Marie Watre.wav

Sickle Cell Stories: A Journey of Advocacy and Care

Summary Of Each Speaker

Geraldine (Interviewer): Representing Plasmo Health, Geraldine facilitated this interview as part of the "Sickle Cell Stories Then and Now" project. Her goal was to document the evolution of NHS care for sickle cell disease over the past 21 years through the lived experience of a parent.

Marie Watre (Participant): A mother who has spent 21 years navigating the NHS for her daughter, who was diagnosed via newborn screening in 2004. Tiki provided a candid account of the emotional and physical toll of the condition, the lack of consistent support, and the challenges of transitioning from pediatric to adult care.

Key Points And Decisions

Diagnosis and Early Support: Tiki shared the shock of receiving the diagnosis at birth and noted a significant lack of follow-up or guidance from the NHS during the early years, which left her feeling isolated and unsupported.

Systemic Inconsistencies: Tiki highlighted that the quality of care varied significantly depending on the location and the specific medical team. She reported instances where her daughter's pain was not believed or treated with the necessary urgency, particularly regarding hip complications.

Transition to Adulthood: The transition from children's services to adult care was identified as a major failure point, described as feeling like the patient was being "dropped" by the system.

Healthcare Education: A primary point of concern for Tiki is the lack of knowledge among general healthcare staff regarding sickle cell disease. She strongly advocated for better training for medical professionals to ensure patients are treated with empathy and competence.

Agreements: Both parties agreed that documenting these personal stories is essential to ensure that the experiences of families are heard and that the NHS improves its approach to sickle cell care for future generations.

Next Steps

Plasmo Health (Geraldine): Will incorporate Tiki's testimony into a project booklet designed to reach and support other families navigating similar journeys.

Tiki (Participant): Will continue to support her daughter as she manages her own health as a young adult and remains hopeful for future medical advancements, such as gene therapy, to provide a potential cure.

SPEAKER 0

[00:00:00,860]Okay, let's do this. So I'll be outside here. Okay, so if you need to

SPEAKER 0
[00:01:05,230]Okay, uh my name is Geraldine and thank you so much for being here today. I'm interviewing you for um Plasmo on behalf of Plasmo Health and our project with Sickle Cell Stories Then and Now which is supported by the National Lottery Fund. So this project is about capturing real stories from real people whose lives have been touched by sickle cell disease.

SPEAKER 0
[00:01:32,810]So we can document how we can, uh, how care has changed over the years and to make sure that those experiences are heard and never forgotten. Okay

SPEAKER 0
[00:01:43,630]Your story is particularly special to us because your daughter, she said, was born in 2004, and that's the same year that the NHS introduced newborn screening for sickle cell disease. That means you were one of the very first parents to go through that experience, and you have spent 21 years watching your daughter grow up with this condition under the NHS. Nobody else in this project can offer that perspective for us, okay? And so as always, there is no wrong or right answer. Please speak naturally in your own words. You can pause at any time.

SPEAKER 0
[00:02:22,240]skip anything you are not comfortable with or you can stop altogether if you need to. So you are in total control. So we'll start with three short questions for recording which will last no more than two minutes. Okay, after that there's some written questions but then we'll still record so that we can record them and put that in later for you. Okay, are you happy for us to begin?

SPEAKER 0
[00:02:46,480]Yeah. Okay, can you tell us your name, please?

SPEAKER 1
[00:02:48,720]Sorry, what?

SPEAKER 0
[00:02:51,830]Your daughter was born in two thousand and four, the same year the NHS introduced newborn screening for sickle cell disease. What was it like to receive the diagnosis when she was just days old? And did the NHS give you the support you needed in those early years?

SPEAKER 1
[00:03:12,610]Well, it was very difficult to hear. As we know, with our background in Africa, if someone is born with sickle cell, you know, the child is not going to last for that many years. So it was a bit of a shock.

SPEAKER 1
[00:03:35,560]and um Second.

SPEAKER 0
[00:03:46,980]I see a mic blinking blue.

