

SIBLING FORUM

Fall, 2009

FROM THE EDITOR:

Welcome to another issue of *Sibling Forum*, the newsletter written just for teens and preteens who have a brother or a sister with a disability. Life with a difference in the family can be interesting, and this newsletter has tried to give you support with your own family situation.

This issue will be the last issue of *Sibling Forum*. I started writing this newsletter around 1980.....almost 30 years ago! So many wonderful brothers and sisters just like you have written to talk about their siblings who have a disability. I think all our readers learned from the stories we shared, and from the information we provided to help understand feelings, learn about differences, and discuss some of the difficulties that go along with living with a disability in the family.

Thank you for being part of the *Sibling Forum* experience. Keep asking questions, educating yourself, and helping others understand your sibling and the world of disabilities. I've enjoyed spending this time with you! I can be reached by e-mail if I can answer any questions for you (slevine@frainc.org). Please check out "The Forum" at the end of this newsletter for other places you can go to learn more about disabilities, and connect with other siblings as well.

Susan Levine

Editor



My Brother Ryan

By Lindsey Conlan



My name is Lindsey and I am 13 years old and I have two brothers. My youngest brother is 6 years old and has Down syndrome. When he was born my parents told us that it might take longer for him to meet certain milestones but that that was just fine. Now I understand the causes and effects of Down Syndrome even more. I know now that you

can't stereotype all people with Down syndrome as the same just as you can't stereotype all girls as the same. We may all have similar characteristics, but we are all still individuals.

While Ryan is a very healthy and happy boy with a great capacity to learn, I still have my occasional moments where I wish things weren't as challenging for him. For example, he struggles with his speech and math. On the other hand, he has made so much progress in the last two years with his speech that we can tell he will be a real talker some day. It will just take practice, practice, practice. I guess that is a very good lesson for the rest of us: do not give up no matter how hard the goal seems. Ryan is an adorable, friendly, active, and music-loving little kindergartener. My friends love coming over to see and play with Ryan because he is so smiley and loving. One friend in particular, Megan, is very interested in learning sign language from Ryan, my mom, and me. We learned a lot of American Sign Language and used it paired with speech to help Ryan communicate before he could speak much. It really worked and now Ryan is at the point where he is dropping his signs for words instead. We still think it is good for Ryan to know his signs, so that we can prompt his speech with them. If he keeps it up, who knows, maybe someday he could help young children with speech delays to learn sign language.



Ryan loves to sing and dance to music. He also likes to play his toy instruments for fun. I hope that he will learn to play an instrument such as the piano, for which he is taking lessons right now.



Now that you know a little bit about Ryan, I'll tell you a little about how his condition affects me. First of all I believe that it has had a very positive effect on my life in many ways. I have learned to respect and appreciate the differences in people by having a brother who is differently-abled and by participating in Buddy Walks (a special program supported by the National Down Syndrome Society designed to educate others in the community about Down syndrome) and other events.

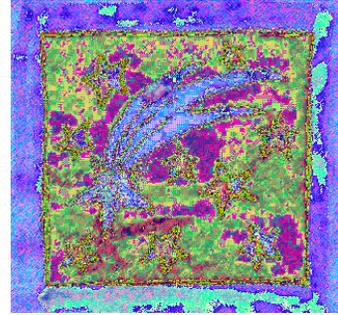


I have enjoyed helping out at the FRA Dance Program and I found it fun to learn sign language. On the other hand, going on vacation can be a little more difficult with Ryan because he is a runner. What I mean is that if he sees somewhere he wants to go he goes right to it, and fast. My mom normally does most of the running with him in order to keep him safe. In general he just loves running; he runs up and down the block and up and down the beach.

Therefore I would like to help him get involved in cross country and track (these are sports that I am involved in and love too!). That brings me to one of my goals for him. I hope that he will always stay active and fit. Perhaps he will be in the Special Olympics!

I would like to see him go for either community college or vocational school so that he can be trained to learn rewarding job skills. Hopefully he can get a decent job and work with kind, respectful people. Because he loves music, he might be able to work in a music store some day! With what Ryan can do now, I'm sure that he could handle living in an apartment or condo with his dog and hopefully a wife, as long as someone checks up on him regularly. I do think he will need help with things such as

bills and money things. In Ryan's spare time (besides spending time with my family) I imagine him doing volunteer work to help people with special needs in some way. I would like to live close to Ryan so I could visit him and check on him often. I'd want him to come with me places that he couldn't go to himself and have him to my house a lot too. These may be big goals for Ryan, but if you aim for the moon you'll always land among stars.



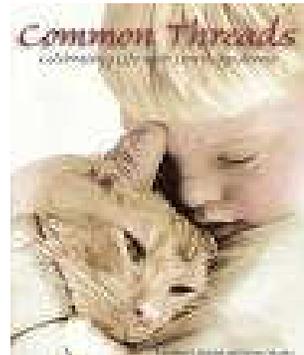
FOCUS ON FEELINGS:

Lindsey has learned so much from her brother, Ryan. Without Ryan, Lindsey might not have any experience with disabilities at all! Now she knows about sign language, Down syndrome and other disabilities too. Lindsey appreciates how hard Ryan works to learn things, and she wishes things were often easier for him. But Ryan shows her that hard work pays off! You may have learned a similar lesson from watching your brother or sister's struggles.

