



March 4, 2016

Charles Grassley, U.S. Senator
Ron Wyden, U.S. Senator
Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510-6200
Submitted via Report_Feedback@finance.senate.gov

Dear Senator Grassley and Senator Wyden:

We want to express our thanks for your engagement on drug pricing and marketing and most importantly, its impact on patients and their access to needed healthcare. Even though Gillette Children's Specialty Healthcare (Gillette), as a specialty hospital, has less encounters with the pharmaceutical vendors than larger full service medical centers, we are grateful for the opportunity to share our concerns and ideas related to the topic. We have a unique perspective in that we serve patients who have life-long conditions.

Gillette is a pediatric hospital that specializes in high acuity services such as trauma, inpatient rehabilitation, and other treatments for short-term and long-term disabilities. We serve patients from every county in Minnesota, and we have clinics in the metro area and outreach clinics throughout greater Minnesota. We also serve patients from all fifty States and from more than a dozen countries based on our focused care of musculoskeletal and neurological conditions. At Gillette, most of our patients are not curable in the traditional sense, they require a lifetime of care for complex conditions, such as cerebral palsy, severe epilepsy, spinal cord injury, and spina bifida. Gillette's care model is structured to help patients maximize their health, function, mobility and independence.

Patients with complex conditions require multiple encounters with a variety of specialists to manage their conditions, and they often require multiple surgeries and hospitalizations throughout their lifetimes. As a specialty hospital, we see patients that are considered, even at the federal level, medically complex and fragile. The acuity of our patients is one of the highest of all independent children's hospitals in America, and is the highest for those serving pediatrics in the State of Minnesota. Gillette also has one of the highest Medical Assistance populations in Minnesota. If you picture a bell curve, Gillette's patients are on the extreme right of the curve for complexity and for cost.

Due to our mission, we are anxiously watching this drug reform process unfold. Proper pharmaceutical pricing and related processes assist hospitals, clinics and related agencies in providing needed care to the patients that we serve, in all settings - urban to rural. Transparency in drug pricing and preserving access to needed drugs is the priority. However, it is important to know that issues around drug pricing are not limited to cancer, hepatitis, and other chronic conditions most frequently seen in adults. Our patients – most of whom are children and experience life-long conditions – are especially burdened by high cost drugs, often for life.

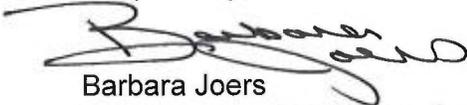
The pricing of single source and orphan drugs, which the Committee asked about, has a significant impact on our patients. As a result of the medical complexity and rare conditions we treat at Gillette, we use an extensive list of orphan and single source drugs that provide valuable treatment for our patients. These drugs are expensive and thus present unique challenges for providers and our care of patients. When the price is too high for a family to afford, our hospital

has to cover the costs of these drugs, diverting resources from other Gillette services. We also experience difficulty with finding a package size for single source drugs that fits our young patients and a lack of payment from the Centers for Medicare and Medicaid Services and private payers for administration if drugs were not purchased by us as the provider.

We thank you for all of your hard work on the hoped for reform around increasingly aggressive drug pricing and related marketing strategies that adversely impact patient access to appropriate treatment and therapy. We hope that as you move forward with your investigation, you do not forget about the unique issues facing children with complex medical conditions. If you have future roundtables or hearings on this issue, we would be happy to contribute to ensure that children and people with complex medical needs are a part of the discussion.

Please feel free to reach out to me through Erin Bailey on my senior team with any questions. Although we are not able to provide specific drug names and pricing publically, we are happy to discuss examples. She can be reached at erinkbailey@gillettechildrens.com or (651)578-5637.

Respectfully,



Barbara Joers
President and Chief Executive Officer

Cc: Senator Al Franken; Congresswoman Betty McCollum