

United States Senate

WASHINGTON, DC 20510

September 21, 2004

The Honorable Charles Grassley
Chairman, Finance Committee
United States Senate
135 Hart Senate Office Building
Washington, DC 20510

The Honorable Max Baucus
Ranking Member, Finance Committee
United States Senate
511 Hart Senate Office Building
Washington, DC 20510

Dear Finance Chairman Grassley and Ranking Member Baucus:

We write to respectfully request that you include as part of the FSC/ETI (S. 1637) conference report the sickle cell amendment that would help treat and expand services for patients with the sickle cell blood disorder. Sickle cell disease affects approximately 70,000 Americans and more than 2,500,000 Americans, mostly African-Americans, have the sickle cell trait. There is still no comprehensive cure.

We are among the 49 Senate cosponsors of the bipartisan, bicameral legislation that is the basis for this amendment (S. 874/H.R.1736) and strongly support its enactment into law. Passage of this amendment in the Senate was great news for the tens of thousands of Americans who suffer from this disease, which affects 1 in 300 African-American newborns. The disease causes normally round blood cells to take on a sickle shape that clog the bloodstream. These obstructions result in severe medical complications including strokes in infants and limit the average lifespan to 45 years of age.

In summary, this legislation is a disease management bill that allows states to combine Medicaid-reimbursed services to target sickle cell disease, and authorizes a small Health Resources and Services Administration grant for research, treatment and community outreach through qualifying community health centers. This bill does not expand Medicaid eligibility or change the federal Medicaid matching formula and has a very small cost to the federal government.

This legislation has received exceptional support from nationally prominent children's, health, African-American, church and union groups including the National Association of Children's Hospitals, the American Medical Association, the NAACP, and the Catholic Health Association of America.

We are hopeful that you will include the sickle cell amendment as part of the FSC/ETI (S. 1637) conference report to help tens of thousands of Americans lead longer, healthier and more productive lives.

Sincerely,



Senator Jim Talent



Senator Chuck Schumer

cc: Senators Hatch, Nickles, Lott, Snowe, Kyl, Thomas, Santorum, Smith, Bunning, McConnell, Gregg, Rockefeller, Daschle, Breaux, Conrad, Graham (FL), Jeffords, Bingaman, Lincoln, Kennedy, Harkin.

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