

Special Edition • August



GIST **AWARENESS** DAY
2019



**GIST
AWARENESS
DAY**

AROUND THE WORLD

GAD July 13th, 2019

GIST Awareness Day, begun in 2014 by The Life Raft Group, is celebrated on July 13th every year. This unique commemoration was created to raise awareness about this rare cancer globally. Our partners around the world continued with the GIST DO IT theme of 2018 and marked the day with educational seminars, patient support group meetings, and luncheons. Not all events were held on July 13th but all met in the spirit of hope and the bond shared by GISTers, family, caregivers, researchers, and advocacy organizations.

Chile



This year we started the GAD 2019 campaign on July 6th on social media to raise awareness and create expectations prior to our July 13th meeting.

Patients, families and friends sent us pictures with a message to complete the sentence: "Collaborating and working together let's make possible..." We mounted the pictures on the frame designed for the campaign and published them on Facebook, Instagram and Twitter.



The initiative had a great acceptance and we have received almost 80 pictures that we will keep on publishing until August 10th, when we will end the campaign on the 5th Anniversary of Fundación GIST Chile.



FUNDACIÓN
GIST Chile
Cánceres Gastrointestinales

We took advantage of the campaign to support our ongoing efforts in Chile advocating for a National Cancer Law that will protect all cancer patients.

On July 13th, we had our monthly meeting with patients, caregivers and friends. Together with Andrea Fernández, psychologist, we had an opportunity to share each person's joys and worries, share information of the Ley Ricarte Soto (which is the law that will cover imatinib and sunitinib for unresectable and/or metastatic GISTs), and also to discuss the urgency for a National Cancer Law to cover the unmet needs of all cancer patients.



We had as a featured speaker, Magdalena Vergara, a psychologist with experience in "Mindfulness," from whom we learned about a meditation and relaxation technique that can help one have a better quality of life by being aware of "the here and the now". We were taught simple exercises that help us to connect with our inner selves and with our emotions. It was a great and inspiring meeting!

Fundación GIST Chile: <https://gist.cl/>

Colombia

Patients and relatives from Bogota met at the SIMMON foundation with the purpose of celebrating the GISTer's party: "GIST Awareness Day". The celebration was not complete as our partners from other cities were missing, who were accompanying us from the heart and from here we extended our friendship to them.

We engaged in great discussions, including reminiscing about GIST Awareness Day. The most remembered campaigns were when in 2014 we set out to make paper boats with messages from patients with the goal of breaking the "Guinness World Record" of origami boats - we never knew if we achieved it because it was impossible to send the amount of paper boats that came to us from all over the country. Or in 2016 when we asked everyone to think what had been the best gift that time had given them. And the 2017 campaign: "Be a H.E.R.O. for Cancer", where the foundations of Latin America countries made a video with the messages sent by the patients. Today we see that video and we cannot avoid tears. Finally, we gave the value to this and the past year we have done: "GIST DO IT", identifying all the changes that we want to see for patients, doctors, research, health systems, and countries.

Leaving aside the nostalgia, we went on to talk about the alliance made with the SIMMON Cancer Foundation, an entity that will formally take charge of the GIST patient care, leaving the GIST Colombia Foundation with the work of education and advocacy.

Finally, we talked about the "Salud con Datos" project and the need to have data that help support research. Patients are aware of the importance of this data and offer to start the process with their own data, thus providing



the initial seed of what will be the Colombian database, as well as leaving records with their respective oncologists, encouraging them to reach out to their patients and ask them to contribute to these records.

We said goodbye with the promise of meeting more often and to realize, in the near future the dream of many patients, such as having a national meeting of GIST patients.

From this, our homeland, we send a fraternal greeting to all the GISTers of the world, who in each of their countries, today have a meeting, showing the world that we are not rare, that, despite being a rare disease, if it is diagnosed on time and it is treated properly, stops being a deadly disease to become a chronic disease.

