

For Siblings Only

Summer, 2009

FROM THE EDITOR:

I hope you are all enjoying a wonderful summer! And I hope you enjoy this issue of *For Siblings Only*, a newsletter written just for young children who have a brother or sister who needs extra help to learn. In every issue, you'll find out about other children, just like you.

When you have a sibling with a disability, you often find that you are the teacher for your brother or sister, even if you are younger than he or she is. Most of the time, you probably like being an important helper in your family. In this newsletter, you'll read about Frankie and his sister, Anna, who has Down syndrome. Frankie even likes to play school with Anna to teach her things. Frankie first wrote this story 8 years ago when he was in second grade. Now that he's in high school, he still takes good care of his sister and tries to help her learn things. In the *Brother/Sister Things To Do* section, you'll read about fun ideas that you can do at home to help your brother or sister learn. The ideas can be fun for the **whole** family!

At the end of the newsletter, you'll read about a way that you can help write the next issue. Write to us and tell us all about how you and your brother or sister spent your summer vacation. We hope to hear from you!

Happy Summer!

Susan Levine

Editor



FRANKIE AND ANNA

By Frankie Matuszak and Susan Levine

My name is Frankie Matuszak. I am 7 $\frac{1}{2}$ years old and in second grade. I am the oldest child in my family. My sister, Anna, is 5 years old and she goes to a special class for 5 to 7 year olds who have trouble learning. Anna has Down syndrome. She can talk a little by putting two words together and she needs extra help to learn. Anna can't say full sentences but she can certainly let us know what she wants! If she's in the kitchen and she wants a cookie, she would probably say something like "Mommy cookie." I also have a brother, Tommy, who is one year old. He is not in school yet!



I really like being the oldest child in the family because I get to teach Anna and Tommy things. It's a lot of fun! Anna especially likes it when I teach her, although she has to be in the mood. I'll say, "Anna, it's time for your personal lesson!" Sometimes it's hard to get her started, but once we get going, she doesn't want to stop! At the end, I'll say, "Anna, I have to go now." But she keeps running after me to do more work.

I usually work with Anna in the playroom. She really likes to write her name and make letters. One time, when we were playing school, I wrote her name on the top of the paper 3 times to show her how to write it. I drew a line to show Anna where to start writing her name herself. She wrote her name a bunch of times. She even



kept going and wrote more on another piece of paper! She was very proud of herself! I always take her papers down to my Dad's desk, and I grade them. I mark a "C" for correct on each one of the words that Anna writes correctly. We show Mom and Dad the papers with all of Anna's good work on them.

Sometimes, she'll even copy pieces of letters when I show her how.

Another thing I have helped Anna with is saying her A-B-Cs. I asked her to say the letters of the alphabet and then I helped her with the ones she had trouble with.

Anna could say most of the letters right except for the letters C, X, and Z. We practiced the right way to say them. I would say the letter and Anna would copy me.

After a while, she said X and Z pretty good, but she kept saying the C sound more like a D sound. Anna just kept

trying and at the end, she was doing a much better job! We showed Mom and Dad how well she could say the A-B-Cs. We were both very proud!

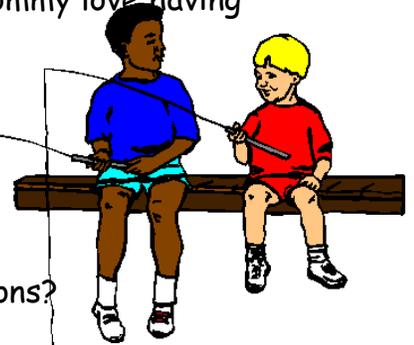


Tommy likes to be with me too. Usually I'll help him by running around with him and saying, "I'm gonna get you!" Tommy isn't ready for playing school yet, but I know we'll have fun when Tommy gets older and can be a student too! Anna also likes to play video games with me. So she doesn't mess up my game, I'll give her the controller than doesn't work. She thinks she's playing with me, but this way, I don't have to worry about her getting in my way.

Another reason I like being the oldest in my family is that I get to sleep on the top bunk in the bunk beds. I really like sleeping up high! Anna and Tommy love having me for their big brother - and their own, personal teacher!

WHAT DO YOU THINK?

- 1.) Why do you think Frankie likes to be a big brother?
- 2.) Why do you think Anna likes it when Frankie gives her lessons?
- 3.) How does Anna feel after her lessons with Frankie? How does Frankie feel?



FOCUS ON FEELINGS:

Frankie had a great story to tell about why being a big brother can be such great fun. When you are the big brother, you can be a teacher too! It feels good to play the part of the teacher and to help your brother or sister learn something too!

