

## More That Matters: Sickle Cell Disease

With Erin Fulbright

Diane (00:00):

Do you know which disease occurs in one out of every 365 African American births? You're gonna find out today on Vax Matters.

Clay (00:16):

The disease we're talking about today is sickle cell disease, which disproportionately affects African Americans. Now, while you may have heard of the disease, we'll help you understand its seriousness and impact, as well as the progress being made to combat it. We're excited to welcome with us, Erin Fulbright. She serves as the executive director of the Sickle Cell Association of South Louisiana, and we are grateful to have, uh, have her here with her expertise and knowledge about this subject. How are you, Erin?

Erin (00:46):

Good. How are you guys?

Clay (00:48):

So let's start at the beginning for people who may not know or understand sickle cell, particularly for those who aren't Mediterranean or African American, what is the sickle cell disease?

Erin (00:58):

It's an inherited blood disorder, um, again, that affects mainly the African American community or those in the, the Mediterranean, Caribbean areas. Um, and it causes their blood, their red blood cells to sickle. Um, they lose their oxygen a lot faster than, um, normal. Um, and this can get really hard and sticky, and, and clog up the blood vessels, so it stops the oxygen from going to the rest of the body. So it can cause complications in other organs. It causes pain, joint pain, bone pain, and other things like that, so.

Diane (01:33):

So there is a actual sickle shape-

Erin (01:35):

Mm-hmm.

Diane (01:36):

... sickle shape?

Erin (01:37):

Yeah. It's kind of-

Diane (01:38):

Oh.

Erin (01:38):  
... cresces, yeah. Like a cresce-, a-

Diane (01:41):  
Y- yeah.

Erin (01:41):  
... sickle.

Diane (01:41):  
Sickle.

Erin (01:42):  
Yeah, like a moon if-

Diane (01:42):  
Yeah.

Erin (01:42):  
... you don't know what-

Diane (01:43):  
Uh-

Erin (01:43):  
... you know, the sickle, (laughs) um-

Diane (01:44):  
Right.

Erin (01:46):  
... instrument looks like or tool.

Diane (01:46):  
It was just an interesting name. I-

Erin (01:48):  
Yeah.

Diane (01:48):  
... don't know how it got th- how it got the name.

Erin (01:50):  
Yeah.

Diane (01:50):

Okay.

Erin (01:50):

So it kind of like shrivels up. We kind of use like displays, um, when we go to like health fairs. Uh, the cranberries and, um, like Red Hots and we put it together. And it just shows you how-

Diane (02:02):

Interesting.

Erin (02:03):

... you know, it kind of shrivels up. I mean, it's, that doesn't show the sickle part, but just-

Diane (02:07):

Uh-huh.

Erin (02:07):

... how it can stop the flow from the, the red blood cells from the-

Diane (02:11):

That's excellent because sometimes you need a visual-

Erin (02:13):

Yeah.

Diane (02:14):

... because you really can't figure out how th- people know that, that it's an inherited, genetic condition.

Erin (02:20):

Mm-hmm.

Diane (02:21):

And they know that it's a red blood cell disorder, but other than that if you're not familiar, you, you, you need education and that's what we're doing today, Clay. Yes.

Clay (02:29):

Yeah. Who's, we talked a little bit about it, but a little more in-depth. Who's most at risk to have the sickle cell disease? And then differentiate the disease versus the trait.

Erin (02:39):

So, um, both of your parents have to have the trait. Um, so when you have the trait, your, uh, your s- ... Don't quote me totally (laughs) on this, but I don't think the cell's sickle or dry. You don't have as much complications. But you carry that gene, that if you get with another person that has that gene, um, then one in four of your children are l- are gonna have the disease.

Clay (03:05):

Hmm.

Erin (03:07):

So the more children you have with someone that has the trait as well, the more like, the more children you will have with the disease. So we have-

Clay (03:15):

Yeah.

Erin (03:16):

... families that have ... You know, we have a client that has like 10, I think there's 10 siblings and, um, three or four of them had the, uh, had sickle cell, um, disease.

Diane (03:27):

And the others had the trait or had nothing at all?

Erin (03:30):

They may have the trait, or they may not-

Diane (03:31):

Really?

Erin (03:32):

... have anything.

Diane (03:33):

Oh.

Erin (03:34):

But yeah. So which-

Clay (03:36):

I have a relative that has, uh, four kids and three of f- three of the four have sickle cell disease.

Erin (03:41):

Mm-hmm.

Diane (03:41):

Oh they do? Okay.

Clay (03:42):

And then actually maybe three years ago, one of them, uh, died from it. So I got a chance to see up close and personal how when they have a crisis, it is very debilitating. It, it wipes them out.

Erin (03:53):

Yes.

Clay (03:54):

Yeah.

Erin (03:55):

That's why it's very important too, to like educate not only the medical field that, that don't really understand it 'cause it's not really, um, studied much. It's like a chapter we've heard like in nursing-

Diane (04:07):

Yeah.

Erin (04:07):

... school, so you don't get, uh, a lot of knowledge on that. Um, but also, the schools and work environments. So that's kind of what our organization does with our clients is kind of be that liaison, um, to let them know that, yeah. It could take them out and they not be able to move. And when it rains, when it's cold, when it's hot, like that can trigger-

Diane (04:28):

Really?

Erin (04:30):

... a crisis and so then they may not be able to get out of bed, you know-

Diane (04:34):

Yeah.

Erin (04:34):

... and come to, to work or school.

Diane (04:36):

So where did the disease come from?

Erin (04:39):

Um, so for here in the U.S., it kind of started in 1910, where this doctor discovered the, the abnormal cells and the change in it through, uh, a man from Grenada in Chicago. So he was from Grenada-

Diane (04:57):

Mm-hmm.

