Mateo is 4 years old and is in preschool. He is charming and always admires a pretty girl. I am proud that he can identify the letters of the alphabet and the corresponding sound of the letter. He is also starting to count numbers up to 10. He is being raised bi-lingual, English and Spanish, and is saying words in both languages.

My favorite moments with Mateo are when I watch him play and see him use his imagination, and when his curiosity is ignited so that he begins to explore how something works. He has figured out how to turn on the DVD player so he can watch his favorite movies like Cars, Toy Story, and Frozen. He is a total techie, figuring out on his own how his iPad works and the different dimensions of apps. At times I notice the language of his apps and or the iPad is set to a foreign language, German or Russian, and it does not faze him… he zooms right along almost as if he understands these languages.

What I love most right now is that I can finally hear his voice! I have waited 4 long years to hear him speak and his voice is beautiful.

When he was born I wish I had known all the love he would receive from family and friends and most importantly, what a rock star he would become! He must have at least 50 honorary aunts and uncles and the list keeps growing….. Mateo has been on CBS news (Christmas Day feature story), appeared in the Chicago Sun-Times and featured as an out-patient at the La Rabida Children’s Hospital Gala Fundraiser. This past year he walked the runway for the first time at the NADS Fashion Show.

I was nervous when he started school this year, afraid that he would not be accepted and that he would not learn in the classroom. I am thankful that my fears were unfounded. Mateo has many friends in school and his teacher is happy to have him in her class. Mateo is indeed learning and thriving in the inclusive environment of his classroom.

Two bits of advice for parents of young children: Love! and Early Intervention.

Love! Love your child from day one with all your might and you will see how quickly they respond. We all go through some soul searching of sorts when we first learn of the DS diagnosis; if we didn’t we would not be human. However, don’t let the diagnosis stop or even delay you from showering your child with lots of true love. Early Intervention is key! I remember being told by my son’s therapist to do leg exercises on him after every diaper change… sounds easy but so difficult when your baby is barely 3 months and he cries each time you do so… you must focus on the big picture and realize that these exercises will help him/her walk better when the time comes and they did!
Bowl-A-Thon Thank You

We are grateful for the many people who made this year’s 30th annual Bowl-A-Thon a success. Thank you to everyone who obtained sponsorships or prizes; who bought or sold raffle tickets, who signed up to bowl, raised money through pledges, and brought family and friends; or who volunteered the day of the event, including members of the NADS Board and NADS Self-Advocates. A special thank you to Ethan Drower for filling in for Rick LaChapelle, who was not able to attend this year, and doing a great job with the announcing. We are grateful for the many people who came to the event and made it a fun day of community. Your support makes it possible for us to continue to serve people with Down syndrome and their families through our conferences and our Parent Support, Hispanic Outreach, Resource and Referral, Hospital In-Service, Public Awareness, Self-Advocate, and More than Down Syndrome programs.

Bowl-A-Thon Grand Raffle Winners

1st Prize: Two Tickets to a 2015 Bears Game in the United Club—Karen Landmeier
2nd Prize: Samsung TabS 16GB—The LaMorte Family
3rd Prize: Strider Bike—Mary Ann Steinbis

New Website for NADS

Our website has a new look! We invite you to visit our redesigned website at www.nads.org, and we also encourage you to sign up for our email mailing list.

ADSC Fitness, Fun for Everyone Run/Walk

The Adult Down Syndrome Center (ADSC) is making plans for a third annual 5K Run/3K Walk to be held May 30, 2015 in the neighborhood surrounding the ADSC office at 1610 Luther Lane, Park Ridge, IL. Last year we welcomed over 200 participants for a morning of fun, exercise, celebration and fund raising. To add to the fun, this year we will feature a DJ, medals for all participants with Down syndrome, and a demonstration by our Zumba class.

