

0:00:00 -> 0:00:03.654 Funding for Yale Cancer Answers is provided  
0:00:03.654 -> 0:00:07.579 by Smilow Cancer Hospital and AstraZeneca.  
0:00:07.58 -> 0:00:09.81 Welcome to Yale Cancer Answers with  
0:00:09.81 -> 0:00:12.497 your host doctor Anees Chagpar.  
0:00:12.497 -> 0:00:14.382 Yale Cancer Answers features the latest  
0:00:14.382 -> 0:00:16.699 information on cancer care by welcoming  
0:00:16.699 -> 0:00:19.303 oncologists and specialists who are on the  
0:00:19.303 -> 0:00:21.449 forefront of the battle to fight cancer.  
0:00:21.45 -> 0:00:24.162 This week it's a conversation about the care  
0:00:24.162 -> 0:00:26.595 of adolescents and young adults with sickle  
0:00:26.595 -> 0:00:28.81 cell disease with Doctor Cece Calhoun.  
0:00:28.81 -> 0:00:31.645 Dr Calhoun is an assistant professor of  
0:00:31.645 -> 0:00:33.785 medicine and hematology and assistant  
0:00:33.785 -> 0:00:35.935 professor of Pediatrics in hematology  
0:00:35.935 -> 0:00:38.837 oncology at the Yale School of Medicine,  
0:00:38.84 -> 0:00:41.654 where Doctor Chagpar is a  
0:00:41.654 -> 0:00:43.78 professor of surgical oncology.  
0:00:43.79 -> 0:00:45.652 Cece, maybe we could start off by  
0:00:45.652 -> 0:00:47.649 you telling us a little bit about  
0:00:47.649 -> 0:00:49.92 yourself and what you do.  
0:00:49.93 -> 0:00:52.426 I like to call myself a lifespan  
0:00:52.43 -> 0:00:54.735 hematologist, and both my clinical  
0:00:54.735 -> 0:00:57.04 and research interests center around  
0:00:57.107 -> 0:00:59.578 the care of young adults with sickle  
0:00:59.578 -> 0:01:01.709 cell disease as they transition  
0:01:01.709 -> 0:01:04.074 from pediatric to adult care.  
0:01:04.08 -> 0:01:05.454 We know it's a really high  
0:01:05.454 -> 0:01:06.37 risk time for them.  
0:01:06.37 -> 0:01:08.35 And so all the work that I do both in  
0:01:08.411 -> 0:01:10.441 the clinic and in the research setting  
0:01:10.441 -> 0:01:12.44 is about making that process better.

0:01:12.92 -> 0:01:15.206 Is sickle cell disease a cancer?  
0:01:15.21 -> 0:01:16.895 Tell us more about what  
0:01:16.895 -> 0:01:18.243 exactly sickle cell disease is  
0:01:18.25 -> 0:01:21.274 and why it's being seen  
0:01:21.274 -> 0:01:23.16 by an oncologist?  
0:01:23.17 -> 0:01:25.762 That's a great question, so actually sickle  
0:01:25.762 -> 0:01:28.489 cell disease is an inherited condition  
0:01:28.489 -> 0:01:31.939 of the red blood cells and so many  
0:01:31.939 -> 0:01:33.854 people are familiar with anemia  
0:01:33.854 -> 0:01:36.508 and conditions of that sort,  
0:01:36.51 -> 0:01:37.985 which affect red blood  
0:01:37.985 -> 0:01:38.87 cells and hemoglobin.  
0:01:38.87 -> 0:01:41.707 And that's what sickle cell disease is  
0:01:41.707 -> 0:01:43.729 a condition of, and it's genetic.  
0:01:43.73 -> 0:01:45.626 So patients are born with it,  
0:01:45.63 -> 0:01:47.798 and what it manifests as is a normal  
0:01:47.798 -> 0:01:49.698 red blood cells are kind of squishy.  
0:01:49.7 -> 0:01:52.132 I like to think of them as Jelly  
0:01:52.132 -> 0:01:53.549 doughnuts because I like food.  
0:01:53.55 -> 0:01:55.3 But when you have sickle cell disease  
0:01:55.3 -> 0:01:56.7 because of a genetic mutation  
0:01:56.7 -> 0:01:58.5 your red blood cells  
0:01:58.5 -> 0:02:00.112 are not squishy and malleable,  
0:02:00.112 -> 0:02:02.127 they can be really stiff  
0:02:02.127 -> 0:02:04.298 and misshapen like a sickle.  
0:02:04.3 -> 0:02:06.47 They can be shaped like a sickle or a banana,  
0:02:06.47 -> 0:02:08.168 and so if you think of  
0:02:08.168 -> 0:02:09.78 your blood cells as pipes,  
0:02:09.78 -> 0:02:11.901 imagine if you had your Jelly doughnuts  
0:02:11.901 -> 0:02:14.02 kind of going through those pipes,  
0:02:14.02 -> 0:02:15.248 bouncing off the walls,

0:02:15.248 -> 0:02:17.49 taking oxygen to where it needs to go,  
0:02:17.49 -> 0:02:19.29 and you replace those cells  
0:02:19.29 -> 0:02:20.37 with sticky stuff,  
0:02:20.37 -> 0:02:22.356 fragile misshapen red blood cells like  
0:02:22.356 -> 0:02:24.469 sickle cells that are scratching up  
0:02:24.469 -> 0:02:26.665 the red blood vessels sticking together,  
0:02:26.67 -> 0:02:28.286 causing blockages, impeding flow,  
0:02:28.286 -> 0:02:30.71 and then you can imagine all  
0:02:30.786 -> 0:02:32.578 the complications that patients  
0:02:32.578 -> 0:02:34.37 with sickle cell face.  
0:02:34.37 -> 0:02:38.821 Most saliently or what patients have  
0:02:38.821 -> 0:02:41.35 to really deal with is a lot of pain.  
0:02:41.35 -> 0:02:42.62 That's the thing that brings  
0:02:42.62 -> 0:02:43.636 them to the hospital.  
0:02:43.64 -> 0:02:46.35 And acute meaning an unplanned basis,  
0:02:46.35 -> 0:02:48.051 but any part of our body where  
0:02:48.051 -> 0:02:49.788 there are blood vessels,  
0:02:49.79 -> 0:02:50.456 those misshapen  
0:02:50.456 -> 0:02:52.787 cells can get clogged up in those  
0:02:52.787 -> 0:02:55.266 blood vessels and cause problems.  
0:02:55.27 -> 0:02:56.622 It's important for patients  
0:02:56.622 -> 0:02:58.65 with sickle cell disease to have  
0:02:58.712 -> 0:03:00.652 regular care by an oncologist  
0:03:00.652 -> 0:03:02.204 who also understands hematology,  
0:03:02.21 -> 0:03:04.514 the blood, to make sure that all their  
0:03:04.514 -> 0:03:06.45 organs are in tip top condition  
0:03:06.45 -> 0:03:08.394 and that we treat anything before  
0:03:08.459 -> 0:03:09.539 there's a problem.  
0:03:09.73 -> 0:03:12.466 Now, I would think that if  
0:03:12.466 -> 0:03:14.88 you're a pediatric patient and  
0:03:14.88 -> 0:03:17.39 this is an inherited condition,

