

Parent Time

A Newsletter for MoSPIN Parents

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Greetings!

Our focus for this issue of Parent Time is **advocating for your child**.

We have four families that will share their experiences and perspectives on the importance of advocating for their children. Jonie Wilson is returning to share information about Cheston and the rest of the family and how they advocate for him in a variety of situations. Three new parents join us in this issue. Kami Patrick shares what she has learned about advocating for her son, Everett, in the medical arena. Claudia Hall provides important information about what she has learned while travelling with her son, Nicodemus. Aleta Jenson shares examples of how her family has advocated for Nathias, with a special focus on social situations. Also, articles and links to resources regarding advocating are included in this issue.

We hope you will enjoy reading about the experiences of our MoSPIN families. Our thanks go out to each of them. We would love to hear from you! We encourage your feedback or your willingness to share your story in Parent Time.

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From the Wilson Family

Hello again from the Wilson family!

As always, it is a pleasure sharing our family with the rest of the MoSPIN families. I am Jonie and my husband John and I have three wonderful children and live in Dixon, MO. Andi is our daughter who is seven and is in first grade. She has kept the tooth fairy very busy this winter losing four teeth in two months. Her looks have changed for sure. She is still keeping us on our toes. Clayton and Cheston are our twin boys. They are getting ready to turn four years old and, boy, how time has flown. Clayton is doing great. He is in love with dinosaurs and farming. He is looking forward to showing animals this year at the fair and playing coach pitch baseball this summer. Cheston is the reason we are a part of MoSPIN. Cheston was born with a rare genetic disorder called microphthalmia, “mini eye syndrome”. He is blind and wears prosthetic eyes. Cheston goes to preschool for half the day and then goes to daycare the remainder of the day. He has been attending preschool now for almost a

year. He has almost every teacher, faculty and staff member at school wrapped around his finger! We did accomplish something major this winter and that was potty training. We have been so excited about this. He has done remarkably well! We had a great holiday season. We are now getting ready and excited about softball and getting ready to show animals. This year the kids are going to show lambs as well as hogs.



This article is about advocating for our child. Having a special needs child is like having another full-time job. Some days I feel like I have four or five full-time jobs. Advocating for our child is something that we do daily even if we do not realize it. Advocacy is defined as: A person who supports and promotes interests of another. Some ways I advocate for Cheston are socially, educationally and medically. Here are some things that I do that help my husband and me to advocate for our children. One of the main things is educating ourselves as much as possible. I am constantly reading on educational items, technologies, toys; just about anything that I feel will help us raise Cheston as a productive individual. I also love to read other peoples' stories about raising a child with vision issues. It is always inspiring to read about others who go through very similar situations that we are dealing with on a daily basis or have dealt with before. Another thing that has probably helped me the most is my background and what I do. I am a Guidance Counselor, so I encourage students to advocate for themselves frequently. When Cheston was born, I remember having so many different emotions and feelings. I was so overwhelmed because I knew

that having a special needs child to raise was going to be difficult. We still struggle with certain things every day. I know that being an educator has helped me advocate for my own child.

Advocating for Cheston in the social aspect is actually not difficult because Cheston has such a powerful personality he does this very well himself. Cheston reminds me of his father so much. He has a very fun, loving, free-spirited personality. He is funny and quirky and can make anyone smile. He has such charisma it is hard not to be drawn to him. Once people are around him for just a few minutes, they become very comfortable around him. I know sometimes it might be awkward for people and people might not know how to act or what to say to a child with special needs. I usually introduce them to him and he instantly says their names back and says hi, and then he never stops talking to them. Also, he will never forget them. We do have to remind Andi and Clayton at times to be nice and sometimes remember that words do hurt and he can hear their words even though he cannot see.

Educationally advocating for Cheston has not been as difficult as I know it could be. Our school district has been very easy to deal with. I started advocating for Cheston educationally when he was one week old. I remember asking his doctor to refer us to the right people so we could get his needed therapies started immediately. Cheston's first Orientation and Mobility appointment was when he was one month old. We met with the specialist multiple times per month until he was three.

