

# Michigan Family Connections

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

**Fall 2015**

*Connecting families of children and youth with special health care needs, and the professionals who help them, with information and news they can use!*

## Conference Scholarships Available

Caring for a child with special health care needs can be a learning experience. In order to give our kids the best possible care, we need to have relevant and current information. We often get the most helpful tips from other parents/professionals who have similar experiences or are on the same journey.

The Family Center for Children and Youth with Special Health Care Needs has been granted privately-supported funds from Dr. James T. Pardee, a Dow Chemical Company founder, and his wife through the Children's with Special Needs Fund (CSN Fund). The CSN Fund supports services and projects for children with special health care needs that are not provided by state or federal funds. This includes allowing a parent and/or youth (14 -21 years) to attend conferences related to caring for their child with special needs.



Families who reside in Michigan are welcome to apply for a scholarship to help cover expenses for one parent and/or one youth (14 -21 years) to attend a conference related to their child's special health care need, diagnosis, condition or treatment. We must receive your application at least 45 days before the start of the conference. Please contact the Family Phone Line at 1-800-359-3722 for more information or to receive a conference scholarship application.

## Catalyst Center Seeking Families

The Catalyst Center is recruiting participants for a research study about inequities in coverage and financing of care for children with special health care needs (CSHCN).

They are currently recruiting parents and/or

caregivers of CSHCN who represent families of color, immigrants and families from diverse cultural backgrounds, those who speak a language other than English, and those with low income.

This project will use telephone interviews to explore the barriers that these families face and services and supports that may help address these barriers. The time commitment for families is about 30-60 minutes for the telephone interview.



For more information <http://www.hdwg.org/catalyst/family-perspective-inequities>

*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.*

# MI F2F Website Events Calendar



Is your group or organization sponsoring an event in Michigan for families of children or youth with special health care needs? Are you looking for a way to help spread the word about your event? Are you interested in connecting with other families and aren't sure where to go?

The MI Family to Family website now offers an event calendar. Whether you are looking to attend a training, support group or social event, or you want to publicize one, the new event calendar is a great way to connect.

To share information about an upcoming event just use the link to our event form on the website.

<https://f2fmichigan.org/upcoming-events/>

## November is Epilepsy Awareness Month

November is Epilepsy Awareness Month. If you're looking for information about epilepsy, the Education Specialists at the Epilepsy Foundation of Michigan can help. Calling their toll-free phone number, setting up an appointment at their Southfield office, or sending them an email, are all ways you can learn more about this complex condition.

Their Education Specialists will spend as much time as needed to answer your questions. When appropriate, educational materials and referrals to other resources will supplement the information provided during the consultation.

Frequently discussed topics include:

- Diagnosis & Treatment
- Seizure and epilepsy types
- Epilepsy self-management
- Seizure First Aid
- Healthcare costs
- Finding and working with a doctor
- Financial issues
- School issues

For individualized education and consultant services call:  
800-377-6226 or visit

[www.epilepsymichigan.org](http://www.epilepsymichigan.org)



## Michigan 211: Get Connected, Get Answers



### Simply call 2-1-1

If calling from outside Michigan or if you have any difficulty reaching 2-1-1, call 844-875-9211

[www.mi211.org](http://www.mi211.org)

Whether you are looking for medical help, shelter or utility assistance, foreclosure assistance programs, help with food or clothing, or any other challenge facing your family, a call to Michigan 2-1-1 may provide the answers you are looking for.

Simply call 2-1-1 (it's free) and you will reach a contact specialist day or night, 24/7. These certified professional specialists are well trained and focused on serving you in a confidential and compassionate manner.

Each contact center is connected to powerful data bases that provide access to 7,500 agencies offering 29,500 programs and services in 180 languages. There are also links to local, state and federal databases.

You can call 2-1-1, or search those databases on your own by going to the 2-1-1 website.

