WINTER 2022

Michigan Family Connections Newsletter

FATHER'S CONFERENCE MARCH 19, 2022

The Family Center for Children and Youth with Special Health Care needs, along with the 21st Century Dads Foundation/Special Fathers Network, is excited to host the **Father Engagement in Families of Children with Special Needs Conference.**

This conference will provide an insider's perspective for fathers, mothers, caregivers, and those who support families of children with special needs. The event is scheduled for Saturday, March 19, 2022 from 9 am to 12 pm. The online event is open to Michigan parents, caregivers and professionals.

Scott Newport will be one of the presenters at the conference. Scott is a mentor to families with children with terminal illness and a MI Family to Family advisory board member. When asked why he thought this conference is important for fathers to attend, he said, "Learning from others was a big help to me. We can't do it alone and we can't fix



everything. Dads need to find other dads to get support from. No one teaches us how to do this. We need to strive to learn to be the best dad possible."

Scott will be teaming up with another father to talk about Siblings & Family Balance. Other topics covered during the conference include Respite & Marriage, and Grieving the Life Anticipated. There will be three sessions each featuring two Special Fathers Network (SNF) Mentors.

The conference will be held via Zoom. The cost of the conference is \$10.00 and with each registration you will receive a resource packet and a Great Dad Coin.

To register, please use the following link:

Eventbrite Father's Conference Registration

Questions? Call the Family Center at 517-241-7630.



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

"LIVING WITH CYSTIC FIBROSIS" PODCASTS AVAILABLE

The Bonnell Foundation is pleased to announce they currently offer a wide variety of podcasts for families. The *Living with Cystic Fibrosis* podcasts were created to inspire you, make you laugh, choke you up with emotion, teach you a lot and make you want to hear more! This series features Cystic Fibrosis from the

This series features Cystic Fibrosis from the perspective of sisters with the disease, a Mom whose son had a transplant in the height of the pandemic, talking to Dr. Francis Collins, the former Director of the National Institutes of Health, and four award winning episodes about CF in Egypt.

These podcasts are for anyone who wants to learn and be inspired, even those not associated with a diagnosis of Cystic Fibrosis.

You can listen to the *Living with Cystic Fibrosis* podcasts on iTunes, Spotify, Google Play, or your favorite podcast source. They are also available on the Bonnell Foundation website at:

The Bonnell Foundation Website/Podcasts



THE FAMILY CENTER IS OFFERING CAMP SCHOLARSHIPS

The Family Center for Children and Youth with Special Health Care Needs is excited to offer a Camp Scholarship opportunity to attend camp in 2022. Families are invited to apply to receive a Camp Scholarship for up to \$250.

The Camp Scholarship is designed to assist families with sending their child with special health care needs to a camp of their choosing. Applications are being accepted now through the end of March 2022, or until funding is gone.

Applicants do not have to be enrolled in Children's Special Health Care Services to be eligible for a camp scholarship. Families will be required to submit a completed Camp Scholarship Application along with an Attendance Registration Form, which will need to be filled out by the Camp Director. Camp scholarships are not just limited to face to face, virtual camps are eligible as well.



The camp must be in Michigan and have a camp license. The camper must reside in Michigan at the time of applying and attending the camp. Exceptions: Camps operated by a university, school district, or city/township park and recreation program are not required to have a camp license.

Funding is limited, so apply soon. Contact the Family Center at 517-241-7630 to have an application emailed to you.

APPLY TO BE A MI-LEND TRAINEE FOR 2022-2023 COHORT

MI-LEND stands for **Mi**chigan **L**eadership **E**ducation in **N**eurodevelopmental and Related **D**isabilities. It is a year-long leadership training program. MI-LEND trains people from many different health-related disciplines. The program also trains persons with disabilities and family members. The goal is to improve the health of infants, children, and adolescents with neurodevelopmental disabilities.

