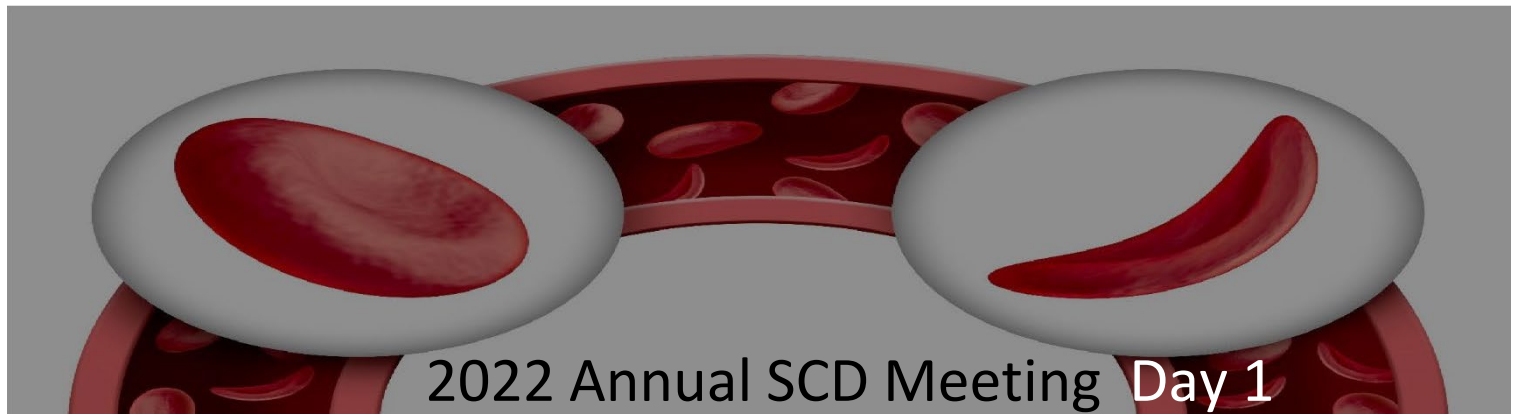


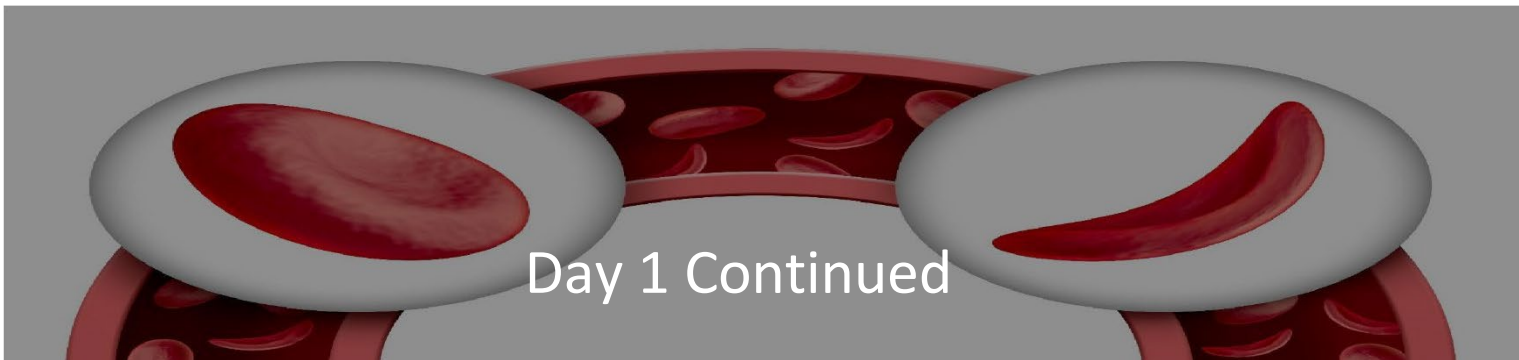
**Annual SCD Virtual Meeting  
August 8-10, 2022**





