Dear Diary: To the brink and back

Quiet onset of 'terminal' cancer and how Gleevec has rewritten the story

By Ilkka Ovaska

ear Diary, April 2001: Just returned home from Toronto. Had a great time with grandchildren. They really like to climb and jump all over me. They must think that I am one big, walking trampoline or something! Those last dives actually hurt my tummy; I better be more careful next time.

May 2001: That's funny, my tummy is still sore from the loving treatment delivered by the kids! My seatbelt really digs in when I go over those potholes and the truck bounces a little. Maybe I'll give my GP a call.

Hey, that was quick. I got my ultrasound appointment in record time and

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Battling gastrointestinal stromal tumor



September 2003 In memory of Maryann Klein, Pat Ford

Vol. 4, No. 9

Symposium to focus solely on GI cancer

January meeting will offer in-depth look at latest in research, care

astrointestinal cancer will be the sole focus of a symposium planned Jan. 22-24 in San Francisco.

The first Gastrointestinal Cancers Symposium will be offered by the American Society of Clinical Oncology (ASCO), the American Gastroenterological Association (AGA), the

American Society for Therapeutic Radiology and Oncology (ASTRO), and the Society of Surgical Oncology (SSO).

The comprehensive educational and scientific program will address issues related to the treatment of gastrointestinal cancers from a multidisciplinary perspective and is intended for individuals with clinical or research interests in the evaluation and management of these cancers.

See SYMPOSIUM, Page 4

Fund-raising drive planned for Thanksgiving



Meeting in Detroit were fund-raising committee members, from left, Jerry Knapp, Allan Tobes, Norman Scherzer and John Poss.

Life Raft Group committee meets in Detroit, will appeal to patients and physicians in coming months

he Life Raft Group fund-raising cochairmen John Poss and Gerald Knapp convened a fund-raising planning group Sept. 13 in Detroit, Michigan. Present at this planning session, in addition to Poss and Knapp, were Allan and Kendra Tobes, Ellen Rosenthal, Tom Overley, Norman Scherzer and Tricia McAleer.

The outcome was the planning of a fund-raising campaign to be launched just before Thanksgiving that will mark the miracle of the drugs that have kept

See FUND-RAISING, Page 5



Ilkka Ovaska is seen Christmas Eve, 2001, just months after starting Gleevec. The young lady in the picture is his daughter, Sirpa, "who was such a helping angel during my difficult times of darkness," says Ilkka.

About Ilkka Ovaska and family:

he Ovaska family lives a few miles outside the city of Thunder Bay, on the edge of Ontario's wilderness, in a house Ilkka built in the mid-'70s, "Moose, deer and an occasional black bear wander through the back yard," says Ilkka.

In a climate where winter typically brings 4 to 5 feet of snow and the temperature can get as low as 40 below, the Ovaska home is 100 percent firewood heated. "Gives me something to do!" quips Ilkka.

Ilkka was 24 and his wife 23 when they packed up their two toddlers (son Jukka was 2 and daughter Sirpa was 1) and left their native Finland and came to Thunder Bay, where an uncle was living.

Why did they move to Canada?

"To tell the truth, we haven't been able to figure it out completely ourselves!" says Ilkka. "There was certainly no valid reason to leave Finland back in 1970. Great place, democratic country, lots of jobs, opportunities for education, etc. But — kids do the darnest things!

"Somewhere between 1970 and today we must have crossed a 'point of no return'," says Ilkka. "Life isn't always a picnic but we have grown and changed over here, and Finland and people over there have done the same — most likely in different directions. Going back has been out of the question for a long time."

The Ontario Ovaskas go back to Finland to visit family (mother and two brothers) whenever possible, "but it's so nice to return to you own cave and clan."

DIARY-

From Page 1

now they have booked a CT-scan. I am getting kind of curious. Usually it takes weeks to get these scans around here.

"What seems to be my trouble, Doctor?"

"You have a large mass in your tummy, behind the bladder. I'll better send you to see a surgeon this week."

June 2001: I'm awake, in the hospital recovery room, and the surgeon walks in.

"Well. Doctor?"

