

Ensuring no one has to face GIST alone

In Loving Memory: Nikhil Guhagarkar, Maria Consuelo Hincapie, Ben Van Horn, Lillian Young, Margaret Chalmers, Joel Oquila Jr., Mali Sinai, Judith Earl, Rebecca Goertemiller, Jennifer Rahlf

GIST & Creativity

by Carolyn Tordella,
Assistant Director of Communications

Artistic expression is an important psychosocial activity. Sometimes we can express ourselves visually or musically when we can't express our experience verbally. Music, drawing, painting, and creating sculpture provide a means of communication and self-expression— and a way to alleviate stress. Art also helps us to change our moods, come out of depression, or simply relax. What do people who are already creative do when they are faced with a cancer diagnosis? Does it help or give hope in the situation? In this two-part series, these GISTers - professional and amateur creatives, share their stories.

Ellen Mayer

Ellen Mayer has had a very interesting journey as an artist and as a GISTer. She has lived with GIST since 2003, with no treatment except her initial surgery and has been NED for 16 years.

A creative individual all her life, her professional career as an artist began right out of high school when the talented young woman landed a job as a fashion illustrator. After several years in fashion, Ellen worked as a graphic artist in various fields and also painted in her free time.

After raising her children, however, Ellen found herself at a part-time job she didn't like and she realized that the commercial art field had shifted toward computer graphics, an area in which she had no experience. With the assistance of the dislocated workers program (a worker whose field has radically changed and they cannot find a job) through the unemployment office, Ellen went back to school and earned her degree in computer graphic design. This was an amazing opportunity for her!

During her final semester at college, however, Ellen began experiencing sporadic bouts of gagging and nausea with no discernible explanation. She commented on this time period, "I thought I'm at that age, it's so much pressure on me now. I'm not feeling well. But I didn't even think of going to the doctor, that's how naïve I was."

This story continues on page 4.



Ellen Mayer and "Balancing Act"

Ellen's work has appeared in group and solo shows at Papp Gallery, Midoma Gallery and A.I.R. Gallery, New York City. She has also exhibited at the Lycian Theater, Sugarloaf, NY, Varga Gallery, Woodstock, NY, Winslow Therapeutic Center "Healing with Horses" Warwick, NY, Harness Racing Museum, Goshen, NY, Howland Cultural Center, Beacon, NY, Newburgh Art Gallery, Newburgh, NY, Painter's Gallery, Cornwall, NY, Hambletonian Fine Art Show and Competition, Sugar Loaf, and many others.

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Bridging the Gap

Autumn can be a difficult season. The leaves are beginning to fall from the trees, summer is fading, and the chill of winter can be felt subtly in the air.

All seasons can be difficult, though. As I look over some of the anniversary dates for those the Life Raft Group has lost, there isn't a season that goes by without the lighting of more than one candle for remembrance. Too many seasons, too many loved ones lost to GIST. When will it be enough?

I wish I could say there was a magic formula and that if we gave it to every GIST patient they would be assured they would survive. If it were magic, more people might pay attention, caught up in the promise that their loved one could survive and thrive. Magic tends to grab people's attention. Look at the cultural phenomenon of Harry Potter.

But it is not magic. Sadly, it is simpler than that. And we have known this simple formula for a long time now. In fact, in the beginning of the quest to find a cure for GIST, one of the answers was referred to by my friend and colleague, Dan Vasella, the former CEO of Novartis Pharmaceuticals as "The Magic Cancer Bullet," referring to imatinib, the first oral chemotherapy drug. But as Dr. David Josephy shared in a recent GIST 101 presentation for advocates around the globe, "It wasn't magic, it was science."

Back in the year 2000, and each year since, we had to figure out what to do with this thing called GIST, and now, we need to do what it is we figured out.

It has three parts:

1. Perform the right diagnostic test on the patient in order to identify the right drug/treatment. This isn't a matter of the acquisition of knowledge. Instead it is the utilization of that knowledge as a standard of care. We have known about mutational testing for well over a decade, yet less than half of patients actually get them.
2. Provide access to all to the available treatments, including off-label. Find ways to overcome the obstacles: financial, insurance, government regulations, access to clinical trials, etc.
3. Take the prescribed drug. Aid patients in personalized side effects management so that they can adhere to their treatment.

Simple, right? Hardly.

In the world of communicable disease, action happens much more quickly, and is usually much more collaborative in nature. The threat is visible, and time is of the essence. I remember standing with my mother when I was a small boy, waiting in line for the polio vaccine. Images of children in iron lungs brought people in droves to protect their children with this newly discovered preventative vaccine. It has often been said that if cancer were contagious, we would have more cures.

But we have been entrusted to make the invisible visible. Not through magic, but through science. And then to shout what we have figured out from the rooftops, so we can make our voices heard and save lives together.

We need your help to do just that. We need you to join our patient registry and tissue bank.

We need you to raise awareness about GIST and ask your doctor "why" if he/she doesn't order a mutational test.

We need you to write the insurance companies and your legislators to fight for access to treatments.

We need you to donate to the Life Raft Group so we can continue this work together.

Autumn is here. It's time.

- Norman J. Scherzer



Highlighting Exceptional Professionals in the Sarcoma Field

The Life Raft Group has developed the Women in Sarcoma program in recognition of the many women sarcoma specialists that engage with our organization and our patient and caregiver community. Their dedication to educating and advocating on behalf of those living with sarcoma is inspiring. They are Cancer Warriors, utilizing their gifts and talents to help patients thrive.



Our aim is to highlight women in the sarcoma medical profession that make a difference in patients' lives, and to share their stories of strength and perseverance dealing with rare patients & diseases with our community. The series will help us gain perspective on women's roles in oncology, and will help us learn the challenges that female medical professionals face while balancing careers and family life. They will also share their expertise as powerful advocates working on behalf of those living with sarcoma.

