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Hello, and welcome to chronic twenties. A podcast from the Immune Deficiency Foundation, which four is living with a rare disease and early adulthood. In part two of our pilot episode, heartbreakingly beautiful, Victoria Metal and Cassie Mummer continue their discussion about hope, support, and learning who to trust with vulnerable truths about their health. Content warning.

This podcast features sensitive subject matter such as mental health, bullying, religion, suicide, and confronting mortality. The views expressed in this podcast do not necessarily reflect the views of the immune deficiency foundation, its employees, sponsors, or Board of Trustees. Listeners discretion is advised

And this is actually kind of interesting that we're doing this podcast here just at Sunday at church, the topic, the sermon was called setback or set up. And basically, it was what you view as a setback was actually god's way of setting you up for something so big. Yeah. So, like, You have I get diagnosed with the PI eight. Don't really know a j.

You don't really know what's going on. I just knew I had to go every Wednesday to Riley hospital and get my V. Like and then I slept all the way home and slept all day. And then three weeks later, however long it was. I don't even know I don't even know what, like, what product that was on or anything.

But it was like, you're so little. You don't know. You just know what you're doing. And then, like, fourteen, you get rediagnosed. CV ID.

I got hypoglycan r's eight. You got CV ID or get diagnosed with CV ID at age fourteen. Well, then it's like, okay, now you know and now you're scared. Yeah. You think you're the only one.

You think you're going to die. You think might as well just go do whatever I want anyway. Like, what's in matter? You're the only one who has it. No one's gonna understand anyway. So, like, just go for it. And I don't know. And then my mom first IDF event was in my first one was in Kansas City, Missouri in twenty fifteen. It was a teen escape. My mom found the brochure on a Tuesday.

We called Wednesday because by the time we got home, it was after hours, I definitely closed. Mhmm. We called Wednesday. We had to leave Thursday. My mom called Dan Antora.

Who used to be in charge of the teens. Him and his wife Kathy, she called him and was like, I don't even know what my daughter qualifies. I don't even know what you guys are. I don't know anything about this. I just found your brochure.

And I I think it would benefit my daughter. Yeah. And he was like, Dan was like, alright. Let's

let's have her, like, you know, technically we're full, but I think we can squeeze. And my mom's like, the only problem is if she doesn't want to go and he's like bring her anyway. And my mom's like, well, I have a younger son, like, her younger brother. He's twenty two months younger than her. He has hypogam. He's not on treatment. Does he qualify? And he's like, yeah. Bring him. That'll help her. Like, sure. Anyone's welcome as long as they have a PI and they're within this age.

Right? Like, yeah. You're you're good. So the whole way there. It's like a eight and a half hour drive without traffic and without stopping.

I sat in the back seat and grumped the whole time. I was I was a little peed off. Yeah. I did not want to go. I informed everyone when we stopped that my mother was taking me our state lines without my consent.

And as as a fifteen year old team like, as a fifteen year old person, this is child abuse. So my mom, you know, being my mom. She's I love her. She put up so much for me. I I probably have to apologize for life, but she would tell the people because they're, like, very concerned obviously, looking around, giving her looks.

We both did nothing. She was like, no. I promise this is my daughter. She's pissed off at me. This is why.

This is where we're going. I have the proof. Like, do not call the cops. And here, all I wanted to do is go back home. I did not care.

I did not wanna go. She had road games planned like the license plate games and travel bingo. And if you did a sheet, You got a prize. Well, I didn't want any prizes. I wanted to go back home.

Yeah. So she gets me there, and I'm like, alright, this is fantastic. Which Now every other IDF event I have been to, I know they did this to me on purpose. Every other IDF event too, event I have been to, they split it up by age. Not at this one.

Dan knew I was going with my brother. Right? Right? He splits it up, boys and girls. At my first event, I should have known better when the next year when I went to the Tina State, they split it up by age.

I shouldn't have known. I did not put this together until I just about probably four years ago. I was like, this is insane. You like, and I think I asked him at one point. You did this to me on purpose.

Like, because I would have been in the same age group as Colby as my brother. I would have been much more comfortable, much more happier. Like, Mhmm. Nope. And it's funny because if you ask the people that men toward me back then, they're like, oh, you were miss independent because you didn't talk.

And you you had your set in your ways. And I'm like, Yeah. And they were like, it's okay. You just didn't wanna be here at first. Yeah.

And I was like, yeah. Yeah. But I'm happier now. Like, we're we're cool now. But it it takes

some time getting used to.

I mean, especially thinking you're the only one. I told my mom when we walked in, great, not only did this was out loud at the breakfast. I said, great. Not only did you drive me across state lines when I didn't wanna go, but she also brought me to the wrong conference. Congratulations.

And I went to walk away. And she said, why do you say that? And I said because all these kids are healthy, and she goes working in the mirror. And that's when it hit me. I was like, oh, okay.

Yeah. You're right. I'll sit down. My bad. I think I'll take a chill pill.

That's that's fine. And so I did. I sat there at the breakfast, and then I don't know. At some point, they got her out of the room. They let her stay for the first little bit because I didn't want her to leave.

I was very foot like petrified. Even though I was with Colby, I was like, yeah, no. And I was misinterpreted. I sat by myself. I didn't want to talk.

