

# JOSH & KATIE MCGRUFF

## RAISING A CHILD WITH DOWN SYNDROME

DEFIANCE #015  
WITH PETER MCCORMACK



## DEF015 - JOSH & KATIE MCGRUFF INTERVIEW TRANSCRIPTION

### RAISING A CHILD WITH DOWN SYNDROME

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**Peter McCormack: 02:42**

Hi Josh. How are you man?

**Josh McGruff: 02:43**

I'm doing good. How are you doing?

**Peter McCormack: 02:44**

Good, thanks. So we've, I tried to figure out how long we've been kind of vibing online. Probably about

**Josh McGruff: 02:49**

It's been a couple of years I'd say, roughly. I got into the space mid 2017 ish, so sometime shortly after that.

**Peter McCormack: 02:56**

Yeah. I remember reading an article you wrote.

**Josh McGruff: 02:58**

Yeah, I used to write. I wish I'd get back more into it. It's just time and things of that nature, but I've always enjoyed writing and things like that. So I find things within the crypto space that are entertaining to me and write something about them, whenever the itch strikes.

**Peter McCormack: 03:11**

Yeah, man. Well, listen, I didn't know this would be the thing we talked about, but I've obviously followed Clara and obviously followed your story with great interest. And so I want ask you some things about it, but

**Josh McGruff: 03:21**

Absolutely.

**Peter McCormack: 03:21**

We should do the whole story, so I can fully understand the experiences you've been through ,and everyone in the background can hear Clara. Hi, Clara. Yeah, so I guess the starting point would have been Katie's pregnancy.

**Josh McGruff: 03:34**

Yep.

**Peter McCormack: 03:34**

I'm going to make the assumption, but tell me if I'm wrong, you have a similar test as we have in the UK when you're pregnant, you can actually find out if your child has Down syndrome. Is that the same?

**Josh McGruff: 03:43**

Yes. Amniocentesis, I believe is how you say that, but there are similar tests. And so with that, Katie was going through her standard ultrasounds, everything looked okay up to that point. We went in for one of them and things were kind of off the rails at that point they'd said "Hey, we have some concerns and things we want to take a look at". They went along, I actually remember I was sitting at work and I got a phone call from her mother, and her mom called and said, "Hey, Katie went in for an ultrasound, things didn't go the way we expected, you need to come down to the hospital". So I said, "okay", let my boss know. She said, "Go take care of whatever you need to do." And so off I went.

**Josh McGruff: 04:21**

Got down to the hospital, she was sitting in the waiting room getting transferred over to a different area. And so I sat down there with her and I was like, well, you know what's going on? And she said they found fluid around the baby. And so that was a condition called Hydrops, Hydrops Fetalis. And, basically some of her different organs had fluid that had built up around it. It wasn't a good condition any way, shape or form. And we found out there was really about a 50% survival rate. And so right off the bat we're like, it's a coin flip for our kid. And so obviously we were terrified. We didn't know. And the worst part about it was is this was an underlying symptom for something. We didn't know what caused it, but you know, it's not a condition just in itself, it's, something caused this.

**Josh McGruff: 05:03**

So we sit down with the doctors, and this is before we did any of the genetic testing, and they said, "Here's a list of things it could possibly be." And a lot of them were different infectious diseases, either genetic conditions and things of that nature. And really, as weird as it sounds, the best outcome would have been Down syndrome. It was the most manageable thing, the most known, treated, worked with thing around. And so after we had the genetic testing done, that's when we found out, yes, it was Down syndrome. And it was good news at that point. It was when you precept it in that direction it, when it gets framed that way, it makes a great news. And so we were excited at that point. Well, we can work with this, we can do this. And so Katie was admitted into the hospital a little bit, for about five weeks and she was down there 24/7 and they had her monitored and things like that.

**Josh McGruff: 05:54**

I was coming back home. Me and Jackson were kind of living our own little bachelor life at that point. Getting him to school, feeding him burnt pancakes and all the things I can't cook.

**Josh McGruff: 06:03**

And once we got through that, we knew Clara was going to have to have a C-section. So they went ahead, they delivered Clara. Initially, things were perfect. She came out, we had no issues. Everything was happy. What ended up happening though is she started having issues with her blood sugar. And so, we're not going to be able to keep her on this side of the hospital, the non NICU side. We've got to move her over to the NICU. She got over there and at that point she started having trouble breathing as well too. She also had some issues with her skin tone, forgive me on this, but she basically had a like jaundice or, she had to go under the UV lamp and things like that to get her back to where she needed to be. So she spent about three, four weeks in the NICU and got discharged and here we are, we came home.

**Peter McCormack: 06:54**

So the reason they do the test in the UK, and obviously this is quite a brutal question, but the reason they do it in the UK is a lot of people choose to terminate first when they've had this. So I've got two children as well. We chose not to have the test because we didn't even want to be put in that position of having the choice. But it must have crossed your mind it, I guess it's the same reason they do here?

**Josh McGruff: 07:15**

Yeah, I would say a lot of times I think that's why most people would probably have it, if it's not a medically induced question or something along those lines. Katie and I are both pro choice, but at the end of the day, we still wanted to have our child. And so regardless of what condition she had or whatever those things were, we still saw her as our baby. That was, whatever it is, we'll work with it. We'll do it.

**Peter McCormack: 07:37**

She's freaking adorable.

**Josh McGruff: 07:38**

Yeah, and we don't regret it for a moment and those little hugs and kisses and things like that, just, they melt you. So

**Peter McCormack: 07:49**

And Katie, how did that, cause you've obviously got two children now, so you've been through two pregnancies. How was that as a second pregnancy for you? Because obviously you've got a lot more to consider. Did it make it more stressful? I mean obviously it did, but like how was that for you?

**Katie McGruff: 08:03**

Overall, I mean being in the hospital for five weeks was extremely stressful, just not being able to prepare like a normal pregnancy. Most women are home and they're nesting and they're getting the crib ready and everything. And I was stuck in the hospital on the phone with him and trying to explain what needed to be done, and then hoping that it was done. But overall I think knowing that she was going to have Down syndrome made it a little less stressful because I knew I was going to get more help than a normal pregnancy, but it turned out great. I mean everything turned out really easy.

