

Help us celebrate GIST Awareness Day!



In Loving Memory: John Lynch, Merlin Gesing, Joyce O'Shea, Louise Leonard, Toy McLaughlin, Gerald Liu, Nancy Reinhardt, John Ryan, Louise Teerink, Todd Gardner, Patricia Hernandez

#ShowUsYourRare for GAD!

By **Erin Kristoff**, Marketing and Communications Director

Last year's inaugural GIST Awareness Day was a huge success, and we know with your help 2015 will be even bigger and better! This year, we're celebrating GIST Awareness Day by creating a photo mosaic made from 10,000 photos uploaded

from all over the world using the #ShowUsYourRare hashtag we've created for our newest awareness initiative.

What is #ShowUsYourRare?

#ShowUsYourRare is the Life Raft Group's most recent effort to bring attention to GIST and other rare cancers through a series of activities that let people highlight the most special, unique parts of themselves.

See **RARE** on page 9



Moving towards a better future

By **Kathrena Aljallad**, LRG Patient Registry Associate

As one of the most common side-effects of Gleevec, Sutent and Stivarga, fatigue is a condition that many GIST survivors are intimately acquainted with. The National Comprehensive Cancer Network defines cancer-related fatigue as "a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning." Due to its



Exercise done properly and safely can lead to a better quality of life.

See **MOVING** on page 7

Jeff Davis: Fan of miracle comebacks

By **Mary Garland**, Marketing and Communications Associate

Back in 1969 the New York Mets, a struggling team at the time, pulled off one of the most amazing comebacks in baseball.



DAVIS

You could say that Jeff Davis, LRG member and state representative for southwest Florida, has much in common with the "Miracle Mets." He has made quite a comeback after a harrowing journey before finally receiving a GIST diagnosis and the treatment he needed to be restored back to health.

Jeff's GIST journey started in January of 2013, when he sought medical attention for fatigue, weakness and abdominal discomfort.

He was no stranger to medical issues. Jeff had battled prostate cancer, and had gone on Disability in 2008 due to

See **MIRACLES** on page 8

Love is at the heart of Henzo Kenya

By **Mary Garland**, Marketing and Communications Associate

As the Life Raft Group continues to grow globally, we will highlight our international friends in each newsletter issue.

In this interview with Ferdinand Mwangura, Chairman of Henzo Kenya, we discover how the seeds were planted for this thriving support group of over 650 CML and GIST patients in Kenya.

Henzo Kenya was formed in June of 2007 by three CML (Chronic Myeloid Leukemia) patients and two volunteers who saw a lack of emotional support resources available for this patient community. By 2009, Henzo Kenya was officially registered as a support group, and recognized as a community based organization by the Ministry of Gender, Children and Social Development in Kenya. Henzo membership includes survivors of CML and GIST as well as their caregivers and volunteers. Their common goal is to support one another in all aspects of life.

Henzo means love in Kiswahili, and the group's motto is "If you want to run fast, you run alone, but if you want to run for a long time, you run as a group."

During our discussion, Ferdinand



"If you want to run fast, you run alone, but if you want to run for a long time, you run as a group."

provided insight into the origins of the organization and his involvement.

Q: How did you personally become involved?

A: "Back in 2007, I was visiting my doctor for a routine checkup on one of the typical clinic days, to get updates on the progress of my condition (CML) and to go back home with a prescription. But this particular

day was slightly different since the doctor engaged me on a topic outside the normal conversation between a doctor and a patient. He mentioned to me the importance of a support group and encouraged me to bring together other patients. He then gave me the contacts of another patient by the name of Francis Kariuki (the late) and advised me to get in touch with him. I met Mr. Kariuki, introduced myself and inquired if he was ready to take up the challenge of working together.

Mr. Kariuki informed me he was a GIST patient not CML. Two weeks later, he reached out to me to say that he was ready to discuss how we could go about the process of starting a support group.

At that point it was apparent that we needed to come up with an interim governing body that would enable us propose a name, create a constitution and register the group with the government of Kenya. Mr. Kariuki took the chairman's position and I became the deputy chairman. We started by recruiting GIST and CML patients who were in the GIPAP (Glivec International Assistance Program). Volunteers and caregivers joined us. This was encour-

See **KENYA** on page 6

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 Erin Kristoff, the Marketing & Communications Director, at ekristoff@liferaftgroup.org of any errors.

