

Executive Director Letter

Our theme for 2020 was Hope. 2020 presented a challenge to us all, but most especially to our patients and caregivers who are seeking to survive this rare cancer. In 2020, The Life Raft Group needed to provide a lifeline to our community, and to offer them hope in the form of increased support as we navigate the challenges of living in a COVID-19 world.

Our Executive Director's Message

GIST Hope hashtag Sometimes it is hard to see hope, especially for those battling a rare cancer and searching to find the right diagnosis, treatment, and support.

In 2020, survival became even more challenging with the onset of the COVID-19 pandemic, but the Life Raft Group once again rose to the occasion.

Despite the worst pandemic in a hundred years and having to close our office and work remotely.

Despite an accompanying fiscal crisis driving a general downturn in charitable giving.

Despite a dramatic reduction in financial and patient support from some key pharmaceutical companies. due to patents ending.

And despite obstacles to accessing treatment within the parameters of quarantine and social distancing.

We continued to launch our life rafts to pick up the ongoing flow of men, women, and children desperate for hope and just trying to stay alive a little longer.

We continued to direct patients to physicians who have experience with our rare cancer, GIST, to assure that they receive the right diagnostic tests to find the right treatment from the growing number of options our scientific colleagues have identified.

We continued to grow our GIST Patient Registry, the largest in the world, to find the latest survival 'needles' in a growing number of haystacks and matched this critical data with our GIST Collaborative Tissue Bank now housed at Oregon Health & Science University (OHSU).

We continued research collaborations with major institutions around the world, hosted webcasts and facilitated several Virtual GIST Tumor Boards including the National Institutes of Health (NIH) Pediatric & Wildtype GIST Clinic (which was not held in-person due to the pandemic).

We launched several regular online support groups and trained a growing number of GIST mentors to support our LRG community and to provide the emotional support our patients & caregivers sorely needed.

And so much more, as you will see in our 2020 Annual Report.

Most importantly, we continued to deliver hope to patients in over 67 countries.

It is our intention to continue to be purveyors of hope in 2021 with your continued support.

- Norman J. Scherzer

Research

In 2020, we saw the research landscape change in order to deal with COVID-19. Clinical trials were challenged by the limitations of the quarantine, and the benefits of telemedicine opened up new opportunities of how we could develop trials in the future.

Engaging our Global Surveillance Group, we gathered information on the number of COVID-19 cases among GIST patients to determine how best to provide information and interventions.

We continued to publish LRG Science, our quarterly publication dedicated to reporting data and research, both traditional and patient-generated as it relates to GIST. The topics included commentary from outside contributors on a published study on Survival, our collaboration with OHSU on the GIST Collaborative Tissue Bank, and our partnership with the National Institutes of Health (NIH) to present Virtual Tumor Boards in lieu of an in-person clinic for SDH-deficient patients.

Our real world evidence team continued to meet on a weekly basis to discuss the data generated from the Life Raft Group Patient Registry, and to share that data where it would generate interest or have impact on research and treatment development. Part of that data gathering included a number of surveys, including one on mutational testing and the challenges patients face in obtaining testing. We began to explore and expand the concept of personalized side effects management, revamping our Patient Registry to efficiently capture data on side effects common to our patients.

Our LRG Patient Registry continued the Regional Registry Project, engaging registries from Latin America, through organizations such as Fundación GIST Mexico, Fundación GIST Chile and Pontificia Universidad Católica de Chile. We also began conversations with organizations in India to discuss potential collaborations with those existing registries.

Our Global Surveillance Group collaborated on a number of unusual case studies, providing information that shaped clinical interventions. Data from our registry led to an ongoing dialogue with researchers in Italy with the potential for a combined study.

We published informal case studies and interviews with GIST experts on the latest treatments in our newsletter.

The LRG had an active presence in the research and medical community. We presented a poster at ASCO (American Society of Clinical Oncology) on an algorithm for diagnostic testing standards for GIST and contributed to an abstract on data from The Consistent Terminology Working Group on biomarker testing terminology. Patient Registry Director, Denisse Montoya, also presented a video about our Patient Registry internationally at the combined SPAEN/ESMO meeting.

As founding members, the LRG continued to participate virtually in the Pediatric & Wildtype Clinic at the NIH by organizing and facilitating several Virtual GIST Tumor Boards.

We continued to be a resource for pharmaceutical companies, aiding them in the development of and the recruitment for clinical trials. It was an exciting year, as new drugs that hold hope for the future came to market.

Our most important effort remains our impact on patient survival. Several case studies emerged that demonstrated that our efforts directly aided patients in increased survival and quality of life, emphasizing the importance of biomarker/mutational testing.

Outreach and Support

In 2020, we were faced with the challenge of reaching out and supporting our members despite the restrictions of the pandemic. The Life Raft Group staff continued to reach out by phone, emails, and through new programs we created to serve our patients and caregivers.

We continued to welcome 288 new members into our community. Our GIST Mentor Program has continued to expand, with 16 mentors and 155 mentees now engaged. In addition, we implemented ongoing support groups for patients and for caregivers, including a Caregiver Support Group led by one of our GIST Mentors, and five eight-week patient support groups led by an LCSW volunteer. We also provided an eight-week mindfulness series led by one of our GIST mentors to support our community in the pandemic. Ongoing regional support groups continued to meet virtually.

The heart of our outreach and support efforts is the Outreach & Engagement team, who continue to provide personal attention to patients and caregivers on a daily basis. From the first phone call to reaching out for follow-up, the team aims to offer information and advice to help patients survive and thrive.

These efforts are enhanced by the dedication of our Patient Registry Team, who work individually with patients via phone calls and email correspondence, helping them to navigate their treatment journey. This was especially important during this pandemic, when patients were feeling anxious.

