

Life Raft Group 2010 Annual Report

This year was about celebration for the LRG, which we showcased as our Life Fest symbol — the famous DNA double helix bursting like fireworks in the night sky.



Contents

<p>A note about the cover: For Life Fest 2010, the LRG wanted to focus not on the negatives of cancer, but highlight all the good things that have come into the lives of GIST survivors since diagnosis. Members were asked to use these moments to create a “Tree of Life,” and tell the world just what this time has meant to them. We used these Trees as place cards at our GIST 2010 Gala so that all in attendance could share in the life of a GISTer. Long-time member, Paula Vettel, agreed to let us use her Tree on our cover as a message of hope to survivors everywhere.</p>	<p>2 Patient Education & Support Life Fest Outreach</p> <p>4 Research The LRG Research Team The LRG Patient Registry</p> <p>7 Advocacy Alianza GIST Struggling for better treatment</p> <p>10 Board of Directors Meet our new board member, David Safford</p> <p>11 Donors</p>
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Throughout this report you will notice photos labeled “A Year in Pictures.” These photos have been pulled directly from the LRG Newsletter to illustrate the important moments we covered in 2010.

The Life Raft Group



Dear Friends,

Looking back, it's clear that 2010 was a year of milestones — milestones grounded in the hope of defeating this disease and heralded by the ten year anniversary of GIST treatment. As we look at our achievements this year, we need to consider them milestones of hope — important steps in bringing us to that ultimate step of curing GIST. And this year we had reason to celebrate. Eleven years ago, GIST was a concept known only to a handful of researchers, but everything changed in 2000. GIST was identified and groundbreaking treatment that saved thousands of lives was introduced. In the last ten years, the GIST community has been on a roller coaster ride of new treatments, experts, innovative research, conferences and seminars — an explosion of information that has not yet subsided. Life Fest 2010, held in Jersey City, New Jersey, celebrated this last decade with award ceremonies highlighting those from the GIST patient, medical, scientific and pharmaceutical communities who have contributed not only to the understanding and treatment of GIST, but also whose accomplishments have made a difference to the survival of GIST patients.

Perhaps it's appropriate that ten years later, we mark an important next step in defeating this disease — the initiation of "Project D-Day" — driven by a team-focused, four-pronged strategy to cure GIST. Launched in July as part of our Pathway to a Cure initiative, Project D-Day is focused on gene sequencing & screening, the examination of thousands of drug compounds and strict validation studies. Like that extraordinary day in 1944, which marked the beginning of the end of World War II, our attack on GIST treatment resistance has reached an historic opportunity for success and we truly believe it is our best hope for a cure.

On the global front, we formally launched our Alianza GIST initiative with a meeting in Monterrey, Mexico that brought together representatives from ten different Latin American countries. This alliance is an effort focused on regional support and advocacy. Our goal is to improve the knowledge of patients & physicians, increase access to adequate treatment and to support collaboration within the patient and physician communities.

Certainly we didn't accomplish everything we set out to do — like establishing plasma and mutational testing as routine measures in GIST management — but we aren't giving up and we hope to mark them as achievements in 2011. We have accomplished a lot — all of us — and that drives us to accomplish more. The Life Raft Group wants 2011 to be a better year than 2010 — we want a year marked by many more milestones in the hope of curing GIST. That will take all of us — but given the great support already of the GIST community to the Life Raft Group — there will be much more to celebrate. Thank you for your considerable support to cure GIST and let's make 2011 the best year of milestones yet.

Sincerely,

Norman J. Scherzer
Executive Director

Jerry Cudzil
President of the Board

Life Fest 2010

On June 25, the Life Raft Group kicked off its fourth biennial Life Fest — an event that occurs only once every two years and brings together patients, loved ones, doctors and representatives from the pharmaceutical industry in a setting that fosters learning and encourages the kind of camaraderie that you can only find amongst people who have been in your shoes.

Life Fest has always been a celebration of survival and hope. We recognize the enormous courage of every patient and family member who has battled and continues to battle GIST.

What made this Life Fest special was the Friday night gala event commemorating ten years of GIST treatment. Doctors, researchers, patient advocates and other key figures in the GIST community were inducted into the newly-formed GIST Hall of Fame. Moreover, Life Fest 2010 offered an opportunity to honor the entire GIST community — patients, friends and family members, GIST medical professionals, researchers and scientists — in a unique opportunity to come together to remember the past and to forge a path forward to find a cure.

The weekend continued with awards for Humanitarian of the Decade, Clinician of the Year and Volunteer of the Year, a star-filled dinner cruise on the Hudson, and numerous presentations and workshops, on topics like complimentary medicine, plasma testing, coping and survival strategies.

GIST Hall of Fame Inaugural Inductees

- | | |
|---------------------------------|--|
| Dr. J. Aidan Carney | <i>Dr. Charles Blanke</i> |
| Dr. Christopher Corless | <i>Dr. Heikki Joensuu</i> |
| Dr. George Demetri | Dr. Michael Heinrich |
| Dr. Brian Druker | Dr. Seiichi Hirota |
| Dr. Jonathan Fletcher | Mr. Jeffrey Kindler & Pfizer |
| Mr. Gilles Frydman & ACOR | The National Institutes of Health Clinic |
| The GIST Patient: | For Sutent: |
| <i>Patient Advocacy Groups</i> | <i>Dr. Zuleima Aguilar</i> |
| For Gleevec: | <i>Ms. Elizabeth Barrett</i> |
| <i>Dr. Elisabeth Buchdunger</i> | <i>Mr. Carlo Bello</i> |
| <i>Dr. Renaud Capdeville</i> | <i>Dr. James Christensen</i> |
| <i>Dr. Laurie Letvak</i> | <i>Dr. Darrel Cohen</i> |
| <i>Dr. Nicholas Lydon</i> | <i>Mr. Stephen Evans-Freke</i> |
| <i>Dr. Alex Matter</i> | <i>Dr. Joseph Schlessinger</i> |
| <i>Dr. Jürg Zimmermann</i> | Dr. Axel Ullrich |
| The Gleevec Trial Doctors: | Dr. Daniel Vasella & Novartis |
| <i>Dr. George Demetri</i> | Dr. James Watson |
| <i>Dr. Margaret von Mehren</i> | |

