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Rebecca Russ: Well, welcome to the Immune Deficiency Foundation podcast. My name is Rebecca Russ, and I'm the grassroots advocacy specialist here at the Immune Deficiency Foundation. Today, I'm gonna be talking with Rafaela Vedia or Ella who I've had the opportunity to advocate with on several occasions over the years here. So Ella is currently studying criminal justice at Marymount University. So welcome, Ella.
We're so glad to have you here.

Ella Vedia: Hi. I'm happy to be here.

Rebecca Russ: So you just had a big birthday. Right? The big two-one?

Ella Vedia: Yeah.

Rebecca Russ: Did you do anything to celebrate?

Ella Vedia: Yeah. I actually we so me and my sister are a day apart. So we usually kind of now older. We like to, like, conjoin our birthdays, and we did, like, a big, like, cut a big trip and went to Nashville. Down.
Okay. You get done.

Rebecca Russ: That's a that's a great way, celebrate. A nice little trip is is always a good time. Yeah. So let's backtrack for a few minutes. So why don't you start by telling us a little bit about you and your diagnosis?

Ella Vedia: Yeah. So I I guess looking at it from, like, a positive point was very fortunate, and I was diagnosed when I was, like -- I was, like, practically born -- when I was a baby. And so I was born in Bolivia. And I've diagnosed in Chile, but they already had an idea of kind of what I had because I had a sister [] that passed away with similar circumstances, I would say. And, like, with that information, they were able to diagnose me with Artemis SCID, which I believe that I just form a, like, no immune system.
I got my first [] chemo and bone marrow transplant donated by my oldest sister wasn't strong enough, so then I got a second round, which was much stronger. And, of course, I don't remember from, like, the stories mine on has told me and everything. It was definitely hard for me that we were able to come to the states. And I was protocol for, I believe, like, a couple years and then was released. []
It's been another long journey. We sometimes, like, to say, like, born twice, since I was, like, in Bolivia and then got chemo and, like, again, in Chile. So I think it's a full story to share and as well going into, like, my faith a bit. My mom told me they would pray every night

when I was in the hospital and everything. And I think with that.
It's just, like, I know, shows, like, how amazing God is through all the law.

Rebecca Russ: Do you wanna talk a little bit about how your family kind of became involved with the foundation? I know you guys have, you know, been involved with us for a while now.

Ella Vedia: I think our first encounter was when we went to the National Conference in DC. I don't know if I was what do you I can't remember the exact year. We were only there for, like, a little bit for a couple hours because then we had to go on on a trip. And that's where we actually met, like, a lot of doctors, and I met David's mom. And I remember something she told me about, like, eyes.
That kind of stuff, if I was like, she told me I had David's eyes. I just thought that was very sweet because I told her I had skid on as well and everything, and I was just like, I don't know, it's it's a special moment for me. We yeah. We've met other doctors after we got came to the states, I was released from NIH. So for, like, majority of, like, my life, I didn't really see any doctors besides pediatricians, but I was still, like, sick.
Like, I was still having problems. And then from there, we got to talk to one of the doctors from Orange and we told him about, like, the problems that I was still having from effects from my chemo when I was little, and that's where I got called again to go back or put back on the protocol for and I and now I go regularly for, like, every once a year. And that has helped their time and just, like, quest like, answers to questions that we've had. And still have. And yeah.
So that's what we learned from that conference. And then I went I believe my first Teen Escape was in Orlando, and I think that one was in two thousand eighteen. And I don't know. That's really fun. I mean, of course, I was nervous.
So it's very lovely. Like, everyone knew each other. Just like it's like when you go to Thanksgiving, you see all your family and friends, like, you haven't seen in a while, and you just felt like that. And it's really cool. Oh, I love how you're going.
So, like, now ever you're going back, it's, like, oh, wait. It's, like, family Thanksgiving So it's, like, really it's really fun and, like, all in, like, whenever you say you haven't, like, go group chats and everything that you talk to. And so yeah. And and and you meet new people every time.
That's amazing.

Rebecca Russ: Love that. Yeah. It it does feel like a family a lot of times that I know. At our advocacy events. I always see you and, you know, the other young adults together.
And and it's really heartwarming to see you all get together every year at different events. That's great. So I know that you're basically an advocacy pro at this point. But do you wanna

talk a little bit about your first advocacy event specifically and what that was like for you to participate?

Ella Vedia: Yes. Sure. Okay. So my first one, I remember it was just me and my mom. There's like no one else.
And I it was really it was really cool. Of course, I was very nervous, but Matt handled it like a champion. I was just there sharing my story, but he is handling like, all the logistical stuff, I would say. But I feel, like, now older, I know more of, like, the logistical stuff so I can I feel old and more confident, like, talking about it and especially like, sharing it from also my point of view as a patient?
And so I think that's really nice. And I think that's, like, the important part of it all is, like, we go through it and, like, let's talk about it and share it with them with people who can actually do something about it.

