



*Sarah, Hope, and Erin Komacki  
at the 2016 Fashion Show*

# NADS News

Newsletter for the National Association for Down Syndrome

September, 2017

## 12TH ANNUAL NADS LUNCHEON & FASHION SHOW:

### “Rockin’ the Runway with the Stars”

**Sunday, October 15th, 2017**

Donald E. Stephens Convention Center  
Rosemont, IL

Our next Fashion Show is coming up! This year’s event will feature a live painting by self-advocate Kelly Wesolek, who will be creating a brand new work of art, which will then be auctioned off. We will also be offering mobile bidding for our silent auction for the first time using a new system, “Ready, Set, Auction.” The highlight of the afternoon is always our fashion show, featuring models with Down syndrome of all ages. This year, Stacey Baca of ABC7 News will be returning as Emcee. The program will also include a special performance by Josh Sylvie and his father’s band. If you are interested in helping with the event, please email [fashionshow@nads.org](mailto:fashionshow@nads.org). For more information, check out our new Fashion Show page on Facebook by searching for [nadsfashionshow](https://www.facebook.com/nadsfashionshow). To purchase tickets, go to [www.nads.org](http://www.nads.org) or mail in the order form on page 11. If you need assistance, please call the NADS office at 630-325-9112. We hope you will be able to join us at the Fashion Show on October 15th!

## October is Down Syndrome Awareness Month

Join us in celebrating Down syndrome awareness month! If you would like one of our speakers to speak to your child’s school or to an organization in your community, October can be a great time to schedule a presentation. If you are interested, contact Linda Smarto at [lsmarto@nads.org](mailto:lsmarto@nads.org).

Here are some ideas from Chicago area families:

- Post something about Down syndrome on social media (some people like to post every day during October).
- Write a letter and share it with your child’s class, daycare, or school.

- Read a children’s book about Down syndrome to your child’s class.
- Donate books or bookmarks to your local library.
- Send in photos and updates about your family to your child’s doctors.
- Display one of our Down syndrome awareness yard signs.
- Work with your local government to proclaim October as Down syndrome awareness month in your community.

If you have other ideas to share, we welcome them! You can post comments on our Facebook page or email suggestions to [info@nads.org](mailto:info@nads.org).

# Contents

2

Welcome Basket Fundraiser  
New Speech Tablet

3

An Interview with Don Hubert  
ADSC Receives Honor

4

Special Recreation

5

Phil's Friends  
Upcoming PAC Events

6

Sam Raymond  
Disability & the Justice System  
Upcoming Events

7

The Joshua Tree Community  
School Resources  
Special Gifts Theatre

8

Research & Medical Care  
Conference  
Parents & Sex Education

9

Participation

10

Family Album

11

Fashion Show Form



Lillian, Samantha, and Natalie Hubert

## Welcome Basket Fundraiser

**M**any thanks to Don and Jessica Hubert, who recently raised more than \$6,000 for our new Welcome Basket program. Their fundraiser was a big success, and we are grateful for their commitment to the program and to their many friends and family members who generously supported it so that we can continue to provide baskets—and hope!—to parents who have a new baby with Down syndrome. With their help as well as the generous giving from others who have donated to the Welcome Basket program, we are getting closer to our goal of making the program available in all communities in the Chicago area.



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** Katie Wood  
**Editor** Ann Garcia

## New Speech Tablet

**T**obii Dynavox, a leading manufacturer of communication devices, recently introduced Indi™, a speech tablet for non-verbal communicators. Unlike other assistive technology products for communication, this new tablet can be purchased without a prescription and is priced to be more affordable for families (under \$1,000, in contrast to the \$5,000-\$10,000 price range of other devices). The software uses a speech program, Core First®, which is based on research by the University of North Carolina at Chapel Hill. To learn more, go to [www.tobiidynavox.com/indi](http://www.tobiidynavox.com/indi).



# An Interview with Don Hubert

## Can you tell us a little about your family?

My wife Jessica and I have been married for 5 years and we have 3 daughters, Natalie (4), Samantha (3) and Lillian (2). As with anyone who has kids, our lives are pretty hectic right now and we are happy to make it through the day in one piece.

