

# NADS NEWS

Ronald and the Geaches

The Newsletter of the National Association for Down Syndrome

January, 2008

## NADS 23rd ANNUAL BOWL-A-THON

Sunday, March 2,  
2008

**Stardust Bowl**  
37 E. Lorraine  
Avenue, Addison,  
Illinois

Registration  
Check-in  
Begins at 11:00 a.m.

Bowling Begins at  
12:00 noon

## NADS 23rd Annual Bowl-A-Thon

Last year we raised over \$104,000 at our Bowl-A-Thon! This event has been a successful fundraiser in the past because of the participation and generous support of NADS members, family members and friends. The Bowl-A-Thon is NADS' major fundraising event, and the funds raised are used for the critical programs we provide for children and adults with Down syndrome and their families. It offers an opportunity for our members to be involved and to support the variety of programs NADS offers, as well as having a lot of fun!!

**Bowlers** - All bowlers must register, and this year you can register online ([www.nads.org/bowlathon](http://www.nads.org/bowlathon)). Since this is our major fundraiser, many members collect hundreds of dollars in pledges, but a minimum of \$100 is required to bowl. For more information, please call our office at 630-325-9112 or download the Bowl-A-Thon information from our website.

A personalized letter will tell those you are seeking pledges from of your involvement with NADS, how NADS has supported you, and the impact NADS has had on your family. Don't hesitate to ask your

family members, friends, neighbors, co-workers, teachers and your child's physicians to pledge for you or your child. Many companies offer a program to match donations made by their employees, so please check with your company's human resource department to see if they will match your donation.

The top four fundraisers will be awarded prizes. In addition, there are a variety of door prizes awarded throughout the day of the event and opportunities to purchase raffle tickets for some great prizes.

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NADS News is a publication of the National Association for Down Syndrome (NADS).

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or visit [www.nads.org](http://www.nads.org)

Exec. Director M. Sheila Hebein

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Editor M. Sheila Hebein

## Grants Help Families with Health-care Costs

The UnitedHealthcare Children's Foundation is a non-profit charity funded by contributions from UnitedHealth Group, UnitedHealthcare and its employees. It was established to help families whose children have medical needs and are not insured comprehensively to provide coverage for all of their medical treatments. This program helps families who have gaps in their commercial health benefit plans. Please note that Medicaid, Medicare, SCHIP or other state or federally subsidized health insurance programs are excluded from this program. For eligible families, grants of up to \$5,000 may be awarded. Services must aim to improve the child's quality of life and can include dental treatments, hearing aids, eyeglasses, physical therapy and speech therapy. Applicants must reside in the U.S., and the child must be 16 or under. For more information, go to UnitedHealthcare Children's Foundation website at: <http://www.uhccf.org> or call 800-328-5979 Ext. 24459.▲

## NADS Collaborates with Family Resource Center on Disabilities

During the summer of 2007, NADS signed an agreement to collaborate with the Family Resource Center on Disabilities (FRCD) on their Parent-to-Parent Training project. This federally funded project is designed to provide information and advocacy training services to parents, persons with disabilities, and professionals.

NADS is one of seven Illinois Collaborating Parent Organizations that will provide the following services:

Phone/ information/referral and linkage services.

Training seminars for parents on special education rights.

NADS staff members, Sheila Hebein and Linda Picchi, have been attending training/planning meetings at the FRCD offices in Chicago. In addition, Roselia Tello, our Spanish Outreach Coordinator, took the FRCD Education Rights training in Spanish, and NADS board member, Jackie Rotondi, also attended a training session in Chicago.

This project will enable NADS to continue to provide the referral services we have always provided, but it will also allow us to provide a new service: Education Rights Training seminars to parents and professionals. We will make these seminars available to local Down syndrome support groups and individuals throughout the Chicago metropolitan area. In addition, we will provide this training in Spanish to interested Latino families.

The National Association for Down Syndrome has worked with the Family Resource Center on Disabilities for over 30 years, and we are very pleased to strengthen this link through the Collaborating Parent Organization initiative.

