



**35th Anniversary Convention
of the National Sickle Cell Disease Program**
National Heart, Lung and Blood Institute, National Institutes of Health
and the
Sickle Cell Disease Association of America, Inc.



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September 17 – 22, 2007

Washington Hilton Hotel and Towers
Washington, DC

Table of Contents

Introduction and Highlights.....	1-4
Program-At-A-Glance.....	5-6
Sponsors/Contributors/Exhibitors.....	7
Convention Summary Chart.....	8
Attendance Profile.....	9
Attendance by Region.....	10
Convention Revenues.....	10
Convention Expenses.....	11
Convention Revenue/Expenses.....	11
Recognitions and Awards.....	12
Convention Memories.....	13 -19
Convention Evaluation Summary.....	20 - 38
Acknowledgements.....	39

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INTRODUCTION

The National Sickle Cell Disease Program and the Sickle Cell Disease Association of America, Inc. share a history that is parallel in years, complementary in work, and united in its mission. The interaction of the entire spectrum of dedicated individuals engaged in sickle cell activities, encompassing basic and clinical scientists, health care practitioners, educators, counselors, members of community-based organizations, patients and families participated in this comprehensive forum.

The tradition of the 5-year combined meeting of SCDA and the NIH 10 Comprehensive Sickle Cell Centers began in 1997 and was the third such meeting and SCDA hopes to continue the 5 year cycle.

HIGHLIGHTS

The combined meeting began on **Saturday, September 16th** through **Tuesday, September 18th** with NIH Clinical Studies meetings: “Best Practices in Transfusion Medicine for Patients with SCD”, Sickle Disease Adult Provider Network, SCD Clinical Disease Network, other presentations, committee meetings and symposiums.

Tuesday, September 18, 2007

SCDA held its Advocacy Day on Capitol Hill. We were honored to hear in person from Congresswoman **Donna Christensen (D-U.S. Virgin Islands)**, chair of the Congressional Black Caucus Health Brain Trust and Congressman **Danny Davis (D-IL)**, who championed and continues to support the Sickle Cell Treatment Act. Congressman **Elijah Cummings (D - Baltimore, MD)** (home of the SCDA national office) sent greetings and encouragement in our efforts to raise awareness and funds for Sickle Cell Disease (SCD) research. The legislative briefing was followed by individual Senate and Congressional office visits by delegations from states such as CA, VA, NC, TX and more. Our poster children, incoming and outgoing, had photo opportunities with their Legislators (TX and GA, respectively).

Wednesday, September, 19th

The **Children's Hospital of Philadelphia (CHOP)** presented "*Asthma and Pulmonary Hypertension: Are they worse in sickle cell disease?*".

David N. Braxton, Chairman, SCDA Board of Directors and **Susan Shurin, MD**, Deputy Director of NHLBI gave opening remarks and Betty S. Pace, MD, SCDA Chief Medical Officer also greeted the audience.

The Roland B. Scott Lecture, "*Polymerization, Blood Rheology and the Adult with Sickle Cell Disease*" was presented by **Cage S. Johnson, MD**.

Other symposiums, concurrent sessions and simultaneous sessions featured abstracts focused on: Quality of Life, Global Health Service Issues, Nitric Oxide Biology, Neuro-Psychological Function I, Psychosocial Issues, Health Services, Stem Cell Biology and Pulmonary Hypertension.

E. Donnell Ivy, MD and **Craigie Saunders, Esq.** were presenters at **The Lonzie Lee Jones Patient Advocacy Symposium: "Synchrisis" Experiencing Alternative Results**".

The Chairman's Welcoming Reception featured the smooth sounds of **Larry Owens** on the saxophone.

Thursday, September 20, 2007

The Charles Whitten, MD Lecture "*Disparity Between Standard of Care and its Delivery in Sickle Cell Disease*" was presented by **Elliott Vichinsky, MD**, Medical Director, Children's Hospital and Research Center at Oakland, CA. Dr. Vichinsky also was honored as the recipient of the **Chairman's Award** for "Outstanding Contribution to the Sickle Cell Community."

The **NIH Hercules Lecture**, "*Kinetics in Sickle Cell Disease: New Insights into Pathophysiology and Treatment*" was presented by **Frank Ferrone, PhD**, Professor of Physics, Drexel University, Philadelphia, PA.

Victor Boulyjenkov, MD, Responsible Officer, Human Genetics, World Health Organization, Geneva, Switzerland was also an invited speaker during Plenary Session II.

Other symposiums, concurrent sessions and simultaneous sessions featured abstracts focused on: Genomics, Sickle Cell Testing and Counseling, Bone Marrow Transplant, Epidemiology, Innovative Programs, Red Cell Biology, Clinical Care and Clinical Trials, Pain, Red Cell Membrane Phospholipids, Creative Coping, Pulmonary Hypertension II and Neuro-Psychological Function II.

During the annual Member Organization Business Meeting, **Sickle Cell Regional Network**, Patricia Lambright, Executive Director and the **Sickle Cell Foundation of Austin, Marc Thomas Chapter**, Linda Thomas Ward, Executive Director, received the “**Chapter of the Year Awards**” for *Distinguished Service to the Community*.

During the Dorothye Boswell Gala Awards Banquet we were honored to be joined by actor and sickle cell disease advocate, **Larenz Tate**, his brothers, Lahmard and Larron, (The Tate Foundation, Chicago, IL) and **Jamal Munnerlyn**, Co-Host of TV One Access. Our newly elected **2007-2009 Poster Child**, 8-year-old **Gabriel George** (nominated by the Marc Thomas Sickle Cell Foundation, Austin, TX) gave a moving speech for which he received a standing ovation. We were also honored to have 11 past SCDA National poster children and a member of their family join us. Kelly L. Bernard of Arlington, Texas received **2007 Kermit B. Nash Scholarship**. Miss Bernard graduated cum laude with a 4.03 grade point average and is attending Baylor University in the pre-nursing program. The **William F. Finn Triumphant Adult Award** was given to **Carolyn Rowley, PhD** (nominated by the Sickle Cell Disease Foundation of California); the **Mary H. Hunter Advocacy Award** was given to **Donzella Thompson, RN** (nominated by SCDA Southern Connecticut Chapter). **Elliott Vichinsky, MD** was honored as the recipient of the **Chairman’s Award** for “Outstanding Contribution to the Sickle Cell Community.” The President’s Award was presented to **Jeannine Knight** for her selfless contribution and steadfast support to SCDA. **Albert Johnson and Sugarfoot Productions**, ended the stellar evening with line dancing and hand dancing. The event was enjoyed by all.

FRIDAY, SEPTEMBER 21, 2007

The annual **Power Breakfast – Meet the Experts** is so popular that roundtable sessions were held in two ballrooms.

The **Pioneer Tributes in Memoriam** honored **Vernon Ingram, PhD**, the Father of Molecular Medicine, **Maurice Rabb , MD**, Ophthalmologic Changes in SCD and **Jeanne Smith, MD**, Outstanding Clinician Educator and Patient Advocate.

Elliott Vichinsky, MD, presented the NHLBI Comprehensive Sickle Cell Centers (CSCC) Study of Neuropsychological Dysfunction and Neuroimaging Abnormalities in Neurologically Intact Adult Patients with Sickle Cell Disease: Methods, Enrollment and Preliminary Findings.

The HRSA/MCHB Sickle Cell Disease Program, Sickle Cell Disease and Newborn Screening Follow-up Program (SCDA) and Sickle Cell Disease Treatment Demonstration Program (RTI) also presented an educational symposium.

SCDA Community-Based Organization Technical Assistance, Professional Development and Educational Concurrent Workshops I and II were held for the remainder of the day.

Throughout the week, 132 posters were displayed during three separate poster sessions.

SATURDAY, SEPTEMBER 22, 2007

During the Government Relations, Media, Policy & Public Relations session, **Sidney L. Strickland, Jr.**, SCDA Board Member and First Vice Chair and **Brian R. Taylor** from Polsinelli, Shelton, Flanigan & Suelthaus gave an update on the 2007 sickle cell disease legislative developments.

The media presentation was facilitated by Shirley H. Miller, SCDA Board Member and Chair of the SCDA PR/Fundraising Committee. **Helen Shelton**, Executive Vice President, Ruder Finn Lifestyle & Multicultural Marketing Group introduced Radio Personality and Columnist **Florence Anthony** and SCDA National Ambassadors, **Josh Childress** of the NBA Atlanta Hawks and Gospel Recording Artists, the **Williams Brothers** who graced those in attendance with several dynamic selections.

After the closing assembly, the convention adjourned at 12:00 noon.

CME credits for physicians, CEU credits for nurses and certificates of attendance for social workers were made available.

The spirit of team work and tireless dedication from those NHLBI/NIH and SCDA made the meeting a resounding success.



**The 35th ANNIVERSARY OF THE
NATIONAL SICKLE CELL DISEASE PROGRAM
THE NATIONAL HEART, LUNG AND BLOOD INSTITUTE
NATIONAL INSTITUTES OF HEALTH
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SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC**

**September 16-22, 2007
Washington, DC**

■ ■ PROGRAM AT A GLANCE ■ ■

SUNDAY, SEPTEMBER 16, 2007

1:00 pm – 3:00 pm

REGISTRATION

3:00 pm – 10:00 pm

NIH CLINICAL STUDIES MEETINGS

MONDAY, SEPTEMBER 17, 2006

8:00 am – 3:00 pm

REGISTRATION

8:00 am – 5:00 pm

NIH CLINICAL STUDIES MEETINGS

TUESDAY, SEPTEMBER 18, 2007

8:00 am – 5:00 pm

REGISTRATION

8:00 am – 5:00 pm

NIH CLINICAL STUDIES MEETINGS

8:00 am – 5:00 pm

**SCDAA ADVOCACY DAY ON
CAPITOL HILL**

5:30 pm-10:00 pm

NIH PROGRAM

6:00 pm-8:00 p.m.

