• The Missouri Family to Family Resource Center •

PARTNERING TOGETHER

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ARMED FOR YOUR HEALTH

Day after day, information about health is thrust at us from our healthcare providers, insurance and pharmaceutical companies, television and radio, websites and online news sources, as well as our family and friends.

Being responsible for your health means that you are able to take in and decipher all this health information and use it to make good decisions about your health and your medical care. This process is also called health literacy.

As an adult, you are responsible for your health. If you are a parent or caregiver, this might mean that you are also responsible for supporting or managing the health of another person. It is especially important for parents and caregivers to be health literate because many times, they are involved in or responsible for making decisions and managing the care of their loved one.

Health can be a very private and confusing matter. It is not surprising that most people don't like talking about it, feel frustrated or confused when hearing or reading about it, and develop anxiety about visiting a healthcare provider. However, people make health decisions that influence their lives every day so it is important to know about all of the factors that affect their health and what they can do to stay healthy!
More on page 2...

TOOLS FORYOUR HEALTH

Without accurate, reliable health information and the skills needed to make decisions that support good health, people are more likely to experience a lower quality of health because they don't seek preventative care as often and they may not take the necessary actions to manage or address a current condition.

The following websites are just some of the many tools you can use to manage and learn more about your health!

Healthcare.gov

At the Healthcare.gov portal, you can explore insurance coverage and options, get help decoding and understanding insurance ifnormation, find out details about the Affordable Care Act and how the Act's changes to the healthcare and insurance industries affect your family, and learn about how the ACA can help you stay healthy through preventative care.

http://www.healthcare.gov

Questions are the Answer

This website, created by the Agency for Healthcare Research and Quality, helps you build your agenda for your medical appointments by providing questions to think about and ask of your healthcare providers. The website helps you build your list of questions for before, during, and after your appointment and has a great resource section with tips and tools on how to get the most out of your relationships with your healthcare professionals.

http://www.ahrq.gov/questions/

Healthfinder.gov

Find information about over 1,600 health topics, locate health services, check out interactive health tools, and see what health topics other people are searching for at healthcare.gov. Spanish information available. Follow healhfinder on Twitter (@ healthfinder) for constant updates to help your family stay healthy!

http://www.healthfinder.gov

For more information on health tools and online resources you can use to help you stay informed, please visit our website at www.mofamilytofamily.org

UPDATE FROM

M•O•F•2•F

THE MISSOURI FAMILY TO FAMILY RESOURCE CENTER

The Missouri Family to Family Resource Center provides quality information and referrals to organizations that may be able to help your family with their needs. We partner with family organizations across the state of Missouri so you can get the services you need how you need them. Trained mentors are available to listen and support you because they've been there. We can also connect you with opportunities to support other families or help change systems and services that families and people with disabilities use through the Family Leadership Network.

This past year, we launched the Brown Bag Lunch Webinar Series. You can connect with us via webinar on the fourth Wednesday of each month online in the comfort of your own home, at work, or with others at one of our host sites. Our webinars are also archived so you can watch them at a time that is convenient for you.

Missouri Family to Family is here because of families like yours. Thanks to the gifts of your time, talent, and experience we are able to help others through Sharing Our Strengths (SOS). Our volunteers also have made it possible to share more quality information through the personal stories they have contributed and by reviewing our products before they go out to families. If you are interested in becoming a volunteer, visit us online at www.mofamilytofamily.org or contact us toll free at 1-800-444-0821!

Current news: What you need to know about the AFFORDABLE CARE ACT

All new health insurance plans must cover preventative health care without charging extra costs on policyholders. Preventative care includes things like screenings and assessments, immunizations, well child exams, well woman exams, and more. For a complete list, visit the MOF2F website.

When does this take effect?
This provision began September 23, 2010. Additional women's preventative health services were added and will go into effect no later than August 2012.

Insurance companies are not able to cancel the policies of people who get sick. If you or a loved one develop a serious illness, insurance companies can no longer say they can't insure you. In addition, insurance companies are also prohibited from canceling your policy because of an unintentional mistake on your paperwork. In the past, insurance companies could search for an error or technical mistake in your application and use it to deny payment for services. Now this is illegal unless the company can prove it was intentional fraud.