# 2022 Annual SCD Meeting Day 1

9:00-5:30pm	<b>MONDAY MEETING TIME (EDT) – August 8<sup>th</sup></b>
9:00-9:10am	<p><b>Welcome and Announcements</b>  <i>Dr. Julie Panepinto</i>, Acting Director, Division of Blood Diseases &amp; Resources  National Heart, Lung, and Blood Institute, NIH</p> <p><i>Dr. Pankaj Qasba</i>, Division of Blood Diseases &amp; Resources  National Heart, Lung, and Blood Institute, NIH</p>
9:10-1:00pm	<b>SYMPOSIUM 1</b>
9:10-10:10am	<p><b>DISPLACE: Top Line Findings</b>  <i>Dr. Julie Kanter</i>, University of Alabama</p> <p><b>Qualitative Assessments in DISPLACE</b>  <i>Dr. Shannon Phillips</i>, Medical University of South Carolina</p> <p><b>Qualitative Findings in DISPLACE</b>  <i>Dr. Alyssa Schlenz</i>, University of Colorado</p>
10:10-10:40am	<p><b>Optimization of Hydroxyurea Dosing in SCD; Literature Review &amp; Results of the REACH Study (Realizing Effectiveness Across Continents With Hydroxyurea)</b>  <i>Dr. Russell Ware</i>, Cincinnati Children’s Hospital</p>
10:40-11:00am	<p><b>The Spleen’s Erythrocyte-Filtration Function and Sickle Cell Disease</b>  <i>Dr. Ming Dao</i>, Massachusetts Institute of Technology  <i>Dr. Pierre Buffet</i>, Université de Paris</p>
11:00-11:20am	<p><b>Leukocyte Driven Resolution of Hepatic Injury in Sickle Cell Disease Mice</b>  <i>Dr. Tirthadipa Pradhan-Sundd</i>, University of Pittsburgh</p>
11:20-11:40am	<p><b>SickleInAfrica: Health and Research in Sickle Cell Disease in Africa</b>  <i>Dr. Julie Makani</i>, Muhimbili, University of Health and Allied Sciences, Tanzania</p>
11:40-12:00pm	<p><b>SCD CARRE: Sickle Cell Disease and Cardiovascular Risk - Red Cell Exchange Trial</b>  <i>Dr. Darrell Triulzi</i>, University of Pittsburgh</p>
12:00-12:20pm	<p><b>Magnetic Characterization of SCD RBCs. Potential for Diagnosis &amp; Magnetic Removal of SCD RBCs From Transfusion Waste</b>  <i>Dr. Jeffrey Chalmers</i>, Ohio State University</p>
12:20-12:50pm	<b>LUNCH</b>
12:50-5:00pm	<b>SYMPOSIUM 2</b>
12:50-3:20pm	<p><b>Curative Therapies for SCD- I</b>  Chair: <i>Dr. Lakshmanan Krishnamurti</i>, Yale University</p> <p><b>Alemtuzumab Clearance, Lymphocyte Count, and T-cell Chimerism After Hematopoietic Stem Cell Transplant in Sickle Cell Disease</b>  <i>Dr. Matthew Hsieh</i>, National Heart, Lung, and Blood Institute</p>



Day 1 Continued

**Improvement of Child Physical and Emotional Functioning After Familial Haploidentical Stem Cell Transplant**

*Dr. Susan Parsons, Tufts Medical Center*

**Clonal Hematopoiesis and the Risk of Hematologic Malignancies After Curative Therapies for Sickle Cell Disease**

*Dr. Courtney Fitzhugh, National Heart, Lung and Blood Institute*

**Primary Caregiver Decision-Making in Hematopoietic Cell Transplantation and Gene Therapy for Sickle Cell Disease**

*Dr. Cynthia Sinha, Emory University*

**Allogeneic Haematopoietic Stem Cell Transplantation Resets T- and B-Cell Compartments in Sickle Cell Disease Patients**

*Dr. Kelen Malmegrim, University of São Paulo*

**Long-term Survival After Hematopoietic Cell Transplant for Sickle Cell Disease Compared to the United States Population**

*Dr. Mary Eapen, Medical College of Wisconsin*

**Long-Term Health Effects of Curative Therapies on Heart, Lungs, and Kidneys for Individuals with Sickle Cell Disease Compared to Those with Hematologic Malignancies**