If you or your organization would like to learn more about this program or would like to schedule an Education Rights Training Seminar for your group, please call the NADS office at 630-325-9112.▲

## NADS Arts Festival

Sheila Hebein

We are in the early stages of planning a special arts festival in Chicago spotlighting the artistic gifts of children and adults with Down syndrome. We hope to feature artists from all areas of the arts – painters, sculptors, sketchers, dancers, musicians and many, many more. If you or someone you know would be interested in working with us to bring this event to fruition, please attend a meeting on Monday, February 25, 2008 at the Adult Down Syndrome Center, 1999 Dempster Street, Park Ridge, IL. Please let us know if you plan to attend, or if you can't attend the meeting but would be interested in helping with this exciting event, please call the NADS office at 630-325-9112.▲



## My Son Kenny

Joe Clayton

**"K**enny," in a word, is Kenny. He gave himself that name. (This from a boy who is basically non-verbal?) He was supposed to be Kenton, but when you are waiting for the school bus, and he repeatedly says, "Kenny go bye-bye, Kenny ride the bus," he just became Kenny.

Kenny is one of the joys of our lives, as are each of our other 3 children: Mitch, Reed, and Lucy. They are all our "special" children.

The impact Kenny has had on our lives is monumental. All 3 of our other children are incredibly compassionate, due in part or in whole because of who they became with the addition of their brother with Down syndrome and Autism. Teachers, friends, and family compliment our children on their empathy and compassion. Even Lucy at age 6 is starting to recognize how he, and she in relationship to Kenny, impacts other people's lives.

Kenny has truly impacted our whole family in so many powerful ways. He has allowed us to foster many incredible relationships that have developed through NADS and various family support groups. The friends we have met are more like family. Some were once just support providers, therapists, or special recreation counselors, and now we have shared holidays, birthdays, vacations and unfortunately even deaths together. Whether it's a group of Dads going to a White Sox game, group dinners with couples, Moms nights out, or just celebrating special events together, our children with Down syndrome brought us together, and now we relish our time together.

## Bowl-A-Thon

Continued from page 1

### Other Ways You Can Help

**Raffle and Door Prizes** – Obtain items or gift certificates for restaurants or merchandise, tickets for sporting events, theater tickets, or hotel packages. We would be happy to send a written request or we will provide you with letters that you may use for soliciting businesses for prizes in person.

**Lane Sponsorship** – Ask your employer, clubs, organizations or businesses that you and your family patronize to sponsor a lane. Lane sponsorships are available in the following amounts: \$2,500, \$1,000, \$500, \$250 or \$100. Sponsors will have a banner showing their name displayed the day of the Bowl-A-Thon. We will also publish their name in NADS News, and on our website. Please contact our office if you would like a letter to present to a business or would like us to send a written request to a business that would be interested in sponsoring a lane.

**Grand Raffle Tickets** – Sell raffle tickets to family, friends, and co-workers. The grand raffle has been very successful, and once again we have some great prizes. Grand raffle tickets will be mailed to our members soon, and you can help support NADS by purchasing and selling these raffle tickets. The grand raffle prize drawing will be held at the Bowl-A-Thon. Winners need not be present. Additional tickets can be obtained by contacting the NADS office at 630-325-9112.

The Bowl-A-Thon offers a great opportunity to see old friends and to make some new ones. We look forward to seeing you on March 2nd, 2008!

.....  
It's been awesome.

Awesome is the opportunity to share our family vacation in Michigan with 4 families from our Down syndrome "network". This gave me an opportunity to get to know Kelly, Colin, Zach, and Mallory on a more personal basis. We had a great time together, as did all the siblings too!

What Kenny brought us was unimaginable when he was born. Now we savor every moment! Kenny has brought us compassion, friendship, empathy (I can't stress that one enough!) vision, determination, and hope.

