



Lexi & Victoria Bailey

NADSNews

Newsletter for the National Association for Down Syndrome

March, 2018

Girl Scout Troop Hosts Dance to Support Parent Support Program *Victoria Bailey*

My name is Victoria Bailey. I am a junior in high school, a Girl Scout Ambassador, and have been blessed with a younger sister with Down syndrome. My sister, Lexi, is my best friend and my inspiration. She has such a contagious laugh and smile, and never fails to brighten a day. Lexi

and I do almost everything together from going to school sporting events, to dancing and singing in the car, to hanging out with friends. Sometimes I wonder where I would be without her and what type of person I would be, because I feel like all of my interests come from being with her

so much. I am the Vice President of my school's Best Buddies Chapter, where I enjoy interacting with our buddies and seeing their happiness when they get to be themselves and have fun. I also volunteer for my church's special needs Religious Ed Program, and have just started working at Lincoln-Way Special Recreation Association. I plan to attend college in 2019 and major in Communication Sciences and Disorders, and hope to one day become a speech therapist working with children with special needs.

Another important part of my life is Girl Scouts, which I have been involved in for ten years. Our troop is constantly striving to find ways to volunteer in our community and become

leaders. We have done many things to "make the world a better place," such as handing out necessity bags full of hygiene products and snacks to the homeless in New York City, making blankets for the homeless in our community, serving at Morning Star Mission, volunteering at the Ronald McDonald House and so many more organizations. In addition to this, each year my troop organizes our service unit's annual Girl Scout Ball, also called the Daddy Daughter Dance. One of the steps in making this a success is choosing an organization to give donations to, and this year we chose NADS. My family receives the NADS newsletters, so my mom



Bailey girls and their dad at the dance

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President Katie Wood
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Diane Urhausen Steps Down as Executive Director

Diane Urhausen stepped down from her position as Executive Director of the National Association for Down Syndrome in January to pursue other endeavors. Throughout her nine-year tenure at NADS, she positively impacted many families while overseeing the operations of the organization. We thank

Diane for her service and incredible dedication to the Down syndrome community. Moving forward, NADS will be restructuring its organizational landscape. Linda Smarto is now the Director of Programs and Advocacy. Linda has been dedicated to NADS for over two decades, and has worked as the Program

Coordinator for the past eight years. The Board of Directors is confident in her ability to successfully direct all facets of programming moving forward. NADS staff continue to maintain the daily operations of the organization and the Board will keep members informed as changes are made.

Special Sparkle Teams Up with Oak Brook Sandlot

A universal playground called the Oak Brook Sandlot is being planned for Central Park in Oak Brook, IL. The playground will be designed to remove physical and social barriers so all individuals, with and without disabilities and/or critical illnesses, can play side by side with their peers and families. For the month of March, a portion of all online sales from self-advocate Kelly Neville's jewelry company, Special Sparkle, will go to the Oak Brook Park District to support the creation of the Oak Brook Sandlot. Visit www.specialsparkle.com to shop, and go to www.universalplayground.org to learn more about the cause.

SAVE THE DATE:

PAC Service Project at Feed My Starving Children

Calling all PAC members! Sign up to help pack meals at Feed My Starving Children on **April 7, 2018**. Contact Linda Smarto at lsmarto@nads.org for more information.

Doctor's Corner

Erin B. Dominiak, M.D.
Adult Down Syndrome Center, Director of Medical Education

Cold season is here! Here is a list of my favorite over-the-counter (OTC) medications. Below is a list of my favorite over-the-counter (OTC) medications. **Guaifenesin** (Mucinex, Robitussin, generics) will thin out mucus which is great for cough and congestion, especially in people with Down syndrome who generally have small nasal passages/sinuses/throats. **Dextromethorphan** ("DM" part of Mucinex DM and Robitussin DM, Delsym, generics) will suppress a

cough and also can cause sleepiness, so I generally recommend taking this at night. **Acetaminophen** (Tylenol) will reduce fever and aches/pains, sore throat, ear pain, etc. **Steroid nasal sprays** (Flonase, Nasacort, Rhinocort) will decrease nasal inflammation, and **Sinus Rinse or Neti Pot** will rinse away mucus. **Pseudoephedrine** (Sudafed, generics) is the preferred decongestant (I don't recommend phenylephrine since there is limited data that it works*). These

products are best when also getting plenty of sleep/rest, fluids/warm tea, chicken soup, and TLC. And of course, if someone is having more than just regular cold symptoms, seek professional medical advice right away.

