

Ensuring no one has to face GIST alone

In Loving Memory: Elaine Wilson, Dulce Ipapo

Hope & Obstacles Along a GIST Journey How a Family's Persistence and the LRG Helped One Patient in a Battle to Thrive

By Carolyn Tordella, LRG Assistant Director, Communications

Many GIST patients around the world struggle with getting the treatment they need to survive and thrive. Access to a GIST specialist, mutational testing and effective drug therapies can be limited by a local oncologist's knowledge of GIST, a country's access to specific drugs and access to researchers and clinicians that can assist in creating an effective treatment plan. Arun Krishnan's story illustrates how collaboration between patient groups and doctors across the globe can affect patient survival.

At 19, Arun Krishnan was a busy university student, following in his older sister Deepa Balakrishnan's footsteps, working toward his degree in software engineering. The youngest of three children, he attended classes in the city of Chennai in southeastern India. In 2009, Arun was plagued with chronic stomach pains, untreated until they proved too much to bear.

The family's primary care physician, believing that Arun could be suffering from appendicitis, referred him to a surgeon. The surgeon discovered a mass in the jejunum (the part of the small intestine between the duodenum and ileum). Upon biopsy and immunohistochemistry staining, it was determined that the mass was a GIST. After recovering from the primary surgery, Arun began imatinib in July of 2009.

For the next two years, Arun dealt with living with the side effects of imatinib, the passing of his father in 2011, finishing his studies, and a recurrence in his liver which necessitated a hepatectomy. After the surgery, Arun continued imatinib until 2015 when his oncologist declared him NED.

His sister, Deepa, who moved to the U.S. in 2014, commented about that period of time, "The doctors told us that Arun had GIST but never talked to us about resistance or mutational testing or the importance of regular scans and continued treatment."

In 2016, while working as a software engineer in the U.K., Arun began to experience stomach pains once again. He returned to India and it was discovered that there was recurrence in the liver and the walls of the peritoneum. As surgery was determined not to be an option at this point, Arun resumed taking imatinib and had regular scans remaining stable until 2018.



Arun Krishnan

▶ ARUN'S STORY continued on page 3

Dear Friends,

The Life Raft Group is facing the same challenges we all are in light of the COVID-19 health crisis. We are doing our best on a daily basis to do the right thing in all matters impacting the well-being of our patients, caregivers, staff and everyone we serve. We want to be intentional without panicking or overreacting.

That being said, we have decided that we will take an approach to the crisis that makes the most sense, continuing to evaluate upcoming events on a regular basis.

We recently decided to postpone our GDOL Tampa, GDOL Denver, and our Life Fest celebration and will continue to make decisions about future events with the most current information. We will strive to keep you updated regularly.

Your health and the health of your loved ones continues to be of utmost importance.

Please know that we will continue to be here for you as we have been consistently for the past twenty years. We will continue to provide services for you regardless of this pandemic, and together we will get through this.

Most cancer patients and their families have had to cope with the changing concept of what is defined as “the new normal” in their lives.

The diagnosis of cancer, the grim expression on a doctor’s face as he describes that the latest treatment hasn’t worked, or the opposite-the exhilaration from a radiologist coming into the room and exclaiming that the latest treatment has worked are all part of the roller coaster ride called cancer.

And just when we at the Life Raft Group thought that we have catalogued all of the medical, logistical and emotional obstacles that a GIST patient might have to face, along comes a virus with a name like a popular beer that has engaged unprecedented global attention.

The reality is that patients with cancer are often immunocompromised, which is sometimes exacerbated by age, which adds at-risk to their new normal world.

As prudent people, we will do everything we can to minimize the challenge of the coronavirus to their already at-risk status. The other reality is that most patients will be just fine. When the dust clears, we should be able to go back to our normal fears about scans or unusual new aches and pains.

One thing I know to be true, if there is any group that can take this in stride, it is those who have looked cancer straight in the eye and decided to live their lives to the fullest.

Do not hesitate to contact us during this difficult time. We are here for you.

Thank you for your patience.

- Norman J. Scherzer, Executive Director



▶ COVER STORY continued

A third recurrence occurred in 2018 and Arun underwent

CyberKnife radiation at Apollo Specialty Cancer Hospital in Chennai in the liver which produced only a partial response. Treatment with sunitinib followed but that brought many side effects that left it too difficult for Arun to continue. Regorafenib also produced too many side effects and did not stop progression.

Deepa, now living in California, was referred to The Life Raft Group by a relative in the U.S. Deepa joined the LRG as a caregiver. Sara Rothschild (Vice President, Strategic Planning) and Sahibjeet (Sebbi) Kaur (Patient Registry Supervisor) helped Deepa and Arun with next steps and options for treatment.