When they did something wrong during the activities, I told them then when they would ask me to fix it, I said, no. Thanks. I was not I was not kind. I wasn't rude, but like, I wasn't I wasn't kind. I just and then it's like you go through the first day.

And it's, like, nervous. Like, nerve wracking, you're nervous. And then the second day, you're, like, oh, this is fun. And then, like, the morning of the third day comes, and you know what you have to say goodbye. And it was, like, well, now I don't wanna leave.

And my mom's like, oh, we have to leave. You wanna go back home? And I'm like, oh, not now. Like, I just started to enjoy this. Yeah.

And so it was, like, act no. It definitely was like I thought it was a setback. And being something so awful being diagnosed than thinking I was going to this god awful conference Mhmm. Turned out to be something really, really cool in life changing both the PI and IDF. Like, independently but also together.

Yeah. And I think that's where, like, heartbreakingly beautiful comes in because it's, like, it's awful, but at the same time. And, like, you struggle so much. And there are very, very bad days, but then you also have very, very good days. And it's like, I don't know, it's cool to see, at least to me, like, in the moments when you're so down.

And then you know there's gonna be another high coming, like, coming up. At any point, you're gonna start going up the hill. Yeah. And it's going to be okay. And so I don't know. I'm very grateful for idea. I'm very grateful for my mom for putting up with me for number one. And for loving me enough and I don't know. For for a scene past, I guess, my teenage moodiness and rhoid rage. And for wanting to help me get better.

Because without her finding that brochure, which was a bad thing in itself, it was in it was the only one that the office had seen, and it wasn't even in an IDF box. It was only in a, like, a medicine box type thing at behind the computer. No one knew at the no one knew at the

office how that brochure got there. So that in itself was a god thing or what I like to call Godwinks. But, like, I'm very grateful for her and mom to, like, see when I'm struggling to help me to put everything aside.

To focus on how she can help me get better. And, like, in prior behalf, I'm super grateful for them for putting up with me for that first team to escape. And for welcoming me back. I can't say that I would have done the same thing. If I were in charge, I probably had been, like, security.

No. All jokes aside. But for just giving, I think, all of us teens and soon to be pre teens. I don't the opportunity, and young adults, not too, because now we have the young adult, like, stuff. Yeah.

Giving us the opportunity to meet others to share our story. To volunteer and give back like we do with the yac and to just meet others like us and form those relationships and friendships because it is truly something really beautiful and something really, I think, rewarding and positive that we could all use. Man, you're making me tear up. Sorry. No. Because you're so right. I remember I mean, like, right when I was diagnosed and even a little bit I just knew something deep down. Was incredibly wrong. You know, I just it it was this unexplainable feeling. I could not shake it.

And it's like every time I walked into school, I just I felt out of place because I looked healthy and I looked fine. I mean, granted, there weren't times that I looked healthy, but I overall, I wasn't in a wheelchair. I was still able to, like, stand on my m two feet. It was it was just really humbling to find out that people with PI oftentimes look very, very healthy, but they're fighting this battle deep inside. And so I had gone throughout high school and middle school knowing something was wrong, never having a name to it.

And honestly, there were many points in the journey that I had just given up and trying to find an answer. So when I was so sick as I entered high school, I was out of school for, like, a month or two collectively just in the beginning of the school year, and I had dropped down to eighty five pounds from my normal. It was, like, hundred, hundred five at the time. In the span of a couple of weeks, you know, everybody pointed it out too. They were like, yeah, something's not something something, like, not okay.

Right. Was so winded. I could barely walk up the steps in my house even the the five steps that are in one flight. I Yeah. Down.

I was so out of breath. My heart rate was consistently fluctuating between, like, one hundred and thirty and one hundred and sixty, just walking. And so at this point, I was in and out of the hospital throughout December and January. And we had gotten to the point where something did not change. My doctor said she was going to admit me because she did not want to seem to get sepsis and that is the way that I was going.

So she did work up and then, you know, she gave me the PI diagnosis. Well, we know we know where that is now, but she gave me the diagnosis and I started infusions. And along

with it, She knew how alone I had felt. She gave me the idea for they had those, like, luncheons. I don't know if you remember those.

Yes. Yeah. The dinners, and they were there for a bunch of my areas. I was like, you know what? Free food?

This sounds great. Free food. Right. And then I went and I actually learned so much about my diagnosis and it was celebrating to meet other people who had gone through a similar situation. However, I was not ready to meet any, like, high school aged kids because Oh, gosh.

I hated high school so much. I from the moment, I was sick and out of out of school. As soon as I came back, everyone treated me like a freak. I'd be bullied. Constantly, they would curse me out, call me names.

I would wear a mask and they treat me like I'd have leprosy or something. It was just absolutely terrible. Everyone just stayed away from me. So at some point, I had just given up on making friends in high school altogether because I was so so tired of trying to appease others' expectations of me. And, you know, I would have to give them some sort of an answer even if I didn't want to. They're like, well, it's for my own safety.

I need to know, you know, if you're not going to I I need to know if you're going to give me something contagious out of my own health. It's not contagious, but I'm not gonna explain the whole spiel to you. And so having to do this over and over again, I had completely lost all faith and tried to make any sort of friendships nicely. So then when we had gone to the or was it the IDF National Conference in National Harbor. My mom was like, I think you should really do this because this would be a great idea for you to meet people your own age.