"Sarcoma. I removed a large tumor but there are numerous small ones all over your small intestine and I couldn't even start taking them all out. There is no other treatment."

"How long do I have, Doctor?" (Pause) "You won't be around in five years. Have a nice day."

Home in five days. Back to hospital next day — pulmonary embolism! Maybe this will finish me off before this sarcoma gets me!

Pathology reports came back from West Coast. They talk about something called GIST, KIT-something or another. Well, nice to know but what's the difference: no treatment.

See a cancer doctor at local cancer center. She's talking about some new drug and wants to send me to see Dr.B in Toronto to see if I qualify for the trial.

No go! I don't qualify because I do not have any measurable disease. I guess those little rascals don't show on their scans.

August 2001: Light in the end of the tunnel starts to get dimmer. I'm losing weight and starting to forget phone numbers. Napping a lot. My brother is visiting from Finland. What a great host I am!

September 2001: Voice is gone but I can entertain the family by doing my flying squirrel routine, flapping my hanging skin under my upper arms.

See MORE DIARY, Page 4

First visitors to new Life Raft office are Californians



Photo by Tricia McAleer

The first visitors to the new Life Raft Group office weren't, as you might imagine, from the East Coast neighborhood. Henry and Bobbie Offen of Carpinteria, Calif., dropped by Monday, Sept. 8, shortly after the new office opened. The Offens were vacationing, and got to meet Executive Director Norman and Anita Scherzer. Anita is seen holding a new carved wooden sign for the office, done by Life Rafter Rachel Tate.

Life Raft Group's 'legal team' meets in Boston

The Life Raft Group "legal team" met July 23 at the Boston office of Life Rafter and attorney Dean Gordanier, partner in Testa, Hurwitz & Thibeault LLP, which has taken on the Life Raft Group on as a pro bono client.

The meeting was held to discuss approaches to designing a GIST tumor bank that would make it possible for patients to obtain better access to information derived from clinical research performed on their own donated tissue while also complying

with existing laws and regulations.

At the meeting were associates Andrew Barofsky, Matthew Aufman and Karen Hansen, Life Raft Executive Director Norman Scherzer, and partners Gordanier and Deborah Birnbach.

SYMPOSIUM: Narrow the focus, increase the quality

From Page 1

Leading experts in the fields of diagnostic imaging, gastroenterology, medical oncology, radiation oncology, and surgical oncology will serve as speakers and presenters at the symposium, which will provide a first-of-its kind forum for the exchange of ideas among the subspecialists who treat patients with gastrointestinal cancers.

Dr. S. Gail Eckhardt, co-chairperson of the symposium, said the decision to create a disease-specific meeting reflects ASCO's commitment to expanding its educational offerings and tailoring programs to fit the particular needs of its members.

"The 2004 Gastrointestinal Cancers Symposium enables us to focus more intently within a disease site," says Eckhardt, associate professor of medicine and director of the Developmental Therapeutics Program in the Division of Medical Oncology at the University of Colorado Health Science Center in Denver. "A lot of times at larger meetings, we try to do too much, and it diffuses the quality of the material being presented. A smaller format with a multidisciplinary focus allows for more one-on-one collaboration and interactions between physicians from

Quote:

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- Dr. S. Gail Eckhardt

different specialties."

The symposium will offer educational sessions on different type of gastrointestinal cancer, with a day each devoted to upper gastrointestinal (esophageal and gastric) cancers, pancreatic and hepatobiliary cancers, and colon and rectal cancers. Within these

divisions, experts will present three general sessions each day: one focusing on the latest in the prevention, screening, and diagnosis of the featured disease; one addressing multidisciplinary management; and one highlighting translational research, molecular therapy, and therapy for advanced disease.

Dr. Bernard Levin, AGA representative on the steering committee who'll speak on "Risk-Based Screening and Surveillance for Colorectal Cancer," believes that ASCO and the collaborating societies are breaking innovative ground with a multidisciplinary symposium dedicated solely to the study and discussion of one set of cancers and their treatments.

"This symposium should become the standard after which other approaches to patient care are modeled," Levin says. "The more complicated the clinical situation, the more a multidisciplinary approach is and should be required."