Humanitarian of the Decade

Dr. George Demetri & Dr. Dan Vasella

Clinician of the Year

Dr. Jonathan Trent

Volunteer of the Year

Vicky Ossio

June 2010 issue

A Year in Pictures



With immense pride, the LRG was able to honor **10-year GIST survivors** at Life Fest 2010. Pictured from left to right: (Standing) Chris Carley, Theresa Hausbeck, Elsie Hernandez, Estelle Lecointe, Jerry Call (on behalf of wife, Stephanie Call), Jas Kiran Kaur, David Epstein from Novartis, Paula Vettel, Alice Sulkowski, Anita Scherzer, LRG Executive Director, Norman Scherzer, Norma Siegel, Dan Cunningham; (Seated) Dr. Joel William Sherr, John Poss, Garnette Draper, Tom Overley.

Invitation to Life Fest 2010



Outreach

Outreach can be defined as a systematic attempt to provide services beyond conventional limits. Nowhere is this more needed than in the global community where patient concerns vary greatly, not only by country but also by region.

The LRG greatly strengthened its outreach efforts by facilitating and supporting the formation of several new international GIST groups and helping existing groups expand their influence.

In Iran, where access issues are at the forefront of patient concerns, the LRG is assisting in the formation of a group to target these very problems.

Additionally, representatives from Colombia reached out beyond their borders by presenting at GIST Tour (Global Interdisciplinary Specialists Training around the World) an international gathering of medical professionals sponsored by Novartis Pharmaceuticals.

In some countries, formal organizations have not yet been created but the patient need is still great. The LRG continues to meet their needs by establishing patient liaisons within the country or region. This year we were able to tap patients in South Africa, Samoa, Nicaragua and Finland as liaisons and will continue to add much-needed support in 2011.

December 2010 issue



Kim Trout, a member of the Life Raft Group and Pennsylvania Local Group Coordinator, got married on May 8, 2010 surrounded by her beloved family and friends. “Don’t

let GIST stop you from doing what’s important in your life,” says Kim, who despite the hurdles she faces with GIST, lives a life that is overflowing with joy.



Cruisin’ at Life Fest

Saturday night at Life Fest 2010 was the favorite part of the down time for all the people who attended. After a day of learning, absorbing as much information as possible at the many classes that were offered, many of the group gathered together for a dinner cruise on the Hudson. We were treated to the indoor pavilion where we could gaze out at the glittering lights of the skyline of New York and Jersey City. The weather was perfect for our cruise as the rain held off seemingly just for us. We were greeted at the top of the plank by the cruise boat captain and welcomed inside for what turned out to be a wonderful evening of entertainment, food and revelries. Before long we were dancing in our seats to the beat of the ’80s hits and not long after it just spilled out onto the dance floor. About the time dessert was being served we were informed by the crew that we should hurry outside to the upper decks to enjoy a fireworks display like no other.

There’s nothing like watching fireworks over the water, with the double joy of seeing the night sky lit up in multicolored patriotism and the same reflection on the water. Soon after the fireworks we began to circle the Statue of Liberty. Having the opportunity to see her that close is a memory I will not soon forget. We were enjoying a full moon on the 26th and that added an amazing ambiance as well as a spectral beauty to our cruise. There’s something about a full moon and a dance floor that just gets a party rocking, cheek to cheek or hip to hip we danced that boat right back to the dock. It’s a memory that so many will cherish for years to come. I know I will.

— Janeen Ryan, LRG Member

The LRG Research Team

In 2006, the Life Raft Group initiated a strategic research plan — Pathway to a Cure — that emphasized cooperation, coordination and accountability and brought together 10 of the finest GIST researchers in the world. Its focus was on identifying projects with the greatest chance of successful outcomes.

For the first four years, Pathway to a Cure laid the groundwork in the search for a cure for GIST and made progress on a broad number of fronts. This progress, reported at a three day event in Monterrey, Mexico, includes the creation of a comprehensive blueprint for understanding the mechanisms of treatment resistance, developing mechanisms to test new drugs in the laboratory, the creation of a comprehensive GIST tissue bank housed at Stan-



Jeroen Pit and his wife, Emelie

ford University which allows researchers to access and test this rare tissue and simultaneously access the clinical histories of the patients, and the critical investigation into understanding why a small number of GIST cells may

survive an otherwise successful drug treatment. Our team has authored over 150 research publications.

In 2010, a Dutch GIST patient named Jeroen Pit, confronting his own struggle to overcome

treatment resistance, was investigating the best way to donate to GIST research and perhaps help save his own life. After consulting several leading GIST researchers, the patient decided that the Life Raft Group Research Team gave him the best chance for finding a cure. He raised 2 million dollars and challenged us to accelerate our efforts to keep him and other GIST

(continued on page 6)

D-DAY EXPEDITES GIST RESEARCH:

The Story of One Dutch GISTer

BY ERIN KRISTOFF
LRG NEWSLETTER EDITOR

“Why are we so passive?” Jeroen Pit asks, “If everyone sits still, not much is going to happen.”

A successful Dutch businessman, Jeroen has never been a passive man. When he was diagnosed with GIST in May 2006, he made his GIST decisions much like he would make business decisions — methodically and with clear purpose.

In June, Jeroen had surgery in Holland to remove a primary GIST tumor. When his GIST metastasized to the liver, he and his wife, Emelie, made the decision to travel to Memorial Sloan-Kettering Cancer Center in New York City. He began 400 mg of Gleevec and eventually, in late 2007, underwent another surgery on his remaining liver metastases.

Unfortunately, in late 2009, progression forced Jeroen to discontinue Gleevec and he was placed on Sutent. Initial scans showed a positive response.

After numerous surgeries,

October 2010 issue

In a short amount of time, Dutch GISTer, **Jeroen Pit** was able to raise an astonishing \$2M to support the LRG’s Research Team with the help of trusted family and friends pictured here.



procedures and drug changes, Jeroen asked himself what was next on his list? It was time to fundraise.

