

# Michigan Family Connections Newsletter

SPRING 2021

## THE STORY OF CAROLINE'S CART

Chances are if you have shopped at your local Kroger, Target and other grocery stores, you have seen a Caroline's Cart. Caroline's Cart is a shopping cart created for children with special needs. It provides parents and caregivers a viable option to transport a child through a store while grocery shopping, without having the impossible task of having to maneuver a wheelchair and a traditional grocery cart at the same time. It is named after Caroline, the daughter of Drew Ann and David Long.

Drew Ann Long saw the need for Caroline's Cart after realizing her daughter would outgrow a typical shopping cart. Knowing what was needed, she founded Parent Solution Group, LLC, designed the cart, applied for a patent, and enlisted the services of legal and business professionals to help her bring the cart to market.

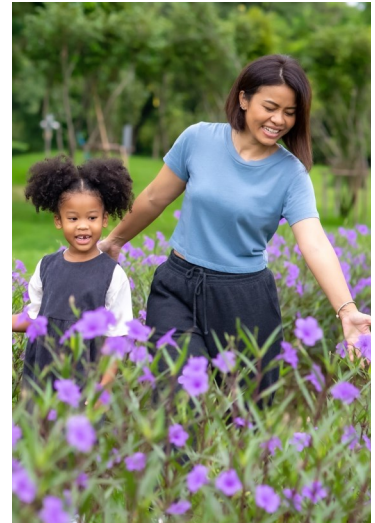
Her mission was to make Caroline's Cart available to retailers everywhere, providing a quality product for children with special needs that further enables their participation in mainstream society with their family through the common activity of grocery shopping.

Caroline's Cart has now become a reality. Retailers such as supermarkets, hypermarkets, shopping centers, and malls offering Caroline's Carts provide a valuable service to the families of over one million children with disabilities in the United States.

Drew Ann's hope is that one day all retailers will provide an equal opportunity shopping experience for parents and caregivers of children with special needs by furnishing them the option of a Caroline's Cart. All families deserve to enjoy the freedom of shopping with their child.

To find a store near you with a Caroline's Cart, visit:

<https://technibilt.com/carolines-cart/find-a-store/>



*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 virtual 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



## SPECIAL OPEN ENROLLMENT PERIOD ON MARKETPLACE

More people than ever before will qualify for help paying for health coverage, even those who weren't eligible in the past. There's a new special enrollment period for the COVID-19 public health emergency. You can enroll in or change Marketplace health insurance plans through August 15, 2021.

There are many ways to get covered, and there is no wrong way to begin. A Health Insurance Marketplace special enrollment period will be open February 15 to August 15, 2021 for anyone who needs to purchase a 2021 health plan.

After that deadline, you may qualify for a special enrollment period if you experience a qualifying life event, such as a job loss or change in household size.

The American Rescue Plan, recently signed into law by President Joe Biden, increases and expands Marketplace subsidies to help you afford health coverage. In some cases, these



subsidies could provide cost-free coverage for the whole year. Learn more and take advantage of these increased savings that began on April 1. The sooner you sign up, the more you can save on the health coverage you need for yourself and your family.

<https://www.healthcare.gov/>

If you need help, you can locate an agent, broker or assister near you. Locate help in your zip code here. <https://localhelp.healthcare.gov/#/>

## GEORGIA TECH CIDI'S ASSESSIBLE COVID-19 RESOURCES

The impact of COVID-19 has been felt across the globe—changing the way people work and live. Public health messages about ways to mitigate the spread of the virus continue to be a key tool. The Centers for Disease Control and Prevention (CDC) works to make essential health information and resources accessible to as wide an audience as possible, including people with disabilities.

The Center for Inclusive Design and Innovation at Georgia Tech is dedicated to improving the human condition through equal access to technology-based and research-driven information, services, and products for individuals with disabilities.

They have been working on a project to increase access to information about COVID-19 for individuals with disabilities. This project was made possible with funding from the CDC Foundation.

