National Organization for Rare Disorders Urges Congress to Protect Funding for Rare Disease Research, Commends Exclusion of Work Requirements for Medicaid in Debt Ceiling Deal

Washington, DC, June 2, 2023 – Last night, the Senate passed a debt ceiling deal (HR 3746) by a 63-36 vote and which now goes to President Biden for his signature. The following is a statement from **Peter L. Saltonstall, President and CEO** of the National Organization for Rare Disorders (NORD):

“The Debt Ceiling Deal protects vital access to Medicaid coverage, ensuring individuals and families with rare diseases continue to have the comprehensive health care they need to survive and thrive; but it threatens the future of lifesaving biomedical research.”

NORD is pleased to see that Congress did not include damaging so-called “work requirements” to the Medicaid program in the Debt Ceiling Deal. Medicaid plays a significant role in supporting the rare disease community; many individuals with rare diseases rely on Medicaid for primary or supplemental health coverage. Work requirements have proven to be both ineffective and inconsistent with the Medicaid program's purpose, while jeopardizing healthcare coverage for millions of Americans. We advocate tirelessly on behalf of the over 25 million Americans with a rare disease to preserve access to high quality health care. We are grateful Congress protected the integrity of this vital program and applaud the federal commitment shown to patients and families impacted by rare disease.

However, while the Debt Ceiling Deal includes provisions important to individuals and families facing rare diseases, the work of our leaders on Capitol Hill is not done. NORD is deeply concerned about the impact *de facto* freezing other health spending at current levels will have on the future of rare disease research. The vast majority of the more than 7,000 rare diseases still do not have any FDA-approved treatments. Federal funding is critical to sustain rare disease research and vital for bringing more safe and effective therapies to the millions of Americans who urgently need them, including many children and adolescents who will not be able to live full and healthy lives without this research. To highlight just one of countless examples, funding for the National Institutes of Health (NIH) National Center for Advancing Translational Sciences (NCATS) supported the development and approval of numerous lifesaving rare disease therapies in recent years. We urge Congress to continue to prioritize rare disease patients and families, and to not jeopardize research into lifesaving therapies through funding cuts.

“NORD has elevated rare community voices for generations, and we will continue to work closely with lawmakers in Congress and the Biden Administration to maintain progress in lifesaving rare disease research and on future efforts to improve the lives of people living with rare disorders.”

To learn more about NORD’s policy work, visit: http://bit.ly/Policy-Issues.

About the National Organization for Rare Disorders (NORD)

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 330 disease-specific member organizations, more than 17,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases.
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