

Ronald & Nick Schubert

NADSNews

Newsletter for the National Association for Down Syndrome

January, 2016

NADS Bowl-A-Thon

MARCH 6, 2016

This year's Bowl-A-Thon will be March 6th at the Stardust Bowl, 37 East Lorraine Avenue in Addison, IL. We hope you will join us! Our website (www.nads.org) has all the information you will need to register and set up a fundraising page. You can register as an individual or part of a team, and we ask that each person bring at least \$100 in pledges.

The Bowl-A-Thon is our biggest fundraiser, and we depend on your support to make it a success. If you are not able to bowl, there are still lots of ways you can help. We are always grateful for the hard work of the NADS community in obtaining donations for

choice raffles and door prizes, selling raffle tickets, identifying potential sponsors, and volunteering at the Bowl-A-Thon. If you would like to find out how you can contribute, please contact the NADS office at 630-325-9112. We would also be glad to help anyone who would like assistance with the registration process.

We hope to see you on March 6th!



25 Years

AT THE NADS BOWL-A-THON *Kathe Doremus*

The 2016 Bowl-A-Thon is a celebration for the Doremus family. It is difficult to believe that 25 years ago, we were facing one of the most challenging times for our family following the birth of our daughter, Kerry, in August of 1991 and the shock of being told she had Down syndrome. As I worked my way through the pain, fear, and mourning for the daughter I thought I would never have, I found "National Association for Down Syndrome" in the phone book — yes, a lot has changed in 25 years — and made a call. Who would have guessed the powerful impact that one call would have on our family these many years later? To consider the

relevance of this, when I was told my daughter had this genetic anomaly, my world was turned upside down. I lay in my hospital room waiting for someone to tell me she had to be put in an institution, I cried, I cursed God for punishing my innocent child for whatever I did wrong, I questioned hers AND our future, and tried to come to terms with the dichotomy of feelings I had — I adored my most beautiful little girl, but grieved for the child she would never be, the experiences she would never have. I had no idea at that time of the most amazing person she would be — it was the beginning of a journey.

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25 Years

Continued from page 1

A woman named Peg Nemec was the voice at NADS when I made that phone call, and she told me that it would be okay — she had a son with Down Syndrome, NADS offered resources, and with the amazing enthusiasm of Peg (may that dear, awesome woman rest in peace — what a legacy she leaves behind), she invited us to participate in the Bowl-A-Thon. Kerry was seven months old when we went to the Stardust Bowl for the first time on a March Sunday in 1992, my husband Dick and our sons, Dan and Bobby were 3 and 4, and we had no idea what to expect — a little timid I was, afraid, protective, and still mourning. I cannot express the magic of that day. We were accompanied by family, neighbors, friends — all who had surrounded us with their love and support — and with our beautiful baby girl in my arms, I was able to realize for the first time what our future truly held. At that event we met another amazing woman who would become my coach,

mentor, and inspiration — Linda Picchi and her young daughter, Angie, along with Sheila Hebein, the then Executive Director of NADS, all who brought inspiration, reassurance, and a sense of warmth and community. We met parents and children and families and friends of families — and I knew, then, that I could do this, WE could do this, SHE could do this, and it would be fine. That Sunday, and all the other Bowl-A-Thons since, we have been overwhelmed with the beautiful faces of people with Down syndrome in attendance and the joy shared by all the families and friends who love them, gathered in the bowling alley for a few hours every year. We are all inspired.

This year will be the twenty fifth year that our family has gone to the Bowl-A-Thon to support NADS. When we first participated in 1992, our boys were little guys, our Kerry was an infant, and we brought our family and a few close friends. Through these twenty five years, we have bowled with so many people who have surrounded our lives with

goodness — our family members, life-long friends, neighbors who became integral parts of our life fabric. The bond of the people who have supported our family through this journey is amazing — and the number of people who have been touched by our daughter is even more incredible. The first year, I held my baby girl in my arms and asked others — what can we expect, what will she do, how will I do this — and now each year that we attend, we see new parents coming to us and asking the same questions, looking for reassurance, support, hope. The Bowl-A-Thon and NADS give us all hope at a time when we desperately need to have hope. In our years with Kerry, the world has changed drastically, there is so much more knowledge, awareness, possibility — but that personal first step, that painful first step, will always remain the same — can I do this? Can I be the parent of this child? Am I strong enough, brave enough, and who will help me when I fall down? NADS has brought so many of us

together to help answer those questions, and the Bowl-A-Thon is a small way we can give back to the organization and reaffirm that we are all the things we need to be, because our children with Down syndrome are strong enough, brave enough, and they are resilient when they fall. Kerry is my hero as she faces her challenges head-on, never gives up, and has held me up so very many times when I have fallen.