Study indicates use of adjuvant imatinib therapy for GIST increasing

By **LRG Science Team**

A recent study published in the *American Journal of Clinical Oncology* found that the use of adjuvant systemic therapy with imatinib for GIST has increased significantly over time, and that patients treated with the therapy have better survival rates than those treated with surgery alone.

Since the discovery of imatinib (Gleevec), treatment for gastrointestinal stromal tumor (GIST) has changed. Survival statistics have shown better outcomes for those treated with adjuvant Gleevec. Therefore, the use of imatinib as a treatment modality for GIST has increased over time.

Parameters and Findings

The study, led by researchers from the American Cancer Society, analyzed data from the National Cancer Data Base, reviewing 4,694

patients with localized GIST who had been diagnosed between 2004 and 2011.

Led by Dr. Helmneh Sineshaw, MD, MPH, the researchers discovered that the use of adjuvant therapy



had increased by more than double between 2006 and 2011, with a decrease in 2011.

Findings indicate that patients who

underwent adjuvant systemic treatment had a 46 percent lower risk of death than those treated with surgery alone.

Prior Study by LRG Research Team Member

Additional trials have also dealt with the issue of adjuvant treatment with imatinib, including those where LRG Research members were participants. The LRG website has links to many of these studies: www.liferaftgroup.org/gleevec/preventative-gleevec/

A randomized clinical trial sponsored by the ACOSOG (American College of Surgeons Oncology Group) in 2014 included participation by Dr. Chris Corless, member of the LRG Research Team. This study found that one year of adjuvant imatinib was able to prolong recur-

See **IMATINIB** on page 10

Virtual tumor board expands to adult GIST cases

By **Mildred Menos**, Assistant Program Director

The Life Raft Group is excited to announce that our Virtual GIST Tumor Boards have been so successful within the global Pediatric GIST community that we are now expanding our applications to review adult GIST cases from around the world.

Our partnerships with the National Institutes of Health and physicians from key medical institutions around the world such as Memorial Sloan Kettering and

Cambridge University Hospitals in England have allowed us to bring together leading experts to discuss GIST cases, while serving as an educational resource for local physicians. It not only provides local doctors with updated treatment options, trials and studies,

it also encourages collaboration between GIST experts, ensuring the best care is offered to patients.



The LRG connects the local treating physicians and their team with key GIST opinion leaders.

The LRG uses cutting-edge technology to connect the local treating physicians and their team with key GIST opinion leaders. Panelists have shared access to radiology films and other necessary medical reports using the internet, secure servers and video conferencing software which allows them to review the case and provide advice in real time.

If you would like your case reviewed by a team of experts in a future Virtual GIST Tumor Board, please have your physician contact Mildred Menos at mmenos@liferaftgroup.org or by phone, (973) 837-9092 x129 and we will provide him/her with the application to get started. ■

“Water of Life” will flow at LRG event

By **Diana Nieves**, Director of Operations

The Water of Life event is the first annual whisky fundraiser hosted by LRG member, Dr. Mathew J. Lurin (co-founder of the Whisky Nerds). The word whisky (or whiskey) comes from the Gaelic uisce/uisge, a shortened version of uisge beatha meaning “water of life.” Dr. Lurin is a whisky aficionado whose stepfather is a GIST patient.

Dr. Lurin was recently asked about his inspiration to create the Water of Life event. He stated, “I’ve been going to whisky tastings for over a decade, traveling to several countries in the process. I’ve always enjoyed meeting the people in the industry, including those that make, market, and appreciate this wonderful elixir.”



When the Whisky Nerds were founded the mission was both education about, and appreciation of, whisky. After attending many wonderful events, the Whisky Nerds wanted to create a unique event to allow for this to happen. And thus the “Water of Life” was born. The event will be a sit-down ‘speed-dating’ type of event, consisting of several tables, each one their own mini-masterclass. It was equally important that this event also be used as a fundraiser to benefit a charity. My stepfather is from Scotland, and played a big role in my early whisky education. He was diagnosed as a GIST patient several years ago, and the Life Raft Group is an organization that helps patients like him through this difficult time. The choice was easy. I hope you can be a part of what should be a



**Wednesday, May 6th, 2015
6pm-10pm • Battery Gardens, NYC**

wonderful evening. Slàinte Mhath!”

