



LOCAL TOOLKIT

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ABOUT GIST AWARENESS DAY

GIST Awareness Day (GAD) was created by the Life Raft Group to help bring attention to a very important and often misdiagnosed disease called GIST (gastrointestinal stromal tumors). GIST is a rare cancer of the gastro-intestinal tract that affects 5,000 new people in the US alone every year. Last summer the LRG launched its successful Rare 13 campaign to highlight the many faces of GIST and draw attention to the fact that 13 people are diagnosed with GIST every day. The overarching objectives of both the Rare 13 campaign and GIST Awareness Day are to bring enough attention to the disease that having heard of GIST won't be considered "rare" either. Even with all these efforts, there is still a huge lack of education that exists and more work that needs to be done.

More information about GIST Awareness Day, the "13 Promises" advocacy campaign and how to help can be found in the GIST Awareness Day Overview Fact Sheet in the appendix.

WHO ARE WE TRYING TO REACH?

GIST Awareness Day was created to help bring attention to an important and often misdiagnosed disease known as GIST (gastrointestinal stromal tumors). The people we are trying to reach are as follows:

- GIST patients and their loved ones
- The general public and media
- Politicians, policy-maker, public authorities



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- Health professionals and hospitals

GENERAL AWARENESS

GIST Awareness Day's main focus is to open the public's eyes about GIST, its importance and the stigma attached to rare diseases. The Life Raft Group took this mission on when it launched the Rare 13 campaign in summer 2013 and took to the streets to engage the public and raise awareness.

ADVOCACY/13 PROMISES

During Sarcoma Awareness month, we plan to rally like-minded advocacy groups and concerned GIST supporters to make an impact on the Hill by launching, with a presenting sponsorship from Bayer Pharmaceuticals, the "13 Promises" campaign, a national advocacy effort to bring the needs of GIST patients directly to top Washington DC policymakers.

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

WHAT IS HAPPENING DURING GIST AWARENESS DAY?

Our awareness goal is to make and display 20,000 origami boats and raise \$200,000 for GIST research! And we need your help to get there.

On July 13th, 2014 the LRG will hold three major GIST Awareness Day events in cities across the United States: Chicago, IL, Los Angeles, CA and Miami, FL. We are also holding virtual events all over the world, with individuals holding their own events to raise awareness for GIST.

CHICAGO GIST AWARENESS DAY: The Peggy Notebaert Nature Museum

LOS ANGELES GIST AWARENESS DAY: Stay tuned for more info



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MIAMI GIST AWARENESS DAY: Sylvester Comprehensive Cancer Center

HOW YOU CAN HELP

We would love to have as many attendees as possible at our key GIST Awareness Day locations on the day; however, we realize that for some this may not be possible. To give everyone an opportunity to participate and help raise awareness for GIST, we created a list of activity ideas for supporting the cause on July 13th, 2014.

1. **HELP US BREAK A GUINNESS WORLD RECORD!**

We've come up with a fun, unique way to raise awareness for GIST by trying to break the Guinness World Record for largest display of origami boats and we need everyone's help! Check out our origami instructions for easy directions, ways to personalize your boats and ideas for creating your own origami folding team! Make your contribution to the 20,000 boats to help break the record.

2. **JOIN FUNDRAISING EFFORTS TO HELP US FIND A CURE FOR GIST**

Our goal is to raise \$200,000 for GIST research on GIST AWARENESS DAY. The more awareness we can build and funds we can raise for GIST, the faster we can find new treatments and a cure. You can make a donation towards this goal or, start a fundraising team of your own. Are you a business owner? Sponsor or donate to one of our flagship events.

3. **BRING FRIENDS AND FAMILY TO A GIST AWARENESS DAY EVENT OR HOST ONE OF YOUR OWN!**

Register to attend one of our flagship events in Chicago, Los Angeles or Miami. Spread the word and encourage friends and family to attend as well! Not in one of these cities? You can join our Virtual Event on July 13 on your own or Plan a BBQ, brunch or get together to celebrate with friends and family!

4. **BE PROACTIVE! EDUCATE GOVERNMENT OFFICIALS, LOCAL DOCTORS AND MEDICAL CENTERS ABOUT GIST!**

There are a number of different ways to bring the needs of the GIST community to your local government officials and medical centers. Request that your city and/or state declare July 13th GIST Awareness Day. You can also write letters to local policymakers about the "13 Promises" or bring GIST information to local oncologists and medical centers.

