in this population.

 $00:11:29.950 \longrightarrow 00:11:33.165$ Had one of those risks and 80% of

NOTE Confidence: 0.84937644

 $00:11:33.165 \longrightarrow 00:11:35.415$ those individuals had no idea that

NOTE Confidence: 0.84937644

00:11:35.415 --> 00:11:38.119 they had this risk the first time

NOTE Confidence: 0.84937644

 $00:11:38.119 \longrightarrow 00:11:40.369$ that they found out was through

NOTE Confidence: 0.84937644

 $00:11:40.448 \longrightarrow 00:11:43.591$ participation in this sort of a sequence

NOTE Confidence: 0.84937644

 $00:11:43.591 \longrightarrow 00:11:45.748$ project project with with population

NOTE Confidence: 0.84937644

 $00:11:45.748 \longrightarrow 00:11:47.768$ screening for this particular risk.

NOTE Confidence: 0.84937644

00:11:47.770 --> 00:11:50.612 So this is the DNA based screening

NOTE Confidence: 0.84937644

00:11:50.612 --> 00:11:53.093 that we anticipate and plan to

NOTE Confidence: 0.84937644

 $00:11:53.093 \longrightarrow 00:11:55.058$ roll out to all participants.

NOTE Confidence: 0.84937644

 $00:11:55.060 \longrightarrow 00:11:57.622$ It offers the chance to uncover

NOTE Confidence: 0.84937644

 $00{:}11{:}57.622 \dashrightarrow 00{:}12{:}00.658$ invisible risks such as this and others.

NOTE Confidence: 0.84937644

 $00:12:00.660 \longrightarrow 00:12:02.630$ And and will go to.

NOTE Confidence: 0.84937644

 $00:12:02.630 \longrightarrow 00:12:04.490$ As I mentioned earlier,

NOTE Confidence: 0.84937644

 $00:12:04.490 \longrightarrow 00:12:06.815$ 44 genes and conditions associated

 $00:12:06.815 \longrightarrow 00:12:09.570$ with risk can expand that overtime.

NOTE Confidence: 0.84937644

 $00{:}12{:}09.570 \dashrightarrow 00{:}12{:}12.020$ But I promised that I'd also talk

NOTE Confidence: 0.84937644

 $00:12:12.020 \longrightarrow 00:12:14.075$ about diagnostic use of the data and

NOTE Confidence: 0.84937644

 $00:12:14.075 \longrightarrow 00:12:16.651$ so I want to go into the first use

NOTE Confidence: 0.84937644

 $00:12:16.651 \longrightarrow 00:12:18.859$ case that we've launched around this.

NOTE Confidence: 0.84937644

00:12:18.860 --> 00:12:21.478 And this builds off of paper that

NOTE Confidence: 0.84937644

00:12:21.478 --> 00:12:24.034 showed up in the New England

NOTE Confidence: 0.84937644

00:12:24.034 --> 00:12:26.274 Journal of Medicine written by

NOTE Confidence: 0.84937644

 $00:12:26.274 \longrightarrow 00:12:29.209$ the team at Columbia in New York.

NOTE Confidence: 0.84937644

00:12:29.210 --> 00:12:30.905 And they offered xom sequencing

NOTE Confidence: 0.84937644

 $00{:}12{:}30.905 \dashrightarrow 00{:}12{:}33.116$ on a research basis to individuals

NOTE Confidence: 0.84937644

 $00:12:33.116 \longrightarrow 00:12:35.346$ with kidney disease and reported

NOTE Confidence: 0.84937644

00:12:35.346 --> 00:12:37.687 out the diagnostic utility of

NOTE Confidence: 0.84937644

 $00:12:37.687 \longrightarrow 00:12:39.148$ screening those individuals.

NOTE Confidence: 0.84937644

 $00:12:39.150 \longrightarrow 00:12:42.078$ The renal team here.

NOTE Confidence: 0.84937644

 $00:12:42.080 \longrightarrow 00:12:44.672$ Came to us in we discussed the fact

00:12:44.672 --> 00:12:47.342 that they can't easily order this kind

NOTE Confidence: 0.84937644

 $00:12:47.342 \longrightarrow 00:12:50.587$ of testing that they love to for the

NOTE Confidence: 0.84937644

 $00:12:50.587 \longrightarrow 00:12:53.035$ patients that are listed for transplant.

NOTE Confidence: 0.84937644

 $00:12:53.040 \longrightarrow 00:12:54.924$ There's all kinds of hurdles to

NOTE Confidence: 0.84937644

 $00:12:54.924 \longrightarrow 00:12:57.193$ getting this kind of testing ordered

NOTE Confidence: 0.84937644

 $00:12:57.193 \longrightarrow 00:12:59.085$ and resulted within healthcare.

