

The National Academies of
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**Committee on Addressing Sickle Cell Disease:
A Strategic Plan and Blueprint for Action
April 16, 2019**

**Keck Building,
500 5th Street, NW, Washington, DC 20004
E Street Conference Room**

OPEN SESSION

9:30 a.m. Welcome and Opening remarks

Marie McCormick, M.D., Sc.D., Committee Chair

**9:45 Panel 1: The Impact of Sickle Cell Disease on Patients, Families,
and Communities**

Facilitator: Charmaine Royal, Ph.D., M.S., Committee Member

Panel Introductions

Derek Robertson, M.B.A., J.D., Patient Advocate; Co-Founder, Maryland Sickle Cell Disease Association

Adrienne Bell-Cors Shapiro, Co-Founder and Science Administrator, Axis Advocacy

Tosin Ola, RN, BSN, Founder & President, Sickle Cell Warriors

Beatrice Bowie, Patient

Discussion

10:50 Break

**11:05 Panel 2: Addressing the Needs of Sickle Cell Patients Across the
Lifespan**

Facilitator: Lori Crosby, Psy.D., Committee Member

Panel Introductions

Tracie Bullock Dickson, Ph.D. Education Program Specialist, Office of Special Education and Rehabilitative Services, Department of Education

Carmen Sánchez, Education Program Specialist, Office of Special Education and Rehabilitative Services, Department of Education

Richard P. Weishaupt, J.D., Senior Attorney, Health and Human Services, Community Legal Services of Philadelphia

Wanda Whitten-Shurney, M.D., CEO and Medical Director, Sickle Cell Disease Association of America, Michigan Chapter, Inc.

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Discussion

12:05 p.m.

Lunch

12:45

Panel 3: Health Care for Sickle Cell: Health Professional Awareness and Education

*Facilitator: **Mary Catherine Beach, M.D.**, Committee Member*

Panel Introductions

Barbara Speller-Brown, D.N.P., P.N.P.-B.C., Director, SCD Transition Clinic;
Lead Sickle Cell Translational Research APN, Children's National Health System

Jeffrey Glassberg, M.D., Associate Professor, Emergency Medicine; Hematology
and Medical Oncology, Mount Sinai

Charles Jonassaint, Ph.D., Assistant Professor of Medicine, Social Work and
Clinical and Translational Science, Department of Medicine, University of Pittsburgh

Discussion

1:40

Break

1:55

Panel 4: Curative Therapies for Sickle Cell Disease

*Facilitator: **Darius Lakdawalla, Ph.D.**, Committee Member*

Panel Introductions

Betsy Myers, Ph.D., Program Director for Medical Research, Doris Duke
Charitable Foundation

Mark Walters, M.D., Program Director, Alpha Stem Cell Clinic; Medical Director,
Jordan Family Center for Bone Marrow Transplant & Cellular Therapies Research,
UCSF Benioff Children's Hospital of Oakland

Edward Benz, Jr., M.D., Executive Director, NIH Cure Sickle Cell Initiative

Celia Witten, Ph.D., M.D., Deputy Director, Center for Biologics Evaluation and
Research, FDA

Discussion

3:00

Public Comments

3:45

Closing Remarks

***Marie McCormick, M.D., Sc.D.**, Committee Chair*

4:00

OPEN SESSION ENDS