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In Loving Memory: Julie Clifford, Daniel Winter, Howard Greenley

It's a journey: Our experience on clinical trials

By Jennifer Moore
LRG Member

I was waiting in line to pick up a new prescription for Gleevec when my husband ran in and told me to forget it. After two surgeries, a year on 400 mg of Gleevec and a miserable few weeks on Sutent, Owen had a few rogue tumors that continued to grow. We were hoping that ramping up the Gleevec to 800 mg would do the trick, but his new oncologist had just called him in the car with the results of



*Jennifer Moore &
her husband Owen*

Journey Continued on Page 12

Global GIST Advocates Convene at LRG Headquarters

By Sara Rothschild,
Senior Director of Program Operations

The Life Raft Group had the pleasure of hosting the global New Horizons GIST meeting this year in our Wayne, New Jersey office. This international meeting traditionally gathers global GIST advocates with the shared vision to unify and support patient advocacy efforts and hear advances in research and treatment of GIST. 31 participants from 15 countries attended this year's convocation.

Our theme was focused on how disease advocacy organizations can utilize real world evidence from patient health data. We kicked

New Horizons Continued on Page 11

Why do cancer patients join clinical trials?

By Jerry Call
LRG Data Analyst

At the most basic level, cancer patients join clinical trials because of perceived value and perceived cost. In this context, perceived cost refers to more than just financial cost, although that is important. Perceived cost includes not only financial costs, but also includes other things such as perceived side effects, any cost in time, which may include time away from family, time away from a job, etc.

The word perceived deserves special emphasis. The patient will ultimately place a value on their various options as well as

a cost based on what they know or think they know.

Perceived Value

How does a patient determine value? The first part of such a determination is based on need. Patients doing well on approved therapies with a good prognosis have little need for a clinical trial, so there is little value to them. At the other extreme, patients that have failed all approved therapies have much greater need.

The second part of placing a value on a trial depends on awareness. In order to have a perception of the value of a trial, the trial must enter into the realm of the patient's

Clinical Trials Continued on Page 14

The Life Raft Group: A Love Story



*In Loving Memory of Anita Scherzer,
Mike Matthews, and all of the others we have
lost to this terrible disease.*



For some time we have been describing the history of the Life Raft Group as being built upon hundreds of love stories.

Parents for their children. Husbands for their wives. Lovers for their soul mates.
And so it is.

Yes, we continue to push science to the brink, advocacy to the edge and caring to the boundaries of exhaustion to provide cover for our love stories to go on.

Many defining moments capture my memory of such love stories. Two will have to serve as examples.

There was Mike's tale: Knowing he had very little time left Mike asked his friends to throw him a going away party at their community club in Nova Scotia. I arrive in late afternoon as their guest and as their surprise for Mike. The scene is surreal. Mike is sitting in an old large chair his friends have brought from his living room. His daughter is sitting at his feet rubbing his legs. And the music, that wonderful music from the sixties plays on for the dozens of dancers determined to make this a great party. And then, Mike gets up and with what little strength he has left asks his wife to dance. Everyone stops. Just the music goes on.

Later that evening Mike is in his hospital bed propped up by a picture window. We stay up late talking into the night, holding hands.

It is time to go. And as my plane descends into LaGuardia airport in NYC Mike dies. His last dance lingers in my memory on the ride back to my home.

My Anita had reached her 16th year on Gleevec and was struggling to overcome a relentless series of medical assaults on her frail body. Multiple infections, hypotension, a stroke precipitating trip after trip to the hospital, rehab. facility, and back. Finally home, she asks me to promise never to send her to a hospital again. She somehow remains cheerful, sometimes faking it so as not to worry me (we had an unwritten pact about such things: she pretended not to be depressed or in pain: I pretended not to notice; kind of like parents and children about the tooth fairy leaving a present under the pillow).

Life revolved around the hospital bed and equipment in our guest bedroom. Nurse's aides stood watch 12 hours a day starting at eight in the morning. Sleep mercifully guarded her much of the evening and night. But at around two a.m. I would hear her voice calling out, "Norman, come change me."

That was when I understood what the highest level of love and commitment really meant.

It's been about fourteen months since Anita called out to me. What I would not give to hear that again.

I hate asking anyone to donate money to the work of the Life Raft Group, but we need your help to continue to provide gifts of time to those GIST patients struggling to stay alive and well. Each day does in fact bring us closer to better treatments and eventually to a cure.

Warmest Regards,

Norman J. Scherzer

Clinical Trials Offer Hope for GIST Patients

By Jerry Call
LRG Data Analyst

The Life Raft Group Clinic Trials Database currently lists 31 trials that are open that are or could be of interest to GIST patients. Many of the most interesting of these new drugs are in phase I clinical trials. Several new approaches are being tried including drugs that target a specific mutation or subtype, immunotherapy, drugs that bind to and/or block new parts of the KIT and/or PDGFRA proteins (the most common problems in GIST) and drugs that block KIT plus other possible alternate kinases. For this review, we have decided to focus on two that appear to be further along with exciting preliminary results and poised to move into pivotal phase III trials.

Resistance to Gleevec (imatinib) remains one of the greatest challenges in GIST; 85% or more of patients with metastatic GIST will eventually become resistant to treatment. The biggest cause of resistance is the emergence of additional mutations in KIT, called secondary mutations. These additional mutations typically occur in exons 13, 14 and 17, with less common mutations in other exons. Patients with resistance due to these secondary mutations, still have the original (primary) mutation, most commonly in KIT exon 11 or exon 9. Thus they now have dual mutations, such as a KIT exon 11/13 or KIT exon 11/17 mutations. In addition, more than one secondary mutation often emerges, often in different tumors.

Sutent (sunitinib) was the first drug to target these secondary mutations, doing a good job at inhibiting the KIT exon 13 and exon 14 mutations, however it was not effective against the KIT exon 17 mutations. Stivarga (regorafenib) was subsequently approved based largely on its ability to inhibit some of, but not all of the secondary mutations in exon 17. Although both of these drugs improved survival, almost all patients still eventually become resistant to these drugs as well. The major remaining problem was the KIT exon 17 mutations that were not inhibited, as well as some reduced activity of regorafenib on the exon 13 mutations.