**Peter McCormack: 08:45**

And help me understand with regards to Down syndrome, because I don't know a lot about it. I'm obviously aware of it as one of my best friends, his brother has Downs syndrome, but I don't fully understand it as a condition. Is it a spectrum? Is it that affects children in different ways?

**Katie McGruff: 08:59**

There's no real spectrum like autism or anything like that. It's not recognised as a spectrum disorder. It's a genetic disorder. So she has a third copy of the 21st chromosome and there are different types of Down syndrome. There's Trisomy 21 which Clara has, there's Mosaic, which is half a copy in comparison to the full third copy. And then there is Translocation, which is genetically bound to the parents. They carry that gene and then they get Translocation Down syndrome. But overall, it more affects speech, motor skills. A lot of people with Down syndrome have low muscle tone, so their normal developmental milestones are lessened. She didn't start walking until about 18 months and usually that's about a skill around one year to 14 months. But it affects everybody differently. I know with Mosaic it's less severe in the way that it develops, the developmental at least is. Other than that it's, I explain it to my son as the same as everybody else, but it just takes her a little bit more help and a little bit more time to do things.

**Peter McCormack: 10:12**

Okay. And so as a baby, does it make a huge difference as a baby, in terms of care?

**Katie McGruff: 10:19**

It was actually easier taking care of her. She doesn't have a lot of severe medical issues. She does have some different heart issues, but nothing that affects her on a daily basis.

So it was easier because she didn't, she wasn't moving around as much. She, so we got to snuggle her a lot longer than a normal child.

**Peter McCormack: 10:42**

Great for a mom.

**Katie McGruff: 10:43**

Exactly. With my son he was a go-getter from the start and so he never really wanted to be held, and we got to hold her longer and it took her longer to be able to walk and move around. So it was more just spending more time as a baby in comparison to moving on to that toddler stage. So

**Peter McCormack: 11:00**

And feeding, does, she feeds fine?

**Katie McGruff: 11:03**

She did have trouble feeding. She had kind of a rough start where she started in the NICU for four weeks and she was fed through a NG tube and I wasn't able to breastfeed her. So I ended up pumping and she got breast milk like that from me, just so that she had a better chance with immunities and everything else, give her a little bit. But she was bottle fed when she came home, which I'm always that key believer in like "fed is good", so any way that you can feed a baby is perfect.

**Peter McCormack: 11:37**

And separate to the Down syndrome condition, she suffered with a few other things, right?

**Katie McGruff: 11:42**

Yes. So she had some liver calcifications that we had to follow up with the liver clinic at Children's. She also, at six months, developed infantile spasms. And so she started having these jerking motions that we found out later were actual seizures. And so she was going in every other week and having EEG's done. We had to stay in the hospital for a week waiting for certain medications to be approved. And then she got two injections daily, that we gave her at home, of steroids.

**Peter McCormack: 12:18**

When did the medication that you mentioned to me come into place, Josh?

**Josh McGruff: 12:22**

Which one is that? Is that the one that had the side effects that we were discussing?

**Peter McCormack: 12:24**

Yeah.

**Josh McGruff: 12:25**

So that was the second round, which was the Vigabatrin. So as we were talking about with the steroids, that was the first like primary round of treatment. And so it's not a guaranteed success rate. I don't know what the percentage is for success or not off the

top of my head. But nonetheless, that was Plan A, didn't work. So we went to Plan B, which was the Vigabatrin. And so one of the side effects of that was, they described to us is that it could cause blindness.

**Josh McGruff: 12:51**

And so I said, that's kind of a real terrifying aspect as a parent, of where you have your child, you know they can't have these spasms, it's a guaranteed death sentence if we don't do anything about it. And we'll slowly just bake her brain. And so, Plan A didn't work, so now we're going to go pull a Plan B and let's give this a shot. Oh by the way, this could possibly blind your child.

**Josh McGruff: 13:17**

So obviously we had to go through the treatment. We really didn't have any other choice. And so we did. And of course, were fortunate enough that it didn't happen with Clara. And as far as we know, we don't have any kind of issues with eyesight or anything. She's got to wear glasses, but that was kind of prior and wasn't expected to be related to that. So yes, that was kind of a terrifying aspect of that. So, I said we got really lucky.

**Peter McCormack: 13:40**

But that's, she's okay with that now?

**Josh McGruff: 13:42**

Yeah. And so what's interesting about infantile spasms, and we hear this a lot from folks on Twitter and stuff like that, we'll mention seizures and they'll say, "Oh hey, have you guys looked into like CBD?" and you know, things like that. And from what we've been explained, they're a different type of seizures. It's not the same as like an epileptic seizure or something of that nature, to the point of where it has a specific signature on an EEG. So when we took her to Neurology, they looked and they're like, "Oh yeah, that's infantile spasms. No doubt." And we got really lucky too, that 45 minutes down the road is one of the leaders in the US in specialising in that disorder. So anyway though, like CBD, things like that don't really have any effects. And so I said those are the options we had really, and that's what we worked with.

**Peter McCormack: 14:26**

And so what are you dealing with now with Clara?

**Josh McGruff: 14:29**

So she, we've got a bunch of different appointments and things of that nature. I know she's got heart issues that she follows up with on a regular basis. Liver issues. She has thyroid medicine she takes on a daily basis. She has some optometry stuff that they do. She's got to wear glasses. She probably should be wearing them right now and isn't, but you can imagine how easy it is to keep glasses on a little girl like that.

**Peter McCormack: 14:51**

I'm not seeing the like strapping on ones, in the picture.

**Josh McGruff: 14:54**

They're around here somewhere. I'll show them to you.

**Peter McCormack: 14:55**

They're like goggles.

**Josh McGruff: 14:56**

Yeah. Pretty much, they look like little aviation goggles almost. So she's got those as well. Overall though, in the grand scheme of things that could have happened with her, she's doing pretty good and she really didn't get the full gambit of what possibilities could have been.

**Peter McCormack: 15:11**

So these, all these separate issues related to Down syndrome or are they independent?

**Josh McGruff: 15:17**

They're all related to Down syndrome. Or at least I don't know, anybody could have them, but specifically pointed towards the genetic issues is why she has them.

