2017 LEADERSHIP SUMMIT & GENERAL ASSEMBLY

EXECUTIVE SUMMARY

Atlanta Marriott Perimeter Center
246 Perimeter Center Pkwy NE
Atlanta, GA 30346

March 16 – 19, 2017
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CONSORTIUM PARTNERS

CREDENTIALED CBOs

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JUNIOR CBOs

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Sutanna C Goode  Monica Rockwell
Matalia Liptrot  Charly Richard
Clarissa Pearson  Nicole C Surjit
Tyler Edwards  Kristi Gayle Hicks
Earliene Liptrot  Teonna L Woolford
Maria Elena Rivera  Shirley Miller, MA
Shabreon Howard  LaToya Tucker
Jazmine Alexis Rivera  Nathaniel Gantz
Alexis J. Wardlow  Jalecia Gantz
Ulysse Guerrier  Lashawn Hutchinson
Stephanie Davis  Tayla Dozier
Brandi Rogers
Marcus McKinley
Lewis Perry IV
Minimarie Andrews
Kentina Moore
K. Moore-Mitchell
Hertz Nazaire
MEETING OBJECTIVES

1. Workshops and training sessions on Best Practices for maintaining strong, effective CBOs.
2. General Assembly of Patients, Caregivers and CBOs
   a. Discuss and prioritize topics placed on the General Assembly Docket
   b. Discuss top three (3) priorities in greater detail, collectively define patient-powered solutions to each priority, and form Special Project Committees comprised of CBOs, advocates and community and corporate partnerships, best equipped to execute solutions.
      i. Chair of each Special Project Committee works closely with the committee to develop a full proposal for each priority.
      ii. Committee engages the larger patient community to develop and execute proposed solutions.
3. Business Meeting – Discuss, vote or table amendments, addendums and other issues related to the Consortium.

AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>1:00 PM</td>
<td>PRESS CONFERENCE: FAIR TREATMENT IN U.S. HOSPITALS &amp; CLINICS</td>
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<tr>
<td>2 PM – 4 PM</td>
<td>OPENING OF THE 2ND SESSION OF THE GENERAL ASSEMBLY</td>
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<td>A GUIDE TO LIVING WITH SICKLE CELL: PATIENT-POWERED LITERATURE</td>
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<td>TACKLING TRANSITION: THE TRANSITION WORKGROUP</td>
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<td>ENGAGING THE YOUNG SICKLE CELL MALE: MENS MENTORSHIP</td>
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<td>SOCIAL MEDIA PRIORITY REVIEW</td>
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<td>SHOW UP AND SPEAK UP FOR SICKLE CELL</td>
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<td>4 PM – 5 PM</td>
<td>OPENING RECEPTION</td>
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<td>5 PM – 8 PM</td>
<td>BEST PRACTICES I: A NEW PLAYBOOK: LEADING THE FIGHT AGAINST SICKLE CELL WITH DIGITAL VISUAL CONTENT</td>
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<td>STORYTELLING WITH HIGH-QUALITY VISUAL MEDIA</td>
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<td>MEDIA LAW AND ETHICS</td>
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FRIDAY, MARCH 17
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<th>Time</th>
<th>Session</th>
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<tr>
<td>9 AM – 10 AM</td>
<td>BREAKFAST</td>
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<td>10 AM – 1 PM</td>
<td>BEST PRACTICES II: CAPACITY BUILDING FOR CBOs</td>
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<td>WHAT’S YOUR PASSION? YOUR NONPROFIT CAN TURN A PROFIT</td>
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<td>PCORI’S EFFORTS WITHIN THE SICKLE CELL COMMUNITY</td>
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<td>HOSPITALS ARE FROM MARS, CBOs ARE FROM VENUS: ENGAGING CBOs IN RESEARCH</td>
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<td>BE THE MATCH: INCREASING ACCESS TO BONE MARROW TRANSPLANT FOR SICKLE</td>
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<td>CELL DISEASE</td>
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<td>1 PM – 2 PM</td>
<td>LUNCH* SPONSORED BY GLOBAL BLOOD THERAPEUTICS</td>
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<td>2 PM – 5 PM</td>
<td>GENERAL ASSEMBLY I</td>
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**SATURDAY, MARCH 18**

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<th>Time</th>
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<tr>
<td>9 AM – 10 AM</td>
<td>BREAKFAST</td>
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<td>10 AM – 1 PM</td>
<td>GENERAL II</td>
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<td>1 PM – 2 PM</td>
<td>LUNCH: LAUNCH OF THE PATIENT-POWERED CLINICAL TRIALS INITIATIVE</td>
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<td>PATIENT SAFETY: THE MOST IMPORTANT ASPECT OF EVERY CLINICAL TRIAL</td>
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<td>CLINICAL TRIALS ROUNDTABLE</td>
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<td>4 PM – 6 PM</td>
<td>BUSINESS MEETING</td>
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**SUNDAY, MARCH 19**

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<tr>
<td>9 AM – 10 AM</td>
<td>BREAKFAST: COLLABORATING WITH YOUR HEALTHCARE AND ACADEMIC PARTNERS ON</td>
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<td>GRANT APPLICATIONS: HOW AND WHY</td>
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<td>10 AM – 12 PM</td>
<td>BEST PRACTICES III: DIGITAL CONTENT WORKSHOP</td>
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<td>10 AM – 12 PM</td>
<td>BEST PRACTICES IV: THE BUSINESS OF RUNNING A CBO</td>
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<td>THE IMPORTANCE OF DIGITAL TRANSFORMATION IN THE NONPROFIT SPACE</td>
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<td>CONSORTIUM PROPOSALS &amp; GRANTS; CREATING SPONSOR PACKAGES &amp; RFFs</td>
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<td>EFFECTIVE ACCOUNTING PRACTICES FOR NON-PROFITS</td>
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EXECUTIVE SUMMARY

