

NADS NEWS



Grace Ramsburg

The Newsletter of the National Association for Down Syndrome

November, 2008

Perseverance Pays Off!

Congress Passes Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act

For almost three years, the Down syndrome community has worked with members of Congress to help pass a bill which would require that accurate, up-to-date information be provided to parents who receive a positive prenatal test result or post-natal diagnosis. The Down syndrome community has long felt the need for physicians and other healthcare professionals to provide more balanced information about Down syndrome to parents and to make sure they are connected to support services. Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS) cosponsored the Prenatally and Postnatally Diagnosed Conditions Awareness

Act to ensure just that. On September 23, 2008, the Senate passed the bill by unanimous consent, and it passed the House on September 25th.



The Down syndrome community has long felt the need for physicians and other healthcare professionals to provide more balanced information



The bill will make it more likely that parents will receive current information about life expectancy, development, and treatment options at the time they learn of their child's diagnosis and will therefore have a more

accurate picture of the possibilities for their child. The bill also recommends referrals to support services, information resources, parent support networks, and programs specific to Down syndrome or other conditions diagnosed before birth. The passage of this bill marks an important step forward. All parents have the right to balanced, accurate information, and this bill will help them receive it.

New Online Early Intervention Resource

A new website, www.brightertomorrow.org, has been established to address the needs of families for balanced, accurate information after they receive a diagnosis of Down syndrome for their child, whether before or after

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Special Needs Trust

The Single Biggest Blunder Parents Make After They Have a Special Needs Trust Drafted For Their Child with a Disability

By Attorney L. Mark Russell

You remember the purpose of a special needs trust, right?

It allows you to leave an inheritance to your child with a disability so your child will still remain eligible for needs-based government benefits such as SSI or Medicaid.

The money in the special needs trust is safe from the state seizing it for residential or health cost-of-care claims.

The money in the trust is generally safe from other commercial creditors if say your child with a disability bought something he or she couldn't afford.

The trustee (a relative, a friend, a bank) will manage the money for your child and also pay for things your child needs.

The special needs trust is the "heart and soul" of special needs planning.

Well, just because you went to the trouble and expense of having an attorney draft a special needs trust for your child doesn't mean you're out of the woods yet.

Here's the story: You can set up the perfect special needs trust but still blow it.

How?

By not paying attention to any asset you own that has a beneficiary designation such as life insurance, retirement plans, IRAs, or annuities.

Let's say you own a life insurance policy. You bought it years ago. You named your spouse as your first beneficiary to receive the money on your death and your children as the secondary beneficiaries.

What happens if you and your spouse die in a car crash? Or your spouse predeceases you? That's right, all your children (including your child with a disability) will receive an equal share outright completely destroying all the reasons you set up the special needs trust in the first place. Your child's share of the life insurance proceeds will bypass the special needs trust and go outright to your child unless the trust is named as beneficiary.

Here's what you should do right now: Let's say you bought your life insurance from the Real Good Life Insurance Company (I thought I'd better not name actual companies for this example). Call them or write them and say "Please send me written confirmation of the beneficiaries on my life insurance policy." You may be able to get this same informa-

tion online, as well.

Why should you do this?

Because even if you remember filling out the Change of Beneficiary form just like your attorney advised to make certain your child's inheritance will end up going into the protected special needs trust, want to know something scary?

Companies lose these records. Or, sometimes they have no record of ever receiving your Change of Beneficiary form.

The written confirmation of the beneficiary designation will also tell you if you have forgotten (easy to do) to fill out a new beneficiary form after you had the special needs trust drafted. Or, if you need to fix the beneficiary designation.

If the financial company's letter confirms you have the right beneficiary designation, then safely file that letter with your Will and trust. After your death, the trustee of the special needs trust will rely on it when contacting the financial company.

Whew!

All's well that ends well. ▲

For lots more information about how to safeguard the future of your child with a disability go to

www.LMARKRUSSELL.com

Reduced Fee Assistance for Estate Planning Available

Families in the Chicago metropolitan area who need to find an affordable attorney to set up a special needs trust for their child now have a place to turn for help. A group of local attorneys have volunteered to set up special needs trusts for NADS families at a reduced fee, based on the family's ability to pay and level of assets. In some cases, this service could be provided free of charge.

