**RARE DISEASE ADVISORY COUNCILS (RDAC)**

**NORD is working to establish well-organized, high-functioning Rare Disease Advisory Councils in every state to support the needs of the rare disease community.**

An estimated 25-30 million Americans are living with a rare disease; that is close to one in ten people. Yet, with over 7,000 known unique rare diseases, it is difficult for state policymakers and government officials to have an in-depth understanding of the entire rare disease community. This lack of awareness contributes to common obstacles that rare disease patients face, such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs and limited access to medical specialists.

Rare Disease Advisory Councils (RDACs) demonstrate enormous promise to address these barriers for the rare disease community. With diverse membership and broad community support, RDACs can be a valuable resource for state governments as our health care system continues to advance. Without RDACs in place, state laws and regulations that affect the rare community will continue to be developed without the consultation of rare disease stakeholders, often leaving this vulnerable population at greater risk for poor health and economic outcomes. With strong RDACs, government officials and the rare disease community can partner together to develop the resources necessary to prevent and address barriers in a strategic way that allows states and their citizens to thrive.

**TIPS FOR STARTING A SUCCESSFUL RDAC:**

1. Include stakeholders from across the rare disease community from the outset and provide opportunities for public engagement.
2. Identify a committed entity to house the council, such as an outside nonprofit, academic institution, or state Department of Health.
3. Encourage a diverse membership that includes: health department officials, elected legislative officials (or their designees), academic researchers, health care providers, industry members, patients and caregivers.
4. Identify clear duties, responsibilities and accountability measures that can serve as a roadmap for action to be taken by the RDAC.

In 2015, the first RDAC was created in North Carolina by patients, caregivers, families, and providers. Since then, rare disease advocates and stakeholders have sought councils in other states to help better represent their communities.

**It's estimated that**

25–30 million Americans (almost 1 in 10) have rare diseases

More than 90% of rare diseases are without an FDA-approved treatment.

**Alone we are rare. Together we are strong.®**

rareaction.org
rarediseases.org
The MN RDAC established a Council Administrator to help drive consensus and action.

The MO RDAC is specifically tasked with advising their state Medicaid program’s drug utilization board.

The PA RDAC has completed two annual reports on the state of rare disease and the barriers to diagnosis, treatment and insurance coverage. In addition, the council keeps in close touch with the rare community via a public Facebook page and website.

The NC RDAC completed a newborn screening (NBS) white paper titled “Newborn Screening and Early Intervention for the Treatment of Rare Diseases,” which analyzed the current status of NBS in North Carolina in comparison to other states and identified future opportunities for improvement.

The CT RDAC was a temporary taskforce that held useful open forums for state agencies and others in the community to share feedback and learn about existing resources.

The PA RDAC has completed two annual reports on the state of rare disease and the barriers to diagnosis, treatment and insurance coverage. In addition, the council keeps in close touch with the rare community via a public Facebook page and website.

The mission of NORD’s Rare Action Network® (RAN) is to connect and empower a unified network of individuals and organizations with the tools, training, and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. To join RAN, go to rareaction.org.

For more information on Rare Disease Advisory Councils or NORD, please contact RDAC@rarediseases.org.