Erin (04:57):

... he comes over. It's cold and then that's when they discover it because he went into a crisis. Um, but, uh, more so, um, Africa or the Caribbean areas, um, kind of where malaria was. Um, they say that it's, um, kind of resistant if you'd had the sickle cell trait or disease, it would resist, um, against malaria. So I guess you wouldn't get malaria with it, but it causes a whole lot of other-

Diane (05:25):

Yeah.

Erin (05:25):

... things, so (laughs) I'm not sure.

Diane (05:26):  
Well, it's a double-edged sword, isn't it?

Erin (05:27):  
Yeah.

Diane (05:27):  
Yeah.

Erin (05:28):  
Um, but yeah. From over in that areas.

Clay (05:33):  
So i- it's, it's interesting the knowledge about it because not everyone's impacted, uh, uh, by this disease. And you kind of talked about where it's come from. Do you think there's better understanding of it now because of some of the high-profile people like Ryan Clark who's, who's from here and who's been a part of this? Is there more, more knowledge of it now because of it being talked about more?

Erin (05:59):  
I think we're getting more knowledge about it. Um, I don't, it's not enough, um, because we still have unfair treatment within the medical, um, from medical providers within our ER. Um, and then they don't understand it. Um, I don't think a lot of our clients even understand or people that may have the trait really understand what it is, uh, because it's not out there. I think early on, um, in the '80s or '90s when they, um, first started testing the babies it may have been talked about. But then it kind of went away and we weren't talking about it. But every, uh, newborn does get tested for sickle cell-

Diane (06:35):  
Right.

Erin (06:35):  
... no matter what, um, race. Uh, so every-

Diane (06:37):  
They all do now?

Erin (06:37):  
Mm-hmm.

Diane (06:37):  
Oh, okay.

Erin (06:39):  
Yeah, so every newborn is tested, but I think that was, um, um, in the '90s sometime that they started that where-

Diane (06:46):

Mm-hmm.

Erin (06:47):

... um, that became mandatory. Um, and I'm not sure if that's in every state, but I know our state does. So a lot of our older clients or people out there may not know that they have the trait, um, because again, they may not experience any crisis or anything like that. Um, they can experience a crisis, but, um, they may not know because they weren't tested. So now, we do know, um, if you have it and then, that's where we come into kind of help s- to help guide. But there still needs to be awareness around it-

Diane (07:21):

An education, yeah.

Erin (07:21):

... because not enough people know unless you have someone tied. And not, not a lot of people talk about it-

Diane (07:27):

Right.

Erin (07:27):

... either, if they have it.

Diane (07:28):

Right. How common, how common is it, Erin?

Erin (07:30):

Um, well, one in 365-

Diane (07:32):

365, yeah.

Erin (07:34):

... have it. You know-

Diane (07:34):

Yeah.

Erin (07:35):

... I think we have, um, one of the things like 10,000 people within the state that maybe-

Diane (07:40):

Okay.

Erin (07:40):

... have it, from the last numbers I saw. Um, but I mean, we, uh, more people have the trait than we know, so, yeah.

Clay (07:51):

So what are, what are the different types of, of sickle cell? Talk about the, how that works, yeah.

Diane (07:57):

I've heard a lot about anemia.

Clay (07:59):

Yeah.

Diane (07:59):

You know, you hear a lot about sickle cell anemia.

Clay (08:00):

Yeah.

Diane (08:01):

And I wasn't really aware that there were other components of the-

Erin (08:04):

yeah.

Diane (08:04):

... disease.

Clay (08:04):

Sure.

Erin (08:06):

Um, SS is I think one of the more severe ones. That's, uh, one that, um, I hear about. I'm still learning all of these things about sickle cell and the trait and stuff. And then there's another one. It starts with a T, and I don't know how to pronounce that name.

Clay (08:20):

(laughs)

Erin (08:20):

I'm sorry. Um, but there, there's that one and then, um, there's one more. And then the anemia.

Diane (08:28):

Mm-hmm.

Erin (08:28):

So SS is the more severe. They'll have more of, um, pain crisis and it can, uh, affect more of their, um, other organs.

Diane (08:39):

Well, do the symptoms too, is it jaundice? Was that another symptom that-



Erin (08:45):  
Yeah.

Diane (08:45):  
... of that? Yeah.

Erin (08:45):  
That's something, um, that some of our clients can get and-

Diane (08:49):  
Yeah.

Erin (08:49):  
... and that's when we're like, "Okay, you need to go. You know, tell the doctor what's going on-

Diane (08:52):  
Got it, right.

Erin (08:53):  
... just because oxygen's not going to certain things.

Diane (08:56):  
So that isn't-

Erin (08:57):  
Kidneys aren't-

Diane (08:57):  
Okay.

Erin (08:58):  
... working or, you know, whatever else but, yeah.

Diane (09:00):  
Mm-hmm.

Erin (09:00):  
Some of our clients do have, um, jaundice or can have that.

Clay (09:05):  
Yeah. It's e- ... Talk a little bit about some of the complications and things that happen. You referenced it in the beginning of our talk about what someone is going through when they're in a crisis. Well, uh, talk a little bit more about that.

Erin (09:17):  
So a lot, you know, with their, their bone, um, pain and bone joints. So a lot of our clients may have to have hip replacement. Um, then the jaundice, uh, the pain crisis. That just happened

where again, uh, they'll have pain in like their hips, different areas of their bodies. Um, that will have them have to stay in or use heating pads, those kinds of things. Um, but those are, are, uh, dehydration of course, and that's why we try to keep them hydrated. Um, tiredness, uh, fatigue. Um, so a lot of our kids within school were like, "Don't ... You know, try to, um, let the school know." Like they may not be able to do the physical activities-

Diane (10:04):  
Right.

