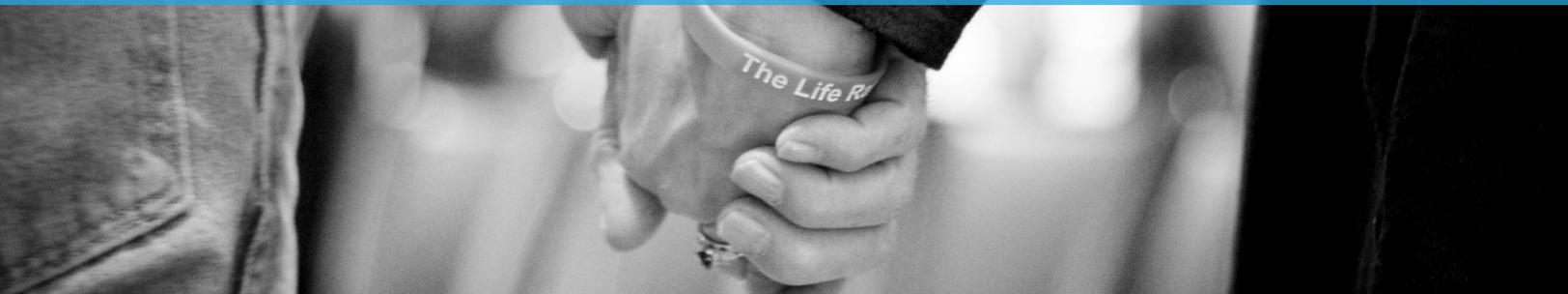


Ensuring no one has to face GIST alone



In Loving Memory: Linda Smith, Erlinda Adajar, Danijel Romić

Faces of Courage

My Journey from Hospice to Life

By **Eve Evidon**, LRG Contributor, GISTer & Thriver

In early December 2008, I acknowledged that my stomach was not feeling normal. I felt better when I skipped meals and instinctively knew something was seriously wrong. I met with my physician who ordered a CT scan. The following morning, he called with the news that the scan detected a “mass” on, or possibly in, my stomach wall.

For a month, I threaded my way through a medical system that didn't know what to do with me. I had no answers, just panic that the mass could be growing. After prodding from family, I called admissions at The Mayo Clinic in Rochester, Minnesota, and was able to schedule an appointment that same day. Although it was 75 degrees in Arizona, where I was living at the time, and 20 below in Minnesota, we hopped on a plane the next morning to Minneapolis, then drove the one and a half hour trip to Rochester and began my experience with the amazing Mayo Clinic system.

Within two days, I had a diagnosis and on the third day I had surgery. The tumor was a sarcoma attached to the upper left quadrant of my stomach wall. The surgery was done laparoscopically, and my tumor was removed with clean margins. After a couple of days I was sent back to Arizona to see if I could find an oncologist who treated GIST patients.

The oncologist I found had never treated GIST, but understood the protocol and had previous experience with Gleevec. I was prescribed 400 mg of Gleevec and within two months was taken off the drug because of the adverse reaction to my liver. After a month off, my dosage was reduced.

▶ see EVE on page 4



Left to right: Dr. Paula Daza, Senator Carolina Goic, Piga Fernández, Dr. Jorge Jiménez de la Jara

Crossing the Finish Line

By **Piga Fernández**, LRG Global Relations Coordinator

I never thought that I would be sitting at the same table with Senators from my country while voting for a law that will potentially dramatically change the lives of cancer patients in Chile. I guess I could say that this is one of the many blessings I have received after being diagnosed, more than 24 years ago, with cancer, and especially with GIST.

▶ see FINISH LINE on page 6

GIST is a Marathon, Not a Sprint

By **Jerry Call**, LRG Data Analyst

Overall survival in GIST patients has improved dramatically over the years. In 2019, the median Overall Survival (OS) is over 12 years when all Life Raft Group registry patients are combined. About 80% of GIST patients are diagnosed with a single tumor and about 20% are metastatic at the time of diagnosis.¹

(See footnote at end of article)

▶ see MARATHON on page 8

From our Executive Director “No More Candles”

Around 19 years ago, a few of us met by telephone to find a name for a handful of GIST patients and their caregivers who were struggling to stay alive with a newly discovered, rare, deadly cancer called GIST. What to call ourselves? The choice came down to two options: The Life Raft Group versus the Gastro intestinal Stromal Tumor Foundation. An article by Richard Palmer, the second editor of the Life Raft Group Newsletter, quoted Gary Golnick, the first newsletter editor, relating how the name of this informal group came to be:

“As the e-mails went back and forth, it was apparent that STI-571 (Gleevec) worked incredibly well for some patients. Ken (Garabadian) wrote in one of his usual wry notes that we were ‘like a group in a life raft.’ The name resonated, and we were The Life Raft Group.”

- Gary Golnick

It has been an incredible journey that we began in 2000. We have made enormous strides in understanding the complex make-up of a cancer called GIST and in identifying a series of targeted treatments leading to countless gifts of life for so many families and friends of those stricken with this cancer. Our members, in over 65 countries, have celebrated our triumphs, but cried together as we lit over 700 candles for those that paid the ultimate price. One of those candles for Anita, my beloved soul mate of over 55 years, still lights my path to the struggle to eliminate this disease from the earth.

The name Life Raft Group best expresses the hope for survival of thousands carrying on. Imagine, if you would, a life raft with four paddlers. Imagine if only one was paddling



toward the shore. Imagine two. Imagine three. Then four. That’s us. We will eventually reach the shore, but imagine how much faster that will be if we all pull together.

I’m tired of watching friends die because time was going faster than we could paddle. So, permit me to ask each of you to do contribute something to the race towards the shore.

At a minimum, **share your medical data** with our patient registry and side effect platforms. That information helps us to understand what is working and what is not in real time and to share that information with others.

