

# Parent Time

**A Newsletter for MoSPIN Parents**

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## Editor's Corner:

Hello!

For those of you who don't know me, let me introduce myself and my family. My name is Stacy Meyer. I am 37, married, and the proud parent of four beautiful children; Katrina 17, Jessica, 15, Lucius, 5, and Gabriel, 9 months.

Our journey started five years ago with our son Lucius. He was diagnosed at birth with Optic Nerve Hypoplasia (small optic nerve); a condition that often accompanies Hypopituitarism. We spent twelve days at Cardinal Glennon Hospital in St. Louis. They told us in the beginning that it was likely that he would be visually impaired. The actual diagnosis that our son was basically blind was a hard one to take. My husband was in Iraq at the time and had to be told over the phone. We asked a lot of how and why questions, followed by, what can be done about it? "What else could be done" was to treat him like I would any of my other children and learn as much as I could so that I could help him to learn.

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We had a functional visual evaluation done at Delta Gamma Center in St. Louis. It consisted of a series of tests/observations to see if your child will respond to any stimulus that might be seen by the eye.

We found out that Lucius can see some light. He doesn't see any details, but we think he may actually have some peripheral sight. It is limited at best. But, watching Lucius play and get around, you would never know he has any vision problems.

We were fortunate enough to have services from First Steps, Delta Gamma and MoSPIN to help guide us through his infant and toddler years. Lucius received therapies like occupational therapy, speech and special instruction. His therapists would come in a few times a week to work with him and my MoSPIN Parent Advisor came in monthly. They made sure we had materials to work with Lucius and to teach the rest of our family how to work with Lucius.

When Lucius turned three, he graduated out of those services and into the Jackson school district. They have done a wonderful job making sure Lucius has everything he needs to learn and develop like he should. We now have an IEP (Individualized Education Program) that we work with. His whole team sits down with us to set the goals he needs. He still receives therapies through the school. With the IEP, we have more specific goals to work toward.

Lucius also became a big brother this past year. I wasn't sure how all that

would work out, but it seems to be a very good thing for him. It was difficult to find ways to tell him that he had a little brother on the way. I let him feel Gabriel kick and move. He didn't seem to really care. Since Gabriel is here and a little older now, he and Lucius interact quite a bit. Lucius loves his little brother.

Since Lucius is still being potty trained, it is like having two babies in the house. But, every day, Lucius gets a little closer to the end result. He can now go into the bathroom on his own, mostly to play in the toilet. (Why do kids do that?) If he wets, he will strip naked. (Thank goodness he ONLY does this at home.) We have him on a pretty steady schedule so hopefully he will start stripping in the bathroom to go potty.

I know that we have a long road ahead of us, but I wouldn't change the way things have turned out. I just hope that I can be a good enough mother, gain enough knowledge, and teach my son about the world around him and his place in it.

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## Connecting Families

*"I'd really like to connect with other families of young children with visual impairments, but I don't know where to start."*

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Many MoSPIN families have expressed an interest in making family connections. Some families would like to make connections with other families in order to share experiences, find support and learn from the experiences of others or to reduce their feelings of isolation. But no matter what your motivation, here are some ideas to consider. (Be sure to keep reading and check out the articles in this issue that will provide more information on these ideas for connecting with other families.)

1. *Contact the Parent-to-Parent Network at 1-800-651-0818*
2. *Access on-line communities.*
3. *Use social networking.*
4. *Become a member of a parent/family organization.*
5. *Attend conferences, conventions or other special events.*
6. *Join (or organize) a local support group.*

These ideas are just a starting point. We encourage MoSPIN families to share their personal experiences or ideas so we can include them in future issues.





## Parent-to-Parent

The Parent-to-Parent program is a joint effort of the Delta Gamma Center for Children with Visual Impairments and MoSPIN to put Missouri parents in touch with another parent of a child with a similar diagnosis or shared experience. This program is committed to providing emotional and informational support through carefully made matches. Parents whose children have recently been diagnosed with a visual impairment, or are experiencing new challenges related to their child with a visual impairment, are matched with trained experienced volunteer parents. Call 1-800-651-0818 to get more information or to get started.

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## Online Communities

[FamilyConnect.org](http://FamilyConnect.org) is a great website for parents of children with visual impairments that is sponsored by the American Foundation for the Blind and National Association of Parents of Children with Visual Impairments. In addition to access to information by age ranges (infants and toddlers, preschoolers, grade schoolers, etc) or by topics, you can connect with other parents on message boards or specialized blogs.

[WonderBaby.org](http://WonderBaby.org) is an online community where parents can:

- Find tips on raising a child who is blind

- Meet other parents of children who are blind
- Learn more about multiple disabilities
- Enter giveaways for fun resources

There are also many online communities that are specific to a particular visual diagnosis.