0:03:17.39 -> 0:03:19.638 you might have a sense of whether or  
0:03:19.638 -> 0:03:21.8 not you have sickle cell disease  
0:03:21.87 -> 0:03:24.228 based on whether your parents did.  
0:03:24.23 -> 0:03:26.988 But somebody had to start with the  
0:03:26.988 -> 0:03:29.049 genetic mutation to begin with.  
0:03:29.05 -> 0:03:30.874 So how many of your patients  
0:03:30.874 -> 0:03:32.773 actually know that they have sickle  
0:03:32.773 -> 0:03:34.633 cell disease from the time that  
0:03:34.633 -> 0:03:36.72 they were born  
0:03:36.72 -> 0:03:39.942 and how many of them present to you acutely?  
0:03:41.67 -> 0:03:43.82 In the United  
0:03:43.83 -> 0:03:46.766 States we have the benefit of the newborn  
0:03:46.766 -> 0:03:49.587 screen that all babies born in hospitals,  
0:03:49.59 -> 0:03:50.965 when they  
0:03:50.965 -> 0:03:52.934 get their heel poked and get that  
0:03:52.934 -> 0:03:54.548 little spot of blood that can test  
0:03:54.55 -> 0:03:56.476 for a variety of genetic conditions  
0:03:56.476 -> 0:03:58.165 and sickle cell disease is  
0:03:58.165 -> 0:03:59.557 included in those conditions.  
0:03:59.56 -> 0:04:02.71 So if a child has an abnormal newborn screen,  
0:04:02.71 -> 0:04:04.758 oftentimes the pediatrician will  
0:04:04.758 -> 0:04:07.675 refer them to a hematologist for  
0:04:07.675 -> 0:04:09.45 further evaluation and work up.  
0:04:09.45 -> 0:04:11.628 And sometimes, even if it's abnormal  
0:04:11.628 -> 0:04:14.41 to show sickle cell trait,  
0:04:14.41 -> 0:04:16.45 which means that you don't have the disease,  
0:04:16.45 -> 0:04:18.028 but you can be a carrier,  
0:04:18.03 -> 0:04:19.85 and if your partner has the disease,  
0:04:19.85 -> 0:04:21.369 you can have a child with sickle  
0:04:21.369 -> 0:04:21.803 cell disease.  
0:04:21.81 -> 0:04:23.706 We can figure that out from

0:04:23.706 -> 0:04:24.654 the newborn screen.  
0:04:24.66 -> 0:04:27.148 So these days we know pretty early on  
0:04:27.148 -> 0:04:29.447 which is critical to the survival  
0:04:29.447 -> 0:04:32.323 of our young children or infants and  
0:04:32.323 -> 0:04:34.366 toddlers and in other countries  
0:04:34.366 -> 0:04:37.61 the newborn screen isn't quite as universal,  
0:04:37.61 -> 0:04:39.476 and so sometimes children could present  
0:04:39.476 -> 0:04:41.549 with swelling of the hands and feet.  
0:04:41.55 -> 0:04:43.57 That's something called dactylitis,  
0:04:43.57 -> 0:04:46.095 which is pretty rare these  
0:04:46.095 -> 0:04:48.268 days as a presenting sign.  
0:04:48.27 -> 0:04:50.846 And then there's some patients with more  
0:04:50.846 -> 0:04:53.25 milder forms of sickle cell disease  
0:04:53.25 -> 0:04:55.704 that don't know until they're older  
0:04:55.71 -> 0:04:56.786 children or young adults,  
0:04:56.786 -> 0:04:59.333 but most of the time we get them in  
0:04:59.333 -> 0:05:01.079 our catchment when they are young  
0:05:01.079 -> 0:05:02.86 because of their newborn screen and  
0:05:02.86 -> 0:05:04.678 can really wrap our arms around them  
0:05:04.678 -> 0:05:06.036 and give them the care they need.  
0:05:06.29 -> 0:05:08.621 Let's suppose you're a newborn baby and  
0:05:08.621 -> 0:05:11.259 you had your heel poked and they tell  
0:05:11.259 -> 0:05:13.73 you that you have sickle cell disease.  
0:05:13.73 -> 0:05:15.776 Well, presumably they don't tell you  
0:05:15.776 -> 0:05:18.218 they tell your parents and you get  
0:05:18.218 -> 0:05:19.913 referred to a pediatric oncologist.  
0:05:19.92 -> 0:05:22.069 If that means that your red blood  
0:05:22.069 -> 0:05:24.601 cells are now more  
0:05:24.601 -> 0:05:26.526 like bananas than squishy Jelly  
0:05:26.53 -> 0:05:29.204 Donuts, what can you do about that?  
0:05:29.21 -> 0:05:30.8 I mean, is it reversible?

0:05:31.08 -> 0:05:33.64 At this time the only cure for sickle  
0:05:33.64 -> 0:05:35.628 cell disease or way to reverse  
0:05:35.628 -> 0:05:37.548 those cells is by replacing your  
0:05:37.616 -> 0:05:39.726 bone marrow with another persons,  
0:05:39.73 -> 0:05:41.806 but that's pretty rare.  
0:05:41.81 -> 0:05:43.594 Later in the show, you get to talk  
0:05:43.594 -> 0:05:45.404 a little bit more about therapies  
0:05:45.404 -> 0:05:47.366 coming down the pipeline for patients,  
0:05:47.37 -> 0:05:49.326 but right now that's the only  
0:05:49.326 -> 0:05:51.09 way to reverse.  
0:05:51.09 -> 0:05:53.113 However, if you are a little baby  
0:05:53.113 -> 0:05:54.98 and your parents find out that  
0:05:54.98 -> 0:05:56.535 you have sickle cell disease  
0:05:56.54 -> 0:05:58.67 the benefit of coming and talking  
0:05:58.67 -> 0:06:00.473 to a pediatric oncologist and  
0:06:00.473 -> 0:06:02.068 hematologist who knows about this  
0:06:02.068 -> 0:06:04.55 is that you now have a team member,  
0:06:04.55 -> 0:06:05.91 somebody on your team that  
0:06:05.91 -> 0:06:06.998 can help your baby,  
0:06:07 -> 0:06:08.41 or you if you're the baby,  
0:06:08.41 -> 0:06:09.69 stay healthy and safe.  
0:06:09.69 -> 0:06:12.538 And what that looks like as a  
0:06:12.538 -> 0:06:15.112 toddler is getting them started on  
0:06:15.112 -> 0:06:16.791 penicillin prophylactically or in  
0:06:16.791 -> 0:06:18.666 advance before there's any problems  
0:06:18.67 -> 0:06:21.838 because we found that as  
0:06:21.838 -> 0:06:25.137 recently as the late 70s,  
0:06:25.14 -> 0:06:26.85 there was kind of a peak  
0:06:26.85 -> 0:06:29.07 in infancy and toddlerhood of death,  
0:06:29.07 -> 0:06:31.015 because patients with sickle cell  
0:06:31.015 -> 0:06:32.96 were getting really bad infections,

