



Kelly Wesolek

NADS News

Newsletter for the National Association for Down Syndrome

November, 2017

Brookfield Zoo Art Collaboration Combines Passion for Art and Animals

Carmella LoCascio

“ART does not reproduce what we see. It makes us see.”

— Paul Klee

Ever since my daughter, Kelly Rose, was in grammar school she wanted to be a veterinarian and work with animals. Yes, all kinds of animals - sharks, dolphins, cats and dogs. As her mother, and a person who is not comfortable around live animals, I just wasn't sure how this was going to work in Kelly's future. They are always so cute in pictures, but what about real life?

Art, however, is a passion we both share. Kelly Rose loves drawing, painting and creating anything with color, shapes and a unique view. She has a keen eye for art and it relaxes her.

Combining these two passions is what the new Art360 class is all about. Finding this amazing class is a true treasure for Kelly Rose. It is a partnership between Community Support Services (CSS) and the Brookfield Zoo. It brings art, learning, creativity and social inclusion full circle and engages young adults in hands on, therapeutic, and social activities through the creative arts and the social atmosphere of the Chicago Zoological Society - Brookfield Zoo.

For Kelly Rose, each week is exciting and she has not only created some remarkable works of art, and

learned so much about her favorite animals at the zoo, but she has also made some wonderful new friends. On a side note, and for those of you who may know Kelly Rose, she also loves getting ready to see her new friends and dressing up for this class.

I would like to thank Cassandra (Cassie) Colucy, Community Art Program Manager at CSS, and Jenny Reeks, Play Programs Coordinator for the Chicago Zoological Society at Brookfield Zoo. We look forward to being a part of it for a long time.

For more information on Art360, visit



**NADS Gala: Reinvented
November 17, 2017**

Moonlight Studios
Chicago
1446 W. Kinzie St.,
Chicago, IL 60642

Tickets and information:
www.nadsgala.org

Questions:
Katie Wood
(630) 945-2974 or
Kwood@nads.org

www.cssservices.org/
css-academy, email
ccolucy@CSSservices.org,
or call (708) 354.4547
x191. Community Support
Services (CSS) is a nonprofit
that has provided services
to individuals with
intellectual/developmental
disabilities and their families
since 1981.

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

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BDI Playhouse Children's Therapy: Finding Strategies That Fuel Great Expectations *Sheri Berk*

I love babies. Nothing on this planet is more full of hope, wonder, and possibility than a newborn. For me, this is especially true of an infant who is born with Down syndrome. Their family is cradling a precious human who truly wants to move about, explore the world, and interact with people, places, and things just as much as any other baby.

I want to tell this new family to keep expectations high, celebrate and cultivate the unique gifts, talents, and temperament that their baby possesses, and invite people into their lives who can help motivate, facilitate, modify, and inspire them along the way. I am privileged to be the clinical director and one of the therapists who work at BDI Playhouse Children's Therapy in Orland Park and Naperville, IL.

We sometimes meet these babies for the first time in a class called "More Than Milestones," where we use infant massage, sensory integration, motor play, positioning, oral motor activities and family and caregiver education to stimulate and facilitate growth and motivation. We often tell our parents: "You bring the expectations and we will provide the strategies." Along the way, we build a team to grow these expectations and strategize together with the ultimate goal of supporting this baby to become his or her very best self.

Not one of us can do this alone. We know these babies come with unique obstacles and limitations such as low muscle tone,

decreased endurance and strength, and other systemic issues that make processes challenging. We also know how to make simple alterations or changes in their everyday routines and physical worlds to foster the growth and learning that can set them up for success.

I describe to families an infant who sees a toy and wants to touch it. He can't yet hold his head in midline and stabilize himself to reach for that toy. He tries

I KNOW THAT THIS EARLY INTERVENTION WILL HELP FORM THE FOUNDATION ON WHICH TO BUILD HIGH EXPECTATIONS

and he fails and he tries and he fails and so he learns NOT to reach. I often refer to this as "I can't, so I won't syndrome" and I watch that baby shut down, stop trying, and develop behaviors and patterns that no longer foster growth and proper development. I know how to position him and where to place the toy to create strength and stability, and with patience and repetition he soon begins to understand that he CAN move, that he CAN interact. He CAN learn to develop more complex patterns of movement. This is exactly why my heart races when a baby with Down syndrome comes to BDI Playhouse. Because I know that this early intervention will help form the foundation on which to build high expectations.