Like, well, but what is I just don't want to? All these people that I've met so far absolutely stuck with, you know, the exception of my my very few close friends at the time. But it was just very hard for me to find my place, and then I went to the conference with my family, my mom, and my my brother and my sister. And I was very, very hesitant going in there at first. I was absolutely terrified.

No. Nobody did not wanna talk to anybody, but I really tried my hardest to not be rude and not be. You didn't pull a cassy. That's that's what I'm hearing. Not at all.

I was a little I was a little spicy. Hey. It's it's all it's all fair. It makes sense. It's like the right of passage.

Yeah. That's where we met. Right? Our first time meeting. That's what I thought.

Yeah. I think that's where I met Ethan too. Yeah. You were all there. Yeah.

Gosh, that was that was a trip. Mhmm. Yeah. And so I've met you too, and I just remember looking up to you guys. Just being like, wow.

They totally know what they're doing. No. That weekend, I went I was winging it. It was so good. I was like, wow.

I had to be more like then. And, you know, after that, that conference, I really tried to, like,

be more active with IDF stuff, and then we had COVID, obviously. So everything was switched to an online format. And it was hard to maintain that sort of friendship that we that all of us who hadn't we hadn't initially met had But, honestly, I think it made it a little bit easier since we were all in different areas of the country. We had gotten so close so quickly, and it was actually I think the first team forum that we had online is where I'm at Jesse. So I mean Yeah. I mean, we can really oh, I see so much. Of our relationships and our friendships to IDF. And I think also, you know, how we went into the conference with so much apprehension, a little bit of fear. We want others who are also going through that stage to near there to support them.

And I think that's why we are not too darn horns, but we're we're pretty great. We try. I don't think we have all this seen that with how parents are talking to us about especially the last teen escaped too. But, you know, we helped a lot of their kids come out of their shelves Yeah. With their mental health.

I don't remember that that one mom oh gosh. We cried. Yes. I remember that. When then of Texas, the summer before, we had that come up to me that said and I don't even remember I I can't tell you whose mom it was.

Yeah. But she came up to me and she gave me hug and she goes, I cannot thank you. And you're the other team leaders? For this weekend. And I was like, oh, like, you're welcome. But honestly, like, thank you for, you know, being here and, you know, like, bringing your team. Like, it was really nice meeting you. And she was, like, no. My team just said, like, at least she said their name. But I don't remember now who it was, but she said they said that they are no longer alone.

That they they have friends and they have people and that she goes, I got a hug from him and I have not had a hug in years. Well, then I cried. And so she's like, it's because of you. Like, it's because you guys and you made him feel safe, you made him feel welcome, then he's actually talking and laughing now. Mhmm.

And I had I had a very similar situation just recently in Chicago, just this past summer, where my dad came up to me. And he shook my hand and he asked if he could give me a hug and I said, sure. And he said, my son is smiling again. And I said, all which he didn't know this, but I actually mentored his son when they were about nine or eight years old at Maryland, at the National Harbor in twenty nineteen. So I have seen this kid now grow up. Yeah. So I've got to mentor them twice, technically. So I'm like, I knew I knew who it was, but I wasn't gonna say. You know, at the time, I was also holding back tears. But they were like, my my son is smiling again.

He's a laughing. He talked out loud in the group that I sat, like, at the door and listened in. Mhmm. He has friends and he he goes, I cannot thank you enough for being there and, like, being a positive person for him. And for helping him.

And I was like, oh, like, you're welcome. But, like, it it I really didn't do much. I just listened.

Yeah. Like, he he's the one that that talked.

Like, I I don't I don't know what to say in those moments because it's like, I should be thanking you. Yeah. Because I got the opportunity and honestly it helps me so much when I know I have made a team or another young adult or a pre team because you know what the conferences you can have even younger. Make them feel safe enough to where they can share their story with me or share their hardships or their problems. Like, it it makes me feel good.

Like, it makes me feel like I've done something right. Mhmm. And, like, you know, kind of going back to what we talked about before about, like, our futures or our dream jobs or goals and like, this is kind of, I guess, what I see myself doing for a long while. Like, I I don't view it as a job per se. But I do view it as my responsibility.

I like, when I am at an IVF event, yes, I have fun. But you have you have a responsibility. And I feel like if I can touch or, like, reach out and connect with one team, one kid, one adult, one young adult. Or like Andy from the senior group. Or and I are like besties now.

Yes. Like, you can it doesn't really matter, like, who they are per se. It's it's just the fact that you have another person that you can connect to. Mhmm. And, like, that was really opening from you and all these parents were, like, thanking me.

And I'm, like, I I don't know how to answer because it's, like, I don't feel like I should be being banked in a way I should be banking them. Yes. So I I get what I get what you're saying in a roundabout way, but Yeah. It's such a surreal experience when we get to do what we do. And, you know, the best type of job is one where you feel like you're not doing work at all.

Yeah. Oh, one hundred percent. It's it's truly such an amazing experience. And I I am forever indebted to IDF for what your foundation has provided me with. And it was I mean, in Chicago, it was incredibly surreal because, obviously, we had the documentary come out. Yeah. That was amazing. Oh, gosh. It was it was amazing. And I had people coming up to me, you know, before the documentary even premiered.