To find out more information, please contact Attorney Robert Hauser at 847-540-9938 or the NADS office at 773-327-5808.▲

Skimming the Surface

By Diane Compton

As I was flopping down a dock in flippers too big, I had no idea I was about to live a life-defining moment. Not a dramatic, make-or-break moment—there would be plenty of those to come. No, this moment, my first snorkeling trip, was more of a whisper, a small road sign easily missed. Honestly, my giraffe-like sprawl into the water and frantic silt-stirring treading as I defogged and vacuum-sealed my snorkeling mask felt more like embarrassment than enlightenment. In between gulps of salty water, I wondered what I had gotten myself into and why my new husband suggested this as fun. However, with my first glimpse underwater, my wondering instantly became wonderment. My awkward flippers suddenly became powerful and just the right size for exploring my new underwater world. A world I had unknowingly already been a part of, but could not see with my surface-skimming gaze. A world I had blindly stirred up and changed with my struggles to remain vertical.

From that moment on, I was hooked like a fishing enthusiast after the 6 foot barracuda we saw relaxing in shallow waters. Snorkeling was not the most convenient hobby for landlocked Midwesterners, so my husband and I spent our first years of marriage traveling to snorkel.

We visited Hawaii, where the ocean taught me that if I relaxed into the big waves, they would support and guide me in a new direction before leaving with a gentle crest. If, however, I became tense, trying to return to the false-security of vertical, the ocean fought me, often tossing me into rocks and stinging creatures of various sorts.

In the Bahamas, I learned that even if required by law and enforced by officials in patrol boats, it is extreme-



ly difficult to snorkel with a life jacket. While the life jacket arguably saved me from drowning—I did survive the trip after all—it forced me to remain vertical. The ocean tossed me about like a cork, as I struggled to keep my head underwater to catch glimpses of the deeper and beautiful world that seemed to elude me.

Our last trip before children was to Australia, where we explored the Great Barrier Reef. All the other reefs we had visited were contained, the end of the reef easily in sight. We were humbled as we became part of an underwater world that seemingly went on forever. We would need months, not hours to explore fish, corals, and plants that only existed in this far corner of our world.

However, as our sense of adventure and wonderment became fulfilled through starting a family, our trips to the sea were taken via memories not airplanes. I did use snorkeling as my focal point, my happy place, when our first child was born. I relaxed into the waves, waiting for the gentle crest for 19 hours—it was a very big ocean. Our second child arrived via C-section, the life jacket of birth.

With children onboard, there was not a lot of time or money for snorkeling. The ocean's call was overshadowed by sleepless nights and joyful giggles. It was a good life, filled with the comforts of success and glorious typicalness. I had a

good career, a great marriage, two amazing children—even strangers would comment on how well-behaved our children were and would call us the perfect family. Of course, I knew we were far from perfect—they hadn't watched us get ready for school after all—yet their comments gave me pride, like a manager taking credit for a team performance review. For the first time in my life, I was in control—or so I thought.

Our third child was an unexpected blessing we were told we couldn't have. Even before we had fully accepted the idea of three, we had our first of many "but wait, there's more," doctor appointments. We went from serious complications to worse. We were strongly encouraged to do the fair thing by aborting our daughter or refusing medical treatment so that she could die peacefully before birth. Genetic counselors, social workers, doctors, and nurses used that word, fair, over and over again—was it fair to our other children to bring a baby with needs into the home—was it fair to our marriage, our budget—was it fair to society to bring a child who will require special services and funds her whole life?

We prayed. We cried. We questioned. In the end, we knew this was our child, our children's sister, and

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Local Support Groups

LAKE COUNTY

Down Syndrome Development Council
www.theddc.org
Patrick Collins: (847) 265-8482
rjohncol@comcast.net
Hispanic: Belinda Hidalgo: (847) 838-4398

NORTHWEST SUBURBS

UPS for DOWNS
www.upsfordowns.org
Sandy Pazerunas: (847) 705-0715
Mike Reninger: (847) 301-0702, (847) 895-2100
Polish: Krystyna Dabrowski: (847) 962-4820
Hispanic: Blanco & Carlos Santillan: (847) 963-1320

WESTERN SUBURBS

West Suburban Support Group for Down Syndrome
www.wspsg.com
Nancy Goodfellow (630) 305-4715

McHENRY COUNTY

Family Ideas Network for Down Syndrome
Mary Fisher: (815) 444-8672
leahsmom0127@hotmail.com

