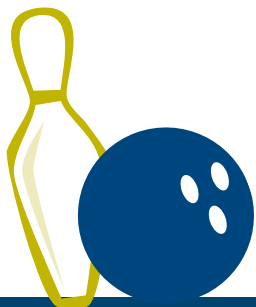


NADS NEWS



The Newsletter of the National Association for Down Syndrome

January, 2009



NADS 24th Annual Bowl-A-Thon

Sunday, March 8, 2009
Stardust Bowl
37 E. Lorraine Avenue,
Addison, Illinois

Registration Check-in
Begins at 11:00 a.m.
Bowling Begins at
12:00 noon

NADS 24th Annual Bowl-A-Thon

*By Sheila Hebein and Bill
McCarthy*

The Bowl-A-Thon is NADS' major fundraising event. The money we raise goes directly towards the critical programs we provide for families. This event has been successful in the past because of the generous support of NADS members and friends. Last year's Bowl-A-Thon raised over \$110,000. We hope you will take advantage of this opportunity to get involved and to support the variety of programs NADS offers—and experience a fun day with friends and family!

New This Year! Online Pledges and Registration for Bowlers

All bowlers must register. Since this is our major fundraiser, many members collect hundreds of dollars in pledges, but a minimum of \$100 is required to bowl.

This year, we are offering a new online resource. We are happy to announce that NADS has partnered with online fundraising service provider Firstgiving™ to give you an exciting new tool to use in gathering pledges for the Bowl-a-Thon. With Firstgiving you can quickly

and easily create your own personal fundraising web page (no experience required) and send it to your friends and family, who can donate by credit or debit card in an easy, secure online transaction. All you need to do is:

1. Create a login for yourself on the NADS Firstgiving web page at firstgiving.com/nads.
2. Build your online fundraising page that will display the NADS banner at the top. You can write a paragraph or two about why you are raising funds,

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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

Exec. Director M. Sheila Hebein

President Jackie Rotondi

Editor M. Sheila Hebein

Bowl-A-Thon

Continued from page 1

- upload your photos or even videos, and set your dollar goal.
3. Email the link to your page to all your potential donors.
 4. Friends and family click on the link in their email to see your personal page and can see your text and photos. They can also see the progress you've made toward reaching your fundraising goal and can read comments left by other donors.

5. Donors can securely use their credit or debit card to donate. They will receive an immediate response that their donation was received, and will receive a receipt that they can use when filing their taxes. It's also easy to send personal thank yous to your donors using the Firstgiving tools.

The Firstgiving NADS page also registers bowlers online. Check it out and create your own page today! Go to www.firstgiving.com/nads.

Other Ways You Can Help

Ask your employer about matching gift possibilities. Obtain items for raffle and door prizes, such as gift certificates or merchandise. Ask businesses you know to sponsor a lane. Sell grand raffle tickets. The grand raffle prize drawing will be held at the Bowl-A-Thon, and winners need not be present. To obtain additional raffle tickets, find out more about lane sponsorship or to donate prizes, please contact the NADS office at 773-327-5508.

We look forward to seeing you on March 8th! ▲

Emma LaMorte

It is not unusual for babies with Down syndrome to go through heart surgeries early in life—almost half are born with heart defects—but Emma LaMorte has already been through four surgeries in the 2 ½ years since she was born. Her most recent heart surgery was in November, 2008. Most of the common heart defects in babies with Down syndrome are relatively easy for surgeons to fix, but in Emma's case, the problems were more complicated. One of her ventricles (the lower chambers, responsible for pumping blood) was too small. Usually the right ventricle pumps blood to the lungs for oxygen, and then the left ventricle pumps the oxygenated blood to the body. In Emma's case, the surgeons removed one of those steps to ease the stress on her heart: now her heart only pumps one way—to the body. After her latest surgery, her blood will circulate to her lungs for oxygen without her heart pumping it there—another miracle of medicine! This surgery should be Emma's last, and her parents are looking forward to putting the medical challenges behind them. We join with all the families who have been concerned about Emma in wishing her a speedy recovery. ▲



Heart Song

By Jennifer Graf Groneberg

Avery loves the piano. He sits tucked in the cup of my lap, where he becomes very quiet and takes quick little breaths, in anticipation. I open the music book to the only two songs I know: "As Time Goes By" and "Someone To Watch Over Me." When I was pregnant with Avery and his fraternal twin brother, Bennett, I'd play the songs over and over, end to end, so that it seemed as if I had a full repertoire.

