

Marie-Clare.wav

Plasma of Hope: A Journey of Advocacy and Lived Experience

Summary of Each Speaker

Speaker 0 (Marie Claire Kofi): As the founder of Plasma of Hope and a patient living with sickle cell disease, she provided deep insights into the challenges of navigating the NHS, the life-altering impact of her stroke, and the necessity of systemic change. She contributed her personal narrative to serve as a foundation for the project's advocacy goals.

Speaker 1 (Interviewer): Acted as the project facilitator, guiding the interview process. They contributed by structuring the conversation to highlight Marie Claire's dual role as both a patient and a leader, ensuring that critical gaps in healthcare and patient experiences were clearly documented for the project's upcoming publication.

Key Points and Decisions

Systemic Gaps: Both speakers identified significant deficiencies in the NHS regarding the transition of sickle cell patients from pediatric to adult care. There is a shared understanding that patients are frequently dismissed or not believed, leading to inadequate pain management and care.

Project Objective: The primary decision is to finalize a digital booklet that captures multi-generational stories of those living with sickle cell. This resource is intended to serve as an advocacy tool to influence policymakers and improve clinical understanding.

Commitment to Awareness: The project is committed to highlighting both the positive care experiences and the traumatic failures within the healthcare system to foster a more supportive environment for the next generation of patients.

Next Steps

Marie Claire: Continue to lead the Plasma of Hope initiative, finalize the content for the digital booklet, and maintain advocacy efforts to engage NHS leadership and healthcare professionals.

Speaker 1: Complete the transcription and editing of the interview session to ensure it is ready for inclusion in the final project materials.

Project Team: Distribute the completed digital booklet to the public and relevant stakeholders to raise awareness and drive improvements in sickle cell care protocols.

SPEAKER 0

[00:00:00,000]um uh something something something else things down there like I said there's such a thing called music Oh this part yeah that sounds great um

SPEAKER 1

[00:00:14,730]Okay, hi Marie Claire, thank you for agreeing to be interviewed as part of this project. I know that for you this is a unique and perhaps unusual position.

SPEAKER 1
[00:00:25,750]being both the person who created this work and one of the people whose story it was built to tell.

SPEAKER 1
[00:00:33,120]that dual role makes your voice one of the most important in the entire booklet.

SPEAKER 1
[00:00:40,200]In your foreword, you already spoke as a leader and as an advocate.

SPEAKER 1
[00:00:45,970]In this interview, we want to hear from you as a patient, as a woman who has lived with sickle cell for over twenty years in the UK, who has survived a stroke and who has navigated the same NHS system

SPEAKER 1
[00:01:04,420]that is at the heart of everything this project explores Always you are completely in control of this conversation You can pause at any time skip anything you do not wish to answer

SPEAKER 1
[00:01:19,030]or stop the recording whenever you choose to The recording will be a maximum of two minutes and written questions can be completed in your own time So whenever you're ready

SPEAKER 0
[00:01:32,300]Thank you. I am ready. Oh, sorry. You were supposed to record that.

SPEAKER 1
[00:01:39,860]It's recording but this has gone off.

SPEAKER 0
[00:01:43,170]No, it means it's not recording Yeah, it shouldn't go off when it's recording Yeah, you're supposed to do that and record

SPEAKER 0
[00:01:55,680]So you record and then, yeah okay, yeah no just leave it, it's recording So, yeah Just keep off here, okay? Yes.

SPEAKER 1
[00:02:05,280]That's going to get on the mic, it's very loud.

SPEAKER 0
[00:02:07,350]It is, yeah Good

SPEAKER 1
[00:02:10,919]Hi Marie Claire, thank you for agreeing to do this interview.

SPEAKER 1
[00:02:19,310]uh as part of this project. I know that for you, this is a unique and perhaps unusual position.

SPEAKER 1
[00:02:27,560]Being both the person who created this work and one of those people whose story it was built to tell. The dual role makes your voice one of the most important in the entire booklet.

SPEAKER 1
[00:02:41,690]In your forward, you already spoken, oh gosh

SPEAKER 0
[00:02:47,400]Sorry.

SPEAKER 1
[00:02:51,960]And you're forward, you already spoke.

SPEAKER 0
[00:02:54,820]Sorry, sorry.

SPEAKER 1
[00:02:55,770]Yeah, so just close it.

SPEAKER 0
[00:02:58,100]Is it closer? Yeah, I have... I wish I could print it. Yeah.

SPEAKER 1
[00:03:01,540]and larger. It's really small so it's just...

SPEAKER 0
[00:03:03,520]Yes.

SPEAKER 1
[00:03:04,560]I'll start again and you can cut that out.

SPEAKER 0
[00:03:07,540]you can, yeah, we can cut you off now.

SPEAKER 1
[00:03:11,260]Good afternoon Marie Claire and thank you for agreeing to be interviewed as part of the Sorry, my screen is crazy.

SPEAKER 0
[00:03:22,650]It's okay.

SPEAKER 1
[00:03:23,960]as part of this project.

SPEAKER 0
[00:03:25,650]No, no, no, start again. We have to have a flow.

SPEAKER 1
[00:03:28,000]I have to have a flower. Yeah.