(Translation services are also available for limited or non-English speaking callers – usually within a minute.)

# Founding "Grayson's Gift" Project

When my son was born hard of hearing it was a huge concern for us what was available for him safety-wise. After finding bed shaker and strobe alarm detectors it was astounding to us what they cost. While we could afford specialty units for my son it worried me of who in my community could not.

I started toying around with the idea of a program that could provide specialty detectors for deaf, hard of hearing and the cognitively impaired children and residence in my area. After some hard work, some research and putting my idea to paper I approached a fire department with the game plan I had come up with. THEY LOVED IT! That's when Grayson's Gift was formed.

We assembled a small board and got to work right away. I'm proud to say in one year time we have raised over \$20,000.00 and are hosting our first training session in November and will then start installing the first 85 units we purchased to go to the children in Roscommon County.

When installing each specialty unit (strobe and bed shaker smoke and carbon monoxide detector) we also ensure each home is properly supplied with safety

Submitted by Kristen Carmany



equipment. We check that homes are up to code with the amount of standard smoke detectors. We provide them if they are in need or if they are nonworking. We also change batteries and provide a standard carbon monoxide detector as well with each specialty unit.

For more information please contact Kristen Carmany at [klcarmany@gmail.com](mailto:klcarmany@gmail.com) or find us on Facebook by clicking the icon.



## Are YOU Prepared For Winter Emergencies?

Emergency preparedness and planning is essential for all members of the community, but especially individuals with a disability or healthcare need.

Taking an active role in emergency preparedness will bring peace of mind for you and your loved ones in the event of an unexpected emergency, such as a winter storm.



Michigan residents are no strangers to winter storms. A big concern is winter weather's ability to knock out heat, power and communications services to your home, sometimes for days at a time.

If your family member relies on electricity for medical equipment or refrigeration for medications, have a generator or a back-up plan. If you require frequent trips to the doctor or hospital or might need an ambulance, make sure there is a pathway cleared for vehicles.

Create an emergency plan and a network of those who can help you. Share the plan with anyone who has a role in the plan.

Alert Emergency Services ahead of time if you might require immediate assistance during an emergency. Some agencies keep a list of individuals who require special help.

Make a 72 hour emergency kit in case you are unable to leave your home. Include non-perishable food items, water and all medications. Include options for light and warmth in case utility services are disrupted.

Never use a stove or grill to provide heat indoors. Dangerous fumes can build up quickly. It is good to ensure you have a carbon monoxide alarm in your home as well.

Keep flashlights and fresh batteries on hand to avoid the use of candles for light as this increases risk of accidental fires.

**The Michigan Prepares Emergency Plan App** is a free, easy-to-use tool that can help you and your family create a basic emergency plan in a few quick steps. Get the app at: <http://www.michigan.gov/michiganprepares/0,4621,7-232-69437---,00.html>



## Birth to Age Three

It is important to address a child's developmental delays as early as possible. Early On Michigan offers early intervention services for infants and toddlers (birth to 3 years) with developmental delay(s) and/or disabilities. Families get services at no cost to them.

Research has shown that addressing delays early (between birth and age 3) can impact a child's development, even into adulthood. Don't worry. But don't wait.

If you think your infant or toddler may have a developmental delay, contact Early On at 1-800-Early-On or complete their online referral form.



[https://1800earlyon.org/online\\_referral.php](https://1800earlyon.org/online_referral.php)

## Transition Resources

Are you a young adult looking for information on health care? Whether you need insurance or aren't sure how the Affordable Care Act impacts you, the Healthy Young America website has all the information you need and can deliver it straight to your inbox.

Their "Find a Doctor" section helps you find both free and paid healthcare options. The "Healthcare FAQs" section helps answer questions about topics like your healthcare options, student health insurance and the new healthcare law.