The goal is accomplished through these activities:

- In-person and virtual leadership training
- Family-centered coursework
- In-person and virtual clinical and community experiences (shadowing other professionals, observing treatment meetings, visiting advocacy organizations)
- Training on how to be culturally competent
- Projects and written papers completed by trainees

MI-LEND Trainees are diverse. They can be:

- Enrolled in or recently completed a graduate program in one of many Maternal Child Health professions (<u>find a list here</u>); or
- A person with a disability (self-advocate); or
- A family member of a child with one or more disabilities or special health care needs.

Trainees benefit by completing 300 hours of instructional, clinical, and communitybased learning.



They connect with a mentor and other LEND trainees around the state. Trainees receive a cash stipend for the year, and are awarded a certificate of completion.

Lily Slavin, MI-LEND Fellow (2020-2021 Cohort) has this to say about her experience:

"I have found my MI-LEND training experiences to be so helpful in partnering with families and having a better understanding of what they are going through. I know that my LEND training has made me a better clinician and better able to serve the families I work with."

Applications to be a long-term trainee for the 2022-2023 cohort year are being accepted from **February 1 to May 1, 2022**.

For more information:

MI-LEND Website

To apply:

MI-LEND Application



TIPS TO PREVENT MEDICATION ERRORS IN CHILDREN

The American Academy of Pediatrics released a policy statement Dec 2021 entitled <u>Preventing</u> <u>Home Medication Administration Errors</u>. This policy statement indicates that home medication administration errors are very common and can lead to serious consequences.

We have gathered some tips for families. Many medication mistakes are preventable, and you can do your part to keep your kids safe.

- Ask for instructions in writing to refer to later. Do not rely on your memory.
 Instructions should include proper dose, when and how to give the medicine, how to store it, and length of time it will be given. This is especially helpful if more than one person will be giving the medicine.
- If you don't understand, ask questions.
 Always ask what the medicine is for and how to give it properly. If you aren't sure about dosage, ask. For example, "Does 'four doses daily' mean every six hours around the clock or just during waking hours?"
 You can verify that you understand by talking with the pharmacist at the pharmacy.
- Use the correct tools to measure. Do not use household utensils used for eating.
 These vary greatly and could result in your child getting too much or too little of the medicine. A dosing syringe or medicine cup is more accurate. Note: if the markings start to wear away, throw away immediately and replace with a new one.
- Find a spot in your home that is safe and keep all medicines there together. Store them away from children and keep an eye on expiration dates. Discard old medicine and do not reuse it later, even if it is for the same condition.



- Keep a list of all medicines your child takes.
 Share the list with your child's doctor at each visit. Be sure to include any over-the-counter medications or supplements. While many pharmacies check for interactions, they may not know everything your child takes, especially if more than one pharmacy is used.
- Do not stop a medicine without talking to the doctor. If side effects are a problem, let the doctor know. With prescriptions such as antibiotics, finish the full course of medicine, even if your child feels better.
 Stopping medicine too soon or abruptly can lead to problems later.
- Read labels. This applies to prescription as well as over-the-counter medications. For over-the-counter medications, read the ingredients. Some cold formulas have medicine in them for pain or fever and administering additional medication can be dangerous. Give dosage according to weight, or check with your child's doctor, particularly if your child is under 2.
- Check new prescriptions to make sure they match the label description. If a prescription refill looks different or it doesn't match the label, double check with the pharmacist.
- It is okay to teach your child how to take their medicine, but provide supervision.
 Even older children and teens need some oversight. Never tell a child that medicine is "candy" to entice them to take it.

CONVERSATION STARTER GUIDE FOR PARENTS OF CHILDREN WITH SERIOUS ILLNESS

Talking about the kind of health care we want through the end of life can be hard. It can be even harder when a child we care for is living with a serious illness.* But it is very important to talk with your child to learn about what matters most to them. If you talk about it, and understand what their wishes are, you will be better able to make health care decisions for them.

Having this talk with a child who is seriously ill is different from having the same conversation with an adult. It can be difficult (or not possible) for a child to share their wishes. And it can be very difficult as a caregiver to accept that a child's time to live may be shortened or painful.

