

# LRG mourns the loss of a great friend, Jeroen Pit

By Christine Schaumburg  
LRG Development Director

Jeroen Pit, who passed away on February 6, was not a man to sit idly by and he certainly did not lose his battle with GIST without a terrible fight. After diagnosis, Jeroen and his devoted wife Emilie, immediately sought after cutting-edge GIST research and came across the Life Raft



Devoted couple: Jeroen & Emilie.

Group.

Since 2009, Jeroen has raised and donated close to \$3 million dollars through incredible persistence to fund the D-Day research project. This brave Dutchman

See JEROEN, Page 13

Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

April 2012

In memory of Tom Overley, Betty Arnett, David Durham, Frank Tondo, Tina Pandolfino, Debbie Brewster, Jessica Marchiando, Robert Hare, Diane Ralston, Simon Price, Reinhardt Jesse & Jeroen Pit

Vol 13, No. 2

## GDOL Update: Speakers Announced

By Tricia McAleer  
LRG Program Director

GIST Day of Learning is a free one-day educational event that will be held at the Deauville Beach Resort in Miami, Fla. on Saturday, May 19, 2012. In addition to sharing hope and friendship, attendees will learn important facts about their cancer, prevailing treatment options, tests as indicators for treatment surveillance, and coping with dietary changes and side-effects of treatment.

In addition to GIST Specialist Jonathan C. Trent, M.D., Ph.D., GIST Day of Learning has added some very prominent speakers to the line-up!

Elizabeth Fontao, M.S., P.A.-C., who works closely with Dr. Trent at the University of Miami Sylvester Cancer Center to support sarcoma patients, will be



presenting for the “Managing Side-Effects” session. We are also honored to have Alan S. Livingstone, M.D. speaking for the “Surgery and Other Options” session. Dr. Livingstone currently serves as the Lucille and DeWitt Daughtry Professor and Chairman of the DeWitt Daughtry Family Department of Surgery at the University of Miami, Miller School of Medicine. Additionally, he maintains a busy surgical practice and serves as the Chief of Surgical Services at Jackson Memorial Hospital and the University of Miami Hospital, as well as the Chief of the Division of Surgical Oncology.

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# LRG Research Team meets in Leuven, Belgium: leaves with renewed energy & commitment to finding the cure for GIST

By Lisa Pereira  
LRG Executive Assistant

The Life Raft Group Research Team met in Leuven, Belgium last month to discuss progress to date, and formulate a plan on how to effectively move GIST research forward. Every member of the research team was in attendance, as well as guests Dr. Adrian Marino-Enriquez

from Brigham & Women’s Hospital, Harvard University and Dr. Agnieszka Wozniak from the Catholic University in Leuven. LRG Executive Director, Norman Scherzer, Science Director, Jerry Call, Board Member, Jim Hughes and Executive Assistant, Lisa Pereira were also at the meeting. Research Team member Dr. Maria Debiec-Rychter of the Catholic University in Leuven was the extremely gracious host. A special

thank you goes out to Genentech® for sponsoring the meeting.

Before getting down to work, the group convened early to take in the beautiful city, including a walking tour of major historical sites. In addition to the famous late-Gothic Style Leuven Town Hall, everyone was particularly captivated by the restored Grand Beguinage which dates back to the 13<sup>th</sup>

See LEUVEN, Page 14

# Meet our new Montana local rep: Dirk Niebaum

By Dirk Niebaum  
LRG Member

I was born August 6, 1961 in Turlock, Calif., and attended high school in Half Moon Bay, Calif. After graduating from California State University, Chico, I married Lori on June 22, 1985. The day after the wedding, Lori and I loaded everything we owned into a 4X8 U-haul and moved to Missoula, Mont. so that I could continue working toward a degree in education. Shortly after graduating we moved to Kalispell, Mont. where I began my teaching and coaching career. I have taught from third grade to twelfth grade, where most of my career was spent in the fourth grade classroom, and where I sometimes felt like the biggest kid in the room. I coached many sports over the last twenty-seven years. High School football, track and wrestling are where I spent most of my afternoons. I continue to count my blessings because of all the wonderful people - young and old - that I have been fortunate to work with during my career.

My wife, Lori, and I live in Kalispell, Mont. We have two wonderful daughters, Kelly, twenty-three years old, and Dayna, seventeen years old. Kelly lives in Colorado and works at Whole Foods and Dayna is a senior in high school. Lori is an office manager for a doctor's office. As a family we are usually on the move enjoying the many wonderful outdoor activities that Montana has to offer. The activities that we enjoy include hiking, camping, kayaking, white water rafting, skiing, hunting, and fishing. Although GIST has changed the level at which I participate in these activities, it has not robbed me of the enjoyment they bring to my life. The activities would mean very little without all the good friends and family with whom I've en-



Dirk and Lori Niebaum on Big Mountain in Whitefish, Montana.

joyed these activities over the years. The support I have received is incredible and the Life Raft Group has played an important part in that support.

I became acquainted with the Life Raft Group shortly after my forty-seventh birthday. On August 7, 2008 I underwent emergency surgery for what was thought to be a ruptured, encapsulated appendix. I went into surgery believing they had finally solved the mystery of the one-and-a-half year-old history of intermittent gastrointestinal bleeding.

See DIRK, Page 12

## 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.html](http://www.liferaftgroup.org/donate.html) 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.

## My Mascot: By Dayna Niebaum

He's that guy that will pick you up when you're having a bad day. He's that guy that will be there for you and love you no matter what happens. He's that guy that always has a smile on his face. That guy is my dad. His passion and love for everything and everyone is what I admire most about my dad. I've always had such great respect for him, but the events that truly opened my eyes into seeing his amazing character started back at the hospital, the day he was diagnosed with cancer. Through his words and actions, he continues teaching me the importance of having a positive outlook on life, putting others before myself, and working hard to achieve my goals.

He has been able to battle cancer and not let it stop or limit the things he loves to do. He is one of the most active people I know, and even though he has a tougher time with fatigue, he pushes past the point of exhaustion because he enjoys living an active lifestyle. The pills he takes twice a day make him feel like he has the flu but he won't let this hold him back. He is able to stay strong and push forward. This has inspired me to always work hard with everything I do. Every day there are new challenges I face and with the inspiration of my dad, I know anything is possible.



