

# Ensuring no one has to face GIST alone



In Loving Memory: Sixto Gonzalez, Elaine Rys , Marvin Frazier, Charles Kossivi, Ward Brockett, Earline Miller

## April Stephens, Long-Term Survivor

by Carolyn Tordella, LRG Assistant Director, Communications

April's GISTory is a quite different from the long-term stories we've shared so far – those of Dina Wiley, Chuck Korte, and John Abrams (see Member Stories on our website). The average GIST patient is in their 50s or older when diagnosed. The rare exception is usually a pediatric SDH-deficient GIST, but April's case is a case of 'the rarest of the rare' in that she was only 20 years old when she first encountered GIST and was not SDH-deficient.

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April Stephens & daughter Mary Catherine

## The LRG Focuses on Biomarker Testing for All GIST Patients in 2021 Campaign

### #TimeToGetTested

by Mary Garland, LRG Director, Communications

Understanding the role of mutations and biomarker testing is one of most important things patients must learn. Uncovering the driving force behind each individual's tumors is not just important, it is critical. Biomarker testing is an opportunity to improve and optimize treatment – possibly avoiding unnecessary treatments and getting to the right treatment sooner. Currently, biomarker testing rates in the gastrointestinal stromal tumor patient population are relatively poor – only about 26.7% of patients have had testing done.<sup>1</sup> The Life Raft Group Patient Registry, which is a group of extremely proactive patients, notes about 52.7% of patients are aware of their mutation.

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## Stopping the Ripple Effect

The lethal time gap for the treatment of GIST is growing, and many of our GIST patients will now die, not because there was not an available diagnostic test to connect to an effective targeted treatment, but because their doctor did not know about it.

Not too long ago the struggle for surviving GIST depended upon researchers finding an effective targeted treatment. After the initial discovery of imatinib for first-line treatment, research priorities shifted to finding a second line treatment. In 2021, we find ourselves with five approved drugs and several more in the pipeline close to approval.

This increase in viable treatments is a result of the identification of more disease subtypes serving as targets. The identification of these subtypes is a direct result of more sophisticated biomarker (mutational) tests. This process has resulted in dramatic improvements in the long-term survival for a cancer once thought to be untreatable.

Twenty years ago, treatment was determined by a simple treatment algorithm:

**Patient is c-KIT positive -> Diagnosis of GIST -> Surgery and/or treatment with imatinib (Gleevec)**

With the discovery of new subtypes, and the development of new testing tools, the algorithm is more complex, providing the ability to hone in on a more precise diagnosis, providing more personalized treatment.

Each new research milestone has created a powerful new healing tool in the hands of an experienced physician while simultaneously adding to the lethal time gap created by the delay in learning about using such a tool by the inexperienced physician.

For the patient in the care of an experienced physician - a GIST specialist - this is great news. For the patient in the hands of an inexperienced physician, this is very bad news.

The underlying problem is that the certification of physician expertise does not go far enough. For a cancer patient navigating the complex world of medical care, the choices of specialists often end at the major categories like oncology, surgery, radiology, pathology, urology and gynecology, and so on.

Patients need to understand that most local oncologists do not see enough GIST patients to acquire the expertise to keep up with the evolving cutting-edge improvements in diagnosis and treatment. Finding one that does can be a difficult task. It is not made any easier by the failure of the medical community to create new layers of certification such as GIST Specialist.

The result is that most GIST patients do not see a specialist and as a result often do not receive even the most basic diagnostic (mutational) testing. This means that too many patients are prescribed drugs that are not the most effective. As a result, they have to endure unnecessary side effects and may experience disease progression, and sometimes death before an effective treatment is found.

The ripple effect is that the patient suffers unnecessarily from an improper diagnosis, the insurance company wastes money and families are left with the ultimate empty chair at the table.