## Can you tell us a little about Natalie? What does she like to do? What do you enjoy most about her?

Natalie is an active, smart, caring little girl. She keeps busy with her therapies and loves to talk about puppies and Paw Patrol. It's hard to pick one specific attribute that I enjoy about Natalie. I enjoy when I walk in the door after a long day of work and she sees me and screams "Daddy's here" and comes running over to give me a hug. I love the way she'll walk into the same room I'm in and ask, "What are you doing?" I'll answer and she'll respond "okay" and turn around and walk away. I secretly love the fact that when I ask her to do something she responds with an emphatic "No." I really just enjoy being around her, my wife and my other two daughters.

## What inspired you to organize a fundraiser for NADS' Welcome Basket Program?

My wife Jessica heard about the Welcome Basket Program through a Facebook group and told me about it. We both knew this was a great idea. We thought back to when Natalie was born and the lack of information we

received from the hospital staff. Jessica and I then went to a Welcome Basket training session and listened to Jenny Di Benedetto talk about the program. This was such a promising idea that could really benefit so many parents and we knew we wanted to try and help the program anyway we could. We thought that if we could raise a little money to help with funding the baskets it would ease the burden from NADS and they could concentrate on getting the baskets into as many hospitals as possible. Jessica and I wanted to play a little part in helping families feel a little less lost, confused and alone during the first critical couple of days after their child is born.

## How do you think the program would have made a difference to your family if it had been available when your daughter was born?

I think back to our first weekend with Natalie and having something like this would have helped greatly on so many levels. First, knowing we are not alone. It was such an emotional time to begin with, and at that moment you think you are the only three people in the world who have gone through this. Hearing from an organization that has experience in this diagnosis would have made it a little more comfortable. Another way this would have helped is taking the stress out of the "What do we do next?" question. Having a basket with organized information dropped off to us would have made it easier to figure out our first couple of

steps. But most important, all we wanted to hear was Congratulations. This was so overshadowed the first weekend because we were scared, scared because this was our first child, scared because she has Down syndrome and scared because we didn't know what to do next.

## What would you most like to share with other parents who have a newborn with Down syndrome?

You're going to have challenging days just as you would with any child. Through the stress of the daily grind you're going to have so many bright spots with your child. You'll see the hard work and therapies pay off when your child does something unprovoked that they have been working on. You'll have a first-row seat and get to see all the accomplishments that seem so minute but are so great on a different level. If you join social media groups, you're also going to come across families who are heavily involved in

different Down syndrome organizations and people who aren't, and that's okay. Take time to figure out what works for you and your family. You don't have to change the Down syndrome community in your child's first year of life. Oh, and don't be surprised at the amount of people you will meet. It seems like everywhere we go, someone is coming up and introducing themselves and sharing their Down syndrome story.

## What would you most like to share with other fathers?

This is a hard question to answer because I'm relatively new to being a father. If anything, try to keep everything in perspective and don't get ahead of yourself. When the time is right, reach out to other fathers who have a child with Down syndrome. I've met a lot of great people in the last 4 years that I would have never met if it wasn't for Natalie. What you can learn from their experience is invaluable.

## ADSC RECEIVES HONOR FROM NDSC

The Adult Down Syndrome Center at Advocate Lutheran General Hospital was selected by the National Down Syndrome Congress to receive their 2017 Exceptional Meritorious Service Award. The award was presented during the NDSC's annual summer convention, which was held this year in Sacramento. In selecting the Adult Down Syndrome Center, the NDSC highlighted the ADSC's 25 years of service helping people with Down syndrome lead happier and healthier lives, the new programs it has introduced, its evolution into the nation's leading clinic for teens and adults with Down syndrome, and its commitment to sharing research with the Down syndrome community.

# Realizing Hopes & Dreams Through Special Recreation

Sherry Manschot,  
Western DuPage Special  
Recreation Association

**C**an joining a soccer team or a dance class dramatically impact your child's life? Will exploring the latest and greatest things to do around town with friends give your child a sense of community? Does a weekend getaway—without you—help develop independence?

