

# Project D Day: our greatest hope for a cure

By Norman J. Scherzer  
LRG Executive Director

For the past four years, the LRG Research Team has been building a strategy that will lead to a cure for GIST and there has been progress on a broad number of fronts including:

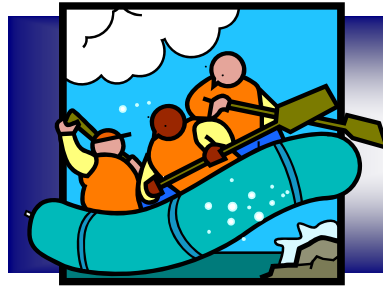
- The creation of a comprehensive blueprint for understanding the mechanisms of treatment resistance that develop following the failure of single drug regimens like Glivec and Sutent
- The development of mechanisms to test new drugs in the laboratory, including genetically engineered mice that transmit particular forms of GIST from



SCHERZER

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Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

October 2010

In memory of Jim Robinson, Omer Mercier, Henry Offen,  
Louis Sill, Patricia Morissy, Ken Schiefelbein, Eleanor Lewis,  
Matt Arluck & Connie Arndt

Vol 11, No. 3

## Breaking GIST News: Novartis suspends plasma testing support

We have recently been advised that Novartis Pharmaceuticals will suspend its financial support of plasma level testing after receiving a letter from the FDA criticizing its promotion of such testing on its CML & GIST Alliance websites. In response, Novartis has closed both websites and advised Avantix Laboratory it was ending its contract



for such testing effective September 30, 2010.

### What next?

The Life Raft Group has since met with Dr. Lynyee Shum, Director of Avantix Laboratory (TDM Pharmaceutical Research) and Herve Hoppenot, President of Novartis Oncology to discuss our concerns about this decision. We will keep our readers advised.



# 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.



PIT

In June, Jeroen had surgery in Holland to remove a primary GIST tumor. When his GIST metastasized to the liver, he and his wife, Emilie, 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, procedures and drug changes, Jeroen asked himself what was next on the 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.’”

Emilie got on the internet and started their investigation into the GIST re-

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# Norman & Anita meet with Dutch GISTers in Amsterdam

*The following excerpt has been reprinted from an article in the Contactgroep GIST newsletter, "Van GISTeren naar morgen" with permission.*

**N**orman Scherzer, the American who founded the Life Raft Group ten years ago, stayed with his wife Anita at the Hilton hotel in Amsterdam during the week of July 5th. He had invited the Contactgroep GIST at the hotel on July 8th. Current chairman Jack Asselbergs, former chairman of the first hour Ton de Keijser, treasurer Gonny Panis, PR Ronald Postma were present on behalf of the Board, and



Drinking health to new research!

2000, when she participated in a Gleevec trial in the USA.

The reason of their visit was the gift of no less than 1 million euros, donated by

a philanthropist from Amsterdam, stipulating the money has to be spent on GIST research (see article on page 1). The generous giver himself is a patient and cannot tolerate Gleevec.

Norman and his wife, however, were in for a big surprise: the huge amount of



Norman discusses GIST research with Dutch GISTers at the Hilton hotel in Amsterdam.

Helmer (IT) & Ellen van Arem (newsletter editor and author of this report).

It was a very enjoyable get together with this friendly American couple. Anita is a GIST patient for ten years now and has taken Gleevec since

one million dollars was "slightly exaggerated", the Dutchman had recently organized a charity evening and each of his guests had to pay 50,000 euros entrance fee. **The man from Amsterdam thus handed over to Norman a 1.7 million euro check. Unthinkable!**

The Life Raft Group in the U.S.A. now has an extraordinary challenge. Norman heartedly hopes that this money will not only provide for the discovery of a better treatment for all GIST patients worldwide, he also hopes that this desired research outcome will be in time for this special patient in Amsterdam!



From left to right, Jack Asselbergs, Ellen van Arem, Gonny Panis, Anita Scherzer, Ton de Keijser, Norman Scherzer, Ronald Postma & Helmer van Arem.

## The Life Raft Group

Who are we, what do we do?

**The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do.** The LRG provides support, information and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, patient education through monthly newsletters and webcasts, one-on-one patient consultations, and most importantly, managing a major research project to find the cure for GIST.

### How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States.

You can donate by **credit card** at [www.liferaftgroup.org/donate.htm](http://www.liferaftgroup.org/donate.htm) or by sending a **check** to:

The Life Raft Group  
155 US Highway 46, Suite 202  
Wayne, NJ 07470

### Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor.

Please advise Erin Kristoff, the Newsletter Editor, at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org) of any errors.

## **International News!**

**Australia-GISTour is taking place in October**

**Nicaragua-Meeting on October 16, Michael Josephy and Elsie Hernandez will be flying in to give a GIST 101 talk**

**Argentina-Asociacion GIST Argentina has officially been formed**

***Wondering if GIST patients and caregivers are holding a meeting in your country?***

***Head over to [www.globalgist.org](http://www.globalgist.org) and email your representative for news.***

# GIST Research: Articles on the Science of GIST

## Antioxidants: useful supplements or should we refrain?

**By Omer Mercier, Ph.D**  
LRG Science Team

*On June 16, LRG Science Team member, Omer Mercier passed away. We could think of no better tribute to him than reprinting an article he wrote for the LRG website.*

**U**nder different forms, antioxidants are in wide use among health-conscious people and even more so among cancer patients. They take the form of such dietary supplements as Vitamin C, E and A, beta-carotene, lycopene, selenium, ginger (*Zingiber officinale*), curcumin (turmeric), or pomegranate juice. Occasional controversies have been raised concerning their use, on grounds of serious or sometimes questionable arguments. Another controversy was raised lately, whereby the authors warned that several antioxidants could

block therapeutic actions of some anti-cancer drugs, among them Gleevec (imatinib), thus suggesting they should not be used.

Today, we are facing total confusion on this topic; should we refrain from taking antioxidants? All of them or just some of them?

My objective is to present a review of pertinent publications on biological actions of antioxidants, with particular emphasis on cancer patients. It does not focus on novel research results but rather attempts to sort out favorable and unfavorable arguments buried in existing publications, making it easier for GIST

patients, and other cancer patients as well, to make decisions while understanding the issues at stake.