The piano is a simple upright made of old, dark wood. Some of the keys stick and it's missing one of the knobs that pulls the cover shut. It's a gift from my friend Phyllis, who plays beautifully. She knew of my secret wish to learn and when she saw the piano at a garage sale, nearly abandoned, its keys stripped of their ivories, she thought of me. She brought it home and cleaned the wood,

repaired the broken strings, glued on new ivory. She worked until, for the first time in years, the piano could be played. It was a surprise birthday gift. She gave me a song. A song, and a piano to play it upon. "It has a lovely tone," she said. "You never would have guessed, looking at it."

As I play now, Avery balanced on my lap, I think about his left ear. When he was first born, we were told many things. We were told he needed to be checked for a heart defect

(which he did not have) and for gastrointestinal problems (again, nothing). We were told he would grow slowly, and would most likely have respiratory issues (also, no). And we were told he was deaf in his left ear.

At the time, the news struck me as inconsequential, compared to what seemed to be the larger fact of his life—Down syndrome. Phyllis said, "He's got two ears, right? And the other one works just fine." But I had darker thoughts. I remembered thinking, at least it's not Bennett. I didn't know if I could handle two babies with special needs (I wasn't sure if I could handle even one baby with special needs). Let Avery take it all, I thought. Let him have all the trouble. I wasn't sure I could be Avery's mother, and I wasn't sure how to talk about that fear. I think part of me was angry at him for being born different than I had expected.

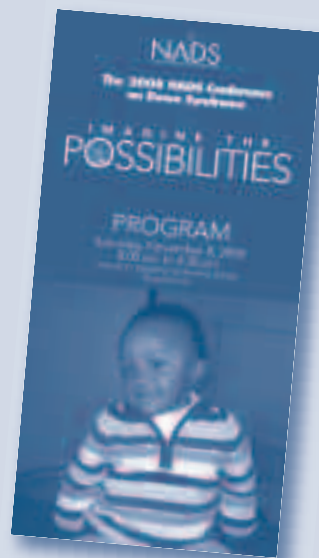
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NADS Conference

On November 8, parents and professionals from the Chicago area and beyond gathered for a day of learning and connecting at the 2008 NADS Conference at the Donald E. Stephens Conference Center in Rosemont. The conference drew more than 600 people. The morning session brought attendees together to hear the keynote speakers, and for many, being in a room with so many other people who shared a connection to Down syndrome was a powerful reminder that they are part of a community—a community filled with many wonderful, resourceful, and caring people. If parents came in feeling burdened by the challenges they face, they only had to look around to realize they need not face them alone.

The first keynote speaker, Patricia Bauer, drew on her experience as a parent and a journalist for her talk, "Something to Look Forward To." The second keynote speaker, self-advocate Carrie Bergeron Desai, spoke about her life experiences, including her recent marriage, inspiring many parents of younger children with the possibilities they might look forward to for their own children. As in past conferences, the rest of the day was devoted to workshops for parents and professionals, including workshops in Spanish for Latino families. Those who attended this year were able to choose from a rich variety, covering all ages and stages. The Conference for Teens and Adults ran concurrently with the main conference.

Many thanks to all who helped out with organizing the conference and assisting the day of the event, to our speakers, and to all who took time out of their weekend to attend. For those who were not able to go to the conference or to a particular workshop, handouts from some of the workshops are available on our website: www.nads.org. ▲



Food for Thought: New Prenatal Test for Down Syndrome

Scientists at Stanford University, the Howard Hughes Medical Institute, and Lucille Packard Children's Hospital have developed a new prenatal test which can accurately detect the presence of chromosomal abnormalities, including Down syndrome. The test involves analyzing genetic material in the mother's blood and would only require a blood sample, which could be drawn without posing a risk to the baby.

Some genetic material from the baby is present in the mother's blood, so if chromosomal abnormalities are present, it should be possible to detect them. However, earlier attempts to develop a test based on maternal blood samples failed because of the difficulty of isolating the baby's cells from the mother's and because of the small amount of fetal DNA present.

