

August 7, 2009

The Honorable Max Baucus
Chairman
Senate Finance Committee
Dirksen Senate Office Building
Washington, DC 20510

Dear Mr. Chairman:

Thank you for your continued efforts and leadership in the ongoing process of developing health care reform legislation to assist the millions of Americans who are underinsured and uninsured. This process represents an unprecedented opportunity to increase access to life sustaining treatments for many Americans with rare diseases. The Plasma Users Coalition is a group of national patient organizations serving those diagnosed with rare and debilitating disorders. These groups represent hundreds of thousands of individuals with chronic genetic conditions who are treated with expensive therapies manufactured and refined from blood plasma. These treatments are life-long, life-sustaining/life-saving, and expensive, costing anywhere from \$30,000 to \$300,000 a year and in some cases over \$1 million.

The Plasma Users Coalition believes it is imperative that our health care system provide access to affordable, quality coverage for all chronically and catastrophically ill Americans. As the health care reform debate intensifies, we have concerns regarding continued access to the specialized, expensive care and therapies our patient's lives and well being depend on to live. Continued and enhanced access to these therapies translates into increased quality of life, less expensive and probable prevention of hospitalizations, and a reduction in the reliance of public assistance/safety net programs such as Medicare and Medicaid.

The PUC would like to share with you and your staff the key principles that our organizations have developed that will yield positive results for the individuals we represent. If you and your staff wish to meet to discuss these principles please do not hesitate to contact Mr. Larry LaMotte with the Immune Deficiency Foundation at (Insert number here). Thank you for your time, attention and above all your leadership in reforming our health care system.

Sincerely,

Alpha-1 Association
Alpha-1 Foundation
GBS/CIDP Foundation International
Committee of Ten Thousand
Hemophilia Federation of America
Immune Deficiency Foundation
National Hemophilia Foundation
Patient Services Incorporated
Platelet Disorder Support Association