THEME: Sickle Cell Community Embracing Change Together

WEDNESDAY - October 9, 2019

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<td>7:00PM</td>
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<td>10:00AM</td>
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<td>Advantage Expo Exhibitor Build Out</td>
<td>Baltimore &amp; Maryland Foyer</td>
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<td>3:00PM</td>
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<td>Exhibitors Set-up</td>
<td>Baltimore &amp; Maryland Foyer</td>
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<td>9:00AM</td>
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<td>SINERGe CBO Meeting</td>
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<td>1:00PM</td>
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<td>HRSA Grant Team Meeting</td>
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<td>6:00PM</td>
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<td>Executive Leadership Council Meeting/Member Training</td>
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<tr>
<td>5:30PM</td>
<td>7:30PM</td>
<td>Community Health Worker Training</td>
<td>Fells Point</td>
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<td>8:00PM</td>
<td>10:00PM</td>
<td>SCDA Board Meeting</td>
<td>James</td>
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Program Subject to Change
THEME:  Sickle Cell Community Embracing Change Together

THURSDAY - OCTOBER 10, 2019

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<td>Poster Set-Up</td>
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7:30AM  8:30AM  **Super Power Hour**

- Breakfast
- Speed Networking

**Special Workshop**

*Stigmas & Discrimination: is this still an issue for Sickle Cell Patients*
Dominique Friend

8:00AM  9:00AM  **Breakfast Federal Hill**

8:00AM  9:15AM  **SCDAA Business Session**

Maryland EDF

9:15AM  10:00AM  **Opening Ceremony**

10:00AM  10:15AM  **Break**

10:15AM  12:00PM  **PLENARY SESSION I**

Maryland DEF

**Community Based Organization Highlights**

- **10:15AM - 10:40AM**  Legislative Victories in Indiana
  Gary Gibson

- **10:40AM - 11:05AM**  HRSA Newborn Screening Grant, Challenges and Successes
  Alysian Thomas, JD

- **11:05AM - 11:30AM**  Legislative Victories in Texas
  Tonya Prince

- **11:30AM - 11:45AM**  A New Way to Learn About Hydroxyurea
  Wanda Whitten-Shurney, MD

**Understanding the Impact of Vaso-occlusion and Vaso-occlusive Crises on Patients With Sickle Cell Disease**

Lunch and Learn Sponsored by Novartis
Kalpna Gupta, PhD
Julie Kanter, MD
Natasha Thomas

11:45AM  1:00PM  **Executive Leadership Luncheon (invite only)**

Fells Point

1:15PM  3:15PM  **CONCURRENT WORKSHOPS SESSION I**

**Beginner’s Track**

Maryland DEF

- **1:15PM - 3:15PM**  Sickle Cell Basics
  Wanda Whitten-Shurney, MD
THURSDAY - OCTOBER 10, 2019

Patient & Family Track I

1:15PM 1:45PM
New Treatments For Sickle Cell Disease: What Might The Future Hold?
James Eckman, MD

1:45PM 2:15PM
A How To Guide for Incorporating Primary Care Into Your Overall Health Care Team
Gwen Poles, DO, FACP

2:15PM 2:45PM
Thriving While Living With Sickle Cell
Andre Harris

2:45PM 3:15PM
Transfusions and Hydroxyurea: What you Need to Know
Kim Smith-Whitley, MD

Nursing Track I

1:15PM 1:45PM
Apheresis in Sickle Cell Disease
Randy Henry, RN, BSN

1:45PM 2:15PM
Pain Management and the use of Toxicology Screenings
Genice Nelson, DNP, APRN, ANP-BC and Teresa Works, LISCW
Non-Pharmacological Pain Management: Virtual Reality And Expressive Arts
Jocelyn Mallard, APN

2:45PM 3:15PM
Panel/Participant Discussion

Physician/Provider Track

1:15PM 1:45PM
Chronic SCD Pain Management in the Era of The Opioid Crisis
Wally Smith, MD

1:45PM 2:15PM
Developing a Sickle Cell Medical Home Within Your Institution
Payal Desai, MD

2:15PM 2:45PM
Management of Acute Pain in SCD
James Eckman, MD
Transition from a Pediatric Perspective: What do Adult Providers Need to Know
Andrew Campbell, MD

Psychosocial Track

1:15PM 1:45PM
Psychosocial Health in SCD
Charles Jonassaint, PhD, MHS

1:45PM 2:15PM
Psychiatric Collaborative Care Model
Judith Cavazos, PhD

2:15PM 2:45PM
Patient Reported Outcomes in Sickle Cell Disease
Patrick Carroll, MD

