

## Israel's leap from support group to proactive non-profit

By Avi Zigdon

Israeli GIST Patients Organization

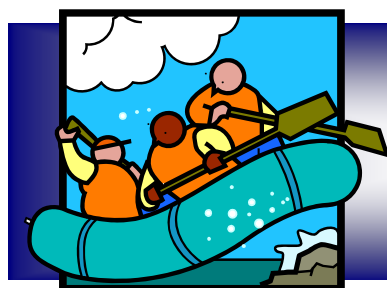
**T**he state of Israel is small. The number of patients diagnosed as GIST patients is estimated at as little as 20 patients per year. The need of GIST patients and their families to obtain updated Hebrew information about the treatments, medications and new developments on GIST cancer-related research, has led to the development of additional tools for the use and service of GIST patients and relatives in Israel.



It happened just 18 months ago. The doctor told me that I have GIST cancer. The news was overwhelming. I looked for all sorts of relevant information that would help me figure out this disease. Although I come from the area of administrative medicine, I had never heard of GIST. It is so rare that only few have heard of it. After many hardships, I came to know a dear person, Mr. Ben

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Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

June 2009

In memory of Ken Klipper

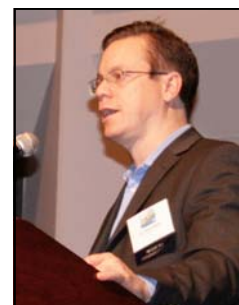
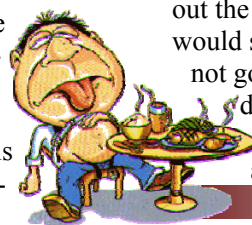
Vol 10, No. 6

## Interstitial cells of Cajal: What are they and why should you care?

By Dr. Brian Rubin

Cleveland Clinic  
LRG Research Team

**I**nterstitial cells of Cajal are pacemaker cells, similar to the pacemaker cells of the heart, which cause the heart to beat regularly. Interstitial cells of Cajal beat rhythmically when stimulated, which is critical to their function. They are present in the wall of the gut and facilitate communication between the nervous system and the smooth muscle of the gut wall (Figure 1, page 5). When the signal arrives from the nervous system to the interstitial cells of Cajal that a person has eaten, the interstitial cells of Cajal begin beating rhythmically and tell the smooth muscle cells within the wall of the gut to contract in a rhythmic and coordinated fashion. This results in a coordinated and rhythmic set of contractions of the gut known as peristalsis, which propels food along the entire length of the digestive tract. Without the interstitial cells of Cajal, food would sit in your esophagus and would not go anywhere and that would be a disaster. I am sure you are appreciating the interstitial cells of Cajal a lot more now.



RUBIN

See ICC, Page 5

## Susan Farmer looks back on a life well-lived; and forward to her garden

By Mark Patankin

The Providence Journal

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**S**he looked just like the Susan Farmer I remembered, still in a classic preppy uniform: fuchsia ribbed turtleneck, black slacks, and of course, her ever-present string of



FARMER

pearls. There is no way you would know she has been fighting a difficult cancer for eight years, or that things have taken a sobering turn.

She cracked the door open, saw me standing there with a photographer, and said playfully, "No comment."

Of course, Susan Farmer always had a comment, which is in part how she

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# NIH announces new program to develop therapeutics for rare and neglected diseases

*The following excerpt is taken from a National Institutes of Health press release.*

**May 20, 2009** — The National Institutes of Health (NIH) is launching the first integrated, drug development pipeline to produce new treatments for rare and neglected diseases. The \$24 million program jumpstarts a trans-NIH initiative called the Therapeutics for Rare and Neglected Diseases program, or TRND.

The program is unusual because TRND creates a drug development pipeline within the NIH and is specifically intended to stimulate research collaborations with academic scientists working on rare illnesses. The NIH Office of Rare Diseases Research (ORDR) will oversee the program, and TRND's laboratory operations will be administered by the National Human Genome Research Institute (NHGRI), which also operates the NIH Chemical Genomics Center (NCGC), a principal collaborator in TRND. Other NIH components will also participate in the initiative.

A rare disease is one that affects fewer than 200,000 Americans. NIH estimates that, in total, more than 6,800 rare diseases afflict more than 25 million Americans. However, effective pharmacologic treatments exist for only about 200 of these illnesses. Many neglected diseases also lack treatments. Unlike rare diseases, however, neglected dis-

eases may be quite common in some parts of the world, especially in developing countries where people cannot afford expensive treatments. Private companies seldom pursue new therapies for these types of illnesses because of high costs and failure rates and the low likelihood of recovering investments or making a profit.

"NIH is eager to begin the work to find solutions for millions of our fellow citizens faced with rare or neglected illnesses," said NIH Acting Director Raymond S. Kington, M.D., Ph.D. "The federal government may be the only institution that can take the financial risks needed to jumpstart the development of treatments for these diseases, and NIH clearly has the scientific capability to do the work."

## Developing Drugs

The drug development process is complicated and expensive. Studies suggest that it currently takes more than a dozen years and hundreds of millions of dollars to take a potential drug from discovery to the marketplace. And the failure rate is high.

"This initiative is really good news for patients with rare or neglected diseases," said ORDR Director Stephen C. Groft, Pharm.D. "While Congress has previously taken important steps to help these patients, such as providing incentives for drug companies under the Orphan Drug Act, this is the first time NIH is providing support for specific, preclinical research and product development known to be major barriers preventing potential therapies from entering into clinical trials for rare or neglected disorders. While we do not underestimate the difficulty of developing treatments for people with these illnesses, this program provides new hope to many people world-wide."

Typically, drug development begins when academic researchers studying the

## 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  
40 Galesi Dr., Suite 19  
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.