Rebecca Russ: You hit it exactly. That's that's the biggest part is you're sharing your story and the lived experience of someone in this community. So Yeah. Like, we can always say it's it's cannot be overseen to how important the work that you add kids do. And I know you've done a lot of in person advocacy, you you know, attended events and whatnot with us and other groups Do you do any kind of online advocacy?
Do you do emails, phone calls, anything like that, or do you prefer being in person in the office?

Ella Vedia: Oh, I because you'd rather be in person in the office. I just I even, like, I'm not a texter. I'm stuck that texter. I'm very much, like, on call based on, like, talking person. And I don't know.
I just feel like you don't, like, a connection and just, like, kinda, like, other eye connection, like, can talk more personal and stuff about it. But as well I wanna mention, I just I love to also it's okay to not know, but I love to, like, educate and so we can, like, know more about it. And I think that's, like, the biggest thing is, like, let's let's, like, talk about it. Let's, like, I I'm here to answer the question that you had. So

Rebecca Russ: Yeah. Yeah. It's definitely a lot of times, like, almost like a conversation where, you know, you're just talking about different topics, people, like you said, might just you don't you can't help what you don't know. And so you sit down and you just talk about it and help educate people. So going forward, they then have that knowledge, which that makes a huge difference.
So what's something I wanna ask that surprised you when you started advocating, like, what's something that kinda may took you off guard or you weren't expecting about advocacy?

Ella Vedia: Honestly, the different coatings, like, I wasn't like, I was surprised about, like, how you would go to one, like, boating, and it was, like, kind of a basement coating or just not. I was, like, well, you're thinking, like, cap like, Congress Capital, like, whoa, fancy voting. So in some are just, like

Rebecca Russ: In

Ella Vedia: the past. Yeah. Yeah.

Rebecca Russ: No window. Yeah.

Ella Vedia: And she's, like, oh, but then other one's in the marble floor. Gorgeous staircases, and I'm just like, oh, the, like, switch is crazy. But yeah. It's really cool. And I just I also think it's, like, crazy.
Also, behind the scenes of, like, how many people are there and doing so many things. Like, I don't I don't know. I think there's just something you don't wanna take in account or, like, realize. Like, in the office, like, there's so many people doing so many things or, like, that senator, congressperson. I was just like, oh, wow.
This is like a team.

Rebecca Russ: Did it surprise you? I know when I first got into advocacy, this would always surprise me. Did you find it interesting that, like, the people you're meeting with are sometimes not that much older than you? I mean, the staffers and whatnot are oftentimes young. Was that something that surprised you the first time?
Or

Ella Vedia: A little bit. I guess, like, I was expecting, like, young people, like, in their twenties, but not, like, high schoolers. When I saw, like, some high schoolers, I was, like, oh. But I I don't know. I think it's going to, like, go you.
You you're like yeah. I bet you're

Rebecca Russ: not They're trying to make a difference with journalism. So let's talk a little bit about, obviously, you know, sharing your story and and advocating is very vulnerable at times and, you know, talking about your diagnosis or day to day life. So, you know, what has that been like for you sharing your story with people in power? And then maybe you can talk a little bit about, like, the response that you've gotten? How do people usually, you know, react or respond when you're sitting in a meeting or, you know, app became to them sharing your story?

Ella Vedia: I feel like, again, it's like I've always just like this has always been my normal kind of my life. And I rather always, like, talk like, educate and talk about it and, like, in everything, you should have not and people just assuming or whatever. And I So going

having the chance to be able to do that with, like I said, people can actually get different to do something about it. I like, there's nothing else I would wanna do. It's like, like, make a difference for the community.
I think people get surprised just sometimes because of, like, my I don't look my age of my parents, and I get that a lot. Like, I I like, in public and everything. But in I don't know. In Congress, I I don't know. I just feel like a little bit I feel confident in walking in the room and talking about what I need to say.
And Oh, no. I I remember one time when I was talking with one of the people in Tim Kaine. I brought up, like, an analogy and she I think it really opened her eyes. She told me of, like, of the point of view. Like, I was talking about how, like, I should how it was in COVID is a lot of, like, or normal and how we work because we always have to be aware of of that and of, like, other people under during searches, or ever because of her immune system.
So COVID was, like and I brought, like, that analogy, and I think she's, like, that opened oh, rise.

Rebecca Russ: Eye opening is definitely something that a lot of staffers would probably say after, you know, a patient or their family has come in and shared their story, it is a lot of times eye opening because, you know, like, our team always says, we we go into these offices and we share the facts and talk policy and all of that. But when you all go in and advocate and share your story and, you know, express that kind of vulnerability about, hey, you know, this is where I am, where I'm coming from. I think that makes a big impact on staffers and on offices to really meet someone that is living, you know, this this story. You talked about making a difference. Right?
And how that's really what driving you when you advocate and and share your story. Do you wanna maybe share a time that you felt like your advocacy work made a difference? Like, if there was maybe it doesn't even have to be, oh, the build passed, anything like that. But just a time where you felt like you really made an impact.

