05/02/23

Conference Committee

Health & Human Services

Minnesota Senate & House of Representatives

Dear Conferees,

Thank you for your leadership this session as you work toward good health for all Minnesotans, including those living with a rare disease.

Since 1965, the Hemophilia Foundation of Minnesota/Dakotas (HFMD) has been an important resource for Minnesotans affected by bleeding disorders. Hemophilia is a rare disease which is life threatening if not treated properly. Thus, the HFMD is committed to seeing that our community members have access to the health care and therapy they need to stay alive and healthy.

In 2019, the state legislature passed the Chloe Barnes bill to establish the Rare Disease Advisory Council of Minnesota. This legislation was initiated by of a broad coalition of rare disease organizations, and by dedicated state lawmakers who were passionate in seeking good health for all Minnesotans. This monumental action was signed by Governor Tim Walz in 2020.

We commend the Minnesota State Legislature on efforts to that end, and respectfully request base funding of this council in 2023 to keep it a strong voice for patients and families affected by a rare disease:

* **Rare Disease Advisory Council funding Bill** **HF 988/SF 705**

HFMD strongly supports the full funding requested for the Minnesota Rare Disease Advisory Council and asks that the Senate version of the bill be moved forward.

Those afflicted with a rare disease often face the challenge of getting the proper diagnosis; in part due to lack of network access and services needed to be accurately diagnosed and treated. It is critical that rare disease patients have direct access to specialists. The HFMD also respectfully requests your inclusion of this bill for the rare disease community which was included in the Senate Omnibus bill.

* **Rare Disease Access/Diagnosis Bill House File 384/Senate File 1029**

Unrestricted access to services required for diagnosis, monitoring, and treatment of rare diseases.

We are fortunate in Minnesota to have lawmakers who are truly committed to keeping this state a model of health care excellence for all! Thank you for considering our requests.

Sincerely,



James Paist

Executive Director