The event will begin at 8:00 am on 5/30, with registration at 7:15 am. Fee will be set at $30 per person; persons with Down syndrome will be free. Visit advocatehealth.com/ADSCRun2015 for details and to register. All proceeds from the race will benefit the ADSC’s health and fitness programs. Mark the date on your calendar and plan to join us. If you have any questions, please call Merrily Smith at 847-318-2310 or Grace O’Connor at 847-318-2304.
Hi, my name is Aubrey Soukup. When I first heard of NADS, my friend Amanda Miller came to my house and her and my parents were talking about it. As I was sitting and listening, I just remember a few facts about NADS. My brother Austin had mentioned about the Magic Show he went to with Amanda and he told me how much fun it was. I didn’t know anything about NADS but I asked if I could go, then Amanda mentioned about the Bowl-A-Thon, and then I got very interested in going to that event. Then I heard about the Fashion Show and all the events help raise money for the Down syndrome community. I told my mom I really wanted to go so as 1 week went by it was Sunday March 8th when Amanda Miller came to pick me up. Once we got there, there was an auction and all I could think about was getting the wide screen TV. I was also so excited to bowl! I got to meet Amanda’s sister Mallory with Down syndrome, but we got to eat lunch together and I could see how we could be best friends. I could only see her fun outgoing personality. I won a stuffed monkey and of course that’s my favorite animal. After I got a strike, then I won a stuffed animal monkey. Right before I left to go home, I was thinking to myself I want to come to more NADS events. I had the best time ever. I forgot to mention I got to meet Ronald McDonald, then someone took a picture and put it on the NADS Instagram page. That was the best time ever. I could not thank you enough. It was a true honor for me to be there supporting the Down syndrome community, and thanks for the experience meeting a whole new group of people I can call Friends!

First Time at the Bowl-A-Thon
Aubrey Soukup

Dream Riders Equine Assisted Therapy Program

This program at the Midwest Center For Children’s Development in Crystal Lake, IL enables children with special needs to accomplish therapy goals while also experiencing the joys of riding on a horse. Equine assisted therapy can help children with sensory processing; core strength, balance and posture; ambulation; and body awareness. For more information, go to www.mccdtherapy.com.

Special Gifts Theatre

Special Gifts Theatre (SGT) is a creative drama program for children, youth and adults with special needs. At SGT, the stage is used as a platform to develop social and emotional skills, speech communication and self-confidence. Learn more about our programs by visiting us at www.specialgiftstheatre.org or calling 847-364-7704. Registration is now open for a variety of programs in multiple locations:

Creativity in Motion
Ages 7-17 years old
Summer Session: Dance & Music Academy, Glenview, Wednesdays 5:30-6:30, June 17-Aug. 5
Theme: A Trip Around the World Through Musicals

Musical Theatre Program
Ages 10-21 years old
Winnetka: Tuesday or Wednesday 4:15-5:30, Sept. 2015 - March 2016
Performance: Shrek Jr.
Performance TBA
Performance TBA

Creating Outside the Lines Adults (18+)
Summer Session: Starland in Deerfield, Thursdays 6:15-7:30, May 28-June 25
Theme: Improv
Fall Session: Sunset Ridge School in Northfield, Monday evenings Sept.-Dec.
Performance: Guys and Dolls

NADS at the NPN Disability Fair

NADS board member, Nancy Andrade, represented NADS at the Neighborhood Parents Network Developmental Differences Resource Fair on March 8.
When we received news from our daughter and son-in-law that they would be expecting a baby in October we were excited beyond belief. This would be our first grandchild. My husband and I both spent our careers teaching special education. He had been retired for 5 years and I was to retire in June. What perfect timing! We would have so much to look forward to!

Our excitement began a little sooner than expected when I was returning home from caring for my mother, who was critically ill. When my flight landed for a layover, I received a text message from my daughter that she had gone into labor and was in the hospital. She had been blessed with a wonderful pregnancy, and labor and delivery went perfectly. After seeing our precious Owen Michael born and resting in the loving arms of his parents, Sara and Mike, we went home for some much needed rest.

