



Matthew LaChapelle
(top left) with campers
from Rising STARS

Photo property of STARS.

NADS News

Newsletter for the National Association for Down Syndrome

November, 2016

The All Inclusive Vacation *Dana LaChapelle*

No, not that kind. The kind where everyone gets to be on vacation and do what they love — together with family, with friends and even alone. It's a true gift to be able to share.

My husband loves to ski...meaning we all needed to learn how to ski. We started taking the family skiing when they were very young. Two of our children quickly surpassed my skiing skills. But, Matthew, our son with Down Syndrome was struggling to get his turn down the mountain. In stepped the adaptive ski program in Steamboat Springs, Colorado — which would later become STARS (Steamboat Adaptive Recreational Sports) — and another powder hound was born. And vacations became for everyone!

Matthew has been skiing with STARS since their inception, benefiting from one-on-one private instruction or "employing" a buddy to ski with for the day. He can ski independently, with family and friends — but often chooses to just ski with HIS friends at STARS. STARS staff and instructors

have watched him grow up and develop as a skier, a young man, and an advocate for people with disabilities.

This summer, Matthew was asked to be a mentor for participants in a Rising STARS Camp in Steamboat for clients from 15-21-year-olds. They went horseback riding, kayaking, swimming, and camping for five days in July. It was no surprise to see a contingent of folks from the Chicago area at the camp — all active members of NADS. Matthew was thrilled to be in the role as a mentor and spoke to the group around the campfire about transitioning after high school. It's the first time he told me how much he relished being with people "just like him." He was also filling a real need of his to have his OWN vacation without the family... though it was nice for us to be close by!

After the camp, Rising STARS Camp Director, Kenna Chapman, reflected: "Rising STARS camp was a huge success. Through activities such as kayaking, horseback riding, and camping we worked to empower our

clients and create independence. This was the first year we had a mentor at the camp and Matthew filled the role perfectly. His encouragement and positivity helped to create new lasting friendships in the group. It was inspiring to see each camper overcome personal challenges throughout the week, especially at the overnight (no-parents) campout. I am already looking forward to working with next year's group."

STARS is a non-profit that offers year-round, affordable recreational and educational programming. There is skiing, snowboarding and snow shoeing in the winter. And kayaking, water skiing, biking, tennis, therapeutic horseback riding and swimming in the summer. The programs are designed for kids and adults with autism, cognitive or physical disabilities, cancer survivors and injured veterans. STARS mission — to empower and enrich lives through adaptive recreational sports— is carried out every day through their

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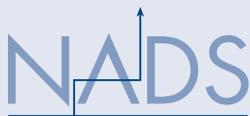
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For more information call or write:

National Association
for Down Syndrome
1460 Renaissance Drive, Suite 405,
Park Ridge, IL 60068

630 325-9112

or visit www.nads.org

Exec. Director Diane Urhausen
President Steve Connors
Editor Ann Garcia

NADS Launches New Welcome Basket Program

NADS recently introduced a pilot program in Lake County to provide welcome baskets to parents who have a new baby with Down syndrome. The baskets include baby items, such as knitted booties, toys, and diapers; books and information about Down syndrome; and information about Down syndrome organizations in the area, including NADS, Gigi's Playhouse, and UPS for DownS. Every baby deserves to have their birth celebrated, and we hope these baskets will be an encouragement to parents as well as a way of welcoming their family to the Down syndrome community.

We are excited to report that our first basket was delivered on October 3 to

a new baby boy and his parents. Jenny Di Benedetto, a Lake County mom who brought the idea of the Basket Program to NADS and is coordinating it in Lake County, took the basket to Highland Park Hospital, where she was able to deliver it in person.

We are currently providing training about the new program to hospital staff in Lake County hospitals and are also training parents who are interested in helping to deliver the baskets. We



are hoping eventually to extend this program to the entire Chicago area. If you would like to help us start a welcome basket program in your community, please let us know! Contact Ann Garcia at [630-325-9112](tel:630-325-9112) or agarcia@nads.org for more information.

New NDSS #DS Works Employment Conference

We were glad National Down Syndrome Society President Sara Hart Weir was able to attend NADS Next Steps conference, where she presented a workshop on the new NDSS employment program, #DS Works. Those who would like to learn more about that

program will now have the chance to attend a whole conference about it. The NDSS is introducing a new Employment Conference, which will take place April 3, the day before their annual Buddy Walk on Washington (April 4-5). The #DS Works Employment Conference will bring together self-

advocates, family members, and employers to discuss how to make employment for adults with Down syndrome a reality. You can attend one or both conferences. For more information or to register, go to www.ndss.org.

