

Parent Time

A Newsletter for MoSPIN Parents

Volume 15, Issue 1

February 2010



Editors Corner:

Hello, again!

Just a little reintroduction: I am Stacy Meyer. I am the mother of three children; two teenagers, Katrina and Jessica, and my little man Lucius. Lucius is almost 3 ½ now. Lucius 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 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.

He is learning to get around places with his cane, socialize with classmates at preschool, sleep all night (not all day) and use his words to get what he needs and wants. He is getting really good with hanging on to his cane and learning to keep it on the floor. We have started to teach him how to move it from side to side in front of him as he walks.

He gets really excited and hops down the hall at school with it in front of him. We practice every chance we get when we are out in public. I want him to learn that he MUST use his cane and why.

Lucius loves interacting with his classmates. They all seem to really like him. He likes them too. It makes me so proud to see him sitting on the floor with them during group time and participating in the activities. His teacher is very good about incorporating his special tools into the other children's learning time as well. He has a paraprofessional that is with him all day. This is a special aide just for him. She is very good with Lucius. She helps get him to his therapies, and with whatever else he may do during the day. She knows Braille and is helping him learn it as well.

Lucius went through a very long 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. The slightest little schedule change would throw his whole system out of balance. Night after night it was a battle to get him to go back to bed. Slowly, with a constant routine and a good schedule, he has learned when it is time to sleep and time to be up. He almost never gets up at night now, unless he is wet and/or cold.

Last but not least has been the issue with him using, or rather not using his words. The kid has this immense vocabulary, but is lazy about it. He won't use his words unless absolutely forced to. He knows what it means to ask for things like a drink or bite. He knows what no means and simple commands like come here. He will talk to me all day long, but his teachers have had to get creative to get him to open up. His stubbornness can be very trying. But, as he has become more comfortable with his teachers and learned what they will and won't accept from him, he is getting better. I imagine soon I will be saying "Lucius, be quiet for a little while please." Until then, we will keep working with him.

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Getting Your Baby to Sleep on a “Normal” Schedule



Are you having trouble getting your child to sleep at night? Then this article may be for you. You can read the whole article at the site listed below. Here are a few of their suggestions for changing sleep patterns:

- Establish a bedtime routine.
- Sleep only in a crib or bed - not couch, playpen, etc.
- Wait a bit before responding to night waking.
- Analyze napping times.
- Keep your child active during the day.
- Consider discussing melatonin with your doctor.
- Keep a sleep diary.

You can read the complete article at:

<http://www.familyconnect.org/parentsites.asp?SectionID=75&TopicID=350&DocumentID=3851/>



Other Articles That Might Be of Interest

Helping You and Your Child Get a Good Night’s Sleep

www.tsbvi.edu/Outreach/seehear/summer01/sleep.htm

Help! My Baby Won’t Sleep

<http://www.wonderbaby.org/articles/baby-sleep.html>

Use of Melatonin in Young Children for Sleep

http://journals.lww.com/ycjournal/Abstract?2002/10000/Use_of_Melatonin_in_Young_Children_for_Sleep.5.aspx



SLEEP Study Needs Nationwide Participants

A sleep study is underway at the Sleep and Mood Disorders Laboratory at Oregon Health and Science University (OHSU) in Portland, Oregon. They are seeking children, ages 5-20, who have little or no light perception to screen for participation in a research study. Contact sleeplab@ohsu.edu or call Amber Laurie, Research Assistant, at 503-494-4677 for more information.



Grants Available for Child Health-Related Expenses

The United Healthcare Children's Foundation has a program that makes grant monies available to help children who need critical health care treatment, services or equipment not covered or not fully covered by their parent's health benefit plans. UHCCF provides grants to families to help pay for services such as speech therapy, physical therapy, occupational therapy sessions, prescriptions and medical equipment such as wheelchairs, orthotics and eyeglasses. Grant applications, criteria and access to online help can be found at <http://uhccf.org/>.

We don't know anyone who has actually used this program, but it might be something your family would want to investigate.



More on Potty Training

Hello again, from Potty Training Central!

Yes we are still working on the potty training. Lucius has made great progress. He will go in the potty, when taken. He has started verbalizing more when he needs to go. I am still trying to teach him that he has to actually say "I need to potty" to someone, not just into the air and hope someone is paying attention. Lucius has figured out how to get his own pants down to go pee. Now, if I could just get him to do it in the bathroom. Instead, it is wherever the mood strikes him. (Cleaning carpets was not in the job description.) Since Lucius is in preschool, his teachers are helping to reinforce what I have already started and continue at home. Maybe by the time his fourth birthday rolls around in the fall, he will have mastered the whole potty training thing. Cross your fingers for us.