Erin (10:04):  
... and especially if the weather is bad because they're gonna get tired a little faster. Um, but those are some of the symptoms that we have seen. Um, or have had some of our clients have. Like the hip, uh, hip surgeries or bone, you know, pain.

Diane (10:20):  
So when you do ... Uh, I'm assuming it's a blood test at birth, so will it show up at birth or is it six months later? Or how? I, I, I don't know.

Erin (10:31):  
No. It, it should show up at birth.

Diane (10:33):  
At birth, okay, okay.

Erin (10:33):  
Yes.

Diane (10:33):  
I didn't know.

Erin (10:34):  
So they'll know and then, um, we like to get ... They, they should be notified and tied to a hematologist by two months. So it'll, it'll-

Diane (10:43):  
Oh, that early? Okay.

Erin (10:44):  
... tell if it has, if you have the disease or the trait. Um, and if you have the disease, they definitely want you to be connected to a hematologist by two months is what they would like. Um, so we work with trying to make sure that they're connected but, so.

Diane (10:57):  
So there are treatments that, that's available-

Erin (11:01):  
Yes.

Diane (11:01):  
... for, for the infant and then as you grow as well?

Erin (11:02):  
Yes. Um, I think penicill-

Diane (11:05):  
It's not curable but it's just-

Erin (11:07):  
Well, some-

Diane (11:07):  
... it's-

Erin (11:08):  
... say it's curable with-

Diane (11:09):  
Really, oh.

Erin (11:10):  
... with, with gene therapy. Um-

Diane (11:13):  
Interesting.

Erin (11:13):  
... but some doctors haven't said like, "It's curable." So there's things that I read. So I don't like to use the word curable.

Diane (11:19):  
Yeah.

Erin (11:20):  
Um, but there are drug treatments that have been, that have become available within the last year and so there's three out there now. So that's why we want to tie them with a hematologist and can get them on these, uh, drug therapies that can help manage. Um, and those try to help stop the cells from sickling, um, so they won't have those pain crises and stuff. Um, but then keeping them up with their primary care doctors-

Diane (11:45):  
Hmm.

Erin (11:45):  
... and all of that kind of stuff is really important. But, yeah. There's three drug, um, therapies out there. There's gene therapy that is, um, two companies are coming out with that. They're not FDA

approved but they're saying, "Coming soon." Um, so there could be that, which again, some people say can cure it because it's changing your genetic in your genes. Um, but that's very expensive too, so-

Diane (12:11):  
Hmm.

Erin (12:12):  
... and a lot of our clients are on Medicaid or a good portion of them. Um, so and I don't know if ... We don't even know if insurance will cover if you do have insurance on that gene therapy, but-

Diane (12:23):  
But there are advancements? There are-

Erin (12:25):  
Yes.

Diane (12:25):  
... when you said that the, the drug treatment, there are three, three new ones in just the past year?

Erin (12:30):  
Well, a couple years. They've been-

Diane (12:31):  
Oh, a couple?

Erin (12:32):  
... yes.

Diane (12:32):  
That's, that's phenomenal.

Erin (12:33):  
Mm-hmm.

Diane (12:34):  
That's great.

Erin (12:34):  
Yes. And one of them, um, I think five or maybe one or two of them, at five, they can start taking them, um, taking that-

Diane (12:43):  
Five years of age?

Erin (12:43):

Mm-hmm, five years of age, so, um, they, they are helping. Our people are living a lot longer. At one time, it was like you weren't expected to live past maybe 19, 18, they were saying, you know-

Diane (12:55):  
You're kidding.

Erin (12:56):  
... like, yeah.

Diane (12:57):  
Oh, I didn't know that.

Erin (12:57):  
But we're having a lot live a lot longer. We have a couple clients that are in their 70s and, you know, we just love it that they stay on their health. Make sure they go to their doctors as well. Um, make sure they, that they're with a hematologist if they can be and, and taking those medications that are prescribed. Um, and then eating right and all of that, um, comes into play too, but having a good village around you-

Diane (13:22):  
Yes, yeah.

Erin (13:25):  
... helps too. It's hard if you don't.

Clay (13:25):  
What about the lifespan of someone with sickle cell versus someone without it, the disease?

Erin (13:32):  
So, yeah. The, it was 16. I mean, we don't know. People are living longer now, um, but because like if you're having issues with your other organs, other things come into play, so kidney diseases.

Diane (13:47):  
Underlying things, yeah.

Erin (13:48):  
We have some, you know, patients that are on kidney diseases or kidney dialysis-

Diane (13:53):  
Right.

Clay (13:53):  
Right.

Erin (13:53):  
... and all of that because they have kidney disease too. And all of that can stem from that, but you never know. Like eyesights can go. That, that-

Clay (14:00):  
Hmm.

Erin (14:01):  
... could be another symptom that happens, um, just because of their sickle cell disease. And so other things can lead to their death, um, earlier on, but it's, it kind of stems from sickle cell because of the blood cells, you know, and oxygen.

Diane (14:19):  
But if you're proactive with your health and you do, you know, the regimen that you're supposed to do, and that you can follow, it can be manageable. It can be managed, and you can have a fairly normal life or completely normal life?

Erin (14:33):  
Yeah. We have a lot of, um, clients that you wouldn't know that. I mean-

Diane (14:37):  
Really? Yeah.

Erin (14:38):  
... you don't look like you have sickle cell. They're-

Diane (14:40):  
Oh, okay. So you don't ... There's no look?

Erin (14:41):  
... you're normal, yes. You, everyday person.

Diane (14:45):  
Yeah.

Erin (14:45):  
You wouldn't even know, and I think that sometimes is a problem when they have to go to the ER and stuff because you don't physically look like you're in pain.