*Dr. Rohini Chakravarthy, Vanderbilt University Medical Center*

**A Decision Support Tool for Allogeneic Hematopoietic Stem Cell Transplantation for Children With Sickle Cell Disease**

*Anirudh Veludhandi, Emory University*

**Diminished Ovarian Reserve in Young Women With Sickle Cell Anemia**

*Dr. Lydia Pecker, Johns Hopkins University*

**Patient Reported Outcomes, Physical Function, and Fertility: STELLAR Study**

*Dr. Lakshmanan Krishnamurti, Yale University*

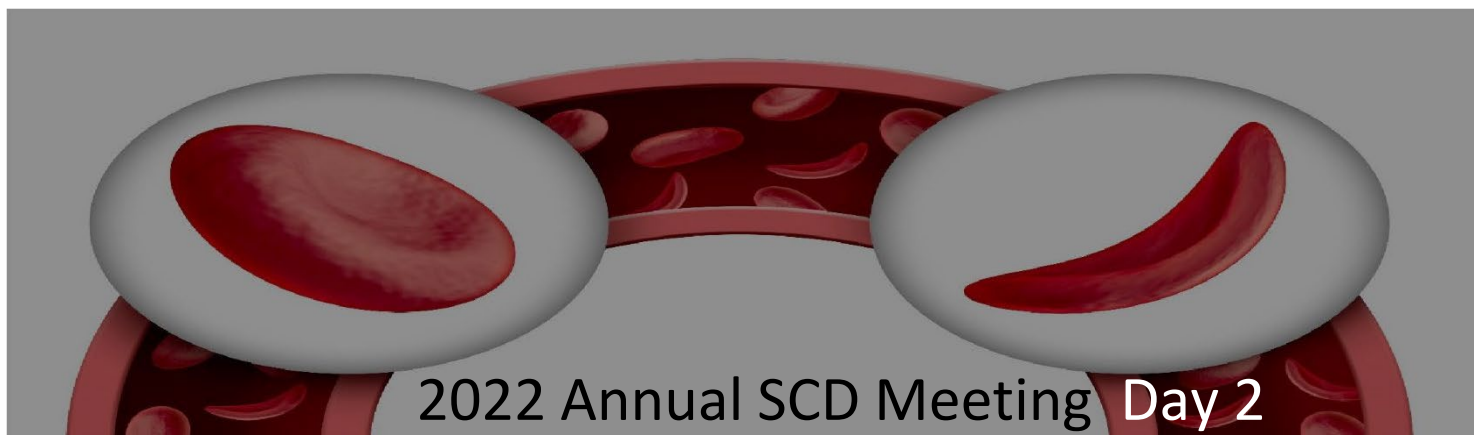
3:20-3:30pm

**BREAK**



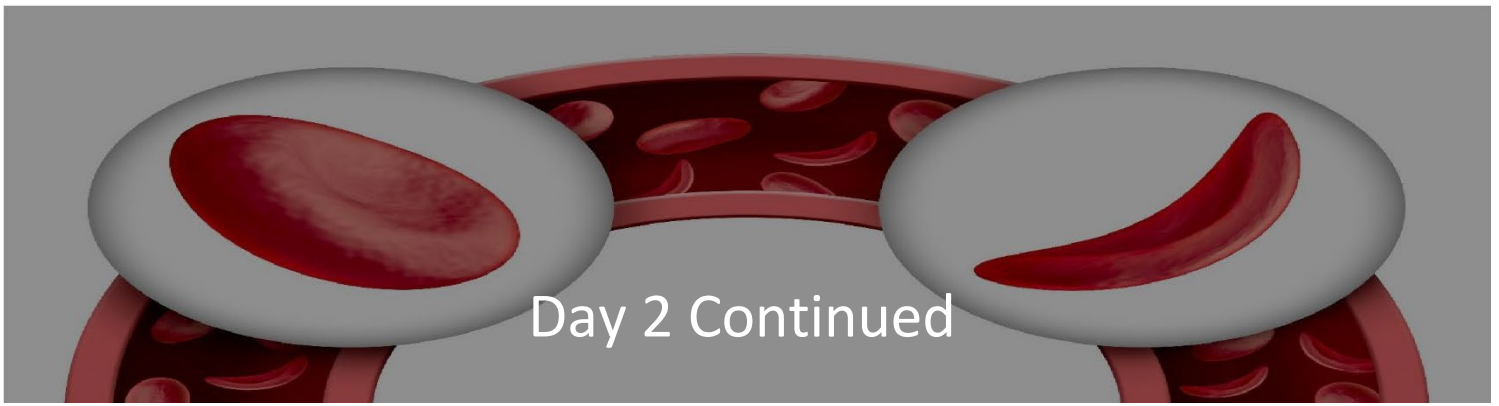
## Day 1 Continued

3:30-5:00pm	<p><b>Curative Therapies for SCD- II (Gene Therapy/Editing)</b> Chair: <i>Dr. Punam Malik</i>, Cincinnati Children’s Hospital</p>
3:30-3:45pm	<p><b>The Sickle Bone Marrow Microenvironment</b> <i>Dr. Leslie Silberstein</i>, Boston Children’s Hospital</p>
3:45-4:00pm	<p><b>Homing and Engraftment of Genetically Modified Cells</b> <i>Dr. Punam Malik</i>, Cincinnati Children’s Hospital</p>