I also get excited to meet the school-aged or older child who is now moving,

communicating, taking on educational frontiers, and wants to interact with peers and within the community. We help parents understand the changes that occur with a growing and older child. We know that setting him or her up for success can seem difficult due to the variety and number of resources available. This success is often not achieved by finding more services, but by finding the right services for each child. Our team works together to help the family find the missing pieces of the puzzle through private therapeutic services that have not just educational but "whole child" relevance.

Many of the children I work with have been with BDI Playhouse since infancy and have grown up knowing that we expect great things of them. When we work on difficult things in physical therapy and they exclaim, "I can't. It's too hard!" I tell them, "It's not too hard. It's just challenging." My clients are often heard telling their own parents and siblings this! Challenges do not determine our level of success in this world, but is the overcoming of those challenges that truly makes us fulfilled and happy.

BDI Playhouse Children's Therapy provides Pediatric Physical Therapy, Occupational Therapy, Speech Therapy, and Aqua Therapy in Orland Park & Naperville. Visit www.bdiplayhouse.com or call (708) 478-1820 for more information.

What it means to have Down Syndrome & Lyme Disease

Sarah Bonilla

In August of 2012, when my daughter Paloma, at age 16, was diagnosed with Lyme disease, I was somewhat relieved. She had experienced a year of migrating joint pain, which was continuing to get worse and impair her function. We had been to multiple doctors and been diagnosed with multiple diagnoses, including growing pains, muscle imbalance, fibromyalgia, and chronic fatigue. I finally took Paloma to a physician I personally knew and trusted. He suggested doing a blood test for Lyme disease. When her test was analyzed and considered positive, I assumed we would be on a course of antibiotics for weeks, maybe months, but would soon be on track and could put this experience behind us. It has been five years since that diagnosis, and we continue to work toward regaining the life Paloma had before she was sick.

I want people to know about our experience



Thank you to everyone who ordered a yard sign to support Down Syndrome Awareness Month. We sold 300 Down syndrome yard signs this year and raised \$2855!

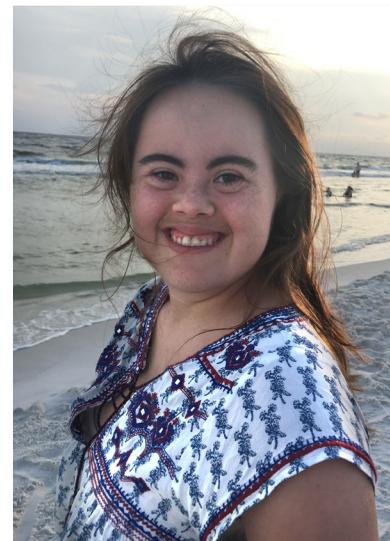
because I can see now that the Down syndrome community is vulnerable. Today, children and adults with Down Syndrome are active in the community. From an early age, our kids are involved in sports, as well as camping, hiking, fishing, boating, riding horses and traveling. But it is important to know that it does not require traveling far to encounter the threats of Lyme and other tick-borne diseases. Anywhere there is grass there is the potential for ticks - the Prairie Path, forest preserves, but most likely your own back yard. Something that used to be considered a disease of the East coast or Northern Wisconsin and Minnesota has settled comfortably in the middle of the country.

In 2015, the Centers for Disease Control changed its predictions of Lyme from 20,000 a year to 300,000. This is a conservative estimate considering how difficult it is to be diagnosed with Lyme. It is not unusual for people to go a decade or more before finding out that the health problems they have suffered with for years are due to Lyme and other tick-borne diseases.

Lyme is a complex, multi-system disease. It can present as GI complaints such as belly pain and food intolerances, to neurological symptoms, headaches, dizziness, blurred vision, and joint and muscle pain. Antibiotics are the primary method of treatment, although most people with Lyme have an additional routine of supplements to address inflammation, nutrition deficiencies, hormone imbalances, and detoxing.