SCD VOLUNTEERS' MEETING

WEDNESDAY, SEPTEMBER 19, 2007

8:00 am – 7:00 pm

REGISTRATION

8:00 am – 7:30 pm

NIH CLINICAL STUDIES MEETINGS

8:00 am – 10:45 pm

PLENARY SESSION I

8:00 AM-11:00 AM

SCDAA BOARD MEETING

11:00 am – 12:30 pm

PLENARY SESSION II

NIH SCOTT LECTURE

12:30 pm – 2:00 pm

LUNCH ON OWN

12:30 pm – 2:00 pm

NCEC MEETING

2:00 pm – 5:30 pm

NIH SCD SCHOLARS SYMPOSIUM

NIH CONCURRENT SESSIONS I

4:00 pm – 5:30 pm

**SCDAA LONZIE LEE JONES PATIENT
ADVOCACY SYMPOSIUM**

6:00 pm – 8:00 pm

POSTER SESSION – AUTHORS PRESENT

7:00 pm – 10:00 pm

**SCDAA CHAIRMAN'S WELCOMING
RECEPTION**

THURSDAY, SEPTEMBER 20, 2007

8:00 PM-6:00 PM

REGISTRATION

8:15 am – 10:30 am

PLENARY SESSION III

SCDAA Whitten Lecture, NIH Hercules Lecture

10:45 am – 12:15 pm

CONCURRENT SESSIONS II

10:45 am – 12:15 pm

SCDAA BUSINESS MEETING

12:00 pm – 2:00 pm

LUNCH ON OWN

12:00 pm- 1:45 pm

SCDAA LEADERSHIP LUNCHEON

(CLOSED)

2:00 pm – 5:00 pm

CONCURRENT SESSIONS III

5:00 pm – 7:00 pm

POSTER SESSION II-AUTHORS PRESENT

7:30 pm- 11:00 pm

SCDAA DOROTHY BOSWELL GALA

FRIDAY, SEPTEMBER 21, 2007

7:00 am- 5:00 pm

REGISTRATION

7:00 am – 8:15 am

POWER BREAKFAST

8:15 am – 9:30 am

SCDAA REID LECTURE

9:30 am –11:30 am

SCDAA EDUCATIONAL SYMPOSIUM

Patients – Updates on Therapies

11:30 am-1:00 pm

FRIDAY LUNCHEON

FRIDAY, SEPTEMBER 21, 2007 (continued)

1:00 pm – 2:45 pm

SCDAA CONCURRENT WORKSHOPS I

3:00 pm – 4:45 pm

SCDAA CONCURRENT WORKSHOPS II

Repeat of I

7:00 pm – 11:00 pm

SPECIAL EVENT

SATURDAY, SEPTEMBER 22, 2007

9:00 am – 12:00 pm

PLENARY IV

*SCDAA GOVERNMENT RELATIONS/
MEDIA and PUBLIC RELATIONS*

12:00 pm – 3:00 pm

**SCDAA BOARD OF DIRECTORS
MEETINGS**

3:00 pm – 5:00 pm

**SCDAA MEMBER ORGANIZATIONS
LESSONS LEARNED**

2007 CONVENTION SPONSORS/CONTRIBUTORS/EXHIBITORS

2006 Outstanding Corporate Citizens
NOVARTIS

2007 Sponsors
Actelion Pharmaceuticals
HRSA
National Heart Lung and Blood Institute
National Institutes of Health
Pharmaceutical Research and Manufacturers of America

2007 Exhibitors
American Institute for Research
Casey's Art
Henry Colby, Timbuktu
The Harrington Group
Hertz Nazaire, Artist
National Heart, Lung & Blood Institute/NIH
National Dairy Council
National Medical Association
Patient Advocate Foundation
Realistic Computing
Theresa Smith, TAZ Designs
XECHEM International

2007 Contributors
Florence Anthony
Joshua Childress
Comcast
Community Health Charities
"Keeping It Real" with Al Sharpton
Adrienne Lockett Designs
Jamal Munnerlyn
The Tate Brothers
"Larenz, Lahmard and Larron"
Russ Parr Morning Show
Williams Brothers
WJZ-TV Baltimore

SCDAA CONVENTION SUMMARY CHART

ITEMS	2004-32nd A.C.	2005-33rd A.C.	2006-34th A.C.	2007-35th A.C.
City	Atlanta, GA	Baltimore, MD	Dallas, Texas	Washington, DC
Hotel	Renaissance Waverly	Renaissance Harborplace	Hyatt Regency Dallas at Reunion	Washington Hilton Hotel and Towers
# Registered	457	435	457	1329
Total Attendance	600	530	426	1213
Economic Impact •	\$645,620	\$519,759	\$441, 336	\$1,483,300
Theme	'Living with Sickle Cell Disease: Overcoming Obstacles, Maximizing Opportunities"	"Strengthening Partnerships, Policies and Services"	"Sickle Cell Disease: Meeting Unmet Needs"	35 th Anniversary Convention NHLBI/NIH and SCDAA
Dates	September 29 – October 2, 2004	September 7 -10, 2005	September 27 – 30, 2006	September 16 – 22, 2007

- Data supplied by the local Convention and Visitors' Bureau

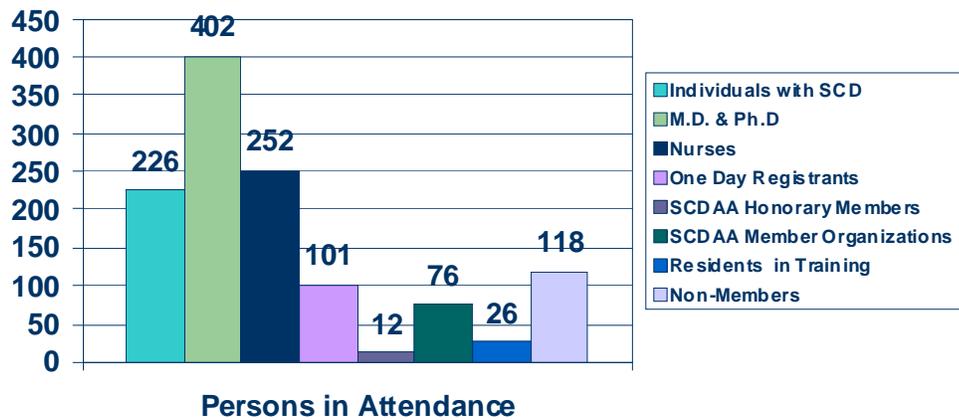
Previous Convention Sites: ▪ 1993 *Tulsa, OK* ▪ 1994 *Miami, FL*, ▪ 1995 *Chicago, IL* ▪ 1996 *Little Rock, AK* ▪ 1997 *Washington, DC* ▪ 1999 *Cleveland, OH* ▪ 2000 *Greensboro, NC*, ▪ 2001 *9/11 No Convention, Planned for Phoenix, AZ* ▪ 2002 *Washington, DC* ▪ 2003 *Beverly Hills, CA* ▪ 2004 *Atlanta, GA* ▪ 2005 *Baltimore, MD* ▪ 2006 *Dallas, TX*

SCDAA Annual Convention Retrospective Report

2007

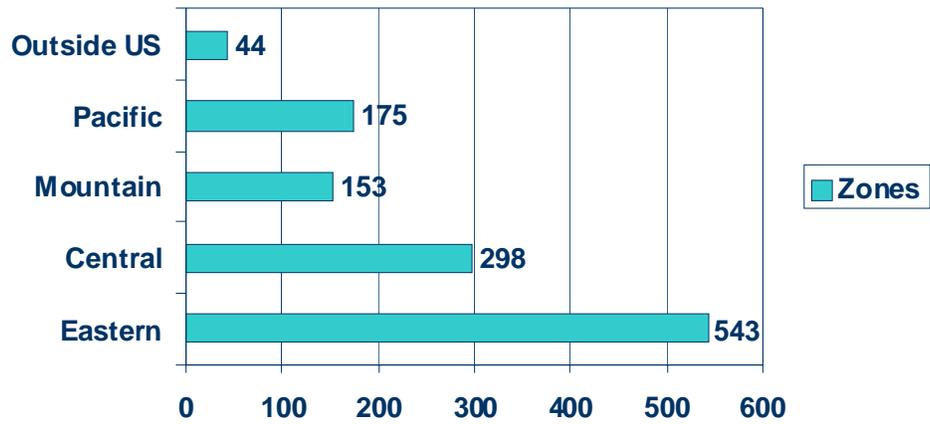
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Attendance Profile



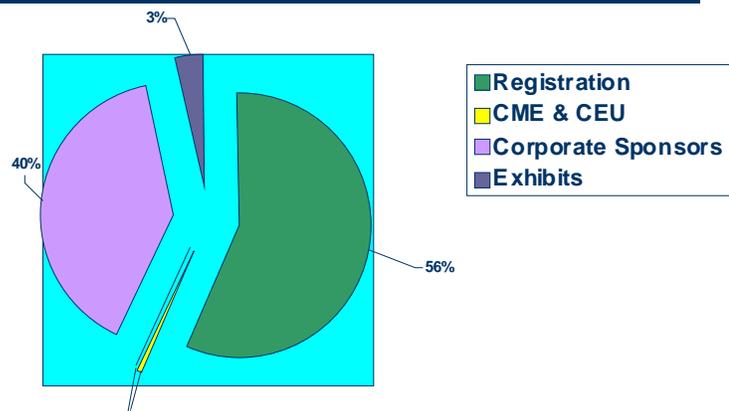
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Attendance by Region



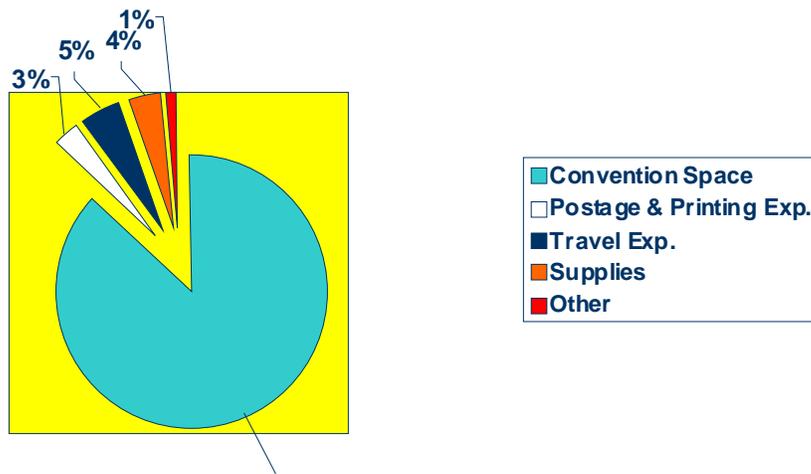
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Convention Revenues



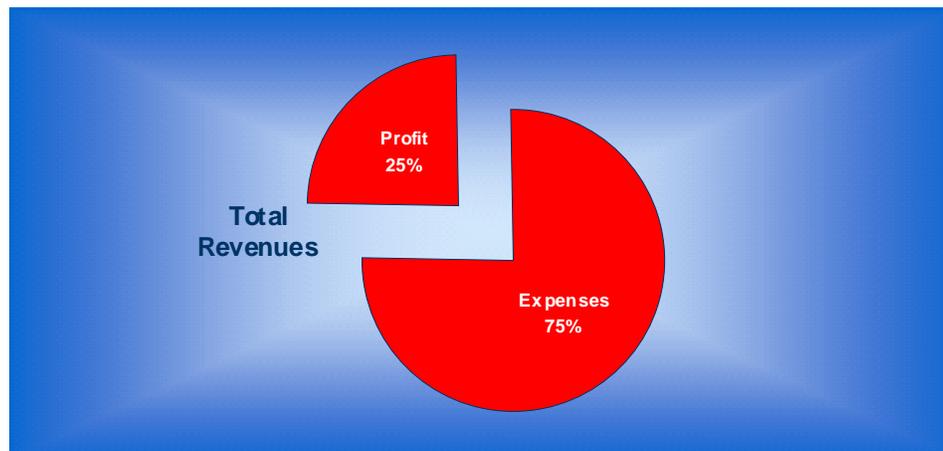
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Convention Expenses



