

True love, the 'bomb squad baby' and cancer

'Never a dull moment'
might be the motto of
detective and Life Raft
member Maura Cesarini

By Maura Cesarini

When I was 25 years old, I was working at a cable TV company, and knew there had to be more to life than what I was doing.

I was the youngest of four kids. My parents had immigrated to Boston from Ireland in the 1950s. I had finished a master's degree at Emerson College in Boston. Three years earlier, I had lived in London after graduating college, returning to Massachusetts to be with my mother who was dying from a rare bone cancer.



Maura Cesarini

My father had died 10 months early from cirrhosis of the liver. I had gone home for his funeral and had no idea I would be coming home so soon for another one.

I knew then the frailty of life. With the death of my mother, I knew that people could come and go from your life in the blink of an eye. I had learned never to take anyone or anything for granted. But with time, these thoughts moved to the back of my head. I started going through the motions of living again until I didn't have

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Battling GIST with Gleevec (STI571)



LIFE RAFT GROUP

February 2003

Vol. 4, No. 2

Life Raft, pathologists forge new partnership

Armed Forces Institute of Pathology researchers meet Life Raft members

Writes Norman Scherzer, executive director of the Life Raft Group: "Marina Symcox, Jerry Call, and I recently visited the Armed Forces Institute of Pathology in Washington, D.C. Their trip reports (here and Page 4) combine to describe an enjoyable and productive visit with two important Life Raft Group colleagues, Drs. Markku Miettinen and Jerzy Lasota.

By Marina Symcox

Often a person has no idea what good fortune the future might hold. This must have been the case when Norman Scherzer weeks ago scheduled Feb. 20 for a meeting of Life Raft Group members and key GIST (gastrointestinal stromal tumor) researchers at the Armed Forces Institute of Pathology in Washington, D.C.

The Armed Forces Institute of Pathology, an agency of the Department of Defense, has long-standing expertise in GIST research, as well as other rare and unusual diseases. The AFIP has served U.S. military and civilians around the world with programs in pathology consultation,

medical education and research. In 2001, the AFIP consulted on 90,000 pathology cases.

Just days before the eagerly awaited meeting between Life Raft Group and AFIP, a record blizzard dumped up to 2 feet of snow in the Washington area. Airports were closed and roads were impassible. Travel to the AFIP appeared iffy.

At the last moment, the weather smiled on a cancer support group already blessed by the miracles of Gleevec. Temperatures warmed just enough to clear roads and airport runways while the ground remained covered in a scenic blanket of snow.

Enthused by this good fortune, Life Raft Group members Jerry Call, Norman Scherzer, and Marina Symcox found their way to the snowy capital, and kept their appointment with GIST researchers Dr. Jerzy Lasota and Dr. Markku Miettinen.

Norman and Lasota first met and exchanged business cards at the Gleevec/GIST conference held in London last September. They arranged the Feb. 20 meeting so that Life Raft Group and AFIP could learn more about each other and discuss ways in which the two organizations might work together.

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Meeting Feb. 20 at the Armed Forces Institute of Pathology in Washington, D.C., were, from left, Norman Scherzer, executive director of the Life Raft Group, Dr. Markku Miettinen, Life Raft member Marina Symcox, Ph.D., Life Raft science team leader Jerry Call, and Dr. Jerzy Lasota.

Institute

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Lasota and Miettinen have authored numerous research and review articles about GIST. Much of their research has focused on the clinicopathologic, immunohistochemical and genetic aspects of GIST. Their study of a large number of duodenal GIST cases is set for publication in the near future.

Over cookies and hot tea, Lasota and Miettinen visited with Life Raft Group members in an informal three-hour meeting. Highlights are as follows.

1) Norman gave an overview of the Life Raft Group organization, with descriptions of the past side effect survey, the Cambridge meeting, membership size, non-profit organizational status and grant, the newsletter, and future plans.

2) Lasota and Miettinen gave an overview of their own work with

GIST. They shared several pieces of information, including what was to Life Rafter a curious finding that stomach primaries from older women favor a particular insertion mutation in c-kit.

