

PARTNERING TOGETHER

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WELCOME TO THE FAMILY PARTNERSHIP

"Your child has (child's diagnosis) ."

If you have received a diagnosis of a special health care need or developmental disability, you might recall feeling like your world has stopped spinning and the clock stopped ticking. Suddenly, fear and anxiety about the future sweeps over you and all kinds of questions start spinning around in your mind.

How will this affect your hopes and dreams for your family? What are your next steps? Where will you turn?

Every family's situation is unique. Although no one will ever understand exactly how you

feel, there is hope for the future. During this time of confusion and chaos, you are not alone! There are many parents and families who have been there, know what you are going through, and are ready and willing to share their knowledge and support with you.

Family Partners are just one example of families who are here to help! Family Partners are parents of individuals with special health care needs who provide information and connect families to other families through one-on-one support and local events. *Continued on page 2...*

(Go online to mofamilytofamily.org to share this newsletter and past issues with friends and family)



ACCESSING THE HEALTHCARE YOUR FAMILY NEEDS



Help your family stay healthy by staying informed about the latest changes in the healthcare world.

What has changed already?

- Plans may no longer exclude coverage or charge a higher premium to children under 19 based on a pre-existing condition (This will expand to include anyone with a pre-existing condition in 2014).
- Insurance companies may no longer set lifetime dollar limits on essential health needs.
- Many insurers are now required to cover preventive services at no cost.

What is going to change?

Starting in 2014, the Health Insurance Marketplace, a key feature of the Affordable Care Act, will open up and allow individuals and families to compare health plans, get answers to questions, find out their eligibility for tax credits for private insurance or health programs like the Children's Health Insurance Program (CHIP), and enroll in a health plan that meets their needs.

Different financial assistance programs will be directly linked in, including Medicaid, CHIP, and tax credits that can help pay private health plan premiums in advance.

In October 2013, you'll be able to get information about the plans available in your area and enroll. You will be able to enroll your family, by logging on to healthcare.gov or calling a toll-free phone hotline. There will also be people available to help you with your choices if you need assistance.

Learn more and get ready at healthcare.gov!



FIND YOUR FAMILY PARTNERS!

The Family Partnership provides free information and support to children and youth with special health care needs and their families. Family Partners can help you discover information and resources, connect with someone who understands, and network with other families in your area.

NORTHWEST REGION
STACEY ANDERSON
 (816) 835-5005
stacey@mofamilypartnership.org

SOUTHWEST REGION
BETH DOODY
 (660) 200-5371
beth@mofamilypartnership.org

SOUTHEAST REGION
PAM DAHLGREN
 (573) 776-1896
pam@mofamilypartnership.org

NORTHEAST REGION
BEV HOLMES
 (573) 473-8873
beverly@mofamilypartnership.org



CONNECT WITH US
 (800) 779-8652
www.mofamilypartnership.org

Welcome to the Family Partnership (continued)

The Family Partnership was created to provide information and support to children and youth with special health care needs and their families. The four Family Partners can help you discover information and resources, connect with someone who understands, and meet other families in your area. They are just an email or phone call away and are here to connect you directly to your local and statewide supports.

for individuals with disabilities or special healthcare needs and their families. We offer a network of free support options so that individuals and families are well informed, hopeful, connected within their communities and know they are not alone in their experience with disability or special health care needs.

As you continue on your journey, you may need support. The Family Partnership can arm you with the tools and information you need to create the life you want for your family.

At Missouri Family to Family we believe in supporting individuals with disabilities or special health care needs and their families throughout their entire life course. We want to live in a world where everyone is valued and treated with respect, fairness and equality; included in their communities; and given opportunities to dream, achieve success and change the world.

The Family Partnership is a collaboration between Missouri Family to Family (MOF2F) and Special Health Care Needs (SHCN). MOF2F is a statewide resource

To visit the Family Partnership online, go to mofamilypartnership.org •

MEET THE FAMILY PARTNERS



STACEY ANDERSON

Northwest Family Partner

(816) 835-5005

stacey@mofamilypartnership.org

My name is Stacey and I am a mom to two outstanding boys: Trent, 12, and Chase, who is two years old.

I had a healthy pregnancy with Chase, but when he was born we quickly realized he had some challenges. Most obviously, eating (breastfeeding and bottle) was not easy for him. This was the beginning of our journey. The unknown was terrifying as we spent many weeks in the hospital the first year. I felt as if overnight I had to become an expert in almost every specialty at our local children's hospital: ENT, Neuro, Ortho, GI, Feeding Clinics, Ophthalmology, Audiology, Dermatology, Genetics, Endocrine and Surgery - just to name a few. I learned to manage feeding pumps, suction machines, insurance, respite care, home health supplies, prescriptions, doctors' appointments, therapy, and more! Our lives completely changed.