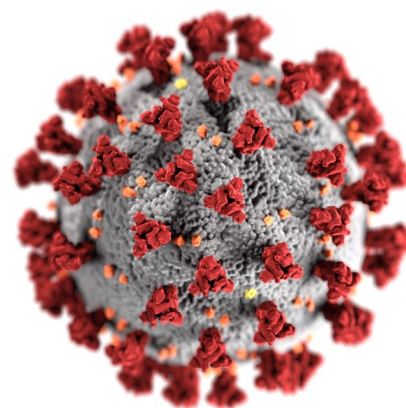
They offer a wide variety of resources that have been adapted from the Center for Disease Control's

COVID-19 guidance, including resources available in braille, documents that are compatible with screen readers and other assistive technology, American Sign Language resources, and simplified text.

They also offer several videos created to help increase knowledge about wearing a mask properly and how to safely socially distance.

To utilize these resources and more, visit the CIDI's Accessible COVID-19 resource page at:

<https://cidi.gatech.edu/covid>



## NEW BRIEF EXAMINES CYSHCN IN FOSTER CARE

Child Trends has recently released a brief that examines the prevalence of children and youth with special health care needs (CYSHCN) in the foster care system. The brief provides an overview of the literature on CYSHCN and their experiences in the foster care system, a detailed explanation of the methodology used for the current brief, an explanation of our findings, and a brief discussion of practice and policy implications.

Their findings suggest that children and youth's reasons for entering foster care, their experiences while in care, and their reasons for leaving care vary depending on whether they have a special health care need.

For their analysis, they utilized the Adoption and Foster Care Analysis and Reporting System (AFCARS) Foster Care File, which provides data on the characteristics and foster care experiences of children and youth who have spent at least one day in foster care during a given fiscal year.

Key findings include:

- Children and youth with special healthcare needs (CYSHCN) comprise at least 24 percent of the foster care population and may require unique services and resources during their time in foster care.



CYSHCN in foster care are more likely to:

- Have experienced an adoption disruption
- Have more than one removal episode
- Experience greater placement instability
- Spend significantly more time in care

In addition, CYSHCN are *less* likely to achieve permanency (i.e., reunification with their family, adoption, guardianship, or living with a relative).

To download a copy of the brief, visit:

[https://www.childtrends.org/publications/children-youth-special-health-care-needs-foster-care?utm\\_source=newsletter&utm\\_medium=email&utm\\_content=Read%20the%20brief&utm\\_campaign=2020.12.17\\_CSHCN\\_Network\\_Newsletter](https://www.childtrends.org/publications/children-youth-special-health-care-needs-foster-care?utm_source=newsletter&utm_medium=email&utm_content=Read%20the%20brief&utm_campaign=2020.12.17_CSHCN_Network_Newsletter)

## FAMILY CENTER OFFERING PARENT CONNECT CALLS

The Family Center for Children and Youth with Special Health Care Needs recognizes how difficult this past year has been for families who have children with special health care needs.

We have been working hard to create new virtual opportunities for families to support you all through these challenging times.

To meet this need, the Family Center is hosting virtual Parent Connect Calls webinars for support and education. These calls will include a short presentation and time for parents to share their own tips or ideas. Parent Connect Calls will be held once a month for an hour long.

Upcoming Parent Connect Call:

**July 14, 2021 at 4:00 pm**— Disability Rights Michigan (DRM)—Mark Williams of DRM will share how advocates and lawyers of DRM advise individuals with disabilities of their rights and responsibilities and advocate for their human, civil and legal rights within the state of Michigan.

[Parent Connect Call Tickets, Wed, Jul 14, 2021 at 4:00 PM | Eventbrite](#)

Click the link above to register or contact the Family Center at 800-359-3722 for more information.





## RESOURCE FOR FAMILIES WITH A NEW DIAGNOSIS

The Midwest Genetics Network has a helpful resource for families called “The Journey Through Diagnosis”. The purpose of the guide is to provide information and support to families whose child has been identified with a genetic condition.

This guide is written from the family perspective and includes information families felt was important when facing a new diagnosis. The material includes advice and tips to help “guide” families on their journey.

The guide was written with the input of multiple families who have a child (or children) with a genetic condition. Some of those families learned of their child’s diagnosis prenatally, some through newborn screening, while others waited months or even years. They share what they have learned and want to pass on to others from their experience.

