

Profile: John G. Boyle



As president of IDF, John Boyle makes it his mission to address PI patients' needs.

JOHN BOYLE was only 6 months old when he was diagnosed with X-linked agammaglobulinemia (XLA), a primary immune deficiency (PI) that occurs almost exclusively in males. People with XLA have very few B cells, the specialized white blood cells that help protect the body against infection. That diagnosis helped shape the course of John's life in unexpectedly positive ways, eventually leading to a career path in the nonprofit sector and opening the door in 2017 to becoming the president and CEO of the Immune Deficiency Foundation (IDF). Today, John works to connect more members of the PI community to the foundation to help improve their standard of care, and he continues to advance IDF's critical advocacy, education and research initiatives. As a PI patient himself, John has a special passion and compassion for helping members of the PI community live healthier, fuller lives.

By Trudie Mitschang

Trudie: You were diagnosed with XLA as an infant. Share a little bit about your story with our readers.

John: I was a bouncing baby boy, but when I was 6 months old, I developed a respiratory infection that went from zero to sixty in no time. Thankfully, the care team in charge saw this looked very unusual, so I was referred to a nearby hospital. Within a short time, I was in the pediatric intensive care unit with a severe form of pneumonia. I was incredibly fortunate they happened to have experts in immunology who realized I wasn't producing antibodies and diagnosed me with XLA. From there, I was started on intramuscular immune globulin (IMIG), which stabilized my condition. Some years later, I was switched to intravenous IG. I am now treated with subcutaneous IG, and I'm doing as well as one could want.

Trudie: How has living with a PI shaped who you are as a person?

John: More than anything, it has given me perspective that I'm grateful for. Because of my condition, I understand something about how fragile life is. Being part of this community has opened my eyes to worlds of perseverance, hidden pain, joy, tragedy and so much more that I would barely have experienced if not for that little mutation in my BTK gene. And because I've seen some remarkable scientific progress in my lifetime, it has made me something of an optimist. Of course, this last year of antimask, antivaccine, antiscience sentiment has challenged that optimism, but I have faith this is another case of "two steps forward, one step back."

Trudie: Tell us about your family's

role in establishing IDF.

John: Relative to other forms of PI, XLA was pretty well understood at the time I was diagnosed. My parents settled into a "new normal," but my mother, Marcia Boyle, IDF's founder, realized many families didn't have access to the same diagnosis, treatment or patient support options. She founded IDF at our family's kitchen table in 1980. In our 40-year history, IDF has grown to become a national model for other patient advocacy organizations, serving tens of thousands of families in the U.S.

Trudie: How long have you been professionally involved in the organization?

John: Aside from a year and a half in public relations after graduating college, I've been part of the nonprofit world my entire career. After a few roles in which my skills as a fundraiser were honed, IDF reached out to me to help launch a peer-to-peer fundraising program (now the IDF Walk for PI). As time went on, my role grew. Once my mother, the previous president, announced her intention to retire, our board of trustees launched a national search. I threw my hat in the ring, and here we are!

Trudie: What prompted you to throw your hat in the ring to become the next IDF president?

John: I was working on my master's degree in nonprofit management. Coincidentally, the announcement at IDF happened just as I was ready to take the next step in my career. Having grown up with a front-row view of the tremendous growth at IDF, I cared deeply about its success. After a national candidate search process, I was offered the position of president and CEO. It's

an honor to help raise a voice for a community that's been part of my life for 40 years.

Trudie: Last year, IDF revised its mission statement. What inspired that decision, and how is it impacting your work?

John: Our mission statements reads: The Immune Deficiency Foundation improves the diagnosis, treatment and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education and research. We updated it by adding the words “fostering a community empowered by” to the previous verbiage. More than anything, it was a reflection that IDF is not simply pursuing a goal as an entity; we advance our goals together as a community. While that was important, it led to something equally if not more important: our vision statement that laid out some of our core areas of focus. Essentially, our vision outlines what patients need and deserve: an understanding of their condition and all available treatment options, an expected standard of care and opportunities for support and connection.

Trudie: In 2020, you wrote an important message about racial disparities in healthcare. How does bias show up in healthcare for PI patients, and how is IDF addressing it?

John: The path to a PI diagnosis can take as long as 15 years, and many members of our community have stories of difficulty getting their diagnosis because they weren't being listened to by healthcare providers. And, most of those people were white and/or otherwise in positions in which they're among the ones who are most likely to be heard. They had access to healthcare and resources. If it's bad for them, what must it be like for those who are more marginalized? Severe combined immunodeficiency newborn screening in

all 50 states has been a great equalizer and has started giving us a clue as to the discrepancies that exist. We're only beginning to get our hands around the issue, but we're trying to learn, establish baseline data and shine a light on the issue. Our strategic objectives over the next five years include working to remove disparities in diagnosis and treatments and to promote more equitable outcomes for all PI patients, not just those with privilege. And we have work to do as an organization; we aim to make sure our own community better reflects the U.S. population.

Trudie: What are some key initiatives for IDF this year?

John: We launched two new initiatives last year that directly addressed issues that were heightened during the pandemic. Protecting the Immunocompromised Collaborative is a joint effort with IDF and four other organizations that are advocating at the federal level to be a collective voice for those with compromised immune systems. Additionally, in response to concerns over the availability of IG therapies, we launched Plasma Hero, which aims to raise awareness about the need for plasma and to celebrate plasma donors. All of our programming has been and will continue to be virtual throughout 2021. One of our large events in 2020 was Rare of the Rare, a virtual summit that focused on the ultra-rare diagnoses that are often overlooked, even in the PI community. We had attendees from several countries, and we will be hosting it again in 2021. And, of course, our largest event, the Primary Immunodeficiency Conference, will be held virtually June 23-26, 2021. We will take advantage of all the lessons learned in holding smaller virtual events over the last year.

Trudie: What motivates and inspires you?

John: Those we've lost. When we went virtual, I took our “The Immune Deficiency Foundation Remembers” plaque from our office. If you're on a Zoom call with me, you'll see it over my shoulder. The needs of our community are so urgent, and I want that to be a daily reminder to me and those I'm interacting with that our issues are ones of life and death.

Trudie: What's the best advice you ever received?

John: “It's a marathon, not a sprint.” We all have to be cognizant of burnout in our personal and professional lives. This goes double for caretakers.

Trudie: What's one thing you wish someone had taught you about living with PI?

John: Treat your mental health like your physical health. Many within our community live with some combination of anxiety, depression, post-traumatic stress disorder, carrier's guilt or survivor's guilt. My personal issue is anxiety. If I had understood how massive a change a small dose of anti-anxiety medicine could make to my day-to-day quality of life, I would have started decades ago. Having a chronic illness is tough, but it's even tougher when you don't get a therapy tune-up or medication when needed.

Trudie: What is your favorite quote?

John: “Be ashamed to die until you have won some victory for humanity.” – Horace Mann 

Editor's note: Just prior to printing this issue, John announced he was stepping down as CEO of IDF to pursue other opportunities.



TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.