

**Last month, we asked you to write to have your Senators sign on to the letter from Senators Talent, Schumer and Burr. We are happy to report that over 26 Senators signed the letter. Now, we need your help again with a letter to go to your individual congressional representatives (in the Senate and the House). Please read the following and take action using the attached letter as a model for your letter!**

**AGAIN, NOW IS THE TIME TO WRITE IN SUPPORT OF FUNDING FOR THE SICKLE CELL DISEASE**

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SCDAA is proud to have initiated and led the grassroots effort to draft and secure passage of the Sickle Cell Treatment Act, working with Dr. Michael DeBaun of St. Louis, Missouri, and Senator Jim Talent's office. Moreover, we are encouraged and grateful for the broadly based community support that this measure has received. <sup>1</sup> Now, we need your support in securing funding for the programs established by this bill. We ask that you write members of your congressional delegation asking to support funding of the Sickle cell treatment act.

Specifically, during the FY06 congressional deliberations on the FY06 Labor-HHS-Education appropriations bill, \$10 million is needed to support a grant program for 40 health centers across the nation, and the establishment of a national coordinating center to collect, monitor and distribute information on best practices related to sickle cell disease (SCD). Grants to the health centers can be used for several purposes, including genetic counseling, continuity of care, testing, and the training of health professionals. Furthermore, the new law permits states to seek federal reimbursement for education and other services related to the prevention and treatment of SCD.

Last year, late in the congressional cycle, and with the leadership of Senator Talent's office, an initial appropriation of \$200,000 was secured to support this effort. It is imperative that every SCDAA member and supporter writes to ensure that the measure is fully funded in FY06.

Additionally, we ask that you support funding for the continuation of the SCD Community Outreach program funded by the Maternal Child Health Bureau, Special Projects of Regional and National Significance (SPRANS) account.

A draft letter to send to your Members of Congress in the U.S. House of Representatives and the U.S. Senate is attached. Time is of the essence. Please do not delay. With your action we would appreciate it if you **send a copy of your letter to SCDAA for our files**. Fax it to 410-528-1495 or email it to our membership services coordinator, Zarek Anderson at [zanderson@sicklecelldisease.org](mailto:zanderson@sicklecelldisease.org).

Thank you for doing all you can to "Break the sickle cycle."

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<sup>1</sup> The bill originally was introduced by Senator James Talent, Senator Charles Schumer, Representative Richard Burr (who now serves in the U.S. Senate) and Representative Danny Davis.

DRAFT LETTER FOR SCDAА SUPPORTERS, MEMBERS, PRESIDENTS AND BOARD MEMBERS

The Honorable \_\_\_\_\_  
U.S. Senate [U.S. House of Representative]  
Washington, DC 20510 [20510]

Dear \_\_\_\_\_:

As a SCDAА supporter, during congressional deliberations on the FY06 Labor-HHS-Education appropriations bill, I write to ask that you support funding of programs related to the research, prevention and treatment of sickle cell disease (SCD). Specifically, \$10 million in funding is needed to support the establishment of 40 treatment Centers that will provide education, counseling and other prevention and treatment services. Additionally, funding will support the establishment of a National Coordinating Center to collect, monitor and distribute information on best practices related to sickle cell disease (SCD). Last year, Congress appropriated \$200,000, to initiate implementation of the Act.

As you may know, SCD is an inherited condition that is a major health problem in the United States. It affects various ethnic groups, but is most common in African Americans. In certain parts of the country, there are large numbers of Hispanic persons 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 (between 70,000 and 80,000) is born with SCD. Over 2.5 million Americans, mostly African Americans, have the sickle cell trait.

Despite the many medical progresses that have been made, persons (adults and children) with SCD often have limited access to health care services and have very few options when seeking treatment or relief. These persons suffer debilitating and chronic pain, and live on average to the age of 45. In terms of access to care, adolescents with SCD face a unique set of challenges. These patients frequently lose medical coverage when they become legally independent of their parents; or, if no local adult care program exists, these patients continue to be treated by pediatricians, even though they are adults.

Full funding of the Sickle Cell Treatment act in FY06 will assist greatly in meeting the needs of SCD patients.

Finally, I ask that you support continued funding of \$4 million for the Community Outreach program funded by the Health Resources Services Administration, Maternal Child Health Bureau (SPRANS account). This initiative supports programs that are distinct from those authorized in P.L 108-357, and strengthens community-based efforts related to new born follow-up, outreach, education, counseling and related services across the nation.

Thank you for your support and assistance. Should you have any questions or concerns, please do not hesitate to contact me.

Sincerely,