

Ensuring no one has to face GIST alone

In Loving Memory: Ron Hallett, Finn Liland, Larry Selkovits

Help MaKayla realize her dream: Donate to double patient survival

By **Diana Nieves**, Development Director

MaKayla Evans was diagnosed with Wild Type GIST in 2011, when she was 14 years old. She wanted to speak knowledgeably with her doctors and understand the terminology they were using to talk about her GIST.

The Life Raft Group was there and



MaKayla Evans helps kick off our holiday campaign.

we have provided MaKayla with the information she needed to help her make the best decisions about her cancer management and treatment. MaKayla has a dream to finish college and to help children and teens like her with cancer.

Help MaKayla realize her dream by donating to the Life Raft Group today.

See **HOLIDAY** on page 8

Living a life of dignity and hope: Henzo Kenya

By **Ferdinand Mwangura**, Chairman and President, Henzo Kenya



The October walk generated awareness about CML, GIST, and osteosarcoma.

GIST/PRIME: An Interactive Patient Registry

By **Erin Kristoff**, Director of Marketing

As a rare cancer treated by the first oral, targeted therapy, GIST has been on the front lines of medical advancement. In the last 16 years working with GIST patients, the Life



Raft Group realized the inherent value in patient-powered data, and utilized our membership's medical data and experiences to build a multifaceted and unparalleled patient registry.

See **GIST/PRIME** on page 6

Henzo Kenya is a patient support group made up of CML, GIST and recently added osteosarcoma patients. The need to support each other as patients inspired the great idea that is Henzo Kenya. Henzo Kenya will be ten years old next year. We have reached great milestones together.

The immediate benefit you derive by joining Henzo, which means Love in Swahili, is the flow of love from this special membership, which has the adage that "if you want to run fast,

See **HOPE** on page 5

A year in review: 2016 Executive Director's report

By **Norman Scherzer**, Executive Director

The Life Raft Group at its core is a love story—a love shared between

a husband and wife, a mother and daughter, a brother, a sister, parents, grandparents and friends. We began this journey together, in the same raft, with our shared goal in our hearts: survival.

We started the Life Raft Group with a simple mission many years ago, to ensure that no one had to face GIST alone. And I believe that amongst our ups and downs, our triumphs and tribulations, we have succeeded on this front. We are there, all of us, for each other.

I want to thank the LRG community for supporting me through the course



SCHERZER

of my own love story. My wife Anita and I shared 55 amazing years together. Many of you stood by our side—if not in person, in spirit—for the past 16 years of that shared life. This has been a hard year for me personally, and I thank each and every member of this community for continuing to stand by my side now.

Many of you know that my own personal mission is to make sure that no man should ever have to ask his wife for a last dance. I am committed to this goal. My staff is committed and we have worked tirelessly throughout 2016 to one day make this a reality.

We have seen so many remarkable findings come out of cancer research in the last few years and continue to be encouraged by the breakthroughs happening. While the Life Raft Group maintains efforts to finding a cure for GIST, we also know that some patients do not have the time to wait for cures. Thus, we have devoted ourselves to drastically increasing patient survival.

In the past year, we have dramatically increased our efforts to support, educate and empower GIST patients, helping them gain the necessary knowledge and tools to support their own GIST care.

We held our eighth Life Fest in California in July, revitalizing our program with new panels and workshops focused on unique patient needs. By helping new patients start their journey with a GIST 101 workshop, holding targeted education presentations on mutational testing, understanding your cancer metabolism and cutting edge treatment, and a new, separate wildtype GIST track, we created a richer learning environment for our attendees.

Additionally, we added new locations and increased the number of “GIST Days of Learning” throughout the United States. In collaboration with Alianza GIST, we held a two-day meeting called Salud Con Datos (Health with Data), to discuss how the LRG and our Latin American partners can work together on the collection of data to learn more about GIST and advance our advocacy efforts.

On the science front, we have identified obstacles to patient survival and used our expertise in patient-powered science by developing a number of scientific platforms that provide real-world insights and smart, actionable data to optimize treatment and enhance quality of life.



