



SCDAA 37TH ANNUAL CONVENTION PROGRAM

“Building Bridges for Change”

TUESDAY, SEPTEMBER 29, 2009

7:00 p.m. – 9:00 p.m.	REGISTRATION	Grand Sierra South
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12 noon – 4:30 p.m.	SCDAA Leadership Council Meeting	Antigua 2 & 3
12 noon – 2:00 p.m.	Volunteers Orientation/Luncheon	Antigua 1
4:30 p.m. – 6:30 p.m.	SCDAA CARES	Antigua 1
6:00 p.m. – 9:00 p.m.	MARAC Meeting	Antigua 2 & 3

WEDNESDAY, SEPTEMBER 30, 2009

7:30 a.m. – 5:00 p.m.	REGISTRATION	Grand Sierra South
7:00 a.m. – 10:00 a.m.	BOARD OF DIRECTORS MEETING	Bonaire 6 & 7
1:00 p.m. – 2:45 p.m.	EXHIBIT and VENDOR SET-UP	Bonaire 1, 2, 3, & 4
3:00 p.m. – 7:00 p.m.	EXHIBITS and VENDORS OPEN	Bonaire 1, 2, 3, & 4

7:00 – 8:00 a.m. **WELLNESS ACTIVITY** **Poolside**

10:30 a.m. – 12:30 p.m. **“SCDAA MEMBER ORGANIZATIONS PRESENTATION”** **Grand Sierra A, B & C**

12:30 - 2:00 p.m. **LUNCH (On Own)**

2:00 – 4:00 p.m. **TECHNICAL ASSISTANCE, PROFESSIONAL DEVELOPMENT AND EDUCATIONAL CONCURRENT WORKSHOPS**

1:00 – 2:00 p.m. **CONCURRENT WORKSHOPS**

- **Sickle Cell 101** **Bonaire 8**
- **Funding Sustainability** **Antigua 3**
- **Nursing Perspectives I** **Antigua 4**
Yvonne Carroll, Lynne Davidson, Elizabeth Guniere
- **Hydroxyurea in Children and Adults** **Bonaire 6**
- **Pain Chronic and Acute** **Antigua 1**
Lennette J. Benjamin, MD
- **Transfusion Therapy and Iron Overload** **Antigua 2**
- **SCDAA Orientation/ Standards for Member Organizations** **Bonaire 7**

2:00 – 3:30 p.m. **Sickle Cell Adult Providers Network** **Curacao 1**

2:30 - 2:45 p.m. **BREAK**

WEDNESDAY, SEPTEMBER 30, 2009

3:00 – 4:00 p.m. **CONCURRENT WORKSHOPS**

- **Sickle Cell 102** (Advances in Sickle Cell Disease)..... Bonaire 8
- **Funding Sustainability**.....Antigua 3
- **Nursing Perspectives II**.....Antigua 4
Yvonne Carroll, Lynne Davidson, Elizabeth Guniere
- **Hydroxyurea in Children and Adults**.....Bonaire 6
- **Pain Chronic and Acute**.....Antigua 1
Lennette J. Benjamin, MD
- **Transfusion Therapy and Iron Overload**..... Antigua 2
- **SCDAA Orientation/Standards for Member Organizations**..... Bonaire 7

4:00 – 5:30 p.m. **LONZIE LEE JONES PATIENT ADVOCACY SYMPOSIUM**.....Curacao 1

7:00 – 9:00 p.m. **CHAIRMAN'S WELCOMING RECEPTION**Grand Sierra E

THURSDAY, OCTOBER 1, 2009

8:30 a.m. – 5:00 p.m.	REGISTRATION	Grand Sierra South
7:30 a.m. – 6:00 p.m.	EXHIBITS and VENDORS OPEN	Bonaire 1, 2, 3 & 4

7:00 – 8:00 a.m. **WELLNESS ACTIVITY**.....Poolside

7:30 – 8:30 a.m. **POSTER SESSION**

8:30 a.m. **OPENING CEREMONY**Grand Sierra A, B, & C

GREETINGS:

*Mayor Buddy Dyer
Mayor of Orlando*

*Geraldine Thompson
District 39, State Representative*

*Kim Berfield
Deputy Secretary,
Dept. of Health and Office of Women's Health Strategy for Florida
Florida Department of Health*