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Resources Regarding Toilet Training

Getting Ready for Potty Training

<http://www.familyconnect.org/parentsites.asp?SectionID=75&TopicID=350&DocumentID=3850>

It's Time to Sit on the Potty

<http://www.familyconnect.org/parentsites.asp?SectionID=75&TopicID=350&DocumentID=3851>

Potty Training Your Special Needs Child

<http://www.wonderbaby.org/articles/potty-training.html>

Toilet Training Children with Deafblindness: Issues and Strategies

www.tsbvi.edu/Outreach/seehear/summer00/toilet.htm



Family Connect

FamilyConnect.org is a great website for parents of children with visual impairment that is sponsored by the American Foundation for the Blind and National Association for Parents of Children with Visual Impairment. It offers access to information by age ranges (infants and toddlers, preschoolers, grade schoolers, etc) or you can browse information featured topics. You can also connect with other parents on message boards or specialized blogs.

For a limited time only, you can join the Family Connect Community and receive a free Braille Trail Fun Kit.



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*

Parents Share Words of Wisdom

"I Wish I had..."

As part of the October 2009 issue of Parent Time I shared the booklet **"I wish I had..."** This publication focused on the wisdom and experiences of parents of children who are deafblind from across the country. I was very touched by many of the articles and immediately thought about all the wisdom and experiences that could be shared right here in Missouri by our MoSPIN families. I encouraged you to share some of your wisdom as a parent of a child with a visual impairment with other MoSPIN families by submitting a short response to the sentence, *I wish I had....* (As an example, you could share how or why you learned a particular lesson or how you could have done things differently.) It was my hope that I could compile your thoughts into a publication to share with our Missouri families. Maybe my timing was "off" and folks were busy with the holidays because I only received a couple of responses. I'd still love to hear from **you!** Just send me a note or email that starts with "I wish I had..." Or ask your Parent Advisor for assistance.

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Publications and an iPhone "App" for Parents

Two booklets are now available for parents of children with disabilities.

The Parent's Guide to Special Education provides information about the identification process and provision of educational services in a user-friendly format.

The booklet can be down-loaded free from www.dese.mo.gov/divspeced/Compliance/specedguidance.html.

Also available is the newly developed **Parents' Bill of Rights**, which lists ten legal rights of parents of a child with a disability.

This document is available at www.dese.mo.gov/divspeced/Compliance/parentbillofrights.html.

For those of you who use iPhones, the Parent Educational Advocacy Training Center (PEATC) has developed an Individualized Education Program (IEP) Checklist iPhone application. The IEP app is offered free of charge. To download the IEP Checklist app, visit the Apple iTunes store, and type IEP Checklist in the search box.



“Spotlight on Visual Impairment”

Retinopathy of Prematurity

Retinopathy of prematurity (ROP) is a condition that can cause vision loss or blindness in infants born prematurely. As the name implies, it is caused by damage to the retina. ROP is one of the leading causes of blindness in children.

Ordinarily, the blood vessels of the retina complete their growth at the baby’s due date. Premature infants are born before the retinal blood vessels have completed their growth. As the vessels continue to grow after a premature baby’s birth, abnormal vessels, as well as scar tissue, can form inside the eye. In extreme cases, the retina may become scarred, distorted, or detached (separated from the back of the eye). This causes visual impairment ranging from a mild decrease in acuity to total loss of vision. Generally, the more premature an infant is and the less she weighs at birth, the greater the risks of developing ROP. Children with ROP may have other health impairments associated with prematurity.

Several types of treatment can often prevent ROP from reaching its most severe stages. Cryotherapy (freezing therapy) and laser therapy can be used to decrease the abnormal growth of blood vessels. Children with ROP can require long-term eye care. Children with ROP are at risk for developing secondary visual impairment. Associated eye conditions may include amblyopia or impaired vision due to the lack of use of one or both eyes, and refractive errors, including nearsightedness, farsightedness, and astigmatism. Strabismus (misalignment of the eyes) and glaucoma (increased intraocular pressure) may also develop and require additional treatment. Families of children with a history of ROP may receive instructions in precautions and activity restrictions in order to prevent retinal detachment.

Children with ROP may exhibit learning difficulties that are associated with neurological problems related to prematurity (and not necessarily vision-related). A multisensory approach to learning may be helpful to the child with ROP. Whenever possible, combine the use of vision with touch and sound. Observation will be helpful in noting how the child uses vision and other senses most effectively. Children with a history of ROP may benefit from high levels of lighting and magnification. Good contrast in materials are easier to see and can be helpful. There may be loss of peripheral vision and the child will need to learn to scan effectively to locate people and objects. The child may use unusual body positions to accommodate for poor vision, vision in only one eye, or reduced visual field and this can lead to fatigue. In school, a number of materials and strategies may be suggested to relieve postural fatigue. Children with ROP are noted to have blue-yellow color deficiency with greater frequency than the general population.

(ROP continued)

ROPARD is The Association for Retinopathy of Prematurity and Related Diseases and may be linked at <http://www.ropard.org/>

Children with Visual Impairment: A Parents' Guide, Holbrook, Woodbine House, 1996.

Fact Sheet: Retinopathy of Prematurity, Blind Babies Foundation.

Low Vision: A Resource Guide with Adaptations for Students with Visual Impairments, Levack, Texas School for the Blind and Visually Impaired, 1994.

In Memoriam



Dakota Corpening
April 26, 2009 - September 2, 2009

Cooper Hibdon
March 1, 2008 - January 6, 2010

Noel Grace Hull
December 17, 2003 - January 29, 2010



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