*The solution seems simple enough.*

***Identify the GIST specialists.***

*This is something the Life Raft Group does on an ongoing basis as well as educating the GIST community to seek one for care.*

*Continued at the top of the next page*



Like so many things in our complex health system, these changes may not happen quickly. Even if a patient knows about needing to see a specialist and can identify one, there are several obstacles to be met. The first obstacle to seeing a specialist is where the nearest specialist is located. Perhaps they are some distance away and in a major and expensive urban area. And then to be considered:

*Is that specialist part of the patient's insurance network coverage?*

*Does the patient have the time and money for travel and lodging?*

*Is the patient healthy enough to travel?*

*Can telemedicine be part of the equation?*

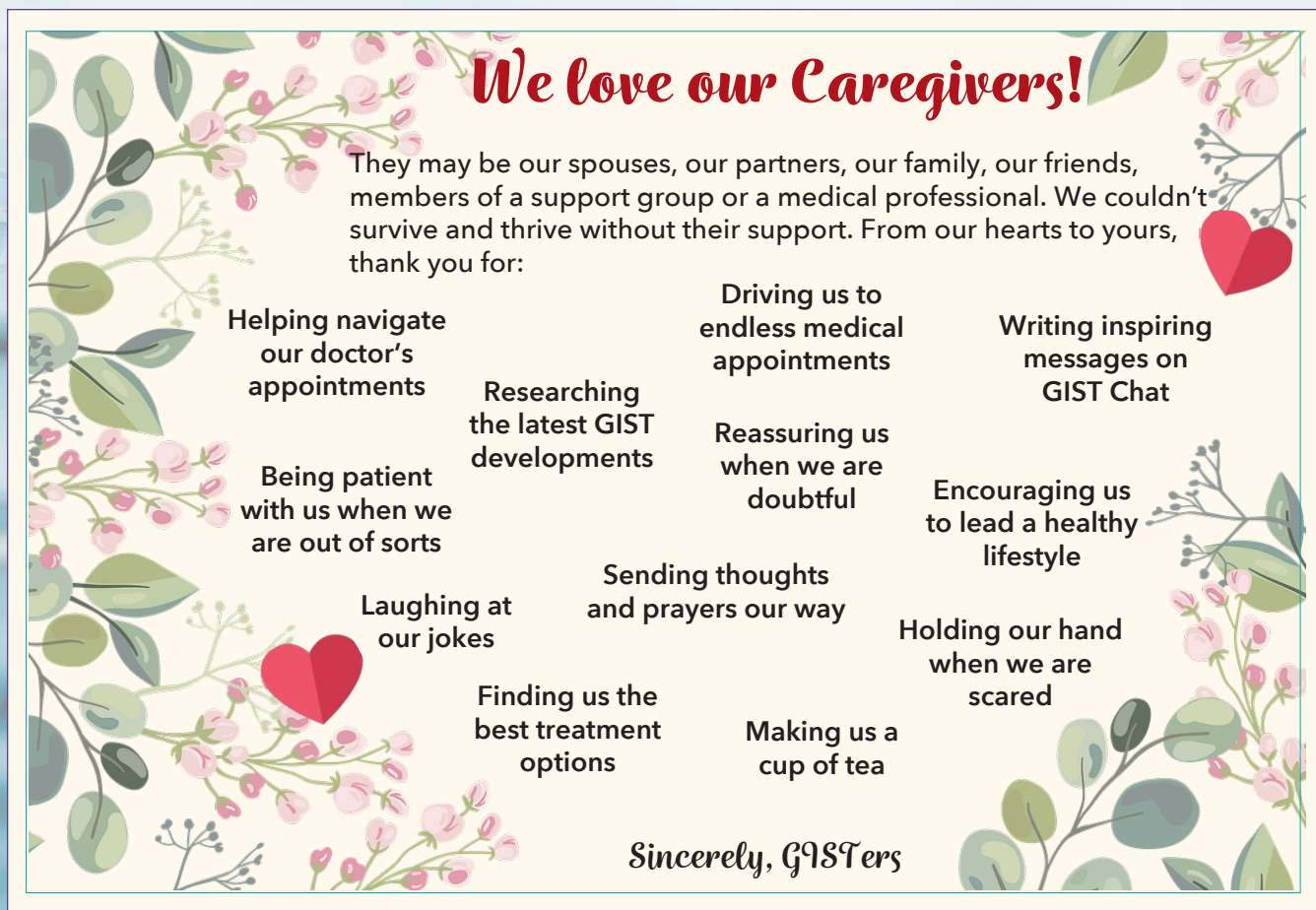
*Would the specialist provide a consult with the general oncologist who is providing the ongoing care?  
Are both doctors willing?*

*Can the insurance infrastructure accommodate these innovations such as a specialist and local oncologist working together or telemedicine appointments?*

If all these obstacles are overcome will this ensure patient survival? Perhaps. If the patient can see a specialist, get the proper diagnostic tests, and be prescribed the right targeted drug, then the question becomes "Is it available and can the patient afford it?"

