

# Life Rafter doesn't let cancer slow him down

With an MBA, a Harley and a love of bicycling, ALF aims to stay active

By Alan L. Fink

I went in for minor surgery in September of 2000. I had herniated my umbilicus while doing sit-ups. When the incision was made to do the repair, a large tumor was discovered — explaining why my abdomen was getting bigger regardless of the number of sit-ups I was doing.

They took samples for biopsies and transferred me from the one-day surgery center directly to the hospital. After three days of tests, I was sent home. I had a follow-up with a local oncologist; he gave me little hope and began working on referring me to another hospital. He suggested Johns Hopkins or Memorial Sloan Kettering. The only type of treatment he knew of was opening me up, taking out the tumor and part of the intestine, pouring in chemo and letting it stay for a few hours, then putting me back together.

I did not really like his ideas, so my friends and I searched the Web for other treatments. One of the places that looked promising was the hospital at the University of Pennsylvania. I vis-



**Alan Fink logs miles on his bicycle, which helps minimize the effects of Gleevec.**

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Battling GIST with Gleevec (STI571)



## LIFE RAFT GROUP

January 2003 In memory of Cynthia Whitson, Kathy Colwell Vol. 4, No. 1

## After one setback, LRG accomplishments grow

Life Raft's first annual report details successes, plans for the future

By Norman Scherzer,  
Executive Director  
The Life Raft Group

The Life Raft Group has been a legal, non-profit organization for only seven months or so, having received this status June 10, 2002 (we were actually notified of this July 16, 2002). We opened our office Sept. 23, 2002. Two weeks later we suffered our first setback when thieves stole all our office computers. This set us back operationally about a month. It also

taught us some valuable lessons about office security (new door, locks and alarm system in place) and about data backup (daily tape backup system in place with a redundant, offsite server to be put in place).

The office is now functioning, staffed by a full time executive director, a part-time administrative assistant and a very part-time integrated technology director. We have an internal computer network and are close to completing our basic administrative data bases, including all LRG members, medical professionals, newsletter distribution lists and donor lists. We have assumed responsibility for dis-

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## GIST patients help researchers zero in on the origins of cancer

Oregon Health Sciences University seeks patent on possible advance

By Joe Rojas-Burke  
The Oregonian

By studying a rare abdominal tumor, researchers in Portland, Oregon, have zeroed in on a likely new

target for treating cancer: a protein that acts like a broken switch to spur cells into runaway growth mode.

The discovery raises hopes for finding another drug like Gleevec — the pill that targets an aberrant signaling protein to fight cancer without the brutal side effects of chemotherapy. Researchers at Oregon Health Sciences

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# Annual Report

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tributing our newsletter and for processing new members. We are planning to increase our support for managing donations, for the Web site and for our medical data base.

Our core group of volunteers is growing in scope and currently includes a newsletter editor (Richard Palmer), Web master (Gary Golnik), list manager (Mia Byrne), Science Team leader (Jerry Call), medical librarian (Linda Martinez) chief financial officer (John Poss), general counsel (Tom Overly), accountant (Roberta Gibson), Los Angeles area coordinator (Floyd Pothoven), Chicago area coordinator (Dick Kinzig), Detroit area coordinator (Alan Tobes) and country representatives in the UK (David Cook), France (Bertrand de la Comble) and Switzerland (Ulrich Schnorf). Combined with our board of directors (Stan Bunn, president; Bernie Kaplan, treasurer, and directors Mike Matthews, Gary Golnik, Rodrigo Salas and Sylvia Williams), this has created a formidable leadership team.

We continue to maintain two closed lists, one for our general membership and one for our Science Team. We also continue to publish a monthly newsletter and have been expanding its readership to an increasing number of laypersons and medical professionals. We are planning a further significant expansion, particularly in our international readership.

Our international development is well underway, with more than 18 countries represented. To move this to another level, I am creating an international planning group to work with me in developing appropriate guidelines and procedures. I expect to call upon country representatives Bertrand de la Comble, Ulrich Schnorf and Dave Cook, newsletter editor Richard Palmer and several board members to assist in this planning effort.

Similarly, our local area develop-



**SCHERZER**

ment is also beginning to evolve. I expect that our local chapters in the greater Chicago, Los Angeles and Detroit areas will serve as models for other new areas to

come. I will be working with Dick Kinzig, Floyd Pothoven and Alan Tobes to build upon their experiences.