The Conversation Project, an initiative of the Institute for Healthcare Improvement, created a guide to help you talk with your child, understand what matters to them, and feel some comfort knowing that you can help guide



their care and honor their wishes. Keep in mind that a conversation can vary depending on the age of the child, the type of illness, and their current treatment options.

To access the guide, visit:

Conversation Starter for Parents of Children with Serious Illness Guide

* A serious illness is a health condition that limits a child's daily function or quality of life, and may shorten their life.

NAVIGATING AUTISM TODAY CONFERENCE MARCH 18, 2022

The Autism Alliance of Michigan invites you to their Navigating Autism Today Conference on March 18, 2022 at Suburban Collection Showplace in Novi, Michigan.

The mission of this conference is to connect professionals directly to Michigan's autism community. Topics include: early diagnosis, education, independent living, employment, and more.

The goal of the conference is for attendees to leave feeling better equipped to navigate their autism journey. There is no cost to attend and complimentary breakfast and lunch will be provided to all attendees.



Help. Hope. Answers. Today.

For more information and to register, visit:

<u>Autism Alliance of Michigan Website/</u> <u>Conference</u>

Can't attend? Each breakout session will be recorded and uploaded to their website following the event to be accessed for free. Sign up to receive notification when the virtual sessions are available.

MICHIGAN'S POST ADOPTION RESOURCE CENTERS

Being an adoptive parent is one of the most rewarding jobs in the world, but can also be one of the toughest jobs. The Post Adoption Resource Centers (PARCs) provide a wide range of support services to families.

The centers serve individuals under the age of 21, who were adopted from Michigan's foster care system or who were adopted in Michigan through an international adoption or direct consent/direct placement adoption and their families. They provide support, education, training, advocacy, information, service coordination and case management services.

Services are also available to children under the age of 18 who were placed in guardianship from Michigan's foster care system and who are eligible for Michigan's guardianship assistance program.

Some of the services provided by PARCs include:

- Educational seminars and trainings for adoptive families
- Support groups for adoptive families and adopted children
- Information and referral to appropriate community services
- Adoption-sensitive, time limited, case management and crisis intervention services
- 24 hour telephone access for adoptive families looking for support services

If your adoption is final, contact a center in your area to learn more.

- Serving Region 1
 U.P. KIDS Website/Post Adoption Resource
 Center
- Serving Region 2/3/4
 Bethany Christian Services Website/Post
 Adoption Resource Center
- Serving Region 5/6

 Judson Center Website/Post Adoption

 Resource Center
- Serving Region 7/8
 Orchards Children's Services Website/Post



Sometimes the smallest things take up the most room in your heart.

~Winnie the Pooh



UPCOMING EVENTS FROM THE FAMILY CENTER

The Family Center for Children and Youth with Special Health Care Needs invites you to attend their upcoming events. Professional Connect Calls are open to any professional that works with families. Parent Connect Calls and Parent Mentor Trainings are open to any family regardless of whether the child qualifies for CSHCS or not. Register soon, space is limited. All events will be held on Microsoft Teams.

Professional Connect Call

Children with Special Needs (CSN) Fund Thursday, February 17, 2022, from 11:00 am—12:00 pm.

Professional Connect Call Registration link

Parent Connect Call

Children's Special Health Care Services Insurance Premium Payment Benefit, Wednesday, February 9, 2022, from 11:00 am—12:00 pm.

Parent Connect Call Registration link

Weekday Virtual Parent Mentor Trainings

Tuesday – Wednesday, 9 am – 11:30 am and Thursday, 9 am – 12 pm.

January 25 - 27, 2022 Registration link
February 22 - 24, 2022 Registration link
March 8 - 10, 2022 Registration link

Saturday Virtual Parent Mentor Trainings:

Saturday from 9:00 am—3:30 pm. February 12, 2022 Registration link

Questions?

Call the Family Center at 517-241-7630

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.



Michigan F2F Website



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 Family Center Website

Disclaimer: The Family Connections newsletter includes information and links to the 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.