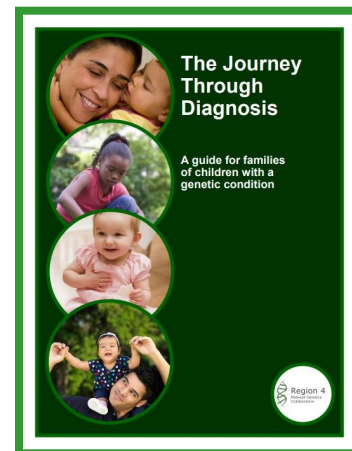
This guide is intended to empower families. It may not answer all your questions, but it can get you started. There is no right or wrong way to use the

information. You can read cover to cover, or just the parts of interest.

There’s a lot of information, and some of it may not apply to you in the moment.

You can come back and revisit chapters as needed. The families who created this guide hope you find it useful, making the “journey through diagnosis” a little easier.

To download a copy of the guide, and other great resources from the Midwest Genetics Network visit: <https://midwestgenetics.org/resources/for-families/>



## INFORMATION AND FUN FROM THE SMITHSONIAN

The Smithsonian Institution is the world’s largest museum, education, and research complex, with 19 museums and the National Zoo—shaping the future by preserving our heritage, discovering new knowledge, and sharing our resources with the world.

Unfortunately, as a public health precaution due to COVID-19, all Smithsonian museums and the National Zoo are temporarily closed to the public.

The Smithsonian shares their extraordinary collections and research with learners of all ages and educators everywhere. All facets of the Smithsonian—19 museums, 14 education and research centers and the National Zoo—are committed to reaching communities near and far by offering free access and activities on their website for kids and teens.

There are many different engaging activities available on a variety of topics including

science, nature, art, history and culture. You can also virtually tour their many fascinating collections.

Whether it is superheroes, Star Wars, minerals and gems, the Smithsonian Institution offerings can delight and inform your child for hours on end. Another fun option is to take a virtual visit of the National Zoo by watching live webcams.

Please visit the Smithsonian Institution website for more information: <https://www.si.edu/kids>



## COVID-19 PROGRAM FOR UNINSURED INDIVIDUALS

The United States Department of Health and Human Services has information available on their website for people who are impacted by COVID-19 and who do not have health insurance. This page helps uninsured individuals find no-cost COVID-19 testing, treatment, and vaccines.

If you are uninsured or undocumented, talk to your provider to see if they will agree to bill the HRSA Uninsured program for COVID-19 services so you do not have to pay any costs.

Everyone is eligible for COVID-19 services, no matter their immigration status. Testing, treatment or vaccinations paid for by the federal government will not affect anyone's immigration status or be shared with immigration agencies.

You do not need a Social Security Number or government ID to receive free COVID-19 services. The doctor, pharmacy, or clinic may ask for this information but it is only to help them confirm you don't have insurance so they can get paid by the Uninsured Program. You will still be treated, tested, or vaccinated for COVID-19 if you are not able to provide a Social Security Number or government ID.

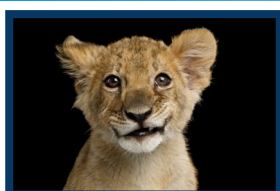
Before your appointment, call your doctor's office and tell them you do not have insurance. You will need to confirm that the provider you will be seeing is willing to participate in the HRSA Uninsured program and bill the federal government, not you.

Some of the services that may be covered include:

- COVID-19 testing (both diagnostic and antibody)
- Testing-related in-person or telehealth visits
- Treatment-related visits at an office, via telehealth, in an emergency room, for inpatient or outpatient/observation, at a skilled nursing facility, or for long-term acute care (LTAC), rehabilitation care, and home health
- Use of medical equipment (e.g. oxygen, ventilator, etc.)
- Ambulance for emergency transportation and non-emergent transfers
- COVID-19 vaccination fees

For more information, use the following link:

<https://www.hhs.gov/coronavirus/covid-19-care-uninsured-individuals/index.html#patients-no-health-ins>



*Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says "I'll try again tomorrow".*

*Mary Anne Radmacher*

## WELCOME NEW MI F2F STAFF MEMBER: STACY FARRELL

Michigan Family to Family Health Information Center, housed at Michigan Public Health Institute, is pleased to introduce the newest staff member to join our team, Stacy Farrell. Stacy previously participated with the Family Leadership Network, and brings with her a wealth of experience as the parent of a child with complex health care needs.

