

Ensuring no one has to face GIST alone



In Loving Memory: John L. Thomas



Stories of hope from the LRG community

lifteraftgroup.org

From the desk of our Executive Director, Norman J. Scherzer

The coronavirus has challenged our modern world in ways we never could have imagined.

The Life Raft Group has faced a challenging few months, but it is important to remember that this is not the first time the world has faced such a challenge. We are navigating a pandemic the likes of which the world had not seen for 100 years.

We have faced tough challenges before. Since the 1918 influenza pandemic, which struck a world trying to navigate WWI, there have been many hopeful breakthroughs on the scientific front. We discovered a new vaccine which overcame the scourge of polio and iron lungs; we brought the incidence of other childhood diseases under control with a series of new vaccines; we did the same for syphilis through contact tracing and new treatments like penicillin - and finally we eradicated smallpox from the face of the earth by very sophisticated contact tracing and a new vaccine.

Here's how we faced the challenge. The Life Raft Group moved its New Jersey based operations to working at home, joining Data Analyst Jerry Call in Virginia and LRG Global Consultant Piga Fernández in Chile who routinely work out of their home offices.

Our Director of Operations and Marketing, Matthew Mattioli, had us up and running virtually almost immediately and our incredible staff settled in for the long haul. Patients and their caregivers needed up-to-date information and support, and we helped them navigate their appointments and clinical trials, frequently through telemedicine. GIST specialists we work with stepped up to the plate and helped us reach out to those who were not even their own patients.

But we needed some silver lining distractions to keep our spirits up as one day phased into the other. The stressors of pandemic "normalcy" began taking its toll with kids off from school competing with the attention of parents trying to work; adults sharing the same space with each other 24 hours a day beginning to get on one another's nerves and those living alone struggled with this extra burden of social isolation.

The Life Raft Group and its GIST partnership community have never been busier:

- ▶ *Blueprint Medicines* announced that its drug, Ayvakit, worked for a rare subset of GIST patients with a D842V mutation that was resistant to Gleevec. (Unfortunately, they failed to get approval for 4th line treatment of KIT mutant GIST).
- ▶ *Deciphera Pharmaceuticals* announced that its drug Qinlock was approved by the FDA as a new fourth line treatment for kit mutant GIST patients who had received 3 or more prior treatments.

- ▶ The *National Institutes of Health* (NIH) reached out to us to request that we partner with them to conduct their annual Pediatric & Wildtype GIST Clinic virtually through two virtual tumor review boards, held on May 21st and June 11th.
- ▶ Several major medical institutions reached out to us to collaborate on gathering data including:
 - *Foundation Medicine* regarding SDH Patients
 - *Weill Cornell* regarding GIST and COVID-19
 - *New York Presbyterian Herbert Irving Cancer Center* continued its evaluation of tissue supplied by the Life Raft Group regarding turning off master regulators to bypass ongoing mutations.
- ▶ We continued to move ahead with a major study of different hispanic patients in collaboration with Dr. Jason Sicklick in San Diego, Dr. Gary Schwartz in New York City, Dr. Jonathan Trent in Miami, and Rodrigo Salas of Fundación GIST México.
- ▶ We finalized an agreement with *Oregon Health and Science University* (OHSU) to house our tissue bank.
- ▶ Our **Pediatric & SDH-Deficient GIST Consortium** continued to meet to carry out the commitment made at the Biden Cancer Summit to find cures for this predominately young GIST patient group.
- ▶ We hosted two webcasts. One titled, "New Treatments Options for GIST & Concerns about Coronavirus" and another called, "GIST, TKIs Effects on Memory as well as Coping with COVID-19."
- ▶ We also hosted various support groups for patients and caregivers as well as launched a **GISTEntertainment** series of virtual group activities for our members.

Finally, ASCO announced over 40 abstracts approved for GIST at its virtual meeting, including co-authorship by the Life Raft Group: "Diagnostic algorithm for gastrointestinal stromal tumor (GIST) using patient registry data impacts pathology guidelines." (<https://meetinglibrary.asco.org/record/189328/abstract>) and a collaborative effort between several key organizations, including the Life Raft Group, called, "Using consistent terms in precision medicine to eliminate patient confusion" (<https://meetinglibrary.asco.org/record/189938/abstract>)

On the COVID-19 front, GIST patients have by and large managed to stay safe by sheltering at home. According to a recent survey of our Global Surveillance group, we actually found no COVID-19 cases among their GIST patients so far.

This current pandemic has brought out the worst and the best in people but thankfully much more the latter. I will cite one story of a young female nurse holding the dying hand of an older man with COVID-19. His family could not visit him and, being poor, did not even have the benefit of a computer connection. The nurse treated him as she would her own father and when he passed, she escaped to the ladies' room and with her knees resting on the cold tile floor cried her heart out. And then she went back to work. The human spirit which defines us all lives on.

We still have a lot of work to do but the hope of new treatments and vaccines visible on the COVID-19 horizon and the bravery and dedication of heroes, like Eric Lindberg and Drs. Jonathan Trent and Matt Lurin whose stories are featured in this issue, provide us with the inspiration to survive and thrive.

Stay safe.

Collaborations in a Time of Challenge

During this historic pandemic, creativity and collaboration have been paired to assure that young GIST patients are not missing out on vital treatment. The regularly scheduled in-person National Institute of Health's (NIH) Pediatric and Wildtype GIST Clinic had to be postponed due to the coronavirus. The NIH turned to the Life Raft Group to help organize a series of two Virtual Tumor Boards to review cases that otherwise would have to wait until the clinic can safely be held.

The LRG collaborated with the NIH in producing this annual Tumor Board virtually with not only NIH doctors but also with experts from the Pediatric & SDH-Deficient GIST Consortium, continuing the mission of the Consortium first put forth at the Biden Summit in 2018.