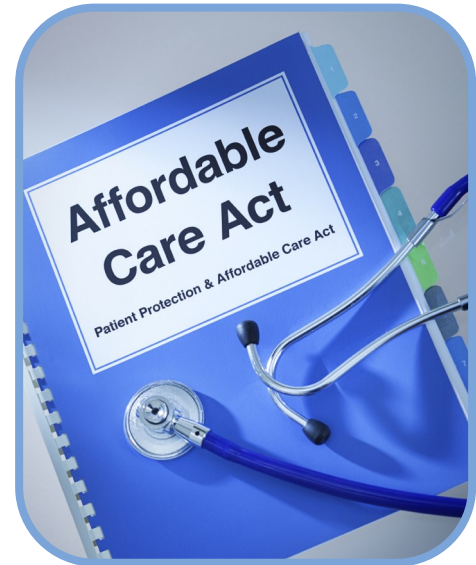
They even have a mobile app to help you discover your healthcare options and find local healthcare services. The app is available for both Android and iPhone users.

For more information visit their website at:  
<http://health.younginvincibles.org/>

## ACA Updates - Open Enrollment Started 11/1

The Affordable Care Act (ACA) helped make affordable coverage available to people who didn't have health insurance. Some states allowed individuals to enroll in Medicaid who weren't eligible before.

The ACA also offers tax credits for people who purchase coverage through the Marketplace. Millions of people have gained coverage because of these options, however millions still remain uninsured.



In a recent news release, the Kaiser Family Foundation shared the results of a new analysis\* that showed that nearly half of the country's uninsured, or 15.7 million people, are eligible for Medicaid or subsidized coverage.

This means there are still many families and individuals who need to be reached during the third ACA open enrollment period, which started **November 1st, 2015**. If you do not have coverage and need information on enrollment, help is available.

You can visit [www.enrollamerica.org](http://www.enrollamerica.org) to use their new web tool called the "Get Covered Plan Explorer". This tool gives a personalized estimate of health care costs and helps determine if prescriptions and preferred doctors are covered under available plans.

They also offer a "Get Covered Calculator" which estimates monthly premiums and expected tax credits, and the "Get Covered Connector" which helps schedule appointments online for in-person assistance and get text and email reminders.

To apply for Michigan Medicaid visit:  
[www.michigan.gov/mibridges](http://www.michigan.gov/mibridges)

To enroll in coverage thru the Marketplace visit:  
[www.healthcare.gov](http://www.healthcare.gov)

\*[Click here](#) to read the Kaiser Family Foundation analysis

# Caregivers - Your Mental Health Matters!

November is National Family Caregivers Month. It is a time to recognize the extraordinary task many face being the primary caregiver for a loved one with special health care needs. With many demands associated with being a caregiver, it can be difficult to remember to take care of yourself. Not only is it important to tend to your physical health, you need to remember that your mental health matters as well.

Respite, or taking a planned break away from caregiving, is one way to recharge and reenergize yourself. While some may not view this as necessary, it can be an important piece of caring for your own mental well-being. There are formal programs that provide respite with trained caregivers providing care in or out of your home. Unfortunately, this option is not available to everyone.

However, respite does not have to be provided as part of a formal program to be helpful. Having a trusted friend or family member step in for a few hours or a day can be all that is needed to give you the break you need. Sometimes it is difficult to let someone else take over for awhile, but it can be an extremely important part of caregiver self-care. Take a walk, read a book, or even enjoy a cup of coffee with an old friend. Chances are you will come back feeling better with more energy to face your everyday tasks.

For 10 Tips for Family Caregivers go to <http://caregiveraction.org/resources/10-tips-family-caregivers>



Michigan Family to Family Health Information Center (MI F2F) is part of a federally funded project.

We share information and resources on disability and health

issues with families of children and youth with special health care needs. We also work with health and other professionals.

MI F2F helps families make educated decisions and supports families to partner with professionals. We work to make services for children and youth with special health care needs better.

For more information and helpful resources, look for us on Facebook or go to our 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.