Transcript for: "01proof BC misinformation.mp3"

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Dr. Rochester: Welcome back to another episode of Bold Conversations, a special series on the Immune Deficiency Foundation's podcast where we delve into topics related to equity, access, and all the things that impact our ability to receive appropriate medical care. Today, we're going to be talking about misinformation, and I am thrilled to have a renowned expert join me: Dr. Cynthia Baur. Dr. Baur is a health literacy and health communications expert. She is the endowed chair and director of the University of Maryland's Horowitz Center for Health Literacy. And I have to say, as a native Marylander and current Maryland resident, we are home to the nation's first academic health literacy center. I'm so pleased to welcome Dr. Baur. Welcome to the podcast, Dr. Baur.

Dr. Baur: Thank you so much, Dr. Rochester. I'm super excited to be here with you today.

Dr. Rochester: And I'm super excited to have you. I mentioned that this episode is focused on misinformation. We often hear the terms misinformation and disinformation — but many listeners may not know the difference. Can you help us understand it?

Dr. Baur: Sure. The basic difference comes down to intent. Misinformation refers to inaccurate or misleading information that isn't necessarily shared with harmful intent — it can just be wrong or outdated. Disinformation is intentionally misleading — someone deliberately shares false information. So while both are harmful, disinformation has that added layer of intent to deceive.

Dr. Rochester: Thank you. Let's go a little deeper. You alluded to the fact that our understanding evolves. What are the "standards," and how does someone even know what those are? What's truth versus fiction?

Dr. Baur: That's a great question, and answers vary depending on the topic. In public health and medicine, information often evolves — especially during novel situations. Think about COVID: our knowledge shifted significantly from spring 2020 onward. That's not because we knew nothing, but because research was ongoing. So what we believe at one point may change later. If you hold onto old information indefinitely, even well-meaning people can unknowingly spread misinformation just because their knowledge is outdated.

Dr. Rochester: That's such a helpful framing. It felt like misinformation exploded during COVID. Do novel situations — like pandemics — create opportunities for bad actors to spread disinformation?

Dr. Baur: Possibly. Uncertainty creates incentives — for example, to sell products that claim to reduce fear. When people feel anxious, they naturally look for answers. Public health has to make decisions with the information available in the moment. We often talk about "lateral reading," a strategy where you seek out additional sources beyond the one you're reading. If you're seeing conflicting opinions across sources, that's a sign to pause and keep exploring. During COVID, the phrase "do your research" gained traction. As a researcher, I appreciate the curiosity — but we also need to evaluate the quality of that research. Where did it come from? Was it rigorous? Not all evidence is equal.

Dr. Rochester: That's a perfect segue into health literacy. Can you define it? And how did you get into this field?

Dr. Baur: I'm trained in communication, but I came to health literacy through a personal experience. About 30 years ago, I became pregnant. I'd been a healthy person, hadn't interacted much with the healthcare system, and suddenly I was hit with a firehose of medical information. Despite being educated and motivated, I felt overwhelmed. One moment stuck with me — I was prescribed a medication while breastfeeding and asked my daughter's pediatrician if it was safe. He said, "In 30 years of practice, I've never seen an issue." That raised a flag for me — what other evidence do you have? That experience and others led me to explore health literacy. Over time, the field has evolved to include not only what individuals can understand but also what organizations can do — we call that "organizational health literacy."

Dr. Rochester: I love that. And I imagine low health literacy makes people more vulnerable to misinformation?

Dr. Baur: Absolutely. I tell students they've become expert information seekers — they've spent years evaluating sources, synthesizing, and interpreting. That's why education level correlates with health literacy. It doesn't mean you know everything, but you know how to start the process. But even people with strong skills sometimes turn to social media to interpret dense research. That's where misinformation can creep in — it's often easier, more accessible, and designed to appeal. We are all "cognitive misers" — our brains want shortcuts. Unfortunately, misinformation is often made to be digestible and engaging.

Dr. Rochester: I hadn't thought about that. The simplest message wins — even if it's wrong.

Dr. Baur: Exactly. That's marketing 101.

Dr. Rochester: And access plays a role too. Not everyone has broadband, or even a computer — they may rely solely on smartphones. Can you talk about how disparities in access contribute to vulnerability to misinformation?

Dr. Baur: Access is foundational. During COVID, we realized many people lacked affordable internet — so investments in broadband expanded. Even with smartphones, some tasks — like filling out forms — are harder than on laptops. Then there's how information is presented: too much jargon, complex graphs — these create inequities too. People prefer talking to real people, but clinician shortages and geographic disparities get in the way. All of this impacts health literacy.

Dr. Rochester: So many layers. Let's focus now on people with rare conditions, like primary immunodeficiencies. What unique challenges do they face with misinformation?

Dr. Baur: Finding accurate, personalized information is extremely difficult. General info isn't enough — patients need to know, "What does this mean for me?" That's why people value the human connection with trusted clinicians. AI tools may help with personalization in the future, but we'll see. Patient advocacy groups, like the Immune Deficiency Foundation, are crucial — they can distill complex info and connect patients with expert sources. Plain language work is vital.

Dr. Rochester: Besides plain language, what else can organizations do?

Dr. Baur: I love when organizations host patient education days. They humanize clinicians and let patients learn from and connect with specialists. Video libraries — brief clips on key topics — are also useful. They meet people where they are with quick, digestible content.

Dr. Rochester: What can individuals do?

Dr. Baur: Ask questions. Even a few thoughtful questions can make a big difference. Give feedback to healthcare organizations. Every time I engage with the system, I get a survey. Use that opportunity. Ask for better communication, clearer websites, or more accessible content. And be cautious before sharing anything online. Pause. Check the source. Ask, "Who benefits from me believing this?" Small steps make a difference.

Dr. Rochester: Thank you, Dr. Baur. I love ending on personal responsibility. We can wait for systems to improve, but we also have power right now. How can people find you or learn more?

Dr. Baur: Please visit the University of Maryland Horowitz Center for Health Literacy — just search for us online. We try to post all our work there, especially resources for professionals and organizations.

Dr. Rochester: We'll include that in the show notes. Thank you again for joining us on Bold Conversations.