SOUTHWEST SUBURBAN

Down Syndrome Support
www.dssupport.net
Jennifer Paganessi: (815) 272-1068
jen@jl-design.com
Hispanic: Monica Archbold: (630) 518-6310

Down in the Southland

Juliette De Nova: (708) 614-6118
www.freewebs.com/downinthesouthland

FOX VALLEY AREA

Carrie Holman: (630) 208-5075
genevacheese@sbcglobal.net

SOUTH SUBURBS

Carol Hill: (773) 208-3058
contact@justchill.org

CHICAGO

South Side
Carol Hill: (773) 208-3058

NORTHWEST INDIANA

Down Syndrome Association of Northwest Indiana
(219) 838-3656

ROCKFORD AREA

Patti Hobbs: (815) 965-5745 x.218
phobbs@il-rk.easterseals.com

Aging and Down Syndrome

A group of scientists from a number of research institutions, including Columbia University Medical Center, the Kennedy Krieger Institute at Johns Hopkins, and the New York State Institute for Basic Research in Developmental Disabilities, have been researching aging in adults with Down syndrome through a twenty year longitudinal study that includes hundreds of participants. Their study is an attempt to gather more data about the aging process in that population. Medical advances have increased the life expectancy of people with Down syndrome, but because those advances are relatively recent, not enough is known about the development of adults with Down syndrome.

In June 2008, the authors published a case history of one of the men in their study, "Successful Aging in a 70-Year -Old Man with Down Syndrome" (Journal of Intellectual and Developmental Disabilities). The authors followed their subject, "Mr. C.," for sixteen years. Though people with Down syndrome are at an increased risk of developing Alzheimer's as they age, the authors concluded that Mr. C. showed no signs of the kind of cognitive or functional decline which would accompany dementia and experienced relatively good health. The authors examined several possible explanations for his successful aging, including variability of gene expression and the influence of family genetic history (both of his parents lived into their eighties and did not develop dementia). Non-genetic factors, such as learning and experience, may also play a role.

This case study demonstrates that it is possible for someone to have Down syndrome and live a long life, experiencing only the normal declines of aging. The researchers believe that with the growing body of data they are accumulating and advances in our understanding of the human genome, it will eventually be possible to understand the effect of Down syndrome on the aging process and to develop strategies to minimize problems and promote successful aging in adults with Down syndrome.▲



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Remembering Luci

Long-time readers of NADS News may remember the series of articles we ran about Luci, who died in 1994 at the age of 83 and was, as far as we know, the world's oldest person with Down syndrome. For readers who have not yet had the privilege of learning about this remarkable lady, we are including a brief summary of her life:

Luci was born in a suburb of Chicago in 1910, when the life expectancy for people with Down syndrome was only 9 years. She was the youngest of seven children, and unlike most babies born with Down syndrome at that time, who were generally institutionalized, Luci was raised in a loving, caring family. Luci's parents treated her like all of their other children, and she went everywhere with them in the community—to church, shopping, and other social events. However, she never went to school (it would be over sixty years before children with Down syndrome were offered educational opportunities, thanks to Public Law 94-142). Despite not receiving a formal education, she could do some reading, could print neatly, and knew her numbers.



After her parents died she lived with her sister, Sue, and later she shared a home with other siblings. When her last surviving brother's health began to fail, he arranged for them to move together into a home for seniors, and Luci stayed there for the last 7 years of her long life. She remained actively engaged with her extended family, including many nieces and nephews, and she participated in the community at her home, where she was popular with other residents and with the staff. She remained alert and active almost to the end, but in the fall of 1994, she fell and broke her hip and had to go to the hospital for surgery. She died about three weeks later, less than a month before her 84th birthday.