0:06:32.96 -> 0:06:34.856 but we found that if we vaccinate them  
0:06:34.856 -> 0:06:36.849 and give them prophylactic penicillin,  
0:06:36.85 -> 0:06:38.6 they live well into adulthood.  
0:06:38.6 -> 0:06:39.407 The challenge becomes,  
0:06:39.407 -> 0:06:41.29 how do we help them when they  
0:06:41.346 -> 0:06:42.586 go from infant to adults?  
0:06:42.59 -> 0:06:43.994 And that's what I work on in my work.  
0:06:44.37 -> 0:06:46.863 So just to back up a little bit when  
0:06:46.863 -> 0:06:49.148 you say prophylactic penicillin,  
0:06:49.15 -> 0:06:51.124 do you mean like every day for  
0:06:51.124 -> 0:06:52.938 the rest of their life?  
0:06:53.39 -> 0:06:55.814 So definitely every day for the  
0:06:55.814 -> 0:06:58.389 first five years of their life.  
0:06:58.39 -> 0:07:00.846 But what it does is it  
0:07:00.846 -> 0:07:02.9 protects them against really bad  
0:07:02.9 -> 0:07:05.185 infections like pneumococcus you know  
0:07:05.185 -> 0:07:07.48 patients with sickle cell disease,  
0:07:07.48 -> 0:07:09.285 their spleen doesn't really work  
0:07:09.285 -> 0:07:11.485 as well as somebody without sickle  
0:07:11.485 -> 0:07:13.802 cell and because of that they are  
0:07:13.802 -> 0:07:15.645 susceptible to certain types of  
0:07:15.645 -> 0:07:17.137 infections and that penicillin  
0:07:17.137 -> 0:07:19.368 every day just like a vitamin helps  
0:07:19.368 -> 0:07:21.03 them to stay healthy and safe.  
0:07:21.72 -> 0:07:24.275 So why is there this transition then  
0:07:24.275 -> 0:07:26.52 from childhood to young adulthood?  
0:07:26.52 -> 0:07:28.506 What's the difference in terms of  
0:07:28.51 -> 0:07:30.298 the disease and how it's managed  
0:07:30.298 -> 0:07:31.999 that requires a specialist like you?  
0:07:33.08 -> 0:07:36.104 Well, I think it's a variety of things.  
0:07:36.11 -> 0:07:37.73 It's not just the disease,

0:07:37.73 -> 0:07:39.641 but it's becoming a young person  
0:07:39.641 -> 0:07:41.276 and learning how to navigate the  
0:07:41.276 -> 0:07:43.047 health care system on your own  
0:07:43.05 -> 0:07:44.74 and earlier we talked  
0:07:44.74 -> 0:07:46.43 about newborns and  
0:07:46.43 -> 0:07:48.482 if you were a newborn and found out  
0:07:48.49 -> 0:07:51.026 you had sickle cell disease that your parents  
0:07:51.026 -> 0:07:53.25 would help you take you to the doctor.  
0:07:53.25 -> 0:07:54.39 Manage your care,  
0:07:54.39 -> 0:07:56.29 give you that prophylactic penicillin.  
0:07:56.29 -> 0:07:57.784 But the beautiful part about being  
0:07:57.784 -> 0:07:59.708 a young adult is you can start to  
0:07:59.708 -> 0:08:01.52 assume some of that care for yourself,  
0:08:01.52 -> 0:08:02.561 so it's pretty  
0:08:02.561 -> 0:08:04.99 multi Factorial is a word I always  
0:08:05.06 -> 0:08:07.553 like to use and I like to  
0:08:07.553 -> 0:08:10.041 think that I was a pretty smart young  
0:08:10.041 -> 0:08:12.052 adult like I made some good decisions.  
0:08:12.052 -> 0:08:13.144 I'm a doctor now,  
0:08:13.15 -> 0:08:15.474 but I still did some foolish things  
0:08:15.474 -> 0:08:17.77 as a 16-17 eighteen year old and  
0:08:17.77 -> 0:08:19.4 that's without a chronic disease.  
0:08:19.4 -> 0:08:21.18 So in sickle cell disease,  
0:08:21.18 -> 0:08:23.441 what we can do as lifespan hematologists  
0:08:23.441 -> 0:08:25.533 and as health care providers is  
0:08:25.533 -> 0:08:27.651 really help our patients as their  
0:08:27.651 -> 0:08:29.234 disease complications may become  
0:08:29.234 -> 0:08:31.568 a little more severe as they're  
0:08:31.568 -> 0:08:33.04 learning to manage themselves.  
0:08:33.04 -> 0:08:35.2 As they're learning to navigate a  
0:08:35.2 -> 0:08:37.189 pretty complex health care system,

0:08:37.19 -> 0:08:39.494 and as they're just trying to be productive,  
0:08:39.5 -> 0:08:40.778 happy young adults.  
0:08:42.24 -> 0:08:44.648 What kinds of things do you  
0:08:44.648 -> 0:08:46.59 talk about with your patients?  
0:08:46.59 -> 0:08:47.95 It sounds like  
0:08:47.95 -> 0:08:49.31 after their five years old,  
0:08:49.31 -> 0:08:51.6 they're no longer on penicillin,  
0:08:51.6 -> 0:08:53.938 but there's still no way to reverse  
0:08:53.938 -> 0:08:55.666 the condition, so you're still  
0:08:55.666 -> 0:08:58.13 at risk of all of those sticky,  
0:08:58.13 -> 0:08:59.622 misshapen blood cells forming  
0:08:59.622 -> 0:09:01.487 clots all over your body,  
0:09:01.49 -> 0:09:03.162 which presumably can cause  
0:09:03.162 -> 0:09:04.834 all kinds of problems.  
0:09:04.84 -> 0:09:07.44 Is it just a matter  
0:09:07.44 -> 0:09:09.623 of telling your patients what to  
0:09:09.623 -> 0:09:12.26 watch for and when to seek help?  
0:09:12.26 -> 0:09:15.156 Or are there things that they can do  
0:09:15.156 -> 0:09:18.467 to reduce the risk of clots and  
0:09:18.467 -> 0:09:21.01 other problems that it can cause?  
0:09:21.73 -> 0:09:23.992 Absolutely, so I want to answer  
0:09:23.992 -> 0:09:26.01 your question in two parts.  
0:09:26.01 -> 0:09:28.284 First, what other parts of the  
0:09:28.284 -> 0:09:30.39 body does sickle cell affect?  
0:09:30.39 -> 0:09:33.18 How does that show up for  
0:09:33.18 -> 0:09:35.4 patients across their lives?  
0:09:35.4 -> 0:09:38.464 One of the things that our patients most  
0:09:38.464 -> 0:09:41.227 deal with is pain every single day.  
0:09:41.23 -> 0:09:43.036 So when those blood vessels get clogged  
0:09:43.036 -> 0:09:45.364 up by those sickle cells and those juicy  
0:09:45.364 -> 0:09:47.32 Jelly doughnut cells can't get through,

0:09:47.32 -> 0:09:48.488 that means oxygen isn't  
0:09:48.488 -> 0:09:50.24 going to where it needs to  
0:09:50.24 -> 0:09:51.2 in our bodies.  
0:09:51.2 -> 0:09:52.48 And because of that,  
0:09:52.48 -> 0:09:54.88 that can result in pretty bad bone pain  
0:09:54.88 -> 0:09:56.978 for patients with sickle cell disease,  
0:09:56.98 -> 0:09:59.348 and this is the thing that really affects  
0:09:59.348 -> 0:10:01.344 their quality of life as young students  
0:10:01.344 -> 0:10:03.448 trying to learn and keep up in school.  
0:10:03.45 -> 0:10:04.955 If you have to be admitted to  
0:10:04.955 -> 0:10:05.91 the hospital several times  
0:10:05.91 -> 0:10:08.448 a year you can imagine how  
0:10:08.448 -> 0:10:11.278 frustrating that can be as a scholar.  
0:10:11.28 -> 0:10:13.264 Other parts of the body that are affected  
0:10:13.264 -> 0:10:15.556 by sickle cell disease are numerous.  
0:10:15.56 -> 0:10:16.74 Though patients with sickle  
0:10:16.74 -> 0:10:18.215 cell disease can have something  
0:10:18.215 -> 0:10:19.499 called acute chest syndrome,  
0:10:19.5 -> 0:10:21.612 which is a really bad infection of the  
0:10:21.612 -> 0:10:23.499 lungs that can be very challenging,  
0:10:23.5 -> 0:10:27.124 they can even have strokes as young people,  
0:10:27.13 -> 0:10:28.908 which is one of the reasons that  
0:10:28.908 -> 0:10:30.865 compelled me as a Med student to  
0:10:30.865 -> 0:10:32.575 pursue hematology was seeing a sickle  
0:10:32.637 -> 0:10:34.485 cell patient eight years old who had  
0:10:34.485 -> 0:10:36.245 a stroke in Pediatrics.  
0:10:36.245 -> 0:10:38.419 And in order to kind of get a jump on these things,  
0:10:38.42 -> 0:10:40.196 we do several things,  
0:10:40.196 -> 0:10:41.528 we do screenings.  
0:10:41.53 -> 0:10:43.47 Something called a transcranial Doppler,  
0:10:43.47 -> 0:10:45.09 which is basically like an ultrasound