SPEAKER 0
[00:03:30,040]It's okay.

SPEAKER 0
[00:03:34,450]Okay. Yeah. Alright, just speak up here. Okay.

SPEAKER 1
[00:03:39,560]Good afternoon Marie Claire and thank you for agreeing to be interviewed as part of this project. I know that for you, this is a unique and perhaps unusual position.

SPEAKER 1
[00:03:52,510]be both the person who created this work and one of the people whose story it was built to tell. That dual role makes your voice very important to this entire booklet.

SPEAKER 0
[00:04:06,650]Sorry.

SPEAKER 1
[00:04:08,520]In your forward, you already spoke as a leader and an advocate. In this interview, we want to hear from you as a patient, as a woman who's lived with sickle cell disease.

SPEAKER 1
[00:04:22,610]for over twenty years in the UK, who has survived a stroke, and who has navigated the same NHS system that is at the heart of everything this project explores.

SPEAKER 1
[00:04:34,930]As always, you are completely in control of this conversation. You can pause at any time, skip anything you do not wish to answer, or stop the recording whenever you choose to.

SPEAKER 1
[00:04:47,970]Recording will be a maximum of two minutes and the written questions can be completed in your own time. So, whenever you're ready.

SPEAKER 0
[00:04:58,660]Okay.

SPEAKER 1
[00:05:00,290]Okay. All right. So, you created this project because of your own lived experience of sickle cell disease.

SPEAKER 1
[00:05:11,260]What did it mean to spend two years gathering other people's stories when you were living one yourself?

SPEAKER 0
[00:05:19,350]Well, two years ago when I came up with the idea of the project. Well, the idea came before that, but we started it two years ago.

SPEAKER 0
[00:05:29,300]I never thought that I would be listening to all the people's stories and reflecting on my own experience of living with sickle cell.

SPEAKER 0
[00:05:42,940]Listening to all those stories that we have recorded in the past two years.

SPEAKER 0
[00:05:50,180]has given me not just the experience of their own lives living with sickle cell but

SPEAKER 0
[00:06:00,960]it showed me that we are the same people. We have the same struggles. And it's really opened my eyes on what sickle cell does to an individual.

SPEAKER 0
[00:06:15,950]because all of these stories are the same. They have very different experiences and that is the beauty that we have captured. So it's meant quite a lot to me especially

SPEAKER 0
[00:06:30,660]living with a condition and listening to people of various ages, what they have gone through, what they have lived

SPEAKER 0
[00:06:40,200]life with sickle cell and how that has impacted their lives.

SPEAKER 1
[00:06:46,630]Thank you so much for that. Okay. Um, so you've lived with sickle cell disease for over twenty years in the UK and you have survived a stroke.

SPEAKER 1
[00:07:00,250]what has what what does that journey through the NHS been like What kept you going

SPEAKER 0
[00:07:08,500]That journey has been a roller coaster. And

SPEAKER 0
[00:07:19,100]I'm not sure where to begin with to answer that question what kept me going Because there were many times where I felt like I could not possibly do this anymore

SPEAKER 0
[00:07:31,890]We have a fantastic healthcare system where it looks after people to the best of their abilities But unfortunately, people like myself live with a condition that

SPEAKER 0
[00:07:46,380]is not widely understood within the NHS. and I have had several experiences of

SPEAKER 0
[00:07:56,680]having to be in hospital within the NHS setting

SPEAKER 0
[00:08:03,620]and did not have the care that I needed. And listening to stories from other people, it has not been anything different.

SPEAKER 0
[00:08:15,040]Don't get me wrong, I've had some fantastic care throughout the years. But I've had some not so good care and this is what we want to establish. What really has changed if at all?

SPEAKER 0
[00:08:29,220]I have been a patient on the NHS for twenty years. And I believe that I would not

be alive today if it wasn't for the NHS.

SPEAKER 0
[00:08:40,870]and that is why Plasma of Hope is dedicated to working with healthcare professionals. But many years ago I suffered a stroke.

SPEAKER 0
[00:08:50,960]Because I was in a setting that did not truly understand what it means to live with sickle cell.

SPEAKER 0
[00:08:58,500]And unfortunately the protocols were not in place to take care of myself and we've heard stories like this across the country over and over again.

SPEAKER 0
[00:09:11,460]That stroke changed my entire life and it was from that moment that I decided that something needs to change.

SPEAKER 0
[00:09:23,470]Yes, it has been challenging but I must acknowledge the fact that I would not be alive today if it wasn't for the NHS.

SPEAKER 0
[00:09:32,980]And I know that as we go along, we will see improvement.

SPEAKER 1
[00:09:40,940]Thank you so much.

SPEAKER 1
[00:09:45,440]Just post it. Not stop it. Just post it. It's really hot.

SPEAKER 0
[00:09:51,600]Oh yeah.

SPEAKER 1
[00:09:52,450]Can I open this? Can we open this? We're literally cooking ourselves. Yes.

SPEAKER 0
[00:09:56,220]It will echo, but I think it should be okay. Yeah.

SPEAKER 0
[00:10:06,460]Yeah. That's why he's sitting there. He's nervous. Ah, under the sun too. Ooh.

