

Narrator:

This program is presented with support from CSL bearing CVS, Specialty Pharmacy, Gryphons forming Amgen, Merck and Company and Takeda.

On average, it takes 9 to 15 years of untreated illness to be diagnosed with and treated for a primary immunodeficiency.

Recent studies estimate that 70 to 90% of those with Pi do not yet have a diagnosis.

You're listening to undiagnosed, an Immune Deficiency Foundation podcast. These are the true stories of the harrowing journey to diagnosis.

Almost certainly at some point in life. Everyone feels as though there's a part of themselves they must hide from the rest of the world. For those with primary immunodeficiency and other rare diseases, this can be painfully isolating. On this episode of undiagnosed, we'll meet a couple who understands the consequences, both good and bad. of vulnerability and authenticity.

Reuben Johnson:

I was always like finding animals and all that.

To the point my mom made a rule. She's like, if you find an animal, you can play with it. But by the end of the day, you got to bring it back to where you found it. Put it under the exact rock you found it under or whatever. She's like, how would you feel if somebody picked you up and put you in a box and kept you there?

Like, that's not fair. She's like, so you find an animal, you play with it, you be careful with it, you treat it kindly and you put it back wherever you found it, and you leave it alone and make sure you know, you know, heard it or damage it or anything like that. So I was just like I was finding animals all over the place, to the point that even after I was diagnosed with CGD, I was I was not supposed to go on fresh water, never mind the swamps.

And I was playing in the swamps constantly, like. Like I had this thing. We called it swamp hop. And so I'd come in from the swamps and I just stank and my to the point where my sister's like, Reuben smells so bad, a swamp like someone please stop him from going in there. He stinks like swamp all the time.

But this is, like, my favorite place to be. Just like, in the muck. And obviously I'm always sick from it.

Sherri Johnson:

And finding critters.

Reuben Johnson:

Yeah, finding critters. Like. I mean, finding critters and getting all these infections and stuff. And, even when the doctors, you know, say, you know, don't do X or Y or Z, I just, I found out a lot of the CGD kids, we have a lot of similarities in that we still do a lot of the stuff we're not supposed to do.

But yeah, so I think that that was one of the times I probably, I probably got pretty, pretty sick from a lot of that. Playing with the muck, but... those were that was like my joy in life was finding snakes.

Sherri Johnson:

And then you just described your adult self too

Narrator:

The voices you just heard. Belonged to Reuben and Sherri Johnson. Reuben was diagnosed with chronic granulomatous disease, or CGD, at the age of ten. So much of his story takes place after his family had found some of the answers that are often elusive for others. That said, as you'll soon learn, his words echo themes which are both recurrent and abundant in his life. Reuben learned early in life that joy is essential and simple.

However, he would soon have to confront the cruelty of sickness and the cold realities of a medical system that either didn't understand him or didn't care. These things formed a perfect storm in the center of his life that threatened to wash away the joy that once came so easily to him.

Reuben Johnson:

I always I was raised like with a lot of independence bunnies and a a very high amount of discipline and obedience was required.

So to the point, like when we were really little, there's there's eight kids in my family, so there's an older set and a younger said, I'm the oldest of the younger set. So the older set were raised with this stuff straight out of the military because they, some of them were were born in the military. Right. So like the white glove test, the, doing the corners like we were taught all of that.

And then we had those bad inspections and all that as little kids. So like, yeah, it was very, very, fastidious, exacting set of standards. He's he definitely taught me a lot about working hard, providing for your family, being responsible. And then he also was someone who who put a lot of value on of service for others.

So I know, like, when I was a little kid, I was probably like 4 or 5 years old. Oh, probably, like now, somewhere between 5 and 10 maybe. I, I can't really remember, but I remember we

used to go to the convalescent home or the nursing home, what they called it back then. And, I, we used to visit people there, and I remember we were visiting and an old black, I don't know if he was a captain or what his rank was.

And, I forget the I think he used to call him captain or captain something, I can't remember. And I'm like, dad, who is that? Who is this man? Like. Like after the after the visit, I'm like, oh, he is he are. Uncle. All we related to him is your grandfather. And my dad just kind of chuckle.

He's like, no, he's like, we're not related to him. He's like, we're just visiting him and giving him some company. He's like, I'm like, why, why, why are we doing that? Because I was just surprised that I didn't recognize him. He's like, because he doesn't have any family here. And he's a black, military officer, and we're one of the few black people out here.

And so it's our responsibility to visit him and give him some company so that, you know, he can see some kids and all that kind of stuff and that, like, kind of left an impression on me because I didn't actually know him or anything like that. And so my dad just like did a lot of stuff like that where he kind of like he would help people, he would do things in the background, but he would never tell anybody about it.

He would never, like, talk about it. He would just do it.

Narrator:

Reuben's parents instilled in him not only the virtue of kindness, but the responsibility. The family was no stranger to the suffering of others. By the time hardship arrived for them.

Reuben Johnson:

I had a sibling who had been really, really sick. Ended up being in a, a coma for a while and was in the hospital. The ordeal for them lasted well over a year. And through that they ended up diagnosing that sibling with it. And then once they knew the sibling had it, then they tested everyone in my family. And then I was diagnosed as having had it. And so for my sibling, they I don't know, I think it kind of caught everyone off guard that they got really sick because it didn't necessarily square up with how mostly healthy they had been.

But for me, they were like, okay, this makes sense. When they were in the hospital for that length of time, that was a massive, massive blow that completely changed the entire environment and the entire spirit of the family because it was went from like kind of being normal family, normal life in our house to being like spending every day at Children's Hospital, and just not even knowing it.