One reason Lyme disease is so difficult to diagnose is that the lab test that can show presence of the Lyme bacteria relies on the patient's immune response. People who have been sick for a long time or who are immune-compromised may not have a clear positive result. So, what effect does having Down Syndrome have? Research presented by the Global Down Syndrome Foundation found that the extra genetic material on the 21st chromosome actively affects multiple metabolic pathways, contributing to a high incidence of Alzheimer's and an impaired immune system. Down syndrome has a significant immune component. Is it possible to improve Paloma's function by addressing metabolic issues inherent in Down Syndrome?

Today, Paloma is doing well. She has not resumed Special Olympics basketball or swimming, which was something she really enjoyed before getting sick. She tends to need more rest and a more relaxed schedule than her peers. But she is involved in special recreation and takes a literacy class for adults with developmental disabilities. My hope is that she will continue to improve and will be free from episodes of pain and fatigue. Beyond Paloma's healing, my hope is that other families would be spared this experience. Being educated about the risks and taking preventive measures could mean avoiding chronic illness. I'm grateful there are so many individuals with Down syndrome out in the community, fully engaged



as they should be. I hope that we can help them stay safe and healthy as well.

PREVENTION IS THE MOST IMPORTANT THING YOU CAN DO

- Avoid high grassy areas; keep grass short in your own yard.
- Stay on walking paths in parks and preserves.
- When engaging in outdoor activities, wear light clothing, pants tucked into socks, and keep head and neck covered. Check the body and hair for ticks after coming inside.
- Use bug spray with Deet.
- If you are bit by a tick, remove it carefully with tweezers. Do not burn it off or use chemicals. Take it in sealed bag to the health department to analyze.
- Use Permethrin, a type of insecticide, to treat clothing or camping equipment prior to possible exposure to ticks.
- If you develop a bull's eye rash, seek immediate medical assistance. Be aware of developing flu-like symptoms, which could mean a tick infection.

PROFILE of: Geoffrey Mikol

Geoffrey Mikol is a professional artist that owns River Bend Gallery with his family, in historic Galena, Illinois. As a person born with Down syndrome, Geoffrey has found a special connection with photography as a means of expressing himself. His artwork is stunning and often technically difficult, catching elusive light that the eye sees but that cameras often miss. He has a talent for capturing moments in nature that still the soul and quiet your senses. Only 23 years old, Geoffrey has studied and practiced his photography now for nearly a decade, with spectacular results.

While in college, Geoffrey started his business exhibiting at Chicagoland

art shows. He has garnered numerous awards for his work; and has developed a following of collectors and enthusiasts. After graduating from Harper Community College, Geoffrey decided that he wanted a full-time career as an artist.

In the spring of 2016, River Bend Gallery was launched on Galena's famous Main Street, housing Geoffrey's entire photography collection, all in one serene, friendly, inviting location. Just one year later, due to overwhelming support and interest, River Bend has opened a more spacious gallery, located at the very start of Main Street!

In addition to his photography, Geoffrey has had a lifelong love

affair with music; including singing, dancing, and acting. He also enjoys, and is really good at, cooking, which he took as an elective while at college!

Geoffrey is one of the many artists who will be featured in the art show at the upcoming inaugural NADS Gala. You can learn more about the Gala at www.nadsgala.org.

River Bend Gallery
313 S. Main Street
Galena, IL
www.riverbendgalleries.com

Editor's Note: NADS News will feature a profile of an



Geoffrey Mikol

adult with Down syndrome in each issue. If you know an adult you would like to see featured, please email nadsnews@nads.org.



Good luck to Ann Garcia

Diane Urhausen

Ann Garcia has been involved with NADS since her daughter Sarah was a toddler—Sarah is now 17—most recently serving as our Family Support Coordinator and Newsletter Editor. Hers was the voice that expectant parents or parents of a

newly diagnosed baby heard when they called the office. She listened to them when they needed someone to listen. Her gentle soul offered support, acceptance, and encouragement when that is what was needed. Hers was the

voice that grandparents, nurses, and social workers heard when they called to welcome babies with Down syndrome into their homes and communities. Parents knew they could count on her knowledge and expertise to guide them throughout their journeys. Most recently, Ann played an instrumental role in developing and implementing our new Welcome Basket program. As our Newsletter Editor, Ann brought our readers stories of encouragement and hope. Parents, grandparents, and

professionals knew they could count on her to provide them with much needed resources in every issue.