SPEAKER 1
[00:03:49,640]Oh yeah.

SPEAKER 0
[00:03:58,510]You see green.

SPEAKER 1
[00:04:00,270]Uh-huh.

SPEAKER 0
[00:04:00,870]Okay Sorry about that.

SPEAKER 0
[00:04:06,930]Okay

SPEAKER 1
[00:04:11,110]It wasn't great news, um but we have to deal with it anyway because the NHS I can say because she was born in London. And what they call, they were really good at the hospital anyway when she's in crisis. Uh, we had a card they gave to me so just called them and then they arranged everything and I got to the hospital.

SPEAKER 1
[00:04:47,520]in that room since they were really good in London. أجنين

SPEAKER 1
[00:04:56,480]at first it was because when she's crying, she was a baby, you don't know why the baby is crying and all that, but it was very difficult. It is very difficult.

SPEAKER 0
[00:05:10,550]Thank you for sharing that.

SPEAKER 0
[00:05:13,290]So you have spent 21 years raising a daughter with sickle cell disease and navigating the NHS on her behalf. What has the journey truly cost you and what has it shown you about yourself?

SPEAKER 1
[00:05:28,000]It was a tough time to start with because at some point I couldn't. I couldn't work that really because uh she was always having crises and being young as she was. So even when I had a job, nobody would really understand the fact that maybe if they call me, she's in crisis and I have to leave the job, I have to attend to her and all that. It was very difficult.

SPEAKER 1
[00:06:00,860]I spent, I can say, uh, that many years looking after her, not thinking of, I can't, not thinking about myself because it was really painful. And in and out the hospital, it was a challenge. It was...

SPEAKER 1
[00:06:23,400]like I would say for me, I was just thinking my life is just to look after her. I couldn't do anything else. So,

SPEAKER 0
[00:06:31,740]literally brought her life to a halt.

SPEAKER 1
[00:06:34,130]Yeah.

SPEAKER 0
[00:06:34,900]Yeah. Thank you.

SPEAKER 0
[00:06:37,360]And your daughter is now 21 and managing her own health and her own life. What do you most want for her future? And what do you want the NHS to do differently for the next generation of children born with sickle cell disease?

SPEAKER 1
[00:06:55,720]Um, I mean, I think they should really, um, teach people about sickle cell because we can see a lot of lots of um,

SPEAKER 1
[00:07:17,230]People now with sickle cell and uh not everybody has a knowledge of the sickle cell. I work at the hospital. I work in A&E. Sometimes you have a patient with sickle cell, you have a colleague that doesn't know that and doesn't understand what sickle cell is. At the point when we have a sickle cell patient coming, it's just for them it's just a normal patient but they don't understand.

SPEAKER 1
[00:07:45,520]I've been living right in the house with a sickle cell patient, which is my daughter. So having a sickle cell at the hospital, people should have real knowledge about how it works, how they feel, what they're going through because honestly they don't understand. So I think NHS should really uh put

SPEAKER 1
[00:08:17,390]How do I place that? Really teach people about sickle cell so that at least when they have a sickle cell patient coming, they know what to do, they know how to react towards that patient that is suffering. But no one is looking. They just think, oh, they are crying, they are complaining about pain. I've been there. I know how it is.

SPEAKER 1
[00:08:40,450]So

SPEAKER 1
[00:08:41,440]usually when I have a sick patient at the hospital, I tend to really put uh my hundred percent into it because I know how they feel at that point. So they just teach people what it is and how to go about it.

SPEAKER 1
[00:09:00,100]Das ist es.

SPEAKER 0
[00:09:00,830]Danke. That is a very passionate appeal, but could you stress a bit more what you want for the future of your daughter?

SPEAKER 1
[00:09:09,020]For my daughter, I just want her to have a normal life. Uh when I say normal life, she's a young adult. She wants to have that normal life as well. But I don't really know how to go about it, I think. Um because when they look at it...

SPEAKER 1

[00:09:38,670]she will only be seen when she's in crisis. She's they really have to they really uh, I don't know how to to say that. She needs support.

