

Life Fest 2024

# SAN JOSÉ

California

SPECIAL EDITION NEWSLETTER - AUGUST 2024



## Notes from Our Executive Director



*Dear Life Raft Group Community,*

As we reflect on the incredible success of Life Fest, I'm filled with immense pride and gratitude for all that we've achieved together. Our journey over the past year has been marked by significant milestones, and I'm excited to share our strategic goals for the future as we continue to build on this momentum.

One of our primary goals is to double our outreach to the global community. We believe that by reaching more patients, we can save more lives. Since I stepped into the role of Executive Director, we have made it a priority to expand our social media presence, increasing our reach by over 400% in just two years. Additionally, we've become more engaged with key stakeholders in the sarcoma and rare disease space. A crucial part of this initiative is the establishment of a health equity council, aimed at reaching patients from diverse ethnic backgrounds, socioeconomic statuses, and those in rural areas who may not yet know about the resources we offer.

Another key focus for us is gaining a deeper understanding of our members. We've been actively working on outreach projects to better comprehend the type of information our members seek and how they access it. It's concerning that only a small percentage of our members learned about us through their physicians. This highlights the need to strengthen our outreach to healthcare providers who have encountered GIST patients in their careers. We are committed to improving this and ensuring that more patients and their families are aware of the vital support we provide.

Lastly, we are excited to accelerate research through innovative technology with our patient registry and tissue bank. We are currently in the process of building a new and improved LRG Patient Registry. This new platform will be a "one-stop shop" for patients, registry staff, and researchers, featuring an interactive registration process, patient-friendly forms, and efficient data entry. By integrating electronic health records (EHR) into our patient registry, we will create a more comprehensive clinical picture, reducing the likelihood of missing critical information and ultimately improving patient care.

As we move forward, I'm inspired by the progress we've made and optimistic about what lies ahead. Together, we will continue to push boundaries, break new ground in research, and most importantly, support and empower the GIST community. To help us achieve our ambitious goals, we're asking for your continued support – whether through volunteering your time, providing funding, or connecting us with potential funding sources. Your involvement is crucial to our efforts. *Thank you for your unwavering dedication and support!*

*With gratitude & hope for the future,*

*Sara Rothschild*





Life Fest 2024 took place this year Friday, July 19th, to Sunday, July 21st, at the beautiful Signia Hilton Hotel in sunny San José, California. Over 140 patients, caregivers, doctors, industry experts, friends & family came together to learn, laugh, connect, offer comfort & support, and provide hope for one another.

Attendees immersed themselves in educational sessions ranging from GIST 101 to current research updates to new treatment options, holistic approaches, interactive panels and beyond.

In addition to these sessions, attendees gathered in groups to share their journeys with one another, offering mentorship and inspiration. The event culminated on Sunday morning with an energizing GIST DO IT Walk around a neighboring park, a few more educational sessions, including the role of artificial intelligence in medicine, and a message from our Executive Director, Sara Rothschild, on what the future holds for the LRG.





## Life Fest Celebration Luncheon



Rob Taylor

Our Celebration of Life Luncheon began with a delicious spread & socializing and was followed by a wonderful time acknowledging #GISTLife through an amazing time of sharing by GIST Advocate & Mentor Rob Taylor. Rob talked about the importance of having a plan, prioritizing your happiness, using your time wisely to enjoy your life, and knowing that the LRG is always there to support you in all steps of the road throughout your GIST journey.

After this time of sharing, Rob, Laura Occhiuzzi, Deputy Director, and Brian Morello, Director of Development, acknowledged long-term survivors, as well as our state leaders and GIST Mentors. The trio, plus advocates from our community, also awarded the highest honors to the Clinician, Volunteer, Humanitarian and Center of Excellence of the Year.

**Dr. Andrew Blakely, NCI, NIH**, was presented with our **Clinician of the Year Award** for an outstanding medical professional who has made a significant impact on the GIST community.

Dr. Blakely shared, *"This is my first standing ovation, so thank you all very much! I don't get embarrassed easily but I can only say thank you. I try to do as much as I can, and it's not enough. We need to do more and we will continue to do all that we can. If there is anywhere I can help, whether it is a second opinion, or whatever is it, I will. Also, as we try to move research forward and expand treatments option, we should try do better by patients. Thank you all so much!"*



Brian Morello & Dr. Blakely



Brian Morello, Carolyn Dewalt & Laura Occhiuzzi

Brian & Laura presented the **Volunteer of the Year Award** to our volunteer Advocacy & Engagement Specialist, **Carolyn Dewalt**. Carolyn has been a tremendous support for many GIST patients during their journey with GIST.