Like at first it was what's wrong with them? And then, oh, this is really bad. And then, oh, now they're in a coma, and then are they coming out of a coma or are they ever coming

home? Are they going to die? And then the doctors prepping us for them potentially dying. And and then my parents happened to have those conversations with the kids and, and ended up also being a thing where it would put a massive financial strain on the family.

That was the other side learning about. It's like things like your health insurance shutting off. A lot of folks in America don't realize that that is a reality, that insurers will stop paying. And now you have to figure that out, which is a huge animal on its own. So there there was a lot of things going on, and, you know, a lot of things as kids, you start as much as my parents are very much about kids are kids, adults are the adults, and they don't bring a lot of their stuff to the kids.

There was stuff they had to let us know about so that we would be prepared. And then there was stuff that you just hear things as a child. You start to like, become aware. And so I think that had a profound influence on making you aware of stuff that you don't even necessarily realize what's going on. And then, you know, just watching it all from a child's vantage point of the fear, the unknown.

And then once I found out I had it, it was now internalizing what I had seen in my sibling and their situation. Now I realize that's potentially going to be me and how you know, how you know, processing that, because that was a lot to process as well. I was born covered in a rash, which they think now might have been some sort of fungal infection.

So from the moment I came out, I was I had issues going on. I was like to run to the letter. I was really small. So I guess like a failure to thrive type of thing. Super, super scrawny. And I was just sick all the time. So for them, it kind of made sense that there was a name to this thing because I was just I was always getting sinus infections, ear infections, respiratory stuff, like, I was just sick all the time.

So, and that way it kind of like, made sense. And it gave me an opportunity to evade some of the serious stuff that they went through, because now that they knew that I. Okay, now we're going to we're going to figure out how do we keep Reuben from getting sick. I ended up getting sick a few years later myself.

I end up getting Aspergillus. All those really poor decisions caught up with me. So I was in the hospital. It wasn't a super long stay, but I was that stay pretty much drilled into my head. I have to start being different, in how I dealt with it. Like for a while I was ten. I remember specifically, the doctor had said to me, you know, you're going to be lucky to make it to 18.

You know, there's a good chance you're not going to live to 18 years old. And almost certainly never get married, never have kids like you. They're very I'm in the 80s, so they're very straight, no chaser. So from ten years old, I had to confront, you know, the existential

reality of death and all these other things. And I that had a profound impact on how I saw myself, the world.

I know a lot of times, like, you see a lot of kids who, like, kind of think they're invincible and they're immortal and I did not suffer from that. I was very well aware that, you know, I would likely die. Yeah, that that was kind of like the my entry point to CGD was figuring that out. I know, like one of the times when I got, really I was really deep down about being in a hospital and all that.

I remember the doctor walking me to where it was like the kid's cancer ward and, you know, letting me know that you're lucky because you're going to go home. You're getting out of here like we're making sure you're getting out of here. He's like, but a lot of these kids in this room, they're never leaving here. They're going to die here.

Like, remember how fortunate you are. And when you get down, remember, you get to go home. And many of these kids you just met, they're not even ever no matter what they do, there's nothing we can do to help them. And so that kind of stuff kind of sat with me as well and had like a deep impact on how I saw just the world in general and like how I think about just illness, chronic illness, a sense of like equity, justice, how I think about other people and empathy and that kind of stuff as well.

Narrator:

Reuben's sibling eventually pulled through, but the months of emotional stress and the medical bills that followed wreaked havoc on the family. The Johnsons found themselves navigating a rare disease and not just one of their children, but two. The sizable age difference prevented them from bonding over the existential nature of their conditions. However, it did not stop them from forming an oddly comforting ritual around one particularly painful symptom.

Reuben Johnson:

We didn't talk a lot about stuff, although granulomas and popping them that was a ritual for us. The weird stuff. Siblings that connect over that was a thing. Burning needles and dancing them was a big thing that was like, cause I don't care what the doctors say, if the doctors had these big old granulomas that were incredibly painful and you knew relief was on the other end of a of a lancing needle, you'd be lancing those things all day long.

So that was something that was like a ritual that was like, okay. And then it was like the comparison who's a bigger? And it's like, I got this big one on my back. Yeah. How big is yours? That's nothing. That's child's play. It's like, so you are a real big one so you can brag about it and then pop them in the mirror, which I know very like, NASTY but but it was definitely.

That was one thing we bonded over and I when they, when they ultimately moved out, I missed that. Which is the weirdest thing when you think about like these big painful things and it's like, but it's also has all this bonding around it.

Narrator:

The 90s and early 2000 were particularly difficult on Reuben and Sherri. Within a year of being married, Rubin had two bouts of intense illness that left him on temporary disability, the first of which was a frightening episode of multiple infections, including mono and pneumonia.

The newlyweds had no choice but to move back in with Sherri's family until they could financially and physically recover. They soon had a child together, and Rubin found himself doing landscape work and other various jobs that exposed him to materials that are put lightly inadvisable for those with CGD. This was at a time when insurers could simply refuse coverage to those with preexisting conditions, so employment insurance was of tremendous importance to the young couple.

Reuben Johnson:

I finally got wise, and I also listened to Sherri -- who would be very upset that I was doing it. She's like Reuben, you used to do hazmat. You have respirators. They they filter out literally everything. Because, you know, I was working with cyanide, acid, all kinds of stuff. So I had the heavy respirators that it could literally filter out anything organic.

And she's like, if you're going to stay at this job, you need to promise me you're going to wear your Elise. You're a half face respirator because she's she. I did not want to be the dude on the job site with a half face respirator with two cones on the side sticking out, but ultimately, I did relent. And I did, where I'd wear the half face respirator while we were spreading the molds.

It'd be like 90 something degrees. I'd be shoveling all this mulch with this big respirator, just pouring sweat. Ultimately, I had to tell the guy I was working for like, he's like, why? Because I'd be. I was, like, sick all the time. I'd be thrown up on the job and all that. I was still trying to hide it, so I didn't want to see.