SPEAKER 0
[00:09:54,940]Okay.

SPEAKER 1
[00:09:55,630]She needs support, she needs people like maybe a group of people that would share that experience, that would share because some of them don't understand themselves what's going on. Yeah. They don't understand how they have to go about their lifestyle, their living, what they need to do, maybe too. I'm not saying they're going to avoid crises, but how to avoid regular crises. Yeah. That's what I want for my daughter, but uh...

SPEAKER 1
[00:10:37,260]if she can be healed. That's what I want. If they can, if we can have something that will be a cure for sickle cell. Honestly, that would be the best because I'm not saying other sicknesses are not, but sickle cell is really difficult to deal with. So if there's a cure, that's what I want for her. At least she can have a normal life, if I can say that.

SPEAKER 0
[00:11:11,020]Thank you.

SPEAKER 0
[00:11:12,180]Thank you so much for sharing that, Tiki. Now we're going to move on to the diagnosis and the early years, if you cast your mind back. Can you please tell us about the moment you found out your daughter had sickle cell disease through the newborn screening? Where were you and what went through your mind at that very moment?

SPEAKER 1
[00:11:33,880]Wow. Um, when I had her, my daughter. Uh, honestly I didn't imagine, I didn't think. I knew I was a secret service uh, carrier.

SPEAKER 0
[00:11:52,450]career

SPEAKER 1
[00:11:53,390]and uh but um I didn't imagine because my partner back then didn't have knowledge about CKD because he's coming from a different background as well. So, he didn't have knowledge. I was asked because I think it's like you're saying. Maybe it's that period because when they knew I was a uh carrier, they asked my partner to come and uh get himself checked. And he didn't want to because he didn't know.

SPEAKER 1
[00:12:32,660]What is it? What is that? So the day they told me when I was I was carrying my baby on my arm and the nurse said, I have some news for you.

SPEAKER 1
[00:12:45,820]I didn't imagine it would be like that. Never imagined in my life. When she said, "Okay, do you know about sickle cell anemia?" I said, "Yeah."

SPEAKER 1
[00:13:01,180]She said, your daughter has sickle cell. I almost dropped my child because it was really...

SPEAKER 0
[00:13:14,540]It's okay. Take your time.

SPEAKER 1
[00:13:22,340]It was sad.

SPEAKER 1
[00:13:32,170]I met people that had sickle cell. It was horrible. So, like I used to say, even to your worst enemy, you would not wish them to have certain sickness. It's not just sickle cell but... and...

SPEAKER 1
[00:13:59,310]She reassured me that it's going to be okay, they are going to look after her, and everything is there because she asked me why I'm that upset. So I explained to her that I know I'm not going to have my kids for long. She said, no, no, no, no. We're going to look after her. And uh...

SPEAKER 0
[00:14:32,280]It's okay. We can pause if you'd like a moment.

SPEAKER 1
[00:14:38,700]And then from there, I just... I was just hoping it wasn't true. To tell you the truth, I was hoping it's not true. Maybe it was a mistake or something.

SPEAKER 1
[00:14:54,020]and they checked again, they told me yeah, she's uh, she's sick of seven million naira. I took it as it was and then yeah.

SPEAKER 0
[00:15:05,020]Yeah

SPEAKER 1
[00:15:05,670]It was difficult.

SPEAKER 0
[00:15:06,900]difficult Thank you. So do you remember, did the NHS give you enough information and support immediately after they told you? Well, what did they provide and what did you think was missing at the time?

SPEAKER 1
[00:15:22,190]Um back then they didn't give me that. She dropped the news, she reassured me that they were going to look after her because of what I said to her. Oh no, we're going to look after her, don't worry and all that. And like I said, when I was calling because she was born um where she was born, I can't remember the hospital name. Uh every time I called, they would just arrange everything. It's not like when we came to Birmingham, it was really, really bad. They would arrange everything. I go in...