Kenny is my third son, and I love him beyond my wildest expectations! He is KENNY!▲

# Behavior Retreat

Each year in the spring, NADS holds a Behavior Retreat for NADS members whose child with Down syndrome has an additional diagnosis, such as Autism or Attention Deficit/Hyperactivity Disorder. If your child has been diagnosed with either of these conditions and you would like to get more information on our 2008 retreat, please call 630-325-9112. ▲

## Obesity-Related Hormone

### Higher In Children With Down Syndrome

Children with Down syndrome are more likely than their siblings to have higher levels of a hormone associated with obesity, according to pediatric researchers. The hormone, leptin, may contribute to the known higher risk of obesity among children and adults with Down syndrome.

A research team from The Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine published their study online in the *Journal of Pediatrics*. The researchers studied 35 children with Down syndrome and 33 of their siblings. All of the children were between the ages of four and 10 and were from the Philadelphia area. The researchers intentionally did not include severely obese children in the study, in order to focus on risk factors for obesity before obesity occurred.

The children with Down syndrome had significantly higher body mass index, a higher percentage of body fat, and higher levels of leptin compared to their siblings. The higher leptin levels persisted even when the researchers adjusted for the effect of percentages of body fat, suggest-

ing that differences in body composition did not account for the difference in leptin levels.

"The normal role of leptin is to suppress appetite and regulate body weight," said senior author Nicolas Stettler, M.D., MSCE, a pediatric nutrition specialist at The Children's

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*The children with Down syndrome had significantly... higher levels of leptin compared to their siblings.*

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Hospital of Philadelphia. "In general, obese people have higher levels of leptin, which suggests that they have some leptin resistance—their bodies do not respond to the hormone properly. Because Down syndrome is a chromosome disorder, children with Down syndrome may have a genetic predisposition to more severe leptin resistance."

Sheela N. Magge, M.D., M.S.C.E., a pediatric endocrinologist at Children's Hospital, the first author of the study, stressed that more

research remains to be done on this question, as the reasons are yet uncertain why patients with Down syndrome are at higher risk of obesity. "Although the study had an advantage in including siblings as a control group, because this decreases the influence of different environments on children with or without Down syndrome, the sample size was limited, so larger studies are necessary. However, our findings may point to a useful approach to understanding why obesity often occurs in Down syndrome."

A better understanding of the causes of obesity opens up new possibilities for treatment. In the meantime, like others who struggle with weight issues, careful nutritional planning and exercise can help individuals with Down syndrome lead healthier lives.

For more information on this research, go to: <http://stokes.chop.edu/publications/press/?ID=371>



Megan Niklas,  
Self-Advocate

## NADS Luncheon & Fashion Show

### Smashing Success Raises Over \$45,000!

Sheila Hebein

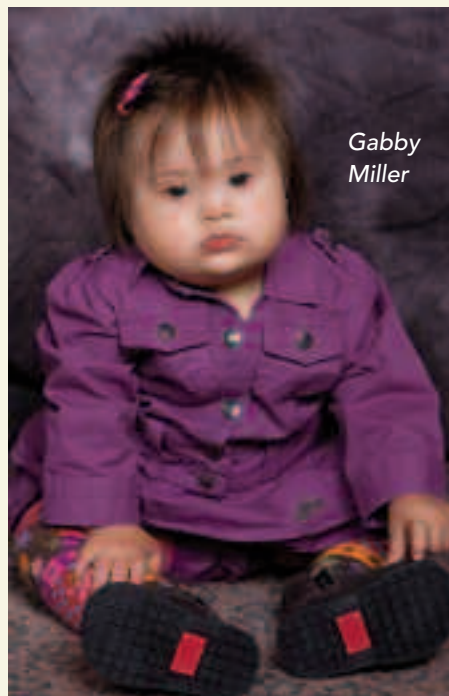
The 2nd Annual NADS Luncheon and Fashion Show was amazingly successful on so many levels. First of all, more than 700 people attended this event, which was held on Sunday, October 21, 2007, at the Donald E. Stephens Convention Center in Rosemont. Self-Advocate, Megan Niklas, addressed the group sharing some of her life experiences, and her theme was "I'm More Alike Than Different." Then the Center Stage Dancers delighted the audience with their energetic performance – each dancer bringing their own inimitable sparkle.