A critical new program that has evolved is the provision of real time consultation support, most of it by telephone, to LRG members and other GIST patients seeking help with medical and financial issues. This number continues to grow, with eight persons

## Quote:

**“Our international development is well underway, with more than 18 countries represented.”**

— Norman Scherzer, on efforts to expand the Life Raft Group’s international outreach

assisted in November and 13 in December. To date we have handled six appeals from members who had been denied financial assistance, and we have succeeded with five thus far.

Behind the scenes, a number of discussions have taken place to create a tissue bank that would focus on finding the reasons for resistance. I shall be working closely with Marina Symcox to complete this important project. These discussions are consistent with other behind-the-scenes networking with key Novartis and clinical doctors that continue to evolve.

We have begun the process of strengthening the interactive and medical content of our Web site and will focus on this initiative in early 2003.

Jerry Call and David Josephy will take the lead in helping to expand the medical content. Jim Roy, our IT director, has begun programming a new, online, interactive membership application. Administrative Assistant Tricia McAleer and I have scheduled meetings with the coordinators of Novartis U.S. and international Web sites to discuss collaborative efforts. Gary Golnik, our Web master, and I will work closely together to provide overall coordination to these initiatives.

Another priority will be the strengthening of our medical data bases. There has been some confusion about this project. Much of this is based upon a misperception as to what a medical data base actually is. First and foremost, it is not a single focused work project with a defined time line. Instead, it is a series of content management tools for helping us to assess problems and guide our decision making. It includes developing an international directory of sarcoma/GIST doctors (there is no board certification for such a specialty; how does one define what such a specialist is?), monitoring the longer term side effects of Gleevec and, most importantly, identifying the longer term patterns of resistance that are evolving. It also includes identifying potential new drugs and compounds, new clinical trials, and new “straws” needed to keep our members alive in the interim.

Some of this data is available in a timely way from traditional sources and, when that is the case, there is no need for us to duplicate it. Some we need to develop on our own. When we do, we shall continue to ensure that any data we collect meet the highest professional and scientific standards. That means that it must be accurate, statistically significant, timely and relevant.

The fact that we have the capability

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## ALF

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ited an aggressive surgeon named Dr. Doug Fraker. He suggested surgery to remove the tumor, some small intestine and, while they had me open, try a new clinical procedure called photodynamic therapy (PDT).

Dr. Doug introduced me to a radiation oncologist, Dr. Steve Hahn. Between the two doctors, an entire surgery plan was mapped out at my first visit.

The surgery was performed at the end of November 2000. A 12-pound tumor was removed along with 2 feet of small bowel and 200 little seed tumors, followed by the PTD. The PTD uses different wavelength lasers to burn off tumor cells. It involved taking a drug that made my entire body sensitive to light. The drug made the tumor cells more susceptible to the laser treatment.

The major drawback was I had to stay out of the sun and avoid bright lights. After the surgery I spent six weeks covering up my body while going outside and dimming every light in the house. At least it was December! I felt like the invisible man — I was covered from head to toe whenever I went outside.

One afternoon I was driving and forgot my gloves. Both hands blistered from the sunlight. At work I would sit with gloves on so the computer monitor did not burn my hands.

It was a long six weeks but a friend bought me the tape, “Abbott and Costello Meet the Invisible Man,” and that cheered me up.

During my July follow-up exam, a few new spots were found in my abdomen — a small one in the liver and three in the lower abdomen. I was referred to Dr. James Stephenson. Dr. Jamie started me on the STI571 clinical trial in August of 2001. I was one of the last people on the trial and was assigned the 800 mg. dose.

At my October 2001 follow-up, one



**Here's Alan in New York City, with the rubble of the World Trade Center in the background. Alan worked there for two weeks following the terrorist attacks of Sept. 11, 2001, to put phone service back into lower Manhattan.**

tumor in my lower abdomen was gone!

During my January 2002 follow-up, another tumor in lower abdomen was gone!

The small spot on my liver and a small spot in my lower abdomen have stayed stable since August of 2001. So far, so good!!

I started riding my bicycle in July of 2000. Dr. Stephenson suggested that the exercise might help reduce some of the side effects of the treatment. A friend had given me Lance Armstrong's book, “It's Not About the Bike.” I said if Lance can ride, I can ride!

