NOTE Confidence: 0.97670954

00:00:00.160 --> 00:00:01.920 Funding for Yale Cancer Answers

NOTE Confidence: 0.97670954

00:00:01.920 --> 00:00:03.679 is provided by Smilow Cancer

NOTE Confidence: 0.97670954

00:00:03.679 --> 00:00:04.180 Hospital.

NOTE Confidence: 0.9530167

00:00:06.160 --> 00:00:08.000 Welcome to Yale Cancer Answers

NOTE Confidence: 0.9530167

00:00:08.000 --> 00:00:08.960 with the director of the

NOTE Confidence: 0.9530167

00:00:08.960 --> 00:00:10.719 Yale Cancer Center, doctor Eric

NOTE Confidence: 0.9530167

00:00:10.719 --> 00:00:11.219 Winer.

NOTE Confidence: 0.97708046

00:00:11.759 --> 00:00:13.860 Yale Cancer Answers features conversations

NOTE Confidence: 0.97708046

00:00:14.000 --> 00:00:14.820 with oncologists

NOTE Confidence: 0.8808917

00:00:16.195 --> 00:00:16.414 and specialists who are on

NOTE Confidence: 0.8808917

00:00:16.414 --> 00:00:17.059 the forefront of the battle

NOTE Confidence: 0.8808917

00:00:17.059 --> 00:00:18.338 to fight cancer. This week,

NOTE Confidence: 0.8808917

00:00:18.338 --> 00:00:18.819 it's a conversation about sickle

NOTE Confidence: 0.8808917

00:00:18.819 --> 00:00:19.555 cell disease with doctor Cece

NOTE Confidence: 0.8808917

00:00:19.555 --> 00:00:21.735 Calhoun. Doctor Calhoun is an

NOTE Confidence: 0.8808917

00:00:21.954 --> 00:00:23.395 assistant professor of medicine in

NOTE Confidence: 0.8808917

00:00:23.395 --> 00:00:25.395 hematology at the Yale School

NOTE Confidence: 0.8808917

00:00:25.395 --> 00:00:27.494 of Medicine. Here's doctor Winer.

NOTE Confidence: 0.98010135

00:00:31.050 --> 00:00:32.890 I usually start off just

NOTE Confidence: 0.98010135

00:00:32.890 --> 00:00:34.090 asking people a little bit

NOTE Confidence: 0.98010135

00:00:34.090 --> 00:00:34.989 about themselves.

00:00:36.649 --> 00:00:37.530 Maybe you could just tell us

00:00:38.570 --> 00:00:40.090 where you grew up and

NOTE Confidence: 0.9617338

00:00:40.090 --> 00:00:41.770 and where you've been and

00:00:42.650 --> 00:00:43.770 how it is that you

NOTE Confidence: 0.9996621

00:00:43.770 --> 00:00:44.670 became interested in

00:00:45.995 --> 00:00:47.854 sickle cell disease in particular.

NOTE Confidence: 0.97818565

00:00:48.795 --> 00:00:50.315 Absolutely. So I usually start

NOTE Confidence: 0.97818565

00:00:50.315 --> 00:00:51.435 off with my title. But

NOTE Confidence: 0.97818565

00:00:51.435 --> 00:00:52.475 since you asked me where

NOTE Confidence: 0.97818565

00:00:52.475 --> 00:00:53.995 I grew up, I'm from

NOTE Confidence: 0.97818565

00:00:53.995 --> 00:00:55.675 Detroit, Michigan. I'm a Midwest

NOTE Confidence: 0.97818565

00:00:55.675 --> 00:00:56.175 girl,

NOTE Confidence: 0.87684166

00:00:56.635 --> 00:00:58.415 born and raised, and

NOTE Confidence: 0.9774535

00:00:59.300 --> 00:01:00.580 had the pleasure of doing

NOTE Confidence: 0.9774535

00:01:00.580 --> 00:01:01.780 my medical school training in

NOTE Confidence: 0.9774535

00:01:01.780 --> 00:01:03.060 Detroit where I'm from, in

NOTE Confidence: 0.9774535

00:01:03.060 --> 00:01:04.500 my community that raised me

NOTE Confidence: 0.9774535

00:01:04.500 --> 00:01:05.540 and really supported me in

NOTE Confidence: 0.9774535

00:01:05.540 --> 00:01:06.680 my own medical journey.

NOTE Confidence: 0.980482

00:01:07.060 --> 00:01:08.020 It was during my time

NOTE Confidence: 0.980482

00:01:08.020 --> 00:01:09.140 in med school that I

NOTE Confidence: 0.980482

00:01:09.140 --> 00:01:10.180 had, I would say, my

NOTE Confidence: 0.980482

00:01:10.180 --> 00:01:11.080 first meaningful

NOTE Confidence: 0.99286026

00:01:11.380 --> 00:01:12.819 exposure to a patient with

NOTE Confidence: 0.99286026

00:01:12.819 --> 00:01:13.959 sickle cell disease.

NOTE Confidence: 0.9709098

00:01:15.185 --> 00:01:16.804 And it, for me, represented

NOTE Confidence: 0.9709098

00:01:16.865 --> 00:01:18.064 the nexus of so many

NOTE Confidence: 0.9709098

00:01:18.064 --> 00:01:19.505 things I like. It was

NOTE Confidence: 0.9709098

00:01:19.505 --> 00:01:21.045 the science. It was hematology.

NOTE Confidence: 0.9709098

00:01:21.185 --> 00:01:22.145 I love the red blood

NOTE Confidence: 0.9709098

00:01:22.145 --> 00:01:22.645 cell.

NOTE Confidence: 0.9332242

00:01:23.104 --> 00:01:23.844 It was,

NOTE Confidence: 0.99373513

00:01:24.944 --> 00:01:27.310 children and young adults with

NOTE Confidence: 0.99373513

00:01:27.310 --> 00:01:28.130 sickle cell,

NOTE Confidence: 0.9593186

00:01:28.590 --> 00:01:30.110 and the disease itself and

NOTE Confidence: 0.9593186

00:01:30.110 --> 00:01:31.250 giving to my community.

NOTE Confidence: 0.98278564

00:01:32.430 --> 00:01:33.630 And so it was there

NOTE Confidence: 0.98278564

00:01:33.630 --> 00:01:34.430 that I was like, this

NOTE Confidence: 0.98278564

00:01:34.430 --> 00:01:35.709 is a career path I

NOTE Confidence: 0.98278564

00:01:35.709 --> 00:01:37.150 wanna pursue. I wanna be

NOTE Confidence: 0.98278564

00:01:37.150 --> 00:01:37.730 a hematologist.

NOTE Confidence: 0.96414894

00:01:38.350 --> 00:01:40.050 And I am a lifespan

NOTE Confidence: 0.96414894

00:01:40.110 --> 00:01:42.115 hematologist here at Yale.

NOTE Confidence: 0.96414894

00:01:42.115 --> 00:01:43.095 That's great.

NOTE Confidence: 0.9536304

00:01:44.194 --> 00:01:46.275 And actually, you're trained

NOTE Confidence: 0.9536304

00:01:46.275 --> 00:01:47.715 as a pediatrician, are you

NOTE Confidence: 0.9536304

00:01:47.715 --> 00:01:48.215 not?

NOTE Confidence: 0.93714136

00:01:48.674 --> 00:01:50.695 Yes. I am.

NOTE Confidence: 0.98685765

00:01:51.155 --> 00:01:52.115 And I know you still

NOTE Confidence: 0.98685765

00:01:52.115 --> 00:01:53.795 do a little pediatrics, but

NOTE Confidence: 0.98685765

00:01:53.795 --> 00:01:55.395 you also very much focus

NOTE Confidence: 0.98685765

00:01:55.395 --> 00:01:57.060 on adults

NOTE Confidence: 0.9950271

00:01:57.540 --> 00:01:59.079 with sickle cell disease.

NOTE Confidence: 0.998291

00:02:00.899 --> 00:02:02.100 Do you mind just starting

NOTE Confidence: 0.998291

00:02:02.100 --> 00:02:03.000 off explaining

NOTE Confidence: 0.9998954

00:02:03.460 --> 00:02:04.680 to our listeners

NOTE Confidence: 0.94111156

00:02:05.539 --> 00:02:08.040 what sickle cell disease is,

NOTE Confidence: 0.94111156

00:02:08.180 --> 00:02:08.919 how it

00:02:11.114 --> 00:02:11.614 occurs?

NOTE Confidence: 0.9781514

00:02:12.474 --> 00:02:13.915 Yeah. Absolutely. I'll do my

NOTE Confidence: 0.9781514

00:02:13.915 --> 00:02:15.514 best to be brief because

NOTE Confidence: 0.9781514

00:02:15.514 --> 00:02:16.955 it's something I'm really excited

NOTE Confidence: 0.9781514

00:02:16.955 --> 00:02:18.235 about.

00:02:19.355 --> 00:02:20.395 This is one where

NOTE Confidence: 0.9781514

00:02:20.395 --> 00:02:21.194 I think we need the

NOTE Confidence: 0.9781514

00:02:21.194 --> 00:02:21.935 full explanation.

NOTE Confidence: 0.90608263

00:02:22.290 --> 00:02:24.050 Okay. Sounds good.

NOTE Confidence: 0.90608263

00:02:24.050 --> 00:02:25.430 And including the malaria connection.

NOTE Confidence: 0.97457546

00:02:25.970 --> 00:02:27.510 Oh, okay. Sounds good. So

NOTE Confidence: 0.97457546

00:02:27.730 --> 00:02:29.090 sickle cell disease is a

NOTE Confidence: 0.97457546

00:02:29.090 --> 00:02:30.130 disease of our red blood

NOTE Confidence: 0.97457546

00:02:30.130 --> 00:02:31.410 cell, which as you know,

NOTE Confidence: 0.97457546

00:02:31.410 --> 00:02:33.250 transports oxygen around our body,

NOTE Confidence: 0.97457546

00:02:33.250 --> 00:02:34.370 helping to keep all of

NOTE Confidence: 0.97457546

00:02:34.370 --> 00:02:35.925 our tissues healthy and safe.

NOTE Confidence: 0.976821

00:02:36.485 --> 00:02:37.925 Normally, a red blood cell

NOTE Confidence: 0.976821

00:02:37.925 --> 00:02:39.205 looks like what I describe

NOTE Confidence: 0.976821

00:02:39.205 --> 00:02:40.725 as a jelly donut. The

NOTE Confidence: 0.976821

00:02:40.725 --> 00:02:42.264 technical term, it's a biconcave

NOTE Confidence: 0.976821

00:02:42.485 --> 00:02:42.985 disc.

NOTE Confidence: 0.9758556

00:02:43.285 --> 00:02:44.325 But when you have sickle

NOTE Confidence: 0.9758556

00:02:44.325 --> 00:02:45.925 cell, you are born with,

NOTE Confidence: 0.9758556

00:02:45.925 --> 00:02:46.905 so you inherited,

NOTE Confidence: 0.9592412

00:02:47.685 --> 00:02:50.040 a genetic change wherein which

NOTE Confidence: 0.9592412

00:02:50.200 --> 00:02:51.239 instead of your red blood

NOTE Confidence: 0.9592412

00:02:51.239 --> 00:02:52.680 cells being shaped like a

NOTE Confidence: 0.9592412

00:02:52.680 --> 00:02:53.659 jelly donut,

NOTE Confidence: 0.9799713

00:02:53.959 --> 00:02:55.000 they're shaped more like a

NOTE Confidence: 0.9799713

00:02:55.000 --> 00:02:57.159 crescent, banana, or a sickle,

NOTE Confidence: 0.9799713

00:02:57.159 --> 00:02:58.120 which is why it's called

NOTE Confidence: 0.9799713

00:02:58.120 --> 00:02:58.939 sickle cell.

NOTE Confidence: 0.9548659

00:02:59.879 --> 00:03:01.079 In addition to being shaped

NOTE Confidence: 0.9548659

00:03:01.079 --> 00:03:02.919 differently, they're also quite sticky

NOTE Confidence: 0.9548659

00:03:02.919 --> 00:03:04.280 and quite brittle. And so

NOTE Confidence: 0.9548659

00:03:04.280 --> 00:03:05.239 if we think about our

NOTE Confidence: 0.9548659

00:03:05.239 --> 00:03:05.835 blood vessels

NOTE Confidence: 0.9737951

00:03:07.915 --> 00:03:09.675 donut cells are carrying oxygen

NOTE Confidence: 0.9737951

00:03:09.675 --> 00:03:11.275 around, very squishy, bouncing off

NOTE Confidence: 0.9737951

00:03:11.275 --> 00:03:12.315 the sides of the wall,

NOTE Confidence: 0.9737951

00:03:12.315 --> 00:03:13.755 delivering oxygen to where it

NOTE Confidence: 0.9737951

00:03:13.755 --> 00:03:14.655 needs to go.

NOTE Confidence: 0.99857306

00:03:14.955 --> 00:03:16.635 But if you replace upwards

NOTE Confidence: 0.99857306

00:03:16.635 --> 00:03:18.155 of ninety five percent of

NOTE Confidence: 0.99857306

00:03:18.155 --> 00:03:18.895 those cells

NOTE Confidence: 0.9885388

00:03:19.290 --> 00:03:20.650 with sickled cells that are

NOTE Confidence: 0.9885388

00:03:20.650 --> 00:03:22.090 shaped differently, that are brittle,

NOTE Confidence: 0.9885388

00:03:22.090 --> 00:03:23.050 that are sticky, you can

NOTE Confidence: 0.9885388

00:03:23.050 --> 00:03:23.550 imagine

NOTE Confidence: 0.93367016

00:03:23.930 --> 00:03:25.210 maybe they're injuring the sides

NOTE Confidence: 0.93367016

00:03:25.210 --> 00:03:26.910 of those blood vessels or

NOTE Confidence: 0.98416567

00:03:27.210 --> 00:03:28.410 sticking to each other or

NOTE Confidence: 0.98416567

00:03:28.410 --> 00:03:29.770 maybe sticking to the sides

NOTE Confidence: 0.98416567

00:03:29.770 --> 00:03:31.070 of the blood vessel wall.