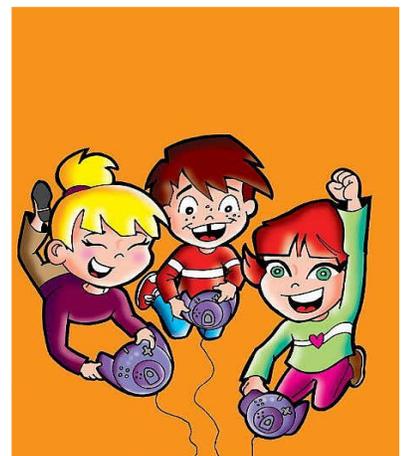


I'm sure many of you have taught your brother or sister with a disability how to do certain things. And some of you have been very good teachers like Frankie, even if you are not the oldest in the family! If you are younger than your sibling with a disability, you still can do many things better than your brother or sister can. So there are many ways to help your sibling learn.

While Anna likes to learn from her brother, Frankie found out that she really has to be in the mood for a lesson. Just because Frankie wants to play school, it doesn't mean that Anna wants to be the student right at that exact time! He may have to give up and try again later. It's best to play school when everyone wants to play.

Sometimes, brothers or sisters with a disability like to copy what their big brother or sister does, even if you are not playing school! If you are doing homework, your sibling might want to sit at the table with crayons and paper too. If you are playing a video game like Frankie, your sibling might try to grab the controls and play too. Sometimes, it can be easy to let your brother or sister play. But sometimes, it can be very annoying!

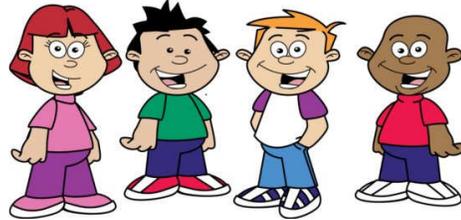
Frankie found a good way to let his sister think she is playing the video game - give her the broken controller and let her pretend to play as much as she wants! But when you are playing ball and your sibling gets in the middle, what can you do then? You can let him play a little and then ask Mom or Dad to get him out of the game. Or you can change the game you are playing to include your brother or sister more, if your friends don't mind. Another idea is to go play at your friend's house - and let their brother or sister get in the way instead of yours!



Kids like you who have a brother or sister with a learning difference don't always feel like helping their sibling learn, and that's okay. You can't always play the teacher!

But as Frankie and Anna found out, it can feel good when you take the time to help. Frankie and Anna both feel very proud about what they did together. Frankie and Anna feel good about what she can learn. Anna helps Frankie feel like a very good teacher. And that is exactly what he is!

Do you help your brother or sister with a disability to learn things? Write and tell us about it! Thank you, Frankie, for sharing your story with all of the readers of *For Siblings Only*. We're very glad you did.



BROTHER/SISTER THINGS TO DO:

In the summer when you are home from school, you probably have more time to play with your brother or sister. If you'd like an idea of something fun you can do together, take a look below. Read the two ideas and pick the one that you think would be the most fun for both of you. Ask mom or dad for help in setting up the activity - in fact the whole family can enjoy the fun!

- 1.) Have some fun with balloons! Blow up big balloons and little balloons. Fill some of the balloons with water. Roll the balloons back and forth to each other in the grass. Let your brother or sister feel how funny the water balloon feels. Talk with your sibling about the things that are the same and different about the balloons. You can match the colors or put all the light balloons together and the heavy balloons together. Talk about big balloons and little balloons. Talk about the difference between the light balloons and the heavy ones. You can bounce the light balloons up in the air by hitting them. If your brother or sister can't do this, let him watch the moving balloons. When you're all done playing with the balloons, you can both throw the water balloons onto the pavement and watch them splash. Think of some other things you can do with balloons. Be sure to handle them carefully so they don't pop and scare you or your sibling!





2.) Summer is a great time to visit the playground! You can help your brother or sister to use the outdoor play equipment. With your parent's help, you can push your sibling on a swing. Be sure they are sitting safely. Use a swing with a seat belt if needed. Talk about swinging high and low, fast and slow. Talk about the wind

blowing in your hair. Make up a swinging song! Another thing you can do is go on a climbing gym or a slide together if your sister or brother can. Make sure an adult is with you to help with this! Some towns have special parks that are considered "accessible." That means even kids in wheelchairs or special strollers or who can't walk can still use many of the things at the playground. Find out from your parents or your school whether there is a special playground somewhere near you. If there is, take a trip there and enjoy! Pack a picnic to make the day even more of an adventure for you and the whole family!



