Great job setting up – now go and have fun in the arcade for 20 minutes before our bowlers start showing up.”

Those were the instructions given to the ten self-advocates who came out early on Sunday, March 4th to assist in the 33rd annual NADS Bowl-a-thon, renamed the “Bowl-a-thon and Family Fun Day,” given the extra activities available at this year’s venue: Bowlero of Buffalo Grove. Besides having 32 bowling lanes, Bowlero offered a full arcade with tickets redeemable for prizes, laser tag and table games.

Nearly 100 people, many of them longtime supporters of NADS, bowled on 20 lanes that afternoon. In addition, there were other family members, friends and supporters who did not bowl but came to play in the arcade or try laser tag, buy tickets for the grand raffle and the choice raffle, catch up with other members of the NADS community, eat pizza provided to bowlers, or (for a few of the littlest attendees) hang out in the party room and watch the Minion Movie or Toy Story. While the location and non-bowling activities were different, many things did not change, including door prizes for each fundraiser, the ever popular “silver dollar minute” (albeit gold dollars were given out), and surprise visits by costumed celebrities (this year Clifford the Big Red Dog and “Pinny” the Bowlero mascot).

Most folks thought the guy on the microphone did an okay job. (Full disclosure: it was me!)

The Bowl-a-thon remains NADS biggest fundraiser and was held successfully for many years at Stardust Bowl in Addison. The NADS board decided to try a new venue this year based on feedback from previous Bowl-a-thon participants which included: holding it at a newer facility, shortening the three-hour timeframe, providing other activities besides bowling, and serving food. Although somewhat less centrally located for our community, Bowlero of Buffalo Grove satisfied many of those criteria at a relatively modest incremental cost.

The Bowl-a-thon’s fundraising mission would not have been possible without the support of:

- Our bowlers and other fundraisers who once

NADS News
Newsletter for the National Association for Down Syndrome
May, 2018

Bowl-a-Thon & Family Fun Day  Joel Spenadel

NADS Annual Meeting

Please join us for our annual meeting to learn more about NADS, including recent and upcoming changes to the organization.

MONDAY, MAY, 14, 2018 AT 6:30 PM

NADS Office: 1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068
RSVP online at www.nads.org

Continued on page 2
Bowl-A-Thon
continued from page 1

again raised a large amount of money from family, friends and the broader community.

- Our 20 sponsors, who were acknowledged at the event on electronic boards over the lanes.
- The businesses and individuals who donated the wonderful grand and choice raffle prizes as well as the door prizes.
- The members of the Bowl-a-thon planning committee (including members of NADS staff and board), the prize procurement committee, and the other members of our community who raised their hand to help during the event.

A special shout out goes to Jackie Rotondi, who spent countless hours putting together the beautiful choice raffle gift baskets!

While all attendees (including the non-bowlers) seemed to enjoy themselves, NADS leadership is still seeking feedback regarding the change in venue ahead of planning next year’s event. If you have feedback, please contact me at jspenadel@gmail.com or contact the NADS office.

THANK YOU TO ALL SPONSORS FOR YOUR GENEROUS DONATIONS:

Momkus McCluskey LLC
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Cook and Kocher Insurance Group
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iit Sourcotech
The Spenadel Family
Moment Design Architecture+Interiors

A big thank you to Dan Reich from the Zion Fire Department who coordinates an annual Trivia Night. He chose NADS as this year’s recipient and the department donated $3,850 to NADS!
Renewal by Andersen Drives Awareness and Diapers  Deborah Plate

It started with a simple survey question to the team at Renewal by Andersen of Chicago, asking their associates to list charitable organizations they are involved with or would like to be considered for future activities. Design Consultant Eric Strons listed the National Association for Down Syndrome (NADS).

Eric’s beautiful daughter Avery Hope is 8 years old, in second grade, and has Down syndrome. At four months old, Avery Hope had open-heart surgery to repair her heart valves. Arthritis forces her to endure a weekly and painful shot to relieve the discomfort. However, there is no doubt Avery Hope is a girly-girl who loves her clothes, especially anything pink or soft. She loves going to school on the bus with her big sister Kelly, and enjoys gymnastics, swimming, and playing at the playground.

