

CELEBRATING 10 YEARS



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OUR NEW LOGO

The LRG began as a small group of patients and caregivers offering support and guidance to each other while facing the early Gleevec trials. The LRG has now grown into an action-oriented, positive force in the GIST community, heavily involved in advocacy work and changing the face of GIST research. The objective we had before us was to keep that sense of hope but adding a clean, modern look.

ABOUT THE COVER

Life Fest 2012 in Las Vegas brought together GISTers, caregivers, and medical professionals from all over the world. This year's cover perfectly illustrates the spirit of this biennial event — camaraderie, support and strength.





Dear Friends,

This past year was one of celebration — our 10-year anniversary. It's an amazing achievement for any non-profit to be able to celebrate an anniversary like this; and for a group such as ours focused on a rare disease, it doubles that pride.

We have been blessed with a small, dedicated community to have been able to accomplish great things: a comprehensive Patient Registry; a Tissue Bank that utilizes medical histories; a leading GIST researcher's expertise with readily available tissue; and a steadfast research team to not only enhance GIST research, but also provide valuable treatment insight through free mutational testing.

Our research progress continues to astound me as we move closer to the cure. Our team has performed the largest known analysis of the GIST genome, identifying over 200 mutations predicted to have biological effect; ranked 11,000 genes in several GIST cell lines in order of functional relevance; tested over 120 compounds, with four drugs being singled out for possible benefit and, perhaps most importantly, found that almost every GIST patient has changes in genes that affect the cell cycle and result in advanced GIST. All of these findings have contributed to our understanding of GIST mechanisms and

resistance and may further contribute to the search for other cancer cures as well.

GIST management and quality of life remained the primary focus at the LRG during 2012. We held our biennial Life Fest event in November where the combination of camaraderie, support, learning and teaching genuinely enhances a GISTer's ability to manage their care. We also started a new event — GIST Days of Learning (GDOL) so that people could get support & information without having to wait for the next Life Fest event, and we have expanded our locations to include Miami, Chicago and California.

Lastly, I'd like to point out the efforts we put into redesigning the LRG website to make it easier to navigate and understand.

We have come so far and nothing but opportunity lies before us. Thank you for being a part of our journey as we take even more risks and challenges on in 2013.

Sincerely,

Norman J. Scherzer
Executive Director



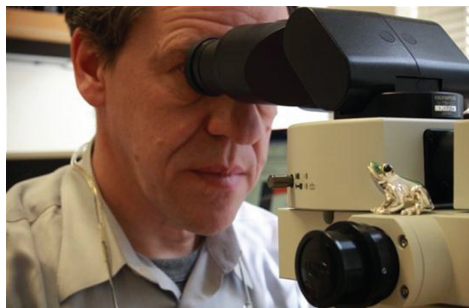
Regrouping After a Loss

In 2012 we were deeply saddened to lose a great friend and true humanitarian, Jeroen Pit, whose generosity did so much to help our research efforts. His battle with GIST ended at his home in Amsterdam on February 6. Rarely does one have an opportunity to cross paths with such a dynamic and proactive philanthropist whose dedicated efforts rose close to \$3 Million since 2009. These funds went specifically towards making significant progress in understanding the mechanisms behind GIST, identifying targets, and unraveling the puzzles of subtypes and treatment resistance. Named the D-Day project, this initiative will forever represent his brave fight and his unwavering commitment to finding a cure.



Jeroen Pit and his wife, Emilie van Karnebeek. Emilie attended Life Fest 2012 and was awarded the Arnie Kwart Philanthropist of the Year award. She accepted in memory of her husband.

Project D-Day is focused on four areas: **Sequencing** the GIST genome, **Gene Knockdown** studies, or screens that examine pathways essential for GIST cell survival, **Drug Screening** of GIST cells against large libraries of drug compounds, and **Validation** studies of important



Matt van de Rijn, MD, PhD, continues his work in gene micro array analysis at Stanford University.

candidates from the first three areas that would allow a timely translation into clinical trials.

In the spring, the team reported that they had identified over 200 mutations predicted to have a biological effect and categorized them by function to better understand their relevance in GIST; identified a compound of a key pathway in GIST that is five times more specific than some previously tested targets and which may help successfully overcome secondary resistance, the most common cause of treatment failure; identified four drugs as being of possible therapeutic value; and did promising work on inhibitors, a therapeutic antibody and tumor cell death.

