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Summer 2020 Gaucher Community Newsletter

Since our first quarterly newsletter in March, the world has changed in ways we never imagined.

We are in the midst of a world pandemic that has dictated the way we live, work, communicate,

and socialize. We are in limbo because we don't know what changes will remain constant and what

will go back to our old ways of functioning. The uncertainty is difficult and challenging, but as

we've all heard many times -- we are in this together. We send this newsletter to you with hopes that you have adjusted to the changes and are faring well.

The Gaucher Community Alliance is an organization that was developed for the patient community, by the patient community. We would love to hear how you are doing and what your needs are so that we can support one another in the best way possible. You can reach out to us at info@gauchercommunity.org or via our [Facebook Page](#). Let us know what you need and work with us to make it happen!

Fondly,

Cyndi Frank & Aviva Rosenberg, Co-Founders and Co-Presidents

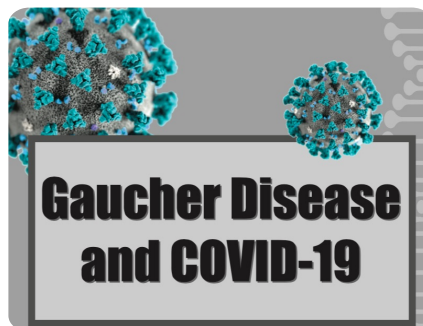
The Importance of Community In the Rare Disease World

*by Christine White
GCA Secretary*



In these challenging times, it is important to remember we can still find comfort in our community and patients and families with Gaucher disease can continue to support one another. The recently formed Gaucher Community Alliance, an international patient support and advocacy group for patients with

COVID-19 Resources



As we navigate our way through the uncertainty of the COVID-19 pandemic, medical experts and community providers have made resources available to the Gaucher community. Below is a list of resources available, some of which are **NEW**.

NEW!

Gaucher Community Safety Box

Click [here](#) if you would like to receive a free safety box of supplies that will help you stay protected while you get your infusion or leave the house. The box includes a mask, gloves, hand sanitizer and special gift. Because of shipping

Gaucher, has become a vital resource for those living with fear, uncertainty and isolation that a diagnosis of a rare genetic disease can bring.

I know from firsthand experience how important community is. My own Gaucher journey began more than a quarter of a century ago when our family received the devastating news that our two infant daughters had type 1 Gaucher disease. At the time of our diagnosis we did not have much information about this disease, and we were petrified of how this could impact our children's future, or indeed if they would even have a future.

About a year after the diagnosis I learned of a patient who wanted to meet other Gaucher families. When I reached out to Mark and his wife Judy, I had no idea the meeting would be the beginning of a lifeline that continues to sustain us to this day. This meeting was the birth of our Canadian Gaucher community. Meeting Mark and a handful of other families helped us to navigate the unknown and offered us hope and a sense of belonging. In fact, just meeting an adult with Gaucher disease made me realize our daughters' diagnoses were not necessarily the death sentence we had feared for our children. We learned from Mark about a new therapy that was being used in the USA for the treatment of type 1 Gaucher, and we advocated for access to this life changing drug. For the first time since diagnosis I went from helpless and terrified to empowered and supported.

Today, many years later, we are in the unique and privileged position in the type 1 community of having access to several life-saving therapies. But, even with these therapies, type 1 Gaucher patients still struggle with many real day-to-day

complications, boxes are available to US residents only. Boxes will ship in mid June.

NEW!

COVID-19 Informational Brochure

Click [here](#) to download an electronic version of a brochure compiled specifically for Gaucher patients and family members by the US Working Group on Gaucher Disease and COVID-19.

Other resources:

- [Video](#) of Dr. Heather Lau on COVID-19's impact on Gaucher disease
- [Webinar](#) by the GCA on early thoughts of Gaucher impacts on COVID-19
- [Letter](#) from leading US Gaucher physicians to patients
- [NIH Patient Survey](#) on COVID-19 Gaucher experience

Staying Healthy with Gaucher Five Things to Help Fight Inflammation

by Dr. Seema Kanwal



Dr. Seema Kanwal is licensed in Naturopathic Medicine in Toronto, Ontario and has been practicing in Vancouver since 2006. She focuses on the prevention of disease by investing the time and attention required to understand the individual needs of her patients. She inspires her patients to actively engage in their own recovery of health and maintenance. By implementing

issues such as fatigue, bone pain, isolation, and fear. This is where the GCA is crucial: just knowing you are not alone, that someone shares the same fears and uncertainty as you, can somehow ease the burden. Today I am the founder and President of the National Gaucher Foundation of Canada, and when I take a call from a newly diagnosed patient, I can share with them my experience and reassure them that there is help as well as hope.

