



## **Life Raft Group** *Ensuring that no one has to face GIST alone!*

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## **LIFE RAFT GROUP ANNOUNCES LATIN AMERICAN GIST COALITION**

### **A Call to Action: New Group Initiates Cancer Awareness Campaign in Latin America**

**Wayne, N.J.**— Life Raft Group (LRG), an international patient-based organization dedicated to finding a cure for a deadly cancer called gastrointestinal stromal tumors (GIST), announced today the foundation of the **Latin American GIST Coalition**, a partnership of patient advocates representing ten Latin American countries who have convened to create the **Latin American GIST Initiative** for the GIST community.

Each year, 5,000-10,000 people in the United States are diagnosed with GIST, a rare form of cancer, for which there is no known cure. Unfortunately, there are no statistics about the incidence of this disease in Latin America; however, research is underway to investigate the rates of this disease in the region. The LRG has identified a need to close the information gap in Latin America among GIST patients, caregivers, and their healthcare professionals. The Latin American GIST Initiative aims to improve the survival rate of GIST patients with current treatment options, close the gap between scientific knowledge and clinical treatment of GIST, identify and reach more patients and key medical professionals, and empower patients to take charge of their own care.

The founding members of the LRG's Latin American GIST Coalition include: Sandra Mesri of Argentina, Vicky Ossio of Bolivia, Dr. Alexandre Sakano of Brazil, Piga Fernandez Kaempffer of Chile, Dr. Rafael Vega of Colombia, Dr. Michael Josephy of Costa Rica, Alejandro Miranda of Dominican Republic, Rodrigo Salas of Mexico, Fabrizio Martilotta of Uruguay, Maria Isabel Gomez de Soriano of Venezuela, and Pat Garcia-Gonzalez of The Max Foundation. Working together, this group has the potential to enable thousands of patients to become experts at navigating their care for this rare cancer, as well as to engage and mobilize the medical community to improve the management of GIST.

In most Latin American countries, cancer patients do not participate in cancer support organizations for reasons such as cultural factors, lack of information or lack of interest. "It is a challenge to identify and reach GIST patients to share more information about their disease. With the LRG's help, we need to find and empower patients and caregivers to stand up for their rights and participate in the decision-making process for their treatment plan. We cannot let patients die due to lack of information on their part or their physicians' part" says Vicky Ossio, the Latin American Coordinator and Facilitator of the Latin American GIST E-mail Community.

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**For more information:**  
<http://www.lifteraftgroup.org/newsroom.html>



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Unlike having the National Institutes of Health in the United States, most of the countries in Latin America do not have a centralized system of care to track statistics and management of cancer cases, nor sufficient treatment options. "Latin American countries are behind in the clinical trial process, making it difficult to extend the lives of many of these patients. We need to collaborate with the teaching and medical institutions in each country to spread awareness about this problem and get diseases such as GIST on the radar screen" says Rodrigo Salas of Mexico, who has already started working with Monterrey Institute of Technology to begin such a collaborative effort.

With the LRG's experience of being a world-renown patient advocacy group, the Latin American GIST Coalition has the right tools to carry out its strategic plan to provide information, education, and new treatment horizons to the Latin American community.

### ***More about the Life Raft Group (<http://www.liferaftgroup.org>):***

*The Life Raft Group (LRG) is an organization that provides support, information and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG offers a range of support and educational services including: an online community for patients and caregivers, local in-person support meetings, websites, monthly newsletters, webcasts and one-on-one patient consultations. In addition, the LRG is aggressively working to find a cure for by funding an international team of GIST research scientists. The LRG blueprint for ensuring the survival of GIST patients is based upon a long-term strategy of finding a cure for this disease through research and an immediate strategy to keep patients alive through information and education.*

### ***More about GIST:***

*GISTs belong to a group of rare cancers called soft tissue sarcomas that can occur in connective tissues, bones, muscles, fat, nerves, blood vessels, and cartilage. About 40-70% of GISTs originate in the stomach, 20-40% in the small intestine, and 5-15% in the colon and rectum. In 2000 scientists discovered a way to properly diagnose GISTs by testing for a mutation in the C-Kit gene. That same year the introduction of Gleevec® (imatinib mesylate), a molecularly targeted drug specific to the C-Kit gene resulted in an 85% response by GIST patients who had previously had few effective treatment options. With patients now developing resistance to Gleevec® LRG is racing against the drug resistance clock to find new treatments to save their lives.*

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