Media Advisory: NHLBI to hold community forum on sickle cell disease

BETHESDA, Md., June 23, 2015 /PRNewswire/ --

WHAT: The National Heart, Lung, and Blood Institute (NHLBI) is sponsoring the Sickle Cell Disease Forum, "Engaging the Community: Developing Solutions." The Forum is designed to assemble members of the sickle cell disease community—including patients and their families, advocates, health care professionals, researchers, community and professional organizations, policymakers, government agencies, and industry—to share insights, experiences and needs and to help chart the future of sickle cell disease research.

WHEN: June 25-26, 2015

WHERE: The Forum will be held at two different locations on the main campus of the National Institutes of Health in Bethesda, Md.:

Thursday, June 25—NIH Clinical Center, Masur Auditorium (Building 10)

Friday, June 26—Natcher Conference Center (Building 45)

Forum highlights include:

Interactive panel sessions and discussions will focus on issues affecting those living with sickle cell disease, as well as the potential role of various stakeholders in addressing these issues, including:

- **Sickle Cell Disease Research: Past, Present, and Future** – Thursday, June 25, 1:30 p.m. – 2:30 p.m.
- **Managing Sickle Cell Disease Pain** – Thursday, June 25, 2:45 p.m. – 3:45 p.m.
- **Innovative Care Models –** Thursday, June 25, 4:00 p.m. – 5:00 p.m.
- **Sickle Cell Disease Transitions –** Friday, June 26, 9:25 a.m. – 10:25 a.m.
- **Importance of Clinical Trials –** Friday, June 26, 10:25 a.m. – 11:25 a.m.

Breakout sessions will address additional topics, including psychosocial issues, the global impact of sickle cell disease, and more.

Forum participants can attend in person or stream the Forum live via webcast and participate in the discussions by asking questions and sharing thoughts directly via social media, @NIH_NHLBI #SCDForum15.

WHY: It is estimated that nearly 90,000 - 100,000 people living in the U.S. and millions more worldwide have sickle cell disease. Sickle cell disease is most common in people whose families come from Africa, South or Central America (especially Panama), Caribbean islands, Mediterranean countries (such as Turkey, Greece, and Italy), India, and Saudi Arabia. Sickle cell disease is a serious disorder in which the body makes sickle-shaped red blood cells that reduce the flow of blood inside the blood vessels and causes lifetime anemia as well as damage to the spleen, risk of pneumonia, bone infections, and extreme pain. And while there is still no widely available cure, research has enabled better treatments and approaches that help people with sickle cell disease live longer, more productive lives.

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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 .

About the National Institutes of Health (NIH): *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. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.*

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SOURCE National Heart, Lung, and Blood Institute

For further information: To speak with an NHLBI spokesperson, please contact the NHLBI Engagement and Media Relations

Branch at (301) 496-4236 or at NHLBI_news@nhlbi.nih.gov.

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