

# Michigan Family Connections

*for Families of Children and Youth with Special Health Care Needs*

**Spring 2016**

*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.**

## Make Water Safety a Priority!

Warmer weather in Michigan often means time to hit the water! June is National Safety Month and it is important to remember that safety is no accident. The importance of safety around water cannot be overstated. Water safety is a part of daily life no matter where you live. Drowning is the second leading cause of unintentional death in children ages 1 to 14 (*Injury Facts*, 2016)

To protect your children:

- Be attentive when your children are near water. Never let children near or in water alone. Designate an adult (or two) to be a “water-watcher” and actively supervise children who are swimming. Drowning can happen silently, in seconds, and in just an inch of water.
- Install a 5 foot tall fence with self-closing latches around your pool or hot tub. Consider door alarms for any door leading to a pool or hot tub.
- Get a good life jacket. Traditional pool floats, like water wings, inner tubes and pool noodles, aren’t designed to keep kids safe. Use a life jacket approved by the Coast Guard to be safer.
- Know what to do in an emergency. Make sure you and anyone who cares for children are trained in CPR, so you’ll be ready if there is a need.

Follow these safety tips:

- Make sure your child knows the basics. Everyone should learn how to float and tread water, and how to figure out how deep the water is. Sign children up for formal lessons if possible.

- Teach kids the differences between swimming in a pool and swimming in open water. Pools or areas specifically set up for swimming are best for young swimmers. Open water like lakes, creeks and other bodies of water can have varying depths, larger waves and strong currents that can make swimming more difficult.
- Keep children out of a hot tub or spa until they can stand on the bottom with their heads above water. They should also limit time in the tub or spa to 5 minutes at a time, especially at the maximum temperature of 104 degrees.
- Follow pool rules. Teach children to get in pool feet first. Stop horseplay around the pool and don’t let kids eat, drink or chew gum in the pool.
- Empty all buckets, bathtubs and kiddie pools of water immediately after use and store upside down and out of children’s reach.

For helpful pool and water safety videos go to <https://www.youtube.com/watch?v=RhU6-2b6nC8&feature=youtu.be>



# Have You Heard About Michigan *BioTrust* for Health?



## We Want You to Learn More!

Soon after birth a few drops of blood are collected from nearly every baby's heel for newborn screening. These blood spots are tested to find rare disorders that must be treated. All of the blood spots are not always needed for newborn screening. The *BioTrust* is a program run by the Michigan Department of Health and Human Services (MDHHS) to oversee storage and possible research use of left-over newborn screening blood spots.

Several groups advise MDHHS on the research use of blood spots. A Community Values Advisory Board gives input on how best to inform new parents and reach all communities. A Scientific Advisory Board provides input on how best to store blood spots, and members review research requests for blood spots to ensure scientific merit. The MDHHS Institutional Review Board (IRB) reviews each study to ensure the rights of human subjects are protected.

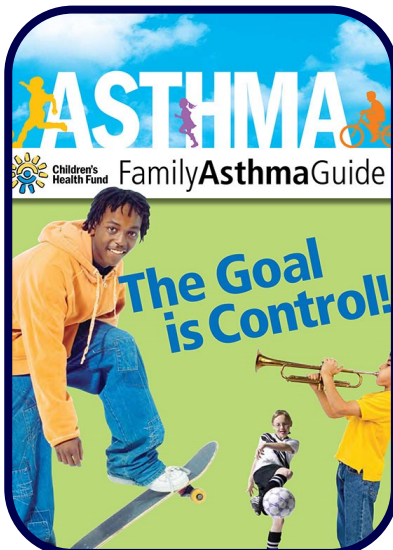
We want people to know about the *BioTrust* and have the chance to make a choice about blood spots. Since May 2010 parents sign a form collected after delivery to let MDHHS know if their baby's blood spots can be used in health research. Blood spots collected prior to this date, going back to July 1984, have also been stored. These older stored spots may be used for research unless a parent or young adult over the age of 18 opts-out by contacting MDHHS.



Today, over 2 million blood spots have been **coded** (names removed) and sent to the Michigan Neonatal Biobank ([www.mnbb.org](http://www.mnbb.org)), for better storage. MDHHS must approve the use of these **coded** blood spots in health research. Approved studies have:

- Helped to develop new and better newborn screening tests
- Tested mercury levels in blood to find out if pregnant mothers are eating safe amounts of fish
- Looked for genetic changes contributing to heart defects, childhood cancers and other birth defects

Please read more about the *BioTrust* including your options by visiting [www.michigan.gov/biotrust](http://www.michigan.gov/biotrust) or calling toll free 1-866-673-9939.



## Family Asthma Guide

Available from the Children's Health Fund, this child-friendly, colorful guide explains what asthma is, what triggers it, and how an asthma management plan can help. Proper asthma management means your child can do more of the things kids love—like sports, music, and playing outside. It's also important to your child's education.

