



Goings on in the Gardens



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Who we are

Nicky's Gardens of Hope is building permanent homes for autistic and intellectually developmentally disabled (IDD) adults. We provide progressive services for an inclusive community, such as employment training, on-site business opportunities & family support & lodging. We are dedicated to providing a revolutionary level of care for America's rapidly growing and aging Autistic and IDD population.

Join the Revolution!

"The harvest is plenty, the workers are few."

Get involved: Donate and/or volunteer

Our contact information

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Update on Recent NGOH Events & Social Media

*As you can see from pictures, our first ever Gardens Gathering went off without a hitch last month on August 17th at Rainey Park in NYC. We had a decent turnout for a first time event and were able to spend time getting to know each other, enjoying some Autism friendly foods, and other treats. The children enjoyed art activities and games as well as the playground. We will look forward to hosting another similar event this fall.

*Our group support phone call for IDD/Autism parents/caregivers happened on August 20th and a few parents spent time chatting about their current challenges and offered support and encouragement to each other. We hope to schedule another group support call soon.

*Adriana, Thomas VanAntwerp & Chris Nicolls met with Naureen Akhter, Deputy District Director, Representative Alexandria Ocasio-Cortez to share information on NGOH. AOC is passionate about IDD employment & intergenerational living & housing! She might be helpful with helping NGOH be known as the voice of all IDD locally. A fruitful meeting!

*Adriana was interviewed by Maria Dornfer of BOLDTVon NGOH-release date as yet to be announced.

*NGOH sponsored podcast, TSC Talks, hosted by Social Media Director, Jill Woodworth did an interview with New Paltz Chief of Police and another officer on their "Occupant with Autism" initiative. Give it a listen! Recent Media (click text to follow): Adriana's Newest Podcast: Max's podcast Adriana's blog on Scary Mommy Adriana's First Podcast IDD & ME: I Wish He Could Talk IDD & ME: Max, Alex & Nicky There Is No Other Choice



Family Perspective

Back to School

So, now summer has past and Jack just started back to school. He had a decent summer and is now attending the “post-grad” program at his local high school. The following post was written the day before he “graduated” and brings to light the fact that many young people with some measure of a disability are not able to receive a high school diploma due to circumstances beyond their control. I was all fired up about this huge issue at the beginning of the summer, but time and more emergent challenges have pulled me away from the fierce frustration I feel when I think about all the loose ends left for Jack to navigate as he works to obtain the skills and knowledge he’ll need to move to counter the lack of an official high school diploma and seek to reach his personal goals of a job, a car, and some measure of independence.

Disability employment continues to be a challenge for many and while there seem to be more and more forward-minded options available, there are often many pieces of this puzzle that have to be considered on behalf of the individual who is seeking such services. Pieces that are often not a part of most of the programs offered through various employment rehabilitation services such as Mass Rehab Commission and other disability hubs that offer tons of options but little thought given to the daily realities of families needing to utilize said services for their loved ones. The main one I would like to mention is transportation. Public transportation is scarce in rural and even suburban areas. Parents & caregivers and/or other family members are often unable to provide transportation consistently to either the place of employment or training program or to other social events designed for those with similar challenges. What seems like a minor issue can often become a major barrier. So as Jack progresses in his “post-grad” program and is able to find some employment opportunities, I am hoping that we will be able to find creative workarounds to enable him to participate.

My son, Jack, 18 with moderate Tuberous Sclerosis Complex is “graduating” from Wachusett Regional High School this very evening. He’s getting a certificate of completion, NOT a high school diploma, which I signed on to for several reasons. Mostly because of TAND. What is TAND? It is land of confusion, is what it really is, but it stands for Tuberous Sclerosis Associated Neuropsychiatric Disorders and is basically the encompasses the entire umbrella of mental health diagnoses.

People that have TSC have a 90% chance of having some degree of TAND and not to digress, but it can be THE most challenging aspect of a TSC diagnosis and often hits just when one has about had it up to the eyeballs with other aspects of TSC. So imagine as a parent, you’re trying to get a handle on your kid’s life-threatening seizures,

stay on top of kidney manifestations, make sure you’re keeping up with the 55 or so prescriptions that need filled, refilled, negotiated, covered by insurance, taken your kid for various pokings and proddings such as blood tests, MRI scans, neuropsychiatric evals, school IEP meetings to name a few....and then, just when you pause to catch your breath, your kid starts acting like a wild animal. Seriously. An uncaged wildebeest. No one knew.

There were whisperings and mutterings of “behaviors associated with TSC” and some writing on it, but not anything that was solid enough to catch the attention of professionals working with those impacted by these unbelievably intense behaviors.

This complete lack of understanding of TAND hijacked his entire educational experience up until about 3 years ago when things started to shift. We had to resort to dire measures including 3 psychiatric placements, locks on all our food and a lot of structure at home, routines, integration of mental health professionals, his medical team and his educational team to address his TAND related issues (aggression, rage, violent outbursts, anxiety, ADHD...probs more I can’t think of). He is now able to manage his behavior without escalating to the point where we have to ride out the TAND wave of anger/frustration/grief/sorrow, 80% of the time. Which is huge, coming from a kid that was attacking me, threatening and terrorizing his siblings, his teachers, his therapists, and basically raising unbridled havoc for a long time period. It was painful to experience for all of us and that certainly includes Jack.