For example:

- [Albinism.org](http://Albinism.org) for children with albinism and/or hypopigmentation
  - [Focusfamilies.org](http://Focusfamilies.org) for children with optic nerve hypoplasia or septo-optic dysplasia
  - [Magicfoundation.org](http://Magicfoundation.org) for children with growth disorders and may be of interest to families of children with optic nerve hypoplasia or septo-optic dysplasia
  - [Wonderbaby.org/maps](http://Wonderbaby.org/maps) for microphthalmia/anophthalmia parent support
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## Social Networking

Social networks are all around us – and they are not new! You probably have many different groups of friends, such as those at church, neighbors, family, club members, hobby groups, etc. They are all part of your social networks; they are your friends! Web based social networking may bring to mind Facebook, Twitter, blogs, etc, but social networking can also occur through any website that allows you to share content, interact, or develop communities around a shared interest. One of the most popular social networking options for parents of

children with vision impairments is FamilyConnect.org. On this website there are various message boards and blogs including “A Parent’s Voice”, “Ask the Experts”, and “Raising a Child who is Blind”. A new social networking component is FamilyFriends. Users can create and post their profile so they can be “found” by others with the same interest such as your child’s eye condition, child’s age or geographic location.

Let us know if you have a favorite website, blog, etc. that you would like to share with other families.

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## Parent Organizations



There are many organizations that families of children with visual impairments might want to consider joining. We will highlight two of those organizations.

NAPVI-The National Association for Parents of Children with Visual Impairments is an international membership organization serving families in the US and in 55 countries. NAPVI helps parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities. NAPVI provides leadership, support and education to assist parents in helping children reach their potential. Contact Pam Stern at 847-433-0809 or [pamstern3@gmail.com](mailto:pamstern3@gmail.com)

NFADB-The National Family Association for Deaf-Blind is a non-profit national family organization established in 1994 that offers support in a variety of ways:

- A toll-free number (answered by a real person) that connects families and others to resources and one-to-one support
- Current information and national updates delivered through a bi-annual newsletter.
- Online resources and support through a website and Facebook page
- A member listserv that connects members by email to hundreds of other members

For more information, contact Lori at 1-800-255-0411 or [NFADB@aol.com](mailto:NFADB@aol.com)

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## Conferences, Conventions, Special Events



Conferences, conventions and special events offer great opportunities for families to access new information and resources and to meet others who share their interests. MoSPIN families have expressed an interest in receiving information about upcoming events. When we hear about these opportunities we share them with families. Information is shared in various ways. Sometimes it is shared in this newsletter – in the February 2011 issue of Parent Time we provided “Hold the Date” information about an upcoming workshop. We also do special mailings to alert families of upcoming events such as we did in April regarding the “Facilitating Friendships and Positive Self-Esteem” workshop. We have used targeted mailings to alert families of conferences in which they may have a particular interest such as the CHARGE Syndrome

Conference. At other times Parent Advisors are requested to share information during their MoSPIN home visits to alert families to an upcoming event such as the recent St. Louis Family Festival. If you know of an event that might be of interest to MoSPIN families, please let us know so we can pass along the information. Currently, several family learning opportunities are being pursued by Missouri School for the Blind staff. We'll keep you posted.

## Preschool, Babies, Potty Training and More

We have come a long way since we first joined MoSPIN. Lucius is a five year old now. He is in his final year of preschool and starting pre-kindergarten testing. He likes to ride the bus to and from school. If he is having a bad morning, the bus driving up usually fixes it. He plays on the play ground with the other kids. They have a bike with two seats that his classmates like to ride on with Lucius. They really seem to like him. He navigates the school using his cane and with some help from his paraprofessional. He eats lunch with the rest of the kids and participates in classroom activities. We have had to adjust Lucius's IEP a few times to get it to work right for him. We needed goals that were attainable for Lucius. We had to move him from a regular preschool room to one that has less students and more one-on-one assistance. Lucius had stopped talking due to the overabundance of auditory input. It was just too much to take in so he started to regress. He is back on track now and starting to talk and communicate like he should. One day at a time, one step at a time.

This past year has been a wild one. We have a new baby in the house. I wasn't sure how Lucius was going to do with him. But, I have been pleasantly surprised. When Gabriel was born, my mother came and stayed with the kids. Lucius cried a lot while I was gone. When I came home from the hospital, it was three days before he would let me hold him or hug him. I thought we were really going to have a problem with him adjusting to the new baby. At first, he wasn't interested at all. He wanted to be on my lap when I was holding Gabriel, but he didn't want Gabriel there. It took some doing but I made room to hold both of them. He started to play with his little brother's feet. I worried he would be too rough, but he is extremely gentle. Somehow, he knew he had to be careful not to hurt Gabriel. He went from that to playing with Gabriel's hands. As Gabriel has grown, Lucius has become more aware of his brother and is more careful about how he plays around him. When told that Gabriel is right behind him on the floor or in his walker, Lucius will move away and resume his

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### Local Parent Support Groups



Some communities in Missouri have active local parent support groups, but many do not. Do you have a parent support group in your area? If so, please provide the location and the contact information for the group to your MoSPIN Parent Advisor or Ginny Williams at 573-295-4808 or [ginwilliams@aol.com](mailto:ginwilliams@aol.com). We will compile the information and share it with other families.