NOTE Confidence: 0.84937644

 $00:12:59.090 \longrightarrow 00:12:59.782$ Currently zero.

NOTE Confidence: 0.84937644

 $00{:}12{:}59.782 \longrightarrow 00{:}13{:}02.204$ I saw this as an opportunity to

NOTE Confidence: 0.84937644

 $00:13:02.204 \longrightarrow 00:13:04.235$ to explore this opportunity for

NOTE Confidence: 0.84937644

 $00:13:04.235 \longrightarrow 00:13:06.647$ down the middle of the slide.

NOTE Confidence: 0.84937644

 $00:13:06.650 \longrightarrow 00:13:09.303$ Here you can see in blue the

NOTE Confidence: 0.84937644

00:13:09.303 --> 00:13:11.322 nephrology just wanting to simply

NOTE Confidence: 0.84937644

00:13:11.322 --> 00:13:12.926 place a clinical order.

NOTE Confidence: 0.84937644

 $00:13:12.930 \longrightarrow 00:13:15.810$ In epic for tests that had the potential

NOTE Confidence: 0.84937644

 $00:13:15.810 \longrightarrow 00:13:18.218$ to offer back positive results,

 $00:13:18.220 \longrightarrow 00:13:20.680$ 29 percent of their transplant patients

NOTE Confidence: 0.84937644

 $00{:}13{:}20.680 \dashrightarrow 00{:}13{:}22.700$ that would influence their care,

NOTE Confidence: 0.84937644

 $00:13:22.700 \longrightarrow 00:13:26.180$ and we had the aspiration of using the

NOTE Confidence: 0.84937644

 $00:13:26.180 \longrightarrow 00:13:28.796$ generations data for this kind of use.

NOTE Confidence: 0.84937644

 $00:13:28.800 \longrightarrow 00:13:32.283$ So to do that we had to move this

NOTE Confidence: 0.84937644

 $00:13:32.283 \longrightarrow 00:13:35.317$ down to the bottom and up top.

NOTE Confidence: 0.84937644

 $00:13:35.320 \longrightarrow 00:13:37.140$ Here offer the patients participation

NOTE Confidence: 0.84937644

 $00:13:37.140 \longrightarrow 00:13:39.504$ in generations as they got identified

NOTE Confidence: 0.84937644

 $00:13:39.504 \longrightarrow 00:13:41.416$ as renal transplant candidates.

NOTE Confidence: 0.84937644

 $00:13:41.420 \longrightarrow 00:13:43.440$ So we started this.

NOTE Confidence: 0.84937644

 $00:13:43.440 \longrightarrow 00:13:47.079$ Back in the fall together with the

NOTE Confidence: 0.84937644

 $00:13:47.079 \longrightarrow 00:13:50.124$ YCCI based, consenting for generations,

NOTE Confidence: 0.84937644

00:13:50.124 --> 00:13:54.192 we now have about 65 individuals.

NOTE Confidence: 0.84937644

 $00{:}13{:}54.200 \mathrel{--}{>} 00{:}13{:}56.818$ Who are on the transplant list and

NOTE Confidence: 0.84937644

 $00:13:56.818 \longrightarrow 00:13:58.447$ have consented into generations

NOTE Confidence: 0.84937644

 $00:13:58.447 \longrightarrow 00:14:00.597$ and their receiving the standard

 $00:14:00.597 \longrightarrow 00:14:03.132$ used to the data, the screening,

NOTE Confidence: 0.84937644

 $00:14:03.132 \longrightarrow 00:14:05.568$ and the Pharmaco Genomics as mentioned.

NOTE Confidence: 0.84937644

 $00:14:05.570 \longrightarrow 00:14:07.600$ And then just this week,

NOTE Confidence: 0.84937644

00:14:07.600 --> 00:14:10.092 the epic team worked hard and stood

NOTE Confidence: 0.84937644

 $00:14:10.092 \longrightarrow 00:14:13.276$ up a Go live order that are not

NOTE Confidence: 0.84937644

 $00:14:13.276 \longrightarrow 00:14:16.267$ for Ologist can now place an order

NOTE Confidence: 0.84937644

 $00:14:16.267 \longrightarrow 00:14:18.901$ for what we're calling the renal

NOTE Confidence: 0.84937644

00:14:18.901 --> 00:14:19.779 gene screen

NOTE Confidence: 0.895264088333334

 $00:14:19.780 \longrightarrow 00:14:22.140$ panel. 27 genes associated with

NOTE Confidence: 0.895264088333334

 $00{:}14{:}22.140 \dashrightarrow 00{:}14{:}25.044$ renal failure that they'll be able