Asthma causes more than 10 million school absences per year, according to the federal government. Children's Health Fund has identified poorly-controlled asthma as one of several key barriers to learning in our Healthy and Ready to Learn Initiative. The Children's Health Fund Family Asthma Guide is made possible by a grant from American Idol's "Idol Gives Back."

[Family Asthma Guide \(English\)](#) or [Guía Familiar sobre el Asma \(Spanish\)](#)

# Well Visit Planner Available



How many times have you walked out of your child's well-child visit thinking, "Gee, I wish I'd remembered to ask about . . ."? Or, "My child's health care provider spent a long time talking to me about topics on his list, but what I really wish we'd had time to talk about was . . ."?

Health care providers typically only have 15 to 20 minutes to spend on a well-visit. Now a new online tool can help you identify the topics about child health and development that are most important to you: the Well Visit Planner.

The Well Visit Planner is an online tool to help families prepare for their children's upcoming well-child visits to the health care provider. It's free to use; is available in English and Spanish; takes 10-15 minutes to fill out before each visit; and can be printed and taken to a visit to help you and your child's doctor discuss your child. It helps families be better partners in their child's health care, and helps health care providers better serve the needs of the child and the family.

To use the Well Visit Planner in English or Spanish, go to: [www.WellVisitPlanner.org](http://www.WellVisitPlanner.org).

By sharing the Well Visit Planner Visit Guide with your child's doctor you give him or her valuable information about what your child is doing and other information that might affect your child's health and well-being. And you can help drive the conversation to those topics that have the most meaning to you at this point in your child's development.

## Parent Mentor Training Opportunity

The Family Center for Children and Youth with Special Health Care Needs is hosting several Parent Mentor Trainings across Michigan this summer.

Remember when your child was newly diagnosed? Would it have helped to have someone to talk with who has "been there"? Are you interested in supporting other parents?

In our free, interactive Parent Mentor Training, learn from a fellow parent about:

- parent-to-parent support
- communication skills
- listening techniques
- community resources

All participants will receive a \$25 gift card, a Family Center notebook and Medical Care binder.

If you are a parent, caregiver, or guardian of a child/youth with special health care needs and would like to make a difference in the lives of others, please join us for a free opportunity to become a trained Parent Mentor. This training is open to all families who have a child with a medical, physical, developmental, behavioral, or emotional condition.

Please use the following links to register:

**Alpena, MI, Friday, June 24, 2016**

<https://www.eventbrite.com/e/alpena-parent-mentor-training-june-24-2016-tickets-25678267389>

**Harbor Springs, MI, Saturday, June 25, 2016**

<https://www.eventbrite.com/e/emmett-parent-mentor-training-june-25-2016-tickets-25680701670>

Please register by June 17, 2016. Space is limited!



# A Family Perspective on Transition

Submitted by Suzanne Eidson

**TRANSITION:** a movement, development, or evolution from one form, stage, or style to another. Everyone encounters many transitions in life. But, for parents and children with special healthcare needs, the process of medical transition can have far-reaching impact. Transitioning a teen with a chronic health issue into an independently functioning adult takes time and teamwork. Remember, transition is a process, not an event.

As the mom of a congenital heart young adult, I have not only had to help him grow up but also take care of his medical needs as well. As our children grow, they really want to be as normal as they can and do all the things their peers do. We have had to think about issues other parents don't. The medical community ideally looks to begin the process of transitioning around age 14. For parents who have taken care of every aspect of your child's care since birth, thinking about and beginning this process is not easy. So here are some initial steps you can take to help you child become their own health advocate.

Around age 14 or when they are able to understand:

- Help them be able to name their diagnosis and give a brief description.
- Teach them the medications they take, what they are for and side effects to look for.
- Know any allergies they have.
- Know their emergency contacts, primary doctors and the phone numbers.

When teens are in high school, start to drive and begin spending more time away from you, a cell phone which keeps their medical file available and emergency contacts is a good idea. But, making sure they are a member of Medic Alert or comparable medical emergency system is also important.

As your child journeys through the transition years, here are some additional steps you can take to foster



independence in adulthood:

- Help your child know the basics of their medical history and develop a Medical Passport.
- Work together to set school, activity, work and social boundaries.
- Have discussions about drugs, alcohol and sexual activity and the impact of these with their medical condition.
- Talk about the future and what their goals are for school, career, family, etc.
- Develop a Medical Advanced Directive and Medical Power of Attorney for your young adult when they turn 18.
- Develop open communication about medical insurance, Social Security Disability and options.
- Lastly, always stress the importance of the continuity of care. As independent adults, they need to care for themselves as much, or more, than you have for all those years.

Most of all, make sure your child knows when to ask for help. By starting early and progressing as they are able, transition can be a positive and productive time.

Being an independent adult with a chronic illness doesn't mean your child doesn't need you- it means as they transition, so does your role as a parent. And I can tell you from experience, that role is just as rewarding, challenging and joyous as all the others I have had.



**“The greatest glory in living lies not in never falling but in rising every time we fall.”**

**-Nelson Mandela**

# Parent Leadership Training Offered

The Parent Leadership in State Government initiative is offering *Parents Partnering for Change* leadership training to Michigan parents this summer. This training was created for parents who are interested in using their voice to help shape services and supports for all families across the state. The goal of this training is to provide new knowledge and skills to inspire and motivate parents to get involved.

