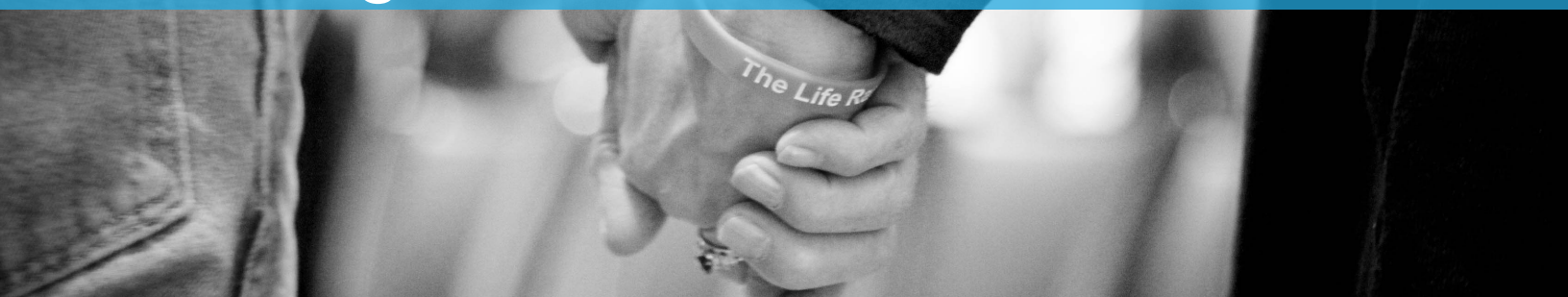


Ensuring no one has to face GIST alone



In Loving Memory: Rebecca Harper, Judy Horn

GIST keep swimming: Words to live by

By **Erin MacBean**, LRG Member and Founder, GISTkids

Life with cancer is like tossing all your dreams, goals and achievements into a bag, shaking it up and dumping it onto the floor to be stomped upon. Some say I was lucky to get my diagnosis at age 16, before I had a career or a family to support.



MACBEAN

What those people don't understand is that young-adult cancer patients have to rebuild their lives, compete

against healthy counterparts for careers, try to forge relationships with a cancer cloud hanging over them and wonder about the risks of starting a family. I thought I had managed to survive those years of my life with a lot of luck, and I even began to believe I had gotten over the worst of it. I still had tumors to deal with; but I got married, had a

See **SWIMMING** on page 10

Leading GIST experts weigh in at ESMO

By **David Josephy**, Life Raft Group Canada



On behalf of The Life Raft Group USA and Life Raft Group Canada, I attended the Sarcoma & GIST 2016 meeting organized by the European Society for Medical Oncology (ESMO) in Milan, Italy, in February.

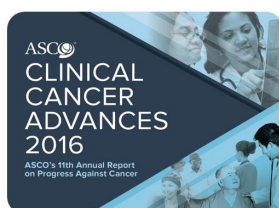
There were 369 participants at the meeting, most of whom were medical oncologists. Several GIST patient-group representatives also attended, including GIST advocates Gabriella Tedone and Anna Costato, from Italy; Markus Wartenberg, from Germany; Helga Meier, from Switzerland and myself. Participants came from 41 countries — mostly from western Europe, but also included many speakers from the U.S.

Meeting sessions were split about 50/50 between GIST and soft-tissue sarcoma (STS). Progress in understanding and treating GIST has been so remarkable that the theme of many

Brief from ASCO's Clinical Cancer Advances 2016

By **Noha Hussein**, LRG Member

On February 4, 2016, Life Raft Group member Noha Hussein attended the American Society of Clinical Oncology's (ASCO) Capitol Hill Briefing on their report, "Clinical Cancer Advances 2016," in Washington, DC at the Rayburn House Office Building. The following is her summary of the meeting.



Julie Vose, MD, MBA, FASCO and ASCO President, announced the release of their 11th annual report on progress against cancer and highlighted two particular advances: immunotherapy and targeted therapy.

Dr. Jedd Wochock from Memorial Sloan Kettering Cancer Center

See **ASCO** on page 5

See **ESMO** on page 6

Second Water of Life event to make a “big splash”

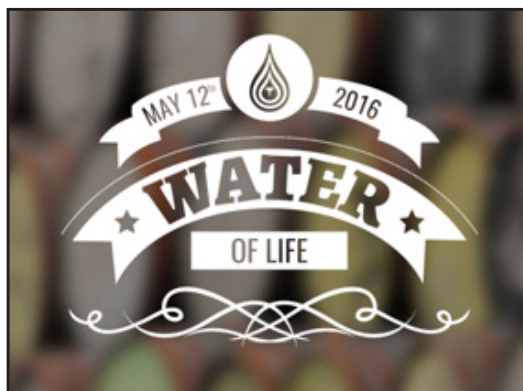
By **Jessica Nowak**, Development Manager

Join The Life Raft Group on May 12, 2016, for our second annual whisky fundraiser, Water of Life! This year, the event will be held at Midtown Loft and Terrace in New York City.

Our unique Whisky Speed-Dat-ing theme will give guests the opportunity to sample more than 25 whisky brands over the course of the night. Whisky Ambassadors at each table will host short sessions with our guests while

they sample different whiskies, accompanied by food pairings.

For cigar lovers, our VIP-ticket option includes an hour of cigar and whisky pairings on Midtown Loft's rooftop, which provides a breathtaking view of the Empire State Building.



This year, we have added special Master classes, such as “This IS Your Grampa’s Whisky Class” and “The Blackadder Experience.” Don’t wait

too long to sign up, as space in these classes is very limited!

Although Water of Life will feature whiskies from all around the globe, those interested in local spirits should be sure to register for the “American Whisky Trail” option to guarantee a stop at all of the tables on the trail.

For whisky lovers old and new, this event is unlike any other. Don’t miss your chance to enjoy a night of drinking, eating, making new friends — and, most importantly — helping The Life Raft Group find a cure for GIST.

For further information, please contact Jessica Nowak: jnowak@lifteraftgroup.com

www.lrgwateroflife.com

Thank you to our Major Donors for January and February for helping support “The Gift of Time”

- Carlos Baldor
- Georgia Bihr
- Bayer HealthCare LLC
- BST Consultants
- David and Maxine Clark
- John Dahne
- Design America
- Dublins Pub
- Eli Lilly and Company
- Genentech
- Jim Hughes
- Novartis Pharmaceuticals Corporation
- Palermo-Ravich Family Foundation
- Pfizer Incorporated
- The Peter and Jean Charitable Fund

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.lifteraftgroup.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, Communication Director, at mgarland@lifteraftgroup.org of any errors.