New Blog for People with Down Syndrome

In My Own Words: People with Down Syndrome is a newly launched blog "dedicated solely to the stories, reflections, and experiences of people with Down syndrome." Katherine Anderson and her son, Sam, who has Down syndrome, created the blog together as a way to give people with Down syndrome a "place to be heard." Katherine, who has a background in journalism, is partnering with Sam to conduct interviews and select content for the blog, and they would love to hear from you! You can send them a message via Facebook or Twitter (links are on each blog page), or email Katherine at katand@sbcglobal.net, or call [630-292-4376](tel:630-292-4376). Check out current posts at www.peoplewithdownsyndrome.com.

Regan and Casey.



Horses Make the Best Teachers

Anne Reinertson

I have always been drawn to horses and little did I know how my daughter's life would be changed because of them. Regan began her love of horses when she was three. It was at our first trip to Ready Set Ride set up by the school district special education PTA. Regan was fearless, she ran right up to this BIG wonderful horse named Casey. I have to admit I was a little intimidated but not Regan.

Regan wasn't speaking many words at 3 but they didn't need words—there was a silent connection that I noticed right away. Casey was so calm and patient with Regan, she instantly made a new friend that would change her life in such a positive way.

Ready Set Ride is a therapeutic recreation facility in Plainfield IL. They use horses to provide therapy in the form of games on horseback which

incorporate physical, speech, occupational, developmental and recreational therapy. When Regan was in a lesson, she didn't see it as therapy, it was FUN. It was a time for Regan to enjoy herself and spend time with her amazing horse friends. After numerous barn visits and lots of carrots, we decided to have Regan's 7th birthday at the barn with her special friends from school. I wanted them to experience the joy that Regan did at the barn. I noticed how her friends and horses all interacted. There was no judging or strange looks, just a feeling of acceptance and respect. It was a birthday party to remember.

Regan shortly after began horse therapy. Weekly she couldn't wait to go to the barn, and neither could I. After several months, I noticed her speaking more, and so did her therapist and teacher at school. Riding was helping her speech. I

never realized how horse riding could really change Regan's life and make such an impact on it. Regan is even reading more.

I would encourage anyone to look into horse therapy in your area. I see children with many different types of physical and developmental disabilities progress weekly. These horses are angels and so are the trainers and tireless volunteers who run these amazing programs. They work! The participants grow and learn so much in so many ways.

Regan has learned so much from the horses: cause and effect, learning to take risks and how to take responsibility and the list goes on.

Regan is now 11 and is training at another local barn named Sunrise Equestrian Center to compete in Equestrian Special Olympics next fall. She is doing amazing. Part of her riding lesson is now caring for her horse, I

Heidi. Regan is taking responsibility for the horse. She is learning and has learned so much from these amazing horses! They have given us so much, and I will always be so grateful to them. Don't horses make the BEST teachers? I think so—just ask Regan.

Ready Set Ride:
www.readysetride.org

Sunrise Equestrian Center:
www.sunrisenorth.org

Special Olympics:
www.soil.org

Vacation

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caring staff and volunteers. They served more than 587 individuals during the 2015-16 year.

For more information on STARS programming go to www.steamboatstars.com or call 888.330.1454.



NADS Next Steps Conference on Down Syndrome

Thank you to everyone who helped with or attended our conference October 1. What a great way to start Down Syndrome Awareness month! We are grateful to the Conference Committee, who spent many hours planning over the past year; to the volunteers who helped coordinate sponsors and exhibitors; to the many people who helped the day of the event; to the wonderful speakers who shared so much valuable knowledge and experience with us; to the National Down Syndrome Society, which helped to sponsor our conference and also presented their new #DS Works program; and to the parents, family members, and professionals who came to the conference and helped to remind us how fortunate we are to have such a vibrant Down syndrome community in the Chicago area.

Donation to Teen & Adult Conference

Many thanks to Ed and Laura Drower for donating the special NADS bags used by the teens and adults during their conference. We are grateful for their many years of support to our organization as well as their assistance, along with many other volunteers, in making that day a success for the teens and adults who participated.