**It can! It will! It does! It's all possible through Special Recreation Associations (SRAs)!**

Most of all, SRAs can help realize many of the hopes and dreams you and your child both may have. Your child can grow as an individual while connecting with the community around them and even have the chance to discover their full potential.

Unique to Illinois, SRAs were created as cooperative extensions of Park Districts throughout the state to provide programs and services for children, teens and adults with disabilities.



Their programs are social and recreational and they welcome people with all disabilities including those with dual diagnosis.

SRAs offer Inclusion Services which allow your child to participate side-by-side with typical developing peers in Park District programs. This is especially beneficial if your child wants to engage alongside peers in the neighborhood or with schoolmates. SRA Inclusion staff work directly with you and the Park District staff to identify any reasonable accommodation that might be needed for your child to participate fully. This is a free service to you.

They also offer their own

programs modeled after traditional Park District programs. You can choose from a wide variety of social, recreational and competitive programs which may include but are not limited to: recreational sports, adaptive sports and Special Olympics; arts and music; social clubs and camps; trips and special events; day programs for adults and more. Each are designed so that your child has the opportunity to enjoy typical authentic life experiences in a safe environment. These are programs that follow your child through their lifetime.

Back to hopes and dreams though, what makes achieving them is what's at the core of special recreation. You will see it on their faces and in their accomplishments.

**Special Recreation focuses on your child's abilities rather than**

**disabilities.** It is all about discovering what your child 'can' do instead of what they 'can't' do. Encouragement and empowerment are built into every program.

**Special Recreation is recreational, social and educational.** Your child will learn, laugh, and share their excitement with peers who are going through the same experiences with them.

**Special Recreation is about creating healthy lifestyles.** Regular physical activity is a vital part of a healthy lifestyle. With special recreation, your child can learn about healthy lifestyles or choose from a variety of activities that incorporate healthy activity disguised as fun.

**Special Recreation is about self-discovery.** Life is about enjoying the things you already love as well as finding new things to enjoy. Your child can do both.



Because programs are year round and available for all ages, your child can grow and discover with special recreation.

**Special Recreation is about connecting with others.** Nothing boosts a child's confidence more than being accepted by peers. For some, nothing is more difficult than learning how to connect with peers. Being able to develop friendships takes time, common interests and sometimes someone to help them navigate those social nuances. As parents it can't always be us. But there is always someone who can help with special recreation.

**Special Recreation is about hopes and dreams... for your child and you.**

Your child will find fun with friends while discovering the world around them and choose how they want to be a part of it. You will find that you can take comfort knowing your child is in good hands. As time goes on, you may find that the foundation of confidence and discovery built through special recreation propels their hopes and dreams. As your child grows, their hopes and dreams grow with them.

It all starts with special recreation.

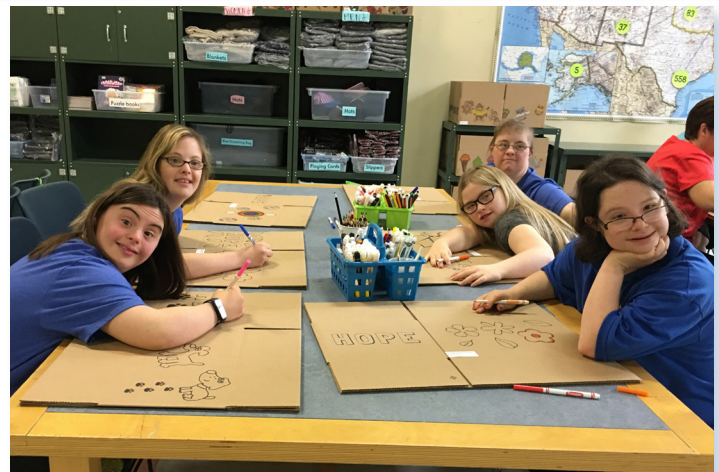
*Editor's Note: You can find the Special Recreation Association that serves your community by visiting [www.specialrecreation.org](http://www.specialrecreation.org).*

*Sherry Manschot is the marketing/public relations manager at Western DuPage Special Recreation Association. She can be contacted at [sherrym@wdsra.com](mailto:sherrym@wdsra.com). More information about WDSRA can be found at [www.wdsra.com](http://www.wdsra.com).*



## PAC Service Project at Phil's Friends

**P**AC members took part in a service project at Phil's Friends in Roselle on June 24, 2017. Phil's Friends ([www.philsfriends.org](http://www.philsfriends.org)) is a non-profit which provides support to those affected by cancer. The volunteers helped to put together care packages and cards. Many thanks to Ashley and Sue McLeod for coordinating the event.