We will highlight this collaboration of the LRG and the NIH and explore our long-standing relationship in future communications.



The Life Raft Group has been a Godsend in my life since receiving my GIST diagnosis a year ago. I've learned so much about my cancer through the experiences of others. I've also talked to three or four Life Raft staff members who have given me guidance and support. But the best part has been the GIST Mentor you assigned to me. Kay has called and encouraged me numerous times and was recently instrumental in getting me a video conference with Dr. Trent in Miami. I'm grateful beyond words!

- Margaret McInteer

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We are currently living in a very complicated world: illness, pandemic, social unrest, separation and loneliness. It is tough to get through each day with a consistent amount of joy, security and comfort but there is hope. Our strength as GISTers is based upon community and us caring for one another.

I just figured out why after many times that I have been in the company of my GIST family that I become overwhelmed and my eyes begin to water. As a black man born in the 50's, I have seen and experienced a good share of racism. It has led me to be sensitive to those that practice racism and treat me differently because of my paint job. I am sorry if this offends anyone who does understand but it just blew me away that I encountered such a kind, loving group of people who did not look like me but treated me with great dignity and respect. I never once felt black but human. I never felt disdain but love. This impacted me greatly and gave me a overwhelming sense of joy.

There is hope because we are able to impact and encourage each other. Collectively we help each other get through this challenging time. We are strong and there is hope because we have each other.

- Robert Taylor

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You Are the Hope

by Mary Garland, LRG Director of Communications

March 13. I remember the day well. The Life Raft Group staff gathered around the conference room table and shared our concerns about alarming reports of a virus that was threatening the health of people globally. We discussed the pros and cons of working remotely, considering both our own well-being and safety, and the ability to provide support for our patients and caregivers.

As we hastily assembled necessities from our offices, I remember being very frightened. I did not know then that we would be physically apart for so long. Over my work desk is a fabric board with pictures of all those I love most, including the beautiful faces of my children and grandchildren. Little did I realize that I would also be apart from them for such a long time.

As the weeks went by, I learned to look for signs of hope wherever I could find them. Some days, they were few and far between. I remember sharing with a friend on one particularly dark day that I didn't see any signs of hope at all.

But then there were days when light came pouring through the darkness. I looked at the faces of my colleagues as they shared on a Zoom call all the remarkable achievements they had accomplished.

Patients were helped with telemedicine consults. Doctors were extending their services to patients outside their regular practice, often without charge. Many put aside their own fears to serve others.

We held two Virtual Tumor Boards with the NIH when their Pediatric and Wildtype GIST in-person clinic needed to be cancelled. Within two days, over 40 global GIST experts responded to a question about COVID-19 and GIST through our Global Surveillance system.

Several new treatment options became approved, opening up hope for patients who had failed other treatment lines.

Hope, like the crocuses that were beginning to poke through the ground, started to emerge.

There were still dark days. When would we return to normal? When could I hug my grandchildren again?

Sometimes, when it is darkest, the small sliver of light appears to help us make our way out of despair.

You became my hope.

Making calls to check on our patients, I spoke with a 94-year old GISTer who is not only surviving for over 16 years on Gleevec, but who is thriving. She shared how her doctor is facilitating her treatment so she can remain safe. She feels cared for.

Some of you served on the front lines, rising above fears for your own welfare. (Eric's story on page 5).

You continued to share daily your strength, hope and experience with one another on GIST Chat. You welcomed newcomers, pointed them in the direction of a GIST specialist, and shared more personally about your fears and how you rose above them. One of you began sharing daily inspirational quotes, moving me to do the same with our staff.

You began to share information on COVID-19, and your experiences in continuing to keep key appointments. Our science folks shared and discussed the latest studies.

Many of you shared your gratitude in just being alive - to have found treatments that are effective in helping you survive and thrive.

I shared this hope with others, telling them how inspired I am each day to hear your stories, and to share them when you allow me that privilege.

On March 13, the day I went into lockdown, I started to write a post-it-note each day. On it is simply the date, and the words, "Thank You." It became my background for the endless Zoom calls. I told the story of how a group of cancer patients who count their blessings every day for their overall survival taught me to look for hope in the ordinary in these extraordinary times. As of this writing, there are 97 of these notes.

Your hope continued to inspire me.

And as if the pandemic were not enough darkness, civil unrest arose around us. How to continue to find hope in yet even more despair?

Again, you shed light in the darkness. I read Rob Taylor's post on GIST Chat, and the heartwarming messages you all shared with him. I was filled with hope in a way I had not been since the March lockdown. (Quoted on cover.)



As I look out my window in my home office, I see promise all around as I watch a robin scurrying across the lush green lawn, and it reminds me of my favorite poem by Emily Dickinson:

"Hope" is the thing with feathers -
That perches in the soul -
And sings the tune without the words -
And never stops - at all -
And sweetest - in the Gale - is heard -
And sore must be the storm -
That could abash the little Bird
That kept so many warm -
I've heard it in the chilliest land -
And on the strangest Sea -
Yet - never - in Extremity,
It asked a crumb - of me."

Hope, like the smallest bird, asks nothing of us, but provides the promise of better things to come.

Making the Right Decisions in Tough Times

How one GIST patient & caregiver are doing during this global health pandemic.

2020 has been quite trying thus far. I call our current semi-lockdown situation "putting life on hold", while SARS-CoV-2 - the virus that causes COVID-19 - attempts to run its course and infect as many of us as it can. Looking at how global infection rates have skyrocketed since the first alert was sounded, it does seem as if it's been quite successful.

Singapore, like the 211 other countries and territories around the world which have been hit by COVID-19, has not been not spared either. In fact, we were one of the first places outside China to officially report cases of the virus. Our first positive case was confirmed on January 23rd this year - a 66-year-old Chinese national who had flown into our country three days earlier. Before that - and as early as January 4th - there had been several suspect cases, all of which tested negative. One of those had been a three-year-old girl also from China, who was found to have Respiratory Syncytial Virus (RSV) instead - a completely different virus that infects almost all children at least once before they are two years old, and that most of the time only causes minor cold-like symptoms.