So like, I try to dig a hole in the ground, throw up, cover the hole over and all that because I was just I was sick all the time, but I had gotten so accustomed to being sick that I could do almost anything while vomiting. Like I could literally anything. So like. And then finally I'm like, because he asked me, he's like, why are you sick?

All the time? So I finally told him, I'm like, well, I actually have a immune disease. And and all these. He's like, he's like, so you shouldn't be doing this kind of work. Then I'm like, no.

He's like, well, I don't know that I want you doing this kind of work because I don't want it. He's like, I've gotten to know you, I like you, and I like your wife and your kid.

He's like, I don't want to be responsible for doing something that's going to kill you. So before the Affordable Care Act, I couldn't get insurance. Like, is it dad? The thing called your uninsurable because you have preexisting conditions, and clearly they're going to label this a preexisting condition. So like it, it wreaked havoc on us financially. Because, like, if I wasn't working at an employer, I couldn't get insurance.

I mean, it affects a lot of things that if you until you were able to get on SSI for a little while, that was why I had to clean. Yeah. So I had to get on because I needed the meds. I could not afford them by any stretch. They just way outside of the average person's ability to pay for them, especially like the actimmune.

So we had taken a huge hit, financially because of hospital care. And then so I ended up having to go on SSI, SSDI, because of the CGD getting on that wasn't too difficult because I have, you know, a huge track record of all this medical stuff. But the problem is, once you're on that, you can only make so much money.

And I did not realize the massive catch 22 that put you in because you're in the moment your income goes up. Not only do you get they they take away benefit, but you also start to have to pay them benefit. And then there's just all these things. It's like this banana is balancing board that has like instead of two sides.

It's got like eight sides and they're all weirdly shaped and they make no sense. That that's, that happened to us. And that wreaked a lot of havoc. And it ended up keeping us in a really bad financial situation because it was always, do I have health insurance so that I can have the health care I need so I can be on the medication?

Or do we make more money? But then we lose health care, access to medication and doctors and then tumble down financially again like we had before. And it literally keeps you in really bad financial situation. And it doesn't make any sense because I never wanted to be there in the first place. So the Affordable Care Act, the Affordable Care actually changed everything for us because then like it was shortly, it was a few years before the Affordable Care Act.

We were I was tired of being trapped in that situation with disability. So we went off a disability, so that we could be able to make more money and not have all the legal implications of because there's all these legal implications, too, like, it's not just financial, it's legal stuff too. So we just said, okay, screw it, we went off of all of it.

And then we just basically went uninsured as long as we could. And then and that was it's scary. And then the Affordable Care Act ultimately came out, and then we immediately did the Affordable Care Act. We got insurance through the marketplace. And that was a massive game changer, too. But then I always had to get side jobs.

So I got jobs through like technical temp agencies that would do placement because I could buy insurance through them. And so I would do that as well. And then with the Affordable Care Act. So that's basically how we would be able to get the insurance that we needed. Because outside of that, if it had I mean, now with the Affordable Care Act, you're good.

But I mean, obviously they're trying to get rid of that now. So I don't know what that looks like for the future. But that's how things were for us. It's it's a really it's a it doesn't make any sense to tie the hands of people who can do a lot better financially. And they like I was happy to be paying into I didn't I didn't bother me to be paying.

And I was happy to, and I think it's like the arguments against people being able to be in a better situation where they can care for themselves don't make any sense.

Narrator:

Vulnerability is paramount to both Ruben and Sherri. They're the founders of Fly Media Productions and SexTech and Chill, both of which focus on sex-positive intimacy and wellness.

But vulnerability has many forms, and it's seldom easy. Ruben's condition cost him multiple jobs early in their marriage. In addition to CGD, Ruben lives with Tourette syndrome and obsessive compulsive disorder. Meanwhile, Shari suffers from myalgic encephalomyelitis, sometimes known as chronic fatigue syndrome. Like primary immunodeficiency, these diseases are poorly understood by the general public and are heavily stigmatized and stereotyped.

They each acknowledge a years long struggle to find the right amount of vulnerability, how much to share with those around them to ensure that their needs can be met.

Reuben Johnson:

We actually did a Twitter chat on Tourette's back in the two teens because we wanted to do amplification around that. And it was a friend, he became ended up becoming a friend.

He's, his handle is deaf Tourette. He has he's deaf and he has Tourette's. And he's an advocate around Tourette syndrome and deafness. And he said something that really hit me like he's like, well, I can't hide that. I'm deaf. He's like. And I don't feel like hiding that I



have Tourette's. If people don't want to work with me or hire me because I got Tourette's, he's like, great, because they can get out of my way.

I can find a company that does want to work with me. He's like, I don't have. He's like, I don't have time to worry about any of that. And it just really hit me. And it also made me realize the, the privilege of having illnesses that are just under severe enough where you can try to hide them, but it's a trap, too, because like he said to me, he's like, I can't hide that I'm deaf.

So I don't try to. And I realize I had fallen into the trap of thinking I could hide things. At a point. When you ask about the vulnerability, I had some really good friends, like, who's my three best friends? It was two girls and a guy, and I was probably somewhere between 16 and 18. And, I remember them saying something and something like Tourette's came up and, like, I didn't know that anyone knew I had Tourette's because I thought I was hiding it.

I'm like, you know, I have Tourette's. And one of my friends, the guy friend, was was talking to the two girls. He's like, and they were like, yeah, we have conversations about it. Like, we all know you have Tourette's. Like you literally thought you were hiding that. They're like, why did you feel like you had to hide that?

