NORD®
National Organization
for Rare Disorders

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April 1, 2025

NORD Statement on Recent Health and Human Services (HHS) Restructuring

The National Organization for Rare Disorders (NORD®), a nonprofit, nonpartisan organization representing the more than 30 million Americans living with rare diseases, is deeply concerned about the impacts the restructuring of the U.S. Department of Health and Human Services (HHS) announced on March 27 and being implemented today will have on the rare disease community. This rapid, large-scale reduction-in-force (RIF) poses great risk to the critical activities that public health agencies, the public health workforce, and researchers do to enable rare disease patient access to vital lifesaving care and treatments across the country.

Americans have benefited from transformative scientific breakthroughs over the past decade. It is critical the federal health agencies charged with protecting and promoting public health continue to evolve to ensure that these innovations can benefit all Americans. However, it is also crucial that these agencies are equipped with the resources and workforce necessary to carry out this work.

That’s why we are urging the Administration to take the following into account:

- **Research funded by the National Institutes of Health (NIH) is critical for developing new and better treatments, saving lives, and reducing health care costs nationwide.** With 95% of the 10,000 known rare diseases still lacking a U.S. Food and Drug Administration (FDA)-approved treatment option, research funding and supportive activities conducted by the NIH are essential for addressing the tremendous unmet medical needs that exist in the rare disease community.
- **FDA staff expertise and capacity play an integral role in evaluating and communicating critical safety information to patients** and health care providers across the nation. Highly qualified scientists and clinicians are essential to fulfill the FDA’s responsibilities to the American people and cannot be easily replaced.
- **Centers for Medicare and Medicaid Services (CMS) support health care access for tens of millions of Americans** who rely on these programs to obtain comprehensive health care services. Health care programs administered by CMS, including Medicare, Medicaid, Children’s Health Insurance Program (CHIP), and the ACA marketplaces support patients with rare diseases who depend on these programs to access comprehensive care that they could not otherwise afford.
- **The Health Resources and Services Administration (HRSA) enables efficacious federal newborn screening activities,** helping to identify children born with certain rare diseases where early intervention is necessary, and often lifesaving.

NORD remains unwavering in our commitment to advocate for individuals and families affected by rare diseases. The reductions to the public health workforce, without notice, comment, or sufficient analysis of the impact on essential work being conducted across health agencies, endangers our nation's ability to meet the complex needs of the rare disease community.

Consistent with our more than 40-year history of working in a bipartisan manner, we will continue to engage with decision-makers on both sides of the aisle to advance our community's interests. NORD urges the Trump Administration to consider the unique challenges facing the rare disease community and take the steps necessary to ensure this fragile ecosystem can continue to innovate and deliver lifesaving care and treatments to patients across the country while ensuring taxpayer investments are wisely made.

Sincerely,

Pamela Gavin

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