**Narrator**: This episode of undiagnosed is presented with support from Takeda, Horizon Therapeutics, CSL Behring, and Grifols. On average, it takes nine to fifteen years of untreated illness to be diagnosed with and treated for a primary immunodeficiency. Recent studies estimate that seventy to ninety percent 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.

No two stories are ever identical. Sometimes the diagnosis journey with primary immunodeficiency is linear. Someone may experience debilitating symptoms throughout life, then begin to live again when they're diagnosed and receive proper treatment. But what happens when the journey is not linear? What happens when the most obvious symptoms stay hidden? If science hasn't progressed far enough, to draw a clear picture of the issues at hand. What happens when PI isn't the only medical challenge someone faces? Moreover, what happens to the single parent who has to navigate the challenges alone? This episode of undiagnosed is somewhat unique and that it's told not through the perspective of a patient, but rather from that of a caregiver, a father faced with impossible decisions. A father whose willingness to share his experiences trailblaze the way we discuss parenting for neurodivergent children. This is the story of Rob Gorski, and his son through adoption, Gavin.

**Rob Gorski**: I I met Gavin when he was a year old. He was thirteen months old when I met him. So I missed the first, like, thirteen months of his life. And it has been Rob and Gavin ever since. Like, we just bonded.

And in in whatever way you can sort of have your a kid be your best friend. Kinda like, it weird because I like, I wasn't his dad. Right? So I was I was like a like a role model in his life for a long time. Right?

And then it just there is something about that here. He changed he changed me who I am, and he he changed everything. When I when I get frustrated with my life or I feel like I'm overwhelmed or whatever, I just remember everything that he has to do, everything he goes through, and never, he always wants to help other people. He if you were home right now, he probably would have knocked on my door twice already. Even knowing that I'm in here doing this because he has this overwhelming need to to find out if there's something he can do to help me today. You know? And such a good kid.

**Narrator**: As an infant and toddler, Gavin developed normally until age four. At that point, Rob describes an almost overnight transformation in Gavin's personality and behavior.

**Rob Gorski**: He was even diagnosed as schizophrenic. Like, everything was it was I mean, every worst case scenario diagnosis, he's childhood disintegrated disorder is a type of autism that he has. He developed typically until he was about four years old and then experienced just massive regression, lost all of his mass master skills, personality change, everything was like a whole new kid.

**Narrator**: Childhood disintegration disorder, also known as CDD, took everything Gavin had learned as a young child away from him. A rare condition in which a toddler loses language, social and motor skills CDD forced Gavin to relearn how to walk and talk. Specialists told Rob that Gavin would never fully regain those skills. As a result, Rob found himself lost, tired, and grieving.

**Rob Gorski**: I was desperate. I was exhausted. I was overwhelmed. Didn't know a single person who would even even knew somebody who was diagnosed with autism. And and this was before all the other medical things happened.

And I I was not coping well with it. Right? I was I missed the child that Gavin used to be. I was grieving the loss of a kid that was still there.

**Narrator**: Eventually, as Gavin's behavioral issues grew more and more complicated, and as Rob's other two sons were diagnosed with autism as well. Rob and the boy's mother made the decision that Rob needed to leave his job as a fire medic, to stay home and take care of the children. He was twenty nine years old.

**Rob Gorski**: So I was a fire medic. And loved my job. And that's one of the things I will say, like, I was good at my job. And I had reached a point where, you know, my wife at the time, my kid's mom, was it was a lot for one person to manage at home. Right?

And her health was declining. There were a lot of mental health issues and Gavin in particular was very, very challenging. And there just came a point where you know, working shift seventy two hours sometimes, like, I would work three days straight and then have, like, four days off. And I was out of town. And that was a lot to put on anyone.

And, you know, and then you reach a point where I I had suffered a major back injuries. I was working through pain. And I I was seeing things that you just cannot you can't unsee. You know, and once, like, once once my two youngest were born, I I I mean, I never look at my kids as is different just because Gavin's adopted doesn't make it any different to me than than the other two. But I experienced the whole process with my other kids.

Right? So there's there's like a different understanding of things. And I I had been on some calls that just that they just broke me, honestly. And between that and the need to be home, we made a choice of time that despite the financial hardship, I was just gonna have to I I had to stay home, you know. And so I would do odd things like I built computers and stuff like that.