# Cellular origin of GIST from the “good” cells’ perspective

**By Dr. Tamas Ordog**  
The Mayo Clinic  
LRG Researcher

## An Introduction to Interstitial Cells of the Gut

The discovery that gain-of-function mutations in KIT, the receptor for stem cell factor (SCF), underlie most GIST<sup>1</sup> has forever changed the way this disease is diagnosed and led to the identification of imatinib (Gleevec) as its primary medical treatment option.<sup>2</sup> The same study also proposed that transformation of interstitial cells of Cajal (ICC), KIT-dependent cells residing within the gut musculature,<sup>3</sup> may represent the cellular source of GIST.<sup>1</sup> A role for activating mutations in platelet-derived growth factor receptor a (PDGFRA) was reported in a subset of GIST lacking KIT mutations some years later.<sup>4</sup> Since PDGFRA-expressing interstitial cells called ‘fibroblast-like cells’ (FLC) also reside in the gastrointestinal musculature, FLC have been proposed to be the source of PDGFRA-mutant GIST.<sup>5</sup> While much effort has since been devoted to studying the nature and effects of various KIT and PDGFRA mutations, much less attention has been given to the proposed cells-of-origin of GIST. However, recent reports suggest that insights from the biology of gut interstitial cells may further our understanding of the pathogenesis of GIST: Firstly, a study by Chi et al.<sup>6</sup> identified ETV1, a regulator of gene transcription expressed in subsets of ICC prone to oncogenic KIT-mediated transformation,<sup>7</sup> as a key factor promoting GIST tumorigenesis. Secondly, our group described ICC progenitor/stem cells (ICC-SC) in the stomach of mice<sup>8</sup> and found that transformed ICC-SC can give rise to imatinib-resistant tumors resembling GIST seen in imatinib-treated patients.<sup>9</sup> Thirdly, the calcium-activated chloride channel anoctamin 1 (ANO1), which was first identified in GIST<sup>10</sup> has been found to play an im-

portant role in ICC electrical activity<sup>11</sup> and ICC proliferation.<sup>12</sup> To promote better understanding of the biology of interstitial cells particularly as it pertains to GIST, this article reviews the physiological functions, development and maintenance of ICC and FLC and identifies some key questions for future research.

The main functions of the gastrointestinal tract are to secrete digestive juices, break down food components, absorb nutrients, reclaim water and excrete waste, which are performed by the mucosal lining of the gut (Figure 1). Due to the length of the digestive system (~30-33 ft or 9-10 m), these functions are highly compartmentalized, requiring precisely timed movement of contents from one segment to another. In addition, food also needs to be mixed with secretions and broken down into smaller pieces. These functions are executed by cells making up the muscular wall of the gut (Figure 1) with input from the central autonomic nervous system. Digestive functions do not require conscious control but rather depend on regulatory loops involving chemical (hormones, neurotransmitters), mechanical (stretch) and electrical signals and reflecting the coordinated actions of several cell types.

The mechanical work required for gastrointestinal motor functions is per-

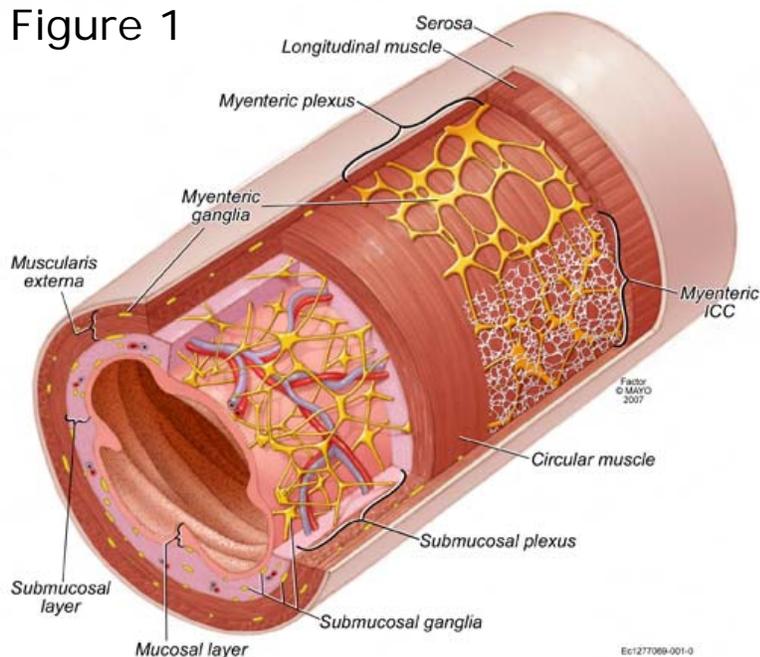


**ORDOG**

formed by smooth muscle cells, which are organized into an inner circular and outer longitudinal layer (Figure 1). Unlike other muscles, smooth muscles can sustain contraction for a long time. The resultant tone permits both relaxation and further contraction. Contraction depends on entry of calcium ions from the extracellular

space via ion channels responsive to electrical depolarization, i.e., loss of the electrical gradient across the cell membrane set up by ion pumps.<sup>13</sup> Depolarization can be triggered by excitatory neural inputs or electrical signals from ICC; whereas hyperpolarization, which causes relaxation, is elicited by inhibitory neurotransmitters. Some ion channels are also directly regulated by mechanical stretch.<sup>14</sup> Since smooth muscle cells are interconnected by so-called gap junction

Figure 1



tions that allow the movement of ions from cell to cell, electrical changes occurring at one point can spread to entire muscle bundles.

The contractile activity of smooth

# Alianza GIST meets in Miami

By Piga Fernández

Alianza GIST-Chile Representative

From March 25 through 28 representatives of 12 Latin American countries got together in Miami with representatives of The Life Raft Group, The Max Foundation, American Cancer Society, CODEVIDA, SixDegrees and the pharmaceutical industry in order to update themselves about GIST treatment and get trained on how to improve education, advocacy and patient support for the GIST community in Latin America.

Regarding GIST treatment, the agenda included interesting topics like GIST treatment updates, side-effects management, substandard drugs, and the Latin American reality regarding treatment access.

Representatives were trained to continue working in their countries in patient support and advocacy. They outlined the importance and goals of their advocacy work and worked through the various levels of advocacy, covering topics such as public policy formation, building strategic alliances, engagement with government authorities and patient navigation.

Roberto Pazmino from The Life Raft Group presented the LRG Patient Registry, an extraordinary tool which uses patient-provided medical data to track trends in GIST treatment and dosage. It is also a very valuable asset to GIST researchers in areas like the GIST Collaborative Tissue Bank, which Roberto Pazmino also presented to us. Initiatives

like the Patient Registry and the Tissue Bank are two ways Latin American GIST patients can participate and be active in life-saving research. These valuable programs enable Alianza GIST to collect important statistics regarding the incidence and survival of the GIST community in Latin America, both of which are unknown in the region. Sara Rothschild, LRG Global Relations Director, presented the newly created Alianza GIST web page, where all local organizations are able to register, participate, share experiences, create forums and send questions and concerns to one another.

Finally, with the guidance of Bob Chapman, Director of US Government and Multilateral Global Health Advocacy of American Cancer Society, Alianza GIST was able to establish three targeted mission areas:

1. Education and Support
2. Advocacy and Access
3. Research and Surveillance

Additionally, Alianza GIST began work on setting up a core infrastructure, in which participants created different committees to further the main vision of the survival of GIST patients in Latin America.