Through our involvement with NADS over these past twenty five years, I have learned how to be an advocate for my child, and more importantly, how to teach her to be an advocate for herself. Twenty five years ago, NADS threw me a lifeline and taught the Doremus family how to travel this road with joy, faith, and belief that our world was a better place because Kerry was a part of our family. The Bowl-A-Thon has been an annual benchmark for us, and a celebration of our journey with those who mean the most to us. The Bowl-A-Thon each year, offers us the promise of the onset of Spring, the promise of a future for those with Down Syndrome and the joy of sharing that future for those of us who love these remarkable people!

On a snowy Sunday this November, I brought Kerry to the NADS Kick-Off for the Partnership Advocacy Council and saw all the young adults that were born around the same time — as they spoke about the importance of THEIR voice, THEIR self-advocacy, THEIR

life choices, I was moved beyond description and in awe of how very, very far we have come. As Kerry and I walked out the door and I asked her what she thought of the gathering, and she responded “It was kind of awesome” — I was overwhelmed by the power of NADS and the impact of these amazing people with a “little something extra” and humbled to be part of their world. The last twenty five years have seen a monumental shift in how the world perceives people with Down syndrome and we, the Doremus family, and Kerry, are so blessed to have been a part of this, benefited, contributed — to have seen the difference, felt the difference, made a difference. Our family looks forward to being here, hanging at the Stardust Bowl on the first Sunday of March and welcoming Spring — for another twenty five years — and oh, what a world we will make for all of us!



Call for Photographers

NADS is looking for professional photographers who would be willing to donate their time to take pictures for projects or events. If you know of anyone who might be interested, please have them contact Diane Urhausen at 630-325-9112 or durhausen@nads.org.

No Boundaries JJ Hanley

At No Boundaries, individuals build skills as colleagues in a real work setting in a central Evanston business district. Through individualized and team-based learning and training, individuals gain hands-on, practical experience in the workplace and in the community. The unique No Boundaries approach integrates on-land and on-line skills that are essential for people with disabilities to achieve workplace and community integration in the 21st Century. These include self-organizing, communications, self-advocacy, Internet safety and on-the-job skills. For more information about No Boundaries, contact JJ Hanley at 847-869-0000 or visit www.search-inc.org/noboundaries.



Alex Tello at No Boundaries

What do you do at No Boundaries?

I just started to go to No Boundaries. I like to go there because they are teaching me new things. I enjoy the way the staff speaks to me. Nice people.

What is your favorite kind of work?

To work on the computer—right now learning how to type and to navigate on the internet better.

How has No Boundaries helped you?

No Boundaries is helping at communicating better, to be more responsible, to advocate for myself, in building my social and life skills.

What else do you like to do outside of work?

I go to my Special Olympics programs at the park and practice my sports—swimming, basketball, floor hockey, softball. In winter, skiing.

What would you like to do in the future?

To have a job, to work in a place that I like and do a great job. I would like to keep working as a Self-Advocate, to tell my story, that people with Down syndrome can be integrated into the community and be successful.

My Brother Joshua *Samantha Talbot*

On August 23rd, 2001, my life changed forever when my youngest brother, Joshua Joseph Taus Talbot, was born into this world. With handsome blonde hair and blue eyes, Joshua was the cutest baby you could ever imagine. He had the sweetest smile and exuded love. Soon after he was born, we found out that Joshua had Down syndrome, but we didn't even care. Every time I held him, I just felt so happy and lucky to be his big sister. It was a feeling of pure love and joy- one that would last a lifetime.

Joshua brought immeasurable joy into our hearts and souls. Full of life and laughter, Joshua enjoyed playing baseball, watching his favorite T.V. shows and movies, making others laugh, learning, hitting on "smoking hot ladies," and, most of all, being a part of a team. Joshua loved his family so much. Born into a big family of eleven cousins, Joshua loved hanging out with his family. He gave us all the best hugs, kisses, and love. Joshua made us dance, laugh, and, most importantly, have fun.