Kinase inhibitors like imatinib, sunitinib and regorafenib, work best against kinases in a certain conformation called the inactive conformation.

Efforts to develop drugs that inhibit the active conformation of the kinase have been going on for quite some time. We are now starting to see more of these drugs enter clinical trials. Two of the more exciting ones for GIST are DDC-2618 by Deciphera Pharmaceuticals and BLU-285 by Blueprint Medicines.

DDC-2618

DDC-2618 is a new investigation drug in phase I clinical trials. It is recruiting for GIST in eight sites in the USA and one site in Canada. New sites in Europe will be added in 2018. Six different cohorts are planned including three specifically for GIST, allowing for patients that have received at least one prior therapy up to five prior therapies.

DDC-2618 works at a different location in the KIT protein than typical kinase inhibitors. Instead of targeting the ATP binding pocket like most kinase inhibitors, DDC-2618 binds to the switch pocket. It blocks a much wider range of mutations, including the active conformation of the kinase, such as mutations in KIT exon 17 that cause secondary resistance and PDGFRA D842V mutations.

Dr. Filip Janku, of MD Anderson Cancer Center, Houston, TX, presented updated results of the phase I trial at the 2017 ESMO meeting in September (abstract 14730). In the phase I trial, doses from 40 to 400 mg either once or twice per day were tested. The dose selected for expansion phase was 150 mg per day.

The logo for Deciphera, featuring the word "deciphera" in a blue serif font, with a stylized orange and yellow swoosh underneath.

Patients in the trial had received an average of 3.4 prior lines of therapy. FDG PET scans, CT scans and plasma cell-free DNA (cfDNA) were used to evaluate response. The majority of patients with KIT mutations showed a response; 22 of 32 (69%) had a partial metabolic response (PET) by EORTC criteria and 5 of 37 achieved partial response per RECIST criteria (significant shrinkage on CT scans). Disease-control rate (DCR) for patients receiving ≥ 100 mg per day was 76% at 12 weeks and 57% at 24 weeks. The median PFS time had not been reached as of July 28th, 2017. There was a marked reduction of cfDNA across all mutation types, and although based on small numbers and still preliminary, use of liquid biopsies appears favorable over tissue biopsies. The most common side effects were; lipase increase, fatigue, anemia, decreased appetite and diarrhea.

These results are quite encouraging and Deciphera is planning a randomized phase 3 study in patients who have received at least three prior drugs, the Invictus trial. Participating countries will include: USA, Canada, Belgium, Finland, France, Germany, Italy, Netherlands, Poland, Spain, UK, Australia and Singapore.

BLU-285

BLU-285 is a new investigational drug currently in part 2 (dose expansion) of a phase 1 clinical trial. The phase I trial is recruiting in 5 sites in the USA, 2 sites in France and one site in Belgium, Germany, Netherlands and the United Kingdom.

Hope Continued on Page 13

Successful Life Raft Group Canada's 6th Annual GIST Day of Learning Held in Toronto



By Malcolm Sutherland

Life Raft Group Canada (LRGC) held its 6th Annual GIST Day of Learning on October 21, 2017 in Toronto.

Topics included:

- "Highlights from New Horizons GIST Conference", presented by LRGD President David Josephy
- "Patient Self-Advocacy: An Approach to Getting the Best GIST Care", co-presented by Laetitia Tam, LRGD Director and Liz Aguiar, GIST patient
- "Strategies in Managing Side Effects of Oral Cancer Drugs", presented by Alia Tawer, Oral Anticancer Pharmacist from Odette Cancer Centre, Toronto
- "Investigational Drugs/Clinical Trials for GIST", presented by Dr. Albi Razak, Site lead for Sarcoma Medical Oncology at Princess Margaret Cancer Centre, Toronto and Mount Sinai Hospital, Toronto.

There was an excellent turnout, with attendees from Costa Rica, Vancouver, Montreal and the Greater Toronto area. GDOL Toronto was sponsored by Pfizer, Novartis and Blueprint Medicines, in attendance.

During the GDOL Self-Advocacy presentation, we introduced the GIST Patient Handbook, which was created by LRGD to help GIST patients take on a more active role by advocating for best care within the Canadian healthcare system. Successful GIST management is a team effort among the patients, caregiver and their healthcare team. The GIST Patient Handbook provides tips and tools to help navigate treatment and acquire important information from the patient's healthcare team. To access the handbook: www.liferaftgroup.ca/en/gist-patient-handbook/

We had informative talks, engaging discussion, & a fun day!

Thank You

We would like to send out big thank yous to two special volunteers who gave so generously of their time and expertise: Colleen Carney, Carney & Associates and David Epstein, Director of Domestic Human Resources for the US office of Doctors Without Borders. We are so grateful to both of you for sharing your vast HR experience with us. Thanks to your help and guidance we now have an updated Employee Handbook – we couldn't have done it without you.

Upcoming Events

GIST Day of Learning - Mayo at Scottsdale, AZ
March 10

GIST Day of Learning - VCU-Massey Cancer Center, Richmond VA
May 12

GIST Day Of Learning - New York City
May TBD

LIFE FEST - Miami
July 13-15

GIST Day of Learning - OHSU Portland, OR
August 5

Interested in having us come to your city for a GDOL?
Email your ideas to Laura at
locchiuzzi@liferaftgroup.org.

Howard Greenley: Pioneer GIST Warrior, Loving Husband, Father and, Grandfather



Howard Greenley, 59, of Houghton, MI, passed away in October 2017, following a very long and courageous battle against cancer.

Born and raised in lower Michigan, Howard was a graduate of Holderness Prep School in New Hampshire and Michigan Technological University in Houghton, MI. He was employed at Michigan Tech for 20 years, starting as Director of the Small Business

Development Center, where he received many awards from the Small Business Administration. He later moved on to be Manager of Douglass Houghton Residence Hall, and then finally to Director of Auxiliary Services, where he implemented many new initiatives which are still in place at the University today.

His passion for travel and adventure found him whitewater

rafting and climbing mountains in New England, to exploring the countryside of Ireland, to snorkeling the Great Barrier Reef in Australia. Besides Houghton, Michigan, Howard also lived in Charleston, South Carolina and most recently in Naples, Florida. He is survived by his wife Renee Greenley, son Ryan (Jill) Greenley, daughter Sierra (Philip Huml) Greenley, two grandchildren, Leo Greenley and Abigail Huml, and his mother Gloria Greenley.