NOTE Confidence: 0.895264088333334

00:14:25.044 --> 00:14:27.786 to offer going forward and hopefully

NOTE Confidence: 0.895264088333334

 $00:14:27.786 \longrightarrow 00:14:30.168$ within the coming months will

NOTE Confidence: 0.895264088333334

 $00{:}14{:}30.168 \dashrightarrow 00{:}14{:}33.423$ have some data to share about the

NOTE Confidence: 0.895264088333334

 $00:14:33.423 \longrightarrow 00:14:36.920$ implementation of this strategy.

NOTE Confidence: 0.895264088333334

 $00:14:36.920 \longrightarrow 00:14:39.920$ Other diagnostic uses of data, of course.

 $00:14:39.920 \longrightarrow 00:14:41.945$ I'm sure that individuals can

NOTE Confidence: 0.895264088333334

00:14:41.945 --> 00:14:44.369 think of many different ways,

NOTE Confidence: 0.895264088333334

 $00:14:44.370 \longrightarrow 00:14:47.410$ and so you know we are open to

NOTE Confidence: 0.895264088333334

00:14:47.410 --> 00:14:49.246 hearing your suggestions and

NOTE Confidence: 0.895264088333334

 $00:14:49.246 \longrightarrow 00:14:52.683$ working with you to stand these U.

NOTE Confidence: 0.895264088333334

 $00:14:52.690 \longrightarrow 00:14:55.161$ The next case that we expect to

NOTE Confidence: 0.895264088333334

00:14:55.161 --> 00:14:58.012 stand up is in the smilow breast

NOTE Confidence: 0.895264088333334

00:14:58.012 --> 00:15:01.173 cancer program where we plan to offer

NOTE Confidence: 0.895264088333334

00:15:01.173 --> 00:15:03.758 enrollment in generations early in

NOTE Confidence: 0.895264088333334

 $00:15:03.758 \longrightarrow 00:15:06.586$ the diagnosis and then deliver back.

NOTE Confidence: 0.895264088333334

 $00{:}15{:}06.586 {\:{\circ}{\circ}{\circ}}>00{:}15{:}08.476$ Results of germline diagnosis to

NOTE Confidence: 0.895264088333334

00:15:08.476 --> 00:15:10.381 those individuals who have been

NOTE Confidence: 0.895264088333334

 $00:15:10.381 \longrightarrow 00:15:11.449$ diagnosed with cancer,

NOTE Confidence: 0.895264088333334

 $00:15:11.450 \longrightarrow 00:15:13.628$ but there's many more potential use

NOTE Confidence: 0.895264088333334

 $00:15:13.628 \longrightarrow 00:15:15.806$ cases and I've already talked to

NOTE Confidence: 0.895264088333334

 $00{:}15{:}15.806 \dashrightarrow 00{:}15{:}17.780$ a number of people about others.

 $00:15:19.790 \longrightarrow 00:15:21.956$ Regarding the research use of generations

NOTE Confidence: 0.8680108

 $00{:}15{:}21.956 {\:{\mbox{--}}}{>} 00{:}15{:}24.665$ data, you know some of you have heard

NOTE Confidence: 0.8680108

 $00{:}15{:}24.665 {\:\dashrightarrow\:} 00{:}15{:}26.744$ me describe generations as a living

NOTE Confidence: 0.8680108

 $00:15:26.744 \longrightarrow 00:15:28.419$ laboratory because of the generosity

NOTE Confidence: 0.8680108

 $00:15:28.419 \longrightarrow 00:15:30.785$ of the volunteers they have made

NOTE Confidence: 0.8680108

00:15:30.785 --> 00:15:32.820 their data available for research,

NOTE Confidence: 0.8680108

 $00:15:32.820 \longrightarrow 00:15:35.130$ and they've also made themselves

NOTE Confidence: 0.8680108

 $00:15:35.130 \longrightarrow 00:15:36.516$ available for callbacks.

NOTE Confidence: 0.8680108

 $00{:}15{:}36.520 \dashrightarrow 00{:}15{:}39.215$ And so there's three categories of data

NOTE Confidence: 0.8680108

 $00:15:39.215 \longrightarrow 00:15:41.730$ or callbacks that we're anticipating.