Nutritional series part 2: Absorbing nutrients after surgery

By **Kathryn Troy**, Patient Registry Health Educator

The digestive system is a group of organs that work together to feed the entire body by converting food into energy and basic nutrients. Food is ingested through the mouth; passed through the esophagus into the stomach; and filtered through the small intestine, pancreas and liver. Based on its particular function, each organ contributes in different ways to turn the food we eat into the nutrients we need.

The stomach allows large volumes of food to mix with digestive juices before it moves to the small intestine, which consists of the duodenum, jejunum and ileum. At this point, the process of absorption begins, which contributes to the body's optimal function and overall good health. The small and large intestines are the body's largest sources of nutrient storage and absorption. The intestinal



Be sure to discuss supplement use with your doctor .

walls absorb digested nutrients. Undigested "leftovers," such as fiber, pass through the colon.

GIST patients who undergo major surgery, including partial or total gastrectomy and resection of the small or large intestines, commonly face issues such as malabsorption and dehydration as a result. Remov-

ing portions of the digestive tract can cause deficiencies in the nutrients those organs would normally absorb, as listed below.

- Duodenum: Absorbs Vitamin A, D, E, and K.
- Jejunum: Absorbs protein, carbohydrates, vitamins and minerals.
- Ileum: Passes food to the colon and absorbs Vitamin B12.
- Ileocecal valve (the junction of the small and large intestine): Controls the passage of food and increases production of nutrients and electrolytes.
- Large intestine: Absorbs fluids and electrolytes (such as sodium and potassium).

See **NUTRIENTS** on page 12

Webcast provides perspective on generic imatinib

By **Sara Rothschild**, Programs Director

On February 1, 2016, the commercial launch of the generic version of imatinib mesylate (Gleevec), originally for CML (Chronic Myeloid Leukemia), was approved by the FDA and became available for the first time in the United States through Sun Pharmaceuticals.

In response to this transition, the LRG provided an educational Webinar to the CML and GIST communities on March 18th entitled "Generic Imatinib: Gaining Perspective."

A panel of experts provided their insight, expertise and perspectives about generics. A question and answer session followed the presentation.

Presenters included:

Michelle Durborow
Patient Registry Director
The Life Raft Group

Bill Hinshaw
Executive Vice President
Novartis US Oncology

Dr. Jonathan Trent
Co-Director Musculoskeletal Center
Sarcoma Medical Research Program,
Sylvester Comprehensive Cancer Center

Melissa Simpson
Senior Program Manager in the
Center for Benefits Access at the
National Council on Aging

Over 100 people participated in this

event. An overview about generics was presented including important concepts such as bioequivalence, bioavailability and the approval process of generics. Participants were interested to learn if there was any published data comparing brand Gleevec and generic imatinib. However, there is a lack of appropriate high-quality randomized trials between generics and originator medicines in published literature.

Novartis provided information about their access and support programs for both the CML and GIST communities, sharing with participants that commercially insured patients could pay only a \$10 co-pay for a 30-day

See **WEBCAST** on page 15

Becoming a “Patient Champion”: Strategies for caregivers

By **Norman Scherzer**, Executive Director of the Life Raft Group

Navigating the waters of medical treatment can be not only confusing, but also potentially deadly. According to the Agency for Healthcare Research and Quality, one in seven Medicare patients in hospitals experiences a medical error. Almost half of the errors were preventable. It is estimated that 440,000 people die each year after suffering a medical error in the hospital, making this the third leading cause of death just behind heart disease and cancer. My personal experience is that the rate of mistakes is much larger than that reported and that its primary cause is not a lack of skills



Lauren Funk, Physicians Assistant at NY Presbyterian, epitomizes quality patient care.

amongst most medical professionals but instead a coordination system

that prioritizes billing and legal protections for the medical provider over a comprehensive and timely communication system that crosses multiple medical disciplines and hospital staffing shifts.

For cancer patients, it is vital to be vigilant about all aspects of care. For many, this means engaging a “patient champion,” to serve as an advocate. In most cases, that will be the spouse or family member of the patient, but if there is a family friend who has the desire, management skills and most importantly fortitude, consider engaging them in the process.

See **CHAMPIONS** on page 15

Local Advocacy: LRG supports NJ bill A-2337

By **Mildred Menos**, Strategic Alliances Director

Although GIST is among the few rare diseases that has available drug therapy treatment options, the cost of these lifesaving medications can sometimes impose deep financial hardship, depending on the terms of the patient’s insurance policy.

Mildred Menos currently serves as the Life Raft Group’s representative to the New Jersey Out-of-Pocket Prescription Cost Limit Coalition (NJ OOP Cost Coalition). The Coalition’s goal is to support state legislation and legislators who seek to lessen the financial burden of critical treatments to patients.

Currently, the most promising of these initiatives is Assemblyman Dan Benson’s bill A-2337, which requires health insurers to limit patient cost-sharing and provide an appeals process concerning certain prescription drug coverage.

The Coalition continues to urge the Assembly Financial Institutions and Insurance Committee to support this critical legislation and refer the bill for consideration by the full Assembly. We would love to add the voice of LRG members to this important conversation.

The Issue: High cost-sharing is a barrier to care

For many years, insurers have used tiered cost-sharing in their drug coverage as a way to encourage patients to try lower-cost medications before turning to more expensive ones. Traditionally, costlier options would appear on the second or third tier of a health plan’s drug formulary — the list of medications covered by the plan — and the patient would pay a flat copay that increased moderately with each tier.

Today, however, it is common for formularies to include a fourth, fifth or even higher tier, where the cost-share is often a percentage of the actual cost of the medicine, rather than a flat copay. Known as coinsurance, this type of cost-sharing can require a patient to pay as much as 50 percent of a medication’s cost, which can translate to thousands of dollars in cost-sharing for just a one-month supply of a medication.

