

March 26, 2018

Representative Matt Dean
401 State Office Building
100 Rev. Dr. Martin Luther King Jr. Blvd
St. Paul, MN 55115

Dear Representative Dean:

On behalf of Children's Hospitals and Clinics of Minnesota and the patients and families we serve, thank you for your leadership and support of House File 2574 .

Children's Minnesota is the state's largest pediatric provider. Last year, we treated more than 135,000 children from every county in the state almost 60 percent of the counties in our surrounding states. With more than 60 pediatric specialties- from anesthesiology to vascular anomalies- Children's Minnesota has the largest and broadest team of pediatric experts in the region. We provide care for some of the state's sickest and most vulnerable kids; kids with both common and rare, critical diseases.

Every day we work with patients and families that are navigating complex and unique conditions; families that feel overwhelmed, isolated, stressed, and confused. Often these families seek care from numerous providers and specialists, and at times, cross state lines in search of appropriate and accessible treatments. Parents are forced to become their child's advocates, care coordinators, care providers, and researchers for new and experimental treatments.

A statewide council aimed at coordinating efforts, researching access and quality of treatments, providing education and awareness, and developing and ensuring best practices for the treatment of rare diseases, would help create a more comprehensive, coordinated and research based approach. It would help ease the burden of our parents and families that have been shouldering this work for so long.

We applaud the interest in these complex and rare diseases and we look forward to working with you further on behalf of the patients and families we serve.

Sincerely,



Maria Christu
Vice President, Advocacy and Health Policy
Children's Minnesota