NOTE Confidence: 0.98416567

00:03:31.290 --> 00:03:32.590 And it is that inflammatory

NOTE Confidence: 0.97883654

00:03:32.889 --> 00:03:34.110 process, that inflammation

NOTE Confidence: 0.94728225

00:03:34.645 --> 00:03:36.005 from damage,

NOTE Confidence: 0.94728225

00:03:36.005 --> 00:03:37.685 that sick sticking together

NOTE Confidence: 0.94728225

00:03:37.685 --> 00:03:39.125 and preventing the flow of

NOTE Confidence: 0.94728225

00:03:39.125 --> 00:03:40.165 blood to other parts of

NOTE Confidence: 0.94728225

00:03:40.165 --> 00:03:40.745 our body

NOTE Confidence: 0.9877535

00:03:41.285 --> 00:03:42.565 that really is behind the

NOTE Confidence: 0.9877535

00:03:42.565 --> 00:03:43.865 physiology or pathophysiology

NOTE Confidence: 0.9745032

00:03:44.325 --> 00:03:45.605 of sickle cell.

NOTE Confidence: 0.9745032

00:03:45.605 --> 00:03:47.045 If I can just jump in

NOTE Confidence: 0.9745032

00:03:47.045 --> 00:03:48.405 for a sec, this all

NOTE Confidence: 0.9745032

00:03:48.405 --> 00:03:48.905 happens

NOTE Confidence: 0.9996332

00:03:49.629 --> 00:03:50.930 because of the substitution

NOTE Confidence: 0.9962862

00:03:51.390 --> 00:03:53.330 of a single amino acid.

NOTE Confidence: 0.9962862

00:03:53.390 --> 00:03:54.370 Is that correct?

NOTE Confidence: 0.9752781

00:03:54.750 --> 00:03:56.110 That's a hundred percent correct.

NOTE Confidence: 0.9752781

00:03:56.110 --> 00:03:57.470 And we found out about

NOTE Confidence: 0.9752781

00:03:57.470 --> 00:03:58.989 this in the early nineteen

NOTE Confidence: 0.9752781

00:03:58.989 --> 00:04:00.849 hundreds that sickle cell was described

NOTE Confidence: 0.9980854

00:04:01.724 --> 00:04:03.905 as just this one small genetic

NOTE Confidence: 0.9980854

00:04:03.965 --> 00:04:05.665 change has so many implications

NOTE Confidence: 0.9985209

00:04:06.125 --> 00:04:07.805 for every organ in our

NOTE Confidence: 0.9985209

00:04:07.805 --> 00:04:09.665 body. But that small genetic

NOTE Confidence: 0.9985209

00:04:09.724 --> 00:04:10.224 change

NOTE Confidence: 0.9993137

00:04:10.525 --> 00:04:12.305 leads to the gene

NOTE Confidence: 0.9488178

00:04:12.924 --> 00:04:14.224 not functioning normally.

NOTE Confidence: 0.99925697

00:04:15.150 --> 00:04:15.650 Absolutely.

NOTE Confidence: 0.9912776

00:04:16.029 --> 00:04:17.070 And so you might say

NOTE Confidence: 0.9912776

00:04:17.070 --> 00:04:18.110 to yourself, well, why do

NOTE Confidence: 0.9912776

00:04:18.110 --> 00:04:19.389 we have this? You know,

NOTE Confidence: 0.9912776

00:04:19.389 --> 00:04:20.830 if this is something that's

NOTE Confidence: 0.9912776

00:04:20.830 --> 00:04:22.430 bad, why does sickle cell

NOTE Confidence: 0.9912776

00:04:22.430 --> 00:04:24.050 disease why is it pervasive?

NOTE Confidence: 0.9984124

00:04:24.509 --> 00:04:25.310 Why is it the most

NOTE Confidence: 0.9984124

00:04:25.310 --> 00:04:27.229 common monogenic disorder in the

NOTE Confidence: 0.9984124

00:04:27.229 --> 00:04:28.509 world? And so you kind

NOTE Confidence: 0.9984124

00:04:28.509 --> 00:04:29.654 of alluded to this

NOTE Confidence: 0.97607636

00:04:30.135 --> 00:04:31.835 a bit earlier in that

NOTE Confidence: 0.97607636

00:04:32.055 --> 00:04:33.335 we believe that sickle cell

NOTE Confidence: 0.97607636

00:04:33.335 --> 00:04:35.435 trait is protective against malaria.

NOTE Confidence: 0.9971521

00:04:36.135 --> 00:04:38.395 So malaria is a

NOTE Confidence: 0.985312

00:04:38.855 --> 00:04:40.615 little kind of protozoa that

NOTE Confidence: 0.985312

00:04:40.615 --> 00:04:41.575 finds a home in our

NOTE Confidence: 0.985312

00:04:41.575 --> 00:04:42.855 red blood cells. It really

NOTE Confidence: 0.985312

00:04:42.855 --> 00:04:44.535 thrives there in a normal

NOTE Confidence: 0.985312

00:04:44.535 --> 00:04:46.000 red blood cell. But if

NOTE Confidence: 0.985312

00:04:46.000 --> 00:04:47.360 that cell is shaped differently

NOTE Confidence: 0.985312

00:04:47.360 --> 00:04:47.860 or

NOTE Confidence: 0.9975711

00:04:48.240 --> 00:04:49.680 if the oxygen is lower,

NOTE Confidence: 0.9975711

00:04:49.680 --> 00:04:50.640 then it can't live there.

NOTE Confidence: 0.9975711

00:04:50.640 --> 00:04:52.160 So sickle cell trait is

NOTE Confidence: 0.9975711

00:04:52.160 --> 00:04:53.460 protective against malaria

NOTE Confidence: 0.9624942

00:04:53.920 --> 00:04:54.720 and which is why it

NOTE Confidence: 0.9624942

00:04:54.720 --> 00:04:56.500 has continued to persist worldwide.

NOTE Confidence: 0.9624942

00:04:56.720 --> 00:04:57.920 And do you wanna just

NOTE Confidence: 0.9624942

00:04:57.920 --> 00:04:58.935 tell us for a second

NOTE Confidence: 0.9624942

00:04:58.935 --> 00:05:00.854 the difference between sickle cell

NOTE Confidence: 0.9624942

00:05:00.854 --> 00:05:02.955 trait and sickle cell anemia?

NOTE Confidence: 0.9919617

00:05:03.574 --> 00:05:05.814 Yeah. Absolutely. So, you know,

NOTE Confidence: 0.9919617

00:05:05.814 --> 00:05:07.414 like many things in life,

NOTE Confidence: 0.9919617

00:05:07.735 --> 00:05:08.694 we get some from our

NOTE Confidence: 0.9919617

00:05:08.694 --> 00:05:09.654 mom and some from our

NOTE Confidence: 0.9919617

00:05:09.654 --> 00:05:11.254 dad. And so sickle cell

NOTE Confidence: 0.9919617

00:05:11.254 --> 00:05:13.495 disease is autosomal recessive, meaning

NOTE Confidence: 0.9919617

00:05:13.495 --> 00:05:14.880 that in order for you

NOTE Confidence: 0.9919617

00:05:14.880 --> 00:05:16.420 to have the physical manifestation

NOTE Confidence: 0.9919617

00:05:16.560 --> 00:05:17.300 of the disease,

NOTE Confidence: 0.9980079

00:05:17.760 --> 00:05:19.040 you need to have one

NOTE Confidence: 0.9980079

00:05:19.040 --> 00:05:20.160 part of sickle cell from

NOTE Confidence: 0.9980079

00:05:20.160 --> 00:05:21.200 your mom and one part

NOTE Confidence: 0.9980079

00:05:21.200 --> 00:05:22.320 of sickle cell from your

NOTE Confidence: 0.9980079

00:05:22.320 --> 00:05:22.820 dad.

NOTE Confidence: 0.98503685

00:05:23.200 --> 00:05:25.120 So those parents can be

NOTE Confidence: 0.98503685

00:05:25.120 --> 00:05:27.040 sickle cell carriers or carry

NOTE Confidence: 0.98503685

00:05:27.040 --> 00:05:27.779 the trait

NOTE Confidence: 0.98823553

00:05:28.160 --> 00:05:29.700 and not have any

NOTE Confidence: 0.9965469

00:05:30.025 --> 00:05:30.845 overt manifestations

NOTE Confidence: 0.98488724

00:05:31.224 --> 00:05:32.745 of sickle cell disease. But

NOTE Confidence: 0.98488724

00:05:32.745 --> 00:05:34.345 sickle cell anemia is when

NOTE Confidence: 0.98488724

00:05:34.345 --> 00:05:35.565 you have both copies

NOTE Confidence: 0.9693336

00:05:35.944 --> 00:05:36.904 and have full,

NOTE Confidence: 0.92312014

00:05:37.944 --> 00:05:40.264 full fully displayed disease. But

NOTE Confidence: 0.92312014

00:05:40.264 --> 00:05:41.865 so having the trait is

NOTE Confidence: 0.92312014

00:05:41.865 --> 00:05:42.360 enough

NOTE Confidence: 0.91812944

00:05:42.759 --> 00:05:44.199 in and of itself to

NOTE Confidence: 0.91812944

00:05:44.199 --> 00:05:46.060 put be protective against malaria.

NOTE Confidence: 0.9903144

00:05:46.759 --> 00:05:48.279 Yes. That is why it

NOTE Confidence: 0.9903144

00:05:48.279 --> 00:05:50.039 has persisted. And when we

NOTE Confidence: 0.9903144

00:05:50.039 --> 00:05:52.439 think about the mechanisms behind

NOTE Confidence: 0.9903144

00:05:52.439 --> 00:05:53.719 that, there are a few

NOTE Confidence: 0.9903144

00:05:53.719 --> 00:05:55.479 different theories. I think, the

NOTE Confidence: 0.9903144

00:05:55.479 --> 00:05:57.259 most common theory is around

NOTE Confidence: 0.99597585

00:05:57.784 --> 00:05:59.464 that cell being completely shaped

NOTE Confidence: 0.99597585

00:05:59.464 --> 00:06:00.985 differently. But the other thing

NOTE Confidence: 0.99597585

00:06:00.985 --> 00:06:02.985 I mentioned earlier was the

NOTE Confidence: 0.99597585

00:06:02.985 --> 00:06:05.085 oxygen environment that's not conducive

NOTE Confidence: 0.99597585

00:06:05.145 --> 00:06:06.604 to replication for,

NOTE Confidence: 0.95813787

00:06:07.145 --> 00:06:09.245 that malaria parasite. So,

NOTE Confidence: 0.94939613

00:06:09.705 --> 00:06:10.824 that is the kinda second

NOTE Confidence: 0.94939613

00:06:10.824 --> 00:06:12.400 thing. If we wanna get

NOTE Confidence: 0.94939613

00:06:12.400 --> 00:06:13.839 really nerdy about it. Yeah.

NOTE Confidence: 0.94939613

00:06:13.839 --> 00:06:15.040 No. No. No. No. That

NOTE Confidence: 0.94939613

00:06:15.120 --> 00:06:15.620 it's

NOTE Confidence: 0.9777484

00:06:17.200 --> 00:06:19.440 it's it's good. And, you

NOTE Confidence: 0.9777484

00:06:19.440 --> 00:06:21.040 know, in a climate where

NOTE Confidence: 0.9777484

00:06:21.040 --> 00:06:22.240 there was a lot of

NOTE Confidence: 0.9777484

00:06:22.240 --> 00:06:22.740 malaria,

NOTE Confidence: 0.98167235

00:06:23.440 --> 00:06:24.560 you know, that is in

NOTE Confidence: 0.98167235

00:06:24.560 --> 00:06:25.060 Africa,

NOTE Confidence: 0.8649957

00:06:26.735 --> 00:06:27.634 then in fact,

NOTE Confidence: 0.9862222

00:06:27.935 --> 00:06:29.294 it makes sense that people

NOTE Confidence: 0.9862222

00:06:29.294 --> 00:06:30.654 with sickle cell trait would

NOTE Confidence: 0.9862222

00:06:30.654 --> 00:06:32.095 have an advantage. They would

NOTE Confidence: 0.9862222

00:06:32.095 --> 00:06:33.694 survive their malaria, they would

NOTE Confidence: 0.9862222

00:06:33.694 --> 00:06:34.914 go on and

NOTE Confidence: 0.8809687

00:06:35.375 --> 00:06:36.194 have children.

NOTE Confidence: 0.96028924

00:06:36.895 --> 00:06:38.435 And some of those children

NOTE Confidence: 0.96028924

00:06:38.735 --> 00:06:39.180 or

NOTE Confidence: 0.95296603

00:06:39.740 --> 00:06:41.419 theoretically, one in four of

NOTE Confidence: 0.95296603

00:06:41.419 --> 00:06:43.039 children from the that

NOTE Confidence: 0.9949081

00:06:43.339 --> 00:06:44.779 that arise from two people

NOTE Confidence: 0.9949081

00:06:44.779 --> 00:06:46.460 who have trait would have

NOTE Confidence: 0.9949081

00:06:46.460 --> 00:06:47.600 sickle cell disease.

NOTE Confidence: 0.986059

00:06:48.460 --> 00:06:49.900 Yes. And we find that

NOTE Confidence: 0.986059

00:06:49.900 --> 00:06:51.820 worldwide, again, sickle cell disease

NOTE Confidence: 0.986059

00:06:51.820 --> 00:06:53.180 is still the most common

NOTE Confidence: 0.986059

00:06:53.180 --> 00:06:53.680 monogenic

NOTE Confidence: 0.95956755

00:06:54.495 --> 00:06:56.175 blood disorder because it's not

NOTE Confidence: 0.95956755

00:06:56.175 --> 00:06:57.935 just Africa, but also sub

NOTE Confidence: 0.95956755

00:06:58.255 --> 00:06:59.635 but also, excuse me, India,

NOTE Confidence: 0.95956755

00:06:59.855 --> 00:07:00.495 parts of,

NOTE Confidence: 0.8425738

00:07:01.135 --> 00:07:02.195 Arab America, Mediterranean,

NOTE Confidence: 0.9750417

00:07:03.295 --> 00:07:05.075 where sickle cell disease persists.

