- NOTE Confidence: 0.97670954
- 00:00:00.160 --> 00:00:01.920 Funding for Yale Cancer Answers
- NOTE Confidence: 0.97670954
- $00:00:01.920 \longrightarrow 00:00:03.679$  is provided by Smilow Cancer
- NOTE Confidence: 0.97670954
- 00:00:03.679 --> 00:00:04.180 Hospital.
- NOTE Confidence: 0.9530167
- $00:00:06.160 \dashrightarrow 00:00:08.000$  Welcome to Yale Cancer Answers
- NOTE Confidence: 0.9530167
- $00:00:08.000 \longrightarrow 00:00:08.960$  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
- $00:00:14.000 \longrightarrow 00:00:14.820$  with oncologists
- NOTE Confidence: 0.8808917
- 00:00:16.195 --> 00:00:16.414 and specialists who are on
- NOTE Confidence: 0.8808917
- $00:00:16.414 \longrightarrow 00:00:17.059$  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

 $00:00:21.954 \rightarrow 00:00:23.395$  assistant professor of medicine in

NOTE Confidence: 0.8808917

 $00{:}00{:}23.395 \dashrightarrow 00{:}00{:}25.395$  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

 $00:00:34.090 \longrightarrow 00:00:34.989$  about themselves.

 $00:00:36.649 \longrightarrow 00:00:37.530$  Maybe you could just tell us

 $00{:}00{:}38{.}570 \dashrightarrow 00{:}00{:}40{.}090$  where you grew up and

NOTE Confidence: 0.9617338

 $00:00:40.090 \longrightarrow 00:00:41.770$  and where you've been and

 $00:00:42.650 \longrightarrow 00:00:43.770$  how it is that you

NOTE Confidence: 0.9996621

 $00:00:43.770 \longrightarrow 00:00:44.670$  became interested in

 $00:00:45.995 \rightarrow 00:00:47.854$  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

 $00:00:50.315 \rightarrow 00:00:51.435$  off with my title. But

NOTE Confidence: 0.97818565

 $00:00:51.435 \longrightarrow 00:00:52.475$  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
- $00:00:56.635 \longrightarrow 00:00:58.415$  born and raised, and
- NOTE Confidence: 0.9774535
- $00:00:59.300 \longrightarrow 00:01:00.580$  had the pleasure of doing
- NOTE Confidence: 0.9774535
- $00:01:00.580 \longrightarrow 00:01:01.780$  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
- $00{:}01{:}04{.}500 \dashrightarrow 00{:}01{:}05{.}540$  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
- $00:01:10.180 \longrightarrow 00:01:11.080$  first meaningful
- NOTE Confidence: 0.99286026
- $00:01:11.380 \longrightarrow 00:01:12.819$  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
- $00{:}01{:}16.865 \dashrightarrow 00{:}01{:}18.064$  the nexus of so many
- NOTE Confidence: 0.9709098

- $00:01:18.064 \rightarrow 00:01:19.505$  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
- $00{:}01{:}22.145 \dashrightarrow 00{:}01{:}22.645$  cell.
- NOTE Confidence: 0.9332242
- 00:01:23.104 --> 00:01:23.844 It was,
- NOTE Confidence: 0.99373513
- $00{:}01{:}24.944 \dashrightarrow 00{:}01{:}27.310$  children and young adults with
- NOTE Confidence: 0.99373513
- 00:01:27.310 --> 00:01:28.130 sickle cell,
- NOTE Confidence: 0.9593186
- $00{:}01{:}28{.}590 \dashrightarrow 00{:}01{:}30{.}110$  and the disease itself and
- NOTE Confidence: 0.9593186
- $00:01:30.110 \longrightarrow 00:01:31.250$  giving to my community.
- NOTE Confidence: 0.98278564
- $00{:}01{:}32{.}430 \dashrightarrow 00{:}01{:}33{.}630$  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
- $00:01:37.150 \longrightarrow 00:01:37.730$  a hematologist.
- NOTE Confidence: 0.96414894
- 00:01:38.350 --> 00:01:40.050 And I am a lifespan
- NOTE Confidence: 0.96414894
- $00:01:40.110 \longrightarrow 00:01:42.115$  hematologist here at Yale.

- NOTE Confidence: 0.96414894
- $00:01:42.115 \longrightarrow 00:01:43.095$  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
- $00:01:47.715 \longrightarrow 00:01:48.215$  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
- $00:01:52.115 \longrightarrow 00:01:53.795$  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
- $00{:}01{:}55{.}395 \dashrightarrow 00{:}01{:}57{.}060$  on adults
- NOTE Confidence: 0.9950271
- $00:01:57.540 \longrightarrow 00:01:59.079$  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
- $00:02:02.100 \longrightarrow 00:02:03.000$  off explaining
- NOTE Confidence: 0.9998954
- $00:02:03.460 \longrightarrow 00:02:04.680$  to our listeners
- NOTE Confidence: 0.94111156
- $00{:}02{:}05{.}539 \dashrightarrow 00{:}02{:}08{.}040$  what sickle cell disease is,
- NOTE Confidence: 0.94111156
- $00:02:08.180 \longrightarrow 00:02:08.919$  how it
- $00:02:11.114 \rightarrow 00:02:11.614$  occurs?

- NOTE Confidence: 0.9781514
- 00:02:12.474 --> 00:02:13.915 Yeah. Absolutely. I'll do my

 $00:02:13.915 \longrightarrow 00:02:15.514$  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

 $00:02:16.955 \longrightarrow 00:02:18.235$  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

 $00{:}02{:}21{.}194 \dashrightarrow 00{:}02{:}21{.}935$  full explanation.

NOTE Confidence: 0.90608263

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

NOTE Confidence: 0.90608263

 $00{:}02{:}24.050 \dashrightarrow 00{:}02{:}25.430$  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

 $00:02:30.130 \longrightarrow 00:02:31.410$  cell, which as you know,

NOTE Confidence: 0.97457546

 $00:02:31.410 \rightarrow 00:02:33.250$  transports oxygen around our body,

NOTE Confidence: 0.97457546

 $00{:}02{:}33.250 \dashrightarrow 00{:}02{:}34.370$  helping to keep all of

NOTE Confidence: 0.97457546

 $00:02:34.370 \longrightarrow 00:02:35.925$  our tissues healthy and safe.

- NOTE Confidence: 0.976821
- $00:02:36.485 \longrightarrow 00:02:37.925$  Normally, a red blood cell

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

NOTE Confidence: 0.976821

 $00{:}02{:}39{.}205 \dashrightarrow 00{:}02{:}40{.}725$  as a jelly donut. The

NOTE Confidence: 0.976821

 $00:02:40.725 \rightarrow 00:02:42.264$  technical term, it's a biconcave

NOTE Confidence: 0.976821

 $00{:}02{:}42.485 \dashrightarrow 00{:}02{:}42.985$  disc.

NOTE Confidence: 0.9758556

 $00{:}02{:}43.285 \dashrightarrow 00{:}02{:}44.325$  But when you have sickle

NOTE Confidence: 0.9758556

 $00:02:44.325 \longrightarrow 00:02:45.925$  cell, you are born with,

NOTE Confidence: 0.9758556

 $00:02:45.925 \longrightarrow 00:02:46.905$  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

 $00:02:51.239 \longrightarrow 00:02:52.680$  cells being shaped like a

NOTE Confidence: 0.9592412

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

NOTE Confidence: 0.9799713

 $00{:}02{:}53{.}959 \dashrightarrow 00{:}02{:}55{.}000$  they're shaped more like a

NOTE Confidence: 0.9799713

 $00:02:55.000 \rightarrow 00:02:57.159$  crescent, banana, or a sickle,

NOTE Confidence: 0.9799713

 $00:02:57.159 \longrightarrow 00:02:58.120$  which is why it's called

NOTE Confidence: 0.9799713

- $00:02:58.120 \longrightarrow 00:02:58.939$  sickle cell.
- NOTE Confidence: 0.9548659
- 00:02:59.879 --> 00:03:01.079 In addition to being shaped
- NOTE Confidence: 0.9548659
- $00:03:01.079 \rightarrow 00:03:02.919$  differently, they're also quite sticky
- NOTE Confidence: 0.9548659
- $00:03:02.919 \longrightarrow 00:03:04.280$  and quite brittle. And so
- NOTE Confidence: 0.9548659
- $00{:}03{:}04{.}280 \dashrightarrow 00{:}03{:}05{.}239$  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
- $00{:}03{:}11.275 \dashrightarrow 00{:}03{:}12.315$  the sides of the wall,
- NOTE Confidence: 0.9737951
- $00:03:12.315 \rightarrow 00:03:13.755$  delivering oxygen to where it
- NOTE Confidence: 0.9737951
- $00:03:13.755 \longrightarrow 00:03:14.655$  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
- $00{:}03{:}18{.}155 \dashrightarrow 00{:}03{:}18{.}895$  those cells
- NOTE Confidence: 0.9885388
- 00:03:19.290 --> 00:03:20.650 with sickled cells that are
- NOTE Confidence: 0.9885388
- $00:03:20.650 \rightarrow 00:03:22.090$  shaped differently, that are brittle,

- NOTE Confidence: 0.9885388
- $00:03:22.090 \longrightarrow 00:03:23.050$  that are sticky, you can
- NOTE Confidence: 0.9885388
- $00:03:23.050 \rightarrow 00:03:23.550$  imagine
- NOTE Confidence: 0.93367016
- $00:03:23.930 \rightarrow 00:03:25.210$  maybe they're injuring the sides
- NOTE Confidence: 0.93367016
- $00{:}03{:}25{.}210 \dashrightarrow 00{:}03{:}26{.}910$  of those blood vessels or
- NOTE Confidence: 0.98416567
- $00:03:27.210 \longrightarrow 00:03:28.410$  sticking to each other or
- NOTE Confidence: 0.98416567
- $00:03:28.410 \longrightarrow 00:03:29.770$  maybe sticking to the sides
- NOTE Confidence: 0.98416567
- $00:03:29.770 \longrightarrow 00:03:31.070$  of the blood vessel wall.
- NOTE Confidence: 0.98416567
- $00:03:31.290 \longrightarrow 00:03:32.590$  And it is that inflammatory
- NOTE Confidence: 0.97883654
- $00:03:32.889 \longrightarrow 00:03:34.110$  process, that inflammation
- NOTE Confidence: 0.94728225
- $00:03:34.645 \longrightarrow 00:03:36.005$  from damage,
- NOTE Confidence: 0.94728225
- 00:03:36.005 --> 00:03:37.685 that sick sticking together
- NOTE Confidence: 0.94728225
- $00{:}03{:}37.685 \dashrightarrow 00{:}03{:}39.125$  and preventing the flow of
- NOTE Confidence: 0.94728225
- $00:03:39.125 \longrightarrow 00:03:40.165$  blood to other parts of
- NOTE Confidence: 0.94728225
- 00:03:40.165 --> 00:03:40.745 our body
- NOTE Confidence: 0.9877535
- $00:03:41.285 \longrightarrow 00:03:42.565$  that really is behind the
- NOTE Confidence: 0.9877535

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

NOTE Confidence: 0.9745032

 $00:03:44.325 \longrightarrow 00:03:45.605$  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

 $00:03:47.045 \longrightarrow 00:03:48.405$  for a sec, this all

NOTE Confidence: 0.9745032

 $00:03:48.405 \longrightarrow 00:03:48.905$  happens

NOTE Confidence: 0.9996332

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

NOTE Confidence: 0.9962862

 $00:03:51.390 \longrightarrow 00:03:53.330$  of a single amino acid.

NOTE Confidence: 0.9962862

 $00:03:53.390 \longrightarrow 00:03:54.370$  Is that correct?

NOTE Confidence: 0.9752781

 $00{:}03{:}54.750 \dashrightarrow 00{:}03{:}56.110$  That's a hundred percent correct.