While trying to calm down enough to sleep, I couldn’t stop thinking about the beautiful boy I had just left! I remember feeling that way when my own children were born, but there is something different when it is a grandchild. He is such a striking mix of his parents… he looks just like a miniature of Mike, but with Sara’s strawberry blonde hair. It feels like his bright blue eyes can see all the way into my soul. I knew from that first night he was born he would have so much to teach us.

We were very surprised by a call from Sara a few hours later telling us that Owen had experienced some breathing problems and was now in the NICU. It wasn’t until the next morning that we were told that Owen showed some “soft markers” for a possible chromosomal abnormality, but he did not have enough signs that would indicate a specific diagnosis. They would run a chromosome study but it could take up to two weeks for results.

In the meantime, we watched Sara and Mike sit by his side day and night. What should have been a time of joy and excitement became a time of fear and helplessness. It was clear they were in so much pain watching Owen struggle and not be able to make it better. Of course, we as parents were experiencing the same pain! No matter how old our children are, it is so difficult to watch them suffer in any way. What words could we say to comfort them? What could we do for them to make this time of waiting and watching more bearable?

After nine days of watching Owen make steady progress toward breathing on his own, gaining weight and resolving his heart issues, the neonatologist approached the cubicle. It was clear he was there to deliver some news. He entered the room and very curtly said, “It is confirmed. He has Down syndrome.”

I was shocked; not by a diagnosis of Trisomy 21, but by the insensitive and uninformed way the news was given. As I watched Sara and Mike fall apart before my eyes, I struggled to think of what to do or say to comfort them. All I knew was how much we had all loved Owen since the minute he was born. I turned to them and said, “I have watched you sit here for the last nine days loving this little boy with all your heart. Just because someone came in here and put a label on him does not change who he is! Do not let that label define him. His name is OWEN! It is not Down syndrome!”

I now watch with so much pride as this loving family grows together. Of course there are struggles! It is so hard not to worry. What will the future bring? What will the best education options be for him? Will he get a job? Will he live on his own? I try to encourage them to live in the moment. It seems cliché to say “take one day at a time,” but I know if we don’t we will miss out on so many wonderful experiences with him. When we allow ourselves to live in the moment and only think about what Owen needs right now, he guides and teaches us about what is important in life.

To me, Owen is just like most 5 month old babies! He breastfeeds like a champ, but also takes a bottle easily. He needs 2-3 naps per day or he gets fussy. He loves to have people play on the floor with him during tummy time. He smiles, babbles, and blows bubbles at us. He enjoys having books read to him and songs sung to him. He loves to put everything in his mouth. Owen has developed a personality all his own! If he is in a cranky mood and I sing “You Are My Sunshine” to him, he stops crying or fussing and smiles. Oh how this little man can melt my heart! Sure his muscle tone could be better and we have to work on not letting him arch his back. He needs encouragement to use both hands and is working on rolling from his back to his tummy. But, when we do these therapy exercises with him, Owen doesn’t know we are doing therapy. He thinks we are just playing and having fun!

Owen Michael has blessed our family and filled me with hope. I have seen so much change in awareness and acceptance in the past 40 years of working with individuals with disabilities. I look at Owen and know he can teach others what it means to have different abilities. He will show all of us that the sky is the limit!
What did Sami do to prepare for her first communion? What did you have to do to make sure she was ready?

Sami attended Sunday School with the other 3rd graders all year. Her teachers were fantastic at modifying materials and helping her follow along with her classmates. We also attended church together each week and she followed along with the order of the service. Our pastor is very welcoming and involves the children beautifully through his children’s sermon. He and Sami have connected in the most beautiful way and she listens so intently to him. My husband I were raised Catholic and Sami’s 2 older siblings received their sacraments in the Catholic Church. Sami just did not “connect” to the services and I just did not feel she was getting the message. All Saints Lutheran Church in Orland Park provided just that, not only for Sami but for all of us. We have been welcomed with open arms and the church has many of the traditions similar to our background in the Catholic Church. Sami just did not “connect” to the services and I just did not feel she was getting the message.

Describe the day— how did it go?