These higher tiers — usually referred to as specialty tiers — have come to include a significant number and range of medications, including drugs that have *no generic or cheaper equivalent*. Another emerging trend is for the highest-cost tier to contain *all the medications* available for a certain condition. For patients who need one of these

See **ADVOCACY** on page 14

ASCO from page 1

presented an example of immunotherapy used to fight melanoma (and also used to manage other kinds of cancer, including: lung, kidney, bladder, liver, head and neck, and Hodgkin's lymphoma). Breakthroughs in immunotherapy have achieved great results recently, including significant tumor shrinkage and controlled tumor growth for much longer periods of time. Immunotherapy is part of the treatment prescribed for former President Carter.

Dr. Liu presented an example of advances in targeted therapy

(similar to Gleevec and other meds used to fight GIST) for ovarian cancer. A phase-II study of targeted therapies Olapanib and Cediranib, when combined, were shown to show significantly delay tumor growth and decrease tumor size.

Key to those advancements have been significant investments in the National Institute of Health (NIH) and National Cancer Institute (NCI) over the past decades. The Federal government has been invaluable in this support.

Congressman Chuck Fleischmann (TN) spoke of his commitment to fighting cancer throughout his three terms in Congress and how Congress fought to provide \$264 million in funding for the NCI. Both his parents died from cancer. He encouraged us to reach out to our senators and representatives to

push for more funding, as dollars become more scarce for this non-partisan fight.

Representative Rosa DeLauro (CT) is a 30-year survivor of ovarian



ASCO president Julie Vose welcomes attendees at Clinical Care Advances 2016.

cancer who serves on the Labor, Health and Human Services, and Education Subcommittee. She is very passionate about the issue and pointed out that today's NIH budget is lower than it was 2003, once we adjust for inflation and the increasing costs of biomedical research. She spoke about Vice President Joe Biden's cancer "moonshot" mission and the internal push to find funding resources to advance progress against cancer.

Wanda Lucas, a patient advocate and survivor of breast cancer, discussed the importance of taking part in clinical trials and the continued need for increases in funding research.

Julie Vose closed the meeting by speaking more about the report and continued to stress the importance of Federal funding to advance

work on the prevention of and fight against metastasis.

The room was packed; the briefing was interesting; and I liked how all the speakers gave short, informative speeches without belaboring medical information. Few questions followed the presentations, but the message came across loud and clear: Federal funding is essential for the fight against cancer and the advancement of biomedical research like immunotherapy and targeted therapies.

A webcast of the briefing is now available at bit.ly/ASCO2016HillBriefing

Are you interested in being more involved with advocacy events? If so, contact Laura Occhiuzzi at locchiuzzi@liferaftgroup.org ■

Help Us Further GIST Research.



If you would like to participate in the Life Raft Group's Tissue Bank, please contact Michelle Durborow, the Patient Registry Director, by phone 973-837-9092, Ext. 125 or email: mdurborow@liferaftgroup.org

ESMO from page 1

of the STS talks was: “How can we build on the GIST model?” Sadly, there are few options for most metastatic STS, mainly the old-style cytotoxic chemotherapy drugs.

This article is not a comprehensive account of the meeting, but will cover a few of the highlights from my point of view — focusing on GIST and not on STS.

Preceptorship Sessions

On the Monday before the main meeting, I attended the “preceptorship,” an all-day session where senior doctors gave an introduction to GIST and STS, aimed at young medical oncologists.

Dr. Paolo Dei Tos, from Treviso, Italy, talked about the pathology of GIST. As long ago as 1962, U.S. pathologist Arthur Purdy Stout, in a paper titled “Bizarre Smooth Muscle Tumors of the Stomach,” first recognized the tumors now known as GIST, even though he called them “leiomyoblastomas.” Stout made this classification on the basis of clinical presentation and pathology. Today, according to Dr. Dei Tos, morphology is less relevant to the diagnosis of GIST. It is essential to do immunohistochemistry (staining) analysis for the KIT and DOG1 proteins that are characteristic of GIST.

During the Q&A period, another doctor asked him about the relevance of the distinction between benign and malignant GIST. Can we ever talk about a benign GIST? Dr. Dei Tos answered that 99 percent of small “micro-GISTs” do not progress.

SARCOMA AND GIST CONFERENCE

Milan Italy
16-17 FEBRUARY 2016

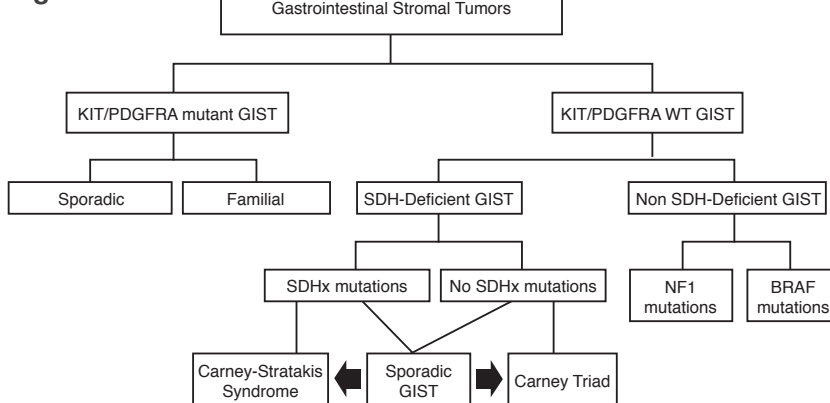
Nevertheless, even a patient with a small GIST has a small risk of metastasis. Therefore, we should probably not call any GIST benign.

Maria Debiec-Rychter, a member of the Life Raft Group Research Team from Leuven, Belgium, presented “The molecular biology of GIST.” She began by noting that 75 percent of GIST patients’ tumors have a mutation in the KIT gene and 15 percent have a mutation in the PDGFRA gene. She said that at their registry in Leuven, 1,862 GIST patients have been characterized by mutational testing. She believes that mutational analysis should be standard clinical practice in GIST.

genetic counseling is needed for the family.

Dr. Heikki Joensuu, a pioneer of imatinib therapy for GIST from Finland, spoke about adjuvant therapy. He reviewed the randomized trials of adjuvant imatinib in GIST (ACOSOG Z9001; EORTC 62024; and SSG XVIII), noting that doctors tend to underestimate the risk of recurrence for many GIST patients. Two ongoing clinical trials are testing whether taking adjuvant imatinib for longer than three years is effective in preventing recurrence. Dr. Joensuu said that he titrates the imatinib dose up to what each patient can tolerate, such as 500, 600, or 700 mg, rather than using the same dose for every patient.