We had a total of 53 models – ranging in age from 6 months to 53!! The younger children were accompanied by their parents or siblings. Some were great hams. Some were more reluctant, some made it all the

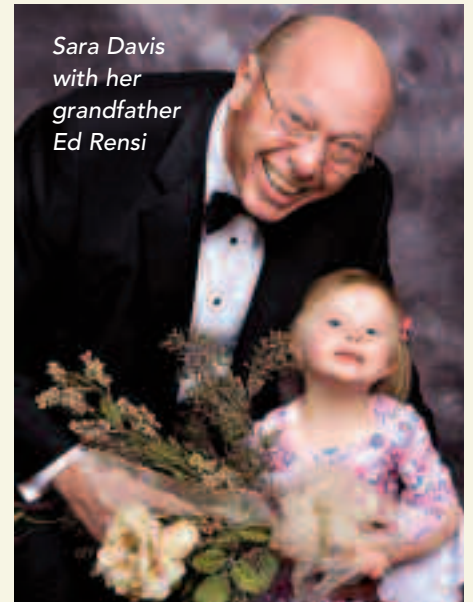
way around the runway, while others decided to sit for a while – it's not always easy walking on a runway with hundreds of people cheering you on, especially when you are 18 months old!! One little guy decided he liked it so much. he ran back the other way – you have to take advantage of these spotlight moments! Fast, slow, reluctant, or enthusiastic – each model brought their own brand of charm, and we were so proud of each of them!!

Special thanks to all those who worked so hard to make this event happen, especially the parents and volunteers. Thanks also to the guests who attended, those who donated prizes, bid in the silent auction, purchased raffle tickets and generously donated. Without your support we would not have raised over \$45,000 – approximately \$15,000 more than was raised last year.

**Gabrielle Miller** – Gabrielle, you never cease to amaze us! Our family is more complete now that you are a part of our lives. God has truly blessed us with one of his angels.



Gabby  
Miller



Sara Davis  
with her  
grandfather  
Ed Rensi

**Sara Davis** – Sara is a vivacious and hilariously funny 5 year-old. One of her favorite things to do is swim. She has become such a mermaid! It was wonderful watching her swim with the big kids and just being a typical kid. Sara also has had big school changes this year. She is in full inclusion kindergarten and loves it. Who would have thought after 2 open heart surgeries, alopecia and celiac disease she would be where she is today?! We love watching the future unfold before her – we are truly blessed. Sara is pictured here with her Grandfather, Ed Rensi who did a wonderful job as MC of the fashion show.

### Model Bios

Written by family members for the Fashion Show Program

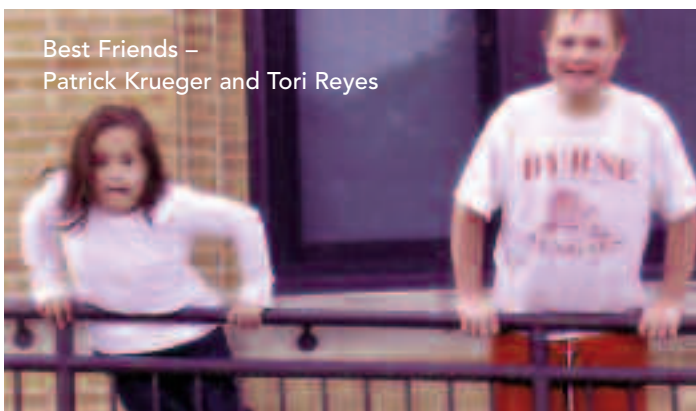
More models will be featured in future issues of *NADS News*

Photos by Kelley Demas  
Photography –  
[www.kelleydemasphotography.com](http://www.kelleydemasphotography.com)  
847-650-5163

# NADS Special Friends

**W**e would like to thank our members who held creative fundraisers for NADS and recently wrote to tell us about them:

Victoria Reyes, born 7/30/98), who went to Kevron Printing and talked to them about the stickers, they donated 500 stickers so we were able to pass out stickers to the students who were able to participate in our out of uniform day. With the support of the administration, staff and students of Michael M. Byrne Elementary



