



The Life Raft
GROUP

2014 ANNUAL REPORT



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About the cover

This year's cover was inspired by our successful GIST Awareness Day campaign that resulted in 130,00 boats being folded by GIST patients, caregivers and friends from all over the world. Following the nautical theme, we recognized that the Life Raft Group has been navigating the waters of GIST advocacy, patient education and support and research for the past 13 years, leading the way towards our goal: Finding a cure for GIST.

The ripples are symbols of the widespread awareness and support that results from our efforts. We will continue to move forward into new ventures that will impact the GIST community.

Navigating the Waters

Anyone who pilots a boat knows that calm seas can turn rough quickly. It takes a prepared captain and crew to take on whatever comes along on the journey. The world of non-profit cancer advocacy is a lot like boating. Some days the water is as smooth as glass and generous sponsors help to support us, new scientific breakthroughs give us hope, and patients celebrate being NED.

But it is in the rough waters that true sailors not only navigate their boats, but also lead the fleet of all the other boats to safety. This year, as research funding was coming to a halt, instead of piloting at high speeds, we slowed down and found the funding necessary to proceed.

We planned new routes to educate and inform. We developed new virtual strategies to compensate for cuts in funding for in-person clinics. At our events such as Night to Fight Cancer and Life Fest, we came together to raise money and share fellowship as well as our strength, hope and experience.

The ripples our boat left behind spread far and wide, with membership increasing globally, and education and advocacy touching lives from Iowa to India.

It is fitting that our GIST Awareness Day symbol was a tiny boat. What started as a small awareness campaign grew into an international effort that resulted in over 130,000 origami boats being folded to raise awareness about GIST.

This mirrors the history of the Life Raft Group itself: what started as a small group of concerned patients and caregivers has grown to be a global organization leading others in our quest to find a cure for GIST. As we share our proven innovative programs like our Patient Registry, GIST Collaborative Tissue Bank, Virtual Tumor Boards, Collaborative Research Team, and GIST Days of Learning, we are moving into newly charted waters by joining data consortiums and new advocacy groups, developing the model for GIST Centers of Excellence and developing Virtual Clinical Trials.

In spite of all the progress we have made over the past 15 years, patients still succumb to this disease. We urgently need your donations to assure that we can find help for those who are resistant to existing treatments, and so that we can develop new strategies for those who struggle for survival.

With your help, we can find a cure.

Sincerely,



Norman J. Scherzer
Executive Director



Jerry Cudzil
President of the Board

This year we managed to commit new funding for our world class research team just in time to enable them to continue their search for a cure. This is particularly noteworthy given the decreases in funding that have left many researchers in dire straits.

Our Patient Registry was converted to a SQL-based platform to provide a foundation for web-based access to patients and researchers in the near future. Backed by our tissue bank housed at Stanford University, our Registry continued to serve as a vital source of research information and to provide empirical information helping guide patients and their physicians through survival decision-making in the absence of more formal clinical trial data.

We continued our support of the NIH in-person clinic for patients with Pediatric and Wildtype GIST. Due to a reduction in federal funding, the NIH had to cut the number of in-person clinics held per year. In response, we collaboratively launched our first Virtual GIST Tumor Boards, allowing medical professionals to present cases to GIST experts remotely using cutting edge technology. Our second Virtual Tumor Board had global reach, with patients from the United States and Eastern Europe. In 2015, we will be expanding to adult GIST cases.

The GIST scientific community was enriched by the launch of *The GIST Cancer Journal*, the official journal of the Life Raft Group, and the first academic journal devoted



The GIST Cancer Journal serves as a comprehensive and authoritative resource regarding advances in the diagnosis and treatment of gastrointestinal stromal tumors.

GIST Awareness By the Numbers

over **2,000**
people participated in
GIST Awareness Day



solely to GIST. Dr. Jonathan Trent was named Editor-in-Chief. This will not only facilitate the sharing of GIST research, but will bring about more knowledge and awareness to those on the front lines such as oncologists, gastroenterologists, radiologists, nurses and surgeons.

Our patient education reach continued to grow in 2014, with GIST Days of Learning (GDOLs) held around the U.S. We continued to provide education through our webcasts, including the popular GIST 101 held by Dr. David Josephy, as well as our Virtual Roundtable series hosted by Science Director, Jerry Call.

Twenty students comprised of GIST patients, caregivers and extended members of the GIST community completed our inaugural six-week GIST Expert Training Program. The course was designed to help participants understand the science behind GIST, and to prepare them to serve as GIST Ambassadors and/or Patient Registry volunteers.

Meetings around the world were hosted and attended by the LRG staff and members, including New Horizons in Switzerland and CTOS in Berlin. New Horizons brought together 44 GIST patient representatives from 28 countries and 32 patient organizations. Alianza GIST members from throughout Latin America also joined the Life Raft Group in Switzerland.

Our members and their supporters are the heart of the LRG. We held our first



Dr. Jonathan Trent addresses attendees at the 3rd Annual Gist Day of Learning (GDOL) on February 9 at the University of Miami Sylvester Cancer Center.