If you have had surgery, **share your tissue** with our researchers. It is likely sitting in a file cabinet in some hospital closet eventually waiting to be thrown out. Don’t know how to share tissue? Just contact our office, sign a consent form, and we will take it from there.

Volunteer your time. Time is the fuel that dramatically increases our capacity to help others.

Finally, **make a donation** if you can afford it.

Together we are so much stronger and can reach the shore called “cure” so much faster.

No more candles.

Norman Scherzer

Share Your Medical Data

Go to lifteraftgroup.org/patient-registry
Or contact: dmontoya@lifteraftgroup.org



Share Your Tissue

Go to lifteraftgroup.org/tissue-bank
Or contact: dmontoya@lifteraftgroup.org



Pediatric & SDH-Deficient GIST Consortium Update

Setting the Pace for the Future

By **Sara Rothschild**, MPH, LRG Vice President, Program Services

In July of 2018 at Life Fest, The Life Raft Group brought together a team of pediatric & SDH-deficient GIST experts for a symposium focused on this rare subset of GIST patients. This gathering culminated in the creation of a collaboration of US and international specialists and patient advocates committed to accelerating research, creating guidelines, developing and expanding clinical trials, and involving patient advocacy groups in this effort to find a cure and improve the quality of life for these patients.

At the Biden Cancer Summit in September 2018, as one of ten featured speakers, LRG Executive Director Norman Scherzer presented the mission and goals of the newly formed Pediatric & SDH-Deficient GIST Consortium. Read more: liferaftgroup.org/pediatric-sdh-deficient-gist-consortium/.

Activities Post-Summit

- Consortium members have met monthly since its inception and discussed global research on SDH-related tumors.
- Members agreed to share tissue and have worked on tissue sharing with several patients to date in the USA and even more in the UK.
- Information from our Patient Registry provoked the creation of an algorithm, which has been fine-tuned by leading pathologists, and will soon be shared (and hopefully) adopted by pathology societies. Once adopted, this can help influence diagnostic decision-making for this population around the world, which we hope will then also influence clinical decision making.
- The Consortium is working on a grant to fund future activities of the group.
- A webinar was presented for patients to educate them about SDH.
- Three Virtual GIST Tumor Boards were held to present challenging cases.
- Patient Advocacy groups are collaborating with the sharing of information and supporting each other's efforts.
- Two clinical trials have been announced as well as one site expansion.

Some Specific Highlights

From abroad, Dr. Maria Pantaleo, University of Bologna, Italy, presented to the Consortium in October, on three research SDH-related projects she is currently conducting. Though the results are not yet published, the team is optimistic about early results and they are engaging pathologists in discussion regarding their decision-making tree.

In the U.S., Dr. Jonathan Trent has opened a HIF2a trial at Sylvester Comprehensive Cancer Center, sharing details with the Consortium in order to evaluate the possibility of SDH-deficient GIST patients as trial candidates.

Dr. Joshua Schiffman, Huntsman Cancer Institute, is focusing on a project for patients with PGL/PCC tumors (plus any SDH-driven tumors). With the Paraganglioma Preclinical Project, his team is working to test therapies and combinations of drugs to identify what can effectively stop these tumors from growing in mice. Read more: liferaftgroup.org/2018/12/new-in-sdh-deficient-research-the-paraganglioma-preclinical-project/.

Dr. Jason Sicklick, UCSD, is focusing on laboratory research with SDH-deficient GIST tissue. Drs. Schiffman and Sicklick are actively searching for tissue from recent surgeries and have appealed to GIST patients through the Consortium members and the resources of the LRG.

The Consortium will continue to meet monthly and future updates on the work of these experts and patient advocacy group will be posted.

Volunteer Your Time

Go to liferaftgroup.org/volunteer
Or contact: DNieves@liferaftgroup.org



Make a Donation

Go to liferaftgroup.org/donate
Or contact: DNieves@liferaftgroup.org



▶ EVE continued from cover

For the balance of the year, I took 200 mg per day. Finding The Life Raft Group was critical to my physical and emotional healing. As everyone who experiences this frightening cancer learns, guidance on navigating the medical system, help with paying for Gleevec and the support of the Life Raft team and ListServ is significant. From 2009 through 2013 I continued with regular scans and the results continued to be NED (No Evidence of Disease)!



Eve Evidon

Life After NED

My husband was diagnosed with Parkinson's disease and as is often the case with caretakers, we stop taking care of ourselves. I put GIST out of my mind, believing in a fantasy that I was 'cured' and stopped seeing an oncologist and doing yearly scans.

My husband died in 2014, and in 2015 I moved back to the Minneapolis area to build a new life near family and old friends. I settled into my new life and was able to follow many of my interests, one of which was to become a Spiritual Director. In the fall of 2017, at 80 years young, I enrolled in school. It was a dream come true, fulfilling, challenging, and exciting. I think of school as plasma for my soul.

GIST Returns

In early 2018 I was experiencing digestive issues. I read about leaky gut, tried acupuncture, met with a naturopath, and then realized I better doctor up and request a CT scan. A couple of days after the scan, my internist called, his voice low and shaky. He asked me how I knew that I needed a scan and I said, "intuition". He continued, "there are three tumors growing together in exactly the same spot, the upper left quadrant of the stomach wall, but they are considerably larger than the one from 2009." He contacted the oncology department at the hospital and I met with my new oncologist a few days later.

She brought up the scan on her computer screen and explained that the tumors were pushing my stomach over to my right side and were also up against my left lung and pancreas. She also explained that I had few options. The first was Gleevec, which I declined because of my previous experience at 400 mg and concerns about cost. She did not press the issue. Surgery was out of the question for a number of reasons including the fact that I would probably not survive. What was offered was a drug trial – immunotherapy. In a state of numbness and shock, I agreed to participate in the trial. A few days later I was infused with two drugs, Opdivo/Nivolumab and Yervoy/Ipilimumab.