NOTE Confidence: 0.9752781

 $00{:}03{:}56{.}110 \dashrightarrow 00{:}03{:}57{.}470$  And we found out about

NOTE Confidence: 0.9752781

 $00:03:57.470 \longrightarrow 00:03:58.989$  this in the early nineteen

NOTE Confidence: 0.9752781

 $00{:}03{:}58{.}989 \dashrightarrow 00{:}04{:}00{.}849$  hundreds that sickle cell was described

NOTE Confidence: 0.9980854

 $00{:}04{:}01.724 \dashrightarrow 00{:}04{:}03.905$  as just this one small genetic

NOTE Confidence: 0.9980854

 $00:04:03.965 \rightarrow 00:04:05.665$  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

 $00:04:07.805 \rightarrow 00:04:09.665$  body. But that small genetic

- NOTE Confidence: 0.9985209
- 00:04:09.724 --> 00:04:10.224 change
- NOTE Confidence: 0.9993137
- $00{:}04{:}10.525 \dashrightarrow 00{:}04{:}12.305$  leads to the gene
- NOTE Confidence: 0.9488178
- $00:04:12.924 \rightarrow 00:04:14.224$  not functioning normally.
- NOTE Confidence: 0.99925697
- $00{:}04{:}15{.}150 \dashrightarrow 00{:}04{:}15{.}650$  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
- $00:04:18.110 \longrightarrow 00:04:19.389$  we have this? You know,
- NOTE Confidence: 0.9912776
- $00:04:19.389 \longrightarrow 00:04:20.830$  if this is something that's
- NOTE Confidence: 0.9912776
- $00{:}04{:}20.830 \dashrightarrow 00{:}04{:}22.430$  bad, why does sickle cell
- NOTE Confidence: 0.9912776
- $00:04:22.430 \longrightarrow 00:04:24.050$  disease why is it pervasive?
- NOTE Confidence: 0.9984124
- $00:04:24.509 \longrightarrow 00:04:25.310$  Why is it the most
- NOTE Confidence: 0.9984124
- $00{:}04{:}25{.}310 \dashrightarrow 00{:}04{:}27{.}229$  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
- $00{:}04{:}28{.}509 \dashrightarrow 00{:}04{:}29{.}654$  of alluded to this
- NOTE Confidence: 0.97607636
- $00{:}04{:}30{.}135 \dashrightarrow 00{:}04{:}31{.}835$  a bit earlier in that
- NOTE Confidence: 0.97607636

 $00:04:32.055 \longrightarrow 00:04:33.335$  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

 $00{:}04{:}42.855 \dashrightarrow 00{:}04{:}44.535$  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

 $00{:}04{:}46.000 \dashrightarrow 00{:}04{:}47.360$  that cell is shaped differently

NOTE Confidence: 0.985312

 $00{:}04{:}47{.}360 \dashrightarrow 00{:}04{:}47{.}860$  or

NOTE Confidence: 0.9975711

 $00:04:48.240 \longrightarrow 00:04:49.680$  if the oxygen is lower,

NOTE Confidence: 0.9975711

 $00{:}04{:}49.680 \dashrightarrow 00{:}04{:}50.640$  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

 $00:04:52.160 \longrightarrow 00:04:53.460$  protective against malaria

NOTE Confidence: 0.9624942

 $00{:}04{:}53{.}920 \dashrightarrow 00{:}04{:}54{.}720$  and which is why it

NOTE Confidence: 0.9624942

 $00:04:54.720 \rightarrow 00:04:56.500$  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
- $00:04:57.920 \longrightarrow 00:04:58.935$  tell us for a second
- NOTE Confidence: 0.9624942
- $00{:}04{:}58{.}935 \dashrightarrow 00{:}05{:}00{.}854$  the difference between sickle cell
- NOTE Confidence: 0.9624942
- $00{:}05{:}00{.}854 \dashrightarrow 00{:}05{:}02{.}955$  trait and sickle cell anemia?
- NOTE Confidence: 0.9919617
- $00{:}05{:}03.574 \dashrightarrow 00{:}05{:}05{.}814$  Yeah. Absolutely. So, you know,
- NOTE Confidence: 0.9919617
- $00:05:05.814 \longrightarrow 00:05:07.414$  like many things in life,
- NOTE Confidence: 0.9919617
- $00:05:07.735 \longrightarrow 00:05:08.694$  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
- $00:05:11.254 \rightarrow 00:05:13.495$  disease is autosomal recessive, meaning
- NOTE Confidence: 0.9919617
- $00:05:13.495 \longrightarrow 00:05:14.880$  that in order for you
- NOTE Confidence: 0.9919617
- $00:05:14.880 \dashrightarrow 00:05:16.420$  to have the physical manifestation
- NOTE Confidence: 0.9919617
- $00:05:16.560 \longrightarrow 00:05:17.300$  of the disease,
- NOTE Confidence: 0.9980079
- $00{:}05{:}17.760 \dashrightarrow 00{:}05{:}19.040$  you need to have one
- NOTE Confidence: 0.9980079
- $00:05:19.040 \longrightarrow 00:05:20.160$  part of sickle cell from
- NOTE Confidence: 0.9980079

 $00:05:20.160 \rightarrow 00:05:21.200$  your mom and one part

NOTE Confidence: 0.9980079

 $00:05:21.200 \longrightarrow 00:05:22.320$  of sickle cell from your

NOTE Confidence: 0.9980079

 $00{:}05{:}22.320 \dashrightarrow 00{:}05{:}22.820$  dad.

NOTE Confidence: 0.98503685

 $00:05:23.200 \longrightarrow 00:05:25.120$  So those parents can be

NOTE Confidence: 0.98503685

 $00:05:25.120 \longrightarrow 00:05:27.040$  sickle cell carriers or carry

NOTE Confidence: 0.98503685

 $00{:}05{:}27{.}040 \dashrightarrow 00{:}05{:}27{.}779$  the trait

NOTE Confidence: 0.98823553

 $00:05:28.160 \longrightarrow 00:05:29.700$  and not have any

NOTE Confidence: 0.9965469

 $00:05:30.025 \longrightarrow 00:05:30.845$  overt manifestations

NOTE Confidence: 0.98488724

 $00{:}05{:}31{.}224 \dashrightarrow 00{:}05{:}32{.}745$  of sickle cell disease. But

NOTE Confidence: 0.98488724

 $00{:}05{:}32.745 \dashrightarrow 00{:}05{:}34.345$  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

 $00:05:35.944 \longrightarrow 00:05:36.904$  and have full,

NOTE Confidence: 0.92312014

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

NOTE Confidence: 0.92312014

 $00:05:40.264 \rightarrow 00:05:41.865$  so having the trait is

NOTE Confidence: 0.92312014

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

NOTE Confidence: 0.91812944

 $00{:}05{:}42.759 \dashrightarrow 00{:}05{:}44.199$  in and of itself to

- NOTE Confidence: 0.91812944
- $00:05:44.199 \rightarrow 00:05:46.060$  put be protective against malaria.

 $00{:}05{:}46.759 \dashrightarrow 00{:}05{:}48.279$  Yes. That is why it

NOTE Confidence: 0.9903144

 $00:05:48.279 \longrightarrow 00:05:50.039$  has persisted. And when we

NOTE Confidence: 0.9903144

 $00{:}05{:}50{.}039 \dashrightarrow 00{:}05{:}52{.}439$  think about the mechanisms behind

NOTE Confidence: 0.9903144

 $00:05:52.439 \longrightarrow 00:05:53.719$  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

 $00:05:55.479 \longrightarrow 00:05:57.259$  most common theory is around

NOTE Confidence: 0.99597585

 $00:05:57.784 \rightarrow 00:05:59.464$  that cell being completely shaped

NOTE Confidence: 0.99597585

 $00{:}05{:}59{.}464 \dashrightarrow 00{:}06{:}00{.}985$  differently. But the other thing

NOTE Confidence: 0.99597585

 $00{:}06{:}00{.}985 \dashrightarrow 00{:}06{:}02{.}985$  I mentioned earlier was the

NOTE Confidence: 0.99597585

 $00{:}06{:}02.985 \dashrightarrow 00{:}06{:}05.085$  oxygen environment that's not conducive

NOTE Confidence: 0.99597585

 $00:06:05.145 \longrightarrow 00:06:06.604$  to replication for,

NOTE Confidence: 0.95813787

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

NOTE Confidence: 0.94939613

 $00{:}06{:}09{.}705 \dashrightarrow 00{:}06{:}10{.}824$  that is the kinda second

NOTE Confidence: 0.94939613

 $00:06:10.824 \longrightarrow 00:06:12.400$  thing. If we wanna get

NOTE Confidence: 0.94939613

 $00:06:12.400 \longrightarrow 00:06:13.839$  really nerdy about it. Yeah.

NOTE Confidence: 0.94939613

 $00{:}06{:}13.839 \dashrightarrow 00{:}06{:}15.040$  No. No. No. No. That

NOTE Confidence: 0.94939613

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

NOTE Confidence: 0.9777484

 $00{:}06{:}17{.}200 \dashrightarrow 00{:}06{:}19{.}440$ 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

 $00{:}06{:}21.040 \dashrightarrow 00{:}06{:}22.240$  there was a lot of

NOTE Confidence: 0.9777484

 $00{:}06{:}22.240 \dashrightarrow 00{:}06{:}22.740$  malaria,

NOTE Confidence: 0.98167235

 $00:06:23.440 \longrightarrow 00:06:24.560$  you know, that is in

NOTE Confidence: 0.98167235

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

NOTE Confidence: 0.8649957

 $00:06:26.735 \longrightarrow 00:06:27.634$  then in fact,

NOTE Confidence: 0.9862222

 $00:06:27.935 \longrightarrow 00:06:29.294$  it makes sense that people

NOTE Confidence: 0.9862222

 $00{:}06{:}29{.}294 \dashrightarrow 00{:}06{:}30{.}654$  with sickle cell trait would

NOTE Confidence: 0.9862222

 $00:06:30.654 \rightarrow 00:06:32.095$  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

 $00{:}06{:}33{.}694 \dashrightarrow 00{:}06{:}34{.}914$  go on and

NOTE Confidence: 0.8809687

 $00{:}06{:}35{.}375 \dashrightarrow 00{:}06{:}36{.}194$  have children.

- NOTE Confidence: 0.96028924
- $00{:}06{:}36{.}895 \dashrightarrow 00{:}06{:}38{.}435$  And some of those children
- NOTE Confidence: 0.96028924
- $00{:}06{:}38.735 \dashrightarrow 00{:}06{:}39.180$  or
- NOTE Confidence: 0.95296603
- $00:06:39.740 \longrightarrow 00:06:41.419$  theoretically, one in four of
- NOTE Confidence: 0.95296603
- $00{:}06{:}41.419 \dashrightarrow 00{:}06{:}43.039$  children from the that
- NOTE Confidence: 0.9949081
- $00{:}06{:}43.339 \dashrightarrow 00{:}06{:}44.779$  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
- $00:06:46.460 \longrightarrow 00:06:47.600$  sickle cell disease.
- NOTE Confidence: 0.986059
- $00{:}06{:}48{.}460 \dashrightarrow 00{:}06{:}49{.}900$  Yes. And we find that
- NOTE Confidence: 0.986059
- $00{:}06{:}49{.}900 \dashrightarrow 00{:}06{:}51{.}820$  worldwide, again, sickle cell disease
- NOTE Confidence: 0.986059
- $00:06:51.820 \longrightarrow 00:06:53.180$  is still the most common
- NOTE Confidence: 0.986059
- $00:06:53.180 \longrightarrow 00:06:53.680$  monogenic
- NOTE Confidence: 0.95956755
- $00{:}06{:}54.495 \dashrightarrow 00{:}06{:}56.175$  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
- $00:06:58.255 \rightarrow 00:06:59.635$  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

 $00{:}07{:}03.295 \dashrightarrow 00{:}07{:}05.075$  where sickle cell disease persists.

NOTE Confidence: 0.9750417

 $00:07:05.215 \longrightarrow 00:07:07.215$  And so we estimate that

NOTE Confidence: 0.9750417

 $00{:}07{:}07{.}215 \dashrightarrow 00{:}07{:}08{.}415$  there are about three hundred

NOTE Confidence: 0.9750417

 $00{:}07{:}08.415 \dashrightarrow 00{:}07{:}10.410$  and sixty thousand new births

NOTE Confidence: 0.9750417

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

NOTE Confidence: 0.99604225

 $00:07:12.090 \longrightarrow 00:07:13.770$  each year. So it continues

NOTE Confidence: 0.99604225

 $00:07:13.770 \longrightarrow 00:07:14.430$  to remain

NOTE Confidence: 0.9894576

 $00{:}07{:}15.130 \dashrightarrow 00{:}07{:}16.970$  super prevalent, and the incidence

NOTE Confidence: 0.9894576

 $00:07:16.970 \longrightarrow 00:07:19.130$  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

 $00{:}07{:}21.050 \dashrightarrow 00{:}07{:}23.130$  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

 $00{:}07{:}26.575 \dashrightarrow 00{:}07{:}28.415$  another step down that sort

NOTE Confidence: 0.9851676

 $00:07:28.415 \longrightarrow 00:07:29.635$  of nerdy pathway

- NOTE Confidence: 0.9791066
- $00{:}07{:}29{.}935 \dashrightarrow 00{:}07{:}32.015$  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
- $00:07:33.535 \longrightarrow 00:07:34.755$  the audience why
- NOTE Confidence: 0.9589031
- $00{:}07{:}35.055 \dashrightarrow 00{:}07{:}35.555$  sometimes
- NOTE Confidence: 0.6328524
- 00:07:36.655 --> 00:07:37.155 in
- NOTE Confidence: 0.9994486
- $00:07:38.330 \longrightarrow 00:07:38.830$  very
- NOTE Confidence: 0.989954
- 00:07:39.210 --> 00:07:40.110 young children,
- NOTE Confidence: 0.9813854
- $00{:}07{:}41.370 \dashrightarrow 00{:}07{:}43.310$  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
- $00:07:45.450 \longrightarrow 00:07:46.570$  isn't really much of a
- NOTE Confidence: 0.9813854
- $00:07:46.570 \longrightarrow 00:07:48.270$  problem at first because
- NOTE Confidence: 0.986887
- $00{:}07{:}48.650 \dashrightarrow 00{:}07{:}50.490$  there's still something else around
- NOTE Confidence: 0.986887
- $00{:}07{:}50{.}490 \dashrightarrow 00{:}07{:}52{.}030$  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
- $00{:}07{:}54.305 \dashrightarrow 00{:}07{:}55.665$  I believe that being a
- NOTE Confidence: 0.9731385

 $00:07:55.665 \rightarrow 00:07:57.605$  nerd is very cool. Obviously,

NOTE Confidence: 0.9731385

 $00:07:57.745 \longrightarrow 00:07:58.645$  I have a bias.

