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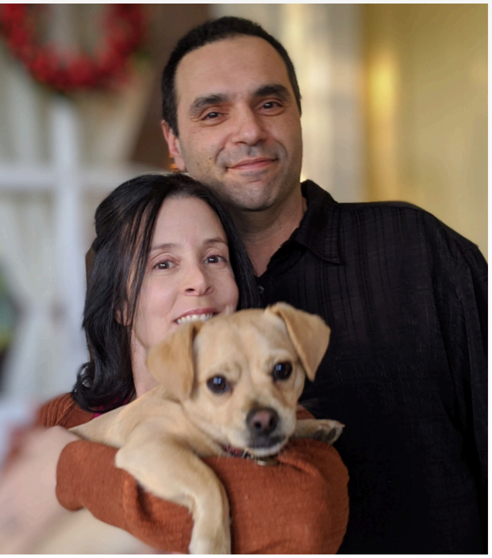
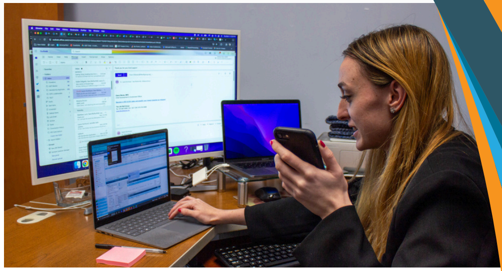
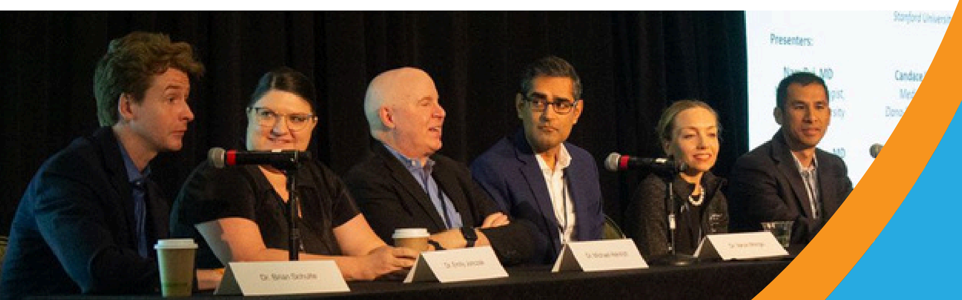
GROUP





Annual Report
2024



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A Message from Our Executive Director

As I reflect on 2024, what stands out most is the strength and heart of this community. This year, we've continued to show up—for each other, for patients navigating GIST and other rare cancers, and for the future we're all working toward. One of our biggest steps forward was launching a new five-year Strategic Plan, setting a bold course rooted in the values we've always held: empowerment, patient-focus, innovation, and collaboration.

This report captures just some of what we've accomplished together, from expanding our advocacy efforts and strengthening our patient navigation, to raising awareness in new ways and deepening our collaborations with clinicians and researchers. These wins weren't just organizational milestones, they were moments that brought real help and hope to people when they needed it most.

Looking ahead to 2025, we know the road forward calls for creativity, urgency, and unwavering focus on what matters: improving lives and reaching for a cure. Our Strategic Plan is a guide, but it's the people in this community—patients, caregivers, partners, and supporters—who make the mission real. We're aiming higher, pushing harder, and keeping the patient voice at the center of everything.
Thanks for being part of it all. Let's keep going together!

With appreciation,

Sara Rothschild

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DEVELOPMENT & INVOLVEMENT

The Development & Involvement (D&I) team serves as an integral unit of The Life Raft Group's mission, fostering support, education, and advocacy for patients and caregivers worldwide. Through global support groups, a robust mentoring program, and educational initiatives, the D&I team continues to build and strengthen a resilient GIST community. In addition to training mentors, the team leads fundraising efforts, including a GIST DO IT Walk, peer-to-peer campaigns, and events that sustain critical programs for those affected by GIST.

Life Fest 2024
SAN JOSÉ
California

Bringing the Community Together: Life Fest 2024

One of the biggest highlights of the year was Life Fest 2024, held in July at the Signia Hilton Hotel in San José, California. Over 150 patients, caregivers, medical professionals, industry experts, and supporters gathered to learn, connect, and offer hope to one another. Attendees immersed themselves in educational sessions covering a wide range of informative topics. Beyond these sessions, participants engaged in meaningful small-group discussions, sharing personal experiences and offering mentorship and inspiration.