2:45PM 3:15PM
Stigma and SCD
Shawn Bediako, PhD

3:15PM 3:30PM
Break
**THURSDAY - OCTOBER 10, 2019**

**CONCURRENT WORKSHOPS SESSION II**

**Patient & Family Track II**  
Baltimore A

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<tr>
<th>Time</th>
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<th>Presenter(s)</th>
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<tbody>
<tr>
<td>3:30PM</td>
<td>Preparing for Transition: It's Never Too Soon</td>
<td>Andrew Campbell, MD</td>
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<tr>
<td>4:00PM</td>
<td>What You Should Know About Gene Therapy</td>
<td>Julie Kanter, MD</td>
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<tr>
<td>4:30PM</td>
<td>My Newborn Has Been Diagnosed with SCD: What Every Parent Needs to Know</td>
<td>E. Leila Jerome Clay, MD, MCTS</td>
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<tr>
<td>5:00PM</td>
<td>Why should I “Get Connected?”</td>
<td>Lewis Hsu, MD, PhD</td>
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**Nursing Track II**  
Baltimore B

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<tbody>
<tr>
<td>3:30PM</td>
<td>Nursing Leadership Running a Comprehensive SCD Center</td>
<td>Genice Nelson, DNP, APRN, ANP-BC</td>
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<tr>
<td>4:00PM</td>
<td>NP Presence in The Emergency Department During an Acute Pain Episodes-Lessons Learned</td>
<td>Tierra Blackmon, MSN, NP-C, AGACNP</td>
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<td>4:30PM</td>
<td>Hospitalist View of the Inpatient Management of the SCD patient</td>
<td>Toniqua Richardson, MSN, NP-c, AGACNP</td>
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<td>5:00PM</td>
<td>Panel/Participant Discussion</td>
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**Physician/Provider Track II**  
Federal Hill

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<tr>
<td>3:30PM</td>
<td>Integrating Community Health Workers into a Comprehensive SCD Care Model</td>
<td>Lewis Hsu, MD, PhD</td>
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<td>4:00PM</td>
<td>Novel Agents in the SCD Pipeline</td>
<td>James Eckman, MD</td>
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<td>4:30PM</td>
<td>Management of Comorbidities in Adults with SCD</td>
<td>Sophie Lanzkron, MD, MHS</td>
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<td>5:00PM</td>
<td>A Focus on Girls and Women Living with SCD</td>
<td>Kim Smith-Whitley, MD</td>
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**Psychosocial Track II**  
Homeland

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<tr>
<th>Time</th>
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<tr>
<td>3:30PM</td>
<td>Defining &quot;Community&quot; from the Perspectives of Individuals with Sickle Cell Disease in a Rural Setting</td>
<td>Raymona Lawrence, PhD</td>
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<td>4:00PM</td>
<td>Shared-Decision Making in Sickle Cell Disease</td>
<td>Lori E. Crosby, PsyD</td>
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<td>4:30PM</td>
<td>Yoga, Mind-Body Practices and Physical Activity for Preventing and Managing Sickle Cell Pain</td>
<td>Beatrice Gee, MD</td>
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<td>5:00PM</td>
<td>Virtual Reality as Complementary Pain Therapy in Hospitalized Patients With Sickle Cell Disease</td>
<td>Simon Robertson</td>
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THURSDAY - OCTOBER 10, 2019

5:30PM  6:30PM  **Young Adult Alliance**  Maryland DEF
Are We There Yet
Kay- Diene Robinson, MPH, CHW
Shanika Walls

5:30PM  6:30PM  **Patient Family Session I**  Baltimore B
How Do You Find Love When You Have An Inherited Blood Disorder?
Moderator: Dr. Marjorie Dejoie- Brewer and Charlotte Flemmings
Tristan Lee Schlachter
Andrew William Schlachter
Jean-Marc Dejoie
Edwige Dejoie

6:00PM  7:00PM  **Poster Session**  Kent
Open to Attendees

7:00PM  8:30PM  **Chairman’s Reception**  Watertable Ballroom
Sponsored by Novartis
THEME:  Sickle Cell Community Embracing Change Together

FRIDAY - OCTOBER 11, 2019

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7:30AM - 8:30AM  
Poster Judging Session  
Kent

7:30AM - 8:30AM  
Super Power Hour  
Breakfast  
Speed Networking  
Federal Hill  
Homeland

8:30AM - 9:00AM  
PLENARY SESSION I  
Charles F. Whitten, MD Memorial Lecture  
The Study of The Microbiome in Sickle Cell Disease Pain  
Amanda Brandow, DO