**Phenylephrine is the decongestant in OTC products. Products containing pseudoephedrine are kept behind the counter because they can be used to make methamphetamine and need to be purchased directly from the pharmacy.*

Profile of: Cristina Cassata

Marylynn Cassata

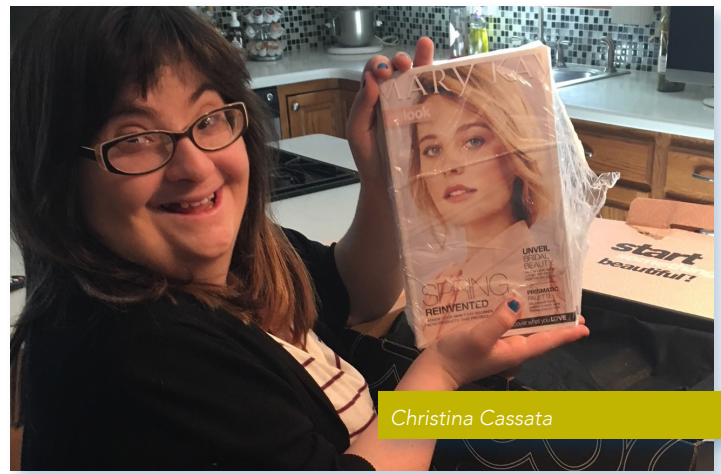
When Cristina was born 22 years ago, we were told by many people that she would never be independent and would have no quality of life. Thankfully, I am happy to say that Cristina has a very full and happy life. She had a great school experience, excellent medical care, positive support from family, friends, and our community that has helped her to reach her potential and live a very fulfilling life.

When we were preparing Cristina for her transition from school to adult life, we were extremely nervous. Again, we were told by many people that exiting school was like jumping off a cliff. There would be no supports and nothing for her to do during the day. Thankfully, things have been gone very well for Cristina. She loves to sing, dance and act – and is currently in her 11th play. Also, she loves to travel with her family all over the United States. She has a wonderful boyfriend, and they spend time going to movies, sporting events, shopping, restaurants and just hanging out. She is also very busy

with two jobs – a paid part-time job at our local library and an independent Mary Kay representative.

Many people have asked us how we got involved with Mary Kay. While we were preparing Cristina to transition from school to adult life, we worked with a non-profit organization called Connect to Community(CTC). They partner with local businesses to create customized employment opportunities for adults with special needs. They confirmed our understanding that Cristina loves anything to do with makeup. Our job coordinator met a Mary Kay representative at a local chamber of commerce meeting and talked to her about Cristina and her love of makeup. She was able to set up a meeting for us all to meet and talk about Mary Kay. At the meeting the representative told us all about Mary Kay, how to be a representative, and let us try many of the products. Cristina loved it!

Cristina and I talked about how being a Mary Kay representative would



Cristina Cassata

require a lot of hard work. Cristina would have to learn all about the products available, how to do home shows to sell her products, and how to be more independent and confident when she spoke. She was so excited and wanted to give it a shot. So, we both became Mary Kay consultants so I could help her out as needed. To celebrate becoming consultants we had a ribbon cutting ceremony at our house. We were hoping to have ten people attend. Instead we had over 45 people come out to support Cristina!

She has worked very hard to establish her business and get customers by doing house parties, sending out emails to family/friends to solicit business, doing a holiday open house in November, and just talking to people about

her business. Cristina completely runs the house parties. She has a script that she wrote that talks about many of the Mary Kay products, she sets up makeup trays for attendees, and then goes on to tell them how to apply the product and what it does for their skin. She has also created a customized bingo game to keep everyone interested and participating in her presentation. She is incredibly proud to be a Mary Kay representative as it gives her a sense of accomplishment every time someone hosts a party, places an order, or just asks her about her business.

If you are interested in booking a party with Cristina or would like additional information; please contact us via our website at www.marykay.com/mcassata.

