

# Parent Time

A Newsletter for MoSPIN Parents

Volume 15, Issue 2

October 2010



## Editor's Corner:

Dear Parents,

Hello again to those who have been with us for a while, and welcome to those of you who are new to MoSPIN. I am Stacy Meyer. I am the mother of three children; two teenagers, Katrina and Jessica, my little man Lucius, and we are expecting a little brother for Lucius in December. Lucius just turned four. He was born with Hypopituitarism, along with this came the diagnosis of bilateral Optic Nerve Hypoplasia. He has some light perception and can distinguish between high contrasting colors (black and white). He sees red as well. We have yet to determine to what extent he can see, but as soon as he is talking like he should be, he will tell us. He is a very intelligent child, curious and mischievous, and most definitely strong willed. I spend most of my time working with Lucius or trying to find new ways to work with him. Everyday has its challenges but we have our rewards too.

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RETINOBLASTOMA**

We started with First Steps. First Steps is for children aged birth to 3 years who have issues that may put them behind developmentally. We also were fortunate enough to have Delta Gamma Center for Children with Visual Impairment in St. Louis. They work specifically with children with visual impairments from ages birth to 3 years. In addition, we've been involved with MoSPIN since Lucius was a baby.

Lucius is now in his second year of preschool through our local school district. He is doing well. This year we are trying something a little different. Last year he went four half-days a week. This year we rewrote his IEP so that he is going to school all day. Lucius seems to like it and we are all hoping that the extra interaction with the other kids will help him as well.

We are very fortunate to have so many teachers and therapists that are willing to work so hard to get and keep Lucius on track. He has an O & M (Orientation and Mobility) specialist. She is working with him on use of his cane and learning his way around the school and playground. He has learned to stop when his cane bumps something. He can identify a step up or down. He readily takes his cane when we are in public now as well. When asked to take his cane he reaches out for it and can adjust it in his hands by himself to where it needs to be.

He has a speech therapist who works with him on his language use. So far he is still being very stubborn about this. He talks a lot at home but not so much for her. He is making progress though; one step at a time.

Lucius has a therapist for fine motor skills. She is trying to teach him to feel and

sort small objects. Most of what she is working on now is considered pre-braille skills. His sense of touch and distinction are what he will use to read Braille among many other things.

Lucius loves interacting with his classmates. They all seem to really like him. He likes them too. This year he has the same teacher in the mornings but the students are new to him. She took each child and introduced them to Lucius and showed them how to approach him and play with him. His teacher is very good about incorporating his special tools into the other children's learning time as well. Because Lucius likes music so well, she sings the class rules and other activities to the class. She frequently asks the other students how they can make the activity so that Lucius can participate.

He has a para-professional that is with him all day. This is a special aide just for him. She is very good with Lucius. Since this is her second year with Lucius, she knows him pretty well. She helps him get to his therapies and whatever else he may do during the day. She knows Braille and is helping him with that as well.

Lucius went through a spell of getting up in the middle of the night. I tried everything I could think of to get him to sleep all night. I took away naps, kept him up late, and did lots of physical activity, all to no avail. He was still only sleeping a couple of hours per night. He was on a pretty rigid schedule. Night after night it was a battle to get him to go back to bed. I finally had to talk to his endocrinologist about starting him on melatonin. Some kids with visual impairments don't make enough of this at night. He is only taking 1 mg a night but it has made all the difference in the world. If any of you are having similar issues, talk to your child's doctor about it.

When it comes to your child's education, don't be afraid to ask questions. Be firm when you know what your child needs. You as a parent are their best advocate. Don't be afraid to introduce

your child to new things and experiences. The more they know the better off they are. If you have other parents around pick their brains as well. I did. I found out all kinds of useful information that way. Until next time, keep working with those little wonders and good luck.

Stacy Meyer

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## Potty Training Continues

YES! We are still working on the potty training. Lucius has made great progress. It is a slow process with him. He is better about telling you he needs to go. If asked if he needs to go to the potty, he will answer yes or no (usually with a nod of his head). He will go in the potty, when taken. Lucius can go into the bathroom on his own if he has to go, but he still needs help getting to the toilet. He can pull his pants down with very little help, and can pull them up without much help at all.

Unfortunately, he is only doing this at home right now. During the day at preschool, his teachers have a set schedule for the kids to go to the restroom. This helps a lot to reinforce what I have already started and continue at home. We have missed the mark for him being totally potty trained by the time he turned four. But I am very proud of the progress he has made. It is easy to forget sometimes how hard it is for these little guys when they can't see the world around them and everything has to be pieced together. I am confident that with the help we are getting from his teachers and the work we are doing here at home Lucius will master the potty soon.

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## *Parents' Bill of Rights*

The following document is available on the Missouri Department of Elementary and Secondary Education (DESE) website for parents to understand their rights during the IEP process.