"Deepa was referred to me probably because it was considered an international case and the first thing I want to say about her is that she is persistent, advocating on her brother's behalf. Arun was on regorafenib at the time of contact and this line of treatment was not successful," Sara shared.

Sara and Sebbi worked with Arun's doctor and encouraged him to have mutational testing performed. Arun's doctor believed at this point that Arun was out of options, but as they worked with the doctor, they were able to convince him to join an LRG Virtual Tumor Board. At an LRG Virtual Tumor Board de-identified cases are presented to an international roster of GIST specialists and experts who brainstorm on cases for which doctors are searching for options. The Tumor Board took place in February of 2019. Among their suggestions was the joint belief that mutational testing was necessary and after that testing was performed, it was determined that Arun's mutation was KIT exon 17.

Sara also introduced Deepa to Dr. Nikhil Guhagarkar, GIST patient, dentist, nutrition for GIST expert, and member of the LRG & Friends of Max in India. Dr. Guhagarkar sent Deepa and Arun to Dr. Sameer Rastogi, a GIST specialist at the All India Institute of Medical Sciences (AIIMS) in New Delhi.

With this new information about his specific mutation and a GIST specialist on his case, it was determined that avapritinib would be the next appropriate line of treatment to try. Unfortunately, avapritinib was not yet approved by the FDA and therefore couldn't be used in India. Sara was able to reach out to Blueprint Medicines, which produces avapritinib*, and facilitate the application for compassionate use. In addition, approval was needed by the hospital to actually use this non-FDA approved drug and much documentation was needed to facilitate this approval as well, a job that Sara and Dr. Rastogi worked tirelessly on. A timely institutional approval was provided by the director of AIIMS, New Delhi which was very helpful.

"It was a sort of trifecta of right place, right time, right people. I'm going to guess that it might have been the first case to get compassionate use for Blueprint in India. And I feel like it set a precedent for future cases in terms of compassionate use and formed a relationship with Dr. Rastogi and his patients," said Sara.

Arun said, "Hats off to the Life Raft Group organization who has always offered a helping hand to their level best whenever we were in utter dismay and supported us with the right treatment at the right time. There are no exact words to describe our gratitude towards the Life Raft Group members and the doctors who have helped me to lead a better life."

Arun began avapritinib in September of 2019. Though he experienced fatigue among the side effects, Arun was able to keep working. Three-month scans showed a good response, but in February of 2020 subsequent scans showed mild progression. Due to this progression, he had to stop this line of treatment and now Dr. Rastogi is pursuing compassionate use for ripretinib, produced by Deciphera, which is expected to be approved by the FDA in 2020. Again, Sara helped Deepa and Dr. Rastogi contact Deciphera and the request is now in progress.

While he awaits approval to take this new drug treatment, Arun is determined to continue his normal routine, not wanting to sit at home focusing on GIST. He is hopeful for his future and expresses it beautifully:

"Above all, I am so grateful to my mom, dad and my other sister who have supported and taken care of me throughout this journey. My mom is the pillar of positivity and strength for me always, my dad who is no more but was a symbol of selflessness and unconditional care before my tumor recurrence and my sister Ratna who is a source of moral support for me and is always there to share my feelings. Without them, I would not have been able to face this brutal challenge of my life."

– Arun Krishnan, age 29, Chennai, India

**January 2020 avapritinib was approved by the FDA and is now marketed as Ayvakit.*

Resources:

Friends of Max - India
<https://friendsofmax.info/>

GIST Specialists Database - U.S. & International
lifteraftgroup.org/gist-specialists/

Mutational Testing information
lifteraftgroup.org/mutations-in-gist/

Ayvakit & other Treatments for GIST
lifteraftgroup.org/treatments-for-gist/

Questions? Need help?

Email or call the Patient Registry Supervisor
skaur@lifteraftgroup.org / 973-837-9092 x114

When Your Mind Wanders

10 TIPS TO STAY IN THE MOMENT

By Angela Edson, LRG Outreach & Engagement Associate

At the Life Raft Group, we often hear from our patients and caregivers that they are struggling with anxiety due to their diagnosis. This anxiety can put a damper on everyday life and make getting through the day challenging by creating intrusive, racing, and ruminating thoughts. Often these thoughts are indicators that something is going on. It is important to acknowledge these thoughts and feelings while finding ways to manage. These thoughts can feel overwhelming - as if they are taking over your entire life.

Creating a set amount of time per day to focus on these thoughts can be helpful but staying in those thoughts and allowing them to take over can feel defeating. If you find yourself distracted by your thoughts and unable to focus on other tasks, grounding techniques can be helpful to bring you back to the present moment. The goal of participating in grounding techniques is to utilize your senses and observe without judgment what is going on around you.

Here are some grounding techniques to try:

1

Pick a color and name everything around you with that color.

