Joy Salaja

Hi Joy, how are you today? I'm good, thank you. Good, thank you so much for being here and for agreeing to share your story with us. My name is Marie-Claire and I am the founder of Plasma of Hope. I also live with sickle cell myself and I understand in a very personal way. What it means to live with the condition. So this project is about capturing the real experiences of families affected by sickle cell so that we can document how care has changed and make such voices like yours be heard. I understand Ethan is four years old. And his story is so important to us because you have had several experiences with him at home and in hospital.

The youngest voices and the newest journeys are just as valuable as the longest ones. And as a parent, it's very important for us to capture that. So there's no right or wrong answers. Please just speak naturally in your own words. You can pause at any time, take your time. So do you have any questions before we begin? No. Good to go. Right, so can you just tell us about the moment that you found out Ethan had sickle cell?

We decided to do a test while he was in utero and that's when we found out around 15 weeks. I think my husband and I decided that we could live with SC, you know, because my first daughter is also SC, HBSC, and we actually wanted to do implantation initially, but with Karis Joy, we just got pregnant, it happened, while we were still doing the consultation. And then with Ethan, we did plan to have him, but we decided we'll give, go natural. And so we said, okay, the worst we can deal with is HVAC because I'm also HVAC. And so when we found out the news, we're like, okay, no.

we'll deal with it uh what come what may and um yeah so at 15 weeks we knew what we were dealing with okay okay and that's that's that's good so you were kind of prepared yes for it and what did the nhs give you in terms of information and support immediately ethan was born and did you feel guided and looked after

Yeah, personally, in terms of, you know, while he was in my womb, the journey, yes, I did feel guided, looked after, because like I said, they consider me high risk. But with Ethan, to be fair to them, they gave us all the information we needed. He told us that he would need medications from a certain age and then they also told us that he would need to be seen annually or every six months. yeah so his first two three years were okay in terms of his health and then um about you know from two three yeah three we kind of experiencing he kind of started experiencing pain okay yeah so

and i'm looking at this as someone who also lives with sickle cell am i correct and what is everyday life for you for you how does that

look and how does it feel like to have sickle cell and also be caring for someone with the condition um oh gosh i don't i don't worry about myself i don't get a chance to worry about myself it's more about the kids like every single pain is like do i need to worry about that or is it just is it just yesterday my daughter was going to have a headache i'm thinking my is this just a headache or is it something else i need to think of um Because of the way my life has been, I didn't even find out

I had sickle cell until I was 16.

When we moved, we moved to Ireland and then they did some tests and then they're like, oh, you have sickle cell. I'm like, okay, what's that? So I've been, I want to say blessed in terms of my health, apart from since pregnancy. Pregnancy has just brought out other things. I'm an adult I can look after myself but for the kids they don't know they don't know why they're taking medications every morning yeah um they're like um the other day my son told me oh I want to be like that guy because it doesn't get poorly and um that broke my heart and then you start blaming yourself that should I why did I bother bringing a child into this

and um it's it's tough especially for Ethan because it's a it seems even though my daughter is HVAC I'm HVAC it seems to be affecting him more

like that's really interesting because you all have the same trait of this condition but it affects Ethan more than it does the two of you and how do you navigate that you know when he's in pain especially

yeah it's it's i'm sorry yeah You want the best for your child. You don't want to see them in pain. And they're so resilient. They're so strong. It's devastating. It's just horrible when it's lying on the floor crying and you don't know how to help them.

You know, you're just trying to get to the A&E as soon as possible. First port of call has its annual ibuprofen, but it never works.

Would you like us to take a break? I'll be fine. Yeah. You just talked about A&E. And I know we've spoken quite a few times about your experiences in hospital. What has it really been like visiting and staying in A&E and being treated in A&E?

Every time it is a struggle. I mean, you would think because you have the history of the child, you would know how to. go about looking after that child and their plan or whatnot because when he was two there was a bout of parvovirus and he contracted parvovirus which sent him into decline he had to go to from Coventry to Birmingham for blood exchange It was intubated. It was a horrible experience. It collapsed at one point. We thought it was going to, you know, die. But thank God it's still here. So that experience has really framed how we look after Ethan, especially when we go to A&E.

