

Sibling Forum

Winter, 2008

FROM THE EDITOR:

There's always a lot to learn in school and from homework, but sometimes the most meaningful lessons are the ones you learn from your own life experiences! Some of those life lessons come from being with our brothers and sisters. We learn to cooperate and to get along, to share and to understand. And when you have a brother or sister with a disability or learning difference, there's even more to learn! You become knowledgeable about medical problems, and particular disabilities. You appreciate differences, and get annoyed about unequal time and attention! You might worry too, and wonder about things your friends have no idea about!

This issue of *Sibling Forum* is filled to the brim with lessons about differences in the family. First, you'll find a discussion about embarrassing moments. If you've ever had an embarrassing situation with your brother or sister, you know how tough it can be, and how very strong your feelings are!

Then, in *Special Definitions*, you'll get a simple science lesson about some very confusing things - chromosomes and genes! And for many of you, these little things have a lot to do with your brother or sister.

I hope you enjoy this opportunity to learn, while having fun at the same time! Do you have any other questions about something to do with your brother or sister with learning differences? Send me an e-mail, and maybe your question will be featured in a future issue!

Susan Levine
(slevine@frainc.org)

Editor





EXAMINING EMBARRASSMENT:

Brothers and sisters present us with lots of opportunities to be embarrassed. Younger siblings can act silly at just the wrong time, and older siblings find ways to tease when you are trying to be cool with your friends. And that's what happens when you have siblings **without** disabilities! When you have a brother or sister with a disability, there are even more chances to have an embarrassing moment or two. Younger and older siblings can act up, even when they would be old enough to know better if they didn't have a disability.

Here are some of the embarrassing moments that have been shared with *Sibling Forum*....

- My sister has Down syndrome. She's always making passes at cute guys she sees at the Mall. I always dread going shopping with her!
- My sister loves to eat! One time we were at McDonald's and had just gotten our food. We were walking back to a table, but my sister couldn't wait to eat. She grabbed a handful of French fries right off of someone else's tray! I wanted to disappear or become invisible!
- My brother is the messiest eater. It seems like he always has food on his face or dripped on his shirt. I hate going out to dinner with him!
- When my brother calls the dog, he screams out the door at the top of his lungs! The whole neighborhood hears it.
- My sister is a big fan of throwing temper tantrums to get what she wants. Her favorite place to have one is in the middle of a store. I just wish I wasn't with her when they happen!



Do any of those difficult moments sound familiar? You could probably add one of your own to this list! The funny thing is that behaviors that might be totally acceptable at home can be a source of embarrassment in public places. The child who loves to sing Disney songs while skipping through the house can be cute at home,

but when she wants to sing in her off-key voice in the middle of a store, you just might want to run and hide!

When you are in your preteen and teen years and trying to find out who you are and how you feel about yourself, you don't need any extra help to feel upset or embarrassed! It's perfectly normal to feel embarrassed and to suddenly wish you were an only child! But learning to cope with difficult moments is part of growing up. These moments certainly can be learning experiences. One fifteen year old told me that she uses two different approaches when her sister starts to cry and throw things in a restaurant. Depending on the situation, sometimes she helps to calm her sister down, while at other times, she excuses herself and goes to the bathroom until the crisis blows over! Often the best way to avoid embarrassing situations is to plan ahead and avoid times that can lead to trouble. For example, you can sometimes choose not to go to the mall with your family, or you can do separate errands while you are there. You can also ask your parents how they will handle a problem if it occurs so you know what might happen ahead of time.



In addition to settings where your sibling is causing a scene, you also may have found yourself in situations where your sibling is being perfectly well behaved but people stare anyway. That was Catherine Martinelli's experience when she and her boyfriend took her brother, Joey, out for ice cream a few years ago. Joey uses a wheelchair to help him get around because he has cerebral palsy and can't walk. In



a matter of minutes, the three of them had drawn a small crowd of children and adults who were staring. Some people will always stare when they see people who are different, because as Catherine stated: "When a person has an obvious disability, it's impossible to go anywhere unnoticed." So, exactly what can you do to keep a trip to the ice cream parlor fun, instead of having it turn into a disaster? There's no perfect solution, but here are a few clues provided by some of our readers.....



- Stay just a short time and leave before you become the center of attention.
- You can do your best to ignore the crowd or the possibly poor behavior of the person with the disability.
- You can explain something about the disability to the people near you (if it's just a couple of people or a young child, and you and your sibling feel comfortable)
- You can talk to your sibling about how rude people can be, saying it loud enough for others to hear.
- You can stare right back or make a comment such as "Can I help you?"

