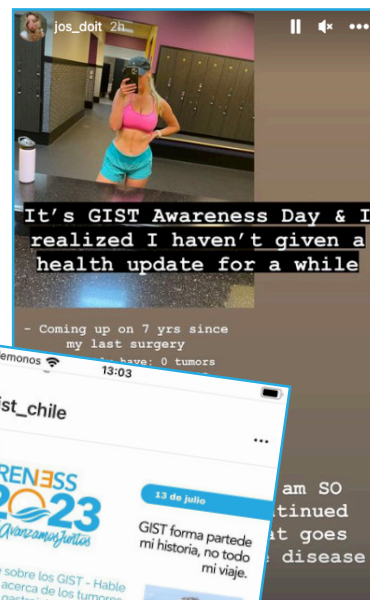




Enhancing survival and quality of life for people living with GIST

AUGUST 2023 • GIST AWARENESS DAY • FUELING GIST RESEARCH • LIFE FEST 2024

GIST
AWARENESS
DAY 2023
#thrivingtogether



July 13th was GIST Awareness Day and thousands of patients, caregivers, and medical professionals shared posts that honored the day and brought awareness to this rare disease. You can read more about GIST Awareness Day and how you can be involved in raising GIST awareness all year long.

<https://liferaftgroup.org/about-gist-awareness-day/>

In Loving Memory: Timothy Watkins, Elena Smirnova, Usha Gite, Kenneth Ullery, Nishi Ranjan Talukdar, Michael Wajnowski, Eric Biegansky

GIST AWARENESS DAY 2023

#thrivingtogether

Larry Luxner is in Tel Aviv, Israel.

July 13 is GIST Awareness Day. To mark the occasion, my story in today's *Rare Disease Advisor* focuses on gastrointestinal stromal tumor, or #GIST—a very rare disease in urgent need of a cure. [The Life Raft Group](#) #GISTAwareness



RARE DISEASE ADVISOR.COM
Life Raft Group Marks GIST Awareness Day With a Webinar on a Recent Rash of Research

Blueprint Medicines @BlueprintMeds · 3m

Join us today to honor Gastrointestinal Stromal Tumors (GIST) Awareness Day. GIST is a rare cancer of the digestive tract; it's important to increase education of this disease and advocate for timely diagnoses, mutational testing and ongoing research. #GISTAwarenessDay2023



National Cancer Survivors Day

Today is #GISTAwarenessDay!

To learn more about this rare sarcoma, head to [LifeRaftGroup.org](#) or [The Life Raft Group](#) #GISTAwarenessDay2023 #ThrivingTogether #Sarcoma #GIST2023

Kenyan Network of Cancer Organizations - KENCO

July 13 is a day to spread awareness about Gastrointestinal Stromal Tumors (GIST). GIST is a rare type of sarcoma cancer that starts in the digestive tract. Most GISTs begin in the stomach, but they can also be found in other parts of the digestive system. They are very rarely found in the rectum. #gistawarenessday2023 #ThrivingTogether #sarcoma @TheLifeRaftGroup



Follow us:
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July, 13th

MESA DE DIÁLOGO

TE INVITAMOS A NUESTRA:
MESA DE DIÁLOGO

#AvanzamosJuntos por la Atención a los Pacientes con GIST en Latinoamérica

CHRISTIE EVANS The Life Raft Group EL PASO, TEXAS	MARTÍN MUÑOZ Fundación GIST CHILE
JARRO REICHERT Fundación GIST Colombia	BERENICE CARRILAL Fundación GIST México
COORDINADORA DEL EVENTO FIDIA FERNÁNDEZ	

FECHA: 12 DE JULIO 2023
MÉXICO - 17:00 HRS
EE. UU. - 19:00 HRS
CHILE - 18:00 HRS
COLOMBIA - 18:00 HRS
ARGENTINA - 20:00 HRS

EN PLATAFORMA ZOOM

#AvanzamosJuntos

Cogent Biosciences @CogentBio · 26m

Cogent was honored to have Dr. David Josephy, PhD, President, GIST Sarcoma Life Raft Group join us to recognize #GISTAwarenessDay2023! We are proud to sport our GIST Busters T-shirts and help raise awareness of this rare cancer. #ThrivingTogether #sarcoma @Liferaftgroup



GIST Chile

LIVE: #AvanzamosJuntos Why is it important to work together? July 13 at 7:30 pm on Instagram @gist_chile
#live #AvanzamosJuntos #GISTChile #GIST
See original · Rate this translation

13 de Julio

LIVE @gist_chile

19:30 horas

¿Por qué es importante trabajar juntos?
CONVERSATORIO:
La importancia de la red de apoyo al paciente.