We always... so we have this orange card that's where we we um show it to them and they try to try us just quickly um and um they always do that quickly enough to be fair but it's when you get onto the world that it's always a struggle a battle you feel like the nurses don't understand they don't they don't they don't they think just because the child because these i don't know maybe it's a sickle cell children thing they have this tenacity they withstand and their pain threshold is high so if a child is not screaming in pain They think, oh no, surely that pain can be that bad.

And this is something that comes across a lot because even for adults, you know, people don't demonstrate a high expression of pain. And because of that, they're not taken seriously. But you believe that... The nurses could do a lot better in understanding.

They need to, because it's vital. And the fact that they don't listen to the parents, I will know my child more than anyone. I'll give you the last example of when he went to A&E. We find that when he takes morphine for pain, it disrupts his in his stomach he it's even it's like it's even worse than the sickle pain itself he's rolling on the floor like a like someone possessed so have they discussed alternatives no no the last time my husband was involved with ethan and he had to say if you do not listen

to this to me there's gonna be issues so i have to tell him to activate them is it Martha's law if they're not gonna listen or to what you're saying so the problem was my i was saying to them i don't want him to take morphine or i'm off like my husband then kind of i don't know with whittling down reading off he's like can you give it to him intravenously And let's see the outcome. The doctor was like, oh, we don't think that will be needed. My husband was insistent that I want it intravenously. Let's see how it goes. Lo and behold, they gave it to him intravenously. This is when he made a tonic for the better.

Right.

Because it's not going into his stomach. so because you insisted yes the boy the boy there was a boy with sickle cell on the other bay and they said oh but we gave that not every child you know they always think this child is the same as this child so because the other boy has taken morphine and it was fine doesn't mean that this other child will take morphine and be fine so uh how did you feel about that it's just it's like

if until you make a threat i'm gonna make a complaint they don't listen to you yeah so that leads me to my next question which is and you've probably answered this already and how has the nhs supported you and especially ethan so far and what has been

good if any and what has been difficult i i can't say that everything is bad because at the end of the day You go to the ANI and you get help in a country where the NHS is accessible to anybody. You don't have to have an insurance card. That's been a blessing and you know he'll be looked after. It's more the listening aspect as a parent. Listen to me listen to my voice i will know my child more than you yeah you have all the experience of being a health specialist a doctor but you don't have my experience you don't have my child's experience so listen to me listen that is just listen because that could be the difference between life and death

the time he was the time he was um you know he had papal virus we had to threaten again that if this anything happens to this boy the issue there again was his stomach and so whenever we go there the first thing we always have to say ensure that he's given he's been given um some you know And ensure that he's not giving Oram off. This should be documented and I shouldn't have to say this again. You know, we know that he has sickle cell. He's probably going to have a crisis in another few months. I shouldn't have to come back and tell you the same story. It should be documented. Just listen and implement.

It's frustrating.

And then it covers all the good they... It sidelines all the good they do. Because you just live with a bitter taste in your mouth. And you just pray that nothing like this happens ever again to your son or daughter.

It's sad that it keeps happening every single time you go back. And my next question is, has there been a moment where... you felt Ethan was not treating you all with the urgency that this condition required and what happened.

Yes. It's like,

it's every time. Every time.

It's like, if they don't see him screaming and in pain and, oh God, and it's like kids, because they want to go home, so when the doctor comes, he pretends like everything is fine, you know. um because he just wants to be out of the hospital and you know dad was saying that this boy needs um for example ncaa you know nor the intravenous medicine they're like oh no we don't because

he'll need a nurse he needs to be moved to another word different excuses

and then most people have to be like then move us to another word just do it do be cool this is a life or death matter you need to be quick you need to act fast so i think the theme that we're getting is complacent um this this lackadaisical complacent and they're not listening yeah um thank you that's that's really really important and again going back to my question how has sickle cell affected his development his play he's only four you know his energy and the things that he can and can't do yes that's been for example on

My daughter and her neighbors go swimming together, and now their youngest daughter is going swimming. On Sunday, it was here, it's like.

