Building Authentic Partnerships: Strategies to Increase HCT Access for Individuals with Sickle Cell Disease

Lakiea Bailey, PhD; Executive Director, Sickle Cell Community Consortium
Jennifer Krajewski, MD; Sickle Transplant Alliance for Research (STAR)
Rae Blaylard, Executive Director for Sickle Cell Foundation of MN

Disclosures

The following faculty and planning committee staff have no financial disclosures:

Name	Institution
Lakiea Bailey, PhD	Sickle Cell Community Consortium
Jennifer Krajewski, MD	Sickle Transplant Alliance for Research
Rae Blaylark	Sickle Cell Foundation of MN

Objectives

At the conclusion of this session, attendees will know how to:

- List strategies for building authentic and respectful partnerships with patients and advocates from the sickle cell community
- Describe barriers to building authentic partnerships with patients and advocates from the sickle cell community
- Describe partnership activities between the NMDP and each organization

Building Authentic Partnerships In and With the Sickle Cell Community

Rae Blaylark, Caregiver

Executive Director
Sickle Cell Foundation of MN

Sickle Cell Patient Family Health Advocate
Children's Hospitals of Minnesota

Disclosures

I have no disclosures

Learning objectives

At the conclusion of this session, attendees will be able to:

- Identify challenges experienced by patients living with sickle cell disease
- Identify members of the sickle cell community
- Describe barriers to building authentic partnerships with patients and advocates from the sickle cell community
- List strategies for building authentic and respectful partnerships with patients and advocates from the sickle cell community

The State of Sickle Cell Disease

1:12 AA have sickle cell trait
In U.S. ~100,000 people live with SCD
1:365 born with SCD each year
1:~1,200 Latino babies diagnosed/yr

1988 - Newborn Screening for SCD, MDH
2015 - Statewide Trait Notification Program, MN

Minnesota (2016):
~ 32 babies born w/SCD
~1,200 babies with abnormal Hb trait

Sickle Cell Foundation OF MINNESOTA

The Sickle Cell Disease Community Narrative

- The U.S. health care system is killing adults with sickle cell disease[3]. Racism is a factor — most of the 100,000 U.S. patients with the genetic disorder are African-American — and so is inadequate training of doctors and nurses. And the care is getting worse, sickle cell patients and their doctors said, because the opioid addiction crisis has made ER doctors extremely reluctant to prescribe pain pills.

- Only 20 percent of family physicians say they feel comfortable treating sickle cell disease, a 2015 survey of more than 3,000 such physicians found, leaving many patients without routine, preventive care.

- The mortality rate for adults with the disease cell has risen 1 percent every year since 1979, the hematology society reported in 2016. Half of adult sickle cell patients are dead by their early 40s[7].

- Every doctor who cares for adult sickle cell patients “knows of one or more who were not treated properly and died,”
- **The result of all these failures is “a breakdown in the system of care for these patients”**

STAT News, 9/18/2017

https://www.statnews.com/2017/09/18/sickle-cell-pain-treatment/?utm_source=STAT+Newsletters&utm_campaign=d1f202aa43-Daily_Recap&utm_medium=email&utm_term=0_8cab1d7961-d1f202aa43-149609073

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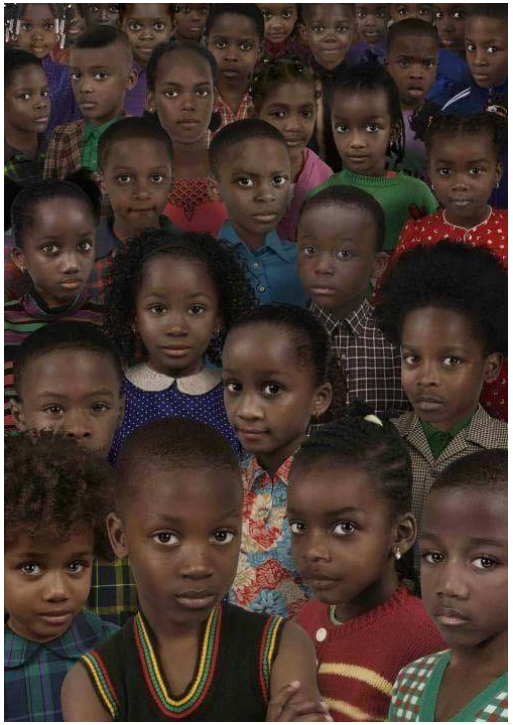
Who belongs to the Sickle Cell Community?

