This year’s cover art is a pencil sketch of a Norman Rockwell painting done many years ago by LRG member Jennifer Bayles. Jennifer, a talented graphic artist, waved goodbye to the art world when an opportunity arose to be a wife and mother. A job she did very well. Jenn died on February 18, 2010, leaving behind an adoring husband, two terrific boys and a lot of GIST friends. Her dear friend Matthew Clay Barnes, another gifted artist, painted this portrait as a gift to her husband and his way of saying goodbye.
Greetings from the Life Raft Group

Dear friends,

The year 2009 was one of many themes.

It was a year of expansion for the Life Raft Group (LRG), particularly in our communications with the world. In 2009, the LRG launched the Latin American GIST Coalition, a group representing ten Latin American countries and whose aims include improving the survival rate of GIST patients in Latin America. The LRG also expanded its range to include social networks like Facebook and Twitter, not only reaching more GIST patients and caregivers, but spreading GIST awareness to a whole new group of people.

Innovation was another key theme for the year as we launched several initiatives that took traditional methods and presented them in new and more effective ways. The GIST Collaborative Tissue Bank was created to allow GIST researchers worldwide to access GIST tissue linked to patient-provided clinical histories. Due to privacy laws, this connection would not be possible without the LRG. The LRG Patient Registry was rebuilt in an effort to make these clinical histories much more concise and informative, finally introducing the “GISTory”, a document containing a patient’s GIST medical history, a tool for patients to better track their diagnosis, treatment and scans. Because of all of this, the LRG was able to publish a breakthrough study on the relationship of Gleevec dosage to progression-free and overall survival in the Journal of Gastrointestinal Cancer.

It was also a year of perseverance for the LRG. Despite the financial turmoil the United States faced, we continued in our quest to find a cure for GIST with the dedication we expected of ourselves as a non-profit. Our successes are a testament to the dedication and generosity of our donors who continued to support us during a time that made it difficult for most to do so.

Thank you all for your help. Together, we will find a cure.

Sincerely,

Jerry Cudzil
President

Norman Scherzer
Executive Director
The LRG’s mission is to direct research to find a cure for GIST and help those affected through support and advocacy until we do. To accomplish this mission, the LRG devotes its efforts to the following major program areas.

Information and Support

Each year, in addition to any new initiatives, the Life Raft Group strives to provide the most useful and up-to-date information to GIST patients and medical professionals through our newsletters, pamphlets, webcasts and websites.

Through these methods we offered information on cutting-edge research updates, breaking news, hereditary GIST, mutational and plasma testing, innovative clinical trials and more.

The new Pediatric GIST website was launched in 2009, bringing Pediatric & Wildtype GIST-specific information to the masses. There, members of the GIST community could read up on Pediatric GISTers’ stories, browse the Pediatric Reference Library or peruse pictures from the NIH Pediatric & Wildtype GIST clinic.

We took the webcast tool a step further this year by tackling new trends in treatment (“Optimizing Gleevec Therapy with Plasma Testing”), focused side-effect issues (“The Superficial Side of GIST: Taking Care of Your Skin During Therapy”), and hot-button issues (“Sutent and its Potential Cardiovascular Effects”).

The LRG also mounted a major translation of our education materials and key web pages into Spanish in combination with our Latin American GIST Initiative.

As always, we continued to provide support through our email communities; the Spanish language group took off in 2009, while the main email community reached a staggering 300-600 email posts per month!

GIST Outreach

Expansion truly was a key theme of 2009; the LRG branched out to 5 new states in the US—Connecticut, Iowa, Montana, Nebraska & New Hampshire—bringing the total of local representatives and chapters to 39 states!

On an international level, the LRG added representatives and groups from Chile, Czech Republic, Macedonia, Nicaragua & South Africa. Forty-nine countries on 6 continents have a place to turn to for support and advocacy.

With the support of my family and friends, I will be hanging onto our “life raft” till the end. I’ve learned to live for today. But I still plan for the future.

– Paula Vettel

In 2008, we promised to “dramatically intensify our efforts to ensure that physicians understand and apply the very latest information for treating GIST.” In 2009, we climbed even higher toward that goal with the launch of the Latin American GIST Coalition.

