TRANSCRIPTION

This program is presented with support from CSL Behring, Grifols, Takeda, Chiesi and Amgen. Welcome to the Immune Deficiency Foundation podcast. At the end of June, more than a thousand people from patients and caregivers to clinicians and nurses came together in San Antonio for the world's largest gathering of the primary immunodeficiency community. We took the opportunity to ask some of the young adults and attendants a few questions, ranging from their conditions and their worries to their joys and hopes. Before we get started, please know that your support helps make content like this possible.
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Eli: My name is Eli Evans. I'm from Fort Wayne, Indiana, and I have other antibody deficiency.

Elena: I'm Elena Kramer, and I am sixteen years old. I'm a rising junior in high school.

Ella: My name is Rafhaela Vedia, or I go by Ella and I was born with severe combined immune deficiency, specifically artemis.

Christopher: I'm Christopher Fontenot, and I have XLA, x linked agamaglobulinemia. Something like that.

Zach Moore: And what is the hobby you enjoy most?

Eli: I love gardening and my bonsai plants. Pronounced bone-sigh, not bonsai.

Elena: I really enjoy doing theater. I do it at my school. I do their musicals especially. Also, honestly, volunteer work like this is kind of one of my hobbies just because I do it so much, and I love it, and just kinda hanging out with my friends.

Ella: Mhmm. Well, I always grew up doing dance. Like, I grew up at a Russian bot studio, so I did that, and then they can to competitive dancing, but now I just go to the gym, bible study with friends and just forever. Yeah.

Christopher: Probably photography. It's a hard split between photography and like playing games.

Zach Moore: What do you do for work?

Eli: I work in disability services at a community college, meaning I help students who have disabilities get equal access to higher education.

Zach Moore: Do you know what you'd like to study when you get out of high school?

Elena: I'm not a hundred percent sure, but I do know that some fields of interest would probably be political science or psychology or just anything that can really help, like, advocate for people like me who have health struggles, but I'm just not really sure what field will get me in that direction?

Ella: I am in college. I'm going into my third year and I'm sitting criminal justice with the minor in psychology.

Christopher: Robotics and photography.

Zach Moore: How many foundation conferences have you been to?

Eli: This is my first conference I've ever been to with the immune deficiency foundation.

Elena: This is my third conference, and then I went to eighteen Escape. For the first time last year in Cincinnati.

Ella: I believe my first one was in two thousand eighteen in Florida, the Teen Escape, and then did a conference and then I think another team escape to more teen escapes, and then I don't have a bunch of advocacy with idea, which I think I love. It's like if I heard one of my favorite things, I really love doing. And, yeah, here at my second conference.

Christopher: I think like four or five.

Zach Moore: How often do you meet people that you can talk to about PI?

Christopher: Not that often.

Eli: I only know one other person in my whole life who has what I have and actually is my coworker. It was a bizarre coincidence that we both found out. It was kind of like that that Spider-Man Pointing mean when we started comparing experiences and she mentioned having infusions. And I was like, wait a second. I do that too.

Elena: On a daily basis, never. But when I come to a foundation or an event like this, I mean, that's what everybody's here for, so it's really easy to find people. But from just like a day to day basis, I if I ever tell them part of my story, I have to do a whole spiel about what it is, so I never really meet anybody.

Ella: I feel like, especially, like, younger or not a lot, not really, just because they wouldn't understand or, like, younger, like, they don't even know what it is. But, I guess, growing up I will growing up more people seem more open or, like, more understanding about it or less judgey, I guess, about it as, like, younger people would say what comes to the heart and being like, wait, what are, like, whatever. But yeah. I don't know. But especially, like, here in

IDF, like, every like, I don't know.
It's just so different. It's like a community about it.

Zach Moore: What is the hardest you have ever left?