OT Tips

Katie Frank, PhD, OTR/L

Registered Occupational Therapist at the Adult Down Syndrome Center

Have you ever felt guilty because your child is not receiving outpatient therapy services? I'm here to tell you it is okay to take breaks. I even recommend it! Therapies are very important, but not so important that it stresses you or your child out to attend multiple therapies every week. Breaks are

beneficial for your child and you, as well as the therapist! It is important to keep therapy interesting, and if your child is going weekly for months at a time, both the child and the therapist can get run down. Therapy is NOT a lifelong commitment! It is important to pursue outpatient therapy services

when your loved one with Down syndrome needs to learn a new skill or if there are some changes in his/her current functional status. Therapy is actually shown to be more effective in short bursts to focus on a specific area of concern. Plus, it is important for individuals with Down syndrome to have the same experiences

as peers. Engaging in activities like Special Olympics, theater groups, book clubs, art classes, etc. can be just as important and satisfying. Developing social connections is essential to living a healthy lifestyle. While parents often feel guilty for something, taking a break from therapy shouldn't be one of them!

Did You Know?

Nancy Wilson

...that the Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Consumer Involvement Program? This program distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice as long as they are directly related to developmental disability issues. The program can assist financially with the many expenses involved with attending a conference such as registration fees, gas, hotel, child care, meals, and more. This program enables self-advocates and family members, who otherwise wouldn't be able to afford it, the opportunity to attend and access information so that they are best able to make positive changes in their lives and be the best advocates that they can be.

Applications need to be sent in and approved prior to registering for the conference. There are a limited number of stipends available per conference, so apply early.

For more details about applying for the Consumer Involvement Program, go to the Arc of Illinois website at www.thearcofil.org under the Resources tab. You can also contact Lee Ann at 815-464-1832 or leeann@thearcofil.org with any questions.

Peggy Delaney – New Board Member

I attended my first NADS Conference ten months after my son Jack was born in 2008. I came home with a notebook brimming with medical facts, new information, necessary tips, and one very invaluable name - Valerie LaMorte. She sat next to me during a session and told me she had started a moms' group and suggested I join them. Although it took me nearly two years to finally get to one of her gatherings, I constantly thought about her invitation and the possibilities behind getting to know more moms like myself. Those who were also juggling therapies, chronic medical concerns, Early Intervention, and so on, and so on, and sooooo on...

I look back at that first conference as a pivotal moment in my journey as a parent. I realize now that when any parent is ready to reach out or accept friendship within this unique community, it can be done so with almost no effort. This tribe is so ready to welcome. NADS opened the door for me, my husband, my older son Charlie, and certainly with welcoming arms to our Jack.

Currently I am reading a book titled *The Education of Little Tree – The Story of a Cherokee Boyhood* with my older son Charlie. In the story, Little Tree's grandfather explains why non-blood relatives are referred to as "kin." He states that, "back before his time 'kin-folks' meant any folks that you understood and had an understanding with, so it meant 'loved-folks'... it meant 'I understand ye.'"



Charlie and I took a few moments to talk about this. It made me think about all the amazing new friends I have made within the NADS community. My new kin-folks.

My community — my tribe — has expanded into a huge blanket of unconditional support. I am surrounded by amazing moms, incredible dads, siblings for Charlie, and life-long friends for Jack. These amazing new friendships also helped me discover educators, therapists, doctors, librarians, tutors, and community organizers who have helped my family create the best balance possible on our journey.

Whether you attend the Bowl-A-Thon, NADS Conference, Fashion Show, Gala, or any other event, the relationships you form, and friendships you harvest, are the magical part of the journey. I love looking around the room and seeing these "tribes" within our

tribe. There is such good that comes from finding your community. I hope to support and foster more relationship building with my new adventure on the NADS Board. I am excited for the future and the new friendships yet to be made.

Peggy and her husband Tom live in Downers Grove with their two children Charlie and Jack. Peggy has supported the annual NADS Yard Signs for the past four years and joined the board this fall. Tom partners with Steve Connors in supporting the NADS Chapter of DADS (Dads Appreciating Down Syndrome). Peggy also works with Linda Smarto on presenting to preschool educators about best methods for supporting children with Down syndrome in the classroom, and provides supports to parents with children entering preschool. See page 6.

Baby with Down Syndrome Named the 2018 Gerber® Spokesbaby

Gerber announced in February the winner of their eighth annual Gerber Baby Photo Search. Baby Lucas from Dalton, Georgia, who has Down syndrome, won the judges over with his glowing and giggly smile and was chosen among more than 140,000 entries. "Lucas' winning smile and joyful expression won our hearts this year, and we are all thrilled to name him our 2018 Spokesbaby," said Bill Partyka, CEO and president, Gerber. "Every year, we choose the baby who best exemplifies Gerber's longstanding heritage of recognizing that every baby is a Gerber baby, and this year, Lucas is the perfect fit."