### Antioxidants: many names and many sources

"An antioxidant is a molecule capable of slowing or preventing the oxidation of other molecules. Oxidation is a chemical reaction that transfers electrons from a substance to an oxidizing agent. Oxidation reactions can produce free radicals, which start chain reactions that damage cells. Antioxidants terminate these chain reactions by being oxidized themselves. Although oxidation reactions are crucial for life [e.g. respiration], they can also be damaging; hence, plants and animal maintain complex systems of multiple types of antioxidants as well as enzymes.

*You can read the rest of this article at [www.liferaftgroup.org/antioxidants.html](http://www.liferaftgroup.org/antioxidants.html)*

### Clinical Trials Update:

Any updates or additions to clinical trials has been added to the LRG Clinical Trials Database. Go to [www.liferaftgroup.org/treat\\_trials.html](http://www.liferaftgroup.org/treat_trials.html) to search the listing

## Vettel reports on ASCO 2010 updates

**By Paula Vettel**  
LRG Science Team

In vitro activity of novel KIT/PDGFRα switch pocket kinase inhibitors against mutations associated with drug-resistant GI stromal tumors.

**A** new type of kinase inhibitor from Deciphera Pharmaceuticals has been developed. Dr. Heinrich reported on pre-clinical testing of inhibitors that bind more fully and tightly to the KIT/PDGFRα ATP binding pocket and block enzymatic activity. He explained that the binding site resembles a swinging gate. If the gate is open, imatinib can come in and bind to KIT and control

GIST. If the gate is closed, the kinase inhibitors cannot bind properly to KIT resulting in tumor growth. Certain secondary mutations can lock the gate making the KIT resistant to kinase inhibitors. Inhibitors were sought that would keep the gate from swinging around and make the binding pocket always available.

Deciphera Pharmaceuticals are developing Switch Pocket Kinase Inhibitors (SPKI) that have long residency times on the kinase, are resilient to ATP interference, show thermal stabilization of the target kinase, and bind to both the active and inactive forms of the kinase, resulting in conformational control (of the gate). Dr. Mike Heinrich, of Oregon Health & Science University, reported testing of three compounds that showed very potent activity as SPKI in the lab, particularly against GIST drug-resistant

mutations. Toxicity screening and pharmacological profiles are very encouraging. Research is continuing to optimize the candidate structure. Phase I clinical trials have not yet begun, but Heinrich hopes to have the optimal candidate identified by the end of 2010.

Nilotinib for patients with advanced GIST who failed imatinib and sunitinib:  
Negative effect of prior major gastrectomy on exposure to nilotinib.

Nilotinib is being tested in patients who have progressed on imatinib and sunitinib. Drug-food interaction studies



# Three girls are going to skydive for GIST!

By Stacey McAully  
LRG Member

**M**y name is Stacey and most of you will have seen us in the April edition of the newsletter. I have always known I have wanted to do something to raise money that can go into research for finding a GIST cure, but there have always been hospital appointments or surgery and recovery getting in the way.

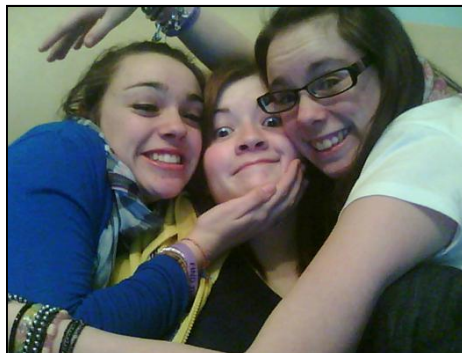
However, now I am in great health and I decided to start organizing a fundraiser. We wanted to do something that people didn't do every day and that was

so out there to raise awareness, hence...

**SKYDIVE FOR GISTS!!!!**

My sister, Sammy, our best friend, Gemma Day and myself will be doing a skydive on

August 7 to raise money for The Sarcoma Trust. This is a UK charity which funds research into soft tissue cancers



Sammy McAully, Gemma Day & Stacey McAully goofing around.

such as GISTs. We are holding many events to raise awareness and sponsorship for our skydive and GISTs.

We have made a page online where people can read my story and sponsor us- [www.justgiving.com/stacey-mcaully](http://www.justgiving.com/stacey-mcaully)

**Editor's Note: As of the printing of this issue, the girls' skydive has been**

**postponed due to bad weather. It is rescheduled for October 24. To date, they have raised £3,570.00.**

## Varmus sworn in as NCI's 14th director

*This article is reprinted from a National Cancer Institute press release.*

Nobel Prize winner Harold E. Varmus, M.D., today took the oath of office to become the National Cancer Institute's (NCI) 14th director. NCI is one of the 27 Institutes and Centers that comprise the National Institutes of Health (NIH).

"It's very exciting to have you back," said Health and Human Services Secretary Kathleen Sebelius during the swearing-in ceremony. "Today is the opening of a new chapter for NCI."

Varmus was director of NIH from 1993 until the end of 1999.

In his opening remarks to a town hall meeting that reintroduced Varmus to the NIH community, NIH Director Francis Collins, M.D., Ph.D., called him "the best person on the planet to take the reins of the National Cancer Institute at this propitious moment."

Varmus was co-recipient of the Nobel Prize in Physiology or Medicine in 1989 for studies of the genetic basis of cancer. He most recently served as president of Memorial Sloan-Kettering Cancer Center in New York City.

Memorial Sloan-Kettering is an NCI-



**VARMUS**

designated cancer center. NCI-designated cancer centers are funded by competitive grants and are characterized by scientific excellence and the capability to integrate a diversity of research approaches to focus

on the problem of cancer.

In his remarks to the town hall, Varmus termed NIH "the most glorious manifestation I know of what government and democracy are capable of doing."

Varmus also spoke of the scientific climate that surrounds his return: "Suddenly we have an incredible specificity about markers and damaged genes in cancer cells. We have better information technology. We understand the biochemistry of the cell more profoundly. We have a portrait emerging of what is happening, one cancer at a time."

Varmus spent 23 years as a faculty member at the University of California, San Francisco medical school, where he worked on the replication cycles of ret-

roviruses and hepatitis B viruses, the functions of genes implicated in cancer, and the development of mouse models of human cancer.

