

Help us celebrate GIST Awareness Day!



In Loving Memory: Marilyn Lee Hoch, Michael Logan Christopher, Susan Rink

Being your own warrior: LRG member Karen Darnell's personal battle

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

Karen Darnell appreciates the value of life jackets. In her GIST journey, she recognizes the importance of having one constructed from the fabric of family support, GIST experts, email communities and the Life Raft Group.



DARNELL

Though her GIST journey began in December 2010, Karen was unfortunately not diagnosed with GIST until 2013. Initially experiencing severe anemia, she was prescribed iron tablets, which did not work. Referred for further testing, nothing was discovered to explain blood loss, and her anemia worsened. Karen received iron infusions for almost a

See **WARRIOR** on page 7

LRG Research Team meets in Cleveland

By **Dr. Brian Rubin**, LRG Research Team



LRG Research Team plans for the future

In early May, the LRG Research Team held a two-day in-person meeting in Cleveland, Ohio, at the Cleveland Clinic, where I conduct my research.

Two primary aims of the meeting were to work on a manuscript describing the genetic landscape of GIST and to plan a large-scale experiment aimed at understanding and targeting quiescence therapeutically.

The manuscript on the genetic landscape of GIST has been led by Dr. Sebastian Bauer but involves virtually every member of the LRG Research Team. It is a massive undertaking,

See **RESEARCH** on page 11

Planning a healthy diet post-gastrectomy

By **Kathryn Troy**, LRG Patient Registry Associate

Part one of a series on nutrition for GIST patients

GIST patients often struggle with their diet and nutrient intake after a partial or total gastrectomy or an ileostomy. These procedures can cause trauma to the digestive system functions, deplete an individual's caloric intake, and may cause a failure to absorb the necessary nutrients for optimal health. The right diet may help the affected organs recover and ultimately improve the digestive process.

After surgical intervention, patients

often experience symptoms that disrupt their ability to maintain normal nutritional intake.

Dumping syndrome (DS) and diarrhea

One of the more challenging symptoms is Dumping Syndrome (DS). Dumping Syndrome occurs when food moves too rapidly to the small intestines, and may include bloating,

See **HEALTHY DIET** on page 10

Life Raft Group at CTTI: Rethinking clinical trials

By **Marisa Bolognese**, Acting Deputy Executive Director

This year, the Life Raft Group joined the Clinical Trials Transformation Initiative (CTTI) to help make clinical trials more efficient and productive and to help accelerate new treatments. CTTI is a consortium that brings together more than 75 stakeholders from government, regulatory agencies, industry (pharma, CROs) medical institutions, academia and patient groups to identify real-world solutions to tough problems that are slowing down the development of new treatments across all diseases. Members include Celgene, Pfizer, Genentech, GSK, Merck, NIH, CDC, FDA, NORD, Dana-Farber Cancer Institute, and many others.

Over the years, the complexity and cost of clinical trials has resulted in a system that is unsustainable and often fails to provide patients with reliable and timely new treatments. CTTI's recommendations help to inform both policy and decision-making in the interest of public health, as well as streamline the operation of clinical trials. By participating in this collaborative environment the Life Raft Group helps keep the

GIST community at the forefront of innovation and the patient as a force of constructive change.

In January, Acting Deputy Executive Director Marisa Bolognese participated in CTTI's Patient Groups and Clinical Trials summit to help determine best practices for effective patient engagement in all phases of

drug development. Ultimately, the project will produce an actionable tool-kit so that patient groups and sponsors can more effectively work together to create more efficient and quality-driven clinical trials. As a first step roles for patients across the clinical trial continuum were identified (see Figure 1).

See CTTI on page 12

Figure 1



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.

Potential combination treatment for imatinib-resistant GIST explored

By LRG Staff

GIST specialist surgeon Dr. Ron DeMatteo, along with colleagues at Memorial Sloan-Kettering Cancer Center (MSKCC), has published a new paper in the April issue of *Cancer Research* with potentially important implications for the GIST community. “Pharmacological Inhibition of KIT Activates MET Signaling in Gastrointestinal Stromal Tumors” explores the science behind the MET receptor, a fairly new avenue of study in GIST research, and the efficacy of two drugs, crizotinib and cabozantinib, which leverage it.



DEMATTEO

Although the c-Kit receptor’s role in GIST has been well documented, DeMatteo’s group observed that treatment with imatinib (Gleevec) also activates a receptor called MET (also

known as c-MET). This news is of special importance to those patients for whom imatinib is not (or is no longer) effective (i.e. imatinib-resistant), since MET is activated in imatinib-resistant cell lines as well.

The group discovered that employing a MET inhibitor such as crizotinib (used in some types of lung cancer), was toxic to the imatinib-resistant cell lines, and the combination of imatinib and crizotinib was more effective than imatinib alone in multiple pre-clinical models of GIST. Their conclusion was that “... MET activation occurs in GIST and upregulation of MET may contribute to imatinib-resistance in vivo. Furthermore, targeting MET is a promising strategy for the treatment of both imatinib-sensitive and – resistant GIST.” DeMatteo’s findings were verified over multiple tests on human specimens with advanced GIST as well as in a genetically engineered mouse model.

In addition to the MET inhibitor crizotinib, the MSKCC group also performed experiments with another drug, cabozantinib. Currently FDA-approved for medullary thyroid cancer, it not only inhibits MET, but is a potent KIT inhibitor as well. Cabozantinib (approved name-Cometriq) demonstrated profound anti-tumor effects in multiple preclinical models including both imatinib-sensitive and imatinib-resistant GISTs.