CALENDAR OF EVENTS

DECEMBER 4, 2016

Patient Gathering Meeting

The Life Raft Group
55 US Highway 46, Suite 202
Wayne, NJ 07470 USA
Time: 10am-12pm

See **REPORT** on page 8

The Life Raft Group

Who are we, what do we do?

The LRG has a simple focus: to cure a form of cancer — gastrointestinal stromal tumors (GIST) – and to help those living with it until then. To do this, the Life Raft Group focuses on three key areas: research, patient support & education, and advocacy.

How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States. You can donate by credit card at www.liferaftgroup.org/donate.html or by sending a check to: The Life Raft Group 155 US Highway 46, Suite 202, Wayne, NJ 07470.

Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. Please advise Mary Garland, Director of Communications, at mgarland@liferaftgroup.org of any errors.

Night to Fight Cancer event raises \$130,000

By **Jessica Nowak**, Development Manager

The thirteenth annual “Night to Fight Cancer” event to benefit The Life Raft Group’s research programs was an overwhelming



success. Held at the Midtown Loft and Terrace on October 13, 2016, the event provided an evening of friendly competition while supporting this important cause. Our Board President and host, Jerry Cudzil, was overwhelmed by the support and generosity that was present that night. Jerry began hosting NTFC in

2004 after his father-in law Bill was diagnosed with GIST. Bill has since passed away, but Jerry continues to hold this annual event in loving memory of him and to help raise awareness and support others with GIST.

NTFC participation almost doubled from last year with 222 participants that helped raise \$130,000 for the LRG. Guests and players enjoyed the Modern Street Food from Scoozi Catering that included unique items ranging from French onion grilled cheese, mini ramen burgers, mini big macs, to the traditional classic NYC hot dog, and finishing off with s’mores pipettes.

Competition was fierce in the poker tournament. The winners of the night



Left to right: Mike DeSanto, Lauren King, Jerry Cudzil, and Andre Michaud.

were Lauren King, Andre Michaud and Mike Disanto. Mike DiSanto was also the first to knockout Jerry Cudzil in the poker bounty. This is our third year having a blackjack section which

See **NTFC** on page 5

LRG advocacy efforts at home and abroad

By **Mildred Menos**, Director of Project Management

The week of October 16 was a busy one for the Life Raft Group’s advocacy efforts.

The week began with a trip to the National Organization of Rare Diseases’ 2016 Breakthrough Summit. Held annually, the Summit brings together representatives from the FDA, rare disease patient organizations, pharma, biotech and the media for two days of updates, innovation, networking and support. The LRG’s Director of Project Management, Mildred Menos, traveled to Arlington, Virginia for this year’s event to spread the word about the LRG’s newest side effect management resource - SideEQ (www.mysideeq.org) and to connect with others in the rare cancer community.

Later that week, Mildred traveled



Mildred Menos networking at this year's **NORD Summit**.

to Montreal to take part in Life Raft Group Canada’s annual GIST Day of

Learning. It was Life Raft Group Canada’s largest annual meeting yet and the kinship in the room was palpable. Patients shared their stories and struggles, gave and received advice and contributed to a brainstorming session on programs and services Life Raft Group Canada could offer to best address the needs of the Canadian GIST community.

It was a busy but enlightening week as the LRG team continues to work to improve SideEQ to be as useful as possible during its beta testing period. If you would like to sign up to be a beta tester, have any feedback to contribute or would just like to sign up to receive help managing side effects please visit SideEQ at www.mysideeq.org ■

CTOS provides international networking opportunities

By **Mary Garland**, Director of Communications

Executive Director Norman Scherzer traveled to Lisbon, Portugal in November to attend the 21st annual meeting of the Connective Tissue Oncology Society (CTOS). CTOS is an annual conference which has grown since its inception to be one of the leading conferences dedicated to presenting new research and clinical issues in the field of sarcoma.



Markus Wartenburg, Kathrin Schuster and Norman Scherzer networking at CTOS.

new paradigms for research. GIST is not just one disease, but many, with complex genetic profiles.