Through the years, Joshua taught me how to be a better person. He taught me how to love unconditionally, how to be the best buddy to everyone, how to laugh until your stomach hurt, and how to enjoy life. Joshua was my very best friend, and even though I was his big sister, I always felt like he was the one teaching me.

In January of 2004, Joshua was diagnosed with AML leukemia. Joshua finished

treatment on July 9th of that year and kicked cancer's butt! After this, we enjoyed many healthy years. On July 14th, 2010, Joshua was diagnosed with a completely different type of leukemia, ALL



Josh Talbot

leukemia. Our family began a long, three-and-a-half year treatment program to combat the leukemia. Even though the treatment was very intense and Joshua must have felt very sick, he never showed it. He persevered and made the journey easier for all of us. In January of this past year, Joshua was re-diagnosed with relapsed ALL leukemia. In March, we knew that

Joshua would need a bone marrow transplant to give him his best chance at surviving. Everyone in our immediate family volunteered to give their bone marrow. We

found out that I was a perfect match for Joshua. In June, Joshua and I became "twinsies" when I gave him my bone marrow. The bone marrow engrafted, and Joshua was cancer free. Unfortunately, Joshua's lungs took a hit from all of the chemo and radiation. Joshua passed on September 8, 2015, surrounded by his loved ones and family.

Every day, I miss Joshua terribly; however, I know just how lucky I was to have him in my life. I

now cherish the memories that Joshua gave me, and I try my very best to honor Joshua by doing good things for others- something that he taught many others and myself. Joshua was an amazing brother, son, grandson, nephew, cousin, and friend. He will forever be loved, remembered, and cherished by all of those who loved and continue to love him.



Bartlett Fire Department Presentations

Linda Smarto, NADS Program Director, and her daughter, Julia, recently were invited to give 3 presentations to firefighters and EMTs at the Bartlett Fire Department. After the first presentation, they gave Julia her very own Bartlett Fire Department baseball hat and badge. A special thank you to Fire Chief Mike Falese, who arranged the series of presentations. If you know of other fire departments or emergency personnel who might be interested in a NADS speaker, please contact Linda Smarto at lsmarto@nads.org.

Special Gifts Theatre Fund

ESTABLISHED IN HONOR OF JOSHUA TALBOT

Ann Fulmer, Director of Operations, Special Gifts Theatre

Joshua had an immeasurable impact not only on his family, but all of those that surrounded him. His love, his laugh, his life will continue on at Special Gifts Theatre as we honor his memory through the Joshua Joseph Taus Talbot Financial Assistance Fund. This fund will support students of SGT that need financial aid in receiving the educational and therapeutic benefits that the theatre arts provide. All donations made to this fund will be matched dollar for dollar through an outside grant. To continue to celebrate the life of this amazing young man who made a difference everyday, please donate by calling 847-564-7704, emailing ann@specialgiftstheatre.org or online and noting it is for "Joshua's fund" at www.specialgiftstheatre.org.

Siblings

Nancy Goodfellow

My youngest daughter is four years younger than her sister, Lily, who has Down syndrome. When Holly was four years old and we were on a plane to California to visit her grandparents, she asked me about my middle name...

"Mommy, what's your middle name?"

"Fischer"

"Why?"

"Because it used to be my last name, and when I married your daddy, I became Nancy Goodfellow. But the name Fischer was important to me, so I wanted to keep it and made it my middle name."

"You can just change your middle name?"

"Well, if there's a name that's really important to you... But your middle name is Diana after your grandma. So she'd be sad if you changed it."

"I want my name to have Fischer in it too. I want my name to include everything that's important to our family."

"So what would you change your name to?"

At this point my daughter spoke very loudly, as if making an announcement to the entire plane. "I want my name to be Holly Diana Fischer Down Syndrome Goodfellow!"

After my initial laughter, and some funny looks from other passengers, I realized how wonderful Holly's announcement was. She saw Down syndrome as an important part of our family. It wasn't something that she was embarrassed about or ashamed of... Lily's diagnosis touched each of us, and that wasn't a bad thing.

Because Lily was born first, explaining Down syndrome to our other children was relatively easy. It was already a part of our lives, so my son and daughter have never known life without it. They heard my husband and me talk about Down syndrome over dinner, they attended NADS fundraisers before they could walk, and they were my audience when I became a public speaker and needed to practice my presentations.