Fundraising & Community Engagement

The Life Raft Group's annual **Water of Life** whisky tasting fundraiser, hosted by Matt Lurin at Keens Steakhouse in New York City, drew nearly 50 enthusiastic supporters. This beloved event raised crucial funds to support GIST research and patient programs. As always, it was a night filled with camaraderie, education, and shared purpose. We look forward to expanding Water of Life events in 2025!

The steadfast support of our **Give Every Month (GEMs)** donors—now 40 strong—remains instrumental in sustaining our work. Additionally, a number of dedicated members continue to organize birthday fundraisers, demonstrating the collective power of small, consistent contributions in making a lasting impact.

G.E.M.
GIVE EVERY MONTH

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D&I CONTNUED FROM PAGE 4

As we closed out 2024, The Life Raft Group launched an exciting new initiative: the **LRG Athletes Program.** This program is designed to empower individuals to achieve their athletic goals while supporting the GIST community. Whether running a marathon, cycling through rugged terrain, or participating in a personal challenge, LRG Athletes push their limits while raising awareness and critical funds for research, advocacy, and patient resources.

Expanding Patient Support & Education

Regular support group meetings continue to provide a vital space for members to connect, share, and find strength in a community that truly understands. Our **GIST Mentor Program** remains a lifeline for those navigating diagnosis and treatment. Since launching in 2019, the program has grown tremendously. In 2024, we proudly feature 42 mentors (U.S. & International) who have provided guidance and encouragement to over 300 mentees. The program thrives under the leadership of Santy DiSabatino, a dedicated patient advocate and LRG Board Member, alongside our Global Coordinator, Piga Fernández.

Recognizing the need for stronger regional leadership, the State Leader Program officially transitioned into our new **Regional Leader Program**. Many of our leaders now oversee multiple states, expanding their impact. Regional Leaders are an invaluable resource, helping patients and caregivers find local support groups, navigate resources, and connect with the broader GIST community.

Education remains a core focus of The Life Raft Group. In 2024, between in-person and virtual sessions, we hosted four GIST Days of Learning (GDOLs), reinforcing our commitment to accessible, expert-led education. These events provided cutting-edge insights and connected patients with leading GIST specialists. In-person GDOLs took place in Chicago in partnership with Northwestern University Feinberg School of Medicine, and in Columbus, Ohio, in collaboration with the Ohio State University Wexner Medical Center. Our virtual GDOLs were held in partnership Sylvester Comprehensive Cancer Center University of Miami Health and the University of North Carolina School of Medicine.

These events engaged hundreds of members of our community, strengthening knowledge and support networks across the GIST landscape. As we reflect on 2024, we remain steadfast in our mission to provide education, mentorship, and advocacy for the GIST community and beyond.

INFORMATION, EDUCATION & ADVOCACY

In 2024, The Life Raft Group remained committed to delivering impactful educational programs for patients and caregivers, empowering them to take a proactive role in their care and advocate for themselves. When patients are equipped with the latest insights from global GIST and sarcoma experts, they are more likely to ask informed questions, explore different treatment options, and chart a course toward the best possible care.

Our work is driven by the needs and voices of patients. Every webinar, educational outreach, and campaign is shaped by the conversations we have with patients about what matters most to them. We take pride in providing the information patients need in formats that are easy for them to access, knowing that this knowledge is crucial for their survival and well-being with GIST.

