



Brogan Hora

NADS News

Newsletter for the National Association for Down Syndrome

January, 2017



NADS 32nd Annual Bowl-A-Thon

Please join us for our 32nd annual Bowl-A-Thon, March 5, 2017 at the Stardust Bowl, 37 East Lorraine, in Addison, IL. For many years, this event has brought together families in the Chicago area, who come both to support NADS and also to reconnect with old friends. If your family has not yet had a chance to come to the Bowl-A-Thon, we would love to see you! The afternoon includes

bowling (with door prizes for every bowler), visits with Ronald McDonald, many wonderful choice raffle items, and a chance to win one of our grand raffle prizes. It is a fun day for children and adults and a great way to include friends and extended family who might enjoy a chance to see the Down syndrome community in action!

VOLUNTEER SPOTLIGHT

Jackie Rotondi has faithfully helped with the Bowl-A-Thon since the time her daughter, Gina, was a toddler. Gina is now 21. When Gina was little, they came to bowl (and soon Gina was bowling with them). Jackie then began helping with the choice raffle table, which for many years was organized by Gail Anderson. When Gail became involved with the NADS Fashion Show, which she has co-chaired with Carmella LoCascio since 2005, Jackie took over responsibilities for the choice raffles and door prizes for the Bowl-A-Thon and has been managing them ever since.

Those rooms of prizes and tables full of beautifully coordinated baskets do not happen by accident, and Jackie found that planning for them was often a year



Jackie Rotondi and Bridget Brown with Ronald McDonald

long process. She would develop themes for some of the baskets and look out for new items to go with that theme, searching clearance racks for possibilities. And of course, she also organized the many items she received from donors and from businesses. Her goal was to make sure that on the day of the Bowl-A-Thon, "everybody goes

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Jackie Rotondi

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home with something."

Jackie went on to become the President of the NADS Board of Directors, serving in that role from 2009-2012, and her position kept her involved with all aspects of the Bowl-A-Thon. Over the years, she has experienced the event from many different angles. Looking back, Jackie recalled that

one of her chief rewards was seeing the look of joy when someone learned they had won one of the prizes they had been hoping to receive. She also loved seeing the parents reuniting with old friends and connecting with new ones, and observed how important that time of sharing was for many families.

Gina has continued to bowl for us and has consistently been among our top fundraisers. Last year she brought in the most pledges. Over the years, the Rotondi family has raised over \$100,000 for NADS. We are very grateful for all they have done for the Bowl-A-Thon and for NADS.

Why Support the Bowl-A-Thon?

The Bowl-A-Thon is our largest fundraiser. It provides most of the revenue for the programs through which we serve individuals with Down syndrome and their families. Here are some of the ways those programs have made a difference:

■ Our Parent Support Program (which includes our new pilot welcome basket program and our information packets for new parents, parent mentors, a resource and referral service, and outreach to Spanish speaking families). "I learned about the valuable support from the National Association for Down Syndrome and began connecting with other parents of children with Down syndrome through their Parent Support Program. Being able to talk to someone who understood what I had experienced and knew the answers to so many of my questions was very comforting."—Jackie

■ Our Public Speaking Program (education for medical professionals, speakers for schools and community organizations, and a speaker training program for Parent/Volunteer Speakers and for Self-Advocates). "Hearing from Michelle

was the best part! The kids were able to better understand what it is like for a person to have a disability and were able to see that she is just like them."

—4th grade teacher

■ Our PAC Program (leadership development and service opportunities for adults with Down syndrome).

"The best part about being part of NADS PAC is being with old friends, making new friends, and being able to make a difference."—Ashley

■ Our More Than Down Syndrome Retreats (which provide respite and resources for parents raising a child with a dual diagnosis).

"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 . . . The information I have gained from the professionals over the years has been invaluable."—Teresa

■ NADS Conference (which includes education for parents and professionals and a separate conference for teens and adults with Down syndrome)

"Thank you NADS for helping to provide current, invaluable

information to parents, siblings, professionals, and the community"

—Joanne

■ NADS News (our newsletter, which is published every other month).

"After 31 years... the newsletter is still inspiring!"—Dana

HOW YOU CAN HELP

Come bowl with us! All you need to do is register (either as an individual or part of a team) and obtain at least \$100 in pledges. You can find sign-up information, pledge sheets, fundraising tips and more on our website, www.nads.org. The registration deadline is February 26.

Not able to bowl? There are still many ways you can assist us:

■ Donate items for door or raffle prizes (gift cards, merchandise, tickets to events, etc.)

■ Contact businesses in your community for donations

■ Share information about lane and event sponsorships with any businesses that might be interested

■ Volunteer to help with the event.

■ Spread the word to friends and family!

UPS For DownS Production of The Lion King Jr

Vicki Kirkpatrick, President of UPS for DownS

On February 2-5th, UPS for DownS Theatre Company will kick off the magnificent 10th Anniversary production of The Lion King Jr!