On the Topic of...
The Top Ten Things I Learned at the NADS Conference

Nancy Goodfellow

On October 1st, I attended the NADS Conference at the Donald E. Stephens Convention Center. I have attended this conference every time it has been held since Lily was born 13 years ago. And, every time I have learned something new. Sometimes, I learn entirely new information. Sometimes, I relearn things I have heard before and forgot. Sometimes, I learn that I have done a good job at remembering a previous lesson and implementing it. Sometimes, I learn that what I have been doing wasn't exactly the right thing to do. Every time, I come away with a few lessons and some action items. Below is a list of my top ten things from this conference.

1. Treat your child with Down syndrome the same as their siblings. If you mess up and your other children call you out on it, acknowledge your mistake and make it right.
2. Discipline your child with Down syndrome with logical consequences that match the offense. Dr. D. gave the example of removing her son from the car and sitting in the rain for 30 minutes when he kept hitting his sibling in the backseat. It may seem a little extreme, but he learned that if he had unacceptable behavior in the car, the car would stop and he would be punished. As a result, he no longer hit his brother (at least in the car!). The consequence needs to be immediate and directly related to the unacceptable behavior.
3. Hold your child with Down syndrome to high expectations, and be prepared for when they reach them.
4. Have realistic expectations for the agencies and organizations that exist to help your child, and hold them to their mission statements.
5. It's never too early to start planning. Start thinking about what kind of future you want for your child and take steps now to make it happen. For example, you don't need to wait for a job evaluation to find out if your child can bag groceries. Take your child shopping with you and use the self-checkout. Most job skills can all be learned and practiced at home.
6. Everyone wants their child to have friends. And, many are struggling with this. But, watching the NADS self-advocates interact with each other demonstrates the friendships that exist among them. Just as we make friends with the people we associate with, our children with Down syndrome can do the same. If your child is struggling to find friends, find new opportunities for them to meet new groups of people.
7. NADS has a new program for self-advocates, NADS Partnership Advocacy Council. It is a service leadership organization led by adults with Down syndrome that focuses on service, leadership, outreach and advocacy. They participate in NADS activities, plan and run their own events, form committees, promote awareness, and work collaboratively with the NADS Board.
8. *Black Day: The Monster Rock Band* is a great book – and movie! Written by a talented young man with Down syndrome, Marcus Sikora, with his mom, Mardra Sikora, it is a great addition to any family library.
9. The best people to learn from can be other parents. Often, the best advice you can receive is from those who have been there and gone through the same things you are going through. Take advantage of opportunities to talk to parents who have older children with Down syndrome.
10. The Teen and Adult Conference attendees get to have WAY more fun than the rest of us!

Three Cheers For Three Cheerleaders

Suzanne Burdett

Sometimes opportunity knocks. Sometimes it yells at the top of its lungs. When that happens, even if it's in a gym full of high school students displaying their school spirit loudly at a pep rally, you simply cannot ignore opportunity. Miles Evans, a student with Down syndrome who attends Glenbard West High School in Glenbard School District 87, didn't. Neither did cheerleading coach, Michelle Gatz.

Coach Gatz has known Miles for years. He used to cheer in the stands for his older brother who ran on the track team. Miles couldn't wait to attend the high school where his brother attended. Then last year, when Miles was a sophomore, the school was having a pep rally to kick off the fall sports season. During the varsity cheerleaders' performance, Miles could no longer contain his enthusiasm. He ran from the bleachers onto the gym floor and joined the cheerleaders in their routine. The students cheered even louder.

When you've worked as a physical education teacher and cheerleading coach for twelve years, it's easy to spot true enthusiasm and spirit. So when Miles asked to join the cheer squad, the coach let him try out. He had to memorize dance routines and cheers just like every other student who'd tried out. He performed to her satisfaction and joined the squad.

"I'm not nervous showing my school spirit in front of lots of students. I like being part of a team," declared Miles.

Glenbard West's assistant cheer

coach, Hilary Masterton, now teaches at St. Vincent Ferrer in River Forest. Previously, she worked at Glenbard West as a teacher's aide, and that's when she started assisting Gatz with the cheer squads. Having taken special education courses, Masterton was very supportive of Miles joining the team.