4:00-4:15pm	<p><b>Overview of Gene Therapy and Gene editing</b> <i>Dr. Dan Bauer</i>, Boston Children’s Hospital</p>
4:15-4:30pm	<p><b>Update on Lentiglobin Gene Therapy for SCD</b> <i>Dr. John Tisdale</i>, National Heart, Lung, and Blood Institute, NIH</p>
4:30-4:45pm	<p><b>Base Editing for Sickle Cell Disease</b> <i>Dr. Annarita Miccio</i>, Imagine, Paris, France</p>
4:45-5:00pm	Q&A
5:00-5:30pm	<p><b>Curative Therapies of SCD-III (Updates on Trials Supported by NHLBI)</b></p>
5:00-5:10pm	<p><b>Updates on Allogeneic Stem Cell Transplant Trials – BMT CTN 1503: Comparison of BMT With Standard Care in Adults With SCD (Chairs: Krishnamurti, Walters) and BMT CTN 1507: HLA haplo-ID BMT for Sickle Cell Disease (Chairs: Kassim, Walters, DeBaun, Brodsky)</b> <i>Dr. Mark Walters</i>, University of California San Francisco</p>
5:10-5:20pm	<p><b>The GRASP Trial, a Phase 2 Trial to Flip the Fetal Switch in SCD</b> <i>Dr. David A. Williams</i>, Boston Children’s Hospital</p>
5:20-5:30pm	Q&A