During his tenure at NIH, Varmus helped to initiate a five-year doubling of the NIH budget. More recently, President Barack Obama appointed him co-chair of the President's Council of Advisors on Science and Technology. He has been a member of the U.S. National Academy of Sciences since 1984 and of the Institute of Medicine since 1991, and has received the National Medal of Science, the Vannevar Bush Award, and several honorary degrees and other prizes, in addition to the Nobel Prize.

By leading NCI, Varmus' scientific career is coming full circle, as his scientific training occurred first as a Public Health Service officer at NIH, where he studied bacterial gene expression with Ira Pastan, M.D., currently chief of the Laboratory of Molecular Biology at NCI.

"We have to remember that the great achievements in science have almost always begun with an individual scientist having an unexpected idea," Varmus said.

# JEROEN

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search landscape.

“We wanted to know if our 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 they could indeed make a difference, Emilie got in touch with Dr. Maria Debiec-Rychter of the Catholic University in Leuven, Belgium, who told her 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, “We 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 re-

This frog means a great deal to Jeroen. After his first surgery, a friend gave him a pet frog as a gift. After his second surgery, he bought him an even bigger frog. When he decided to donate to the LRG team, he gave each member a small silver frog as a gift and a reminder of the patients they are trying to save.



Jeroen & Emilie brought together all of their supporters (as well as Executive Director, Norman Scherzer & his wife Anita) for a day of celebration and information about GIST research.

search team differs from traditional cancer research. The LRG eliminates the overhead costs institutions usually taken, 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.



Emilie addresses the Dutch supporters.

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 (Learn more about Project D Day on page 1).

“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



# Cancer tattoos mark milestones but know the risks

By Belinda Ehrlich

From hearts and flowers to skulls and daggers, tattoos grace the bodies of millions of people across the globe whether they are rock stars or neighborhood housewives.

Although many choose this once rebellious art form to represent love, hobbies, or special occasions, one milestone that is beginning to make its mark in the tattoo industry is cancer survival.

Biographix Tattoo Studio in Syracuse, N.Y., holds a yearly “Ink for Cancer” event benefitting the American Cancer Society.

“This event took off like wild fire last year,” said Mike Haines, owner of Biographix. “We raised \$1000 for the [American Cancer Society] in ’09. We hope to generate more this year, but it’s more about getting the word out there that you can survive this. Hope this year’s will be even bigger!”

So what is an appropriate image for a cancer survivor tattoo? Pink ribbon tattoos, for example, symbolize breast cancer awareness. Words such as “Survivor,” “Hope,” “Faith,” and “Courage” can also represent someone’s battle with cancer. Some people choose images that symbolize beating the disease.

David Allen of Insight Studios in Chicago’s Wicker Park neighborhood said he’s done about 50 cancer-related tattoos.

“Most survivor tattoos involve a ribbon for sure,” he said. “Also, many people include important dates for milestones. The idea is to create a fitting tribute, so any imagery that ties into the struggle, journey, and family all works.

“One of my memorable tattoos is the word *hope* created out of the cancer ribbon. It seemed to strike a chord, and I’ve had numerous requests for it. I’ve had people fly in and get other words created out of ribbon as well.”

LRG member Jennifer Engstler of New York chose a sea turtle for her tattoo after falling in love with the animal while diving in Indonesia. She also admired the symbolism of the sea turtle, including intelligence and long life.

“I know the symbolism of the turtle became a lot stronger after I was diagnosed, that is for certain,” Jennifer said.

“When I look at it, I recall the absolute peace and beauty I had when I first went diving there... it relaxes me when I’m anxious.”

There are, however, risks involved when getting tattooed, and patients taking Gleevec or other cancer treatment drugs have additional concerns, according to Dr. Jonathan Trent of MD Anderson Cancer Center in Houston.

“I would not recommend getting a tattoo while on Gleevec,” Dr. Trent said.

“The tattooing process may result in

adverse reactions that could be confused with Gleevec toxicity.

This could result in unnecessary delays or discontinuations of therapy.”

According to MayoClinic.com, if the equipment used to create your tattoo is contaminated with infected blood, you can contract various blood-borne diseases, including hepatitis B, hepatitis C, tetanus and HIV – the virus that causes AIDS.

“Viral hepatitis is rare but can occur as a result of poor sterilization procedures,” Dr. Trent said. “This could damage the

liver and decrease the ability to tolerate Gleevec.” Some medications –



Engstler's tattoo.

such as Gleevec and Sutent – can cause a thinning of the skin that may make healing more difficult. Life Raft Group member Steven Petrera of New York and Naples, Fla., was taking Gleevec when he got a tattoo.

“He knew that bleeding easily was a factor since he would only lightly scrape

his skin and bleed,” said his wife, Annette. “He didn’t bleed much at all as a matter of fact.”

Jennifer got her tattoo while taking Sutent and said the healing time took a little longer but was minimal.

According to the Centers for Disease Control website, tattoo shops should take the following precautions:

**Use single-use, disposable needles and razors.** Disposable piercing needles, tattoo needles, and razors are used on one person and then thrown away. Reusing needles or razors is not safe.

**Safely dispose of needles and razors.**

Used needles and razors should be thrown away in a biohazard-labeled, disposable container to protect both the client and the person changing or handling the trash bag from getting cut.

**Wash hands before and after putting on disposable gloves.** Gloves are always worn while working with equipment and clients, changed when necessary, and are not reused.

**Clean and sterilize reusable tools and equipment.** Some tools and equipment can be reused when creating body art. Reusable tools and equipment should be cleaned and then sterilized to remove viruses and bacteria.

**Frequently clean surfaces and work areas.** Chairs, tables, work spaces and counters should be disinfected between procedures to protect both the health of the client and the artist. Cross-contamination (spreading bacteria and viruses from one surface to another) can occur if surfaces are not disinfected frequently and between clients.



**D DAY**

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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.
- The creation of a comprehensive GIST tissue bank housed at Stanford University which allows significant numbers of researchers to access and test this rare tissue as well as to access the clinical histories of the patients that is maintained by the Life Raft Group in its Patient Registry
- 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.

- Authoring over 150 research publications.