We are a community-based musical theatre that works under the direction of Orion Couling. Orion Couling, our Director from E.D.G.E, works tirelessly with his team to make each production better than the year before! E.D.G.E. has been partnering with UPS for DownS since 2008! Moreover, E.D.G.E. of Orion has been working with children of marginalized communities for several years and has produced over 100 plays with its youth theater groups. E.D.G.E. believes in meeting each participant as an individual, determining his or her abilities and capabilities and holding our participants to a standard of excellence at which they can succeed! I can tell you, that is hard work! This theater program is so much different than most. Each play has a double cast. That means two of the shows might have the Character be in our case, someone who has Down syndrome. The other two shows, might be a typical developing peer in that same role. Each show is unique and awesome. Children 10 and up with Down syndrome and their typical peers are expected to audition, learn

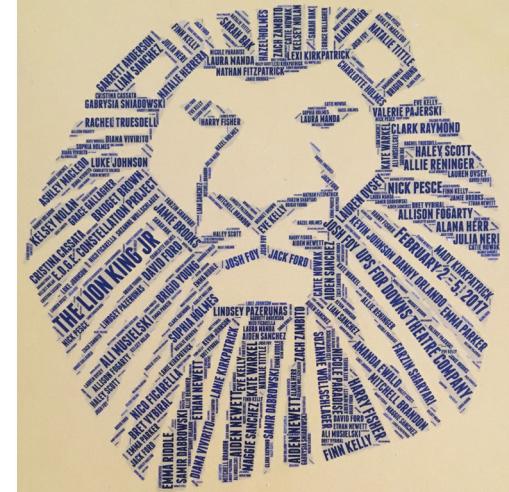
their lines and choreography, with no excuses. I feel like Orion and his team from E.D.G.E just "Get it!"

My husband, Gregg, and I have 4 daughters. Our youngest, Mady, has Down syndrome. We have always wanted her to be treated like everyone else and given the same opportunities. For my oldest daughter, Lexi, this will be her 3rd play with the UPS for DownS Theatre. For my other daughter, Laney, this will be her 2nd. Mackenzie, is looking forward to joining when she is old enough.

This year, Orion called me and asked if Mady would like to join the cast and be "Baby Simba." I immediately said "Yes!" He mentioned that he would want to talk with her about it as well. He did. He asked her if she would like to join the cast and told her what he expected. She gladly said, "Yes!" and high fived him! This is what I mean, when I say that they "get it!" Orion and his team expect hard work and dedication from all who participate. That is why he talks with each of them ahead of time. He and his crew treat everyone equal and not special.

This has been a wonderful experience for my family. Everyone practices their lines and songs together. Lexi said, "I love that I have made so many new friends outside of

UPS for DownS Theatre Company



TENTH ANNIVERSARY PRODUCTION OF

THE LION KING JR

Community-based musical theatre for people with Down syndrome, friends, and YOU!

school! We all have a lot in common. For some of us, we have a sibling with Down syndrome. For others, we have friends with Down syndrome. It's so cool when we all meet our potential! Everyone helps everyone and is always cheering you on" Laney said, "I never knew I wanted to be a part of a group like this, until I auditioned! It is like nothing I have ever experienced before!" Mady can't wait to make her first appearance on the big stage! Mackenzie loves to help the girls with their lines and songs!

Go out and buy your tickets! I promise you will not be disappointed!

7pm Thursday February 2

7pm Friday February 3

6pm Saturday February 4

1pm Sunday February 5

Presale online: \$11

All show pass: \$30

At the door: \$15

All shows will be performed at

the Prairie Center for the Arts in

Schaumburg.

www.udflionking.eventbrite.com



A Boy's Best Friend

Editor's Note: The mother and son featured in the following story are Tracy Taylor, who has been a Parent Support Volunteer for NADS and served on our Board of Directors, and her son, Colin Guerrero. Their story about adopting a rescue dog, Merit, was also covered by the Chicago Tribune: <http://www.chicagotribune.com/lifestyles/pets/ct-pets-merit-folo-0804-20150805-story.html>. These excerpts from "Merit's Story" are reprinted with permission from the Trio Animal Foundation website, www.trioanimalfoundation.org.

MERIT'S STORY

It was about a week before Memorial Day when Merit's lifeless emaciated body was first spotted under the lilac bushes in Chicago's Grant Park. It was initially thought that it was too late and that Merit had passed away before help could arrive. However, when Merit noticed the water that the kind staff of Lakeshore Athletic Services had set out for him, he lifted his head and let them know that he had not given up...

