



Delaware Enacts Law to Address Needs of Rare Disease Patients and Families

Delaware is the 27th state to establish a Rare Disease Advisory Council to raise awareness and inform state health policies

July 26, 2023, Dover, DE – Today, patients and families in Delaware’s rare disease community celebrated the passage of Senate Bill 55 (SB 55) with Amendment SA 1, which officially establishes a Rare Disease Advisory Council (RDAC) in their state.

The Rare Disease Advisory Council will be made up of a diverse group of stakeholders including patients, caregivers, researchers, and health care providers. Their expertise will be an asset to the entire state, creating a platform to educate the public, state agencies, and the General Assembly about rare diseases and to make policy recommendations that improve patient access to critical health care services.

The National Organization for Rare Disorders (NORD) publishes an annual [State Report Card](#) that tracks, among other things, the establishment of RDACs nationwide. Delaware is the 27th state to establish an RDAC since 2015, when the first Council was established in North Carolina, and the third state to do so in 2023, following Maryland and Indiana earlier this year. More than half of states have now committed to better supporting their state’s rare disease community’s often complex health needs by creating an RDAC.

“An estimated one in ten Americans is living with a rare disease, but many patients struggle to find knowledgeable health care providers with relevant expertise and access to necessary care and treatment for their complex condition,” said **Heidi Ross, Vice President of Policy and Regulatory Affairs at the National Organization for Rare Disorders**. “NORD is thrilled to see Delaware join the growing number of states looking to support their rare disease community by establishing a Rare Disease Advisory Council and we are so thankful to Senator Poore, Representative Griffith, Lt. Governor Hall-Long, and Governor Carney for their efforts to create an RDAC in Delaware.”

Jan Meyer, a patient living with a rare disease in Delaware said, "I am so excited Delaware is taking on the challenge of forming a Rare Disease Advisory Council. This will open doors to increased advocacy, new and improved treatment options, and funding research for these diseases that are often overlooked. The forming of the RDAC ultimately equals more hope for those of us within the rare disease community and we all need hope."

“Those who live with rare diseases face many hurdles, beginning with the great challenge of even finding a diagnosis for what are often debilitating, painful and life-threatening conditions. I’m hopeful that the work of this Advisory Council will give Delawareans greater access to specialists who can provide diagnoses and treatment; affordable access to therapies; and medication to treat rare diseases. I’m also excited for the opportunities this Advisory Council may present for research and development of new treatments for rare diseases,” said **Rep. Krista Griffith**, the bill’s lead House sponsor. “I’m grateful to everyone who worked to advocate for and pass this bill, and I’m looking forward to hearing about the positive impacts this council will have for so many residents.”

“Delawareans living with rare diseases face challenges that should never be experienced - struggles with diagnosis, treatment, and everyday life. But I am so hopeful for the future with the establishment of Delaware's Rare Disease Advisory Council. This council, brought to life by SB 55, will give patients, caregivers, and families a seat at the table to address concerns and support a foundation for further innovation to create treatments and improve services,” said **Lt. Governor Bethany Hall-Long, Ph.D., R.N.**, who led efforts to get the legislation introduced. “I am thankful for the leadership of Sen. Poore, Rep. Griffith, and the National Organization for Rare Disorders to make this bill a reality. I look forward to seeing the council get to work breaking down barriers, raising awareness, and supporting Delawareans living with rare diseases.”

The National Organization for Rare Disorders (NORD®) established Project RDAC in 2020 to increase the number of Rare Disease Advisory Councils across the country and help optimize existing councils. For more information on Project RDAC, visit rarediseases.org/rare-disease-advisory-councils-2. To learn more about NORD’s policy work, visit rarediseases.org/driving-policy/.

Rare Disease Facts and Impact:

1. It’s estimated that 25 - 30 million Americans have a rare disease.
(Source: www.nih.gov/about-nih/what-we-do/nih-turning-discovery-into-health/rare-diseases)
2. Half of individuals with a rare disease are children.
(Source: ncats.nih.gov/files/NCATS_RareDiseasesFactSheet.pdf)
3. An accurate diagnosis can take more than four years.
(Source: genomemedicine.biomedcentral.com/articles/10.1186/s13073-022-01026-w)
4. Patients with rare diseases face medical costs that are three to five times higher than people with non-rare diseases.
(Source: ncats.nih.gov/files/NCATS_RareDiseasesFactSheet.pdf)
5. Patients with rare disease incur nearly half of all hospital costs in the U.S.
(Source: www.nature.com/articles/s41436-021-01241-7)

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About the National Organization for Rare Disorders (NORD)

With a 40-year history of advancing care, treatments and policy, the National Organization for Rare Disorders (NORD) is the leading and longest-standing patient advocacy group for the 25-30 million Americans living with a rare disease. NORD, a 501(c)(3) nonprofit, is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 330 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research and policy. For more information, please visit <https://rarediseases.org/>.