The new test developed by lead author Stephen Quake and his team simply analyzes all the genetic material in the sample, without worrying whether it belongs to the baby or the mother. They used their method to analyze blood samples from 18 pregnant women, and their test accurately identified which women were carrying babies with genetic abnormalities and which without. The results of their analysis were then confirmed by amniocentesis or CVS testing.

Further testing on larger samples of women is needed before the test will be ready for use as a diagnostic tool. If the results hold up through additional studies, this test will offer a safer diagnostic method than amniocentesis or CVS, both of which carry a risk of miscarriage. The authors also point to the quicker timeline on results for the new test—a few days vs. several weeks to culture cells, a waiting period which can be agonizing for parents. The new test can also be done earlier in pregnancy, so any problems will be detected sooner. At the moment, screening tests can be done early in pregnancy, but they only assess percentage of risk and are not definitive. Because this new test will be taking into account actual fetal DNA, it can, if the method is validated, potentially offer a diagnosis, just as amniocentesis or CVS can. Quake believes that receiving a diagnosis early in pregnancy will benefit parents and help them better prepare for the future. ▲

*this test [may] offer
a safer diagnostic
method than
amniocentesis or
CVS*



David Jonaitis

Another Successful Fashion Show

Sheila Hebein

On Sunday, October 19th, 2008 more than 700 people gathered at the Donald E. Stephens Convention Center in Rosemont for the NADS 3rd Annual Fashion Show and Luncheon. Prior to the fashion show, we were entertained by Chris Hebein at the piano, followed by the Center Stage Dancers, who never fail to bring joy to everyone with their colorful costumes, creative set, and fancy moves. The self-advocate this year was David Jonaitis. David told about his life with his family in Wilmette, IL – his jobs at Walgreens and Jewel and about his social life.

There were 54 models – some of whom strutted their stuff on the runway on their own, while others were carried by moms or dads (it's hard to walk down a runway when you're only 8 months old). Others were accompanied by siblings, cousins or friends. Some were delighted to be in the spotlight and wanted to hang out and enjoy it, while a few were more reluctant. Some of the models were definitely "cool," and others were more sophisticated; some found the applause to be just too much, while others basked in the attention, but reluctant or eager, each one was beautiful, and I can't imagine a more energetic, dazzling group of models.

I also want to thank the brothers and sisters who accompanied their sibling down the runway – some were escorts, while others coaxed and cajoled the younger children to keep moving – and in the right direction at that!

Thanks also to Ed Renzi, who once again did a wonderful job as MC.

Special thanks to the parents and volunteers who worked so hard to make this such a successful event. Thanks also to the guests who attended, those who donated prizes, bid on items in the silent auction, or sold and bought raffle tickets. I'm pleased to report that more than \$40,000 was raised on this joyful day. THANK YOU ONE AND ALL.▲

Fashion Show Bios:



Mandie Polizzi

Our daughter, Mandie Michelle, was born on February 25, 2008. We knew how special she would be before she was born and could not wait to meet her. Mandie is our third daughter, born just 18 months after twin sisters, Katie and Emilie. Mandie was born with a heart condition, although it did not stop her from gaining weight and remaining healthy. She had successful heart surgery on July 16, 2008. Her quick and amazing recovery surprised her family as well as the hospital staff. We began to see incredible determination and energy in Mandie. She even began rolling over only 12 days after surgery. She is such a happy baby and has a smile that is contagious. She thinks it is so funny to pull on Daddy's beard. She loves spending time with her grandparents and extended family. Her Godfather, Uncle Keith, is proud to be her escort for the Fashion Show. We have been amazed at the support from our family,

friends, and everyone in the Down syndrome community. Thank you! Also, thank you Jen and Brian Hora, our NADS support parents. We appreciate your friendship. We love Mandie and look forward to your exciting future! Proud Parents, Steve & Michelle Polizzi



William Jarvis

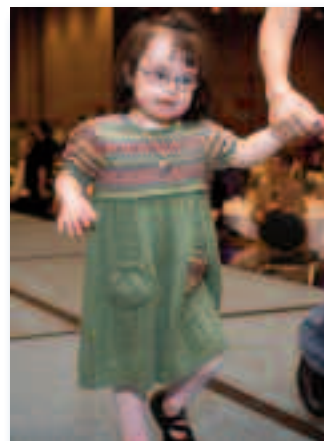
Wil Jarvis (named for his grandfather and uncle), burst onto the scene in November of 2006. He came so fast, he forgot to tell anyone he had Down syndrome. After a short stint in Children's Memorial Hospital, his parents, Jim and Tanya, happily brought him home. They had no idea what they were in for.