The Water of Life event will be unique in that it will have a seated speed dating format, where pourers host short sessions with five guests at a time, and share drams (a small amount of whisky) and stories for 12

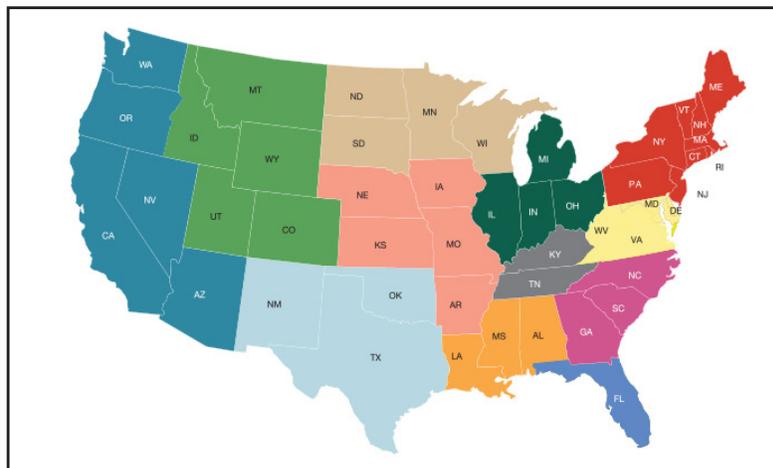
See LRG EVENT on page 10

LRG state leaders connect in first virtual meeting

By: **Mildred Menos**, LRG Assistant Program Director

On Wednesday, February 11, the Life Raft Group’s state leaders had their first opportunity to gather virtually and to discuss the best strategies for bringing together and building a support community for patients and caregivers in their local area.

As the reach of the Life Raft Group has expanded, the LRG State Leader program (and the accompa-



nying country leader program) has become increasingly important as a

means for GIST patients and caregivers to meet each other and share support and experiences in person. State leaders also provide guidance and become a friendly face for new members. The LRG currently has 39 leaders in 33 states.

Over 25 leaders participated in the meeting by phone and online and had a chance to listen to

See LEADERS on page 11

Advocacy in Chile moves forward: an update

By **Piga Fernandez**, LRG Global Consultant

New steps have been taken in Chile that will benefit patients who need high cost treatments.

Piga Fernández, LRG Global Consultant in Chile, together with representatives of 26 patient organizations has been working on a thorough revision of law project: “Ley Ricarte Soto.” They have created a document outlining the main observations and concerns they have, including:

1. High copayments and deductibles: The proposal in this law project does not resolve the financial catastrophe that patients’ families have to face.

2. Requiring scientific evidence of the efficacy of treatments to be covered: considering that most of the rare diseases that this law would cover have very few patients and no possibility of making scientific evaluations in our country, the proposal states consensus evidence and studies made abroad should be considered when scientific evidence is unavailable.

3. The project does not clearly establish the right to free and equal access to high cost treatments, which are intended to improve the quality of life of people affected by a disease. This right should be addressed in this new law.

4. The project establishes that the



Representatives of patient organizations with Senator Goic

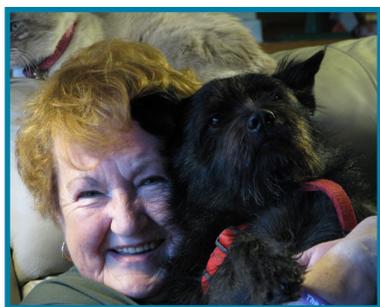


validation and modification of covered high cost treatments would be done every three years. The proposal is to change this to a shorter period of time, which will then allow for the evaluation of new treatments sooner.

The alliance of patient organizations met in early March with senators and deputies of different Political Parties who are members of the Congress Health Commission.

Hard work has been done, but there’s still much to do! ■

CANCERVERSARY



Pat Berg

I had a “surprise” diagnosis of GIST in April, 2009, and thanks to the Life Raft Group and its knowledge and an excellent surgeon along with the assistance of Gleevec for about five years, I am enjoying life more than ever. Most of all, I enjoy my special pals that are seen in the picture, and the ability to travel with my husband. We will be in Hawaii during my “cancerversary” month of April.



