

July 11, 2016

Tim Boyd
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Governor Bruce Rauner
Office of the Governor
207 State House
Springfield, IL 62706

Re: Community Support for HB 4576 (Rare Disease Commission)

Dear Governor Rauner:

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, urge you to support HR 4576, an act creating the Illinois Rare Disease Commission.

As the voice for the rare disease community in Illinois, 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 Illinois is living with a rare disease.

Supporting the medical needs of the rare disease community is about more than just accurate and timely screening. The Illinois 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 an Illinois Rare Disease Commission could provide for our rare disease community. Please join us in giving a voice to Illinoisans living with rare diseases – many of whom are too young or too sick to speak for themselves – by supporting HB 4576.

Sincerely,

Amyloidosis Support Groups Inc.

Cicatricial Alopecia Research Foundation (CARF)

Cornelia de Lange Syndrome Foundation

Cystic Fibrosis Research, Inc.

Cystinosis Research Network

EveryLife Foundation for Rare Diseases

National Foundation for Ectodermal Dysplasias (NFED)

National Organization for Rare Disorders (NORD)

Neurofibromatosis Network

PKU Organization of Illinois

United Leukodystrophy Foundation