The drug trial's expectation was that these drugs would target the tumors and shrink them, which it did not. What it did though was target my healthy immune system and caused microscopic colitis. For almost three months I had uncontrollable extreme diarrhea. I stopped eating and drinking in an attempt to control what was unstoppable. I lost over 15 pounds, which I could not afford. After a couple of weeks going to the hospital every day for IV fluids the doctor said I needed to be hospitalized. Meanwhile the tumors were slowly growing.

Saying Goodbye

In May I told my classmates and teachers that I would not return in the fall because I was dying. I received such an outpouring of love and support, it was sad and at the same time, uplifting. In July my oncologist said I had probably four to six months to live and she recommended that I needed a palliative team and should go on Hospice, to which I agreed. Because my stomach was so compromised by the tumors, I was only able to eat very small amounts of soft foods; otherwise I had increasing pain and bouts of vomiting.

I reviewed my will and my last wishes, shredded some files, closed credit card accounts, had lots of talks with my children, and signed the DNR which was then taped to the refrigerator. Hospice began their visits, which was comforting.

I have deeply held spiritual beliefs, one of which is that death may be the end of life as Eve, but my soul is eternal. This helped me to move into a peaceful acceptance that I was dying. I felt deep compassion for my family and dear friends who were grieving this news. At the same time, I acknowledged that the world is full of suffering and mine is no more important than it is for anyone else. It can be a teachable moment. I vowed that I would handle my last months with as much grace as possible.

Except for GIST, I've been a healthy, active person, I'm curious, love learning, and write for fun, love beading, read anything and everything including recipes. I love to cook and spend quality time with my friends sharing deep conversations about the meaning of life. I've lived a life that has held joy, love and tragedy – all material for learning, in an attempt to understand the 'why' of some of the events in our lives. Living into the questions, facing our shadows, becoming authentic, these are my passions but also led me to my only question directed to God - why now? I've finally become the person I knew was buried deep within. I recognize that I am now what is called a 'wise elder' and planned to share my hard-earned wisdom, experience and love in Spiritual Direction. But now you are telling me "never mind". It felt wrong, but I assume every human when faced with death has a similar question.

One Saturday evening in mid-August I was clicking through hundreds of emails, deleting most without reading them

when I was drawn to one from “The Guardian”. It was a science issue, which I decided to open and read. The seventh article down the list was headed by the statement, “Since ablation is so successful at killing Sarcoma tumors, why isn’t it used more often?” You can’t imagine the shock that went through my body. Further, the article quoted at length a radiologist who is a professor and physician at Mayo Clinic in Rochester, Minnesota. I read the article over at least three or four times and then went online, found an application for an appointment, found my patient number in my records from 2009 and sent it off. I couldn’t sleep the entire weekend and first thing Monday morning called Mayo directly. I had a conversation with admissions, then was transferred to oncology for another round of questions and was told that my request would be submitted to a team of doctors and I would receive a call back no later than Friday. The next day I received a call from scheduling!

Five days later my eldest daughter who lives in Minneapolis, a close friend and I drove to Rochester. After labs, and a scan, a few hours later I met with a team of sarcoma specialists, a department that Mayo did not have in 2009. The physician who took the lead in our meeting was Dr. Steven Robinson. The news I didn’t like so much was that ablation would not work because of the location of my tumors; the process would cause serious damage to surrounding organs. Then the suggestion that I knew was coming. Gleevec!

Dr. Robinson said, “Eve, I know you had a bad experience with Gleevec. I’m asking you to take a deep breath and hear me out. Although 400 mg was the prescribed dosage from Novartis, we now know that much less is still effective. Also, you need to know that Gleevec is a silver bullet for KIT gene, exon 11 tumors. We will shrink these tumors down, hopefully kill them off, and we should be able to do this at 100 mg per day. Further, the oncology department secretary will help you with the application for financial aid from Novartis for Gleevec.” Hope, disbelief, shock and tears, we were stunned hearing that maybe, I/Mom/Dear Friend is not dying after all, at least not yet.

Reaching out to The LRG

As mentioned earlier, I had lost touch with The LRG once I started taking care of my husband, but after my meeting with the Mayo Clinic, and being a bit hesitant going back on Gleevec, I decided to pick up the phone and call The LRG to see what their thoughts on going back on Gleevec were. Sebbi picked up the phone and I explained the situation to her. She comforted me and assured me that The LRG would work with me and the sarcoma team at Mayo to try to find the best possible game plan. That’s exactly what they did. Sebbi had a call with Dr. Robinson and they discussed Gleevec and my concerns about going back on it but thought of ways to manage the adverse reaction with my liver. She made sure to fill me in on any conversations she had with the Mayo Clinic and even

Novartis when I was having trouble getting financial aid for Gleevec. It was such a process, but Sebbi made me comfortable and helped me through the journey.

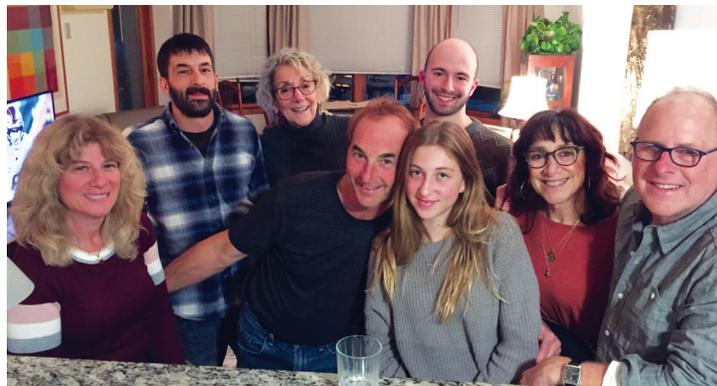
The following week I received my first month’s pills; of course I transferred my care to Mayo and gently fired Hospice. The social worker from Hospice came to my apartment for me to sign the necessary paperwork; we had a wonderful conversation, and she was so happy for me. “It’s quite unusual,” she said, “People usually leave hospice feet first and you are walking out on your own.” I couldn’t believe it myself. **I truly believe that without picking up the phone and calling The Life Raft Group, I’d be leaving hospice as the social worker said - feet first.**

At the end of August, I sent the following email to my fellow students and teachers: “Time for an update – I decided not to die! Short version – went to Mayo Clinic, found out there is a medicine that shrinks tumors, had outpouring support and guidance from The Life Raft Group, and transferred my care to the sarcoma team at Mayo. Decided to choose joy and gratitude for life and that includes all you guys. So, I am back! See you in September. Much love, thanks for all your messages of love and support, Eve”

I’ve been on Gleevec for over two months, and although I won’t have a scan until December*, I know the tumors are shrinking because I can eat, though carefully, without problems. The side effects of Gleevec are minimal and I think my system is adapting to its presence.