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

KENYA from page 2

aging for the patients to see non-patients volunteering and joining us. This was actually the turning point. Our highly motivated group started advocacy work in earnest.

I took the mantle as the Chairman of the group when Francis passed away in 2012.”

Q: How has the organization grown? How many members do you currently serve? How many are GIST patients?

A: “The organization has grown in leaps and bounds ever since. We take pride in being the most active patient-driven GIST organization in Africa. Our trademark “Cycling To Stomp Out Cancer” event has been held in Nairobi for the last four years. This outdoor event has enabled us be visible in the media as well as the general public. We have been able to lobby the Kenyan Government on a number of occasions to respond to our needs.

Most importantly, we have put our patients first by holding general meetings every year to bring them all together, share our stories and encourage one another. In these meetings we usually bring on board experts to answer any questions that

might arise. Family members of GIST patients also come together and share stories.

We also provide materials designed to educate our patients on the basics of GIST. This initiative has equipped our patients with the necessary information to enable them to live a comfortable life.

We currently have about 650 patients, 80 who have GIST.”

Q: What would you like to see for the future of the organization?

A: “I would like to see Henzo Kenya grow to become the voice of all GIST patients in Africa, a pan-African patient-driven advocacy group that knows no boundaries. I would like to see us mentoring other GIST groups in Africa and becoming the unifying and uplifting GIST group in the continent.”

Q: What kind of help would you like from the international community?

A: “My kind request to the international community is to make more GIST medicines available. We have had access to Glivec free of cost through the GIPAP program for 13 years running. Many patients live a good life thanks to Novartis and The Max Foundation. However, there are a small number of patients who get resistance, and without access to second



and third-line treatments, that becomes their sad ending.

I would also like to see GIST monitoring be affordable and accessible, and I wish for Henzo Kenya be part of the Global GIST Community.”

The Life Raft Group has already welcomed the organization into the global GIST community, extending information, advice and support. We facilitated an exchange of information with Henzo Kenya and other disease groups to share best practices and strategies for advocating for private and government support so that all GIST and CML patients in Kenya receive the treatment they need and deserve.

Henzo Kenya will participate in this year’s GIST Awareness Day activities, and will be represented at the New Horizons meeting.

We have begun to provide the group with informative materials. The LRG also will be working on creating easy-to-understand GIST literature, so that information can be accessible to patients with all levels of literacy.

Love from the global community reaches across oceans and continents in an effort to support all those who suffer from GIST. ■



“I would like to see Henzo Kenya grow to become the voice of all GIST patients in Africa, a pan-African patient-driven advocacy group that knows no boundaries.”

MOVING from page 1

difficulty to quantify and/or or treat, patients may find it both physically and emotionally debilitating. However, fatigue in cancer patients may have more than one cause. While cancer treatments (i.e. chemotherapy, radiation, surgery) themselves are certainly the primary source of fatigue, other causes including anemia, not getting enough calories and nutrients, loss of muscle weight, and being less active may also be contributing factors.

Research has linked physical exercise with fatigue reduction as well as increased muscular strength and sleep duration. Studies have also concluded that the higher number of steps a person took per day was correlated with higher physical activity and better levels of social functioning.

In other words, the more you move, the better you will feel. Although there have not been many studies on this topic, all existing studies have shown promising results which have led to exercise programs becoming a standard part of many patients' treatment plans.

Cancer institutes across the country have begun offering patients supervised exercise classes and consults with experienced exercise physiologists. These programs are targeted specifically for cancer patients and are available with a doctor's approval. There are other options available if a cancer institute is not nearby. The LIVESTRONG Foundation has partnered with the YMCA to offer classes

for adult cancer survivors. Another option is searching through the American College of Sports Medicine (ACSM) to find a trainer who is a certified cancer exercise trainer in your area. There are also ways you can exercise at home, but before trying anything at home always consult your physician.

