The Life Raft Group

unlocking the Cure



Greetings from the Life Raft Group



Dear Friends,

Over the past year, a record number of people facing the challenge of a Gastrointestinal Stromal Tumor (GIST) diagnosis reached out to the Life Raft Group and found the connection and support they were looking for.

Life Raft Group connects people affected by GIST through a variety of different programs and services. This snapshot will show how we've grown from a handful of patients to an international organization that reaches thousands of patients each year.

- Our website, www.liferaftgroup.org, receives visitors from over 100 countries
- Our newsletter reaches over 5,000 subscribers each month; this includes a great number of medical professionals
- Our email listservs support online communities of over 700 GIST patients and caregivers
- Our office handles over 1,000 patient assistance calls per year
- Our patient education initiative has enabled the distribution of thousands of informational pamphlets per year
- Our local chapters facilitate face-to-face meetings across the United States, Canada and Europe
- Our work with sister organizations around the world enables us to network patient resources on the Global GIST Network, www.globalgist.org

The need for the Life Raft Group's services continues to grow due to the development of resistance to Gleevec, a life saving drug. We are addressing this issue with the Life Raft Group Resistance Research Team. We have committed 2 million dollars, with the help of Novartis, to finding a cure. The research will be focused on implementing a strategic plan created by this world class team of experts.

It is thanks to you ~ our donors, members, volunteers and friends ~ that we can continue our work in the fight against cancer. Thank you for your support and dedication to our cause.

Sincerely,

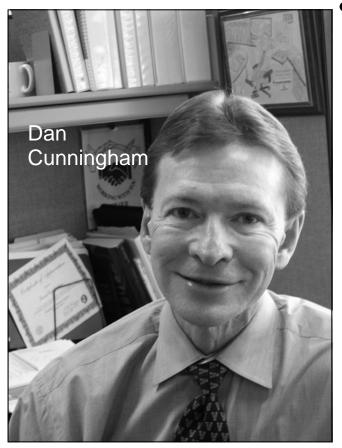
Stan Bunn President Norman J. Scherzer Executive Director

Morman J. Scherger

Looking through the keyhole

The Life Raft Group (LRG) is the world's leading 501-C-3 non-profit organization providing information, support, and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG supports research to find the answers to treatment resistance and to strengthen disease management.

Mission: The mission of the LRG is to ensure the survival of GIST patients while maintaining the quality of their lives. To accomplish this mission, the Life Raft Group devotes its efforts to five major program areas: Support, Research, Surveillance, Information & Education and Advocacy.



Dan was misdiagnosed with Leiomyosarcoma in 1996. Doctors found more tumors in his liver in 2000. Finally, in 2001, he was diagnosed with GIST. Dan began taking Gleevec and the tumors shrank. Thanks to Gleevec Dan was able to continue working and send his daughters off to college. Dan is still stable and he has just passed his five-year milestone on Gleevec. Dan has been an LRG member since 2002.

Support Connecting patients and caregivers via the internet and in-person groups

In May of 2005, the LRG hosted the first Pediatric GIST meeting for the children and their families afflicted with this disease. This peer-to-peer networking is invaluable for pediatric GIST families trying to manage the care of a rare disease for a child.

The LRG co-founded and maintains a key role in the coordination of the Global GIST Network which connects patients all over the world to resources available in their home country and language.

GIST patients and caregivers continued to count on the LRG online communities for daily information and support and upon the LRG websites, online communities and monthly newsletters for the latest news. Local LRG groups met face-to-face in intimate settings across the world in cities such as Detroit, Chicago, Los Angeles, Dallas and Amsterdam. Hundreds of patients, caregivers and physicians contacted the LRG office to seek information about treatment options and access to treatment. No one was turned away. The LRG's International GIST Specialist Directory continued to grow as a source of lifesaving information for patients seeking medical expertise for this rare disease.

