Battling GIST with Gleevec (STI571)



November 2002

In memory of Nora Shaulis, Chet Duszak Vol. 3, No. 10

Life Raft gleans facts at oncology meeting

By Norman Scherzer Life Raft Group **Executive Director**

erry Call, our Science Team Leader, and I attended the Connective Tissue Oncology Society meeting held Nov. 1-2 in San Francisco, Calif. CTOS is an international organization of physicians specializing in the family of cancers called sarcomas, of which GIST is a part.

For those of you who do not know Jerry Call, let me tell you that he is one of the smartest people I know. Jerry is a self-taught scientist with the incredible ability



Norman Scherzer addresses the Connective Tissue Oncology Society meeting.

to understand and articulate complex scientific issues affecting GIST.

The following report is based upon a combination of our notes,

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Foundation helps by providing Gleevec

Max Foundation offers help to GIST patients outside North America

By Michael Josephy

Readers of this newsletter and, especially GIST patients outside North America, should be aware of the services offered by the Max Foundation. This foundation offers Glivec to patients with GIST who qualify.

The Foundation was established in 1996 with the mission of improving the lives and survival rates of children of Hispanic origin who suffer from leukemia. Subsequently its mission was broadened to include people of all ages and backgrounds with blood related cancer. It is dedicated to the memory of Maximiliano M. Rivarola from Argentina who died of leukemia at the age of 17.

It is responsible for the admini-

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Glivec-chemo combinations warrant study

Pre-clinical studies identify novel ways to enhance chemotherapy

FRANKFURT, Germany — Researchers have found that blocking the action of a growth factor on tumour stroma cells increases the uptake of cancer drugs by the tumour. The findings could be crucial for efforts to make standard chemotherapy work better.

Kristian Pietras of the Ludwig Institute of Cancer Research in Uppsala, Sweden, has shown in animal studies that inhibiting plateletderived growth factor (PDGF) signaling increases the tumour uptake

of cytotoxic (cell-killing) drugs two- to five-fold. There was no increase seen in the levels of cytotoxic drugs in normal tissue.

Treatment studies with Glivec (imatinib), which blocks PDGF signaling, in combination with either of the cytotoxic drugs

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CTOS: Three new drugs may work against GIST

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recollections and meeting abstracts. It is subject to human error and should be read with appropriate caution. We have tried to achieve a balance between clarity and scientific detail, but have not always succeeded.

I had the opportunity to make a 20-minute presentation to the conference on the experience of the Life Raft Group. If you would like a copy, please write to me privately (nscherzer@liferaftgroup.org). You will need Microsoft PowerPoint to open it; it is basically the same as the one I gave in London.

CTOS is a relatively new organization and is, to the best of our knowledge, the only medical organization focusing upon sarcomas, It is poorly funded and loosely organized, but getting stronger in such areas as scientific exploration and collaboration. I have asked the secretary of the CTOS Board of Directors, Dr. Robert Benjamin of M. D. Anderson Cancer Center in Houston, Texas, U.S.A., for their membership list and permission to post it to the Life Raft Group Web site. Dr. Benjamin seemed agreeable. If we are successful, this will give us an international directory of sarcoma specialists, something GIST patients have long sought.

The agenda of the meeting, including its posters (posters are scientific exhibits set up in a separate room for meeting participants to review) was broad based and only a very small part of it focused upon GIST or Gleevec. The topics were often tough for the layperson to follow (even one as bright as Jerry). An example: "Antisense Inhibition of Hyaluronan Synthase-2 in Hu-

man Osteosarcoma Cell Line, Mg-63, Inhibits Hyaluronan Retention and Tumorigenicity of the Cells." The talks began at 7:30 a.m. and ended late in the day.

The general sarcoma highlights that may have some relevance to GIST included:

- A report demonstrating the reliability of ultrasonagraphy in detecting chest wall sarcomas (Italy).
- A report that PET scanning is

Quote:

"The [Gleevec] trials continue and preliminary reports are that the activity of Gleevec in GIST is long lasting. We would caution that these reports are based on the one-year mark."