NOTE Confidence: 0.9750417

00:07:05.215 --> 00:07:07.215 And so we estimate that

NOTE Confidence: 0.9750417

00:07:07.215 --> 00:07:08.415 there are about three hundred

NOTE Confidence: 0.9750417

00:07:08.415 --> 00:07:10.410 and sixty thousand new births

NOTE Confidence: 0.9750417

00:07:10.410 --> 00:07:10.910 worldwide,

NOTE Confidence: 0.99604225

00:07:12.090 --> 00:07:13.770 each year. So it continues

NOTE Confidence: 0.99604225

00:07:13.770 --> 00:07:14.430 to remain

NOTE Confidence: 0.9894576

00:07:15.130 --> 00:07:16.970 super prevalent, and the incidence

NOTE Confidence: 0.9894576

00:07:16.970 --> 00:07:19.130 is also increasing. So before

NOTE Confidence: 0.9894576

00:07:19.130 --> 00:07:21.050 we talk about some of

NOTE Confidence: 0.9894576

00:07:21.050 --> 00:07:23.130 the complications from sickle cell

NOTE Confidence: 0.9894576

00:07:23.130 --> 00:07:23.630 anemia,

NOTE Confidence: 0.99396926

00:07:24.975 --> 00:07:26.035 Maybe we can take

NOTE Confidence: 0.9851676

00:07:26.575 --> 00:07:28.415 another step down that sort

NOTE Confidence: 0.9851676

00:07:28.415 --> 00:07:29.635 of nerdy pathway

NOTE Confidence: 0.9791066

00:07:29.935 --> 00:07:32.015 as you described it. And

NOTE Confidence: 0.9791066

00:07:32.015 --> 00:07:33.535 you could just explain to

NOTE Confidence: 0.9791066

00:07:33.535 --> 00:07:34.755 the audience why

NOTE Confidence: 0.9589031

00:07:35.055 --> 00:07:35.555 sometimes

NOTE Confidence: 0.6328524

00:07:36.655 --> 00:07:37.155 in

NOTE Confidence: 0.9994486

00:07:38.330 --> 00:07:38.830 very

NOTE Confidence: 0.989954

00:07:39.210 --> 00:07:40.110 young children,

NOTE Confidence: 0.9813854

00:07:41.370 --> 00:07:43.310 that is after they're born,

NOTE Confidence: 0.9813854

00:07:43.450 --> 00:07:45.450 that that sickle cell disease

NOTE Confidence: 0.9813854

00:07:45.450 --> 00:07:46.570 isn't really much of a

NOTE Confidence: 0.9813854

00:07:46.570 --> 00:07:48.270 problem at first because

NOTE Confidence: 0.986887

00:07:48.650 --> 00:07:50.490 there's still something else around

NOTE Confidence: 0.986887

00:07:50.490 --> 00:07:52.030 that that helps them.

NOTE Confidence: 0.9731385

00:07:52.785 --> 00:07:54.305 So I do wanna say,

NOTE Confidence: 0.9731385

00:07:54.305 --> 00:07:55.665 I believe that being a

NOTE Confidence: 0.9731385

00:07:55.665 --> 00:07:57.605 nerd is very cool. Obviously,

NOTE Confidence: 0.9731385

00:07:57.745 --> 00:07:58.645 I have a bias.

NOTE Confidence: 0.94021654

00:07:59.505 --> 00:08:00.005 But,

NOTE Confidence: 0.9832529

00:08:00.785 --> 00:08:02.245 just to answer your question,

NOTE Confidence: 0.9832529

00:08:02.385 --> 00:08:03.745 absolutely. And I think we'll

NOTE Confidence: 0.9832529

00:08:03.745 --> 00:08:05.185 revisit this concept as we

NOTE Confidence: 0.9832529

00:08:05.185 --> 00:08:06.385 move further along in our

NOTE Confidence: 0.9832529

00:08:06.385 --> 00:08:07.445 conversation. But,

NOTE Confidence: 0.926468

00:08:07.939 --> 00:08:08.819 you know, as we talked

NOTE Confidence: 0.926468

00:08:08.819 --> 00:08:10.500 about sickle cells inherited. And

NOTE Confidence: 0.926468

00:08:10.500 --> 00:08:11.800 so as you mentioned,

NOTE Confidence: 0.96367794

00:08:12.259 --> 00:08:13.939 people and infants are born

NOTE Confidence: 0.96367794

00:08:13.939 --> 00:08:15.379 with sickle cell. But when

NOTE Confidence: 0.96367794

00:08:15.379 --> 00:08:17.240 they're younger, the physical manifestations

NOTE Confidence: 0.9977178

00:08:17.699 --> 00:08:19.000 are not as prominent.

NOTE Confidence: 0.99958766

00:08:19.539 --> 00:08:20.715 And it's not just because

NOTE Confidence: 0.99958766

00:08:20.794 --> 00:08:21.855 children are resilient

NOTE Confidence: 0.984773

00:08:22.315 --> 00:08:24.395 and, their regenerative capacity of

NOTE Confidence: 0.984773

00:08:24.395 --> 00:08:26.155 youth is greater, but it's

NOTE Confidence: 0.984773

00:08:26.155 --> 00:08:27.595 also because of the presence

NOTE Confidence: 0.984773

00:08:27.595 --> 00:08:28.574 of fetal hemoglobin,

NOTE Confidence: 0.99145347

00:08:29.275 --> 00:08:30.715 meaning the hemoglobin that we

NOTE Confidence: 0.99145347

00:08:30.715 --> 00:08:31.935 make when we're a baby.

NOTE Confidence: 0.9812472

00:08:32.395 --> 00:08:34.235 These cells are even larger.

NOTE Confidence: 0.9812472

00:08:34.235 --> 00:08:35.195 I describe them to my

NOTE Confidence: 0.9812472

00:08:35.195 --> 00:08:37.130 patients as really fat, juicy

NOTE Confidence: 0.9812472

00:08:37.130 --> 00:08:38.410 cells that hold on to

NOTE Confidence: 0.9812472

00:08:38.410 --> 00:08:39.949 oxygen quite well

NOTE Confidence: 0.9845243

00:08:40.250 --> 00:08:41.389 and really mitigate

NOTE Confidence: 0.95945156

00:08:41.769 --> 00:08:42.990 a lot of the symptoms,

NOTE Confidence: 0.95945156

00:08:43.050 --> 00:08:44.750 clinical symptoms of sickle cell.

NOTE Confidence: 0.95959944

00:08:45.370 --> 00:08:47.069 When we think about persistence

NOTE Confidence: 0.95959944

00:08:47.130 --> 00:08:48.649 into adulthood, so people with

NOTE Confidence: 0.95959944

00:08:48.649 --> 00:08:49.769 sickle cell disease who have

NOTE Confidence: 0.95959944

00:08:49.769 --> 00:08:51.209 more fetal hemoglobin tend to

NOTE Confidence: 0.95959944

00:08:51.209 --> 00:08:52.785 do better. And, certainly, as

NOTE Confidence: 0.95959944

00:08:52.785 --> 00:08:53.605 we think about

NOTE Confidence: 0.9968138

00:08:53.985 --> 00:08:56.145 our disease modifying therapies and

NOTE Confidence: 0.9968138

00:08:56.145 --> 00:08:57.125 curative therapies,

NOTE Confidence: 0.9971425

00:08:57.745 --> 00:08:59.605 really increasing that fetal hemoglobin

NOTE Confidence: 0.9971425

00:08:59.665 --> 00:09:00.885 is something we target.

NOTE Confidence: 0.99937934

00:09:01.825 --> 00:09:02.325 Wow.

NOTE Confidence: 0.9917835

00:09:03.985 --> 00:09:05.045 So let's

NOTE Confidence: 0.9953645

00:09:05.429 --> 00:09:06.790 talk a little bit about

NOTE Confidence: 0.9953645

00:09:06.790 --> 00:09:08.470 what happens when all those

NOTE Confidence: 0.9953645

00:09:08.470 --> 00:09:10.710 sticky cells clog up all

NOTE Confidence: 0.9953645

00:09:10.710 --> 00:09:11.770 the blood vessels.

NOTE Confidence: 0.9936623

00:09:12.710 --> 00:09:14.150 And maybe you could talk

NOTE Confidence: 0.9936623

00:09:14.150 --> 00:09:15.530 about both some of

NOTE Confidence: 0.9875903

00:09:16.309 --> 00:09:18.070 the common symptoms that people

NOTE Confidence: 0.9875903

00:09:18.070 --> 00:09:19.190 have first, and then we'll

NOTE Confidence: 0.9875903

00:09:19.190 --> 00:09:20.470 get into some of the

NOTE Confidence: 0.9875903

00:09:20.470 --> 00:09:21.075 sort of

NOTE Confidence: 0.97780037

00:09:21.715 --> 00:09:23.795 organ damage and complications that

NOTE Confidence: 0.97780037

00:09:23.795 --> 00:09:24.535 can arise.

NOTE Confidence: 0.9923399

00:09:25.715 --> 00:09:27.635 Absolutely. So the hallmark of

NOTE Confidence: 0.9923399

00:09:27.635 --> 00:09:29.155 sickle cell disease clinically is

NOTE Confidence: 0.9923399

00:09:29.155 --> 00:09:29.655 pain.

NOTE Confidence: 0.99632084

00:09:30.515 --> 00:09:31.875 I believe that when most

NOTE Confidence: 0.99632084

00:09:31.875 --> 00:09:33.335 people if you have

NOTE Confidence: 0.991484

00:09:33.795 --> 00:09:35.475 a personal connection to someone

NOTE Confidence: 0.991484

00:09:35.475 --> 00:09:36.775 with sickle cell disease,

NOTE Confidence: 0.9992637

00:09:37.320 --> 00:09:38.540 then you think about

NOTE Confidence: 0.8975252

00:09:38.920 --> 00:09:39.500 about unpredictable,

NOTE Confidence: 0.9735267

00:09:40.040 --> 00:09:41.960 severe, debilitating pain that affects

NOTE Confidence: 0.9735267

00:09:41.960 --> 00:09:43.100 their quality of life.

NOTE Confidence: 0.9784494

00:09:43.640 --> 00:09:44.520 That has a lot to

NOTE Confidence: 0.9784494

00:09:44.520 --> 00:09:45.400 do with the lack of

NOTE Confidence: 0.9784494

00:09:45.400 --> 00:09:47.320 that oxygen blood flow, but

NOTE Confidence: 0.9784494

00:09:47.320 --> 00:09:48.840 also that return of oxygen.

NOTE Confidence: 0.9784494

00:09:48.840 --> 00:09:50.280 Like, if your arm has

NOTE Confidence: 0.9784494

00:09:50.280 --> 00:09:51.480 ever fallen asleep and then

NOTE Confidence: 0.9784494

00:09:51.480 --> 00:09:52.815 the circulation comes back,

NOTE Confidence: 0.9950037

00:09:53.695 --> 00:09:54.815 but that pain is severe

NOTE Confidence: 0.9950037

00:09:54.815 --> 00:09:56.495 and often equated to something

NOTE Confidence: 0.9950037

00:09:56.495 --> 00:09:57.795 like a long bone fracture,

NOTE Confidence: 0.99837244

00:09:58.655 --> 00:09:59.955 and can be very disruptive.

NOTE Confidence: 0.99109733

00:10:00.655 --> 00:10:02.335 But because sickle cell disease

NOTE Confidence: 0.99109733

00:10:02.335 --> 00:10:03.135 is a disease of the

NOTE Confidence: 0.99109733

00:10:03.135 --> 00:10:04.255 red blood cell, that means

NOTE Confidence: 0.99109733

00:10:04.255 --> 00:10:06.095 everywhere that blood goes, sickle

NOTE Confidence: 0.99109733

00:10:06.095 --> 00:10:07.155 cells can impact.

NOTE Confidence: 0.9975313

00:10:07.570 --> 00:10:08.690 And so when we think

NOTE Confidence: 0.9975313

00:10:08.690 --> 00:10:10.209 about other types of organ

NOTE Confidence: 0.9975313

00:10:10.209 --> 00:10:10.709 damage,

NOTE Confidence: 0.9980262

00:10:11.170 --> 00:10:12.550 we we screen for,

NOTE Confidence: 0.97066945

00:10:13.170 --> 00:10:14.929 eye damage like retinopathy. We

NOTE Confidence: 0.97066945

00:10:14.929 --> 00:10:16.209 think about the kidneys and

NOTE Confidence: 0.97066945

00:10:16.209 --> 00:10:17.329 making sure the kidneys are

NOTE Confidence: 0.97066945

00:10:17.329 --> 00:10:17.829 okay.

NOTE Confidence: 0.9696529

00:10:18.610 --> 00:10:19.809 Here at Yale, one of

NOTE Confidence: 0.9696529

00:10:19.809 --> 00:10:21.250 our trainees is really looking

NOTE Confidence: 0.9696529

00:10:21.250 --> 00:10:23.365 at the impact of neurologic

NOTE Confidence: 0.9696529

00:10:23.505 --> 00:10:25.445 complications both subclinical

NOTE Confidence: 0.9715843

00:10:26.065 --> 00:10:28.145 and overtly, most notably stroke,

NOTE Confidence: 0.9715843

00:10:28.145 --> 00:10:29.025 which is what we have

NOTE Confidence: 0.9715843

00:10:29.025 --> 00:10:29.905 a lot of data and

NOTE Confidence: 0.9715843

00:10:29.905 --> 00:10:31.425 information about in sickle cell

NOTE Confidence: 0.9715843

00:10:31.425 --> 00:10:32.705 disease, but people don't talk

NOTE Confidence: 0.9715843

00:10:32.705 --> 00:10:33.205 about.

NOTE Confidence: 0.99923885

00:10:33.825 --> 00:10:35.585 Sickle cell disease affects every

NOTE Confidence: 0.99923885

00:10:35.585 --> 00:10:36.645 part of the body.

NOTE Confidence: 0.8555953

00:10:38.890 --> 00:10:40.490 And typically when people are

NOTE Confidence: 0.8555953

00:10:40.490 --> 00:10:40.990 diagnosed,

NOTE Confidence: 0.9922798

00:10:41.370 --> 00:10:43.130 are they diagnosed as young

NOTE Confidence: 0.9922798

00:10:43.130 --> 00:10:43.630 children?