Our ongoing mission is to stop the ripples from occurring in the first place and to cut them off before they continue to spread.

*- Norman J. Scherzer*



Though she can say she has been a GIST survivor since she was 20, April wasn't officially diagnosed with GIST until two years later. To understand the 'official' designation here, April said what happened to her in 1998 when she suffered extreme stomach pain that her doctors believed was an ileus (intestinal obstruction) or appendicitis. During the subsequent emergency surgery, doctors removed her appendix and what was believed to be a Meckel's diverticulum.\* She had no health issues again until 2000.

At 22, she had experienced vague stomach discomfort and had even gone to the emergency room once due to the pain, but after x-rays and blood tests, she was presumed to be suffering from constipation.

Her gynecologist noticed a potential ovarian cyst or tumor during a routine ultrasound late in 2000. After a CT confirmed there was indeed a mass, assumed to be a benign ovarian cyst, April had surgery. The surgery, however, revealed a large cancerous tumor - 32 cm, which had metastasized throughout her abdomen.

Her treatment team took another look at the tissue from the 1998 surgery and it was confirmed to be GIST. April is thankful for the prior misdiagnosis. April shared, "If I had been diagnosed with cancer in 1998...I was in the middle of college, about to start my junior year. I would have most likely started chemotherapy treatment (although it was not notably effective in GIST, but there were no other treatment options in 1998) and deal with its side effects. So, I think it's just part of God's plan that it happened the way it did. I am thankful that when I was diagnosed with GIST in December 2000, that there was a new targeted drug that could possibly work. And it did."

At the time of the cancer diagnosis, April was in college working toward a double major in exercise science and dietetics & nutrition and was newly married to Heath, her husband of 20 years. Her pathology report revealed GIST. She said that after her diagnosis, she thought of her grandmother who had recently passed away from cancer.

*\* A Meckel's diverticulum is an outpouching or bulge in the lower part of the small intestine. The bulge is congenital (present at birth) and is a leftover of the umbilical cord. It is the most common congenital defect of the gastrointestinal tract. It occurs in about 2% to 3% of the general population. (Source: Cleveland Clinic)*

"My grandmother had died in April of 2000 from a sarcoma and had gone through chemo. I drove her to several of her appointments. My GIST diagnosis was hard at first. I remember my grandmother said she never asked 'Why me? Why did I get cancer?' That came to my mind when I was diagnosed. You just have to move forward and start fighting GIST."

April's local oncologist, Dr. Dan Bradford, has been a part of her treatment team since her official diagnosis in 2000. Additionally, with Dr. Bradford's recommendation, she has been followed by GIST expert Dr. Suzanne George and GIST surgeon Dr. Chandrajit Raut at Dana Farber Cancer Institute since 2011.

“ This 20 year journey has shown me that God’s timing and plans are always perfect even if I don’t understand them at the time. He has provided new drugs each time I needed them, guided me through nine surgeries and placed family and friends in my life to help support me along the way.

- April Stephens

”

Dr. Bradford and his team knew of the imatinib trials for GIST patients at MD Anderson and April applied to participate, but because there was no evidence of disease after her surgery, she was unable to join the trial. The doctors developed a protocol

and applied for compassionate use of the drug and she began imatinib in March of 2001. Gleevec was approved for GIST in May of 2001 and April stayed on that treatment until December of 2013 with a few tweaks to dosage and another surgery in 2011 and in 2013. During this time, April finished her undergraduate degrees and her masters in Nutrition, in addition to working in her field and having a baby.

Daughter Mary Catherine was the focus of a very large tweak in treatment. In the early days of Gleevec, it was a common thought that perhaps a GIST patient who was on Gleevec for five years with no recurrence could stop treatment. In 2006, April and Heath began researching what was and was not recommended for GIST patients on Gleevec and pregnancy. They talked with Dr. Bradford and he reached out to other GIST experts. April herself emailed some experts, and followed a CML patient on Gleevec and the story of her pregnancy.