Elena: Oh, jeez. I don't know. One time I was performing well, I wasn't performing. I was rehearsing. And one of my friends was doing a high kick, and she fell on her butt.
Like, from the high kick. Or also I saw my three friends in a community theater show. I wasn't in it, but I watched it, and it was really really funny. I don't honestly know if my friend who fell and won't be saying that, but it's okay. I didn't say her name.
She's fine.

Ella: I feel like my sister or especially when it's like inside jokes. And, like, we just, like, blurted out or said out or, like, memories that become inside jokes are, like, so funny. Like, one of our favorite ones is, like, diva down. And it's, like, when someone, like, falls and we're, like, oh, no. Like, diva is down.
And yeah. Just, like, oh, inside jokes. Stuff like that that we have. I like one being, like, when we have, like, a dump, like, a little slow, dumb dumb moment where, like, oh, you're so pretty and stuff like that. You're just, like, little inside jokes are so funny that just yeah. Especially if you do in the right timing.

Christopher: One time I was in the car camping trip and it was, like, almost the middle of the night and my friend told the joke so funny. I had to use my inhaler. []
It was so funny. Yeah.

Zach Moore: Do you remember what the joke was?

Christopher: I do not! It was like eleven. We're we're studying up our tents. We're getting ready to get out of the car and set up for tents, and he just told the joke so funny.

Zach Moore: What calms you down when you stressed your angry?

Eli: I love connecting with my best friends. We live a little far away, but we I'll hop on the Discord call and we play Minecraft and we just vent where we sit in silence or we they sing silly songs to make me laugh and I do the same to them and we just have a lot of fun together and that makes me melt all the worries away. They're my biggest supporters.

Elena: My mom, and music. And I also really like coloring when I'm nervous.

Ella: I think, honestly, I really just shocked me a lot. It's like when I'm just scrolling my phone. I know usually it's a bad thing, but like it distracts me when I'm like, you're scrolling my phone and I see, like, a funny TikTok and it gets my mind off what I was thinking of.

Christopher: Knowing that people to support me. As well as just like talking to people I know.

Zach Moore: What do you find yourself worrying about?

Eli: My biggest worry is if I'm gonna get fired from my job because I've been sick a lot. And my boss has sat me down and said, if you your job is to be here and if you can't be here, we'll have to find someone else. I was on treatment that was working really well for me unfortunately, after a year of it, it just was as if I wasn't on it at all. And so right now, I'm fighting with insurance to get new medication and a new treatment plan.

Elena: Worrying? Everything. Mainly a lot about like what my health will look like in the future just because of everything that's happened. I don't know if it's gonna be like if I'm done or which, you know, I'm like not because there always be underlying things. But just kind of there's always been a what next factor and just kind of worrying about that.
And then also just like basic teenage worries, like, about college and friend dynamics and all of those things.

Ella: Well, I'm an overthinker. So once I get into a rabbit hole about something I tend to go over, especially, like, I feel like I think overthink a lot with, like, people's feelings. Like, oh, did I do that wrong or I didn't even hurt them and, like and all of that are, like, relationships. But Yeah. That's, I would say, what I would overthink about.

Christopher: Just like the future in general, like getting a job and making sure I can get all my medicines.

Zach Moore: How does PI show up most in your life?

Christopher: Being sick, it's definitely the answer pretty much.

Eli: It shows up in the fatigue and exhaustion and energy measuring that I have to do where you you have three things you need to do today. What's the most important that you spend the most time on? And then what else can you put aside and think about later? Because you're just too tired to do the rest. So it's energy management and missing in person events with friends.

