

Parent Time

A Newsletter for MoSPIN Parents

Volume 17, Issue 2

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Greetings!

This issue of Parent Time has a special focus: LITERACY!

Literacy literally starts at birth! A baby's early experiences at home with family are crucial to the development of early literacy. That is why we asked three MoSPIN families with children of various ages and visual diagnoses to share their early literacy experiences with their children. Also, a grandmother shares her special poem about "Understanding Blake's Sight". You can also read about how Blake inspired her "Thoughtful Children's Book" project. You'll also find articles regarding braille, twin vision books, story boxes and much more in this issue. We hope you enjoy this issue of Parent Time and are motivated to try some new activities with your child as you continue down the path to literacy together!

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From the Wilson Family

Hello fellow MoSPIN parents:

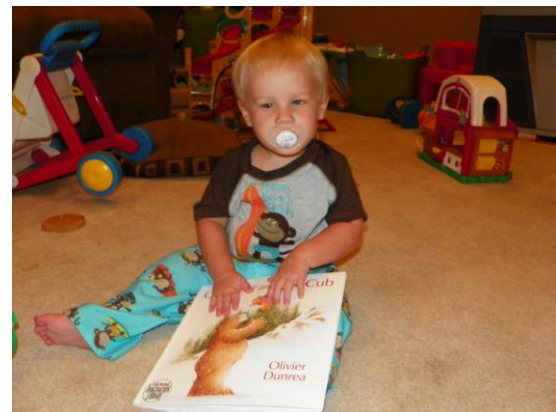
Let me start by introducing myself, my family, and why we are a part of the MoSPIN family. My name is Jonie Wilson. My husband John and I live in the small rural area called Dixon, MO. We have three beautiful children. Our daughter, Andi, is four years old and in preschool. She is our spitfire child who never runs out of energy. Clayton and Cheston are our twin sons who are nineteen months old. Clayton is a man of few words but he loves to follow his big sister and does whatever she is doing. Cheston is a man of many words and is a lover. He cuddles and hugs and is the most charming individual ever. We are part of the MoSPIN family because of our son Cheston. When Cheston was two days old he was diagnosed with a very rare genetic disorder known as microphthalmia, aka, "mini eye syndrome". Once the boys were born we had our suspicions about Cheston when he never opened his eyes. We finally got our answer when the boys were two days old. We were discharged from the hospital and were sent straight to the Pediatric Ophthalmologist where he diagnosed Cheston with severe bilateral microphthalmia. One week later we were at St. Louis Children's Hospital seeing another Pediatric

Ophthalmologist where they did an ultrasound to determine our next move. Cheston did have very small eyes, about the size of a pencil eraser. His chances of having any vision would be very slim. At the time of Cheston's birth he had started growing cysts under his right eye lid. We were sent to an Oculofacial Plastic and Reconstructive Surgeon and an Ocularist, his prosthetic eye maker. In the last nineteen months Cheston has had five sets of conformers, two MRI's, has had both of his eyes enucleated (removed), tubes put in his ears from ear infections, and now has the most beautiful set of eyes you have ever seen - painted exactly to match his mothers blue eyes. Cheston is blind and wears his prosthetic eyes at all times.

As our fellow Parent Time lead writer used to always say, "Everyday has its challenges but we have our rewards too." For my husband and me the last nineteen months have been full of challenges, but it has also been full of many rewards that we are very thankful for. Our biggest reward has been Cheston himself. He is the most handsome, charming boy. He talks up a storm, repeats anything he hears. He has just started taking his first steps by himself walking through the living room. He navigates himself through our house just like the other children do. He loves music, but don't try to take it away from him because he will tell you all about it. We have had a few challenges. Most of Cheston's doctor's appointments and his ocularist are three hours away from our home and with both my husband and I working full time jobs it gets to be challenging at times to accomplish all the demands, not only financially but time-wise as well. Having to sit through two different five hour surgeries was difficult as well, as any surgery for a loved one is. We have had to learn how to deal with Cheston taking out his prosthetic eyes and teaching him not to do that. Now he just does it when he knows he is somewhere he can show off. Yes, he now does it for everyone new he meets. I have lost them a few times but luckily found them very quickly.