In no time, Wil busied himself defying his therapists by rolling over, both ways, at 1 month of age. By 6 months we knew we could quell his crying fits by handing him over to a pretty lady – any pretty lady. The flirting continued with constant kiss-blowing and by 1 ½, we knew to add an extra 10 minutes to each grocery store trip. Various clerks and cashiers need kisses from Wil, and they get their wishes every other Wednesday around

2 p.m. at the Jewel – if anyone else is interested.

Wil loves music. He head bangs to it, and he plays the drums as loud as humanly possible on any and all hard surfaces. Clearly his personality is such that a Mohawk was the only option for his hair. He is also a truly magnetic little person. People don't pass him up or avert their eyes or even act uncomfortable around Wil and his mom and dad. They stop. They play with him. They ask his parents questions about Wil and Down syndrome. Most importantly, they seem to walk away a little changed, a little more understanding and a little happier.

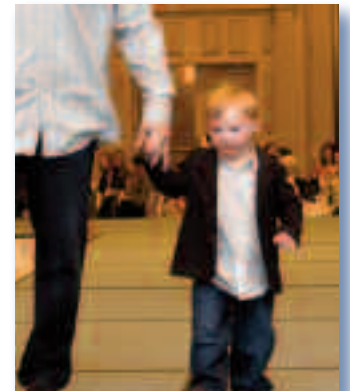
Wil Jarvis has got big plans for this world. His parents can't wait to see what he does. His parents couldn't be more proud to be a part of his world and family. Rock on "Little Dude."



Maddy Gillespie

Madeline "Maddy" Gillespie is 4 years old this month! She will be attending her 2nd full year at Stock Preschool on the Northwest Side of Chicago. She started to ride the "big yellow bus"

when she was only 2½ years old. She could not even see over the window near her seat at that time. She loves the bus ride and gives the driver and her aide hi-fives and kisses each day. Maddy has 2 siblings, Sarah (5) and Liam (1). Maddy and Sarah are the best of friends so obviously, Sarah is walking the runway with Maddy. Maddy adores her younger brother, Liam, and is very affectionate and gentle with him. Maddy takes 2 gymnastics classes a week and also plays soccer on the lakefront! She likes to climb over furniture and jump from window sills, with her sister by her side. Maddy loves to sing to the Annie soundtrack and dance with her Daddy to Frank Sinatra. Maddy is a wonderful daughter, friend, and sister, and we are all so proud of you and we love you!



Brogan Hora

Brogan exploded onto the scene in December 2004. With his blazing red hair and piercing blue eyes, Brogan cannot help but melt hearts. Brogan is a big fan of the silver screen, and any Pixar production is high on his list. Brogan

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Fashion Show

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loves to learn. It seems from day one, he was fascinated by books. He loves school and the challenges it brings. Being a preschool trendsetter at Deer Path School in Cary takes a lot of time and effort, yet Brogan always finds time for a friendly wink, hug or a kiss. But it is not all work for the 'Bear.' Brogan's little brother, Gavin, loves to play and spend time with his big brother and mentor, 'Brogie.' Brogan loves hockey, baseball, and cannot get enough of Hi-5, Yo Gabba Gabba, and Gigi's Playhouse. Brogan's future is bright, and his personality will only endear him to everyone he meets.▲

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Model bios written by family members for the Fashion Show Program.

Photos by Kelley Demas Photography, www.kelleydemasphotography.com; (847) 650-5163.

Editor's Note: Other Fashion Show models will be featured in future editions of NADS News.

Blueprint for System Redesign in Illinois

Many of you may have seen an earlier article in NADS News or elsewhere about where Illinois ranks in its services to people with developmental disabilities. In the most recent State of the States report, Illinois is ranked towards the bottom in many categories and is dead last in providing community-based residential options and services. In response to Illinois' abysmal record, the Illinois Council on Developmental Disabilities and the Human Services Research Institute are developing a plan, The Blue Print System for Redesign in Illinois, to increase community based supports and move Illinois away from its reliance on large institutions.