**Peter McCormack: 15:26**

Okay. And so you mentioned the Facebook group, so I guess there's what, communities that you can look to, there's other people you can talk to.

**Josh McGruff: 15:33**

Absolutely. So there are all kinds of special need groups and things like that. And so, one of the ones not related specifically to social media, but here in the area, the Down Syndrome Association of Greater Cincinnati. And so as I was discussing earlier, they came out on Thursday and came through to the house and they brought us kind of like a welcome basket and they're getting us integrated in with like a year group of people who have had children with Down syndrome in 2018 when Clara was born. There's a dads group I'm going to be joining and different things like that to have that, that social aspect and exposure to other parents who may have gone through something and work with them.

**Peter McCormack: 16:09**

So there's obviously social support there. There is like a year group for her to have friends with.

**Josh McGruff: 16:15**

Absolutely.

**Peter McCormack: 16:15**

And then a bunch of dads to get on the pub.

**Josh McGruff: 16:17**

Yep. We were late to get integrated in with them but we are now, and like I said, we just, all we really had to do is just send him an email and then they sent somebody out to the house to come meet us and sit and talk.

**Peter McCormack: 16:26**

Okay. And so what are the different stages you have to consider now for her life? Like as she grows up and how this is going to affect you in terms of, what do they do with regards to schooling?

**Josh McGruff: 16:35**

So she has, by chance, my son's aunt works at the school she'll go to, my son goes to the same school as well. So she's already kind of known at the school there. So they already expect that she'll come through there and things like that. But she gets to start school a year early. She'll start at age three and so she'll go through pre-K twice. And we don't know yet, whatever she needs, they'll kind of help us out with.

**Peter McCormack: 16:58**

Is it a specialist class? Or does she have specialist support in a class with children without Down syndrome?

**Josh McGruff: 17:04**

We won't know yet. But

**Peter McCormack: 17:05**

It could be though.

**Josh McGruff: 17:06**

It could, yeah. We'll push to try to get her integrated into a standard class and have an aide versus a special education class or something like that. And really a lot of that just purely has to do with how does she respond cognitively, how does she do? And if she has the social skills and can keep up with whatever the academic aspect of it is, she can. She can maintain a standard class with an aide or something like that.

**Peter McCormack: 17:29**

So I am aware that, ongoing, that there are people with, I'm trying to think of how do you get, what's the current way to say, do you say people with Down syndrome? Is that?

**Josh McGruff: 17:37**

Typically that's what people would say.

**Peter McCormack: 17:39**

Who actually move towards independent living?

**Josh McGruff: 17:41**

Yeah. So, actually here at the University of Cincinnati, they offer degree programs for people with Down syndrome to go achieve a degree. And then there's, I can't remember the name of the television show off the top of my head, but we actually watched it for a while because it gave us some insight. It was when Clara was very young, or might even be more when Katie was still pregnant, but nonetheless, it was a reality TV show around people with Down syndrome who are now adults and kind of what they do in their

independent daily life. And people had apartments, they had jobs, they drove a car, all those different things of that nature.

**Josh McGruff: 18:10**

And so, it breaks a lot of the stigmas I think, or kind of some of the stereotypes people may have when they see someone who's like severely disabled and that's the picture they get. And so that's also another reason why I like doing the Twitter account for her is for that exposure, that advocacy, that normalcy of putting a face to things. The guy promised I wouldn't say his name, but there's a person on Twitter who's got a pretty decent following. He actually just messaged me, I just told Katie about this the other night and it caught me off guard, but it kind of clicked and this was like a really rewarding moment for doing her account. And so he said, hey, he says I wanted to give me some ass about saying, about me and Clara. And he's like, you ruined a joke for me. This guy kind of comes off as brunt, but he's got a soft heart underneath there. I hope he listens to this cause he'll know exactly who he is.

**Josh McGruff: 18:59**

Anyway, he says, you ruined a joke for me, or you and Clara did it. And I said, well, what was that? I said, were you going to call someone retarded or something like that? He says, yeah kind of. He said, he says, we're talking about Crypto Twitter and he said, being like popular in Crypto twitter is like being a smartest kid with Down syndrome. And he says, but I stopped, and he says, and I thought about you and Clara with that. And he says, I felt bad about saying that. And I said, yeah. I said, I would have certainly raised an eyebrow and been like, that probably wasn't a proper thing to say in any way, shape or form, but it hit me that our story impacted him enough to stop, pause and realise what the implications of that could possibly mean and see the human aspect of, there's a person, it's not just a condition. And so that was a really rewarding moment for me when I was like, this is why I want to do this. I want to advocate for her.

**Peter McCormack: 19:48**

Listen, I love following the updates. I can't remember if I follow up Clara, but I see your updates. I love following. I think it's really interesting. But the question from that then, so you will probably regularly hear people use the word retarded, right? Without thinking about it. Does that affect you? Do you care?

**Josh McGruff: 20:03**

No, and so honestly I did. I used to say it and things like that too, before I had Clara and I tried to obviously not say it anymore. I think context has a lot to do with what someone's trying to say. I think

**Peter McCormack: 20:14**

I mean most times people are trying to say that's dumb. They're not thinking of the comparison to someone who has some kind of condition.

**Josh McGruff: 20:21**

Sure, and I think that's it is, are you being malicious towards a person with a disability or are you just saying a word? If you really break down and look at it, it just means slow. You know? It means to regress and things of that nature. It's just been tied now to a

condition, a medical, things of that nature. But again, I don't think the majority of the people who use it are actively thinking of a disabled person when they say it and are being malicious. I think that's a big differentiator versus someone who's just being malicious and using it as hate.

**Peter McCormack: 20:49**

And do you, when you're out and about, do you have to witness people, do people stare a bit more? Do you have to deal with that? Is that something that you notice or

**Josh McGruff: 20:55**

No, she's.

**Peter McCormack: 20:55**

Or do you just blend in, not even caring about it?

**Josh McGruff: 20:58**

I'll take that back. Yes, she does get a lot of attention, but it's almost always positive. I've never to date had a negative interaction with the public, with her. She's normally Belle of the Ball, people come up waving at her, they're trying to pick her up, they're wanting to do things with her and she just wins hearts.