Laura shared, *"I can't think of anyone more deserving than Carolyn to get this award. She is there when you need her; she has so many ideas. Her commitment, her passion, her energy and her unwavering willingness to go that extra mile makes her an extraordinary advocate."*



The **GIST Center of Excellence Award** was awarded to the **OHSU Knight Cancer Institute** and was accepted by **Dr. Michael Heinrich & Dr. Limin Zhu**.

*"There are so many parts of our Cancer Center, there is the lab part & clinical part and there is the regular care part that is not part of the clinical research. It takes a village or maybe a small city to do all of that so we are honored to stand here for Cancer Center. The work we've done together has been an honor. But is not because of me but our whole team,"* shared Dr. Heinrich.



*Drs. Heinrich & Zhu*



*Rodrigo Salas*

Former LRG Board Member & President of Fundación GIST México, **Rodrigo Salas**, was presented with our **Humanitarian of the Year Award**. In his acceptance speech, Rodrigo shared his story of how he found the LRG and the impact it had for him and his family.

Rodrigo shared, *"Thank you so much. It has been quite an honor to be part of a group that day by day works in leaving things better than we find them. That is what we do here at The Life Raft Group."*

And at the end of the celebration our Board of Directors gave a surprise, heartfelt tribute to Deputy Executive Director **Laura Occhiuzzi** for her amazing, productive tenure with the LRG.



Visit our Life Fest 2024 page for more photos, videos & PDFs of presentations:

<https://liferaftgroup.org/life-fest-2024/>

## Life Fest 2024 Presentations

### GIST 101

David Josephy, PhD

### SDH 101- SDH-Deficiency & GIST

Dr. Andrew Blakely

### Coast to Coast: State of GIST Research Update

Dr. Candace Haddox,  
 Dr. Nam Bui

### New Treatment Landscape

Dr. Michael Heinrich

### Germline Testing & What It Means for Families

Samantha Greenberg,  
 PhD, MS, MPH, CGC

### GIST Pathology & ctDNA Biomarker Testing

Dr. Matt van de Rijn,  
 Dr. Emily Jonczak

### GIST Surgery

Dr. Andrew Blakely

### Clinical Trials Panel

Dr. Michael Heinrich  
 Dr. Andrew Blakely  
 Samantha Greenberg  
 Jim Hughes

### Nutrition Presentations

Greta Macaire, MA, RD, CSO  
 Danielle Baham, MS, RD

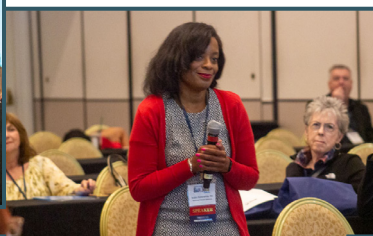
### Artificial Intelligence in Cancer Care:

Sanju Sinha, PhD

### Building a Future Together

Sara Rothschild, MPH

*...and many other special topics & panels! See our recorded presentations on YouTube.*

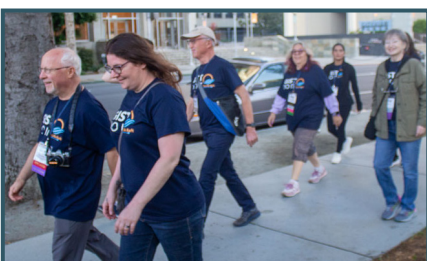




## San José GIST Do It Walk



One of the highlights of Life Fest is our GIST DO IT Walk. These walks are held in memory of GISTer Ted Wolf. We walk in unity to raise awareness of GIST & funds for GIST research.