"This is such a proud moment for us as parents knowing that Lucas has a platform to spread joy, not only to those he interacts with every day, but to people all over the country," said Lucas' mom, Courtney Warren. "We hope

this opportunity sheds light on the special needs community and educates people that with acceptance and support, individuals with special needs have the potential to change the world – just like our Lucas!"

Former NADS Board President Steve Connors shared that when his daughter Avery was born 20 years ago, one of the doctors at the hospital sat him down for a pep talk about what Avery's life might be like. "I will never forget one thing he said to me – 'it is okay to grieve - you guys were expecting a Gerber baby and that's not what you got.'" Gerber's announcement truly exemplifies progress in how the world views Down syndrome.

The Gerber announcement also provides opportunities for families to raise awareness through social media and other outlets. One post on the Gerber Facebook page

by NADS board member Peggy Delaney is a great example!

*Dear Gerber,
I want to thank you for recognizing the beauty in Lucas Warren. As a parent of a child with Down syndrome it is so awe-inspiring to see Gerber acknowledge that Lucas, and all other children born with differing abilities, are precious and worthy of celebration.*

I also want to let you know that many individuals with differing needs rely on your products beyond the early years. Many children, like my son Jack (10), still consume soft-diet foods due to medical needs or sensory issues. Jack has never been able to move to crunchy foods due to early health issues and other various oral issues. EVERY MORNING Jack eats Gerber Oatmeal Cereal mixed with milk, applesauce, and cinnamon. The nutritional value of the Gerber Cereal adds



vitamins and minerals that Jack needs to balance out his day of nutrition since he is so limited in what he can consume within his diet.

I want to thank you for celebrating Lucas. I cannot tell you how big my smile will be every morning when we pour our bowl of cereal! Your dedication to creating generations of healthy eaters goes beyond anything you might have imagined. THANK YOU!



Thank you!

Holiday Bar Crawl Fundraiser

Matt Spiewak

Thank you to Aaron and Erin Setchell of Chicago for their incredibly generous donation to NADS! For the past five years, they have organized an annual ugly sweater train crawl as a fundraiser. The event begins in Wicker Park and concludes in Palatine, making stops for food and drinks along the way on the Metra route. Local bars contribute prizes for raffle tickets that are purchased by participants. This year, Aaron and Erin decided to donate the proceeds to NADS to support the Down syndrome community and their nephews Peter and Isaac Spiewak. One "crawler" was able to match the funds raised through his employer, for a total donation of \$4860! What a fun way to raise money and awareness!

Preparing your Child for a Successful Preschool Transition

Peggy Delaney

Preschool can be a hard transition for some children and ALL parents/guardians. These simple ideas will help your child adapt to their new routine and alleviate some of your fears about separating from your child. By partnering with your teacher and support team on these simple steps, you can ensure that your entire family will be ready for this big step.

Teacher Bonding

- **Visual Support for getting to know their new teacher.** One way to help your child overcome their first day jitters with a new teacher is to request a photo of him/her to share with your child. It is extremely beneficial to print the photo and frequently show the photo to your child. Express how exciting their first day will be. Your teacher will not feel like a stranger to your child if they have become more familiar with his/her face prior to the first day. This will greatly aide in separation anxiety for your child... and you.

Daily Schedule

- **When does your program begin?** If it starts at 8:00 a.m., be sure your child spends a few weeks prior to their first day of preschool getting up at least one hour before school and eating a nutritious breakfast. Setting the morning routine early will ensure they are bright-eyed for the new routine. If your child will be attending an afternoon program that starts at 12:00 p.m., be

sure nap schedules are changed so your child is prepared to have an afternoon of learning that is not impeded by afternoon sleep habits. Also, be sure to keep these routines over the weekend. This may be a challenge, but your child will be more successful when they return to school on Monday if their routine is consistent seven days a week.

- **When is snack and lunch served?** Being hungry can impede focused learning. Find out when snacks or lunch breaks occur at the preschool. A few weeks prior to the first day of school, begin to serve snack and lunch at the same time as the school schedule. This will help your child's body regulate their eating patterns. It will also help you determine how robust your snacks and lunches need to be.