In the words of his wife, Renee, "Howard was one of the original trial members with Gleevec, which he started in December, 2000, after having been originally diagnosed in 1998. He was a valiant warrior against this disease, moving from trial to trial, and surgery after surgery. His strength and fortitude was an example and encouragement to many others who struggle with this nasty disease called cancer. He will be greatly missed."

LRG Executive Director, Norman Scherzer, adds: "Howard and my Anita were in the original clinical trial for Gleevec together and helped create a path for so many others to follow."

Memorial gifts may be made to the Life Raft patient advocacy group (liferaftgroup.org) or the Omega House (hospice) in Houghton, MI (www.omega-house.org)

LRG Presents Poster at CTOS, 2017

By Jerry Call
LRG Data Analyst

The Life Raft Group recently presented a poster at the 2017 CTOS (Connective Tissue Oncology Society) meeting in Hawaii. The subject of the poster was; "What do we know about response of SDH-deficient GIST to drugs"? The question presents several challenges. First, most GIST patients do not get mutational testing, and even among those that do, testing usually stops if a mutation is not found in the KIT or PDGFRA gene. This means that the vast majority of SDH-deficient patients remain un-identified; even in a proactive patient group like the Life Raft Group.

The mutational testing rate has risen significantly over the years and approximately 70% to 75% of patients recently diagnosed are reporting mutational testing to the registry. However nearly 50% of living registry patients still don't know, or haven't reported their mutation type to the registry. As reported in the LRG poster, 117 patients reported some type of mutation other than KIT or PDGFRA. In the past, these would all be grouped as "wildtype". Wildtype basically meant, "we tested KIT and PDGFRA" and they were normal, but we still think you have GIST. Our understanding of this group today had improved dramatically and testing can identify the molecular defect responsible for the vast majority of these GISTs.

Of the 117 patients in the registry with mutational testing, but without KIT or PDGFRA mutations, 98 remain "unclassified" wildtype and only 28 could be positively identified as SDH-deficient. SDH-deficient patients can be classified either with a mutational test that reveals a SHDx mutation, or a negative

SDH-stain.

SDH-deficient GIST is thought to respond poorly to current drugs, so 28 patients is not enough to really get a good idea of drug response. In order to increase numbers, we also considered histories of patients "likely to be SDH-deficient". We did this by looking at criteria that predicted SDH-deficiency, both within the LRG registry as well as previously published criteria and found 58 patients with "likely SDH-deficient" GIST. We then tested how similar they were to known SDH-deficient GIST with respect to response to imatinib and overall survival. The likely SDH-deficient group were very similar to the known SDH-deficient group, which allowed us to combine the two groups. This tripled the number of cases available to look at drug responses, at the expense of possibly including some non-SDH-deficient patients in the group.

Even with triple the number of treatment cases to look at; the total number of cases was still small, especially considering the responses to drugs are poorer than the typical adult type GISTs. Given the significant limitations of the study, the results were not definitive. However, there were hints of activity in two areas; patients reported shrinkage more often with sunitinib (Sutent) than with other drugs, and, in very small numbers, patients seemed to stay on regorafenib longer than other drugs.

Our conclusions were that GIST patients need to have mutational testing and in cases negative for KIT and PDGFRA mutations, testing must continue to identify SDH-deficient GIST and other subtypes. In addition, better treatments are needed for SDH-deficient GIST.

CTTI Meeting Promotes Innovation

By Erin Kristoff
Marketing Director

The Clinical Trials Transformation Initiative (CTTI) held its quarterly Steering Committee meeting this past September in Washington DC, which focused largely on effective ways to increase adoption of clinical trial recommendations.

CTTI, created as a partnership between the FDA and Duke University, strives to develop and drive adoption of practices that will increase the quality and efficiency of clinical trials. Their ultimate goal is a “high quality clinical trial system that is patient-centered and efficient, enabling reliable and timely access to evidence-based therapeutic prevention and treatment options”.

The LRG is a member of the CTTI Steering Committee, which provides input into decisions about CTTI priorities, projects and recommendations.



In addition to the main focus on driving adoption of recommendations, Dan Ariely (pictured left), James B. Duke Professor of Psychology and Behavioral Economics at Duke University, keynote speaker at the meeting, sparked engaging discussion on how to use the concepts associated with behavioral economics to identify and overcome behavioral obstacles to driving change in clinical trials.

Members from all corners of the industry participate in steering committee meetings—including pharmaceuticals, hospitals, government and of course, patient advocacy. The atmosphere was highly collaborative, with breakout sessions focusing on taking ideas from concept to action. The LRG has been a CTTI member for the last several years and looks forward to the opportunity to bring the patient voice to developing new strategies for clinical trial innovations.

Night to Fight Cancer Overwhelming Success

By Jessica Nowak
Outreach and Engagement Manager

The fourteenth annual “Night to Fight Cancer” to benefitting the Life Raft Group’s research programs took place on October 19, 2017 at Midtown Loft and Terrace in New York City. This year Jerry Cudzil, LRG Board President, was joined by co-host Matthew Knopman. Mr. Knopman, who considers Jerry not only a friend, but also a mentor, joined this year to help give back to a cause that is close to Jerry’s heart.

They were elated by the immense amount of support and generosity from friends and family who attended. Each year we are blown away by the number of participants, and this year’s number did not disappoint! With 244 participants, The Life Raft Group was able to raise close to \$200,000. Our attendees enjoyed the no-nonsense barbecue food provided by Pig Beach NYC, which included BBQ chicken, pulled pork sandwiches, Pig Beach burgers, mac n’ cheese and braised greens.

While the poker event took place on the main floor, guests

enjoyed casino games on the Terrace. The winners of the night were, Jerry Cudzil in 1st place, Daniel Znaty in 2nd place, and Brian Gelfand in 3rd place!



