

# FOR

# SIBLINGS ONLY

Spring, 2007

Vol No 10



## FROM THE EDITOR:

It's Spring! The snow is really gone now, and we can start playing outside, planting flowers, going to baseball games and having fun in the sun. There are so many things to do in the Spring. What a great time to play with your brother or sister who needs extra help to learn. When you play, you help to teach something new.

But some brothers and sisters who need extra help to learn are hard to play with. Maybe they don't understand the rules of the games you play or maybe they are always making a mess of your things. Maybe they aren't interested in the kinds of things you like to do and it's hard to figure out exactly what you can do with them! This is how it is in *Grace Huegel's* house. Read more about *Grace* and her family. You'll see how *Grace* has learned to play with each of the other three children in her house.

Be sure to answer the questions in *Calling All Kids* at the end of the newsletter. You can mail or e-mail your answers, and then you'll see your name in the next issue! See *Calling All Kids* for the details.

Susan Levine  
Editor



## GRACE, THE "BIG" LITTLE SISTER

By Grace Huegel and Susan Levine



Hi! My name is Grace Huegel. I am six years old and in first grade. I like singing, reading, playing soccer, swimming, and doing arts and crafts. I have a brother, Cal, who is 8 and two sisters, Faith, age 7, and Mary who is just 2. Cal and Faith both go to a special school for children who have trouble learning. They both were born with autism, as well as something called Bardet Biedl syndrome - I'll bet you've never heard of that! Kids who have autism need extra help to learn, talk, and play. Things that are easy for me are hard for them to do. Kids with Bardet Biedl syndrome gain extra weight and sometimes they need to be on a diet.

They also have trouble seeing, and this can get worse as they get older. At first, we thought Cal and Faith just had autism, but it's more than that.

We were worried about my little sister Mary, too, when she was really little. But we had her tested and she is doing better than most children her age. She had some extra help for a while, but she is really doing great now and she is very fun to play with! She is a good learner, just like me!

Even though Cal and Faith both have Bardet Biedl syndrome, they are different from each other. Cal can talk and he can read. He even does some easy math problems in school. Cal can swim too with a helper and plays on a special soccer team. He loves to watch movies, and he is a baseball, football and soccer fan. Cal wears glasses, but his vision is getting worse. He bumps into walls more than he used to. Cal and I watch TV and movies together, and we like to go places, including to the circus and Dunkin Donuts. We also go together to his favorite stores, Target and Blockbuster to buy videos, and Cold Stone Creamery for ice cream and smoothies. During the summer, we go to the boardwalk rides to ride the bumper cars. Cal likes them and the roller coaster. I don't like the roller coaster so my dad does that with Cal.

*"For Siblings Only" newsletter is published in print and on-line with partial funding from the Monmouth County Board of Freeholders.*

*We thank the Page Hill Foundation for its support to mail these quarterly newsletters.*



I do get angry with Cal sometimes, because he likes to scream a really loud high-pitched scream that hurts my ears! I can't scream back at him though or mom would get mad. So I just say firmly and quietly, "CALVIN!" and that makes me feel better. Cal gets to watch TV in the morning before school and I don't. That's just not fair! I also worry about Cal because he eats so fast, and I'm afraid he will choke. When mom is out of the room or if she is not paying attention, I will tell Cal to take a drink or slow down. I tell Cal what to do a lot and I kind of act like the mom, even though I am younger than he is. That's because I worry about him and I think he needs the help.

Faith can't talk, but she points to pictures to tell us what she wants. And she can shake her head yes too. She does some babbling and she yells when she wants something, but it doesn't hurt my ears! In fact, I think the sounds she makes are really kind of cute! Faith goes to a special dance class for children who need extra help and she just loves watching TV! Faith is heavier than Cal, and she likes to take food off of people's plates, so we really have to watch that she doesn't get things she shouldn't eat. Even though she can't talk and I can't really play with her, I like to sit and have special talks with her. We both like going to the town pool, so in the summer, we get to play together there. She can't really swim but she likes jumping up and down in the water and laughs a lot which makes me laugh.