Support also was provided by helping patients navigate finding telemedicine appointments and guiding them towards clinical trials.

Member stories are powerful tools to evoke both hope and provide information. We continued to distribute our Patient of the Month profiles, highlighting a member of our Patient Registry on our website and in our newsletter, thereby bringing the patient journey to life. In 2020, we added Caregiver of the Month profiles, as caregivers are the cornerstone of a patient's support team.

We continued to support the GIST community in times of celebration, and in times of loss. We offered support for those grieving on our In Memoriam website, and called attention to this type of loss in our "No More Empty Chairs" holiday campaign.

GIST Days of Learning (GDOLS) were held remotely in Denver and Tampa providing over 181 patients, caregivers and new medical professionals with access to the latest information on GIST treatments and research..

Events remained an important part of networking with members of our community, as well as presenting the Life Raft Group to the community-at-large.

Life Fest 2020 was planned for New Orleans in July, but was reconfigured, due to the covid pandemic, as a virtual event. The theme was #GISTHope. Although only together on the screen, there was still an abundance of up-to-date information, and a sense of being together in spirit. We launched our GIST Cook Cookbook with a virtual cooking demonstration, and invited folks to do a Virtual Walk in addition to the informational modules which included a GIST 101 and updates on GIST treatments There were 196 participants for this virtual event.

Our GIST Do It Walks, held in memory of Ted Wolf, were successful fundraisers, with our second New Jersey walk, socially distant and masked, raising both funds and awareness.

We launched our "Women in Sarcoma" program, culminating in a gala that honored both medical professionals and patients.

GIST Awareness Day, celebrated each year on July 13, had strong support from Latin America and India. Our theme was #GISTHope, with suggestions of how to support efforts on an ongoing basis.

Our Annual Holiday Campaign 'No More Empty Chairs' focused on assuring that patients have access to accurate diagnoses and effective treatments.

The ongoing support of our GIST community continues to fuel our efforts in both research and patient support.

Information, Education, and Advocacy

Over the years, we have seen evidence that empowered and educated patients have higher survival rates, and that by raising awareness about GIST, we can help save lives.

Educating patients and caregivers as well as the community-at-large is a core function of the Life Raft Group. From the initial call when we connect with a patient, to webinars presented by medical experts, to a regional GIST Day of Learning meeting, an article in our newsletter, content on our website or through our biennial Life Fest conference, we are continually encouraging patients to take a greater role in their treatment journey.

In 2020, we had the additional challenge of providing not only communication, but crisis communication. We expanded content on our website to include information on COVID-19, as well as updating key information about GIST and adding more articles on coping with this rare disease. Our website continues to be an information hub for newly diagnosed patients and for anyone seeking general information about GIST. We had 390,722 visitors to our site this year alone. Through our webposts and articles, we educated patients about new treatments and about navigating clinical trials, which was vital in 2020 as access to trials became more complex.

Informative webcasts included a series on "Conversations with the LRG," which began with a candid conversation with Executive Director Norman Scherzer "Coping with COVID-19," followed by "Staying Alive in Difficult Times," supported by Jerry Call and Dr. David Josephy. Other topics included: "Conversations with the LRG: GIST Mentors"; "New Treatments and Coronavirus" presented by Dr. Heinrich; "GIST, TKI and Effects on Memory" presented by Dr. Anette Duensing and Dr. Robert J. Ferguson, "Genetics 101" presented by Margarita Raygada, PhD, "Understanding the Link Between Pheo, Para and GIST" with Dr. Jason Sicklick, and "How to Read Your Pathology Report," presented by Dr. Kelsey McHugh. Two additional presentations supported our Women in Sarcoma programs: "Women in Sarcoma: Cancer Warriors," and "Women in Sarcoma - Case Presentations."

Our newsletter is an important source of information for our member community with inspiring personal stories, informative articles on the latest trends in GIST treatment and updates on the LRG's collaborative efforts worldwide. The LRG Science Bulletin provides scientific content to educate and inform and engages GIST specialists and researchers in commentary. Topics in 2020 included an overview of our collaborative virtual tumor boards with the National Institutes of Health (NIH), an overview of our new GIST Collaborative Tissue Bank at OHSU, and a review of our research paper on overall survival with commentary from experts in the field.

At all of our GIST Days of Learning (GDOLs), informative presentations reach a larger regional audience, providing important information for patients and caregivers. We managed to hold these virtually.

Advocacy

The Life Raft Group continues to be a powerful advocate for change for patients and caregivers both nationally, and internationally.

We advocated personally on a case-by-case basis for patients to be able to access treatment including through telemedicine, as well as participated virtually in several organizations both nationally and internationally as collaborative efforts.

On the international front, our Global Relations Coordinator, Piga Fernández continues to aid patients around the world, while making a vital impact in Latin America. Her ongoing efforts have influenced legislation to support access to cancer treatment in Chile in spite of working through lockdown.

We continue to be involved in NORD (National Organization for Rare Disorders), with staff members virtually attending their annual conference and meetings of the Rare Disease Council for NJ.

We maintain a presence as members of the Sarcoma Coalition joining with other rare disease non-profits to share best practices and discuss national advocacy issues with pharma, patients, and patient advocacy organization staff.

The LRG remains part of the Milken Institute's Faster Cures, as one of the original members of TRAIN (The Acceleration and Innovation Network).

Locally, we maintain ties with other non-profit organizations by regular attendance at conferences and roundtables, albeit virtually this year.

Through the power of social media, we continue to rally our global community in support of issues relating to the access and affordability of treatment. We also reach out to the global community as moderators of the GIST Survivor Facebook Group, which engages hundreds of international patients and caregivers.

We began a soft launch of a campaign to advocate that all GIST patients receive mutational testing, which will continue into 2021.