



NAVIGATING TOWARD A **CURE FOR RARE DISEASES**

Strategic Plan
2025-2030





A MESSAGE FROM OUR EXECUTIVE DIRECTOR

The Life Raft Group is pleased to present its strategic plan for the next five years (2025-2030). This comprehensive plan outlines key objectives and initiatives that will guide the organization's efforts to enhance its impact and address the challenges posed by rare diseases.

The strategic plan encompasses core goals, including expanding our impact, diversifying disease support, enhancing community engagement, and innovating patient data management. Each objective aligns with the organization's overarching mission to improve the survival and quality of life for individuals affected by Gastrointestinal Stromal Tumor (GIST) and other rare diseases.

Embedded within the plan are the organization's core values — **Empowerment, Patient Focus, Innovation, and Collaboration (EPIC)**. These values serve as a foundation, shaping the organization's decisions, actions, and its cohesive, purpose-driven community.

The accompanying financial strategy underscores the organization's commitment to leveraging diverse funding sources. A significant component of this strategy is the anticipated launch of a capital campaign for the expansion of the organization's registry, which is a crucial step toward ensuring long-term financial sustainability.

This strategic plan is a roadmap that reflects the collective dedication of The Life Raft Group to its mission. Stakeholders, supporters, and collaborators will be invited to engage with and contribute along this shared journey. Together, we will work toward a future free from the challenges posed by rare diseases.

Thank you for your continued support and commitment to the mission of The Life Raft Group.



Sincerely,

Sara Rothschild

Executive Director



*"We have the power to
create positive change for
the GIST community."*



OUR MISSION

The Life Raft Group is committed to enhancing the survival and quality of life for people living with Gastrointestinal Stromal Tumor (GIST), and other rare diseases, through patient-powered research, education and empowerment, and global advocacy efforts.

At the heart of our organization lie core values that serve as the guiding principles shaping our mission and vision.

These values not only define who we are but also drive the decisions we make and the actions we take. Grounded in a commitment to excellence, integrity, and innovation, our core values create a foundation that empowers us to navigate challenges, foster meaningful relationships, and consistently deliver impactful outcomes.

In this pursuit of our goals, these core values serve as the compass that directs our efforts and unites us as a dedicated and purpose-driven community.



CORE VALUES

- » Empowerment
- » Patient Focus
- » Innovation
- » Collaboration



OUR VISION

To empower a future fueled by data, guiding our journey toward **cures for rare diseases.**





25 YEARS OF SERVICE to the GIST Community

OUR
PARTNERS



5 YEAR
PLAN

GOALS

1

Expand our Impact

2

Diversify Disease
Support

3

Enhance Community
Engagement

4

Innovate Data
Management
& Research

2030



Thank you, LRG, for all you do for us. Thank you, caregivers! We couldn't fight the fight without you!

- Manuel Salinas, GIST Patient



STRATEGIC PLAN GOALS & METRICS

Expand our Impact

1

Extend our reach to a wider community, aiming to significantly increase the number of new patients benefiting from our services annually.

Five-Year Metrics to Evaluate Core Goals

- Double the number of new patients assisted annually.
- Measure the percentage increase in the geographical coverage of our membership.
- Track the diversity of services provided to ensure a well-rounded impact.

Enhance Community Engagement

3

Foster a stronger sense of community involvement by doubling the number of individuals contributing to and supporting our mission, thereby creating a more robust network of advocating for our cause and donating to our mission.

Five-Year Metrics to Evaluate Core Goals

- Double the number of individual donors contributing to our mission.
- Measure growth in social media engagement through analytics.
- Conduct surveys or feedback sessions to gauge the community's perception of our mission and their level of involvement.

Diversify Disease Support

2

Broaden our commitment to health advocacy by expanding the range of diseases we address, ensuring a comprehensive approach to healthcare support.

Five-Year Metrics to Evaluate Core Goals

- Expand to three additional diseases.
- Monitor the engagement level for each disease category.
- Assess the effectiveness of educational programs tailored for each supported disease.

Innovate Data Management & Research

4

Launch an updated, state-of-the-art patient registry platform and extend its scope to encompass three additional diseases, facilitating more comprehensive and impactful solutions for the community.

