

# PARTNERING TOGETHER



**PAGE 8**  
**Keeping Children and Teens Healthy**  
Well-Child Checkups



**PAGE 11**  
**Seeing is Believing**  
Staying Focused on Eye Exams



**PAGE 13**  
**Is it an Emergency?**  
Knowing when to go to the ER ...



## HEALTH CARE ... WHAT DOES IT MEAN TO YOU?

**W**hen you hear the words “health care”, what is the first thing that comes into your mind? Is it a doctor, nurse or maybe even a place like a hospital?

There are many components to caring for our health. Health care goes beyond the people who help to take care of us and into areas that may not seem so common to us. Merriam-Webster’s online dictionary defines “health care” as ‘the maintaining and restoration of health by the treatment and prevention of disease especially by trained and licensed professionals (as in medicine,

dentistry, clinical psychology and public health)’. Source: merriam-webster.com.

This issue of ‘Partnering Together’ is about caring for our health and offers information about programs and services available, how to pay for the cost of our health care, keeping track of our well-being, and so much more.

We hope that you’ll find what you read helpful. If there is something you’d like to know more about, give us a call at 800-444-0821 or send us an e-mail at [moddrc@umkc.edu](mailto:moddrc@umkc.edu) ●





# M•O•D•D•R•C

MISSOURI'S FAMILY-TO-FAMILY DISABILITY & HEALTH INFORMATION RESOURCE CENTER

**T**he Missouri Developmental Disability Resource Center is a one stop resource center that provides supports to parents and self-advocates so that they are “not alone” in their experience with disability. We do this by providing free information and referral services, peer support (one on one mentoring), and volunteer and leadership opportunities to any Missouri residents.

One of our goals is to make sure that every family in Missouri that experiences a disability or special health care need will know about the services of the MODDRC. However, there are times when we talk to families that they often say, “I never knew you existed, I wish I had known about you sooner.”

One of the ways we hope to change this is by building new partnerships or strengthening existing partnerships with differ-

ent organizations across Missouri to use our services and to get the word out to families. One such organization we have been working with is the Missouri Planning Council for Developmental Disabilities (MPC). In addition to being one of our primary funders, the MPC is made up of individuals who have a lot of knowledge about services and resources for individuals and families with developmental disabilities. MODDRC and MPC staff will be meeting regularly to ensure that services offered are of the utmost quality and truly meet the needs of Missouri's families as well as look at innovative ways of supporting other family support organizations to access the resources of the MODDRC.

We have also partnered with the Thompson Center in Columbia Missouri. (*To read more about them, see page 5*) Families who call or come to the Thompson Center can immediately be matched



to a trained MOD-  
DRC-Sharing Our  
Strengths (SOS)  
mentor who has  
experience with  
Autism without  
having to call the  
MODDRC directly.  
The Thompson  
Center Family Men-

tor is a trained SOS Mentor of the MOD-  
DRC who can make matches using the over  
400 volunteers in the MODDRC database  
throughout Missouri. This allows families  
to use this service without having to make  
another phone call or to reach out to one  
more organization to get the support they  
may need. In addition, as families come in  
contact with the Thompson Center who  
don't have autism but are seeking services or  
support, Thompson Center has a means of  
sending them directly to the MODDRC so  
we can meet that family's information and  
peer support needs. This partnership assists  
the MODDRC to reach more families and  
provides an additional level of support for  
families received services from the Thomp-  
son Center, a win-win for everyone.

When we met with our stakeholders in  
October, they also confirmed that we were  
meeting the needs of those that knew about  
our services however it was clear that we  
needed to develop a plan to get connected  
to the other parents, self-advocates and  
professionals who didn't know about us.  
To meet this need we will be working with  
individuals like you and the many organiza-  
tions you come in contact with to develop  
the best strategy to get connected to others  
who may need our services. If you have  
ideas of how we can do this or know of  
organizations we should be working with,  
please give us a call or join our stakeholder's  
group. We look forward to working together  
to meet the needs of families in Missouri.  
Contact us at 800-444-0821 or  
moddrc@umkc.edu ●

# • SHARING OUR STRENGTHS •

Here's what families are saying about Sharing our Strengths  
peer support network at the Thompson Center:

*"If I needed more help I feel like I could go to her."*

*"She gets how overwhelmed I am and she helps me to prioritize and gives me  
permission to accomplish one thing at a time."*

*"It's so nice to unload on someone who has been there, since she also has a child  
with Autism she gets where I'm coming from."*

*"We've been feeling like an Island, having (mentor) takes away the sense that we  
are alone. It makes life more manageable."*

*"I'm so thankful for that piece (the mentoring) in our life."*



THE MODDRC  
AND THE  
UMKC  
INSTITUTE FOR  
HUMAN  
DEVELOPMENT  
HAVE MOVED

All of our phone numbers, e-mail addresses and web sites have remained the same, but our  
new mailing address is:

**215 W PERSHING RD, 6th FLOOR • KANSAS CITY MO 64108-4308**

If you'd like to come see our new location, give us a call at 800-444-0821.

THE MODDRC/F2F PARTNERING TOGETHER IS SUPPORTED WITH FUNDING FROM:



Since its launch in 2005, the Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri has become a national leader in confronting the challenges of autism and other developmental conditions through its collaborative research, training and service programs.

The Thompson Center partners with families and other support services to provide vital clinical services and promise for tomorrow through groundbreaking research and training.

The Thompson Center provides diagnostic, assessment and treatment services for children, youth and young adults, serving over 1700 individuals during the past year. Our programs emphasize individualized services that are comprehensive, coordinated, and caring. We offer a broad range of specialized medical, therapeutic, educational and behavioral interventions. Our aim is to enhance the ability of every individual to reach his or her full potential.

