

Ensuring no one has to face GIST alone



In Loving Memory: Morton Wagman

Camp Kesem Provides a Week of Fun to Children of Cancer Patients

By Mildred Menos

Assistant Program Director

Approximately less than one minute into talking with Mariel and Terrance Pridmore, one thing became very clear—they cannot wait to go back to camp. While every kid is usually looking forward to summer vacation and catching up with friends, Camp Kesem stands apart from the crowd for the relief it brings its campers.

“It’s SO fun” they both agree, bobbing their heads excitedly.

“It just has made me a happier person” Mariel says.

Founded in 2000, Camp Kesem provides children ages six to six-

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GIST AWARENESS
DAY

JULY 13TH 2014

Check out Page 6
for more info

Complete Resection May Result in Long-Term GIST Survival

By Leah Lawrence

www.cancernetwork.com

The results of a retrospective study indicated that patients with metastatic gastrointestinal stromal tumors (GIST) who are able to achieve complete macroscopic surgical resection of their disease may be able to achieve long-term survival.



an unequivocal recommendation for surgery but that it does support a surgical approach in carefully selected patients, especially with metastases restricted to one organ system,” wrote researchers led by Sebastian Bauer, MD, of the West German Cancer Center, University of Duisburg-Essen, Germany. “The decision for surgery and the procedure itself should exclusively be done in experienced, interdisciplinary teams.”

To date, the role of surgical resection in patients with metastatic disease was largely unknown. Several studies have shown that metastasectomy in GIST is safe, but there may only be a small window of opportunity in which a surgical procedure will have an effect on survival.

In this study, Bauer and colleagues used data on 239 consecutive patients with GIST who underwent metastasectomy

“We believe that this data does not allow

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Premier issue of the GIST Cancer Journal released



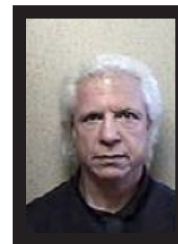
The Life Raft Group is pleased to announce the release of the first issue of The GIST Cancer Journal, the official journal of the Life Raft Group and the first academic journal devoted solely to GIST.

The journal is intended to serve as a comprehensive and authoritative resource of scientifically valid information for physicians and allied health care professionals regarding advances in the diagnosis and treatment of GIST. Editorial content focuses on the impact of translational research in oncology and gastroenterology relating specifically to GIST. As the official medical journal of the Life Raft Group, it also provides a forum for GIST patient advocacy. It will be published quarterly.

We are very pleased to have Dr. Jonathan Trent, Co-Director, Musculo-skeletal Center, Director, Sarcoma Medical Research Program, and Professor of Medicine at the University of Miami in Miami, Florida as our Editor-in-Chief, as well as a medical advisory board consisting of some of the world's most prominent physicians treating GIST:



Dr. Peter Reichardt from the Helios Klinikum in Berlin, Germany



Dr. Andrew Rosenberg from the University of Miami in Miami, Florida



Dr. Matias Chacon from Instituto Medico Alexander Fleming in Buenos Aires, Argentina



Dr. Yoon-Koo Kang from Asan Medical Center in Seoul, South Korea.



Dr. Michael Heinrich from Oregon Health and Science University in Portland, Oregon

The LRG is very proud to be able to provide a quality publication like this to the GIST community. We believe that it is an important step forward in our role as a patient advocacy group, and allows us to disseminate scientific information to a much wider audience. While as an academic publication we expect physicians and other health care professionals to take advantage of the content in the journal, we are confident that patients will also benefit from it by learning about current developments in the science of GIST, as well as advocacy related information. The journal is available free of charge for members of the GIST community.

Go to www.thegistcancerjournal.org to learn more about the journal and to read articles from the current issue.