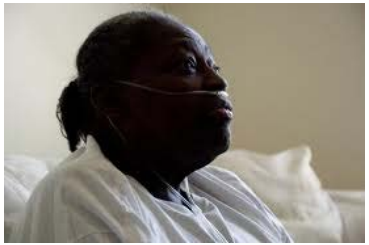
The Sickle Cell Community - Warriors

SICKLE CELL WARRIORS

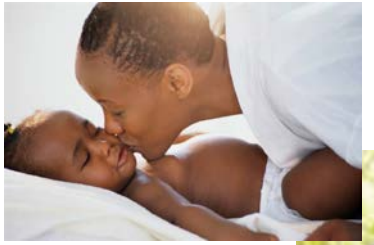


SCDAA
"Break The Sickle Cycle"®

sickle cell community consortium



The Sickle Cell Community - Caregivers



The Sickle Cell Community - Medical

The Sickle Cell Community – At Large

Barriers to Building Partnerships

- **Education, Education, Education!**
- **Shared Knowledge**
- **Community Trust**
- **Access Points**
- **Collaboration**
- **Motivation**
- **Creativity**

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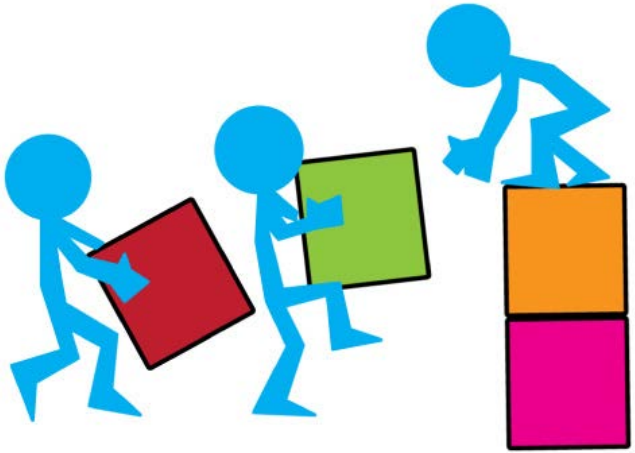
The Building Process



3 Principals of Authentic Relationship Building

- **Genuine regard for the community**
- **Synergistic interactions**
- **Intentional outcomes**

Sickle Cell Foundation OF MINNESOTA

The Building Process

Genuine Regard for the Community

- Get to know us
- Connect and commit
- Value diversity
- Embrace new experiences
- Be the partner/take the backseat

The Building Process

Synergistic Interactions

- **Who's at the table?**
- **When were they invited?**
- **Listen, really listen!**
- **Value interdependence**
- **Promote shared ideas**
- **Wear multiple hats.**

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The Building Process

Intentional Outcomes

- **Identify the need**
- **Assess capacity**
- **Make the ask**
- **Utilize multiple partnerships**
- **Execute w/flexibility**
- **Evaluate & share results w/others**

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SICKLE CELL FOUNDATION OF MINNESOTA (SCFMN)

Sickle Cell Foundation OF MINNESOTA

: www.sicklecellmn.org

: info@sicklecellmn.org

: @sicklecellmn

: @sicklecellmn

: @sicklecellmn

Sickle Transplant Alliance for Research: Curing sickle cell. Improving lives.

Jennifer Krajewski, MD
Clinical Assistant Professor, Rutgers New Jersey Medical School
Hackensack University Medical Center
Hackensack, NJ

To Date, Hematopoietic Cell Transplantation Remains The Only Curative Therapy

THE NEW ENGLAND JOURNAL OF MEDICINE Sept. 20, 1984

BONE-MARROW TRANSPLANTATION IN A PATIENT WITH SICKLE-CELL ANEMIA

F. Leonard Johnson, M.B.B.S.,
A. Thomas Look, M.D., Jon Gockerman, M.D.,
Mary R. Ruggiero, P.N.P.,
Luciano Dalla-Pozza, M.B.B.S.,
and Frederic T. Billings III, M.D.

- St. Jude Children's Research Hospital
- 8 year old female with HBSS diagnosed with AML
- CR after two cycles of induction chemotherapy
- Bone marrow transplantation from 4 year old, HLA identical brother

Hematopoietic Cell Transplantation (HCT)

- First HCT for Sickle Cell Disease – 1984
- Rationale based on preliminary experience for b-thalassemia
- Approximately 1500 HCT to date
  - Predominantly sibling donor HCT
- Much fewer compared with b-thalassemia
  - More variable clinical course
  - Limitation of HLA matched donors
  - Limitation of patient eligibility

Sickle Transplant Alliance for Research (STAR)

- A non-profit organization established in 2014 by a group of pediatric hematology and stem cell transplant physicians
- **Mission**: Enhance the lives of children suffering from sickle cell disease through blood and marrow transplantation research to create better transplant approaches- ones that safely achieve cure for the greatest number.

