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FROM THE PRESIDENT'S PEN

*By Nagla Moussa*

You know that picture of one set of footprints in the sand and the story that goes with it reminding everyone that during times of trouble when you see only one footprint in the sand and you wonder where God's footprint is that walks with you as He promised; then God answers that there is only one set of footprints in the sand because He is carrying you. The other day I found myself reminding God that he needs to carry me and that I was unable to walk any longer. Stress and difficulties are very difficult at times, and when that thought came into my head, I realized that I've been trying to ignore my stress and just logically think of what I can do to get through the hard time I was experiencing without dealing with my emotions. I was fearful that if I let go and gave in to my feelings I would drown and not be able to deal with the very difficult circumstances I found myself facing.

Looking around me, I can think of at least 20 different families who have children with autism dealing with very traumatic circumstances beyond the normal day to day problems that ensue with having a child with autism. Problems like divorce, onset of seizures, aging parents who need them and are very sick, sudden worsening of behaviors and school difficulties, losing a job and having to move, the list goes on and on. These circumstances are extremely stressful and we so often just try to put one foot in front of the other to keep going, and we neglect our feelings and the severe stress we are experiencing. Then we pay the price, a heavy price that we didn't expect. Our health suffers, our marriage suffers, our children suffer, and our mental health suffers.

Staying in touch with your feelings, acknowledging the stress you are feeling, and doing something to relieve it is crucial. I'll say it again because it's important, acknowledge your stressful situation and take care of yourself! Look around you, find a sympathetic ear and people who can help you deal with the stressful situation you are facing. Ask for help and don't be shy. Find some time to do something that rejuvenates you, it can be as simple as making some time for a bath, to read a book, to sit and watch a show you enjoy. Stay in touch with yourself and how you are feeling on a regular basis. Recognize when you are very stressed and allow yourself to acknowledge that you have every right to your feelings, it's a difficult situation you face after all. If you need to seek professional help, like counseling do it! Don't sweat the small stuff, the laundry will keep you can always pick up some inexpensive underwear and t-shirts at Target, the house can be cleaned another day, and the grocery store does have rotisserie chicken available for a quick dinner. Intentionally think about things

## FROM THE PRESIDENT'S PEN

that are going well, pat yourself on the back for what you have already done to deal with your stressful situation and give yourself credit for how hard you work. Reward yourself with a massage when time allows. A massage can help relax you, release stress from your body and help you focus on what needs to be done. Finally get some sleep. Sleep is elusive when we are very stressed. Our brain can be very busy thinking of our problems instead of shutting down and allowing us to sleep. Being aware of that helps us to intentionally do things that will make it easier to sleep. Personally I diffuse some lavender essential oil at bedtime, I try to take a 20 minute Epsom salt bath and read a book.

I'm dealing with the stress I'm experiencing better, but I also realize that it is ongoing so I have to stay vigilant and not allow myself to ignore my stress. I wish you all a stress free winter, but if you do find yourself stressed, I wish you a healthy way of dealing with your stress.

## UPCOMING EVENTS

### **Lyme Disease from Diagnosis to Treatment with Dr. Amy Offut M. D.**

Dr. Amy Offutt is the founder and owner of Wellness Works, a functional medical practice located in Marble Falls, TX. Dr. Offut believes in treating root causes of illness and not just symptoms. Dr. Offut has a great deal of experience treating Lyme disease. Join us to learn about diagnosing LymeDisease, and all the different treatments available.

Please RSVP for this meeting by emailing: [nagla\\_alvin@verizon.net](mailto:nagla_alvin@verizon.net) <mailto:nagla\_alvin@verizon.net>

When: November 1st, 2016 7pm

Where: St. Andrew United Methodist Church, Theater Rm, 2nd floor, 1401 Mira Vista, Plano, TX 75093



### **Annual Holiday Party**

It's time for our annual holiday party. Bring your entire family to this not-to-be missed event where the kids take a picture with Santa, make crafts, play in a bounce house and enjoy holiday lunch and allergen free desserts. This is one holiday party where your child can be their true self. Admission is free

When: Saturday, December 10th, 2016 11:30a.m.- 2:30p.m.

