

Missouri Families for Effective Autism Treatment

Providing autism information, resources, and supports for Missouri since 1997



June 2009

MO-FEAT

NEWS AND NOTES

Families Helping Families

We want you to know how important we think it is for you to reach a parent when you call the MO-FEAT office. We believe there is a common bond between families even though we may live in different regions and have different experiences with autism. So, we “get it.” We understand what life is like for families and what it’s like to feel frustrated when trying to find the help you need. We’ve “been there” interacting with doctors and professionals, providers and therapists, family members and neighbors; helping siblings cope; and feeling the stares of strangers.

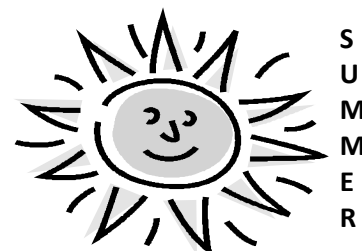
We want other families to know that they’re not alone, and that one of the most helpful coping strategies is talking with other parents and networking. Our staff shares information, but we also share your desire to have a life that’s just a little easier. Behavior tips, recommendations for a new doctor, places to get a sensory-friendly haircut, summer camps...whatever the need is, we know how the little answers can make such a big difference. Support and encouragement are *not* just the icing on the cake. They are the ingredients that give us hope, keep us going, and help us to cope.

Each of the MO-FEAT staff has one or two children who are on the autism spectrum. If we are out of the office tending to our own kids, we make every attempt to call you back within 24 hours, even though we only total 1.5 full-time staff. Yes, that’s all! Yet, we think 1.5 staff who really “get it” is worth 10 who haven’t walked in your shoes. It may take us a little longer to get the directory updated, or to accomplish long-term projects, but you can rest assured, that when our projects are finished, they are truly tools that will help you. To learn more, call us or visit our website. We “get it.”

2388 Schuetz Rd. A-49,
St. Louis, MO 63146

314-993-0806 or 1-877-275-8988

www.mofeat.org, info@mofeat.org



What is MO-FEAT?

Missouri Families for Effective Autism Treatment (MO-FEAT) is a non-profit 501c3 whose mission is to provide education, advocacy, and support for families and the autism community, and to promote early diagnosis and effective treatment.

What Do We Do?

- Connect families to resources and supports through our toll-free warm line phone, email help, and news through our active listserve.
- Match parents with mentors.
- Publish a statewide autism resource directory, a guide to navigating Missouri services, and other print and web publications.
- Hold parent-professional educational meetings and family outings.
- Advocate for improvements in state autism policy.

L o s e t h e T r a i n i n g W h e e l s

MO-FEAT’s first annual Lose the Training Wheels (LTTW) camp was held during the week of June 8th in partnership with the Down Syndrome Association of Greater St. Louis. Thanks to a generous donation from the estate of Anna Baumer and memorial donations made in her name, MO-FEAT was able to cut the program fee in half for 20 Lose the Wheels participants. “I think it’s an amazing thing. I really do. I’d say it’s one of the 10 best things I’ve seen in my life,” said Sharon Moeller of MO-FEAT who co-directed the program. Ninety percent of the campers with autism learned to ride in just five days of 90-minute sessions. The program, which will be held again in June 2010, is ideal for children ages eight and older and uses specialized bikes to gradually increase the difficulty level and balance needed.

Congratulations Kids!



The Missouri Commission on Autism Spectrum Disorders

The Missouri Commission on Autism Spectrum Disorders met in May for its first meeting following reappointments to the commission by Governor Jay Nixon. Members received an update on the proceedings of the Missouri Autism Guidelines Initiative, reviewed the new *Navigating Autism Services* guidebook, and finalized the committees that will conduct the work of the commission. Four committees will be formed:

- Education
- Healthcare
- Workforce Development
- Individual and Family Supports

A steering committee, comprised of the committee chairpersons, will also serve to integrate the committee recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for Missouri individuals of all ages with autism spectrum disorders. Anne Roux, Executive Director of MO-FEAT, will serve as the Family Supports committee chair. Your input is always welcome!


Thanks for all of your support that helped to make Heart and Sol 2009 a successful event!

Thank you to all those who have been raising funds to support MO-FEAT! We are continually amazed at the generous support of the autism community in Missouri.



