Sickle Cell Warriors, IASNAPA, and Sickle Cell 101

presents

SICKLE CELL DISEASE

Patient & Family Symposium

THURS to SUN
July 28-31, 2016

LOEWS HOLLYWOOD HOTEL
1755 Highland Ave,
Los Angeles, CA 90028

Theme: “Spirit Indestructible”
Inspired by @SCAF_Nigeria

www.sicklecellconvention.com

Powered by Sickle Cell Community Consortium
Welcome
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Thank You to Our Sponsors

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Global Blood Therapeutics

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ONLINE MEDIA INTERACTIVE

Marrow for Life

St. Jude Children's Research Hospital

Prolong Pharmaceuticals

ALASC - Danny Thomas, Founder
At-A-Glance

THURSDAY, JULY 28

- Registration
- Peer Navigators
- Opening Reception
- Visual Explorers
- Warriors After Dark | Insomniacs Cafe

FRIDAY, JULY 29

- Plenary
- Breakout Sessions
- Lunch
- Breakout Sessions
- Warriors After Dark

SATURDAY, JULY 30

- Parenting Issues from Birth to Adult
- Caring for the Caregiver
- Plenary
- CBO & Research Spotlights
- Physician Education in the Emergency Department
- Get Connected
- Patient-Powered Sickle Cell Literature Project
- FSCDR
- Abstract 1
- Abstract 2
- Abstract 3
- Lunch
- Breakout Sessions
- Awards Gala

SUNDAY, JULY 31

- Breakfast with the Warriors
- Closing & Business Meeting
- Advocacy Training and Certification
About the Hosts

Sickle Cell Warriors, Inc.

Sickle Cell Warriors, Inc. (SCW) is a non-profit charitable organization dedicated to education, empowerment, and awareness about sickle cell disease. Our mission is to inspire those affected by sickle cell and educate the public on sickle cell disease.

Over the last 7 years, SCW has grown into a dynamic community with over 18,000 members. We are the largest patient-run sickle cell community-based organization on Earth and have members from almost every single country in the world. We are predominantly web-based. This gives us the ability to interact regularly with our community, gather valuable intel, receive almost-instant feedback, and engage our users across multiple platforms, countries, and demographics.

We have several projects, classes, and events throughout the year that focus on our core mission pillars. Most notably the Advocacy Training Program, Mentorship Program, Warriors Annual Gathering (in July of every year), and our collection of classes and challenges geared toward educating our community. We also have several strategic partners, sponsors, and events throughout the year in various cities across the world.

International Association of Sickle Cell Nurses and Physician Assistants

IASCNAPA is committed to strengthening the relationship between nurses and physician assistants who care for patients with sickle cell disease. Nurse and physician assistants make significant contributions that further the depth of knowledge about sickle cell disease. Our cooperative efforts allow us to play vital roles in clinical research as demonstrated by our participation in NIH studies that have defined the natural history of sickle cell disease and proven the efficacy of prophylactic penicillin for children with the disease.

The Association strives to unite and organize sickle cell nurses and physician assistants throughout the world in order to benefit professionals and patients, while establishing guidelines for standards of nursing care for individuals with sickle cell disease. IASCNAPA also supports the development of research protocols that surface during sickle cell studies funded by governmental or private agencies.
About the Hosts

Sickle Cell 101

Sickle Cell 101 (SC101) is a 501(c)(3) non-profit organization educating all people affected by sickle cell through the use of social media. The SC101 team consists of certified sickle cell educators and expert physicians within the field of hematology.

SC101’s main outlets include their social media platforms, website (sc101.org), and online newsletter. SC101’s information is liked, commented on, shared, and reposted, and any given one of their posts can reach up to 50,000 users. Their information is accessed by followers from over 72 countries on six continents.

SC101’s “social media education” program, is comprised of quick sickle cell facts with supporting graphics, perfect for those looking to learn more about sickle cell in a quick and condensed manner. Additional programs include “Ask Dr. Q, the Sickle Cell & Thalassemia Expert Physician”, which is a popular resource to patients who don’t have access to a sickle cell doctor; and the Sickle Cell Advocate of the Year Awards, which recognizes sickle cell advocates making a difference in the sickle cell community.