I'm like, because I hate it. It's so embarrassing. They're like, they're like, Reuben. We talk about it on the side because we're always trying to figure out how we can be there for you, and we're always worried about your well-being and everything, but like, you're not hiding it. If you think you're hiding it, you're doing a terrible job.

Like there's no way for you to hide it like it's there. But we've been trying to figure out, how do we help you? Because we know you're going through stuff. You can see it. It just shows. And it just, like, hit me. The fact that I have friends who cared enough to call each other and talk on the phone, like, have whole last conversations about how do we be there for Reuben with his Tourette's?

I know he doesn't like to talk about it. How do we talk about it when he doesn't want to talk about it? And I was just because I was just so deeply ashamed of it because I, you know, I had gotten a lot of hell for it. Be black, be disabled, and have Tourette's and OCD in Massachusetts in the 1980s.

That was not fun. It's a process. It's a process I've been working toward over the last like 30 years. I know, like when Sherry Lee got together, I was just then starting to talk more about having a kid in, like, telling her that I had it in because I wanted her to have, like, the full picture. And then she told me she had a chronic illness.

And I think you told me first, maybe about about yours. Something I can't remember, but it seems it feels like a thing you would have done for like, it's it's it's a process. It's it's been 30 years in the making, but I think it takes a lot less effort to just be fully present and be your full self, whatever that looks like, than it does to try to put yourself into different buckets at different times and in different locations.

I think that takes way more effort. And I think at the end of the day, you you lose some of your potential. I don't know, that's the way I see it. I know it in no way do I say that is a universal thing. Everyone should do that. Because I also know on the flip side, there is implications to it.

It can still have adverse effects, and you've got to be ready and aware of the risks that that come with it. And you have to be in a position to be able to deal with those risks, too. Because that is all there. It's very easy to just say, be 100% authentic no matter what. And it's not fair to tell people to do that without following up with saying there are risks, there are consequences, and sometimes it's going to go badly for you.

Being your full self all the way around, full circle is that is something I would advise everyone to consider. How can they work toward that? What is their tolerance for the amount of risk involved and sacrifice? Because I think it comes with all of those things. But I think they need to be aware of what's involved in that decision all the way around.

Sherri Johnson:

I think in my young mind, we both have chronic illness. Something to relate about. Like, and I think I was more I my recollection of back then is more around the Tourette's and OCD that was more visible to me because I didn't see as much of the illness side. At least I didn't know if it wasn't like I didn't see it so much, you know, until like, we first got married and then it just kicked into overdrive, like we signed a contract and then it came in.

It was full effect. It was. Yeah. Yeah, pretty much echo what he said. It's only been like recent years that we're both actually trying to be more open about that. We live with this because it's, it's it impacts us like every single day in so many ways. People have no idea. And, and the energy drain, just trying to present normal all the time is a lot.

And so we've been we're both like figuring out what that looks like to talk about it and how to talk about how much to talk about it. You know, balancing the like we're okay and we can do this job. And, you know, you don't have nothing to worry about with them. Tired? Are you tired?

Narrator:

When asked what advice they have for younger people with chronic illness, Reuben and

Sherri emphasized the importance of finding oneself a finding community and freeing oneself of shame and maybe most importantly, expressing gratitude.

Reuben Johnson:

I see the generation now and how free they are because they're not hiding everything, and how much lighter they seem to live and move about the world without this weight of shame and hiding who you are and hiding these big parts of yourself. It's huge. Like what I told Sherri. Like I didn't know exactly how she would take it, but I'm like, okay.

I remember writing it down like in my like, journal. I had like, you know, like to me, notebooks or whatever I had when I used to put journals in and all that. And anytime I was going to make a decision, I do like the yes no maybe and all that kind of stuff to like, way through. And I remember, like, I have to tell her about CGD, I have to tell her about OCD and Tourette's.

I was more afraid to try to have to tell you about Tourette's and OCD than the CGD is. Only one of those things is going to potentially kill only one of those things, she said. I might not live. Yeah, exactly. But I was more afraid and more ashamed of the Tourette's and OCD than the CGD. Like, the CGD was like, you know, I mean, I think to the vulnerability thing that we keep circling around to it, that's part of why we are trying to be more open about our own things.

And then now being on camera for like our, our work and stuff. I'm like, I am, I like I know for myself like my weight fluctuates and like sometimes I look like I'm dragging and dead. And the other times I like full of life. And I'm like, it's a lot of pressure to come on and be perfect all the time.

When you can't, you can't like, you can't hide something. It's invisible to a point. But people who see you all the time can see the differences and the fluctuation. It's same with you. Like with your Tourette's. You can't always. You can see it now. Like on camera. It's on camera. You're in. I mean, it is almost a certainty you're going to be dealing with internalized shame about walking around and existing in your body that is disabled.

And I think it's important for you to figure out, like, how that might have given you a level of shame that you carry, that you can divest yourself of and you can have a happier and more pleasant experience in the world that I think would be a big thing. And that also help you to find friends that you're happy with, build a family or a found family or chosen family that makes you feel happy and satisfied, and then be able to give back to the world in a way that doesn't ask too much of you and more than you're able to do, and is not unreasonable for whatever your circumstances are.

And and I would. My final thing I would say is understand that your life is -- You probably already know this, but understand it's okay that your life doesn't always have consistency and find the ways for you to to be okay with that regardless, because that is the biggest thing, is that having chronic illness means you're consistently inconsistent, and it's not your fault that you can't get on the right schedule.

Like, and it's going to change forever and ever. Don't give up on that either. Yeah, keep trying. Keep trying on your little wins and celebrate them how you can and you're

Sherri Johnson:

And count your blessings.

Reuben Johnson:

Yes, gratitude is huge.