Each year, 5,000 to 10,000 people in the United States are diagnosed with GIST. Adjusting for population, the numbers in Latin America are likely greater, roughly 7,000 to
The LRG has identified a need to close the information gap in Latin America among GIST patients and 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 Latin American GIST Coalition (LAGC) include: Sandra Mesri of Argentina, Vicky Ossio of Bolivia, Dr. Alexandre Sakano of Brazil, Piga Fernandez of Chile, Dr. Rafael Vega & Rafael Becerra of Colombia, Dr. Michael Josephy of Costa Rica, Alejandro Miranda of the Dominican Republic, Rodrigo Salas of Mexico, Fabrizio Martilotta of Uruguay and Maria Isabel Gomez de Soriano of Venezuela.

We were also privileged to see the advancement of sister groups this year as Israeli, Spanish and Colombian groups declared themselves to the world! The Israeli GIST Patients Organization became a proactive non-profit in 2009, with the goals of raising public awareness of GIST, promoting medical research, and educating Israeli GIST patients about relevant medical information. Spanish GISTers, with a little help from LAGC members formed a country-wide sarcoma group in an effort to help more patients.

The Fundación GIST Colombia also formed this year to provide information to Colombian patients about the disease and access to care so that they can become proactive managers of their cancer. The Colombian GIST group became a non-profit and also held their first meeting in Bogota.

This year, the LRG also expanded their presence in the worlds of Facebook, Twitter and other social networking sites, reaching out to not only more patients and caregivers but also medical professionals and supporters who were not yet well-versed in the world of GIST.
By diving into the Social Networking world head first, the LRG has spread GIST awareness to thousands of people all over the world. Our Facebook profile receives nearly 500 visits per week, while our cause has over 1,000 members!
Treatment & Surveillance

After its launch in late 2008, the Clinical Trials database was further refined by the Science Team at the LRG. In order for patients to more easily sift through the world of clinical trials, a set of basic components were created. One component, “Predefined Searches” allows the user, without entering any search criteria, to do a targeted search of the over 115 GIST-relevant trials in the database, such as a search for trials for patients who are resistant to Gleevec and/or Sutent. Another component of note is the “Drug Watch List”. This page is the place to go if you just want more information about a particular drug. The list shows the various names for the drug, manufacturer, and more detailed information like the drug’s known targets.

In 2009, the LRG continued its campaign to make mutational testing in GIST patients a routine practice. Despite a growing body of knowledge that mutational status can affect treatment effectiveness, most GIST patients still have not had this test performed and most treatment facilities still do not include mutational testing as a routine part of patient evaluation.

The LRG also encouraged patients taking Gleevec to undergo plasma (or blood level) testing in 2009. We believe that knowledge of plasma levels is an important piece of information for treatment management and that integrating such a test into routine clinical practice should start immediately. In 2010, the LRG will continue to devote its energies to these important campaigns.

The meticulous planning and sacrifices of earlier years in research paid off for the LRG in 2009. Progress was achieved by our Research Team on a broad number of fronts including:

- The development of a comprehensive blueprint for understanding the mechanisms of treatment resistance that develop following the failure of single drug regimens like Gleevec and Sutent
- The development of mechanisms to test new drugs in the laboratory, including genetically engineered mice that transmit particular forms of GIST from generation to generation and immortal cell lines (that can be replicated indefinitely) against which novel drugs can be tested
- Pre-clinical screening of drugs to evaluate both their potential efficacy and toxicity. A large number of these drugs have already entered clinical trials and others are in the planning stage
- The critical investigation into understanding why a small number of GIST cells may survive an otherwise successful drug treatment and methods of reverting these cells into a state in which they may more easily be killed.

As a part of its research efforts, the LRG launched the GIST Collaborative Tissue

Don’t pretend that everything’s okay, everything’s not okay, everything’s changed. It’s okay to cry and feel weak. It doesn’t mean you are weak; it just means you’re having a bad day.

- Janeen Ryan

Patrick Maguire

So I would cry alone in my bedroom at night, but afterwards collect myself, and vow to be brave, persevere, and accept whatever the future would bring and face it with as much dignity and courage I could muster.

- Patrick Maguire

Innovation Expansion

Perseverance
Choosing not to have my own children, so I can stay on Gleevec was not easy. The last couple of years were a roller-coaster ride for us, since we started the adoption process. Now we know that it was all worth it and we are blessed with our little milagrito (little miracle)...
Antonio Marcelo.
-Carolina Ponce-Williams
Vera Krstevska was born in November 1955 in Skopje, Macedonia. She works in a laboratory of the Clinical Center in Skopje. She is a proud mother of two sons and loving grandmother of four grandsons.

Vera was diagnosed with GIST in August 2007. She had her first gastrectomy with the tumor removed from her intestines. One year later, she had a recurrence in the stomach, intestines and liver. A second operation was successful at removing the tumors from her stomach and intestines, but two cysts remained in her liver. After consultation with her local oncologist and a GIST specialist located in Greece, Vera started Gleevec in January 2009.