Lasota and Miettinen described the current difficulty in predicting malignant potential in GIST cases lacking metastatic disease at diagnosis. They discussed the need for additional research to identify which clinicopathologic factors are the most reliable prognostic indicators of malignant potential. Understanding these factors would help physicians in treatment management decisions regarding adjuvant or neoadjuvant therapy.

They commented on discrepancies in the literature regarding the incidence of GIST cases with un-mutated c-kit (wild type). Reported incidences fall anywhere from 8 percent to 35 percent, depending on the laboratory. In general, GIST cases with wild type c-

kit are less responsive to Gleevec than those with mutated c-kit.

They stated systematic studies into the variables of protocol methodology and manner of tumor sample preservation will be needed to resolve the issue. In this regard, access to both fresh-frozen and paraffin-embedded samples would be helpful.

3) Norman described the concept of a Life Raft Group tissue bank for Gleevec-resistant tissue, as well as Life Raft's potential to serve as an expanding, epidemiological surveillance system with the ability to coordinate donation and placement of fresh tissue to interested researchers.

The Life Raft Group representatives discussed the desire of many patients to receive data generated from their tumor samples. Norman suggested data could be categorized three ways: 1) sensitive data not yet available to patient; 2) data made available as sta-

Cesarini

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to pretend to be alive, I *was* alive again.

I realized I wanted to make a difference in people's lives. I decided to become a police officer.

Now, I had a boyfriend. He was very nice but there were no sparks. He was an accountant and a little boring. On the first day of the Police Academy, I met Michael. He looked mean, tough, really physically fit and very intimidating. The kind of cop you would hate to see walking up to your car in the rear-view mirror. We were put together as running partners to record each others times.

He was fast, and I was embarrassed at how slow I was by comparison. I was sure he thought I didn't belong there. Nonetheless, as the months passed we became friends. He told me about his girlfriends; I continued seeing my nice boyfriend on the weekends but began to think about Michael more and more. He was five years younger than me and I didn't think he would have any romantic interest in me.

Graduation day came and I was thrilled and relieved to have made it. But also a little sad as I thought that was the end of seeing Michael as we were going to work in different cities. After the ceremony, I was talking to a group of friends when Michael came up and asked if he could call me "sometime." I was thrilled but wondered if maybe this was a mean joke. Believe it or not, the Police Academy is a little like high school with the cool and the not-so-cool kids. Michael was definitely cool and I considered myself one of the latter.

Anyway, "sometime" turned out to be the next day. We made plans to go to the St. Patrick's Day parade in South Boston. We spent the day together and he dropped me off — not so much as a peck on the cheek, but he did say he'd call. And he did, a few



Maura Cesarini carries little baby Bella as husband Mike totes Michaella in Acadia National Park in Maine, U.S.A. The photo was taken two months after Maura's GIST diagnosis.

hours later and we went out again that night.

That was the last of the accountant. Michael and I bought a condo in Boston and got married in 1998. Around the same time, I was made a detective. Everything was going great.

About a year later we decided to have a baby. My sweet Michaella was born Jan. 1, 2001. But she didn't come easy.

She was due Dec. 26, which came

and went. On Dec. 30, we had a huge snowstorm. That, of course, was when my contractions began. We were living in a small town south of Boston and Mass General hospital was 30 miles away. We made it to the hospital through the snow drifts, only to learn it wasn't quite time yet and return home.

New Year's Eve came. I had really painful contractions all day. I refused to go to the hospital if they were only

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Institute II

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tistical compilations for the entire study group; and 3) individual data reported to patients and their physicians.

Norman added that Life Raft Group members likely would be willing to sign waivers/disclaimers protecting the testing institution against liability.

Lasota explained that data disclosed to patients must be collected in laboratories practicing certain quality control guidelines, such as those labs that are CAP-approved (College of American Pathologists).

Lasota and Miettinen agreed to inquire further within their institution regarding possible arrangements for a repository of Life Raft Group tissue at AFIP, with the understanding that the tissue would be made available to other institutions. They requested Life Raft Group submit a written proposal outlining the project.

4) Lasota and Miettinen agreed to arrange a link of their GIST data to the Life Raft Group Web site. Arrangements would depend upon institutional approval by AFIP and full citation credit to AFIP by Life Raft Group. The data link might include a global mutation database for GIST, and information extracted from publications.