I started by rebuilding my 20-year-old bike from college and rode around the neighborhood. One mile leads to 5

miles, then 10 miles. Before long I was riding five days a week, about 10 miles a day.

I bought a new bicycle in August and set my sites on riding in the local MS 150 Bike to the Bay at the end of September. I was riding almost 125 miles a week getting ready. The MS 150 is a 75-mile ride from upper Delaware to Dewey Beach on Delaware Bay and then back the next day. It was tough but extremely worth it. I completed the ride and also raised almost \$1,000 for MS! Two weeks later I rode in a 62-mile ride for Habit for Humanity! It felt great!

In 2002, I set my sites on several other rides. I rode in the following:

- The American Cancer Society

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## Report: Keeping GIST at forefront

From Page 2

to do this, and to disseminate what we learn through our newsletter, has created an extraordinary leverage for the Life Raft Group in relating to the medical and research community.

I will be submitting a proposed budget for 2003 to the Board of Directors. Having spent many years working on budgets, it is often hard to determine which comes first: the anticipated level of funding or the needed level of activities. We have been quite fortunate so far to have received a generous startup commitment from Novartis backed by some significant individual contributions. We are working to develop a viable plan for raising funds. We must match \$50,000 for the second part of the Novartis grant. We will then need to move beyond that to sustain and to expand our activities.

We have been a key participant in an ad hoc national coalition of cancer support organizations and pharmaceutical companies working together to try to reform Medicare to provide coverage for oral cancer drugs like Gleevec. Currently only intravenous cancer drugs, or oral drugs that began life as IV drugs, are covered.

We have achieved a level of recognition way beyond our small numbers. In May 2002, we convened our first membership meeting in Cambridge, Massachusetts, U.S.A., and were joined there by Dr. Daniel Vasella, the CEO of Novartis, Dr. Edward Benz, president of Dana-Farber Cancer Institute, Dr. George Demetri of Dana-Farber, a principal investigator for the Gleevec trials, and Gilles Frydman, president of the Association of Cancer Online Resources. Three days later I found myself on the podium with Dr. Vasella and U.S. Sen. Ted Kennedy, along with a number of distinguished guests, at the opening of Novartis new research facility in Cambridge. In June I was the only non-doctor invited to attend the National Cancer Institute's

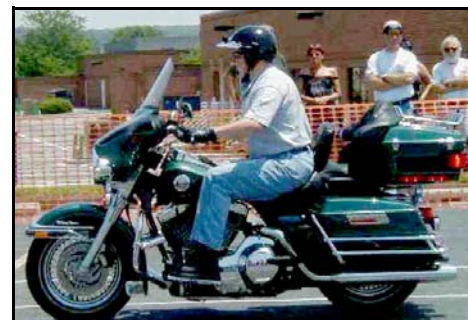
State of the Science Meeting for Sarcoma in Rockville, Maryland. In September I had the privilege of speaking to 450 European physicians gathered in London at the first medical conference focused on GIST and Gleevec. In November I gave a presentation to some 200 U.S. sarcoma specialists at the Connective Tissue Oncology Society meeting in San Francisco, California. I was joined at this key meeting by Jerry Call, our Science Team leader. A few weeks later I participated on a panel at the American Medical Informatics Association in San Antonio, Texas. In the past few weeks I have been asked by the American Society of Clinical Oncology to serve as a consultant regarding their Web site and by Novartis to participate in an summit meeting in Switzerland of key international cancer patient groups. The two other U.S. cancer support organizations represented are Cancer Care and the Leukemia-Lymphoma Society. Word has just reached us that the Life Raft Group will be invited to provide a booth at ASCO's June meeting in Chicago and to attend a reception there of key patient organization leaders.

As important as the visible roles we have been privileged to play at these critical meetings are the opportunities this has provided to network key researchers and clinicians to learn what is going on with regard to GIST treatment and to attempt to influence the continued identification of new drugs and compounds that may play a role in overcoming Gleevec resistance. This is an outgrowth of a strategic decision to focus our very limited resources on existent drugs and compounds as opposed to trying to raise and contribute small amounts of money toward very expensive and very long-term research to develop new drugs, a process that can take many more years than some of our drug-resistant patients have.

