

THEME: Sickle Cell Community Embracing Change Together

WEDNESDAY - October 9, 2019

START TIME	END TIME	ACTIVITY	ROOM
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7:00PM	9:00PM	Registration	Foyer
7:00PM	9:00PM	Get Connected Kiosk	Foyer
10:00AM	4:00PM	Advantage Expo Exhibitor Build Out	Baltimore & Maryland Foyer
3:00PM	9:00PM	Exhibitors Set-up	Baltimore & Maryland Foyer

9:00AM 4:00PM SiNERGe CBO Meeting
Invitation Only Gibson

1:00PM 5:30PM **Special Trainings**
HRSA Grant Team Meeting
Invitation Only Baltimore A

6:00PM 8:00PM Executive Leadership Council Meeting/Member
Training
Invitation Only Baltimore A

5:30PM 7:30PM Community Health Worker Training Fells Point

8:00PM 10:00PM SCDA Board Meeting James

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THURSDAY - OCTOBER 10, 2019

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7:30AM	5:00PM	Registration	Foyer
7:30AM	5:00PM	Get Connected Kiosk	Foyer
7:30AM	10:00AM	Exhibitor Set-up	Baltimore & Maryland Foyer
11:00AM	5:30PM	Exhibits Open	Baltimore & Maryland Foyer
3:00PM		Poster Set-Up	Baltimore & Maryland Foyer
7:30AM	8:30AM	Super Power Hour Breakfast Speed Networking	Federal Hill Homeland
8:00AM	9:00AM	Special Workshop Stigmas & Discrimination: is this still an issue for Sickle Cell Patients Dominique Friend	Baltimore A
8:00AM	9:15AM	SCDAA Business Session	Maryland EDF
9:15AM	10:00AM	Opening Ceremony	
10:00AM	10:15AM	Break	Baltimore & Maryland Foyer
10:15AM	12:00PM	PLENARY SESSION I Community Based Organization Highlights	Maryland DEF
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	
11:45AM	1:00PM	Understanding the Impact of Vaso-occlusion and Vaso-occlusive Crises on Patients With Sickle Cell Disease	Maryland DEF
		Lunch and Learn Sponsored by Novartis Kalpna Gupta, PhD Julie Kanter, MD Natasha Thomas	
11:45AM	1:00PM	Executive Leadership Luncheon <i>(Invite only)</i>	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	

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Patient & Family Track I

Baltimore A

- | | | |
|--------|--------|--|
| 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

Baltimore B

- | | | |
|--------|--------|--|
| 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 |
| 2:15PM | 2:45PM | Non-Pharmacological Pain Management: Virtual Reality And Expressive Arts
Jocelyn Mallard, APN |
| 2:45PM | 3:15PM | Panel/Participant Discussion |

Physician/Provider Track

Federal Hill

- | | | |
|--------|--------|--|
| 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 |
| 2:45PM | 3:15PM | Transition from a Pediatric Perspective: What do Adult Providers Need to Know
Andrew Campbell, MD |

Psychosocial Track

Homeland

- | | | |
|--------|--------|---|
| 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

- 3:30PM 4:00PM Preparing for Transition: It's Never Too Soon
Andrew Campbell, MD
- 4:00PM 4:30PM What You Should Know About Gene Therapy
Julie Kanter, MD
- 4:30PM 5:00PM My Newborn Has Been Diagnosed with SCD: What Every
Parent Needs to Know
E. Leila Jerome Clay, MD, MCTS
- 5:00PM 5:30PM Why should I "Get Connected?"
Lewis Hsu, MD, PhD

Nursing Track II

Baltimore B

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

Physician/Provider Track II

Federal Hill

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

Psychosocial Track II

Homeland

- 3:30PM 4:00PM Defining "Community" from the Perspectives of Individuals
with Sickle Cell Disease in a Rural Setting
Raymona Lawrence, PhD
- 4:00PM 4:30PM Shared-Decision Making in Sickle Cell Disease
Lori E. Crosby, PsyD
- 4:30PM 5:00PM Yoga, Mind-Body Practices and Physical Activity for
Preventing and Managing Sickle Cell Pain
Beatrice Gee, MD
- 5:00PM 5:30PM Virtual Reality as Complementary Pain Therapy in
Hospitalized Patients With Sickle Cell Disease
Simon Robertson

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5:30PM	6:30PM	Young Adult Alliance Are We There Yet Kay- Diene Robinson, MPH, CHW Shanika Walls	Maryland DEF
5:30PM	6:30PM	<i>Patient Family Session I</i> How Do You Find Love When You Have An Inherited Blood Disorder? Moderator: Dr. Marjorie Dejoie- Brewer and Charlotte Flemmings Tristian Lee Schlachter Andrew William Schlachter Jean-Marc Dejoie Edwige Dejoie	Baltimore B
6:00PM	7:00PM	<i>Poster Session</i> Open to Attendees	Kent
7:00PM	8:30PM	Chairman's Reception Sponsored by Novartis	Watertable Ballroom