The two researchers agreed to send links to Jerry Call to begin process of selecting appropriate material.

5) Lasota and Miettinen volunteered to write a science article for the Life Raft Group newsletter. Norman added the circulation of the newsletter would soon expand into the thousands.

6) Near the end of the meeting, Miettinen presented a tutorial with stained microscope slides. He illustrated the differences between GIST and leiomyosarcoma for the expression of several markers including KIT, actin, CD34 and desmin. He further explained microscopic cell features and morphology.

For the Life Raft representatives, long locked into protracted and some-

Some observations on GIST research and a tumor bank

The simplicity of GIST makes it a model for research, treatments

By Jerry Call

The success of Gleevec for GIST has created an enormous interest in molecularly targeted therapy and GIST. Prior to Gleevec, GIST was notorious for its resistance to all treatments except surgery. Gleevec changed GIST from a cancer that rarely responded to chemotherapy to a cancer where more than 80 percent of patients on Gleevec show clinical benefit (shrinkage or stability). For many patients the durability of response has been long lasting, reaching the 2 ½-year mark and further adding to the enthusiasm for molecular target approaches.

GIST is a genetically a relatively simple cancer. It has fewer karyotype abnormalities (losses or gains of chromosomal regions) than most types of cancer. The mutation of a single gene, c-kit, seems to be an early and critical event in up to 90 percent of GISTs. Recently, another mutation in a second gene, PDGFRA, was identified as an ap-

parent early and critical mutation in about 5 percent of GISTs. Blockage of aberrant signaling caused by the mutation of a single gene, c-kit, by Gleevec is responsible for its tremendous success in GIST patients. Gleevec also inhibits PDGFRA signaling, but how effective it is in GIST patients with PDGFRA mutations has not yet been reported.

The relative simplicity of GIST and the overwhelming importance of KIT signaling make GIST a model for studying molecular therapy in solid tumors. The following charts (see Page 5) illustrate the complications facing the studies of genetically more complex cancers. In the event the molecularly targeted therapy fails, which cancer affords researchers a better chance of discerning the underlying mechanisms of resistance? (Note: the chart is for purposes of illustration and does not depict all of the genetic alterations that occur in GIST).

Other signals besides KIT are involved in GIST. KIT signaling causes activation of downstream signals such as PI3K, AKT, STAT1, STAT3 and MAPK. In

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times grave battles with GIST, the images on the slides evoked an intriguing yet sobering moment of reflection. The images on the slides seemed deceptively innocuous.

For a few minutes, the eyes of Life Raft gazed upon the microscopic stuff of deep human tragedy and yet amazing medical breakthroughs. Through the lens of a microscope, the Life Rafter were strangers no longer with their protagonist ... a nemesis, and in per-

verted way, a mentor too.

As the meeting closed, Miettinen remarked that the visit by Life Raft Group would inspire them to work harder at their GIST research. The comment brought a round of smiles and nods of approval by all.

The AFIP meeting demonstrated that direct contact by Life Raft Group with key GIST researchers may facilitate collaborative projects with the goal of helping GIST patients.

GIST: A model cancer in several ways

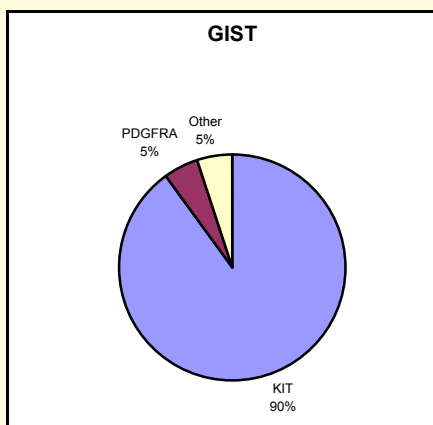
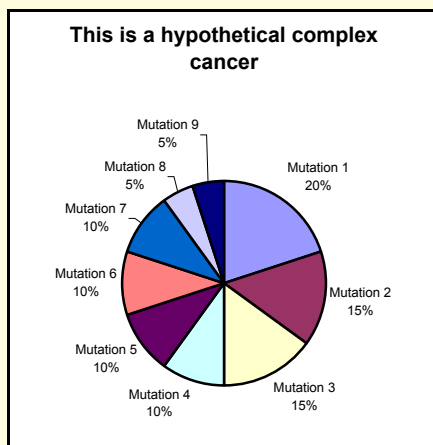
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general, all of these downstream signals are common in other cancers. The PI3K/AKT pathway is particularly interesting, and several new drugs are being developed to target some of these pathways. It is probable that some day treatment for GIST might consist of a “cocktail” of several different drugs with multiple molecular targets.

