

January 23, 2007

The Honorable Edward M. Kennedy, Chairman
Senate Health, Education, Labor, and Pensions Committee
United States Senate
Washington, DC 20510

The Honorable Michael B. Enzi, Ranking Member
Senate Health, Education, Labor, and Pensions Committee
United States Senate
Washington, DC 20510

Dear Mr. Chairman and Senator Enzi:

The National Organization for Rare Disorders (NORD) wholeheartedly supports your efforts to encourage the 110th Congress to act quickly on the *Genetic Information Nondiscrimination Act*. The rare disease community of nearly 30 million Americans living with one of the 6,000 to 7,000 known rare diseases has waited for too long to see this important legislation become the law of the land. Today, its time has come. Now is the time to act.

The promise of genetic medicine is far-reaching, but its most powerful potential impact is on personal health and well-being. However, without the protections provided for in *GINA*, rare disease patients may not actively seek testing to determine whether they may be predisposed to a particular rare hereditary disease or condition such as mucopolysaccharidosis (MPS), Sickle Cell Anemia, Early-Onset Alzheimers and Tay Sachs. Thousands of others may never be allowed the opportunity to take the best course of action in determining preventive strategies, treatments and family planning.

When people refuse to be tested, or are tested using an alias or other device, they lose the benefit of more complete medical histories. When genetic information is abused, it has the potential to destroy careers and cause long-term damage to individuals and their families. We must err on the side of caution and ban all genetic discrimination.

On behalf of the 130 voluntary health organizations and 6,000 individual patients, clinical researchers and healthcare providers represented by NORD, we wholeheartedly endorse your efforts to ensure passage of The *Genetic Information Nondiscrimination Act*.

Sincerely,

Diane E. Dorman
Vice President