When asked why this is of immediate relevance, Dr. DeMatteo stated, “We are trying to say that cabozantinib could be applied to human GIST right away, given how effective it was in our models. Ideally, we could start with a clinical trial, but off-label treatment is potentially possible and the drug is already FDA- approved for a form of thyroid cancer.”

While a cabozantinib clinical trial is

See **IMATINIB** on page 11

Social Security disability benefits for GIST patients

By Deanna Power, SSD Office

While many GIST patients are able to continue working throughout their treatment, there may be a time when cancer and its associated complications can progress to the point that work becomes difficult. Social Security Disability benefits can be helpful to those seeking to maintain an independent lifestyle, while being able to afford the treatment they need.

When this happens, it may be wise to apply for Social Security Disability benefits, though it’s important to note that the process can take several months, and many applicants may

be denied initially and will need to appeal.



The United States Social Security Administration (SSA) pays disability benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death.

Federal law requires this very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not.

Specific disability claims are evaluated against the Social Security Administration’s guidebook of techni-

cal medical criteria, the blue book, in order to determine whether the case in question could be considered disabling.

The blue book contains sections for adults and children, and is divided according to body region. In general, cancers are evaluated under Section 13.00: Malignant Neoplastic Diseases.

Applicants whose medical conditions are so serious that they meet disability standards are considered Compassionate Allowances (CAL). CALs are a quick way for the SSA to identify disabled individuals who

See **BENEFITS** on page 12

Sixth annual meeting of Alianza GIST in Miami

By **Sara Rothschild**, Program Director

Representatives from ten Latin American countries gathered on May 17 in Miami, Florida, to discuss issues related to advocacy work in their region, last year's accomplishments and to set goals for the coming year.

Areas reviewed included:

- Education of the future generation of medical professionals: Two webinars will be introduced this year: "GIST Advances in Diagnosis and Treatment" to be scheduled in July 2015 with Dr. Marcelo Garrido, from The Cancer Center of the Catholic University of Chile, and a webinar on Pathology by Dr. Pablo Bejarano from The Cleveland Clinic, Florida to be scheduled in September 2015.
- The new website for Alianza GIST, new educational materials, and the work done in Central America by Silvia Castillo de Armas.

- Latin American Patient Registry, Mutational Studies, Genomics Surveillance Program and Latin American Research Consortium.

Under the guidance of Dr. Juan Manuel Acuña of Florida International University, the group performed a diagnostic exercise on how they viewed Alianza GIST as well as how they viewed their individual organizations. Next, the group reviewed the Alianza GIST mission, vision, and objectives, as well as participated in an exercise to identify their individual missions and objectives.

Representatives from the organizations together set the following goals for 2015-2016:



Representatives from ten countries throughout central and South America as well as the Caribbean met in Miami, Fla.

- Create a presentation in Spanish emphasizing the importance of sharing data about GIST for representatives to share with doctors and institutions.
- Create a simplified, core database for representatives to collect and capture data.
- Design a focused surveillance system using a survey to collect

See ALIANZA on page 13

Miami hosts New Horizons meeting

By **Diana Nieves**, Operations Director

GIST advocates from around the world gathered in Miami for the annual New Horizons conference. This international meeting was launched by Novartis Oncology in 2003 with the title, "New Horizons in Treating CML and GIST," with the goal of uniting patient organizations representing people living with CML and GIST. A few years ago, the conference divided into two separate meetings—one focused on GIST and the other on CML. Since then, the New Horizons



Over 30 representatives from 20 countries met in Miami to discuss issues of the global GIST community.

GIST Conference has been organized by a GIST Steering Committee that aims to unify the global GIST patient advocacy community with key opinion leaders and facilitate ways to increase survival worldwide.

This year, The Life Raft Group hosted the meeting for a second time in Miami, Florida. Nearly 30 representatives from over 20 countries came together to discuss critical information about GIST impacting the global GIST patient and medical communities. The topic of the conference was "Celebrating 15 Years of GIST Treatment: GIST Therapies on the Horizons." The group examined the treatment of GIST as observed by the patient, caregiver, medical expert and pharmaceutical community. The goal of the conference was to open up a discussion, and make changes and improvements.

See HORIZONS on page 13

GIST support Austria: A community of hope

By **Amy Bruno-Lindner**, GIST Support Austria

International support for the GIST Patient Community continues to grow. In this article, Amy Bruno-Lindner reports on GIST Support Austria.

Since the summer of 2013, GIST patients in Austria have had someone to turn to when they need information and support. That's when GIST Support Austria was founded by two GIST patients and a caregiver: Amy, Barbara, and Rainer.

When Amy received her diagnosis of advanced GIST in July 2011, one of the first things she did was to turn to the internet. "The webpage and the listserv of the Life Raft Group answered so many of my questions and made me feel like I was part of a larger international patient

community," she recalled. It was clear for her that she also wanted to join an Austrian community of GIST patients, but at that time there were none. Encouraged by her oncologist, Austria's prominent GIST specialist, Dr. Thomas Brodowicz of the General

Hospital in Vienna, Amy contacted Rainer and Barbara, who had also been thinking about founding a patient group – GIST Support Austria was born.

"From the very beginning, one of our goals was to try and reach GIST patients all over Austria. We thought it would be most effective if we went to the treatment centers in different parts of country, talked to

the oncologists personally and tried to organize local patient meetings," Rainer stated. Since the group's founding, they have held several informal patient get-togethers in different Austrian provinces – often in convivial settings, like traditional Austrian wine-taverns, and with a local GIST specialist in attendance to answer patients' questions.