 Norman Scherzer, Life Raft Group executive director, reporting on the CTOS meeting held in San Francisco

not useful for detection of lung metastases (U.S.A.).

- A report that centralization of treatment in specialty centers improves survival, local control and patient care (U.K.).
- A report that a positive surgical margin is associated with a higher risk of local relapse but not necessarily with survival (U.S.A.).
- A report comparing doxorubicin and ifosfamide in treating advanced or metastatic soft tissue sar-

- comas, concluding that for the majority of patients for whom single-agent chemotherapy is appropriate, doxorubicin remains the drug of choice (Belgium).
- A report that for radiation treatment of sarcomas of the pelvis, proton beam technology is predicted to yield a higher proportion of patients who are rendered tumorand complication-free (U.S.A.). Note: this technology is quite expensive and not available at most medical centers.
- A report that adjuvant therapy with Gleevec may be useful in c-kit negative soft tissue sarcomas where there is an activated form of AKT. AKT is a cytoplasmic serine/ threonine kinase, which is a common target for RTK phosphorylation, thought to be alternative targets for the RTK inhibitor, Gleevec).

There was little new presented on GIST. The trials continue and preliminary reports are that the activity of Gleevec in GIST is long lasting. We would caution that these reports are based upon the one-year mark

Most of what we learned about GIST took place in informal sessions with a number of key sarcoma experts, including Dr. George Demetri of Dana-Farber Cancer Institute in Boston, Dr. Margaret von Mehren of Fox Chase Cancer Center in Philadelphia, Dr. Robert Maki of Memorial Sloan-Kettering in New York City, Dr. Mary Lou Keohan of Columbia-Presbyterian Medical Center in New York City and M.D. Anderson's Benjamin (there were many more we had

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Bernie, the 'On Again, Off Again Man'

When Judgment Day comes six or seven times a year

By Bernie Kaplan

am a GIST patient being treated for my cancer with Gleevec at Dana Farber Cancer Institute in Boston. I began Gleevec on Jan. 31, 2001 and am continuing my normal activities.

My administrative assistant at work is a warm, thoughtful person who has followed my progress as a cancer patient with great care and interest. She herself is a caregiver for her husband who suffers from various heart difficulties. When I recently returned from my latest periodic checkup in Boston, she was keenly interested, as usual, in hearing the results.

Two years ago I was diagnosed with GIST, for which no effective treatment existed. Fortunately, Gleevec became available. My case is unusual, however. I have reacted well to the drug but a side effect has been elevated liver enzymes. The potential damage to the liver has forced the doctors to take me off the drug periodically until the liver enzymes go back to normal. Off the drug or with too low a dosage, however, some of my GIST tumors grow rapidly.

Dr. George Demetri, my oncologist, reduced my dosage to a quarter of the normal dose (100 mg) to try to achieve a balance. Miraculously, in my case, the drug is usually effective at a low dosage while allowing the liver enzymes to be near normal.



Photo by Paul Zalewski, RavenwoodPhoto.com

That's Bernie Kaplan, right, with his wife, Bracha, and Dr. Dan Vasella, the president and CEO of Novartis, maker of Gleevec. The Kaplans got to meet Vasella at the Life Raft Group gathering held in Boston last May.

One day my assistant asked me to describe my feelings when my wife and I waited for the doctor to enter with the results on our trip to Boston. I asked her twice if she was prepared to hear the truth. I then described to her that we were in a state of panic, we were trembling, we didn't know who was going to enter — whether it would be the Angel of Death or the Angel of Life!

Each of the several times in the last year that I underwent scans and tests it invariably felt as if I was experiencing the Day of Judgment —who will live a full life and who not. I always carry a book of Psalms with me to the waiting room.

I have learned that my reaction is normal. One woman in my cancer support group is in remission from breast cancer for more than 20 years. Nevertheless, she reports that each time she goes for her bi-annual checkup she still experiences terrible fears. This type of reaction is common among cancer patients as well as their caregivers. Another friend's wife is taking the same medicine as me. The week before her tests, the husband goes into a total panic.

On my visit last summer, thank God, the Angel of Life walked through the door. "Awesome, stupendous" were the words of the smiling doctor. He told me I could take future blood tests less often and come back to the hospital after three months rather than one month.