Simultaneously, advance research initiatives by spearheading cutting-edge endeavors and collaborating with leading experts to propel breakthroughs in the rare disease field.

Five-Year Metrics to Evaluate Core Goals

- Successfully launch new patient registry platform within the first year (2025).
- Monitor the platform's adoption rate among patients/caregivers, researchers, and other rare disease advocates.
- Measure the number of collaborative research initiatives implemented.

KEY AREAS OF FOCUS



INCREASE EMPOWERMENT & ENGAGEMENT



PARTNERSHIP & COLLABORATION



RESEARCH



GROWTH & DEVELOPMENT

STRATEGIC PRIORITIES

INCREASE EMPOWERMENT & ENGAGEMENT



- Enhance member engagement by implementing targeted communication strategies.
- Establish a feedback mechanism to continually assess the level of empowerment within the organization.
- Introduce initiatives that recognize and celebrate achievements, fostering a culture of engagement.
- Foster ways to reach communities of color to educate and spread awareness about rare diseases.
- Develop and implement training programs to empower staff and community members.

RESEARCH



- Identify key research priorities
 - Influence the future of clinical trials
 - Prioritize data collaborations
 - Focus on both internal and external research
 - Launch a tissue/data sharing campaign to acquire and provide tissue access to researchers
- Establish partnerships with research institutions to leverage expertise and resources.
- Develop a research roadmap with clear timelines and milestones.
- Allocate resources for data collection, analysis, and dissemination of research findings.

PARTNERSHIP & COLLABORATION



- Identify potential partners whose goals align with the organization's mission.
- Establish and nurture relationships with key stakeholders, including other organizations, medical professionals, government health agencies, and industry partners.
- Facilitate collaboration through joint initiatives, events, or projects.
- Evaluate and measure the impact of partnerships on organizational objectives.
- Increase media presence and awareness about rare diseases through collaborative campaigns and shared initiatives with partners.

GROWTH & DEVELOPMENT



- Expand the board by identifying and recruiting passionate individuals with diverse backgrounds and expertise for advancing the organization's mission.
- Establish a Health Equity Advisory Council to provide insights and guidance on organizational strategies.
- Foster a culture of collaboration and engagement with our Medical Advisory Board and Science Team, recognizing and celebrating achievements.
- Implement targeted training programs to enhance staff skills and foster professional development.

OUR FINANCIAL STRATEGY

At The Life Raft Group, we are committed to ensuring a vibrant and sustainable future. To achieve this, we've crafted a comprehensive financial strategy that embraces diversity and innovation in funding sources:

» Diverse Funding Landscape

- Explore a range of funding avenues, including individual donors, corporate partnerships, grants, and strategic alliances. Actively seek new funding opportunities aligned with our mission and initiatives.

» Engaging Donors

- Develop strong relationships with individual and major donors, ensuring transparent communication about the impact of their contributions.
- Educate community about long-term support through multi-year and planned giving options.

» Build a Larger Volunteer Base

- Utilize a community of volunteers to support our mission.

» Strategic Partnerships

- Initiate collaborations with other organizations to ensure mutual benefit to maximize resources, open new funding opportunities, and extend our reach.

» Innovative Revenue Streams

- Explore avenues that align with our mission to offer consultation services and expand our registry platform. These efforts aim to support a wider range of diseases while ensuring financial sustainability for our organization.

» Investing in Insights: Expanding the Patient Registry

- Expand our current registry platform by securing the necessary resources for long-term financial stability, ensuring sustained impact for years to come.

» Digital Fundraising and Technology

- Leveraging technology, embrace online fundraising campaigns, crowdfunding, and digital platforms to reach a broader audience.

» Transparent Financial Reporting

- Maintain transparency in financial reporting, showcasing how funds are utilized to build trust with our supporters.

» Continuous Adaptation

- Maintain a dynamic financial plan, adapting to changing economic conditions, donor trends, and organizational needs.



Ensuring a Sustainable Future

By embracing this multifaceted approach, we ensure that The Life Raft Group remains resilient, adaptable, and well-positioned to advance our mission and create positive, lasting change.



OPERATIONALIZING THE PLAN

This operationalization plan serves as the backbone of our implementation strategy, ensuring the dynamic and effective execution of The Life Raft Group’s 5-year strategic plan.