NADS staff members, including

Sheila Hebein, first got to know Luci in 1988. They were able to keep in touch with her over the years before her death and became very fond of her. They wrote accounts of some of their visits in earlier editions of NADS News, where they described Luci's wonderful sense of humor, her amazing memory, her room full of "treasures," which she kept in impeccable order, her passion for collecting stamps, and her deep affection for her family. As Sheila wrote, "It appears that the strongest ingredient in Lucille's life has been love – she was dearly loved by her parents, brothers and sisters, and continues to be loved by the two younger generations of her family – and it is clear that she returns that love a hundred-fold." ▲

New Global Institute for Down Syndrome

A new global institute, the Linda Crnic Institute for Down Syndrome, was recently established at the Anschutz Medical Campus of the University of Colorado, Denver. The Institute will focus on helping to eliminate some of the problems which can accompany Down syndrome through a combination of research and clinical care. William C. Mobley, a world-renowned neurologist, has been selected to be the Executive Director. He most

recently served as Chair of the Department of Neurology and Neurological Sciences and Director of the Center for Research and Treatment of Down Syndrome at Stanford University.

The Institute was made possible by a \$34 million commitment from the Anna and John J. Sie Foundation. The Sies were inspired to establish the Institute by their granddaughter, Sophia, who has Down syndrome. It is named in

honor of a professor of pediatrics and psychiatry at the medical school there who died in a bicycle accident. She had become a close friend of Sophia's parents after they received the prenatal diagnosis that Sophia would have Down syndrome. The Institute will be the first to combine comprehensive research with clinical care and has the potential to improve the lives of people with Down syndrome across the globe.▲

Letter from our 2008 Grand Prize Raffle Winners

Hi NADS,

My parents, Jerry & Judy Millard, were the Grand Prize winners of the NADS 2008 Raffle. My son Zachary has Down Syndrome. My wife & I (Michelle & Wayne Millard) sold them the tickets. They also invited us to go and share the experience in Maui, Hawaii. The timing of this vacation could not have been more perfect, since my parents are celebrating their 40th wedding anniversary this year and my wife and I are celebrating our 11th anniversary. Zachary is six years old and starting first grade this year. We wanted to share our vacation pictures with you and the rest of the NADS families.

First we would like to extend a huge *ThankYou* to Lyn Brown and her husband Frank for the donation of the amazing facilities in Maui, and to NADS another great *ThankYou* for the \$1000 spending cash... Grandma and Grandpa did not share that! haha

This vacation was by far the greatest vacation we have ever taken. We did so many amazing things! The resort we stayed at was in Ka'anapali Beach. It is located on the West shore of Maui. We flew non-stop from Chicago O'Hare to Maui. On the way home we had to make one stop on Kona on the big island of Hawaii. The flights were great both ways, except they lost Zach's bag when we arrived back in O'Hare.



In Maui we swam in the most beautiful ocean every day. We snorkeled and went scuba diving through amazing coral reefs. We biked down the side of Haleakala Volcano from approximately 8500' (peak is approximately 10,400 feet). My parents golfed in Makena, located on the south central part of Maui. We drove the road to Hana and swam in waterfalls along the way. In Hana (the Eastern part of the island), we swam some more. The beaches of Hana have black sand. We visited the Maui ocean center which has open water pipes directly connected to the ocean so fish can swim in and out of the reef viewing tanks. On the last day we learned how to surf.

We ate fresh pineapple everyday, along with some of the best seafood we have ever tasted. The sights and scenery were absolutely spectacular. The hospitality was great and the accommodations were perfect. Again, many thanks to all the people involved in making this trip possible!

Sincerely,

Jerry, Judy, Wayne, Michelle & Zachary Millard

Call for Stories

NADS is looking for stories from families. If you have a "human interest" story to share, if your child is involved in an activity you think other parents might like to know about, if you have an event or milestone to celebrate or a story about your child you would like to share with NADS readers, let us know! You can submit articles to shebein@nads.org or mail them to: NADS, P.O. Box 206, Wilmette, IL 60091. We would love to hear from you. ▲



Family Raises Money for NADS

Many thanks to the Tauer family, who donated to NADS the proceeds of their booth at the Lemont Heritage Festival on July 12th. All the members of their family—Michelle and Rick and their children, Michaela (9), who has Down syndrome, James (7), Conrad (7), and Aidan (5)—helped in running the booth, “Radar Speed Pitch.” They raised a total of \$286. Thank you to the Lemont community for their support and to the Tauer family for their hard work and generosity.

Cars4Charities

Two cars were donated recently through Cars4Charities (www.cars4charities.org), bringing in a total of \$731.25 for NADS. One was an anonymous donor from Chicago. The other was donated by Michael Welf of Homewood, IL. Many thanks to all who have donated to NADS through this program.

