



# SCDAA 36th ANNUAL CONVENTION

*"Sickle Cell Disease: A Global Approach"*  
*An Interactive and Accredited Educational Conference*

## PROGRAM

**TUESDAY, SEPTEMBER 23, 2008**

|                       |                           |  |
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| 7:00 p.m. – 9:00 p.m. | <b>REGISTRATION</b> ..... | 3 <sup>RD</sup> Floor Registration Counter |
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| 12 noon – 6:00 p.m.    | SCDAA Leadership Council Meeting .....  | Marlboro A     |
| 2:00 p.m. – 7:00 p.m.  | Sickle Cell Adult Providers Network presents<br>Best Self Management Practices:<br>A Client Panel Perspective ..... | Marlboro B     |
| 6:00 p.m. – 9:00 p.m.  | Volunteers Meeting/Dinner .....   | Newberry/Ascot |
| 6:00 p.m. – 10:00 p.m. | MARAC Meeting .....   | Windsor Room   |

**WEDNESDAY, SEPTEMBER 24, 2008**

|                        |   |  |
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| 7:00 a.m. – 5:00 p.m.  | <b>REGISTRATION</b> .....               | 3 <sup>rd</sup> Floor Registration Counter |
| 8:00 a.m. – 11:00 a.m. | <b>BOARD OF DIRECTORS MEETING</b> ..... | Newberry/Ascot                             |
| 1:00 p.m. – 2:45 p.m.  | <b>EXHIBIT and VENDOR SET-UP</b> .....  | Belle Chasse/Rosedown                      |
| 2:45 p.m. – 7:00 p.m.  | <b>EXHIBITS and VENDORS OPEN</b> .....  | Belle Chasse/Rosedown                      |

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| 11:00 a.m. – 1:00 p.m. | <b>"LESSONS LEARNED: SCDAA MEMBER ORGANIZATIONS"<br/>AND LEGISLATIVE UPDATE</b> .....   | Jefferson Ballroom   |
| 1:00 – 3:00 p.m.       | <b>NCEC MEETING – INVITATION ONLY</b> .....   | Melrose Room   |
| 1:30 – 4:30 p.m.       | <b>TECHNICAL ASSISTANCE,<br/>PROFESSIONAL DEVELOPMENT<br/>AND EDUCATIONAL CONCURRENT WORKSHOPS</b>  |  |
| 1:30 – 2:45 p.m.       | <b>CONCURRENT WORKSHOPS</b>   |  |
|                        | <ul style="list-style-type: none"> <li>• Sickle Cell 101 .....</li> <li>• Fundraising 101 .....</li> <li>• Nursing Perspectives I .....</li> <li>• Hydroxyurea in Children and Adults .....</li> <li>• Pain Chronic and Acute .....</li> <li>• Transfusion Therapy and Iron Overload .....</li> <li>• SCDAA Requirements/<br/>Standards for Member Organizations .....</li> </ul> | <ul style="list-style-type: none"> <li>Elmwood</li> <li>Oak Alley</li> <li>Jasperwood</li> <li>Magnolia</li> <li>Jefferson Ballroom</li> <li>Newberry/Ascot</li> <li>Windsor Room</li> </ul> |

- 2:45 p.m.           **BREAK**
- 3:00 – 4:30 p.m.    **CONCURRENT WORKSHOPS**
- Sickle Cell 101 ..... Elmwood
  - Fundraising 101 ..... Oak Alley
  - Nursing Perspectives I ..... Jasperwood
  - Hydroxyurea in Children and Adults ..... Magnolia
  - Pain Chronic and Acute ..... Jefferson Ballroom
  - Transfusion Therapy and Iron Overload ..... Newberry/Ascot
  - SCDA A Requirements/  
Standards for Member Organizations ..... Windsor Room
- 4:30 – 6:00 p.m.    **LONZIE LEE JONES PATIENT ADVOCACY SYMPOSIUM**..... Jefferson Ballroom  
*“Advocacy on a Personal Level”*  
*Shirley H. Miller, B.B.A., Presiding*
- 7:00 – 10:00 p.m.    **CHAIRMAN’S WELCOMING RECEPTION**..... Versailles Ballroom

**THURSDAY, SEPTEMBER 25, 2008**

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| 8:30 a.m. – 5:00 p.m. | <b>REGISTRATION</b> ..... 3 <sup>rd</sup> Floor Registration Counter |
| 7:30 a.m. – 6:00 p.m. | <b>EXHIBITS and VENDORS OPEN</b> ..... Belle Chasse/Rosedown         |

