Michigan Family Connections Newsletter

Summer 2022

Honoring the Life of Julie Beckett

It is with great sadness we share that Julie Beckett passed away on Friday, May 13, 2022.

Passionate, visionary, and inexhaustible, Julie was an amazing advocate for improving health care for children with special health care needs and disabilities throughout our country for over 35 years, beginning with her daughter Katie Beckett.

Julie made an incredible impact on families of children with special health care needs and disabilities through her advocacy. Her determined work on behalf of her daughter, Katie, resulted in the creation of the Medicaid Home and Community Waiver, a program that has gone on to allow thousands of families to care for their loved ones at home rather than in institutions.

She co-founded Family Voices to promote the inclusion of families' voices in all levels of health care decision-making for children, work that Family Voices continues almost 30 years later. Julie's advocacy helped create federally-funded **Family-to-Family Health Information Centers** (F2Fs) in every state and Washington, D.C. (now also serving five U.S. territories and three tribal communities). F2Fs provide critical support to millions of families of children with special health care needs (CYSHCN). Julie's legacy lives on.

For more information on Julie's lifelong work to improve services for families, visit **The Family Voices website**.

A newsletter for families of children and youth with special health care needs, and the professionals who care for 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

Meet FLN Member Samantha Oard

In this edition, we would like to introduce Family Leadership Network member, Samantha Oard. Samantha represents Region 5 (Claire, Gladwin, Arenac, Isabella, Midland, Bay, Gratiot, and Saginaw Counties).

Tell us a little about yourself and your family?
My husband and I have two boys, ages 12 and 8. We live in a small rural town in Michigan where both my husband and I grew up. The boys keep us busy with their activities but when we do have time to sneak away for a bit we love to camp and travel when we can.

Why were you interested on serving on the Family Leadership Network?
When my 8-year-old son was diagnosed with Autism before he even turned two years old, I felt so alone. No one in my life was personally touched by Autism at the time and given the small community we live in; I didn't even have any friends or acquaintances impacted by special needs of any sort. I have learned a lot along our journey and want to make sure that others have support as they go through tough journeys and that no one ever feels alone. The additional resources and information provided from being a part of the FLN is a bonus too!

What are some of your interests/passions?
I am a full-time corporate career mom of two so do not have a lot of time for my own passions and interests, though advocating and volunteering is at the very top of my list. I sit on many community boards including school, special needs and athletics and enjoy them all for different reasons. It really gives me a sense of purpose and I thoroughly enjoy helping others.

What started you on your parent leadership journey?
A few years back the school was looking for a Parent Advisory Committee member to represent our school. I was asked and accepted with pride. I was very humbled to be chosen to represent our schools. Since then I have learned so much!

What advice would you give to parents of a newly diagnosed child in your area?
One piece of advice I'd give to parents of a newly diagnosed child is to never, EVER, give up! Do not let anyone tell you at any age, whether 18 months old or 10 years old, what your child may *never* do. Instead, challenge them to tell you what they CAN do. So long as they have someone in their corner, then there's ALWAYS hope!

What do you see are the biggest needs or challenges for parents of children with special health care needs?
The most difficult piece of special needs parenting and care for me has been the fight for services, the fight for diagnosis, the fight for appointments, it's just a constant fight. For some children, they just simply do not have anyone able to continue that fight. I'd love to see a day where the fight is not necessary!

For more information on the Family Leadership Network, visit the F2F Website/FLN

August Is SMA Awareness Month

Lylah Gritter was diagnosed with Spinal Muscular Atrophy just before turning six months old. Spinal muscular atrophy is a genetic disorder characterized by weakness and wasting in muscles used for movement (skeletal muscles). It is caused by a loss of specialized nerve cells, called motor neurons that control muscle movement.

A few amazing facts about SMA…

- Children with SMA are not affected cognitively. In fact, they are known to be off the charts smart!
- In the last 5 years multiple life-saving treatments have been FDA approved for SMA.
- 3 years ago SMA was added onto Michigan's Newborn Screening.

When Lylah was diagnosed doctors told her parents, Holly and Don, she wouldn't survive past her second birthday. After months of research Holly found a clinical trial that was enrolling children in a promising drug called Spinraza. A drug given through the spine that helps her body create protein.

Seven years later the Gritters are still in the drug trial and travel to Dallas, Texas for Lylah to receive life saving treatment. Lylah loves unicorns, hanging out with her friends, and watching her big brother, Easton, play hockey. She turns nine in August and is thriving.

For more information and support, please visit the **Cure SMA** website.

Michigan Child Protection Registry Available

Have you ever worried about how safe your children are while online? Michigan families, especially minors, are increasingly inundated with advertisements from alcohol, tobacco, pornography, illegal drugs and gambling marketers through different internet and cell phone inboxes.

Thankfully, the State of Michigan offers a free program to stop adult advertisements from reaching e-mails, text messages, Instagram, Snapchat and Twitter. The Michigan Child Protection Registry, like the federal Do Not Call List, is a free do-not-contact service for Michigan's families and can be located at the **Michigan Child Protection Registry website**.

Michigan Family to Family and the Family Center for Children and Youth with Special Health Care Needs are strong supporters of this registry.

We encourage you to sign your entire family up for the registry and inform your friends and colleagues about how they can protect children and families from unwanted adult advertising.

Spotlight On: Courageous Parents Network

Courageous Parents Network (CPN) is a non-profit organization and educational platform that orients, empowers, and accompanies families and providers caring for children with serious illness.