*Laura Dortch-Edler, Ed.D
President, Sickle Cell Disease Association of Florida*

THURSDAY, OCTOBER 1, 2009

- 8:45 a.m. **CHARLES F. WHITTEN, MD**
MEMORIAL LECTURE**Grand Sierra A, B, & C**
Kim Smith-Whitley, MD
Children's Hospital of Philadelphia
- 9:15 am **SPECIAL PRESENTATION**
Centers for Disease Control, RuSH
- 10:15 – 10:30 a.m. **BREAK**
- 10:30 – 12:30 noon **SCDAA BUSINESS AND AWARDS SESSION**
 ❖ Review of Annual Convention Rules
 ❖ Adoption of 2008 minutes
 ❖ Committee Appointments
- STATE OF SCDAA**
 ❖ 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
- 12:30 – 2:00 p.m. **LUNCH** (*On Your Own*)
- 12:30 – 2:00 p.m. **LUNCHEON – INVITATION ONLY**.....**Curacao 1 & 2**
(Presidents/Executive Directors Leadership Summit)

Status of Community-Based Programs.....*Mary Brown*

Panel Discussion.....*Duane Bruce, Elizabeth Simpson, Rosie Peterson*
- 12:30 – 2:00 p.m. **BE SICKLE SMART**
EMPOWERMENT LUNCHEON (By Invitation Only).....**Bonaire 6 & 7**
Keynote Speaker: Dr. Jawan Ayer-Cole

THURSDAY, OCTOBER 1, 2009

2:00 – 3:00 p.m.	PLENARY SESSION Grand Sierra A, B & C SCDAA Strategic Legislative Update
3:00 – 3:15 p.m.	BREAK
3:15 – 5:20 p.m.	SIMULTANEOUS SESSIONS
	A. CLINICAL UPDATE AND PRACTICE I Antigua 1
3:15 p.m.	Peripheral Blood Stem Cell TXP in Adults with SCD Beth Link
3:40 p.m.	Safety & Efficacy of the Once-Daily Oral Iron Chelator Deferasirox (EXJADE) in the Treatment of Pts with SCD: 3.5 yr f/u Elliott Vichinsky, MD
4:05 p.m.	Identification of a Novel Hematological Risk Marker for Proteinuria in SCD Micheline Maier-Redelsperger
4:30 p.m.	Asthma in SCD as a Risk Factor for Acute Chest Syndrome in Pediatric Patients Andrea Borns
4:55 p.m.	Low Bone Mineral Density in SCD Mathieu Luckson
	B. INNOVATIVE PROGRAMS & SERVICES Antigua 2
3:15 p.m.	An Innovative Parenting Program for Families Affected by Sickle Cell Elaine Southwood
3:40 p.m.	From Student to Peer Educator: A Novel Approach to Outreach Verna Ademu-John
4:05 p.m.	Home Away From Home Mary Campbell
4:30 p.m.	Enhanced Newborn Screen Follow-up: Community Based Collaboration & Case Management Beth Kladney
4:55 p.m.	"Say it Loud: Conversations on Sickle Cell Disease" Bridging Partnerships to Successful Outreach Mary LaMar
	C. PSYCHOSOCIAL AND PUBLIC HEALTH ISSUES Antigua 3
3:15 p.m.	Association Between Hydroxyurea Treatment and Employment Patterns in Sickle Cell Patients Robert Bauserman
3:40 p.m.	Patient Perceptions of Barriers and Strategies for Adherence to Hydroxyurea Lori Crosby
4:05 p.m.	Trends in Adolescent and Adult Sickle Cell Disease-related Mortality in the US 1985-2005 Althea Grant
4:30 p.m.	Impact of a Dedicated Acute Care Facility for Adults with SCD on Admission and Readmission Rate David Mandy
4:55 p.m.	National Burden of ED Care for SCD: Impact of Age, Insurance Status Ruchik Goel

THURSDAY, OCTOBER 1, 2009

- D. ADVOCACY Antigua 4**
- 3:15 p.m. Successful Screening for Sickle Cell Trait
Using Established Community Partners..... Yvonne Carroll
- 3:40 p.m. Systematic Surveillance & Legal Advocacy Towards
Achieving the Educational Rights of Children with SCD..... Lawrence Newman
- 4:05 p.m. RUSH- Engaging Stakeholders in the Development of a National Surveillance
System for SCD Melissa Creary
- 4:30 p.m. Sickle Cell Trait and the Athlete Scott Galloway
- 4:55 p.m. SC Patient Communications/Education with Social Media..... Kevin Elwood
- 3:15 – 5:20 p.m. **INTERACTIVE PARENT FORUM.....Curacao 3 & 4**
What's Discipline Got To Do With It? ... Raising the Bar
in Comprehensive Care and Management of Young Children
with Sickle Cell Disease.... Renee Robinson, PhD
- 7:00 – 10:00 p.m. **RECEPTION & DOROTHYE BOSWELL GALAGrand Sierra E
AWARDS BANQUET**