"We wanted to be able to say to ourselves, 'At least we did everything we could. At least we don't blame ourselves.'"

Jeroen got on the internet and started his investigation into the GIST research landscape.

"I wanted to know if my fundraising efforts would make a difference. What are the amounts researchers are working with and who are the key researchers in the field?" said Pit.

Once satisfied that he could indeed make a difference, Jeroen got in touch with Dr. Maria Debiec-Rychter of the Catholic University in Leuven, Belgium, who told him about the LRG Research Team.

In November 2009, Jeroen & Emilie met with LRG Executive Director, Norman Scherzer to discuss research and fundraising opportunities.

"Norman is inspiring," Jeroen recalls, "I went home and thought, 'We can make a difference and this research team is the right choice.'"

"Other [research] alternatives were good," he adds, "But the impact of your dollar is better at the LRG."

This impact stems from a number of areas in which the LRG research team differs from traditional cancer research. The LRG eliminates the overhead costs institutions usually take, which can range from 50 to 75 percent of the donation. In addition, the LRG research team stresses collaboration and sharing amongst its researchers, who are required to meet in person, as well as submit routine progress reports.

While Jeroen worked on a way to enhance GIST research, his GIST tumors had an entirely different plan. Jeroen was beginning to fail Sutent.

Over the next few months, Jeroen would undergo radiation, RFA and embolization treatments to control his metastases. In March, his doctors at MSK decided to start him on Nexavar.

With another hurdle overcome, Jeroen began to think about a fundraising plan again.

"In April, my CT scan showed that Nexavar was working, so we decided to go for it."

Choosing a quality over quantity approach, Jeroen asked a small group of people to donate larger amounts than he normally might. His plan worked.

Within a matter of weeks, Jeroen had raised over 1.7 million euros for GIST research, roughly two million dollars.

"[That approach] was easier for me because of my network of colleagues."

But Jeroen wasn't satisfied with handing a check over without assurances that there was a firm plan in mind for his hard work.

Using the combined ingenuity of the LRG research team, a new plan was formed: Project D-Day.

Taking the knowledge, understanding and achievements the researchers have acquired in the last four years, the team would launch a four-pronged strategic attack on GIST treatment resistance.

The four distinct project areas are sequencing, gene knockdown, drug screening and validation. Each of these complex areas would have a unique team leader to ensure maximum coordination, communication and assess progress at all times.

"The sequencing and knockdown project areas will enable researchers to understand what is going on in GIST tumors," says Pit.

Ever mindful of his personal struggles with GIST, Jeroen made sure drug screening would be a part of the research plan. This research, which involves testing GIST cells against thousands of drugs and compounds, is



This frog means a great deal to Jeroen. After his first surgery, he got a pet frog as a gift from a friend, and after his second surgery, a bigger frog. Later, Jeroen donated a small silver frog to each member of the LRG team in appreciation of the patients they are trying to save.

specifically targeted at those patients who have failed first-line treatment.

"Every patient thinks to themselves, what if Gleevec doesn't work anymore?"

Why are we so passive?

With Project D-Day underway, Jeroen is proud of what he and his family have accomplished. But he still wonders why this type of effort is not more common in the GIST community.

Because GIST is such a rare disease, funding by government and most

pharmaceutical companies is very difficult. This makes GIST research largely dependent on private donations.

"If GIST cases in the US range from 5,000 to 10,000 diagnosed a year, and 10,000 people donated just ten dollars a month, we would have 1.2 million dollars a year for GIST research."

Jeroen encourages others to follow his lead and spearhead their own fundraising efforts by reaching out to friends and colleagues.

"You can only create when you do things together."

While Jeroen's situation may seem different, the principles are still the same. "Put it on paper," he says, "By writing, you further develop your proposition."

Using information from LRG researchers about past achievements and future plans, Jeroen created and circulated a brochure addressing why donating is important and the impact of private donations.

As for Jeroen, he has recently taken up the mantle of spreading awareness of GIST treatments in the Netherlands (probably the next item on his To Do list).

But with Project D-Day finally a reality, he can't help looking forward just a little, "I really think they are going to find something that will help us all."

This is an excerpt from an article that appeared in the LRG Newsletter, October 2010 issue.

Alianza GIST



Our three day meeting in Monterrey, Mexico, brought together some of the best GIST researchers in the world. But a large part of that event focused on a coalition of patient representatives from all over Latin America, who met for the first time to outline their mission and commitment to promoting the survival of GIST patients in Latin America.

The Coalition, which would eventually become known as Alianza GIST, gathered in a room lined with flags representing ten countries across Latin America and the United States. The circle of flags symbolized the unity among the patient community and its



Norman Scherzer (center), pictured with Rafael Becerra and Rafael Vega of GIST Colombia in Monterrey

belief that change can only be achieved through solidarity.

Important alliances were achieved, including one with the

Tecnológico de Monterrey, an institution committed to the development of the first center for cancer research in Mexico, and another with The Max Foundation and the Life Raft Group, organizations dedicated to improving the lives and survival rates of patients with rare cancers worldwide.

These alliances provided a number of resources to help Alianza GIST identify and reach GIST patients and disseminate information and education into Latin America. Rodrigo Salas, the Mexican representative of the Coalition, summed up the purpose of the meeting and resulting alliances as “an extraordinary historic event paired with expertise from our partnership organi-

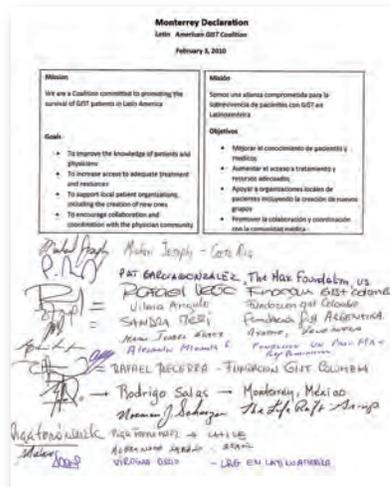
zations to strengthen our efforts at promoting survival of GIST patients.” The meeting reached its climax when the Coalition proudly announced their plan to promote survival of GIST

patients, which they called the Monterrey Declaration, focused on four key principles:

- To improve the knowledge of patients and physicians.
- To increase patient access to adequate treatment and resources.
- To support local patient support organizations, including the creation of new ones.