Where: Prince of Peace Catholic Community (Cana Center) 5100 Plano Pkwy Plano, TX 75093

# MONTHLY SUPPORT GROUP MEETINGS

## Parent Get Together and Support Group Meeting

For parents of children with autism of all ages:

When: 2nd Tuesday of each month, 9:30a.m.-11:00a.m. and 3rd Tuesday of each month, 11:30am — 1:00pm, during the school year

Where: Corner Bakery, 941 N. Central Expy, Plano (Near Collin Creek mall)

## Spanish Parent Get Together and Support Group Meeting

For parents of children with autism of all ages - meetings will be conducted in Spanish

When : 1st Saturday of each month 6 7 pm – 8:30 pm

Where: St. Mark Pastoral Center 1100 W. 15th St. Rm 202 Plano, TX  
Hosted by : Rose Henke , July Talevara Bekker, and Jesus Betancourt

## Self-Advocacy Group

For Teens (7th Grade and up) & Adults with Autism Participants will learn about autism and its' effect on their lives while developing a great appreciation for their individual gifts and talents. It is important that participants know they have autism. Trained volunteers including some with autism, facilitate this group. Bring an object, book, picture or other item that represents your talents and interests, \$5.00 to pay for pizza, snacks and drinks.

When : Tuesday, May 3rd, 2016 at 7:00 pm

Where : St. Andrew UMC, 1401 Mira Vista Blvd. Please check in at the Theater room upstairs on the 2nd floor), Plano, TX 75093



Do you have a teenager or older family member?

## Sibshop Group

Siblings ages 6 to 10 years old will have a fun time with activities, snacks and friends who share their same experience of having a brother or a sister with ASD

When: November 5th, 2016 7 pm – 8:30 pm

Where: St. Mark Pastoral Center 1100 W. 15th St. Rm 201 Plano, TX  
Hosted by : Rose Henke Please RSVP Rosehenke@yahoo.com <mailto:Rosehenke@yahoo.com>

# COMMUNITY EVENTS

Another memorable NAA-NT Mom's Day out was hosted on Sep 18th, 2016! 160 moms got to enjoy a day by the pool with refreshments, massages and yoga class. That was followed by a delicious dinner, and inspirational talk from our fellow warrior mom Dawn Neufeld and amazing raffle gifts! Thank you to all our volunteers who helped make this happen, and to all our generous sponsors for helping us pamper this group of deserving moms!



# COMMUNITY EVENTS



## Mom's Event Sponsors

### Diamond Platinum Level

NAA-NT

Concept Connections - Jenny Keese BCBA

### Gold Level

Secure Benefit Services, LLC - Steve Duncan

Help Hope Solutions – Cristina Busu BCBA

Glen Eagles Country Club

Arthur Murray Dance Studio

### Silver Level

University Park Counseling and Testing Center – Erica Sewell LSCW  
Sherry and Scott Pearson

Progressive Pediatric Therapy – Neneitte Tabani OTR

Top Pediatric Therapy – Betsy Williams OTR

Speech and Occupational Therapy of North Texas – Becky Hary SLP

All Behaviors Considered – Archana Dhurka BCBA

The Wayman Center – Gail Wayman BCBA

Speech TX – Julie Liberman SLP

Therapy and Beyond – Regina Crone PHD

Hair by Amy – Amy Beechum

Easter Seals North Texas

Rose and Scott Henke

Foga de Chao

Body Bar Pilates

Tone Artistic Massage & Spa

### Bronze Level

Beckloff Pediatric Behavioral Center

Stacy's Sensory Solutions

Pala Photography – Jill Hornok

The Behavior Exchange – Tammy Cline BCBA

Lakewood Brewing Company – Linda Busch

Leah Tesfa

United Through Hope

Geisha Grill

Wholesome Grub

A1 Nails



## COMMUNITY EVENTS

On September 23rd, 2016, NAA-NT hosted a bubble ball fun event for kids with autism at PSA II. 40 kids with autism enjoyed a sensory experience through this event, which was sponsored by the Ernie Ems Foundation, PSA II and Dallas Bubble Soccer LLC. A huge thank you to our sponsors for making this much-awaited event possible.



