

# Parent Time

A Newsletter for MoSPIN Parents

Volume 18, Issue 2

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## Greetings!

This issue of Parent Time has a special focus on Transitions. Transition often refers to a change from one phase of life to another. Transitions can be exciting, sometimes challenging, but certainly inevitable. In the following articles, three of our MoSPIN families share their excitement and concerns about their child moving from First Steps to preschool. The Egglestons share how they made a detailed plan to help smooth their transition to preschool. In “Transitions Farris Style” Sherah focuses on how they deal with challenges when they move from one activity to another in their daily routine. The Wilsons share how the activities in their daily routine change when they transition from school days to summer time. Other articles provide resources and information that may assist MoSPIN families in their transitions from First Steps to preschool or to Kindergarten or a new educational program.

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## The Eggleston Family

Hello, everyone!

This is the Eggleston family again. I'm Tiffany, my husband's name is Jarrad, and we have one beautiful four and a half year old little girl named Emmalin. For those of you that don't remember, our daughter 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 diagnosis of cortical vision impairment (CVI), strabismus, and nystagmus. You could definitely say that Emmalin is a little complicated! So when it came time for Emmalin to transition from the First Steps program into the school system, I was a mess!! To me, it seemed like it was going to be such an intimidating, nerve wracking and stressful transition! To be honest, I was feeling overwhelmed! I was worried about the IEP and all that goes along with it. I was worried about having

to start all over with brand new people, and what the therapists would be like. I was worried about school in general being too much for Emmalin. I was worried about the staff at the school taking me seriously, genuinely listening to my concerns, and hoping they would want to work as a real "team" so we could set Emmalin up to succeed to the best of her ability.



It was not long after I started thinking about all of this that I had a scheduled visit with my amazing MoSPIN Parent Advisor. I spoke with her about all of my concerns and how intimidating I thought everything seemed. She let me know that we were going to be able to take the next several visits to talk/learn about the IEP and how to help make the transition easier. She also suggested that I try to contact the special education director at our school so we could introduce ourselves, and even ask if I could go on a tour of the building that Emmalin was going to be spending her time in each day.

Our Parent Advisor did a great job of helping us think of different ways to make the transition go smoothly. She also did an amazing job on educating us about what everything meant in the IEP and gave us a better understanding of what I could expect. She explained to us that everyone that sat in on Emmalin's IEP meeting was considered "Emmalin's team" and that Jarrad and I were a very crucial part of that team. Yes, the school was going to be getting the notes from First Steps, but she explained that it was Jarrad's and my job to make sure we helped the rest of the team understand anything about Emmalin that they would need to know to help her be successful at the school and to help the transition go as smoothly as possible.

So I started to think about Emmalin's daily/weekly routine. I wanted to make sure I covered Emmalin has a "whole". Of course I wanted to address Emmalin's seizures, medication and therapies, but more importantly I wanted to make sure that they had a chance to try to understand all of the other amazing things about Emmalin. I wanted them to understand all of her little quirks that, to me, were just as important as the medical and therapy stuff. Things like knowing her favorite toys, her likes, dislikes, how she reacted in certain situations, how she didn't like change and so on...

While I was thinking about all of this, I also started to think about how making new transitions means working with new therapist and teachers. And these therapist and teachers were all going to have their own ways of trying to teach Emmalin to do things. And even though I am always up for learning new things (and new ways of doing them), teaching Emmalin how to do something a different way (other than what she has already been taught) was going to be very confusing for her. For example, Emmalin has two different places that she goes for PT and OT, so if each of those therapists had a different way of teaching her to sit up...honestly, I think that many different ways would confuse anyone!

I tried to think of it like this:

If you have 5 rooms that are dirty in exactly the same way and you ask 5 different people to each clean one of the rooms...each person is going to start in a different place, use different cleaning products, and take different amounts of time to get the room cleaned. But at the end of the day, they are all going to do what was asked of them - get the room clean!

So in trying to do everything we could to make this huge transition easier, we made it our goal to do our best to find ways for every person on "team Emmalin" to (as much as possible) be able to "clean their room" the same way. We put together a "transition packet" that had several different documents in it, some we created and some we got from different places. We thought that we would share Emmalin's transition packet with you.

## **Emmalin's Transition Packet:**

**Diagnosis Letter:** Since Emmalin's diagnosis is so rare I brought the letter that our geneticist gave us so they could try to understand more about CDKL5.