As part of the ongoing series, two webinars were presented in September and October. An Interactive Multidisciplinary Panel of Experts debuted on Sept 24th with Dr. Gina D'Amato, an oncologist from the Sylvester Comprehensive Cancer Center as moderator.

Dr. Marion Brody, Radiologist, Mercy Fitzgerald and Mercy Philadelphia Hospitals; Dr. Aimee M. Crago, Surgeon, Memorial Sloan Kettering Cancer Center; Dr. Anette U. Duensing, Associate Professor of Pathology, University of Pittsburgh Cancer Institute; Dr. Suzanne George, Oncologist, Dana Farber Cancer Institute; Tracy Havnaer, Registered Nurse, OHSU Knight Cancer Institute; Marlene Morales, Licensed Clinical Social Worker, Sylvester Comprehensive Cancer Center; and Dr. Neeta Somaiah, Oncologist, MD Anderson Cancer Center were the panelists from this session.

Dr. D'Amato and the panelists shared from their personal experiences on their mentors, work/life balance, and why they chose sarcoma as a career focus.

They also answered questions from patients and caregivers such as, how to organize a second opinion and ask the right questions, how a decision is made between surgery and medication, and how ctDNA liquid biopsies are used and what the future holds in that area.

During the presentation, radiologist Marion Brody gave a simple, but excellent explanation of monitoring tools CT, PET scan, and MRI, and how each was different. It was discussed that an MRI is sometimes better for a GIST patient with GI issues or kidney issues due to the prep needed for CT and PET, and noted that sometimes insurance could be a barrier.

The second panel will debut in late October and will cover Case Presentations on topics relevant to the sarcoma patient's journey and feature oncologists Dr. Vaia Florou, University of Utah, Huntsman Cancer Center, and Dr. Ciara Kelly, Memorial Sloan Kettering Cancer Center, and and Nurse Practitioner Sandra R. Brakert, Ronald Reagan UCLA Medical Center. A recording of this live presentation will also be available on our YouTube channel in November.

The culmination of this dynamic series will be the Women in Sarcoma Gala, a new annual event, hosted by the Life Raft Group. On December 10, 2020, we will present awards to outstanding providers. This virtual event will also feature inspirational speakers (themselves sarcoma patients), and bring a bit of fun into what can be a very serious topic. Register for the Gala on our website event page.

The series is made possible by the generous support of our sponsors Pfizer Oncology, Jeffries LLC, and Credit Suisse.



Women in Sarcoma Gala

Join us as we honor outstanding professionals in the field of sarcoma.

This virtual event will be held on Dec. 10 at 6pm and features an awards ceremony, in addition to presentations given by those who have walked the GIST journey as patients, caregivers, and friends. Sign up on our website.

Continued from front cover.

And I just kept on pushing through. It wasn't a steady kind of sickness. I didn't get up in the morning and say, 'Something is wrong. It was on and off.'



"Holding On"

After graduating with honors, she landed a job as a computer graphic artist for a newspaper as she continued to paint and show her work while building her own graphic design business called The Original Eye. The sporadic symptoms continued for some time until finally one day, Ellen, white as a ghost with an actual bleed, was rushed to the hospital by her husband. Life changed forever that day.

Twenty-four hours later, after a series of diagnostic tests, it was determined that Ellen had GIST. Fortunately, the gastroenterologist on call was familiar with GIST enough to determine the need for surgery was immediate due to internal bleeding. The Mayers believed they should go to NYC for her surgery, thinking Ellen would get better care there, but was advised to stay and have the surgery immediately. The surgery was performed with clear margins by a general surgeon. No treatment was prescribed, because at that time Gleevec was not yet even thought of for GIST.

Just to illustrate how important art was to Ellen and how cancer wasn't going to determine how she lived her life, she shared that she participated in a large art show several weeks after the surgery that was planned well before this interruption. Her determination and upbeat personality shone though she felt the stress on her body physically.

"I'm not a woe is me kind of person. I just deal with it. I came from the Bronx. The projects. A tough cookie, you know?"

Ellen has been NED since her surgery but still has side effects to this day from the tumor resection and for the first decade following, she had routine scans every three months. Currently she goes for scans every two years.

"I want people to understand that even though I haven't had this GIST (recurrence) in seventeen years, it's always in the back of my mind as soon as I don't feel well. I want people to know you can live a productive life with this disease and not be in fear every minute about having GIST."

Ellen's art has evolved from her pre-GIST days.



"Seeing Red"

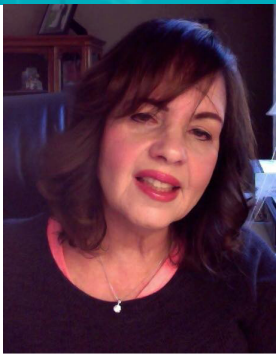
"I'm more conscious of people that do have illnesses and other issues and my subjects are a little different now too. Even this last painting I did with my daughter-in-law, who is a PA, and how that painting helped so many people and ended up being in the hospital. My career has evolved into helping people," said Ellen. The painting, titled "Holding On", is dedicated to the front-line heroes of the Covid crisis and is on permanent display in the Englewood Hospital Emergency Room.

Ellen says that she finds her ideas for painting from what she's going through in life.

"We loved to go out a lot before Covid, always out and about, and that's where I get a lot of my ideas. People and places inspire me. I'll get a 'burst' and I'll think about it. And then I just start painting."

Ellen continues to work as graphic designer though her fine art paintings have been shown and sold for decades. One notable piece is titled "Balancing Act", Ellen's contribution to The Hope Murals Project, won a competition sponsored by Lilly Oncology for New York City. This piece speaks of Ellen's GIST journey.