## Nicole Wallace

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According to the Merck Manual website. A gene is a segment of DNA containing the code used to synthesize a protein. A chromosome contains hundreds to thousands of genes. Every human cell contains 23 pairs of chromosomes, for a total of 46 chromosomes.

When we discuss genetic testing, **what are we really testing?** The Chromosomal MicroArray (CMA) looks for missing and extra regions of chromosomal material across every chromosome, not just one specific region on one chromosome. Whole Exome Sequencing (WES) looks for changes at the level of individual genes. Courtagen has several tests, one that looks in depth at about 1000 proteins that play an important role in mitochondrial processes and another that is specific to markers involved in epilepsy. 23andme tests variations in the DNA sequence at particular locations, called single nucleotide polymorphisms, or SNPs (pronounced "snips"). As parents we really want to know, can any of that data, help us determine the best supplements or medications to help our children live long, healthy, prosperous, rewarding lives. Or can we do anything with the information from the test results?

CMA and/or WES are more traditional labs that may be ordered by your primary care doctor, neurologist, or possibly your developmental pediatrician. Each may be covered by insurance and may be useful if abnormalities are found. Two newer genetic labs being used in the ASD community are Linegan and Courtagen testing. Courtagen's CEO, Dr. Boles, spoke at the Autism Education Summit held in Dallas in September. Dr. Boles shared some compelling cases showing how his company's testing could lead to useful treatment in some children. One of Courtagen's tests is the EPISEEK which is designed to provide genetic analysis of epileptic and seizure disorder phenotypes. It also includes a drug metabolism guidance for 24 classes of anti-epileptic drugs. Another test NucSeek shows genes associated with mitochondrial disorders which is a concern in our population. And yet another is for neuro-developmental disorders.

The test results must be interpreted by the ordering physician. Fortunately Dr. Boles spends most of his time going over tests with doctors and teaching them how to interpret results. Curious doctors will take the time to learn how this testing can help their ASD patients. In Facebook groups it has been shared that Courtagen testing was extremely helpful in some cases, and not particularly helpful in other cases. Courtagen works with insurance and has a program that helps family with the cost of the testing.

The other type of genetic testing you often read about is SNP testing. There are several companies offering SNP testing. Single Nucleotide Polymorphism - SNPs are the most common type of genetic variation among people. Each SNP represents a difference in a single DNA building block, called a nucleotide. Dr. Amy Yasko was doing SNP testing and interpretation ten or more years ago and she still is. Dr. Ben Lynch made it more popular with his MTHFR.org website.

Today 23andme is a cost effective way to learn about your personal SNPs. You can order this test online without a doctor. 23andme is marketed as a way to learn your ancestry. Years ago when it first came out, health reports or SNPs related to serious illnesses like Alzheimer's were shared with the client. But the FDA got involved and health reports were stopped and interpretation of the SNP data by 23andme was removed.

## GENETIC TESTING - WHICH ONE IS RIGHT FOR ME?

Today you can run the raw data provided by 23andme through several different programs (for a price) like GeneticGenie, Prometheus, LiveWello, Nutrahacker, StateGene or MTHFRsupport program to get more

information. Genetic Genie creates a short report related to methylation. It analyzes 26 different genes. MTHFRsupport has about 20 pages of over 200 SNPs and is separated into categories like detox, thyroid, methylation, mitochondrial and allergy. Prometheus provides risk factors for many conditions and your likelihood for interaction with about 100 common drugs. Nutrahacker lists gene function, possible consequences, this to consider and things to avoid. LiveWello is very comprehensive and would give geek hours of fun reading. StateGene is Ben Lynch's ([mthfr.org](http://mthfr.org)) latest SNP program.

For most of us, it is most helpful to have someone knowledgeable interpret the data for you after you run it through one of these programs or allow the practitioner to do it for you. The analysis programs indicate which supplements may be helpful.

The bottom line is that there is still much to be learned from genetic testing in autism. And you will likely have to do some legwork for genetic testing to be helpful to you. You might have to seek out a geneticist for CMA or WES testing, a PCP or functional ASD doctor for Courtagen or Linegan testing and a naturopath to read your 23andme test results. All these tests may help with determining the more effective medication or supplements, may help only to rule out known abnormalities, or may not be of much help at all.