As the largest center in Missouri specializing in ASD and other developmental disorders, the Thompson Center serves as a centralized resource for families, educators, health care providers, researchers and state agency service providers. In 2007, it was designated a Missouri Center for Autism by the Missouri Department of Mental Health, along with sister programs in St. Louis and Kansas City. MU Thompson Center faculty facilitate the development of innovations in ASD programming and training curricula at these three centers, which together seek to establish a model for high quality ASD service delivery in Missouri.

## FOR CLINIC APPOINTMENTS

Phone: 573-884-6052

### More information

300 Portland Street, Suite 110 • Columbia, MO 65201

Phone: 573-882-6081 • Fax: 573-884-1151

E-mail: [thompsoncenter@missouri.edu](mailto:thompsoncenter@missouri.edu)

Web site: [thompsoncenter.missouri.edu](http://thompsoncenter.missouri.edu)

# THE YOUTH ADVISORY COUNCIL

INSPIRES CHANGE

**T**he Youth Advisory Council is an amazing team of young men and women who have transitioned or will transition soon from pediatric services to adult services. Our main focus is to find ways to make a seamless and effective transition for all. Our council provides a forum in which ideas are shared and plans are made to inspire change.

The Youth Advisory Council is a part of the Missouri Partnership for Integrated Community Services (ICS) project for Children and Youth with Special Health Care needs. The ICS project is a partnership between the Missouri Bureau of Special Health Care Needs, Family Voices of Missouri, and University of Missouri-Kansas City-Institute for Human Development. One of the primary goals for this program is *to support youth with special health care needs and their families to make a successful transition to adulthood.*

With that goal in mind we are convening five focus groups around the state to gain a better understanding of the transition from pediatric health care to adult care. Specifically, we will ask the following questions:

- Are the healthcare needs of YSHCN being met?
- Do the services they receive align with their personal priorities and meet their needs?
- What are their perceptions of availability and access to needed community services and supports?
- Do they have adequate insurance

to cover needed services?

- What types of services will they likely need in the beginning years of their transition?
- In what ways, is it anticipated that their needs for services will change in the early years of adulthood?
- What are the specific considerations YSHCN and their families should take into account as they decide whether to get a job or go to college?

We are looking for families, youth with special healthcare needs who are between 18 and 25, and professionals who work with individuals with special health care needs to participate in the focus groups. The focus groups will be co-facilitated by youth with special health care needs and staff from the UMKC - Institute for Human Development. Please come and:

- **Share your ideas**
- **Receive travel expenses and a \$20 stipend**
- **Help youth with special healthcare needs**
- **Help us make real change**

We plan to hold focus group meetings in the following areas between November 2009 and February 2010: Kansas City, Columbia, Kirksville, Springfield, and Poplar Bluff. Please contact us as soon as possible if you are interested in participating or in learning more. You may contact George Gotto at UMKC - Institute for Human Development at: [gottog@umkc.edu](mailto:gottog@umkc.edu) or (816)235-5334. ●



# SPECIAL HEALTH CARE NEEDS

**T**he Bureau of Special Health Care Needs (SHCN) provides statewide health care support services, including service coordination, for children and adults with disabilities, chronic illness and birth defects. State and federal funding support SHCN services. To be eligible for SHCN services, individuals must be a Missouri resident, have a special health care need and meet medical and financial eligibility when required. There is no fee for applying for these services.

## CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) PROGRAM

The CSHCN Program provides assistance statewide for children and youth with special health care needs from birth to age 21. The program focuses on early identification and service coordination for children and youth who meet medical eligibility guidelines.

As payer of last resort, the program provides limited funding for medically necessary diagnostic and treatment services for children whose families also meet financial eligibility guidelines. Children with special health care needs are those who have, or are at increased risk for a disease, defect or medical condition that may hinder their normal physical growth and development. These children require health and related services that go beyond those required by children in general.

## HEALTHY CHILDREN AND YOUTH (HCY) PROGRAM

The HCY Program provides service coordination and authorization for medically necessary services for MO HealthNet recipients with special health care needs from birth to age 21. Service coordination includes assessment through home visits and links to services and resources that enable participants to remain safely in their homes with their families. Authorized services may include in-home personal care, in-home nursing care and skilled-nursing visits.

## PHYSICAL DISABILITIES WAIVER (PDW) PROGRAM

The PDW Program provides service coordination and authorization for medically necessary services to MO HealthNet recipients with serious and complex medical needs who have reached the age of 21 and are no longer eligible to receive services through the HCY Program. Participants must require medical care equivalent to the level of care received in an intermediate care facility, not be enrolled in another waiver and have been eligible for private duty nursing through the HCY Program. Authorized services may

include in-home personal care, in-home nursing care, skilled nursing visits, supplies and equipment.

## FAMILY PARTNERSHIP INITIATIVE

The Family Partnership provides information and support to children and youth with special health care needs and their families. These individuals are also given the opportunity to network with each other through various settings including regional and statewide meetings.

Family Partnership members include individuals with special health care needs as well as their parents, legal guardians or siblings. SHCN utilizes information from Family Partnership members to enhance the relationship between SHCN and the individuals and families they serve. *(See pages 6-7 to learn more and meet your Family Partner.)*

## ADULT HEAD INJURY (AHI) PROGRAM

The AHI Program assists Missouri residents, ages 21 to 65, who are living with a traumatic brain injury (TBI).

Through service coordination, the program links participants to resources to enable each person to obtain goals of independent living, community participation and employment.