Webinars

The Life Raft Group partnered with experts in the field and patient advocates to host thirteen webinars in 2024. All webinars are available for patients to refer to on our website and YouTube channel. Topics and speakers of 2024 webinars were:

Gaining Insight on the INSIGHT Phase 3 Clinical Trial
Speaker: Dr. Neeta Somaiah, MD Anderson Cancer Center
Date: April 11, 2024

How to Educate Yourself on GIST Research: Searching the Web for GIST Science Publications
Speaker: Jim Hughes, LRG Clinical Trials Database Coordinator
Date: April 30, 2024

Demystifying Clinical Trials: Insights from Experts & Participants
Speaker: Dr. Candace Haddox, Dana-Farber Cancer Institute and Kandee Evans, GIST Patient Advocate
Date: May 22, 2024

Updates from ASCO
Speaker: Dr. Herber Loong, Chinese University of Hong Kong
Date: June 18, 2024

GIST Awareness Day: A Focus on GIST Research
Speaker: Dr. Matthew Hemming and Favour Akabogu, PhD Candidate of UMass Chan Medical School
Date: July 13, 2024

Managing Side Effects of GIST Therapies
Speaker: Dr. Mia Weiss, Washington University School of Medicine in St. Louis
Date: August 19, 2024

Locoregional Therapies for Treatment of GIST in the Liver
Speaker: Dr. Edward Kim, Mount Sinai Medical Center
Date: September 9, 2024

IDRX-42: Trial Design and Emerging Data from the StrateGIST 1 Study
Speaker: Dr. Suzanne George, Dana-Farber Cancer Institute
Date: October 7, 2024

Know Your Mutation: Why is Biomarker Testing Important in GIST?
Speaker: Dr. Calvin Chao and Michelle Harris of Tempus
Date: November 6, 2024

GIST Updates from CTOS
Speaker: Dr. Thierry Alcindor, Dana-Farber Cancer Institute
Date: November 25, 2024

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INFORMATION, EDUCATION & ADVOCACY CONTINUED FROM PAGE 6

Biomarker Testing Campaign

The LRG strongly recommends biomarker testing for all GIST and sarcoma patients considered for drug therapy, provided that sufficient tumor material is available for testing. We have established close collaborations with leading GIST experts, whose work has highlighted the significant benefits of genomics-driven targeted treatments. Thanks to our commitment to testing, patients in the LRG registry have higher rates of biomarker testing and improved survival outcomes compared to the general patient population.

In 2024, The Life Raft Group brought together a diverse group of GIST Patient Advocates with lived experience to establish the LRG Health Equity Council (HEC). This marks a major step in our mission to provide every GIST patient with the resources and education they need not just to survive, but to thrive. The HEC, which currently has seven members, meets biweekly to research and develop strategies for engaging marginalized groups of GIST patients, ensuring they receive crucial information about biomarker testing. The Life Raft Group is confident that the formation of this council will significantly increase biomarker testing rates, particularly among our most vulnerable patients.

Additionally, The Life Raft Group continues to offer free biomarker testing to U.S.-based GIST patients through our partnership with Tempus.

DATA MANAGEMENT & RESEARCH

Data Management & Research has had an extraordinary year marked by groundbreaking achievements in advancing research, fostering global collaborations, and driving innovation to improve outcomes for patients with gastrointestinal stromal tumor. This report outlines our major accomplishments, including scientific contributions, conference presentations, strategic partnerships, and the establishment of transformative initiatives that position us as leaders in the field.

Scientific Contributions and Conference Presentations

Our department has actively engaged with the global scientific community, presenting pioneering research and collaborating with leading institutions and researchers to push the boundaries of GIST research. *Below are the key highlights:*

Posters Presented at Scientific Conferences

1. **ASCO GI (American Society of Clinical Oncology Gastrointestinal Cancers Symposium) Characteristics and Predictors of Outcomes with Neoadjuvant Imatinib in Gastrointestinal Stromal Tumors: Real World Data from a Large Patient Registry**
   This innovative study, conducted in collaboration with Dr. Udhayvir Grewal (University of Iowa), provided critical insights into treatment outcomes and predictors, contributing to the optimization of neoadjuvant therapy strategies.

2. **ESMO (European Society for Medical Oncology) Real-world efficacy of imatinib in patients with advanced GIST: The LRG registry.** In partnership with Dr. Adrianne Victor and Dr. Gim Gahyun, this research highlighted real- world treatment efficacy, offering valuable data to inform clinical decision-making and improve patient outcomes.

3. **GISTT Summit - Essen, Germany**
   - Unlocking Insights: The Power of the LRG Patient Registry
     This presentation showcased the extensive capabilities of the LRG Patient Registry in driving research and unlocking actionable insights for the GIST community.
   - Dual Mutations in SDH-Deficient GIST
     This study shed light on the complexity of SDH-deficient GISTs, providing a foundation for future research into dual mutations and their clinical implications.
   - The Life Raft Group was proud to be a Platinum Sponsor of this event.