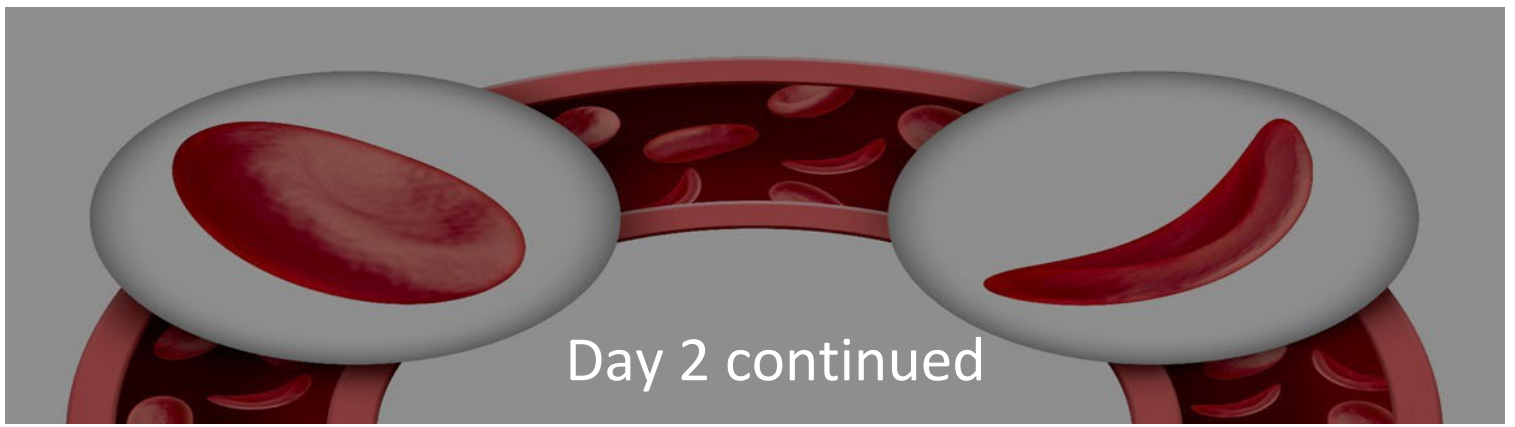
## 2022 Annual SCD Meeting Day 2

9:00-5:10pm	<b>TUESDAY MEETING TIME (EDT) - August 9th</b>
9:00-9:05am	<b>Welcome and Announcements</b>
9:05-12:40pm	<b>SYMPOSIUM 3</b>
9:05-10:30am	<p><b>SCDC Surveillance System</b> <i>Dr. Mary Hulihan, Center for Disease Control and Prevention</i></p> <p><b>SCDC &amp; Data Modernization</b> <i>Dr. Jane Hankins, St. Jude Children's Hospital</i></p> <p><b>SCDC &amp; Healthcare Utilization</b> <i>Dr. Mariam Kayle, Duke University</i></p> <p><b>SCDC &amp; Access To Healthcare</b> <i>Dr. Jhaqueline Valle, California Department of Public Health</i></p> <p><b>SCDC &amp; Healthcare Policy</b> <i>Dr. Sarah Reeves, University of Michigan</i> <i>Dr. Dominic Smith, Michigan Department of Health and Human Services</i></p> <p><b>SCDC &amp; COVID-19</b> <i>Dr. Angela Snyder, Georgia State University</i></p>
10:30-12:00pm	<p><b>Findings From the Sickle Cell Disease Implementation Consortium(SCDIC-1)</b> <i>Chair: Dr. Robert Gibson, Augusta University</i></p>
10:30-10:38am	<p><b>Overview of SCDIC</b> <i>Dr. Robert Gibson, Augusta University</i></p>
10:38-10:48am	<p><b>Transforming Sickle Cell Care: A Collaborative Journey: Value of a Community Stakeholder Advisory Board</b> <i>Beverly Chukwudozie, Dorinda Lawrence, Bridget Reynolds, Dr. Lewis Hsu, University of Illinois at Chicago</i></p>
10:48-11:00am	<p><b>Life Time Narratives From Unaffiliated Individuals With SCD</b> <i>Dr. Robert Gibson, Augusta University</i> <i>Dr. Siera Gollan, Augusta University</i></p>
11:00-11:12am	<p><b>Multi-level Influential Factors of Hydroxyurea Adherence in Sickle Cell Disease</b> <i>Dr. Jane Hankins, St. Jude Children's Hospital</i></p>
11:12-11:24am	<p><b>ALIGNing Expectations for the Treatment of VOE in the ED</b> <i>Dr. Paula Tanabe, Duke University</i></p>
11:24-11:36am	<p><b>Evaluation of the Impact of COVID-19 on Individuals With Sickle Cell Disease in the U.S. Using Patient Reported Outcomes</b> <i>Dr. Priya Parikh, UCSF</i></p>
11:36-11:48am	<p><b>High Body Mass Index in Adults with Sickle Cell Disease: A Report from the Sickle Cell Disease Implementation Consortium Registry</b> <i>Dr. Stephanie Ibemere, Duke University</i></p>
11:48-12:00pm	<p><b>Fertility &amp; Infertility Outcomes Among Males &amp; Females With Sickle Cell Disease in the SCDIC Registry</b> <i>Dr. Eleanor Stevenson, Duke University</i></p>