Participants who meet financial eligibility requirements may also receive rehabilitative services to help them achieve identified goals. Rehabilitative services include counseling, vocational training, employment supports and home and community-based support training. ●

## HOW TO CONTACT US

Missouri Department of Health and Senior Services  
Special Health Care Needs  
930 Wildwood Drive  
P.O. Box 570  
Jefferson City, MO 65102

Phone: 573-751-6246

Fax: 573-751-6237

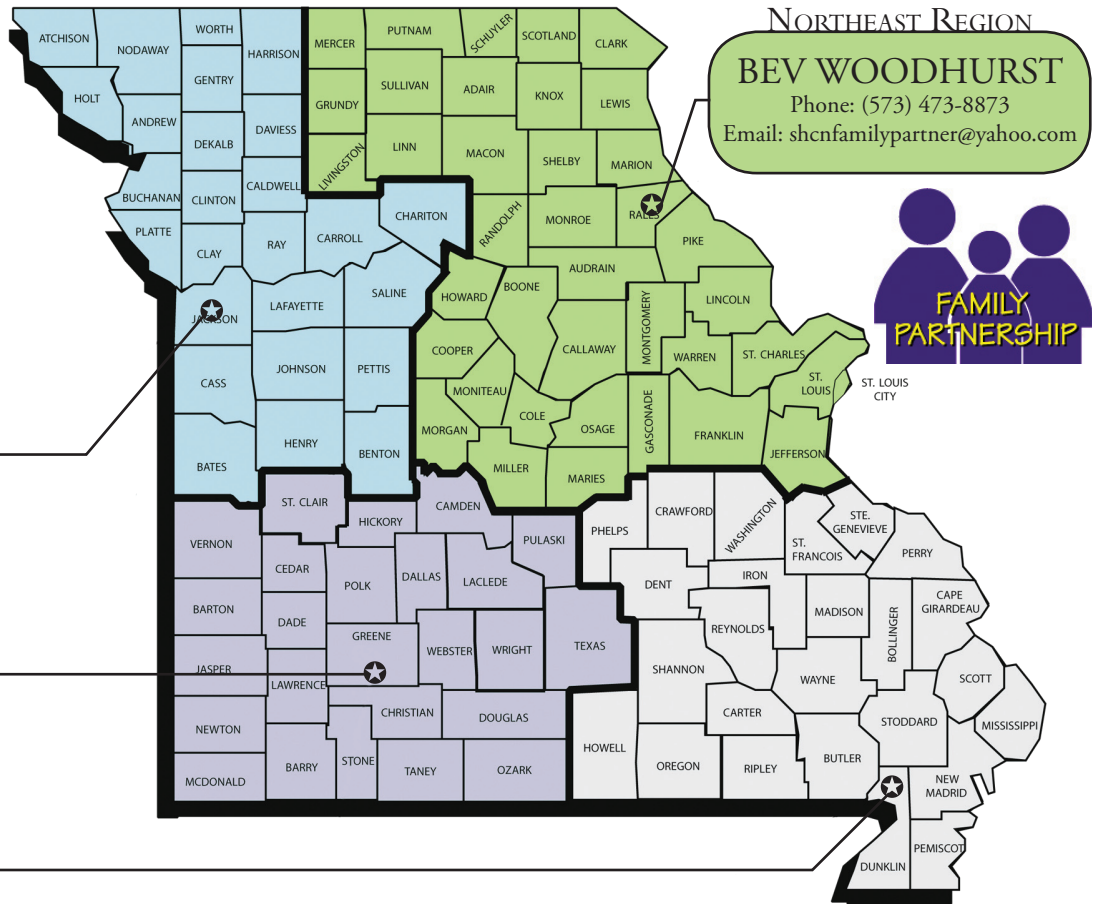
Toll-Free: 1-800-451-0669

Web site: [www.dhss.mo.gov/SHCN](http://www.dhss.mo.gov/SHCN)



Bureau of Special Health Care Needs  
**FAMILY PARTNERSHIP INITIATIVE**

The Family Partnership's mission is to communicate, advocate, and network through a family and agency team-supported effort to enable individuals with special health care needs to reach their fullest potential throughout life. ●



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**TRACY DAMARIO**

**RESPITE** - a word we know, love, and get so little of! As parents of children with special health care needs respite is something we so desperately need. The idea is to take a “break” and get yourself rested up so you can be ready for the next day. Respite can mean going to dinner, movies or even just getting to take a long bath or reading a book while someone is caring for your child. Another important benefit is having time to connect with other parents.

Having three children with disabilities, I know firsthand the need for respite. I understand the challenges of finding someone you can feel comfortable leaving your child with. This did not come easy for me and it took quite some time before I was able to enjoy a break. For me just having a set of eyes on my child so I could do the laundry, pay bills or even watch TV was very helpful even if I was still at home.

I would like to encourage to you make an effort to ask your family, friends, school staff, therapists or others if they have anyone they would recommend. Once finding someone, take your time interviewing them, check references carefully and know it's okay to even ask them to spend some visits with your child while you are at home.

As Family Partners we offer regional meetings and an annual retreat. These meetings provide information, resources and an opportunity to network with other parents. Some of the best information I've ever received came from other parents and our friendships continue to this day!

If you ever have questions or need help, please feel free to contact me at tsimmons8103@aol.com or 816-213-8103. ●

NORTHEAST REGION

**BEV WOODHURST**

As winter comes upon us, we all think about the flu, and other viruses being passed around. If you or your family needs help in getting immunizations, contact your local health department if you don't have a family physician. Even though the cold weather isn't here yet, the colds and other things are coming. Over the counter medications for colds can be purchased fairly inexpensively if you start thinking about it now.



Always check with your child's doctor before giving any over the counter medications. Also remember hand washing is the key to not spreading germs.

Bev Woodhurst  
Northeast Family Partner  
573-473-8873  
shcnfamilypartners@yahoo.com ●

SOUTHEAST REGION

**MAMIE BENSON**

I found that IT'S OK TO LET GO!



My granddaughter Mandi had graduated from the state school. She had turned twenty-one, but what would she do now? Talking to several people, I was very hesitant about her going to the local activity center for adults. Working with people with disabilities, I knew about the center but would it be the right fit for Mandi. I finally made a decision she doesn't want to be at home all the time and I can't be selfish. I made plans to meet with the coordinator to discuss it and then we met at the center. Having several health needs that had to be attended to we weren't sure the center would be able to meet her needs. In many ways she has needs similar to that of a young child. What makes it even more complicated is that she doesn't speak. What if she got hurt, if she got sick, if she cried, if she wanted something or needed me, how would that need be met and how would we know it was what she wanted?