The seated partners of the Second Session of the Sickle Cell Community Consortium’s Leadership Summit and General Assembly of Patients, Caregivers and CBOs convened on Thursday, March 16th at the Atlanta Marriott Perimeter Center in Atlanta, Georgia. The Summit began with a Press Conference to announce the launch of the Fair Treatment for Warriors initiative, followed by a review of 2016 outcomes and priority progress reports. Best Practices presentations and workshops focused on capacity building, fiscal sustainability and the business of running a CBO. General Assembly I and II defined new Consortium priorities and the Business Meeting convenience to further develop Consortium infrastructure. Partner Services were available throughout the duration of the Summit.

PRESS CONFERENCE

Justice For Warrior: Improved Treatment for Sickle Cell Patients in U.S. Hospitals and Clinics
#TakingOurStand

“Of all the forms of inequity, injustice in Health Care is the most shocking and inhumane!”
- Dr. Martin Luther King Jr.

The Summit began with a Press Conference focused on shining a light on consistently poor treatment experienced by individuals living with sickle cell disease. The patients, caregivers, advocates and community-based organizations of the Sickle Cell Community Consortium joined forces to launch “JUSTICE FOR WARRIORS: IMPROVING CARE IN U.S. HOSPITALS AND CLINICS” and announce the formation of the National Sickle Cell Disease Task Force for Improved Care in U.S. Hospitals and Clinics. The story was picked up by three news agencies including Atlanta’s FOX 5.

A call was issued for all patients, advocates, community leaders, legislative champions and medical allies to join in the fight to stand against the culture of injustice, cruelty and mistreatment of adults with sickle cell throughout the U.S. Footage from the Press Conference aired numerous times over the course of 8 days. Full footage was shot by the videographer hired by our PR firm and will be uploaded onto the Consortium YouTube page. Appendix A
Full engagement and participation by sickle cell patients and caregivers is necessary in assuring the success of any sickle cell initiative, program or platform. We believe that the patient and caregiver must be central in all areas of research, legislation, education, advocacy and policy. We do this in part by strengthening CBO infrastructure, preparing each to become full partners in local and national initiatives, providing the tools for strong community engagement and interaction.

The 2017 Leadership Summit included Best Practices presentations and workshops, along with an array of Partner Services, to further this objective.

**Best Practices I: A New Playbook: Leading the Fight Against Sickle with Digital Visual Content**
The objective of this multi-session mini-series was to increase the media literacy of all participants by offering a solid foundation of basic knowledge and technique that will aid in the creation of visually appealing digital content that is on par with industry standards, using resources already available. These sessions covered media law and ethics, quality and standards, and fostering a loyal audience.

**Best Practices II: Capacity-Building for CBOs**
These morning sessions, taught by a diverse range of experts in the nonprofit sector, are devoted to providing lessons and workshops on building strong community-based, not-for-profit organizations.

**Best Practices III: Digital Content Workshop**
This program was designed to be a panel presentation and a multi-session workshop that takes place throughout our 2017 Leadership Summit and General Assembly. The presentation portion focused on the creation of digital visual content and was broken up into three umbrella topics: media law and ethics, storytelling with high-quality visual media, and fostering a loyal audience. Participants had access to the Creative Content Lab for hands-on experience with studio-quality film and photography equipment.

**Best Practices IV: The Business of Running a CBO**
This session focused on proposal development, budgets and requests for funds (RFFs).

**Partner Services**

**Headshots with Jamie Starr of Xcintric Media, LLC**
A headshot is a good opportunity to make a lasting impression in a professional manner. Jamie Starr of Xcintric Media will be on site to capture headshots photography for each partner. The image will be available to save on your Consortium flash drive the following day.

**Sickle Cell Voices with Story Corps**
StoryCorps Atlanta as part of the Consortium Sickle Voices Initiative. The mission of StoryCorps is to preserve and share humanity’s stories in order to build connections between people and create a more just and compassionate world. This project will continue throughout the year.

**Accounting Consultations with Doris Bailey and Eric Frempong, CPA**
Sign-up for a 30 minute one-on-one session with the Consortium’s Director of Finance. Come prepared to ask specific questions related to your CBOs. Non-profit 990s are due soon. This is an excellent opportunity to get your questions answered.
Digital Content Check-Ups with Pat Smith of Online Media Interactive
These 30 min one-on-one consultations with Patricia Smith will review your website and/or social media profiles to ensure full optimization and utilization, and how to best cater to your web-based audience.

Product Placement and CBO Branding Photos with Jamie Starr of Xcintric Media, LLC
Bring your CBO merchandise and models to obtain professional photography for your websites, publications and social media profiles. We will not be providing hair and make-up during these photography sessions. Come ready to shoot and go.

CBO Spotlights with Minimarie Andrews
Minimarie Andrews of Purpose-Filled Mommy will be on-site to capture CBO profile videos. Copies of these videos will be available for CBO use and may appear as a spotlight in Consortium media projects. Sign-up for your spotlight interview at registration.