At the time, COVID-19 didn't seem like very much to worry about. It was just one case. But our government had dealt with SARS (Severe Acute Respiratory Syndrome) - the 2003 respiratory disease with a 10% mortality rate - before, and was taking no chances.

Before the number of infections had a chance to escalate, our country commenced a step-by-step lockdown that first began with border closure, followed by the implementation of social distancing measures, and finally the progressive shutting down of entertainment venues, schools, workplaces, public amenities, and all "non-essential" businesses. Supermarkets and certain eateries were allowed to remain open, but with dine-ins not permitted.

In the midst of all this, my husband, Andrew, a GIST patient since April 2019, still wanted to keep his medical appointments. I was extremely worried he might get infected, especially since



by Amelia Yeo

Caregiver, LRG Country Liaison - Singapore

one of the nurses at the hospital he goes to was diagnosed with COVID-19. We ended up postponing his MRI scan, but he still went for his routine blood test and oncologist's appointment.

At the oncologist's office, I asked his doctor if we had any cause for worry, and whether any of our country's official COVID-19 cases were also cancer patients. While we were advised by him to observe better hygiene and avoid crowds, we were also told - surprisingly - that not a single coronavirus patient here was also a cancer sufferer, according to records from the National Cancer Centre Singapore which he had just requested a day

before. Our oncologist said possible reasons might be that cancer patients practice better hygiene compared to the average person, or take better care not to put themselves in risky situations, such as going to places with high human traffic. All these actions greatly lower their chances of getting infected.

Andrew's oncologist's words comforted us a great deal. It just goes to show that, as long as we are mindful and take greater precautions, we can see this pandemic through. Being sensible, taking the right action, and making the correct decisions can really make a difference.

Singapore is still in the midst of our COVID-19 battle. So far, new cases have mostly come from known clusters, and community spread seems to have slowed down a lot. Certain shops have now been given the green light to reopen. Bit by bit, our country is coming to life again. Not that soon, but when it does, we know that all we have to do to continue to stay safe, is choose wisely.



Do you have a global story to share?

Contact Mary Garland,
LRG Director, Communications,
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Long-Term Survivor Stories

For GIST patients, long term survival is the ultimate goal. A number of factors may influence long term survival – some of these are demographic and clinical, like mutational subtype and genetic factors. However, there are a number of others that are perhaps more subtle, such as lifestyle, attitude, and access to treatment, experts, and advice. Illustrated here are the anecdotal accounts of two long-term survivors and how they managed to survive and thrive for over 20 years (and counting) with GIST.

Chuck Korte knows a little something about long-term survival. Originally misdiagnosed in 1996 at 53 with leiomyosarcoma (LMS), he has lived with GIST for over 24 years. Treated with two rounds of traditional chemotherapy, Chuck's tumor was not responsive. The tumors continued to grow. There seemed to be no clear answers.



Chuck Korte

"When I first found out I had cancer, it was terrible, just devastating. It was like being in a pit for three days. We were distraught, frightened and depressed. However, I'm a very optimistic person so it was just a few days of being really very down. People always commented on me being in such a good mood because, you know, cancer, but I was always hopeful," said Chuck sharing about his initial feelings about being diagnosed with cancer, "but I always felt I would survive.

Chuck kept searching for answers and learned about a new clinical trial for STI-571 (imatinib) through fellow LMS patients on the LMS Listserv. Chuck commented that he thought that it was a good thing he didn't actually have LMS because he'd learned about this powerful new drug. "The question at that point was, did I have the mutation that this drug could treat? So, I wanted to have that variation because then I could be on the clinical trial."

He joined the first clinical trial for imatinib for GIST patients in 2001. In that trial, there was no placebo and all participants were on either 400 or 600 mg; Chuck began on 400 mg. After the first month's treatments, scans revealed progression and though that was discouraging, the team at Dana Farber upped his dosage to 600 mg. The next month's result showed rapid shrinking. Though that was thought to be the proper strategy at the time, now the doctors believe what was considered progression was possibly an inability to gauge

the size of the tumors accurately with the tools available at the time. It may just been a temporary enlargement prior to the start of shrinking.

Chuck was able to maintain his career as a professor of social psychology and gerontology. He simply lived his life with GIST. He credits a rich spiritual life, a great family foundation, and a close-knit community as tremendous blessings and GIST as a real obstacle that's he's been able to overcome with a miracle medicine.

While Chuck was able to maintain the 600 mg dosage for close to 18 years, his kidneys began to fail. Reducing his dose two years ago to 400 mg stabilized his creatinine levels, and this April during a telemedicine visit, his doctor lowered his dosage once again, to 300 mg for the sake of his kidneys. He's feels fortunate that his side effects have been manageable and he's been able to maintain a healthy lifestyle with wife Peggy's help.

Chuck has also been an active member of the LRG's GIST Listserv (since its creation and presently on its newest incarnation GISTChat), staying in touch with other GIST patients for support and to encourage others on their own journeys.

He knows that he'll be on Gleevec for the rest of his life and he's ok with that.

"I'm always in a good mood. Doctors told me, 'You're not going to die from GIST'. It's incredibly receptive to Gleevec.

Exceptionally so. I do have to worry about my kidneys and the damage that's been done, but I'm so gratified that the cancer is being very well controlled by the Gleevec and will as long as I keep taking it. There are just too many instances where tumors have grown again. I'm fine taking it."