We met with the director of the center, took a tour of the facility and decided she would start on Monday. Another what if – what if she wasn't ready or was it just me? The bus came and she almost ran to get on it, as I cried silent tears. Of course I did drive by the center several times, but didn't stop. Time came for her to be home and I was waiting. The center called and she had a great day; everyone loved her. She actually made it without me or PapPaw.

It is ok to let go, just check out where your loved one will be, ask questions and visit. Today, she is a very HAPPY young lady, sharing her day with people her age and she is safe. Think of your loved ones health and happiness, they will always need you but they need some independence and space from you too. If you want to talk or need some help, please feel free to call or e-mail me.

Mamie Benson – Family Partner-Southeast Region,  
573-919-4143, mamielbenson@yahoo.com ●

SOUTHWEST REGION

**KELLY BASS**

My name is Kelly Bass I am the new Southwest Family Partner covering areas such as Springfield, Branson, Lebanon, Joplin, Camdenton, & Clinton. I am a 34 year old mother of three ages 2 to 15 and (one on the way). We live in Springfield, MO. I am also a full time nursing student at St. Johns/ Southern



Baptist University, and have hands on experience taking care of a child with disabilities. My older two children were born perfectly healthy but Chloe, my youngest, was born with severe bi-lateral cleft lip and palate. She has had three surgeries and regularly undergoes testing for hearing and speech. She is the reason I chose to return to nursing school so I can work toward educating future parents of children with disabilities.

If you have any questions or concerns please feel free to contact me at: klylbass@yahoo.com or 417-833-2349 ●





# KEEPING CHILDREN AND TEENS HEALTHY

## • W E L L - C H I L D C H E C K U P S •

“When vision problems go undetected, children almost invariably have trouble reading and doing their schoolwork.

They often display fatigue, fidgeting, and frustrations in the classroom – traits that can lead to a misdiagnosis of dyslexia or other learning disabilities.”

American Optometric Association

**Y**our child or teen may be feeling fine, but to keep them feeling this way it’s important to schedule a “well-child” exam with their pediatrician or primary care physician (PCP). Even with special health care needs, it’s just as important to take your child or teen to their PCP when they are well.

Well-child checkups are important because they allow the doctor to make sure your child is healthy, growing well, and detect and prevent health conditions early. They also give you a chance to ask questions and discuss any concerns you may have.

In 2008, the American Academy of Pediatrics (AAP) updated their recommended guidelines for well-child checkups from birth through age 21. The new guidelines strengthen the focus on prevention and finding “problems” early when

treatment can be more successful. In general, the update includes more well-child visits in the early years and some changes in the testing done during these visits. These extra visits can help their doctor get to know your child better by seeing your child develop more closely and build a trusting relationship with the both of you.

### INFANT, TODDLER AND ELEMENTARY YEARS

One of the biggest changes to AAP’s guidelines is the addition of screening for autism disorders in the second year of life. This change helps doctors identify the signs of autism and refer children for treatment early. Early intervention – meaning to provide support and treatment to the child and family early – has been shown to have long-term benefits.

Another big change is checking newborns within 3-5 days of birth rather than waiting two weeks





to make sure they are eating properly and to check for early signs of jaundice. Also, AAP now recommends that children see a dentist beginning at their first birthday.

### TEENS, YOUNG ADULTS AND THE WELL-CHILD EXAM

Well-child visits are not just for young kids. Teenage years are when kids are most likely to not receive health check-ups because they're not sick as often. Today's teens deal with new social and educational pressures that we may not have been faced with. They are learning more about themselves and relying more on their friends for support. Plus, their bodies are going through changes as fast as when they went from being an infant to toddler. This is an excellent time to keep your teen on track for having a healthy adulthood.

At these visits, the doctor may ask questions about your teen's health, development and safety. Answering these questions are personal and could be uncomfortable for your teen. The doctor may ask you to step out of the room with your teen's permission. If

you decide to stay in the room, try to sit behind your teen to where they can't see your facial or body expressions. It's also important to understand they may not be able to answer all the questions or may answer questions differently from your expectations. Still, to keep a comfortable environment avoid asking or responding to questions.

For example, questions might be about: driving, like seatbelt safety and speed limits; job safety; tanning/sun screen; breast or testicle self-exams; how they're doing in school/if they're considering dropping out; and plans/feelings about their future. They will also screen for high risk behavior by asking questions about alcohol, drugs and tobacco; suicide/depression; interest in guns; and sexual activity – testing/protection/contraception.

### REMEMBER THE GOAL ... SAFE AND HEALTHY KIDS!

Don't be afraid to ask the doctor about anything regarding the care of your child/teen. It doesn't necessarily need to be health related – it could be about safety in the home or even teen driving. If you have concerns about your child or teen, talk with the doctor about them. Sometimes if a child/teen hears what you're saying to them coming from their doctor, they'll be more apt to believe in what you're telling them. This can be especially important during the teen years when "parents just don't understand".

Keep in mind that doctors and health care staff are required to maintain confidentiality, but they are also mandated reporters. When talking to children and teens, any concern about potential abuse in or outside the home require them to report it to appropriate authorities. Remember ... this is to keep your kids growing, safe and healthy! ●

### WHAT HAPPENS AT A WELL-CHILD CHECKUP?

During a well-child checkup, the PCP:

- Does a complete physical exam
- Checks your child's development and nutrition
- Checks your child's vision, hearing and teeth
- Gives immunizations, as needed
- Orders lab work (e.g., blood lead test) as needed
- Gives you health information about your child
- Finds health conditions before they become serious
- Gets to know your child so when your child is sick, the PCP can take better care of him/her

If your child plays school sports, the sports physical can be done at the same time as the well-child checkup. If you have a specific form your child's sport requires, i.e. Missouri State High School Activities Association – which is the most common & required form, visit [mshsaa.org](http://mshsaa.org).

