

**Special Edition - September 2022** 





2022 Life Fest Celebration GIST Awareness Day



#### From the desk of our Executive Director



I think many of us would agree that Life Fest New Orleans was a magical experience. Of all the Life Fests I have been to, I think this was by far the best one we have ever had! Not only was it incredible to celebrate with all of our GIST brothers, sisters, and families for our 20th anniversary but it was amazing meeting face-to-face for the first time in four years!

The energy around the event was palpable. Our incredible staff worked tirelessly to make this event a success despite the pandemic and air travel issues. We had participants from all over the world including Bolivia, Canada, Costa Rica, Chile, Israel, Macedonia, Mexico, Switzerland, and the UK!



Our presenters shared important topics and discussions that left the participants hungry for more information and interaction and then they were generously open to discussion and Q&A. We were inspired and encouraged by Dr. mOe Anderson as she shared her story and presented some very special people with awards as Life Fest Honorees for excellence in



courage and service to our community.

We walked in solidarity to raise awareness of GIST in this city and in honor of those we've lost. We bonded over the memories and milestones documented in our 20-Year celebration video. We learned, we made new friends as we embraced old ones, we ate and laughed and toured a great city.

And we left this conference with a renewed sense of hope for a better tomorrow!

- Sara Rothschild





To all our friends, family, sponsors, Sara, Laura, the LRG staff, our amazing GIST Mentors, doctors and the medical community, LRG Board, caregivers, and most of all, our patient-members,

because of all of you we continue to serve a vital purpose in helping those afflicted with GIST. And thankfully, the "State of the Life Raft Group" is strong.

Life Fest 2022 was a spectacular success. It had been far too long since we had all been together in the same room. The emotions we felt seeing and being with everyone in New Orleans, BEING with everyone at Life Fest, transcended words. Friday night, emotions swelled up inside simply witnessing members from around the globe picking up their name tags, sipping drinks and sharing stories.

For me, the emotions were strong all weekend as I marveled as (1) the good we do, (2) the amazing success and growth of our incredible pay-it-forward mentorship program,

(3) the progress being made by the "GIST Mount Rushmore of Oncology," all in attendance, and (4) most especially, the unyielding strength of our community. Finally, like I do every day, I remembered those who could not be with us, especially my father, Lawrence J. Glasser, who fought GIST until October 2011.

Since we last gathered, the LRG has evolved significantly. After founding this important organization and two decades of leadership, Norman Scherzer stepped down as Executive Director. Fortunately for the LRG, we had a deep bench and are fortunate now to have a focused, creative and dynamic new Executive Director in Sara Rothschild, and the continued steady leadership of Laura Occhiuzzi as Deputy Director. Norman was honored with a special award at Life Fest, accepted on his behalf by the equally indomitable Josalin Dunn, longterm pediatric GIST survivor.

In addition to Norman's retirement, after serving as the President of the LRG Board for seemingly 125 years, Life Fest birthday boy Jerry Cudzil stepped down as well, and I was elected President. Fortunately for the LRG (and me), Jerry remains a confidant and an influential and important member of our Board. Jerry was also awarded special recognition at Life Fest, and accepted his award with characteristic humility, citing everyone else's contributions and refusing to acknowledge his own. The LRG would not be the success we are today without the guiding hands of Norman and Jerry.



**CLOCKWISE - THE LRG BOARD:** SANTY DISABATINO, TEENA PETERSOHN, EXEC. DIR. SARA ROTHSCHILD, DEPUTY EXEC. DIR. LAURA OCCHIUZZI, GARY GLASSER, STAN BUNN, JERRY CUDZIL, KAY STOLZER, DR. MOE ANDERSON, STEVE PONTELL, RODRIGO SALAS, JIM HUGHES (MISSING: PAT BONDA-SWENSON, BILL BORWEGEN, ERIC BIEGANSKY)



Our Board has grown in numbers, experience and ideas. The Executive Committee of the Board now also includes Steve (Pontell) as Vice President, Kay (Stolzer) as Secretary and "Santy" (DiSabatino) as Treasurer. Santy is such a force that, like Pelé and Madonna, he needs only one name. The Board also includes past presidents Stan Bunn and Jerry Cudzil and current Board members Dr. mOe Anderson, Eric Biegansky, Bill Borwegan, Patricia Bonda-Swenson, Jim Hughes, Teena Petersohn, and Rodrigo Salas.