The most important part of living a physically active lifestyle is to make



Gardening promotes tranquility and healing.

sure you are having fun. After receiving the sign off by your health care team, here is a short list of fun ways to remain active:

- **Walking** - With summer right around the corner it is the perfect time to go for a stroll. Brisk walks can increase energy levels by boosting blood circulation and increasing oxygen supply to each and every cell in your body helping you feel more alert. Just remember to stay hydrated and protect yourself from sun exposure.
- **Stationary Cycling** - If balance is a concern for you, try cycling on a stationary bicycle. Riding a stationary bicycle regularly helps

your heart become stronger and more efficient at pumping blood throughout your body. The more blood you circulate, the more oxygen and nutrients are transported to all living cells. You can even grab a nice book and read while getting your exercise in.

- **Yoga** – This is a great way to gain flexibility and strength, while reducing stress levels. Yoga focuses on harmonizing both the body and mind through the use of precise posture, breathing exercises, and meditation. The techniques incorporated in yoga can help lessen chronic pain, lower blood pressure, and reduce insomnia.
- **Gardening** - Enjoy being outdoors? With spring here, it is the perfect time to begin a garden, whether it is a flowerbed or a vegetable patch. Gardening is associated with mental clarity and feelings of reward. It has also been shown to promote tranquility and healing. Just be cautious of any excessive heavy lifting and sun exposure.
- **Dance** – If traditional exercise is not for you, dancing is a great way to get moving and have fun. It is a full body workout without the boring, repetitious movements of conventional exercise programs. Dancing improves body shape, promotes stronger bones, improves balance and raises endorphin levels. Make a playlist of your favorite songs and start moving!

There are endless types of exercise you can do beyond the ones provided above. The benefits of exercise, if done properly and safely, can lead to a better quality of life and increase your overall well being. Whether it's a short workout found online or a personalized exercise plan designed for you, the main part is to just get up and start moving. ■

MIRACLES from page 1

myasthenia gravis (A chronic autoimmune neuromuscular disease of the skeletal (voluntary) muscles of the body). This time, though, he was to face a long and life-threatening series of delays in diagnosing GIST, which eventually led him to the treatment that would restore his health.

Seen by a GI specialist, Jeff underwent a series of colonoscopies within a year, having had several pre-cancerous growths removed. He became severely anemic, and was placed on a regimen of iron pills, which garnered slight improvement.

In September of 2013, he was rushed to the emergency room, and required multiple transfusions due to internal bleeding. In spite of a series of tests (but no CAT scan), no definite reason was found. He was referred to a hematologist at an oncology center, where he received iron infusions. His hemoglobin levels somewhat improved.



CALENDAR OF EVENTS

APRIL 14

GIST Day of Learning Chicago

MAY 6

First Annual Water of Life
Battery Gardens, NYC

MAY 16

GIST Day of Learning Miami

JUNE 10, 2015 - JUNE 12

NIH Wild Type GIST Clinic
National Institutes of Health
(NIH), Bethesda Maryland

JULY 13



Three months later he stopped the iron infusions, but in January 2014, he was still weak. He received more iron treatments, and finally returned to the GI specialist. A CAT scan was finally ordered. In February 2014, a mass was found in his abdomen and he was then scheduled for a consult at H. Lee Moffit Cancer Center.

“I get up every morning with one thought in mind: We’re one day closer to finding a cure for GIST.”

Later that month, Jeff ended up in the ER. He couldn’t keep food down, and had become severely dehydrated. After being released, he was called back in for an additional CAT scan, which showed blockage in his intestine. He was admitted to clear the blockage, and was also diagnosed with pneumonia. This was a low point for him.

Finally, in March of 2014, Jeff met with a surgeon at Moffit, who gave him the bad news that the tumor was inoperable: it was too vascular and was wrapped around the small intestine. His cancer had also metastasized to the liver.

But the physician finally gave Jeff some good news. Although the diagnosis was GIST, there was a treatment that had proved effective on his other patients: Jeff was placed on 400 mg of Gleevec.

Jeff did experience side effects, which included loss of appetite, skin rash, and sleeping difficulties. When he became severely depressed, he knew he needed help. He joined a cancer support group at a local hospital, and eventually was put in touch with another GIST patient, who shared that her daughter had found the Life Raft Group online. Jeff googled the LRG, and registered as a member in late spring of 2014.

