



Family to Family Michigan Update

VOLUME 1, ISSUE 1

SPRING 2014

F2F Michigan provides:
“Resources, information and education for children and youth with special health care needs; the families who love them and the professionals who help them.”

Welcome to the Family to Family (F2F) Michigan Update! It has been a busy year for F2F and we will provide this newsletter quarterly to update families and community partners. We will provide news, information and educational opportunities with F2F and our partners across the state. In this newsletter we would like to highlight some of the activities and work that has been accomplished over the past year.

On October 30, 2013, F2F held an open forum for families and community partners to share our vision for the upcoming year. This was a chance to meet and hear from our state and community partners as well as from parents. At the open forum, participants were encouraged to discuss ideas for



collection of information and resources for our website, review the work plan and ask questions as well as sign up for workgroups or the advisory board.

In December, a workgroup met to decide how to collect, provide and share resources and information about supports and services for families and youth with special health care needs. Participants discussed what resources for families already exist, how families seek out and access them, and how to work together to best fulfill the vision of the F2F.

The advisory board convened in February and again in May, 2014. The advisory board is made up of organization and agency representatives as well as parent representatives. The 25 advisory board members share their ideas and voices to provide structure and direction for the work of F2F.

Much of the work has centered on the creation of a new website that will collect and provide resources and information to families and youth. Look for this website to launch soon.

We will continue to reach out to partner with other agencies and organizations that work with children and youth with special health care needs and look forward to being a valuable resource to families, youth and professionals in our communities and across Michigan.

Welcome from F2F Advisory Board Co-Chair

Hello from the Advisory Board Parent Co-Chair. My name is Devin Doty and I was recently elected as the parent representative co-chair for the Family to Family Health Information Center advisory board. I would like to introduce myself and my family. I grew up in Mid-Michigan and lived in Nevada for a time before returning to Michigan where I met my wife, Jessica.

We have three energetic children. Our youngest daughter has a chromosome deletion on the 15th chromosome. It has been a learning experience since we found out about her deletion. With our youngest daughter's diagnosis we wanted to get involved as well as help where opportunities were available, which brought me to the advisory board.

I have a personal and educational background in automotive, health care, security and business. I look forward to serving on the advisory board and serving as a voice for other families in the Michigan.

Enthusiastically,
Devin Doty

PPC Parent Leadership Training Held In Grand Rapids



On May 14-15, 2014, F2F hosted a *Parents Partnering for Change* leadership training opportunity in Grand Rapids. Parents have unique expertise about the goals, outcomes, and real impact of services for themselves and their children. The PPC training demonstrates to families how to impact decision-making. It encourages them to engage in policy development, and participate on boards, committees and councils. This two day event was attended by 24 parents of children and youth with special health care needs from the greater Kent County area. After the training, parents are invited to join the PPC Yahoo list serv and Facebook page. Openings to serve on boards, committees and councils are shared with parents as well as other leadership development opportunities. For more information on this and other parent leadership training opportunities, please contact us at F2Fmichigan@mphi.org.



“Leadership and learning are indispensable to each other.”

~John F. Kennedy



Allergy & Asthma Network Launches Free Prescription Assistance Program

Patients and families with asthma, allergies and other health conditions now have access to a simple and free Prescription Assistance Program through Allergy & Asthma Network Mothers of Asthmatics (AANMA) offering savings of up to 75 percent on prescription medications, both brand and generic.

“We hear far too often from patients who cannot afford their life-saving medications or don’t take the full amount recommended,” says Tonya Winders, AANMA president and CEO. “The Prescription Assistance Program helps relieve a huge financial burden many families with chronic illnesses feel at the

pharmacy counter and helps keep families healthy.”

A 2003 study published in The Journal of Allergy and Clinical Immunology estimated the annual costs for asthma treatment at more than \$4,900 per person.

Through the program, people receive a free wallet-size card they can present to pharmacies when they purchase prescription medication. The card is accepted at more than 56,000 national and regional pharmacies around the country, including CVS, Walgreens, Rite Aid, Walmart, Kmart and Target. The free Prescription Assistance Program was launched by Allergy & Asthma Network, in

cooperation with United Networks of America, to help patients with high deductible prescription plans, who take prescriptions not covered by insurance, or do not have prescription coverage.

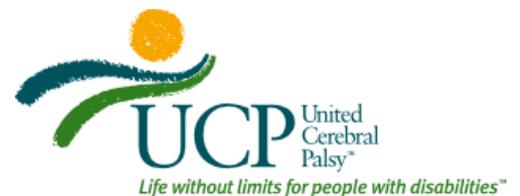
The program is available to anyone, no matter what their medical needs or insurance coverage, with no restrictions to membership, no income requirements or age limitations, and no applications to fill out.

Simply visit the AANMA website at www.aanma.org to download and print out a card and look up participating pharmacies. Cards are also available by calling AANMA at 800.878.4403.