Figure 1



Recent progress in classifying wildtype tumors

She also discussed wildtype GIST, which does not have KIT or PDGFRA mutations. She used this scheme of Boikos and Stratakis to review the recent progress in classifying these tumors: (see figure 1 above)

Carney-Stratakis syndrome is associated with germline (inherited) mutations in succinate dehydrogenase (SDH) genes. In these GIST cases,

Dr. Peter Reichardt, from Berlin, discussed targeted therapy of metastatic GIST. He reviewed the early days of imatinib therapy for GIST and discussed alternatives for the treatment of wildtype GIST. During the Q&A period, Dr. Mikael Eriksson of Sweden asked: “Do you think it is ethical to use a placebo control in a trial of a new drug?” Dr. Reichardt answered that he thought it could

be justified in order to get a new drug approved more quickly. Dr. Eriksson responded: “No, it is not ethical, because we already know what will happen to patients on a placebo.”

Main Conference Presentations

The main conference began on Tuesday. Markus Wartenberg was one of the people invited to the stage to welcome the delegates, and he spoke eloquently on behalf of Sarcoma

See ESMO on page 7

ESMO from page 6

Patients EuroNet (SPAEN; www.sarcoma-patients.eu). He presented a model in which Patient Advocacy Groups can act as an interface between patients and caregivers on one side; and on the other, between doctors, research organizations, regulatory agencies and drug companies. I was happy to observe the very positive and respectful way in which ESMO and the medical community interacted with the patient advocates throughout the meeting.

Dr. George Demetri (Dana Farber Cancer Institute, Boston), another pioneer of imatinib therapy, discussed the medical treatment of GIST. Interestingly, he made the point that “Patient Zero,” the female patient who was the subject of the 2002 New England Journal of Medicine report that first announced the efficacy of imatinib in GIST, was actually treated according to a formally written and committee-approved clinical trial protocol. It was not just a one-shot trial, as some people may think. He stressed that 15 percent from this very first group are long-term survivors, who have been treated with imatinib since approximately 2001. With regard to adjuvant imatinib, he asked provocatively: “Why would a young person who has a high-risk GIST ever stop adjuvant imatinib?”

Dr. Demetri gave a list of new options that may become available for metastatic GIST:

- Inhibitors that target the PDGFRA D842V mutation
- BRAF-specific drugs (in patients with mutations in that gene)
- Metabolic targeting for DSH-deficient GIST
- Anti-KIT monoclonal antibodies

- TKI (tyrosine kinase inhibitor) drug combinations
- MEK and FGFR inhibitors
- Immuno-oncology

Dr. Reichardt then spoke on “The clinical challenge of secondary resistance to imatinib in GIST.” He listed the possible major cause as secondary resistance mutations. Other possible factors include insufficient drug getting to the tumor, over-expression of the KIT target, and loss of KIT

“ According to LRG Research Team member, Maria Debiec-Rychter, “Mutational analysis should be standard clinical practice in GIST.”

expression resulting from “de-differentiation” of the tumor cells.

A strategy now being studied in clinical trials is to alternate between two drugs, such as imatinib/regorafenib or sunitinib/regorafenib.

Dr. Reichardt discussed the situation in which a patient stops adjuvant imatinib, for example, after three years of treatment. He said that patients should be monitored closely after discontinuation, with imaging done every three months. Some outstanding questions that need to be answered with regard to adjuvant imatinib include:

- Should treatment continue for longer than three years?
- Should exon 9 patients receive 800 mg per day?
- Should PDGFRA D842V patients receive any adjuvant treatment?

There appears to be no consensus on whether to use 800 mg for adjuvant

treatment of exon 9 patients. After this talk, Dr. Trent asked the audience for a show of hands as to whether doctors are prescribing 800 mg. The response was mixed.

Immunotherapy and the search for a cure

On Wednesday, Dr. Robert Maki (Mount Sinai Hospital, New York) spoke on “Immune therapy in STS: Where are we?” He discussed the many new immune-modulation strategies being developed. These include new vaccines, monoclonal antibodies, activated “T-cells,” drugs that can trigger the stimulation of T-cells, and “immune checkpoint inhibitor” drugs that can release a pre-existing but otherwise repressed immune response. His overall conclusion is that he expects to see a plethora of new options for immunotherapy in GIST.

Finally, Dr. Ron DeMatteo (Memorial Sloan-Kettering Cancer Center, New York) discussed immunity in GIST and the high-level challenge: “How are we going to cure GIST?” His suggestions included better adjuvant therapy, better surgery for residual disease, new and better TKI drugs, and immunotherapy.

It would have been wonderful if a landmark announcement of the success of a new drug or immunotherapy had been announced at the meeting. Although that did not happen, it was encouraging to see the rapid progress that is being made on the classification and characterization of GIST. GIST can certainly no longer be regarded as a single disease, but rather a group of several related diseases. Many new developments are being made in drug and biological therapies, such as immunotherapy. I had the satisfying feeling that the whole GIST community shares a spirit of cooperation and dedication to the challenge of treating the disease — ready to share new ideas and experimental systems (like GIST cell lines) and keeping communication channels open. ■



LIFE FEST 2016



The Life Raft Group is excited to announce its 8th anniversary of our biennial Life Fest conference, which gives patients and caregivers the opportunity to gather for a weekend of camaraderie, unique access to global leaders in the field, and a wealth of new information about the latest advances in GIST management and research.

This year's Life Fest theme is focused on The Gift of Time and the logo is an hourglass. Each grain of sand in the hourglass represents a moment in time; a precious memory that we cherish. Each morning we awaken to receive 86,400 seconds. Take a moment to calculate how many seconds you have been given since your GIST diagnosis or the diagnosis of a loved one. The fact that there are viable treatments for your disease has meant the gift of those precious seconds. At Life Fest we invite attendees to share treasured moments with us by recording them on paper "grains of sand" and displaying them on our Gift of Time hourglass display.

Life Fest will be celebrated July 15th – 17th

to incorporate the celebration of GIST Awareness Day at the Redondo Beach Marriott in Torrance, California. While the conference will be held July 15 to 17, we have secured the hotel room discounted rates for Wed. July 13th to Monday July 18th so that conference participants may enjoy the Redondo Beach/LA areas before and after our event if they choose to do so.