Meeting attendees included:

Melisa Biman and Sandra Mesri (Argentina), Vicky Ossio (Bolivia), Piga Fernández (Chile), Rafael Vega and María Helena Matamala (Colombia), Michael Josephy (Costa Rica), Silvia Castillo de Armas (Guatemala), Xiomara Barrientos (Honduras), Rodrigo Salas



The fun is written on their faces (left to right): LRG Global Relations Director, Sara Rothschild, Piga, and LRG Latin American liaison Vicky Ossio.

(México), María Teresa Ponce (Nicaragua), Maurice Mayrides (Perú), Alejandro Miranda (Dominican Republic), María Isabel Gómez (Venezuela), Norman Scherzer, Sara Rothschild and Roberto Pazmino (The Life Raft Group).

The invited panelists were: Dr. Jonathan Trent, Dr. Elizabeth Fontao, and Dr. Monica García-Buitrago, from the Sylvester Cancer Center. Erin Schwartz from The Max Foundation, Debbie Freire from Novartis, Margalit Edelman from Pfizer, Siobhán Ní Bhuachalla from SixDegrees Healthcare Consulting, Feliciano Reyna from CODEVIDA, and Bob Chapman and Dr. Daniel Armstrong from the American Cancer Society.

All participants were able to share experiences and were motivated to continue working on behalf of GIST patients in Latin America. We look forward to continuing our outreach, advocacy, and program activities in the region.

For more information, please contact [info@alianzagist.org](mailto:info@alianzagist.org).



# And they're off! 1st 'Harness a Cure' is a success

By **Christine Schaumburg**  
LRG Development Director

**T**welve year GIST survivor and former harness driver, Bobby Kinsey, had two goals when he started planning "Harness a Cure" – to raise awareness about GIST and raise money to cure this disease. With over one hundred participants in the walk and donations continuing to arrive, Dover Down's first Harness a Cure event to benefit the Life Raft Group's research was a huge success thanks to Bobby who tells his fellow raftmates in the email community, "Keep Rowing."

Bobby asked both drivers and horse

owners to pledge a portion of their purses for "Harness a Cure", one of fifteen races held on March 25. In addition, the Delaware Standard Bred Owners Association agreed to match the horsemen's contributions, up to \$5,000. Immediately following the races, Bobby led over one hundred participants, including Congressman John Carney, in a 5/8 mile walk around



**KINSEY**

the Dover Down's race track to raise GIST awareness. Walkers made contributions and received pledges to participate.

Bobby is already making plans for "Harness a Cure" 2013. It was my sincere pleasure to work with Bobby and his family and friends on this event and like Bobby, I know that this will continue to grow as an annual event. The Life Raft Group thanks Bobby, his volunteers, the Dover Downs and the Dela-

ware Standard Bred Owners Association for their time, talent and generosity.



Kinsey shrouded his horses in his favorite colors, purple (which represents gastric cancers) and gold, (representing pediatric cancer) showing his support of all GISTers.



## NoCal GISTers meet!

Back Row from left to right: Erick Ammons, Lynn Whelan, Linda Fish, Iris Berke, Bill Corliss, Jan Kaprielian, Mark K., and Carlo Alesandrini

Front Row from Left to right: Erika Gasaway, Karen Ammons, Mary Corliss, Michael Shorb, Martha Zielinski, Paula Vettel, Barbara Alesandrini

# NJ GIST gathering serves up support & smoothies

**By Tricia McAleer**  
LRG Program Director

The Life Raft Group held our local group meeting on March 4, 2012. We were thrilled to have special guest Pamela Stofberg, R.D. and intern, Jackie Piemonte volunteer their time to talk to us about nutrition. Pamela is an outpatient oncology dietitian who provides coverage to all divisions of the John Theurer Cancer Center at Hackensack University Medical Center in Hackensack, N.J. She has more than thirty years of professional experience and has worked in the areas of oncology nutrition, surgical nutrition research, corporate consulting and community nutrition outreach programs.

For this meeting, each attendee brought a healthy dish and a recipe to share with each other and after a very informative talk on general nutrition and GIST-specific issues Pam made healthy smoothies for everyone! For those that missed the meeting, we have included the family smoothie recipe she shared with us at the meeting below. Pam also



The group was all smiles after Pam & lovely assistant Trish (left) whipped up some nutritional and yummy smoothies.



presented a wealth of very helpful information, especially regarding one major concern for the group having trouble with

digestion and diarrhea, for which she suggested adhering to a low residue diet that focuses on consuming foods that are more easily digested. You can read more about it at [www.webmd.com/ibd-crohns-disease/low-residue-diet-foods](http://www.webmd.com/ibd-crohns-disease/low-residue-diet-foods). For more recipes and information please visit this article on [www.gistnews.org](http://www.gistnews.org).

Thank you, Pam for coming out and spending the time to answer all of our questions and for making the delicious smoothies! We would also like to thank our friends at Trader Joe's in Wayne, N.J. for donating ginger tea, cookies and dark chocolates for the meeting.

## Strawberry Banana

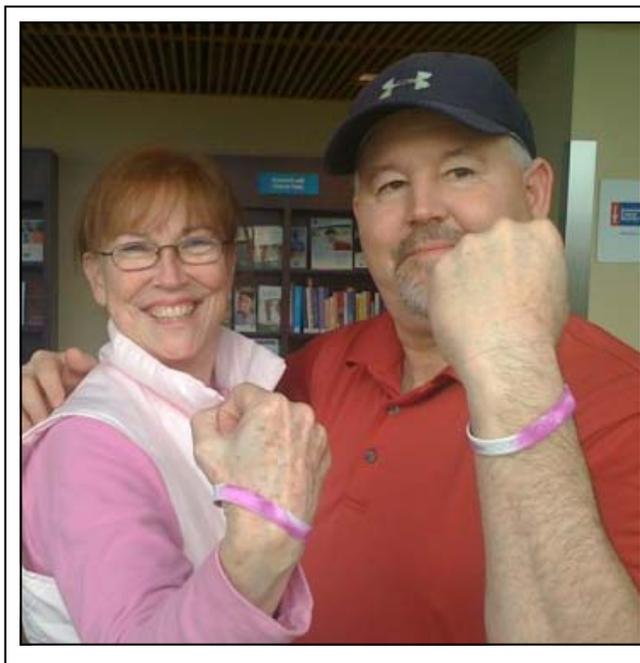
### Citrus Smoothie

**(Pam Stofberg Family Recipe)**

- \* 1 Banana
  - \* 8 oz. container of vanilla yogurt
  - \* 8 oz. orange juice
  - \* 1 cup frozen whole strawberries
1. In a blender, process the first 3 ingredients. Add frozen strawberries and process until smooth.