"Eventually, my doctors did say I could stop it [Gleevec] but I needed to know about the risks involved and the possibility that the tumors could come back. As long as I was informed, then they were willing to give me some time to try to start a family. They wanted to do a scan after a three-month period with no treatment to see if I was a 'rapid relapser'," said April.

When April was first diagnosed with GIST and couldn't get on the trial and receive Gleevec, the doctors were going to put in a port so that she could receive chemo. At that point, April was advised to consider fertility preservation because the chemo would affect her chances of getting pregnant later.

"I was going to do fertility preservation, but it was just all too much for me at that time. So, we didn't do it. It was all so overwhelming. We went to the first appointment (with the fertility specialist) but we didn't pursue it," April shared.

The scan at three months showed no evidence of disease and she and her husband had the green light to try to get pregnant. Several more scans were clear before April became pregnant in December of 2006. Mary Catherine was born in August, a healthy 9.1-pound baby following a healthy, uneventful pregnancy. Thankfully they were able to avoid a c-section, which is an important consideration for future surgeries.

The plan after Mary Catherine was delivered was to have a scan as soon as possible but before she could even schedule the scan, April noticed tenderness in her abdomen. A scan revealed a recurrence that was 7cm tumor along with several other smaller metastases. April then resumed Gleevec and her scans, six weeks later, were clear. April and her medical team assumed that she would probably be on Gleevec for life. Mary Catherine is now a healthy, active thirteen-year-old junior high student.

April's treatment story doesn't stop at Gleevec. In 2013, several months after another surgery, there was progression and in December of that year she began Sutent. The side effects from this drug were much worse than Gleevec and though her disease was stable for a time, there was no real shrinkage. Gradually her

disease showed slow progression and in 2015, she was switched to Stivarga. 2016 and 2017 brought more surgery and due to slow wound healing and tumor growth not seen on scans but discovered in surgery, her doctors concluded that Stivarga was not working effectively. April joined the BLU-285 (avapritinib) trial in January 2018, but by June between cognitive side effects and tumor growth, she was removed from that trial. After a washout period, April was accepted to the DCC-2618 (ripretinib) trial and remains on that trial currently.



*The Stephens Family: Heath, Mary Catherine, April*

Patients who undergo so many surgeries and so many treatment lines experience a variety of consequences from the surgeries and side effects from the various drugs. April is thriving and surviving as long-term GISTer. She credits several things for sustaining her throughout the past two decades. Her faith, family, close friends and her husband, above all.

"This 20-year journey has shown me that God's timing and plans are always perfect even if I don't understand them at the time. He

has provided new drugs each time

I needed them, guided me through nine surgeries and placed family and friends in my life to help support me along the way," said April, "I feel pretty good even though I have dealt with fatigue on all of the drugs. I have to keep a positive outlook on things and I can't let myself get down about my GIST diagnosis or the side effects of treatments."

She continued about husband Heath specifically, "He's always the one that's there, if things have progressed or if I am going to have to switch drugs; he keeps me from going down the 'what if' and 'why' paths. He's says this is going to work and you'll tolerate it well. You're strong, you'll do great."

*April Stephens' story continues on page 6*

**Are you interested in reading more long-term survivor stories?**

**Check out the [Member Stories](#) section on our website.**

**Interested in encouraging others with your long-term survivor story?**

**Email Pete Knox at [pknox@liferaftgroup.org](mailto:pknox@liferaftgroup.org)**





**April Stephens, exon 11, 17  
Arkansas, USA**

The LRG recently conducted a survey of long-term survivors where we asked them a number of questions to help understand what they felt contributed to their long-term survival, as well as other topics.

### *What makes a long-term survivor?*

"I think that staying in good overall health, eating healthy, and exercise have all helped me. I try to stay on top of what's going on in the GIST world as far as new treatments, trials and research, so that I can ask appropriate questions when I go to my doctor appointments."