SPECIAL DEFINITIONS:

MITOCHONDRIAL DISEASE:

In order for us to walk and run and play and work, we need energy! Most of the time, we feel good and strong so we can do many things each day. When we have a cold, for example, we feel more tired and cranky and we don't want to do as much. Kids who have mitochondrial diseases are weaker most of the time. They probably feel like we do when we are sick! We get better from colds and other illnesses - that is how our bodies are supposed to work. Kids with mitochondrial diseases

can't make as much energy to help them feel good. Because their bodies are weaker, it is harder for them to learn and move and grow. Kids with this disease can become very sick. They can develop seizures. They can also develop heart and breathing problems and vision and hearing problems too. Children with mitochondrial disease often need to be on a special diet and a special formula gives their bodies the right



kinds of things to help them feel stronger and have more energy. When the children feel better, they can learn and move better too. To feel better, they may always need to be on this special diet and formula.

Kids with mitochondrial diseases are born this way - it isn't something you "catch" like a cold. Medical and learning problems usually start to show up when the child is very young. Doctors do blood tests and other tests to find out what is wrong, and then work to find the best diet and the best therapy to help them learn and grow.

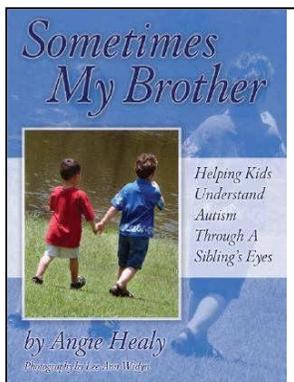
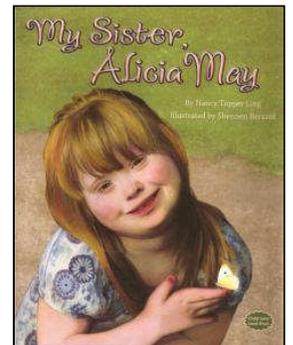


LET'S VISIT THE LIBRARY:

Summer is a great time to visit the library! There are so many books to discover and so many things to learn about. Because you have a brother or a sister who needs extra help to learn, you might be interested in reading about other children, just like you, who have a sibling with some differences. When you go to the library or bookstore, look for these story books filled with great pictures.....

MY SISTER ALICIA MAY by Beverly Beckham.

This book is written for children ages 4 to 8. The girl in this story has a sister who has Down syndrome. Rachel tells us about her sister and about her feelings for her. Mostly, she loves Alicia May and feels very proud of her. But she also gets frustrated with her and, sometimes feels jealous too. Rachel is a great big sister who watches out for Alicia May and helps her learn so many new things. Does this sound like you with your brother or sister?



SOMETIMES MY BROTHER: HELPING KIDS UNDERSTAND AUTISM THROUGH A SIBLING'S EYES by Angie Healy.

Gavin is the big brother in this family, but because he has autism, it sometimes seems like he is the little brother, even

though his younger brother, Foster, is only 3 years old. Gavin does things that might seem unusual to others, like watching flashing lights or things that spin. But there are some things he can do really well. He learned to read when he was 3 years old, and he uses the computer better than anyone in his family! He doesn't always like to talk to others, so when he says "hi" to a friend, the family goes out to celebrate with ice cream! You'll learn all about Gavin and Foster and autism in this children's book. The family photos of the boys help bring the story to life. If you've ever wondered about autism, this book gives a simple explanation.



At the end of the story, the author gives parents some tips on how to create their own story book about their children and disability issues.

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CALLING ALL KIDS:

How are you spending your summer vacation? Are you going to day camp or summer school? Are you going on a vacation, or taking a trip to visit friends or family far away? We'd like to know all about your summer plans and the time you are spending with your brother or sister who needs extra help to learn! Answer the questions below and mail them back to *For Siblings Only*, 35 Haddon Ave, Shrewsbury, NJ 07702, or e-mail them to slevine@frainc.org. Our readers would love to hear from you!



1.) Are you going to any camps this summer? _____
What camps are you going to? _____

2.) Is your brother or sister who needs extra help to learn going to summer school or a day camp? _____ Tell us about it!

3.) Is your family going on a trip or a summer vacation? _____
Tell us where you are going and what you are doing!

4.) How are you spending time with your brother or sister this summer?

5.) Are you playing together, doing projects, helping your sibling learn something new? Tell us all about it!

Send in a picture of you and your sibling from one of your summer adventures!

Your name _____ Age _____

Your brother or sister's name _____ Age _____

Disability _____

Your address _____

Thanks for writing to us at *For Siblings Only*, and for reading this newsletter too.

Look for your next issue in the Fall, after school starts again!

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A Newsletter for brothers and sisters of children with disabilities

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