Vera’s case is not much different from other GIST patients. What sets her apart, however, is the country in which she lives and its health system. Located in Southeastern Europe, the Republic of Macedonia is one of the successor states of the former Yugoslavia. Macedonia has a public health insurance system in which most treatments, operations, and general care are supposed to be covered by the government with little cost shared by the patient.

There is, however, a gap in the system—in particular for rare disease patients. The Ministry of Health has not prioritized funding treatment costs for rare diseases; therefore, most patients are left to find other ways to access life-saving treatment. When Vera began Gleevec, it was only through the generosity of donated pills. At that time, Gleevec was only covered for one rare disease, chronic myelogenous leukemia (CML, but within a year, a Ministry of Health policy change meant Gleevec would not be covered for anyone.

After a few tragic patient cases and coordinated outreach efforts among the Macedonian GIST, CML and rare disease communities, the Ministry of Health finally approved a program in 2009 to fund the treatment of rare diseases. Although this seems like a triumph, over a year has passed and the implementation of this program has yet to begin due to budgetary constraints.

With the help of the Life Raft Group and other international advocacy groups such as European Cancer Patient Coalition (ECPC), an aggressive letter-writing campaign was then initiated. It urged the Macedonian Minister of Health to advocate that Gleevec be covered by the Health Fund.

Over the past year, in conjunction with the letter-writing campaign, individual patients and the Macedonian Society of CML Patients (to which the GIST patients belong) have organized aggressive media campaigns to increase awareness to the public about the problems they have encountered.

Numerous meetings have been held with officials in the Ministry of Health and the Health Fund. Promises were made, yet no positive results have been achieved. As of today, people like Vera are still awaiting a positive response from the health authorities.

In order to keep patients like Vera alive, her family has appealed to the international GIST community to advocate for patients and push the Macedonian health authorities to cover Gleevec treatment in their Health Fund.

Vera’s plight and the plight of so many Macedonian patients is not restricted to one country. GIST patients continuously face barriers in accessing treatment in countries all over the world—including the United States. The LRG vows to continue advocating for GIST patients and to strengthen its efforts in 2010 so that no patient will ever be denied treatment.
Jerry Cudzil, President Managing Director, High Yield Debt - Global Capital Markets, Morgan Stanley, New York, NY

Jerry Cudzil trades high yield debt ranging from aviation to energy and paper and packaging. Jerry most recently worked for a hedge fund for the past 5+ years where he managed a multi-strategy portfolio. The portfolios focused on investing mainly in fixed income securities. Jerry’s 13+ years of investment experience spans from investment banking to portfolio management. Jerry joined the Life Raft Group 6+ years ago shortly after his father-in-law, Bill, was diagnosed with GIST. Bill lost his battle with GIST on Oct 15, 2008. Jerry is also on the board of Beat-the-Streets Philadelphia. BTS is a non-profit focused on bringing wrestling to inner city Philadelphia middle schools and high schools. The organization focuses on holistic development of these children. Jerry graduated from the University of Pennsylvania with a Bachelor of Arts in Economics and a minor in English. Jerry currently resides in New York with his wife and two children.

Stan Bunn Customer Relationship Management Practice Manager, BST Global

Stan Bunn leads the CRM Practice at BST Global, a Florida-based organization that delivers practical business solutions to project driven organizations throughout the world. His responsibilities include critical areas such as assisting firms with CRM strategies, system analysis, business process improvement and integration consulting. His 12 years of technology experience spans from multiple enterprise resources planning applications to numerous CRM solutions such as Siebel and Microsoft CRM. He is a member of the Society for Marketing Professional Services and Professional Services Management Association. He is also a Certified Microsoft Business Solutions Professional.

Robert Book Elanco Products Company, a division of Eli Lilly, Carmel, Indiana (retired) U.S. Marine Colonel (retired)

Mr. Book was awarded the Lifetime Career Award for his 28 years with Elanco Animal Health eventually serving as group vice president of agricultural marketing for 11 years. Mr. Book received his B.S. in animal sciences in 1952. Book was instrumental in starting the Indiana Institute of Agriculture, Food and Nutrition Inc. He also served on the board of directors for the Farm Foundation Inc., the United States Grain Council, the Center for Global Food Issues and other organizations. He currently serves as an advisor to the Indiana 4 H Foundation; on the board of directors of Neogen Corporation, the Agricultural Alumni Foundation Seed Corporation, the Indiana Partners of the Americas and as chairman of the board of the Carmel St. Vincent’s Hospital. In addition to his professional duties, he served 35 years of active and reserve duty in the U.S. Marines.

