Sickle Cell Disease Patient & Family Symposium

August 1-5, 2018
Sheraton Downtown Memphis

www.sicklecellconvention.com
Powered By Sickle Cell Community Consortium
WELCOME TO THE 5th ANNUAL PATIENT & FAMILY SICKLE CELL SYMPOSIUM!

We are excited to have your attendance at the 5th Annual Sickle Cell Disease Patient & Family Educational Symposium! This annual meeting has become something of an annual Warrior Family Reunion. We look forward to seeing our fellow warriors, families, healthcare providers, and research scientists from all over the country as we venture forward with our convention this week.

Every year, we gather together in a city chosen by the Sickle Cell community for the opportunity to share our experiences, learn new strategies for life improvement and in making lifelong friends. This weekend presents as an opportune time to recharge yourself, take a break and even enjoy a little vacation as well as meeting and reconnecting with your family in the Sickle Cell Community!

The 2018 Symposium is hosted by the Sickle Cell Foundation of Tennessee, Sickle Cell Champions Association and HOPE for SCD. Over the course of this symposium, we will be joined by experts representing a diverse range of fields, who will provide insight into managing Sickle Cell disease. We invite you to attend and participate in the presentations, breakout sessions, workshops and panel discussions that we have scheduled and are aimed to equip you with the tools needed to live vibrant productive lives.

This year, included in our Symposium are the continuation of the Kids Track, hosted by HOPE for SCD, as well as that of the continued effort to engage the Sickle Cell men within the community, on the part of Sickle M.A.N. and the Sickle Cell Champions Association. Additionally, a mental health track has been added into this year's Symposium, in order to better understand the emotional and psychological impacts and repercussions associated with the experiences of having Sickle Cell Disease. These sessions will be broadcast live during the Symposium.

Friday afternoon has been left completely open to enable participants to enjoy the sights and tourist destinations of Memphis. On Saturday evening, our Warriors will be returning to Wakanda in our Warriors of Wakanda Awards Gala and Prom.

We have an eventful few days ahead of us, complete with educational and memory-making opportunities. Be sure to pace yourselves, stay hydrated, and as always be ready to teach, learn and have loads of fun!!

2018 Symposium Host Committee
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bluebird bio is committed to individuals and families affected by severe genetic diseases and cancer, including severe sickle cell disease, transfusion-dependent β-thalassemia, also known as β-thalassemia major, cerebral adrenoleukodystrophy and multiple myeloma.

Thank you Sickle Cell Community for all that you do for those living with sickle cell disease.

Please visit us at www.bluebirdbio.com to learn more.

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Novartis proudly joins Sickle Cell Community Consortium and the 5th Annual Sickle Cell Patient and Family Education Symposium.

Your dedication to helping patients with Sickle Cell is applauded.

At Novartis, our mission is to discover new ways to improve and extend people's lives. We use science-based innovation to address some of society’s most challenging health care issues. We discover and develop breakthrough treatments and find new ways to deliver them to as many people as possible.

We are passionate about what we do and the impact we have on society, especially patients, including those living with Sickle Cell. We are Novartis, and we are reimagining medicine.
OUR CONFERENCE APP

Using the Mobile Web App

Access the schedule, attendee directory, speaker profiles, and other information about the Symposium on your mobile phone! Easy as 1-2-3!

1. Simply locate the Sched.com App on the Google Play Store or on the Apple Store and install it!

2. Once it’s installed, search for our event by entering “Patient Symposium” in the search bar!

3. Use your Sched.com login and gain access to your schedule and other helpful information about the Symposium!
# AT-A-GLANCE SCHEDULE

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5TH ANNUAL SICKLE CELL PATIENT & FAMILY EDUCATIONAL
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HOPE FOR SCD

Hope for SCD is a Health Literacy NPO that was started by parents of a child with Sickle Cell Disease. Based in Raleigh, NC, we work with consumers, medical providers, and the pharmaceutical industry to increase international access to research based medical education materials. Our mission is to bridge the gap between providers and the lay community through research-based health literacy tools and programs. As our background lies in education, our focus remains solely on the learning connected to this chronic illness from birth through adult. Every person, regardless of educational background should feel empowered to speak up, spread the word, and educate in their community. Accurate, user-friendly literature is key to this if we want to increase the visibility of Sickle Cell Disease.