• To encourage collaboration and coordination with the physician community.

Alianza GIST is a partnership of patient advocates from 10 Latin American countries. The following Coalition members were present at the Monterrey meeting: Sandra Mesri of Argentina, *(continued on page 8)*



April 2010 issue

Representatives from ten Latin American countries gathered in Monterrey, Mexico to discuss regional patient issues and how best to combat them.



Hope

(continued from page 7)

Vicky Ossio of Bolivia, Dr. Alexandre Sakano of Brazil, Piga Fernandez Kaempffer of Chile, Dr. Rafael Vega of Colombia, Rafael Becerra of Colombia, Michael Josephy of Costa Rica, Alejandro Miranda of the Dominican Republic, Rodrigo Salas of Mexico, Maria Isabel Gomez de Soriano of Venezuela, Norman Scherzer of the Life Raft Group and Pat Garcia-Gonzalez of The Max Foundation.

Struggling for Better Treatment

Mutational Testing

In 2010, the LRG continued its strong support of mutational testing, urging clinicians to make mutational testing a routine part of GIST treatment and to use this knowledge to their advantage in choosing a clinical trial for Gleevec resistant GIST patients.

In the not too distant future, we may have newer KIT inhibitors that overcome most types of GIST resistance. But for the present, it is becoming increasingly clear that GIST can be divided into four main types based on



Researcher Maria Debiec-Rychter presenting at the research meeting in Monterrey, Mexico.

mutational status: KIT exon 11, KIT exon 9, PDGFRA D842V and wild-type GIST. In addition, there is another group comprising the “rare” mutations (KIT exons 13 & 17, etc). The different types have different initial responses to Gleevec and resistance occurs via somewhat different mechanisms. GIST patients and doctors can use this not only for clinical trials but, in some cases, to consider off-label treatment options.

The GIST clinical trial era began in earnest in 2000 with the first Gleevec trials. For almost ten years now, almost all GIST trials have been inclusive trials allowing most or all of the various sub-types of GIST. Today, some clinical

trials have broad inclusion criteria designed to “cast a wide patient net.” While this approach has the potential to find unexpected benefit, it also has a downside, especially in registration trials. The downside is that the trial may not show enough overall benefit to be considered successful.

Conversely, a trial can be designed with more rigid criteria in an attempt to “enrich” the patient population. The goal would be to enroll only patients that are predicted to respond.

Plasma Testing

In 2009, we made the case that... “At this time, plasma level testing may be the biggest potential opportunity to significantly improve GIST patient survival in the near future. The question remains: Will plasma testing go the way of mutational testing, with only a lucky few being offered the test?”

In 2009, plasma testing gained ground and acceptance as a possible treatment tool culminating in the launch of a Novartis oncology program, GIST Alliance, which encouraged patients to learn about plasma (blood level) testing and financially supported this testing.

On April 21, 2010, the U.S. Food and Drug Administration (FDA) issued a warning letter to Novartis criticizing its promotion of blood level testing on its CML and GIST Alliance websites which led to the eventual termination of these programs and its financial support of these tests.

Since the FDA’s warning and the subsequent cancelation, the Life Raft Group has worked tirelessly behind the scenes to try and resume this critical testing procedure. At the close of 2010, we were happy to report that plasma testing would be renewed in 2011 and we will remain committed to promoting this practice in the GIST medical and research communities.

February 2010 issue

● A Year in Pictures



Josalin Dunn, the little girl who stole hearts at Life Fest 2006, is now 12 years old and celebrated her five-year cancerversary in 2010.

FIGHT OR FLIGHT:

A Chance Encounter in the Sky Compels One GISTer to Do Her Part

BY PIGA FERNANDEZ

My journey as a cancer fighter began fourteen years ago during a routine gynecological checkup in December 1995, when a tumor was detected.

After a large resection, a round of radiation therapy followed. Four years later, in 1999, I had a local recurrence that was again resected and due to complications, a temporal colostomy was required, followed by brachytherapy treatment.

Until that time, I trusted my attending physician, but the following year (2000), when a new cancer recurrence surfaced, he failed to give it any significance, which led me to seek a second opinion as I lost faith in him. Maybe he thought the battle was lost, something that I could not let enter my mind.

The oncologist I consulted later approached my case with commitment and empathy. He asked for a few days to study my medical chart and requested more specific tests, which confirmed how far off base my previous physician had been. The new diagnosis was "local recurrence with hepatic metastasis." This again required surgery to resect the tumor and a permanent colostomy. A month later, I underwent a hepatectomy to resect three metastatic nodules.

In 2002, two more nodules were detected in the liver, but this time a resection was impossible due to location. Again, my oncologist took his time and consulted with other specialists in the United States. He then discussed with me what he felt was my only chance; pending test results, a new drug treatment was being used in CML which could help me. Waiting for the results of the tests was extremely difficult. I was facing the temporality of life, although filled with great hope and faith, I saw before me a light, a chance

to keep on living.

The results were as expected; it was GIST and reacted to this new drug whose name was unknown to us at the time. The race to learn more about what a GIST was began in earnest and to try to get a hold of this new miracle drug.

We learned about The Max Foundation and the Novartis Glivec International Patient Assistance Program (GIPAP) program and I applied immediately. I started my treatment with Glivec, followed by periodic checkups every three months in Guatemala.

The power and magic of the solidarity around me does not cease to amaze me! I remember having received the gift of airplane tickets to travel to my checkups from good people that I didn't even know, and I remember with immense gratitude the support of my family and friends who looked after my children while I was away.

Once again and every day, I give thanks to the Lord for the gift of life, for the generosity of Novartis, for the effective and close way The Max Foundation monitors my treatment, for the solidarity of my friends near and far, and for the strength shown by my children and their support throughout this journey, as they are the main reason behind my drive to fight this battle. Thanks to all of them, I have been able to look at the future with new and hopeful eyes.

