

NORD Statement on Passage of the Inflation Reduction Act

Washington, DC, August 12, 2022 – Following the passage of the Inflation Reduction Act, **Peter L. Saltonstall**, President and CEO, the National Organization for Rare Disorders (NORD), issued the following statement:

“The Inflation Reduction Act is a significant step forward in helping ensure that individuals and families with rare diseases have access to the comprehensive health care they need to survive and thrive.

The extension of enhanced Advanced Premium Tax Credits for three years will keep quality health insurance accessible to millions of Americans, and the creation of an annual out-of-pocket cap on prescription drug costs for Medicare beneficiaries will provide a vital protection to patients who struggle to afford their medications.

NORD is pleased to see that Congress did not include damaging changes to the Orphan Drug Tax Credit (ODTC) within the *Inflation Reduction Act*. We advocated tirelessly on behalf of the over 25 million Americans with a rare disease to preserve this critical incentive when significant changes to the ODTC were considered by Congress last fall. We are grateful the current 25% tax credit for clinical trial testing services remains unchanged and believe it is a critical tool to help foster robust rare disease drug development. We applaud the federal commitment shown to ensure access to safe and effective treatment for rare disease populations is maintained, and future research efforts for new therapies are incentivized by protecting the ODTC.

While this bill includes provisions important to individuals and families facing rare diseases, the work of our leaders on Capitol Hill is not done. NORD has elevated rare community voices for generations, and we will continue to work closely with lawmakers in Congress and the Biden Administration on the implementation of this legislation 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. Visit rarediseases.org.