The past half-year has been a busy time for GIST Support Austria. Not only did they launch a website for Austrian GIST patients (www.gistsupport.at), but they also organized the annual GIST patient conference at the Vienna General Hospital, which took place in March. Although it was the sixth such conference to be held in Austria, it was a first for the organization. "We were in charge of organizing it – we developed the program, invited the speakers, arranged for catering, and all the rest," shared Barbara, who spent many hours ensuring



The annual GIST patient conference was held in Vienna.

See **AUSTRIA** on page 14

Patient Registry presented to Columbia University

By **Mildred Menos**, Assistant Program Director

On Friday, May 22, members of the Life Raft Group traveled to Colum-

bia University's Mailman School of Public Health to

share the technology, capabilities and data of the LRG Patient Registry. The presentation was part of the Epidemiology Department's ongoing disease-focused "Cluster Seminar" which draws researchers, professors and graduate students from both Columbia's Public Health and Medical campuses.



Representatives from the LRG staff in attendance included Patient Registry Director Michelle Durborow, Strategic Planning

Director Pete Knox, Technology Consultant James Lee and Assistant Program Director Mildred Menos. The team presented an overview of the registry's operation and management, the science behind GIST, the technical details behind the registry's construction, and the facilitation of data sharing and collaboration with

interested academic partners.

Enrollment in the Patient Registry is free with Life Raft Group membership and all data provided is kept secure and private. Registry participants enjoy the double benefit of receiving valuable information and support as well as the opportunity to directly assist GIST researchers in their work towards a cure. To join the Patient Registry today please visit: <https://liferaftgroup.org/life-raft-group-membership-application-form/> or contact Michelle Durborow at mdurborow@liferaftgroup.org. ■

2015 GDOL's on the road: Chicago and Miami

By LRG Staff

The 2015 GIST Day of Learning Tour continues to be successful. A GIST Day of Learning (GDOL) is a free, one-day program that provides both education and support to the GIST community. Medical professionals who have specialties in GIST cancer give presentations on issues relevant to their fields of expertise. GDOL's provide an opportunity not only to meet and interact with local expert practitioners in an intimate setting, but also for patients to connect with one another in a supportive environment.

On the evening of Tuesday, April 14, the Lurie Cancer Center of Northwestern University Medical Center in Chicago, Illinois played host to the

second stop in the nationwide GIST Day of Learning tour schedule. Sixty-five GIST patients, caregivers, family members, physicians and medical staff attended the event.

Speakers for Saturday's event included Mildred Menos, Assistant Program Director at the Life Raft Group, who emceed the event and spoke about the varied services, resources and projects the Life Raft Group is involved in. LRG volunteer Clinical Trials Coordinator and Illinois state leader, Jim Hughes, briefed the group on the clinical trial resources page he maintains



Medical professionals from the Lurie Cancer Center show off their rare.

on the LRG website as well as the website he runs for the Chicago GIST

See **GDOLs** on page 14

First annual Water of Life event makes big splash

By Diana Nieves, Operations Director

The Water of Life fundraising event inspired and hosted by Dr. Matt Lurin on Wednesday, May 6th was a huge success. Held at New York City's Battery Gardens, which overlooks the Statue of Liberty, this unique event was enjoyed by over 75 participants including ambassadors representing over 25 brands of whisky.

The whisky "speed dating" theme provided a unique format for the event. Guests received one of two different types of Glencairn whisky glasses etched with the Water of Life logo based on ticket tier in order to sample the brands. In this way, the

pourers were able to identify the VIP guests. While hors d'oeuvres were passed, guests selected a whisky cocktail from the bar as they scoped out the various whisky tables.



The ambassador from the Macallan Distillery displays three single malt including the Macallan Rare Cask.

The whisky speed dating theme was unique for many. Newcomers especially enjoyed this as small groups were matched with a pourer who hosted 15-minute sessions of stories, food pairings, and select tastes of

their brand. Intrepid guests were able to sample up to 22 whiskies. Some of the whiskies that were enjoyed were

the Highland Park Odin, the Glenmorangie 25, the Balvenie Portwood 21, Arran 10, and Balblairs, just to name a few. VIPs drank top-notch selections including rare single malt scotches like The Macallan Rare Cask. All guests also enjoyed a first-rate dinner buffet. It was an evening for whisky aficionados, newcomers and industry professionals to come together for a great cause.

In the end, the inaugural event proved to be a great fundraiser for the Life Raft Group, which we hope many will enjoy for years to come.

We would like to thank Dr. Lurin and all of our sponsors, ambassadors and attendees for supporting this event. We hope to see you next year!

To see a listing of the brands and the event's photo gallery visit: www.lrgwateroflife.org/

WARRIOR from page 1

year, with her levels finally reaching an acceptable range.

After becoming ill while on vacation, her doctor discovered her hemoglobin level was at 6. The normal range is between 12 to 15.5 g/dl. Karen was admitted to the hospital for evaluation. Several tests did not show any abnormalities. A colonoscopy was recommended, but since she was weak, Karen declined, opting for a CAT scan instead, which showed a large mass on her small intestine. The surgeon suspected GIST, but admitted he did not have much experience with it. After receiving blood transfusions, she underwent successful surgery and looked forward to being restored to good health.