Best Friends –  
Patrick Krueger and Tori Reyes

## Out of Uniform Day

Joann Krueger

NADS is a wonderful resource for parents of children with Down syndrome and I am proud of my son, Patrick, born 8/21/95 and I'm proud to be a NADS member. With October being Down Syndrome Awareness Month, I decided to ask my son's school for an out of uniform day for awareness of our children. I also passed along the book "Our Brother has Down Syndrome" for teachers to read to the students, so our students would have a better understanding of Down syndrome. The response was unbelievable and the last few weeks have been so positive. With the help of Rebecca Reyes (proud parent of

School, we would like to donate our proceeds, amounting to \$702, to your wonderful organization. Please keep up your hard work and dedication to our children.

## Holly-Days Event

Holly Simon

Happy Birthday to our magical and miraculous son, Nathaniel!

In honor of our son, Nathaniel Simon's 5th birthday we would like to donate \$975 to NADS. I recently held the 2nd annual Holly-Days event in our Chicago neighborhood. Once again it was a huge success! We featured 14 local artists and vendors who sold their goods throughout the evening. 10% of the night's sales are being donated to NADS.



Holly and  
Nathaniel Simon

If anyone is interested in having a one-of-a-kind purse party where a percentage of the sales can go directly to NADS please contact me through the NADS office.

## Holly-Days Part 2

Nancy Krickl

On October 18, my family and I hosted a Holly-Day party with the intent to honor our son, Henry, and celebrate Down Syndrome Awareness Month. In addition to many friends weathering a major storm to shop for the cause, we also received donations from those who couldn't make it.

While 22-month old Henry charmed shoppers with his smile, Marty, Jack

and Andy who are 8, 6 and 4, sold their fuser bead collections as well. The savvy salesmen are shown in the picture below. Please use our donation of \$260 where there is the greatest need. Our boys also contributed money from their sale.

Holly Simon is truly using her talents to honor her family and it was great to meet her. Just another example of the good people we have met through having a child with Down syndrome.

Your newsletter, with inspiring and informative articles and wonderful pictures, has touched us in a very positive way. The website has been a great resource as well. Please



Marty, Jack, Andy  
and Henry Krickl

continue your work to show the gifts of having a child with Down syndrome.

## We Can Help You Help Us

If your child's school is interested in doing an out of uniform day or if your employer would allow a "Dress Down" day or, as they did at Harris Bank, a "Jean Day" for NADS we would be delighted to provide you with bookmarks to hand out at school or at work. Just call us or send us an e-mail request to [info@nads.org](mailto:info@nads.org).

## South Suburbs Also Show Support for NADS

### Wine and Microbrew Tasting for NADS

A big thank you to Cave Wine and Spirits located at 18700 Wolf Road, Mokena, who hosted a wine and microbrew tasting evening on October 26, 2007. This event raised \$376 for NADS

### More Generosity from Mokena

NADS' member, Ellen Bailey, nominated NADS to receive a donation from the Mayor of Mokena's Charity Foundation, and her request was granted! A check in the amount of \$600 was presented to NADS' board member, Marlene Sekula, at a meeting of the Mokena Board

of Trustees on November 12, 2007. Thanks to Ellen and her daughter, Lexi, and to Mayor Joseph W. Werner.

### Jean Days for NADS

We received the following note and a check for \$1,022 from NADS' member, Adam Vander Woude:

"I am an employee of Harris Bank in Frankfort, IL. My daughter, Paige, is 4 years old and has Down syndrome.

The leadership team of the Harris Bank branches in Frankfort, New Lenox and Manhattan, IL were kind enough to designate the first two Fridays in October (in celebration of Down Syndrome Awareness Month) as Harris Jean Days. The employees of these seven branches, also known as the Lincolnway Region of Harris, were allowed to wear jeans on these two Fridays if they donated money to NADS. Over these 2 weeks, the



Paige Vander Woude

employees of Harris raised over \$1000!!