And then after and I had one, you know, I had many moms and parents come up to me after the fact, they're saying that one of their daughters is now growing up with a pretty severe PI diagnosis. And they don't know how it's going to affect their future. And by their child is about five or six years old. So, you know, it's a long, long road ahead of forth. Yeah.

Yeah. But they they are filled with so much light and somewhat light. Passion for life and you see that, you know, at such a young age and it she feels like that light is going to burn out because of all of her health issues. When she said seeing you, seeing your interviews, and hearing you speak made me realize that she's going to be absolutely okay. And if she turns out, to be anything like you, I will be so incredibly grateful.

That's cool. Now I'm gonna try. And I did. Oh, I tried so much that again. But it's I mean, I still can't believe that we are in the position in IDF to be making those sort of connections

and being able to share our story.

I don't know. It's just it's insane to me still. I I can't I can't conceptualize it. But, you know, no. It's just great.

It's wonderful. And the connections we've made with people the families that we've created throughout the organization, it's just been it's just been an incredibly rewarding experience. I agree. It it's really something like unlike anything else. And I think until you're in the position, like this and you've had the life.

Not that it's it's I guess it's it's weird because, like, you all have a common ground. You all have a PI. You all have an immune deficiency. Mhmm. But none of you have walked the same story.

None of you have the same story. None of you have walked the same road, the same path. You don't have the same life. You may have the same condition. But, yeah, you you all have and you all know the same loneliness.

Or, like, you know, anxiety, fears, like, the darkness, the sadness that comes with it. Yet when you can be in the position. And, like, until you've had that experience of being, like, on that road and meeting someone else and meeting then so many others. Like you, but in a different way is really, really rewarding in itself. And then forgetting to be, like, for being able to, I should say, and we've, like, been given this opportunity to then work with others and mentor others and talk to others and outreach to others.

That you know, like, could have the same feelings that you have or or had or have or had the same like, hardships and diagnosis and everything. It's, like, really unlike anything else of being able to connect and be there for them and also kinda grow together. And then we at the same time. Very cool. What's it is to say?

It almost makes you feel like that you don't have a PI at all because you're able to connect with all of these people and you're able to help them. And it all of a sudden makes all of the pain that you've been dirt so worthwhile. And for a moment, you forget that you're actually in pain Yeah. Or have suffered. And I think that's that's so wonderful.

And it's not something that you would expect to happen either. I mean, you're conversing with these kids and parents who have gone through such hardship, but, you know, walked the same path with a chronic illness, you'd expect, you know, there to be this looming sense of pity or sorrow. Yeah. But, I mean, while we still have feelings of sorrow and loneliness, you have that greater sense of togetherness and community and belong. It makes you forget anything terrible that you've experienced.

Yeah. And I know you being in Chicago. You know this, but for everyone that doesn't or didn't realize, I had just gotten on the day that we arrived in Chicago, I had just gotten an IV pulled. I had I was on fourteen days Mhmm. Of daily, rocinfin antibiotics, obviously given IV. And I have PTSD for needle sticks. And so you can imagine how awful those fourteen days were. But knowing that the day that I got my last IV cold, I was going to go and see what I

called my second family. Was unlike anything else. That's honestly what got me through the fourteen days to begin with.

I had to go home with the IVs and stuff. Like, I think I only got three or three different IVs for the whole fourteen days luckily. But it was still very hard. And then when I got to Chicago, I was walking with a walker because I have a lot of, like I said, a lot of, like, joint pain and chronic pain. And I just got diagnosed with PCOS.

And I've gotten a lot of, like I've gained a lot of weight, and it's not been good overall for my health. And I've gotten a couple other new diagnosis as well that I've just been really hard on my body and, like, in itself and my body doesn't wanna move like it used to. I can barely walk or could barely walk, and so I was using this walker. And even at home, if I were to walk around the house, I had so much pain from walking from my recliner to the bathroom, I had to take a break. In fun fact, that whole weekend in Chicago that I walked with my I walk with my walker, and I do not remember being in pain.

No. I know I was in pain, but I do not remember feeling it. So when you said you when you're with the people and you're, like, in that moment and it makes everything bad that you're feeling or all the pain, And I think when you said that you meant, like, like, internal pain Mhmm. Or at least how I took it. But I can say, well, I remember looking back and I think in the moment, I know I had to have had pain because I was a lot of walking every day.

I don't remember feeling pain. Yeah. So I it is it is, like, interesting when you have a positive mindset on how your mind shifts between, like, good and bad. And when you're in a good moment, I don't think you feel a lot about things, obviously. But when you're in a bad moment, it's like everything is way worse or you tend to go to worst case scenario.

And so I don't know. I just love what you said when you're like, all the pain goes away. I mean, not made me want to share that. So No. I mean, I was also, like, pumped up with steroids too when I was in Chicago.

I mean, you know, because I had, like, so many flare ups of the joint pain. And then I was having a lot of gastrointestinal problems too. A lot of volume is the worst. It was just terrible. But I was so so right before I went, I was put on a bunch of steroids just so I would be able to get through the weekend because I know it was going to be a lot.

There would be a lot of socialization, a lot of walking involved. I just needed to be okay. And I remember telling Zach too. I'm like, I just I am the zoman right now. I don't know what's going on.