## Upcoming PAC Events

### Feed My Starving Children Service Project

The next PAC service project will be at Feed My Starving Children in Aurora on September 16 from 9 – 11 am. You will need to sign up on their website, [www.feedmystarvingchildren.org](http://www.feedmystarvingchildren.org). If you need help registering to volunteer, please contact Diane Urhausen at 630-325-9112 or [durhausen@nads.org](mailto:durhausen@nads.org).

### Committee Skills Training

Our summer Committee Skills Training event is being rescheduled (date to be determined). Come join us to learn skills and options for serving on a committee:

- Learn advocate skills by serving on a committee.
- Learn committee etiquette.
- Serve on a committee to make a difference.

The meeting will end with a dance and refreshments! To find out more or to register, please contact Diane Urhausen at [durhausen@nads.org](mailto:durhausen@nads.org).

# Profile of Sam Raymond

Sam Raymond is one of the many artists providing work for the international art show and auction at our inaugural Gala. He is also a young man with Down syndrome who has a full life in his community. Sam has been cultivating his artistic talent since he was a boy and is a gifted painter and ceramic artist. He took his first art classes in elementary school alongside his peers and continued throughout school. He was in an inclusive educational program through 6th grade, but by high school, he had moved into special education classes—except for art. Though he was enrolled in the Life Skills program at St. Charles East, he was always able to take mainstream art classes. His art teachers supported him, and with their encouragement, he entered one of his pieces in a state wide art show. Sam generously provided one of his paintings for our auction, but painting is actually not his main interest—his greatest strength is ceramics. He has given away many of his best ceramic pieces and has found they have made very popular gifts! His parents proudly display his work in their home—including one of his mother's favorites, a painting called "Scary Halloween," which is effective at capturing the spirit of the holiday, complete with a scary black tree against an orange background.

Sam is now a high school graduate, but he still finds a way to pursue his interest in art. He is currently studying with Linda Palmer, an art instructor at Joshua Tree

(see article on page 7), a unique program for adults with intellectual disabilities (see the article below). He created the painting he donated for the NADS Gala, a cityscape, during his art class there, where he has been learning to work with oils and pastels and clay. Through Joshua Tree, Sam has also gotten to visit art studios in the western suburbs and see how professional artists work.

Sam has many other interests besides art. He participates in Fox Valley Special Recreation's Day Break program and has participated in track, swimming, and basketball through Special Olympics, though for the last two years, he has been focusing on his favorite: Special Olympics basketball. He enjoys his independence, walking to many of his programs. Most of all, he enjoys volunteering in the community. Through Joshua Tree, he volunteers at the Northern Illinois Food Bank, works in the community garden, and also helps with sales at the St. Charles Farmer's Market, where he thrives on his contact with the public. His week includes a variety of opportunities to learn, to contribute, and to be engaged within the community—but he is disposed to appreciate whatever activity he is doing. As his mother says, he is a "stay in the day kind of person"—a talent we could all learn to cultivate!

We are grateful to Sam and to his family for their generosity in providing his painting for our upcoming Gala. Come join us and see it for yourself!



Sam Raymond

## Disability & the Justice System

The spring issue of *Impact*, the journal of the University of Minnesota's Institute on Community Integration, is devoted to articles from over 24 authors across the U.S. about individuals with disabilities and the justice system. The potential for misunderstandings between law enforcement professionals and people with disabilities has been highlighted by recent encounters covered in the news, some with tragic consequences. This issue brings together the most current thinking about how communities can work together to address these challenges. To find out more, go to <https://ici.umn.edu/products/impact/301/#Cover>.