The conference was a valuable opportunity for Norman to network with respected leaders in the field of GIST and sarcoma research, including catching up with members of the LRG Research Team, including Dr. Matt van de Rijn, Dr. Jonathan Fletcher, and Dr. Sebastian Bauer.

Meeting with our European colleagues, including Markus Wartenburg and

Kathrin Schuster from Sarcoma Patients EuroNet (SPAEN), many of the emerging advocacy issues became clear, including the difficulties in Europe to get reimbursement for high-priced drugs that are repurposed for other cancers. Potential future gatherings were also discussed.

Norman also met with the Executive Director and CEO of SARC (Sarcoma



Left to right: Dr. Matthew van de Rijn, Dr. Sebastian Bauer, Norman Scherzer, Dr. Jonathan Fletcher

Alliance for Research through Collaboration), Denise Reinke, to discuss future opportunities to work together.

Further networking discussions with leaders from Sarcoma Foundation of America, Sarcoma Alliance, National LeioMyoSarcoma Foundation and others hold promise of future collaborative efforts, including burgeoning interest in our three new platforms: InterGR, SideEQ and GIST/PRIME, as well as the potential for combined educational events. ■

LRG Networking at Partnering for Cures

By **Erin Kristoff**, Director of Marketing

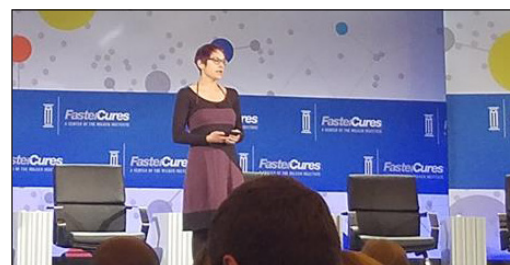
LRG staff members, Michelle Durborow and Erin Kristoff attended the Partnering for Cures 8th Annual Meeting hosted by FasterCures on November 13-15 in NYC.

Partnering for Cures is a gathering designed to bring together innovators from patient groups, pharma, academia, government and industry with the common goal of improving the health and future of the American people, reducing the cost of disease

to society, and developing ways to get new and better treatments to patients faster.

Of special interest in this year's conference was the focus on how to navigate the transition with a new administration in office, while remaining dedicated to the concept of patient-centered solutions.

Partnering for Cures provides an unprecedented opportunity for networking and the potential for



Pediatrician and breast cancer survivor, Janet Sollod, gives a touching Time=Lives talk, "Approaching the Abyss."

See **NETWORKING** on page 10

HOPE from page 1

you run alone, but if you want to run for a long time, you run as a group.”

This adage reflects our true character. By bringing cancer patients together and providing the support they need not only do we play a key role in enabling them to fight the disease better, but also give them the confidence to live a life of dignity and hope.

Educating people about these three cancers is also extremely important to Henzo Kenya, since education leads to more public awareness of the diseases. A big part of our organization’s mission is ensuring patients and families have comprehensive information. Getting quality information to patients and their doctors is vital and I greatly appreciate that this organization, through its patient centered service, is spreading the word about symptoms, treatment options and various clinical trials.

We in Henzo believe instead of sitting back, we can try to help families write

a different narrative about cancer – one filled with hope. We enjoy the relationships we have with people who have walked with us on the same path...people who understand what it’s like to have cancer strike a family. One such organization that has greatly walked with us is The Life Raft Group. They have not only been our source of important information but they also have supported our course in ensuring that cancer patients are educated and confident.

For me, as the Chairman of Henzo Kenya, seeing my pool of volunteers give so much of their time is inspiring. The Henzo community of volunteers that we have are people I wouldn’t know if I weren’t involved with the cancer advocacy network, so it means a lot to have volunteer heroes who are making a difference for patients today and also those who will come after us.



Members of Henzo Kenya share their stories.

In the month of October, Henzo Kenya organized a walk which was well attended. The main objective was to create awareness. We had a banner with three ribbons: Yellow for osteosarcoma, Orange for CML, and Purple for GIST. After the walk we converged together and had speakers who gave touching testimonies on their journey with cancer.