NOTE Confidence: 0.99021363

00:10:44.890 --> 00:10:46.350 So here in the US,

NOTE Confidence: 0.99021363

00:10:46.490 --> 00:10:48.170 due to the collaboration of

NOTE Confidence: 0.99021363

00:10:48.170 --> 00:10:50.090 many centers across the United

NOTE Confidence: 0.99021363

00:10:50.090 --> 00:10:51.150 States and

NOTE Confidence: 0.927882

00:10:51.524 --> 00:10:52.985 tremendous advocacy efforts,

NOTE Confidence: 0.99711215

00:10:53.444 --> 00:10:54.725 children with sickle cell disease

NOTE Confidence: 0.99711215

00:10:54.725 --> 00:10:55.845 born in the US are

NOTE Confidence: 0.99711215

00:10:55.845 --> 00:10:57.444 diagnosed on a newborn screen

NOTE Confidence: 0.99711215

00:10:57.444 --> 00:10:57.944 test.

NOTE Confidence: 0.9795747

00:10:58.324 --> 00:10:59.605 So many of the audience

NOTE Confidence: 0.9795747

00:10:59.605 --> 00:11:00.644 may remember they have a

NOTE Confidence: 0.9795747

00:11:00.644 --> 00:11:01.764 kid, and maybe they'll do

NOTE Confidence: 0.9795747

00:11:01.764 --> 00:11:02.725 a heel prick and get

NOTE Confidence: 0.9795747

00:11:02.725 --> 00:11:03.764 a drop of blood. And

NOTE Confidence: 0.9795747

00:11:03.764 --> 00:11:05.625 it tests for many inherited

NOTE Confidence: 0.9795747

00:11:05.764 --> 00:11:06.745 genetic disorders,

NOTE Confidence: 0.977908

00:11:07.350 --> 00:11:08.309 and one of those is

NOTE Confidence: 0.977908

00:11:08.309 --> 00:11:09.910 sickle cell. And what that

NOTE Confidence: 0.977908

00:11:09.910 --> 00:11:11.190 has allowed us to do

NOTE Confidence: 0.977908

00:11:11.190 --> 00:11:13.290 is detect sickle cell early

NOTE Confidence: 0.977908

00:11:13.350 --> 00:11:15.510 and intervene early because though

NOTE Confidence: 0.977908

00:11:15.510 --> 00:11:16.550 children may not have a

NOTE Confidence: 0.977908

00:11:16.550 --> 00:11:17.589 lot of pain because of

NOTE Confidence: 0.977908

00:11:17.589 --> 00:11:19.209 that fetal hemoglobin and protection,

NOTE Confidence: 0.9683359

00:11:19.670 --> 00:11:21.670 they're still quite susceptible to

NOTE Confidence: 0.9683359

00:11:21.670 --> 00:11:22.570 really, really,

NOTE Confidence: 0.9730126

00:11:23.715 --> 00:11:25.155 severe infections that could be

NOTE Confidence: 0.9730126

00:11:25.155 --> 00:11:27.075 fatal. And we diagnose them

NOTE Confidence: 0.9730126

00:11:27.075 --> 00:11:29.175 and we start penicillin prophylactically

NOTE Confidence: 0.9954609

00:11:29.715 --> 00:11:30.835 to really protect them and

NOTE Confidence: 0.9954609

00:11:30.835 --> 00:11:31.875 give them the best chance

NOTE Confidence: 0.9954609

00:11:31.875 --> 00:11:33.975 of thriving into adulthood. And

NOTE Confidence: 0.9954609

00:11:34.115 --> 00:11:35.315 how long does that fetal

NOTE Confidence: 0.9954609

00:11:35.315 --> 00:11:37.635 hemoglobin typically stick around? I

NOTE Confidence: 0.9954609

00:11:37.635 --> 00:11:38.535 mean, you mentioned

NOTE Confidence: 0.9582588

00:11:38.910 --> 00:11:40.110 that there are some people

NOTE Confidence: 0.9582588

00:11:40.110 --> 00:11:41.550 who have persistence of fetal

NOTE Confidence: 0.9582588

00:11:41.550 --> 00:11:42.050 hemoglobin

NOTE Confidence: 0.8642667

00:11:42.670 --> 00:11:43.170 who

NOTE Confidence: 0.9430894

00:11:43.550 --> 00:11:45.070 even into adulthood who may

NOTE Confidence: 0.9430894

00:11:45.070 --> 00:11:46.350 have a more mild case,

NOTE Confidence: 0.9430894

00:11:46.350 --> 00:11:48.029 but typically, it doesn't stay

NOTE Confidence: 0.9430894

00:11:48.029 --> 00:11:49.649 around all that long. Isn't

NOTE Confidence: 0.9430894

00:11:49.870 --> 00:11:51.845 that No. In people who

NOTE Confidence: 0.9430894

00:11:51.845 --> 00:11:53.385 don't have sickle cell disease,

NOTE Confidence: 0.99848914

00:11:53.845 --> 00:11:55.625 the hemoglobin begins to transition

NOTE Confidence: 0.99848914

00:11:55.684 --> 00:11:56.804 from the mom to the

NOTE Confidence: 0.99848914

00:11:56.804 --> 00:11:57.304 baby,

NOTE Confidence: 0.9982726

00:11:57.925 --> 00:11:58.804 as soon as six to

NOTE Confidence: 0.9982726

00:11:58.804 --> 00:12:00.024 eight weeks after birth.

NOTE Confidence: 0.9720965

00:12:00.404 --> 00:12:01.925 And people who have conditions

NOTE Confidence: 0.9720965

00:12:01.925 --> 00:12:03.125 of the red blood cell,

NOTE Confidence: 0.9720965

00:12:03.125 --> 00:12:04.725 that hem fetal hemoglobin can

NOTE Confidence: 0.9720965

00:12:04.725 --> 00:12:06.084 try to persist on its

NOTE Confidence: 0.9720965

00:12:06.084 --> 00:12:07.750 own, but it really doesn't

NOTE Confidence: 0.9720965

00:12:07.750 --> 00:12:09.290 last outside of the tolerant

NOTE Confidence: 0.9720965

00:12:09.350 --> 00:12:11.429 infancy period, except for those

NOTE Confidence: 0.9720965

00:12:11.429 --> 00:12:12.330 rare instances

NOTE Confidence: 0.99493974

00:12:12.950 --> 00:12:14.550 where patients have a genetic

NOTE Confidence: 0.99493974

00:12:14.550 --> 00:12:16.309 predisposition to keep that fetal

NOTE Confidence: 0.99493974

00:12:16.309 --> 00:12:17.990 hemoglobin. Again, evolution is really

NOTE Confidence: 0.99493974

00:12:18.150 --> 00:12:19.750 a really cool thing. Love

NOTE Confidence: 0.99493974

00:12:19.750 --> 00:12:21.105 science. Humans are amazing.

NOTE Confidence: 0.85278744

00:12:22.304 --> 00:12:22.804 But,

NOTE Confidence: 0.95321494

00:12:23.904 --> 00:12:24.644 most people,

NOTE Confidence: 0.9635761

00:12:24.945 --> 00:12:26.385 you know, it's gone when

NOTE Confidence: 0.9635761

00:12:26.385 --> 00:12:28.545 they're, it it is, gone

NOTE Confidence: 0.9635761

00:12:28.545 --> 00:12:29.584 by the time they're into

NOTE Confidence: 0.9635761

00:12:29.584 --> 00:12:31.285 their even school age.

NOTE Confidence: 0.99692136

00:12:32.144 --> 00:12:33.365 Got it. And

NOTE Confidence: 0.9537967

00:12:34.200 --> 00:12:35.420 the fetal hemoglobin,

NOTE Confidence: 0.9776295

00:12:36.200 --> 00:12:38.140 I mean, you mentioned transitioning

NOTE Confidence: 0.9776295

00:12:38.200 --> 00:12:39.020 from maternal

NOTE Confidence: 0.9986973

00:12:39.880 --> 00:12:40.380 hemoglobin

NOTE Confidence: 0.97329026

00:12:40.760 --> 00:12:42.280 to to the hemoglobin of

NOTE Confidence: 0.97329026

00:12:42.280 --> 00:12:42.940 the child,

NOTE Confidence: 0.99831647

00:12:43.480 --> 00:12:45.260 but is that fetal hemoglobin

NOTE Confidence: 0.96636105

00:12:45.640 --> 00:12:46.760 in some way related to

NOTE Confidence: 0.96636105

00:12:46.760 --> 00:12:47.820 maternal hemoglobin?

NOTE Confidence: 0.98406893

00:12:49.655 --> 00:12:51.515 So, you know, it switches.

NOTE Confidence: 0.98406893

00:12:51.575 --> 00:12:52.934 So, you know, we make

NOTE Confidence: 0.98406893

00:12:52.934 --> 00:12:53.815 all of the cells in

NOTE Confidence: 0.98406893

00:12:53.815 --> 00:12:55.255 our blood. Our warehouse is

NOTE Confidence: 0.98406893

00:12:55.255 --> 00:12:56.235 our bone marrow.

NOTE Confidence: 0.973374

00:12:56.615 --> 00:12:57.895 And but when we're inside

NOTE Confidence: 0.973374

00:12:57.895 --> 00:12:59.495 of our mother, she's supporting

NOTE Confidence: 0.973374

00:12:59.495 --> 00:13:00.855 us through the placenta. And

NOTE Confidence: 0.973374

00:13:00.855 --> 00:13:02.054 so as we start to

NOTE Confidence: 0.973374

00:13:02.054 --> 00:13:03.434 ramp up our own production,

NOTE Confidence: 0.9600101

00:13:04.215 --> 00:13:04.715 again,

NOTE Confidence: 0.96429497

00:13:05.059 --> 00:13:06.500 science is cool, humans are

NOTE Confidence: 0.96429497

00:13:06.500 --> 00:13:08.420 amazing, we recognize, hey. I

NOTE Confidence: 0.96429497

00:13:08.420 --> 00:13:09.620 have the capacity to make

NOTE Confidence: 0.96429497

00:13:09.620 --> 00:13:10.980 my own red blood cells,

NOTE Confidence: 0.96429497

00:13:10.980 --> 00:13:12.339 and our reliance on those

NOTE Confidence: 0.96429497

00:13:12.339 --> 00:13:13.459 cells that were present from

NOTE Confidence: 0.96429497

00:13:13.459 --> 00:13:14.980 our mother are are no

NOTE Confidence: 0.96429497

00:13:14.980 --> 00:13:16.980 longer necessary. And so that

NOTE Confidence: 0.96429497

00:13:16.980 --> 00:13:18.040 that first hemoglobin

NOTE Confidence: 0.99936473

00:13:18.500 --> 00:13:19.925 is the fetal hemoglobin

NOTE Confidence: 0.9934714

00:13:20.304 --> 00:13:21.045 that's made?

NOTE Confidence: 0.929623

00:13:21.505 --> 00:13:22.465 So I always tell my

NOTE Confidence: 0.929623

00:13:22.465 --> 00:13:24.145 patients f for heated fetal

NOTE Confidence: 0.929623

00:13:24.145 --> 00:13:25.745 hemoglobin because that's what they're

NOTE Confidence: 0.929623

00:13:25.745 --> 00:13:26.945 making when's that when they're

NOTE Confidence: 0.929623

00:13:26.945 --> 00:13:28.865 inside mom. But it takes

NOTE Confidence: 0.929623

00:13:28.865 --> 00:13:30.485 over and becomes more predominant

NOTE Confidence: 0.99075586

00:13:30.865 --> 00:13:31.985 once we're outside of the

NOTE Confidence: 0.99075586

00:13:31.985 --> 00:13:33.949 body. Got it. Well, we're

NOTE Confidence: 0.99075586

00:13:33.949 --> 00:13:35.069 gonna have to take a

NOTE Confidence: 0.99075586

00:13:35.069 --> 00:13:35.889 break now,

NOTE Confidence: 0.9917144

00:13:36.429 --> 00:13:37.949 but I'm sure everyone's gonna

NOTE Confidence: 0.9917144

00:13:37.949 --> 00:13:39.790 be back because you're so

NOTE Confidence: 0.9917144

00:13:39.790 --> 00:13:40.290 engaging.

NOTE Confidence: 0.99888414

00:13:42.429 --> 00:13:43.949 We'll be back

NOTE Confidence: 0.99888414

00:13:43.949 --> 00:13:45.309 in just a minute to

NOTE Confidence: 0.99888414

00:13:45.309 --> 00:13:46.449 continue our conversation

NOTE Confidence: 0.9688061

00:13:47.305 --> 00:13:49.225 with Cece Calhoun, the director

NOTE Confidence: 0.9688061

00:13:49.225 --> 00:13:50.425 of the sickle cell program

NOTE Confidence: 0.9688061

00:13:50.425 --> 00:13:51.085 at Yale.

NOTE Confidence: 0.9577569

00:13:51.465 --> 00:13:53.225 Funding for Yale Cancer Answers

NOTE Confidence: 0.9577569

00:13:53.225 --> 00:13:55.085 comes from Smilow Cancer Hospital,

NOTE Confidence: 0.99817544

00:13:55.465 --> 00:13:57.305 offering spiritual care to patients

NOTE Confidence: 0.99817544

00:13:57.305 --> 00:13:58.985 and caregivers seeking peace in

NOTE Confidence: 0.99817544

00:13:58.985 --> 00:14:00.185 the midst of their cancer

NOTE Confidence: 0.99817544

00:14:00.185 --> 00:14:00.685 journey

NOTE Confidence: 0.9989313

00:14:01.029 --> 00:14:02.570 while respecting the philosophies,

NOTE Confidence: 0.97698647

00:14:02.950 --> 00:14:05.110 spiritualities, and religions of patients

NOTE Confidence: 0.97698647

00:14:05.110 --> 00:14:05.929 and caregivers.

NOTE Confidence: 0.8098148

00:14:06.550 --> 00:14:07.050 Smilowcancerhospital

NOTE Confidence: 0.9964093

00:14:07.990 --> 00:14:08.809 dot org.

NOTE Confidence: 0.9832286

00:14:10.470 --> 00:14:12.950 The American Cancer Society estimates

NOTE Confidence: 0.9832286

00:14:12.950 --> 00:14:14.230 that more than sixty five

NOTE Confidence: 0.9832286

00:14:14.230 --> 00:14:16.170 thousand Americans will be diagnosed

NOTE Confidence: 0.9832286

00:14:16.230 --> 00:14:17.665 with head and neck cancer

NOTE Confidence: 0.9832286

00:14:17.665 --> 00:14:18.324 this year,

NOTE Confidence: 0.9989042

00:14:18.704 --> 00:14:20.144 making up about four percent

NOTE Confidence: 0.9989042

00:14:20.144 --> 00:14:21.685 of all cancers diagnosed.