**Peter McCormack: 21:16**

Well, I mean I was all right with it. And then I saw the queen shirt. The wicked, we're good, you're a queen. She's absolutely adorable. She doesn't stop smiling. She's absolutely adorable. I love, like I say, I love seeing the pictures on. I also noticed since I've been here, so you talked that she'll have speech developmental problems, but she's saying "Hi". So she will learn to talk?

**Josh McGruff: 21:37**

Yes, certainly.

**Peter McCormack: 21:39**

It will just take, what, longer?

**Josh McGruff: 21:41**

That's another interesting thing that you bring up, so she does have hearing issues, too. And so she had tubes in her ears at one point, they've fallen out already, she may have to get them re-put back in, but they say that she talks muffled, you know, put that hand over your mouth and talking. That's about how it sounds for her. And so, and the reason why she's has a ton of fluid and stuff that keeps building up within there and when the tubes aren't in, it can't release and so that could affect her speech in more, how she pronounces, things of that nature.

**Peter McCormack: 22:08**

Okay. So I just got distracted by her.

**Josh McGruff: 22:10**

Yes, understandable.

**Peter McCormack: 22:13**

She's so adorable. But I noticed also, you observed, I picked up on the signing. So is the first stage to teach to sign as she learns to speech.

**Josh McGruff: 22:20**

I don't know the methodology behind it, but I know that's something that everywhere that we've read, we've talked with people, start integrating as soon as you can. And so we use it as, we try to teach her words in general. As you point at something you say, do you want more? We'll make the sign for "more" and things like that. And so that's it. We just try to kind of, I guess teach both at the same time or try to build that association between the words and the sign. And so I don't know if we really have a method to our madness, we just kind of mix it in.

**Peter McCormack: 22:51**

So I guess everything is just trying to make life as normal as possible.

**Josh McGruff: 22:55**

Absolutely.

**Peter McCormack: 22:55**

I mean, obviously you've got to deal with certain issues and be aware of certain things, but I guess you just, the breaking down of the stigma is by just trying to give Clara the opportunity to live as standard a life say as her brother.

**Josh McGruff: 23:09**

Absolutely. And so that's the main goal, is whatever deficiencies or weaknesses she has, find the social programs or what we can do to plug those so she can live a standard, normal life.

**Peter McCormack: 23:20**

And I'm aware there's charities, I mean it might not be charity might even be a commercial company, but that work at helping place people with Down syndrome into companies.

**Josh McGruff: 23:29**

I'm not familiar with it, but I'm sure

**Peter McCormack: 23:30**

I saw a documentary about it.

**Josh McGruff: 23:32**

I'm sure the Down Syndrome Association are on it and that's why we're so happy now that we're integrated with those folks because like I said already, we talked about financial aid and some things like that and they told us, hey, some of those things you guys may not be, shouldn't have had to pay for. These people should have told you about these programs or this or that. And they said there's no promises, but some of those things have time limits, but hey, we're going to try to help you guys, see if we can

get some of that stuff backdated and things of that nature. But it's that assistance, those people that are experts that deal with the stuff on a daily basis, that know where to point you and navigate to this versus hey, we're just kind of winging it and hey maybe somebody will casually tell me about a program I can Google into first, hey your daughter's now going to be going in the workforce, go check this out or whatever.

**Peter McCormack: 24:16**

Okay. So we're going to talk about the medical side of things as well in terms of like the cost and such. There was one other thing I want to ask you about that and it's kind of a tough question because I don't want to trigger something that you ever think about it, but it's something I'm aware there is a different life expectancy for someone with Down syndrome. Right?

**Peter McCormack: 24:34**

That's right.

**Josh McGruff: 24:35**

About 50-60 I believe.

**Peter McCormack: 24:35**

Yeah. Okay. I just want to check that was correct cause I'm sure I'd heard of that. I take some interest in as well on the way and I love the synchronicity of life sometimes. So we've got a, there's a guy in the UK called Mark. There's a guy in the UK called Mark Kermode who does film reviews. And I'll only ever listen to the show when I'm in the car. And he wrote a letter in, it's typical, I'm 10 minutes from here, he has a letter somebody wrote in to say, I have my 14 year old son's birthday tomorrow, he's got Down syndrome. He struggles with speech, but not whenever they put a musical film on, whenever they put Frozen on, he can sing every song all the way through. And I was just like, what synchronicity is that that happened on the way? Have you noticed that she responds to any, anything such as music?

**Josh McGruff: 25:21**

Absolutely. So she loves

**Peter McCormack: 25:22**

Is that why she's a Queen fan?

**Josh McGruff: 25:24**

Yeah, she loves, well really she just started dancing, or what I would call dancing, here recently. There's a toy duck out there that when you touch the top of its head starts playing all kinds of music, spins around and lights up and stuff. And she does this sideways wiggle, shuffle thing that she does. And she'll only do that when that ducks on. But, in general, ever since she could start crawling, she would get interacted with anything that would light up, colour or things of that nature. Music, she loves that stuff. I have some lullabies that I've made up so to speak and I sing those to her whenever she gets upset and a lot of times those will soothe her and calm her down. She definitely responds to music.

**Peter McCormack: 26:05**

So everything seems pretty chilled and cool since I've been here. It seems very much like my house when my kids were young. How much of this is like cause I'm here or like other additional stresses and pressures that I'm not aware of that it's put on you or you just seem to have coped with it and not giving a fuck, excuse my language, not giving a fuck right?

**Josh McGruff: 26:24**

No, you're fine with us. Yeah. So either way though. No, I think that's an honest observation. And so the only additional stressors I would say that maybe aren't visible as you sit here in the household is just the time consumptions that happen. Like I said, it's not so much that she may have something actively going on, it's the potential for what can develop. And so because of that, she has numerous, numerous follow ups and check ups and things of that nature.

**Josh McGruff: 26:48**

So if something does happen, we're right on the cusp and bleeding edge to get in front of it. And so like I said, my wife used to work full time and so she dropped to part time because she has usually, I mean at least four or five, six appointments a month at minimum. And some of those are in a single week, depending on how they fall. And the problem is a lot of those things may be six months out for bookings, so you're at the mercy of whatever they have available. And so I think that's really the only additional thing. Otherwise, I mean this is life as normal. She hangs out in that play area there. She runs around, she gets into the DVDs and stuff she's not supposed to. Then I got to go restack them or I make a brother do it to his dismay. Yeah, we go around and just try to live life as normal as we can.