5

Convention Revenue in Relation to Expense



6

Recognitions and Awards

Chairman's Award
Elliott Vichinsky, MD



President's Award
Jeannine Knight



SCDAA Member Organization Awards
Sickle Cell Regional Network,
Sickle Cell Foundation of Austin, Marc Thomas Chapter



"Charles F. Whitten, M.D. Lecture"
Elliott Vichinsky, MD



"Roland B. Scott Lecture"
Cage Johnson, MD



"NIH Hercules Lecture"
Frank Ferrone, PhD



"2007-2009 SCDAA Poster Child"
Gabriel George



SCDAA Ambassadors
Josh Childress and Williams Brothers



"William F. Finn Triumphant Adult Award"
Carolyn Rowley, PhD



"Mary H. Hunter Patient Advocate Award"
Donzella Thompson, RN



"Kermit B. Nash Academic Scholarship"
Kelly L. Bernard

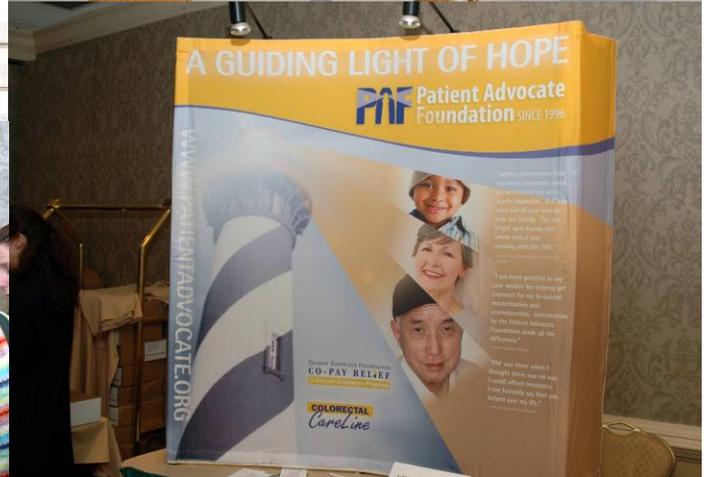
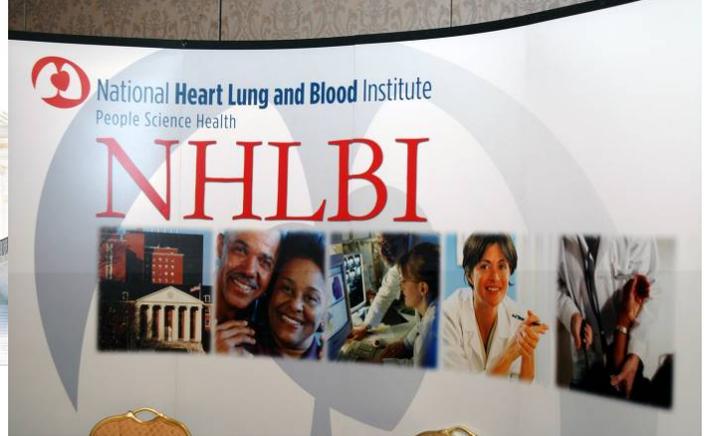
CONVENTION MEMORIES



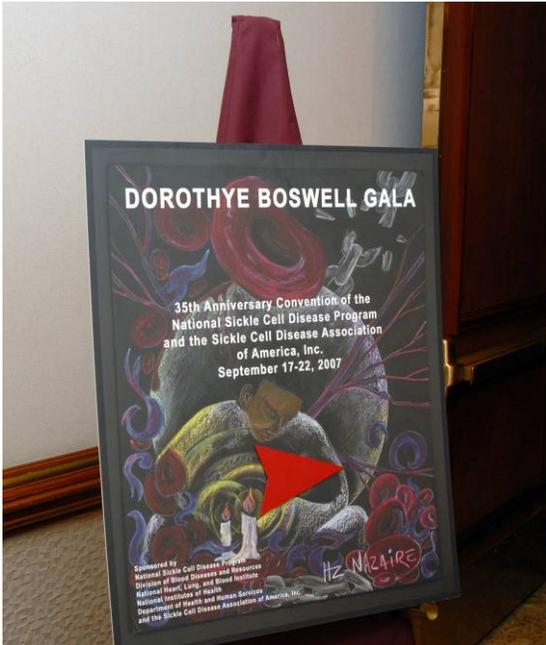
CONVENTION MEMORIES



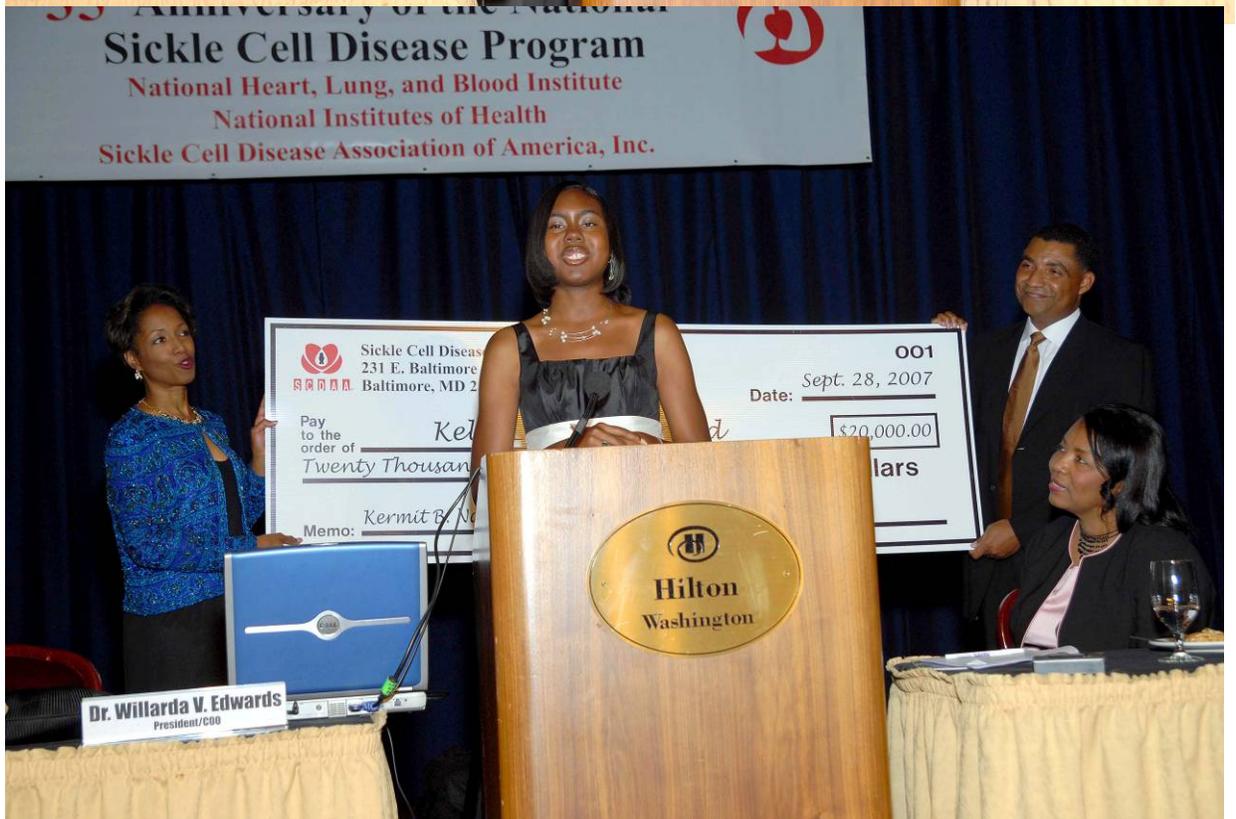
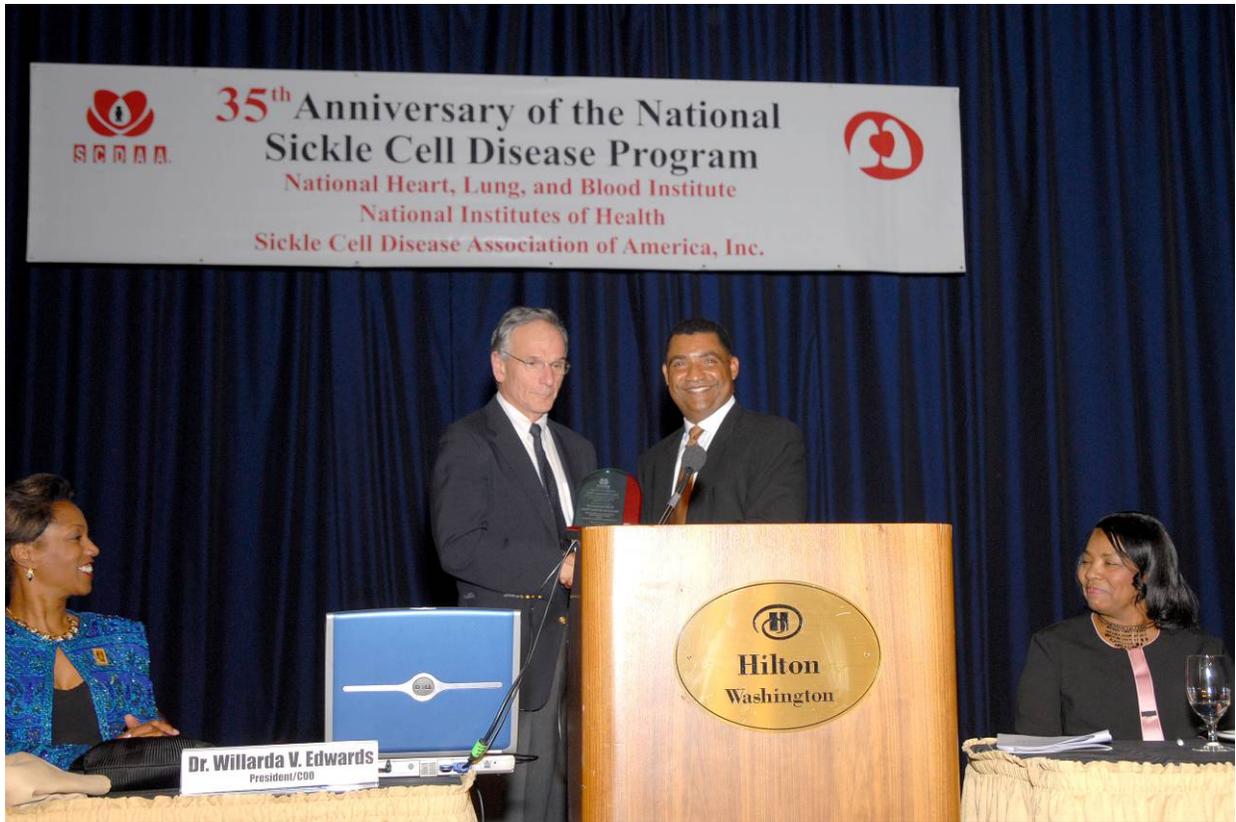
CONVENTION MEMORIES