- 7:30 – 8:30 a.m.    **POSTER SESSION I** ..... Belle Chasse
- 8:30 a.m.           **OPENING CEREMONY** ..... Jefferson Ballroom
- Greetings**  
Dr. Charles Scher
- Lorri Burgess  
*President, Louisiana Statewide Sickle Cell Foundations*
- 8:45 a.m.           **CHARLES F. WHITTEN, MD LECTURE**  
Dr. Donald Rucknagel, MD
- 9:15 am             **THE FUTURE OF SICKLE CELL DISEASE –  
NATIONAL HEART LUNG AND BLOOD INSTITUTE/CDC/HRSA**  
Susan Shurin, MD, Marie Mann, MD, Dr. Atrash
- 10:30 – 12:00 noon   **SCDAA BUSINESS AND AWARDS SESSION**
- ❖ Review of Annual Convention Rules
  - ❖ Adoption of 2007 minutes
  - ❖ Committee Appointments

**STATE OF SCDA**

- ❖ Chairman’s Report
- ❖ Chief Medical Officer’s Report
- ❖ President/COO Report.

**COMMITTEE REPORTS**

- ❖ Nominating Committee
- ❖ By-Laws Committee
- ❖ Treasurer
- ❖ CHC Report

**AWARDS**

- ❖ Community-Based Organization Distinguished Service to the Community
- ❖ Kermit B. Nash Scholarship Award
- ❖ Mary H. Hunter Patient Advocacy Award
- ❖ William Finn Award
- ❖ Chairman’s Award
- ❖ President’s Award

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| 12:30 – 3:00 p.m. | <b>LUNCH</b> ( <i>On Your Own</i> )   |
| 12:30 – 2:30 p.m. | <b>LUNCHEON – INVITATION ONLY</b> ..... Versailles Ballroom<br>( <i>Presidents/Executive Directors Leadership Summit</i> )  |
| 3:00 – 4:15 p.m.  | <b>PLENARY SESSION I</b> ..... Jefferson Ballroom<br><br><b>SCDAA/MCHB: Sickle Cell Disease and Newborn Screening Follow-up Program</b><br><br><b>NCEC Update – “Successes and Lessons Learned”</b> |
| 4:15 p.m.         | <b>BREAK</b>  |
| 4:30 – 6:00 p.m.  | <b>SIMULTANEOUS SESSIONS</b>  |
|                   | <b>A. CLINICAL UPDATE AND PRACTICE I</b> ..... Jefferson Ballroom   |
| 4:30pm            | High Frequency of Asthma, Sepsis, and Acute Chest Syndrome in Children with Sickle Cell Disease and Pulmonary Hypertension.....Claudia R. Morris MD   |
| 4:45pm            | Evaluation of Treatment with Deferasirox (ExJade), a Once-Daily, Oral Chelator, in Patients with Sickle Cell Disease: Update of 2.7-Year Data from the Extension Study ..... Elliott Vichinsky, MD  |
| 5:00pm            | Review of Two Years of Clinical Screening for Sickle Cell Vasculopathy Using Transcranial Doppler Ultrasonography..... Nagina Parmar  |

- 5:15pm Influence of Disease Type, Gender, Race, and Chronic Transfusion on the Incidence of Pulmonary Hypertension Among Children with Sickle Cell Disease... Anthony N. Audino, MD
- 5:30pm Stable Long-term Donor Engraftment Following Reduced Intensity Hematopoietic Cell Transplantation for Sickle Cell Disease.....Lakshmanan Krishnamurti, MD
- 5:45pm Allogeneic Stem Cell Transplantation for Children with Sickle Cell Disease Using Immunosuppressive Reduced Intensity Conditioning ..... Shalini Shenoy, MD

**B. INNOVATIVE PROGRAMS & SERVICES ..... Oak Alley**

- 4:30pm Individualized Pain Plans and a Standard Protocol for Children with Sickle Cell Disease Can Improve Pain Management, Decrease Hospitalization from the Emergency Room and Length of Stay in Hospital....Lakshmanan Krishnamurti, MD
- 4:45pm Sickle Cell Disease Specific Care: Post Hospital Stay Continuity of Care Improves Outcomes ..... Lanetta Jordan, MD, MPH, MSPH
- 5:00pm Use of an Internet-Based, Care Coordination Tool In Patient Centered, Collaborative Care..... Thomas Webb, MD, MSc
- 5:15pm Partnering with Local School Programs ..... Eileen Murray
- 5:30pm Updating Counseling for Sickle Cell Disease/ Traits and Community Screening ..... Victoria O. Odesina
- 5:45pm Beyond Grants: Sustainable Projects Through Partnerships between Sickle Cell Centers and Community-Based Sickle Cell Disease Organizations ..... Kenneth Rivlin, MD, PhD