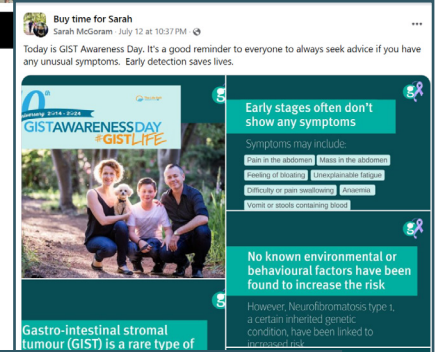


# 10<sup>th</sup> Anniversary 2014 - 2024

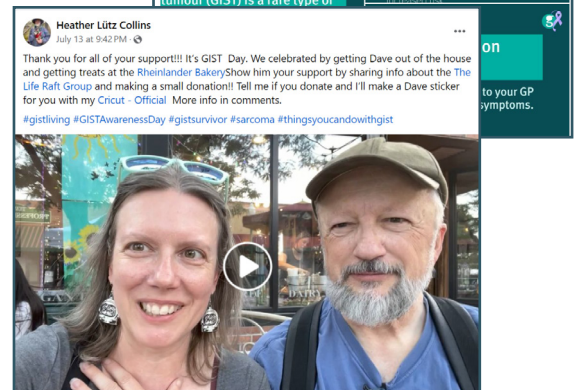
## GIST AWARENESS DAY

### #GISTLIFE

GIST Awareness Day (GAD), July 13th, stands as the yearly pinnacle of our education, awareness, and advocacy efforts, offering those outside the GIST community an opportunity to learn about and support this important cause. This year marked the 10th Anniversary of GAD, and below are some examples of how our community celebrated.



Henzo Kenya celebrated by sharing their journeys with GIST and appreciating the nurses at Nairobi Cancer Centre.





# 10<sup>th</sup> HAPPY Anniversary!

On August 10, 2024, *Fundación GIST Chile* celebrated its 10th Anniversary.

The meeting was held at the Universidad Mayor auditorium with 12 participants. During the meeting, Piga Fernández, President of Fundación GIST Chile, LRG representative in Chile & LRG Global Relations Coordinator, shared with the audience the history of Fundación GIST Chile, what motivated her to start it, and the many barriers she faced at the beginning as well as the many achievements over the past 10 years. She presented a stop-motion video in which showed the work done in GIST Chile's four pillars of action: patient support, education and information, advocacy, and contributions to research.



An important section of the agenda was an interesting multisectoral panel in which the panelists spoke of the reality of cancer in Chile, the challenges patients face and how the collaborative efforts each one of the panelists from their perspectives contribute to solutions and solve these challenges to benefit cancer patients.

The panelists were: Dr. Enrique Paris, former Health Minister, Dr. Sung Kim, Chief of the National Department of Cancer Control and Prevention from the Ministry of Health, Dr. Marcelo Garrido, gastrointestinal oncologist and GIST specialist, and four representatives of the social society and patients: Jorge Fernández, from Fundación Vi-Da, Sandra Hernández, a GIST patient, Purísima Neira, a colorectal cancer patient, and Mauricio Clerc, a gastric cancer patient.



During the meeting Dr. Marcelo Garrido received an award as recognition for all the support he has given to GIST patients and to Fundación GIST Chile this past decade.



## Thank You to our Life Fest Sponsors!



## Upcoming Events

[bit.ly/LRGEvents2024](https://bit.ly/LRGEvents2024)

**Locoregional Therapies for Treatment of GIST in the Liver**



September 9, 2024  
12 PM ET

Dr. Edward Kim  
Mount Sinai Medical Center



**GIST DAY OF LEARNING OHIO**



SEP 14, 2024  
8:00 AM-2 PM



**GIST DAY OF LEARNING Calgary**

Please join us for a full-day GIST Day of Learning event in Calgary, Alberta on Saturday, September 28, 2024.

**Location:** Hotel Alt East Village – Calgary  
**Time:** 9:00 – 5:00pm - Refreshments and Lunch will be provided. Patients, caregivers and family are all welcome at this FREE event.

**Keynote Speaker:**  
 Dr. Xiolan Feng, medical oncologist, Tom Baker Cancer Centre, will be speaking about mutational analysis.

We will also have updates on current clinical trials including Cogent's Peak Trial. [More details on registration page.](#)

[bit.ly/GDOL-Calgary](https://bit.ly/GDOL-Calgary) **REGISTER NOW**



GIST Sarcoma Life Raft Group Canada  
 Groupe Sarcomes GIST Sarcome Canada  
 Ensuring that no one has to face GIST alone

**IDRX-42: Trial Design & Emerging Data from the StrateGIST 1 Study**



October 8, 2024  
12 PM ET

Dr. Suzanne George  
Sarcoma Center at Dana-Farber Cancer Institute



**NIGHT TO FIGHT CANCER**

11.7.24