Elena: So the thing with SCID is that I am no longer immunocompromised due to my bone marrow transplant, but I live on a day to day basis with the side effects from the bone marrow transplant plant and just other diagnoses that kind of snowballed from my initial diagnosis and treatment. So, really, it's just taking a bunch of medications. I recently developed pots postural orthostatic tachycardia syndrome, so that's really been challenging just with stamina and everything. It kinda makes friend dynamics hard because I don't want people to see me as my health and I've had moments where, like, obviously,

they're being good friends, but they kinda have to think, like, oh, can she do this with her health? And obviously, that's very considerate, but I don't want people to think of me like that.
And also just growing up my graft versus host disease left, scarring. I don't really know just hyper pigmentation in my skin and growing up, I had a really hard time when kids would ask me, oh, what are those freckles on your skin? Just because I was so insecure about it and I never saw anybody with it. And for so long, I didn't understand that. My skin is like kind of just something that shows that I survived.
But, you know, when you're in first grade, kids are constantly asking you what's on your skin, that's not what you think about. I kind of honestly through IDF and everything. That's how I have gotten better with everything.

Ella: I was born with [PI]. So I feel like I always like it's just I can never tell what's normal, not normal because I've just always had it. And, like, I feel like that's why I'm so, like, open about sharing my story and just, like, I'm talking about it just because it's just always been a part of my life and talk and talking about and telling people, I just never know what's like, oh, is that just like normal everyday feeling or is that like out of the ordinary?

Zach Moore: What is the most valuable thing you've learned at an immune deficiency foundation event?

Eli: I've already met people who are just like me. It doesn't matter what age they are. They've gone through what I've been through and moreover. And it's wonderful to meet other people who have similar struggles as I do. I mean, it sucks that they do, but it's that sense of community that you're not alone.

Elena: Kinda basic but that I'm like not alone. There are so many other people who whether it's dealing with skid and post transplant complications or meeting other kids who are just constantly going to doctors appointments or meeting other people with pots just all of that stuff meeting other parents who have been through things like what my mom did. Just it really made me realize, like, there are other people who have this experience. And although on your day to day life, you kinda have to go through it alone. You aren't the only person in the world who goes through this

Ella: that you're not alone. And I think it's just always like a reminder of that.

Zach Moore: Every single person I have interviewed for this has said exactly that.

Christopher: I learned that, like, the the community is one of the most important things you can learn from. Other people who have the same or similar conditions that you can connect to.

Zach Moore: How important is it, and what does it mean when people from outside the PI community take an interest and start to show up for the community?

Christopher: It means that we are seen. And we are... we matter to those people. And that we can make a difference as well as them.

Eli: When someone who doesn't know or doesn't have a PI, has some knowledge or is able to support you. It means you don't have to overexplain yourself or you don't have to give excuses as to why you are the way you are or why you're why you're acting weird or why you can't go to the event even though you just you would seem fine. Well, you have to think about what tomorrow looks like. And tomorrow has important things going on.
And you can't be too tired or too exhausted for tomorrow's event, so you have to skip today's. And they understand the people who understand PI.

Elena: I remember when I posted the oh, not I posted, but my IDF posted my day into life reel. It caused a few of my friends to start following the Immune Efficiency Foundation on Instagram and it was so little, but it meant so much because it was my friends, like, taking an interest in something and paying attention to something that they never would have paid attention to without like me doing my advocacy work or even just people learning about my experiences, whether it's my friends or doctors, who are or med students who come in, it just really means a lot because the more people that know about what I've went through and what my friends have went through, the more that it'll help people in the future have an easier time.

Ella: I think that it shows, like, a lot, not only about the foundation, but the people and the people that you make and, like, knowing, like and it's funny, we were kinda talking about this earlier about, like, It doesn't even have to be blood related family, but it's just the people who show up and care for you and, like, time of need is, like, all it just shows you the person and, like, we want and who are in your life for life. The bad and the good.

Zach Moore: Do you have anything else you'd like to say? Those are all the questions I have.

Eli: I'm happy to talk about this because it's not often I get to share this stuff. My job is listening to students who struggle with stuff like this, but I don't get to share of my own experience. I'm really grateful to be here because I without the scholarship that I received, I would not be here. I would not have been able to afford attending this conference. And so thank you.