CONVENTION MEMORIES



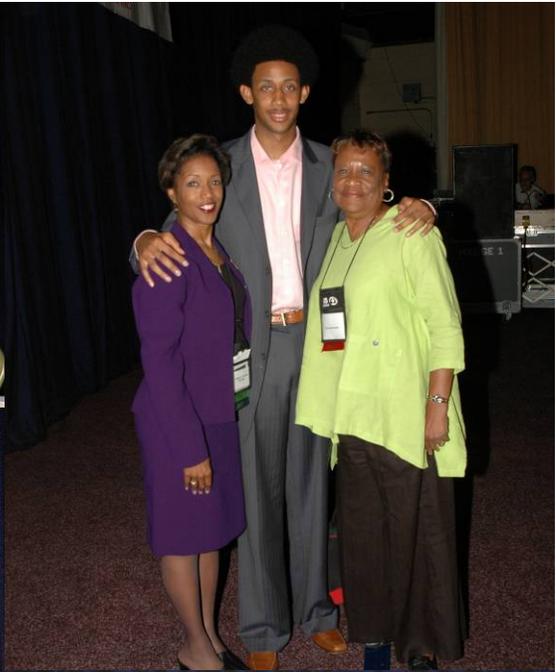
CONVENTION MEMORIES



CONVENTION MEMORIES



CONVENTION MEMORIES



CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Overall Impression of convention	98			1%	12.2%	26.5%	44.9%	15.3%	3.61
Registration, Check-in, and Assistance	102			13.7%	22.5%	28.4%	21.6%	13.7%	2.99
Meeting Rooms	101			10.9%	30.7%	35.6%	15.8%	6.9%	2.77
Exhibits	97			1%	22.7%	44.3%	23.7%	8.2%	3.15
Meals	83			9.6%	14.5%	36.1%	36.1%	3.6%	3.10
Hotel Accommodations	93			6.5%	9.7%	31.2%	37.6%	15.1%	3.45
<i>Objective #1: Demonstrate a better understanding of sickle cell disease best practices regarding treatment regimen currently employed by nationally and internationally recognized experts in the field.</i>	97			1%	2.1%	15.5%	52.6%	28.9%	4.06
<i>Objective #2: Gain an appreciation of current basic science, clinical and psychological research with regard to its contribution to the goals of controlling and curing sickle cell disease.</i>	97				2.1%	11.3%	57.7%	28.9%	4.13
<i>Objective #3: Assemble a network of professional colleagues with whom to solve problems, share experiences and provide mutual professional support.</i>	97				5.2%	19.6%	42.3%	33%	4.03
<i>Objective #4: Describe various sickle cell community models and innovative programs.</i>	94				2.1%	18.1%	59.6%	20.2%	3.98
<i>Objective #5: Participate in an organize self and group advocacy networks for and by persons with sickle cell disease.</i>	90				6.7%	28.9%	52.2%	12.2%	3.70
Relationship of objectives to overall purpose/goals of activity	80				2.5%	11.3%	61.3%	25%	4.09
Best Practices in Transfusion Medicine for Patients with SCD Conference(Sat)	8						62.5%	37.5%	4.38
<i>Do you feel that any of the presentations above were biased toward any specific commercial products?</i>	24		100%						
Best Practices in Transfusion Medicine for Patients with SCD Conference(Sun)	6						83.3%	16.7%	4.17
CSCC Steering Committee Meeting (Sun)	12					25%	25%	50%	4.25
<i>Do you feel that the presentations above were biased toward any specific commercial products? Yes or No</i>	22		100%						
CSCC Steering Committee Meeting(Mon)	6					16.7%	33.3%	50.0%	5.17
SWITCH	14					14.3%	42.9%	42.9%	4.29
SCHReQoL Field Testing Meeting	3						66.7%	33.3%	4.33

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
HU Consensus Conference Speakers (Closed Meeting)	0								
Do you feel that the presentations above were biased toward any specific commercial products?	19		100%						
SCD Clinical Research Network (Tues)	11					18.2%	36.4%	45.5%	4.27
SCDAA Advocacy Day on Capitol Hill	0								
BABYHUG	7					42.9%	57.1%		3.57
IASCNAPA	17					11.8%	58.8%	29.4%	4.18
Annual Sickle Cell Adult Provider Network Symposium "Health Care Delivery for Adults with Sickle Cell Disease – Challenges and Opportunities"	35				2.9%	17.1%	45.7%	34.3%	4.11
Silent Infarction Trials	8				12.5%	50%	25%	12.5%	3.38
Do you feel that the presentations above were biased toward any specific commercial products?	29		100%						
Education and Research Symposium, Children's Hospital of Philadelphia (CHOP) (Wed)	21					14.3%	38.1%	47.6%	4.33
Plenary Session I									
Susan Shurin, MD, Deputy Director, NHLBI	67				3%	23.9%	52.2%	20.9%	3.91
Sickle Cell Disease Research Programs – Community, Academic Treatment Centers and Government, <i>Betty S. Pace, MD, Chief Medical Office, SCDAA</i>	80					13.8%	58.8%	27.5%	4.14
Roland B. Scott Lecture: Polymerization, Blood Rheology and the Adult with Sickle Cell Disease, <i>Cage Johnson, MD</i>	81				1.2%	28.4%	43.2%	27.2%	3.96
Plenary Abstracts									
Therapeutic Inhibition of Endothelial Cell Tissue Factor Expression In Vivo by Nitric Oxide and Arginine in Sickle Transgenic Mice, <i>Robert Hebbel, MD</i>	50					24%	50%	26%	4.02
Attitudes of Health Care Providers towards Sickle Cell Patients with Vaso-Occlusive Crisis, <i>Neda Ratanawongsa, MD, MPH</i>	70					18.6%	42.9%	38.6%	4.20
CSCC Scholars Symposium									
The Role of Rac GTPases in erythropoiesis. #138 - <i>Theodosia A. Kalfa, MD, PhD</i>	28				8.7%	39.1%	39.1%	13%	3.57
Studies of The Regulation Of SS RBCs Adhesion by Epinephrine: Effect of Propranolol Therapy on In Vitro Adhesion of Human SS RBC, <i>Laura De</i>	28				3.6%	25%	57.1%	14.3%	3.82

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
<i>Castro, MD</i>									
Abnormalities in von Willebrand Factor Profile in Sickle Cell Disease: Relationship to Sleep Hypoxemia, <i>Suba Krishnan</i>	30					30%	46.7%	23.3%	3.93
Possible Functional Role of a Putative GATA-1 Binding Site 5' Upstream of the G-Gamma-Globin Gene, <i>Hong-Yuan Luo, PhD</i>	25				12%	40%	36%	12%	3.48
Enhanced Scrambling in Oxidatively Challenged Sickle Red Blood Cells, #187 - <i>Kitty de Jong, PhD</i>	26				7.7%	30.8%	46.2%	15.4%	3.69
Red Cell Antibodies in Children with Sickle Cell Disease Receiving Chronic Transfusions: The Cooperative Blood Donor Program ERA, <i>Kim Smith-Whitley, MD</i>	33				3.0%	9.1%	39.4%	48.5%	4.33
Hemoglobin E and Red Blood Cells: An Overview & Update <i>Qiuying Chen, PhD</i>	28			3.6%		35.7%	42.9%	17.9%	3.71
A Novel MRI Technique for Reliable, Non-Invasive Iron Assessment in a Single Breathhold Based on R2 Quantification- <i>Claudia M. Hillenbrand, PhD</i>	28					32.1%	46.4%	21.4%	3.89
Sickle Cell Nephropathy in Children, <i>Amy M. Becker, MD</i>	31				3.2%	19.4%	54.8%	22.6%	3.97
Rheology of SS + AA Red Blood Cell Mixtures: Is there an Optimum Combination? <i>Tamas Alexy, MD, PhD</i>	25				4%	12%	72%	12%	3.92
Simultaneous Session I									
A. Quality of Life									
The Sickle Cell Health-Related Quality of Life Questionnaire: Making Sure Questions are Meaningful and Responses are Valid, <i>Maureen Maurer, MPH</i>	20					35%	45%	20%	3.85
Do conventional domains of quality of life adequately capture the experiences of children and adolescents with sickle cell disease? An exploratory factor analysis of health-related quality of life measure for pediatric sickle cell disease, <i>Ross Hetherington, PhD</i>	21					42.9%	28.6%	28.6%	3.86
Past Interpersonal Experiences with Medical Care and Trust in Medical Profession Among Adults with Sickle Cell Disease, <i>Carlton Haywood, Jr. MA</i>	24					25%	45.8%	29.2%	4.04
Utilization of Pediatric Health Related Quality of Life (HRQoL) Data from the Comprehensive Sickle Cell Centers (CSCC) Patient Registry, <i>Carlton Dampier, MD</i>	18					22.2%	61.1%	16.7%	3.94
Quality of Life in Children with Sickle Cell Disease and History of Chronic Blood Transfusions. Preliminary Data from US09 CICL 670A, <i>Ofelia</i>	20					30%	40%	30%	4.00

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
<i>Alvarez, MD</i>									
B. Global Health Service Issues									
Comparison of the costs and efficiency if intensification treatment in pediatric patients with severe sickle cell disease: a monocenter experience in Creteil, France, <i>Cecile Arnaud, MD</i>	9					22.2%	55.6%	22.2%	4.00
Public Policies on Sickle Cell Disease in Brazil – The Experience of Salvador in Bahia, Maria Candida <i>Alencarde Queiroz</i>	2					50%		50%	4.00
Home Care of Sickle Cell Disease Patients in Enugu State, Nigeria, <i>Ifeoma Uyanwuune, BS, BA</i>	12					25%	58.3%	16.7%	3.92
Attitude Counts: Pain, Self Efficiency and Negative Thinking Affect Health Care Utilization and Costs in Adolescent Sickle Cell Disease, <i>Jerilynn Radcliffe, PhD</i>	16					18.8%	68.8%	12.5%	3.94
Working Towards a Comprehensive Team Approach to the Care of Children with Sickle Cell Disease, <i>Philippa Sprinz, MD</i>	13					7.7%	53.8%	38.5%	4.31
C. Nitric Oxide Biology									
Sexual Dimorphism in Whole Blood Nitrate and Susceptibility to Hypoxic Sickle Cell Vaso-Occlusive Injury in Mice, <i>Lewis HSU, MD, PhD</i>	10						50%	50%	4.50
The % Tetrahydrobiopterin (BH4) and Serine 1177 Phosphorylation is Reduced in Sickle Cell Transgenic Mice, <i>Mary Fabry, PhD</i>	11					18.2%	54.5%	27.3%	4.09
Reduced Oxidative Stress and Increased Nitric Oxide (NO) Bioavailability in Fetal Hemoglobin (HbF) Expressing Transgenic – Knockout Sickle Cell Mice is a Mediated by Decreased Sickling, <i>Dhananjay Kaul, PhD</i>	12					8.3%	58.3%	33.3%	4.25
NO binding to Hb inhibits polymerization through tertiary structure changes, <i>Frank Ferrone, PhD</i>	14					7.1%	50%	42.9%	4.36
Sickle Red Blood Cell Adhesion to Vascular Endothelium is Reduced by Inhaled Nitric Oxide in Mice, <i>Pedro Montero-Hewta, MD</i>	12					8.3%	58.3%	33.3%	4.25
D. Neuro-Psychological Function I									
Effect of sickle cell anemia on intellectual performance in children <i>Mikolaj Pawlak, MD, PhD</i>	27				3.7%	11.1%	59.3%	25.9%	4.07
Developmental Screening in Three-Year-Old Children With Sickle Cell Disease, <i>Kelvin Bates, MS, EdS</i>	24					12.5%	70.8%	16.7%	4.04
Assessment of Attention With The Corners' Continuous Performance Test In A Sickle Cell Clinic Setting <i>Kofie Anie, PhD</i>	19					10.5%	78.9%	10.5%	4.00
Brain Morphometry and IQ measurements in children with Sickle Cell	23				4.3%	17.4%	60.9%	17.4%	3.91

