

Owen Paris and his dad Mike

# NADS News

Newsletter for the National Association for Down Syndrome

March, 2016

## The PAC Self-Advocacy Workshop *Sarah Weinstein*

Two weeks ago I attended the NADS PAC (Partnership Advocacy Council) Self-Advocacy Workshop at Elmhurst College with 21 other aspiring self-advocates. We practiced skills and techniques to help us be confident in telling other people about our preferences, our skills, interests and our goals and dreams. It was so much fun to get to know other adults with Down syndrome. Everyone was excited to share their proud

accomplishments, our jobs, hobbies and enthusiasm for learning new things. (I think our parents had fun talking with each other too. They were invited either to stay and listen to the workshop or to hang out and network about programs and services around the Chicago suburban area.)

Janice Weinstein, Executive Director of Total Link2 Community, helped us get comfortable with one another using improv and drama games. You could feel the energy level go up when Janice asked us to stand in a circle facing one another. After a few minutes, we were all tuned in and focused as we took turns speaking and trying out new dialogs. Every one participated and felt supported by our group. We practiced asking someone to help us with a goal or a specific request for help. We talked about the important role our families, friends and role models play in helping us to identify and reach our goals. We realize we need help with certain things at different times even though we see ourselves as adults. Some of the common themes that came

up were: opportunities to share our hardships and struggles with healthy choices and peer pressure, telling other people how to help us when our feelings are hurt or we see someone mistreated or bullied and finding ways to let others know we want more opportunities to help out and work by sharing our talents and gifts. There were so many talented people in the room and we took the time to hear each person's voice. We also had a lot to say about what we're good at and how we want other people to view us — as capable and confident adults.

At the end of the workshop, we brainstormed ideas for things we'd like to do together. We put together a "bucket list" of activities we want to accomplish including: having a fun party, helping out by volunteering, going out in the community and working and having social opportunities like Special Olympics, theatre and public speaking, staying connected to close friends both old and new.

*Continued on page 11*



## Contents

- 3**  
Down Syndrome Enters  
A New Era  
Book Review
- 4**  
On the Topic Of: Summer  
Camps
- 5**  
Camp Chi
- 6**  
Upcoming Events  
Summer Camps in the Midwest
- 7**  
Multiplying Your Blessings  
Someone Special Books
- 8**  
NADS Public Speaker Training  
Transition Planning Tips  
Corporate Sponsorships for  
NADS Conference
- 9**  
David Jonaitis
- 10**  
Family Album
- 11**  
Fundraising



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

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](http://www.nads.org)

**Exec. Director** Diane Urhausen  
**President** Steve Connors  
**Editor** Ann Garcia

## World Down Syndrome Day

**M**arch 21 is World Down Syndrome Day. It is also an opportunity to raise awareness about Down syndrome within your community. Perhaps you will choose to bring Down Syndrome International's "Lots of Socks" campaign to your local school or business. Or you could distribute some of NADS' colorful bookmarks, featuring paintings by an artist with Down syndrome. Or you might be inspired to come up with your own campaign. You can find lots of ideas on the World Down Syndrome Day website (<https://worlddownsyndromeday.org/>), as well as information about the WDSO conference, held at the United Nations in New York City. The theme for this year's conference is: "My Friends, My Community"—The benefits of inclusive environments for today's children and tomorrow's adults.



## Illinois Includes Conference

**A**re you a parent who would like to see your child have a more inclusive educational experience? Are you a teacher, administrator, social worker or therapist who would like to learn strategies for successful inclusion? The Illinois Includes conference brings people together to "share ideas for growing inclusive opportunities in Illinois schools and communities." This year's conference will be held May 5-6 in Oakbrook. Topics covered will include the inclusive IEP, early childhood for all, cooperative learning, supporting friendships, and building classroom community. For more information or to register, go to [www.illinoisincludes.org](http://www.illinoisincludes.org).

## New Report Shows Increase in Inclusion

**T**he U.S. Department of Education's 37th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, released late last year, shows that since 2013, more than 60% of school-aged children served under IDEA spent 80% or more of their school day in a regular education classroom. Those figures represent an increase from earlier reports. To see the full report, go to [www2.ed.gov/about/reports/annual/osep/2015/parts-b-c/37th-arc-for-idea.pdf](http://www2.ed.gov/about/reports/annual/osep/2015/parts-b-c/37th-arc-for-idea.pdf).

## Wyatt Deborah Nelson

*"Opportunity is missed by most because it is dressed in overalls and looks like work."*

— Thomas Edison

**M**y son Wyatt's new teacher sent me an email this morning, and this quote is part of his signature line. Stopping to think about why a special education teacher would use a line from a great inventor for his calling card, a light bulb went off over my head. Mr. Cosby gets what we parents of kids with Down syndrome know! While it takes a lot of extra work for our students to learn and it's often more messy than glamorous, the opportunity and the reward are that much greater. So go ahead and wear your overalls with a tiara or top hat -- Wyatt style!