It was a very happy day and very sentimental. Our family was joined by extended family and friends. Many of the friends were able to join us at the communion rail when Sami received the gifts of bread and wine. She was very sincere and very prayerful throughout the service......until she realized that receiving the gifts of bread and wine meant that she no longer receives the blessing (Don putting his hand on her head). So, Pastor Don has promised her that even though the bread and wine are GOD’S blessings.....he will add in blessings of his own each week to her as well. :)

How has this event made a difference for you and your family? For your church?

This entire experience has made the experience of church and communion more “real” for us. Every Sunday the service feels like a celebration and a reunion with friends and God. We feel more connected to our faith after watching Sami blossom and grow in her own faith. She has become quite a celebrity in the church and brings joy to the service through shaking hands, dancing in the aisle when the choir sings a particularly “upbeat” song, and in being the very first to sit at the front even before Pastor Don calls up the children for the sermon (it has somewhat become anticipated that Sami would be sitting there before he even turns around).

What were your favorite memories from the day?

My favorite parts were Sami being called up front when all of the communicants were introduced and she looked out at all of the people with a look of awe. She also had such a sweet and sincere face when Pastor Don finally handed her the bread. Then, afterwards, we had a celebration with several of our friends. Watching her celebrate, dance and smile was priceless, but also watching her hug each and every guest as they were leaving as she told them thank you melted my heart.

Editor’s Note: Photo courtesy of CurlyGrace Photography. For more information, please visit their Facebook page.

Sami’s First Communion  An interview with Deb Mirabelli, NADS Board Member

Update on Michael Johnson

Michael Johnson, a Chicago area artist with Down syndrome, has some new achievements to add to his impressive record: four of his paintings won in a contest for artists with disabilities, the ACTion Art Juror’s Choice Award, which is sponsored by Artists Creating Together. The winning artists received a cash prize, and their paintings will also be entered into an international art competition, ArtPrize 2015. Michael Johnson’s award winning paintings are featured in the following Facebook post: https://www.facebook.com/ArtistsCreatingTogether/posts/736497366465194Congrats. Michael’s paintings were on display in Long Island for World Down Syndrome Day, and he will also have a display at the Amway Grand Plaza Hotel in Grand Rapids during September and October—just in time for Down Syndrome Awareness Month. His art can also be viewed on his website: www.artistmichaeljohnson.com.
Long before our daughter Gina was born, our family was committed to our church and the many activities that go along with our participation. It is much more than a place for us to worship; I have often referred to it as our spiritual health club. Many of the members of our congregation are like family. It’s a comfortable place where we are always welcome.

Although there is no program for special needs children, we have always found a way to include our daughter. The accommodations have always been embraced by the staff and congregation. Over the last 19 years, Gina has participated in Sunday school, youth group and lighting candles for the service. She is now a deacon in the Presbyterian church, and each Sunday she greets and passes out bulletins before the worship service. Most recently she has visited some of our elderly shut-in members as part of the Deacon visitation team.

Our particular church has a membership of 262 people. Small enough to know all the regular attendees and to notice visitors when they walk in the door. In seeking to be more hospitable, we created a welcoming coffee shop area (known as “Holy Grounds”). Most Sunday mornings, Gina and I head to church early so we can set up and start brewing our 3 kinds of coffee. Because there are many volunteers that staff the coffee area, we have a specific routine to follow so there is consistency to our set up and coffee brewing. This routine has provided a very easy task list for Gina and me to follow. Doing these jobs weekly has been a good way to teach Gina what it takes to run our coffee area. She is most helpful with bringing carts from the kitchen, unpacking the carload of supplies and putting them in their assigned spots.

At this point in time Gina prepares the serving table by counting coffee cups (so we know how many people we serve), putting out napkins and small plates, making cookie trays and setting out the apple juice in a pitcher. When the coffee is finished brewing, she carefully carries out the air pumps and sets them in the correct order so no one goes to get Decaf coffee and ends up with Hazelnut! She also assists in setting up the station with all the coffee fixings, such as cream, sugars, various cappuccino mixes and hot chocolates.