Today, I also want to express my heartfelt thanks to the Life Raft Group for their invitation to participate in their Alianza GIST initiative. At this point, I want to share with you something that happened during my return trip home after participating in the Alianza GIST planning meeting in Monterrey, Mexico.

A Uruguayan lady who lives in New York sat beside me on the plane, and just after we had exchanged but a few words, one of those magical moments when two souls connect occurred. She began telling me part of her personal story.

Her husband had passed away two years prior after a battle with cancer. When she was describing to me the de-



Piga (center) with Dr. Alexander Sakano (left) and Vicky Ossio (right) at the first meeting of Alianza GIST.

velopment of his illness, it was as if she was narrating my own story... an initial diagnosis, surgeries, radiations, metastasis and, in his case, also chemotherapy. The similarities were uncanny, the big difference was that her husband was dead and I was alive.

So many questions filled my mind! Was he diagnosed properly and given appropriate treatment? Did he have access to enough information to decide whether or not to trust his diagnosis? Could it have been a misdiagnosed GIST? And if so, had it been identified and treated properly, as in my case, could he still be alive?

Of course, we will never know the answer to all those questions, but after the Monterrey meeting I felt compelled to return to my country to try to do my bit in the fight against this disease. This conversation further cemented my decision and confirmed the need to provide physicians with all the information possible related to this cancer so they can draw upon such information when making a diagnosis.

It also confirmed the need to arm GIST patients with all the wealth of information available so they may better understand what is happening inside their bodies. I need to support them so they never feel alone in this fight for their lives, and in some way, give to others the same gifts I have received during my journey.

This is an excerpt from an article that appeared in the LRG Newsletter, February 2011 issue.

The LRG would like to extend deep thanks to its generous and committed Board of Directors. Each year our Directors strive to push themselves further in support of GIST patients and in 2010, the Board raised a combined \$175,000 to support GIST research and patient support, education and advocacy.

- Robert Book
- Stan Bunn
- Mia Byrne
- Chris Carley
- Jerry Cudzil, President
- Jim Hughes
- Jerry Knapp
- Ray Montague
- John Poss
- Marietta Robinson
- David Safford
- Rodrigo Salas
- Lawrence Selkovits
- Silvia Steinhilber

Also this year, the LRG Board welcomed a new director, **David Safford** to its ranks.

David became a member of the GIST family on January 21, 2010. After receiving an initial diagnosis that gave little room for hope due to the extensive nature of his metastatic cancer, pathology reports later confirmed kit+ GIST and a new mission was formed. David is inspired by the stories of GIST patients and is dedicated to helping not only control the positive outcome of his own disease but in those of the new GIST friends he has made, by participating in the efforts of the Life Raft Group.

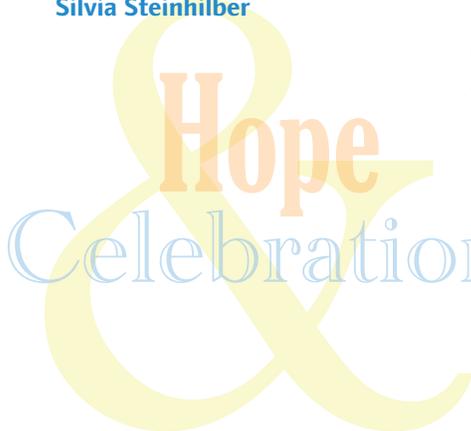
David Safford is the Chief Business Development Executive for Insight e-Tools, a growing high tech services



David Safford

provider with business clients large and small, all across the USA. David's professional sales management career has included positions in both Fortune 500 and small business environments for specialty product distribution, business services and high tech data solutions. Areas of expertise include strategic corporate partnerships, innovative problem solving, group dynamics, neuro-marketing, keynote addresses and other public speaking engagements. David is also a member of Vistage Key Executive Group in Seattle.

He has been married to his wife, Cherry for over 18 years and has three wonderful daughters, Natalie, Kiana and Alani.



December 2010 issue



In August 2010, LRG Board Member, Marietta Robinson's husband, **Jim Robinson** (on right), passed away from GIST. Jim was a dedicated and outspoken public servant, who frequently wrote and spoke on criminal justice issues. He was Dean and

a Professor of Law at Wayne State Law School, served as the President of the State Bar of Michigan and in 1998 he was appointed by President Clinton to be Assistant Attorney General in charge of the Criminal Division of the U.S. Department of Justice. He touched the lives of so many and is truly missed.

April 2010 issue



Kate Poss, daughter of LRG Board of Director and GISTer, John Poss not only managed to run the Austin Marathon in February 2010, she also managed to raise a

tremendous \$7,000 while she did it! And when Kate finished that last mile, John was waiting for her with a big smile.

Celebration



Long-time LRG member, Ruijia Mu, gives each month to our patient support efforts, even after the passing of his father, Xiangjie (left), in March 2008.

\$100,000 & Above

BST Consultants
Novartis Pharmaceuticals
Pfizer Inc.

\$20,000 – \$99,999

Carlos & Liana Baldor
Helen Frey
Rodrigo Salas

\$10,000 – \$19,999

Jerry Cudzil
Jim Hughes
Arbor Foundation Inc
Jerry Knapp
Marietta Robinson
RTI
Lawrence Selkovits

\$5,000 – \$9,999

Michael DiMaio
Genentech
Martha Smart
Pat Brady & David Smith
Synta Pharmaceuticals Corp

\$1,000 – \$4,999

Nasser Ahmad
ASCO
Brian Behrens
David Bell
Ettore Bianchi
Bob Book
Kathryn Byrne
Mia & Mike Byrne
KS Carberry
Celtic Therapeutics
Fred Chamanara
Benji Cheung
Perry DeVitto
DiMaio Ahmad Capital LLC
Dublin's Pub

Robert & Jeanie Eller
Daniel Erlichman
Thomas & Jane Green
Pierre Grellet-Aumont
Carolina & Dan Heflin

Jan Hofstetter
Michael Hofstetter
Steven Hollender
Douglas Horst
Arrow Steel Inc
Paul Karpowich

Joe Kippels
John R. Kirk
Joy & Douglas Knopp
Louise W. Korder
Jack R. LaDue
Robert Lynn