# Down Syndrome Enters A New Era

Dr. Peter Smith, Associate Professor of Pediatrics, University of Chicago

## Current Processes Are Not Working

Individuals with Down syndrome are living longer and healthier lives than ever. There is consensus that complete information needs to be offered to all parents of children with Down syndrome (both pre- and postnatal) regarding the current experiences, health outcomes, lifespans, and quality of life for individuals with Down syndrome. Down syndrome represents a dramatic “success story” and the lives of individuals with Down syndrome are improving in every way measurable. Unfortunately, this good news is too often not being shared with new and expectant families. Doctors are not prepared for this task and parents report frustration with the process.

## On the Cusp of Potentially “Game Changing” Therapies

In addition to the dramatic changes that have already occurred, Down syndrome as a clinical and research arena is on the cusp of developing even newer therapies that have the potential to improve cognitive outcomes. Multiple research teams have protocols already enrolling study subjects. For example, the team at the Jerome Lejeune Institute in Paris has an active study underway (<https://clinicaltrials.gov/ct2/show/NCT01576705>) that employs a combination of folic acid and thyroid

hormone, targeting infants and primarily measuring cognitive performance during and after therapy. Their preliminary work has shown significant promise and preliminary results might be released later this year. Because of their early successes, there are ongoing efforts to mount a similar study here in the United States. The NIH has recognized this new era and has launched an international registry (see <https://dsconnect.nih.gov>). However, this “breaking news” has not been widely disseminated. Many worry that recruitment to these studies could be diminished due to the lack of awareness by primary care providers and the general public, which would slow the progress of the studies.

## A Growing Number of States Have Addressed the Issue: Including Illinois

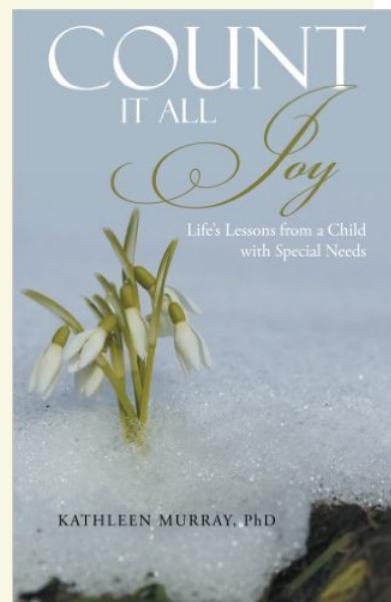
Because of the lack of general knowledge of both the dramatic improvements in the lives of individuals with Down syndrome and the emerging clinical trials in Down syndrome, a coalition led (of course) by family support organizations has emerged. They have initiated a new “information rights” movement that includes clinicians, policymakers, legislators, and researchers that has worked to enact new state laws addressing the problem of misinformation. The first to successfully pass legislation was Massachusetts: in 2012, a

## BOOK REVIEW

### COUNT IT ALL JOY: LIFE'S LESSONS FROM A CHILD WITH SPECIAL NEEDS

Kathleen Murray, PhD.  
Westbow Press, 2015; \$11.95

“Joy” is the operative word in this new memoir from local mom and speech therapist, Kathleen Murray. She had to forge her own path towards joy, starting, as so many new parents do, from a place of grieving and struggle, but she comes to delight in her son, Christian, and his place in their family. She writes candidly about the difficulties they faced together, from her son’s heart surgery in his first year to the Autism diagnosis he received a few years later, but she also realizes the many valuable lessons she learned through raising her son. The book is a summary of those lessons. The chapters, with headings such as “Doors,” “Hugs,” and “Bedtime,” use beautifully rendered vignettes of their life to reveal insights gleaned from caring for her son. Each lesson is also paired with a quote from scripture, and spiritual lessons are part of her journey, but her main motive in writing the book is to show other parents raising a child with special needs how they, too, can find their own joy. For parents who are not yet able to see that possibility, she provides the image of the snowdrop—the cover art she selected for her book. The snowdrop emerging from the frozen ground reminds us: “New growth is possible in every heart.”



Signed, personalized copies are available from Dr. Murray by email ([kathleenmurray1000@gmail.com](mailto:kathleenmurray1000@gmail.com)) or online at WestBow Press, Amazon, or Barnes & Noble

coalition helped to pass a state law, mandating that clinicians provide accurate information and referral to parent support organizations. Most recently, Illinois passed unanimous legislation in 2015 (see <http://www.ilga.gov/legislation/>

[publicacts/fulltext.asp?Name=099-0142](http://publicacts/fulltext.asp?Name=099-0142)), which proves that this is truly a bipartisan issue.