Potty Support

- **Transition from Diapers.** Most children are not potty trained by three, so don't feel that there is a rush. All children will potty train in their own time. However, in preschool there will be several times a day that your child will be asked to attempt to use the bathroom. This means sitting on the toilet (with support from a teacher). For children who are still in the early stages of potty training, this may be confusing if they don't have experience sitting on a toilet. You can do three simple things to help prepare them for potty support at preschool:

- 1. Transition your child to pull ups if they are still in diapers. It is much easier for teachers to support "potty attempts" if they don't have to struggle with tab diapers for quick moments on the potty.
- 2. Introduce sitting on a potty to your child at home. Even if your child only sits on the potty for three seconds, you are making huge strides in ensuring your child is ready for their first attempts at school.
- 3. Ensure your child has good hygiene routines and washes their hands with soap after every attempt on the potty.

Get to know your Playground

- **Safe Play.** Playgrounds can pose challenges that you might not have thought about. When children are more familiar with a playground, they can be shown safe and appropriate ways to navigate their new play environment. Take time to visit your new playground several times prior to your first day of preschool. Spend time assisting your child on how to use the equipment safely. Not only will your child feel more comfortable on the first day, they also will feel "at home" while enjoying their outside play time. Be sure to ask yourself some simple questions while visiting the playground:
 - Does your child know how to walk on unstable surfaces such as mulch? If not, practice walking on the surface together.
 - Can your child swing

safely by holding on with both hands and do they know to steer clear of others while swinging?

- Can they walk up the ladders or stairs safely?
- Do they know basic rules such as "slides are for going down, not climbing up" and "feet first only when going down slides?"

Walking

- **Independent walking.** If your child is able to walk on their own they will be expected to do so throughout the day. In most cases they will hold a teacher's hand or the hand of a classmate while walking down the hall. They may be walking to the library, out to the playground, or around the school for various reasons. In the weeks leading up to preschool you can support your child's independent walking by doing several things:
 - Ensure you are not carrying your child in lieu of walking.
 - Take frequent moments walking hand-in-hand while going to the park or taking a stroll in your neighborhood.
 - Be sure to reinforce safety rules such as: looking forward when walking, not walking too fast or running, and not letting go of our partners' hands.
- **Shoe Safety.** Ill-fitting or improper footwear can cause unnecessary tripping injuries for young walkers. Be sure your child has shoes that support safe walking. Do their shoes stay on their feet

and are not easily pulled or kicked off? Are there long laces or open toes that can pose tripping hazards?

Library Time

■ **Navigating the LRC (Learning Resource Center).** Your child will make weekly trips to the LRC and all those books can be intimidating and overwhelming. Also, "quiet voices" can be hard to contain when your little one is excited in a new environment. To prepare for preschool LRC time, frequent your local library prior to the first day of preschool and be sure to always end your visit with checking out books. Ensure your child has their own library card and allow them to be the ones to check out their books.

Your preschool experience is going to be one filled with a lot of "firsts" and new adventures. Always remember that your teachers and support team want your child to be successful and are going to be their biggest fans and cheerleaders. Your partnership in preparing your child can ensure the first few days are more successful, less stressful, and fun-filled.



PAC Leadership Training at Elmhurst Hospital

The PAC Leadership Training held on January 21, 2018, was a great success! The goals were to learn:

- SELF-ADVOCACY SKILLS — advocating for self
- ADVOCACY SKILLS — advocating for self and others
- LEADERSHIP SKILLS — making a difference in the world on behalf of something, someone and/or an important issue

18 self-advocates participated in the afternoon workshop. Many of the participants presented to the group and shared some of the amazing things they are doing in their life that require leadership skills. Two self-advocates own their own businesses, and many are in plays and enjoy singing and

dancing. Many participants were sports enthusiasts and Special Olympic athletes.

Participants made posters identifying their gifts and strengths and then shared them with the group. They each told what they care about and the things they are doing in their life to make a difference.

Strong leaders are great problem solvers. The self-advocates were presented with some everyday problems in the work place and some problems they may face with friends and relationships. They brainstormed solutions to these problems together and came up with fabulous ideas that included: being honest, speaking up for self and others, asking for help when needed, speaking up for what is right, listening,

and trying to find solutions to problems.

The self-advocates practiced professional skills that included introducing themselves to others, shaking hands, and greeting people appropriately.

Cindi Swanson from the ARC of Illinois shared ways self-advocates can get involved in legislative issues and local community issues that are important to them. Linda Smarto shared how advocates can participate in NADS events and programs.

Overall the day was fabulous. Each and every participant was exceptional and it was a day filled with pride, hope and leadership! Thank you to all who participated.

Thank you Luster Haircare and the Peters Family!

