

For Siblings Only

Winter 2007

FROM THE EDITOR:

When I think of winter, I think of snow, cold mornings, hot chocolate, and doing art projects in the house. Winter sometimes means days off from school - that's always fun! Winter can mean getting sick too, with the usual colds and viruses. But some brothers and sisters who need extra help to learn, also get sick more often than you do. The story this month is about seven year old Meghan Craig and her almost 2 year old sister, Shannyn. Shannyn sometimes gets so sick that she has to go to the hospital. You'll find out more when you read Meghan's story. Meghan's other two sisters, Erin who is 5 and Katie who is 3, helped with the story too.

Of course, Valentine's Day is coming up soon. For ideas on how to make valentines with your brother or sister who needs extra help to learn, check out *Brother/Sister Things to Do* inside. On a snow day, there's nothing more fun than making hot chocolate and reading a new book! You'll find ideas for interesting books to read inside too.

Happy Winter, everyone! And don't forget to write to *For Siblings Only!* Next month, we'd love to hear from you!

Susan Levine
Editor

HAVING A LITTLE SISTER LIKE SHANNYN

By Meghan Craig and Susan Levine



Hi! My name is Meghan Craig. I am 7 $\frac{1}{2}$ years old and in second grade. I have 3 little sisters, Erin who is 5 and in kindergarten, Katie who is 3 and in pre-K, and Shannyn who is almost 2. Erin, Katie and I take lots of dance classes every week. I take modern dance, jazz, tap, hip hop, and ballet, but my favorite is a class that teaches lots of flipping.

Shannyn is too little for dance classes, but even when she is older, I'm not sure she'll ever be able to dance. Shannyn is missing part of her brain called the corpus callosum. That part of the brain helps you think really good. She has a hard time keeping her head up and she can't see, except maybe light and dark. Shannyn also has trouble eating and swallowing, so she has a feeding tube in her stomach. The formula goes right through the tube into her stomach so she doesn't have to chew or swallow. I know a lot about tube feeding, how to turn the machine on and off and how to watch the numbers on the machine so she gets the food the right way.

Shannyn also gags and chokes a lot even though she doesn't eat food. She chokes on her spit and can't swallow easily like we can. One time when she was choking really badly, it seemed like she stopped breathing so we had to call 911. That was really scary. I don't want that to ever happen again! Shannyn can't talk, but she can cry. She mostly cries when she is upset, like when she is choking or when something hurts her. Her eyes also roll up toward the top of her head and she gets really squirmy. When Shannyn is happy, she is very calm and she even smiles a little bit. Shannyn likes it when I sing to her, play with her and hold her. Sometimes I sing a special song I made up just for her!

Shannyn doesn't go to school, but she has therapists who come and work with her at home. They stretch out her legs, massage her and show her toys. Shannyn also has nurses who come some of the time so mom and dad can go out or get things done. It's a lot of work to take care of a sister like



Shannyn! My sisters and I can't help a whole lot because we're still pretty young. Shannyn also goes to a lot of doctors and she sometimes has to stay over at the hospital for a few days. Even with her tube feedings, she sometimes gets dehydrated, which means she doesn't have enough fluid in her. When that starts to happen, my parents give Shannyn "pedialyte" with her formula tube feedings. It can be hard for all of us to go out together with Shannyn. Often, she'll stay home unless it's a really important party or a family vacation. That's just the way it is when you have a sister like Shannyn!



When my friends first meet Shannyn, they sometimes don't want to go near her because they think they might catch something. I tell them not to be scared and that it's not something you can catch, like a cold or a virus. She was just born that way. Once they get used to it, my friends are really good with her. Some friends though, take longer to get comfortable than others.

Even though she has lots of problems, Shannyn can really make us laugh. She makes funny faces and sometimes she moves her arms and legs so much that she punches herself in the face! She doesn't do it hard enough to hurt herself, but it looks so funny. Even though Shannyn is younger than my 3 year old sister, she has more hair than her. We think that is funny too.

When Shannyn was first born, I felt like nobody else had a sister like her. But now I know lots of other kids who have a brother or sister who has trouble learning. I go to a sibling group just for kids who have brothers or sisters with differences. That makes me feel good. When I grow up I want to be a dance teacher for kids with special needs. My two sisters also want to teach with me. I would like to call the dance studio "Special People, Special Ways". My sister, Shannyn, will be our first student, and we'll do our best to help her dance!

Special People, Special Ways
DANCE STUDIO

Meghan's 5 year old sister Erin added these thoughts about Shannyn:

"When Shannyn chokes and coughs, we try to help her. Mom and Dad use a suction machine to clear the stuff out of her mouth. They hold her and pat her back. I sometimes play with her and let her feel different toys. I sit next to her and put blankets on her. It was scary when we had to call 911. I hope we don't have to do that again!"

Three year old Katie had something to say too!

"I like it when Shannyn sleeps in my room. Shannyn is happy when I talk to her. One time I drove her in my Barbie car and she really liked that too! When Shannyn cries, I know she is sad. I love my whole family!"