**Seizure Definitions:** Since seizures are a part of Emmalin's everyday life, I found a website that had a bunch of seizure type descriptions on it and I took the ones that described the types of seizures that Emmalin was having at the time. It's not that I expected them to have this memorized, I was just trying to give them a "heads up" on some of the seizure types that Emmalin could possibly have while they were working with her.

**Seizure Log:** Emmalin has seizures randomly throughout the day. If she had one while she was working with one of the therapists or teachers, I wanted them to be able to record it (what it looked like, how long it lasted, what she was doing right before the seizure started, and what she did afterwards). The reason this was so important was so I knew what went on when I wasn't there.

**Therapy Maps:** I literally took each therapy that Emmalin did and put them on their own piece of paper. I wrote the name of the therapy in the middle of the page and then drew a circle around it. Then I wrote the things we were working on around that therapy in the middle of the page (and then connected each thing with a line). The reason I did this was so that each therapist would be able to have a quick reference on what Emmalin was working on at that time.

**Vision Evaluation:** We gave a copy of Emmalin's most current vision evaluation to everyone. The reason we gave a copy of this to everyone was not because we expected them to be able to understand all of the doctor terms; we gave them all a copy of Emmalin's most current evaluation because it gave us an opportunity to make sure we could talk about Emmalin's vision and what she can and cannot see with everyone all at one time. This way if anybody had a question they would all hear it and also hear our answer. But more importantly, the reason Jarrad and I included this in the packet

was because we both feel that any person that is going to be working with Emmalin needs to have a general understanding of what Emmalin can see (and not see) to be able have a better understanding of how to help her succeed to the best of her ability.

**Photo Books:** Because there are SO many ways to "clean a room" I wanted to show them exactly how Emmalin was being taught at her other therapy facility to sit up, stand, and so on.... So I literally took my camera to therapy one day and took pictures of how the therapist was positioned while she was working with Emmalin (and also how Emmalin was positioned). Next I went and bought the cheap \$1 photo books from the store. I then took the

pictures back with me to therapy the following week and the therapist wrote down what she was doing step by step in the pictures. So I had the picture on one side of the photo book and an index card on the other side explaining what was going on in the picture. This idea actually came from a therapist and I LOVED IT! At the IEP meeting each therapist had their own book on how Emmalin was being taught to do things at the other therapy facility.

## **Evaluation Letter from Her Other Therapy Places:**

Again, I know they got notes from First Steps, but I wanted to make sure that they realized what/how Emmalin was doing at *all* of her therapy facilities - not just with one.

**Medical Letter:** We had a seizure action plan from the doctor and a letter that had any other medical issues they felt needed the school's attention.

**X-Rays:** Emmalin also has hip dysplasia and so I brought her most recent hip x-rays in so that the therapists would literally be able to see what her hips looked like themselves. I thought this was important because after looking at them, they might decide that they want to be more cautious about doing certain activities with Emmalin when it comes to moving her hip sockets.

**All About Emmalin:** This was the paper that literally had all of the other amazing things on it that I felt were important to know to really be able to understand Emmalin, so they really could help her succeed to the best of her ability. I even put a picture of her on it. One of my friends (whose son has CVI along with other things) did the short version of this and laminated a few things and called it "All About Christian". She put these facts by the handle of his wheelchair (on a little ring). Her thoughts were that even if there was a sub (or whatever) they would be able to look at those "facts" and quickly be able to have a little understanding of who Christian really was, what he liked to do (or not do), and any important medical things that any person caring for him would need to know.

I realize this all probably seems like "over kill", but as I said before, it was the only way we could think of to try to make this transition process easier on Emmalin, and by doing all of this it gave us peace about helping Emmalin be able to succeed at a new place. When it literally came to the "official" meeting day, Jarrad and I made sure we had a folder (with the packet information inside) to pass out to every single person that was there for Emmalin's IEP meeting (and then went over it with them). We didn't want to come across as over-bearing, but we were hoping that by providing all of this information that they would realize that we were taking this very seriously. We also made sure to let them know that we were excited and grateful to be starting this new "adventure" together. 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!

My hope in writing all of this is that maybe it will help one of you as you are gearing up for your next transition. It can be such a stressful time and honestly, I don't know what I would have done without my Parent Advisor and the MoSPIN program! It was because of this program that I feel that Jarrad and I were able to have our first major transition and IEP meeting at school be a success!! Thank you, MoSPIN, for having such an amazing program and being willing to help educate us!

Good luck to all of you out there! I hope that your next transition goes smoothly!

## From the Wilson Family

"Hello" again from the Wilson Family!