He lost 50 pounds between March and September, but after only two months, the tumor had shrunk by 25 percent. By his next visit, it had shrunk by 50 percent, and the spots on his liver had disappeared.

Having become informed through his contact with the Life Raft Group, Jeff recognized the importance of mutational testing, requested that it be done, and discovered he was Exon 11. He decided he wanted to see a GIST specialist, and found Dr. Jonathan Trent of Sylvester Comprehensive Cancer Center. When he consulted with Dr. Trent in December 2014, he found that there continued to be shrinkage, and he remains on his 400 mg dosage of Gleevec.

Today, he feels 100 percent better than he did a year ago. He attributes this to his positive attitude, strong will and support system headed by his wife, Adrienne. They will celebrate their 47th wedding anniversary this coming August. He is also grateful for the support of fellow GISTers in the Life Raft Group, and his family and friends.

A graduate of the GIST Expert Training course, Jeff decided to volunteer as an LRG state leader because he felt the skills he developed through careers as a sales manager, teacher and financial advisor could be utilized in this role to help others. He would like to help others avoid the misdiagnosis that took 15 months of his life before receiving a proper GIST diagnosis.

His advice to newly diagnosed patients is straightforward: Seek out a GIST expert, join a support group, don’t be afraid to ask for help from friends and family, and don’t give up hope.

Jeff is a fan of miracles. “I get up every morning with one thought in mind: We’re one day closer to finding a cure for GIST.” ■

RARE from page 1

We want to redefine what the word rare means to the world and in doing so increase the quality of diagnosis and treatment afforded to those branded “rare.”

Why Rare? We often hear the phrases “the common good” and “the needs of the many” in reference to healthcare. The problem is, what if your needs fall outside of the common good. What if we can no longer see the trees for the forest?

“So, when did rare become such a scary word? When did it become something to ignore?”

In the world of cancer, diseases are split into two camps: rare and common, and with cuts in cancer research funding increasing each year, rare cancers suffer disproportionately. With over 200 cancers vying for research funds and only five percent of proposals being awarded funds from the NIH (the largest contributor to cancer research in the world), rare cancers regularly fall by the wayside.

So, when did rare become such a scary word? When did it become something to ignore?

We are asking the world to help us shine a spotlight on that which makes us...unique, beautiful, powerful, brave... in other words—rare.



LRG staffer Kathrena Aljallad shows off what makes her special to support #ShowUsYourRare: “My multi-ethnic family and traditions make me rare!”

Ways to participate in the #ShowUsYourRare campaign

Participating is easy:

- To help spread awareness and contribute to the mosaic, you can post a status, photo or video to Twitter, Instagram, Pinterest or on the LRG Facebook page with the hashtag #ShowUsYourRare and encourage your friends to do the same. It can be anything you want that expresses what makes you or

See **RARE** on page 10

Are you or a loved one social media savvy? Become an LRG Social Media Ambassador and #ShowUsYourRare!

Everyone is special in some way. Maybe you have a winning smile, rare coin collection, great group of friends? Snap a pic and post to one of these social media platforms: Instagram, Twitter, Pinterest and the Life Raft Group’s Facebook page with the hashtag: #ShowUsYourRare. It’s that easy!

Email or call Erin at ekristoff@liferaftgroup.org or 973.837.9092 x117 with questions or ideas.



Rare was in the air on February 27, as LRG Marketing & Communications Director, Erin Kristoff and hundreds of rare disease advocates came together for Rare Disease Day at the National Institutes of Health.

Though GIST differs from most rare diseases, due to our relatively larger patient population and the good-fortune of having several FDA-approved drug treatments, we are united in many ways: Lack of research funding and recognition by the greater health community are obstacles we all face, out of this comes a general sense of camaraderie borne from knowing that we are all in this together—and together we can succeed.

At this year’s event, presentations were made on a variety of topics including community building, translational research and maintaining meaningful dialogue amongst advocates, medical professionals and policy makers. Representatives from the Rare Diseases Clinical Research Network, including the National Center for Advancing Translational Sciences and the Coalition of Patient Advocacy Groups shared innovative models for keeping the needs of rare disease patients at the forefront of research.

Erin enjoyed learning from these pioneering organizations and sharing the LRG’s new awareness-building #ShowUsYourRare campaign with patients and advocates alike.