I I I did a I had a small contracting business for a few years. And, you know, I I did whatever I could to kinda piece together enough to survive on. It was always hard. And, you know, even today, I mean, it's still the business side of this is relatively new, and it's it's still growing. And I'm learning that I can't always do things for free, like I would love to be able to do for for free because I just wanna help everybody all the time.

But it was it was very difficult, and there were a lot of people who didn't understand. Like, why would you do that? You know, or Rob things are hard, just go get a job. You can't just go get a job sometimes. Right?

Like, you have a kid who needs infusions twice a week, or you have a kid that has to go to the hospital all the time, and you never know. Or you have kids that are, and you have to go pick them up at school because they had an issue at school. I mean, it's constant. It's absolutely constant and it's coming from three different directions in three different ways. There there was no other sustainable approach.

And I know so many parents that find themselves in the same boat, and you get judged, and and you get people who are like, well, just, you know, do this or do that. I mean, there are no simple solutions. If it was that simple, I would have done that fifteen years ago and and not be in this place where I'm forty five years old trying to plan for my retirement now, like, all of these things that I had no bandwidth for. You know, over the years because everything I had I gave to my kids. And and now it's it's playing catch up.

You know? And do I regret it? Nope. Like, I would do it all over again if I had to. I would maybe try and do things a little bit smarter, like just knowing what I know now, but it was a nest it was an unavoidable thing, you know.

And And it was an emotional.... It was an emotional blow too. I mean, like as a dad, I wanted to be the provider. I wanted to do all these things and make life better. And and for a long time, it was just survival.

You know, it it was everything I could do to keep Gavin alive. Or healthy, or the kids in their therapy sessions, or making progress. My youngest didn't because he was four and a half. You know what I mean? So so learning sign language and ways to communicate and navigating his health issues.

He had bizarre health issues too. And and making sure that my seventeen year old who was diagnosed last wasn't lost in the shuffle. Right? Because, like, there's just all these different directions and and It was it was the right decision for the right reasons. And yes, it complicates things, and yes, it makes life harder now.

But I also got to experience my kids growing up and be a part of everything.

**Narrator**: Roughly a decade passed for the Gorskis in their new version of normal. In Gavin's early teens however, things got even more complicated. It was Gavin's gastroenterologist who flagged an issue with his IG levels, which set the Gorski's on a remarkably rapid path to diagnosis. But as was usually the case with Gavin, there was more than one issue at play.

**Rob Gorski**: For as bad as it is, I would have thought he would be sick all the time. You know? And and I'm learning that that's not always the case. I'm not entirely familiar with how most people get diagnosed, but he was it was sort of accidentally discovered. And he never showed signs when he was growing up.

So he was never, like, sicker than what I think most kids would be. There were never any I mean, like no one flagged anything, not as pediatricians, you know, nothing. And he we started noticing that he was having some food sensitivities. Right? So we had him to the gastro.

And they ran what and it was like a routine blood panel. And and then, like, twenty four... within twenty four hours, we got a phone call saying, you need to get him into the hospital right now. And And that's how we found out. And he was twelve years old, ish, something like that. I mean, so And and what what we found out was that his his IgG and his IgM were incredibly low. And what he did produce wasn't functioning properly, I guess, if that makes sense. And he needed to be started on IVIG infusions. And it was something that I mean, we had no idea what any of that meant. But it was it was scary in the sense that it was like, we can't do this tomorrow. We need to do this today.

Like, this needs to happen now. And so there's that sense of urgency, you know, which was really scary just because we didn't understand. But he he started once a month infusions where he was at Akron Children's Hospital and he would It was like a sometimes it would be a four hour it's however long it would take for him to they would infuse that IV bag. Sometimes it took longer than others. And you know, ultimately he was diagnosed with CVID common variable immunodeficiency, which I'm sure you guys know.

And and then that was added. We just started down that path. And then he had a series right at the time that he was diagnosed with CVID, he was also diagnosed with epilepsy, and an autonomic disorder that they never really put a name to because there's only, like, five kids that have ever been seen to present the way that he did. And it's sort of like an extreme version of

pots But so everything happened all at the same time. And so it was like the immune stuff happened, then it was the epilepsy and then it was this other thing and it was like this whirlwind of things that all happened when he was about it it was all within like a six month period of time. And and nothing happened prior to that and and then it just sort of was there. And so I'm not I don't understand exactly the logistics of everything, like, biologically would lead to all of this. You know, when his doctors you know, they say that he was he was just born immunodeficient. And in my head, I have a hard time wrapping wrapping my head around that just because he was never it was never anything. Like, nobody saw anything.