My daughter, Paige, is an absolute joy to our family and brings smiles to faces everywhere she goes. She is smart, fun, helpful and a great sister to her siblings, Jake and Averi.

I hope this donation will assist NADS to continue its great work with families and friends of people with Down syndrome.

Thank you so much Adam and WAY TO GO HARRIS EMPLOYEES!!



## Congratulations Blake!

Blake Webber's Volleyball team won the Gold Medal at the Illinois Special Olympics state meet that was held in Rockford. Blake's family is very proud of him, and so are we!

Blake Webber with parents Joe and Penny

## Conferences

### **8th Annual Least Restrictive Environment (LRE) Institute**

January 25, 2008

Holiday Inn Select & Convention Center, Tinley Park, IL 60477.

This program is appropriate for people with disabilities, family members, teachers, administrators, and related service personnel.

### **Best Practices in Early Childhood Forum**

February 15, 2008

Grizzly Jack's Grand Bear Lodge  
Utica, IL 61373

For more information on the above conferences, go to the Project Choices Website at: [www.projectchoices.org](http://www.projectchoices.org) or call 630-629-0551.

### **Planning for Children & Adults with Special Needs for Today & Tomorrow –**

Presented by Brian Rubin, J.D., Sherri Schneider, QMRP 7 Matt Cohen, J.D. Sponsored by The Arc of IL

January 19, 2008

Options & Advocacy  
Crystal Lake, IL

For more information contact The Arc of IL at [www.thearcofil.org](http://www.thearcofil.org) or call Janet Donahue: 708-206-1930.

### **National Down Syndrome Congress - Annual Convention - Boston, MA**

July 11 – 13, 2008.

For more information, go to the NDSC website at: [www.ndsccenter.org](http://www.ndsccenter.org).

## Hairdresser for Kids with Special Needs

“Kids Cuts” is a small beauty salon that specializes in haircuts for children with special needs. Children with Down syndrome, Autism or any disability are welcome. The setting is personal without the extra stimulation that you find in many beauty salons. It is located at 2746 Maple Avenue, Downers Grove, IL – phone: 630-986-0026.▲

## Treadmill Training

ANN ARBOR, Mich.—Starting infants with Down syndrome on treadmill training for just minutes a day can help them walk up to four or five months earlier than with only traditional physical therapy, a new study from the University of Michigan says. The study also suggests that infants who do high intensity treadmill training may walk even sooner. Getting infants walking is critical because so many other skills arise from locomotion: social skills, motor skills, advancement of perception and spatial cognition, says professor Dale Ulrich of the University of Michigan Division of Kinesiology and principal investigator on the treadmill training project. “The key is if we can get children to walk earlier and better then they can explore their environment earlier and when you start to explore, you learn about the world around you,” Ulrich said. “Walking is a critical factor in development in every other domain.” Infants with typical development learn to walk independently at about 12 months of age. Babies with Down syndrome typically take up to 16 months longer.

In the study, 30 infants were randomly assigned lower intensity, generalized treadmill training, or high intensity, individualized treadmill training, implemented in the homes by their parents. The training was used as a supplement to physical therapy. Initially, all parents worked with their infants on the treadmill for eight minutes a day, five days a week. The parent sat on a bench that straddled the treadmill and held the infant as the child took steps on the treadmill, Ulrich said. All of the parents began with low intensity training, but after the infant could take 10, 20, and 30 steps per minute, intensity was gradually increased for half the infants, Ulrich said. High intensity training included increasing the treadmill belt speed, using longer durations, and adding light weights to the ankles, with intensity tailored to each child. The results suggest that infants in the higher-intensity, individualized training group increased their stepping more dramatically over the course of training, and attained most of the motor milestones at an earlier mean age. The results also provided support for the results of their earlier treadmill training study reported in 2001.

For more information on this study and on Dale Ulrich, go to: [http://www.ur.umich.edu/0102/Nov12\\_01/11.htm](http://www.ur.umich.edu/0102/Nov12_01/11.htm).

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**Editors Note:** We strongly advise parents who are interested in trying treadmill training with their child to consult with their child's physical therapist and doctor.

