

# Parent Time

A Newsletter for MoSPIN Parents

Volume 19, Issue 2

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## Greetings!

The focus of this issue of Parent Time is the **importance and enjoyment of reading with your child.**

Several of our MoSPIN families will share how their families read books together. I think the emphasis they put on books in their lives and the joy they share when reading with their children will be evident! Information on Braille and resources for obtaining books are also included in this issue. In addition, a “graduate” parent reflects back on her time in MoSPIN and shares some words of wisdom. And, just for fun, I’ve included a link to Halloween costumes for kids using strollers and wheelchairs.

I hope you enjoy this issue of Parent Time! As always, I’d love to hear your feedback and ideas for future issues.

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## Reading With the Farris Family

I cannot believe it is already time for the October Newsletter! I’m sure I’m not the only one who feels like the summer went by much too quickly. We were just enjoying the Spring Hippotherapy (horse riding therapy) sessions, and now it’s almost time to bring out the mums and fall decorations. I have enrolled in a fall college class: Introduction to Braille! I have to admit, it is pretty fun to be learning Braille. It’s going to be great to help Lilly with all of her school work, and teach her a few things myself. We want to be as involved in Lilly’s education as we possibly can be, and this is going to make that possible!

If you’re new to the MoSPIN family, I’m Sherah Farris. My husband, Wesley, and I have three beautiful children. Currently, they are three and under. Yes, I believe we are crazy! Lilly, our oldest, will turn four this month, Jonah is two, and John Wesley is almost four months old. Lilly was diagnosed with Optic Nerve Hypoplasia, and Septo-Optic Dysplasia when she was just a teeny four months old. Of course, our little drama queen has not let that hold her back! She never stops growing and progressing, and of course giving us a run for our money. She is finding her voice, and we are thrilled to hear it! Lilly is also working on potty training, which is very much hit and miss. Sometimes she walks to the bathroom, opens the door, and goes to the toilet

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by herself. If we could just get her to sit on the toilet next instead of splashing in the water we might have a potty trained girl!

It was a fun summer for our family as we welcomed our new addition, John Wesley! Lilly had no issues bringing her new baby brother home. As long as he's happy, Lilly is happy. She has even held her baby brother a few times; a different reaction compared to two years ago when her little brother Jonah came home with us. Our summer was full of long walks on the nature trail and family cook outs on the deck, which are some of Lilly's favorite things to do. Since the weather has cooled off, the children are enjoying many of their meals on our deck. Lilly and Jonah both love eating outside, especially now that most of the bugs are gone. While Lilly enjoys being outside, and the occasional taste of dirt, I enjoy being inside; snuggled up on my bed or couch with my children, enjoying a cup of coffee and a good book.

Lilly does not have a favorite book, but she does have a favorite author. I can read poems and rhymes to Lilly all day, but she has always preferred the creativity of Dr. Seuss above all others. Sure, we can sneak in some, "Llama Llama Red Pajama", but it just won't ever be as interesting as "Yurtle the Turtle." Reading stories is a great place to start teaching children the importance of reading, even if the books aren't in Braille. After all, since Lilly was a teeny little newborn in the NICU, her nurses told us to read to her because it would be good for her in more ways than one. It was a little odd at first, especially after we learned Lilly was blind, but we have always read to Lilly. Reading books to our children not only provides a foundation for literacy, but it also gives our children positive childhood memories that they will remember and cherish for their entire lives.

While we're cuddled up on my bed or on the couch reading a book, drinking coffee and milk, I take Lilly's hand and run it across the Braille. I am hoping and praying she's getting the idea that the Braille is what I am reading; in the same way that Jonah will see me looking at the print and realize that's where the story lies. In true motherly multi-tasking style, I'm making memories with my precious children and teaching them at the same time.