In addition to the web-based programs, SC101 also provides sickle cell education in local schools, sickle cell camps, seminars, CEU courses, and within the workplace.
Planning Committee

**Lakiea Bailey, PhD**  
Executive Director  
Sickle Cell Community Consortium  
director@sicklecellconsortium.org

**Yvonne Carroll, RN, JD**  
President  
IASCNAPA  
yvonne.carroll@stjude.org

**Pat Corley, RN**  
Director  
IASCNAPA  
patcorle@usc.edu

**Jew-EL Darbone**  
Chief Financial Officer & Co-Founder  
#BoldLipsForSickleCell  
jeweldarbone.blfsc@gmail.com

**Kimberly Davis**  
Administrative Coordinator  
Sickle Cell Community Consortium  
kdavis@sicklecellconsortium.org

**Tosin Ola, RN**  
Founder & President  
Sickle Cell Warriors, Inc.  
tosin@sicklecellwarriors.org

**Cassandra Trimnell**  
President & Founder  
Sickle Cell 101  
ctrimnell@sc101.org

**Shamonica Wiggins**  
Chief Executive Officer & Co-Founder  
#BoldLipsForSickleCell  
shamonicawiggins.blfsc@gmail.com
## Agenda

### THURSDAY, JULY 28

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>1:00 pm – 5:00 pm</td>
<td>Registration</td>
<td>Echo Park Foyer</td>
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<tr>
<td>2:00 pm – 4:00 pm</td>
<td>Peer Navigators Ify Osunkwo MD, MPH</td>
<td>Echo Park</td>
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<tr>
<td>4:00 pm – 5:00 pm</td>
<td>Opening Reception Sponsored by St. Jude Children’s Hospital</td>
<td>Echo Park Foyer</td>
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<tr>
<td>5:00 pm – 7:00 pm</td>
<td>Visual Explorers Station-to-station effective communication strategies (role-playing) and activities</td>
<td>Echo Park</td>
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<tr>
<td>10:00 pm</td>
<td>Warriors After Dark Hosted by #BoldLipsForSickleCell Insomniacs Cafe: Games and drinks after dark (limited drinks)</td>
<td>TBA</td>
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### FRIDAY, JULY 29

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>10:00 am – 11:00 am</td>
<td><strong>Plenary: Sickle Cell Warrior - Spirit Indestructible</strong> Tosin Ola-Weissmann, RN</td>
<td>Echo Park Foyer</td>
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<tr>
<td></td>
<td><strong>BREAKOUT SESSIONS</strong></td>
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<tr>
<td>11:00 am – 11:30 am</td>
<td><strong>Understanding Gene Therapy</strong> Brian Robinson, MD</td>
<td>Silver Lake</td>
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<tr>
<td>11:30 pm – 12:00 pm</td>
<td><strong>Navigating the Adult Healthcare System</strong> Coretta Jenerette, DNP</td>
<td>Silver Lake</td>
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<tr>
<td></td>
<td><strong>Navigating the Pediatric Healthcare System</strong> Tandua Washington, MD</td>
<td>Trousdale Estates</td>
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www.sicklecellconvention.com
FRIDAY, JULY 29 (cont’d)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>12:00 pm – 12:30 pm</td>
<td><strong>Understanding Bone Marrow Transplant</strong>&lt;br&gt;Yvonne Carroll, RN, JD</td>
<td>Silver Lake</td>
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<td></td>
<td><strong>Traditional Herbal Medicine: Lessons from Nigeria</strong>&lt;br&gt;Lakiea Bailey, PhD</td>
<td>Trousdale Estates</td>
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<tr>
<td>1:00 pm – 2:00 pm</td>
<td><strong>LUNCH</strong> Sponsored by Global Blood Therapeutics</td>
<td>Elysian Park</td>
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<td></td>
<td><strong>BREAKOUT SESSIONS</strong></td>
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<tr>
<td>2:00 pm – 3:00 pm</td>
<td><strong>Professional’s Roundtable</strong></td>
<td>Silver Lake</td>
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<td></td>
<td><strong>Parent-To-Parent Roundtable</strong></td>
<td>Trousdale Estates</td>
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<tr>
<td>3:00 pm – 4:00 pm</td>
<td><strong>Couple’s Roundtable</strong></td>
<td>Silver Lake</td>
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<td></td>
<td><strong>Transition with Power</strong></td>
<td>Trousdale Estates</td>
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<tr>
<td>4:00 pm – 5:00 pm</td>
<td><strong>Mental Health Roundtable</strong></td>
<td>Silver Lake</td>
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<tr>
<td>9:00 pm</td>
<td><strong>Warriors After Dark</strong>&lt;br&gt;For men hosted by Dr. Trevor Thompson,&lt;br&gt;For women hosted by Dr. Tandua Washington</td>
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## Agenda