Believe it or not, even good news takes time to fully accept. Sometimes this adjustment period is measured in days or even

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More CTOS

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brief interactions with). I continue to be pleased and impressed with the candor and cooperation that these experts accord to the Life Raft Group.

New drugs

RAD: The new Novartis drug called RAD (RAD001) appears to be on track (though these tracks can never be fast enough for GIST patients) and has cleared the federal regulatory pre-clinical-trial hurdles. It is now awaiting approval from Dana-Farber's review board and our best guest is that trials for his new drug are about two months away in the U.S. (probably at Dana-Farber), but are getting underway now in Belgium.

This drug targets a component of the mTOR (mammalian target of the drug Rapamycin) pathway, which is one component of the AKT pathway (a downstream pathway in KIT signaling). Pre-clinical experiments (in vitro experiments in chronic myelogenous leukemia) have suggested that targeting downstream components of Bcr-Abl, including the mTOR pathway, have resulted in greater effectiveness than Gleevec alone. So this drug would be given in combination with Gleevec.

Note's Jerry Call: "An existing drug, Rapamycin, already targets this pathway. Analogs of Rapamycin are being developed. I believe that the reason an analog of a drug might be developed (not necessarily in direct relation to GIST or Gleevec interests) is that it might be either more efficient than the parent drug, and/or less toxic than the parent drug. In theory, it would

be possible that Gleevec and Rapamycin could be given together in an off-label indication, if you could find a doctor willing to do that.

Toxicities or effectiveness of this combination are unknown."

One Life Raft Group GIST patient is being treated by his physician with a combination of Gleevec and Rapamycin. It is too soon to evaluate its effectiveness.

Genasense: Talk is underway with the biopharmaceutical company Genta about a trial combining Gleevec with Genasense. Genesense works by inhibiting the production of Bcl-2, a protein made by

Quote:

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— Jerry Call, Life Raft Group
Science Team leader

cancer cells that blocks chemotherapy-induced cell death. As a result, it may enhance the effectiveness of treatments like Gleevec. It is beginning clinical trials for Gleevecresistant chronic myelogenous leukemia. Remember that this drug is just in the discussion stage: there is no clinical trial on track yet for GIST.

Note by Jerry Call: "This antisense drug reduces the amount of Bcl-2 mRNA (part of the instructions to manufacture the Bcl-2 protein). In theory, this drug should tip

the balance between pro- and antiapoptosis proteins towards more apoptosis (cell death). Trials with this drug have been conducted in melanoma, however, I am not aware of the results, other than it did seem to reduce Bcl-2 protein levels."

Levels of cooperation (or at least intent to cooperate) seemed high at the meeting between Europeans, Canadians and Americans. There was, however, a general concern regarding the difficulty in overcoming government "over-regulation." Many medical professionals feel that government has swung so far towards the side of protecting "patient rights" that it is very difficult to get things done. In particular, it is difficult to get much help from the National Cancer Institute due to bureaucratic obstacles, and it is difficult for the U.S. to collaborate/share trials with Europeans (and presumably Canadians as well).

SU011248: The new Sugen drug SU011248 has been in phase 1 clinical trial at Dana-Farber for several months. Preliminary information (take this information with great caution; this is a phase I trial designed to measure drug safety levels, not effectiveness) is that a significant number of GIST patients not responding to Gleevec do respond to this drug in combination with Gleevec. It would be reckless at this point to assign a public statistic to the term "significant." A new trial is to begin shortly at Memorial Sloan-Kettering. One is also expected in Canada, but we were unable to get any information about start dates there.

There is also a note of concern raised by the fact that Sugen has

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Life Rafter finds hot fishing spot — in the Amazon

he 19-pound peacock bass is impressive enough, but the location where John Poss caught it is even more impressive — the Jufari River, a tributary of the Amazon.