Recently, 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 patients resistant to Gleevec and Sutent (the only two FDA approved

## Project D-Day Research Programs

Data and information will continue to be shared; progress reports will be prepared every 3 months. The four phases of research include:

**Sequencing Team:** Christopher Corless, MD, Oregon Health Sciences University (OHSU), project leader

Sequencing the GIST genome via two projects led by Cristina Antonescu, MD of Memorial-Sloan Kettering Cancer Center (MSKCC) and Christopher Corless, MD of OHSU. The two projects will sequence the entire GIST genome, identifying additional genes, like KIT/PDGFR, which are activated by clear-cut mutations in GIST. The presence of an activating mutation has historically been the most powerful predictor of whether a particular gene represents an important therapeutic target in cancer.

**Gene Knockdown Team:** Jonathan Fletcher, MD, Brigham & Women's Hospital, Harvard Medical School, project leader

In this study, four different gene knockdown screens (also called functional screens) will examine pathways essential for GIST cell survival. In effect, individual genes in individual cells are turned off one at a time to find the most important genetic targets. These efforts will be led by Jonathan Fletcher, MD of Brigham & Women's Hospital, Anette Duensing, MD of the University of Pittsburgh Cancer Institute.

**Drug Screening Team:** Brian Rubin, MD, Cleveland Clinic, project leader

Lead by Brian Rubin of Cleveland Clinic and Jonathan Fletcher of Brigham and Women's Hospital, advanced screening will take place to evaluate drug candidates. The libraries accessed include more than 250,000 compounds and include late-stage and approved drugs.

**Validation Team:** Michael Heinrich, MD, OHSU, project leader

The first three research areas are expected to produce a large number of leads that will need to be verified. This validation phase will be led by Michael Heinrich, MD, of OHSU and include Sebastian Bauer, MD of West German Cancer Center, University of Essen in Germany; Maria Debiec-Rychter, MD of Catholic University/Belgium; Matt van de Rijn, MD and PhD of Stanford University Medical Center and Christopher Corless, MD of OHSU.

drugs for this cancer) alive (Read more about Jeroen's story on page 1). We added one million dollars and the result is the aptly named D Day Project. Like that extraordinary day in 1944, when the Allied forces stormed the beaches of Normandy, our attack on GIST treatment resistance has reached an historic opportunity for success.

Recent decreases in the costs of genotyping combined with the largest privately-funded GIST research initiative in history has given us the best opportunity to date to find a cure for GIST. We have in place an initial three million dollar war chest over an 18 month period and a strategy that will optimize our chances for success.

## The Plan

The LRG research team will continue to share data and information and maintain its collaborative approach to research. Progress reports will now be shared every three months instead of every six months. The level of determination has never been greater.

The D Day Project's research plan is organized into four distinct project areas: sequencing, gene knockdown, drug screening and validation. It is believed that these four distinct areas hold the key combination to unlocking the cure for GIST. Each of these complex areas will have a unique team leader to ensure maximum coordination, communication and to assess progress.

## Eliminating Overhead

### Research Institution Administrative Overhead = 0

As we have an existent contract mechanism in place with each of the LRG Research Team Institutions that

# 'Tis the season for holiday giving

**By Toni Bodrato**

LRG Development Associate

**I**t is the close knit community of GIST patients, families and friends that keeps the Life Raft Group afloat. As the hope of GIST patients and families continues to float in the arms of the Life Raft Group, we are thrilled to have you aboard our raft in the fight against GIST. It's the time of year again which Life Rafter and our friends know and love. Our yearly Holiday Fundraising Campaign is fast approaching.

We will be asking GIST survivors and families to send out note

cards, letters and emails asking their friends and family for their support. Donations to the LRG help to support our research project, *Pathway to a Cure*. We have opted, with your support, to fund the top GIST scientists in the world and focus directly on areas that are crucial to finding a cure. To date, we have contributed over \$5 million to *Pathway to a Cure*.

Your generous donations may also support our Programs.

The Life Raft Group provides support, information and assistance to patients and families with this rare cancer to help keep them alive until there is a cure. The LRG

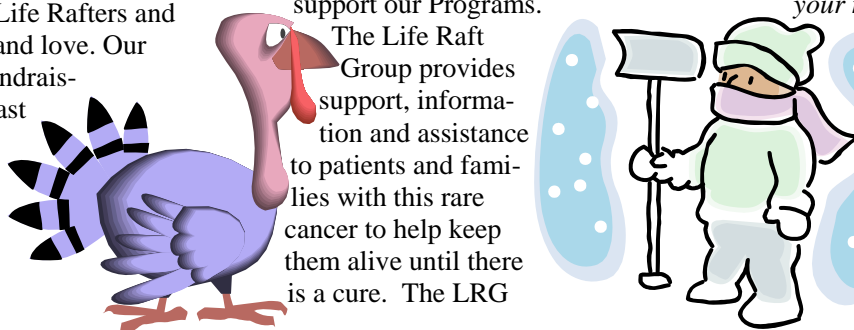
achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, and patient education through pamphlets, monthly newsletters, webcasts, and one-on-one patient consultations.

We won't just wait for a cure. We have to make it happen. Join us in the fight against GIST.

*Fundraising materials for this year's holiday campaign should be arriving in your mail within the next few weeks.*

*Please email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org) or call us at (973) 837-9092 if you have any questions or comments.*

*For information on Pathway to a Cure and our programs go to [www.liferaftgroup.org](http://www.liferaftgroup.org)*



## Eighth annual patient summit for CML & GIST held in Austria

*Excerpts reprinted with permission from Novartis Pharmaceuticals publication.*

The 8th annual "International New Horizons Conference for Organizations Representing People with CML or GIST" was held this year in Vösendorf, Austria, from June 18 to 20, 2010. Sponsored by Novartis, the conference provided patient advocate leaders with an opportunity for 3 days of learning, companionship and the chance to share experiences across national boundaries. This year's conference was held on a particularly celebratory note, as it marked the 10th anniversary of imatinib and its revolutionary impact on the treatment of CML and GIST.