**Peter McCormack: 27:32**

Hey mom, do you want to tell me about the appointments? Give Josh a break. So you're obviously juggling a lot more than most moms. You're juggling a family, you're juggling your job, and a husband, he probably doesn't do everything you want all the time because us men are a bit fucking useless. But you talked a little about and then all these additional appointments on top, like so how much is involved with this?

**Katie McGruff: 27:56**

Like he said, I usually do the bookings about six months out depending on what's going on. But I think at this point, she has roughly around nine specialists that I follow up with and it always seems to happen that all of the appointments are in one single week and all of her specialists are at least an hour away. And then on top of that I have Help Me Grow come out to our house every other week. And then on the opposite week we go for speech therapy. It's very time consuming and a lot of gas mileage as well. Crock pots, crock pots are how I do it, making meals ahead of time and just, that's how I run the house.

**Peter McCormack: 28:39**

So you have to be super organised and arranged and disciplined.

**Katie McGruff: 28:42**

Yeah. And that's my problem, I am not organised at all. It's always last minute and I'm always on the phone with Josh. God love him. And hearing me becoming really agitated because I forgot where I put something and I'm blaming him for misplacing the object that he's probably never seen in his life. That's about, yeah.

**Peter McCormack: 29:02**

I think we're all winging it as parents. I'm divorced, so when I'm not here traveling doing my interviews I'm home with my kids and I'm absolutely winging it. Is there a shirt ready for school in the morning? Have you done your homework? It's all, everything's, I think most parents are doing that. I wouldn't worry about that. So that's a lot of appointments though. And it sounds to me like you're saying that you're the one who has to keep up on it rather than to you.

**Katie McGruff: 29:23**

Yes, unfortunately Children's, our Children's I think is second in the nation, but unfortunately because so many people go there, their scheduling is really difficult to where every time I have to call and follow up and make sure that I'm setting these appointments cause if I'm not and I wait til the last minute, I usually can't get an appointment until six months later and then I'm a year behind on the appointments. Yeah, it's difficult to follow up sometimes because I do find myself, especially when she has some type of health issue, like when infantile spasms came up and we were at the hospital every other week, I found myself falling behind on appointments that were specialties that weren't as acutely important at that time. And then having to go in nine months later and explain why I was late to come to the follow up appointment.

**Katie McGruff: 30:14**

But luckily I work nights and so she doesn't have to go to daycare, so she's not usually around a bunch of other sick children and we try to cut down on as many appointments and keep them kind of synchronised together so I'm not running around every week of the month trying to keep up with it.

**Peter McCormack: 30:33**

And the switch to nights essentially puts you two as tag team, right?

**Katie McGruff: 30:38**

Yeah, we do. Yeah. We tag team and say I usually, cause I work part time, I work two twelves and I usually work Mondays and Fridays. So I have the whole week off of work and then I work into the weekend so that we're both here.

**Peter McCormack: 30:54**

You seem like a pretty good team. And her brother, how's his understanding of it? Cause, so he's eight, so I'm guessing he was about six when she was born.

**Katie McGruff: 31:02**

Yes.

**Peter McCormack: 31:03**

No, no, he's not eight. We've all got that wrong now.

**Katie McGruff: 31:05**

I know, yeah.

**Peter McCormack: 31:07**

Every one of us. He's just going to be eight for now. Yeah.

**Katie McGruff: 31:10**

You've looped me into this chaos age.

**Peter McCormack: 31:13**

So he was five when she was born.

**Katie McGruff: 31:15**

Yeah.

**Peter McCormack: 31:15**

And how's his understanding of her condition and do you have to teach him to be a bit more patient with her or?

**Katie McGruff: 31:22**

Yes, we do have to get him to be more patient with her because he gets agitated when she does something that a baby would do, even like going off and pulling his hair, taking his toy or not playing something the way that he wants to play. And he gets extremely agitated with her and we have to kind of remind him that she's a baby. Like, it's okay.

**Peter McCormack: 31:42**

I'll let you into a secret. So my son's 15 and my daughter's nine, and that still happens.

**Katie McGruff: 31:47**

It happens.

**Peter McCormack: 31:48**

Yeah, so that's no different. Oh, actually you know something really interesting that we found out when we got here? My son's birthday is April. My daughter's birthday is February.

**Katie McGruff: 31:55**

Really?

**Peter McCormack: 31:55**

Yeah. And then like five days apart as well. Madness. Okay. But he understands, right? But he just forgets?

**Katie McGruff: 32:04**

Yeah, her being a baby, he forgets to be patient with her in that aspect. With Down syndrome, I wouldn't say his understanding with it, we've told him multiple times and I've used books and kind of explain that she has Down syndrome and the only thing that is different with that is that it might take her a little bit more time and that he might have to help her a little bit more with things.

**Katie McGruff: 32:28**

When I told him he was just like, okay, like that's not a big deal. But then again in our home and around other family members, a lot of times we don't even think about her having Down syndrome. She's just in the family and she's Clara and that's who she is. We more wanted him to hear the word Down syndrome in reference maybe just in case he hears it from one of his school friends or a teacher because we're well known in the school. And I would hate for him to become defensive or hear something that might upset him just because he didn't have a reference of knowledge regarding her.

**Peter McCormack: 33:06**

Yeah. All right, cool. So one of the biggest differences for me being in the UK and you've been here is we have something called the NHS, which is the National Health Service, which is a social healthcare system, which comes with its own problems, without doubt. Private health care in the UK is fairly cheap because what they want to do is, it's kind of operates alongside the NHS. So if they can take any pressure off the NHS, it's useful. So I have private health care in the UK for me and my children, but it's a very, very low cost. For the three of us, it's 120 pound a month. Now, there are lots of restrictions and things in there that you'll understand. What I've come to understand out here in the US, it's a very complicated system and a very expensive system that you can become totally trapped in and can essentially, it can also bankrupt you. So at the stage where you were pregnant, was that a different fear that was already in your head, of like oh shit, we've got the medical side coming on, the fees.

