

# Sibling Forum

Summer, 2008

## FROM THE EDITOR:

I hope you are all having a great summer! Many of you are enjoying the sun and fun at the beach or other vacation spots. Some of our readers may also be using their free time to do volunteer work or to even have a paid job – that extra money sure is nice! Brothers and sisters of children with disabilities sometimes find volunteer or work opportunities in settings that have to do with children and disabilities. Perhaps you are using some of your time with this type of learning experience out of the classroom.

Marielle Coutrix from Paris, France who is one of our readers, had a chance to do just that this summer! You might recall that Marielle wrote to *Sibling Forum* last summer as well. Look inside for Marielle's story. Another sibling helped with writing this month's newsletter. Kelly King from Marlboro, NJ helped educate other students in her school when she wrote something about Down syndrome for her school newsletter. You'll see Kelly's information inside as well.

If you have had an interesting learning experience this summer, or if you have information to share about another disability, please send your thoughts to me at [slevine@frainc.org](mailto:slevine@frainc.org), or via mail at FRA 35 Haddon Ave., Shrewsbury, NJ 07702. As always, we love to hear from our readers!

Happy Summer!

Sue Levine

Editor

## SOME THOUGHTS FROM YOU:

Brothers and sisters like you and Marielle learn about many things from growing up with your brother or sister. You are learning firsthand about the world of disabilities. You have the opportunity to learn about things like speech therapy and physical therapy, shunts, seizures, and medical equipment, Down syndrome, cerebral palsy and autism. Your friends probably don't have a clue about all of these things...that is, unless you've told them!



Because of all that you are learning, you might have a greater interest than other students have in information about therapy, medicine and differences in the world. You might be involved in a special activity in your community like Special Olympics, or you might be volunteering or working in a program having to do with your brother or sister.

Marielle Coutrix wanted to find out more about careers that are related to disabilities. She found the perfect learning experience in a hospital in Paris! Read about Marielle's adventures at the St. Vincent DePaul Hospital in France. You might learn about an interesting job that you had never thought about before from Marielle's article!

### Internship at Saint-Vincent dePaul Hospital

#### Paper written by Marielle Coutrix

##### Introduction:

Cochin- Saint-Vincent de Paul Hospital, which is part of the "Assistance Publique Hopitaux de Paris" known as AP-HP, treats around 86 000 patients every year. Within this hospital there exists a division between the Cochin site for adults and the Saint-Vicent de Paul one truly devoted to the well being of children and young adults.

For last year's internship, I worked at Centre Claire Girard, a school for children with special needs. This experience awakened my desire to continue learning about different jobs which help people, and more precisely, children who have special needs. Having a brother with one of the Leukodystrophy diseases, my family and I are very active members of ELA, the European Leukodystrophy Association. Leukodystrophy is a genetic disease which attacks the myelin of the brain, the central nervous system and the peripheral nervous system. Those who have this disease can be paralyzed at birth or can gradually lose their ability to walk, talk, eat, hear, breathe and live. I became curious about the medical reasons behind psychological and behavioral problems and therefore wished to learn more about

professions linked to the hospital but for which teaching and helping is still of paramount importance. This inspired me to work at Saint-Vincent de Paul's neurological sector where I was warmly welcomed and was therefore able to learn, understand, share, give, and most importantly, for a short week, engage in the hospital's circle of trust.

During my internship, I worked with many professionals dedicated to helping the patients and their families at the hospital and also in their everyday life.

*Working with the nurses:*

I interviewed Florence, a nurse, and learned about a nurses' education, work hours, as well as the different qualities and standards they need to possess.

The first "trick" the nurses taught me was how to correctly wash my hands in order for the germs still present on my hands to glide up my arm and not down my hand.

I also learnt how to take the patients' pulse, tension and temperature as well as interpret these results.

*Working with the doctors:*

I also worked with the doctors of the endocrine and neurological service. In order to work in France doctors must study for 9 years after graduating from college and must, like the nurses, have a wide range of experience working at hospitals or at doctor's offices. I observed that just like nurses, doctors spoke very clearly and not only provided medical attention, but also personal assistance and emotional support to their patients.

*Working with the psychologists*

At the hospital clinical psychologists give support to patients and their families both in person and over the phone. I also interviewed the school psychologist about her six year training in France. This school psychologist evaluates the children's abilities using standardized tests. By observing the children and by analysing their test results she is able to make recommendations to improve their success in an educational environment. I was able to spend the day with this psychologist and saw the procedure that she follows when administering psychological tests.