Creative Content Laboratory Open Space
Lights. Camera. Action! Participants of the Digital Content Workshop will have access to the lights, cameras and backdrops in the Creative Content laboratory. Use of this space will be explained during the opening digital content best practices session.
CLINICAL TRIALS INITIATIVE

Improving Patient Participation & Engagement in Clinical Trials

African Americans represent 12% of the U.S. population but only makeup 5% of clinical trial participants. The ethnic diversity gap is visibly greatest when you look at clinical trials aimed at diseases disproportionately affecting minority communities (ex. Sickle cell disease). It is important to identify context-specific, culturally shared and distinct factors that deter or enhance patient participation in clinical research.

In response to this, the patient, caregiver and CBO network of the Sickle Cell Community Consortium created a Clinical Trials workgroup and subsequently launched the Clinical Trials Initiative. Led by Dr. Marie Ojiambo, this patient-powered initiative will apply the collective power of the patient, caregiver and CBO General Assembly to define patient-identified barriers to minority participation in clinical trials.

The main/specific aims of this work stream are to:

- Define and understand patient-identified barriers to minority participation in clinical trials.
- Address and help bridge these barriers so as to:
  - Increase enrollment of patients suffering the disease in clinical trials.
  - Better communicate the importance of participating in clinical trials.

This initiative is launched as part, and in continuation, of the Patient-Centered Outcomes Initiative (PCOI), launched March 2016. Under the guidance of Dr. Rayona Lawrence, PCOI was established to directly involve patients and caregivers in topic generation and prioritization for Patient-Centered Outcomes Research and in patient-focused development of alternative endpoints and surrogate markers in clinical trial design. The Clinical Trials Initiative is part of this on-going effort.

Launch of the Sickle Cell Community Consortium Clinical Trials Initiative | Marie Ojiambo, Lakiea Bailey, PhD

Patient Safety: The Most Important Aspect of Every Clinical Trial | Jeffrey Keefer MD, PhD
GENERAL ASSEMBLY
The General Assembly is the primary organ and decision-making body of the Consortium and is comprised of patient and caregiver community leaders and the leadership of credentialed CBOs, junior CBOs and sponsored patient organizations. This group is tasked with defining and prioritizing top needs and gaps within the sickle cell community; developing community-based/patient-powered solutions; and identifying the CBOs, community and corporate partnerships best equipped to execute those solutions. Working in partnership with healthcare/research advisers and community partners, members of the General Assembly then lead the teams dedicated to tackling each priority. Submissions to the General Assembly Docket were accepted electronically via Google Forms. The Docket closed end of day, March 1, 2017.

Appendix B

General Assembly I
A full quorum is met; however, unequal representation patient/caregiver to CBO.

Docket Items
1. SICKLE CELL TRIGGERS
   Submitted by: Monica Rockwell, Patient Advocate

2. PATIENT EDUCATION MODULES
   Submitted by: Shirley Miller, MA, Patient Advocate

3. DEVELOPMENT OF A PATIENT DRIVEN NATIONAL AGENDA
   Submitted by: Kenneth Del Carson

4. PRAYER WARRIORS
   Submitted by: Kenneth Del Carson, Patient Advocate

5. SICKLE CELL ANTHOLOGY
   Submitted by: Kadeem Gayle, Patient Advocate

6. OPIOID ADDICTION
   Submitted by: Marjorie Dejoie (Dr Dej), CBO Partner, Provider

7. NUTRITION AND SICKLE CELL DISEASE
   Submitted by: Marjorie Dejoie (Dr Dej), CBO Partner, Provider

8. TRANSITION FOCUSED CAMP
   Submitted by: Alexis Wardlow, Patient Advocate, Consortium Intern

9. WARRIOR FOCUSED NUTRITION
   Submitted by: Alexis Wardlow, Patient Advocate, Consortium Intern

10. CARE COORDINATION IN A HOLISTIC APPROACH
    Submitted by: Velvet Brown-Watts, CBO Partner, Spokesperson of the General Assembly

11. SICKLE CELL TOOL KIT
    Submitted by: Wanda Shurney, Provider


Priority 1. Sickle Cell Tool Kit

Team Lead: Dr. Wanda Whitten-Shurney
Votes: 31

Summary of Proposed Strategy: Community input to develop a physical tool kit that will allow sickle cell warriors to competent, educated patients prepared to communicate needs with healthcare providers. Tool kit could include patient medical journal, alternative strategies to pain management, how to respond to medical mistreatment, and other items that warriors might need for self-care.

Committee List

- Red Chair Project
- Sickle Cell 101
- Martin Center Sickle Cell Initiative
- Sickle Cell found Minnesota
- ASAP
- Sickle Cell Natural Wellness Group
- Cayenne Wellness Center
- Sickle Cell Support Group of Georgia

Advocates:

- Ken Carson
- Stephanie Davis
- Minimarie Andewes
- Janeen Greene
- Joyceln Mason Mitchel
- Teonna Woodford

Priority 2. Sickle Cell Anthology

Team Lead. Kadeem Gayle, Warrior
Votes: 30

Summary of Proposed Strategy: Development of an anthology to put a face of the sickle cell warrior. A collection of fiction and non-fiction authored by the patient/caregiver community. This group would work to gather patient and caregiver stories and essays. Could also potentially contain artwork.