David Malvern
Valerie Matthews
John Matway
Patrick Moore
Salvatore Muzio
Network for Good

Roberta Offen
Stephen Oplinger
Melinda & John Poss
Andrew Roberts
Jonathan Rosee

Steve Rosenberg
Norman & Anita Scherzer
Jacky Lewkovich Schiestel
Carlos Sorrentino

Nicole Sparks
Silvia Steinhilber
Stanford University
Systems Plumbing LLC
Jean & John Talken

Andrew Tarica
Brian Tilyou
Gail & Frank Tondo
Angelo Vasiento
Cali Wojdyla

John Young
Kim & Chris Zimmer

\$500 – \$999

Alison Anderson
Paul Andiorino
Scott Ascherman
Ryan Atkinson
John Atorino

Richard Azevedo
Glen P. & Elizabeth J. Banks
Joe & Melissa Barbey
David Bayles
Ian Behar
Randy Beil

Wayne Bellet
Eric Bischoff
Marisa & Richard Bolognese
Joe Bonavita
Joseph Brachfeld

Ann Amer Brennan
Timothy Brennan
Pam Broadus
Bruce E. Brockstein
Kelly Buckley

Chris Carley
Bryan Carroll
Thomas Carroll
Lyon Carter III
Jiayi Chen

Nick Chiara
Jae Choi
David & Maxine Clark
Cohn & Wolfe
Michael Cudzil

Cuyahoga Cnty Land
Revitalization Corp
Doris Dallow
Doug Davies
Deciphera Pharmaceutical

John Denning
Joseph DiMaria
Vicki Dotson
Michael Fargione
Alexis Feliciano

Timothy Fischer

Michael Ginsberg
Gary Glasser
Gary Godshaw
Andrew Goldman
Mark Green
Glen Gregorio
Robert Grillo
Sharon & Jim Guizzetti
Todd Hirsch
Michael Hommeyer
Matt Howard
Paul Huchro
Vince Irwin
Jennifer James
R. Jesse
Sachin Jhangiani
Timothy Joyce
Levent Kahraman
Richard & Sue Kinzig
Matt Knopman
Mark Landis
Marc Lavine
Lai Oy Louie
Steven Luskey
James McAuliffe
Mark McCarthy
Michael McKean

Michael Meyer
Middlegate Insurance
Frank Moretti
Matthew Morris
Vincent Murray
Norma Nadeau
Allen Oppici
Parente/Risner Family Fund
Donald Perlman
Thomas Perneti
Floyd Pothoven
Project Flag
James Pryor
Qualcomm Matching Gift Program
John W. Rafal
Vivek Raman
Andrew Rich
Darren Richman
Ricky Romano
Ellen Rosenthal
Armin Rothauser
Tom Saxton
John Scarrone
Linda B. Schroeder
Dudley Scott
Ross Shapiro

February 2010 issue



Not only did **Carolina Ponce-Williams** celebrate her four-year cancer anniversary in 2010, she was blessed with the one thing she always wanted—a child. “I am so thankful to be able to celebrate my four year NED anniversary this year, especially because I am still a wife, a teacher, a daughter, a friend and now I am also a MOM!!”

HOPE Celebration

Mali Sinai
Derek Smith
Robert Spellman
Rajeev Srivastava
Alice B. Sulkowski
Thomas Tarantino
Jordon Thompson
Timothy V. Turpin
Richard Vandermass
Bohn Vergari
Marc Wasserman
Ira Weidhorn
Duane Williams
Hans Wyss

\$100 – \$499

Sunil Aggarwal
Rizwan Akhter
David Alexander
AMA Laboratories
Steven Ammann
Erick Ammons
Karen S Ammons
Catherine Avila
Harold K Baldwin
Sandra L. Banks
Harold & Gloria Baston
Lisa & Andy Batchelor
Richard Bellofatto
Betty Benjamin
Wayne Bennett
Brian Berg
Kris Berg
Patricia M. Berg
Louis & Joan Berge
Ken Berger
Isadore Bergner
John Bertrand
Margaret O. Beyers
Storrs & Suzanne Bigelow
Kerry Birch
John Birdsall
Ben & Susan Bishop
Kathleen A. Bishop
Terry & Susan Bishop
James & Patricia Blake
Dena Blood
Barbara Bodinson
Patricia Bonda-Swenson
Henry H. Borland
Leigh Borland
Pat Borland
Albert Boyle

Alice Boyle
Paul Bradshaw
Dr. David Brandis
Susan Brandt
Brian Brauth
Susan Brazier
Linda & Kenneth Brecko
James Breitman
Brian Brennan
Michelle Brophy
Timothy Brown
Barbara & Wayne Bruce
Alexandra Buchanan
William Buchanan
Stan Bunn
Lynn B. Burrows
Ann G. Byrne
Tom Byrne
Ashley Candy
Nick Caradonna
Tom Castelnuovo
Kevin Cavolo
Karl Cerny
Ilya Chalyt
Robert Chernow
Mark R. & Bette Christofersen
Sharon Clarke
Vincent Coccia
Kenneth Cook
Deedee Corradini
Anna Costato
Myrna Cramer
Crew of Motor Yacht Bayou
Maureen Culhane
Dan & Mickey Cunningham
Pam & John Curtis
Patricia Dahl
Daniel & Monica Dean
Peter Deering
Carl & Mary Del Balzo
Dell Direct Giving Campaign
Michael Deluca
Neal Desai
Dr. Tanya DeSanto
Jerome Diamond
Karl Heinz Didshun
Ann & Sam DiMisa
Robert K. Dobbs
Mary Dowski
William Chip Douglas
Jennifer Dunn
Julius M. Dziak