Collaboration Sets Us Apart

Under the leadership of Dr. Jonathan Fletcher of Brigham & Women's Hospital at Harvard University, the team has made this cutting edge concept its hallmark since its inception in 2005, well before collaboration became the new trend in cancer research.

Of the many gestures of support that exist within the team, the following is an example worth noting. Recently, one of our researchers was in

need of funding to develop a new GIST mouse model line that was essential in advancing their research. Learning of this dilemma, a fellow team member stepped forward and made the funding available from his lab. These types of gestures keep momentum and morale high, advancing the team as a whole towards their common goal.

Emerging Role of Immunotherapy

The LRG also responded in 2012 to the emerging role of immunotherapy in cancer research, beginning work on setting up a parallel research team that would focus specifically on this promising area. Immunotherapy approaches are now being tested in clinical trials, and we hope to get the best researchers in the field working on a cure for GIST.

Strides in Pediatric GIST

The LRG has been at the forefront of new developments in the understanding of Pediatric and Wildtype GIST. As the role of alterations in the SDH, or succinate dehydrogenase protein in these subtypes becomes clearer, our Research Team will be responding to help find new possibilities for treatment.



LRG Science Director Jerry Call explains mutational testing while GIST community members respond to his thought provoking questions.

Celebrating 10 Years of Dedication

As the Life Raft Group reached the milestone of 10 years of support and education for patients with GIST, we marked the occasion with an event that focused on that very mission; Life Fest 2012: Celebrating 10 Years of Dedication. Held in the legendary city of Las Vegas in November, the glamour of the city could only be eclipsed by our immense joy of reconnecting with old friends and meeting so many new faces. People from around the country and across the globe came together for three spectacular days of learning and fellowship.

At Life Fest, we honored those who have played a role in helping us support and educate

our members. At the Friday Gala, Dr. Mike Heinrich received the Clinician of the Year award, the Global Outreach Award to Alianza GIST was accepted by Piga Fernandez and Vicky Ossio, the Jeroen Pit Science Award by Dr. Brian Rubin, the Arnie Kwart Philanthropist of the Year Award by Emilie van Karnebeek. Sanofi, awarded the Patient Outreach Award, accepted through a heartfelt video message. The Humanitarian of the Year award went to Dr. Jonathan Trent and the Volunteer of the Year Award to our volunteer photographer, Kim Tallau. Among those inducted into our GIST Hall of Fame were the Baldor Family, Dr. Jerzy Lasota, Dr. Markku Miettinen, our Executive Director Norman J. Scherzer, and the Max Foundation.



Piga Fernandez, accepts the Global Award of Excellence on behalf of Alianza GIST as Vicky Ossio and David Josephy look on.

On Saturday, Drs. Heinrich and Rubin answered many questions from attendees after presenting the latest information on GIST.

We hold a Life Fest event every two years, and they continue to be one of the best ways we can support our members.



Far left, LRG Executive Director Norman Scherzer shares a hug with David Josephy and another attendee at Life Fest 2012.

Left, Support and camaraderie shared among Life Fest attendees.

PATIENT SUPPORT AND EDUCATION



From left, Dr. Andrew Rosenberg, Jerry Call, Alice Sulkowski, Dr. Steven Rodgers, Elizabeth Fontao, and Dr. Jonathan Trent gave outstanding presentations at the First Annual GIST Day of Learning.



GDOL attendees enjoy meeting with presenters to ask them questions about GIST.