**C. PSYCHOSOCIAL AND SOCIO-ECONOMIC ISSUES ..... Jasperwood**

- 4:30pm Coping and Psychosocial Issues .....Chavis Patterson, PhD
- 4:45pm Physical and Mental Health in Adults Hospitalized with Sickle Cell Disease: Impact on Resource Use..... Nicole Artz
- 5:00pm Patient Advocacy Through Community Partners: Education of Local Hospitals and Providers.....Marietta Douglas, RN
- 5:15pm Self Reported Depression and Suicidal Ideation In Patients with Sickle Cell Disease ..... Christopher Edwards, PhD
- 5:30pm The Effects of John Henryism (JH) on Weight

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|                  | And Functionality in African Americans with Sickle Cell Disease (SCD) .....   | Christopher Edwards, PhD   |
| 5:45pm           | Missing Data in a Daily Diary<br>Telephone Study of SCD Pain Among African American Children .....  | Chase L. Lesane Brown, PhD |
|                  | <b>D. BASIC RESEARCH</b> .....  | Magnolia                   |
| 4:30pm           | A Novel Murine Model of Short Chain Fatty Acids (SCFA) – Mediated embryonic Gene Up-Regulation During Definitive Erythropoiesis .....                 | Himanshu Bhatia            |
| 4:45pm           | The Genomic Analysis of Erythrocyte microRNA Expression In Sickle cell Diseases .....   | Jen-Tsan Ashley Chi        |
| 5:00pm           | Effects of Hydroxyurea and Transfusion Upon Fetal Hemoglobin Silencing in Children and Adolescents with Sickle Cell Anemia .....                      | Patricia A. O’Neal, MD     |
| 5:15pm           | Improvement of the Mass Production of Nicosan <sup>TM</sup> /Xickle <sup>TM</sup> , An Herbal Medicine that Contains Strong Antisickling Agents ..... | Toshio Asakura, MD, PhD    |
| 5:30pm           | Sickle Hemoglobin Fiber Depolymerization, A Potential Modifier of Pathology: Fracture, Fragments, Vanishing Times & Stochastics.....                  | Jiang Cheng Wang           |
| 4:30 – 6:00 p.m. | <b>INTERACTIVE PARENT FORUM</b> .....   | Elmwood                    |
|                  | My Child Has Sickle Cell Disease...What’s Next? .....   | M. Renee Robinson, PhD     |
|                  | My Child Has Sickle Cell Disease ... What’s Next? Differential Effects of Employment Status on Caregiver .....  | M. Renee Robinson, PhD     |
|                  | My Child Has Sickle Cell Disease...What’s Next? The Use Of Multi-Method Education Strategies To Improve Caregivers’ Competence.....                   | Nina Anderson, PNP         |

7:30 – 11:00 p.m.      **RECEPTION & DOROTHY BOSWELL GALA AWARDS BANQUET** ..... Grand Ballroom C  
 SCDAA 2007 – 2009 Poster Child ..... Gabriel George  
 SCDAA HONOREES  
 Xernona Clayton; Pauletta Washington; Senator Landrieu

**FRIDAY, SEPTEMBER 26, 2008**

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|-----------------------|--|--|
| 8:30 a.m. – 5:00 p.m. | <b>REGISTRATION</b> .....              | 3 <sup>rd</sup> Floor Registration Counter |
| 7:30 a.m. – 6:00 p.m. | <b>EXHIBITS and Vendors OPEN</b> ..... | Belle Chasse/Rosedown                      |

7:00 – 8:15 a.m.      **POWER BREAKFAST: MEET THE EXPERTS**  
*(Limited Space: Sign-up at Registration)*..... Melrose

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| <ul style="list-style-type: none"> <li>❖ <b>Medical Management of Sickle Cell Disease – Best Practice Guidelines</b></li> <li>❖ <b>Transition From Pediatric to Adult Care</b><br/>Joseph Telfair, DrPH</li> <li>❖ <b>For Women Only –</b><br/>Shirley Miller, Betty Nwabuonwu</li> </ul> | <ul style="list-style-type: none"> <li>❖ <b>For Men Only -</b><br/>Chavis Patterson, PhD; Trevor Thompson</li> <li>❖ <b>Sickle Cell Disease Clinical Trials</b></li> <li>❖ <b>Case Management – Community Based Organizations &amp; Social Services</b></li> <li>❖ <b>Newborn Screening Follow-up</b><br/>James Rogers</li> </ul> |
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7:30 – 8:30 a.m.      **POSTER SESSION II** ..... Belle Chasse

8:30 a.m. – 3:30 p.m.