0:10:45.09 -> 0:10:47.382 of your head where you can look at the  
0:10:47.382 -> 0:10:48.83 blood vessels and make sure you're  
0:10:48.83 -> 0:10:50.51 not at risk for having a stroke.  
0:10:50.51 -> 0:10:53.905 We always make sure that our patients  
0:10:53.905 -> 0:10:56.11 have their eyes checked because  
0:10:56.11 -> 0:10:57.83 sometimes in sickle cell disease  
0:10:57.885 -> 0:11:00.148 you can have vision changes and a  
0:11:00.148 -> 0:11:02.118 regular follow up with a hematologist  
0:11:02.118 -> 0:11:04.81 can help you notice any changes  
0:11:04.81 -> 0:11:06.726 before they cause problems.  
0:11:06.73 -> 0:11:08.543 One of the biggest things and one  
0:11:08.543 -> 0:11:10.542 of the things we know works and  
0:11:10.542 -> 0:11:11.415 helps prolong life  
0:11:11.42 -> 0:11:13.828 in sickle cell patients is a use of  
0:11:13.828 -> 0:11:15.759 a medication called Hydroxyurea.  
0:11:15.76 -> 0:11:18.288 Now, some of your listeners may be familiar,  
0:11:18.29 -> 0:11:21.391 because sometimes this can be used in  
0:11:21.391 -> 0:11:24.016 patients who have certain cancer diagnosis,  
0:11:24.016 -> 0:11:26.176 but in sickle cell disease,  
0:11:26.18 -> 0:11:28.45 the dose that we use is much lower and the  
0:11:28.51 -> 0:11:30.562 way that we use it as a bit different.  
0:11:30.57 -> 0:11:32.922 And we know that it kind of helps  
0:11:32.922 -> 0:11:35.312 you have more juicy fat  
0:11:35.312 -> 0:11:37.636 cells then bananas and so your body  
0:11:37.636 -> 0:11:39.846 overall does better in the long term.  
0:11:41.23 -> 0:11:43.526 So just to follow up on a few  
0:11:43.526 -> 0:11:45.158 things that you just said.  
0:11:45.16 -> 0:11:47.53 First off taking that last  
0:11:47.53 -> 0:11:49.9 comment about Hydroxyurea making  
0:11:49.9 -> 0:11:52.036 You have more fat and juicy like  
0:11:52.036 -> 0:11:54.616 blood cells rather than sickling bananas,

0:11:54.62 -> 0:11:57.154 is it true that if you  
0:11:57.154 -> 0:11:59.02 have sickle cell disease,  
0:11:59.02 -> 0:12:01.106 not all of your blood cells are  
0:12:01.106 -> 0:12:03.194 bananas and it is possible to  
0:12:03.194 -> 0:12:05.45 increase the number of Jelly doughnut  
0:12:05.45 -> 0:12:07.766 blood cells that you have instead  
0:12:07.766 -> 0:12:09.641 of bananas?  
0:12:10.66 -> 0:12:13.985 Absolutely, and that is up until  
0:12:13.985 -> 0:12:16.095 recently, the only FDA  
0:12:16.095 -> 0:12:18.104 approved medication that we have had  
0:12:18.104 -> 0:12:19.958 for our patients is Hydroxyurea  
0:12:19.96 -> 0:12:22.84 to increase the amount of non sickle cells,  
0:12:22.84 -> 0:12:25.492 Jelly doughnut cells and ensure that  
0:12:25.492 -> 0:12:27.663 you're pain complications are lower  
0:12:27.663 -> 0:12:30.029 and that your organs can really get  
0:12:30.029 -> 0:12:32.07 the oxygen they need to thrive.  
0:12:32.6 -> 0:12:34.712 So an obvious question is why  
0:12:34.712 -> 0:12:36.766 not use more and make  
0:12:36.766 -> 0:12:39.059 all of your blood cells Jelly Donuts?  
0:12:39.06 -> 0:12:40.568 But hold that thought.  
0:12:40.568 -> 0:12:43.681 Because first we need to take a short  
0:12:43.681 -> 0:12:46.211 break for medical minute. Stay tuned  
0:12:46.211 -> 0:12:48.173 to learn more about adolescents and  
0:12:48.173 -> 0:12:50.165 young adults with sickle cell disease  
0:12:50.165 -> 0:12:52.3 with my guest doctor CeCe Calhoun.  
0:12:52.79 -> 0:12:54.92 Funding for Yale Cancer Answers  
0:12:54.92 -> 0:12:57.05 comes from Smilow Cancer Hospital.  
0:12:57.05 -> 0:12:59.558 Fifteen care centers offer access to  
0:12:59.558 -> 0:13:01.23 oncologists committed to providing  
0:13:01.293 -> 0:13:03.645 patients with cancer and blood diseases.  
0:13:03.65 -> 0:13:05.51 Individualized innovative care.

0:13:05.51 -> 0:13:08.922 Find us. Milo Care Center near  
0:13:08.922 -> 0:13:10.46 you at [yalecancercenter.org](http://yalecancercenter.org).  
0:13:12.55 -> 0:13:15.035 There are over 16.9 million  
0:13:15.035 -> 0:13:17.981 cancer survivors in the US and  
0:13:17.981 -> 0:13:19.898 over 240,000 here in Connecticut.  
0:13:19.898 -> 0:13:21.446 Completing treatment for cancer  
0:13:21.446 -> 0:13:23.709 is a very exciting milestone,  
0:13:23.71 -> 0:13:25.66 but cancer and its treatment can  
0:13:25.66 -> 0:13:27.73 be a life changing experience.  
0:13:27.73 -> 0:13:30.124 The return to normal activities in  
0:13:30.124 -> 0:13:32.139 relationships may be difficult and  
0:13:32.139 -> 0:13:33.919 cancer survivors may face other  
0:13:33.919 -> 0:13:36.02 long term side effects of cancer,  
0:13:36.02 -> 0:13:37.745 including heart problems,  
0:13:37.745 -> 0:13:38.32 osteoporosis,  
0:13:38.32 -> 0:13:41.195 fertility issues and an increased  
0:13:41.195 -> 0:13:43.18 risk of second cancers.  
0:13:43.18 -> 0:13:45.785 Resources for cancer survivors are  
0:13:45.785 -> 0:13:47.869 available at federally designated  
0:13:47.869 -> 0:13:49.119 Comprehensive cancer centers  
0:13:49.119 -> 0:13:51.099 such as the Yale Cancer Center  
0:13:51.099 -> 0:13:53.458 and at Smilow Cancer Hospital to  
0:13:53.458 -> 0:13:55.493 keep cancer survivors well and  
0:13:55.493 -> 0:13:57.256 focused on healthy living.  
0:13:57.256 -> 0:13:59.516 The Smilow Cancer Hospital Survivorship  
0:13:59.516 -> 0:14:01.676 Clinic focuses on providing guidance  
0:14:01.676 -> 0:14:04.052 and direction to empower survivors to  
0:14:04.052 -> 0:14:06.438 take steps to maximize their health,  
0:14:06.44 -> 0:14:08.74 quality of life and longevity.  
0:14:08.74 -> 0:14:11.172 More information is available  
0:14:11.172 -> 0:14:12.628 at [yalecancercenter.org](http://yalecancercenter.org). You're