### Hummus

- \* 2 (15 oz.) cans of chick peas, one drained, one with liquid (to cut down on starch replace liquid with water)
  - \* ¼ cup raw sesame seeds
  - \* 1 tablespoon olive oil
  - \* ¼ cup lemon juice
  - \* 2 garlic cloves, peeled
  - \* 1 teaspoon cumin
  - \* Salt
1. Place all ingredients, except salt, into a blender or large food processor in the order mentioned.
  2. Blend until smooth and season to taste with salt.



New Portland member, Sandie Ross was so excited to receive her LRG bracelet, she and Dirk Niebaum (see page 2 for his story) decided to show their LRG pride off for the camera.

Got any bracelet pictures of your own that you want to show off? Want to order LRG bracelets? Email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org) for any and all questions!

# New report finds most hospital errors go unreported

By **Diana Nieves**  
LRG Program Associate

In a January 6, 2012 *New York Times* article, “Report Finds Most Errors at Hospitals Go Unreported” by Robert Pear, the author explained that federal investigators have shown in a new report that hospital employees recognize and report only one out of seven errors, accidents and other events that harm Medicare patients while they are hospitalized and improve care.

According to the study from Daniel R. Levinson, inspector general of the Department of Health and Human Services, “hospitals are to track medical errors and adverse patient events, analyze their causes and improve care.” In Mr. Levinson’s report he stated, “Despite the existence of incident reporting systems, hospital staff did not report most events that harmed Medicare beneficiaries.”

Pear also detailed in his article that the “most serious problems including some that cause patients to die, were not reported.”

“Adverse events include medication

errors, severe bedsores, infections that patients acquire in hospitals, delirium resulting from overuse of painkillers and excessive bleeding linked to improper use of blood thinners.”

Independent doctors reviewed patients’ records and identified more than 130,000 unreported events in hospitals in a single month to federal investigators as detailed in the article. It was also stated that “many hospital administrators acknowledge that their employees were underreporting injuries and infections that occur in hospitals.”

There are two main reasons why this has occurred.

- Hospital employees do not recognize “what constitutes as patient harm or do not realize that particular events harmed patients and should be reported.”
- Employees assume someone else would report the episode or they thought it was so common, isolated incidents that it did not need to be reported.



Training would be an appropriate step to take in remedying these types of issues. To this effect, Medicare officials will develop a list of reportable events that hospitals and their employees could use for reporting and training purposes. However, it is now up to the hospitals to ensure staff will put this into actual practice.

The *Times* article also noted that “the inspector general found that hospitals made few changes to policies or practices after employees reported harm to patients because hospital executives state the events did not reveal any systemic quality problems.” Very few patient cases that are actually reported to hospital managers lead to changes in policies or practices.

The article also stated that “more than 2900 hospitals have joined the administration in a ‘partnership for patients’ intended to reduce errors and save 60,000 lives in three years. There are also 27 states having laws that require hospitals to report publicly on infections that patients develop in the hospital.”

## HAPPY CANCER-VERSARY TO BRENDA BANNON!

By **Phil Avila**  
LRG Staffer

**B**renda Bannon of Berne, New York, calls her 10-year cancer-versary more of a marker or a stepping stone than a celebration. A stepping stone to a cure.

“We get closer to a cure every year,” she says. “I want to be able to tell my children there’s a cure. It’s a hard fight, but we keep on trying.” She says LRG executive director Norman Scherzer is “like a general in our army.”

Brenda remembers the day



when she made her first post to the Life Raft Group listserv and immediately connected with another GISTer, who told her “you and I are going to outlive this.” The 46-year-old mother of three

children, ages 11, 15 and 18, plans to do just that. She’ll turn 47 on April 15<sup>th</sup>. Her goal is to live until she’s 90.

In June, she’ll watch her oldest child, Matthew, graduate from high school, something that seemed nearly impossible when she was first diagnosed with GIST

in March 2002. She says her children have become her best caregivers. She also gets support from relatives, co-workers, church and, of course, fellow GISTers.

She’s been on several different drug treatments, including Gleevec, Sutent, Tasigna and Nexavar, and has participated in a clinical trial. She says her best response has been to Sutent, which she is currently taking. Brenda is diagnosed with wild-type GIST.

Because of the tumors in her liver, Brenda says she has coped with “looking nine-months pregnant” for the past 10 years. “There can be an advantage to that,” she says ironically, pointing out how strangers are often kind to her.

# Thomas G. Overley, 1952-2012: Toledo lawyer played guitar, sang in group

**By Mark Zaborney**  
Toledo Blade Staff Writer

*Reprinted with permission.*

**T**homas G. Overley, a lawyer and guitarist who developed a niche practice of manufactured home law and played in local rock bands, died Wednesday, March 14 in his Ottawa Hills home. He was 59.

For nearly 12 years, he dealt with gastrointestinal stromal tumors, a rare cancer. Surgery and medication kept it largely under control until recent months, his daughter Maggie said.

He appeared in court the last week of February, the day after a hospital stay. He asked to see case files, even as he received hospice care at home.

"He cared so much about clients and the work he did," said his daughter, who was his secretary.

He typically represented mobile home parks.

"He was highly respected as a lawyer," said Jim Yavorcik, a lawyer, neighbor,

and longtime friend. "He was sort of a go-to guy in Toledo for that area of practice.

"Everybody admired Tom," Mr. Yavorcik said. "He battled this cancer. He never felt sorry for himself. People wanted his advice who were going through tough times. Instead of worrying about his troubles, he couldn't move fast enough to help somebody else out."

They played together for years in the Plat Three Band, named for their subdivision. They also played in the Kirbys after the death last year of their friend and fellow lawyer Neil Light.

Mr. Yavorcik said Mr. Overley was an underrated singer and smooth lead guitarist. "He let the other people in the band come to the forefront, and he played some very tasteful lead guitar licks."

He played because he needed to, his daughter said. "While he couldn't do it for his bread and butter, it was what he needed to do for his soul," she said.

Mr. Overley was born Aug. 9, 1952, in Detroit to Aileen and Paul Overley. He was a graduate of a Fort Wayne, Ind.,

high school and of Indiana University. He was a 1984 University of Toledo college of law graduate.

He wrote poetry and had a way with words on the job and with family and friends.

"You could explain something in your own words," his daughter said. "He could come back and say it the way you wanted to say it but didn't have the ability to."

Mr. Overley belonged to a fellowship that held Bible studies in members' homes. Several members through the years said that "because of him they found their way back to God," his daughter said.

He was formerly married to Kellie Overley. Surviving are his daughters, Margaret Aileen Overley, Elizabeth Ellen Overley, and Allison Faye Overley, and brother, William.

The family suggests tributes to the Life Raft Group, which offers support to those with gastrointestinal stromal tumors, [liferaftgroup.org](http://liferaftgroup.org).

