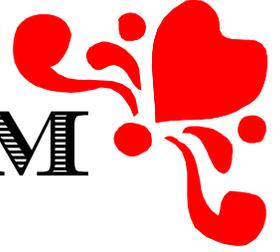


SIBLING FORUM



Winter 2009

FROM THE EDITOR:

Hello everyone! Welcome to another issue of *Sibling Forum*, the newsletter written just for preteens and teens with a brother or sister with a disability. In this issue, you'll find a very interesting article written by fourteen-year-old Ally Lennon about life with her twelve-year-old sister, Emily, who has autism. She shares some interesting facts, funny moments, and explains what it's like to be Emily's sister. "Life with a Sister with Autism" was written as a speech which Ally gave at a 2007 fundraiser for children with autism. Following the speech, in the **Focus on Feelings** section below, you'll find some additional comments Ally wrote in an article for school. Ally offers some practical advice on how to be a tolerant sister or brother when you have a sibling with a disability. Thank you, Ally, for letting us share all your words of wisdom!

I'm excited to bring your attention to **Library Corner** inside this issue. One of the books highlighted is a book that I recently wrote with my friend and colleague, Brian Skotko. Brian grew up with a sister with Down syndrome. He is now a doctor living and working in Boston. Brian shares what it is like to grow up with a sister with learning differences. I share much of what I have learned working with brothers and sisters just like you. Together, Brian and I wrote "Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters."

Sibling Forum is always looking for brothers and sisters like you, who are interested in sharing your personal story about life with your sibling. Send your story to me at slevine@frainc.org. Then you can be in print in the Spring issue!

Susan Levine

Editor



LIFE WITH A SISTER WITH AUTISM

By Ally Lennon



My name is Ally Lennon. My little sister Emily is autistic. Before anyone assumes this is completely depressing or terribly sad I want to assure you it is not. Emily can be lots of fun to play with and always finds ways to crack me up. She is the most energetic kid that I know . . . she runs all around our yard, swims in our pool like a seal, and goes from room to room like a tornado hit it!! It's really pretty funny to see how fast my Mom can make a bed and watch Emily unmake it even faster!!

Emily doesn't always like to play with me - but when she does, it's pretty cool. She especially likes to be tickled. She doesn't say many things - but when she says "tickle me" I jump right in and tickle her.

Going to a restaurant with my family is really pretty interesting. Salt being spilled on the table, napkins being shred, crawling under and on the table - but enough about how my Dad acts. But seriously, it's always very eventful with Emily.

It's obviously not always fun and games with my sister. She gets upset at all sorts of things and can make a scene in public which can be very embarrassing. I keep working on being more tolerant of her behaviors - but it's hard. One time I came home and she destroyed a school project that I worked really hard on. Boy, did I want to kill her! But of course I didn't. She couldn't help it. There were tiny little pieces that interested her and she felt the need to play with them all over the floor! I think in some ways Emily's acting up has forced me to be a more mature and forgiving, so I guess it can't be all that bad right?



I see the puzzled looks people often give Emily at times. I think most of the time people are just wondering "what is she thinking or what does she want?" It's a great feeling when I know what Emily wants right away and I can help her. For instance, when my family sits for dinner Emily raises her glass and says "4 to us", that means she wants all four of us to clink our glasses for a toast and say "to us"!



There are only a few people in the world that Emily is really comfortable around and that's probably true for most people - the difference is that Emily will hand you your coat and say "goodbye man" or "goodbye lady" at any given time. I'm sure we've all felt like doing that at least once in our lives!

Emily's favorite person in the world without a doubt is my mom and for good reason. My mom takes such great care of us. When my mom goes out (even for a little while) Emily will walk around asking "mommy?" which translates to "where is mommy" and "get her back right now." It's a good thing my mom stays in good shape because Emily can be really exhausting to keep up with. A lot of nights Emily has a hard time going to sleep or staying asleep. I'm sure most of the moms of autistic kids can relate to that huh? Well Emily sometimes wants to get up in the middle of the night and she stays up. And she sometimes needs mom to lay next to her to fall back asleep.

None of us know why our loved ones are autistic, nor do we know when they will have a cure. I pray for Emily and no matter how bad it seems at times my dad always reminds me that some other people have it tougher. My mom and dad tell me it's OK to be sad sometimes, but that there are good things to think about also. I think that people everywhere are getting better and better at dealing with kids like Emily. I think that scientists and doctors will figure this puzzle out and are going to find a cure for autism.

I know that I love my sister very much and that will never change. I know my parents love us both very much and that will never change either.



