

May 11, 2022

To: Senate and House Health and Human Services Conference Committee Members

Dear Chair Abeler, Chair Utke, Chair Benson, Chair Koran, Senator Hoffman, Chair Liebling, Chair Schultz, Chair Pinto, Chair Gomez, and Representative Albright,

Thank you for your leadership this session as you worked to address Minnesota's health and human service needs. We are grateful to see several of the bills Gillette Children's supports in the omnibus bills.

This year Gillette Children's is celebrating 125 years of cutting-edge treatments, better outcomes and more joyful lives for children with complex medical challenges. We provide care for more than 25,000 patients every year from every county in Minnesota at our 60-bed hospital, and clinics throughout the state. We could not do this work without the support of our community, including the Minnesota Legislature.

## **Gillette Children's Priority Issues**

Gillette Children's supports making changes to Minnesota's Rare Disease Advisory Council (SF4410, Article 3, Sections 1, 13 & 15 and HF4410, Article 22, Sections 2 & 20)

The Minnesota legislature created the Rare Disease Advisory Council in 2019. Gillette Children's supported this effort. We are now supporting the legislation this session that would make needed changes to the existing council structure which includes moving the council to the Minnesota Council on Disability. This move will allow the Rare Disease Advisory Council to have autonomy and the ability to work directly on public policy on behalf of the rare disease community.

Gillette Children's supports increasing access to services for the diagnosis, monitoring, and treatment of rare diseases (HF4076, Article 7, Sections 6 & 7)

Under this legislation no health plan company may restrict the choice of an enrollee as to where the enrollee receives services from a licensed health care provider related to the diagnosis, monitoring, and treatment of a rare disease or condition, defined as a disease or condition that affects fewer than 200,000 persons in the United States and is chronic, serious, life-altering, or life-threatening. This legislation also removes financial penalties for seeking this needed care out-of-network. In the U.S. it can take on average seven years to obtain a proper diagnosis for a rare disease after seeing eight providers (four primary care physicians and four specialists). This provision attempts to reduce this diagnostic odyssey by allowing patients to have more timely access to a specialist with knowledge and experience in treating rare diseases.

Gillette Children's supports lifting the 40-hour cap on personal care services (SF4410, Article 1, Sections 17, 36 & 38 and HF4076, Article 9, Sections 15, 19 & 19)

Currently, there is a 40-hour weekly household limit on the number of hours a parent of a minor, or spouse, can be reimbursed for providing disability-related care to the minor child or spouse under CFSS or CDCS. The 40-hour limit does not consider the number of parents providing care in the household, the number of people needing services in the household or the type of services the individual receiving care is eligible for.

Clinic locations: Brainerd Lakes Burnsville Mankato Maple Grove Minnetonka Phalen St. Paul



## Additional Provisions Gillette Children's Supports

## Gillette Children's supports the establishment of the Nurse Licensure Compact (NLC) (SF4410, Article 14, Sections 14 & 15)

37 states are already members of the NLC. Gillette Children's serve patients from around the country. If Minnesota were a member of the NLC, our nurses would be able to remotely provide follow up care to our out-of-state patients without each nurse going through the process of obtaining a separate license in each state. This would ensure patients have continuity of care, in their home-state, from Minnesota nurses familiar with their unique care plan and status.

Gillette Children's supports prohibiting pharmacy benefits managers or health carriers from requiring that clinician-administered drugs be covered as a pharmacy benefit, a practice commonly known as "white bagging" (HF4076, Article 6, Section 45)

We support this legislation because "white bagging" policies are increasingly common and impact patient and provider choice. These policies can delay patient care, create potential safety risks and needlessly drive-up out-of-pocket costs. The legislation does not prohibit the practice of "white bagging" as this may be an appropriate option for patients and care providers, but it does prohibit mandating the practice of "which bagging" as it could have adverse effects.

Gillette Children's supports providing continuous MA eligibility for 12 months for children (HF4076, Article 3, Section 18)

Continued Medicaid enrollment for individuals 20 years old or younger would eliminate costly disruptions in access to care and reduce health disparities.

Gillette Children's supports prohibiting pharmacy benefits managers and health carriers from requiring or demonstrating a preference for a biological product. Requiring equivalent or preferential coverage for biosimilar and interchangeable products (HF4076, Article 6, Sections 44, 48, 49 & 59)

Many of the specialty drugs coming into the market that are beneficial for Gillette Children's patient population are biological products or a biosimilar. This legislation protects patient and provider choice related to the prescribing and dispensing of biological products. From a patient perspective biosimilars provide a more affordable option for expensive treatments, including treatment for rare diseases. From a provider perspective it is difficult and expensive for providers to maintain several different brands of a biosimilar drug.

Thank you again for your service to our state and your support of the patients we serve with complex, rare and traumatic conditions and their families. Please reach out to either of us with questions.

Sincerely,

Barbara Joers
President and CEO

Marnie Falk
Director, Public Policy