### *April's advice to other GISTers just beginning this journey:*

"Getting to a GIST Specialist and finding a doctor that you have a good rapport with - they take time with you, they answer your questions thoroughly, you can get in touch with them when you need to. I recommend getting a second opinion if you need to, if there's ever a question or doubt about something. And the same thing with the insurance. They can deny certain procedures, tests, drugs, or doctors. Don't take a no, but make an appeal to the insurance company, by calling or writing a letter. One of my insurance companies wasn't going to approve my surgery out of state with a GIST Specialist, so I found the NCCN guidelines for GIST and documented where it said if you had advanced GIST you need to see a GIST surgeon, a specialist, and I sent that in and finally they approved it. Be your own advocate."

### *Has the LRG been a help and support along the way?*

In the early days of her diagnosis, April's mom, Cathy, started doing research and found the GIST Listserv (a private email community for those who were facing a new diagnosis of GIST vs LMS) which was very young (now replaced by GISTChat) and had information about the imatinib trial. April also commented, "Definitely. I always read the newsletters. Several years ago, I read about the trials on the website and I even talked to an LRG staff member about information they had on a specific trial. I also enjoy reading the personal stories that are published. It's been a huge help to me. I'm grateful for the educational resources of the Life Raft Group and how they have helped me make treatment decisions along the way."

## Resources on Pregnancy & GIST

In our LRG community, we've seen many examples of GISTer family planning but also women who have found out they had GIST while they were pregnant. *What are some of the considerations in both situations and where can patients go for resources and information?*

### **Begin with a GIST specialist.**

Whether you are a newly diagnosed patient, a patient currently on treatment desiring to get pregnant, or a pregnant patient diagnosed with GIST, we strongly recommend that you consult with a GIST specialist. This specialist may be able to work in conjunction with your local oncologist if distance to a GIST specialist is an issue.

**You may want to involve other specialists** - It is also important to have a specialist in maternal-fetal medicine on your team to assess all aspects of your pregnancy.

### **Additional Considerations:**

It is critical to know your mutation. If you don't know your mutation, have a biopsy performed to find out your mutation and risk of recurrence.

### **If you're newly diagnosed...**

This depends where you're starting. If you are newly diagnosed and have not begun treatment, you may want to consider consulting a fertility specialist and discussing the possibility of preserving your fertility. This option applies to both female and male patients. It is essential to consider that future surgeries and drug treatments could affect your ability to get pregnant or bear children safely. There is also the consideration that you might not be able to stop your treatment long enough to ensure that the drugs are out of your system and that scans show no evidence of disease or recurrence before you even try to get pregnant.

### **If you are pregnant and discover you have GIST or on treatment already?**

Cases of discovering a GIST while pregnant are rare, with only 11 reported. Adjuvant imatinib therapy, which targets the most common driver mutations, KIT and PDGFRA, is recommended for patients with high-risk GIST, but it has known teratogenicity (capable of producing congenital malformations) in the

first trimester. Because of this, tumor molecular profiling is critical.<sup>1</sup> Each individual case will need assessed based on mutational testing results and risk of recurrence.

Here are some great resources and stories to help you sort through some of these issues:

**[What to Expect When You're Trying to Expect](https://liferaftgroup.org/2017/04/what-to-expect-when-youre-trying-to-expect/)** - <https://liferaftgroup.org/2017/04/what-to-expect-when-youre-trying-to-expect/>

**[April Lopossa - A young mother finds out she has GIST while pregnant.](https://liferaftgroup.org/2020/12/delivering-hope-a-modern-day-miracle-of-birth/)** <https://liferaftgroup.org/2020/12/delivering-hope-a-modern-day-miracle-of-birth/>

**[Carolina Ponce - An SDH-deficient patient makes family planning choices.](https://liferaftgroup.org/2013/04/family-planning-with-gist/)** <https://liferaftgroup.org/2013/04/family-planning-with-gist/>

**[Carrie Broussard - GISTer discovers she's pregnant while on treatment.](https://liferaftgroup.org/2013/06/carrie-broussard-and-her-little-brave-warrior/)** <https://liferaftgroup.org/2013/06/carrie-broussard-and-her-little-brave-warrior/>