While preparing for a presentation for doctors one day, my son, Luke, handed me a little slip of paper. He was four at the time and he had meticulously written the name of everyone in our family on it, including the cat. Everyone except Lily.

"What's this, Honey?" I asked.

"It's in case you forget."

"Forget what?"

"Forget to talk about the rest of us at your presentation. It's so you remember not to just talk about Lily."

Oh boy, I thought to myself. Maybe talking about Down syndrome all the time wasn't the best way to handle this... Maybe I needed to be focusing less on Down syndrome and more on making sure each one of my children knew they were special and loved and worth talking about.

So I started attending workshops and panel discussions about siblings of individuals with Down syndrome, including those led by Dr. Brian Skotko. Dr. Skotko has a younger sister with Down syndrome and is one of the country's leading medical clinicians, geneticists, and Down syndrome researchers. At one of Dr. Skotko's



Holly, Lily & Luke Goodfellow

workshops, he said that his family always discussed his sister's Down syndrome, but it was never the center of dinner conversation. So at least I hadn't been totally off in talking about Down syndrome. But I also knew I needed to find a better balance.

Central themes and ideas have come up at each workshop and panel I have attended. Siblings want to be treated equally. The sibling with Down syndrome still needs to have consequences for their actions, still needs to have chores and responsibilities, and still needs to abide by the same set of rules as everyone else. Holly is quick to point out when Lily doesn't receive the same punishment for pushing or forgetting to clean her room. And I am then quick to apologize and institute the same treatment for all. I don't want Lily to ever use her Down syndrome as an excuse for her behavior, so I have to remind myself at times not to do that myself.

Siblings also want time with their parents, time that isn't spent with the rest of the family or the sibling with Down syndrome. My husband and I tend to have many opportunities to spend time alone with

Lily, whether it's at doctor or therapist appointments, DS-related events, or Special Olympics. But we've also made it a priority to spend quality time with each of her siblings. My husband and son have always had soccer and lacrosse to do together, but I needed to create one-on-one time with my son. Fortunately for me, my son loves books and he still lets me read to him almost every night. Over the course of three years we read all of the Harry Potter series, culminating in a surprise trip for his 10th birthday to The Wizarding World of Harry Potter at Universal Studios. We arrived at the park early each morning and stayed until closing each night. We never stopped to rest or sit down, and rather than taking a break for lunch, we settled for snacks while waiting in lines. We'd finally eat dinner only after the park closed, usually after 9pm. Not only was it an incredible opportunity for me to spend time with my son, but it was also an experience that would have been totally different if Lily had been there. My son had three days to go full-steam. He got to ride every ride, regardless of the line,

Continued on page 11



Healing Garden at the ADSC

The Adult Down Syndrome Center at Advocate Lutheran General Hospital recently dedicated a new healing garden, which was made possible by a generous gift from Frank ten Brink and Jeannine Cleary in honor of NADS former Executive Director Sheila Hebein, as well as

longtime former NADS staff members Peggy Nemec and Linda Picchi. NADS conceived the idea for the ADSC and partnered with Lutheran General Hospital to make that idea a reality and has also provided over \$1,000,000 to support the Center over the years since its founding.

The Healing Garden was formally opened October 17 with a ribbon cutting ceremony, at which almost 150 people were present, including Sheila, Chris, and Peter Hebein; Art Picchi and his daughter, Angie; current NADS Executive Director, Diane Urhausen; the ADSC Medical Director,

Dr. Brian Chicoine, and other members of the Center staff; and many friends and supporters. The garden will provide a tranquil retreat for patients and their families, as well as providing therapeutic and educational opportunities. A garden club is planned for the spring.

The PAC Kick-Off Was A Great Success!! Nancy Brown

The Kick-Off for the Partnership Advocacy Council (PAC) was held on Nov. 22nd at Elmhurst College. Over 50 people attended to learn about PAC, meet new people and dance together. The participants were very enthusiastic about this new group that will focus on friendships, service, leadership, outreach and advocacy. The group will be led by adults with Down syndrome and work in partnership with NADS.

