WEBVTT

00:00:00.000 --> 00:00:03.654 Funding for Yale Cancer Answers is provided

NOTE Confidence: 0.950186938571429

00:00:03.654 --> 00:00:07.579 by Smilow Cancer Hospital and AstraZeneca.

NOTE Confidence: 0.950186938571429

00:00:07.580 --> 00:00:09.810 Welcome to Yale Cancer Answers with

NOTE Confidence: 0.950186938571429

00:00:09.810 --> 00:00:12.497 your host doctor Anees Chagpar.

NOTE Confidence: 0.950186938571429

00:00:12.497 --> 00:00:14.382 Yale Cancer Answers features the latest

NOTE Confidence: 0.950186938571429

00:00:14.382 --> 00:00:16.699 information on cancer care by welcoming

NOTE Confidence: 0.950186938571429

00:00:16.699 --> 00:00:19.303 oncologists and specialists who are on the

NOTE Confidence: 0.950186938571429

00:00:19.303 --> 00:00:21.449 forefront of the battle to fight cancer.

NOTE Confidence: 0.950186938571429

00:00:21.450 --> 00:00:24.162 This week it's a conversation about the care

NOTE Confidence: 0.950186938571429

00:00:24.162 --> 00:00:26.595 of adolescents and young adults with sickle

NOTE Confidence: 0.950186938571429

00:00:26.595 --> 00:00:28.810 cell disease with Doctor Cece Calhoun.

NOTE Confidence: 0.950186938571429

00:00:28.810 --> 00:00:31.645 Dr Calhoun is an assistant professor of

NOTE Confidence: 0.950186938571429

00:00:31.645 --> 00:00:33.785 medicine and hematology and assistant

NOTE Confidence: 0.950186938571429

00:00:33.785 --> 00:00:35.935 professor of Pediatrics in hematology

NOTE Confidence: 0.950186938571429

00:00:35.935 --> 00:00:38.837 oncology at the Yale School of Medicine,

NOTE Confidence: 0.950186938571429

00:00:38.840 --> 00:00:41.654 where Doctor Chagpar is a

NOTE Confidence: 0.950186938571429

00:00:41.654 --> 00:00:43.780 professor of surgical oncology.

NOTE Confidence: 0.963814074736842

00:00:43.790 --> 00:00:45.652 Cece, maybe we could start off by

NOTE Confidence: 0.963814074736842

00:00:45.652 --> 00:00:47.649 you telling us a little bit about

NOTE Confidence: 0.963814074736842

00:00:47.649 --> 00:00:49.920 yourself and what you do.

NOTE Confidence: 0.98679355125

00:00:49.930 --> 00:00:52.426 I like to call myself a lifespan

NOTE Confidence: 0.98679355125

00:00:52.430 --> 00:00:54.735 hematologist, and both my clinical

NOTE Confidence: 0.98679355125

00:00:54.735 --> 00:00:57.040 and research interests center around

NOTE Confidence: 0.98679355125

00:00:57.107 --> 00:00:59.578 the care of young adults with sickle

NOTE Confidence: 0.98679355125

00:00:59.578 --> 00:01:01.709 cell disease as they transition

NOTE Confidence: 0.98679355125

00:01:01.709 --> 00:01:04.074 from pediatric to adult care.

NOTE Confidence: 0.98679355125

00:01:04.080 --> 00:01:05.454 We know it's a really high

NOTE Confidence: 0.98679355125

00:01:05.454 --> 00:01:06.370 risk time for them.

NOTE Confidence: 0.98679355125

00:01:06.370 --> 00:01:08.350 And so all the work that I do both in

NOTE Confidence: 0.98679355125

00:01:08.411 --> 00:01:10.441 the clinic and in the research setting

NOTE Confidence: 0.98679355125

00:01:10.441 --> 00:01:12.440 is about making that process better.

NOTE Confidence: 0.913707616666667

00:01:12.920 --> 00:01:15.206 Is sickle cell disease a cancer?

NOTE Confidence: 0.913707616666667

00:01:15.210 --> 00:01:16.895 Tell us more about what

NOTE Confidence: 0.913707616666667

00:01:16.895 --> 00:01:18.243 exactly sickle cell disease is

NOTE Confidence: 0.913707616666667

00:01:18.250 --> 00:01:21.274 and why it's being seen

NOTE Confidence: 0.913707616666667

00:01:21.274 --> 00:01:23.160 by an oncologist?

NOTE Confidence: 0.973517131764706

00:01:23.170 --> 00:01:25.762 That's a great question, so actually sickle

NOTE Confidence: 0.973517131764706

00:01:25.762 --> 00:01:28.489 cell disease is an inherited condition

NOTE Confidence: 0.973517131764706

00:01:28.489 --> 00:01:31.939 of the red blood cells and so many

NOTE Confidence: 0.973517131764706

00:01:31.939 --> 00:01:33.854 people are familiar with anemia

NOTE Confidence: 0.973517131764706

00:01:33.854 --> 00:01:36.508 and conditions of that sort,

NOTE Confidence: 0.973517131764706

00:01:36.510 --> 00:01:37.985 which affect red blood

NOTE Confidence: 0.973517131764706

00:01:37.985 --> 00:01:38.870 cells and hemoglobin.

NOTE Confidence: 0.973517131764706

00:01:38.870 --> 00:01:41.707 And that's what sickle cell disease is

NOTE Confidence: 0.973517131764706

00:01:41.707 --> 00:01:43.729 a condition of, and it's genetic.

NOTE Confidence: 0.973517131764706

00:01:43.730 --> 00:01:45.626 So patients are born with it,

NOTE Confidence: 0.973517131764706

00:01:45.630 --> 00:01:47.798 and what it manifests as is a normal

NOTE Confidence: 0.973517131764706

00:01:47.798 --> 00:01:49.698 red blood cells are kind of squishy.

NOTE Confidence: 0.973517131764706

00:01:49.700 --> 00:01:52.132 I like to think of them as Jelly

NOTE Confidence: 0.973517131764706

00:01:52.132 --> 00:01:53.549 doughnuts because I like food.

NOTE Confidence: 0.973517131764706

00:01:53.550 --> 00:01:55.300 But when you have sickle cell disease

NOTE Confidence: 0.973517131764706

00:01:55.300 --> 00:01:56.700 because of a genetic mutation

NOTE Confidence: 0.973517131764706

00:01:56.700 --> 00:01:58.500 your red blood cells

NOTE Confidence: 0.973517131764706

00:01:58.500 --> 00:02:00.112 are not squishy and malleable,

NOTE Confidence: 0.973517131764706

00:02:00.112 --> 00:02:02.127 they can be really stiff

NOTE Confidence: 0.973517131764706

00:02:02.127 --> 00:02:04.298 and misshapen like a sickle.

NOTE Confidence: 0.973517131764706

00:02:04.300 --> 00:02:06.470 They can be shaped like a sickle or a banana,

NOTE Confidence: 0.973517131764706

00:02:06.470 --> 00:02:08.168 and so if you think of

NOTE Confidence: 0.973517131764706

00:02:08.168 --> 00:02:09.780 your blood cells as pipes,

NOTE Confidence: 0.973517131764706

00:02:09.780 --> 00:02:11.901 imagine if you had your Jelly doughnuts

NOTE Confidence: 0.973517131764706

00:02:11.901 --> 00:02:14.020 kind of going through those pipes,

NOTE Confidence: 0.973517131764706

00:02:14.020 --> 00:02:15.248 bouncing off the walls,

NOTE Confidence: 0.973517131764706

00:02:15.248 --> 00:02:17.490 taking oxygen to where it needs to go,

NOTE Confidence: 0.973517131764706

00:02:17.490 --> 00:02:19.290 and you replace those cells

NOTE Confidence: 0.973517131764706

00:02:19.290 --> 00:02:20.370 with sticky stuff,

NOTE Confidence: 0.973517131764706

00:02:20.370 --> 00:02:22.356 fragile misshapen red blood cells like

NOTE Confidence: 0.973517131764706

00:02:22.356 --> 00:02:24.469 sickle cells that are scratching up

NOTE Confidence: 0.973517131764706

00:02:24.469 --> 00:02:26.665 the red blood vessels sticking together,

NOTE Confidence: 0.973517131764706

00:02:26.670 --> 00:02:28.286 causing blockages, impeding flow,

NOTE Confidence: 0.973517131764706

00:02:28.286 --> 00:02:30.710 and then you can imagine all

NOTE Confidence: 0.973517131764706

00:02:30.786 --> 00:02:32.578 the complications that patients

NOTE Confidence: 0.973517131764706

00:02:32.578 --> 00:02:34.370 with sickle cell face.

NOTE Confidence: 0.973517131764706

00:02:34.370 --> 00:02:38.821 Most saliently or what patients have

NOTE Confidence: 0.973517131764706

00:02:38.821 --> 00:02:41.350 to really deal with is a lot of pain.

NOTE Confidence: 0.973517131764706

00:02:41.350 --> 00:02:42.620 That's the thing that brings

NOTE Confidence: 0.973517131764706

00:02:42.620 --> 00:02:43.636 them to the hospital.

NOTE Confidence: 0.973517131764706

00:02:43.640 --> 00:02:46.350 And acute meaning an unplanned basis,

NOTE Confidence: 0.973517131764706

00:02:46.350 --> 00:02:48.051 but any part of our body where

NOTE Confidence: 0.973517131764706

00:02:48.051 --> 00:02:49.788 there are blood vessels,

NOTE Confidence: 0.973517131764706

00:02:49.790 --> 00:02:50.456 those misshapen

NOTE Confidence: 0.973517131764706

00:02:50.456 --> 00:02:52.787 cells can get clogged up in those

NOTE Confidence: 0.973517131764706

00:02:52.787 --> 00:02:55.266 blood vessels and cause problems.

NOTE Confidence: 0.973517131764706

00:02:55.270 --> 00:02:56.622 It's important for patients

NOTE Confidence: 0.973517131764706

00:02:56.622 --> 00:02:58.650 with sickle cell disease to have

NOTE Confidence: 0.973517131764706

00:02:58.712 --> 00:03:00.652 regular care by an oncologist

NOTE Confidence: 0.973517131764706

00:03:00.652 --> 00:03:02.204 who also understands hematology,

NOTE Confidence: 0.973517131764706

00:03:02.210 --> 00:03:04.514 the blood, to make sure that all their

NOTE Confidence: 0.973517131764706

00:03:04.514 --> 00:03:06.450 organs are in tip top condition

NOTE Confidence: 0.973517131764706

00:03:06.450 --> 00:03:08.394 and that we treat anything before

NOTE Confidence: 0.973517131764706

00:03:08.459 --> 00:03:09.539 there's a problem.

NOTE Confidence: 0.98555431125

00:03:09.730 --> 00:03:12.466 Now, I would think that if

NOTE Confidence: 0.98555431125

00:03:12.466 --> 00:03:14.880 you're a pediatric patient and

NOTE Confidence: 0.98555431125

00:03:14.880 --> 00:03:17.390 this is an inherited condition,

NOTE Confidence: 0.98555431125

00:03:17.390 --> 00:03:19.638 you might have a sense of whether or

NOTE Confidence: 0.98555431125

00:03:19.638 --> 00:03:21.80 not you have sickle cell disease

NOTE Confidence: 0.98555431125

00:03:21.870 --> 00:03:24.228 based on whether your parents did.