## Day 2 Continued

12:00-12:40pm	<p><b>ASH Research Collaborative: Using a Clinical Trial Network to Generate Real World Evidence in SCD</b></p> <p><i>Chair: Dr. Charles Abrams, University of Pennsylvania Dr. Nicole Mortier, American Society of Hematology Dr. Kathleen Hewitt, American Society of Hematology Dr. Emily Tucker, American Society of Hematology Dr. Alexis Thompson, Children’s Hospital of Philadelphia Dr. William Allen Wood Jr., University of North Carolina</i></p>
12:40-1:00pm	<b>LUNCH</b>
1:00-5:10pm	<b>SYMPOSIUM 4</b>
1:00-1:30pm	<p><b>The Abnormal Presence of Mitochondria in Circulating Red Blood Cells Associated With Stress Erythropoiesis in the Mouse Model</b></p> <p><i>Dr. Angela Rivers, University of California</i></p>
1:30-3:30pm	<p><b>Transformative Technologies to Assess Blood Component Function in Sickle Cell Disease</b></p> <p><i>Chair: Dr. Vivien Sheehan, Emory University</i></p> <p><b>OcclusionChip: a Functional Microcapillary Occlusion Assay Complementary to Ektacytometry for Assessing Red Cell Health in Sickle Cell Disease</b></p> <p><i>Dr. Umut Gurkan, Case Western Reserve University</i></p> <p><b>RBC Functional Analysis After Curative Cellular Therapies</b></p> <p><i>Dr. Tami John, Texas Children’s Hospital/Baylor College of Medicine</i></p> <p><b>Leveraging Microfluidics Assays as Functional Analysis Tools in Sickle Cell Disease</b></p> <p><i>Dr. Christina Caruso, Emory University</i></p> <p><b>Production of Extensively Expanded Erythroblast Progenitors From Human Peripheral Blood By Bmi-1 Overexpression</b></p> <p><i>Dr. John Roback, Emory University</i></p> <p><b>Technologies for Assessing Red Cell Polymerization and Biomechanics and Whole Blood Rheology</b></p> <p><i>Dr. David Wood, University of Minnesota</i></p>
3:30-4:10pm	<p><b>H3 AFRICA</b></p> <p><i>Drs. Solomon Aquah; Ambroise Wonkam</i></p>
3:30-3:50pm	<p><b>The SickleGenAfrica Cohort: Collaborative Resource for Clinical and Translational Research in Sickle Cell Disease</b></p> <p><i>Dr. Solomon Aquah, University of Ghana</i></p>
3:50-4:10pm	<p><b>Why We Should Invest in African Genomic Variation</b></p> <p><i>Dr. Ambroise Wonkam, University of Cape Town</i></p>



4:10-5:10pm	<b>TOPMED</b> <i>Drs. Telen, Reiner and Early</i>
4:10-4:30pm	<b>Biologic Measures and Multi-omics as Prognostic Factors in SCD</b> <i>Dr. Marilyn Telen, Duke Cancer Institute</i>
4:30-4:50pm	<b>Proteomic analysis of Sickle Cell Trait in TOPMed</b> <i>Dr. Alex Reiner, University of Washington</i>
4:50-5:10pm	<b>Genome-wide Association of Early Ischemic Stroke in Brazilian Sickle Cell Disease Confirms Early Onset Stroke Gene ADAMTS2, CDK18, and Uncovers 12 Novel loci</b> <i>Dr. Eric Early, RTI International</i>



## 2022 Annual SCD Meeting Day 3

9:00-4:45pm	<b>WEDNESDAY MEETING TIME (EDT) – August 10th</b>
9:00-9:05am	<b>Welcome and Announcements</b>
9:05-12:45pm	<b>SYMPOSIUM 5</b>
9:05-11:05am	<p><b>Multidisciplinary and Alternative Chronic Pain Management for Adults with Sickle Cell Disease</b>            Chairs: <i>Dr. JJ Strouse, Duke University School of Medicine</i>  <i>Dr. Julie Kanter, University of Alabama</i></p>
9:05-9:10am	<p><b>Welcome and Introduction</b>  <b>The Challenge of Today</b>  <i>Dr. JJ Strouse, Duke University School of Medicine</i></p>
9:10-9:30am	<p><b>Psychology and Other Mind Based Approaches for Pain</b>  <i>Dr. Charles Jonassaint, University of Pittsburgh</i></p>
9:30-9:50am	<p><b>Acupuncture and Other Non-pharmacologic Modalities for Sickle Cell Disease Pain</b>  <i>Dr. Judith Schlaeger, University of Illinois-Chicago</i></p>
9:50-10:10am	<p><b>Antidepressants and Antiepileptic Drugs for Pain</b>  <i>Dr. Elizabeth Prince, Johns Hopkins School of Medicine</i></p>
10:10-10:30am	<p><b>Buprenorphine for Chronic Pain in SCD Sickle</b>  <i>Dr. Patrick Carroll, Johns Hopkins University</i></p>
10:30-10:50am	<p><b>Panel: Question and Answer Panel Moderators:</b>  <i>Drs. Kanter and Strouse</i></p> <p><b>Panel Participants</b>  <i>Dr. Elizabeth Prince, Johns Hopkins University</i>  <i>Dr. Patrick Carroll, Johns Hopkins University</i></p>
10:50-11:05am	<p><b>NASCC Update and Closing Remarks</b>  <i>Dr. Julie Kanter, University of Alabama</i></p>
11:05-11:25am	<p><b>Modifying Sickle Cell Therapies based on Symptomatology</b>  <i>Dr. Modupe Idowu, UTHealth Houston McGovern Medical School</i></p>
11:25-11:45am	<p><b>Hematopoietic Stem Cell Transplantation Reverses White Matter Injury in Sickle Cell Disease Patients</b>  <i>Dr. Thalita Costa, University of São Paulo</i></p>
11:45-12:15pm	<p><b>CureSC Metadata Catalog</b>  <i>Dr. Helen Pan, RTI International</i></p>
12:15-12:45pm	<p><b>What's New With Arginine Therapy in Sickle Cell Disease?</b>  <b>Results of Phase 2 Randomized Controlled Trials in the US and Nigeria</b>  <i>Dr. Claudia R. Morris, Emory University School of Medicine</i></p>