0:14:12.628 -> 0:14:13.9 listening to Connecticut  
0:14:13.9 -> 0:14:14.83 Public Radio.  
0:14:15.32 -> 0:14:17.48 Welcome back to Yale Cancer Answers.  
0:14:17.48 -> 0:14:19.914 This is Doctor Anees Chagpar and I'm  
0:14:19.914 -> 0:14:22.56 joined tonight by my guest Dr. Cece Calhoun.  
0:14:22.56 -> 0:14:25.024 We're talking about the care of adolescents  
0:14:25.024 -> 0:14:27.175 and young adults with sickle cell  
0:14:27.175 -> 0:14:29.245 disease and bright before the break  
0:14:29.25 -> 0:14:32.533 CeCe was mentioning that while sickle cell  
0:14:32.533 -> 0:14:35.08 disease is completely  
0:14:35.08 -> 0:14:37.7 irreversible,  
0:14:37.7 -> 0:14:40.316 that actually using a drug called  
0:14:40.316 -> 0:14:43.075 Hydroxyurea can help your body to  
0:14:43.075 -> 0:14:45.873 create more of these quote juicy  
0:14:45.873 -> 0:14:48.904 cells which are normal red blood cells  
0:14:48.904 -> 0:14:52.034 and less of these quote banana like  
0:14:52.034 -> 0:14:54.35 cells which are the sickle cells.  
0:14:54.35 -> 0:14:56.948 So my question to you was.  
0:14:56.95 -> 0:15:01.062 before we had the break, is why  
0:15:01.062 -> 0:15:03.834 not just give more Hydroxyurea?  
0:15:03.84 -> 0:15:06.522 I mean if it helps your body to produce  
0:15:06.522 -> 0:15:09.27 more normal cells and less sickle cells,  
0:15:09.27 -> 0:15:10.908 wouldn't that be a way to kind  
0:15:10.908 -> 0:15:12.299 of reverse it?  
0:15:13.77 -> 0:15:16.045 I would love if it could be  
0:15:16.045 -> 0:15:17.93 totally reversed by Hydroxyurea  
0:15:17.93 -> 0:15:19.898 but we know that when our  
0:15:19.898 -> 0:15:21.694 patients are awesome, take their  
0:15:21.694 -> 0:15:23.704 medications every day as prescribed,  
0:15:23.71 -> 0:15:26.164 there's still an upper limit to  
0:15:26.164 -> 0:15:29.04 how many of those juicy fat

0:15:29.04 -> 0:15:31.44 cells they can replace.  
0:15:31.44 -> 0:15:33.904 They can produce to replace the banana cells,  
0:15:33.91 -> 0:15:36.574 so there's a threshold of how  
0:15:36.574 -> 0:15:38.7 effective the drug can be,  
0:15:38.7 -> 0:15:39.948 but it can really,  
0:15:39.948 -> 0:15:41.508 really help enough to help  
0:15:41.508 -> 0:15:43.14 your organs stay healthy.  
0:15:43.88 -> 0:15:46.352 So this Hydroxyurea is something  
0:15:46.352 -> 0:15:48.315 that you're taking every day?  
0:15:48.315 -> 0:15:49.669 For your whole life?  
0:15:49.669 -> 0:15:52.941 And the other thing  
0:15:52.941 -> 0:15:55.652 that you mentioned before the break  
0:15:55.652 -> 0:15:59.178 and I wanted to pick up on as well  
0:15:59.18 -> 0:16:02.18 was this concept of pain and the fact  
0:16:02.18 -> 0:16:05.171 that many of these patients they present  
0:16:05.171 -> 0:16:08.449 with pain and they have pain every day  
0:16:08.45 -> 0:16:11.922 which impairs their ability to  
0:16:11.922 -> 0:16:14.808 concentrate at school or maybe place  
0:16:14.81 -> 0:16:18.626 boards so what do you do about that?  
0:16:18.63 -> 0:16:20.555 I mean, are these patients  
0:16:20.555 -> 0:16:22.095 treated with daily painkillers?  
0:16:22.1 -> 0:16:24.333 Or do you tell them to simply  
0:16:24.333 -> 0:16:26.742 wait until they have pain and  
0:16:26.742 -> 0:16:28.57 then prescribe pain medication?  
0:16:28.57 -> 0:16:31.009 I mean how do they get through their day  
0:16:31.009 -> 0:16:33.677 to day life if they're in pain everyday?  
0:16:34.51 -> 0:16:37.863 Yeah, so sickle cell patients are warriors  
0:16:37.863 -> 0:16:41.57 and you'll often see that described because  
0:16:41.57 -> 0:16:44.84 despite having pain of variable severity,  
0:16:44.84 -> 0:16:47.688 they managed to live life and be productive.  
0:16:47.69 -> 0:16:50.498 That's one of the most awesome things

0:16:50.498 -> 0:16:52.81 about working with sickle cell patients.  
0:16:52.81 -> 0:16:55.06 So in terms of pain prevention,  
0:16:55.06 -> 0:16:56.28 what can we do?  
0:16:56.28 -> 0:16:58.506 Number one Hydroxyurea and get more juicy  
0:16:58.506 -> 0:17:00.788 cells around so you have less pain.  
0:17:00.79 -> 0:17:03.13 And recently there are a couple  
0:17:03.13 -> 0:17:05.23 of medications on the market  
0:17:05.23 -> 0:17:07.56 that help with pain prevention.  
0:17:07.56 -> 0:17:10.518 Also just keeping yourself well hydrated.  
0:17:10.52 -> 0:17:12.308 My patients are so wonderful in  
0:17:12.308 -> 0:17:14.289 that they often know their bodies.  
0:17:14.29 -> 0:17:15.214 They know their triggers.  
0:17:15.91 -> 0:17:18.276 And what situations make their pain worse.  
0:17:18.28 -> 0:17:19.468 And what kind of things can  
0:17:19.468 -> 0:17:20.26 make their pain better.  
0:17:20.26 -> 0:17:22.808 So really being attuned to those things  
0:17:22.81 -> 0:17:25.156 in terms of addressing pain acutely  
0:17:25.156 -> 0:17:28.008 when it happens and it's not planned,  
0:17:28.01 -> 0:17:31.916 we have a couple of things in our toolkit.  
0:17:31.92 -> 0:17:33.9 Yes, pain medication is something  
0:17:33.9 -> 0:17:36.53 that we give frequently for pain,  
0:17:36.53 -> 0:17:38.658 but we can also use red  
0:17:38.658 -> 0:17:40.858 blood cell transfusions if we need to.  
0:17:40.86 -> 0:17:43.116 If somebody is having pain often,  
0:17:43.12 -> 0:17:46.126 but many times we can't predict  
0:17:46.13 -> 0:17:47.35 when the pain will come,  
0:17:47.35 -> 0:17:49.246 or how severe it will be,  
0:17:49.25 -> 0:17:51 and so because of that our patients  
0:17:51 -> 0:17:53.16 have to get care in the ED sometimes  
0:17:53.16 -> 0:17:54.84 to get treatment for their pain.  
0:17:55.55 -> 0:17:57.06 You mentioned something