Clay (14:54):  
Right.

Erin (14:55):  
And a lot of them are strong. Like they've had to deal with this their whole life, so they know how to manage that pain, or hide it, or just, you know, deal with it.

Diane (15:03):  
Deal with it, yeah.

Erin (15:05):

And if they have to go to the ER because ... Uh, and a lot of them will wait until it's like to the point. Um, people just think that they are seeking, you know, because you do have to have that high-level pain medication to help with the pain, um, and so when you're going in, you're usually seeking for that medication, um, to stop the pain. And then, you know, if you need fluids, um, blood transfusion, or whatever, you know, might be going on. But yeah. You don't ... You, you're normal. So they live other-

Diane (15:39):  
There's no outward, yeah.

Erin (15:41):  
Yeah. They live, uh, normal lives. They work, they go to school, graduate with their masters, PhDs, all of that. Um, they just have to manage, you know, just like a diabetic and all of that, just know what they're doing. But they will sometimes have those pain crises where, "Okay, I might be out for two or three days."

Diane (15:58):  
Hmm.

Erin (15:59):  
'Cause no matter how well you're doing, you never know when a pain crisis is gonna-

Diane (16:04):  
Yeah.

Erin (16:04):  
... hit.

Clay (16:05):  
That's right. You, you mentioned earlier that it could be triggered by something as simple as the weather, but are there a list of triggering factors as it relates to a crisis?

Erin (16:14):  
So being dehydrated. So we provide hydration. We try to help provide that and encourage drinking lots of water, Gatorade, the sports drinks. Um, stress. So we try to, um, you know, encourage our, our clients to do things to d- uh, de-stress-

Diane (16:34):  
Hmm.

Erin (16:34):  
... uh, but life-

Diane (16:38):  
That's hard to do though. Yeah.

Erin (16:38):

Yeah.

Diane (16:38):  
Stress is, yeah.

Erin (16:38):  
Yeah, that's hard. Um, um, obviously staying warm or, you know, cool like depending on the, the weather. So listening to your body with that and, and not staying in the heat too long. Um, again, just back to that hydration, getting your sleep, and then nutrition. Making sure you're getting those vitamins and those things that you get out of food, um, that you need out of food. That can help, um, a lot of greens, and stuff like that. They've, they say there's some things like folic acid, stuff like that, that you can get from foods that can help you, um, manage it a lot better.

Clay (17:15):  
Man, it's, it's destructive when you see it up close to, to someone and like s- she talked about the pain and not being able ... I've actually seen that up close. The immunization regimen for someone with sickle cell as it relates to vaccines or-

Erin (17:29):  
Mm-hmm.

Clay (17:30):  
... their routine, what does that look like and what, what's your recommendation?

Erin (17:33):  
We, um, recommend them to get their vaccines and a lot of stuff came out from National Sickle Cell Association, um, that we, to, for us to encourage our clients to get the COVID, uh, vaccine when that was, you know, starting and all of that because your immune system-

Diane (17:52):  
So you did encourage?

Erin (17:52):  
Yes.

Diane (17:52):  
Okay.

Erin (17:52):  
We did.

Diane (17:52):  
Okay.

Erin (17:53):  
Um, again, it's by choice for everyone, but we did try to push it and the National Sickle Cell was pushing it, Association was pushing it. So we were too, that it was safe for them, but they're in that



risk factor because of their immune system and all of that. And if they get sick, it could just make it a lot worse. Um, so, um, we say, "Stay up on your vaccines because it's only going to help you-

Diane (18:16):  
Mm-hmm.

Erin (18:16):  
... and to prevent from something else coming into your body." So we try to encourage them to get that, um, but we know that there is some, um, fear around it and just in general-

Diane (18:29):  
Oh, sure, yeah.

Erin (18:29):  
... and just with them too, with the medical, um, providers and everything that they endure. But we're just like, "No. It's safe." We have doctors that, you know, were hematologists. And our hematologists that see like our, our young folk, our pediatrics, they were encouraging them too, you know, pushing them and so they were behind them pushing, "Well, you know, the doctor said to get it." You know?

Diane (18:52):  
Yeah.

Erin (18:52):  
And just trying to encourage that. So we, we stand behind vaccines.

Diane (18:56):  
Is there any, anything as far as, uh, as the vaccines that really you have to go on a case-by-case basis and say, "You know, it's not, not that it's bad, but it might not be good." for the particular individual in their particular case or is it pretty well, "Just talk to your, your, your hematologist, your health care provider-

Erin (19:15):  
Yeah.

Diane (19:15):  
... for what's best for you"?

Erin (19:17):  
Yeah. I haven't heard of any being not, uh, and-

Diane (19:19):  
Okay, good.

Erin (19:20):  
... some of the doctors are-

Diane (19:21):

Yeah.

Erin (19:22):  
... are on it. And if they have a client that's not, uh, doesn't want to take vaccines-

Diane (19:27):  
Mm-hmm.

Erin (19:28):  
... um, any of them-

Diane (19:29):  
Any of them, yeah.

Erin (19:30):  
... uh, 'cause we deal with a lot of more of the pediatric side because there's not a lot of adult hematologists. So a lot of our clients are on the pediatric sides and those are the doctors, the hematologists that we do communicate with. And they're always, "Try to encourage them to take ..."  
So they're encouraging it. So I don't, I don't know if there's any. I would think it would be on, uh, on a-

Diane (19:49):  
Yeah.

Erin (19:50):  
... case-by-case-

Diane (19:51):  
One.

Erin (19:51):  
... so that doctor would let them know, "Okay, you shouldn't take this one, but take this one." But, I've seen them encouraged.

Diane (19:59):  
Mm-hmm.

Erin (19:59):  
All of them.