FOCUS ON FEELINGS:

Meghan has a very busy family with 3 little sisters. Meghan, Erin and Katie all know a lot about Shannyn, even Katie who is only 3. You can tell that the girls' mom and dad have explained all about Shannyn so they understand her problems. It sounds like they can be very helpful with their sister too. Meghan knows how to make her friends feel more comfortable with Shannyn. She does a good job explaining about the tube feedings so it's not so scary to kids who haven't seen it before.



All three of the girls worry the most about Shannyn's health. They don't like it when she has to go to the hospital or when they have to call 911. They know that their mom and dad and the nurses are doing their best to keep her healthy so that won't have to happen. Moms and Dads take care of things and do most of the worrying so the other kids in the family don't have to worry so much. Just like Meghan, Erin and Katie, if you are worried about something, ask your mom or dad about it. Usually they can make you feel better or let you know that they are taking care of everything so you can worry less!

Meghan is very glad that she gets *For Siblings Only* in the mail. She also goes to a sibling group with other kids who have a brother or sister with a

disability who needs extra help to learn. Now she knows that other kids have brothers or sisters like Shannyn, and that makes her feel better too! A great big "thank you" to Meghan, Erin and Katie for sharing their story with *For Siblings Only!*



BROTHER/SISTER THINGS TO DO:

Winter is a great time to do things inside with your brother or sister. You teach your brother or sister things when you play together. Here are two crafty ideas for the two of you to do. Mom or Dad can help you gather the things you need for your projects. Pick the activity you like best and have fun!

- 1.) **Fun with Clay or Play Dough:** Playing with play doh or clay is always fun! It feels good on your hands and there are so many things you can do with it! Start by rolling the dough with your hands to make a round ball or long skinny shapes. Roll it with a rolling pin to make it flat. Take cookie cutters and cut shapes or poke into the flat clay with your fingers or a fork or small stick to make little holes. Pull the clay apart and squish it back together again! Use the clay to make a simple shape like a ball or a triangle or make something harder like a small snowman or a bird. You can make pretend food like peas and apples and birthday cake! Help your brother or sister with this activity if they need help. Put the clay in his hands and help him poke and roll it. Talk about how the play doh feels and all the things you are making together. You can even make hearts for Valentine's Day! Be sure he doesn't put any of it in his mouth!



If you don't have any clay or play doh, you can make your own using this recipe: Mix together the following ingredients:

- 1 cup water
- $\frac{1}{2}$ cup of salt
- 1 cup flour
- 1 tablespoon of cream of tartar
- 1 tablespoon of cooking oil or olive oil



Use food coloring to color the dough any color you'd like!
Store the homemade play dough in a plastic container or plastic bag to keep it fresh. You can use it again and again!

2.) **Let's Make Valentines:** January and February are the perfect months to make your very own valentines. You can make special valentines with your brother or sister for special people like your Mom and your Dad, grandparents or a favorite teacher. You can even make valentines for each other!



You'll need red, pink and white construction paper, lace doilies, magic markers or crayons, scissors, glue and maybe some stickers. You can cut out hearts in all shapes and sizes. Then cut and paste your shapes together and decorate them for a wonderful holiday gift. Let your sibling do as much as she can herself. You can help by showing her where to color and where to put the glue to glue things together. Help her scribble if she needs your help.

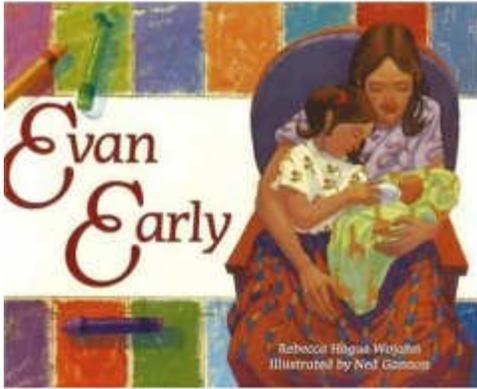


If your sibling is learning to cut with scissors, you can draw a heart shape with a thick magic marker and help her follow the line. You can also glue yarn in the shape of a heart on the paper. After it dries, show your sibling how to color inside the yarn shape. While you are working, talk about the colors and shapes you are making. Find other red and pink things around the house and put them all together. Then make a pile of all the red things and all the pink things. This is a great way to work on teaching colors!



When you are finished, don't forget to clean up! It's good to teach your brother or sister how to clean up too. Give him a job to do. Take turns putting things away. When you are done, show Mom or Dad your finished valentines. Won't they be surprised! Take a picture and send it to *For Siblings Only* so we can show everyone what you made!