What began as a clinical trial for Chuck has turned into a clinical study conducted at Dana Farber to examine the long-term effects of imatinib. While life with cancer is a life of constant surveillance, it is one he feels he has lived well. He attributes living well to his basic outlook on life, which is very optimistic, as well as his wife Peggy's support. "I have incredible support, beginning with my wife. I couldn't have done this without her. It's been a real team approach."



Chuck & Peggy Korte

Chuck and Peggy met as college freshman and have been married for over 50 years. They have two children (a son and a daughter) and four grandchildren, the oldest of whom just graduated from North Carolina State. Chuck is enjoying his retirement and is very active these days on GIST Chat (the new incarnation of the

Listserv) encouraging other GIST patients to stay positive and keep looking for answers.

He also has had no great worries over COVID-19 since his community has always been very close and watches out for each other. He and Peggy have been able to stay home, work on various hobbies and reading and connect with family, friends, and doctors virtually.



Dina Wiley

Factors in long-term survival can't always be measured by statistics or medical best practices. Chuck Korte sees his positivity and faith as a major factor in his overall survival, but for Dina Wiley, her determination was her driving force. Both patients have factors in their lives that have affected their successful long-term survival.

Dina, like Chuck, had false starts as far as a firm GIST diagnosis. In 1986, Dina was working as a human resources specialist in southern California and was married to husband Sam for only about a year when a tiny lump was discovered in the lining of her rectum and vagina. Categorized as a small, benign fibroid, neither her doctor nor Dina was overly concerned. "I guess this happens, people get fibroids, and life goes on. And it did for 10 years," commented Dina.

The fibroid remained stable until 1996, when within a year it doubled in size and continued to grow. Surgery was performed at a local hospital in 1996 and she was given a diagnosis of leiomyoma, a benign smooth muscle tumor that very rarely becomes cancer. Dina was relieved that she didn't have cancer.

But by 2002, the fibroid had returned and Dina became quite concerned. Growth was checked every three months, but by the end of the year it had grown significantly and surgery was recommended again. In the spring of 2003, she had a second surgery. The

biopsy performed during the surgery revealed a diagnosis of leiomyoma once again and because this was a second surgery, there was no possibility of clear margins.

Dina's world was turned upside down when her doctor shared results shared from a second pathologist (at a world-renown hospital in the East coast) who said it was leiomyosarcoma (LMS), a rare type of cancer that affects smooth muscle tissue. Dina and Sam's world changed when they heard the word cancer. "We didn't know what that was. We didn't know what was going to happen. Neither of us have ever experienced any kind of cancer, and had no way of understanding it," said Dina. "I was also very concerned that the bleeding I'd been having from the surgery hadn't stopped."

Dina's surgeon explained that without clear margins the cancer was likely to return and surgery shouldn't be delayed. Another surgeon she consulted, a sarcoma specialist, also believed there was no other option but radical surgery to eradicate the possibility of recurrence. The treatment plan was to remove her rectum and vagina completely and perform a colostomy. Dina considered the enormity of the changes she would undergo physically and emotionally, and refused the surgery. "I opted out. I didn't believe the diagnosis. Perhaps I was hard-headed, but I refused to accept this diagnosis and treatment."

"So, I was faced with this cancer diagnosis, but the lump had been removed and the cancer wasn't there right now. What if it never came back? I didn't see any reason to go in and do this horrible surgery.

continued on page 8

Long-Term Survivor Stories - Dina Wiley, continued from pg 7

They said they could partially reconstruct the vagina, but I'd still have to deal with a colostomy," said Dina, "Perhaps I was hard-headed, but I refused to accept this diagnosis and treatment."

Dina pursued other opinions. "My husband had my back. He kept me going and he gave me the hope and the faith that I needed to believe that something was going to work." A second surgical oncologist, at a nearby cancer research hospital, confirmed the LMS diagnosis and recommended radiation therapy, an option that Dina also passed on as she felt it would do too much damage. Another specialist, in colorectal surgery, felt he had a surgical technique that wouldn't require a large incision and there would be no reason to have a 'permanent' colostomy. Even though this was offered by a renowned specialist at yet another cancer research hospital, Dina was still skeptical and wondered if it would work. Her options seemed

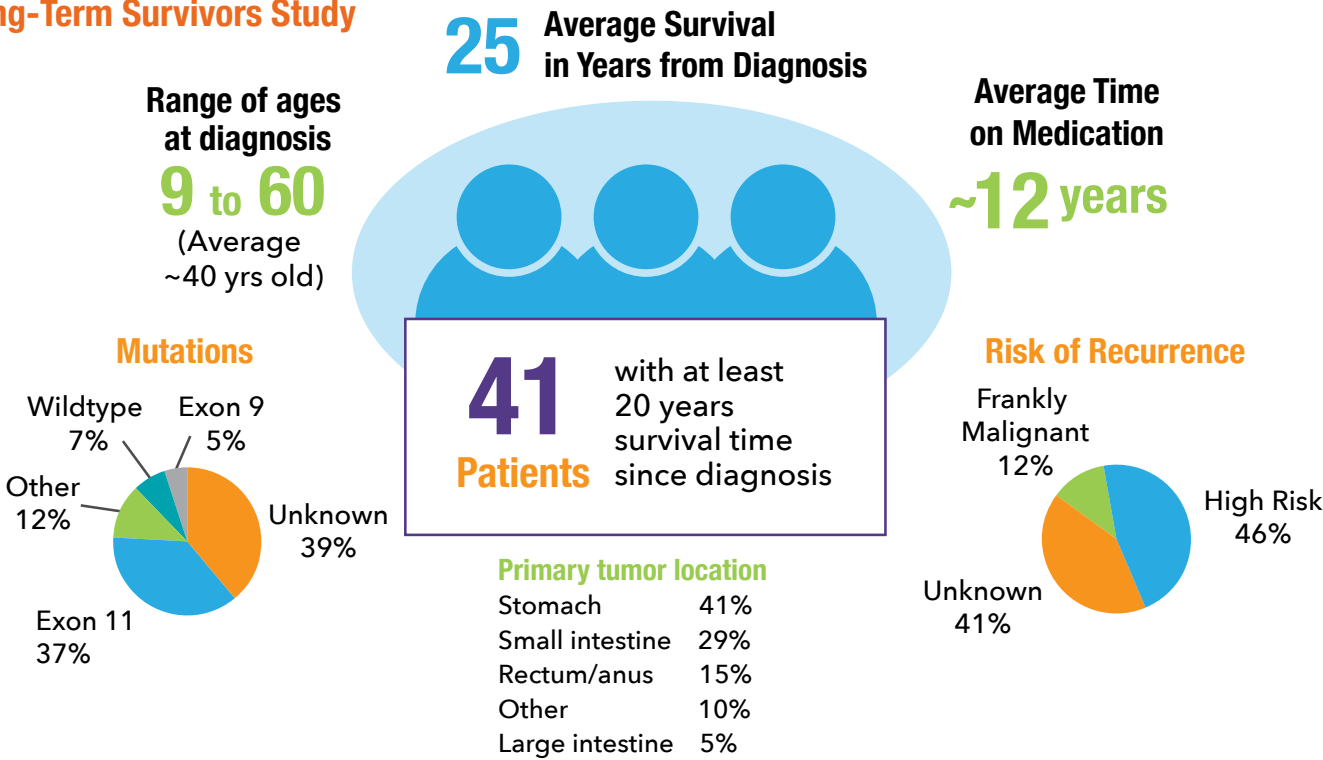
limited and she was actually considering the surgery when she met Dr. Gene Sherman, a local oncologist. He presented her case to the tumor board at Torrance Memorial Medical Center and the unexpected happened.