Sickle Transplant Alliance for Research (STAR)

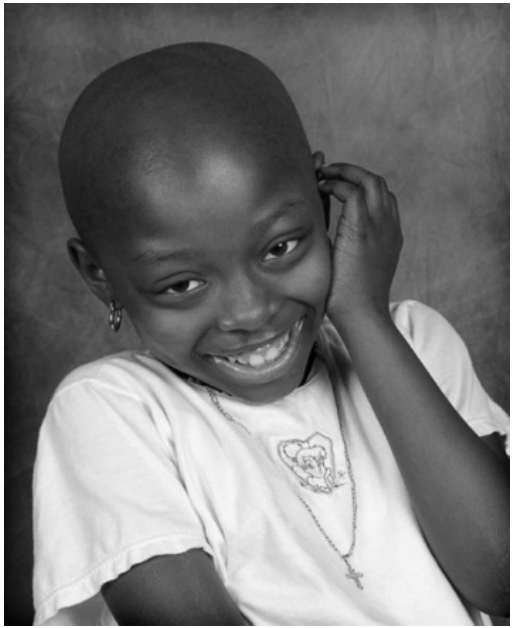
- The only national organization solely committed to improving the cure for sickle cell disease
- Organizes clinical trials and collects and shares data and best practices among 21 pediatric hospitals across the US and Canada
- The only consortium dedicated to researching the best use of BMT for children and young adults afflicted with sickle cell disease

STAR Centers

Alberta Children's Hospital/University of Calgary (Calgary, Canada)	C.S. Mott's Children Hospital / University of Michigan (Ann Arbor, MI)	Nationwide Children's Hospital / Ohio State University (Columbus, OH)
Ann & Robert H. Lurie Children's Hospital of Chicago / Northwestern University (Chicago, IL)	University of Florida (Gainesville, FL)	Nemours Children's Hospital (Orlando, FL)
Boston Children's Hospital / Harvard University (Boston, MA)	Hackensack University Medical Center (Hackensack, NJ)	New York Presbyterian Morgan Stanley Children's Hospital / Columbia University (New York, NY)
Children's Healthcare of Atlanta / Emory University (Atlanta, GA)	Indiana Hemophilia and Thrombosis Center (Indianapolis, IN)	University of North Carolina (Chapel Hill, NC)
Children's Hospital of Philadelphia (Philadelphia, PA)	Levine Children's Hospital (Charlotte, NC)	Phoenix Children's Hospital (Phoenix, AZ)
Children's National Health System / George Washington University (Washington, DC)	Medical University of South Carolina (Charleston, SC)	St. Louis Children's Hospital / Washington University in St. Louis (St. Louis, MO)
Texas Transplant Institute (San Antonio, TX)	The Hospital for Sick Children (Toronto, Canada)	Yale University (New Haven, CT)

STAR Centers

STAR Clinical Trials



Retrospective Registry Trial

- **Primary objective:** To investigate the long-term outcomes of HCT in pediatric SCD, related to transplant, disease complications, and organ function
- Baseline, transplant, and long-term outcome data were collected from 10 STAR centers
- Included 196 patients transplanted between 1993-2016
- **Results:**

Abatacept for Preventing Graft-versus-host Disease (GVHD)

- **Study design:** A multicenter, single arm pilot study (n=25)
- **Eligibility criteria:**
  - Patients with severe SCD between ages 2 and 21
  - High risk for GVHD (unrelated donor or matched related donor where the patient or sibling over 10 years).
- **Currently enrolling patients at 7 centers**

Early Transplantation in Children with Matched Related Donors

Aims:

- To prospectively assess the safety and efficacy of HLA matched related HCT using the reduced intensity conditioning regimen fludarabine, alemtuzumab and melphalan in children with less severe sickle cell disease (SCD)
- To address current gaps in our understanding of the long term effects of HCT in children with SCD, by longitudinally assessing ovarian reserve, sickle cell related cerebrovascular disease, sickle cell related nephropathy and health related quality of life.
- **Eligibility criteria**:
  - Patients with moderate Hb SS or SB0 disease less than 10 years.
  - Have a MRD who is also <10 years.
- Open for enrollment by Spring 2018

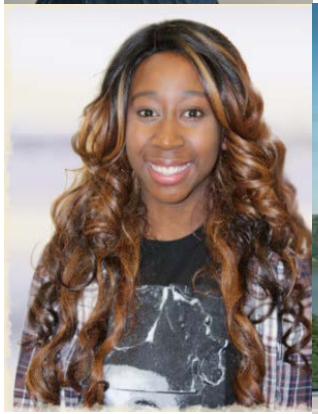
BMT-CTN 1503 (STRIDE 2)

