

The CIDSO News

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"A Brighter Tomorrow"

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826-5775

A New Step in My Journey

By Renée Schultz, Westhampton, MA

Maybe I'd become complacent or hopeless. Maybe I was just plain old worn out. Sometime in the last few years, I'd lost the buoyancy that kept me going for 24 years. Frankly, my husband and I were ready for a sabbatical after our son's heart surgery almost three years ago, the endless advocacy to have our son's needs met, and the challenges of having Ian move into a group home a little over a year ago. Friends, farther down the road than us, admitted that they, too, had had a period when they'd simply needed a break. So, I cut myself some slack and allowed time off from the endless pursuit of an answer to Ian's complex behavioral issues. Well, not a total break. We continued attending team meetings as Ian's behavior continued plummeting. We reconnected him with a previous therapist, who had been more helpful than anyone in acknowledging that Ian had complex psychiatric needs as well as cognitive and physical challenges. We attempted to let go a bit more as others helped in the care of our son.

So, you might ask, why did we attend the NDSC Convention in Boston? I heard from a friend that this year's convention was going to be held just a few hours from our home; and, coupled with the hope that Ian might benefit from being around other young adults with Down syndrome, I signed us up. I'd stopped my NDSC membership years ago, in part because I was simply tired of all those cheery success stories. Despite high expectations, big dreams and the help of numerous professionals, my son, Ian, seemed to be heading down a dark slippery slope.

I have great compassion for all of us —particularly parents with infants and young children—who need to have a hopeful vision for our sons' and daughters' lives. I was no different when my son was a baby and we pursued every possible avenue to help him. What parents don't want the best for their children? When Ian was young, I was fighting the outdated idea that children with DS were *trainable*, at best. We fought hard to make sure our son would learn to read, and that he'd be given the opportunity to be included with the other students in our small school community, in Boy Scouts and other recreational activities. And we succeeded! But when Ian became a young adult, the problem behaviors that had been a struggle when he was younger; suddenly escalated. New symptoms appeared. It seemed impossible that we'd ever unravel the complexity of Ian's issues.

At the convention, my husband and I were quick to attend the sharing meeting entitled, *Complex Needs, Mothers and Fathers*. Suddenly we realized that we weren't, in fact, alone. We came to recognize that despite the splash of success stories, many parents feel shame and isolation because our sons and daughters aren't what I've come to refer to as the *Super Stars of the Down Syndrome World*. In fact, there may be far

Continued on page 2

Movie Review: "Mr. Blue Sky"

Information from Kristy Colvin

This is a beautifully made film with well known actors such as Chaney Kley who is best known for his role as "Kyle Walsh" in the film "DARKNESS FALLS" "HOME IMPROVEMENTS", Side kick, Richard Karn and actress Ashley Wolfe whose last role Was in the film "JEWEL" with Farrah Fawcett.

Mr. Blue Sky is an unconventional love triangle between three childhood buddies; two girls, one born with Down syndrome and one boy, who all grow up fighting who they are inside, how they are perceived by society as a whole, and who they ultimately strive to become as individuals through the obstacles that are inherently present

This ground breaking film explores the romantic relationship of a woman born with Down syndrome and a "normal" male, as perceived by today's society. *Mr. Blue Sky* attempts to break-down society's barriers, much like "Guess Who's Coming To Dinner?" did in the 1960's, as it aims to "change lives" through "changing minds."

Mr. Blue Sky is a heart grabber that will ultimately change the way society views all people as "individuals" first and foremost.

Visit the website www.mrblueskymovie.com for more information. Not only by bringing hope to new families of children with Down syndrome and other developmental disabilities, but also, and maybe more importantly the message it will bring to the general society that just because someone has a disability, does not mean they can not lead a "normal", productive life!

Sign the 'guest book' on the website This will help the cast and crew know who wants this movie in their theater and will boost their ability to get it out world wide

My Journey....continued from page 1

more of us than I ever imagined struggling to unravel the challenging mysteries associated with our children.

I have to admit I was dubious that I'd get much from attending the NDSC Convention, except for the joy of helping my son be a bit more accepting of his disability (he'd still much prefer not to have DS). But, here it is barely two weeks later and I am writing to say thank you to all the hardworking people who have given so much of themselves to make the NDSC happen and to support the ongoing research that ultimately will better the lives of people with DS, and no doubt, their families. Since the convention, we have already discovered our son has celiac disease. Although we'd resisted acknowledging that he probably also has sleep apnea, we've signed him up for a sleep study. We've come to understand that the mental health issues of adults with DS are far more multi-layered than we'd known. (In one study, 21 of 22 adults with DS and behavioral issues had sleep apnea.) We don't have all the answers in addressing our son's complex needs, but learning from other parents and professionals has given me a boost to once again rally to meet both my son's needs and my own. For that, I say a big Thank You.

Renée Schultz is the mother of two children, Ian, 24, and Mia, 19. She is a marriage and family therapist in private practice and the co-author of The Mother-Daughter Project: How Mothers and Daughters Can Band Together, Beat the Odds, and Thrive Through Adolescence

Last Call for the Buddy Walk

Although pre-registration is over, it is never too late to join in on the fun. Join us at Carden Park, behind Priaireland School in Normal at 8:00 am to get signed up, grab a bite to eat, and check out the \$1 raffle. The walk will begin at 9:30 am followed by the raffle drawing. This is a great opportunity to show your support for CIDSO and the people in your life who are touched by Down syndrome.

Great Glasses

Having a hard time finding glasses that fit? Wish the frames you had would stay on your child's? Do your child's glasses look too big for his or her face? Check out www.specs4us.com. They make glasses specifically designed for people with Down syndrome.

Mark the Date:

September 11

Buddy Walk Pre-Registration Due

September 27:

Buddy Walk

October 13:

CIDSO Board Meeting

October 14:

CEC Bowling at ISU
7-8:30 pm

October 28:

CEC Bowling at ISU
7-8:30 pm

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.