**Josh McGruff: 34:10**

I knew that we were going to start accruing medical bills, but I don't think I realised quite how much that was going to become. We had, at least what I thought or considered, good medical insurance. My wife works at a hospital, and so she has medical insurance through them and typically, medical facilities give good medical insurance.

**Peter McCormack: 34:32**

But there's a fine print?

**Josh McGruff: 34:34**

Well I don't even know if it's a fine print or just until you're exposed to it, you still don't realise just how much that stuff costs versus what the insurance company's going to actually end up covering. So, cause like I said, we had talked a little bit earlier about some of her treatments and with those treatments, the specific one was those steroid shots that she was taking for her infantile spasms. With that, it was almost kind of a predatory situation that that became with those.

**Peter McCormack: 35:03**

Is that the one that went from \$40 to \$35,000? Which I find mind blowing.

**Josh McGruff: 35:08**

And so obviously we didn't directly pay \$35,000 per vial, but our insurance also didn't cover all of that. So if you take the insurance out of the equation for the total amount of her treatment, it costs more than our house. And so, it's an insane amount of money for something that says, you have to give this to your child or your child can die.

**Peter McCormack: 35:29**

What I don't understand is how someone can, did the company buy the patent or something?

**Josh McGruff: 35:33**

So I'm not a hundred percent all accurate, but with that being said, they definitely bought the rights to it, there's no generic version to it and they locked it all down to they're the only company that creates it. And once that happened, those prices insanely skyrocketed.

**Katie McGruff: 35:51**

So with the steroid medication, before you said it was \$40 because it was used solely for ACTH and that's what they were selling. And then a company came through and bought the patent for the medication and they were trying to market it as a Parkinson's medication, simply for those symptoms. And because of that, it raised the price on this simple steroid medication, just so that they could make more money off of it.

**Katie McGruff: 36:21**

And unfortunately I feel like that happens a lot. And when they have a patent towards a drug, they can only keep it for so many years without having a generic medication made of it. And because of that, they were able to skyrocket it that price up to, I think it was 35,000 a vial. And what was insane about it was, it was cheaper for us to stay in the hospital for the seven days waiting for insurance to verify that medication and say that it was covered than it was to go home and just have the medication. So we were stuck in limbo for seven days inpatient. I think it was like \$16,000 overall for the seven day stay in just the medication, cause we were just getting one shot a day until, the medication was literally shipped to the hospital, had to be brought up to the room and put into my hands before I could leave the hospital. And it was just a lot, it was a lot of, plus paying for the medication that wasn't covered.

**Peter McCormack: 37:24**

So, the only time I was aware of this before, I just had to look up the name of, but is that guy Martin Shkreli, the Pharma Bro guy, who's now in jail. He was a guy who, there was a lifesaving drug and he did the same. He bought the patent on the drug, the height of the probe.

**Josh McGruff: 37:37**

Daraprim?

**Peter McCormack: 37:37**

Yeah, maybe it was, yeah, maybe it was. So, I'm aware of that happening before. I can't understand how that can happen. Like I can see somebody buying it and say it was 40 bucks and they raised it to 100 bucks. It's still not great, but like, okay, you know you've bought the patent.

**Katie McGruff: 37:50**

Doable.

**Peter McCormack: 37:50**

Yeah. It's doable. To go from 40 bucks to 35,000, to me, I don't know, it's just, it's egregious, it is terrible.

**Katie McGruff: 38:00**

It's preying on people, that even with Parkinson's, the ones that need the medications to help their symptoms.

**Peter McCormack: 38:07**

Is it preying on people? Or is it preying on the insurance companies because they know the insurance companies

**Katie McGruff: 38:12**

Both, because with people that don't have insurance, then it's kind of like choosing, what do we do? Like we can't even afford-

**Peter McCormack: 38:20**

You wouldn't be able to get, you may be able to do that because I mean, how many?

**Katie McGruff: 38:23**

They would have to stay in the hospital, inpatient, and receive that medication every single day.

**Peter McCormack: 38:28**

Sorry, explain it to me. So if you're an inpatient you

**Katie McGruff: 38:30**

They worked it into your stay. So you're charged by drug when you're in the hospital. So they were billing us for the one, I think it was one millilitre, one millilitre per day of the medication into our bill until we were able to get the vials for ourselves. So other children that were unable to have their insurance verify that drug or weren't able to be qualified for Medicare to get the drug, they would probably have to stay inpatient.

**Peter McCormack: 39:00**

Well, okay. I mean, there's a lot of detail you could go in, but I think an easier way to get a grip of what the situation is like for you is, there's a couple of kind of easy questions I can ask. Like, do you know what the total costs of her medical care has been to date? Are we talking hundreds of thousands?

**Josh McGruff: 39:18**

No.

**Peter McCormack: 39:19**

Tens of thousands?

**Katie McGruff: 39:20**

Tens of thousands.

**Josh McGruff: 39:21**

Probably about 20 grand total.

**Katie McGruff: 39:22**

So far.

**Peter McCormack: 39:23**

Is that, is that 20 grand to you? No, no. I want, I mean the total, like including what the insurance would have paid.

**Katie McGruff: 39:31**

No, I have no idea. I know that looking at some of the bills, yeah, that would be hundreds.

**Josh McGruff: 39:37**

Just her steroid treatment was probably 160, 170.

**Peter McCormack: 39:40**

So we're talking hundreds of thousands. So we're talking over her childhood, it's probably going to be millions.

**Katie McGruff: 39:46**

Possibly. Yes.

**Peter McCormack: 39:47**

Okay. But to you it's 20,000 so essentially about \$10,000 a year. And is that something, now, are you able to plan ahead and think, okay, I think it's going to cost us \$10,000 a year every year until she's 18 or something? How do you?

**Katie McGruff: 40:03**

I don't think we've ever thought of it like that, but yeah, we could plan out to set aside, I don't know. Yeah, I've never really thought about how much it would add up over the years. I think we just, we're kind of go with the flow people, and so as bills come along we're like, oh, another bill.

**Peter McCormack: 40:23**

But how does that work? Because most people I know if they get a huge bill, suddenly, they can't pay it. Is there a certain, do they give payment plans, a certain amount of protection?