Pictured Left to Right: 2nd Place Winner Daniel Znaty, 1st Place Winner & LRG Board President Jerry Cudzil, and 3rd Place Winner Brian Gelfand

We would like to thank our NTFC Ambassadors including Brian Behrens, Lyon Carter III, Benji Cheung, Michael DiMaio, Sal Morale and Armando Petrucci for their continued support year after year. An extra special thank you goes out to our corporate sponsors. Our Club Sponsors, which donated \$10,000 included: Bank of America, Morgan Stanley, Palmero-Ravich Family Foundation, Pfizer, and RBC. Our Hearts’ Sponsors, which donated \$5,000, included Cantor Fitzgerald, ICE, Goldman Sachs,

Investors Bank, and Tradeweb Markets. Many thanks to our major donors and co-sponsors Jerry Cudzil and Matt Knopman for their very generous contributions. In addition, we would like to thank Lyon Carter III who was our beverage sponsor, Michelle Mattioli for donating her photography services, our volunteers Anthony Cashin, Cora Ramadan, Dominique DeRose, Juliette Sabella, and Jess Trusio, and our awards donor Murray Rosenthal.

2017 GIST Award Goes to Dr. Adrian Siefert, Dresden

By Helga Meier

The GIST Group Switzerland, the support group for patients with gastrointestinal stromal tumor (GIST) has awarded its science prize for the eighth time. The 2017 GIST prize, worth CHF 10,000, was awarded to Dr. Adrian Siefert of the University Hospital, TU, Dresden, Germany for his publication on "PD-1/ PD-L1 Blockade Enhances T-Cell Activity and Antitumor Efficacy of Imatinib in Gastrointestinal Stromal Tumors."

The study was published in the Journal of Clinical Cancer Research, 2017, doi:10.1158/1078-0432.CCR-16-1163©2016 American Association for Cancer Research.

A summary of Professor Siefert's research follows: Gastrointestinal stromal tumors (GIST) are the most common sarcomas and the oncogenic driver is usually a KIT or PDGFRA mutation. Although GISTs are often initially sensitive to imatinib or other tyrosine kinase inhibitors, resistance generally develops, necessitating additional therapeutic strategies. The immune system contributes to control of tumor growth and plays a major role in the response to cancer therapy.

Both T cells and tumor associated-macrophages (TAMs) were important in the maintenance of the tumor microenvironment and were altered by treatment with imatinib. The inhibitory receptor PD-1 played a crucial role. In a mouse model of GIST, PD-1 and PD-L1 blockade enhanced the antitumor effects of imatinib by increasing T cell effector function. TAMs had anti-tumoral properties in human GIST, but became pro-tumoral after imatinib therapy.

Immunotherapy may provide an important adjunct to imatinib in the treatment of GIST.



Dr. Adrian Siefert, Helga Meier, & Dr. Michael Montemurro

The award ceremony took place on November 23, 2017 at the semi-annual meeting of the Swiss Group for Clinical Cancer Research (SAKK), held in Zurich. The laudation was held by Dr. Michael Montemurro, CHUV Lausanne, member of the GIST Group Award Committee.

GIST Group Switzerland

The GIST Group Switzerland is an organization for the support of those affected by gastrointestinal stromal tumors. It supports every effort to improve the treatment of GISTs. To this end, the GIST Group awards an annual prize to

organizations or individuals committed to achieving this goal. The prize is awarded for lectures, publications, panel discussions, scientific or socially relevant projects. The award of CHF 10,000 is donated by the GIST Group Switzerland. Further information: www.gist.ch, gist@gist.ch

SAKK

The Swiss Group for Clinical Cancer Research (SAKK) is a non-profit organization, which has been conducting clinical trials in oncology since 1965. Its primary objective is to research new cancer therapies, to develop existing treatments further and to improve the chances of a cure for patients with cancer. This takes place through cooperative projects within Switzerland and in collaboration with centers and study groups abroad. The SAKK is supported by a service-level agreement with the State Secretariat for Education, Research and Innovation (SERI) and also by partners such as the Swiss Cancer League and Swiss Cancer Research.

For more information, go to www.sakk.ch, info@sakk.ch

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Andrea Torres: A story of hope and optimism



By Andrea Torres
LRG Member

My name is Andrea Torres, and I am 24 years old. I am from Tegucigalpa, Honduras.

I was diagnosed with GIST in December 2015 here in Honduras. I was 22 years old. It began when I woke up one morning with a strong pain in my stomach. At first it was tolerable, but after a few hours it became much worse. No matter what I did, the pain increased, so I went to the emergency room. During an ultrasound and MRI, they decided I needed to have emergency surgery. They had found a mass between the stomach and pancreas, which had broken, causing internal bleeding and pain. A month later, they gave me the results of the biopsy, which indicated that it was a 10cm tumor with a mitotic rate of 5/50. At this point, none of the doctors specialized in GIST.

When you hear the word “cancer”, you immediately relate it to painful processes until you get to death. When I received the news, I had my family at my side. I felt anguish and fear, but that was something I could not show because I had to be strong for them. In the most serene way, I immediately asked

the question, “Now, what’s next?” I must confess that when I heard that the type of chemotherapy I would receive would not make my hair fall out, I felt very relieved. I know that was not the most important thing, but I think that as a woman that kind of thing comes to matter a lot.

At the beginning, one of the most difficult things was finding information about GIST. In my country, I did not receive any information about this disease. It really was almost one year that I did not have the most basic and important information about GIST. One year later, my first contact was with Piga Fernandez, president of Fundacion GIST Chile. She immediately guided me to the LRG, and together with them, I was able to educate myself about everything I have been doing until now.

It was not until more than a year after I was diagnosed when I learned the importance of a mutational test. No one had ever told me until I found the LRG and they were able to inform me. It was until November 2017 when I was able to do the mutational test. I am still waiting for the results.

My life has changed a lot since my diagnosis. I still remember at the time I was diagnosed I was working on a social project in Honduras with people diagnosed with cancer, never imagining that after working years ago with cancer foundations, that I would also be a part of this group.

For that reason, I had to stop going to hospitals. I always felt a love of working with children in special conditions, but after my diagnosis and having my defenses low, my doctor’s advice was to stay away from hospitals where it is easy to get a virus or infection.