Braille is something very important to my husband and me for Cheston to learn. Literacy is a big topic that we discuss in our MoSPIN meetings with our MoSPIN parent advisor. In our O & M therapy sessions we also incorporate braille lessons. The O & M has given us wonderful ideas of what all we can do now to incorporate Braille into our family. One thing we do is leave either a braille book or a sheet with Braille on it so that Cheston can find it when he is playing with the rest of his toys. We have done many activities with Andi

where she gathers items from around the house that are associated with a book we are reading and she hands things to Cheston while we are reading the story. This works great with the Mercer Mayer Little Critter books. We have also done our own version of "what do you see" books where we put different textures on index cards that feel similar to the animal or item in the book. We sometimes will put items in brown bags and they have to dig for the items. Of course the bag is always the favorite item! We have also placed braille/print stickers on items throughout our house of what each item is. You can get these from American Printing House for the Blind (APH). It is really interesting when people say to us "why do you have a sticker on the television that says television?" I tell them to look closer, it has Braille on it. We have started a nice collection of braille/picture books for Cheston, but also for Andi and Clayton. They all three enjoy books and love listening to us read to them. There are many sources we receive books from such as APH and Seedlings. The most recent book that we received was ordered thanks to a MoSPIN alert that the APH and Dolly Parton's Imagination Library partnership could provide six free braille books a year for visually impaired children until they are six years old. I applied for the books and shortly after we received Cheston's first book *Old Bear and His Cub*. He was so cute with it I took his picture, pajamas and pacifier and all. I sent both APH and Dolly Parton's Imagination Library an email thanking them for the book and the program along with Cheston's picture. They then asked me if they could put his picture on the website and of course I said yes! He is too cute not to. These are just examples of wonderful programs that they have for children who are visually impaired that we can utilize for our entire families. My family is definitely grateful for them.



This has definitely been a journey for our family. When we first brought the boys home from the hospital we tried explaining to Andi, who was then three that her

If you have anything that you would like to share with me on your experiences with your child or have any questions for me, please feel free to contact me.
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From the Farris Family

How We Read!

My husband, Wes, and I are young parents in our early twenties. We have two under two. That is until Lilly's second birthday, which is in two days. Our Lilly was crowned a Drama Queen at two days old, and she has spent every day since then living up to her title. Our newest addition to the family, Jonah, is four months old and was born smiling. I think he knew we would need a smile while his big sister was busy being stubborn.

Like many other parents of visually impaired children, I vividly remember every detail of the moment we were told our sweet baby girl was blind. We already knew in our hearts, but we still had hope. Lillian was diagnosed with Optic-Nerve Hypoplasia, and later Septo-Optic Dysplasia, which has no cure. Our first thoughts were how would we make it through the day? How would we raise a blind child? What were we to do next? Literacy was the last thing on our minds. Now that we have a year and a half under our belts, literacy is on our minds daily.

We started reading to Lilly when she was still in the womb. We would read anything from pregnancy books to the newspaper; it was a great family bonding time. When we found out Lilly was blind, I felt like reading

was not going to be important. I figured Lilly would go to school and learn Braille, and I would never be smart enough to pick it up. Of course, I was incredibly wrong. Our wonderful parent advisor from MoSPIN brought us a video on literacy. The content hit us right between the eyes. Now we make sure that we read to Lilly every day. To engage and catch Lilly's attention we use different methods. A story box with different items she can manipulate and connect to the stories is a wonderful tool. It's like Lilly gets to see the story with her hands.

We quickly learned Lilly had her own author preference; Dr. Seuss. Other rhymes and poetry can hold her attention for a few minutes, but anytime we read a Dr. Seuss book, Lilly is automatically intrigued, and is smiling and listening until the last word.

Through Lilly's orientation and mobility specialist, and APH's new partnership with Dolly Parton, Lilly now has many books that are brailled. While Lilly does not know Braille, she is being introduced to it, and I believe she is starting to link the Braille to the story like a sighted child first links print to the story in the book. Her interest in Braille has helped greatly when we are reading a book that is not a Dr. Seuss masterpiece. The books that go along with popular songs such as *The Itsy Bitsy Spider* or *The Wheels on the Bus* are also some of Lilly's favorites. She loves music, and anytime it can be incorporated into an activity it grabs her attention.

We have learned that literacy is a vital part to Lilly's developmental success. Our philosophy is to do everything we can to prepare Lilly to be an independent adult and contributing member to society. Of course reading and exploring the adventure in books at an early age is a wonderful way to help fulfill our goals as parents. I taught myself Braille, which is still a work in progress, through a book MoSPIN gave to us. It is wonderful to know we are in a program that helped our family realize how important it is for our children to explore through books, no matter what obstacle we face.



From the Eggleston Family

Hello, my name is Tiffany. My husband, Jarrad and I have a beautiful little girl named Emmalin. Emmalin is getting ready to be 4 the end of this month and she is our only daughter. When Emmalin was 16 months old, she was diagnosed with a very rare gene deficiency called CDKL5. In fact this gene deficiency is so rare, that there are only about 300 known cases in the world (but more are being diagnosed all the time). Having the CDKL5 gene deficiency can mean many different things. For Emmalin it means that she is non-verbal, has multiple seizures (and multiple seizure types) every day, she has cortical vision impairment (CVI), she's developmentally delayed in every area, she has low tone (Emmalin is still working on her head control and sitting up), and has a feeding tube. Actually in the "vision category", along with CVI, Emmalin has also been diagnosed with strabismus, nystagmus, and ocular motor apraxia.

