



January 20, 2021

The Honorable Luke E. Torian
Chair, House Appropriations Committee
Virginia House of Delegates
Pocahontas Building
900 E. Main St.
Richmond, VA 23219

Re: Support for House Bill 1995

Dear Chairman Torian and Members of the Appropriations Committee:

On behalf of the 1-in-10 individuals in Virginia with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for putting House Bill 1995(HB1995) on the Health, Welfare, and Institutions Committee's agenda. HB1995 establishes a Rare Disease Advisory Council (RDAC), which if passed, would help to give a voice to the rare disease community within Virginia's state government. NORD urges you to vote in support of HB1995 and swiftly move it out of your committee.

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 Virginia will give rare disease patients a unified voice in Virginia 's state government, helping to provide 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 Virginia to better understand and meet the needs of their constituents. Since this council would include broad participation from the different health care sectors present in



Virginia, it will also serve as an educational resource to all stakeholders about the ways rare disease patients interact with our health care system.

In creating this council, Virginia will be joining sixteen other states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) who have already enacted similar legislation in support of their rare disease community.

Once again, on behalf of the Virginia rare disease community, we thank you for putting HB1995 on the Appropriations Committee's agenda and urge its swift passage. For any questions, please feel free to contact Annissa Reed via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Heidi Ross".

Heidi Ross
Director of Policy
National Organization for Rare Disorders

A handwritten signature in black ink that reads "Annissa Reed".

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

CC: Members of the House Appropriations Committee