IMATINIB from page 3

rence free survival after resection of a primary gastrointestinal stromal tumor (GIST). Further clinical trials have indicated the benefit of three years of adjuvant treatment. Although there has not been a definitive study to determine the benefits of adjuvant treatment for more than three years, we have seen patients that derived benefit from continuing adjuvant treatment for a longer period of time.

More about this study can be found on our website: <http://bit.ly/ACOSOG-clinical-trial>

As new treatments develop for GIST, it will be vital to continue these types of studies to help physicians and patients in their treatment decision-making process.

It will be important to identify populations who are not being treated with these lifesaving drugs, and to find ways to disseminate this information to them.

We at the LRG hope that more trials like this one will occur in the future, and will be sure to update you with ongoing information.

A summary of the study can be found here: <http://bit.ly/imatinib-therapy> ■

LRG EVENT from page 4

minutes, before they move on to their next 'whisky date'. Over the course of the evening, guests will have the opportunity to try over 25 whiskies, accompanied by food pairings at each table, passed hors d'oeuvres, buffet dinner and desserts.

Some of the pourers will include: Aberfeldy, Amrut, Balblair, The Balvenie, Benromach, Blackadder, Brenne, Bunnahabhain, Compass Box Whisky Co., Craigellachie, Deanston, Dewar's, The English Whisky Co., The Famous Grouse, Glenfiddich, Glenmorangie, Gordon & MacPhail, Highland Park, Hudson Whiskey, Kilchoman, The Macallan, Single Cask Nation, Still Waters

Distillery, Sullivan's Cove, Tamdhu, and Tullamore Dew.

If cigars are your thing, a VIP ticket will be just what you need. There will be two terraces open at the event where VIPs will get the chance to sit outside for an hour straight with one brand, enjoying a pairing of their whiskies and cigars. There will be VIP pours and a special commemorative glass as well.

The Water of Life event will be held on Wednesday, May 6 at 6pm at Battery Gardens, 1 Battery Place in NYC. For more information and to register for this event, please visit our website: www.liferaftgroup.org/events/water-of-life?=/ ■

RARE from page 9

someone you care about special.

- Not a social media user? Send the pictures to us and we'll post them for you!

Help us celebrate GIST Awareness Day

There are so many ways to celebrate GAD! Help us bring attention to this disease by educating your friends and family and joining our call to action.

You can support our efforts through participating in advocacy efforts, holding an awareness day event and of course, spreading the word through social media and participating in the #ShowUsYourRare campaign. No matter how you choose to celebrate GIST Awareness Day, you will be helping to shine a light on GISTers around the world- THANK YOU!

The LRG and members of the GIST community will also hold in-person events leading up to the week of July 13, which will feature photo booths strategically placed in hospitals, LRG patient gatherings, and public areas like festivals and boardwalks inviting passers-by to create and pose with their own "_____ makes me rare!" sign. On July 13, we will virtually unveil the #ShowUsYourRare mosaic, as well as pick winners from our top social media supporters for fun prizes.

If you have any questions or unique ideas to share, please contact Erin at ekristoff@liferaftgroup.org or 973.837.9092 x117. ■

Latest GIST Cancer Journal out!



The GIST Cancer Journal is the first journal specifically focused on Gastrointestinal Stromal Tumors (GIST).

ALL INQUIRIES:

Pete Knox
 Director of Strategic Planning
 973-837-9092 x123
pknox@liferaftgroup.org

LEADERS from page 4

some of the latest projects the LRG is working on including: presentations on the newly distributed State Leader Handbook, communications initiatives including GIST Awareness Day 2015, and services such as the LRG Patient Registry and Tissue Bank. After the presentations, state leaders had a chance to engage in an interactive discussion with one another where veteran leaders were able to provide their advice to those trying to re-engage or start up groups in their state.

For a full list of state and country leaders please visit: www.liferaftgroup.org/find-a-support-group/. If you are interested in assisting your state leader or becoming one yourself please contact Mildred Menos at mmenos@liferaftgroup.org to get started. ■

Joyce Elaine O'Shea: Friend to all

Joyce Elaine O'Shea, aged 61, passed away at home in Aptos, California on Thursday, February 26, 2015. She courageously fought cancer, never losing her spirit of faith.