Committee List:

- Bold Lips for Sickle Cell
- Sickle Cell 101
- Red Chair Project
- IASCNAPA
- Sickle Cell International Family Coalition
- Axis Advocacy
- Sickle Cell Strong Inti of Kenya
Advocates:

- Teonna Woodford
- Nicole Surnjit
- Daquan Felton
- Hertz Nazaire
- Kamm Mitchell

**PRIORITY 3. TRANSITION TOOL KIT (PREVIOUSLY TRANSITION CAMP)**

**Team Lead:** Lewis Perry, Caregiver  
**Votes:** 21

**Summary of Proposed Strategy:** Development of a tool kit focused on transition needs and how to better address the concerns of this population and their caregivers. This tool kit would be made available to sickle cell camps. The tool kit would be developed by the patient and caregiver community with input from the transitioning population. This group would determine what already exists, what items are missing as proposed by the transitioning community and development of missing items. This would serve as a training tool, education kit and resource guide – from Warriors to Warriors. Lakisha Johnson of Sickle Cell Support Services would like to pilot this at her annual sickle cell camp.

**Committee List:**

- Sickle Cell Support Services
- Hope for SCD
- Natural Wellness Group
- Kids Conquering Sickle Cell Foundation

**Advocates:**

- Kamm Moore Mitchell
- Kayla Jernigan
- Lewis Perry
- Nathaniel Gantz
Business Meeting
The Business Meeting was convened Saturday, March 18th. Held annually, the focus of this general meeting is to maintain the infrastructure of the Consortium through the ten main (standing) committees and to address items placed on the Business Meeting Docket. Docket items were submitted electronically, were added until end of day, March 1, 2017, and could include proposals for addendum or amendments to the By-laws or Rules of Procedure, and/or any other matter related to Consortium business operations. Appendix C

Docket Item & Resolution:

Partner Support Fees/Dues

Summary: An amendment to the by-laws to include a partners and junior partner support fee/dues. This fee would begin in 2018 for all.

Resolution: Passed by popular vote. To be reviewed by the Administrative and Budgetary Committee. Exact method to be determined and put to the General Assembly to approve.

Credentialing Timeline
Submitted by: Jewel Darbone, Bold Lips for Sickle Cell

Summary: An amendment to the credentialing timeline so that CBOs submit re-credentialing paperwork every two years. Currently re-credentialing occurs yearly.

Resolution: Approved. To be reviewed by the Credentialing Committee and rolled out immediately.

Consortium Charter
Submitted by: Consortium Board of Directors
Summary: Appendix D
Resolution: Approved by unanimous vote

Fundraising & Travel/Lodging Support
Submitted by: Jewel Darbone, Bold Lips for Sickle Cell
Summary: An amendment to Chapter VI, Article 16 of the Bylaws regarding I propose concerning involvement in fundraising for the Consortium. It needs to be required and if not met then the Consortium will not assist with travel and lodging
Resolution: Rejected. Did not pass.

Bylaws – Amendments and Addendums
Submitted by: Board of Directors
Summary: Decisions regarding amendments and addendums to the Bylaws
- Chapter II, Article 5 & 6
- Chapter III, Article 7 - reorganization of main committees
- Chapter VII, Article 18

Resolution: To be reviewed by the Consortium Policy and Infrastructure Committee. To be placed before the General Assembly during the 2018 General Assembly.

*Code of Practice on Relationships Between the Pharmaceutical Industry and Patient Organizations*

Submitted by: Dr. Lakiea Bailey

Summary: Appendix E

Resolution: To be reviewed by the Policy and Infrastructure Committee. To be placed before the 2018 General Assembly.
The Main Infrastructure Committees

First Committee: Consortium Policy & Infrastructure
Concerned with defining and creating the needed foundation basis to build and strengthen the infrastructure of the Consortium through policy, procedure, and capacity building and implementation of rules and regulations.

Committee members:
- Velvet Brown-Watts, Chair
- Lisa Rose
- Yvonne Carroll
- Alexis Perry
- Nicole Surjit
- Stephen Agyenim-Boateng
- Bill Cummings
- Nathaniel Gantz
- Ulysse Guerrier

Second Committee: CBO Capacity Building & Infrastructure Support
Concerned with developing and maintaining CBO capacity and infrastructure support.

- Adrienne Bell-Cors
- Lakisha Johnson
- Dominique Friend

Third Committee: Credentialing
Concerned with maintaining and updating the credentialed list, annual review of credentials and/or progress reports and updates. This committee develops and maintains the credentialing process (ie. credentialing application forms, patient/caregiver advocate profiles, etc.) and completes annual review of the credentials, fiscal and ethical compliance of new and existing partners. Concerns are flagged for Ethics & Oversight Committee.

- Velvet Brown-Watts, Chair
- Adrienne Bell-Cors
- Jewel Darbone
- Sharonda Sikes
- Nicole Surjit

Fourth Committee: Ethics & Oversight
Concerned with maintaining the ethical and fiscal integrity of the Consortium and Consortium partners.

- Teonna Wolford
- Adrienne Bell-Cours
- Jazmine Rivera
- T.J. Brown
- Stephanie Zapata
• Angela Woods
• Eric Frempong
• Shelly Ann-Crosby
• Yvonne Carroll
• Stephen Agyenim-Boateng
• Shamonica Wiggins
• Jeremiah Watts

*Fifth Committee: Patient/Family Advisory Council*
Concerned with providing platforms to ensure that the sickle cell patient/family voice remains central to all Consortium projects, platforms and initiatives.