♦Sam Malek of More Than Coffee in Ballwin raised \$200 through their Cup of Kindness for MO-FEAT campaign in April and arranged for donations of pizza and drinks for our Parents Night Out event in April.

♦Angela LaMacchia and staff from Dr. John Pruet’s Cognitive and Perceptual Development Laboratory at Washington University School of Medicine raised \$530 through donations to their St. Louis Marathon team.

♦Student members of the Night Out organization at Washington University in St. Louis raised nearly \$850 through their Autism Awareness fundraising in April. Night Out provides free childcare for families who have children with autism so parents can have a Night Out during the school year. Contact MO-FEAT this fall for information on Night Out respite.

Sponsor-a-Family Initiative To Provide MO-FEAT Publications for 534 New Families

<p>We would like to specifically recognize those who raised funds for MO-FEAT’s Sponsor-a-Family campaign and providers who contributed to our 2009 MO-FEAT Autism Resource Directory publication:</p> <p>Friend (Sponsored up to 5 families)</p> <p>Laurie Berger, DC* Lisa Cooseman, OTR/L* Rebecca Fehlig Christine Mattson Midwest Music Therapy Services* Julie and John Northrip Dr. Gary Olson* Donnell Probst Angela Quigless Ride on St. Louis* Jackie Swinnie Stephanie Thompson</p>	<p>Guide (Sponsored up to 10 families)</p> <p>Anonymous Rebecca Blackwell Jeff Caul, Ph.D.* Diane Marchiando, MSpEd* Sharon Moeller PS Kids, LLC* The Hairy Elephant* Mary Unger-Boyd, DC* Robyn Weilbacher</p> <p>Navigator (Sponsored up to 20 families)</p> <p>Martha Brown, Atty* Jim Burchett, DMD* Tom Cunningham, OD* Aurelia Dunagan, DMD, PC* Woods Mill Pediatrics* Sara Wright, Ph.D., Wright & Wright*</p>	<p>Mentor (Sponsored 50 or more families)</p> <p>Anonymous Maureen and Ray Hamtil Steve Kanne, Ph.D. Paul Shattuck, Ph.D.</p> <p>Special Recognition</p> <p>Betty Schaefer (55 families) Anonymous (100 families)</p> <p>*These Provider contributions helped to support families to receive the Resource Directory.</p> <p>Congratulations to Betty Schaefer, the winner of this year’s Sponsor-a-Family campaign!</p>
--	---	--

Autism at Home Series



Are We There Yet? Vacation Tips for Families

Carolyn Radicia, MO-FEAT
Resource and Information Specialist
www.mofeat.org, cradicia@mofeat.org

Vacations are a time to get away from the routine of daily life and to have some togetherness in a different environment. Your vacation may be to go visit relatives, a weekend at a lake, or flying to Disney World. Wherever your vacation may take you, it may take a bit of extra planning and thinking about accommodating your family member who has autism.

There are many things to consider, but here are some suggestions to make your family vacation go a bit smoother for all of the family members.

- **Talk to your family member with autism** about where your family is visiting, what you will see, and what is going to happen on vacation. Show pictures to help with understanding.
- **Call ahead** to see if there are special amenities available such as a refrigerator in a hotel room, a disability-friendly tour, special passes, etc. This may help ease transitions from one place or activity to another if you are aware of what is available.
- **Involve your children in the planning.** If you have already chosen the destination, allow them to help make the list of what needs to be done. For example, what to bring, places to visit, packing the suitcases, load the car, etc. Again, show pictures to help the person with autism understand the process and order of getting ready for vacation. They can then help with completing the list, one item at a time.
- **Plan to bring some special items**, like sensory toys, earplugs or headphones, favorite books and games, and special snacks. Children will feel more comfortable knowing some of their own toys are with them. You may also want to provide a very small new toy or book each day as a special surprise for vacation time.
- **Plan activities, games, and sites to see each day that are interesting to your child.** It may be as simple as choosing to count the number of



times you see farm animals during a day's drive or visiting a tourist site where everyone is free to visit at your own pace. This will help keep children engaged during the vacation.