Research Funding research to find tomorrow's cure

Resistance Research Initiative

Armed with a generous start up grant from Novartis, the Life Raft Group began developing the first strategic research plan to find a cure for GIST. After many months of work assembling a world class research team, and building an innovative grants infrastructure to support it, we completed the plan and have posted it to our website. We succeeded in setting a cap on indi-

rect costs of 10% at every one of the grantee institutions. We created two tissue banks, one at Stanford for adult GIST and one at Memorial Sloan Kettering for Pediatric GIST, and we adopted a common protocol for submitting tissue that will be used by both banks. We believe that we have established a frame-work for unprecedented collaboration between researchers, including appointing team leaders who will coordinate their projects across institutional boundaries. Grant awards to implement this plan are planned for Catholic University (Leuven, Belgium), Dana-Farber/Brigham & Women's Hospital, Oregon Health & Sciences University/Portland VA Hospital, Memorial Sloan-Kettering, Stanford University, and the University of Washington.



The LRG's internal research, which draws upon information provided by patients, continued to discover

important new information to further the survival and well-being of GIST patients. This internal research is designed to provide us with information that is not currently available from clinical trials. The LRG was the first to publish that Gleevec was an effective treatment and that its side effects got better over time. Last year the LRG presented cutting edge

information about the relationship between the dosage level of Gleevec and the development of resistance. To strengthen this research, the LRG began development of a more robust database. The LRG's pediatric GIST database, the largest in the world, continues to accumulate information about this critical subset of the disease.

Data is being collected to investigate the relationship between dosage level and preventive treatment, something which none of the ongoing clinical trials are addressing, to continue to study GIST treatment resistance, to conduct a familial GIST study and to investigate underreporting of GIST cases.

A note about Life Raft Group research: Dr. Daniel Vasella, CEO of Novartis described our research as follows: "The Life Raft Group ... has provided various people, patients, doctors, investigators with a unique kind of data bank that cannot be replicated anywhere else, not even in patient trials."

Surveillance Staying up-to-date on new treatments and clinical trials

In addition to our research, we aggressively tracked new drugs and compounds before they even entered clinical trials for GIST. We sought out and published clinical trial information in our newsletter and website before any other trial listing service, private or government. We tracked these clinical trials via patient reports as they began and evaluated the efficacy and side effects of the new drugs on an ongoing basis. We shared this information with patients and doctors through our newsletter and website.

Information & Education *Providing the latest information to patients and doctors*

Life Raft continued its efforts to strengthen the scientific and support content for its website, newsletter and online communities.

In 2005, two informational pamphlets were produced and distributed for newly diagnosed GIST patients. Life Raft also

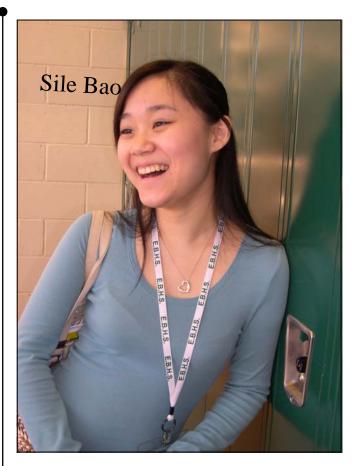
responds to all correspondence from the newly diagnosed to those facing a recurrence.

A new online community was established solely for pediatric patients and their families.

The LRG continues to connect patients to local resources throughout the world through the Global GIST Network.

Advocacy Overcoming hurdles to help patients access treatment

Life Raft's advocacy efforts contributed to the federal government's decision to cover Gleevec, the most effective oral drug therapy for GIST patients, under the Medicare Demonstration Act and under the comprehensive Prescription Drug Program. Life Raft continued its efforts to oppose the use of placebos in clinical trials for GIST patients for whom no other treatment alternative was available. Several pharmaceutical companies reached out to the LRG for input and assistance in planning clinical trials for GIST patients.



Sile was misdiagnosed with iron defiency anemia and ulcers by the time she was fifteen. Eventually, in July of 2004, she was diagnosed with GIST and had surgery to remove a seven centimeter tumor. In January 2005, more tumors were found and she was put on Gleevec. Because of severe side effects Sile was forced to stop treatment. Sile is now sixteen years old and enjoying her life. She does all the things a teenager should. She will be placed on Sutent in the summer of 2006 and aspires to one day help children fight cancer. Sile and her parents have been LRG members since 2004.

Meet the LRG Board of Directors

Allan Tobes, Michigan

A very special thank you to Board Member Allan Tobes who served as the LRG's Secretary-Treasurer, pro-bono Accountant and Local LRG Coordinator for Michigan. Allan recently lost his battle with GIST and he is truly missed.