We will begin the weekend on Friday, July 15 with registration and an optional GIST 101 session. The evening will be our Gala and we will celebrate GIST Awareness Day. There will be a special photo booth that will display The Gift of Time hourglass with your posts of treasured moments (grains of sand). We will also share the Gift of Time celebration video and honor some outstanding people whom have contributed so much to our community. These include:

- **Erin MacBean** – Allan Tobes Volunteer of the Year
- **Ronald DeMatteo, MD** – Jeroen Pit Science Award
- **Matthew Lurin, MD** – Arnie Kwart Philanthropist of the Year
- **Friends of Max-India** – Global Award of Excellence
- **Jason Sicklick, MD** – Clinician of the Year
- **Ray Montague** – GIST Hall of Fame
- **Michael LaQuaglia, MD** – GIST Hall of Fame

“Inspiring information and hope.”

The rest of the weekend will be filled with medical and research updates, long term survivor and side effects strategies, integrative medical therapies, future innovation sessions, etc. and plenty of time to network and have fun with fellow GISTers, caregivers and friends. Saturday night we will hold a Celebration of Life Ceremony at the hotel's Zen Garden. This will be an opportunity for us to celebrate the lives of GISTers who are no longer with us through a special performance dedicated to them. We will then devote the rest of the evening to enjoying the Redondo Beach area with an optional fun outing that will be announced soon. Sunday we will focus on advancing health data to help us find a cure, LRG's GIST survival plan and coming attractions.

The LRG member fee to participate in Life Fest remains the same as in previous years: \$155 per person for the entire weekend, due to the generous support of sponsors. We do have a limited number of scholarships available to those seeking to enhance their GIST awareness regardless of financial situation. Scholarships are made possible by the generosity of the LRG Board of Directors and donors. To register for Life Fest, download the agenda and scholarship application, and learn more about this event, please visit:

liferaftgroup.org/lifest/

Like to give a “Gift of Time” to someone?

Sponsor a Life Fest Scholarship. Go to: bit.ly/LifeFestScholarship

Sponsors



“Glad we came. We learned a lot.”

“Excellent opportunity to ask questions of the experts in a more casual setting.”

“Enlightening and I love the time to connect with others.”



Holistic workshops were a great success



Jeff and Adrienne Davis



Dina Wiley and Jerry Cudzil



Alice Brown, Norman Scherzer and Bonnie Emerson



Sheryl and Michael Ginsberg

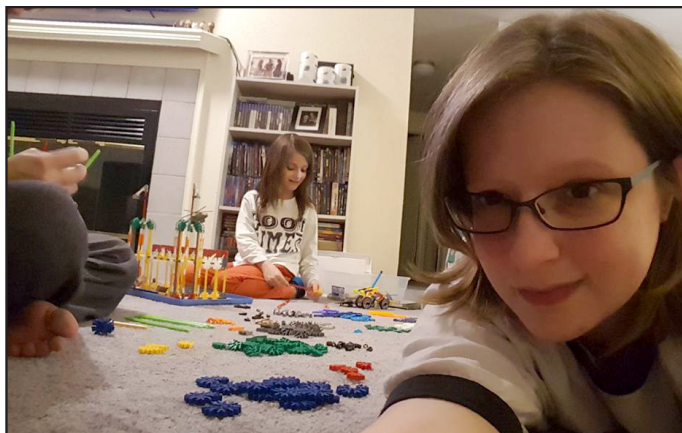
SWIMMING from page 1

child and bought a house. Life was going well.

Then the market crashed, jobs and insurance were lost and medical expenses went up. It was like getting diagnosed with cancer all over again. Quietly, I slipped into a hard depression. I didn't talk about it much, as I felt my life had been easier than many other cancer patients — my tumors, thus far, have been manageable. However, I felt worthless because my family lost everything we had due to my health. It wasn't until the LRG threw a lifeline to me that I began to believe my life had some value once again.

In the past, I coped with depression by helping others. That's why, years ago, I started volunteering for the Life Raft Group. In 2014, the LRG invited me to Life Fest on a scholarship provided by generous donors. I met with a group of young patients, as well as children of GIST patients, and we formed a branch-off group called GISTKids. During one of our meetings, we reflected on how the character of Dory in the movie,

Finding Nemo, sang this advice for when times got bad: "Just keep swimming." Moments later, we all agreed that "*GIST Keep Swimming*" would be the GIST-kids motto. Little did I know that this motto would get my family through some of our hardest times to date.



Erin and her family settling into their new apartment.

Once I got home from Life Fest, I threw myself into creating a place for GISTkids to go. Building a website, finding research content and translating it all into kid-friendly terms turned out to be more of a trial than I thought it would be. During each challenge, I would sing *GIST Keep Swimming*. With the help of a few great friends,



we got a website up. Our biggest achievement, however, is that this year's Life Fest 2016 will have its own pediatric and wildtype GIST panels and meetings!

Not only are things looking great for GISTkids, but life has turned around for me as well. My husband and I took a leap of faith and moved from Florida to Washington state. There were more jobs available in my husband's field in Washington, and we learned that being a resident of the state yielded a better chance at landing a job. So, we sold everything to move and my husband took on two part-time jobs just to make ends meet. The first few months were rough and money was extremely tight, but we kept singing *GIST Keep Swimming*.

In October, my husband got a call and was told he was hired for his dream job! That same company learned of my story, saw the skills I had gained as a volunteer and, on March 1st, hired me as well. They even let me work from home, which allows me to finally get off disability and focus on rebuilding my life again.

If it wasn't for the scholarship to Life Fest, I may have never found my purpose and learned to sing a motto that has helped me through the challenges of life. If you haven't experienced a Life Fest, please consider attending this year. You won't regret it. To those who have donated to the LRG in the past, or those who are thinking about donating now, please know that it is money well-spent. Your donations give people like me a lifeline — or, in this case, provides a life raft for us all. ■

Send us your video "Gifts of Time"

Our Life Fest and GIST Awareness Day theme is the Gift of Time. Our logo is an hourglass, with each grain of sand representing a moment in time; a precious memory we celebrate.

