



February 19, 2020

The Honorable Brian Kemp
Governor of Georgia
111 State Capitol
Atlanta, GA 30334

The Honorable Geoff Duncan
Lieutenant Governor of Georgia
240 State Capitol
Atlanta, GA 30334

Re: NORD Support for Georgia Rare Disease Advisory Council

Dear Governor Kemp and Lieutenant Governor Duncan,

On behalf of the 1-in-10 individuals in Georgia with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) supports the idea of establishing a rare disease advisory council (RDAC) in the state. This important council will give a voice to the rare disease community within Georgia's government. NORD urges the state to pursue the RDAC through legislation--but in the absence of legislation, at least do an executive order and then enact legislation to codify it at the earliest possible time, including this session if possible.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.

Creating an RDAC in Georgia will give rare disease patients a unified voice in our state government, helping to providing educational awareness and make recommendations to elected officials and other state leaders on how rare diseases are handled and treated in the state. From providing information on the diagnostic journey, to making recommendations on state programs such as newborn screening, the council will serve as a tremendous opportunity for important decision-makers in Georgia to better understand and meet the needs of their constituents. What is more – because this council would include broad participation from the different health care sectors present in Georgia – such as physicians, nurses, insurers, manufactures, and researchers – it will also serve as an education resource to all stakeholders about the ways rare disease patients interact with our health care system.



NORD and our Rare GA chapter have been heavily engaged in establishing an RDAC in Georgia since 2015. In creating this council, Georgia will be joining eleven other states who have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, and Pennsylvania.

Once again, on behalf of the Georgia rare disease community, we thank you for considering the creation of an RDAC. Please give a voice to Georgia residents living with rare diseases – many of whom are too young or too sick to speak for themselves. For any questions, please feel free to contact Heidi Ross at hross@rarediseases.org or Beth Nguyen at Beth.Nguyen@rareaction.org. Thank you for your consideration.

Sincerely,

Heidi Ross, MPH
Director of State Policy

Beth Nguyen, RN
Georgia Rare Action Network Volunteer State Ambassador