At her post-op visit, believing that she was “cured,” Karen received the news that she had high risk for recurrence due to the size, location, and mitotic count of her tumor. Gleevec was prescribed. Although her oncologist was not a GIST specialist, she knew and felt comfortable with him. With his office staff’s help she received co-pay assistance from Novartis for Gleevec.

Dealing with this news was difficult. Her oncologist recommended that she look in the mirror every morning and repeat; “I am doing everything I can to keep this cancer from coming back.”

Karen began extensive research, joining several email communities including the LRG’s.

Her oncologist received her mutation testing results, indicating a mutation in the D842v of the PDGFra gene. She was told to stop taking Gleevec as it wouldn’t work for her mutation type, and that there wasn’t anything she could do.

Karen felt like her life jacket had been ripped off: It was “sink or swim.” At that moment, she became her own “warrior.” She kept searching for someone with a similar story but failed. Everything she read about this mutation didn’t fit with her tumor. Something told her that she didn’t have the PDGFRA D82v mutation. She soon gave up questioning the diagnosis, since she was just a layperson.

The LRG call for PDGFRA D842 tissue for research prompted Karen to donate hers. After receiving her tissue, Patient Registry Director, Michelle Durborow requested her original mutation study results. The next day Michelle advised her there might have been a mistake in the previous mutational test. Her tumor profile did not fit with D842v mutations. The lab at Oregon Health and Sciences University (OHSU) performed mutational testing on her tissue before using it for research, discovering the mistake. She didn’t

have the PDGFRA D842v mutation but was Kit Exon 11, and should have been on Gleevec since her diagnosis.

Karen felt vindicated. She had been right to question this. She informed the hospital where she had surgery and the lab that performed her initial tissue testing about the mistake to prevent this from happening to future GIST patients. They changed their protocol for GIST as a result.

The lesson Karen learned is that anyone receiving a GIST diagnosis should seek expert treatment and if you feel something is wrong, “trust your gut.”

She now sees a GIST specialist and is evaluating treatment recommendations, armed with as much information as she can gather.

Her advice for someone newly diagnosed? “Seek a GIST expert. Be your own warrior.” Karen has had to go out of her way for expert treatment, but that can be a life-saving decision.

Karen is surrounded by a loving family and friends, including her supportive husband, Jeff, two sons and seven grandchildren. “They hold me up and keep me going.” She dons her life jacket every day, armed with the information, love and support she needs to stay afloat. ■

CANCERVERSARY



10 YEARS

Josalin Dunn

“Staying positive about my cancer isn’t always easy,... but I keep reminding myself that there are others who have it worse. I am blessed!”



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



The Max Foundation @stompoutcancer · May 16
Rare photo of rare expert physicians showing their rare #showusyourrare
#stompoutcancer



View photo

THANK YOU to our 2015
GIST Awareness Day sponsors



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Clifford Kopp > The Life Raft Group
April 19 · Grand Rapids, MI · 📍

#showusyourrare 5 generations having fun.



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Jim Mathis added a new photo to The Life Raft Group's
timeline — with Nichole Mathis.
May 27 at 6:23pm · 📍

Nichole, Jim, Gianna and Aja Mathis supporting GIST and other rare
cancers...GIST Awareness Day July 13th #ShowUsYourRare



Like · Comment · Share · 33 3 1



#ShowUsYourRare is the Life Raft Group's most recent effort to bring attention to GIST and other rare cancers. It harnesses the power of social media and allows people to highlight the most special, unique parts of themselves. 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."

People all over the world have posted pictures of what makes them special to Twitter, Instagram, and Facebook with the hashtag #ShowUsYourRare.

View all of the rare photos at
www.liferaftgroup.org/photo-gallery/

Elizabeth Lilibet Whitney Stanke and The Life Raft Group posted about this.

Elizabeth Lilibet Whitney Stanke added a new photo to The Life Raft Group's timeline — with Alec Stanke and 4 others.
April 21 · Edited · 📍

To Raise Awareness

He was one of a kind - rare.
Our story was rare.
He had a rare kind of cancer. His doctor said his rare cancer was the most resistant she had ever dealt with - rarer still... See More



Unlike · Comment · Share · Buffer · 327 76 22

Stephen Lupo and The Life Raft Group posted about this.

Stephen Lupo > The Life Raft Group
April 30 · Westerly, RI · 📍

#ShowUsYourRare
I'm rare because I have a passion for crafting love songs and recording demos.



Like · Comment · Share · Buffer · 6 3 1

Joyce Murdoch Aleckna • The Life Raft Group
April 13 - Mount Airy, NC - 1h

#ShowUsYourRare



Like · Comment · Share · Buffer · 10 1

Chelle Durbin
@chelledurbin

A new friend fr Nairobi, Kenya wore slippers w/peacock feathers at the conference for. #GIST in #Miami. #ShowUsYourRare



9:30 PM · 18 May 2015

GIST AWARENESS DAY

The LRG is gathering all our #showusyourrare photos for inclusion in our Rare Mosaic, which will be unveiled on **July 13- GIST Awareness Day**. We will be celebrating at LRG headquarters with a GIST informational webcast and a luncheon for those who can attend.

GAD celebrations will be taking place around the world. It's not too late for you to join the celebration. There are many ways to participate, from snapping a "rare" photo and uploading it to social media, or by hosting a GAD event of your own. Check our website for featured events and for information on how to plan your own local event.

We will be at the State Fair Meadowlands in East Rutherford, NJ on July 3 with our Photo Booth to capture more "rare" moments and invite participants to enter our contest.