Every person with Down syndrome 18 years of age or above is encouraged to join and participate in a variety of events throughout the

year. The future goal is for self-advocates to participate in NADS activities, plan and run their own events, form committees, promote awareness, and work collaboratively with the National Association for Down Syndrome.

At the Kick-Off, Self-Advocates talked to the participants about the NADS Bowl-a-Thon, the Fashion Show, the NADS Conference and many ways that PAC members can get involved. Janice Weinstein presented some information about self-advocacy training, and Julia Smarto shared her experience as a public speaker. Everyone

had a chance to order PAC t-shirts.

The afternoon ended with a dance for all the participants.

If you were not able to attend the PAC kick-off and you are interested in participating in this exciting new group, please send an e-mail to Diane Urhausen at durhausen@nads.org. You will receive a calendar of events and more information about being a PAC member.



Next PAC Meeting

January 24, 2016

Check the NADS website in January for details or contact

Diane Urhausen at

630-325-9112 or

durhausen@nads.org.

Matthew LaChapelle & Collaboraction Theatre Company

Collaboraction is a 20 year old non-profit theater company with locations in Wicker Park and downtown Chicago. The company dramatizes urgent issues facing us today, such as segregation, education, veterans' mental health, and our relationship with technology. Ten years ago, when Matthew LaChapelle was a senior at New Trier High School, he and his father, Rick (whom many may remember from his years of announcing at the NADS Bowl-A-Thon), went to meet with Anthony Moseley, the Artistic Director, about the possibility of Matthew doing his senior project at Collaboraction. That internship was the beginning of a 10 year involvement for Matthew, who is now an Associate with the company.

As Anthony Moseley recalls, at their first meeting, he and Matthew "clicked." Matthew loved theater, and Anthony found Matthew charming, charismatic, and funny with "amazing energy." The two of them together are described by others in the company as a "supernova." Initially, Matthew helped with casting plays, preparing the theater for rehearsals and performances, and organizing costumes, but soon he found his way into the limelight. He often became an unofficial cohost at Collaboraction events, such as their annual Beggars' Banquet fundraiser. Anthony Moseley observed that Matthew was always "ready and willing to steal the spotlight," and the two developed a routine where Matthew would end up with

Anthony's gold lamé jacket.

Eventually he was cast in their Sketchbook Festival and has performed in a number of Collaboraction productions over the years. Matthew recalled that one of his hardest roles was in "Tower of Learning," where he played a son who was given a fatal dose by his mother and ends up dying. "Playing a dead person was hard," he noted. He loves being part of the productions at Collaboraction and working with the directors and actors and thinks of them like a second family. He knew from the moment he set foot in the theater that he had found a place where he belonged.

Matthew continues to be involved with Collaboraction, but he is also working on the skills that will help him to live an independent life. No Boundaries helps him prepare for employment, and the Center for Independent Futures works with him on life skills, such as cooking and handling money. He also has many interests and hobbies. He loves to cook and to play sports, such as basketball, softball, and volleyball, and he also likes meeting new people. But Collaboraction—and the people there—hold a special place in his heart.

Moseley attributes Matthew's success at Collaboraction in part to his charm and personality, but he also acknowledges that their theater company provides a perfect environment for someone like Matthew. Their program has always embraced diversity and valued connecting as a community,



and Matthew "added an important nuanced voice to our choir of human experience." Matthew always confounded people's expectations, Moseley noted, and made those around him think about what was important. "Matt

is wise and joyful. He has taught me a lot," Moseley said, adding, "Life lesson: leave your eyes open, your ears open, your heart open, your door open."

Editor's Note: For more information on Collaboraction, go to www.collaboraction.org



DS AWARENESS MONTH DONATIONS

For Down Syndrome Awareness month this year, Paul Wilson and his wife, Kathy Menighan Wilson, organized several fundraisers to benefit NADS and to honor their 10 year old son, Emmett, who has Down syndrome. Paul, who owns Art + Science Salon, offered free haircuts for people with Down syndrome on October 7 and also donated \$1 for every product sold in each of his Salon's four locations. Kathleen, through her real estate business, Homed360.com, donated \$10 for each person who came to her open houses during the month of October. Together, they gave more than \$3,500 to NADS. We are very grateful for their generosity and for their dedication to raising awareness about Down syndrome.

Reflections on the More Than Down Syndrome Retreat *Theresa Malkowski:*

Tell us a little about your family.

