

Parent Time

A Newsletter for MoSPIN Parents

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Editor's Corner:

Hello!

This is hello for the first time to those of you new to MoSPIN, but it is also my last time writing as the Parent Editor for Parent Time. Lucius is now five and our family will be "graduating" from MoSPIN in a few months. For those of you who have just joined MoSPIN, I am Stacy Meyer. I am a proud mother of four very active children. Katrina, 18, is a senior in high school. Jessica, 15, is a sophomore in high school. Lucius, five, is in Early Childhood/Pre-K, and Gabriel is my baby. He is one. They all keep me very busy, but all of us work together with Lucius. Lucius is the reason that we are a MoSPIN family.

When Lucius was born he had very low blood sugars that resulted in seizures. The doctors at Southeast Hospital did further testing and sent him to Cardinal Glennon Hospital in St. Louis to a

Pediatric Endocrinologist. They diagnosed him with Hypopituitarism. His pituitary gland didn't develop all the way. With this came the diagnosis of Optic Nerve Hypoplasia and Septo-Optic Dysplasia. Sounds menacing, but it means a small optic nerve and that he has two or more endocrine issues. Lucius takes hormone replacement and will for the rest of his life. But he functions and plays like any other child.

We started with programs early. First Steps and Delta Gamma Center for Children in St. Louis are services for children who are birth to three years of age. MoSPIN is a service for families of children birth through five years of age. In the beginning, services were more to teach me how to teach him. We also had in-home therapy for Lucius through First Steps. Delta Gamma Center worked with us on how to teach him about his world. They also did a functional vision evaluation. These tests and observations focused on how Lucius responded to anything that might be seen by the eye. He has light perception, can see high contrast (black and white), and some red. He does use this to get around the house and around his older sisters' things. These agencies helped us get supplies and learning tools for Lucius. When Lucius was two, I applied for a grant from Light House for the Blind for an embosser and a brailier. Because Lucius' First Steps therapists wrote recommendation letters for us, we were given the grant and the equipment. I now braille everything

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I can for Lucius and play with him on the braille to teach him how to use it.

When he turned three, he graduated out of First Steps and entered the Early Childhood program at our school district. They have been instrumental in helping us get Lucius the things he needs in Pre-K. They provided a wealth of information for me. There are so many people I can contact and ask any question. If they don't know the answer they will find it or someone who has it. Lucius is five now, and we are graduating out of MoSPIN. We are going to miss being a part of this program. But, as most parents before me already know, you never really graduate out. We are a family of sorts that can lean on each other and learn from each other. I have learned a great deal from many of you. Thank you.

We are still working on the potty training. We have had many hurdles to overcome and certainly our share of ups and downs. But, he is putting it together slowly but surely. They work with him every day at school, and we have a strict schedule here at home that seems to be working well. Trial and error has played a huge part in figuring out what works best for getting positive results. For those of you who feel like your child will never get potty trained hang in there, it will happen.

Recently, Lucius was given the diagnosis of Autism. Since children who are visually impaired may have some behaviors similar to autism, they couldn't truly separate out what is visual impairment related and what is autism. The therapies will help either way. We also began seeing a Developmental Pediatrician at Cardinal Glennon Hospital in St. Louis. Lucius had a rather large vocabulary before he went to Early Childhood/Pre-K. Shortly after, we noticed he was losing his words. His teachers worked with us to help get him to talk. It just seemed to become less and less. Eventually, Lucius stopped talking pretty much all together. As a result, I sought help from our Autism Center and the Developmental

Pediatrician. Before the month is out, they will be running an EEG and an MRI. The EEG is to see if he is having seizures that cannot be detected. They tell me it is rare, but sometimes happens with children who have Septo-Optic Dysplasia. If he is having the seizures, they will put him on medication for them, and he could get his words back. The MRI is to make sure that there are no tumors that may have caused this. From there, if all of this is ruled out, we stick with our therapies and keep pushing forward. I don't know what the outcome will be, but we will handle it like always. One day at a time.

In the meantime, his teachers and therapist are trying anything they can to get to him to communicate. They use music, and an iPad with a neat fireworks app, and getting to swing. They work with him on orientation and mobility to teach him to get around in his school and other places with his cane. He has occupational therapy to work on his fine motor skills. He also has Speech and Language therapy and a para-professional to assist him. We are very fortunate to have the people we have working with Lucius. I hope and pray that the rest of you are so fortunate.

Even though I won't be writing any more Editor's letters for Parent Time, you can still email me at stacym@spector-webdesigns.com to pick my brain. I would be delighted to help. I have thoroughly enjoyed sharing my experiences with all of you. I will miss it. Take care and remember, our "sight" is only limited to our imagination.





Hold the Date!