"Someone [the main figure of the painting] is balancing on the earth and what's happening is - when I was actually going through it - that this person is me. I'm trying to stay balanced on the earth and this is everyone else on the earth too. And they are holding onto each other to keep me from falling off. This is how I felt about GIST." This incredibly personal painting was eventually reproduced as a mural in Indianapolis, Indiana.



Art in one form or another, has always been, and will always be, an important part of Ellen's life. Ellen shared, "Art completes me because I feel like if I'm not doing something creative then I feel that there's a piece of me that's missing. I feel uncomfortable." *Ellen is currently NED, mutation unknown, not on treatment.*

During the Life Raft Group Rare 13 Campaign of 2014, Ellen said about her work, "Intense, swift strokes of strong dark colors and textures with quick motion and layering of paint are the core of my work. Inspired by the feelings of motion and emotion, my hand paints what I feel and incorporates the imbalance in shapes and color I see in life and people. My oils on canvas and acrylic on board paintings, influenced by Max Beckman's bold black outlines and Edvard Munch's intense emotions, translate the true depth of my feelings about contemporary issues. See more of Ellen's work & about her GIST journey.

Visit: www.mayergalleryart.com



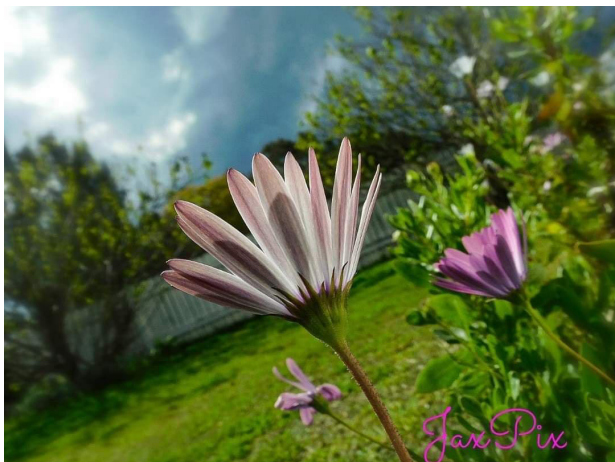
Jacqui Bartlett

Jacqui Bartlett, a canteen supervisor at a local army training base, shared that she'd been up at 4:30 am the day she gave this interview. It's spring in Toowoomba, Queensland, and she ventured out early to explore nature with her camera. Her interest

in photography is recent; her creativity, however, manifested originally with some painting, but after splurging on a camera on which she'd had her eye, she's been dedicated to learning all she can about the craft.

Cancer was a shocking diagnosis for Jacqui. Admittedly she'd had some strange symptoms for quite some time, but her doctor didn't think much of it. Two years before her diagnosis, she told him she was getting very full after eating small meals and her doctor believed it was caused by an ulcer.

"I hadn't been able to eat much for ages. I was given 'ulcer tablets.' Whatever they are. There was no follow-up on it, so I just got used to it. But then, sometime later, when I was at work, I would start crashing. I was so tired. I'd get home and just go to sleep. I was 48 at the time so I just thought it was menopause," said Jacqui.



At the end of the second year, edema became a chronic symptom, too. Jacqui visited the chemist thinking vitamins would help with this and the extreme fatigue. A week later she was still experiencing swelling in her legs. After checking her blood pressure and pulse rate, she was sent to the doctor. An ECG and blood tests were performed, and a few days later, the pathologist called saying she needed to meet the doctor at the hospital. Jacqui didn't understand her concerns.

"I had no idea what she was talking about. She didn't want me to drive to the hospital. When I got there, I found out they were concerned about bleeding. I thought to myself if I was lightheaded and bleeding, I'd be very worried and I would have been there sooner. But I wasn't," she said.

A full workup was performed and a mass was discovered during the endoscopy procedure. Apparently, the tumor had been bleeding slowly, causing Jacqui's symptoms. Surgery was performed and Jacqui, a single mom, was back at work 16 days later.

"It all happened so quick I didn't have time to comprehend fully," said Jacqui. "Life went on. After healing, I went on Gleevec, which lasted 19 days. I had an allergic reaction - a rash from neck to toes.

Continued on page 6.



Neither antihistamines or steroids helped, so the oncologist said to stop the treatment and within a few days, the rash disappeared."

Jacqui worked with an oncologist in Toowoomba, about two hours west of Brisbane on the eastern coast of Australia. At this point, there were no other options for treatment for Jacqui. In the Australian healthcare scheme, she could not be prescribed Sutent, the second line of treatment for GIST, until there was a recurrence or metastases. Thirteen months later, tumors were found in the perineum. After a biopsy and CT, Sutent was begun, though no mutational testing had yet been performed. The tumors shrunk by 75% in a couple of months, but several months later scans revealed new growth. After growth, they applied for Stivarga on compassionate grounds as it's not covered under Australia's PBS and Jacqui stayed on Sutent. Her next scan showed NED.

Treatment for a sunspot (melanoma) halted her regime for GIST a year later, and when Jacqui resumed the Sutent, she developed neutropenia, which is an abnormally low white blood cell count in the blood which can be a side effect of some cancer treatments, increasing the risk of life-threatening infection.

"I've never thought of myself as sick. I had some side effects but I didn't feel like I had cancer. Everyone thinks of cancer as chemo and radiation. Getting diagnosed with GIST was a shock, of course, and then I had surgery, and I had an allergic reaction to Gleevec so they put me on Sutent for two years but now, I've been tumor-free for 13 months. The side effect I hated the most was losing my sense of taste. And now that's returned and I've been able to gain a little weight," said Jacqui. Jacqui finds that photography helps her maintain focus. Her journey as a photographer started with birds but has expanded to many subjects. Everything, she says, because at this moment it's all new. She explained, "I'm sort of doing everything at the moment because it's all new. Sunsets, moonshots, smoke photos, whatever occurs to me. Macro lenses

stuff - bees, zoom - the moon. Natural stuff, nature. I'm just totally focused on what I'm doing and what's inside that lens. I want to get the light right. I can get immersed for ages. I pretty much disappear. I'm always pulling over in the car. I'm learning."