Growing larger every year, the conference welcomed more than 220 participants and a record of 144 patient advocates from 56 different countries in Europe, North America, Asia, Africa, Middle East and Latin America. It fea-

tured 30 hours of presentations from a dedicated and enthusiastic faculty of medical experts and stakeholders. Patient advocacy has made significant advances since the 1st New Horizons in 2003, and the conference demonstrated what advocacy groups can achieve in 8 years of cooperation. Many delegates remarked that New Horizons 2010 was the "best ever."

### Patient Participation in Research

This year's meeting explored the impact of patient participation on CML and GIST research. Patient involvement can make a real difference in clinical research and advocates were shown concrete examples from other disease fields. These outlined how patient knowledge can be used to generate more meaningful research, find acceptable solutions to ethical problems in trials, boost trial awareness, recruitment and even im-

prove trial data quality through direct research such as patient's surveys. Both CML and GIST advocates were united in their call for patient advocacy groups to become more active in this field.

This is a new frontier in advocacy, and the challenges facing advocacy groups are numerous. Two main hurdles facing advocacy groups are how to convince researchers of the value of patient experience and how to empower patients to contribute. Patients have a unique perspective on clinical treatments. Their experience makes research relevant and useful.

### Interactive Advocacy Experience

New this year was the Advocacy Market Place dynamic. The practical issues of running advocacy groups are a prime concern for advocates. The Advocacy Market Place provided an opportunity



# LRG welcomes David Safford to board of directors

**D**avid Safford is the chief business development executive for Insight e-Tools, a growing high-tech services 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



SAFFORD

of Vistage Key Executive group in Seattle.

David received his Bachelor of Sciences degree with a double major in Business Administration and Economics at Linfield College. In addition to being recognized by the Oregon Sports Hall of Fame as the Most

Outstanding College Student/Athlete in the State of Oregon in 1989, David was an All-American pitcher on the baseball team with many school records that still

stand today.

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

David Safford 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.

## ASCO

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on the bioavailability of nilotinib show the importance of the stomach in nilotinib absorption. The authors conclude that nilotinib was active and safe in patients with advanced GIST resistant to both imatinib and sunitinib. Prior gastrectomy seemed to decrease the bioavailability of nilotinib significantly, at least in some patients. Monitoring of plasma drug concentration may be particularly important for proper nilotinib therapy in GIST patients with major gastrectomy. This may also be very important for patients taking sunitinib. A scientist from Novartis commented to us that imatinib is much more easily dissolved and absorbed in the stomach than other kinase inhibitors. This information is important for all GIST patients who have had large amounts of stomach removed.

Long-term follow-up of patients with GIST undergoing metastasectomy in the era of imatinib (IM)  
Dr. Sebastian Bauer, of the West Ger-

man Cancer Center, University of Essen in Germany, conducted a study to follow the overall survival of GIST patients who had metastasectomy to reduce tumor loads. He found a possible long-term benefit from R0/R1 metastasectomy (clear margins) in patients with metastatic GIST. In contrast, incomplete resection, including debulking surgery, appears not to be beneficial to overall survival. Debulking surgery can be beneficial for symptom relief. The location of the metastases is an important factor.

Activity of GDC-0941, an inhibitor of phosphoinositol 3 kinase (PI3K), in gastro intestinal stromal tumor (GIST) xenograft and duration of response after discontinuation of treatment in combination with imatinib.

Dr. Maria Debiec-Rychter, of the Catholic University of Leuven in Belgium, has studied the combination of imatinib and GDC-0941, a PI3K inhibitor in mice bearing KIT exon 11 mutation. She found that the combination of

GDC-0941 and imatinib has extensive antitumor efficacy in GIST mice, inducing more substantial cell death and durable effects than imatinib alone. This effect was sustained even after treatment withdrawal. These results highlight the success that various research teams are finding with combinations of KIT and mTOR inhibitors such as GDC-0941 and everolimus (RAD001).

Pharmacoeepidemiology of clinically relevant hypothyroidism and hypertension from sunitinib and sorafenib

The authors studied hypothyroidism and hypertension in patients receiving at least 45 days of sunitinib or sorafenib by analyzing the Medco database of about 60 million individuals. They found significant side effects between months two and months seven of sunitinib treatment requiring blood pressure monitoring and thyroid replacement medication. Hypertension, but not hypothyroidism was found with patients on sorafenib. It would be worthwhile for patients on sunitinib to talk to their doctors about monitoring heart and thyroid condition. Hypothyroidism could be a contributing factor to fatigue on sunitinib.

# Arluck passes away surrounded by family

**M**atthew Allen Arluck, of Chicago, passed away at his parents' home surrounded by his immediate family on Thursday, Nov. 26, 2009. He was 39 years old.

The son of Richard and Yvonne Arluck, Matthew was born Feb. 4, 1970, in Cupertino, Calif. He was raised in San Jose, Calif., and lived briefly with his family in the Philippines and Okinawa. Matthew graduated from San Jose's Piedmont Hills High School in 1988 and eventually settled in Chicago to pursue a music career.

He was a well-known and very popular figure in Chicago's alternative music scene, where he played guitar and performed vocals in several local bands. Employed by Urban Outfitters Inc., he



worked as a shipping and receiving supervisor at one of their Anthropologie retail stores in the Chicago suburbs. He was a dedicated skateboarder, an avid fan of heavy metal rock music and prolific collector of rock music memorabilia. He also loved the game of hockey; his favorite team was the Chicago Blackhawks.

Surviving family members include his father and mother of Sammamish; sister Denise Howitt; brother-in-law Joel Howitt; and young nephews Luke and

Reece Howitt of Federal Way. Besides loving family members, Matthew leaves many wonderful friends and fans mourning his passing.

A memorial service will be scheduled for some time in the future.

The family suggests donations in Matthew's name be made to Grind for Life, an organization dedicated to providing financial assistance to cancer patients in need, at [www.grindforlife.org](http://www.grindforlife.org). Donations in his name can also be made to the American Cancer Society, or Providence Hospice of Seattle, 425 Pontius Ave. N., No. 300, Seattle, WA 98109.

Friends are invited to view an expanded obituary and photo gallery, share memories and sign the family's online guest book when posted on [www.flintofts.com](http://www.flintofts.com).