NOTE Confidence: 0.98555431125

00:03:24.230 --> 00:03:26.988 But somebody had to start with the

NOTE Confidence: 0.98555431125

00:03:26.988 --> 00:03:29.049 genetic mutation to begin with.

NOTE Confidence: 0.98555431125

00:03:29.050 --> 00:03:30.874 So how many of your patients

NOTE Confidence: 0.98555431125

00:03:30.874 --> 00:03:32.773 actually know that they have sickle

NOTE Confidence: 0.98555431125

00:03:32.773 --> 00:03:34.633 cell disease from the time that

NOTE Confidence: 0.98555431125

00:03:34.633 --> 00:03:36.720 they were born

NOTE Confidence: 0.98555431125

00:03:36.720 --> 00:03:39.942 and how many of them present to you acutely?

00:03:41.670 --> 00:03:43.820 In the United

NOTE Confidence: 0.986541653333333

00:03:43.830 --> 00:03:46.766 States we have the benefit of the newborn

NOTE Confidence: 0.986541653333333

00:03:46.766 --> 00:03:49.587 screen that all babies born in hospitals,

NOTE Confidence: 0.986541653333333

00:03:49.590 --> 00:03:50.965 when they

NOTE Confidence: 0.986541653333333

00:03:50.965 --> 00:03:52.934 get their heel poked and get that

NOTE Confidence: 0.986541653333333

00:03:52.934 --> 00:03:54.548 little spot of blood that can test

NOTE Confidence: 0.986541653333333

00:03:54.550 --> 00:03:56.476 for a variety of genetic conditions

NOTE Confidence: 0.986541653333333

00:03:56.476 --> 00:03:58.165 and sickle cell disease is

NOTE Confidence: 0.986541653333333

00:03:58.165 --> 00:03:59.557 included in those conditions.

NOTE Confidence: 0.986541653333333

00:03:59.560 --> 00:04:02.710 So if a child has an abnormal newborn screen,

NOTE Confidence: 0.986541653333333

00:04:02.710 --> 00:04:04.758 oftentimes the pediatrician will

NOTE Confidence: 0.986541653333333

00:04:04.758 --> 00:04:07.675 refer them to a hematologist for

NOTE Confidence: 0.986541653333333

00:04:07.675 --> 00:04:09.450 further evaluation and work up.

NOTE Confidence: 0.986541653333333

00:04:09.450 --> 00:04:11.628 And sometimes, even if it's abnormal

NOTE Confidence: 0.986541653333333

00:04:11.628 --> 00:04:14.410 to show sickle cell trait,

NOTE Confidence: 0.986541653333333

00:04:14.410 --> 00:04:16.450 which means that you don't have the disease,

NOTE Confidence: 0.986541653333333

00:04:16.450 --> 00:04:18.028 but you can be a carrier,

NOTE Confidence: 0.986541653333333

00:04:18.030 --> 00:04:19.850 and if your partner has the disease,

NOTE Confidence: 0.986541653333333

00:04:19.850 --> 00:04:21.369 you can have a child with sickle

NOTE Confidence: 0.986541653333333

00:04:21.369 --> 00:04:21.803 cell disease.

NOTE Confidence: 0.986541653333333

00:04:21.810 --> 00:04:23.706 We can figure that out from

NOTE Confidence: 0.986541653333333

00:04:23.706 --> 00:04:24.654 the newborn screen.

NOTE Confidence: 0.986541653333333

00:04:24.660 --> 00:04:27.148 So these days we know pretty early on

NOTE Confidence: 0.986541653333333

00:04:27.148 --> 00:04:29.447 which is critical to the survival

NOTE Confidence: 0.986541653333333

00:04:29.447 --> 00:04:32.323 of our young children or infants and

NOTE Confidence: 0.986541653333333

00:04:32.323 --> 00:04:34.366 toddlers and in other countries

NOTE Confidence: 0.986541653333333

00:04:34.366 --> 00:04:37.610 the newborn screen isn't quite as universal,

NOTE Confidence: 0.986541653333333

00:04:37.610 --> 00:04:39.476 and so sometimes children could present

NOTE Confidence: 0.986541653333333

00:04:39.476 --> 00:04:41.549 with swelling of the hands and feet.

NOTE Confidence: 0.986541653333333

00:04:41.550 --> 00:04:43.570 That's something called dactylitis,

NOTE Confidence: 0.986541653333333

00:04:43.570 --> 00:04:46.095 which is pretty rare these

NOTE Confidence: 0.986541653333333

00:04:46.095 --> 00:04:48.268 days as a presenting sign.

NOTE Confidence: 0.986541653333333

00:04:48.270 --> 00:04:50.846 And then there's some patients with more

NOTE Confidence: 0.986541653333333

00:04:50.846 --> 00:04:53.250 milder forms of sickle cell disease

NOTE Confidence: 0.986541653333333

00:04:53.250 --> 00:04:55.704 that don't know until they're older

NOTE Confidence: 0.986541653333333

00:04:55.710 --> 00:04:56.786 children or young adults,

NOTE Confidence: 0.986541653333333

00:04:56.786 --> 00:04:59.333 but most of the time we get them in

NOTE Confidence: 0.986541653333333

00:04:59.333 --> 00:05:01.079 our catchment when they are young

NOTE Confidence: 0.986541653333333

00:05:01.079 --> 00:05:02.860 because of their newborn screen and

NOTE Confidence: 0.986541653333333

00:05:02.860 --> 00:05:04.678 can really wrap our arms around them

NOTE Confidence: 0.986541653333333

00:05:04.678 --> 00:05:06.036 and give them the care they need.

NOTE Confidence: 0.978533178636364

00:05:06.290 --> 00:05:08.621 Let's suppose you're a newborn baby and

NOTE Confidence: 0.978533178636364

00:05:08.621 --> 00:05:11.259 you had your heel poked and they tell

NOTE Confidence: 0.978533178636364

00:05:11.259 --> 00:05:13.730 you that you have sickle cell disease.

NOTE Confidence: 0.978533178636364

00:05:13.730 --> 00:05:15.776 Well, presumably they don't tell you

NOTE Confidence: 0.978533178636364

00:05:15.776 --> 00:05:18.218 they tell your parents and you get

NOTE Confidence: 0.978533178636364

00:05:18.218 --> 00:05:19.913 referred to a pediatric oncologist.

NOTE Confidence: 0.978533178636364

00:05:19.920 --> 00:05:22.069 If that means that your red blood

NOTE Confidence: 0.978533178636364

00:05:22.069 --> 00:05:24.601 cells are now more

NOTE Confidence: 0.978533178636364

00:05:24.601 --> 00:05:26.526 like bananas than squishy Jelly

NOTE Confidence: 0.978533178636364

00:05:26.530 --> 00:05:29.204 Donuts, what can you do about that?

NOTE Confidence: 0.978533178636364

00:05:29.210 --> 00:05:30.800 I mean, is it reversible?

NOTE Confidence: 0.982871064

00:05:31.080 --> 00:05:33.640 At this time the only cure for sickle

NOTE Confidence: 0.982871064

00:05:33.640 --> 00:05:35.628 cell disease or way to reverse

NOTE Confidence: 0.982871064

00:05:35.628 --> 00:05:37.548 those cells is by replacing your

NOTE Confidence: 0.982871064

00:05:37.616 --> 00:05:39.726 bone marrow with another persons,

NOTE Confidence: 0.982871064

00:05:39.730 --> 00:05:41.806 but that's pretty rare.

NOTE Confidence: 0.982871064

00:05:41.810 --> 00:05:43.594 Later in the show, you get to talk

NOTE Confidence: 0.982871064

00:05:43.594 --> 00:05:45.404 a little bit more about therapies

NOTE Confidence: 0.982871064

00:05:45.404 --> 00:05:47.366 coming down the pipeline for patients,

NOTE Confidence: 0.982871064

00:05:47.370 --> 00:05:49.326 but right now that's the only

NOTE Confidence: 0.982871064

00:05:49.326 --> 00:05:51.090 way to reverse.

NOTE Confidence: 0.982871064

00:05:51.090 --> 00:05:53.113 However, if you are a little baby

NOTE Confidence: 0.982871064

00:05:53.113 --> 00:05:54.980 and your parents find out that

NOTE Confidence: 0.982871064

00:05:54.980 --> 00:05:56.535 you have sickle cell disease

NOTE Confidence: 0.982871064

00:05:56.540 --> 00:05:58.670 the benefit of coming and talking

NOTE Confidence: 0.982871064

00:05:58.670 --> 00:06:00.473 to a pediatric oncologist and

NOTE Confidence: 0.982871064

00:06:00.473 --> 00:06:02.068 hematologist who knows about this

NOTE Confidence: 0.982871064

00:06:02.068 --> 00:06:04.550 is that you now have a team member,

NOTE Confidence: 0.982871064

00:06:04.550 --> 00:06:05.910 somebody on your team that

NOTE Confidence: 0.982871064

00:06:05.910 --> 00:06:06.998 can help your baby,

NOTE Confidence: 0.982871064

00:06:07.000 --> 00:06:08.410 or you if you're the baby,

NOTE Confidence: 0.982871064

00:06:08.410 --> 00:06:09.690 stay healthy and safe.

NOTE Confidence: 0.982871064

00:06:09.690 --> 00:06:12.538 And what that looks like as a

NOTE Confidence: 0.982871064

00:06:12.538 --> 00:06:15.112 toddler is getting them started on

NOTE Confidence: 0.982871064

00:06:15.112 --> 00:06:16.791 penicillin prophylactically or in

NOTE Confidence: 0.982871064

00:06:16.791 --> 00:06:18.666 advance before there's any problems

NOTE Confidence: 0.982871064

00:06:18.670 --> 00:06:21.838 because we found that as

NOTE Confidence: 0.982871064

00:06:21.838 --> 00:06:25.137 recently as the late 70s,

NOTE Confidence: 0.982871064

00:06:25.140 --> 00:06:26.850 there was kind of a peak

NOTE Confidence: 0.982871064

00:06:26.850 --> 00:06:29.070 in infancy and toddlerhood of death,

NOTE Confidence: 0.982871064

00:06:29.070 --> 00:06:31.015 because patients with sickle cell

NOTE Confidence: 0.982871064

00:06:31.015 --> 00:06:32.960 were getting really bad infections,

NOTE Confidence: 0.982871064

00:06:32.960 --> 00:06:34.856 but we found that if we vaccinate them

NOTE Confidence: 0.982871064

00:06:34.856 --> 00:06:36.849 and give them prophylactic penicillin,

NOTE Confidence: 0.982871064

00:06:36.850 --> 00:06:38.600 they live well into adulthood.

NOTE Confidence: 0.982871064

00:06:38.600 --> 00:06:39.407 The challenge becomes,

NOTE Confidence: 0.982871064

00:06:39.407 --> 00:06:41.290 how do we help them when they

NOTE Confidence: 0.982871064

00:06:41.346 --> 00:06:42.586 go from infant to adults?

NOTE Confidence: 0.982871064

00:06:42.590 --> 00:06:43.994 And that's what I work on in my work.

NOTE Confidence: 0.98259738

00:06:44.370 --> 00:06:46.863 So just to back up a little bit when

NOTE Confidence: 0.98259738

00:06:46.863 --> 00:06:49.148 you say prophylactic penicillin,

NOTE Confidence: 0.98259738

00:06:49.150 --> 00:06:51.124 do you mean like every day for

NOTE Confidence: 0.98259738

00:06:51.124 --> 00:06:52.938 the rest of their life?