And photography, in comparison to painting gives her completion and an instant gratification.

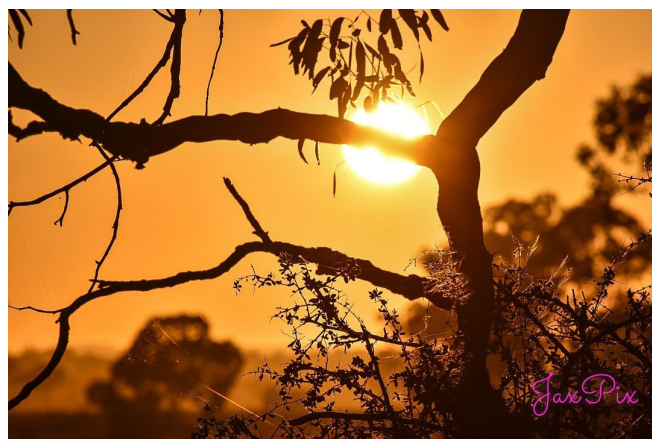
"It's given me a creativity I haven't had for ages. First, I was focused on raising my son, then dealing with GIST, and now I'm focused on this. I think that if I get sick again, I'll have my photography to help me cope and keep my focused. And I'm concentrating on something I can leave to remember me by, you know?" Jacqui said.

Jacqui knows there's always a possibility that she'll have to deal with GIST again, but she's a dedicated patient researcher. When she was first diagnosed, she learned a lot from GIST Support International and connected with other GIST patients from Australia and New Zealand on Facebook as well as the Rare Cancers Australia GIST group and GIST Survivor, and also, The Life Raft Group.

"It's good to have these groups so that you can exchange information about GIST Specialists and talk with others in the area who are going through the same thing. I do my research and go to my oncologist with questions and a 'I need to know these things' attitude. I keep up with the latest news about GIST."

Jacqui is currently NED, exon 11 and 13, currently not on any treatment protocol.

You can see more of Jacqui's photography on her Facebook page: Type **loxnum95** into the search and the **JaxPix** page will appear.





MaKayla Evans

MaKayla Evans is the youngest GISTer interviewed for this article. Currently NED, her GIST journey has been a complicated one which has included multiple surgeries, gastroparesis, and an eating disorder, in addition to all the life changes a young woman

encounters through high school and college. She's also not unfamiliar with the power of creativity in healing and recovery and expressing herself has been in her 'toolbox' for years.

Her education in GIST began at 14 years old, when, in 2011, MaKayla had an endoscopy to uncover the cause of ongoing GI distress. The procedure revealed three lumps on the stomach which were removed and labeled benign GIST tumors. The tumors were removed with clear margins and it was five days before she was released. Treatments were discussed, but none were begun at that time. MaKayla's scans remained clear for four years until mets were discovered on her stomach and on her liver. They appeared indolent (slow growing), and monitoring was advised, rather than surgery.

All was well until 2018, when MaKayla began experiencing more GI pain. The doctors felt that the tumors were probably the cause of this pain and a second surgery was recommended. This surgery was more extensive. A Surgeon at Huntsman Cancer Institute removed the tumors on the liver and about 25% of MaKayla's stomach. Her hospital stay this time was longer and MaKayla said she wasn't feeling great at all.

"I couldn't eat. I kept having episodes that were like low blood sugar symptoms. Couldn't figure out what was going on. I felt like I wasn't recovering from the surgery," she said.

After eight days, MaKayla went home, but still didn't feel right. She lost a lot of weight and ended up getting very ill and returned to be readmitted to the hospital.

MaKayla shared, "The doctor told me that it was very possible that my Vagus nerve** was accidentally clipped during surgery. I ended up having a feeding

tube placed - one through my nose for about eight months, and then I had one placed in my abdomen. Today, I still deal with Reactive Hypoglycemia and severe Gastroparesis. Outside of the cancer, it's the complications from the cancer that have caused the most issues for me. I still struggle quite a lot with both these issues as well as not being able to eat and drink enough fluids, which requires me to be on and off tubes and infusions."

Art has helped MaKayla with her GIST journey. She enjoys painting in acrylics and watercolor, and indulging in photography and mixed media. She thinks that sometimes it's easier to express what you're going through with art.

"I had always seen others artistic abilities and wished that I could be that artistic and that came from just wanting to build another skill, and then honestly, when I was going through my recovery for an eating disorder (unrelated to GIST), we were taught in therapy to use art as a form to work through our traumas, our struggles. So, I learned about how art could be healing and that was really interesting for me," she said.

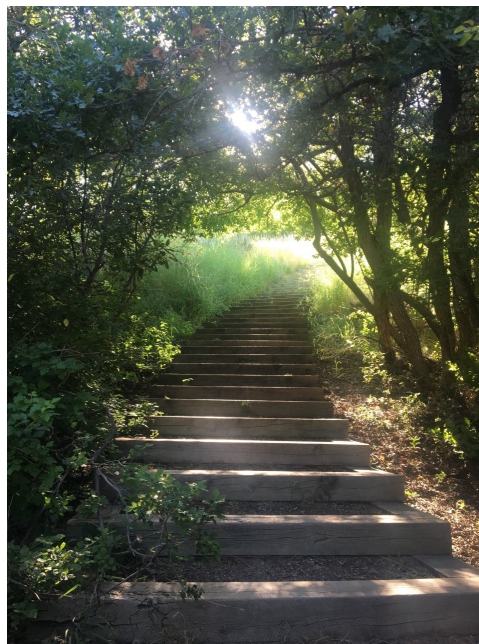
It's helped in her journey with GIST as well. MaKayla is developing her techniques by expressing how's she's feeling.