The first of these multi-drug clinical trials combines Gleevec with an “mTOR” (mammalian target of Rapamycin — a downstream target of AKT) inhibitor called RAD001. This trial recently began signing on patients in Europe and will soon start in the United States. Imagine trying to assess the relative contribution of inhibiting mTOR in the “complex cancer” shown in the chart (above). How many of these pathways signal through mTOR? It seems logical that assessing the effectiveness of inhibition of downstream pathways would be easier in a “simple” cancer like GIST.

If molecularly targeted therapy is going to play a major role in more common (and more complex) cancers, then techniques will have to be developed to match the properly targeted drug to patients carrying the corresponding molecular defect. Staining for the presence of KIT (CD117) in GIST cells is the simplest example of matching a molecular marker with a molecularly targeted drug (Gleevec).

Even this simple example is more complex than it appears. First, the pathologist must determine that the tumor is GIST (staining for KIT helps do this), because the mere presence of KIT on other cancer cells does not mean KIT is activated or plays any role in the cancer. Just as we learn to walk before we learn



to run, it will probably be easier to develop some of the technology for matching treatments to molecular defects in a simple well-studied cancer rather than in a complex one fraught with variability.

All cancers need tumor tissue samples for research. Because GIST appears to be a model cancer, research on GIST may help not only GIST patients but could advance the methods and technologies for other cancers as well.

For the type of sophisticated research needed, both paraffin-embedded samples and frozen-tissue samples will be needed. Frozen-tissue samples require that tissue be “flash-frozen” immediately upon surgical removal.

Ideally, the Life Raft Group would

like to see that all GIST researchers receive all of the tissue they need for their research. However, the Life Raft Group is not interested in research alone.

We would also like to see some of the results learned from members’ tissue samples shared with the patient in order to improve that patient’s medical management. We recognize that such disclosure of data to the patient is a radically different concept than most traditional tumor banks, but our survival may well depend upon this.

In summary, research of GIST has a high level of interest, and tissue donation will facilitate the pace for discovery about mechanisms of resistance to Gleevec in GIST.

Due in large part to the relative simplicity of GIST, it is a model cancer in several ways:

1. Studying resistance to treatment should be easier. Some of the lessons learned may be applicable to other cancers.
2. Downstream signaling may be easier to identify and evaluate its importance to the progression of the cancer.
3. The techniques/methods developed in GIST research/treatment can also serve as models for other cancers. Techniques and methods will have to be developed to:
 - a. Identify multiple genetic defects.
 - b. Determine if the identified defects are relevant (how much are they contributing to the cancer?).
 - c. Match genetic defects with targeted therapies. Identify whether the target is affected (for instance, is KIT inhibited?).

Cesarini II

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going to send me home again. By 10 p.m. the pain was unbearable, and we set out for Boston.

However, when we got off the highway, the streets were crowded with people. It was the annual First Night Celebration. We couldn't get through the traffic and I knew the baby was coming. Thankfully, we saw a fellow police officer working crowd control. My husband quickly told him of our situation and the officer called for the nearest vehicle to escort us through the traffic. The closest car turned out to be a Bomb Squad truck and crowds certainly parted when they saw that coming through. We made it in time and my perfect angel was born shortly afterwards!

The following year, I was again expecting. In my sixth month of pregnancy, I started to have a nagging pain in my left side. I went to the obstetrician thinking something was wrong with the baby. An ultrasound showed the baby was fine but I was told there was a large "cyst" growing in my abdomen and they would keep an eye on it.

Well, the pain became worse and subsequent ultrasounds showed the "cyst" growing very fast. I was sent to a surgeon who advised me to wait until after I had the baby and that it might even go away on its own. I went for a second opinion and was told that it did look like a cyst but since it was growing so fast I should have it removed right away.

