Transcription for: "02PROOF Community Days podcast.mp3" (Uploaded File) (New Transcription)

This program is presented with support from CSL Behring, Grifols, Adma Biologics, Amgen, CVS Specialty Pharmacy, GC Biopharma USA, Kedrion Biopharma, Pfizer, Pharming, and Quest Diagnostics. The Immune Deficiency Foundation would also like to thank the sponsors of our twenty twenty six Boston event, which was canceled due to dangerous weather conditions. Care partners, Chiesi, Haemonetics, PromptCare, Soleo Health, and Vital Care of Cambridge. Hello, Walkers. Welcome to the Immune Deficiency Foundation Walk and Community Days podcast.
As you walk, we hope you enjoy the insights and stories in this special audio presentation. Lace up your sneakers and get ready to move, whether it's morning, noon, or night, all while raising money and awareness to help improve the lives of those with primary immunodeficiency. Don't forget, there's still time to get your twenty twenty six walk and community day's t shirt. Simply raise one hundred dollars to receive a shirt with this year's Go Zebra go design. Throughout this audio presentation, you will hear from five members of our community, Cindy Cutshall-Kisik, Eli Evans, Rafaella Vedia, Elena Kramer, and Dustin Palmer, discussing everything from life with PI to their connections to the foundation.
First up, hear from them about the hobbies that enrich their lives. But before we do, are you ready to walk? On your mark, get set, go.

Hobby I enjoyed the most? I like weight lifting. I'm a big fitness person. So anything that's weight lifting or any type of mobility exercises like functional mobility is my jam.

Traveling. I mean, this year, we went to Thailand. So my husband, he's from Peru. So we go to Peru alone, which It's amazing.

I love gardening and my bonsai plants. Pronounced bonsai, not bonsai.

Well, I always grew up doing dance, like, I grew up at a Russian ballet studio, so I did that and then moved into competitive dancing. But now I just go to the gym, bible study with friends.

I really enjoy doing theater. I do it at my school. I do their musicals, especially favorite role was probably either when I was Karen in Mean Girls or this last year we did Chicago, and I was one of the Cell Block Tango Girls. That was so much fun.

Narrator: We hope your walk is off to a strong start. Here are a few statistics to remind you of the work your steps are raising money and awareness for. Last year, our website, primaryimmune dot org, received two million visitors. This, of course, is our main hub for essential resources. The clinician finder, which allows users to find and connect to a clinician in their area, was accessed by nearly fifteen hundred people.

There's also ask IDF. A portal where specialized foundation staff are waiting to answer questions about diagnoses, navigating insurance coverage, and more. Not to mention hundreds of blog posts, webinars, podcasts, and other content. Your walk today also supports our legislative advocacy efforts. Our foundation has a team of dedicated policy experts who work both on federal and state levels with the help of a small army of volunteers.
In twenty twenty five, our advocates sent three thousand six hundred and eighty four messages to legislators in order to better inform them of the needs of their immunocompromised constituents. Also in twenty twenty five, our federal advocacy day in Washington DC had more than a hundred and fifty participants visiting offices on Capitol Hill. Thanks in part to our advocates. Congress renewed the rare pediatric disease priority review voucher program this February, giving children with rare diseases new hope by incentivizing the development of novel treatments where families once had no options.
We've also got an eye on tomorrow.
We actively seek out and support the scientific research that will shape the future of immunology. Last year, we awarded two hundred thousand dollars in grants to researchers across the country whose labs are doing the work we'll use to guide care for decades to come. Now, let's hear from our community panel on a new topic, how they discuss their condition with others.

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 the whole spiel.
I have, like, a, like, a ten second version, a thirty second version, and then a solid, like, five, ten minute version depending on if they have questions.

I... I've only... Honestly, I've only ever met them here. We have a group of us that are about my age, a little bit younger, that we're able to talk to one another. But otherwise, when I was younger and going through this, there wasn't really anyone that I could talk to.
So Now that I'm older, it's a little easier, but I'm still an adult patient talking to a lot of the parents. So it's still a little difficult to find people my age.

With my work, I meet people fairly often. That I talked to about it. From a peer to peer and from mental health side of things, I definitely feel it helps me connect with individuals who are newly diagnosed.

I only know one other person in my whole life who has what I have. And she actually is my coworker. It was kind of like that that Spider Man pointing meme when we started comparing.

Not a lot, not really. Just because no one understands or like they don't even know what it is.

Narrator: At this point, we'd like to give a special shout out to everyone who registered and had planned to attend the twenty twenty six Boston Walk, which unfortunately had to be canceled due to dangerous weather conditions. There's nothing like walking together in person. But we hope this special presentation has helped you feel connected to the cause. We are all here for the same purpose and that is to improve the lives of immunocompromised individuals. While the immune deficiency foundation aims to do this through our efforts in advocacy and research, as well as social connections and emotional support.
We could not do it without your help. In twenty twenty five, a hundred and fifty one teams and more than twenty two hundred participants in locations across the country wore their proverbial stripes to show the world, in person and online. Just how many zebras there really are. Soon, we'll hear from walk manager Jessica Kutza on how our community has done in twenty twenty six. But first, let's hear from our community panel again.
This time discussing how their conditions show up in their daily lives.