This will bring your attention to the 'here and now' by focusing on the objects in space

2

Count by 7's. 7, 14, 21, and so on.

This will challenge your mind and give it something else on which to focus around you.

3

Hold an ice cube in your hand.

What does it feel like? Focus on the cold temperature around you.

4

Focus on your breath by breathing in through your nose and out through your mouth.

Feel the sensations in your body, inhaling cold air, exhaling hot air.

5

Peel an orange or any form of citrus and eat it.

What observations can you make by using your senses of touch, sight, hearing, smell and taste?

6

Describe in depth how to make a peanut butter & jelly sandwich

Don't forget to open the lids before putting the knife in!

7

Recite positive affirmations.

"I am strong."
"I am brave."
"These feelings will pass."
"I am in control."
"I can and I will."

8

Hold your pet.

How do they feel?
Are they making any noises?

9

Intently listen to music.

Pay attention to the lyrics, the rhythm, all the instruments, and other sounds.

10

Choose a category and create a list.

For example, ice cream flavors. Name all of the flavors you can think of or try listing all 50 states. Make it more challenging by adding state capitals.

When you are experiencing anxiety, you feel that everything is out of control. Simple techniques such as these can be a way to regain some control. As always, if the feelings become unmanageable, please know that there is help available. Listed to the right are articles concerning anxiety and depression which can be found on our website.

Resources

Coping With Emotional Side Effects From GIST
lifaftgroup.org/2013/08/coping-with-depression-from-gist/
Fighting Anxiety & Depression on Your GIST Journey
lifaftgroup.org/2020/02/fighting-anxiety-depression/
Depression and Cancer : Shining a Light on an Under Recognized Problem
lifaftgroup.org/2014/09/depression-and-cancer-shining-a-light-on-an-under-recognized-problem/

Volunteer, Advocate, and Caregiver Marlene Nei, Wisconsin, USA

By Angela Edson, LRG Outreach & Engagement Associate

Marlene Nei from Wisconsin has been a member of the Life Raft Group since 2011. She was referred to the Life Raft Group by her husband Bill's surgeon, Dr. Kevin Roggin, at University of Chicago Hospital, after he was diagnosed with GIST. Marlene has a long history of volunteerism for which she credits her mother who modeled helping anyone and everyone. Marlene holds a Bachelor of Science degree in Nursing and is a retired registered nurse. She has a passion for helping others and used her degree to help medically compromised patients. She has volunteered with the deaf community, struggling families, and 12-step programs. When Bill received his diagnosis, Marlene was not shy about expressing her needs as a caregiver. She recognized the importance of reaching out for support in an effort to be a reliable and effective caregiver for her husband of 56 years.

As an active member of the Life Raft Group, Marlene advocates for the needs of the caregiver community because she feels they are an underrepresented group. It is her mission to advocate for Bill as well as the entire GIST community making sure they are equipped with the appropriate resources on their GIST journey. She has become a vital support for caregivers in our GIST Mentor program; a program which links patients and caregivers with others who have walked a similar path. Marlene believes caregivers need a mentor in times of crisis and search for connection to others who can empathize. She also understands it takes a lot of courage to ask for help. Marlene works to find the delicate balance between overwhelming her mentees with support and taking a step back and reminding them she is available when they are ready.

Through all the challenges Marlene and Bill have faced during their GIST journey, Marlene has held the philosophy of never giving up. She believes if you give up, you hit a wall because you don't have anywhere else to go.

Her message to other caregivers is this:

"Be there as an advocate for others, your spouse, your children. Whomever the GISTer is, whomever you love. The connection I have with the members in the LRG is that we are like sisters and brothers. We are family. Don't give up. Be an advocate. Don't be afraid to let people in. Give love and show love."



Science Forum Convened to Better Understand the State of GIST Research

By Pete Knox, LRG Senior Director, Research

Recently the LRG held its inaugural virtual meeting of the newly formed LRG Science Forum. As research regarding GIST and other relevant topics is extensive and dynamic, consensus among the Real World Evidence Team was that it would be a good idea to convene a group tasked with monitoring and assessing this research.

This forum serves a two-fold purpose: first, to monitor ongoing research and identify papers and projects of which our patient community should be aware. Secondly, to identify studies and researchers that could potentially benefit from an LRG collaboration and then reach out to those researchers to facilitate such alliances.

Current members of the group include LRG staff -

Executive Director Norman Scherzer, GIST Patient Registry Director Denisse Montoya, Data Analyst Jerry Call, Clinical Trials Coordinator Jim Hughes, and Senior Director of Research Pete Knox, and David Josephy, Professor of Biochemistry at University of Guelph, Canada, and Michael Josephy, former Professor of Mathematics at Universidad de Costa Rica (retired) - both with an extensive knowledge of GIST.