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FOCUS ON FEELINGS:



Ally certainly expressed many different emotions in her speech, including love and embarrassment, anger and worry. You can also tell that Ally and her family share a good sense of humor! Being able to laugh in the middle of an embarrassing or frustrating moment can make the difference between being miserable and being happy. Ally and her family seem to make the best of what can surely be a tough situation at times. If you do this at your house, you know that humor can be your best friend!

In another article Ally wrote, she offered some additional advice for brothers and sisters of children with disabilities. First of all she reminds you to "talk to your parents about your feelings. It helps to express how you feel. Your parents may experience the same emotions as you. Times are tough when it comes to raising sibling" *with a disability*. "Parents can make things better if you talk about it."

"Next, when your brother or sister has an outburst, explain to people that he or she has special needs. Outbursts or meltdowns can come at anytime and anywhere. It might be because they can't explain what they want or need. It's not uncommon that people stare when your sibling is crying, so just explain to them and don't get embarrassed. Be patient and try to understand what's causing the problem and figure it out quickly."

"Lastly, some kids with autism may do certain things that you don't understand. For instance, they might destroy your belongings without meaning to. They may not know boundaries and take things that are important to you. Understanding that your sibling can do these things makes you more aware. You

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can teach your sibling not to do these things. If all else fails, just hide your belongings! Being understanding and patient is the key to being a good sibling!"

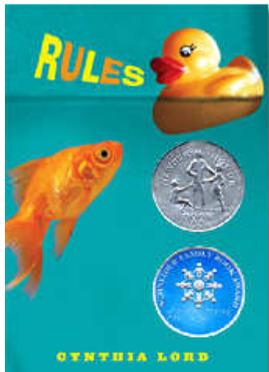
Thank you Ally, for all of your valuable and thoughtful advice!



LIBRARY CORNER:

Looking for a good book to read for fun or use as a book report or an essay for school? The first book is a fictional account of life with a brother with autism. Ally, and many of our readers can relate! If your sibling has another disability besides autism, this book will still be of interest. Many aspects of the world of disabilities are explored in this story.....

Rules by Cynthia Lord (A Newbery Award Book)



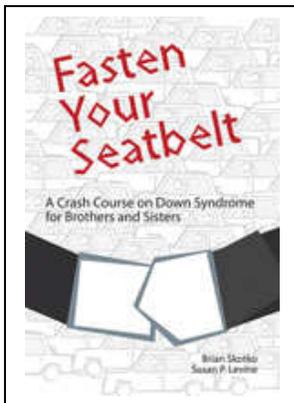
Catherine is twelve years old, and she just wants a normal life. But, because she has a brother with autism, that's not really possible! Her brother can be really embarrassing, especially out in public, so Catherine tries to teach her brother all the rules so going out won't be so difficult. Catherine has many rules, including "Keep your pants on in public," "No toys in the fish tank," and "No hugging the video store man!" Catherine wants to make a new friend in the neighborhood, but she worries about what the girl will think of her brother. And then, she meets a boy named Jason who uses a wheelchair and communicates by pointing to pictures in a book because he can't talk. Catherine finds that the world of disabilities has a lot to teach her!



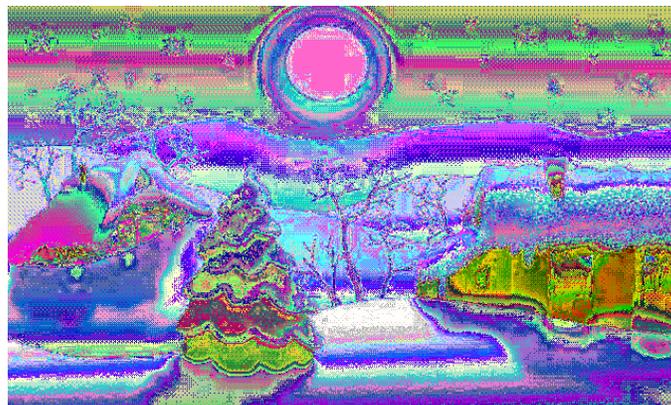
As I mentioned in my note from the editor, I'm pleased to share my very own book here! The book was written by me, the editor of Sibling Forum and my colleague, Brian Skotko. I have been working with brothers and sisters through this sibling newsletter and in sibling groups for the past 30 years. Brian is a doctor who has two sisters, one of whom has Down syndrome.

The book can be ordered now from Woodbine House, the publisher, and is due to be in stores in February, 2009. Brian and I also run sibling workshops together, and we certainly had fun writing the book! If your brother or sister has Down syndrome, I think you'll like what we had to say.

Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters by Brian Skotko and Susan Levine



This new book from Woodbine House answers more than 100 questions asked by brothers and sisters about living with someone with Down syndrome. Some of the questions came directly from the readers of *Sibling Forum*! The book provides some facts about Down syndrome, with answers explaining medical concerns, how children with Down syndrome learn, and what people with Down syndrome can do when they are adults. Other parts of the book help brothers and sisters deal with embarrassing moments, frustrating behaviors and getting enough attention at home. The book is expected to be available in February, 2009, and can be ordered from www.woodbinehouse.com.