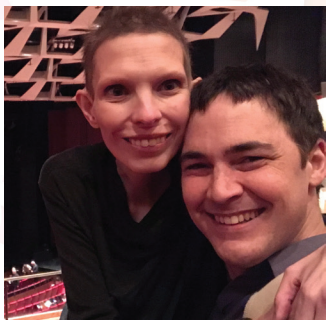
The biggest challenge for me is to continue learning. GIST is a very rare disease, and luckily today in 2017, there are many studies and clinical trials for patients. In this disease being educated above all is the key to survival.

Despite the challenges, I am inspired by my optimism for life and my faith. To quote the bible in Job 5:18, “For he inflicts pain, and gives relief; He wounds, and His hands also heal.” I hope one day to continue doing what I love as a professional, and as a human being.

My heroes during this journey are my family and other special people in my life. They are my main reason to be strong, and to keep going.

I have received great support from the entire LRG family, and at all times have felt that I am important to them. They have answered all my doubts.

Andrea is our new country liaison for Honduras.



Samantha Wexler - 9 Years!

I learned about GIST almost 9 years ago. Before that I had no idea that it existed. We all hear about the big population cancers like breast cancer or lung cancer, but it is just as important that smaller population cancers are highlighted as well, probably more so because they get less funding for research.

I not only do I have GIST, but I have Wildtype GIST which is notoriously difficult to treat. I have had many hospital adventures in my almost nine years. I have gotten to know the people who transport the patients around the hospital pretty well and now they even say hi to me in the hallways!

I have also done a lot of things that I was putting off for the future. I went back to school, finished my BFA (with distinction), I am almost finished my MA in Art History and I have learned to be a pretty good public speaker. Something this introvert never thought that I would enjoy!

I think that life is to be lived no matter our limitations. We should push ourselves to do things that scare us every day and when we get to our time, we can be proud of who we became and the accomplishments that we achieved despite living with this unrelenting disease."

April Stephens - 17 Years!



On December 7th, I will celebrate my 17th cancer anniversary. I was just 22 years old and newly married when I was diagnosed with GIST following surgery. At that time Gleevec was still in clinical trials and we knew that I would likely benefit from it, but I did not qualify for the trials since I had just had surgery. Thanks to my doctors who pushed to get Gleevec through a compassionate use program, I was able to start on Gleevec in March of 2001. I am forever grateful for being able to tolerate Gleevec well and for it to give me 12 1/2 years of being cancer free. After Gleevec, I was on Sutent for two years and then Stivarga for two years. Now, I am very excited about the hope of several promising new drugs in clinical trials. I am so thankful for the time each of these drugs has given me and I pray for continued developments in new treatments and eventually a cure for GIST.

This 17-year journey has shown me that God's timing and plans are always perfect even when I don't understand them at the time. He has provided new drugs each time I needed them, guided me through multiple surgeries, and placed family and friends in my life to help support me along the way. I am grateful for each and every day I get to spend with my family, especially my 10-year old daughter. GIST has taught me so many things early on in life, but most importantly to focus on the positive things in every situation. Thanks to the Life Raft Group for being a tremendous resource to me and my family from the beginning in 2000. Your educational resources have helped me to make treatment decisions along the way and educated me about GIST through the years.



Peter Bick - 20 Years!

Hi, Life Raft Group friends! I am very grateful to be celebrating my 20th year GIST Cancer anniversary.

I was 41 years old (November, 1997) when a softball size tumor was discovered attached to the outside of my stomach.

This was terrible news for my wife and I as we were a young family with three children under the age of eight years old. We maintained a positive attitude, bought a juicer and made vats of carrot juice, hoping this would help (my surgeon said to enjoy the grinding the carrots and enjoy the juice, but expect no miracles from it).

As I was carving the pumpkin for Halloween on a Saturday afternoon, I got an urgent call that I needed to report to the hospital for surgery on Monday. My wife and I really began to recognize the seriousness of this journey, and it was only the beginning of the three surgeries I had from 1998-2000.

In February 2001, at Mount Sinai Hospital in Toronto, I participated in the Novartis STI-571 (Gleevec) Phase Three trial at 400mg daily. I had a great response. I am still taking Gleevec daily, and have been stable ever since and feeling great. Some minor side effects, but nothing serious.

The support from my wife, Diana, family, healthcare professionals, workplace and the Life Raft Group has been amazing.

My children are now in their early to late 20's, and my wife and I happily married for 31 years, are planning to retire next year in a home we have built north of Toronto.

Cheers, and my very sincere wishes for good health and happiness to all.

Annual Holiday Campaign Seeks to Make an Impact



Go to www.liferaftgroup.org/videos
to watch Bella's video

By Diana Nieves
Outreach and Engagement Director

The Life Raft Group's annual holiday campaign officially launched on #GivingTuesday, November 28th, 2017. #GIVINGTUESDAY is an opportunity to come together as a community to make an impact on the lives of GIST patients by helping to ensure their survival.

On #GIVINGTUESDAY, we shared GIST Patient Bella Rocco's story. At just seven years old, Bella was undergoing surgery after being diagnosed with cancer: a rare form of cancer called pediatric GIST. While GIST is considered a rare cancer, pediatric cases are even rarer with very limited treatment options. Although her surgery was successful, Bella experienced recurrences of her disease several years later.

LRG recently celebrated its 15-year anniversary as a non-profit organization. During that time, we have worked tirelessly to improve patients' lives. Through our education, support and research efforts, we have been able to provide Bella and her family with information and guidance on clinical trials and available treatments that helped to save Bella's life. We have and will continue to be there for her and patients like her through our projects and educational initiatives. Today, Bella is thriving. She is playing field hockey, checking out colleges and traveling to Europe during her school breaks.

We need your help so we can continue to support Bella and patients like her. Over the next few weeks during this holiday season, we will continue to 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.

Please help to save the lives of others living with GIST.

Please donate today by going to www.liferaftgroup.org/donate

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New Horizons from Page 1

off the meeting with a presentation of a survey we conducted among 29 global advocates and the important topics that address unmet needs of the GIST population around the world.

Drs. Suzanne George, Dana Farber Cancer Institute, and Bill Tap and Ciara Kelly, Memorial Sloan Kettering Cancer Center, provided a lot of hope that there are emerging therapies for GIST currently in clinical trials with the aim of targeting specific mutational types. Additionally, we learned about the role of liquid biopsy and circulating tumor DNA in GIST and its implications on treatment.