Now that he is almost four we have transitioned from First Steps to the school system. This did take some research and lots of education, and communication between us and his IEP team. I researched and researched different technologies, goals, expectations, and funding. For example, when we were writing goals at his IEP meeting, I questioned why they suggested only a 60% target for completion of a goal. My question was, what are regular education students' mastery levels?

The reply was 80%. Then, there is no reason why he cannot have a mastery level of 80%. I did not want him to know 60% of the alphabet when this knowledge will be used every day for the rest of his life. I did not feel bad that I had high expectations for his learning. Knowing your rights and your child's abilities are among the best ways you can advocate for your child. One quote I have found interesting is "Do what is best for your child, not best for everyone else."

Advocating for Cheston medically has been a chore since the day he was born. This is another full-time job that we have as a parent of a special needs child. Juggling doctors' appointments, hearing tests, ophthalmologist appointments, surgical appointments and follow-up appointments is stressful. On top of that, there are the medical bills. Then, there are the insurance companies. I remember when Cheston swallowed one of his prosthetics and I was on the phone with the insurance company for days to try to get an answer as to whether the replacement would be covered. I remember explaining the situation to the insurance providers and them laughing about it. Having to deal with medical providers and insurance companies is a part of advocating for our child because we want the best treatment and services we can get for them. I have found it helpful to ask lots and lots of questions of the doctors. It also helps to take someone else along because they might hear something in a different way than I did and put it in a different perspective for me.

Networking with other parents who have special needs children is one of the best things I can suggest. I have a dear friend who has a daughter who has Down syndrome. She has taught me so much about IEPs, educational issues for special needs children and just basic things about having a special needs child. She is great about putting things in perspective for me. I can totally trust her to tell me I am overreacting and to take a step back and think about the situation before I react. She also taught me that disciplining Cheston is something that needs to be done or we are giving

him another disability. I am so glad she did this because now that Cheston's personality has flourished, he would easily have discipline problems if we had not started early disciplining him in ways that are appropriate for him. I am truly blessed to have this person in my life to keep me in my place when need be. Another strategy is to try to maintain positive relationships with the individuals we deal with when advocating for our children. I have had times when my words have gotten the best of me, but now I try to make my points in a very positive manner when I am upset with something. Is this always easy? No, it is not! I usually try to give myself some time and try to figure out the best, and most productive way to solve the issue at hand. I have found that using a little sugar and not vinegar gets me a little farther. I do not want to be that parent that when I walk in they think, "Oh my goodness there is that woman!" I have always tried to be as positive and nice as I can be when approaching a situation that has caused me displeasure. Also, I always try to remember to show how much I appreciate the individuals who help us by verbally expressing our appreciation and also remembering them on special occasions. I have found some really nice Braille gifts that I have been able to make and give to the individuals who help us, especially his teachers and paraprofessional.



Advocating for our children is not an easy task. At times, it can be very difficult. But this is something that we will always have to be prepared to do. It is a lot of work and parents of children with special

needs have many difficult responsibilities. But with all of these difficulties, come many rewarding opportunities. John and I are very blessed to have such wonderful children. We were taught that everything happens for a reason. Some days we think we have figured out why God gave us Cheston and other days we are still scratching our heads and questioning ourselves as to if we are doing the right things for him. But we do know that we are truly blessed and will do anything to make sure he is a happy, loving and remarkable person.



The Patrick Family - Advocating for Everett

Hi! I'm Kami Patrick.

My husband, Chris, and I have three amazing children. Christian, our oldest, is seven and in the first grade, Willow is four and has started her first year of preschool and Everett just turned one in January.

Everett was diagnosed with CHARGE syndrome when he was three months old. CHARGE is a genetic disorder that affects 1 in 10,000. The word "CHARGE" is an acronym for the set of features it entails. C stands for coloboma of the eye, H for heart defects, A for atresia, R for restricted growth, G for genital abnormalities and E for ear abnormalities and deafness. CHARGE is the leading cause of deafblindness.

