Preliminary Agenda

Tuesday, November 16, 2010

Masur Auditorium, Building 10

10:00 a.m.  Welcoming Remarks
Donald A. B. Lindberg, M.D., Director, National Library of Medicine
Susan B. Shurin, M.D., Acting Director, National Heart, Lung, and Blood Institute

10:15 a.m.  Session I: Sickle Cell Disease in Historical Perspective

10:15 a.m.  James B. Herrick and his Contributions
Alan N. Schechter, M.D., National Institute of Diabetes and Digestive and Kidney Diseases

10:30 a.m.  Panel Discussion: Historical and Cultural Perspectives
*Moderator: John Ruffin, Ph.D., Director*
National Center on Minority Health and Health Disparities

This panel discussion would be preceded by brief comments by each participant and the moderated conversation will cover James B. Herrick and his contributions as well as social and cultural perspectives on the history of sickle cell disease and its relationship to modern science and medicine.

**Sickle Cell Anemia and the Vexed Crossroads of Race and Disease in America**
Stephen Pemberton, Ph.D., New Jersey Institute of Technology

**Sickle Cell Patients Are ____? How the Science of Treatment Has Shaped What Medical Professionals Think About Their Patients**
Carolyn Rouse, Ph.D., Princeton University
Cultural Histories of Mild Sickle Cell Anemia in Senegal, West Africa
Duana Fullwiley, Ph.D., Harvard University

12:00 p.m. Questions and Answers
12:15 p.m. Lunch (on your own)

1:15 p.m. Experiences of People With Sickle Cell Disease Seeking Health Care for Pain
Mary Catherine Beach, M.D., M.P.H., Johns Hopkins University

1:30 p.m. Panel Discussion: Personal Perspectives
Moderator: Lanetta B. Jordan, M.D., M.P.H., M.S.P.H., Chief Medical Officer, Sickle Cell Disease Association of America, Inc., and Memorial Healthcare System, Hollywood, FL

Screening Student Athletes for Sickle Cell Trait: Where Do We Go From Here?
Vence L. Bonham, Jr., J.D.

Living Life Like It’s Golden
J. Hoxi Jones, Texas Health and Human Services Commission

TBD
Robert F. Murray, Jr., M.D., Howard University School of Medicine

Reflections
Wanda Whitten-Shurney, M.D., Wayne State University/Children’s Hospital of Michigan

2:15 p.m. Session II: International Perspectives
Moderator: Roger I. Glass, M.D., Ph.D., Director
John E. Fogarty International Center for Advanced Study in Health Disparities

2:20 p.m. Sickle Cell Disease: The Contribution From Africa in the Next 100 Years
Julie Makari, M.D., MRCP, Muhimbili University of Health and Allied Sciences (Tanzania)

2:35 p.m. Sickle Cell Disease in Africa: History and Disease Burden
Kwaku Ohene-Frempong, M.D., University of Pennsylvania School of Medicine/Children’s Hospital of Philadelphia

2:50 p.m. The Caribbean Contribution to Sickle Cell Disease
Graham R. Serjeant, M.D., FRCP, Sickle Cell Trust (Jamaica)
3:05 p.m.  **Sickle Cell Disease in the United Kingdom: Epidemiology, Clinical Aspects and Morbid Anatomy**  
Sebastian Lucas, M.D., FRCP, FRCPath, King’s College London School of Medicine (United Kingdom)

3:20 p.m.  Questions and Answers

3:50 p.m.  Adjourn

4:00 - 5:30  **Tours of the National Library of Medicine Exhibits and Rare Book Collection (Building 38)**

6:30 p.m.  **Dinner:** Tragara Ristorante, Bethesda. People wishing to attend the dinner must register and pay by Monday, November 1.

**Sickle Cell Disease: An Historic Perspective**  
H. Franklin Bunn, M.D., Brigham and Women’s Hospital/Harvard Medical School

**Kenote Speech:**  
Sickle Cell Anemia and the Origins of Molecular Medicine  
Sir David Weatherall, M.D., FRCP, FRS, University of Oxford (United Kingdom)
Wednesday, November 17, 2010

Natcher Conference Center, Building 45

8:00 a.m.  Welcoming Remarks
Susan B. Shurin, M.D., Acting Director, National Heart, Lung, and Blood Institute
Sonja L. Banks, President and Chief Operating Officer, Sickle Cell Disease Association of America, Inc.