She is very active within her community and volunteers as an advisory council member for the Ronald McDonald House in Ann Arbor, a member of the Livingston Diversity Council, and Pride Alliance.

She enjoys spending time with her family, reading, and taking her Brittany Spaniel for walks.

She will provide input and support to both the Michigan Family to Family and Parent Leadership in State Government projects.

We are excited to have her as part of our team. Welcome, Stacy!



## UPDATES FROM THE EPILEPSY FOUNDATION OF MI

The Epilepsy Foundation of Michigan provides a wide range of services for people with epilepsy, family members, and the professionals who serve them. Through their *Here for You Helpline* – 800-377-6226 – anyone can access individualized education and consultation regarding epilepsy and related issues. This includes diagnosis, treatment options, finding appropriate epilepsy care, managing psychosocial and cognitive impacts, seizure first aid and safety, and supporting school success. You can also connect with the epilepsy community and programs and services offered by the foundation, including the following:

### **E-SMART (Epilepsy Self-Management, Advocacy, and Resilience for Teens)**

This new six-week, Zoom-based program for teens with epilepsy will be offered over the summer (contact the Foundation to get your teen on a wait list for the program). Featuring a combination of group discussion, instruction, goal setting, and fun activities, this program will help teens better understand their epilepsy and how to manage it and build skills to cope with the ups and downs of epilepsy as they approach adulthood.

### **Recorded Educational Sessions**

If you'd like to learn more about an epilepsy-related topic, chances are you'll find a recorded presentation that meets your needs on Epilepsy Foundation of Michigan's YouTube channel. You can browse through this extensive collection of topics and expert speakers at: <https://www.youtube.com/channel/UCXGfK15RTt9klvwgJHW8d8A>



### **Additional 2021 Events:**

- Learn & Share Conference Calls: 1st Wednesday of the month (upcoming topics include epilepsy and intellectual disability, Children's Special Health Care Services, psychiatric medications, transition planning, integrative medicine, staying safe with seizures, and more)
- Virtual Camp Discovery (for children with epilepsy, ages 7 – 15): July 13 - 16
- Virtual Solstice Camp (for teens, ages 16 -17, with epilepsy or other chronic health conditions): July 20 - 23
- Virtual Back to School Conference: August 7
- Wellness & Epilepsy Conference: November 13

For more information or to register for any of these events, please visit <https://www.epilepsymichigan.org/>

or call the Epilepsy Foundation at: 800-377-6226.



Be kind whenever possible.  
It is always possible.  
~Dalai Lama



## UPCOMING VIRTUAL PARENT MENTOR TRAINING

The Family Center for Children and Youth with Special Health Care Needs invites you to attend a Virtual Parent Mentor Training for parents.

In this interactive Parent Mentor Training you'll learn from a fellow parent about:

- Parent-to-Parent Support
- Communication Skills
- Listening Techniques

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 an 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.

Training dates are:

**Saturday, June 26, 2021 from 9:00 am to 3:00 pm EST on Microsoft Teams.**

Registration for this event can be completed at:

<https://www.eventbrite.com/e/parent-mentor-training-tickets-157694383145>

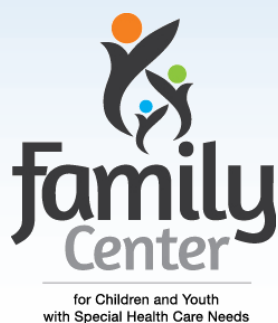
All participants will receive a \$50 gift card Family Center Notebook, and a Medical Care Binder (you must attend all days to receive the gift card)

Register soon as spots are limited.



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](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.

**Family Phone Line 800-359-3722**

[www.michigan.gov/familycenter](http://www.michigan.gov/familycenter)

**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.