I haven't I didn't have a drink. Like, I think that that entire first a day of the conference. Oh, gosh. It's like, oh, we're we're having a great time. And I don't ever remember being in pain. Yeah. Even after, like, the night was over. And we've I finished talking to people. And I said, good night to everybody. I I know I did have some some rough nights, but I do not remember ever being in any sort of pain.

Yeah. Because all I remember is the good stuff. Yeah. It's just it's so strange to look back on

it because it feels like, honestly, not so long ago. Like, I know.

Right? And we've just come we've just come such a long way too, but I mean, I'm indebted to you, Cassie, for second, late to me, for IDF, for Jesse, my family, Zach. I mean, Pat, there's the whole like, it could just be, like, miles and miles along with all the thank yous. But, I mean, I really don't think we would be in this position or have the mindset that we do if it weren't for it. The people we have in our lives and for this amazing organization.

So I agree. I agree. And I love what you said earlier. I'm in a backtrack a little bit, but when you were talking about how hard it was for any friends, or having a hard time, like, trusting people and stuff. And I don't know if I've ever, like, shared this with you fully, but back in, like, eighth grade, I was bullied pretty bad in school.

Also trigger warning of, like, death threats and self harm. And so they I don't even remember what, like, started it. But I just remember being, like, bullied every day, like nitpicky, little little petty stuff. Like, I don't like your hair. I don't like your clothes.

Like, you're weird. There's there's a lot of things that I had to quote unquote, I guess, or air quotes, change about myself. To fit into whatever they were nitpicking me about. But I can never truly win, like anything I did. They still picked.

They still chose to make fun of. They they chose to, like, ruin. And I just didn't really care or at least I didn't show that I cared. I cared a lot at home after I would get home from school. And so that also was a bad time for me like mentally.

But it ended up escalating. I should have done something sooner in hindsight, but, you know, like I said earlier, if I had known what I know now, it would have been different, but you can't change the past. So but I do wish I would have said something to an adult sooner because it escalated pretty quickly. We're at lunch one day. And I forget.

I don't have I don't even know what started. We were sitting there in the two, quote, you know, or quotes, friends that I was sitting by. Apparently, didn't like something that I said. I think is how it happened. I don't really know what triggered them to do this, but they threatened to corner me in the bathroom and shut brace hiccups down my throat.

And I am highly allergic to peanut butter. And I used to still carry my medical kit on me, but I used to carry it in a little wristlet. And it had, like, my nose my inner history nose spray. I've been a driller. I have my EpiPen.

I have my inhaler, like, my girlfriend, everything that I would need in an emergency. They threatened to take that away, and then shove Racy cups down my throat, which, you know, would kill me. And I remember I ran out of the lunchroom, down, like, the the long haul way. And I went to one of the bathrooms, and I just sat on the floor and cried. And I didn't show up to fifth period.

I didn't show up to sixth period. I went to seventh period only because it was on the high school side and my older brother was in high school. So I knew if anything were to happen, he would be there. And so which prior to the death, like, the threat of it, they had sent me

messages on my phone, and I chose to ignore them. But they said, like, we pray to god to send a dark angel or to send an angel to watch over you, but he sent it back.

And when I asked why he said because people like you are supposed to die and go to hell, basically. And so they're like, you like, you're not a good person. You, you know, you you don't deserve basically what what I had. Like, you don't deserve what you have. And they they had sent me this other text that said if you're dumb enough to show up because it happened on, like, Thursday or something or Wednesday.

They text me and said if you're dumb enough to show up to school tomorrow. Like, that's when they also reiterated the the efforts with the Reese cups. But they had said they had tried to get me to, like, cut myself to self harm in multiple ways. They they tried to come and speak to kill myself. They told me that no one liked me, no one wanted me, they they felt pity for me, and that's why they were my friend.

And just very, very hurtful things that and at the age of fourteen, know you you believe them because it's like, of course, you're gonna believe them. Like, they're your friends, why wouldn't you? And it was hard. And I showed my mom the messages after I had the death threats because when we got out of school, my older brother obviously walked me out of school. And we make normally, I'm I'm a happy, pretty bubbly person.

I just sat there. I didn't sing. I didn't notice any music. I just sat there. When we got home, my mom was like, hey, do you have me, like, dinner?

And I was like, no. And it's very weird because I remember this day vividly, but if you asked me to call any, like, recall back from me straight. I remember nothing. Mhmm. But this day, I remember, like, very vividly.

And she's like, can't I help me any dinner in the house? And I remember I went to my room, and I shut the door, and I sat on the floor and cried. Until my mom made dinner and she went to find me and found me on the floor asleep. But like you could tell I had been crying and stuff. And so she woke me up and that is when I showed her my phone.

And that is when I told her what happened. And she took me to school the next day. And basically, the school said that there is nothing I can do about it because it sounded spiritual the text about the angel or whatever, which the guy went the principal went to church with us at the time, so no offense. Why is it yeah. Take that as you will.

And then he he said that basically there is nothing he could do because they didn't technically threaten me with a weapon. And what did he want us what did what were we expecting of him to go and through their lunchbox and take out all their peanut butter? He technically can't do that. And so Romeo was barking again. And so he basically said there was nothing to do.