- **Study Design:** Phase II, multi-center trial of **HCT vs. standard of care** in adolescents and young adults with severe SCD. Participants are assigned to either arm based on the availability of HLA-matched related or unrelated donor
- **Primary Objective:** Compare the overall survival (OS) at 2 years after biological assignment between those assigned to the donor arm and to the no donor arm. Those assigned to the donor arm are expected to undergo HCT and those on the no donor arm to receive standard of care & supportive therapy
- **Eligibility criteria**:
  - Patients are between 15 – 39 years of age with severe Hb SS or Hb SC or
  - Patients have not undergone HLA typing previously
- Currently enrolling patients at 30 sites

BMT-CTN 1507

- **Study Design**: Phase II, single arm, multi-center trial, designed to estimate the efficacy and toxicity of haploidentical transplant in patients with SCD. Patients are stratified into two groups: (1) children with SCD with strokes; and (2) adults with severe SCD.
- **Primary Objective**: Event free survival (EFS) at 2 years after transplant in both age groups
- **Eligibility criteria**:
  - Patients with SCD (Hb SS or Sß° Thalassemia) ages 5 - 15 years who have had overt strokes
  - Patients with severe SCD (Hb SS or Sß° Thalassemia) aged 15 – 45 years
- **Because this study competes with 1503, centers must choose to open either 1503 or 1507**
  - The exception to this is that pediatric centers may open the pediatric arm of 1507 if they also have 1503 open

STAR Outreach Initiatives



STAR Engagement Committees

- Composed of 14 STAR members, both physicians & non-physicians
  - Advocacy committee
  - Education committee
  - Outreach committee

Advocacy

- Goals:
  - Partner with advocacy organizations to grow the voice and community of STAR
  - Sickle Cell Disease Association of America
    - Participate in the monthly conference calls
    - Become involved in their research and clinical trials priority, especially in terms of helping disseminate this information out to the sickle cell communities
  - Sickle Cell Community Consortium
  - Sickle Cell Disease Association of Canada
  - Sickle Cell Foundation of Alberta
- We will be reaching out to founding members of these advocacy organizations in order to “get the word out” about BMT for sickle cell.

Education

- Goals:
  - Partner with the National Marrow Donor Program/ Be The Match to educate patients and families.
    - **Participate in webinar on sickle cell disease and transplantation & in the annual council meeting**
    - Co-brand educational materials for health care professionals, patients, and families about transplant for sickle cell disease
    - Help NMDP recruit & educate potential donors in the sickle cell communities
  - Partner with various professional societies
    - ASH coalition
    - ASPHO
    - ASBMT
  - Increase access to transplant information for patients, caregivers, and families
    - Hope to form an alliance with BMTinfo.net in order to inform patients & families about BMT for sickle cell disease
- Increase engagement with health care professionals caring for patients with sickle cell disease
  - Develop a standard presentation that STAR physicians can use to educate referring providers
  - Develop educational conferences for referring providers

Education

- Goals:
  - Match patients with trained volunteers who are transplant recipients to increase education and knowledge about transplantation for sickle cell disease
    - Develop a similar system for matching parents/families with other families who have been through transplant
  - Organize and participate in fundraising opportunities to reach a larger network of the sickle cell community & raise funding for specific STAR trial activities
    - Work towards creating an annual 5K race for STAR

Thank you!

Questions, comments, thoughts?

SICKLE CELL COMMUNITY CONSORTIUM

SCCC

Unity. Commitment. Progress.

BUILDING AUTHENTIC PARTNERSHIPS

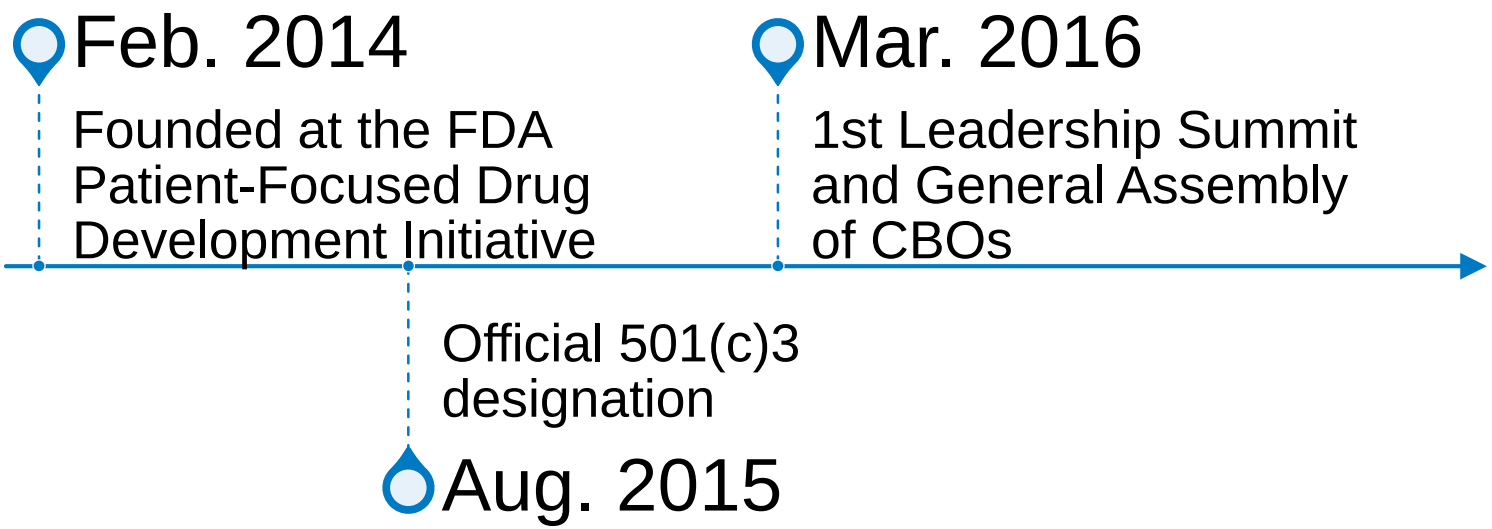
Lakiea Bailey, PhD
Executive Director, Sickle Cell Community Consortium

