



March 9, 2020

The Honorable Rusty Crowe
Chair, Senate Health and Welfare Committee
425 5th Avenue North
Suite 720 Cordell Hull Bldg.
Nashville, TN 37243

Re: NORD Support for SB 2124 to create the Tennessee Rare Disease Advisory Council

Dear Chairman Crowe and Members of the Senate Health and Welfare Committee,

On behalf of the 1-in-10 individuals in Tennessee with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to swiftly move Senate Bill 2124 (SB 2124) through your committee. SB 2124 establishes a rare disease advisory council (RDAC) within the state, which if passed, would help to give a voice to the rare disease community within Tennessee's 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.

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 Tennessee will give rare disease patients a unified voice in Tennessee'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 Tennessee 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 Tennessee including physicians, nurses, insurers, manufacturers, and researchers, it will also serve as an education resource to all stakeholders about the ways rare disease patients interact with our health care system.



In creating this council, Tennessee 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, on behalf of the Tennessee rare disease community, we thank you for considering the creation of a Rare Disease Advisory Council. Please support this legislation to give a voice to Tennessee residents living with rare diseases – many of whom are too young or too sick to speak for themselves. For any questions, please feel free to contact me via email at hross@rarediseases.org. Thank you for your consideration.

Sincerely,

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

Heidi Ross
Director of State Policy

A handwritten signature in black ink that reads "Terry Jo Bichell".

Terry Jo Bichell
Rare Action Network
Tennessee State Ambassador

CC: Members of the Senate Health and Welfare Committee