My name is Jonie and my husband John and I have three wonderful children; Andi, 5, and two year old twin boys, Clayton and Cheston. We are a part of MOSPIN because of our son Cheston. Cheston was born with severe bilateral microphthalmia, AKA "mini eye syndrome". Cheston is blind but thriving every day. We have had a great summer and are ready for the big "transition" from long hot summer days to shorter cooler days.

The main topic of this issue of our Parent Time Newsletter is "transitions". Since Cheston is two and half we are currently scheduled to have Cheston's first transition meeting with First Steps and school folks. We have not had to go through all of that yet, but we are ready and getting prepared for that meeting which is very soon.

Another transition that Ginny thought other families might find interesting is how our daily routine changes when school is out for the summer. I work in education so I have the opportunity to spend the summers with my children at home. When our MOSPIN Parent Advisor came to our house for our monthly June visit, we kept our routine exactly the same as the children and I did every day so she could see what a typical day is like for us. After breakfast and getting the children dressed the first thing we would do is head outside for the daily chores. We usually started with the chickens. Clayton and I would walk to the chicken house with the egg basket and feed bucket. Andi and Cheston would ride the Barbie jeep down to the chicken house. Typically, Cheston would play with the Barbie radio and talk to "Barbie" while the rest of us collected eggs and fed the chickens. After the eggs were collected and chickens were fed, Andi and Cheston would get back in the Barbie jeep and drive down to the barn to feed the pigs. Our daughter Andi



shows pigs at local fairs, so we typically spend time with them in the morning getting to know them and practice working with them. Cheston likes to stand at the fence and yell their names. This year their names were “Sheldon” & “Leonard”. The pigs would usually come up to Cheston and nub him with their noses which he liked at first but would tire of that very quickly. After we were done with the pigs, we would get in the van and drive down to my in-laws’ house and feed the other chickens we were raising at the time. After feeding the animals, we would swing and play outside while I would pick the garden. There is always something to do outside. Cheston loves to do outside chores. He knows and anticipates his daily “ride” in the Barbie Jeep and enjoys playing with the Barbie radio. It is pretty hilarious watching the two kids ride around our land (I don’t say farm because it’s not really a farm!) in the Barbie jeep. And yes, Cheston loves to drive the Barbie jeep which is something we do let him do with supervision. I love the daily routine with the kids and the animals because it teaches them responsibility but it also gives them a chance to spend time together. Our MoSPIN Parent Advisor is always so positive about how Cheston communicates and interacts with his siblings. We always try to do things that involve the entire family, including Cheston, which at times can be challenging. Our family is about routine. If we get out of routine Andi usually lets us know about it. Friday night is pizza, popcorn and movie night. Cheston loves the pizza and popcorn but not the movies so much. We usually try to watch movies with music in them so he can enjoy it

and stay with us and watch it. If he gets bored he will bug his siblings, or his new “trick” is repeating the movie WORD FOR WORD! Yes, it gets annoying. Cheston’s newest “trick” includes repeating everything he hears. EVERYTHING! He even mocks his siblings when they cry!

As we transition from summer to fall, we are starting to enjoy doing things together that most families would do during the fall. We pick apples, pears and of course, pumpkins. One big “transition” we went through this fall was our daughter Andi going to Kindergarten. Andi is for sure the comedian in our family and always has something to say. One day at school she told her librarian that her brother was going to start to come to school there later this year. The librarian responded to her by saying, “Oh, you can wave at him when you see him in the hallway.” She informed the librarian that her brother couldn’t see but she would for sure be giving him a hug!

This is not directly related to transition, but I thought other MoSPIN families might be interested in a conference we attended. We traveled to Chicago this summer to go to the iCAN Conference which is the International Childrens Anophthalmia Network for children who have the same genetic disorder as Cheston. (Andi also has this genetic disorder, having only a mild form in her left eye.) We enjoyed this so much because we got to meet other families with children who have Microphthalmia and it was especially wonderful to meet the older children and see how they thrive. We got to meet a young family from Wisconsin who also has a son with Anophthalmia. We have stayed in contact and one thing I have come to realize about living in Missouri is that we have some of the best resources for our blind children - more than other states do. Our family and our son are truly blessed to have the therapists and resources we have. One of those resources is our MoSPIN Parent Advisor. Our two-hour visit every month is something that we all always look forward to.



## Transitions Farris Style

Hi, everybody!

In case you've forgotten, or are new to the newsletter, I'm Sherah Farris. My husband, Wesley, and I have two beautiful children, Lilly and Jonah. Lilly was diagnosed with Septo Optic Dysplasia when she was four months old. When she was just a year and a half old, she got a new baby brother! Jonah is walking now, and he is spending a lot of his time pestering his big sister.