SPEAKER 1
[00:10:17,200]Yeah.

SPEAKER 0
[00:10:18,140]It would have been nice under the sun, but no. Okay.

SPEAKER 1
[00:10:22,250]Okay, so, uh, question three. How long is that?

SPEAKER 0

[00:10:28,850]Yeah.

SPEAKER 1
[00:10:32,450]Okay. So you build Plasma of Hope from your own pain and your own determination. What do you want this booklet and this project to change?

SPEAKER 0
[00:10:44,810]Well, yes, about Plasma of Hope from my own experience, and not just my own experience, but from the experience of people.

SPEAKER 0
[00:10:55,410]Living with a condition within my community and, and what I would love for this project, not just the booklet, to highlight.

SPEAKER 0
[00:11:04,870]It's the gaps that are within the system in supporting people like myself across the nation with sickle cell disease.

SPEAKER 0
[00:11:14,520]I want this, this, this, this project to highlight the fact that there are people, real people, that have a really severe chronic illness regardless of their age.

SPEAKER 0
[00:11:28,790]They have had some form of treatment, not so good and good, good treatment.

SPEAKER 0
[00:11:37,050]So, we have interviewed people across generations and we want to see what the experiences have been. We've spoken to people that are over sixty, we've spoken to parents.

SPEAKER 0
[00:11:51,330]We've spoken to teenagers and we just want to establish what has changed over the years. And I do hope that things are moving forward.

SPEAKER 0
[00:12:04,330]But looking at where we are and what is going on across the country, it really breaks my heart. Because sickle cell is one of the fastest growing genetic conditions in the UK.

SPEAKER 0
[00:12:19,310]But there isn't enough research to understand how the quality of life can be improved for these people.

SPEAKER 0
[00:12:29,350]So, I want this project to highlight all the gaps and also highlight the fantastic work of the clinicians, the hematologists.

SPEAKER 0
[00:12:39,520]The researchers, the community people, the community organizations and every family that has been affected by sickle cell is doing to improve the lives of people like myself.

SPEAKER 0
[00:12:51,560]So as much as there hasn't been a lot of improvement, we are hoping that this project will highlight the gaps. And in so doing, the NHS can use that

SPEAKER 0
[00:13:03,380]to make adjustments and make improvements where it needs to be.

SPEAKER 1
[00:13:09,100]That's fantastic. Thank you so much. So, uh, let's go back to when you were diagnosed with sickle cell disease and what you remember about the first understanding.

SPEAKER 1
[00:13:21,990]What does it meant for your life that you've just been diagnosed with sickle cell?

SPEAKER 0
[00:13:26,880]Well, I do not remember much because I was diagnosed when I was about three years of age. And

SPEAKER 0
[00:13:36,970]I ma- from what my parents told me, I wasn't sick initially when I, at that young age, but as I was growing up

SPEAKER 0
[00:13:45,650]I became quite sick and it was very evident because my older brother also had sickle cells. So when I got tested, you know, it was quite evident.

SPEAKER 0
[00:13:54,810]But it was very challenging and I have shared my experiences, uh, time and time again. You know, living with sickle cell as a young person, as a little girl.

SPEAKER 0
[00:14:05,890]Put me in a position in society where I did not quite feel like a little girl that had love.

SPEAKER 0
[00:14:14,950]Uh, my family and my immediate siblings care about me and love me very much. But the society, the community that I grew up in did not fully understand what sickle cell was all about and

SPEAKER 0
[00:14:29,240]and as a result, I wasn't treated with much kindness. But things have improved. There is a lot of awareness. And we're hoping that as we continue to create awareness, people will become more aware and more tolerant.

SPEAKER 0
[00:14:44,410]of those living with sickle cell. And more supportive.

SPEAKER 1
[00:14:48,990]Yeah. That's very true. So, in that same light, thinking about your care, what was your experience of sickle cell care like in the years before you came to the UK?

SPEAKER 1
[00:15:02,840]How did that compare to what you encountered under the NHS here?

SPEAKER 0
[00:15:08,030]Well, that's interesting because, um, it was tough. It was tough. It was difficult.

SPEAKER 0
[00:15:17,060]Um, there wasn't a lot of knowledge and care and medical intervention. And unfortunately,

SPEAKER 0
[00:15:31,440]people that are born with sickle cell in Africa, some of them don't live up to the age of five due to the lack of, you know, medical intervention and the resources aren't readily available.

SPEAKER 0
[00:15:45,300]So it was really a challenge. And there were so many moments where I thought, and my family thought, that that was going to be the end of it. But luckily, I am here today.

SPEAKER 0
[00:15:58,330]So it was really difficult growing up and, uh, the treatment was not as you would have wished, but I believe they did their best with the resources that they had. Yeah.

SPEAKER 1
[00:16:11,750]Thank you. You're welcome.

SPEAKER 1
[00:16:15,820]I pause again 'cause the sun is moving and the shadow is coming.

SPEAKER 0
[00:16:20,500]Okay, I have to move. Yeah. Yeah. I just need to move.

SPEAKER 1
[00:16:26,580]Your shadow is so small.

SPEAKER 0
[00:16:29,050]Oh, I see. Right. You can put that chair down. Put it down. Oh, you need to sit faster.