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?

Well, I have to take injections. I take those thrice weekly. And so I have to make sure that I am getting my injections on time, making sure that I have things planned around that, and also knowing what my patient, if my patients are sick, I can't see them or I have to mask up, I have to be safe. So probably the safety is the biggest thing for me.

I don't feel like it shows up too much, but of course, when I'm sick, can definitely kind of show up sometimes when I have to get my treatments and I need a day to myself during that time. Just a lot of self care I think is important.

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 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 kind of 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.

It shows up in the fatigue, an exhaustion, an 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?

Narrator: Those are real stories from real members of our community, and they deserve more than a quick moment. So let's slow down together, take a deep breath in, and let it out. As you walk, think about the people in your life who are part of this story, whether that's you, a family member, or a friend. Who comes to mind? What would you want them to know?
We'll give you a few minutes with some music. Just walk and reflect. Thank you. Every step you are taking today carries those stories forward. Now let's hear from Jess, who leads our Walk this season.

Hi, Walkers. I hope you're having fun getting those steps in. My name is Jessica Kutza, and I'm the Manager of the Immune Deficiency Foundation's Walk and Community Day's Events. Hopefully, if you've been to one of our in person events this year, you and I have had a chance to meet one another. Now that the twenty twenty six walk season is coming to a close, I wanted to take a moment to share some of the exciting numbers from this year's events.
This year, we have had over a hundred and twenty five teams participate and over fifteen hundred participants registered. In total, we have raised over a hundred and thirty five thousand dollars to date. Don't forget, you can continue to fundraise until December fifteenth. So there is still time to get a walk t shirt or one of our other great incentives. Now, I'd like to say thank you to our coast to coast walk sponsors.
Thank you to CSL Behring, Grifols, Adma Biologics, Amgen. CVS Specialty, GC BioPharma USA, Kedrion BioPharma, Pfizer, and farming. Due to inclement weather, the Boston Walk was canceled this year, so I'd also like to say a big thank you to our local Boston Walk sponsors. Thank you to care partners, Chiesi, Haemonetics, prompt care, Soleo Health, and Vital Care of Cambridge. Next, I'd like to recognize our twenty twenty six top five fundraising walk teams.
In fifth place from Philadelphia, it's Gwen's friends. In fourth place from Tampa is zebra

tastic. In third place we have, from Philadelphia, Ashland's antibodies. Coming in in second place from Boston is Sadie Smiles, and our number one team this walk season from Milwaukee is team Cucco. Congratulations, and thank you to all of our teams and participants for the fundraising you have done this year.
And for making twenty twenty six an amazing walk season. We are finalizing our twenty twenty seven dates and locations and look forward to sharing that information with you in the New Year. Thanks for walking with us everyone.

Narrator: There are two types of people at every immune deficiency foundation event. There are, of course, the zebras themselves, or those living with a rare condition. But there are also caregivers, family members, and friends, people who show up to support and learn more so that they can help carry the overwhelmingly heavy load that immunodeficiency brings with it. As our time together is coming to a close, let's hear from our community panel one more time about foundation events, the lessons they've learned, and how much it means when the people in their lives prove to them that they are not alone.

This is my third conference and then I went to Teen Escape for the first time last year in Cincinnati.

So we gotta start all the... I think of all the team count. Gosh. Probably over

fifteen. Too many to count since I was about four and I'm almost forty five.

This is my first conference I've ever been to with the Immune Deficiency Foundation.

I believe my first one was in two thousand eighteen in Florida, Teen Escape, and then did a conference, and then I think another Teen Escape []. And then I done a bunch of Advocacy with IDF, but I think I I love. It's like if I heard one of my favorite things, I really love doing.

I think I've learned that everybody's diagnosis is different, and I think I've learned how important community is

that I am not alone.

That you're not alone. That I'm like not alone.

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.

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, it's that sense of community that you're not alone.

It's great to have people want to learn and educate themselves about what others are going, what are going on in other people's lives. I mean, and and especially if it's a family member or friend or spouse or someone like that, it it definitely shows that extra support.

I'm it's really really important. I remember when IDF posted my day into life real, it caused a few of my friends to start following the Immune Deficiency 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.

When someone who doesn't know or doesn't have 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 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.

It's funny that you're kinda talking about this earlier about, like, it does 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, oh, it just shows you the person and, like, who you want and you are in your life for, like, the bad and the good.

Narrator: Thank you all for walking with us. We'll see you in twenty twenty seven.