We invite you to celebrate your "gifts of time" by making a short video which will be featured at our Life Fest celebration in July.

For information on how to make a short video, please contact Diana Nieves: dnieves@liferaftgroup.org or go to our GIST Awareness Day Download Center. www.liferaftgroup.org/download-center/





How to Participate

Help us bring awareness and education about GIST to your friends and family and by joining us in celebrating GIST Awareness Day!

HOW CAN YOU PARTICIPATE IN GAD?

- Attend Life Fest and participate in sharing your “gift of time.”
- Hold a GIST Awareness Day event at a local hospital/cancer center. Ask if you can set up an hourglass banner (order from the LRG) and invite patients to post their “gifts of time.” Take a photo of your completed banner and we will display it at Life Fest and on our website.
- Throw a family party. Ask friends and family to make signs of moments they have shared with you that they are thankful for. Take photos and email them to the LRG.
- Take photos in front of clocks or with timepieces. Hold a sign saying, “I am grateful for the gift of (insert your number) years of survival.” Post on the LRG Facebook page and on your own social media page with the hashtag **#GiftsofTime**
- Ask to set up a table at a community event, fair or festival to raise awareness about GIST. Ask the LRG for materials.
- Make a short video where you talk about the Gifts of Time you have received. Send it to us and we will put it in our video collage.
- Write your gifts of time on the webpage we have created.
- Bake a cake. Decorate with symbols of your “gifts of time.” Photograph it and others enjoying this delicious treat.
- Send 13 letters raising awareness about GIST. These could be to legislators, oncologists, your local paper, etc.
- Request that your city and/or state declare July 13 GIST Awareness Day.



SPONSORS



NUTRIENTS from page 3

- **Colon:** Breaks down dietary fiber and begins development of fatty acids.

It is important for anyone who has had a surgery that modifies any stage of the digestive process to discuss ways to retain these nutrients with their physician. You can use the following information from the National Institutes of Health (NIH) and Medscape to guide your conversation.

Vitamin A is a fat-soluble vitamin used to maintain normal vision and

immune system functions. It also supports organs such as the heart, lungs and kidneys. This is highly relevant to GIST patients on long-term medication, as many drugs can lead to dehydration and eventual kidney impairment. Stocking up on Vitamin A will help support the kidneys and prevent toxicity.

Vitamin D is another fat-soluble vitamin used to promote calcium in the gastrointestinal tract, enable bones to grow and strengthen, and prevent osteoporosis.

Vitamin E is a fat-soluble antioxidant that enhances immune functions, prevents cardiovascular disease and protects cognitive abilities. It is particularly valuable for GIST patients, who often have weakened immune systems that can make them more susceptible to other illnesses and co-morbidities.

Foods to promote Vitamins A, D and E include dark leafy greens, almonds, avocados, broccoli, canned tuna and salmon. Water-soluble forms are a viable option if the ileum has been removed.

Vitamin K is often associated with the process of blood clotting and even bone health. Deficiencies may occur if patients have GI disorders, therefore levels should be monitored regularly. There are a number of dietary options for increasing Vitamin K levels to discuss with your doctor. These include dark leafy greens, healthy oils (such as olive and canola), oats, beans and whole wheat. A physician may recommend administering Vitamin K intravenously if medically necessary.

Vitamin B12 supports red blood cell formation, as well as neurological functions. Vitamin B12 is found in red meat, fish and shellfish, egg yolks and cheeses (Swiss, Parme-

san, Mozzarella). If necessary, B12 supplements can be taken by injection every one to three months.

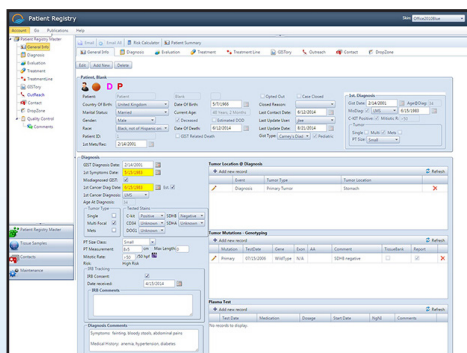
Patients who experience acute and chronic side effects from surgery often take probiotics to promote a healthy immune system and optimal digestion. The Mayo Clinic, Probiotic.org and the NIH recommend these probiotic strains to maintain digestive health:

- **Lactobacillus acidophilus:** Aids in improving bowel regularity. Side effects may include diarrhea and antibiotic-related bowel symptoms.
- **Lactobacillus reuteri:** Improves the overall wellness of adults, specifically those with gastrointestinal-related infections and illnesses.
- **Sachromyces boulardii:** Reduces gastrointestinal disorders and symptoms of diarrhea.
- **Bifidus bacteria:** Enables the body to metabolize sugars and regulate pH levels in the GI tract to ultimately improve digestive functions.

Probiotics should be taken in 5.5–50M units. Since probiotics consist of live bacteria, make sure to obtain them from trusted sources. They should be sealed in blister packs and should not be exposed to heat or moisture.

Again, it's essential to talk with your doctor before starting any preventative health treatment to avoid unnecessary complications, especially in a post-operative state. Discussing blood work and other evaluation details will give you a better understanding of how your body is changing and the available interventions to help you achieve and maintain good health. ■

Did you find this article helpful?



Join the LRG Patient Registry to access more helpful information and one-on-one personalized support, as well as to contribute to vital data that moves us closer to a cure.

For more information and to join, visit our website:

www.liferaftgroup.org/patient-registry/

CONGRATULATIONS

Please join us in welcoming Teena Petersohn as the newest member of the Life Raft Group Board of Directors.



As an LRG member, Teena has been an advocate for GIST patients since joining the LRG in 2011, promoting GIST awareness locally, and participating in OVAC's lobby day.

We are excited to have her join the team, as she is an inspiration to all of us.

"I was very honored to be offered a position on the Board of Directors of the Life Raft Group. I would like to thank each one of you for having confidence in me. (Especially Norman, the other Directors and the staff at LRG) I am very excited about adding this experience to my GIST journey!!!"

-Teena

Side effects management vital to the quality of life

In a recent article in Cure Today, LRG Marketing Director, Erin Kristoff, details the importance of side effects management and the role the LRG plays in helping to extend survival and to improve the quality of life for GIST patients.