NOTE Confidence: 0.94021654

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

NOTE Confidence: 0.9832529

 $00:08:00.785 \longrightarrow 00:08:02.245$  just to answer your question,

NOTE Confidence: 0.9832529

 $00{:}08{:}02{.}385 \dashrightarrow 00{:}08{:}03{.}745$  absolutely. And I think we'll

NOTE Confidence: 0.9832529

 $00{:}08{:}03.745 \dashrightarrow 00{:}08{:}05.185$  revisit this concept as we

NOTE Confidence: 0.9832529

 $00:08:05.185 \longrightarrow 00:08:06.385$  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

 $00:08:10.500 \longrightarrow 00:08:11.800$  so as you mentioned,

NOTE Confidence: 0.96367794

 $00:08:12.259 \longrightarrow 00:08:13.939$  people and infants are born

NOTE Confidence: 0.96367794

 $00:08:13.939 \longrightarrow 00:08:15.379$  with sickle cell. But when

NOTE Confidence: 0.96367794

 $00:08:15.379 \rightarrow 00:08:17.240$  they're younger, the physical manifestations

NOTE Confidence: 0.9977178

 $00{:}08{:}17.699 \dashrightarrow 00{:}08{:}19.000$  are not as prominent.

NOTE Confidence: 0.99958766

 $00:08:19.539 \rightarrow 00:08:20.715$  And it's not just because

- NOTE Confidence: 0.99958766
- $00:08:20.794 \longrightarrow 00:08:21.855$  children are resilient
- NOTE Confidence: 0.984773
- $00{:}08{:}22.315 \dashrightarrow 00{:}08{:}24.395$  and, their regenerative capacity of
- NOTE Confidence: 0.984773
- $00:08:24.395 \longrightarrow 00:08:26.155$  youth is greater, but it's
- NOTE Confidence: 0.984773
- $00{:}08{:}26.155 \dashrightarrow 00{:}08{:}27.595$  also because of the presence
- NOTE Confidence: 0.984773
- 00:08:27.595 --> 00:08:28.574 of fetal hemoglobin,
- NOTE Confidence: 0.99145347
- $00:08:29.275 \dashrightarrow 00:08:30.715$  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
- $00:08:32.395 \longrightarrow 00:08:34.235$  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
- $00:08:37.130 \longrightarrow 00:08:38.410$  cells that hold on to
- NOTE Confidence: 0.9812472
- 00:08:38.410 --> 00:08:39.949 oxygen quite well
- NOTE Confidence: 0.9845243
- $00{:}08{:}40{.}250 \dashrightarrow 00{:}08{:}41{.}389$  and really mitigate
- NOTE Confidence: 0.95945156
- $00{:}08{:}41.769 \dashrightarrow 00{:}08{:}42.990$  a lot of the symptoms,
- NOTE Confidence: 0.95945156
- $00{:}08{:}43.050 \dashrightarrow 00{:}08{:}44.750$  clinical symptoms of sickle cell.
- NOTE Confidence: 0.95959944

 $00:08:45.370 \dashrightarrow 00:08:47.069$  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

 $00:08:49.769 \longrightarrow 00:08:51.209$  more fet al hemoglobin tend to

NOTE Confidence: 0.95959944

 $00{:}08{:}51{.}209 \dashrightarrow 00{:}08{:}52{.}785$  do better. And, certainly, as

NOTE Confidence: 0.95959944

 $00{:}08{:}52{.}785 \dashrightarrow 00{:}08{:}53{.}605$  we think about

NOTE Confidence: 0.9968138

 $00:08:53.985 \dashrightarrow 00:08:56.145$  our disease modifying the rapies and

NOTE Confidence: 0.9968138

 $00:08:56.145 \longrightarrow 00:08:57.125$  curative therapies,

NOTE Confidence: 0.9971425

 $00{:}08{:}57.745 \dashrightarrow 00{:}08{:}59.605$  really increasing that fet al hemoglobin

NOTE Confidence: 0.9971425

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

NOTE Confidence: 0.99937934

 $00:09:01.825 \longrightarrow 00:09:02.325$  Wow.

NOTE Confidence: 0.9917835

 $00:09:03.985 \longrightarrow 00:09:05.045$  So let's

NOTE Confidence: 0.9953645

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

NOTE Confidence: 0.9953645

 $00{:}09{:}06{.}790 \dashrightarrow 00{:}09{:}08{.}470$  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

 $00:09:10.710 \longrightarrow 00:09:11.770$  the blood vessels.

- NOTE Confidence: 0.9936623
- $00:09:12.710 \longrightarrow 00:09:14.150$  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
- $00:09:16.309 \rightarrow 00:09:18.070$  the common symptoms that people
- NOTE Confidence: 0.9875903
- $00{:}09{:}18{.}070 \dashrightarrow 00{:}09{:}19{.}190$  have first, and then we'll
- NOTE Confidence: 0.9875903
- $00:09:19.190 \longrightarrow 00:09:20.470$  get into some of the
- NOTE Confidence: 0.9875903
- $00{:}09{:}20{.}470 \dashrightarrow 00{:}09{:}21{.}075$  sort of
- NOTE Confidence: 0.97780037
- $00:09:21.715 \rightarrow 00:09:23.795$  organ damage and complications that
- NOTE Confidence: 0.97780037
- 00:09:23.795 --> 00:09:24.535 can arise.
- NOTE Confidence: 0.9923399
- $00:09:25.715 \longrightarrow 00:09:27.635$  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
- $00{:}09{:}30{.}515 \dashrightarrow 00{:}09{:}31{.}875$  I believe that when most
- NOTE Confidence: 0.99632084
- $00:09:31.875 \rightarrow 00:09:33.335$  people if you have
- NOTE Confidence: 0.991484
- $00{:}09{:}33.795 \dashrightarrow 00{:}09{:}35.475$  a personal connection to some one
- NOTE Confidence: 0.991484
- 00:09:35.475 00:09:36.775 with sickle cell disease,
- NOTE Confidence: 0.9992637

- $00{:}09{:}37{.}320 \dashrightarrow 00{:}09{:}38{.}540$  then you think about
- NOTE Confidence: 0.8975252
- 00:09:38.920 --> 00:09:39.500 about unpredictable,
- NOTE Confidence: 0.9735267
- $00:09:40.040 \dashrightarrow 00:09:41.960$  severe, debilitating pain that affects
- NOTE Confidence: 0.9735267
- $00:09:41.960 \longrightarrow 00:09:43.100$  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
- $00{:}09{:}45{.}400 \dashrightarrow 00{:}09{:}47{.}320$  that oxygen blood flow, but
- NOTE Confidence: 0.9784494
- $00:09:47.320 \longrightarrow 00:09:48.840$  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
- $00:09:50.280 \longrightarrow 00:09:51.480$  ever fallen as leep and then
- NOTE Confidence: 0.9784494
- $00:09:51.480 \longrightarrow 00:09:52.815$  the circulation comes back,
- NOTE Confidence: 0.9950037
- $00{:}09{:}53.695 \dashrightarrow 00{:}09{:}54.815$  but that pain is severe
- NOTE Confidence: 0.9950037
- $00:09:54.815 \rightarrow 00:09:56.495$  and often equated to something
- NOTE Confidence: 0.9950037
- $00:09:56.495 \longrightarrow 00:09:57.795$  like a long bone fracture,
- NOTE Confidence: 0.99837244
- $00{:}09{:}58.655 \dashrightarrow 00{:}09{:}59.955$  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
- $00:10:02.335 \longrightarrow 00:10:03.135$  is a disease of the
- NOTE Confidence: 0.99109733
- $00:10:03.135 \longrightarrow 00:10:04.255$  red blood cell, that means
- NOTE Confidence: 0.99109733
- $00:10:04.255 \rightarrow 00:10:06.095$  everywhere that blood goes, sickle
- NOTE Confidence: 0.99109733
- 00:10:06.095 --> 00:10:07.155 cells can impact.
- NOTE Confidence: 0.9975313
- $00{:}10{:}07{.}570 \dashrightarrow 00{:}10{:}08{.}690$  And so when we think
- NOTE Confidence: 0.9975313
- $00:10:08.690 \longrightarrow 00:10:10.209$  about other types of organ
- NOTE Confidence: 0.9975313
- 00:10:10.209 --> 00:10:10.709 damage,
- NOTE Confidence: 0.9980262
- $00:10:11.170 \longrightarrow 00:10:12.550$  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
- $00:10:14.929 \longrightarrow 00:10:16.209$  think about the kidneys and
- NOTE Confidence: 0.97066945
- $00:10:16.209 \longrightarrow 00:10:17.329$  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
- $00{:}10{:}19{.}809 \dashrightarrow 00{:}10{:}21{.}250$  our trainees is really looking
- NOTE Confidence: 0.9696529
- $00:10:21.250 \longrightarrow 00:10:23.365$  at the impact of neurologic
- NOTE Confidence: 0.9696529

 $00:10:23.505 \rightarrow 00:10:25.445$  complications both subclinical

NOTE Confidence: 0.9715843

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

NOTE Confidence: 0.9715843

 $00:10:28.145 \longrightarrow 00:10:29.025$  which is what we have

NOTE Confidence: 0.9715843

 $00{:}10{:}29{.}025 \dashrightarrow 00{:}10{:}29{.}905$  a lot of data and

NOTE Confidence: 0.9715843

 $00{:}10{:}29{.}905 \dashrightarrow 00{:}10{:}31{.}425$  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

 $00{:}10{:}32.705 \dashrightarrow 00{:}10{:}33.205$  about.

NOTE Confidence: 0.99923885

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

NOTE Confidence: 0.99923885

 $00{:}10{:}35{.}585 \dashrightarrow 00{:}10{:}36{.}645$  part of the body.

NOTE Confidence: 0.8555953

 $00{:}10{:}38{.}890 \dashrightarrow 00{:}10{:}40{.}490$  And typically when people are

NOTE Confidence: 0.8555953

 $00:10:40.490 \longrightarrow 00:10:40.990$  diagnosed,

NOTE Confidence: 0.9922798

 $00:10:41.370 \longrightarrow 00:10:43.130$  are they diagnosed as young

NOTE Confidence: 0.9922798

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

NOTE Confidence: 0.99021363

 $00:10:44.890 \longrightarrow 00:10:46.350$  So here in the US,

NOTE Confidence: 0.99021363

 $00{:}10{:}46{.}490 \dashrightarrow 00{:}10{:}48{.}170$  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
- $00:10:50.090 \longrightarrow 00:10:51.150$  States and
- NOTE Confidence: 0.927882
- 00:10:51.524 --> 00:10:52.985 tremendous advocacy efforts,
- NOTE Confidence: 0.99711215
- $00:10:53.444 \rightarrow 00:10:54.725$  children with sickle cell disease
- NOTE Confidence: 0.99711215
- $00{:}10{:}54.725 \dashrightarrow 00{:}10{:}55.845$  born in the US are
- NOTE Confidence: 0.99711215
- $00{:}10{:}55{.}845 \dashrightarrow 00{:}10{:}57{.}444$  diagnosed on a new born screen
- NOTE Confidence: 0.99711215
- $00{:}10{:}57{.}444 \dashrightarrow 00{:}10{:}57{.}944$  test.
- NOTE Confidence: 0.9795747
- $00:10:58.324 \longrightarrow 00:10:59.605$  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
- $00{:}11{:}00{.}644 \dashrightarrow 00{:}11{:}01{.}764$  kid, and may be they'll do
- NOTE Confidence: 0.9795747
- $00:11:01.764 \longrightarrow 00:11:02.725$  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
- $00:11:03.764 \longrightarrow 00:11:05.625$  it tests for many inherited
- NOTE Confidence: 0.9795747
- 00:11:05.764 --> 00:11:06.745 genetic disorders,
- NOTE Confidence: 0.977908
- $00{:}11{:}07{.}350 \dashrightarrow 00{:}11{:}08{.}309$  and one of those is
- NOTE Confidence: 0.977908
- $00{:}11{:}08{.}309 \dashrightarrow 00{:}11{:}09{.}910$  sickle cell. And what that
- NOTE Confidence: 0.977908