The Case for Inclusion

Every year since 2006, United Cerebral Palsy (UCP) - an international advocate, educating and providing support services for children and adults with a spectrum of disabilities through an affiliate network- produces The Case for Inclusion, an annual ranking of how well state Medicaid programs serve Americans with intellectual and developmental disabilities (ID/DD). Individuals with ID/DD, including the aging, want and deserve the same freedoms and quality of life as all Americans. The Case for Inclusion ranks all 50 states and the District of Columbia (D.C.) - not on their spending



- but on their outcomes for Americans with ID/DD.

The Case for Inclusion shows how well each individual state is performing overall; how each state matches up against other states regarding key data measures; and, most importantly, the top performing states with policies and practices that should be replicated.

For more information and to view the report, visit:

<http://cfi2014.ucp.org/>

Detroit Hosts *Empowering Families* Training

On March 28, 2014, F2F sponsored a learning opportunity for families in the Detroit area. The *Care Coordination: Empowering Families* training was developed by Region 4 Midwest Genetics Collaborative for parents of children with complex medical needs. The purpose of the training is to demonstrate to parents the benefits of engaging in a health partnership with their child’s care providers. The training helps parents gain the knowledge and skills to increase their confidence and ability to coordinate care for their child. It helps them identify new resources and organize information. The event was hosted by Adult Wellbeing Services on Detroit’s East side. Eighteen participants attended the one-day training and enjoyed the opportunity to not only gain new information but to also meet and network with other parents from the area.



“To hear other parents helped me to feel ‘I’m not the only one’ going through a tough time with a child’s illness.”
~A Detroit parent

Affordable Care Act Information

Healthy Michigan Plan:

Some Michigan residents may be eligible for the Healthy Michigan Plan, a new health coverage program that began on April 1, 2014. The Healthy Michigan Plan provides health care benefits to Michigan residents at a low cost so more people can have health coverage. Individuals are eligible for the Healthy Michigan plan if they:

- Are age 19-64 years
- Do not qualify for or are not enrolled in Medicare
- Do not qualify for or are not enrolled in other Medicaid programs
- Are not pregnant at the time of application
- Have income at or below 133% of the federal poverty level* (\$16,000 for a single person or \$33,000 for a family of four)
- Are a resident of the State of Michigan



For more information, visit:
www.HealthyMichiganPlan.org
or call 855-789-5610

*Eligibility for the Healthy Michigan Plan is determined through the Modified Adjusted Gross Income methodology.

Transition Corner



Think College!

Doors to colleges are opening for people with intellectual and other developmental disabilities in many different ways all over the country. There is a website designed to share what is currently going on, provide resources and strategies, let you know about training events, and give you ways to talk to others. Think College is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability. With

a commitment to equity and excellence, Think College supports evidence-based and student centered research and practice by generating and sharing knowledge, guiding institutional change, informing public policy, and engaging with students, professionals and families. www.thinkcollege.net

DID YOU KNOW?

Less than half of US youth with special health care needs receive the health care transition supports and services they need, according to the 2009-10 National Survey of Children with Special Health Care Needs.



CSHCS Family Center Welcomes New Director

Children's Special Health Care Division, Bureau of Family, Maternal & Child Health, Department of Community Health was pleased to announce the new Director of the Michigan Family Center for Children and Youth with Special Health Care Needs, Candi Bush. Candi has been the Executive Director for Parent to Parent of Southwest Michigan (P2P), a non-profit community organization offering services to families who have

children with disabilities or special needs. At P2P, she was responsible for leading a comprehensive family resource center utilizing the Parent-to-Parent model of support. Candi has a Bachelor of Science degree in Family Life Education from Western Michigan University, and is certified as a Family Life Educator. Candi is also a parent walking the journey of raising children with special health care needs. Her professional and personal

experience as a parent of children with special health care needs, and as Executive Director of P2P have prepared her with the necessary skills and passion to lead the Family Center for Children and Youth with Special Health Care Needs. We all would like to congratulate Candi and welcome her to her new position.



For more information contact:
F2Fmichigan@mphi.org

or call the CSHCS Family Phone Line at:
(800) 359-3722

Michigan Family to Family Health Information Center (F2F HIC)

assures that families of children and youth with special health care needs (CYSHCN) are able to participate in decision-making at all levels and be satisfied with the services they receive.

How Can F2F HIC Help?

F2F HIC can help families with CYSHCN because they are staffed by family members who have experience. They know firsthand how to navigate the maze of health care services and programs for CYSHCN. F2F HIC staff understand the issues families face. They help families make informed decisions.

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 Grant H84MC26214



“Providing information, resources and education on health issues to help families navigate systems, become more confident and partner with professionals in decision making.”



Disclaimer: The Michigan Family to Family newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by Michigan Family to Family Health Information Center, Michigan Public Health Institute or our funders. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care.

How to contribute to upcoming newsletters:

F2F Michigan is interested in sharing on topics of interest to families of children and youth with special health care needs across Michigan. If you have an upcoming event, learning opportunity, educational resource or other items you would like to share, please contact us at:
F2Fmichigan@mphi.org.