The GIST Foundation of St. Louis will be holding a GIST course, "Diagnosis and Treatment of Gastrointestinal Stromal Tumor (GIST) on Saturday, October 23, 2010

## **Location**

The Charles F. Knight Executive Education Center

Washington University Danforth Campus, St. Louis

**Course Chair:** Joel Picus, M.D.

## **Presented By**

The Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

## **LEARNING/PERFORMANCE OBJECTIVES:**

This course is designed for gastroenterologists, medical oncologists, pathologists, radiologists, primary care physicians and allied health care professionals in these specialties, plus GIST patients. The course is designed to improve the diagnosis and management of gastrointestinal stromal tumors (GIST). The intended result of this activity is increased knowledge/competence, enhanced performance and improved patient outcomes. After completion of this course, the participant should be able to:

- Discuss tools used in the diagnosis of GIST.
- Identify the immunohistochemical and genetic tests used in GIST.
- Explain the role of surgery and neoadjuvant and adjuvant therapy in the management of GIST.
- Summarize the management of primary and metastatic GIST.



**Go to [www.gistl.org](http://www.gistl.org) for more information on this event.**

# A life well spent, Offen passes at 72

**H**enry William Offen came into this world as Heinrich Wilhelm Albert Offen in Uelzen, Germany, on April 28, 1937. He left his frail body at his Carpinteria home surrounded by his family, pets and garden on Sunday, April 25, just three days before his 73<sup>rd</sup> birthday.

The Offen family immigrated to the United States in 1953. Henry graduated from Harmony High School in Minnesota in 1954. The owner of the bank in Harmony noticed Henry's academic ability and graciously gave financial assistance for Henry's four years at St. Olaf College in Northfield, Minnesota. Henry graduated Phi Beta Kappa with a

B.A. in Chemistry June, 1958. That summer found him on the road to UCLA in his beloved 1949 Ford (with fender skirts) where he became a graduate student in the Chemistry Department.

Two years later as a Physical Chemistry teaching assistant, Henry met his future wife, Roberta (Bobbie) Gluckman, an undergraduate in Chemistry. They married in the fall of 1961 and their son Karl Henry was born December, 1962, one day before Bobbie's birthday and six months after Bobbie's graduation. Henry received the Ph.D. in Physical Chemistry June 1963 and the small family moved up the coast to Santa Barbara. That summer Henry accepted a position as an Assistant Profes-

sor in the UCSB Chemistry Department. Daughter Julia Lynn joined the family July 1964.

During his more than 40 years at UCSB, in addition to attaining the rank of Professor, Henry was Associate Dean of the Graduate Division, Acting Director for numerous departments, Director of the Marine Science Institute, Natural Land and Water Reserves System, Natural Reserve System, Professor Emeritus in the Department of Chemistry (1994), and following retirement was recalled as Interim Director of the Natural Reserve System (NRS). He was instrumental in helping to bring the Valentine Eastern

See OFFEN, Page 15

**THURSDAY, NOVEMBER 18TH, 2010**  
**MIDTOWN LOFT IN NYC**  
**DOORS OPEN AT 6:00 P.M.**

**THE 7TH ANNUAL**  
**LRG POKER TOURNAMENT**  
**HOSTED BY JERRY CUDZIL**  
**[WWW.LIFERAFTGROUP.ORG/DONATEPOKER.PHP](http://WWW.LIFERAFTGROUP.ORG/DONATEPOKER.PHP)**

**\$500** Buy-in to play, enjoy hors d'oeuvres and drinks

**\$100** Donation for guests who want to cheer you on

*The last one standing wins a seat at the  
World Series of Poker worth **\$10,000!***

Please **RSVP** to Tricia McAlleer at 973-837-9092 or [tmcaleer@liferaftgroup.org](mailto:tmcaleer@liferaftgroup.org)



## JEROEN

From Page 5

screening would be a part of the research plan. This research, which involves testing GIST cells against thousands of drugs and compounds, is 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 still continues on Nexavar and 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.”

## Prosecutor, Dean, husband and friend, Robinson was respected by all

**J**ames K. Robinson, a high-level official in the U.S. Justice Department during both the Clinton Administration and the Carter Administration, a member of President Obama’s transition team, and an appointee of Chief Justice Rehnquist to a Committee of the United States Judicial Conference, passed away on Friday after a battle with gastrointestinal cancer. Mr. Robinson was 66. At the time of his death, Mr. Robinson was a partner in the Washington, DC office of the law firm of Cadwalader, Wickersham & Taft.

Mr. Robinson’s forty year legal career was wide-ranging and varied. In addition to serving for 25 years in private practice and being recognized by numerous organizations as one of the leading trial lawyers and appellate lawyers in the United States, Mr. Robinson was a federal prosecutor, a law school dean, President of the State Bar of Michigan, and a drafter of the Federal Rules of Evidence.

Mr. Robinson’s legal career began in 1968, following his graduation from Wayne State University Law School in Michigan, where he was Editor-in-Chief of the Wayne Law Review. Mr. Robinson first worked as a law clerk to Judge George C. Edwards of the United States Court of Appeals for the Sixth Circuit, and then went into private practice in Detroit. In 1977, at the age of 33, Mr. Robinson was nominated by President Carter to be United States Attorney for the Eastern District of Michigan, the chief federal prosecutor in Detroit, a position he held until 1980. Following his tenure in that post, Mr. Robinson

returned to the Detroit law firm of Honigman Miller Schwartz & Cohn, where he headed the litigation department. From 1990 to 1991, he also served as President of the State Bar of Michigan.



James K. Robinson, right, talks with Sen. Carl Levin before his nomination hearing for assistant attorney general in 1998.

One of Mr. Robinson’s primary legal interests was the rules of evidence. While in private practice, he chaired the committee that drafted the Michigan Rules of Evidence, he regularly taught law school classes on evidence, and he co-authored a three-volume treatise and a courtroom handbook on the rules of evidence. In 1993, Chief Justice Rehnquist appointed Mr. Robinson to the Advisory Committee on the Federal Rules of Evidence, the body responsible for proposing to the United States Supreme Court revisions to the Federal Rules of Evidence. Mr. Robinson remained a member of the Committee for five years. In addition to writing the Rules of Evidence, from 1975 until his death, Mr. Robinson served on the five-member committee of the National Conference of Bar Examiners which drafts

## D DAY

From Page 7

conditions our funding on their waiver of administrative overhead rates we plan to extend these contract provisions to this new funding. This will provide for an enormous savings as the typical overhead rates range from 65 percent to 75 percent.