Clay (20:00):  
Uh, you talked about the two parents having a trait and the likelihood of, uh, of a child having the disease. Because it's genetic, is there any way to prevent it?

Erin (20:11):  
Um, just knowing what your-

Clay (20:13):  
Just know.

Erin (20:13):  
... partner, yeah, if your partner.

Clay (20:15):  
Yeah.

Erin (20:15):  
But again, I mean, you can't tell. I always say, you can't tell someone who they (laughs) love-

Diane (20:21):  
Right, yeah.

Erin (20:21):  
... or if you do have one. But just having that knowledge, um, so that if you both do have the, the trait, that you're prepared once you get pregnant that, "Okay. That-

Diane (20:32):  
May have, right. Yeah.

Erin (20:32):  
... child may have sickle cell disease and then what are we gonna do-

Clay (20:36):  
Mm-hmm.

Erin (20:36):  
... or they may have the trait?" Um, but we do want to encourage our young ones to, to ask that when, you know, if the time comes, just know-

Diane (20:45):  
Mm-hmm.

Erin (20:46):  
... um, if that person has it, when you know that you have the trait or if you have the disease. Uh-

Diane (20:51):  
And, you know, that goes with the family too, the mom and dad. They need to have a heart-to-heart conversation with the young people, you know, with their children to let them know early on if they have the disease, or if they have the trait-

Erin (21:04):  
Mm-hmm.

Diane (21:04):

... if they don't. I mean, uh, everybody has to be aware, and do the right thing for your family, and for your family members.

Erin (21:13):  
Yeah.

Diane (21:13):  
So it, it's you have to have that conversation. I can imagine that would be a pretty hard one, but you still need to be aware and proactive, as you said.

Erin (21:18):  
Yeah, yeah. I mean, that's not something ideal to ask when, you-

Diane (21:18):  
Right.

Erin (21:18):  
... know, you're getting with someone, but yeah. And for the families to know-

Diane (21:18):  
Mm-hmm.

Erin (21:18):  
... it's important.

Clay (21:27):  
What about, um, you talked about some of the pain medicine earlier and if someone goes to the ER or a doctor, they're in crisis. What does that medicine do for them, uh, outside of numbing the pain? Is there anything you can talk about with what the treatment does for a person in crisis?

Erin (21:42):  
So I know when they go into the ER, for one, one of the things may be dehydration, so getting them on fluids.

Clay (21:50):  
Mm-hmm.

Erin (21:50):  
So maybe they would need an IV just to g- receive that, you know, get hydrated a lot faster. Um, that would help. Um, blood transfusions sometimes. Maybe they just need to have that transfusion. Get that, uh, those bad blood cells out. Get new blood cells in. Um, but the pain medication, I think just really just eases that pain while you're-

Clay (22:14):  
Going through-

Erin (22:14):

... figuring out-

Diane (22:15):  
Mm-hmm.

Erin (22:15):  
... yeah. Yeah.

Clay (22:16):  
How long does crisis last typically?

Erin (22:19):  
I think that depends on-

Clay (22:20):  
It, it-

Diane (22:20):  
Yeah.

Erin (22:20):  
Yeah.

Clay (22:21):  
Okay, it varies based on the person.

Erin (22:22):  
Yeah, and then depending on, um, how severe that pain is. There's some clients that they say they can just maybe take some Tylenol or something and they'll be fine. And they can weigh it out. And, and there's things like, you know, putting heating pads on, doing ... Um, we try to give out those because that can kind of soothe it. Um, doing relaxation stuff, just to get their mind off it. So, um, I guess it can pass if it's not bad, but some of ... If it gets too severe and then they have to go to the ER. And then, they're waiting in there for-

Diane (22:56):  
Oh, gosh.

Erin (22:56):  
... hours.

Clay (22:56):  
Yeah, yeah.

Erin (22:57):  
Then that can turn into something else because it was like, "Well, if we just gave them fluids, or if we just gave them, seen if we needed to give them, uh, a blood transfusion or something." And I think

most of the time if it's, you could have just given them fluids, maybe and just that could have helped them, on top of with their pain medication. Um, if they came into the ER, then they're in severe pain.

Diane (23:21):  
Yeah.

Erin (23:21):  
So, um, yeah.

Diane (23:22):  
You're talking about blood transfusions too.

Erin (23:24):  
Yes, blood transfusions.

Diane (23:25):  
What about bone marrow and stem cell transplants? How, how does that tie in with everything, Erin?

Erin (23:33):  
So that's where people say that the cures come in-

Diane (23:36):  
Oh.

Erin (23:36):  
... uh, the bone marrows, I think 'cause that can change your, your genes. Uh-

Diane (23:41):  
The makeup of your genes?

Erin (23:42):  
... yeah.

Diane (23:42):  
Okay.

Erin (23:44):  
Um, we've only had one client that I know that was a client before I got there and they said that their son did have, um, I think the bone marrow transplant-

Diane (23:56):  
Mm-hmm.

Erin (23:56):  
... or something with that, but they had to go out of state for it. Um, and that he is cured. Um, and so he just visits the doctor, I believe once a year to, to check in. Um, but some things that I've read is,

um, yeah, that can help. But then, it years later can cause other things can pop up. So that's where I'm not-

Diane (24:18):  
Hmm.

Erin (24:18):  
... sure if it's necessarily cured and then with the gene therapy, that stuff is really coming out now. And so we're trying to learn more and asking these companies, "Hey, can you explain to us, what does this mean? What does this look like, um, for our patients?" But, um, we don't have too many clients that are doing that. But I think because that changes your neg- and, and can stop the, the cells from sickling.

Diane (24:42):  
Mm-hmm.