### UPCOMING EVENTS

#### Chicagoland Buddy Walk October 8, 2017

Bolingbrook Golf Course  
2001 Rodeo Dr, Bolingbrook, IL 60490  
[chicagolandbuddywalk.org](http://chicagolandbuddywalk.org)

#### 13th Annual Statewide Transition Conference October 23-24

Prairie Capital Convention Center  
Springfield, IL  
[www.illinoistransitionconference.org](http://www.illinoistransitionconference.org)

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

Moonlight Studios Chicago  
1446 W Kinzie St, Chicago, IL 60642  
Tickets and Information: [www.nadsgala.org](http://www.nadsgala.org)  
Questions: Katie Wood at (630) 945-2974 or [Kwood@NADS.org](mailto:Kwood@NADS.org)

## The Joshua Tree Community

Amy Singer, Founder and CEO

**W**elcome to the Joshua Tree Community. We are a group of intellectually disabled adults, each with his or her own experience in life, each with his or her own set of capabilities. We come together to grow and learn, to have fun, and to make new friends.

Our goal is to participate and to educate. We participate in the community by volunteering at nonprofit foundations and public-serving entities, such as the Northern Illinois Food Bank, St. Mark's Church, and more. On Fridays we sell lemonade and crafts at the Farmers Market, and we have our own plot at the James O'Brien Community Garden.

We educate, too. We want to be seen as capable, unique individuals. We want the world to know who we truly are, to recognize the potential we all hold deep inside. We, too, are working toward a more purposeful life, and we see every day as an opportunity to do better. Therefore, we engage. We don't just sit inside, we go

out in the world, we find our role, and we take part.

Lastly, we have fun. We do yoga and tai chi; we visit the library; we read, write, watch movies, play mini golf, go out to lunch, and much, much more.

We are lifelong learners, adventure seekers, creators, and friends. We smile, and we make others smile, too. We have come together for a purpose, and that is to help enrich the lives of our peers, and to build a better, more understanding, world.

*The Joshua Tree Community is a group of intellectually disabled adults over the age of twenty-two, or eighteen but no longer in the public school system, who meet every day at St. Mark's Church in the heart of downtown Geneva. The program is designed to engage members in real-life, purposeful activities. From fro-yo to yoga, volunteering to venturing, members of the Joshua Tree participate in a myriad of different activities every day. For more information, go to [www.joshuatreecommunity.com](http://www.joshuatreecommunity.com).*

## School Resources

**D**o you have children heading back to school this month? Here are some resources to help in partnering with your child's educational team:

- Send in an "All About Me" introduction about your child for the teacher. You can come up with your own summary or use an existing template. A comprehensive one is available from the Down Syndrome Association of Greater St. Louis: <http://dsagsl.org/wp-content/uploads/2014/04/All-About-Me-Booklet.pdf>.
- Get ready for your child's next IEP meeting by taking advantage of IEP planning resources. Here is one: <https://www.kcdsg.org/files/content/iep-toolkit1.pdf>.
- Share inclusion resources with your child's teacher, such as:
  - "Meaningful Inclusion for Students With Down Syndrome: A Resource Guide for Elementary Educators" ([www.mdsc.org/infojustforyou/EdManual.cfm](http://www.mdsc.org/infojustforyou/EdManual.cfm))
  - The Inclusive Class <http://www.theinclusiveclass.com/>
  - "Inclusion in the Classroom—Tips and Resources" [http://allbornin.org/wp-content/uploads/2012/11/Inclusion\\_Classroom\\_Tips.pdf](http://allbornin.org/wp-content/uploads/2012/11/Inclusion_Classroom_Tips.pdf)
- Practice skills at home. Here are some learning resources:
  - The Topics in Down Syndrome series from Woodbine House Publishing ([www.woodbinehouse.com](http://www.woodbinehouse.com))
  - Down Syndrome Education Online ([www.down-syndrome.org](http://www.down-syndrome.org))
- Take one of the workshops or webinars on special education offered by the Family Resource Center on Disabilities ([www.frcd.org](http://www.frcd.org)).