Ann recently resigned from both positions to accept a new career opportunity — but she is not going far. You may see her in her new role as a Patient Advocate at the Adult Down Syndrome Center. Please join me in thanking Ann for her years of service and commitment to NADS and in wishing her well in her new position!



A BIG thank you to the Yee-Fisher family.

THEIR NEW BABY WELCOME BASKET FUNDRAISER IN HONOR OF LUKAS FISHER RAISED \$3645.00.

PAC volunteers at Buddy Walk

NADS PAC members volunteered at the Buddy Walk on October 8th and enjoyed a beautiful day. Newest member Jacob Spenadel did a great job selling raffle tickets!



NADS Partnership Advisory Council (PAC) Supports Hungry Families

Cheryl Crosby

On September 16th, NADS PAC members, families, friends, and other volunteers participated in a service project for Feed My Starving Children in Aurora. Together they packed 172 boxes of meals! That equates to 74,304 meals for hungry children in countries like Africa, the Caribbean, North and Central America, Asia, and others. Way to go!

According to the Feed My Starving Children website:

- Each volunteer packs about \$50 worth of food
- Meals are donated to FMSC
- The meals are specifically formulated for malnourished children around the world

- FMSC receives no government aid. They can only send meals as they have funding.

If you were not able to attend, but want to donate, you can contribute financially at www.fmsc.org.

A BIG thank you to the following NADS volunteers who participated:

Ryan Burke & Kevin Burke
Jacob Spenadel & Joseph Jacob Shimanek & Pat Shimanek

Erika Kissel, Franz Kissel, & Zachary

Diane Urhausen
Cheryl Crosby





Buddy Up Tennis Katie Finke

My name is Katie Finke and I am a proud mother of four kids (an 11-year-old daughter, twin 6-year-old boys, and a 3-year-old son). Jake and Owen are my twins and Owen has Down syndrome.

From the time our twins were born, my husband and I made a promise to ourselves to raise them in a similar fashion. Despite Owen's diagnosis, we knew it was going to be important to do our very best to include Owen in all the same activities, events, and interactions as Jake. Therefore, they started in all the same sports and joined all the same groups. When the twins were five and both playing soccer, I noticed Owen falling behind. Owen has tremendous motor skills and work ethic, but he just doesn't have the same stamina and speed as typical kids his age. I knew then that we would have to consider finding alternative ways for Owen to take part in sport and athletic activities. At about the same time, I was introduced to Buddy Up Tennis.

Recognized by the United

States Tennis Association in 2016 as the Adaptive Tennis Program of the Year, Buddy Up Tennis is a high-energy, adaptive tennis and fitness program for individuals with Down syndrome. The program was founded in Columbus, Ohio and is now nationwide. The mission of Buddy Up Tennis is to provide individuals with Down syndrome – called Athletes – an enjoyable and supportive environment where they can learn and play tennis while engaging in activities that will improve their athletic, social, and emotional development. Athletes can participate in Buddy Up Tennis at the age of five or older. Every Athlete is paired with a Buddy and Buddies are the heart of the program. Buddies are volunteers and provide the one on one support to the Athletes during each clinic. Buddies enjoy building and fostering relationships with our Athletes, seeing the direct positive impact they have on each participant, and giving back to our local community. Buddies are directed by Coaches.

Coaches are tennis professionals with teaching and/or coaching experience. Coaches explore, research, and implement ways to help our Athletes reach their maximum potential during every Buddy Up Tennis clinic.

Five Star Tennis, our local tennis club, committed to partnering with me to bring this fun and rewarding 90-minute tennis and fitness clinic to the western Chicago suburbs on a near-weekly basis. Since our launch last fall, the Naperville chapter of Buddy Up Tennis has grown at almost every session. Athletes get to learn at their own pace, and build

confidence as they learn the lifelong sport of tennis.