Management and treatment of cancer in Africa has a long way to go. Henzo Kenya has a lot to learn and achieve before we reach the optimal care a cancer patient needs.

I believe in partnerships that can help us grow and learn. We feel secure because we have partners like The LRG who have achieved a lot in this field and have vast knowledge to share with us to help us improve the lives of our cancer patients. ■

NTFC from page 3



Norman Scherzer and Jerry Cudzil celebrate another successful NTFC.

continues to become a growing attraction. This year’s winners included Dan Gardella, Brian Iorio, and Meg Hoave.

A special thank you goes out to our corporate sponsors. Our Club Sponsors included Bank of America, Pfizer, RBC, and Morgan Stanley. Our Hearts’ Sponsors included ICE, Investors Bank, Tradeweb, Palermo-Ravich Family Foundation and Laird Landman. In addition, we would like to thank Lyon Carter III who was our beverage sponsor, Michelle Mattioli for donating her photography services, and our awards donors, Murray Rosenthal and Nicholas Chiara.

We look forward to everyone joining us next year. For more information on how to get on the

mailing list, email us at dnieves@liferaftgroup.org or visit our Facebook page at www.facebook.com/NighttoFightCancerLRG ■



Competition was both friendly and fierce.

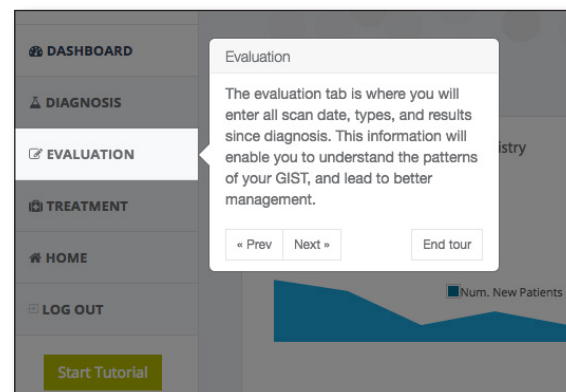
An interactive patient registry for GIST

The LRG has expanded the registry and created an interactive front end to form GIST/PRIME. This online tool gives GIST survivors and caregivers an easy way to monitor their GIST history and contribute their data, making it easier for them to work with their medical team to improve their medical care, as well as participate in cutting edge research that will improve outcomes on existing GIST treatments and accelerate the development of new ones.



Welcome Tutorial

Our welcome tutorial helps users input and update medical data and walks you through the charts and demographics so that you can make the most of all the information available.



Diagnosis

The diagnosis tab holds all pertinent information regarding your original GIST diagnosis, including mutation and the details needed to determine Risk of Recurrence.

Evaluation

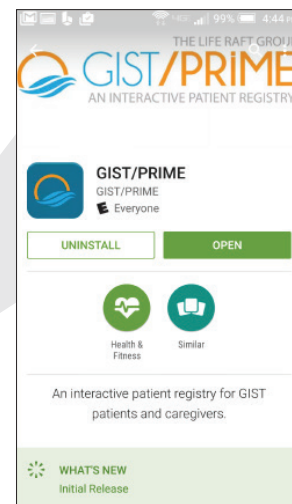
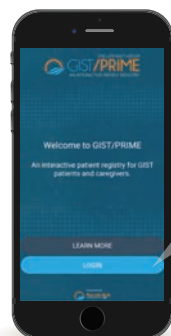
The evaluation tab is where you will enter all scan dates, types, and results since diagnosis. This information helps you understand the patterns of your GIST, and leads to better management.

Treatment

The treatment tab is the source of all medication and surgery details. The most recent treatment information will update your Current Medication and Surgery Analysis on the dashboard.