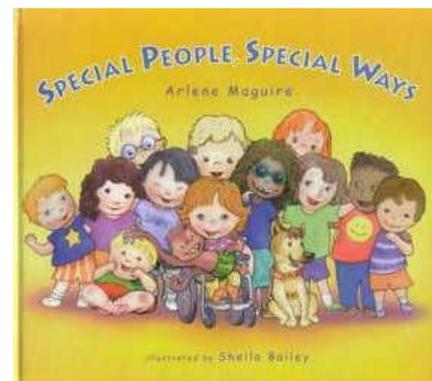
LET'S VISIT THE LIBRARY:**EVAN EARLY** by Rebecca Hogue Wojahn, Woodbine House, 2006

Natalie's baby brother was born too early. He can't come home from the hospital because he is too sick and has to grow bigger and stronger. Natalie counts down the days until Evan can come home, but nobody seems to know how long it will take - not even the doctors. When Natalie gets to visit her brother in the hospital, she is surprised by how tiny he is. He is red

and bald and naked and looks like a raw chicken! Evan has lots of tubes and wires around him that count his heartbeat and his breaths. Mom and Dad are worried and they spend a lot of time in the hospital. When Mom comes home, she is too tired to play. Natalie feels mad and lonely. Mom knows that Natalie is sad and that it is hard for her to wait for her parents and Evan to come home. Mom reminds Natalie that they love her very much and that will never change. At the end of the book, there are more questions and answers about premature babies.

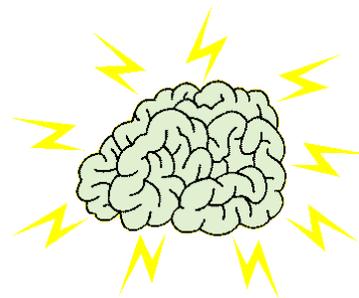
SPECIAL PEOPLE, SPECIAL WAYS by Arlene Maguire, Future Horizons, Arlington, Texas, 2000.

This little book, with lots of rhymes and cute drawings of all kinds of children, talks about how we are different and how we are the same. Some children use computers or sign language to talk, and others use wheelchairs or walkers to walk. Some children need help to read or dress themselves. Seeing eye dogs help children who can't see to get around better. But even if they learn differently or do things differently than most children do, every child has feelings and is really a lot like you! We can all reach out to help someone or to make someone smile.



SPECIAL DEFINITIONS:

SEIZURES: Some children and adults have something called seizures. A seizure happens when the brain doesn't work quite right and sends out the wrong messages or signals to the body when it shouldn't. It makes the person act or move in strange ways when he doesn't want it to. In fact, the person often doesn't even know it's happening to him. The wrong signal caused by a problem in the brain is called a seizure. Seizures may also be called epilepsy. Mostly seizures happen to people who have brain damage or serious learning problems but they can happen to other people too.



When the person has a big seizure that makes the whole body move, it is called a *grand mal seizure*. If the person is standing, he may fall down. This can be dangerous to the person, especially if things are in the way. Some people just have little seizures that last for a few seconds. These little seizures may make the person's arm or leg shake, or their head nod, or their eyes blink a lot. These are called *petit mal seizures*.



Seizures may look scary, but they don't hurt the person, although it may be uncomfortable. For most children and adults, taking certain medicines usually keeps the seizures from happening anyway. It can take a doctor a long time to find the right medicine to help stop the seizures. One medicine might not work at all while another medicine might make the child too tired or cranky. They might have to try many medicines to find the one that is best. Doctors check the child's blood every few weeks to make sure that he is not getting too much medicine. It is important to take the medicine to stop seizures because seizures can make it hard for the child to pay



attention and learn. If a seizure starts, there is usually nothing that can be done to stop it, but usually it just lasts a few seconds. If they last much longer, the child's mom or dad may call the doctor or even take the child to the hospital.

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DID YOU KNOW....

This newsletter is for children aged 4 to 10 who have a brother or sister who needs extra help to learn. Did you know that there is another newsletter for children who are aged 10 and up? That newsletter is called **Sibling Forum**. If you think you might like to move up to this newsletter for older children, you can get a free copy of **Sibling Forum** by writing to me at FRA, 35 Haddon Ave., Shrewsbury, NJ 07702, or by calling 732- 747-5310.



CALLING ALL KIDS:

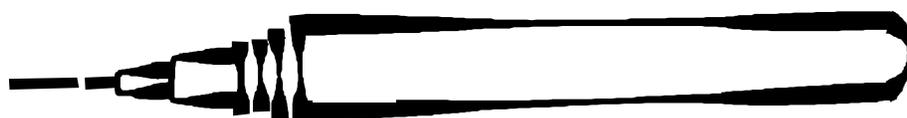
Now it's your turn to write to *For Siblings Only* about your brother or sister who needs extra help to learn! You can answer the questions here and send them to *For Siblings Only, 35 Haddon Ave., Shrewsbury, NJ 07702* and you will see your name and your answers in the next newsletter. The other children who read *For Siblings Only* would love to hear what you have to say!

1.) Sometimes I help my sister or brother who needs extra help to learn when I:

2.) Sometimes my sister or brother even helps me when he/she:

3.) Something I don't understand about my brother or sister is:

4.) I can tell a story about me and my brother or sister! Here it is:



5.) My name _____ My age _____
My sibling's name _____ age _____
My sibling's disability _____
My address _____

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