Fundación GIST Colombia:
<http://fundaciongistcolombia.org/>

Fundación SIMMON:
<https://www.simmoncancer.org/>



Spain

Colectivo GIST España, also a member of Alianza GIST, published on their social networks the history of how GIST Awareness Day was born and its purpose. In one post they say: "We want it to be like the annual summit of our educational efforts, awareness and defense efforts, and it gives those outside the GIST community the opportunity to learn and lend their support to this important cause." GIST DO IT.

GIST DO IT is focused on equity in the treatment of all patients:

- Equity for quick and correct diagnoses



- Equity to receive the necessary treatments
- Equity for access to reference centers
- Equity for access to the arsenal of all available drugs
- Equity for access to clinical trials

The work being carried out by the Spanish sarcoma research group, GEIS and the Spanish society of pathological anatomy, SEAP IAP, is leading the project that aims to improve the diagnosis and treatment of

sarcoma and to improve the quality of life of the patients. The project presents the alert criteria in primary care, criteria to send the patient to a reference center and the impact of the network of pathologists as a solution to current problems.

Colectivo GIST:
<https://colectivogist.wordpress.com/>





Academic Sessions

An academic session to train physicians was held at IMSS in Family Medicine Unit 31, located in Mexico City. Two more sessions were also held on July 24th in the General Hospital No. 13 of Matamoros, and July 31th at IMSS in the Family Medicine Unit 67 of Ciudad Victoria, Tamaulipas.

GIST Day of Learning

A day of learning about GIST was held in Monterrey on July 12th, where there was the presence of a Surgical Oncologist, a Psychologist and a Social Worker to answer questions from 15 patients and caregivers. On July 16th, a meeting was held to commemorate GAD in Mexico City.



Incidence in Public Policy

Three Local Deputies of different parties that are in the Health Commission of the Local Congress sent videos which were shared on social networks with messages to our community of patients.

Fundación GIST México: <http://fundaciongist.org/>

Brazil

The Oncoguia Institute, a member of Alianza GIST, created a presence on social networks to celebrate GIST Awareness Day. Oncologist Tulio Pfifer, of the Syrian Lebanese hospital, was interviewed about this rare type of cancer.

The Institute also reminded their patients that on their website they have a complete manual that explains GIST and its diagnosis. In another post they published the life story of one of their patients.



The Institute's website is:
<http://www.oncoguia.org.br/cancer-home/tumor-gastrointestinal-gist/52/171/>



Other countries

Argentina, Guatemala, Honduras, and Peru were very active in social networks contributing to the dissemination of the GIST Awareness Day faithful to the objectives of dissemination and awareness of GIST in the population of each one of their countries. The replication of campaigns carried out worldwide achieves the desired multiplying effect.

Peru - Esperantra: <http://www.esperantra.org>

On Facebook:

Argentina: @GistArgentina

Honduras: @gsthonduras

Guatemala: @ASOPALEU





"We had a successful GIST World Awareness Day on 20th July 2019 where we invited an Oncologist, a Nutritionist, a Pharmacist, and a Physiotherapist.

They all made their presentations using our National language "Kiswahili" for all our patients and caregivers to understand.

The patients had time to share their journeys with GIST and to encourage one another".

Henzo Kenya: <https://www.henzokenya.or.ke/>

Faces from the United States

New York

GISTER Pat Bonda-Swenson organizes a yearly luncheon at Bethpage State Park in Farmingdale, NY to mark GIST Awareness Day.



LRG Calendar



For more information

<https://liferftgroup.org/event/lifest2020/>



For more information

<https://liferftgroup.org/event/gist-day-of-learning-ottawa/>

Thank you to our Major Donors for May, June, & July

Carlos Baldor

Iris Berke

Blueprint Medicines

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Helen Fray

Gerald Knapp

Novartis Pharmaceuticals Corp.

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ALL YEAR LONG

GIST Awareness Day is an amazing way to educate the medical community and general public about GIST. But it is a once-a-year effort. Our theme of "GIST DO IT" encourages our members and friends to be proactive.