"I often find myself using words, just random, like feeling words, adjectives in my paintings and then just trying to create something off of what those feeling words are. I have to be in touch with how I'm feeling to be able to create something."

Artistic expression may prove to be healing not just for her but also for other GISTers.

"I'm lucky right now because I'm 23. I work part-time. I finished my medical assistant program this past January. I'm functioning and I'm just grateful I'm living and doing what I can do with what I have," MaKayla said, "I want to create something about my GIST journey that is really meaningful to me. On our GISTers art page, I love seeing that people are still trying to live their best life despite the trials they've been given. They are posting things like sunsets and nature, and you know, we take those things for granted a lot of the time. I think through art we're able to see the things that have meaning. It might not mean the same to other people but it can have a very powerful meaning for ourselves."

MaKayla has epigenetic SDHC-deficient GIST, no treatment protocol, currently NED.



How Can B12 Help GIST Patients?

A Cure-All for Fatigue?

by **Amelia Yeo**, Caregiver, LRG Country Liaison for Singapore & LRG Contributor

Fatigue is a common symptom experienced by GIST patients. Many factors may cause or contribute to lethargy, such as insomnia, malnutrition, iron deficiency to name a few, but a vitamin B12 deficiency in particular could be the root of the issue for some GIST sufferers.

What Does B12 Do?

Vitamin B12, also known as cobalamin or cyanocobalamin (the form found in most over-the-counter supplements), is an essential water soluble nutrient responsible for keeping the body's nerve and blood cells healthy and helping make DNA, the genetic material in all cells. Vitamin B12 also helps prevent a type of anemia called megaloblastic anemia that makes people tired and weak.

A deficiency of B12 can cause:

- Weakness, tiredness, or light-headedness
- Heart palpitations and shortness of breath
- Pale skin
- A smooth tongue
- Constipation, diarrhea, loss of appetite, or gas
- Nerve problems like numbness or tingling, muscle weakness, and problems walking
- Vision loss
- Mental problems like depression, memory loss, or behavioral changes.

Please note however, that many of these issues can occur for reasons other than B12 deficiency, and the only way to verify you are deficient is to get a test from your doctor. Consult with your physician before making any changes in diet, lifestyle, or supplements.

Sources of Vitamin B12

Human beings cannot produce their own B12 and thus must obtain it from dietary sources, bacteria in our gut, or supplements.

Beef liver and clams are typically the best sources of this nutrient. Fish, meat, poultry, eggs, milk and other dairy products also contain B12.

Other sources include some breakfast cereals, nutritional yeasts and other food products that are fortified with B12. To find out if vitamin B12 has been added to a food product, check the product labels.

How is B12 Absorbed?

The absorption mechanism requires:

- a glycoprotein called intrinsic factor that is secreted by parietal cells of our gastric mucosa; and
- a functioning ileum (the third and final part of the small intestine - see image)

Assuming the ileum is functionally intact, approximately 50% of extracted vitamin B12 will be delivered to the liver, with the remainder going to other tissues. In fact, the liver's storage of vitamin B12 is significant enough that it could take a year or more before B12 deficiency manifests

into clinically relevant pathology

Causes of B12 Deficiency

A person may become deficient in vitamin B12 if insufficient amounts of the vitamin is consumed; and/or the body does not absorb or store enough of the vitamin.

Usually, insufficient vitamin B12 consumption only occurs in people who do not consume any animal products (such as vegans). If a vegan mother breastfeeds her infant, the infant may also be at risk of vitamin B12 deficiency. Deficiency due to inadequate consumption is unlikely in other people, except the severely malnourished.

The most common cause of vitamin B12 deficiency is inadequate absorption. A number of conditions and factors can cause absorption to be inadequate, but here are some that may be more relevant for GIST patients:

- Surgery that removes part of the ileum
- Drugs such as antacids and metformin
- Lack of intrinsic factor

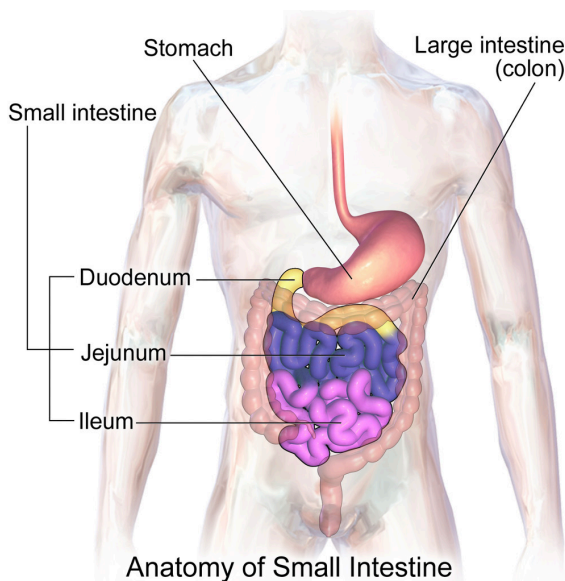


Image source: Wikipedia

- Insufficient storage
- Low stomach acidity

Testing for B12 Deficiency

So, what if you are facing one of the issues described above and think you might have a B12 deficiency? What should you do? The first step would be to speak to your doctor about getting a test for B12 levels.

Several lab tests may be conducted to help identify people with a possible vitamin B12 deficiency:

- Complete blood count (CBC) - Evaluates the state of blood cells. Macrocytosis and/or cells with abnormal physical characteristics are associated with a B12 deficiency and are often detected during a routine CBC.
- B12 blood level - Measures vitamin levels in the liquid portion of the blood. If low, a deficiency is indicated, though the cause is not identified.
- Methylmalonic acid (MMA) - If B12 is low, MMA is generally high. May be ordered to detect mild/early B12 deficiency.
- Homocysteine - Seldom ordered; may be elevated if B12 is deficient.