As you can see, Emmalin is a multi-handicapped child and like many of our children, Emmalin faces MANY different challenges every day. Along with everything else that I have listed above, Emmalin does not like to use her hands. So you can see how learning to read Braille or even finding ways to discover the world around you can be a challenge. Although one day we hope that Emmalin will start holding things in her hands, as of this moment, the only thing that she will consistently hold is someone's finger.

When it comes to literacy, because of all of Emmalin's challenges, she is not learning Braille and if I'm being completely honest, Emmalin doesn't even like to touch the books. But all that being said, Jarrad and I still feel it is SO important to read to Emmalin. When we read with Emmalin, no matter what kind of crazy things might have happened throughout our day, we love the fact that we can always grab a book, cuddle up together and go on an adventure from our very own house. Whether it's a story about a princess, learning a lesson with the Berenstain Bears, having fun adventures with Dr. Seuss, or even reading poetry from Shel Silverstein, books give us a moment of calmness (no matter how big or little the "storm" with the rest of the day might have been).

Another reason we like reading books with Emmalin, is that it gives us another opportunity to help Emmalin

learn about the world around her. Yes, most of the books we read with Emmalin are fiction, but they still talk about/describe things that are a part of the everyday world that she is still in the process of learning A LOT about!!

We have actually found a couple different ways we can read books with Emmalin. The first one is in our bedtime routine. We always read books with Emmalin before she goes to bed. This is a great time for Emmalin to start winding down and of course it's a great time to get lots of snuggling in also ;)

Another way we have found that we can read books with Emmalin is for Jarrad and me to actually record our voice reading the book. We have done this in two different ways. One way is where we have literally just recorded one of us reading one of Emmalin's books onto a CD. This gave us the opportunity to play this CD of the book for her in the car, while she was playing in her room, or even at her grandma's house. While Emmalin is at Grandma's house and we are not there, Emmalin seems to find it comforting to be able to hear our voices. The second way we found to record ourselves reading a book was on the books that they literally call "recordable books". With these books, you push a button on each page and record yourself reading it. I think Hallmark has a couple of different ones in their stores (especially around the holidays) and I know that you can also find them on amazon.com.

There is one other way that we have discovered to be able to get books on a type of tape (I was told the "tape" was really more comparable to a thumb drive). It is a FREE resource for children who are visually impaired (actually the official Wolfner Talking Book and Braille Library website states that, "it's a free library service for Missourians who are unable to use standard print materials due to a visual or physical disability"). It is a program at the Wolfner Talking Book and Braille Library (they seem to just call it the Wolfner Library for short) and it is based out of Jefferson City. This library has a lot of other things that they offer besides the books on tape (like braille books and large print), but books on tape is just how we are choosing to utilize this resource at this time. The Wolfner Library literally mails you your items you are requesting and then you mail them back when you are done with it for FREE. To be honest, we just found this resource and are getting

Grandma's Story Telling Nurtures Thoughtfulness

Judy K. Johnson's grandson, Blake Michael, was born a micro-preemie in 2004. His bravery and determination as he faced multiple challenges including blindness resulting from retinopathy of prematurity so touched his grandmother that she began to write. One of her poems is included in this issue of Parent Time. Judy's first book was written about Blake and "his blindness issues and how other children can best play and interact with him". This became the inspiration for her "Thoughtful Children's Books" project. Visit her website at www.thoughtfulchildrensbooks.com to learn more about her other books, the project and how your own special family story can become a "thoughtful children's book".



"Understanding Blake's Sight"

By Judy K. Johnson, Grandmother, Leona, TX

*I am blind, but my fingers are my sight,
soft and nimble, carefully exploring, feeling
surfaces and textures.
Through my fingers, I see the world around me,
gently guiding me through each experience of my
life.
I see warm, comforting, sunlight shining on my
hands
as I swing outside in fresh morning breezes.
I see my round, bouncy ball, sometimes jumping
back
into my hands when I throw it away.
I see my special book with straight, flat edges
and bending smooth or textured pages, hearing
grandma's
voice telling my favorite story over again.*