At the tumor board, another pathologist questioned the results because he suspected GIST and performed a test for c-KIT. "Not only did this amazing pathologist test the most recent specimen for GIST, he went back to storage and pulled my specimen from 1996, and tested it," said Dina, "Dr. Sherman could barely control his amazement when he delivered the news that it was GIST and not LMS." Of course, Dina was surprised at this and wanted to know why it mattered. The doctor explained that GIST could be treated with a pill once a day - Gleevec.

Dina finally had an option that she could live with. "I was so happy I wanted to hug him!" said



Patient Registry Data
Long-Term Survivors Study



► In an effort to better understand the factors that affect long term survival, both of a demographic/clinical and a more subtle nature, the LRG has identified a subset of long term survivors and will be conducting a survey in the coming weeks. The infographic above summarizes some of the key demographic/clinical characteristics of our survey population, which consists of some of our longest term survivors. The goal of our survey is to learn what the more subtle factors are, and then to tell our patient community about them so they can benefit from the advice of their fellow patients.

Dina. Her big takeaway from this experience was to never accept the first diagnosis. "And from my experience, it isn't always the top research hospitals that can be trusted, my little town hospital did what a larger, major hospital could not," declared Dina.

For 17 years, Dina has taken Gleevec, though not without ups and downs. After about nine months, Dina had had enough of the muscle cramping and stomach upset so she decided to stop taking the medicine of her own accord. After a year, she experienced a recurrence and was given the choice of another surgery or Gleevec. Dina resumed Gleevec at 400mg until 2015 when she experienced stage 4 kidney disease and was severely anemic. Since then she's taken 200mg a day.

Dina's tools for survival were many - not taking the first diagnosis for the final word, her determination to keep looking for solutions, the support of her husband, and also the support of others like her. She joined the

Cancer Support Community in Redondo Beach, CA, and met Dave Murphy, of the Sarcoma Alliance, who knew the LRG's Executive Director, Norman Scherzer, and this is how she

connected with the people and resources of the Life Raft Group. She's also regularly attended support group meetings of The Sarcoma Alliance in Los Angeles since 2004.

Today, Dina is a dedicated patient advocate, active with the LRG as southern California's State Representative and a voice for

GIST in several support groups, both online and in-person. Dina's positive words bear testament to her survival story, "I was always hopeful it was something else, and I always knew it would be okay."

Be your own truth seeker!

- Dina Wiley



I was told I would probably never live to see the oldest of our children graduate from high school and now I have seen all five of them graduate from college. By the grace of God, I have also been here for the weddings of all of our children and welcomed eight beautiful grandchildren into the world. I am so thankful for my beloved and supportive husband and our dear children and their families. Their faith and prayers have helped carry me through the hard times. I am thankful for my Savior who has lightened my burdens and brought me peace.

I'm thankful I found the Life Raft Group. I'm thankful for Norman and Jerry and their beloved wives, who were the pioneers. I am thankful for all of my LRG friends, those departed and you who live. I feel like I know all of you from reading your posts. I pray each of you may be blessed as I have been. I am rejoicing and celebrating this day!

- Carrie Callister

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The GIST MENTOR PROGRAM has been very helpful, informative and inspiring. My GIST Mentor, Karen Meyers, shared all these qualities with me which gave me encouragement during this time in my life. We became friends sharing a common cause. Spiritually with GOD'S help I can live a full life as a GIST survivor. Please continue to offer such programs to GIST survivors.

- Nadeane Buckson

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I got connected to a GIST Mentor very quickly and talking to her was great! I felt a sense of relief after speaking to her and it really helped me realize I'm not alone.

- April Lopossa

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Through the GIST support group, I feel I have made a 'new best friend'. I don't think there could be a better match for me. Marlene Nei is not only encouraging on the GIST journey, but with life in general. While there are many states between us, and we have never met face-to-face, we have a closeness that can't be compared to other friendships

- Linda Brooks Geiss

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Heroes on the Frontline



Dr. Matthew Lurin
LRG Major Donor & Fundraiser

Dr. Lurin is the Associate Director of Emergency Medicine at Mount Sinai South Nassau in Oceanside, NY, USA.