Everett was born with microphthalmia and a coloboma in his right eye and has anophthalmia on his left side. He was also born with a severe hearing loss, cleft lip and palate, and a heart defect. To say his first year of life has been busy is an understatement. We joined MoSPIN in hopes to learn more about his vision and how we can help him. We do know that Everett can see light and reflected light. We are currently working with a TVI once a week.



When asked to write the article for advocating, I had a lot of ideas but thought our experience this past fall would be a great example of how to advocate for your child in the medical realm. As I stated before, with CHARGE, heart defects are one of the traits. Everett was diagnosed with Double Outlet of the Right Ventricle with Pulmonary Stenosis. Thankfully, they found his heart problem at our 30 week ultrasound. We were told and prepared for Everett to require surgery right after birth. The great thing about Everett is that he loves to beat to his own drum and after he was born he did not need surgery right away. They decided to let him get older and gain weight; the cardiologist wanted him at 10 pounds and five months old. They told us the many signs to look out for that would mean he was going into heart failure. Some of these were turning blue, have difficulty breathing, lethargy and poor weight gain. We left the NICU after two months and started our journey at home. We made a plan to see the cardiologist every month to make sure Everett did not go into heart failure.

When the five month marker hit and Everett was over 10 pounds we jumped for joy. I couldn't wait till the next appointment with the cardiologist. You might think why would you be excited for open heart surgery? We knew that he had to have his open heart surgery before he could have any other of the surgeries he needed. Everett and I went to the appointment and I just knew we would get a date for surgery. We did everything the cardiologist had asked. Our cardiologist said from his standpoint Everett was non-emergent (not an emergency) and his surgery was an elective procedure. I was blown away but thought he is the expert and I should follow his lead. He told us to come back in a month.

This was my first experience with my "Parent Instincts" telling me that what the doctor was saying and what I

knew was going on with Everett was not matching up. Over the next month, Everett put on more weight but was starting to be very lethargic and sleeping most of the day. He would have periods of faster breathing and his appetite started to suffer. Also, he was not gaining developmentally because he was tired all the time.

We would go back to the cardiologist two more times and I would explain what was going on with Everett. Every time they would ask if he was turning blue and I would say no. Then, they would say the symptoms I was explaining were not due to his heart defect and that he was a non-emergency case. Looking back, I realize I should have fought a little harder sooner. But, finally, my "Parent Instincts" won out and I decided to write everything down that was going on with Everett and bring it to the next appointment. I also decided to have someone come with me. I did this because, as you all know, when you are trying to watch your little one and listen to the doctor it can be hard. I wanted to have the doctor's full attention. The next appointment came and I was prepared for all their reasons why Everett wasn't ready for surgery and then I gave my reasons. We got a date scheduled after that appointment for his surgery! Everett had his open heart surgery on Oct. 14th and he recovered amazingly.

It was one of the toughest days because I have always been taught to listen to the experts and doctors; that they know best. The realization that I finally had was that all doctors have the best intentions but they are not with our children day-in and day-out like parents are. We have a keen sense of awareness of our children. We know when they are hurting, and their likes and dislikes, even more so when that child has special needs. I love being a mother to Everett but on that day I also realized I needed to be his advocate. The role of being Everett's advocate can change on a daily basis. Sometimes it is in big ways like pushing for his heart



surgery and sometimes in smaller ways when his siblings are playing with him and he doesn't like to have his hands pulled. Every day I learn something new that I, as his advocate, can pass on to his therapists, doctors and family members. I am a big believer that knowledge is power and as the parent of a special needs child we have the most knowledge to share and empower others on how to help our children.



From Claudia Hall - Advocating for Your Child While Travelling

Hello everyone! We are new to the MoSPIN family. My son Nic just turned two, and he has cerebral palsy which includes hearing and vision impairment, motor impairment, seizures and the need for a feeding tube. Like many of you, I've got a full-time job getting my little man to appointments and therapies. When I was asked to write about how to advocate for your child, I knew I wasn't prepared to write about dealing with the schools, but one thing I have learned how to do is to advocate while travelling.