**SATURDAY, JULY 30**

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<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>9:00 am – 9:30 am</td>
<td><strong>Parenting Issues from Birth to Adult</strong>&lt;br&gt;Adrienne Bell-Cors</td>
<td>Trousdale Estates</td>
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<tr>
<td>9:30 am – 10:00 am</td>
<td><strong>Caring for the Caregiver: Dealing with Burnout &amp; Guilt</strong>&lt;br&gt;Velvet Brown-Watts</td>
<td>Trousdale Estates</td>
</tr>
<tr>
<td>11:00 am – 11:15 am</td>
<td><strong>Plenary: Using Our Voice to Influence Research &amp; Policy</strong>&lt;br&gt;Lakiea Bailey, PhD</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>11:00 am – 11:15 am</td>
<td><strong>COMMUNITY BASED ORGANIZATIONS &amp; RESEARCH SPOTLIGHTS</strong></td>
<td></td>
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<tr>
<td>11:00 am – 11:15 am</td>
<td><strong>Physician Education in the Emergency Department</strong>&lt;br&gt;Kirshma Khemani MD</td>
<td>Silver Lake</td>
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<tr>
<td>11:15 am – 11:30 am</td>
<td><strong>Get Connected</strong>&lt;br&gt;Asabi Jeter</td>
<td>Silver Lake</td>
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<tr>
<td>11:30 am – 11:45 am</td>
<td><strong>HBCU Sickle Cell College Tour</strong>&lt;br&gt;Jew-EL Darbone</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>11:45 am – 12:00 pm</td>
<td><strong>Patient-Powered Sickle Cell Literature Project</strong>&lt;br&gt;Cassandra Trimnell</td>
<td>Silver Lake</td>
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<tr>
<td>12:00 pm – 12:15 pm</td>
<td><strong>Foundation for Sickle Cell Disease Research</strong>&lt;br&gt;Lanetta Bronte, MD</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>12:15 pm – 12:30 pm</td>
<td><strong>Sickle Options</strong>&lt;br&gt;Diana Ross, MSN, RN</td>
<td>Silver Lake</td>
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<tr>
<td>12:30 pm – 12:45 pm</td>
<td><strong>Sickle Cell Awareness Across the Curriculum</strong>&lt;br&gt;Judy Johnson</td>
<td>Silver Lake</td>
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## Agenda