We would like to take it to the next level and encourage everyone to "GIST DO IT All Year Long."

How to keep the momentum going? Below are some suggestions.

No matter what you do, have fun! #GISTDOIT

WALK	Organize a GIST DO IT Walk. We are happy to help! Email dnieves@lifteraftgroup.org .
SHARE	Share your story. Offer to speak at a local cancer center or event. Send your story to a local newspaper. Make a short video (no more than two minutes) where you talk about what having GIST has meant in your life. Send them to us (mgarland@lifteraftgroup.org or dnieves@lifteraftgroup.org) so we can use them as part of an awareness campaign on social media.
ADVOCATE	Contact your local and national legislators to encourage them to support funding for cancer research. Find your reps: https://www.usa.gov/elected-officials
DISTRIBUTE	Distribute information about GIST to local doctors and medical institutions. You can download PDFs of useful info: https://lifteraftgroup.org/library/
CELEBRATE	Create a birthday fundraiser on social media.
VOLUNTEER	Become a state leader or GIST Peer - https://lifteraftgroup.org/lrg-gist-peer/
HOST	Host a local meeting. Contact your LRG state or country leader to ask how you can help. Don't know your state or country rep? Look them up here: https://lifteraftgroup.org/find-a-support-group/
POST	Share information about GIST on social media. #GISTDOIT #lifteraftgroup. Our website is a great resource. GIST Education: https://lifteraftgroup.org/powered/
SHOW	Show the world how resilient GIST patients are. Have someone take photos of you as you GIST DO IT - hiking, kayaking, playing with your grandchildren. Send them to us or post on social media. #GISTDOIT #lifteraftgroup
ACT	Become a Patient Researcher by filling out our surveys, joining The LRG Patient Registry (see https://lifteraftgroup.org/patient-registry) and/or joining our side effects management platform SideEQ (mysideeq.org).
PRACTICE	Self-care is an important part of living well with GIST as a patient or caregiver. Before you give to others make sure your needs are taken care of.

If you have any photos, stories or original ideas to, please email: mgarland@lifteraftgroup.org.

Enrich the LRG Community with YOUR gifts & talents...GIST VOLUNTEER!

LRG volunteers are a tremendous resource for our organization. Our volunteers diversify and expand our skill sets and allow us the opportunity to better serve our GIST community. They help us reach more patients, caregivers, medical professionals and others. LRG volunteers not only expand our reach and services to patients and caregivers but also help us increase GIST awareness to the general public and funding towards GIST research.

Our volunteers are at the heart of everything the we do, and they serve as a strong representation of who we are in the GIST community. Whether they are State Leaders, GIST Peers, Focus Group or Fundraising Committee Members, our LRG volunteers bring to our team a wealth of knowledge and skills plus an abundance of energy and enthusiasm. We currently have over **160** volunteers in our GIST community who help support thousands of GISTers and their caregivers. *If you are interested in becoming a volunteer, the LRG is currently recruiting for the following positions: Science Writer, Wordpress Web Expert, and State Leaders and more.*

HOW

WE SERVE THE
GIST COMMUNITY

WHO?

PEOPLE LIKE YOU
ACROSS THE
WORLD



PLUS

DOZENS OF VOLUNTEERS THAT PRESENT
AT GDOLS, LIFE FEST, AND PRODUCE
WEBCASTS FOR THE GIST COMMUNITY.

CAN I SERVE?

CONTACT US AT LIFERAFTGROUP@LIFERAFTGROUP.ORG
VISIT [HTTPS://LIFERAFTGROUP.ORG/VOLUNTEER/](https://LIFERAFTGROUP.ORG/VOLUNTEER/)

The Life Raft Group Global Community

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Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director,
 Outreach & Engagement - dnieves@lifteraftgroup.org

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior Vice President
locchiuzzi@lifteraftgroup.org

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