Buddy Up Tennis gives Owen and dozens of other kids in our community with Down syndrome an athletic activity they can call their own. Owen has learned so much and I love seeing the bond between the Athletes, Buddies, and Coaches every week. Come join us!



Owen Finke

For more information, visit buddyuptennis.com or email Katie at naperville@buddyuptennis.com. There is also a Buddy Up program in Arlington Heights.

ON THE TOPIC OF...

Always Learning Nancy Goodfellow

I officially have a high schooler.

In many ways, that statement terrifies me. It means the future is coming fast and I have to start preparing for what Lily's life will look like after high school. It means that no matter how badly I want to press pause and enjoy my children at the ages they are at I can't. I have no control over time and how fast it seems to pass.

But, in many other ways, I am thrilled. I am excited for Lily and all of the experiences that high school will bring. She is ready for this. She is enthusiastic to go to school each day. When someone asks her how she likes being a freshman, her smile stretches from ear to ear. Her entire face lights up and she beams with pride.

I marveled at how well she transitioned to high school. She knew her schedule and could find her way around the building in just a few days. She was open to joining clubs and getting involved, even if she didn't know anyone else. She navigated the crowded hallways and cafeteria with confidence, despite being one of the smallest people in the school.

But it's always when I'm marveling at her abilities, that I am reminded of her challenges.

This past week Lily was supposed to meet a friend at the vending machines for lunch. We have had a few issues with lunch recently. They are not Lily's issues though. I have realized they are mine. Every day Lily's friends from junior high and grade school ask her to sit with them. Some days she joins them. Other days she

chooses to sit by herself. Oftentimes, she will also leave the cafeteria to sit outside the classroom of her next period, long before lunch is actually over. Every day I ask Lily who she sat with at lunch. And on the days that she says she sat alone, I feel sad. I picture her sitting by herself and it reminds me of the fears I experienced in the days after her diagnosis. Fears of her being excluded. Teased. Ignored.

But the reality is that Lily is not being excluded. Or teased. Or ignored. Lily is choosing to be alone because it's the only part of her day when she can be. She needs the time to decompress. Talking and socializing with others is hard, especially when they are typically-developing 14-year-old girls. And a large group of them can be overwhelming, which is why Lily was meeting one friend at the vending machines. One of her girlfriends, Macy, noticed how talkative Lily was when it was just the two of them eating together. And she reached out to me to see if she could help Lily feel more comfortable at lunch.

But, Lily wasn't at the vending machines, and when Macy went to go look for her, she found her sitting with others.

I was disappointed in Lily for not keeping to the plan. I told her that she hadn't been a good friend because she didn't go to the vending machines. That was when she said, "Yes, I did. Macy wasn't there."

You know when you have those "Aha" moments and something dawns on you? Something you should have already known or



remembered? That's exactly what I experienced because why would Lily have actually waited for Macy at the vending machines? She went there to meet Macy and Macy wasn't there. She didn't think about the fact that Macy's classes aren't near the cafeteria like hers are. She didn't think about the fact that Macy would have to go to her locker first, and then come to the cafeteria. She didn't wait for one very important reason: I never taught her how.

Every so often, I get caught up in how well Lily is doing. I marvel at her accomplishments. And I forget that for individuals with Down syndrome, EVERY SINGLE thing must be taught. Lily knows to wait when someone is going to pick her up. But, she didn't understand how to wait for someone when you make plans to meet somewhere. This realization, like so many others in the past, led to other realizations of things Lily does not yet know - and the opportunity to teach them to her.

In this case, it was the chance to teach her that when you organize a time and meeting place with someone, you need to:

1. Wait for the person at specified location, giving them a specific amount of time to get there. (For

example, Lily needs to give Macy five minutes to get to the cafeteria.)

2. Know what waiting for five minutes feels like. Have a watch or phone available so you know how long you have been waiting.
3. Contact the person to see if they are still meeting you either by text or a phone call.
4. If you can't reach the person, wait for another five minutes before leaving.