My little Bella Danielle was induced one month early. She stayed in the hospital for 10 days and had to be fed through a tube in her nose. One week after having Bella, I returned to the hospital to have the "cyst" removed. Even then, life was still certain.

On July 16, 2002, I woke up in the recovery room of Mass General. My obstetrician was there with the surgeon. They both looked very sad. I

Quote:

"I am so happy to be here, to be a mom. I am so thankful they still have a mom in their lives."

— Maura Cesarini

hazily heard them tell me I had cancer. My "cyst" was actually a GIST. Parts of my stomach, pancreas and entire spleen had been removed. There were too many lesions on my liver to take them out. I knew devastation. All I could do was cry. I couldn't believe this was happening to me. I had two babies to take care of. I was only 33 years old. I questioned how could God be so cruel. I wasn't a bad person. I was a vegetarian. I exercised. I took care of myself. Why was this happening?

Well, seven months later, I still don't have any answers but I am still here. Life goes on.

My husband is an avid runner and cyclist. In our "pre-cancer" days we both read Lance Armstrong's book, "It's Not About the Bike." After my surgery we both reread it. On one of my darker days in the hospital, Michael came in with a large wrapped bag. In it was an autographed picture of Lance, who had written the words, "Stay Strong, Maura" on it. My husband always seems to know what I need.

I am still here for my wonderful Michael, who surprises me and impresses me every day. I have learned he is so much more than a tough, intimidating cop. He is so loving, so committed, so loyal. In December, he surprised me with a trip to St. John's in the Virgin Islands. He had a limo pick us up and on the way to the airport, a billboard read, "MAURA, I LOVE YOU!"

I am still here to go on our hiking trips to Maine and New Hampshire. He has again surprised me with a planned trip to Ireland in March. My sister lives with her family there and again on my gloomier days I have something else to look forward to.

I am still here for my children. My girls are growing so fast. My little Michaela is speaking in full sentences. She can say, "I love you, Mommy" and I am here to say it back. I can read her a story at night and kiss her boo-boo's. There is nothing like the love you feel from a 2-year-old who believes that your kisses makes the boo-boo's better. My little Bella is starting to sit up and trying to crawl. I am here to rock her back to sleep at night when she awakens. I am here to see her smiles and hear her babbles. I am so happy to be here, to be a mom. I am so thankful that they still have a mom in their lives.

Cancer is such a frightening disease but many times it shows us such goodness in people. Eight of my fellow police officers walked a marathon in my name to raise money for cancer research. My co-workers and academy friends organized a softball game with my police department playing my husband's. They had a big party for us afterwards. Friends I hadn't seen in years came out for it. It was a little like being at my own wake but I guess I would prefer to see such a good turnout now rather than when I am not here to enjoy it.

I often wonder if I am having the same thoughts about life and death and motherhood that my mom had when she was diagnosed. I wish that I had been able to talk more to her about cancer, but at the time if I even tried to speak about it, only tears came out.

I don't know why I have cancer. I learned the mortality lesson a long time ago. I do know that if I dwell on the why, it will not change my diagnosis. I try to keep on living each day, enjoying my family and friends and appreciating all that life has to offer. That's all any of us can do ...



Dick Kinzig, standing at right, talks to Life Rafterers attending the Chicago area gathering held the Wellness Place, a cancer support facility in Inverness, Illinois, U.S.A.

Chicago area Rafterers gather, plan next meet

By Richard Kinzig

The Chicago area chapter of the Life Raft Group held its second meeting Saturday, Jan. 11. The meeting was at the Wellness Place in Inverness, IL, a cancer support facility. Many thanks go to the Wellness Place staff for providing such a friendly and supportive environment for our meeting.

Nine Life Rafterers, some with spouses and caregivers, attended for a total of 16 people. Three of the couples came from Indiana, one was over four hours' drive. There were three new members that joined Life Raft within the last two months and they experienced a good deal of benefit from the dialogue and exchange of ideas from all the group.

Amazingly, two of our members have 11 and 12 years of survival of GIST, offering the rest of us a good deal of hope for the future.