**“Other [research] alternatives were good, but the impact of your dollar is better at the LRG.”**

**-Jeroen Pit (benefactor)**

### Life Raft Group Overhead = 0

As we have a research support infrastructure in place within the Life Raft Group we will support the planning and implementation of this additional funding without charging any overhead at our end.

## The Bottom Line

Instead of writing checks to individual investigators with the simplistic objective of supporting GIST research and hoping for the best, the D Day project is built upon an understanding that researchers will be held accountable for

their individual roles in implementing a strategic plan, including a requirement that they report back to us every three months to assess progress and strengthen cooperation. This al-

lows for rapid course-correction, in keeping with the fast-paced world of GIST research.

This is quite unlike traditional methods for funding cancer research, a generally unsuccessful approach that encourages competition instead of collaboration and which rewards publications over in-

creased patient survival. Instead, LRG priorities are set based upon a common strategic plan. Collaboration replaces competition. Accountability is enhanced by individual contracts which require budget reports and progress reports. Communication and coordination is strengthened by requiring that team members share data and information on an ongoing basis.

We believe this D Day project represents the best chance we have ever had for finding the cure for GIST. We have the resources to launch this attack, but we cannot finish it alone.

**“All the investigators are intent on taking the fastest possible track to more effective treatments/cure for Gleevec resistant GIST. I am confident that major therapeutic advances will result from this research.”**

**-Dr. Jonathan Fletcher (LRG Research Team Leader)**

**“We have the best in their field, with four years of knowledge and teamwork under their belt, coming together in a four-pronged strategic attack on treatment resistance at a time when research costs have lowered significantly.”**

**-Norman Scherzer (LRG Executive Director)**

## HELP WANTED

Additional funding is not only necessary to this plan, it's vital.

Additional funding will permit us to significantly widen the scope and the timing of this project, including new sequencing projects focusing on the GIST exome (the one percent of the genome that contains the DNA that codes for making proteins), additional drug screens, and expanded gene knockdown projects to allow for more extensive screening of the GIST genome.

Please go to [www.liferaftgroup.org/donate.html](http://www.liferaftgroup.org/donate.html) to help the LRG continue its research efforts.

## Beloved woman, missed by all

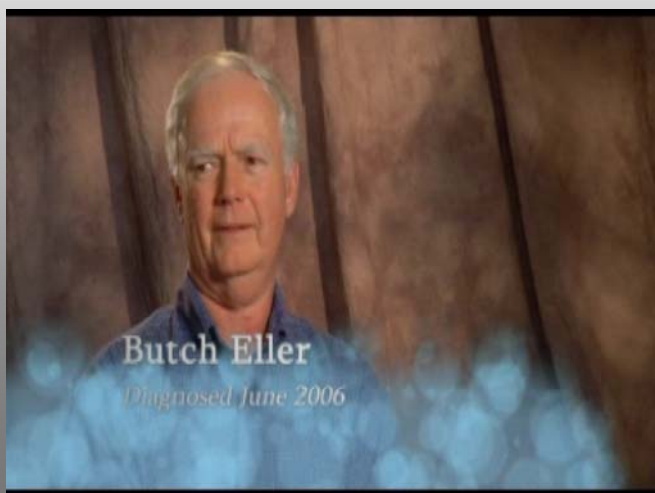
Eleanor Marie Lewis was born November 29, 1934 in Independence, Missouri. She died on Wednesday September 22, 2010 in Arizona. Her courage and determination serve as an example for her family and friends of tireless perseverance during her many years of living with cancer of several types. She will be greatly missed by her husband of 56 years, Stephen B. Lewis, and her three children. She has two loving sisters Maxine Bailey and Nancy Kwak who have been her life-long friends.



Eleanor took pride in her four grandchildren and one great-grandchild. Eleanor graduated from the Independence Sanitarium School of Nursing in 1955 in Independence, Missouri. In her professional life, she served countless patients as a caring and loyal nurse. An important quality of her life was the dedication she had for following the work of her father, Alfred H. Yale, by being a faithful Christian and servant of the Lord. Besides being a devoted wife and tender mother, Eleanor enjoyed reading, music, needlework, painting, playing bridge, ballroom and square dancing.

## The 10 Year Anniversary of GIST treatment video is now available on the LRG website!

Created for and first shown at Life Fest 2010's gala dinner, *GIST 2010: A Decade of Difference*, this video chronicles the last ten years of GIST treatment through the eyes of the doctors and patients who have lived it. Please go to [http://www.liferaftgroup.org/video\\_GIST2010.html](http://www.liferaftgroup.org/video_GIST2010.html) to view it.



## Mark your calendars!

**Look out for our Holiday Fundraising packages in the mail!**



- **October 16: 2nd Annual GIST CANCER Walk for a Cure! Yakima, WA**
- **October 24: San Jose GIST Cancer Walk for a Cure, San Jose, CA**
- **October 24: NY GIST Cancer Walk for a Cure, Rockland Lake State Park, Congers NY**
- **Go to [www.gistinfo.org](http://www.gistinfo.org) for details about these walks**
- **November 18: LRG Poker Tournament at the Midtown Loft in NYC (Please see page 11 for details)**

## ROBINSON

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the evidence questions for the Multistate Bar Exam.

In 1993, Mr. Robinson decided to turn his attention full-time to the academic world and he was named Dean and Professor of Law at the Wayne State University Law School. During his tenure as Dean, Mr. Robinson was responsible for expanding the Law School's curriculum and establishing a strong connection between the law school and legal community.