I have 3 children, Mark and Kristin are twins (26 yrs old) and Sarah is 24. We live in Batavia. Kristin attends an Adult Day



Program for adults with Autism/Developmental Delays at AID. Mark is a High School teacher and Director of Campus Ministry at Marmion Academy, and Sarah is a Special Education teacher (K-2) in a self-contained classroom in Batavia. I am a Special Education teacher by trade and currently substituting in West Aurora. We are a family of educators, as Kristin has taught many people acceptance, patience and understanding.

Both Mark and Sarah are extremely close to their sister, Kristin, who has Down syndrome and Autism. The love and support they show her is immeasurable. They take on many roles — that of being her sister, her brother, friend, caretaker and advocate. Kristin was first diagnosed with ADHD at 7 due to her extreme hyperactivity, then as she started to regress and the challenges became greater,

she was diagnosed with Autism.

How long have you been coming to the Retreat?

I have been coming to the Retreat since its inception: approximately 18 years. I have always felt privileged to be able to attend year after year. When my husband was alive, he too looked forward to going each year, at first with reservation, but he soon realized the value it held for us as a family, for him as a Dad, as well as the opportunity it gave Kristin to do something special.

What have been some of the highlights of past Retreats?

Many highlights over the years which include:

- Relationships that Kristin developed with the individuals who take care of her. She always remembered their names year to year and would ask for them on the way to the retreat. One of the individuals came back to be with her each year even after she moved out of state.
- Learning new ideas and strategies for dealing with behavior from the various behavior specialists (ideas I still use today). My husband and I always felt energized and renewed, ready to try the new strategies we may have learned.
- An opportunity to obtain information from various physicians regarding additional diagnosis, medications, health-related issues as well the importance of taking care of oneself.

Having my daughter Sarah

attend the last few retreats has been a very positive experience for me. She offers a great sense of support not only to me but to her sister as well. It's a wonderful opportunity to be able to discuss the retreat afterwards and to bounce ideas off of each other.

Tell us a little about Kristin's experiences at the Retreat.

Over the years Kristin has truly enjoyed going to the retreats at the "hotel." As she got a bit older and spring would be approaching, she would start saying the word "Hotel" and naming people that she had worked with at past retreats and naming all the foods she gets to eat. She could sense it was time for another retreat. I knew then it was something she really looked forward to each year. Something that truly touched my heart was when Kristin's care taker invited her to her wedding. What a wonderful evening that was. The first time she had ever been invited to a "party" that was not family related. When she was younger, she really enjoyed swimming at the retreat. Now she loves hanging out with the adults, listening to music, watching videos and going to music therapy. The retreat has become a comfortable place for her to be. A place where she is respected for who she is.

What have been the most valuable parts of the Retreat for you?

One of the most valuable parts of the retreat is having the opportunity to be with other parents who understand and relate to the challenges you face

raising a child with a Down syndrome with an additional diagnosis such as Autism or ADHD who presents with significant behavioral challenges. It is a comfort knowing you and your child will not be judged by others around you. There are times you feel very isolated from the Down syndrome world, perhaps because your child has not been able to partake in other activities successfully. The retreat is a place where the parents can share/laugh/cry and get support from each other, while the children are being well cared for with a host of activities for them to do. The information I have gained from the professionals over the years has been invaluable. By attending these retreats, I was able to seek out the appropriate professionals to help determine Kristin's additional diagnosis of Autism. Although it was difficult to hear, it confirmed my suspicion and opened many doors. I have my dear friend Sheila Hebein to thank for beginning this amazing concept of the retreat and for NADS to continue to see the value it holds for the families with exceptional challenges. I couldn't be more grateful!

Reflections from Sarah Malkowski:

I started going to the retreats once I graduated college in 2013. My experience has been very positive. I have felt a growing sense of welcoming and belonging within the group of families who regularly attend the retreat. The realness of the stories that are shared are incredibly (almost too)

relatable which, in my experience, is something that cannot be offered in any other environment. One of my biggest “take-aways” from the retreats is that we are not alone and that there are resources available to support our family members with this dual diagnosis. The advice and consultation that is offered through the professionals who are brought in to speak is greatly beneficial because it can be geared towards the specific challenges and struggles that each family is facing. As a sibling, I feel a sense of responsibility and make it a priority to be well versed in “everything Kristin.” It is no secret to me that her needs are complex and that the remainder of her adulthood will be a constant ebb and flow of challenges and growth. The retreat has given me an avenue to gain resources and support so that I can feel more confident in my ability to continue to be her advocate, caretaker, and cheerleader.

