

Special Bulletin

August/September 2014 - Vol. 15, Issue 4



GIST AWARENESS DAY

Ensuring no one has to face GIST alone



In Loving Memory: Lane Barton, Earle Heath, Donald Samuelson, Raul Ramirez, Harry Smith, Louise Ladd,
Michael Byrne, & David Safford

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.



Young Hula Dancers Captivate the Crowd in LA

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.



Fun for All at the Chicago 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.



Miami Heat Dancers Support GAD

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



Long Island GAD Lunch

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



Chile volunteers gather for GAD event.

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 Alianza 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



First GAD in Mumbai

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!!!**

LRG staff heads to DC to kick off GAD

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 **polymakers** 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

Photos from GAD events around the world

90,000 origami boats ...and counting



...setting the stage to shatter the standing world record for the largest display of origami boats in history!



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

Life Raft Group founders featured in local New Jersey newspaper



Norman and Anita Scherzer

"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.

NorthJersey.com
NO. 1 IN BREAKING LOCAL NEWS

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


TWEETS 1,338PHOTOS/VIDEOSFOLLOWINGFOLLOWERS

**themocollins** @THEMOCOLLINS · Jul 13
7/13 GIST Cancer Awareness Day! Join us today in LA, Chicago & Miami for events! GistAwarenessDay.org @SU2C @Liferaftgroup #CureNeeded


**The Life Raft Group** @Liferaftgroup · Jul 10
July 13, 2014: It's time for GIST to get its day #GISTAwarenessDay
Expand

**CancerCare** @CancerCare · Jul 9
We are proud to be a part of GIST Awareness Day on 7/13! Join our #GIST webcast: aw.ly/yUVNZ
Expand

**Sylvester** @SylvesterCancer · Jul 9
GIST Awareness Day 2014 -- Dr. Trent from Sylvester Comprehensive Cancer Center discusses Gastrointestinal... fb.me/71Acehzvt
Expand

**Lurie Cancer Center** @LurieCancer · Jul 8
Join @Liferaftgroup 7/13: #GIST day of free food, fun and learning liferaftgroup.org/events/gist-aw... Dr Bilimoria to speak re: the surgeon's role. Chicago, IL
Expand

facebook

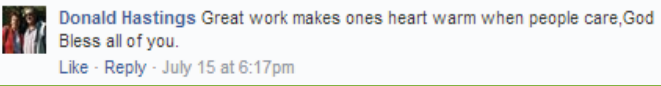



The Life Raft Group July 14 · ph

We're still trying to break the world record for the most origami boats. Over 3500 boats were made at #GISTAwarenessDay <http://bit.ly/1BLL46>

The LA #GISTAwarenessDay event was a huge success. Check out some photos in the gallery <http://bit.ly/1c8V8e6>

Like · Comment · Share



 **Donald Hastings** Great work makes ones heart warm when people care,God Bless all of you.
Like · Reply · July 15 at 6:17pm

Email or PhonePassword

☐ Keep me logged inForgot your password?

Log In

Create Page

Recent

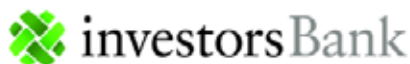
2014

2013

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
 Gilda's Club
 Starbucks
 Vanille Patisserie
 Fred Chamanara
 Santiago
 Sahara Henna Designs
 The Space/Movement Project
 We Band Together
 Chicago Yacht Club
 Adam Grabowski
 Tourbound Golf Academy
 Northwestern 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.