### WELL CHILD CHECKUP 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.

- 3 to 5 days
- 1 month
- 2 months
- 4 months
- 6 months
- 9 months
- 12 months
- 15 months
- 18 months
- 24 months
- 30 months
- 3 years
- 4 years
- And once every year thereafter for an annual health supervision visit that includes a physical exam as well as a developmental, behavioral, and learning assessment

*Source: American Academy of Pediatrics' Bright Futures Recommendations for Pediatric Preventive Health Care 2008*



# GET ORGANIZED!

## KEEPING TRACK OF YOUR HEALTH CARE



Getting organized doesn't mean you need to keep every piece of paper you've ever received



**H**ave you made a new year's resolution to get your child's health care records organized? If not, there are many great reasons why you should consider doing this. For example, having all of the information in one location can help your next appointment go more smoothly. Getting organized doesn't mean you need to keep every piece of paper you've ever received - but instead making it easy for you to find things when you need them.

A health care notebook can look any way you'd like for it to. The most important thing is that you can find information when you need it. Seattle Children's Hospital has developed a wonderful set of forms that are available online and FREE that you can print out to help you put together your own notebook. Visit [www.cshcn.org](http://www.cshcn.org) and look for 'care notebook' under 'Planning & Record Keeping'.

If you do not have access to a computer and the internet, here are some tips on how to develop your own.

### 1. Get a notebook & tabbed dividers

Although your child may have a considerable health care history, generally a 2" notebook with pockets on the inside is convenient and easy to carry. Tabs can be as "pretty" and inexpensive as you'd like, but those that allow for everyday use will help keep your notebook in order and looking nice for years to come.

### 2. Gather information you know

Think about all of the doctors, specialists, medicine, hospital stays, surgeries, test results, education plans, immunization records, etc. you or your child currently sees or has in the past. Write them down. You may want to separate them out by category. For doctors, specialists and hospitals, write down their role in your health care, address and phone number. If you can remember surgery information i.e. dates and what the surgery was for, that's always helpful too. You may also want to think about including family health history like, heart disease, stroke and diabetes.

### 3. Getting information you don't have

Calling the medical records department of your doctor's office or hospital will help you get copies of helpful information you may not have. Be sure to allow the staff time to pull them together and print them out for you, especially if there has been quite a bit of health care for the patient. They may charge you for the copies, so be sure to ask up front if there's a charge and how much.

### 4. Put your notebook together

Select which sections you want to track and make your tabbed dividers, then put the information together so that it's easy for you to find the information when you need it. ●



# SEEING IS BELIEVING

STAYING FOCUSED ON EYE EXAMS

**S**tarting eye exams early can help prevent mistaken learning disabilities and costly treatments.

Did you know that when we're born we have to learn how to use our eyes? That's right! We may be born with the tools but it's up to us to figure out how to use them. Like most, you probably also didn't know that our eyes have over 17 skills they use to allow us to read, learn and play sports. Because seeing and learning are connected, a problem with our eyes or eyesight can be easily mistaken as having trouble learning. A "learning-related visual problem" can even make a big difference on how we stay focused.

Starting eye exams early can quickly catch any trouble a child is having and may lower the danger for a delay in their growth. Optometrists suggest that children have their first eye exam six months after birth. It's hard to imagine how doctors can actually tell if a baby is having trouble seeing but amazingly, they can! If no problems are found, optometrists then advise having another exam at three years.

Following Kentucky's lead, on July 1, 2008, Missouri became the second state in the nation to highlight the importance of early screening, diagnosing and treatment for children's eyes. The law is known as Senate Bill 16 or the Children's Vision Law (CVL). This law requires children entering kindergarten or first grade in any Missouri public elementary school to have a comprehensive eye exam from a state licensed optometrist or physician by January 1 of the enrolled school year. It also calls for children in first and third grade to have a vision screening and guarantees

that those who need follow-up care receive it. Yet, those who haven't had an exam won't be kept out of school. Parents and caregivers can request to opt out of participating by writing their appropriate school administrator.

The Children's Vision Law also created a governor-appointed "Children's Vision Commission". It includes two optometrists, two ophthalmologists, one school nurse, a representative of the Department of Secondary and Elementary Education and a representative from the Missouri School Board Association. The purpose of the Commission is to develop statewide guidelines for the exams and decide how schools are to report that students have received eye exams.

Luckily, getting an appointment for an eye exam has become easier and affordable now that many retailers offer optical/vision departments in their stores. If your child has Mo HealthNet, vision screening is a covered service through HCY/EPSTD (learn about HCY/EPSTD on page 12). For children who have HealthCare USA, transportation or gas reimbursement may be available for a vision screening appointment also under HCY/EPSTD. For more information or to arrange transportation, call HealthCare USA at (800) 688-3752. For children with other types of health insurance, contact the customer service department located on your benefit card to see if they offer transportation assistance or payment for similar services.