Finding that connection between the company, the team, and the community is extremely important to Renewal by Andersen. They believe in bringing a greater meaning and purpose to all their efforts. As the replacement division of Andersen Corporation, they are guided by a century-plus old core value of Corporate Citizenship, making a positive impact in the communities in which they live and work. So, the team selected NADS for a recent donation drive and collected items for the Welcome Basket Program.

We often focus on how such a donation benefits a charitable organization, but for Renewal by Andersen they took away something from this effort that has no material or monetary value. Having a stronger awareness of organizations such as NADS, making the commitment to make a difference, and being inspired by individuals such as Avery Hope Strons is simply invaluable. Together as a company, they found a cause that hits home, and together they made an impact.

Thank you to Deborah Plate and Renewal by Andersen of Chicago for the generous donations of items for the Welcome Baskets, along with cash and gift cards!
Introducing Chris Newlon

**NADS NEW PARENT SUPPORT COORDINATOR**

Chris Newlon is the new Parent Support and Outreach Coordinator for NADS, with plans to also expand the New Baby Basket program that started over a year ago. Chris has been involved in the Down syndrome community since the birth of her youngest, Rebecca, almost 15 years ago. While Rebecca was still in the NICU, she received a call from a NADS parent support volunteer offering support and information. Chris was comforted in knowing that there was another mom who understood her feelings and fears. She has been a NADS public speaker for many years, focusing on further educating medical professionals in the hospitals and community, students in elementary schools to college classes, and teachers during their in-service and continuing education seminars. Chris served on the board of GiGi’s Playhouse McHenry County, as a consultant to the National Therapeutic Committee for GiGi’s Playhouse, Inc., and is a retired psychiatric occupational therapist. Chris is the mother of five and she and her husband, Shaun, live in McHenry County. She spends her free time gardening, reading, and is attempting to learn yoga.

Please welcome Chris to her new role! She can be reached at 630-325-9112 and cnewlon@nads.org.

NADS thanks Nancy Wilson for her work as the previous Parent Support Coordinator!

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**Doctor’s Corner**

**Erin B. Dominiak, M.D.**
**Adult Down Syndrome Center, Director of Medical Education**

It’s spring – think green (and other colors)! Vegetables are filled with nutrients and fiber and undoubtedly promote good health. I recommend assessing your diet and eating more vegetables if you aren’t already eating many; we recommend at least 2 ½ cups a day. They can be fresh or frozen, raw or cooked, in soups or stews, in salads, in smoothies, added to pizza or other dishes – any way you prefer! It’s okay to use a little butter, cheese, sauce, and dressing to make them more preferable to you. Farmers markets are starting up again and searching for new vegetables can be fun! Please also check out the Adult Down Syndrome Center’s resource page at [www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/resources/](http://www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/resources/) for videos and visuals on healthy eating.

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**OT Tips**

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

Being able to interact in a socially appropriate manner is an important skill in order to have healthy relationships, including friendships and romantic relationships. Individuals with Down syndrome often imitate the behaviors of others; those closest to them should act as role models and demonstrate appropriate social behaviors in their presence. In addition, people with Down syndrome can learn these behaviors from their peers, either in social skills groups or by watching videos. We often hear that families and caregivers find it challenging to teach about who and how we can touch. The Adult Down Syndrome Center (ADSC) has created a video on appropriate touch to help people with Down syndrome know how they can touch the people in their lives. It can be found on the ADSC Facebook page at [www.facebook.com/adultdownsyndromecenter/videos/10155386416123576/](http://www.facebook.com/adultdownsyndromecenter/videos/10155386416123576/). The ADSC also offers a variety of social skills groups for individuals 12 and older. If your loved one with DS is under 12 years of age, talk with the OT or SLP at school to see if they offer social skills groups in that setting.
Play with Heart — Building an Inclusive Playground

Lara Suleiman

When our daughter Jayda was born 8 years ago with Down syndrome, we were given sage advice from fellow special needs families about the ongoing struggles and successes they had with inclusion. They told us about the many doors closed when it came to school or recreational programs, or social opportunities lost because of lack of awareness or exposure to individuals with diverse needs. However, the stories of successful inclusion tipped the scale and led me to a life-long mission of advocacy for my daughter and others like her. From Mommy & Me music classes to ballet and school birthday parties, Jayda will always be fully included and celebrated in all avenues of life.