Abstracts for the symposium are being accepted. For details and registration information online, see http://www.asco.org/ac/1,1003,_12-002144-00 18-0029923,00.asp

MORE DIARY: Remarkable recovery in three months

From Page 2

What, they don't think its funny?

Who's that guy in the bathroom mirror? I know, he's called Jolly Roger. I have seen his picture on flags. Where is that light disappearing?

Tried again to get on the Gleevec trial in Toronto: Don't qualify, you're too sick!

Sept. 28, 2001: Miracle out of the blue! Canadian approval for Gleevec came out this week and I am holding my first capsules in my bony, trembling hand! Hey, that light is on again!

Oct. 5, 2001: My son and some

friends are installing a new heating system for the house. I'm still weak but the brain is working and I can supervise. Who needs that stupid cane anyway!

I can't believe how fast this Gleevec started working! I'm feeling great! I hope it's not all in my imagination.

Dec. 24, 2001: Family is here and I AM HERE. I made it so far. Santa brings me a music cassette. First piece starts: "This is the first day of the rest of my life and I'm gonna spend it better than yesterday." I think I'll start

listening to this every day.

January 2002 to June 2002: Six CT scans, one ultrasound and one MRI. All clear, they tell me. I talk my surgeon into taking a peek inside my tummy with a laparoscope. Result: little rascals are still there but in smaller numbers than two years ago. I take this as positive news; Gleevec seems to be working. I'm feeling great and keep taking my 400 mg. every day, high noon, rain or shine. I keep humming: "This is the first day"

Cancer can be beaten!

Southern California Life Rafters gather

os Angeles area coordinator Floyd Pothoven again hosted a gathering of Southern California Life Rafters at his Lakewood home on Sunday, Sept. 7.

"We all had a great time," reports Floyd. "As usual we all told our various stories, some were similar, but in general we all had our different ways of discovering the predicament we find ourselves in.

"It was good to see several new faces this time — except for the reason they were there, of course.

"I think the thing that impressed me the most from the meeting is the great lengths some spouses will go to help the one afflicted," Floyd adds. "The depth of research and the common usage of the Web by all was most impressive."



Pictured from left are Vadim Schukin, Dina Wiley, Natasha Schukin, Glen Wishon, Beverly Wishon, Henrietta Olson, Art Olson, Paul Eddy, Gary Kirk, Lee Kirk, Peter Henning, Judy Henning, Joyce Pothoven and Floyd Pothoven.

FUND-RAISING: It will aid in reaching patients, doctors

From Page 1



Fund-raising committee members got to sit in on the monthly meeting of the Detroit chapter of the Life Raft Group held at Gilda's Club. Executive Director Norman Scherzer is seated on the couch to the right of Life Raft Group general counsel and Detroit member Tom Overley.

so many Life Raft Group members and other GIST patients alive.

The campaign will also focus on the urgent need to respond to increasing drug resistance, and to reach the many GIST patients and their doctors around the world.

The strategy will be to launch a two-pronged approach. The first will ask Life Raft Group members to reach out to 10 others in their circle of family and friends to ask for their financial assistance. The second will be an appeal from Life Raft Group members who are also physicians to the many professionals around the world who are working with GIST patients.

"We have never before asked medical professionals to contribute financially to the Life Raft Group," said Scherzer, "and are hopeful that they will respond generously."

Loyola doctors focus on STAT3 signaling

Science may be key to figuring out therapy for Gleevec-resistant GIST

By Jerry Call Life Raft Science Coordinator

octors at the Loyola University Medical Center are helping to define signaling that occurs downstream of KIT in GIST patients. Since some GISTs are resistant to Gleevec, understanding downstream signaling might provide additional effective therapies for GIST patients.

It is likely that a combination of different drugs may someday prove to be more effective than a single drug in treating GIST. We are starting to see some of these "cocktail" mixtures move into clinical trials.

A team of doctors — Gladell Paner, Simone Silberman, Grace Hartman, Kenneth Micetich, Gerard Aranha and Serhan Alkan — recently published an article about GIST signaling in the journal "Anticancer Research." This article provides an analysis of the JAK2/STAT3 pathway in GIST.