The point of all this, of course, is not

personal or organizational fame but increased leverage with the research and medical communities in promoting and accessing medical care.

I hope that I have contributed to that. To any extent that I have, it is largely due to the support and inspiration of some extraordinary people in this group, and also to the incredible human being I am married to, who awes me with her quiet courage and determination. Finally, it is risky to choose but one out of our many volunteers for special recognition, but I have to cite one such person — Richard Palmer, whose monthly labor of love in producing our professional newsletter has given a voice and a human face to the Life Raft.



Alan cruises on his Harley-Davidson.

## ALF

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Bike-a-thon in July (62 miles);

— The Lancaster Covered Bridge Ride in August (62 miles);

— The MS 150 Bike to the Bay in September (150 miles in 2 days);

— The Salisbury Metric Century in October (62 miles);

The side effects of Gleevec have been the usual but minimal for me. The more I ride, the fewer problems I have with the chemo. I'll keep riding!

I'm 43 years old with a wife, Betty, and two kids; Jessica, 21, and Matthew, 13. I have an MBA and ride a Harley. I'm not very typical, but I'm having fun. I do spend time talking to other cancer patients. My goal is to prove to people that you can still lead an active life!

## OHSU

From Page 1

University have filed for patent protection on the new findings and said they have signed a contract with an undisclosed drug company to pursue new treatments.

“We predict these mutations will be found in other cancers,” said lead investigator Dr. Mike Heinrich, an associate professor at OHSU and the Portland Veterans Administration Medical Center. The study was published Jan. 9 on the Web site of the journal *Science*.

“I think they are probably right,” said Julie Cherrington, a scientist and vice president at Sugene, a biotechnology firm in South San Francisco that has developed a drug for GIST now in early clinical trials. She said the study will probably spark an all-out hunt for the mutations in other tumor types. Sugene was not involved in the new study, but the company has an ongoing relationship with Heinrich and colleagues at OHSU.

The discovery wouldn't have been possible without the cooperation of patients with a rare form of cancer, called a gastrointestinal stromal tumor, or GIST. Fewer than 10,000 such cancers are diagnosed each year in the United States. Patients typically die within a year or two of diagnosis.

Less than five years ago, researchers in Japan identified the genetic defect responsible for more than 85 percent of cases. It produces a broken signaling protein called KIT. The drug

Gleevec, originally developed for leukemia, has proved helpful in treating many patients with GIST because the KIT protein is closely related to the defective protein that causes chronic myeloid leukemia.

But the cause of 15 percent of cases was never accounted for. And nobody could explain why some patients respond to Gleevec while others do not. “The search has been on to find what may be driving those tumors,” Cherrington said.

The OHSU researchers joined with Dr. Jonathan Fletcher of Harvard Medical School to solve the problem. Fletcher's lab had developed a powerful new method to detect proteins that are abundant and active in a tumor. The test revealed a signaling protein called PDGFR alpha. The OHSU scientists compared normal gene sequences with the PDGFR genes from their sample tumors. The comparison revealed seven mutant sequences. Further tests proved that the mutated genes caused cells to produce defective signaling proteins.

“We are the first to show that these types of mutations can activate the gene,” said Dr. Christopher Corless, an associate professor at the Portland VA and OHSU, and a co-author of the study.

Cherrington said the work could lead to new treatments for GIST — and for more common forms of cancer. Faulty signaling in the PDGFR pathway has already been implicated in a number of malignancies, from cancers of blood cells to solid tumors of the brain and other organs.

“It's likely that PDGFR mutations are playing a role in other types of cancer,” she said.

Sugene has already developed a drug called SU11248 that targets PDGFR alpha and two closely related signaling proteins, called KIT and FLT3. In an early phase clinical trial — intended

## Quote:

**“For the most part, we still classify cancer using technology and systems from the 1800s — light microscopes and where the tumor was found.”**

— Dr. Mike Heinrich, lead investigator and associate professor at OHSU

primarily to test safety and tolerability — the agent shrank tumors in a small number of patients. Cherrington said Sugene is beginning a second phase of studies in a variety of solid tumors including GIST.

Other important questions remain unanswered. Researchers still can't account for the cause of about 5 percent of GIST cases. It's not yet clear whether cases with PDGFR mutations will require different medical treatment than tumors with the more common KIT mutations. Heinrich said tumors with PDGFR mutations should respond to treatment with Gleevec.