Narrator:

Thank you for listening to undiagnosed. Your support of the Immune Deficiency Foundation helps ensure that people like Reuben get the education, advocacy, and support they deserve. To learn more about our mission and to donate, visit [primaryimmune.org/donut](https://primaryimmune.org/donut).

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If you want, I can do a **second pass** that *only* fixes obvious auto-transcription errors (e.g., sponsor names, “[primaryimmune.org/donate](https://primaryimmune.org/donate)”, “Grifols”, “CSL Behring”, “Sex Tech and Chill”, etc.) while leaving the phrasing intact otherwise.

yes, please do that. Only obvious errors, but don't worry about minor grammar things. Only worry about things that can lead to miscommunications

Done — here’s a **second pass** with **only obvious, high-impact corrections** (things that could miscommunicate names, orgs, URLs, meds, conditions, brands). I did **not** “smooth” grammar or rewrite sentences.

Key fixes made:

- Sponsor line: **CSL Behring, CVS Specialty Pharmacy, Grifols, Amgen, Merck & Co., Takeda**
- “Pi” → **PI** (primary immunodeficiency) where it’s clearly that acronym
- “heard it” → **hurt it** (context: animals)
- “Ruben / Rubin / Shari” → **Reuben / Reuben / Sherri** (uniform)
- “the 90s and early 2000” → **the ’90s and early 2000s** (clarity)

- “spreading the molds” → **spreading the mulch** (context: landscaping)
  - “Actimmune” capitalized as the medication name **Actimmune**
  - Tourette’s / OCD standardized: **Tourette syndrome / obsessive-compulsive disorder**
  - URL: **primaryimmune.org/donate** (instead of “donut” and spacing)
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And finding critters.

Reuben Johnson:  
Yeah, finding critters. Like. I mean, finding critters and getting all these infections and stuff. And, even when the doctors, you know, say, you know, don't do X or Y or Z, I just, I found out a lot of the CGD kids, we have a lot of similarities in that we still do a lot of the stuff we're not supposed to do.

But yeah, so I think that that was one of the times I probably, I probably got pretty, pretty sick from a lot of that. Playing with the muck, but... those were that was like my joy in life was finding snakes.

Sherri Johnson:  
And then you just described your adult self too

Narrator:  
The voices you just heard belonged to **Reuben** and **Sherri Johnson**. Reuben was diagnosed with chronic granulomatous disease, or CGD, at the age of ten. So much of his story takes place after his family had found some of the answers that are often elusive for others. That said, as you'll soon learn, his words echo themes which are both recurrent and abundant in his life. Reuben learned early in life that joy is essential and simple.

However, he would soon have to confront the cruelty of sickness and the cold realities of a medical system that either didn't understand him or didn't care. These things formed a perfect storm in the center of his life that threatened to wash away the joy that once came so easily to him.

Reuben Johnson:  
I always I was raised like with a lot of independence bunnies and a a very high amount of discipline and obedience was required.

So to the point, like when we were really little, there's there's eight kids in my family, so there's an older set and a younger said, I'm the oldest of the younger set. So the older set were raised with this stuff straight out of the military because they, some of them were were born in the military. Right. So like the white glove test, the, doing the corners like we were taught all of that.

And then we had those bad inspections and all that as little kids. So like, yeah, it was very, very, fastidious, exacting set of standards. He's he definitely taught me a lot about working hard, providing for your family, being responsible. And then he also was someone who who put a lot of value on of service for others.

So I know, like, when I was a little kid, I was probably like 4 or 5 years old. Oh, probably, like now, somewhere between 5 and 10 maybe. I, I can't really remember, but I remember we used to go to the convalescent home or the nursing home, what they called it back then. And, I, we used to visit people there, and I remember we were visiting and an old black, I don't know if he was a captain or what his rank was.

And, I forget the I think he used to call him captain or captain something, I can't remember. And I'm like, dad, who is that? Who is this man? Like. Like after the after the visit, I'm like, oh, he is he our uncle. All we related to him is your grandfather. And my dad just kind of chuckle.

He's like, no, he's like, we're not related to him. He's like, we're just visiting him and giving him some company. He's like, I'm like, why, why, why are we doing that? Because I was just surprised that I didn't recognize him. He's like, because he doesn't have any family here. And he's a black, military officer, and we're one of the few black people out here.

And so it's our responsibility to visit him and give him some company so that, you know, he can see some kids and all that kind of stuff and that, like, kind of left an impression on me because I didn't actually know him or anything like that. And so my dad just like did a lot of stuff like that where he kind of like he would help people, he would do things in the background, but he would never tell anybody about it.

He would never, like, talk about it. He would just do it.

Narrator:

Reuben's parents instilled in him not only the virtue of kindness, but the responsibility. The family was no stranger to the suffering of others. By the time hardship arrived for them. I had a sibling who had been really, really sick. Ended up being in a, a coma for a while and was in the hospital.

Reuben Johnson:

The ordeal for them lasted well over a year. And through that they ended up diagnosing that sibling with it. And then once they knew the sibling had it, then they tested everyone in my family. And then I was diagnosed as having had it. And so for my sibling, they I don't know, I think it kind of caught everyone off guard that they got really sick because it didn't necessarily square up with how mostly healthy they had been.

But for me, they were like, okay, this makes sense. When they were in the hospital for that length of time, that was a massive, massive blow that completely changed the entire environment and the entire spirit of the family because it was went from like kind of being normal family, normal life in our house to being like spending every day at Children's Hospital, and just not even knowing it.

Like at first it was what's wrong with them? And then, oh, this is really bad. And then, oh, now they're in a coma, and then are they coming out of a coma or are they ever coming home? Are they going to die? And then the doctors prepping us for them potentially dying. And and then my parents happened to have those conversations with the kids and, and ended up also being a thing where it would put a massive financial strain on the family.