SPEAKER 0
[00:17:17,130]and just sweep it. Yeah. Yeah.

SPEAKER 0
[00:17:27,550]It's okay. It's okay.

SPEAKER 1
[00:17:33,150]So we just finished the care experience. Okay. Now we're going to.

SPEAKER 0
[00:17:47,560]OK. Ouais. Cool.

SPEAKER 1
[00:17:52,770]All right. So, um...

SPEAKER 1
[00:17:57,610]Over more than twenty years under the NHS, what has your experience of the care been like? Well, where has it served you well and where has it let you down?

SPEAKER 0

[00:18:09,920]Well, I would say the majority of the time it has served me well. I have had some really great care. I have had two children. And living with sickle cell.

SPEAKER 0
[00:18:23,420]And being pregnant is not something that, you know, has to be taken lightly. But I have been supported throughout the process of my pregnancy, throughout the process of delivery. It was a challenge.

SPEAKER 0
[00:18:36,550]but the NHS was there for me. I have had multiple episodes of crisis and I have been given the care that I needed most of the time.

SPEAKER 0
[00:18:49,990]It's rather unfortunate that I suffered a stroke, um, in the hands of people that should have catered for me. Uh, but I believe that

SPEAKER 0
[00:19:01,140]we've learned from that process and I hope that we have truly learned from that process. But personally, I have received some great care from the NHS. And again,

SPEAKER 0
[00:19:14,180]I would not be alive today if it wasn't for them. Yes, things could be done to improve it. And that's why we work very closely with healthcare professionals and university establishments.

SPEAKER 0
[00:19:27,430]to raise awareness and provide the education that is needed to provide care to people like myself.

SPEAKER 1
[00:19:35,800]Thank you. So still in care, have there been moments when you felt dismissed, not believed, or not treated with the urgency your condition required? How did that affect you?

SPEAKER 1
[00:19:50,110]I know you mentioned the stroke. Yeah, but could you tell us a bit more?

SPEAKER 0
[00:19:54,480]There have been several moments aside from when I had the stroke, and several moments where I have had an encounter with healthcare professionals that do not fully understand sickle cell.

SPEAKER 0
[00:20:09,960]moments where I have been in severe pain and they did not take my pain seriously.

SPEAKER 0
[00:20:18,760]moments where I have asked for things like morphine and it wasn't given to me in time to take care of my pain because

SPEAKER 0
[00:20:31,600]the healthcare professionals did not believe that I was truly in that much pain and of course what happened when I had a stroke. So, and listening to what is happening across the country and people.

SPEAKER 0
[00:20:45,930]talking about the experiences of not being believed. It breaks my heart, especially following the No One's Listening report which came out in twenty twenty-one.

SPEAKER 0
[00:20:58,700]And we would think that things like that will not be happening. It still is. And I hope that this project will not only collect experiences of people living with the condition.

SPEAKER 0
[00:21:12,650]but also highlight some of those gaps that need to be filled because a lot still has to be done to cater for people with sickle cell.

SPEAKER 1
[00:21:23,480]Thank you so much.

SPEAKER 1
[00:21:27,900]Okay, so the questions are long.

SPEAKER 0
[00:21:32,000]Ah, we got uh I have a lot.

SPEAKER 1
[00:21:34,910]Twenty questions. And we are just on number five.

SPEAKER 0
[00:21:39,440]So I need to cut it short then. I don't know if you talk too much.

SPEAKER 1
[00:21:42,950]Yeah, but the sun keeps moving, so the shadow is following us. And we need to keep moving, moving, moving.

SPEAKER 0
[00:21:50,790]Yeah, it's becoming basic.

SPEAKER 1
[00:21:52,440]Can we have the lights on?

SPEAKER 0
[00:21:54,330]Oh, that's the thing.

SPEAKER 1
[00:21:55,780]Let's see.

SPEAKER 0
[00:21:57,480]Will it make any difference?

SPEAKER 1
[00:22:00,130]No, I mean inside. If we go inside and put the lights on, would it be brighter?

SPEAKER 0
[00:22:05,780]I couldn't see that picture up there either.

SPEAKER 0

[00:22:12,770]Cool. Wait, let me, let me try something. Awesome. Let me try something.

SPEAKER 0
[00:22:25,030]Ah, c'est bon, non ?

SPEAKER 0
[00:22:30,170]Abraça Não, vamos over. It's like a few because the light is behind you.

SPEAKER 1
[00:22:39,000]Oh yeah, come on, look.

SPEAKER 0
[00:22:43,960]Ligar

SPEAKER 0
[00:23:04,220]你看看这个，这个是，这个是。

SPEAKER 0
[00:23:11,930]어, 그거 내가 했다고 하면 안 되는 거야? 我叫你不要动，你动了。

SPEAKER 0
[00:23:20,760]这是什么东西？

SPEAKER 1
[00:23:34,790]Yeah, I'll try and make short answers today. This one's for you.

SPEAKER 0
[00:23:40,130]这啥呀，真他妈难闻。No, it's gonna cost a lot of money. Oh gosh. It's a quick event.

SPEAKER 0
[00:23:47,010]Come on. Yeah. Okay.