NOTE Confidence: 0.8680108

00:15:41.730 --> 00:15:43.900 The first is healthy controls,

NOTE Confidence: 0.8680108

 $00:15:43.900 \longrightarrow 00:15:46.630$ so researchers that have a group of

NOTE Confidence: 0.8680108

 $00{:}15{:}46.630 \dashrightarrow 00{:}15{:}49.096$ patients with the disease or condition

NOTE Confidence: 0.8680108

 $00:15:49.096 \longrightarrow 00:15:52.538$ that are looking for age or gender or

NOTE Confidence: 0.8680108

 $00:15:52.538 \longrightarrow 00:15:55.178$ other criteria matched healthy controls.

 $00:15:55.180 \longrightarrow 00:15:57.445$ We anticipate having those controls

NOTE Confidence: 0.8680108

 $00:15:57.445 \longrightarrow 00:16:00.588$ available for either sharing of data sets

NOTE Confidence: 0.8680108

 $00:16:00.588 \longrightarrow 00:16:03.423$ or for calling back individuals for studies.

NOTE Confidence: 0.8680108

00:16:03.430 --> 00:16:05.194 As you can imagine,

NOTE Confidence: 0.8680108

00:16:05.194 --> 00:16:07.399 there also be genetically defined.

NOTE Confidence: 0.8680108

00:16:07.400 --> 00:16:07.815 Cohorts,

NOTE Confidence: 0.8680108

 $00:16:07.815 \longrightarrow 00:16:10.305$ so relatively rare snips that individuals

NOTE Confidence: 0.8680108

 $00:16:10.305 \longrightarrow 00:16:13.177$ want to study patients that have them.

NOTE Confidence: 0.8680108

 $00{:}16{:}13.180 \dashrightarrow 00{:}16{:}16.484$ We can find them within that this cohort,

NOTE Confidence: 0.8680108

 $00:16:16.490 \longrightarrow 00:16:18.824$ and we've already done that together

NOTE Confidence: 0.8680108

00:16:18.824 --> 00:16:21.440 with somebody in David Hafler's Group,

NOTE Confidence: 0.8680108

 $00:16:21.440 \longrightarrow 00:16:23.918$ and then there's clinically defined cohorts.

NOTE Confidence: 0.8680108

 $00:16:23.920 \longrightarrow 00:16:25.568$ Individuals that have a

NOTE Confidence: 0.8680108

 $00:16:25.568 \longrightarrow 00:16:27.216$ medical issue or problem,

NOTE Confidence: 0.8680108

00:16:27.220 --> 00:16:29.285 and bringing back those individuals

NOTE Confidence: 0.8680108

 $00{:}16{:}29.285 \dashrightarrow 00{:}16{:}31.770$ who are looking at those data.

 $00:16:31.770 \longrightarrow 00:16:32.913$ So we are,

NOTE Confidence: 0.8680108

 $00:16:32.913 \longrightarrow 00:16:35.199$ we stand ready to generate letters

NOTE Confidence: 0.8680108

 $00:16:35.199 \longrightarrow 00:16:37.889$ of support for grant proposals.

NOTE Confidence: 0.8680108

00:16:37.890 --> 00:16:40.761 To to work with you to give you genomic

NOTE Confidence: 0.8680108

 $00:16:40.761 \longrightarrow 00:16:43.378$ datasets that will require that you have

NOTE Confidence: 0.8680108

 $00:16:43.378 \longrightarrow 00:16:45.656$ an IRB approved protocol to receive

NOTE Confidence: 0.8680108

 $00:16:45.656 \longrightarrow 00:16:48.183$ such datasets and to do callbacks and.

NOTE Confidence: 0.8680108

00:16:48.190 --> 00:16:51.412 And we've we've stood this up

NOTE Confidence: 0.8680108

 $00:16:51.412 \longrightarrow 00:16:54.380$ in all three categories so far.

NOTE Confidence: 0.8680108

 $00{:}16{:}54{.}380 \dashrightarrow 00{:}16{:}56{.}546$ The last thing that I'll mention

NOTE Confidence: 0.8680108

 $00{:}16{:}56.546 \dashrightarrow 00{:}16{:}59.528$ is many of you familiar with this.

NOTE Confidence: 0.8680108

 $00{:}16{:}59.530 \dashrightarrow 00{:}17{:}01.980$ The Nomad database is available

NOTE Confidence: 0.8680108

 $00:17:01.980 \longrightarrow 00:17:04.780$ online for individuals that want to

NOTE Confidence: 0.8680108

 $00{:}17{:}04.780 \dashrightarrow 00{:}17{:}07.684$ go onto it and look up a gene or a

NOTE Confidence: 0.8680108

 $00:17:07.684 \longrightarrow 00:17:10.162$ variant and find out the frequency

 $00:17:10.162 \longrightarrow 00:17:12.202$ within this large data set,

NOTE Confidence: 0.8680108

 $00{:}17{:}12.202 \dashrightarrow 00{:}17{:}14.578$ which which includes large cohorts from

NOTE Confidence: 0.8680108

 $00:17:14.578 \longrightarrow 00:17:17.346$ across the country and across the world.

