

March 4, 2024

To: Senate Health and Human Services Committee

Re: Support for Minnesota Debt Fairness Act

Dear Chair Melissa Wiklund, Ranking Member Paul Utke, and the members of the committee,

I am writing on behalf of the Minnesota Rare Disease Advisory Council to express support for the inclusion in SF 4602 of a ban on co-pay accumulator programs as stated in the directive that health plan companies must count amounts paid by the enrollee or paid on behalf of the enrollee by another person towards the enrollee's cost sharing amounts. The Minnesota Rare Disease Advisory Council (RDAC) is an executive branch state agency whose mission is to improve diagnosis and care for the 1 in 10 Minnesotans living with a rare disease.

The prohibition on patient assistance programs when copay accumulator programs are used by health plans are inappropriate for individuals with rare diseases and disproportionately impact them for two reasons. First, individuals with rare diseases face an even higher amount of costs compared to more common diseases. A series of recent studies, including one conducted by the NIH, found that healthcare costs for people with rare diseases are 3-5 times greater the costs for people without a rare disease¹. Patient assistance programs are vital to relieving some of this burden.

Second, less than 9% of the over 7,000 rare disease patient communities have any FDA approved treatment and the communities with an approved treatment often have only a single treatment option. The use of a copay accumulator programs whose stated purpose is to encourage patients to choose cheaper alternatives to expensive medications is therefore inappropriate for the rare disease community and simply increases the financial burden on individuals with rare diseases who already pay higher prices for specialty drugs.

We thank the authors for including the prohibition on copay accumulator programs in SF4065/HF4100. While controlling the cost of drugs that Minnesotans pay is an understandable priority, the Council does not feel that this should be done through limits on cost sharing programs.

Sincerely,



Executive Director, MN Rare Disease Advisory Council

¹ [Can you hear us now? The impact of health-care utilization by rare disease patients in the United States | Genetics in Medicine \(nature.com\)](#)
[NIH Study Suggests People with Rare Diseases Face Significantly Higher Health Care Costs | National Center for Advancing Translational Sciences](#)