Ella Vedia: Okay. I don't know. I feel like every time just going into conversation, just sharing my story with anyone, it was just making a difference.

Rebecca Russ: It's the best answer ever.

Ella Vedia: Yeah. That would be great. True. That would

Rebecca Russ: be great to present true. I love that. Yeah. You do great work. You and your family have done amazing advocacy at Absy Day multiple years.
So we always love to have you guys there. Like you said, making a difference. How about do you wanna talk about any maybe other issues that you advocate on? Do you mainly just advocate in the PI space? Or have you done advocacy in any other parts of your life before?

Ella Vedia: I have done it in other parts. I love advocating. Like I said, just for, like, people not, like, people who can't always have the opportunity to do use their voice. And I'm happy to, like, do that as I'm finding my own and have found my own within this community. But with, like, in high school, I worked a lot with kids with disabilities, and I enjoy advocating for that very much.
They're wonderful. I love working with kids in the IDB community on as well as I'm as recent in my major's criminal justice, and I've been looking a lot in the field of anti human trafficking. And so I've been advocating a lot with non profit organizations on anti human trafficking. And that's also been wonderful. And I've learned a lot.
And I think that's also another topic that needs to be talked about more.

Rebecca Russ: Absolutely. That's awesome, Ella. I mean Yeah. Wow. You're you're busy, aren't you?
You stay busy. That's awesome. That's awesome. Is there any issue, you know, in the kind of PI world or you know, that the foundation works on, that you're particularly passionate about. Any anything that maybe impacts you and your family or you're just passionate about in general?

Ella Vedia: I understand passionate about in general, of course, but I guess, one topic. I remember, like, one of my favorite on because he's got romantic. I think I can't remember. I think this is third. Just, like, one I can't remember one, but he's kinda recent.
Is when we were talking about the insurance policy or, like, insurance? That is something big that I thought for just because since PI isn't, like, very, of course, like, common, and people don't know about it. Insurance, like, suggesting act like it's not a thing and ignore it and especially for, like, treatment that's needed or affected because of this disease. Going back again, it's okay if you don't know, but, like, let me talk to you like, let me tell you how it does have any effects. And yeah.
So that's definitely one thing. And I know insurance is just always like a pain, but I think it gets to your point when it's actually, like, really affecting with people's lives.

Rebecca Russ: Absolutely. Yeah. That's definitely an issue. I think a lot of people in our community are passionate about and that affects so many people in the community. And obviously, when you're in your twenties too, you're starting to think about insurance more because it's like a grown up stuff.
Like, you have to Yeah. Your own insurance one day and all that. So, yeah, that's that's definitely an important issue. Is there anything else that you wanna share about, you know, your yourself or your advocacy or anything like that?

Ella Vedia: I really love walking on Capitol Hill. I I feel like I'll want. I like, oh, yep, loving it. The confidence and everything. And I think it's I it's it just makes you feel of course, you

have, like, a voice, but, like, that to actually use it and to actually do something about it and, like, going back when you said early, like, that like, the change in the difference that you're making.
And so I think it's just it's really it's really cool. I just I always really like public policy and everything, so that's also just we're, like, learning and educating myself more on how everything works. These laws and billmaking takes time, but how he always need to keep pushing and working. The whole process of it for me is, like, just really fascinating. It's just me a little nerding out a little bit and be like, oh, wait.
It's so cool.

Rebecca Russ: Oh, yeah. I mean, I nerd out on it all the time. But they're still there. Obviously, you're so good at it and have such an interest. Have you ever considered maybe in the future some kind of career on Capitol Hill or anything like that or no?

Ella Vedia: I've I've definitely thought about it like an advocacy work. Like I mentioned, like, I'm very interested in, like, anti human trafficking. Type part. So I think maybe in the future, I'll do something like that. I'm interested in being a therapist for first responders or get guns. And so maybe after working with Sanitec, maybe taking it onto the hill to do some more action. Because I don't know. I love their I love their strong believers, like, actions or louder than words. So I think this is why it's very important for me to actually do something about it and use my voice and I shouldn't make a difference. And I'm persistent about it.
So I'm like, let's do something.

Rebecca Russ: You're amazing, Ella. The community is very lucky to have you advocating on behalf of so many people. And like you said, not everyone is able to advocate or be there, you know, in person. So Yeah. Very lucky to have you and and so many others like you advocating on behalf of the community.
So I guess with that, we'll wrap it up. Thank you again for joining us for the podcast. It was so nice to chat with you.

Ella Vedia: Thank you for having me again. I enjoyed it.