Erin (24:44):  
Um, so we've again, I've only had one client say that they have had that, and that they're cured. They don't have any more pain crises or any issues. So that is great, and he was, um, he's young, so-

Diane (24:56):  
I was gonna ... How old is he? I was just-

Erin (24:57):  
Yeah.

Diane (24:58):  
... curious about that.

Erin (24:58):  
I want to say he may be 16 now, but I think he-

Diane (25:00):  
Okay.

Erin (25:00):  
... he did it a few years back and so-

Diane (25:01):  
Years before that. So earlier I guess, maybe catch it-

Erin (25:05):  
Yeah.

Diane (25:05):  
Yeah.

Erin (25:05):

Yeah. So, uh, but then again, I think with cost and stuff, so I don't think that's available, um, to a lot of our clients.

Clay (25:14):

What about some of programs here in Louisiana? We were, before we started the podcast, kind of, uh, waxing sentimental about the late Lorri Burgess, who was, for those listening in other parts of the state, she was a former member of the Baton Rouge City Council and actually was the first female mayor pro tem in the history of the, of the city. But she ran the local Sickle Cell Foundation here before passing away a few years ago. Are there a number of programs like that across the state of Louisiana? And if so, talk about them.

Erin (25:43):

Yeah. So there's, uh, four other, um organizations that are just like us here, um, in Baton Rouge. Um, and we work closely with them and they're doing the same thing that we're doing here in Baton Rouge. We, we have expanded, so we cover, new, uh, from New Orleans up to Lafayette, everything in between. That was something Ms. Burgess was doing-

Clay (26:02):

Yeah.

Erin (26:03):

... uh, right before she had passed, um, because those two areas didn't have one. But there's, um, an organization in Shreveport, Monroe, um, la- um, Shreveport, Monroe, Alexandria, and Lake Charles.

Clay (26:17):

Okay.

Erin (26:17):

Um, um, some of those, two of those have lost their CEOs, their executive directors. Uh, Lake Charles lost theirs during COVID.

Diane (26:25):

Hmm. Okay, gosh.

Erin (26:26):

Um, so around the same time that Ms. Burgess had passed. Um, and then another one, uh, I think that person just stepped down. So those, those two programs are getting back up and they're thriving. And, and getting back into the community, which is great, um, you know, to help out-

Diane (26:42):

Yeah.

Erin (26:43):

... those are in that area. So we do have those, us five, um, counting it all together, that are doing some of that work. Uh, providing resources for the clients, working with LDH, um, the, uh, genetics



office, in making sure that we're connecting to newborns and helping them s- find that path. That medical path, um, and staying on that with a hematologist. And anything else that they may need, but then also, uh, we're charged with spreading awareness. So the education and all of that, um, on top of that.

Erin (27:18):

Um, those are really the only programs outside of some of our, our hospitals that have, um, good programs. Tulane, um, has a good program, um, pediatric-wise and adults, adult care, as well. They do a good transition program, um, and so that's another issue within the state, especially our rural areas. Um, but making sure we transition our pediatric side 'cause we know pediatric patients in anything get, you know, the best care 'cause they're little, but-

Clay (27:47):

Sure.

Erin (27:47):

... then going over to the adult side, when your mom's not gonna be in charge so much and you got to speak up for yourself. So they do a great job with that as well as Our Lady of the Lakes Children's Hospital. They do that as well. There's a sickle cell, uh, clinic within Our Lady of the Lake off of, uh, Airline for adults. And so they work together and able to transfer over, uh, transition those kids, as, uh, well, when they get past 21. But yeah.

Diane (28:15):

You know, our listeners, today, there, there is all kinds of information available and they, they shouldn't be afraid to ask. They shouldn't be afraid to inquire. You know, we talk about this on this podcast a lot about misinformation.

Clay (28:30):

Right.

Diane (28:30):

Oh, my gosh. Oh, my gosh, you know, and that, that's the fear, you know, you, y- people will hear something and think, "I don't want to do this. I can't do this because I'm afraid of this and such, and, and whatever." But that is what you're wanting to do, your organization and the others in the state, to give solid information, to talk about what needs to be talked about, and to give them the best quality of life possible.

Erin (28:52):

Yes.

Clay (28:52):

Right.

Erin (28:53):

Yes.

Clay (28:54):

Yeah.

Erin (28:55):  
Information education is the key I think to a lot of our issues-

Diane (29:00):  
Mm-hmm.

Erin (29:00):  
... you know if people just understood it, uh, but then also had empathy for-

Diane (29:04):  
Yeah.

Erin (29:06):  
... the person that is going through it. Um, they may not look like you. It doesn't, it does not affect everyone like cancer. Um, that's kind of where we kind of compare, where we compare, but not compare, just because our patients go to oncology hematologists too. So they're, uh, alongside cancer patients, but, um, but just to have empathy and to want to learn about this-

Diane (29:28):  
Yeah.

Erin (29:28):  
... disease as well. Yeah. It may not affect everyone like cancer, but I'm sure you know someone that has the trait, or the disease, or someone in their family does, you know?

Diane (29:39):  
You know, what was, what, you know, the point that you made earlier, I think Clay did too, that sometimes people don't look sick. They-

Clay (29:46):  
Right.

Diane (29:46):  
... they look, they look fine.

Clay (29:47):  
Yeah.

Diane (29:48):  
And how many times have you just in general said, "Well, you know, so-and-so has it, but, boy, she looks great"?

Clay (29:52):  
Right.

Diane (29:52):  
She doesn't look like or he doesn't look like it, but this is, this is serious-

Erin (29:56):  
Yeah.

Diane (29:56):  
... you know?

Erin (29:57):  
Yeah.

Diane (29:58):  
And take them seriously too.

Erin (29:59):  
Yeah. It's all internal, so-

Diane (30:00):  
Mm-hmm.