Contact Mark Zaborney at: [mzaborney@theblade.com](mailto:mzaborney@theblade.com).

## *Words of Wisdom from TomO...*

Pay attention to your bucket list and move the "people" parts of your list to the top.

Be the person who slides into the next life with a body which is worn and tattered and saying "What a ride!"

Don't let cancer define you. Let life.

Forgive the ones who don't deserve forgiveness. It is a gift that you give to your self.

It is what it is, and will be what will be, 'cuz the worrying today, is not groovy for me.

When you think you have come to the end of the line on your gist journey, tie a knot in it and hold on.

When troubles get you down and you find yourself on the pity pot, stay for a bit and then move over...someone else needs to use the facilities

Perhaps the need to give and receive love is the elusive sixth sense. It is easy and it starts with a smile.

No one has ever guaranteed you another sunrise. Enjoy the one you have for all it is worth.

*It is seeing the best in life and helping spirits renew.  
Seeing half full glasses and the power of one in a few,  
Drinking life's nectar from the cool, sweet, wet morning dew.  
Walking the walk and talking the talk to the end,  
Sharing the love and touching the life of a friend.*

- an excerpt from "Tax Day and Cancer Care" by TGO

Tom, you are in our hearts forever.

Love,  
Your friends at  
The Life Raft Group



# Durham lived life with passion and pride

**D**urham, David A. age 53, of Grand Rapids, Mich. and Minnetonka, Minn. won his eighteen-year battle with cancer and transitioned peacefully forward surrounded by his loving family on March 1, 2012. Survived by his wife, Carolyn; sons, David Paul and Eric Durham; parents, Don and Kathy Durham of Greenwood, S.C.; sisters, Donna Shea and Lisa (Kim) Titus; brothers, Jeff Durham and Christopher (Jen) Durham; brothers-in-law, Bill (Carol) Howe, Bob (Toni) Howe and Rick (Cindy) Howe; sister-in-law, Marianne (Jerry) Zipp; Also survived by many extended family members and wonderful, loving friends. Preceded in death by brother-in-law, Tim Shea; and niece, Mary Lynn Shea; father-in-law

and mother-in-law, Richard and Betty Howe.

David was an exceedingly honest, loyal, noble man, committed to his family, friendships and business relationships. He was an iconic outdoorsman whose passion for hunting and fishing served as the window through which many of us were able to truly know him. We are so thankful for every line and lure cast, every field crossed in his presence. The man poured himself into his sales career in the financial industry which was measured by honest relationships, loyal commitments and significant success.

He and his family want to recognize the generosity of people who supported his pursuits, especially his friends at



Regis and his partners in Cincinnati.

David wasn't an enlisted man, but he was very much a soldier. He woke every day for eighteen years, donned the uniform and went to battle. Cancer never knew such a determined adversary. He loved us, engaged us, supported us, championed us, and entertained us. Sometimes he terrified us :) but he always inspired us and made us think about who we are. Rest in peace, Dave, having completed everything God sent you here to do.

In lieu of flowers, memorials preferred to The Life Raft Group, [www.liferaftgroup.org](http://www.liferaftgroup.org), 155 US Hwy 46, Suite 202, Wayne, N.J. 07470 or charity of your choice.

## Did you Hear?



Norman & Dr. Jonathan Trent were on a Rare Disease Radio Tour, raising much needed awareness about GIST!

You can listen to a full transcript of these interviews at

[www.liferaftgroup.org](http://www.liferaftgroup.org)

## Help Wanted!

Do you live in the Chicago area? Meet GIST Specialists and top oncologists, while supporting the LRG by helping us man our Patient Advocate booth at ASCO. Not in Chicago but still want to volunteer your time? Email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)

## Did you Know?

The Life Raft Group's 10-year anniversary as a formal organization is June 10. We want to celebrate that in our next newsletter by highlighting our favorite moments from the last ten years. **But we want to hear from you too!** Send your favorite moment to Erin at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org).

## Arizona GISTers meet!

**By Janeen Ryan**  
LRG Program Associate

**O**n February 25, the Arizona chapter of the LRG gathered together at Pinnacle Oncology, in Scottsdale, Ariz. the offices of Dr. Michael Gordon, MD who so generously offered his facility.

We all shared our experiences, treatments, discoveries and generally got to know each other. There was a special camaraderie that was established once we met face-to-face. Online chatting, email sharing and talking on the phone

are wonderful, but nothing compares to meeting another person facing the same hurdles and walking the same path. Nine members and several guests were in attendance, some meeting other GISTers for the first time.

Dr. Gordon gave a short presentation on the basics of GIST, and current and off-label treatments and then moved into the Q&A portion of our meeting. It is extremely rare to get the full attention of a GIST specialist for two hours, so everyone had questions regarding treatment, trials, side-effects. Dr. Gordon answered all of our inquiries and even demonstrat-

ed on the white board how trough level testing works and the uses of the information that can be gathered.

The Arizona Chapter has not met in a very long time, but we are planning to meet every six months at different locations in Arizona. I want to give a big thank you to Jennie Kim at the Life Raft Group for sending us bracelets and pamphlets for all the attendees and to Dr. Gordon and his assistant, Carol McConnel for all their time and effort. To all who attended, thank you! And I'm so sorry I forgot my camera - we'll get a picture next time.

## ORDOG

From Page 1

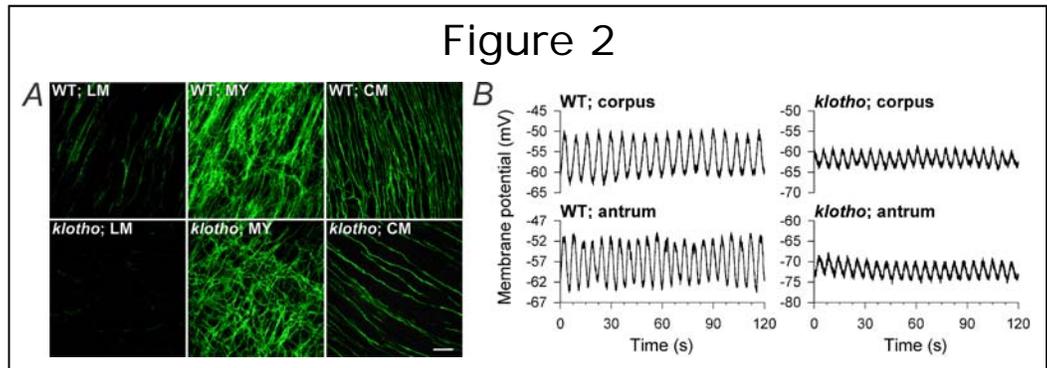
muscles is regulated and organized into reflexes and stereotypic, migrating patterns by the enteric nervous system consisting of a large number ( $\sim 10^8$ ) of neurons and glial cells that form interconnected ganglia between the muscle layers (myenteric ganglia) and on the inner surface of the circular smooth muscle layer (submucosal ganglia) (**Figure 1**).<sup>15</sup> Neurons can promote contraction or relaxation, regulate ICC or the secretion of digestive juices from the mucosal layer. Neurons can also carry sensory information to other neurons within the gut or to the central nervous system.