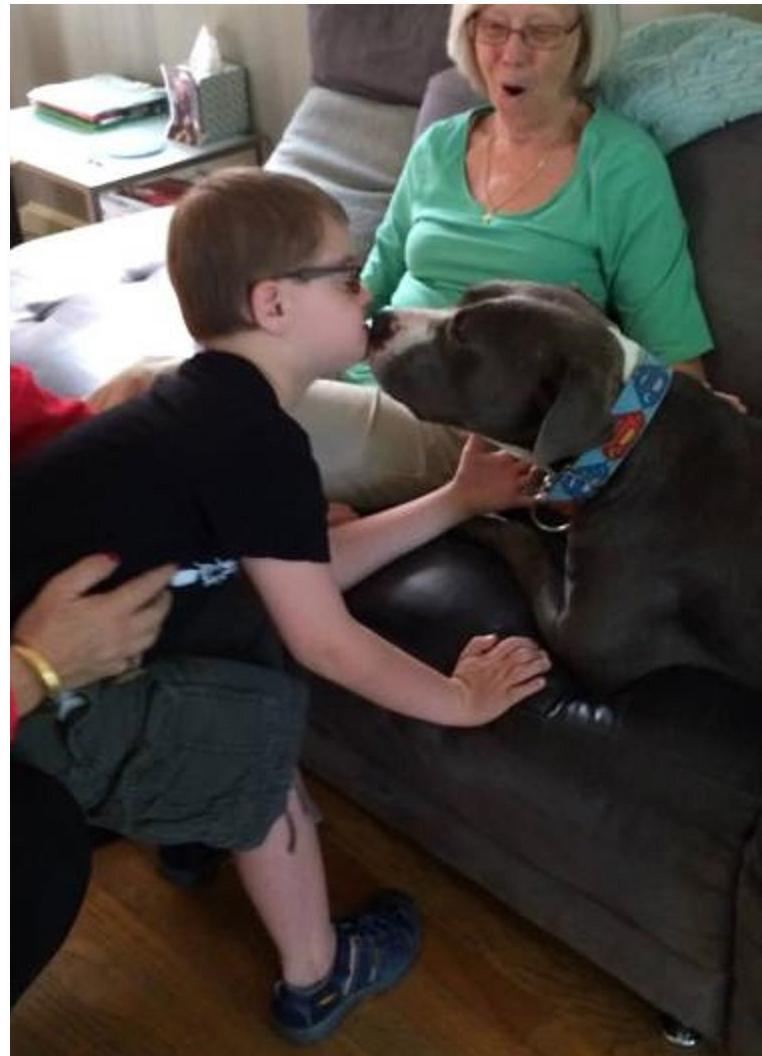
The Trio Animal Foundation spent about two months working with Merit to help him heal both physically and mentally. As it turned out, Merit LOVED other dogs and would light up when he saw the dogs from TAF's Canine Rehabilitation Team. This was a big surprise to us as he was so antisocial in every other situation with people...

Unsure what the outcome would be for a dog such as Merit, we decided to take a leap of faith and put Merit up for adoption. Almost

immediately, we were contacted by a single mom who had a ten year old son who was born with Down syndrome and was autistic. She said that at age six her son was diagnosed with autism and has not spoken since.

The woman was looking for a companion for her son as he does not like to be around people. She also needed a dog that would not jump on him and one who wouldn't be too disruptive to the routine that is necessary for her son. The hope was that Merit and her son would provide each other with the no pressure companionship that they both needed. The kind of friendship and loyalty that only a dog could provide.

The woman came to meet Merit to see if he might be a good fit for her son. It did not bother her that Merit did not run up to greet her as most potential adopters would... she appreciated that which made Merit different. In fact, it made her like him more.



Within days, Merit was brought over to meet the woman's son to see if there was connection between the two.

When greeted at the door, Merit left Bridgid's side and for the first time was confident enough to walk in on his own. In a scene straight out of a movie, Merit walked straight to the couch and sat next to the young boy. With no words said, the boy gently patted Merit on the head and put his arm around him.

They sat quietly together and it was as though they had picked up where they had once left off... an unspoken connection between two souls. There is no denying that something very special happened at that moment.

With his mom and grandma by his side, Merit found his purpose and a little boy found his best friend... it is truly a match made in heaven.

Take Our Newsletter Survey

We would love to hear from you about ways we can improve our newsletter and about new options for communicating with you. Let us know what you think! Take our newsletter survey at:

<https://www.surveymonkey.com/r/NADSNews>

New Year's Resolutions

Nancy Goodfellow

I'm sure many of us make New Year's resolutions every year. A list of things we are going to do differently that we believe will make our lives better. Go to the gym. Eat healthy. Watch less TV. Read more. Spend less time working and more time with family.

And, as parents of a child with special needs, our list probably includes at least one or two resolutions that have to do with our child - with making their life better. Rather than just share a list of my own, I sought the help of friends who also have a child with Down syndrome. Perhaps it will give you an idea of one or two things you can do to help your own child. Perhaps it will give you the opportunity to pat yourself on the back for already having accomplished these goals. Perhaps it will remind

you of the list you made last year...