Lilly may pull her hand away and try to walk away from the challenge. My heart drops a tiny bit because I dream of the day she is reading Braille. I think

of how exciting it will be when Lilly is reading books to me. Then there are the times Lilly lets me help her feel the words, and she smiles her beautiful bright smile. I get all mushy and overjoyed. "Lilly! You're reading! Reading is fun! Wow, Lilly. You are being such a big girl!" With that, she hops off my lap and finds a toy to play with. Or laughs and throws her hands up around my neck, wanting to be tickled rather than read. It's okay, I think to myself. We will press on and keep trying. Like many mothers of children with all kinds of needs, I know my efforts are not in vain.



When Wesley reads to the children, all bets are off! It starts as a sweet quiet story time and ends in tickles, and a wrestling match between Lilly, Jonah, and Daddy. Of course, if it happens to be right before bed, bedtime is postponed another thirty minutes because the children have too much energy to think about sleeping. I believe they prefer their dad to read to them over me, but its okay. As long as the early reading experiences are fun and positive, I am happy. I know the kids will grow to enjoy reading themselves because the memories will form a positive attitude toward reading.

If you haven't read to your child with a visual impairment routinely, it's not too late to start. I know sometimes, in the first years, it seems unimportant. Between hospital trips and therapy sessions galore, a parent can feel very drained. I once felt like Lilly didn't care about the stories, but I kept on reading. I made it a part of our daily routine and a part of our bedtime routine. Whether it's in the middle of the day or at bedtime, I always try to read to my children.



## The Wilson Family

Hello, MoSPIN families!

It is an honor to write again for the MoSPIN newsletter and share with you our family. My name is Jonie and my husband John and our three kids live in Dixon, MO. Andi Jo is our 6 year old daughter in the 1<sup>st</sup> grade. Clayton and Cheston are our three year old twin sons. Cheston was born with a rare genetic disorder, "microphthalmia", meaning mini eye syndrome. As always, the Wilson household has been very busy and crazy. I will update you later in the column.

Microphthalmia is a huge part of our family. Not only does Cheston have this genetic disorder, but so does our daughter Andi Jo. It affects both of them differently though. Cheston has severe bilateral microphthalmia, meaning it affected both of Cheston's eyes in the worst possible way. Cheston's eyes were so small and he does not have the optic nerves, so he is blind. Andi has a mild case of microphthalmia and coloboma and it only affects her left eye. Her left eye is smaller than her right eye and her left optic nerve is under developed. Andi's vision in her left eye corrected is 20/200. Her right eye is 20/30. Our family is in a genetic study through the Albert Einstein Medical Center in Philadelphia and through genetic testing with a geneticist who specializes in Microphthalmia/Anophthalmia. We have learned that my husband and I both have the recessive trait, but we do not have the outward affects of it. Our son Clayton has no vision problems at all. With all this, it definitely makes learning DIFFERENT for all of our children.

This Parent Time issue is about the importance of reading to your child. To John and me, reading is very important. Both of our children's grandmothers were teachers. John's mother was a Reading teacher for 31 years. My mother was a Family and Consumer Science (Home Economics) teacher for 33 years. Education was very important and instilled in John and me growing up so it is obviously something important to the both of us. We started reading to Andi when she was very small. Andi loves being read to and it is still one of her favorite things to do. Clayton loves being read to as well. At his age, keeping his attention is difficult at times because he tends to get tired of it quickly. Cheston is the most difficult one. He has a hard time keeping his interest in the story. Usually about halfway through the book he tells us "I'm done" and wants to get down. We will have to hold him tight

to sit through a book. Keeping his interest is very difficult.

We have a variety of books for the children. We have multiple educational books that teach the alphabet, numbers, shapes, colors etc. We also have many of the board books that are very good for Cheston's and Clayton's age right now. For Andi, we have a variety of girly books such as Barbie, princesses, and Hello Kitty. We have started buying Andi the "I Can Read" books. We have a variety of print/braille books also. We also have audio books which work well for Cheston. "Pete and His Four Groovy Buttons" is a favorite. We have a variety of seasonal books that we rotate throughout the year depending on the season or holiday. We are currently reading our fall and Halloween books. Soon we will get out our Thanksgiving, Christmas, and winter books. Andi and Clayton also enjoy magazines. We have a variety of magazines that we receive (which we can get for free\*) that they enjoy.