0:17:57.06 -> 0:17:59.29 that I found kind of intriguing.  
0:17:59.29 -> 0:18:01.474 You said that we have medications  
0:18:01.474 -> 0:18:03.74 for pain prevention, like what?  
0:18:04.27 -> 0:18:07.006 Hot off the press I know,  
0:18:07.01 -> 0:18:09.565 so recently there's been  
0:18:09.565 -> 0:18:11.609 an FDA approved medication,  
0:18:11.61 -> 0:18:13.78 Adakveo or crizanlizumab  
0:18:15.9 -> 0:18:18.716 but I try not to say  
0:18:18.716 -> 0:18:20.7 that because crizanlizumab,  
0:18:20.7 -> 0:18:23.724 but that can be used to prevent pain  
0:18:23.724 -> 0:18:26.659 as an infusion given once monthly.  
0:18:32.01 -> 0:18:33.87 And another medication that's recently been  
0:18:33.87 -> 0:18:36.449 approved is something called Oxbryta  
0:18:36.45 -> 0:18:38.9 and really, what that does is increase  
0:18:38.9 -> 0:18:40.779 patients with sickle cell disease,  
0:18:40.78 -> 0:18:41.512 their hemoglobin,  
0:18:41.512 -> 0:18:44.44 and so the thought is if their  
0:18:44.52 -> 0:18:46.75 hemoglobin is better they  
0:18:46.75 -> 0:18:49.025 may in turn have less pain,  
0:18:49.03 -> 0:18:51.61 but the primary medication that  
0:18:51.61 -> 0:18:54.75 is out there for pain  
0:18:54.75 -> 0:18:56.68 prevention is Adakveo.  
0:18:57.49 -> 0:18:59.225 That sounds like a  
0:18:59.225 -> 0:19:00.621 pretty good deal, right?  
0:19:00.621 -> 0:19:02.727 If instead of having pain everyday,  
0:19:02.73 -> 0:19:05.018 if you had an infusion once a month,  
0:19:05.02 -> 0:19:07.092 does that infusion kind of really get  
0:19:07.092 -> 0:19:09.458 rid of the chances of having pain?  
0:19:09.46 -> 0:19:10.54 Or not really?  
0:19:11.51 -> 0:19:14.59 I think that the medication is pretty  
0:19:14.59 -> 0:19:17.925 new and patients themselves are

0:19:17.925 -> 0:19:19.145 are individuals,  
0:19:19.15 -> 0:19:20.686 and so I've had some patients  
0:19:20.686 -> 0:19:21.97 who it's worked great for.  
0:19:21.97 -> 0:19:23.476 I've had some patients that we  
0:19:23.476 -> 0:19:25.229 just have to try other things.  
0:19:25.23 -> 0:19:27.28 I think the wonderful thing  
0:19:27.28 -> 0:19:28.92 about being a physician  
0:19:28.92 -> 0:19:30.132 scientist and sickle cell,  
0:19:30.132 -> 0:19:32.232 or even being a patient right now  
0:19:32.232 -> 0:19:33.786 who has sickle cell is that it is  
0:19:33.786 -> 0:19:35.75 such a fertile time for discovery.  
0:19:35.75 -> 0:19:37.568 In terms of sickle cell disease,  
0:19:37.57 -> 0:19:38.894 how to prevent complications  
0:19:38.894 -> 0:19:40.549 and how to cure it.  
0:19:40.55 -> 0:19:42.608 So you just have to work with  
0:19:42.608 -> 0:19:43.866 your hematologist to find  
0:19:43.866 -> 0:19:45.416 the right regimen for you.  
0:19:46.12 -> 0:19:48.15 So I want to pick up on  
0:19:48.15 -> 0:19:50.698 that discovery and some of the  
0:19:50.698 -> 0:19:52.526 new advances that are going on  
0:19:52.526 -> 0:19:54.17 in terms of sickle cell research.  
0:19:54.17 -> 0:19:56.922 But before that I had one other question  
0:19:56.922 -> 0:19:58.945 about the complications  
0:19:58.945 -> 0:20:01.465 you had mentioned before the break.  
0:20:01.47 -> 0:20:04.06 One of the impetuses for you to  
0:20:04.06 -> 0:20:05.606 become a pediatric climatologist  
0:20:05.606 -> 0:20:08.864 was an 8 year old who had a stroke,  
0:20:08.87 -> 0:20:12.31 which just I mean is heartbreaking to me.  
0:20:12.31 -> 0:20:14.97 But clearly if you think about these  
0:20:15.042 -> 0:20:17.038 sickle cells, it makes sense, right?  
0:20:17.038 -> 0:20:18.73 These sickle cells kind of glom

0:20:18.73 -> 0:20:20.122 together and they cut off blood  
0:20:20.122 -> 0:20:21.909 supply to a part of your brain  
0:20:21.909 -> 0:20:22.985 that's called the stroke.  
0:20:22.99 -> 0:20:25.258 Now when we think about  
0:20:25.258 -> 0:20:26.837 older patients who  
0:20:26.837 -> 0:20:29.308 may be at risk of stroke or who may  
0:20:29.308 -> 0:20:31.316 be at risk of heart attack or who  
0:20:31.316 -> 0:20:33.028 may be at risk of other clotting,  
0:20:33.03 -> 0:20:35.082 whether it's in their lungs or  
0:20:35.082 -> 0:20:37.18 in their legs or whatever,  
0:20:37.18 -> 0:20:39.6 we often use blood thinners,  
0:20:39.6 -> 0:20:41.64 so are sickle cell patients put  
0:20:41.64 -> 0:20:44.006 on blood thinners to  
0:20:44.006 -> 0:20:45.416 prevent these complications?  
0:20:45.42 -> 0:20:46.765 Since we know that they're  
0:20:46.765 -> 0:20:48.11 at risk of getting clots.  
0:20:48.33 -> 0:20:51.151 So the blockages that occur in sickle  
0:20:51.151 -> 0:20:54.031 cell disease are a little bit different  
0:20:54.031 -> 0:20:56.97 than your normal blood clot, which is  
0:20:56.97 -> 0:20:59.96 caused by a different series of events,  
0:20:59.96 -> 0:21:02.2 and so for patients with sickle cell disease,  
0:21:02.2 -> 0:21:03.574 though they are at an increased  
0:21:03.574 -> 0:21:04.9 risk to have those  
0:21:04.9 -> 0:21:07.196 traditionally, what we think of blood clots,  
0:21:07.2 -> 0:21:09.16 we don't put them on blood thinners  
0:21:09.16 -> 0:21:11.038 to try to prevent complications  
0:21:11.038 -> 0:21:12.986 with sickle cell disease.  
0:21:12.99 -> 0:21:14.803 We know those blockages can be stuck  
0:21:14.803 -> 0:21:16.73 like a clot, or they can be transient,  
0:21:16.73 -> 0:21:18.15 they come and go because of the  
0:21:18.15 -> 0:21:19.286 cells sticking together.

