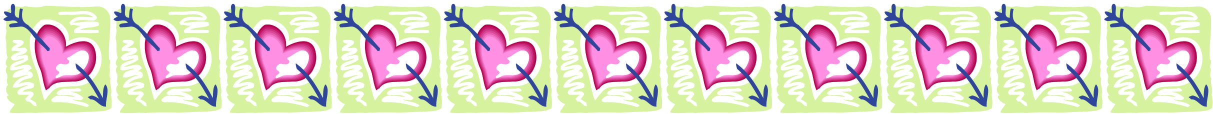
Parent Time

A Newsletter for MoSPIN Parents

Volume 19, Issue 1 February 2014



Greetings!

This issue of Parent Time has a special focus on Social Media and Connecting with Others. We know that many folks use Facebook, Twitter or other social media to make connections and keep connected with others. I admit to checking Facebook to keep up with my grandkids, but no tweets for me. Each of our parent contributors will share how they use (or don't use!) social media, but I am interested to find out how much our other MoSPIN families are using social media.

How important is social media in your life? Do you use it to keep in touch with friends, to make new friends by connecting with people with similar interests, to find information (maybe about your child's diagnosis), to get inspired or because it is simply entertaining? We'd love to hear more about your interests.

Maybe there are ways we at the Missouri School for the Blind could use social media to support you. For example, I am currently developing a few resource boards on Pinterest at www.pinterest.com/ginny1396. One board has resources and information regarding Cortical Visual Impairment, another on Braille and another board has resources for Families of Children Who Are Visually Impaired. Let me know if you have other ideas.

Of course, there are many other ways to make family connections. This issue includes articles that will provide more information on ideas for connecting with other families. Here's to making new connections!

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The Farris Family and Social Media

Hello, MoSPIN families!

I am Sherah and my family includes Wes, my husband, and our children Lilly and Jonah. I cannot believe it is already another year. Time just flies by faster each year. The Farris family has had a busy time since the last newsletter. I, Mom, am attending Missouri Southern State University full time, and Dad is taking on the Mr. Mom roll during the day! Lilly, our three year old who has Septo-Optic Dysplasia, has been enjoying her new big girl bed for the last few months. Much to our surprise the transition was easy for Lilly and she loves her new toddler bed. Jonah, our eighteen month old, is running and talking non-stop, and always trying to be near his big sister. We have also found out we are expecting another sweet baby boy this June! Our family is blooming more and more.

We had a great time over Thanksgiving and Christmas. There were a lot of snow days between and after the breaks, so it felt like Lilly did not go to school for a month straight! It was nice to spend all day with the children, playing and dancing, which is Lilly's favorite daily activity. We had such a good time bonding that I did not want to go back to school after Christmas Break!

With so much going on, it's hard to see all of our family as much as we would like to. Even though we're not with our extended family every day, we make sure we keep them updated on the milestones our children are meeting. It's very easy for me to upload a picture or video to Facebook for all our friends and family to see what is going on with the Farris family. Everybody is always excited to see Lilly progressing with use of her cane. We always get the response of how sweet, smart, and all around wonderful Lilly is. Of course, we agree that she is an awesome little girl.

We also use Facebook to share current events of the Farris family. When Jonah decides to climb on top of the kitchen counters, or Lilly says a new word or phrase, we are more than excited to share with our family and friends. When we upload a quick status or picture, all of the people we love can chime in and celebrate everything going on. If we're going through a rough patch, we can also receive encouraging words through Facebook.

Another really fun way for us to connect with our close family is by using Face Time on our iPhones. Lilly and Jonah both come to sit on my lap when I start calling my mom or sisters because there is a distinct ring they recognize. Lilly enjoys talking to her "Gamma" in particular. Most likely because "Gamma", or grandma, spoils her rotten with hugs, kisses, and candy. Jonah enjoys talking to all of his cousins through Face Time. It is really neat to see all of the kids connect and share memories of silly Face Time calls. This kind of use of technology makes it a very positive thing in our lives.

It is interesting to see how kids grow and connect in the new age of social media. I hear my nieces and nephews say, post that on Facebook, and what did everybody say? I know it is only a matter of time before my children are saying and asking the same questions! My favorite part of new technology is Face Time hands down! Not only do I love seeing and talking to my family while I'm talking "on the phone", but Lilly and Jonah enjoy it as much as I do.

The Eggleston Family

Hello again from the Egglestons!

