

GASTRO INTESTINAL STROMAL TUMOR

PATHWAY

TO A *Cure*

LIFE RAFT GROUP 2011 ANNUAL REPORT





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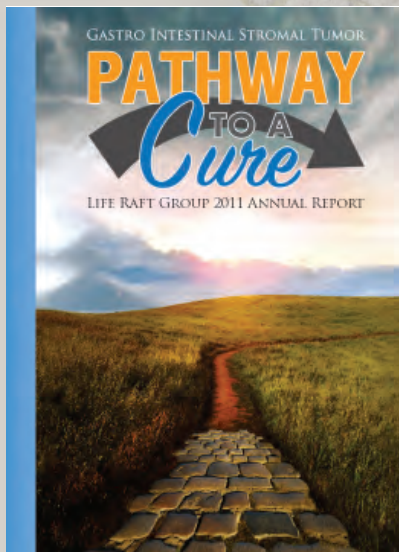
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ABOUT THE COVER:

This year's cover was inspired by none other than the LRG Research Team. When the Life Raft Group was envisioning all the hard work it would take to one day reach the cure, we imagined a cobbled, winding path that we were building block by block. It takes the efforts of the entire GIST community — researchers, staff, survivors, caregivers and more to help build this pathway. Together, we will reach the end and find the cure for GIST.

Dear Friends,

This past year felt full of possibility.

We came off 2010 on a high note. We celebrated ten years of successful GIST treatment and formally launched two initiatives, including a new research effort, *Project D-Day*, and our advocacy venture, *Alianza GIST*.

In 2011 we saw these programs take off — *Alianza GIST*, the once grassroots effort to increase the level of patient knowledge and support in Latin America became the guiding hand of local groups that cropped up all over the region. Eager country representatives took a stand to tackle the issues that mattered most in their areas, as well as the growing threat of counterfeit drugs.

Our LRG Research Team delivered its first *Project D-Day* progress report and the results were more promising than we could have hoped for. Our enthusiasm for this project and its hope of finding a cure is matched only by our researchers. Recently, Dr. Mike Heinrich, team member and GIST Specialist at Oregon Health & Science University said, “This innovative model has markedly accelerated research progress and already resulted in several new drugs advancing to clinical studies. I am deeply appreciative of the support the LRG has provided to the GIST research community.”

That level of appreciation and dedication is what drives the LRG and reminds us constantly that a cure is in our reach.

We also saw new initiatives take off in 2011. After years of struggling to make mutational and plasma testing common practice, the LRG made its first significant steps to success by forming beneficial partnerships, which will finally bring mutational and plasma testing to the forefront of the GIST community’s mind.

We are encouraged by our research progress and very proud of the LRG’s accomplishments in providing support and education to the GIST community, while also increasing awareness in the world, but we also know that these efforts must be sustained while researchers hunt for the cure. We need your support in order to continue these life-saving efforts. Please consider making a donation today and help us save and enrich the lives of GIST survivors and caregivers until the cure is found.

Sincerely,



Norman J. Scherzer
Executive Director



Jerry Cudzil
President of the Board

Making Strides

In 2011, the LRG made several strides in the area of research.

We sustained our support and participation in endeavors like the NIH Pediatric & Wildtype GIST Clinic, which continues to make discoveries in the understanding of this rare subset of GIST.

We were also honored to present a paper on the relationship between Gleevec dosage and long-term survival at the prestigious Connective Tissue Oncology Society (CTOS) conference in November. This was the second time our study has been updated at CTOS.

Additionally, we presented a poster highlighting survival data from the LRG Patient Registry, which currently contains data on 1,347 GIST patients. In the poster, LRG Science Director, Jerry Call, showed how a mutation profile varies with the age of onset of GIST.

Our Research Team

Last year, we were also very encouraged by the first progress report of our D-Day initiative.

This research project is the result of years of knowledge building, and bringing together the best in their fields to consider and develop a very detailed strategic plan to find a cure.

“The Life Raft Group has revolutionized the way we do research by relieving traditional barriers to collaboration and encouraging a group dynamic.”

*—Brian Rubin, MD, PhD;
The Cleveland Clinic, USA*



Our world class team identified several new mutations besides KIT in its Sequencing group; an important gene — critical for GIST cell survival — was identified by the Gene Knock-Down group as well as more relevant targets and resistance factors; our Drug Screening group, which was created to fast-track effective treatments for patients in need while the lengthier process of finding the cure is underway, found several drugs that could potentially inhibit GIST growth. All of the major discoveries by the team also began the next step — the vetting process by the Validation group.