0:21:19.29 -> 0:21:20.949 It's not like the other proteins in  
0:21:20.949 -> 0:21:22.699 your body are swimming over there,  
0:21:22.7 -> 0:21:23.956 making a huge clot.  
0:21:23.956 -> 0:21:26.769 What we do in our young people  
0:21:26.769 -> 0:21:28.125 to maximize stroke prevention  
0:21:28.125 -> 0:21:30.15 is we do screenings like the  
0:21:30.15 -> 0:21:31.774 Transcranial Doppler I mentioned.  
0:21:31.774 -> 0:21:34.21 And if we notice any kind  
0:21:34.284 -> 0:21:35.8 of abnormality at all,  
0:21:35.8 -> 0:21:37.558 we have a couple of options.  
0:21:37.56 -> 0:21:40.682 One we can start them on chronic  
0:21:40.682 -> 0:21:43.11 transfusion to decrease the  
0:21:43.11 -> 0:21:45.835 amount of sickle cells circulating in their  
0:21:45.835 -> 0:21:48.208 blood and give them more normal cells.  
0:21:48.21 -> 0:21:50.457 Or if somebody has been  
0:21:50.457 -> 0:21:52.264 on transfusions,  
0:21:52.264 -> 0:21:54.204 their transcranial dopplers looks fine,  
0:21:54.21 -> 0:21:56.754 we can switch them to again Hydroxyurea  
0:21:56.754 -> 0:21:59.089 put more Jelly Donuts around,  
0:21:59.09 -> 0:22:00.802 have less sickle cells,  
0:22:00.802 -> 0:22:02.942 decrease the risk of complications,  
0:22:02.95 -> 0:22:04.81 and that's again why it's important  
0:22:04.81 -> 0:22:05.74 to connect with your  
0:22:05.74 -> 0:22:07.08 friendly hematologist so we  
0:22:07.08 -> 0:22:09.09 can help you on that journey.  
0:22:09.46 -> 0:22:11.212 Yeah, but presumably you would have  
0:22:11.212 -> 0:22:13.129 already been on the Hydroxyurea  
0:22:13.13 -> 0:22:16.16 so if that transcranial Doppler finds  
0:22:16.16 -> 0:22:19.84 that you're at increased risk  
0:22:19.84 -> 0:22:21.772 I guess the transfusion  
0:22:21.772 -> 0:22:23.086 is your only alternative,

0:22:23.086 -> 0:22:26.2 but the issue there is if you keep  
0:22:26.273 -> 0:22:28.985 getting transfusions on a regular basis,  
0:22:28.99 -> 0:22:31.552 doesn't that increase your risk of  
0:22:31.552 -> 0:22:33.26 transfusion reactions and potentially  
0:22:33.322 -> 0:22:34.934 ultimately developing antibodies such  
0:22:34.934 -> 0:22:37.746 that there are fewer and fewer blood  
0:22:37.746 -> 0:22:39.726 types that you can actually take?  
0:22:42.36 -> 0:22:43.5 Absolutely.  
0:22:43.5 -> 0:22:46.92 For patients who have chronic transfusions,  
0:22:46.92 -> 0:22:48.93 they're a variety of risks that  
0:22:48.93 -> 0:22:50.27 come along with that.  
0:22:50.27 -> 0:22:51.56 There's obviously a clear benefit  
0:22:51.56 -> 0:22:53.432 in that it keeps you safe  
0:22:53.432 -> 0:22:54.747 and protects you against stroke  
0:22:54.747 -> 0:22:56.05 and may decrease your pain.  
0:22:56.05 -> 0:22:57.498 But you're absolutely right,  
0:22:57.498 -> 0:22:58.584 our bodies recognize  
0:22:58.584 -> 0:23:00.15 things that aren't foreign,  
0:23:00.15 -> 0:23:03.3 and that's why we really work in tandem  
0:23:03.3 -> 0:23:05.125 and together with our transfusion  
0:23:05.125 -> 0:23:06.91 medicine colleagues to do extended  
0:23:06.91 -> 0:23:08.806 typing in patients with sickle cell  
0:23:08.806 -> 0:23:10.639 disease to prevent that risk of  
0:23:10.64 -> 0:23:12.145 developing antibodies.  
0:23:14.19 -> 0:23:16.045 Another big risk is something  
0:23:16.045 -> 0:23:17.158 called iron overload,  
0:23:17.16 -> 0:23:19.582 where excess iron from the blood deposits  
0:23:19.582 -> 0:23:22.01 in different organs like your liver,  
0:23:22.01 -> 0:23:23.59 your heart, or your eyes.  
0:23:23.59 -> 0:23:26.355 So we measure that regularly and again,  
0:23:26.36 -> 0:23:28.82 medicine is so cool because we're

0:23:28.82 -> 0:23:30.911 always ideally moving forward and  
0:23:30.911 -> 0:23:33.599 there's also a procedure  
0:23:33.599 -> 0:23:35.15 called Erythrocytosis  
0:23:35.15 -> 0:23:36.836 which I don't too much mind  
0:23:36.836 -> 0:23:37.96 saying five times fast,  
0:23:37.96 -> 0:23:40.074 but I like it, which can help  
0:23:40.074 -> 0:23:41.56 decrease that risk of iron overload.  
0:23:49.07 -> 0:23:50.953 Let's talk a little bit  
0:23:50.953 -> 0:23:52.93 about some of the exciting advances  
0:23:52.93 -> 0:23:55.132 in terms of sickle cell disease.  
0:23:55.14 -> 0:23:56.908 Tell us about what you think are the  
0:23:56.908 -> 0:23:58.52 most exciting things that are on the  
0:23:58.52 -> 0:24:00.195 forefront that you think are really going  
0:24:00.195 -> 0:24:01.945 to make a difference for your patients.  
0:24:03.07 -> 0:24:06.11 I think there are a lot of  
0:24:06.195 -> 0:24:09.527 medications in the works to address pain  
0:24:09.527 -> 0:24:12.598 and complications of sickle cell disease.  
0:24:12.6 -> 0:24:15.885 But one of the things I think that is  
0:24:15.885 -> 0:24:19.507 most exciting is the idea of a cure  
0:24:19.507 -> 0:24:22.318 through gene therapy,  
0:24:22.318 -> 0:24:23.766 and that's pretty awesome.  
0:24:23.77 -> 0:24:27.82 There's been some media, the  
0:24:29.98 -> 0:24:32.154 New York Times has published about it  
0:24:32.154 -> 0:24:34.158 and the Washington Post as  
0:24:34.158 -> 0:24:37.174 well about how we can use different  
0:24:37.174 -> 0:24:38.998 scientific technologies like CRISPR  
0:24:38.998 -> 0:24:41.152 technology or use different vectors  
0:24:41.152 -> 0:24:43.69 like viral vectors to take somebody's  
0:24:43.69 -> 0:24:46.162 stem cells and correct that defect  
0:24:46.162 -> 0:24:49.111 in their DNA that caused them to  
0:24:49.111 -> 0:24:51.535 be making sickle cells and then

