Ensuring no one has to face GIST alone
From Los Angeles to Mumbai: GIST Awareness Day Successfully Unfolds

From sunny LA to the colorful streets of Mumbai, our first GIST Awareness Day unfolded with great enthusiasm as our community joined together to spread the word about GIST and our efforts to find a cure.

Los Angeles

At the beautiful South Coast Botanical Garden, the day began with a GIST Day of Learning (GDOL) attended by over 30 people, featuring medical experts Sandra Brackertt, RN, Dr. Bartosz Chimielowski, Dr. Michael Heinrich and Dr. Jason Sicklick presenting the latest medical findings on GIST.

In the afternoon, at the scenic Koi Pond, over 130 people gathered to watch the Ka Pa Hula O Keahialaka hula dancers, singer Melissa Faye Klein and accompanist Joe Lawrence. Origami boats hung throughout the Koi Pond amid activity centers of face painting, origami lessons, nautical knot making and GIST informational displays. Over 22,000 origami boats were displayed.

Mo Collins, our event emcee, provided some levity and personal perspective to the presentation which included words by LRG Board Jerry Cudzil, Dr. Michael Heinrich and Dina Wiley, LRG’s local rep who worked tirelessly to engage the community and raise awareness about GIST. With over 30 prizes contributed by local businesses, the first GIST Awareness Day LA proved to be a true community event.

Chicago

GAD Chicago was a successful two-part event, with 55 attendees at GDOL in the morning, and the GAD festival in the afternoon. Families from as far away as California were in attendance.

From magic and balloon art, arts and crafts, caricature art, henna and face painting, dancing, live music and stand-up comedy, to the incredible catering and dessert tasting table, everyone enjoyed the unique local flair of this event.

Miami

GIST Awareness Day Miami was co-hosted with the University of Miami Sylvester Cancer Center and included a number of speakers from Sylvester, including Dr. Stephen D. Nimer, Director of Sylvester, Dr. Jonathan Trent, Co-Director of the Musculoskeletal Center and Director of the Sarcoma Medical Research Program; Dr. Breelyn Wilky and Dr. Pasquale Benedetto, medical oncologists that both serve the GIST and sarcoma communities.

Attendees had the opportunity to mingle with one another, speak with experts from Sylvester, as well as enjoy activities throughout the event. Some of the highlights of the event included an appearance by the Miami HEAT Dancers, beautiful serenades from the Brazilian Voices a cappella group, yoga, free massages, and face painting.

Go to liferaftgroup.org/gist-awareness-day/ to read more about the events.
Member hosted events around the world

**Georgia**
Lee Kenworthy distributed literature and raised awareness about GIST, interacting with over 75 people.

**Iowa**
Teena Petersohn advocated for GIST awareness with a booth at the Ringgold County Fair. Over a five-day period, information about GIST was distributed. A door prize (1 hour massage) was raffled off, with over 90 people entering. People stopped by, not only to learn about GIST, but also to make origami boats and to show their support. Teena also put articles in two of her local papers.

**Long Island**
On July 13 at Taste 99 Restaurant in the beautiful Bethpage State Park, overlooking the golf course that has previously hosted the U.S. Open, 13 members of the GIST community shared their inspiring stories, and discussed ways to get the word out about GIST. Executive Director of the Life Raft Group Norman Scherzer joined in the lunch and discussion. Pat Bonda-Swenson, New York local group leader, coordinated this event.

**Chile**
GAD was held in Santiago, Chile on August 9, 2014. Representatives from the Patient, Medical, Health Ministry, Academia, Civil Society and Cancer Center communities convened to address the issues most relevant to GIST patients. Three inspiring patient testimonies highlighted these key concerns: access to treatment, quality of treatment and correct and on-time diagnosis.

Mrs. Lea Derios, representative of the Health Ministry stated, “It is not a coincidence that today patients, physicians, psychologists, patient advocacy leaders, representatives of the pharma of the civil society and the media are together in this room. You have done a great job, this is a great opportunity to strengthen our relations to work together.”

Participants contributed to the GAD world record efforts by making origami boats.

**Venezuela**
With the support of Bayer, Venezuela, origami boats continue to be contributed. There have been several radio interviews about GIST, including one on Radio Comunidad about GAD and Alizanza GIST’s activities. They will continue with two family events for origami boat folding, and a workshop for health journalists.

**Other Latin American Events were held in:**
- Bolivia
- Brazil
- Costa Rica
- Colombia
- Guatemala
- Mexico
- Puerto Rico
- Venezuela

**Mumbai, India**
On July 12, Max Foundation and Friends of Max, their support group arm for GISTers and their family members, held the first ever GIST Awareness Day with a special meeting at Tata Memorial Hospital.

Over 40 survivors and their caregivers from in and around Bombay gathered together to share their experiences and to spend quality time with their treating physicians in an informal atmosphere. There was time for open dialogue, which is a big step towards establishing an ongoing support system for patients and their caregivers, and to bring GIST awareness into all areas of patient care.

A special part of the day included the folding of origami boats, and the joy the children express in actually launching them.