Erin (30:01):  
... you know, the pain that they're going through and they're strong people. I mean, we call them sickle cell warriors because they're really like fighting this battle, you know, against so many things, while they're like enduring pain (laughs) in their body, you know, and they're carrying on with life, so.

Clay (30:17):  
Well, people often don't look like they're doing as poorly as they are, so-

Erin (30:22):  
Yeah.

Clay (30:22):  
... uh, and, and where we are right now, to Diane's point, the outer exterior could just be a mask. And, and you don't know-

Diane (30:27):  
Yeah.

Clay (30:28):  
... but with sickle cell, especially it just I mean, they, th- it's, it's, it is one of those things. Is there anything? Uh, what are some myths or misnomers about sickle cell that you could, if there are, that you could clear up for us?

Erin (30:40):  
Well, one of the big ones that we, is that they are drug seekers and then, with the opioid issue that we have-

Clay (30:45):  
Yeah.

Erin (30:47):  
... um, that just makes it harder for, uh, the sickle cell community because they're going in and they need the pain medication.

Diane (30:56):  
The stronger drugs-

Erin (30:56):  
Yeah.

Diane (30:56):  
... and they have to have it, yeah.

Erin (30:56):  
The stronger ones-

Diane (30:57):  
Yeah.

Erin (30:57):  
... yes, and that sometimes is the only thing that can mask. And, um, and, yes. It can be addictive, so maybe someone does get addicted, but we try to, "Okay, let's get on a good medical path. You know, what's, uh, the drug therapy that can help, so you don't have to go to ... Or what can we help you do in your life, so you don't have to go to the emergency room as much?" I mean, we would love the, uh, ...

Erin (31:20):  
There is a Louisiana, uh, Sickle Cell Commission, so that all of us organizations are a part of that I named the five of us. And there's a s- a senator, state rep, um, and some doctors that are on that. And so we just want ... We're working, um, in to spread the awareness and to, to let people know that there, it's not just, they're not just drug seekers. But if we could also have, uh, uh, clinics where it's for sickle cell patients to be able to go in, where you can get that drug transfu- uh, that blood transfusion, um, or the, uh, the fluids, the IV-

Clay (31:59):  
Yeah.

Erin (32:00):  
... that they wouldn't have to go to the ER. And that would save the state some money too. But, um, but yeah. If we could just have more understanding. (laughs)

Diane (32:09):  
Yeah. Uh, with so many things.

Clay (32:10):  
Right.

Diane (32:11):  
Before we close our, our podcast today, you both, I think had talked about, is it Ryan Clark?

Clay (32:16):  
Ryan Clark, yeah.

Diane (32:17):  
I would like ... Yeah, I don't know his story and I venture to say that a lot of our listeners do not, so could you talk about his story and why he's so impor- important to be a part of our community when he comes?

Erin (32:29):  
Yeah. Um, so he's been a part of the organization as long as I've known. They said Ms. Burgess went after him to, "Hey, be a part of this." But-

Clay (32:38):  
They're both graduates of LSU, so-

Erin (32:39):  
Yeah.

Diane (32:39):  
Okay, okay.

Clay (32:39):  
Yeah.

Diane (32:39):  
Okay.

Erin (32:39):  
Um-

Diane (32:42):  
So he's from here?

Clay (32:44):  
He, he's from Marrero, in the New Orleans area.

Diane (32:45):  
Okay.

Clay (32:46):  
Yeah.

Erin (32:46):  
Yeah.

Clay (32:46):  
Played in the NFL, uh, he for the Steelers. I guess if he got to play in the NFL you [inaudible  
00:32:51]-

Diane (32:50):  
(laughs)

Erin (32:50):  
(laughs)

Diane (32:52):  
Okay.

Clay (32:53):  
I'm a 49ers fan, but-

Diane (32:54):  
Oh.

Clay (32:54):  
... uh, anyway, uh-

Diane (32:56):  
Okay. Oh, so I get to pull ... This is the plug for the Chiefs right now? Okay.

Erin (32:59):  
Mm-hmm.

Diane (32:59):  
That's-

Clay (32:59):  
Is there a delete button out here? (laughs)

Diane (33:00):  
Yeah. No. (laughs)

Clay (33:00):  
(laughs)

Erin (33:00):  
Oh, my God where's the Saints fans. (laughs)

Diane (33:06):  
(laughs) That could be you. Yeah.

Clay (33:11):  
S- says a lady from California, right?

Erin (33:11):  
I'm, I'm a Raiders fan too.

Clay (33:11):  
Okay. All right.

Erin (33:11):  
I, I, I like both.

Diane (33:11):  
I love it.

Erin (33:11):  
Uh-

Diane (33:14):  
So did we, did we get, did we kind of go-

Clay (33:15):  
Uh-

Diane (33:16):  
... you know, a little sidestep here?

Clay (33:17):  
... my fault. My fault.

Diane (33:18):  
No, no. But I was just curious about-

Erin (33:19):  
Yeah.

Diane (33:20):  
... the rest of the story.

Clay (33:20):  
Yeah.

Erin (33:20):

But he was, he was playing. Um, he went to Denver, um, and high altitudes, that is something as well that can trigger-

Diane (33:28):  
Oh.

Erin (33:28):  
... something and and isn't, uh, safe, um, for them, but playing in Denver, uh, I think something happened with his spleen and-

Clay (33:35):  
Yeah.

Erin (33:35):  
... he went to the hospital. He wasn't able to play. He's talked about this on his podcast. Like he-

Clay (33:39):  
Yeah.

Erin (33:39):  
... wanted to go back out and play-

Diane (33:41):  
Yeah.

Clay (33:41):  
Yeah.

Erin (33:42):  
... and stuff. Um, but he almost died.

