Transcription for: "01PROOF Jorey and Paula.mp3" (Uploaded File) (New Transcription)

Welcome to the Immune Deficiency Foundation podcast. On this episode, CEO, Jorey Berry, sits down with the foundation's new medical director, doctor Paula Henao, to discuss her career, her new role, and the state of immunology. Let's get started.

Jorey Berry Paula, I have been waiting for this time with you for a full month I am just so excited to introduce you to our immune deficiency foundation in our broader community. And for you to be able to share more about about yourself and why you chose to join our organization and our mission. And that's kind of my first question. This is a big shift in your career. I know you and I talked about that.
Even when from the interview process, even it comes up just when we talk during the week, what drew you into leaning into patient advocacy?

Dr. Paula Henao Absolutely, Jorey. First of all, thank you so much for having me. I am so excited to be here and to be able to talk to our community at large and to be able to have this special time with you. So in many ways, this isn't a sudden shift. It's been more of a natural progression of how I've always practiced medicine.
And, you know, in clinical practice, I repeatedly saw gaps and delayed diagnoses, fragmented care, barriers to treatment. And that really has led to a realization that doing everything right clinically when you are able to do that isn't enough. The system itself needs improvement. And my hope has been to move beyond a one to one care, even though I still will maintain my one to one care and I value that so much. A hope of really impacting patients and communities at large at a bigger scale, which is something that the foundation does in such an impactful way.
So advocacy really has flowed from my influence in my mission and education, awareness, access, and policy. So even though I'm still, still deeply invested clinically, I also want to be a part of applying things at a broader systems level, grounded in listening to patients, but also incorporating their lived experiences in a wider scope. So not leaving medicine rather expanding its reach and impact has been the idea for me to leave and broaden my mission and joining this outstanding organization.

Jorey Berry Sometimes, you know, even though I know that you are the perfect fit for this role, then you'll say what you just said, and I am reminded if you are absolutely the perfect fit for this role. You couldn't it's almost like you describe our organization. When you describe the need and where you want to lean in and service. But you mentioned kind of the we and you mentioned that kind of one on one patient interaction. You're keeping clinical hours.
And I know that you see patients in your own community at least every week. I know some

weeks even more than that. Are you excited to meet and as you so eloquently said to advocate for patients not just in your community, but nationwide.

Dr. Paula Henao Yeah. Absolutely. So that's one of the most exciting and unique aspects of of this transition. So continuing to maintain clinical care really keeps me grounded in real patient experiences. One day a week, it ensures that I have a perspective and I stay authentic in that one to one interaction.
And I'm able to really expand what I see clinically at a national level. What a unique opportunity that I don't think very many physicians have to be able to see a patient challenge in a one to one interaction and see that that patient isn't unique. It is an opportunity to learn about all patients that are facing similar issues and advocate for them at a stronger national level, bridging that individual care with that system level impact that we're able to bring with the immune deficiency foundation.

Jorey Berry Oh, I love that. Bringing that, which I love when talking about how there is a patient that may seem very unique when you're just looking at looking at that within one community. But then when you step back to a national level, you realize, oh my gosh, they're all you know, we talk about we represent rare conditions, but sometimes rare is not so rare. There's more there's, you know, there's there's power in numbers, there's learning in numbers and the fact that you'll have that perspective on a nationwide level. I think it's gonna be so helpful to driving our mission forward.
So I I've you and I've also talked about this some about *aha* moments. I'm always curious about, okay, you have made that shift in your career for all the reasons that drew you to this role But sometimes on the outside looking in, it can look different. Or just when you're in the role, there could be things that you learned that you didn't even realize. It was a a new area of focus or a new challenge to tackle or new opportunity you didn't know existed. What if you had any?
And if so, would you share any aha moments from what's been quite literally your first month in the new role?