A HUGE thank you to Luster Hair Care for the incredibly generous donation of \$5,000! Luster Hair Care is a client of Accord Carton and NADS member Dave Peters. Jackie and Gina Rotondi were able to visit Luster Hair Care to receive the donation. They were told by the Luster family that business was better than they had predicted this past year, so they proudly chose to give back to the community. Jackie said that it was a privilege to meet this wonderful group and the Luster family. Dave Peters said, "we are blessed to have Luster Products as a client and a support group like NADS." Thank you to Luster Hair Care, Accord Carton and Dave Peters!



Five Questions You Need Answered about Illinois ABLE

JJ Hanley, Director, IL ABLE

- 1. Why Illinois ABLE?** Because individuals with disabilities and their families need to be able to save money for additional expenses that come with having a disability and to improve their quality of life! Disability advocates fought for 10 years to make it possible for people with disabilities to build stronger financial futures without losing their federal means-tested benefits, like SSI and Medicaid.
- 2. What is ABLE?** ABLE stands for "A Better Life Experience." An ABLE account is a savings and investment account that qualifying people with disabilities can open. When you have an ABLE account, you can withdraw the funds from your ABLE account and use the funds for disability-related expenses. Taxes on earnings from the ABLE account are deferred, and you don't pay any taxes on the money you withdraw from your ABLE account as long as you use it for disability-related expenses.
- 3. Who can have an ABLE account?** You can open an ABLE account if you have a disability and 1) the symptoms of your disability were present before you turned 26 years old, and 2) your disability meets the criteria set by the Social Security Administration's definition of disability.
- 4. What can I do with an ABLE account?** You can save up to \$100,000 without losing your SSI monthly benefits. You can save and invest your own money. You can pay for qualifying disability expenses, such as housing, therapy, transportation, training and many other expenses. You can save money from your job. You can gain some control and independence.
- 5. Where do I go to get more information or to open an Illinois ABLE account?** Visit www.ilsavewithable.com or the Illinois State Treasurer's website at www.illinoistreasurer.gov. You can also plan to attend JJ Hanley's presentation, "Making the ABLE Program Work for You – A Better Life Experience Essentials Workshop" at the NADS Conference in August. See below.

SAVE THE DATE! NADS 2018 Conference

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Family • Educators • Community

August 11, 2018

NEW LOCATION! St. Ignatius College Prep

1076 West Roosevelt Road, Chicago, IL 60608

This new location is easily accessible via public transportation and offers free parking

Quick Tax Tips

Mary Anne Ehlert from Protected Tomorrows

Tax time is upon us. Below is a quick list of common questions for taxes that are due this year:

- 1. Is the SSI (Supplemental Security Income) that my child receives considered taxable income?**
NO, SSI does not need to be reported as income.
- 2. Are the SSDI disability benefits considered taxable income?**
It depends on the total income for the person receiving the benefit. The combination of other income with SSDI might cause the SSDI to be taxable. It is important to go through the process of calculating total income to identify what is taxable.
- 3. If my child is receiving SSI, can I still take him or her as a dependent on my tax return?**
It depends upon how the SSI was filed. If your child is not getting the full amount and gets a reduced amount due to the fact that you subsidize their living, then the answer is maybe. Check with your accountant. If your child is getting the full amount of SSI, as they are paying you rent, etc., then the answer is NO, you should not take them as a dependent. Your child has already said they are independent and not getting resources from you, so you would not be providing for the child, and thus cannot take them as your dependent.

4. Should my child file their own tax return?

It is again dependent upon the situation. If your child does not work, and their only income is SSI, they don't need to file. If your child works, and has taxes withheld from their check, they may file to get a refund. If your child is over 25 and working, they might be able to claim an Earned Income Tax Credit when they file.

5. My child has a Special Needs Trust. Do we need to file a tax return for the trust?

If there are no funds in the special needs trust, no tax return is required. If the trust has its own TAX ID, the answer is maybe. If the trust is a grantor trust, you MIGHT be able to put that income on your own tax return. The trust may also just use the parent's social security number, and the income then might be taxable to the parent.

6. If your child pays you rent, should you claim that as income on your tax return?

Yes. You should file a Schedule E, claim the rent but don't forget to deduct the appropriate expenses. You probably won't owe any more taxes, if you apply this information correctly.

Not every tax accountant understands many of these nuances of your tax return. Call Protected Tomorrows at **847-522-8086** or visit www.protectedtomorrows.com with questions.

