Media Advisory: NIH to host sickle cell disease symposium

Event marks 100th anniversary of first paper published in Western medical literature describing the condition

WHAT: More than 30 experts from around the world are scheduled to present Nov. 16-17 in Bethesda, Md., at the James B. Herrick Symposium – Sickle Cell Disease Care and Research: Past, Present, and Future. The free event, hosted by the National Institutes of Health, will examine the past century of work toward understanding sickle cell disease. Presenters will also discuss the current state of care and future research possibilities.

WHEN and WHERE: Nov. 16-17 on the NIH campus in Bethesda, Md.

- Tuesday, Nov. 16, 10 a.m. to 3:50 p.m., Masur Auditorium, Clinical Center, Building 10
- Wednesday, Nov. 17, 8 a.m. to 5 p.m., Natcher Conference Center, Building 45

WHO: Featured participants include NIH Director Francis S. Collins, M.D., Ph.D.; National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Director Griffin P. Rodgers, M.D., a noted sickle cell disease researcher, and Sir David Weatherall, M.D., FRCP, FRS, University of Oxford, United Kingdom, a leading blood diseases researcher and winner of the 2010 Lasker Award.

National Heart, Lung, and Blood Institute (NHLBI) Acting Director Susan B. Shurin, M.D., a board-certified hematologist and sickle cell researcher, will deliver opening remarks on both days. She will be available for press interviews from 10:30 a.m. to 11 a.m. on Wednesday, Nov. 17.

Symposium highlights include:
• **Personal Perspectives**, a panel discussion on topics ranging from life with sickle cell disease to the impact of screening college athletes for sickle cell trait, 1:30 p.m., Tuesday, Nov. 16.

• **Sickle Cell Disease: The Contribution from Africa in the Next 100 Years**, Julie Makani, M.D., MRCP, lecturer, Muhimbili University of Health and Allied Sciences, Tanzania, 2:20 p.m., Tuesday, Nov. 16.

• **Accelerating the Therapeutic Agenda for the First Molecular Disease**, Dr. Collins, 8:45 a.m., Wednesday, Nov. 17.

• **Sickle Cell Anemia: 100 Years later**, Dr. Rodgers, 9:15 a.m., Wednesday, Nov. 17.

• **James Herrick Display**, a collection of historic documents related to Herrick will be on view in the Reading Room at the National Library of Medicine (NLM), Tuesday, Nov. 16 and Wednesday, Nov. 17.

**WHY:** Sickle cell disease affects between 70,000 and 100,000 Americans. Those who inherit this disease carry two copies of the sickle globin gene. The gene produces abnormal hemoglobin, the protein in red blood cells that delivers oxygen throughout the body. This genetic defect leads to the production of misshapen red blood cells, many of which have the sickle shape that gives the disease its name. Those who live with sickle cell disease have life-long anemia and can experience severe pain episodes known as crises.

The disease is most prevalent in individuals of African descent, though individuals of Middle Eastern, Mediterranean, Central and South American, and Asian Indian heritage can inherit the disease.

About 2.5 million Americans have sickle cell trait, which means they carry one copy of an altered globin gene. Most people living with trait have few, if any, complications from the condition but can pass the globin gene on to their children. Persons with sickle cell trait may have problems when overheated, dehydrated, or exposed to low oxygen pressures as may occur at high altitude or flying in unpressurized airplanes.

The symposium is presented by NHLBI, NIDDK, the National Human Genome Research Institute, the *Eunice Kennedy Shriver* National Institute of Child Health & Human Development, the National Institute of Neurological Disorders and Stroke, the National Library of Medicine, the Office of Rare Diseases Research, and the National Institute on Minority Health and Health Disparities.

**CONTACT:** Media interested in attending the symposium or scheduling interviews with speakers should contact the NHLBI Communications Office at (301) 496-4236 or at [NHLBI_news@nhlbi.nih.gov](mailto:NHLBI_news@nhlbi.nih.gov).

*Part of the National Institutes of Health, the National Heart, Lung, and Blood Institute (NHLBI) plans, conducts, and supports research related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases; and sleep disorders. The Institute also administers national health education campaigns on women and heart disease, healthy weight for children, and other topics. NHLBI press releases and other materials are available online at [http://www.nhlbi.nih.gov](http://www.nhlbi.nih.gov).*
The National Institutes of Health (NIH) — The Nation's Medical Research Agency — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit http://www.nih.gov/.

Resources:

- NHLBI Sickle Cell Disease Information Center: http://www.nhlbi.nih.gov/new/sicklecell.htm