As “graduation day” has been approaching and I consider the implications of this choice, I feel the need to share a glimpse of Jack’s story. I am offering a disclaimer at the start so those who might sense they need to brace themselves for a sob story or an angry rant, or a gut-wrenching tale of victimhood and persecution, you need not. The fact that this is happening is that there is no one to blame and doing so would only create further divisiveness and my goal in sharing this glimpse is to encourage connection and collaboration.

As I mentioned earlier, Jack was born with Tuberous Sclerosis Complex which is a condition that causes benign tumors to grow in different organs of the body. Jack started having seizures very early on in life and has been on many different medications to control his seizures. He’s also on many other medications to manage other aspects of his TSC, such as blood pressure medicine and one that controls the growth of tumors in his kidneys. Jack has had many hospitalizations, medical procedure, tests, and appointments and will need to manage the medical aspects of his disease for the rest of his life. While he is medically stable, and the prognosis is good for a typical life span, that requires close monitoring, frequent communication with his doctors and the pharmacy and much more.

Jack had seizures that lasted over 2 hours. Jack also had to change schools about 7 times during the course of his education within the WRSB to classrooms that were able to support the level of need his disability presented. There were no adequate programs for Jack anywhere that we could find because his behavior was so challenging.

“Tuberous sclerosis complex (TSC) is associated with a wide range of cognitive, behavioral and psychiatric manifestations. These manifestations are often of greater concern to individuals with TSC and their families and caregivers than other symptoms of TSC such as epilepsy, skin lesions or kidney problems. TAND (TSC Associated Neuropsychiatric Disorders) is a new terminology to describe the interrelated functional and clinical manifestations of brain dysfunction in TSC, including aggressive behaviors, autism spectrum disorders, intellectual disabilities, psychiatric disorders, neuropsychological deficits, as well as school and occupational difficulties.”.

Jack went through 3 psychiatric placements and many years of intensive therapy to learn to manage his behavior to the degree that he was able to learn to read. His behavior was so frightening at certain points that we thought he'd need residential placement. He was attacking his own family and we all needed to work together as a team to help support Jack as he started to learn to manage his own behavior.

Jack also had problems managing his impulsivity in relation to food. Because of his increasing weight and metabolic issues, his family went to desperate measures to limit his access to food that has included installing locks on fridge/freezer and pantry.

Jack has lost close to 100 lbs since we locked everything up. Jack has finally started to read beyond a first-grade level.

Jack finally was able to participate in some school-related activities such as helping manage the JV men's basketball team

Jack has overcome more in his short 18 years than most people will in a lifetime yet he is not earning a high school diploma.

So when he walks across that stage tonight, I will weep tears of joy and despair at the same time. Joy that he has made it this far and we did not have to institutionalize him. He is a happy, overall well-adjusted kid with TSC. Despair because despite all this, he reads at a third-grade level, he cannot fill out a job application, drive a car or manage his prescriptions or many medical and other appointments, communicate with social service providers, or interact with the team members of his hs “post-grad” program. All that falls on me, well, not just me. Of course. It's never just one person. There's many, but on the frontlines, yes, it's me. And mind you, I am not complaining, but I am tired.

There are many positives for Jack and I am confident he will make his way, with my help, my partner's help, his father's help, and the help of a significant number of other people in his life. There are incredible unknowns with TSC/TAND and Jack. I've got decent relationships with the team at his program to continue to facilitate his trajectory in an upward trending fashion. So what is my problem? I guess it's just this continual wake-up call to the reality of the fact that there are not a lot of long term solutions for our kids and I'm going to be helping him for a while yet. TAND gets complicated, is complicated and for us, it took almost everything we had to get to the point where we weren't existing in some level of fear daily. Behaviors started early. Schools are not prepared to understand

TAND but now we have documentation to validate and advocate. I do not live with regrets but take advantage of the tools we have available to us in the TSC community, the TS Alliance, various Facebook boards, etc, etc. My two cents. Happy Graduation Day Jack. You've done your best and you and everyone who knows you is exceptionally proud.



Under pressure?

“ There is no mask or damper that can keep the intrusions of thought at bay.

I can go long periods generally upbeat and hopeful but it requires constant motion and constant escape into working and thinking and doing with full immersion. As I pause to reflect and remember; the history, the losses, the weight of it, I feel incredible hopelessness and despair and want to escape and act out. However, I also remember that I have many positives in my life, and allow myself to stop and honor the pain, sadness and despair and let it be until something within and without, something like blind faith, lifts me up and carries me to the next phase of this journey. Until then, I'm really really sad. And that

”
is just the way it is. – Parent



From The Kitchen~with Gitta

Gitta Lakatos is an Alternative Healing Therapist at Healing Infocus and is a practitioner of Massage, Magnet and Reflexology. One of her roles at Nicky's Gardens of Hope is developing a line of food products that use natural, locally sourced ingredients for those with IDD/Autism with the goal of improving overall nutrition and minimizing gastrointestinal issues common to these populations. Food sensitivities often go undiagnosed, particularly in non-verbal individuals and issues such as inflammation, mood instability, sleep difficulties can often be traced to poor diet and gut health. Gitta is building all the food items from the ground right up to the edible product. She's utilizing spices & herbs in different combinations to ensure maximum flavor with minimal post-meal discomfort and directly contributing to improved health and overall quality of life.