This reported progress was an incredible breakthrough and provided even more reassurance that our research is on the right (and fast) track for finding a cure for GIST.

Expanding our Support & Education Efforts

The Life Raft Group has always been dedicated to the support, education and needs of GIST patients and caregivers. In 2011, we increased and strengthened our support programs as well as launched a physician outreach program.

We increased our patient counseling efforts and held brainstorming meetings bringing the patient in need, our Executive Director, Norman Scherzer, our Science Director, Jerry Call, and key members of the Science Team and medical community together in order to establish a treatment roadmap, so that the patient finds the best possible next step.

We also expanded our US local groups, and began efforts to keep our local group leaders more engaged and well-informed in order to increase the benefit from those meetings.

In a similar vein, we created a formal Physician Outreach program, with a goal to reach more patients, especially those who might not be able to find us on the internet, through their doctors.

The Bill Buchanan Life Raft GIST Support Group

When Bill Buchanan, an active member of the Chicago Area GIST patient group, passed away in November 2010, he left us with a legacy that will benefit patients for years to come.

Concerned that some people who were facing GIST did not have the same opportunity for support that he did, he wanted to establish a local support group at Cook County Hospital to serve that need. Patients in this area sometimes don't have access to the internet to learn about their disease and often have trouble even getting to appointments.

"I am truly excited how extraordinary and unique this research effort is. It is empowering patients to participate and substantially contribute to the advancement of science."

**—Sebastian Bauer, MD, PhD;
University of Essen, Germany**



Bill expressed his wishes to the LRG and to his wife Maureen. His passing sparked a flurry of donations to the Life Raft Group, which were provided to Cook County Hospital to build this program under our mentorship.

On October 22, The Bill Buchanan Life Raft GIST Support Group held its first meeting at the John Stroger Hospital of Cook County, located in Chicago. Not only was it a success, but new meetings for the coming year were immediately scheduled.



Top left: Dr. Bill Tap (left) answers patient questions at a New Jersey local group meeting;
Top right: Bill Buchanan at Life Fest 2010;
Left: John Stroger Hospital of Cook County

Ensuring Safe & Effective Treatment Access

One of the many things the LRG expanded in 2011 was our advocacy efforts. From the early days of helping patients with access issues on a one-on-one basis and reporting on trends we saw in dosage and survival, the LRG has now become an active presence in making change. We still helped patients access drugs; we just did it more often and in some cases, in new ways.

Many cancer patients around the world have poor access to cancer therapy, especially in parts of Latin America. For those who cannot afford or access the original branded medicine, they

are left with alternative options. Those medicines may be less safe, of lesser quality, or not produce the desired therapeutic effect as the original counterpart. Thus, patients' lives are at risk.

The LRG is committed to keeping people safe and helping them to receive safe medicines and we believe that all patients must be made aware of the type of drugs they are being given, whether original or non-original and understand the potential risks and side effects.

Therefore, we took a firm stand on this issue by creating a petition with the rest of the global GIST community.

Another goal that we have had for years is the routinizing of mutational and plasma testing. We believe that, armed with these tools, physicians can more effectively tailor treatment plans to the specific needs individual patients require. Mutational testing can help identify if a patient may be less likely to respond to a drug, or particular dosage, while plasma level testing can help a physician and patient feel more comfortable about a dose reduction when side-effects are present, and when a patient is not getting a proper response, dose escalation.

A liquid chromatography-mass spectrometry (LS-MS) machine used in plasma level testing





Patients and advocates meet and share at Alianza GIST meeting in Brazil

In 2011, we took this further than before by first reestablishing temporary free plasma testing through TDM Pharmaceutical Research, when the program could no longer be supported. Second, we launched a major survey, targeting both patients and doctors, which aimed to find the root causes for lack of participation in these tests and how we can improve it.

Global Outreach

Alianza GIST, our Latin American patient group alliance made great strides in 2011, increasing both its educational and advocacy efforts. New formal country organizations were established, such as Fundación GIST Colombia (www.fundaciongistcolombia.org), Fundación GIST México (www.fundaciongist.org) and Asociación GIST Argentina.

Alianza GIST representatives also met for the first time (as a formal organization) in 2011 in Brazil and committed themselves to

helping patients in this region by focusing on three worthy areas: adequate diagnoses; access to safe, effective and affordable treatment; and increased efforts to establish more viable treatment options.