Editor's Note: This article is the first in a series about the new law.

# On the Topic Of: Summer Camps Nancy Goodfellow

I don't remember what age Lily was the first time I signed her up for VBS. Prior to having children, I had no idea what VBS even stood for... But once Lily and Luke were old enough, probably 5 and 4, I decided to give a local Vacation Bible School program a try. It had come highly recommended by parents of older children, and many thought that Lily would love it. I remember standing in a long line with other mothers in a back hallway of the local Lutheran church, wondering if I shouldn't be there because we weren't actually Lutheran. And, wondering if I was going to finally get to the front of the line just so they could tell me, "I'm sorry, we can't accommodate children with special needs." I'd arrived early to ensure spots for my kids in the camp, and even though I'd emailed the program director to find out if it was appropriate to register Lily, I still worried that she would somehow end up being excluded. I don't think that worry ever really goes away.

I finally reached the front of the line and handed in my forms. The woman looked over the part where it asked if your child had any special needs or requirements for camp. She looked up and smiled. "I think we emailed this week. I'm glad you decided to sign your kids up. We're looking forward to meeting Lily. I think I have a camp counselor who will love hanging out with her." Phew. Not only was she okay about Lily being at camp, but she had already thought about who would be best to spend time with my daughter.

That was the first of many years that Lily attended that VBS. She loved each year even more than the one before. They filled the three hours each day with songs, games, crafts, snacks, stories, and more songs. Lily always had friends that attended with her, and by the second year, the director and staff knew her well enough that she didn't need one-on-one assistance.

She attended and enjoyed the camp alongside her friends and siblings. I volunteered to work registration each year. It allowed me to be there the first day to make sure she got settled, ended up in a group with her friends, and just spy on her a little. I would have volunteered to help out each day at the camp, but Lily does better when I'm not around. She associates me with home, so even if she's having a great time, she asks to go home as soon as she sees me. It has meant

*Lily's counselor cried as she gave Lily the 'Joyfulness Award,' saying how Lily had brought incomparable joy to her and all of the other campers each day with her contagious smile and excitement.*

that I didn't get to volunteer at the class parties in school and chaperone field trips over the years, but I'd rather she stay and enjoy those times. And I usually had a friend who worked the party or went on the field trip and could act as my spy and report back to me.

Once Lily was a little older, I tried some other summer camp programs. She participated in Spotlight Theater Camp one week of each summer for at least five years. This presented a new challenge, because it was all day and involved staying for lunch and changing for daily water activities. Again, I emailed with the director ahead of time to go over what difficulties Lily might have, what assistance she would need, and what I could do to help. The program director was more than happy to make sure Lily had whatever help she needed to make her camp experience successful. Of course, I still volunteered the first morning of

camp, and even signed up to deliver the pizzas for lunch the final day. Any opportunity to spy on her is always worth it! Lily loved being on stage the last day in front of her family and friends. And that love of performing has led to her current involvement in a local theater group.

After succeeding in the full day program at Spotlight, I decided to try an all-day VBS that our own church was hosting one year called SpringHill. It advertised all kinds of activities you would do at sleep-away camp, but brought to a local location. There was a bungee trampoline and huge inflatable waterslide in the church parking lot, a climbing wall in the hallway, and

even a flying squirrel trapeze-type apparatus and a giant swing set up in the church auditorium. When I looked at the registration materials, it was clear that the camp was for anyone and that all individuals with special needs were welcome. I could select on the form if I wanted a 1-1 aide, and all activities could be modified to fit Lily's needs. By the first day of camp, I'd already received a phone call from the camp counselor who would be her assistant. We discussed Lily at length and the young woman gave me her cell phone number so that I could contact her directly any time during the week. I never did feel the need to check in with her. She was always keeping me well informed through texts and photos of all the wonderful things Lily was doing each day. At the end of the week, the counselors all handed out awards to each of the kids. It was amazing to see how well they knew each child after only five days. Lily's counselor cried as she gave Lily the "Joyfulness Award," saying how Lily had brought incomparable joy to her and all of the other campers each day with her contagious smile and excitement. Unfortunately, Lily was too old to participate in the day camp version of SpringHill the next

## TO FIND OUT MORE ABOUT THE CAMPS MENTIONED:

Spotlight Theater Camp: [www.spotlight.org](http://www.spotlight.org)

SpringHill Camps: [www.springhillcamps.com](http://www.springhillcamps.com).

year, but they offer week-long camps in Michigan and Indiana that we may consider in the future.

