



March 9, 2021

The Honorable Ralph Northam
Governor of Virginia
P.O. Box 1475
Richmond, VA 23218

Re: Support to sign HB 1995 and HB 2332 into law

Dear Governor Northam,

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) urges you to sign House Bill 1995 (HB 1995) and House Bill 2332 (HB 2332) into law. HB 1995 will establish a Rare Disease Advisory Council (RDAC) to increase the rare disease patient voice in state government and HB 2332 will create a state-based reinsurance program to help strengthen the individual market. Both pieces of legislation will greatly benefit the rare disease community and we ask for your support by signing them into law today.

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. We believe that all individuals with a rare disease should have access to quality and affordable health care that is best suited to meet their medical needs.

HB 1995 will create an RDAC to increase the rare disease patient voice in state government and better understand their needs. The council will be tasked with conducting research and consulting with experts to make recommendations, improving access to health care and other services for individuals with rare diseases, understanding the impact of health insurance coverage, studying the impact of providing coverage under the state program for medical assistance, and publishing a list of publicly accessible resources. Since this council will include 21 members from all the different health care sectors present in our state, it will also serve as an educational resource to all stakeholders about the ways rare disease patients interact with our health care system at large.

In establishing 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.

Additionally, HB 2332 will support the rare disease community that purchases their health insurance from the individual marketplace by creating a state-based reinsurance program. A reinsurance program will stabilize the Virginia marketplace and significantly lower the cost of



health insurance for Virginians who need relief today. Reinsurance programs help insurance companies cover the claims of high-cost enrollees, which in turn keep premiums lower for other individuals, including rare disease patients, that purchase insurance on the individual market.

So far, 14 other states have implemented reinsurance programs and proven them to be of value to their market. A 2019 analysis found that in the first year of a reinsurance program, states saw premiums drop by an average of 16.9%.¹ Reinsurance programs are largely funded through the federal government, through so-called pass-through funding. The programs reduce federal costs because reinsurance lowers premium tax credits the federal government would have provided to state's residents absent the reinsurance program, minus the credits the federal government will continue to provide.²

Virginians who are impacted by rare diseases need increased representation at the state level to meet their varied needs and access to quality, affordable health care insurance options. We urge you to help the rare disease community in Virginia by swiftly signing HB 1995 and HB 2332 into law today. For any questions, please feel free to contact Annissa Reed via email at areed@rarediseases.org. Thank you for your consideration and all you do already for the rare disease community.

Sincerely,

Annissa Reed

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

Jana Monaco

Jana Monaco
Virginia Volunteer State Ambassador
Virginia Rare Action Network

¹ <https://avalere.com/press-releases/state-run-reinsurance-programs-reduce-aca-premiums-by-16-9-on-average>

² <https://www.cbpp.org/research/health/reinsurance-basics-considerations-as-states-look-to-reduce-private-market-premiums#:~:text=What%20is%20reinsurance%3F,the%20amount%20of%20the%20subsidy>.