The Loyola team studied tumors from 11 c-kit positive GIST patients. They found that STAT3, a protein downstream from KIT, was constitutively activated in all 11 cases. To further study the effects of STAT3 activation, the team generated two primary GIST cell lines from tumors with exon 11 mutations. They then exposed these two cell lines to several inhibitors including inhibitors of c-kit (Gleevec), JAK2 (AG490), MAPK (PD98059) and PI-3K (LY294002).

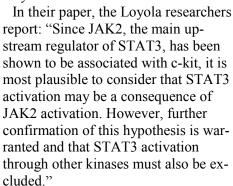
The results:

- •Gleevec (c-kit) -greater than 95 percent inhibition of cellular proliferation.
- •AG490 (JAK2)-82 percent inhibition of proliferation with evidence of apoptosis (cell death).

- •PD98059 (MAPK)-partial inhibition of proliferation, but no evidence of apoptosis.
- •LY294002 (PI-3K)-a slight increase in absorbance compared to control cells, indicating no inhibition, and rounding of the cells, but no apoptotic bodies.

The results for Gleevec are not surprising; it remains the gold standard for treating GIST. What was somewhat surprising, to this reporter, was how effective AG490 was. While STAT1 and STAT3 have been identified as

being part of the KIT pathway (see slide 15 from a presentation by Dr. Jonathon Fletcher given at the London GIST conference, at http://liferaftgroup.org:8185/medical/LondnPPT/Fletcher/Fletcher_files/frame.htm), this paper provides some quantification of how important the STAT3 pathway may be in GIST.



Dr. Serhan Alkan, associate professor of pathology at Loyola, says that AG490 is not ready for use in patients. It has not even been tested in animals at this time, but identifying likely drug targets are an important first step.

Alkan's research focus is in the field of hematological cancers (Hodgkin's disease, non-Hodgkin's lymphoma, multiple myeloma, and leukemia). Because c-kit and STAT3 is important is some of these cancers, Alkan was interested in evaluating these pathways

in GIST, since KIT signaling is so prominent in GIST.

This is another indication of the disproportionate interest in GIST (compared to its frequency of occurrence) due to its interesting biology. Since GIST cell lines are not readily available, Alkan created two GIST primary cell lines. These are different than immortal types of cell lines, in that they are only viable for a limited number of cell divisions. This allowed the Loyola team to perform these experiments.

According to Alkan, lack of access to GIST cell lines is the largest obstacle to more GIST research of this kind. Alkan goes on to add, "No functional or physiological questions can be answered from frozen cells, for more comprehensive work you need cell lines."

While there may not be any currently available drugs targeting either JAK2 or

STAT3, the Loyola team also found that bcl-2 was expressed in all 11 of the GISTs they studied. Bcl-2 inhibits apoptosis and therefore prevents tumors from dying. They found that there was a marked reduction in Bcl-2 expression in the GIST cells following treatment with AG490 compared to control (untreated) GIST cells.

Clinical trials of Gentasense, a drug that targets Bcl-2 will soon start at Dana-Farber. In these phase I trials, Gentasense will be given in combination with Gleevec.

The work of the Loyola team provides further rational for the use of drugs that target Bcl-2 in GIST, and drugs that target JAK2 or STAT3 when they become available. These drugs would be an addition to the current primary strategy of inhibiting KIT (or PDGFRA in some cases). Inhibit-



Dr. Serhan Alkan

GIST'ers strike rich friendships at The Nugget



A small gathering of GIST patients and caregivers met Wednesday, Aug. 27, at The Nugget restaurant in Summerland, south of Santa Barbara, California, once a favorite of President Ronald Reagan and staff. Pictured from left are Wayne and Barbara Bruce, Cindy Dunigan, Richard Palmer and his mother, Elizabeth, and Henry and Bobbie Offen.

Walk for a Cure slated Oct. 19 in New York

he Third Annual GIST
Walk for a Cure will take
place Sunday, Oct. 19 at
Rockland Lake State
Park in Congers, New York.