8:20 a.m.  The NHLBI Sickle Cell Guidelines: A First Look
Barbara Yawn, M.D., M.Sc., University of Minnesota
George Buchanan, M.D., University of Texas Southwestern Medical Center at Dallas

8:30 a.m.  Sickle Cell Anemia: Past, Present, and Future
David G. Nathan, M.D., Dana-Farber Cancer Institute

8:45 a.m.  Accelerating the Therapeutic Agenda for the First Molecular Disease
Francis S. Collins, M.D., Ph.D., Director, National Institutes of Health

9:10 a.m.  Session III: Sickle Cell Disease Pathophysiology
Moderator: Eric D. Green, M.D., Ph.D., Director
National Human Genome Research Institute

9:15 a.m.  Sickle Cell Anemia: 100 Years later
Griffin P. Rodgers, M.D., M.A.C.P., National Institute of Diabetes and Digestive and Kidney Diseases

9:35 a.m.  Evolving Concepts of Brain Vasculopathy and Stroke in Sickle Cell Disease
Robert J. Adams, M.D., Medical University of South Carolina

9:55 a.m.  Genetic Contributions to Pain
Clifford Woolf, MB, B.Ch., Ph.D., Children’s Hospital Boston/Massachusetts General Hospital

10:15 a.m.  Lung Disease and Sickle Cell Disease
Elliott Vichinsky, M.D., Children’s Hospital & Research Center Oakland

10:35 a.m.  Genetic Modifying Factors in Sickle Cell Disease
Swee Lay Thein, F.R.C.Path., F.R.C.P., D.Sc., F.Med.Sci., King’s College London (United Kingdom)

10:55 a.m.  Break
11:15 a.m.  
**Session IV: Clinical and Social Impact Across the Lifespan**  
*Moderator: Alan Guttmacher, M.D., Director*  
*Eunice Kennedy Shriver National Institute of Child Health and Human Development*

11:20 a.m.  
**Sickle Cell Disease: Maternal/Fetal/Neonatal Prospective**  
John C. Morrison, M.D., University of Mississippi Medical Center

11:40 a.m.  
**The Triumphs and Challenges of the Study of Sickle Cell Disease in Infants, Children and Adolescents**  
Michael R. DeBaun, M.D., M.P.H., Washington University in St. Louis

12:00 p.m.  
**Improving the Lives of Adults With Sickle Cell Disease**  
Sophie Lanzkron, M.D., Johns Hopkins School of Medicine

12:20 p.m.  
**Are You Listening to Me? Challenges in Sickle Cell Patient-Provider Communication**  
Carlton Haywood, Jr., Ph.D., M.A., Johns Hopkins University School of Medicine

12:40 p.m.  
Lunch (on your own)

1:20 p.m.  
**Voices of Patients Video**  
Introduction: Wally R. Smith, M.D., Virginia Commonwealth University

1:35 p.m.  
**Session V: Sickle Cell Disease Treatment**  
*Moderator: Walter J. Koroshetz, M.D., Deputy Director*  
*National Institute of Neurological Disorders and Stroke*

1:40 p.m.  
**Hematopoietic Stem Cell Transplantation for the Treatment of Adults With Sickle Cell Disease**  
John F. Tisdale, M.D., National Heart, Lung, and Blood Institute

2:00 p.m.  
**Hydroxyurea for Sickle Cell Disease: Fact, Fiction, and Fantasy**  
Russell E. Ware, M.D., Ph.D., St. Jude Children’s Research Hospital

2:20 p.m.  
**From Mechanisms of Sickle Pathophysiology to Novel Therapies**  
Punam Malik, M.D., Cincinnati Children's Hospital Medical Center

2:40 p.m.  
Break

2:55 p.m  
**Session VI: Molecular Studies**  
*Moderator: Griffin P. Rodgers, M.D., Director*  
*National Institute of Diabetes and Digestive and Kidney Diseases*

3:00 p.m.  
**Transcription Factor Networks and Long Range Interactions**  
Frank Grosveld, Ph.D., Erasmus MC  
(The Netherlands)
3:20 p.m.  Control of Hemoglobin Switching and HbF Silencing  
Stuart H. Orkin, M.D., Harvard Medical School/Dana-Farber Cancer Institute

3:40 p.m.  Inflammation and the Genetically Influenced Systems Biology of Sickle Disease  
Robert P. Hebbel, M.D., University of Minnesota

4:00 p.m.  Session VII: Future Prospects  
Moderator: Stephen C. Groft, Pharm.D., Director  
Office of Rare Diseases Research

4:05 p.m.  Genome Sequencing  
TBD

4:25 p.m.  Gene Transfer to Increase Fetal Hemoglobin Production  
Arthur W. Nienhuis, M.D., St. Jude Children's Research Hospital

4:45 p.m.  Induced Pluripotent Stem (iPS) Cells and Gene Replacement Therapy for Sickle Cell Disease  
Tim M. Townes, Ph.D., University of Alabama at Birmingham

5:05 p.m.  Concluding Remarks  
Susan B. Shurin, M.D., National Heart, Lung, and Blood Institute

5:10 p.m.  Adjournment

Last updated 10/12/10