

# Reaching Out

Publication of FRIENDS: The Association of Young People Who Stutter

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## Connections: The St. Louis Youth Day

by Susan Castleberry

**O**ur St. Louis Youth Day was all about connections.

A nine-year-old boy thanked his mother for bringing him, as he told the group he had made the choice to come to the workshop instead of going to his friend's party.

A twelve-year-old girl said that this had been the best day of her life.

One adult who stutters told the group that perhaps his life would have been different if he had been to such a day when he was younger.

One of the adult facilitators, who does not stutter, said she knows what it is like to not be in control because she has an eating disorder and can't always control what or how she eats.

One of the fathers, whose son is three and a half, said that he understands now that it will be all right if his son continues to stutter, but, he asked, could I tell him how to be a better listener?

One by one, people said that they hoped we could do this again.

What a lucky group of parents and

speech-language pathologists who heard Bill Murphy's message that we can help kids understand it is ok to stutter! Bill discussed empowerment tools for children: 1. Helping children with appropriate ways to talk about their stuttering; 2. Helping children with appropriate ways to motorically manage their speech; and 3. Helping children to think appropriate, self-esteem building messages.

Mary Anne Posnanski started the kid's day off with singing and noise-making group activities that got everyone in on the action. At the same time, Stacey MacDonald and Ed Weiss facilitated a discussion group for adults and teens. I wasn't allowed in, but I can tell you that Stacey was moved to tears on more than one occasion.

What a lucky group of children who had the fun of receiving bug stickers, life-size ladybugs and ants that stuck securely to arms and faces, for each time they stuttered voluntarily. Some of the little boys looked as though they had chicken pox!

And, best of all, the kids and adult speech-language pathologists walked to Wendy's, beautifully bug-covered, and ordered treats, stuttering all the way. Now that is feeling the freedom to stutter. Lynne Shields and Lee were al-

most as bug-covered as the kids.

While the buggy activities were going on, the older kids worked on the wonderful theme of puzzles with Connie Dugan and Bill. They explored the puzzlement of stuttering and other things that can be fun to figure out. It wasn't much of a puzzle to see new friendships being made as kids worked together and shared common experiences.

Bonnie McKenzie facilitated a discussion panel of adults who stutter. Their stories enlightened the audience of parents and speech-language pathologists who asked wonderful questions. More than one "fluenter" came to tell me how brave they thought this diverse group of adults was.

The bravery continued during the closing "open mic" session, when anyone who wanted could speak before the entire group.

Light was shed on relationships of all kinds. A brother spoke about his sister. A wife spoke about her husband. A father spoke about his son. A speech-language pathologist spoke about her client. An adult who stutters spoke about her life. A child spoke just to say "thank you."

I felt privileged to be part of the day.

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# Understanding Worry

by Denise Bartos

Everybody worries. It is a universal emotion. You can worry about whatever you like, justify it however you like, and then live with it. We cannot choose those events that we worry about. They weave in and out of our daily lives without warning. I knew I had to transfer the draining energy of my worry into something positive.

Anyone who has children understands worry. You worry about their health, well-being and self-esteem. All my fears came to life when I first began to hear my daughter stutter. The day I heard my daughter repeating one syllable

five to ten times, my worries became real. An otherwise highly articulate child became hesitant when she tried to express herself.

When her stuttering was at its worst, she would simply shrug, put her head down and stop trying. My daughter did not want to speak during these frustrating situations.

At that point, I knew that I had to act. A lot of people are afraid of doctors and experts. Having a child evaluated by these experts was, again, a worry. Like all parents I only want the best for my child, and I knew that I had to take advantage of the opportunities

available. I had to be my child's best advocate.

I was fearful of meeting with doctors and therapists. I was afraid of my child being labeled. How can I let my child live with that stigma? I had a choice to make. I could be afraid and suspicious of the services that were available to us, or I could take control of my worries.

I am happy and proud to say that I truly believe my husband and I made the right choices and put our faith in a system that has been successful. Twenty months of therapy have changed my daughter's life. She is much more capable of expressing herself without hesitation and shame. She is happier, friendlier and more confident. Isn't that what every mother wants?

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## Chris Never Sits It Out: We Love Him So Much

by Janice Albrecht

(This is from Listen With Your Heart. It was originally published in Staff, the publication of Aaron's Associates.)