## Special Gifts Theatre Fall Offerings Jenni Von Tobel, Executive Director

**A**nnie, Jr., Beauty & the Beast, High School Musical! Special Gifts Theatre, Inc. is an educational and therapeutic theatre for individuals with special needs. We use the stage as a platform to teach speech and language, social skills, and promote self-advocacy! This season, we have 5 different casts, performing 3 different musicals! Would you be interested in joining one of our casts? Registration is OPEN!

**ANNIE, JR.!** (ages 10+)  
Skokie School in Winnetka  
Sept – Mar  
Tuesday OR Wednesday  
cast options from  
4:15-5:30 pm

**BEAUTY & THE BEAST!**  
Ebinger School in Chicago  
OR Sundling School in  
Palatine  
Thursdays 4:30-6:00 pm  
Chicago cast runs  
Sept – Feb (ages 8+)  
Palatine cast runs  
Nov – April (ages 10+)

**HIGH SCHOOL MUSICAL!**  
(ages 22+)  
Northfield on Mondays  
6:15-7:30 pm  
Sept – Dec

**CREATIVITY IN MOTION**  
Therapeutic Movement/  
Dance Class (ages 7 – 17)  
Crow Island School in  
Winnetka  
Mondays from 5:00-6:00 pm  
Sept - Nov

To register for any of our programs, please visit our website at [www.specialgiftstheatre.org](http://www.specialgiftstheatre.org) OR call (847) 564-7704 for more information.

# Chicagoland Down Syndrome Research & Medical Care Conference

Sarah Anderson

On June 7 the National Association for Down Syndrome (NADS) and the Global Down Syndrome Foundation came together in collaboration in Chicago. Both organizations are devoted to improving the lives of people with Down syndrome and their families, but Global also specializes in scientific and medical research. Starting off the event between the two groups was the keynote speaker, Michelle Anderson, talking about her life as a person with Down syndrome. Introducing

both organizations in their separate speeches, Diane Urhausen of NADS and Martha Cronin Keele of Global, provided background about each's contribution to the community.

During the conference two major projects involving medical research to further study Down syndrome took the stage quite prominently, the Crnic Institute Human Trisome Project and DS-Connect. The Crnic Institute, a facility in Colorado that specializes in researching Down

syndrome and medical care that comes associated with the condition, is an affiliate of the Global Down Syndrome Foundation. Much like NADS, their goal is to change society's perception of Down syndrome with an additional focus on autism and genetics. Which brings us to the Human Trisome Project, a database meant to extract information regarding medical treatment for conditions and diseases more likely found in people with Down syndrome. Participation for this project was made available at the conference, where participants voluntarily gave a blood sample. Blood samples from people with Down syndrome are required and their parents are encouraged, but an interesting aspect of the project was the need for siblings to participate. Siblings are said to play a large role in understanding medical conditions for those with Down syndrome; after all full blooded siblings share the genetic traits they would get from both their parents. So once they have sets of DNA from the siblings, researchers can analyze which genetic traits were inherited and whether or not some of those traits will have an impact on people with Down Syndrome.

The second major project brought into the spotlight at the conference was DS-Connect: the National Down Syndrome Registry. By running a series of clinical trials testing for cognition, behavior, and medical aspects, the Registry collects data about people

with Down syndrome for a better understanding of their overall health. As well as connecting with outside researchers and health care providers, they are able to display an understanding better than most about Down Syndrome's medical details. According to Dr. Melissa Parisi, Down syndrome is a gift to biomedical research and could be the key to understanding Alzheimer's, as well as potentially curing the condition.

The following presentations and Q&As helped in expanding the audience's knowledge about the lives of people with Down syndrome. In a joint presentation given by Dr. McGuire and Bryn Gelaro, the audience was given an opportunity to know how people with Down syndrome see and feel as they take control of their daily lives. At the conference, people were amazed at how some individuals are able to make their circumstances work. While there was a sense of accomplishment, some of the reality learned was a bit shocking, such as how some teachers are unable to educate themselves about their students with Down syndrome and how studies of it are terribly underfunded. This conference did fulfill its purpose with the gathered people from the two organizations in gaining a deeper understanding of Down syndrome; now we can only hope that more decide to see it as well.