The Blueprint is a seven year plan, starting in June of 2008, to change the way services are delivered. It covers everything from access to the system to the infrastructure through which services are provided. The plan addresses problems in Illinois' current system, including underfunding; lack of choice; the inefficiency of relying on large state institutions, which are more expensive than community-integrated residences and also generally offer a poorer quality of life; and the large numbers of people on waiting lists.

This proposal has the potential to bring about a number of positive changes in Illinois. If the Blueprint is successfully implemented, individuals with disabilities will have more opportunities to stay in the communities they know—and to stay close to their family and friends—and the state will have a more flexible, efficient, and humane system for meeting the needs of individuals with disabilities.

We encourage you to learn more about the Blueprint for System Redesign and to let your legislators know what you think. The Illinois Council on Developmental Disabilities is sponsoring a series of Blueprint Town Hall Meetings across the state, where residents can ask questions and learn more about the plan. For additional information or to find out about the next Town Hall Meeting, contact the Illinois Council on Developmental Disabilities at (312) 814-2080 or go to www.gettoknowtheblue.org. If you would like to become more involved in legislative issues, you can contact Cathy Morgan, NADS Legislative Co-chair, by calling the NADS office at (773) 327-5808.▲

Agreement with State Provides Housing Choices for People with Disabilities

In November 2008, the State of Illinois struck a deal to avoid trial in a class action lawsuit filed three years ago on behalf of nine adults with disabilities who had been living in large institutions. The federal lawsuit maintained that the facilities were not able to provide appropriate services and that the state had denied plaintiffs the option of a community-based residence by denying funding. The deal agreed to by the state would ensure evaluations of all people with developmental disabilities currently in large institutions to determine their needs. Those who would be better served by a community-based group home will be able to move to one within six years, and the state will be required to pay for it. The agreement is subject to approval by a federal judge.▲

Behavior Retreat

Each spring, NADS holds a Behavior Retreat for NADS members whose child with Down syndrome has an additional diagnosis, such as Autism or ADHD. If you would like to get more information about this year's retreat, please contact the NADS office at 773-327-5808.▲

Heart Song

Continued from page 3

We scheduled an appointment to have Avery's hearing retested when he was three months old. The test was inconclusive. We went again when he was nine months old, and he passed. The audiologist said, "This is the most beautiful tympanogram I've ever seen. I wish all children had such clear ear canals."

Sometimes when I play the piano—Avery sitting on my lap, the solid, undeniable weight of him—I look down at his left ear, and wonder about the failed hearing test. I have all sorts of theories: there was fluid in it from the C-section. Or, the machine malfunctioned. It was simply a bad test. Or, his ear canals were too small. He just needed time to grow.

I needed time to grow, too. I needed time to forget the son I imagined I was having, and allow this new son to show me who he is. At three years old, Avery is a boy who loves music. He loves to read. He loves our elderly cat, Cosmo, and tends to him with sweet concern. He will eat oatmeal until his little round belly looks likely to pop; or yogurt; or

apples; or peas. He will pick the meat out of a sandwich and eat it, but discard the bread; he dislikes potatoes. He has a weak spot for spoonfuls of raspberry jam, straight from the jar.

I have learned, too, that Down syndrome is a part of Avery, but not the most interesting part. There is more to him than meets the eye; a whole person you might never have guessed at, just looking at him. If I can learn that, maybe others can, too. These are my hopes, and my hopes are the notes of our song. Avery is bouncing his legs and clapping his hands to the sound from the piano, the only child of mine who can keep a beat. Soon Avery is plinking the keys too, and I am forced to abandon my usual repertoire and go off the page. We play together, he and me, a boy and his mama, making music from the heart.