NOTE Confidence: 0.989668970833333

00:06:53.390 --> 00:06:55.814 So definitely every day for the

NOTE Confidence: 0.989668970833333

00:06:55.814 --> 00:06:58.389 first five years of their life.

NOTE Confidence: 0.989668970833333

00:06:58.390 --> 00:07:00.846 But what it does is it

NOTE Confidence: 0.989668970833333

00:07:00.846 --> 00:07:02.900 protects them against really bad

NOTE Confidence: 0.989668970833333

00:07:02.900 --> 00:07:05.185 infections like pneumococcus you know

NOTE Confidence: 0.989668970833333

00:07:05.185 --> 00:07:07.480 patients with sickle cell disease,

NOTE Confidence: 0.989668970833333

00:07:07.480 --> 00:07:09.285 their spleen doesn't really work

NOTE Confidence: 0.989668970833333

00:07:09.285 --> 00:07:11.485 as well as somebody without sickle

NOTE Confidence: 0.989668970833333

00:07:11.485 --> 00:07:13.802 cell and because of that they are

NOTE Confidence: 0.989668970833333

00:07:13.802 --> 00:07:15.645 susceptible to certain types of

NOTE Confidence: 0.989668970833333

00:07:15.645 --> 00:07:17.137 infections and that penicillin

NOTE Confidence: 0.989668970833333

00:07:17.137 --> 00:07:19.368 every day just like a vitamin helps

NOTE Confidence: 0.989668970833333

00:07:19.368 --> 00:07:21.030 them to stay healthy and safe.

NOTE Confidence: 0.984842465833333

00:07:21.720 --> 00:07:24.275 So why is there this transition then

NOTE Confidence: 0.984842465833333

00:07:24.275 --> 00:07:26.520 from childhood to young adulthood?

NOTE Confidence: 0.984842465833333

00:07:26.520 --> 00:07:28.506 What's the difference in terms of

NOTE Confidence: 0.984842465833333

00:07:28.510 --> 00:07:30.298 the disease and how it's managed

NOTE Confidence: 0.984842465833333

00:07:30.298 --> 00:07:31.999 that requires a specialist like you?

NOTE Confidence: 0.98446344875

00:07:33.080 --> 00:07:36.104 Well, I think it's a variety of things.

NOTE Confidence: 0.98446344875

00:07:36.110 --> 00:07:37.730 It's not just the disease,

NOTE Confidence: 0.98446344875

00:07:37.730 --> 00:07:39.641 but it's becoming a young person

NOTE Confidence: 0.98446344875

00:07:39.641 --> 00:07:41.276 and learning how to navigate the

NOTE Confidence: 0.98446344875

00:07:41.276 --> 00:07:43.047 health care system on your own

NOTE Confidence: 0.98446344875

00:07:43.050 --> 00:07:44.740 and earlier we talked

NOTE Confidence: 0.98446344875

00:07:44.740 --> 00:07:46.430 about newborns and

NOTE Confidence: 0.98446344875

00:07:46.430 --> 00:07:48.482 if you were a newborn and found out

NOTE Confidence: 0.98446344875

00:07:48.490 --> 00:07:51.026 you had sickle cell disease that your parents

NOTE Confidence: 0.98446344875

00:07:51.026 --> 00:07:53.250 would help you take you to the doctor.

NOTE Confidence: 0.98446344875

00:07:53.250 --> 00:07:54.390 Manage your care,

NOTE Confidence: 0.98446344875

00:07:54.390 --> 00:07:56.290 give you that prophylactic penicillin.

NOTE Confidence: 0.98446344875

00:07:56.290 --> 00:07:57.784 But the beautiful part about being

NOTE Confidence: 0.98446344875

00:07:57.784 --> 00:07:59.708 a young adult is you can start to

NOTE Confidence: 0.98446344875

00:07:59.708 --> 00:08:01.520 assume some of that care for yourself,

NOTE Confidence: 0.98446344875

00:08:01.520 --> 00:08:02.561 so it's pretty

NOTE Confidence: 0.98446344875

00:08:02.561 --> 00:08:04.990 multi Factorial is a word I always

NOTE Confidence: 0.98446344875

00:08:05.060 --> 00:08:07.553 like to use and I like to

NOTE Confidence: 0.98446344875

00:08:07.553 --> 00:08:10.041 think that I was a pretty smart young

NOTE Confidence: 0.98446344875

00:08:10.041 --> 00:08:12.052 adult like I made some good decisions.

NOTE Confidence: 0.98446344875

00:08:12.052 --> 00:08:13.144 I'm a doctor now,

NOTE Confidence: 0.98446344875

00:08:13.150 --> 00:08:15.474 but I still did some foolish things

NOTE Confidence: 0.98446344875

00:08:15.474 --> 00:08:17.770 as a 16-17 eighteen year old and

NOTE Confidence: 0.98446344875

00:08:17.770 --> 00:08:19.400 that's without a chronic disease.

NOTE Confidence: 0.98446344875

00:08:19.400 --> 00:08:21.180 So in sickle cell disease,

NOTE Confidence: 0.98446344875

00:08:21.180 --> 00:08:23.441 what we can do as lifespan hematologists

NOTE Confidence: 0.98446344875

00:08:23.441 --> 00:08:25.533 and as health care providers is

NOTE Confidence: 0.98446344875

00:08:25.533 --> 00:08:27.651 really help our patients as their

NOTE Confidence: 0.98446344875

00:08:27.651 --> 00:08:29.234 disease complications may become

NOTE Confidence: 0.98446344875

00:08:29.234 --> 00:08:31.568 a little more severe as they're

NOTE Confidence: 0.98446344875

00:08:31.568 --> 00:08:33.040 learning to manage themselves.

NOTE Confidence: 0.98446344875

00:08:33.040 --> 00:08:35.200 As they're learning to navigate a

NOTE Confidence: 0.98446344875

00:08:35.200 --> 00:08:37.189 pretty complex health care system,

NOTE Confidence: 0.98446344875

00:08:37.190 --> 00:08:39.494 and as they're just trying to be productive,

NOTE Confidence: 0.98446344875

00:08:39.500 --> 00:08:40.778 happy young adults.

NOTE Confidence: 0.980201562307692

00:08:42.240 --> 00:08:44.648 What kinds of things do you

NOTE Confidence: 0.980201562307692

00:08:44.648 --> 00:08:46.590 talk about with your patients?

NOTE Confidence: 0.980201562307692

00:08:46.590 --> 00:08:47.950 It sounds like

NOTE Confidence: 0.980201562307692

00:08:47.950 --> 00:08:49.310 after their five years old,

NOTE Confidence: 0.980201562307692

00:08:49.310 --> 00:08:51.600 they're no longer on penicillin,

NOTE Confidence: 0.980201562307692

00:08:51.600 --> 00:08:53.938 but there's still no way to reverse

NOTE Confidence: 0.980201562307692

00:08:53.938 --> 00:08:55.666 the condition, so you're still

NOTE Confidence: 0.980201562307692

00:08:55.666 --> 00:08:58.130 at risk of all of those sticky,

NOTE Confidence: 0.980201562307692

00:08:58.130 --> 00:08:59.622 misshapen blood cells forming

NOTE Confidence: 0.980201562307692

00:08:59.622 --> 00:09:01.487 clots all over your body,

NOTE Confidence: 0.980201562307692

00:09:01.490 --> 00:09:03.162 which presumably can cause

NOTE Confidence: 0.980201562307692

00:09:03.162 --> 00:09:04.834 all kinds of problems.

NOTE Confidence: 0.980201562307692

00:09:04.840 --> 00:09:07.440 Is it just a matter

NOTE Confidence: 0.980201562307692

00:09:07.440 --> 00:09:09.623 of telling your patients what to

NOTE Confidence: 0.980201562307692

00:09:09.623 --> 00:09:12.260 watch for and when to seek help?

NOTE Confidence: 0.980201562307692

00:09:12.260 --> 00:09:15.156 Or are there things that they can do

NOTE Confidence: 0.980201562307692

00:09:15.156 --> 00:09:18.467 to reduce the risk of clots and

NOTE Confidence: 0.980201562307692

00:09:18.467 --> 00:09:21.010 other problems that it can cause?

NOTE Confidence: 0.986505172727273

00:09:21.730 --> 00:09:23.992 Absolutely, so I want to answer

NOTE Confidence: 0.986505172727273

00:09:23.992 --> 00:09:26.010 your question in two parts.

NOTE Confidence: 0.986505172727273

00:09:26.010 --> 00:09:28.284 First, what other parts of the

NOTE Confidence: 0.986505172727273

00:09:28.284 --> 00:09:30.390 body does sickle cell affect?

NOTE Confidence: 0.986505172727273

00:09:30.390 --> 00:09:33.180 How does that show up for

NOTE Confidence: 0.986505172727273

00:09:33.180 --> 00:09:35.400 patients across their lives?

NOTE Confidence: 0.986505172727273

00:09:35.400 --> 00:09:38.464 One of the things that our patients most

NOTE Confidence: 0.986505172727273

00:09:38.464 --> 00:09:41.227 deal with is pain every single day.

NOTE Confidence: 0.986505172727273

00:09:41.230 --> 00:09:43.036 So when those blood vessels get clogged

NOTE Confidence: 0.986505172727273

00:09:43.036 --> 00:09:45.364 up by those sickle cells and those juicy

NOTE Confidence: 0.986505172727273

00:09:45.364 --> 00:09:47.320 Jelly doughnut cells can't get through,

NOTE Confidence: 0.986505172727273

00:09:47.320 --> 00:09:48.488 that means oxygen isn't

NOTE Confidence: 0.986505172727273

00:09:48.488 --> 00:09:50.240 going to where it needs to

NOTE Confidence: 0.986505172727273

00:09:50.240 --> 00:09:51.200 in our bodies.

NOTE Confidence: 0.986505172727273

00:09:51.200 --> 00:09:52.480 And because of that,

NOTE Confidence: 0.986505172727273

00:09:52.480 --> 00:09:54.880 that can result in pretty bad bone pain

NOTE Confidence: 0.986505172727273

00:09:54.880 --> 00:09:56.978 for patients with sickle cell disease,

NOTE Confidence: 0.986505172727273

00:09:56.980 --> 00:09:59.348 and this is the thing that really affects

NOTE Confidence: 0.986505172727273

00:09:59.348 --> 00:10:01.344 their quality of life as young students

NOTE Confidence: 0.986505172727273

00:10:01.344 --> 00:10:03.448 trying to learn and keep up in school.

NOTE Confidence: 0.986505172727273

00:10:03.450 --> 00:10:04.955 If you have to be admitted to

NOTE Confidence: 0.986505172727273

00:10:04.955 --> 00:10:05.910 the hospital several times

NOTE Confidence: 0.986505172727273

00:10:05.910 --> 00:10:08.448 a year you can imagine how

NOTE Confidence: 0.986505172727273

00:10:08.448 --> 00:10:11.278 frustrating that can be as a scholar.

NOTE Confidence: 0.986505172727273

00:10:11.280 --> 00:10:13.264 Other parts of the body that are affected

NOTE Confidence: 0.986505172727273

00:10:13.264 --> 00:10:15.556 by sickle cell disease are numerous.