Dr. Paula Henao Absolutely. So, you know, looking outward, it's always been incredible to see the reach and the sheer helpfulness of this foundation. As an immunologist, I've I've used our resources many, many times and have really directed a lot of my patients to the immune deficiency foundation for care. I was just at a conference this week where I talked to several immunologists and they're like, yes, I've referred my patients constantly to the immune deficiency foundation. I'm really impressed with the work that you do.
So it really is this, from an immunologist perspective, this huge organization that really helps our patients in a very measurable way. Coming in, it's mostly been the people that have been that aha moment. So it's been humbling to see how incredible this team works

together in all facets of what they do. I've always been impressed with just seeing how passionate every single person in the team is about the mission. I I have never encountered a team that just has such joy energy ideas.
There's a constant evolution and movement, which has just been something I've never quite encountered at this level throughout my career. And I think each person really genuinely believes in the mission. They feel personally invested. Several of our team members are personally affected by immunodeficiency either with themselves or with family members. And that drives the mission, drives the work, and that feeling throughout the organization that isn't only palpable, contagious, and makes you want to do more, be more, just because everybody really holds that energy that drives us forward.

Jorey Berry Well, first of all, thank you for all that. That would be you to say your aha moment is about how, you know, the team is. So first of all, that just speaks to to you and thank you for that. But you're also validating a lot of people do think that the organization is much larger than it is based upon the the work that we do, which we're proud of that. We we like to Mhmm.
Like to be that's our our little secret. But but you're right. Even I because I've been here a little over four years. And every day I'm impressed with this team because we we have good days and we have challenging days. But even on our worst days, you know, individually or collectively, we have a face in front of us and it's the face of our of our community who is counting on us.
And so that kinda makes us, you know, get over whatever it is and per and persevere because our community does. And we know that that we need to do that as well. But thank you for that.

Dr. Paula Henao We have this amazing community. So yeah. It's that

Jorey Berry They teach us a special whatever share with them.

Dr. Paula Henao Yeah.

Jorey Berry This question has actually been asked to me this question was asked to me when I was interviewing for the immune deficiency foundation world that I have, believe it or not. So I've learned and and I act I appreciate it. Sometimes you don't like some of the questions you're not expecting in the interview process, but I actually appreciated it. So I've started seen of people. So I think I'm gonna ask it of you now.
What is one thing that is not on your resume that you want people to know about you?

Dr. Paula Henao Yeah. That's such a great question. And there's so many ways to answer and so many things I wanna share with you and our community. But I'm I'm Colombian and and I actually immigrated several times before coming to the US. And several of my family

members have been refugees in different parts of the world.
So I really appreciate the challenges and vulnerability of that that results from the immigrant experience. And that in part has led to a lot of my work and that feeling that it's our duty as humans to take care of and protect the most vulnerable people in our community, which is the case for many of our patients with immunodeficiency. So that really drives much of my work at IDF and why I so quickly felt that home within this organization because our mission really is to get voice empower segments of our population that are vulnerable through advocacy, policy, and really enacting real change. So feel like that's a part of me that I would love to share, but there are many, and I would love to share more in the future.

Jorey Berry Well, first of all, thank you for sharing that. I think I learned some new things as well about you. So first of all, thank you for that. But also, another reason. This is such a perfect fit, and I can see that I can see that in your approach to our work.
Because, you know, at the end of the day, in a lot of different ways, whether it's you know, the immigrant experience, whether it's a vulnerable or marginalized population, whether it's someone with a rare condition that not a lot of people understand. We're all trying to make the invisible visible. And and I think that's that's a key value within the organization, and you've just so effortlessly folded into that. So thank you for that.

Dr. Paula Henao I couldn't have said it better myself that making the invisible visible. I think it really does engage a lot of our humanity, which is like our our common thread. Right?

Jorey Berry So you've built a career at this intersection of science and service. You actually talked about that at the beginning a little bit. When did you realize that those two things didn't necessarily have to be separate?

Dr. Paula Henao Oh my goodness. Jorey, very early on, very early on. So it's actually extremely fitting that my clinic days are Wednesdays because all throughout high school. That was my service day. So for for high school, I volunteered on Wednesdays at a hospital for children that were undergoing rehabilitation and actually resided in the hospital.
So it was a very low income hospital. It's called the Luzvi Thal de Infacton O'Hir David Gassion. And this was in Guatemala when I when I lived there. And I I immediately got drawn to this population that was very vulnerable, that really needed some warmth and excitement. So initially, I would come in, read to the children.
Then I started I I play the violin. And back then, I was much better than I am now, so I would bring my violin and I would play to the children. And there one child, Checha, who would he was had a severe mental delay and he would just get so, like, enthralled and moved with the music. And then over time, I started bringing more of my friends over to a volunteer at

the hospital. So we would do wheelchair races in the parking lot, which I don't know how we got away with that, but it was the most fun thing and the kids were just so enthralled And so that was actually what drew me to medicine.
And in just that intersection between service and I had this scientific mind, and so it was a perfect mix of being involved with people. Connecting with people and really being at the forefront in that way, but using my scientific mind to help in that way.