NOTE Confidence: 0.9933062

00:14:22.384 --> 00:14:24.464 When detected early, however, head

NOTE Confidence: 0.9933062

00:14:24.464 --> 00:14:25.904 and neck cancers are easily

NOTE Confidence: 0.9933062

00:14:25.904 --> 00:14:27.444 treated and highly curable.

NOTE Confidence: 0.9563748

00:14:28.144 --> 00:14:30.130 Clinical trials are currently underway

NOTE Confidence: 0.9563748

00:14:30.130 --> 00:14:32.850 at federally designated comprehensive cancer

NOTE Confidence: 0.9563748

00:14:32.850 --> 00:14:34.930 centers, such as Yale Cancer

NOTE Confidence: 0.9563748

00:14:34.930 --> 00:14:36.690 Center and at Smilow Cancer

NOTE Confidence: 0.9563748

00:14:36.690 --> 00:14:37.190 Hospital,

NOTE Confidence: 0.9970368

00:14:37.570 --> 00:14:39.410 to test innovative new treatments

NOTE Confidence: 0.9970368

00:14:39.410 --> 00:14:40.710 for head and neck cancers.

NOTE Confidence: 0.98383653

00:14:41.445 --> 00:14:43.125 Yale Cancer Center was recently

NOTE Confidence: 0.98383653

00:14:43.125 --> 00:14:44.825 awarded grants from the National

NOTE Confidence: 0.98383653

00:14:44.885 --> 00:14:46.725 Institutes of Health to fund

NOTE Confidence: 0.98383653

00:14:46.725 --> 00:14:48.085 the Yale Head and Neck

NOTE Confidence: 0.98383653

00:14:48.085 --> 00:14:50.745 Cancer Specialized Program of Research

NOTE Confidence: 0.98383653

00:14:50.805 --> 00:14:51.305 Excellence

NOTE Confidence: 0.71524113

00:14:51.685 --> 00:14:52.585 or SPORE

NOTE Confidence: 0.98880094

00:14:52.965 --> 00:14:54.805 to address critical barriers to

NOTE Confidence: 0.98880094

00:14:54.805 --> 00:14:56.010 treatment of head and neck

NOTE Confidence: 0.98880094

00:14:56.010 --> 00:14:58.010 squamous cell carcinoma due to

NOTE Confidence: 0.98880094

00:14:58.010 --> 00:15:00.430 resistance to immune DNA damaging

NOTE Confidence: 0.98880094

00:15:00.570 --> 00:15:01.870 and targeted therapy.

NOTE Confidence: 0.9614975

00:15:02.490 --> 00:15:04.170 More information is available at

NOTE Confidence: 0.9614975

00:15:04.170 --> 00:15:05.950 yale cancer center dot org.

NOTE Confidence: 0.9614975

00:15:06.170 --> 00:15:07.930 You're listening to Connecticut public

NOTE Confidence: 0.9614975

00:15:07.930 --> 00:15:08.430 radio.

NOTE Confidence: 0.95732576

00:15:09.845 --> 00:15:11.365 Hello. This is Eric Winer

NOTE Confidence: 0.95732576

00:15:11.365 --> 00:15:13.045 again welcoming you back to

NOTE Confidence: 0.95732576

00:15:13.045 --> 00:15:14.505 the second half of our

NOTE Confidence: 0.9978219

00:15:16.325 --> 00:15:17.065 show tonight.

NOTE Confidence: 0.91231173

00:15:17.525 --> 00:15:19.145 This is Yale Cancer Answers,

NOTE Confidence: 0.9822005

00:15:19.685 --> 00:15:21.845 and we're speaking with doctor

NOTE Confidence: 0.9822005

00:15:21.845 --> 00:15:24.120 Cece Calhoun, director of the

NOTE Confidence: 0.9822005

00:15:24.120 --> 00:15:26.060 sickle cell program at Yale.

NOTE Confidence: 0.9986333

00:15:27.080 --> 00:15:28.440 So we've been talking a

NOTE Confidence: 0.9986333

00:15:28.440 --> 00:15:30.360 lot about sickle cell disease

NOTE Confidence: 0.9986333

00:15:30.360 --> 00:15:31.580 and some of the manifestations.

NOTE Confidence: 0.9997037

00:15:32.520 --> 00:15:34.620 We haven't yet touched on

NOTE Confidence: 0.9997037

00:15:34.680 --> 00:15:35.180 treatments

NOTE Confidence: 0.9256256

00:15:35.720 --> 00:15:37.720 and maybe we can begin

NOTE Confidence: 0.9256256

00:15:37.720 --> 00:15:38.940 talking about treatments

NOTE Confidence: 0.9968207

00:15:40.365 --> 00:15:43.005 and what's available today for

NOTE Confidence: 0.9968207

00:15:43.005 --> 00:15:44.225 for people who are

NOTE Confidence: 0.9882733

00:15:44.764 --> 00:15:46.204 struggling to live the best

NOTE Confidence: 0.9882733

00:15:46.204 --> 00:15:47.485 life they can with sickle

NOTE Confidence: 0.9882733

00:15:47.485 --> 00:15:48.225 cell disease.

NOTE Confidence: 0.9722521

00:15:48.685 --> 00:15:49.485 Yes. This is,

NOTE Confidence: 0.9897961

00:15:50.445 --> 00:15:52.464 a interesting question, a complicated

NOTE Confidence: 0.9897961

00:15:52.524 --> 00:15:53.425 question. So

NOTE Confidence: 0.99433863

00:15:53.750 --> 00:15:54.950 we talked a little bit

NOTE Confidence: 0.99433863

00:15:54.950 --> 00:15:56.470 earlier about how we've known

NOTE Confidence: 0.99433863

00:15:56.470 --> 00:15:57.850 about sickle cell disease,

NOTE Confidence: 0.9798744

00:15:58.230 --> 00:15:59.209 and its manifestations

NOTE Confidence: 0.9207292

00:15:59.910 --> 00:16:01.269 for over about a hundred

NOTE Confidence: 0.9207292

00:16:01.269 --> 00:16:02.329 and twenty years.

NOTE Confidence: 0.97668666

00:16:02.870 --> 00:16:04.410 But really up until,

NOTE Confidence: 0.9892021

00:16:05.670 --> 00:16:07.769 about nineteen ninety eight, we

NOTE Confidence: 0.9892021

00:16:07.829 --> 00:16:08.329 had,

NOTE Confidence: 0.96799815

00:16:09.115 --> 00:16:11.055 where the FDA approved hydroxyurea

NOTE Confidence: 0.96476305

00:16:11.995 --> 00:16:12.954 for the treatment of sickle

NOTE Confidence: 0.96476305

00:16:12.954 --> 00:16:14.154 cell disease. There were really

NOTE Confidence: 0.96476305

00:16:14.154 --> 00:16:14.654 no,

NOTE Confidence: 0.9467566

00:16:15.355 --> 00:16:17.755 disease modifying medications. We used

NOTE Confidence: 0.9467566

00:16:17.755 --> 00:16:18.954 blood because it is a

NOTE Confidence: 0.9467566

00:16:18.954 --> 00:16:20.315 disease a disease of the

NOTE Confidence: 0.9467566

00:16:20.315 --> 00:16:21.820 red blood cell, but had

NOTE Confidence: 0.9467566

00:16:21.820 --> 00:16:22.560 no interventions

NOTE Confidence: 0.9979874

00:16:22.940 --> 00:16:24.639 to treat actual sickle cell.

NOTE Confidence: 0.9668411

00:16:25.180 --> 00:16:26.639 In nineteen ninety eight, hydroxyurea

NOTE Confidence: 0.96948844

00:16:27.660 --> 00:16:29.420 was FDA approved, and then

NOTE Confidence: 0.96948844

00:16:29.420 --> 00:16:30.700 there was about a twenty

NOTE Confidence: 0.96948844

00:16:30.700 --> 00:16:31.440 year gap,

NOTE Confidence: 0.9993418

00:16:31.820 --> 00:16:34.320 until additional treatments were introduced.

NOTE Confidence: 0.9834302

00:16:35.735 --> 00:16:37.415 Then we got Indari, which

NOTE Confidence: 0.9834302

00:16:37.415 --> 00:16:39.015 is an amino acid powder

NOTE Confidence: 0.9834302

00:16:39.015 --> 00:16:40.215 that's taken three times a

NOTE Confidence: 0.9834302

00:16:40.215 --> 00:16:42.695 day, really thought to help

NOTE Confidence: 0.9834302

00:16:42.695 --> 00:16:43.195 with,

NOTE Confidence: 0.93337697

00:16:43.815 --> 00:16:45.495 that environment in which cells

NOTE Confidence: 0.93337697

00:16:45.495 --> 00:16:46.875 sickle and prevent that.

NOTE Confidence: 0.9779916

00:16:48.310 --> 00:16:49.670 Then we were able to

NOTE Confidence: 0.9779916

00:16:49.670 --> 00:16:51.050 FDA approved Crizanlizumab,

NOTE Confidence: 0.9886045

00:16:51.670 --> 00:16:53.110 which is a type of

NOTE Confidence: 0.9886045

00:16:53.110 --> 00:16:54.250 infusion medication,

NOTE Confidence: 0.9898983

00:16:54.950 --> 00:16:56.230 which tries to make that

NOTE Confidence: 0.9898983

00:16:56.230 --> 00:16:57.670 environment less sticky. We talked

NOTE Confidence: 0.9898983

00:16:57.670 --> 00:16:58.710 about how those sickle cells

NOTE Confidence: 0.9898983

00:16:58.710 --> 00:17:00.070 are sticky. They stick together.

NOTE Confidence: 0.9898983

00:17:00.070 --> 00:17:01.065 They block flow.

NOTE Confidence: 0.9623608

00:17:02.745 --> 00:17:04.845 Also a medication called OxBryta

NOTE Confidence: 0.9623608

00:17:04.905 --> 00:17:07.065 was introduced, which binds to

NOTE Confidence: 0.9623608

00:17:07.065 --> 00:17:08.265 that spot where oxygen would

NOTE Confidence: 0.9623608

00:17:08.265 --> 00:17:09.065 sit in the red blood

NOTE Confidence: 0.9623608

00:17:09.065 --> 00:17:10.525 cell to prevent sickling.

NOTE Confidence: 0.9929738

00:17:11.145 --> 00:17:11.945 But about,

NOTE Confidence: 0.9938085

00:17:12.585 --> 00:17:14.345 four weeks ago, that medication

NOTE Confidence: 0.9938085

00:17:14.345 --> 00:17:15.805 was abruptly discontinued.

NOTE Confidence: 0.99347705

00:17:16.789 --> 00:17:19.270 And so these are options

NOTE Confidence: 0.99347705

00:17:19.270 --> 00:17:20.730 to treat sickle cell disease,

NOTE Confidence: 0.9671922

00:17:21.350 --> 00:17:22.950 that we have now. Now

NOTE Confidence: 0.9671922

00:17:22.950 --> 00:17:24.070 you're saying Cece, but I

NOTE Confidence: 0.9671922

00:17:24.070 --> 00:17:25.270 heard about gene therapy. What

NOTE Confidence: 0.9671922

00:17:25.270 --> 00:17:26.230 do you mean? I thought

NOTE Confidence: 0.9671922

00:17:26.230 --> 00:17:27.609 that was for sickle cell.

NOTE Confidence: 0.9671922

00:17:27.669 --> 00:17:28.630 I'm picking up on the

NOTE Confidence: 0.9671922

00:17:28.630 --> 00:17:29.609 vibes. Okay?

NOTE Confidence: 0.99712235

00:17:30.734 --> 00:17:31.855 And even before,

NOTE Confidence: 0.9934606

00:17:32.415 --> 00:17:33.535 gene therapy, we did have

NOTE Confidence: 0.9934606

00:17:33.535 --> 00:17:34.895 one curative option, which is

NOTE Confidence: 0.9934606

00:17:34.895 --> 00:17:36.035 bone marrow transplant.

NOTE Confidence: 0.98225886

00:17:36.335 --> 00:17:37.935 We talked about early earlier

NOTE Confidence: 0.98225886

00:17:37.935 --> 00:17:39.215 that the factory for our

NOTE Confidence: 0.98225886

00:17:39.215 --> 00:17:40.494 red blood cells, our white

NOTE Confidence: 0.98225886

00:17:40.494 --> 00:17:42.015 blood cells, and our platelets

NOTE Confidence: 0.98225886

00:17:42.015 --> 00:17:43.530 is our bone marrow. And

NOTE Confidence: 0.98225886

00:17:43.530 --> 00:17:45.130 so if you replace someone

NOTE Confidence: 0.98225886

00:17:45.130 --> 00:17:46.490 who has sickle cell disease,

NOTE Confidence: 0.98225886

00:17:46.490 --> 00:17:47.530 if you replace their bone

NOTE Confidence: 0.98225886

00:17:47.530 --> 00:17:49.609 marrow with the marrow of

NOTE Confidence: 0.98225886

00:17:49.609 --> 00:17:51.050 someone who doesn't have sickle

NOTE Confidence: 0.98225886

00:17:51.050 --> 00:17:52.570 cell disease, who maybe even

NOTE Confidence: 0.98225886

00:17:52.570 --> 00:17:53.630 only has trait,

NOTE Confidence: 0.99818724

00:17:53.930 --> 00:17:55.369 then you can cure the

NOTE Confidence: 0.99818724

00:17:55.369 --> 00:17:55.869 disease.

NOTE Confidence: 0.95077056

00:17:57.015 --> 00:17:58.668 But that's very It's a

NOTE Confidence: 0.95077056

00:17:58.668 --> 00:18:00.081 it's a it's a harsh

NOTE Confidence: 0.95077056

00:18:00.081 --> 00:18:01.494 treatment too. Absolutely. And and

NOTE Confidence: 0.95077056

00:18:01.494 --> 00:18:01.815 there's,

NOTE Confidence: 0.99763125

00:18:02.295 --> 00:18:03.335 some number of people who

NOTE Confidence: 0.99763125

00:18:03.335 --> 00:18:04.375 don't make it through that

NOTE Confidence: 0.99763125

00:18:04.375 --> 00:18:05.595 treatment. Mhmm.