When does this take effect?
This affected some families in 2010, but took effect officially in 2011, and is in effect now.

Families can help adult children maintain health insurance by keeping them on the family insurance policy until age 26, unless they get coverage through their employers. Young adult children whose employers don't offer insurance are eligible to stay on family policies, even if they are no longer students, no longer live at home, are financially independent or are married (although their spouse cannot be covered).

When does this take effect?
This provision took effect for insurance policies starting at the beginning of the first plan year after September 23, 2010 and is in effect now.

Now, adults with high prescription drug costs on Medicare Part D are paying less for their medications. People whose prescription drug expenses are high enough to put them into the non-reimbursed "donut hole" are receiving discounts and rebates to deflect their own out-of-pocket expenses. The "donut hole" refers to the situation encountered by people who have Medicare Part D coverage and have exceeded the initial coverage limit in drug costs, forcing them to pay out of pocket for prescriptions. Last year, people who fell into the donut hole received $250 rebates; in 2011 drug companies had to give them half off discounts on brand-name drugs and cheaper prices for generic drugs as well.

When does this take effect?
The discounts will increase over time until the year 2020 when the donut hole will be closed entirely.

You now have your choice of health care providers. You now have the right to choose any available participating primary care provider for yourself or your families and any available participating pediatrician for your children.

When does this take effect?
This provision took effect September 23, 2010, for all newly-issued plans and for existing plans which have changed substantially.

Children with special healthcare needs or developmental disabilities (called "pre-existing conditions" in the legislation) cannot be denied coverage. Employer-based health plans and new individual plans are no longer allowed to deny or exclude coverage for your children if they are under age 19 and have a special healthcare need or developmental disability.

When does this take effect?
This provision went into effect on September 23, 2010, for new plans and existing group plans. In 2014, neither children nor adults will be denied for a special healthcare need/disability. ●

For more tools to help you understand how the Affordable Care Act affects your family, check out the Catalyst Center's publications online at hdwg.org/catalyst/publications

FAMILY PARTNERSHIP

CONTACT INFORMATION | Toll-free: 1-866-809-2400 ext. 308

Northwest Region

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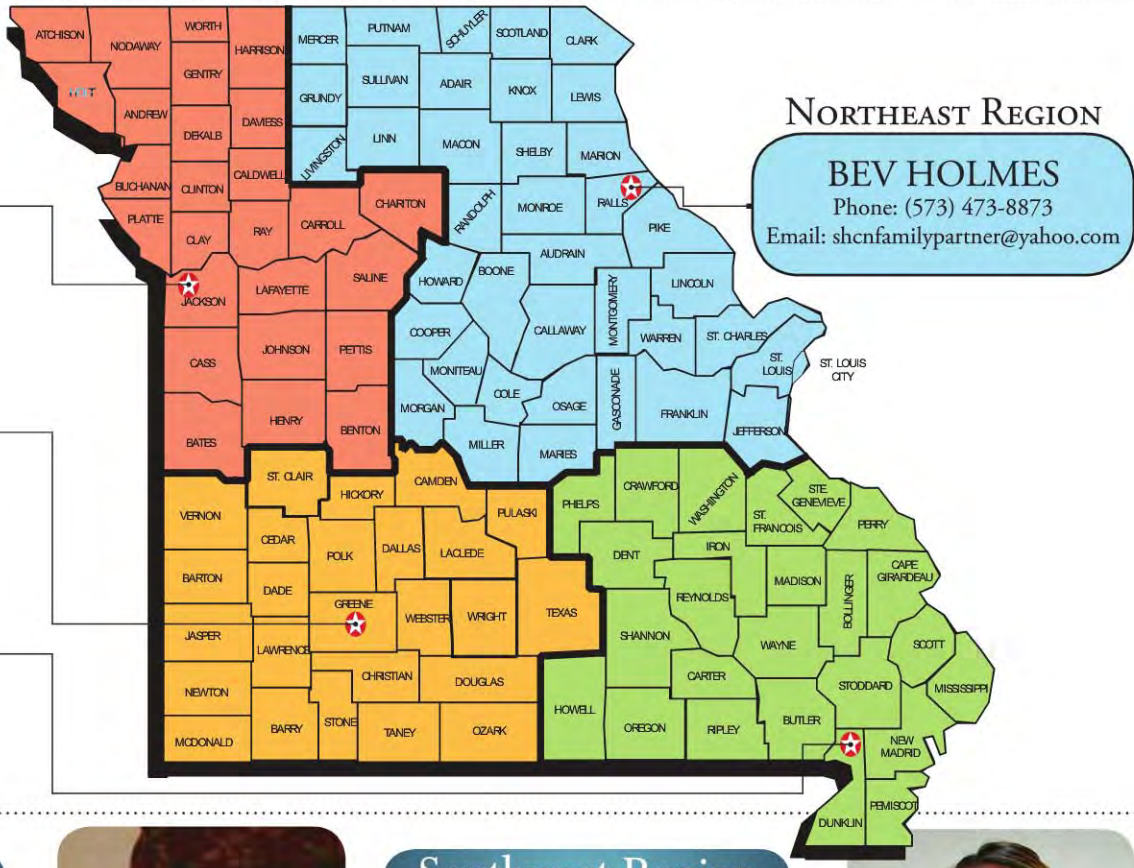