• Teonna Woolford
• Lewis Perry
• Kadeem Gayle
• Clayton Andrews
• Kemba Gosier
• Joycelyn Mason-Mitchell
• Maria Rivera

*Sixth Committee: Administrative and Budgetary*
Concerned with Consortium administrative and financial infrastructure. Works closely with Finance team to review and approve budgets.

• Eric Frempong
• Carolyn Rowley
• Stephanie Zapata
• Lakisha Johnson
• Carla Lewis
• Stephanie Davis

*Seventh Committee: Financial Growth & Development*
Concerned with Consortium fiscal growth and development.

• Doris Bailey, Chair
• Angela Henderson
• Kamms Mitchell
• Janeen Green
• Jalicia Gantz
• Marie Ojiambo
• Shirley Miller
Eighth Committee: Immediate response committee
Concerned with new and emerging issues/concerns of the collective patient population. Prepare report, submit to President, distributed by secretary, for immediate action. Recommends actions.

- Sharonda Sikes
- Adrienne Bell-Cours
- Kayla Ann-Jernigan

Ninth Committee: Legislative & Legislative (Political Action Committee)
Concerned with policy, political advocacy and legislative matters of importance to the sickle cell community. This group works with the community to define, prioritize and develop the legal and legislative agenda for the Consortium.

- Adrienne Bell-Cours
- Ken Carson
- Bill Cummings
- Kamms Mitchell-Moore
- Dominique Friend

Tenth Committee: Public Relations & Marketing
Concerned with the forward face of the Consortium through public relations and marketing.

- Omeka
- Diamond Ray Edmonson
- Sharonda Sikes
- Jazmine Rivera
- T.J. Brown
- Shamonica Wiggins
- KAMMs
- Stephanie Davis
- Matalia Liptrot

APPENDIX A: Press Kit & References

APPENDIX B: General Assembly Docket

APPENDIX C: Business Meeting Docket

APPENDIX D: Consortium Charter

APPENDIX E: Code of Practice on Relationships Between the Pharmaceutical Industry and Patient Organizations
Justice for Warriors: Improved Care in U.S. Hospitals and Clinics

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane" – Dr. Martin Luther King, Jr.

The Patients, Caregivers and Community-Based Organizations (CBOs) of the Sickle Cell Community Consortium announce the launch “JUSTICE FOR WARRIORS: IMPROVING CARE IN U.S. HOSPITALS AND CLINICS” and the formation of the National Sickle Cell Disease Task Force for Improved Care in U.S. Hospitals and Clinics.

For years Warriors in the sickle cell community have been encouraged to be patient, to be silent, to endure. Though our fear of repercussion we have learned to smile, to accept discrimination and ignore cruelty. We try to wait out the crisis, to stay home in intense pain, to do anything to avoid emergency departments. We put our lives in the balance and on the line, weighing out the pain of this disease against the hurt and humiliation of being treated with disregard, cruelty, and disrespect. The burden of being labeled a drug seeker is often compounded by the “invisible nature” of the disease and by the inability of the medical community to comprehend the unseen pain and the seemingly random episodes. We’ve been told to hold on to hope, to hold our peace, to hold our tongues. We are no longer willing to suffer in silence.

Now we are holding those responsible, accountable. We are Taking Our Stand!

We call upon all patient and caregiver advocates, community leaders, legislative champions and medical allies to join us as we stand against the culture of injustice, cruelty and mistreatment in hospitals and clinics throughout the U.S.

#TakingOurStand  #JusticeforWarriors  #StopMedicalDiscrimination

Share your experience: Justice@sicklecellconsortium.org
Statement of Action: https://www.petitions24.com/sickle_cell_warriors_taking_our_stand
Mailing List: http://eepurl.com/cCPwwD

For more info please contact: Dr. Lakiea Bailey (706) 825-3487 or Dominique Friend-Project Manager (678)665-5307
Sickle cell disease is often accompanied by acute and unpredictable pain, which can be indicative of life-threatening internal issues. But because pain is subjective in nature, attending doctors and nurses, especially in emergency room settings, often incorrectly categorize sickle cell patients as drug-seekers or even opioid addicts, denying care or causing patients to wait extended periods of time for treatment – potentially leading to bodily harm and even death.

That is why sickle cell warriors are asking hospitals and providers to join us in a pledge to deliver patient-centered care, and take part in the sickle-cell patient-care training program.

We want healthcare facilities to Partner with the sickle cell community in order to deliver Patient-centered care which will enhance Patient and Provider satisfaction.

This partnership is a way for hospitals and providers to better understand the needs of sickle cell patients, so that providers are better equipped to treat this particular patient population. Programs will include:

- Training and education efforts on how to address concerns from the sickle cell community when evidence-based care is not provided.
- Educational prerequisites for health care providers involved in the care of sickle cell patients, including cultural sensitivity training.
- Inclusion of a sickle cell patient and caregiver on advisory councils so that each hospital actively includes the voice of these patients in the decision-making process.

The patient-centered training program has three main objectives:

1. **Provide a clear explanation of sickle-cell disease as it relates to the special treatment needs with which providers may be presented.** Providers must understand and recognize the extreme pain these patients suffer so that diagnosis and dosage can be adequately prescribed at the outset.

2. **Train providers to never make assumptions about pain or urgency of treatment based solely or largely on the physical appearance and vital signs of a patient.** Sickle Cell is not the only disease or condition which doesn’t manifest itself through visible symptoms. There are objective methods of triage, and they should be learned and followed.