That was the other side learning about. It's like things like your health insurance shutting off. A lot of folks in America don't realize that that is a reality, that insurers will stop paying. And now you have to figure that out, which is a huge animal on its own. So there there was a lot of things going on, and, you know, a lot of things as kids, you start as much as my parents are very much about kids are kids, adults are the adults, and they don't bring a lot of their stuff to the kids.

There was stuff they had to let us know about so that we would be prepared. And then there was stuff that you just hear things as a child. You start to like, become aware. And so I think that had a profound influence on making you aware of stuff that you don't even necessarily realize what's going on. And then, you know, just watching it all from a child's vantage point of the fear, the unknown.

And then once I found out I had it, it was now internalizing what I had seen in my sibling and their situation. Now I realize that's potentially going to be me and how you know, how you know, processing that, because that was a lot to process as well. I was born covered in a rash, which they think now might have been some sort of fungal infection.

So from the moment I came out, I was I had issues going on. I was like to run to the letter. I was really small. So I guess like a failure to thrive type of thing. Super, super scrawny. And I was just sick all the time. So for them, it kind of made sense that there was a name to this thing because I was just I was always getting sinus infections, ear infections, respiratory stuff, like, I was just sick all the time.

So, and that way it kind of like, made sense. And it gave me an opportunity to evade some of the serious stuff that they went through, because now that they knew that I. Okay, now we're going to we're going to figure out how do we keep Reuben from getting sick. I ended up getting sick a few years later myself.



I end up getting Aspergillus. All those really poor decisions caught up with me. So I was in the hospital. It wasn't a super long stay, but I was that stay pretty much drilled into my head. I have to start being different, in how I dealt with it. Like for a while I was ten. I remember specifically, the doctor had said to me, you know, you're going to be lucky to make it to 18.

You know, there's a good chance you're not going to live to 18 years old. And almost certainly never get married, never have kids like you. They're very I'm in the 80s, so they're very straight, no chaser. So from ten years old, I had to confront, you know, the existential reality of death and all these other things. And I that had a profound impact on how I saw myself, the world.

I know a lot of times, like, you see a lot of kids who, like, kind of think they're invincible and they're immortal and I did not suffer from that. I was very well aware that, you know, I would likely die. Yeah, that that was kind of like the my entry point to CGD was figuring that out. I know, like one of the times when I got, really I was really deep down about being in a hospital and all that.

I remember the doctor walking me to where it was like the kid's cancer ward and, you know, letting me know that you're lucky because you're going to go home. You're getting out of here like we're making sure you're getting out of here. He's like, but a lot of these kids in this room, they're never leaving here. They're going to die here.

Like, remember how fortunate you are. And when you get down, remember, you get to go home. And many of these kids you just met, they're not even ever no matter what they do, there's nothing we can do to help them. And so that kind of stuff kind of sat with me as well and had like a deep impact on how I saw just the world in general and like how I think about just illness, chronic illness, a sense of like equity, justice, how I think about other people and empathy and that kind of stuff as well.

Narrator:

Reuben's sibling eventually pulled through, but the months of emotional stress and the medical bills that followed wreaked havoc on the family. The Johnsons found themselves navigating a rare disease and not just one of their children, but two. The sizable age difference prevented them from bonding over the existential nature of their conditions. However, it did not stop them from forming an oddly comforting ritual around one particularly painful symptom.

Reuben Johnson:

We didn't talk a lot about stuff, although granulomas and popping them that was a ritual for us. The weird stuff. Siblings that connect over that was a thing. Burning needles and

dancing them was a big thing that was like, cause I don't care what the doctors say, if the doctors had these big old granulomas that were incredibly painful and you knew relief was on the other end of a of a lancing needle, you'd be lancing those things all day long.

So that was something that was like a ritual that was like, okay. And then it was like the comparison who's a bigger? And it's like, I got this big one on my back. Yeah. How big is yours? That's nothing. That's child's play. It's like, so you are a real big one so you can brag about it and then pop them in the mirror, which I know very like, nasty but but it was definitely.

That was one thing we bonded over and I when they, when they ultimately moved out, I missed that. Which is the weirdest thing when you think about like these big painful things and it's like, but it's also has all this bonding around it.

Narrator:

The '90s and early 2000s were particularly difficult on Reuben and Sherri. Within a year of being married, Reuben had two bouts of intense illness that left him on temporary disability, the first of which was a frightening episode of multiple infections, including mono and pneumonia.

The newlyweds had no choice but to move back in with Sherri's family until they could financially and physically recover. They soon had a child together, and Reuben found himself doing landscape work and other various jobs that exposed him to materials that are put lightly inadvisable for those with CGD. This was at a time when insurers could simply refuse coverage to those with preexisting conditions, so employment insurance was of tremendous importance to the young couple.

Reuben Johnson:

I finally got wise, and I also listened to Sherri — who would be very upset that I was doing it. She's like Reuben, you used to do hazmat. You have respirators. They they filter out literally everything. Because, you know, I was working with cyanide, acid, all kinds of stuff. So I had the heavy respirators that it could literally filter out anything organic.

And she's like, if you're going to stay at this job, you need to promise me you're going to wear your — your half-face respirator because she's she. I did not want to be the dude on the job site with a half-face respirator with two cones on the side sticking out, but ultimately, I did relent. And I did, where I'd wear the half-face respirator while we were spreading the **mulch**.

It'd be like 90-something degrees. I'd be shoveling all this mulch with this big respirator, just pouring sweat. Ultimately, I had to tell the guy I was working for like, he's like, why? Because

I'd be. I was, like, sick all the time. I'd be throwing up on the job and all that. I was still trying to hide it, so I didn't want to see.