Are you seeing a lot of patients with COVID-19?

Yes. Our department has treated more than 1,300 cases since March, but fortunately we are now seeing fewer than just a couple of weeks ago.

How are you dealing with the stress of the pandemic?

Amazingly, I have had little time for stress. Having trained in Emergency Medicine, I go to work planning on doing the best I can, and having recently moved, I spend my free time working on my new house. Thanks to online internet cameras and programs I have been able to chat with friends and stay connected. Also, I caught up on a few movies and TV shows as well.

What keeps you motivated?

I have to believe we will get through this. The disease itself is quite devastating, and I am seeing things I could never have imagined in medicine. Social distancing and isolation may help with the spread of disease, but also makes this even more challenging for everyone. I guess my motivation is to get to the other side of this pandemic and to see how beautiful life can be, again.

What are some of the most important things that a GIST patient can do during this pandemic for their health and peace of mind?

Practice what everyone has been saying, wash your hands, wear masks, and keep up the social distancing. I can only imagine how difficult it would be to face both COVID and GIST at the same time, feeling alone. But remember, though we may be isolated, we are not alone. Call or text or video chat with friends. I have had whisky tastings with people from all over the world, from my backyard. Use technology to help with your own mental health.

What acts of heroism have you seen on the 'frontlines' since this pandemic has begun?

Everyone naturally talks about doctors and nurses and EMTs, and they have been at the forefront during this fight. However, there are others who work with us, phlebotomists, respiratory therapists, our ED techs, registration, radiology and housekeeping who are taking the same risks we are, as we are all in this together. I think anyone showing up and doing their job, at the risk of their own peril is showing an act of heroism, but at the same time we all feel this is simply what we are supposed to do.

What moments have given you hope during this time?

For every discharge or extubation (taking someone off the respirator) our overhead notification in the hospital plays "Here Comes the Sun" or "Just Breathe", to remind us that folks are getting better. Intellectually, seeing the numbers of cases and following the trends gives me hope that what we are doing is working, and that we will get through this.

How can the LRG support you during this time?

The best way for anyone to support what we do is to keep faith, and do your best to live your life during this difficult time. As long as groups like the Life Raft Group are able to stay on mission and support those with GIST, it makes us feel we are doing the right thing and helping the world get back to closer to normal.

Anything else you'd like to share?

All the free food sent to work has been amazing, and the clapping has felt nice too. I hope the kindness towards our fellow man continues long after we get past this. I look forward to raising a few glasses with friends once this is a memory. *Slàinte Mhath**

*Good health to you!

Heroes on the Frontline

Eric Lindberg, GIST Patient & GIST Mentor, North Carolina, USA

Every GIST patient has had to make difficult decisions during this pandemic. To keep appointments, to have that scan, to work in the office – daily choices about how to stay safe and how to maintain emotional balance in very uncertain times. Eric Lindberg, diagnosed with GIST in 2017, works as an emergency room nurse and has been on the frontlines throughout this pandemic.

Eric shared what it was like to work the ER during the worst of the pandemic. The hospital, located in a retirement community area in Hendersonville, admitted quite a few COVID patients in the early days of the crisis but saw a volume drop since cases that would normally come to the ER stopped. Fear kept people out of the hospital. "We even have people that have stayed at home after having a heart attack and some did very poorly because they didn't come in. They'd just call their doctor the next morning," Eric noted.

As a GIST patient, Eric had his tumors successfully resected and since he has a high risk of recurrence, lifelong adjuvant treatment with imatinib is recommended. Eric wasn't given an option to not work during the crisis but says that his hospital hasn't had an issue getting proper protective equipment. "It's not been a huge concern for me. I use the gear and I work. My coworkers do their best to avoid sending me obvious virus patients, but screening people can be hard. At the beginning, the turnaround for testing was 48 hours. The rapid test will change the whole ballgame. We've been fortunate that no one yet on our emergency room staff has contracted the virus."

Currently the hospital is opening up for selected, elective surgeries again such as postponed cancer surgeries and knee replacements and the like. Eric noted that if there's a quality of life issue, you're probably eager to get these surgeries done and the hospital has now put these operations at the top of the priority list. Every patient admitted for surgery is tested for COVID-19.

His perspective on the virus and how it will affect him is pragmatic. "It's inevitable that some of us [GIST patients] will get the virus. And this helps to flatten the curve. We're going to see people trickle in for a few months. I'm not sure it'll ever go away completely." Being in the healthcare field, Eric is required to have an annual flu shot which he feels is ineffective since he has gotten influenza causing him to feel as if he's naturally susceptible to certain viruses. "Hopefully one of the vaccines like remdesivir will be approved," said Eric.

People will probably have a lot of anxiety about going out in public for some time. "If you have GIST and other comorbidities, like congestive heart failure and diabetes, you have to take that into consideration."

Eric says that he and his family are staying positive during these trying times by keeping busy outdoors. "I've still been camping. I don't do campgrounds. I like to hike out and I'm fortunate because where I live, I'm surrounded by forest.

A lot of parks are closed now, but it's still not that hard to get outside and find places to go hike and fish. Been doing that a lot."

Equally pragmatic is his view on GIST patient cancer care. He suggests that the best course of action would be to put off your imaging and labs for the time being if you can and do what you can virtually and by phone. "You have to live your life. Do what you can. Practice your social distancing and stay healthy. Try not to put off your cancer care. In today's information age and with electronic medical records, it's not too difficult to see a specialist virtually or by phone for surveillance," shared Eric, when asked about his advice for GIST patients concerning their cancer care.

Eric shared that he's glad the LRG is there for him too, for this crisis, and throughout his GIST journey. "I may not need help right now. I feel pretty good most days just knowing you're [the LRG] there and you've helped me a lot and given me the opportunity to help other GIST patients. I feel for GIST patients especially if they've been diagnosed in the last three months. They can definitely use extra support."