*I see my soft, furry lamb with long silky ears,
tickling whiskers, button eyes and fluffy tail,
keeping me company in my bed at night.
I see the most special faces of my mom and dad
always smiling.
I see their hair, noses, ears and lips giving kisses,
my favorite, favorite, favorite thing.
I see my puppies' cold, pointy noses and beneath
their
wet, scratchy tongues reaching for my cheeks.
My fingers and hands are sensitive even to your
touch
With your touch, I anticipate your intentions and
emotions.
Friendly and trustworthy, or cautious and nervous.
A heavy touch of insistence without my choice
makes me dread my surroundings and not reach
out to see them.
Focused and worried by unexpected, quick
movements I feel,
I can become uneasy and unable to trust and very
quiet.
Happily, I feel a careful, sincere invitation with your
light touch.
Eagerly, I feel each careful movement of your hands
beneath mine,
steadily allowing me to trust unknown things you
hold to show me.
Your touch can also become for me a welcome, an
explanation,
a nonverbal conversation or perhaps even an
invitation for a hug.
Your touch shows me how we can interact and
communicate.
Your touch and soothing voice have power to build
my confidence
allowing me to see even more unknown things with
such a big smile.
Guide me with a steady touch which enables me to
direct my own hands.
Encourage me to see all that I can through my
fingers.
I will see, observe, explore and have my very own
ideas.
My fingers are my sight.*



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

New Programmed Instruction in Braille, Fourth Edition
SCALARS Publishing
www.scalarspublishing.com

Instruction for Braille Transcribing
American Printing House for the Blind
www.aph.org

Introduction to Braille
Hadley School for the Blind
www.hadley-school.org



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

Seedlings – braille labels placed on print books and other twin-vision books for purchase
www.seedlings.org

American Action Fund for Blind Children and Adults – twin-vision books on loan
www.actionfund.org

Wolfner Library – twin-vision books on loan
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



Braille Basics

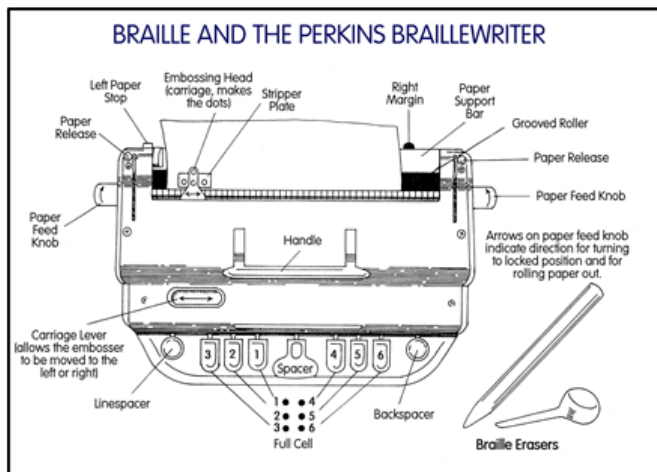
Though many of you are familiar with Braille, some of you may not be. The American Foundation for the Blind provides this information on their website at www.afb.org

What Is Braille?

Braille is a series of raised dots that can be read with the fingers by people who are blind or whose eyesight is not sufficient for reading printed material. Teachers, parents, and others who are not visually impaired ordinarily read Braille with their eyes. Braille is not a language. Rather, it is a code by which languages such as English or Spanish may be written and read.

What Does Braille Look Like?

Braille symbols are formed within units of space known as braille cells. A full braille cell consists of six raised dots arranged in two parallel rows each having three dots. The dot positions are identified by numbers from one through six. Sixty-four combinations are possible using one or more of these six dots. A single cell can be used to represent an alphabet letter, number, punctuation mark, or even a whole word. The enclosed braille alphabet and numbers card illustrates what a cell looks like and how each dot is numbered.



Story Boxes = Hands-On Literacy

What is a story box? It is a box (or a bag or any other container) that holds a book and a collection of simple items that are mentioned in the story.

Why create a story box? A story box can promote your child's interest in books by providing a hands-on literacy experience.

How are story boxes used? Start by allowing your child to explore the items you have collected in your story box. Then you can read the book and share the objects as they are mentioned in the story. After you complete the book, you can get in the routine of putting the items back in the story box and reviewing the story.

Where can I learn more about story boxes? You might want to check out these resources.

www.familycrafts.about.com/od/homemadebooks/a/storysackindex.htm
www.kansasprojectsuccess.org
www.pathstoliteracy.org/making-story-box



Website Supports Literacy

www.pathstoloteracy.org

This website is the result of a joint project between [Perkins School for the Blind](#) and [Texas School for the Blind and Visually Impaired](#) (TSBVI). By combining their resources and expertise, they hope to assist educators and families in the quest to provide literacy experiences for children who are blind or visually impaired.

The information on this site ranges from a basic overview of literacy to various stages of development and special challenges, as well as an exploration of different media (print, braille, auditory strategies).

Cassie Scarbrough
May 18, 2009 - May 18, 2012

Lynia Watson
January 8, 2010 - June 13, 2012



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.

Ginny Williams

Lead Parent Advisor for MoSPIN



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