"The LRG has been collecting data in our Patient Registry for the last 15 years. One of the most dominant trends that has surfaced is that more than 49 percent of our members report experiencing side effects as a result of their drug therapies. Out of a sample group of 1,462 patients, patients reported 827 cases when side effects became so burdensome that they interrupted their drug therapy usage. In light of the fact that they have the ability to influence a patient to either temporarily or permanently discontinue their potentially lifesaving drug, the importance of effectively managing side effects cannot be overstated."

Please share this important article with the greater GIST community

bit.ly/CureTodayLRG

CANCERVERSARIES



Susan Brandt 6 YEARS

"As my 6th Gist cancellersary approaches, I realize that the two most important things in my life now are Hope and Thanks. Hope is for a cure for all of us Gisters, and a prayer for many more days ahead of us. Thanks is for the love, support, and prayers from my family and friends, the doctors that care for us, and the diligent research conducted every day that is getting us closer and closer to that cure. Someone once said "Yesterday is history, tomorrow is a mystery, but today is the present." God's gift to us all. "Rejoice and be glad in each day". Life, sweet and beautiful in spite of GIST."



ADVOCACY from page 4

treatments, even a generic option will involve a high cost-share.

The growing prevalence of high deductibles make this problem even worse. This year, the average combined deductible in bronze plans sold through state market-places is \$5,249 and, in silver plans, \$2,658. These plans commonly require consumers to *meet their full deductible before any coverage is provided*.

Typically, specialty tiers contain medications taken only by one-to-five percent of the patient population. These patients face diseases and conditions that — while relatively limited in incidence — are usually chronic, debilitating and/or often life-threatening. These include: cancer, multiple sclerosis, epilepsy, rheumatoid arthritis, HIV/AIDS, hemophilia and other rare diseases. Specialty tiers require these patients to shoulder a disproportionate share of the cost of their medications, thus negating the purpose their insurance is supposed to provide — which is to protect from financial hardship in case of serious illness — in the first place.

This benefit design is not only unfair, it is also potentially harmful to patient health. High cost-sharing has been shown to lower medication utilization and adherence, leading to poor health outcomes and to an increase in longer-term costs associated with treating disease progression and complications. According to several studies, prescription abandonment rates increase significantly when patient cost-sharing exceeds \$100. Perhaps it's not surprising, then, that drug adherence is a problem estimated to cost the U.S. \$290 billion annually.

The Solution: Reasonable limits on out-of-pocket costs

We believe that A-2337 offers a straightforward solution to this issue: Depending on a health plan's level of coverage, a patient cost-share for a 30-day supply of a medication would be limited to \$100–\$200. These limits would apply pre-deductible, meaning they would be applied to patients' out-of-pocket costs, regardless of whether they have satisfied their plan's deductible. Otherwise, patients with

higher deductibles are unlikely to experience any improvement in affordability when they fill their prescriptions each month.

We encourage New Jersey LRG members to become involved in this important advocacy issue. Please write or call your Assembly representative to voice your support for this legislation (phone and email scripts are provided in the Advocacy section of the LRG website). Or, contribute your personal experience with high out-of-pocket drug costs and the impact it has had on you at the next Assembly hearing. You can keep your participation anonymous, if you choose. You can also narrate your story to an LRG writer if you would prefer not to write a statement.

To participate in this initiative, or to join the LRG's Advocacy Committee and stay up to date on all global advocacy issues in which we are involved, please contact Mildred Menos at mmenos@liferaftgroup.org. ■



CALENDAR OF EVENTS

MAY 9, 2016

GIST Day of Learning Chicago
NorthShore University
HealthSystem - Evanston Hospital
5:00 PM - 8:15 PM
bit.ly/GDOLChicago2016

MAY 12, 2016

Water of Life 2016
Midtown Loft
New York, NY
5:00 PM - 11:30 PM
www.lrgwateroflife.org

JUNE 29, 2016

GIST Day of Learning New York
American Cancer Society
132 West 32nd Street - New York
5:00 PM - 7:45 PM
bit.ly/GDOLNewYork2016

JULY 15-17, 2016

Life Fest 2016
Torrance Marriott Redondo Beach
3635 Fashion Way
Torrance, CA 90503
REGISTRATION NOW OPEN



CHAMPIONS from page 4

For the past twenty plus years, I have been the “champion” for my wife, Anita. During this time, I have learned many lessons, and have been able to intervene in many situations that were potentially life threatening.

It is my intention to share with LRG members and the wider GIST community important strategies I and others have learned to help prolong the life of my loved one, in order to help others to do the same. We will publish a series of articles and hold webcasts in the future dealing with topics relevant to becoming a “patient champion.”

Two valuable tips I will share today as a preview: Keep fastidious records and develop a team of medical professionals and an agreed upon system to encourage treatment collaboration.

Lauren Funk, Physician’s Assistant at New York Presbyterian, is one of the treatment professionals who became a valuable part of my wife, Anita’s team of “champions.”

I look forward to hearing about your strategies that can be shared in future articles- with the goal of extending survival for GIST and all cancer patients. ■

WEBCAST from page 3

supply of Gleevec. Finally, for those participants who were Medicare beneficiaries, they received an overview of the Medicare Part D plan and resources of where to go for more assistance.

We wanted to give a special thank you to the National CML Society for helping to promote this event and encouraging both disease groups to come together around a common issue.

To view the video archive of the event as well as to read more about generics, visit our website: www.liferaftgroup.org/generics/ ■

In Memoriam

Rebecca Theresa Harper – Inspiration to others, woman of faith

Rebbecca Theresa Harper was born January 24, 1951 in Atchison, KS to Victor Edmond and Pauline Mary (Maday) Kesse and after a long and faith-filled fight with cancer, died March 14, 2016 in Kansas City, MO.

Becky graduated from Hayden High School in 1969 and Washburn University in 1973 in Topeka, Kan., and received a Master’s Degree from UMKC in 1988. She taught first grade at Carbondale Grade School in Carbondale, Kan. for ten years, and also taught first grade at Junction Elementary School in Kansas City, Kan. for 12 years until she was diagnosed with Gastrointestinal Stromal Tumor (GIST) in 1996.



She married Don Harper on July 24th, 1982 in Topeka, Kan.