Miles' success on the cheer squad was not lost on his good friends, Sarah Bak and Sidney Garza, who are also students with Down syndrome. Both are juniors this year. Though Sarah had participated on the Glenbard West dance squad her sophomore year, and was no stranger to showing her school spirit, she wanted to try something different. Sidney was looking for an activity where she too could display her school spirit. All three students thought it would be great fun to cheer together. So did coaches Gatz and Masterton. But the coaches made it clear that Sarah and Sidney would have to try out just as Miles had. They would have to be able to memorize dance routines and cheers just like other squad candidates.

So Sidney and Sarah started to practice. And they practiced. And practiced. In May they attended the cheer squad tryouts. Both students memorized and performed a dance routine and cheer. Coach Gatz was satisfied with each of their performances, so Sidney and Sarah were awarded a spot on the varsity

squad. And then they continued to practice, even over the summer.

To help Miles, Sarah and Sidney manage important details associated with the squad, Coach Gatz assigned a "Cheer Buddy" to each of them. Two buddies are cheerleaders and one,



Sidney Garza, Sarah Bak & Miles Evans

though not a cheerleader, supports her buddy with cheer squad. The buddies help Miles, Sarah and Sidney learn the new cheers and routines. They will also help out with reminders about how to dress for the games,

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Special Chronicles at the NADS Conference

Daniel with Marcus Sikora

Daniel Smrokowski covered the NADS Next Steps conference for his website, Special Chronicles (www.specialchronicles.com/NADS2016). Check out his podcasts and interviews with guests such as NDSS President Sarah Hart Weir; keynote speakers Marcus and Mardra Sikora; Ali and David from GiGi's Playhouse Hugs&Mugs; Shepherds College; Buddy Cruise; Special Sparkle Jewelry Company; Dr. Kathleen Murray, and many more.



Homeschooling Our Son

Lori Reifsteck

“If you move our son to the Life Skills Program we will homeschool him!” Those were the words my husband stated at our son’s 6th grade IEP meeting. In my mind I laughed and said “Yeah, right! That’s not going to happen!” Once we left that meeting and I started doing some research, my thoughts surprisingly changed to... “Maybe we will homeschool him for 7th grade.”

My husband rarely attended IEP meetings for our son, Ben, who has Down syndrome. There had never been any issues in the IEP meetings, so I was always able to handle them on my own. For Ben’s 6th grade IEP meeting, my husband was free that morning and decided to go. Once the meeting started, we were surprised as all the staff at the table took turns telling us everything our son had been doing wrong all year. Nothing like this had ever happened before, and my husband and I listened patiently as story after story was told. They told each story as if it was a recurring problem, only to find out that each incident had only happened once. When they were all done with the stories, we discovered the reason for them: for 7th grade, they wanted to move Ben from the Instructional Skills Program (ISP) down to the Life Skills Program (LSP). ISP was more like real junior high, and the children went to different classes during the day that were modified for special needs children. LSP was a

self-contained special ed classroom for children with more severe disabilities. We were shocked, and my husband asked if Ben was having behavioral problems. Their response was, “No. He just requires more of our attention than we are able to give him.”

Since we didn’t really know much about the LSP classroom, we were encouraged to observe the program to make a more informed decision. When we visited the program we were not happy with what we saw. The classroom had children that were much more “needy” than our son. The teachers and the aides worked with the other children, who needed more of their attention, while our son sat quietly at the table waiting to be told what to do next. The other children were non-verbal, and some had behavioral issues. Our son was able to speak, but was very shy, and had no behavior issues. My husband and I both agreed this was not the classroom we wanted our son placed in.

A few weeks later, we had a follow-up IEP meeting to discuss our observations. My husband was unable to go this time, and I thought I could handle it on my own. I informed the team that we did not want our son in the LSP class. We felt he would be better off in his current classroom where the children were higher functioning. Their response was, “The team has decided his placement should be in LSP next year.” Through tear-filled eyes, my response was, “Our son will not be



Benjamin Reifsteck and Meghan Collie going to Homecoming at Oswego High School

here next year because I will be homeschooling him.” I walked out of that meeting and never looked back. I went straight home and started figuring out what I needed to do to homeschool him in 7th grade.

