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03/26/2024

To: Senate Health and Human Services Committee:

RE: Letter of Support for SF 3927

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

We would first like to thank the committee for holding a hearing on SF 3927, the bill for funding the Rare Disease Advisory Council (RDAC) and structural changes to allow RDAC to more easily bring on members with certain areas of expertise when the Council is deliberating on various topics.

We commend you on your ongoing efforts to see that every Minnesotan has access to the health care they need. Hemophilia and other chronic bleeding disorders are a serious and potentially life-threatening condition. Maintaining access to the health care our members need is of utmost importance to this organization. ‘An ounce of prevention is worth a pound of cure’ is so true for our community.

We are very glad that the Rare Disease Advisory Council (RDAC) of Minnesota was established in 2020. This council composed of medical experts, those affected, and Legislative Members was created to give a voice to the rare disease community and for it to have the ability to weigh in on important matters of public health and public policy. Although partial funding for the RDAC was approved by the state legislature in 2023, we urge you to support ongoing efforts in 2024 to secure the full funding needed for the RDAC with **SF 3927**.

Since 1965, the Hemophilia Foundation of Minnesota/Dakotas (HFMD) has been an important resource for Minnesotans affected by hemophilia and other chronic 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.

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 your consideration of this letter.

Sincerely,

A handwritten signature in blue ink that reads "James Paist".

James Paist
Executive Director
Cell: 651-587-0482
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