Newsletter for members of the National Association for Down Syndrome

December: 2018



## Joanne's Journey

by Linda Mahnke

September 21, 2018 was a monumental day in my family's life. It was my sister's 75th birthday.

My sister, Joanne Armstrong, was born on September 21, 1943, the youngest of 5 children in Wasco, California. She was a beautiful baby with blond curly hair. As she got older she seemed a little different but was just as responsive and interested in learning as most children are. At age five and ready to start kindergarten, she was turned away. That was the first time I heard the word "Mongoloid." I didn't know what that meant but I discovered that it was a bad word to me and other families. It was later changed to "Mentally Retarded" and eventually to "Down Syndrome."

We met other families that kept their "special" children out of the public view because the public was unprepared and uneducated about accepting someone different. They would stare and then laugh and call our loved ones "Mongoloids."

Visit NADS.org to read the rest of



## 13th Annual Fashion Show A "Shining" Success!

n October 28, over 400 attendees and 35 models celebrated the beauty and individuality of people with Down syndrome at our 13th annual fashion show. The show – appropriately named "Shine Bright Like A Diamond" – was our biggest and brightest yet!

Emceed by Channel 7's meteorologist Cheryl Scott, the event featured amazing models highlighting their own styles, and entertainment by Allie Renninger and Garret Anderson who act with the EDGE of Orion's Constellation Classics group (edgeoforion.com/about-constellation).

We were also entertained by Candie Schwaner from Center Stage Dance

Continued on page 2

## **JANUARY 20 PAC Bowling Party**

**Brunswick Zone** Glendale Heights Lanes 558 E. North Ave. Glendale Heights

Time: 1-3p.m. (pizza, bowl and shoes included)

Reply by Jan. 11th to: Ismarto@nads.org 630-779-4245

See page 9



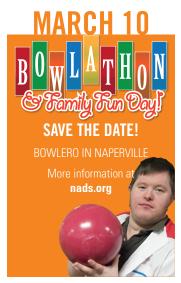
## **FEBRUARY 2**

## **More Than** Down Syndrome Workshop Day

FREE seminar focused on "Is it Sensory or Is it Behavior?"

> **Holiday Inn Itasca** 9:00a.m.-1p.m. (welcome at 8:30a.m.)

Register by: Friday, January 11th Ismarto@nads.org 630-779-4245





## **Fashion Show** Wrap-Up Continued from page 1

Studio in Bloomingdale.

Along with the fashion show, guests enjoyed a silent auction and choice raffle, a delicious luncheon and a truly fun and uplifting experience.

> Thanks to the efforts of NADS board members and co-chairs Jennifer Hora and Erin Komacki, we surpassed last year's proceeds, raising almost \$30,000 for our programs and services.

We are also grateful to all of our wonderful volunteers and board

members who donated their time and talent to make the event such a huge success.

If you are interested in modeling or volunteering next year, please reach out to NADS at info@nads.org. See you next year!

A huge thanks to ABC-7 for letting us come on the air a week before to promote the event!

\$29,000+ Raised at this year's Fashion Show

400+

Families, friends and guests



40 Volunteers made it all happen!







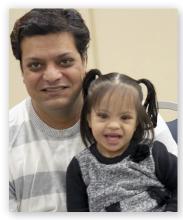


Left: Channel 7's Stacy Baca and Mark Rivera on the set

### Smile! [and help NADS]

o to smile.amazon.com and designate the National Association for Down Syndrome when you shop online! Amazon will donate a portion of the purchase price to us. It's that simple!









## NADS has moved!

We only moved three floors down, but we're excited about our new space! If you're in the neighborhood, please stop by anytime! We're at 1460 Renaissance Drive, Suite 102 in Park Ridge.



Top left: NADS Staff Members Debbie, Chris and Linda along with NADS Self-Advocate Julia. Top Right: Joe, Joel, Mark along with Self-Advocate Jacob. Right: Self-Advocates Julia and Jacob lend a big hand!







## **Want More News from NADS?**

Sign up to receive news, stories, resources, event information and more... all in your email inbox!

To Join the NADS Email List. Go To: nads.org/contact-nads

## Thank you!

huge thanks to
Operation Warm Hearts who selected us as one of six local organizations to receive hand-made donations. This wonderful group was organized in 2010 and the members make hats, scarves, mittens, socks and booties, sweaters and lap robes for area families to use and enjoy.