Nobody thought that there was ever anything wrong. He was never hospitalized for being, you know, sick or anything like that. And so it's like, how did he exist for this amount of time without having with no one picking up on anything. We never really saw anything prior to the diagnosis, and we never really saw anything after the treatment started, if that makes sense. And but we know, I mean, we know that his immune system isn't functioning properly and why he doesn't maybe he's just incredibly lucky that it just was the way it was.

The only the only issues that we found with the treatments were complications with the autonomic issues. So what would happen was he and he hasn't had one in a very, very long time. But what would happen was he would he would start acting funny. Right? So but funny, I mean, like, he would be lethargic, he would start slurring his speech, almost like, I guess, blood sugar was low or something like that, if that wasn't the case.

And his heart rate would get erratic. And there were times that he would he would have like syncable episodes. He would he would black out. And we would when we would start seeing those things, we knew that we had to head to Akron Children's, which was about a half hour drive, but they were the closest facility that was even remotely equipped to manage this. And and what would happen was he would he would he would lose consciousness, he would be unresponsive, his he would have to be put on supplemental oxygen, and they were just sort of managing the symptoms.

They would they would provide a sedative for him. Right? Which you would think would be the wrong thing to do, but what they were doing was suppressing his nervous system so that it would stop whatever it was doing and let his body sort of pick back up and take over. And sometimes it worked and sometimes it didn't. And the doctor who was his main provider at the time to Cleveland Clinic, he was ahead of pediatric neurology.

And he had only seen, like, five cases in the world of of kids that presented like him. And so it was very much kind of figure it out as as we go along. But he would also have this there was this, like, red rash that he would get and we called it a transient rash because you could watch it move across his body. It was like a it wasn't a handprint, but it would it would almost be like a handprint. Right?

And then it would start like on his leg, and then it would move up his torso, and it would move up his neck, or it moved down his arms, and and then it would go away, and then that crisis would sort of subside. And really weird, very scary. There were times where they were looking at life fighting him. There were times that they were gonna put him in the pick you when he was when he was younger. And there were times they told us that, like, look, you guys are gonna have to prepare for the worst because there's nothing that we can do.

There's there's because you can't force the brain to do something that is not, you know, and then it just stopped happening. You know, we had to he had to have his fluid intake, precisely managed every every day. Like, he had to have exactly I don't remember. It was, like, six liters of of water a day. We had to measure everything out.

He had to take salt tablets. To help his body to maintain that fluid volume because when he when he would have a crisis, his veins, his vessels wouldn't constrict. Right? And so everything his pressure would bottom out and his heart would race to try and compensate. And then that would just lead him down that that path of sort of decompensation.

And it was really, really scary. Very, very scary. We would drive to Akron children's he would end up destabilizing in the car and end up in the emergency room on sort of supportive care because what would happen was his, like, his brain would just stop controlling his blood pressure and his body temperature and and he would just sort of they would they would have to just do supportive care. There was no magic fix for anything. His his his brain would just have to kind of work through it and then sort of pick up and start functioning properly again.

And they couldn't they had no idea what was causing it or what was going on. But the the one hour or the one day infusions, he was not tolerating that very well. It it was hard on his system, and so he would end up crashing. And and crashing by I mean, like, his blood pressure would bottom out as heart rate would spike, like, that kind of stuff. That I that I think, like, isn't necessarily tied to the infusion itself, but it was a complication of it was like the two things working together that were problematic.