Poss, treasurer of the Life Raft Group, has a group of friends who go on fishing trips around the world. "They invited me to go on this one earlier this year and I said 'why

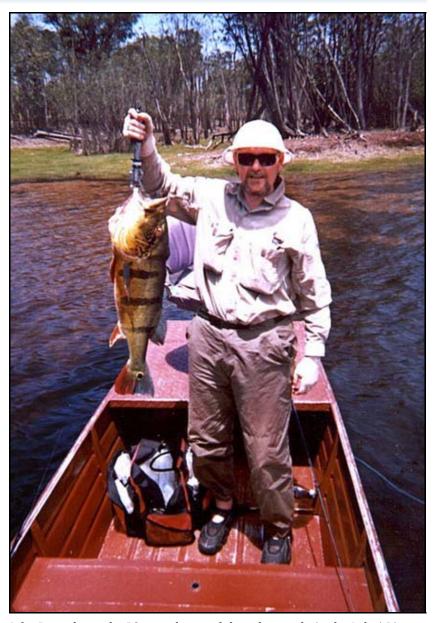
not?"

Poss asked his clinical trial physician, Dr. George Demetri, if he thought it was OK to go off into the Amazonian jungle for seven days. He said, "John, we developed Gleevec so you could live. So go live."

"It sounded like excellent advice," says Poss, "so I went on the trip."

This section of the Jufari is two hours by float plane from Barcelos, the closest civilization, in the heart of the jungle.

"The trip was fabulous," reports Poss. "We flew to Manaus, then to Barcelos, then by float plane for a couple of hours to the Jufari River. We slept in tents on pontoons floating



John Poss shows the 19-pound peacock bass he caught in the Jufari River.

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More CTOS 2: Much is learned behind the scenes

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been bought by Pharmacia, which in turn has been bought by Pfizer. The new research and marketing bureaucracies may change the focus of interest in certain drugs.

We found that the most cuttingedge information is often best obtained via behind-the-scenes professional networking. We are getting new reports of GIST resistance to Gleevec; not enough to panic, but sufficient to galvanize our energies to, 1) identify new, existing drugs and compounds (we cannot wait the 10-plus years it takes to develop brand new drugs) and, as important, 2) to influence the decisions of drug companies in bringing new drugs to trial and to market. I was concerned, for example, that Novartis was not represented at the CTOS meeting and I am fol-

lowing up to find out why.

Our bottom line issue with every researcher must be: what are you doing to overcome current and potential resistance to Gleevec? It is becoming increasingly clear that GIST will ultimately be treated by a combination of drugs, not just Gleevec alone.

We must make sure that these arrive on time.

Combinations

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5-fluorouracil (5-FU) or paclitaxel, or with the experimental drug, EPO906 (epothilone B), have also been completed. In all cases the combination therapies induced better anti-tumour effects in the animals than the single treatments with chemotherapy alone.

The increase in effect occurred without any signs of increased toxicity.

The findings could lead to changes in the way some drugs are used in combination chemotherapy regimens. Studies in patients will be needed to determine whether these novel combinations can improve the lives of patients with some cancers.

"If our findings in animal tests hold up in patients, then we are definitely on to something that could explain why some cancers are more treatable in one type of patients than another and this would be very important," said lead researcher Dr. Arne Östman of the Ludwig Institute.

"We therefore look forward very much to the results from the patient study that we hope to start around the beginning of next year."

Östman spoke Nov. 20 at a news briefing at the Symposium on Molecular Targets and Cancer Therapeutics in Frankfurt, sponsored by three groups, the European Organisation for Research and Treatment of Cancer, the National Cancer Institute and the American Association for Cancer Research.

"There are two types of beneficial effects one can envisage if one could improve drug uptake in tumours — either the same therapeutic effect as now with a reduced dose of drug and reduced side effects, or better therapeutic effects with the maximum tolerated dose."

PDGF receptor expression in the tumour stroma, and high IFP, may occur in many types of tumours, including those of the breast, colon and lung, so the findings could have potential application in a range of common cancers. "If future clinical trials based on these experiments show the same results that we have seen in animal models, then we have identified a new and possibly widely applicable strategy for improving drug treatment for cancer patients," said Östman.



Fishing

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in the river. Each day, they would move the camp further up the river, so we never fished the same waters twice.