Cal and Faith don't really hug me, but I go over and give them hugs when mom asks me to. My little sister Mary, though, is really good at giving hugs and she is really fun to play with. I like helping mom and dad by cleaning up around the house and Mary helps me with that too. Because I help my parents with my brother and sisters, I really am the "big" sister at my house!



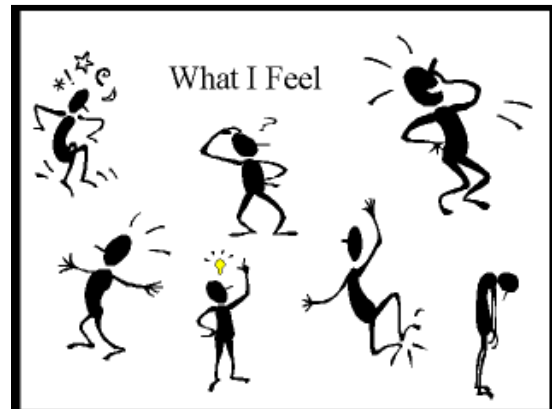
## WHAT DO YOU THINK?

- 1.) What kinds of things can Cal do that Faith can't do?
- 2.) What worries Grace about Cal and Faith?
- 3.) Why do you think Grace likes playing with Mary best?
- 4.) What are Grace's favorite things to do?



## FOCUS ON FEELINGS:

Grace lives in a very busy house! Any house with four children is busy, but when two of the children have trouble learning and need to be watched so carefully, everyone else has to help out. Grace likes to help her mom and dad with cleaning up, and she even likes acting a little bit like her mom! She watches out for both Cal and Faith. Even though she is younger than they are, she really acts like the oldest because she can do so much more than they can. Grace worries about her brother and sister too, because of their eating problems and because they can't see so well either. Every now and then, Cal accidentally bumps into Mary when he is walking down the hall.



Grace sometimes gets angry with Cal especially, because his screaming really bothers her. He likes being alone a lot and he doesn't always want to be bothered. So that can be frustrating too. Grace gets angry, but she tries really hard not to yell back at Cal because she knows her mom wouldn't like it. Grace has figured out a way to let Cal know she is mad. She gets her anger out in a better way - by saying firmly, "Calvin!" You **do** have to let your feelings out, but it's good to do that in a way that doesn't hurt anyone. How do you share your angry feelings?

I think Grace would like it if Cal and Faith were better playmates, because it's hard for her to play with them. They like watching TV more than they like playing games.

Grace does watch TV with them sometimes and they can go places together. But Mary is the most fun because she wants to play with Grace and she gives her big sister a lot of attention.



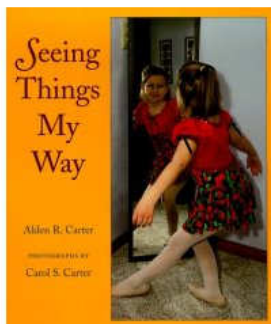
Even though it's hard to play with her big brother and sister, Grace has found that her sister Faith is special to be with because she can have private talks with her. Cal likes sports and Grace does too, so she knows that is always something they

can do together. She has figured out a way to spend time with each child in her family! And with so much going on, Grace also likes to spend time alone with just her mom or just her dad. She looks forward to that! When Grace has questions about her brother or sister, she knows she can talk to her mom and dad. They help her understand Cal and Faith's problems, and show her how she can help them and play with them too.

Thank you, Grace, for sharing your family story with *For Siblings Only*. You are a very helpful "big" little sister!

## LET'S VISIT THE LIBRARY:

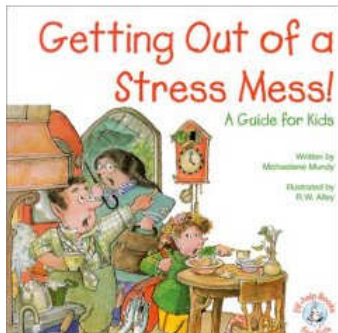
**SEEING THINGS MY WAY**, by A. Carter, Albert Whitman and Company, 1998.