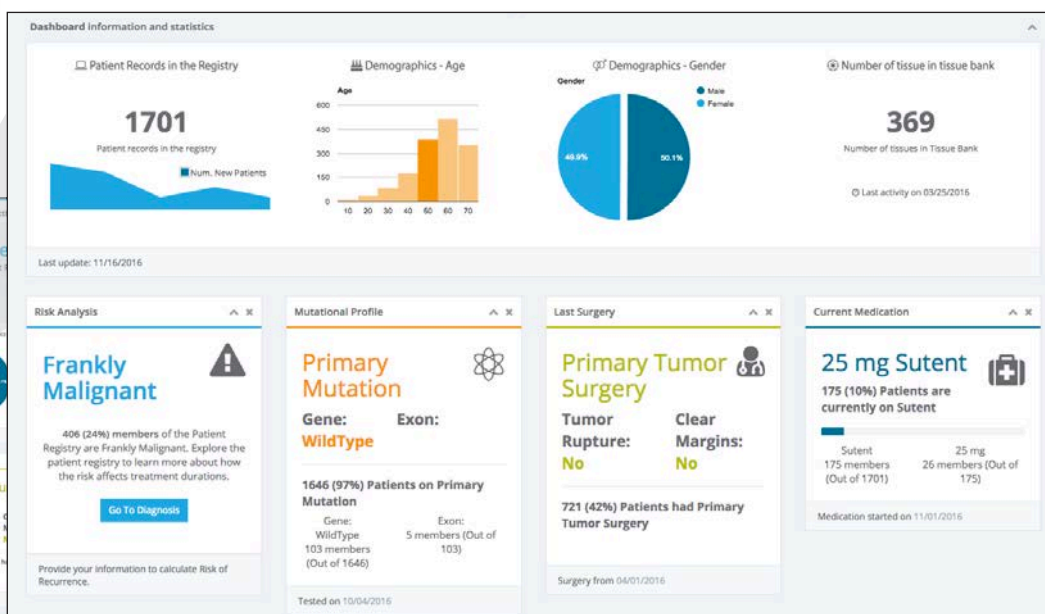
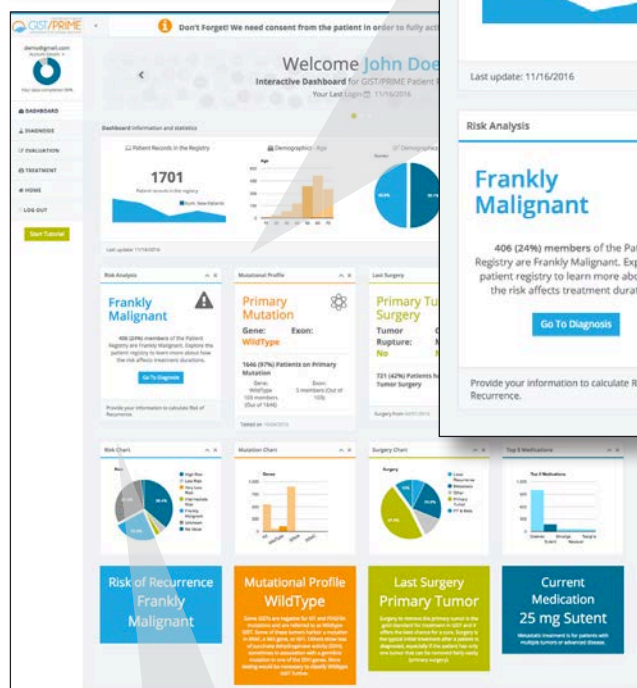
Mobile Application

Bringing your GIST medical history to doctors appointments is now easier than ever. The mobile application allows you to access your record anytime and anywhere, giving you full access to your information.



Dashboard

The dashboard is a direct link to your personalized dashboard shown upon login.