The three clinicians highlighted innovative approaches to prolong survival by sharing various case studies of GIST patients they treated such as those with localized disease, metastatic disease, and SDH-Deficient GIST. This interactive panel among the clinicians was important for advocates to see how critical a collaborative medical team can be in the treatment of GIST cases as well as the role of a tumor board.

As we saw from the start of the conference about the importance of collecting data from randomized clinical trials to help bring drugs to market for the survival of patients, we also focused on the importance of other forms of real world data in the decision-making process made by clinicians and patients. A panel of experts spent time highlighting each of their perspectives in what real world data means to them and its importance in making an impact on survival. Moderated by Norman Scherzer, Executive Director of the Life Raft Group, the panel consisted of Rodrigo Salas, Fundacion GIST Mexico; Dr. Suzanne George, Dana Farber Cancer Institute; Dr. Theresa Mullin, FDA Center for Drug Evaluation and Research; and Dr. Carl Asche, Center for Outcomes Research at University of Illinois College of Medicine. A best practice presentation was provided by Michelle Durborow,

The Life Raft Group, about the collaborative intersection of patient, clinical and pharma perspectives in understanding the patient experience by examining data from a patient registry. She presented ways to utilize a patient registry as a valuable tool in understanding the unmet need of patients by identifying barriers to treatment.

With all the updates in GIST treatments and molecular testing emphasized throughout the meeting, one key question remains among global advocates: How are they to access diagnostic testing and treatments? Pat Garcia Gonzalez of The Max Foundation shared an update about her organization's strategy to tackle this issue. Her aim is to

decrease mortality through humanitarian access to treatment, care and support.

More best practices were presented as Gerard van Oortmerssen, Chairman of Board of Contactgroep GIST in Netherlands, shared a novel tool he uses in his research to search patient forums for common themes that patients discuss, and the importance of how we can address those themes with programs and support. Amy Bruno-Lindner, President of GIST Support Österreich Austria, engaged the group in an interactive exercise in how we can

improve our communication as patient advocates with the patients we serve.

Lastly, we divided conference participants into small groups based on region and country-type, as we explored how to tackle the issues that came out of the pre-meeting survey. We aim to continue to tackle these issues throughout the year as we believe it is important to mobilize the community on an ongoing basis to support our efforts.

Many thanks to the New Horizons sponsors, Blueprint Medicines, Novartis and Pfizer for their continued support and vision to help us provide vital information to strengthen our global efforts to help GIST patients survive.

Lastly, a thank you to the steering committee who worked synergistically over the course of the year to make this meeting a success: David Josephy, GIST Sarcoma Life Raft Group (Canada); Piga Fernandez, Alianza GIST (Chile); Markus Wartenberg, Das Lebenshaus (Germany); Martin Wettstein, Swiss GIST Group (Switzerland); Ginger Sawyer, GIST Support International (USA); and Norman Scherzer, The Life Raft Group (USA).

Journey from Page 1

his mutation test, which identified his GIST type as PDGFRA D824V.

We left the Gleeevec at the pharmacy and followed up with Dr. Brockstein a few days later. He told us that Owen wasn't in immediate danger, but that without treatment, would likely only live another year or two. Since D824V is completely resistant to Gleeevec and Sutent, a clinical trial would be the best next step.

This strategy didn't seem too hopeful to us at the time. We both held the opinion that experimental cancer drugs were often dangerous and ineffective — an unlikely last-ditch effort for people who don't have any other hope. That's one of many reasons why we're so fortunate to have the Life Raft Group. We found Dr. Bruce Brockstein — a GIST specialist — on the LRG database (<https://lifteraftgroup.org/gist-specialists>), who helped dispel our fears that a trial would be a shot in the dark, and the research and support that the LRG provides is instrumental in helping us (or rather, helping me help Owen) remain aware of and understand his options.

Now it's more than six years and two trials later — with a few surgeries between to reset the clock and let science catch up — and my beloved is still with me (well actually, he just left to go watch football with a friend).

Choosing a trial

Before we chose Dr. Brockstein, we had consulted with a different GIST specialist. She told us that she didn't know of any studies currently recruiting patients with Owen's mutation, but to look for future trials on National Cancer Institute's website. Luckily, the LRG makes that process far less overwhelming.

The LRG clinical trials database (<https://gisttrials.org/index.html>) tracks those that are specifically for GIST and lets you search by treatment stage and status, trial phase and location. Clinical Trial Coordinator Jim Hughes and Data Analyst Jerry Call are fountains of knowledge who can help you further narrow your results. Between the LRG and your oncologist, you will not have to find a trial on your own.

For Owen's first trial, Crenolanib, Jim Hughes, LRG's Clinical Trials Coordinator, put me in direct contact with its principal investigator, Dr. Michael Heinrich, at Oregon Health & Science University (OHSU). His research assistant, Tracy Walker, spent about an hour on the phone with me to explain the study's principles and procedures in layman's terms and to determine whether Owen would qualify.

I guess the choice was easier for us than most because it was the only trial at the time that targeted his D824V mutation. But the logistics can be a bear — especially for frightened, stressed-out patients and caregivers — so here's my advice for those of you who are considering the journey.

Travel

Participating in a trial literally is a physical journey if you don't live near a site where it's held. We live in the Chicago area, so both of Owen's trials involved a temporary relocation to Portland, Oregon. He had to be there once a week the first month for a checkup and labs and every two weeks for the second month. After that, it was monthly trips with a scan every other month.

We don't have kids and I am able to work remotely, so it was easier for us to stay in Portland for those first two months. OHSU put us up in a Residence Inn for the Crenolanib trial. For his BLU-285 trial, which he started in August 2016, we drove out and rented an apartment through Airbnb. We love the city and considered that stay to be the experience of a lifetime — ironically, one we wouldn't have gotten if Owen didn't have GIST. I know that different circumstances won't allow the same opportunity for everyone and that we've been very blessed.

In a certain sense, that honeymoon is over. For the next eight months, Owen flew out monthly and I only went if he had a CT scan. Now I go with him every month because the side effects of the drug make the trip exhausting for him. He might argue with me on this, but it's better that I'm there to make sure we cover everything we need to during his appointments. Travel could become harder if his health deteriorates, but easier if trial protocol extends the time between visits.