Becky enjoyed spending time with her family and church activities and was a member of Lenexa Baptist Church. She especially appreciated her time with Stephen Ministry and prayer ministries. She is survived by her husband, Don Harper; her mother, Pauline Kesse; one son, Paul (Denise) Johnson; three grandchildren; Theresa, Maxwell and Veronica; one great grandson, Ryker, and her brother Vic (Deb) Kesse.

In lieu of flowers, please consider making a memorial contribution to Lenexa Baptist Church Benevolence Fund or the Life Raft Group (the support group which is providing information and raising money

to find a cure for Becky’s cancer (GIST), 155 US Highway 46, Suite 202, Wayne, NJ 07470. A Celebration of Life service was held on March 26, 2016 at Lenexa Baptist Church, 15320 W. 87th Street Parkway, Lenexa, Kan. ■

*Every life
leaves something
beautiful behind*

Contact the LRG at info@liferaftgroup.org for ways to honor your loved one.

THE LIFE RAFT GROUP

LRG STAFF

Executive Director	Norman Scherzer
Deputy Executive Director	Marisa Bolognese
Patient Registry Director	Michelle Durborow
Communications Director	Mary Garland
Strategic Planning Director	Pete Knox
Marketing Director	Erin Kristoff
Strategic Alliances Director	Mildred Menos
Development Director	Diana Nieves
Program Director	Sara Rothschild
Senior Patient Registry Associate	Kathrena Aljallad
IT & Design Manager	Matthew Mattioli
Development Manager	Jessica Nowak
Patient Registry Health Educator	Kathryn Troy
Website Manager	Thomas Cordasco
Operations Associate	Angela Edson
Global Relations Consultant	Piga Fernandez
Grants Consultant	Kathleen Gronet
Patient Registry IT	James Lee
Assistant Program Director	Laura Occhiuzzi
Patient Registry Associate	Josette Pierre
Operations Associate	Victoria Pinero
Finance Director	Lorraine Ramadan

LRG VOLUNTEERS

Pediatric GIST	Erin MacBean
Official Greeter	Gail Mansfield
Latin America Liaison	Vicky Ossio
Clinical Trials Coordinator	Jim Hughes
Photographer	Kim Tallau
Newsletter Editor	Jennifer Moore
Special Projects Asst.	Eileen Glasser
Science Team	Tanya DeSanto
	Jim Hughes
	David Josephy
	Michael Josephy
	Rick Ware
	Glenn Wishon
	Paula Vettel

BOARD OF DIRECTORS

Executive Committee
Jerry Cudzil — President
Stan Bunn — Past President
Gary Glasser — Secretary/Treasurer
Chris Carley
Jim Hughes
Jerry Knapp
Teena Petersohn
John Poss
Rodrigo Salas
Larry Selkovits
Mia Byrne (Ex Officio)
Ray Montague (Ex Officio)

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

Arizona	Ellen MacDonald
California	Dina Wiley
	Martha Zielinski
Delaware	Cindy Bones
Florida	Anny Riley
	Jeff Davis
Georgia	Barbara Auw
Idaho	Janet Conley
Illinois	Jim Hughes
	Marlene Nei
Iowa	Barbara Kepple
Kentucky	Cindy Betz

Louisiana	Jackie Welsh
Maine	Jodi Merry
Massachusetts	Charles Burke
Michigan	Ellen Rosenthal
Michigan - West	Cliff Kopp
Missouri	Katie Bloss
Montana	Dirk Niebaum
Nevada	Joan Smith
New Hampshire	Julie Thorne
New Jersey	Anita Getler
New York	Pat Bonda Swenson
Oklahoma	Jane Rowan

Pennsylvania	Jeffrey Bernstein
	Carol Heller
South Carolina	Paula Stover
Tennessee	Alice Sulkowski
Texas	Dee Hawkins
Texas -West	Tatiana Avila-Isaias
Utah	Mike Ginsberg
	Carrie Callister
Virginia	Sally Jackson
West Virginia	Susan Caperton
Wisconsin	Rick Ware

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

Argentina	Sandra Mesri
Australia	Roy Neil
Austria	Amy Bruno-Lindner
Belgium	Gerard van Oortmerssen
Bolivia	Virginia Ossio
Brazil	Valeria Hartt
Bulgaria	Juliana Popova
Canada	David Josephy
Chile	Piga Fernández
China	ZeeZee Zhenxi Zhong
Colombia	Maria Helena Matamala
Costa Rica	Michael Josephy
Cyprus	George Constantinou
Czech Republic	Jana Pelouchová
Dominican Rep.	Alejandro Miranda
Finland	Marjo Vaisanen
France	Estelle LeCointe
Germany	Markus Wartenberg
Greece	Lefteris Patapis
Guatemala	Silvia Castillo de Armas

Honduras	Xiomara Barrientos
Hungary	Tünde Kazda
India	Nikhil Guhagakar
Iran	Negar Amirfarhad
Ireland	Carol Jones
Israel	Avi Zigdon
Italy	Gabriella Tedone
Japan	Sumito Nishidate
Jordan	Sameer Yaser
Kenya	Ferdinand Mwangura
South Korea	HyunJung Yang
Macedonia	Dejan Krstevski
Malaysia	Choo Sian Yong
Mexico	Rodrigo Salas
Namibia	Lon Garber
Netherlands	Gerard van Oortmerssen
New Zealand	Joy Rycroft
Nicaragua	Maria Teresa Ponce
Norway	Frøde Homb
Pakistan	Muhammad Shahid Rafique

Peru	Eva María Ruiz
Philippines	Rod Padua
Poland	Piotr Fonrobert
Puerto Rico	Eileen Rolon
Romania	Simona Ene
Russia	Tanya Soldak
Samoa	Leasi John Galuvao
Saudi Arabia	Mohamed-Elbagir Ahmed
Scotland	Stacey McAully
Singapore	Kie Go
South Africa	Annette Mentasti
Spain	Luis Herrero
Sudan	Mohamed-Elbagir Ahmed
Switzerland	Helga Schnorf
Thailand	Kittikhun Pornpakakul
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



Facebook
facebook.com/liferaftgroup
Twitter
twitter.com/liferaftgroup
LinkedIn
[http://linkd.in/liferaftgroup](https://linkd.in/liferaftgroup)
YouTube
[http://www.youtube.com/LifeRaftGroup](https://www.youtube.com/LifeRaftGroup)