



March 15, 2021

The Honorable Christopher R. Hart
Chair
House Subcommittee I, Health and Environmental Affairs
432B Blatt Building
Columbia, SC 29201

Re: Support for House Bill 3956 – to establish a Rare Disease Advisory Council

Dear Chairman Hart,

On behalf of the 1-in-10 individuals in South Carolina with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support and report House Bill 3956 (H3956) favorably out of your Subcommittee. H3956 will establish a rare disease advisory council (RDAC) within the state that will help increase the rare disease patient voice in state government.

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.

Typically, the needs of rare disease patients and families do not receive adequate attention from policy makers in state government due to the nature and complexity of rare diseases. To amplify the voice of the rare disease community in state government, NORD launched [Project RDAC](#) at the end of 2020 which aims to increase the number of high impact rare disease advisory councils or "RDACs" across the country. At this time, 16 states have created RDACs (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) and have proven that they are a valuable resource for the rare disease community and state government officials with minimal government funding.

H3956 will create a robust state council to give rare disease patients a unified voice in our government. Additionally, the RDAC will act as the advisory body on rare diseases to the South Carolina Legislature and state departments. It will also be tasked with: 1) convening public hearings, making inquiries, and soliciting comments from the general public; 2) consulting with experts to develop policy recommendations; 3) researching and identifying policy priorities related to treatment and services to develop policy recommendations, including safeguards against discrimination, or on issues including emergency preparedness; 4) publishing a list of resources on the state's website; 5) identifying and distributing educational resources for health



care providers; and 6) researching and identifying best practices to reduce health disparities and achieve health equity.

RDACs have proven to be innovative and meaningful to state government with minimal reliance on state funding. For example, in 2020, Tennessee's RDAC successfully passed with a fiscal note of \$60,500 to their state budget and as part of its 2021 budget, Michigan appropriated \$70,000 to administer a rare disease review committee. In 2019, Minnesota appropriated \$150,000 each year for four years to hire a full-time administrator for the Council, which is the only RDAC NORD is tracking that includes a full-time employee.

Additionally, several other states recently passed RDACs and received no fiscal impact during their legislative process, including Kentucky (2019), New Hampshire (2019) and Massachusetts (2021). Instead, many RDACs rely on volunteer assistance and outside grant funding to carry out their duties set forth in legislation. In South Carolina's bill (H3956), there is language that would allow the Council to seek outside grant funding for this purpose. Based on NORD's experience, we feel confident that this language will help ease the burden on the state and allow the Council to thrive for the benefit of the rare disease community in the state.

South Carolinians who are impacted by rare diseases need increased representation at the state level to meet their varied needs. We urge you to help the rare disease community today by making South Carolina the seventeenth state with a Council and report H3956 favorably out of your Subcommittee. For any questions, please feel free to contact Rose Gallagher at rgallagher@rare diseases.org. Thank you for your consideration.

Sincerely,

Rose Gallagher
Associate Director of Policy
National Organization for Rare Disorders



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Re: Support for House Bill 3956 – to establish a Rare Disease Advisory Council

Dear Chairman Hart and Members of the Subcommittee on Health and Environmental Affairs:

My name is Kerri Nelson, and I am the South Carolina Volunteer State Ambassador for the National Organization for Rare Disorders (NORD). NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease. An estimated one in ten South Carolinians are affected by a rare disorder.

I am not only a caregiver for a child with a rare disorder, but an advanced practice nurse as well. This is the drive behind what I do as the South Carolina Volunteer State Ambassador. My role allows me to meet others within the rare community, hear the struggles they are faced with daily, and advocate for their needs. Enacting a Rare Disease Advisory Council (RDAC) in the state of South Carolina would provide an outlet for the rare community to be heard. The RDAC would address various issues that the rare community faces and provide support in improving their special health care needs.

My son has Mosaic Trisomy 22, which was a devastating diagnosis that we received three weeks after he was born. He has had to live the last seven years of his life with hearing “we’ll see,” which is unfortunately our normal. Had Mason been born with Full Trisomy 22, we most likely would not have him blessing our lives today, as it is incompatible with life. Mason spent two weeks in the NICU, has had endocrine specialists, cardiologists, and developmental peds follow him. We are now dealing with stressors within the school system as a second grader. Unfortunately, our story is like so many others within the rare community. We are fortunate that Mason is with us today and he continues to thrive, which is certainly not the “norm” within the rare community. We will continue to fight and attack each new challenge he is faced with as he grows older, and “we’ll see”.

The last year has been detrimental to Americans, especially those within the rare community. The already fragmented system was even more challenging for the rare community to navigate. Specific challenges South Carolinians faced was difficulty in obtaining care, prescription drugs, and access to treatments. Through the implementation of a RDAC, South Carolina legislators and other state decision-makers could have a better grasp on these issues and provide support to this community.



Our great state of South Carolina can join the current sixteen states who have already enacted a RDAC (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) and show the rare community that we support them. These sixteen states have paved the way and proven that a RDAC is effective and a much-needed step in improving health care for all. I ask that you vote to support House Bill 3956, and show your support to our rare, loved ones, because “alone we are rare, but together we are strong”.

Sincerely,

Kerri Nelson
South Carolina Volunteer State Ambassador
South Carolina Rare Action Network

CC: Members of the Subcommittee on Health and Environmental Affairs