



Shauna Whisenton - Credit: Sarah Grille / Mesa7

How a Clinical Trial Participant Became an Advocate for the Sickle Cell Community

Shauna Whisenton was once an individual living with sickle cell disease (SCD). Now she's an advocate for better therapies, a cure, and better understanding of SCD.

Whisenton was born with SCD, a painful, inherited disorder where red blood cells are misshaped, restricting blood flow and oxygen to parts of the body.

"It was all going pretty well until I had my third son," she says. "Then my health started to take a turn for the worse."

While nursing, she was admitted to the hospital every few weeks and despite best efforts, was not replenishing enough fluids for her body to function properly and had major organ complications.

Her doctor asked her to consider a bone marrow transplant clinical trial to cure SCD.

She didn't believe she could be cured and some members of her family were unsure she should undergo the treatment. For many in the minority community, there is a fear that medical testing may exploit patients instead of helping them. However, clinical trial oversights ensure safety during participation.

After consulting an SCD patient advocate, she realized, "Although a cure is not guaranteed, this could be an amazing opportunity. If that is not possible for me, researchers could learn something from my participation to save others."

Finding a donor

The best chance for a donor match would be a family member. Whisenton lost her parents

when she was a child and her sister wasn't a match; but her nine-year-old son, Dorian was a 50% match.

A successful transplant meant a better life for Whisenton and her family.

"I felt like my children had suffered enough watching my pain," she says.

Whisenton's son had marrow extracted from his pelvis bone. It was a one-day procedure for him but the start of a two-year ordeal for his mother.



Journey

Whisenton's journey was tough. She was hospitalized, receiving anti-rejection medications and had to undergo chemotherapy. She persevered with support from family and medical team. For her, treatment beyond the transplant was an important part of procedure preparation and recovery. This included coordinated care to provide relief from the symptoms of her disease and the transplant, including pain and detoxing from opiates, but also the physical and mental stress from the procedure.

"It's important to equip someone who's received a curative therapy with tools to rebuild their lives

during and after recovery," she says.

Within nine months of receiving the bone marrow transplant, Whisenton received the news that she was SCD free and now only carries the trait. Now, 10 years later, her transplant was a complete success.

Whisenton calls the date of her transplant her birthday.

Patient advocate

Whisenton has made it her life's work to help those living with SCD. She's the manager of sickle cell disease community engagement for the ASH Research Collaborative (ASH RC) Sickle Cell Disease Clinical Trials Network (CTN), established by the American Society of Hematology, the world's largest professional society concerned with the causes and treatments of blood disorders.

Whisenton is carrying out the mission of the ASH RC CTN to improve the lives of individuals with SCD by expediting the development of new therapies through innovative clinical trial research. Whisenton ensures that the voice of the patient is heard at all stages of these clinical trials.

"SCD warriors, don't lose hope. There are many treatments in the pipeline to help those living with this disease have a better quality of life. Our hope is that advances in research will bring more effective treatments to individuals living with SCD."

To learn more about how the ASH RC is accelerating progress in hematology, visit: www.ashresearchcollaborative.org.



Clinical Research Participation:

On the frontlines of diversity and inclusion

The importance of clinical research is widely recognized and while many decide to participate in clinical trials, there is a lack of representation of individuals from underserved communities. In 2019 alone, 46,391 individuals participated in clinical trials that resulted in the approval of 48 new drugs, yet a limited number of study volunteers identified as black/African American, Asian, and/or Hispanic.

Current efforts to address this lack of representation include a guidance document released by the FDA encouraging pharmaceutical companies to broaden their eligibility criteria and to recruit individuals from diverse communities and establishing study sites in areas that lack clinical trial opportunities. While these efforts are critical in increasing diversity and inclusion in clinical trials, it is equally important to understand how clinical research is viewed from a broad audience.

Every two years, the Center for Information and Study on Clinical Research Participation (CISCRP) conducts a global online study to gather insights on the public and patients' perceptions and experience with clinical research. Responses from over 12,450 individuals were collected, with representation from many communities, including black (6%), Asian (10%), and Hispanic (13%). These are some highlights that can be applied to promote diversity and inclusion in clinical research studies.

The Importance of Clinical Research

Individuals across many races and ethnicities acknowledge the value of clinical research studies. Many consider clinical trials to be "somewhat/very important" to the discovery and development of new medicines. Additionally, the greatest benefits of participation in clinical research include helping to advance science and the treatment of patient's disease/condition (26 percent) and the possibility of improving or saving the lives of others with the same condition (21 percent). This highlights how individuals perceive and understand the positive impact participation can have – by potentially helping themselves

and others through research. Yet few individuals had recently seen or heard about a clinical trial opportunity, notably 53 percent of Asian and 52 percent of Hispanic individuals did not recall recently learning about an available trial.

Where To Look For Clinical Trials?

Many would begin looking for a clinical trial opportunity by asking their healthcare provider or by using an online resource. For example, over half of black individuals (52 percent) would use an online clinical trial registry, such as clinicaltrials.gov, and 42 percent of Asian individuals would use an internet search engine like Google. Recommendations from family members are also important to underserved populations in their search for clinical trials.

The relationship between healthcare providers and their patients can be leveraged to increase awareness of and participation in clinical trials. It is important to many that their healthcare provider be aware of ongoing clinical trials in their local communities. Additionally, 66 percent of black individuals report being more willing to participate if their own doctor is conducting the trial. However, less than 25 percent of Hispanic and black individuals learn about a clinical trial opportunity through their healthcare providers, highlighting a significant gap between where individuals prefer to learn about clinical research and where they look for opportunities.

Pharmaceutical companies can take an important first step by informing healthcare providers about new clinical trial opportunities in underserved communities. These providers can then share these opportunities with their patients in a trusted and comfortable environment. Recognizing where patients currently begin their search for trial opportunities also presents an opportunity for pharmaceutical companies to target recruitment efforts in these areas to better engage this audience.

To learn more about how CISCRP is educating and informing the public and patient communities about clinical research, visit: www.ciscrp.org