And so my pediatrician at the time being fourteen was, like, fine. We're home bounding her. Like, if you're not gonna do anything, this is not good for her. So she had bound me because in the meantime, I started passing out, and that is eventually how I got diagnosed with my

opinion disorder based illegal, which I still currently have. But and pass out but not as often as I did.

But it was definitely something when you were talking about making friends and trusting new people and wanting to open up to new people. I struggled with that for a long time. I didn't talk to people. I wanted to be right by my mom because my mom was my safe person. And, like, even around the house, I didn't really want to stay with anyone else. I wouldn't stay home alone. I wouldn't stay with my brothers, I wouldn't stay with my grandma. Now they were all fine and I trusted them. It's just I did not feel safe. I was scared that these people were gonna come find me and that thought really scared me and then, you know, go on.

To then the next year getting diagnosed with CBID. And trying to, you know, figure all that out. And then when my mom took me to Kansas City, I think it was very valid for the ways that I was feeling and, you know, the things that I did. But what was very cool and very interesting and I hope to one day that I can meet up with her again. I don't know if you know her, but Amanda Jensen from IDF.

She was my mentor. She was on the teen council when I went to my first teen escape. And she took me under her wing, basically, and she is the one that got me out of my shell. She is the one the where we stayed the hotel had a mall attached to it. And so on one of our breaks before, like, after our lunch or our last session, but before we had to meet for Dave and Buster's, we had this, like, hour and a half break.

When my mom was like, alright, I'm gonna go up, like, what do you guys wanna do? We can go up to the room and rest. And I was like, oh, actually, I'm gonna go with Amanda and we're going to the mall. And she was like, what? And I was like, we yeah.

That's okay with you. Like, you know, like, I have my phone, I have my wristlet. Like, I have all my stuff, and my mom kinda tried a little bit, like, tiered up a little bit, and I don't know if she knows it, but I did catch on that she realized that I was okay. Like, I didn't have to be with just her. I didn't I didn't have to rely on her so much.

That I could do things for myself and I could trust again. Amanda is and was Ant is an amazing person, and she is one that I will forever forever forever forever be grateful for. Because if I didn't meet her, I don't know if I would have ever went back tidy up. I don't know if I would have ever been able to make that step. And that like, almost, like, advanced that I did in my life.

And then after talking with her and staying in contact and, like, texting in between the different escapes, it was like, you could tell she was a true friend, and she wasn't going to hurt you, and true friends don't hurt you. Like, they're not going to say mean things. They're not going to be selfish or nitpicky or petty. Like, sure you can have your bad days and stuff and everyone does, but they're not going to purposely set up to hurt you. And I think after that and realizing that, like, who my people were.

And I I'm not I mean, I'm gonna be completely honest. I don't have too many friends outside of IVF. I have one really good friend, Rebecca, who goes to craft class and card class with me. Mhmm. She's really cool.

I have, I think, a couple others, Kim. Just just a few. Pretty much anyone else I name, that's my friend is from India. And honestly, I'm okay with that because that's pretty much all I need. I mean, sometimes the best friends are the ones that live far away, and you don't have to talk all the time.

You can might go two or three months without talking. And if you can pick up right where you left up. It's like no time has passed between. And it's really cool to see. I have one really good friend.

He lives in Michigan, but he he helped me a lot. He was actually a hockey player and stuff, and it was really cool to see him be himself when you think of like hockey players, you think of this certain like type of person, you think of this certain type of personality that would be for the game. And they were the complete opposite. They were so funny, outgoing, they were just true to themselves. And that was something that I really admired about them and, like, just seeing them and, like, how they went through their struggles in life, but still made it positive.

And they they are another person that I'm forever, like, great before. And I think intended to to for, like, always be thankful too because they also brought me out of my shell and, like, kinda showed me it's okay to trust and it's okay to be yourself. You don't have to change. You don't have to be someone else to fit in because fitting in is not it's not a thing. You will find your crowd if you are who you are.

Mhmm. And I don't I don't like when there's cliques. I don't like when there's little groups of people and, like, you know, they're, you know, like, they think they're better. And it's just, like, you're not you're not gonna get anywhere by thinking you're better than anyone else. You're not I mean, I don't know.

Now I'm just gonna go on a tangent on this, but I'll stop myself now. But, no, I I do think it's good. I will reinstate you. Oh, I do think it's good to have a good support system. And with with people who truly have your best interest and are truly supportive of you.

No. It was really difficult for me to begin to trust again, and it's so difficult because you've been wrong so many times. So it just it, you know, it becomes sort of ingrained into your mind that there will be people who come into your life only for them to leave. Mhmm. I know that so this is actually not too long ago.

It was just last year. It was right before the Chicago escape. But I had a friend who I had met through school. And so we had gotten pretty close pretty quickly. She was a big, like, support worker system for me.

However, things started to change, like, around May of last year when school started to die down and we weren't as busy. It started with this really insignificant argument. So we had

planned to go on this this trip. It was going to be her and two of my other best friends. And we were going to go rent a cabin in New York State.

We were going to stay there for a couple of days. And so we had wanted to get on a call to plan. However, I had fallen ill. And there was a miscommunication in what time we were going to, you know, talk about it. And she just didn't understand that I was not feeling well to talk.