And, you know, after we maybe we battled with that for maybe the first year and and then it got to the point where we couldn't even get him in the car to drive him because he was ended up having to be hospitalized. Because he wasn't tolerating the car. Right? And we we switched to the at home fusions, and we did twice a week. And and he's handled those really really well. So we haven't had any issues since we we switched to the at home stuff. And, you know, he did all the preventative things like the Benadryl and the, you know, the the Tylenol and all those sort of preparatory things to kind of help his body to to better handle that infusion of medication, But for him, it was just I I don't know what it was, but it was just it was problematic in that sense if if that makes sense. But but like I I think if he hadn't had that autonomic dysfunction, I don't know that there would have been that problem if that makes sense. I think it was just it was you know, when when you receive donor anything, right, that that puts a stress on your body. And I think it was that stress put on his body that maybe he would have otherwise been able to handle, but it it was just a triggering thing for for everything else and it would just sort of tip over that first domino and then there would be a whole, you know, trail of things that we had to deal with as a result.

But you couldn't not do it. Right? So we we I mean, once you know that the problem is there, you can't ignore it. And and if there's complications, then we have to find ways of of working around it or working through it. And so that's what we our solution was to do it at home.

**Narrator**: The CVID diagnosis took everyone in the family by surprise. Much like the case with the first autism diagnosis, Rob had very little idea of what he was dealing with. He found, however, that his experiences helped him to better navigate the medical system.

**Rob Gorski**: I think going down the path with the autism stuff with Gavin at a very early age, helped with learning to manage things. You know? I remember when he got his autism diagnosis, I had no idea what it was. Like, I'd heard the word before and I'd seen Rain Man like everybody else. And I was like, well, how does he... how is this autism? Like, we're not dropping toothpicks on the floor, and he's not counting them constantly, or he he's not, like, you know, counting cards or whatever, like like you see on TV back then. And I I had to I had to learn Right? And I had to research and I had to kind of dig in and educate myself,

which was not something I mean, not that I didn't educate myself before that, but I never exposed that growing up. Like, there were we never dealt with anything like that I was the first person in my family to have to take something like this on. And I learned to just try and manage a situation.

I learned to trust my instincts as best that I could even though I overthink everything. And and to ask questions. And and, you know, not allow even somebody who knows more about something than I do to shake my confidence in in what I know is best for my kids. Like, if I if I feel like something's wrong and everybody tells me everything is okay, I'm gonna trust my gut that something's not right because I know him better than anybody else does. I I I had learned to do that because there were a lot of times that people would blow us off because they've never seen anybody like him.

And you really have to you have to push. You know, it's just like IEPs at school or whatever. Like, you you have to you have to advocate for your kids until they can advocate for themselves. And that helped me to be better prepared, I think, to navigate the PI stuff, for example, or any of the autonomic or neurological things that were going on, because they're different it's sort of different context, but it's the same principle. Right?

You can apply what I learned from this, help me navigate that. And what I learned with this other stuff help me to better navigate some of the autism related things. You know, managing multiple care providers or therapies or medications or schedules or know, I mean, I was doing at times three. And we had to have like a dozen appointments a week sometimes. And that is a lot. I mean, it was it was a lot, but you find what works and you run with it. And and not let what the world tells you, shake you. You know, you're gonna have to make decisions and do things that people aren't gonna understand. But you know it's best for your situation and I'm very lucky to have supportive family. My parents are amazing.

My siblings are amazing. You know, so I have that support system in place, but not everybody does, you know.

**Narrator**: Around the time of the PI diagnosis, Doctors also diagnosed Gavin with epilepsy. This harsh combination of illnesses led to the sickest, scariest period of Gavin's life. Any amount of heightened stress on Gavin's body caused autonomic episodes that would often leave him hospitalized and fighting for his life. Eventually, even the car ride to the clinic for IVIG infusions would cause this overreaction of the nervous system. On top of that, Rob had become a single dad to three boys, all of whom were on the autism spectrum.

He found himself facing impossible decisions alone.

**Rob Gorski**: There is a huge emotional side to this that I don't know that that I don't know whether it's not talked about a lot you know, because we we focus on the kids. But, you know, I I lived in constant fear. That he was going to that I I was gonna outlive him. That I mean, that's that's I was convinced that that I would that I was gonna outlive him. That he would he would already based on what we had gone through, me at forty five right now, him at twenty three, he would have been gone for years already.

And and then it's like, what do you do? Do you do you pursue quality of life over quantity? Like, do you want to rob them of these experiences because you might get sick if he goes. Like, that was such a difficult thing to navigate. You know, it's one of the reasons why he was pulled out of school.