A scientist performing drug synthesis in a laboratory.

underlying cause of a disease discover a new molecular target or a chemical that may have a therapeutic effect. Too often, the process gets stuck at the point of discovery because few academic researchers can conduct all the types of studies needed to develop a new drug. If a pharmaceutical company with the resources to further the research does get involved, substantial preclinical work begins with efforts to optimize the chemistry of the potential drug. This involves an iterative series of chemical modifications and tests in progressively more complex systems - from cell cultures to animal tests - to refine the potential medicine for use in people. Only if these stages are successful can a poten-

# June 2009 clinical trials update

By Jim Hughes

LRG Clinical Trials Coordinator

**BKM120 Phase 1:** A new Novartis PI3K inhibitor, BMK120, is now recruiting at Sarah Cannon in Nashville, Tenn. As with most Phase 1 trials, this trial is for “Solid Tumors” which should include GIST. BMK120 inhibits PI3K but unlike the other Novartis PI3K inhibitors, BEZ235 and BGT226, it does not also inhibit mTOR.

**Nilotinib Versus Imatinib:** 15 new sites are listed as recruiting in Austria, Brazil, Canada and Japan



As we have been reporting recently, the size of the Clinical Trials Table has grown so large that we decided to give it its own publication. You can still find monthly trial updates here, but the trial listing is now a “Clinical Trials Bulletin” sent separately each month. You can find this bulletin at: <http://www.liferaftgroup.org/docs/ClinicalTrials/June2009.pdf>

If you have any questions, please email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org).

## WEBSITE OF WORTH

The CCC or Care. Commit. Change. believes that every cancer survivor deserves the chance to receive a college education. Yet the burden of medical debt, side effects of treatment, and limited access to financial and informational resources leaves many young adult cancer survivors with little hope of attending college.

In 1999, while working at a camp for terminally ill children, 17-year old Carolyn Rubenstein came up with the idea of “Carolyn’s Compassionate Children”, a pen-pal program that would



**CosmoGIRL! of the month**  
While working at a camp for terminally ill children, CAROLYN RUBENSTEIN, 17, of Boca Raton, FL, realized many sick kids were lonely. “They would tell me how much they missed their friends and being a regular kid,” she says. So she started Carolyn’s Compassionate Children, a group that’s partnered more than 700 healthy teens with pen pals who have life-threatening illnesses. “The sick kids get to hear about normal stuff like boyfriends and school,” she says. “And the healthy kids learn about courage.” To become a pen pal, go to [childlifeccc.com](http://childlifeccc.com).

link childhood cancer patients to their

healthy peers in order to help alleviate the social isolation felt by many children. But the CCC has grown over the years into a nonprofit organization dedicated to improving the quality of life for young adult cancer survivors by increasing opportunity for college access

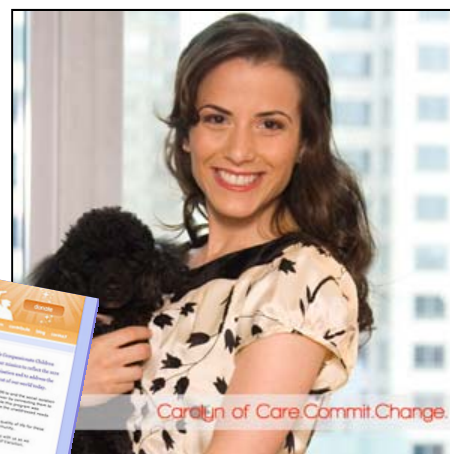
and success through the following initiatives:

- An annual college scholarship program that recognizes survivors who demonstrate leadership, commitment to education, and betterment of their community
- An online community managed by CCC that connects, supports and empowers survivors in pursuit of higher education
- Scholarship management guidance and resources, including an online database that contains information on thousands of national scholarships for young adult cancer survivors

The CCC website, [www.cccscholarships.org](http://www.cccscholarships.org), hosts the “CCCpedia”, a comprehensive database with over 3,000 scholarships totaling over \$5.8 million available to young adult cancer survivors.

The CCC also gives out a few of its own scholarships:

\$1,000 scholarships available to survi-



RUBENSTEIN

vors who demonstrate commitment to education, community, and hope.

\$1,500 scholarship available to an individual who exemplifies survivorship, character, and strength.

\$2,000 scholarship awarded to an individual who exemplifies leadership, survivorship, and self-awareness.

The CCC also publishes a monthly newsletter as well as a blog which features general cancer news, scholarship workshops and tips for dealing with cancer.

# ISRAEL

From Page 1

Shtang, of blessed memory, who was sick and founded a support group for GIST patients.

Ben recognized the need to share, assist and contribute knowledge about the disease to other patients. Only four months after we first spoke on the phone, Ben passed away.

I immediately decided that the other patients must not be abandoned and I made up my mind to renew the GIST support group activity in Israel and expand the activity of the Organization, registered by Ben just a few months earlier. I tracked down a few other patients about whom I found out through Ben and renewed the support meetings with their help. Reuven Halfi, one of the oldest “veterans” of this disease, was harnessed for the challenging position of the Israeli GIST Patients Organization General Manager.

Together, we decided that in order to promote the activity of the support group, we must take certain steps to spread out the word about the organization to all Israelis. We decided our goal was to track down all Israeli GIST patients and bring them together under the same roof (the Israeli GIST Patients Organization).

We did a preliminary screening of the number of GIST patients in Israel in order to get some general estimate of the overall number of patients. To do so, we used data gathered by Israel National

Cancer Registry, the Ministry of Health. To execute the second stage of our plan, we needed a budget. We approached Novartis,

which came to our aid and contributed money for our cause. However, the challenges did not come to an end here. All of the Organization members are volunteer patients, some of whom work and are busy during the day. This is why we founded a virtual office to accept calls of

new patients. The office is based on a 24/7 call center, and an Organization member who holds a beeper to receive messages from patients calling the “office” – this step was taken to meet the need of distressed GIST patients to get an almost real-time response. Next, we exposed the entire Israeli population to the Organization through various means. We issued posters and brochures (shown above) and distributed them in all Israeli Hospitals’ Oncology and Gastrointestinal Clinics. We established and enhanced the relationship with the Life Raft Group (LRG) in the United States and got their consent to translate professional materials taken from the LRG website and distribute them publicly. We

established an Internet website ([www.gist.org.il](http://www.gist.org.il)) in Hebrew and contacted oncologists to spread the word about the Organization amongst their GIST patients.