Eric is a GIST Mentor and is active on GIST Chat, both are support services available to LRG members. If you would like more information about becoming an LRG member, joining our GIST Patient Registry or having a GIST Mentor, please contact the LRG at liferaft@liferaftgroup.org or call 973-837-9092, 9-5 EST.



Heroes on the Frontline

Dr. Jonathan Trent, Sylvester Comprehensive Cancer Center, Florida, USA

Effective Telemedicine During the COVID-19 Health Crisis



Dr. Jonathan Trent

Cancer patients around the world have faced unique obstacles when coping with the stay-at-home mandates. Dealing with the stress and anxiety of self-isolation, fear of physician and hospital visits as well as not being able to have their regular schedule of monitoring

(scans, etc.) are just a few of the issues that patients have had to work through. There are, however, some very hopeful examples of how our health care systems (U.S.) have learned flexibility during this crisis in order to meet patients' needs. The LRG was fortunate to get a few minutes with GIST specialist, Jonathan Trent, MD, Sylvester Comprehensive Cancer Center, who shared his experience with his patients over the past few months.

Shared Decision-Making with Patients

The burning question that all GIST patients wanted answered was "Do I go to have my regular scans and appointments with my GIST specialist, if they are scheduled?"

This proved to be a multi-layered answer based partially on patient needs and payer and industry requirements. Dr. Trent strongly felt that there first needs to be a conversation between the patient and physician about whether scans and appointments could be postponed.

"Staying home is most important. So, the first question is 'Can I postpone the visit until it's safe?' If the patient had their GIST resected six years ago and I'm only seeing them once a year, then I can postpone their visit for two or three months and then reevaluate at that time. If we can do that, it's better because they don't have to be exposed at a CAT scan or in a lab. Normally, we see about 25 patients on an average clinic day and we've been able to postpone about five patients a day. Right there we've pushed about 20% of these appointments into mid- and late summer," responded Dr. Trent.

There are other considerations as to whether a patient should keep their appointments. Dr. Trent continued, "If they have had their GIST resected less than two years ago, they may still be at risk for recurrence, so we are getting scans on those patients. We're getting labs. They are getting these tests done locally and then mailing and emailing imaging studies and lab results to our clinic."

Telemedicine has become an integral part of how Dr. Trent and his team are communicating with patients currently. With labs and scans being mailed in to the clinic, the nursing staff can coordinate that information with the doctors and the doctors can 'see' patients via teleconferencing tools from their home so that patients don't have to travel.

"Sylvester has been very supportive of these efforts and wants us to do whatever it takes to care for our patients and minimize their potential exposure to the Coronavirus. Some institutions across the country continue to require patients to visit in person." Dr. Trent went on to explain that, "The ability of a physician to see patients by telemedicine also varies from state to state creating regional differences. For instance, I recently had a new telemedicine visit with a GIST patient who lives in Nebraska. She didn't want to have to appear in person and risk exposure to COVID-19. Luckily, at Sylvester we have been able to do telemedicine visits with patients around the country that weren't comfortable with in person visits but couldn't do televisits with their regular oncologist. Additionally, we have had televisits with patients from Brazil, Ecuador, El Salvador, and even Russia. Personally, I'm still seeing 50-60 patients a week. Not one patient has demanded they be seen in person."

Dr. Trent says that it's a "hard decision-making process with patients balancing the potential risk of COVID-19 outweighing the potential risk of recurrence. Some patients adamantly just want to postpone their imaging and labs. And like I said, as far as medications, we have the capability to mail tyrosine kinase inhibitors and self-administered clinical trial medications to all of our patients. So that's a huge advancement. We do a lot of liquid biopsies, or circulating tumor DNA, in order to determine KIT resistance mutations and guide subsequent therapy. We work with a company to perform this testing at the patient's home."

GIST patients have been concerned about their status as immunosuppressed or immunocompromised. Dr. Trent spoke about one situation with a patient on imatinib. "I spent 45 minutes talking with a patient about whether he's immunosuppressed or not as he's on imatinib. He doesn't want to go into work and everything he does at work he can do at home, but his boss doesn't believe in working from home. The boss wants everybody to be physically in their offices. The patient was panicking. I had to reassure him that it's [imatinib] not really considered immunosuppressive, although

we don't have a lot of data. It's not a traditional immunosuppressive agent. I gave him some guidance on gloves and surgical masks and things like that, because it's, you know, he can't lose his job or he loses his insurance. It's a very fine line we are all walking these days."

How the Team at Sylvester is Coping

Staying connected visually has strengthened the process of telemedicine for both the patients and the staff. Dr. Trent says that his team is faring pretty well conferencing by video at least twice a week to review new patients and make sure there's no missing information so that the televisit is as productive as possible. "Even though it's on Zoom, seeing somebody's face is so much better than just a teleconference," said Dr. Trent. In addition to clinic held two times a week, the staff also does a virtual tumor board which can include oncology radiologists, pathologists, nurse practitioners, nurses, surgeons, and fellows who are in training and learning from different disciplines twice a week.

"And then, our team, my nurse Vilma Sanchez, nurse practitioner Morgan Mount, and myself are in clinic all day on Tuesday and Wednesday. We're on Zoom together the whole day basically, and then we usually have a three-way telephone call on the side so that when we exit the clinic in Zoom, we are able pick up the phone and talk to each other. Just like we were sitting next to each other so we've been able to keep engaged and connected. The video is the savior, I think that that really helps us stay connected. We've had a few Friday evening happy hours too, where we all Zoom and congratulate each other on working hard this week and then just have some fun. We've had a couple of virtual

birthday parties and a graduation.