When people arrive, she is happy to greet them. She always has something to share with them, whether it’s her newest Special Olympics medal, a picture of her most recent heart throb or something from the Sunday morning newspaper. People always look forward to her greetings and it makes them feel welcome!

Although I do not think she will be working at Starbucks anytime soon, I know that this consistent weekly activity has given her self-esteem, confidence and the feeling that she is a valued member of our congregation. I marvel at the relationships she has created over the years, and I know that there are many who see her as a contributing member of our church.

Resources for the Church

Adaptive Finding God Program
Loyola Press
This program for children with special needs uses a multisensory approach to teach children with disabilities the basics of the Catholic faith. It is designed to be used by parishes, schools, and families. For more information, go to www.loyolapress.com/adaptive-finding-god.htm or call 800-621-1008. Loyola Press also has other special needs resources.

Joni and Friends International Disability Center
Joni and Friends provides many resources for churches trying to start a disability ministry as well as a search tool for finding churches with existing disability ministries. To learn more, go to www.jonifriends.org/church-relations.

Bethesda Lutheran Communities
As part of their commitment to enhancing the lives of people with developmental and intellectual disabilities, Bethesda Lutheran Communities has developed a series of resources for people with special needs, including prayer books and books for children. To learn more, visit www.bethesdalutherancommunities.org/FaithResources.

UPCOMING EVENTS

ADSC 5K Run/3K Walk
May 30
8:00 a.m.
Adult Down Syndrome Center
1610 Luther Lane
Park Ridge, IL
www.advocatehealth.com/ADSCRun2015

NDSC Convention
June 25-28
Phoenix, AZ
correction.ndsccenter.org

10th Annual NADS Fashion Show
October 18, 2015
Donald E. Stephens Convention Center
Rosemont, IL
630-325-9112
Farewell to Tim Nemec

Sheila Hebein, Former NADS Executive Director

I am sad to tell you that our friend Tim Nemec died February 16th, one day after his Dad’s 82nd birthday. He was 36 years old. There was a wonderful celebration on February 25th where his Nemec, Floress, Garden Center and NADS families celebrated Tim’s life – it was a joyful tribute to a unique, well-loved guy. Tim’s mom, Peggy, was a dear friend to many in NADS. I remember talking to her shortly after Tim was born. She became a parent support volunteer, a member of the Board of Directors and then she joined our staff in 1984, and she and I worked together for 20 years.

Tim was diagnosed with kidney disease the same month his mom, Peggy, was diagnosed with cancer. Peggy died just a few months later, and many of us remember her death in 2004 with great sadness. Tim’s life was not easy during the past 10 years, but as I now reflect on his life, I see all the beauty, care and love he received from so many. I frequently said that if Tim had not had such wonderful care, he would not have lived for 10 years with the very serious kidney disease that he had. The medical professionals in Tim’s life realized that smiles, hugs and kindness were just as important as the expert medical care they provided. Tim’s kidney disease was not related to Down syndrome in any way.

After Peg’s death, I was honored to be close to Tim and his dad, John. I went to all his doctor appointments and attended his staffings at the Garden Center in Burbank, a wonderful agency that operated the CILA (group home) where Tim lived and also his vocational program. He was extremely happy at the Garden Center and he repeatedly told his dad how much he loved all the staff. Tim knew everyone’s shifts—who was taking vacation and when they would be back. They worked with Tim when challenges arose and they never gave up on him.

To show you how much his father, John, appreciated the Garden Center and all they did for Tim, last winter he told their Executive Director, “This is the next best place to heaven.” Well, I believe that he is now in the best place with his beautiful mom. For the past 10 years, he said repeatedly “I miss my mother.” Be at peace, Timmy – we love you and will miss you so much.

CAU Honors Sheila Hebein

Community Alternatives Unlimited (CAU) recently honored Sheila Hebein, who served as NADS Executive Director for 30 years, with their Advocate of the Year award, which they presented to her during a ceremony on March 16. The engraving on the award read: “Visionary, Servant Leader, Inspirational Trail Blazer.” Congratulations to Sheila on this well-deserved honor!