- $00:11:09.910 \longrightarrow 00:11:11.190$  has allowed us to do
- NOTE Confidence: 0.977908
- $00:11:11.190 \longrightarrow 00:11:13.290$  is detect sickle cell early
- NOTE Confidence: 0.977908
- $00:11:13.350 \rightarrow 00:11:15.510$  and intervene early because though

 $00:11:15.510 \longrightarrow 00:11:16.550$  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

 $00{:}11{:}17{.}589 \dashrightarrow 00{:}11{:}19{.}209$  that fet al 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

 $00:11:21.670 \rightarrow 00:11:22.570$  really, really,

NOTE Confidence: 0.9730126

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

NOTE Confidence: 0.9730126

 $00{:}11{:}25{.}155 \dashrightarrow 00{:}11{:}27{.}075$  fatal. And we diagnose them

NOTE Confidence: 0.9730126

 $00{:}11{:}27.075 \dashrightarrow 00{:}11{:}29.175$  and we start penicillin prophylactically

NOTE Confidence: 0.9954609

 $00{:}11{:}29{.}715 \dashrightarrow 00{:}11{:}30{.}835$  to really protect them and

NOTE Confidence: 0.9954609

 $00:11:30.835 \longrightarrow 00:11:31.875$  give them the best chance

NOTE Confidence: 0.9954609

 $00:11:31.875 \longrightarrow 00:11:33.975$  of thriving into a dulthood. And

NOTE Confidence: 0.9954609

 $00{:}11{:}34{.}115 \dashrightarrow 00{:}11{:}35{.}315$  how long does that fet al

NOTE Confidence: 0.9954609

 $00{:}11{:}35{.}315 \dashrightarrow 00{:}11{:}37{.}635$  hemoglobin typically stick around? I

- NOTE Confidence: 0.9954609
- 00:11:37.635 --> 00:11:38.535 mean, you mentioned
- NOTE Confidence: 0.9582588
- $00{:}11{:}38{.}910 \dashrightarrow 00{:}11{:}40{.}110$  that there are some people
- NOTE Confidence: 0.9582588
- $00:11:40.110 \longrightarrow 00:11:41.550$  who have persistence of fetal
- NOTE Confidence: 0.9582588
- 00:11:41.550 --> 00:11:42.050 hemoglobin
- NOTE Confidence: 0.8642667
- $00{:}11{:}42.670 \dashrightarrow 00{:}11{:}43.170$  who
- NOTE Confidence: 0.9430894
- $00:11:43.550 \longrightarrow 00:11:45.070$  even into a dulthood who may
- NOTE Confidence: 0.9430894
- 00:11:45.070 00:11:46.350 have a more mild case,
- NOTE Confidence: 0.9430894
- $00:11:46.350 \longrightarrow 00:11:48.029$  but typically, it doesn't stay
- NOTE Confidence: 0.9430894
- $00{:}11{:}48.029 \dashrightarrow 00{:}11{:}49.649$  around all that long. Isn't
- NOTE Confidence: 0.9430894
- $00:11:49.870 \longrightarrow 00:11:51.845$  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
- $00{:}11{:}53.845 \dashrightarrow 00{:}11{:}55.625$  the hemoglobin begins to transition
- NOTE Confidence: 0.99848914
- $00:11:55.684 \longrightarrow 00:11:56.804$  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

- $00:11:58.804 \rightarrow 00:12:00.024$  eight weeks after birth.
- NOTE Confidence: 0.9720965
- $00{:}12{:}00{.}404 \dashrightarrow 00{:}12{:}01{.}925$  And people who have conditions
- NOTE Confidence: 0.9720965
- $00:12:01.925 \longrightarrow 00:12:03.125$  of the red blood cell,
- NOTE Confidence: 0.9720965
- $00{:}12{:}03{.}125 \dashrightarrow 00{:}12{:}04{.}725$  that hem fet al 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
- $00:12:09.350 \longrightarrow 00:12:11.429$  infancy period, except for those
- NOTE Confidence: 0.9720965
- 00:12:11.429 --> 00:12:12.330 rare instances
- NOTE Confidence: 0.99493974
- $00{:}12{:}12{.}950 \dashrightarrow 00{:}12{:}14{.}550$  where patients have a genetic
- NOTE Confidence: 0.99493974
- $00{:}12{:}14.550 \dashrightarrow 00{:}12{:}16.309$  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
- $00:12:18.150 \longrightarrow 00:12:19.750$  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
- $00:12:23.904 \rightarrow 00:12:24.644$  most people,

- NOTE Confidence: 0.9635761
- $00{:}12{:}24.945 \dashrightarrow 00{:}12{:}26.385$  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
- $00:12:28.545 \longrightarrow 00:12:29.584$  by the time they're into
- NOTE Confidence: 0.9635761
- $00:12:29.584 \longrightarrow 00:12:31.285$  their even school age.
- NOTE Confidence: 0.99692136
- 00:12:32.144 --> 00:12:33.365 Got it. And
- NOTE Confidence: 0.9537967
- $00:12:34.200 \longrightarrow 00:12:35.420$  the fetal hemoglobin,
- NOTE Confidence: 0.9776295
- 00:12:36.200 --> 00:12:38.140 I mean, you mentioned transitioning
- NOTE Confidence: 0.9776295
- $00:12:38.200 \longrightarrow 00:12:39.020$  from maternal
- NOTE Confidence: 0.9986973
- 00:12:39.880 --> 00:12:40.380 hemoglobin
- NOTE Confidence: 0.97329026
- $00:12:40.760 \longrightarrow 00:12:42.280$  to to the hemoglobin of
- NOTE Confidence: 0.97329026
- $00:12:42.280 \longrightarrow 00:12:42.940$  the child,
- NOTE Confidence: 0.99831647
- $00{:}12{:}43{.}480 \dashrightarrow 00{:}12{:}45{.}260$  but is that fet al hemoglobin
- NOTE Confidence: 0.96636105
- $00{:}12{:}45.640 \dashrightarrow 00{:}12{:}46.760$  in some way related to
- NOTE Confidence: 0.96636105
- $00:12:46.760 \longrightarrow 00:12:47.820$  maternal hemoglobin?
- NOTE Confidence: 0.98406893
- $00{:}12{:}49.655 \dashrightarrow 00{:}12{:}51.515$  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

 $00:12:52.934 \longrightarrow 00:12:53.815$  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

 $00:12:55.255 \rightarrow 00:12:56.235$  our bone marrow.

NOTE Confidence: 0.973374

 $00{:}12{:}56.615 \dashrightarrow 00{:}12{:}57.895$  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

 $00:12:59.495 \longrightarrow 00:13:00.855$  us through the placenta. And

NOTE Confidence: 0.973374

 $00{:}13{:}00{.}855 \dashrightarrow 00{:}13{:}02{.}054$  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

 $00{:}13{:}06{.}500 \dashrightarrow 00{:}13{:}08{.}420$  amazing, we recognize, hey. I

NOTE Confidence: 0.96429497

 $00:13:08.420 \longrightarrow 00:13:09.620$  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

 $00{:}13{:}10.980 \dashrightarrow 00{:}13{:}12.339$  and our reliance on those

NOTE Confidence: 0.96429497

 $00:13:12.339 \rightarrow 00:13:13.459$  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
- $00{:}13{:}14{.}980 \dashrightarrow 00{:}13{:}16{.}980$  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
- $00{:}13{:}20{.}304 \dashrightarrow 00{:}13{:}21{.}045$  that's made?
- NOTE Confidence: 0.929623
- 00:13:21.505 --> 00:13:22.465 So I always tell my
- NOTE Confidence: 0.929623
- $00:13:22.465 \longrightarrow 00:13:24.145$  patients f for heated fetal
- NOTE Confidence: 0.929623
- $00:13:24.145 \longrightarrow 00:13:25.745$  hemoglobin because that's what they're
- NOTE Confidence: 0.929623
- $00{:}13{:}25.745 \dashrightarrow 00{:}13{:}26.945$  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
- $00:13:28.865 \rightarrow 00:13:30.485$  over and becomes more predominant
- NOTE Confidence: 0.99075586
- $00{:}13{:}30.865 \dashrightarrow 00{:}13{:}31.985$  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
- $00:13:39.790 \longrightarrow 00:13:40.290$  engaging.
- NOTE Confidence: 0.99888414
- 00:13:42.429 --> 00:13:43.949 We'll be back
- NOTE Confidence: 0.99888414
- $00:13:43.949 \longrightarrow 00:13:45.309$  in just a minute to
- NOTE Confidence: 0.99888414
- 00:13:45.309 --> 00:13:46.449 continue our conversation
- NOTE Confidence: 0.9688061
- $00{:}13{:}47{.}305 \dashrightarrow 00{:}13{:}49{.}225$  with Cece Calhoun, the director
- NOTE Confidence: 0.9688061
- $00:13:49.225 \longrightarrow 00:13:50.425$  of the sickle cell program
- NOTE Confidence: 0.9688061
- 00:13:50.425 --> 00:13:51.085 at Yale.
- NOTE Confidence: 0.9577569
- $00{:}13{:}51{.}465 \dashrightarrow 00{:}13{:}53{.}225$  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
- $00:13:55.465 \rightarrow 00:13:57.305$  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
- $00:13:58.985 \longrightarrow 00:14:00.185$  the midst of their cancer
- NOTE Confidence: 0.99817544
- 00:14:00.185 --> 00:14:00.685 journey
- NOTE Confidence: 0.9989313
- $00:14:01.029 \rightarrow 00:14:02.570$  while respecting the philosophies,

- NOTE Confidence: 0.97698647
- $00:14:02.950 \longrightarrow 00:14:05.110$  spiritualities, and religions of patients
- NOTE Confidence: 0.97698647
- $00:14:05.110 \longrightarrow 00:14:05.929$  and caregivers.
- NOTE Confidence: 0.8098148
- 00:14:06.550 --> 00:14:07.050 Smilowcancerhospital
- NOTE Confidence: 0.9964093
- $00{:}14{:}07{.}990 \dashrightarrow 00{:}14{:}08{.}809$  dot org.
- NOTE Confidence: 0.9832286
- 00:14:10.470 --> 00:14:12.950 The American Cancer Society estimates
- NOTE Confidence: 0.9832286
- $00:14:12.950 \longrightarrow 00:14:14.230$  that more than sixty five
- NOTE Confidence: 0.9832286
- $00:14:14.230 \longrightarrow 00:14:16.170$  thousand Americans will be diagnosed
- NOTE Confidence: 0.9832286
- $00{:}14{:}16{.}230 \dashrightarrow 00{:}14{:}17{.}665$  with head and neck cancer
- NOTE Confidence: 0.9832286
- $00:14:17.665 \longrightarrow 00:14:18.324$  this year,
- NOTE Confidence: 0.9989042
- 00:14:18.704 --> 00:14:20.144 making up about four percent
- NOTE Confidence: 0.9989042
- $00:14:20.144 \longrightarrow 00:14:21.685$  of all cancers diagnosed.
- NOTE Confidence: 0.9933062
- $00{:}14{:}22{.}384 \dashrightarrow 00{:}14{:}24{.}464$  When detected early, however, head
- NOTE Confidence: 0.9933062
- $00:14:24.464 \rightarrow 00:14:25.904$  and neck cancers are easily
- NOTE Confidence: 0.9933062
- $00{:}14{:}25{.}904 \dashrightarrow 00{:}14{:}27{.}444$  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
- $00{:}14{:}34{.}930 \dashrightarrow 00{:}14{:}36{.}690$  Center and at Smilow Cancer
- NOTE Confidence: 0.9563748
- 00:14:36.690 --> 00:14:37.190 Hospital,
- NOTE Confidence: 0.9970368
- $00{:}14{:}37{.}570 \dashrightarrow 00{:}14{:}39{.}410$  to test innovative new treatments
- NOTE Confidence: 0.9970368
- $00{:}14{:}39{.}410 \dashrightarrow 00{:}14{:}40{.}710$  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
- $00{:}14{:}43.125 \dashrightarrow 00{:}14{:}44.825$  awarded grants from the National
- NOTE Confidence: 0.98383653
- $00{:}14{:}44{.}885 \dashrightarrow 00{:}14{:}46{.}725$  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
- $00{:}14{:}51.685 \dashrightarrow 00{:}14{:}52.585$  or SPORE
- NOTE Confidence: 0.98880094
- $00{:}14{:}52{.}965 \dashrightarrow 00{:}14{:}54{.}805$  to address critical barriers to
- NOTE Confidence: 0.98880094
- $00{:}14{:}54{.}805 \dashrightarrow 00{:}14{:}56{.}010$  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
- $00:14:58.010 \rightarrow 00:15:00.430$  resistance to immune DNA damaging
- NOTE Confidence: 0.98880094
- $00{:}15{:}00{.}570$  -->  $00{:}15{:}01{.}870$  and targeted the rapy.
- NOTE Confidence: 0.9614975
- $00{:}15{:}02{.}490 \dashrightarrow 00{:}15{:}04{.}170$  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
- $00:15:06.170 \longrightarrow 00:15:07.930$  You're listening to Connecticut public
- NOTE Confidence: 0.9614975
- $00{:}15{:}07{.}930 \dashrightarrow 00{:}15{:}08{.}430$  radio.
- NOTE Confidence: 0.95732576
- $00{:}15{:}09{.}845 \dashrightarrow 00{:}15{:}11{.}365$  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
- $00{:}15{:}13.045 \dashrightarrow 00{:}15{:}14.505$  the second half of our
- NOTE Confidence: 0.9978219
- $00:15:16.325 \rightarrow 00:15:17.065$  show tonight.
- NOTE Confidence: 0.91231173
- 00:15:17.525 --> 00:15:19.145 This is Yale Cancer Answers,
- NOTE Confidence: 0.9822005
- $00{:}15{:}19.685 \dashrightarrow 00{:}15{:}21.845$  and we're speaking with doctor
- NOTE Confidence: 0.9822005
- $00:15:21.845 \longrightarrow 00:15:24.120$  Cece Calhoun, director of the
- NOTE Confidence: 0.9822005
- $00{:}15{:}24.120 \dashrightarrow 00{:}15{:}26.060$  sickle cell program at Yale.
- NOTE Confidence: 0.9986333
- $00{:}15{:}27.080 \dashrightarrow 00{:}15{:}28.440$  So we've been talking a
- NOTE Confidence: 0.9986333

 $00:15:28.440 \longrightarrow 00:15:30.360$  lot about sickle cell disease

NOTE Confidence: 0.9986333

 $00{:}15{:}30{.}360 \dashrightarrow 00{:}15{:}31{.}580$  and some of the manifestations.