Print copies and article reprints can also be ordered via the website by contacting either schapman@liferaftgroup.org or fiorio@liferaftgroup.org

LRG Appreciation Event brings together local supporters



By Marisa Bolognese
LRG Consultant

Life is hectic. For most of us our days are filled with work, school, children, family and friends. When cancer strikes a family, everyone's life is disrupted in unimaginable ways. Riding the roller-coaster that is cancer treatment requires a lot of support and encouragement. Day in and day out, help or just small acts of kindness can make all the difference. In this spirit of appreciation, the Life Raft Group invited the local GIST community

to a special dinner just to say thanks. Appreciation was offered by many to many: from patients recognizing daughters, parents, sisters, neighbors, friends; to the Life Raft Group thanking volunteers, staff, business associates, donors and pharmaceutical companies. What do all these people have in common? They are —in big and small ways—making someone else's life a little easier, better and even happier. Whether it's finding new treatments or helping someone get to treatment, educating doctors about treatment options or getting a patient to a

doctor's appointment, all of these efforts make a difference and are deserving of a special thank you. Ray Montague, LRG Board Member, and Norman Scherzer, Executive Director, thanked the many people who make the work of The Life Raft Group possible and all those who work to improve the lives of GIST patients every day. To this end, we invite everyone to take a moment and thank that special person in your life who drove you to the doctor, brought you some cookies to cheer you up or perhaps most importantly, did something to make you smile.



Life Insurance and Cancer

By Kristofer Hunte

Marketing and Communications Associate

People around the world acquire life insurance policies for different reasons. It's a common approach to protect one's assets and cover debts should any life-changing circumstance occur, such as cancer. Similar to health insurance, an individual, cancerous or not, can pay a monthly premium to maintain a life insurance policy for a number of years based on his or her qualifications. However, unlike health insurance, having a serious disease such as cancer can drastically affect one's ability to acquire a decent policy, if at all. Fortunately, although there are numerous factors to take into account, it is not impossible to acquire life insurance as a cancer patient, even for a rare one such as GIST.

Once diagnosed with cancer, the criteria for applying for life insurance are slightly more detailed and specific. Insurance companies are required to gather as much information as possible with regards to the diagnosis to direct that applicant in the proper direction. Some of the more basic questions asked will be about the type of cancer, the date of diagnosis, and what type of treatment or medication is being implemented. Others can be more specific and may ask an applicant about what stage the cancer is in, how long it has been present, and whether or not it has spread, or metastasized. In addition, companies may also conduct an investigation of their own to the applicant's doctor

for more information.

This type of process can generally be time-consuming, especially for cancer patients. Companies prioritize their policies around the more frequently diagnosed cancer types, mainly cancers of the skin, breast, and prostate, reducing the chance to get a policy for less common types, such as GIST. The average waiting period between these three cancers is approximately 1.3 years. Some of the deadlier cancers, such as lung cancer, leukemia, and bone cancer, have a much longer waiting period to obtain a life insurance policy, spanning up to 10 years.

Representatives from some of the largest insurances companies in the United States shared information about their life insurance policies for cancer patients. Although there were no available records of GIST patients, each representative stated that applicants follow the same procedure with additional criteria added for those with cancer, and are sometimes not always given the best options.

A representative from Prudential, who himself was a victim of thyroid cancer 20

years ago, stated that his company's life insurance policy for cancer patients is adequate. Like most companies, Prudential's application for cancer patients will inquire about the type of cancer, the stage it is in, what treatment is being used, the date of diagnosis, and the cancer's severity. In addition, Prudential will write a letter to the applicant's doctor for a more detailed report on the diagnosis. If an applicant

qualifies, he or she will most likely be offered a preferred rate, which usually is not the best option when attempting to obtain life insurance.