**Katie McGruff: 40:32**

They do set up payment plans. I know at least at the hospital she was born at, gave a payment plan to where they called you and asked what can you pay on this? And it could be anything from \$5 to thousands of dollars a month, but then you have to take in that interest was acquiring on the bills as well. And it's, I think we ended up paying, Josh could probably explain it more because I unfortunately hate calling people, especially hospitals and talking with their finance companies. So I kind of pushed that onto him.

**Peter McCormack: 41:09**

Do you end up arguing with them?

**Katie McGruff: 41:10**

Yeah, I do.

**Peter McCormack: 41:11**

Motherfuckers.

**Katie McGruff: 41:13**

I do. I get so mad at them. Well, especially because she was born at a hospital that I work at and the discount really wasn't very much and I have my insurance through that hospital and it was kind of like, "I work here and I'm still having to pay you while I work here because the bills were so much and we required so much". And it's become even increasingly frustrating now that we have learned through the Down Syndrome Association that there were things that they could have told us about that would have covered her medical bills 100% for the first month she was alive. And so those medical bills that we put on credit cards and paid for out of pocket would have been covered. Yeah, they would have been completely covered. No questions about it.

**Peter McCormack: 42:01**

So, you had to result to credit cards to be able to do this. What if you couldn't have got a credit card?

**Josh McGruff: 42:07**

Fortunately we had one already. We had pretty good credit ahead of time and things like that, took care of our stuff. But one of the reasons why we really moved over to credit card versus like staying on that monthly plan was because we were offered discounts if we paid the entire medical bill in full from the hospital verse making that \$25-\$50 a month, whatever payment. So at the time when it was just like one bill, it's like, okay, well we can put four grand on the credit card, whatever, no problem. But then down the pipe, here comes another bill, something else comes up and the next thing you know you look at the credit card and there's like 15 grand on it and you're like, oh shit.

**Peter McCormack: 42:45**

Scary stuff.

**Josh McGruff: 42:45**

Yeah. And so then the problem with that is, is the monthly payments on the credit cards have now gotten so high that we're basically just paying seven, \$800 a month in just interest. And so trying to just get out of the hole and get back to where it was. And so we make our monthly payments on it right now, but we flutter around kind of what that cusp is on it because we can't get out from behind the interest at this rate.

**Josh McGruff: 43:11**

So then I've looked into things like trying to refinance it, consolidate loans, things like that. But then they look at our debt to income ratio and they say, well you guys have, you 20 grand in debt, no, we're not going to give you a loan. So we're stuck. All we can do is kind of keep making that monthly payment until, I don't know, something changes. Over years, as things have gotten a little bit better, for a while we were definitely, during the big crypto run there we supplement our income with that. We did great. Then the bear market hit and that got yanked out from underneath us and everything and so we lost that supplemental income at that point. She started picking up shifts here and there randomly to kind of keep things going and

**Peter McCormack: 43:49**

But you're both working and I guess there's going to be people in even worse situations than you that, does it get to the point where you cannot afford treatment and therefore you won't be treated? Does that happen?

**Josh McGruff: 44:03**

We had the luxury at least that treatment would never be turned away. So, just the debt would continue to accrue. And so, pile it on top until you get to the point of where he can't afford it anymore and file for bankruptcy or something I suppose. But

**Peter McCormack: 44:14**

I thought you can't eradicate medical bills in bankruptcy in the US? Am I wrong about that?

**Josh McGruff: 44:19**

I don't know, to be honest with you. Fortunately I've not had to look into that.

**Peter McCormack: 44:23**

Yeah, no, it's, I'm pretty sure that something I've read, but I could be wrong. I'll double check that. Okay. I mean it's obviously a terrible situation to be in, but like you're not going to not treat her.

**Josh McGruff: 44:32**

Absolutely.

**Peter McCormack: 44:33**

So did Obama aid make any difference? Because I've heard people say that's brilliant. I've also had people say it actually, it's made things worse.

**Katie McGruff: 44:41**

I think it depends on what side of Obamacare you're on.

**Peter McCormack: 44:45**

There's two sides?

**Katie McGruff: 44:45**

Yes.

**Peter McCormack: 44:46**

Oh God, I didn't even know that.

**Katie McGruff: 44:46**

So, there are some people that it makes health care much more affordable for them because they were unable to get any type of private insurance. There are some people that can't, are unable to get Medicare anything else, but then there are other people that based on their income, Obamacare is more expensive for them. Overall, where I work in the emergency room, it's you come in and you're seen. We don't check your insurance before you're brought back to see a doctor, that is registration. So no matter what happens, you're going to be seen by a doctor that day.

**Peter McCormack: 45:22**

But not every hospital is like that. Right?

**Katie McGruff: 45:24**

No. We do find that

**Peter McCormack: 45:26**

I've heard about they're checking pockets.

**Katie McGruff: 45:27**

Yes. We do find that a lot of people come in because we're a very public hospital. We have a very diverse population that comes in, we have a lot of homeless population that comes in, and we treat everybody that is seen. Unfortunately, we do find that some of the other hospitals will have people show up and be like, well, this hospital told me to come here because they weren't going to see me. Or they're kind of pushed away.

**Peter McCormack: 45:52**

Sort of reputation.

**Katie McGruff: 45:53**

Yes, we do have people that come in every single day to the hospital, and it's almost like a hobby that they come in, and they're seen for some symptom that they have and then they're sent on their way and a lot of people, it's because they are homeless and when we, it starts to get colder, we have people coming in just for a blanket, just for food. And we try to help with that by just offering them blankets and food so they're not coming in to see a doctor and possibly holding up somebody else or even getting a bill and somebody tracking them down later for it. We'd rather just let them sit in the lobby and

stay warm and give them food and give them a blanket of possible. It's insane how many people actually come in every day.

**Peter McCormack: 46:38**

So.

**Katie McGruff: 46:39**

It's never empty.

**Peter McCormack: 46:40**

Never empty. As I was asking previously, you've obviously got observations of, you're aware of what we have in the UK cause when I said NHS you're aware, and you're obviously well aware of your own health system. From where you are, what are the worst things about the US system that you think needs to change?