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Disease, <i>Mikolaj Pawlak, MD, PhD</i>									
NHLBI Comprehensive Sickle Cell Centers (CSCC) Study of Neuropsychological Dysfunction And Neuroimaging Abnormalities In Neurologically Intact Patients With Sickle Cell Disease: Preliminary Neuropsychological Findings, <i>Jeffery I. Gold, PhD</i>	27					3.7%	51.9%	44.4%	4.41
Correlation of Diffusion Tensor Imaging with Neurocognitive Function in Children with Sickle Cell Anemia, <i>Kathleen Helton, MD</i>	23				4.3%		65.2%	30.4%	4.22
Lonzie Lee Jones Patient Advocacy Symposium : 'Syncrisis', Experiencing Alternative Results	4					25%	25%	50%	4.25
Simultaneous Session II									
E. Psychosocial									
Self-Efficacy as a Predictor of Self-Reported Sickle Cell Disease Symptoms Among Young Adults and Adolescents, <i>Anya Griffin, PhD</i>	13					46.2%	30.8%	23.1%	3.77
Gender Differences in Coping with Sickle Cell Disease: Financial and Psychosocial Challenges, <i>Daneile Reid, BSc</i>	13				7.7%	23.1%	38.5%	30.8%	3.92
Are Perceptions of Public Attitudes towards Sickle Cell Related to Psychosocial Outcomes? - <i>Shawn Bediako, PhD</i>	19					5.3%	57.9%	36.8%	4.32
Associates of School Absenteeism in Adolescents with Sickle Cell Disease. <i>Lisa Schwartz, PhD</i>	11					27.3%	54.5%	18.2%	3.91
Psychosocial Adaptation of Healthy Siblings of Adolescents with Sickle Cell Disease, - <i>Elizabeth R. Gonzalez, MS</i>	13					38.5%	38.5%	23.1%	3.85
Community Knowledge and Awareness about Sickle Cell Disease and Trait: Relation to Trait Testing, <i>Marsha Treadwell, PhD</i>	13					7.7%	46.2%	46.2%	4.38
F. Healthcare Services									
Disease Specific Adult Sickle Cell Hospital Unit: Figuring Out What Works, <i>Patricia Adams-Graves, MD</i>	25					4%	28%	68%	4.64
Adjusting The Health Care System to Allow Families To Take Advantage of Hydroxyurea Therapy, <i>Elizabeth McDonough, RN, BSN</i>	26					7.7%	46.2%	46.2%	4.38
Comparing Abstract Numerical and Visual Depictions of Risk in Survey of Parental Assessment of Risk in Sickle Cell Hydroxyurea Treatment, <i>Chavis Patterson, PhD</i>	27					11.1%	55.6%	33.3%	4.22
Chart Cared as a Tool for Improving Emergency Room Care for Patients with Sickle Cell Disease: A Preliminary Report, <i>Lynne Neumayr, MD</i>	31			3.2%	3.2%	9.7%	51.6%	32.3%	4.06

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Succeed®, A Web Based Sickle Cell Clinical and Patient Tracking and Scribe®, A De-Identified Registry Can Serve As Resource for Clinical Care And Research, <i>Lakshmanan Krishnanmurti, MD</i>	23					13%	43.5%	43.5%	4.30
Management of sickle cell disease in Ghana; the role of Nurse Case Managers ("Mmofra Nnamfo"), <i>Delaena Ocloo, PNO Public Health</i>	20					5%	70%	25%	4.20
G Stem Cell Biology									
Berkeley Sickle Cell Disease Mice Exhibit Multifaceted Immune Activation, and Avidly Reject Allogenic Bone Marrow Transplantation, Berkeley Sickle Cell Disease Mice Exhibit Multifaceted Immune Activation, and Avidly Reject Allogenic Bone Marrow Transplantation, - <i>Leslie Kean, MD, PhD</i>	6						66.7%	33.3%	4.33
Globin Lentiviral vector design to reduce the potential for proto-oncogene activation, <i>Byoung Ryu, PhD</i>	6					16.7%	66.7%	16.7%	4.00
Gamma-Globin Lentiviral Vector-Mediated Gene Therapy of Murine Sickle Cell Disease, <i>Derek Persons, MD, PhD</i>	3						100%		4.00
Regulation of erythroid gene expression by chromatin loops, <i>Gerd Blobel, MD, PhD</i>	2						50%	50%	4.50
Haploidentical in Utero Hematopoietic Cell Transplantation Reverses the Lethal Phenotype in Canine Leukocyte Deficiency and Allows for Postnatal Minimally Myeloablative Transplants in a Nondiseased Canine Model, <i>William Peranteau</i>									
H. Pulmonary Hypertension									
The effects of Vaso-occlusive pain crisis and cycloergometer exercise on pulmonary pressures in adults with sickle cell disease, <i>Roberto Machado, MD</i>	26						65.4%	34.6%	4.35
Erythrocyte Glutamine-To-Glutamate Ratio: A Novel Biomarker Of Pulmonary Hypertension In Sickle Cell Disease, <i>Claudia R. Morris, MD</i>	29					6.9%	62.1%	31%	4.24
Prospective evaluation of clinical and echocardiographic risk factors for elevated tricuspid regurgitant jet velocity in children and adolescents with sickle cell disease, <i>Caterina Minniti, MD</i>	31					6.5%	45.2%	48.4%	4.42
Asthma, Sepsis And Acute Chest Syndrome: Risk Factors for Pulmonary Hypertension in Children with Sickle Cell Disease, <i>Claudia Morris, MD</i>	42					11.9%	47.6%	40.5%	4.29
The Natural History Of Persistent Oxyhemoglobin Desaturation in Children with Sickle Cell Disease, <i>Korshie Dumor, MD</i>	34					5.9%	61.8%	32.4%	4.26
Pulmonary Function Tests and their Correlation with Tricuspid Regurgitant Jet Velocity in Pediatric Sickle Cell Disease Patients, <i>Manuel Arteta, MD</i>	40					5%	70%	25%	4.20

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Poster Session I –Authors Present	16				6.3%	12.5%	62.5%	18.8%	3.94
Do you feel that the presentations above were biased toward any specific commercial products? Yes or No	49	4.1%	95.9%						
Plenary Session II									
<i>Charles F. Whitten Lecture: Elliott Vichinsky, MD</i>	64					1.6%	15.6%	82.8%	4.81
NIH Hercules Lecture, Frank Ferrone, MD, Kinetics in Sickle Cell Disease: New Insights into Pathophysiology and Treatment	76					7.9%	43.4%	48.7%	4.41
SCD Summit Update	80				2.5%	11.3%	31.3%	55%	4.39
Invited Speaker:									
<i>Victor Boulyjenkov, MD, World Health Organization</i>	71				5.6%	21.1%	43.7%	29.6%	3.97
Plenary Abstracts									
Inhibition of Nitric Oxide Synthase by ADMA in Sickle Cell Disease: Abnormal Levels and Correlations with Hemolysis, Desaturation, Pulmonary Hypertension, and Leg Ulcers	82				1.2%	11%	42.7%	45.1%	4.32
Understanding Health Related Quality of Life: Perspectives from Adults with Sickle Cell Disease	80					13.8%	46.3%	40%	4.26
Simultaneous Session III									
A: Genomic									
HbF Reactivation, DNA methylation, and Chromatin Structure, <i>Donald Lavelle, PhD</i>	7				14.3%	42.9%	42.9%		3.29
Characterization of Histone Deacetylases Involved in γ -Globin Gene Regulation, <i>Shalini Muralidhar, MS</i>	6					66.7%	16.7%	16.7%	3.50
The Stability of beta-globin mRNA is Enhanced by Site-specific Mutations within its 3'UTR, <i>Osheiza Abdunakil, DVM</i>	3						66.7%	33.3%	4.33
Novel Transcripts of the KCl Cotransporter-3 (KCC3) gene in erythroid cells are derived from alternate splicing within exon 1, <i>Clinton Joiner, MD, PhD</i>	6					33.3%	50%	16.7%	3.83
Genomic Techniques Produce Opportunity to Revisit the Clinical Implications of β -Globin Locus Haplotypes, <i>Li Lui, PhD</i>	5					20%	60%	20%	4.00
Hematopoietic Stem Cells derived from Sickle Mice are oxidatively stressed and demonstrate significant impairment in engraftment potential,	4						75%	25%	4.25

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
<i>David Archer, PhD</i>									
B: Sickle Cell Testing and Counseling									
Western Pennsylvania Sickle Cell Network: Accomplishments through Integration, Education, and Product Development, <i>L. Krishnamurti, MD</i>	24					12.5%	54.2%	33.3%	4.21
"Your child has sickle cell disease...": The New Parent Sickle Cell Disease Education Protocol, <i>Nina Anderson, CRNP</i>	26					11.5%	53.8%	34.6%	4.23
Sickle cell Foundations in Brazil- a struggle for public policies, <i>Altair Lira</i>	14					14.3%	57.1%	28.6%	4.14
Overcoming Barriers to dialogue about sickle cell disease among African Americans: Enhancing acceptance of genetic testing and counseling, <i>L. Krishnamurti, MD</i>	24					12.5%	45.8%	41.7%	4.29
Identification of Specific Community Needs when Planning Sickle Cell Trait Counseling Programs: The Colorado Experience, <i>Kathryn Hassell, MD</i>	24					4.2%	58.3%	37.5%	4.33
A Novel Model for Community Based Follow-Up of Sickle Cell Trait Detected on Newborn Screening, <i>L. Krishnamurti, MD</i>	17					11.8%	58.8%	29.4%	4.18
C: Bone Marrow Transplant									
A Novel Allogeneic Transplant Conditioning Regimen Designed for Tolerance Induction in Patients with Severe Sickle Cell Disease, <i>Matthe Hsieh, MD</i>	34					17.6%	29.4%	52.9%	4.35
Sibling Donor Cord Blood Transplantation for Hemoglobinopathies, <i>Mark Walters, MD</i>	34					14.7%	38.2%	47.1%	4.32
Cerebral Vasculopathy Outcome after Stem-Cell Transplantation for Sickle Cell Disease, <i>Suzanne Verthac, MD</i>	34					26.5%	35.3%	38.2%	4.12
Hematopoietic Cell Transplantation for Sickle Cell Anemia and Thalassemia Major, <i>Mark Walters, MD</i>	36				2.8%	8.3%	50%	38.9%	4.28
Genetic Modifiers of Severity of Sickle Cell Anemia, <i>Paola Sebastiani, PhD</i>	31				3.2%	25.8%	45.2%	25.8%	3.94
Genome-Wide Association Study using Pooled DNA Samples Reveals New Genetic Modulators of HbF Concentration, <i>Paola Sebastiani</i>	22				9.1%	18.2%	45.5%	27.3%	3.91
D: Epidemiology									
Sickle Cell Disease through Adult Life: A Cornucopia of Vulnerabilities and Disparities, <i>Samir Ballas, MD</i>	31					6.5%	41.9%	51.6%	4.45
Sickle Cell Disease [SCD] In the United States 2007: An Update from the Collaborative Data Project [C-DATA] of the Comprehensive Sickle Cell	30						53.3%	46.7%	4.47