But, you know, I was more than happy to do it over text. This spiraled into her not accepting the fact that I did not have a moment to to call her about this. Basically, she had blamed me for being sick. Not, you know, answering as soon as I could, not responding at the drop of the hat. And it was like some there were so many expectations that I thought she understood because I had explained to her so many times what my illness is and and what it entails and that there are some days that I just won't have the mental energy to even pick up my phone.

There are some days that I won't be on my phone, like, at all, and I will just sleep. Alright. And that's just pretty understandable too. Yeah. And that's just what you have to do sometimes to to recharge.

However, she got really, really angry, and we left off on a very sour note. However, I made the mistake of going on this trip anyways, and while on this trip, she threatened my life. And I, as well as my two best friends, we were away from home. We were four hours away from home. We carpool, so we couldn't go down.

Unless, you know, it was twelve. Thirty at night at this point. So and I tried calling my mom, but she has do not disturb. So her her thing didn't go through And it's like, you know what? I'm not gonna bother anybody.

It's it's going to be fine. But her argument with me had given had made me go through such a visceral fissile physical reaction that the entire trip I was nauseous, I was vomiting, I was fainting, and felt like a feeling of unease, like a permanent feeling of unease. Sure. And, you know, when I would have my episodes, she would still be yelling at me for things that just weren't in my control. And there would be, you know, things that she, you know, wanted to argue about that weren't even related to me.

But I digress, it was it was a very difficult sort of transition because I had been so sick and then it was the next moment she would you know, raise me up and treat me like, you know, she was going to take care of me and everything was going to be okay. What do you need? You know, I'm here for you in any way. And then, you know, the next moment, she's here cursing me out and threatening my life. And, you know, then it all went down came down to the fact that she didn't think that I was taking this trip seriously and that I was using my illness as an excuse to get my way.

Mhmm. When, you know, in the reality that's that's not how we for you. No. Not at all. For not.

No one no one with the chronic illness fakes being sick. We fake being okay. Yes. No. So it was it was a painful couple of days along with her.

And I think, you know, as you know, being surrounded by people who you do not trust or, you know, have taken your way. Your ability to trust. You feel so powerless, especially when you're off whoa. Gosh. You know, we had we went back home safely.

And, you know, I had she had I got into arguments with a couple of my friends as well. And I came home and my grandma asked me, she's like, oh, how is your trip? I was like, oh, no. No. It's older.

I'm like, when I got into glorious New Jersey soil. I wanted to get out of the car and kiss the ground. I was I was not in New York anymore. Oh, So, you know, as soon as you tell your family about what's going on with many of your friendships or relationships, that's it. It's over.

There's no coming back from it. So I had, you know, cut ties with her, but it was still this cycle of her trying to get her way her blaming me for my illness. You know, to sort of manipulate her way back into my life and make me feel guilty about her feelings and how much reacted to all the stress. Yeah. And she's like blaming you for being sick, but, you know, like, you can't control that.

That's not your fault. You just as much as any of the other girls wanted to enjoy the trip. Like, you would have been perfectly fine if that stuff didn't happen happier in fact. Like, I'm really sorry that happened to you. That is awful.

Sorry that that happened to you as well. It was just, you know I mean, these these experiences are so terrible, and it's, like, up until that point. You finally think that you have found, like, a true group of friends. And they completely blindsided blindsided you. So it's like, well, I thought that I was able to trust you in telling me very intimate details of my health and my life.

Is this how you really think of me? So then just stopped trying to talk to other people. Like trying to get close to other people because it's this it makes you wonder if that's the way that other people really think of you. But they're just hide hiding it. And so that lack of trust that those trust issues, they're really very prevalent Exactly.

If you have chronic illness. I mean When I I mean, it could make you feel like when you do tell someone, like, at that age or your age now, like, does it make you feel like that they're incapable of understanding or just they just don't want to accept it or they just truly don't know and they just automatically assume you're in an quote unquote, an attention seeker. Yeah. And I know, I mean, I've been called that a lot and it is by far the truth. Like, it is or not the truth, I should say.

Mhmm. You know what I mean? But, like, it's just it's one of the things where, like, you you do want to just shut down. You don't want to tell people. Because when you do tell people, all they do is either get upset if it's plans or you're making plans or you're doing something

or you cancel last minute, well, then you'll flake.

Because Congratulations. Like, I couldn't make it. So it's it I know I've, like, had those experiences, and it's just, like, I don't know. It's one of the things that we're like, also, it makes you grateful for the people who do understand. Awesome.

And, like, you know who you can go to. But in those moments, it's so hard to see that.

Exactly. I mean, I from that trip, I mean, I have had those two friends since the beginning of high school. So that they have really stuck with me throughout all of it.

But, you know, it just it really truly tests who the people in your life are. Mhmm. How they feel about you and how much they care about your well-being when you're in those situations. So I agree. I think, like, how I determine who I can trust now is based on how you treat me.

How you treat me when it is just you and I or in a group setting. Like, do I feel like I am? Cared for and safe. Do I feel like I can, like, fully trust you with anything? I tell you that you're not gonna flip it behind me behind my back or, you know, make it sound like like, I do like, I guess, like, I am an attention seeker or whatever.