SPEAKER 1
[00:15:59,630]I don't need to wait uh in A&E or anything. So I just call them, I'll go in. That's the only thing I could get. But like uh follow-up, I didn't. I never had follow-up. I never had any support. I never knew I could get any support from the NHS or whatsoever. Like I said, I couldn't work, I couldn't do anything because she was still young. So I didn't have that money. I didn't have anything. At the time I was all by myself.

SPEAKER 1
[00:16:34,940]I didn't have anything at all. I didn't have my partner, who wasn't with me close to me at the time. So it was a struggle. Everything was going into my head.

SPEAKER 1
[00:16:47,090]So, but God did it. I'm here today.

SPEAKER 0
[00:16:52,420]Danke gut Thank you. That's good to know. Alright.

SPEAKER 0
[00:16:57,250]So, what did you do in those early weeks and months to prepare yourself and your family for raising a child with sickle cell disease?

SPEAKER 1
[00:17:08,630]Well, I was young, what could I have I I I I didn't think about anything. Just be there. Das

SPEAKER 1
[00:17:21,500]I didn't have anything in mind to prepare anyone. My family was... my mom was devastated. My sister, everybody was devastated.

SPEAKER 1
[00:17:36,340]But uh right there. What could I have... what can I do? The news is there.

SPEAKER 1
[00:17:47,570]So, for me, I just have to live with it because sometimes we may think, oh, it's just a child, but the parent also is suffering. The family around will suffer. The illness of whatever they have, the relatives they have. So, I didn't think about anything else but just living.

SPEAKER 1
[00:18:12,830]for me, I didn't, I didn't honestly, I didn't even think she would come to this age. I didn't believe that they could get to this age.

SPEAKER 1
[00:18:22,790]because they were not clear explanation or don't worry we're gonna take look after her but the explanation how

SPEAKER 0
[00:18:32,100]prolific

SPEAKER 1
[00:18:32,830]In my mind, she's not going to last long. That's how I was living day by day. That if it happens, it happens. Does

SPEAKER 0
[00:18:42,710]So it must be scary. Thank you. So were there things, so she said there were things that you wished somebody had told you at the beginning that you find out for yourself later on.

SPEAKER 1
[00:18:58,290]or what about

SPEAKER 0

[00:19:00,090]About the diagnosis, yeah.

SPEAKER 1
[00:19:03,010]Yeah, if I mean, if um I knew when I was pregnant, to tell the truth, I knew I would like I said, I knew I was a carrier, but if I knew my partner was a carrier as well, I don't think I would have... I know it's cruel, but for me, I was avoiding the sufferings of the child and myself. So but I didn't know.

SPEAKER 0
[00:19:37,230]Yeah, it makes sense. It makes total sense, yeah.

SPEAKER 0
[00:19:40,740]All right. We're just going to move on to navigating the NHS how you've dealt. How has your experience of the NHS been as the mother of a child with sickle cell disease? Has it been consistent or has it varied depending on where or who you have to deal with?

SPEAKER 1
[00:19:58,950]is when she was at children's hospital it wasn't that bad.

SPEAKER 1
[00:20:08,610]um because she had follow-up appointments and all that. So, but it came to the point where, uh, she was when she started having the hip pain, uh, they didn't listen.

SPEAKER 1
[00:20:25,300]So, what I would say is that they do basic things but they don't go deep into what should be done. So, when she had the hip pain, they were not listening until it got worse and she had to have an operation. That's all I can say. They're not really consistent in what they should do.

SPEAKER 1
[00:20:56,450]no Is it because they don't really know what's going on? Is it because they don't have that much knowledge? Is it because

SPEAKER 1
[00:21:05,820]I don't know. But they left it that long so that it got worse. So that's the NHS anyway.

SPEAKER 0
[00:21:17,130]Okay So, have there been times when you had to fight for your daughter to receive the care that she deserved? Are you able to tell us a moment when that happened? Yeah. Yeah.

SPEAKER 1
[00:21:30,750]Yes

SPEAKER 1
[00:21:31,360]like I said, when she had the hip, when she started having the hip pain, I had to really fight for it. At first, they ignored it until she couldn't walk.

