



February 11, 2021

The Honorable L. Louise Lucas
Chair, Senate Health and Education Committee
Virginia Senate
Pocahontas Building
900 E. Main St.
Richmond, VA 23219

Re: Support for House Bill 1995

Dear Chairwoman Lucas and Members of the Senate Health and Education 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 Senate Health and Education 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 Senate Health and Education 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,

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

Heidi Ross
Heidi Ross
Director of Policy
National Organization for Rare Disorders

CC: Members of Senate Health and Education Committee



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Dear Chairwoman Lucas and Members of the Senate Health and Education Committee:

My name is Jana Monaco of Woodbridge, VA and I am the Virginia Rare Action Volunteer State Ambassador for National Organization for Rare Disorders. NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease.

I am honored to be here today on behalf of the one in ten Virginia residents with a rare disease to share my support for House Bill 1995, which would establish a rare disease advisory council in Virginia.

Rare disease patients in Virginia face 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.

As the mother of two children with a rare disease, I can certainly relate to some of these unique challenges. My son, Stephen, was born with a rare metabolic disorder called isovaleric acidemia, which is detectable through newborn screening. Unfortunately, isovaleric acidemia was not a part of Virginia's newborn screening panel at the time of his birth, so his disorder was not diagnosed until he was 3 ½ years old resulting in a traumatic brain injury and multiple complex medical issues. Thanks to knowledge gained from Stephen, my daughter was diagnosed with the same disorder before birth. Her early diagnosis enabled her to receive immediate treatment for her disorder preventing her from sharing in his fate. She will graduate from virtual high school this year and go on to college.

Since their diagnosis, we have faced various challenges over the years. Finding a pharmacy to fill their prescriptions for the medications to treat their disorder has been difficult. There have been hurdles in obtaining their medical formula and receiving insurance coverage for it. The current pandemic poses new problems. They are in the high-risk category, so we have been keeping them primarily at home, but we still have no access to the vaccine in our county yet. Furthermore, I am the primary caregiver for Stephen, but do not fall into a prioritized category for the vaccine. These are just a few examples of struggles we and others in the rare disease



community across the Commonwealth face on a daily basis and are left to find solutions on our own.

The Virginia Rare Disease Advisory Council would help address the challenges faced by rare disease patients, their families and their caregivers by providing a forum for stakeholders across the state to analyze the needs of the rare disease community and make recommendations on how to improve public policy.

To date, sixteen states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) have created a Rare Disease Advisory Council and proven that it is an effective way to ensure better government engagement and action on issues of importance to the rare disease community. I want to thank Delegate Murphy for being a champion for those of us affected by rare diseases and sponsoring this important legislation. I urge you to vote in support of HB 1995 and help Virginia become the 17th state to enact an RDAC.

Sincerely,

Jana Monaco
Virginia Volunteer State Ambassador
Virginia Rare Action Network

CC: Members of Senate Health and Education Committee



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Re: Support for House Bill 1995

Dear Chairwoman Lucas and Members of the Senate Health and Education Committee:

My name is Allison Herrity of Arlington, Virginia and I'm testifying today as an employee of the National Organization for Rare Disorders, also known as NORD. NORD is a national patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. In addition to working at NORD, I am a Virginian living with a rare disease myself, having been diagnosed with Ehlers-Danlos Syndrome 3 years ago at the age of 19.

I am here today to express my support, and NORD's support, for House Bill 1995, which would establish a Rare Disease Advisory Council, or RDAC, in Virginia.

Rare disease patients in Virginia and across the country face unique barriers to care due to the low prevalence of our conditions. Obtaining an accurate diagnosis is often difficult, finding and accessing medical specialists who have the knowledge and resources necessary to treat our conditions can be even harder, and obtaining insurance coverage for medically necessary treatments is an exhausting and time-consuming battle.

I began having medical issues in middle school, but I wasn't diagnosed with Ehlers-Danlos Syndrome until I was 19. My personal diagnostic odyssey took place over seven years and brought me to five different states and almost 15 physicians before I got an accurate diagnosis.

Since EDS impacts my connective tissue, I can require special considerations in many aspects of my medical care. Finding providers who understand this has been challenging, and despite having good health insurance, I'm still unable to obtain coverage of certain medications and the physical therapy I need to maintain a quality of life similar to that of a healthy 22-year-old. Additionally, even when medications and appointments are covered, copayments add up over time — I spent close to \$4,000 out-of-pocket on copays for covered medications and doctor's appointments in 2020. Sadly, issues like mine are common in the rare disease community, but they could also be addressed through good policies that protect patients and enable them to get quality, affordable care and treatment.



Creating a Rare Disease Advisory Council in Virginia would help give the one in ten Virginians who live with a rare disease a stronger voice in our state government by bringing together stakeholders across the state to identify the needs of the rare disease community and make recommendations on how to improve state policies to enable those like me to thrive. I urge you to vote in support of HB 1995 to enact a Rare Disease Advisory Council in Virginia.

Sincerely,

Allison Herrity
National Organization for Rare Disorders

CC: Members of Senate Health and Education Committee