The objectives and goals of the organization are:

- Collecting and receiving GIST-related medical information from national and international centers and delivering it to GIST patients and their families
- Holding monthly support meetings
- Raising public awareness in Israel for the admission of GIST medications into the Israeli health basket
- Promoting medical research on GIST
- Fundraising in order to assist patients and financing the GIST organization activities
- Advising and helping GIST patients concerning their rights in medical institutions and various authorities
- Escorting GIST patients and their families on topics related to the disease.

## Future plans

Being a patient-based organization, our main need is raising funds in order to assist patients in financing medication not indicated as GIST medication, although professional literature may have found them to be potentially life-prolonging and disease treating medications. To do so we initiated public fundraising campaigns and next year we plan to launch the opening of the Israeli GIST Patients Organization at a conference aimed at all Israeli GIST patients.

*We thank Novartis and Life Raft Group (LRG) for their support and assistance in achieving this significant change.*

**Global GIST Network adds new GIST representatives**



**Chile**  
**Piga Fernández**  
[piga.fernandez@gmail.com](mailto:piga.fernandez@gmail.com)



Israel National Cancer Registry, Cancer Incidence Tables

Gastro-Intestinal Stromal tumor 2006

Age group קבוצת גיל	Jews יהודים		Arabs ערבים	
	Male זכר	Female נקבה	Male זכר	Female נקבה
0-4				
5-9				
10-14				
15-19				
20-24				
25-29				
30-34	1	0.53	1	0.53
35-39				
40-44				
45-49				
50-54	1	0.60	2	1.12
55-59	3	2.57	1	0.79
60-64				
65-69	1	1.17	1	0.96
70-74	2	2.74	2	2.11
75+	3	2.45	3	1.65
	11	0.80	10	0.35
		0.30		0.22

\* All rates are per 100,000, Standardized to the "World Standard Population"  
 \* "All Israel" rates are based on a 1,000,000 population  
 \* Updated October 2008 registration

The Israeli National Cancer Registry, GIST incidence table.

testinal Clinics. We established and enhanced the relationship with the Life Raft Group (LRG) in the United States and got their consent to translate professional materials taken from the LRG website and distribute them publicly. We

# ICC

From Page 1

The interstitial cells of Cajal were studied in relative obscurity for over 100 years, that is, until the discovery that gastrointestinal stromal tumors (GIST) arise from interstitial cells of Cajal or an interstitial cell of Cajal-like precursor cell.

ligand. Other cells in the area of the interstitial cells of Cajal produce stem cell factor to try to send messages to the interstitial cells of Cajal. The messages basically tell the interstitial cells of Cajal to mature and grow or stop growing and so forth. Once KIT finds stem cell factor, it “turns on” the portion of the receptor that is inside the cell, known as the kinase domain. The kinase domain is the mechanism that allows KIT to talk to other proteins inside the cell to tell them to turn “on” or “off” which in the end, results in modification of cellular behavior.

When an interstitial cell of Cajal acquires a KIT mutation that permanently turns KIT “on”, even in the absence of stem cell factor, then the cell will divide incessantly without any rhyme or reason. When this happens, a GIST is formed. Therefore, a GIST can be formed by an interstitial cell of Cajal that cannot stop dividing because it has a KIT mutation. As GISTs progress to higher grade malignancies, they acquire more mutations in other proteins important for their behavior.

However, since KIT is the protein that has acquired the initiating mutation which causes the interstitial cell of Cajal to divide and turn into GIST, then inhib-

iting KIT with drugs like Gleevec and Sutent cause the GIST cells to stop dividing. Unfortunately, even though Gleevec and Sutent can stop GIST cells from dividing, many GIST cells still survive. This is the biggest problem that patients with GIST face and it results in the requirement of GIST patients to remain on Gleevec or Sutent indefinitely while increasing the likelihood those tumors will develop secondary KIT mutations that are resistant to Gleevec and Sutent.

A lot has been written recently about tumor stem cells. These are a renewable compartment of cells within each tumor that give rise to more “differentiated” cells within the tumor. The more “differentiated” cells have lost the characteristics of stem cells and there is mounting evidence in several types of cancer that tumor stem cells are more resistant to therapies than the more differentiated tumor cells. It is entirely possible that the GIST cells that do not die within Gleevec- or Sutent-treated GIST are tumor stem cells. Since interstitial cells of Cajal or interstitial cell of Cajal precursor cells give rise to GIST, important clues may be provided by their study to help develop additional therapeutic strategies to kill GIST cells. There is a couple of ways that this can be done.

One strategy is to differentiate the tumor stem cells so that they become susceptible to therapies. This can be done in a variety of ways as there are many chemicals or biological agents/proteins that cause stem cells to differentiate. However, the key is to find the perfect chemical/biological agent to differentiate the stem cells of interest. This is great in theory but it has not worked out that well in practice with a few notable exceptions.