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Centers Program, <i>Zora Rogers, MD</i>									
Sickle Cell Disease Population Estimation: Application of Available Contemporary Data to Traditional Methods, <i>Kathryn Hassell, MD</i>	33					3%	36.4%	60.6%	4.58
Sickle Cell Disease: Current Activities, Public Health Implications and Future Directions, <i>Melissa Creary, MPA</i>	32					6.3%	46.9%	46.9%	4.41
A Review of Sickle Cell Disease in Ghana, <i>Kwaku Asare, MBChB</i>	35					11.4%	57.1%	31.4%	4.20
Pneumococcal Conjugate Vaccine in Children with Sickle Cell Disease: Impact on Invasive Disease, <i>Thomas Adamkiewicz, MD, MSCR, FRCPC</i>	39				5.1%	12.8%	51.3%	30.8%	4.08
Simultaneous Sessions IV									
E: Innovative Programs									
STRIVE: Sickle Cell Teens Raising Awareness, Initiating Change, Voicing Thoughts and Empowering Themselves, <i>Rajan Sonik, MD</i>	20					10%	45%	45%	4.35
Clinical and Community Collaborations, <i>Eileen Murray</i>	18				5.6%	11.1%	50.0%	33.3%	4.11
The Sickle Cell Sabbath: A Faith Based Community Program Increases First-time Blood Donors in the African American Faith Community, <i>Michael Johnson, BA</i>	16					6.3%	37.5%	56.3%	4.50
Community Trait Testing: Get the word out, <i>Eileen Murray</i>	15					6.7%	46.7%	46.7%	4.40
Using an Electronic Health Record to Improve Self-Management of Sickle Cell Disease, <i>Patricia Kavanagh, MD</i>	15					13.3%	40%	46.7%	4.33
NHLBI Summer for Sickle Cell Science Program: the Oakland experience, <i>Frans Kuypers, PhD</i>	12					8.3%	33.3%	58.3%	4.50
F: Red Cell Biology									
Restoration of Blood Flow and Inhibition of Leukocyte Adhesion in Sickle Cell Mice by Pan-selection Antagonist, GMI-1070, <i>John Magnani, PhD</i>	7						71.4%	28.3%	4.29
Expressional profile of KCl cotransporters in human erythroid differentiation, <i>Dao Pan, PhD</i>	6					16.7%	66.7%	16.7%	4.00
Anti-Inflammatory Therapy Inhibits Neutrophil-Endothelial Cell Interactions and Erythrocyte Capture Under Low Shear Flow in vitro <i>Eileen Finneqan</i>	6						83.3%	16.7%	4.17
Inhibition of cell surface associated Protein Disulfide Isomerase Reduces Erythrocyte Dehydration via decrease in Gardos Channel activity, <i>Alicia Rivera, PhD</i>	5						80%	20%	4.20
Sickle Cell Fibers Deform Red Cells by a Brownian Ratchet Mechanism: A Minimally Invasive Model for Pathogenic Events, <i>Robin Briehl, MD</i>	7						57.1%	42.9%	4.43
Epinephrine Induces Murine Sickle Red Cell Adhesion In Vitro and In Vivo,	8						50%	50%	4.50

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
<i>Marilyn Telen, MD</i>									
G: Clinical Care and Clinical Trials	1						100%		4.00
Potential Molecular Mechanisms of Hypertensive Complications in Sickle Cell Disease Pregnancy <i>Julia Brittain, PhD</i>	25					12%	72%	16%	4.04
Arginine Therapy Does Not Benefit Children with Sickle Cell Anemia. CSCC Multi-Center Study, - <i>Lori Styles, MD</i>	33					15.2%	48.5%	36.4%	4.21
Ten years longitudinal follow up study of sickle cell disease with hydroxyurea in four English centres, <i>Annette Gilmore RN, BSc, MSc</i>	37					16.2%	56.8%	27%	4.11
Rescue of severely ill sickle cell disease patients with decitabine, <i>Yogen Sauntharajah, MB, BCh</i>	36					19.4%	52.8%	27.8%	4.08
Characteristics of Successfully Completed Clinical Studies in Sickle Cell Disease, <i>Kathryn Hassell, MD</i>	34					8.8%	41.2%	50%	4.41
Recruitment and Retention of Children with Sickle Cell Disease in Longitudinal Research, <i>Beth Ely, BSN, MS, PhD</i>	27					11.1%	51.9%	37%	4.26
H. Pain									
Pain Site Frequency and Location in Sickle Cell Disease: The PISCES Project, <i>Wally Smith, MD</i>	31				3.2%	3.2%	51.6%	41.9%	4.32
Clinical and Patient-Reported Measures of Healthcare Quality for Sickle Cell Vaso-Occlusive Crisis, - <i>Mary Catherine Beach, MD, MPH</i>	31				3.2%	16.1%	51.6%	29%	4.06
The Physician's Call for Better Treatment of Her Sickle Cell Pain Answered - - <i>Samir Ballas, MD, FACP</i>	29				6.9%	17.2%	41.4%	34.5%	4.03
Pain Barriers: Used to Tailor Multi-media Education for Patients with Sickle Cell Disease, <i>Diana Wilkie, PhD, RN, FAAN</i>	29				3.4%	24.1%	44.8%	27.6%	3.97
UGT2B7 single nucleotide promoter polymorphism -840G>A contributes to the variability in hepatic clearance of morphine in patients with sickle cell disease, <i>Deepika Darbari, MD</i>	27				7.4%	18.5%	55.6%	18.5%	3.85
I. Red Cell Membrane Phospholipids									
Acyl-CoA: Lysophosphatidylcholine Acyltransferase in Red Blood Cells, <i>Frans Kuypers, PhD</i>	5					20%	60%	20%	4.00
Rapid deactivation of flippase activity contributes to short life-span of sickle cells, <i>Kitty de Jong, PhD</i>	7					28.6%	57.1%	14.3%	3.86
Lysophosphatidic Acid Metabolism in Sickle Red Blood Cells, <i>Frans Kuypers, PhD</i>	4						100%		4.00
Sickle Red Blood Cell Flippase Activity in Yeast Vesicles, <i>Frans Kuypers,</i>	5						100%		4.00

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
<i>PhD</i>									
Aminophospholipid Translocase Activity is Markedly Decreased in Dehydrated Sickle Red Blood Cells, <i>Latorya Arnold, BS</i>	3						100%		4.00
J. Creative Coping									
Home educating families and patients affected with sickle cell disease (SCD) dramatically improves their knowledge of the disease, #62 – <i>Mariane De Montalembert, MD</i>	27					14.8%	25.9%	59.3%	4.44
Photovoice by Youth with Sickle Cell Disease, #40 – <i>Seema Mhatre, MPH, MSW</i>	28					10.7%	28.6%	60.7%	4.50
Sickle Cell Disease: I Have It, It Does Not Have Me. An Educational DVD and Resource Manual, #228 – <i>Philippa Sprinz, MD</i>	26					11.5%	26.9%	61.5%	4.50
Religious Coping and Pain Self-Management among Adults with Sickle Cell Disease, #85 - <i>Shawn Bediako, PhD</i>	27					14.8%	44.4%	40.7%	4.26
Guided Imagery for Pain Management by Children with Sickle Cell Disease Ages 6 To 11 Years, #68 – <i>Cassandra Dobson, DNSc, MS, BS, BC, RN</i>	20					20%	30%	50%	4.30
K. Pulmonary Hypertension									
Placenta Growth Factor-Endothelin-1-Hypoxia Inducible Factor-1? Axis Augments Inflammation and Likely Contributes to Pulmonary Hypertension in Sickle Cell Disease (SCD), <i>Vijay Kalra, PhD</i>	10					30%	60%	10%	3.80
Preliminary Estimates of the Prevalence And Incidence of Left Ventricular Dysfunction in Chronically Transfused Patients with Sickle Cell Anemia and Thalassemia, <i>Lynne Neumayr</i>	13					15.4%	53.8%	30.8%	4.15
Hemolysis-Associated Pulmonary Hypertension in Adults and Children with Sickle Cell Disease in Nigeria: Prevalence and Clinical Characteristics, <i>Zakari Aliyu, MD, MPH</i>	17					17.6%	58.8%	23.5%	4.06
Risk Factors for Survival in Adults with Pulmonary Hypertension in Sickle Cell Disease, <i>Ward Hagar</i>	16					12.5%	62.5%	25%	4.13
Low Circulating Endothelial Progenitor Cell Counts and Pulmonary Hypertension in Adults with Sickle Cell Disease, <i>Gregory Kato, MD</i>	17					17.6%	58.8%	23.5%	4.06
L. Neuro-Psychological Function II									
The Excess Burden of Stroke Among Adults with Sickle Cell Disease, #251 – <i>John Strouse, MD</i>	32					15.6%	37.5%	46.9%	4.31
Cerebral Vasculopathy In A Newborn Sickle Cell Cohort: The Monocenter Creteil Experience, <i>Francoise Bernaudin, MD</i>	31					6.5%	45.2%	48.4%	4.42