While I was growing up, I always looked at the retreat as something special that my sister did with my parents every year. She always talked about “going to the hotel” and the people that she would see there. Even as a little girl, I remember appreciating that Kristin had this opportunity each year to do something that she really looked forward to and genuinely enjoyed. The staff at the retreat meet Kristin where she is each time she walks through the door of a new retreat. They allow her to set the pace and really listen and attend to where she is on that given day. I also especially appreciate that the staff I have been able to meet treat Kristin as a

peer, and not as a student or client. They appear to genuinely enjoy their time with Kristin and always celebrate the positive parts of her day. It is incredibly refreshing and comforting to know that my sister is not only well cared for but is treated with dignity and respect. It has been such a joy to be able to share this experience with her over the past couple of years.

The most valuable part of the retreat is the feeling of camaraderie which surrounds you as families share their stories, full of both celebrations and challenges. Being a sibling, I hadn’t had too much exposure to the other families in similar situations in having a family member with the dual diagnosis of Down syndrome and Autism when I was growing up. The sibling groups that I attended were supportive in theory, but were always tainted with the dull sting of knowing that despite the challenges that the other siblings were sharing, mine were different. My struggles, challenges, and even celebrations couldn’t quite be understood amongst the other siblings of children with disabilities surrounding me in the room. The retreat does not come with this same sting. The retreat offers such a unique and carefree environment that allows for stories and experiences to be shared openly. I feel safe in sharing stories of my sister, knowing that there will be no judgment. I feel comforted in listening to the stories of other families, knowing that we are not alone in the unique challenges that my sister might bring to our family life. I, without fail, leave the retreat with a renewed sense of

NOTRE DAME IMPACT PARTNERS PROGRAM:

What We Learned Lauren Elliott

“Feedback is the breakfast of champions.”

— Ken Blanchard

The National Association for Down Syndrome in partnership with Notre Dame Impact is thrilled to share some of our learnings from the past few months. As many of you know, in April we kicked off a consulting project to think through growth opportunities for NADS. We reached out to many of our members via interview and survey, and would like to say THANK YOU for your feedback; everyone’s input has been invaluable in shaping NADS’ future strategy.

We would like to share some of the results that were uncovered over the past few months so that you are aware and part of the conversation regarding NADS’ future. The recommendations were organized into three key parts.

- First, to prioritize resources spent on our services based upon their ability to be scaled and reach more members. Here we identified opportunities to expand our membership connections via social media, partner with other DS organizations, and expand our current programming to help people of the teen/adult demographic.
- Second, to continue personalizing the NADS brand experience. We are so grateful for the stories around how we’ve impacted various members’ lives, and want to ensure that all members’ interactions are consistent with many of your experiences. We are working to ensure this same personalized experience is available to everyone by leveraging more volunteer resources to help with outreach and organizing our member databases to ensure we keep track of everyone’s experiences seamlessly.
- Third, expand volunteering to help us with each of our new initiatives. We learned that most members are willing to donate up to 4 hours a month to help NADS, thank you for your generosity here. We want to partner with you more to help different initiatives, many of which can be done from the comfort of your own home!

We are excited about the future prospects for NADS and look forward to continuing to grow with you and better serve your needs.

Until next time,

The NADS & ND Impact Team

confidence that my sister can and will continue to be well cared for throughout her life, as well as a sense of assurance that despite the challenges, there is always something to laugh about—something that happens often at the retreat—and that

I am forever grateful for the gift of my sister.

Editor’s Note: *Our next retreat will be April 9. If you would like to find out more, please contact Diane Urhausen at 630-325-9112 or durhausen@nads.org.*

familyalbum



Katherine & Richard Jegen



Zane Shropshire and Dale DeBarba



Abigail Adams



Maria Alzamora



Taylor Kaiser

Siblings

Continued from page 5

and he never had to take a break.

But siblings also don't need a big trip to count as quality time. Playing a game, making dinner together, or just going to McDonald's to share an order of fries count too. Over the years my children have started asking for "dates" with Mom and Dad, reminding us if it's been awhile since we've had time to focus on just them. And we do "dates" with Lily too, so that not everything we do with her focuses on Down syndrome or having special needs.

