



PRESS RELEASE

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Medical and Research Advisory Committee
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NIH PANEL CONCLUDES HYDROXYUREA IS UNDERUTILIZED IN SICKLE CELL DISEASE

National Institutes of Health (NIH) panel of experts have issued a consensus statement recommending adoption of hydroxyurea as a frontline therapy in adults and adolescents with sickle cell disease. This recommendation comes 10 years after the Food and Drug Administration (FDA) authorized the use of hydroxyurea in adults with sickle cell anemia. The Medical and Research Advisory Committee (MARAC) of SCDAA fully supports this recommendation, and strongly urges adults and adolescents with sickle cell disease to discuss with their doctors whether hydroxyurea is appropriate for the management of their disease. When you go to the doctor, ask about hydroxyurea!

The office of Medical Applications Research (OMAR) and the National Heart Lung and Blood Institute (NHLBI) of NIH called a consensus meeting to discuss why hydroxyurea is not widely used to treat patients who have sickle cell disease. This two-day meeting held February 25-27, 2008 was planned by a 27-member committee including representation by the Sickle Cell Disease Association of America (SCDAA) that selected members of the conference panel.

The conference panel of 14 members was charged to help find answers to the following questions:

- a) What are the results from clinical studies of hydroxyurea treatment for adults, pre-adolescents and children with sickle cell disease?
- b) What is the effectiveness of hydroxyurea treatment in the every day life of patients with sickle cell disease?
- c) Are there side effects of hydroxyurea treatment?
- d) What are the obstacles of hydroxyurea treatment for patients who have sickle cell disease, and how can we remove these obstacles?
- e) Is more research needed in all of these areas?

The conference panel listened to presentations and testimonies from 22 doctors, scientists, nurses and social workers with expertise in various aspects of sickle cell disease, health policy and management, toxicology, oncology and a public representative. After much deliberation and discussion, the panel made several specific recommendations. A summary of their conclusions include the following:

1. Research has shown that sickle cell patients on hydroxyurea experience fewer pain crises and hospital admissions. There should be increased utilization of this drug with appropriate monitoring, such as frequent blood cell counts.
2. Risks of serious side effects of hydroxyurea appear to be lower than previously expected, and these risks are acceptable when compared to the risks of not treating sickle cell disease in adults and adolescents.
3. Safety and efficacy data of hydroxyurea in younger patients is limited, but supportive of use in this population. Ongoing studies will help resolve this issue in the future.
4. Many patients lack a single healthcare provider to direct their management, and there is a lack of providers with the knowledge, skills, and experience to effectively manage adults with sickle cell disease, including treating them with hydroxyurea.
5. Limited resources and lack of culturally competent providers set the stage for inadequate care for patients who have sickle cell disease.
6. Medicare and Medicaid should cover sickle cell patients of all ages.

Full text of the NIH Consensus Development Conference Statement on hydroxyurea treatment for sickle cell disease is available without charge to the general public at <http://consensus.nih.gov/>.

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 throughout the United 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 the SCDAA website at www.sicklecelldisease.org