“We're trying to figure out if different types of mutations might respond differently,” for instance, requiring higher drug doses, he said.

The work highlights how cancer care is evolving rapidly toward a new model based on the genetic profile of a tumor.

“For the most part, we still classify cancer using technology and systems from the 1800s — light microscopes and where the tumor was found,” Heinrich said. In the future, he said, the choice of treatment will rely far more on the determination of what genes are active in a tumor.

*From the Jan. 10 issue of The Oregonian. Reprinted with permission.*

## Quote:

**“The search has been on to find what may be driving those tumors.”**

— Dr. Julie Cherrington, scientist and vice president at Sugene

## Canadian Life Rafterers gather in Guelph, Ontario

On Saturday evening, Oct. 5, Life Raft Group members from Ontario, Canada, gathered at the house of David Josephy in Guelph, an hour's drive west of the city of Toronto.

Attending were Sheila and Al Murphy from Jordan Station, near Niagara; Jeannette Scobie from "a little place called the Presqu'ile, near Owen Sound," which is a few hours' drive north of Guelph; Lee Cousins from Milton (close to Toronto), and Linda Hampson from Toronto.

"We spent the evening together, eating most of a turkey, and thereby stealing a one-week head start on Canadian Thanksgiving," said David. "All the guests brought dishes to make it a pot-luck dinner."

Some of the group had met previously. "The conversation never slowed down," reports David. Topics paralleled those that regularly appear on



**Life Rafterers from Ontario, Canada, at the home of David Josephy. They're pictured, from left, Sheila and Al Murphy, Jeannette Scobie, Lee Cousins and Linda Hampson.**

the e-mail forum. Also discussed were issues affecting Canadians, including doctors and health insurance.

"Everyone agreed that it is better to meet in person than on the Internet," said David.

## Davises become first Life Rafterers to visit LRG office

Terry Davis didn't let a cold stop he and Claire from being the first Life Rafterers to visit the LRG office in Totowa, New Jersey.

Here's how Terry tells it: "I had a consult with George Demetri of Dana Farber, which went very well. It was originally set for Dec. 4, 2002, however, his office called and wanted to move it up to Dec. 2. So my wife and I decided to drive up and visit her brother in Connecticut.

"I caught a cold the night of Dec. 2 and stayed longer than planned. I called Norman and told him I would try to stop by to see him. He was also trying to get over some sort of bug. Well, Dec. 4 after a late start I called Norman and told him I would stop by. I must have given him at least 10 minutes warning. He, in his misery, gave me directions, and soon we were there (good directions!).



**Terry and Claire Davis were the first Life Rafterers to visit the LRG office in Totowa, New Jersey. They're shown with Executive Director Norman Scherzer.**

"We got out of the car just as Norman pulled in, coffee in his possession. It was cold and coffee was inviting. He showed us the Life Raft office and told us that we were the first visitors, what a surprise. It was nice talking to him and Trish, the office was

nice and proper for a group our size. It has a nice view and large windows.

"Well, we left just before rush hour in New Jersey," Terry says. However, "the next day we went through the ice storm that hit Charlotte, North Carolina. Just to make travel interesting."

# Kathy Colwell tells of her 100,000 friends

'My life could be longer, but in no way could it have been better'

By Kathy Colwell

I'm lucky, not because of cancer, but because I have one hundred thousand friends. Each of you is a best friend. Every short visit, talk, letter, meeting, and laugh is in my memory, and I think back and smile, and laugh, and sometimes cry.

You all know who you are. My devotion to you never dwindled or faded. My only regret is that I can't write down every little thing — but all of my hundred thousand friends can pull up at least one good time, or thought, and remember for me. Won't those air waves from here to heaven twitch and fizzle, spark and send vibrations sky-rocketing up to God and my many guardian angels?

I can hear the laughter increase exponentially. It's all good, positive strength and I want it set loose so that others can share some of the greatest things I have experienced. I have had way more than my fill.

I read something yesterday—that it is not holding on to something that is so hard; it is harder to let it go.

So here it goes.