Both anatomically and functionally, ICC and other interstitial cells “slot in” between the smooth muscle cells and the enteric nerves. ICC and FLC residing within smooth muscle layers are spindle-shaped or elongated with few, fork-like branches (**Figure 2A**). They form synapse-like connections with nerves and electrical junctions with smooth muscle cells and also with other ICC and FLC.<sup>5,16</sup> Intramuscular ICC mediate both excitatory and inhibitory neural signals to smooth muscle cells,<sup>16</sup> whereas FLC transmit a specific form of inhibitory signals.<sup>17</sup> ICC also regulate smooth muscle membrane potential by releasing the gaseous mediator carbon monoxide.<sup>18</sup> In addition, certain intramuscular ICC contribute to sensory signaling by transmitting mechanical stimuli<sup>14</sup> to the nervous system.<sup>19</sup> These and other functions of ICC are supported by a specific pattern of gene expression.<sup>7</sup>

The majority of gastrointestinal smooth muscles exhibit rhythmic contractile activity driven by monotonous electrical oscillations called slow waves (**Figure 2B**).<sup>3</sup> These oscillations are always present, even when the smooth muscle cells are not sensitized by excitatory inputs to respond to them with contractions.

Electrical slow waves mainly originate from multipolar ICC forming networks surrounding the myenteric ganglia between the longitudinal and circular muscle layers (myenteric ICC; **Figures 1 and 2A**). The mechanisms of slow wave generation involve spontaneous “miniature” depolarization events arising from calcium cycling between intra-

wave generation.<sup>11</sup> The upstroke of the slow wave also involves a voltage-sensitive ion channel, which can be activated by depolarizing stimulus from neighboring ICC. This communication is critical for orderly propagation of slow waves.<sup>20</sup> When ICC networks are depleted, slow waves can diminish, disappear or become arrhythmic causing abnormal

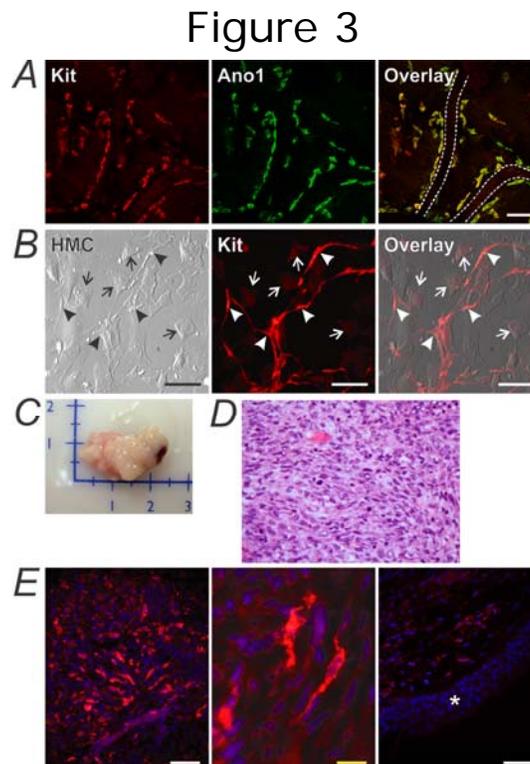


cellular organelles and the cytoplasm in the vicinity of the cell membrane, as well as voltage- and calcium-sensitive ion channels including ANO1, which mediates calcium-activated flow of chloride out of the cell. This ion flux then further depolarizes the membrane and leads to the summation of mini-events into the plateau of the slow wave. ANO1 is critical but not sufficient for slow

propagation (**Figure 2**).<sup>3,20,21</sup>

ICC are reduced in many diseases and conditions such as gastroparesis, slow-transit constipation,<sup>18</sup> diabetes<sup>3</sup> and aging<sup>21</sup> (**Figure 2**). Depletion could result from cell loss, impaired regeneration or combination thereof. ICC have regenerative capacity that can restore their networks once the underlying cause has been corrected. The ICC-SC we identified<sup>8,9</sup> may underlie this regenerative capacity, which is reduced with aging as both ICC-SC and ICC decline.<sup>21</sup>

ICC-SC reside in the vicinity of small blood vessels (**Figure 3**) and also under the serosal lining of the stomach. They do not resemble ICC and express less KIT, ANO1 and other ICC-specific genes.<sup>8,9</sup> In contrast, they express CD34, which is often found in GIST, and insulin-like growth factor 1 receptor (IGF1R), which is amplified in wild-type GIST.<sup>22</sup> Interestingly, they also express some PDGFRA raising the possibility that these cells are also precursors of FLC. Unlike mature ICC, ICC-SC display increased proliferation in response to IGF1 and soluble SCF but they do not depend on KIT signaling for maintenance.<sup>9</sup> Their differentiation into ICC is stimulated by cell membrane-bound SCF and occurs spontaneously, albeit at a low rate, both



See ORDOG, Page 12

## DIRK

From Page 2

Unfortunately, I woke up to discover that I had a rare form of cancer called GIST but I was told not to worry. The surgeons had been able to successfully remove a tumor the size of a grapefruit from my small intestine with clear margins, and the likelihood of recurrence was small. Ignorance was bliss until I began researching GIST and came across this little life raft called LRG, and began to realize that I needed this information, because my doctors at this point in time had no idea how GIST was treated. The information I received from the Life Raft Group saved my life. I ended up scheduling an appointment at Oregon

Health & Science University (OHSU) and learned that there was close to a hundred percent chance of GIST returning if I didn't start on Gleevec. I started the drug the very next week and everyone on the raft was amazing. I learned that there was no such thing as a dumb question. All I had to do was ask and the responses just rolled in and they were extremely helpful. I feel that I have hundreds of friends that I can call on any time and they would paddle on over to help.

I retired a year and a half ago when GIST was discovered in my liver. I was ramped up to 800 mg of Gleevec and

found that having an inflexible schedule and being on-stage most of the day wasn't allowing me to get the rest that I needed to fight this dragon. I love teaching and it was an extremely difficult decision to retire. Now that I have, I know that it was the right move. I have always believed that if I ever showed up to school just trying to make it through the day, instead of trying to make someone else's day, it would be time to pass the torch to the next generation of teachers.

Currently, I am a dream ski volunteer. I ski with young adults with disabilities one day a week. Every year, I volunteer for a week at First Descents, a kayaking camp for young adults with cancer and I continue to coach track at the high school for a couple of hours a day in the afternoon.

