



March 12, 2020

The Honorable Jim Justice
Governor of West Virginia
State Capitol, 1900 Kanawha Blvd. E
Charleston, WV 25305

Re: Support for SB 269 – West Virginia Rare Disease Advisory Council

Dear Governor Justice,

On behalf of the 1-in-10 individuals in West Virginia with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to sign Senate Bill 269 (SB 269) into law. This important legislation to establish a Rare Disease Advisory Council in West Virginia passed both chambers unanimously in the 2020 legislative session and has broad support from the patient community. NORD applauds the legislature for their passage of SB 269 and looks forward to - your signing SB 269 into law and giving a voice to the rare disease community.

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.

The West Virginia Rare Disease Advisory Council will give rare disease patients a unified voice in the state government by providing them a forum to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on the provider-patient relationship to identifying best practices, the council will coordinate with legislators and other government leaders to improve public policy for the entire state. It will require broad participation from patients, nurses, doctors, and patient organization representatives and this legislation has no fiscal note attached, so the Council can seek outside funding sources.

In creating this council, West Virginia 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, we urge you to sign this legislation into law and give a voice to West Virginia residents living with rare diseases – many of whom are too young or too sick to speak for themselves. We look forward to working with your office to successfully enact the West Virginia Rare Disease Advisory Council, which will provide incredible support for the state's rare disease community. For further questions, please feel free to contact us at hross@rarediseases.org.

Sincerely,

Heidi Ross,
Director of State Policy

CC:

Brian Abraham – General Counsel