Turtle Wax “Make a Difference” Day

Turtle Wax, Inc. in Willowbrook recently held a “Make a Difference” day, in which associates who made a \$5 donation would be entered into a raffle for a prize of 2 tickets to a Cubs game. Through a combination of employee donations and company matching, \$730 was raised and donated to NADS in honor of Kelly Derobertis, the granddaughter of Rich Kelly, who works in their Research and Development department. Thank you to Turtle Wax and its employees and to the Kelly family.

Three Friends Make Donation to NADS



Dear Sheila,

During the summer, three friends, Megan Pelos, Zoey Sideris, and Amanda Sideris created a bracelet company called ZAM’s (Zoey, Amanda and Megan). They spent the whole summer beading, marketing and selling their bracelets so that their profits could be donated to NADS. They did a little research and found that through Baxter’s matching gift program, they could double their donation.

You will find enclosed a check for \$450.00 with a pledge form from Baxter’s matching gift program. The total that the girls would like to donate to NADS comes to \$900.00.

The girls are a true inspiration. They have shown that through their own creativity, you can be inspired by friends and family in your own community to give to others (Megan’s sister Christie has Down syndrome). What positive role models for us all!!

Sincerely,
The Pelos and Sideris Families

We are grateful to Zoey, Amanda, and Megan for their hard work and commitment to helping NADS. Thank you!

HollyDays are Here Again

Holly Simon will be sponsoring her third annual “HollyDays in November” on November 6th from 6:00-9:00 p.m. It will be held in Beverly at 10425 S. Talman, Chicago, IL 60655. As in past years, the event will feature a variety of vendors and artists, and 10% of the proceeds will go to NADS. It is always a fun occasion, so mark your calendars now! ▲

New Online Community

The Beach Center on Disability at the University of Kansas has set up a new online community to bring together families, researchers, practitioners, and policy leaders, who can connect with each other online and share documents, photos, and links. The purpose of the site is to promote sharing of wisdom and experience among these different groups. The multiple discussions are moderated by a facilitator. Membership is free, and members can join in a conversation or post comments later. To access the website, go to the main site for the Center, www.beachcenter.org, and click on Communities of Practice, then click on the Early Childhood Family Support link.▲

Intervention Resource

Continued from page 1

birth. The website for families has three main sections: Questions and Answers, which covers the questions most commonly asked by new or prospective parents; Life Glimpses, which provides photographs and family stories; and Family Resources, which includes brochures about prenatal diagnosis, breastfeeding, medical issues, and lists of organizations and other resources. ▲

Skimming

Continued from page 3

she needed us. Just as we, or any parent for that matter, would provide medical treatment for our other children if they were hurt or sick—so would we help our littlest daughter. She wasn't any less our little girl just because we hadn't met her face-to-face yet.

With that decision, we began our journey to the Great Barrier Reef of parenting. Our fears seemed endless, yet so did the comforting kindness of people doing everything they could to help us. Nationwide prayer chains were formed. Baby gifts, notes of encouragement, and anonymous donations appeared daily.

As doctors predicted, Erin Faith arrived two months premature, with Down syndrome and just about every complication that came with it. She weighed in at 3 lbs and required a major abdominal surgery on the first day of her life. A second abdominal surgery and open heart surgery followed. Four months of her first year were spent in hospitals. Nights and days were filled with round the clock medications, feeding tubes, and oxygen monitors, as my husband and I obtained do-it-yourself medical degrees.

As we had predicted, Erin is a beautiful little girl, who, despite all she went through, smiled on January 22, 2005, two days after her original due date and on time according to

the development charts. Now, at age three, Erin knows about 200 words in sign language, happily teaching them to others. She takes swimming and music classes, and is working on pre-reading skills. While we are still a long way from perfect, Erin has completed our family in a way no other child could.

With fewer medical concerns, we've had time to vacuum-seal our face masks and see the amaz-

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We had been skimming the surface, missing so much human goodness.

.....

ing world around us—a world we had always been a part of, but didn't know. We had been skimming the surface, missing so much human goodness. Our two older children have the luxury of growing up in this world, easily accepting and loving their little sister. Their whole life will be spent below the surface, growing up in the beauty of service and unconditional love. This year they both decided to use their birthday parties to raise money for kids with special needs. What started out as a small birthday party has grown into so much more, with people offering to help, making donations, and writing newspaper articles.