3. **Remind providers that when it comes to chronic diseases, the patient is often the expert.** Instead of dismissing patient ‘opinions’ medical professionals should be taught to solicit, assess and act on the expertise that the patient is able to share with them.

Sickle cell warriors are committed to ending discrimination in the hospital system, and over the next few months, we will call on hospitals and providers to join us in our efforts.

For more information about how to join us in this effort, please contact Lakiea Bailey director@sicklecellconsortium.org.
Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. - Declaration of Human Rights, Article 25

At the center of the human rights movement is the notion that all people are entitled to have their body’s physical needs met in a humane and decent way, which includes the right to survive and to live free of reasonably preventable suffering.

In accordance with the principles of accountability, quality, and participation and integrity, the National Sickle Cell Disease Task Force for Improved Emergency Department Care asks the following:

**Accountability:** Commit health care administrators and entities to develop a mechanism to address concerns from the sickle cell community when evidence-based care is not provided.

**Quality:** Commit to develop educational prerequisites for health care providers involved in the care of sickle cell disease patients and require that they demonstrate knowledge of the disease and its management, as well as require they undergo cultural sensitivity training.

**Participation and Integrity:** Commit to include a sickle cell adult patient and a sickle cell pediatric caregiver on Advisory Councils so that each hospital actively engages a sickle cell patient in order to ensure that the voice of the sickle cell community is heard and is involved in the decision-making process.
The National Sickle Cell Disease Task Force for Improved Care in U.S. Hospitals and Clinics was created to address health inequalities in the provision of care to individuals living with sickle cell disease. The Task Force is comprised of a diverse group of leaders from the CDC, sickle cell patients and caregivers, medical allies and faith-based leaders.

- Dominique Friend, Patient, Activist, Founder of Sickle International Family Coalition (GA)
- Lakiea Bailey, Ph.D. Patient, Executive Director of the Sickle Cell Community Consortium (GA)
- Althea Grant, MD, Ph.D, Senior Advisor for Science office of Noncommunicable Diseases, Centers of Disease Control & Prevention (GA)
- James Eckman, M.D., Professor Emeritus, Hematology & Oncology, Emory University School of Medicine (GA)
- Iris Buchanan-Perry, MD, MSc, Morehouse School of Medicine, Aflac Sickle Cell and Blood Disorders, CHOA at Hughes Spalding (GA)
- Coretta Jenerette, PhD., RN, CNE, AOCN, Carolina Center for Public Service, Univ. of North Carolina at Chapel Hill, International Assoc. of Sickle Cell Nurses and Prof. Associates (NC)
- Alison Maynard, BSN/Nurse and warrior for Sickle Cell Disease (GA)
- Chandra White-Cumming, Caregiver, Managing Director, Ourselves Black, Black Mental Health Outreach (VA)
- Rev. Dr. Arnold Howard, Senior Pastor Enon Baptist Church (MD)
- Daniel Efiom-Ekaha, MD, Provider, Hematologist (PA)
- Shakir Cannon, Patient, Information Specialist NYS Department of Health (NY)
- Clair Francamano, MD, Provider, Clinical Molecular Genetics (MD)
- Professor Kenya Ross-Beatty, MBA, NRCMA, NRCPT/ Caregiver (GA)
LITERATURE REFERENCES BY CATEGORY

1. There are racial biases in pain assessment and treatment that lead to Black Americans and minorities being undertreated for pain when compared to White Americans.

2. The stigmatization of patients with sickle cell disease is well-documented and has not improved over time. The intersection of race, discrimination, and stigma enhance the burden of the disease and often results in poor outcomes for patients with sickle cell.

3. Little has been done to address the stigma of sickle cell disease including allocation of research funds equivalent to the burden of the disease and numbers of individuals affected.

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Ahmad Hazem, Victor M. Montori, M. Hassan Murad; “Disparities in Evidence;” Newsletter of the International Society for Evidence-Based Health Care Newsletter 3; International Society for Evidence-Based Health Care/Evidence-Based Clinical Practice Office at McMaster University, Canada; April 2011, p. 4.


GENERAL ASSEMBLY DOCKET

Items to be reviewed, discussed and prioritized by the seated partners of the Second Session of the General Assembly of Patients, Caregivers and Community Based Organizations.

1. SICKLE CELL TRIGGERS
Submitted by:
Monica Rockwell, Patient Advocate

An item has been submitted to the docket regarding what triggers a Sickle Cell Crisis. How can crisis be reduced or better managed when you know what triggers it [and] sometimes help medical professionals with better treatment. The rationale for this item is to [improve] patient self-care.

2. PATIENT EDUCATION MODULES
Submitted by:
Shirley Miller, MA, Patient Advocate

An item has been submitted to the docket regarding the gap in educational material that speaks to the basics of sickle cell disease and how to be aware of potential decisions that could cause harm later on in life as this is a lifelong disease. The rationale for this item is to [improve] patient self-care. Decisions made now may impact the quality of life you experience later in life. Education is key for every patient and caregiver to make informed decisions.

As a community we tend to rely on what we are told by others instead of seeking out the answer for ourselves. Sometimes the information is written in a way that it is beyond our comprehension level and it needs to brought down to a level that is more understandable so that it benefits many. If the community does not find this product to be a benefit it should not be adopted for the entire community.