A representative from AAA stated that the company's life insurance policy is slightly stricter for cancer patients. In addition to the aforementioned criteria, an applicant's date of diagnosis must be five years or more prior to the

application. An exception to this would be prostate cancer patients, whose date of diagnosis only needs to be two years and also depends on the size of the tumor. Another specification is if a patient with recurrent basal cell carcinoma, a form of



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GDOL Miami Attracts Large Attendance This Year

By Sara Rothschild
Program Director

Over 80 GISTers and their loved ones gathered from all over to attend the 3rd annual GIST Day of Learning (GDOL) in Miami, held on February 9, to hear from the team of experts at University of Miami Sylvester Cancer Center. This conference would not be possible without the support and cooperation of our friend and colleague, Dr. Jonathan Trent, the Co-Director of the Musculoskeletal Center,

gave an excellent GIST 101 presentation. Not only did Dr. Wilky provide a very good foundation of basic GIST knowledge to the group, but she made herself available to speak with participants throughout the day.

Dr. Trent followed with a presentation on "GIST Therapy after Standard Meds." As always, he captivated the group by sharing new information and advancements in GIST treatment.

Assessment and Resection of GIST" by Dr. Floriano Marchetti. Participants learned about surgical procedures leading to the surgical resection prior and post drug therapy.

A nice lunch was served followed by a roundtable discussion by experts. Participants had the opportunity to ask a variety of questions to the team.

Participants were then excited to hear a presentation by Dr. Loretta Williams, a



Director of the Sarcoma Medical Research Program, and Professor at the University of Miami (UM). His knowledge, commitment, and passion for helping the GIST community have fostered a true collaboration between LRG and Sylvester, enabling us to provide excellent conferences such as GDOL.

The event began with an introduction by Dr. Stephen D. Nimer, the Director of Sylvester Comprehensive Cancer Center. It was an honor to have Dr. Nimer introduce the day and participants were able to hear the commitment that Sylvester has in servicing the GIST community.

Next, Dr. Breeelyn Wilky, a medical oncologist who joined Dr. Trent this past year,

Following the coffee break was pathologist Dr. Andrew Rosenberg, one of our favorite featured speakers at GDOL! Dr. Rosenberg has an ability to take the field of pathology and engage everyone in the room on how GIST is diagnosed and the role of mutational testing.

Next was molecular geneticist Dr. Olaf Bodamer, who gave a talk on "Genetic Testing in GIST and the Role of Next Generation Sequencing." This topic was important to highlight as this is the direction medicine is going toward and Dr. Trent has been one of the few GIST oncologists to incorporate it into his practice.

The next presentation was on "Surgery

nurse who travelled from MD Anderson Cancer Center, to give a presentation on "Managing Side Effects: Updated Data on GIST Side Effects." Dr. Williams shared a survey that she conducted in which she asked 150 patients every one to two weeks for one year to rate their symptom burden (severity of important symptoms and interference of symptoms with daily functioning). Some of the most severe symptoms highlighted were fatigue, drowsiness, general weakness, disturbed sleep, and muscle soreness or cramping. Following Dr. Williams, Elizabeth Fontao, a Physician Assistant who works with Dr.

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July 13th 2014



GIST AWARENESS DAY

Check out the website for info about
the event and to sign up for updates

www.gistawarenessday.org

LIFEFEST

2014

November 7th-9th

New Jersey

Registration Opens April 15th

Check out the website for info about the event and to see a sample agenda

www.lrglifefest.org

Tissue Bank Update – Resistant Tissue is Scarce

By Janeen Ryan
LRG Consultant

Drug Sensitivity of Donated Tissue

Early imatinib treatment	1
Imatinib resistant	14
Mixed	4
Multiple TKI resistant	30
Pre-imatinib	371
Recurrence during no treatment period	4
Recurrence on low dose of Gleevec	1
Responding on imatinib	21
Stable on imatinib	47
Unknown	4
Pending Classification	44
Grand Total	541

In recent years we have been able to gain valuable information from the data produced by tissue donations to the GIST Collaborative Tissue Bank. Much of this data has been the basis for many of the statistics we have been able to share with our members.