Judy & Robert Earl
Patricia Ehresmann
Laura Eldred
Gail A. Ellis
Russel & Bonnie Emerson
Tessie & Arthur Epstein
Joshua Feiler
Steven Feinberg
Rita & Mario Ferraro
Christopher Flammia
Lisa & Peter Fleming
Glenn & Beth Franz
Ralph & Joyce Fredericks
Effie French
Liz & Jeff Friedman
Shawn Gallagher
Joseph Gallo
Pat Garcia-Gonzalez
Dan Gardella
Elizabeth Gardner
Matthew Gardner
Jaime Garland
Marion "Pat" George
Saju Georgekutty
Anita Getler
Kristen L. Getler
Christine & David Ginsburg
Robert & Sandra Glassman
William Goebelbecker
Sachin Goel
Mr. & Mrs. Roger Goldberger
Gerald Alan Goldman
Jay Goldsamt
Eli Goldschmiedt
Maria Isabel Gomez
Felicia Graziano
Adam Norton Green
Avi Greenberg
Gesche Haas
Hajduk Family
Joseph & Allyson Hall
Patricia Hampel
Robert & Sue Hare
Basil Harrison
Evelyn Harrison
Marcia Harrison
Margaret Lynn Hartman
C. Douglas Hartsell
Theresa & Edward Hausbeck
Arthur Hawkins
Paul Hill
Janet Hines
David Hinton
Stanley Hladik
Ed & Terri Housbeck
Angela & Daniel Howell
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Independent Fiduciary Services Inc
United Seamen's Service Inc.
International Longshoremens' Assoc.
Israeli GIST Patient's Org
Jim Jacobson
Ann C. Johnson
Carol Jordan
David Josephy
Michael Josephy



In 2010, the LRG offices went "intern"-ational when Samantha Lecointe flew all the way from France to be the newest LRG intern. Here she is (left) posing in the "Raft" with her sister, Estelle, at Life Fest 2010.

James Kaletta
Geneva Kanter
Bracha Kaplan
Sherman Kaplan
Jim & Dot Kase
Russell & Cindy Kaye
David Kern
Su Young Kim
Marlin Kirshenbaum
Sam Kirshenbaum
Mark Klizas
Alexis Knopp
Stephen J. Korn
Chuck & Peggy Korte
Jeff Korte
Marc Kosaka
Erin K. Kristoff
Phillip Kukucka
Cathryn K. Kwart
Cayetano Lacroze
Malcolm Lane
Joseph Lanzisera
Estelle Lecointe
Christopher Leech
Jeanine & Michael Lemker
Jonell & Isadore Lenglet
David Levene
Cameron Lewis
Michael Lightle
Abbe Lindebaum
Clare Lindquist
John Lofaso
Joshua Lonsk
Albert Lotz
Timothy P. Lowney
Adrienne Lucier
Kevin Lynyak
M.M. & P. Mates Program
Edward Mackiewicz
Lucille Madsen
Michael Mahoney
Chet Malhorta
Timothy & Gail Mansfield
Donald & Gwen Marcus
Mary Culhane & William Marre
William L. Marre
Friends of Mike Matthews
Richard W. May
Tricia A. McAleer
Peter McAree

Brian McBride
Sam McCandless
Terry McCarty
Ellen McDonald
Rhonda McGhee
Stephanie Meltzer
Terrill Meyer
Glenn & Linda Miller
Jeff & Robyn Miller
Martha E. Miller
Stephanie A. Miller
James Mills
Robert C. Minion
Alejandro Miranda
Mina Mitby
Angelo Monello
Ray Montague
Ruijia Mu
Sean Mullen
Francis Mulvey
Seishin Murahashi
Jessie & Lita Naldo
Michael Neal
Richard Nechtow
Brian & Amy Newman
Marie Niemann
Sumito Nishitate
Dr. Geoffrey Oddie
James Oliver
Christina Osborn
Joyce O'Shea
Vicky Ossio
Thomas Overly
Terrasa & Stair P.A.
Slevin & Hart P.C.
Anne Pacifico
John Pagan
Elizabeth Reamer Palmer
Umesh Patel
Abbas Patni
Jim & Beth Patti
Tina Paulsen
Susan & Christian Pedersen
Christopher Perneti
Armando & Susie Petruccelli
Randi Pezzuto
Permit Popp
David Portnoy
Kate Poss
Purcells Cove Social Club
Amit Rametra



From left: Henji Cheung (2nd Place), Cayetano Lacroze (1st place) & Jonathan Rosee (3rd place) were this year's winners at our annual NYC Poker Tournament.

Sendhil Revuluri
 Thomas Richetti
 Andrew Rick
 Amit Rihal
 John Risner
 Carlos Rizov
 James & Cindy Robbins
 Charles Roberts
 Mike & Juli Rodriguez
 Roger Rosenblatt
 Arnold Rosenthal
 Lisa Rosenthal
 Sara R. Rothschild
 Jane Rowan
 Tammy Roy
 Roger D. Ruggles
 Ken & Jane Runyon
 Mackenzie Russel
 Lawrence & Janeen Ryan
 Hassan Safdar
 David Safford
 Steven Saggese
 Arun & Jayshree Sanghvi
 Ashleigh & John Santamaria
 James Sarvis
 Marjorie Schecker
 Sheldon Scher
 Raymond & Cynthia Schiestel
 K.M. Schlichting
 John F. Schmelzer D.O.
 Helga Schnorf
 Karen A. Kelley & Joseph V. Schuder
 David Schulte
 Margaret F. Scott
 Oren Shaked
 Saul & Carolyn Shenberg
 Richard Schoenbohm
 Amer Siddiqui
 Norma & Robert Siegel
 Lawrence F. Signora
 Howard & Lois Silberberg
 Bob & Debbie Silverstein
 Karam Singh
 Diana Smith
 Peter Smith
 Roger S. Smith
 Sunista Smith
 Thomas L. Smith
 Bruce Sneed
 Benjamin Snouffer
 Sobel & Company CPA
 Ann Spar
 Philip Steinhauer
 John Stinson
 Jean Stride
 Tania Stutman
 STV Engineers/Architects/Planners
 Kelley Suwak
 Thelma Swindell
 Kim Tallau
 Susan Tayman
 Andrew Templar
 David Templar
 John & Susan Thompson
 Linda A. Thompson
 Pat Tikkanen