3. DEVELOPMENT OF A PATIENT DRIVEN NATIONAL AGENDA
Submitted by:
Kenneth Del Carson

An item has been submitted to the docket regarding unification in our community and identification of our National Leadership. The increase in the number of SCD organizations. The rationale for this item is the need for unification, leadership and an agreement on the path of change can only come from the concerted efforts of gathering such as this and the follow up work that is created from our efforts!
4. PRAYER WARRIORS
Submitted by:
Kenneth Del Carson, Patient Advocate

An item has been submitted to the docket regarding An Organized Effort by the People of Faith in our community, to address the issues affecting those living with SCD and caring for our Warrior's, using the greatest weapon of Warfare, Prayer! In America, SCD is predominantly an African American problem and as with all things that challenge our community our Faith has been our greatest ally!

5. SICKLE CELL ANTHOLOGY
Submitted by:
Kadeem Gayle, Patient Advocate

There are many articles on sickle cell that discuss treatment and care, however patient experience is often absent from research. A sickle cell anthology is a great way for us to connect as sickle cell warriors and see the challenges face for the sickle cell community.” The rationale for this item is to address the sickle cell community [and] to show what sickle cell warriors are capable of and diminish the stigmatization of sickle cell.

6. OPIOID ADDICTION
Submitted by:
Marjorie Dejoie (Dr Dej), CBO Partner, Provider

An item has been submitted to the docket regarding the subject of opioid addiction. The opioid epidemic will deeply affect our population and we need to be aware and educated. We need a good understanding of what their knowledge is of this item and how they will be affected.

7. NUTRITION AND SICKLE CELL DISEASE
Submitted by:
Marjorie Dejoie (Dr Dej), CBO Partner, Provider

An item has been submitted to the docket regarding nutrition as part of the treatment paradigm. Many individuals are unaware of the healing properties found in food as it relates to their illness and this should be an essential part of their long term treatment protocol. Medicine through Food. The basic principles should be adopted by the entire community and they also serve as a resource.
8. TRANSITION-FOCUSED CAMP
Submitted by:
Alexis Wardlow, Patient Advocate, Consortium Intern

An item has been submitted to the docket regarding the many individuals having issues transitioning from Pediatrics to Adult Care. They don't have the proper guidance or medical/peer support to clearly and efficiently identify a pathway to the type of Adult care they need. The rationale for this item is to make headway in helping young adults during transition, and bring them the needed guidance and information to continue healthier and well-balanced lives.

9. WARRIOR FOCUSED NUTRITION
Submitted by:
Alexis Wardlow, Patient Advocate, Consortium Intern

An item has been submitted to the docket regarding nutrition that specifically focuses on creating meal plans and substitutions for every individual sickle cell warrior. Certain foods and supplements, when taken the right way, can benefit a sickle cell warrior's health in great ways. The rationale for this item is to make Great strides by adding a nutritional health aspect to sickle cell warriors long term care.

10. CARE COORDINATOR IN A HOLISTIC APPROACH
Submitted by:
Velvet Brown, CBO Partner, Spokesperson of the General Assembly

An item has been submitted to the docket regarding A discussion as to how to better incorporate holistic care coordinating. Is there a model that care be designed using the chronic disease model, whereas it can be added?

11. SICKLE CELL TOOL KIT
Submitted by:
Wanda Shurney, Provider

Many providers are not knowledgeable about sickle cell disease and some are hesitant to take care of patients because they are so complex. I would like to have a brainstorming session on "tools" for self care. This will allow our patients to present themselves as competent and educated. Prepared to participate in their care. Tool would include a medical journal, alternative approaches to pain management, information about anti-inflammatory diets etc. Adult patients frequently state that they encounter physicians who tell them that they don't know anything about sickle cell disease. Sometimes I encounter patients who are on medications but don't know why or lab tests are ordered that they don't understand.
Items to be reviewed, discussed and voted on by the seated partners
Second Session of the General Assembly of Patients, Caregivers and Community-Based Organizations.

1. PARTNER SUPPORT FEE/DUES
Submitted by:
Velvet Brown-Watts, Supporters of Families with Sickle Cell, Chairperson of the General Assembly.

An amendment to the by-laws to include a partners and junior partner support fee/dues. This fee would begin in 2018 for all. Fee would go by 990’s. Organizations with a 501 c 3 and income is between $25,000 to $50,000 would be charged $100 per year, $50,000 to $100,000 would be charged $200 per year, over $100,000 would be $300 per year, under $25,000, we would ask for a donation of $50.00. They could pay monthly, quarterly and or yearly, but all dues would need to be pay in full by conference. If they are a junior CBO a donation of $100 would be asked for. New CBO would have a grace period of one year, and would begin the next year with payment according to their 990.

The goal is to have CBO understand ownership. Most people who give, will get involve, and they will work.

2. CREDENTIALING TIMELINE
Submitted by:
Jewel Darbone, Bold Lips for Sickle Cell

An amendment to the credentialing timeline so that CBOs submit re-credentialing paperwork every two years. Currently re-credentialing occurs yearly.

3. CONSORTIUM CHARTER
Submitted by: Consortium Board of Directors

(Document Attached)

4. FUNDRAISING AND TRAVEL/LODGING SUPPORT
Submitted by: Jewel Darbone, Bold Lips for Sickle Cell

An amendment to Chapter VI, Article 16 of the Bylaws regarding I propose concerning involvement in fundraising for the Consortium. It needs to be required and if not met then the Consortium will not assist with travel and lodging.
5. BYLAWS - AMENDMENTS AND ADDENDUMS  
Submitted by: Board of Directors

Decisions regarding amendments and addendums to the Bylaws

- Chapter II, Article 5 & 6
- Chapter III, Article 7 - reorganization of main committees
- Chapter VII, Article 18

(Document Attached)

6. CODE OF PRACTICE ON RELATIONSHIPS BETWEEN THE PHARMACEUTICAL INDUSTRY AND PATIENT ORGANIZATIONS
Submitted by: Dr. Lakiea Bailey

(Document Attached)
SECOND SESSION OF THE NATIONAL SICKLE CELL COMMUNITY CONSORTIUM
GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS AND CBOs.