SPEAKER 0
[00:24:17,260]Yeah, there it is. She's making croissants.

SPEAKER 1
[00:24:25,440]So we're just on number five.

SPEAKER 0
[00:24:28,110]Okay. Trying to keep it short.

SPEAKER 1
[00:24:32,680]Okay, tell us about the stroke you suffered. Okay.

SPEAKER 1
[00:24:42,900]Okay. Um, can you tell us about the stroke you suffered? What happened and how did it change your life?

SPEAKER 0
[00:24:52,350]Well, that was a horrible experience. I had had a CVA prior to the stroke. I had a

CVA.

SPEAKER 0
[00:25:01,400]uh sickle cell crisis that had gone on for several days and it wasn't getting better, it was only getting worse.

SPEAKER 0
[00:25:10,540]I was back and forth to the hospital and one of the days that I got discharged, I was feeling quite unwell, so I had to go back into A&E.

SPEAKER 0
[00:25:23,610]and when I got into A&E.

SPEAKER 0
[00:25:26,920]Unfortunately, I wasn't seen within the timeframe that I would have loved to be seen.

SPEAKER 0
[00:25:34,070]and I was kept waiting for some time and unfortunately my body gave up on me.

SPEAKER 0
[00:25:42,790]And as a result of that, I suffered a stroke, and that changed my entire life.

SPEAKER 0
[00:25:49,360]and you know, but again, it was from that experience that plasma of hope was born.

SPEAKER 0
[00:26:01,580]So, as much as I regret having that experience, it's led to something great that can change people's lives.

SPEAKER 1
[00:26:12,440]That might be a very frightening moment. But do you remember how the NHS responded in the immediate aftermath of your stroke? Did you feel well supported in your recovery?

SPEAKER 0
[00:26:25,430]To an extent, yes, to an extent. I unfortunately had to spend quite a while in hospital. uh very long time and I was supported to the best of my ability.

SPEAKER 0
[00:26:37,620]I would say that. Uh, but unfortunately again, I wasn't, I wasn't put through the right recovery process.

SPEAKER 0
[00:26:46,840]there's a lot of things that could have been done for the effects of the stroke not to have lasted as long as it has. Obviously, it's been it's been over

SPEAKER 0
[00:26:59,000]fifteen years ago and I'm still suffering from, you know, the effects of the stroke on my left side and and uh they did their best they could but I think a lot more could have been done.

SPEAKER 0
[00:27:11,830]Yeah.

SPEAKER 1
[00:27:14,390]So, how has surviving a stroke shaped the way you think about sickle cell disease, about healthcare, and about your own future?

SPEAKER 0
[00:27:25,990]I think not just stroke, but the stroke actually highlighted a few things for me. Living with sickle cell is so unpredictable. Anything can change.

SPEAKER 0
[00:27:38,700]your life can change at any time. I was able and working and

SPEAKER 0
[00:27:45,690]Within the twinkle of an eye, I had to depend on other people to enable me to have a quality of life.

SPEAKER 0
[00:27:55,110]So it really opened my eye and it's changed the way I live and the way I see life because

SPEAKER 0
[00:28:03,700]I always say that I take one day at a time but I try to make the most of every single day because living with sickle cell you are never sure what tomorrow is going to be like.

SPEAKER 0
[00:28:16,060]Nobody's sure what tomorrow's going to be like, but living with sickle cell is even more so, because you can be sitting here and having a fantastic day and the next minute, you are in a severe crisis.

SPEAKER 0
[00:28:28,760]and being saved in the ICU. That is the life that we live and the stroke highlighted to me that I have to cherish every moment I am well.

SPEAKER 0
[00:28:41,150]every moment I have to spend with my loved ones. And that's what I do every single day.

SPEAKER 1
[00:28:47,510]That's very inspirational, but just lastly on the stroke, what did you have to rebuild after the stroke, physically, emotionally, and professionally?

SPEAKER 0
[00:28:59,610]Sigh. Yeah. I had to rebuild a lot. I couldn't use all of my left side. I had to learn how to do certain things again. Um.

SPEAKER 0
[00:29:11,240]And I think the most difficult thing that I had to build again was my emotional well-being, my mental well-being.

SPEAKER 0
[00:29:21,350]it took me to a place where I did not believe that I was going to be strong again

and live a normal life.

SPEAKER 0
[00:29:32,840]It was very difficult for me to come out of that, but thankfully with the support of my family and friends,

SPEAKER 0
[00:29:41,960]I was able to come out of that place and I am still struggling with it today, but I am in a much better place because I have lived to understand that I am not the only one living with this challenge.

SPEAKER 0
[00:29:55,960]and working through Plasma of Hope and experiencing other people's challenges has given me the hope to not only keep going but keep working together with every single person that lives with sickle cell.

SPEAKER 0
[00:30:09,160]and inspiring them to know that we have got this and we've got to keep going regardless.

SPEAKER 1
[00:30:16,050]Thank you, Maria.

SPEAKER 0
[00:30:18,540]You're welcome.

SPEAKER 0
[00:30:20,960]Okay, I need to go and get some more water.

SPEAKER 1
[00:30:25,240]No, um, ninety percent are gonna go.