Northwest Region

HELPING OTHERS TO BE AWARE OF *YOUR* HEALTH NEEDS

Recently my 22 year-old daughter had a week-long visit to Mayo Clinic, one of only 3 clinics in the country specializing in her condition. She had more tests and appointments than I can count with neurologists, cardiologists and nurse educators. In the end we had a plan of action and a lot of paperwork. Now we have to go home and she has to go back to school. What if she has an episode at school? Her condition causes her to pass out, so she can't just tell someone how to help her. The doctors and EMTs in this small rural area neeed access to this information and education on her condition and how it is treated.

When she returned to school she met with the first responder coordinator in her campus town to explain the diagnosis, but it's a small rural area where doctors rotate in and first responders are volunteers; turnover is high. Her medical record needs to stay with her at all times. We purchased a medical bracelet that provides her diagnosis and says "please check flash drive on key ring." We loaded all of her medical records onto 3 flash drives. She keeps one on her key ring, one with her roommate, and one at her college. We blacked out her personal information when we scanned the PDF files, provided her test results, and a brief overview of her condition. We don't know if medical professionals will check or not, but we know that we have made sure that those who need to can access her health information quickly. ●

Southwest Region

UNDERSTANDING & DECIPHERING HEALTH INFORMATION

Have you ever gone into the doctor's office and left unclear about what they told you? Understanding information can be quite a struggle even when it comes from your doctor's office. If you don't have a medical background or degree you may leave with more questions than when you came.

I would like to share a few tips. First, start slow. Put away the information your doctor's office gives you while talking to your doctor. Review it at home and keep a file. Pay close attention to specifics such as new medication, dosage amounts and frequencies, and how long the medication is given, as well as side effects that may accompany a new prescription. If you have a new diagnosis, start looking for reference material on what to expect, common treatments, and medical specialists in your area. Make time to review information one page at a time. Use reputable websites to make sure the information is accurate and up to date. Lastly, schedule a follow-up visit to discuss any questions you may have that you didn't get answered. Your physician may not have the time to address all of your questions in the initial visit and it gives you time to prepare for the question and answer session. ●

MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES
BUREAU OF SPECIAL HEALTH CARE NEEDS

Southeast Region

COMMUNICATION FOR EVERYONE

I recently took a group of youth to a district function where they would receive spiritual influence, spend time getting to know each other better, and meet other youth in the area. When the event was over they all piled in my van and headed for a restaurant. As we were driving to the restaurant, I quickly noticed no one was talking. I adjusted the rear view mirror and saw little lights coming from cell phones. They were all texting. We agreed as a group that they would complete their "text" conversations and put away the phones and use their voices to talk to each other for the rest of our outing. My friend stated, "You know people have lost the art of good conversation." How true her statement was of today's electronic techno world. We email, text, and Facebook instead of having real conversation that allows us to use our senses and emotions to build relationships.

