

PRESS RELEASE

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FOR IMMEDIATE RELEASE

Willarda V. Edwards, MD, MBA
President and COO
Sickle Cell Disease Association of America, Inc.
231 E. Baltimore Street
Suite 800
Baltimore, Maryland 21202
(800) 421-8453
wvedwards@sicklecelldisease.org
www.sicklecelldisease.org



SCDAA and NHLBI Address the Realignment of the Sickle Cell Disease Comprehensive Centers

Baltimore, MD -- On March 10, 2008, The National Heart, Lung, and Blood Institute (NHLBI) announced the beginning of a comprehensive and innovative restructuring of its research program in sickle cell disease (SCD). The Sickle Cell Disease Association of America (SCDAA) has been working since the announcement to better understand the direct impact of changes to individuals with SCD, their families and the implications to the broader Sickle Cell Disease Community. Given the size of the NHLBI and the scope of the changes, it will take some time to appreciate fully the intended changes.

Nevertheless, SCDAA has an initial response to these changes, particularly from the perspective of our mission to advocate for a cure and to improve the quality of life for those affected by the disease. SCDAA's advocacy remains a part of the strong working relationship enjoyed between SCDAA and NHLBI as exemplified by the September 2007 joint convention we shared. SCDAA has maintained a position throughout this relationship that there are inequities in the system as it relates to research and clinical investments in the SCD community. Therefore, we are encouraged by the focus the NHLBI is bringing to this issue. As communicated in their announcement, we look forward to working with NHLBI in developing an appropriate and effective education campaign that resonates with the population most affected by the disease and benefits the most from the information conveyed. SCDAA is equally favorable toward the plans to increase basic research to find a much needed universal cure for SCD.

There are elements of the announcement that we still seek to better understand. For instance, we are working to ensure that the reconfiguration of the 10 Comprehensive Sickle Cell Centers legislated by Congress does not result in any loss of services to patients with SCD, or the dilution of support for the number of centers and the nature of vital research infrastructure available to the SCD Community. SCDAA maintains a position that SCD is not as well supported in its current state as other less prevalent diseases, and is optimistic that this renewed focus will promote greater parity. SCDAA will continue to work with key stakeholders including individuals with SCD, families, SCD Community-Based Organizations, our legislative champions, NHLBI, other Government Agencies, and the greater SCD community to ensure the proper recognition of our recommendations and concerns related to the emerging programmatic changes underway at the NHLBI.

We look forward to the collaborative work ahead, and working to ensure that any proposed modifications have an indelible and positive impact on individuals with SCD.

About Sickle Cell Disease: Sickle Cell Disease (SCD) is an inherited blood disorder that is a major health problem in the United States and worldwide. It affects various ethnic groups, but is most common in African Americans in the U.S. In certain sections of the country there are large numbers of Hispanic individuals with SCD as well. In the general population, one in every 4,000 Americans is born with a form of SCD. Among African Americans, one in every 400 (about 80,000 total) is born with SCD. Over 2.5 million Americans, mostly African Americans, have sickle cell trait.

About Sickle Cell Disease Association of America, Inc.: For more than 35 years, the Sickle Cell Disease Association of America (SCDAA) and its 100-plus Member Organizations and affiliates, located in more than 38 states, have demonstrated how community-based organizations can work as partners with local and state government agencies in furtherance of national health care objectives. In collaboration with member and other stakeholder organizations, SCDAA's national efforts involve five broad categorical areas: research, public health education, professional health education, patient services and community services.

For more information regarding sickle cell disease and the work of SCDAA, please call 800-421-8453 or visit our website at www.sicklecelldisease.org