March 10 – MoSPIN families are invited to attend the upcoming Delta Gamma Center’s Parent Conference in St. Louis: INSIGHTS – An Inspirational One-day Conference for Parents of Children Age 6 and Under. More information is provided in the enclosed separate announcement.

April 23 – Availability for Learning: The Forgotten Senses of Balance and Pressure. The focus of this free one-day workshop provided by the Missouri Deafblind Technical Assistance Project is on the importance of balance and pressure senses for all aspects of child development. The workshop will provide information on how these senses work, how the senses interact for effective functioning, reasons for difficulties with balance and pressure senses, and simple adaptations to facilitate learning for the student. The workshop will be held in St. Louis at the Missouri School for the Blind.

July 13-15 – National Family Association for Deafblind (NFADB) will hold a symposium in Austin, Texas titled: “Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century, Advocating for Individualized Supports to Access Information.”



Braille Fun for the Whole Family

Braille Bug Interactive Website

<http://www.afb.org/braillebug>

This is a fun interactive website from the American Foundation of the Blind (AFB). Your whole family will enjoy learning about Braille through games and riddles. Also has information about Louis Braille and Helen Keller.

Braille Fun with Arthur

<http://pbskids.org/arthur/print/braille/>

A great website for siblings of MoSPIN children. You write a message and it will be transcribed into two dimensional Braille for children to see.



High-Tech vs. Low-Tech



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!



iPad As a Teaching Tool

**Do you have an iPad?
Are you using it with your young child with a visual impairment?**

MoSPIN parents may be interested to know that iPads are being used with great success as a teaching tool for young children who are visually impaired, including babies! In case you are not familiar with an iPad, <http://www.techterms.com/definition/ipad> defines the iPad as "a tablet computer developed by Apple. It is smaller than a typical laptop, but significantly larger than the average smartphone. The iPad does not include a keyboard or trackpad, but instead has a touchscreen interface, which is used to control the device". This touchscreen, along with a brightly lit screen, portability, bright colors, placement options at various distances and angles (and much more), has parents and educators excited about the learning opportunities now available to young children. A few of the ways iPads are being used are to promote visual attention skills, cause and effect, reaching, communication and early literacy. The following articles provide much more information on this exciting new learning tool, including possible funding sources.



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*

Eric Jerman on Accessible iPad Apps

http://support.perkins.org/site/R?i=hDkze3FuR3I_J2K95QeDAA

Eric has a 3 year old son, Jake, who has a CVI (cortical visual impairment) diagnosis. Dad feels that his iPad's high contrast display and sensitivity to touch make it just right for motivating his son. Through trial and error, he determined the best distance and angle needed to position his iPad to promote Jake's interaction with the device. Eric also shares apps that he has used successfully with Jake.

Gloria: the iPad and Apps for children with CVI

<http://www.cadbs.org/news/gloria-the-ipad-and-apps-for-children-with-cvi/>

This article provides information on some of the work by Dr. Muriel Saunders at the University of Kansas. She uses iPads with children with cortical visual impairment to initially teach visual attention skills, promote reaching and teach cause and effect.

Blogs about using iPads with Babies

www.babieswithipads.blogspot.com/

Bloggers share their ideas for using their iPads, including their favorite free apps. Earlier posts include information regarding iPad grants and "give aways".

Tot-n-Tech Newsletter

http://tnt.asu.edu/files/iPad_Newsletter_4-11-11.pdf

Tots-n-Tech has an entire issue of their newsletter focused on the iPad.

iPad Accessibility

<http://www.wonderbaby.org/srticles/ipad-accessibility>

This article includes information on how to configure an iPad so it is more accessible for a child with visual impairment or motor delay.

Help for Getting an iPad for a Child or Student with Special Needs

<http://www.scribd.com/doc/54423509/Help-for-Getting-an-iPad-For-a-Child-or-Student-with-Special-Needs/>

Provides information regarding specific grants opportunities (many are available!) and ideas for fundraising.

7 Ways to Get an iPad

<http://blog.friendshipcircle.org/2011/03/23/on-a-tight-budget-7-ways-to-get-an-ipad-for-your-child-with-special-needs/>

This post is part seven of a series: Special Needs iPad and App Series.

"Dad, Where's the Plunger?"



I recently read a delightful and informative article in the Texas School for the Blind's newsletter at <http://www.tsbvi.edu/attachments/newsletter/fall11.pdf>. It was written by Richard Holloway, father of Kendra and Vice President of the Georgia Organization of Parents of Blind Children. In his article, "Dad" describes how he helped his 8 year old daughter, Kendra, (who is blind) increase her understanding of the world around her.

It all started with Kendra's inquiry - "Dad, do we have a plunger? I want to know what a plunger feels like."

