WebMD Announces 16th Annual 2023 Health Heroes

Newark, NJ, October 11, 2023 – WebMD announced today the winners of the 2023 WebMD 16th annual Health Heroes Awards, which includes 4 categories: Lifelong Advocate, Patient Pioneer, Selfless Survivor and Driving Force. This year's theme is activism and patient involvement. The winners were involved in disease-based research through awareness, activism or their own nonprofit organizations.

"This year's Health Heroes are not only doing amazing things but they also have data or other measurable results that demonstrate the impact of their work," said Dr. John Whyte, Chief Medical Officer of WebMD, "These inspiring individuals are changing the landscape for patient-led research."

Lifelong Advocate

During the first U.S. wave of COVID-19 in 2020, **Hannah Davis,** a data analyst and generative artist with a focus on tools for countering bias in machine learning datasets, tested positive for COVID. Fully expecting to get better within two weeks, her symptoms persisted — and then got worse.

Driven by a desire to help others with Long COVID, Davis and other Long COVID patients helped to organize the Patient-Led Research Collaborative (PLRC) and put their skills as researchers formally to work.

In April 2020, the PLRC created a survey for Long COVID patients, analyzed the results, and within 9 days produced the first published study of Long COVID. With their findings in hand, they began meeting with public health leadership at the Centers for Disease Control and Prevention, National Institutes of Health, and World Health Organization to forge a path toward more research on Long COVID.

Today, the PLRC has grown to 50 staff and volunteers with expertise in biomedical and participatory research, neuroscience, cognitive science, public policy, machine learning, human-centered design, and health activism.

Patient Pioneer

Victoria Gray's first 33 years of life had been riddled with restrictions, painful crises and heart troubles requiring hospitalization. Gray has sickle cell disease, which is an inherited red blood cell disorder that affects the oxygen-carrying proteins (hemoglobin) in red blood cells, contorting them into a crescent moon shape, making movement through the body and oxygen delivery to tissues difficult.

Then in 2019, Gray met Haydar Frangoul, MD, MS, a hematologist/oncologist and leading sickle cell researcher, who offered her the chance to be the first to take part in a clinical trial for a revolutionary gene-editing therapy using a tool called CRISPR.

Even though Gray would be the first person in the U.S. to try this treatment for a genetic disorder, she didn't hesitate. Frangoul and a team at Sarah Cannon Research Institute and HCA Healthcare's The Children's Hospital At TriStar Centennial in Nashville collected Gray's stem cells, a lab reengineered them, and then he transplanted them back into Gray's bloodstream.

Four years have passed since her treatment, and Gray remains symptom-free. She sees Frangoul every six months to monitor her hemoglobin and check in. Gray has become a public face of CRISPR therapy, speaking to patient and researcher audiences around the world. CRISPR has been tested in at least 75 people since Gray's treatment and could be approved in the United States this year.

Selfless Survivor

Josh Sommer suffered persistent headaches during his first-year at Duke University, which sent him on a diagnostic journey. It was revealed that he had chordoma, a rare bone tumor at the base of the skull that affects only 1 in 100,000 people.

During and after recovery, Sommer pored over medical literature about his condition and made a connection that led Sommer on a new path. A medical oncologist at Duke Cancer Institute, Michael J. Kelley, MD, was a co-author of a paper on the genetics of chordoma. When Sommer returned to Duke, he sought out Kelley to volunteer in his lab. He learned the many hurdles of studying a rare disease.

During this period, Sommer joined an online support group of other chordoma patients and family members who were also motivated to improve the outlook for the disease. Together they brainstormed the idea for the Chordoma Foundation.

Since the foundation's formation 16 years ago, research and clinical trials have evolved immensely. The organization has secured over $20 million in research investments, brought together more than 300 researchers, screened 6,000 drugs against chordoma cell lines and provided free, personalized support for over 3,000 families.

Driving Force

When **Neena Nizar** was a child, doctors attributed skeletal problems she was facing to polio, then later, rickets, both of which she would later learn were incorrect. It would take 32 years, multiple surgeries, and a dogged pursuit of a diagnosis before she found answers.

After earning a bachelor's, master's and a doctorate in education, she and her husband started a family. As her two sons started to grow, she began to notice some worrying signs. Many doctors and one seven-hour drive later, Neena discovered her and her sons are one of about 30 people worldwide facing a rare disease: Jansen's metaphyseal chondrodysplasia, or Jansen's disease.

Her passion and newfound knowledge inspired her to start The Jansen's Foundation — in the six years since, she has helped fund preclinical research and clinical trials at the NIH, which has helped Jansen's patients and medical experts across the world learn more about the rare disease.

For additional information on the 2023 WebMD Health Heroes, click here:
https://www.webmd.com/healthheroes/default.htm

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