Whatever way you choose to celebrate GAD, please share with us your photos, and stand in solidarity with all of those living with GIST.

Vicki Dotson • The Life Raft Group
May 2 · 1h

My hat makes me an explorer! #ShowUsYourRare



Like · Comment · Share · Buffer · 2 2

Kathy A @SweetPea1222 · Apr 18
And who said science majors can't be artsy #ShowUsYourRare



2 2 View photo

Pete Knox @knox_pete · 14h

Raise awareness for #GIST cancer by telling people what makes you rare. For me it's my #BJJfamily. #showusyourrare



View photo

HEALTHY DIET from page 1

nausea, diarrhea, rapid pulse, dizziness or light-headedness, weakness and fatigue, sweating and abdominal cramping. DS can occur anywhere from 15-30 minutes to two to three hours following a meal, and affects up to 75 percent of gastrectomy patients. DS occurs due to the partial or complete loss of the stomach, and the increased pace of processing food towards the small intestine for digestion. Combining food and liquid intake at the same time is a primary reason why diarrhea occurs, so it is helpful to avoid drinking liquids during meals, waiting 30 minutes to one hour after a meal before drinking.

The type of foods you consume can also make dumping syndrome worse. Proper diet can help reduce or allay the symptoms. Certain foods should be included, and some avoided.



Foods to eat

- Protein should be consumed in every meal: Eggs, meat, fish, poultry, nuts, milk, yogurt, dried beans, lentils, nut butters are good protein sources.
- High-fiber foods should be eaten as often as possible. Whole grains including whole wheat bread and/or pasta, fruits, vegetables, and fiber-fortified cereals are all appropriate choices.

Foods to avoid

- High-Sugar foods such as soda, fruit juices, desserts, candy, fruits cooked with sugar, honey

and jellies, should be limited or avoided. Simple carbohydrates should be limited or avoided.

Abdominal pain, constipation, or bloating

If a patient is experiencing these symptoms it may be due to **lactose intolerance**. This will typically affect patients who have had an operation near or involving the small intestine, as the enzyme for digesting lactose is located in the jejunum. It is possible that the lactose intolerance symptoms are only temporary. Once a patient has improved during the recovery process post-surgery, they can consider re-introducing dairy slowly, in smaller portions.

If a patient is experiencing these symptoms and has removed dairy from their diet, another solution may involve introducing more complex carbohydrates (see fiber list above) into their diet in order to find relief.

It is advised to eat smaller portions, and more frequently throughout the day (no fewer than six small meals per day). The smaller portions will allow the body to become re-accustomed to obtaining food by processing it and collecting its nutritional value. The frequent meals will ensure that some nutrients are being collected at all times, rather than just three times a day and quickly flushed through the system.

Water intake also plays a role involving these post-operative symptoms, please see above (DS and diarrhea) in order to create an individualized and manageable liquid intake schedule.

Foods to eat

- If dairy is removed from the diet, calcium can be sourced from green leafy vegetables, nut-based or soy milks, salmon, and tuna

Foods to avoid

- Milk, and ice cream should be avoided. Hard cheeses and yogurt

have fewer lactose amounts and may be consumed by individuals transitioning dairy back into their diet. Soft cheeses such as mascarpone still have a fair amount of lactose, especially those that are aged.

Anemia

Anemia can occur from a vitamin B12, folate, or iron deficiency, and may not be recognizable for up to one year post-gastrectomy. Symptoms include: chills, fatigue, numbness in extremities, and dizziness.

B12 is typically absorbed within the ileum (within the small intestine), which means if a person has a partial gastrectomy and their small intestine is also removed or partially removed, the protein is not blending with the acid within the stomach lining and transitioning into the small intestine for optimal absorption. B12 supplements may be advantageous for individuals whom are experiencing malabsorption.

Iron and Folate are absorbed through the duodenum (part of the small intestine), therefore in the case of a gastrectomy, the stomach acid normally utilized is lacking and ultimately hinders the conversion of iron into the blood stream.

Foods to eat:

- Lean, red meats, dark green, leafy vegetables, poultry, fish, dried and citrus fruit, iron-fortified cereals (B12 and multi-vitamin supplements may be an option based on a consultation with a physician)

Although the scheduling and management of food and liquid intake, as well as side effects and health issues may seem like a daunting and time-consuming task, after time it will contribute to a higher quality of life. GIST patients will gain an overall greater understanding of their anatomy and its capabilities as they recover after a major gastrointestinal procedure. ■

IMATINIB from page 3

already being planned in Europe for GIST patients, it could in theory be prescribed off-label for patients resistant to the three FDA-approved GIST drug therapies. Whether or not it would be covered by insurance is unclear at this point.

According to Dr. DeMatteo, “Because cabozantinib is so effective, we speculate that it may even be preferable to imatinib up front.” LRG Science Director, Jerry Call agrees, citing cabozantinib, in his opinion, as the most

promising next drug for KIT mutation GISTers who are resistant to approved therapies.

He provides the caveat, however, that to his knowledge the drug has yet to be tried in a GIST patient and therefore, there is only limited information available about potential side effects.