Recently our reading strategies at night have changed. With Andi being in the first grade this year, she has started to learn to read. It actually amazes us as how much Andi has learned already and how well she can read considering we are not even a quarter of the way through the school year. Andi will bring home her reading book from school, and we are making it a family affair to listen to her read. We think that this not only encourages her to do a good job, but also encourages the boys. It shows them they will one day also learn how to read. Andi's biggest problem with reading is her comprehension. She does have difficulties comprehending what she reads. We constantly ask her questions about the story so she can start not only reading but understanding what she is reading.



Andi Jo is our spitfire child. We have our hands full with this girl. She always has a smile on her face and is always talking to someone. She is the social butterfly of the family. Sometimes, this tends to get Andi in trouble. But that is her personality. In school,

Andi participates in a couple of reading incentive programs. One is the Pizza Hut BOOK IT! Program where they read books to earn free pizzas from Pizza Hut. The other program is the Six Flags ticket program. If she reads so many hours, she receives a free ticket to Six Flags. She loves these kinds of things. As soon as she brings the sheets home, she goes and gets all the books she needs to read for the month and wants to do it that first day. These programs have encouraged her to read. So off we headed to Six Flags this summer for a fun filled day. She loves theme parks and loves the rides. She is already asking when we get to go back. This past summer, Andi showed her hog "Si" at the local county fair. She also played on her softball team which she was awarded the Most Improved Player. Andi also had eye muscle surgery on her left eye this summer. She learned how to swim and do a back dive in the swimming pool. She was a very busy girl this summer.

With Andi's vision problems, some things are a struggle for her. Her handwriting is not the best. She does not stay in the lines very well. She does tend to get her head very close to the book or paper that she is reading. We do not allow her to use her vision problem to hold her back or allow her to use it to get out of doing things. We know some of the things that are hard for her to do, but we still make her do them.



Clayton is our curious child. He is always curious and wanting to learn things. He is like a sponge especially when it comes to things about animals. He loves farm animals and dinosaurs. He tends to read books that he is interested in such as farm books, tractor books, dinosaur books. Clayton has a book he loves to read, "The Little Red Barn". He has worn this book out. Now it is the dinosaur book we got in the \$1 bin at Target. He loves dinosaurs. He also enjoys reading the Xplor magazine that is published by the Missouri Department of Conservation, and it is \*FREE. He calls it his "mail" and is always asking for his new "mail" to come. He loves to sit and listen to books. We also have to watch the movie "Walking with Dinosaurs" on a daily basis.

Cheston, who is enrolled in MoSPIN, is our wild man. We call him the tornado. He is always on the go; always moving and exploring and getting into trouble. He is still obsessed with the phone. He and the 911 operator had TWO great conversations in one day. So we have had to put all of the home phones up so he cannot get to them anymore. He has gotten better with the echolalia issue (repeating everything he hears). We worked very hard this summer to work on this problem. We are still working on potty training with him. He will, hopefully, get this accomplished very soon. He still loves music.



Cheston goes to Pre-School for a half a day at Dixon Elementary. He has his teacher, his aide, and his TVI (teacher of the visually impaired) that comes and sees him regularly. He then goes to the day care for the other half of the day. Cheston is thriving at school. He is learning Braille and all the things that every preschooler should learn. His favorite things at school are riding the bus, snack time, and recess. We are still trying to keep up with the prosthetic (artificial) eyes. He does usually keep them in at school. He has taken them out for his classmates one time so far this year.

One struggle with Cheston is sitting and listening during story time, or sitting and doing anything that requires sit down time. He tends to get bored very easily and keeping his attention is difficult. We know it could be easy to just let him get up and not listen, but to us, it is very important to learn to sit, listen, do the activity, and eventually, learn to read on his own. Cheston learning Braille is very important to John and me. Several ways we encourage Cheston to sit and read with us are using books that make noise and the audio books. We have an alphabet book and a number book that do keep his interest. The touch and feel books are also ones he really likes. He also enjoys the audio books - especially ones that incorporate music. We can get these audio books from Scholastic or a variety of them on Amazon and can also check them out at the local library.