Amanda is a second grader who can't see as well as other children. She was just born that way. In the story, we meet her family, her doctors and the people in her school. Amanda shows us different things that help children with vision problems to see better. She is a busy and happy girl who likes to do many different things. Even though she has trouble seeing, she is just like the other students in her class in every other way. The book has many photos of Amanda and her friends.



**GETTING OUT OF THE STRESS MESS: A GUIDE FOR KIDS, by Michaelene Murphy, Abby Press, 2000, Meinrad, Indiana.**

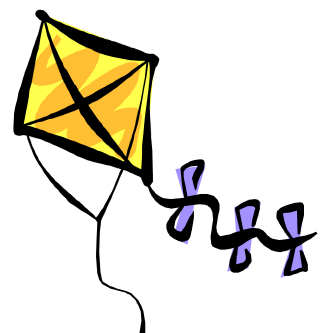


This book teaches children about stress - that feeling of having too much pressure. Stress usually happens when there is too much going on, or when you feel like you are being pushed and pulled in too many directions! Stress feels like worry, or sadness, or anger. Some stress is normal - everybody has some! But what can you do when you are feeling too stressed? You can always talk to your parents - talking can help. But there are other things to do too. You can take a deep breath, you can laugh, you can plan ahead so you know how to handle the problem, and you can relax! This little book will show you how to handle stress well.

**BROTHER/SISTER THINGS TO DO:**

Did you know that all children learn by playing, having fun and doing new and different things? So finding a fun activity is a great way to teach your brother or sister something new while you both have a great time! Like Grace in our story this month, it can be hard to figure out what your brother or sister might be interested in. To help you out, here are three exciting Spring-y ways for you to play with your brother or sister. By playing with him you will help him learn and you will both share some very special time together! Look at the activities below and choose the one that sounds the best for the two of you to do together. Ask mom or dad for help setting up the activity so it works smoothly and everyone has fun!

- 1.) A windy Spring day is the perfect time for flying a kite! Kite flying is something just about everyone can enjoy. Of course, you'll need a kite and a grown-up to help you get it launched. You and your brother or sister can take turns holding the string, or you can help your sibling hold the string if he can't do this alone. You can both feel the string as the wind pulls it tightly or lets it fly more loosely. If your sibling is in a wheelchair, special seat or stroller, try tying the string onto it, then carefully pull the chair or stroller backward and watch the kite really fly! Follow the path of the kite as it flies back and forth through the sky. Talk about the colors and the



wind and the way the string feels. If you've learned a song about kites or the wind, sing it for your sister or brother. Happy sailing!

2.) On a warm Spring day, you can do these barefoot activities! It's fun to feel different textures on your bare feet. This kind of activity is good for a child who is learning to walk or run, or balance better. Feeling different things with your feet helps you wiggle your toes and feel every part of your foot. One great



thing to do is to stand or walk on sand. This is easy if you have the beach near your house! If you don't, you can use your sandbox or get a small bag of sand and fill a plastic bowl big enough to stick your feet in. Take turns putting your feet in the sand, wiggling your toes and covering up all of your feet. Another fun but messy texture to feel on your feet is Jell-O! Make

two boxes of Jell-O in a plastic bowl and let it harden just a little bit. Take it outside on the grass or the patio and bring a bowl of water and a towel too! Take turns stepping in the Jell-O and wiggling your toes!



Talk about how squishy it feels. When you are done wiggling your toes and jiggling around, step in the bowl of water and then dry your feet with the towel. Help your brother or sister if they need help. Can you think of other textures to feel with your feet?

3.) How about playing a copy cat game? If your brother or sister is little or has a hard time following directions, follow this easier way to play! Start the game by sitting or standing facing your sibling. Do an action that your sibling would think is interesting and can copy - such as banging the table, clapping hands, sticking out your tongue or jumping up and down. Say: "you do it." If he needs help, then you or mom or dad can help him copy you. Be sure to say "good job" or "hooray" or something else to let him know that you're happy he copied you. After you both do one action, do another and another!



