February 1, 2022

The Honorable Sharon Cooper
Chair
House Health and Human Services Committee
436 State Capitol
Atlanta, GA 30334

Re: Support for House Bill 918: Georgia Rare Disease Advisory Council

Dear Chair Cooper and Members of the House Health and Human Services Committee:

On behalf of the 1-in-10 individuals living in Georgia with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for holding a hearing on House Bill 918 (HB 918). If passed and signed into law, HB 918 would establish a Rare Disease Advisory Council (RDAC) in Georgia and give a voice to all Georgians who are part of the rare disease community. We urge you to support this important legislation and swiftly advance it out of your Committee.

Any condition that affects fewer than 200,000 Americans is considered rare. There are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While individual RDACs are organized differently in each state, overall, they provide a forum for patients, families, and experts across the state to analyze the needs of the community and make recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, or publish and compile resources related to rare diseases.

NORD recommends that HB 918 be further strengthened by adding a representative from the Georgia Department of Public Health and a representative who is a pediatric specialist trained in the care of children with rare diseases as members of the council. These additions will help the RDAC to better meet the needs of Georgia's rare disease community. Several states that have

already created RDACs have found that including representation from their Department of Health has provided their lawmakers with valuable insight from the public health perspective and including a pediatric rare disease specialist adds a critical level of expertise to the council, as rare diseases disproportionately affect children, adolescents, and young adults.[1]

In creating this council, Georgia will join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource. Those states are Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Chair Cooper, we thank you, Vice Chair Newton, and Representative Cheokas for your leadership and sponsorship of HB 918 and urge its swift passage with the suggested modifications. For any questions, please contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

Annissa Reed

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the House Health and Human Services Committee

[1] Tisdale, A., Cutillo, C.M., Nathan, R. et al. The IDeaS initiative: pilot study to assess the impact of rare diseases on patients and healthcare systems. Orphanet J Rare Dis 16, 429 (2021). https://doi.org/10.1186/s13023-021-02061-3