To my surprise, it was quite easy to withdraw Ben from the public school system and begin homeschooling. All I had to do was write a letter to the school stating his withdrawal and my plan to homeschool instead. I started ordering curriculum based on what I wanted him to learn. I decided to teach him what I thought he needed to survive everyday life. We would work on his handwriting, addition/subtraction, money handling, and telling time. I ordered a lot of workbooks from Amazon. My favorite series was the Daily Math and Handwriting Practice books from Evan-Moor. There were also many free websites with worksheets I could print each day. My favorite math website was Math-Aides.com, because I was able to select what addition or subtraction problems I wanted him to

work on. They also had great worksheets for telling time.

Even though he was entering 7th grade, I decided we were starting over. His handwriting was not great, so we started with the basics: learning how to write each letter and each number till it was legible. For math, we started with addition using Touch Math. I started with adding 1’s, then 2’s, then 3’s, and so on. Once he mastered simple addition, we moved on to subtraction. Once he mastered addition and subtraction, we moved on to simple word problems. His reading comprehension had always been low, so word problems helped him to read with the added benefit of solving math problems too.

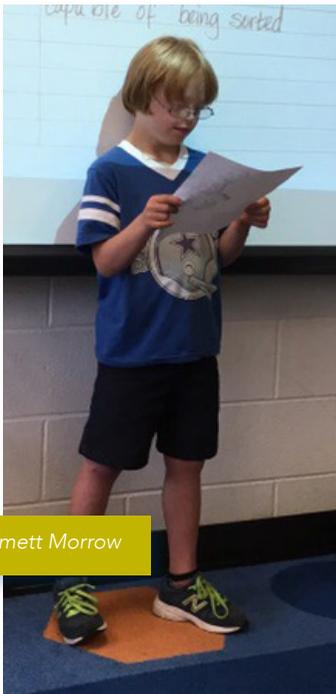
For Ben’s 8th grade year, we decided to re-enroll him in Jr. High, but only so he could receive speech services. We were told that to be eligible for speech, he needed to be enrolled in at least 2 classes at the Jr. High. So for his 8th grade year, he went to school from 8-10:30 each day. I picked him up each day at 10:30,

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Kipling Elementary Presentation

Trish Morrow

A huge thank you goes out to Linda and Julia Smarto for coming to Kipling Elementary in Deerfield. The teachers were very impressed by Julia's portfolio and the way she presented herself along with her terrific power point presentation. The key ingredient that the education professionals took from the presentation was, "high expectations."



Emmett Morrow

Linda and Julia's visit to Kipling was first discussed during last spring's RED Week (Respect Everybody's Differences). Kipling Assistant Principal, Svetlana Sutic, was excited to learn about NADS Self-Advocates presenting to teachers, staff and students. Since the presentation at the start of this year, helpful exchanges have continued in regards to differentiating for our son Emmett, which can also be used for several types of

learners.

The photo on the left demonstrates one of the many ways that the professionals at Kipling adapt, share and apply new information to help students become independent learners. Emmett recently rehearsed a poem with his resource teacher and practiced presenting to an audience using highlighted cues which reminded him when to look up from his paper. Emmett confidently read the poem to his peers due to the excellent support and suggestions taken from Julia's power point.

The poem itself was also very pertinent. Emmett is working with the school psychologist/social worker and his teachers on how to think win win, be a good and safe problem solver as well as synergizing by working together during recess. When challenges arise, it is important for Emmett to understand that these situations are wonderful opportunities to learn and grow.

The professionals at Kipling are very grateful to Linda and Julia for taking the time to make a big difference in the lives of many students, families, teachers and education professionals. Thank you Linda and Julia for your effective, inspiring and timely efforts and thank you to Emmett's third and fourth grade teams for outstanding collaboration and implementation.

2016 Chicagoland Buddy Walk



Self-Advocates at the Buddy Walk

Volunteering at the Chicagoland Buddy Walk has become a tradition for our Self-Advocates, and a number of NADS Self-Advocates were present on October 9 to help with the event. Rachel Giagnorio had a chance to represent the group on stage this year and spoke to the crowd on being a NADS Self Advocate and what the Buddy Walk has meant to her over the years. Here is an excerpt from her speech:

"I love the Buddy Walk and the idea of meeting new people, having a good time, and celebrating life together. It's so much fun seeing so many people getting together for such a great cause. I look forward to this every year and I have a blast!"

I also enjoy being a NADS self-advocate because it gives me a chance to tell people about myself and to have my voice heard. I like speaking to groups because it gives the world a chance to get to know more about me and my very full life. I have a very busy schedule as I work 2 jobs and I am always on the go with activities with my friends and family.