Two of our nurse practitioners, Solange Sierra and Morgan have young babies and they hold their babies up to the camera for us to interact with their kids. We mix up our Zoom backgrounds; have some fun. Dr. D'Amato has a background that says, 'What the hell is sarcoma?'"

Dr. Trent shared that he's been playing a lot of basketball and cooking, too. "I have two sons in college and a daughter in high school. They ended up being at home in virtual school since the middle of March. So, I've been playing a lot of 2-on-2 basketball on the small court in my driveway. Of course we've been cooking a lot. It's one thing that you have to do and you can do together when you are home and you can't go out. I like to barbecue so we've been having a lot of brisket, ribs and grilled vegetables. To keep things fun, we had a Thanksgiving dinner a few weeks ago. We did turkey and stuffing, potatoes, green beans, rolls just like the one in November. Tonight, we're having Christmas dinner."

How the LRG can help

Dr. Trent says that the biggest thing the LRG can do for him right now (and more importantly for patients) is to let know that he is available by telemedicine to any patient, even on a temporary basis if they do not feel comfortable going into an office or hospital setting. "There's very few reasons that you have to go into clinic and potentially expose yourself to COVID-19. At Sylvester, we're happy to see anybody even on a temporary basis until the pandemic is over. If they need to talk to somebody about GIST or have somebody review the scans, we are happy to do that until they can get back to their regular doctor."

If you want to connect with Dr. Trent virtually, please contact Sahibjeet Kaur, our LRG Patient Registry Dept. Supervisor, for more information: skaur@liferaftgroup.org
You can also check our GIST Specialist Database for a GIST specialist in your area.

“

I know that good things are going to come out of our current situation. People are already stepping up to help one another. There are more positive results ahead. May we all make the changes we need in our lives to stay well!

- Carolyn Dewalt



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Thank you to our major donors for April & May!

Carolyn Dewalt	Renee Shaw
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and to our GISTEntertainment Sponsors
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Virtual Life Fest 2020, July 10th-July 13th

2020 brought a global health crisis that has challenged GIST patients. Even though we can't be together physically for our biennial Life Fest celebration and we won't be together for GIST Awareness Day, we can unite and spread a message of hope and positive messages while raising GIST awareness across the globe. Thanks to the generosity of our sponsors, we still have a wonderful virtual weekend planned, with some of the same elements Life Fest always provides.

With the latest information being shared in both our traditional GIST 101 presentation with Dr. David Josephy, and through several panels featuring top GIST specialists and researchers, a program targeted to the SDH community as well as fun events including a cooking demonstration, Virtual Life Fest will prove that even with the restrictions on gathering, you cannot keep the GIST community from sharing their strength, hope and experiences.

REGISTER for Virtual Life Fest at: lifteraftgroup.org/event/virtual-life-fest/



Virtual GIST DO IT Walk, July 12th

As part of our Virtual Life Fest celebration, we are hosting a Virtual GIST DO IT Walk on Sunday, July 12, 2020. The walk is held in memory of Ted Wolf, who lost his battle with GIST in 2018.

A virtual walk is a real walk, but on your terms. You get choose your own course, what time you start, and who walks next to you!

REGISTER: lifteraftgroup.org/event/virtual-gist-do-it-walk/



GIST Awareness Day, July 13th



The ultimate goal of GIST Awareness Day (GAD) is to bring so much attention to GIST that knowing what it is will no longer be so "rare". GIST Awareness Day serves as the yearly pinnacle of our education, awareness and advocacy efforts and provides those outside the GIST community a chance to learn about and lend their support to this important cause.

Our theme for GIST Awareness Day 2020 is **#GISTHOPE**.

During this pandemic, we have seen images of hope that people are sharing on social media.

We invite you to spread the message **#GISTHope** by painting this message on rocks and placing them on trails or pathways in your community.

- ▶ Paint or draw an image of a rainbow, the universal sign of hope, and the hashtag **#GISTHope**.
- ▶ Want to go bigger? Paint a **#GISTHope** sign, or make a quilt, design jewelry, create a mural, or hang a banner.
- ▶ You can find our Facebook frames by searching Life Raft Group in the area where you add a Profile Frame on Facebook.
- ▶ Check out our GAD page for downloads and more ideas for your **#GISTHope** activities.

Send your stories, photos and messages of hope to Mary Garland, Director of Communications: mgarland@lifteraftgroup.org



Visit our GAD page:

lifteraftgroup.org/about-gist-awareness-day/



See the full list of events:
lifteraftgroup.org/event/

For events in Canada visit:
GIST Sarcoma Life Raft Group Canada
lifteraftgroup.ca/welcome/

In Loving Memory of Ted Wolf

NEW JERSEY
**GIST
DO IT**
The Life Raft
GROUP

September 26th, 2020

Mark your calendar! Walk rescheduled for
September 26th in Verona Park, NJ.



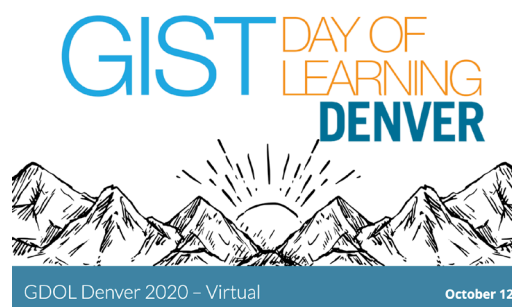
July 23-25, 2021

Virtual GDOLs
Scheduled



GDOL Tampa 2020 - Virtual

October 10



GDOL Denver 2020 - Virtual

October 12

SPREADHOPE

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Donate today

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The Life Raft Group needs
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Read & write fluently in a
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Contact:
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connect

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

We need **YOUR** feedback - Take the
User Experience Survey & tell us how
our website measures up -----> <https://bit.ly/LRG-website-survey>

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Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director, Outreach & Engagement
dnieves@lifteraftgroup.org

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior VP
locchiuzzi@lifteraftgroup.org

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