**MEDICAL RESEARCH, CLINICAL EDUCATION and ADVOCACY**

*Betty S. Pace, MD, Presiding*

8:30 a.m.      **PLENARY SESSION II**..... Jefferson Ballroom

8:30 – 9:00 a.m.      **CLARICE REID, MD LECTURE**      Dr. Marilyn Gaston

9:05 –9:45 a.m.      **MINORITY SERVING INSTITUTION RESEARCH PARTNERSHIP (MSIRP) IN SICKLE CELL DISEASE RESEARCH**..... Mr. Theodore Callier

10:00 a.m. - 12:00 PM      **PLENARY PANEL: Children’s Hospital of Philadelphia (CHOP) “Sickle Cell Disease & The Brain”**

12 noon – 1:30 p.m.      **LUNCH** *(Taste of New Orleans)* ..... Napoleon Ballroom

1:30 – 3:00 p.m.      **PLENARY SESSION III** ..... Jefferson Ballroom  
*Government and Media Relations*  
**HEALTH DEPARTMENTS**.....*New Orleans and surrounding area*

3:00 – 4:30 p.m.

**SIMULTANEOUS SESSIONS**

**E. EDUCATION SERVICES AND ACTIVITIES**..... Elmwood

3:00pm Educational Materials and System Navigation Tools  
For Parents of Young Children with Sickle Cell Disease: Experience  
of the National Coordinating and Evaluation Center..... Nancy P. Callanan, MS, CGC

3:15pm Parental Knowledge and Awareness of Sickle Cell Trait ..... Kusum Viswanathan, MD

3:30pm Importance of Parental Testing in Newborn Screening  
Trait Follow-up .....Kusum Viswanathan, MD

3:45pm Back In Stride: A School Liaison Program to Help Children  
With Sickle Cell Disease Keep Current with School Work  
Even When They Are Sick .....Lakshmanan Krishnamurti, MD

4:00pm Using Peer Educators to Increase Sickle Cell Awareness  
Detection and Prevention ..... Delores Williams-Edwards

4:15pm Unique Family Plays Valuable Role  
In Medical Student Education..... Kathleen M. McKie, MD

**F. CLINICAL UPDATE AND PRACTICE II** ..... Rosewood

3:00pm Pregnancy, Sickle Cell Disease, and the Impact on Infant Mortality..... Kimberly Lamar

3:15pm Prevalence of Blindness in Adult Patients  
with Sickle Cell Disease ..... Samir K. Ballas, MD

3:30pm Red Blood Cell Transfusion Practices within the Institutions of the New England  
Pediatric Sickle Cell Consortium..... Allison Paroskie, MD

3:45pm Adherence To Deferasirox In Children And Adolescents With Sickle Cell Disease  
During One Year Of Therapy..... Ofelia Alvarez

4:00pm Gene Regulations Therapy for Sickle Cell Disease  
Utilizing Ferritin Heavy Chain .....Robert H. Broyles, PhD

4:15pm An Incidental Finding: Chronic Pain in Adults with Sickle Cell Disease  
Is Aggravated by Severe Vitamin D Deficiency ..... Patricia Adams-Graves

3:00 – 4:30 p.m. **G. SPECIAL PRESENTATION** ..... Jasperwood

Unrelated Donor Hematopoietic Cell Transplantation for  
Children with Severe Sickle Cell Disease Using a  
Reduced Intensity Conditioning Regime ..... Shalini Shenoy, MD  
Nayish Kamani, MD

4:30 p.m.

**F R E E - T I M E**

**SATURDAY, SEPTEMBER 27, 2008**

|                        |  |  |
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| 8:00 a.m. – 10:00 a.m. | <b>REGISTRATION</b> .....              | 3 <sup>RD</sup> Floor Registration Counter |
| 8:30 am – 1:00 p.m.    | <b>EXHIBITS and Vendors OPEN</b> ..... | Belle Chasse/Rosedown                      |

7:00 – 8:00 a.m.      **WELLNESS ACTIVITY – YOGA** .....TBD

8:30 – 11:30 a.m.      **PLENARY SESSION IV** ..... Jefferson Ballroom  
*Local Host Medical Institution*  
TULANE UNIVERSITY SCD DAY HOSPITAL

11: 30 a.m. – 12 noon      **SCDAA CLOSING ASSEMBLY & CONVENTION ADJOURNMENT**

1:00 – 2:00 p.m.      **SCDAA Outgoing Board Meeting**.....Newberry/Ascot  
2:00 – 3:00 p.m.      **SCDAA Incoming Board Meeting** .....Newberry/Ascot  
4:00 – 5:00 p.m.      **Executive Committee Meeting** .....Newberry/Ascot