The walk was started and is organized by Tania Stutman and her husband, Robert, to raise money for GIST research. To date their efforts have resulted in the following grants: \$15,000 to Dr. Robert Maki of Memorial Sloan-Kettering Cancer Center, New York; \$10,000 to Dr. George Demetri at Dana Farber Cancer Institute, Boston; \$10,000

to Fox Chase Cancer Center, Philadelphia, and \$15,000 to Oregon Health & Sciences University, Portland.

Robert Stutman recently voiced enthusiasm about the support being generated for this year's walk. Novartis, the maker of Gleevec, has given generously to the walk in past years, and the Stutmans hope to add another major corporate sponsor this year, in addition to businesses that previously supported the walk, including Rockland Cardiology and White Plains Dodge.

Dozens of members of Phi Sigma Sigma from Muhlenberg College of Allentown, PA, have made the walk one of their sorority projects this year.

Registration will start at 9 a.m. with the 3-mile walk around the lake to begin at 10 a.m.

All contributions are tax deductible (EIN 13-4182988) and will be used for GIST research.

Tania can be reached at (845) 634-6060 or via e-mail at tania5kids@aol.com, or at 55 Saw Mill Rd., New City, NY 10956.

Patricia Ford, 48, was a teacher's aide in Polo, III.

Patricia A. Ford, 48, of Polo, Illinois, U.S.A., died Saturday, Sept. 6, 2003, in the University of Wisconsin Hospital at Madison.

Patricia was born March 18, 1955, in Palmdale, Calif., the daughter of James Woodrow and Dixie (Wheeler) Smith. She married Bradley D. Ford on May 9, 1988, in Las Vegas, Nev. Patricia worked as a teacher's aide for the Polo school system, and was a



Pat Ford

member of First United Methodist Church in Polo. Survivors include her husband, Bradley; son, David Ford; daughter Laura Ford; and mother, Dixie

Smith, all of Polo; a brother, James R. (Jene') Smith of Winfield, Kan.; and

two nephews.

Services were held Sept. 10 at the First United Methodist Church with the Rev. Bonnie Davies officiating. Burial followed at Oakwood Cemetery in Dixon, Ill. Preston-Schilling Funeral Home of Dixon was in charge of arrangements. A memorial has been established at the First United Methodist Church, 105 S. Congress Ave., Polo, Il 61064.

Maryann Klein, 56, participated in 3 clinical trials

Maryann (Bono) Klein, 56, of Utica, New York, U.S.A., died Thursday, Sept. 4, 2003 at Faxton Hospital with her family by her side.

Born Sept. 28, 1946, in Ilion, NY, Maryann was the daughter of Fanny (Paratore) Bono and the late Salvatore "Leo" Bono. She graduated from Frankfort-Schuyler Central High School in 1964, she obtained her associate's degree in business at the Utica School of Commerce. She married Gary A. Klein on Aug. 9, 1975.

Maryann was an administrative assistant with United Cerebral Palsy for six years, until GIST forced her retirement in 1999. Previously she was employed with ICL Computer Components and with General Electric.

In the face of her illness, her faith

never wavered but became more steadfast. Maryann maintained a positive attitude toward her life, toward her illness, and toward the obstacles she faced. She fought for her life and for the ability to live that life in a purposeful manner, one that might someday lead to a cure for others. She willingly and courageously volunteered to par-

See KLEIN, Page 9

In Memoriam

There have been 29 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 Betsye, 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 Aiclinn

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.

Michael Cornwell, April 19, 2002, husband to Cathy.

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.

Abdul Hai, 76, Feb. 26, 2003.

William Lawson, 56, July 3, 2003, husband to Gwen, father of Cory, Jennifer and Rhonda.

Laura Blanchette, 47, Aug. 4, 2003; wife of Mitch, mother of Sarah and Curtis.

Maryann Klein, 56, Sept. 4, 2003; wife of Gary, mother of Michelle, grandmother to Brandon.

Pat Ford, 48, Sept. 6, 2003; wife to Brad, mother to David and Laura.