FRIDAY, OCTOBER 2, 2009

8:30 a.m. – 5:00 p.m.	REGISTRATION.....Grand Sierra South
7:30 a.m. – 6:00 p.m.	EXHIBITS and Vendors OPEN.....Bonfire 1, 2, 3 & 4

- 7:00 – 8:00 a.m. **WELLNESS ACTIVITY.....Poolside**
- 7:00 – 8:15 a.m. **PATIENT EMPOWERMENT BREAKFAST: MEET THE EXPERTSCuracao 1
(Limited Space: Sign-up at Registration)**

- ❖ **Medical Management of Sickle Cell Disease – Best Practice Guidelines**
- ❖ **Transition from Pediatric to Adult Care**
- ❖ **For Women Only - Betty Nwabuonwu**
- ❖ **Pain Management - Samir Ballas, MD**
- ❖ **For Men Only**
- ❖ **Sickle Cell Disease Clinical Trials**
- ❖ **Case Management – Community Based Organizations & Social Services**
- ❖ **Transfusion and Iron Overload Therapy**

FRIDAY, OCTOBER 2, 2009

7:30 – 8:30 a.m. **POSTER SESSION II**

8:30 a.m. – 3:30 p.m. **MEDICAL RESEARCH, CLINICAL EDUCATION and ADVOCACY**

8:30 a.m. **PLENARY SESSION II.....Grand Sierra A, B & C**

8:30 – 9:00 a.m. **CLARICE REID, MD LECTURE**
Gladys A. Robinson, PhD
Executive Director, Piedmont Health Services and Sickle Cell Agency

9:05 –9:45 a.m. **SPECIAL PRESENTATION**
Sickle Cell Disease: A Global Perspective

10:00 a.m. - 12:00 noon **PLENARY PANEL: Children’s Hospital of Philadelphia (CHOP)**

12:15 – 1:30 p.m. **LUNCHEON.....Grand Sierra E**

1:30 – 3:00 p.m. **PLENARY SESSION III.....Grand Sierra A, B, & C**

SPECIAL PRESENTATION – Novartis Pharmaceuticals
Paul A. Swerdlow, MD
Barbara Ann Karmanos Cancer Institute
Associate Professor; Wayne State University Detroit, MI

1:30 – 6:30 p.m. **HOLY LAND EXPERIENCE (By Invitation Only)**

3:00 – 3:15 p.m. **BREAK**

3:15 – 5:20 p.m. **SIMULTANEOUS SESSIONS**

E. EDUCATION SERVICES AND ACTIVITIES.....Antigua 1

3:15 p.m. Assessing the Educational Impact & Feasibility of
Providing SCD Education in Barbershops/Salons
in the African American Community Cecilia Rajakaruna, MS

3:40 p.m. Reported School Experiences of Young People Living
with Sickle Cell Disorder in England..... Simon Dyson, MD

4:05 p.m. School Ethos and its Impact on the Lives of Young People
with Sickle Cell at School Sue Dyson

4:30 p.m. Youth Engagement in SCD Community Education Janelle Hines

4:55 p.m. Education Through Collaborative Efforts.....Linda Drawhorn

FRIDAY, OCTOBER 2, 2009

- F. PUBLIC HEALTH ISSUES II AND INNOVATIVE PARTNERSHIPS..... Antigua 2**
- 3:15 p.m. Burden of Influenza Related Hospitalizations
Among Children w/ SCD David G. Bundy, MD, MPH
- 3:40 p.m. Creating Partnerships with Community Cultural Brokers Zemoria Brandon
- 4:05 p.m. Leadership Education in Neurodevelopmental Disabilities (LEND) &
Comprehensive Sickle Cell Centers..... Lawrence Newman
- 4:30 p.m. Needs Assessment of Families with Sickle Cell Disease
in an Inner City Population Yana Pennant
- 4:55 p.m. Individual Pain Plans Result in Improved Pain Management
Patient Satisfaction & Decrease in Admissions for Pain Crisis Mary Campbell
- 3:15 – 4:30 p.m. **SPECIAL PRESENTATION – SCDA A CARES.....Antigua 3**
- 7:30 – 8:00 p.m. **SCDA A CLOSING ASSEMBLY & CONVENTION ADJOURNMENT**
Rosen Center
- 8:00 – 10:00 p.m. **FLORIDA HOST ORGANIZATIONS EVENT**
Rosen Center

SATURDAY, OCTOBER 3, 2009

- 7:00 – 8:00 a.m. **WELLNESS ACTIVITY.....Poolside**
- 9:00 – 10:15 a.m. **SCDA A Outgoing Board Meeting..... Antigua 2 & 3**
- 10:15 – 10:30 a.m. **BREAK**
- 10:30 a.m. – 12:00 p.m. **SCDA A Incoming Board Meeting.....Antigua 2 & 3**