Mia Byrne C.P.A, MKM Ventures, LLC, Ann Arbor, Michigan

Ms. Byrne earned a BS in Industrial Management from the Georgia Institute of Technology. Ms. Byrne has spent the focus of her accounting career specializing in taxation in both the public accounting and corporate tax arenas.

Chris Carley

Chris Carley is a 15-year GIST cancer survivor. He was one of the two first survivors to take the trial drug Gleevec for a solid tumor 10 years ago. He is on the Advisory Board of the Lurie Cancer Center at Northwestern University, a member of the Dana-Farber Cancer Center Development Committee, on the Board of Directors of the Wendy Will Cancer Foundation, a regional member of the Lance Armstrong Foundation, and Chicago advisor of Gilda’s Club. Mr. Carley’s “Survivor’s Story” is featured in the book LiveStrong by the Lance Armstrong Foundation. It is one of 10 stories featured to inspire and encourage cancer survivors.

Thomas J. Hughes Director of Sales, N-Soft of America, Evanston, Illinois (retired)

Mr. Hughes is a graduate of Loyola University, Chicago where he earned a BA in Philosophy. Before graduation, Mr. Hughes served as an officer in the United States Army and with 3rd Bde 4th Infantry Division in Vietnam. During Mr. Hughes’ 35-year career in the telecommunications
industry, he held management positions including engineering, long-range planning, program and product management. He is the father of two children including GIST patient Nancy Hughes Welsh (1967-2005) who was an early member of The Life Raft Group. He and his wife, Margi, continue to remain active in the Chicago chapter.

**Gerald Knapp** President & CEO of U.S. Computer Services Cable Data, Sacramento, California (retired)

Mr. Knapp earned a BA and a MBA from the University of California, Berkeley.

Knapp is currently retired and working as a consultant/investor with small to medium sized technology companies in the Sacramento area. Mr. Knapp retired in 1995 after 22 years with U.S. Computer Services. Additionally, he served on the company's board of directors from 1978 until 1995. During his 22 years with the company annual revenues grew from a $2 million company focused on the U.S. cable television market to a $225 million international company serving the telecommunications market.

Prior to U.S. Computer Services, Knapp served as an officer in the U.S. Marine Corps. While at U.S. Computer Services he served as a board member on the Walter Kaitz Foundation. Mr. Knapp currently serves as a board member for several small technology companies. He is an advisor to Summerbridge Sacramento, a program encouraging disadvantaged youths to get a college education. He also participates in HOSTS, a weekly tutoring program for middle school children.

**Raymond Montague**

Ray Montague graduated from Rutgers University in 1973. He has owned several businesses and is currently the vice president for Art Guild Inc., a tradeshow company.

Mr. Montague has four children including Jonathan who died from GIST in 2002 at the age of 23.

**John Poss** Management Consultant

Mr. Poss is the principal in Poss Consulting, a firm that specializes in workouts and turnarounds of troubled companies. During his 35-year business career, he has served as a senior officer or director of both public and private companies in diverse industries, including real estate, construction, oil & gas, mining and telecommunications. Mr. Poss and wife Melinda currently reside in New Braunfels, Texas.

**Rodrigo Salas** Owner & CEO, Maprex International Inc., Laredo, Texas & Nuevo Leon, Mexico

Mr. Salas is a CPA with an MBA from Instituto Tecnologico de Monterrey (Monterrey Institute of Technology). Salas has maintained his position as owner and CEO of Maprex for the past six years. Maprex manufactures solid wooden doors for the Mexican and American markets. He is also a co-owner of Isitax, a company dedicated to obtain sales tax reimbursement in the U.S. for Mexican nationals.

Previously, he served for 14 years as Management Director of Benavides Industrial Group, a group of companies dedicated to the production of Penicillin and its derivatives as well as pharmaceutical laboratories that produced different kinds of generic drugs for the social security sector in Mexico.

Mr. Salas also serves on the board of directors of the John Paul II Institute, a non-profit that focuses on family science and social degrees. Since 2006, he has been serving on the board of Directors of the School of Health Science and Innovation at Monterrey Institute of Technology. Mr. Salas is also part of the Inter-Institutional Comity for the Development of Clinical Research, an effort between Monterrey Tec and the Government of his home state of Nuevo Leon, to promote the implementation of clinical trials in the government’s hospitals and clinics.