The good news is that as you get older, you are less likely to be embarrassed by differences with your brother or sister. Older teens and young adults have said that they are more able to ignore the stares of others now. They care less about what other people think and are more supportive of their sibling. One college student I know remembers being extremely embarrassed by his older sister with Down syndrome as a preteen and young teen. He even got into an occasional fight with peers as a result. But, when his sister was a senior in high school and needed a date for the prom, he volunteered to be his sister's very proud date! He remembers that as a very special time - and you can bet his sister feels the same way too!

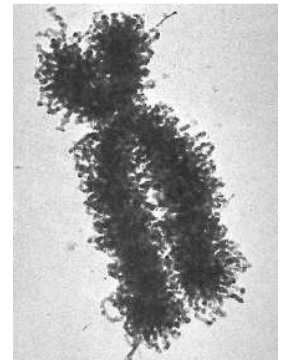
Being embarrassed can be tough to deal with. But it's nice to know that the difficult moments can become less upsetting - and you can focus more on the positive experience of spending time with your sibling. The next time you are in a situation where you are feeling embarrassed by your sibling with a disability, remember that you are not alone! Many brother and sister have been in your shoes and know exactly how you feel! Then you can come home and write about your experience and send it to *Sibling Forum* so others can learn from you!



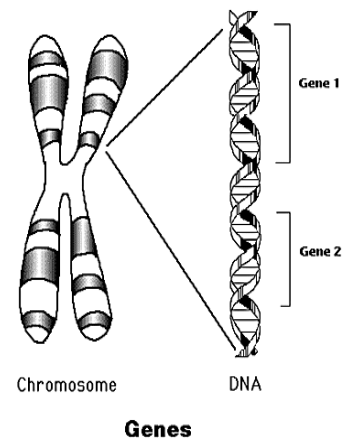
SPECIAL DEFINITIONS:

Are you ready for a science lesson? We are going to talk about genes and chromosomes -- things that can cause a number of different medical and learning problems that people can be born with. Your brother or sister might have a problem in their chromosomes or genes that is the cause of their challenges. Scientists are learning more and more about our genes and making new discoveries every day. So, get ready for a closer look.....

CHROMOSOME: Every part of our body is made up of tiny things called cells. In each cell there are even smaller items called chromosomes. Chromosomes look like tiny "X" shapes. All of our cells contain 46 separate chromosomes. Half of these come from our fathers and half come from our mothers, forming 23 pairs. The chromosomes contain things called genes. These genes provide important information about who we are - what color our eyes are, what our hair is like, how tall we will grow, how healthy we will be, and lots of other information. When you look under a very powerful microscope, the chromosomes look something like this:



GENES: There are more than 25,000 different genes in the 46 chromosomes in each cell in our bodies. Thanks to the Human Genome Project, we are beginning to learn exactly where those genes are on the chromosomes. Each chromosome holds certain genes which fall in a special order on the chromosome. With so many scientists studying the genes, we are learning just exactly what each gene does. Scientists can actually see a pattern of the genes on a chromosome, and it looks like different color bands or rings. One gene provides the information on our hair color, while another controls whether we are able to roll our tongues! Still others determine whether we might be born with an illness or disability. They have begun to label genes that lead to the development of things like Asperger's syndrome (a form of autism), and cystic fibrosis (a serious medical condition).



EXTRA CHROMOSOMES: Sometimes, a baby is actually born with an extra chromosome, which means they have extra genes. While you would think that having more of something is actually a good thing, in the case of chromosomes and genes, more is actually confusing to the body! Except for chromosome 21, having an extra chromosome usually means the baby won't be able to survive. But having an extra number 21 chromosome is actually the cause of Down syndrome. It's also called "trisomy 21" which means each cell in the body contains 3 of the number 21 pair of chromosomes.

MOSIAC CHROMOSOME DISORDERS: In some cases, a child may have an extra chromosome, but not in every single cell in the body. In other words, some of the cells have the extra chromosome but many do not. In that case, the condition is known as a mosaic trisomy of chromosome # ____.

CHROMOSOME DELETIONS: Sometimes, a small piece of a chromosome is missing in each of the cells in the body. Maybe it's just a tiny section making up a couple rings on the chromosome, or sometimes it's one of the "arms" of the chromosome. Remember, a chromosome looks like a tiny "X". The upper arms of the "X" are called the "p" arms, and the lower arms of the chromosome are called the "q" arms. Having a missing piece of a chromosome is confusing to the body as well, and it leads to certain serious medical and developmental problems in the baby.