Memorial gifts benefit the Life Raft

he never had a chance to become a member of the Life Raft Group, but the friends of Ester Lucas have nonetheless given to the Life Raft in her memory.

Last month, Esther's co-workers at CheckFree Corp. in Owings Mills, Maryland, U.S.A., made a \$685 donation to the Life Raft.

"Through all of her suffering with GIST these past five years, Esther made every moment count," wrote co-worker Susie Kanow in a letter to the Life Raft Group. "She never thought of herself first. She came to work each day and managed to keep her illness to herself."

"Esther would have been so happy

to know that more than 30 associates attended her memorial service."

"I would be very honored if you would accept these funds with Esther in mind. My only regret was that we discovered the Life Raft Group too late to help Esther," Kanow added. "May all of your research, time and efforts help the next Esther."

Frank Novelli didn't even have GIST, but his son-in-law does. Ken Lundell of Chicago is a GIST patient and Life Raft Group member. When Frank died recently, Ken and Corrine Lundell requested donations to the Life Raft Group in lieu of flowers.

Last month, Corrine Lundell wrote to the Life Raft Group and enclosed a check for \$200 representing the donations of seven family and friends. "An additional 23 to 25 envelopes were taken home with people," she wrote. "We anticipate more donation will follow."

Norman Scherzer, executive director of the Life Raft, confirmed that the group has since received a number of donations.

"In both situations, friends and family thought of the Life Raft Group," he said. "Their caring and concern is a wonderful testament to their loved ones. We salute that memory, and thank them for their compassion."

KLEIN: Husband, daughter, grandson among survivors

From Page 8

ticipate in several clinical studies on cancer cures. She was on the phase II trial of Gleevec for GIST, the phase I Sugen trial, and was the second patient on the Gleevec+RAD trial, all at Dana-Farber Cancer Institute in Boston.

She is survived by her beloved husband of 28 years, Gary; her daughter and son-in-law, Michelle and Paul Williams of Utica, N.Y.; and her grandson, Brandon Williams, who was

the light of her life, her little buddy and playmate. Maryann is also survived by her mother, Fanny Bono of Frankfort; a brother and sister-in-law, Salvatore "Sam" and Cindy Bono of Herkimer; and her sister and brother-in-law, Anna and Ronald Smithson of Frankfort; many nieces, nephews, great-nieces, great-nephews, and cousins. She was especially close with Shari and Joey Scarafile, the children of her late sister, Rosalie.

Maryann also enjoyed the love and loyalty of her canine companions, Carmella, Brandi and Sassy.

The family offers its sincere gratitude to the third floor staff at Faxton Hospital for their care and dedication. Thanks is also extended to Drs. Brownstein, Ferraro, Butala, Kussin, Gibs, Garramone and Demetri.

Services were Sept. 9 at the Church of Our Lady of Lourdes, followed by interment at Carr Cemetery in Marcy.

LOYOLA: Several downstream targets may be key

From Page 6

ing KIT signaling would still be the most important part of therapy, but in some cases inhibition of one of these secondary targets may add to the therapy.

It should be noted that the downstream targets discussed here are not the only targets being explored in GIST and they may not even turn out to be the most important targets. Other important downstream targets include the AKT/mTOR pathway and PKC. Other important downstream pathways that have been shown to be important

in KIT signaling in non-GIST cells, pathways such as PLCgamma, are conspicuously absent in the literature on GIST (although PKC is typically in the PLCgamma pathway in non-GIST c-kit pathways). It remains to be seen if they play any part in GIST.

THE LIFE RAFT GROUP

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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. Many 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. Several new drugs are now in clinical trials.

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 articles 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, incorporated in New Jersey, U.S.A.,

Executive Director Administrative Assistant Chief Financial Officer IT Director General Counsel Accountant List Manager Newsletter Editor Science Coordinator Web Master Fund-raising co-chairmen

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as a 501-c-3 nonprofit organization, are tax deductible in the United States.

Donations, payable to The Life Raft Group, should be mailed to:

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We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. As for the newsletter, every effort to achieve accuracy is made but we are human and errors occur. Please advise the newsletter editor of any errors.