My husband and I are self-employed and travel often for work. A lot of times, this means both of us and our son in cars, on airplanes, and dealing with hotels and restaurants that are unprepared for his issues.



Focusing on flying, a few things we have learned that might help are:

- 1) If you can, drive. When you drive your own vehicle you have access to storage and can keep your routines much more easily than if you fly or take public transit. This means more time, but often the tradeoff is worth it with enough advance planning.
- 2) If you can't drive, then try to get there as quickly as possible. With our small person, ANY change in routine is the End of His World. Therefore, we do a lot of advance planning before we fly. Some things that will help you fly include:
 - a) Bookmark [this page](http://www.tsa.gov/travelerinformation/children-disabilities) <http://www.tsa.gov/travelerinformation/children-disabilities> and print it out a day or two before you fly so you have the MOST recent information and can show the agents. Yes, you WILL go through a ridiculous amount of screening. Plan for that and go early. While at this writing they are not supposed to ask you about the child's disability, I have found that being upfront with the big stuff, saying things like "he has cerebral palsy and a feeding tube, this three cases of liquid is his formula" often makes them more willing to help. Also, different agents WILL enforce rules differently. As best you can, be compliant with the silly stuff (we had an agent make us take all the diapers out of his bag once) because it gives you leverage when you have to be polite but firm on the big stuff ("no sir/ma'am, we cannot check this case of liquid, it is medically necessary food"). ALWAYS be polite. If you are getting nowhere with an agent, ask for a supervisor. They usually have more training and tend to be more responsive.
 - b) Always assume it will take double the time than without the passenger with disabilities. Bring LOTS of extra things to do, eat, all medications they need and whatever you need to give it to them, and so forth.
 - c) When possible, get a non-stop flight. That way you only need to be concerned with getting to one airplane per trip, not two or more.
 - d) Consider joining the TSA PreCheck list if you fly frequently. <http://www.tsa.gov/tsa-precheck>. It is \$85 for 5 years. There are background checks involved, but if you are able to, this can be a way to skip at least some of the screening time. Also expensive, but worth it if you travel, is getting a passport for the child. <http://travel.state.gov/content/passports/english/passports/under-16.html>.
- e) Airlines offer help for people with disabilities and they are usually good about posting the information on their websites. A search should reveal both the airline and airport policies on the kind of help you can get. It usually requires a couple of days' notice to get assistance, but is worth it. We have been able to ask the airlines for assistance going through the security line. We are still subject to screenings, but the line is much shorter with assistance.
- f) Airlines are, in fact, responsible for medical equipment and a whole host of other aspects of flying. The Air Carrier Access Act is your friend. <http://airconsumer.dot.gov/rules/382short.pdf>. This lists what accommodations the airlines MUST make for people with disabilities. Knowing your rights, and your responsibilities, can help you navigate the process. Make sure the airlines properly label your medical equipment. We often have to remind them, since our son's wheelchair looks sort of like a stroller to the uninitiated. But that label makes the difference between them replacing it or not if they damage it.
- g) Evaluate your luggage needs. One of the things that make it hard to travel with a child who has disabilities is that he or she has a lot of things that must be carried on, and additionally you probably will have clothes and other items that need to be carried. For us, it has been worth it to price airline tickets including the cost of checked bags, and then we check everything we can do without. What we have to carry through security we make sure to pack in easy-to-carry wheeled bags. Remember that medical equipment does not count against carry on limits.
- h) When in doubt, ask! It means a lot more time on the phone with the airlines, but asking questions ahead of time can help infrequent flyers understand the process better. Also, ask for help from the airline. I have found calling their customer support and saying "My son has several disabilities, I need

help with this issue” usually gets me the assistance I need.

- i) Finally, don't be afraid to fly. It takes lots more time and planning, but so far we have made it to three countries and several states with him safe and sound.

Fly safe! Peace, Claudia



We Are the Jenson Family!

Hi everyone!