SPECIAL DEFINITIONS:

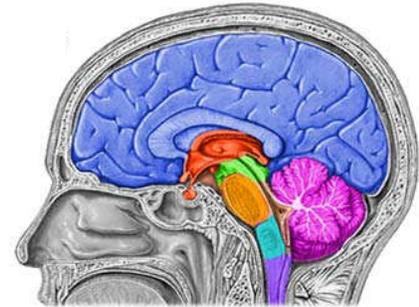


Seizures, or epilepsy, is a medical condition that can lead to doctor's visits, lots of tests, medication and even hospitalizations. Read on to find out more....

SEIZURES:

Seizures are abnormal or erratic brain impulses (electrical messages) which cause the body to jerk or move uncontrollably. Seizures can result from problems at birth, brain damage, high fevers, or head injury.

The person has no control over the seizure and can do nothing to stop it. Medication is often used to control the problem. Some seizures can be controlled easily with a certain medication, while other seizures can be controlled only with a combination of medicines. Finding the right medication or combination of medicines to work can take time.



Seizures are usually diagnosed by giving the child a test in the hospital called an EEG. To do the test, wires (electrodes) are placed in different places on the child's head. The test looks at the electrical activity going on in the brain. Everyone's brain contains electrical activity. When someone is having seizures the electrical activity patterns are different from what is usually seen. The pattern of the abnormal brain waves can help doctors determine what kind of seizure is happening and what medicine is best to use to treat them. Some children who have learning problems or a disability diagnosis are sometimes at greater risk for developing seizures. There are two main types of seizures:



Petit Mal Seizures:

Petit mal seizures are short seizures that involve a small body movement such as brief periods of staring, drop of the head, chewing actions, a jerk of an arm or leg, head shaking or startle reactions. Just one such action may occur at a time or the movement might be repeated several times in a few minutes. The seizure interrupts what the child was doing at the time. They may have missed what was said in a conversation or forget where they were in the book they were reading, for example. Some children may have many of these a day or they may be completely controlled with medication. There is nothing that can be done to stop the seizure once it starts and the person is usually okay after it happens and may not even be aware that they had a seizure.



Grand Mal Seizures:

Grand mal seizures involve the whole body and are a more serious type of seizure. The person loses consciousness (awareness of his surroundings) and collapses, and the body begins to move in large jerky patterns. The person may lose bodily functions briefly (he may vomit, drool, urinate or have a change in breathing pattern.) Afterwards, the person may be very sleepy or irritable and may not remember the seizure. You can't stop the seizure once it starts. The best thing to do is to turn the person on his side and move objects out of the way to avoid self-injury.

A grand mal seizure that lasts a very long period of time (several minutes) might require the need to call 911. In these rare cases, the child might need to be hospitalized and given a strong dose of medicine to try to stop the seizure.

Another type of seizure that can happen to a child in the first few months of life is called Infant Spasms. Infant spasms are diagnosed when the doctors see a certain kind of abnormal brain activity on the EEG test. The seizure often involves a series of jerking movements or head drops in a quick repeating pattern. These seizures can be very difficult to control. Many children with infant spasms have very serious learning problems as well.



THE FORUM:

Sibling Forum is always looking for students who would like to contribute their thoughts to the pages of this newsletter. Including the thoughts, ideas, concerns and advice of our readers is what makes this newsletter so helpful to others.

We'd like to hear from you, too! You can e-mail your own, personal story to **Sibling Forum**, or you can answer the questions below and send them in. Either way, we're counting on you to be a part of the action next month!

- 1.) In this month's story, Ally Lennon shares some funny and not so funny moments with her sister. A sense of humor helps the Lennon family. How does your sense of humor help at your house? Got a funny story to share?

- 2.) Ally shares some thoughtful advice on how to be a good sibling for a brother or sister with a disability. What advice would you give to someone who has just found out that their sibling has a disability?

3.) Your Name _____ Age _____

Your sibling's name _____ Age _____ Disability _____

Your address _____

Your e-mail address _____



Thanks for reading **Sibling Forum**. See you in the Spring!



If you live locally, why not call FRA to join our **Sibling Group** for siblings aged 10-15 who have a brother or sister with a disability or developmental delay.

We meet quarterly. Three meetings a year take place at Memory Lanes Bowling Alley in Shrewsbury, NJ and one meeting is held on the Point Pleasant, NJ Boardwalk.

"Sibling Forum"

A Newsletter for Preteens & Teens with Siblings with Disabilities

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