I realized that this skill is so much more important than Lily meeting a friend to sit together in the cafeteria. It will apply to when she's meeting friends for dinner when she's older, or maybe even meeting someone for a date. It will apply to when she has an appointment for a job interview or is meeting an employer at a specific location. Even the steps listed above will need to be retaught for each specific situation.

I didn't let this reminder of Lily's challenges detract me from marveling at her abilities though. I accepted it as a teachable moment and an opportunity for her to learn from a "real-world experience." It was a minor incident with potential for major learning.

And we're always learning – both Lily and I.

NDSS Launches National “Law Syndrome” Campaign to Spotlight Laws that Hinder Individuals with Down Syndrome

The National Down Syndrome Society (NDSS) has launched a new campaign – “Law Syndrome.” The campaign addresses the challenges people with Down syndrome confront when they want to follow their career dreams, get married, and live independent, productive lives. Current laws exist that jeopardize critical government supports most individuals with disabilities rely on, such as health care. The “Law Syndrome” campaign aims to shed light on misconceptions that current federal public policy does not address and show how these laws adversely affect individuals with Down syndrome and their families.

According to a new website dedicated to this campaign,

www.lawsyndrome.org, “Law Syndrome” affects 100% of people with Down syndrome. It’s a series of antiquated laws that impede the pursuit of a career or living independently without risking Medicaid benefits.”

The website states that the NDSS is currently working on legislation that will allow individuals with Down syndrome and other disabilities to:

1. **Seek competitive employment opportunities** by increasing income limitations and ending sub-minimum wage practices
2. **Work and live where they desire** by creating a more portable Medicaid program with greater flexibility

3. **Benefit from more job opportunities** driven by new tax incentives that small businesses and corporations will receive when hiring someone with Down syndrome or another disability
4. **Achieve economic-self-sufficiency** from the expansion of successful disability programs like the National ABLE Program

By visiting the website and filling out the online form, the NDSS will send a message directly to your representative. You can use the message provided, or add a personal story. The “Law Syndrome” campaign hopes to give all individuals with Down syndrome, their families, the larger disability community, and the general public a voice and provide



a platform to encourage congressional leaders to act.

“NDSS is leading this historic national effort by showcasing to the world that Down syndrome doesn’t stop people with Down syndrome – it’s “Law Syndrome” that holds them back,” said NDSS President and CEO Sara Hart Weir. “By launching this campaign, we are calling on our leaders in Congress to join our efforts to reform these complex but misguided laws – and to help us change #LawSyndrome.”

Visit www.ndss.org and www.lawsyndrome.org for more information.

Brian Skotko Featured on DSAIA Podcast to Discuss Recent Research

Dr. Brian Skotko, co-director of the Down Syndrome Program at Massachusetts General Hospital, was recently featured on the Down Syndrome Affiliates in Action (DSAIA) podcast to discuss his latest research study. The study estimates for the first time the number of people with Down syndrome in the United States from 1950 until 2010. According to Dr. Skotko, the most recent paper brings all the research together and highlights very accurate estimates for the Down syndrome community.

The most surprising discovery from this research was the actual number of people with Down syndrome living in the United States today. As of

2010, the last year for which data is available, the current estimate is 206,000 people. The previous number used before this research was 400,000. Dr. Skotko stated that the numbers “were well-intentioned guesses, but we didn’t know the actual best estimate.” There have never been 400,000 individuals with Down syndrome living in the United States. However, there are more people living with Down syndrome in the United States today than ever before. The number of 206,000 exceeds the number used to classify a “rare condition,” which is 200,000.

The study also addressed how recent prenatal screening advances are affecting birthrate.

According to the most current research data from 2011, 1 in every 787 babies born has Down syndrome. However, the actual impact of the new non-invasive prenatal screening is impossible to measure at this point. Because the screenings were introduced in late 2011, no data is available yet. Once the data is collected and publicly released, Dr. Skotko and his colleagues will update the fact sheet that coincides with the study. The fact sheet is available at www.brianskotko.com under Publications.

When asked how this information should be used among the Down syndrome population, Dr. Skotko said that all fact sheets about Down syndrome should be

updated and conversations about Down syndrome and advocacy need to use the same, most accurate numbers. Because Illinois is one of nine states that collects data about babies with Down syndrome, there are specific numbers for the state, including how many babies are born and the termination rate. NADS plans to use this information to measure the efficacy of our outreach efforts and ensure that we are reaching as many families as possible who have a child with Down syndrome.