This data is proving to not only have the ability to drive research, but also (for in-

stance) to provide a guideline to use when patients are facing medication changes or dose escalation. Knowing the mutation can be an important part of choosing how to move forward.

In the future, as Tissue Bank participation increases, this information will become an even more valuable tool in the search for the cure. World renowned laboratories and researchers need to have access to many different types of GIST tissue in order to advance their goals.

However, the overall majority of what is available is from pre-imatinib (Gleevec) tumors. This donated tissue is from a tumor sample taken prior to the patient having ever having taken Imatinib. These

too are very valuable; however, less than 1% of what we have received originated from resistant tissue. Just 44 samples of this type have been made available.

"We have a reasonable idea of what resistance mutations accumulate after imatinib and sunitinib treatment. Of particular interest right now are specimens obtained after a patient has failed multiple

kinase inhibitors, including regorafenib or sorafenib. Such specimens are rare, but are important for ongoing GIST research. We need to better define the mechanisms of resistance to multiple kinase inhibitors in order to advance new therapies." said Chris Corless - MD Ph.D of Oregon Health and Science University

Knowing this, we are asking that anyone who has had, or, is planning on having surgery for a resistant mass, contact us to see how you can help. Tissue from these tumors can be sent in by the lab that received it after surgery. A Tissue Bank information packet will be sent upon request with only your signature required to release tissue for this research. While not every surgery will result in enough tissue being harvested, and not all labs will release it, please do allow us to request it on your behalf.

"The LRG Tissue Bank is a very valuable collection because it connects treatment and outcome information with each specimen."

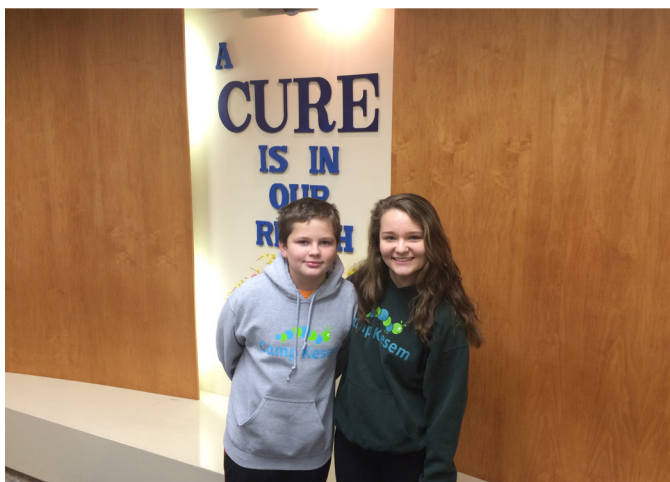
- Chris Corless

For more information or, to request a packet, please contact Magdalena Sarnas at **973-837-9092 ext. 114** or **msarnas@liferaftgroup.org**

Resistant tissue **can be donated** from a surgery performed after having taken any TKI in which the tumors were no longer responding to the medication.

Camp from Page 1

teen the opportunity for a week-long sleep away camp experience in an environment free of the sometimes overwhelming emotional pressures that coping with a parent's cancer can bring. It is estimated that there are currently over three million children living in the US today who have a parent with cancer. As our GIST community knows all too well, cancer touches the lives of many more people than just the patient. Children are a uniquely vulnerable population in this sense- because they are not sick themselves, they may feel hesitancy or guilt in expressing their own needs, problems or happiness, leading to issues in emotional, social and developmental growth.



Part of Camp Kesem's success may be the excellently planned, fun-filled days it provides its campers. Each year a theme is chosen for the camp week and all activities are tailored to that theme. "The themes are my favorite part. The counselors tell you where you're going next and it's usually a surprise, there's not even any clocks" says Terrance.