- **Remember to be flexible and creative too!** If you unexpectedly run into noise or activity levels that your child with autism cannot tolerate, have a back-up plan. You might switch the activity to a different day, or decide to sleep in and play in the hotel pool all day, or watch a movie at Grandma's and have your own picnic on the living room floor.
- **Allow choices.** Vacations can often be unpredictable and therefore somewhat stressful. If everyone in the family is allowed to take turns to decide things, then all may feel more comfortable. Choices might include where to have dinner or what to choose to eat, what to see, or where to go on certain days, which movie to watch, what book to read, or which path to hike in the park. When you allow choices, you are creating opportunities for kids to have positive control and keeping them engaged.
- **Keep your basic home rules and routines.** This will help with consistency for children with autism. They may not understand that places are different, but you can help by following the same morning, meal-time, and bedtime routines, and enforcing rules such as "hands to self" or "inside voices".
- **Make sure your child has identification.** It can be carried in her pocket or backpack, put on shoelaces, or pinned to the back of her shirt. Keep a photo of your child with you at all times.

Tips for Families From Families

Resources on Traveling with Autism

Family Travel and Autism: www.autismtravel.org
Autism and Travel: search www.autism.about.com for articles and blogs
Autism Society of America: www.autism-society.org
Autism Speaks: www.autismspeaks.org
Autism Cruises: www.autismontheseas.com

Autism at Home Series

READY, SET, GO!



If you flip this page over, you will see the article on enjoying family vacations. But before you know it, the summer will be over and another school year will be upon us! Time flies when you are having fun! But take a tip from someone who has done this before, it is best to start early to prepare for the new school year.

Many families with children on the autism spectrum must do a little extra preparation to make sure our children are well-prepared for the new year. It might even be a year of transition: to kindergarten, to middle school, or to high school, which may take even more preparation. Here are some ways you can take full advantage of the opportunities to get ready for school.

Review the IEP

- Read the IEP again and familiarize yourself with the different sections (present level of performance, goals, accommodations, etc.) for your child.
- Make a list of updates, including new concerns or progress your child made over the summer to share with school staff.
- Schedule an informal meeting with the team of teachers, therapists, assistants and aides to share summer progress and any updates about your child with autism.

Open House

- Meet the teacher and special education staff for the new school year. Have your child meet him or her and get to know one another. Even if the child is having the same teacher, it is good to see him again after the summer break.
- Introduce your child to peers (and their parents) who will be in the class and request a class list.

- Write down dates for upcoming events taking place at school and in the classroom. Make a calendar with your student.
- Ask about a school supply list if not already available, and a class schedule so you are aware of daily activities and special education service time.
- If new, take a tour of the school with your student and get familiar with where things are. If not new, it's a good review to walk the grounds and talk with your child about what takes place where.
- If needed, plan to have someone show your child the process of the lunch line and sitting with peers. Ask about lockers and purchase a lock in advance to practice opening and closing the lock.
- Discuss what the best way is to communicate about your child's daily activities and concerns. Is it email? Is it a notebook passed back and forth?
- Visit with the nurse to discuss medication for your child if needed, or potential bathroom issues. You may want to provide a change of clothes as well.

Odds and Ends

- Discuss sensory breaks and what activities your child will be doing during them. Do school staff recognize the signs your child may show to let them know a sensory break is needed?
- Review transportation details (which bus your child will take and what time to expect her home; where to pick him up if you are driving him, etc.).
- Take a picture on the first day of school to record your child growing up! Enjoy these moments!

More Resources for Transition to a New School Year



- **Autism Society of America**, www.autism-society.org
- **Missouri Parents Act (MPACT)**, Missouri's Parent Training and Information Center, www.ptimpact.org, or call 1-800-743-7634
- **National Dissemination Center for Children and Youth with Disabilities** www.nichcy.org
- **Pacer Center**, www.pacer.org
- **Wrightslaw**, www.wrightslaw.com

MO-FEAT Board Says Goodbye and Hello

The MO-FEAT Board bid farewell this month to Patti LaVesser, Ph.D., an Occupational Therapist and instructor at Washington University in St. Louis, who has served on our board for the past four years. Dr. LaVesser, who is loved by families who participated in her research projects and clinics, will be relocating to Colorado. Steve Kanne, Ph.D., a Neuropsychologist at the Thompson Center for Autism, has also served on the MO-FEAT board for many years. He will be moving to an Advisory Board position, and we are thrilled to have his continued input.