We were fortunate to have Dr. Harvey Wolf as our guest, who has 25

years in the oncology field. He covered the emotions a person encounters dealing with cancer and he urged us each to take responsibility for our health care and our emotions, even providing some useful tips on doing so.

The group decided to hold its next meeting Saturday, May 3, at the Wellness Place. All are invited and we welcome any new members from the area.



Above, Dr. Harvey Wolf spoke to the group about the emotional aspects of cancer. At left, Elaine Rys, in white top and scarf, looks at Paula Vettel, the discussion leader for the meeting. On the far side of Elaine is Gwen Lawson, wife of LRG member Bill Lawson.

In Memoriam

There have been 23 deaths in the Life Raft Group to date:

Debbie Nance, 38, Oct. 2, 2000, wife to Eddie, mother of Chris.

Jim Ackerman, 49, Jan. 16, 2001, husband to Betsy, father of Jill and Tom.

Jim Perham, 63, May 2001, husband to Karen, father of Craig, Kathy, Jennifer.

Amy Barney, 25, June 10, 2001, wife to Reed, mother of Joshua.

Jeff Prichard, 52, July 11, 2001, husband to Joyce, father of Gregory and Scott.

Ron Martinez, 60, July 25, 2001, husband to Jo Ann, father of Ron, Wendy, Natalie.

Ehud Nehemya, Aug. 7, 2001, father to Einat Zelinger, father-in-law of Ophir Zelinger, Hadar Nir.

Bruce Gunn, 43, Nov. 8, 2001, husband to Roisin, father of Seamus, Liam, Brendan and Aislinn.

Robert Carr, Dec. 30, 2001, father of Robert, Steven, Scott and Melissa.

Jonathan Montague, 23, Jan. 19, 2002, son of Ray and Sheila Montague, brother to Jamie, Adam, Meghan.

Robert Lecca, 49, Jan. 28, 2002, husband to Diane.

Jacob Winfield Waller III, 67, March 31, 2002, husband to Jerry, father to Rita, Richard

Mary Golnik, 50, April 18, 2002, wife to Gary, mother to Timothy

Ana Maria Baldor-Bunn, 30, April 19, 2002, wife to Stan, mother to William.

Stewart "George" Wolf, 51, April 19, 2002, husband to Maggy, father to Thomas.

Jerry Pat Rylant, 61, May 5, 2002, husband to Pamela, father of four, grandfather to 10.

Jill B. Meyer, 53, June 9, 2002, mother of Aliza.

Todd Hendrickson, 44, June 29, 2002, husband to Janet, father to Max, Tyler and T.J.

Chet Duszak, 79, Oct. 5, 2002, husband to Kay, father to Lori.

Nora Shaulis, 42, Nov. 4, 2002, wife to David, mother to Griffin.

Howard Delapenha, 41, Dec. 14, 2002, husband to Sandra, father to Joshua and Hannah.

Kathy Colwell, 45, Jan. 5, 2003, wife to Tom, mother of Katherine, Mary and Tom.

Cynthia G. Whitson, 64, Jan. 19, 2003, wife to Jerry, mother to Steve, Jill, Randy and Donna.



Billie Baldwin, left, Dick Kinzig, Eleanor Lewis and Darlene Vaughan got together Feb. 21 in Scottsdale, Arizona, U.S.A.

Desert dwellers plus one

A quartet of Life Raft members met Feb. 21 at the Virginia Piper Cancer Center in Scottsdale, Arizona, U.S.A. Billie Baldwin, Eleanor Lewis and Darlene Vaughan were joined by Dick Kinzig, a Chicago resident who spends some of the winter in Arizona. Susan Luft, registered nurse and cancer care coordinator, spoke to the group about the new Virginia Piper center and its growing impact with

the metropolitan Phoenix area.

"We shared our stories of dealing with the dragon and each of us found a common thread of hope, miracles and the wonderful chance to share and support each other," said Eleanor. "It is our hope to continue meeting and be able to include others who were unable to come this time."

Billie Baldwin will be the coordinator for the next Arizona meeting.

Information about Novartis and Gleevec

Novartis, maker of Gleevec, maintains a Gleevec telephone hotline for U.S. patients and doctors. Phone 877-453-3832, weekdays from 8:30 a.m. to 5:30 p.m. EST.

