



July 26, 2016

Re: Community Support for a Kansas Rare Disease Commission

To Whom it May Concern:

We, the undersigned rare disease patient organizations and advocates, on behalf of the 30 million Americans with one of the nearly 7,000 known rare diseases, request your support for the creation of a Kansas Rare Disease Commission.

As the voice for the rare disease community in Kansas, we are dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Any disease affecting fewer than 200,000 Americans is considered rare. With nearly 7,000 rare diseases identified and 30 million Americans affected, it is estimated that nearly 1 in 10 residents of our state is living with a rare disease. We believe strongly that every patient deserves the medical care that is best suited for their medical situation and that is most likely to give them the best results.

Rare diseases are present across the broad spectrum of medical conditions. For example, all but a few types of cancer are rare. Other examples of rare diseases include PKU, ichthyosis, histiocytosis, Rett syndrome, and Huntington’s disease. For patients suffering from these or other rare conditions, it can take several years to receive an accurate dosage. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.

The Kansas Rare Disease Commission would give rare diseases patients a voice in our state government and provide educational resources for elected leaders on critical issues related to access, coverage, and the diseases themselves. From providing information on the healthcare provider-patient relationship to access issues to vital life-saving medications and therapies, the Commission will work as a partner with legislative and administration leaders.

We hope you consider the incredible support that a Kansas Rare Disease Commission could provide for the Kansas rare disease community. Approximately one in ten of your constituents has a rare disease, and they and their families would be heartened to know their Representative is standing up for them.

If we can supply additional information, please do not hesitate to let us know. Tim Boyd, the Associate Director of State Policy for the National Organization for Rare Disorders, is available to assist as needed. Tim can be reached at (202) 545-3830 or via email at tboyd@rarediseases.org.

Sincerely,