In Memoriam



Stan Bunn, President, Florida

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. Stan lost his wife, Ana Maria, to GIST. He also serves on the Executive Committee.

John Poss, Texas

John Poss, Vice President Finance, Celerity Logistics

John Poss is the former CFO of NYSE Company and former CFO and shareholder of DSI. He is currently Vice President of Finance at Celerity Logistics. Celerity and its wholly owned subsidiary, Segue Distribution, Inc. provide Routed Distribution services in 31 states to large companies in the retail, pharmaceutical, medical supply, photo processing and other industries. Since its founding in 1999, the Company has grown to over \$30 million per year in sales by offering superior services and prices when compared to its major competitors. John and Celerity Logistics played a key role in getting relief to victims of Katrina.



John is a GIST patient. He also serves on the Executive Committee and as a co-chair of the Fundraising Committee for the Life Raft Group.



Robert Book, Indiana

Elanco Products Company, a division of Eli Lilly (retired)

U.S. Marine Colonel (retired)

Bob 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. He received his BS in Animal Sciences in 1952. He 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. Bob is a GIST patient.

Mia Byrne, Michigan *MKM Ventures, LLC*

Mia Byrne earned her BS in Business Management at the Georgia Institute of Technology. She devotes her time to raising awareness for GIST. She and her family and friends have also participated in many marathons and hosted a casino night to raise funds for GIST research. She also devotes her time to volunteer work that is invaluable to the Life Raft Group. Mia's husband, Michael, is a GIST patient. Mia has also served as a manager to the Life Raft Group's email community since it was established.





Chris Carley, Illinois

Founder & Chairman of the Fordham Company

Chris Carley is the founder of the Carley Cancer Research Care Facility at Northwestern Memorial Hospital in Chicago, Ill. He also serves as the chairman of the Chicago Lance Armstrong Foundation Peleton, an annual Bike to Fight Cancer event. His company, The Fordham Company is currently developing the United States tallest skyscraper, The Spire, to stand at a spectacular height of 2,000 feet tall.



Managing Director, Dimaio Ahmad Capital

Jerry Cudzil earned his BA in Economics at the University of Pennsylvania. He is a Portfolio Manager at Dimaio Ahmad Capital. DA Capital is a Hedge Fund that invests primarily in fixed income instruments. The fund targets 8-12% annual returns.

His volunteer efforts include fundraising and work to raise awareness for GIST. Jerry's father-in-law is a GIST patient. He is also a co-chair of the Fundraising Committee for the Life Raft Group.



Arnold Kwart, MD, Maryland

Chairman of the Department of Urology, Washington Hospital Center

Dr. Arnold Kwart is Diplomat of the American Board of Urology and Fellow in the American College of Surgeons and belongs to numerous professional organizations including the American Urologic Association, the Society of University Urologists, the Society of Urologic Oncologists, the Washington Urologic Society, the District of Columbia Medical Society, and the American Medical Association. He is routinely recognized professionally as a top urologist by Washingtonian Magazine and earns recognition by Washington Consumer Checkbook, as well as Who's Who in America (in medical care). His professional subspecialty in-

terests are the clinical and surgical management of benign and malignant prostate disease, genitourinary malignancies, urinary stone disease and vasectomy. Arnold is a GIST patient.



Director of Sales, N-Soft of America (retired)

Jim Hughes is a graduate of Loyola University, Chicago where he earned a BA in Philosophy. During his 35 year career in the telecommunications industry, he held management positions including engineering, long range planning, program management, product management and sales. He served as an officer in the Army and as a Public Information Officer with 3rd Bde 4th Infantry Division, Vietnam, 1969. Jim attends medical conference for the Life Raft Group to assist other members in gaining information. Jim lost his daughter, Nancy Welsh, to GIST last year.





Gerald Knapp, California

President & CEO of U.S. Computer Services Cable Data (retired)

Jerry Knapp earned a BA and an MBA from the University of California, Berkeley. He is currently retired and working as a consultant/investor with small to medium-sized technology companies in the Sacramento area. He 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 to a \$225 million international. Prior to U.S. Computer Services, he 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. Jerry 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. Jerry is also a cochair of the Fundraising Committee for the Life Raft Group and serves as the BOD liaison to the LRG Resistance Research Team. Jerry is a GIST patient.