Chicagoland Buddy Walk.

## **Chicagoland Buddy Walk**

The 16th Annual Chicagoland Buddy Walk was a huge success this year.

NADS was out in full force handing out information and interacting with the

wonderful families in attendance. Thanks to the National Down Syndrome Society, NADS received a generous portion of the proceeds.

## **PAC Kickoff Party Fun for All**

ast month the PAC (Partnership Advocacy Program) had their first event of the year! Special thanks to Sarah and Maria Alzamora and their family for their generous donation to our group. Also a huge thank you to the fantastic disc jockeys from Esskape Productions, who made the event so fun. If you are interested in learning more about PAC, please contact Linda Smarto at 630-779-4245.







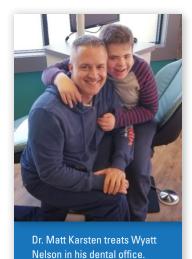
## Why is dental such a pain?

## Some answers from a concerned mother

Deborah Nelson, mother of Wyatt

t was like pulling teeth: Trying to find the right dental care for my son Wyatt, who is 13 and has Down syndrome.

We were already connected with a good neighborhood dentist when it came to routine check-ups. We also had a wonderful oral surgeon — Dr. Matthew Gautier — who tenderly performed three outpatient surgeries at Northwest Community Hospital for



In addition to these fabulous dentists, we are so happy with Dr. Matthew Busch and his awesome team who are dedicated to orthodontics for people with Down syndrome and other special needs.

Unfortunately, none of these wonderfully skilled practitioners could help Wyatt's dental emergency the day he began screaming that his mouth hurt. I couldn't get a very good look inside because he's very sensitive about having his mouth probed (and uses his 140 pounds to show it). Finally, with a flashlight and the help

of his sister Sophie, it looked like an abscess by his upper molar.

We took Wyatt to the emergency room, only to find the physician was unable to get into his mouth to look so sent us home. She told us to call the dentist in the morning. We did and she too couldn't get a good enough look that far back. We were told Wyatt needed sedation in the dental office. That's when the trouble really started.

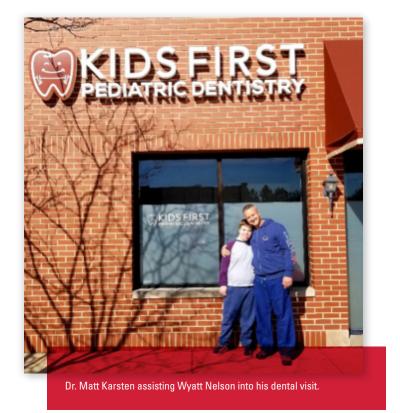
Reaching out to Drs. Gauthier and Busch, hospitals, universities and agencies, I realized that we were in the midst of a sort of dental quagmire.

### What we needed was a dentist with hospital privileges. And those are very rare

Was this a medial issue or a dental issue? It was some of both. A dentist couldn't do what we needed, nor an oral surgeon. What we needed was a dentist with hospital privileges. And those are very rare, at least around us.

The answer was a referral from Dr. Gauthier to pediatric dentist Dr. Matthew Karsten of Kids First Pediatric Dentistry (kidsfirstpd.com) with offices in Schaumburg and Elgin, Illinois. He has hospital privileges to perform the necessary exploration and treatment with sedation so a child like Wyatt can be comfortable.

While it was taking me over 15 minutes to coax Wvatt out of our car (transitions are rough for him), Dr. Karsten came out, gave Wyatt a highfive in the backseat and sparked him with guy chatter so he trotted right inside to the dental chair.



Dr. Karsten is not only the solution to Wyatt's emergency, he's a very dedicated, humble and caring man, father, and professional who really does put "kids first."

It's a good thing Dr. Karsten is the Wyatt Whisperer. That's given this mom a sense of relief to feel, well ... sedated. And if our experience helps ease the dental pain for one family, it will be well worth it. ■



## New Federal Funding for Research

ederal officials are committing millions of new dollars to Down syndrome research and they say even more money may be on the way.

The National Institutes of Health said this month that it has awarded \$22.2 million to studying the chromosomal disorder and related issues.