Because he was he wasn't getting sick necessarily, but he would his body wasn't handling the

stress anymore. To the best of my end, the best that I can kind of piece this together was that Anything that put his body under stress, whether it be emotional stress or physical stress. Right? He it was it was triggering for him. It was causing some type of sort of cataclysmic event to occur in his body.

And whether it was it was PI related or it was autonomic related or emotionally related. I I felt like they were all intertwined and and there was no way we were unable to parse everything and pick things apart and say for sure, this was all PI, this was all this, this was all that. One impact to the other. And so high school is a petri dish. Right?

I mean, and and it it was a school for kids with learning disabilities and autism. So hygiene is a little bit questionable at times and and they're at that age where they're like too cool to wash their hands and whatever. And so he never really got sick, but you could tell he was fighting something off. And and just that that stress on his body of fighting off a cold for example, like, that many people do all the time. And even a simple thing, like a cold would it would be enough to destabilize him.

And then he'd end up in a hospital with his pressure bottomed out or his heart rate skyrocket or he's unconscious, like, And and so he wasn't retaining a lot back then because developmentally he was still probably six years old. And it's not that he didn't understand or want to learn or try his best, but it was is is the risk benefit kind of thing there? And and the reality was he was failing a lot of classes, which then made him very emotional and upset, which then caused more issues. He wasn't retaining that information at the time. And he was ended up being he had to be hospitalized all the time.

And so it was like, okay. Let's he was almost sixteen, so I pulled him out when he was fifteen going on sixteen. So I I know that because in the age sixteen in Ohio, you can withdraw from high school. And we tried the at home stuff, like, they would come out and tutor him, and it just wasn't he was just getting too stressed out. And and so it became about trying to limit the amount of stress in his life and smooth things out.

And he he will tell you that he he understands why I made that decision, but then he will also tell you that the timpact it had on him emotionally was devastating. I'm grateful that he doesn't hate me for that. You know, because, I mean, he could, but you don't you never know what to do. You know? And it's like I've I've beat myself up over the years for that, but if if I even if if I had to go through it again, protecting his life, to me, I didn't wanna lose him.

I didn't wanna lose him. And it was whatever it took to keep him around. And I wish I had found a better balance, you know, or or or I had been more aware of the emotional impact that that had on him because he would have a whole conversation with you about that. He he was very depressed and it It was tough, very tough. And just because he's autistic... he's very social. And so he wants that social interaction. But it was too it was too risky at times, you know. And so it's like I feel for all parents out there who were going through something similar where they're trying to make decisions about whether they go to Christmas with their family and risk them picking up something I might be going around or you know, I mean, there's there's just it's a it's a very scary thing. Even when you understand it, it can be very very scary.

**Narrator**: Gavin's isolation left him severely depressed and without purpose. On an episode of the autism dad podcast, he and Rob discussed the devastating emotional impact it had on him and examined what independence means to Gavin.

**Gavin Gorski**: And I lost my purpose of friends. Mhmm. And I really, really took a toll on me emotionally.

Rob Gorski: Yeah. It did.

**Gavin Gorski**: And, like, I was I was holed up in my room. I was depressed. I I felt like a worthless piece of trash.

**Rob Gorski**: This was a kid that I was told would never be able to do anything. Because he had lost so much, and there were so many behavioral issues, there were so many medical issues that I mean, he wasn't able to regulate any part of his life. You know? And to see where he is right now. And to I remember, he was sitting in his chair right here where I am.

And I was sitting on my bed, and we were just you know, he had to mic and I had to mic, we were just talking. And I'm just sitting there thinking like, my... and I think I said it. It's like, I'm in a I feel like I'm in a therapy session. Like, he is so wise, you wouldn't you can tell when you talk to him that there's there's something going on. Right?

But the wisdom that he still possesses is It's it's unreal. And and he he's he's one of those it was it was challenging with him because I mean, none of my kids look any different. Right? Because that's the thing with autism, like, people like, well, he doesn't look autistic. I was like, well, what the heck does that even look like?

Right? Like, just dumb questions. And he was always the kid that as soon as he would start talking to somebody, they would be like, oh, okay. Something's going on here. Right? But you hear you hear the things that he's saying And I felt like I walked away from that, and I live with them every day. And I'm just I wish I had been recording a video for that, and I I wasn't. But I was just in shock. Just hearing him talk about like, his his outlook. I I mean, I know he has a really good outlook, but, like, I never thought to ask him what independence meant to him

Like, what does this mean to you? What do you want? Right? Because it it was it seemed like it had always been predetermined. Right?