While I had originally feared strangers' comments and stares, I now know Erin would want it no other way. As she smiles,

waves, and gives people her best "hiilo," I have the pleasure of watching their first glimpses into the underwater world we call home now. Most won't stay long, but others are changed forever by our little ambassador.

I also discovered a whole industry of people who chose to jump into the deep water to help those of us who are thrown in unexpectedly. From therapists to camp volunteers, our family is so grateful for people who somehow knew this deeper world existed and became its lifeguards.

I still do have moments where I try to return to the false-security of vertical, and I even sometimes mourn the loss of our easier, surface-skimming days. However, after crashing into a few rocks and stinging creatures, I relax into the waves, joyfully anticipating my new direction and waiting for the gentle crest.▲

Editor's Note: *Diane's essay is featured in "The Mothering Heights Manual for Motherhood, Volume 1: What we wish we knew before becoming a ~~short order cook, shuttle driver, laundress~~ Mother" which is available online at amazon.com and bn.com (MH Press, \$12.95).*

The Joy of Learning

By Sarah Bonilla

My daughter Paloma just started seventh grade at West Chicago Middle School. I felt like the last nine years, three years of pre-school and kindergarten through sixth grade, we have floated along on a wonderful inclusion bubble. She was fully included all those years, and great effort was taken to ensure her success in the class.

Now we have entered into a new world. She was taken off the regular bus, which she was on for six years, and put on a special ed bus. Now we are told that the social studies and science classes she has been in for a few weeks are not appropriate for her. They cannot provide the necessary modifications to remain in those classes because of the large discrepancy between the course content and Paloma's cognitive abilities.

They offer an alternative Life Skills class that will teach her things "more appropriate," such as measuring, reading a map and a bus schedule, and down the road, how to balance a check book.

I remind the school staff that Paloma is 12 years old and is driven around by her mother like ALL suburban kids, and as far as balancing a checkbook, does anyone even do that anymore?

The Life Skills class has value, but it is not a substitute for science and social studies. I would like my daughter to be treated like the young person she is and be allowed to learn all the interesting things about our world that other seventh graders are allowed to learn, like the rainforest, the planets, and the weather, or different people and cultures around the world. Who is to assume this is not appropriate for my child to learn?

I am told I need to "adjust my expectations."

I am fully aware that much of the



course content may go over Paloma's head. Nevertheless, I expect her to be in the class, with her peers, where she belongs.

They tell me the material in these classes is way too hard for her, and it is too costly and time-consuming to modify the curriculum. I ponder the legality of what they are saying to me but keep that thought to myself.

The fact is that no one, not a teacher or facilitator or even I, knows definitively what my child may learn from being in those classes. I know she does retain kernels of information. These kernels grow into stalks and bloom forth when you least expect it.

We are sitting on a bench at the park the same day as my meeting with the school. Paloma tells me in an excited voice about some project they did that day in science. Something about "soil" and a seed and folding paper. With her limited communication skills, I have no idea what she is saying or what they actually did. But that is irrelevant. She is excited.

My doubts about fighting to keep her in science lessen. The joy of learning is exciting! This is what school should be about. Does a teacher look out on their class of 30 and alter the curriculum according to the potential of every student? Do we not teach calculus to some kids because they may end up doing

manual labor? Of course not. So what's the point? Of course not. Each regular-ed kid is given equal opportunity to explore a range of intellectual endeavors, but people with cognitive disabilities are not. It is assumed that they do not share the same thrill of learning. It is assumed it is a waste of time because they are going to end up in a menial job.

Intellectual pursuits don't necessarily have anything to do with careers.

I have found in these last few weeks, much to my disappointment, that many well-meaning and likeable people in the special education system have a limited and rigid view of the potential of our kids and what the education system can offer them.

I know what a central joy in life learning can be. This is why we read novels and magazines and surf the internet for hours. We go back to school midlife. We take vacations to interesting places and listen to foreign language tapes in the car. We do this our whole lives, and how dull life would be if we didn't.