Thanks for coming and supporting the Buddy Walk. Let's make today EPIC!"



Rachel Giagnorio speaking from the Buddy Walk stage

NADS Partners with the ADSC on New Video Series

The Adult Down Syndrome Center at Advocate Lutheran General Hospital in Park Ridge is currently collaborating with NADS to produce a series of videos about healthy living. The videos feature teens and adults from our PAC program. Dr. Brian Chicoine, the Medical Director of the ADSC, explains his vision for the new series in the following interview:

Tell us about the new video series from the ADSC. What are you hoping to accomplish through the videos?

The video series will be aimed at 3 separate audiences:

- people with Down syndrome
- families and caregivers
- professionals

Some of the videos for all the families and professionals will have people with Down syndrome as actors. Essentially all the videos for people with Down syndrome will have people with Down syndrome as the actors. The videos for people with Down syndrome have a primary goal of encouraging and providing skills for people with Down syndrome to participate in their own health promotion. For the other audiences, the videos will be educational about a variety of topics.

Why did you choose to have them feature individuals with Down syndrome?

There is an approach to educational videos or videos promoting change in behavior called self-modeling. Ideally the person (watching the video) is themselves the actor. However, it has been found that next best is a person who looks as much like the person as possible. Therefore, we are using people with Down syndrome to promote healthy behavior in other people with Down syndrome.

What are some of the topics the series will cover?

Ultimately we see having (perhaps) hundreds of videos that would promote healthy behaviors in physical health (handwashing, eating at an appropriate rate, good hydration, healthy food selection, sleep hygiene etc.), social skills (dating, employment issues, healthy behavior in a variety of settings).

How does this project fit in with your ongoing research?

We will present findings in videos. We will study the use of videos as a patient education tool for people with Down syndrome to determine effectiveness, best approaches, etc.

If someone with Down syndrome would like to become involved in your research on patient education, what should they do to enroll in your study?

Individuals can sign up for our first video study at the link below. The survey also gives one an opportunity to let us know they don't want to participate in this study but would like to be contacted about future studies: goo.gl/hdfZfP

What are some recent highlights of your work at the ADSC?

I am participating in the development of Health Care Guidelines for Adults with Down Syndrome through the Down Syndrome Medical Interest Group.

We have completed studies on mammograms and pap smears for our patients.

We also completed a study on mortality in our patients.

We are working on a number of studies on the incidence of a variety of conditions, use of the emergency room, and hospitalizations.

We are reaching out to a variety of people and organizations across the country on possible collaborative efforts on a number of studies.

What is coming up for the ADSC?

I am expanding to 2 research days per week.

We are expanding our education program—teaching more residents and medical students and providing more webinars and other presentations.

We have hired Dr. Katie Frank—she will be providing occupational therapy services, including sensory evaluations, and also running social skills groups.



Karen and Kelly Neville at the Naperville Police Department

Safety Presentations

We were honored to have Mike Falese, the Fire Chief for the Bartlett Fire Department, presenting a workshop at our conference October 1 and teaching the teens and adults with Down syndrome about fire safety. We are continuing our outreach to first responders through presentations by NADS Self-Advocates and public speakers at local police and fire departments. If you are interested in having a speaker come to your community, contact Linda Smarto at lsmarto@nads.org.

New Mural Honoring Kay McGee

A mural of Kay McGee, the founder of NADS, was included with a new series of murals by artists from the Little Bits Workshop depicting notable residents of River Forest, where the McGee family lived for many years. For those who may not have had the privilege of knowing Kay (who passed away in 2012 at age 91), here is an excerpt about her from "The History of NADS," written by former NADS Executive Director Sheila Hebein:

NADS "was founded in 1960 by Kay McGee shortly after her daughter Tricia was born with Down syndrome. In those days the standard operating procedure in hospitals was for physicians to advise parents to institutionalize their newborn infants with Down syndrome. Parents who did not follow this advice took their babies home without support or services. Kay and Marty McGee chose to ignore the advice of their pediatrician and they took Tricia home. After the initial shock of learning that their baby had Down syndrome, Kay, with the support of Marty, began to reach out to professionals and other parents of children with Down syndrome, and that was the beginning of an organization that would always recognize the great value of individuals with Down syndrome and of parents helping parents. . .