## Parents & Sex Education

*Katie Frank, Occupational Therapist, Adult Down Syndrome Center*

Parents have expressed the desire to be sexuality educators for their children with Down syndrome. However, they do not always know what to talk about, when to talk about it, or how to talk about it so their child will understand. Here are some things parents should consider in regards to sexuality education for their loved one with Down syndrome:

- Sexuality education begins when you talk about body parts and emotions and continues through the lifespan.
- Consider your child's chronological age when considering the topics that should be discussed and their preferred learning style when considering how to teach those topics.
- Your child with Down syndrome has all of the emotions and desires of typically developing peers.
- Forget about this topic as a one-time talk; use teachable moments that occur naturally to bring up the topic of sexuality. It makes talking about sexuality topics more comfortable for the parent and the child and allows you to continue to talk about these topics as your child ages into adulthood.
- Do not wait until your child asks specific sexuality questions because then important sexuality topics may never get discussed.
- Do not be afraid of making mistakes; fear of making a mistake may prevent healthy sexuality education.

There is currently a research study being conducted about this topic at the ADSC. For more information about the topic or any questions, feel free to contact Katie Frank, PhD, OTR/L at the Adult Down Syndrome Center at [katherine.frank@advocatehealth.com](mailto:katherine.frank@advocatehealth.com) or 847-318-2331.



## ON THE TOPIC OF...

# Participation Nancy Goodfellow

I have always wanted my daughter to be included with her typically developing peers. When she entered kindergarten, my husband and I insisted that she be in a general education class, and we continued to advocate for that setting throughout all of grade school and junior high.

But we always insisted on more than just inclusion. We insisted on participation.

Lily's participation may not always look the same as everyone else's, but as long as she is doing her best to be a part of the class, then she is being successfully included.

This goes beyond school as well. When Lily turned three, we enrolled her in park district programs and took advantage of the assistants provided by the special recreation association in our area. We used the aides to help her stay focused, or help her swing a bat and catch a ball. As she got older, she no longer needed the extra assistance and we were able to sign her up for programs she could participate in independently. But again, Lily's participation may have been a little different.

Swim team is a perfect example. Lily has been swimming for our neighborhood swim team for over five years. When she was younger, I would drop her off at practice each morning and make sure that she got in the water. Then I would drive the five minutes home and turn on the computer to check the pool webcam. Almost every day, by the time I got home and checked, Lily was already

out of the water. She would complete one or two laps and decide that was enough for the day.

As she got older, we raised our expectations. She had to stay in the water for 15 minutes, then 30. She had to complete five laps, then ten. She was doing really well staying in the water and practicing with the rest of the team... until last summer. She was now in the 13-14 year old age group, which meant practices were even earlier in the morning and lasted longer. She would swim for about 10-20 minutes and then get out of the pool, regardless of what the coach asked or how much of the workout she had completed. And she was constantly asking to skip practice – something she hadn't done in the past.

It wasn't until the very end of the season that it finally dawned on me that Lily was totally overwhelmed. Her coach would write the morning workout on a large whiteboard each day and place it at the end of the lanes for the kids to check. Because the 13 and 14 year olds practice with the high school kids, the distances were long. The expectations were high. The amount of swimming was daunting.

Lily wasn't being stubborn or losing her interest in swimming. She just knew that she couldn't complete the workouts. They were so overwhelming that it was easier to not swim at all than to try to swim part of them.

I worried that we'd reached an age where Lily could no longer realistically participate in swim team.



I didn't want to keep bringing her to the pool each morning and have her feel sad or overwhelmed about her abilities and the expectations. Perhaps it was time to stop swimming for the summer swim team and just focus on Special Olympics swim instead.

But, fortunately for us, Lily has an incredible swim coach. Brian has been the head coach for the swim team since Lily joined, and we couldn't be luckier. He has always been supportive of Lily, and incredibly patient. So when I expressed my concerns and explained my theory about the workouts, he came up with an easy solution.