Why is this a problem? We begin learning to build relationships as children which, in the past, included playing with toys that were not electronic, talking, playing games that taught sharing, good sportsmanship, and critical thinking strategies. Today we have electronic stimulation that isolates us from using our skills that build personal relationships. It is important that we understand the importance of communication when building relationships with our family, co-workers, agencies, and medical and educational professionals we must deal with. Without good communication we will not be able to build relationships that grow through the years in ways that sustain and assist us during crisis.

I will never forget a slide that was in a presentation I previously did for parents. The slide stated to assume honorable intentions from all parties. As we advocate for our children or ourselves we must learn three key skills: to listen, communicate in a way that states our concerns with facts not accusations, and ask open-ended and close-ended.

To create a positive change in relationships with people in our lives, we have to apply all these points. When we practice listening, skillful representation of our position, and the asking of questions, we will set the environment for, as my friend said, "The art of good conversation." Good conversation builds good relationships. ●

Northeast Region

WHAT TO ASK YOUR DOCTOR

Many times preparing for a doctor's appointment is much like making a grocery list. Most of the time, you get little time to actually "talk" with your doctor because of scheduling. One way to ensure a your visit goes well is to make a list of questions ahead of time.

Think of matters relevant to the doctor you are going to see. Questions might relate to immediate issues, treatment, time to allow for results, other things that may come about during treatment, follow-up and/or if another doctor needs to be consulted as well. Sometimes there may to be several appointments before things are resolved.

Another thing to consider is your insurance. If medication, surgery or medical equipment is necessary, what will your insurance pay and how much will be out of pocket for you? This is a concern with which the nursing staff and/or doctor may be able to assist, or there is usually someone in the office that can find this information for you before you leave.

It's always good to inform your doctor of things relevant to your child's needs at home. Doctors see so many patients they don't always have time to take other issues into consideration. It's a matter of writing and script and sending you on your way. When you have scheduled a time, you need to make sure that they understand all needs pertaining to your child that they can help with, and make sure to have all your questions answered or at least discussed before they leave the room! Your appointment time is allotted just for you! Use it! ●

BUREAU OF SPECIAL HEALTH CARE NEEDS
P.O. Box 570
Jefferson City, MO 65102-570
Toll-Free: (800) 451-0669

MILLER COUNTY HEALTH CENTER
P.O. Box 2
Tuscumbia, MO 65082
Toll-Free: (866) 809-2400 ext. 308

MANAGING YOUR FAMILY'S HEALTH:

ORGANIZING YOUR FAMILY'S HEALTH CARE RECORDS

As the caregiver and primary decisionmaker for your family, it is empowering for you to have your information readily at hand so you can be the best advocate for your family's needs!

Have you decided it's time to get organized? There are many great reasons to organize your family's health care records. Having all of your information in one place makes it easier to understand your diagnosis and medications, prepare for visits with your doctor, and work with insurance companies. As the caregiver and a primary decisionmaker for your family, it is empowering for you to have your information readily at hand so you can be the best advocate for your family's needs!

Organizing your information means making it easy to find what you need when you need it, not that you have to start keeping everything or getting rid of documents. Your health care records include information about diagnosis, medication, tests, and surgeries as well as correspondence with insurance companies, your school, and other providers who may need information about your child's health.

There are many ways you can organize your health care information and everyone has a different organizational style. Some people use a bin or tub and throw all of their information into that with a label. Other people find that using a filing system for information and pamphlets, bills and statements, as well as other information works well. You may also choose to maintain your records electronically or through the use of a health care notebook. Consider your family's health care needs and experiences to help you decide what is important to you. The most important thing is that you have the ability to find your information when you need it. There are examples of care notebooks online or you may have received a notebook from a service coordinator or provider.

