

Michigan Family Connections Newsletter

FALL 2019

ATTENDING SCHOOL WITH ASTHMA

Sending your child to school when they have asthma can be scary. Can your child access their medication quickly, or is it locked in a cabinet in the nurse's office? Does the school have a fulltime nurse, or will a teacher help a student during an asthma episode? You need to have a plan to ensure your child has access to their medication when necessary.



[Michigan law](#) permits school children to carry inhalers and self-administer medication if they suffer from asthma, providing written approval from a physician and parent is given to the school. So how do you make sure your child has access to their medication during the school day?

- Determine if your child is ready to self-carry and administer by completing a free, online [Student Readiness Tool](#) from the American Lung Association. This tool will the parents and school nurse gage the student's understanding of asthma and triggers, recognizing and treating symptoms, and how to administer medication.
- Meet with the school nurse. Ask if they are familiar with and following the state law. If not, work with the nurse or administration to raise awareness of the law and to develop strategies to make sure it's followed. If there is not a nurse at your school, these tasks should be assigned to an appropriate staff member. This staff member should receive training in asthma basics, management and emergencies.
- Ask what the "school's policy" (often different than the state law) is to self-carry and administer. Some schools require a district-approved asthma action plan signed by the doctor. Others require a letter from your healthcare provider stating your child can self-carry and administer. An example of an asthma plan can be found here: <https://getastmahelp.org/actionplans.aspx>

Your child with asthma needs you to advocate for asthma-friendly schools. Schools should always be a place where students can breathe easy, so they are ready and able to learn.



*A newsletter
for families of
children and
youth with
special health
care needs, and
professionals who
help them.
Connecting you
with information
and news you
can use!*

A quarterly publication
brought to you by the
Family Center for Children
and Youth with Special
Health Care Needs and
Michigan Family to Family
Health Information Center

WHAT TO DO ABOUT FEEDING ISSUES IN CHILDREN (OR...HELP! MY CHILD WON'T EAT!!)

Feeding issues can be caused by a variety of special health care needs. Some common conditions are cleft palate, sensory disorder, autism, asthma, and cerebral palsy. Feeding issues can look different in each child. It can be stressful for children and their families. It can also be a challenge for therapists.

Common issues can include:

- refusing to eat
- coughing or gagging when eating
- problems chewing or swallowing
- spitting up
- eating only certain textures or foods
- crying or having melt downs when eating
- breathing issues when eating
- not gaining weight, or losing weight

Feeding issues may be caused by oral motor or sensory issues. Oral motor issues are not being able to properly move food around in the mouth. This can lead to vomiting, gagging, and spitting out of food. Sometimes a child will refuse to eat to avoid these reactions. A sign of an oral motor related feeding issue is the lack of ability to chew and break down the food.

Sensory issues can present in different ways. This can be hypo-sensitivity or hyper sensitivity. Hypo-sensitivity means **not enough** oral awareness. This can lead to food stuffing or leftover food pieces in the



mouth. Hyper-sensitivity means **too much** oral awareness. This can lead to gagging or vomiting, spitting food out, or having a meltdown when eating.

All children can experience these issues from time to time. If you feel it is becoming a problem, contact your child's doctor. The doctor can order tests to figure out the cause. Then he or she can make referrals for treatment if needed.

Treatment may be done by a team. The treatment team may include:

- occupational therapist
- physical therapist
- doctor or nurse
- dietician or nutritionist
- developmental specialist
- social worker
- breastfeeding consultant (if relevant)

Treatment may include medicine(s), feeding therapy, trying new foods, changing food textures, gum massaging, position changes, and behavioral therapy.

There are various treatment options for feeding issues throughout Michigan. Two programs available are at Helen DeVos Children's Hospital (Grand Rapids) and C.S. Mott Children's Hospital (Ann Arbor).

The Intensive Feeding Program at Helen DeVos Children's Hospital includes day treatment, inpatient and outpatient programs.

For more information, please visit <https://www.spectrumhealth.org/patient-care/childrens-health/neurosciences/intensive-feeding-program>.

The Interdisciplinary Pediatric Feeding Program at C.S. Mott Children's Hospital includes intensive and outpatient programs, as well as consulting services.

For more information, please visit <https://www.mottchildren.org/conditions-treatments/feeding-disorders>.

MEET A MEMBER OF OUR FAMILY LEADERSHIP NETWORK

NIKKI DOWD-MCKECHNIE

This month's article features Family Leadership Network Member Nikki Dowd-McKechnie from the Upper Peninsula.

Tell us a little about yourself and your family?

I am married with two children. Sawyer is 16 and Adeleigh (Addi) is 14. Both have ASD but thriving with consistency and perseverance.