### SATURDAY, JULY 30 (cont’d)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>12:45 pm – 1:00 pm</td>
<td><strong>Sickle Cell Community Consortium</strong>&lt;br&gt;Lakiea Bailey, PhD</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>1:00 pm – 2:00 pm</td>
<td><strong>LUNCH</strong> Sponsored by Emmaus, Mast, Pfizer</td>
<td>Elysian Park</td>
</tr>
<tr>
<td>2:00 pm – 2:30 pm</td>
<td><strong>The Science of Sickle Cell</strong>&lt;br&gt;Julie Kanter MD</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>2:30 pm – 3:00 pm</td>
<td><strong>Workers Rights/Navigating the Workplace</strong>&lt;br&gt;Yvonne Carroll RN, JD</td>
<td>Silver Lake</td>
</tr>
<tr>
<td>3:00 pm – 3:30 pm</td>
<td><strong>Traveling with Sickle Cell</strong>&lt;br&gt;Tandua Washington, MD</td>
<td>Trousdale Estates</td>
</tr>
<tr>
<td>3:30 pm – 4:00 pm</td>
<td><strong>Eating for Health</strong>&lt;br&gt;T.J. Brown</td>
<td>Silver Lake</td>
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<tr>
<td></td>
<td><strong>School: 504 Plan/IEP</strong>&lt;br&gt;N. Peterson, V. Brown-Watts, L. Toure</td>
<td>Trousdale Estates</td>
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</tbody>
</table>
# Agenda

## SATURDAY, JULY 30 (cont’d)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>7:00 pm – 10:00 pm</td>
<td><strong>Sickle Cell Stars Awards Gala</strong>&lt;br&gt;Hosted by Sickle Cell 101</td>
<td>Elysian Park</td>
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## SUNDAY, JULY 31

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>9:00 am – 11:00 am</td>
<td><strong>Breakfast with the Warriors</strong>&lt;br&gt;Sponsored by ProLong</td>
<td>Elysian Park</td>
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<tr>
<td>11:00 am – 11:30 am</td>
<td><strong>Closing &amp; Business Meeting</strong></td>
<td>Echo Park</td>
</tr>
<tr>
<td>12:00 pm – 4:00 pm</td>
<td><strong>Advocacy Training &amp; Certification</strong></td>
<td>Echo Park</td>
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Speaker Profiles

Lakiea Bailey, PhD | Executive Director, Sickle Cell Community Consortium
director@sicklecellconsortium.org

Traditional Herbal Medicine: Lessons from Nigeria
Plenary: Using Our Voice to Influence Research & Policy
Sickle Cell Community Consortium

Adrienne Bell-Cors | Co-founder, Axis Advocacy
adrienne@axisadvocacy.org

Parenting Issues from Birth to Adult
This presentation outlines issues and solutions faced by parents as they support their children living with sickle cell disease.

Lanetta Bronte, MD | Founder, FSCDR
lanetta
Foundation for Sickle Cell Disease Research
Speaker Profiles

T.J. Brown  |  President, Sickle Cell Natural Wellness Group, Inc.
sccantstopme@gmail.com

Eating for Health
Sickle cell diet and wellness

Velvet Brown-Watts, MSQ, CM  |  Chairperson, Supporters of Families with Sickle Cell Disease, Inc.
swithsicklecell@att.net

Caring for the Caregiver
“Often times, we focus so much on the needs of others, we do not think about resetting and recharging ourselves, and soon, we find ourselves crippled and overwhelmed under the strain of caregiving. How to we recharge or reset ourselves?”

Yvonne Carroll, RN, JD  |  President, IASCNAPA
yvonne.carroll@stjude.org

Understanding Bone Marrow Transplant
Understanding Bone Marrow Transplant for sickle cell disease
a) To understand the different types of bone marrow transplant for sickle cell disease
b) to understand the complications of bone marrow transplant for sickle cell disease

Workers Rights/Navigating the Workplace
You have sickle cell disease; what are your rights in the workplace?
a) To understand the American with Disabilities Act (ADA) as it affects people with sickle cell disease in the workplace
b) Applying workplace accommodations for people with sickle cell disease
Speaker Profiles

Jew-EL Darbone | CFO & Co-Founder, #BoldLipsForSickleCell
jeweldarbone.blfsc@gmail.com

HBCU Sickle Cell College Tour
Presentation on #Boldlipsforsickle & Sickle Cell 101 HBCU college tour. What it is? Why we need it? Where we are headed? What it will accomplish!