A friend recently commented, “Eve, you really had a near death experience.” Yes, that’s true. This past year has brought me a miracle and has been full of challenge, learning, pain and love. I now live “closer to the bone”. I think both death and life live side by side in me. I can tear up over almost anything. I feel passionate about life, grateful that we have freedom to choose how to be in this world, and that everything, no matter how painful, holds a lesson and a gift.

*Eve’s December CT scan showed shrinkage of her tumors!



Eve and her family

▶ FINISH LINE continued from cover



Seminar Participants included academia, physicians, investigators, patient group representatives, pharma industry representatives, and lawyers.

In the same tone and spirit, Dr. Paula Daza, Subsecretary of Health, and Dr. Jorge Jiménez de la Jara addressed the audience. Dr. Daza highlighted the importance of having an equitable, robust and integral National Cancer Plan, that will ensure access to health to everybody, independent from their economic and migratory situation.

After these presentations, it was my turn to speak as president of the ACHAGO. Speaking in public is one of the things that most stresses me in life, but it seems that life has had a mission to make me go beyond my comfort zone and it challenges me again and again to overcome my fears and insecurities.

After I was initially asked to speak, I spent many sleepless nights not knowing what I would say, and finally, I had one thing clear: I would present no technicalities, no numbers, no statistics. I wanted to talk from my heart and my feelings, trying to be the voice of many cancer patients who, as myself, desperately needed a law that would protect our rights.

In the second part of the program, Mr. Sebastián Pavlovic (the former Superintendent of Health) made a comparison between the project of law presented by the civil society, and the one presented by the government. This was followed by a workshop in which the audience was divided randomly in three groups. Each group brainstormed ideas. Everybody had the chance to analyze and comment what each one of us thought of the project of law presented by the government. We worked hard to summarize all of our comments and on Tuesday, January 15th, I was invited to a session of the Senate Health Commission at our Congress in Valparaiso, where I was chosen to present a summary of the work done by the three groups in the seminar.

It was an amazing experience. As I said at the beginning of this article, it is one of the blessings I have received in my life: to be a part of the process of a law that in the future will change the lives of cancer patients. It was just amazing and overwhelming!

Sitting at the same table with senators when they said: “I approve” and hearing senator Carolina Goic, who was leading the session, ring a bell and say: “This commission approves the legislation of the law.” It was BREATHTAKING!

Carolina and I looked at each other and I could feel and see that we both had “watery eyes” - HUGE APPLAUSE!

ADVOCACY IN ACTION!

On January 10th, a group of cancer patients, together with the National Cancer Forum and the Chilean Association of Cancer Groups (ACHAGO, of which I am president), organized a Seminar called: “National Cancer Law – A Critical Analysis and Proposals within the Government’s Presentation”. The goal of the meeting was to gather representatives of the different health sectors in Chile and hear their ideas about the project of law presented by our President.

In the first part of the seminar, Senator Carolina Goic welcomed the audience, highlighting the importance of this meeting, one in which we were witnesses to a huge step our country is taking after more than five years of advocacy work: To consider cancer a “national priority”, which will mean a qualitative change of how cancer is dealt with in Chile.



Piga's Speech

"When I was asked to speak today, two words came to my mind: In the first place: **Gratitude**.

Gratitude - for the opportunity of being here representing many people that like me, have cancer.

Gratitude - for being part of a very special day in which we are a part of a huge challenge: we are giving the first steps that will take us to having in Chile, a National Cancer Law, that will protect the rights of all cancer patients, with no distinctions.

Gratitude - for all those, who for many years have been working, without lowering their arms and losing enthusiasm, even through the many difficulties found on the road.

Gratitude - for all cancer patients, their families and friends, who all along Chile forgot their personal needs and didn't hesitate about being a part of the National Cancer Law Movement, and dedicated many hours to organize the March in December 2018, demonstrating the huge strength that can be accomplished when we can count on unwavering commitment to reach a common objective.

Gratitude - to our President for signing the National Cancer Plan and the National Cancer Law, enabling this project to start its parliamentary process looking forward for it to become a reality.

The second word was **Hope**.

Hope - that the National Cancer Plan and the National Cancer Law will address the real needs and hopes of cancer patients.



Piga Fernández, LRG Global Consultant and Director of Fundación GIST Chile, speaking at January's meeting with President Sebastián Piñera, the National Cancer Forum, and ACHAGO.

Hope - that the parliamentary process won't take long, that the congressmen understand that we cancer patients do not have much time to wait.

Hope - that all cancers will be considered, with no distinctions among them.

Hope - that the law will consider creative financing strategies, so that all cancer patients will have access to the treatments we need to live, to see our families grow, and to continue working and making a positive contribution to our society.

Hope - that the law will consider tributary incentives, which will encourage donations to develop projects to benefit cancer patients.

Hope - that the assignment of resources to develop the National Cancer Law will be quick, transparent, and focused on the patients' needs.

Hope - that cancer patients won't be the object of employment discrimination.

Hope - that the law will favor investigation, patient registries, tumor banks, and oncology fellowships, making it possible to have enough oncologists to cover our country's needs.