As Lily gets older, it becomes more difficult to find camping options that don't involve her going away overnight. I'm sure she is probably more ready for that than I am, but the right opportunity hasn't presented itself yet. I wouldn't want to send her to camp without a friend, and the camps that her friends go to right now don't seem appropriate for her. She has gone back to the local VBS camp to work as a volunteer, and we stayed very busy last summer with swim team and summer school. I take advantage of the time when my other two children are at camp to focus solely on Lily. While her siblings spent their days at SpringHill last summer, Lily learned how to do laundry, cook chicken nuggets for herself, prepare a grocery list, and navigate the grocery store. It may not have been as much fun as a trampoline or climbing wall, but she seemed to appreciate the one-on-one time with her mom. Even without the water slide, songs, games, etc., she still deserved a "Joyfulness Award" at the end of the week. And I did make sure to provide some pretty great snacks!

*\*Please note that all of the camps listed here are Christian programs. They just happen to be the programs that were the best fit for our family. There are other great programs available that do not involve religious denominations. Many are provided by local special recreation associations (SRAs), which not only host camps for individuals with special needs, but also provide 1-1 assistants for children attending camps through their local park districts.*

*Editor's Note: Our "On the Topic Of" series features topics of interest to families with school-aged children. Past columns by Nancy have covered friends, presentations, and siblings. The newsletters in which they appear are available on our website ([www.nads.org](http://www.nads.org)) under Resources/NADS Publications.*

## Camp Chi

Jennifer Phillips

When I was growing up, Camp Chi was not just a place I went for the summer; it was the place I called home. While at camp, I learned the meaning of friendship, gained self-confidence, grew more independent and explored new activities, all things that prepared me for who I am today.

After nine months on the Chi year-round staff, I see even more clearly how my camper experience is so similar to the experiences of campers today. I recognize their pride of being at a place they love and call home. All campers, with special needs or without, have the opportunity to have a camp experience to teach them acceptance, happiness and the meaning of true friendship.

Camp friends are camp friends. Our approach to inclusion encourages campers to help their peers no matter what challenges they have. This could just as easily be a situation where a camper needs assistance walking or a camper is struggling with feeling homesick. Every camper has his or her own story and experience that would not be the same if it weren't for the support of friends.

In the past few months, I've been part of one event that truly shows how we include campers of all abilities at Camp Chi. A longtime camper, Miles, had completed his camper years, and was looking forward to being an SIT. Miles is like many other campers at Chi; he enjoys hanging out with friends and being an amateur photographer. Miles, though, has Down Syndrome. I had worked with Miles' parents to explore options for next summer, including having Miles spend an additional summer in Noar. Everything was going according to plan until Miles' camp friends heard that he was not joining their SIT class.

They could not imagine having someone who was such a big part of their cabin group since they were ten years-old miss the milestone of being an SIT. These friends decided they needed to advocate for their friend and reached out to us. They questioned why Miles would be treated any different than them. Miles was a Camp Chi camper and deserved his time to become a SIT. These boys were right – if we are an inclusive camp, then our leadership program needs to be inclusive too.

Thanks to the support of his friends, Miles is joining the SITs of 2016. Camp taught Miles independence, self-confidence, respect and the meaning of friendship, but it also taught his camp friends the exact same thing.

*Jennifer Phillips is Camp Chi's first year-round Inclusion Coordinator and also works for our partner in inclusion, Keshet.*

*Editor's Note: Reprinted with permission from the Camp Chi blog ([www.campchi.com](http://www.campchi.com)).*



## UPCOMING EVENTS

### Special Needs

#### Planning Presentation

Oak Wealth Advisors  
April 4, 2016  
6-7:30  
Adult Down Syndrome  
Center  
1610 Luther Lane  
Park Ridge, IL  
RSVP to Grace  
O'Connor or  
Merrily Smith  
847-318-2303

#### More Than Down Syndrome Spring Retreat

April 9  
8-4  
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

#### Down Syndrome Research Conference

April 23  
9 - 1  
Indiana Wesleyan  
University  
West Chester, OH  
www.dsagc.com/events/  
researchconference

#### Illinois Includes Conference

May 5-6  
DoubleTree by Hilton  
Chicago-Oak Brook  
1909 Spring Road  
Oak Brook, IL  
www.illinoisincludes.org

#### SAVE THE DATES

NADS Conference  
October 1, 2016

NADS Fashion Show  
October 30, 2016

## Summer Camps in the Midwest:

### Illinois

Camp Callahan; [www.campcallahan.com](http://www.campcallahan.com); 217-228-2707  
Camp Hope; [www.camphopeillinois.org](http://www.camphopeillinois.org); 312-401-HOPE  
Camp Little Giant; [www.ton.siu.edu](http://www.ton.siu.edu); 618-453-1121  
Camp New Hope; [www.cnhinc.org](http://www.cnhinc.org); 217-895-2341  
Camp Red Leaf; [www.jcys.org](http://www.jcys.org); 312-726-8891  
Easter Seals Camps at Timber Pointe; [www.easterseals.com/ci/](http://www.easterseals.com/ci/); 309-365-8021  
Keshet Special Needs Camps; [www.keshet.org](http://www.keshet.org); 847-205-0274  
Penguin Project Arts Camp at Timber Pointe; [www.penguinproject.org](http://www.penguinproject.org) or [www.easterseals.com/ci/](http://www.easterseals.com/ci/); 309-365-8021  
Shady Oaks Camp; [www.shadyoakscamp.org](http://www.shadyoakscamp.org); 708-301-0816  
Special Camps; [www.specialcamps.org](http://www.specialcamps.org); 630-690-0944  
Walcamp Outdoor Ministries Summer Camps; [www.walcamp.org](http://www.walcamp.org); 815-784-5141