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FRIDAY - OCTOBER 11, 2019

START TIME	END TIME	ACTIVITY	ROOM
7:30AM	5:00PM	Registration	Foyer
7:30AM	5:00PM	Get Connected Kiosk	Foyer
7:30AM	7:00PM	Exhibits	Baltimore & Maryland Foyer
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	Maryland EDF
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	Maryland EDF
10:30AM	11:30AM	Healing The Healer Healthcare Provider Session Wanda Whitten-Shurney, MD	Baltimore A
10:30AM	11:30AM	Parent/Caregiver Family Session Rob Mitchell Andrea Armstead Angela Nivens Cassandra White-Rivers Carla Lewis	Maryland EDF
11:30AM	11:45AM	Break	
11:45AM	12:45PM	Sickle Cell Disease & Brain Health <i>Sponsored by Global Blood Therapeutics</i> <i>(Registration Required)</i> Carolyn Hoppe, MD Melanie Fields, MD, MSCI Jeremie Estep, MD	Maryland EDF
11:45AM	12:45PM	Lunch with IASCNAPA In Our Own Words - The Impact of Living with Sickle Cell Disease <i>Pre-Registration Required</i>	Federal Hill
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	Maryland EDF
1:30PM	1:45PM	Break	

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SIMULTANEOUS SESSION I

Clinical Research

Baltimore B

1:45PM	2:00PM	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 Michael Grimley, MD
2:00PM	2:15PM	Addressing The Viewpoints On Contraception Of Adolescents With Sickle Cell Disease Phanirekha Chandra
2:15PM	2:30PM	New Educational Initiative To Enhance TCD Implementation: Results From The Displace Study Julie Kanter, MD
2:30PM	2:45PM	Utilization Of Echo® Telementoring Sessions To Increase Knowledge In The Treatment Of Sickle Cell Disease For Providers Of Care Rosalyn Stewart, MD, MS, MBA, FAAP, FACP
2:45PM	3:00PM	The Sickle Cell Disease Adult Patient Experience: The Milestones That Map The Emotional Journey Cassandra Trimnell
3:00PM	3:15PM	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) Gregory Kato, MD
3:15PM	3:30PM	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) Gregory Kato, MD
3:30PM	3:45PM	Results From The Randomized Placebo-Controlled Phase 3 Hope Trial Of Voxelotor In Adults And Adolescents With Sickle Cell Disease Carolyn Hoppe, MD
3:45PM	4:00PM	Safety And Efficacy Of Lentiglobin Gene Therapy In Patients With Sickle Cell Disease Julie Kanter, MD
4:00PM	4:15PM	Pediatric Sickle Cell Disease Screening Using Cellulose Acetate Electrophoresis At A Hospital In Uganda James Mubiru, PhD
4:15PM	4:30PM	Introducing the Sickle Cell Disease Index James Taylor, MD
4:30PM	4:45PM	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) Kenneth I. Ataga
4:45PM	5:00PM	SCD-101: Novel Anti-Sickling Agent Reduces Pain, Fatigue And Improves Vascular Flow In Patients With Sickle Cell Disease Khalid Elbashir, MD, MPH

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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

Baltimore A

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

4:15PM 4:30PM Sickle Cell Condition Advocates (SICCA): Making A Positive Impact In Our Community In Ghana.
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.

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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

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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

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SATURDAY - OCTOBER 12, 2019

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8:30AM	3:00PM	Registration	Foyer
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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	Plenary IV Clinical Trial Update	Maryland DEF
11:45AM	1:15pm	Lonzie Lee Jones Patient Advocacy Symposium <i>Sponsored by Pfizer</i>	Maryland DEF
1:15pm	2:15pm	Lunch and Learn <i>Sponsored by Cycleron</i>	Maryland DEF
1:15pm	2:15pm	Patient Empowerment Luncheon (<i>Registration Required</i>) <i>Sponsored by UCONN</i>	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 Beverly 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 Cherenzia 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

A Need For Universal Sickle Cell Disease Screening In New Born Babies In Uganda
And Sub-Suهران Africa
James Mubiru

The Impact Of Psychosocial Factors In Patients With Sickle Cell Disease (SCD)
Jessica Miller

A Year In The Life Of A CBO-Building An Outreach Team
Mark Goodwin

Interpretation Of Pain And Use Of Non-Pharmacological Measures By Persons With
Sickle Cell Disease In Bahia -Brazil
Evanilda Carvalho

Ohio School Nurse Assessment Program (OSNAP 2019) - Knowledge And Comfort
Treating Sickle Cell Disease
Lisa Shook, MA, MCHES