We are the Jenson family. There are seven of us total. Cory, my husband, myself, Aleta, Maren 17 yrs., Preston 15 yrs., Alivia 14yrs., Bethany 12 yrs., and Nathias 3 yrs. Nathias joined our family in 2012 through adoption. He was born in San Francisco, CA. Before his birth we knew he had hydrocephalus and would face developmental delays among other problems. When he arrived and the tests began we learned of his optic nerve hypoplasia and multiple brain malformations. Although we were told all sorts of issues that would arise due to his condition we were never really told the severity of his eye diagnosis. At first the doctors were just saying, “Well, he sees,” as if there wasn't a real problem. Our family doctor said we should address the issues related to his visual impairment through occupational therapy because there was nothing that could be done to help him really except for surgery for his strabismus. So we felt a little clueless but figured things would work out. It surprises me even now that the professionals told us so little in the beginning of how to proceed and what the future would hold in regard to his visual impairment. We had been told plenty about his delays but not how his lack of good vision would play into things. I asked around for resources and, at first, it was as if no one even knew what to do for him. Neither his occupational therapist nor any of his other therapists had even worked with children who are visually impaired and they did the best they could to work with

his situation. It wasn't until he had been in the First Steps program for several months when we received an email telling us that we could receive vision services. At first, I was excited, annoyed and angry all at the same time. I had provided a comprehensive diagnosis from the beginning and was confused at why I was just now being informed. Even though it was later than we thought it should have been we were excited that there was help on the way. It's strange how when faced with a visual impairment you sometimes have the impression that kids just must learn how to get along in life without much assistance until the school years. Despite my frustration and annoyance we had him evaluated by the TVI. She discussed with me ways we could begin to help improve his vision and suggested books and other resources. That was the day that the light really came on for us that there was work to be done to help him. So we got busy!

When it was again time to take him to the eye doctor we discussed the possibility that he had cortical visual impairment (CVI). That is when they told us that his condition is so much more than the CVI and they broke things down further for us and officially gave him a diagnosis of legally blind. Wow! We had come a long way since “Well, he sees”. This was quite a switch. But this allowed us as a family to embrace the diagnosis and move forward. We really didn't spend a lot of time being sad about it because now we had more resources and information to help us move forward.



Once we really understood the situation better, we knew we now had the responsibility to do even better in advocating for him in all aspects - with family, therapists, and social situations. I remember my mother visiting when he was nine months old, just after we really started to understand his visual impairment. She came to say hello to him and noticed that he couldn't really respond to her with his eyes in the way the other

grandchildren did. She spent a good part of her visit crying about it. When she returned home, she called me nearly every day with some new thought about the situation and how sad it was and so on. This wasn't the first time we had had to advocate for Nathias with our family but it was significant. Instead of crying with her, I told her how happy I was to finally understand the situation and to be able to help him. I also made light of the situation by telling her all the good things I saw in it. Although this isn't what I would wish for any child, there are a lot of things we will never worry about. Staying positive and keeping it light helps not only you but those around you as well. We have felt it is important to make him feel as normal as possible and not make it a big issue when it isn't necessary, but make it an issue when it needs to be an issue.

Probably more difficult than dealing with family was the daunting task of informing and helping his many therapists to be more effective in his therapies. I passed out pamphlets and books and asked everyone to read them. I worked with them one-on-one to help them find ways to catch his interest and help him move forward. Even now, there are times that he stumps us all and we don't know what to do for him. But it is certainly easier than it used to be when all of us were trying to understand things from his perspective.

It has been interesting how often we have had to advocate for Nathias in social situations. There are two main social situations you will find our family participating in: the performing arts and church. All of our kids are musically or otherwise talented: band, choir, piano, theater, dance etc. My husband performs in plays often at our local community theater and I play piano and organ and teach the piano among other things. So, we have lots of performances we attend. And, this often means, we need to consider Nathias and his participation in these events and how he can enjoy them best. We learned right away that Nathias loves music so he definitely came to the right house! His world has greatly benefited from the music we have not only at home but in the community.