However, it is important to note that some test results may still show up as being "normal" even in people who are B12 deficient. Two case studies showing how false normal assay results have led to errors in diagnosing B12 deficiency have been documented here and here respectively.

GIST patients who have undergone an ileum resection can opt to do the Schilling test instead, which is an indicator of the degree of terminal ileal dysfunction. Results of the Schilling test are proportional to the length of ileal resection, up to 60 cm. Patients with resections of 20-60 cm can be assumed to be at high risk of developing B12 deficiency, while those with resections >60cm can be assumed to ultimately become B12 deficient.

In GIST patients who have undergone a total gastrectomy, vitamin B12 deficiency is an inevitable and rather early metabolic sequela. Among those who have undergone a partial gastrectomy, the elderly with low pre-operative vitamin B12 levels are more likely to experience B12 deficiency post-operation. Thus, pre-operative measurement and regular post-operative monitoring of vitamin B12 levels are necessary for early detection and treatment of post-gastrectomy vitamin B12 deficiency.

Treating B12 Deficiency

If you've determined via a test that you have a deficiency, the next step would be treating it. This would involve taking in additional B12, which can be done either by injection or orally.

The traditional approach for administering vitamin B12 is via intramuscular injections (delivered into the muscle). More recently, subcutaneous injections (delivered into the layer of fat beneath the skin) have also been used. Both these administration routes are effective, and recommended especially for people who are unable to absorb B12 orally due to reasons such as lack of intrinsic factor and ileum resection.

For those who are still able to absorb B12 orally, research has shown that B12 supplementation via tablets containing 1000-2000 mcg per day is as beneficial as intramuscular supplementation (i.e. B12 shots), especially once baseline levels have been attained.

In conclusion, for GIST patients - especially those who have had part of their stomach and/or ileum resected - a possible cause of fatigue may be vitamin B12 deficiency, which can result in anemia. Certain TKIs such as sunitinib and imatinib have also been shown to induce macrocytosis, which is an indicator of B12 deficiency. Vitamin B12 injections may be administered in cases where the nutrient may not be absorbed orally. Also, as previously mentioned above, it is important to note that there may be other causes for fatigue besides B12 deficiency, so changes in diet, lifestyle, and other factors may also be warranted. If you suspect you are deficient, the only way to confirm this is through a test ordered by your doctor. While standard tests may be done to check if you are B12 deficient, results may not always be accurate. It is best to estimate your risk based on your unique situation, then request the appropriate test - if available - to confirm things.

References for this article will be available on our website.

Interested in a Support Group? New groups start for GIST Patients, Nov. 11th, and for Caregivers, Nov. 4th. Register on website.

Australian GISTers Volunteer as LRG Country Liaisons

Helping to Support Patients on their GIST Journeys

Australia is the sixth largest country, by area, in the world, with a population of over 25 million people and GIST comprises about 3% of all GI cancers there. Reaching patients and oncologists with current information on such a rare disease can be a daunting task which is why The Life Raft Group is pleased to welcome Shari Reid, of Victoria, and Dr. Amy Kenworthy of Gold Coast, as country liaisons, representing the LRG with support for GIST patients.

Shari Reid, Victoria, exon 11, Gleevec, NED



Shari Reid

Shari Reid, formerly a System Administrator in Health & Safety, is currently a proud, full-time mum to son Robbie. Though she's living in regional Victoria with her husband, Glenn, and son, Shari was born in the U.S. and her family moved to Australia when she was a baby.

Shari's GIST diagnosis came during an emergency room visit due to excessive bleeding, after seven years of visiting multiple doctors, chasing a diagnosis for symptoms that didn't match a treatable disease. Symptoms that one of her doctors eventually concluded 'were all in her head', which included edema, weight loss, joint, Achilles tendon and hip pain, bloating and swelling, seizures, dizziness and fatigue.

Shari's journey as a patient fueled her desire to work with other patients facing the same challenges. Diagnosed in December 2019, she is currently on Gleevec, and scans show NED.

When Shari learned she had GIST, medical people advised her not to Google anything because it would upset her, but Shari and her husband were determined to do the research on GIST. Shari found the GIST Survivor Facebook group online, where she saw the LRG mentioned. Upon learning about the LRG, she became aware of the importance of mutational testing and having a GIST specialist on her treatment team. Shari had mutational testing, which showed her mutation to be exon 11, and genetic testing, also, since she needed to know if it was possible to pass GIST onto her son.

Now, Shari wants to make sure that other GISTers have the information and support they need on their own GIST journey.

"I just want to pay it forward. I'm a bit of an altruistic person anyway and I like to help people.

I remember saying to Stephanie (Gachette, an LRG Patient Registry Associate), I would love to help out at some stage as a volunteer or something, because knowing that there's people out there not getting the right help is distressing to me - because the help wasn't there for me. I know how they feel; I guess it's an empathy thing."

Shari would also like to be able to support GIST patients with the Australian/New Zealand Facebook group help combat misinformation about GIST, including issues surrounding the necessity of mutational for every GIST patient and finding GIST specialists in her area.

"The LRG put me on the right track. They basically changed my outcome. There's a lot of good information they've put together and the network they have is just awesome. I just want to help by sharing that information," Shari said.

Shari is not one to take no for an answer, not when it comes to life and death situations. After looking so long for answers prior to her diagnosis, she realized that she might have been diagnosed earlier, had any of the doctors requested a simple CT.

"If my situation is anything to go by, don't give up. Get the CT. Get the test. If it shows nothing, then great."