NOTE Confidence: 0.986505172727273

00:10:15.560 --> 00:10:16.740 Though patients with sickle

NOTE Confidence: 0.986505172727273

00:10:16.740 --> 00:10:18.215 cell disease can have something

NOTE Confidence: 0.986505172727273

00:10:18.215 --> 00:10:19.499 called acute chest syndrome,

NOTE Confidence: 0.986505172727273

00:10:19.500 --> 00:10:21.612 which is a really bad infection of the

NOTE Confidence: 0.986505172727273

00:10:21.612 --> 00:10:23.499 lungs that can be very challenging,

NOTE Confidence: 0.986505172727273

00:10:23.500 --> 00:10:27.124 they can even have strokes as young people,

NOTE Confidence: 0.986505172727273

00:10:27.130 --> 00:10:28.908 which is one of the reasons that

NOTE Confidence: 0.986505172727273

00:10:28.908 --> 00:10:30.865 compelled me as a Med student to

NOTE Confidence: 0.986505172727273

00:10:30.865 --> 00:10:32.575 pursue hematology was seeing a sickle

NOTE Confidence: 0.986505172727273

00:10:32.637 --> 00:10:34.485 cell patient eight years old who had

NOTE Confidence: 0.986505172727273

00:10:34.485 --> 00:10:36.245 a stroke in Pediatrics.

NOTE Confidence: 0.986505172727273

00:10:36.245 --> 00:10:38.419 And in order to kind of get a jump on these things,

NOTE Confidence: 0.986505172727273

00:10:38.420 --> 00:10:40.196 we do several things,

NOTE Confidence: 0.986505172727273

00:10:40.196 --> 00:10:41.528 we do screenings.

NOTE Confidence: 0.986505172727273

00:10:41.530 --> 00:10:43.470 Something called a transcranial Doppler,

NOTE Confidence: 0.986505172727273

00:10:43.470 --> 00:10:45.090 which is basically like an ultrasound

NOTE Confidence: 0.986505172727273

00:10:45.090 --> 00:10:47.382 of your head where you can look at the

NOTE Confidence: 0.986505172727273

00:10:47.382 --> 00:10:48.830 blood vessels and make sure you're

NOTE Confidence: 0.986505172727273

00:10:48.830 --> 00:10:50.510 not at risk for having a stroke.

NOTE Confidence: 0.986505172727273

00:10:50.510 --> 00:10:53.905 We always make sure that our patients

NOTE Confidence: 0.986505172727273

00:10:53.905 --> 00:10:56.110 have their eyes checked because

NOTE Confidence: 0.986505172727273

00:10:56.110 --> 00:10:57.830 sometimes in sickle cell disease

NOTE Confidence: 0.986505172727273

00:10:57.885 --> 00:11:00.148 you can have vision changes and a

NOTE Confidence: 0.986505172727273

00:11:00.148 --> 00:11:02.118 regular follow up with a hematologist

NOTE Confidence: 0.986505172727273

00:11:02.118 --> 00:11:04.810 can help you notice any changes

NOTE Confidence: 0.986505172727273

00:11:04.810 --> 00:11:06.726 before they cause problems.

NOTE Confidence: 0.986505172727273

00:11:06.730 --> 00:11:08.543 One of the biggest things and one

NOTE Confidence: 0.986505172727273

00:11:08.543 --> 00:11:10.542 of the things we know works and

NOTE Confidence: 0.986505172727273

00:11:10.542 --> 00:11:11.415 helps prolong life

NOTE Confidence: 0.986505172727273

00:11:11.420 --> 00:11:13.828 in sickle cell patients is a use of

NOTE Confidence: 0.986505172727273

00:11:13.828 --> 00:11:15.759 a medication called Hydroxyurea.

NOTE Confidence: 0.986505172727273

00:11:15.760 --> 00:11:18.288 Now, some of your listeners may be familiar,

NOTE Confidence: 0.986505172727273

00:11:18.290 --> 00:11:21.391 because sometimes this can be used in

NOTE Confidence: 0.986505172727273

00:11:21.391 --> 00:11:24.016 patients who have certain cancer diagnosis,

NOTE Confidence: 0.986505172727273

00:11:24.016 --> 00:11:26.176 but in sickle cell disease,

NOTE Confidence: 0.986505172727273

00:11:26.180 --> 00:11:28.450 the dose that we use is much lower and the

NOTE Confidence: 0.986505172727273

00:11:28.510 --> 00:11:30.562 way that we use it as a bit different.

NOTE Confidence: 0.986505172727273

00:11:30.570 --> 00:11:32.922 And we know that it kind of helps

NOTE Confidence: 0.986505172727273

00:11:32.922 --> 00:11:35.312 you have more juicy fat

NOTE Confidence: 0.986505172727273

00:11:35.312 --> 00:11:37.636 cells then bananas and so your body

NOTE Confidence: 0.986505172727273

00:11:37.636 --> 00:11:39.846 overall does better in the long term.

NOTE Confidence: 0.982428856923077

00:11:41.230 --> 00:11:43.526 So just to follow up on a few

NOTE Confidence: 0.982428856923077

00:11:43.526 --> 00:11:45.158 things that you just said.

NOTE Confidence: 0.982428856923077

00:11:45.160 --> 00:11:47.530 First off taking that last

NOTE Confidence: 0.982428856923077

00:11:47.530 --> 00:11:49.900 comment about Hydroxyurea making

NOTE Confidence: 0.982428856923077

00:11:49.900 --> 00:11:52.036 You have more fat and juicy like

NOTE Confidence: 0.982428856923077

00:11:52.036 --> 00:11:54.616 blood cells rather than sickling bananas,

NOTE Confidence: 0.982428856923077

00:11:54.620 --> 00:11:57.154 is it true that if you

NOTE Confidence: 0.982428856923077

00:11:57.154 --> 00:11:59.020 have sickle cell disease,

NOTE Confidence: 0.982428856923077

00:11:59.020 --> 00:12:01.106 not all of your blood cells are

NOTE Confidence: 0.982428856923077

00:12:01.106 --> 00:12:03.194 bananas and it is possible to

NOTE Confidence: 0.982428856923077

00:12:03.194 --> 00:12:05.450 increase the number of Jelly doughnut

NOTE Confidence: 0.982428856923077

00:12:05.450 --> 00:12:07.766 blood cells that you have instead

NOTE Confidence: 0.982428856923077

00:12:07.766 --> 00:12:09.641 of bananas?

NOTE Confidence: 0.97928670125

00:12:10.660 --> 00:12:13.985 Absolutely, and that is up until

NOTE Confidence: 0.97928670125

00:12:13.985 --> 00:12:16.095 recently, the only FDA

NOTE Confidence: 0.97928670125

00:12:16.095 --> 00:12:18.104 approved medication that we have had

NOTE Confidence: 0.97928670125

00:12:18.104 --> 00:12:19.958 for our patients is Hydroxyurea

NOTE Confidence: 0.97928670125

00:12:19.960 --> 00:12:22.840 to increase the amount of non sickle cells,

NOTE Confidence: 0.97928670125

00:12:22.840 --> 00:12:25.492 Jelly doughnut cells and ensure that

NOTE Confidence: 0.97928670125

00:12:25.492 --> 00:12:27.663 you're pain complications are lower

NOTE Confidence: 0.97928670125

00:12:27.663 --> 00:12:30.029 and that your organs can really get

NOTE Confidence: 0.97928670125

00:12:30.029 --> 00:12:32.070 the oxygen they need to thrive.

NOTE Confidence: 0.978295229545455

00:12:32.600 --> 00:12:34.712 So an obvious question is why

NOTE Confidence: 0.978295229545455

00:12:34.712 --> 00:12:36.766 not use more and make

NOTE Confidence: 0.978295229545455

00:12:36.766 --> 00:12:39.059 all of your blood cells Jelly Donuts?

NOTE Confidence: 0.978295229545455

00:12:39.060 --> 00:12:40.568 But hold that thought.

NOTE Confidence: 0.978295229545455

00:12:40.568 --> 00:12:43.681 Because first we need to take a short

NOTE Confidence: 0.978295229545455

00:12:43.681 --> 00:12:46.211 break for medical minute. Stay tuned

NOTE Confidence: 0.978295229545455

00:12:46.211 --> 00:12:48.173 to learn more about adolescents and

NOTE Confidence: 0.978295229545455

00:12:48.173 --> 00:12:50.165 young adults with sickle cell disease

NOTE Confidence: 0.978295229545455

00:12:50.165 --> 00:12:52.300 with my guest doctor CeCe Calhoun.

NOTE Confidence: 0.945679804

00:12:52.790 --> 00:12:54.920 Funding for Yale Cancer Answers

NOTE Confidence: 0.945679804

00:12:54.920 --> 00:12:57.050 comes from Smilow Cancer Hospital.

NOTE Confidence: 0.945679804

00:12:57.050 --> 00:12:59.558 Fifteen care centers offer access to

NOTE Confidence: 0.945679804

00:12:59.558 --> 00:13:01.230 oncologists committed to providing

NOTE Confidence: 0.945679804

00:13:01.293 --> 00:13:03.645 patients with cancer and blood diseases.

NOTE Confidence: 0.945679804

00:13:03.650 --> 00:13:05.510 Individualized innovative care.

NOTE Confidence: 0.945679804

00:13:05.510 --> 00:13:08.922 Find us. Milo Care Center near

NOTE Confidence: 0.945679804

00:13:08.922 --> 00:13:10.460 you at yalecancercenter.org.

NOTE Confidence: 0.986365794166666

00:13:12.550 --> 00:13:15.035 There are over 16.9 million

NOTE Confidence: 0.986365794166666

00:13:15.035 --> 00:13:17.981 cancer survivors in the US and

NOTE Confidence: 0.986365794166666

00:13:17.981 --> 00:13:19.898 over 240,000 here in Connecticut.

NOTE Confidence: 0.986365794166666

00:13:19.898 --> 00:13:21.446 Completing treatment for cancer

NOTE Confidence: 0.986365794166666

00:13:21.446 --> 00:13:23.709 is a very exciting milestone,

NOTE Confidence: 0.986365794166666

00:13:23.710 --> 00:13:25.660 but cancer and its treatment can

NOTE Confidence: 0.986365794166666

00:13:25.660 --> 00:13:27.730 be a life changing experience.

NOTE Confidence: 0.986365794166666

00:13:27.730 --> 00:13:30.124 The return to normal activities in

NOTE Confidence: 0.986365794166666

00:13:30.124 --> 00:13:32.139 relationships may be difficult and

NOTE Confidence: 0.986365794166666

00:13:32.139 --> 00:13:33.919 cancer survivors may face other

NOTE Confidence: 0.986365794166666

00:13:33.919 --> 00:13:36.020 long term side effects of cancer,

NOTE Confidence: 0.986365794166666

00:13:36.020 --> 00:13:37.745 including heart problems,

NOTE Confidence: 0.986365794166666

00:13:37.745 --> 00:13:38.320 osteoporosis,

NOTE Confidence: 0.986365794166666

00:13:38.320 --> 00:13:41.195 fertility issues and an increased

NOTE Confidence: 0.986365794166666

00:13:41.195 --> 00:13:43.180 risk of second cancers.

NOTE Confidence: 0.986365794166666

00:13:43.180 --> 00:13:45.785 Resources for cancer survivors are

NOTE Confidence: 0.986365794166666

00:13:45.785 --> 00:13:47.869 available at federally designated

NOTE Confidence: 0.986365794166666

00:13:47.869 --> 00:13:49.119 Comprehensive cancer centers

NOTE Confidence: 0.986365794166666

00:13:49.119 --> 00:13:51.099 such as the Yale Cancer Center

NOTE Confidence: 0.986365794166666

00:13:51.099 --> 00:13:53.458 and at Smilow Cancer Hospital to

NOTE Confidence: 0.986365794166666

00:13:53.458 --> 00:13:55.493 keep cancer survivors well and

NOTE Confidence: 0.986365794166666

00:13:55.493 --> 00:13:57.256 focused on healthy living.