SPEAKER 1
[00:21:47,840]She had to, they gave her a wheelchair, they gave her crutches. At school it was difficult for her. I have to fight for it. Until it gets worse, I have to tell them, is this normal?

SPEAKER 0
[00:22:02,580]Hmm.

SPEAKER 1
[00:22:03,370]Can you check again? When they did the scan, they realized everything was off. And they asked me why I didn't speak up on time. I said I did.

SPEAKER 1
[00:22:16,650]I did every appointment I came here, I highlighted this, but you guys, you guys ignored it. But what can you do?

SPEAKER 0
[00:22:29,120]That was pretty hard. Okay. So have there been times when your daughter was not believed or not treated with the urgency she needed? And how did that make you feel as a mother apart from the hate?

SPEAKER 1
[00:22:44,760]uh not believe when she was um young I can't really say they did not believe

SPEAKER 1
[00:22:57,860]Because like I said, Children's Hospital, they were really good. They were really good when we went as well, like as A and E, we had to go through A and E. They would take care and do what is necessary to do.

SPEAKER 0
[00:23:18,960]Yeah, okay.

SPEAKER 0
[00:23:20,920]So how has the care your daughter received changed as she has grown from baby into a young adult? Has it improved or has there been moments where the system let her down? I know you've mentioned that moving from children paediatrics to adults was a bit challenging. Can you tell us about...

SPEAKER 1
[00:23:41,920]Yeah, it was very challenging and it still is challenging because I can't really say there's a good follow-up. And I think when she went, she started going to the young adults, the follow-up wasn't the same as when she was, you know. And it's hard. Even now it's hard. Even the energy, that's why I said at the beginning, they need to teach people what sickle cell is.

SPEAKER 1
[00:24:18,790]because even when she goes to the hospital, they don't want to do what is necessary to do, but they think maybe she's lying or that she's in pain or things like that. They don't believe it. So, that's really typical, I can say.

SPEAKER 0
[00:24:44,370]Okay, so we're going to move on to school, community and her daily life. How did your daughter's school handle her condition over the years? Did you feel she was properly supported and included?

SPEAKER 1
[00:24:59,610]to start with she wasn't. She wasn't supported because um especially when she started, she had a problem with limping.

SPEAKER 1
[00:25:13,880]when she had a crisis, they knew about her condition, I can say. They were aware

of it. So that wasn't a problem. But when she started limping, she didn't have the the facilities for her to go around the school to, you know,

SPEAKER 1
[00:25:40,000]So it was a bit difficult to start with, but I think at some point, um, they had to send a letter to the school so that they can try and help, you know, give uh put facilities for her, like she can use the lift, things like that which she couldn't go when she started limping, she couldn't go for the stairs. So, it

SPEAKER 1
[00:26:08,080]they need to be, even the school need to be, uh to receive that teaching about, you know, suicide, what is it, how to support the child, how to go about it. So, yeah.

SPEAKER 0
[00:26:24,050]Okay.

SPEAKER 0
[00:26:26,570]Thank you so much for that too. So what role has your wider family, community or faith played in supporting you and your daughter through these difficult times?

SPEAKER 1
[00:26:39,920]I can say my family, they try to be there for me. It's mainly, if I can say, it's mainly me, my uh partner and our little family. We try hard to be there for her, to, you know, every time she's down or she has a crisis. Everybody just, you know, gives their best to support her.

SPEAKER 0
[00:27:18,020]Okay. Let's get to know each other. How has raising a daughter with sickle cell affected your own life, your work, your relationship, and your own health and well-being?

SPEAKER 1
[00:27:32,940]Well, it affected my work a lot. I can say I spent maybe ten, ten years I couldn't do really, uh, I couldn't work properly because especially when she was young, she got to the young adult state.

SPEAKER 1
[00:28:00,170]I was

SPEAKER 1
[00:28:01,750]Every time I had a job, it was difficult because I had to call off. I had to, so it was difficult. My life was, I can say my life was on pause because of my daughter and all that, and it wasn't easy. And even with that, I didn't receive support for that. Either for, for, I don't know. I didn't receive any support.