## ORDOG

From Page 11

in vitro and after transplantation into diabetic mice in vivo (**Figure 3**). We also found that after spontaneous transformation, isolated ICC-SC transplanted into immune-deficient mice gave rise to imatinib-resistant, KIT-low tumors resembling GIST seen in imatinib-treated patients with relatively few differentiated, ICC-like cells (**Figure 3**). Whether these cells also confer an inherent resistance to GIST in humans remains to be investigated.

In summary, recent data indicate that by studying normal ICC we can increase our understanding of the natural history of GIST and identify novel therapeutic principles. However, several questions remain: Firstly, do KIT-low ICC-SC exist in humans? Do they contribute to the failure of imatinib and related drugs to cure GIST? What is the relationship between ICC-SC, ICC and FLC? Do genes other than KIT which are selectively expressed by ICC contribute to GIST pathogenesis? Can these genes be targeted pharmacologically? Answering these and many other questions will require that we not only focus the "bad" cells but also their "good" counterparts.

Read more at [www.gistnews.org](http://www.gistnews.org)

## Spunky Texan fought GIST bravely

**B**etty Hayes Arnett went to be with our Lord and Savior Tuesday, Feb. 28, 2012 at age 64, after a long and courageous battle with cancer. She was born Aug. 23, 1947 to Ruel and Mattie Hayes in Corsicana, Calif. She was a beloved mother, grandmother and wife. She was a longtime member of Missionary Baptist Church of Corsicana.

Betty worked at Southwestern Bell for many years before graduating from Navarro College with a degree in Occupational Therapy. She worked at Heritage Oaks Retirement Center in Corsicana and Trinity Nursing Home in Italy. She was a lady of deep Christian faith and was devoted to her family. She was so proud of all of her children and grandchildren.

She was preceded in death by her parents and two sisters, Billie and Theresa. She is survived by her husband, Ronnie Arnett of Corsicana; her daughter, Stacey Goodwin of Corsicana; son, Dar-

ren Arnett and wife Melissa of Richardson; grandchildren, Jacob, Macy and Sam Cole of Corsicana and Lela Arnett of Richardson; brother, Johnny Hayes and wife Anda of Corsicana; sister, Peggy Whitney of California; and numerous nieces and nephews.

An online guestbook is available at [www.corleyfuneralhome.com](http://www.corleyfuneralhome.com) by selecting the Betty Arnett obituary.



### Mark your calendars!

- The New Horizons international summit will be held **April 26-May1**.
  - GIST Day of Learning will be storming Miami on **May 19**, see back page for details.
  - The American Society of Clinical Oncology Conference (ASCO) will be held in Chicago **June 1-4**.
  - A Global GIST Network event will be held at ASCO on **June 1**, email [srathschild@liferaftgroup.org](mailto:srathschild@liferaftgroup.org) for info.
  - The LRG's 10-Year anniversary is **June 10**, see page 10 for info on how to join the celebration!
  - The next NIH Clinic will be held **June 13-15**.
  - This year's NYC Poker Tournament will be **September 13**, details coming soon!
- Life Fest 2012 in Las Vegas will be held November 9-11. More details to come!**

## GDOL

From Page 1

Joining to give a talk on “Understanding Pathology and the Role of Mutations in GIST Treatment” will be Andrew E. Rosenberg, M.D., Professor of Pathology, Director of Bone and Soft Tissue Pathology and Director of Surgical Pathology at the University of Miami. During his 27 years working in the pathology field, Dr. Rosenberg has published numerous research papers and has held the prestigious honor of serving as a professor at Harvard Medical School, Boston, Mass.

We are very grateful to all of our speakers for generously donating their time to educate the GIST community. We are also honored to collaborate with University of Miami Sylvester Cancer Center for this endeavor.

For more information about GIST Day of Learning, please contact Trish McAleer at [tmcaleer@liferaftgroup.org](mailto:tmcaleer@liferaftgroup.org) and 973-837-9092, ext. 111

To register for the event (agenda shown right), please go to: [www.liferaftgroup.org/gdol.html](http://www.liferaftgroup.org/gdol.html).

AM	PM
8:00 AM BREAKFAST & MINGLING	12:30 - 1:30 LUNCH - ROUNDTABLE DISCUSSIONS: HOW CAN WE (THE PHYSICIANS AND THE LRG) BETTER SERVE THE GIST COMMUNITY?
9:00 - 10:15 GIST: THE BASICS - OVERVIEW OF HISTORY, BIOLOGY, & TREATMENTS	1:30 - 2:15 CLINICAL TRIALS EXPLAINED AND EXPLORED
10:15 - 10:30 COFFEE BREAK	2:15 - 3:00 MANAGING SIDE EFFECTS
10:30 - 11:30 UNDERSTANDING PATHOLOGY AND THE ROLE OF MUTATIONS IN GIST TREATMENT	3:00 - 3:15 COFFEE BREAK
11:30 - 12:30 SURGERY AND OTHER OPTIONS	3:15 - 4:00 NUTRITION
	4:00 - 5:00 Q&A WITH EXPERTS

REGISTER ONLINE  
<http://www.liferaftgroup.org/gdol.html>

## AGENDA

## JEROEN

From Page 1

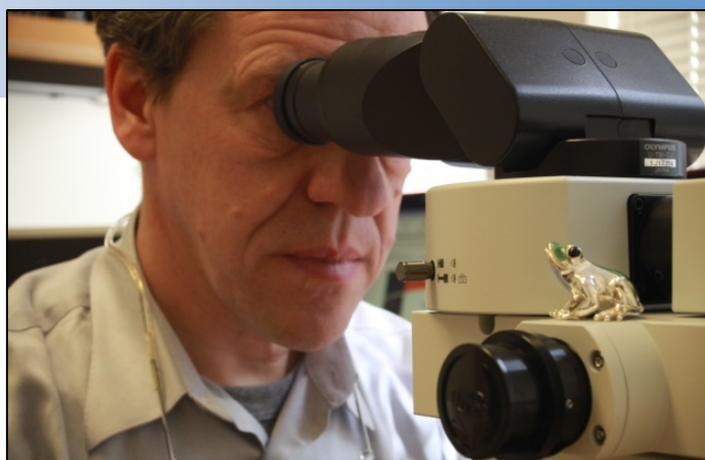
challenged the Life Raft Group's team of scientists to save his life and the lives of others battling GIST. Sadly, the cure could not be found in time for Jeroen, but this project has drastically changed the outlook for GIST patients everywhere by allowing the top scientists in their field to move at a much faster pace and precision toward finding a cure.

“Today I mourn the premature loss of another friend to GIST. In Jeroen’s name, we **will** find a cure for this disease,” said Life Raft Group's Executive Director, Norman Scherzer. Scherzer went on to say that in his fifty years in public health service, he has never met anyone as determined as Jeroen Pit. And according to Scherzer, it was that determination that motivated Jeroen’s Dutch friends to fund this important research

project and inspired the Life Raft Group scientists to work harder in finding a cure.