The grants are part of the agency's INvestigation of Cooccurring conditions across the Lifespan to Understand Down syndromE, or INCLUDE, project. The initiative, which launched in 2018, was spurred by a congressional directive and is aimed at addressing health and quality-of-life issues among those with the condition. With the new funding, the NIH said that its investment in the chromosomal disorder for 2018 is now at \$59 million. The agency indicated that it plans to up its spending on the condition in 2019, if money is available.

"We have a unique opportunity to improve health outcomes for those with Down syndrome by increasing their inclusion in research." said Francis Collins, director of the NIH. "People with Down syndrome are at risk for many of the same conditions as the general public such as Alzheimer's disease, sleep apnea, heart disease and autism, and it is my hope that this effort will provide meaningful insights to find treatments that benefit both populations."

The funding is going to clinical trials addressing co-occurring conditions that are common in those with Down syndrome as well as research projects that address the basic science of the condition or develop a large study population so as to understand the disorder at various developmental ages, the NIH said.



### Seasons of

## **Good Cheer!**

Jody Chisholm

Audrey Chisholm loves cheerleading and cheer competitions! She is 13 years old, has Down syndrome and started cheering when she was 5 years old. Audrey is a serious athlete and she is a very good cheerleader. She cheered for our local recreation team but after a coaching change, Audrey was excluded from the competition squad even though the cheer association had scoring in place to have a fair, inclusive experience. It was the first time we felt the sting of exclusion and it was devastating! As her mother and her advocate, I wasn't going to let setbacks stop her from doing what she loves! We went to a neighboring community and asked permission for Audrey to cheer on their squad the following season. As I offered to send a video of Audrey's skill, the coach stopped me and said she knew who Audrey was and she had seen her perform at an earlier exhibition. She was impressed with her passion, skill and heart, and said she would be thrilled to be her coach! Coach O warned me that she is tough on her squad and she told me that Audrey had to be prepared to learn

the routine and follow instructions. She couldn't wait for the next season to begin! I didn't realize it at the time but Coach O's team just finished an undefeated season and won the State Championship!

The following season, Coach O introduced Audrey as the newest member of the squad and she was immediately surrounded by her new cheer family. From the very first practice, all of the girls accepted her. This was remarkable as they were going into the season defending their State title with a new cheerleader; a cheerleader with Down syndrome! The girls treated Audrey as a peer, and the coach treated her like any other cheerleader. On the day of the first competition with the new squad, Audrey's coach did not tell the judges that she had a cheerleader with a disability on the squad. After the competition, a judge approached the coach and asked if she had a cheerleader on the squad with Down syndrome. The judge told our coach that she should have let them know about the disability so they could have taken into consideration a late jump

or a missed skill. The Coach said that Audrey is a cheerleader with strengths and weaknesses, just like any other girl on the squad. She didn't feel it was necessary to let the judges know. The girls won first place without the acknowledgement of a cheerleader with a disability. This squad continued to work hard, and together, they won every competition and a second State title! At the end of her first season, the coaches awarded Audrey with the "Most Spirited Cheerleader" award. Audrey was so moved by the gesture that she sobbed as she held





her award. It was a tender moment for everyone as they all felt the joy in Audrey's heart.

The next season flew by and again, this squad went undefeated and won their third consecutive State title!

This year the girls are in 8th grade and their recreational cheer careers will be over after this season. There have been many times we as parents have choked back tears as we mourn each experience that we won't have next year! Homecoming is one of those "last times." Each and every girl in cheerleading dreams of being on the Homecoming Court and every girl would LOVE to be voted Homecoming Queen. This year was no different; except, these cheerleaders put their dreams to the side so they could make one special girl's dream a reality. The girls each received a ballot and voted for the Homecoming Court. The cheerleader with the highest number of votes would be crowned Homecoming Queen. As they tallied the results, Audrey's name was circled on 21 of 22 ballots! There was a ballot that had every cheerleader circled with the exception of Audrey ... that was Audrey's ballot! She voted for every girl except herself! They announced

the homecoming court at their final rehearsal. When Audrey was named Homecoming Queen, the squad cheered in delight. It wasn't until the following Saturday when they put the tiara and the Homecoming Queen sash on Audrey that the magnitude of the

### As her mother and her advocate, I wasn't going to let setbacks stop her from doing what she lovest

gesture was felt full force! The girls were thrilled to crown Audrey as their Queen and to see the joy in her face! While the cameras flashed and the line for selfies with their Queen grew longer and longer, our family, friends and other spectators watched in awe and wiped away their own tears of happiness. It was a glorious day, one that everyone will remember for the

selfless actions of this amazing group of 13 year old young ladies ... three-time state champion cheerleaders. We want to thank

the Mokena Burros Football and Cheerleading Association for their incredible program and for the parents who raised their children to see the beauty in everyone.