Jorey Berry Oh, my gosh. Paula, you're in high school doing that level of service.

Dr. Paula Henao It was so it makes a lot

Jorey Berry what makes me think about, you know, what I was or wasn't doing in high school and to that level, and you just you may be you may be wanna go back and be a better teenager. You may wanna go back and be a better person. And I love that You won't hear people wanting to go into medicine of the scientific field because, I mean, obviously, I feel our clinicians are brilliant. So they have these amazing scientific minds, whether it's it's math and science, whatever it may be, but it often hear another reason, like, the story that you shared. So that's a very higher calling in a way, and I'm really I'm really appreciative that you shared that.
And I also go completely guilty about what was I doing when I was in high school. Oh my gosh.

Dr. Paula Henao No. And medicine truly is a calling. So I it's not in it it it it really like, if you're not called to it, I tell people don't go into medicine. It's truly it's a humongous sacrifice in every way, but it truly is a calling. And I'm so glad that I was able to be called to that profession and to be able to enjoy all the different aspects that that career has brought me.

Jorey Berry I've had many aha moments related to our community since I began. I've had such learning from them and about this world of immune deficiency. But I also had a aha moment interacting so closely with so many clinicians, physicians, nurses, whomever. And that was my aha moment was, oh my goodness, the sacrifice that is made. I'm it just it it increase the level of respect that I didn't think that I could increase at that time.
Alright. So I'm interested. What did your training not prepare you for that you've kind of had to learn on the job?

Dr. Paula Henao Oh my goodness, Jorey. So much here, but one of my favorite poets, Antonio Machado. He's a Spanish poet. He says and I'll say the Spanish but translate in English. Caminante like Camino, so roughly translated to traveler, there is no road.
You make your own path as you walk. And what's most interesting about this job is and it's something you've also alluded to is that we're paving the road forward. So in terms of not

being prepared, every single day, I'm learning. We're creating new projects. There's new paths based on the needs of our community.
And that means that I am in many ways totally unprepared for the job in terms of we are learning and we are paving that road and learning new things and really eager to make mistakes and learn from them and create an even better mission moving forward.

Jorey Berry I I have I think maybe even we've talked about it. I I used the phrase a lot. We're kind of building especially with this role and all the that possibility that we're building the road as we're driving on it. But can I just say the poetry you shared sounded so much better than, you know, whatever I say, I could listen to I could listen to that all day, but that's but that's the sentiment? Right?
So much in life, you're just doing it as you are doing it. Yeah. Cool. Okay. So tell me about a patient interaction maybe recently that reminded you exactly why you kept the clinical hours that we were talking about.

Dr. Paula Henao Yeah. And I hope my goodness. There are so many dory. And, you know, The patients that have gotten to know me over the years know that I'm a hugger. So I get just big hogs from some wonderful people of whom I'm to privilege to and humble to be a part of their lives.
And very recently, maybe a couple weeks ago, one of my longstanding patients had an asthma exacerbation. As you know, we take care of asthma allergy and immunology patients. And I tried to really focus on my immunology patients, but I have a long standing history with many of my asthma and allergy patients. And as she had this asthma exacerbation, we navigated closely together.
She unfortunately was hospitalized. And after a last clinic visit, she gave me the biggest hug. And I think because I was moving to the foundation, she just said, I love you. Don't you dare go anywhere. We need you here, and it was such a beautiful reminder of what I love about clinical medicine and those bonds that you create over time.
And why I'm still a part of my clinical medicine and why it's so hard to leave my practice and have to keep that little clinical sliver so that I can continue to maintain those bonds with my long standing patients.

