



Patient Power

PERSONAL JOURNEYS OF COURAGE

The power of patients is palpable, powerful, and pervasive. Patient-centricity has evolved into patient engagement. The distinction, while subtle, is also palpable, powerful, and pervasive. Engagement requires active participation. Rather than being passively placed in the center of vague initiatives, patients are actively engaging in strategic decisions that affect their health and that of others.

We are proud to publish our fourth annual Patient Voices issue. This special issue is designed to capture the voices of patients as well as track some of the biggest trends surrounding their health journeys.

We all know COVID-19 has cast a long shadow over all aspects of drug development from patient recruitment to clinical trials to basic patient care. However, there are some bright spots. Through the gloom some important advances are emerging, such as a more intense focus on addressing health inequity, improving patient and caregiver education,

embracing virtual care in a more substantive and sustainable way, and capitalizing on DCT or hybrid trials. We look forward to pursuing the dozens of other important patient-focused areas of interest in future issues.

We would like to thank all of the patients who participated in this special issue for sharing their very personal stories — the struggles as well as the triumphs. Their ability to persevere under some of the most trying circumstances is truly inspiring.

We hear from Estela Lugo, whose lifelong struggle with Charcot-Marie-Tooth (CMT) led her to become a patient advocate who is changing drug development. And there's Daniel Garza's moving story and how he became his own best educator, enlightening not only his family but the AIDS community. We can't help but be inspired by Claire Synman's grit and determination as she fought and gained control after being diagnosed with a brain tumor. Dana Deighton's compelling journey

takes us through her diagnosis with Stage 4 esophageal cancer just one year after losing her mother to colorectal cancer. And we can't help but be uplifted by Barby Ingle's overwhelming optimism despite the pervasive pain she contends with day in and day out.

We also hear from Roxanne, who is an MS patient whose podcast *Spilling Tea with Roxy* discusses all thing MS-related; Chien-Chi Huang, a breast cancer survivor, and founder of Asian Breast Cancer Project, and executive director of Asian Women for Health; Monique Gore-Massy, a global and national lupus patient advocate and motivational speaker; Shantana Hazel, who lives with endometriosis and rheumatoid arthritis, and founder of the Sister Girl Foundation; NASH expert Wayne Eskridge, founder of Fatty Liver Foundation, who is shining a light on non-alcoholic fatty liver disease; Cancer Be Glammed breast cancer survivor Lisa Lurie, whose patient experience taught her how important it is to take a holistic view of healing; Judith Mayer, a Stage 4 breast cancer patient, whose patient-support group Breast Cancer Straight Talk has become a beacon of hope; and Stacy Hurt and her son's virtual care journey.

The insights from these patients and their personal journeys have the power to create meaningful change.