Clay (33:43):  
He almost died, yeah.

Erin (33:45):  
Yeah. And they were able to, to-

Diane (33:46):  
Hmm.

Erin (33:46):  
... save him and all of that. And so I think like the next time they went to play, like coach wouldn't, uh, the Steelers coach-

Clay (33:51):  
They wouldn't let him go.



Erin (33:51):  
Yeah.

Clay (33:51):  
Yeah. Mike Tomlin's like-

Erin (33:51):  
Yeah.

Clay (33:51):  
... "You can't go."

Diane (33:51):  
Oh, oh, really-

Clay (33:53):  
Yeah.

Diane (33:53):  
... "You're done."

Erin (33:53):  
Yeah.

Diane (33:53):  
Yeah.

Erin (33:56):  
Um, but he has been, um, a great supporter-

Clay (33:59):  
Mm-hmm.

Erin (33:59):  
... for us. Our biggest fundraiser here in Baton Rouge is named after him, the Ryan's-

Diane (34:04):  
Hmm.

Erin (34:04):  
... Run.

Clay (34:05):  
Yep.

Erin (34:05):

We have it every, now, September. It was August, um, and we have it in September and it's still going.

Diane (34:11):  
Excellent, yeah.

Erin (34:11):  
Um, and he supports us with that. If he can be here, he comes-

Clay (34:17):  
Yeah.

Erin (34:17):  
... out and supports-

Diane (34:17):  
Mm-hmm.

Erin (34:18):  
... but, um, but, yeah. He's just been great and, and a good, um-

Diane (34:20):  
He's a role model.

Erin (34:21):  
... ambassador for our-

Diane (34:22):  
He's, uh, he's-

Erin (34:22):  
Yeah.

Diane (34:22):  
... a role model. Yeah.

Erin (34:24):  
Yes.

Clay (34:24):  
He, he, he really, really is.

Diane (34:24):  
Yeah.

Erin (34:24):

Yes.

Clay (34:24):  
He's done a lot in media-

Diane (34:24):  
Yeah.

Clay (34:26):  
... and to Erin's point, he's been back a lot.

Erin (34:28):  
Mm-hmm.

Diane (34:28):  
Mm-hmm.

Clay (34:28):  
Now, he's not just there. Generally, when he attends, he runs, so he'll-

Erin (34:31):  
Mm-hmm.

Clay (34:31):  
... he'll be a part of it, and stay around, and talk to people for a while. So he's not just coming in saying, "Oh, I got to leave."

Diane (34:36):  
He's not just a face. Just not a face.

Clay (34:36):  
No, no. He's-

Diane (34:36):  
He does it. Yeah, he is involved.

Clay (34:39):  
... and t's important to him and he had such great, has such great respect for, for Lorri as, as-

Diane (34:44):  
Uh, yeah.

Clay (34:45):  
... most of us who were around her-

Diane (34:46):

Yeah.

Clay (34:46):

... always have and, and will. And congrats to her family after having a street named after here-

Erin (34:51):

Yeah.

Clay (34:51):

... after her here in Baton Rouge.

Diane (34:51):

That's fabulous. Yeah.

Clay (34:53):

Well, listen, uh, I think we ... Is there anything we left out?

Erin (34:56):

Um, no. I think we, we touched it all, but if, if anybody wants to, to get involved in, to help make a difference, blood donations are important.

Clay (35:04):

Okay.

Diane (35:05):

Oh, okay.

Erin (35:05):

So if you could go and give blood-

Diane (35:08):

All types, all types of-

Erin (35:08):

Yes.

Diane (35:08):

Okay.

Erin (35:08):

But we do encourage the African American community to go donate more just because a lot more of our clients are African American-

Clay (35:15):

Yeah.

Erin (35:15):  
... and we know that, that matches better-

Diane (35:18):  
Okay.

Erin (35:18):  
Um, but we encourage the blood donations, but then also get involved with one of your local organizations like here, us here in Baton Rouge or one of those other areas, um, up North. And I think on LDH website that it lists all of our organizations in the state.

Clay (35:35):  
Yeah.

Erin (35:35):  
So find one. See how you can help out with them to volunteer. They all have events as well for fundraising and awareness-

Diane (35:41):  
Mm-hmm.

Erin (35:42):  
... around, um, the disease. So, yes.

Diane (35:44):  
This was just so interesting because I had no idea-

Clay (35:48):  
Yeah. No.

Diane (35:48):  
... about the whole scope of it. As I said, I, I remember talking about, you know, for years sickle cell anemia. I really didn't know what it meant. I didn't know the full impact, so I think this podcast has been just ... It's been amazingly informative for people all across, all across all boards-

Clay (36:07):  
Yeah.

Diane (36:07):  
... all, you know, all genders-

Clay (36:09):  
Yeah.

Diane (36:09):  
... all races.

Clay (36:10):  
Um-

Diane (36:10):  
So, so in closing, anything else?

Erin (36:13):  
Um, no. Thank you guys for having, um, and I-

Diane (36:15):  
Yeah.

Erin (36:15):  
... hope people just go and, and from this information that they've gotten here, just dig a little bit deeper to learn more, um, about sickle cell disease.

Diane (36:24):  
And not be afraid to ask.

Erin (36:25):  
Yeah. Not be afraid. Yeah.

Diane (36:26):  
And to find out about it.

Erin (36:27):  
Yeah, yeah.

Diane (36:27):  
And to find out about it. So you have been lovely. Thank you-

Erin (36:30):  
Thank you.

Clay (36:30):  
(laughs)

Diane (36:30):  
... so much for being here today. And we all, I, especially learned a lot from this particular podcast. And thank you to our listeners for tuning into this special episode. And we hope you'll join us again next week for our next Vax Matters.