*More resources on next page.*

## Resources

(1) Charo LM, Burgoyne AM, Fanta PT, et al. A Novel PRKAR1B-BRAF Fusion in Gastrointestinal Stromal Tumor Guides Adjuvant Treatment Decision-Making During Pregnancy. *Journal of the National Comprehensive Cancer Network: JNCCN*. 2018 Mar;16(3):238-242. DOI: 10.6004/jnccn.2017.7039. <https://pubmed.ncbi.nlm.nih.gov/29523662/>

Florou V, Ramdial, J, Trent, JC. GIST in Pregnancy: The Role of Circulating Tumor DNA to Define the Assessment of Risk of Rapid Progression and Response to Imatinib. *Journal of Clinical Oncology* 2018 36:25, 2659-2660. [http://gotoper-com.s3.amazonaws.com/\\_media/\\_pdf/ajho\\_17.11\\_GI.pdf](http://gotoper-com.s3.amazonaws.com/_media/_pdf/ajho_17.11_GI.pdf)

Zarkavelis G, Petrakis D, Pavlidis N. Gastrointestinal stromal tumors during pregnancy: a systematic review of an uncommon but treatable malignancy. *Clinical & Translational Oncology : Official Publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico*. 2015 Oct;17(10):757-762. DOI: 10.1007/s12094-015-1315-x. <https://pubmed.ncbi.nlm.nih.gov/26055339/>

## Patient Advocacy in Brazil



by Luciana Holtz de Camargo Barros

President & Founder Instituto Oncoguia, Brazil

*I am a proud wife and mother of two twin boys and the President and Founder of the cancer patient advocacy organization,*

*Instituto Oncoguia, in São Paulo, Brazil. I am a psycho-oncologist with a specialization in bioethics.*



I worked with patients and their families as a psycho-oncologist until 2010. During this

time, I often became frustrated when my patients would come to me after a cancer diagnosis with inaccurate information that led to depression, anxiety and other avoidable mental stress. To address this need, in 2003 I launched the Oncoguia Portal, a reference website to provide accurate, quality, and digestible information to patients and caregivers about prevention, diagnosis and treatment of cancer. The success of Oncoguia Portal demonstrated the need for further action.

In 2009, I collaborated with other health professionals and volunteer cancer patients to establish the nonprofit, Instituto Oncoguia, with the objective of helping patients with cancer live better lives. Instituto Oncoguia develops programs and initiatives related to health promotion, disease prevention, wellness and patients' rights through increasing access to quality information, educating the community, empowering patients with support services, and advocacy.

*Instituto Oncoguia has six strategic objectives:*

- 1) to provide quality information for patients, families and communities;
- 2) to educate patients and communities about the importance of self-care, wellness, and quality of life;

- 3) to empower patients and communities by offering them a voice and supporting their needs;
- 4) to promote and facilitate access to legislative rights for patients;
- 5) to increase citizen participation and engage legislators to improve public policies related to cancer control;
- 6) to promote a multidisciplinary health approach.

With this strategy in mind, Instituto Oncoguia has two main platforms: the Oncoguia Portal, an informative and interactive online resource for those seeking accurate and quality information, and the National Support Program for Patients with Cancer (PAP), which provides resources and support through a toll-free number.

On November 23, 2020, we at Instituto Oncoguia celebrated our 11th anniversary. Over the years, we have learned a lot - the good, the bad, and the inspiring! The greatest benefit I have experienced through my work is being able to interact with patients and their families and to support them through the most difficult moments of their lives.

It has been such a blessing to develop close relationships with our patients and volunteers and to see the positive quality of life many have, including those living with advanced disease. With this, of course, comes many challenges, as well. In Brazil, our public health system is not equal. This can be very difficult and frustrating when our patients are unable to access the treatment and care they need and deserve. We know without a doubt that lives have been needlessly lost because patients did not receive health services in a timely manner. This is what drives us and keeps us motivated to continue fighting.

To address these inequities, we have worked in partnership with other patient organizations to pass two specific laws that are designed to expedite service

*Advocacy in Brazil continues on page 8*



delivery for patients. First, the 60-day law, passed in 2012, requires that patients receiving care through the public health system must begin treatment within a maximum of 60 days from the date of signature on the pathology report diagnosing the malignancy. We know, however, that implementation of this law is inconsistent and delays are also found during the pathology and diagnostic phase.

As such, in 2019, the 30-day law was passed that requires test results confirming malignant neoplasms be received by patients through the public health system within a maximum of 30 days.