*Nicole Wallace is a warrior mom , who through her support and knowledge, has been an invaluable resource to the autism community. She works as a Care Manager at the Kotsanis Institute in Grapevine, TX. The information provided in this article is her opinion, and cannot be substituted for medical advice.*

## PLEASE SUPPORT OUR SPONSORS

St. Andrew United Methodist Church

Region 10 Educational Service Center

Concept Connections-Jenny Keese

RBC Wealth Management (Plano)

Junior League of Collin County

Therapy and Beyond - Regina Crone Ph.D

The Behavior Exchange - Tammy Cline-Soza

Help, Hope, Solutions – Cristina Busu

Gordon Biersch Restaurant/Kraft Works Corporation

## PARENT RESOURCE PACKET

Looking for an autism friendly pediatrician, dentist, private school, hair salon, attorney , therapy providers for speech, OT, ABA, or just about any services that make your child lives easier?

Email **Nagla Moussa** at [nagla\\_alvin@verizon.net](mailto:nagla_alvin@verizon.net) for a comprehensive parent resource packet. It's invaluable!

## Amy Offutt

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### Could Your Child Have P.A.N.D.A.S. or P.A.N.S.?

Modern times have brought about some interesting culture shifts in parenting and growing up. Only 100 years ago, it was commonplace for children to die from acute infections. In fact, my grandmother was the second born of 9 children and lost 4 siblings before any of them reached the age of 10. My grandmother's mother also died in childbirth when my grandmother was only 16 years old. When I consider what it might have been like to be a mother and/or a doctor in the United States in 1916, I am amazed at what has changed. In 1916 (only 100 years ago),

- 8% of homes had a telephone
- 6% of adults had graduated from high school 10% of all babies died before the age of 1 year 20% of all children died before the age of 5 years

Clearly, times were different. One hundred years ago, when a child had a behavioral issue or a developmental delay, the strategy for care was much different from now. If the unusual behavior or developmental issue was mild, the child stayed home with his parents and was considered "different" or if moderate to severe, the child was placed in a home for children with disabilities. Because of poor sanitation, limited education, and lack of therapeutic interventions, kids were just the way they were, and parents were grateful if their children survived childhood.

Now, I see medical technology everywhere. Parents are protective and child mortality is (thankfully) very low. We have made great strides in eradicating infections before they become life-threatening in a majority of cases. However, I now see some conditions that were not described 100 years ago, and I have to wonder what has happened that could have created these new conditions or disease states. One of these new conditions is P.A.N.D.A.S. or P.A.N.S..

### Could your child have P.A.N.D.A.S. or P.A.N.S.?

The two conditions are both relatively new terms in the medical world. Both are describing Pediatric Autoimmune Neuropsychiatric conditions. These conditions are estimated to affect 1 in 200 children. In basic terms, both diagnoses may be considered for a child with new onset neuropsychiatric symptoms (mostly considered for new onset obsessive-compulsive symptoms and / or tics) that start after an acute (or fairly recent) infection. The following list of questions for parents are provided to heighten awareness of the possibility of these conditions. This is not diagnostic but rather a good list of screening questions:

1. Did any of the following symptoms arise after a sore throat or upper respiratory infection (within approximately the past 24 hours to 6 months)
2. Obsessive-compulsive symptoms (fear of dirt or germs, fear of contamination, a need for symmetry, order and precision, religious obsessions, preoccupation with body wastes, lucky and unlucky numbers, sexual or aggressive thoughts, fear of illness or harm coming to oneself or relatives)
3. Anxiety
4. Extreme moodiness and / or depression
5. Irritability or aggressive behavior
6. Learning / cognitive symptoms / confusion
7. Behavioral regression

## HOLISTIC HEALING FOR PANDAS

8. Sensory symptoms
9. Hallucinations
10. Motor symptoms
11. Urinary symptoms
12. Sleep disturbance / fatigue
13. Dilated pupils
14. Tics / twitches

As I review this list from the perspective of a physician, I can see that many of the children that are seen in a doctor's office may need to have this condition considered as a possibility. Parents and concerned family members, as advocates for children, can also bring heightened awareness to this possibility when visiting a physician for specific health concerns.