The squad has been undefeated for 4 straight years. The Pop Warner organization created a special sportsmanship award for Audrey's squad and they qualified for Nationals to be held next week on the ESPN Disney stage. They will be competing against squads from all over the country! To my knowledge, Audrey is the only athlete with Down syndrome. The coach helped Audrey's dream of being a flyer come true! She created a stunt for Audrey and put it in the center to showcase her pride! This story is extra special because it is their final year together and all of these amazing friends will be going to 4 different high schools and they will have memories to last a lifetime!

Visit NADS.org/good-cheer to watch a video of Audrey and her team in practice!



## **Visual Learning Supports**

Katie Frank, PhD, OTR/L Registered Occupational Therapist Adult Down Syndrome Center

e know and understand that many individuals with Down syndrome are better visual learners than they are auditory learners. When they are young, school teachers or therapists often use a visual schedule in the classroom or a visual reward system. There may be a stop sign on the door or labels around the classroom. What I have found is we never grow out of using visual supports, but the supports may grow and change with us.

Visual supports are pictures, words, or other images utilized to help communicate, share or manage expectations/rules, provide reminders, or teach new skills. Visual supports are another way for us to process information. We all use visual supports, whether it is a to-do list, our grocery list, or even our calendar. Look at your smart phone! The apps are an image with verbiage. How many of you use emojis to express information in texts and social media?

If you want to learn more about how visual supports can be used to help your loved one with Down syndrome, talk to your private or school-based speech therapist or occupational therapist. If you don't have access to those services or still have questions, you can always reach out to me and I would be happy to help! At the ADSC we use visual supports all of the time! We even have some available on our website under the resource section. (goo.gl/A8M7Q6) =

## **SAVE THE DATE!**

"MORE THAN DOWN SYNDROME'

Saturday, Feb. 2 8:30a.m.-1p.m. **Holiday Inn Itasca** 

Parents and/or family members of an individual with Down syndrome and a secondary diagnosis such as ADHD will greatly benefit from the information presented.

To register, please e-mail Linda Smarto at Ismarto@nads.org.

More at **NADS.org** 



## Our favorite Main Event wrestler... Myles Keenan!

Teresa Keenan

eet Myles Keenan, a 7th grader at Geneva Middle School South in Geneva, IL. Myles is a 2nd year wrestler with his fellow Viking teammates! His wrestling commitment involves wrestling practice on Mon/Wed/Fri after school, and wrestling meets on Tuesdays and Thursdays. Myles is so fortunate to be surrounded by incredibly kind and caring teammates and coaches. His teammates take turns practicing with him and doing drills, and the coaches are eager to help him improve weekly and to secure an opponent for him at

almost every single meet.

Watching Myles wrestle is a dream come true every single week for us,

## Watching Myles wrestle is a dream come true every single week for us

his family. We cannot believe how fortunate we are to watch this little boy of ours participate in such an amazing sport. The smiles grow earto-ear throughout the gym after every single match, when Myles cannot wait to circle the wrestling mat and give a celebratory high-five to the entire opposing team and their coaches. Oftentimes there is a great big hug for the referee as well. We are so incredibly thankful for our team and their families, our coaches, and all of the teams we have met throughout this season who have made it so exciting for our son to wrestle.

It's not whether you win or lose, it's how you play the game.

## What Parents Are Saying...

Our families are the reason we continue to do our critical work in the community. We visit hospitals every day of the year to provide support, referrals and welcome baby baskets to new parents.

The feedback we receive from parents makes our work so fulfilling and rewarding.

"I like to describe it as a breath of fresh air and the warmest welcome to an amazing group of people. My husband dove right in and started reading everything right away. I needed some time to accept and reflect, but once I was ready, I had everything I needed to begin this journey on the right foot."

