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The Patient Inside Us All...

At some point in our lives we have been or will be a patient...and yet we are so much more. We are also parents, aunts, uncles, caregivers, in addition to the roles we embody as leaders in the healthcare ecosystem. We asked the patients interviewed for this second annual Patient Voice issue to define themselves beyond their disease. Their answers — found throughout this month's articles — are inspiring and thought-provoking.

Many of us have the benefit of possessing insights into how the system works, or is supposed to work. But for hundreds of thousands of others who are suddenly — because nobody plans to be sick — thrust into the complex world of clinical development, payer reimbursement, healthcare education, etc. the journey can be daunting.



This special issue is intended to highlight patients' perspectives on a number of trends, challenges, and opportunities that impact their world. We can't thank enough the more than two dozen patients and patient advocates who bravely agreed to share their personal stories. Patients such as Bill Clark who joined the COPD Foundation after receiving what he perceived to be death sentence at 48. It took a wake-up call from a friend to get Bill to begin to start living again. He became educated on his disease and took greater control in how his disease was being managed. Joining John Walsh to help form what is now the COPD Foundation has turned into one of most rewarding experiences of his life. As he says, he is no longer a victim, but a part of the cure.

Today real patients are asking for — even demanding — a realistic portrayal of what it means to be afflicted with a disease: the good, the bad, and the ugly. Whitney Petit, an epilepsy patient and advocate, believes her story could change lives. "I want to tell my whole story — the ugly, messy, raw parts — not just the fluffy, pretty, two-minute clips you see on TV or in a social media ad," she says. "My story is about the long nights battling my condition and the amazing mornings, which give me a story to tell. I would tell it over and over if it meant helping someone fight and push through and make a difference."

Biopharma companies are in a position to internalize these stories and take patients' insights to heart all along the drug development and commercialization continuum. This is a mandate that is particularly important in the rare disease space, where patients and caregivers face unique challenges outside the standard journey of care. Ryan Mason, chief creative officer at closerlook and parent of a child with Kawasaki disease, a rare autoimmune inflammatory condition that affects the blood vessels of young children, says programs can be built to match families who are just beginning the journey with a disease alongside those families who have already traveled that path.

Rick Karl, president of the Cure Tay-Sachs Foundation (CTSFF), understands deeply the pain of a rare disease. When his daughter, Krystie, was 8 months old, he and his partner realized she wasn't keeping up with developmental milestones. After being diagnosed with Tay-Sachs, the couple undertook heroic measures to extend her life. Sadly, the couple lost their daughter when she was just 9. Today, Rick continues his work to help find a treatments for this devastating disease.

Patients are truly the unsung heroes of the healthcare system, and we salute them for their innovative and enduring spirit.

Taren Grom
Taren Grom
Editor

Their word...

DENISE MYSHKO

Managing Editor



Patients are taking a more active role in their own health, and this is reshaping

traditional models of drug development.

ROBIN ROBINSON

Senior Editor



It's not rocket science; pharma needs to partner with patients from bench to bedside

and beyond in order to fill the unmet needs in healthcare.

KIM RIBBINK

Features Editor



Parents are on the frontline in the search for cures and treatments when it comes to rare

diseases.

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- ▶ The Past, Present, and Future of Personalized Medicine
- ▶ Brand Bonds: Agency & Client Connections
- ▶ R&D: Biosimilars
- ▶ Healthcare Businesswomen's Association: Rising Stars & Luminaries
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