

**Tosin Ola, RN, BSN**

**Founder & President, Sickle Cell Warriors, Inc.** Tosin Ola, BSN, RN

knows firsthand the challenges of living with sickle cell disease. The practicing registered nurse and mother of twin toddlers, launched the Sickle Cell Blog in 2005 to bond with others and share her experience living with



this debilitating and deadly disease. The term “sickle cell warrior” was coined by Tosin in 2005, when she wrote a post that resonated with millions around the world rejecting the word “sickler” and the negative associations with it. To some, it's just words, but people like Tosin recognize that change happens because of words. Many patients adopted this term and it spread into all echelons of the sickle cell community. Her words shifted the dynamics of the provider-patient relationship, restoring dignity and respect in situations where one is often most vulnerable.

A short two years later in 2007, the sickle cell advocate created an online platform – the Sickle Cell Warriors website – to broaden the discussion and give the patient community a much-needed voice. The educational site is the largest collection of articles (over 600) written by Sickle Cell Warriors, those affected directly by sickle cell disease. The Sickle Cell Warriors website is designed to raise public awareness of this complex chronic medical condition, and empower patients a greater level of self-care management, discuss the serious complications of the disease, provide expert advice to patients, share latest research news, spotlight videos, promote SCD events, increase patient engagement and so much more. Also, the portal highlights “Warriors in the Spotlight” - people living with sickle cell disease who share their personal experiences and are a source of inspiration for others.

To complement these efforts, the Sickle Cell Warriors Facebook Page located at [www.facebook.com/sicklecellwarrior](http://www.facebook.com/sicklecellwarrior) supports and encourages members to engage with others going through the same daily struggles. The leading social media channel has connected almost 24,000 members, making it the largest online group of people affected by this disease. Sickle Cell Warriors, Inc. also runs social media channels on YouTube, Twitter, and Instagram.

Tosin strives to create a community where people can feel comfortable asking (and getting answers to), their most pertinent and personal questions related to sickle cell disease. There has not been a topic that Tosin shies

away from or is afraid to address. She is dedicated to presenting positive and uplifting messages about sickle cell to the society, as well as empowering sickle cell patients to take control of their disease and think differently about life with sickle cell. She believes that sickle cell does not define you, and that one can have a beautiful and fulfilling life regardless of sickle cell.

Tosin has worked as a registered nurse in healthcare for over 16 years, squashing the myth that those with sickle cell cannot physically thrive in a professional setting. She has experience in the trauma ICU, telemetry, CCU, oncology, and surgical setting, with leadership in multiple arenas. She also worked for a pharmaceutical company for 3 years on the EPIC-study, a clinical research study for sickle cell disease. Although it did not meet the clinical endpoint, the EPIC study ended up enrolling 388 patients, the largest phase III study ever conducted in sickle cell disease. Tosin has been a public speaker and educator at over 50 sickle cell advocacy events and programs. She is currently in high demand as an accomplished speaker, inspiring teacher, experienced advocate, and passionate community activist for sickle cell disease.

Tosin has partnered with many governmental agencies like the FDA to advance treatments and support for those with sickle cell disease. She has also collaborated with pharmaceutical and research entities to push for advanced cures, provide educational support for numerous clinical trials and fiercely advocate for patients living with sickle cell disease. Sickle Cell Warriors is one-third of the only three national sickle cell disease patient advocacy groups to be a part of the Sickle Cell Disease Coalition [www.conquerscd.org](http://www.conquerscd.org) and one of the founding member partners of the Sickle Cell Community Consortium SC3 [www.SickleCellConsortium.org](http://www.SickleCellConsortium.org).

Part of her accomplishments include the co-creation of the only national patient conference, the Sickle Cell Patient and Family Conference (aka the SCD Warriors Convention) which is now producing its Sixth Edition in the summer of 2019. Visit their website at [www.sicklecellconvention.org](http://www.sicklecellconvention.org) This conference is the first national conference powered by the Sickle Cell Community Consortium [www.sccommunityconsortium.org](http://www.sccommunityconsortium.org) with three revolving patient advocacy organizations annually co-hosting the conferences. The conference is the only national conference that focuses specifically on education for patients and caregivers living with sickle cell disease. This growing national 5-day Conference has been held in the Bahamas (cruise), Atlanta (x2/years), Los Angeles, and Memphis, TN. Visit older editions, 2012-2018 years and including the strategic planning year of 2014 live here at [www.scdconference.org](http://www.scdconference.org) The year 2019 will be in Texas, and 2020 will be in Las Vegas, NV.

Tosin co-developed the VOICE Crisis Alert app, the first sickle cell disease app available in the United States for patients and caregivers living with SCD. The app stores all its data locally on your phone, so its private. In addition to being a crisis pain tracker tool storable for 90 days with an in-app pain diary to share with your health care provider and the ED, the Voice Crisis Alert app has an avatar expression of the pain scale, complete with personalizations. The app has a medical history section and is also a crisis alert notifier to three specified emergency contacts in your phone.

In addition to numerous awards for her advocacy work in the sickle cell community including the nomination in 2011 for Nurse of the Year for the State of Oregon, activist of the year by WegoHealth and patient advocacy award from Wellsphere, Tosin has lent her expertise and been a source for print publications like ESSENCE, Glamour, Minority Nurse, True Shine; online media like the New York Times, U.S. News & World Report, WEGOHealth, Wellsphere, BlogTalkRadio, BioCentury, SF Bay News, Buffalo Times, and many more. Tosin was also featured in 2017 by the National Lung, Heart, Blood Institute in *Today's Faces of Sickle Cell Disease*.

Tosin got her Associate's Degree in Nursing from Oakwood University in Huntsville, AL. In 2018, she was honored to give the commencement address to the nursing graduating class. She has a Bachelor's Degree in Nursing from the University of Phoenix. Currently, Tosin is working on her Master's Degree in Nursing and Master's Degree in Business Administration with an emphasis in Healthcare Management. She serves as an authoritative speaker, sickle cell community educator, professional advocate, rare disease expert, and a reliable source to all media and book authors. Tosin lives in Encinitas, California with her toddler twins and husband. Visit the Sickle Cell Warriors website, or email Tosin directly [Tosin@SickleCellWarriors.com](mailto:Tosin@SickleCellWarriors.com) or [SickleCellWarrior@gmail.com](mailto:SickleCellWarrior@gmail.com)