NOTE Confidence: 0.8680108

00:17:17.350 --> 00:17:18.592 Luckily for us,

NOTE Confidence: 0.8680108

 $00:17:18.592 \longrightarrow 00:17:21.076$ muenkel like who's in our Department

NOTE Confidence: 0.8680108

00:17:21.076 --> 00:17:23.609 as a speaker in this workshop.

NOTE Confidence: 0.8680108

 $00:17:23.610 \longrightarrow 00:17:25.927$ Was one of the drivers of standing

NOTE Confidence: 0.8680108

 $00:17:25.927 \longrightarrow 00:17:28.346$ up this this database and will be

NOTE Confidence: 0.8680108

 $00{:}17{:}28.346 \dashrightarrow 00{:}17{:}30.893$ working with us to create a mini

NOTE Confidence: 0.8680108

 $00{:}17{:}30.893 \dashrightarrow 00{:}17{:}33.557$ version of this and internal HIPAA

NOTE Confidence: 0.8680108

 $00{:}17{:}33.557 \dashrightarrow 00{:}17{:}35.209$ compliant version where individuals

NOTE Confidence: 0.8680108

 $00:17:35.209 \longrightarrow 00:17:37.761$ within Yale can go in and look up

NOTE Confidence: 0.8680108

 $00:17:37.761 \longrightarrow 00:17:40.150$ genes and variants within generations.

NOTE Confidence: 0.8680108

 $00:17:40.150 \longrightarrow 00:17:42.030$ Data set to do queries.

NOTE Confidence: 0.8680108

 $00:17:42.030 \longrightarrow 00:17:43.910$ So with that I'll end.

NOTE Confidence: 0.8680108

 $00:17:43.910 \longrightarrow 00:17:46.661$ I'll thank the many many people who

 $00:17:46.661 \longrightarrow 00:17:49.177$ have helped to get us this far.

NOTE Confidence: 0.8680108

 $00{:}17{:}49.180 \dashrightarrow 00{:}17{:}51.490$ An R hopefully cheering us on to

NOTE Confidence: 0.8680108

 $00:17:51.490 \longrightarrow 00:17:54.302$ go further and to thank all the

NOTE Confidence: 0.8680108

 $00:17:54.302 \longrightarrow 00:17:56.054$ volunteers who have participated.

NOTE Confidence: 0.8680108

 $00:17:56.060 \longrightarrow 00:17:57.590$ In the last slide here,

NOTE Confidence: 0.8680108

00:17:57.590 --> 00:18:00.030 if you're within the sound of my voice,

NOTE Confidence: 0.8680108

 $00:18:00.030 \longrightarrow 00:18:01.860$ that means that you're a potential

NOTE Confidence: 0.8680108

 $00:18:01.860 \longrightarrow 00:18:03.080$ volunteer for generations also,

NOTE Confidence: 0.8680108

00:18:03.080 --> 00:18:04.904 and we invite you to join

NOTE Confidence: 0.8680108

 $00:18:04.904 \longrightarrow 00:18:05.816$ if you're interested.

NOTE Confidence: 0.8680108

 $00:18:05.820 \longrightarrow 00:18:07.350$ Here's how to reach us,

NOTE Confidence: 0.8680108

 $00{:}18{:}07.350 \dashrightarrow 00{:}18{:}09.541$ including a QR code will leave this

NOTE Confidence: 0.8680108

00:18:09.541 --> 00:18:11.954 up during the Q&A so that you can

NOTE Confidence: 0.8680108

00:18:11.954 --> 00:18:13.736 scan your phone over and generate

NOTE Confidence: 0.8680108

 $00:18:13.736 \longrightarrow 00:18:16.192$ an email to either ask us a question

 $00{:}18{:}16.192 \dashrightarrow 00{:}18{:}18.270$ or or reach the consenters who can

NOTE Confidence: 0.8680108

 $00{:}18{:}18.270 \dashrightarrow 00{:}18{:}20.160$ get you consented into the project.

NOTE Confidence: 0.8680108

 $00:18:20.160 \longrightarrow 00:18:21.680$ And with that I'll stop.

NOTE Confidence: 0.8680108

00:18:21.680 --> 00:18:22.622 Thanks very much.