Rodrigo Salas, Mexico

Owner & CEO, Maprex International Inc., Laredo, Texas & Nuevo Leon, Mexico Rodrigo Salas is a CPA with an MBA from Instituto Tecnologico de Monterrey (Monterrey Institute of Technology). He has maintained his position as owner and CEO of Maprex for the past three 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 it's derivatives as well as pharmaceutical laboratories that produced different kinds of generic drugs for the social security sector in Mexico. He also serves on the board of directors of the John Paul II Institute, a non-profit that focuses on family science and social degrees; The School of Medicine and the Center for Health Innovation and Knowledge Transfer of the Tec de Monterrey, an institution that will focus on clinical oncology research in Mexico. Rodrigo recently lost his wife, Cordelia, to GIST. In addition to serving on the board, Rodrigo is the Life Raft Group's Country Representative for Mexico.

Silvia Steinhilber, Canada

Co-founder and Managing Partner of NSW Plastics Ltd (retired) Silvia earned her degree in biochemistry at Red River College, in Winnipeg, Manitoba. For a time she worked at the Health Science Center, a teaching and research hospital in Canada, in the Radiopharmacy Department producing the injections that are used in nuclear medicine scans. Although she loved working in the health sciences, Silvia moved on to open NSW Plastic Ltd, an injection molding company, with her father. In the last year and a half, Silvia has sold off much of the business.



Silvia's mother, Jeanne, is a GIST patient. Her husband is a fifteen-year survivor of a different rare cancer. Due to these experiences, Silvia has become involved in the LRG and other online support programs for cancer. She is also a source of support for others in her community who are struggling with cancer. Silvia is now retired and intends to become even more involved in the fight against cancer.



Life Raft Group Staff & Volunteers

Norman Scherzer, Executive Director

Norman began a career in public health as a disease management specialist for the Centers for Disease Control. He has served as a director of the New York City Department of Health's Sexually Transmitted Disease Program and as a director of the New York City Prison Health Services Program. After serving as the New York Regional Consultant for Disease Control for the United States Public Health Service, Norman went on to become the Assistant Commissioner of Health for New York City where he helped spearhead the city's childhood immunization initiative and its response to the AIDS crisis. Following his formal

retirement from public health, Norman became the Chief Executive Officer of Graham-Windham services to families and children, the oldest non-sectarian child care agency in the United States, founded in 1806. Norman then became the President and CEO of a health policy and management consulting firm called 22nd Century Health Concepts, Inc. whose clients included the Harvard University Institute for International Development. When his wife, Anita, a GIST patient entered the first clinical trial for GIST, Norman helped found the Life Raft Group. He has served as Executive Director since 2002.

Executive Assistant Administrative Assistant IT Director/Web Master **Program Coordinator** Research and Admin. Coordinator Elizabeth Braun Research Assistant Science Coordinator

Tricia McAleer Erin Kristoff James Roy Sara Rubinoff Pamela Barckett Jerry Call

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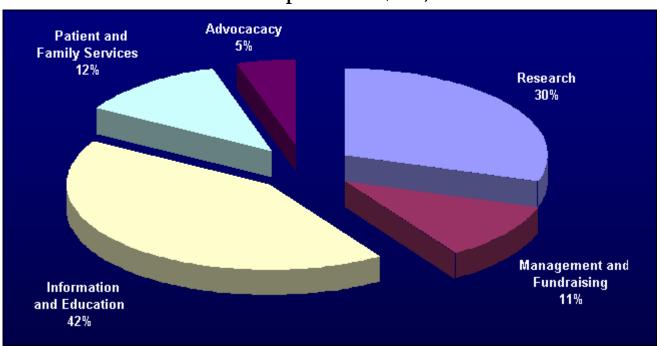
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Allocation of Funds for 2005

Total Expenditures \$ 497,000



We believe that donations to the Life Raft Group should be totally accounted for. A transparent budget with professional checks and balances and a clear explanation of expenditures is clearly defined on the LRG website.

All contributions to the Life Raft Group are acknowledged in writing, as required by the IRS. A copy of the report that we are required to file with the IRS (990) is posted to our website. A detailed operating budget is also posted once it has been approved by our Board of Directors. We retain an independent CPA firm to conduct an annual financial audit and we make copies of this extensive audit available upon request. Finally, we welcome and respond promptly to all questions.

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