(To be reviewed by the Board, approved by the General Assembly, and entered into Consortium governance)

CHARTER OF THE SICKLE CELL COMMUNITY CONSORTIUM

WE, THE PATIENTS, FAMILIES, COMMUNITY-BASED ORGANIZATIONS AND HEALTHCARE ADVISORS OF THE SICKLE CELL COMMUNITY CONSORTIUM

DETERMINED to equip and empower sickle cell patients and caregivers to become full participants in sickle cell-related healthcare and research initiatives. Having understood that direct engagement with sickle cell patients is central to progress and development, we have purposed to create a platform to harness and amplify the power of the patient voice through direct involvement in education, advocacy, research, legislation and policy.

AND FOR THESE ENDS to provide a platform for sickle cell patients and caregivers to identify and define problems, needs and gaps within the sickle cell community and to develop and implement patient-powered solutions to these needs. Supported by a diverse group of sickle cell stakeholders, sickle cell patients and caregivers are the driving force to create sustainable change.

HAVE RESOLVED TO COMBINE OUR EFFORTS TO ACCOMPLISH THESE AIMS

Accordingly, our respective Community-Based Organizations (CBOs), through representatives assembled in the city of Atlanta, who have exhibited their full powers found to be in good and due form, have agreed to the present Charter of the Sickle Cell Community Consortium and do hereby establish a collaborative organization to be known as the Sickle Cell Community Consortium.

Entered into Governance, on this day of ……. By the Partners of the Second Session of the General Assembly of Patients, Caregivers and CBOs.

_______________________________________________
Executive Director, Sickle Cell Community Consortium

_______________________________________________
Date
BOARD OF DIRECTORS

__________________________________________________________
Director of Development

__________________________________________________________
Director of Finance

___________________________________________________________
Associate Director of Finance

____________________________________________________________
Executive Administrator

__________________________________________________________
Director of Research

___________________________________________________________
Associate Director of Research
2017 PARTNERED COMMUNITY-BASED ORGANIZATIONS

Journeys By Grace Global Missions

Sickle Cell Foundation of Minnesota

Hope for SCD

IASCNAPA

Kids Conquering Sickle Cell Disease Foundation

Advancing Sickle Cell Advocacy Project, Inc.

S.C.A.R. Inc.

Sickle Cell Support Services

Sickle Kan Cic
The Red Chair Project
Bold Lips for Sickle Cell
Sickle Cell 101
The Committee on Better Racial Assurance
Supporters of Families with Sickle Cell Disease
SCDAA, Philadelphia/Delaware Chapter
As One Foundation
Sickle Cell Warriors, Inc.
AXIS Advocacy
Lockhart Morgan Foundation
Sickle Strong Initiative, Kenya
Martin Center Sickle Cell Initiative
Cayenne Wellness Center & Children’s Foundation
Sickle Cell Natural Wellness Group
Sickle International Family Coalition
No Pain in the Playroom
Sickle Cell Champions Association
Tillo Cilly Cell Foundation Intl.
Transition with Power
SECOND SESSION OF THE NATIONAL SICKLE CELL COMMUNITY CONSORTIUM
GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS AND CBOs.

CODE OF PRACTICE ON RELATIONSHIPS BETWEEN THE PHARMACEUTICAL INDUSTRY AND PATIENT ORGANIZATIONS

(To be reviewed by the Board, approved by the General Assembly, and entered into Code of Practice)

The Sickle Cell Community Consortium applies the principals set forth by the European Federation of Pharmaceutical Industries and associations (EFPIA), together with pan-European patient organizations, in the Code of Practice on relationships between the pharmaceutical industry and patient organizations.

Consistent with Consortium policy of full transparency, and in an effort to ensure that all relationships between the pharmaceutical industry and Consortium community-based organizations (CBOs) take place in an ethical and transparent manner, avoiding real or perceived conflicts of interest between pharmaceutical industries and Consortium CBOs. All partners agree to adopt Code of Practice created and modified by EEPIA...

Patient Organizations

- The independence of patient organizations, in terms of their political judgement, policies and activities, shall be assured.
- All partnerships between patient organizations and the pharmaceutical industry shall be based on mutual respect, with the views and decisions of each partner having equal value.
- The pharmaceutical industry shall not request, nor shall patient organizations undertake, the promotion of a brand-specific, prescription-only medicine.
- The objectives and scope of any partnership shall be transparent. Financial and non-financial support provided by the pharmaceutical industry shall always be clearly acknowledged.
- The pharmaceutical industry welcomes broad funding of patient organizations from multiple sources.

Pharmaceutical Industries: Points of Commitment

- Clarity: Written agreements defining pharmaceutical companies’ support
- Use of Logos: written permission for the use of logos or materials
- Editorial Control: no influence of editorial content to favor commercial interests
- Transparency: information about who pharmaceutical companies support and how
- Diversified Funding: encourage multiple sources of funding for patient organizations
- Reasonable Hospitality: hospitality limited to a reasonable level