

## WHAT IS GIST AWARENESS DAY? WHY IS IT IMPORTANT?

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.

GIST Awareness Day will not only be an extension of our Rare 13 campaign, but because it falls during the month of July—Sarcoma Awareness Month—it serves the dual purpose of also helping raise awareness of sarcomas as well, of which GIST is the most common type. On July 13 we will stand together in support and solidarity and raise awareness about this "rare" cancer among the general population.

However, GIST awareness should not be limited to July 13 alone. To that end, the Life Raft Group, in conjunction with Bayer Pharmaceuticals, have launched its"13 Promises" campaign, a national advocacy effort to bring the needs of GIST patients directly to top Washington DC policymakers.

## **HOW CAN I PARTICIPATE?**

## 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 a donation to help us spread greater awareness and cure GIST!

The more awareness we can build for GIST the more programs and research funding we can provide to the GIST community. Are you a business owner? Sponsor or donate to one of our flagship events. You can make donations, start a fundraising team of your own, or learn more about other support options at gistawarenessday.org.

# Bring friends and family to GIST Awareness Day!

One of the best ways to help us raise awareness is bringing your loved ones to a GAD event (or host your own!) so they can learn more about GIST and its importance.

## Be proactive! Let your local government know!

There are a number of different ways to bring the needs of the GIST community to your local government

officials. Request that your city and/or state declare July 13 GIST Awareness Day. You can also write letters to local policymakers about the "13 Promises". You can find templates for all of these letters in our Download Center at gistawarenessday.org.

#### Be a GIST Awareness Maven!

Whether you plan to attend GAD, 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. Just use the hashtag #GISTAwarenessDay or #GISTkeepfolding on Facebook, Twitter, Instagram or Pinterest to support the cause and enter fun contests!

#### **WHAT HAPPENS ON JULY 13?**

GIST Awareness day promises to be an afternoon of fun and even a little learning to raise awareness about GIST and give a stronger voice to the GIST community. Weekend events will be held in Miami, Los Angeles and Chicago with a festival atmosphere featuring games and treats for the whole family. Each location will support local vendors and will have its own unique flair. The main attraction will be a group effort to break the Guinness World Record for the largest display of origami boats coupled with contests and prizes. Local and international GIST groups will also hold mini-events to create worldwide GIST solidarity.

#### WHAT IS GIST?

GISTs – or gastrointestinal stromal tumors – are sarcomas and originate in the soft connective or supportive tissues that surround other body organs and structures. GISTS derive from a specific type of connective tissue called stromal tissue and can be found in bones, muscles, fat, nerves, blood vessels and cartilage.

In the gastrointestinal track, most GISTs arise from the stomach, but can be found in the small intestine, colon, rectum and esophagus.

Early in the disease there are usually no symptoms and symptoms that appear can be associated easily with other illnesses, like IBS or anemia. This can make diagnosis a difficult slow process, which further illustrates the need for awareness—especially in the medical community.

GIST Awareness Day and the Rare 13 campaign—an awareness initiative launched in August 2013 and seeking to take the rare stigma out of a rare cancer—are driven by the Life Raft Group, a non-profit organization with a simple focus: to cure a form of cancer – GIST (gastrointestinal stromal tumors) – and to help those living with it until then. Our mission is to ensure the survival of GIST patients through a comprehensive approach connecting individual patients' needs, the worldwide community of GIST advocates and the global health and research environment. To achieve this, we focus on three key areas: Patient Support & Education, Advocacy and Research.