.....
Jennifer Graf Groneberg lives and writes at the end of a twisty gravel road with her husband of fifteen years and their three young children. She is the author of Roadmap to Holland: How I Found My Way Through my Son's First Two Years with Down Syndrome (NAL/Penguin, 2008). You can read more about her and her family at www.jennifergrafgroneberg.com ▲



Zach Wincent

Royalty for a Day

A survey of newspapers around the country from the fall of 2008 reveals an interesting trend—a number of young men and women with Down syndrome were elected by their high school classmates to their school's Homecoming Court. Kristen Pass was named Homecoming Queen at Aledo High School in Texas. Victoria Alba was selected to be Homecoming Queen at Abraham Lincoln High School in Iowa. Annie Bright was chosen by her peers at Mary G. Montgomery High School in Alabama. Jesse Campbell was elected Homecoming

King at Choteau High School in Montana. Kelli Stein was named Homecoming Queen in Hankinson, ND, and in the Chicago area, Anne Jennings was chosen to be Homecoming Queen by her classmates at

It is encouraging to see these individuals receive this kind of affirmation from their peers.

Libertyville High School (Anne Jennings' story was covered by the Chicago Tribune in their October 18, 2008 edition and by the November 2008 newsletter of the Down syndrome Development Council, available at www.theddc.org). In addition, last spring, St. Charles resident Zach Wincent was elected Prom King when he was a senior at St. Charles North High School—which we covered in the July 2008 edition of NADS News.

It is encouraging to see these individuals receive this kind of affirmation from their peers. We hope that schools will continue to nurture a culture of acceptance and inclusion so that all students with Down syndrome can be appreciated for their particular gifts. The list above, which covers states from many different parts of the country, suggests that some teenagers with Down syndrome are already being recognized as integral, valuable members of their high school communities.▲



Holly-Days Donation

Dear NADS,

Please accept this donation on behalf of our son Nathaniel's 6th birthday! As you know, I have been hosting a "HollyDays" event for the past 3 years to celebrate and honor our amazing son. This party is becoming one of the most anticipated events of the Holiday season. The night includes 11 local artists who sell their wares and donate a portion to NADS. Not only are the vendors fantastic but friends of ours donate their house for the night as well. This year's house was one of the most beautiful houses in our neighborhood. The evening was jammed with people, from near and far. It always amazes me how people just have to meet Nathaniel once and they are ready to help with this event in any way that they can.

I have always known that Nathaniel was a gift to us. A magical human being brought here to do bigger things than I have ever imagined. As each year passes, I am more aware of his gifts. A woman in line at the store just yesterday said to me, "If only everyone was as friendly as he is . . ." From Nathaniel's simple "Your name?" question to "You're pretty," he warms and brightens even the gloomiest of days. May we all celebrate these amazing children not only on their blessed birthdays but each and every day. I thank God that I am Nathaniel's mom and with NADS there to guide and hold the hands of all new moms, my wish is that they too feel the same way. Happy 6th Birthday, Nathaniel.

Sincerely,
Holly Simon

Holly Simon donated \$1,695.00 to NADS. Thank you, Holly, for your generous donation—and happy birthday to Nathaniel! Many thanks to all who helped make the HollyDays event this year a success.

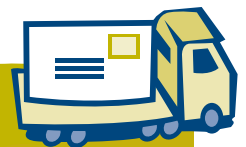


Dress Down Day at St. Francis Xavier School

On October 17, 2008, St. Francis Xavier School in Wilmette held a "Dress Down for Down Syndrome Day," which raised more than \$500 for NADS. At the most recent NADS Fashion Show, Caroline Waltman presented Sheila Hebein, NADS' Executive Director, with the money given by the students. Thank you to all involved with this event!▲

Mokena Makes Another Donation to NADS

Last year, we reported that NADS had been nominated by NADS member Ellen Bailey to receive a donation from the Mayor of Mokena's Charity Foundation. This year, we were nominated again and selected again! The Mayor of Mokena's Charity Foundation recently sent NADS a check for \$600. Thanks again to the Mayor of Mokena.▲



Moving?

Please be sure to let us know when you move so that we can continue to get NADS News to you. If you e-mail Kathi Rutili at krutili@nads.org and provide your OLD and NEW addresses, Kathi will update our mailing list. Please put "NADS News Address Change" in the subject line. Or, you could let us know of the change via snail mail at: NADS - P.O. Box 206, Wilmette, IL 60091.▲

The PACE Program:

An Educational Alternative

By Linda and Bob Hauser

The PACE Program is a two-year postsecondary educational program affiliated with National-Louis University in Skokie, Illinois. The goal of the school is to provide students with the skills necessary to allow them to become productive and independent adults. In other words, to create an environment in which "work is accomplished, play is learned, love is felt, and life is enjoyed." A class of 25 new students is admitted each fall.