“Jeroen made this personal for our Research Team. They knew him and his wife, Emilie, and wanted to save his life,” said Scherzer.

It is the custom of the Life Raft Group to light a candle at sundown and celebrate the life of a friend who has died from GIST. “Thousands of candles will be lit in



LRG Research Team member, Matt van de Rijn, conducts research with his frog friend at his side. The frog had special meaning for Jeroen and he gave each researcher one to remind them of the patients they are trying to save.

memory of our dear friend Jeroen tonight,” remarked Scherzer who continued, “and tomorrow we will rededicate our efforts toward a cure—in his name.”

# LEUVEN

From Page 1

century. It was in one of these restored buildings that team meetings took place.

After the first full day of meetings, the group was joined at dinner by Catholic University officials and collaborators Raf Sciot (Director of Pathology Department), Patrick Schoffski (Director of General Medical Oncology Department), Erik Legius (Director of Center for Human Genetics), and Peter Vandenberghe (Director of Cancer Program).

The meeting wrapped up with renewed energy and a commitment from every researcher to continue this collaborative approach to finding a cure.

To wind down after two days of intense meetings, the group took a quick side trip to the fascinating city of Bruges, where they did their part to support local chocolatiers, taking home bags of goodies to share!

Below is a summary of some of the teams'

progress in the last year, prepared by LRG researchers and staff. More detailed updates will be coming in the following issue.

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## SUMMARY: Life Raft Group Research Team Meeting Progress Report D-Day Project, March 11-13, 2012

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

*chance of successful outcomes. In 2010, a Dutch GIST patient named Jeroen Pit, struggling to overcome treatment resistance, was investigating the best way to donate to GIST research. After consulting several leading GIST researchers, he decided that the LRG research team gave him the best chance for finding a cure. The funds he raised, when added to funds already raised by the*



Pictured left to right: Dr. Chris Corless, Dr. Matt van de Rijn, Dr. Brian Rubin, Dr. Jonathan Fletcher, Dr. Anette Deusing, Dr. Mike Heinrich, Dr. Maria Debiec-Rychter, Norman Scherzer, Jerry Call, Dr. Agnieszka Wozniak, Dr. Adrian Marino-Enriquez, Jim Hughes & Dr. Sebastian Bauer.

*LRG, have served as a catalyst for the rapid identification and validation of relevant treatment strategies. Though Jeroen passed away in early 2012, his legacy and tenacity continues on in the work the research team is doing for all the patients like him, present and future.*

Project D-Day is focused on four areas: *Sequencing* of the GIST genome, *Gene Knockdown* studies, or screens that examine pathways essential for GIST cell survival, *Drug Screening* of GIST cells against large libraries of drug compounds, and *Validation* studies of important candidates from the first three areas that would allow a timely translation into clinical trials. Some highlights of recent accomplishments in these areas are as follows:

### Sequencing

- Performed the largest known analysis of the GIST genome, identifying 214 mutations predicted to have a biological effect, and validated them to exclude false positives.
- Categorized mutations by function to better understand their relevance in GIST.

### Gene Knockdown

- Performed RNA screens for two imatinib-sensitive cell lines and are currently doing so on a third.
  - Ranked 11,000 genes in several GIST cell lines in order of their functional relevance for GIST.
  - Identified a component of a key pathway in GIST that is five times more specific than some previously tested targets and which may help successfully overcome secondary resistance, the most common cause of treatment failure.
  - Identified promising therapeutic targets that may be critical for GIST cell survival.

### Drug Screening

- 127 compounds have been tested, with validation of existing GIST drugs acting as a reference.
- 4 drugs have been identified as being of possible therapeutic value.
- Identified several traditional chemotherapies that have in-vitro activity against GIST.

### Validation

- Found that almost every GIST patient has changes in genes that affect the cell cycle and result in advanced GIST. This could point toward common genetic “events” that may yield a treatment strategy.
- Continued promising work on inhibitors, a therapeutic antibody, and tumor cell death.
- Analyzed how knockdown and sequencing screens influence each other and converge.

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# GIST Day of Learning

A COLLABORATION BY  
THE LIFE RAFT GROUP

SATURDAY  
MAY 19TH



## AGENDA

8:00 AM  
BREAKFAST & MINGLING

9:00 - 10:15  
GIST: THE BASICS -  
OVERVIEW OF HISTORY,  
BIOLOGY, & TREATMENTS

10:15 - 10:30  
COFFEE BREAK

10:30 - 11:30  
UNDERSTANDING  
PATHOLOGY AND  
THE ROLE OF MUTATIONS  
IN GIST TREATMENT

11:30 - 12:30  
SURGERY AND OTHER OPTIONS

12:30 - 1:30  
LUNCH - ROUNDTABLE  
DISCUSSIONS: HOW CAN  
WE (THE PHYSICIANS  
AND THE LRG) BETTER  
SERVE THE GIST  
COMMUNITY?

1:30 - 2:15  
CLINICAL TRIALS  
EXPLAINED AND EXPLORED

2:15 - 3:00  
MANAGING SIDE EFFECTS

3:00 - 3:15  
COFFEE BREAK

3:15 - 4:00  
NUTRITION

4:00 - 5:00  
Q&A WITH EXPERTS

6:30 PM  
DINNER

EVENT WILL BE HELD AT  
**THE DEAUVILLE  
BEACH RESORT**  
6701 COLLINS AVE  
MIAMI, FL 33141



## THE MEETING

This meeting will focus on learning about **Gastrointestinal Stromal Tumor (GIST)**. If you or someone you know has GIST and would like to learn more about this cancer, available treatments, and managing care, please join us to hear from experts.



## FEATURING DR. TRENT



**Jonathan C. Trent, MD, PhD** is the Co-Director of the Musculoskeletal Center, Director of the Sarcoma Medical Research Program and professor of medicine at the University of Miami Sylvester Comprehensive Cancer Center.

## NEED A HOTEL ROOM?



We've made arrangements with the **Deauville Beach Hotel** and there will be rooms available for \$129 per night (plus taxes and fees) Please call (800) 327-6656 or visit their website and use the group code GDOL2012 for the discount.

## FLYING INTO MIAMI?



The Deauville is about 13 miles from Miami International Airport. There is a shuttle service called **Super Shuttle** that charges \$22 per person or you can take a cab for a flat rate of \$38 (a better choice for 2 or more people).

## HAVE ANY QUESTIONS?



Feel free to email or call Trish McAleer at [tmcaleer@liferaftgroup.org](mailto:tmcaleer@liferaftgroup.org) or 973.837.9092 x 111 for any questions you may have.

## REGISTER ONLINE

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