## Day 3 Continued

12:45-1:15pm	<b>LUNCH</b>
1:15-4:45pm	<b>SYMPOSIUM 6</b>
1:15-2:50pm	<p><b>SESSION I:</b>  <b>Refining the Research Agenda for Pain in SCD</b>  <b>Pain in Sickle Cell Disease</b>  <i>Chairs: Drs. Wally Smith, Cheryl Stucky and Kalpna Gupta</i></p>
1:15-1:30pm	<p><b>Reconceptualizing Pain in SCD</b>  <i>Dr. Wally Smith, Virginia Commonwealth University</i></p>
1:30-1:50pm	<p><b>Advances in SCD Pain: Bridging Basic Research and Clinical Practice</b>  <i>Dr. Cheryl Stucky, Medicine College of Wisconsin</i>  <i>Dr. Amanda Brandow, Medical College of Wisconsin</i></p>
1:50-2:05pm	<p><b>Current State of the Science in Pain Diagnosis and Management</b>  <b>Pain Sensation and Response in SCD</b>  <i>Dr. Claudia Campbell, Johns Hopkins University</i></p>
2:05-2:20pm	<p><b>SCD Pain Phenotyping and Expression, Descriptors</b>  <i>Dr. Nitya Bakshi, Emory University</i></p>
2:20-2:35pm	<p><b>Opioid and non-opioid treatment for SCD: Guidelines and Practice</b>  <i>Dr. Patrick Carroll, Johns Hopkins University</i></p>
2:35-2:50pm	<p>Q&amp;A, Panel Discussion (All Speakers)</p>
2:50-4:35pm	<p><b>SESSION II:</b>  <b>Integrative and Technology Enhanced Approaches to Target Sickle Cell Pain</b>  <i>Chairs: Dr. Kimberlei Richardson, Howard University</i>  <i>Dr. Kalpna Gupta, University of California</i></p>
2:50-3:08pm	<p><b>Treating Sickle Cell Pain by Means of Transcranial Focused Ultrasound</b>  <b>Neuromodulation</b>  <i>Dr. Bin He, Carnegie Mellon University</i></p>
3:08-3:26pm	<p><b>Approachable Mechanism-based Integrative Strategies to Ameliorate Pain</b>  <i>Dr. Kalpna Gupta, University of California</i></p>
3:26-3:44pm	<p><b>Targeting the Orexin System for Sleep Interventions and Pain Sensitivity in SCD</b>  <i>Dr. Kimberlie Richardson, Howard University</i></p>
3:44-4:02pm	<p><b>Computational Analysis/Wearable Device/Sleep-pain Acquisition</b>  <i>Dr. Michael Khoo, University of Southern California</i></p>
4:02-4:20pm	<p><b>Overcoming Socio-ecological Stressors With Integrative Interventions to Ameliorate Pain</b>  <i>Dr. Sarah Martin, University of California</i></p>
4:20-4:35pm	Q&A
4:35-4:45pm	Closing Remarks
	<b>Conference Adjourn</b>