Jorey Berry Well, so first of all, we're thrilled that you are able to do that because all the reason you said, I mean, you're still seeing patients, but you're also still having those experiences that you just described, because you know, I think people have different approaches in in care and you being able to bring that warmth as well as the standard of care, you know, medically and keeping your patients healthy, but also for them to have that that connection with you. I mean, that's that's the secret sauce. So Mhmm. We're I guess, we're okay sharing you a little bit with your patience. We're actually very okay with doing

that.
Thank you. We talked we think that a little bit about making the invisible visible. It's a little bit of a look, a little bit of a segue, but kind of sort of in that spirit. Yeah. How do you make sure the patients you you can't see.
The ones in rural areas, underinsured, underrepresented, underserved, how do you work to try to help them have a seat at the table?

Dr. Paula Henao Hi, goodness, Jorey. And gosh, this is such a huge problem. So many patient voices, as you've mentioned, become invisible. And the biggest issue is that we have these unbelievable advances in medicine. And there are so much that we can do to help patients at different levels with different conditions.
But many of the therapeutics that we have are not reaching our patient population and are because of lack of awareness, because of lack of access, because patients are uninsured or underinsured, And so, and because of the cost of certain therapeutics period, many of the newer interventions are over a million dollars and can't be accessed even with very good insurance. There's a lot of hoops [] to navigate. So I think the immune deficiency foundation does really step in here and give voices to immunodeficiency patients and really get them a seat at the table as you mentioned, be able to write letters to Congress, our policy the team works really hard to make those individual patients visible, but there's so much work to do on the sphere. And I'm I'm energetic to be a part of we're gonna be doing a small amount, but I'm so energetic to be able to really persevere and make these patients be seen in Congress, in in by insurance companies and other ways to make sure their voices are heard.

Jorey Berry It's somewhere, I know our chief public policy officer is clapping because you just pretty much described our policy agenda and where they spend so much time removing those barriers to accessing care. I mean, we're fortunate to have so many treatments available, especially in the broader immune deficiency space, but certainly for primary immune deficiency, but access is still very challenging. So we are thrilled to have you, and I know you and I will be together soon actually walking those halls of of congress to share to share that message about access. Alright. I have an unfair question to ask.
Okay. That's always a great lead in. That's a great lead in. Because I'm gonna ask you to pick one thing. And if you cheat and pick more than one, of course, that's what we thought.
I usually do that one. I people try to restrict me to one thing. If you could change one thing about the healthcare system, how it interfaces with patients who have as we've been describing chronic or complex immunological conditions. What would it be?

Dr. Paula Henao Oh, yes. And restricting to one thing is is hard, Jorey. So complex conditions require interdisciplinary care. So that would be the main change that I would I

would enact. So many of my patients struggle not only with access of care, but also just how long they have to wait to see a special list.
And then these complex conditions may require five more specialists that may or may not be talking to one another. And a lot of our patients see that. They especially if they're different specialists are within other institutions, there's even less cross sectional talk. So creating an interdisciplinary clinic in different locations that takes care of these very complex conditions that require multiple physicians. They think is necessary and would be something that the healthcare system could really fast forward and advance for complex immunodeficiency patients that have autoimmunity They have problems that link a lot of different specialists that don't necessarily know about all the other aspects of care and need communication about these very highly complex patients.

Jorey Berry I it's it's as if you were with me a few weeks ago, I wasn't asked a question, and I think kind of simply put where do patients, especially in primary immunodeficiency, where are they getting stuck? And I mentioned specifically the diagnostic journey, and I talked about exactly what you just said. It's very often our patients are being seen by a specialist for personal particular symptoms. And then they're being seen by different specialists for different symptoms and no one's connecting the dots. So you describe that beautifully. And your solution, I need my magic wand, because your solution is also actually makes perfect sense.

Dr. Paula Henao Thank you, Jordi.

Jorey Berry My next question is where and I know we just have a few more. Where do you think the biggest gap is right now between maybe what science knows, but also then what patients are actually receiving?

Dr. Paula Henao Yeah. Yeah. No, that's a great question, Jorey. So the biggest gap really isn't knowledge. It's how we deliver to patients.
And science is advancing so rapidly. I think it's it's almost impossible to keep up with the scientific advances. There's so many new diagnostic

Jorey Berry Yes.

Dr. Paula Henao Treatment there's a novel understanding of different disease processes even in rare disease, but there's still significant delays in translating that knowledge into real world care. And that lack of awareness leads to delayed diagnosis. We always talk in the rare disease world about the diagnostic odyssey, so patients wait ten years. Or more. They've had some of these symptoms since childhood and then they're forty or fifty when they get diagnosed.
I have I have heard those cases many times. So And so this delay diagnosis is a huge issue.