PARTICIPAN:

- Dr. Directo
- Pige Presid
- Silv. Cuitac
- San Pacien

Fundación GIST

As part of the Commemoration of #GISTAwarenessDay2023 we present the patient Fernando Valencia, who shares a photograph of the people who drive him to continue #AvanzamosJuntos

#SarcomaAwarenessMonth #AvanzamosJuntos #MesDelSarcoma #gist #gistawarenessday2023 #ThrivingTogether #sarcoma

See original · Rate this translation

Sandra Welter

Today on the 13th JULY is GIST awareness day! Spread awareness about GIST - Tell someone about Gastrointestinal Stromatunors today. = YESTERDAY About 5,000 people a year are diagnosed with this rare disease and some subgroups receive no treatment after surgery. Mutation tests after a GIST diagnosis are crucial in choosing an effective treatment pathway. All GIST patients should be subjected to a mutation test as soon as possible after diagnosis... See more
See original · Rate this translation



JULY 13

me tell you about gastrointestinal stromal tumor.

Stupid Strong Charitable Foundation

Today, we come together to recognize and support GIST Awareness Day, an essential initiative by the @LifeRaftGroup to raise awareness about Gastrointestinal Stromal Tumors (GIST). This rare cancer affects t ...see more



Approximately

5,000 people

diagnosed with a
stinal Stromal Tumor.

July 13

Fernando Valencia



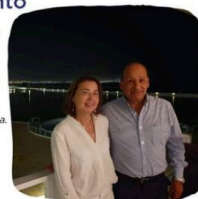
Les comparto a 2 fuentes de bendición y fortaleza que me han permitido enfrentar y salir adelante en este desafío que curso:
1. Mi Fé, Esperanza y Confianza en Dios, quien es Bueno, Fiel y para siempre es su Misericordia.
2. Mi familia, cuyo acompañamiento y Amor han sido invaluable para mí y por supuesto un reconocimiento especial para su Fundación que se ocupa de nosotros. ¡¡¡Gracias!!!!

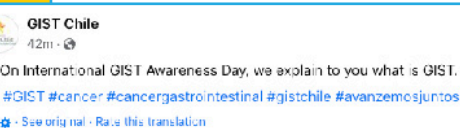
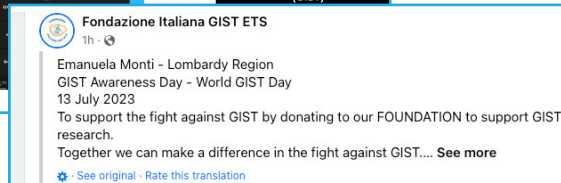
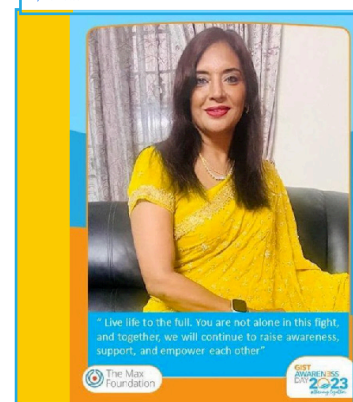
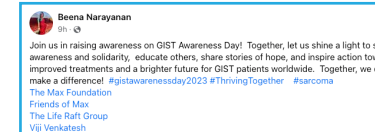
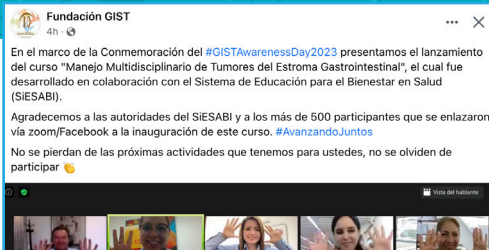
#AvanzamosJuntos

13 de Julio

#AvanzamosJuntos

"Avanzar junto a mi familia, me hace el camino más fácil".
Gloria Yudis Pareja.





August 1st, 2023

Sara Rothschild
Executive Director, The Life Raft Group
155 US Highway 46, Suite 202
Wayne NJ, 07470

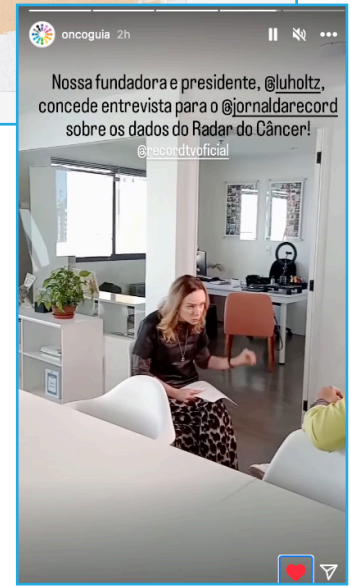
Dear Sara,

Every year, in solidarity with the patient advocacy community Deciphera looks for new, fun ways to engage our employees in raising awareness and support for GIST awareness Day and Sarcoma Awareness month. This year we had an internal virtual bingo game/fundraiser where employees purchased bingo cards and collected personal donations to help support the incredible work you do to support GIST patients.