You can listen to the entire podcast for free by visiting the DSAIA website at www.dsaia.org and clicking on News.

A Homecoming Dance 'How It Should Be' By Katelyn Stanek, The Woodstock Independent



Luis Padilla and Nikki Durante have much in common. Both are students at Woodstock North High School. Both take part in school activities. Both plan to attend college in Wisconsin.

So when Nikki asked Luis to the school's homecoming dance last month, he gladly accepted. That's a story that will repeat itself thousands of times this fall in high schools across the country. But it's their differences — Luis is in mainstream classes, while Nikki, who has Down syndrome, is a special education student — that make their friendship special.

"We like each other because he's so independent," said Nikki, a junior from Woodstock.

The pair got to know each other in the school's dance class, where Nikki is a student and Luis, a senior

from Wonder Lake, runs the sound system. They started eating lunch together, too, after agreeing to go to homecoming. At the dance Sept. 30, Luis was named homecoming king — a title he wasn't expecting because most of his friends had forgotten to vote.

"It was so much more fun than last year," Luis said. "... Despite the homecoming king thing, it was really enjoyable to go with someone who enjoyed it as much as I did."

"We were dancing like crazy," Nikki added.

Diane Durante, Nikki's mother, said homecoming is just one example of how well teachers and students have integrated students with special needs into the wider school community.

"Since we came to Woodstock North, it's been like a whole different world," Diane Durante said.

"Even in talking to teachers, I think with this generation, the teenagers are much more open-hearted and accepting than I have ever seen before, and it's very comforting."

After graduating from high school next year, Nikki, who loves to cook and bake, plans to attend McHenry County College before taking off for Shepherd's College, where she wants to study culinary arts. The three-year post-secondary school in Union Grove, Wis., offers educational programs for students with special needs.

Luis, an honors student with a long resumé of extracurriculars, will graduate this spring. He plans to attend the University of Wisconsin-Oshkosh, where he's considering majoring in biology.

In the meantime, while they're still classmates, the pair hope people can take a little inspiration from their friendship.

"I had a lot of people who said, 'Oh, you're such a nice

UPCOMING EVENTS

November 17, 2017
NADS Gala: Reinvented

January 21, 2018
Leadership Training,
1:00p.m. - 6:00 PM

March 4, 2018
Bowl-A-Thon

March 18, 2018
Service Project

August 11, 2018
NADS Conference
New Location!
St. Ignatius College
Prep, 1076 W. Roosevelt
Road, Chicago, IL 60608

guy,' but I didn't do it for praise or to be nice," Luis said. "I just wish everyone could see that this is how it should be."

This article first appeared in the Woodstock Independent on October 18, 2017, and was reprinted with permission.

Sign Up for Action Alerts from The Arc

Visit www.thearc.org/what-we-do/public-policy to learn about The Arc's advocacy work and to join the Disability Advocacy Network list. As federal programs like Medicaid, the Affordable Care Act (ACA), Supplemental Security Income (SSI), Social Security, Medicare and civil rights laws like the Americans with Disabilities Act (ADA) are threatened, The Arc is calling on all individuals with an intellectual disability and their families to join them in reaching out to the President, Congress, Governors, and state legislators.

You can also follow **#JoinOurFight** and **#WeActWednesday** on Twitter to learn more about how to take action and support critical policies.

family album



Yasmeen, Talek & Tarek T.



Hope M.



We Need Photos!

Send your Family Album photos to NADS!
shebein@nads.org



Jessica B. & her dad



Josh S. & Shawn S.



Joanne, Erich & Nick S.