NOTE Confidence: 0.986365794166666

00:13:57.256 --> 00:13:59.516 The Smilow Cancer Hospital Survivorship

NOTE Confidence: 0.986365794166666

00:13:59.516 --> 00:14:01.676 Clinic focuses on providing guidance

NOTE Confidence: 0.986365794166666

00:14:01.676 --> 00:14:04.052 and direction to empower survivors to

NOTE Confidence: 0.986365794166666

00:14:04.052 --> 00:14:06.438 take steps to maximize their health,

NOTE Confidence: 0.986365794166666

00:14:06.440 --> 00:14:08.740 quality of life and longevity.

NOTE Confidence: 0.986365794166666

00:14:08.740 --> 00:14:11.172 More information is available

NOTE Confidence: 0.986365794166666

00:14:11.172 --> 00:14:12.628 at yalecancercenter.org. You're

NOTE Confidence: 0.986365794166666

00:14:12.628 --> 00:14:13.900 listening to Connecticut

NOTE Confidence: 0.986365794166666

00:14:13.900 --> 00:14:14.830 Public Radio.

NOTE Confidence: 0.907110633333333

00:14:15.320 --> 00:14:17.480 Welcome back to Yale Cancer Answers.

NOTE Confidence: 0.907110633333333

00:14:17.480 --> 00:14:19.914 This is Doctor Anees Chagpar and I'm

NOTE Confidence: 0.907110633333333

00:14:19.914 --> 00:14:22.560 joined tonight by my guest Dr. Cece Calhoun.

NOTE Confidence: 0.907110633333333

00:14:22.560 --> 00:14:25.024 We're talking about the care of adolescents

NOTE Confidence: 0.907110633333333

00:14:25.024 --> 00:14:27.175 and young adults with sickle cell

NOTE Confidence: 0.907110633333333

00:14:27.175 --> 00:14:29.245 disease and bright before the break

NOTE Confidence: 0.907110633333333

00:14:29.250 --> 00:14:32.533 CeCe was mentioning that while sickle cell

NOTE Confidence: 0.907110633333333

00:14:32.533 --> 00:14:35.080 disease is completely

NOTE Confidence: 0.907110633333333

00:14:35.080 --> 00:14:37.700 irreversible,

NOTE Confidence: 0.907110633333333

00:14:37.700 --> 00:14:40.316 that actually using a drug called

NOTE Confidence: 0.907110633333333

00:14:40.316 --> 00:14:43.075 Hydroxyurea can help your body to

NOTE Confidence: 0.907110633333333

00:14:43.075 --> 00:14:45.873 create more of these quote juicy

NOTE Confidence: 0.907110633333333

00:14:45.873 --> 00:14:48.904 cells which are normal red blood cells

NOTE Confidence: 0.907110633333333

00:14:48.904 --> 00:14:52.034 and less of these quote banana like

NOTE Confidence: 0.907110633333333

00:14:52.034 --> 00:14:54.350 cells which are the sickle cells.

NOTE Confidence: 0.907110633333333

00:14:54.350 --> 00:14:56.948 So my question to you was.

NOTE Confidence: 0.907110633333333

00:14:56.950 --> 00:15:01.062 before we had the break, is why

NOTE Confidence: 0.907110633333333

00:15:01.062 --> 00:15:03.834 not just give more Hydroxyurea?

NOTE Confidence: 0.907110633333333

00:15:03.840 --> 00:15:06.522 I mean if it helps your body to produce

NOTE Confidence: 0.907110633333333

00:15:06.522 --> 00:15:09.270 more normal cells and less sickle cells,

NOTE Confidence: 0.907110633333333

00:15:09.270 --> 00:15:10.908 wouldn't that be a way to kind

NOTE Confidence: 0.907110633333333

00:15:10.908 --> 00:15:12.299 of reverse it?

NOTE Confidence: 0.97454897

00:15:13.770 --> 00:15:16.045 I would love if it could be

NOTE Confidence: 0.97454897

00:15:16.045 --> 00:15:17.930 totally reversed by Hydroxyurea

NOTE Confidence: 0.97454897

00:15:17.930 --> 00:15:19.898 but we know that when our

NOTE Confidence: 0.97454897

00:15:19.898 --> 00:15:21.694 patients are awesome, take their

NOTE Confidence: 0.97454897

00:15:21.694 --> 00:15:23.704 medications every day as prescribed,

NOTE Confidence: 0.97454897

00:15:23.710 --> 00:15:26.164 there's still an upper limit to

NOTE Confidence: 0.97454897

00:15:26.164 --> 00:15:29.040 how many of those juicy fat

NOTE Confidence: 0.97454897

00:15:29.040 --> 00:15:31.440 cells they can replace.

NOTE Confidence: 0.97454897

00:15:31.440 --> 00:15:33.904 They can produce to replace the banana cells,

NOTE Confidence: 0.97454897

00:15:33.910 --> 00:15:36.574 so there's a threshold of how

NOTE Confidence: 0.97454897

00:15:36.574 --> 00:15:38.700 effective the drug can be,

NOTE Confidence: 0.97454897

00:15:38.700 --> 00:15:39.948 but it can really,

NOTE Confidence: 0.97454897

00:15:39.948 --> 00:15:41.508 really help enough to help

NOTE Confidence: 0.97454897

00:15:41.508 --> 00:15:43.140 your organs stay healthy.

NOTE Confidence: 0.962217094

00:15:43.880 --> 00:15:46.352 So this Hydroxyurea is something

NOTE Confidence: 0.962217094

00:15:46.352 --> 00:15:48.315 that you're taking every day?

NOTE Confidence: 0.962217094

00:15:48.315 --> 00:15:49.669 For your whole life?

NOTE Confidence: 0.962217094

00:15:49.669 --> 00:15:52.941 And the other thing

NOTE Confidence: 0.962217094

00:15:52.941 --> 00:15:55.652 that you mentioned before the break

NOTE Confidence: 0.962217094

00:15:55.652 --> 00:15:59.178 and I wanted to pick up on as well

NOTE Confidence: 0.962217094

00:15:59.180 --> 00:16:02.180 was this concept of pain and the fact

NOTE Confidence: 0.962217094

00:16:02.180 --> 00:16:05.171 that many of these patients they present

NOTE Confidence: 0.962217094

00:16:05.171 --> 00:16:08.449 with pain and they have pain every day

NOTE Confidence: 0.962217094

00:16:08.450 --> 00:16:11.922 which impairs their ability to

NOTE Confidence: 0.962217094

00:16:11.922 --> 00:16:14.808 concentrate at school or maybe place

NOTE Confidence: 0.962217094

00:16:14.810 --> 00:16:18.626 boards so what do you do about that?

NOTE Confidence: 0.962217094

00:16:18.630 --> 00:16:20.555 I mean, are these patients

NOTE Confidence: 0.962217094

00:16:20.555 --> 00:16:22.095 treated with daily painkillers?

NOTE Confidence: 0.962217094

00:16:22.100 --> 00:16:24.333 Or do you tell them to simply

NOTE Confidence: 0.962217094

00:16:24.333 --> 00:16:26.742 wait until they have pain and

NOTE Confidence: 0.962217094

00:16:26.742 --> 00:16:28.570 then prescribe pain medication?

NOTE Confidence: 0.962217094

00:16:28.570 --> 00:16:31.009 I mean how do they get through their day

NOTE Confidence: 0.962217094

00:16:31.009 --> 00:16:33.677 to day life if they're in pain everyday?

NOTE Confidence: 0.9824606785

00:16:34.510 --> 00:16:37.863 Yeah, so sickle cell patients are warriors

NOTE Confidence: 0.9824606785

00:16:37.863 --> 00:16:41.570 and you'll often see that described because

NOTE Confidence: 0.9824606785

00:16:41.570 --> 00:16:44.840 despite having pain of variable severity,

NOTE Confidence: 0.9824606785

00:16:44.840 --> 00:16:47.688 they managed to live life and be productive.

NOTE Confidence: 0.9824606785

00:16:47.690 --> 00:16:50.498 That's one of the most awesome things

NOTE Confidence: 0.9824606785

00:16:50.498 --> 00:16:52.810 about working with sickle cell patients.

NOTE Confidence: 0.9824606785

00:16:52.810 --> 00:16:55.060 So in terms of pain prevention,

NOTE Confidence: 0.9824606785

00:16:55.060 --> 00:16:56.280 what can we do?

NOTE Confidence: 0.9824606785

00:16:56.280 --> 00:16:58.506 Number one Hydroxyurea and get more juicy

NOTE Confidence: 0.9824606785

00:16:58.506 --> 00:17:00.788 cells around so you have less pain.

NOTE Confidence: 0.9824606785

00:17:00.790 --> 00:17:03.130 And recently there are a couple

NOTE Confidence: 0.9824606785

00:17:03.130 --> 00:17:05.230 of medications on the market

NOTE Confidence: 0.9824606785

00:17:05.230 --> 00:17:07.560 that help with pain prevention.

NOTE Confidence: 0.9824606785

00:17:07.560 --> 00:17:10.518 Also just keeping yourself well hydrated.

NOTE Confidence: 0.9824606785

00:17:10.520 --> 00:17:12.308 My patients are so wonderful in

NOTE Confidence: 0.9824606785

00:17:12.308 --> 00:17:14.289 that they often know their bodies.

NOTE Confidence: 0.9824606785

00:17:14.290 --> 00:17:15.214 They know their triggers.

00:17:15.910 --> 00:17:18.276 And what situations make their pain worse.

NOTE Confidence: 0.9824606785

00:17:18.280 --> 00:17:19.468 And what kind of things can

NOTE Confidence: 0.9824606785

00:17:19.468 --> 00:17:20.260 make their pain better.

NOTE Confidence: 0.9824606785

00:17:20.260 --> 00:17:22.808 So really being attuned to those things

NOTE Confidence: 0.9824606785

00:17:22.810 --> 00:17:25.156 in terms of addressing pain acutely

NOTE Confidence: 0.9824606785

00:17:25.156 --> 00:17:28.008 when it happens and it's not planned,

NOTE Confidence: 0.9824606785

00:17:28.010 --> 00:17:31.916 we have a couple of things in our toolkit.

NOTE Confidence: 0.9824606785

00:17:31.920 --> 00:17:33.900 Yes, pain medication is something

NOTE Confidence: 0.9824606785

00:17:33.900 --> 00:17:36.530 that we give frequently for pain,

NOTE Confidence: 0.9824606785

00:17:36.530 --> 00:17:38.658 but we can also use red

NOTE Confidence: 0.9824606785

00:17:38.658 --> 00:17:40.858 blood cell transfusions if we need to.

NOTE Confidence: 0.9824606785

00:17:40.860 --> 00:17:43.116 If somebody is having pain often,

NOTE Confidence: 0.9824606785

00:17:43.120 --> 00:17:46.126 but many times we can't predict

NOTE Confidence: 0.9824606785

00:17:46.130 --> 00:17:47.350 when the pain will come,

NOTE Confidence: 0.9824606785

00:17:47.350 --> 00:17:49.246 or how severe it will be,

NOTE Confidence: 0.9824606785

00:17:49.250 --> 00:17:51.000 and so because of that our patients

NOTE Confidence: 0.9824606785

00:17:51.000 --> 00:17:53.160 have to get care in the ED sometimes

NOTE Confidence: 0.9824606785

00:17:53.160 --> 00:17:54.840 to get treatment for their pain.