Everyone at Deciphera is committed to working together to support and improve the lives of GIST patient and their families!

Sincerely,

Stephanie E. Bryant MPH
Senior Director, Patient Advocacy & E



FUELING GIST RESEARCH

Our community in action!

Our spring fundraising campaign was focused on Fueling GIST Research and we shared examples of all the ways The Life Raft Group is involved in GIST research and accelerating

outcomes that affect patient survival and how our community is helping us move forward & raise funds to do so. We committed to raising \$25K for this campaign. We showed how partnerships with other patient advocacy organizations advance GIST survival & empowers patients. Through advocacy, collaborations, patient support, international networking, and research initiatives, The Life Raft Group is a key player in actively addressing access challenges and making a positive impact on the lives of GIST patients.

Cultivating partnerships was highlighted in our feature on ASCO 2023, showing how relationships with medical institutions and pharmaceutical companies advance research and drive clinical trials. We visited with researcher Dr. César Serrano who shared about the importance of GIST research & collaboration among institutions to build a vision of new treatments & a cure. The LRG's Data Management & Research team shared on their curation and maintenance of the largest GIST Patient Registry in the world, emphasizing the power of your data to influence research.

On July 13th, we wrapped up the campaign on GIST Awareness Day with a webinar by Drs. Bulusu, Glod, and Sicklick who presented on GIST treatment updates and took questions from our community. Over 100 people attended this informative webinar.

You can read all these highlights & view the videos via this link:

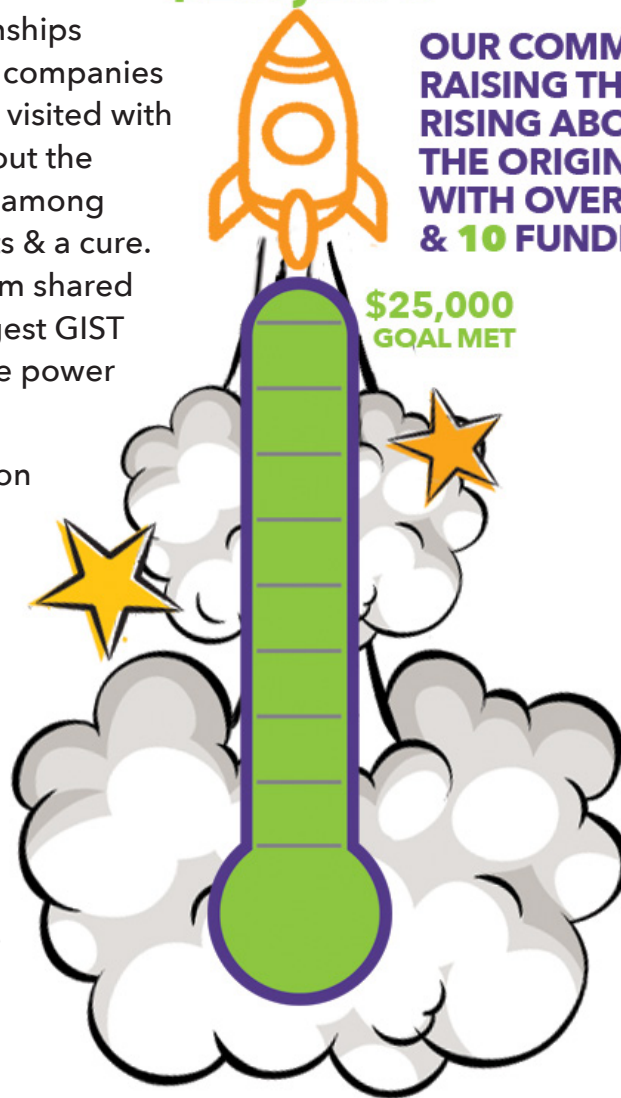
bit.ly/FuelingGISTRecap

We are grateful for our community's involvement in this campaign and encourage you to keep donating and keep creating fundraisers because our work is not done yet and won't be until a cure is found.

\$29,100

**OUR COMMUNITY KEPT
RAISING THE TARGET,
RISING ABOVE
THE ORIGINAL GOAL
WITH OVER \$29K
& 10 FUNDRAISERS**

**\$25,000
GOAL MET**



Help us support patients across the globe! Click button, use QR code or use the URL to donate.

DONATE TODAY



bit.ly/DONATE-LRG



LIFE FEST is a unique event where hundreds of patients and caregivers come together for a weekend to interact with each other and the medical and scientific communities that serve them. Faced with a rare form of cancer, GIST patients have a great need for information about this disease, particularly as the science evolves and our understanding reveals a complex set of subtypes of GIST, each responding differently to available treatments. Each year brings a wealth of new information, and patients are eager to learn about the latest treatments.

