

# SIBLING FORUM

A newsletter for brothers and sisters of children with disabilities

Fall, 2007



## FROM THE EDITOR:



Welcome to another issue of *Sibling Forum*! As the school year gets underway, I hope you and your sibling are starting out with a good feeling about the year ahead. And speaking of school, this month's story is interesting for several reasons. First of all, it was written by a student from Paris, France! You might remember that a sibling group in Paris had written to *Sibling Forum* during the summer. One of the students, Marielle Coutrix, sent an essay she wrote for a class project, and added some additional information about her brother, Ben. Marielle's essay gives us an idea of what a special education school is like in France. You'll learn about several different classes at Ben's school and the students who attend there. You'll also learn more about Ben's disability, which is not as common as things like Down syndrome and autism.



Marielle's essay contains some terms that probably are not as familiar to you. You'll see a star (\*) next to those words and will find the definitions in the "Special Definitions" section. I think you'll enjoy reading Marielle's story which shows that while school might be a bit different in France, brothers and sisters get along much the same as they do in the United States.



Why not share **your** story with the readers of *Sibling Forum*? No doubt that just like Marielle, you have many interesting experiences to share about life with your brother or sister with learning challenges!



Merci beaucoup!

Susan Levine

Editor



## Marielle Coutrix

### Spring Internship Project

My name is Marielle, I'm fourteen years old and live in Paris, France. At the end of ninth grade, every student has to choose a work internship experience for one week. I chose to work at my brother Benjamin's school for children with special needs. My brother Ben is 18 years old and has a **leukodystrophy\*** disease called Pelizeaus Merzbacher disease. He lacks **myelin\*** in his brain consequently making it difficult to send and receive messages along his central nervous system. He's in a wheel chair and communicates using mono- syllabic words and occasionally an **alpha talker\***. I admire my brother's ability to understand and speak two languages and to be as socially present given his limited physical capacity to engage others.



My brother, Ben, and I get along very well. We are very close and laugh a lot. He loves it when I call him my big brother and I refer to myself as his little sister. When we were younger we played with puppets and toys and as we get older our interests change but we still have a lot of fun doing other activities. We love to sing, watch DVDs of Sponge Bob, talk together, bake, make a lot of noise, pet and play with our dog, go for walks, shop and much more.....I love spending time with my brother but as I get older I have to spend more time at school. We therefore don't see each other as often during the week and spend more time together during the weekend.

My friends are very welcoming with my brother. He goes ice skating with my Girl Scout troop and attends my birthday parties. When I was younger, one of my friends was scared of Ben as she had never seen a boy in a wheelchair. At the time I did not understand her reaction. This is one of the reasons I help the **association ELA\*** communicate with the public about my brother's disease.

For me, Ben does not have disabilities. I am so accustomed to Ben's abilities and weaknesses that I don't focus on his disabilities. Although he is in a wheelchair and communicates with difficulty, he has a good sense of humor, understands, reacts, laughs and is a full member of all groups he is in.

Soon Ben will be going on a seaside trip with his classmates, teachers and therapists for a week. He is very happy to become more independent. In a few years he may leave home and live in a medically assisted home with his friends, just as I will be going to college. We have more in common than differences. I love my brother!

I'd like to tell you a little bit about my experience as a teacher's aide at my brother's school during my internship. Centre Claire Girard is the global name for three different dav schools that welcome children.

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physical and mental deficiencies. The main goal of all the centers is to promote the children's well-being and foster as much personal independence as possible. This is accomplished with the help of many professionals including: a doctor, physical therapists, occupational therapists, speech therapists, psychologists, social workers, teachers and teacher's aides.

My brother's current school is called Versailles, where 12 young adults from the age of 16 to 21 are encouraged to become more independent adults. Indeed they try to learn how to successfully carry out adult tasks and therefore become more independent and aware of society as a whole.

Centre Claire Girard in Sevres is another very important school as it has the youngest and largest population of children with special needs and administration. There are 5 classes in which the students are divided up depending on their needs, age, comprehension, communication and independence levels.

For the first half of my first day, I helped the teacher in a class of 13 students at Sevres. I was very surprised and impressed about how serious, demanding and energy consuming the class was as I never knew the children had homework or poems to learn. I went to the swimming pool and swam with the children and then supervised the recreation with another staff member.