So like, I try to dig a hole in the ground, throw up, cover the hole over and all that because I was just I was sick all the time, but I had gotten so accustomed to being sick that I could do almost anything while vomiting. Like I could literally anything. So like. And then finally I'm like, because he asked me, he's like, why are you sick?

All the time? So I finally told him, I'm like, well, I actually have an immune disease. And and all these. He's like, he's like, so you shouldn't be doing this kind of work. Then I'm like, no. He's like, well, I don't know that I want you doing this kind of work because I don't want it. He's like, I've gotten to know you, I like you, and I like your wife and your kid.

He's like, I don't want to be responsible for doing something that's going to kill you. So before the Affordable Care Act, I couldn't get insurance. Like, it's a thing called you're uninsurable because you have preexisting conditions, and clearly they're going to label this a preexisting condition. So like it, it wreaked havoc on us financially. Because, like, if I wasn't working at an employer, I couldn't get insurance.

I mean, it affects a lot of things that if you until you were able to get on SSI for a little while, that was why I had to clean. Yeah. So I had to get on because I needed the meds. I could not afford them by any stretch. They just way outside of the average person's ability to pay for them, especially like the **Actimmune**.

So we had taken a huge hit, financially because of hospital care. And then so I ended up having to go on SSI, SSDI, because of the CGD getting on that wasn't too difficult because I have, you know, a huge track record of all this medical stuff. But the problem is, once you're on that, you can only make so much money.

And I did not realize the massive catch-22 that put you in because you're in the moment your income goes up. Not only do you get they they take away benefit, but you also start to have to pay them benefit. And then there's just all these things. It's like this banana is balancing board that has like instead of two sides.

It's got like eight sides and they're all weirdly shaped and they make no sense. That that's, that happened to us. And that wreaked a lot of havoc. And it ended up keeping us in a really bad financial situation because it was always, do I have health insurance so that I can have the health care I need so I can be on the medication?

Or do we make more money? But then we lose health care, access to medication and doctors and then tumble down financially again like we had before. And it literally keeps you in really bad financial situation. And it doesn't make any sense because I never wanted

to be there in the first place. So the Affordable Care Act, the Affordable Care actually changed everything for us because then like it was shortly, it was a few years before the Affordable Care Act.

We were I was tired of being trapped in that situation with disability. So we went off a disability, so that we could be able to make more money and not have all the legal implications of because there's all these legal implications, too, like, it's not just financial, it's legal stuff too. So we just said, okay, screw it, we went off of all of it.

And then we just basically went uninsured as long as we could. And then and that was it's scary. And then the Affordable Care Act ultimately came out, and then we immediately did the Affordable Care Act. We got insurance through the marketplace. And that was a massive game changer, too. But then I always had to get side jobs.

So I got jobs through like technical temp agencies that would do placement because I could buy insurance through them. And so I would do that as well. And then with the Affordable Care Act. So that's basically how we would be able to get the insurance that we needed. Because outside of that, if it had I mean, now with the Affordable Care Act, you're good.

But I mean, obviously they're trying to get rid of that now. So I don't know what that looks like for the future. But that's how things were for us. It's it's a really it's a it doesn't make any sense to tie the hands of people who can do a lot better financially. And they like I was happy to be paying into I didn't I didn't bother me to be paying.

And I was happy to, and I think it's like the arguments against people being able to be in a better situation where they can care for themselves don't make any sense.

Narrator:

Vulnerability is paramount to both Reuben and Sherri. They're the founders of Fly Media Productions and SexTech and Chill, both of which focus on sex-positive intimacy and wellness.

But vulnerability has many forms, and it's seldom easy. Reuben's condition cost him multiple jobs early in their marriage. In addition to CGD, Reuben lives with Tourette syndrome and **obsessive-compulsive disorder**. Meanwhile, Sherri suffers from **myalgic encephalomyelitis**, sometimes known as chronic fatigue syndrome. Like primary immunodeficiency, these diseases are poorly understood by the general public and are heavily stigmatized and stereotyped.

They each acknowledge a years long struggle to find the right amount of vulnerability, how much to share with those around them to ensure that their needs can be met.

Reuben Johnson:

We actually did a Twitter chat on Tourette's back in the two teens because we wanted to do amplification around that. And it was a friend, he became ended up becoming a friend.

He's, his handle is deaf Tourette. He has he's deaf and he has Tourette's. And he's an advocate around Tourette syndrome and deafness. And he said something that really hit me like he's like, well, I can't hide that. I'm deaf. He's like. And I don't feel like hiding that I have Tourette's. If people don't want to work with me or hire me because I got Tourette's, he's like, great, because they can get out of my way.

I can find a company that does want to work with me. He's like, I don't have. He's like, I don't have time to worry about any of that. And it just really hit me. And it also made me realize the, the privilege of having illnesses that are just under severe enough where you can try to hide them, but it's a trap, too, because like he said to me, he's like, I can't hide that I'm deaf.

So I don't try to. And I realize I had fallen into the trap of thinking I could hide things. At a point. When you ask about the vulnerability, I had some really good friends, like, who's my three best friends? It was two girls and a guy, and I was probably somewhere between 16 and 18. And, I remember them saying something and something like Tourette's came up and, like, I didn't know that anyone knew I had Tourette's because I thought I was hiding it.

I'm like, you know, I have Tourette's. And one of my friends, the guy friend, was was talking to the two girls. He's like, and they were like, yeah, we have conversations about it. Like, we all know you have Tourette's. Like you literally thought you were hiding that. They're like, why did you feel like you had to hide that?

I'm like, because I hate it. It's so embarrassing. They're like, they're like, Reuben. We talk about it on the side because we're always trying to figure out how we can be there for you, and we're always worried about your well-being and everything, but like, you're not hiding it. If you think you're hiding it, you're doing a terrible job.