NOTE Confidence: 0.9997037

 $00:15:32.520 \longrightarrow 00:15:34.620$  We haven't yet touched on

NOTE Confidence: 0.9997037

 $00:15:34.680 \longrightarrow 00:15:35.180$  treatments

NOTE Confidence: 0.9256256

 $00{:}15{:}35{.}720 \dashrightarrow 00{:}15{:}37{.}720$  and may be we can begin

NOTE Confidence: 0.9256256

 $00:15:37.720 \longrightarrow 00:15:38.940$  talking about treatments

NOTE Confidence: 0.9968207

 $00{:}15{:}40.365 \dashrightarrow 00{:}15{:}43.005$  and what's available today for

NOTE Confidence: 0.9968207

 $00:15:43.005 \longrightarrow 00:15:44.225$  for people who are

NOTE Confidence: 0.9882733

 $00{:}15{:}44.764 \dashrightarrow 00{:}15{:}46.204$  struggling to live the best

NOTE Confidence: 0.9882733

 $00:15:46.204 \rightarrow 00:15:47.485$  life they can with sickle

NOTE Confidence: 0.9882733

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

NOTE Confidence: 0.9722521

 $00:15:48.685 \rightarrow 00:15:49.485$  Yes. This is,

NOTE Confidence: 0.9897961

 $00:15:50.445 \rightarrow 00:15:52.464$  a interesting question, a complicated

NOTE Confidence: 0.9897961

 $00:15:52.524 \rightarrow 00:15:53.425$  question. So

NOTE Confidence: 0.99433863

 $00{:}15{:}53{.}750 \dashrightarrow 00{:}15{:}54{.}950$  we talked a little bit

NOTE Confidence: 0.99433863

 $00:15:54.950 \dashrightarrow 00:15:56.470$  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
- $00{:}15{:}58{.}230 \dashrightarrow 00{:}15{:}59{.}209$  and its manifestations
- NOTE Confidence: 0.9207292
- $00{:}15{:}59{.}910 \dashrightarrow 00{:}16{:}01{.}269$  for over about a hundred
- NOTE Confidence: 0.9207292
- $00:16:01.269 \rightarrow 00:16:02.329$  and twenty years.
- NOTE Confidence: 0.97668666
- 00:16:02.870 --> 00:16:04.410 But really up until,
- NOTE Confidence: 0.9892021
- $00:16:05.670 \longrightarrow 00:16:07.769$  about nineteen ninety eight, we
- NOTE Confidence: 0.9892021
- 00:16:07.829 --> 00:16:08.329 had,
- NOTE Confidence: 0.96799815
- $00:16:09.115 \rightarrow 00:16:11.055$  where the FDA approved hydroxy urea
- NOTE Confidence: 0.96476305
- 00:16:11.995 --> 00:16:12.954 for the treatment of sickle
- NOTE Confidence: 0.96476305
- $00:16:12.954 \rightarrow 00:16:14.154$  cell disease. There were really
- NOTE Confidence: 0.96476305
- 00:16:14.154 --> 00:16:14.654 no,
- NOTE Confidence: 0.9467566
- $00:16:15.355 \rightarrow 00:16:17.755$  disease modifying medications. We used
- NOTE Confidence: 0.9467566
- $00{:}16{:}17.755 \dashrightarrow 00{:}16{:}18.954$  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

- $00:16:21.820 \longrightarrow 00:16:22.560$  no interventions
- NOTE Confidence: 0.9979874
- $00:16:22.940 \longrightarrow 00:16:24.639$  to treat actual sickle cell.
- NOTE Confidence: 0.9668411
- $00:16:25.180 \rightarrow 00:16:26.639$  In nineteen ninety eight, hydroxyurea
- NOTE Confidence: 0.96948844
- $00:16:27.660 \longrightarrow 00:16:29.420$  was FDA approved, and then
- NOTE Confidence: 0.96948844
- $00{:}16{:}29{.}420 \dashrightarrow 00{:}16{:}30{.}700$  there was about a twenty
- NOTE Confidence: 0.96948844
- 00:16:30.700 --> 00:16:31.440 year gap,
- NOTE Confidence: 0.9993418
- $00:16:31.820 \longrightarrow 00:16:34.320$  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
- $00{:}16{:}37{.}415 \dashrightarrow 00{:}16{:}39{.}015$  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
- $00:16:40.215 \longrightarrow 00:16:42.695$  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
- $00:16:45.495 \longrightarrow 00:16:46.875$  sickle and prevent that.
- NOTE Confidence: 0.9779916
- $00{:}16{:}48{.}310 \dashrightarrow 00{:}16{:}49{.}670$  Then we were able to
- NOTE Confidence: 0.9779916
- 00:16:49.670 --> 00:16:51.050 FDA approved Crizanlizumab,

- NOTE Confidence: 0.9886045
- $00:16:51.670 \rightarrow 00:16:53.110$  which is a type of
- NOTE Confidence: 0.9886045
- $00:16:53.110 \longrightarrow 00:16:54.250$  infusion medication,
- NOTE Confidence: 0.9898983
- $00{:}16{:}54{.}950 \dashrightarrow 00{:}16{:}56{.}230$  which tries to make that
- NOTE Confidence: 0.9898983
- $00:16:56.230 \rightarrow 00:16:57.670$  environment less sticky. We talked
- NOTE Confidence: 0.9898983
- $00{:}16{:}57.670 \dashrightarrow 00{:}16{:}58.710$  about how those sickle cells
- NOTE Confidence: 0.9898983
- $00:16:58.710 \longrightarrow 00:17:00.070$  are sticky. They stick together.
- NOTE Confidence: 0.9898983
- $00:17:00.070 \longrightarrow 00:17:01.065$  They block flow.
- NOTE Confidence: 0.9623608
- $00{:}17{:}02.745 \dashrightarrow 00{:}17{:}04.845$  Also a medication called OxBryta
- NOTE Confidence: 0.9623608
- $00:17:04.905 \longrightarrow 00:17:07.065$  was introduced, which binds to
- NOTE Confidence: 0.9623608
- $00:17:07.065 \longrightarrow 00:17:08.265$  that spot where oxygen would
- NOTE Confidence: 0.9623608
- $00:17:08.265 \longrightarrow 00:17:09.065$  sit in the red blood
- NOTE Confidence: 0.9623608
- $00{:}17{:}09.065 \dashrightarrow 00{:}17{:}10.525$  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
- $00{:}17{:}14.345 \dashrightarrow 00{:}17{:}15.805$  was abruptly discontinued.
- NOTE Confidence: 0.99347705

 $00:17:16.789 \longrightarrow 00:17:19.270$  And so these are options

NOTE Confidence: 0.99347705

 $00:17:19.270 \longrightarrow 00:17:20.730$  to treat sickle cell disease,

NOTE Confidence: 0.9671922

 $00{:}17{:}21.350 \dashrightarrow 00{:}17{:}22.950$  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

 $00{:}17{:}24.070 \dashrightarrow 00{:}17{:}25.270$  heard about gene the rapy. What

NOTE Confidence: 0.9671922

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

NOTE Confidence: 0.9671922

 $00{:}17{:}26.230 \dashrightarrow 00{:}17{:}27.609$  that was for sickle cell.

NOTE Confidence: 0.9671922

 $00:17:27.669 \longrightarrow 00:17:28.630$  I'm picking up on the

NOTE Confidence: 0.9671922

 $00:17:28.630 \longrightarrow 00:17:29.609$  vibes. Okay?

NOTE Confidence: 0.99712235

 $00{:}17{:}30{.}734 \dashrightarrow 00{:}17{:}31{.}855$  And even before,

NOTE Confidence: 0.9934606

 $00:17:32.415 \longrightarrow 00:17:33.535$  gene therapy, we did have

NOTE Confidence: 0.9934606

 $00:17:33.535 \longrightarrow 00:17:34.895$  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

 $00{:}17{:}37{.}935 \dashrightarrow 00{:}17{:}39{.}215$  that the factory for our

NOTE Confidence: 0.98225886

 $00:17:39.215 \longrightarrow 00:17:40.494$  red blood cells, our white

- NOTE Confidence: 0.98225886
- $00:17:40.494 \rightarrow 00:17:42.015$  blood cells, and our platelets
- NOTE Confidence: 0.98225886
- $00{:}17{:}42.015 \dashrightarrow 00{:}17{:}43.530$  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
- $00:17:45.130 \longrightarrow 00:17:46.490$  who has sickle cell disease,
- NOTE Confidence: 0.98225886
- $00:17:46.490 \longrightarrow 00:17:47.530$  if you replace their bone
- NOTE Confidence: 0.98225886
- $00:17:47.530 \longrightarrow 00:17:49.609$  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
- $00:17:52.570 \longrightarrow 00:17:53.630$  only has trait,
- NOTE Confidence: 0.99818724
- $00:17:53.930 \longrightarrow 00:17:55.369$  then you can cure the
- NOTE Confidence: 0.99818724
- $00{:}17{:}55{.}369 \dashrightarrow 00{:}17{:}55{.}869$  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
- $00{:}18{:}00{.}081 \dashrightarrow 00{:}18{:}01{.}494$  treatment too. Absolutely. And and
- NOTE Confidence: 0.95077056
- $00:18:01.494 \longrightarrow 00:18:01.815$  there's,
- NOTE Confidence: 0.99763125

 $00:18:02.295 \rightarrow 00:18:03.335$  some number of people who

NOTE Confidence: 0.99763125

 $00:18:03.335 \longrightarrow 00:18:04.375$  don't make it through that

NOTE Confidence: 0.99763125

 $00{:}18{:}04{.}375 \dashrightarrow 00{:}18{:}05{.}595$  treatment. Mhmm.