With the diversity of our family, John and I still look for new ways to embrace our children and all their different personalities and their different learning styles. We know it will be an eventful fun ride with our children in the next few years with them all learning to read.



Instead of us reading to them, they will be reading to us. Our children are growing up so fast! Reading and literacy are very important aspects to every child's educational experience. And with our quirky, wonderful family, we have learned that every child learns differently. But there are some things that can be consistent. No matter how they learn, taking the time to read to anyone is very beneficial. With all of this, and it getting close to winter time, we will for sure be doing our fair share of reading in the upcoming months. Until next time.

The Wilsons

John, Jonie, Andi Jo, Clayton & Cheston

**\*Free magazines:** You can register online for the Xplor magazine if you go to the Missouri Department of Conservation website. Another free one is the Lego magazine. You can go to the Lego website and there is a form online to fill out as well. American Girl magazine is one that we signed up for on their site. It is more of a shopping magazine, but it also tells the story about each girl (each American Girl has a "story"). Then each doll comes with a book as well. But Andi enjoys the magazine.



## Reading Aloud is a Gift!



Reading with your child is such a great opportunity to share a special time together and lay a positive foundation for your child. Don't let your child's visual impairment keep you from reading together. When you are reading, rhyming, repeating, singing, you are developing a trusting, close relationship with your young child. Just remember - reading aloud with your child is a gift, both to your child and to you!

Here are some words of wisdom from the Reading is Fundamental website at [www.rif.org](http://www.rif.org):

- "Reading aloud is a gift you can freely give your children from the day you bring them home from the hospital until they leave the nest... and it is as much fun for you as it is for your children."
- "Reading aloud is an expression of love, an act of giving that means you care enough to share your time."
- "Start young and stay with it!"



## Our Gift to You: Elizabeth's Story

Our families will soon be receiving a gift from MoSPIN. The DVD "**Discovering the Magic of Reading: Elizabeth's Story**" will be mailed to you or delivered by your MoSPIN Parent Advisor. In this video, parents share books with young children with visual impairments during the early months of infancy, through the toddler years and on to the preschool years. Examples of how to encourage your child's participation in read aloud time are demonstrated. Various types of books are shown including commercially available books, twin vision books, tactile books and even directions on how to make and use a story box. We hope you will enjoy learning new ways to promote positive attitudes about reading and promoting early literacy skills. Discover the magic of reading with your child today!



## Braille Fun for the Whole Family

Your whole family will enjoy learning about Braille through games and riddles. The following websites also include information about Louis Braille and Helen Keller.

### Braille Bug Interactive Website

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

This is a fun interactive website from the American Foundation of the Blind (AFB).

### 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.



## Twin-Vision Books

Many families use twin-vision books with their young children. These books contain both print and Braille and are great for those of us who don't read Braille but want to expose our child to Braille. They are also good because many of us don't know whether our child will eventually read print or Braille. Though we are not recommending any particular source for these books, we'd like to pass along some sources.

The National Braille Press – offers Braille Book of the Month Club for purchase

[www.nbp.org](http://www.nbp.org)

Seedlings – braille labels placed on print books and other twin-vision books for purchase

[www.seedlings.org](http://www.seedlings.org)

American Action Fund for Blind Children and Adults – twin-vision books on loan

[www.actionfund.org](http://www.actionfund.org)

Wolfner Library – twin-vision books on loan

[wolfner@sos.mo.gov](mailto:wolfner@sos.mo.gov)

<http://www.sos.mo.gov/wolfner/>

American Foundation for the Blind – source list for braille books and magazines

[www.braillebug.org/resource.asp](http://www.braillebug.org/resource.asp)



## Braille for Adults

Many MoSPIN parents are interested in learning more about Braille, but don't know where to start. Here are some sources for instructional materials on Braille for adults. Though we are not recommending any particular source, you might want to know that Just Enough to Know Better was developed especially for parents. Some of the other sources are geared to future teachers and tend to be more detailed. You may want to check out some of these sources of Braille for adults.