SELF-ADVOCATES CORNER

Self-Advocates at Dominican University

NADS Self-Advocates Bridget Brown, Megan Niklas, Michelle Anderson, and Kelly Neville, along with parent speaker, Karen Neville, and NADS Board Member Dr. Erin Dominiak of the Adult Down Syndrome Center gave a presentation at Dominican University on March 26th in honor of World Down Syndrome Day.

U-46 Resource Fair

Self-Advocates Kelly Neville, Michelle Anderson, Lindsey Pazerunas, Rachel Giagnorio, Julia Smarto, Peter ten Brink, Adam Swanson, and Alex Tello each had a chance to give a short (5-7 min.) presentation at District U-46’s 5th Annual Special Needs Parent Resource Fair.
Keeping your Wandering Child Safe

For years I have worried about my daughter, who is non-verbal and has Down syndrome, wandering from our home – and I know that I am not alone! A 2011 study conducted by the Interactive Autism Network found that nearly half (or 49%) of children with autism attempted to elope from a safe environment, a rate nearly four times higher than their unaffected siblings. In addition, wandering is ranked among the most stressful behaviors by parents of children with autism who wander.

Thankfully, my daughter has always returned safely, but sadly that is not always the case. According to the National Autism Association, between 2009 through 2011, accidental drowning accounted for 91% of the total U.S. deaths reported in children with autism ages 14 and younger subsequent to wandering. Two out of three parents of wanderers reported that their missing children had a “close call” with a traffic injury with 32% having a “close call” with drowning.

The Interactive Autism Network study also found that more than 1/3rd of children with autism who wander are never or rarely able to communicate their name, address or phone number. These children should wear/carry some type of ID. There are a number of great products available — bracelets, anklets, necklaces, shoe or jacket tags, ID cards, clothing labels, permanent ink ID on t-shirts or undergarments are all good options. Some products to consider include: RoadID.com, medicalert.org or MyIDsport.com. However, in order for an ID to be useful, parents must consider what is best for their child. Parents must take into consideration the specific needs of their child, including sensory issues. If the child will remove a bracelet/necklace or anklet, it is obviously not a good choice. When my daughter wandered away, she left the house without her shoes (which included an ID tag), and her communication device (which also contained personal information). An innovative option is the use of prepared washable tattoos that bear ID information (http://www.tattooswithapurpose.com/). In order for an ID to be effective, parents must consider the unique needs of their child when choosing an appropriate ID.

The Autism Wandering Awareness Alerts Response and Education (AWAARE) collaboration, whose mission it is to prevent autism-related wandering incidents and deaths, has some wonderful information and resources for parents. Their Autism-Wandering Prevention Brochure covers information about securing your home, including installing locks, alarms and stop signs (as a visual prompt) on all doors and windows. It also emphasizes the importance of teaching your child how to swim and even practicing with shoes and clothes on. Although they are quick to point out that knowing how to swim DOES NOT ENSURE that your child will be safe in the water. The brochure also provides information and resources on tracking devices, and how to alert and educate your neighbors and first-responders about your child.

AWAARE’s Big Red Safety Toolkit, which can be found at http://awaare.nationalautismassociation.org/, includes toolkits for both care-givers and first-responders.

Their Caregiver Toolkit includes:
- Family Wandering Emergency Plan (FWEP)
- First-responder profile form
- Swimming Lessons Tool
- Root-cause Scenario & Strategies Tool
- Stop Sign Prompts
- Social Stories
- Caregiver Log
- Sample IEP Letter (Never allow restraint/seclusion practices into any IEP)
- How to Get Tracking Technology in Your Town
- General Awareness Letter to share with schools, homeowners’ associations, law enforcement
- Five Affordable Safety Tools
- Caregiver Resources One-sheeter

The First Responder Toolkit is something that should be shared with first-responders in your area PRIOR to any wandering incident. It includes basic information on autism, wandering, checklists, resources and tips on how to interact with a missing child with autism once found. It is very important that first-responders understand that children with autism have a decreased sense of fear causing them to engage in high-risk behaviors such as seeking water, active road ways, heavy equipment or railroad tracks. Responders must also be made aware that the missing child may not be able to respond to the rescuer and may, in fact, run and hide from rescue teams. Every effort should be made to educate all children to “go to” police or other uniformed first-responders. As children get older, parents should be aware that wandering can also lead to high-risk contacts with law enforcement or members of the general public.