**Thanks to everyone’s efforts we have passed our fundraising goal of $200,000!!!**
In order to make GIST awareness a reality on all levels the Life Raft Group joined One Voice Against Cancer’s annual Lobby Day on the Hill on July 7 – 8. OVAC’s coalition is one of the largest and strongest voices in the fight for cancer research, and this year the asks included lobbying for a $5.26 billion cancer research funding package to benefit some of the top GIST research facilities in the world including the NIH and NCI. A very special thank you in particular to LRG member Liz Skree who joined Pete Knox and Mildred Menos on the advocacy trip. Liz is a member of the inaugural NIH in person wild-type clinic and was able to campaign for increased NIH funding from a very passionate and personal place. We were so grateful for the time she took away from her busy career to join us in this venture. In all, we took meetings with Senators Booker and Menendez and Representatives Frelinghuysen and Runyon. They were all extremely positive about the appropriations bill we were championing for increased cancer researching funding for the NCI, NIH and CDC, with three of the four signing on to a letter of support and Senator Booker sending his own individual letter of support in addition. We hope to convert the lessons and training we learned from this year into a GIST-specific lobby day of our own in the future.

Gaining Legislative Support through Congressional Briefings

On July 8, 2014 Life Raft Group joined One Voice Against Cancer (OVAC) in a full day of Congressional briefings in Washington D.C.

The 13 Promises for GIST

Life Raft Group and Bayer developed 13 Promises for GIST to share with policymakers in the nation’s capital in an effort to help expand patient support and advance research and treatment options.

1. Fund GIST research
2. Fund sarcoma research
3. Secure a unique GIST reimbursement code
4. Encourage compassionate use programs
5. Ensure public payer coverage for medications
6. Expand clinical trial enrollment
7. Fund HCP education on sarcomas
8. Ensure adequate sick leave policies
9. Enhance social services for sarcoma patients and families
10. Protect patient job security
11. Ensure paid sick leave for caregivers
12. Encourage speedy regulation processes
13. Incentivize for continued innovation

Resulting in 3 New Jersey representatives signing petitions for 2 calls-to-action:

- National Cancer Institute to dedicate $5.2 billion to GIST research
- Center for Disease Control and Prevention to dedicate $510 million to GIST prevention and screening
GIST Awareness Day kicked off our campaign to break the Guinness Book of World Records for the largest display of origami boats. Each event featured opportunities for folding and personalizing what became the symbol of GIST Awareness Day. At the LA event alone, 22,000 boats were displayed. As we continue to raise awareness about GIST, we continue to encourage the folding of boats, which will be displayed at Life Fest 2014, November 7 – 9 in New Jersey.

Go to liferaftgroup.org/gist-awareness-day/gallery/ to view more photos.
Generating Public Awareness of GIST Around the World

National spokespeople Dr. Jonathan Trent and Mo Collins conducted interviews with radio stations across the country raising awareness about GIST.

The LRG has announced GIST Awareness Day on July 13 in an effort to allow those faced with GIST... to stand tall together in support and solidarity. Their goal is to make and display 20,000 origami boats and raise $200,000 for GIST research. LRG is teaming up this year with Bayer HealthCare (based in Whippany) on GIST Awareness Day activities this year.

13 airings reaching 11,660,607 listeners

Flagship Events in 3 Markets

MIAMI
WTVJ-TV (NBC) segment featured GIST patient Carolina Williams and Dr. Jonathan Trent

CHICAGO
WFLD-TV (FOX) reported on event and featured footage of origami boats and booth onsite

LOS ANGELES
KVTA-FM segment featured Dr. Jonathan Trent and actress, comedian and GIST patient Mo Collins, promoting event
Spreading GIST Awareness through Social Media Channels

More than 265 tweets* issued
reaching 2,445,558 followers

*Inclusive of ReTweets

55 Facebook posts
602 Total Likes
A Special Thank You to All Who Made GIST Awareness Day Possible

NATIONAL SPONSORS

Cohn & Wolfe

LOS ANGELES
Mo Collins
Hula Dancers: Ka Pa Hula O Keahialaka: Led by Lehua Riveira with Jacqueline Kim, Theresa Lu and Ruth Kelsey
Melissa Faye Klein and Joe Lawrence
Photographers: Keith Lent, Isabella Bolognese
Origami Artists: Atsuko Fukunaga, Sharon Kato
GirlScout Troop 4345
The Awesome Helpers from Lincoln Elementary School
Face painting: Karen Lent & Mary Varieur
Nautical Knot Making: David Thomas, Pacific Sailing
Hona-Gami, Gardena, Honami Uchiyama, Jewelry
Julio Granados, artist
Rolling Robots
Starbucks
Cheesecake Factory
UCLA Health
UCSD
Hostaria Piave Restaurant, Redondo Beach: Angelo Calderon, Owner
Trax, Mary Cleveland, hair stylist, Riviera Village
Roberto Monroy Hair Studio, Roberto and Ingrid, Riviera Village

CHICAGO
PJ Weber
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Starbucks
Vanille Patisserie
Fred Chamanara
Santiago
Sahara Henna Designs
The Space/Movement Project
We Band Together
Chicago Yacht Club
Adam Grabowski
Tourbound Golf Academy
Nowrthwestern University
Wrigley
Barbara Cleveland, Cook County Hospital

MIAMI
Brazilian Voices
Sylvester Comprehensive Cancer Center
Miami Heat Dancers
Walgreens
LoveJOYoga Therapy
Serenity Therapeutics
Jose Tovar Sound Engineers
Educating Hands School of Massage
Senior Home Care
Donald Edgar Photography

A special “Thank You” goes out to all our members who work so tirelessly year-round to generate awareness about GIST. In particular, kudos to those who helped arrange GAD events across the globe, including:

Dina Wiley, Jim and Margi Hughes, Lee Kenworthy, Teena Petersohn, Pat Bonda-Swenson, Piga Fernandez and all those at Alianza GIST, The Max Foundation and Friends of Max, Eileen Glasser and all the children and children-at-heart across the globe who continue folding boats for us.