I'm Tiffany and my husband's name is Jarrad. Since writing the article in the last newsletter, our daughter Emmalin has had a birthday. So now we have a FIVE year old living in our household. For those of you that don't remember the details about Emmalin and her diagnosis, I thought I would briefly explain it again. Emmalin has multiple disabilities. She has a rare gene deficiency called CDKL5 and for Emmalin that means that she is non-verbal, has low tone, has multiple seizures daily. She's developmentally delayed in every area and has a feeding tube. In the vision area, she has the diagnoses of Cortical Vision Impairment (CVI), Strabismus, and Nystagmus. You could definitely say that Emmalin is a little complicated!

I have to be honest with you, when I was asked to write this article, I got nervous when I found out the focus was social media and connecting with others. When it comes to me getting all the information to help Emmalin in the vision area, I typically get it from my MoSPIN Parent Advisor, Emmalin's vision teacher, and/or my friends who also have visually impaired children. I am NOT very knowledgeable in the social media area in ANY way. I don't use Twitter, Instagram, or Pinterest. I do have a blog site (www.emmalinsjourney.blogspot.com) where I blog some about what is going on with Emmalin, but I don't follow anybody's blog...so I don't really do that either. I am on Facebook, but I am more of one of those people that just read what everyone else has posted instead of posting a bunch of stuff about myself. As far as YouTube goes, I do get on there some, but not that often. Even when it comes to iPads, Emmalin can't use one because of the fact that she has a Vagus Nerve Stimulator (VNS) and we don't have any other type of device like that, and so even the "app" world is something that I am pretty clueless about.

Now that I have helped you understand the minimal amounts that I utilize that social media world, after thinking about this topic, there are two different areas that I do feel like I could at least "share what I know". The information will be very minimal, but I figure if there is one person out there that may not have known about them, then it would be worth talking about…so that's what I am going to be talking about this time.

The first thing I want to mention is that on Facebook, there is a closed page for Cortical Vision Impairment (CVI). It's officially called Cortical Vision Impairment (CVI) Awareness. As I said, it is a closed group and so you have to request to "join". When I went to this actual page, I looked for a type of description that would explain more on what this Facebook group was about, this is what I found:

"…This group is open to anyone interested in learning more about Cortical Visual Impairment, its etiology, diagnosis, and treatment; and educational options for individuals, educators, and family members affected by CVI. It is also a forum for individuals to share information and contacts in an effort to further the cause of educating themselves and others about this condition."

Just like my normal Facebook page, in this group I do not normally post anything, but I do check it from time to time. On this page I have seen posts about a couple of different things - people trying to find/connect with other people in their area, people asking questions about different things that their child is doing or not doing, or to get some suggestions on what other people have done in their situation. Sometimes I have even seen people post pictures of different toys (or just different things) that have worked for their child with CVI so that other people have the chance to check them out and see if it is something that could possibly work for their child. Remember, I said that I don't get on that page a bunch, but when I have been on there, those seem to be the main topics of the posts.

The second thing that I thought I would talk about is some different videos that I have found on YouTube. I had never really used YouTube a whole lot until one day my mom was watching Emmalin and I called to check on her and my mom told me Emmalin was watching a YouTube video. Now you need to understand that Emmalin is a HUGE light gazer, and she will always find the biggest source of light in the room that she is in and stare at it (and sometimes the biggest source of light is the TV). So when it comes to Emmalin "watching" a video on TV or the computer screen, it doesn't matter if it is a cartoon or a documentary, she will stare at it all the same way (but it never seems like she is actually engaged in what the show is talking about, she's just staring at the lights). So when my mom told me Emmalin was watching a YouTube video, I couldn't believe it! When I picked up Emmalin later that day, my mom got back out her laptop and showed me. Sure enough, Emmalin was REALLY watching it.

This was HUGE, because as I said before, she had NEVER engaged in anything before when it came to videos/TV!! The other thing that blew me away was the fact that the YouTube video was NOTHING that I would have ever thought Emmalin would have liked… the video was pretty slow paced, and it had single objects (for the most part), but I still thought it would have been too "complicated" for her to look at when actually engaging in something. I also thought it would be too long for her because Emmalin typically has a pretty short attention span with things and this video is almost 10 minutes long.

The name of the YouTube song Emmalin liked is called *Animal Alphabet Song* and it is 9:47 minutes long. If you want to look this actual video up to have your child watch it, you will need to know that it is the alphabet song by asian8beauty. The only reason I am telling you this is because I have found there are A LOT of alphabet songs on YouTube!

