



March 31, 2023

Dear Chair Wiklund and members of the Senate Health and Human Services Committee,

Thank you for your thoughtful consideration in putting together an Omnibus bill that improves health care services and access for Minnesotans. We are grateful to see several of the bills Gillette Children's supports in SF 2995a-2.

Gillette Children's operates an independent, nonprofit, specialty care, 60-bed pediatric hospital in St. Paul along with pediatric specialty clinics across Minnesota, including clinics in Burnsville, Maple Grove, St. Paul, Baxter, Bemidji, Duluth, Willmar and Mankato.

We serve children with complex disabilities, rare conditions, and traumatic injuries with a focus on brain, bone and movement conditions needing specialized expertise. Each year, we treat patients from all 87 Minnesota counties.

Thank you for including:

- Expansion of the membership of the DHS Drug Formulary Committee to increase specialty expertise and consumer representation.
- Additions to the DHS Drug Formulary Committee provisions to provide a 30-day notice to the public of the drug, drug class, and prior authorization requirements that will be discussed at the upcoming committee meeting, as well as an accurate archive of previous versions of the preferred drug list that is available to the public as this will help increase transparency and public input.
- Full funding of Minnesota's Rare Disease Advisory Council. As a newly created state agency, the funding will assist the council in fulfilling their many (needed) duties as listed in statute and ensure the expertise this council brings can assist the state in developing resources, information and policy.
- Hospital Payment Rate Modification - modifying the procedures that govern inpatient hospital rate rebasing.
- Access to a liquid form of a medication for patients who utilize tube feedings, and access to liquid methadone, without barriers or harmful delays.
- Directing the state to continue information technology updates that were put on hold due to the public health emergency
- Medical Assistance coverage for seizure detection devices
- Healthy Beginnings, Healthy Families Act, Developmental and Social Emotional Screening with Follow-up
- Comprehensive and Collaborative Resource and Referral System (Help Me Connect) for Children



We ask that you please consider adding:

- Unrestricted Access to Services for the Diagnosis, Monitoring, and Treatment of Rare Diseases (SF 1029). This legislation has strong support from both providers and the patient advocacy community and will help to address the long diagnostic odyssey experienced by so many rare disease patients. It is essential that Minnesota providers can make timely referrals to the right provider outside of their own hospital or health system when they know where a patient needs to be seen, without network barriers or delays. Health and quality of life can be negatively impacted when appropriate, timely interventions are not provided or are delayed.

We also want to thank you for including Medical Assistance 12-month continuous eligibility for children under 21, and continuous eligibility for children birth through age 6 as a provision in SF49-DE1.

Thank you for working so hard this session to improve the lives of all Minnesotans, including children and adults with rare diseases, disabilities, and complex conditions, and their families. Please reach out to Marnie Falk, Gillette's Director of Public Policy, with any questions at marniefalk@gillettechildrens.com.

Sincerely,

A handwritten signature in black ink, appearing to read "Barbara Joers".

Barbara Joers
President and CEO
Gillette Children's Specialty Healthcare