5. **BE A GIST AWARENESS MAVEN!**

Whether you plan to attend GIST Awareness Day, host your own party, fold boats or make a donation, say it loud & proud by using your social media profiles to let the world know what you are doing to support the GIST community and raise awareness for a rare disease. Use the hashtags #GISTAwarenessDay or #GISTKeepFolding on Facebook, Twitter, Instagram or Pinterest to support the cause and enter fun contests! Submitted photos and videos will be used to compose a Virtual Quilt which will be displayed at GIST Awareness Day flagship events and can be seen in our Gallery.



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CAMPAIGN MATERIALS

Available to you in the appendix of this toolkit are several tools that can be helpful to you as you plan your awareness activity. These tools can also be easily downloaded from the “Downloads” section of the GIST Awareness Day website: <http://www.gistawarenessday.org>

LOGO

Logos are an important part of any campaign, and play a vital role in making sure the message is being spread. The GIST Awareness Day logo is unique in that it combines all of the LRG’s GIST awareness campaigns into one. The paper boat motif (a central component of GIST Awareness Day) is displayed, and the number “13” (a reference to the RARE13 campaign, <http://therare13.com/>) has been integrated into the word ‘awareness’. The logo is also printed using the organization’s theme colors to ensure uniformity. Please use this logo in all communications regarding GIST Awareness Day (i.e. stickers, t-shirts, flyers, etc.). DO NOT change colors or proportions, and refrain from inappropriate use of the logo.

OVERVIEW FACT SHEET

This fact sheet is very helpful for informing people about GAD and its various components. While a postcard (below) may be easier to inform people of the event, the Fact Sheet offers a little extra information that would be useful for approaching sponsors, hospitals, and the media.

SAVE THE DATE POSTCARD

Prior to July 13th, this postcard-sized announcement can be distributed as a reminder (or and invite) to attend an event that you are organizing, or simply a general reminder of the day and its purpose.

SPONSORSHIP & DONATION FORM

Events like this are not possible without the support of corporations and businesses. This form, coupled with other informative materials like the GAD Overview Fact Sheet, can help you reach out for donations of food, drink, entertainment and of course funds, in order to make your own hosted GAD event a fundraising success!

FLYER

This flyer will highlight the main components of the GIST Awareness Day, and can be distributed, or posted wherever possible. You can also use it as template to create your own flyer. This will be helpful if you are holding an event with non-English speakers.

ORIGAMI INSTRUCTIONS

To help us reach our goal and break the Guinness World Record for a paper boat display (20,000), easy-



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to-follow, step by step instructions on how to make a paper boat is also made available to you on our website. These boats can be made using regular orange, blue or white 8 ½ by 11 inch printer paper.

ONLINE RESOURCES

Website

The GIST Awareness Day website is www.gistawarenessday.org and this is how it is listed in our GAD messaging. However, www.gistawarenessday.com will “autodirect” to the same page which will help drive traffic to the site and ensure that a typo in the URL will still lead to the correct place. When posting about GIST Awareness Day on other sites, please be sure to refer to, and include a link to this website as the official GIST Awareness Day site using the correct address: .org.

Social Media

One of the best ways to increase awareness for GIST is to utilize social media. Hashtags (Whether you love them or hate them!) are great for spreading the word about a single issue or event, not just on Twitter, but also Facebook and Instagram. For GIST Awareness Day, we are using two hashtags, #GISTAwarenessDay and #GISTKeepFolding (This hashtag can be really helpful for encouraging others to help us toward our goal of breaking a World Record for Largest Display of Origami boats). Our various social media sites are as follows:

Facebook - www.facebook.com/liferaftgroup

Twitter – Follow @liferaftgroup

Instagram - www.instagram.com/liferaftgroup

Pinterest – www.pinterest.com/liferaftgroup

Youtube – youtube.com/liferaftgroup

Use these social media outlets to invite your family and friends to join you in raising awareness for GIST. The more people who join, the more effective we will be at raising awareness for GIST!

Video Quilt

Film a short video or Vine of your origami skills or any other way you and your friends are working to get the word out about GIST for inclusion in the GIST Awareness Day film that will play at our national events around the country.

THIS TOOLKIT

This tool kit is a guide to help you raise awareness on the July 13th, 2014 GIST Awareness Day, and make it easier for you to organize your own communication around the day.

For more information on how you can help, or to share the details of your awareness campaign, media coverage and photos from your GIST Awareness day email Mildred Menos at mmenos@liferaftgroup.org