Hope - that once a patient is diagnosed, they will receive the necessary support to navigate the Health System, especially regarding the complicated administrative paperwork we need to go through.

Hope - that representatives of all sectors related to cancer will be considered, and that we will all be able to sit at the same table to talk, discuss, make decisions together, and leaving aside individual benefits, be able to reach patient-centered agreements.

With huge **Gratitude** and **Hope**, I welcome each one of you and I invite you to be part of this big challenge: having in Chile a National Cancer Law."

(Translated from Spanish)

▶ MARATHON continued

The high percentage of patients diagnosed with a single tumor and the effectiveness of adjuvant treatment for these patients contributes significantly to the long overall survival. GIST patients require a long-term strategy for the best results. **Alternate stats:** The 5 year OS is 82% and the 10 year OS is 61%.

Treatment is usually long-term. Long-term treatment can be challenging for the patient. There are ways to address these challenges:

Dose Escalation

Dose escalation is an under-utilized tool in GIST treatment. For most drugs and most patients, starting at half of the standard dose and taking a few weeks to ramp up dosage is more effective. Starting at full-dose (especially with Stivarga) too often results in a dose reduction or even a dose interruption. It's also harder on the patient. It's usually better to give the body a chance to ease into the drug and get used to side effects. This often results in the ability of a patient to get to a stable normal dose quicker.

Side Effect Management

Drugs don't work in people that don't take them. Effective side effect management is one of the most important ways to improve the patient's quality of life and allow for optimum compliance (ability to take the full prescribed dose on a regular basis).

Aging with GIST

The median age of GIST patients in the LRG registry is 60 years old (somewhat younger than a population-based study group). This means that GIST patients are not only dealing with GIST, but most of them are dealing with aging as well. With aging there are hormonal shifts, we are often less active, weight-gain is often an issue, loss of bone density, loss of muscle mass, more chances of cardiovascular disease, aches and pains from joints, loss of flexibility and mobility, increased risk of diabetes, and the list goes on.

With all of the things that come along with aging, it's often hard to tell what's related to aging, what's related to GIST and what's related to GIST treatment. An all too common occurrence is to blame GIST treatment for things that are probably related to aging.

Reduce Stress

In addition to the normal stress that occurs in day-to-day living and getting older, GIST patients and their families and caregivers have tremendous additional stress caused by GIST. Given the positive effects of exercise (or

at least activity!) on general health, to combat aging and to reduce stress, it would be at the top of the list of ways to reduce stress. In addition, eating a well-balanced healthy diet can help to balance physiological stress. Pursuing integrative techniques such as meditation, yoga or pursuing activities that are pleasurable can increase serotonin levels and reduce stress hormones such as cortisol.

Stay Active

What's the old saying? Use it or lose it! Not only is this important for normal health, to reduce stress and to combat aging, it also can be a great way to combat fatigue (although adequate rest including adequate sleep is also important to for both fatigue and stress). Preventative maintenance isn't less important, it's more important.

Cancer patients sometimes have a tendency to put off normal "maintenance" health issues because they are "dealing with something more urgent (cancer)". There is no doubt that the TKI's used to treat GIST greatly increase survival; the benefits far exceed the risk for most patients. However, the drugs do have unwanted side effects. In many cases, they can act almost as a "co-factor". Normal aging predisposes you to certain conditions, for example, a decrease in bone density.

These drugs can sometimes "team up" with normal aging to increase the chances or magnitude of some of these normal aging processes. For our bone density example, imatinib can affect bone remodeling; causing an increase in bone density in some parts of the body and a decrease in others (most notably a decreased density in the neck of the femur). The result might be things like an increased risk of hip fractures.

Preventative Maintenance Not to Ignore (partial list!)

1. Dental checkups
2. Monitor for and correct high blood pressure
3. Screening for other cancers (mammograms, colonoscopies, dermatological exams, etc).
4. Monitor kidney health and practice preventative measures (treat high- blood pressure, limit salt intake, hydrate, etc)
5. If you have cardiovascular risk factors, consider adding a cardiologist to care for your heart (treat your cancer while caring for the heart)
6. Monitor bone density

Form a Medical Team

Local oncologists, nurses, and support staff will most likely be the core of your medical team. However, overall

strategy is best accomplished with the help and direction of a GIST expert team, usually led by an oncologist, but including others such as expert surgeons and pathologists.

Dermatologist – Experts at dealing with skin issues such as rash and hand and foot syndrome

Endocrinologist – Experts at dealing with glands and the hormones they make, electrolyte imbalances, bone metabolism, etc.

Nutritionist – While nutrition shouldn't be used to treat cancer, it should be used to optimize the body and to correct deficiencies that can be related to treatments or to GIST itself. While the advice to "get your nutrition from what you eat" may be great, it's often hard to do. In addition, treatment can often cause additional abnormalities that go beyond normal aging. Note that there may be some overlap between things a nutritionist and an endocrinologist can help with.

Cardiologist – While the typical GIST patient may not need a cardiologist on their team, anyone with additional risk factors may need one. In addition, for anyone starting Sutent, their oncologist should order cardiac monitoring such as an echocardiogram or a MUGA scan. If those tests find any abnormalities, then it's time to get a cardiologist involved in the treatment plan (See Sutent Cardiotoxicity – better monitoring . . . lifaftgroup.org/2009/03/sutent-cardiotoxicity-better-monitoring-for-sutent-related-heart-problems-may-be-warranted/)

Learn to Become an Advocate

We believe that patients that have a voice in their own medical care do better. Learn to become an advocate for your own health. If you have a partner or caregiver, so much the better! Let them help! It might help not only you, but them as well.