In addition to being available for GIST patients and spreading accurate information among GISTers on the Aussie Facebook page, Shari hopes to interact with doctors.

"My big plan is to be able to pick up the phone and speak to a GIST specialist and say: 'who are you training up at the moment - would you be interested in phoning the LRG?' I'm trying to think in terms of stepping things up. How many people could be saved if we spread good information about GIST?"

GISTers wanting to connect with Shari can contact the LRG Patient Registry at patientregistrydepartment@liferaftgroup.

Amy Kenworthy, Gold Coast, Gleevec, NED

Professor Amy Kenworthy, also born in the U.S., was raised in Massachusetts and immigrated to Queensland, Australia, after finishing her PhD in 1999. She and her husband, George, are both professors at Bond University on the Gold Coast. They have two teens, Bryce, 13, and Mariel, 17.

The year 2011 was a critical one for Amy. She and George had just been married in June, and in July, she was promoted to the rank of full professor. In August of that same year, her tumor was found by chance. Amy was asymptomatic and her tumor was discovered during a routine colonoscopy. It took two needle biopsies to confirm the diagnosis. The local oncologist she was referred to knew little about GIST - he was a breast cancer oncologist who admitted to Googling 'GIST treatment' just prior to meeting with Amy and her husband. That was all they needed to hear. Amy contacted the team at Peter MacCallum Cancer Center in Melbourne and got an appointment with a GIST specialist there. After a surgery with clear margins (performed in the States), Amy still travels to Melbourne to see her specialist for monitoring.

Amy endured six surgeries after the resection - an ileostomy plus fistula repairs, and has been on Gleevec for seven years. Due to a high mitotic rate, Amy has decided to continue treatment until her youngest child finishes high school with the hope that more will be known about GIST and that more data will guide her decision to continue additional years of treatment or stop Gleevec. Currently, Amy is NED.

"Unfortunately, the problem now is that GIST is not entirely unheard of, so most GPs or most regular oncologists will do what that first person we met with tried to do; they don't do mutational testing because they don't know how to do it or how important it is and they say 'here's the standard treatment - you're on Gleevec for three years, then you'll be done'. Anyone who is diagnosed with GIST needs to have mutational testing done and needs to meet with a GIST specialist. Those are not 'nice to haves,' they are live-saving 'must haves' as part of anyone's GIST treatment" said Amy.

She learned about the LRG early in her GIST journey from her dad, who attended a GDOL (GIST Day of Learning) in the U.S., and she immediately recognized the importance of the GIST Patient Registry. "I'm a researcher and I know that you can't do research without data."



Left to right: Bryce, Mariel, and Amy

Amy continued, "It's not okay that the doctor I was referred to initially was a breast cancer specialist. It's not ok that he didn't know about my cancer. He needed to know GIST in order to treat me. This is a really big message that I want to share. You need to be an advocate for yourself, and you need to be working with GIST specialists because there's a lot to know and no one can know everything, and that's why we have specialists. If you don't have a GIST specialist, you need to get one. You shouldn't be on this journey without that. I passionately believe in working with people who have knowledge about our cancers; in my case, if I had stayed with the doctor who was recommended to me, who knows if I would still be here today or not."

Amy hopes to help other GIST patients find the support and the connectedness they need on this journey.

This story continues on page 12.



A Blessing from GIST

One of the truly remarkable things that has happened as a result of Amy's journey with GIST is that her son, Bryce, at nine years old, watched what she was going through and couldn't believe that children had to go through the same things. . He decided to take action and created a project in 2016 called Super Max & Bryce (www.supermaxandbryce.org). "Love through the stars is what we do" is their tagline and with good reason.

"Bryce saw me going through all my surgeries and treatments and thought about how scary it must be to be a child diagnosed with cancer going through the same thing. He wanted to raise money to buy Super Max the Turtle™ Nightlights specifically designed for children in treatment because they can be fully sanitized." Amy explained.

This allows the nightlights to be brought into sterile areas, like the ICU or isolation, where kids can't bring their favorite blankets or stuffed toys. These nightlights, designed by the US-based Cloud b company, who worked with children's oncologists to develop the product, display a wonderful projection of stars. Bryce's initial goal was to raise enough money for six Turtles, and he raised quickly enough for 54 via bake sales and such.

When Cloud b learned of Bryce's goal, they supplied the Turtles at cost. Linda Suh, Cloud b's CEO, is quoted on Bryce's website as saying, "Bryce is an angel and a fierce friend helping children fight their battle of childhood cancer. Something no child should experience! We are so touched and inspired by Bryce's work, and are so proud and grateful to be a partner of Super Max & Bryce."

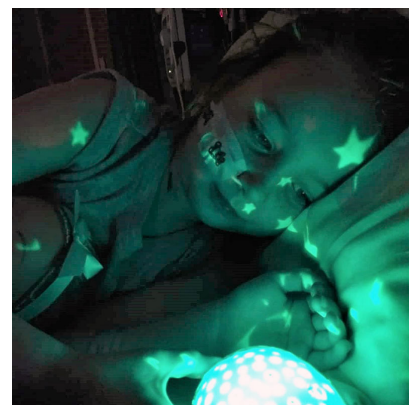
Bryce & his family raised enough money during that first year that they gifted 244 children in treatment across Australia with the Turtles for that Christmas. Now, just four years later, Bryce has gifted over 3,500

turtle night lights. This special family now gives away 1,000 turtles every year - one to each child diagnosed with cancer or a life-threatening hematology-based disease in Australia and New Zealand. In addition, they also give star-covered scarves to the moms and star-covered socks to the dads, symbolizing that every single person on this journey is connected through the stars. The Turtle (aka Amy's daughter Mariel) also visits the children's wards lavishing the kids with high-fives and hugs where possible.