We intend to invite other researchers and clinicians to this forum to present their findings and/or potential projects. Updates on the LRG Science Forum will be posted as information becomes available.

If you are interested in joining this Forum, please contact: Pete Knox, Senior Director, Research: pknox@lifteraftgroup.org



GIST DAY OF LEARNING SAN FRANCISCO

August 29



See the full list of events:

liferaftgroup.org/event/

For events in Canada visit:

GIST Sarcoma Life Raft Group Canada

liferaftgroup.ca/welcome/

What is a GDOL or Life Fest?

liferaftgroup.org/powered/

LRG WEBCAST SERIES

GIST, TKI Treatments & Effects on Memory

Presented By:



Anette Duensing, M.D.
Associate Professor of Pathology
University of Pittsburgh School of Medicine



Robert J. Ferguson, Ph.D.
Assistant Professor of Medicine
University of Pittsburgh School of Medicine
and Hillman Cancer Center



GIST, TKI Treatments & Effects on Memory

May 14th, 2pm

This discussion will review cancer-related cognitive impairment (CRCI) in general, and how a person who is being treated for GIST could be affected. We will also talk about strategies that can help ameliorate CRCI and discuss our new research on CRCI and GIST. Also, in light of the COVID-19 pandemic, we will give advice on how cancer survivors can best cope with and care for themselves during this unusual global health event. You can resregister for this event through our Events page.

What's Happening with Life Fest?

It was a difficult decision, but our team has decided to postpone Life Fest, which was scheduled for this July 10-12, because we care about your safety and well being. Life Fest New Orleans has been rescheduled for **July 23-25, 2021**.

Although we won't be gathering in person this July, we will be hosting virtual events to celebrate GIST Awareness Day this July 11-13th with our GISTHope events - GISTCook, GISTArt and more.

You can keep track of all our current events on the LRG Events calendar which is accessible from our homepage.



GIST PATIENT REGISTRY

**MOST COMMONLY REPORTED
SIDE EFFECTS AMONG
PATIENT REGISTRY MEMBERS
UNDERGOING TREATMENT**



Fatigue 397

Diarrhea 247

Nausea 233

Edema 188

Cramping 125



GISTEntertainment

During this global pandemic, The Life Raft Group wants to reassure you that, as always, we are in this together. The LRG is offering virtual opportunities for you to connect with others and have fun while supporting our goal of raising funds for our GIST Community! We believe that with your help, we can lessen the impact of this coronavirus crisis on our mission of helping those living with GIST.

We have been working diligently to provide you with the most up to date information regarding COVID-19 and navigating your cancer diagnosis. However, we recognize that there are many stressors that come along with this challenging time.

To help with deal stress, we have created a series of virtual fundraising events called **GISTEntertainment**. We will be hosting several virtual events over the next few months to keep our community feeling connected. We hope you'll be able to join us for some relaxation, laughter, and fun!

There is a suggested donation for each event, but for those interested in sponsorship opportunities, please reach out to Jessica Nowak, Director of Outreach & Engagement at: jnowak@lifteraftgroup.org



GISTMeditate, April 30th at noon.
Suggested donation for this event is \$10.

Register for events as they are posted:
lifteraftgroup.org/event/

Other Upcoming Virtual Events:

GISTBe, May 15
GISTTrivia, May 22
GISTRead, June 11
GISTWatch, June 25

You can donate at anytime by visiting
lifteraftgroup.org/donate

*Many thanks to
our major donors
for February
& March*

Carlos Baldor
BST Consultants
Dublin's Pub



SPONSORSHIP OPPORTUNITIES

Bronze \$100 - sponsor names announced at beginning of event, post on social media platforms

Silver \$250 - sponsor names announced at beginning of event, post on social media platforms, highlight in newsletter

Gold \$500 - sponsor names announced at beginning of event, post on social media platforms, highlight in newsletter, name displayed on website

Platinum \$1,000 - sponsor names announced at beginning of event, month sponsorship, post on social media platforms, highlight in newsletter, name displayed on website

Ultra Platinum \$2,000 - sponsor names announced at beginning of event, sponsorship for all months, post on social media platforms, highlight in newsletter, name displayed on website

"During times of struggle, we have options:

1. Do nothing and hope that things somehow gets better,
2. Continue to use the resource and hope that someone shores it up so that we can continue to benefit.
3. Become the somehow, the someone and take the opportunity and responsibility to give and support the resource that has benefited us much. I choose to be the somehow and the someone, I choose to give."

- Rob Taylor, GIST Patient, GIST Mentor & GISTEntertainment Sponsor



The Life Raft Group Global Community

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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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Life Raft US Representatives Find info for a local & global reps at lifteraftgroup.org/find-a-support-group/

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Life Raft Global Liaisons See global news & resources in our **International section** on our website.

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