In June 2011, Alianza GIST put these beliefs into effect by creating the first event for “Best Practices in Latin America”, which we held in collaboration with the Max Foundation at the American Society of Clinical Oncology (ASCO) conference in June and brought American & Latin American physicians together with others to study abnormal GIST cases in the region.

“This innovative model has markedly accelerated research progress and already resulted in several new drugs advancing to clinical studies. I am deeply appreciative of the support the LRG has provided to the GIST research community.”



**—Mike Heinrich, MD, PhD;
Oregon Health & Science University, USA**



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Clinical Trials Coordinator



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Russ DiMinni
Daniel Erlichman
Michael Fargione



The piano concert was a unique opportunity to coordinate a community event that both entertained my friends and family, educating them about GIST, my story and raised money towards the D-Day project.

— David and Cherry Safford

Alexis Feliciano
Sean Finnerty
Timothy Fischer
Glenn O. Franz
Glen Gregorio
Robert Grillo
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James Higgins
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Joseph & Anna Zappala
Joseph Zawacki

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Roberta Veatch
Marc Wasserman
Duane A. Williams
Lawrence J. Wolfson
Jack Wright
Leon Wyant
Hans Wyss
Choudhary Yarlagadda
Joseph & Anna Zappala
Joseph Zawacki

“Overall, I am delighted with the progress, and I can tell you that the excitement and anticipation on the part of the scientists is through the roof! I am certain that many thousands of GIST patients will benefit from this life-saving research, and we are doing everything possible to ensure that you benefit.”

— Jonathan Fletcher, MD, PhD; Brigham & Women's Hospital, Harvard University, USA



“The LRG research project was for me from the start as a breath of fresh air, and it continues to be a stunning experience. It has opened the door for discoveries on untouched areas in an atmosphere of unprecedented openness, mutual respect and trust, and collaborative support and efforts. I feel really lucky and privileged to be a part of the team.”

**—Maria Debiec-Rychter, MD, PhD;
Catholic University of Leuven, Belgium**



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 Seishin & Eiko Murahashi
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In October, 2011, LRG Member Jason DeLorenzo raised money for the LRG by participating in the Marine Corps Marathon. The marathon was more than a fundraising opportunity to Jason; it was a personal challenge.

“Cancer and marathons have a lot in common. They both challenge and expand you emotionally, physically, spiritually, and mentally, and whenever someone thinks they can survive either, their answer is usually a resounding ‘no way.’ In the end of both, there are far fewer things you claim you can’t do.”

—Jason DeLorenzo

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“The annual Life Raft Group poker tournament is a fantastic experience. The event is extremely well-run, which makes for a great evening for a great cause. I have a ton of respect for Jerry Cudzil and everyone else from the Life Raft Group who work behind the scenes to make it all happen.”
 — Patrick Moore, Brownstone Investment Group

\$50 – \$99

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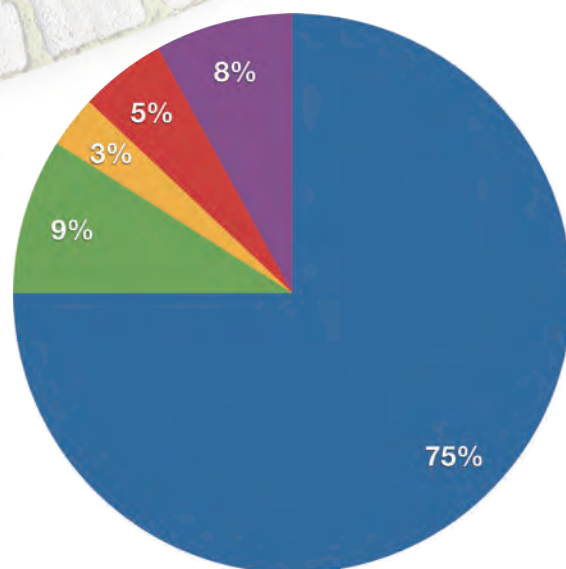
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Allocation of Funds for 2011

Total Expenditures:
\$2,835,317

- Research
- Information & Education
- Patient & Family Services
- Advocacy
- Management & Fundraising



The Life Raft Group

We direct research to

find a cure

for a rare cancer and help those affected

through **support and advocacy** until we do.

ensuring that no one has to face GIST alone

The Life Raft Group
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