4. **CTOS (Connective Tissue Oncology Society)**
   - D842V - A Tale of Two Stages: Comparative Analysis of Overall Survival and Treatment Response in GIST Patients with PDGFRA D842V Mutations - This analysis offered a comprehensive understanding of the unique challenges and opportunities in treating patients with D842V mutations.
   - Loss of PTEN Expression in MiniGISTs and Clinically Relevant GISTs Conducted in collaboration with Dr. Joanna Przybyl (McGill University) and Dr. Xiaolan Feng (Tom Baker Cancer Center)
     This study explored the molecular underpinnings of PTEN loss and its implications for GIST progression.

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5. Additional Research

Predicting the Imatinib Response of PDGFRA Exon 18-Mutant Gastrointestinal Stromal Tumor Using In Vitro Models led by Dr. Michael Heinrich and Ph.D. candidate Homma Khosroyani (OHSU), this research leveraged cutting-edge in vitro models to predict treatment response, paving the way for personalized medicine approaches.

Speakers at Scientific Conferences

ASCO (American Society of Clinical Oncology) Denisse Evans, Senior Director of Data Management and Research, served as a distinguished faculty speaker, delivering a presentation on Leveraging Patient Engagement Through Collaboration for Improved Global Health Outcomes in Sarcoma. This work emphasized the importance of patient-centric approaches and cross-institutional partnerships in addressing disparities and improving outcomes in sarcoma care worldwide. This impactful presentation was followed by a chapter contribution to the ASCO Educational Book, developed in collaboration with Dr. Matias Chacon (Alexander Fleming Cancer Center) and Lynne Hernandez (Executive Director, Desmoid Tumor Foundation).

GISTT Summit - The GISTT Summit provided a comprehensive state-of-the-science review on GIST biology and treatment strategies while fostering collaboration among researchers, clinicians, industry, and advocacy groups to advance high-priority projects. Jerry Call, Data Analyst for The Life Raft Group, highlighted the challenges of overcoming resistance in GIST treatment. He noted a "Catch-22" where imatinib's success discourages innovation, despite tumors becoming more aggressive in later stages. Call stressed the importance of early intervention, especially for KIT-driven GIST, to improve outcomes and work toward a cure.

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Strategic Partnerships and Initiatives

Establishment of SDH-Deficient Biobank and Centralized Database

In a landmark achievement, The Life Raft Group has partnered with the National Institutes of Health (NIH) and the University of California, San Diego (UCSD) to establish the SDH Biobank. Spearheaded by Dr. Andrew Blakely (NIH) and Dr. Jason Sicklick (UCSD), this initiative represents a transformative step in advancing research on SDH-deficient GIST. The biobank facilitates the collection, analysis, storage, and distribution of biospecimens, creating a centralized resource for researchers worldwide. This collaboration underscores our commitment to accelerating discoveries and fostering innovation in rare tumor research.

Data Collaborations

In 2024, we made significant strides in understanding GIST through strategic data collaborations, including valuable insights derived from our LRG Patient Registry, which now hold 2824 GIST patients from around the world. These partnerships have advanced our knowledge in several key areas:

- Neoadjuvant Gleevec Studies: Collaborations with leading institutions, supported by data from our patient registry, identified predictors of response and outcomes for neoadjuvant Imatinib (Gleevec) therapy, providing actionable strategies to optimize treatment plans.
- SDH-Deficient Mutations: Working with researchers from multiple institutions, we leveraged registry data to deepen our understanding of SDH-deficient mutations, uncovering their unique biological mechanisms and potential therapeutic targets.
- Dual Mutations in GIST: Collaborative studies, informed by patient registry data, explored the complexities of dual mutations, shedding light on their role in treatment resistance and disease progression.
- Biomarker Identification: Through global partnerships and data from our registry, we identified potential biomarkers for diagnosis and treatment efficacy, advancing personalized medicine approaches.
- Imatinib Sensitivity Research: Joint projects with academic institutions, utilizing registry data, enhanced our understanding of Imatinib sensitivity, refining therapeutic protocols to improve patient outcomes.
- GIST Risk Collaboration: A global working group of academic institutions collaborated to optimize risk tools for GIST patients. This effort aims to better characterize the risk of recurrence, providing more precise assessments to guide clinical decisions.

