PRELIMINARY REPORT

OF THE

BEST PRACTICES DEVELOPMENT CONFERENCE
FOR THE MANAGEMENT OF
ACUTE AND CHRONIC PAIN
IN ADULTS WITH SICKLE CELL DISEASE

September 25 – September 27, 2007

Dallas, Texas

Supported by National Heart Lung and Blood Institute
National Institutes of Health
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I. AGENDA
**Day 1, September 25, 2006**

**Session 1: Noon-6:00 p.m.**

**Introductions and Charge to Panel**

1:00 p.m. Welcome, Introductions, and Charge to the Panel  
James Eckman, M.D., Conference Chairman  
Kathryn Hassell, M.D.

**State-of-the-Art Lectures:**

1:30 p.m. New Revelations about Sickle Cell Pain – The PiCES Study  
Wally R. Smith, M.D.

2:15 p.m. Sickle Cell Pain in the Emergency Department

Introduction:  
Pain, Sickle Cell Disease and Emergency Departments  
Knox Todd, M.D.

The American Pain Society Guideline and Analgesic Management in the Emergency Department – Results from a Multi-Center Project  
Paula Tanabe, R.N.

The Emergency Department Treatment of SCD: The Evidence  
Bernie Lopez, M.D.

Victoria Thornton, M.D.

3:30 – 3:45 p.m. Break

3:45 p.m. Acute Sickle Cell Pain in the Inpatient Setting  
Management of Acute Sickle Cell Painful Crises in the Hospital  
Samir Ballas, M.D.

Healthcare Disparities & Sickle Cell Disease: Inpatient Management  
Kristi Woods, M.D.
5:00 p.m. Chronic Sickle Cell Pain

Chronic Pain Pathology Management in Sickle Cell Disease
Lennette Benjamin, M.D.

Chronic Pain in Sickle Cell Disease: Basic Principles of Assessment and Management
Marsha Treadwell, M.D.

Nutrition and Pain in Sickle Cell Disease
Maciej Buchowski, Ph.D.

The Psycho-Spiritual Impact on Patient’s Well-being
Rev. Violet Dease, M.Div., M.S.W.

6:00 p.m. Challenges to Implementation of Best Practices

A Qualitative Assessment Of Sickle Cell Needs In Rural Georgia Communities: A Patient’s Perspective
Melissa S. Creary, MPH

Adult Sickle Cell Pain Management: Opportunities for Improvement
James Eckman, M.D.

7:00 p.m. Adjourn

Day 2, September 26, 2006

Session 1: 8 a.m. - 1 p.m.

Specific Best Practices Development: Open Full Panel Discussion

8:00 a.m. Emergency Department Practices
Led by Knox Todd, M.D.

9:30 a.m. Break

10:00 a.m. Inpatient Practices
Led by Samir Ballas, M.D.

1:30 p.m. Lunch

Session 2: 2:00 p.m. – 6 p.m.

2:00 p.m. Chronic Pain Management
Led by Lennette Benjamin, M.D.

4:30 p.m.  Break

4:45 p.m.  Implementation Strategies
Led by James Eckman, M.D.

Evening  Preparation of summary of materials and slides for presentation
Drs. Eckman and Hassell

Day 3, September 27, 2006

8 a.m. – 11:30 a.m.

8:00 a.m.  Presentation, discussion and review of best practices and
implementation strategies in each area
Full Panel

10:30 a.m.  Discussion of slides to be present at the SCDAA Public Forum

Noon  Presentation of meeting summary to the SCDAA “Meeting Unmet Needs” forum  for
public commentary and feedback

II.  PANEL MEMBERS
Panel Chairs

James Eckman, M.D.  
Meeting Chair and Chair, Implementation Panel  
Professor of Hematology, Oncology  
Emory University School of Medicine  
Director, Georgia Comprehensive Sickle Cell Center  
49 Jesse Hill Jr. Drive S.E.  
Atlanta, GA  30303  
Phone:  404-778-1340  
Email:  James.Eckman@emoryhealthcare.org