As parents of a child with a visual impairment, you know the importance of using words to describe the world to your child, as well as the importance of providing opportunities for hands-on exploration. But, sometimes, that is easier said than done. The "ick" factor can cause a problem as can size (e.g. Empire State Building), distance (e.g. the moon), and safety factors (e.g. a chain saw). But in this story, Dad comes up

with a great solution - a trip with Kendra to Home Depot. Not only could she tactually explore a brand new (clean) plunger, but so much more! There were toilets, toilet seats, tubs, showers of all shapes and sizes to describe, discuss and touch and explore - and this was just the plumbing aisle of Home Depot!

This experience really got Dad thinking. What about other stores? Could there be possibilities for learning at Sports Authority? Absolutely! Dad thought about all kinds of balls (baseball, football, bowling ball, golf ball, etc.) and unique shoes for various sports that could be explored. And, everything was in one place for learning by description, comparison and exploration. No purchase necessary! It was just a fun trip together for Kendra and Dad.

This article provides a great reminder of how families can use everyday events as opportunities to share new, or missing, information about the world around them with their children! You can read the **complete article** at the link at the top of the page.

Ginny Williams
Lead Parent Advisor for MoSPIN

New Literacy Website Available

Are you looking for literacy strategies for children with sensory losses? Children who do not use a formal language system? Children who have multiple disabilities and complex learning challenges?

If the answer is YES then you are encouraged to visit a **new literacy website** developed by the National Consortium on Deaf-Blindness (NCDB 2.0).

When you visit <http://literacy.nationaldb.org> you will find strategies, examples and resources that build on communication as the foundation for early literacy and move children along a continuum toward ever-increasing skill levels.

NCDB 2.0 provided this promotional information regarding their new literacy website.



Brain Power

Want to learn more about your child's brain and how it works? Here are two websites that may help.

Baby Brain Map

<http://www.zerotothree.org/child-development/brain-development/baby-brain-map.html>

Learn more about different portions of the brain, including the vision section. On this website you can select an age range (2-6 months, 12-18 months, etc.) and learn more about how a baby's brain develops during this period. Also provides ideas of what you can do to promote the child's development.

Effective Strategies for Working with Children with Multiple Disabilities – With or Without Deafblindness: The Brain and Arousal States.

www.wdta.wi.gov. Go to the Video Conferences tab and learn more about the brain as Millie Smith presents information on highly effective strategies for severely challenged learners.

"Spotlight on Visual Impairment"

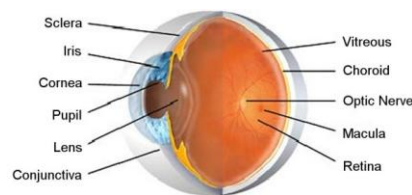
Astigmatism

By Jill Grattan

Nevada Dual Sensory Impairment Project
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What is astigmatism?

Astigmatism is a condition that results in blurred vision, which is caused by an irregularly shaped cornea (corneal astigmatism) or curvature of the lens (lenticular astigmatism) (Mayo Clinic 2011). For example, a typical cornea has a rounded shape like a basketball; however with astigmatism, the cornea may be shaped more like a football. The irregular shape of the cornea or lens prevents light from focusing in the correct place on the retina. It can change as an individual ages and may worsen over time. Per the American Optometric Association (AOA), astigmatism is very common.



What causes astigmatism?

At this time, the causes of astigmatism, in the majority of cases, are unknown. Astigmatism can be hereditary and is typically present from birth. It is possible for astigmatism to develop after an eye injury or eye surgery. Astigmatism may also be caused by a rare condition called keratoconus (the cornea becomes thinner and more cone shaped).

Is vision affected with astigmatism?

Astigmatism (depending on the degree of severity) can cause blurred or distorted vision, headaches, eyestrain, and/or eye discomfort. Blurred or distorted vision can occur at any distance; that is, it is not limited to either near or farsightedness. Nearsightedness or farsightedness frequently occurs with astigmatism.

How is astigmatism diagnosed?

Astigmatism is diagnosed through a comprehensive eye exam, the same exam which determines prescriptions for contact lenses and/or glasses.

How is astigmatism treated?

Astigmatism is typically corrected through prescription glasses and/or contact lenses. Other treatments for some types of astigmatism include:

1. Laser surgery, which uses a laser to change the shape of the cornea.
2. Orthokeratology (ortho-k) involves wearing a series of specially designed rigid contact lenses to gradually reshape the curvature of the cornea.

Keratoconus is corrected through prescription contacts or a corneal transplant.

References and Images Retrieved From:

American Optometric Association (n.d.). *Astigmatism*. Retrieved March 17, 2011 from, <http://www.aoa.org/Astigmatism.xml>

Mayo Clinic (January 15, 2011). *Astigmatism*. Retrieved March 17, 2011 from, <http://www.mayoclinic.com/health/astigmatism/DS00230>

Eye image retrieved on March 17, 2011 from, <http://.freedomscientific.com/resources/vision-anatomy-eye.asp>

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