The next day, I brought Lily later to practice so that she would only swim the last 30 minutes. Brian had already talked to Lily's private swim instructor to see what Lily could handle and he had written a personalized workout for her on a sheet of paper. He wet a kickboard and stuck Lily's workout to it, placing it at the end of a lane for her to look at between laps. It wasn't too difficult. It

wasn't overwhelming. It was just for Lily – and it worked perfectly.

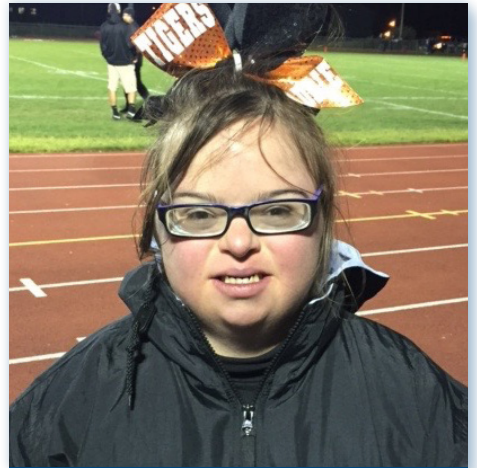
When swim team started this summer, we now knew exactly what to do. We increased our expectations and added time onto her workout, in addition to longer distances. Every morning I dropped her off at the pool for the last 45 minutes of practice, and every morning Brian had a workout waiting for her at the end of a lane. He even had her stay after some mornings to work on diving... although we discovered that he needed to write that on the morning workout if he expected her to do it. Apparently if it's not included in her workout, she isn't going to do it!

Lily may not have swum the same distances or completed the same workouts as the rest of the team this season, but she participated. We hope the same is true for all areas of her life, whether it be swim team, school, or her community... She is not just included. She is part of it.

# family album



Tommy Nee and his sister Annamae



Madisyn Ross



Jacob Jordan Lopez



Zack Donatello



Jonathan Crabb



We Need Photos!

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



Rylie Weil

# NATIONAL ASSOCIATION FOR DOWN SYNDROME

presents

## ROCKIN' THE RUNWAY WITH THE STARS 12TH ANNUAL LUNCHEON & FASHION SHOW

SUNDAY, OCTOBER 15, 2017

DONALD E. STEPHENS CONVENTION CENTER - ROSEMONT

This event will feature children and adults with Down syndrome modeling their own style.

Doors open at 10:30 AM with the Silent Auction and Choice Raffle, Reserved Luncheon Seating begins at 11:30 AM and the Fashion Show at 1:00 PM.

Proceeds from this event support the programs NADS provides to children and adults with Down syndrome and their families.



## NADS 12<sup>TH</sup> ANNUAL LUNCHEON & FASHION SHOW

Space Is Limited...RSVP by October 1, 2017

Yes, I/We will attend \_\_\_\_\_ Tickets @ \$65 each = \$ \_\_\_\_\_  
\_\_\_\_\_ \$600 Reserved Table (Seating for 10 guests)  
\_\_\_\_\_ \$1,000 Runway Table (Seating for 10 guests)

Guest Names: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I would like to be seated with: \_\_\_\_\_

No I/We cannot attend, but would like to make a contribution as indicated:

\$1,000  \$500  \$250  \$100  \$50  \$25  Other: \_\_\_\_\_

Check Enclosed  Credit Card\* Additional processing fees may apply with a credit card payment.

Total \$ \_\_\_\_\_ To be charged to:  Visa  Mastercard  AmEx  Discover

Account No: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

CCV: \_\_\_\_\_ Signature: \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_ City, State, Zip \_\_\_\_\_

Email Address \_\_\_\_\_ Phone Number \_\_\_\_\_

Please mail to: NADS Fashion Show, 1460 Renaissance Drive, Suite #405, Park Ridge, Illinois 60068

Reservations, sponsorship, and contributions can also be made online at [www.nads.org](http://www.nads.org).

Please contact NADS at 630-325-9112 or [fashionshow@nads.org](mailto:fashionshow@nads.org) for more information.

**THANK YOU FOR SUPPORTING THE NATIONAL ASSOCIATION FOR DOWN SYNDROME!**



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.