NOTE Confidence: 0.9690082

00:18:06.055 --> 00:18:07.255 And there are many reasons

NOTE Confidence: 0.9690082

00:18:07.255 --> 00:18:09.015 for that, not least of

NOTE Confidence: 0.9690082

00:18:09.015 --> 00:18:10.935 which being it's important to

NOTE Confidence: 0.9690082

00:18:10.935 --> 00:18:11.835 have a perfect

NOTE Confidence: 0.98373413

00:18:12.289 --> 00:18:13.650 match. We wanna have a

NOTE Confidence: 0.98373413

00:18:13.650 --> 00:18:15.570 perfect match for someone undergoing

NOTE Confidence: 0.98373413

00:18:15.570 --> 00:18:17.350 bone marrow transplant. And

NOTE Confidence: 0.9962299

00:18:17.890 --> 00:18:19.250 due to the genetic diversity

NOTE Confidence: 0.9962299

00:18:19.250 --> 00:18:20.150 in us all,

NOTE Confidence: 0.96870315

00:18:20.850 --> 00:18:22.210 again, we get half of

NOTE Confidence: 0.96870315

00:18:22.210 --> 00:18:23.409 that needed match from our

NOTE Confidence: 0.96870315

00:18:23.409 --> 00:18:24.609 mom, half of that needed

NOTE Confidence: 0.96870315

00:18:24.609 --> 00:18:26.195 match from our dad. The

NOTE Confidence: 0.96870315

00:18:26.195 --> 00:18:27.395 best person is usually a

NOTE Confidence: 0.96870315

00:18:27.395 --> 00:18:28.835 full sibling, which isn't always

NOTE Confidence: 0.96870315

00:18:28.835 --> 00:18:29.575 an option,

NOTE Confidence: 0.9705533

00:18:29.955 --> 00:18:31.734 and then enters gene therapy.

NOTE Confidence: 0.9906685

00:18:33.075 --> 00:18:34.195 Got it. And and, of

NOTE Confidence: 0.9906685

00:18:34.195 --> 00:18:36.035 course, an identical twin wouldn't

NOTE Confidence: 0.9906685

00:18:36.035 --> 00:18:37.075 do you any good because

NOTE Confidence: 0.9906685

00:18:37.075 --> 00:18:38.615 that twin would also have

NOTE Confidence: 0.99322236

00:18:38.915 --> 00:18:40.835 sickle cell disease. Yes. Likely

NOTE Confidence: 0.99322236

00:18:40.835 --> 00:18:42.510 so. Yep. Yep. Exactly.

NOTE Confidence: 0.95124304

00:18:44.090 --> 00:18:45.770 So tell us about gene

NOTE Confidence: 0.95124304

00:18:45.770 --> 00:18:46.730 therapy which,

NOTE Confidence: 0.99736434

00:18:47.530 --> 00:18:48.030 has

NOTE Confidence: 0.9626967

00:18:48.730 --> 00:18:49.929 been talked about a lot

NOTE Confidence: 0.9626967

00:18:49.929 --> 00:18:50.890 over the last year or

NOTE Confidence: 0.9626967

00:18:50.890 --> 00:18:52.750 two. Yeah. It's very exciting

NOTE Confidence: 0.9626967

00:18:52.809 --> 00:18:53.309 time.

NOTE Confidence: 0.9629011

00:18:54.090 --> 00:18:55.290 A new time, a time

NOTE Confidence: 0.9629011

00:18:55.290 --> 00:18:56.830 of still so much discovery.

NOTE Confidence: 0.95598394

00:18:57.885 --> 00:18:59.005 But another time I can

NOTE Confidence: 0.95598394

00:18:59.005 --> 00:19:00.365 say being nerdy is cool.

NOTE Confidence: 0.95598394

00:19:00.365 --> 00:19:02.065 Science is fun because,

NOTE Confidence: 0.99919206

00:19:02.845 --> 00:19:04.605 you know, we're able to

NOTE Confidence: 0.99919206

00:19:04.605 --> 00:19:06.525 mitigate that challenge of not

NOTE Confidence: 0.99919206

00:19:06.525 --> 00:19:08.205 having a good match by

NOTE Confidence: 0.99919206

00:19:08.205 --> 00:19:09.885 allowing a person to be

NOTE Confidence: 0.99919206

00:19:09.885 --> 00:19:11.025 their own match

NOTE Confidence: 0.9952941

00:19:11.389 --> 00:19:11.889 for,

NOTE Confidence: 0.9930381

00:19:12.350 --> 00:19:13.649 a curative option.

NOTE Confidence: 0.98192513

00:19:14.190 --> 00:19:15.230 And so there are two

NOTE Confidence: 0.98192513

00:19:15.230 --> 00:19:16.830 main ways in which we

NOTE Confidence: 0.98192513

00:19:16.830 --> 00:19:18.429 do that now. One of

NOTE Confidence: 0.98192513

00:19:18.429 --> 00:19:19.730 those is through a technology

NOTE Confidence: 0.98192513

00:19:19.789 --> 00:19:21.330 called CRISPR Cas9

NOTE Confidence: 0.95740694

00:19:22.029 --> 00:19:23.549 where a certain spot in

NOTE Confidence: 0.95740694

00:19:23.549 --> 00:19:24.830 our genetic code can be

NOTE Confidence: 0.95740694

00:19:24.830 --> 00:19:25.330 identified

NOTE Confidence: 0.99542326

00:19:26.025 --> 00:19:27.005 and then removed.

NOTE Confidence: 0.9722263

00:19:27.545 --> 00:19:28.525 In that instance,

NOTE Confidence: 0.98539776

00:19:29.065 --> 00:19:30.685 the goal of that intervention

NOTE Confidence: 0.98539776

00:19:30.825 --> 00:19:32.045 and therapy is to

NOTE Confidence: 0.9772924

00:19:32.345 --> 00:19:33.785 take away that gene that

NOTE Confidence: 0.9772924

00:19:33.785 --> 00:19:35.305 tells us when we're kids

NOTE Confidence: 0.9772924

00:19:35.305 --> 00:19:37.005 to stop making fetal hemoglobin

NOTE Confidence: 0.9772924

00:19:37.145 --> 00:19:38.525 like we talked about earlier.

NOTE Confidence: 0.97157776

00:19:38.929 --> 00:19:40.230 So then your fetal hemoglobin

NOTE Confidence: 0.97157776

00:19:40.289 --> 00:19:41.429 starts to ramp up,

NOTE Confidence: 0.9800441

00:19:41.730 --> 00:19:43.250 and your percent of sickled

NOTE Confidence: 0.9800441

00:19:43.250 --> 00:19:45.090 cells are decreasing, thus offering

NOTE Confidence: 0.9800441

00:19:45.090 --> 00:19:46.549 a cure. And

NOTE Confidence: 0.99796075

00:19:47.090 --> 00:19:48.530 in that setting, how much

NOTE Confidence: 0.99796075

00:19:48.530 --> 00:19:50.049 fetal hemoglobin do you wind

NOTE Confidence: 0.99796075

00:19:50.049 --> 00:19:50.710 up with?

NOTE Confidence: 0.99802744

00:19:51.105 --> 00:19:52.465 So it can even be

NOTE Confidence: 0.99802744

00:19:52.465 --> 00:19:53.825 as much as half of

NOTE Confidence: 0.99802744

00:19:53.825 --> 00:19:54.325 your,

NOTE Confidence: 0.99854004

00:19:54.865 --> 00:19:55.365 cells

NOTE Confidence: 0.9364231

00:19:55.825 --> 00:19:58.304 making fetal hemoglobin, thus making

NOTE Confidence: 0.9364231

00:19:58.304 --> 00:19:59.265 you more like a trait

NOTE Confidence: 0.9364231

00:19:59.265 --> 00:20:00.545 status like we talked about

NOTE Confidence: 0.9364231

00:20:00.545 --> 00:20:02.385 earlier where the symptoms aren't

NOTE Confidence: 0.9364231

00:20:02.385 --> 00:20:03.205 as obvious,

NOTE Confidence: 0.93557656

00:20:03.609 --> 00:20:05.130 it doesn't affect your organs,

NOTE Confidence: 0.93557656

00:20:05.369 --> 00:20:06.409 the quality of life is

NOTE Confidence: 0.93557656

00:20:06.409 --> 00:20:08.029 totally And half is enough?

NOTE Confidence: 0.92450917

00:20:08.570 --> 00:20:10.250 It is ideally more, but

NOTE Confidence: 0.92450917

00:20:10.250 --> 00:20:11.450 half is enough to take

NOTE Confidence: 0.92450917

00:20:11.450 --> 00:20:12.909 you to trait status. Yep.

NOTE Confidence: 0.9715086

00:20:13.210 --> 00:20:14.570 Wow. So you said there

NOTE Confidence: 0.9715086

00:20:14.570 --> 00:20:15.850 were two ways of doing

NOTE Confidence: 0.9715086

00:20:15.850 --> 00:20:17.684 this, I think. Yes. The

NOTE Confidence: 0.9715086

00:20:17.684 --> 00:20:20.005 second way is through something

NOTE Confidence: 0.9715086

00:20:20.005 --> 00:20:21.285 we say we call using

NOTE Confidence: 0.9715086

00:20:21.285 --> 00:20:22.505 a viral vector

NOTE Confidence: 0.88391817

00:20:22.885 --> 00:20:23.705 or using

NOTE Confidence: 0.9552822

00:20:24.164 --> 00:20:25.304 the the

NOTE Confidence: 0.9896926

00:20:26.005 --> 00:20:28.244 intelligence of viral viruses and

NOTE Confidence: 0.9896926

00:20:28.244 --> 00:20:29.145 viral infections

NOTE Confidence: 0.99965596

00:20:29.640 --> 00:20:30.380 to introduce

NOTE Confidence: 0.9994133

00:20:31.080 --> 00:20:32.619 new genetic code

NOTE Confidence: 0.99888057

00:20:33.000 --> 00:20:33.500 into

NOTE Confidence: 0.99042076

00:20:34.119 --> 00:20:35.400 our stem cells or the

NOTE Confidence: 0.99042076

00:20:35.400 --> 00:20:37.160 parent cells of our red

NOTE Confidence: 0.99042076

00:20:37.160 --> 00:20:37.900 blood cells.

NOTE Confidence: 0.9579022

00:20:39.080 --> 00:20:40.760 Actually, that method has been

NOTE Confidence: 0.9579022

00:20:40.760 --> 00:20:42.680 around longer than the CRISPR

NOTE Confidence: 0.9579022

00:20:42.680 --> 00:20:43.740 Cas9 technology.

NOTE Confidence: 0.99546695

00:20:44.385 --> 00:20:45.585 And what that does is

NOTE Confidence: 0.99546695

00:20:45.585 --> 00:20:46.725 it actually creates

NOTE Confidence: 0.87354344

00:20:47.185 --> 00:20:48.565 non sickling hemoglobin.

NOTE Confidence: 0.96137077

00:20:49.265 --> 00:20:50.625 So rather than saying, hey.

NOTE Confidence: 0.96137077

00:20:50.625 --> 00:20:52.725 I wanna increase hemoglobin f,

NOTE Confidence: 0.97697335

00:20:53.265 --> 00:20:54.725 and really get that going.

NOTE Confidence: 0.9823419

00:20:55.025 --> 00:20:56.545 This one says, actually, I

NOTE Confidence: 0.9823419

00:20:56.545 --> 00:20:57.665 want you to make new

NOTE Confidence: 0.9823419

00:20:57.665 --> 00:20:59.265 hemoglobin that doesn't sickle at

NOTE Confidence: 0.9823419

00:20:59.265 --> 00:21:00.859 all. And again, the goal

NOTE Confidence: 0.9823419

00:21:00.859 --> 00:21:02.000 is to have a robust

NOTE Confidence: 0.9823419

00:21:02.299 --> 00:21:03.600 amount of that new hemoglobin

NOTE Confidence: 0.9823419

00:21:03.820 --> 00:21:05.580 around such that sickle cells

NOTE Confidence: 0.9823419

00:21:05.580 --> 00:21:06.559 are not impacting,

NOTE Confidence: 0.9967906

00:21:07.820 --> 00:21:09.039 the person's organs,

NOTE Confidence: 0.9487132

00:21:09.500 --> 00:21:10.559 clinical manifestations,

NOTE Confidence: 0.9979311

00:21:11.179 --> 00:21:12.494 and or quality of life.

NOTE Confidence: 0.9979311

00:21:12.815 --> 00:21:13.775 And when was the first

NOTE Confidence: 0.9979311

00:21:13.775 --> 00:21:15.375 time gene therapy was given

NOTE Confidence: 0.9979311

00:21:15.375 --> 00:21:16.675 for sickle cell disease?

NOTE Confidence: 0.96798146

00:21:17.535 --> 00:21:18.575 Do you mean in an

NOTE Confidence: 0.96798146

00:21:18.575 --> 00:21:20.335 FDA approved setting or in

NOTE Confidence: 0.96798146

00:21:20.335 --> 00:21:22.434 a research setting? In a

NOTE Confidence: 0.9687705

00:21:23.375 --> 00:21:24.815 let's say a research setting

NOTE Confidence: 0.9687705

00:21:24.815 --> 00:21:26.095 even. Oh, okay. So it's

NOTE Confidence: 0.9687705

00:21:26.095 --> 00:21:27.690 been years, actually. I mean,

NOTE Confidence: 0.9687705

00:21:27.769 --> 00:21:28.809 there's a great group at

NOTE Confidence: 0.9687705

00:21:28.809 --> 00:21:30.809 the NIH led by John

NOTE Confidence: 0.9687705

00:21:30.809 --> 00:21:32.809 Tisdell and Courtney Fitzhugh, who

NOTE Confidence: 0.9687705

00:21:32.809 --> 00:21:34.350 are really amazing transplanters,

NOTE Confidence: 0.985363

00:21:35.129 --> 00:21:36.750 who have done the preliminary

NOTE Confidence: 0.985363

00:21:37.049 --> 00:21:38.029 work for this,

NOTE Confidence: 0.9773971

00:21:39.369 --> 00:21:40.250 have been doing this for

NOTE Confidence: 0.9773971

00:21:40.250 --> 00:21:41.655 many, many years. It was

NOTE Confidence: 0.9773971

00:21:41.655 --> 00:21:43.494 FDA approved in December of

NOTE Confidence: 0.9773971

00:21:43.494 --> 00:21:45.415 last year. So Wow. Yeah.

