

Senate Bill 2224- In Support
Senate Human Services Committee
67th Legislative Assembly of North Dakota
March 8, 2021

Chairman Weisz and members of the Senate Human Services Committee Members

My name is Donene Feist and I am the Executive Director for Family Voices of North Dakota. As the Director of Family Voices we have assisted many families who have a child or youth with a metabolic disorder.

I stand to support Senate bill 2224. I am also a member of the Medicaid Medical Advisory Committee and Services/Codes subcommittee which reviewed and evaluated requests of metabolic supplements.

Currently, due to unavailability of New Drug Application numbers (NDAs) for certain supplements, Medicaid does not cover the hydroxycobalamin (vitamin B12) injection product necessary to treat infants/children with methylmalonic acidemia, a metabolic disease in which some subtypes are treated by injections of vitamin B12.

Failure to treat can result in a buildup of toxic substances in the body that result in a decompensation event. Note that hydroxycobalamin injection must be compounded to be dosed correctly in infants and children. This means that currently Medicaid will pay for this medication when infants and children are hospitalized but will NOT pay for infants and children to receive this daily medication when outside of the hospital.

Additional examples of metabolic supplements without NDAs that are not covered by Medicaid but are necessary to treat particular metabolic diseases include: biotin (vitamin B7) for biotinidase deficiency (given orally to prevent intellectual disability, seizures, vision and hearing loss, hair loss, and skin disease), riboflavin (vitamin B2) for diseases affecting metabolism of fat, protein and carbohydrates (given orally to prevent cardiac problems, seizures and other nerve disease, coma, and even death).

Thiamine (vitamin 1) for Maple Syrup Urine Disease (to prevent encephalopathy, seizures, coma, and death), and ADEK, a vitamin supplement that provides higher doses of the fat soluble vitamins A, D, E, and K for patients with a variety of malabsorption conditions, including cystic fibrosis.

The cost of these supplements is relatively insignificant compared with the cost of formula and other medications necessary for disease management- many of which *are* covered by Medicaid-and certainly *much* less expensive than emergency department visits and hospitalizations associated with suboptimal treatment of any/all of these diseases.

Therefore, the subcommittee recommended that Medicaid cover metabolic supplements without NDAs in cases where metabolic supplements are part of standard recommendations for treatment but no suitable product with a NDA number is available for use.

While I am no expert on metabolic supplements, I do believe we at Family Voices are very cognizant on family's need and the support they receive.

Many families struggle to put food on the table, many of the families who have an infant or child who need these supplements long term without access to them due to costs, clearly the child's health would be in jeopardy. Particularly when one or more is needed to treat the metabolic disorder.

On a personal note, I take many supplements due to an autoimmune disorder. I know what the cost of supplements are. Before I prepared my testimony, I thought of years past, when we were not financially able to support those costs and what a strain it would have put on us as a family financially. Not to mention the years it took to finally reach some sort of diagnosis.

Additionally, as you know I have a now adult son with a disability. While the scenarios are not the same, the financial impact of his diagnosis, many times left us literally unable at times to afford necessities. Food, clothing, shelter. Many times we were juggling who was going to get paid for the month, what we could postpone till the next paycheck or can we ask our parents to help us. The economic hardships that families are under now in 2021 are much more significant than they were when we were raising our son. I can't imagine what it would feel like, having this loom over your head month after month after month. The "what if's" would be detrimental.

As a mom, this would be heart wrenching knowing that these supplements may mean life and death, or that without them, developing a compounded illness or intellectual disability, all of which increase the long term costs for care.

Most of our children don't fit a mold. All are uniquely their own, and many have multiple diseases or disorders so rare that often doctors have never seen. Early on families realize with a heavy heart, the world we live in isn't built for our children.

Each and every day families are fighting someone about some aspect of their care. It could be a doctor, nurse, therapist, educator, or an insurance company. Every day families launch battles for what we know our children need to thrive, and sometimes our fight ends in defeat. We cry in our bedrooms at night. In the dead of night, many families lie awake, overcome by fear of the unknown.

Every day many families are fighting a battle against a disability, disease or chronic illness that we will never beat. Most of families know the very real implications of what can happen to our children at any given time. All we want is for our children to not have to fight so hard to simply be. Families need support often to get from point a to point b. This is an ever fluid and changing environment.

Families are not looking for handouts, but they do often need a rope to hang on to, to keep from drowning in an every changing system. Let us be sure we are supporting our most vulnerable children and families.

Please support SB 2224, for children with a metabolic disorder, their life could be dependent upon it.

Donene Feist
FVND Director
701-493-2634; fvnd@drtel.net