SPEAKER 0
[00:30:28,470]Ooh! Um, I didn't tell you yet. No, I have a violin.

SPEAKER 1
[00:30:33,790]Is it on the laptop?

SPEAKER 0
[00:30:35,090]I don't know where it is, to be honest. I've been looking for that part my whole life.

SPEAKER 1
[00:30:39,850]So maybe the questions on the laptop I could take it.

SPEAKER 1
[00:30:44,730]Oh, really? Oh, goodness.

SPEAKER 0
[00:30:50,170]Mm-hmm.

SPEAKER 1
[00:32:02,940]Okay.

SPEAKER 1
[00:32:06,970]But we lost it. I just got it. Okay, this is another one.

SPEAKER 1
[00:32:20,420]Okay.

SPEAKER 1
[00:32:28,530]Okay.

SPEAKER 1
[00:32:34,500]So we talked about the stroke and its aftermath.

SPEAKER 1
[00:32:42,690]Being a patient and a leader. Okay.

SPEAKER 1
[00:32:48,390]Ready?

SPEAKER 1
[00:32:53,040]Thanks again, Mary Claire. Now we're going to talk about being a patient and a leader.

SPEAKER 1
[00:32:59,300]So you founded Plasma of Hope whilst living with sickle cell disease yourself. How have you managed your own health alongside building a leading building and leading an organization like that?

SPEAKER 0
[00:33:13,800]Oof. It has not been easy. Uh, we started Plasma of Hope when I just had a baby. It was tough.

SPEAKER 0
[00:33:27,360]Um, but over the years, I've had the privilege to work with some wonderful people who have dedicated their lives to supporting people like myself.

SPEAKER 0
[00:33:40,300]so I wouldn't say that it's been something that has been on my shoulder alone. It has not been easy being a leader and also being a patient.

SPEAKER 0
[00:33:54,670]because there are moments where my body will just tell me I need a break because it is tough living with sickle cell, your energy level is 50% or less most of the time.

SPEAKER 0
[00:34:08,750]But then again, you are dedicated to leading a charity that supports people living with the condition. And I think for me, the one thing that has always inspired me

SPEAKER 0
[00:34:22,110]is the passion for this work. And that alone has given me the energy and the inspiration that I needed.

SPEAKER 0
[00:34:30,540]So, I believe that's where my energy is coming from because if you ask me again, I

truly do not know how I do it.

SPEAKER 0
[00:34:38,770]but working with people and seeing the impact that, you know, our intervention brings to their lives gives me the inspiration and the momentum and the zeal to keep

SPEAKER 0
[00:34:52,510]going Yeah.

SPEAKER 1
[00:34:55,080]You sound very passionate about the work. So, has your lived experience of sickle cell ever been dismissed or underestimated in professional settings or even as the CEO of a sickle cell charity?

SPEAKER 0
[00:35:10,050]Well, my lived experience has been dismissed most of my life. Uh, but it's how I navigate that's important.

SPEAKER 0
[00:35:19,080]Um, I've had several moments where I have not been taken seriously because I demonstrate strength most of the time.

SPEAKER 0
[00:35:29,050]and it can make people think that, you know, when you talk about the challenges that comes with sickle cell, some people find it very difficult to

SPEAKER 0
[00:35:43,700]to believe you and I've had that several times even within my own close family unit, within my friends, within the community. And it makes it really hard for you to

SPEAKER 0
[00:35:57,620]just make people understand that yes you are living with something that you know half of the time you're not able to carry yourself but we do

SPEAKER 0
[00:36:07,190]So, yeah, I have faced those moments. Yeah.

SPEAKER 1
[00:36:13,390]Thank you. So, what does it feel like to be interviewing others about the experience of the condition you're also living with every day?

SPEAKER 0
[00:36:23,100]Wow, it's very inspirational. Um, when we started this project

SPEAKER 0
[00:36:33,610]It made me reflect a lot on my own life. on living with the condition and just understanding what it has done to me as a person.

SPEAKER 0
[00:36:46,850]I have had the, you know, the privilege of listening to most of the stories and experiences of those who have been part of this project.

SPEAKER 0

[00:36:58,850]And it's been a really special moment because everyone has a different experience.

SPEAKER 0
[00:37:09,110]and some of those who have taken part have been so kind, we share them in their most vulnerable state.

SPEAKER 0
[00:37:18,920]and it's giving me even more reasons to keep going and keep doing this work because it's some of these stories and challenges and good moments that I would love to highlight through this project.

SPEAKER 0
[00:37:33,650]for people to understand exactly what it means living with the condition, especially for those within the healthcare setting. Yeah.

SPEAKER 1
[00:37:47,260]Looks like you're doing an amazing job. So how has your own experience as a patient shaped the kind of organization Plasma of Hope has become?

SPEAKER 0
[00:37:58,270]Uh, I think Plasma of Hope started from my own personal experience and every single thing that

SPEAKER 0
[00:38:07,120]I have put in it every single effort that I have put within the organization has been based on my own personal experience.

SPEAKER 0
[00:38:15,610]Every story, every project that I have brought forth has been from my own personal experience because I know truly what it means living with the condition.