THE CONSORTIUM

The Sickle Cell Community Consortium is a U.S.-based non-profit comprised of sickle cell patients (Warriors), caregivers, community-based organizations (CBOs), community partners and medical/research advisers.

Collectively, these partner groups make up the GENERAL ASSEMBLY of Patients, Caregivers and CBOs, the decision-making body of the Consortium

HISTORY


Feb. 2014
Founded at the FDA Patient-Focused Drug Development Initiative
Mar. 2016
1st Leadership Summit and General Assembly of CBOs
Official 501(c)3 designation
Aug. 2015

MISSION

PATIENT/CAREGIVERS:

To equip and empower sickle cell patients and caregivers to be full participants in sickle cell advocacy, education, research, legislation and policy.

COMMUNITY-BASED ORGANIZATIONS:

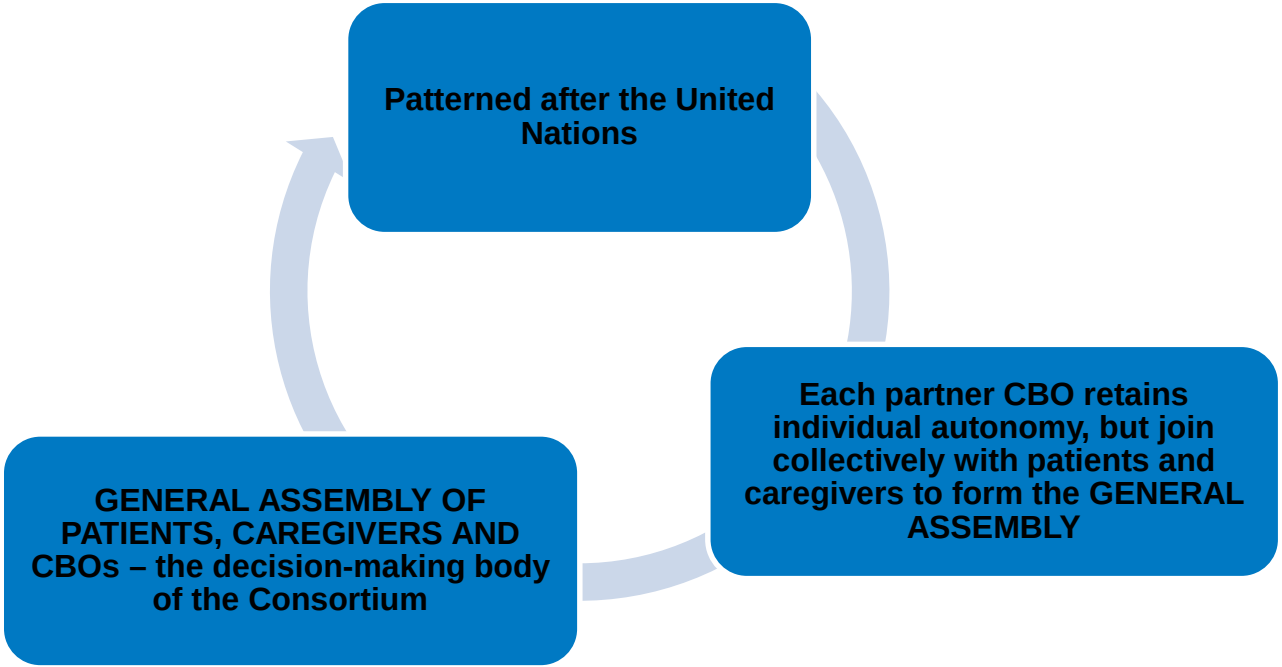
To provide infrastructure support, best practices training and access to resources, otherwise unavailable to partner CBOs.