Like there's no way for you to hide it like it's there. But we've been trying to figure out, how do we help you? Because we know you're going through stuff. You can see it. It just shows. And it just, like, hit me. The fact that I have friends who cared enough to call each other and talk on the phone, like, have whole last conversations about how do we be there for Reuben with his Tourette's?

I know he doesn't like to talk about it. How do we talk about it when he doesn't want to talk about it? And I was just because I was just so deeply ashamed of it because I, you know, I had gotten a lot of hell for it. Be black, be disabled, and have Tourette's and OCD in Massachusetts in the 1980s.

That was not fun. It's a process. It's a process I've been working toward over the last like 30 years. I know, like when Sherry Lee got together, I was just then starting to talk more about having a kid in, like, telling her that I had it in because I wanted her to have, like, the full picture. And then she told me she had a chronic illness.

And I think you told me first, maybe about about yours. Something I can't remember, but it seems it feels like a thing you would have done for like, it's it's it's a process. It's it's been 30 years in the making, but I think it takes a lot less effort to just be fully present and be your full self, whatever that looks like, than it does to try to put yourself into different buckets at different times and in different locations.

I think that takes way more effort. And I think at the end of the day, you you lose some of your potential. I don't know, that's the way I see it. I know it in no way do I say that is a universal thing. Everyone should do that. Because I also know on the flip side, there is implications to it.

It can still have adverse effects, and you've got to be ready and aware of the risks that that come with it. And you have to be in a position to be able to deal with those risks, too. Because that is all there. It's very easy to just say, be 100% authentic no matter what. And it's not fair to tell people to do that without following up with saying there are risks, there are consequences, and sometimes it's going to go badly for you.

Being your full self all the way around, full circle is that is something I would advise everyone to consider. How can they work toward that? What is their tolerance for the amount of risk involved and sacrifice? Because I think it comes with all of those things. But I think they need to be aware of what's involved in that decision all the way around.

Sherri Johnson:

I think in my young mind, we both have chronic illness. Something to relate about. Like, and I think I was more I my recollection of back then is more around the Tourette's and OCD that was more visible to me because I didn't see as much of the illness side. At least I didn't know if it wasn't like I didn't see it so much, you know, until like, we first got married and then it just kicked into overdrive, like we signed a contract and then it came in.

It was full effect. It was. Yeah. Yeah, pretty much echo what he said. It's only been like recent years that we're both actually trying to be more open about that. We live with this because it's, it's it impacts us like every single day in so many ways. People have no idea. And, and the energy drain, just trying to present normal all the time is a lot.

And so we've been we're both like figuring out what that looks like to talk about it and how to talk about how much to talk about it. You know, balancing the like we're okay and we can

do this job. And, you know, you don't have nothing to worry about with them. Tired? Are you tired?

Narrator:

When asked what advice they have for younger people with chronic illness, Reuben and Sherri emphasized the importance of finding oneself a finding community and freeing oneself of shame and maybe most importantly, expressing gratitude.

Reuben Johnson:

I see the generation now and how free they are because they're not hiding everything, and how much lighter they seem to live and move about the world without this weight of shame and hiding who you are and hiding these big parts of yourself. It's huge. Like what I told Sherri. Like I didn't know exactly how she would take it, but I'm like, okay.

I remember writing it down like in my like, journal. I had like, you know, like to me, notebooks or whatever I had when I used to put journals in and all that. And anytime I was going to make a decision, I do like the yes no maybe and all that kind of stuff to like, way through. And I remember, like, I have to tell her about CGD, I have to tell her about OCD and Tourette's.

I was more afraid to try to have to tell you about Tourette's and OCD than the CGD is. Only one of those things is going to potentially kill only one of those things, she said. I might not live. Yeah, exactly. But I was more afraid and more ashamed of the Tourette's and OCD than the CGD. Like, the CGD was like, you know, I mean, I think to the vulnerability thing that we keep circling around to it, that's part of why we are trying to be more open about our own things.

And then now being on camera for like our, our work and stuff. I'm like, I am, I like I know for myself like my weight fluctuates and like sometimes I look like I'm dragging and dead. And the other times I like full of life. And I'm like, it's a lot of pressure to come on and be perfect all the time.

When you can't, you can't like, you can't hide something. It's invisible to a point. But people who see you all the time can see the differences and the fluctuation. It's same with you. Like with your Tourette's. You can't always. You can see it now. Like on camera. It's on camera. You're in. I mean, it is almost a certainty you're going to be dealing with internalized shame about walking around and existing in your body that is disabled.

And I think it's important for you to figure out, like, how that might have given you a level of shame that you carry, that you can divest yourself of and you can have a happier and more pleasant experience in the world that I think would be a big thing. And that also help you to find friends that you're happy with, build a family or a found family or chosen family that

makes you feel happy and satisfied, and then be able to give back to the world in a way that doesn't ask too much of you and more than you're able to do, and is not unreasonable for whatever your circumstances are.

And and I would. My final thing I would say is understand that your life is -- You probably already know this, but understand it's okay that your life doesn't always have consistency and find the ways for you to be okay with that regardless, because that is the biggest thing, is that having chronic illness means you're consistently inconsistent, and it's not your fault that you can't get on the right schedule.

Like, and it's going to change forever and ever. Don't give up on that either. Yeah, keep trying. Keep trying on your little wins and celebrate them how you can and you're

Sherri Johnson:

And count your blessings.

Reuben Johnson:

Yes, gratitude is huge.

Narrator:

Thank you for listening to *Undiagnosed*. Your support of the Immune Deficiency Foundation helps ensure that people like Reuben get the education, advocacy, and support they deserve. To learn more about our mission and to donate, visit **[primaryimmune.org/donate](https://primaryimmune.org/donate)**.