# Will Your Special Needs Trust Truly Meet Your Child's Changing Needs?

By: Attorney L. Mark Russell

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If you are a parent who has a child with a disability, and you want to build a fortress of safety around your child's life after you are gone, then this article will give you a core guiding principle to follow and three easy-to-implement tips.

But, before I get to the estate planning principle and my three tips, I've got to tell you a quick story: I'll never forget one January night when the temperature in Chicago was 17 degrees below zero. My Dad phoned me around 8 p.m. and told me my older brother Jon, who is dual diagnosed with an intellectual disability and a bipolar disorder, was just admitted into the hospital for a relatively routine problem. Dad without a thought about waiting until the morning trudged out to his car and drove over an hour through a wind-storm of blinding snow to look in on Jon.

At that time...Dad was eighty-four-years-old and battling heart disease, prostate cancer, diabetes, eyesight problems, and the onset of vascular dementia!

I muttered to myself in awe and respect...a parent's job ain't ever over...

Parents get that. So much so that I still have to remind some parents that hoping that they will live just one day longer than their child with a disability just ain't a plan.

Of course, the opposite is true: You have to plan that your child with a disability will probably live 20, 30, or even more years after you pass away.

Another story: A few years earlier, we celebrated Dad's 80th birthday by

having a family reunion down on Sanibel Island, Florida. Dad looked and acted like he was 60. He raced across the tennis court playing singles with his wife, Eleanor, a former model from West Virginia. Eleanor was 18 years younger than Dad and looked more like my wife than Dad's. (My mother died years earlier.) Dad even pedaled a rented single-speed bike for a 20-mile stretch through Ding-Darling wildlife refuge in 90

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*The ONLY thing you can count on is the fact that THINGS WILL CHANGE over the lifetime of your child with a disability.*

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plus heat with an ear-to-ear grin plastered on his face. Dad's only admission to his advancing years was he took up golf that year declaring he needed a backup sport in the event his tennis legs didn't hold up in his 90s!

KerPOW! Just 7 years after our family reunion down in Florida... Eleanor had died of Alzheimer's. Dad battled dementia, so we moved him into our home. But because Dad's legs were too wobbly to climb the stairs to get to his second-floor bedroom, our family moved again into a home that had a downstairs bedroom with a full bath for Dad. My wife quit her corporate job after 19 years to care for Dad and our two kids under age 7. And my brother Jon aged out of two residential pro-

grams and was hospitalized at least a half dozen times.

Things change. Stuff happens. And I have no doubt you have your own family "war" stories while being in the privileged (I genuinely mean that!) role of caring for your loved ones.

Here's the planning "takeaway": The ONLY thing you can count on is the fact that THINGS WILL CHANGE over the lifetime of your child with a disability. Laws will change. Your child's wants and needs will change. The health of the trustees and guardians may change. Finances may change...and on and on. And, of course, the most stinging change in your child's life will be when you pass away.

Till now, you have relied on your own resiliency to conquer or untangle the constant barrage of problems or puzzles that arise when caring for your child with a disability. And that's exactly why when your special needs trust is drafted you have to consider giving the trustee the legal resiliency and flexibility to pilot a course of care through changing times and the ups and downs of your child's life by including the right language in the special needs trust.

(Note: As most of you know, you generally want to leave your child with a disability's inheritance to a special needs trust, so the trustee can manage the money and so that the inheritance you leave won't disqualify your child from receiving need-based government benefits such as Supplemental Security Income or Medicaid. Also, typically the special needs trust funded with the parent's money prevents the