Goodbye's are sad but open new doors. MO-FEAT's newest board member, Krista Peyton, J.D., is the proud parent of a son who has autism and a daughter. She brings enthusiasm, passion, motivation, and real life experience to our board. When asked what she would recommend to families, Krista said that it helps to view your journey with autism as a marathon, instead of a race. In her own words...

My life is a balancing act. I live between the typical world and the world of autism. Every day I spend at least a moment with my foot in both worlds. Most days I am stuck in a maze of therapy appointments, chauffeuring, dirty laundry, and professional responsibilities. And most days I find myself looking for a ray of light and hoping for a moment of inspiration.

There are moments that come into our lives that change us, that define us, or perhaps refine us. There are moments when my son on the autism spectrum is 'stimming,' having a tantrum because he can't fully communicate, or responding to sensory overload. Those moments stay with me long after the event.

There are those moments when behaviors test my patience and perseverance. There are those moments when I celebrate my daughter's typical growth and development. And again there are those moments when I grieve as I watch my son struggle developmentally and socially. Then, there are those joyous moments that have a wonderful way of balancing out the not so great moments, for instance when progress is made on an IEP goal or when a step in an ABA program is accomplished.

Each and every moment, irrespective of whether happy or sad, has made me a better person, more tolerant, less judgmental, more patient, more appreciative, and mentally stronger. I encourage everyone with a loved one on the autism spectrum to strike a balance between the tears of frustration with the tears of joy that come from succeeding in spite of the obstacles. I challenge us all to find a moment of inspiration, or at least an opportunity to soak up a ray of light. -Krista Peyton

Initiative Focuses on Developing Missouri's First Autism Standards

Work continues on Missouri's first statewide standards for screening, diagnosing and assessing autism. This project, known as the **Missouri Autism Guidelines Initiative (MAGI)**, is led by a team of 40 physicians, service providers, educators, state agency representatives, and several family members. A full list of the 40 MAGI participants is available at www.dmh.mo.gov/mrdd/new/magi.htm.

MAGI is a direct outcome of the Missouri Blue Ribbon Panel on Autism which recommended that "there should be established a committee of major stakeholders to adopt screening, diagnosis, assessment and treatment standards for Missouri." MAGI's goal is simple: To facilitate early and accurate diagnosis of Autism Spectrum Disorders (ASD) leading to the early interventions that are critical to a child's development and quality of life.

Two MAGI meetings have already taken place, with the most recent on June 8th, 2009. Topics of discussion included qualifications needed by diagnosticians; a Community Collaboration Model; a Tiered Model of Care—ranging from single discipline care by a physician or psychologist to multidisciplinary teaming for persons requiring a more intensive level of care. The third MAGI meeting will be held in October, with published guidelines anticipated in early 2010. The guidelines will be available in both print and electronic formats.

A representative of the MAGI project will meet with The Missouri Advisory Committee on Autism, comprised of parent representatives of the regional Autism Projects, to give information and answer questions about the Guidelines.



2388 Schuetz Rd., Suite A-49
St. Louis, MO 63146

Non-Profit Org.
U.S Postage
PAID
Chesterfield, MO
Permit #26

Return Service Requested

➔ Recommended Summer Reading List

The Official Autism 101 Manual by Karen Simmons and others. (2006). Visit <http://autism101manual.com/>



Making Autism a Gift: Inspiring Children to Believe in Themselves and Lead Happy, Fulfilling Lives. (2007) by Robert Cimera.

The *Living with Autism* series from the Autism Society of America at www.autism-society.org. Here is a sample of the topics:

- Next Steps: A Guide for Families New to Autism
- Growing Up Together (for talking with kids about autism)
- Supporting Appropriate Behavior in Students with Asperger's
- Moving From Preschool to Kindergarten
- Transition Across Grade Levels, to Middle School, and to Adulthood

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns (2005) by B. Myles and J. Southwick.

A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed (2005) by Wilmschurst & Brue. And/Or *Negotiating the Special Education Maze* (2008).

NOW AVAILABLE

2009 MO-FEAT Autism Statewide Resource Directory

Navigating Autism Services: A Community Guide for Missouri

Produced through a family-professional partnership between Missouri's Office of Autism Services and MO-FEAT.

These resources can also be downloaded from our website at www.mofeat.org.

To request a print copy, call 314 993-0806 or 1-877-275-8988, or email us at info@mofeat.org. Please provide us with a mailing address.

Donations are appreciated to cover the cost of printing and mailing.