



February 24, 2021

Rep. Liz Reyer
575 State Office Building
100 Rev Dr. Martin Luther King Jr. Blvd.
St. Paul, MN 55155

Sen. Rich Draheim
3227 Minnesota Senate Building
95 University Ave West
St. Paul, MN 55155

Dear Rep. Reyer and Sen. Draheim:

On behalf of the Hennepin Healthcare System, I am writing to thank you both for authoring HF626/SF464 which would allow unrestricted access to diagnosis and treatment for those living with a rare disease. Hennepin Healthcare is accustomed to dealing with complex patient populations and complex medical conditions.

According to the National Human Genome Research Institute, a rare disease is defined as a condition affecting fewer than 200,000 people in the United States. There are roughly 7,000 rare diseases affecting an estimated 25 million to 30 million Americans.

For patients suffering from a rare disease, the journey to an accurate diagnosis can take years and many consultations and tests. Some estimate it takes on average seven years to receive a proper diagnosis, during which time they are passed from doctor to doctor, spending weeks and months waiting for appointments, tests, and results. Ultimately, every week spent waiting could be a lost chance to flourish and develop in life.

With so many people affected by rare diseases, we have a duty to do everything we can to identify and tackle them and that means timely access to providers. There is also a strong economic case to make: if we can accelerate this process we will not only prevent a lot of suffering, we will also significantly reduce the costs incurred by health care providers during the diagnostic process, as well as those incurred when someone is given the wrong treatment following a misdiagnosis (which can in itself subject patients to unnecessary side effects), freeing up resources that can instead be invested in better treatment and prevention. However, solving this issue is a complex challenge.

Navigating insurance networks can be yet another barrier in the journey to a rare disease diagnosis and can delay needed treatment. We support easing this for Minnesotans already dealing with unprecedented stress in regard to their health.

Thank you for authoring this important legislation.

Sincerely,

A handwritten signature in black ink that reads "Meghan M. Walsh MD MPH".

Meghan M. Walsh, MD MPH
Chief Academic Officer

A handwritten signature in black ink that reads "David R. Hilden MD MPH FACP".

David R. Hilden MD MPH FACP
Vice President of Medical Affairs / President of the Medical Staff

Hennepin Healthcare

If you have questions for Hennepin Healthcare System, please reach out to Susie Emmert, Sr. Director of Policy and Advocacy, at Susie.Emmert@hcmcd.org