Learn more on page 11 >>

# familyalbum

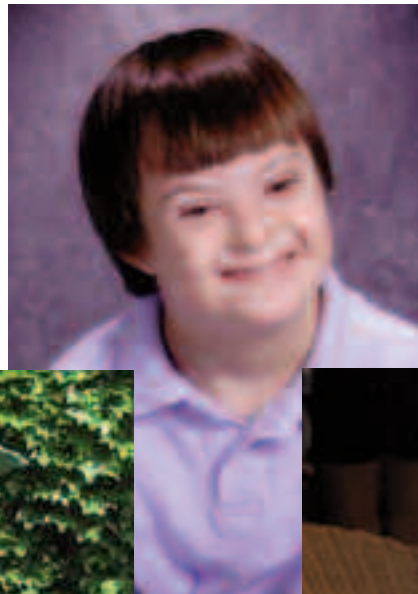
Colin Guerrero



*Natalie Latka and  
big sisters,  
Veronica & Abigail*



*Miles  
Evans*



*Madison Rose Turner*

*Frankie Severino*



*Elizabeth Gottlieb*



# Special Needs Trust

*continued from page 9*

state from seizing your child's inheritance for medical or residential cost-of-care claims.)

Here are three easy-to-implement tips to instantly give the trustee of the special needs trust the (legally-authorized) agility to react to change:

Consider adding an amendment clause to the special needs trust. In this way, after your death, the trustee will have the authority to amend the trust to comply with changes in the laws.

If you name an individual as a trustee or co-trustee, consider giving the acting individual trustee the power to name successor trustees or co-trustees.

For example, let's say you name your brother or sister (your child's aunt or uncle) as the trustee of your child's special needs trust after you die. But you're hoping that someday one of your other kids when old enough will be trustee. If the trust language permits the acting trustee (your brother or sister) to name successor trustees, then even years after your death, your brother or sister as trustee can name one of your other children to succeed them as a trustee (or as co-trustee with a bank) once your brother or sister believes your "non-disabled" child is old enough and mature enough to handle the job of trustee.

Finally, go over with your attorney (with a fine tooth comb!) the part in the special needs trust that talks about what the trustee can buy for your child with a disability. In general, you usually want to give the trustee as much discretion as possible to meet the changing needs and wants of your child with a disability. Many special needs trusts are unnecessarily restrictive in what the trustee can buy for the child with a disability. Ask your attorney LOTS of questions about what exactly the trustee can buy for your child with a disability.

Local Attorney and nationally recognized conference speaker L. Mark Russell has advised hundreds and hundreds of parents how to safeguard the future of their child with a disability. Go to [www.LMARKRUSSELL.com](http://www.LMARKRUSSELL.com) to get your hands on more free information. Or, you can call Mark at **847-991-7451**.▲

# Book Reviews

## **Win-Win Advice for the Inclusive Classroom**

By Barbara Tien, B.Sc., R-SLP and Claire Clelland, B.Com.

Woodridge Prep Centre  
Calgary, AB

[www.prepprogram.org](http://www.prepprogram.org)

174 pages \$29:99 Cdn.

*Reviewed by Diane Gomboz*

This book covers various opinions, inspiring stories and strategies for inclusion. With a user-friendly approach for all parents and professionals, this is an example of real teamwork! All age groups are covered with helpful tips and practical solutions. This book can be used as a resource for anyone involved in educating children with Down syndrome in an inclusive school situation.

## **Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality – A Guide for Parents and Professionals**

Terri Couwenhoven, M.S.

Woodbine House  
Bethesda, MD

[www.woodbinehouse.com](http://www.woodbinehouse.com)

400 pages - \$24.95

The author of this book is the mother of a teenager with Down syndrome and is also an educator on sexuality. Ms. Couwenhoven's unique background enables her to address sometimes challenging issues that children and adults with Down syndrome experience. The book contains practical ideas for teaching children with Down syndrome about their bodies, puberty and sexuality, giving parents the confidence to speak comfortably about these sometimes difficult topics. This book has a "parent" feel – it is written in a non-clinical, easy to read style. It is recommended for parents and professionals who have or work with children and adults with Down syndrome.

NADS members may have heard Terri present at NADS conferences, and she has also presented at many national conventions. We have received very positive feedback from several parents who have read this book – described by one as a "must read."



P.O. Box 206  
Wilmette, IL 60091

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www.nads.org

# Membership Application

Membership dues can be paid online at [www.nads.org](http://www.nads.org)

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\*Please indicate professional involvement: .....

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