On the Topic Of: Staying Fit Nancy Goodfellow

I remember reading once that Lily's metabolism would start slowing down when she was five years old. After that point, she would only burn about the half the calories as someone else doing the same activity. I'm not sure how accurate that is, but it stuck with me. I knew that the time would come when we'd have to focus on the amount of activity she did and balance it with proper nutrition to ensure that she would not gain weight and then struggle to lose it as so many adults with Down syndrome seem to do.

Fortunately, Lily loves sports and always has. She loves to swim, run track, play soccer, wrestle with her dad, and do Tae Kwon Do. But she also loves chicken tenders and French fries, deep dish pizza, soda, and ice cream. So, we have been working hard over the past few years, especially since she hit puberty, to make sure that she knows how to balance her diet and reserve her favorite foods for the weekend. She knows that she's allowed to drink one "pop" a day, but only on Friday, Saturday and Sunday. This may become

harder to enforce as she gets older and spends more time away from us, which is why we are trying to instill good habits now and hope that the love of routine that is also common with Down syndrome will help us out.

In the meantime, we are also trying to instill a love for exercise and being physically fit, and help her to understand that participating in the sports she enjoys is much easier and she can be more competitive if she is lean and strong. That's why we were thrilled to discover DuPage Valley

Special Athletes (DVSA) this past fall. Lily is able to participate in a wider variety of sports, as well as exercise programs, that challenge her at her level. Through DVSA, as well as our local special recreation association WDSRA, and Special Olympics, Lily has the opportunity to remain active well into adulthood. For right now, I'm trying to make sure she'll want to stay fit and truly understand the importance of it.

You can read the following article to learn more about DVSA.

Recreation Spotlight: DuPage Valley Special Athletes Offers Innovative Sports Opportunities

Kish Pisani, Founder DVSA

DuPage Valley Special Athletes (DVSA) is an organization for athletes with special needs, or as the coaches like to say, "different abilities," based in Naperville, IL. The mission of DVSA is to develop and nurture positive health habits through athletic activities for individuals with physical and/or developmental disabilities by providing positive coaching, teamwork, and competitive opportunities. The primary age of athletes and volunteers is 14 and up.

DVSA is not affiliated with a park district, school, or other organization. A small group of parents and athletes started DVSA because they wanted a Special Olympics Unified Sports program in their area. According to the Special Olympics website, "Unified Sports joins

people with and without intellectual disabilities on the same team. It was inspired by a simple principle: training together and playing together is a quick path to friendship and understanding. In Unified Sports, teams are made up of people of similar age and ability. That makes practices more fun and games more challenging and exciting for all. Having sport in common is just one more way that preconceptions and false ideas are swept away."

DVSA holds programs on Sunday afternoons to encourage peer, sibling, parent and friend involvement in all sports. Since starting Unified Soccer, DVSA has developed a large social network of peers and athletes. Young adults with different abilities are motivated and inspired by peers, and the relationship



extends way beyond the practice field. The typical peers have become friends with their disabled teammates.

In addition to Unified Soccer, DVSA offers an Alpine Ski program, Special Olympics Soccer, Flag Football, Spirit Squad, Track & Field, and Special Olympics Unified Golf. The teams have won many state championships, traveled to out of state tournaments, and made an impact on the sports community being known as "that purple team." Future sports

offerings include archery, tennis, running club and snow shoeing.

This past January, DVSA partnered with Fitness by Anthony Parker in Naperville for a Sunday afternoon fitness boot camp. In this program, participants exercise for a full 60 minutes using boxing bags, resistance bands, body weight movements, and general cardio without the use of weights or specialized equipment. They work out as a team with lots of motivation

Continued on page 11

familyalbum



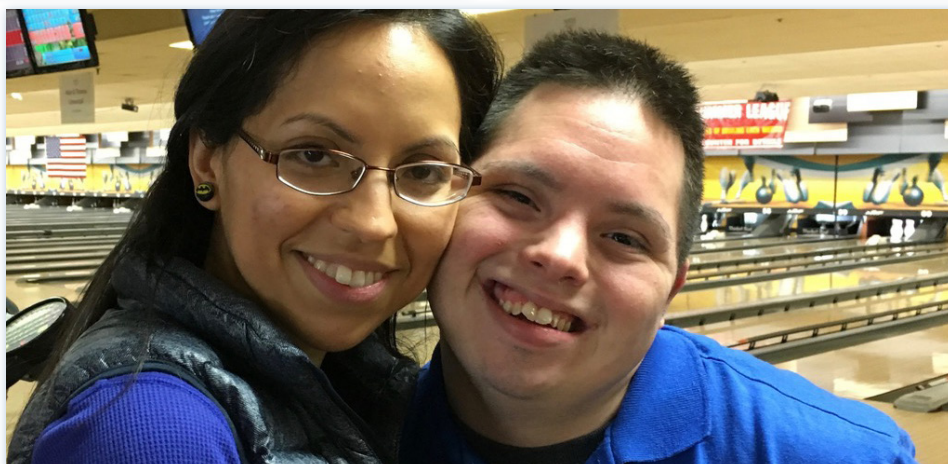
Tommy V.