I am the mother of a ten-year-old boy who has stuttered since he was three years old. His name is Chris. I guess I am writing because I need to talk about it, and there are no other people who seem to really understand what it's like to know and love someone with this problem.

For almost eight years my husband and I have watched our son struggle to express himself. He has been to many specialists and has speech trouble since the age of five. He has a wonderful speech therapist in school who sees him four times a week.

All of Chris' fluency tests place him in the "very severe" category. Seventy-five to eighty percent of Chris' speaking

time is dysfluent. He is bright, affectionate, and funny. He has so many things he wants to talk about. He is in the fifth grade, and I know that as hard as it has been for him, it is going to get harder. He is heading into the social years (girls, dances, parties). He wants to call a girl that he likes but has not. I know that I shouldn't think too far into the future, but it's hard not to. He is very special.

People have said that a disorder like this will make him a stronger person, but I don't want my child to have to suffer like this to be strong. The feeling of helplessness is overwhelming sometimes, although seeing how well Chris has coped, makes it easier for us. We need to do everything we can to help Chris continue to cope the way he has and never stop letting him know what a great kid he is and how much we love him.

Chris has a little brother (age 4) who is just becoming aware of the dysfluency, and an older brother (age 18)

who has always shown great patience and understanding. Our lives are very hectic; my husband and I work full-time, and Chris and his older brother are involved in sports year-round. One of the things I have tried to do (unsuccessfully) is keep things calm and easy-going in the house. This seems impossible most of the time, but as hectic as things get, Chris knows that we always have time to listen to what he has to say, no matter how long it takes him to say it. Chris has close friends on our block who have known him since he was four years old, and many friends in school.

In school, he raises his hand to answer questions, reads out loud, and has had to give presentations in front of the class. I try to think positively about what is happening. I know that it's good that he continues to volunteer to answer and speak, but it breaks my heart because I know not a day goes by that he isn't teased or mimicked. I also know that ever second that he is blocking and strug-

gling must feel like an eternity to him. How many times do people look away when he is talking to them because it is difficult to watch him struggle? How much longer will he want to talk to people before he gives up? How do I help him? I love him so much.

I have read everything I can get my hands on about stuttering since Chris began experiencing it. I know I'm like other parents who hope that one day he will wake up and it will be gone. I wish I didn't feel so helpless. You never want your child to struggle in anything they do, and here he struggles on almost every word he wants to say. I know how important it is to keep him feeling good about himself. That is what we concentrate on most.

He recently had to do a debate with another student in front of the class. I asked him how he felt about it, and for the first time he admitted to me that he was embarrassed and uncomfortable about doing it. (He was having an especially dysfluent couple of weeks.) My first reaction was to call the teacher and tell her that I did not want him to do it. She had given him the option of not speaking in front of the class since the beginning of the school year.

Chris never sits out. I told him that once in a while, if he is having more difficulty than usual, and he really didn't feel good about doing something, that it would be okay to take a break and let that challenge go by. He said, "No." So we practiced what he wanted to say, and the next day he got up in front of the class. He got through it, but with much difficulty. After school, we talked about how he felt. He said that he did have a lot of trouble, and he was relieved it was over.

Times like that it is hard to know what to say. I told him how proud I was of him; that a lot of other people would not have been able to do what he did; that I wanted him to think about how good it is that he is talking — to concen-

trate on the fact that he is saying things, not how he is saying them; that he should be proud of himself for that; and that it takes a very strong person to go ahead and do what he did in the face of the fear he was feeling.

Lately, when kids make fun of him, he ignores them — for a while. I guess they keep it up to see what he is going to do about it. I will say he is very patient about it, but when he has taken more that he can stand, he hits them. I do not condone this, but I am not sure I would not handle it the same way if I were he. I know that this is not the best thing to do, and I have told him so, but in each case the child has not bothered him again. Obviously, he only does this when the teasing is relentless; otherwise, he would be fighting constantly.

In one case, a child was not only teasing him in school but calling our house and tormenting him over the phone. I heard Chris asking him, "Why are you doing this? Stop calling me!" I picked up the phone and listened to Chris plead with this boy. While Chris was pleading, this boy was imitating him. I wanted to get in my car and drive over and strangle the kid myself; but, instead, I told the boy to never call our house again. He called a couple of more times anyway.