For the most part, if it is just a musical performance we don't worry about advocating for him and making sure he has seating to where he would be at the best visual advantage. In fact, sometimes when it is a big band performance the further away the better since he can be sensitive to loud sounds. But, if there is a performance where being close to the performers may enhance his experience, we take steps to get accommodations for him. The first time we tried this ended up being a bit of a disaster. It was for a visual performance. We spoke with the person in charge before the tickets went on sale with a request for seating accommodations for a person who is visually impaired. We then received an email that the organization was a private entity and they would not be taking special seating requests for any reason and they could deny services to anyone. Well, you can imagine how it made us feel and how upset we were. I tend to be a rather stubborn person and I felt that even if they felt they didn't have an obligation, it really was just plain rude. Why would anyone not want to assist Nathias to have a good experience like all the other paid guests? So, we did our research and learned that they actually had to do something to accommodate the situation by law because the location of the event was a public venue. My husband, who has a legal background, wrote them a letter explaining the situation, providing suggestions including those used by the Fox Theater and others. He tried to be as kind and diplomatic as possible without backing away from the situation. Within two days, we had our accommodation. It wasn't fun, it was very uncomfortable, but it needed to be done. We felt it was important we stick our neck out to educate others on the laws and how to go about it. Very often people truly do not understand that a visual impairment needs extra attention in how it is accommodated in a public situation.

Another social situation where we have had to advocate for Nathias is church. Once he was old enough to attend the nursery we had meetings to discuss how we could provide a good situation for him. We were

fortunate to have a special needs teacher who was willing to be in the nursery to help out while my husband and I tended to other responsibilities. That worked for a while but as time went on and more children started attending the nursery, Nathias started having more problems. The noise level was too loud and he did not have adequate assistance to help him participate. Once again we had meetings to discuss the situation. It was decided that I would be the helper in the nursery for a time to help him adjust and to educate others on how to work with him. Although it would be nice to have a break to attend my church meetings, I would rather not be worrying about him not being able to participate and then having him brought to me because he is screaming and then ruining church for both of us. It has been fun to prepare lessons that not only Nathias can enjoy but all the kids can enjoy and we are all learning together. I hope that in time I will be able to once again leave him but I will always be on hand to help them understand ways to help him be involved in what is being taught at church. It will never be a perfect scenario and we know that, but if we can't advocate for him then no one else will! We feel very strongly it is our job to help him participate in as much as possible and we know it is helping him to enjoy his world.



Resources for Advocating for Your Child

1. General

- The art of effective advocacy:
<http://ptimpact.org/Training/TrainingDetailed.aspx?TrainName=The%20Art%20of%20Effective%20Advocacy>
- Family record keeping:
<http://ptimpact.org/Training/TrainingDetailed.aspx?TrainName=Steps%20to%20Success:%20Family%20Record%20Keeping>
- Taking the “us versus them” out of advocacy:
<http://articles.complexchild.com/sept2013/00497.html>
- Learning advocacy:
<http://articles.complexchild.com/sept2013/00497.html>

2. Educational

- Special education: what you need to know:
<http://ptimpact.org/Training/TrainingDetailed.aspx?TrainName=Special%20Education:%20What%20Need%20to%20Know>
- Tips for successful advocacy:
<http://www.familyconnect.org/info/browse-by-age/infants-and-toddlers/education-iaandt/advocating-for-your-child/1235>
- Advocating for your child – getting started:
http://www.wrightslaw.com/advoc/articles/advocacy_intro.htm
- Department of Elementary and Secondary Education links to early intervention resources:
<http://dese.mo.gov/special-education/first-steps/advocacy-disability-education-resources>
- Parent’s Guide to Special Education:
<http://dese.mo.gov/sites/default/files/ParentGuide.pdf>

3. Medical

- Advocating for your medically fragile child:
<http://www.guidetogoodhealth.com/Articles/SpecialNeeds/MedicallyFragileChildren.asp>
- When no one is listening: advocating successfully with your medical team:
<http://articles.complexchild.com/nov2009/00169.html>
- Creating a care notebook for your child:
<http://www.articles.complexchild.com/00018.html>
- You are your kid’s voice:
<http://articles.complexchild.com/jan2012/00359.html>