If you'd like more information on diseases of the eye or common eyesight challenges, visit our website at [www.moddrc.org](http://www.moddrc.org) or give us a call! ●

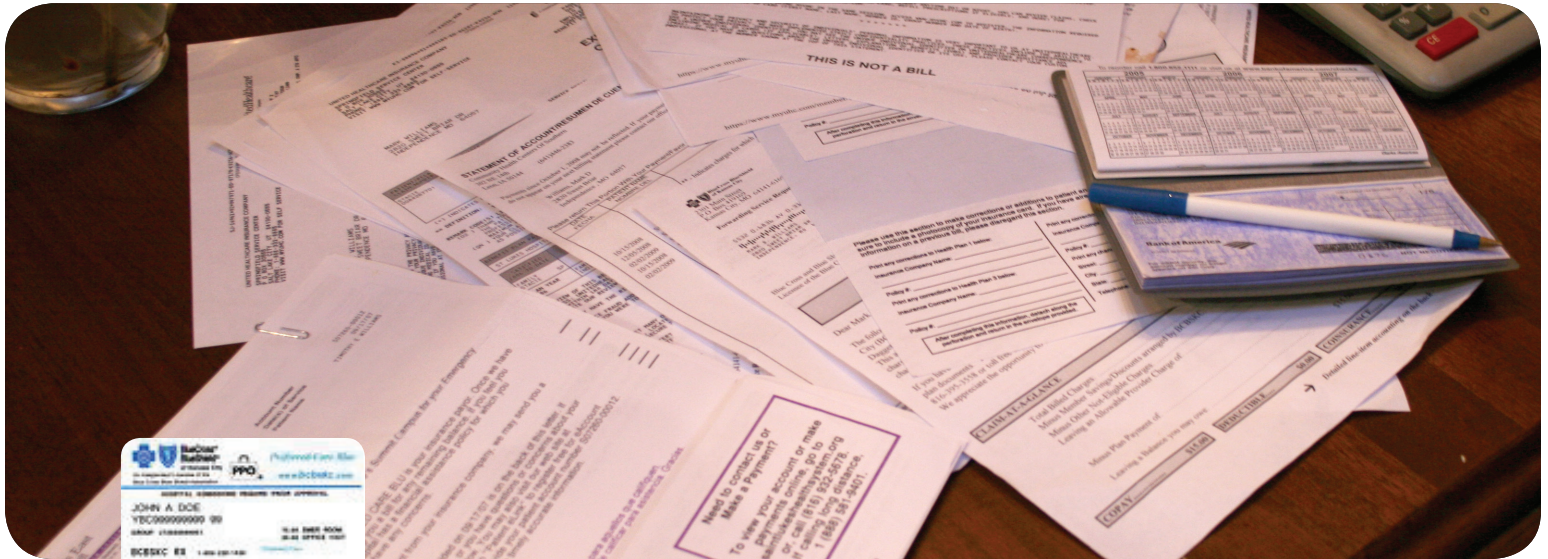
"When vision problems go undetected, children almost invariably have trouble reading and doing their schoolwork. They often display fatigue, fidgeting, and frustrations in the classroom – traits that can lead to a misdiagnosis of dyslexia or other learning disabilities."

American Optometric Association

"25% of students in grades K-6 have visual problems that are serious enough to impede learning."

American Public Health Association





# MAKING INSURANCE WORK FOR YOU

GETTING WHAT YOU NEED AND KEEPING IT WITHIN YOUR BUDGET

## TIPS AND TOOLS

- Make a list of your health care needs.
- Stay Positive – you'll get further
- If your claim is denied, don't pay. Insurance companies anticipate out of pocket payment.
- Who can help you.
  - Your provider
  - Advocate
  - Legal support
  - Insurance regulator.
- Document
  - Messages
  - Conversations
  - EOBs
  - Bills
  - Denial reasons
  - Letters of appeal or medical necessity
  - Medical records
- Keep your information together.
- Use an organizational system that works for you.

**S**election of an insurance carrier is potentially complicated. Questions surrounding the type of policy and interpretation of insurance language can be confusing. After selecting your policy and trusting an insurance carrier, there may be complications receiving payment and handling denied claims. In the quest to get the most out of your insurance carrier there are tools to simplify the process.

When selecting an insurance carrier, list your health care needs. Compare plans with a summary of what each one covers. Check with your health care provider or potential providers to see if they accept the plan, if not what out-of-network benefits can you expect. After selecting a policy, read carefully to understand the details. Know what services are covered, rules and regulations, as well as limitations or exclusions. Make sure you know the policies on medical necessity and experimental procedures. Be proactive, if a procedure is not covered appeal to your carrier before it is performed. Your doctor can help by writing a letter providing support for the procedure based on research in the language insurance carriers use. Always document all

correspondence with your insurance carrier and providers.

If your claim is denied don't pay it right away. Make every effort to get the issue corrected. Insurance companies anticipate out of pocket payment on claims they deny. Stay positive, as the adage goes, you can catch more bees with honey than vinegar. The reason for denial should be on your Explanation of Benefits (EOB), make sure you have it in writing and maintain this information for your records. Call your provider to ensure their receipt of the denial, ask what their contracted rate for that particular service is with your insurance carrier. Some errors can be corrected and resubmitted for payment. They may have supporting documents or experience working with the type of denial. If you call your insurer some things can easily be fixed. Don't accept no as an answer, ask to speak to a supervisor. If you can't get a definite answer ask when you can expect to hear back from them. Record the time and date they give you, if you don't then document that there was no reply and make contact. In a dispute your documentation can be used to your benefit. ●



**M**ost of us have watched them on TV and some of us even feel like they're our second home. When our kids become sick or injured, it's natural to have almost a knee-jerk reaction to head to the ER. We are their primary caregivers, so we want the highest quality of health care and ERs are there for us all the time.

Generally, the best person to see when you need health care is your personal doctor. He or she will often know your child's medical history and specific health care needs. Nevertheless, you need to seek emergency care when their life or health depends on it.

Most of today's ERs have different levels of health care available within them. Going there, especially if it's the middle of the night, takes the guilt away for us because we know they have what it takes to diagnose and treat our child's condition. On the other hand, we all pay for that convenience. The cost for a trip to the ER is about four times that of an urgent care clinic or visit to the doctor. It's in the middle of the night. What do I do? If you don't think your child has life-threatening symptoms or injury, call their doctor first. Doctors typically have an answering service available to patients during non-office hours. If you receive an answering machine, listen to the message. They may offer a phone number to their service or another doctor who is taking your doctor's phone calls.