- Getting my son back into shape with a more active lifestyle. (He put on some weight after his bout with pneumonia last year.)
- Figure out how to navigate the "teenage years." (Yikes – we've got some teenage attitude!!!!)
- Make efforts to help my son develop more friendships.
- Be more conscious of identifying opportunities for my son to be more independent at home - cooking, walking the dog, doing his own laundry.
- Be a stronger advocate for my daughter academically in high school.
- Help the high school come into the 21st century and realize our kiddos are capable of

so much more! Always more...

- Help my daughter find a part time job! (Outside of her school job training.)
- Start building relationships that will help my daughter when she gets to high school next fall, like getting in touch with the swim coach now to see how she can be on the team.
- Focus on the importance of physical activity and nutrition so that she can independently identify healthy choices, portion sizes, etc. (And understand why she needs to participate in P.E. class!)
- Follow through on all (or at least most) of the things that therapists and doctors suggest, like what vitamins to take, daily exercises to

do, techniques to try to alleviate bad habits - or dry skin - or poor sleep, etc.

- And, most importantly:
- Give myself a little grace when I don't accomplish everything or the resolution fades into the reality of everyday life.

Because the reality is that life can be busy and crazy and hectic. And despite that, we do everything we can to help our children (not just the ones with Down syndrome), and we will continue to do everything we can day after day, month after month, new year after new year.

And I will continue to use the resolutions involving my children to justify why I didn't accomplish the others... especially going to the gym!

FUNDRAISING

We are continually impressed and grateful for the many creative ways people raise money to support NADS. Here are some recent fundraisers which have benefited NADS:

■ **Miles Evans** raised money for NADS and for the Adult Down Syndrome Center through selling his cards (which feature his award winning photography) at Namaste Salon during the month of October, holding a photography show/sale at FT Portfolios in Wheaton, and donating a week's earnings from his job. Thank you, Miles!

■ **Nick Schubert** and his mom, Joanne, did fundraising and public awareness at Grove Dental for Down Syndrome Awareness Month. We are grateful for their work in the community and for their donation.

■ **Sarah Malkowski**, who created a fundraising page through First Giving (firstgiving.com) for her first ever marathon, raising money for NADS in honor of her sister, Kristin (who has Down syndrome), her students (Sarah is a special education teacher), and of Down Syndrome Awareness Month. Many thanks to Sarah for her generosity to NADS.



Nick Schubert with Dorothy, his hygienist, at Grove Dental

UPCOMING EVENTS

**The Lion King Jr.
UPS for DownS Theatre
Company
February 2-5**

Prairie Center for the Arts
Schaumburg, IL
www.udflionking.eventbrite.com
www.upsfordowns.org

**NADS Bowl-A-Thon
March 5**

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

**NADS Spring Family
Retreat
April 22**

Holiday Inn
Itasca, IL
www.nads.org
For more information, please
contact Diane Urhausen at
durhausen@nads.org.

2016 DOWN SYNDROME AWARENESS YARD SIGNS

Many thanks to Peggy Delaney and KinderCare for another successful public awareness yard sign campaign. It raised over \$7,497 for NADS and also helped spread a positive message about Down syndrome in our communities. We are grateful for all who participated in this campaign!

My Brother Wyatt

Sophie Shepley

High school is like a musical to me.

Act one, Freshman year, I was rushing out the door every morning to catch the bus as Wyatt pranced around the living room listening to Disney Sing-Along Songs. The VCR tapes played without fail through my first-day jitters, making of new friends and paralyzing finals.

By Sophomore year, it was all about The Muppets. I stopped myself from humming "Rainbow Connection" while memorizing the Periodic Table of the Elements and even on my first date. I realized algebra was kind of my thing as I completed my homework to the scenes of Muppets in Manhattan.

My brother's entertainment became downright bothersome for me during junior year, however. Wyatt was now using our family laptop to watch a Swiss comedy about an anthropomorphic penguin called Pingu on YouTube. So began the battle of the computer.

One night I marched up to the laptop with guns blazing to print my AP English essay and register for the next ACT. My mom made me wait for her to finish closing an ad sale (after all, her work did put a roof over our heads). But it was Wyatt who threw a violent tantrum if his cherished gibberish-mumbling penguin character was interrupted.

Though I sound thoroughly irritated, Wyatt gets an exception. Wyatt has Down syndrome, as well as a tic disorder

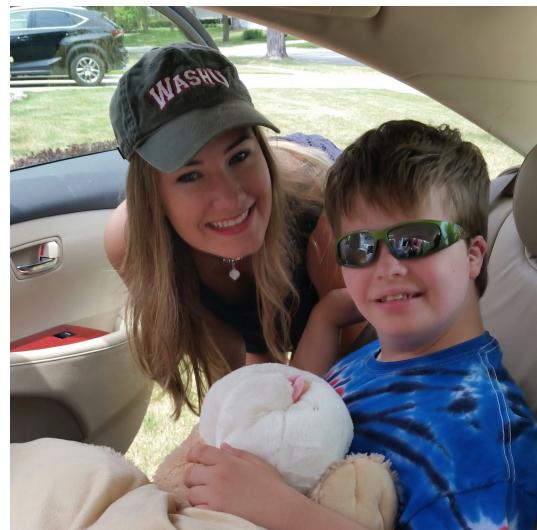
and complex behavioral issues still in the process of being diagnosed. People with Down syndrome often enjoy repetition, which explains his contentment with sticking with one program for the better part of a year.