9:00AM - 10:00AM  
Men living with Sickle Cell Disease 2.0  
Kevin Wake  
Jerry Nwokorie  
Oladipo Cole, MD  
Dexter Darden  
Rev. Dr. Jimmie Williams

10:00AM - 10:30AM  
ASH SCD Guidelines  
Robert I. Liem, MD, MS  
Ronisha Edwards-Elliott, MSW, LSW

10:30AM - 11:30AM  
Healing The Healer Healthcare Provider Session  
Wanda Whitten-Shurney, MD

10:30AM - 11:30AM  
Parent/Caregiver Family Session  
Rob Mitchell  
Andrea Armstead  
Angela Nivens  
Cassandra White-Rivers  
Carla Lewis

11:30AM - 11:45AM  
Break

11:45AM - 12:45PM  
Sickle Cell Disease & Brain Health  
*Sponsored by Global Blood Therapeutics  
*(Registration Required)  
Carolyn Hoppe, MD  
Melanie Fields, MD, MSCI  
Jeremie Estepp, MD

11:45AM - 12:45PM  
Lunch with IASCNAPA  
Federal Hill

In Our Own Words - The Impact of Living with Sickle Cell Disease  
*Pre-Registration Required*

1:00PM - 1:30PM  
PLENARY SESSION II  
Clarice Reid, MD Lecture  
The Case for Compassionate Comprehensive Care for Children and Adults with Sickle Cell Disease  
Marie Russell, MD

1:30PM - 1:45PM  
Break

Program Subject to Change
### FRIDAY - OCTOBER 11, 2019

**SIMULTANEOUS SESSION I**

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<tr>
<th>Time</th>
<th>Title</th>
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<tr>
<td>1:45PM</td>
<td><strong>Clinical Research</strong></td>
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<td>ARU-1801, An Investigational Gene Therapy Using A Modified Gamma-Globin Vector And Reduced-Intensity Bone Marrow Conditioning, Shows Promising Correction Of Sickle Cell Disease Phenotype</td>
<td>Michael Grimley, MD</td>
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<td>2:00PM</td>
<td>Addressing The Viewpoints On Contraception Of Adolescents With Sickle Cell Disease</td>
<td>Phanirekha Chandra</td>
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<td>2:15PM</td>
<td>New Educational Initiative To Enhance TCD Implementation: Results From The Displace Study</td>
<td>Julie Kanter, MD</td>
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<td>2:30PM</td>
<td>The Sickle Cell Disease Adult Patient Experience: The Milestones That Map The Emotional Journey</td>
<td>Cassandra Trimnell</td>
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<td>2:45PM</td>
<td>A Prospective Phase II, Open-Label, Single-Arm, Multicenter Study To Assess The Efficacy And Safety Of SEG101 (Crizanlizumab) In Sickle Cell Disease Patients With Priapism (SPARTAN)</td>
<td>Gregory Kato, MD</td>
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<td>3:00PM</td>
<td>A Phase II Randomized, Double-Blind, Placebo-Controlled Multi-Center Study To Assess The Safety, Tolerability, And Efficacy Of Riociguat In Patients With Sickle Cell Disease (Sterio-SCD)</td>
<td>Gregory Kato, MD</td>
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<td>3:15PM</td>
<td>Results From The Randomized Placebo-Controlled Phase 3 Hope Trial Of Voxelotor In Adults And Adolescents With Sickle Cell Disease</td>
<td>Carolyn Hoppe, MD</td>
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<td>3:30PM</td>
<td>Safety And Efficacy Of Lentiglobin Gene Therapy In Patients With Sickle Cell Disease</td>
<td>Julie Kanter, MD</td>
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<td>3:45PM</td>
<td>Pediatric Sickle Cell Disease Screening Using Cellulose Acetate Electrophoresis At A Hospital In Uganda</td>
<td>James Mubiru, PhD</td>
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<td>4:00PM</td>
<td>Introducing the Sickle Cell Disease Index</td>
<td>James Taylor, MD</td>
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<td>4:15PM</td>
<td>A Multicenter, Open-Label, Randomized, Phase II Study Evaluating The Effect Of Crizanlizumab Plus Standard Of Care Versus Standard Of Care Alone On Renal Function In Patients With Sickle Cell Disease And Chronic Kidney Disease (STEADFAST)</td>
<td>Kenneth I. Ataga</td>
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<td>4:30PM</td>
<td>SCD-101: Novel Anti-Sickling Agent Reduces Pain, Fatigue And Improves Vascular Flow In Patients With Sickle Cell Disease</td>
<td>Khalid Elbashir, MD, MPH</td>
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**FRIDAY - OCTOBER 11, 2019**

| 5:00PM - 5:15PM | A Randomized, Double-Blind, Phase III Study (Stand) Of Crizanlizumab Versus Placebo, With Or Without Hydroxyurea/Hydroxycarbamide In Adolescents And Adults With Sickle Cell Disease And Vaso-Occlusive Crises  
Wally Smith, MD |
|-----------------|----------------------------------------------------------------------------------------------------|
| 5:15PM - 5:30PM | Moringa Oleifera Extract Regulates The Expression Of Some Sickle Cell Related Genes  
Mojisola Cyril-Olutayo, PhD |