One of the things I am most proud of is the GCA's commitment to working with families who have been diagnosed with types 2 and 3 Gaucher. We need to bring together the types 1, 2, and 3 communities. The 2/3 community desperately needs the help of the type 1 community, and I dream of the day when I can chat with type 2 and 3 parents and reassure them that things will be okay. The GCA has been successful in obtaining a Listening Session with the FDA for families affected by type 3 Gaucher. This is a major accomplishment and that it happened so early on in the organization's mandate shows the deep level of commitment the GCA has in supporting neuronopathic Gaucher patients and families. I look forward to future successes and would encourage all patients and families with Gaucher to reach out to each other and lend their voice. Together we can continue to fight this disease and secure a healthy future for everyone living with Gaucher.

Thank you to Cyndi Frank and Aviva Rosenberg for their vision, dedication and hard work. This newly formed organization is a vital community asset that works in conjunction with both the US and Canadian Gaucher foundations. The more support the better!

lifestyle modifications and adding interventions as required, patients learn how to stay healthy.

Summer in some parts of our world has arrived, or we have hints in our gardens that it's around the corner. That means hotter and sunnier days are upon us. Stepping outside and enjoying the great outdoors can be a wonderful way to increase activity and gain mood-stabilizing benefits.

However, given the unprecedented time we are in, this may be a daunting thought or even unlikely for some. This time we are in may bring for some, many feelings of uncertainty, fear and doubt, which when we look at the stress response in our body, has the capability of creating higher levels of inflammation. With Gaucher, this is going to be critical in managing.

Now more than ever, we need to support our bodies through various nutrients to ensure we remain strong throughout the uncertain months ahead. Below are five important tips to ensure you have a successful summer with supportive nutrients:

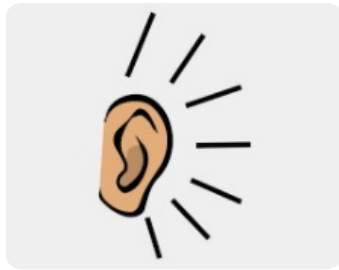
Buy In-Season Veggies

Veggies become more abundant in the summer, such as cauliflower, broccoli, cabbage, chard, and green beans, and they all contain high amounts of Vitamin A, which is important for anti-infection. My family likes these vegetables roasted with a bit of salt and pepper, and is easy to incorporate into your diet. Remember to rotate vegetables each week so you don't tire of what you're eating.

Salads

In Chinese and Ayurvedic Medicines, summer is the time to eat raw vegetables which can be difficult for the body to digest, so it is important to incorporate warming, easily digestible foods with your salads. Warm herbal teas such as peppermint can be made cooler as a flavorful

FDA Listening Session A Chance for Type 3 Families to Be Heard



We are excited to bring three type 3 families to talk to FDA regulators in Washington DC this September 3rd for the first ever Neuronopathic Gaucher FDA Listening Session. The purpose of this session is to provide context to the FDA of the struggle our families living with neuronopathic Gaucher disease have and the lack of approved treatments for this type of Gaucher disease. Our families will be joined by Gaucher specialist Dr. Ozlem Goker-Alpan and Tanya Collin-Histed, CEO of the International Gaucher Alliance.

If you would like to share your personal story and struggle with type 3 Gaucher disease with the FDA regulators, we would be happy to bring along all personal stories from our community. Please email your story and photos to us at info@gauchercommunity.org and we will make sure to pass it along to the FDA.

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iced tea and will also boost the immune system. My personal favorite is to add sun dried tomatoes and artichokes to salads, so I can lessen the amount of dressing used.

Hydration!

This is much easier to do when the weather is warmer, versus when tis cold outside. I tend to drink less water in the winter, and if drinking water is difficult for you as well, replace it with lots of herbal, non-caffeinated teas which will count towards water intake. Fall and winter is a very drying time of year. If you are prone to nose bleeds, or sinus infections, you want to ensure you maintain hydration to moisten the mucous membranes to prevent dryness. This will prepare you for the summer months ahead.

Get Enough Vitamin D

This is an important one for Gaucher. Cold and flu season occurs when there is less sun. Vitamin D is critical in maintaining our immunity at a time when the sun is unable to help replenish our vitamin D. As the Summer months are upon us, get outside without sunscreen for at least 10-20 minutes a day, then apply the sunscreen. Time in the sun depends on the color of your skin. If you have darker skin like I do, the upper limit (15-20 min) is the time you will likely need to ensure adequate D conversion from the skin. Vitamin D has an inverse relationship with melatonin, so if you are taking vitamin D supplements, take your vitamins in the morning with breakfast, especially if you have sleep disturbances.

Sugar

Sugar is a culprit like no other. Sugar has been shown in research to create inflammation. When someone is down in the immune department, one serving of sugar will decrease their immune function for up to six hours. Especially for Gaucher, fatigue can actually increase with the inflammatory aspect that sugar has on the cellular level.