I found it valuable to reach out to other families who may have a complex child. Personally, I felt as if I was "left in the dark" with many of these systems and learned on my own to navigate, research and advocate for the best interest of my son. If your world includes a child with a special need, I hope that you take the opportunity to connect with a seasoned Family Partner who can offer insight. ●



BEVERLY HOLMES

Northeast Family Partner

(573) 473-8873

beverly@mofamilypartnership.org

My name is Beverly. I live in NE Missouri with my husband, Bill, and my son, Keith. I am a mom and step-mom to four, and I have a step-grandson. My son, Keith, is 24 and the light of my life! He has many abilities and always wakes up with a huge smile to make all the daily challenges seem so insignificant.

I have been a Family Partner for almost nine years now. I have enjoyed helping families find resources and information as well as encouraging them to always take that extra step to make things happen! I have worn many hats over the years: served on many councils and committees, done lots of advocacy work, and even graduated from Partners in Policymaking in 2001, but none of these have come close to the experience I've had raising and caring for my children.

I am easy to get along with but can also be very outspoken when I need to. I love talking in large groups and sharing information. In our spare time, our family is very involved in our church. We are a typical, dysfunctional family full of fun, laughter and love. Each day arises with a new chance to make a difference in someone's life and we embrace it fully and hope at the end of each day, we have done just that! ●



BETH DOODY

Southwest Family Partner

(660) 200-5371

beth@mofamilypartnership.org

My name is Beth. My husband Ernie and I live in rural Vernon County. We raised two adult children, have 5 grandchildren and are currently raising our special needs, adopted daughter. I am so excited to have the privilege of serving special needs families in the Southwest region, as your new Family Partner.

We were given a rather bleak glimpse of our child's future by a number of professionals and spent years with doctors, specialists and therapists. After our daughter started losing her therapies due to sweeping budget cuts, we decided to make a few changes. We began homeschooling her, which by far has been the best decision we ever made for her. We realized we were regaining a normal life style. As our schedule became more relaxed and allowed our daughter to learn and grow at her own pace, her personality blossomed. Our daughter's special needs will always be with her, but she is making progress we were told would never be achieved. ●



PAM DAHLGREN

Southeast Family Partner

(573) 776-1896

pam@mofamilypartnership.org

My name is Pam. I am excited about being the new Family Partner for the Southeast region. I look forward to being able to assist you with your needs!

I live in Poplar Bluff with my wonderful husband, two biological children; my oldest son, who was recently married, and my daughter, who is a junior in high school. Our family has been foster parents for five years and has been home to over 23 children. We have adopted our miracle child; she is five with many issues. We are currently adopting two brothers who have autism, ages four and fifteen months.

I am meanwhile enrolled at Three Rivers College working toward my degree in Occupational Therapy Assistant. I am serving on the board of SE Regional Foster & Adoptive Parent Advisory Board for the 36th district. I am also a board member for our local Foster/Adoptive support group. I look forward to meeting and assisting you and your family. Feel free to contact me at any time. ●



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OUR PARTNERS

TIPS



For Kids

TIPS for Kids

Training in Interdisciplinary Partnerships and Services (TIPS) for Kids is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

training program in Missouri. The LEND program provides intensive training for advanced graduate students and post-doctoral fellows in the field of neurodevelopmental and related disabilities.

(573) 882-0757

tips4kids.org



Department of Health & Senior Services, Special Health Services

Provides statewide health care support services, including service coordination, for children and adults with special health care needs who meet eligibility requirements. Programs include: Children and Youth with Special Health Care Needs, Healthy Children and Youth, Medically Fragile Adult Waiver, and Adult Brain Injury.

(800) 451-0669

health.mo.gov/living/families/shcn



Family Partnership

The Family Partnership was formed by Special Health Care Needs (SHCN), of the Missouri Department of Health and Senior Services, to enhance the relationship between SHCN and the families they serve. The Family Partnership also serves as a means to provide support and information to families of individuals with special health care needs and identifies ways for families to connect with each other.

(800) 779-8652

mofamilypartnership.org



INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

The Institute for Human Development, located within the University of Missouri-Kansas City, is an applied research and training center for human services. It exemplifies the University's goals of academic excellence and a campus without borders by helping people, agencies, and the community reach their fullest potential.

(800) 444-0821

www.ihd.umkc.edu



Missouri Developmental Disabilities Council

MDDC is a federally-funded,

23-member, consumer-driven council appointed by the Governor. Its mandate under P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act, is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration in all aspects of community life.

(800) 500-7878

moddcouncil.org



Missouri Family to Family

At the MOF2F, we offer Missouri individuals with disabilities and/or special health care needs of all ages, their families and professionals support, connections and opportunities to strengthen leadership skills and participate in program & service decision-making. When you connect with us, you are linking directly with self-advocates, parents, caregivers and family members whose lives are touched daily by healthcare or disability celebrations and challenges. Because of our experiences, our information is offered in a person-centered, easy to understand, and culturally friendly way.

(800) 444-0821

mofamilytofamily.org