Various access we just talked about, how challenging it is to find a specialist barriers to treatment, insurance coverage is a huge issue. And then the guidelines to certain things exist, but there's inconsistent implementation. Different physicians operate with different mindsets that can be very complicated and makes things harder, care is very widely, so care provided by physicians as very widely between location, provider, And the system just seems to move slower than science and the way patients need it to move.
So the key gaps are the translation of science to access and implementation,

Jorey Berry I feel like while those are significant challenges, I also feel like the new deficiency foundation can have a role in almost all of it and moving that needle. Absolutely. Which is which is one of the reasons that we needed this role last question. Of course, it's a big one. But but I know that you will bring a unique perspective to it.
Where do you think the field of immunology is going?

Dr. Paula Henao Oh my goodness. This is this is a huge, huge question, Jorey, and I love to answer it. There is so much that's happening in the field of immunology and it's exciting because in many ways actually immunology touches pretty much every single organ system. You know, a lot of like immunotherapy. It works is used in cardiac care, gastroenterology care.
And it really expands in a really interesting way. In terms of primary immunodeficiency, we're seeing really, really interesting research for instance, for people that couldn't find a matched donor or For bone marrow transplantation, we are now able to create bone marrow transplants that are gene edited, so you can receive your own bone marrow transplant that limits the risk of bone marrow transplantation in many important ways, but we genetically edit it so that there is the disease is edited out So that's fantastic. That can be done with something called CRISPR technology, which is basically taking a pair of scissors that I'm over simplifying it, but basically taking a pair of scissors into into the gene and creating breaks. To be able to insert a new gene that doesn't have the problem and then later creating a transplantation without the same risks of rejection that and transplant from another person would have. We're also having different gene editing technologies where you can directly without a bone marrow transplantation directly, insert genes through potentially like a viral vector, so the virus might take in the gene into the cells that need editing, and that could be really powerful in terms of being able to change genes that need changing because they're causing disease.
So limit there's some ethical considerations with all of gene therapy, but this would be specific for genes that cause disease. Make make insertions of that of the gene that's correct or adding some what we call basis into the gene so that we don't have a disease anymore. And that's that's huge for those patients that have a lot of infections, especially viral infections because that affects a lot of our population, say, with a CMV virus, that that

especially when people are very immunocompromised, we are they're creating virus specific t cell therapy so that t cells can be brought in to specifically attack the type of virus when there is no better way to handle that virus, so that is huge and will be a big change in for our population that is having severe viral illness. AI is going to be enormous in our field in terms of early recognition detection and also advancing research strategies. So there is so much that's coming up in our field is there's there's a revolution happening in our field where our field ten years ago is nothing like the field.
That we have now. And our field ten years from now is gonna be completely different from what we have now. So very exciting time in the world of immunology.

Jorey Berry When you were talking, the two words that came to mind. The first word was, oh my gosh, it's fascinating. But then as you spoke more, I thought, oh my gosh, it's so hopeful. Their the the future is so hopeful. And what is on the horizon and in the lives that are gonna be impacted?
And then you're you're speaking about potential curative efforts and really reducing the time of diagnosis and, you know, so that we can put an end to always sick. Really, really impacting lives in the hear and now. And to hear you say, because I'm not a part of the this community ten years ago, that we were in such a different place now. And where we're gonna be in ten years? Who knows?
I don't know. I think I'll leave I'll leave with hopeful. Well, I also know that I am the only thing standing between you and catching a flight so you can go represent the immune deficiency foundation in a leadership role in within the clinician and science community, I don't want to do anything to get in the way of that because you're really making sure that we're at the right tables and doing that just a month in. So thank you so much for your time. This is gonna be such a wonderful introduction to our community, and I've learned more than I thought that I would learn.
And I just can't wait to see how you grow and kind of evolve our research arm and overall how we're gonna show up as a thought leader in this space. And I won't say it as beautifully as you said earlier, but how we truly kind of build this road as we walk on it. So thank you again. Thank you so much, Jorey. I'm so grateful to be here and so grateful to be

Dr. Paula Henao a part of this incredible community.

Jorey Berry Thank you.