Let's not deny this joy to our own precious children.▲

NADS familyalbum

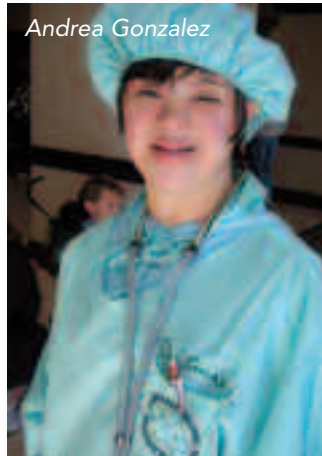
Colin Guerrero



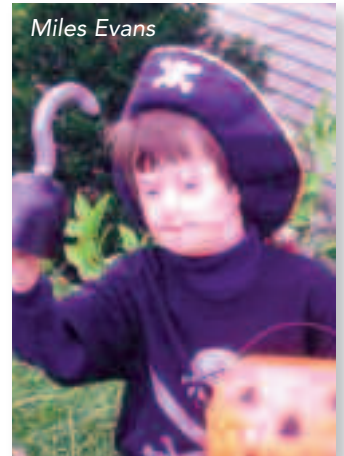
Regan Reinertson
& her Sister



Andrea Gonzalez



Miles Evans



Ryan Christiansen



Kamren Bell



Zack Borst

Educational Resources

Here are some resources for parents who are interested in learning more about the special education process and the rights of their child.

Parent Resources

The Family Resource Center on Disabilities

www.frcd.org
(312) 939-3513

The Family Resource Center offers special education seminars, advocacy training, parent workshops, and information about special education.

Wrightslaw

www.wrightslaw.com
Online special education advocacy organization offering publications, information, and training about special education law.

Books

Anderson, Winifred, Stephen R. Chitwood, Deidre Hayden, and Cherie Takemoto, **Negotiating the Special Education Maze: A Guide for Parents and Teachers**, 4th Edition (Woodbine House Publishing, 2008).

Wright, Peter and Pam, **Wrightslaw: From Emotions to Advocacy**, 2nd Edition (Harbor House Law Press, 2006).

Educational Consulting Organizations

Everyone is Welcome

www.eiwelcome.com
(630) 584-0970
Everyone is Welcome was established in 1996 by Mark Doyle to provide services to increase inclusion for individuals with disabilities. Advocacy services include meeting attendance, IEP assistance, educational program assessment, and transition planning.

Project Choices

www.projectchoices.org
(630) 629-0551
Project Choices is a least restrictive environment initiative funded by the Illinois State Board of Education. Consultants help facilitate inclusion in different learning environments, including public schools. The organization has two divisions: Choices, which supports school age children, and Early Choices, which supports preschool age children.

New Books for Children

Colin Gets a Chance

Brian A. Beale
AuthorHouse, 2008
www.authorhouse.com
23 pages \$14.95

This charming book for children tells the story of Colin, a young boy with Down syndrome, who dreams of finally getting a hit for his baseball team. He doesn't give up on his dream even after he arrives at the biggest game of the season to find that, yet again, his coach wants him to sit on the bench—but with the support of his teammates, Colin finally gets a chance.

Brian Beale was inspired to write this story by his son with Down syndrome, Colin, in hopes that through this book, other children will also get a chance. All of the illustrations in the book were done by individuals with Down syndrome, ranging in age from 6 to 23. The art work is engaging, and some of the pictures are skillfully done—which again highlights the book's emphasis that we shouldn't underestimate the abilities of people with Down syndrome.

In My Shoes: Humor, Beauty, Spirit

Amy Fox, Theresa Mezebish, and Susan Sklansky
Dancing Rhinoceros Press, 2007
60 pages \$17.95

This beautifully produced book aims to capture the magic in everyday

things. The book is organized around a variety of subjects, including elements from the natural world, such as trees and flowers; elements from the domestic world, such as taking a bath; and elements from a child's world, such as music, jumping, and running. Each section includes beautiful photographs and art work, many of which feature children (including a little boy with Down syndrome), and the art is accompanied by questions designed to help an adult engage a child in what they are seeing. The language is by turns playful and poetic and aims to teach by encouraging children to look more closely at the world around them.

My Up & Down And All Around Book

Marjorie W. Pitzer, M.Ed.
Woodbine House Publishing, 2008
www.woodbinehouse.com
16 pages \$10.95

This board book introduces children to common prepositions through colorful photographs of children with Down syndrome, where the concepts are illustrated through their activities. This book is a follow-up to Marjorie Pitzer's *I Can, Can You?* and follows a similar format. It also includes a section at the end written by Libby Kumin, in which she explains how parents can help expand their child's language skills.

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