

The CJD SO News

VOLUME 3, ISSUE 12

MARCH 15, 2008

"A Brighter Tomorrow"

President:

Jean Bates
452-2555

Vice President:

Rick Bauersfeld
874-2038

Secretary:

Brenda Harms
378-2388

Treasurer:

Steve Newbold
668-0928

Newsletter & Buddy Walk:

Dawn Mattia
750-9164

Gala & Open:

Bill Crutcher
452-5556

Social Chair:

Judy Bates
726-1145

Sibs, the Good Life

By Oliver Moll, age 15

Reprinted from Down Syndrome News, Volume 30 #4

Growing up with a brother with a disability has made me realize how good my life is, but not for the reasons you might think. My older brother Francis, who is 16, has Down syndrome and many complex needs. He doesn't talk, he doesn't read, and he isn't potty trained. Francis needs help dressing, bathing, and feeding himself. He is supervised all of the time and has a few ongoing medical problems that my parents are on top of. Despite all of this, we would not change a hair on his head. Francis is the greatest guy I know.

As a young child, about four years ago, I realized that my brother was different, but never thought anything of it. I always viewed him as my older brother. As I got older, I realized just how different he was—even from most other people with disabilities—yet it didn't seem at all strange to me. I never asked any questions about my brother's condition, because, it just never occurred to me to have questions.

In second grade my brother and I were practicing to receive our First Holy Communion. When my mother asked the class if anyone had questions about my brother, the whole church was filled with little raised hands. That's when it dawned on me that I was witness to a different way of life. My experience as Francis' brother was rarer than a Mickey Mantle rookie year baseball

card and he was right under my nose the whole time. I always felt special for having Francis as my older brother. I didn't know anybody who had a brother with DS but me.

Reading "Down Syndrome News", I see many highlights of people with DS who have minimal support needs, and I'm inspired by their accomplishments. I felt compelled, however, to highlight the intangible accomplishments of my brother who has complex needs. To begin with, he's gentle, funny, happy and patient. His complex needs have given my family the unique ability to see life in a different way. We are "unembarassable," don't sweat the small stuff, find humor in all of our shortcomings and we're accustomed to helping one another without resentment.

People ask me if I feel bad for my brother, or if I would want him to be normal. No. My brother has an amazing quality of being able to bring out the best in even the toughest people. If only we were as nice to one another as people are to Francis, the world would be a much better place. My brother, sister, and I often kid around that we're supposedly "normal," and there is something wrong with him? When, in fact, he is the best of the four of us.

When I think about my brother's future, I know it will involve me. I'm not afraid of it; I embrace it as an opportunity to continue to have my brother in my *Continued Pg2*

The Good Life, Continued from Page 1

life. I like reading "Down Syndrome News" because I love seeing other people with DS. It brings a smile to my face, seeing other people like Francis evolving, experimenting, and challenging themselves in the world. However, Francis' progress is measured in inches not miles and our family celebrates every inch of his progress as we would for the rest of us kids. I guess what strikes me is the definition of success. If your brother or sister with DS isn't a movie star or in a rock band or delivering newspapers, figure out what he or she is bringing to the table and celebrate that every day. While many people may strive to be more "normal," perhaps we should strive to be more like Francis.

Francis and I are more alike than we are different; it is just that the differences have huge practical implications. All things considered, I feel lucky to have him in my life just the way he is. No one can tell us what is going to happen with Francis, but by the same token, no one can tell me what is going to happen to me either. I guess that is just one more thing we have in common, my brother and me.

Literacy Program Meeting

On April 6th from 3-4 pm in the Parlor Room at the Calvary United Methodist Church Kelli Appel will be speaking to families involved with or interested in the Literacy Program. This is open to all families who are currently enrolled in the program and those that are interested in becoming enrolled or anyone who would just like to learn more about the program in general. Kelli will be talking about what they have been doing this semester in the program, how it is working and projections for the future. This meeting will be followed by the CIDSO Board Meeting.

Tips for Parents

Reprinted from Disability Solutions, Volume 2, Issue 3

Do not force siblings to help with your child with special needs. It needs to be a choice.

Talk with your children about what is happening with their sibling in a way they can understand. Be open and honest.

Allow and encourage siblings to express their feelings. Feelings of hate, jealousy, resentment and even depression are not uncommon.

Help each child, with or without a disability, explore and cultivate their own interests, outlets, and hobbies.

Invite siblings to be involved in the decisions-making process, including family decisions, IEP/IFSP meetings, medical concerns, and so on.

Reinforce positive behavior, advocacy, and compassion. Surround yourself with people who are positive. Encourage your children to do that too. Attitudes make a difference.

Celebrate each child's accomplishments.

Keep the challenges of parenting in perspective and try not to let them "swallow up" you or the siblings.

When you talk about plans, procedures or a new diagnosis, have children repeat what they are hearing to you. Reflective listening and repeating what is understood is a helpful tool.

Try to read your children's cues when they need extra attention. This may happen during stressful times when you, yourself, need extra attention. Tell you children without special needs to let you know, in a positive way, when they are feeling that they are not getting enough attention.

From Sibs to Parents

Give children equal responsibilities based on abilities.

Remember that being a sibling to someone with special needs is an ever-changing process.

Let kids be kids. Some teasing and fighting is part of a healthy family.

Don't put your head in the sand. You will not live forever. Things will not magically fall into place for your child after you are gone when no planning has taken place. Plans must be made.

The sooner you start the better. Update your plans for the future as your children grow or as circumstances change.

Treat each child as a special child whether or not they have a disability. All children need to be recognized as a special person.

Just keep trying. Your children will feel your efforts and find them very comforting.

Mark the Date:

April 6:

Literacy Program Meeting

April 6:

Board Meeting

September 29:

Buddy Walk

Don't Forget!

Applications for the Enrichment & Participation Fund can now be found online at CIDSO.org

Everyone is welcome to attend the CIDSO Board Meetings

If you are interested in joining the Buddy Walk Committee, please contact Dawn at 750-9164

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with your health care professional.