Novartis AG is one of the largest health care businesses in the world, with core businesses in pharmaceuticals, consumer health, generics, eye care and animal health.

In 2000, Novartis businesses had

collective sales of \$17.2 billion and a net income of \$3.9 billion. The businesses invested approximately \$2.4 billion in research and development.

Novartis is headquartered in Basel, Switzerland. Novartis companies employ about 70,000 people in more than 140 countries.

— Novartis, www.novartis.com.



Pictured at the March 2 Southern California, U.S.A. gathering are, in back from left, Vadim Schukin*, Bobbie Offen, Henry Offen*, Wayne Edwards, Jackie Edwards*, Pat Thomas*, Henrietta Olson*, Barbara Bruce*, Wayne Bruce, Cindy Dunigan* and Lee Kirk; in front from left, Floyd Pothoven*, Natasha Schukin, Joyce Pothoven, Gary Kirk*, and Steven Friedman* (* GISTers).

Big turnout at Southern California meet

The second Southern California area gathering of the Life Raft Group took place Sunday, March 2, at the Lakewood home of Life Rafter Floyd Pothoven.

People came from a 100-mile radius to attend, from San Diego to the south, north as far as Santa Ynez, and east as far as the Palm Springs area, reports Floyd.

“We had a great time getting to know each other and swapping sto-

ries,” says Floyd. “We went around the room and everyone related their past medical history with GIST.

“It certainly seems common that few people know the disease is present until something fairly drastic happens or it is discovered by chance.”

Vadim Schukin and Steven Friedman were relatively new to the disease and were interested in finding out all they could, said Floyd. “Cindy [Dunigan] and Henrietta [Olson] were our only repeats from the first get-

together, so we had lots of new faces.

“It was great fun and we will do it again in a few months,” he said. Several additional people were planning on coming but couldn’t make it for one reason or another.

Anyway, says Floyd, “judging by the e-mails I’m getting, it was well worth the effort. My 9-year-old granddaughter, Kelsey, and her friend, Megan, acted as hostesses at the beginning of the meeting and got us all off to a good start.”

Some Internet sites with information for patients and caregivers

National Cancer Institute:
www.nci.nih.gov/
 American Cancer Society:
www.cancer.org/
 Oncolink — Cancer information for professionals and lay persons:
www.oncolink.upenn.edu/
 CancerNet:
<http://cancernet.nci.nih.gov/>

Pub Med — free searches of U.S. National Library of Medicine:
www.ncbi.nlm.nih.gov/entrez/query.fcgi
 CancerNet: PDQ - NCI's Comprehensive Cancer Database
<http://cancernet.nci.nih.gov/pdqfull.html>
 Cancer Information and Support Net-

work: <http://www.cancer-info.com/>
 Medscape Oncology Home Page
<http://www.medscape.com/Home/Topics/oncology/oncology.html>
 American Society of Clinical Oncology: <http://www.asco.org/>
 National Coalition for Cancer Survivorship
<http://www.cansearch.org/>

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Who are we and what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization providing support through education and research to patients with a rare cancer called GIST (gastrointestinal stromal tumor). The Association of Cancer Online Resources provides the group with several listservs that permit members to communicate via secure e-mail. Most members are being successfully treated with an oral cancer drug Gleevec (Glivec outside the U.S.A.). This molecularly targeted therapy inhibits the growth of cancer cells in a majority of patients. It represents a new category of drugs known as signal transduction inhibitors and has been described by the scientific community as the medical model for the treatment of cancer.

How to join

GIST patients and their caregivers may apply for membership free of charge at the Life Raft Group's Web site, www.liferaftgroup.org or by contacting our office directly.

Privacy

Privacy is of paramount concern, and we try to err on the side of privacy. We do not send information that might be considered private to anyone outside the group, including medical professionals. However, this newsletter serves as an outreach and is widely distributed. Hence, all newsletter items are edited to maintain the anonymity of members unless they have granted publication of more information.

How to help

Donations to The Life Raft Group, which is incorporated in New Jersey,

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We are patients and caregivers, not doctors. Any information shared should be used with caution, and is not a substitute for discussion with your doctor.

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