Please take the time to visit the AWAARE website to learn more. Hopefully, by becoming more educated on this issue and instituting these strategies, you can decrease the risks associated with your child wandering, and maybe even decrease your stress level a little.

* The links mentioned in this article are offered by the manufacturer to the consumer. Easter Seals DuPage & Fox Valley does not endorse nor support the content of third-party links, benefit from this linkage and is not responsible for the content of a third-party web site.

Editor’s Note: This article is reprinted from the blog of Easter Seals DuPage & Fox Valley. Read more and sign up to follow the blog at EasterSealsDFVR.wordpress.com. For more information about Easter Seals, visit www.eastersealsdfvr.org.

Though the resources mentioned in this article are primarily designed for people with Autism, they may also be appropriate for children with Down syndrome who have a tendency to wander.
This week our son’s school principal wrote a beautiful piece encouraging students to perform a random act of kindness. He included a TED talk video where Drew Dudley shares his story known as a lollypop moment. The gist of his story emphasizes how performing a kind act could be a life changer. In other words, YOU, yes you, change people’s lives for the better without knowing it.

The generosity of our neighbor, Natasha Essed, who recently executed a kind act for our family, has graciously multiplied six times over. How did she do it? One day she nonchalantly asked, “Would you mind if I wrote a story about Emmett being my running partner?” She wanted to include a picture in her story and planned to send it off to Strider bikes to see if he could win a bike.

My neighbor and her husband have two wonderful children of their own and she took the time to stop and reflect about our sweet child who was born with Down syndrome eight years ago. As a result, our neighbor won our son Emmett a brand new shiny blue Strider bike. Strider generously donated an additional six bikes which will be dispersed through fundraisers by NADS.

We are grateful for our neighbor’s kind act and for the leaders in our community who encourage children to perform kind acts on a daily basis. In our case it has been a healthy life changer and an example of how parents in the community can be excellent role models.

NATASHA’S ESSAY:
Emmett - 7 yrs old - is my neighbor and my running partner. This last summer I would pick him up in the morning and we would run around the block in our neighborhood. We had so much fun together. He is the most honest and laid back 2nd grader I’ve ever seen. There’s something so beautiful about him, he’s so pure in the way he expresses himself. I love it when I ask him something and he replies: “sure!” Emmett is such a happy boy and every time I see him, he makes me smile. Emmett also loves sports! He runs and plays soccer and is a big Green Bay Packers fan.

It would be so nice if he had a STIDER bike so he and I can bike through the neighborhood.

Here is a link to the blog where he is featured!
www.striderbikes.com/blog/strider-gives-back/item/5496-strider-gives-back-week-7-winners

Editor’s Note: One of the 6 donated Strider bikes was a Grand Raffle prize at this year’s Bowl-A-Thon. The remaining bikes will be used as prizes at various Chicago area Down syndrome events.

Strider Balance Bikes
Strider Bikes makes balance bikes for children and adults (bikes without pedals, which allow riders to keep their feet on the ground). They also offer a line of bicycles designed for children with special needs. This year Strider has also added race classes for special athletes, and they have earmarked over $200,000 in donations for the special needs community through their Rider Fund. For more information, visit www.striderbikes.com.

Center Stage Dance Donation
We are grateful to the Center Stage Dance Studio and the performers at the Friends and Family show on February 22, which raised $670 for NADS. We appreciate this generous gift and the studio’s ongoing support.