Another strategy is to isolate and study the stem cells to understand why they are not sensitive to therapy. There appear to be important signal transduction pathways such as the hedgehog (yes, that’s the correct name) pathway that are important to stem cells but not the more differentiated cells. Chemical inhibitors exist for some of the proteins in these

**Figure 1**

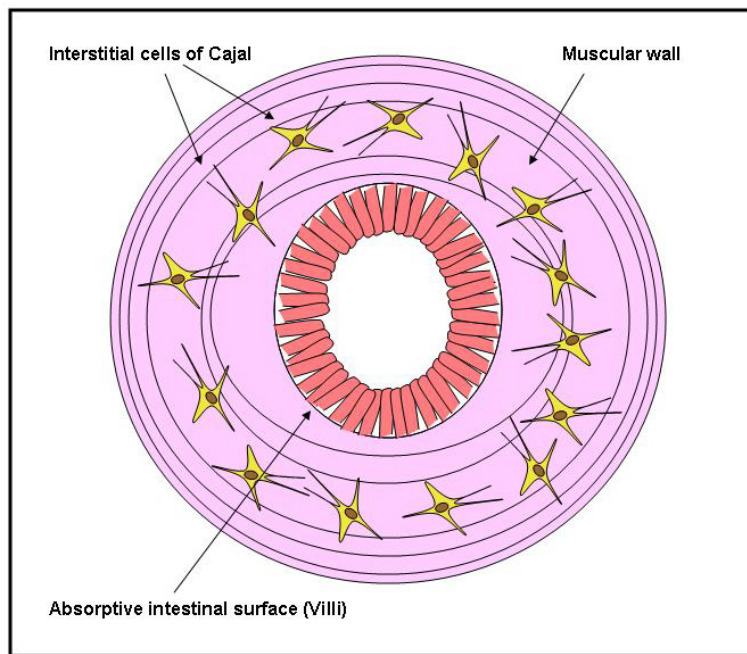


Diagram of the wall of the small intestine. The intestinal tract is basically a tube that extends from the mouth to anus. The interior of the intestinal tract is lined by an absorptive layer of epithelial cells known as villi that are involved in absorbing nutrients and water. The interstitial cells of Cajal are within the muscular wall of the intestine and are involved in coordinating peristalsis.

Cancers arise from normal cells within the body that acquire genetic mutations which cause them to lose control over growth and cell division. Interstitial cells of Cajal are dependent on a protein known as KIT for their development and maintenance. The interstitial cells of Cajal produce a lot of KIT because it is a very important protein for them. KIT is a receptor tyrosine kinase, which means that it has a portion that is outside of the cell and another part that is inside of the cell. The part that is outside of the cell has a receptor that binds to another protein known as stem cell factor or KIT

# FARMER

From Page 1

achieved a place in history, becoming the first woman in Rhode Island to win statewide office.

She was secretary of state for two terms, starting in 1983. Usually, few voters can name the person in that post, but everyone could when Farmer was in office. She was a striking blond figure, unafraid to get out front. Once, she flew to meet with the secretary of the Navy after hearing some Rhode Island bases might be closed.

She went on to lose a tough race for lieutenant governor in 1986, but for the next 17 years, ran Rhode Island's public TV station, Channel 36, in a way that kept her a household name.

When she took the job, the station was raising a mere \$300,000 a year and there was talk it would go dark. By the time Farmer stepped down, she'd gotten it to \$2 million.

They discovered cancer in her stomach in October of 2001. It was a rare form called GIST — Gastrointestinal Stromal Tumors. Hoping to get rid of it, they removed half her stomach. Fifteen months later, in 2003, it had spread to her liver. They told her the usual survival is less than two years. But they began experimental drugs that put the tumors to sleep for over triple that time. A month ago, the tumors started growing again, and now there are few options. One is for half of her liver to be removed. It is considered major surgery. Her doctors are weighing it.

"But I'm going on eight years," Farmer told me. "Very few live that long."

Despite there being no good alternative, part of her would welcome a reprieve from such an operation.

"The sun's coming out," she told me. She wants to golf and garden. "I love having my hands in the dirt."

She shares her home with her husband Malcolm Farmer, lawyer and one-time Providence councilman. Their two daughters are grown and married.

Her father, Ralph Lawson, ran a manufacturing firm producing elastic knitting in Pawtucket. Farmer went to the Wheeler School, then the Stoneleigh-Burnham School for girls in Greenfield, Mass. She went on to Garland Junior College, which later merged with Simmons College. She studied at Brown, as well.

In her 20s, Farmer was among the more competitive female amateur tennis players in the state. Many expected her to simply live an East Side, fundraising life, but she was intrigued with problems beyond.

One day, she read in the paper that the Marathon House drug rehab center — now Phoenix House — was in such financial difficulty that residents were getting only two meals a day. On impulse, she drove to the building and asked a simple question: "Tell me what I can do."

She eventually became its board chair for four years. That was the start of Susan Farmer's public life.

Some, she knew, assumed she was a privileged preppy who couldn't possibly be serious about people in need. But she worked hard and won respect. In time, she began programs at the girls' Training School, served on the Providence Human Relations Commission and was named court-appointed advocate for abused children.

By 1982, she was leaving the East Side for factory gates, bowling alleys and senior centers running for secretary of state. I asked if she considered changing her look to better appeal to Rhode Island's blue-collar electorate.

"If I put on tattered blue jeans and a sweatshirt, you'd know what I was," said Farmer of her preppy bearing and ever-present pearls. Folks, she felt, respected both her work and her honesty about who she was. She won the election.

Afterwards, playing off a line from the best-selling Preppy Handbook, a Journal columnist imagined people from the right clubs saying, "Look, Muffy, a secretary of state for us." The line and nickname stuck, and Farmer told me she's still amused by both today.

She ended her long career on June 1, 2004, when she retired from Channel 36. She had worked there almost three years with cancer, and it was time.

"It was hard to give it up," she said. "Even now it makes my eyes water." She was speaking not just of the station job, but public life.

"I loved it," she told me.

When I asked her age, she winced and said, "I can barely say it; s-s-sixty-six."

Then she flexed her arms and said she works out. I told her she seemed to have barely aged.

"You know," she said, "dim lights and Estee Lauder make a woman look so good."