I believe ours is a story of successful inclusion because we started immediately. We were blessed to find a preschool program at the Oak Brook Park District that made inclusion a key part of their curriculum, done discretely and effortlessly. Children played alongside each other, sometimes not knowing whether they had a disability or not. Children were taught to be kind, patient and accepting of all. Because of this inclusive philosophy Jayda’s communication skills, confidence and personality soared. She continues to participate in park district programs and looks forward to their summer camp every year. The top-notch swim instructors helped make her the avid swimmer she is today.

Because of the impact the Oak Brook Park District has had on my daughter and our family, I was thrilled to find an opportunity to pay our gratitude forward by helping raise funds to build Oak Brook Park District’s SANDLOT Universal Playground Project—a playground that serves kids of all abilities. This project is a natural extension of their inclusive mission – and mine.

Playing will always be critical to social, emotional, cognitive and physical development. Even more, supporting an accessible and universally designed playground in centrally located Oak Brook makes this truly a destination playground. This project is designed to remove physical and social barriers so individuals can play alongside their peers and families. It provides things like safe, spongy surfacing, ramps, specialized seating and handholds, full fencing and opportunities for parallel play. The functional, yet fun, design fully accommodates individuals with physical impairments, or sensory needs.

The vision for this playground seems like a dream, but it can be achievable with help and support. So far $25,000 has been raised toward the efforts from generous individuals and businesses. It is estimated the project will cost close to $1 million. The goal is to complete the playground by Summer 2018.

If you would like to contribute to the creation of the playground, visit www.universalplayground.org. You can contact Lara Suleiman at laransuleiman@gmail.com or llittwin@obparks.org with any questions, or call 630-645-9521. The Oak Brook Park District Foundation is a 501 (c) 3 non-profit organization so all donations are tax deductible.

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To join the NADS Email List, go to: nads.org/contact-nads
Brush With Greatness
Young Painter on the Cusp of Discovery
Libby Elliot

This story first appeared in The North Shore magazine and was reprinted with permission.

When emerging artist Emmett Kyoshi Wilson staged his first public art exhibition late last year in Chicago and Glenview, nearly 400 people came out to view the 39 colorful canvases that comprised his debut solo show, “My Paint.”

Between the two shows, Emmett sold 67 giclée prints and canvas reproductions of his bright, whimsical paintings, making his debut art show - by all industry standards - a resounding success. But what made Emmett’s event so extraordinary was not the number of paintings he sold, or the buzz of the crowd. It was the fact that Emmett Wilson is only 12 years old. And he has Down syndrome.

What’s more, Emmett donated the bulk of the proceeds from his show to charity, giving $2,000 to The Needy Family Fund at Our Lady of Perpetual Help Church, and more than $6,000 to the National Association for Down Syndrome (NADS), a non-profit the Wilsons have regularly tapped for support and guidance over the past decade.

“Emmett is making a name for himself, and his artwork speaks for itself,” said his aunt, Glenview resident and former daytime soap As the World Turns actress Kelley Menighan. “He’s proof there’s nothing you can’t do.”

From the time his parents, Paul Wilson and Kathy Menighan Wilson, first put a brush in his hand at age 4, Emmett has painted almost daily in the small art studio the Wilsons installed inside their Glenview home, working spontaneously in short, 20-minute bursts while listening and dancing to his favorite music. With no formal training or direct input from parents or teachers, Emmett’s talent is innate; he paints with no preconceived notions of artistic form or function. “There’s a purity of expression,” said Paul. “Emmett has no ego. He just paints from his heart.”

Over the past 8 years, Emmett has amassed a large collection of paintings, many created as gifts for his parents, as well as the extended family and close friends who form his inner circle of loyal fans. A large canvas entitled “Dragon” was painted for his father’s birthday. “Nirvana,” a series of three smaller paintings, pays homage to Emmett’s favorite band. “We’ve loved everything he’s ever done, but this is the first time we’ve ever put it all together in one show,” said Kathy.

