

RARE → READY

A GENETIC CONDITION COALITION



Dear members of the Minnesota House Committee on Health Finance and Policy:

We are contacting you on behalf of Rare & Ready: A Genetic Condition Coalition, consisting of 46 non-profit rare disease grassroots patient organizations from across the U.S. that include patients, caregivers, and advocates in Minnesota. Our efforts are not disease- or treatment-specific; rather, we seek to address concerns of the broader rare disease community.

Rare & Ready is particularly concerned about ensuring that as new rare disease therapies come to market, patient access in Medicaid is not arbitrarily limited beyond the eligible patient population as stipulated in the Food and Drug Administration (FDA) approved label. Increasingly, as transformative rare disease therapies are approved, Medicaid agencies – and payers more generally – are looking for ways to limit access. This is largely based on cost, with no consideration of the critical patient need that the therapy may address.

This is a profound patient access issue, and we need your help. We urge you to support HF 2261, which would prevent Medicaid in Minnesota from creating overly restrictive coverage criteria for newly approved rare disease therapies.

According to the National Institutes of Health (NIH), there are more than 7,000 identified rare diseases, but only about 5 percent of those conditions have an approved treatment. That said, there is a focused effort underway within the biopharmaceutical sector, NIH, research institutions, and patient advocates to advance innovation for rare disease therapies. However, we must ensure that as these innovative treatments are researched, developed, and ultimately approved, timely and meaningful coverage is provided for patients who stand to benefit the most. **Decisions related to the correct course of treatment need to be left up to providers and patients - not staff at the state's Medicaid agency.**

This is literally a life-changing issue for patients living with rare conditions. There are a limited number of treatments available, and these conditions are often progressive in nature. As such, timely and meaningful access to newly approved rare disease therapies must be of paramount importance.

Your support for HF 2261 will make it easier for rare disease patients in Minnesota to access much-needed, medically appropriate therapies. We hope you will support us in leaving no patient behind, and we are happy to discuss our concerns in more detail at your convenience. Thank you for considering our request.

Sincerely,

Members of the Rare & Ready Coalition

Learn more at www.rareandready.org