

Dear Chair Wiklund and Members of the Senate Health and Human Services Committee,

The signed organizations would like to express our support for SF 1029, a bill to increase access to services required for diagnosis, monitoring, and treatment of a rare disease. We thank Senator Morrison and the co-authors for supporting this important legislation.

Rare diseases are often complex, chronic, progressive, degenerative, and life-threatening. Many rare diseases affect several aspects of the body, requiring care from different types of specialists. Access to a provider that has the knowledge and experience to obtain a correct diagnosis or prescribe the correct course of management and treatment can result in improved health outcomes, has the potential to reduce overall health care costs, and, in some cases, can mean the difference between life or death.

Minnesota is fortunate to have a number of specialists who are experts in various rare diseases. However, with over 7,000 known rare diseases, it is not possible for any one physician or any one network to have knowledge and experience of all rare diseases. Access to a specialist, or even to a specialist who focuses their practice on rare disease patients, is not enough; patients need access to a physician who has knowledge of and the necessary experience to diagnose, manage, or treat their rare disease. These specialists are understandably spread across multiple health systems.

As organizations serving or advocating for and with rare disease patients and their families, we believe this legislation has the potential to reduce the diagnostic odyssey, increase quality of life, provide cost savings to both the health care system and to individual patients and their families, and most importantly positively impact timely and appropriate access for rare disease patients.

We ask for your support of SF 1029.

Sincerely,