If you don't know of any support groups in your area, consider starting one! Keep in mind, a local support group could be as small and informal as a telephone or email buddy who is always there for you or a few friends that share a cup of coffee and some conversation. At the other end of the spectrum, could be a group of parents that has regularly scheduled meetings and even sponsors special events. No matter what interests you, these resources could be helpful:

<http://family-friendly-fun.com/support/parent.htm>

[www.tsbvi.edu/seehear/summer97/parent.html](http://www.tsbvi.edu/seehear/summer97/parent.html)

[http://nhfv.org/files/parent\\_support\\_groups.pdf](http://nhfv.org/files/parent_support_groups.pdf)



**From Stacy's Perspective:**

bounding or bopping around in a new location. He hugs Gabriel and even rubs his head from time to time. It is hard to keep up with both, but I love it.

It is amazing how much you take for granted when you can see. Just watching Gabriel move around and take in the world around him has helped me with Lucius. I watched Gabriel playing with toys, moving from one room to another, turning to sounds that he hears as children who see do, but for Lucius it is different. There may be no real meaning or purpose for him when he hears new sounds. So for everything he touches or hears, I have to give him ten times the input for him to grasp it. I guess that is why it has taken so long with the potty training. He understands certain aspects of it and not others. In a way, it is like having an infant all the time. He has to have repeated input for the same thing to get it. Then, when he gets one small part of something, we move on to the next part. Eventually, he gets the whole of whatever we are doing. Potty training is no exception. He understands to go in the potty. He understands telling you he needs to go. He has not put it together that he should tell you before he goes. He knows where the bathroom is. He knows that when he is taken in there it is to use the potty. But he has not put it together that he should go in the bathroom when he needs to go. Instead he wanders in there after he has wet or just to play in the toilet (yuck). But he has all the pieces to the puzzle. Now, to just get him to put them all together for the whole.

If you have any suggestions or stories about introducing and playing with younger siblings or about potty training, I would love to hear them. You can email me at [stacy@spector-webdesigns.com](mailto:stacy@spector-webdesigns.com)



### Assistive Technology Funding Available

Funding information that may be of interest to families.

The Kids Assistive Technology (KAT) program administered by Missouri Assistive Technology can help Missouri families with a child (up to the age of 21) with a disability access assistive technology when funding is not otherwise available. The KAT program can provide limited assistive technology and vehicle or home-access modification. Applications received for children in low-income families receive priority. Additional information about the KAT program can be found at <http://www.at.mo.gov/kat.html> or by contacting Eileen Belton by phone at 800-647-8557 or via email at [eileen.belton@att.net](mailto:eileen.belton@att.net).

Halloween Ideas!



Are you ready for Halloween? We found these great ideas for Halloween costumes that cover wheelchairs in the Texas SenseAbilities newsletter. They agreed to let us share these pictures with Missouri families. So get your glue gun, some paint, a cardboard box and some imagination together and get started on a great costume!



Another costume article with pictures and instructions is titled "Halloween Costume Ideas for Canes and Wheelchairs". It can be found at

[www.wonderbaby.org/articles/halloween-costume-ideas-canes-and-wheelchairs](http://www.wonderbaby.org/articles/halloween-costume-ideas-canes-and-wheelchairs) .

# “Spotlight on Visual Impairment”

## Cataracts

A cataract is an opacity or clouding of the lens of the eye that affects vision. The lens is the part of the eye that helps to focus light on the retina and must be clear for retina to receive a sharp image. If the lens is cloudy from a cataract, the image seen will be blurred. The clouding can range from a few spots to covering the entire lens. What a child can see, or the visual acuity, is related to the density and location of the cataract. An early detection sign of a cataract is squinting or turning in of the eye, known as strabismus, due to lack of visual stimulation caused by the cataract. Several factors can lead to a cataract, including heredity, prematurity of birth, drugs, injury, infection or metabolic disorder. The treatment for a cataract (based on the size, density and location of the cataract) is a surgical procedure to remove the lens (resulting in aphakia or absence of the lens) to allow for the development of vision. However, once the lens is removed, the eye is no longer able to change its focus from a distant object to a close object. Bifocals, reading glasses or contact lenses are normally required after surgery to allow a child to view objects up close. A child with a congenital cataract should be seen by her primary eye care physician on a regular basis, because her need for eyeglass correction may change as changes within the eye occur.

For a child who is aphakic (has had the lens removed), good contrast in materials and lights with rheostats or adjustable arms may be helpful in controlling the amount and direction of light and avoiding glare. Directing light from behind can help to reduce glare. A loss of depth perception may also result. A child who is aphakic should wear contact lenses or glasses as prescribed.

Resources: Texas School for the Blind and Visually Impaired [www.tsbvi.edu](http://www.tsbvi.edu)  
National Eye Institute [www.nei.nih.gov](http://www.nei.nih.gov)



### ***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**

**Ginny Williams**

**Lead Parent Advisor for MoSPIN**



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