1If we removed some of the long-term survivors diagnosed prior to the introduction of imatinib (due to survivor's bias), it's about a year less, but still quite impressive. Remember, the median is just the person in the middle; half of all patients live longer than this, some much longer! Note: LRG patient registry members join the registry voluntarily (they are self-referred). Patients at low risk have less incentive to join the registry, so as a group, the registry has both more high-risk as well as more patients that are metastatic at diagnosis compared to the entire world-wide GIST population. As a result, the overall survival of ALL GIST patients world-wide (including the low-risk patients) is probably even greater than the numbers mentioned above.



Holiday Campaign Update

By **Diana Nieves**, MPH, LRG Senior Director, Outreach & Engagement

Each one of our members has a unique story to tell, but they all reflect the intrinsic courage of those who face the challenges of cancer head on, with dignity, strength and passion for life. Our 2018 holiday campaign, "Faces of Courage," kicked off on #GivingTuesday.

We shared the stories and celebrated the courage of Jason DeLorenzo, Liz Skree and Eve Evidon. While we didn't share the stories of every single one of our patients, we celebrate you each and every day here at the LRG. We thank all of our donors who contributed on #GivingTuesday and throughout the campaign to help us raise over \$130,000.

Together, as a community, we have made an impact on the lives of GIST patients by helping ensure their survival. We have more than doubled the survival rate of GIST patients since we became a formal nonprofit in 2002. Thanks to our generous donors, we will continue to provide research, patient support & education, and advocacy to help ensure the survival of GIST patients in 2019 and beyond.



Jason DeLorenzo

Liz Skree

Eve Evidon

Help Us Continue Working Towards a Cure: Donate Today!

A Conversation with Breeelyn Wilky, M.D.

Colorado, Clinical Trials & Immunotherapy

By **Carolyn Tordella**, LRG Web & Design Associate

Dr. Wilky, Director of Sarcoma Translational Research at the University of Colorado, broke for a few minutes from her jam-packed schedule to talk with The LRG about her move from Miami to Colorado, designing clinical trials, and immunotherapy for sarcoma and GIST patients.

New Work in Colorado

When asked what precipitated her move from Sylvester Comprehensive Cancer Center in Miami to the University of Colorado Anschutz Medical Campus in Aurora, Colorado, Dr. Wilky said that her purpose in Miami was to learn how to care for patients, run clinical trials, and build her clinical skills.

“I was in Miami for five years, under the guidance of a fantastic mentor, Dr. Jonathan Trent,” said Wilky, “and I had the opportunity to design a clinical trial using immune therapy, which I never thought I’d get into.” She found that it was really important to learn why it worked and why it did not work for patients. She says she got ‘kind of obsessed’ with that and learning how to make it work for more people.

“To do that effectively, you can’t just study patients. You really have to get biopsies and blood samples, and study the tumors in mice, sometimes. I wound up asking questions that I didn’t have the ability to necessarily answer [in Miami],” Wilky said. “I wanted to switch my focus to immunology, both in the laboratory and translational work that’s designed to go from patients into the lab and then back to patients again. That translational focus is extremely strong in Colorado and I just couldn’t say no to this opportunity.”

Designing Trials

When asked how ideas for trials come about, Dr. Wilky shared that sometimes researchers are approached by drug companies with a specific interest, but more often the ideas come from patients. The idea for Wilky’s recent clinical trial in Miami came about because a patient with an exceedingly rare sarcoma walked into her clinic in 2014. She commented that these types of encounters can give you the motivation, or an idea, to try something different or to put together a trial or combination of approaches of which you might not have thought.

“I think in GIST, we’re learning more and more about how patients respond but there might be a patient who does really, really well with a particular treatment, and then you



Dr. Wilky participating on a panel at Life Fest Miami 2018.

study that patient in detail, and you find out ‘this worked for a patient because of this’ and that’s how ideas for trials can happen, too,” said Wilky.

The infrastructure needed for monitoring a clinical trial, analyzing the data, and making sure that patients are protected is very expensive.

“Clinical trials are really expensive, not so much the drug itself, because that’s often a big cost, but,” said Wilky, “the process of enrolling patients. There’s a tremendous amount of support needed to make sure that patients are protected in clinical research. That they are not being used as guinea pigs and are not getting a treatment that’s unlikely to help them or too risky.”

Funding for the trial has to be secured. The drugs may come from a pharmaceutical company, though some drug companies may not have sarcomas and GIST as high priorities for drug development because they are so rare. An agency like the National Cancer Institute (NCI) has programs where you can submit an idea and if they agree with the premise, they may help supply the drugs for the study. Another avenue is to try to use standard-of-care drugs when possible, as these are often covered by insurance companies may be made available from this source.

Dr. Wilky explained her timeline for the trial in Miami and how that compares to a normal timeline to get a trial started.

“It depends on how complicated the study is and what obstacles and roadblocks you hit along the way. For example, for the study we wrote in Miami, I had to write a proposal for the drug company and that was in October of 2014. Then it went back and forth with the drug company with their edits for a time. Once we were in agreement, we had to go and get approval from the FDA. We had to write the trial, get it approved, get the budget, get all this stuff done, and then the first patient started in March of 2016. That was basically a year and a half, and that it was really fast. Most of the time it takes a couple of years to get a study from idea to patients in trial.”

Once each phase of the trial is complete, the process begins again. In the Miami trial, the results were amazing – over 50% of the sarcoma patients involved had shrinkage of their tumors. Compounding that success is the fact that it is the first report of immune therapy working for that particular sarcoma. However, sometimes, even when the data is exciting, there is additional expense in taking a drug forward to the FDA for approval.

“There are a lot of reasons why trials that you think look promising may not be approved. This is what is so frustrating for patients. The process of getting from an idea or laboratory findings to a patient and then having it be approved so that a patient can actually have access to it is not only a long and expensive process, but it’s also one that’s very prone to failure at many times along the way. This is why cancer research is challenging and we have not found a cure for many cancers thus far,” said Wilky.