We learned in last month's "From the Kitchen" that all food is linked to some degree of flatulence, also known as gas! The food you eat allows different bacteria to thrive, which impacts gas composition. Trouble comes when bacteria in your gut go into fermenting overdrive. To combat gas try eliminating gas-causing foods from your diet. Here some popular vegetables that make your family sing! :)

1. Beans

Beans of all kinds are tops of the gassy culprits, but particularly soybeans, navy beans, black beans, lima beans and pinto beans. All are exceptionally high in certain indigestible carbohydrates known as oligosaccharides. Raffinose is the most prevalent and worst of these.

*You can reduce the amount of raffinose in dried beans by soaking them overnight in water with a tablespoon of edible vinegar. Drain them before you cook them in freshwater. Adding some naturally anti-gas fennel seeds to any recipe with beans can also help you get back to enjoying your beans, gas-free!

*Or, more effectively, a capsule of this **vegetarian Bean-zyme**, taken at the same time as high raffinose food, like beans, peas and some of the other gassy vegetables ahead, will provide the digestive enzymes needed to break down oligosaccharides before they can cause bloating and gas.

2. Peas, Lentils and Legumes

Chickpeas, commonly used in Indian and Middle Eastern recipes like hummus, can be particularly bad for excessive gas and are well worth avoiding if you have an important meeting the next day.

*Black-eyed peas and lentils are also very gassy legumes and will usually produce quite a bit of windiness if used as a main ingredient in a meal. Peanuts are another legume that can cause gas for some people, though usually only in much larger amounts than chickpeas or lentils.

*What is interesting with peas, beans and other legumes is that eaten on their own they often cause large volumes of intestinal gas, but not generally a particularly offensive smell. Who knew?

3. Broccoli

Broccoli is an extremely healthy vegetable recently identified to be full of anti-cancer compounds and well worth eating. Like most cruciferous vegetables though, broccoli is also high in sulfur compounds and this is where stomach pain and gas problems with this veggie usually start. Broccoli also contains a fair amount of fiber and raffinose, which no doubt contributes to its reputation for bad gas. That said, small amounts of broccoli shouldn't be a problem for a healthy digestive system.

4. Cabbage

Cabbage is another high sulfur food like broccoli that can cause some very bad smelling gas, particularly when eaten in large amounts. While a very nutritious vegetable, cabbage is actually even more healthy when fermented as sauerkraut. In this form it is predigested by beneficial bacteria and there is much less chance of gas problems eating sauerkraut rather than regular cabbage. Yay!

Peppermint tea can also greatly reduce intestinal gas and also freshens the breath and even body odor after eating smelly vegetables like cabbage. Try sipping on a cup just before or even during your meal for less gas.

5. Cauliflower

While not usually quite as bad for gas, cauliflower is still a cruciferous vegetable like broccoli, Brussels sprouts, kohlrabi or cabbage and has reasonably high levels of both sulfur compounds and oligosaccharides. Often you can build up your digestive tolerance of healthy cruciferous vegetables by starting with a small amount at first and slowly increasing the amount you eat over time.

6. Kale, Arugula, Watercress and Bok Choy are also cruciferous vegetables that can cause gas and bloating, but usually not at the same level as cauliflower, cabbage, Brussels sprouts or broccoli. Try these lower gas alternatives if you still want to receive the many health benefits of these kinds of veggies.

7. Onions, Garlic, Leeks and Shallots

While considered a prebiotic, the fructans in onions, leeks, shallots and garlic can cause gastrointestinal issues for many people, including bloating, excessive gas and even diarrhea and an aggravation of IBS symptoms.

*If you experience intestinal pain after eating a meal with a lot of onion in it then a cup of **ginger tea** can usually help relieve it (and minimize onion breath as well).

8. Mushrooms

Not usually thought of as a gas-forming food, mushrooms contain moderate amounts of both raffinose and fructans and are therefore a potential source of bad gas if you eat too much of them at once.

*Some mushroom varieties, such as portobello, button and Swiss brown mushrooms are also high in sugar alcohols like mannitol. While Asian oyster, black fungi and shimeji mushrooms are noted as some of the lowest in FODMAPs.

Many people have found cooking flatulence causing vegetables like this with a teaspoon of these **organic fennel seeds** can greatly reduce gastrointestinal issues when they eat them.

*Also, a cup of **fennel tea** is one of the most effective herbal remedies for bloating and intestinal cramps, no matter which gas-causing food is responsible for the problem.



This is our Chief Inspirational Officer, Nicky 🍷

Thank you for taking the time to read it and contact us if you have questions, would like to volunteer or help!!