PURPOSE

To provide a platform for patients/caregivers/CBOs to become directly involved in defining problems/needs/gaps in the sickle cell community and identifying strategies to address those problems/needs/gaps.

Provide a centralized infrastructure to develop multi-stakeholder strategies to implement community solutions and determine the CBO, Community, and Corporate partnerships best equipped to achieve significant and sustainable change.

ORGANIZATION



PARTNERS

Credentialed Partner CBOs

Sickle cell disease 501c3 non-profit. Ethically and fiscally responsibility.

Junior CBOs

New CBOs actively working towards independent 501c3 status.

Sponsored Patient Groups

Organized patient groups (such as support groups) sponsored by a provider or healthcare facility

PARTNERS

Independent Patient/Family Advocates

Committed patient/caregiver advocates. Serves as the voice of the patient/caregiver on all projects, platforms and priorities. Maintains an active advocate profile.

Medical/Research Advisors

Consult on projects and platforms.

Community Partners

Non-sickle cell specific orgs, businesses and other entities which provide services for sickle cell community or whose purpose or mission aligns with the collective goal of the Consortium.

Partners collectively form the

GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS AND CBOs

GENERAL ASSEMBLY PURPOSE

The purpose of the GENERAL ASSEMBLY is to serve as a bridge to give voice and action to the estimated 100,000 individuals living with sickle cell disease in the United States and their caregivers. Working collectively, this group will ensure that the needs and goals of the sickle cell community are identified and met.

GENERAL ASSEMBLY

Main deliberative, policymaking and representative organ of the Consortium

Responsible for maintaining the infrastructure of the Consortium

Meets annually during the Leadership Summit in Atlanta, GA

- **Applies the model of collective Impact to identify and prioritize problems, needs and gaps in the sickle cell community, then work collectively to define and execute patient-powered solutions to these needs.**
- **Work in partnership with community partners and healthcare/research advisers, patients and caregivers lead the teams dedicated to tackling each priority.**

COLLECTIVE IMPACT

- Coordinate all partners to effectively engage individuals living with sickle cell disease to ensure that the voices of the patients are heard.

- Unite to develop a common agenda, and with open and continuous communication, outline and coordinate mutually reinforcing activities for each partner CBO to ensure that the SCD patient is included in every stage of healthcare, policy, education, research, and legislation.

COLLECTIVE IMPACT & PARTNERSHIPS

- Collective impact brings people together, in a structured way, to achieve social change.
- It starts with a common agenda. That means coming together to collectively define the problem and create a shared vision to solve it.
- It establishes shared measurement. That means agreeing to track progress in the same way, which allows for continuous improvement.
- It fosters mutually reinforcing activities. That means coordinating collective efforts to maximize the end result.
- It encourages continuous communication. That means building trust and relationships among all participants.

POWER OF THE PATIENT VOICE: OUTCOMES

- #Show-Up and #Speak-Up for Sickle Cell
- Annual Leadership Summit & General Assembly of CBOs
- Annual Sickle Cell Patient and Family Education Symposium
- Patient-Centered Outcomes Initiative (PCOI)
- Patient-Powered Clinical Trials Initiative
- Pediatric-to-Adult Transition Workgroup
- Educational Webinar Series for patient advocates and CBOs
- Justice for Warriors: A call to action for improved care in U.S. hospitals and clinics
- Patient-Powered Educational Literature Series

#SHOW-UP AND #SPEAK-UP FOR SICKLE CELL

Warriors and Caregivers used their voices and shared their experiences throughout the country as part of an initiative to #ShowUpSpeakUp for Sickle Cell

Over $65K in scholarships to Warriors and Caregivers for registration, transportation and/or lodging.

ANNUAL LEADERSHIP SUMMIT

- Held annually in Atlanta, Georgia every March
- Serves as Consortium Business Meeting
- Provide Best Practices Training for advocates and CBOs
  - Grant writing
  - CBO Branding, Marketing and Messaging
  - Navigating Corporate Partnerships
  - Non-profit accounting and fiscal responsibilities
  - Creative Digital/Visual Content Workshops
  - Much, much, more…
- Hosts annual GENERAL ASSEMBLY of Patients, Caregivers and CBOs.

ANNUAL WARRIOR CONVENTION

- Over 150 patients, caregivers, community partners, healthcare providers and research scientists
- Over $35,000 in scholarships
- Co-hosted annually by a partnership of CBOs
- Yearly destination chosen by patient community
- ALL topics, workgroups and panels created by the community
- Specific Track dedicated to Warrior Men
- Specific Track dedicated to Children and Parents
- Annual Community Awards Gala
  - The Warrior Prom

PATIENT-CENTERED OUTCOMES INITIATIVE

Directly involve sickle cell patients and caregivers in identify priorities for patient-centered outcomes research

Collectively define alternative patient-focused endpoints for sickle cell disease clinical trials.