NOTE Confidence: 0.9773971

00:21:45.415 --> 00:21:46.615 So it's still very, very

NOTE Confidence: 0.9773971

00:21:46.615 --> 00:21:47.815 new, and we're still learning

NOTE Confidence: 0.9773971

00:21:47.815 --> 00:21:48.555 so much.

NOTE Confidence: 0.99912393

00:21:48.935 --> 00:21:50.395 And what are the complications

NOTE Confidence: 0.99912393

00:21:50.615 --> 00:21:51.675 of gene therapy?

NOTE Confidence: 0.994854

00:21:52.135 --> 00:21:53.415 Yeah. So, you know, we

NOTE Confidence: 0.994854

00:21:53.415 --> 00:21:54.775 didn't talk in detail about

NOTE Confidence: 0.994854

00:21:54.775 --> 00:21:56.475 the bone marrow transplant process,

NOTE Confidence: 0.994854

00:21:56.720 --> 00:21:58.400 but it mirrors very much

NOTE Confidence: 0.994854

00:21:58.400 --> 00:21:59.780 the gene therapy process.

NOTE Confidence: 0.9834696

00:22:01.359 --> 00:22:02.320 First, we have to pick

NOTE Confidence: 0.9834696

00:22:02.320 --> 00:22:03.840 the right candidate. Who is

NOTE Confidence: 0.9834696

00:22:03.840 --> 00:22:05.359 a person that whose organs

NOTE Confidence: 0.9834696

00:22:05.359 --> 00:22:06.560 are healthy enough to be

NOTE Confidence: 0.9834696

00:22:06.560 --> 00:22:07.440 able to go on this

NOTE Confidence: 0.9834696

00:22:07.440 --> 00:22:09.220 journey? Who has the psychosocial

NOTE Confidence: 0.9834696

00:22:09.359 --> 00:22:10.400 support that they need to

NOTE Confidence: 0.9834696

00:22:10.400 --> 00:22:11.794 go on this journey? Who

NOTE Confidence: 0.9834696

00:22:11.794 --> 00:22:12.195 has,

NOTE Confidence: 0.9766611

00:22:12.674 --> 00:22:14.195 proximity and treat, to a

NOTE Confidence: 0.9766611

00:22:14.195 --> 00:22:15.315 treatment center that can do

NOTE Confidence: 0.9766611

00:22:15.315 --> 00:22:16.455 this safely. Right?

NOTE Confidence: 0.9828152

00:22:16.994 --> 00:22:18.215 Once that's established,

NOTE Confidence: 0.9617103

00:22:18.674 --> 00:22:20.115 then, you know, we, in

NOTE Confidence: 0.9617103

00:22:20.115 --> 00:22:21.414 the gene therapy process,

NOTE Confidence: 0.99437267

00:22:22.275 --> 00:22:23.875 you have to harvest someone's

NOTE Confidence: 0.99437267

00:22:23.875 --> 00:22:24.994 stem cells. And so you

NOTE Confidence: 0.99437267

00:22:24.994 --> 00:22:26.275 can do that through a

NOTE Confidence: 0.99437267

00:22:26.275 --> 00:22:27.770 process called, apheresis,

NOTE Confidence: 0.9976539

00:22:28.070 --> 00:22:29.109 which we use in sickle

NOTE Confidence: 0.9976539

00:22:29.109 --> 00:22:30.010 cell to replace

NOTE Confidence: 0.9929979

00:22:30.470 --> 00:22:31.590 abnormal red blood cells with

NOTE Confidence: 0.9929979

00:22:31.590 --> 00:22:33.190 normal ones. But that may

NOTE Confidence: 0.9929979

00:22:33.190 --> 00:22:35.030 require several rounds of that

NOTE Confidence: 0.9929979

00:22:35.030 --> 00:22:35.530 procedure.

NOTE Confidence: 0.99467355

00:22:36.310 --> 00:22:37.270 And while that,

NOTE Confidence: 0.99628735

00:22:37.750 --> 00:22:39.350 those stem cells are off

NOTE Confidence: 0.99628735

00:22:39.350 --> 00:22:41.109 being processed and made new

NOTE Confidence: 0.99628735

00:22:41.109 --> 00:22:41.850 and whole,

NOTE Confidence: 0.99145496

00:22:42.345 --> 00:22:43.465 the person can we have

NOTE Confidence: 0.99145496

00:22:43.465 --> 00:22:44.424 to keep them healthy. Right?

NOTE Confidence: 0.99145496

00:22:44.424 --> 00:22:45.465 We gotta continue to make

NOTE Confidence: 0.99145496

00:22:45.465 --> 00:22:46.505 sure their sickle cell isn't

NOTE Confidence: 0.99145496

00:22:46.505 --> 00:22:48.025 having a deleterious effect on

NOTE Confidence: 0.99145496

00:22:48.025 --> 00:22:49.705 their body. And when it's

NOTE Confidence: 0.99145496

00:22:49.705 --> 00:22:51.645 time to receive those cells,

NOTE Confidence: 0.9772776

00:22:52.105 --> 00:22:53.065 this is when it really,

NOTE Confidence: 0.9772776

00:22:53.065 --> 00:22:54.505 really mirrors bone marrow transplant.

NOTE Confidence: 0.9772776

00:22:54.505 --> 00:22:55.705 So the person has to

NOTE Confidence: 0.9772776

00:22:55.705 --> 00:22:56.845 come into the hospital,

NOTE Confidence: 0.94739324

00:22:57.359 --> 00:22:58.340 They get chemotherapy,

NOTE Confidence: 0.9466611

00:22:59.200 --> 00:23:00.980 which helps their body recognize,

NOTE Confidence: 0.9466694

00:23:01.440 --> 00:23:02.640 make room for those cells

NOTE Confidence: 0.9466694

00:23:02.640 --> 00:23:03.840 and make sure that their

NOTE Confidence: 0.9466694

00:23:03.840 --> 00:23:05.119 body doesn't attack these new

NOTE Confidence: 0.9466694

00:23:05.119 --> 00:23:05.619 cells.

NOTE Confidence: 0.97378904

00:23:06.160 --> 00:23:07.600 That means during this time,

NOTE Confidence: 0.97378904

00:23:07.600 --> 00:23:09.440 their immune system is nearly

NOTE Confidence: 0.97378904

00:23:09.440 --> 00:23:11.625 zero. Right? Because this chemotherapy

NOTE Confidence: 0.97378904

00:23:11.625 --> 00:23:12.505 is not just taking out

NOTE Confidence: 0.97378904

00:23:12.505 --> 00:23:13.945 the red blood cells, it's

NOTE Confidence: 0.97378904

00:23:13.945 --> 00:23:14.984 taking out our white blood

NOTE Confidence: 0.97378904

00:23:14.984 --> 00:23:16.185 cells that help us fight

NOTE Confidence: 0.97378904

00:23:16.185 --> 00:23:17.405 infection and our platelets

NOTE Confidence: 0.97640485

00:23:17.785 --> 00:23:19.465 that help us, helps prevent

NOTE Confidence: 0.97640485

00:23:19.465 --> 00:23:21.305 bleeding acutely. And so we

NOTE Confidence: 0.97640485

00:23:21.305 --> 00:23:22.845 become their immune system.

NOTE Confidence: 0.99121237

00:23:23.225 --> 00:23:24.585 We become their platelets. And

NOTE Confidence: 0.99121237

00:23:24.585 --> 00:23:25.385 so they have to stick

NOTE Confidence: 0.99121237

00:23:25.385 --> 00:23:27.010 with us during that. The

NOTE Confidence: 0.99121237

00:23:27.010 --> 00:23:28.770 type of chemo chemotherapy that

NOTE Confidence: 0.99121237

00:23:28.770 --> 00:23:30.210 they get can have impacts

NOTE Confidence: 0.99121237

00:23:30.210 --> 00:23:32.130 on fertility and other organ

NOTE Confidence: 0.99121237

00:23:32.130 --> 00:23:32.630 functions.

NOTE Confidence: 0.8963811

00:23:33.410 --> 00:23:34.470 And then eventually,

NOTE Confidence: 0.96796376

00:23:34.850 --> 00:23:35.990 after some time,

NOTE Confidence: 0.9834324

00:23:36.530 --> 00:23:37.970 then those cells begin to

NOTE Confidence: 0.9834324

00:23:37.970 --> 00:23:39.090 grow on their own, those

NOTE Confidence: 0.9834324

00:23:39.090 --> 00:23:40.150 new stem cells.

NOTE Confidence: 0.9989467

00:23:40.635 --> 00:23:41.135 And

NOTE Confidence: 0.96588254

00:23:41.435 --> 00:23:42.415 so we take,

NOTE Confidence: 0.9636381

00:23:43.035 --> 00:23:44.335 this is a a journey,

NOTE Confidence: 0.8377401

00:23:44.795 --> 00:23:45.295 certainly,

NOTE Confidence: 0.99584985

00:23:46.234 --> 00:23:47.835 and the risks are high,

NOTE Confidence: 0.99584985

00:23:47.835 --> 00:23:49.435 but the reward is also

NOTE Confidence: 0.99584985

00:23:49.435 --> 00:23:50.335 quite high.

NOTE Confidence: 0.9748689

00:23:50.955 --> 00:23:52.875 But not necessarily for the

NOTE Confidence: 0.9748689

00:23:52.875 --> 00:23:54.779 faint of heart. Oh, no.

NOTE Confidence: 0.9748689

00:23:54.779 --> 00:23:56.940 Absolutely not. And, you know,

NOTE Confidence: 0.9748689

00:23:56.940 --> 00:23:58.460 we think about how we

NOTE Confidence: 0.9748689

00:23:58.460 --> 00:23:59.899 deliver gene therapy and keeping

NOTE Confidence: 0.9748689

00:23:59.899 --> 00:24:00.960 the patient safe.

NOTE Confidence: 0.9976711

00:24:01.340 --> 00:24:02.139 But one of the things

NOTE Confidence: 0.9976711

00:24:02.139 --> 00:24:02.859 that I think is a

NOTE Confidence: 0.9976711

00:24:02.859 --> 00:24:03.919 hallmark of,

NOTE Confidence: 0.997764

00:24:04.619 --> 00:24:06.080 a good sickle cell center

NOTE Confidence: 0.98934424

00:24:06.700 --> 00:24:07.200 is

NOTE Confidence: 0.9719317

00:24:07.525 --> 00:24:09.065 caring for the whole patient

NOTE Confidence: 0.9719317

00:24:09.205 --> 00:24:10.565 and, you know, not just

NOTE Confidence: 0.9719317

00:24:10.565 --> 00:24:11.525 when they're with us, but

NOTE Confidence: 0.9719317

00:24:11.525 --> 00:24:12.345 also ensuring

NOTE Confidence: 0.9519319

00:24:12.725 --> 00:24:13.605 the goal is for them

NOTE Confidence: 0.9519319

00:24:13.605 --> 00:24:14.804 not to just survive, but

NOTE Confidence: 0.9519319

00:24:14.804 --> 00:24:16.005 to really thrive. And that

NOTE Confidence: 0.9519319

00:24:16.005 --> 00:24:16.505 means

NOTE Confidence: 0.9467003

00:24:16.885 --> 00:24:18.244 how is their life affected

NOTE Confidence: 0.9467003

00:24:18.244 --> 00:24:19.285 by the treatments that are

NOTE Confidence: 0.9467003

00:24:19.285 --> 00:24:21.119 gonna cure them? How are

NOTE Confidence: 0.9467003

00:24:21.119 --> 00:24:23.060 their families affected their children,

NOTE Confidence: 0.9933675

00:24:23.520 --> 00:24:24.640 you know, really keeping them

NOTE Confidence: 0.9933675

00:24:24.640 --> 00:24:25.600 whole. So

NOTE Confidence: 0.98063326

00:24:26.320 --> 00:24:26.820 Wow.

NOTE Confidence: 0.99537724

00:24:28.320 --> 00:24:30.240 Well, I'm sure that, in

NOTE Confidence: 0.99537724

00:24:30.240 --> 00:24:31.920 the years ahead, we will

NOTE Confidence: 0.99537724

00:24:31.920 --> 00:24:34.285 somehow figure out ways of

NOTE Confidence: 0.99537724

00:24:34.285 --> 00:24:36.205 delivering this therapy and having

NOTE Confidence: 0.99537724

00:24:36.205 --> 00:24:37.425 it be more tolerable.

NOTE Confidence: 0.97981817

00:24:38.285 --> 00:24:39.965 And in the meantime, there'll

NOTE Confidence: 0.97981817

00:24:39.965 --> 00:24:41.425 be some people who will

NOTE Confidence: 0.95260113

00:24:41.805 --> 00:24:43.085 who are choosing to do

NOTE Confidence: 0.95260113

00:24:43.085 --> 00:24:44.925 this. Yes. Yes. Certainly. I

NOTE Confidence: 0.95260113

00:24:44.925 --> 00:24:46.260 think plant there are

NOTE Confidence: 0.99510825

00:24:46.820 --> 00:24:47.780 more than just a few

NOTE Confidence: 0.99510825

00:24:47.780 --> 00:24:48.820 people who are choosing to

NOTE Confidence: 0.99510825

00:24:48.820 --> 00:24:49.960 do this because

NOTE Confidence: 0.976219

00:24:50.580 --> 00:24:52.180 of life with sickle cell

NOTE Confidence: 0.976219

00:24:52.180 --> 00:24:54.580 disease. That risk becomes worth

NOTE Confidence: 0.976219

00:24:54.580 --> 00:24:55.400 it. So

NOTE Confidence: 0.997377

00:24:55.780 --> 00:24:56.280 Yeah.