Emmett also collaborated with the Chicago-based artist Matthew Hoffman, known for his “You Are Beautiful” art installations around the city. At the Glenview show, Emmett’s parents raffled off a large “You Are Beautiful” piece of wall art bearing his signature brush strokes, raising an additional $1,500 for NADS.

After years of hearing praise for Emmett’s work, the Wilsons recently created the website emmettkyoshiart.com, and began selling reproductions of his paintings online. A large Emmett Kyoshi Wilson canvas reproduction typically sells for $250; a giclée print goes for $215. “We’re saving the originals for a museum exhibit one day,” said Emmett’s aunt Kelley. “And truth be told, my sister just can’t bear to part with any of his original work.”

Currently a 6th grader at Springman Middle School in Glenview, Emmett will receive state-funded educational services until the age of 22. His parents hope the continued sale of his art will help support him in adulthood.

“Our goal is to create a business he’ll have forever,” said Kathy. “We want him to work and be part of the community in a field where he excels.”

Emmett was diagnosed with Down syndrome five days after his birth. While still in the hospital, the Wilsons christened their son with the middle name, “Kyoshi,” meaning “teacher” in Japanese. “At the time, we said to ourselves, ‘he is going to teach us and we are going to be the students,’” said Kathy. “And that’s exactly what he’s done. Emmett is showing the world that everyone has an ability, this just happens to be his.”

Thank you to Emmett and the Wilson family for the generous donations and continued support!
Profile of: Chris Hebein
Sheila Hebein

Chris celebrated his 25th Anniversary on April 26, 2018 working as a Mail Clerk at Rotary International’s World Headquarters in Evanston, IL. Chris attended Park School, a Special Education School in Evanston, and was lucky to have a team of professionals who saw it as their job to equip him with job skills that he would be able to use as an adult. They also saw it as their responsibility to provide Chris and other students with a wide array of work experiences while they were still in school. Therefore, Chris had many jobs while he was still a student and that gave him an idea of what he would like to do after he graduated. His vocational coordinator developed a job for Chris at Rotary and trained him in the position while Chris was still in school. He also provided intermittent support during Chris’s first year of employment. Initially Chris worked part-time at Rotary and attended school part-time. He became a full-time employee after he graduated and has been working full-time ever since without a job coach, but with a team of people who have always seen his gifts as well as his challenges. I think the key to success for persons with Down syndrome is not in job coaching, although that is important, but in the team that works with the individual day in and day out.

Living in Evanston we are fortunate to have public transportation. Chris takes the Chicago Transit Authority (CTA) to work, which offers another level of independence. Again, Park School staff taught Chris to take public transportation and that also is a life-long skill.

So, Chris was really lucky to find a full-time job with benefits when he was 21, but it has taken hard work and dedication on his part to hold that job for 25 years. He is very punctual and conscientious and he loves going to work. He works with a great group of people in the Mail Center and Print Shop. Chris’ manager greatly values teamwork and she says that Chris is a valued member of the team. I remember when Chris was a little boy people would ask me what I wanted him to have when he became an adult. I used to say that I wanted him to have options in his life. I didn’t have a crystal ball and I still don’t, but now in looking back I think I would say the same thing – I want him to have options and I want him to have a good life. On June 9th he turns 46 and I would say that he has a pretty good life. I believe that Chris would say he has a GREAT life!

I encourage parents who have children in school to advocate strongly for all the services they will need to be productive adults. Always ask, “Will this teach her or him a marketable skill?” It’s the exact same question that some parents ask when their typical 18-year-olds go off to college!

Thanks!

Thank you to David Campbell for the opportunity to celebrate World Down Syndrome Day with students at Eichelberger Elementary School! NADS speakers Karen and Kelly Neville visited the school on March 21st and spoke to over 150 students. David’s daughter, Avery, is featured with some of David’s students wearing their crazy socks for WDSD.
Below are just a few of the breakout sessions for families and professionals:

The Importance of Yoga for Individuals with Down Syndrome Across all Ages
Presented by: Angela Rodriguez — Trainer & Health Coach BS Kinesiology
Navigating Nutritional Concerns Through Infancy and Toddlerhood
Presented by: Amy Manojlovsk, Registered Dietitian, Licensed Dietitian Nutritionist, Early Intervention Provider and Private Practice