Appreciation Dinner, inviting the local GIST community to join us just to say “Thanks” to all those who in big and small ways make someone else’s life a little easier or happier.

Poker played a big hand in our fundraising efforts this year, with the Poker for Hope event in Caesar’s Palace, Las Vegas and the Night to Fight Cancer tournament in New York. Both were events that brought together the community for elegant evenings of fun that raised over \$100,000 for our life-saving efforts.

Support for our community both locally and worldwide was enhanced by our first GIST



265 tweets, reaching
2,445,558 followers





The Life Raft Group invited the local GIST community to a special Appreciation Dinner just to say thanks.

Awareness Day (GAD). As an offshoot of our successful Rare13 campaign, the goal was to raise awareness about GIST, bringing together people in a collaborative effort to educate and inform the public. As a symbol of GAD and of hope, we raised the challenge of folding 20,000 origami paper boats. Little did we know that this would become a worldwide effort, with over 130,000 boats from as far away as Mumbai folded and delivered to the LRG in time to be displayed in a photo booth at Life Fest 2014.



The year culminated in our biennial Life Fest celebration, held in November in Teaneck, New Jersey. Countless dedicated hours were spent preparing for this successful event. Researchers, members, caregivers, holistic practitioners and pharmaceutical representatives came together once again to support and learn from one another, to celebrate the lives of those whom we have lost, and to increase the critical knowledge of those struggling to survive.

Science Director Jerry Call and Executive Director Norman Scherzer ended the weekend by introducing the Survival Plan, an ongoing series to be continued in 2015 that will outline strategies to double survival for those diagnosed with GIST.



LRG staff members joined together with One Voice Against Cancer in Washington, DC in July to lobby for a \$5.2 billion cancer research funding package to benefit some of the top GIST research facilities in the world, including the NIH and NCI.

We also held an informative webcast on “Affecting Change from the Top” that provided members with a format for advocating for change.

Our members are our most fervent advocates, with GIST Awareness Day reaching hundreds of people through three main events in LA, Miami and Chicago, and also through booths at state fairs, book signings, local GDOLs and by placing articles in local newspapers.



Life Fest 2014 convention held at the Teaneck Marriott at Glenpointe in New Jersey brought together researchers, members, and caregivers to support and learn from one another.




55 Facebook posts
602 total likes

Jerry Cudzil's 11th Annual Night to Fight Cancer was an overwhelming success and helped generate over \$80,000.



Jerry Cudzil
President



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Clinical Trials Coordinator



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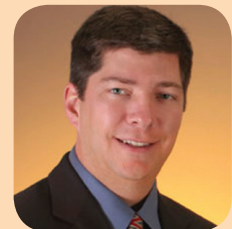


In Memoriam

As the year drew to a close, we experienced some heavy losses. Board member Dave Safford lost his courageous battle with GIST but showed us all what true heart looked like.

Shortly before, Michael Byrne, spouse of Board Member Mia Byrne, passed away having fought GIST for over a decade. He had planned to run the Chicago Marathon with a family friend Jennifer Hartzler. With no time at all to prepare, Mia decided to run two miles as a token gesture to honor Michael's memory. With strength that nobody could understand, that defied all logic, Mia kept on running and somehow managed to finish the 26.2 mile course. We choose to believe that she ran on the wings of Michael, her hero.

We will continue to "run the good race" in their honor in 2015, and going forward, their light will continue to shine in our hearts.



David Safford
July 3, 1967 - August 12, 2014



Michael C. Byrne
June 19, 1963 - August 9, 2014
Husband of Mia Byrne

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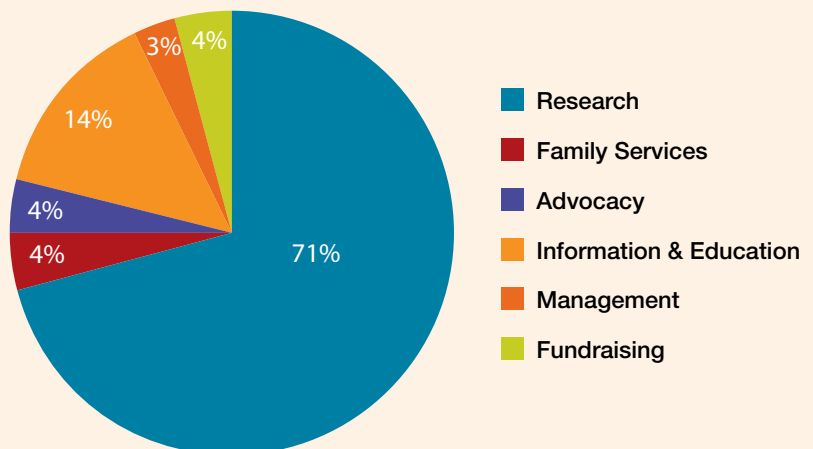
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We apologize for any inadvertent omissions or inaccuracies in our donation roster. We humbly apologize, and will be happy to note the discrepancy in a forthcoming publication.

Allocation of Funds





The Life Raft Group
155 Route 46 West, Suite 202
Wayne, NJ 07470 USA
www.liferaftgroup.org

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.