Courageous Parents Network programs and services are rooted in the experience of CPN's founder, Blyth Lord. From this, the Network has grown to include the insights and experiences of dozens and dozens of families and pediatric providers who stress the importance of creating an environment of mutual understanding and shared decision-making. They emphasize this importance through education, community, and advocacy.

- Education: Providing easily accessible, expertly vetted information and tools that address families' spoken, and unspoken, questions and concerns.
- Community: Connecting families and providers sharing personal stories and questions about the illness journey, to minimize isolation and promote the benefit of shared experience.
- Advocacy: Increasing awareness of and demand for pediatric palliative care to enhance quality of life for the whole family.

In addition, a password-protected Provider Portal offers materials that give voice to the parent perspective and promote mutual understanding and empathy. These materials are appropriate for providers just beginning their careers, and for those seeking ongoing educational opportunities.

To access all this and more, visit

Courageous Parents Network website

Newborn Screening Family Education Program

The Newborn Screening Family Education Program is dedicated to developing opportunities for all families to learn about newborn screening.

Newborn screening is an essential public health service that is important for families to understand. It ensures that all babies are screened for certain serious conditions at birth, and for those babies with the conditions, it allows doctors to start care before more harmful effects happen.

Typically performed within 24-48 hours after a baby is born, newborn screening is made up of three parts including a blood test, hearing screen and heart screen.

The Newborn Screening Family Education Program has created a number of resources for families.

For more information and to access the family resources, including an online educational module, webinars, and other resources, visit their website at: The **Newborn Screening Family Education Program** website.

Circle of Care Guidebook

Being a caregiver for a child with a rare disease or other serious medical condition can be both enormously gratifying and extremely challenging. For most, the experience is life-altering, and for some, all-consuming. In particular, the long and winding diagnostic odyssey and daily complexity of navigating care, treatment and support services can be overwhelming.

Global Genes partnered with the National Alliance for Caregiving and other caregivers, organizations, and experts to call attention to the unique needs of those caring for a child with a rare and serious illness, and developed the Circle of Care Guidebook as a resource.

The extensive array of topics covered in the guidebook (nearly 100) underscores the many aspects of life and care that are impacted when caring for a child with a rare disease.

Fortunately, there are a wide variety of resources and organizations available to help caregivers, many of which are highlighted in this document.

The Circle of Care Guidebook is intended to help caregivers navigate through the varied experiences and challenges of rare and serious medical conditions, guided by the insights, achievements, and learnings of other caregivers and experts.

You can access this resource at the **Circle of Care Guidebook website**.

CDC Shares Updated Developmental Checklists

The Centers for Disease Control and Prevention's (CDC) *Learn the Signs. Act Early.* program, recently funded the American Academy of Pediatrics (AAP) to convene an expert working group to revise its developmental surveillance checklists.

The goals of the group were to identify evidence -informed milestones to include in CDC checklists, clarify when most children can be expected to reach a milestone (to discourage a wait-and-see approach), and support clinical judgment regarding screening between recommended ages.

Subject matter experts established eleven criteria for CDC milestone checklists, including using milestones most children would be expected to achieve by specific ages and those that are easily observed in natural settings.

These materials were developed to help parents to recognize typical development and prompt parents to voice concerns about their child's development. This helps improve discussions between parents and doctors about a child's development, and support screenings when there are concerns.

To view the updated milestones checklists as well as learn more about what to do if you are concerned about your child's development, visit the **CDC's website** for more information and resources.

Trainings And Other Events

Parent Connect Calls

- Topic: Adult Sibling Support, Wednesday, Aug 10, 2022, from 11:00 am to 12:00 pm. **Adult Sibling Support Parent Connect Call Eventbrite**

Professional Connect Calls

- Topic: Family Center for Children and Youth with Special Health Care Needs (Family Center) Thursday, August 18, 2022, from 3:00 pm to 4:00 pm. **FC 101 Professional Connect Call Eventbrite**

Parent Mentor Trainings

Weekday Virtual Parent Mentor Trainings:

- Tuesday – Wednesday, 9 am – 11:30 am and Thursday, 9:00 am – 12:00 pm.
- August 16—18, 2022 **August Parent Mentor Eventbrite**
- Sept 13—15, 2022 **September Parent Mentor Eventbrite**

Saturday Virtual Parent Mentor Trainings:

- Saturday from 9:00 am to 3:30 pm on Microsoft Teams.
- August 20, 2022 **August Saturday Parent Mentor Eventbrite**
- September 24, 2022 **September Saturday Parent Mentor Eventbrite**

Navigating Healthcare Training for Families of Children with Epilepsy

An online, interactive, medical advocacy training created to provide families with the information, tools, and resources needed to help navigate healthcare systems. This training will have a special focus on supporting families of children with a diagnosis of epilepsy (seizure disorders).

- Open to any Michigan parent (bio, adoptive, foster, step, kinship, etc.) with a child (birth to 18) with epilepsy (seizures).
- Date: August 17th and 18th.
- Training is from 9:30 am to 12:30 pm on both days.
- Parents who complete the training are eligible for a $100 stipend.

To register for this training, call Kristen Reese at 517-324-7396.

Who We Are:

The Michigan Family to Family Health Information Center (MI F2F) is a federally funded project. They share resources and information 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 various professionals. They 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 visit our website

MI F2F Website

Like us on **Facebook**

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 Center direct line 517-241-7630

CSHCS Family Phone Line 800-359-3722

Family Center Website

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

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.