Understanding and Improving Behavior — A Sensible Approach
Presented by: Diane Gould, LCSW, BCBA

The DS Biobank: Accelerating the Advancement of Research
Presented by: Lito Ramirez, CEO, Down Syndrome Achieves

Special Needs Legal and Future Planning
Presented by: Brian Rubin - Attorney and Parent - Rubin Law, A Professional Corporation

Ensuring Healthy Relationships for Individuals with Down Syndrome
Presented by: Katie Frank, PhD, OTR/L

Stages of Reading Development
Presented by: Dr. Jacqueline Brito, Literacy Coach, Children’s Literacy Initiative

Transitioning Your Baby to Solids Using the Baby-Led Weaning Approach
Presented by: Jill Rabin - Pediatric Speech Pathologist and International Board-Certified Lactation Consultant - New Mother New Baby and Private Practice

Sibling Support
Presented by: Amy Halm, LCSW, Sibling Leadership Network (SLN) & Supporting Illinois Brothers and Sisters (S.I.B.S) and Emily Bryan, Arc of Illinois Board Member

Full descriptions of each breakout session, along with additional information and links to register, are available at www.nads.org/events/nads-conference-2018.
Local Business Honors World Down Syndrome Day During Monthly Kindness Initiative

Tracy Janowitz

On the 21st of every month I share kindness. This is a statement that echoes throughout my athleisure clothing brand sweatyswag. On the 21st of each month I wake up with the intent of sharing kindness with strangers in my community in hopes to inspire others to create opportunities to share kindness. A woman I met last year, who has a daughter with Down syndrome, told me that March 21st is World Down Syndrome Day (WDSD). Since my monthly Kindness Initiative falls on the same date, I wanted to celebrate Down syndrome for my March project!

My clothing is designed for the everyday. I am inspired by everyday people so it just makes sense that my acts of kindness revolve around people we meet, well, every day. When I started to think of how I can highlight kids with Down syndrome it began with my t-shirt design Kindness is Special. 21% of the shirt sales benefit Special Kids Day, a non-profit organization in Elmhurst, IL that consistently creates events and programs for kids/adults with special needs. I am passionate about creating these acts of kindness because I have small children. I want to tell my kids to be kind and show them, and I want to include them in these acts of kindness. I want to show them that even though they are small, they too have the power to influence and impact someone in a positive way and create the world they want to live in.

In March, we invited friends with Down syndrome to celebrate WDSD at our gym, Patriot Sports and Fitness, with obstacle courses, soccer, tug-of-war, cake, balloons, and of course a dance party! This event was to celebrate kids with Down syndrome and all that makes us different, but more importantly all that makes us the same.

I believe kindness toward each other can literally change the way we view ourselves and the world - and that is special. Everyone is worthy of being recognized, celebrated and loved. I truly believe that small acts of kindness, every day, can change the world we live in. To learn more the Kindness Initiative or to purchase a Kindness is Special t-shirt, visit www.sweatyswag.com. You can also visit www.specialkidsday.org to learn more about upcoming events.

Pink Pewter Provides Makeovers to Celebrate World Down Syndrome Day

Mereya Villareal

Pink Pewter, a local business in Bartlett, Illinois that manufactures hair accessories and cosmetics, invited in five lovely young ladies from NADS to be a part of a “girls day out.” Each young woman was provided a wardrobe, hair accessories, up-do and make-up to fit their unique style and personality. Our goal was to participate in an event to empower these young women and promote inclusiveness in our community during the month of March to promote World Down Syndrome Day and Down syndrome awareness. The event was broadcasted by NBC and Telemundo. The newscast can be viewed on the NADS website at www.nads.org/beauty-brand-gives-makeovers-on-world-down-syndrome-day. You can find out more about Pink Pewter at www.pinkpewter.com.
A HUGE THANK YOU

to DS Support for their generous donation of $11,000 from the 2017 Chicagoland Buddy Walk and for their ongoing support of the Down syndrome community!