So once I discovered Emmalin liked this song, I found some different videos on YouTube that I thought would have been more along the lines of something she would like (simplicity wise, they were shorter in time, and so on), but so far Emmalin hasn't liked any of them. Saying that, I thought I would go ahead and mention the names of them in case your child might like them. Here are the names of the groups that have had some songs that I have tried with Emmalin: KidsTV123, Super Simple Songs, Hey Bear, BlackWhiteRedOnline, and weeseeworld.

Believe it or not, all of this YouTube video stuff has actually taught me a little lesson. As I said earlier, the YouTube video *Animal Alphabet Song* is something that I would have NEVER thought to try. For whatever reason, it works for Emmalin and she really likes it. I've learned that I need to try to be open to trying some new things every once in a while, even if I don't think that it will work. Because it seems to be that when I least expect it, Emmalin will surprise me!

I hope these two little tips have been able to help someone. I hope that 2014 is treating you all well and that you are all staying warm!!

From the Wilson Family

Hello again to everyone from the Wilson family.

I am Jonie, and my husband John and I are blessed to be sharing our family again with the rest of the MoSPIN families. In this Issue, I am going to be updating you on everything that is happening in the Wilson household and also sharing with you how we use "social media" to connect with others. As you may remember John and I have three children. Andi just turned six and is in Kindergarten and we have twin boys, Clayton and Cheston, who are getting ready to turn three in March.

The kids had a wonderful Christmas and holiday season. I believe "Santa" made good on their wishes and got them what they had asked for. The kids have enjoyed the snow and have made multiple snowmen this winter. Clayton and Cheston are getting ready for their third birthday party soon. We are a part of MoSPIN because of our son Cheston. Cheston was born with microphthalmia, aka, mini eye syndrome. Cheston has the most severe form of microphthalmia. He is blind and wears his beautiful blue prosthetic eyes. To John and me, these past three years have gone by so fast. We feel like it was just yesterday we were bringing them home from the hospital and saying "Oh, we have a long time to worry about Cheston starting school." Now here we are three years later getting ready for that big first day of school.

Along with the "terrible three-year stage" we have other obstacles to deal with. We are transitioning out of First Steps and into the school system. We have already had all the important transition meetings and we have written his IEP. He has met his preschool teacher, his new TVI (Teacher of the Visually Impaired), and his para as well. He is going to have all kinds of new braillers and machines once he starts school. We are very excited and nervous about this transition for him and hope it is a smooth one. His brother is not going to go to school with him, so that will be a rough transition for Clayton as well to stay at the Day Care while Cheston gets to ride the big school bus to school. Another obstacle I am having is potty training Cheston. Clayton is fully potty trained but we are still working with Cheston. He has been difficult to train. He can say the words and knows the toilet is where you go potty, but doesn't tell us when he has to potty. That is a task I am going to be working on this summer. We still have some sleep issues with Cheston. We started giving him melatonin this fall and this has helped a lot, but he still likes to get up in the middle of the night and wander the house. That is something we struggle with and continue to work on.

I want to share with you a little about Cheston and his personality. Cheston is the most loveable individual ever, but he is also very head strong. He can throw a three year old fit like a champ when he does not get his way. He is a lover though, and loves to snuggle and hug and kiss. He loves three major things:

The phone. He is obsessed with the phone. He will ask anyone, "Can I have your phone?" It gets very annoying. He loves phones for the fact that he can push the buttons and they make noises, or when he tries to call someone on the home phone and the operator talks to him. He has also figured out that "Siri" on the iPhone talks to him. He can have a full conversation with "Siri". He asked "Siri" one day to call Santa Claus. She told him there was no cellular reception at the North Pole. He also loves phones because they play music. He will even tell you when your phone is ringing. "Hey, your phones ringing!"- with the most country slang possible.

Food. He loves food. Especially the foods that are not good for him. There are three major favorites: cheese balls, oatmeal pies, and Twinkies. Those are his most favorite foods ever. He also loves cheesecake and birthday cake and ice cream. He loves to eat.

Mr. Repeat. Cheston loves to talk. Especially repeating everything he hears. He has very good speech. But he repeats everything to where it is cute, funny, and annoying all at the same time. He also has funny sayings that are very humorous. Such as when he walks into the room he says "Hey Buddy". I whispered to him one day at church that it is quiet time and to be quiet. He yelled "Hey, it is quiet time, be quiet" while the preacher was in the middle of his sermon. With his impeccable speaking habits, he also has a great ability to repeat songs word for word. He loves music and even tells you which ones are his favorites and are not his favorites. We love to hear his sweet voice when he sings.