Gary A. Gibson | President/CEO, Martin Center Sickle Cell Initiative
ggibson@themartincenter.org

Keynote Speaker at Sickle Cell Stars Awards Gala
"Touch and Inspire"

Coretta Jenerette, DNP | Director, IASCNAPA
jenerett@email.unc.edu

Navigating the Adult Healthcare System
In order to manage both chronic and acute aspects of living with sickle cell disease, individuals often have to enter a complex healthcare system. The presentation will include strategies to assist the adult living with sickle cell to navigate the healthcare system. The audience will understand the importance of sickle cell knowledge, knowing your body, and strategies to communicate health care needs.
Speaker Profiles

Asabi Jeter
Get Connected

www.scerinc.org

Sickle Cell Awareness Across the Curriculum
The purpose of the Curriculum Development Guide is to provide guidelines for educators and support for our students as they navigate the challenges of their studies and interact with their peers. While we don't want to single a child out for attention, these lessons lends itself to feelings of value and importance. It also increases the likelihood that their peers will be less likely to target others for bullying for being different.

Charles Jonassaint PhD, MHS | University of Pittsburgh, Dept of Medicine

Mental Health and Stress Management
1) The types of mental health condition affecting patients with SCD
2) Prevalence estimates of these conditions and the potential causes
3) Link between mental health/stress and pain
4) What symptoms do I need to look out for? When is it time to consult someone (e.g. my physician or a psych professional)?
5) What is psychotherapy all about? What should I expect?
6) Mental health/Stress management interventions you can do on your own?
Speaker Profiles

Julie Kanter, MD  
kanter@musc.edu

The Science of Sickle Cell  
Discussing the current understanding of the pathophysiology of sickle cell disease and how that relates to new and upcoming therapies.

Kirshma Khemani, MD.  |  Emory University/AFLAC Cancer & Blood disorders Center, Pediatric Bone Marrow Transplant Division

Physician Education in the Emergency Department  
Providing education and Quality Improvement Strategies for Pediatric Emergency Department Physicians on sickle cell pain crisis based on NIH guidelines.

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

Plenary: Sickle Cell Warrior - Spirit Indestructible
Speaker Profiles

Ify Osunkwo MD, MPH  |  Medical Director & Adult Sickle Cell Program Carolinas Healthcare System / Levine Cancer Institute;  Associate Professor, UNC at Chapel Hill

Peer Navigators
The power of peer to peer navigation in successfully coping with transition into adulthood as an individual affected by sickle cell disease

Nikki Peterson, Velvet Brown Watts, and Lisa Dean Toure

School: 504 Plan/IEP

Brian R. Robinson, MD  |  Vice President, Medical Affairs, bluebird bio

Understanding Gene Therapy
A short introduction to human genetics and gene therapy.
**Speaker Profiles**

**Diana Ross, MSN RN | Research Coordinator, Emory University**
diana.ross@emory.edu

**Sickle Options**
Decision Making regarding treatment of Sickle Cell Disease

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**Jeremy Shepard**

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**Cassandra Trimnell | President & Founder, Sickle Cell 101**
ctrimnell@sc101.org

**Patient-Powered Sickle Cell Literature Project**
An overview of the Patient-Powered Sickle Cell Literature Project, a collaborative effort to engage the sickle cell community to create sickle cell literature by us, for us. Literature provides a comprehensive understanding of the disorder, and will be distributed to health institutions densely-impacted with sickle cell nationwide.

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**Tandua Washington, MD | General Pediatrician, TSPMG**

**Navigating the Pediatric Healthcare System**

**Traveling with Sickle Cell Disease**
About the Sickle Cell Community 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) non-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, 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).
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 you that you do for those living with sickle cell disease.

Please visit us at www.bluebirdbio.com to learn more.
Global Blood Therapeutics (GBT) is dedicated to developing therapies to transform the treatment of patients with severe blood disorders, including sickle cell disease.

GBT440, is a novel, oral, once daily therapy for sickle cell disease (SCD) in clinical trials. Designed to inhibit red blood cell sickling, GBT440 has the potential to treat the underlying cause of SCD.

We hope you will join us for lunch on Friday July 29th for a discussion of GBT440 and the clinical trial process.

Please visit us at www.globalbloodtx.com for more information