Samir Ballas, M.D.  
Chair, Inpatient Pain Management  
Professor of Medicine  
Director, Sickle Cell Program  
Thomas Jefferson University  
Philadelphia, PA  19107  
Phone: 215-955-8485  
Email:  Samir.Ballas@jefferson.edu

Lennette Benjamin, M.D.  
Chair, Chronic Pain Management  
Professor of Medicine  
Albert Einstein College of Medicine  
Clinical Director Comprehensive Sickle Cell Center  
Montefiore Medical Center  
111 E. 210th Street  
Bronx, NY  10467  
Phone:  718-798-5095  
Email:  Lbenja2725@aol.com

Knox H. Todd, MD, MPH  
Chair, Acute Pain ER Medicine  
Professor of Emergency Medicine  
Director, Pain and Emergency Medicine Institute  
Department of Emergency Medicine  
Beth Israel Medical Center  
Albert Einstein College of Medicine  
First Avenue at 16th Street  
New York, NY  10003  
Phone: 212 420 2813  
Email:  ktodd@chpnet.org

Panel Members
Maciej Buchowski, Ph.D.
Research Associate Professor
Vanderbilt University Medical Center
S-3408 Medical Center North
Nashville, TN  37232
Phone: 615-343-4192
Email:  maciej.buchowski@vanderbilt.edu

Melissa Creary, MPH
Division of Hereditary Blood Disorders
National Centers on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Road, MS E-64
Atlanta, GA  30333
Phone:  404-498-2811
Email:  Mcreary@cdc.gov

Reverend, Violet Dease
Abyssian Baptist Church
132 Odell Clark Place
New York, NY  10030
Phone: 212-862-7474
Email:  VLDease@abyssian.org

Bernard Lopez, M.D., M.S.
Associate Professor of Emergency Medicine
Thomas Jefferson University
Philadelphia, PA  19107
Phone: 215-503-6988
Email:  Bernard.lopez@jefferson.edu

Paula Tanabe, PhD, RN
Research Assistant Professor
Department of Emergency Medicine
Feinberg School of Medicine, Northwestern University
259 E. Erie, Suite 100
Chicago, IL  60611
Phone: 312-926-6483
Email:  ptanabe2@nmff.org

Victoria Thornton, M.D., MBA, FACEP
Assistant Professor of Surgery (Emergency Medicine)
Duke University Medical Center
Duke North 1681, DUMC 3096
Durham, NC  27710
III. CONFERENCE OBJECTIVES AND GOALS
“Best Practices Development Conference for the Management of Acute and Chronic Pain in Adults with Sickle Cell Disease” represents the first in a series designed to address challenging areas in the clinical management of adults with sickle cell disease. The overall goals of the program series include:

1. Establishing a panel of experts in sickle cell disease, appropriate associated specialists (emergency medicine, pain medicine, psychology), primary care providers, sickle cell disease patients and members of the community to review available management recommendations, experience and observations.

2. Assembling the panel before an audience of all interested providers at an annual conference to present management recommendations, research priorities and quality assurance outcomes measures for discussion and consensus development.

3. Preparing a conference proceedings and appropriate publications to disseminate management recommendations, and devising strategies to facilitate awareness and acceptance amongst providers and patients.

The sentinel symptom of sickle cell disease is acute, severe pain which may require potent narcotic analgesic intervention. A number of treatment recommendations and algorithms have been developed and may be routinely employed in day-hospitals and other settings where some sickle cell disease patients receive care. However, a large number of adults with sickle cell disease seek care in other settings including emergency departments and hospitals served by primary care providers. Implementation of treatment recommendations in these settings can be erratic due to lack of familiarity with the disease, provider biases, and other challenges.

As importantly, adults with sickle cell disease can develop severe chronic pain. Poor adaptation to recurrent pain events, inadequate nutrition and drug addiction may complicate management of chronic pain. There are few guidelines or recommendations regarding the evaluation of prolonged or chronic pain in sickle cell patients. Optimal pain management may be achieved by the integration of non-opiate therapies including anti-inflammatory and antidepressant medications, oral opiates, and non-pharmacologic approaches, based on the recognition of the sources of chronic pain.

