

41st Annual Convention

MOVING FORWARD: "ADVOCATING FOR NEW DISCOVERIES,
ADVANCEMENTS AND BREAKTHROUGHS"

PROGRAM AT A GLANCE

TUESDAY, SEPTEMBER 24, 2013

"MOVING FORWARD: PREPARATION AND PLANNING"

7:00 p.m. – 9:00 p.m.	REGISTRATION	Foyer
1:00 p.m. – 4:00 p.m.	Grant Writing Institute.....	Grand H
6:00 p.m.– 8:00 p.m.	SCDAA Executive Leadership Council Meeting (Dinner Meeting)	Grand D

WEDNESDAY, SEPTEMBER 25, 2013

"ADVANCING THE COMMUNITY-BASED AGENDA"

7:30 a.m. – 5:00 p.m.	REGISTRATION	Foyer
9:00 a.m. – 1:30 p.m.	EXHIBIT and VENDOR SET-UP	Grand A-C
1:30 p.m. – 7:00 p.m.	EXHIBITS and VENDORS OPEN	Grand A-C
3:00 p.m.	POSTER PRESENTATION SET-UP	Grand D
7:30 a.m. - 8:45 a.m.	Breakfast	Grand A-C
8:30 a.m.- 10:30 a.m.	SCDAA BUSINESS SESSION	Grand F-H
	• Review of Annual Convention Rules • Adoption of 2012 minutes • Committee Appointments	
	STATE OF SCDAA	
	• Chairman's Report • President/COO Report • Chief Medical Officer's Report • Treasurer's Report	
	COMMITTEE REPORTS	
	• Nominating Committee • Government Relations Committee • CHC Report	



WEDNESDAY, SEPTEMBER 25, 2013

10:30 a.m. - 10:45 a.m.	BREAKGrand A
10:45 a.m. - 12:15 p.m.	Community-Based Best PracticesGrand F-H
10:45 a.m.– 11:15 a.m.	<i>“Building Strong Camp Programs”</i>
11:15 a.m. –11:45 a.m.	<i>“Support Group Best Practices”</i>
11:45 a.m.—12:15 p.m.	<i>“Strengthening Your New Born Screening Follow-up Program”</i>
12:15 p.m. - 1:30 p.m.	Lunch On Your Own
12:15 p.m. - 1:30 p.m.	LUNCHEON – INVITATION ONLYGrand E Member Organization Presidents/Executive Directors Partner Collaborative Meeting
1:30 p.m. – 5:15 p.m.	TECHNICAL ASSISTANCE, PROFESSIONAL DEVELOPMENT AND EDUCATIONAL CONCURRENT WORKSHOPS
1:30 p.m. – 2:30 p.m.	Educational LecturesGrand F - H
1:30 p.m. – 2:00 p.m.	<i>“The Medical Home Model of Care”</i>
2:00 p.m. – 2:30 p.m.	Care Coordination: <i>“Improving SCD Care”</i>
2:30 p.m. – 3:45 p.m.	CONCURRENT WORKSHOPS - SESSION I
	A. Sickle Cell 101.1Grand H
	B. Nursing PerspectivesWashington
	C. Pain Chronic and AcuteVirginia
	D. Long Term Therapies: Hydroxyurea in Children and AdultsDelaware
	E. Transfusion Therapy and Iron OverloadMaryland
	F. Sickle Cell Trait Update: What Every CBO Needs To KnowPennsylvania
3:45 p.m. – 4:00 p.m.	BREAK
4:00 p.m. – 5:15 p.m.	CONCURRENT WORKSHOPS – SESSION II
	A. Sickle Cell 101.1Grand H
	B. Nursing PerspectivesWashington
	C. Pain Chronic and AcuteVirginia
	D. Long Term Therapies: Hydroxyurea in Children and AdultsDelaware
	E. Transfusion Therapy and Iron OverloadMaryland
	F. Sickle Cell Trait Update: What Every CBO Needs To KnowPennsylvania



WEDNESDAY, SEPTEMBER 25, 2013

6:30 p.m. – 8:30 p.m.	CHAIRMAN'S RECEPTION	Front Foyer
8:00 p.m. – 9:30 p.m.	SCDAA BOARD MEETING	Delaware

THURSDAY, SEPTEMBER 26, 2013

"DISCOVERING NEW PARADIGMS IN PATIENT ADVOCACY AND CARE"

7:30 a.m. – 5:00 p.m.	REGISTRATION	Foyer
7:30 a.m. – 7:00 p.m.	EXHIBITS OPEN	Grand A-C
7:30 a.m. – 8:30 a.m.	POSTER SESSION I	Grand D

7:00 a.m.— 8:00 a.m.	Breakfast	Grand D
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8:30 a.m. – 12:30 p.m.	PLENARY SESSION I	Grand F- H
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8:30 a.m. - 10:45 a.m.	OPENING CEREMONY	Grand F-H
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8:30 a.m. - 9:00 a.m.	Welcome Remarks	
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Keynote Address: *"Continuing the Legacy "Building - Community Based – Treatment – Research Programs - A Coordinated Approach"*