Be sure to SAVE THE DATE for this year’s walk on October 7, 2018! Registration is now open at chicagolandbuddywalk.org.
ON THE TOPIC OF:

Summer Plans

Nancy Goodfellow

It’s crazy to think how early we have to start planning for summer. Registration for most camps opens in January or February, and I actually stayed up until midnight one night so I could register my typically-developing daughter for camp as soon as registration opened to ensure her spot.

Much like every other aspect of Lily’s life, ensuring that she is happy, active and engaged during the summer months requires organization and preparation. This is the first year that Lily will actually be going away for camp... so there is a lot to prepare for! I’m using it to my advantage though. Every time Lily asks for help getting dressed, brushing her hair, pouring milk into her cereal, etc., I simply respond, “You need to do that yourself. I won’t be there to help you at camp.” I get an eyeroll in return, but she is excited to go to camp, so she ultimately completes the task on her own.

Lily will also be working for the first time this summer. We have been active members of our neighborhood pool for years, so the staff was extremely gracious when I asked if Lily could apply for a clerk position. I made it clear that I didn’t expect her to be a paid employee, but she will be assigned shifts and expected to do the same job as everyone else. She’ll be accompanied by one of the paid staff, but only to oversee and help when needed. The pool manager was incredibly receptive to the idea and even had her come in for an interview in January just like the other applicants. We are now preparing for the job by practicing how to greet members as they arrive at the pool and ask for their names, as well as perfecting skills like taking out the garbage and cleaning the bathroom!

However, there have been plenty of summers when I have found that May has arrived and I have yet to make plans. For those who may be in that same boat this year, the best place to start is your local special recreation association (SRA). The SRAs work in conjunction with local park districts to provide assistants for campers with special needs, but also provide their own camps and programs. You can go to www.specialrecreation.org to find a listing of all SRAs in Illinois by city. You can also view a list of summer camps in a previous issue of NADS News online at www.nads.org/wp-content/uploads/2017/08/NADS-News-May-2017-Final.pdf.

Spice Shop Featured on Local News

A Pinch of Happiness, Spice Shop in Oswego, IL, is dedicated to providing opportunities to individuals with intellectual disabilities. Rebecca Christiansen has a son with Down syndrome and is the founder of Celebrate Differences, an organization committed to creating a place for families of children with disabilities to feel a part of a larger, accepting community. This mission led to the creation of a spice shop that was recently featured on Channel 7 news. Christiansen says the goal is for employees to “go through our program, they work here for a couple months and then we try to find them employment outside of the spice shop. So the idea is that someone with disabilities doesn’t come to the spice shop and work here all the time, it’s to get the training and get the skills to be able to move out into the community.” The full report can be viewed at abc7chicago.com/business/oswego-spice-shop-servesup-opportunities-for-adultswith-disabilities/3194254/. For more information, visit www.celebratedifferences.org and www.pinchofhappiness.com.

50th Anniversary of Special Olympics Celebration in Chicago

The first ever Special Olympics Games were held at Soldier Field in 1968, so it is fitting that Chicago serve as the global stage for celebrating the 50th Anniversary year. A series of exciting, historic events will take place in July including a Global Day of Inclusion at Soldier Field and a Celebratory Concert at Northerly Island on July 21st. Families and athletes are encouraged to attend, and there are many volunteer opportunities available. Visit www.specialolympics.org/50th.aspx to learn more.

Opportunities to Participate in Research Studies

NADS frequently receives requests for members to participate in research studies. Two current studies are looking for parents or primary caregivers of young adults with Down syndrome who have stopped attending high school within the past 5 years, or caregivers of individuals who have both intellectual disabilities and dementia. If you fit the requirements and are interested in participating in either of these, please contact Chris Newlon at cnewlon@nads.org.

The young adults in NADS Partnership Advocate Council (PAC) made blankets for the Linus Project as their latest service project. The blankets will be distributed to hospitals, shelters and social service agencies to help comfort seriously ill and/or traumatized children. Thank you to all who participated. To learn more about the Linus Project, go to www.projectlinus.org.
Membership Application

Membership dues can be paid online at www.nads.org

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Address............................................................................................................................................
City............................................................................ State............... ZIP...........................................
Phone (home)..................................................................................................................................
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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: (check one)
- Contributor
- Benefactor
- Patron ($100 +) ($500 +) ($1000 +)

- Check if Renewal

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