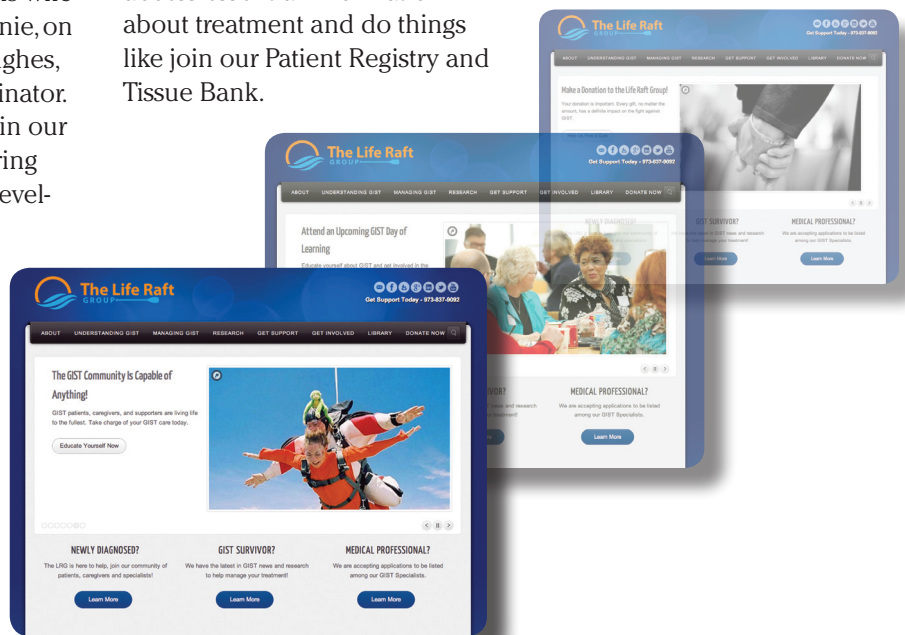
Our First GIST Day of Learning

But 2012 also stood out for another LRG event — our first-ever GIST Day of Learning — held in Miami in May. Partnering with Dr. Trent and the University of Miami Sylvester Cancer Center, we were able to provide education and support for over 50 GISTers and caregivers who traveled to the event. One of the highlights of GDOL was a presentation on clinical trials by Jerry Call, Science Director at LRG and caregiver to his wife and GIST survivor Stephanie, on clinical trials with Jim Hughes, LRG Clinical Trials Coordinator. Jerry, who often appears in our email community answering questions from GISTers, developed a GIST-specific clinical trials database and also oversees our Science Team and Patient Registry. The event was such a success that we scheduled two more GDOLs for 2013 — one in Chicago and one in Miami.

Harnessing Technology

LRG members also probably noticed a big change in our outreach efforts in 2012 as we expanded our social media and web presence, making sure GISTers can access the latest information on research and treatment. In 2012 we prepared for the launching of our new website, which made its debut early in 2013. The site has a cleaner look, is easier to navigate and provides a newsfeed on the home page. Members can still access essential information about treatment and do things like join our Patient Registry and Tissue Bank.

Those who follow us on Facebook and Twitter have grown dramatically in number as we began to provide daily updates, ranging from links to new studies on GIST to profiles of GISTers and upcoming events. We believe this is a great way to continue the dialogue with our members and encourage newly diagnosed patients to join our community. We continue to look for new ways to harness technology to support and educate our members.





You Can Count on Us

We continued to advocate for wider use of mutational and plasma-level testing in 2012, while representing GISTers at key forums such as the American Society of Clinical Oncology (ASCO) meeting in Chicago, the Connective Tissue Oncology Society (CTOS) conference in Prague and the New Horizons international GIST meeting in Paris.

These forums give us the opportunity to advocate for our members and share our expertise with others in the wider cancer community.

One of the highlights was the presentation at CTOS of a study produced by LRG Special Projects Coordinator Peter Knox on the obstacles to wider implementation of mutational and plasma-level testing. We strongly believe these tools can extend patient survival, yet we found that 45% of doctors don't always order mutational testing. While some practices did the test automatically, there was a significant correlation between whether the doctor discussed the test and whether it was received. Patients demonstrated both awareness and understanding of mutational testing. Clearly, more work needs to be done to educate both doctors and patients about

the benefits of mutational testing in an era where treatments can be targeted at specific mutations.

Working With Our Latin American Friends

On the international stage, we also bolstered our ties with Latin American GISTers by strengthening Alianza GIST. The group not only launched a new website and held its first webinar, but also met in Miami in March to develop a game plan for advocating throughout the region. Advocacy and access was a big part of the plan as Alianza GIST began to set up a core infrastructure. LRG Administrative Director Roberto Pazmino, who was born in Ecuador, presented information on the value of LRG's Patient Registry and Tissue Bank, and later in the year produced a study on how to overcome obstacles in Latin America to participating in the Tissue Bank. The Patient Registry and Tissue Bank are not only valuable tools for GIST researchers, but can be used by patients to help guide their treatment plans.

In 2012, Alianza GIST also joined forces with a Brazilian partner, Oncoguia, to work together to benefit GIST patients in Brazil, and advocated in Guatemala to help reach an agreement in the Central American country to secure entry of the GIST drug Gleevec into the nation.

GIST patients and caregivers take part in an exercise sharing important advances and continued needs for the GIST community in Latin America.



Back in the U.S.