SPEAKER 1
[00:28:27,320]really

SPEAKER 1
[00:28:28,690]imagine you're not working, you're looking after, it's when uh I don't even know when we start having the support. I don't know who started talking about it. And when I met Plasma, hope that I knew that there's

SPEAKER 0
[00:28:52,390]support

SPEAKER 1
[00:28:53,290]there to support you, but all those years I didn't know. So I was caring for my daughter. couldn't work

SPEAKER 1
[00:29:04,050]I couldn't get any money. I didn't have anything. So, it affected me a lot.

SPEAKER 1
[00:29:10,820]physically, mentally, emotionally. I was living, it wasn't easy anyway. Os homens

SPEAKER 1
[00:29:24,400]I didn't give up.

SPEAKER 0
[00:29:27,470]Thank you. So what is the hardest thing about watching your child live with sickle cell disease every day? For you?

SPEAKER 1
[00:29:36,460]The hardest thing is to see her in pain, to see her not having a life like others. It's hard for me because I think to myself, I did it. It's because of me she's suffering. So it's very difficult because eh-eh sometimes I'm just thinking why I wasn't, I didn't take it seriously.

SPEAKER 0
[00:30:06,130]Yeah.

SPEAKER 1
[00:30:06,940]you know, things and then I got there and now she's suffering because of me. I just think it's because of me she's suffering.

SPEAKER 0
[00:30:19,280]Please.

SPEAKER 1
[00:30:20,130]so I blame myself in every way possible. Yeah.

SPEAKER 0
[00:30:27,610]understand Thank you.

SPEAKER 0
[00:30:30,170]Alright, we're going to move on to transition to adulthood. I know you've mentioned a few about how she moved from children's services to adults, but when she was moved from the children's services to adult care, what was the transition like? Was it well managed or did you feel like she was being dropped?

SPEAKER 1
[00:30:50,540]At first she was just being, you know, dropped like, you know what? We're done with you.

SPEAKER 0
[00:30:56,790]Yeah

SPEAKER 1

[00:30:57,360]Вот это

SPEAKER 1
[00:30:58,210]So, yeah. But although, um, the nurse that was looking after her in the children's hospital, she sat us down, she told us what's going to happen, uh, when she goes to the other side and all that. But she did

SPEAKER 1
[00:31:20,340]She told us what was going to happen. But it's just by the end you feel like, you know, oh we are done we are done with you.

SPEAKER 0
[00:31:30,440]Yeah.

SPEAKER 1
[00:31:30,980]just

SPEAKER 0
[00:31:32,050]Okay.

SPEAKER 0
[00:31:33,440]So now that your daughter is 21 and managing her own health, how does it feel to step back from being her primary advocate? Is that easy or difficult for you?

SPEAKER 1
[00:31:46,920]It is difficult because she's like you're saying, she's an adult, a young adult now. So, um, that means I was the one, uh, making sure she had her medication, her appointment. I was, I I I I didn't play with anything. But her being a young adult now is a bit difficult because they want to make their own decisions, they want to do their own things. So it's very difficult because the lifestyle they're living or when I was looking after her was different.

SPEAKER 1
[00:32:27,320]So it is difficult. That's why I was saying they sometimes need to have a group of people sitting down. shared room Yeah share their experience

SPEAKER 1
[00:32:41,740]maybe they will learn from it, but at the same time, they are young adults. They want to do their own things. It is difficult because at some point they don't take their medication, they don't live a good lifestyle, they don't drink.

SPEAKER 1
[00:32:57,440]Hello It's difficult, but it's difficult for me because I can't really say anything at this point. So I have to let her be. So, yeah.

SPEAKER 0
[00:33:08,020]Hello. Thank you. Do you still worry about her in the same way you did when she was a child, or has that changed?

SPEAKER 1
[00:33:17,700]has changed because I believe if she understands what she has to do, she will live longer and a better life.