Fortunately, Dr. Wilky confirmed, patients participating in a trial, such as the one in Miami, can continue on the trial treatment, “We allow patients to stay on the trial as long as it’s helping them. Patients that benefit could stay on until it stopped working or until they had to come off for some other reason. We still have one patient who is getting treatment on the study (Miami). But for most patients the drugs simply stop working, so the study is not a cure. This is true for most studies but in general drug companies will make drugs available for patients even after the studies are over if they are still benefiting. Most people have to move onto other treatments.”

Where is Immune System Research Going?

Our immune system is designed to be adaptive. It’s designed to learn and remember and change. Chemo drugs are not. Chemotherapy and chemo pills are not designed to change over time, but cancer cells do change over time.

“The one thing that might be able to keep up with your cancer cells is your immune system, but it needs help. To basically that’s what I want to learn – how to figure out how to make the immune system work better in fighting the cancer cells,” said Wilky. “It’s truly a field where the

knowledge is changing on a daily basis. It’s so exciting and gives us so much hope for the next five to ten years,” said Wilky.

Dr. Wilky said there are multiple trials in the works, but nothing that is GIST specific right now. She would say they are designing future trials using immunotherapy and continuing to focus on biomarkers, so basically, looking at biopsies and blood samples to try to make treatments better. There’s also a lot of interest in new types of drugs, new types of treatments; such as cancer vaccines, and CAR T-cells research as another type of immune therapy for GIST and sarcomas.

On Staying Positive for Patients & Their Families

“There are good days and there are bad days as with anything. To see a patient without treatment options and then to come up with a clinical trial or a laboratory experiment testing your ideas and see it help someone, that is the coolest, most amazing experience I’ve had as a physician. I try not to let myself get caught up in the failures. Though I try to help everybody there are patients that I can’t help and you have to focus on the people that you did help and on keep trying to make it better for more people. For me, the key is to be involved with the research because that’s where the hope is. For most sarcomas in the metastatic setting we don’t have good treatment options. The only way we’re going to make things better is through clinical trials and research. That’s what keeps me going.”

For further info on immunotherapy:

“The Immune System in GIST and Implications for Future Therapies” - Dr. Wilky’s presentation at a GIST Day of Learning Miami in 2017. www.youtube.com/watch?v=Mln39piCLWI

“Checkpoint Inhibitors and Sarcomas” from The GIST Cancer Journal Interview with Dr. Wilky, liferaftgroup.org/wp-content/uploads/2019/02/GIST-v3n2_7.22.pdf

Clinical Trial Q&A www.conquer.org/profiles/breelyn-wilky-md

Dr. Wilky, Conquer Cancer video youtu.be/gcpa3bXSOLA

The ritual of lighting a candle to honor a lost loved one’s memory is a part of many cultural traditions. Our tradition at The Life Raft Group is to light a candle at sundown when we learn of one of our members’ passing.

Our new site
lrginmemoriam.org
 gives you a chance to light a virtual candle
 to honor those who have passed from GIST.

State Leader Spotlight

Wendi Lax, Maryland, USA

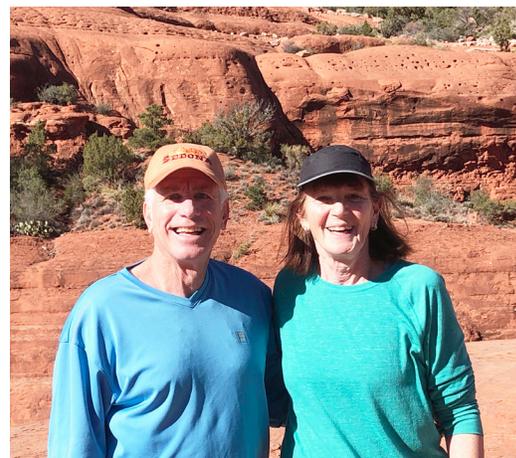
By **Merilyn Marmora**, LRG Outreach & Engagement Associate

Wendi Lax is our wonderful state leader for Maryland. She is currently residing in Maryland, where she is helping the Life Raft Group create unity among the local patients and caregivers. For many years, Wendi devoted her time to helping exceptional children as a Special Education Teacher. After she retired, she continued helping those in need the most by becoming a part-time Home Hospital Teacher. Now that she has more free time, Wendi wanted to find yet another way to continue helping others. One day as she was scrolling through the Life Raft Group website, she read that our organization was in need of state leaders, and that is when her interest in the position began.

Wendi has been a state leader for a several months and loves her role. She loves connecting with our members and realizing they have a lot in common, besides just GIST. She hosted her first meeting over Sunday football, which happened to be the Raven’s playoff game. The members connected so strongly that they were able to talk for hours.

Her goal as a leader is to increase the number of responses from the members she is reaching out to. She would also like to create events where not only the local members can assist, but everyone who has been touched by GIST. Wendi wants to reassure them so that they know they are not alone!

Wendi & husband Mitch vacationing in Sedona, AZ



Interested in becoming a State Leader? Contact Diana - DNieves@liferaftgroup.org



Global Representative Spotlight

Florence Thwagi, Kenya

My Journey with GIST

My name is Florence Thwagi, and I am 53-years-old. I am an Executive Board Member of Henzo Kenya, an advocacy group that creates awareness and support GIST patients in Kenya.

My journey started in February 2018 when after living with chronic fatigue for close to 3 years, I had an endoscopy and a big mass was found in the stomach. Surgery was scheduled immediately and it was after the surgery

that I was informed I had GIST. According to the Doctor, there was nothing to worry about as the procedure was successful and so I thought I was fine and done with doctors.

A month after the surgery, the Surgeon asked me to go to an Oncologist for follow up without much explanation. My world came crumbling down! “Why an Oncologist?” I asked. At the time I had not heard of any other person with the same condition. I felt alone. I was looking for someone with my condition to talk to. Devastated and confused, I frantically searched through the internet for information and that’s how I learned about The Life Raft Group and Henzo Kenya.