I can't believe it's already fall! The Farris family had a great summer. Overall we had wonderful weather, so we got to spend a lot of time in the great outdoors. Lilly got to go fishing for the first time and she thought it was great. We spent a lot of time fighting the temptation of chewing on pebbles. Other than that, Lilly's favorite part was touching a slimy Rainbow Trout!



Lilly went to school throughout the summer and she loved it. We have also gotten to spend time with another child that is visually impaired and has Septo Optic Dysplasia as well. It was great getting to talk to another parent and see our children interact.

Since Lilly is turning three this fall, we are embarking on something new; the transition into the public school system. This past spring we had the transition meeting from First Steps to our school district. This would have been intimidating if we had not had our MoSPIN Parent Advisor help

guide us through what was going to happen. We made it through that meeting feeling like we had done our jobs as parents, which, of course, was to be our child's voice. My advice to parents who will be going through the transition into the public school system is to be prepared and educated of the process and not to be afraid to say what you're thinking or ask questions. We went in with a list of things we wanted to know, and when we left, the questions had been answered. Just this week I got a letter from the school; I had a concern, and called the Preschool Special Education Director to discuss my concern. Of course, she was happy to talk to me and answered my questions. They are there to help all of our families and children, so don't be afraid to ask!

Of course, that is just one transition in our life. Sometimes I forget how many transitions there are in our day-to-day life. Over the summer, I noticed every time we got home, when we walked in the door, Lilly would throw herself down and start kicking and crying. After a week or two of this, I got pretty frustrated. I thought Lilly didn't like being home and that made me feel like something was wrong. Then I realized that Lilly just didn't know how to handle the transition of simply walking into the house. So, Wes and I decided we weren't talking her through the transition enough, and also that we needed to do something when we stepped in that Lilly enjoyed. We started talking to her, telling her we were walking to the house, we were going to unlock the door and go in, and we were going to have fun being home. After we came in, we took Lilly straight to her bed, which is a place that comforts her. Over the period of a month or so, we did more talking and interaction and less going straight to her bed. Now Lilly opens the door herself and walks straight to her favorite chair to sit for a moment. We almost always have one of her favorite toys and furry blanket waiting at the chair for Lilly. There are no more meltdowns when we come home!

I have used this concept for all transitions that Lilly needs help getting through. Sometimes all she needs is a fun activity to get her mind off the last activity and to prepare her for the next. When she's having a fit and won't be calmed down, we take that time to do a sensory activity. It doesn't

Change happens all the time. For you or me, it may be easy. For a visually impaired child change can be confusing, frustrating and scary. They need time to transition with direction and patience! If you're like me, you may have to practice the patience part. We have found the easiest way to help Lilly through transition, is to take her perspective and listen to her language whether it is verbal or nonverbal. When it comes to school transitioning, we're definitely not pros, but educating ourselves and speaking up makes us feel empowered to make the right choices for Lilly. That is what this journey is all about - making sure we do everything we can to make sure Lilly has everything she needs to have a great life!



“However scary it seems, there are ways to ease the transition into preschool and prepare both you and your child for the experience.

- Read the complete article at the great parent website: [www.familyconnect.org](http://www.familyconnect.org).

You can watch a free webcast on “Families as Partners in the Educational Team” at <http://www.perkins.org/resources/webcasts/families.html>

This is just one of many free webcasts on this site for families.

## Transition Times for MoSPIN Families

Two major transitions that MoSPIN families face are at age 3 when your child moves out of First Steps usually to a preschool program and after age 5 when you prepare for your child to move to Kindergarten or a new educational program. The following articles will provide information and resources to help you prepare for these transitions. In addition, two parents share their experiences and ideas for a smooth transition for you and your child. And don't forget, you may always ask your Parent Advisor for information and resources as you prepare for an upcoming transition or IFSP (Individualized Family Service Plan) or IEP (Individualized Education Program). You may also contact Ginny Williams, Lead Parent Advisor, at [ginwilliams@aol.com](mailto:ginwilliams@aol.com) or 573-295-4808

### Transition Information for Families of Children Under 3

#### Transition from First Steps to Early Childhood Special Education (ECSE)

"The period of time an infant/toddler is in First Steps is relatively short; therefore, it is important to plan for transition from the time the child enters First Steps.

The discussion of transition prepares the family for a smooth transition as their toddler leaves First Steps to attend a preschool, child care, Early Childhood Special Education (ECSE) or other community program.

Steps toward transitioning out of the First Steps program must be addressed at every Individualized Family Service Plan (IFSP) meeting, regardless of a child's age.