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
TNF haplotype association with large vessel stroke risk in SCA children from the CSSCD and STOP cohorts, <i>Carolyn Hoppe, MD</i>	30					10%	56.7%	33.3%	4.23
Genetic Influence on the Systems Biology of Sickle Stroke Risk Detected by Endothelial Gene Expression, <i>Robert Hebbel, MD</i>	18					16.7%	66.7%	16.7%	4.00
Risk Factors and Outcomes of Primary Hemorrhagic Stroke in Children with Sickle Cell Disease, #173 – <i>John Strouse, MD</i>	31					9.7%	54.8%	35.5%	4.26
Poster Session II – Authors Present	9				11.1%	11.1%	55.6%	22.2%	3.89
Do you feel that the presentations above were biased toward any specific commercial products? Poster Session III – Authors Present	55	3.6%	96.4%						
Power Breakfast: Meet The Experts	23				4.3%	13%	43.5%	39.1%	4.17
Poster session III	9					11.1%	33.3%	55.6%	4.44
Plenary Session III	11					18.2%	45.5%	36.4%	4.18
CLARICE REID, MD LECTURE, <i>Lennette J. Benjamin, MD,P=MC²</i> : A Theory of Relativity for Pain Care Model Development in Sickle Cell Disease	23					21.7%	39.1%	39.1%	4.17
Plenary Abstract									
NHLBI Comprehensive Sickle Cell Centers (CSCC) Study of Neuropsychological Dysfunction And Neuroimaging Abnormalities In Neurologically Intact Patients With Sickle Cell Disease: Methods, Enrollment, And Preliminary Findings, <i>Elliott Vichinsky, MD</i>	62					9.7%	35.5%	54.8%	4.45
Educational Symposium HRSA/MCHB Sickle Cell Disease Program Sickle Cell Disease and Newborn Screening Follow-up Program (SCDAA) and Sickle Cell Disease Treatment Demonstration Program (RTI) <i>Judy Hagopian, MSW, MPH, MSW & Joseph Telfair, DrPH, MPH, MSW</i>	41					22%	36.6%	41.5%	4.20
HRSA Grantee Presentations: Newborn Screening Grantees and SCDTP Regional Collaborative Demonstration Projects: NCEC and NCC-RTI	30					30%	36.7%	33.3%	4.03
SPECIAL PRESENTATION									
SPEAR Pain Management Symposium “A Global Perspective” <i>Lennette J. Benjamin, MD and Marsha Treadwell, PhD, Co-Chairs</i>	14					14.3%	42.9%	42.9%	4.29
Community Based Organization Technical Assistance, Professional Development, And Educational Concurrent Workshops I									
Sickle Cell 101, Onyinye Onyekwere, MD									

CONVENTION EVALUATION SUMMARY

Topic	N	Yes	No	Poor	Fair	Average	Very Good	Excellent	Mean Score
Adult Forum: Coping Strategies, <i>Chavis Patterson, PhD and Shawn Bediako, PhD</i>	14					14.3%	35.7%	50%	4.36
Grant Writing I, <i>Rosie Peterson, BS, PAHM</i>	9					11.1%	44.4%	44.4%	4.33
<i>The Camp Experience: "Joy and Successes", Mary E. Brown</i>	9					11.1%	66.7%	22.2%	4.11
Community Based Organization Technical Assistance, Professional Development, And Educational Concurrent Workshops II									
Sickle Cell 101, Onyinye Onyekwere, MD	19					10.5%	21.1%	68.4%	4.58
Sickle Cell Disease, Childhood Through Teenage Years <i>Renee Robinson, PhD</i>	8						50%	50%	4.50
Grant Writing II, <i>Rosie Peterson, BS, PAHM</i>	8				12.5%		37.5%	50%	4.25
Fund Development, Arthur G. Affleck, III	7						57.1%	42.9%	4.43
Do you feel that the presentations above were biased toward any specific commercial products?	34	11.8%	88.2%						
Plenary Session IV									
<i>Government Relations, Media, Policy & Public Relations</i>	7						71.4%	28.6%	4.29
Closing Assembly & Convention Adjournment	8					12.5%	62.5%	25%	4.13
SCDAA Board of Directors Meeting	2					50%	50%		3.50
SCDAA Member Organizations Best Practices Meeting	2					50%	50%		3.50
Do you feel that the presentations above were biased toward any specific commercial products?	10		100%						
Evaluation For CME and CEU credit:									
Participation in this educational activity increased my knowledge and skills and improved my potential for better patient care.	89				1.1%	16.9%	50.6%	31.5%	4.12
Presenters were well balanced, supported by scientific information and provided a fair description of all therapeutic options.	89					11.2%	53.9%	34.8%	4.24
I was informed about financial support received by this program as well as the financial relationships that speakers have with entities that make or sell products or services related to the content of this program.	81	86.4%	13.6%						

CONVENTION EVALUATION SUMMARY

id	Comments
1	Rooms were cold; It would have been nice to have the Williams Brothers earlier in the conference. More People would have been able to appreciate their music. It would have been an excellent "kick off" instead of a closing.
2	CME documentation and evaluate sheet poor and confusing. This is not a good way to document CME. This part was poorly organized. Not all lectures are listed for CME credits. Overall the lectures and presentations were great.
3	The week was a mountain top experience. The educational experience was excellent and exceeded any educational conference that I have attended in the past. The challenges were mind twisting and overwhelming at time. The content of this conference has a positive effect on my own clinical practices.
4	Many meeting rooms too small, Problems with hotel computers, disrupted several presentations. Registration site kept changing- confusing. Could not buy extra abstract books or a CD. If it ends up on web that would be fine also. Suggest: Better hotel in the future.
6	Wednesday sessions meeting rooms too small for number of participants, Friday morning poster session too early, posters not well attended, posters should be kept up all day for viewing.
7	Great conference, very busy the whole time. Great party, keep up the good work.
8	There were multiple changes in the schedule that were not announced and then confusing among the participants about where tables were held.
9	Hotel expenses, made reservations 1 1/2 months ago, showed to hotel at 5:00pm got room arrangement at 10:00pm, meeting rooms were too small on Thursday. Great meeting attendance and excellent organization/session.
13	Hotel Convention services were poor, meeting room size and locations, AV / Computer support. CME forms are duplicative.
15	Meeting rooms too small and crowded
17	Too much going on at the same time
18	This was the most disorganized meeting I've been to ever. The CME was not well done. If I had known how little was offered, I would not have resigned up. This evaluation form is way too complicated. The timer for the different sessions didn't overlap. Sessions were excellent. Organization needs work.
20	Many thanks to all who's hard work culminated in an OUTSTANDING conference! The abstracts were well chosen and particularly I enjoyed the variety of topics available (basic science- psychosocial). I was somewhat disappointed there were not enough rooms in the conference hotel. My only recommendation is to ask that moderators please help speakers on time. It was very difficult to attend abstract presentations in different rooms as some went over time and others finished early. I missed one talk I had been looking forward to because the session ended early.
22	Need larger rooms; most of the rooms were very crowded. Did not have a place to set. Also one larger area for partner presentation.

CONVENTION EVALUATION SUMMARY

id	Comments
24	The scientific content was outstanding. Presentations were very well organized and of exceptional quality. Moderators did an excellent job of keeping people on time. Posters were well done. Dr. Vichinsky's Whitten lecture was extraordinary. The problems with the conference were in organization and facilities. Rooms were cold; Plenary session I very poorly laid out; no pointers for speakers; technical assistance was limited. When sessions started late, it was because staff had not set up rooms. Food was problematic in that there was often none in lunch and dinner time meetings, yet there was too much at the power breakfast and at the reception. The system of having people in the room signaling the speaker time was effective but they were not in every room. CME system unclear to staff and participants spoke too soon about the presenters- did anyone tell Gerry Luty how much time he had? He went on and on.
28	Sign in session for CME not available at all sessions. Meeting had more energy, more positive feeling, more realistic
29	Too expensive, no CME, food included. Disorganized could not find registration, ran out of ID badges. Same abstract listed in two places in poster session. No numbers for abstract. Please include CME money and food. (at least cookies & brev. In the registration fees.
30	I was disappointed in the degree of disorganization including having to make four attempts to pay for CME, lack of clarity on how to obtain CME & still not receiving my receipt for payment for this conference(which I did in the beginning of August). Many slides were difficult to read, Most professional conferences include CME payment in the registration fee. This should be considered going forward"(participants can check off a box for CME & include additional payment with registration fee. Also given the enormous amount of time physicians & other health care professionals spend at this conference, more CME credits should be available- 9.5hrs is unacceptable for a 7-8 day commitment. Consider room temperature for those living with Sickle Cell
32	The content of the conference was excellent. Speakers were outstanding. Dr. Kim was patient & complete. The staff from CHOP were outstanding, unfortunately this sessions was not on evaluation or on the CME forms. CME-Horrible. No written directions for process. The context excellent the presentation and organization of the meeting poor.
33	The hotel rooms at the Hilton were not very clean, and the air quality was poor. Maybe consider using a different site next time. The most disappointing aspect of the conference was the amount of CME credit afford. We paid additional money for CME to only discover that best of the sessions attended were listed. This process needs to be connected.
34	Overall- Scientific program and content was good, Presenters were knowledgeable and unbiased. The conference was very poorly organized, However. The NIH meetings changed rooms on Monday without any signs or notice to direct people. The presenters all week had no IT support, and often used their own laptops and laser pointers. The thursday "Executive & Director" lunch was by invitation only but tickets had been handed out randomly at registration- so it was unclear who was supposed to be there & why, and whether anyone was aware by chronologic order. Without an effective index- which I have never seen at the 20 plus medical conferences I have previously attended. Usually Abstracts are organized by first author name or by abstract numbers. When I arrived for registration on Monday morning, The registration staff were visibly and obviously Fighting (not just disagreeing) over how the registration booth was being staffed, and an attendee's apparently lost registration forms. Very unprofessional. These are just a few examples- It was very Clear in multiple ways that the conference staff were disorganized and overwhelmed. If this is to become the global leader in Sickle Cell, there is a long way to go. I suggest starting with a professional conference organizer.
35	Very good conference, plenary sessions and oral presentations were outstanding. However, CME credits could be improved. Sign-in attendance sheets were not there on Wednesday. There they were added unannounced. Some oral presentations had credits (Why?). Fees were too Expensive. The entire process should be improved & sign-in sheets abandoned.
36	Conference provided a wonderful opportunity to network w/ other clinical, researches & pes with an interest in SCD. I would recommend the following to strengthen the program: (1) Streamline the registration (onsite), so that those who pre-registered can quickly move through the registration process. (2) The \$ to CME credit fee seemed a bit higher than other, medical conferences charge. In particular, I think the maximum number of CME credits should be