Life Fest workshops provide patients with emerging medical information, and they come away with a deeper knowledge of the disease, treatments and side effect management. They find hope in knowing the scientific community is working toward a cure and hope is such a vital asset for survival. In addition to our traditional educational workshops, Life Fest features scientific presentations highlighting the newest research and the latest treatments.

You can view previous Life Fest events here: <https://lifteraftgroup.org/life-fest/>

Life Fest 2022 was held in New Orleans, and Life Fest 2024 will be held in San José, California.

LifeFest2024

SAN JOSÉ

California

**REGISTER & BOOK
YOUR HOTEL EARLY!**

bit.ly/LifeFest2024

JULY 19-21, 2024

UPCOMING WEBINARS

**Getting the GIST of It:
How to Manage Side Effects of GIST Therapies**
September 18th, 2023 • 12pm ET



Emmeline C. Academia,
PharmD, BCOP
Beth Israel Deaconess
Medical Center



SEPTEMBER 18, 2023 @12PM ET

Understanding GIST & Desmoid Tumors
October 12th, 2023 • 11am ET



Dr. Steven Bialick
Sylvester Comprehensive
Cancer Center



Dr. Jonathan Trent
Sylvester Comprehensive
Cancer Center



OCTOBER 12, 2023 @11AM ET

bit.ly/LGREvents2023

GIST DAYS OF LEARNING

A GIST Day of Learning (GDOL) is a free one day event to help patients and caregivers learn more about this rare cancer, find support, and enhance their knowledge base to help them navigate their cancer journey. The Life Raft Group has a simple focus: to cure a form of cancer - GIST - and to help those living with it until then.

To do this, the Life Raft Group focuses on three key areas: research, patient support & education, and advocacy, which lay the foundation of our mission 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.

Register today for an in-person GDOL in Philadelphia or Colorado. It's not too early to register as having an accurate headcount as early as possible aids in planning our GDOL sessions.

For virtual GDOLs, all are welcome to benefit from the expertise of the specialists at the hosting center. The next virtual GDOL is Michigan with the specialists at Rogel Cancer Center.

To experience a prior GIST Day of Learning visit:
<https://liferaftgroup.org/gist-day-of-learning/>

Visit the Events link below for all the registration links for GDOLs, LRG webinars and Support Groups.

**For all events
& support groups:**
bit.ly/LGREvents2023

2023

GIST DAY OF LEARNING PHILADELPHIA

HOSTED BY:



SATURDAY, SEPT 30

2023

GIST DAY OF LEARNING COLORADO

HOSTED BY:



SATURDAY, OCTOBER 28

2023

VIRTUAL GIST DAY OF LEARNING MICHIGAN

HOSTED BY:



FRIDAY, NOVEMBER 17

Thank you to our **G.E.M. Donors!** GIVE EVERY MONTH



Opal Level

Ron Cotoni
Linda Gosser
Charlie Grana-Benn
Claire Monaghan
Elizabeth Skree
Cheryl
VanDeKerkhove



Ruby Level

Heather Anderson
Rene Carrillo
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Liana Baldor
BST Consultants
Lucina Stricker
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Wes and Jacob Treder

Why Become a GEM?

A. It's convenient.

Your donation of \$10 a month or more can be automatically paid each month. No fuss or remembering to send in a payment.

B. It's a consistent source of funding.

Even a donation of \$10 a month helps us continue to produce webinars, GDOLs, educational materials, participate in global advocacy, and contribute to #GISTresearch.

Become a GEM!

<https://liferaftgroup.org/donate-2/>

Private Facebook LRG Groups for Patients



Qinlock (ripretinib)-Discussion Group for Patients



Cogent Clinical Trial Discussion Group – Cogent...



PDGFRA GIST Patient/Caregiver Support...



IDRx- Clinical Trial Group Discussion for GIST...



A private email community for GISTers

<https://forum.gistchat.org/>



Subscribe to our Channel today!

@LiferaftgroupOrg

Interested in Volunteering?

Contact: Diana Nieves, Chief Development & Involvement Officer
dnieves@liferaftgroup.org

The Life Raft Group Global Community

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Deputy Executive Director	<i>Laura Occhiuzzi</i>
Chief Development & Involvement Officer	<i>Diana Nieves</i>
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Director, Finance	<i>Robin Elia</i>
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Website Manager	<i>Eddie Delgado</i>
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Grant Consultant	<i>Rebecca Pauley</i>

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155 US Highway 46, Suite 202, Wayne, NJ 07470
phone 973.837.9092 fax 973.221.9738 email liferaft@liferaftgroup.org website liferaftgroup.org