He was always gonna live with me. He was always gonna have these health issues. We're always gonna have to, like, keep him at home and keep him away from people and limit his exposure and whatever. And his big thing, and I was just talking about this on a in an interview yesterday, he wants to live in a group home. I mean, I didn't even know he knew what that was.

And I wanna live with friends, and then on the first day that I'm living there, he's like, I wanna I wanna watch it. I have like a movie night and order DoorDash. And and if my friends, like, they wanna eat, he's like, I'll order them food too. And that's like his And if that's independence for him, then that's independence for him. It doesn't have to be what I would want or what someone else would want.

And he has helped me to see that It's so different for everybody. And we need to slow down and stop making assumptions about our kids and ask them what they want out of life because just because there there is some cognitive impairment or or there may be something going on doesn't mean that they don't have hopes and dreams and and know what they wanna do with their life. And it's our job to help direct them where we need to, but but help them to find whatever it is that makes them happy. And the fact that he is twenty three, he's still alive, healthier than he's ever been in his life. He's finally gaining weight.

So his infusions are going better. He's he's work he's at day service right now. He's managing his

own work schedule. He buys his own groceries. He gets his own transportation back and forth to work, he's gonna move out next year.

That's the goal. And it's just, you know, one step at a time, but he's I I need to get him calling the the specialty pharmacy to like, to request his refills every month. That is the one thing that we have not done yet. He doesn't I don't know. We'd have to, like, have a script card for that, and I'd have to call them ahead of time and, like, whatever.

But It's totally doable. It's absolutely doable. And that's that's sort of the last piece of managing his daily medications and everything. He does everything else on his own. You know, so it it's amazing.

**Narrator**: So where did Rob find the strength and determination to help care for Gavin and facilitate his son's independence? He owes some of that to an online journal he started in two thousand nine. Desperate for an outlet. Rob started publishing what he thought was a private blog. He discussed his desperation, his loneliness, and his guilt.

But eventually, others found his blog online. This private journal eventually became the acclaimed autism dad website and podcast, and connections developed. This led Rob to another hard earned lesson, the importance of self care.

**Rob Gorski**: And so I started writing on this blog. It was called Lost and Tired. I used it as like a diary. I thought it was private. I thought that I had to sign in to write.

I had no idea how the Internet worked back then. And I would write what I was thinking and feeling, walk away from it, like, That was it. Right? I wasn't carrying it with me. I I I wasn't like that those birds you see on the beach that have like those big the collection of, like, salt, the collects rot and weighs them down.

I didn't wanna be that. I I sort of envisioned everything that I was carrying like that. And so I was doing this. I thought it was private. And it wasn't.

And so parents started to read it. And it turns out I was the first person. I I was the first person to start publicly talking about this stuff. And I did it inadvertently. I didn't I didn't intentionally do that, but I filled a vacuum.

And what I found was that sharing what I was feeling and thinking, validated what other people were experiencing, and it provided a level of comfort and connection that so many people were missing. I I still have parents today that reach out. They're like, I'm so glad we found this. We thought we're the only ones. And that that that's twenty, you know, well, fifteen years since I've been doing this.

But that's, like I mean, all of them stuff is everywhere. Right? Like, I don't know how you can but it's still that case, people still feel isolated, they still feel alone. And knowing that I was able to use what I was experiencing to help other people navigate that or not make the same mistakes or fall into the same holes, that was therapy for me. That gave me purpose.

More something bigger than just helping my kids, which would have been enough. Helping my kids is always enough. But I was a fire medic before that. You know, and so I had this driving need to help people. And when I had to retire from that and I stayed home with my kids, I needed something to kind of replace that.

And I and then I found this and, you know, being able to make a difference in people's lives, that I've never met, probably never will, allows me to say and process things that I need to say and process and then it helps someone else to navigate something they haven't been through. And that that has been my self care. And then, you know, I I fit periods of, like, major burnout I this

time last year, I hit a wall. It was it was this month last year, I hit a wall, and it was really bad. Just to be, like, completely honest, like, it was the darkest it was a darkest that I had ever been. And I had I had just reached a point Well, I wasn't telling anybody that I was struggling. And I had... You can mask it really well when you're a parent, and you can mask it until you can't. Right? And so I I reached a point where I knew my thoughts were really starting to scare me. And I knew that if I did not get help, that I was not gonna I wouldn't make it.