Ajshe Fejza



Bike Ride Raises Over \$2,000 for NADS

My name is Ajshe Fejza and I work for the Federal Home Loan Bank of Chicago. I was a founder and board member for the Albanian American Women's Organization (AAWO) that helps underprivileged women. Through the AAWO I learned of an Albanian woman who had taken in twenty male and female children and adults with Down Syndrome. This woman inspired me

to help individuals with Down syndrome. I was also inspired by my stepbrother who lives in Europe and has Down syndrome. He does not have the resources that we have here. I found the NADS organization and did my first 100 mile ride in 2016 and raised \$1,725. I did the same ride this year for NADS and raised \$2,025. Thankfully, I had the best supporting sponsors that helped me accomplish my goals: David F. Szczecin & Associates, LTD., A&B Jewelry and Loan, RELIA Insurance Group, Mobile Auto Tech, and Neverending Cycle.

Welcome Nancy Wilson

Nancy Wilson is new to the role of Family Support Coordinator, but she is not new to NADS. Nancy reached out to NADS for support and information before the birth of her son Jeremy more than 23 years ago. Nancy served as a parent support volunteer, was involved with the medically fragile group for many years, and completed the NADS Public Speaking training. She attended a family retreat (now called the More Than Down Syndrome Retreat) in 2001 with her son, and has attended nearly every year since. In 2004, she began coordinating the Parent Program for the More Than Down Syndrome Retreat and continues in that role today.

Nancy worked as the Patient Advocate at the Adult Down Syndrome Center from 2004-2011, an opportunity which gave her significant experience navigating the service system for both children and adults, as well as assisting families with IEP's and entitlement programs such as Medicaid, Medicare, and Social Security. Nancy put that experience and knowledge to use in 2011 as a private consultant for families because of her passion for connecting families to the resources they need. Nancy has worked in a group home for adults, and for the past four years worked as a teacher's aide in a therapeutic school for children and young adults with autism. Nancy has benefited from many of the programs and supports that NADS offers and she is now looking forward to providing support for families.

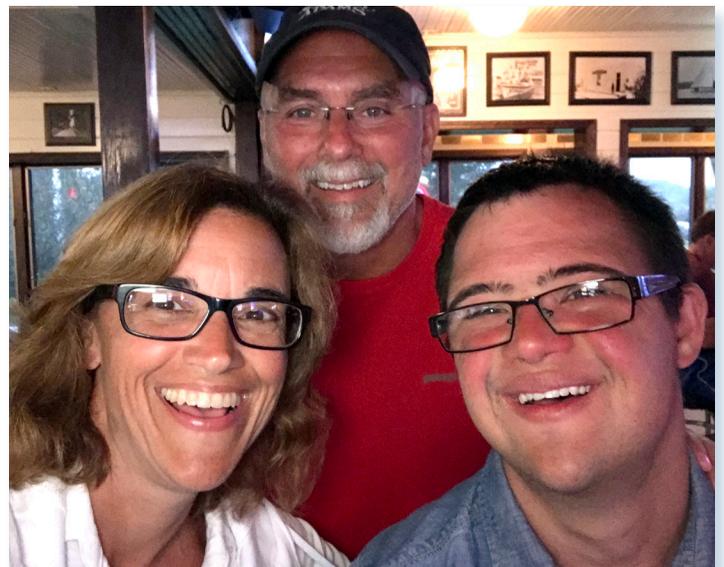
Nancy and her husband, Scott, live in the western suburbs. As a family, Nancy, Scott, and Jeremy enjoy being physically active and encouraging others to find a healthy lifestyle balance.

Please welcome Nancy to her new role! She can be reached at 630-325-9112 and nwilson@nads.org.

A note from the editor:

Nancy Goodfellow

I can't tell you all how excited I am to be officially working for NADS as the newsletter editor! I have been an active volunteer since my daughter, Lily, was born 14 years ago. Because I had a prenatal diagnosis, I was ready to jump into the world of Down syndrome and get involved as soon as Lily arrived. I attended the parent support training when she was just three months old, and served as a parent support volunteer for over four years. I have also served on the Board of Directors, and have been presenting to hospitals and schools as a NADS public speaker for over nine years. In addition, I create the slideshow for the fashion show each year, and have been writing a regular column for the newsletter for the past year. Ann Garcia's shoes are tough ones to fill, but I promise to do my best and continue including content in each issue that is useful, informative, and encouraging. Please contact me if you have an idea for an article, a photo or story to share, or an event to promote at nadsnews@nads.org.





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