The one thing I would like to achieve as a representative, is to make sure every GIST patient including the illiterate get the right information about their diagnosis so that they can own up the process of monitoring and treatment. I want to be that person who will be there for anyone wanting to talk, to encourage them and give them hope.

We Love Our Donors!

Without your generous support over the last 16 years, we would not have been able to accomplish all that we have. You have been a part of important milestones such as:

- Doubling the rate of patient survival
- Producing real world evidence that side effects diminish over time, leading to greater patient adherence
- Reaching out across the globe to advocate that patients receive access to treatment and medication
- Assembling the greatest GIST experts in the world to provide research and education for our patients
- Being recognized by the Biden Cancer Initiative for assembling a world class consortium of international GIST experts to share data, tissue and resources to find treatments for pediatric and SDH-deficient GIST patients...and so much more.

Your contributions have made these milestones possible. 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.

Sincerely - **The Life Raft Group**

In Memoriam - Erlinda Adajar

Erlinda (Linda) Adajar, loving and dedicated wife, mother, grandmother, sister and friend, passed away on December 24, 2018 at Memorial Sloan Kettering Hospital in NYC. She was 77 years old. Linda was born on July 18, 1941 in Alitagtag, Batangas, Philippines to Aurora and Dr. Lauro C. Hernandez. She was the second of ten children. Linda received her Bachelor's Degree in Pharmacy at the University of Santo Thomas in Manila in 1964. Soon after she married Oscar M. Adajar in 1968, they immigrated to the United States and settled in New Jersey where they raised their only child, Gay Margaret.

Linda was an avid world traveler and most of all a devout Catholic. Although she pursued a career in food technology Linda's greatest role was that of a mother. She was kind and nurturing not only to her own daughter but also to many nieces, nephews and cousins who sought her advice throughout the years. She was known to many as "Mama Linda." Linda is survived by Oscar, her devoted husband of 50 years, daughter, Gay and son-in law, Ken Kasegrande, her grandchildren, Isabella and Emma, and siblings (Lettie, Larry, Cellie, Sonia, Mar, Joven, Menel and Baby). Her light will be greatly missed by all who loved her.

Viewing was held Sunday, December 30th, 2018 at Mack Memorial Home 1245, Paterson Plank Road Secaucus, NJ 07094 and a mass was performed Dec. 31st at Immaculate Conception Church 1219 Paterson Plank Road, also in Secaucus.

Linda's family requested that In lieu of flowers please consider making a donation in memory of Linda to either of the following institutions: gistinfo.org/about-gist-cancer-research-fund/gist-resources/ or lifaftgroup.org/the-lrg-mission-vision/.



UPCOMING EVENTS



March 8th, 2019, 7pm
 Town Tavern DC
 2323 18th St. NW
 Washington, DC 20009
lifaftgroup.org/events



April 27, 2019

<https://lifaftgroup.ca/events/day-of-learning/registration-for-the-gist-day-of-learning-vancouver-is-now-open/>

Saturday, May 4th, 2019
 7am-11am
 Verona Park
 Verona, NJ



In Loving Memory
 of Ted Wolf

lifaftgroup.org/event/gistdoitnj

Thank you to our Major Donors
 for December & January

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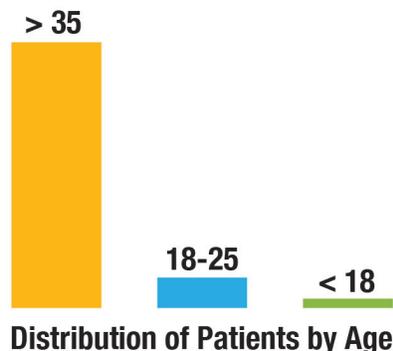
Appeal for LRG History Stories

As we begin the 17th year of The Life Raft Group's designation as a nonprofit, we are compiling a history of our organization. We are seeking member recollections about significant Life Raft Group events and experiences over the years.

Were you a part of something special? Are you one of the original members of The LRG? Did you attend the first Life Fest, or the first NIH clinic? Do you have memories of LRG staff providing help? How about some of the more humorous experiences?

We would love to hear from you. Please email Mary Garland at mgarland@lifaftgroup.org with any and all memories you would like to share.

Patient Registry Data



Since the Year
2016

New members enrolling per year jumped from 36 in 2016 to 124 new members in 2018.

New members = More data = Real World Evidence

Join the Patient Registry today and help us improve patient survival, compile real world data, and work toward finding a cure.

lifaftgroup.org/patient-registry or call 973-837-9092.

LRG
SCIENCE

Patient Powered Real World Evidence

The Life Raft Group was built on a foundation of patient powered science: real world data (RWD) and real world evidence (RWE) that enhances survival and quality of life for GIST and other cancer patients. As participants in the Biden Cancer Initiative, we believe strongly in the mission to find solutions that will double the rate of progress against cancer. We believe that the sharing of RWD and RWE is the linchpin of these solutions.

We will be sharing valuable real world data and real world evidence through our newest publication, the LRG Science Bulletin. Available on the LRG website, content will include data from our Patient Registry, side effects management platform, SideEQ, our new initiative, Project Surveillance, and our collaborative efforts such as the Pediatric and SDH-Deficient GIST Consortium. It will also include content and commentary from GIST experts, case studies, editorials on vital issues and breaking news.

To introduce ourselves, the first online issue is a white paper that illustrates the LRG's Research Model: Real World Evidence in Action. **Full issue available here:** lifaftgroup.org/2019/02/the-life-raft-group-research-model/

Want the LRG Science Bulletin emailed to you directly? Contact Mary Garland at mgarland@lifaftgroup.org

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Interested in Volunteering?

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

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior Vice President
locchiuzzi@liferaftgroup.org

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Life Raft Regional Chapters: Find info for a local rep at liferaftgroup.org/find-a-support-group

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Life Raft Global Liaisons: Learn more about the Global GIST Network & find contact info for your rep at globalgistnetwork.com

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