And I am all my kids have, I can't I can't not be there for them. I I will not be a person who leaves them. And so I, you know, I spent the last year reinvesting in in self care. And, you know, I had to make some adjustments to my life. I, you know, I hit the I'm back at the gym two hours a day, like I've My meds have been revamped.

I was diagnosed with ADHD last year, which is that explains so much of my life. And I am building forward. Finally, like, I'm I'm not in that sink or swim, that survival mode anymore. And I am very much aware that I have to prioritize myself in order to be the person that my kids need me to be. And that it's that it's okay to be selfish sometimes.

You have to be selfish before you can be selfless. And so the self care thing is is absolutely vital doing this? this puts back into my jar for the whole day. I've had people reach out to me and and and tell me that they that they are only here because they found an article that I wrote that made them realize that they aren't alone. You know, and I mean, if that doesn't fuel you to keep helping people, you know, and that's just the people that you hear from. Like, how many other people are are benefiting or having finding the strength to just pick back up and move forward.

And then they help somebody else. Right? It just spreads. And, you know, it's all all because you you are going through something and you want other people to not have to go through that. You know, so so that's that's my thing.

And I have, I mean, I have the best girlfriend in the world. She is so supportive. That's a huge help. My kids are at an age now where they -- I did an interview with Emmett actually about self care because I thought, you know, does he get resentful if I'm going to the gym or I'm hanging Kelly or whatever. And he's he's like, no.

He's like, I want you to do that. I need you to do that and take care of yourself. And so, you know, I mean, it's it's good to have the ability to do that. But when they were younger, that was it was not always possible. Man, there are times I would lock myself in a bathroom. And I'd be like, guys, I have to go to the bathroom. And I'm just sitting in in in the bathtub crying. Or I'll just sit in the bathtub and listening to music or watch YouTube or something just just to steal five minutes for myself just to stop that purge of bandwidth. And if that's what self care is for someone, then that's what self care is. You know, you build on it.

There's no payment upfront for it, which is I think is what's frustrating for some people. They don't recognize that, like, you have to put the effort in first in order to start to feel better. And and there's that, like, the plates are already overfilled and they don't wanna take on more, whatever but the more you do it, the more consistently you do it, the better you're gonna feel, the better you can parent your kids, the better version of yourself you can be, the more comfortable you feel in your own skin, and the more that you feel that, you recognize the importance and you can find more time to steal away, to put more into yourself. So that you can do even more and you can sustain that long term. It was it was a journey.

It was a journey. But, you know, I mean, I I have, you know, I mean, there there was a lot of pain along the way, you know, learning things you know, that I didn't know at the time. And in learning to to kind of pick up and move on forward by myself. Right? With with the kids, never thought I would survive that.

And I learned that I am so much stronger than what I ever gave myself credit for. I'm more capable than I thought that I could ever be, and that the most important thing that I can provide for my kids is me. Right? And that's not like an egotistical thing. Like, it's it's my my kid's, like, presence is is so important.

And, you know, my kids don't know what it's like to have tons of money and to be able to get whatever they want, whenever they want. But, like, we're we're moving forward. Right? We're in the right direction. Everything is better.

This day is better than one before it. And, you know, business is is doing well. Podcast hit, like, number ten on Apple, like, in parenting stuff. That's -- I'm a one person operation. Like, there's just me doing this.

Right? And now I get to work with my kids. But I mean, how bet like, that doesn't get any better than that? You know, like, I get to give Emmett a voice and Gavin a voice and Elliott a voice. Like, They talk about whatever they want to talk about and people just love it.

They love hearing their perspectives and they love hearing what they think and feel and it's so empowering for them. And everything that I went through led me to that. It led me to my girlfriend because we connected when her daughter was diagnosed, And if I hadn't been doing what I was doing, we would have never connected. And and that changed the whole course of my life. You know?

And you know, it's it's not perfect. It's not always pretty and sometimes it's messy. And I have days where I really feel like failure. But then I have to stop and turn around and look at how far I've come. You know?