SPEAKER 0
[00:38:26,980]And I believe that when I put myself within the projects that we have run, which we are running.

SPEAKER 0
[00:38:37,790]I believe that people will relate, especially the families that are affected with the condition because many a times you get healthcare professionals willing to help but you do

SPEAKER 0
[00:38:48,640]do not understand how to help, but for someone living with the condition, I have first-hand experience.

SPEAKER 0
[00:38:56,370]of what it takes to live with it, what it takes for my family to go through living with all the challenges that I face.

SPEAKER 0
[00:39:05,960]So it has been not only personal but something truly inspirational to put myself within the very thing that I put to support people.

SPEAKER 0
[00:39:18,770]So it means a lot to me that I suffer with sickle cell and I provide the support. And

especially those who have dedicated themselves, we also have our volunteers who are also sickle cell patients.

SPEAKER 0
[00:39:31,970]We have volunteers who have never heard about sickle cell but are now experts in sickle cell. And that little unit of people dedicated to serve

SPEAKER 0
[00:39:45,370]has given me even more inspiration to keep doing this work.

SPEAKER 1
[00:39:49,630]Yeah. It's fantastic. Okay. So we're going to move on now to the uh what this project has meant to you. So over the years of gathering these stories

SPEAKER 1
[00:40:01,640]What has surprised you the most about what you have heard?

SPEAKER 0
[00:40:08,770]Oof, a lot of things have surprised me. We have spoken to people of different ages.

SPEAKER 0
[00:40:20,650]People have shared different experiences. But one of the things that really was highlighted to me was the fact that

SPEAKER 0
[00:40:33,080]there is a big gap, a transition gap. We have spoken to many parents and young people living with sickle cell that have

SPEAKER 0
[00:40:44,760]Some of those young people have transitioned into adult care. And those experiences have not been very good to listen to. They've had great care as pediatrics as when they were children.

SPEAKER 0
[00:40:58,660]But from the moment they went into adult care, it wasn't so good, especially at the very early stages.

SPEAKER 0
[00:41:07,120]So the one thing that has been highlighted to me in this project is that a lot of care and attention needs to be put, a lot of work needs to be put within the transition process for those living with sickle cell and

SPEAKER 0
[00:41:22,300]there has to be a proper framework, not just involving the patients but the whole family, the schools, the local authority, the psychologist.

SPEAKER 0
[00:41:32,730]Everybody needs to come in together and work as a collective to prepare these young people transitioning into adult care because their care is going to be in their own hands.

SPEAKER 0
[00:41:43,910]and they have no idea what to do. And we don't want that happening. So yeah.

SPEAKER 1
[00:41:51,630]Yes. Thank you. Now, having heard other people's stories and experience of sickle cell, has it changed how you see your own?

SPEAKER 0
[00:42:03,580]It has to an extent. And again, you know, sickle cell affects people differently. and some of the experiences that I have heard, I thought I had it bad. No, I didn't.

SPEAKER 0
[00:42:17,680]I've had people that have had worse experiences than me and still get up every morning, every single day, doing what they love doing, even in the most difficult moments.

SPEAKER 0
[00:42:31,850]So, what that has taught me is that yes, we live with sickle cell but we cannot let it define us. Whatever purpose that we have as individuals living with a condition

SPEAKER 0
[00:42:45,310]We have to keep fulfilling those purposes and living life truly and enjoying every bit of it despite the challenges.

SPEAKER 1
[00:42:57,440]Thank you so much. So, we're moving forward. What has been the most difficult part of leading this project as someone who is also living with the story it tells?

SPEAKER 0
[00:43:12,020]Yeah, there's been quite a lot of challenges. I think for me the the most difficult part has been having to to reschedule a lot of

SPEAKER 0
[00:43:25,240]appointments because we are dealing with people that live with a condition that is very unpredictable. And there are moments where we've had to

SPEAKER 0
[00:43:37,140]canceled many interviews because people have been unwell.

SPEAKER 0
[00:43:41,970]And there are also moments that I've had to listen to some really difficult experiences that I've had to take a break, not just for me, but for the entire team.

SPEAKER 0
[00:43:55,800]and some of these experiences have been so traumatic that thankfully the National Lottery Heritage Fund has provided resources for us to seek

SPEAKER 0
[00:44:09,550]you know, counseling throughout this process. But it has been very difficult to listen to some of these experiences. And it makes me think of how grateful I am to be alive.

SPEAKER 0
[00:44:23,400]and having the opportunity to do this work.

SPEAKER 1
[00:44:27,890]Thank you. So, um, what do you most want readers of this booklet to take away from your story?

SPEAKER 1
[00:44:36,820]specifically not as the CEO, but more importantly as the patient.

SPEAKER 0
[00:44:42,640]Sigh. Yeah, thank you for that. So, as part of this project, we are going to be producing booklets that will be available digitally so that everyone can have access to it.

SPEAKER 0
[00:44:54,780]And what I truly want to be highlighted in this booklet is for people to see the experiences of those living with a condition

SPEAKER 0
[00:45:03,880]and see how the treatment and management of sickle cell has evolved over the years. We've had the privilege of speaking with some of the experts within the sickle cell community.