— Mayra (Emma's mom)





"I was so surprised and honored to receive a basket from NADS. I had a birth diagnosis so the first few weeks were full of emotions, unknowns, and fears. The welcome basket itself provided education, support, and a warm welcome to the Down syndrome family. Meeting Melody (who dropped it off) was another blessing — finally a mom who had gone through the same thing I had and could tell me "It's going to be more than okay!" She was so positive, welcoming and helpful. Thanks to NADS for all that you do!

— Kelli (Laney's mom)

"When Kayleigh was born, the neonatologist asked if we had any genetic testing done and informed us that he thought that Kayleigh may have Down syndrome. The news was surprising and we began to process what our future would look like and hold. It was several days later that we found out that she indeed had Down syndrome. Once we found out that she had Down syndrome, we started scouring the internet looking for information and resources and found many organizations that offer support. Once I was home from the hospital, I had reached out to National Association for Down Syndrome (NADS) and talked to this amazing woman who, as I cried, listened to me and spoke with me about many things. I could feel the support as she too, had a child with Down syndrome. She congratulated me on my baby and made me feel some sort of comfort for this journey I would be on. She took my information down and gave me some additional information and resources. She also told me that they have a parent support program where another parent in my area would contact me. This was just what I



needed at that time. My husband and I have been looking for ways to be more involved so this year we attended the NADS conference in Chicago. Attending the event was a wonderful experience since we were able to break into different learning sessions and gather information on topics that interested us and that we wanted to learn more about."

- Karen (Kayleigh's mom)

Learn more about the NADS Parent Support Program at NADS.org/programs/parent-support

## **Hospital Impact**

ADS makes it a priority to visit as many hospitals as possible throughout the area, educating medical professionals on how best to work with new parents of babies born with Down syndrome.

Linda Smarto, NADS Director of Programs and Advocacy, spends countless hours traveling and speaking to more than 8,000 people each year.

"Thank you so much for your visit and the information. It is always good to refresh and remind all of us about our options for providing assistance to our families."

— Jennifer Perkins, MSN, RNC-NIC. **Professional Development** Specialist - New Life Maternity Center and Pediatrics, Department of Professional Practice, Northwestern Medicine Delnor Hospital

NADS is also grateful to connect parents with older children with Down syndrome to hospitals and new parents.

Linda Smarto recently attended Pediatric Pearls Conference at Silver Cross Hospital in New Lenox. NADS was pleased to connect with 140 attendees, including doctors and

Does your organization or hospital need a speaker? NADS provides complimentary presentations for schools and religious classes (youth ministry at churches or synagogues). Contact us for more information! ■





## **PAC Bowling Event**

### SUNDAY, JANUARY 20TH

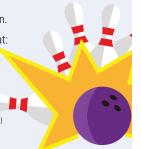
Help prepare for NADS Bowl-A-Thon which will be held on Sunday, March 10th!

Please contact Linda Smarto at Ismarto@nads.org, so that we know you will be able to join us. In exchange for a great time bowling, all that we ask, if you can kindly bring a \$5 gift card or donation to help collect door prizes for our upcoming Bowl-A-Thon.

This great PAC event will be at:

**Brunswick Zone** Glendale Heights Lanes 558 E. North Ave. **Glendale Heights** 

1-3p.m. (pizza, bowl and shoes included)



## What is **Planned Giving?**

Planned giving encompasses a variety of ways that gifts can be made to NADS from accumulated resources.

### **Benefits of Planned Giving:**

- Leaves a lasting legacy
- An estate tax charitable deduction
- Reduces tax burden to your

Planned gifts are either outright gifts (i.e. gifts of appreciated securities, real property, personal property, etc.) or deferred gifts (i.e. bequests, charitable gift annuities, charitable trusts). Bequests can be designated to the general fund or endowment.

You can make a bequest simply by including language in your will or trust or by using a beneficiary designation form.

Please contact Jill Sterling at (630) 325-9112 for questions or assistance.

### Are you 70½?

Want to Donate your Required Minimum Distribtuion to NADS tax free?

### Meet the requirements:

- Must be at least 70 1/2
- Can transfer up to \$100,000 per person without any tax consequence
- Transfer must be done by December 31st

### **How to Transfer:**

Funds must be transferred directly from the IRA to the eligible charity by the IRA trustee.