Just Enough to Know Better

The National Braille Press

[www.nbp.org](http://www.nbp.org)

Ashcroft's Programmed Instruction: Unified English Braille (API-UEB)

SCALARS Publishing

[www.scalarspublishing.com](http://www.scalarspublishing.com)

Instruction for Braille Transcribing

American Printing House for the Blind

[www.aph.org](http://www.aph.org)

Introduction to Braille

Hadley School for the Blind

[www.hadley-school.org](http://www.hadley-school.org)



## Looking Back: Reflections from a MoSPIN “Graduate” Family

Greetings from the Eggleston family!!

My name is Tiffany, my husband’s name is Jarrad and our beautiful daughter’s name is Emmalin. For those of you that don’t remember our family, Emmalin is our only child and will be 6 the end of this month. Emmalin is very complicated. She has a rare gene deficiency called CDKL5. Although CDKL5 is rare, it can mean a lot of things. For Emmalin, having CDKL5 means she has multiple seizure types and multiple seizures daily, she is non-verbal, low muscle tone, has a feeding tube, hip dysplasia, positional scoliosis, and she is developmentally delayed in every area. The other main area that Emmalin is complicated in because of CDKL5 is vision. In the vision area, Emmalin has cortical vision impairment (CVI), strabismus, and nystagmus.

Since Emmalin turned 5 and aged out of the MoSPIN program, Emmalin has been staying busy between therapies and a couple new activities that we have started now that she is a big girl (lol). Emmalin is doing baseball at the Miracle League in Springfield, which is a special needs baseball league. Also this year we are trying out Girl Scouts because we were able to find a special needs Girl Scout troop for grades Kindergarten through 12<sup>th</sup> grade (for Springfield and the surrounding cities). So far so good with both activities!



The other REALLY big thing for our family was that Emmalin got to be the flower girl in my sister’s wedding in September. I don’t know why, but for some reason it was a really big deal to me for Emmalin to walk down the aisle and throw her flowers the way every other flower girl would normally do (and for those that don’t know Emmalin, she uses a wheelchair and she doesn’t sit up on her own or have all of her head control). I am happy to say that with determination and

A LOT of assistance (and even though we only walked a VERY small amount of the aisle), Emmalin DID IT!! She WALKED down the aisle and threw her flowers!!!

As we started trying all of these new and exciting activities, each activity definitely has had its own challenges! We had to find ways to participate in each activity so that Emmalin would understand what was going on and to make sure we were setting her up for success. It was right around this time that I was contacted to see if I would write an article for the newsletter again. Since Emmalin has aged out of the program, this time I was asked to write something about, “what I have learned” or “what I wish I would have done differently”. I thought it was great timing to be asked to write this on the particular topic! You see, it is because of the education from the MoSPIN program that we (as her parents) now have the tools, resources and confidence to be able to set Emmalin up for success. So after thinking about these two different statements, this is what I have come up with:

As far as reflecting on my time in the program and what topics or activities have helped me the most... honestly it is VERY hard for me to pick one thing! You see, I truly felt that the entire program was beneficial to me and my family, and I find myself using all of the tools and resources on a daily basis! I feel like the MoSPIN program helped me have a better understanding of Emmalin’s vision impairment, and how to help her be successful in different environments (not just at home). This program also helped me feel more confident in helping my daughter as we got closer to going to kindergarten and aging out of the program (as her mom AND as her advocate).

As I got further in the MoSPIN program it helped me realize that in order for a person to really be able to understand Emmalin, they had to understand Emmalin’s visual impairment. Also, if a person didn’t understand how Emmalin’s visual impairment worked; they were not going to be able to help her succeed to the best of her ability. So as we got closer to aging out of the program, I started to realize how important it was for me to find a way to help educate ANY person that was going to be working with Emmalin. It was not long after this that, with the help of my AMAZING MoSPIN Parent Advisor; we came up with the idea of a packet. The packet had different papers (and one photo album) in it to help individuals understand Emmalin, and how to help her be able to succeed to the best of her ability. It would help them not only