Our daughter, Alexandra Hauser, is in her second year of the PACE Program. During the application process, we had to provide school records and recommendation letters. Also, Alex had to interview with the administrative staff.

Alex has a full life at school. She lives in a dorm with a roommate from Washington D.C. She spends three days a week at an internship site. This year she is working in the laundry at a local hotel. She attends classes the other two days. During the evening and weekend hours, she has many social and fun activities.

On a work day, she takes public transportation to her



Continued on page 11

Parents Alliance Employment Project

The Parents Alliance Employment Project is now accepting applications from high school students to receive individualized job development, job placement, and job coaching services under a grant funded by DuPage County/DuPage Workforce Development. This youth grant is unique in that students can begin adult services during their last year of high school to ensure success upon graduation.

The Benefits of Beginning Adult Services Early:

Students will benefit from overlapping school vocational services, while receiving individualized employment services from a PAEP Employment Specialist.

Unlike school personnel, PAEP Employment Specialists are not limited to certain hours of the day for job coaching (i.e., if a student gets placed at a restaurant, a PAEP job coach will be available to coach in the evening and on the weekends).

Student will most likely be placed in a job before graduation and therefore will be ready for the adult world earlier.

There will be no waiting time for adult services upon graduation.

For more information, please contact either Ami Sedan at **630.955.2077** or Sarah Pasch at **630.955.2078**.

Internships and Mentoring Programs for Students with Disabilities

The Midwest Alliance, a collaboration between the University of Wisconsin, the University of Illinois, and the University of Northern Iowa, is offering internships and mentorship programs for high school and college students or alumni with disabilities. Mentees are provided with stipends of \$200 and mentors \$300 for a 16 hour commitment. The Midwest Alliance also offers students and recent alumni assistance in finding internships and provides \$500-\$1,000 in stipends. Applications and lists of eligible majors and fields are available on their website: www.stemmidwest.org.

For more information, please contact one of the Outreach Coordinators:

For Wisconsin and Eastern Iowa:

Dan Nordstrom
(608) 890-0992; dnordstrom@wisc.edu

For Illinois and Western Iowa:

Tina Lam Rolfe
(217) 244-1571; tinarolfe@illinois.edu

Letter from the Krickl Family

Dear NADS,

In celebration of Down syndrome awareness and our son Henry, please find enclosed some donations to be used as you see best.

My husband mentioned to his co-workers at MF Global that we were collecting donations to benefit NADS, and they responded with great generosity. We were overwhelmed by their kindness. Our family has greatly benefited from your newsletter and the support you provide to many families. Thank you, and please continue your outreach.

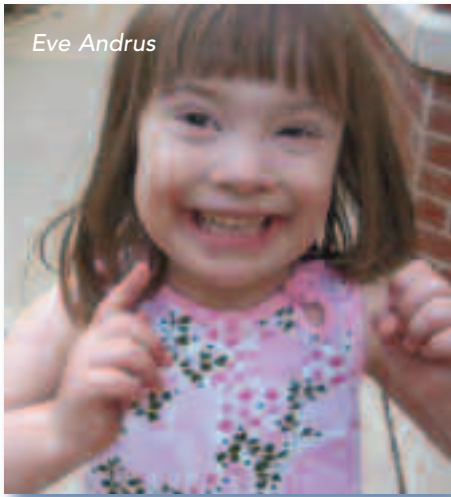
Kind Regards,

The Krickl Family

And our friends as MF Global

.....
Our heartfelt thanks to Bill, Nancy, Marty, Jack, Andy, and Henry Krickl and to Bill's colleagues at MF Global for their gift of \$2,100. We are grateful for their generosity.

familyalbum



Eve Andrus



Jeremiah Carter



Eddie Sitzman

Quincy Bane

Zach Borst



Lily Thompson

We are always looking for good pictures to use in NADS News and other publications. You can send photos to shebein@nads.org – but please note that we cannot process large numbers of photos sent electronically. If you could limit your submissions to a few at a time, we would appreciate it!