Wyatt's disability has certainly been a challenge for my family. But what is even more noticeable is how much my family has grown because of him. I am very grateful to Wyatt for giving me not only a one-of-a-kind sibling relationship, but also a unique perspective including more patience and greater appreciation for the ways in which people are different and yet similar.

Having Wyatt as a brother has opened my eyes to issues people face every day because of physical and intellectual disabilities. This has helped shape my career goals. While I don't want to go into special education (though it seems everyone would recommend it for me), I want to make a difference for people through medicine and public health.

This year, senior year, is all about Shrek The Musical. College applications, rigorous courses, dance company and extracurriculars are almost as difficult as crossing the fiery bridge to Princess Fiona's tower.

At first, I found it difficult to focus on writing with flashy show tunes playing just a wall away. But now



I realize that I don't need to tune it out; the songs I once found irksome are the soundtrack of my high school career. So why can't I type an acceptance-worthy essay to the beat of Shrek's opening number?

The future holds many changes for us. I will be living away from home. Wyatt will have to be the big kid of the house in my absence. Letting go of my family will be difficult, but I am beyond thrilled to start a new act.

A year from now, when I reminisce on the application process, vivid memories of clicking the big red SUBMIT button on commonapp.org will be accompanied by my current scene: Wyatt singing along to the reprise version of "Big Bright Beautiful World" (a Shrek knee-tapper I highly recommend).

Even after teary nights due to Wyatt ripping homework assignments in half or feeling sad because Wyatt's disabilities limit our visits with extended family, it is the happiest times of singing, dancing and rough-housing I always remember most. Although I won't be home to experience Wyatt's new favorite show, my next four years will be to a soundtrack I compile.

Robert Olson 1954-2016

Many NADS members may remember long-time NADS Board Member, Robert Olson, one of the first Self-Advocates to serve on our board of directors. We are sad to report that he passed away on October 18, 2016 at the age of 62. For those who did not have the privilege of meeting him, the following reflection from former NADS Executive Director, Sheila Hebein, will give you a sense of why he was an important part of our organization.

Remembering a Very Special Gentleman

Sheila Hebein, Executive Director of NADS 1979-2009

Robert N. Olson – known to everyone as “Bobby”—was a guy with great warmth and charm. Bobby and his sister, Margaret, were raised in the south suburbs of Chicago by their parents, Robert and Helen. He attended public school, had neighborhood friends and didn’t know what a trail-blazer he was. He was also a Deacon at First Christian Church of Chicago Heights. In 2007 Bobby was mentioned in a Chicago Tribune article and I received a call in the NADS office from a guy in Florida – he said he grew up with Bobby on the same block in the fifties. He said Bobby was a Boy Scout, they played baseball, basketball and other games together as kids and he was so happy to have a chance to reconnect with his childhood friend. Bobby had a full life of inclusion before it became popular – but Bobby was always popular!

After his mother died in 1989, Bobby moved to Park Ridge to join the community of Avenues for Independence. Bobby thrived in Park Ridge, where he lived a full-life. He was an active member of the Park Ridge Presbyterian Church and he was also a long-time active member of the Park Ridge Kiwanis Club. Bobby worked for over 20 years at Jewel/Osco Supermarket....I

remember they gave him a Jewel/Osco jacket to mark the occasion and he wore it with great pride.

I first got to know Bobby in 2002 and I was delighted when he joined the NADS board in 2003 and he served from 2003-2010. He was an active board member – taking an interest in many activities. He was always at the Bowl-A-Thon – raising money and generally having a good time. He used to come to the Bowl-A-Thon with his cousins and also with Tim Kelly and Tim’s family – Tim and Bobby were roommates at Avenues and were great friends. During his time on the NADS board, Bobby was a regular visitor and patient at the Adult Down Syndrome Center (ADSC) – we referred to him as the Mayor of the ADSC. He walked there once a week from his home to get weighed and to charm everyone he met.

If a NADS board member was sick, they could count on a card from Bobby – wishing them well and reminding them that he loved them. When I retired in 2009, Bobby came to the celebration and he reminded me of all that I would miss when I retired! I did miss him and I will never forget him.

Bobby was caring, warm and thoughtful and he was a lot of fun. Rest well my friend; you earned your wings here.