NOTE Confidence: 0.968010386363636

00:17:55.550 --> 00:17:57.060 You mentioned something

NOTE Confidence: 0.968010386363636

00:17:57.060 --> 00:17:59.290 that I found kind of intriguing.

NOTE Confidence: 0.968010386363636

00:17:59.290 --> 00:18:01.474 You said that we have medications

NOTE Confidence: 0.968010386363636

00:18:01.474 --> 00:18:03.740 for pain prevention, like what?

NOTE Confidence: 0.974010345

00:18:04.270 --> 00:18:07.006 Hot off the press I know,

NOTE Confidence: 0.974010345

00:18:07.010 --> 00:18:09.565 so recently there's been

NOTE Confidence: 0.974010345

00:18:09.565 --> 00:18:11.609 an FDA approved medication,

NOTE Confidence: 0.974010345

00:18:11.610 --> 00:18:13.780 Adakveo or crizanlizumab

NOTE Confidence: 0.974010345

00:18:15.900 --> 00:18:18.716 but I try not to say

NOTE Confidence: 0.974010345

00:18:18.716 --> 00:18:20.700 that because crizanlizumab,

NOTE Confidence: 0.974010345

00:18:20.700 --> 00:18:23.724 but that can be used to prevent pain

NOTE Confidence: 0.974010345

00:18:23.724 --> 00:18:26.659 as an infusion given once monthly.

NOTE Confidence: 0.974010345

00:18:32.010 --> 00:18:33.870 And another medication that's recently been

NOTE Confidence: 0.974010345

00:18:33.870 --> 00:18:36.449 approved is something called Oxbryta

NOTE Confidence: 0.974010345

00:18:36.450 --> 00:18:38.900 and really, what that does is increase

NOTE Confidence: 0.974010345

00:18:38.900 --> 00:18:40.779 patients with sickle cell disease,

NOTE Confidence: 0.974010345

00:18:40.780 --> 00:18:41.512 their hemoglobin,

NOTE Confidence: 0.974010345

00:18:41.512 --> 00:18:44.440 and so the thought is if their

NOTE Confidence: 0.974010345

00:18:44.520 --> 00:18:46.750 hemoglobin is better they

NOTE Confidence: 0.974010345

00:18:46.750 --> 00:18:49.025 may in turn have less pain,

NOTE Confidence: 0.974010345

00:18:49.030 --> 00:18:51.610 but the primary medication that

NOTE Confidence: 0.974010345

00:18:51.610 --> 00:18:54.750 is out there for pain

NOTE Confidence: 0.974010345

00:18:54.750 --> 00:18:56.680 prevention is Adakveo.

NOTE Confidence: 0.98545874

00:18:57.490 --> 00:18:59.225 That sounds like a

NOTE Confidence: 0.98545874

00:18:59.225 --> 00:19:00.621 pretty good deal, right?

NOTE Confidence: 0.98545874

00:19:00.621 --> 00:19:02.727 If instead of having pain everyday,

NOTE Confidence: 0.98545874

00:19:02.730 --> 00:19:05.018 if you had an infusion once a month,

NOTE Confidence: 0.98545874

00:19:05.020 --> 00:19:07.092 does that infusion kind of really get

NOTE Confidence: 0.98545874

00:19:07.092 --> 00:19:09.458 rid of the chances of having pain?

NOTE Confidence: 0.98545874

00:19:09.460 --> 00:19:10.540 Or not really?

NOTE Confidence: 0.920879997692308

00:19:11.510 --> 00:19:14.590 I think that the medication is pretty

NOTE Confidence: 0.920879997692308

00:19:14.590 --> 00:19:17.925 new and patients themselves are

NOTE Confidence: 0.920879997692308

00:19:17.925 --> 00:19:19.145 are individuals,

NOTE Confidence: 0.920879997692308

00:19:19.150 --> 00:19:20.686 and so I've had some patients

NOTE Confidence: 0.920879997692308

00:19:20.686 --> 00:19:21.970 who it's worked great for.

NOTE Confidence: 0.920879997692308

00:19:21.970 --> 00:19:23.476 I've had some patients that we

NOTE Confidence: 0.920879997692308

00:19:23.476 --> 00:19:25.229 just have to try other things.

NOTE Confidence: 0.920879997692308

00:19:25.230 --> 00:19:27.280 I think the wonderful thing

NOTE Confidence: 0.920879997692308

00:19:27.280 --> 00:19:28.920 about being a physician

NOTE Confidence: 0.920879997692308

00:19:28.920 --> 00:19:30.132 scientist and sickle cell,

NOTE Confidence: 0.920879997692308

00:19:30.132 --> 00:19:32.232 or even being a patient right now

NOTE Confidence: 0.920879997692308

00:19:32.232 --> 00:19:33.786 who has sickle cell is that it is

NOTE Confidence: 0.920879997692308

00:19:33.786 --> 00:19:35.750 such a fertile time for discovery.

NOTE Confidence: 0.920879997692308

00:19:35.750 --> 00:19:37.568 In terms of sickle cell disease,

NOTE Confidence: 0.920879997692308

00:19:37.570 --> 00:19:38.894 how to prevent complications

NOTE Confidence: 0.920879997692308

00:19:38.894 --> 00:19:40.549 and how to cure it.

NOTE Confidence: 0.920879997692308

00:19:40.550 --> 00:19:42.608 So you just have to work with

NOTE Confidence: 0.920879997692308

00:19:42.608 --> 00:19:43.866 your hematologist to find

NOTE Confidence: 0.920879997692308

00:19:43.866 --> 00:19:45.416 the right regimen for you.

NOTE Confidence: 0.984839055714286

00:19:46.120 --> 00:19:48.150 So I want to pick up on

NOTE Confidence: 0.984839055714286

00:19:48.150 --> 00:19:50.698 that discovery and some of the

NOTE Confidence: 0.984839055714286

00:19:50.698 --> 00:19:52.526 new advances that are going on

NOTE Confidence: 0.984839055714286

00:19:52.526 --> 00:19:54.170 in terms of sickle cell research.

NOTE Confidence: 0.984839055714286

00:19:54.170 --> 00:19:56.922 But before that I had one other question

NOTE Confidence: 0.984839055714286

00:19:56.922 --> 00:19:58.945 about the complications

NOTE Confidence: 0.984839055714286

00:19:58.945 --> 00:20:01.465 you had mentioned before the break.

NOTE Confidence: 0.984839055714286

00:20:01.470 --> 00:20:04.060 One of the impetuses for you to

NOTE Confidence: 0.984839055714286

00:20:04.060 --> 00:20:05.606 become a pediatric climatologist

NOTE Confidence: 0.984839055714286

00:20:05.606 --> 00:20:08.864 was an 8 year old who had a stroke,

NOTE Confidence: 0.984839055714286

00:20:08.870 --> 00:20:12.310 which just I mean is heartbreaking to me.

NOTE Confidence: 0.984839055714286

00:20:12.310 --> 00:20:14.970 But clearly if you think about these

NOTE Confidence: 0.984839055714286

00:20:15.042 --> 00:20:17.038 sickle cells, it makes sense, right?

NOTE Confidence: 0.984839055714286

00:20:17.038 --> 00:20:18.730 These sickle cells kind of glom

NOTE Confidence: 0.984839055714286

00:20:18.730 --> 00:20:20.122 together and they cut off blood

NOTE Confidence: 0.984839055714286

00:20:20.122 --> 00:20:21.909 supply to a part of your brain

NOTE Confidence: 0.984839055714286

00:20:21.909 --> 00:20:22.985 that's called the stroke.

NOTE Confidence: 0.984839055714286

00:20:22.990 --> 00:20:25.258 Now when we think about

NOTE Confidence: 0.984839055714286

00:20:25.258 --> 00:20:26.837 older patients who

NOTE Confidence: 0.984839055714286

00:20:26.837 --> 00:20:29.308 may be at risk of stroke or who may

NOTE Confidence: 0.984839055714286

00:20:29.308 --> 00:20:31.316 be at risk of heart attack or who

NOTE Confidence: 0.984839055714286

00:20:31.316 --> 00:20:33.028 may be at risk of other clotting,

NOTE Confidence: 0.984839055714286

00:20:33.030 --> 00:20:35.082 whether it's in their lungs or

NOTE Confidence: 0.984839055714286

00:20:35.082 --> 00:20:37.180 in their legs or whatever,

NOTE Confidence: 0.984839055714286

00:20:37.180 --> 00:20:39.600 we often use blood thinners,

NOTE Confidence: 0.984839055714286

00:20:39.600 --> 00:20:41.640 so are sickle cell patients put

NOTE Confidence: 0.984839055714286

00:20:41.640 --> 00:20:44.006 on blood thinners to

NOTE Confidence: 0.984839055714286

00:20:44.006 --> 00:20:45.416 prevent these complications?

NOTE Confidence: 0.984839055714286

00:20:45.420 --> 00:20:46.765 Since we know that they're

NOTE Confidence: 0.984839055714286

00:20:46.765 --> 00:20:48.110 at risk of getting clots.

NOTE Confidence: 0.978102746875

00:20:48.330 --> 00:20:51.151 So the blockages that occur in sickle

NOTE Confidence: 0.978102746875

00:20:51.151 --> 00:20:54.031 cell disease are a little bit different

NOTE Confidence: 0.978102746875

00:20:54.031 --> 00:20:56.970 than your normal blood clot, which is

NOTE Confidence: 0.978102746875

00:20:56.970 --> 00:20:59.960 caused by a different series of events,

NOTE Confidence: 0.978102746875

00:20:59.960 --> 00:21:02.200 and so for patients with sickle cell disease,

NOTE Confidence: 0.978102746875

00:21:02.200 --> 00:21:03.574 though they are at an increased

NOTE Confidence: 0.978102746875

00:21:03.574 --> 00:21:04.900 risk to have those

NOTE Confidence: 0.978102746875

00:21:04.900 --> 00:21:07.196 traditionally, what we think of blood clots,

NOTE Confidence: 0.978102746875

00:21:07.200 --> 00:21:09.160 we don't put them on blood thinners

NOTE Confidence: 0.978102746875

00:21:09.160 --> 00:21:11.038 to try to prevent complications

NOTE Confidence: 0.978102746875

00:21:11.038 --> 00:21:12.986 with sickle cell disease.

NOTE Confidence: 0.978102746875

00:21:12.990 --> 00:21:14.803 We know those blockages can be stuck

NOTE Confidence: 0.978102746875

00:21:14.803 --> 00:21:16.730 like a clot, or they can be transient,

NOTE Confidence: 0.978102746875

00:21:16.730 --> 00:21:18.150 they come and go because of the

NOTE Confidence: 0.978102746875

00:21:18.150 --> 00:21:19.286 cells sticking together.

NOTE Confidence: 0.978102746875

00:21:19.290 --> 00:21:20.949 It's not like the other proteins in

NOTE Confidence: 0.978102746875

00:21:20.949 --> 00:21:22.699 your body are swimming over there,

NOTE Confidence: 0.978102746875

00:21:22.700 --> 00:21:23.956 making a huge clot.