4. Social Situations

- Deciding what to tell strangers about my baby:
<http://www.familyconnect.org/forum/parents-of-blind-infants-and-toddlers-forum/strangers/12>
- You don’t have to yell: handling inappropriate comments:
<http://articles.complexchild.com/sept2009/00156.html>

- Surviving a friend's r-bombs:
<http://articles.complexchild.com/march2011/00274.html>



5. In the Community

- Taking your child out in the world:
<http://www.perkinselearning.org/webcast/parents-perspective-helping-your-child-multiple-disabilities-engage-world-around-them>
- Making a difference by changing a community or system:
<http://www.familieslead.org/index.php/power-families/impacting-community-or-system/>

6. Family

- Family leadership:
<http://www.familieslead.org/index.php/what-family-leader/>
- Maintaining your life balance:
<http://www.familieslead.org/index.php/family-leadership-learning-materials/maintaining-your-life-balance/>
- Acceptance is a rollercoaster:
<http://articles.complexchild.com/may2009/00125.html>
- Making a difference by supporting other families:
<http://www.familieslead.org/index.php/power-families/supporting-other-families/>
- Practical Strategies for Helping Parents in Conflict: Assisting Divorced or Estranged Parents Through the IEP Process:
<http://www.directionservice.org/cadre/feinbergwebinar.cfm>
- Using children's books to support siblings:
<http://www.articles.complexchild.com/jan2010/00177.html>

7. State and National Level

- The importance of telling your story and communicating with teachers, public officials and legislators:
<http://www.familieslead.org/index.php/family-leadership-learning-materials/advocacy/>

MPACT: Parent Training and Information Center

MPACT is a great resource for Missouri families. This program description is from their website www.ptimpact.org.

“MPACT is a statewide parent training and information center that serves parents of children with all disabilities. Our primary goal is to assist parents in their effort to effectively advocate for their children's educational rights and services. MPACT staff and volunteers are located throughout Missouri and work with public and private agencies, parent groups, professional organizations and advocacy groups to achieve that goal.

We provide up-to-date information online, as well as training sessions that take place year-round throughout the state. We encourage you to call our toll-free number (1.800.743.7634) and let our staff answer any questions you may have. You may also request more information through Missouri's education agency or your local school district.”



Learning Opportunities for Parents and Educators

**The Importance of Touch and Hands for Children
and Youth with Deafblindness
and/or Multiple Disabilities
April 28, 2015, Columbia, MO**

Barbara Miles -- Perkins School for the Blind and author of Remarkable Conversations – will present

a free day-long workshop focusing on the importance of touch as a foundational sense for children and youth with combined vision and hearing loss, as well as other disabilities. <http://msb.dese.mo.gov/outreach-services/pro-development.html>

Vision Summit for Parents and Educators of Children with Visual Impairments /Blindness: Resources for Success
May 18, 2015, Columbia, MO

This will be a free seminar meant for parents and educators of school age children who are visually impaired/blind. Among the planned topics is a session on Effective Advocacy. For more information contact Diana L. Lawson, 573.722.3584 ext. 110 or dlcat44@yahoo.com or see the enclosed information and registration form.



2013 Parent Time issue, she shared what her family did to prepare for Emmalin’s first IEP meeting. Here is a review of the documents the family included in Emmalin’s Transition Packet:

- Diagnosis Letter
- Seizure Definitions
- Seizure Log
- Therapy Maps
- Vision Evaluation
- Photo Books
- Evaluation Letter from “Other” Therapists
- X-rays
- All About Emmalin

The Egglestons passed out these documents to the team members at Emmalin’s IEP meeting. As Tiffany said, “We wanted to set the entire “Team Emmalin” up for success and so that Emmalin would then have the opportunity to succeed to the best of her ability.” Find more information about Emmalin’s Transition Packet at <http://msb.dese.mo.gov/outreachservices/documents/ParentTimeOct2013.pdf>



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*

**Contact Ginny Williams,
Lead Parent Advisor for MoSPIN**

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A Transition Packet for Preschool (ECSE)

In Tiffany Eggleston’s family article, in the October



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