**Larry Selkovits** President, The Kirkland Group Inc., Methuen, MA

Lawrence Selkovits was born in Pittsburgh, Pennsylvania and grew up in Aliquippa, Pennsylvania.

He graduated from Harvard College, University of Pittsburgh School of Law, and Harvard Business School. Upon graduation from business school Mr. Selkovits joined a major commercial property development company, headquartered in Boston. During the next 20 years he was responsible for the development of over 5,000 multi-family units located throughout New England and the Mid-Atlantic states. He was also a partner in several large office and commercial projects in the Boston area. In 1985, Mr. Selkovits formed The Kirkland Group as a holding company for his real estate and other investments.

For many years, Mr. Selkovits has been a member of an advisory board for the Department of Psychiatry at Massachusetts General Hospital in Boston. He is also a major supporter of the East End Cooperative Ministry in Pittsburgh whose work is dedicated to helping adults and at-risk children in Pittsburgh’s East End Community. Mr. Selkovits and his wife have lived in Cambridge Massachusetts for over 40 years.

**Silvia Steinhilber** Co-founder and Managing Partner of NSW Plastics Ltd., Manitoba, Canada

Ms. Steinhilber was educated in biochemistry but decided to partner with her father to establish an injection molding firm. NSW Plastic Ltd. specializes in custom injection molding, vacuum forming, mold making, and R.F. sealing.
Above $100,000
Sacramento Region Community Foundation
Novartis Pharmaceuticals Pfizer Pharmaceuticals Emilie van Karnebeek & Jeroen Pit Rodrigo Salas

$20,000-$99,000
Carlos & Liana Baldor The Arnold M. Kwart Family Trust Anthony Lauto Family Fund

$10,000-$19,999
Arbor Foundation Jerry Cudzil James Hughes Jerry Knapp Mackey & Mackey P.L.L.C Ray Montague Marietta Robinson Lawrence Selkovits

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$500-$999
A & M Label Dorothy Battles Ettore Bianchi Reno Bianchi John Birdsall Eric Bischoff Anthony Bonanno Barbara Brandwein Ann Brennan Timothy & Tracey Brennan Bruce E. Brockstein, M.D. Doug Brown Bryan Carroll Thomas Carroll

Twice a year, Janice Gaulton and members of the Purcell’s Cove Social Club hold a pool tournament for the LRG in memory of Mike Matthews (left). Mike died in 2004, but 5 years later, his friends are just as devoted. New friends keep coming to PCSC, but soon find themselves “old friends” with Mike. “Mike was, and his memory still remains, a very big part of our “family” up here in Purcell’s Cove,” says Janice.
"We felt stunned, confused, and desperate when my husband was diagnosed with GIST."

- Richard & Therese Pedemonte

"Timely information on the LRG site & newsletter, prompt & caring responses to our many questions, and news about the latest research into the disease helped carry us through to today."

Scott and Barbara Abel
Cheryl Abhau
William Adams, MD
Therese M. Ahlers
Kristin Brown & Mahmoud Ajamia
Scott and Barbara Abel
Cheryl Abhau
William Adams, MD
Therese M. Ahlers

To whom it may concern,

Hi my name is Samuel Richmond. I am in grade 4 at U.S.D.S. Bathurst Campus. I was assigned a project about a charity that touched my heart. I chose your charity because my grandmother, Gloria Richmond has cancer. For my fundraiser I had a ministorch tournament, mini-basketball and the class had and made snow cones. Inside this envelope there is a cheque supporting your charity and pictures of my lesson. The Life Raft Group really touched my heart.

Sincerely,
Samuel Richmond.
Perseverance

Barbara and Carlo Alesandrini
Sidney Arfa
Jerry and Bonnie Ashbrook
Peter Atherton
Sandia L. Banks
Leon and Takako Bassett
Betty Benjamin
Bradley A. Bentson
Louis & Joan Berge
Renee Bernard
Jerome Blumenthal
Robert and Ann Bonda
Andrew & Lisa Boschma
C.B. Boucher
Steven & Janet Boucher
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G. Ann Byrne
James Cameron
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Innovation

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For a full list of donations and honorees for these donations, please visit www.liferaftgroup.org

Allocation of Funds for 2009

Total expenditures $1,767,722.00

Research Grants: 18%
Research Management & Support: 7%
Information & Education: 55%
Patient & Family Services: 11%
Advocacy: 8%
Management & Fundraising: 7%
The Life Raft Group

We direct research to

find a cure

for a rare cancer and help those affected

through support and advocacy until we do.

ensuring that no one has to face GIST alone