These collaborations, enriched by the data from our patient registry, highlight the power of collective expertise and shared resources, reinforcing our commitment to leveraging partnerships for groundbreaking discoveries and improved care.

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DATA MANAGEMENT & RESEARCH CONTINUED FROM PAGE 10

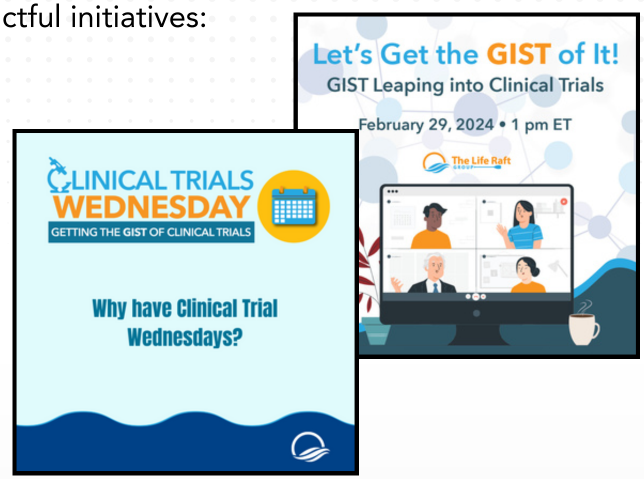
LRG Virtual Tumor Board

In 2024, we hosted a LRG Virtual Tumor Board, uniting experts from multiple institutions to review a particularly complex GIST case. This multidisciplinary forum enabled in-depth analysis of treatment resistance and mutation profiles, fostering collaborative decision-making.
The session highlighted the value of shared expertise in addressing a challenging case and reinforced our commitment to advancing GIST research and improving patient care.

LRG Patient Membership and Educational Events

In 2024, we welcomed 309 new members to the LRG community, strengthening our network of patients, caregivers, and advocates. To educate and inspire our growing membership, we launched several impactful initiatives:

- "Let's Get the GIST of It" Series: This educational program focused on understanding GIST mutations, their role in the disease, and related topics such as clinical trials and pathology reports.
- "Clinical Trials Wednesday": A new initiative aimed at educating members about clinical trials, empowering them to explore innovative treatment options.
- Patient of the Month Stories: We highlighted the brave and empowering journeys of our patients, sharing their stories to inspire and connect our community.
- Free Tissue Testing Initiative: To ensure every patient receives mutational testing, we offered free tissue testing, providing critical insights for personalized treatment planning.



These efforts underscore our commitment to providing valuable resources, fostering education, and celebrating the resilience of the GIST community.

LRG PATIENT REGISTRY - Advancing the LRG Patient Registry

We are excited to share progress on our new and improved LRG Patient Registry platform, set to launch in 2025. This enhanced platform will integrate cutting-edge technology to provide patients with advanced tools for tracking and managing their GIST journey.

As part of the upgrade, we are optimizing the data fields we capture to include new features such as tumor evolution tracking, which will allow patients and researchers to monitor tumor response and progression over time. Additionally, the platform will include a user-friendly dashboard, enabling patients to easily view and update their health information while accessing personalized insights into their disease and treatment outcomes.

These enhancements reflect our dedication to leveraging innovation to empower patients, improve research efforts, and drive meaningful progress in the fight against GIST.

Rare Disease Initiatives Beyond GIST

This year, TGCT Support proudly marked its 5th anniversary! Over the past five years, we have overcome numerous challenges and touched the lives of countless patients. Guided by our mission to support those affected by TGCT and GCT, we have made remarkable strides in raising awareness and harmonizing the global management of these rare diseases.

In 2024, we achieved a groundbreaking milestone by analyzing, submitting, and presenting the first-ever patient-driven research project in TGCT. This project shed light on the unmet needs and challenges faced by patients navigating various healthcare systems. Additionally, we presented two impactful posters highlighting the patient experience with TGCT. Our efforts culminated in presenting this data as a podium talk at the Connective Tissue Oncology Society (CTOS) annual conference and submitting it for publication in a medical journal. Fueled by our passion, we initiated three additional research projects this year—and we're just getting started! Our support groups have grown to over 1,000 members from 48 countries,with six virtual groups designed to connect our geographically diverse community. We remain committed to providing accessible resources and fostering a global network of support for all patients, regardless of location.