### Indiana

Camp Anderson Woods; [www.andersonwoods.org](http://www.andersonwoods.org); 812-639-1079  
Camp Millhouse; [www.campmillhouse.org](http://www.campmillhouse.org); 574-233-2202  
Camp Riley; [www.bradwoods.org](http://www.bradwoods.org); 765-342-2915  
Camp Red Cedar; [www.campredcedar.com](http://www.campredcedar.com); 260-637-3608  
SonRise Camps; [www.bethesdalutherancommunities.org](http://www.bethesdalutherancommunities.org); 920-206-4495  
Springhill Camps; [www.springhillcamps.com](http://www.springhillcamps.com); 812-497-0008

### Iowa

Camp Courageous; [www.campcourageous.org](http://www.campcourageous.org); 319-465-5916  
Easter Seals Camp Sunnyside; [www.easterseals.com/ia/](http://www.easterseals.com/ia/); 515-289-1933

### Michigan

Camp Fish Tales; [www.campfishtales.org](http://www.campfishtales.org); 989-879-5199  
Camp Grace Bentley; [www.campgracebentley.org](http://www.campgracebentley.org); 313-962-8242  
Fowler Center for Outdoor Learning; [www.thefowlercenter.org](http://www.thefowlercenter.org); 989-673-2050  
Freddy's Friends Camp; [www.pineridgecamp.com](http://www.pineridgecamp.com); 616-696-8675  
Friendship Camp; [www.cranhillranch.com](http://www.cranhillranch.com); 231-796-7669  
Indian Trails Camp; [www.indiantrailscamp.org](http://www.indiantrailscamp.org); 616-677-5251  
Joni and Friends Family Retreats; [www.joniandfriends.org](http://www.joniandfriends.org); 818-707-5664  
Springhill Camps; [www.springhillcamps.com](http://www.springhillcamps.com); 231-734-2616  
Skyline Camp; [www.campskyline.org](http://www.campskyline.org); 810-798-8240  
St. Francis Camp on the Lake; [www.saintfranciscamp.org](http://www.saintfranciscamp.org); 517-688-9212  
Summer Serve Camp; [www.compheart.org](http://www.compheart.org); 616-748-6011

### Wisconsin

Badger Camp; [www.badgercamp.org](http://www.badgercamp.org); 608-348-9689  
Camp Daniel; [www.campdaniel.org](http://www.campdaniel.org); 715-757-3880  
Camp Matz; [www.bethesdalutherancommunities.org](http://www.bethesdalutherancommunities.org); 920-206-4495  
Camp SOAR; [www.childrensresearchtriangle.org](http://www.childrensresearchtriangle.org); 312-726-4011  
Easter Seals Camps; [www.eastersealswisconsin.com](http://www.eastersealswisconsin.com); 800-422-2324  
Easter Seals Respite Camps; [www.easterseals.com/wi-se/](http://www.easterseals.com/wi-se/); 414-449-4444  
Special Touch Getaway Retreats; [www.specialtouch.org](http://www.specialtouch.org); 715-258-2713

### Chicago Area Camps

Brookfield Zoo Camp (in partnership with the National Inclusion Project); [www.czs.org](http://www.czs.org)  
Camp-N-Play Lekotek, Chicago Botanic Gardens; [www.chicagobotanic.org](http://www.chicagobotanic.org)  
Camp PALS Chicago, Elmhurst College, Elmhurst, IL; [www.palsprograms.org](http://www.palsprograms.org)  
Peggy Notebaert Nature Museum Summer Camps; [www.naturemuseum.org](http://www.naturemuseum.org)

Check with your local special recreation association (SRA) for day camp programs in your area. To find your SRA, go to [www.specialrecreation.org](http://www.specialrecreation.org).

# Have You Thought of Multiplying Your Blessings?

Stephanie Thompson, NDSAN Director

The National Down Syndrome Adoption Network had a banner year in 2014. We helped with the adoption of 44 children with Down syndrome into adoptive families. What that means logistically is that approximately the same number of families were removed from our registry. At present, we have 75 families on our registry -75

they will tell us in very specific detail what they are looking for in a family. In the registry, our adoptive families have given us great detail about them, and have told us in very specific detail what they are looking for in a child.

