



May 22, 2009



Honorable Charles E. Grassley
Ranking Republican
Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510



RE: ***“Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans”***

Dear Senator Grassley:



We sincerely appreciate your efforts to create reforms that will provide adequate, affordable health care for all Americans, and would like to take this opportunity to provide requested feedback on your May 14, 2009 options paper entitled, *“Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans.”*



We are writing on behalf of the nearly 30 million Americans with **rare chronic diseases**, whom we represent. Your options paper has addressed several issues that are very critical for our constituents. In particular, we applaud you for trying to eliminate rating based on pre-existing conditions. It is especially crucial that individuals with rare chronic conditions have access to affordable coverage for all necessary care, regardless of any pre-existing condition. Many **rare chronic conditions** are based on genetic disorders, which are by definition, “pre-existing.” Insurers must not be permitted to deny coverage for a disease with which an individual is born and that may take years, or even decades, to diagnose.



We are also extremely pleased and appreciative that the Committee included an option to eliminate limitations on benefits; we urge you to maintain your stance to ensure that plans cannot include lifetime limits on coverage or annual limits on any benefits. Individuals with rare chronic diseases must not be impeded in accessing necessary health care nor should they be impoverished with unreasonable lifetime or annual limits on benefits and unreasonable out-of-pocket expenses.

These reforms will help all Americans. However, as you further consider comprehensive health care reform, we strongly urge you to address some of the individualized needs of those with rare chronic diseases, many of which are caused by known genetic defects. These conditions present a particular challenge, as they often require very complex and specialized treatments, which are often very expensive. Without timely, appropriate treatment, these individuals may develop complications resulting in unnecessary additional costs. Providing individuals with **rare chronic diseases** with the treatments they need allows them greater opportunity to lead healthy lives and be productive members of society. Appropriate treatment for these individuals includes access to specialized treatment that is appropriate to each condition, access to health care specialists with expertise in treating their diseases, access to specialized “centers of excellence,” which may or may not be available locally, and access to the full range of treatments available for each condition.

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We call upon all policymakers engaged in the current health care reform process to ensure that the system fully addresses the needs of all Americans including the specialized needs of individuals with rare chronic diseases. If you have any questions or would like additional information, please contact Diane Dorman (202 258-6457 or ddorman@rarediseases.org) or Larry LaMotte (443-632-2552 or llamotte@primaryimmune.org).

Sincerely,

National Organization for Rare Disorders
GBS/CIDP Foundation International
Committee of Ten Thousand
Hemophilia Federation of America
Immune Deficiency Foundation
National Hemophilia Foundation
Platelet Disorder Support Association