Following LRG Research Team member Dr. Maria Debiec-Rychter’s 2013 CTOS poster, DeMatteo’s

“Although the c-Kit receptor’s role in GIST has been well documented, DeMatteo’s group observed that treatment with imatinib (Gleevec) also activates a receptor called MET.”

article marks the second top-tier research group to publish encouraging results with cabozantinib. In their conclusions the authors

noted, “Given that most patients who develop imatinib resistance eventually experience disease progression on the three currently approved tyrosine kinase inhibitors, imatinib, sunitinib, and regorafenib, there is an urgent need for additional therapeutic options, and our findings have immediate clinical relevance.” ■

RESEARCH from page 1

which describes the genetic makeup of Gleevec-sensitive, and Gleevec-resistant GIST in more detail than has ever been described previously. Importantly, this analysis provides a thorough understanding of how genes known as tumor suppressors, which normally act as “brakes” on cancer, are lost as GISTs become more aggressive. Surprisingly, any of three major tumor suppressors, TP53, CDKN2A, or RB1, could be lost to cause tumor progression. This paper is being resubmitted for publication at the end of May after receiving favorable reviews from the primary submission. However, it is a large and complex paper, which requires considerable effort to revise for resubmission. Hopefully we will see it in print soon.

There was also a lengthy work session on the team’s funded joint research program, which aims to lengthen the duration of therapeutic response to Gleevec in GIST patients. There are two goals of this program, which seeks effective drugs that can be combined safely with Gleevec. The first goal is to target GIST cell quiescence, the process by which some GIST cells survive Gleevec therapy.

We hope these strategies can lead to a higher cure rate for GIST. The second goal is to target Gleevec-resistant GIST cells, which cause clinical progression during Gleevec therapy. The group research in the first year of the program has already identified promising approaches that will be studied in detail in the next year. We hope to expand the funding for these urgent studies.

Finally, members of the LRG Research Team highlighted ongoing work in their individual laboratories. Several laboratories described novel mechanisms of Gleevec resistance, noting that treatment is primarily still focused on targeting KIT. New GIST models were described that will be useful in screening for new drugs against GIST. Drs. Corless and Heinrich highlighted their work in SDH-deficient GIST which is focused on genotyping these lesions and developing models for testing novel therapies. Finally, several research team members presented ideas about how to use new technologies to study GIST. Others discussed projects aimed at examining the peripheral blood (so-called “liquid” biopsies) of GIST patients to find tumor DNA in those fluids. This technology has the potential to diagnose GIST, monitor therapy, identify when patients progress, and even detect Gleevec-re-

sistant GIST mutations before they are clinically obvious. These findings could result in less radiological studies which would be a very desirable outcome.

We would like to thank our sponsor Sanofi for supporting this meeting for researchers to come together and provide valuable updates on GIST research. ■



CALENDAR OF EVENTS



ACTIVITIES:

JULY 3

#ShowUsYourRare at the State Fair Meadowlands

State Fair Meadowlands, East Rutherford NJ

JULY 13

Living with GIST Webcast and Luncheon at LRG Headquarters

SEPTEMBER 17

Night to Fight Cancer 2015

Manny Cantor Center,
New York NY
Learn more - bitly.com/NTFC2015

BENEFITS from page 3

most obviously qualify for allowances based on objective medical information. CAL cases will receive expedited processing within the context of the existing disability determination process. These cases are similar to terminal illness claims, although not all CAL cases involve terminal illness. For example, a person with a spinal cord injury could qualify as Compassionate Allowance, even if he or she is expected to live for many years.

CTTI from page 2



In March, Executive Director Norman Scherzer participated in the bi-annual steering committee meeting in Washington D.C. where new recommendations for the use of single Institutional Review Boards (IRBs) in multi-site trials were approved. The LRG has long been a strong advocate for this as repetitive IRB processes have contributed to the inefficiency and delay of clinical trials including many for GIST.

The LRG is also now involved with CTTI's Mobile Clinical Trials project, which is looking at novel technologies that will permit patients to enroll in trials without having to travel to a central location. Such technology is already utilized for the Life Raft Group/National Institute of Health (LRG/NIH) Collaborative Tumor Boards and hopefully will continue to play an important role as we plan for innovative GIST clinical trials in the near future. ■

CAL conditions are developed as a result of:

- Information received from public outreach hearings,
- Comments received from the Social Security and Disability Determination Service communities,
- Counsel from medical and scientific experts, and
- SSA's research with the National Institutes of Health (NIH)

Those applying for disability benefits with a cancer will have to show the origin of the cancer, how far it has spread throughout the body, and what treatments have been received and the results of each therapy.

Patients with Gastrointestinal Stromal Tumors that are inoperable, unresectable, extend to surrounding structures, are recurrent or have distant metastases are also available for immediate awarding of benefits through the CAL. This allows those with certain obvious and more severe health conditions that are clearly disabling to receive benefits quickly. People who apply for Social Security benefits and qualify under a compassionate allowance will typically receive their first benefit payment within three weeks. The compassionate allowance listing for GIST can be accessed here: secure.ssa.gov/apps10/poms.nsf/lnx/0423022963

In general, most applicants for Social Security Disability benefits will be applying for either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI).

SSDI is a program for disabled workers who have paid Social Security taxes for a number of years. The Social Security Administration requires applicants to have earned enough work credits to qualify for SSDI. As such, a substantial work history is required for SSDI applications. The amount of work credits

required varies depending on the age of the applicant, but the rule of thumb is that you must have worked any five of the past ten years.

SSI is a program for elderly and disabled people with low income. The program bases eligibility on meeting certain financial limits, such as on income and asset values. SSI does not require a work history, which makes it a suitable option for children and those who have not been able to hold a job. SSI requires that an individual applying for benefits does not own more than \$2,000 in assets.