Costs

Of course, there are costs associated with a clinical trial. Our initial terror for Owen's first was the medical bills. Back then, he had an individual insurance plan (not provided by an employer) and we assumed the trial would be considered out-of-network. Tracy Walker explained that patient care costs related to treatment outside of the study — such as regular checkups and scans you'd have anyway — would be covered by our insurance. Costs directly related to the study — such as the drug itself and testing for research purposes — are typically covered by the trial sponsor/drug manufacturer.

I called Owen's insurance company to confirm this for ourselves, and everything from there on was handled by the OHSU clinic. I would insist on this and be suspicious of a trial that doesn't provide this help. We haven't had any problems, even for his current trial, now that he's covered by Medicare and a supplement.

Travel and lodging differ by trial and location, so I can only speak from our own experience. Flights for patient and caregiver are reimbursed in full, as well as parking at the airport and transportation to the clinic. We're expected to find a reasonable airfare (not first- or business-class) but direct flights are okay. Our hotel costs were completely covered for Owen's first trial without us ever putting any money down. Lodging for his current trial is covered to a limit. The state

Journey from Page 1

of Oregon provides a stipend of about \$60 for meals on the day of the appointment. That sounds like a lot, but meals can be expensive in a city, especially when you're too tired for anything but room service.

Reimbursement doesn't happen until after the visit, which can be a problem if you can't pay off your credit card in the interim. We got a credit card from the airline we use and put all expenses on that to make accounting easier and earn more miles. Save all receipts and keep copies of what you submit. No offense to the medical team, but it's far easier to meet and work directly with the clinic's financial department. For instance, Owen ran the numbers to show that driving out and renting would be cheaper than weekly flights and hotels, and the finance team agreed to reimburse us for the equivalent amount.

Care

It would be so much easier if all of Owen's care could be handled at OHSU. Side effects are going to happen no matter what, and they're probably going to be increasingly difficult. My best advice — which we didn't learn until after trial one — is to maintain your relationship with your primary

care doctor and oncologist at home. Owen is getting the most advanced treatment for his cancer and we love the OHSU team, but it's impossible to handle everything from a distance.

We tend to blame every health issue as a result of the drug — and frankly, it usually is — although it's not a matter of blame, but of what can be done about it. For instance, since OHSU began coordinating blood tests with his oncologist at home, we no longer have to hightail it to the ER when he needs a transfusion for his anemia. His terrific primary care doctor also does what he can to help us cope with the rest.

It isn't easy, but clinical trials have given Owen and I not only hope, but several additional wonderful years together. It's an up and down experience, as I know my ramblings attest. When the LRG asked me to write this article a few weeks ago, I wasn't sure if I could do it because I didn't think I'd have anything positive to say. I now realize that is not true, we were only having a bad week. Although we've been optimistic and despondent several times since this battle began, I just asked Owen again, and he's confident that it's still worth it. I am too.

Hope from Page 3

Updated results of the ongoing trial were presented on November 10th, at the 2017 Connective Tissue Oncology Society (CTOS) meeting in Maui, Hawaii. Dr. Michael Heinrich of the Knight Cancer Institute, OHSU, Portland, Oregon, presented the data.

Part 1 of the phase I study is complete and the maximum tolerated dose was determined to be 400 mg per day. The dose that was recommended for phase II was 300 mg per day. Part 2 of the phase I trial is currently enrolling and is divided into two arms, PDGFRA with D842V mutations and unresectable GIST after imatinib and at least one other TKI. Fifty patients will be enrolled into the PDGFRA D842V arm.

At the CTOS meeting, Blueprint announced it had recently increased the enrollment target for the third-line or later arm from 50 to 100 patients.

Data was presented at CTOS on 116 patients. In 30 patients that received doses of between 300 and 400 mg and that had KIT mutations, 20 of them (67%) had tumor shrinkage; 5 of these met RECIST 1.1 criteria for a response (16.7%) and 16 met Choi Criteria for a response (53%). For these 30 patients, the median progression-free survival (PFS) time was 11.5 months and 69% were progression free at 6 months. Data was also presented on 31 patients with D842V mutations (primary mutations) in PDGFRA. In contrast to the

data above, all dose levels were included in this report. All 31 patients achieved either a partial response ($n = 30$) or a complete response ($n = 1$) by Choi Criteria and 21 patients (68%) achieved a response by RECIST 1.1 criteria. The median PFS was not reached at the last report; however 78% of patients remained progression-free at 12 months.

The most commonly reported side effects were nausea, fatigue, periorbital edema and vomiting.



Based on these encouraging results, Blueprint has added a second-line expansion cohort that is now recruiting patients, and is planning a randomized phase 3 study comparing BLU-285

to regorafenib in third-line GIST. This study is planned to begin in the first half of 2018. Patients who are interested in opportunities to participate in Blueprint's trials can contact the company at studydirector@blueprintmedicines.com.

Although it's difficult to make comparisons from one clinical trial to another, both DCC-2618 and BLU-285 appear to have significant clinical activity that seems to compare very favorably to the two drugs currently approved for imatinib-resistant GIST, sunitinib and regorafenib. It seems quite possible that GIST patients might have some new options in the future, and for those eligible for clinical trials, they appear to have a new option now.

Clinical Trials from Page 1

awareness. This awareness can come from a number of different sources.

- Their local oncologist, or their support staff
- The local oncologist might be affiliated with a network or a local or regional hospital that offers clinical trials
- An oncologist (or other doctor) at a GIST expert center (GIST referral center)
- A recommendation from other patients (e.g., LRG listserv)
- Consultation with a patient support/advocacy group
- Their own research
- Recommendations of family or friends

For patients that have both need and awareness of a trial, they must then start the process of assigning value and assessing the costs of the trial (even if they are unaware that they are doing so) and then comparing this trial with all of their other options, including other trials, off-label treatment (if available) and no treatment. The patient must place a value and a cost on all of those options as well. Placing a value and a cost on their options doesn't necessarily mean an actual number, or a checklist, although some patients might be that organized. It can simply be a process of mentally coming to a decision based on the things they know.