## Video



If you would like to see a video of Susan Farmer gardening & talking about her views on life go to [www.projo.com/lifebeat/markpatinkin/](http://www.projo.com/lifebeat/markpatinkin/) and click on the Susan Farmer article.

I asked what a typical day is like for her now.

She sleeps more than she used to, explaining it happens with medication.

She likes to cook, read and do crossword puzzles. She visits her mom, who is 94, at the Epoch extended care facility. She likes to spend time with her two daughters, both 40ish and married. One is in real estate in Rhode Island. The other runs a production company in California and just visited with her two young children. "I was bereft when they left," she said.

Last month, 49 years after graduation, she vacationed in Florida with her

**"Look, Muffy, a Secretary of State for us."**



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## ICC

From Page 5

pathways and they show a lot of promise for eradicating the stem cell compartments in at least a couple of cancers.

With respect to GIST, we are beginning to learn about the interstitial cell of Cajal stem cell. In a recent paper from Tamas Ordog (an interstitial cell of Cajal expert) and his laboratory at the Mayo Clinic, he has begun to characterize the interstitial cell of Cajal stem cell and to

determine its growth requirements (Figure 2).<sup>1</sup> Ordog and colleagues have shown that these stem cells express lower levels of KIT than mature interstitial cells of Cajal. This alone is significant because it suggests that these cells might not be as dependent on KIT as differentiated interstitial cells of Cajal/GIST cells, which express a lot of KIT. Since KIT is the target of Gleevec, this raises the possibility that GIST tumor stem cells with low KIT expression might not be very sensitive to Gleevec/Sutent. However, I'd like to emphasize

that this is very preliminary work and interstitial cell of Cajal stem cells appear to require stem cell factor, which binds to KIT, for survival and differentiation.

Another interesting finding is that interstitial cell of Cajal stem cells express insulin growth factor-I receptors and insulin growth factor-I is essential for structural and functional maintenance of the interstitial cell of Cajal network. Much has been made recently of inhibition of insulin growth factor receptor signaling in GIST and there is an trial currently being planned in pediatric GIST

with an insulin growth factor receptor inhibitor. Thus inhibition of insulin growth factor receptor signaling may have the added benefit of targeting the stem cell compartment of GIST.

While this article has been brief, I hope that you have a greater appreciation for the interstitial cell of Cajal and its relationship with GIST, especially with respect to unique opportunities for targeting the GIST stem cell compartment. I will not be surprised if the interstitial cell of Cajal or the interstitial cell of Cajal stem cell provides the critical information that results in eradication of GIST.

### References

1. Lorincz A, Redelman D, Horvath VJ, Bardsley MR, Chen H, Ordog T. Progenitors of interstitial cells of Cajal in the postnatal murine stomach. *Gastroenterology* 2008;134:1083-1093

Figure 2

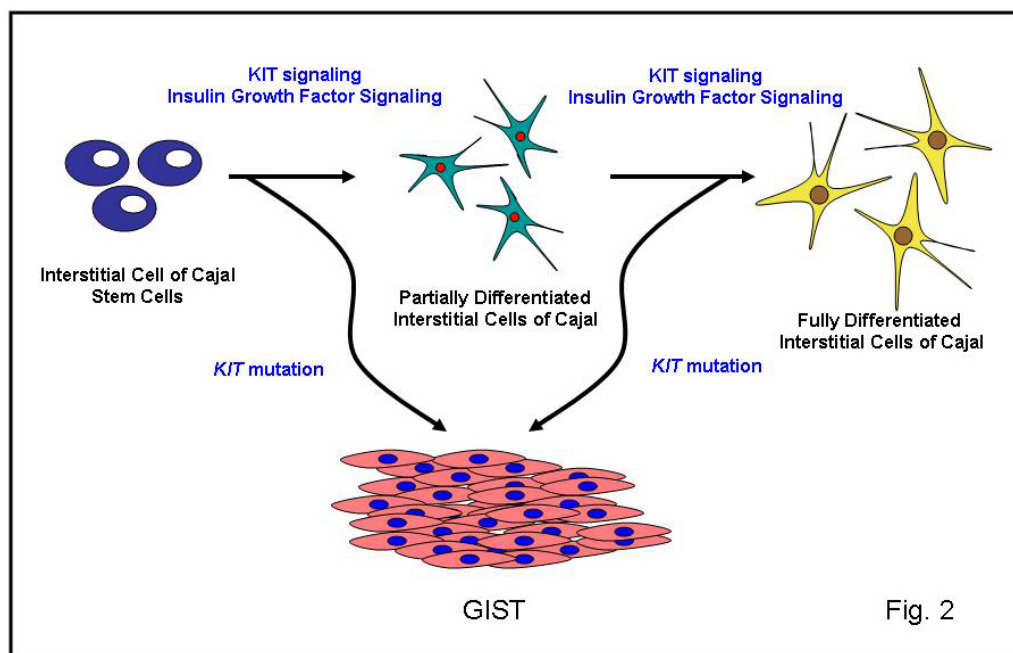


Fig. 2

Pathway of interstitial cell of Cajal maturation and GIST formation. Interstitial cell of Cajal stem cells mature to partially differentiated and later fully differentiated interstitial cells of Cajal under the influence of KIT signaling and insulin growth factor signaling and likely many other growth and development factors. KIT or mutation in other genes such as platelet-derived growth factor receptor A leads to GIST formation.

## Michigan GISTers meet at Gilda's!

The Michigan LRG chapter met on Saturday, May 9 at Gilda's Club in Royal Oak, Michigan. According to Chapter Leader, Ellen Rosenthal, "It was the best attended meeting we've had in quite a while. There were some old faces and some new members in the group, which included Jim Martin, Jim Mills, Gordon and Loosha Simmons, Mary Welzen and her daughter Mary, Connie and Ray Arndt, David Davis, Ted and Nancy Wahl and Nancy's mom, Cara Catallo, Doug and Lennis Horst, and Sue Severini. Since we had new members, we went around the room and introduced ourselves and gave our GIST histories. We discussed treatments, side-effects, doctors, the LRG tissue bank and Project Flag, amongst other things."