SPEAKER 1

[00:33:34,100]Well, when she was young, I wasn't thinking, I was thinking, no, she's not going to get to this age. But now that I see that with the treatment, when you really take your treatment and see all the people when sometimes I come to the plasma, you know, gathering, I can see all the people, it gives me hope that she will get there as well.

SPEAKER 0
[00:34:01,720]Yeah

SPEAKER 1
[00:34:02,060]начали Слава Богу.

SPEAKER 0
[00:34:03,530]Yeah, that's fantastic. Right.

SPEAKER 0
[00:34:06,290]So we're going to look back a little bit and then move forward where your daughter is concerned. So do you wish you had uh do you wish or what do you wish had been done differently by the NHS over the course of your daughter's life?

SPEAKER 1
[00:34:23,960]I don't know what to say. Just support and um... um...

SPEAKER 1
[00:34:35,210]Just support basically, good treatment, uh good follow up. That's all.

SPEAKER 0
[00:34:43,330]Okay. Thank you. What do you want healthcare professionals to understand about what it's like to be a parent of a child with sickle cell disease?

SPEAKER 1
[00:34:57,870]Oh, they need to understand that it's difficult to have a... a sick child.

SPEAKER 1
[00:35:07,680]Yeah, because today we are talking about sickle cell because it's something that is not well known, if I can say, but there are many sicknesses you can find yourself with. But they need to know that it's difficult for us parents to cope with a sickle cell child, especially when they're in crisis.

SPEAKER 1
[00:35:35,950]and when they have them at the hospital, give them that support as well. C'est quoi ça ?

SPEAKER 0
[00:35:44,370]So, gene therapy for sickle cell has now been approved. What does that mean for you as a mother?

SPEAKER 1
[00:35:55,270]I didn't get that.

SPEAKER 0
[00:35:57,090]So this new gene therapy where you sort of alter the genes of the patient to try to improve their health and possibly cure sickle cell.

SPEAKER 1
[00:36:09,910]Mmm.

SPEAKER 0
[00:36:10,600]Yeah, how does that make you feel as a mother knowing that that is out there?

SPEAKER 1
[00:36:18,020]That's a good thing. If you can help, I will be more than happy to see him get the treatment.

SPEAKER 0
[00:36:27,800]Nope, okay. What message would you give to a parent who has just found out through newborn screening that their child or baby has sickle cell disease?

SPEAKER 1
[00:36:40,550]Um, I would tell them that it's not the end. That's for once. And get as much support they need because they will need support. They will need someone to be there for them because it's hard.

SPEAKER 1
[00:37:03,400]but they shouldn't give up

SPEAKER 1
[00:37:08,880]If they have support, the appropriate support with them, they would not really feel it because I wish I had that support when she was growing up. If I had that, I wouldn't really feel it, but I didn't have

SPEAKER 1
[00:37:26,920]So. basically she really has that support around her.

SPEAKER 0
[00:37:33,540]Yeah.

SPEAKER 0
[00:37:36,440]Well, thank you so much. That's all for today. Um, your story had love, it had compassion, it had real passion. I could see that you're passionate about your daughter. So this is all going to be part of the booklet now and will reach a lot of people who truly need to hear it. So it will help them on their own journey. We really appreciate you coming in today to do this. Thank you so much.

SPEAKER 1
[00:38:04,020]Welcome. Thank you.

SPEAKER 0
[00:38:05,490]Thank you.

SPEAKER 0
[00:38:13,440]Okay. I'm so done.

SPEAKER 1
[00:38:17,380]southern

SPEAKER 0

[00:38:18,250]Yeah. Thank you so much.

SPEAKER 1
[00:38:25,930]What's

SPEAKER 0
[00:38:27,390]Yeah

SPEAKER 1
[00:38:27,870]How do you take that?

SPEAKER 0
[00:38:28,910]Oh, this is my connection.

SPEAKER 1
[00:38:31,010]Oh, okay.

SPEAKER 0
[00:38:32,650]Thank you.