NOTE Confidence: 0.978102746875

00:21:23.956 --> 00:21:26.769 What we do in our young people

NOTE Confidence: 0.978102746875

00:21:26.769 --> 00:21:28.125 to maximize stroke prevention

NOTE Confidence: 0.978102746875

00:21:28.125 --> 00:21:30.150 is we do screenings like the

NOTE Confidence: 0.978102746875

00:21:30.150 --> 00:21:31.774 Transcranial Doppler I mentioned.

NOTE Confidence: 0.978102746875

00:21:31.774 --> 00:21:34.210 And if we notice any kind

NOTE Confidence: 0.978102746875

00:21:34.284 --> 00:21:35.800 of abnormality at all,

NOTE Confidence: 0.978102746875

00:21:35.800 --> 00:21:37.558 we have a couple of options.

NOTE Confidence: 0.978102746875

00:21:37.560 --> 00:21:40.682 One we can start them on chronic

NOTE Confidence: 0.978102746875

00:21:40.682 --> 00:21:43.110 transfusion to decrease the

NOTE Confidence: 0.978102746875

00:21:43.110 --> 00:21:45.835 amount of sickle cells circulating in their

NOTE Confidence: 0.978102746875

00:21:45.835 --> 00:21:48.208 blood and give them more normal cells.

NOTE Confidence: 0.978102746875

00:21:48.210 --> 00:21:50.457 Or if somebody has been

NOTE Confidence: 0.978102746875

00:21:50.457 --> 00:21:52.264 on transfusions,

NOTE Confidence: 0.978102746875

00:21:52.264 --> 00:21:54.204 their transcranial dopplers looks fine,

NOTE Confidence: 0.978102746875

00:21:54.210 --> 00:21:56.754 we can switch them to again Hydroxyurea

NOTE Confidence: 0.978102746875

00:21:56.754 --> 00:21:59.089 put more Jelly Donuts around,

NOTE Confidence: 0.978102746875

00:21:59.090 --> 00:22:00.802 have less sickle cells,

NOTE Confidence: 0.978102746875

00:22:00.802 --> 00:22:02.942 decrease the risk of complications,

NOTE Confidence: 0.978102746875

00:22:02.950 --> 00:22:04.810 and that's again why it's important

NOTE Confidence: 0.978102746875

00:22:04.810 --> 00:22:05.740 to connect with your

NOTE Confidence: 0.978102746875

00:22:05.740 --> 00:22:07.080 friendly hematologist so we

NOTE Confidence: 0.978102746875

00:22:07.080 --> 00:22:09.090 can help you on that journey.

NOTE Confidence: 0.9752394125

00:22:09.460 --> 00:22:11.212 Yeah, but presumably you would have

NOTE Confidence: 0.9752394125

00:22:11.212 --> 00:22:13.129 already been on the Hydroxyurea

NOTE Confidence: 0.9752394125

00:22:13.130 --> 00:22:16.160 so if that transcranial Doppler finds

NOTE Confidence: 0.9752394125

00:22:16.160 --> 00:22:19.840 that you're at increased risk

NOTE Confidence: 0.9752394125

00:22:19.840 --> 00:22:21.772 I guess the transfusion

NOTE Confidence: 0.9752394125

00:22:21.772 --> 00:22:23.086 is your only alternative,

NOTE Confidence: 0.9752394125

00:22:23.086 --> 00:22:26.200 but the issue there is if you keep

NOTE Confidence: 0.9752394125

00:22:26.273 --> 00:22:28.985 getting transfusions on a regular basis,

NOTE Confidence: 0.9752394125

00:22:28.990 --> 00:22:31.552 doesn't that increase your risk of

NOTE Confidence: 0.9752394125

00:22:31.552 --> 00:22:33.260 transfusion reactions and potentially

NOTE Confidence: 0.9752394125

00:22:33.322 --> 00:22:34.934 ultimately developing antibodies such

NOTE Confidence: 0.9752394125

00:22:34.934 --> 00:22:37.746 that there are fewer and fewer blood

NOTE Confidence: 0.9752394125

00:22:37.746 --> 00:22:39.726 types that you can actually take?

00:22:42.360 --> 00:22:43.500 Absolutely.

NOTE Confidence: 0.98044038625

00:22:43.500 --> 00:22:46.920 For patients who have chronic transfusions,

NOTE Confidence: 0.98044038625

00:22:46.920 --> 00:22:48.930 they're a variety of risks that

NOTE Confidence: 0.98044038625

00:22:48.930 --> 00:22:50.270 come along with that.

NOTE Confidence: 0.98044038625

00:22:50.270 --> 00:22:51.560 There's obviously a clear benefit

NOTE Confidence: 0.98044038625

00:22:51.560 --> 00:22:53.432 in that it keeps you safe

NOTE Confidence: 0.98044038625

00:22:53.432 --> 00:22:54.747 and protects you against stroke

NOTE Confidence: 0.98044038625

00:22:54.747 --> 00:22:56.050 and may decrease your pain.

NOTE Confidence: 0.98044038625

00:22:56.050 --> 00:22:57.498 But you're absolutely right,

NOTE Confidence: 0.98044038625

00:22:57.498 --> 00:22:58.584 our bodies recognize

NOTE Confidence: 0.98044038625

00:22:58.584 --> 00:23:00.150 things that aren't foreign,

NOTE Confidence: 0.98044038625

00:23:00.150 --> 00:23:03.300 and that's why we really work in tandem

NOTE Confidence: 0.98044038625

00:23:03.300 --> 00:23:05.125 and together with our transfusion

NOTE Confidence: 0.98044038625

00:23:05.125 --> 00:23:06.910 medicine colleagues to do extended

NOTE Confidence: 0.98044038625

00:23:06.910 --> 00:23:08.806 typing in patients with sickle cell

NOTE Confidence: 0.98044038625

00:23:08.806 --> 00:23:10.639 disease to prevent that risk of

NOTE Confidence: 0.98044038625

00:23:10.640 --> 00:23:12.145 developing antibodies.

NOTE Confidence: 0.98044038625

00:23:14.190 --> 00:23:16.045 Another big risk is something

NOTE Confidence: 0.98044038625

00:23:16.045 --> 00:23:17.158 called iron overload,

NOTE Confidence: 0.98044038625

00:23:17.160 --> 00:23:19.582 where excess iron from the blood deposits

NOTE Confidence: 0.98044038625

00:23:19.582 --> 00:23:22.010 in different organs like your liver,

NOTE Confidence: 0.98044038625

00:23:22.010 --> 00:23:23.590 your heart, or your eyes.

NOTE Confidence: 0.98044038625

00:23:23.590 --> 00:23:26.355 So we measure that regularly and again,

NOTE Confidence: 0.98044038625

00:23:26.360 --> 00:23:28.820 medicine is so cool because we're

NOTE Confidence: 0.98044038625

00:23:28.820 --> 00:23:30.911 always ideally moving forward and

NOTE Confidence: 0.98044038625

00:23:30.911 --> 00:23:33.599 there's also a procedure

NOTE Confidence: 0.98044038625

00:23:33.599 --> 00:23:35.150 called Erythrocytosis

NOTE Confidence: 0.98044038625

00:23:35.150 --> 00:23:36.836 which I don't too much mind

NOTE Confidence: 0.98044038625

00:23:36.836 --> 00:23:37.960 saying five times fast,

NOTE Confidence: 0.98044038625

00:23:37.960 --> 00:23:40.074 but I like it, which can help

NOTE Confidence: 0.98044038625

00:23:40.074 --> 00:23:41.560 decrease that risk of iron overload.

NOTE Confidence: 0.98044038625

00:23:49.070 --> 00:23:50.953 Let's talk a little bit

NOTE Confidence: 0.976624390526316

00:23:50.953 --> 00:23:52.930 about some of the exciting advances

NOTE Confidence: 0.976624390526316

00:23:52.930 --> 00:23:55.132 in terms of sickle cell disease.

NOTE Confidence: 0.976624390526316

00:23:55.140 --> 00:23:56.908 Tell us about what you think are the

NOTE Confidence: 0.976624390526316

00:23:56.908 --> 00:23:58.520 most exciting things that are on the

NOTE Confidence: 0.976624390526316

00:23:58.520 --> 00:24:00.195 forefront that you think are really going

NOTE Confidence: 0.976624390526316

00:24:00.195 --> 00:24:01.945 to make a difference for your patients.

NOTE Confidence: 0.981700256521739

00:24:03.070 --> 00:24:06.110 I think there are a lot of

NOTE Confidence: 0.981700256521739

00:24:06.195 --> 00:24:09.527 medications in the works to address pain

NOTE Confidence: 0.981700256521739

00:24:09.527 --> 00:24:12.598 and complications of sickle cell disease.

NOTE Confidence: 0.981700256521739

00:24:12.600 --> 00:24:15.885 But one of the things I think that is

NOTE Confidence: 0.981700256521739

00:24:15.885 --> 00:24:19.507 most exciting is the idea of a cure

NOTE Confidence: 0.981700256521739

00:24:19.507 --> 00:24:22.318 through gene therapy,

NOTE Confidence: 0.981700256521739

00:24:22.318 --> 00:24:23.766 and that's pretty awesome.

NOTE Confidence: 0.981700256521739

00:24:23.770 --> 00:24:27.820 There's been some media, the

00:24:29.980 --> 00:24:32.154 New York Times has published about it

NOTE Confidence: 0.981700256521739

00:24:32.154 --> 00:24:34.158 and the Washington Post as

NOTE Confidence: 0.981700256521739

00:24:34.158 --> 00:24:37.174 well about how we can use different

NOTE Confidence: 0.981700256521739

00:24:37.174 --> 00:24:38.998 scientific technologies like CRISPR

NOTE Confidence: 0.981700256521739

00:24:38.998 --> 00:24:41.152 technology or use different vectors

NOTE Confidence: 0.981700256521739

00:24:41.152 --> 00:24:43.690 like viral vectors to take somebody's

NOTE Confidence: 0.981700256521739

00:24:43.690 --> 00:24:46.162 stem cells and correct that defect

NOTE Confidence: 0.981700256521739

00:24:46.162 --> 00:24:49.111 in their DNA that caused them to

NOTE Confidence: 0.981700256521739

00:24:49.111 --> 00:24:51.535 be making sickle cells and then

NOTE Confidence: 0.981700256521739

00:24:51.535 --> 00:24:54.404 give it back to them in a safe way,

NOTE Confidence: 0.981700256521739

00:24:54.410 --> 00:24:56.042 and then when those new and

NOTE Confidence: 0.981700256521739

00:24:56.042 --> 00:24:57.550 improved cells from their bodies

NOTE Confidence: 0.981700256521739

00:24:57.550 --> 00:24:58.681 replicate

NOTE Confidence: 0.981700256521739

00:24:58.681 --> 00:25:00.566 they are no longer affected

NOTE Confidence: 0.981700256521739

00:25:00.566 --> 00:25:02.249 by sickle cell disease.

NOTE Confidence: 0.981700256521739

00:25:02.250 --> 00:25:04.546 They may still make some sickle cells,

NOTE Confidence: 0.981700256521739

00:25:04.550 --> 00:25:06.482 but will effectively be cured or

NOTE Confidence: 0.981700256521739

00:25:06.482 --> 00:25:08.654 be like somebody who just has the

NOTE Confidence: 0.981700256521739

00:25:08.654 --> 00:25:10.340 trait and that's one of the things

NOTE Confidence: 0.981700256521739

00:25:10.340 --> 00:25:11.770 I think that's most exciting.