If your brother or sister is older and can do more for himself, then play this copycat game like "Simon Says." Stand or sit facing each other. Before you do an action say what you will do (for example, "Simon Says touch your nose" or "Simon Says clap.") Tell your brother or sister that he should copy you. Play the

game slowly at first and help your sibling so he feels good about being able to do the game. Then change places and let him be the "Simon Says" caller. Your mom or dad might give you ideas of the kinds of things to ask your sibling to do, things that he needs to learn. If your brother or sister is working on talking, then trying to get him to copy words or sounds might be a very good game. I'm sure you'll come up with great ideas! Be sure to praise your sibling when he tries to copy you.

### DID YOU KNOW?



Did you know that FRA has another newsletter called *Sibling Forum* for kids aged 10 through the teen years? If you're getting older, and you are beginning to outgrow this newsletter, write to us and we will send you a sample copy and subscription information!

### SPECIAL DEFINITIONS:

**BRAIN:** Your brain is what is inside your head! Our brain is the reason we can do just about everything we do. It helps us think and talk and tells our bodies when and how to move. Our brain makes us learn things and remember things too.



**CEREBRAL PALSY:** Children with cerebral palsy have a problem in the part of their brain that tells our bones and muscles when and how to move. This part of the brain helps us sit, roll over, crawl, dance, run, play sports, pedal a bike and do many other things. When this part of the brain is damaged, the child may have a hard time walking, crawling, doing even simpler things like holding their heads up or balancing themselves on both feet to stand. Talking may be hard too because the lips and tongue have muscles too. If the child has trouble moving these muscles, it may be very hard to talk or eat well. Some children with cerebral palsy have muscles that seem very tight and hard to move. Other children have muscles that seem too loose. Cerebral palsy may cause a problem in every part of the child's body, or just in one arm or leg. How many movement problems the child has depends on how much brain damage there is in this area of the brain.

Children with cerebral palsy may need special arm or leg braces to help them move better. They may need surgery to loosen some muscles too. Some children who have



very little control of their muscles may even need a wheelchair to get around. But even though a child may have cerebral palsy, he or she still loves to play and have friends too, just like you!



**CALLING ALL KIDS:**

Do you want to help write the summer issue of "For Siblings Only?" All you have to do is answer the questions below and mail or e-mail the answers back. Your answers will be in the next newsletter and you'll be famous, just like Grace Huegel is! The address to return your answers is as follows: *For Siblings Only, 35 Haddon Ave., Shrewsbury, NJ 07702*, or e-mail at [slevine@frainc.org](mailto:slevine@frainc.org).

There is a famous saying about the months of April and May, and it goes like this: "April showers bring May flowers." So think about this and fill in the blanks in these sentences:

1.) My brother or sister cries like an April shower when

---

---

---

---

2.) My brother or sister is happy like a garden of May flowers when

---

---

---

---

3.) I feel happy like a garden of May flowers when

---

---

---

---

4.) I act like an April shower when

---

---

---

---

5.) My brother/sister and I feel like a room full of sunshine when we do this together

---

---

---

---

6.) My name \_\_\_\_\_ My age \_\_\_\_\_

My sibling's name \_\_\_\_\_ Age \_\_\_\_\_

Disability \_\_\_\_\_

Our address \_\_\_\_\_

Thank you for reading **For Siblings Only**. Look for the next issue in your mailbox this summer!

**"For Siblings Only"**  
A Newsletter for brothers and sisters of children with disabilities  
Editor: Susan P. Levine  
Published by: Family Resource Associates, Inc., 35 Haddon Ave., Shrewsbury, NJ 07702  
Phone: 732-747-5310 Fax: 732-747-1896  
No Part of this newsletter may be printed without the permission of  
Family Resource Associates, Inc.

**For Siblings Only**

Family Resource Associates  
35 Haddon Avenue  
Shrewsbury, NJ 07702