## LRG announces GIST Collaborative Tissue Bank initiative

Innovative project will allow GIST researchers worldwide to access GIST tissue linked to patient-provided clinical histories

**May 28, 2009**— Life Raft Group (LRG), the pre-eminent patient-based organization dedicated to finding a cure for a deadly cancer called gastrointestinal stromal tumors (GIST), today an-

nounced the launch of the GIST Collaborative Tissue Bank, a partnership between twelve internationally-renowned GIST researchers and the Life Raft Group, whose Patient Registry houses the world's largest patient-provided GIST clinical database. The cutting-edge project will promote sharing of tissue as well as the data generated from the studies of this tissue. The Stanford University School of Medicine will serve as the tissue repository and data host through its Tissue Microarray website (<http://tma.stanford.edu>).

"Partnering with a patient-based registry which has the potential to mobilize thousands of GIST patients on a world-

wide scale to contribute not only their tissue, but also in-depth clinical histories, creates enormous potential for ma-



**VAN DE RIJN**

major research breakthroughs" said Dr. Matt van de Rijn, professor of pathology at Stanford and lead researcher on the tissue bank project. "Scientists studying tissue usually have limited information about that patient's clinical history. Being able to examine tissue in one patient over time and compare that to tissues from other patients with similar disease pro-

See TISSUE, Page 11

## Nicole Sparks and family raise over \$2,700 in honor of Uncle Butch and his fellow GISTers

**By Tricia McAleer**  
LRG Director of Operations

**N**icole Sparks, niece of Life Rafter Butch Eller, recently contacted the LRG to find out what she could do to help. Nicole had plenty of her own ideas and with just a little help from the LRG office, she and her family were off and running to start their fundraising in honor of their beloved Butch.

Nicole started working with Yankee Candle and Popcorn Palace to raise money through the sales of candles and gourmet popcorn, respectively. She also had purple and white Life Raft Group wristbands created so that contributors could have an avenue to proudly show their support. They were able to raise over \$2,700!

Nicole said, "I am so glad

that we were able to do the fundraiser and raise that amount of money. Uncle Butch is so dear and special to me and my family. I can't say it enough. He is the most amazing person I know. He has been so strong throughout this battle with GIST. Knowing that there are other people affected with GIST and that they have family/friends that feel that

same way I do about Uncle Butch make this so worthy."

Nicole isn't stopping anytime soon, she and her family are currently planning a Shrimp Feast fundraising event for this fall.

The LRG would like to thank Nicole and her family on behalf of all the GISTers that will benefit from their efforts.



Butch Eller, Nicole Sparks and her son, Dylan, raised nearly \$3,000 for the Life Raft Group through the sales of candles and gourmet popcorn.

## Chicago-area GISTers meet



### Want to find a LRG meeting in your area? Want to host your own get-together?

**For many people facing illnesses, a face-to-face meeting is essential to the coping process. LRG Local Group leaders range from meeting organizers to a shoulder to lean on. Go to [www.liferaftgroup.org/about\\_support\\_programs.html](http://www.liferaftgroup.org/about_support_programs.html) to find an in-person group near you. If you can't find one, start your own! Email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org) and ask us how.**

Chicago-area GISTers met on Sunday, May 3. The group, which totaled 19, watched Dr. Heinrich's plasma testing webcast (you can view this presentation and others at [www.liferaftgroup.org/libray\\_videos.html](http://www.liferaftgroup.org/libray_videos.html)), discussed which doctors would be doing plasma testing in the area, how to use the free kits, as well as logistical issues that have come up with this type of testing. To find out about further meetings, email Jim Hughes at [tjhughes43@comcast.net](mailto:tjhughes43@comcast.net).

## Mark your calendars!

- The American Society of Clinical Oncology (ASCO) will be holding its 2009 conference **May 29-June 2** in Orlando, Fla. Abstracts can be viewed at [www.abstract.asco.org](http://www.abstract.asco.org).
- New Jersey-area Life Rafterers will be meeting on **June 14** at the home of Norman & Anita Scherzer. To RSVP or request details, email Trish at [tmcaleer@liferaftgroup.org](mailto:tmcaleer@liferaftgroup.org)
- The biannual NIH Pediatric & Wildtype GIST Clinic is being held **June 18-19**.
- Cancer Care is holding another telephone workshop: Survivors too: Family, friends, and loved ones: Managing the fatigue of caregiving on **June 23**. Go to [www.cancercare.org](http://www.cancercare.org) for information.



## FARMER

From Page 6

boarding school suite-mates. But she doesn't go to many events anymore, in part because she can't predict when she might feel ill.

She does like connecting by computer. "I'm really cool because I'm on Facebook," she said.

She doesn't miss the pace of public life, having spent years being out almost every night. But strangers still approach her, often at the East Side Marketplace, where she shops.

"Thank you for the work you did," some will say. "I just love Rhode Island PBS."

Or they'll just ask: "How are you doing?"

She'll smile and tell them she's trying hard to set medical records. Often, if people are interested, she'll offer details. She said it helps her to speak openly.

"Lots of people clam up and don't talk

about it," said Farmer. She feels it's more painful to have it bottled up. And she hopes sharing thoughts could help others who face illness.

"Enormous gifts come with cancer," she told me. "Everyone raises their eyebrows when I say that but those who have cancer agree."

Being put on notice, she explained, makes you realize that petty resentments are a waste of time.

"I don't hold grudges anymore," said Farmer. "You can resolve differences. You learn forgiveness."

She has also slowed down.