NOTE Confidence: 0.99584675

00:24:57.619 --> 00:24:58.600 So I wanna

NOTE Confidence: 0.80016637

00:24:58.900 --> 00:24:59.400 end,

NOTE Confidence: 0.9476131

00:25:00.655 --> 00:25:02.835 on a somewhat different note,

NOTE Confidence: 0.99587584

00:25:03.455 --> 00:25:04.434 and as

NOTE Confidence: 0.9999502

00:25:04.975 --> 00:25:05.475 challenging

NOTE Confidence: 0.99974924

00:25:06.095 --> 00:25:07.695 and horrific as it can

NOTE Confidence: 0.99974924

00:25:07.695 --> 00:25:08.195 be

NOTE Confidence: 0.9863013

00:25:08.494 --> 00:25:09.455 to have to deal with

NOTE Confidence: 0.9863013

00:25:09.455 --> 00:25:10.895 the pain of sickle cell

NOTE Confidence: 0.9863013

00:25:10.895 --> 00:25:12.835 disease and everything with it,

NOTE Confidence: 0.9776667

00:25:14.720 --> 00:25:15.700 I think that

NOTE Confidence: 0.97642523

00:25:16.400 --> 00:25:17.300 one of the,

NOTE Confidence: 0.9989878

00:25:17.680 --> 00:25:19.700 in many ways, equally painful

NOTE Confidence: 0.94288236

00:25:20.080 --> 00:25:21.760 parts is that, I think,

NOTE Confidence: 0.94288236

00:25:21.760 --> 00:25:22.900 for many years,

NOTE Confidence: 0.98774594

00:25:23.440 --> 00:25:25.359 sickle cell being largely a

NOTE Confidence: 0.98774594

00:25:25.359 --> 00:25:26.660 disease in the US

NOTE Confidence: 0.994505

00:25:27.119 --> 00:25:28.800 that arose in people who

NOTE Confidence: 0.994505

00:25:28.800 --> 00:25:29.619 are black

NOTE Confidence: 0.9902415

00:25:30.105 --> 00:25:32.265 was a disease that I

NOTE Confidence: 0.9902415

00:25:32.265 --> 00:25:34.345 think people very often didn't

NOTE Confidence: 0.9902415

00:25:34.345 --> 00:25:35.785 get the kind of treatment

NOTE Confidence: 0.9902415

00:25:35.785 --> 00:25:37.005 that they should have.

NOTE Confidence: 0.9994746

00:25:37.625 --> 00:25:38.125 And

NOTE Confidence: 0.98744434

00:25:38.744 --> 00:25:40.665 I remember being a young

NOTE Confidence: 0.98744434

00:25:40.665 --> 00:25:41.165 doctor,

NOTE Confidence: 0.99931514

00:25:41.945 --> 00:25:42.445 and

NOTE Confidence: 0.9996955

00:25:42.990 --> 00:25:44.910 I will just share that

NOTE Confidence: 0.9996955

00:25:44.910 --> 00:25:45.650 the way

NOTE Confidence: 0.9968798

00:25:46.109 --> 00:25:47.790 people talked about patients with

NOTE Confidence: 0.9968798

00:25:47.790 --> 00:25:49.490 sickle cell disease wasn't

NOTE Confidence: 0.9922844

00:25:49.950 --> 00:25:51.090 wasn't okay.

NOTE Confidence: 0.98880744

00:25:52.910 --> 00:25:53.410 And

NOTE Confidence: 0.9941905

00:25:55.005 --> 00:25:56.125 just like you to reflect

NOTE Confidence: 0.9941905

00:25:56.125 --> 00:25:58.365 a little bit on on

NOTE Confidence: 0.9941905

00:25:58.365 --> 00:26:00.365 the disparities patients with sickle

NOTE Confidence: 0.9941905

00:26:00.365 --> 00:26:01.665 cell disease face

NOTE Confidence: 0.9718252

00:26:02.285 --> 00:26:03.885 and how much of that

NOTE Confidence: 0.9718252

00:26:03.885 --> 00:26:05.665 is due to just the

NOTE Confidence: 0.9718252

00:26:05.725 --> 00:26:06.225 fundamental

NOTE Confidence: 0.96183616

00:26:06.605 --> 00:26:08.125 racism that exists in our

NOTE Confidence: 0.96183616

00:26:08.125 --> 00:26:08.625 society.

NOTE Confidence: 0.99215734

00:26:09.619 --> 00:26:11.619 Absolutely. So, you know, we

NOTE Confidence: 0.99215734

00:26:11.619 --> 00:26:13.139 know that how we deliver

NOTE Confidence: 0.99215734

00:26:13.139 --> 00:26:13.639 care,

NOTE Confidence: 0.99867046

00:26:14.820 --> 00:26:15.320 and

NOTE Confidence: 0.9643485

00:26:16.019 --> 00:26:18.259 our capacity as providers and

NOTE Confidence: 0.9643485

00:26:18.259 --> 00:26:20.679 ultimately health outcomes are driven

NOTE Confidence: 0.99922526

00:26:21.700 --> 00:26:23.775 by larger things. So we

NOTE Confidence: 0.99922526

00:26:23.775 --> 00:26:24.515 know that

NOTE Confidence: 0.997367

00:26:25.054 --> 00:26:25.794 as prejudice

NOTE Confidence: 0.9984261

00:26:26.095 --> 00:26:26.835 and racism

NOTE Confidence: 0.99352103

00:26:27.775 --> 00:26:29.475 infuses into our institutions,

NOTE Confidence: 0.9829184

00:26:29.855 --> 00:26:31.715 those affect our policies.

NOTE Confidence: 0.9673649

00:26:32.494 --> 00:26:34.434 Those policies affect our environments.

NOTE Confidence: 0.9494173

00:26:34.734 --> 00:26:36.174 Right? Whether it is a

NOTE Confidence: 0.9494173

00:26:36.174 --> 00:26:37.075 living environment,

NOTE Confidence: 0.9607915

00:26:37.869 --> 00:26:40.030 funding environments for research and

NOTE Confidence: 0.9607915

00:26:40.030 --> 00:26:40.530 innovation.

NOTE Confidence: 0.936851

00:26:41.309 --> 00:26:43.010 And those things affect ultimately

NOTE Confidence: 0.936851

00:26:43.230 --> 00:26:43.730 diagnosis,

NOTE Confidence: 0.9655868

00:26:44.109 --> 00:26:45.809 treatment, and then really mortality.

NOTE Confidence: 0.9695233

00:26:46.590 --> 00:26:47.789 It's not even in just

NOTE Confidence: 0.9695233

00:26:47.789 --> 00:26:49.150 sickle cell disease. We know

NOTE Confidence: 0.9695233

00:26:49.150 --> 00:26:50.270 that that is across the

NOTE Confidence: 0.9695233

00:26:50.270 --> 00:26:51.809 board. I think most notably,

NOTE Confidence: 0.9695233

00:26:51.869 --> 00:26:53.494 we saw that. Most recently,

NOTE Confidence: 0.9695233

00:26:53.555 --> 00:26:54.515 we saw that during the

NOTE Confidence: 0.9695233

00:26:54.515 --> 00:26:55.494 COVID pandemic.

NOTE Confidence: 0.9526098

00:26:56.035 --> 00:26:57.075 And then also when we

NOTE Confidence: 0.9526098

00:26:57.075 --> 00:26:58.295 look at data around,

NOTE Confidence: 0.9419404

00:26:58.755 --> 00:27:00.695 black infant and maternal mortality.

NOTE Confidence: 0.99681497

00:27:01.234 --> 00:27:01.734 Absolutely.

NOTE Confidence: 0.99665564

00:27:02.355 --> 00:27:03.715 The stigma with sickle cell

NOTE Confidence: 0.99665564

00:27:03.715 --> 00:27:04.215 disease

NOTE Confidence: 0.9918029

00:27:04.755 --> 00:27:06.055 mirrors the stigma

NOTE Confidence: 0.99902797

00:27:06.929 --> 00:27:07.669 of being

NOTE Confidence: 0.9993717

00:27:08.289 --> 00:27:09.350 an African American

NOTE Confidence: 0.96482223

00:27:09.730 --> 00:27:11.350 in the US health system.

NOTE Confidence: 0.96482223

00:27:11.649 --> 00:27:12.850 And then also having a

NOTE Confidence: 0.96482223

00:27:12.850 --> 00:27:14.070 disease that

NOTE Confidence: 0.93533504

00:27:14.450 --> 00:27:15.809 has pain, which is treated

NOTE Confidence: 0.93533504

00:27:15.809 --> 00:27:17.649 by opioids. Right? So there's

NOTE Confidence: 0.93533504

00:27:17.649 --> 00:27:18.710 this other layer.

NOTE Confidence: 0.9709795

00:27:19.330 --> 00:27:20.289 We see that come up

NOTE Confidence: 0.9709795

00:27:20.289 --> 00:27:21.029 in funding,

NOTE Confidence: 0.9680351

00:27:22.034 --> 00:27:23.475 again, which which is which

NOTE Confidence: 0.9680351

00:27:23.475 --> 00:27:24.595 for us drives a lot

NOTE Confidence: 0.9680351

00:27:24.595 --> 00:27:26.294 of innovation like gene therapy.

NOTE Confidence: 0.9598948

00:27:26.674 --> 00:27:27.955 We see the funding disparities

NOTE Confidence: 0.9598948

00:27:27.955 --> 00:27:29.715 between other diseases, like people

NOTE Confidence: 0.9598948

00:27:29.715 --> 00:27:30.835 like to compare to CF

NOTE Confidence: 0.9598948

00:27:30.835 --> 00:27:32.034 a lot, which is another

NOTE Confidence: 0.9598948

00:27:32.034 --> 00:27:32.774 rare disease.

NOTE Confidence: 0.92713135

00:27:33.970 --> 00:27:35.330 We see that in provider

NOTE Confidence: 0.92713135

00:27:35.490 --> 00:27:37.409 CF meaning cystic fibrosis. Yes.

NOTE Confidence: 0.92713135

00:27:37.409 --> 00:27:39.350 Cystic fibrosis. I'm so sorry.

NOTE Confidence: 0.91210145

00:27:40.289 --> 00:27:41.429 Yes. Cystic fibrosis.

NOTE Confidence: 0.9840237

00:27:41.970 --> 00:27:43.429 We see that in,

NOTE Confidence: 0.9624337

00:27:43.809 --> 00:27:44.950 provider attitudes,

NOTE Confidence: 0.9384612

00:27:45.730 --> 00:27:47.425 like in training, like what

NOTE Confidence: 0.9384612

00:27:47.425 --> 00:27:48.625 you just mentioned and kind

NOTE Confidence: 0.9384612

00:27:48.625 --> 00:27:49.665 of, like, working on that

NOTE Confidence: 0.9384612

00:27:49.665 --> 00:27:50.165 stigma.

NOTE Confidence: 0.95217544

00:27:51.185 --> 00:27:52.244 We see that,

NOTE Confidence: 0.9965732

00:27:53.425 --> 00:27:53.925 in

NOTE Confidence: 0.9696974

00:27:54.305 --> 00:27:56.145 how society views persons with

NOTE Confidence: 0.9696974

00:27:56.145 --> 00:27:57.685 Sickle Cell Disease as well.

NOTE Confidence: 0.9696974

00:27:57.825 --> 00:27:59.105 And it's a very salient

NOTE Confidence: 0.9696974

00:27:59.105 --> 00:28:00.929 and current issue. I think

NOTE Confidence: 0.9696974

00:28:00.929 --> 00:28:02.390 what we are doing now,

NOTE Confidence: 0.9745922

00:28:03.169 --> 00:28:05.169 acknowledging that this exists and

NOTE Confidence: 0.9745922

00:28:05.169 --> 00:28:07.090 then thinking about in the

NOTE Confidence: 0.9745922

00:28:07.090 --> 00:28:08.470 scope of our own power,

NOTE Confidence: 0.9745922

00:28:08.690 --> 00:28:09.730 how do we change that?

NOTE Confidence: 0.9745922

00:28:09.730 --> 00:28:11.010 So is it educating our

NOTE Confidence: 0.9745922

00:28:11.010 --> 00:28:12.609 peers? Is it making the

NOTE Confidence: 0.9745922

00:28:12.609 --> 00:28:14.049 right decision for the right

NOTE Confidence: 0.9745922

00:28:14.049 --> 00:28:15.590 patient at the right time?

NOTE Confidence: 0.98951846

00:28:16.005 --> 00:28:17.925 Is it creating space and

NOTE Confidence: 0.98951846

00:28:17.925 --> 00:28:20.165 acknowledging the historical disparities and

NOTE Confidence: 0.98951846

00:28:20.165 --> 00:28:21.285 inequities that have led to

NOTE Confidence: 0.98951846

00:28:21.285 --> 00:28:22.805 this point? You know, there's

NOTE Confidence: 0.98951846

00:28:22.805 --> 00:28:25.045 so many ways to to

NOTE Confidence: 0.98951846

00:28:25.045 --> 00:28:26.905 address this issue that continues

NOTE Confidence: 0.98951846

00:28:26.965 --> 00:28:27.945 to remain pervasive

NOTE Confidence: 0.9995691

00:28:28.484 --> 00:28:29.385 in our industry.

NOTE Confidence: 0.96203715

00:28:29.970 --> 00:28:31.730 Doctor Cece Calhoun is an

NOTE Confidence: 0.96203715

00:28:31.730 --> 00:28:33.410 assistant professor of medicine and

NOTE Confidence: 0.96203715

00:28:33.410 --> 00:28:35.010 hematology at the Yale School

NOTE Confidence: 0.96203715

00:28:35.010 --> 00:28:35.750 of Medicine.

NOTE Confidence: 0.9754471

00:28:36.290 --> 00:28:37.490 If you have questions, the

NOTE Confidence: 0.9754471

00:28:37.490 --> 00:28:39.170 address is cancer answers at

NOTE Confidence: 0.9754471

00:28:39.170 --> 00:28:40.530 yale dot e d u,

NOTE Confidence: 0.9754471

00:28:40.530 --> 00:28:41.809 and past editions of the

NOTE Confidence: 0.9754471

00:28:41.809 --> 00:28:43.570 program are available in audio

NOTE Confidence: 0.9754471

00:28:43.570 --> 00:28:44.935 and written form at yale

NOTE Confidence: 0.9754471

00:28:44.935 --> 00:28:46.775 cancer center dot org. We

NOTE Confidence: 0.9754471

00:28:46.775 --> 00:28:47.815 hope you'll join us next

NOTE Confidence: 0.9754471

00:28:47.815 --> 00:28:48.775 time to learn more about

NOTE Confidence: 0.9754471

00:28:48.775 --> 00:28:49.995 the fight against cancer.

NOTE Confidence: 0.9651949

00:28:50.375 --> 00:28:51.975 Funding for Yale Cancer Answers

NOTE Confidence: 0.9651949

00:28:51.975 --> 00:28:53.655 is provided by Smilow Cancer

NOTE Confidence: 0.9651949

00:28:53.655 --> 00:28:54.155 Hospital.