I have a BS in Human Services from Lake Superior State University and a MSA in Administration with a concentration in Leadership from Central Michigan University. I live in the Upper Peninsula otherwise known as "God's Country"!

I am the Executive Director of the E.U.P. Community Dispute Resolution Center. We offer mediation as an alternative to the court process. Our mission is to provide citizens the opportunity to mediate disagreements, determine their own solutions and resolve differences using a process that is respectful and educational.

Why were you interested on serving on the Family Leadership Network?

I have two kids with special needs. I feel as if I have been an advocate for their needs at an early age in a rural area. I also feel as if I am a leader in my community and have ended up being a "go to" person locally for parents of children with disabilities.

This made me feel like I would be a good fit to expand my knowledge base and connect with people with similar interests and lifestyles.

What are some of your interests/passions?

My interests/passions include traveling to warm climates, volunteerism, and spending time with my family and friends.

What started you on your parent leadership journey? (what inspired you?)

I was inspired because somehow people look to me to advocate and share information



about parenting children with special needs. I feel like life chose me to join the journey.

What advice would you give to parents of a newly diagnosed child in your area?

Look for services, parent groups, and the internet for information related to their child's disability.

What do you see are the biggest needs or challenges for parents of children with special health care needs in your area?

Services can be difficult to navigate and determine eligibility.

Anything else you would like to add?

I am thankful for the opportunity to be a part of this team!

WANT MORE INFO ON THE FAMILY LEADERSHIP NETWORK?

Visit the Michigan Family to Family website for more information. We currently have open positions in several regions, and applications are accepted at any time.

<https://f2fmichigan.org/who-we-are/family-leadership-network/>

TEN COSTLY MISTAKES TO AVOID WHEN PLANNING FOR A LOVED ONE WITH SPECIAL NEEDS

No one likes to think about what will happen to our loved ones with special needs when we are no longer here. Unfortunately, the most popular estate plan in the United States is doing nothing.

While not a good idea for anyone, it is especially troubling if there is a loved one with special needs. If you do nothing, your estate is managed under the rules set forth in your state's probate code. The state probate code does NOT consider whether a loved one has special needs. This could cause the wrong person to be named to oversee your loved one's care, or even cost your loved one access to essential benefits. Doing nothing really isn't a good option.

For more information, and the other nine costly mistakes most families make when



planning for a loved one with special needs, see the following guide from the Academy of Special Needs Planners. They encourage the use of this guide for background material and urge you to contact a trusted estate planning attorney to plan for your particular needs.

<https://mielderlaw.com/wp-content/uploads/2016/04/10-Costly-Special-Needs-Planning-Mistakes.pdf?x52646>

HEALTH LITERACY—ELECTRONIC HEALTH RECORDS

Technology has changed our world. Smart phones, tablets, and other devices impact our daily lives and how we communicate. This is true of health care as well. Electronic health records have changed the way health care is delivered.

An Electronic Health Record (EHR) is just a digital version of a patient's medical chart. It is collected over time and includes all key info related to that person's care. It includes personal data like name, address, birthday and insurance info.

It also contains your medical info, such as progress notes, medications, vital signs, past medical history, and lab and other test results. It gives the provider more complete records that are easier to access. EHR systems are designed to store data accurately and securely.

Complex health conditions often require a



team of health care providers. Each provider may have limited time with the patient, based on their specialty. This can result in fragmented care for the patient.

EHRs can organize and share info with authorized providers involved in the patient's care. With EHRs, providers can get accurate, up-to-date info. Better care coordination leads to higher quality care and improved patient outcomes.

Increased access to health records can also reduce medical errors and unnecessary tests. It lowers the risk that one doctor will not know about an unrelated (but relevant) condition being treated by another doctor. EHRs can expose potential safety concerns, like drug interactions.

EHRs can also support a patient's involvement in their care. Providers and patients can work together to make health decisions. Providers and patients can message through patient portals tied into their EHR system. Quick and easy communication between patients and providers may help identify health concerns earlier.

For a short video about Electronic Health Records from a patient's perspective, watch this video:

<https://www.youtube.com/watch?v=n1L4nKdYr6E>

BCBSM NOW COVERING FORMULA FOR INBORN ERRORS OF METABOLISM*

Inborn errors of metabolism (IEM) are inherited genetic disorders that interfere with specific metabolic pathways. These interferences may result in either a deficiency or excess of a particular product. There are three major categories of IEMs: protein disorders, fatty acid oxidation disorders, and carbohydrate disorders.