Work Incentive Planning and Assistance (WIPA) Presentation

for Families of Transitioning Students with Disabilities

Tricia Luzadder

No Boundaries-Train for Work, Train for Life, proudly presents Britney Qualls, Community Work Incentive Coordinator (CWIC), of the Illinois Assistive Technology Program. On Monday, February 6, 2017 at 6:30 PM, Britney will provide information about the Work Incentive Planning and Assistance (WIPA) program, and information on SSI, SSDI, healthcare options and more. Her presentation will take place at No Boundaries, 824 Dempster Street, Evanston. RSVP to Tricia Luzadder at **847-869-0000** or tluzadder@search-inc.org. For more information, go to www.search-inc.org/no-boundaries.

NEW BOOK

Teaching Math to People with Down Syndrome and Other Hands-On Learners, 2nd Edition

DeAnna Horstmeier

Woodbine House, 2016; \$29.95

This new edition contains a wealth of strategies and activities for teaching math concepts to people with Down syndrome. She focuses on real world instances of math, such as keeping score in a game, counting money, or keeping a schedule. The appendix includes more than 150 activities, games, and worksheets.

Creating Awareness while "Enjoying Downtime"

Marisa Tompkins

On October 12th, 2016, Holly Francis, Leanne Lally and I hosted our first "Enjoying Downtime" fundraising event at Emmett's Ale House in our village of Downers Grove, Illinois. Our goals were simple: as three moms of young children with Down syndrome, we determined that we wanted and needed to create greater awareness within our community for people with Down syndrome. Holly, Leanne and I realized that there is still too much fear and misunderstanding surrounding a Down syndrome diagnosis and perceptions of life with Down syndrome. We felt compelled to do our part by showing our community how beautiful, joyful- and normal- life can be with Down syndrome.

We live in a thriving, close-knit community that feels like a small town where everyone knows one another. One night, over a glass of wine, the three of us decided that we should reach out to the small businesses in our community and pitch our idea for generating greater Down syndrome awareness by doing a fundraising event highlighting small local artists, crafters and professionals. We asked them to partner with us and help us create an experience during Down syndrome awareness month. The response was fantastic! Virtually everyone we asked wanted to participate in some way, whether it was by donating items or a gift

basket for raffle or by being a vendor and donating a portion of proceeds to a Down syndrome non-profit organization like NADS. We all like to relax and have fun so we decided to brand our event "Enjoying Downtime" as a play on words to both represent how we enjoy downtime with each other, but also with our children who have Down syndrome, thus, "Enjoying Downtime" was born!

Holly, Leanne and I then canvassed our downtown, got support from many of our local small businesses, hung up posters advertising our event, posted on social media and sent out an Evite to everyone we knew! The response was amazing and we were awe-inspired by the communities' participation! Although a wet, rainy Wednesday night, we energetically filled the entire restaurant with close to 300 people, had an impressive successful silent auction and raffle, as well as great vendor sales. We were also lucky enough to have the support of several NADS self-advocates who were there to represent NADS as well as to help sell raffle tickets. These ladies did a fantastic job and helped make our raffle a huge success! All of our vendors were able to generously donate to the two non-profits we chose to support: NADS and Lumind Foundation (for cognition research for Down syndrome). In total "Enjoying Downtime" was



enjoyingdowntime
creating awareness by caring and sharing

able to raise over \$8000 (without taking credit cards!) which we divided equally and donated to NADS and Lumind Foundation.

Our first "Enjoying Downtime" event was an incredibly special and humbling event for all of us. Our entire community "showed up" and people really understood what we were trying to do from a Down syndrome awareness and fundraising standpoint. We all felt overwhelming kindness, acceptance, generosity and support from our friends and our community of Downers Grove. We concluded the event feeling a beautiful collective sense of well-being and have built an entirely new network of support within our community. We accomplished our primary goal! We are now starting to think about our next event, a family fun run for World Down syndrome Day in March, as well as other opportunities to partner with businesses to continue "Enjoying Downtime" and raise awareness and support for Down syndrome. Ultimately, we all feel so lucky and blessed to have been brought together

by our young children with Down syndrome, my daughter Emily (almost 3 years old), Holly's son Hank (1 years old) and Leanne's daughter Teaghan (1 ½ years old). Life is interesting and having a child with Down syndrome makes it that much more so, there is nothing "down" about it! We are so excited to watch our children grow and thrive in a community that loves and accepts them. We will continue our commitment to creating Down syndrome awareness and "Enjoying Downtime" in the process! If you're interested in supporting or contributing to "Enjoying Downtime" please contact us at start@enjoyingdowntime.com.

Editor's Note: We are grateful to Marisa, Holly, and Leanne and for organizing "Enjoying Down Time" and for their generous support of NADS. We also appreciate their commitment to raising awareness about Down syndrome. Thank you to all involved with this event!

An Interview with "Enjoying Downtime" Organizers

MARISA TOMPKINS,
HOLLY FRANCIS, AND
LEANNE LALLY

How did the three of you meet?