When applying for either program, it is wise to gather all documentation needed to prove disability eligibility. SSDI applicants will need employment information, while SSI applicants should prepare financial information.

GIST patients applying for SSD benefits will also need significant medical documentation, usually in the form of hospitalization records, diagnosis of condition, supporting laboratory results, doctor's notes, and treatment history.

Adults may begin the application on the Social Security Administration's website, www.ssa.gov/disabilityssi or in person at an SSA office. You may also call the toll-free number at 1-800-772-1213 to make an appointment at your local office. If you are deaf or hard of hearing, please call the toll-free TTY number, 1-800-325-0778, between 7am and 7 pm on business days. If you schedule an appointment, you will be sent a Disability Starter Kit to help you get ready for your disability claims interview. The Disability Starter Kit is also available online.

The process may seem overwhelming, but with the support of your treatment team to provide documentation and the professionals at the Social Security Administration, it is possible for GIST patients to qualify and receive the Disability benefits that will provide assistance in their time of need. ■

ALIANZA from page 4

information on side effects for brand and generic drugs.

- Compile a summary chart of generics available in the region to be placed on the website.
- Create a Latin American Pathology Consortium.
- Create a Latin American Advisory

Group of GIST Clinicians.

- Create a database of GIST specialists from Latin America.
- Edit the current strategic plan to focus on the four key strategic areas in which Alianza GIST will focus its work for the following year.

Despite the hard work of the group, representatives did get to enjoy relaxing dinners and a chance to catch up in Miami. Alianza GIST

has become more than a successful, cohesive coalition, it has become a family that reaches beyond borders. GIST is not the only unifying factor in this group; the friendship shared has become one of its defining characteristics. We look forward to more updates throughout the year.

To learn more, please visit: www.alianzagist.org or visit their Facebook Page: www.facebook.com/AlianzaGIST

HORIZONS from page 4

Leading GIST experts such as Dr. Matias Chacon from Alexander Fleming Institute in Buenos Aires, Argentina; Dr. Jonathan Trent from Sylvester Comprehensive Cancer Center in Miami, Florida, USA; and Dr. Peter Reichardt from Helios Klinikum Berlin-Buch in Berlin, Germany (virtually) had the opportunity to present medical and scientific updates about GIST to the group. Drs. Pablo Bejarano from Cleveland Clinic, Florida and Alan Livingstone from Sylvester presented on pathology and surgery.



Participants discuss 2016 strategies

Bray Patrick-Lake from Clinical Trials Transformation Initiative, Steven Young from Addario Lung Cancer Medical Institute and Karen van Rassel from Lymphoma Coalition.

Participants also engaged in round-robin discussions regarding plans of action for

the New Horizons group and how to work towards resolutions on a global level. Topics discussed included patient education, mutational testing

and improving access to treatment. The group identified common global strategies and formulated ways they can expand their reach to each other through in-person communications and a virtual education platform. New Horizons' steering committee members adjourned the conference with closing remarks on the vision for the group and its future discussions.

Many thanks to the New Horizons GIST group supporters who made this meeting possible – Novartis Oncology, Pfizer Inc. and Bayer AG. It is through their unwavering support that New Horizons exists and continues to develop a highly knowledgeable global community of GIST patients and caregivers. ■

Besides the scientific discussions around GIST, participants had the opportunity to interact with one another, exchange best practices and to exchange strategies for promoting patient involvement in clinical trials and combination drug trials. Most importantly, external speakers were invited to the meeting to share best practices and identify mutual areas of interest. These speakers included



On Thursday, April 16 Gerard van Oortmerssen, Board Chairman of Contactgroep GIST Netherlands and Professor in the Information Sciences Department at Tilburg University, visited the Life Raft Group offices to discuss how applying information technologies such as crowdsourcing to social media platforms could prove valuable in discovering trends and commonalities among GIST patients.

AUSTRIA from page 5

that everything ran smoothly. The program included a range of lectures on topics that affect GIST patients and their caregivers directly including basic facts about GIST, side effects management, optimal nutrition, complementary medicine and palliative care.

A special guest from the German

GIST group, Das Lebenshaus, Markus Wartenberg, presented important information about the role of clinical trials. Dr. Brodowicz closed the conference with a brief review of new and promising treatments, among them the technique of liquid biopsy, which is still in the development stage.

"I think the conference was a success," said Barbara, "because we were able to get our main messages across – that no GIST patient in

Austria needs to be alone and that GIST should always be treated by experts."

The founders of GIST Support Austria are grateful for all the help they have received from the GIST-Gruppe Schweiz and Das Lebenshaus. They have also learned a great deal about patient advocacy from participating in the annual New Horizons conferences, which bring together GIST patient advocates from all over the world. ■

GDOLs from page 6

community to keep in touch (GISTChicago.org). Expert medical presentations were provided by clinical oncologist Dr. Mark Agulnik, surgeon Dr. Jeffrey Wayne and Oncology Fellow Dr. Nisha Mohindra. After the presentations, the doctors sat on a panel, fielding questions directly from the audience. A topic of particular interest was the factors that went into determining the best dosage and treatment for a patient. The team at Northwestern believes that although Sutent is commonly referred to as the "second line of treatment", adjusting Gleevec dosage is often just as effective, serving as the "second line in practice."

In addition to the session's speakers, the meeting featured hosted tables by Lurie's Patient Navigator program Pfizer Pharmaceuticals, who were on hand to provide literature and answer questions. Participants also took part in the LRG's newest awareness campaign, #ShowUsYourRare, by taking photos highlighting what made them "rare".