We continue to monitor the data available through the public health system as well as the patient experience

to ensure these laws are implemented appropriately. Our hope is that anyone seeking care is able to receive a fast diagnosis and begin treatment using the best medication and technology available to facilitate a positive health outcome and quality of life.

Our work with GIST has been ongoing for many years. Our priority has been to ensure patients and families have access to quality information and receive patient support. GIST is among a group of rare cancers in Brazil that have an extra burden of finding and accessing the appropriate specialists who are experts in the area.

This is one of the greatest barriers for our patients living with GIST in Brazil. Many oncologists are not familiar with GIST and patients often face many challenges to simply reach a diagnosis. It is not uncommon for patients to have to seek the opinion of many doctors and specialists for a diagnosis and then begins the additional barriers to biopsy and treatment delays that disproportionately affects patients living with GIST because of the lack of familiarity with the disease.

We know that there is a lot to be done to meet our objective of ensuring patients living with cancer live better lives. For patients living with GIST, the challenges are even greater. But with the support and partnership of Life Raft Group, we are strengthened and motivated to continue providing quality information and support for patients and families so that every person impacted by cancer knows they are not alone.

Visit Instituto Oncoguia at: [oncoguia.org.br/](http://oncoguia.org.br/)



YJ Kim, Seoul, South Korea

## Welcome to Young Jae Kim!

The Life Raft Group is pleased to welcome Mr. Young Jae Kim (YJ) as the new LRG representative (liaison) in our global network! YJ calls Seoul, South Korea home. He

began his GIST journey in 2017 when a GIST was discovered during a routine gastroscopy (a type of endoscopy). Testing showed the mutation to be exon 11 so Glivec was prescribed post-surgery. YJ continued his job as a salaryman - a 9-6 worker, after surgery, and scans showed no evidence of disease (NED) throughout his treatment on Glivec. YJ choose to discontinue Glivec in 2018.

YJ's scan remained clear until May of 2020 when metastases were discovered in his liver, pancreas,

and bladder. Thankfully, Glivec was begun again and YJ's last scans in October showed that the tumors are shrinking. With the advent of the mets, YJ chose to work as a freelancer in order to take care of his health. As long as he is able, he has a desire to helps others like himself.

Dr. Yoon-Koo Kang, a GIST specialist in South Korea at the Asan Medical Center, introduced YJ to the LRG. YJ wants to help Korea's GIST patients by sharing resources and educational information as well as sharing success stories nationally and globally to encourage others in their GIST journeys. He would also like that to be reciprocal - he would like to share stories from around the globe to encourage and bring hope to Korean GIST patients.





*This story is continued from cover*

Despite discussions among professionals, numerous publications, and web presentations on this topic, biomarker testing still has not become the standard of care across the board for cancer patients. Even with the strong recommendations of the National Comprehensive Cancer Network (NCCN) and the European Society for Medical Oncology (ESMO), non-profits that write guidelines for cancer care in the USA and Europe, biomarker testing is not a regular component of the standard of care that each GIST patient receives. Without biomarker testing, treatment is not meeting these expert guidelines for the best care of patients.

This is why the LRG is launching the *It's Time* campaign. It is time to stop talking and take action to assure patients get tested. The goals of this campaign are to improve the understanding of biomarker testing in the cancer community and increase the number of patients tested.

Through this targeted campaign, the LRG will focus on increasing our Patient Awareness and Education initiatives. Because of our assertive focus on the importance of testing, patients in the LRG patient registry have higher rates of biomarker testing and survival than the general population. Our goal is to expand that reach exponentially (Let's Get This Done

in 2021!). We will engage with and educate patients about biomarker testing through a series of focused webcasts, patient testimonial videos, and animation videos produced in collaboration with clinicians who champion biomarker testing. This will serve as a model for other cancer advocacy groups.

In the last few years, we have actively sought to impact the use of biomarker testing by working with key opinion leaders to lobby for changes to the College of American Pathologists (CAP) and National Comprehensive Cancer Network (NCCN) guidelines. Many medical providers and other stakeholders refer to the LRG as a model for championing biomarker testing as a best practice. Our years of outreach and advocacy experience, and our unique partnership with physicians and researchers focused on the urgency of biomarker testing, has positioned us to provide the expertise and structure needed to support the *It's Time: The Life Raft Group Biomarker Testing Campaign*.