NOTE Confidence: 0.9690082

 $00{:}18{:}06.055 \dashrightarrow 00{:}18{:}07.255$  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

 $00{:}18{:}09{.}015 \dashrightarrow 00{:}18{:}10{.}935$  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

 $00:18:17.890 \longrightarrow 00:18:19.250$  due to the genetic diversity

NOTE Confidence: 0.9962299

 $00:18:19.250 \longrightarrow 00:18:20.150$  in us all,

NOTE Confidence: 0.96870315

 $00:18:20.850 \longrightarrow 00:18:22.210$  again, we get half of

NOTE Confidence: 0.96870315

 $00:18:22.210 \longrightarrow 00:18:23.409$  that needed match from our

NOTE Confidence: 0.96870315

 $00{:}18{:}23.409 \dashrightarrow 00{:}18{:}24.609$  mom, half of that needed

NOTE Confidence: 0.96870315

 $00:18:24.609 \longrightarrow 00:18:26.195$  match from our dad. The

- NOTE Confidence: 0.96870315
- $00:18:26.195 \longrightarrow 00:18:27.395$  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
- $00:18:28.835 \longrightarrow 00:18:29.575$  an option,
- NOTE Confidence: 0.9705533
- $00:18:29.955 \rightarrow 00:18:31.734$  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
- $00{:}18{:}34{.}195 \dashrightarrow 00{:}18{:}36{.}035$  course, an identical twin wouldn't
- NOTE Confidence: 0.9906685
- $00:18:36.035 \longrightarrow 00:18:37.075$  do you any good because
- NOTE Confidence: 0.9906685
- $00{:}18{:}37{.}075 \dashrightarrow 00{:}18{:}38{.}615$  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
- $00:18:44.090 \longrightarrow 00:18:45.770$  So tell us about gene
- NOTE Confidence: 0.95124304
- $00:18:45.770 \longrightarrow 00:18:46.730$  therapy which,
- NOTE Confidence: 0.99736434
- $00{:}18{:}47{.}530 \dashrightarrow 00{:}18{:}48{.}030$  has
- NOTE Confidence: 0.9626967
- 00:18:48.730 --> 00:18:49.929 been talked about a lot
- NOTE Confidence: 0.9626967
- $00:18:49.929 \longrightarrow 00:18:50.890$  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
- $00:18:52.809 \longrightarrow 00:18:53.309$  time.
- NOTE Confidence: 0.9629011
- 00:18:54.090 --> 00:18:55.290 A new time, a time
- NOTE Confidence: 0.9629011
- $00:18:55.290 \longrightarrow 00:18:56.830$  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
- $00:19:02.845 \longrightarrow 00:19:04.605$  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
- $00:19:06.525 \longrightarrow 00:19:08.205$  having a good match by
- NOTE Confidence: 0.99919206
- $00:19:08.205 \longrightarrow 00:19:09.885$  allowing a person to be
- NOTE Confidence: 0.99919206
- $00{:}19{:}09{.}885 \dashrightarrow 00{:}19{:}11{.}025$  their own match
- NOTE Confidence: 0.9952941
- 00:19:11.389 --> 00:19:11.889 for,
- NOTE Confidence: 0.9930381
- $00:19:12.350 \longrightarrow 00:19:13.649$  a curative option.
- NOTE Confidence: 0.98192513
- 00:19:14.190 --> 00:19:15.230 And so there are two
- NOTE Confidence: 0.98192513
- $00:19:15.230 \rightarrow 00:19:16.830$  main ways in which we

- NOTE Confidence: 0.98192513
- $00:19:16.830 \longrightarrow 00:19:18.429$  do that now. One of
- NOTE Confidence: 0.98192513
- $00:19:18.429 \rightarrow 00:19:19.730$  those is through a technology
- NOTE Confidence: 0.98192513
- 00:19:19.789 --> 00:19:21.330 called CRISPR Cas9
- NOTE Confidence: 0.95740694
- $00{:}19{:}22.029 \dashrightarrow 00{:}19{:}23.549$  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
- $00:19:24.830 \longrightarrow 00:19:25.330$  identified
- NOTE Confidence: 0.99542326
- $00:19:26.025 \longrightarrow 00:19:27.005$  and then removed.
- NOTE Confidence: 0.9722263
- $00:19:27.545 \longrightarrow 00:19:28.525$  In that instance,
- NOTE Confidence: 0.98539776
- $00:19:29.065 \longrightarrow 00:19:30.685$  the goal of that intervention
- NOTE Confidence: 0.98539776
- $00:19:30.825 \longrightarrow 00:19:32.045$  and therapy is to
- NOTE Confidence: 0.9772924
- $00:19:32.345 \longrightarrow 00:19:33.785$  take away that gene that
- NOTE Confidence: 0.9772924
- $00{:}19{:}33{.}785 \dashrightarrow 00{:}19{:}35{.}305$  tells us when we're kids
- NOTE Confidence: 0.9772924
- $00{:}19{:}35{.}305 \dashrightarrow 00{:}19{:}37{.}005$  to stop making fetal hemoglobin
- NOTE Confidence: 0.9772924
- $00{:}19{:}37.145 \dashrightarrow 00{:}19{:}38.525$  like we talked about earlier.
- NOTE Confidence: 0.97157776
- $00:19:38.929 \longrightarrow 00:19:40.230$  So then your fetal hemoglobin
- NOTE Confidence: 0.97157776

- $00:19:40.289 \longrightarrow 00:19:41.429$  starts to ramp up,
- NOTE Confidence: 0.9800441
- $00{:}19{:}41.730 \dashrightarrow 00{:}19{:}43.250$  and your percent of sickled
- NOTE Confidence: 0.9800441
- $00:19:43.250 \rightarrow 00:19:45.090$  cells are decreasing, thus offering
- NOTE Confidence: 0.9800441
- $00{:}19{:}45{.}090 \dashrightarrow 00{:}19{:}46{.}549$  a cure. And
- NOTE Confidence: 0.99796075
- $00{:}19{:}47.090 \dashrightarrow 00{:}19{:}48.530$  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
- $00{:}19{:}52{.}465 \dashrightarrow 00{:}19{:}53{.}825$  as much as half of
- NOTE Confidence: 0.99802744
- 00:19:53.825 --> 00:19:54.325 your,
- NOTE Confidence: 0.99854004
- $00{:}19{:}54.865 \dashrightarrow 00{:}19{:}55.365$  cells
- NOTE Confidence: 0.9364231
- 00:19:55.825 --> 00:19:58.304 making fetal hemoglobin, thus making
- NOTE Confidence: 0.9364231
- $00:19:58.304 \longrightarrow 00:19:59.265$  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
- $00{:}20{:}00{.}545 \dashrightarrow 00{:}20{:}02{.}385$  earlier where the symptoms aren't
- NOTE Confidence: 0.9364231
- $00:20:02.385 \longrightarrow 00:20:03.205$  as obvious,

 $00:20:03.609 \rightarrow 00:20:05.130$  it doesn't affect your organs,

NOTE Confidence: 0.93557656

 $00:20:05.369 \longrightarrow 00:20:06.409$  the quality of life is

NOTE Confidence: 0.93557656

 $00:20:06.409 \longrightarrow 00:20:08.029$  totally And half is enough?

NOTE Confidence: 0.92450917

 $00{:}20{:}08.570 \dashrightarrow 00{:}20{:}10.250$  It is ideally more, but

NOTE Confidence: 0.92450917

 $00:20:10.250 \longrightarrow 00:20:11.450$  half is enough to take

NOTE Confidence: 0.92450917

 $00{:}20{:}11.450 \dashrightarrow 00{:}20{:}12.909$  you to trait status. Yep.

NOTE Confidence: 0.9715086

 $00{:}20{:}13.210 \dashrightarrow 00{:}20{:}14.570$  Wow. So you said there

NOTE Confidence: 0.9715086

 $00{:}20{:}14.570 \dashrightarrow 00{:}20{:}15.850$  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

 $00{:}20{:}17.684 \dashrightarrow 00{:}20{:}20{.}005$  second way is through something

NOTE Confidence: 0.9715086

 $00:20:20.005 \rightarrow 00:20:21.285$  we say we call using

NOTE Confidence: 0.9715086

 $00{:}20{:}21{.}285 \dashrightarrow 00{:}20{:}22{.}505$  a viral vector

NOTE Confidence: 0.88391817

 $00{:}20{:}22{.}885 \dashrightarrow 00{:}20{:}23{.}705$  or using

NOTE Confidence: 0.9552822

 $00{:}20{:}24.164 \dashrightarrow 00{:}20{:}25.304$  the the

NOTE Confidence: 0.9896926

 $00{:}20{:}26.005 \dashrightarrow 00{:}20{:}28.244$  intelligence of viral virus es and

NOTE Confidence: 0.9896926

- $00:20:28.244 \longrightarrow 00:20:29.145$  viral infections
- NOTE Confidence: 0.99965596
- $00:20:29.640 \longrightarrow 00:20:30.380$  to introduce
- NOTE Confidence: 0.9994133
- 00:20:31.080 --> 00:20:32.619 new genetic code
- NOTE Confidence: 0.99888057
- $00{:}20{:}33.000 \dashrightarrow 00{:}20{:}33.500$  into
- NOTE Confidence: 0.99042076
- 00:20:34.119 $-\!\!>$ 00:20:35.400 our stem cells or the
- NOTE Confidence: 0.99042076
- $00{:}20{:}35{.}400 \dashrightarrow 00{:}20{:}37{.}160$  parent cells of our red
- NOTE Confidence: 0.99042076
- $00:20:37.160 \longrightarrow 00:20:37.900$  blood cells.
- NOTE Confidence: 0.9579022
- $00:20:39.080 \longrightarrow 00:20:40.760$  Actually, that method has been
- NOTE Confidence: 0.9579022
- $00{:}20{:}40.760 \dashrightarrow 00{:}20{:}42.680$  around longer than the CRISPR
- NOTE Confidence: 0.9579022
- $00:20:42.680 \longrightarrow 00:20:43.740$  Cas9 technology.
- NOTE Confidence: 0.99546695
- $00:20:44.385 \longrightarrow 00:20:45.585$  And what that does is
- NOTE Confidence: 0.99546695
- $00:20:45.585 \rightarrow 00:20:46.725$  it actually creates
- NOTE Confidence: 0.87354344
- 00:20:47.185 --> 00:20:48.565 non sickling hemoglobin.
- NOTE Confidence: 0.96137077
- $00:20:49.265 \longrightarrow 00:20:50.625$  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
- $00:20:53.265 \rightarrow 00:20:54.725$  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
- $00:20:57.665 \rightarrow 00:20:59.265$  hemoglobin that doesn't sickle at
- NOTE Confidence: 0.9823419
- $00{:}20{:}59{.}265 \dashrightarrow 00{:}21{:}00{.}859$  all. And again, the goal
- NOTE Confidence: 0.9823419
- $00{:}21{:}00{.}859 \dashrightarrow 00{:}21{:}02{.}000$  is to have a robust
- NOTE Confidence: 0.9823419
- $00:21:02.299 \longrightarrow 00:21:03.600$  amount of that new hemoglobin
- NOTE Confidence: 0.9823419
- $00:21:03.820 \longrightarrow 00:21:05.580$  around such that sickle cells
- NOTE Confidence: 0.9823419
- $00:21:05.580 \longrightarrow 00:21:06.559$  are not impacting,
- NOTE Confidence: 0.9967906
- $00:21:07.820 \longrightarrow 00:21:09.039$  the person's organs,
- NOTE Confidence: 0.9487132
- 00:21:09.500 --> 00:21:10.559 clinical manifestations,
- NOTE Confidence: 0.9979311
- $00:21:11.179 \longrightarrow 00:21:12.494$  and or quality of life.
- NOTE Confidence: 0.9979311
- $00{:}21{:}12.815 \dashrightarrow 00{:}21{:}13.775$  And when was the first
- NOTE Confidence: 0.9979311
- $00:21:13.775 \longrightarrow 00:21:15.375$  time gene therapy was given
- NOTE Confidence: 0.9979311
- $00:21:15.375 \longrightarrow 00:21:16.675$  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

 $00:21:20.335 \longrightarrow 00:21:22.434$  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

 $00:21:28.809 \longrightarrow 00:21:30.809$  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

 $00{:}21{:}32{.}809 \dashrightarrow 00{:}21{:}34{.}350$  are really a mazing transplanters,

NOTE Confidence: 0.985363

 $00:21:35.129 \longrightarrow 00:21:36.750$  who have done the preliminary

NOTE Confidence: 0.985363

 $00:21:37.049 \longrightarrow 00:21:38.029$  work for this,

NOTE Confidence: 0.9773971

 $00{:}21{:}39{.}369 \dashrightarrow 00{:}21{:}40{.}250$  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

 $00{:}21{:}43{.}494 \dashrightarrow 00{:}21{:}45{.}415$  last year. So Wow. Yeah.

NOTE Confidence: 0.9773971

 $00:21:45.415 \rightarrow 00:21:46.615$  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
- $00:21:47.815 \longrightarrow 00:21:48.555$  so much.
- NOTE Confidence: 0.99912393
- $00{:}21{:}48{.}935 \dashrightarrow 00{:}21{:}50{.}395$  And what are the complications
- NOTE Confidence: 0.99912393
- $00:21:50.615 \longrightarrow 00:21:51.675$  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
- $00:21:54.775 \rightarrow 00:21:56.475$  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
- $00:21:58.400 \longrightarrow 00:21:59.780$  the gene therapy process.
- NOTE Confidence: 0.9834696
- $00:22:01.359 \longrightarrow 00:22:02.320$  First, we have to pick
- NOTE Confidence: 0.9834696
- $00:22:02.320 \longrightarrow 00:22:03.840$  the right candidate. Who is
- NOTE Confidence: 0.9834696
- $00:22:03.840 \longrightarrow 00:22:05.359$  a person that whose organs
- NOTE Confidence: 0.9834696
- $00:22:05.359 \rightarrow 00:22:06.560$  are healthy enough to be
- NOTE Confidence: 0.9834696
- $00{:}22{:}06{.}560 \dashrightarrow 00{:}22{:}07{.}440$  able to go on this
- NOTE Confidence: 0.9834696
- $00{:}22{:}07{.}440 \dashrightarrow 00{:}22{:}09{.}220$  journey? Who has the psychosocial
- NOTE Confidence: 0.9834696

 $00:22:09.359 \rightarrow 00:22:10.400$  support that they need to

NOTE Confidence: 0.9834696

 $00:22:10.400 \longrightarrow 00:22:11.794$  go on this journey? Who

NOTE Confidence: 0.9834696

00:22:11.794 --> 00:22:12.195 has,

NOTE Confidence: 0.9766611

 $00{:}22{:}12.674 \dashrightarrow 00{:}22{:}14.195$  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

 $00{:}22{:}15{.}315 \dashrightarrow 00{:}22{:}16{.}455$  this safely. Right?