Robert Tikkanen
 Gary Trombley
 Ayumi Tsuno
 Joyce & Stanley Tucker
 Patricia Ann Tyler
 John Venderzyden
 Paula & Philip Vettel
 Linda B. Volkening
 Frank Vondrasek
 Judith A. Wagman
 James Wang
 Sydney Wasserman
 Margot Weber
 Rebecca Wedgworth
 Ruth Weigand
 Susan Weigand-Smith
 Charles Weinberger
 Karen & Ronald Wertheimer
 Richard Whiteman
 Peggy & David Wicker
 Wimal Wijenayake
 Carolina Williams
 Geoffrey Williams
 Robert Wilson
 World Wide Events
 Joseph & Anna Zappala
 Glenda Zick
 Martha Zielinski
 Joshua Zucker

\$50 - \$99

Cheryl Abhau
 Janet & Marvin Adelman
 Joel & Judith Adelman
 Therese M. Ahlers
 Cheryl Asato
 James Baer
 Cheryl Barr
 Ronald Baynor
 Andrew Bell
 David & Ruth Bell
 Carole Blood
 Robert & Ann Bonda



The LRG would like to give big thanks to Kim Tallau of Innovative Images who donated her time and experience as a photographer in 2010, helping us keep these moments alive for many years to come.

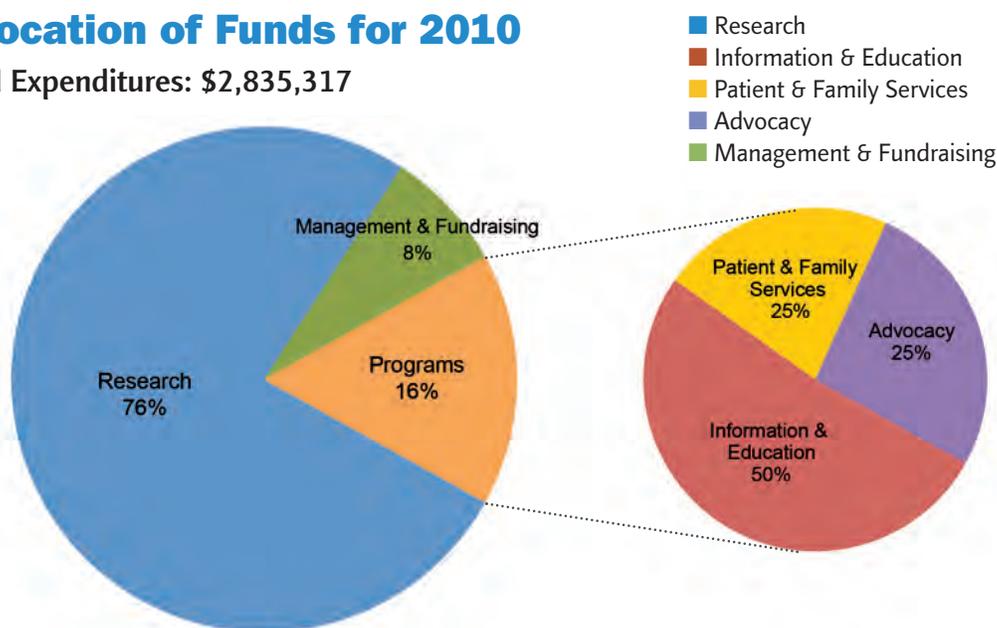
Gary & Chris Borda
 Beverly Brooks
 James & Joy Brossia
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 Troy & Janet Burns
 Jerry & Stephanie Call
 Kendra Cerda
 Alice May Clark
 Dale Claypoole
 Ellen Colucci
 Robert & Regina Cooley
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 Maria Cutrone
 Megan E. Danielson
 Howard & Arlene Danziger
 Peter & Jane Del Vecho
 Christina DiLullo
 Paul W. Dunn & Family
 Jackie Edwards

Stuart Elson
 Eleanor Falkenstern
 Marco Filipovic
 Henry M. Forster
 Daniel & Meg Foster
 Bonnie Glenn
 Anne Goodwin
 Louis & Suzanne Greenwald
 Bill & Judy Griesel
 J. Robert & Helen Hall
 Bonnie & Gary Halvorsen
 Robert & Heather Hamilton
 S.A. Hann
 Rebekah Hardie
 Patrick Wayne Hare
 Elaine Hauptman
 Elizabeth Healy
 Craig Hobbs
 Marc Holloway
 Nancy C. Howie
 Eunice Howley
 Abraham Hussein
 Sharon & John Iota
 Jim Kardong
 Marcia Keane
 Karen Kelley
 Gale Marie Kenny
 Maureen Keyhani
 Ann & Mitch Kremer
 Claudia Lapcevic
 Thomas W. Lynch
 Eric Markowitz
 Sally McCarthy
 Robert Melillo
 Howard & Sandra Meridy
 Audrey Merry
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 James Mullen
 Marsha G. Mullera
 Michael & Diana Neirink
 Colleen O'Brien
 Jennifer Olcovich
 Marilyn Jane Oosterhuis
 Alejandro Ortega

Pat & Mark Ostroff
 John Padgett
 David Palacios
 Dorrie Pariser
 Partners Healthcare
 Larry Payne
 Bonnie Pedigo
 Paul C. Perkus
 Precision Payroll Service
 Rose & Richard Pridgen
 Ted L. Purcell
 Otto Raggambi
 Robert Rennak
 P. Rocca
 Pablo Rodriguez
 Mary Rohr
 Gary R. Rottmann
 Troy & Marie Saliba
 Magdalena Sarnas
 Richard Schoenbohm
 Rexford Schroyer
 Darlene Shaw
 J. Bert & Linda Smith
 John Snyder
 Lawrence C. Sparks
 Lesley & Harvey Spencer
 Akshay Sura
 Thomas J. Tax DDS
 Kendra Tobes
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 Joan Urban
 JoEllen Urban
 Frederick H. Vanderbeek Jr.
 Pradeep Vijayakumar
 Inna Voloshina
 Maren & Stanley Waksmundski
 Rebecca Warren
 Stephen & Teri Weisenstein
 Daniel White
 Scott Wicker
 Charles Wilson
 Nancy P. Zinser

Allocation of Funds for 2010

Total Expenditures: \$2,835,317



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

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