During my third day at Sèvres, I assisted another class. I observed their morning circle routine which is a series of questions about the weather, the day of the week, how they are feeling and their daily plan. I attended and enjoyed the outing at the pony club. I helped the students be confident and maintain their balance while riding the pony. For the second time, I returned to the pony club in the afternoon to help a more physically challenged group of children. This activity was more demanding and the students spent more time petting and grooming the animals than riding.

In the afternoon of my fourth day, I visited the school my brother attends in Versailles. I had to adjust my vocabulary and intonation to be appropriate for this developmentally older level. I learnt communication techniques for a deaf and mute 18 year old boy. The young adults were proud to show me their work area and the pictures of the trips and activities they have organized this year.

This internship has been an amazing learning experience in many ways. Indeed, I have gained an abundance of information about the school itself, the children that study there and the staff members as well as learned more about myself. I believe that helping the students has highlighted my qualities and my personal challenges.



Marielle's story was so interesting! How nice it must be to go to a school that has a pool, and horseback riding. In the United States, there are many horseback riding programs for students with disabilities, but they are not usually right at the child's



school! Some schools here have pools, but most do not. Having such things available for students who have trouble with movement is a very good thing.

It was also interesting to learn that students in France, like Marielle, have to do a work internship at the end of ninth grade and write a lengthy paper about it. In the United States, some schools encourage students to do volunteer work in the community, or they have clubs that do volunteer and charity work as well. Marielle chose to learn more about her brother's school and she became more comfortable with many different types of disabilities. You have probably met students with different disabilities because of your brother or sister with developmental challenges. You might have met those students through your brother or sister's recreation activities (like Special Olympics or a special dance class or travel group), or through special classes in their school.

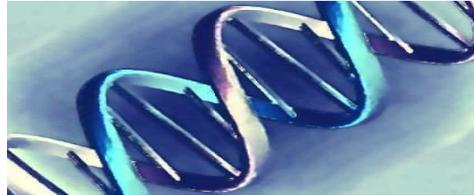
Marielle explains that she and her brother get along well. They can have conversations (although Ben can't easily express his thoughts) and share laughs. Marielle has been an advocate for her brother and others with his disability. She knows a lot about leukodystrophy and helps explain things to others who don't understand it. Being around someone in a wheelchair has just been part of life for Marielle, and her friends have learned to become comfortable with this too. She and Ben both educate others every day!



Most brothers and sisters of individuals with learning challenges act as an advocate at one time or another. Probably, you have been an advocate too! Maybe you explained the disability to a friend, a teacher, or a stranger. Perhaps you've helped to introduce your brother or sister to other children on the playground or at the soccer field, or helped to interpret your sibling's speech to a child or adult who has difficulty understanding. You might have written a paper or done a science project about the disability so your whole class can learn more. That's what it means to be an advocate - standing up for someone who needs the support and educating others to be more understanding.

Being an advocate can make you feel good. But some situations though, can make you a bit uncomfortable. If people are staring or kids are teasing, you might feel like disappearing instead of educating! Everyone has a rough moment or two in the role of an advocate. Each opportunity to teach is a small opportunity to make the world a better place!

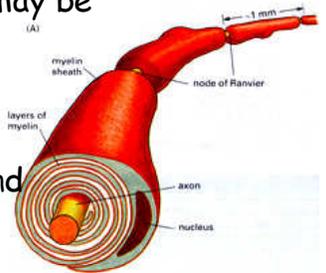
Thank you, Marielle, for sharing your story and your project with the readers of *Sibling Forum!*



## SPECIAL DEFINITIONS:

**Leukodystrophy:** Leukodystrophy is a genetic defect (a problem in the genes) affecting the myelin, the protective covering around the nerves in the brain and spinal cord. The myelin acts like the covering around electrical wires. It helps the nerves work and send messages from the brain to the body at great speeds. When the covering around the nerves is damaged, the brain and nerves are not able to send the signals to the body very well. There are 10 different chemicals that make up the myelin. And there are many different types of leukodystrophies. Each kind is related to how only one of the chemicals in the myelin works. Babies and very young children with leukodystrophy often seem like they have low muscle tone or floppy muscles. They have trouble coordinating their movements, which might look "jerky". They may have trouble with their eyes and with eating. They may be slower with learning as well.