PACE

Continued from page 11

job site and works a full day. Her on-campus days include three or four classes, such as assertiveness training, computer technology, life skills (such as money management, time management, organization and personal care), social skills, art or music, and consumer math. In the evening, she has free time, dinner with friends and a number of evening options that might include a meeting, doing homework, working out at the fitness center, hanging out with friends and doing chores like laundry and cleaning. Every weekend a different group activity is planned, such as a trip to a Northwestern football game, dinner and a movie, bowling, or even a dinner dance.

Alex is enjoying her time at PACE. She loves the independence, her job and the new friends she has made. She does her own laundry, cleans her room, does her homework, is involved in several clubs, goes to the fitness center, takes the bus, writes checks for spending money and budgets her money. When she graduates from PACE in June 2009, we're hoping that she'll have the opportunity to participate in the PACE Transition Program, which focuses on apartment living, getting a job and participating in the community.

As parents, of course, our dream for Alex is for her to have a life of her own that is productive and as independent as possible. We're glad we found the PACE Program for her, to give her the chance to experience a college atmosphere and begin a transition that helps her become an independent, vital and happy young woman with a full and complete work and social life.

If you're interested in more information on the PACE Program, you can go to the National Louis University website. Or, contact Carol Burns, the Director of the PACE Program at 1 224 233 2000.

Other Post-Secondary Resources

College Living Experience
(800) 486-5058; www.cleinc.net

Elmhurst Life Skills Academy
(630) 617-3752; <http://public.elmhurst.edu/elsa>

Shepherds College
(262) 878-5620; www.shepherdscollege.org

Call for Input

The Adult Issues Committee would like to get input from NADS families on the types of support they would like us to provide. We are also looking for more information about how adults with Down Syndrome are involved in their communities, including volunteering or community service work. Please send your stories or suggestions to info@nads.org. ▲

BOOK REVIEWS

I Just Am

By Bryan and Tom Lambke

Five Star Publications, 2006; \$14.99

Tom Lambke has written two books about his 27 year-old son with Down syndrome, Bryan. The first book, *Spirit, Courage & Resolve: A Special Olympics Athlete's Road to Gold*, covers his family's experiences with Bryan, culminating in Bryan's participation in the 2003 Special Olympics in Ireland, in which he won a gold medal in Unified bowling. The second book, *I Just Am*, was co-authored with Bryan. The book shares Bryan's thoughts about his disability and his dreams, as well as information about Down syndrome. You can view a short video on *I Just Am* at www.youtube.com/watch?v=XYdkWGuYWWU. For more information about the book, go to www.ijustam.org. Both books are also available through Amazon.

America According to Connor Gifford

By Connor Gifford and Victoria Harris

Hargrave Press, 2008; \$24.95

Connor Gifford, a young man with Down syndrome, has written a history of America and its 400 year effort to "get it right." His book, which touches on civil rights, women's rights, why wars begin, religious freedom, and individual responsibility, includes his reflections on major events in our country's history, accompanied by a number of his delightful pictures. His book was endorsed by Tim Russert and featured on the Today Show and is available through the website www.connorgifford.com or through Amazon.

A Soup Opera

By Jim Gill

Jim Gill, 2008; \$22.00

Local musician, author, and child development expert Jim Gill has just released a new book and CD. His latest sing along picture book, *A Soup Opera*, is about a man and a bowl of soup and was inspired by his work with orchestras across the country. His previous work has won awards from organizations such as the American Library Association and the Parents' Choice Foundation. For twenty years, Jim Gill directed music programs for families of children with special needs in the Chicago area. He maintains an active schedule presenting concerts of "music and play" to families across the country. For more information about his products and concerts, go to www.jimgill.com.



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www.nads.org

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Membership dues can be paid online at www.nads.org

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Address:

City: State: ZIP:

Phone (home): Phone (work):

Email Address:
 Please add me to the NADS e-mail alert list

Category of Membership (check one)
 Parent \$25.00 (1 Year) \$70.00 (3 Year) Child's birthdate:/...../.....
 Professional* \$30.00 (1 Year) \$85.00 (3 Year)

*Please indicate professional involvement:

Donation level: Contributor (\$100+) Benefactor (\$500+) Patron (\$1000+)

Check if Renewal

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\$20 per recipient should be enclosed and sent to:
 National Association for Down Syndrome (NADS), P.O. Box 206, Wilmette, IL 60091

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