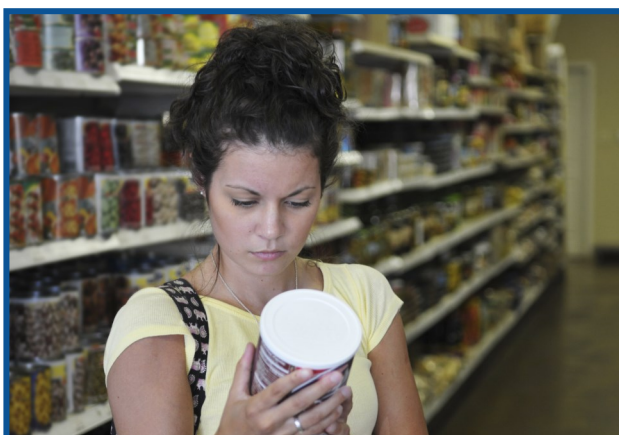
Special foods are required to treat inborn errors of metabolism in order to avoid long-term complications which can result in mental impairment, seizures, coma or death. The clinical symptoms in many of these disorders can be prevented if diagnosis is made early and necessary treatment is started immediately.

Treatment involves the exclusion of the offending substance and supplementation of nutrients. For some conditions this requires purchase of specially-manufactured formula. The medical formula is required for life. The safety and effectiveness of oral medical formula for individuals with inborn errors of metabolism have been established.

Unfortunately, despite the medical need, this formula is not always covered by health insurance. Blue Cross Blue Shield of Michigan published recently that oral medical formula is considered a covered benefit when specific policy criteria are met as described below*:

Inclusions: Oral medical formula for individuals of any age, is considered established when all of the following are met:

- The individual has a diagnosis of an inborn error of metabolism



- The oral medical formula is labeled and used for nutritional management of an IEM that interferes with the metabolism of specific nutrients (for example, phenylketonuria, homocystinuria, maple syrup urine disease)
- The oral medical formula nutrition is ordered by a clinical or medical biochemical geneticist or by other qualified medical professionals in consultation with a clinical or medical biochemical geneticist

Exclusions:

- Formula for any condition other than an inborn error of metabolism (for example, diabetes, hypercholesterolemia)
- Formula that does not require a physician order for purchase
- Formula not specifically used for the nutrition of an individual with IEM
- Medical food product that is not *formula* (for example, food modified to be low in protein, such as meat or cheese substitutes, or pasta)
- Nutrition by tube feeding (refer to the Enteral Nutrition policy for guidelines)

*This policy went into effect Jan 1, 2019. Must use an appropriate contracted vendor. For more information please see the following:

https://www.bcbsm.com/content/dam/microsites/corpcomm/provider/the_record/2019/jun/Record_all_articles.shtml

ANNUAL FAMILY STORIES EDITION— CALL FOR STORIES

Every year Michigan Family Connections features an edition of Family Stories. We would like to ask our readers to share a bit about their family and some of the joys and challenges of raising their child. Stories are accepted on a range of topics and can include any perspective, including, but not limited to: parent, child, sibling, friend, even grandparent or other extended family. We will be accepting story submissions until **January 15th**.

We will review all submissions and choose five to feature in the next newsletter. The authors of the stories featured in the newsletter will receive a \$50 Visa gift card. All stories submitted will be shared on the MI Family to Family website.

All work must be original and previously unpublished to be considered. Stories should be no more than 750 words in length and are subject to editing before publishing. You are welcome to submit pieces other than stories, such as poems or songs you've written. Get creative and share your story using the link below:

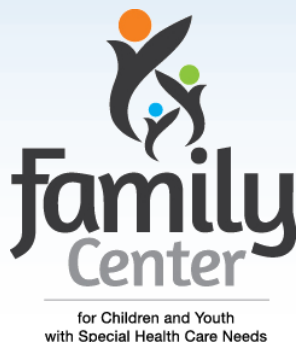
<https://f2fmichigan.org/family-stories/submit-your-story/>



Michigan Family to Family Health Information Center (MI F2F) is a federally funded project. They share information and resources on disability and health issues with families of children and youth with special health care needs. MI F2F also works with health and other professionals. MI F2F helps families make educated decisions and supports families to partner with professionals. They work to make services for children and youth with special health care needs better.



www.f2fmichigan.org



The Family Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). The primary role of the Family Center is to offer emotional support, information and connections to community-based resources to families of children and youth with special health care needs, including all children who have, or are at an increased risk for: physical, developmental, behavioral or emotional conditions.

Family Phone Line 800-359-3722

Disclaimer: The Family Connections newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by the Family Center for Children and Youth with Special Health Care Needs, Michigan Family to Family Health Information Center, or our funders. The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is funded by Health Resources Services Administration Maternal and Child Health Bureau under Grant H84MC26214. The information or content and conclusions of the author should not be construed as the official policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. Furthermore, the information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. Please direct any questions through the Family Phone Line or MI F2F website listed above.