Marisa: My daughter, Emily, is the oldest of the three children. We all live in Downers Grove, which is a very close-knit community. We all knew of one another through friends and live fairly close to each other. I knew Holly before she had Hank, and Leanne was a friend of a friend. When I learned they had had babies with Down syndrome, I wanted to reach out and let them know life would be okay, and actually, really great!

Can each of you share a little about your family?

Holly: My youngest child of three, Hank, will be 1 in a few weeks. We were surprised with his diagnosis of Down syndrome at birth. Our family was lucky enough to know several families of children that have Down syndrome WAY before Hank was born, including Leanne and Marisa's. Seeing the joy that each of these families has inspired us to be confident knowing that everything was going to be great. We are thankful for those families that have paved the way for us! We also have very supportive, very open-minded, and accepting family and friends.

We are so proud of Hank - he is an absolute joy and we are so lucky that he's ours! It

is really beautiful watching our older children's pride in their little brother and how few differences they see. My oldest son recently stated, "Now I can see how Hank has Down syndrome - he's just like us!" - exactly!

Leanne: Teaghan, is our 4th child, she is 7 years younger than our third child, and 12 years younger than our oldest. We felt pressure from our doctors due to my age to take the MaterniT21 test, and at 12 weeks, it came back positive. My husband and I didn't tell anyone because we didn't want further opinions on options for the pregnancy. We were thrilled to be pregnant! Teaghan was born a week early, and we had such a sense of relief when we saw her perfect face! My older children loved her immediately! My son created a presentation about Down syndrome and shared it with his class, the last line of his presentation was, "... and she's happy every day and she loves us unconditionally." From the beginning it was beautiful!

Marisa: I also had a prenatal diagnosis, with MaterniT21 testing at 12 weeks. I got lots of "I'm sorry's" from people because they didn't know what to say. A nurse at the hospital connected me with another mom in Downers Grove, who told me that this was the beginning of a beautiful journey for our family and how much we would love our baby- she was so right! When Emily was born, she surprised us and came 12 weeks early. She was in the NICU for 2 months before she could come home. Down syndrome became an afterthought —We just wanted her to live.

It has been a beautiful,



Leanne, Marisa and Holly

amazing journey so far. Emily has changed our lives in such a positive way. We are so much stronger as a family, and our two boys are so proud of their little sister!

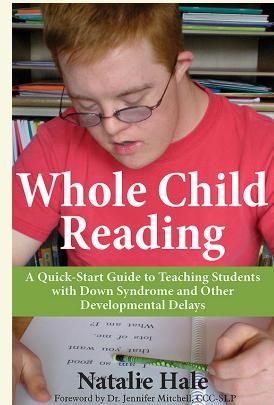
What inspired you to do the fundraiser?

Marisa: We wanted to create a community of acceptance and inclusion, to help everyone see what we see- our beautiful, capable children and the joy that they bring us. Our collective goal is building positive awareness and a strong network in our community.

Leanne: We wanted to engage our local community during Down syndrome month. Sharing "downtime" with family and friends was important to all of us!

Holly: We wanted to host an event that raised awareness in our community, which is SO important... there can never be enough awareness! It is critical that we inspire our community to recognize the joy that comes with having a loved one with Down syndrome. Doing that will adjust the attitudes of those in our communities which will support the todays and futures of those with Down syndrome.

NEW BOOK



Whole Child Reading: A Quick-Start Guide to Teaching Students with Down Syndrome and Other Developmental Delays

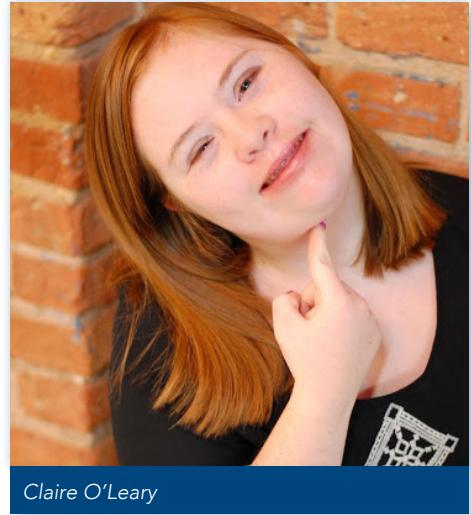
Natalie Hale
Woodbine House, 2016;
\$18.95

National reading expert, Natalie Hale, who also has an adult son with Down syndrome, designed this book for parents and teachers to use with readers of any age. Rather than focusing on phonetics, she emphasizes reading for content and includes suggestions for getting struggling readers excited about books. Her strategies are based on research about how students with Down syndrome learn.