Named for the Hebrew word for magic, Camp Kesem gives kids a chance to just be kids. With a full time national program staff and 41 chapters around the country, Camp Kesem is always retooling and expanding its offerings to bring campers a wide variety of camp activities in the areas of sports, arts, crafts and drama. Indeed, its success speaks for itself with most campers, including the Pridmores, being repeat visitors year after year and many transitioning to be counselors or opening their own Camp Kesems at the colleges they attend.

"I definitely want to be a counselor at Camp Kesem when I get to college" confirms Mariela, currently a member of the Camp's Teen Program, "and if they don't have one at the college I'm at, I'll start my own."

For more information on how to get involved in the magic: visit www.campkesem.org

Insurance from Page 4

skin cancer, applies for AAA's life insurance, a policy can still be offered after an investigation.

The most questionable life insurance policy comes from American Continental, a subsidiary of Aetna. This is mainly due to the fact that there were two contrasting pieces of information given regarding qualifications for cancer patients. Initially, a representative stated that cancer patients did not qualify for life insurance under any circumstances. However, Dana Pearson, a supporter of the Life Raft Group who was diagnosed with GIST in 2012, was given a policy with American Continental in February 2014. A second representative then stated that cancer patients are eligible for life insurance, so long as their date of diagnosis was at least two years prior to the application. Therefore, make sure you are well informed before applying for life insurance.

As stated earlier, there are not many records from insurance companies for applicants with GIST, but some Life Raft Group supporters were kind enough to share

their experiences with me of attempting to obtain life insurance, and some of them had great difficulty. Although Dana Pearson was given life insurance with American Continental, she did not get the best rate. "I just recently took out a policy for \$10,000, which I know is bare bones but I figured it was better than zero," stated Pearson. "It only pays 100 percent if I live for two years from the issue date, otherwise it will pay what I have paid into it plus four percent."

Another GIST patient, Michela Hernandez, who has had no evidence of disease (NED) for the past four years, has life insurance with Prudential, but with a significant handicap due to the fact that she has had a GIST diagnosis within the last seven years.

"I'm only allowed about a 20 percent payout of what my colleagues are allowed," said Hernandez.

Unfortunately, not every cancer patient gets the opportunity to obtain life insurance due to their condition, as is seen with LRG patient registry member Maria Teta. Teta works for a small hairstyle business and was diagnosed with GIST in 2010, but

is currently NED. She attempted to apply for life insurance with AAA, which she said promised her that she would not be turned down because of her health. It did not work out that way.

"Sure enough I was turned down," replied Teta. "I reapplied again after a year and again after careful consideration they turned me down because of my health history."

According to Teta, there was no detailed explanation on her rejection.



Life insurance is essential to all who desire to relieve their friends and families of any burdens, but for cancer patients it continues to be as much of a struggle as fighting the disease itself. For a disease such as GIST, it can possibly be even more of a struggle.

Does its rarity attribute to that likelihood? Are insurance companies well-informed of this particular cancer? If so, would it change the success rate of obtaining a policy for GIST patients? Let us know what you think on our Facebook page "The Life Raft Group" and on Twitter @liferaftgroup. If you have any other stories regarding life insurance, feel free to send it to us via email at liferaft@liferaftgroup.org.

Research from Page 1

and received imatinib taken from the EORTC Soft Tissue/Bone Sarcoma Group. They looked at overall survival and progression-free survival outcomes and examined the data to identify prognostic factors that may help to determine which patients could benefit from metastasectomy. The results of the study were published in the European Journal of Surgical Oncology.

Looking at the rate of surgical resection, the researchers found that those patients achieving complete resection (R0/

R1; n = 177) had a median overall survival of 8.7 years compared with 5.3 years in patients with R2 resection (P = .0001). When the analysis excluded those patients who had progressing disease at the time of surgery, the median overall survival for the R0/R1 group was not reached compared with 5.1 years in the R2 group (P = .0001).



Image of a 6.5-cm GIST of the stomach.

The researchers also examined whether the site of metastasis affected outcomes. They found that median overall survival was not reached in patients with only liver metastases compared with 7 years in those with peritoneal disease, and 3.7 years in those with both liver and peritoneal disease.

