



National Organization for Rare Disorders

The following letter regarding health care reform was sent today to members of Congress by the National Organization for Rare Disorders (NORD).

July 31, 2009

Dear Members of Congress:

On behalf of the 30 million Americans who are affected by one of the nearly 7,000 rare disorders, we urge you to pass comprehensive health reform legislation designed to assure that every American, regardless of health status, has access to affordable, meaningful health insurance coverage. Failure to pass such long-overdue legislation this year would be devastating and an unacceptable option for people with rare diseases and their families, as well as the millions of other Americans who similarly are burdened by chronic illness.

Today, far too many people under the age of 65 with serious medical conditions have inadequate or no access to health insurance. In most areas of the country, in the absence of employer-based coverage, medical underwriting practices by insurers can, and too often do, result in pre-existing condition limits on coverage, higher health insurance premiums and, for many, outright denials of coverage. People with rare diseases customarily incur substantial medical expenses, first in efforts to obtain an accurate diagnosis, and thereafter from hospitalizations, physicians' office visits, and—for those fortunate enough to have a therapeutic drug, biological, device or medical food—from costs of these treatments, some of which amount to tens of thousands of dollars per year.

As such, for people with rare diseases—and indeed for all Americans—three basic principles should be part of any acceptable reform. First, health reform must prohibit insurance companies from denying or limiting coverage, or charging patients more for premiums based on health status. Second, patients must be protected against catastrophic out-of-pocket costs and annual or lifetime insurance caps. Third, health reform must

include tax credits and other direct financing support sufficient to assure that lower and middle income patients can afford coverage.

We recognize and accept that with these critically important health care benefits comes an individual responsibility to purchase health insurance. Moreover, NORD will be a constructive force in supporting measures that provide for necessary savings and revenues to ensure that these benefits are paid for and managed in a fiscally prudent fashion.

We are pleased that many Congressional leaders are pursuing policies that achieve NORD's principles. While comprehensive federal health reform cannot be all things to all people, it must not be an empty promise to Americans, including those who currently suffer from, and those who will develop, rare diseases.

Finally, we understand and accept that compromises will be made as health reform legislation makes its way through the legislative process. While the basic patient protections outlined above are fundamental to any reform, we recognize that there will be design approaches that would not be our first choice. However, we pledge that we will not allow the perfect to be the enemy of the good. To be clear, though, we also strongly believe that failure to act is an explicit policy choice to preserve the unacceptable status quo. Such a choice has dire access and cost consequences that are intolerable for individuals, families, and the country.

We thank you for your commitment to meaningful health reform. We are eager to work with you to assure passage of legislation that makes health insurance affordable and accessible for every American, regardless of health status.

Sincerely,



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