For more information about chromosomes and genes, visit one of these "teen friendly" websites:



www.childrenshospital.org/wellness/info/kids

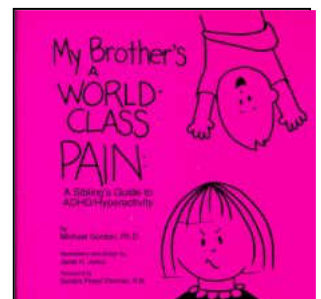
www.genome.gov

www.londonideas.org/internet/public/games/cgi.html

LIBRARY CORNER:

MY BROTHER IS A WORLD CLASS PAIN by *Michael Gordon*,
GSI Publications, DeWitt, NY, 1992.

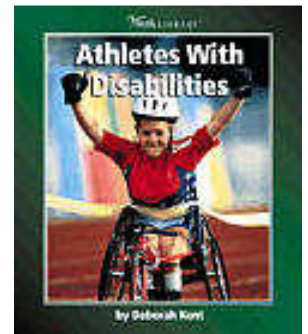
This book describes life in a family with a child with ADHD, better known as attention deficit hyperactivity disorder. Siblings with



this learning problem are often very active and have a hard time focusing on things in school and at home too. Having a child with ADHD places a lot of extra demands on everyone in the family. The importance of problem solving at home and rules to help control the child's behavior is mentioned. Also described are the frustrations and feelings of the brothers and sisters. This is an enjoyable and humorous story that helps you understand ADHD.

ATHLETES WITH DISABILITIES by Kent, 2003.

Gr. 5-7. *Athletes with Disabilities* presents the stories of many different athletes with differences, both ones who compete now, and those who competed in the past. One of the athletes covered in the book is Jean Driscoll, a recent winner of the Boston Marathon women's wheelchair division. You'll also learn more about the history of sports events for athletes with disabilities, as well as an important law called the Americans with Disabilities Act.



This Act helps insure that people with disabilities have the same opportunities as anyone else, and prevents discrimination against them. The book includes interesting photos of athletes in action.



SOME THOUGHTS FROM YOU:

In the Fall issue of *Sibling Forum*, we asked a few questions of our readers, and received these thoughtful answers in reply. You'll probably find that some of the comments provided sound a lot like life in your family too!

- 1.) Do you think your parents get stressed by your brother or sister with a disability? How can you tell?
 - Everyone answered, "Yes!" And they can tell because ...parents start to yell! Sometimes, parents get stern and more serious.
- 2.) How do you handle it when your parents are stressed or distracted by your sibling?
 - try to stay out of the way and not make waves
 - try to understand the problem, some of the time

- help out with sibling, when I'm asked

But by far the most popular answer was.....

- I get angry with my brother or sister for making life so difficult!

3.) What makes your parents stressed out the most?

- When my brother curses and screams and says 'No, I don't care!'
- When she doesn't listen
- When she pushes everything off the table when she is frustrated

4.) What makes you stressed out the most?

- Wherever I am, that's where she wants to be. I feel like she's my shadow!
- Just about everything about my brother stresses me out
- It's stressful when I have to watch her, because she won't eat what I give her and she makes a mess.
- I try to do everything I can to make my brother a better person.

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THE FORUM:

You and the other readers of *Sibling Forum* are our best advisors! You have the experience of living with someone with a learning difference, so you probably have a lot to say in answer to the questions listed below. We'd like to share your thoughts about how to handle some tough feelings or situations, so why not write and let us know what you think! You can e-mail your answers to slevine@frainc.org or write to *Sibling Forum* 35 Haddon Ave., Shrewsbury, NJ 07702.

1.) How do you deal with it when people stare at your sister?

2.) Do you think your life would be easier if your brother or sister didn't have a disability? Why or why not?

3.) If your brother or sister could have one day without having a disability, what would you want him or her to experience?

4.) Your name _____ Age _____

Your sibling's name _____ Age _____

Your sibling's disability _____

If you'd like to write about your experiences with your sibling for a future issue of *Sibling Forum*, you can write and submit your own story, or you can give your contact information here, and we'll contact you for an interview. Then, we'll write the story, and you just have to do the talking!

_____ (phone or e-mail)

Thanks for reading the newsletter! Look for the next issue of *Sibling Forum* in the spring!

"Sibling Forum"

A Newsletter for Preteens & Teens with Siblings with Disabilities

Editor: Sue Levine

Published by Family Resource Associates, Inc. 35 Haddon Avenue, Shrewsbury, NJ 07702

Phone: 732-747-5310

Fax: 732-747-1896

www.frainc.org

www.techconnection.org

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Family Resource Assoc., Inc.

35 Haddon Ave.

Shrewsbury, NJ 07702

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