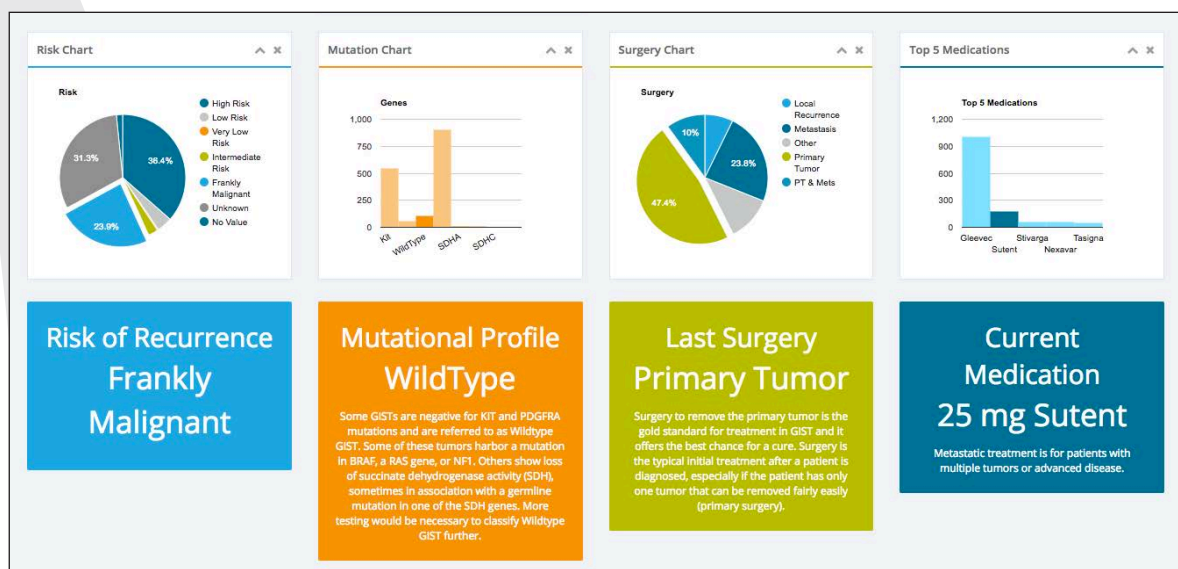


Info & Statistics

Displays demographics of the entire GIST/PRIME population and updates in real time.

GIST Overview

This information is your GIST diagnosis and treatment overview, which will generate personalized feedback and educational text.



Charts

After entering your information above, you will be able to see how you relate to the GIST/PRIME population.

Analysis

Personalized analysis is calculated based on the information you submitted in diagnosis and treatment. These are important details to consider while making decisions as you navigate GIST.

REPORT from page 2

This summer, we introduced SideEQ (www.MySideEQ.org), a side effects management platform to help people living with GIST and other cancers track and manage their side effects and improve their daily lives.

We are also proud to announce that we have expanded our GIST Patient Registry and created an interactive front end, now called GIST/PRIME. By giving our membership a tool to monitor their GIST history and contribute their data, they can then work with their medical team to improve their medical care. (See our *GIST/PRIME* article on page 1), GIST/PRIME will launch in 2017.

We have also worked hard throughout the year on our clinical research tool – InterGR – which is built off our sophisticated Registry platform and fosters accelerated research through collaboration. By combining research efforts, we can hasten the time it takes to go from a question in the mind of a researcher to an effective therapy in the hands of a patient.

As its first project, the LRG has formed a collaboration with Columbia University and six other top GIST centers to utilize existing technology to identify possible treatments based on genes called “master regulators”. This is the true definition of precision medicine and will help clinicians treat the individual and not just the disease. The Life Raft Group’s registry functions as the monitoring arm of the investigation, tracking the trajectory of the disease and allows us to provide support to patients enrolled in the study.

We are incredibly excited by our progress thus far and invigorated by our new projects going forward. With your help, we can accelerate our progress towards doubling patient survival. ■

HOLIDAY from page 1

We’ve done a tremendous amount in the 16 years the Life Raft Group has been around. We’ve built a sophisticated and unparalleled patient registry that has provided data that has saved countless lives. We launched a virtual tumor board to fill the needs of patients far removed from GIST centers of excellence. Our tissue bank contributes to ongoing GIST research, and our Expert Training course, GDOLs and webcasts continue to empower patients with education. Our efforts have resulted in empowered and educated patients who live longer. We have also built a family – a family who supports each other through this journey called GIST.

But it is not enough. VP Biden’s Cancer Moonshot initiative implores us to step up our efforts, and although we have already begun, the next phase of the Life Raft Group is crucial to our own “moonshot” goal – to double patient survival. We need you to make it happen, so that patients, caregivers and families can be granted additional time to make memories and to enjoy life to the fullest.