**Katie McGruff: 46:57**

Follow up care. When people come in, especially for psychiatric patients and mental health patients, there is not a lot of follow up care. I know with our hospital we have emergency psychiatric services, but a lot of times those people that come in, they're released 24 hours later after talking, and they don't have that follow up care. And so they end up right back in the ED possibly hurting themselves or not having their medication because they can't afford it. And so it's just an ongoing cycle of people coming in to get treated, then they can't afford their outpatient care, and so they come back to the emergency room and it's just a merry-go-round and they just can't get off of it. And it's horrible, because you see it every single day.

**Peter McCormack: 47:38**

What about socialised health care though? Do you, there's a lot of push back, especially from Republican sides, to have socialised health care like we have in the UK. I'm not going to say the UK is imperfect, but, you know I've wanted to move to America, I love it out here, but the health system is something that concerns me. Is there much of a debate whereby people in the US want a health system like the UK or do they just want the US system to be better?

**Katie McGruff: 48:01**

I think it's depends on who you talk to. A lot of people that are older like the system, how it is and I think it's because they're so used to it, and change is something that people rarely like to do especially easily. And change is hard. I would say you have to revamp everything from the inside out, and that really irritates people because it's hard work to change something. But then you have people that are coming up, especially I think the younger generation and even around my age, that middle kind of ground, that don't mind seeing the change because in the long run it will make things easier. Like I said, getting follow up care will be easier. People won't have to come into the emergency room to get a flu swab or to have any type of simple procedure done. We have people that come up just for a medical screening because they can't afford going to a private or a primary care doctor because they're not accepted or they don't have insurance that they're going to accept.

**Katie McGruff: 48:56**

And then if you don't have insurance and you're going to a private physician, then they're going to turn you away because they want their out-of-pocket copay right up front. So people come in and see us. But I think revamping the medical system and allowing people to get affordable health care is extremely important because when you're asking somebody to give \$1,000 out-of-pocket just to be seen for a simple medical screen, to even get a job, because jobs are requiring that. How do you tell them, no, I can't do that for you. You can't afford it. Well, I can't get a job without doing it.

**Katie McGruff: 49:35**

And so I think it becomes difficult and people get lost in the health care system of what do I do next because I don't know what's going to happen and I can't afford what's going to happen. Especially when people get older and more medical things happen because they're not following up at a younger age. So I know I'm really bad about that, going to the doctor, and so is Josh, but at least if something were to come up, we could afford to do it because we have insurance and then there are people that don't go because they can't, they can't afford it. Yeah. It's a black hole kind of, and it's run like a business in the United States. A lot of times I think hospitals are a business.

**Peter McCormack: 50:16**

One thing I've noticed coming across here, which really stands out is, if I'm watching TV, is the number of adverts for medicines and treatments for things I've never heard of, which by the way, you had those really funny 30 seconds at the end where it's like [inaudible]... and you might die.

**Katie McGruff: 50:34**

Yes.

**Peter McCormack: 50:34**

Yeah. I'm like, what? Honestly, it's insanity, but it's almost like the industry is trying to convince people there's things wrong with them that don't exist because they want us to sell them something or they want to get them to use their

**Katie McGruff: 50:48**

It's like a competition, like, oh, don't, don't use them. Like we have one less side effect and ours is so much better and look at these happy people on the screen that actually don't have what you have and you could be them.

**Peter McCormack: 50:59**

Or convincing you that you have something that you didn't realise you had.

**Katie McGruff: 51:02**

No, that's definitely true.

**Peter McCormack: 51:04**

Yeah. I find competition in medicine very difficult because obviously competition has been great for innovation. The discovery of new medicines and the innovation in machinery, and I think it's been great but at the same time I also find it very scary

because people are seen as with dollar signs about the head is profit, you know, make you sick or convince you you're sick or if you are sick and then let's charge you.

**Katie McGruff: 51:27**

I know that, I feel like that's something that the United States just has like their finger on and I've heard from other people from different places that coming here is just like a smack in the face because the United States is like nowhere else, where you can see multiple billboards for like lawyers and medical companies and adverts on the television for different medicines. And it's like chasing problems that don't exist yet, but we have the cure for it.

**Peter McCormack: 51:59**

It's part of, it feels integrated into the American dream.

**Katie McGruff: 52:01**

It is. Yeah.

**Peter McCormack: 52:02**

The American Dream. By the way, we're going to just make medicine a part of this and that's the bit that concerns me. All right, well listen, this has been fantastic. It's been like fascinating to learn things. What's the near term future for you guys in terms of Clara and the things you're having to think about?

**Katie McGruff: 52:18**

Right now, since her health is, this year has been fantastic. Her health has been great. It's been the, right now she is knocked out.

**Peter McCormack: 52:28**

Yeah.

**Katie McGruff: 52:28**

Right now I'm thinking more towards her going to preschool because she's about to turn two and at the year or at the age of three, as soon as she turns three, she starts preschool. And she'll be going there five days a week and it's more the thoughts towards the future of advocating for her schooling and her being integrated into the classroom with her peers. Cause I think it's important for everybody. I mean, diversity is such a huge thing now and everybody's pushing diverse cultures and I don't want her to kind of fall to the wayside. I want everybody to experience what being friends with Clara is like and she is just fantastic.

**Peter McCormack: 53:09**

Well, she is absolutely adorable. And Josh, it's been great to get to know you in this, this weird world where you get to know somebody online and then you finally get to meet them. But we've, say we vibed back and forth for a good 18 months and you're a great guy.

**Josh McGruff: 53:21**

Thanks, I appreciate that.

**Peter McCormack: 53:23**

Obviously a great dad. I think she's adorable and I wish you both the best and if I can ever do anything for either of you, well, you know you can reach out to me.

**Josh McGruff: 53:29**

Now, I appreciate it and I really appreciate you taking an interest in her. And you know, again, this is one of the things that I really wanted was to get her story out and advocate for her, and normalise the stigmas and get people to understand that she's a person, and she might be a little bit different, but she's got her own thing going on and it's pretty cool.

**Peter McCormack: 53:47**

Dude, I'm a little bit different.

**Josh McGruff: 53:49**

I think we all are in a way.

**Peter McCormack: 53:50**

All right, mate. Well listen, if people want to get in touch with you, follow what's going on with Clara, what's the best way ?

**Josh McGruff: 53:55**

It's at Clara Crypto on Twitter.

**Peter McCormack: 53:57**

All right, cool man. Well listen, all the best of both of you.