Many thanks to supporters Carole and Alan Kushnir for their generosity and passion for supporting the Gaucher Community Alliance and helping others with Gaucher disease. The Kushnirs live in the San Francisco Bay Area near Stanford University. They own Supercuts franchises in California, New Hampshire, Massachusetts, and Rhode Island, and in June they will be married 56 years!

Carole was diagnosed with type 1 Gaucher disease when she was in her early 20s. She was generally asymptomatic except for a low platelet count. A few years after diagnosis with no treatments yet available, Carole's hip started to give out, but she never had any spleen or liver involvement. Carole is now 77 years old and is doing well after having hip replacement surgery and being on enzyme replacement therapy for 24 years.

Thank you Carole and Alan for your dedication and support – we are forever grateful. And Happy Anniversary!

Advocating for Early Intervention

by Dena Feingold
Gaucher Parent

Stay tuned for more articles from Dr. Kanwal on how diet can improve Gaucher symptoms. If there is any information you would like to see in her upcoming articles, please [email us](#) to let us know!

Our Fearless Leaders

New Board Member: Marc Garelick



Welcome to our newest member of the Board of Directors, Marc Garelick!

Marc Garelick is a family law attorney based out of Orange County, CA, where he resides with his wife and son. He was diagnosed with type 1 Gaucher disease when he was 22 years old and suffering from Non-Hodgkin's Lymphoma. After a long battle, Marc's cancer went into remission and he got his Gaucher involvement and symptoms under control. Marc is excited to be a part of the Gaucher Community Alliance to help grow community awareness and strengthen its bond.

Eating Healthy with Gaucher Simple Ways to Stay Healthy

by Jamie Koll
Gaucher Patient



When my husband and I first discovered our youngest child Eli (7 years old) was born with type 1 Gaucher disease, we had already invested several years of thought and research into what the disease would mean to him and our family. My two daughters, 13 and 9, provided my husband and I with the first inclination of what to expect when we discovered both were carriers of a single mutation for type 1. Through the years we learned and devoured as much as we could about the disease and its clinical progression. Moreover, we attended patient meetings and met several adults who spent the better part of their childhood on crutches or in a hospital bed. These learning experiences shaped our role as advocates for our son and our desire to intervene early with treatment.

Eli has been on ERT (Cerezyme) for two and a half years. Getting him on treatment proved to be a bit challenging because there was no set determination or guidelines to follow for starting treatment. Although his liver and spleen were enlarged and his labs were just okay, I consulted with several experts around the world and each one had a different opinion on when to start ERT. One doctor suggested waiting until he started breaking bones and experiencing nose bleeds, and then the other couldn't believe he still was not on treatment. Moreover, several doctors emphasized that Eli had a mild mutation and



Jamie Koll was diagnosed with type 1 Gaucher in 2018 when she was 26. After receiving her diagnosis, she committed to significantly changing her lifestyle to be healthier and is now passionate about living a clean and non-toxic life. Jamie is a certified Health Coach with a goal to share health and wellness tips so all people with Gaucher can live their best lives with a chronic illness.

As Dr. Seema Kanwal has mentioned above, there are a number of healing foods that can help to reduce inflammation in the body. "Food is Medicine" is a saying for a reason. Summer is one of the best times to try in-season produce, including a variety of fruits and veggies. Our bodies tend to crave foods seasonally, and it is important to eat a variety of colored fruits and veggies to ensure our bodies get the right vitamins and nutrients.

Below is a list of summer seasonal produce. The best places to get these items are at your local farmers market, a grocery store that acknowledges local produce, through a local farm CSA, or through subscription services like [Misfits Market](#), [Imperfect Produce](#), or [Hungry Harvest](#)

could live a fairly normal life forgoing treatment well into his seventh or eighth decade of life. I questioned the term mild because this is a disease that presents with a spectrum of symptoms; what may be mild in one person may be severe in another. To withhold or delay treatment based on a genetic mutation would not serve to benefit him as a young person through many decades of life. I felt this protocol was a blind spot in rationalizing the need for treatment.

After reading many research papers, weighing medical opinions, and speaking with now teen and adult patients who spent the better part of their childhood in and out of hospitals, my husband and I determined that Eli would need to begin ERT as soon as possible to provide the best outcome for him and his long-term health. Although he had been seen by different doctors, including regular visits with his pediatrician, Eli's metabolic storage disorder doctor is the one who stepped in and said "let's start him now." It was reassuring to have someone in our corner backing up our desire and commitment to the belief that early intervention would be the greatest advantage to thwart any negative outcomes associated with the disease.



Our message is simple. Early intervention is the

(delivery will vary based on where you live).

