NORD®
National Organization
for Rare Disorders

RARE
UT

March 9, 2020

The Honorable Lee B. Perry
Utah House of Representatives
977 W 2390 South
Perry, UT 84302

Re: NORD Support for HB 106 to create the Utah Rare Disease Advisory Council

Dear Representative Perry,

On behalf of the 1-in-10 individuals in Utah with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you again for introducing legislation to establish a rare disease advisory council (RDAC) within the state, which if passed, would help to give a voice to the rare disease community within Utah's government. NORD thanks you for your leadership on this important issue and urges you to work with your colleagues to swiftly move HB 106 through the legislature before the end of session.

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 Utah will give rare disease patients a unified voice in our state government, helping to providing 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 Utah to better understand and meet the needs of their constituents. What is more – because this council would include broad participation from the different health care sectors present in Utah – such as physicians, nurses, insurers, manufactures, 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, Utah 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 Utah rare disease community, we thank you for considering the creation of an RDAC. Please give a voice to Utah 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,

Heidi Ross

Heidi Ross
Director of State Policy