Awarded 2017 PCORI Tier A Pipeline-to-Proposal Contract to further this initiative.

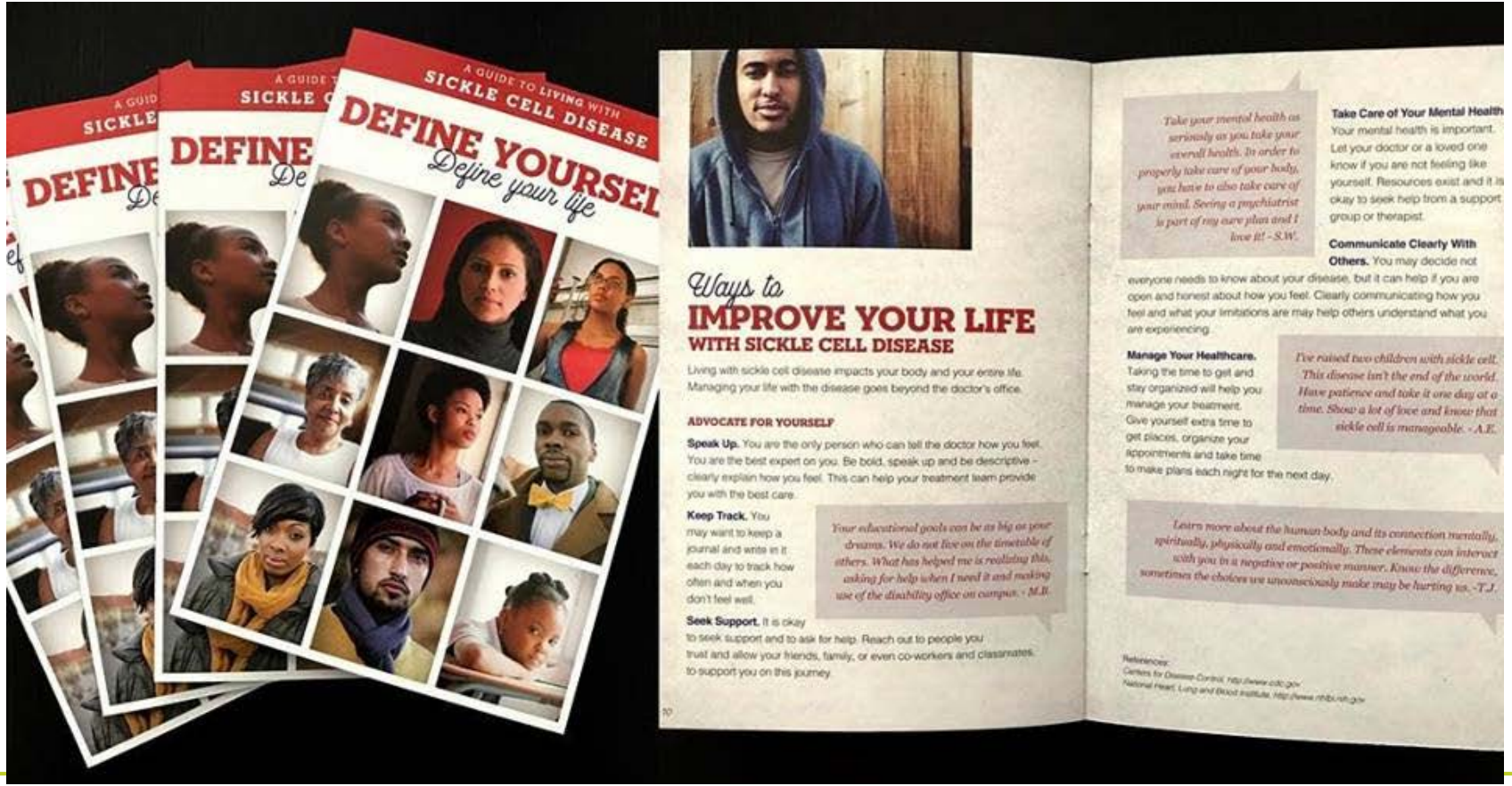
- COMPASS: **Com**munity **P**articipation to **A**dvance the **S**ickle Cell **S**tory

TRANSITION WORKGROUP

- DELPHI Transition Survey with Emory/SERC-SERGG partners to understand transition
- PINPOINT study focus group for Warriors Age 13-17 to gamify transition education materials in partnership with Hilton Publishing.
- *"CRISIS AVERTED"* Patient/Caregiver-Designed Mobile Application in Partnership with Tinashe Seremwe at the University of Bath in the United Kingdom
  - Symptom Tracking
  - Medication Tracking
  - Hospital Rating
  - Interaction with other users
  - Advice & Tips
  - Simplified PROTOTYPE available to view on YouTube
- Awarded PCORI Transition contract in partnership with Dr. Ify Osunkwo to add a mentoring component to transition. Consortium Director of Research, Dr. Raymona Lawrence, co-PI.