SPEAKER 0
[00:45:18,430]We've spoken to consultants who have shared their experience as clinicians.

SPEAKER 0
[00:45:27,540]And some of those experiences have been quite touching because sickle cell has been in the UK for a very long time.

SPEAKER 0
[00:45:36,580]And unfortunately things are not moving as fast as we would love to, but again, they are moving and I do appreciate that it is not easy, it takes time, it takes resources.

SPEAKER 0
[00:45:50,320]But I want people to understand what it truly means to live with a condition. that you wake up one morning and not sure what day you're going to have.

SPEAKER 0
[00:46:02,250]or if you're going to end up in hospital or spend moments with your friends and family. So that's what I want people to understand about the condition.

SPEAKER 1
[00:46:15,800]must be hard to navigate. Right, so we're going to move on to the future of this whole project. What does the future where this booklet has made a real difference look like to you?

SPEAKER 0
[00:46:30,030]Well, the whole point of this project was to highlight the journey of sickle cell within the UK.

SPEAKER 0
[00:46:38,580]And I'm hoping that from the work that we have done, it will highlight some of the things that need improving.

SPEAKER 0
[00:46:48,740]and also highlight some of the good practices and wonderful experiences that people have experienced, not just within the community but more so within the clinical setting.

SPEAKER 0
[00:47:00,900]And we want to highlight how the management has and treatment has evolved throughout the years.

SPEAKER 0
[00:47:10,030]And I'm hoping that from that thing that we are trying to highlight, policymakers will act on this and see that this

SPEAKER 0
[00:47:22,990]a lot that needs to be done and we're happy and so are all the other organizations working so hard to provide care and support to people living with the conditions.

SPEAKER 0
[00:47:33,700]So I hope that this project will highlight all of that and give room for better things to come.

SPEAKER 1
[00:47:40,950]It's amazing. So if you could speak directly to the NHS leadership responsible for sickle cell care, what would you say to them?

SPEAKER 0
[00:47:50,880]What I would say is that please listen to your patients and believe them when they say that they need help.

SPEAKER 0
[00:48:00,870]The NHS is doing a fantastic job caring for the community, caring for every single person who walks through the door.

SPEAKER 0
[00:48:10,750]but there is a lot of lack of awareness, lack of resources, and there are so many healthcare professionals that are willing and ready

SPEAKER 0
[00:48:21,990]to care because that is what they signed the oath for. But they do not have the resources to provide that care that is needed.

SPEAKER 0
[00:48:32,170]So I am hoping that the NHS will provide the resources, be it advocacy, be it education, be it financial.

SPEAKER 0
[00:48:44,910]to healthcare professionals and also to remember that we as community organizations can work very closely with the NHS to achieve some of these goals.

SPEAKER 0
[00:48:58,530]And I hope that they will take this on board.

SPEAKER 1
[00:49:01,980]Well, you surely hope they do. What do you want for the next generation of people born with sickle cell disease in the UK?

SPEAKER 0
[00:49:12,380]I want the next generation to believe about their condition, to be supported both

physically and mentally.

SPEAKER 0
[00:49:24,510]to know that there are people not just within the community but within the healthcare setting that are available and ready to cater for them.

SPEAKER 0
[00:49:34,610]and also for them to understand that there are opportunities for those living with the condition, be it at work, whatever you want to become in life.

SPEAKER 0
[00:49:48,090]there has to be that opportunity for young people to be able to express themselves, express the challenges that they face

SPEAKER 0
[00:49:58,080]So that they can get the help that they need to flourish as young people and become somebody in the future. We've had the privilege to interview a lot of young people in this project. And I do hope that this will inspire other young people to share their experiences so that we can have better improvement of the service that we will provide.

SPEAKER 1
[00:50:21,370]That's just really amazing. But just one last question. After everything you have been through and everything you have built, what gives you the most hope?

SPEAKER 0
[00:50:32,890]Oh, what gives me the most hope is that things are going to get better. Because that's why we're doing all of this work. I believe that someday we will live in a world where everyone is being treated fairly regardless of their medical needs. And there's a lot of good things happening in sickle cell. We have new developments in treatments and interventions.

SPEAKER 0
[00:51:01,000]So, new therapies are coming up, so it gives me hope that the quality of life of individuals living with the condition is only going to go on an upward trajectory. So, all we need to do is to work closely with healthcare professionals, with researchers, community leaders, and families to just provide the care that each and every single person living with a chronic illness needs.

SPEAKER 1
[00:51:29,970]Yeah. Thank you so much, Marie Claire. Your story is the heart of this project. The courage it takes to share it alongside leading it is remarkable. Thank you once again.

SPEAKER 0
[00:51:42,240]Thank you so much. Thank you. My pleasure.

SPEAKER 0
[00:51:46,210]Okay, do some time for Amazon. Oh, sis. How long? Yeah, like I have a lot of work to cut this here.

SPEAKER 0
[00:51:57,370]It's uh forty-one minutes. It's okay, not to talk for an hour, so that's good. Yeah, I don't know what he's gonna just put this, but all of this has to go on Facebook.

SPEAKER 1

[00:52:10,770]Okay.

SPEAKER 0

[00:52:11,529]Sorry, I'm getting close.