The next stop was Miami, where on Saturday May 16th, The Life Raft Group hosted a GDOL at Sylvester Comprehensive Cancer Center.

Dr. Jonathan Trent provided opening remarks and shared information about the expert multidisciplinary team at Sylvester Comprehensive Cancer



Drs. Breelyn Wilky, Jonathan Trent, Alan Livingstone, and Pablo Bejarano show off their rare in Miami.

Center, a key center of excellence servicing the GIST community. He also highlighted some interesting clinical trials that his Center has open for GIST patients.

Dr. Breelyn Wilky, an oncologist at Sylvester, unraveled complex science information about GIST and provided tips on side effects management. The next speaker was new to the GDOL conference but not new to Sylvester. Lisa Marie Merheb, LCSW, an oncology social worker, spoke about her role in helping patients and their families navigate strategies to get additional support and strategies to cope with the psychosocial

implications of cancer. Dr. Pablo Bejarano, a pathologist from Cleveland Clinic Florida, and Dr. Alan Livingstone, surgeon at Sylvester, then provided expert medical presentations. Participants were able to understand the importance of mutational testing as well as the incredible value of the surgeon's role at different stages of disease.

The last session was a Question & Answer Panel that provided participants an opportunity to ask questions to the medical team. Recurrence was a major topic of discussion. Whether someone is new to the disease or a long-term survivor, it is an issue that permeates many peoples' minds. We are thankful to the medical professionals present that day who instilled a level of confidence that patients are in good hands at Sylvester.

The LRG is thankful to sponsors Genentech, Novartis, and Pfizer for helping to support this important gathering of patients and their families in Miami. We extend an additional thank you to Adrienne and Jeff Davis for volunteering to do registration. Thank you, also, to Donald Edgar for photographing our meeting. To view Donald's work, please visit donalddedgarphotography.com.

If you are interested in having the LRG come to your city for our next GDOL, email your ideas to Mildred Menos at mmenos@liferaftgroup.org. ■

Michael Logan Christopher: Blessing to all who knew him

Michael Logan Christopher, 62, of Estes Park, CO went to be with his Jesus on Resurrection Sunday, April 5, 2015. He is survived by his wife of 37 years, Kristi, and their two sons, Robert L. Christopher of Chicago, and Michael L. Christopher of Denver.



Michael was born in 1952 in the Denver area. He graduated from Denver's South High School in 1970. Following his graduation, Mike's family moved to Texas, where he graduated from the University of Texas at Arlington. After that, he earned his MBA from SMU, and moved back to Denver in 1977 and married his wife, Kristi. For 27 years Mike worked for Super Value Foods in Albuquerque, Denver and Des

Moines. After being transferred to Des Moines, IA to run the Super Value distribution center, Mike was diagnosed with stomach cancer in 1999, at which time he had a total gastrectomy.

Mike and Kristi moved to Estes Park in 2003, where they built a home. After receiving his broker's license, he started a real estate business. In 2007, the cancer returned to the liver, and Mike began taking oral chemo drugs and enjoyed a normal life. During that time, Mike and Kristi started Estes Park Vacation Rentals, managing vacation properties. In the past year, the chemo drugs had ceased working. After 15 years of battling cancer, the Lord took him home.

Mike liked golfing and fishing when

his health permitted. When he was 18 he earned his Order of the Arrow Eagle Scout award. Mike was always actively involved with church activities. He taught Bible studies, Sunday school for kids, Awanas and was on many church boards. He was also the Area Director of the Republican Party in Estes Park and was involved in the Estes Park Tea Party. He loved his country, and fought to restore our Founders vision of freedom and liberty. Mike's kind, helpful and generous nature will be missed by all his friends and family. He truly was a blessing to all who knew him. Although we grieve his passing, we rejoice that he is now in God's presence.

A memorial service was held on Monday, April 13 at Rocky Mountain Church in Estes Park. ■

In loving memory of Marilyn Lee Hoch

Marilyn Lee Hoch of Huron, Ohio passed away Saturday, May 16, 2015 in Stein Hospice Services, Sandusky.

She was born November 22, 1932, in Marion, Ohio, the daughter of the late Lucille Thompson.

Marilyn cherished spending time with her best friend and husband of 65 years, Loren. One of their favorite activities was the thrill of riding the fastest and tallest roller coasters at Cedar Point. She and her husband were residents of Pickerinton, Ohio, from 1964 to 1977, where he served as pastor at Epiphany Lutheran



Church, Pickerinton.

Marilyn retired from JC Penney where she was head of information technology for the Northern Ohio District. She also worked as an accountant for Cedar Point and Lutheran Social Services.

She was a member of Zion Lutheran Church, Huron. She was an active member of the Republican State Committee.

Marilyn is survived by her loving husband, Reverend Loren Hoch of Huron; children, Marcia (Roy) Lawson, Loren (Cheryl) Hoch, Mary Hoch, Jacquelyn Lagerholm and Jeed Salakjit Nopakun; grandchildren, Bo (Debbie) Drake, Lisa (Jeff) Miller, Jessica (Tim) Barr and Nick Hoch; and great-grandchildren,

Paige Miller, Boston Drake, Hunter Drake and Sadie Barr.

A funeral service was held on Wednesday, May 20 at Zion Lutheran Church in Huron.

Memorial contributions may be made to Zion Lutheran Church, 930 S. Main Street, Huron, Ohio or to the church of your choice. ■

*Every life
leaves something
beautiful behind*

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

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