Education has been another cornerstone of our work in 2024. We hosted three webinars, a TGCT Day of Learning (TDOL), and expanded our efforts internationally by hosting one patient conference session in Italy. These events brought together 40 patients in Italy and 60 in Colorado, showcasing the strength and unity of our community to providers and pharmaceutical partners. In a first for TGCT Support, we collaborated on a Continuing Medical Education (CME) course with PeerView, equipping healthcare providers with the latest advancements in TGCT management. Together, we have solidified TGCT Support as a vital resource for patients, providers, and researchers.

In the United Kingdom, we launched a groundbreaking initiative to develop referral criteria for patients with diffuse TGCT. By partnering with key opinion leaders, we aim to create a standardized approach to help patients navigate the NHS and ensure timely, multidisciplinary care. The positive response from UK providers highlights the significance of this effort and the resource challenges they face.

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TGCT SUPPORT CONTINUED FROM PAGE 12

Our commitment to raising awareness and amplifying the patient voice remains unwavering. We collaborate with stakeholders across sectors to ensure patients guide all activities, fostering a brighter future for those affected by TGCT.

As we celebrate these accomplishments, we also look forward to the future. The past five years have proven that our collective resilience, resources, and determination can change the course of this rare disease for the better.

Thank you to everyone who has supported us—your contributions fuel our mission. Together, we will continue to drive progress and make an even greater impact in the years to come.

Webinars

TGCT in the Youngest Patients
Speaker: Dr. Thomas Scharschmidt, Nationwide Children's Hospital Date: September 18, 2025

Navigating Insurance and Claims
Speaker: Monica Bryant, Triage Health
Date: August 6, 2024

Educational Events - Day of Learning (TDOL)

TGCT Days of Learning are free, one day events for TGCT patients and their families to benefit from hearing important educational topics related to this rare disease, gain support from one another, and spend quality time with doctors who share cutting-edge disease information.

On July 27th, 2024, TGCT Support partnered with University of Colorado Anschutz Medical Campus to host a TGCT Day of Learning event. Over 70 patients and caregivers convened to engage with the TGCT medical community and learn about the latest treatment options, surgical information, orthopedic perspectives, and coping mechanisms.

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LIPOSARCOMA SUPPORT NETWORK

Since our launch in October, we have made remarkable strides in fulfilling our mission to connect, support, and empower liposarcoma patients and caregivers worldwide. We are proud to have welcomed members from across the globe and all sub-types of liposarcoma. This community underscores the universal need for resources and support for this rare disease.

During this time, we have had the privilege of connecting with many sarcoma specialists who share in our commitment to improving patient support and advancing awareness and research in the sarcoma community. As a result, partnering with Dr. Neeta Somaiah of MD Anderson for our first a webinar was pivotal in demonstrating our commitment to providing valuable resources and support to patients.

We are proud to have offered our first patient support group series to the liposarcoma community. This has quickly become a cornerstone of our efforts, offering a safe space for individuals to share experiences, exchange valuable insights, and foster meaningful connections.

In addition, we launched a comprehensive newsletter that highlights program updates, shares stories from our community, and delivers educational content tailored to our members' needs. The response to the newsletter has underscored its value as a resource for keeping our community informed and inspired.

Lastly, our commitment to raising awareness and sharing our work on a global scale led to the creation of a compelling poster that was showcased in the patient advocacy lounge at the 2024 Connective Tissue Oncology Society (CTOS) Annual Meeting. This opportunity not only highlighted our program's approach but also fostered collaborations with experts and organizations dedicated to advancing our shared goals.

As we reflect on these accomplishments, we are inspired by the resilience and enthusiasm of our community. Together, we have laid a strong foundation for continued growth and impact, and we look forward to building on this momentum in the coming year.

Our first educational webinar was:
Liposarcoma 101
Speaker: Dr. Neeta Somaiah, MD Anderson Cancer Center
Date: December 6, 2024

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