In this newsletter I was asked to share about social media and ways I do and do not use social media. I will say, I am more on the "do not use" rather than the "use". I do not have Facebook, Twitter, Instagram, Tumbler or anything like that. I do not do any of these things mainly because of time. Finding the time is very difficult for me. Here is what I do that helps me stay connected and get ideas. I do have a Pinterest account that I actually just started about a month ago (on one of my many snow days I had at home). On Pinterest, I look up recipes or new snack ideas for the kids. I love to look up neat craft ideas for school things such as teacher or student gifts. I am not very crafty so I like easy things to do. I do look up braille jewelry and other braille idea items. One item I have found interesting lately was a braille chocolate mold that you can make your own individual chocolate candy bars. I found the mold on Amazon, which was very reasonably priced. I always want to incorporate Braille in all Cheston's gifts to his teachers, classmates, family and friends, because that will be a huge part of his education. I even braille his Valentine cards to the kids at the daycare.

I have two main Blogs that I read that are by women who have blind children. I love these two blogs because they are very inspirational. One blog I read is www.mymommyhasissues.com. I have it to where anytime she posts something new, it comes straight to my email. I like this blog because she has a child with a similar diagnosis as Cheston's. Not only does she blog about having a child who is blind, she also blogs about raising a child with special needs. Another good blog I enjoy reading is www.thomasmarshalldoesitall.blogspot.com. It has a lot of neat and interesting day-to-day articles of Thomas Marshall who is a blind boy as well. I always love to research new blogs to read.

I do like YouTube. When we do have a chance, John and I will research certain videos of children who are blind and visually impaired. I enjoy watching things that they do such as singing the national anthem at a ball game or playing the piano or all kinds of neat things that YouTube has. My kids love YouTube, but for watching cartoons and listening to music.

I do a lot of photo sharing and video sharing over text messages. That is about the extent of my social media usage. I do this a lot with my family such as our parents and siblings. I also have a few friends who I love to share pictures with, and videos of Cheston and the other kids. That is about the extent of it. I would say I use texting as the most common form of keeping people updated about Cheston. It is also how I stay connected with people that I have met who have children with a similar diagnosis as Cheston.

Through Cheston coming into our lives, we have found that a sense of humor is a great thing to have. My husband has a great sense of humor and Cheston does as well. He gets his loving personality from his father. We have so many interesting stories and would love to be able to share those stories with individuals who are going through a similar situation. One thing that I would love to do in the future is to learn how to post videos on YouTube of Cheston and also possibly start a blog. It is just finding the time to get all of this started and keep it going. Maybe once the kids all get bigger and start school I can work on this.

I hope everyone has a great summer.

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Connecting Families

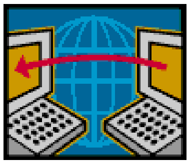
"I'd really like to connect with other families of young children with visual impairments, but I don't know where to start."

MoSPIN families report that they 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, the next articles may provide some ideas to consider.

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 314-776-1300 to get more information or to get started.

Online Communities



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 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 for children with albinism and/or hypopigmentation
- Focusfamilies.org for children with optic nerve hypoplasia or septo-optic dysplasia
- 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 for microphthalmia/anophthalmia parent support

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 a national organization serving families. NAPVI enables 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 Doreen Frappier at
dcfrappier@yahoo.com

NFADB -The National Family Association for Deaf-Blind is a nonprofit national organization of families of individuals who are deaf-blind that offers support in a variety of ways:

- A toll-free number 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
- Potential participation in a national training opportunity

For more information, contact Lori at 1-800-255-0411 or NFADB@aol.com

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. Information regarding the Power Up 2014 Assistive Technology Conference and Expo is included in this issue. We also do special mailings to alert families of upcoming events. We have used targeted mailings to alert families of conferences in which they may have a particular interest such as the CHARGE Syndrome or PKS Conferences. At other times, Parent Advisors are requested to share information during their MoSPIN home visits to alert families to an upcoming event. **Financial support maybe available for family attendance and participation**. **Just ask**. 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.

In Memory Of

Dante Washington
May 19, 2013 – January 27, 2014

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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

Power Up 2014 Conference and Expo

REGISTER NOW!

Power Up 2014 Assistive Technology
Conference and Expo

will be held April 14 & 15, 2014
at the Tan-Tar-A Resort, Osage Beach, Missouri

Presented by
Missouri Assistive Technology

www.at.mo.gov/powerup/index.html

Power Up 2014

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