PATIENT-POWERED EDUCATIONAL LITERATURE SERIES

- Series began as an observation from a young warrior: “Why are there never any pamphlets or brochures about sickle cell in the hospital or doctors office?”
  - Many sickle cell warriors and caregivers agreed with her an posted comments.
- Educational Material created by the sickle cell community, for the sickle cell community.
- Patient-Powered, MD-Reviewed


A GUIDE TO LIVING WITH
SICKLE CELL DISEASE
DEFINE YOURSEL
Define your life
Ways to
IMPROVE YOUR LIFE
WITH SICKLE CELL DISEASE
Living with sickle cell disease impacts your body and your entire life. Managing your life with the disease goes beyond the doctor's office.
ADVOCATE FOR YOURSELF
Speak Up. You are the only person who can tell the doctor how you feel. You are the best expert on you. Be bold, speak up and be descriptive – clearly explain how you feel. This can help your treatment team provide you with the best care.
Keep Track. You may want to keep a journal and write in it each day to track how often and when you don't feel well.
Your educational goals can be as big as your dreams. We do not live on the timetable of others. What has helped me is realizing this, asking for help when I need it and making use of the disability office on campus. - M.B.
Seek Support. It is okay to seek support and to ask for help. Reach out to people you trust and allow your friends, family, or even co-workers and classmates to support you on this journey.
Take your mental health as seriously as you take your overall health. In order to properly take care of your body, you have to also take care of your mind. Seeing a psychiatrist is part of my care plan and I love it! - S.W.
Take Care of Your Mental Health
Your mental health is important. Let your doctor or a loved one know if you are not feeling like yourself. Resources exist and it is okay to seek help from a support group or therapist.
Communicate Clearly With Others. You may decide not everyone needs to know about your disease, but it can help if you are open and honest about how you feel. Clearly communicating how you feel and what your limitations are may help others understand what you are experiencing.
Manage Your Healthcare. Taking the time to get and stay organized will help you manage your treatment. Give yourself extra time to get places, organize your appointments and take time to make plans each night for the next day.
I've raised two children with sickle cell. This disease isn't the end of the world. Have patience and take it one day at a time. Show a lot of love and know that sickle cell is manageable. - A.E.
Learn more about the human body and its connection mentally, spiritually, physically and emotionally. These elements can interact with you in a negative or positive manner. Know the difference, sometimes the choices we unconsciously make may be hurting us. -T.J.
References:
Centers for Disease Control, http://www.cdc.gov
National Heart, Lung and Blood Institute, http://www.nhlbi.nih.gov
10

A GUIDE TO LIVING WITH SICKLE CELL DISEASE

- Over 100 warriors and caregivers participated in 3 online focus groups and 1 in-person focus group to create and design the first Patient-powered, MD-reviewed educational resource
- “A Guide to Living with Sickle Cell Disease” written by Warrior, for Warriors. First in series.
- Funded by a generous grant from Bluebird Bio.
- Project managed by Cassandra Trimnell of Sickle Cell 101, in partnership with Bold Lips for Sickle Cell
- Powered by the Sickle Cell Community Consortium

COLLECTIVE IMPACT & PARTNERSHIPS

- Make sure your organization is on the same page(write the vision, make it plan).
- You need a powerful champion for your cause (who's in your winners circle).
- Partner with uncommon people, organizations, businesses (think outside of the box).
- Know your community (survey, talk-communicate with those you intend to serve, get buy-in).
- Never assume you know what the community wants (find those with lived experiences, how do they feel about what your planning to do? Will they help?).
- Surround your self with those who know more than you (learn from others, ask questions. Don't be an island unto yourself).
- Partner with local state agencies, civil, public schools, higher learning institutions, faith based, non-profits, planning agencies, etc.., in your state (become relevant to the community).
- Tell your story (most power thing is why your connected to the cause).
- Working together requires checking your ego's and pride at the door (remain humble and teachable).
- Funding (you need money, you cannot achieve your mission without the green)

No One Ever Told Me It Would Be Easy, They Said It Would Be Worth It!

Collective Impact & partnerships

- http://www.fsg.org/publications/channeling-change
- http://www.census.gov
- http://www.collaborationforimpact.com/collective-impact/

Evaluation Reminder

Please complete the Council Meeting 2017 evaluation in order to receive continuing education credits and to provide suggestions for future topics.

We appreciate your feedback!