



March 3, 2025

Chair Wiklund and Members of the Conference Committee,

On behalf of ALD Connect, we write in strong support of SF 1175 which establishes a presumptive disability determination process for medical assistance eligibility, particularly for infants with a positive newborn screening or a compassionate care allowance determination. This legislation is an essential step toward ensuring timely access to necessary medical care for some of our most vulnerable children.

Currently, delays in disability determinations can leave infants and children with severe or life-threatening conditions without access to critical medical services. By aligning presumptive eligibility with a positive newborn screening result or a compassionate care allowance determination, this bill ensures that infants with urgent medical needs receive immediate access to care, reducing barriers and preventing adverse health outcomes.

This policy will have profound impacts by ensuring children with adrenoleukodystrophy (ALD) and other rare diseases have immediate access to care. ALD is a progressive, genetic disorder that affects the nervous system and adrenal glands, with symptoms ranging from adrenal insufficiency to devastating cerebral ALD, which can lead to rapid neurological decline and death if left untreated. Regular monitoring, including MRIs and adrenal function tests, allows for early identification of disease progression, enabling timely interventions such as steroid replacement and hematopoietic stem cell transplantation (HSCT). Without routine monitoring, individuals with ALD may miss the narrow treatment window where therapies are most effective, leading to severe disability or loss of life. There is even more urgency for other leukodystrophies and rare diseases. We stand with the entire rare disease community in advocating for timely diagnosis, proactive monitoring, and access to life-saving care for all patients.

For these reasons, ALD Connect urges your support for SF 1175. We stand ready to work with you to advance this critical legislation and ensure that all eligible infants receive the timely and necessary medical assistance they deserve.

Thank you for your leadership and commitment to improving healthcare access for Minnesota's children. Please do not hesitate to contact me at kelly.miettunen@aldconnect.org should you have any questions or require further information.

Sincerely,

A handwritten signature in dark ink that reads "Kelly Miettunen".

Kelly Miettunen
Executive Director
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