Because we don't we don't like to look behind us right you don't want to dwell in the past, but sometimes When it's hard to see progress, you have to stop and turn around and look behind you to see how far you've come. And yes, you still have progress you need to make, but you've already gotten this far, so so it helps you to kind of keep perspective. You know, and that's that's probably the biggest thing is trying to maintain perspective, that I'm I'm not gonna be where most people in my age are right now because I was dealing with things that most people couldn't imagine. You know, and the fact that we survived together as a family will be at least the boys and I, like, we survived COVID. We've we've survived the worst pandemic in our lifetimes. Right? That's an accomplishment. And Gavin was at high risk. Like, there's all these things that I have to remind myself that we've survived, that we've done. And, you know, every day is better than the one before it.

And Gavin's moving out. He's doing his own thing. Elliott graduated high school a whole year early. Emett's on course to do the same thing. He's gonna be taking college courses, probably starting next year as a sa junior.

And, like, that's, like, how you know, when we measure success, I would say that we did pretty well, honestly. And and I it's taken me a long time to recognize that, but how do I get my credit my my kids all the credit in the world because they they could have they could have experienced all of these things and gone a whole different direction. And they are not defeated by anything. They just keep getting up and moving forward. And I could not be prouder. Could not be prouder.

**Narrator**: In many stories and in life, People expect a clear turning point; a single moment where things get substantially better or worse. In the case of the Gorski's, at least from the outside, there's hardly any one moment. Instead, struggles, triumphs, and hard earned lessons are constant and intimately intertwined. Instead of resenting the many turns his life has taken, Rob's

voice quivers with pride and love when he talks about his kids. He's made it part of his life's mission to share his experiences in order to help others battle the loneliness he himself has faced.

**Rob Gorski**: I have always wanted to be a dad. I always wanted to be a dad. Right? And my kids have been through so much. And I feel like they've taught me more than I've ever been able to teach them.

I get like I get I get so emotional with with them. They they are the best humans that I've ever known in my life. And and and I have the privilege of of watching them grow. You know, I I've been through everything with them. It's always been me and the boys, whether I'm taking them to school or picking them up or whatever.

Doctors appointments we've been through everything together. And I try my best to lead by example and I am the farthest thing from perfect that there is. Right? But I I can model I can model emotional behaviors for them. And and it is like speaking three different languages because they all need something different.

And there's never a one size fits all approach that just cover covers all the bases with everybody. And so it's a lot of hit and miss and trial error and whatever. But we we have just found something that works. And it's fragile sometimes. It's like that fragile piece, you know. But there is no doubt in my mind that no matter what happens, these guys would be there for each other in a heartbeat, no matter what, Gavin, especially Gavin, is the kind of kid who's like, he he'll he'll have, like, his infusion thing going on. So he's got these tubes hanging out and he's got his pump and he's, like, walking all hunched over because he doesn't like to, like, stand up straight because he has no belly fat. Right? So it just goes into his muscles and hurts. And, you know, one of one of his brothers was dealing with some bullying at school about two years ago. And I remember I brought him home from school and he was really upset and Gavin was like, he's like, let's go. Let's go good. I'm like, no one's gonna mess with my little brother. Like, then he's barely standing up. You know?

But like like he was he was so protective of his brothers. And and even though they don't always get along, they they are bonded in that way. And they have been through things with their mom leaving and, you know, they don't have any contact with her anymore. And there there are things that they they have experienced. I think that that bonds them in ways that a lot of siblings don't have, which is maybe a good thing, I guess.

But they they have an innate understanding of each other and yet still have a lot of work to do in that area too. So and I guess the last thing that I will say You know, we talked about self care, which is really important, but is, like, you guys are doing a good job. You know, parenting is hard. Your parenting is very, very hard when you're dealing with neurotypical. Kids is one thing we're dealing with neuro divergent kids.

It's a whole another thing. And we're dealing with kids that have complicated health issues. It's a whole another world of parenting. And you're doing a great job. You're doing a great job. You don't have to be perfect, but your kids are lucky to have you.

**Narrator**: Your support of the immune deficiency found nation helps ensure families like the Gorski to get the advocacy, education, and community support they deserve. To donate, volunteer, or learn more of about primary immunodeficiency. Visit primary immune dot org.