Now is the time when you can make a significant impact to our community. As the Life Raft Group continues to

focus on doubling patient survival, we need your help now more than ever to reach our financial goal during LRG’s holiday campaign which is to double it from the \$45K raised last year to \$90K this year. These needed funds will help the LRG to continue to empower GIST patients and their caregivers through research, treatment and cancer management, support and education.

Our 2016 holiday campaign officially launched on November 29th with MaKayla’s message of how the LRG has helped her and her dream for the future. Over the next several weeks during this holiday season, we will share with you the personal stories and dreams of some of the patients and caregivers we assist each year. We have been there for them and want to continue to be there. Join us in our commitment of doubling patient survival and help them to realize their dreams by donating to the LRG today. And please don’t just stop there. We urge you to encourage your friends and family to donate too. Together we can do it. ■

Fundraising Committee

Jerry Cudzil

Teena Petersohn

Amy Schelesky

Cliff Kopp

Becky Strauss

Samantha Wexler

CANCERVERSARY



Elsie Maria Hernandez

16 YEARS

“First of all, I thank God for this time I’ve been given to share with my dear family and my friends. To celebrate this anniversary last weekend, I went with my husband to Villa Blanca, a mountain hotel near my hometown, San Ramon. We could walk the trails in the tropical rain forest surrounded by peace and quiet.”

If you have a Cancerversary, let us know. Contact us at info@liferaftgroup.org and we may feature you in a future newsletter!



Impacting Patients and Caregivers **Worldwide**



Jennifer & Owen Moore

The LRG makes my husband and me confident that we're making the best decisions about his treatments and care.



Elsie Hernandez and Michael Josephy and Family

Elsie and I thank the Life Raft Group for their support these sixteen years. Our initial contact with Norman helped send Elsie to the clinical trial of STI-571 in January 2001, and she continues on Gleevec to this day. We thank God for all these years to be able to see our children achieving their goals.



Isobel Barrett

I am a new GIST patient living in the United Kingdom. I came across the Life Raft Group during my research regarding my GIST.

Since then I have been welcomed with open arms hands across the sea you would say. I've been given so much information to support my campaign re: my treatment in the UK. I no longer feel alone and even my Macmillan cancer nurse has taken the Life Raft details to pass onto other UK GIST patients she has contact with. From my contact with the Life Raft group I have been put in contact with the UK GIST support group also.

What friends I now have across the sea and around the world, each day. I learn more about my GIST treatment and survival. You can be sure I'm going to inform my local doctor and others whom suffer from GIST tumours that there is support out there.

A big thank you from a new member.

Issie Barrett - Diagnosed June 2016



NETWORKING from page 4

collaborative ventures with other organizations focused on similar goals.

One of the major themes centered on patient engagement, and ways in which organizations and researchers can better meet patient needs. Although many organizations have been talking about this for years, implementing patient perspectives into practice isn't easy. Culture change is necessary, especially around the information collected from patient registries. This confirms what the LRG has recognized: the power of patient data as a tool not only for research purposes, but also for patient engagement.

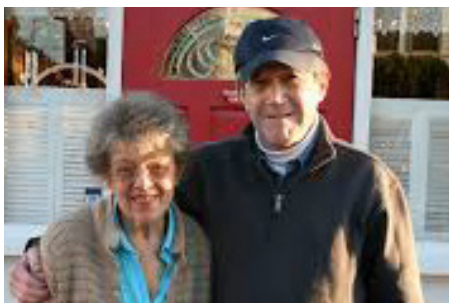
The importance of patient data, and the process involved in not only collecting data efficiently, but turning it into "smart data" was a major part of the panel discussions as well. This provided an opportunity for discussing our new initiatives, especially GIST/PRIME, our expanded interactive patient registry.

Interspersed with the innovative panels were inspiring talks such as Janet Sollo'd's presentation, Time=Lives Talk on "Optimistically Approaching the Abyss." A breast cancer survivor and a pediatrician, she had to face the challenges being a cancer patient undergoes, seeing life from a new perspective. It was a reminder to never forget the patient story while providing treatment.