If you're not sure it's an emergency but you have a gut feeling it's serious – it's always best to call 9-1-1 or head to the ER immediately. Your child's life may depend on it.

### WHAT IS TYPICALLY CONSIDERED AN EMERGENCY?

A medical condition qualifies as an emergency when it happens suddenly and threatens organ or bodily functions. Conditions are also emergencies if they happen suddenly and pose a significant threat to health. Here are some warning signs to look for and should be checked out by emergency health care providers.

# THE ER

T O G O O R N O T T O G O ?

- Any significant change from normal behavior
  - Confusion or delirium
  - Decreasing responsiveness or alertness
  - Excessive sleepiness
  - Irritability
  - Seizure
  - Strange or withdrawn behavior
- Severe headache or vomiting, especially following a head injury
- Uncontrolled bleeding
- Inability to stand up or unsteady walking
- Unconsciousness
- Abnormal or difficult breathing
- Skin or lips that look blue or purple (gray for darker-skinned children)
- Feeding or eating difficulties
- Increasing or severe, persistent pain
- Fever accompanied by change in behavior (especially with a severe, sudden headache accompanied by mental changes, neck/back stiffness, or rashes)
- Severe or persistent vomiting or diarrhea

### WHEN TO GO TO THE URGENT CARE CLINIC

Urgent care is for symptoms that happen suddenly and don't meet the definition of an emergency. But they do need prompt care to keep them from getting worse. A few examples are sudden rash with fever; sprains; minor fractures or burns and mild reactions to medicines.

### POISON CONTROL - (800) 222-1222

If your child ingests something, call them first. Often they can help you determine whether it is serious enough for them to go to the ER and how quickly. Also, if you tell them, they will call the ER to let them know you will be coming and call to check your child's progress. ●





# MEDICATION ERRORS

KNOWING MORE ABOUT WHAT WE TAKE HELPS TO REDUCE THEM

**H**ave you ever realized that you've received the wrong medication or maybe the directions on the label weren't what you thought you heard the doctor tell you?

Although doctors and pharmacists try their best to prevent them, mistakes still happen. Everyone makes mistakes. Unfortunately when it comes to medicine, what is designed to keep us healthy can also make us very sick. Adding yourself to the team with the doctor and pharmacist will add another checkpoint to help keep you or your loved ones safe ... and possibly alive.

Here's how to be a team player with your doctor and pharmacist.

## DOCTOR

When you receive the prescription from your doctor make sure you can read the directions and you understand them. Then, ask him/her these questions.

- What condition is this medication used to treat?
- How much do I take and when?
- When should I notice that the medicine is beginning to work?
- What are the potential side effects from using it? What should I look for and if I find them, what do I do?
- What do I do if I miss a dose?
- Do I need to make a follow-up appointment with you? If so, when?

## PHARMACIST

When you receive the medication from the pharmacist, most often they'll ask if you have any questions. Take this opportunity to ask them. A lot of mistakes can be prevented simply by reading the label.

- Check the patient's name and address information. Is that you or your loved one? Is the address correct? If not, let the pharmacy know.
- Read the name of the medication. Is it the same as what your doctor said you'd be taking? If not, ask the pharmacist. It may be a generic name, but it's always best to verify it's the right medicine.
- Look at the medication itself. Often the label will have what the pill should look like and the numbers the pill will have on them. Do they match?
- Do the directions look like what you read on your doctor's prescription? If not, ask the pharmacist to go over them with you and double check the original prescription.



If you find that there's been a serious error, try to work it out with the pharmacist first but also let your doctor know what has happened. If you feel the error was critical and are not satisfied with the way the situation is being handled, contact the Missouri Board of Pharmacy at 573.751.0091, [pharmacy@pr.mo.gov](mailto:pharmacy@pr.mo.gov), or webpage <http://pr.mo.gov/pharmacists.asp>. ●

# WHAT'S HAPPENING AROUND THE STATE ...

A QUICK GUIDE TO LOCATING HEALTH RESOURCES IN YOUR AREA

## COVERING THE COST OF HEALTH CARE

Federal Info  
 • [www.disability.gov](http://www.disability.gov)  
 • [www.healthfinder.gov](http://www.healthfinder.gov)  
 • [www.healthreform.gov](http://www.healthreform.gov)

## MISSOURI EARLY HEARING DETECTION & INTERVENTION (EHDI)

573-751-6266

## MISSOURI FIRST STEPS EARLY INTERVENTION PROGRAM

(birth to three years)  
 866-583-2392  
 E-mail: [webreplies@desemissouri.gov](mailto:webreplies@desemissouri.gov)  
 Web page: [desemissouri.gov/divspeced/FirstSteps/whatisfs.html](http://desemissouri.gov/divspeced/FirstSteps/whatisfs.html)

## MISSOURI DEPARTMENT OF INSURANCE

573-751-4126  
 Web page: [insurance.mo.gov/consumer/lhindex.htm](http://insurance.mo.gov/consumer/lhindex.htm)

## MO HEALTHNET FOR KIDS

888-275-5908  
 Web page: [dss.mo.gov/mhk/index.htm](http://dss.mo.gov/mhk/index.htm)

## MO HEALTHNET BENEFITS CENTER

888-275-5908  
 Web page: [www.dssapp3.dss.mo.gov/fmw-famisweb/](http://www.dssapp3.dss.mo.gov/fmw-famisweb/)  
 Provider Search: [dssapp.dss.mo.gov/ProviderList/sprovider.asp](http://dssapp.dss.mo.gov/ProviderList/sprovider.asp)

## MISSOURI HEALTH INSURANCE POOL

800-821-2231  
 Web page: [www.mhip.org/](http://www.mhip.org/)

## MISSOURI RX (PRESCRIPTION) PLAN

573-751-3425  
 Text Telephone: 800-735-2966  
 Web page: [morx.mo.gov/](http://morx.mo.gov/)