*Working with the social workers:*

The social workers have a very important role in the well being and protection of the children at the hospital. At the hospital, Mme. Lupter, a social worker, focused on the patient's and children's bill of rights to make sure that the children lived in the safest and best environment as possible. In the neurological section and obesity section many children needed to be integrated in special centers due to their eating problems or special needs. The social worker helped these children be accepted by special schools by writing recommendation letters and by advising them on appropriate placement.

*Working with the hospital's teacher:*

The hospital's teacher has a special library where students from the endocrine and neurological section can come relax and learn away from the agitation and stress of their medical exams.

To be a teacher for children with special needs and to work at the hospital she studied psychology and took other courses about teaching. The Teacher, Marie Annick talks and plays games with the children but also builds a relationship with their parents. In this way, she helps the family feel more comfortable at the hospital. As part of the medical staff, Marie-Annick sometimes shares her observations of the child's relationship with other children, with his or her parents and even with her authority as well as the information she receives from the family.

I truly enjoyed spending time with the patients making them feel happier in a place which can be frightening and stressful. I loved seeing them smile and laugh as we played monopoly, or as we talked and played ball if they could not leave their room. I also drew with a toddler who had special needs and talked to some of the patient's parents.

*Working with the nutritionist:*

I was very interested in seeing how the nutritionist worked with children who had weight problems and especially with children who having neurological problems who could not eat their food properly. Before my internship, I had never realized how much a nutritionist must be precise in calculating the caloric and mineral intake of her patients. I observed the nutritionist fill out two nutrition sheets and learnt about oil and milk substitutes which can be added to an individual's diet in order to increase this individual's intake in calories and protein.

*Despite their extensive and fundamental work to ensure the hospital's harmony, the following professionals are still sometimes unappreciated and unvalued:*

At the hospital, I observed the maintenance staff who cleans the floor, empties the garbage, serves the food and bathes the children. On other floors like that of surgery, separate people clean the children and the hospital due to the extremely strict hygiene rules. It is important to appreciate the role of the maintenance staff especially at the neurological sector who not only do their job but also have daily contact with the patients. These people are of paramount importance to the proper functioning of the hospital.

**Conclusion:**

Even though working at the hospital is very rewarding in that there is a true closeness and friendship which can be created by a patient and a professional, it must be very difficult to diagnose children with diseases and have to be the first to tell their families the bad news. Communicating this information must not only be hard to formulate but also unpleasant to give as even though the doctor might not show it, he or she could feel empathy for the patient and could also be upset.

To conclude, this internship has been a wonderful experience. I have learnt a lot about the human body, different diseases as well as participated in activities and carried out different tasks which have let me understand the functioning of the hospital. I am glad I was able to help families and workers. It was very interesting and invigorating to help and learn more about others. In addition, I have realized that this internship has enabled me to learn more about myself and has allowed me to set myself new goals.

I will go back and visit the hospital when my brother goes for check-ups and treatments. I can't wait to see the patient's smile. This internship has also helped me pictured myself working as a clinical psychologist, a social worker or a teacher. Perhaps I will work in a hospital setting for my career.

What a wonderful learning experience! Marielle saw so many different people at work in a hospital for children with disabilities. She observed teachers, doctors, social workers, nurses, nutritionists, psychologists and nursing assistants busy working with the children and their families. There were so many interesting careers to choose from! Someday, Marielle might find herself as a psychologist, social worker or teacher helping children with disabilities just like her brother! If you think you might be interested in some type of work related to your brother's or sister's special medical or learning needs, look around, like Marielle did, for an opportunity to volunteer for a school, agency or hospital. Thanks to your brother or sister, perhaps you'll find that there is a world of possibilities out there for you! Thank you Marielle, for sharing your experiences with us!



## **SPECIAL DEFINITIONS:**

### **DOWN SYNDROME (written by Kelly King, age 12):**



Many children in America do not know what Down syndrome is. Down syndrome is a condition that affects children physically and mentally. It is a disability like autism, except scientists have found out what causes it. It is caused by an extra chromosome that people with Down syndrome are born with. This can

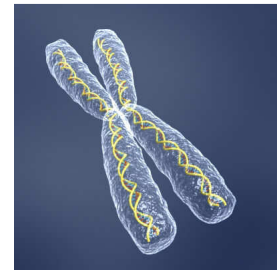
cause the child to learn slower and have some physical disabilities. The kinds of disabilities and how fast they learn can range depending on the child.

Since my brother, Jason, was born with Down syndrome, we do things in my house to help him more. Although Jason is 4 years old, he doesn't talk yet so we use sign language to communicate to him in the house. We use American Sign Language (ASL) which is a very interesting way of communicating. Most of the signs are based on the letters that they start with. It was difficult to learn sign language, but we have gotten used to it.