NOTE Confidence: 0.981700256521739

00:25:11.770 --> 00:25:13.180 The possibility of a cure

NOTE Confidence: 0.988097628333333

00:25:13.350 --> 00:25:15.840 in our future.

00:25:18.090 --> 00:25:21.078 And is that 10-15, 30-50 years from now?

NOTE Confidence: 0.97579093

00:25:21.300 --> 00:25:23.586 No, the time is totally now,

NOTE Confidence: 0.97579093

00:25:23.590 --> 00:25:25.458 so there are clinical,

NOTE Confidence: 0.97579093

00:25:25.458 --> 00:25:27.793 active clinical trials going on

NOTE Confidence: 0.97579093

00:25:27.800 --> 00:25:29.930 to better understand the safety

NOTE Confidence: 0.97579093

00:25:29.930 --> 00:25:32.060 and efficacy of this process

NOTE Confidence: 0.97579093

00:25:32.140 --> 00:25:34.429 for patients and so

NOTE Confidence: 0.97579093

00:25:34.429 --> 00:25:36.480 that's happening now.

NOTE Confidence: 0.97579093

00:25:36.480 --> 00:25:38.688 Wow, that's

NOTE Confidence: 0.989792367142857

00:25:38.700 --> 00:25:41.486 super exciting. What else is going on?

NOTE Confidence: 0.945825903333334

00:25:42.420 --> 00:25:45.164 So I think the other main things are

NOTE Confidence: 0.945825903333334

00:25:45.164 --> 00:25:47.211 the development of oral medications

NOTE Confidence: 0.945825903333334

00:25:47.211 --> 00:25:49.785 to improve pain and to decrease

NOTE Confidence: 0.945825903333334

00:25:49.785 --> 00:25:51.939 complications from sickle cell disease.

NOTE Confidence: 0.945825903333334

00:25:51.940 --> 00:25:53.011 That one medication,

NOTE Confidence: 0.945825903333334

00:25:53.011 --> 00:25:56.020 Adakveo, the way that it works,

NOTE Confidence: 0.945825903333334

00:25:56.020 --> 00:25:57.624 it's something called

NOTE Confidence: 0.945825903333334

00:25:57.624 --> 00:25:58.827 a B selection inhibitor.

NOTE Confidence: 0.945825903333334

00:25:58.830 --> 00:26:00.775 And so they're more medications

NOTE Confidence: 0.945825903333334

00:26:00.775 --> 00:26:03.309 coming around that look at that.

NOTE Confidence: 0.945825903333334

00:26:03.310 --> 00:26:06.946 And there's some additional

NOTE Confidence: 0.945825903333334

00:26:06.946 --> 00:26:09.698 oral medications coming that target

NOTE Confidence: 0.945825903333334

00:26:09.698 --> 00:26:12.018 different mechanisms and other blood

NOTE Confidence: 0.945825903333334

00:26:12.018 --> 00:26:14.110 problems like thalassemia and

NOTE Confidence: 0.945825903333334

00:26:14.110 --> 00:26:16.658 they want to see if those medications

NOTE Confidence: 0.945825903333334

00:26:16.660 --> 00:26:18.412 can work well in

NOTE Confidence: 0.945825903333334

00:26:18.412 --> 00:26:20.090 patients with sickle cell disease.

NOTE Confidence: 0.945825903333334

00:26:20.090 --> 00:26:22.241 So I think that fact that we are shining

NOTE Confidence: 0.945825903333334

00:26:22.241 --> 00:26:24.531 a light on this community of people

NOTE Confidence: 0.945825903333334

00:26:24.531 --> 00:26:27.258 with sickle cell disease and that we as

NOTE Confidence: 0.945825903333334

00:26:27.258 --> 00:26:28.938 a scientific community have committed

NOTE Confidence: 0.945825903333334

00:26:28.940 --> 00:26:31.460 to making their quality of life better,

NOTE Confidence: 0.945825903333334

00:26:31.460 --> 00:26:33.780 that's the thing that's most exciting to me,

NOTE Confidence: 0.945825903333334

00:26:33.780 --> 00:26:36.130 because oftentimes I think my

NOTE Confidence: 0.945825903333334

00:26:36.130 --> 00:26:38.480 patients feel unseen and unheard,

NOTE Confidence: 0.945825903333334

00:26:38.480 --> 00:26:42.520 and so it's great to see so many people,

NOTE Confidence: 0.945825903333334

00:26:42.520 --> 00:26:44.050 brilliant people standing up for them

NOTE Confidence: 0.945825903333334

00:26:44.050 --> 00:26:45.968 and helping to make their lives better.

NOTE Confidence: 0.987636803529412

00:26:46.320 --> 00:26:46.994 That's awesome.

NOTE Confidence: 0.987636803529412

00:26:46.994 --> 00:26:50.145 I guess the last question that I have is

NOTE Confidence: 0.987636803529412

00:26:50.145 --> 00:26:52.437 really with regards to clinical trials.

NOTE Confidence: 0.987636803529412

00:26:52.440 --> 00:26:55.555 I mean, it sounds like there's so

NOTE Confidence: 0.987636803529412

00:26:55.555 --> 00:26:58.288 many great things on the horizon.

NOTE Confidence: 0.987636803529412

00:26:58.290 --> 00:27:01.458 Do you find that young people

NOTE Confidence: 0.987636803529412

00:27:01.458 --> 00:27:04.302 adolescents are interested in clinical

NOTE Confidence: 0.987636803529412

00:27:04.302 --> 00:27:07.507 trials and willing to participate?

NOTE Confidence: 0.987636803529412

00:27:07.510 --> 00:27:10.320 Are there barriers to participation?

NOTE Confidence: 0.987636803529412

00:27:10.320 --> 00:27:11.946 How has that been going along?

NOTE Confidence: 0.976098925833333

00:27:12.510 --> 00:27:14.580 Yeah, so anybody who has lived

NOTE Confidence: 0.976098925833333

00:27:14.580 --> 00:27:16.930 with sickle cell or chronic pain,

NOTE Confidence: 0.976098925833333

00:27:16.930 --> 00:27:18.755 I think is enthusiastic about

NOTE Confidence: 0.976098925833333

00:27:18.755 --> 00:27:21.229 finding a way to have a better

NOTE Confidence: 0.976098925833333

00:27:21.229 --> 00:27:23.338 life and to come have a better

NOTE Confidence: 0.976098925833333

00:27:23.338 --> 00:27:25.961 quality of life and to find a cure.

NOTE Confidence: 0.976098925833333

00:27:25.961 --> 00:27:27.995 When it comes to clinical trials,

NOTE Confidence: 0.976098925833333

00:27:28.000 --> 00:27:31.704 there's a careful balance

NOTE Confidence: 0.976098925833333

00:27:31.704 --> 00:27:33.911 between understanding clinical

NOTE Confidence: 0.976098925833333

00:27:33.911 --> 00:27:36.368 studies and not wanting to feel like

NOTE Confidence: 0.976098925833333

00:27:36.368 --> 00:27:37.852 an experiment and understanding

NOTE Confidence: 0.976098925833333

00:27:37.852 --> 00:27:39.994 how the medical system can wrap

NOTE Confidence: 0.976098925833333

00:27:39.994 --> 00:27:41.788 around you to keep you safe.

NOTE Confidence: 0.976098925833333

00:27:41.790 --> 00:27:43.810 As we understand more about

NOTE Confidence: 0.976098925833333

00:27:43.810 --> 00:27:46.510 how to help you have a cure.

NOTE Confidence: 0.976098925833333

00:27:46.510 --> 00:27:49.429 And so when I think about

NOTE Confidence: 0.976098925833333

00:27:49.430 --> 00:27:50.450 my young people,

NOTE Confidence: 0.976098925833333

00:27:50.450 --> 00:27:52.490 are they interested in clinical trials?

NOTE Confidence: 0.976098925833333

00:27:52.490 --> 00:27:55.316 I think that they have a lot of excellent

NOTE Confidence: 0.976098925833333

00:27:55.316 --> 00:27:57.294 questions about the benefits and

NOTE Confidence: 0.976098925833333

00:27:57.294 --> 00:27:59.694 risks of participating in clinical trials.

NOTE Confidence: 0.976098925833333

00:27:59.700 --> 00:28:01.340 But many of them ultimately,

NOTE Confidence: 0.976098925833333

00:28:01.340 --> 00:28:04.175 when we sit and talk and take the time,

NOTE Confidence: 0.976098925833333

00:28:04.180 --> 00:28:05.902 they understand that it is their

NOTE Confidence: 0.976098925833333

00:28:05.902 --> 00:28:07.759 contribution to not only their health,

NOTE Confidence: 0.976098925833333

00:28:07.760 --> 00:28:09.769 but the community of sickle cell patients.

NOTE Confidence: 0.976098925833333

00:28:09.770 --> 00:28:11.653 And that's the beauty of having providers

NOTE Confidence: 0.976098925833333

00:28:11.653 --> 00:28:13.700 that have known you through the lifespan.

NOTE Confidence: 0.976098925833333

00:28:13.700 --> 00:28:14.880 You have a relationship.

NOTE Confidence: 0.976098925833333

00:28:14.880 --> 00:28:17.010 They know that I care for them.

NOTE Confidence: 0.976098925833333

00:28:17.010 --> 00:28:18.054 They can trust me.

NOTE Confidence: 0.976098925833333

00:28:18.054 --> 00:28:20.409 And so when I offer them this option,

00:28:23.270 --> 00:28:24.745 then there's a little bit

NOTE Confidence: 0.976098925833333

00:28:24.745 --> 00:28:25.925 more willingness to enroll.

NOTE Confidence: 0.96922971

00:28:26.960 --> 00:28:29.006 Dr Cece Calhoun is an assistant

NOTE Confidence: 0.96922971

00:28:29.006 --> 00:28:31.120 professor of medicine in hematology

NOTE Confidence: 0.96922971

00:28:31.120 --> 00:28:32.908 and assistant professor of

NOTE Confidence: 0.96922971

00:28:32.908 --> 00:28:34.249 Pediatrics in hematology,

NOTE Confidence: 0.96922971

00:28:34.250 --> 00:28:37.085 oncology at the Yale School of Medicine.

NOTE Confidence: 0.96922971

00:28:37.090 --> 00:28:38.390 If you have questions,

NOTE Confidence: 0.96922971

00:28:38.390 --> 00:28:39.690 the address is canceranswers@yale.edu

NOTE Confidence: 0.96922971

00:28:39.690 --> 00:28:42.490 and past editions of

NOTE Confidence: 0.96922971

00:28:42.490 --> 00:28:45.403 the program are available in audio and

NOTE Confidence: 0.96922971

00:28:45.403 --> 00:28:48.210 written form at yalecancercenter.org.

NOTE Confidence: 0.96922971

00:28:48.210 --> 00:28:50.234 We hope you'll join us next week to

NOTE Confidence: 0.96922971

00:28:50.234 --> 00:28:52.187 learn more about the fight against

NOTE Confidence: 0.96922971

00:28:52.187 --> 00:28:53.922 cancer here on Connecticut Public

NOTE Confidence: 0.96922971

00:28:53.922 --> 00:28:55.645 radio funding for Yale Cancer

NOTE Confidence: 0.96922971

00:28:55.645 --> 00:28:57.295 Answers is provided by Smilow

NOTE Confidence: 0.96922971

00:28:57.295 --> 00:28:59.998 Cancer Hospital and Astra Zeneca.