I want to go swimming and I have to tell him you can't go swimming for now until I sort out what's going on um with the swimming pool um because I don't want you to get poorly yeah so I'm always having to think about sports he can do because we we don't want him to do football yeah he's so full of energy we we don't I have to tell him when he plays you can't play rough because if he gets if he comes up with a bruise i know that oh my gosh it is crisis is coming up because it's so while it's so full of energy it's just really affecting him it looks feeble and picking up on the swimming he said

he can't do swimming can you just tell me what happened why so twice this year now he's gone swimming and sorry that's a lie so maybe two or three times he's gone swimming and that week he will have a sick crisis and definitely and prior to this we stopped him from swimming when he was two because he would always be sick after swimming so we complained

they're like oh no it's it's the right um temperature as per policy and then when this final time that he went away and to the hospital i decided to put in a complaint and that we can't do this anymore we had to withdraw him out of the club and um because it's getting so poorly and the council basically just i said is there any accommodation you can make i'm not saying hit the whole pool if there's a small pool that he can swim in and and i'll get other people that maybe we can rent it out i brought up options they were like um no not really they just they turned it in so we can't hit the whole pool

so they misrepresented my ass right okay so you feel like he wasn't supportive and because of that he's not being thank you for thank you for letting us know that yeah so i have to look for support so not no he can't do football because if he get kicked in crisis so i've decided maybe he'll do golf or something something singular that he nobody can hurt him you know yes and so he can do a lot and my sister does a lot of activities so she's always going over it's like i can't do do you feel like the people around you your family friends do you feel that they understand and support you yes yeah um our close network too they know grandma

is always there whenever you know maybe dad has to go to the hospital she also takes a shift in the hospital as well we have neighbors who look after us and yeah that's good you know community is good very good i'm really pleased to hear that and have you connected with other parents of children with sickle cell that's one thing i've not done okay and um how has plasma of hope supported you and what has that meant for you oh god i don't know when you want me to start um i can only say it's been a blessing meeting you and being introduced to plasma of hope

just having that listening voice even that's all I need even when you know I was pregnant and I would text you I mean hey Annie and you're not listening to me you know someone to rant at you know um that and and just all the other you know benefits that I didn't I was aware that I wasn't aware of that I could apply for and that's been helpful towards me and my kids

and so um yeah i'm so pleased to hear that and you know this is about looking forward ethan is

growing and the children are growing what worries you most about the future with sickle cell

I always use myself as a benchmark and I've said to myself, if I can survive it, and I lived in Nigeria, where healthcare has not been the best, I think they'll be fine. And we've kind of trained them to know what they can and can't do. You can't be too cold, always have your layers on, drink, hydrate yourself. So they know you can't eat too much junk because you'll have a polytomy, stuff like that. I'm not worried about the future. It doesn't stop them from achieving what they want to achieve. They will always, they will shine brighter than the star. So that's not a worry.

I just hope healthcare in terms of sickle cell will get better so that I don't always have to feel like I need to be there to advocate for them. I'll always be there of course but I want to be safe in the knowledge that yes the healthcare is there if I'm maybe in another country and they'll So, you know, sometimes I do think that maybe I will go, especially for Ethan, maybe he'll get, we'll do maybe a bone marrow transplant or this new gene therapy. Okay,

That's leading on to my next question, which I'm glad you know about. Gene therapy for sickle cell has now been approved. Yeah. What does that mean to you?

When I heard it, I was like, okay. I was googling, can Ethan get it? But I know it has to be 12 or something. It'll be the first thing I get for him.

Hopefully.

Honestly, it'll be the first thing I do.

And we're coming towards the end of it. What do you want the NHS and the wider world to understand about what it means to raise a very young child with sickle cell?

It's... I mean, children are a joy, but... That's all. He's in school now. You're worried that I hope he doesn't fall, so that he doesn't go into a crisis. You always feel like there's a limit to his play. And that's all children want to do. All they want to do is play. so um i just want the wider world has everyone to know that sickle cell just because

you can't see it doesn't mean it's not real just because we are not displaying pain we're just we are in so much pain that it's just better not to ex exert too much energy to exacerbate the pain

So when we come to you at the point that we are at the hospital, that means we are in dire need of help. Listen to us and just look after us.

That's so powerful. Thank you. And my last question is, what would you say to another parent who has just found out that their child...

has sickle cell . It's not the end of the world. It'll be fine, you'll make it, you'll survive. I don't like to compare tragedy but you know, just take the blessing that God has given you and give him the pain and give him the rest. He'll look after you. Your kids will be fine.

Amazing. They will be fine. Thank you so much. This was a very powerful interview. And your children are lucky to have you. And thank you once again for sharing your story.

Thank you.