As this condition can cause significant problems for kids and their families, a roadmap for recovery is part of what has to be created for each individual once the condition is suspected and diagnosed. I use an integrative medicine approach to this condition that includes:

1. Nutrition - attempting to alkalinize the body to decrease inflammation
2. Sleep - optimizing rest to promote healing, restore energy and improve immunity
3. Detoxification - checking for toxicities that impede healing and working to remove them
4. Boosting healthy digestive flora - this interacts much more closely with the brain than many realize
5. Treatment - prescription medications and / or herbal appropriate options to eradicate infection/ colonization
6. Environment - education and support from external sources promotes healing

From an integrative health perspective, I must question the deeper underlying causes of these symptoms. In other words, what made this child susceptible to this condition? What patterns should I be watching for if I wish to prevent problems such as these? If I can thoughtfully approach such a condition, is it possible to find an underlying cause? If I can find an underlying cause, is there a possibility of reversing or alleviating the symptoms?

As I mentioned, a lot has changed in the past 100 years. Many of these changes were at a pace greater than could have been imagined at that time in history. However, the doctors of that time had great anticipation of progress as is seen in the editorial comment from the New England Journal of Medicine from 1912:

"Perhaps in 1993, when all the preventable diseases have been eradicated, when the nature and cure of cancer have been discovered, and when eugenics has superseded evolution in the elimination of the unfit, our successors will look back at these pages with an even greater measure of superiority."

Clearly, the doctors of that time had high hopes for future generations. I am not sure what was special about 1993, but I do have optimism that the human spirit of hope and inspiration can reveal helpful information and contribute to the healing of our children and our families. I look forward to sharing more with you during the fall conference!

*Dr. Amy Offutt is the founder and owner of Wellness Works, a functional medical practice located in Marble Falls, TX. Dr. Offutt believes in treating root causes of illness and not just symptoms. Dr. Offutt has a great deal of experience treating Lyme disease. She can be reached at belladoc@yahoo.com.*

## DO YOU SHOP AT AMAZON?

Support families with Autism all year round just by doing your normal shopping!

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National Autism

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## DO YOU HAVE A CHILD THAT WANDERS?



Keep your  
child safe!

The National Autism Association's Big Red Safety Box is back in stock! If you have a child that wanders or know one that wanders, please click on this link <http://nationalautismassociation.org/big-red-safety-boxes-now-available/> to learn how you can get this box with tools to help keep children with autism safe.

## BUYING OR SELLING A HOUSE?

We are excited to have the generous support of a real estate agent, Kirk Iverson! Kirk will donate 25% of net proceeds directly to NAA-NT anytime someone buys or sells a home and mentions NAA-NT as a referral.

Check out his page <https://www.facebook.com/kirk.iverson.942?fref=ts> or <http://BuyHousesSellHomes.KWRealty.com>

Support our  
sponsor

## Betsy Williams

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Occupational therapy is frequently recommended when children get an early diagnosis of autism. Frequently OT is recommended due to possible concerns with gross and fine motor delays and/or behaviors associated with sensory processing disorders. Many times our kiddos reach a point in their occupational therapy when they can be discharged. Other times, occupational therapy is still recommended in later childhood and during the teenage years. Many of my clients have been with me for several years and while their progress has been good, there are still areas of concern that warrant continued occupational therapy. Some children also get referred for occupational therapy at a later age when some clinics believe their window for progress is closed. Here are some things to think about when deciding to start or continue therapy with your older child or teen:

1. **The brain continues to make changes.** We see progress at all ages. Our brains are amazing and continue to form new pathways and change current pathways based on experiences. Getting a later start on sensory motor therapies or continuing therapy can still develop these pathways and help your child feel better and work more efficiently in their bodies.
2. **Revisit your child/teen's sensory diet.** Fill out a daily schedule and see when your child is most needing sensory input. Test your tried and true activities and see if they still work. Try out some new activities and see if these simple changes work better during your child's day.
3. **Get a fresh set of therapy eyes on your child.** We frequently share clients at TOP. I love this because we all get used to doing the same things. When we get a new therapist into the mix, they bring their expertise into the team and we usually see a jump in progress. New therapists have new ideas to help with the ongoing concerns.
4. **Revisit programs that helped them in the past.** We frequently start therapy and use several sensory protocols and tools (Wilbarger, various listening programs, reflex integration, interactive metronome, to name a few). As our children progress in therapy we phase out these protocols when they may still be beneficial to them.
5. **Focus on more independent life skills.** Continue to make sure sensory systems are regulated so that goals can be met in the area of life skills. Use of visual schedules help in working to sequence tasks or remind our kiddos to perform a list of skills or chores.
6. **Find a social group.** Social groups are a fun way for our children and teens to learn assertiveness, problem solving, other interests, interpersonal and social skills, independent living skills, self-awareness, stress management, wellness, etc... A social group can be clinic based or more community based such a youth group, work out or a running group.



The most important part of any therapy is carry over at home and school. As

## OCCUPATIONAL THERAPY FOR THE OLDER CHILD

occupational therapists we see your children for 1-2 hours per week. Continued work at home with the parents is the most important part of any therapy program. Make sure you really understand the programs and homework that is being suggested for home so that the most progress can be made.

Lastly, know that breaks from therapy are okay. Decide if you (and your child) just need a break. It's okay to take a break from therapy. Most of my parents understand their child's sensory system way better than I do. Our children understand too and typically know what types of input their bodies need. Parents and children know what types of input are needed and when to help their bodies feel better. When a break from therapy is needed, I support it and my clients know that if sensory needs change or behaviors change, they are always welcome back at TOP and I am available during their breaks and after.

There are lots of books and literature out there for our older kiddos and teens with sensory processing disorders. Here is a list of wonderful books:

The Out-of-Sync Child Grows Up: Coping with Sensory Processing Disorder in the Adolescent and Young Adult Years by Carol Kranowitz

The Sensory Team Handbook: A hands-on tool to help young people make sense of their senses and take charge of their sensory processing by Nancy Mucklow

Too Loud, Too Bright, Too Fast, Too Tight: What to Do If You Are Sensory Defensive in an Overstimulating World by Sharon Heller

*Betsy Williams is the owner of TOP pediatric therapy, providing Occupational Therapy and Speech and Language Therapy for children with autism and other special needs. She can be reached at [betsy@toppediatrctherapy.com](mailto:betsy@toppediatrctherapy.com)*

## NAA-NT BOARD

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**Did you know that ....**

- all the money the NAANT raises goes directly to help families dealing with autism in the North Texas area?
- the NAANT uses donations to educate and serve our community by holding educational and advocacy seminars?
- the NAANT gives grants to local families with annual salaries below \$50,000 for autism treatments?
- the NAANT works with the law enforcement to ensure the safety of our kids?
- the NAANT holds weekly parent support groups including one in Spanish?
- the NAANT provides fun events to help families dealing with autism relax?
- the NAANT provides support for autism couples and financial assistance for counseling?
- the NAANT has an online parent and professional support yahoo group: <http://health.groups.yahoo.com/group/ascc2/> ?
- the NAANT has a Parent Resource Packet that is free?

The National Autism Association of North Texas (NAA-NT) is a 501C3 chapter of the National Autism Association (NAA). The mission of the National Autism Association is to educate and empower families affected by autism and other neurological disorders, while advocating on behalf of those who cannot fight for their own rights. By donating to NAANT you are helping children and their families who live in our community.

*"No person was ever honored for what he received. He was honored for what he gave." – Calvin Coolidge*

**NAA-NT honors each and every one of our contributors that have made all of the above programs possible.** It is from what you give that our families are able to move forward with success. Please consider a donation of any denomination. With your help, our new year will bring many new beginnings for our families affected by Autism.

Donations can be made by check to PO Box No. 261209 Plano, TX 75026-1209 or online at: <http://naa-ntorg.eventbrite.com>

This letter can serve as your tax deductible contribution receipt.

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