0:24:51.535 -> 0:24:54.404 give it back to them in a safe way,  
0:24:54.41 -> 0:24:56.042 and then when those new and  
0:24:56.042 -> 0:24:57.55 improved cells from their bodies  
0:24:57.55 -> 0:24:58.681 replicate  
0:24:58.681 -> 0:25:00.566 they are no longer affected  
0:25:00.566 -> 0:25:02.249 by sickle cell disease.  
0:25:02.25 -> 0:25:04.546 They may still make some sickle cells,  
0:25:04.55 -> 0:25:06.482 but will effectively be cured or  
0:25:06.482 -> 0:25:08.654 be like somebody who just has the  
0:25:08.654 -> 0:25:10.34 trait and that's one of the things  
0:25:10.34 -> 0:25:11.77 I think that's most exciting.  
0:25:11.77 -> 0:25:13.18 The possibility of a cure  
0:25:13.35 -> 0:25:15.84 in our future.  
0:25:18.09 -> 0:25:21.078 And is that 10-15, 30-50 years from now?  
0:25:21.3 -> 0:25:23.586 No, the time is totally now,  
0:25:23.59 -> 0:25:25.458 so there are clinical,  
0:25:25.458 -> 0:25:27.793 active clinical trials going on  
0:25:27.8 -> 0:25:29.93 to better understand the safety  
0:25:29.93 -> 0:25:32.06 and efficacy of this process  
0:25:32.14 -> 0:25:34.429 for patients and so  
0:25:34.429 -> 0:25:36.48 that's happening now.  
0:25:36.48 -> 0:25:38.688 Wow, that's  
0:25:38.7 -> 0:25:41.486 super exciting. What else is going on?  
0:25:42.42 -> 0:25:45.164 So I think the other main things are  
0:25:45.164 -> 0:25:47.211 the development of oral medications  
0:25:47.211 -> 0:25:49.785 to improve pain and to decrease  
0:25:49.785 -> 0:25:51.939 complications from sickle cell disease.  
0:25:51.94 -> 0:25:53.011 That one medication,  
0:25:53.011 -> 0:25:56.02 Adakveo, the way that it works,  
0:25:56.02 -> 0:25:57.624 it's something called  
0:25:57.624 -> 0:25:58.827 a B selection inhibitor.

0:25:58.83 -> 0:26:00.775 And so they're more medications  
0:26:00.775 -> 0:26:03.309 coming around that look at that.  
0:26:03.31 -> 0:26:06.946 And there's some additional  
0:26:06.946 -> 0:26:09.698 oral medications coming that target  
0:26:09.698 -> 0:26:12.018 different mechanisms and other blood  
0:26:12.018 -> 0:26:14.11 problems like thalassemia and  
0:26:14.11 -> 0:26:16.658 they want to see if those medications  
0:26:16.66 -> 0:26:18.412 can work well in  
0:26:18.412 -> 0:26:20.09 patients with sickle cell disease.  
0:26:20.09 -> 0:26:22.241 So I think that fact that we are shining  
0:26:22.241 -> 0:26:24.531 a light on this community of people  
0:26:24.531 -> 0:26:27.258 with sickle cell disease and that we as  
0:26:27.258 -> 0:26:28.938 a scientific community have committed  
0:26:28.94 -> 0:26:31.46 to making their quality of life better,  
0:26:31.46 -> 0:26:33.78 that's the thing that's most exciting to me,  
0:26:33.78 -> 0:26:36.13 because oftentimes I think my  
0:26:36.13 -> 0:26:38.48 patients feel unseen and unheard,  
0:26:38.48 -> 0:26:42.52 and so it's great to see so many people,  
0:26:42.52 -> 0:26:44.05 brilliant people standing up for them  
0:26:44.05 -> 0:26:45.968 and helping to make their lives better.  
0:26:46.32 -> 0:26:46.994 That's awesome.  
0:26:46.994 -> 0:26:50.145 I guess the last question that I have is  
0:26:50.145 -> 0:26:52.437 really with regards to clinical trials.  
0:26:52.44 -> 0:26:55.555 I mean, it sounds like there's so  
0:26:55.555 -> 0:26:58.288 many great things on the horizon.  
0:26:58.29 -> 0:27:01.458 Do you find that young people  
0:27:01.458 -> 0:27:04.302 adolescents are interested in clinical  
0:27:04.302 -> 0:27:07.507 trials and willing to participate?  
0:27:07.51 -> 0:27:10.32 Are there barriers to participation?  
0:27:10.32 -> 0:27:11.946 How has that been going along?  
0:27:12.51 -> 0:27:14.58 Yeah, so anybody who has lived

0:27:14.58 -> 0:27:16.93 with sickle cell or chronic pain,  
0:27:16.93 -> 0:27:18.755 I think is enthusiastic about  
0:27:18.755 -> 0:27:21.229 finding a way to have a better  
0:27:21.229 -> 0:27:23.338 life and to come have a better  
0:27:23.338 -> 0:27:25.961 quality of life and to find a cure.  
0:27:25.961 -> 0:27:27.995 When it comes to clinical trials,  
0:27:28 -> 0:27:31.704 there's a careful balance  
0:27:31.704 -> 0:27:33.911 between understanding clinical  
0:27:33.911 -> 0:27:36.368 studies and not wanting to feel like  
0:27:36.368 -> 0:27:37.852 an experiment and understanding  
0:27:37.852 -> 0:27:39.994 how the medical system can wrap  
0:27:39.994 -> 0:27:41.788 around you to keep you safe.  
0:27:41.79 -> 0:27:43.81 As we understand more about  
0:27:43.81 -> 0:27:46.51 how to help you have a cure.  
0:27:46.51 -> 0:27:49.429 And so when I think about  
0:27:49.43 -> 0:27:50.45 my young people,  
0:27:50.45 -> 0:27:52.49 are they interested in clinical trials?  
0:27:52.49 -> 0:27:55.316 I think that they have a lot of excellent  
0:27:55.316 -> 0:27:57.294 questions about the benefits and  
0:27:57.294 -> 0:27:59.694 risks of participating in clinical trials.  
0:27:59.7 -> 0:28:01.34 But many of them ultimately,  
0:28:01.34 -> 0:28:04.175 when we sit and talk and take the time,  
0:28:04.18 -> 0:28:05.902 they understand that it is their  
0:28:05.902 -> 0:28:07.759 contribution to not only their health,  
0:28:07.76 -> 0:28:09.769 but the community of sickle cell patients.  
0:28:09.77 -> 0:28:11.653 And that's the beauty of having providers  
0:28:11.653 -> 0:28:13.7 that have known you through the lifespan.  
0:28:13.7 -> 0:28:14.88 You have a relationship.  
0:28:14.88 -> 0:28:17.01 They know that I care for them.  
0:28:17.01 -> 0:28:18.054 They can trust me.  
0:28:18.054 -> 0:28:20.409 And so when I offer them this option,

0:28:23.27 -> 0:28:24.745 then there's a little bit  
0:28:24.745 -> 0:28:25.925 more willingness to enroll.  
0:28:26.96 -> 0:28:29.006 Dr Cece Calhoun is an assistant  
0:28:29.006 -> 0:28:31.12 professor of medicine in hematology  
0:28:31.12 -> 0:28:32.908 and assistant professor of  
0:28:32.908 -> 0:28:34.249 Pediatrics in hematology,  
0:28:34.25 -> 0:28:37.085 oncology at the Yale School of Medicine.  
0:28:37.09 -> 0:28:38.39 If you have questions,  
0:28:38.39 -> 0:28:39.69 the address is canceranswers@yale.edu  
0:28:39.69 -> 0:28:42.49 and past editions of  
0:28:42.49 -> 0:28:45.403 the program are available in audio and  
0:28:45.403 -> 0:28:48.21 written form at yalecancercenter.org.  
0:28:48.21 -> 0:28:50.234 We hope you'll join us next week to  
0:28:50.234 -> 0:28:52.187 learn more about the fight against  
0:28:52.187 -> 0:28:53.922 cancer here on Connecticut Public  
0:28:53.922 -> 0:28:55.645 radio funding for Yale Cancer  
0:28:55.645 -> 0:28:57.295 Answers is provided by Smilow  
0:28:57.295 -> 0:28:59.998 Cancer Hospital and Astra Zeneca.