Due to Jason's special needs, he has to go to therapy. Sometimes when he goes with my mom, I have to stay home alone. He throws tantrums when he doesn't get what he wants and it is hard for him to communicate with me and my family. Even though he can be bothersome, just like any other brother or sister, I still love him.

Some other things about Jason are that he can get upset when he is in a really loud place. His ears are really sensitive and he always holds his ears when we're at a noisy place. I'm writing this article to inform students of Down syndrome and to let you know what it is. I hope that now you know more about Down syndrome, you will know what children are going through when you see them.

(Great job, Kelly! Thanks for sharing your article with *Sibling Forum!*)



## LIBRARY CORNER:

Rather than going to the library for books, why not visit the library, movie theater, video store, or your TV "On-Demand" movies for a video or two about someone with a disability? You will probably enjoy the movie, and learn something too! Here are a few to look for.....

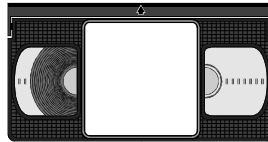
**The Memory Keeper's Daughter:** This made-for-TV movie is based on the book by the same name. It is about the experiences of two families: the one who gave their child with Down syndrome up for adoption in the 1950's, and the family that



adopted the child. It's a movie to watch and appreciate with your parents!

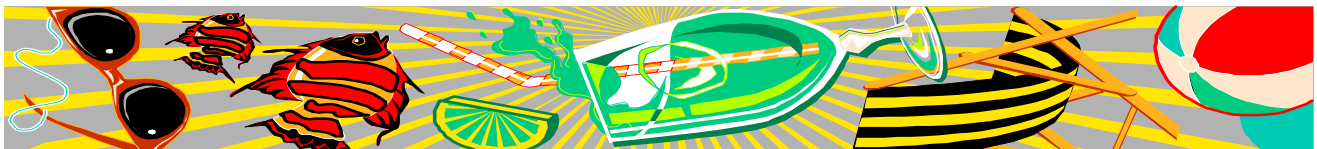
**Praying with Lior:** This is a movie about a boy with Down syndrome who loves to pray. He is studying for his bar mitzvah, and family members share their experiences with Lior. Visit the website to watch a trailer and to get more information at [www.prayingwithlior.com](http://www.prayingwithlior.com).

**The Ringer:** Rent the video or check movie listings on TV for your chance to see this comedy about a man who pretends to have a disability so he can compete and win in the Special Olympics. The great thing about this movie is that many people with disabilities are the actors!



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This issue of *Sibling Forum* featured an article by Marielle Coutrix from Paris, France, and Kelly King from Marlboro, NJ. Both girls shared information on their experiences and things they have learned because of their brothers who have disabilities. Do you have a story or interesting experience you'd like to share? You can send something to be published in *Sibling Forum* at any time! Simply e-mail to [slevine@frainc.org](mailto:slevine@frainc.org), or mail to Family Resource Associates, Inc., 35 Haddon Ave., Shrewsbury, NJ 07702. But if sending in an article or story is too much work, just send in your answers to the "Quick Questions" below. We'll print all the answers with or without your names attached (as you prefer) in the next issue! Again, e-

mail or mail your answers back! If you e-mail, just number and list your answers, and add your name!

1.) Have you done any volunteer work with kids with disabilities? If yes, where, when and what???

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2.) If you answered "no" to the question above, would you like to do something one day? If so, what would you want to do?

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3.) Do you think you'd like to have a job working with children or adults with disabilities one day? \_\_\_\_\_ If yes, what would you like to do?

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(If you're stuck for ideas, check out Marielle's article again)

4.) Have you had a chance to visit your brother or sister at his or her school or recreation program? If yes, what did you see and what did you think?

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5.) What's the first thing you think about when you see another child with a disability out at the mall, the beach, or at a fair?

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6.) What's the most important thing you do to help your brother or sister who has a disability?

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7.) Do you have any ideas for articles or information you'd like to see in a future issue of Sibling Forum?

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8.) Your name \_\_\_\_\_ Age \_\_\_\_\_

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

Disability \_\_\_\_\_

Do you want your name included in the next issues of *Sibling Forum*?

Yes \_\_\_\_\_ No \_\_\_\_\_

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

Thanks for reading *Sibling Forum*! Have a great summer!

<p style="text-align: center;">"Sibling Forum" A Newsletter for Preteens &amp; 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 <a href="http://www.frainc.org">www.frainc.org</a>                              <a href="http://www.techconnection.org">www.techconnection.org</a> (No part of this newsletter may be reprinted without permission of Family Resource Assoc., Inc.)</p>
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