I have traveled the United States and most of the world. I have met so many wonderful people and pets. I have ridden horses on Carmel Beach. I have spent hours watching my beloved brothers playing baseball, and sometimes just the drive home — with Mom and Dad, Mike, Dave, Steve, Dan and I in the car, with the family dog, Navy blue baseball uniform windbreakers snapping in the breeze from the station wagon window — has been the best part of the fading day.

I have the most loving, devoted partner in my husband, Tom. And my three gorgeous healthy, funny, smart, proud, independent kids. A beautiful

**Kathleen Theresa Francis Powers Colwell** of Olathe, Kansas, U.S. A. died Jan. 5, 2003 at her home, surrounded by family. She was 45. Services were held at Prince of Peace Catholic Church.

Kathy was born July 30, 1957, at Fort Benning, Georgia, the daughter of Col. John and Dortha Powers, of Carmel, California. She graduated from Santa Catalina School for Girls in Monterey, California, and from the University of California at Santa Barbara. Kathy married to Thomas G. Colwell Jr. on June 4, 1987. She spent nine years serving her country in the United States Navy, and more than 12 years in the insurance industry, in both California and Kansas.

In addition to her husband of 15 years, she is survived by her daughters, Katherine, 14, and Mary, 5, a son, Tom III, 12; her parents and brothers Mike, Dave, Steve and Dan Powers.

Kathy was a selfless, fun-loving,



wonderful mother and wife who will be dearly missed by her family and friends. In lieu of flowers, Kathy requested memorial contributions be made to The Life Raft Group, 555 Preakness Ave., Level Two East, Suite 2, Totowa, NJ 07512, to help other patients in their battle with GIST.

home in a beautiful state. I've had great jobs, a work ethic I will never let go of. My life could be longer, but in no way could it have been better.

I always seemed to be the one who laughed the loudest, stayed up the latest, ate the most, pushed for just "one more," wanted to win one more game. The leader most times, but recently seeing that it's OK to let others take over and carry the torch for me, even for a little while. I have so much trust in my heart now, which is something I have learned from Tom and Tom's family, and my own family of brothers. And it's great to sit and rest for just a little while.

I have been so happy in the Midwest, and something about the change of seasons has touched me, and has given me an understanding of life that I

couldn't learn in a book.

A year ago in October, when Tom and I got the initial diagnosis of cancer, I was afraid that I wouldn't have time for a lot of little things that needed to be done — but I do remember asking God if He thought one more year of seasons was too much to ask. I wanted to see the snow and have Christmas with Kate, Tommy, and Mary. I wanted to see my mother-in-law's spring plants in her backyard, and think of the endless orchids my own mother has in tubs at the side of her house in Carmel. I wanted to spend another warm summer with my wonderful friend Marianne, at her house, and go swimming and teach Mary how to swim, and to have margaritas and

# Founding member Cynthia Whitson, 64

**C**ynthia Griffin Garrett Whitson of LaGrange and Orange Beach, Alabama, U.S.A., died Sunday, Jan. 19, 2003, at her home. She was 64.

Mrs. Whitson, born Feb. 10, 1938 in Jackson Miss., was the daughter of the late William Paxton and Vivian Scott Griffin. She was a 1956 graduate of LaGrange High School and attended South Georgia College. She was a member of First United Methodist Church of LaGrange and Orange Beach United Methodist Church. She assisted in the operation of The Sign Shop for 22 years and was formerly employed with West Georgia Health Systems and LaGrange Moulding.

She was one of the founding members of the Life Raft Group, and started one of its offshoots, the Christian support group of Life Rafters.

Survivors include her husband, Jerry Whitson of LaGrange; a son and daughter-in-law, Steve and Missy Garrett; a daughter and son-in-law, Jill and Scott Hale; a stepson, Randy Whitson, a stepdaughter and her husband, Donna and Keith Lankford, all of LaGrange; six grandchildren, Shelly and Lindsey Garrett, Holeigh and Pax Herrin, Laura Hale and Gunner Lankford; a sister and brother-in-law, Sue and Bill Goodwin; nieces, Catherine Goodwin of Pine Mountain, Ala-



**Captured during a happy moment at the first Life Raft Group gathering in May 2002. At left, Cynthia Whitson with husband, Jerry; standing next to Cynthia is Dr. George Demetri of Dana-Farber Cancer Institute, with Marina Symcox at right. Seated next to Jerry is Maryann Klein with husband Gary.**

bama, Virginia Lovell of Pace, Florida, and Laurie Reece of Canton, Alabama; and aunt and uncle, Clara and Charles Birdsong of Winter Haven, Florida, her in-laws, Mr. and Mrs. Thomas Whitson of Coker, Alabama; a sister-in-law, two brothers-in-law, and several nieces and nephews.