CONVENTION EVALUATION SUMMARY

id	Comments
	increased from 9.5 to at least 10-20 credits given the # of sessions available for participants to attend during the meeting. (3) Would suggest in future meetings that attendees should not be required to sign in for CME credit. This is not standard @ other conferences. (4) It would be helpful for attendees (fellows & junior faculty) to have a session focused on funding opportunities in SCD (NIH, AHRQ CDC, and RWJ). (5) Would suggest that the poster session be placed in a separate room then the exhibit hall. The current setup was too crowded. It was difficult to move from poster to poster given the narrow aisle. *PLEASE NOTE THAT SOME OF THE SESSIONS ARE NOT LISTED ON THE CME CREDIT CLAIM FORM FOR ATTENDEES TO CLAIM.
37	Excellent meeting.
39	Inadequate seating for Wednesday morning sessions. Inadequate managing to complicate all conference participants (new seats placed-couldn't hear speaker or see slides). Very few people directing traffic or available for assistance. Noise transmission between ballrooms was quite high, disruptive to talks; rooms were all too cold on temperature settings.
40	The organizers needed a lot more help.
41	Opening Plenary room was too small. Registration space was limited, Consider having 2 cashiers and multiple booths for on-site registration. It may also have been helpful to have a printer on-site for name tags. It would be helpful to participants if name tags included location of participant.
42	Have rooms large enough to accommodate anticipated attendees. After drinks/snacks throughout conferences and advertise when/where they'll be. Included map of conference meeting rooms in program book. Organize abstracts in program book by number chronologically.
43	Need to have larger rooms :(Both for presentations & posters). Better temperature control of room. Provided snacks & beverage in morning & during breaks. Keep on schedule. Censor speaker when necessary (going way over schedule).
44	Staff running conference registration was friendly but disorganized: I paid by check and received a receipt with no documentation of the meeting title; My name tag/registration badge took 3 days before they printed out & gave to me. Meeting room sizes too small, not enough seats. Scientific presentations were excellent.
47	Many of the rooms were too small for the audience-people were forced to leave sessions/ not attend. The plenary sessions were excellent on Thursday.
48	Many of meeting rooms much too small. Hotel space too limited if didn't register way ahead of time. Many of talks that I attended not listed on form to CME credit. (i.e. pulmonary hypertension session on Wed- there were 7 Talks, only 3 listed for credit). Abstracts difficult to find in book--should be in numerical order!
49	Hotel accommodations were difficult to obtain. Reservations were changed without my knowledge- I found this disruptive. It would be helpful to publish the institution, not just name of authors, in the abstract book.
51	CEU form missing many posts. Should get CEU for any activity that provides CME'S form is very disjointed & many typos. Conference itself also very disorganized. Blocks of rooms not for entire length of conference. Rooms not sized for size of anticipated audience. No supplies @ registration 1st day. Many problems & AV equipment across rooms.
53	Registration was disorganized. Great level of expertise speakers. Wednesday the facility was not comfortable - too crowded.

CONVENTION EVALUATION SUMMARY

id	Comments
54	I attended workshops (such as "Quality of Life" sessions) which were not included on CEU form. All workshops should be on your form. Is it possible to have continental breakfast items such as coffee, tea etc? I anticipated that these items would be complimentary. Individuals at your registration desk, specifically the CEU area, provided conflicting information forms etc. Each individual are not aware of protocols for CEU's. The format of the Gala/Dinner/Dance was wonderful. Your speakers were awesome. I really enjoyed Lorenz Tate and Sickle Cell poster child. Great choice for speakers.
55	Poor check in!! Info/ Payment for CEU!! Not organized, No food, No hotel room!!! No one has ever said I needed to pay or would get a certificate in past years. I asked for past CEU certification and was told no. I attended LA, Dallas, Memphis and have no CEU certification. Your organization needs to be better at informing attendees they have to pay & should be more understanding regarding misunderstandings and should give CEU to past attendees!!!!
57	Very cramped rooms for presentations on Tuesday & Wednesday. CEU/CME arrangements were very confusing & Disorganized.
60	The registration and check in process was extremely disorganized and frustrating. My groups experience began with our arrival at the hotel. On 9/14/07 we called to confirm that our two rooms were set for the conference, and was confirmed. Imagine our surprise when upon our arrival we only had one room. Our group consists of 1 male and 2 female which did not make getting by with one room, an option. Our physician spent 2 nights in Maryland. On 9/19/07 lectures were supposed to begin at 8:00, I came down at 7:45 a.m. to register for CEU's, I had checked in 9/18/07 for the conference.) I was told to come back because the table for CEU's was not ready. When the table appeared ready, there was confusion about which forms should be filled out for MSA in attendance. I then got in line to pay for CEU'S which was a complete surprise to me, that the CEU's were not included in the registration fee. I wanted to pay by credit card and the machine was not working. I was asked to fill out a form with my credit card # and it would be entered later. Given the confusion and disorganization. I was not comfortable leaving my credit card # on a piece of paper to be entered at some later time. I was then asked to return later. People were not in the room and prepared to begin until well after 8:00 am. I was told by several workers that there were new systems in place and they were volunteers. I appreciate that a conference like this takes an incredible amount of work, but I believe that technical equipment should be set up and running properly, staff should be prepared an oriented so that registrations check in can run smoothly and timely.
62	Maybe get program upon website- a little sooner if possible. Excellent conference overall- I really wish I can stay for entire conference. THANK YOU VERY MUCH!
63	Registration, Check-in, and Assistance unorganized, Little frustrating.
66	Multiple Sign in sheets per activity very confusing.
67	There should be a way to obtain CMU in all lectures. Speakers listed in this booklet were not listed on the CMU credits form.
68	Obtain larger space for general sessions. Encourage participants to Exit quietly during Q & A period. Provide morning refreshments & Coffee tea at least. Train conference registration personnel about the details of signing up for CEU's, etc. Post signs participants they must sign name before entering certain presentations if CME's needed. Have multiple computers available for registration personnel to use, why can't participants use computers to register for CEU/CME? Why did the NIH speakers talk so much about the programs they had in place for CANCER??? Very little said about Sickle Cell!!!! Add a presentation on Sickle reteopathy in a break-out session, CME & CEU forms does not have all the lectures listed. Poster displays should have been placed along the walls and the vendors should have been placed in the middle of the floor to allow access to posters.
69	Expand on clinical care components, especially nephrology and orthotic issues. Use of technology in patient tracking & communication.
70	Accommodations- Posters Session were inadequate (too close), certain rooms that were chosen for plenary sessions were too small, sound system not good.
71	Hotel accommodations could have been better, as far as switching back to host hotel. Sound systems in some rooms not good.

CONVENTION EVALUATION SUMMARY

id	Comments
72	Poster Session III presentation were not numbered. Clarice Reid was not there- 3 other speakers. The first meeting room we were in was very cramped with no tables to use for writing.
73	I don't think it was appropriate to have a company like FDI here. They were quite pushy in their endeavors + made it clear they were recruiting me so that I would then go and recruit other people. They called it "passive name". My understanding is that is a pyramid type thing + again I want to reiterate how inappropriate I think it was to have them here. I spent 5 or 10 Minutes just trying to fend off their pushy sales tactics. I came here to learn and enjoy, not be pressured to become a sales rep. for a questionable company. Second I believe the parents + patients should have a voice in front of the plenary session. Hearing all the science is great, but I think everyone needs to learn from the patients + parents that come here + I believe they have this right. Not to just have closed session.
74	Would liked to see more targeted opportunities for specific caregivers(such as nurses, social workers, etc) to meet, network, + compare experiences in informal settings such as round table lunches or breakfasts. This was my 1st time attending this conference-it was Wonderful! CEU applications process seemed confusing +cumbersome-too many forms for the same thing. Should be included in registration fee! Many sessions I attending did not offer CEU'S - I didn't find this out until after. A big part of traveling to conferences is obtaining CEU's- this need to be made clearer at the beginning + somehow the process should be made more streamlined + efficient. THANK YOU
76	In the future, more sessions should address basic disease pathology in Sickle Cell Disease and treatment for the new providers/ in SCD. It is okay to have current research seminars however current treatments should be addresses in some seminary e.g. What has been found the current tx for PULHTN. For the future, please include CEU registration and payment in your total conference fee. Tack it on if needed (to total piece if fear for total price, to consider making the gala optional and a separate fee if wanting to participate (you can always break the price down. Overall all medical people need + want CEU/CME.
77	I think a session that incorporates the latest research and best practices for treatment would have been beneficial. The large group rooms were very cold. Offer more CEU's for some of the sessions on Wednesday/ some sessions didn't even count. The cost of CEU should be included at the conference cost.
78	Include also practical thing about caring for SC patients, not just new research, as someone who has only been caring for SC patients for a few months I learned a lot but wanted info about current best practice as well. Need more CEU's available on Wednesday - attended sessions all day & only got 2.5 credits.
79	Very disorganized, Thought that syllabus for conference was hard to follow, once again everyone was very nice, but organization seemed lacking, great information was shared within the conference. Easier ways to designate in book what CME/CEU are given.
80	Better hotel accommodations/ larger meeting rooms, Excellent variety of speakers.
84	Poor catering - no coffee for breakfast. Poor videos- too small, people standing. Registration disorganized. Good scientific content.
85	Rooms too small, no food between sessions
86	It would be nice if list of participants was broken either by discipline (MD, NP, SW, Radiology, scientist...) or by state or center. CME's not well organized. No information at registration or in packet on getting CME or need to "sign -in " at lectures. On-line registration asked if CME's where needed \$45 should have been added to total cost of my registration when I checked Yes. Down size Gala + reallocate funds so there is coffee in morning session + drinks at afternoon sessions. Name badges need professional title for all disciplines, and municipal city +/- or state the person comes from.
87	Registration desk- very chaotic & disorganized- no leadership. East/ West International- no microphones. I feel I got the wrong CEU papers to complete but was told I do Not. The form does not reflect accurately. The many sessions I attended & I feel I will not be given the proper amount of CEU's due to me. Research is great but not enough on what to do with the results in a clinical setting.

CONVENTION EVALUATION SUMMARY

id	Comments
90	Most of the psychosocial and coping presentations were late in the afternoon. It would have been nice to attend some that were not so late in the afternoon. Overall, the conference was great!
91	Expert breakfast- Labeling needed prior to arrival in the room. Overall impressed by the experience.
94	I found that a number of pts. An SCD attended this meeting include my pt. Although there have been excellent presentations on scientific + clinical advances, I don't see any programs for Sickle Cell pts. + their family. I'd like to see more programs which are geared for the patients at their level as patients attend this meeting, e.g., opportunity for patients present their experience, how to coop with parents, schools, work, etc. in round-table sessions. In that expect, I enjoyed.
95	The hotel accommodations were atrocious. No morning coffee, no room for participants. People sitting on the floor, standing in the room for hours- couldn't read slides because they would not be seen.
96	Registration was very unorganized. I received by program book a pen & cup no bag. CEU were available Wed, when it should have been done w/ registration. During registration people were treated like cattle. No one knew where we needed to be. Some of the individual were rude and uninformd. The meeting room on Wednesday was extremely uncomfortable. I was unable to see the projectors, the speaker and could barely hear the speaker. Maybe planning ahead would allow for better housing? I was unable to get a room at the Hilton and had to stay at the Churchill Hotel. There was an incident of receiving the wrong lunch ticket and being treated as if it was my mistake. When I asked about the list for the luncheon I was told there wasn't a list. When I walked back to the Churchill, where I gave the ticket taker the ticket she responds you are not an executive and have the wrong ticket.
97	The abstract book need to be more organized. If the abstracts were arranged by sessions adequately divided/sectioned headers would have been helpful. Another resolution would be to just list them in numerical order.
98	I'm sorry to say that the organization of the meeting (registration, billing, rooms for sessions, timing) was not up to standards. At national meetings of this size sessions must (and can) start on time and end on time. Organization of abstract booklet was not logical and made it very difficult to access abstracts for a given session. Instructional affiliation on program and many abstracts is important for networking and learning what's going on nationally (this was lacking)

We wish to gratefully acknowledge the commitment and relentless efforts of the following individuals who were critical to the preparation of this Convention.

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