Born September 13, 1953 in San Jose, California, she lived in Red Bluff before settling in Aptos. She worked at Starlight Elementary as Office Manager from 1989 until retiring in 2011.

Her husband, Richard O'Shea, her grandson, Ryan Grachek, and parents, Jeanne and Boyd Allwardt, preceded her in death.



She leaves behind daughters Janell Gomes of Santa Cruz and Jodie O'Shea of Aptos; brothers, Jim and Jeff Allwardt of Red Bluff; and grandchildren, Brandon Grachek and Alina Grachek of Santa Cruz.

Joyce was a great friend to all and always kept them laughing. She loved music and dancing, and adored the family dog, Cooper. What she loved most was being Grammy to her grandchildren.

A Celebration of Life was held in March. Memorial contributions are welcome and should be mailed to the O'Shea Family, 146 Dolphin Drive, Aptos, CA, 95003. ■

Louise Leonard: cornerstone of her family

Louise Leonard, 78, of Girard, Ohio, beloved wife, mother, grandmother and friend passed away on February 2, 2015 surrounded by her loving family.

Born November 22, 1936 in Youngstown, Ohio, the daughter of the late Arthur and Tiva Orsine Callard. Louise was a member of St. Rose Church,

and was a former member of the Girard Junior Women's Club. She thoroughly enjoyed her time spent with family and many friends. Louise was the cornerstone of her family and confidante to her friends.

Louise was the consummate lady: elegant, beautiful, kind, thoughtful and



impeccable to the end. She enlivened every space she entered with her warm smile and her sparkling eyes that shone with such love and care and thoughtfulness. She always had a kind thought and gesture for everyone. We have lost a truly wonderful person who was loved by all and will forever be missed.

As her son John stated, "She was the best part of all of us and I hope I have a small piece to carry with me forever."

She leaves to cherish her memory her husband, John D. Leonard Sr., her children, Karla (Phillip) Smith of Akron, John D. (Suzana) Leonard Jr. of Shaker Heights, and Bob (Danielle) Leonard of Rocky River; sister, Linda (Dick) Ross of Girard;

brother, Louis (Chrissy) Cera of Hope Sound, Florida; and her grandchildren, Audrey and Emma Smith, Adam (Janice) and Hannah Smith, Daniel and Stefan Leonard, Alex Sapp, and Andrew and Anna Leonard.

Her family provided strong support for Louise during her illness, finding the best care for her regardless of how far they needed to travel. Her son John, a physician, shared, "I want to live to see the day that one metastatic cancer can be cured. Hopefully that cancer will be GIST."

The family requests that any material contributions be made to GIST Cancer Research Fund, 5 Sawmill Road, New City, NY 10956, or www.gistinfo.org in Louise's memory. ■

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THE PATH TO GIST AWARENESS

JULY
13

OUR GOAL:

Increase GIST awareness worldwide, and...



Connect survivors with helpful services



Increase medical professionals' GIST understanding



Speed up the process from symptoms > diagnosis > treatment

JUNE

MAY

 **GIST**
AWARENESS
DAY

GIST Awareness Day (July 13) brings awareness to GIST, (Gastrointestinal Stromal Tumors), a rare cancer of the gastrointestinal tract. By holding events, participating in the "ShowUsYourRare" campaign, and reaching out to the public, we can move toward our ultimate goal: To cure GIST.

Ways to celebrate GIST Awareness Day

- Snap photos of people showing off their rare at local fairs
- Throw a BBQ and create a #ShowUsYourRare photobooth
- Go big! Fit as many people as you can in a GAD photo and share your feat



APRIL

#ShowUsYourRare

The #ShowUsYourRare campaign begins in April, with a year-round goal to raise awareness of GIST and other rare cancers through social media. People from around the globe will show their rare qualities by sharing pics with the hashtag: #ShowUsYourRare

How to #ShowUsYourRare

- Show off your rare by posting to Facebook, Twitter, Instagram or Pinterest with the hashtag
- Tweet your favorite celeb "What makes you special?" #ShowUsYourRare and support #rarediseases
- Encourage your friends to post and share

Visit us at www.liferaftgroup.org/awareness