So after I put all the parameters into a query, a report is generated of families who would be

child with Down syndrome. It probably never occurred to you that it may even be needed. So I am here to plant that seed with you.

First, take a look at our website, [ndsan.org](http://ndsan.org). You'll find it's a great introduction to what the National Down Syndrome Adoption Network does for both birth and adoptive families. Take a look at the Adoptive Families page for a little more information on the process.

Second, head over to our Facebook page, [facebook.com/dsadoption](https://www.facebook.com/dsadoption), and please make sure to "Like" the page. You will see posts about adoption resources, stories from families who have adopted, and children who are in public custody who need families (we do not share our private situations online, those are kept confidential).

Third, contact me. You may have questions about the adoption process, or you may just need to talk about the "feeling" you have after reading this article. I would be happy to talk with you and answer any questions and, if you decide to take the journey of adoption, I will walk you through the process. Feel free to email me at [stephanie@ndsan.org](mailto:stephanie@ndsan.org) or call me at 513-709-1751.

I look forward to hearing from you!

.....  
*Reprinted with permission from Stephanie Thompson, [stephanie@ndsan.org](mailto:stephanie@ndsan.org).*

*My dream would be to have an average of four very different, but just as wonderful adoptive families in every state across the US.*

families who are home-study ready, and want to adopt a child with Down syndrome. In order to be included on our registry, you must have a home study, which is a legal document that approves you to adopt.

75 families may sound like a good amount of families for a birth family to choose from, but let me explain further how our process works. When we get a call from the birth family, the first thing we do is educate them on Down syndrome. They are provided with up-to-date information and resources. We answer any and all of their questions about parenting. We want every birth parent to be able to make a fully informed decision, whether it be parenting or making an adoption plan.

If a birth parent decides to make an adoption plan,

the best possible fit in all areas. So that list of 75 is easily filtered down to approximately 5 (or fewer) possible families.

Which brings me to what our goal is for the NDSAN: Our goal is to increase the number of adoptive families on our registry. My dream would be to have an average of four very different, but just as wonderful adoptive families in every state across the US.

Here is where you come in. We are seeing an increase of birth families asking that the adoptive family have experience with Down syndrome by either having a child with Down syndrome already, or having a relative with Down syndrome, or having experience through their job or some other affiliation.

You've probably never thought about adopting a

## Someone Special Books

Two Chicago-area teachers, Kate Ryan and Heather McCarthy, have launched a new business to personalize picture books for children with special needs. The inspiration for their business came when McCarthy designed a book to explain her daughter's rare medical condition to her daughter's preschool class. Her fellow teacher, Kate Ryan, saw Heather's book and realized other families might also benefit from being able to tell their child's unique story. Their website contains options for creating a personalized storybook, with space for parents to share their own message about their child's condition. Special needs categories include Down syndrome, Autism, ADHD, food allergies, and other conditions, such as diabetes. The books, which are designed for young readers, can be used to share information about the child's disability with siblings, classmates, teachers, or friends. Ryan and McCarthy hope the books will help "teach acceptance, confidence, and respect." For more information, go to [www.someonespecialbooks.com](http://www.someonespecialbooks.com).

## NADS Public Speaker Training

NADS will be training new public speakers this spring. Our public speakers go into hospitals, schools, churches, fire departments, and many other organizations. The training is open to parents or others who have an interest in educating the public about Down syndrome. We will also be offering speaker training for self-advocates, who are an integral part of our presentations in the community.

### Speaker Training for Parents/Public Speakers

**Saturday, April 16th**  
10 am – 2 pm  
NADS Office,  
1460 Renaissance Dr.,  
Suite 405, Park Ridge

**Monday, April 25th**  
6 pm – 9 pm  
Conference Room, 1550  
Northwest Highway,  
Park Ridge

### Speaker Training for Self-Advocates

**Sunday, April 10th**  
12 pm – 4 pm  
NADS Office, 1460  
Renaissance Dr., Suite  
405, Park Ridge

**Monday, April 25th**  
6 pm – 9 pm  
Conference Room, 1550  
Northwest Highway,  
Park Ridge

For more information or to register, please contact Linda Smarto at [lsmarto@nads.org](mailto:lsmarto@nads.org) or 630-779-4245.

## Transition Planning Tips

*Kim Patton, M.Ed., Doctoral Student in Special Education at University of Illinois*

Transition planning can be difficult. As a middle school, special education teacher for 10 years, I was often helping parents and students start to navigate this process. In Illinois, the transition process should begin when a child is 14.5 years of age. As a special education teacher, I had many transition planning responsibilities, including:

- Interviewing students and their families about their future goals to develop transition goals
- Writing transition goals (with input from the student, parents, and other team members)
- Providing parents with information about the adult service delivery system.