At one workshop, I learned about the idea of letting your child talk "off the record." It means that you give your children without Down syndrome the opportunity to talk to you without fear of consequences. I explained this concept to my son saying that if he's ever embarrassed or sad about Down syndrome, or if Lily has done something that has made him really angry, it's okay to come to me and talk about it. I told him that there are times when I need to go "off the record" too. That sometimes I have a "bad Down syndrome day" when it's not easy to be patient and ignore Lily's teeth grinding, or I'm tired of having to schedule life around doctors' appointments and therapies. I assured him that sometimes we can feel sad or frustrated, but that doesn't mean we love Lily any less or wish that her Down syndrome would go away.

In 2011, Dr. Skotko conducted a study that evaluated survey responses

from brothers and sisters age nine and older who had a sibling with Down syndrome. Of the siblings who responded, 94% expressed feelings of pride about their sibling, and 88% said they felt they were better people because of their sibling with Down syndrome. Less than 10% had any negative feelings associated with their sibling with Down syndrome.

In a 2014 interview for the National Review, Dr. Skotko summed up his own feelings for his sister. "Kristin fills in the missing pieces in terms of, when I am selfish she reminds me not to be. When I want to give up, she reminds me to keep on going. When I get frustrated when I didn't achieve a goal, she reminds me of all the smaller steps along the way that were successful. When I lose sight of the big picture, she reminds me to focus on the goodness that's there. When I am stressed, she reminds me that it's going to be OK."

Like all parents, I worry about what challenges all of my children might face as they get older. I worry about the challenges Lily will face because she has Down syndrome, and the challenges her siblings will face because Lily is their sister. I worry about them feeling like they need to look out for Lily, or that she is their responsibility. I worry that they might be teased because of Lily, or that they'll be embarrassed by her. But then I think about Dr. Skotko and all of the siblings I have heard speak over the years, and their message is always the same. They do not resent or regret having a sibling with Down syndrome, just as we don't feel that way as parents.

I don't think that Holly would want to have 'Down Syndrome' in her name anymore, but it's nice to know that it's still an important part of our family, and it is more often a source of pride than any other emotion.



NEW DOCUMENTARY ON DOWN SYNDROME

Dominican University student, Emilia Walasik, recently created a documentary about Down syndrome, "Perfection in Imperfect Lives," which features a number of NADS Self-Advocates and their families. The documentary is available on YouTube at <https://youtu.be/0gTtwMGHPes>.

UPCOMING EVENTS

"Glitter and Glue" Benefit for LuMind Foundation

Featuring Kelly Corrigan, NYT bestselling author

January 30, 2016
7:00 pm

Hotel Baker
St. Charles, IL

Tickets:
<http://glitterandglue.brownpapertickets.com>
Info: Nicole Gibbard
gibbardna@gmail.com or
lumindfoundation.org

5th Annual Trivia Night Fundraiser

Saturday, February 20, 2016

Inn at Market Square
2723 Sheridan Rd. Zion, IL.

6 pm – 10 pm

Sponsored by Zion Firefighters Fundraising, Inc.

Elmhurst Learning and Success Academy Transition Fair

February 24

Elmhurst College

6-7 pm ELSA Info Session

7-9 pm Transition Fair

www.elmhurst.edu/elsa

More Than Down Syndrome Spring Retreat

April 9

8 a.m. – 4 p.m.

Holiday Inn, Itasca

Contact Diane Urhausen
at 630-325-9112 or
durhausen@nads.org

2016 Buddy Walk Conference and Buddy Walk on Washington

April 10-12

Washington, DC

www.ndss.org

SAVE THE DATE NADS Conference

October 1, 2016

NADS Fashion Show

October 30, 2016



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Membership Application

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

Name.....

Address.....

City.....State.....ZIP.....

Phone (home).....

Phone (work).....

Email Address.....

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

Category of Membership (check one)

Parent: ☐ \$25.00 (1 Year) ☐ \$70.00 (3 Year) Child's birthdate/...../.....

Professional:* ☐ \$30.00 (1 Year) ☐ \$85.00 (3 Year)

*Please indicate professional involvement.....

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

☐ Check if Renewal

Make checks payable to: **NADS** and send to:

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