

## Chronic Twenties Podcast: Demystifying Advocacy

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### Intro

**Narrator:** Hello, and welcome to *Chronic Twenties*, a podcast from the Immune Deficiency Foundation, which explores living with a rare disease in early adulthood.

**Rebecca Russ:** Alright, hey everyone! My name is Rebecca, and I'm IDF's grassroots advocacy specialist. I'm part of the public policy team, and my role is essentially to work closely with IDF-sponsored advocates to ensure that the voices of the PI community are being heard. Eric?

**Eric Feigen:** Thanks, Becca. My name is Eric, and I help the foundation's policy team with regulatory and federal-level advocacy. And just to dive right in, I'm super excited that today we're chatting about demystifying advocacy. It's such an apt name because things are always evolving and complicated in the policy world. So it's crucial to discuss at a high level what advocacy is, how our voices can influence decision-makers, and most importantly, some key issues where advocacy can help spread and scale the right policies that directly improve the day-to-day lives of young adults living with chronic conditions.

**Rebecca Russ:** Yeah! So let's dive into what advocacy actually means. It can mean different things depending on the context. But in today's episode and the work we do at IDF, advocacy means promoting a cause or policy that supports the needs and interests of an individual or a group of people with shared concerns. In this case, we're supporting people with PI and the broader PI community.

And today, we're focusing specifically on issues impacting young adults in their twenties. Advocacy aims to change existing policy or create new policies and programs that improve lives across the PI community. It's important to remember: **you don't need to be an expert to advocate.** As Eric said, policy is constantly evolving and complex. What matters is that you're an expert in *your* story. Sharing your experiences demonstrates how laws and policies impact real people. If you leave with one message today, let it be this: **your voice matters.**

At IDF, we generally focus on two types of advocacy: **legislative** and **agency-level.**

**Legislative advocacy** involves working with elected officials at the state or federal level. That could mean emailing your legislators, meeting them, testifying at a hearing, tagging them on social media—any of that. When our community participates in Advocacy Day or our state workshops, that's legislative advocacy too.

Eric, want to explain agency-level advocacy?

**Eric Feigen:** Sure! I completely agree with what you said. Patient voice and representation are really at the heart of both legislative and agency advocacy. The difference is that **agencies implement** the policies passed by Congress.

The federal agency we work with the most is Health and Human Services (HHS), which includes sub-agencies you might recognize: the FDA, NIH, CMS, CDC, and others. We submit comments on how to implement policies within these agencies.

For example, we might advocate for the FDA to factor in whether people with PI prefer IG therapy intravenously or subcutaneously when evaluating new treatments. At the end of the day, both types of advocacy are about making sure the voices of people with chronic conditions influence policy decisions.

**Rebecca Russ:** Exactly. Now that we've covered what advocacy means, let's look at real-life examples. One of our biggest recent focuses has been **Medicaid**, especially during congressional reconciliation.

Medicaid is really important to a lot of people in our community, especially young adults. When we had Advocacy Day and our Young Advocates Academy, so many participants told us how Medicaid had been essential at some point in their lives—whether during college, job searching, or just getting on their feet.

We want to ensure Medicaid coverage remains strong for our community. And over the past few months, advocates have really stepped up. During Advocacy Day alone, 152 members of the PI community met with 186 congressional offices to urge them to protect Medicaid. That's over a third of Congress in a single day! It's mind-blowing.

Plus, IDF advocates have sent over 2,000 messages to legislators through our action alerts. A huge number of those were from teens and young adults. It was amazing to see all of you raise your voices.

Eric, want to talk about where things stand?

**Eric Feigen:** Definitely. First of all, those numbers still blow me away. That kind of turnout shows the power of our community.

As background, Medicaid is a state-federal program for low-income individuals. It covers long-term care, specialized treatment, home health services—all crucial for rare disease patients. Coverage varies by state, but the federal government helps fund it.

Around **1 in 5 people with PI are on Medicaid**, so we were very concerned about proposed cuts in H.R. 1, sometimes called the "One Big Beautiful Bill." Unfortunately, parts of the bill passed that we opposed, like **reductions to the federal provider tax match** and the **introduction of work requirements**.

Work requirements mean people have to work 80 hours a month to qualify. People with PI should qualify for exemptions, but implementation is the concern. Applying for a waiver, proving disability, dealing with paperwork—these are all real access barriers.

The good news? These provisions haven't gone into effect yet. The provider tax reduction won't kick in until 2028, and work requirements still need to be implemented at the state level. That's why **advocacy is still essential**.