The Sickle Cell Foundation of Tennessee

The Sickle Cell Foundation of Tennessee (SCFT) is a 501 (C)(3) non-profit organization founded in 2008, by the late Dr. Trevor K. Thompson and Cherry N. Whitehead-Thompson. As an educator (Administrator with Memphis City Schools) and sickle cell disease consumer, Dr. Thompson championed the call for advocacy, educational support and social services for citizens impacted by sickle cell disease in Memphis, across the state of Tennessee, and in the regions of north Mississippi and eastern Arkansas. His efforts have enabled SCFT to provide educational awareness, through direct contact, via television, radio, print, and social media to more than 1,000,000 citizens across the Mid-South area.

The Sickle Cell Champions Association (S.C.C.A.)

The Sickle Cell Champions Association (S.C.C.A.) is a not-for-profit community-based organization (CBO) made up of men and caregivers living with sickle cell disease. Formed as a partner of the Sickle Cell Community Consortium, we were the founding organization of the Sickle Mens Action Network (Sickle M.A.N.). Under the leadership of Clayton Andrews, S.C.C.A. focuses on the empowerment, motivation and overall growth of adolescent males living with sickle cell disease. Five young men with a similar vision and a common cause came together to create a male mentoring program for children and adolescents with Sickle Cell Disease and Sickle Cell Trait. The S.C.C.A. came together as a group of advocates who endure the pain and discomfort of living with (SCD). The S.C.C.A. banded together, as affiliate advocates, to represent a male voice and bring awareness to this disease, to inform the patient, family, and community. The members and officers of S.C.C.A. strive for the mentorship and guidance of the youth that have been stricken with this blood disorder. We have designed a positive mentoring program, to guide the youth through their transitioning years into adulthood.
ABOUT THE CONSORTIUM

In February of 2014, during the FDA Patient-Focused Drug Development Initiative, a group of community-based organization leaders and patient advisors met to lay the foundation of what would become the Sickle Cell Community Consortium. Organized by Dr. Lakiea Bailey, this group made the collective decision to join efforts to create a unified platform to bring the sickle cell patient to the forefront of all matters regarding health, research, advocacy, education and awareness.

Over the span of the 18 months that followed, Dr. Bailey, Velvet Brown-Watts and Kena Drew would build upon this foundation to develop a cohesive, 501(c)(3) not-for-profit, created to harness and amplify the sickle cell patient voice.

Organized in a manner similar to the United Nations, Consortium Partner CBOs from all over the Country retain their individual autonomy, while uniting to apply a model of Collective Impact to tackle deeply rooted social, medial and legislative problems and barriers. The CBOs, along with Community Partners and Patient/Family Advisors, work together to identify and directly address community needs. The General Assembly, comprised of Partner CBOs and Advisors, to form the decision-making body of the Consortium tasked with forming mutually beneficial partnerships to develop and execute strategies and solutions to address the needs, gaps and problems identified by the collective sickle cell community.

Joined by a diverse Board and Staff of patients, caregivers and supporters, the Consortium provides the infrastructure to coordinate the activities of strategic partnerships, provide training and support to Partner CBOs, and push forward collective Consortium platforms and initiatives. Last year, 2015, was focused on organizing and providing support for patients and families to “Show Up and Speak Up” at sickle cell and/or rare patient meetings and conferences. In 2016 we will build upon this by also working to actively further sickle cell research and clinical trials through our Patient-Centered Outcomes Initiative (PCOI 2016).
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2018 AWARDS GALA & PROM

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