**Community Based/Psychosocial Research**

| 1:45PM - 2:00PM | Youth And Caregiver Perspectives On Barriers And Facilitators To Hydroxyurea Uptake In Pediatric Sickle Cell Disease  
Aimee Hildenbrand, PhD |
|-----------------|------------------------------------------------------------------------------------------------------------------|
| 2:00PM - 2:15PM | Likelihood And Motivations For Patients To Enroll In A Sickle Cell Disease Registry  
Cortney Alleyne |
| 2:15PM - 2:30PM | Patient-Reported Complications Of Sickle Cell Disease With The Greatest Impact On Quality Of Life  
Anjulika Chawla, MD, FAAP |
| 2:30PM - 2:45PM | Transportation & Health: Improving Access To Care For Pediatric Patients With Sickle Cell Disease Through Rideshare Apps  
Lindsay Thomson BS, MBS, Simone Vais, BA |
| 2:45PM - 3:00PM | Strategies Used For Management Of Sickle Cell Disease And Evaluation Of Patient Satisfaction Levels: An Interim Analysis Of The International Sickle Cell World Assessment Survey (SWAY)  
John James |
| 3:00PM - 3:15PM | Beyond Pain: The Symptoms And Impacts Of Sickle Cell Disease On Children And Their Caregivers  
Clark Brown, MD, PhD |
| 3:15PM - 3:30PM | Advocating for Senate Bill 600/House Bill 761: Archival Research on Sickle Cell Disease  
Rayna Wallace, BS |
| 3:30PM - 3:45PM | Faces Of Sickle Cell Disease (SCD) Storytelling Program: The Power Of Patient Narratives  
Ashley Valentine, MRes |
| 3:45PM - 4:00PM | John Henryism And Sickle Cell Disease: Active Coping With Stress  
Kayla Cooper, BA |
| 4:00PM - 4:15PM | Investigating ‘No Shows’ At A Hospital-Based Pediatric Sickle Cell Disease Clinic  
Nicole Bohnker, MPH |
Prof. Aba Bentil Andam |
| 4:30PM - 4:45PM | Assessing Post-Traumatic Stress Disorder, Anxiety And Depression In Caregivers Of Children With Sickle Cell Disease.  
La'Shardae Scott, BS |
| 4:45PM - 5:00PM | Patient Centered Video Education: A New Information Resource Focused On Avoiding Blood Transfusion Complications.  
|
FRIDAY - OCTOBER 11, 2019

Ashley Singleton, MPH

5:00PM 5:15PM
Group Healthcare Education for Sickle Cell Adolescent Patients Transitioning to Adult Care
Ronisha Edwards-Elliott, MSW, LSW

5:15PM 5:30PM
The Impact Of Sickle Cell Disease Symptoms On Patients' Daily Lives: Interim Results From The International Sickle Cell World Assessment Survey (SWAY)
Ifeyinwa Osunkwo

Public Health

Maryland EF

1:45PM 2:00PM
Evaluation Of Variables Affecting The Care Of Patients With Sickle Cell Disease By Us Location
Julie Kanter, MD

2:00PM 2:15PM
Hospitalizations For Older Adults Living With Sickle Cell Disease – Data From The California Sickle Cell Data Collection Program 2004-2016
Mary Hulihan, DrPH

2:15PM 2:30PM
Leveraging A Community Health Worker Program To Improve Access To Health Care For Sickle Cell Disease In Georgia
Jeanette Nu'man

2:30PM 2:45PM
Sickle Life Adolescent Mentorship Project
Emmanuel Kofi Danso

2:45PM 3:00PM
Motivators And Barriers Of Physical Activity Among Adolescents With Chronic Disease: Literature Review
Olalekan Olorunyomi, MS

3:00PM 3:15PM
Identification Of Sickle Cell Super-Utilization, A Single Institution Experience
Titilope Fasipe, MD, PhD

3:15PM 3:30PM
"Lessons Learned" From Community Health Workers During The Habit Study
Yina Castillo, BA Lucy Soriano, AA