Perceived effectiveness

Via Recommendation; Someone told you about effectiveness with need of a trial established and the patient becoming aware of the trial as an option, including meeting eligibility requirements (the process of verifying eligibility may come early, or it could come later), the patient will typically next look to perceived effectiveness of the drug or therapy. Some of the steps that have taken them to this point will already have started the process of assigning a perception of efficacy. For example, when a patient's oncologist informs a patient about a trial, the oncologist will almost always give the patient their impressions of the trial, both good and bad. In fact, the patient will usually place some value on the trial just because the oncologist recommended it or even just informed them about it.

No matter what the source of awareness was, each of the other sources, perhaps more accurately, resources, might be consulted about the trial. The patient will then begin assessing a value based on the strength of the recommendation as well as their confidence in the resource. The following are examples illustrating the extremes that a patient might be exposed to:

- A local hospital clinical trial team informs the patient that there are no GIST specific trials, but they do have several trials for which the patient may be eligible. Since the recommendation is based solely on eligibility and not on any GIST-specific rationale, this might result in a low valuation of potential efficacy by the patient.
- A patient hears about another (or more than one)

patient that is enrolled in a trial. They often hear about this from other patients, such as on the LRG listserv. In fact, with hundreds of other patients with the same disease, this is probably the best place to learn about trials that other GIST patients are on. From an email community you find out not only that a trial exists, but often even how they are doing including (sometimes early) reports of efficacy, side effects, logistics, etc.

- A patient goes to a GIST expert center and is offered a GIST-specific clinical trial (or in some cases, even a choice between two or more trials). Since the recommendation is coming from a GIST expert, it might be assigned a higher value from the patient; especially if there is a positive report of early signs of efficacy or strong rationale from the expert GIST doctor.
- A patient receives a recommendation from a well-meaning, but not very informed friend, that trials are for guinea pigs and that they should forget about them and try an alternative treatment that they read about on the internet.
- The previous example is not intended to cast an aspersion on friends or family; very often they are your number one resource. It is especially common for a spouse or significant other to assume the role of "chief researcher" in the family. But this role is also often filled by other family members as well and less often by friends.

Via Research

You did your own research into effectiveness. Many patients may skip this step entirely, relying solely on recommendations from their resources. However, some patients will do significant research into drugs/trials they are thinking of joining. For these patients, the ability to read and process the often technical information they find is important. Their ability to understand and more importantly, to evaluate this information is often related to how long they have been a patient and how much they have already learned about this process in the past.

Resources that this group of patients might use include:

- LRG Clinical Trials Database
- Clinicaltrials.gov database
- Other databases
- Meeting abstracts; ASCO is an especially important source of these
- Expanding your list of recommendation resources, such as consulting with the LRG Clinical Trials Coordinator to learn about options, or calling the LRG office, following leads by contacting and actually talking to the people conducting the trials or doing the research that led to the trial.
- Search engines may lead to articles from other sources, such as a newspaper article, such as a medical journal article, etc.

Clinical Trials from Page 1

Perceived Cost

As we mentioned earlier, cost refers to more than just money; It's really the total "cost" to the patient. Another way to think about it is, it's everything negative about a trial; the negative side of a balance sheet.

Just like when looking at value, the word "perceived" is important. Perception may be different than reality, but perception is reality for the patient. Financial cost is often a consideration when considering a trial. Few GIST trials are offered at so many centers that a patient is likely to find one locally. Travel, especially travel by air is often required to participate in a clinical trial. Luckily, most trials only require a patient to be seen at two to three month intervals. Often there are more visits required earlier in the trial, such as a return at one month, and expanding to three months or so between visits. A typical visit to a trial that requires air travel might incur costs similar to this:

- \$700 – Air travel for a patient and caregiver (often a spouse or significant other)
- \$300– Hotel cost for two nights stay (often only 1 night's stay is required)
- \$150 – Car rental or taxi fares
- \$150 – Food

Luckily, most, if not all, medical costs are usually covered by insurance. There is typically no cost for the trial medications, as they are typically not yet approved for general use.

In addition to placing a value on possible benefit, patients will place a value (typically a negative value) on potential side effects. In some cases, such as an early phase I trial, side effects will be unknown. However, in most cases, patients

Perceived Value	Perceived Cost
Benefit	Risk
Positive	Negative
Pluses	Minuses
Need	Non-covered expenses
Perceived Effectiveness	Travel/Air fare (usually for 2!)
Recommendations	Hotels
Research	Car rental
Compared to other options	Food
How much do I trust the source?	Non-covered medical expenses
Resources	Side Effects
Local oncologist/support staff	Time
Local trial resources (network, local/regional hospital)	Away from family
GIST Expert center	Away from work
Family/friends	Away from school
LRG, GIST support groups	
Listserve, Newsletters, Consultations, GDL, support groups	

can learn about previous reports of side effects from early trial reports, their doctor, or from patients already or previously enrolled in the trial.

Time is another potential cost to the patient. Time away from their jobs or their family. This can become more important if the patient thinks their time might be limited. However, with time it can also work the other way; if the patient believes that the trial might be very effective, they may think that it could buy them more time with family.

Cancer therapies have become more effective in recent years; in some cases, much more effective. With this shift patients, have come to expect more potential benefit from trials. The days of entering a clinical trial with only an altruistic motive of possibly helping someone in the future are fading. Patients, especially GIST patients, are starting to look to trials as a means of extending their therapeutic options. With this comes the need for resources to help them evaluate their options. Resources like doctor recommendations, patient experiences, help from family and/or friends and trial databases...and the tools to be able to evaluate their options.

Life Raft Group Canada is looking for recipes

At the GIST Day of Learning in Toronto, all the GISTers present were asked "How many of you have problems with food and digestion?" Almost everyone put up their hand. So Life Raft Group Canada (LRGC) is going to produce a "GISTers Cookbook" that contains yummy recipes and dishes as well as "hints and tips" geared specifically to the needs of GIST patients. Most GISTers have discovered and developed recipes that "work for them".

Please share your recipes and hints & tips with your brother and sister GISTers by sending them to Fred Nagy, a Canadian GISTers who loves to cook. fred.nagy@liferaftgroup.ca

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61
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