Also: we had a few **wins**. Per capita caps were proposed but removed from the final bill. These would have given states a fixed amount of money per Medicaid enrollee, regardless of their actual care needs—a big problem for PI patients relying on lifelong IG therapy, which costs ~\$38k-\$43k/year.

We also helped push for the inclusion of the **Orphan Cares Act**, which supports rare disease research.

Becca, you had a big win at the state level too, right?

**Rebecca Russ:** We did! In Maryland, IDF worked to ensure **copay accumulator programs** would be addressed. These programs essentially prevent copay assistance from counting toward your deductible, which can block access to treatment.

With help from two incredible Maryland advocates, who gave virtual testimony, we supported legislation that passed this year after a multi-year effort. We're now at nearly 25 states that have passed similar protections. It really showed how **even just one or two voices can tip the scales**.

**Eric Feigen:** That's so cool. Were they in-person?

**Rebecca Russ:** They testified virtually, which was great because it made participation easier. One good thing about the shift to virtual during COVID is that **advocacy has become more accessible**.

And testimony can be intimidating! But IDF is here to help you prep. They both did an incredible job. So proud of them.

**Eric Feigen:** Absolutely. It also shows how **local-level advocacy often has immediate impact**.

Let's pivot to another issue: **vaccines** — especially in college settings.

**Rebecca Russ:** Vaccines have always been a priority for IDF, long before COVID. But in the past few years, they've become even more prominent.

Young people often have less control over their environments — dorms, shared housing, classrooms. That's where **herd immunity** is so important. It protects immunocompromised people by making infections less likely to spread.

Eric and I were both in college when COVID hit. I was a senior, he was a freshman. It was a scary, uncertain time. Even for those of us not immunocompromised, it drove home how important vaccination is for community protection.

But we also saw a rise in **misinformation**, which presents challenges.

Eric, want to share what's going on now?

**Eric Feigen:** Sure. Recently, HHS leadership replaced the entire **Advisory Committee on Immunization Practices (ACIP)**, which advises the CDC. That committee's recommendations influence **which vaccines insurance covers**.

If that guidance changes due to poor science or political influence, it could limit access to essential vaccines. That's especially worrying for immunocompromised people who rely on **community vaccination to stay safe**.

At the state level, IDF's been active too.

**Rebecca Russ:** Yeah, like in **Louisiana**. At our Baton Rouge workshop, advocates worked to oppose a bill that would have eliminated key public health protections.

Thanks to those efforts, the bill didn't pass — a big win for maintaining herd immunity.

Across the country, we continue to push for science-based vaccine policy that protects the PI community.

**Eric Feigen:** Exactly. And it's important to remember that **some people with PI can't be vaccinated**, which makes herd immunity critical.

**Rebecca Russ:** Right. Another major issue for young adults with chronic conditions is **mental health**. Managing chronic illness is stressful. Add school, jobs, housing, and it can feel overwhelming.

One solution we advocate for is **telehealth**.

**Eric Feigen:** Yes. With shortages in both mental health and immunology providers, telehealth ensures continuity of care. It's critical for those who can't easily travel or need flexible options.

The **Telehealth Modernization Act**, reauthorized last December, extended telehealth flexibility for Medicare. That needs reauthorization again this year.

**Rebecca Russ:** Which is another example of how there's **always work to do**. Whether reauthorizing good policies or pushing for new ones, advocacy is ongoing.

So before we wrap up, let's talk about how **you** can get involved.

First, **sign up for IDF Action Alerts**. Go to our website, click the "Get Involved" tab, and find the Advocacy or Policy page. Once signed up, you'll get emails when action is needed.

You can customize your message and send it to your legislators with just a few clicks.

Second, **join our events**. - **Advocacy Day** and **Young Advocates Academy** take place in D.C. every spring, and we cover all your costs. - We also host **state workshops** both virtually and in person.

Third, consider becoming a **Health Access Advocate** if you're ready for a deeper level of involvement.

We rely on **you** — your story, your voice. Our policy team is small but mighty, and we can talk all day about these issues. But when someone like *you* shows up and shares your experience, **that's what moves people**.

**Eric Feigen:** Couldn't agree more. Whether it's sending action alerts, attending events, or talking to officials, your voice amplifies the impact of our work and drives meaningful change.

**Rebecca Russ:** Thank you all so much. And remember, our inboxes are always open. We're here for you, and we're so grateful for the work you do. Let's keep making change together.