This document does not confer any right or rights beyond those conferred by federal or state law and is intended for informational purposes only.

For additional information, contact the Department of Elementary and Secondary Education, Division of Special Education at (573) 751-0699 or [webrepliespeco@dese.mo.gov](mailto:webrepliespeco@dese.mo.gov).

January 1, 2010

As a parent of a child with a disability, you have the right to:

1. Attend individualized education program (IEP) meetings and represent your child's interests.
2. Have an advocate or expert present at individualized education program (IEP) meetings.
3. Receive a copy of your child's evaluation, disagree with it, and request one independent educational evaluation at public expense.
4. Provide a written report from outside sources as part of the evaluation process.
5. Examine all education records pertaining to your child and be provided with a copy of the individualized education program.
6. Disagree with the decision of the individualized education program (IEP) team and pursue complaint procedures, including: filing a child complaint with the Department of Elementary and Secondary Education, state paid mediation, have an impartial due process hearing, and appeal the due process decision to the court.
7. Participate in reviews of the individualized education programs (IEPs) and in any decision to change any aspects of the IEP, as well as receive a written notice of action before a change in your child's educational placement or the provision of a free and appropriate public education.

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| <p>8. Have your child placed in the least restrictive environment and in a general education classroom to the greatest extent appropriate.</p> <p>9. Request an accommodation to provide effective communications if you have limited English language proficiency.</p> <p>10. A free appropriate public education for your child with an individualized education program designed to meet your child's unique needs, which may include, but not be limited to, special education and related services, such as</p> | <p>assistive technology devices and services; transportation; speech pathology services; audiology services; interpreting services; psychological services, including behavioral interventions; physical therapy; occupational therapy; recreation, including therapeutic recreation; counseling services, including rehabilitation counseling; orientation and mobility services; school health services; school nurse services; social work services; parent counseling and training; and, medical services for diagnostic or evaluation purposes.</p> |
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### **Children Who Are Deaf-Blind**

*Information in this article was provided by the National Consortium on Deaf-Blindness ([www.nationaldb.org](http://www.nationaldb.org)) in the November 2007 issue of "Practice Perspectives".*

“Although the term deaf-blind implies a complete absence of hearing and sight, in reality, it refers to children with varying degrees of vision and hearing losses. The type and severity differ from child to child. The key feature of deaf-blindness is that the combination of losses limits access to auditory and visual information.

Children with deaf-blindness require teaching methods that are different from those for children who have only hearing or vision loss. When both vision and hearing are affected, especially from birth or early in life, natural opportunities to learn and communicate can be severely limited.

More than 90% of children who are deaf-blind have one or more additional disabilities or health problems and some may be identified as having multiple disabilities rather than deaf-blindness. In these cases, the impact of combined hearing and vision loss may not be recognized or addressed.”

Each year every state provides a count of the number of children, from birth through age 21, who have been identified as deaf-blind. We have 188 children on the Missouri Deafblind Census. Support for the families and professionals who serve these children is provided by the Missouri Deafblind Technical Assistance Project. Susan Bonner is the Coordinator of the Project and can be reached at 314-776-4320, ext. 3255 or [sbonner@msb.k12.mo.us](mailto:sbonner@msb.k12.mo.us).



## “Stay-Put” Play Spaces For Your Child

Would you like your child to have a play environment that:

- \* Includes high interest, multi-sensory materials?
- \* Is anchored down?
- \* Allows for repeated, self-initiated exploration?
- \* Is easily adaptable to your child’s unique needs?
- \* Can be used individually or with others?
- \* Is inexpensive and easy to make?

If you answered “yes”, then you will want to check out “Hold Everything: Twenty “Stay-Put” Play Spaces for Infants, Preschoolers and Developmentally Young Children with Sensory Impairments and Other Special Needs”.

<http://www.ohiodeafblind.org/assets/files/products/holdon.pdf>



### Need Web Assistance?

Many of the articles in this issue of Parent Time refer you to websites. If you do not have access to the internet, just ask your MoSPIN Parent Advisor to assist you. I am also available to provide information or hard copies of resources. You can contact me at 573-295-4808 or at 800-622-5672 (to leave a message).

Ginny Williams  
Lead Parent Advisor for MoSPIN



## Tots 'n Tech Newsletter on Using Low-Tech Assistive Technology and Adaptations

The Tots 'n Tech Research Institute (TnT) has published its August 2010 newsletter, which provides tips on using low-tech assistive technology (AT) and adaptations that are inexpensive, easy to make, and useful for increasing young children’s participation in daily activities and routines. The newsletter is available online at <http://tnt.asu.edu/files/August2010.pdf>

Their March 2010 newsletter contained an interesting article on “Using Arms and Hands in Activities and Routines”. It focused on opportunities throughout the day to use low-tech AT and easy adaptations with household items during daily routines. It included pictures of easy to make adaptations and a breakdown of ideas according to “morning routine, bath time, meal time, outdoor play,” etc. Take a look!