Friends, these tireless volunteer-leaders help support the LRG with generous contributions of their time, their money, their sweat, ideas and their LOVE. It is truly an honor of a lifetime to serve with this Board and the LRG staff. Thank you, all, from the bottom of my heart.

Our membership is now 3500 members strong. Our programs, support groups, events, website, social media, chat forum and more have included tens of thousands of messages and takeaways over the past few years that Department Heads Diana, Denisse and Mary and the staff each undoubtedly address. They assure that the wisdom learned from each other is shared to benefit the whole community.

We may have met in the Big Easy, but as we all know, GIST ain't Easy. Members, we've got the leadership and team in place, but we face uncertain times.

We need help, especially financially if we are to ensure the LRG can continue to serve our members until the end of GIST. Pharma funding is highly uncertain and continues to decline. A recession looms for the global economy. Like everyone else, the LRG needs to do more with less. Sara and Laura, with the Board's unanimous support, have taken some difficult, bold steps to reduce our personnel and rent expenses. We know that our Leadership Dream Team will continue to be vigilant in carefully spending every dollar, euro, yen, peso, franc or pound we receive in donations. Continuing the theme of doing more with less, there are plans to increase volunteer activities.

But reducing our expenses will unfortunately not be enough. We need to raise additional funds. Friends, every little bit helps. Every good idea helps. Every email you send to support others helps. Every "ask" you make of your friends and family helps. There are a lot of worthy causes out there, and I'm sure there are many that deserve our support, but we all feel what the Life Raft Group does: Life Fest, education, research support, outreach, mentorship, registry data...saving lives...all help us to survive and thrive.

Please help us with anything you can contribute or volunteer any time you can give. I ask this from the bottom of my heart.

To those of you who attended Life Fest 2022, thank you for making the flight, drive, train ride or trek to NOLA. To those of you who were unable to attend we will make sure you've got access to all the knowledge that was presented there. To the untiring LRG staff and volunteers, thank you for assuring Life Fest would be the success it was. To the Board, thank you for your unwavering leadership. And to our members and all of us, thank you for being a supportive, loving community.



# **SPREADH** PE bit.ly/DONATE-LRG CHECK OUT ALL THE DIFFERENT WAYS TO DONATE TODAY!



## Life Fest 2022 New Orleans

#### July 29th - 31st

BY DIANA NIEVES, SENIOR DIRECTOR, OUTREACH & ENGAGEMENT

The Life Raft Group was proud to celebrate the 20th anniversary of serving our GIST community with patients, caregivers, friends,

and presenters at our biennial Life Fest conference. Life Fest, which had not been celebrated in person since 2018, was held in New Orleans at the Hyatt Regency July 29<sup>th</sup> - July 31<sup>st</sup>.



Our community traveled from around the globe to participate in a weekend of camaraderie and access to medical and research leaders in the field of GIST. Every meeting brings a wealth of new information about the latest advancements, treatments, and side effects management with panel discussions for each track.

Life Fest 2022 was an amazing event filled with inspirational stories, laughter, hugs and tears shared by GISTers, caregivers, mentors, medical professionals, pharmaceutical representatives, staff, board members, and friends. Over 130 people participated throughout the weekend. We are grateful to our Board of Directors and donors who made



possible the Life Fest Scholarship Fund again this year. Scholarships were awarded to families who needed help to participate in Life Fest. Almost \$7,000 was raised to provide ten families with support to attend and stay in New Orleans for the weekend conference.

We are so grateful for our expert speakers and presenters who shared with us not only their knowledge but also their dedication and passion for the GIST community. It is also worth noting that participants noted on their evaluation forms that this was the best Life Fest yet and are looking forward to you joining us at our next one in 2024!

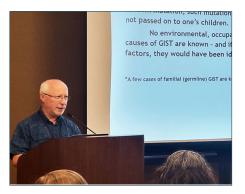
#### Stay tuned for details!





## **Life Fest 2022 Presentations**

The weekend kicked off Friday afternoon with a GIST 101 session presented by David Josephy, President of GIST Sarcoma Life Raft Group Canada. This informative presentation was followed by an informal gathering for all the participants on Friday evening. Our weekend was filled with general sessions designed to inform, educate and provide tools for patients and caregivers alike. Saturday morning's main program consisted of two tracks - one for the adults and another for SDH patients and their caregivers.