Like, I I try to really focus on how you make me or how, I guess, instead of speaking like that. Like, I guess, I try to focus on how they they make me feel more so than just like how they speak to me, how they are around me type of thing. Like, how do I feel? And it would I be like when I think about telling someone about my PI or about my illnesses in general or even about like how I'm doing mentally. Do I feel comfortable sharing?

And if it's I don't tell them. I tell them like, oh, I'm okay. Things could be better, but I'm okay.

And if they're like, well, and I'm here if you wanna talk, I just say thank you. Vicky, I know I take you up whenever you're like, well, I'm here if you wanna talk.

I'm like, oh, good. Do I have pee? But but No. If I have like a ant feeling, I'll be like, things could be better. But if I have a I am not comfortable with sharing that to them.

I follow my gut, follow my heart, and I pray about it a lot. I'm like, if this is the person, I am supposed to trust, like, you know, or sometimes there's been times where I have been out. I was at goodwill one time. This was a couple of years ago, probably before COVID, so more than a couple, like a couple times too. I was like, I had this feeling that I was supposed to go up to this woman and tell her my and I was like, there is no way that I was holding a Zebra print purse, which we all know as Zebra stand for.

Like, we are zebras, you know. And I was like, this is my purse, it's super print, and I was so excited. And I saw this lady to my left, and I had this feeling on my heart, like, God put it there. You need to share your story with the lady. And I just kinda remember looking around and being like, that is the most out of the left field thing I could do right now.

Like, no. And this lady kept walking closer. She's walking down the aisle and it was almost like God was whispering. Tell her your story. Tell her your story.

Tell her why you picked up this deeper purse. And so I was with my grandma. And so I said

grandma, hang on a sec. I say, you can go look around, but I'm mostly right here for a moment. And when this lady walks past me, I was like, if I'm supposed to tell her, she will speak first.

So she goes to walk past me and she goes, that is such a cute purse. Talking about the zebra one. And I would have just, like, looked up at the ceiling. I'm, like, mhm. Alright. So then I'm, like, yeah. I really love it. And then I, like, tell her, like, proceed to tell her. Why I chose the purse, why I felt called to the purse, and then I told her about my PI and told her about my story and being diagnosed. And it was a lot, and she goes, Did you just say you have an immune deficiency?

And I said yes, and she said, you said it was c v l d? And I said, yes, and she goes, that's what my daughter just got diagnosed with a week ago. And I got goosebumps. I was like, so most of the time, I get the feeling that I trust someone. Other times, which does only happen once.

I have the feeling where God is, like, you need to tell them. Yeah. Or, you know, you have if you're not Christian or you're not religious, I think you could still have those feelings of your gut telling you you could trust them. Yeah. And and that you can tell them.

And there are strangers out there who I think could use and could benefit from hearing the story because, like, it's so rare. It's so, like, common when you look at all of us. Like, when we're all together, it's like, wow. This is a lot of people. It's more common than you think, but it's still there.

And so it's like, you never know who you can impact or who you could potentially, I guess, help if you were to share your story. So I think it's all about how you feel and about how you feel when you think about telling someone, about your illnesses or your mental health or, you know, just you in general is how I determine it. Yeah. You bring up really excellent points. And I think that was a beautiful short I can't speak. Beautiful story.

I genuinely think that that was a sign from God because She has probably been dealing with the diagnosis as well as, you know, her daughter and Jim not knowing who she can go to for support. Or feeling alone, and you probably helped her a tremendous amount that day. Yeah. I hope so. Yeah.

I've never seen any events, but then again, I don't know if I would recognize. The person I saw. So Exactly. Yeah. For me, it's trusting people is a little bit of a gamble.

I mean, and I think that goes with trusting anybody, you know, even if it's person who you stay lifelong friends with. Initially, when you are meeting them and you are deciding whether or not to entrust them with intimate details of your life, it is a gamble because the reality is at any point in time, you know, they could abuse your trust. And that's not, you know, to put it out there or, you know, wish it into the universe that that is going to happen. But that's just that's the truth and that's how people are sometimes. But I think that being within the IDF community has also allowed me to trust other people more with my story

and because it is so personal and I'm so personal to each and every one of us, having a safe space where we are able to share our hardships and struggles and even the really ugly parts of ourselves.

Mhmm. It really gets you out of your comfort zone. It's not something that I ever thought I would be able to do personally because it was always more so I'm going to keep to myself and people who don't need to know don't need to know. I just won't tell them. But I think there's so much power in sharing your story and being able to trust people almost blindly because at the end of the day, not everyone is out to get you.

I fourteen year old me would have to disagree with you, Jeremy, on the one. But looking back now, I have a feedback perspective that's that you know, just to trust people wholeheartedly. If I don't feel safe, telling others initially or I have that gut feeling or, like, you know, God is speaking to me that, you know, I should not be able to entrust someone with with this information, then I just won't even bother. But, you know, if I do decide to pursue it, then I think I just hope for the best in that relationship. So in that way, I mean, I've I've trusted people who have let me down, and I've trusted people who have really stepped by me through thick and thin, and that's the reality of all of our experiences.

So it's really a gamble, but to just blindly trust the people that you have a good feeling about, you know, not expecting the worst. Mhmm. I think that's really what what has helped me not only make new friends, meet new friends, but help others as well. Now we're flat.

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