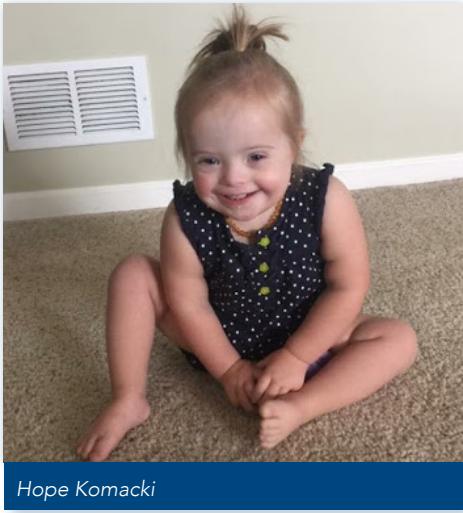
family album



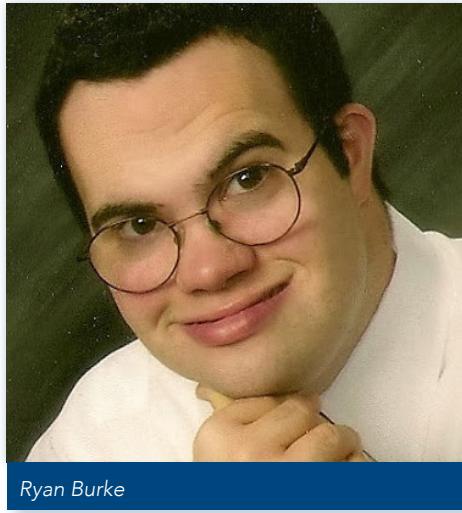
Owen Paris



Claire O'Leary



Hope Komacki



Ryan Burke



Jackie Kearns



Sam Friedland

We Need Photos!

Send your Family Album photos to NADS!

shebein@nads.org

A yellow graphic featuring a camera icon inside a circle. Below the icon, the text "We Need Photos!" is written in white. Underneath that, it says "Send your Family Album photos to NADS!" and provides an email address: "shebein@nads.org".

NADS PROGRAM SPOTLIGHT:

Public Awareness

In addition to our ongoing outreach to first responders, we often go into schools and universities to provide education about Down syndrome. Here are some highlights of recent presentations:



Linda Smarto, Kelly Wesolek, & Director of the Police Department, Michael Witz

Franklin Park Police Department Presentation

Carmella LoCascio recently arranged for her daughter, Kelly, to speak to members of the Franklin Park Police Department along with NADS Program Director, Linda Smarto. The event was covered by the Chicago Tribune. See the article at: <https://goo.gl/YZgxxl>.



Presentation at Disney II Magnet School in Chicago

On October 23, 2016, Linda Smarto gave a presentation to the 2nd grade class at Disney II Magnet School with our youngest Self-Advocate, Adilyn Morales. Adi helped Linda read a book to the class, and then she gave her own Power point presentation. According to the teacher, Mrs. Hunt, her classmates were very receptive: "We loved having you into our classroom! It's always so great to see our kiddos developing a sense of understanding and awareness. They were asking such thoughtful questions which shows me that they understood and were truly interested. Thank you so much!"



"Spreading the Good News" for October Down Syndrome Awareness Month

Erika Kissel

As a member of the NADS Self- Advocates, I have had the chance to present at different locations.

My paid job in the community keeps me very busy every day, which I enjoy very much. But I still make time to also volunteer. One of the locations that I volunteer at is Tate Woods School. I am a volunteer teacher assistant when I have an occasional day off from my regular job.

Since October was "Down Syndrome Awareness" month, I thought this would be a great time to "spread the good news" about Down syndrome to the classes at Tate Woods. So I decided that the first step that I needed to take was to contact the principal of the school, Wesley Gosselink and tell her of my plans and get her approval. She welcomed and approved my coming to the school! Then I decided to contact Linda Smarto, NADS Program Coordinator, and let her in on my plan to present! Once all of this was coordinated, my Mom was notified that I had initiated this presentation all on my own, much to my Mom's surprise, since she was the

last to know.

Finally, I had accomplished my goal.

I presented to 4 different classes. In my presentation, I shared some of my own life story as a person, who happens to have Down syndrome. I also shared part of a DVD, which showed my life from when I was born to now as an adult. When one of the little students from last year, saw me, she called out, "that's my teacher!" I was thrilled that she still remembered me since she had not seen me in a while. The principal told my Mom and Dad that I had made quite an impression (positive) on this little girl.

Since some of the classes had the theme of "Kindness is my Superhero," the message of my talk was also about kindness and respect for all your classmates, regardless of their ability. After I presented, Linda and I still had time to read a book to the class. Teachers came up to my parents after the presentation and told them what an impact I had made on them with sharing some of my personal story.

October is Down Syndrome Awareness month and it is about celebrating our abilities and accomplishments!

The editor of this newsletter reserves the right to make any such corrections as necessary in accordance with established editorial practice in material submitted.

NADS does not promote any therapy, treatment, institution or professional system, etc.

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