3:30PM 3:45PM
Establishing A Sickle Cell Center In The New York City (NYC) Public Hospital Setting
Linda Bulone, RN, OCN, CCRC

3:45PM 4:00PM
Supporting The Student With Sickle Cell Disease: Promoting Proactive Planning Through The Use Of A Comprehensive School-Based Handbook
Trudy Tchume-Johnson, LSW, Kaitlin Murtagh, BA

4:00PM 4:15PM
Legal Processes For Access To Health And Social Assistance In Sickle Cell Disease In Brazil
Evanilda Carvalho

4:15PM 4:30PM
Diagnosis And Short-Term Follow-Up Of Newborns Identified With Sickle Disease By Newborn Screening In California, 2011-2018
Patricia McLendon, MPH

4:30PM 4:45PM
Older Adults Living With Sickle Cell Disease – Data From The California Sickle Cell Data Collection Program 2004-2016
Susan Paulukonis

4:45PM 5:00PM
Short and Long Term Goals of Young Adults with Sickle Cell Disease
Tahirah Austin, MPH, Evelyn Stevens, MPH
FRIDAY - OCTOBER 11, 2019

5:00PM - 5:15PM  Patients' Experience With Sickle Cell Disease: Treatment Patterns, Management Of Vaso-Occlusive Crises, And Barriers To Care
   Jincy Paulose, MD

6:00PM - 6:45PM  Red Carpet Reception
   Featuring Red Carpet Interviews
   Maryland CDEF

7:00PM - 10:30PM  UNITY SOIREE
   Theme: Caribbean Night
   Maryland CDEF
THEME: Sickle Cell Community Embracing Change Together

SATURDAY - OCTOBER 12, 2019

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<td>Exhibitor Breakdown</td>
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7:30AM 8:30AM | Super Power Hour  
Breakfast  
Speed Networking | Baltimore Foyer  
Homeland |

8:00AM 10:00AM | Community Health Worker Training | Fells Point |

8:00AM 10:00AM | SCDAA Board Meeting | James |

9:30AM 11:45AM | Clinical Trial Update | Maryland DEF |

11:45AM 1:15pm | Lonzie Lee Jones Patient Advocacy Symposium  
Sponsored by Pfizer | Maryland DEF |

1:15pm 2:15pm | Lunch and Learn  
Sponsored by Cyclerion | Maryland DEF |

1:15pm 2:15pm | Patient Empowerment Luncheon (Registration Required)  
Sponsored by UCONN | Homeland |

2:15PM 3:15PM | National Partner Updates  
American Society of Hematology  
National Heart, Lung, and Blood Institute  
Health Resources and Services Administration  
Center for Disease Control  
Food and Drug Administration  
Office of Minority Health | Maryland DEF |

3:15PM 3:30PM | Closing Assembly & Adjournment  
Beverley Francis-Gibson | Maryland DEF |
Title/Author
Why Adult Provider Readiness Is More Important Than Patient Readiness During Transition
Teresa Works, MSW, LCSW

Improving Appointment Adherence Among Pediatric Patients With Sickle Cell Disease
Joseph Delagrange, MSSA, LSW

Dreamsickle Kid's Foundation Mission to #MakeSickleCellPopular in Nevada
Georgene Glass

Treatment Of Moderate To Severe Anemia In Sickle Cell Disease: Results From A 2018 Us Patient Chart Analysis
Robin Howard

Sickle Cell Trait Identification, Notification, And Education In Maryland: Provider Survey
Monika Piccardi, RN, BSN, MS

Greater Depression Increases Risk Of Suicide For Adults With Sickle Cell Disease (SCD)
Brianna Jones, M.A

An Integrative Review Of The Prevalence Of Depression Among Pediatric Patients With Sickle Cell Disease
Kendall Moody

Engaging Individuals with Sickle Cell Disease and Their Caregivers in Clinical Research Education through Sickle Cell Community Research 101
Delores Quasie Woode

Sickle Cell Disease And Legs Ulcers: Barriers To Access The Health Care In Bahia - Brazil
Evanilda Carvalho

Sickle Cell Team: Timely, Effective, Approach, Multidisciplinary
Katie Cherenzenia MSN, RN, ACCNS-AG, OCN

Building Sustainable Networks To Combat Blood Donation Shortages Starts With Community Engagement
Nina Anderson

Knowledge, Attitudes, And Practices Study Of Sickle Cell Disease Students And Their Parents At A Secondary School In Uganda.
James Mubiru, PhD
Brazilian Man’s Conversations: Discussions On Prispism In Sickle Cell Disease
Evanilda Carvalho

Advocating For Clinic-Based Newborn Sickle Cell Screening In Rural Africa
Derek Mubiru

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