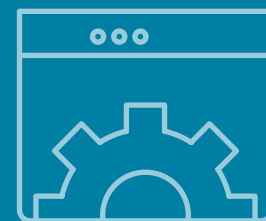
Here are **three key steps** we will take to transform our strategic vision into a “living plan” that guides our actions, fosters accountability, and adapts to change.



STEP ONE

Strategic Communication

- Disseminate the 5-year strategic plan to our community.
- Utilize LRG and related events to share our vision for the future.
- Integrate the plan into ongoing staff discussions, board and advisory meetings, and other areas.



STEP TWO

Strategy Dashboard

- Develop a comprehensive strategy dashboard organized around the plan’s goals and initiatives, incorporating high-level Key Performance Indicators (KPIs).
- Share the dashboard with staff and the board on a yearly basis to transparently communicate progress and facilitate informed decision-making.



STEP THREE

Strategy Refresh

- Schedule a strategy “refresh” approximately 18 months after the adoption of the plan.
- Focus on environmental changes, incorporate lessons learned, reassess priorities, and validate the relevance of financial projections, KPIs, and other indicators.
- Ensure that the strategic plan remains agile, responsive, and aligned with the organization’s evolving needs and context.

My GISTory



ROB TAYLOR

GIST Patient & Advocate
GIST Mentor

At age 60, it was time for me to get a routine colonoscopy. I went to my doctor to get her to write an order for the procedure, but she wanted to examine me first. I thought this was a waste of time because I was eating clean and exercising regularly. During the exam, she said that she felt something in my stomach and ordered a CT scan. The evening after my scan, I felt a severe pain in my stomach and passed out. At the hospital I was told I had a large mass in my stomach and needed an operation. The surgery was unsuccessful; the surgeon could not remove the tumor. The surgeon told me I had a tumor called a “GIST”; however he did not explain what that was and did not tell me it was cancerous.

I was then referred to another surgeon and scheduled for a Whipple procedure at different hospital. This surgeon was also unable to remove the tumor. He told me that there is nothing that he could do and to see an oncologist.

My oncologist told me that she was not familiar with GIST and referred me to the Director of Sarcoma at a university hospital for advice. I was getting CTs, MRIs and PET scans. The surgeon and the two oncologists had conflicting opinions on my tumor and could not confirm if the tumor was growing or stable.

With each visit I was getting a different story and my anxiety, and hopes were like a yo-yo. I couldn’t stomach anxiety medication, and my oncologist suggested that I join a support group. I knew that this was not happening because that is not the manly thing to do.

“I eventually found The Life Raft Group online and was impressed. I signed up and started going to the meetings.”

I was doing research from the information shared with me and had workable knowledge of each mutation as I was waiting on my mutation report to come back. When the report came back it conveyed that I had no known mutation and considered “wildtype”. The Director Oncologist told me that I had a 90% chance to live only 6-9 months and he did not see a need for additional testing.

"You all are a great collection of selfless people who compassionately care for folks that have great need. You listened to Santy's heart and supported his vision (for the GIST Mentor Program). You treat us Mentors like gold and we have learned to have great love for each other. Thank you for each time that you have brought us together."



I had the great opportunity to attend ASCO and volunteered at The Life Raft Group's table (something I will never forget). I had the chance to meet LRG Executive Director Sara Rothschild and Deputy Executive Director Laura Occhiuzzi.

I was very impressed with how hard they were working to advocate for us. They took time to talk to me and put me on the right path. I could tell that they genuinely cared and were committed to helping me.

They introduced me to one of the leading GIST specialists in the country and helped me to get an appointment with him.

The GIST specialist put my tumor sample through additional testing. The tests indicated a variant of unknown significance in NF-1. My LRG state leader, Jim Hughes had me get a comparative study of all my previous CTs and examined my mutational reports. After his research, Jim wrote to the oncologist that he felt that my mutation was in NF-1 and suggested that I be prescribed a recently approved drug (selumetinib).

That was four years ago, and I currently have no tumor growth.

"I am extremely grateful. I have a new perspective on life. I've come to appreciate life more & to be grateful & to show people how grateful I am."

- Rob