One day in school, Chris beat him up, and I did not blame him. I couldn't get through to the boy, who obviously had problems of his own. The teachers told him he was to stay away from Chris and not speak to him. He stopped calling our house and stopped teasing, too.

Talking about the problems and writing things down really does help. You go through every day, trying to keep feeling positive. I know that I have to convey positive feelings to Chris, but many times I wonder how I can help him feel positive when I feel so helpless and discouraged myself.

Your publication (Staff) is very helpful to us. It helps to know there are other people who are experiencing some of the same feelings. When I first got Staff for Chris, he didn't show a lot of interest. After a while, he started to read it more and more. He even wrote to you and you published his letter on the front page. I cannot tell you how much that meant to him. He took it to school this year and showed his teachers. We saw this as a big step for Chris. He never really wanted to talk about his problem or bring any added attention to it. To have shared this with his teachers and a couple of friends, showed that Chris was accepting his problem in a positive way. He also wrote letters to two pen-pals.

Dear Lee,

My presentation went great. The kids asked a lot of questions. Thank you for all the materials for it. I don't think I stuttered very much. I felt nervous, but I think the kids knew that.

I did not feel as nervous as if I did the presentation in another classroom.

Also, are you a male or a female. Please let me know?

Sincerely,

Maureen Rowe,  
Hillsboro, NH

Ed. Note: Lee is a female for those who did not know.

# Hit Back in Ink

by John Ahlback

**A**s I was retyping Mrs. Albrecht's moving confession about her son Chris, I got an idea, and I would like to know what you think of it.

When people describe ways to counteract bullying and teasing, it often involves coming up with verbal comebacks designed to put off, shame, or make light of a tormentor's attacks. We who stutter, however, are in a unique position. This method of defusing the situation and showing strength and poise calls upon us to use the most fragile part of ourselves — and the very thing being ridiculed. In that situation, our natural tendency is to withdraw into silence, and even if we could find the nerve to strike back verbally, our "zingers" might lose their effectiveness if they come out in a dysfluent manner. It can be like blocking on the punch line of a joke.

Making the attacker afraid of us by physically striking back the way Chris did is . . . well, it strikes me as very understandable and fair enough in extreme cases when no other option has worked. Herman Melville has his tragic, stuttering hero, Billy Budd, finally lash out when he is driven beyond his tolerance by his tormentor. There is not much that is constructive in violence though, and, again, some of us do not have the physical stature nor demeanor to make use of this option anyway.

No, we want to take the high road if at all possible; we want to show that we are indeed "bigger" than our bullies, "bigger" in a real sense, not a superficial one. I have said the best way to deal with those who torment us is to go public ourselves by giving a class presentation on our stuttering. By doing this we take responsibility for our stuttering, teach others about the disorder, and make public what makes us different, therefore taking a lot of the "teaser's" fun away.

("Hey, Charlie, we know Paul stutters. He told us why he does it and how it feels. He has nothing to hide. You've obviously got the problem, not he.")

But, hey, many kids are not ready for that, especially if the stuttering is severe. Chris was not. He was moving towards it by bringing his article in to show his teachers, but he was not ready to talk to the class yet. Heck, I wasn't ready for that until I was in college.

So I got another idea: publish a response. Many schools have a newspaper which would be an ideal public forum for "coming out" against your teasers and for all victims of ridicule. Parents and SLP's could help the young person write a very effective piece which could accomplish all that a class presentation does and reach a potentially wider audience at the same time. One could describe the kind of teasing you have received — without using any

names — and have time and space to create some good, constructive "zingers" to deflect the teasing. You could use the space to ask for tolerance for all those who are different and subject to ridicule. I trust that teachers in the school would respond well to this theme and probably read your letter to their class.

And challenge your tormentor to write a response to your article. Challenge him to make his remarks public if he or she thinks they are so funny. This allows you to choose the field of battle, and challenges them to go public — something which all the studies say bullies are not good at — or pack it in. I suspect their writing skills and grammar are not be too refined either.

If your school does not have a newspaper, there are other forums you could use to get a written reflection out there . . . or you could volunteer to begin a school newspaper yourself. What do you think?