Mr. Robinson left the deanship in 1998 when President Clinton nominated him to be Assistant Attorney General in charge of the Criminal Division at the Justice Department, a position he held until the end of that Administration. As Assistant Attorney General, Mr. Robinson helped increase and expand the Division's focus on transnational crime and, in particular, on the fights against

international terrorism, drug trafficking, money laundering, and computer crime. During his tenure, the Division stationed federal prosecutors at U.S. Embassies throughout the world in order to coordinate international law enforcement efforts more effectively. As part of these efforts, Mr. Robinson headed the U.S. delegation to the G-8 government/industry cybercrime conference in Paris and to the South American Justice Ministers conference in Argentina. He also co-chaired the Commission on Crime and Security at U.S. Seaports and was a member of the Presidential Advisory Commission on Holocaust Assets. Following his service as Assistant Attorney General, Mr. Robinson was retained as a consultant by the United Nations Center for International Crime Prevention in Vienna to conduct a global study on the transfer of funds of illicit origin with respect to the negotiation of the United Nations Convention Against Corruption.

In recognition of his many legal ac-

complishments, Mr. Robinson was inducted as a Fellow of the American College of Trial Lawyers, the International Society of Barristers, and the American Academy of Appellate Lawyers. He also was invited to be a Member in the American Law Institute, and a Master in the Edward Bennett Williams Inn of Court. Mr. Robinson's interest in international legal issues led him to a position as a Visiting Professor on the Faculty of Law of Utrecht University in the Netherlands, where he taught Introduction to American Law and a seminar on Comparative Approaches to Adjudication in Civil and Common Law Legal Systems.

Apart from his legal work, Mr. Robinson was an avid sailor and motorcyclist. He is survived by his wife of 28 years, Marietta Robinson, a member of the LRG Board of Directors, his son Steven of Grand Blanc, Michigan, his daughter Renee Stromberg of Stockholm, Sweden, five grandchildren, his mother and five siblings.



## OFFEN

From Page 11

Sierra Reserve, Sierra Nevada Aquatic Reserve, Coal Oil Point Reserve, Carpinteria Salt Marsh, Santa Cruz Island Reserve, Kenneth S. Norris Rancho Marino Reserve, and Sedgwick Reserve into the UCSB Natural Reserve System of protected natural land. Henry was the author or co-author of over 80 research publications in physical chemistry, specifically high-pressure spectroscopy. He supervised ten PhD graduates and eight Master's graduates.

Along with his family, one of Henry's greatest loves was his garden, which at one time included over 100 fruit trees and berry vines. His garden not only supplied fruits and vegetables to the family, the friends, the neighbors, and colleagues of Bobbie's, but also to the animals at the Santa Barbara Zoo. Henry was diagnosed with GIST in the fall of 2001. In spite of the ups and downs associated with this type of cancer, he and Bobbie managed several wonderful trips to visit relatives and National Parks, and he taught several seminars in the UCSB Freshman Honors program as a volunteer. He felt very strongly about the wonders of the natural world, and that one of the most valuable gifts he could bring to these youngsters was to open their eyes to the global issues involved in living sustainably and preserving our planet for the future.

In addition to, Bobbie, his wife of 48 ½ years, Henry leaves his two children, Dr. Julia Offen, Dr. Karl Offen (engaged to Dr. Chie Sakakibara), his granddaughter Antonia Gitana Rodriguez Offen, Antonia's mother Dr. Clemencia Rodriguez, his two sisters: Magdalene Hagedorn (Dr. Henry Hagedorn), Gisela Sadler (Dan Sadler), his brother, Dr. Walter Offen (Susie Offen), his uncle Gerhard Offen (Lillian Offen), in-laws Sara & Doug Miller, Patricia Leupold, and many nieces, nephews and cousins both in the US and Germany. He was preceded in death by his father, Henry Offen and his mother, Magdalena Meyer Offen.

## AUSTRIA

From Page 8

for close and active interaction with experts in advocacy management. Here, advocates could attend four sessions of their choice dealing with topics such as fundraising, the internet and social media, working with the pharmaceutical industry, collaborating with physicians, mobilizing patients for advocacy, helping patients find clinical trials, and volunteer engagement. The small size of the groups meant that delegates could discuss these topics directly with their fellow advocates and presenters.

### Scientific Update on GIST

Throughout the meeting, advocacy leaders stressed the importance of staying up to date on current, unbiased medical information. The medical update sessions were an opportunity for patients to listen to experts present the latest clinical news and to discuss issues that concern them. The presentations were well pitched to both experienced and new delegates. Introductory CML and GIST workshops conducted by patient advocates, with physician support, gave first-time delegates basic information necessary for a better understanding of approved treatments, whilst medical update sessions provided results of clinical trials recently presented at medical conferences as well as insights into new therapies being developed.

Resistance to imatinib is the most pressing issue facing GIST patients today. Primary and secondary resistance to imatinib remain life-threatening events for most GIST patients. New treatment strategies must be investigated to overcome resistance with lasting results. The molecular biology of resistance remains a crucial focus of investigation and delegates learned about new research into hopefully promising molecular targets. However, more research and efforts are needed here to identify the best drugs and drug combinations, and the need for International collaborations in achieving this goal was underscored. "Treating resistance" and "Avoiding and prevent-

ing resistance" were in fact the first and second preferred topics indicated by GIST delegates in their conference evaluation reports, significantly proving that resistance is a priority concern calling for life saving solutions.

### Adherence a big challenge

Adherence to oral TKI therapy remains a problem in both CML and GIST. Poor adherence can have a considerable effect on drug response and can play a strong role in the development of resistance. Providing information about managing side effects is one way that advocacy groups can work towards improving adherence issues. In comprehensive sessions given by experienced healthcare professionals, the most common side effects associated with TKIs were presented and strategies for overcoming these reviewed.

### 10 Years Anniversary

Some of the conference's most moving moments came during a special session dedicated to the 10th anniversary of survivors and imatinib. Imatinib started a revolution in molecular targeted therapies and turned CML and GIST into more manageable diseases, giving hope to patients and changing the definition of what it means to survive cancer. Imatinib's use in the treatment of CML was a prototype for molecular targeted therapy, whilst in GIST, the intersection of new science and the availability of imatinib led to better treatment and understanding of the disease. Most of the advocates at New Horizons have had their lives radically changed by imatinib, and this session became a celebration of life as delegates were given the opportunity to share their stories of what the added years of survival have meant to them.

This feeling of celebration prevailed throughout the conference, and as the meeting moved to a close, the delegates were left with happy memories of time well spent with friends.

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\*Omer passed away on June 16, 2010 and is greatly missed by all.

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