"I was always very type-A. Now I'm a Type-B and I like it. If I get in a traffic jam, it doesn't matter. I used to want to get as far as I could as fast as I could. Now, I'm happy to be where I am. I'm very calm."

Farmer has few low moments.

"I've never even thought, 'Why me?'" she said. "Why anybody?" And then: "If I start getting all sad and down, it ruins another day."

I asked what she's proudest of.

"Raising two wonderful women. That's the best thing I am, a mother."

Better than secretary of state and head of Channel 36?

"Those are a very close second."

And she said she likes to think she opened a door for women in politics.

When I first talked to Susan Farmer a few weeks ago, she was ready for the liver surgery. I called her the other day, and she said her doctors were now unsure it would help. That leaves her medical future equally unsure.

She did not seem upset.

She said she was looking forward to getting into her garden.

## TRND

From Page 2

tial treatment move to clinical trials in patients.

Unfortunately, the success rate in this preclinical process is low, with 80 to 90 percent of projects failing in the preclinical phase and never making it to clinical trials. And the costs are high: it takes 2 to 4 years of work and \$10 million, on average, to move a potential medicine through this preclinical process. Drug developers colloquially call this the “Valley of Death.”

TRND will work closely with disease-specific experts on selected projects, leveraging both the in-house scientific capabilities needed to carry out much of the preclinical development work, and contracting out other parts, as scientific opportunities dictate. Its strategies will be similar to approaches taken by pharmaceutical and biotechnology companies, but TRND will be working on diseases mostly ignored by the private companies. Importantly, TRND will also devote some of its efforts to improving the drug development process itself, creating new approaches to make it faster and less expensive.

If a compound does survive this preclinical stage, TRND will work to find a company willing to test the therapy in patients. There are several stages to the clinical trials process that can take several years before the safety and efficacy of a new drug is determined. FDA will only approve a drug for general use after it passes these trials. The clinical trials process is also expensive, but the failure rate is lower at this stage.

“NIH traditionally invests in basic research, which has produced important discoveries across a wide range of illnesses,” said NHGRI Acting Director Alan E. Guttmacher, M.D.

“Biotechnology and pharmaceutical companies have enormous strength and experience in drug development, but to maximize return-on-investment work primarily on common illnesses. TRND will develop promising treatments for rare diseases to the point that they are sufficiently “de-risked” for pharmaceuti-

cal companies, disease-oriented foundations, or others, to undertake the necessary clinical trials. NIH’s goal is to get new medications to people currently without treatment, and thus without hope.”

NIH already has many components of the drug development pipeline within its research programs. TRND will begin its work in collaboration with the NIH Chemical Genomics Center (NCGC), a center initially developed as part of the NIH Roadmap for Medical Research. NCGC has developed a robotic, high-throughput screening system and a library of more than 350,000 compounds that it uses to make basic discoveries and probe cellular pathways. NCGC also has developed a team of researchers skilled in developing assays representing disease processes that can be tested in its screening system, and has extensive experience building collaborative projects with investigators from across the research community. Molecules with potential therapeutic properties that emerge from the NCGC screening process could be fed into the TRND drug development pipeline.

“With this new funding, TRND will develop teams of scientists who can do the hard work of optimizing chemicals that we or others discover that may treat rare diseases and turn them into actual drugs,” said NCGC Director Christopher P. Austin, M.D., who is also the Senior Advisor for Translational Research to the NHGRI Director. “This will still be hard work and it will take time and produce failures. Unlike traditional drug development, however, where only successes are published, we will publish our failures as well, so everyone in the drug development community can learn from them. That alone could be revolutionary.”

If all the preclinical hurdles can be crossed, a possible treatment must still be tested in a series of clinical trials. TRND will seek to take advantage of several NIH resources that can help launch human studies, including the NIH Clinical Center, the NIH Rapid Access to Interventional Development (NIH-RAID), and the Clinical and Translational Science Awards (CTSA) program.

## External Partners

Numerous obstacles impede the development of new drugs for rare and neglected diseases. In addition to the reluctance of private companies to risk their capital on a potentially low return, relatively few basic researchers study rare diseases, so the underlying cause of the illness frequently remains unknown. And, because rare diseases are rare, researchers often have difficulty recruiting enough people with the disorder to participate in a clinical trial once a candidate compound reaches the stage where it can be tested in people. Moreover, for many rare diseases, the natural history of the disease is poorly understood, so researchers lack the needed clinical measures (such as blood pressure) that can demonstrate whether a treatment is working.

To address these difficulties, TRND will seek a wide range of collaborations with academic researchers, as well as partnerships with patient advocacy organizations, disease-oriented foundations and others interested in treatments for particular illnesses. TRND’s leaders hope that the collaborations will help lay the groundwork for clinical trials once that point in drug development is reached.

TRND is currently setting up an oversight process to help it decide which projects that address thousands of rare and neglected diseases will be pursued. Leadership currently envisions a small number of diseases being studied each year, with strict criteria used to determine which molecules will be studied for which diseases. NIH expects to use existing intellectual property policies to transfer licenses for TRND-discovered drugs to private companies or others for development, clinical testing and marketing.

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### Frequently asked questions (FAQ) about this new program are available online at:

FAQ on the Therapeutics for Rare or Neglected Diseases (TRND) program: [www.genome.gov/27531965](http://www.genome.gov/27531965)

For more information on TRND, go to <http://www.rarediseases.info.nih.gov/TRND>.

## TISSUE

From Page 8

gression patterns will significantly accelerate our understanding of the underlying mechanisms of GIST.”