Parents (biological, adoptive, foster and kinship) of a child(ren) ages birth to 18 who have utilized specialty public services in Michigan are eligible to attend the training at no cost to them.

The training is two days in length and participants must attend both days. Parents receive mileage and childcare reimbursement, a stipend (\$200), and meals during the training.

At the training, parents learn how to be leaders and active participants. Training topics include:

- Understanding communication styles
- How an advisory board works
- Making meetings effective
- Conflict management

Once they complete the training, parents are encouraged and supported to get involved in their community.



Training dates, locations and registration links are below:

**Mt. Pleasant/Isabella County** June 21 & 22, 2016  
<https://mph.wufoo.com/forms/zcceotr0xn4k9q/>

**Sault Ste. Marie** July 19 & 20, 2016  
<https://mph.wufoo.com/forms/zw5fw2f1syropoc/>

**City of Flint** July 26 & 27, 2016  
<https://mph.wufoo.com/forms/zbsewi80e9nqr0/>

## ACA News—Special Enrollment

Open Enrollment for a 2016 health plan is over. For most people, the last day to enroll in a health plan for 2016 was January 31st, 2016. But did you know that there are some cases that you may still be able to get coverage this year? Here are two ways to still get coverage for 2016:

- With a Special Enrollment period. If you experience a life change—like getting married, having a baby or losing coverage—that qualifies you for a Special Enrollment period. You may be able to enroll in a Marketplace plan outside of Open Enrollment.
- Through Medicaid or MiChild. You can apply for free or low-cost coverage through Medicaid or MiChild at any time, all year. If you qualify, you can enroll now.

For more information visit:

<https://www.healthcare.gov/coverage-outside-open-enrollment/your-options/>



# MI Family Support Subsidy Program

Michigan has a program to help families caring for a child with severe disabilities at home. The Family Support Subsidy Program can pay for special expenses the family has caring for their child. Supporting families of children with severe disabilities allows families to stay together.

Families may be eligible for this program if they have a child under age 18 who has been identified by Michigan's public school system as having an educational category of:

- Cognitive Impairment (CI)\*
- Severe Multiple Impairment (SXI)
- Autism Spectrum Disorder (ASD)\*\*

\*Children with eligibility category of CI may be eligible if their development is in the severe range of functioning as determined by the public school system.

\*\*Children with ASD must be receiving special education services in a program designed for students with autism or in a program designed for students with severe cognitive impairment or severe multiple impairments.

If the child is not receiving special education services or if it is not known if the child is receiving special education services, parents may contact the director of special education at the local or intermediate school district. They can also call Early On at 800-Early-On.

Families can be birth parents, adoptive parents, or legal guardians. Foster parents who are also legal are not eligible.

Under the law, the Michigan taxable income for the

family may not exceed \$60,000. In addition, the family cannot receive reimbursement from the Medical Subsidy Program for Adoptive Children if they choose to apply for the Family Support Subsidy.



## How to Apply:

You can apply for the subsidy program at your local Community Mental Health (CMH) office. Your local CMH determines eligibility for this program.

If you cannot find the number, call the Family Support Subsidy office in Lansing at 517-241-5774. The TTY number is 711.

You may apply at any time. You must renew yearly before or during your child's birth month.

The following papers must be turned in with your application:

- A copy of the child's legal birth certificate
- Your family's most recently filed Michigan Income Tax Return (MI-1040)

Providing a copy of the child's social security card is encouraged but not mandated. In addition, you must contact your child's school and request that they send or fax directly to the CMHSP written proof that certifies the child's educational eligibility category and programming if the classification is ASD.

**“Let us not be surprised when we have to face difficulties. When the wind blows hard on a tree, the roots stretch and grow the stronger.**

**Let it be so with us.”**

**- Amy Carmichael**



# Looking For Summer Reading?

Summer is near and that may mean some time to do some reading. Are you looking for a book to take to the pool or while traveling in the upcoming months? Did you know that Michigan Family to Family Website has a book list on our website to help you find something new to read?

Browse through the list to find books on all different topics, from Attention Deficit Disorder to Traumatic Brain Injury. We also have a list of fiction books. Whether your ready to load up your Kindle or hit the public library, check out our list for some great reading ideas.

Do you have a recommendation of a book you've read? Please use the contact form on our website to share with us and we will add it to the list.

To find the book list and other great resources, visit:

<https://f2fmichigan.org/news/>



Michigan Family to Family Health Information Center (MI F2F) is part of 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.

For more information and helpful resources, look for them on Facebook or go to their website at:



[www.f2fmichigan.org](http://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.

Children do not have to be enrolled in CSHCS to receive services from the Family Center.

**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.

If you have something you would like to share in a future newsletter, please contact us for information on how to submit articles, events, etc. We welcome contributions from families, caregivers, youth, healthcare and other professionals, as well as agencies and organizations. Thank you.