The first step in organizing your documents is to gather the information you know you have. Think about the education and health records you already have such as 504s, IEPs, immunization records, test results, etc. your child currently has or has had in the past. Keep the most current information where it is easy to access. If you're missing information call your doctor's office or hospital to get copies of helpful information you may not have. Make sure to give enough time for them to pull the information together, and make sure you know how much they will charge for the copies if there is a fee. After that use whatever system works for you, based on what you want to track. Put your information together so that it is easy to find when you need it. ●

WELL CHILD VISITS

MAKING SURE YOUR CHILDREN ARE HEALTHY

Your child is growing and changing and well-child visits are a way to make sure that they are as healthy as possible. Well-child visits give you a chance to ask your doctor questions and discuss concerns you may have about your child's development, behavior, and general well-being. They give your doctor a chance to make sure that your child is healthy, growing well, and detect and prevent health conditions early as well as the opportunity get to know you and your child better to build stronger relationships and trust.

Now, through the Affordable Care Act, well-child visits are free through private insurance as well as government programs, such as MoHealthnet. This means that you don't even have to pay a copay when you take your child to see the doctor for a well-child visit.

The American Academy of Pediatrics (AAP) recommends well child checkups for children from birth through age 21. These checkups are focused on prevention and finding "problems" early so treatment can be more successful. During a well-child visit your doctor completes a physical exam, checks your child's development and nutrition, gives immunizations as needed, checks your child's hearing, vision, and teeth, orders lab work as needed, and provides education and guidance about health and development to you and your child.

Well-child visits are important for children of all ages. They help make sure that newborns are eating properly and check for early signs of jaundice 2-5 days after they are discharged from the hospital. Dental screenings are recommended starting at 12 months old. Developmental screenings are recommended at 9, 18, and 30 months. One of the biggest changes is screening for autism spectrum disorders between 18 and 24 months so children can experience the long-term benefits of early intervention. Your child still will need checkups during the school and teen years as well. For your teenager some questions the doctor asks are personal and your teen may want you to step out of the room, make sure to respect your teen's wishes and keep the environment comfortable by avoiding asking questions during this time or responding to questions that you are not asked. Remember that these checkups are for you and your child. Don't be afraid to ask your doctor about anything regarding your child's health and needs.

If your child plays sports, his or her physical exam can be done at the same time as the well-child visits. Remember that insurance companies may have their own schedules for well-child visits. Make sure to check your policy to see how many well-child visits are covered.

Your child's well-child visits are important to his or her health and well-being. You know your child best, if you are concerned about your child's health and development talk to your child's doctor or nurse. ●

WELL-CHILD VISIT SCHEDULE

While the American Academy of Pediatrics recommends the following schedule, children and youth with special health care needs may need "well-child" exams more often.

Be sure to check with your insurance company first to make sure your visit will be covered under your health care plan.

- Newborn (2-3 days)
- 1 month
- 2months
- 4months
- 6months
- 9 months
- 12months
- 15 months
- 18 months
- 24 months (2 years)
- 30 months
- 3 years
- 4 years
- 5 years
- 6-7 years
- 8-9 years
- 10-11 years
- 12-13 years
- 14-15 year
- 16-17 years
- 18-19 years
- 20 years

For more information about well-child visits, contact Missouri Family to Family at 1-800-444-0821 or online at www.mofamilytofamily.org.

Missouri Family to Family Resource Center

UMKC Institute for Human Development
215 W. Pershing Road, 6th floor
Kansas City, MO 64108

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Our Partners

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
www.tips4kids.org

UMKC - IHD, 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.
800-452-1185
www.ihd.umkc.edu

The Department of Health and Senior Services
The DHSS serves the citizens of Missouri by working to improve the health and quality of life for Missourians of all ages. Within DHSS is the Special Health Care Needs which provides services for children and adults with disabilities, chronic illnesses, and birth defects. The services available from SHCN depend on the condition or illness of the individual and include diagnostic and treatment services, service coordination and Adult Brain Injury Rehabilitation Services.
800.451.0669
health.mo.gov/living/families/shcn/

Missouri Planning Council For Developmental Disabilities
MPCDD 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
www.mpcdd.com

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.
866-809-2400 ext. 308
health.mo.gov/living/families/shcn/familypartnership/

Missouri Family to Family Resource Center
The Missouri Family to Family Resource Center provides 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
www.mofamilytofamily.org