9:00 a.m. - 10:00 a.m.	CHARLES F. WHITTEN, MD MEMORIAL LECTURE	
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9:00 a.m. - 9:30 a.m.	<i>"Moving the Clinical Research Agenda Forward"</i>	Grand F-H
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9:30 a.m. - 10:00 a.m.	<i>"Building Programs That Close the Gap in Health Disparities"</i>	Grand F-H
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10:00 a.m. - 10:15 a.m.	BREAK	
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PLENARY SESSION II	Grand F-H
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10:45 a.m. – 12:15 p.m.	LONZIE LEE JONES PATIENT ADVOCACY SYMPOSIUM Putting SCD Awareness Back on the Map – <i>"Expanding Awareness of SCD and Treatment Disparities"</i> (Proposed to be covered by BET and Webcasted)	
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12:15 p.m. – 1:15 p.m.	Lunch on Your Own	
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THURSDAY, SEPTEMBER 26, 2013

- 1:30 p.m. - 2:45 p.m. **SCDAA LONG-TERM PARTNERS**.....Grand F - H
 “Sickle Cell Programs and Policy Progression “
- *“Growth in SCD Outreach”* - Health Resources and Services Administration (HRSA)
 - *“Progress in SCD Public Health Initiatives”* - Centers for Disease Control and Prevention (CDC)
 - *“Advancements in Research”* – National Heart Lung & Blood Institute (NHLBI)
 - *“Incorporating the Patient Voice into FDA’s Regulatory Processes”* – Food and Drug Administration (FDA)
 - *“Building Strong Alliances”* – American Society of Hematology (ASH)
- 2:45 p.m. - 3:15 p.m. **LEGISLATIVE UPDATE**.....Grand F-H
 Panel: *“Understanding the Climate of Congress –
 How It Affects Getting the SCD Treatment Act Reauthorized”*
- 3:15 pm. - 5:15 p.m. **SIMULTANEOUS SESSION I**
 Oral Presentation of Selected Abstracts
- A. COMMUNITY BASED PROGRAMS**.....Maryland
- B. PATIENT FAMILY**.....Pennsylvania
- C. PATIENT CARE I**.....Delaware
- D. PSYCHOSOCIAL AND PUBLIC HEALTH**Virginia
- 5:45pm – 7:00 p.m. **CORPORATE ADVISORY VIP RECEPTION** Delaware
- 7:00 p.m. – 10:00 p.m. **SCDAA “UNITY SOIREE”**.....Grand Ballroom E- H
 “Celebrating the Legacy of Great Pioneers and Champions”



FRIDAY, SEPTEMBER 27, 2013

"BREAKTHROUGHS IN SICKLE CELL TREATMENT AND RESEARCH"

8:30 a.m. – 5:00 p.m.	REGISTRATION
7:30 a.m. – 5:00 p.m.	EXHIBITS and VENDORS OPENGrand A-C
3:00 p.m. – 5:00 p.m.	EXHIBITS and VENDORS BreakdownGrand A-C
7:30 a.m. – 8:30 a.m.	POSTER SESSION II Grand D

7:30 a.m. - 8:30 a.m.	Breakfast..... Grand D
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8:30 a.m. – 12:00 p.m.	PLENARY SESSION IIIGrand F-H
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8:30 a.m. – 9:00 a.m.	CLARICE REID, M.D. LECTURE
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"The Future of Sickle Cell Disease Research"

9:00 a.m. - 9:30 a.m.	WALTER CLEMENT NOEL LECTURE
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"Patient Centered Care: Medical Professional – Patient Relationship"

9:30 a.m. - 10:00 a.m.	<i>"Healing The Healer"</i>Grand F-H
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10:00 a.m. - 10:15 a.m.	Break
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10:15 a.m. –11:00 a.m.	<i>"Get Connected"– Novel Ways to Reach the Consumer and Provider Population</i>Grand F-H
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11:00 a.m. – 11:30 a.m.	<i>"Global Initiatives in Sickle Cell Disease"</i> Grand F-H
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11:30 a.m. – 12:30 p.m.	Lunch on Your Own
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11:30 a.m. - 12:30 p.m.	PATIENT EMPOWERMENT LUNCHEON: Meet the Experts ..Grand E
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(Limited Space: Sign-up at Registration)

- Medical Management of Sickle Cell Disease – Best Practice Guidelines, Adults
- Transition from Pediatric to Adult Care
- For Women Only
- Pain Management
- For Men Only
- Clinical Trials Participation
- Case Management – Community Based Organizations & Social Services



FRIDAY, SEPTEMBER 27, 2013

12:30 p.m.– 1:30 p.m.	PLENARY SESSION IVGrand F-H INNOVATIVE TREATMENT AS WE SEARCH FOR A CURE
12:30 p.m. - 1:00 p.m.	<i>“New Advancements in Stem Cell Research”</i>
1:00 p.m. - 1:30 p.m.	<i>“Mast Cell Activation and Pain”</i>
1:30 p.m. – 1:45 p.m.	BREAKGrand D
1:45 p.m. – 3:15 p.m.	SIMULTANEOUS SESSIONS II Oral Presentation of Selected Abstracts A. COMMUNITY BASED PROGRAMSMaryland B. PATIENT CARE IIDelaware C. PSYCHOSOCIAL AND PUBLIC HEALTHVirginia D. NURSING SYMPOSIUMPennsylvania
3:15 p.m. – 3:30 p.m.	SCDAA CLOSING ASSEMBLY & ADJOURNMENTGrand F-H Call to Action

5:00 p.m. – 6:15 p.m.	SCDAA Outgoing Board Meeting.....Delaware
6:15 p.m. – 6:30 p.m.	BREAK
6:30 p.m. – 8:45 p.m.	SCDAA Incoming Board Meeting..... Delaware

Program subject to change