I received some instruction on transition in my college courses and had occasional professional development meetings to learn how to complete transition paperwork. However, I felt I had limited knowledge about the adult service delivery system. While I recognized the importance of having a quality

transition plan, I often felt that I did not know all of the information that was required of me. I went back to school for my doctoral degree so that I could better understand the transition process and share information with others.

Through my research focused on how parents and teachers work together during the transition process, I've learned some tips that I think can assist parents as their children transition. Tips include:

- Students and their families need to have active roles in transition planning.
  - Speak up in your child's meeting!
- Transition plans should be individual and unique for each child based on each child's desires, strengths, and needs.
  - Make sure the transition plan meets YOUR child's needs.
- Teachers should conduct student and parent interviews when writing transition plans.
- Parents should talk with their children about their goals for the future--make sure the teacher knows what your child wants to do in the future.
  - Ask your child about future goals with respect to employment, independent living, education/training, and recreation.
- Parents should talk to other parents and families who have been through the transition process; what worked well? What did not work?
  - Ask your special education teacher to put you in touch with families who have been through the transition process.
- Parents need to learn about the adult service delivery options.
  - Join the IPADD listserv which provides information about adult services (<https://groups.yahoo.com/neo/groups/IPADDUnite/info>)
- Parents and teachers need to work with adult service agencies; such agencies should be invited to be a part of the transition IEP team.
  - Invite representatives from the Division of Rehabilitative Services and the Pre-Admission Screening Agency (go to <http://www.dhs.state.il.us/> to find the correct agencies).
- Parents need to have high expectations for their children.
  - Let your expectations drive the transition process—not what services are available.

Transition planning is an important process. By being actively involved in the process, you can ensure it is a positive experience for your child.

## Corporate Sponsorships for NADS Conference

We are looking for corporate sponsors for our fall conference on October 1, 2016. If you are aware of any businesses which might be interested, please let us know and someone from our sponsorship committee will reach out to them. Please contact Diane Urhausen at [durhausen@nads.org](mailto:durhausen@nads.org) or call our office at 630-325-9112.

# David Jonaitis

## Eagle Scout, Literary Model and Consultant on Down Syndrome

Peter Ferry

Someone asked me recently how I got the idea of creating a character with Down syndrome in my new novel *Old Heart*.

Well, David Jonaitis gave it to me. David, who has Down syndrome, works collecting shopping carts in the parking lot of a grocery store in which I frequently shop, and he often sings Beatles songs as he does his job. His favorites include *Here Comes the Sun* and *In My Life*. David has the ability to make you smile, to make you stop and think on a gray or busy day when you are hurrying into the store for a gallon of milk. Some people ignore him, but more say hello to him.

"Afternoon David."

"Hi Sir."

"You're in fine voice today."

"Thank you Sir."

David is a thirty-three years old graduate of New Trier High School in Winnetka, Illinois just north of Chicago, where he was the manager of the Varsity Basketball team for three years. He is an Eagle Scout and for many years has participated in Special Olympics, in which his favorite events include bowling, basketball and track and field.

I know these things because David and his mother told them to me. When I decided to include a character with Down syndrome in *Old Heart*, I wrote a letter to David's parents, gave it to the

store manager and asked her to give it to them if she felt comfortable doing so. The letter explained my purpose, said that I was a writer and gave my credentials and references. It asked if I could get to know David better and spend some time with him. David's mother, Ann, invited me to their home in nearby Wilmette, where David lives with her and his dad, Charlie. There I also met his sister Katie, his brother-in-law Brian and their baby Audrey, who were visiting.

That first day David and I went out to lunch at a little diner a couple blocks from his home. It took us a while to get there. David walks slowly and is in no hurry. Waiting for the light to change on busy Greenbay Road, David said 'now' one second before the light turned yellow. "How'd you do that?" I asked.

"I don't know," he said.

Conversation with David lacks pretense and subterfuge. It is easy and full of unpregnant pauses. David feels no need to fill the air with talk. He speaks when there is something to say. He is comfortable in his skin and seems to me to lack social self-consciousness.

My purpose that day was to watch David, to study his appearance, his mannerisms, his speech patterns, how he ate his sandwich, drank through a straw, ordered off the menu, spoke to the waitress, related to me. Before lunch was half over, I felt guilty. I was being clinical. I realized that I would never be so ruthlessly analytical and intrusively observant with any other person. I was treating David like a lab rat.

I was also treating him like a child. I was being



patronizing and artificially patient, and David is not a child. He is a man with Down syndrome with equal emphasis on both of those things.

He is also well known in his small town, and as we sat there at our sidewalk table, two people stopped to say hello to him: a family friend and one of his Special Olympics coaches. Neither spoke to him as a child, and with both of them David had adult exchanges.

"Oh," I thought to myself.