**Myelin:** Myelin is the fatty covering around the nerves in the brain and spinal cord. The myelin protects the nerves and helps them work to send signals from the brain to the body.

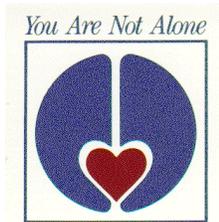


**Alpha Talker:** This is a device that is made to help people who have trouble with their speech. It is a small computerized piece of equipment that you can program to talk for you. It operates with the push of a button. The person using the device can operate it by touching the picture or



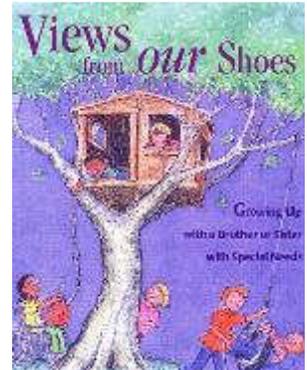
word they want to say, or by using a switch which can operate the alpha talker with a head nod or a touch pad.

**Association ELA:** This is the European Leukodystrophy Association. It is an organization that provides information on the disability, provides support to families, helps find treatments and raises funds for research. In the United States, the organization is called the United Leukodystrophy Foundation. You can find them on the web at [www.ulf.org](http://www.ulf.org). If you'd like to read more about leukodystrophy, visit this website.



## LIBRARY CORNER:

**VIEWS FROM OUR SHOES: GROWING UP WITH A BROTHER OR SISTER WITH SPECIAL NEEDS.** Edited by Don Meyer, Woodbine House, Bethesda, MD, 1996.



*Forty-five siblings ranging in age from 4 to 18 share their experiences as the brother or sister of someone with special needs. The good and bad aspects, as well as many thoughtful observations are included. Their siblings have a variety of diagnoses including Down syndrome, cerebral palsy, autism, hydrocephalus, developmental delays, chronic medical problems and vision and hearing impairments. The writer's name and age is located at the top of each chapter so you can easily find the thoughts and comments of individuals who are your age. You'll also find it interesting to read what younger and older students are thinking as well.*

***Sibling Forum** is especially pleased to report that three students, who have read and contributed to this newsletter, have chapters in this book. Be sure to read what **Sharon Siber**, then age 11, **Justin Mann**, then age 12, and **Jeanne Marie**, then age 13 had to say. We're very proud of them!*

## THE FORUM:

Growing up with a brother or sister with a disability, you lead a very interesting life! There are days when your family feels just like any other family, and days when things feel very different! Because of your experience, you can help others who might need some help with how to deal with the differences. The questions



listed here have to do with parents - that's always a good topic! How do your parents handle your sibling with a disability, and how do *you* handle your parents?

1.) Do you think your parents get stressed by your brother or sister? How can you tell?

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2.) How do you handle it when your parents are stressed or distracted by your sibling? Do you (circle all that apply):

- Stay out of the way and try not to make waves?
- Make extra noise so you get attention too?
- Talk to your parents and try to help them problem solve the situation?
- Try to be understanding about the problem?
- Get angry at your brother or sister for making life so difficult?
- Help out with your sibling as much as you can?

Tell us more about the answers you circled:

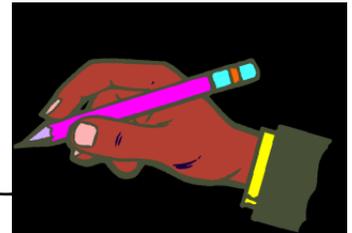
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3.) What makes your parents stressed out the most?

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4.) What makes you stressed out the most?

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Your name \_\_\_\_\_ Age \_\_\_\_\_

Your sibling's name \_\_\_\_\_ Age \_\_\_\_\_

Disability \_\_\_\_\_

Your address \_\_\_\_\_

5.) Can we print your answers along with your name in the next issue of *Sibling Forum*? Yes \_\_\_ No \_\_\_

Thanks for writing to *Sibling Forum*! Look for the next issue of the newsletter in your mailbox or on the web at [www.frainc.org](http://www.frainc.org) in the New Year.

"Sibling Forum"

A newsletter for Preteens & Teens with Siblings with Disabilities

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