Cameron T.



Sarah G.



Seline & Alex T.



Thomas



WE NEED PHOTOS!

Send your
Family Album
photos
to NADS!

shebein@nads.org

Girlscout Dance

Continued from page 1

read an article on the Welcome Basket and Parent Support Program. She told my troop leader about it, thinking we would be able to do something for it. It was at one of our planning meetings for the dance that we talked about the NADS Parent Support Program. My parents can say that this program would have been very helpful for them when my sister was born, because 14 years ago they did not receive the information and resources that these baskets give to families. Knowing how helpful the program is, my troop and I thought it would be a perfect way to raise awareness and support of Down syndrome and special needs families. With each permission slip for the dance, a donation letter was attached that listed the needed donations. Each father and daughter couple brought in items such as diapers, bottles, and little baby outfits. Everyone enjoyed shopping for these newborn babies!

Recreation Spotlight

Continued from page 9

and individual attention. Each session ends with a motivating message by Anthony Parker, a former NFL player who struggled with speech and hearing issues as a young boy. Parents are inspired and encouraged to see their young adults pushing their fitness limits. Parker's motto is "stay in your lane" and his program adapts to different fitness levels and abilities.

This partnership aligns well with DVSA's coaching philosophy. "We want to meet the athletes where they are, at their ability, then step it up a notch," said Volunteer Coach and Athletic Director Paul Pisani. "We treat these young adults as athletes first, not special needs athletes. If they're late for practice, they run a lap, just like they would in any 'typical' sports program."

The DVSA mission emphasizes teamwork and competitive opportunities. While teams may be divided based on abilities, DVSA

believes in developing athletes regardless of their skills. They strive for improvement, sportsmanship, and respect at each practice and competition. All athletes and coaches sign a code of conduct, and sportsmanship toward opposing teams and officials is expected. The future of DVSA is limitless as athletes (and their families) need and deserve meaningful and fulfilling athletic and social opportunities that will last a lifetime. For information email dvspecialathletes@gmail.com or visit www.dvspecialathletes.org.

Editor's Note: We hope to feature a recreation spotlight in each issue, highlighting different social, athletic, artistic and extra-curricular opportunities for children and adults with disabilities. If you know of a great program in your area, we want to hear about it! Contact Nancy at nadsnews@nads.org.

World Down Syndrome Day

March 21st is World Down Syndrome Day (WDSD), a global awareness day which has been officially observed by the United Nations since 2012. To learn more about WDSD and how to celebrate, visit www.worlddownsyndromeday.org or see the article on WDSD included in the March 2017 NADSNews at www.nads.org/wp-content/uploads/2014/11/NADS-News-03.2017-rev5.pdf

Target and Tommy Hilfiger Offer Adaptive Clothing

Both Target and Tommy Hilfiger have created sensory-friendly and adaptive clothing lines to accommodate the needs of individuals with disabilities, including items like pants with Velcro and magnetic closures and adjustable hems. Both retailers first offered clothing for children, but are now offering adaptive clothing for adults as well. At the moment, Target only has adult adaptive clothing for women. Both retailers offer the clothing items online at their websites at www.target.com/c/adaptive-clothing/-/N-ksyrz and usa.tommy.com/en/tommy-adaptive

Who Have We Reached? Outreach Numbers for 2017

Through our Parent Support Program and Public Awareness Program (which includes education and hospital in-service presentations), NADS provided positive messages and information about Down syndrome to the following audiences during 2017:

Medical: 730 attendees (32 locations)

Higher Education: 526 attendees (11 locations)

Public Awareness: 4,460 attendees (42 locations)

If you have a school or organization you would like to have a NADS public speaker and self-advocate present to, please contact Linda Smarto at lsmarto@nads.org.

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☐ Please add me to the NADS e-mail alert list

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*Please indicate professional involvement.....

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