

CLINICAL TRIALS

MEDIA
PLANET

A close-up portrait of Shauna Whisenton, a Black woman with voluminous, curly, reddish-brown hair. She is wearing large, dark red, teardrop-shaped earrings and a black top with a white floral pattern. The background is a solid, muted blue-grey color.

Shauna Whisenton

Follow one woman's journey
from patient to advocate

Here's why female-focused trials for HIV are so important

For patients in clinical trials, caregivers are more important than you think

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

Shauna Whisenton thought she'd live with sickle cell disease for the rest of her life — until one clinical trial changed everything.

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, now 41, 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 con-

sider a bone marrow transplant clinical trial to cure SCD.

Whisenton didn't believe she could be cured and some members of her family were unsure if 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 9-year-old son, Dorian, was a 50-percent 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, received anti-rejection medications, and had to undergo chemotherapy. She persevered with support from family and her medical team. For Whisenton, 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 was SCD-free and now only carries the trait.

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." ■

Kristen Castillo

PHOTO: SARAH GRILLE/MESA7

What Information Matters Most When Deciding to Participate in a Clinical Trial?

In a recent survey, people from around the world provided their thoughts on what they need to know when deciding whether a clinical trial is right for them.

When facing a serious illness, it's natural for patients and their loved ones and caregivers to seek every potential resource. One of the most promising of those resources is often the most intimidating: the clinical trial. While any decision should begin with a conversation with a trusted doctor, people will have different concerns that go beyond the purely medical. Being able to answer these questions can make the decision to participate much easier. That's why the Center for Information and Study on Clinical Research Participation (CISCRP — www.ciscrp.org) recently asked over 12,450 public citizens and patients from around the world for their thoughts about clinical trials.

Universal concerns

The most common concern people expressed is the most obvious. Eighty-one percent of the respondents said knowing the potential risks and benefits of a trial is “very important.” Knowing the purpose of the clinical trial (74 percent) and the types of medical procedures required (71 percent) followed closely. Many people are naturally concerned about how participation in a trial might affect their everyday lives, with 58 percent of respondents noting that potential costs and reimbursements were very important, 57 percent responding they would be concerned about the physical location of the study clinic, and 54 percent considering the duration of the study to be an important factor.

Individual concerns

The journey to clinical trial participation may be paved with uncertainty, but having answers to important questions can help make the decision process a smoother one. The Perceptions and Insights Study helps identify better ways for the public, patients, and clinical research professionals to work together to develop new medical treatments.

Jeff Somers



Understanding the Patient-Centered Approach to Treating Sickle Cell Disease

Sickle cell disease (SCD), the most common inherited blood disorder, affects an estimated 100,000 Americans. It's a painful lifelong disease but clinical trials may help develop new treatments and even find a cure.

SCD, is marked by abnormal hemoglobin protein inside red blood cells, causing those cells to be rigid and C-shaped, like a sickle. These sickle cells can block blood flow to organs and cause severe pain and complications, including organ damage and stroke.

In the United States, it's most common among African American and Hispanic people; however, it can occur in other racial and ethnic groups.

Clinical trials

While there is no cure, currently there are U.S. Food and Drug Administration (FDA)-approved drugs. More than 40 therapeutics are in development to treat or cure SCD. Those new treatments will need to be tested and approved by the FDA for patient use. That means there will be increased need for SCD patients to participate in clinical trials.

“We are entering a new age in SCD research,” says Chuck Chesson, Ph.D., the director of the ASH Research Collaborative (ASH RC) SCD Clinical Trials Network (CTN). “We are all excited to

be a part of finding better treatments for those living with sickle cell disease.”

In 2018, the American Society of Hematology established ASH RC, which launched the SCD CTN to foster expediting therapies and facilitating clinical trial research innovations.

Patient-centered approach

“We are really focused on building a research community within the sickle cell population,” says LaTasha Lee, Ph.D., MPH, senior manager of partnership engagement for the SCD CTN.

Patients and the community don't always realize all medicines need clinical trials to test efficacy and safety, so the CTN is focused on educating the SCD community about clinical trials. They've hosted many in-person community engagement workshops across the country with members of the sickle cell community.

This patient-centered approach is helping patients and their families understand the clinical trials process and ask questions comfortably. The ASH RC encourages the advancement of research that meets the needs of the SCD Community.

“If not you, then who?” a SCD Community Workshop attendee shared. “If no one stands up to participate in clinical trials, we won't have any advancements in the field.” ■

Kristen Castillo