With the help of a few other parents, Kay formed an informal board, and for many years their meetings were held in the home of Kay and Marty McGee. Kay ultimately became the Executive Secretary, and she was the driving force behind the organization from 1960 to 1975. (Kay actually completely filled the role of president, but in 1960, women were not usually seen as presidents of organizations.) In addition to the day-to-day running of the organization—handling all phone calls in her home, doing the clerical work and information flyers (keep in mind that NADS didn't begin using computers until 1989)—Kay organized regular meetings for parents in downtown Chicago, bringing in speakers from as far away as Germany. All the Down syndrome conferences in the 1960's and early 1970's were held in the Chicago area. Kay and the other parent founders of NADS were truly pioneers as they developed support systems for each other and especially for new parents.

In the 1960's there were no mandated programs or services for children with special needs, so many parents started programs in church basements and in other community buildings. Many of the private agencies that currently serve adults with developmental disabilities throughout the Chicago area were started



in this way. They not only built a strong foundation for our organization, but they also fought vigorously for early intervention and education services locally and nationally. We will be forever indebted to those courageous parents."

Kay advocated for her daughter and for people with Down syndrome and their families throughout her life. She and fellow mom, Marge Lee, started an outreach to hospitals—which we still continue through our hospital in-services. She fought for educational opportunities for her daughter and other children with Down syndrome, and Tricia was the first student with Down syndrome to be included in a regular education 1st

grade class at her local elementary school in River Forest. Kay was also one of the founders of the National Down Syndrome Congress.

After school, Tricia moved to an independent living apartment at Misericordia Heart of Mercy on the north side of Chicago, where for many years she has lived a very active and full life. She was able to see and appreciate the new mural of her mother during a recent trip to River Forest with her brother, Michael. Kay McGee was a pioneer and a national force in the Down syndrome community, but to Tricia, she will always be "Mom."

Editor's Note: For "The History of NADS," see our website: www.nads.org/about-us/history-of-nads/.

For footage from the 2009 NADS Fashion Show during which Kay McGee was honored for her work with NADS, go to: <https://youtu.be/OHNxfIAAUfg>

<https://youtu.be/S0FGgKQuscE>

For information on the mural, go to: <https://goo.gl/44VUZZ>

family album



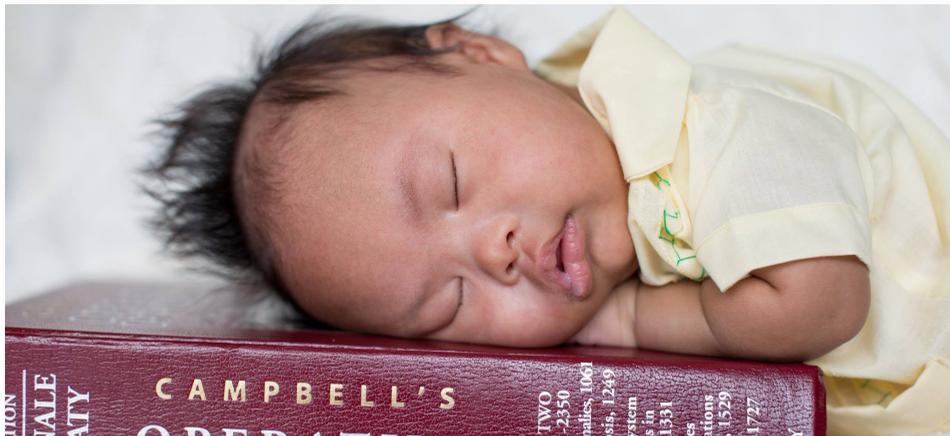
James Webb



Daniella Thomas



Glada Moratti



Nico Alejandro Brito



Tracy Taylor & Colin Guerrero



We Need Photos!

Send your
Family Album
photos
to NADS!

shebein@nads.org



Deborah, Sophie & Wyatt Nelson

Cheerleaders

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where to go and when to be ready for the bus which transports the cheerleaders to the away games.

"All the cheerleaders interact with Sidney, Miles and Sarah on a daily basis. In placing students with their peers, I use my best judgement..." explained Coach Gatz.

A huge smile sweeps over Miles face when he talks about Kevin. "Kevin is my cheer buddy and he helps me to learn the cheers and the routines and we stand together in the gym."

Sidney's response is more reflective. "My cheer buddy is Tess. She's not on the team, but she gives me support."