*If you would like to talk to someone about mutational testing, please contact our Director of the Life Raft Group Patient Registry, Denisse Montoya at [dmontoya@liferaftgroup.org](mailto:dmontoya@liferaftgroup.org)*



**GIST** PATIENT  
REGISTRY

**52.7%** LRG Patient Registry members know their mutation  
**26.7%** GIST patients (not in the LRG Patient Registry) know their mutation<sup>1</sup>

**Reference:** <sup>1</sup> Florindez J, Trent J. Low Frequency of Mutation Testing in the United States: An Analysis of 3866 GIST Patients. Am J Clin Oncol. 2020 Apr;43(4):270-278. doi: 10.1097/COC.0000000000000659. PMID: 31904710.

## Vinyl Destination T-shirt & Bling Fundraiser Raises \$5K



*Lorie Perry*

Life Raft Group Member Lorie Skelton Perry sadly passed away from GIST on November 11, 2020. In honor of her passing, Lorie's husband, Ben Perry and his family decided to organize a fundraising effort to craft a legacy for her and raise some money in her memory. Ben's brother Dan and his dad, Dave, own an all-vinyl record store in Lowell, MA, called Vinyl Destination, but for the month of December they have changed the name of the store from Vinyl Destination to Cupcake Records, in honor of Lorie's amazing ability to bake the best cupcakes you've ever tasted.

Dave Perry shared, "In honor of our dear Lorie, we raised \$5,000 for the cause. I can imagine how many donations you get and I'm sure that to many that's comparatively small. But I promise you this—it was fun for us. It gave us meaning to go into the store each weekend, and it let people know who Lorie was and what made her special. And it reminded us constantly of the good within people. And boy, do we need that."

*We are very grateful to Vinyl Destinations for their generous effort and donation in Lorie's name!*



## Dear Donors & Our Entire Life Raft Group Community,

Without your generous support over the past year, we would not have been able to accomplish all that we have during a dark year. Donors of the Life Raft Group have been a part of important accomplishments and bringing light to our community such as continuing to:

- Double the rate of patient survival
- Produce real world evidence that side effects diminish over time, leading to greater patient adherence
- Reach out across the globe to advocate that patients receive access to treatment and medication
- Assemble the greatest GIST experts in the world to provide research and education for our patients during our virtual GDOLs, Life Fest, various webcasts, and Conversations with the LRG
- Collaborate with the National Institute of Health (NIH) to facilitate a virtual Pediatric & Wildtype GIST clinic
- Provide help through our GIST Mentors, weekly support groups and other wellness programs
- Communicate up-to-date information on COVID 19, treatment options, research, etc. through our various social media platforms, website, newsletter, emails, and phone calls and so much more.

Your contributions have made these accomplishments possible during 2020 and beyond. We want to thank you for supporting our efforts and look forward to the great privilege of working together as we continue to search for a cure.



*With heartfelt thanks,*

**The Board of Directors & Staff of the LRG**



**LRG Patient and Caregiver Support Groups are meeting regularly online. Please check the Events calendar on our website.**



[rarediseases.org/showyourcolors](https://rarediseases.org/showyourcolors)

Remember to use  
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Life Raft Group  
as your charity.



## Thank you to our major donors for November, December & January!

Eric Biegansky

Georgia Bihr

BST Consultants

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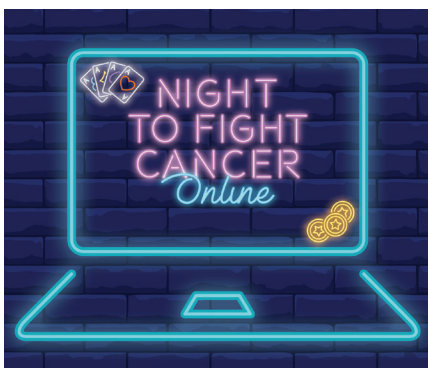
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### Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director, Outreach & Engagement [dnieves@lifteraftgroup.org](mailto:dnieves@lifteraftgroup.org)

### Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior VP  
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