Other members of the GIST Collaborative Tissue Bank include: Dr. Cristina Antonescu and Dr. Peter Besmer, Memorial Sloan Kettering Cancer Center; Dr. Sebastian Bauer, West German Cancer Center, Germany; Dr. Chris Corless & Dr. Mike Heinrich, Oregon Health & Science University; Dr. Maria Debiec-Rychter, Catholic University of Leuven, Belgium; Dr. Anette Duensing, University of Pittsburgh Cancer Center; Dr. Jonathan Fletcher, Brigham & Women’s Hospital; Dr. Brian Rubin, The Cleveland Clinic; Dr. Constantine Stratakis, National Institutes of Health, Pediatric & Wildtype GIST Clinic and Dr. Rob West, Stanford University School of Medicine.

Each year, 5,000-10,000 people in the U.S. are diagnosed with GIST, a rare and often deadly sarcoma, for which there is no known cure. Over the last ten years, with the advent of oral targeted chemotherapies such as Gleevec™ and Sutent™, patients can often remain stable for years. However, the majority of

patients become resistant to treatment over time, making the need for more assertive research much more pressing.

“The LRG has aggressively funded GIST research for the last three years but as a patient-driven organization we knew that we could play an even greater role in the search for a cure” said Jerry Cudzil LRG, Board President “Now patients can donate their tissue and medical histories becoming active participants in the research process which is very empowering for patients and family dealing with a life-threatening disease.”

Since its founding, the LRG has maintained an extensive GIST patient registry, which cuts across institutional and geographical boundaries, by collecting medical updates directly from GIST patients. Today, with over 1,100 GIST patient clinical histories, it is the largest database of its kind. In 2006, LRG began funding a team of leading GIST experts who have been working together collaboratively and cooperatively through its Pathway to a Cure research effort. As with other rare diseases, one of the most urgent research needs identified by the team was for GIST tissue. Working together, the LRG and researchers came up with a unique model that could not only deliver tissue but could also provide the even more elusive

puzzle piece: comprehensive GIST clinical histories linked to tissue. The key was involving patients who could gain accesses to their tissue samples in the form of paraffin tissue blocks, which are archived in the hospitals where surgery took place. Patients and family members will have their paraffin tissue blocks from surgical procedures (sometimes conducted over many years at different facilities) sent to the LRG Patient Registry. The LRG, in turn will forward the tissue and clinical histories (de-identified to comply with research privacy regulations) to Stanford University, the tissue repository and data host. With this novel system, researchers will now be able to study annotated GIST tissue in ways that have never been possible before. For example, scientists will be able to compare primary tumor tissue and metastasized tumor tissue from individual patients and then look for genetic similarities in other patients.

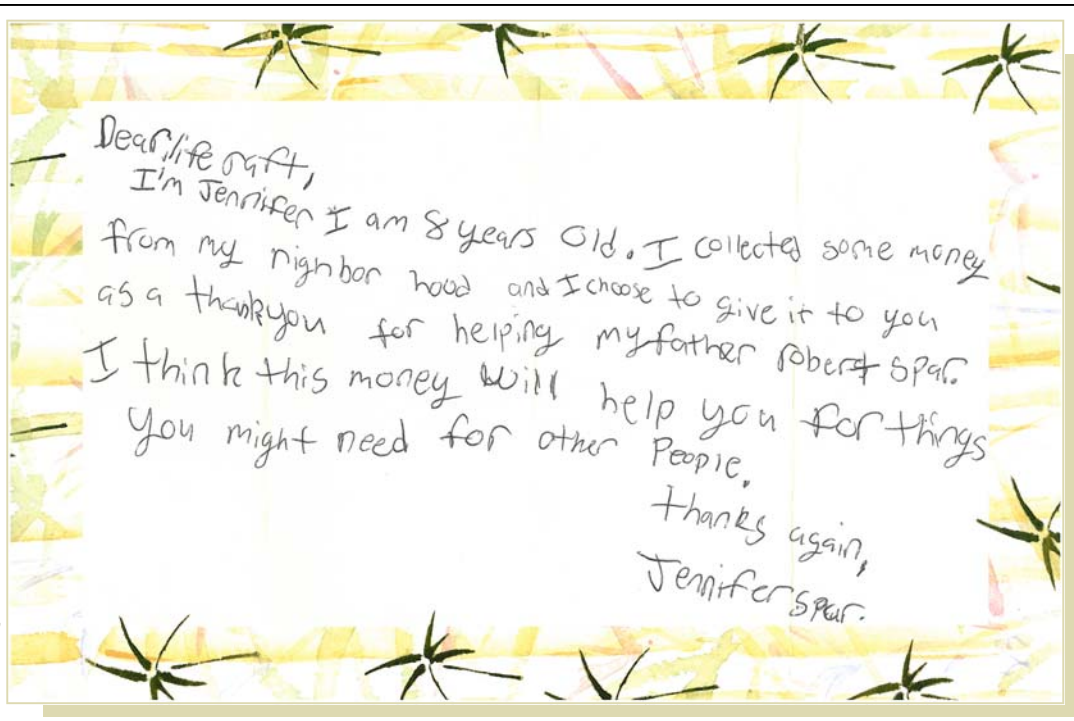
“Being able to do something to help find a cure for my disease gives me hope that a cure will be found faster” says Anne Pacifico, one of the first GIST patients to donate tissue to the project, “I’d much rather that my tissue is put to good use by scientists than just sit in a file. Research is our best hope and I want to be part of it.”

### From the mailbox

*The LRG receives correspondence from members on a daily basis. They come in various forms like donations, requests for information, changes in address or sometimes a simple, “Thanks for the help.”*

*Occasionally, we get a letter that makes everyone in the office stop thinking about the task at hand for just a few moments and focus on the big picture.*

*Recently, we received one of these letters and wanted to share it with our friends in the GIST community. It comes from a young girl, whose father passed away in April 2008, after fighting GIST for almost three years.*



# THE LIFE RAFT GROUP

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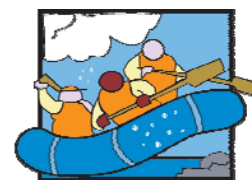
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