Closer to home, we expanded our network of local leaders in states throughout the nation, who are GIST patients or caregivers who donate their efforts to help fellow GIST patients in their area. The LRG has leaders across the United States and they continue to find creative ways of advocating with and for us. One event that was particularly notable was Bobby Kinsey's "Harness a Cure" held in March at Dover Downs. Bobby asked both drivers and horse owners to pledge a portion of their purses for "Harness a Cure," aiming to both raise funds for the LRG and boost awareness about GIST.

And in our home state of New Jersey, the LRG joined forces with several other cancer-patient organizations to help restore \$1 million in funding for cancer research that had been cut out of the state budget.

Piga Fernandez of Santiago, Chile, shares information with an American Cancer Society representative at the Alianza GIST meeting.



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IN MEMORIAM



Bob Book

A 1948 graduate of Arsenal Technical High School, Bob enlisted in the U.S. Marine Corps Reserve that year and spent 31 years in both the U.S. Marine Corps and U.S. Marine Corps Reserve, retiring in 1983 with the rank of colonel.

His board memberships included the Marine Corps League, the Indiana Military Coalition, Military Officers of America Association, the Farm Foundation, Neogen Corporation, Ag Alumni Seed, U.S. Feed Grains Council, National FFA, the Fine Arts Society of the University of Indianapolis and the Life Raft Group of GIST research.

ADDED IN 2013



Gary Glasser



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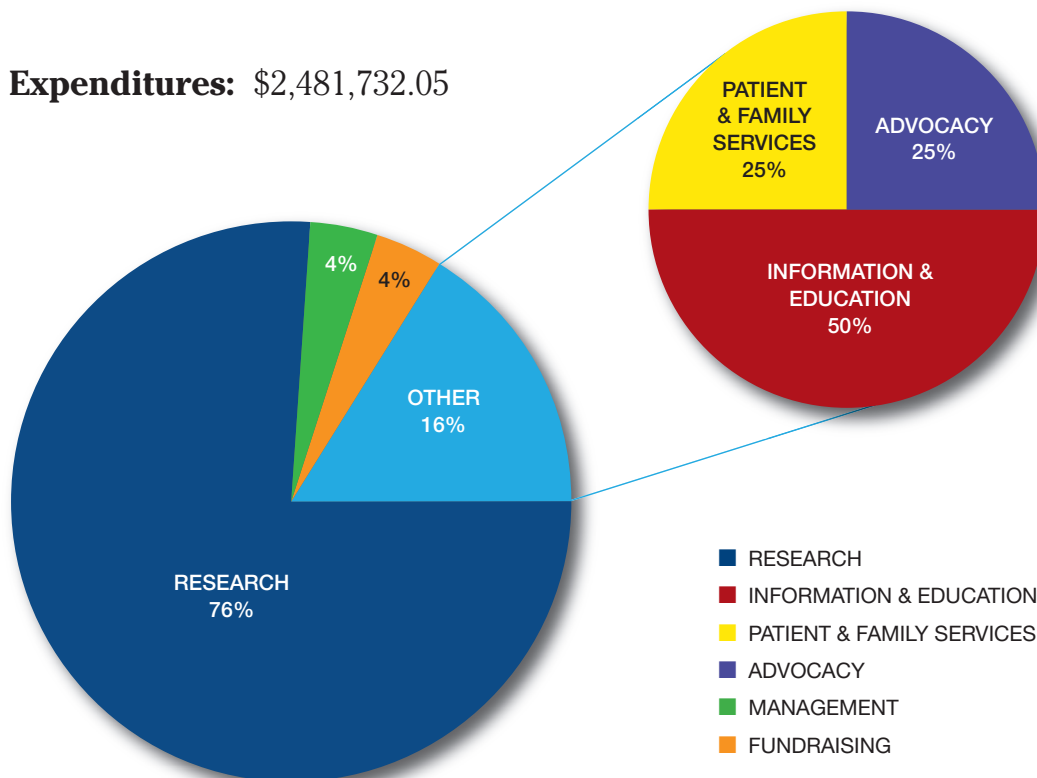
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While maintaining our commitment to research, we were able to expand our programmatic reach throughout the world, stepping up our global alliances and support. In the United States, we expanded outreach by holding a “GIST Day of Learning” event in Miami, and began identifying ways to strengthen local group participation around the nation. We strive to honor donor intent and to put each dollar donated towards making a difference. These charts illustrate the allocation of our incoming funds.

Expenditures: \$2,481,732.05



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The Life Raft Group
has a simple focus: to
cure a form of cancer—
GIST (gastrointestinal
stromal tumor) — and
to help those living with
it until then.



The Life Raft Group
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