NOTE Confidence: 0.9828152

00:22:16.994 --> 00:22:18.215 Once that's established,

NOTE Confidence: 0.9617103

 $00:22:18.674 \longrightarrow 00:22:20.115$  then, you know, we, in

NOTE Confidence: 0.9617103

 $00:22:20.115 \longrightarrow 00:22:21.414$  the gene therapy process,

NOTE Confidence: 0.99437267

 $00{:}22{:}22{.}275 \dashrightarrow 00{:}22{:}23.875$  you have to harvest some one's

NOTE Confidence: 0.99437267

 $00{:}22{:}23.875 \dashrightarrow 00{:}22{:}24.994$  stem cells. And so you

NOTE Confidence: 0.99437267

 $00:22:24.994 \longrightarrow 00:22:26.275$  can do that through a

NOTE Confidence: 0.99437267

00:22:26.275 --> 00:22:27.770 process called, apheresis,

NOTE Confidence: 0.9976539

 $00:22:28.070 \longrightarrow 00:22:29.109$  which we use in sickle

NOTE Confidence: 0.9976539

 $00{:}22{:}29{.}109 \dashrightarrow 00{:}22{:}30{.}010$  cell to replace

NOTE Confidence: 0.9929979

 $00:22:30.470 \longrightarrow 00:22:31.590$  abnormal red blood cells with

- NOTE Confidence: 0.9929979
- $00:22:31.590 \longrightarrow 00:22:33.190$  normal ones. But that may
- NOTE Confidence: 0.9929979
- $00{:}22{:}33{.}190 \dashrightarrow 00{:}22{:}35{.}030$  require several rounds of that
- NOTE Confidence: 0.9929979
- $00:22:35.030 \longrightarrow 00:22:35.530$  procedure.
- NOTE Confidence: 0.99467355
- $00:22:36.310 \longrightarrow 00:22:37.270$  And while that,
- NOTE Confidence: 0.99628735
- $00{:}22{:}37.750 \dashrightarrow 00{:}22{:}39.350$  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
- $00:22:41.109 \rightarrow 00:22:41.850$  and whole,
- NOTE Confidence: 0.99145496
- $00{:}22{:}42{.}345 \dashrightarrow 00{:}22{:}43{.}465$  the person can we have
- NOTE Confidence: 0.99145496
- $00:22:43.465 \longrightarrow 00:22:44.424$  to keep them healthy. Right?
- NOTE Confidence: 0.99145496
- $00:22:44.424 \longrightarrow 00:22:45.465$  We gotta continue to make
- NOTE Confidence: 0.99145496
- $00:22:45.465 \longrightarrow 00:22:46.505$  sure their sickle cell isn't
- NOTE Confidence: 0.99145496
- $00:22:46.505 \longrightarrow 00:22:48.025$  having a deleterious effect on
- NOTE Confidence: 0.99145496
- $00:22:48.025 \longrightarrow 00:22:49.705$  their body. And when it's
- NOTE Confidence: 0.99145496
- $00{:}22{:}49.705 \dashrightarrow 00{:}22{:}51.645$  time to receive those cells,
- NOTE Confidence: 0.9772776
- $00:22:52.105 \longrightarrow 00:22:53.065$  this is when it really,
- NOTE Confidence: 0.9772776

 $00:22:53.065 \rightarrow 00:22:54.505$  really mirrors bone marrow transplant.

NOTE Confidence: 0.9772776

 $00{:}22{:}54{.}505 \dashrightarrow 00{:}22{:}55{.}705$  So the person has to

NOTE Confidence: 0.9772776

 $00{:}22{:}55{.}705 \dashrightarrow 00{:}22{:}56{.}845$  come into the hospital,

NOTE Confidence: 0.94739324

00:22:57.359 --> 00:22:58.340 They get chemotherapy,

NOTE Confidence: 0.9466611

 $00{:}22{:}59{.}200 \dashrightarrow 00{:}23{:}00{.}980$  which helps their body recognize,

NOTE Confidence: 0.9466694

 $00:23:01.440 \longrightarrow 00:23:02.640$  make room for those cells

NOTE Confidence: 0.9466694

 $00{:}23{:}02{.}640 \dashrightarrow 00{:}23{:}03{.}840$  and make sure that their

NOTE Confidence: 0.9466694

 $00:23:03.840 \longrightarrow 00:23:05.119$  body doesn't attack these new

NOTE Confidence: 0.9466694

 $00{:}23{:}05{.}119 \dashrightarrow 00{:}23{:}05{.}619$  cells.

NOTE Confidence: 0.97378904

 $00:23:06.160 \longrightarrow 00:23:07.600$  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

 $00:23:09.440 \rightarrow 00:23:11.625$  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

 $00:23:12.505 \longrightarrow 00:23:13.945$  the red blood cells, it's

NOTE Confidence: 0.97378904

 $00:23:13.945 \longrightarrow 00:23:14.984$  taking out our white blood

NOTE Confidence: 0.97378904

 $00:23:14.984 \longrightarrow 00:23:16.185$  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
- $00:23:19.465 \longrightarrow 00:23:21.305$  bleeding acutely. And so we
- NOTE Confidence: 0.97640485
- $00:23:21.305 \rightarrow 00:23:22.845$  become their immune system.
- NOTE Confidence: 0.99121237
- $00{:}23{:}23{.}225 \dashrightarrow 00{:}23{:}24{.}585$  We become their platelets. And
- NOTE Confidence: 0.99121237
- $00{:}23{:}24.585 \dashrightarrow 00{:}23{:}25.385$  so they have to stick
- NOTE Confidence: 0.99121237
- $00:23:25.385 \longrightarrow 00:23:27.010$  with us during that. The
- NOTE Confidence: 0.99121237
- $00{:}23{:}27.010 \dashrightarrow 00{:}23{:}28.770$  type of chemo chemotherapy that
- NOTE Confidence: 0.99121237
- $00:23:28.770 \longrightarrow 00:23:30.210$  they get can have impacts
- NOTE Confidence: 0.99121237
- $00:23:30.210 \longrightarrow 00:23:32.130$  on fertility and other organ
- NOTE Confidence: 0.99121237
- $00:23:32.130 \longrightarrow 00:23:32.630$  functions.
- NOTE Confidence: 0.8963811
- $00:23:33.410 \longrightarrow 00:23:34.470$  And then eventually,
- NOTE Confidence: 0.96796376
- $00:23:34.850 \longrightarrow 00:23:35.990$  after some time,
- NOTE Confidence: 0.9834324
- $00{:}23{:}36{.}530 \dashrightarrow 00{:}23{:}37{.}970$  then those cells begin to
- NOTE Confidence: 0.9834324
- $00:23:37.970 \longrightarrow 00:23:39.090$  grow on their own, those
- NOTE Confidence: 0.9834324

- $00{:}23{:}39{.}090 \dashrightarrow 00{:}23{:}40{.}150$  new stem cells.
- NOTE Confidence: 0.9989467
- $00{:}23{:}40.635 \dashrightarrow 00{:}23{:}41.135$  And
- NOTE Confidence: 0.96588254
- $00:23:41.435 \longrightarrow 00:23:42.415$  so we take,
- NOTE Confidence: 0.9636381
- $00:23:43.035 \longrightarrow 00:23:44.335$  this is a a journey,
- NOTE Confidence: 0.8377401
- $00:23:44.795 \longrightarrow 00:23:45.295$  certainly,
- NOTE Confidence: 0.99584985
- $00:23:46.234 \longrightarrow 00:23:47.835$  and the risks are high,
- NOTE Confidence: 0.99584985
- $00{:}23{:}47.835 \dashrightarrow 00{:}23{:}49.435$  but the reward is also
- NOTE Confidence: 0.99584985
- 00:23:49.435 --> 00:23:50.335 quite high.
- NOTE Confidence: 0.9748689
- $00{:}23{:}50{.}955 \dashrightarrow 00{:}23{:}52{.}875$  But not necessarily for the
- NOTE Confidence: 0.9748689
- $00{:}23{:}52{.}875 \dashrightarrow 00{:}23{:}54{.}779$  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
- $00:23:56.940 \longrightarrow 00:23:58.460$  we think about how we
- NOTE Confidence: 0.9748689
- $00:23:58.460 \rightarrow 00:23:59.899$  deliver gene therapy and keeping
- NOTE Confidence: 0.9748689
- $00:23:59.899 \longrightarrow 00:24:00.960$  the patient safe.
- NOTE Confidence: 0.9976711
- $00{:}24{:}01{.}340 \dashrightarrow 00{:}24{:}02{.}139$  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
- $00:24:04.619 \longrightarrow 00:24:06.080$  a good sickle cell center
- NOTE Confidence: 0.98934424
- $00{:}24{:}06{.}700 \dashrightarrow 00{:}24{:}07{.}200$  is
- NOTE Confidence: 0.9719317
- $00:24:07.525 \rightarrow 00:24:09.065$  caring for the whole patient
- NOTE Confidence: 0.9719317
- $00{:}24{:}09{.}205 \dashrightarrow 00{:}24{:}10{.}565$  and, you know, not just
- NOTE Confidence: 0.9719317
- $00:24:10.565 \longrightarrow 00:24:11.525$  when they're with us, but
- NOTE Confidence: 0.9719317
- $00:24:11.525 \rightarrow 00:24:12.345$  also ensuring
- NOTE Confidence: 0.9519319
- $00{:}24{:}12.725 \dashrightarrow 00{:}24{:}13.605$  the goal is for them
- NOTE Confidence: 0.9519319
- $00{:}24{:}13.605 \dashrightarrow 00{:}24{:}14.804$  not to just survive, but
- NOTE Confidence: 0.9519319
- $00:24:14.804 \longrightarrow 00:24:16.005$  to really thrive. And that
- NOTE Confidence: 0.9519319
- $00{:}24{:}16.005 \dashrightarrow 00{:}24{:}16.505$  means
- NOTE Confidence: 0.9467003
- $00{:}24{:}16.885 \dashrightarrow 00{:}24{:}18.244$  how is their life affected
- NOTE Confidence: 0.9467003
- $00:24:18.244 \rightarrow 00:24:19.285$  by the treatments that are
- NOTE Confidence: 0.9467003
- $00{:}24{:}19.285 \dashrightarrow 00{:}24{:}21.119$  gonna cure them? How are
- NOTE Confidence: 0.9467003
- $00{:}24{:}21.119 \dashrightarrow 00{:}24{:}23.060$  their families affected their children,
- NOTE Confidence: 0.9933675

- $00:24:23.520 \rightarrow 00:24:24.640$  you know, really keeping them
- NOTE Confidence: 0.9933675
- $00{:}24{:}24{.}640 \dashrightarrow 00{:}24{:}25{.}600$  whole. So
- NOTE Confidence: 0.98063326
- $00:24:26.320 \longrightarrow 00:24:26.820$  Wow.
- NOTE Confidence: 0.99537724
- $00:24:28.320 \longrightarrow 00:24:30.240$  Well, I'm sure that, in
- NOTE Confidence: 0.99537724
- $00:24:30.240 \longrightarrow 00:24:31.920$  the years ahead, we will
- NOTE Confidence: 0.99537724
- $00{:}24{:}31{.}920 \dashrightarrow 00{:}24{:}34{.}285$  somehow figure out ways of
- NOTE Confidence: 0.99537724
- $00:24:34.285 \rightarrow 00:24:36.205$  delivering this therapy and having
- NOTE Confidence: 0.99537724
- $00:24:36.205 \longrightarrow 00:24:37.425$  it be more tolerable.
- NOTE Confidence: 0.97981817
- $00{:}24{:}38{.}285 \dashrightarrow 00{:}24{:}39{.}965$  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
- $00{:}24{:}44{.}925 \dashrightarrow 00{:}24{:}46{.}260$  think plant there are
- NOTE Confidence: 0.99510825
- $00:24:46.820 \longrightarrow 00:24:47.780$  more than just a few
- NOTE Confidence: 0.99510825
- $00:24:47.780 \longrightarrow 00:24:48.820$  people who are choosing to
- NOTE Confidence: 0.99510825
- $00:24:48.820 \longrightarrow 00:24:49.960$  do this because

