March 28th, 2023

TO: Madam Chair Liebling and Health Finance and Policy Committee

FROM: Minnesota Rare Disease Advisory Council (RDAC)

Chair Liebling,

On behalf of the Minnesota Rare Disease Advisory Council please accept our letter of support of the inclusion of funding for **Developmental and Social Emotional Screening with Follow-up (HEALTHY BEGINNINGS, HEALTHY FAMILIES ACT)** in the [DE Amendment HF2930](https://www.house.mn.gov/comm/docs/EYyf_8ULXkOWW5d5c9wCcQ.pdf) .

The Minnesota Rare Disease Advisory Council exists to improve care for the 1 in 10 Minnesotans living with a rare disease. Children make up roughly half of the rare disease community and the majority of rare diseases are chronic and complex. Because the rare disease diagnostic journey is characterized by significant delay in diagnosis and frequent misdiagnosis, we believe that this program is of particular benefit to our community. This program will support families and children by ensuring that children who receive developmental screening also receive follow-up; a component that is critical to ensure that children with rare, complex diseases are not under-identified or fall out of the system post-screening before they are able to be diagnosed.

Thank you for your work to improve health for all Minnesotans.

Sincerely,



Erica Barnes, M.A, CCC-SLP

Executive Director