Topics for the Adult GIST track included a GIST Research Update session by Dr. Michael Heinrich, OSHU Knight Cancer Institute, Dr. Jason Sicklick, UC San Diego Health, and Dr. Jonathan Trent, Sylvester Comprehensive Cancer Center. Next was a panel conversation entitled, "Insights for Patients & Caregivers." This module was moderated by Dina Wiley, our SoCal state representative and Drs. Trent and Heinrich were joined by Drs. Ramesh Bulusu (Cambridge Hospitals, UK), Gina D'Amato (Sylvester), Breelyn Wilky, University of Colorado Cancer Center, and Arun Singh (UCLA Health).

On parallel tracks, the SDH contigent was updated on clinical trials, research updates by Drs. Sicklick, Buluus, and Heinrich as well as Dr. Andrew Blakely (National Cancer Institute), while Patient Advocate Carolina Ponce hosted a session focusing on Meditation & Breathing Techniques for Stress Reduction. Carolina also presented, "Mind & Body Wellness," which was an interactive session with Dana Croschere and Krisana Sextion later in the morning with the movie Love Heals (lovehealsfilm.com), followed by a presenation on Nutrition & Exercise Goals. The SDHrs continued their morning with panel conversations with Drs. Blakely, Bulusu, Heinrich,

Sicklick and Trent as the Adult GIST track concentrated on Surgery in GIST (Drs. Blakely, Sicklick, and Dr. Aimee Crago, Memorial Sloan Kettering Cancer Center). Drs. Singh and Wilky discussed Immunotherapy for GIST Patients and David Josephy moderated a conversation with Drs. D'Amato and Singh on Navigating the Treatment Landscape, The Women Warriors (MaKayla Evans and Drs. Crago, D'Amato, and Wilky) settled in a for a conversation on Patients as Partners.

After this comprehensive schedule of GIST information and discussion, everyone gathered for lunch and our traditional Celebration Ceremony with a delicious menu, comraderie, memories and awards!



BACK ROW LEFT TO RIGHT: DR. ARUN SINGH, DR. MICHAEL HEINRICH, DR. RAMESH BULUSU, DR. JASON SICKLICK, DR. JONATHAN TRENT, DR. GINA D'AMATO, DR. ANDREW BLAKELY FRONT ROW: SAHIBJEET KAUR (LRG), DR. AIMEE CRAGO, LAURA OCCHIUZZI (LRG), DR. BREELYN WILKY, DENISSE MONTOYA (LRG), JESSICA NOWAK (LRG)



### Life Fest 2022 Honorees



**Dr. Monica "mOe" Anderson**, Mistress of Ceremonies for our awards luncheon, presented the **Nikki Morales Courage Award** to Patient Advocate **MaKayla Evans**. Nikki Morales epitomized both bravery and perseverance. She was a true warrior, who faced every challenge with a smile. This award was created to honor patients who inspire others through their determination and courage. Dr. mOe shared, "You fit into this category, Makayla; just like Nikki, you teach others through example to live life to the fullest beyond any obstacles you may face."

**Dr. Breelyn Wilky** was presented with our **Clinician of the Year Award** for outstanding medical professionals who have made an impact on the GIST community. Dr. mOe shared, "Dr. Wilky, you are being honored not only because of your contributions, but because you are personally responsible for increasing patient survival. You have always been a supporter of The Life Raft Group and our efforts to help patients survive and thrive. We truly appreciate you and your passion and dedication, not only to patients and caregivers, but also in your continuing research efforts."





The GIST Center of Excellence Award was awarded to the Ronald Reagan UCLA Medical Center, accepted by Dr. Arun Singh. "The Center is being honored because of its research contributions, involvement in clinical trials, focus on extraordinary treatment to the GIST community and its multi-disciplinary approach to the well-being of patients and their families. The multidisciplinary team of oncologists, surgeons and nurses go above and beyond to treat the GIST community. We honor these exceptional medical professionals for their informed clinical care, the patients for their strength and courage and the caregivers for their unwavering support, all of whom play an integral role in patient survival," said Dr. mOe.

**Patient Advocate Josalin Dunn** accepted an award on behalf of **Norman Scherzer**, retired Executive Director & Founder of the LRG, for his decades of exceptional advocacy. In her tribute to 'Mr. Norman', Josalin shared the enormous impact that he had had not only on her own life but on the lives of so many patient and families. "Thank you Mr. Norman for keeping the 'music' going that gives so many of us a reason to dance and celebrate. What are we celebrating? We are celebrating hope; hope that comes as a direct result of all you have done to shine a light on our rare illness. And that light has brought changes that have helped to extend our lives," Josalin shared.