## Family Information Guide to Assistive Technology & Transition Planning



This 50 page guide is aimed at providing families with the information they need to effectively prepare for and participate in periods of transition in their children's lives.

Individuals may order one free copy of the guide. Visit their homepage,

[www.fctd.info](http://www.fctd.info), and click on the link to fill out an order form.

## New Programs Available

Two new programs are available for children who are visually impaired in Missouri. The Comprehensive Low Vision Project (CLVP) focuses on school age children (3-21 years) in eastern Missouri. The Drury University Children's Center for the Visually Impaired (DU CCVI) focuses on infants and toddlers (birth-3 years) in southwestern Missouri. Though each program has a different focus and will serve children of different ages in different geographic areas, we wanted to make sure MoSPIN families were aware of these new programs.

### The Comprehensive Low Vision Project

“The purpose of CLVP is to provide school age children who are visually impaired, ages 3-21, with clinical low vision evaluations, prescribed optical devices, and instruction in device use. Your child will receive, at no cost to you or your child's school district, a comprehensive low vision evaluation, a complete written report with recommendations for appropriate low vision devices, any devices prescribed (with a few exceptions such as CCTVs or computers), and instruction in the use of those devices in your child's school, home, or community until he or she is proficient in using his or her new tools. Low vision clinics take place throughout eastern Missouri to best accommodate families from a variety of locations throughout the region.”

For more information contact Jennifer Coy: [jenniferkcoy@hotmail.com](mailto:jenniferkcoy@hotmail.com); [jcoy@lhbindustries.com](mailto:jcoy@lhbindustries.com); 573-579-4359.



### Drury University Children's Center for the Visually Impaired

“In response to a need in the community of Springfield, the Ozarks, and beyond, the Drury University Children's Center for the Visually Impaired (DU CCVI) has been established. The purpose of the DU CCVI is to provide children with visual impairments ages birth to three and their families with the initial supports to have a positive impact on development. In its initial phase, the DU CCVI is collaborating with the Children's Center for the Visually Impaired in Kansas City to ensure that the referral process and other initial supports are in line with approved practices for work with this population.

Some of the supports provided by the DU CCVI include home visits to collect information on functional vision and other needs, consultation provided to parents and other care providers on how to best meet the needs of young children with visual impairments, and to point to other community, state, and national resources readily available to these children and their families.

As DU CCVI is just beginning, the initial aims of the project will focus on awareness and training for families and doctors or other professionals that will be held on the campus of Drury University in Springfield. The plan is to integrate infants and toddlers into an expanding service model for pre-school age children in Phase 2 of the project goals.” For more information contact Ashley Perry at [aperry02@druary.edu](mailto:aperry02@druary.edu) or 417-6856.

**Announcing: INSIGHTS Family Conference**

**An Inspirational One-Day Conference  
For Parents of Children Age 6 and Under**

**Delta Gamma Center for Children with Visual Impairments  
1750 South Big Bend Blvd., St. Louis, MO 63117**

**Saturday, October 16, 2010  
9:00 am – 4:00pm**

**You won't want to miss this exciting opportunity  
To hear from incredible speakers and connect with friends!**

**To register, contact Ashley Quinn, (314) 776-1300 or [aquinn@cdgkids.org](mailto:aquinn@cdgkids.org)**

**Limited childcare available – Reservations required – Register today!**

**"Spotlight on Visual Impairment"**

**Retinoblastoma**

Retinoblastoma is a "malignant tumor (cancer) of the retina, generally affecting children under the age of 6. Usually hereditary, retinoblastoma may affect one or both eyes. Retinoblastoma has a cure rate of over 90 percent if treated early. Without prompt treatment, the cancer can spread to the eye socket, the brain, and elsewhere. Depending on the size and location of the tumor, treatment options include laser surgery, cryotherapy (a freezing treatment), radiation, and chemotherapy. In some cases, the affected eye may need to be removed." This information comes from the American Foundation for the Blind website in the "Eye Conditions" section at <http://www.afb.org/Section.asp?SectionID=93#R>

Suggested resource: [www.instituteforfamilies.org/retinoblastoma.html](http://www.instituteforfamilies.org/retinoblastoma.html)



Statement of Non-Discrimination: "Missouri School for the Blind, as part of the Department of Elementary and Secondary Education does not discriminate on the basis of race, color, national origin, sex, disability or age in its programs and activities. Inquiries related to Department programs may be directed to the Jefferson State Office Building, Title IX Coordinator, 5<sup>th</sup> Floor, 205 Jefferson Street, Jefferson City, Missouri 65102-0480; telephone number 573-751-4212."