Please contact Jill Sterling at (630) 325-9112 to discuss pledging securities.

# §FAMILYAlbum

















## Regan's hidden 'superpower'

n the eve of Regan's 13th birthday I went to the mailbox. There it was — an American Girl catalog. Would Regan's picture be in it? I couldn't wait to open it up and see. YES it was! I was filled with so many emotions. If someone would have told me the day she was born on the eve of her 13th birthday that I would see her in an American Girl Catalog and be a model I wouldn't have believed you.



I am still trying to grasp all that is happening with Regan and realizing that through her disability she was given a 'Superpower.' It's the best way I can think to describe it. I truly believe that everyone with a disability has this amazing gift. Regan has

### If for one minute Regan can take one person to a positive place then she has done her job

the power to change someone's fears, worries, and concerns and give them FAITH. How lucky is she to have been given such a gift. I have to believe that one person who has seen her photos or other projects has changed them. Maybe they are more accepting of people with disabilities. Maybe it's a struggling parent or grandparent needing reassurance

Our journey with Regan came by chance. Mattel was looking for models with disabilities. The ages were from 2-11 and Regan was 12 at the time so I wasn't going to send any pictures in. A friend convinced me to send in some random photos. I also included her sister Lauren as they requested other family members in the photographs as well. A month later I received a call saying that the girls were chosen for a casting call. We went into the city and 2 months later received a call from Mattel. They wanted to hire both my girls! They were both photographed for this year's American Girl Holiday campaign. I never knew until afterward how rare it is to be chosen, let alone someone with a disability. I am proud that companies like Mattel are realizing that most families have a 'Regan' in their lives.

We were encouraged to meet with a Talent and

Modeling Agency. They signed Lauren right away and didn't know how much work Regan would get because of her disability. I appreciated how honest they were. They said it is very rare to have someone with a disability represented professionally because of lack of work. They would keep me updated if any jobs would come her way. The next day I received a call saying they had someone interested in hiring Regan. Needless to say, we were given a contract immediately. Regan has since received numerous calls. The owner was pleasantly surprised and just as excited for Regan. The world slowly seems to be

The last project Regan did was The March for Life 2019 Unique from Day One National campaign. This video will be shown nationally and at The Right to Life Rally in Washington DC on January 18, 2019. We are excited to attend as a family and they are excited to meet Regan.

I can't even imagine how many people will be positively affected by Regan's "superpower" and this very powerful video. I know she can be the hope that someone needs. Life isn't always fair and is far from easy but if for one minute Regan can take one person to a positive place then she has done her job.

Because of Regan I now believe all our friends with Down syndrome have a 'Superpower' regardless if they are in magazines or not. They have this amazing gift and use it every day in big and little ways without even knowing it.

I don't know Regan's future in the world of modeling but I do know that right now she has the ability to change a life in a positive way. I think that's pretty amazing. Regan and all our friends have more power than they realize just by being themselves. We should all be so lucky.



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 Park Ridge, IL 60068

630 325-9112

or visit www.nads.org

Jill Sterling, Editor Katie Wood, President



1460 Renaissance Drive, Suite 102 Park Ridge, IL 60068

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Become a NADS member Igno.sbsn.www.nads.org!

## Consider This:

### **SMUIRARONOH**

Donating to NADS in someone's name is a wonderful gift to someone who has been helped by NADS.

### **MEMORIALS**

Consider making a donation to NADS in memory of a loved one.

### **MATCHING GIFTS**

Ask your employer if they're willing to match your generous donations to NADS.

### **MAKE A PLANNED GIFT TO NADS**

When planning your estate, you can designate NADS as one of your beneficiaries. Call the NADS office at **630-325-9112** to learn more.

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MDS Member: ☐ \$50.00 (Annually recurring) Receive MADS News & UADS E-Blasts  MADS Patron: ☐ \$10.00 (Monthly recurring) Receive MADS T-Shirt, MADS News & UADS E-Blasts  Benefactor: ☐ \$250.00 (Annually recurring) Receive WADS T-Shirt & Coffee Mug, MADS News & UADS E-Blasts
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Membership Application

Make checks payable to: NADS and send to: 1460 Renaissance Drive, Suite 102, Park Ridge, IL 60068

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