Clearly, for these three, the emphasis is more on the "buddy" as Sarah notes. "My cheer buddy is Lauren. She helps me with routines and helps me to know what to wear and when to show up. One time, during the summer, Lauren and Kevin came to my house to help me learn some routines."

There is no mistaking that this is a very demanding extra-curricular activity. Miles, Sarah and Sidney practice two hours after school, two days a week. Then there are the games to attend on Saturday afternoons, which require them to be present well before the game begins.

Sarah and Sidney state emphatically that they both love school and even though cheer practice takes up a lot of time, it's "easy" to be there.

Miles has gotten used to being busy, folding cheer practice in with other activities, such as his photography, which

has received such artistic acclaim, he has his own line of note cards. Currently, Sarah is juggling cheer squad with the drama club's rehearsals for the upcoming production. And their school coursework is always the number one priority.

When asked what they liked best and least about being on the cheer squad, each responded quickly.

Miles said, "I like when the cheerleaders huddle and cheer right before the game starts. We all get excited. I do like performing at the games. But I don't like doing the push-ups when our team scores points."

Glenbard West's cheer squad has a tradition that the cheerleaders do a push-up for every point the football team scores during a game.

"I like learning the new cheers and routines" responded Sidney.

Sarah replied, "I like performing the routines at half-time." When asked what she doesn't like about being on the cheer squad, Sarah answered, "There's nothing I don't like about it."

Best of all, Miles, Sarah and Sidney have unwavering support from their fellow cheerleaders. And when cheering at a game, the student body makes it clear, it has way more than three cheers for these cheerleaders.

Editor's Note: Suzanne Burdett is a freelance writer. Her work has appeared in the Chicago Tribune and other publications.

Homeschooling

Continued from page 6

and we went back home for some more homeschooling time.

By the time his Jr. High school years were finished, Ben was able to add anything, subtract almost anything, and we even started on multiplication. He was able to tell time down to the minute and his handwriting improved greatly. In addition to the "book smarts" he achieved, he also learned a lot of everyday life skills. Since we weren't in a hurry to rush out the door to school, he was able to learn how to take a shower and dress himself independently.

At the end of 8th grade, we began researching the high school program. To our surprise, the high school program appeared to be a better fit. The program and the children seemed to be closer to Ben's level. We decided to start his 9th grade year at the high school but only go half a day. He went from 7:15-12 and had all the core subjects. I picked him up every day at 12 to continue his homeschooling. Ben loved high school, and his teacher was amazing. By the end of the 1st semester, we decided Ben should go full time, and our homeschooling experience came to an end.

What started out as a simple threat during an IEP meeting in 6th grade turned out to be one of the best decisions we ever made for Ben. By the end of junior high, Ben learned so much more than we ever could have hoped. Now he continues to build upon that homeschool base in high school.

EVENTS

NADS More Than Down Syndrome Retreat November 19, 2016

Holiday Inn, Itasca, IL
Info: Contact Diane at durhausen@nads.org

NADS Bowl-A-Thon March 5, 2017

Stardust Bowl
Addison, IL
www.nads.org

NDSS #DS Works Employment Conference April 3, 2017

Westin Arlington Gateway Hotel
Arlington, VA
www.ndss.org

NDSS Buddy Walk on Washington April 4-5, 2017

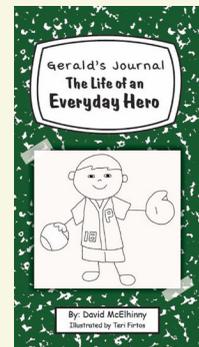
Washington DC
www.ndss.org

BOOKS

Gerald's Journal: The Life of an Everyday Hero (Volume 1)

David McElhinny
Armonia Publishing, 2016;
\$8.99

This new series features an everyday hero with a difference—Gerald has Down syndrome. Much like the author's son (who also has Down syndrome), Gerald likes to record his thoughts in a journal. He writes about the things he likes—pizza, ice cream, recess—and the things he doesn't like, such as not being invited to a birthday party. At school, he is included in a regular education class but not always included in all the social activities. These challenges provide opportunities for Gerald to teach others about the value of kindness and acceptance. The second installment, *Gerald's Journal, Volume 2: Friends, Foes, and Forgiveness*, will be released in December. The series is appropriate for children ages 6-12.





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