Additionally, patients with complete surgical resection also had a median time

to progression that was not yet reached compared with a median time of 1.9 years in patients with R2 group.

“Of course, patients selected for surgery are more likely to have fewer comorbidities, most likely a lower tumor load, better response to imatinib therapy (per se), and have also been treated at high volume centers which may have given them access to more salvage therapies through clinical trials,” the researchers wrote. “These outcome data may therefore only represent our ability to pick those patients for surgery that may have lived longer anyway.”

Overall the researchers wrote that the results of this study do not support the use of debulking surgery as routine care, except for in cases of symptom relief. However, since randomized surgical trials are difficult to complete, retrospective analysis such as this one, “may serve as the only reference for decision-making.”

GDOL from Page 5

Trent, provided a natural transition into how patients can monitor these common side effects and ways to manage them.

Lastly, Dr. Ashwin Mehta finished the day with an excellent presentation on using integrative medicine while living with

GIST. He summed up well how certain techniques, ranging from diet to finding pressure points in the body to help with nausea, can help provide patients with a better quality of life.

We want to thank Dr. Trent, his family, the University of Miami Sylvester Comprehensive Cancer Center and all the volunteers who helped make this day a success!

We would also like to acknowledge Novar-

tis and Pfizer for their generous support for sponsoring the GIST Day of Learning.

Thank you to our volunteer photographer Don Edgar of DL Photography for capturing GDOL as well as our volunteer videographer Chloe Domont and her colleague Brian for recording the meeting on video.

To view photos and videos, please visit: liferaftgroup.org/2014/02/gist-day-of-learning-photos-2014/

GIST DAY OF LEARNING
CHICAGO • LOS ANGELES
JULY 13TH 2014

STAY TUNED FOR MORE INFO COMING SOON

Southern California group gathers



By Dina Wiley
Southern California Local Group Leader

Eighteen Life Raft Group "GISTers" and caregivers from Southern California (and one from Colorado) attended an informal meeting at my home on February 22, 2014. Dr. Bartosz Chmielowski, a sarcoma and GIST specialist from UCLA, spoke to us about GIST, its diagnosis, treatments, and surgical options.

An outstanding dialogue ensued about the types of GIST, kit mutations, and Gleevec tolerance. Jerry Call provided succinct explanations of current research in new GIST treatments, and helped correct some misunderstandings along the way.

Overall it was a successful meeting, as members went away with a lot of great information and new friends. Some commented that "I would not have been able to get this kind of information from my doctor, since the follow-up questions ignited more ideas and discussion."

Stay tuned for more information on the Southern California chapter's next informal meeting on Dec. 6, 2014, in San Diego!

Illinois Caregiver group gathers



By Marlene Nei
Illinois Local Caregiver Group Leader

Our Life Raft GIST Caregiver Support Group has been meeting for almost a year now. We meet at The Wellness Place in Palatine, IL 4 to 5 times per year for 2 hours on a Sunday morning. Our mission is for all to have a safe place to express their thoughts, feelings, fears, and questions or just sit quietly if need be. A place to share with other caregivers and loved ones dealing with the journey of our Gister and the effect it has on our lives. We talk, laugh, cry, learn and support one another. We are here if and when the caregivers have a need for support. The cookies & other goodies we bring are also very good.

Northern California local group meets



from Left to Right: Linda Fish, Lynn Whelan, Alec G., Iris B., Therese Llanes, Nina, Seishin M., Karen Ammons, Erick Ammons, Janet Mendoza, Mike Mendoza, Jan K., Mark K., Paula Vettel, Jett S., Linda F. Smith, Martha Zielinski

Thanks to John Zielinski for the photo of the Northern California Local Group

13 Gisters and 6 support people attended

Held at the lovely Cancer Support Community facility in Walnut Creek, CA

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

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