"My children now know, through this project, that no matter what happens to me, they can and will survive. They've seen so many families of children in treatment and been a part of so many of their journeys. They know about living every day with gratitude and love and the importance of connectedness, and being part of this larger family of people who never wanted to be on these journeys but are. And now we're all on our journeys together - no one is alone - we are all connected through the stars with love, hope, happiness, and comfort." said Amy.

This journey, which no one would have chosen, has opened up a new world full of people the Kenworthys might never have met otherwise and illustrates to Amy the importance of connectedness.

"Knowing that you're not alone on this unwanted, terrible journey brings you gratitude for things you never knew you could have gratitude for, and you find love and beauty in places you wouldn't have found it before. One of those things is connectedness with people you meet. It's a very special thing."



www.supermaxandbryce.org

The 2020 Wolf Strong Award

by Angela Edson, MSW, LRG Contributor

This year the LRG has awarded Carolina Ponce the Wolf Strong Award. This award was created by the LRG in honor of GISTer Ted Wolf, who was the first recipient in 2018, at our very first GIST DO IT Walk at Life Fest Miami. Ted bravely endured an eight-year journey with GIST. The award recognizes patients who continue to persevere despite their health challenges, and who spread awareness about GIST, advocate for themselves, and give back to the community.

Carolina, a GIST patient, stepped up to host an eight-week mindfulness series for patients and caregivers in the height of the pandemic. During these sessions, she taught mindfulness-based, stress-reduction techniques to help participants find a sense of calm in the chaos.



It's hard to put into words what I feel right now from getting this award. I want to thank you [Tammy], of course, Ted - I know he's here with us, and the Life Raft Group for this. I was never expecting an award like this but at the same time. I know this is also in honor of Ted and I'm so, so grateful that I was able to somehow connect with you and him through mindfulness. It's interesting because mindfulness teaches you compassion; teaches you kindness and interconnectedness. It's a natural result and effect from sending out from sending out that energy. I believe that when I was doing the Mindfulness Series, it became not just a mindfulness practice or breathwork - I think we formed a little family there. We really connected on a different level. And when you do that, when you send things out like that, they usually come back in the form of love. It's funny how the universe will just send you love back. And I really appreciate the Life Raft Group too. I can never be grateful enough for what they've done for me. They saved my life. They helped my family cope with this. They actually in many ways encouraged me to adopt my son. They gave me hope and with hope you see challenges turned into opportunities. It's amazing what faith and hope does in your life. I'm excited to use this award as another motivator to keep on doing many other things for GIST patients and their caregivers like you [Tammy]. To continue helping other and sharing the love.

- Carolina Ponce



Carolina was diagnosed with GIST at 26 years old, as she was completing a dual Master's Degree program in Gifted and Talented Education and Bilingual Education.

Carolina juggled finishing her degree and starting treatment for GIST. She persevered through her health challenges and managed to graduate but the path she envisioned for herself post-graduation, however, had changed drastically. She was angry and in denial about her diagnosis and filled her free time with distractions to cope.

After Carolina came to terms with her diagnosis and processed her feelings, she felt she had two options: to be a cancer patient, or do something bigger. While Carolina's life did not develop as she pictured, she has been able to create a beautiful life for herself while managing her GIST journey. She struggled with the potential risks of becoming pregnant and stopping treatment, but becoming a mother was so important to her that she pursued adoption and her son was placed with her at birth.

Searching for a silver lining in her diagnosis, she had an intuition she was meant to help others. During one of her hospital stays, Carolina learned breathing techniques to deal with pain, stress, and anxiety.

At the time, Carolina did not realize she was actually practicing mindfulness. She began to develop a daily practice of mindfulness and felt an innate desire to share this with others after experiencing all the benefits it offered and went on to become a mindfulness coach. It was important to Carolina to give the Life Raft Group community an opportunity to learn these tools, too, as the social-emotional part of a cancer diagnosis can be very taxing.

The strength that Carolina has demonstrated to build a fulfilling life despite these challenges and give back to others is remarkable. She credits her strength to building a support network of family and friends on whom she can rely, as well as her own inner strength to advocate for herself.



Carolina Ponce

Check out the events section on our website for the dates of Carolina's next Mindfulness series in 2021. You can see Ted Wolf's wife, Tammy, presenting this award to Carolina on video on our YouTube channel:

<https://www.youtube.com/watch?v=ZIUhe1aj5xo>

Give Every Month (GEM)

This regular system of giving, whether it is \$10, \$20, or \$30 or more a month, will assure a consistent and steady stream of support to GIST patients and their families.

When you become a GEM, you will receive recognition on the LRG website and be highlighted in our Newsletter. With each level you will receive a complimentary GEM recognition item. Below are the GEM levels. Every GEM will be recognized at our various educational events, GDOLS, Life Fest and webcasts.

We are grateful for your support and ask that you consider a new way to support the LRG's efforts. The needs of GIST patients and the work of the LRG cannot stop during hard times.



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Share your story, suggestions, life experience with GIST - give & get encouragement on:

GIST Chat* (a private email community for GIST patients)

GIST Survivor on Facebook (private, moderated by The LRG)

*For info, email info@lifteraftgroup.org

In Memoriam - Dr. Nikhil Guhagarkar

Nikhil Guhagarkar found opportunities to balance life as a father, husband, medical professional, patient advocate and cancer survivor. When he travelled around the world, he found beauty in whatever he saw and shared it with others. I loved meeting with him and hearing how proud he was of his son being a chess champion.

He brought such light to every meeting we had. He had such a sweet smile and you couldn't help but like him! It was inspiring to watch him grow over the years with his confidence as a patient advocate. He assisted so many GIST patients and families in India but he also shared his knowledge and experience with topics such as nutrition and dental health with the global GIST community through virtual presentations with the Life Raft Group and other patient advocacy groups.

- Sara Rothschild, VP Program Services

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