Summer Produce List:

Basil
Berries (raspberries, blueberries, strawberries, and blackberries)
Cherries
Figs
Garlic
Green Beans
Melons (Honeydew, Cantaloupe, Watermelon)
Nectarines
Peaches
Pears
Sweet Corn
Zucchini

Best Way to Clean Produce

It is important to properly clean your produce to remove bacteria, viruses, and parasites as your produce picks up germs en route to you. I prefer to clean fruits and veggies by filling the kitchen sink with cold water, and for every cup of water (I estimate) add 1 tbsp of apple cider vinegar and let sit for 15 minutes. Then rinse with cold water and dry. I suggest doing this for fruits and vegetables with tough skins and anything with thin skins, such as berries, should be done right before you eat them.

Another great tip to store lettuce like kale and herbs in the fridge longer, is to place the stocks in a small glass vase or jar with water.

best way to approach any medical issue. Why wait until things become unmanageable before initiating treatment or an approach to care? Much like how a vaccine can prevent disease or long-term health problems in a child, my husband and I viewed the treatment for Gaucher the same way – step in early. We felt that the best outcome for our child would be to start treatment to disrupt the effects and progression of disease manifestations at the earliest point possible. While ERT does not build immunity like a vaccine, it does provide for the benefit of protection against the potential medical consequences of Gaucher.

Today, Eli is totally healthy, super energetic and participates in mixed martial arts, football, baseball and tennis. He is a positive, happy child and growing without any skeletal disorders, and he has a normal-sized liver and spleen. If we did not step in or push for treatment, we are not sure of where he would be today. Initiating treatment early is giving Eli the very best opportunities in life.

Gaucher Community Wheels An Event to Raise Awareness for Our Community



We are pleased to announce **Gaucher Community Wheels**, a North American campaign for **Gaucher Awareness Month** during the month of October. The campaign has three primary purposes: engage and empower the Gaucher community, raise awareness of Gaucher



Sweet Corn & Zucchini Salad

(serving size is one large salad or two side salads)

Below is a recipe that focuses on seasonal produce and uses real whole foods that help to reduce inflammation in the body. The recipe is easy, dairy free, gluten free, and can be changed to use any proteins or toppings you have in your fridge.

1 zucchini
1 tbsp olive oil
1 cup sweet corn (can use canned, frozen, or fresh)
2 strawberries, sliced
Sprinkle of salt & pepper

Lemon Dijon Vinaigrette:

1/8 cup olive oil
1 tbsp fresh lemon juice
1/2 garlic clove chopped
1/2 tsp dijon mustard (read the label to make sure there is no added cane sugar)
1/2 tsp fresh thyme (you could use other fresh herbs like rosemary, oregano, basil)
Sprinkle of salt & pepper

Directions

in the general community, and raise funds and resources that will help Gaucher patients and their families.

In September we will send out 6-inch car magnets to all families with Gaucher disease, and we want YOU to display the magnet on your car for the month of October. Take a photo of yourself with the sticker on the car and show what state your license plate is from. We aim to get photos of ALL States and Provinces in North America to rally support of Gaucher Awareness Month in October.

We may not have your address, so click [here](#) and join our mailing list if you'd like to get a bumper magnet and raise awareness for Gaucher!!

This event is generously sponsored by by Prevail Therapeutics, Avrobio and Takeda.

Thank YOU!!

Our Volunteers Make It Happen



Fan, you did it again! Fan Ding, Board member and volunteer extraordinaire, held a Facebook fundraiser for her birthday to support the Gaucher Community Alliance and raised over \$700! Go Fan! On behalf of the Gaucher patient community, thank you. Funds will help us to provide resources for patients across North America.

1. Heat a skillet or pan on high heat and add corn with a sprinkle of salt and pepper, stir frequently until corn is charred
2. Using a wide vegetable peeler, peel zucchini lengthwise to create ribbons, sprinkle some salt to remove excess water and let sit for 5 minutes
3. Mix all vinaigrette ingredients together in a small bowl
4. Once corn is cooked, pat dry the zucchini with a paper towel and mix corn, zucchini, and sliced strawberries together
5. Drizzle on dressing and top the salad with your favorites: microgreens, fresh herbs, goat cheese, chickpeas, or grilled chicken

Are you interested in hearing more from Jamie? Follow her on her personal Instagram [@jaykoll](#), and her food Instagram [@girlswhoeat](#) where she shares healthy recipes. You can also visit her website www.jamiekoll.com to learn more about her.

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Thank you Stacey Feuer, PsyD, and Wayne Rosenfield, PhD and Board Treasurer, for hosting **Gaucher Community Connect, Social Connection and Conversation** for Gaucher patients and their families. These online web sessions were offered as an opportunity to make connections within the Gaucher community to share experiences during the current shelter-in-place social distancing order.

Stay tuned for more opportunities to connect online!

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For Patients, By Patients
Together We Can Make Change

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