Many documents have been developed to assist with educating service coordinators, providers and parents about the importance of a successful transition from First Steps."

These documents may be found at: <http://www.dese.mo.gov/se/fs/FirstSteps/TransitionIndexpg.htm>

This article and more may be found on the Department of Elementary and Secondary Education (DESE) website at: [www.dese.mo.gov](http://www.dese.mo.gov)

#### A Transition Packet for Preschool (ECSE)

In Tiffany Eggleston's family article she shared what her family did to prepare for Emmalin's first IEP meeting. Here is a quick 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." For more information about Emmalin's Transition Packet, go to page 1 to read the Eggleston's Family article.



## Transition Information for Families of Children Turning 5

When your child nears the age your school district sets as the starting point for Kindergarten -- most likely, five years old -- it's time again to think in terms of another transition. For most children with special needs, this will mean a transition from a preschool program (ECSE) to a Kindergarten program. It may also involve a transition from a partial day to a full day, from one school to another or from one type of educational program to another.

### Transitioning from Preschool (ECSE) to Kindergarten: A Parent's Perspective

*(NOTE: Kristin, a previous parent editor, wrote this article to describe her preparations for Nathan's transition to Kindergarten. She shares thoughts, useful websites and transition ideas for parents and children.)*

Transition time is coming near for my family as Nathan turned five in December. Not only will he be transitioning out of MoSPIN, Head Start, and ECSE (Early Childhood Special Education), but will be transitioning into Kindergarten this fall. I believe transition out of any program that supports you and your family into a new unknown setting can be scary for parents but also for our children.

To help in these transition periods, I think we as parents need to educate ourselves as much as possible about what to expect at Kindergarten or any other grade level. You need to talk to your school district to see what the expectations are for each grade level.

Nowadays Kindergarten has become the First Grade that many of us grew up with, where our children are learning basic math and reading skills on top of developing their social skills.

The Missouri Department of Elementary and Secondary Education (DESE) has a great handout on their website to help parents prepare their kids for school. It gives ideas for transition activities that parents and educators can do to help children have a smoother, less stressful transition into the Kindergarten setting.

The website link is:

<http://www.dese.mo.gov/eel/el/pdf/PrepareKids.pdf>.

They also have another handout that gives parents ideas to help their child in the area of Early Social and Emotional Development, that can be located at:

[http://www.dese.mo.gov/eel/el/reK/Social\\_Parent.pdf](http://www.dese.mo.gov/eel/el/reK/Social_Parent.pdf)

The next articles contain some ideas that I hope will be helpful for you and your child when transitioning into Kindergarten.







## *Parents' Bill of Rights*

*The following document is available on the Missouri Department of Elementary and Secondary Education (DESE) website for parents to understand their rights during the IEP process.*

*This document does not confer any right or rights beyond those conferred by federal or state law and is intended for informational purposes only.*

*For additional information, contact the Department of Elementary and Secondary Education, Division of Special Education at (573) 751-0699 or [webrepliespeco@dese.mo.gov](mailto:webrepliespeco@dese.mo.gov)*

As a parent of a child with a disability, you have the right to:

1. Attend individualized education program (IEP) meetings and represent your child's interest.
2. Have an advocate or expert present at individualized education program (IEP) meetings.
3. Receive a copy of your child's evaluation, disagree with it, and request one independent educational evaluation at public expense.
4. Provide a written report from outside sources as part of the evaluation process.
5. Examine all education records pertaining to your child and be provided with a copy of the individualized education program.
6. Disagree with the decision of the individualized education program (IEP) team and pursue complaint procedures, including filing a child complaint with the Department of Elementary and Secondary Education, state paid mediation, have an impartial due process hearing, and appeal the due process decision to the court.
7. Participate in reviews of the individualized education programs (IEPs) and in any decision to change any aspects of the IEP, as well as receive a written notice of action before a change in your child's educational placement or the provision of a free appropriate public education.
8. Have your child placed in the least restrictive environment and in a general education classroom to the greatest extent appropriate.
9. Request an accommodation to provide effective communications if you have limited English language proficiency.
10. A free appropriate public education for your child with an individualized education program designed to meet your child's unique needs, which may include but not limited to, special education and related services, such as assistive technology devices and services; transportation; speech pathology services; audiology services; interpreting services; psychological services; including behavioral interventions; physical therapy; occupational therapy; recreation, including therapeutic recreation; counseling services; orientation and mobility services; school health services; school nurse services; social work services; parent counseling and training; and, medical services for diagnostic or evaluation purposes.



***You can contact me at 573-295-4808***

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