- NOTE Confidence: 0.976219
- $00:24:50.580 \longrightarrow 00:24:52.180$  of life with sickle cell
- NOTE Confidence: 0.976219
- $00:24:52.180 \longrightarrow 00:24:54.580$  disease. That risk becomes worth
- NOTE Confidence: 0.976219
- 00:24:54.580 --> 00:24:55.400 it. So
- NOTE Confidence: 0.997377
- $00{:}24{:}55{.}780 \dashrightarrow 00{:}24{:}56{.}280$  Yeah.
- NOTE Confidence: 0.99584675
- 00:24:57.619 --> 00:24:58.600 So I wanna
- NOTE Confidence: 0.80016637
- $00:24:58.900 \rightarrow 00:24:59.400$  end,
- NOTE Confidence: 0.9476131
- 00:25:00.655 --> 00:25:02.835 on a somewhat different note,
- NOTE Confidence: 0.99587584
- $00{:}25{:}03.455 \dashrightarrow 00{:}25{:}04.434$  and as
- NOTE Confidence: 0.9999502
- $00:25:04.975 \longrightarrow 00:25:05.475$  challenging
- NOTE Confidence: 0.99974924
- $00{:}25{:}06.095 \dashrightarrow 00{:}25{:}07.695$  and horrific as it can
- NOTE Confidence: 0.99974924
- $00{:}25{:}07.695 \dashrightarrow 00{:}25{:}08.195$  be
- NOTE Confidence: 0.9863013
- $00{:}25{:}08{.}494 \dashrightarrow 00{:}25{:}09{.}455$  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
- $00{:}25{:}10.895 \dashrightarrow 00{:}25{:}12.835$  disease and everything with it,
- NOTE Confidence: 0.9776667
- $00{:}25{:}14.720 \dashrightarrow 00{:}25{:}15.700$  I think that
- NOTE Confidence: 0.97642523

- $00:25:16.400 \rightarrow 00:25:17.300$  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
- $00:25:21.760 \longrightarrow 00:25:22.900$  for many years,
- NOTE Confidence: 0.98774594
- 00:25:23.440 --> 00:25:25.359 sickle cell being largely a
- NOTE Confidence: 0.98774594
- $00{:}25{:}25{.}359 \dashrightarrow 00{:}25{:}26{.}660$  disease in the US
- NOTE Confidence: 0.994505
- $00:25:27.119 \longrightarrow 00:25:28.800$  that arose in people who
- NOTE Confidence: 0.994505
- $00:25:28.800 \longrightarrow 00:25:29.619$  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
- $00:25:34.345 \longrightarrow 00:25:35.785$  get the kind of treatment
- NOTE Confidence: 0.9902415
- $00:25:35.785 \longrightarrow 00:25:37.005$  that they should have.
- NOTE Confidence: 0.9994746
- $00{:}25{:}37.625 \dashrightarrow 00{:}25{:}38.125$  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
- $00{:}25{:}41{.}945 \dashrightarrow 00{:}25{:}42{.}445$  and

- NOTE Confidence: 0.9996955
- $00:25:42.990 \longrightarrow 00:25:44.910$  I will just share that
- NOTE Confidence: 0.9996955
- $00{:}25{:}44{.}910 \dashrightarrow 00{:}25{:}45{.}650$  the way
- NOTE Confidence: 0.9968798
- $00:25:46.109 \rightarrow 00:25:47.790$  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
- $00{:}25{:}52{.}910 \dashrightarrow 00{:}25{:}53{.}410$  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
- $00:25:58.365 \rightarrow 00:26:00.365$  the disparities patients with sickle
- NOTE Confidence: 0.9941905
- $00:26:00.365 \longrightarrow 00:26:01.665$  cell disease face
- NOTE Confidence: 0.9718252
- $00:26:02.285 \longrightarrow 00:26:03.885$  and how much of that
- NOTE Confidence: 0.9718252
- $00:26:03.885 \longrightarrow 00:26:05.665$  is due to just the
- NOTE Confidence: 0.9718252
- $00:26:05.725 \longrightarrow 00:26:06.225$  fundamental
- NOTE Confidence: 0.96183616
- $00{:}26{:}06{.}605 \dashrightarrow 00{:}26{:}08{.}125$  racism that exists in our
- NOTE Confidence: 0.96183616
- $00:26:08.125 \longrightarrow 00:26:08.625$  society.
- NOTE Confidence: 0.99215734

- $00:26:09.619 \rightarrow 00:26:11.619$  Absolutely. So, you know, we
- NOTE Confidence: 0.99215734
- $00{:}26{:}11.619 \dashrightarrow 00{:}26{:}13.139$  know that how we deliver
- NOTE Confidence: 0.99215734
- 00:26:13.139 --> 00:26:13.639 care,
- NOTE Confidence: 0.99867046
- $00{:}26{:}14.820 \dashrightarrow 00{:}26{:}15.320$  and
- NOTE Confidence: 0.9643485
- 00:26:16.019 --> 00:26:18.259 our capacity as providers and
- NOTE Confidence: 0.9643485
- $00{:}26{:}18.259 \dashrightarrow 00{:}26{:}20.679$  ultimately health outcomes are driven
- NOTE Confidence: 0.99922526
- $00:26:21.700 \longrightarrow 00:26:23.775$  by larger things. So we
- NOTE Confidence: 0.99922526
- $00{:}26{:}23.775 \dashrightarrow 00{:}26{:}24.515$  know that
- NOTE Confidence: 0.997367
- $00{:}26{:}25{.}054 \dashrightarrow 00{:}26{:}25{.}794$  as prejudice
- NOTE Confidence: 0.9984261
- $00{:}26{:}26{.}095 \dashrightarrow 00{:}26{:}26{.}835$  and racism
- NOTE Confidence: 0.99352103
- 00:26:27.775 --> 00:26:29.475 infuses into our institutions,
- NOTE Confidence: 0.9829184
- $00:26:29.855 \longrightarrow 00:26:31.715$  those affect our policies.
- NOTE Confidence: 0.9673649
- $00:26:32.494 \rightarrow 00:26:34.434$  Those policies affect our environments.
- NOTE Confidence: 0.9494173
- $00:26:34.734 \longrightarrow 00:26:36.174$  Right? Whether it is a
- NOTE Confidence: 0.9494173
- $00:26:36.174 \longrightarrow 00:26:37.075$  living environment,
- NOTE Confidence: 0.9607915
- $00:26:37.869 \rightarrow 00:26:40.030$  funding environments for research and

- NOTE Confidence: 0.9607915
- $00:26:40.030 \longrightarrow 00:26:40.530$  innovation.
- NOTE Confidence: 0.936851
- $00{:}26{:}41{.}309 \dashrightarrow 00{:}26{:}43{.}010$  And those things affect ultimately
- NOTE Confidence: 0.936851
- 00:26:43.230 --> 00:26:43.730 diagnosis,
- NOTE Confidence: 0.9655868
- $00:26:44.109 \rightarrow 00:26:45.809$  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
- $00:26:47.789 \longrightarrow 00:26:49.150$  sickle cell disease. We know
- NOTE Confidence: 0.9695233
- $00:26:49.150 \longrightarrow 00:26:50.270$  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
- $00:26:51.869 \longrightarrow 00:26:53.494$  we saw that. Most recently,
- NOTE Confidence: 0.9695233
- $00:26:53.555 \longrightarrow 00:26:54.515$  we saw that during the
- NOTE Confidence: 0.9695233
- 00:26:54.515 --> 00:26:55.494 COVID pandemic.
- NOTE Confidence: 0.9526098
- $00{:}26{:}56.035 \dashrightarrow 00{:}26{:}57.075$  And then also when we
- NOTE Confidence: 0.9526098
- $00{:}26{:}57.075 \dashrightarrow 00{:}26{:}58.295$  look at data around,
- NOTE Confidence: 0.9419404
- $00{:}26{:}58.755 \dashrightarrow 00{:}27{:}00.695$  black infant and maternal mortality.
- NOTE Confidence: 0.99681497
- $00:27:01.234 \rightarrow 00:27:01.734$  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
- $00{:}27{:}06{.}929 \dashrightarrow 00{:}27{:}07{.}669$  of being
- NOTE Confidence: 0.9993717
- 00:27:08.289 --> 00:27:09.350 an African American
- NOTE Confidence: 0.96482223
- $00{:}27{:}09{.}730 \dashrightarrow 00{:}27{:}11{.}350$  in the US health system.
- NOTE Confidence: 0.96482223
- $00{:}27{:}11.649 \dashrightarrow 00{:}27{:}12.850$  And then also having a
- NOTE Confidence: 0.96482223
- $00:27:12.850 \longrightarrow 00:27:14.070$  disease that
- NOTE Confidence: 0.93533504
- $00{:}27{:}14.450 \dashrightarrow 00{:}27{:}15.809$  has pain, which is treated
- NOTE Confidence: 0.93533504
- $00{:}27{:}15{.}809 \dashrightarrow 00{:}27{:}17{.}649$  by opioids. Right? So there's
- NOTE Confidence: 0.93533504
- $00:27:17.649 \longrightarrow 00:27:18.710$  this other layer.
- NOTE Confidence: 0.9709795
- $00:27:19.330 \longrightarrow 00:27:20.289$  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
- $00{:}27{:}26.674 \dashrightarrow 00{:}27{:}27.955$  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
- $00:27:30.835 \longrightarrow 00:27:32.034$  a lot, which is another
- NOTE Confidence: 0.9598948
- $00{:}27{:}32.034 \dashrightarrow 00{:}27{:}32.774$  rare disease.
- NOTE Confidence: 0.92713135
- $00:27:33.970 \longrightarrow 00:27:35.330$  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
- $00:27:41.970 \longrightarrow 00:27:43.429$  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
- $00:27:47.425 \longrightarrow 00:27:48.625$  you just mentioned and kind
- NOTE Confidence: 0.9384612
- $00{:}27{:}48.625 \dashrightarrow 00{:}27{:}49.665$  of, like, working on that
- NOTE Confidence: 0.9384612
- 00:27:49.665 --> 00:27:50.165 stigma.
- NOTE Confidence: 0.95217544

- $00:27:51.185 \longrightarrow 00:27:52.244$  We see that,
- NOTE Confidence: 0.9965732
- $00{:}27{:}53.425 \dashrightarrow 00{:}27{:}53.925$  in
- NOTE Confidence: 0.9696974
- $00:27:54.305 \rightarrow 00:27:56.145$  how society views persons with
- NOTE Confidence: 0.9696974
- $00{:}27{:}56.145 \dashrightarrow 00{:}27{:}57.685$  Sickle Cell Disease as well.
- NOTE Confidence: 0.9696974
- $00{:}27{:}57{.}825 \dashrightarrow 00{:}27{:}59{.}105$  And it's a very salient
- NOTE Confidence: 0.9696974
- $00{:}27{:}59{.}105 \dashrightarrow 00{:}28{:}00{.}929$  and current issue. I think
- NOTE Confidence: 0.9696974
- $00:28:00.929 \longrightarrow 00:28:02.390$  what we are doing now,
- NOTE Confidence: 0.9745922
- $00:28:03.169 \rightarrow 00:28:05.169$  acknowledging that this exists and
- NOTE Confidence: 0.9745922
- $00{:}28{:}05{.}169 \dashrightarrow 00{:}28{:}07{.}090$  then thinking about in the
- NOTE Confidence: 0.9745922
- $00:28:07.090 \rightarrow 00:28:08.470$  scope of our own power,
- NOTE Confidence: 0.9745922
- $00:28:08.690 \longrightarrow 00:28:09.730$  how do we change that?
- NOTE Confidence: 0.9745922
- $00:28:09.730 \longrightarrow 00:28:11.010$  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
- $00{:}28{:}12.609 \dashrightarrow 00{:}28{:}14.049$  right decision for the right
- NOTE Confidence: 0.9745922
- $00:28:14.049 \longrightarrow 00:28:15.590$  patient at the right time?
- NOTE Confidence: 0.98951846
- $00:28:16.005 \rightarrow 00:28:17.925$  Is it creating space and

- NOTE Confidence: 0.98951846
- $00:28:17.925 \rightarrow 00:28:20.165$  acknowledging the historical disparities and
- NOTE Confidence: 0.98951846
- $00:28:20.165 \longrightarrow 00:28:21.285$  inequities that have led to
- NOTE Confidence: 0.98951846
- $00:28:21.285 \longrightarrow 00:28:22.805$  this point? You know, there's
- NOTE Confidence: 0.98951846
- $00:28:22.805 \longrightarrow 00:28:25.045$  so many ways to to
- NOTE Confidence: 0.98951846
- $00{:}28{:}25.045 \dashrightarrow 00{:}28{:}26.905$  address this issue that continues
- NOTE Confidence: 0.98951846
- $00{:}28{:}26.965 \dashrightarrow 00{:}28{:}27.945$  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
- $00{:}28{:}31{.}730 \dashrightarrow 00{:}28{:}33{.}410$  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
- $00:28:35.010 \longrightarrow 00:28:35.750$  of Medicine.
- NOTE Confidence: 0.9754471
- $00:28:36.290 \longrightarrow 00:28:37.490$  If you have questions, the
- NOTE Confidence: 0.9754471
- $00{:}28{:}37{.}490 \dashrightarrow 00{:}28{:}39{.}170$  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
- $00{:}28{:}40{.}530 \dashrightarrow 00{:}28{:}41{.}809$  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

 $00{:}28{:}43{.}570 \dashrightarrow 00{:}28{:}44{.}935$  and written form at yale

NOTE Confidence: 0.9754471

 $00{:}28{:}44{.}935 \dashrightarrow 00{:}28{:}46{.}775$  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

 $00{:}28{:}47.815 \dashrightarrow 00{:}28{:}48.775$  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.