In fulfilling the programmatic goals listed above, utilizing the approach detailed in the Methodology section, the objectives of this conference are to:

1. Develop best practices recommendations that can be utilized as the basis for institution-specific acute and chronic pain management pathways in various care settings, including:
   a. emergency department
   b. inpatient hospital services, especially on general medical services
   c. outpatient settings, especially by primary care providers

2. Create work products that will result in a quality improvement plan to establish best practices for the treatment of sickle cell pain.

3. Identify strategies for the successful dissemination and implementation of best practices in collaboration with representative partners, including:
   a. professional societies (specialty, emergency medicine, primary care)
   b. agencies (health care services, governmental)
   c. patient advocacy groups

IV. METHODOLOGIES
The topic of best practices in the management of sickle cell pain was divided into four areas of focus: Acute Pain Management in the Emergency Department, Acute Pain Management in the Inpatient Setting, Chronic Pain Management, and Best Practices Implementation Strategies. Chairpersons were selected for each section and panel members were chosen by these chairs to obtain input from a variety of professionals (physicians, nurses, psychologists, medical social workers, clergy) from multiple disciplines (hematology, emergency medicine, hospital medicine, nutrition, pharmacology, psychology, religion/spirituality, health services delivery). Those affected by sickle cell disease were also included on the panel.

The follow tasks were be completed by panel members prior to the actual conference:

1. Review of the available literature. In some cases, formal searches of available medical literature were supported by research library support staff (emergency medicine) or grant support staff (acute pain management)
2. Solicitation of input from other resources and experts with in care networks, sites of practice, or agencies.
3. Preparation of a 20-30 minute presentation about the state-of-the-art in their area of expertise/experience
4. Development of proposed specific best practices for management of acute and chronic sickle cell pain in various care settings.
5. Identification of areas in need of further research.
6. Development of strategies for dissemination and implementation of consensus results, and measures of quality assurance and outcomes.

The conference was held from September 25-27, 2006 in conjunction with the annual national Sickle Cell Disease Association of America meeting in order to permit attendance at both meetings and input from stakeholders.

On Day 1 of the conference, guest speaker Wally Smith, M.D., principal investigator for the PiCES Study, presented data regarding the nature and frequency of sickle cell pain in adult patients. State-of-the-art lectures were presented and reviewed by panel member to serve as background and a basis for subsequent discussion.

On Day 2, the chair of each focus area led the full panel through the development of an outline of best practices. The outline was organized into six areas:

Scope: specification of the target population and site of implementation
Terminology: commonly used terms and their definition/meaning in the context of the practice setting
Assessment: important elements related to pain, including physical/medical comorbidities, psychosocial considerations, health care utilization
Treatment: best practices in the management of pain which may serve as a tool for development of specific treatment pathways
Coordination: opportunities for integration of practices into overall management strategies
Monitoring: recognition of beneficial and harmful effects of intervention
Outcomes: indicators of successful implementation and effective therapy
Implementation: mechanisms to promote broad adoption of best practices and development of specific pathways at sites of practice
Discussion and input from the panel was captured by a note taker using a flipchart for easy reference, and by professional meeting support staff from American Institutes of Research, who created two electronic documents, one with summarized text and the other a bulleted outline. Audience members included adult hematologists, nurses, clinical care coordinators and members of sickle cell support groups from various parts of the country (e.g. California, New York, Colorado, Ohio, Vermont), who actively participated in all discussions.

Through the evening of Day 2, Dr. Eckman and Dr. Hassell compiled information from all sources into a final outlined proposal of best practices in each of the four sections. They also created a brief summary slide set for presentation to the public SCDAA forum.

On Day 3, the outline of each section was presented to the full panel for further discussion. At the completion of this session, the slide set was reviewed and revisions made as suggested by panel members.

Dr. Eckman presented a summary of the conference to the “Meeting Unmet Needs” public session of the Sickle Cell Disease Association of American National Meeting, after which public commentary was invited. There were an estimated 200 attendees to this session. Feedback and commentary from this forum was noted and will be incorporated into the final proceedings.