Lindsey has thought a lot about the future, and what her role might be with Ryan some day. When you have a sibling with a disability, you often have questions about the future. Thankfully, parents usually plan ahead and have their own vision for their child's future. They may even have something called a "Letter of Intent" which explains their hopes for their child with a disability, and maybe even outlines where and with whom they would live. Parents often begin saving money for their children's college education. For their children who are unable to go to college, they save for housing and care requirements. If you are worried about the future for your sibling, and how you might be asked to help, talk to your parents! You might be relieved to know that they have some things arranged, and that you and your other siblings won't have to handle everything! If your parents don't have some plans in mind, perhaps talking about this as a family will help them begin to work on their vision for the future. And that will help everyone in the years to come.

LIBRARY CORNER:

COMMON THREADS: CELEBRATING LIFE WITH DOWN SYNDROME by Cynthia S. Kidder and Brian Skotko, Published by Band of Angels Press, Rochester Hills, MI 48306.



Common Threads is a book for the whole family to read and enjoy. It is filled with beautiful black and white photos of children with Down syndrome with their families and friends. There are quotes and stories about the accomplishments of people with Down syndrome. You'll read about children who are artists and musicians and community volunteers. There is a story of a boy with Down syndrome who is a black belt in a form of karate. You'll also read about a boy who is an Eagle Scout. Several of the children are involved in fund raising activities. Another teen gives speeches to his high school football team to rally them before they go out on the field! One of the authors, Brian Skotko, does sibling programs for teens with Down syndrome. He has a story in the book about his sister, Kristin, who has Down syndrome. Kristin gets into a dance contest with Brian as her partner! Because Kristin loves to dance and perform, she thoroughly enjoys the moment, and much to the surprise of her brother, they win the contest! Brian says, "In that single night, Kristin taught me never to be afraid of the unknown....She didn't care what others thought. She didn't care about messing up. She only cared about fulfilling a dream. For that, she will always be my hero."



SPECIAL DEFINITIONS:

GENETIC COUNSELING:

Parents of a child with an unusual disability like hydrocephalus, or a chromosome abnormality such as Down syndrome may go to a particular doctor called a genetic counselor. (You might remember that chromosomes contain genes, the materials in our bodies that determines how we look, how healthy we may be and how we will grow.) The genetic counselor can help to diagnose the problem and can also give

information about the possibility of the problem occurring in future children or grandchildren.

Genetic counselors generally take a family history that includes any unusual illnesses, health problems or disabilities in the family backgrounds of both the mother and the father. They gain information as far back as it is available on siblings, aunts and uncles, grandparents, great-grandparents, etc. The genetic counselor also examines the cause of the disability in the child they are examining. Blood tests on parents and all children in the family, chromosome studies, X-rays etc may also be done as needed to aid in diagnosis. Using all this information, the counselor can make informed judgments about the chances of the disabling condition occurring again, even if a true diagnosis cannot be made.

If your parents have gone to a genetic counselor, they can probably tell you what your chances might be of some day having a child with a disability like your sibling's. That can be important information for you to know. Genetic counseling centers are located in most major hospitals particularly in large cities. Names of genetic counselors can be obtained from family doctors, pediatricians or the March of Dimes in your area.

SPINA BIFIDA

Spina bifida is a birth defect that occurs early in the development of the fetus. For an unknown reason the spine does not fully close when the baby is developing, leaving exposed the nerves and the fluid which runs through the spine. The baby may be born with an open wound on the back or the opening may be covered by a sac of skin. The opening can occur at any point along the spine or backbone.



Although the opening can be surgically closed, the deformity leads to other problems, which can be mild or severe. Often the child has limited or no feeling in his legs and lower abdomen because the nerves are damaged. Therefore, walking and crawling can be difficult and walkers, braces and crutches may become necessary. Due to the lack of feeling in the lower body, the child may not have bladder or bowel control so toilet training becomes difficult or impossible. Some

children need medications to help regulate bowel movements. There can be problems with the kidneys too.

Children with spina bifida can function on many different levels, ranging from average intelligence and learning ability to severe learning and physical problems. Some children are able to walk while others may need to use a wheelchair to get around. For more information on spina bifida visit www.spinabifidaassociation.org.



THE FORUM:

As Sibling Forum comes to an end, I want to be sure you have ideas for ways to continue to connect with other students who have brothers and sisters with disabilities. Here are some thoughts:

- You can find several of the back issues of *Sibling Forum* on this website: www.frainc.org. When you visit, click on "family support", and then "sibling support", and then on "newsletters" to see the issues you can download.
- Be sure to visit your local library for books about disabilities and brothers and sisters. You can also look for books on www.amazon.com and search "books for children" and "disabilities").
- If your brother or sister has a diagnosis, you can find disability organizations on line connected with his or her disability. For example, if your sibling has Down syndrome, visit www.ndss.org or www.ndscenter.org. If your sibling has cerebral palsy visit www.ucp.org. If your sibling has a cognitive impairment or a significant developmental learning disability, visit

www.thearc.org. And for autism, look for www.nationalautismcenter.org or www.autism-society.org.

- To find a sibling group near you, go to www.siblingsupport.org.

Thanks again for your support of Sibling Forum!

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