## MISSOURI SPECIAL HEALTH CARE NEEDS

800-451-0669  
 Web page: [dhss.mo.gov/SHCN/index.html](http://dhss.mo.gov/SHCN/index.html)

## INSURANCE COMPARISON CHECKLIST:

• [dhss.mo.gov/SHCNpdfs/inscomparison.pdf](http://dhss.mo.gov/SHCNpdfs/inscomparison.pdf)

## PRIVATE INSURANCE - HMO SERVICE AREAS

See list for individual phone numbers  
[insurance.mo.gov/consumer/hmo/HMOserv.htm](http://insurance.mo.gov/consumer/hmo/HMOserv.htm)

## OFFICE OF AUTISM SERVICES

Telephone: 573-526-3848

## CHILDREN'S DIVISION

615 Howerton Court • P.O. Box 88  
 Jefferson City, MO 65102-0088  
 Telephone: (573) 522-8024  
 Web page: [www.dss.mo.gov/cd/](http://www.dss.mo.gov/cd/)

## DIVISION OF DEVELOPMENTAL DISABILITIES

1706 E. Elm St.  
 P.O. Box 687  
 Jefferson City, MO. 65102  
 Local: 573-751-4122  
 Toll-Free: 800-364-9687  
 TT Phone: 573-526-1201  
 Fax: 573-751-8224  
 Email: [dmhmail@dmh.mo.gov](mailto:dmhmail@dmh.mo.gov)

## DIVISION OF YOUTH SERVICES

3418 Knipp, Suite A-1  
 P.O. Box 447  
 Jefferson City, MO 65102-0447  
 Telephone: 573-751-3324  
 Fax: 573-526-4494  
 Web page: [www.dss.mo.gov/dys/](http://www.dss.mo.gov/dys/)

## FAMILY SUPPORT DIVISION

615 Howerton Court  
 P.O. Box 2320  
 Jefferson City, MO 65102-2320  
 Telephone: 573-751-3221  
 Web page: [www.dss.mo.gov/fsd/](http://www.dss.mo.gov/fsd/)

## MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

P.O. Box 570  
 Jefferson City, MO 65109  
 Telephone: 573-751-6170  
 Fax: 573-751-5350  
 Web page: [www.dhss.mo.gov](http://www.dhss.mo.gov)  
 E-mail: [CLPHS1@dhss.mo.gov](mailto:CLPHS1@dhss.mo.gov)

## REHABILITATION SERVICES FOR THE BLIND

State Office  
 P.O. Box 2320  
 615 Howerton Court  
 Jefferson City, MO 65102-2320  
 Telephone: (573) 751-4249  
 Fax: (573) 751-4984  
 Web page: [www.dss.mo.gov/fsd/rsb/](http://www.dss.mo.gov/fsd/rsb/)  
 E-mail: [askrsb@dss.mo.gov](mailto:askrsb@dss.mo.gov)

## FIND A HEALTH CARE PROVIDER

All specialties: [nlm.nih.gov/medlineplus/directories.html](http://nlm.nih.gov/medlineplus/directories.html)  
 Mo HealthNet: [dssapp.dss.mo.gov/ProviderList/sprovider.asp](http://dssapp.dss.mo.gov/ProviderList/sprovider.asp)  
 Mental Health: [mentalhealth.samhsa.gov/databases/kdata.aspx?state=MO](http://mentalhealth.samhsa.gov/databases/kdata.aspx?state=MO)

## FIND A COMMUNITY HEALTH CENTER MISSOURI PRIMARY CARE ASSOCIATION

573-636-4222  
 Web page: [mo-pca.org/healthcenters.htm](http://mo-pca.org/healthcenters.htm)

## COMPARING HOSPITALS

• [www.nlm.nih.gov/medlineplus/directories.html](http://www.nlm.nih.gov/medlineplus/directories.html)  
 • [www.qualitynet.org](http://www.qualitynet.org)

## ORAL HEALTH MISSOURI DENTAL ASSOCIATION

573-634-3436  
 Web page: [www.modental.org](http://www.modental.org)

## MISSOURI DENTAL HYGIENIST ASSOCIATION

Web page: [mdha.org/consumerinformation.html](http://mdha.org/consumerinformation.html)

## MISSOURI PRIMARY CARE ASSOCIATION

573-636-4222  
 Web page: [www.mo-pca.org/healthcenters.htm](http://www.mo-pca.org/healthcenters.htm)

## ORAL HEALTH NETWORK OF MISSOURI

573-634-4022  
 Web page: [www.ohnm.org/](http://www.ohnm.org/)



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

• THE MISSOURI DEVELOPMENTAL DISABILITY RESOURCE CENTER/FAMILY-TO-FAMILY HEALTH INFORMATION CENTER •

# PARTNERING TOGETHER

VOL. 1, ISSUE 3 • WWW.MODDRC.ORG

## 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 | [www.tips4kids.org](http://www.tips4kids.org)



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

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](http://www.ihd.umkc.edu)

#### UMKC - IHD

The Institute for Human Development, located within the University of



#### Family Voices of Missouri

FVMO is a

statewide organization dedicated to informing, strengthening, educating and empowering Missouri's children, youth and young adults with special needs and their families to become respected & valued

leaders and to collaborate with professionals who care for them.

417-597-3197 | [www.fvmo.org](http://www.fvmo.org)



#### 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 Head Injury Rehabilitation Services.  
800.451.0669 | [www.dhss.mo.gov/SHCN/index.html](http://www.dhss.mo.gov/SHCN/index.html)



#### 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](http://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 | [www.dhss.mo.gov/FamilyPartnership/](http://www.dhss.mo.gov/FamilyPartnership/)



#### Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center

At the MODDRC/F2F, 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 | [www.moddrdc.org](http://www.moddrdc.org)