North Shore Academy WDS Day Socks Fundraiser
Thank you to North Shore Academy’s Student Council and to all who took part in their World Down Syndrome Day celebration. They sold socks and wore them in honor of World Down Syndrome Day, and they generously chose to donate the money they raised (more than $500) to NADS. We appreciate this gift and all that North Shore Academy did to help raise awareness about Down syndrome.
We Need Your Photos!

Send your Family Album photos to NADS!
c/o shebein@nads.org
**ADULT MATTERS**

New Chair for the Adult Matters Committee

Welcome to Karen Neville, who will be taking over leadership of the Adult Matters Committee. Karen has been actively involved on the committee for many years and often presents with her daughter, Kelly, who is one of NADS’ Self-Advocates. She also helps Kelly with her Special Sparkle jewelry business.

We are grateful for Laura Drower’s many years of faithful service leading the committee. Though she is stepping down as Chair, she is planning to remain involved. If you are interested in joining the Adult Matters Committee, we welcome your participation. For more information, contact us at info@nads.org or 630-325-9112.

Soft Skills

Laura Drower, Adult Matters Committee

What are “Soft Skills” and why do our teens and adults need them?

I had the pleasure of attending a workshop on Transition Planning at this year’s Illinois Speech and Hearing Convention. The presenters focused on the importance of acquiring “soft skills” or “people skills” in order for students to be successful in getting and keeping a job. Soft Skills as identified by the US Dept of Labor include:

- Networking
- Problem solving and critical thinking
- Professionalism
- Communication
- Enthusiasm and attitude
- Teamwork

The presenters discussed using the IEP and transition plan to insure that these skills are focused on in school. One of the more interesting points made, was that some modifications and accommodations can both help and hinder progress. For example, reduced workloads can help when learning a new or difficult task, however, they can inadvertently set up lower expectation and decrease a student’s ability to tolerate tasks that are difficult or non-preferred. This can translate into a worker who is not able or willing to perform tedious or boring parts of a job. The presenters stressed the importance of continuously updating the IEP goals to make sure that modifications and accommodations are considered part of a continuum and don’t stay in place past the point of usefulness. In writing goals, they noted that the language used should be job placement focused such as what skill a student will need to do when employed and how the student’s program can address those skills.

Here are 2 great resources with information, goals and activities for soft skills.

- [www.dol.gov/odep/topics/youth/softskills/](http://www.dol.gov/odep/topics/youth/softskills/)
- [www.isbe.net/ils/social_emotional/standards.htm](http://www.isbe.net/ils/social_emotional/standards.htm)

**CALLING ALL ADVOCATES: Illinois Advocacy Efforts**

Steve Connors, NADS President

There are two legislative agenda items in the works that will impact people with Down syndrome and their families in the future. Down syndrome organizations across the state of Illinois will be organizing efforts to speak with one voice to our government leaders in Springfield. Do you want to get involved?

Illinois Down Syndrome Information and Awareness Act - The bill requires the Illinois Department of Public Health to make available up-to-date and accurate information about Down syndrome to health care providers and genetic counselors. This information, along with contact information of local Down syndrome support groups, is to be provided to all expectant or new parents who receive a prenatal or postnatal diagnosis of Down syndrome.

Illinois ABLE (Achieving a Better Life Experience) Act – On December 19, 2014, President Barack Obama signed into law the Achieving a Better Life Experience (ABLE) Act. This legislation allows people with disabilities (with an age of onset up to 26 years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life. The next step is for the Department of Treasury to finalize regulations, and issue guidelines to states on ABLE accounts. Each state will then be responsible for establishing and operating an ABLE program.

To be a part of these advocacy efforts, please email info@nads.org your contact information, including your home address so we can collect district information. For more information on both these bills, visit the Governmental Affairs section of our website at: [www.nads.org/programs/governmental-affairs/](http://www.nads.org/programs/governmental-affairs/).

**FUNDRAISING**

Trivia Night

Many thanks to Dan Reich and the Zion Firefighters, who once again sponsored their Trivia Night fundraiser. Several of NADS’ Self-Advocates attended this year’s event, which raised approximately $4,000 for NADS. Thank you for this generous donation!
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