Current Board President **Gary Glasser** gave a heartfelt tribute to outgoing Board President **Jerry Cudzil** for the his long, productive tenure with the LRG. Gary praised Jerry's passion for the LRG as well as his motivation, tenacity, vision, and humility. Jerry would spearhead many fundraisers most notably Night to Fight Cancer which began in 2004 and runs yearly. His strategic vision and problem-solving abilities have guided the LRG though many transitions through his nearly two decades of leadership. As his late father-in-law Bill once said, "My son-in-law is a very giving, dedicated person. He really cares."



### Life Fest New Orleans GIST DO IT Walk



The Life Fest GIST DO IT Walk was held on Sunday morning, July 31<sup>st</sup>. These Walks raise awareness about GIST and honor both survivors and those we have lost. GIST DO IT Walks were created in memory of GISTer Ted Wolf who passed away in 2018.

### **Life Fest 2022 Presentations continued**

After the GIST DO IT Walk, the information kept flowing with a presenation on Side Effects Managment by Drs. D'Amato and Wilky followed by "Making a Difference from the Ground Up: Your Side Effects" from James Romano of Care & Cure Partners, LCC. GIST Mentor Piga Fernández finished off the schedule with a focus on survival planning.

Visit this link to view PDFs of the Life Fest presentations:

# liferaftgroup.org/life-fest-2022/

Visit this link to view our Life Fest 2022 Highlight video:

# bit.ly/LifeFest22HighlightVideo



### **Partnering with Cogent Biosciences**



The LRG partnered with one of our event sponsors, **Cogent Biosciences**, to create a 'GIST Mosaic' for Life Fest 2022. On GIST Awareness Day,

Cogent began collecting photos of patients & caregivers to be a part of this visual that would represent our GIST community. During Life Fest many participants had their photos taken on-site and Sunday, the last day of Life Fest, the

result was revealed. The final product was made up of over 500 tiny instant photos.



#### Thank you to Cogent for this amazing gift!



Interested in attending an in-person GIST Education event? Learn about our GIST Days of Learning here:

# bit.ly/GDOLSanDiego22 bit.ly/GDOLMiami2022



## **Thank You to:**

#### **Our Sponsors**

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### **Our Presenters & Moderators**

Dr. Monica "mOe" Anderson Dr. Andrew Blakely Dr. Ramesh Bulusu Marianne Bowman Dana Croschere Dr. Aimee Crago Dr. Gina D'Amato Josalin Dunn MaKayla Evans Piga Fernández Dr. Michael Heinrich David Josephy Denisse Montoya Carolina Ponce **James Romano Krisana Sexton** Dr. Jason Sicklick Dr. Arun Sinah Dr. Jonathan Trent Dina Wiley Dr. Breelyn Wilky



# Our GIST Mentors, Board Members, and LRG Staff (on-site & in NJ) and Our Special Event Volunteers:

Alyssa Occhiuzzi, Sam Evans, Sukvir Parmar, Casey Raynis & Sydney Stern

# & Thank You to All Who Attended Life Fest!



# Many media & pharma participated, sharing facts & patient stories.

GIST



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### Thank You for Making Our 20-20 Campaign a Success!

With your generous support & the promised matching gifts, we exceeded our goal of \$20K for this special campaign!

Check out our 20-Year Anniversary video which was presented at Life Fest New Orleans:

## bit.ly/LRG-20Years

Subscribe to our **>** YouTube channel today!



#### Thank you, also, to our Major Donors for February - July

Dr. Monica Anderson Richard Becker BST Consultants Helen Frey Idea Village Products

Claudia & John Link Camille Mayotte Teena Peterson Kay Stolzer Lucina Stricker The Benevity Community Impact Fund Vanguard Charitable Wendy Williams Tammy Wolf

#### And our newest Opal GEM (Give Every Month) Donor:

Claire Monaghan (What's a GEM? Visit the Donate link below to find out how the GEM program works!)

#### **YOUR DONATIONS MATTER!**

Life Fest and GDOLs (GIST Days of Learning) are great examples of how your donations support our GIST community. We also produce educational webinars, support groups, research, run a GIST Patient/Caregiver Mentor program and so much more for the benefit of patients and caregivers.

It's not too late to help us to continue to fulfill our mission. You can donate anytime or join our GEMs program! View the different ways you can help today: **bit.ly/DONATE-LRG** 

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#### Volunteers

Exciting updates coming in our next newsletter! If you are interested in sharing your skills & talents as a volunteer with the LRG, please apply here:

https://liferaftgroup.org/volunteer/

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Venezuela Angel Selena Rodriguez