Funeral services were held at Hunter-Allen Myhand chapel with the Revs. Helen Henry and Richard Brooks offi-

ciating. Entombment was in Shadowland Mausoleum.

Contributions may be made to Orange Beach United Methodist Church, Canal Road, Orange Beach, AL, 36561 or the GIST Research Fund, Dana-Farber Cancer Institute, 44 Binney St, Boston, MA 20115, or the Mary Will Thompson Sunday School Class of First United Methodist Church of La Grange.

## Meetings set in Michigan, Arizona, California

Regional meetings of Life Raft Group members have (or were) slated in Michigan, Arizona and California.

First is the Michigan Life Raft Group, which slated its second meeting Saturday, Feb. 1 at Gilda's Club house in Royal Oak.

Gilda's Club is located at 3517 Rochester Road, phone 1-248-577-0800. Their facility is just north of 13 Mile Road on the west side of Rochester Road.

Coordinator Alan Tobes has arranged for a deli tray at about noon and the meeting to begin about 12:30 p.m.

"I'm looking forward to seeing all of you who have previously contacted me as well as any other member, caregiver or family member associated with a GIST patient," he says.

For more information, e-mail Alan at atobes@comcast.net

The next meeting will happen in Scottsdale, Arizona, on Friday, Feb.

21. Those interested in meeting fellow Life Rafters and caregivers should contact Linda Martinez on or before Feb. 7. Linda, the Life Raft Group's medical librarian, can be reached via e-mail at Linda.Martinez1@cox.net

Also, Floyd Pothoven is organizing another meeting at his home in Lake-wood, Los Angeles area. Tentative date in Sunday afternoon, March 2. All are welcome; for information, e-mail Floyd at floyd@lasersealer.com



## 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.

## 100,000 friends

From Page 7

laugh and laugh. I wanted to see the autumn with my favorite colors, and have a Halloween party, and feel cool fresh air on my face, and wear hats and scarves and sweaters, and eat the extra candy, and think of costumes.

God not only gave me this year of seasons, he gave it to me in a big way. He handed me more than a full year, and it was a beautiful, pain-free year. I could work, I could do things around my house. I spent many extra minutes holding hands with my beautiful baby Mary, and brushing her hair and getting her ready for tea parties, and listening to her stories. I laughed for hours with Kate and Tommy, and went over funny stories when they were little. I was able to write them letters, their own little books, of how they were as babies, and things I want them to remember. Not too sad, because there are so many happy and fun things to think about. I let them know what is important to me, what I want them to keep in mind as they grow up, some good books to read, how to treat others, how to work hard and earn

## Quote:

**"God not only gave me this year of seasons, he gave it to me in a big way. He handed me more than a full year, and it was a beautiful, pain-free year. ... I'm sorry I won't be around for a lot, but I am also very grateful that I was here at all ."**

— Kathy Colwell

what they deserve.

I'm sorry I won't be around for a lot, but I am also very grateful that I was here at all. Everyone has such a good

start on the first part of their journeys — and the seasons help us move the journey into a plan.

Every night before I close my eyes, I tell Tom and Kate and Mary and Big Tom how much I love them. But when my eyes close, and I say good night to God, and thank him for my day, and all the good that came from that day. I can really rest, and fall asleep, and trust in anything that happens next.

Sometimes, I even look forward to my next journey — as hard as it is to let go of this one.

I love you all. Remember me, and at least one story. I promise it will find me again, and I will grab the opportunity to recount the story to maybe one angel that hasn't heard it yet — and you will hear us cracking up, maybe sneaking a small glass of champagne behind cloud.

Listen for a little rain on the window sill, the drop of a spring flower on a patio board, a dry leaf rustling across a playground in the wind, a snow flake melting on your eyelash. It's me, laughing, and thinking of you.

# 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. 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](http://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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## Disclaimer

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.

As for this newsletter: read at your own risk! Every effort to achieve accuracy is made, but we are human and errors occur. Please advise the newsletter editor of any errors.