When I sold my novel *Old Heart*, two of the first people I told were David and Ann Jonaitis. We went out to breakfast and toasted each other. I explained to David that when a book comes out, there is a party to launch it, I was going to have one at a bookstore in Evanston, and I would like his mom and him to be there. I asked if it would be alright to introduce them as my consultants on Down syndrome and to say that they had taught me all I know about it. They liked that idea. David is proud to be a person with Down syndrome and happy to talk about it.

So when the novel was published, I took David a copy and signed it for him.

I explained that that's what authors do, and I asked if at the book launch, he would like to sign books, too. He asked if he should sign as David or as Tony, the character in *Old Heart* who has Down syndrome. "No, no," I said. "As David."

So on that June evening David and I stood side by side signing books: "P Ferry" and "David."

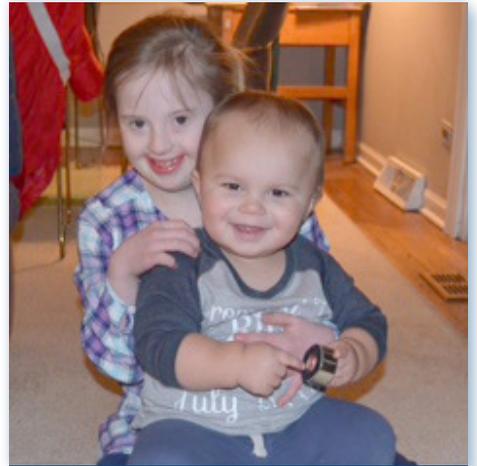
But what have I really told you about David Jonaitis? Not much in human terms. Let me borrow some words from *Old Heart* I used to describe my character Tony but also my friend David: "He was a rule follower who never cursed or swore, a hard worker who was never happier than when he had a job, a tender, sensitive boy who [loved] dog[s]... sentimental songs and silly puns, appreciated pretty girls, and was as loyal as the day was long; he became a [lifelong] Pirates fan when his [sister] moved to Pittsburgh."

I think that more than anyone I know, David lives his life without guile, but I do not mean for a moment to suggest that he is perfect. He's not. He's a human being, and that after all is exactly the point.

# family album



Blake Weber



Jane Kracik and her cousin Clark



Eleanor Olsen



Cameron Tucker



Joshua Martin



Sarah Bak



We Need Photos!

Send your  
Family Album  
photos  
to NADS!  
[shebein@nads.org](mailto:shebein@nads.org)



Angie Picchi



## NHS Students at the Chicagoland Buddy Walk

*Krista Smarto, NHS President*

**O**n behalf of Bartlett High School's National Honor Society, we all agreed that volunteering for the Buddy Walk was a lot of fun and most rewarding. We had the opportunity to pair up with some of the NADS Self-Advocates and spent the day running the game booths, making popcorn and selling raffles. It was a day to remember!



## Center Stage Dance Donation

**O**n Sunday, January 31st, the Center Stage Performing troupe danced at Addison Trail High School. Donations were collected with most of the proceeds going to NADS. We are grateful for their generous gift.

## Chicagoland Buddy Walk Donation

**W**e are grateful to Down Syndrome Support for their generous donation of \$21,000 to NADS from the 2015 Chicagoland Buddy Walk and for their ongoing support of the Down syndrome community. Thank you to the many volunteers and participants who made the event a success.



## PAC Workshop

*Continued from page 1*

I'm so excited about all our upcoming PAC events. Thank you NADS and Total Link2 Community for believing in us and helping us to voice our opinions and dreams. A big thank you, too, to Caren Miller, art teacher and consultant who helped us all out with her guidance and support.

*By: Sarah Weinstein (yes – my mom is Janice Weinstein and I love her the best. Another common theme in our workshop was our deep love and appreciation for our biggest fans – our parents and families.)*

*Editor's Note: For more information about the PAC program, please contact Diane Urhausen at [durhausen@nads.org](mailto:durhausen@nads.org).*



1460 Renaissance Drive, Suite 405  
Park Ridge, IL 60068

Change Service Requested

[www.nads.org](http://www.nads.org)

## Membership Application

Membership dues can be paid online at [www.nads.org](http://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:  
**1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068**

**Special Gift!**  
 A NADS Membership is the perfect gift for grandparents, aunts and uncles and even your child's favorite teacher!

**NADS GIFT MEMBERSHIP**  
 Please send a NADS gift membership to:

Name: .....

Address: .....

From: .....

Phone: .....

Relationship: .....

\$20 per recipient should be enclosed and sent to:  
**National Association for Down Syndrome (NADS), 1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068**

Disclaimer Policy Statement  
The editor of this newsletter writes as a non-professional. NADS does not promote any therapy, treatment, institution or professional system, etc. The editor reserves the right to make any such corrections as necessary in accordance with established editorial practice in material submitted.