Having the opportunity to learn about innovative approaches, explore creative, patient-centered solutions, while also being able to engage in the discussion of how the Life Raft Group can contribute to making a difference was a valuable experience. We came away with the potential to collaborate with movers and shakers in the industry to accomplish what the LRG continues to strive for – increasing patient survival. ■

In Memoriam

Larry Selkovits, LRG Board Member and Shelley Selkovits, his wife of 56 years



LRG Board member, Larry Selkovits passed away on November 6, 2016. He was predeceased by Shelley, his wife of 56 years, who died on October 19, 2016. They are survived by their son David and his wife Sarah of Boston, and Larry's sister, Myrna Zelenitz of Pittsburgh, Pennsylvania. Larry was interred next to his wife at Mt. Auburn Cemetery, Cambridge Massachusetts.

"Larry was an incredibly caring person, who never hesitated to give generously to the Life Raft Group. Many GIST patients have benefitted from his generosity, especially those who were able to attend our Life Fest gatherings on scholarships he provided."

—Norman Scherzer
Executive Director, the Life Raft Group

*Every life
leaves something
beautiful behind*

Contact the LRG at
lifteraftgroup.org for ways to
honor your loved one.

Become an LRG state leader!

Have you ever wanted to become more involved in giving back to the GIST community but don't know how?

Become an LRG State Leader!

State leaders are an important part of the LRG network, providing important person-to-person contact to help members know they are not in this journey alone.

Responsibilities include:

- Being a point of contact for members in your state
- Welcoming new members
- Planning meetings and get togethers for your state

If you are interested or just want to learn more, please contact Laura Occhiuzzi at locchiuzzi@lifteraftgroup.org

LRG BY THE NUMBERS

12 **mutation categories represented**

Kit Exon 11
Kit Exon 9
Kit Exon 13
Kit Exon 17

PDGFRA 18
PDGFRA 14
PDGFRA 12
SDHA

SDHB
SDHC
Wildtype
NF1

As of **10/27/2016**, we have a total of

1697 **patient registry members**



The Number of Tissues in the Tissue Bank

763 **paraffin blocks**

392 **total patient donors**

5 **GDOL events in the US**

Our website reaches users from

147



different countries

6 **Webcasts** presented in our



2016 Webcast Series

24,000 **website pageviews** on average per month

Thank you to our Major Donors for September and October for helping to double patient survival

- Ryan Atkinson
- Carlos Baldor
- Bank of America
- Paulette Banner
- Brian Behrens
- David Blackmore
- BST Consultants
- Benji Cheung
- Jerry Cudzil
- Dublins Pub
- Sandra Gallagher
- Alison Garnett
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- Maximilian Ibel
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- Matt Knopman
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- Andrew Roberts
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- Schmidt Ocean Institute Employee Giving
- Charles Sorrentino
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THE LIFE RAFT GROUP COMMUNITY

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Senior Director Programs	Sara Rothschild
Director of Communications	Mary Garland
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Operations Associate	Victoria Pinero
Finance Director	Lorraine Ramadan

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Photographer	Kim Tallau
Staff Photographer	Michelle Mattioli
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Mia Byrne (Ex Officio)
Ray Montague (Ex Officio)

•Larry Selkovits passed away on November 6, 2016.
We hold him in our hearts each and every day.

Life Raft Regional Chapters: Find your reps info at liferaftgroup.org/find-a-support-group/

Arizona	Ellen MacDonald
California	Dina Wiley
	Martha Zielsinski
Delaware	Cindy Bones
Florida	Anny Riley
Georgia	Barbara Auw
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West Virginia	Susan Caperton
Wisconsin	Rick Ware

General Support Charles Burke

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

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Belgium	Gerard van Oortmerssen
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Turkey	Haver Tanbay
Ukraine	Larisa Kutovenko
U.K.	Nicola Wardle
Uruguay	Fabrizio Martilotta
Venezuela	María Isabel Gómez

155 US Highway 46, Suite 202
Wayne, NJ 07470
p: 973-837-9092
f: 973-837-9095
e: liferaft@liferaftgroup.org
w: www.liferaftgroup.org



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