understand her visual impairment, but it would also help them have an idea of what Emmalin did in other areas of her life so they could understand Emmalin “as a whole”. To give you an idea of what was inside the packet; some of the main things were stuff like Emmalin’s diagnosis letter of CDKL5, a vision diagnosis description of CVI, a diagram showing what she was working on in each of her therapies, even stuff like Emmalin’s favorite color and what she liked to do for fun. For me, the packets that we put together were SO useful!! In fact even just last week (almost 3 years since I made the packets) I had one of Emmalin’s new therapists at school say she had been looking at Emmalin’s packet to help her get a better understanding of Emmalin. Yes, by now it needs a little updating, but the general facts were still just as useful (CDKL5 diagnosis letter, CVI diagnosis description and so on...). It is because of this, that I think the packet is one of the best things that I can talk about on how I used (and continue to use) everything that I learned in MoSPIN to educate others on how to understand Emmalin!!

(I actually talked about these packets and everything I put in them a previous newsletter. If you would like more information on these packets, go to the archived Parent Time newsletters on the Missouri School for the Blind’s website at [www.msb.dese.mo.gov/documents/Parent-Time-Oct-2013.pdf](http://www.msb.dese.mo.gov/documents/Parent-Time-Oct-2013.pdf).)



Moving on to the second statement about something that I wish that I might have done differently...since Emmalin’s vision is a little complicated to understand, it would have been useful to work with my MoSPIN Parent Advisor to come up with a little “training” session that I could have done with all of the therapists, teachers, paraprofessionals, and honestly ANYONE that was going to be working with Emmalin (I would have even done it with my family members, too). I don’t think the training would need to be anything

super long, just a couple different activities where you blindfold each person to help them all understand a little better on what it was like to have the visual impairment. I know this probably sounds crazy, but my MoSPIN Parent Advisor did some of these activities with me blindfolded, and I feel like it helped me understand what it was like for Emmalin on a COMPLETELY different level!!.

If this is something that you think you may be interested in doing, I would recommend trying to see what kinds of activities your child was going to be doing at school (or wherever they would be having a different caregiver besides you). I would set up some of those same activities for your child’s caregiver /teacher/therapist/family member (s), and have them do them BLINDFOLDED!\* If you need help coming up with things, that’s where your MoSPIN Parent Advisor will be a GREAT resource and advocate to help you make your training a big success!!

Well, I hope some of the information that I have talked about has been helpful for some of you! The MoSPIN program was SUCH a life changing program for us in how it helped us understand Emmalin better and how to help her be successful in ALL areas of her life. I hope that the MoSPIN program will do the same for you and your family!!

**\*Editor’s Note:**

*Simulation experiences can be a learning tool for some but they are not for everyone. Of course, everyone understands that no one can truly understand what a child with visual impairment is experiencing by spending a short amount of time under a blindfold or other simulator. However, if the goal is to illustrate challenges and identify solutions, such as the value of effective instructional strategies or importance of accessible materials and environments, then a simulation experience can be useful and positive, just as Tiffany shared.*





NAPVI

# National Family Conference

National Association of Parents of Children with Visual Impairments

**SAVE THE DATE**



**July 10-12, 2015 • Chicago, Illinois**

Location:

**Chicago Lighthouse for the Blind**  
1850 W Roosevelt Road, Chicago, IL

Conference hotel:  
Chicago Marriott at Medical District/UIC

Visit [lighthouseguild.org](http://lighthouseguild.org)  
for conference updates.

For more information contact Susan LaVenture, Executive Director NAPVI at  
[laventures@lighthouseguild.org](mailto:laventures@lighthouseguild.org) or 800-562-6265



## Halloween Costumes

It is almost Halloween! Do you need ideas for costumes? Go to [www.pinterest.com/ginny1396](http://www.pinterest.com/ginny1396) to see some great ideas for Halloween costumes for kids using strollers or wheelchairs. Other Pinterest boards that you might find interesting at the same link are:

- Children with CVI (Cortical Visual Impairment)
- Children who are Visually Impaired and their Families
- Braille
- Orientation and Mobility
- Children who are Deafblind



### 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.*

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