

June 15, 2020

The Honorable J. Stuart Adams
President of the Senate
Utah State Senate
3271 E. 1875 N.
Layton, UT 84040

The Honorable Brad R. Wilson
Speaker of the House
Utah State House of Representatives
350 N. State St. Suite 350
Salt Lake City, UT 84114

The Honorable Jerry W. Stevenson
Chair, Executive Appropriations Committee
Utah State Senate
466 S. 1700 W.
Layton, UT 84041

The Honorable Bradley G. Last
Chair, Executive Appropriations Committee
Utah State House of Representatives
1194 S. 180 W.
Hurricane, UT 84737

Re: Coalition Support for HB 106 - the Utah Rare Disease Advisory Council

Dear President Adams, Speaker Wilson, Chair Stevenson and Chair Last:

On behalf of the undersigned organizations representing individuals with chronic, acute or rare diseases, we thank you for your efforts during the 2020 session to pass House Bill 106 (HB 106), to establish the Utah Rare Disease Advisory Council (RDAC). As you know, this legislation passed the House 66-1 and the Senate 25-0 in March with \$9,500 appropriated to help the Department of Health perform their duties under the bill.

Though we are facing unprecedented times during the COVID-19 crisis, and we recognize the budgetary pressures facing the state, we write to urge that HB 106 be fully enacted as intended. There is no greater time for a council like this in Utah to help address issues pertaining to the rare disease community arising from this current or future crisis. Patients with rare disorders are a high-risk population that have often been overlooked in the COVID-19 discussion. In addition, rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, across the country 74% of rare disease patients have had a medical appointment cancelled and approximately 70% are concerned about medication and medical supply shortages.¹

Creating an RDAC in Utah will allow the rare disease community to share their concerns and make recommendations on how rare diseases are treated and handled in the state with elected officials and other state leaders. From providing information on the diagnostic journey, to making recommendations on how the state can better serve patients during a crisis like COVID-19, 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

¹ <https://rarediseases.org/new-community-survey-from-nord-reveals-significant-impact-of-covid-19-on-americans-living-with-rare-diseases/>

researchers – it will also serve as an education resource to all stakeholders about the ways rare disease patients interact with our health care system regularly and during a crisis.

While the RDAC funding level reflects a de minimis use of state resources, it represents enormous value to our organizations and the patient communities we serve. Continuing to fund the RDAC will allow the RDAC to directly hear from a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the RDAC would help relieve some of the burden from the Department of Health by expeditiously delivering direct feedback solutions and resources with one community voice.

In creating this council, Utah will be joining thirteen 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, Pennsylvania, Tennessee, and West Virginia.

Once again, on behalf of the undersigned organizations, we thank you for working to ensure that HB 106, creating an RDAC in Utah, proceeds as intended to help the Utah rare disease community. For any questions, please feel free to contact Heidi Ross with the National Organization for Rare Disorders at hross@rarediseases.org. Thank you for your consideration.

Sincerely,

Alpha-1 Foundation
ALS Association Rocky Mountain Chapter
ALS Crowd
American Diabetes Association
American Kidney Fund
Chronic Care Policy Alliance
Chronic Disease Coalition
Cystic Fibrosis Research Inc.
Epilepsy Foundation
Epilepsy Foundation Utah
GBS|CIDP Foundation International
Global Healthy Living Foundation

Hemophilia Federation of America
International Foundation for Autoimmune &
Autoinflammatory Arthritis (AiArthritis)
Leukemia & Lymphoma Society
NAACP Salt Lake Branch & State Conference
ID-NV-UT
National Hemophilia Foundation
National Infusion Center Association
Neuropathy Action Foundation
National Organization for Rare Disorders
Rett Syndrome
Utah Hemophilia Foundation

CC:

The Honorable Allen Christensen
The Honorable Paul Ray
The Honorable Lee B. Perry
The Honorable Luz Escamilla