"We visited a village where the people literally lived in grass huts. They had a small school room, and a teacher that came for a few months each year," Poss says. "We were very impressed with the village, so when we got back, eight of us who were on the trip contributed to buy an encyclopedia in Portuguese and had it shipped to the village, Villa do Caju.

"We saw quite a bit of wildlife, including many caymen (alligators)," Poss adds. "I also caught several piranha, as well as four other kinds of fish with teeth — and I mean serious teeth. We didn't see any anaconda, although the whole area looked very 'snakey."

"The fishing was pretty intense. We'd leave early in the morning, fish until noon, then have lunch on the banks of the river. Our guides would then hang a hammock so we could take a nap. Really tough going, but somebody has to do it."

Bernie

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weeks. It is difficult for others to understand this reaction, which I personally ascribe to a type of post-traumatic stress syndrome. Even knowing all this, I can still assure you that the day I go back for my next tests will again be Judgment Day.

Postscript: Since writing this

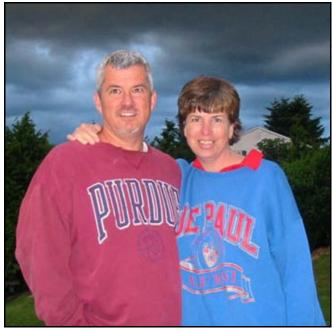
article, Bernie's dosage was increased to 200 mg a day to deal with growth of some of his tumors. The middle of November, he had to stop taking Gleevec due to elevated liver enzymes. Thanksgiving week, the enzymes were down significantly and Bernie, the "On Again, Off Again Man," was back on Gleevec.

Nora Shaulis: Faith never failed her

n Aug. 8, 1960, President Eisenhower called upon Congress to ratify a civil rights bill. The State Department warned that Cuba's relationship with the Soviet Union posed the "gravest danger" to the hemisphere. Wilt Chamberlain became the highest paid professional athlete in signing with Philadelphia Warriors. But to James and Mary Parker, the most important thing in the world was the birth of their little girl, Nora Dale.

Nora and her siblings, Jan and Jimmy, were raised and nurtured in a family of faith. Her parents had served God all their lives. Her sister has been a missionary to Japan. Nora's uncles and aunts served as ministers and missionaries. Serving God and his people was Nora's way of life.

After graduating from high school



David and Nora Shaulis, pictured this past July 4th.

in 1978, Nora entered Carson Newman College in Johnson City, Tenn., and began a ministry that took her to Lake Placid, New York; Camp Smokey in Gatlinburg, Tenn.; Ledyard, Conn.; Biloxi, Miss.; Corpus Christi, Texas; and

Virginia Beach, Va. In January 1986, Nora began attending seminary in Louisville, Ky. She also served in a youth ministry, traveling throughout the western U.S., Alaska and Hawaii, and in Japan, Korea and Taiwan. Upon graduating from seminary Nora returned to Japan to serve alongside her sister, Jan. With all of her traveling, it isn't surprising that Nora met David Shaulis on a plane flight Dec. 21, 1989. Nora and David both say it was "love at first sight."

David was working in Portland, Oregon, and Nora was serving the Wilsonville

Baptist Church in Portland as their director of Community Ministries. They were married Aug. 15, 1992 at the 110-year-old Frog Pond Church outside of Wilsonville, Ore. Their son, Griffin, was born

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In Memoriam

There have been 20 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 Aislinn.

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

Jonathan Montague, 23, Jan. 19, 2001, 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, husband to David, mother to Griffin.

Max Foundation

From Page 1

stration of the Glivec International Patient Assistance Program (GIPAP), sponsored by Novartis for CML and GIST patients around the world. They say it is the most generous and far-reaching drug donation program ever developed for a cancer therapy.

My wife, Elsie Hernandez, may not be typical, but let me tell you about her case briefly. She was diagnosed with and operated for leomyoblastoma here in Costa Rica in 1984. Much later, in 2000, a routine medical check-up sent her to surgery again, and a diagnosis of GIST.

Some rapid research on the internet led us to Norman Scherzer and the Life Raft Group, and from there to the Glivec clinical trial at Columbia-Presbyterian Hospital in New York City with Dr. Mary Louise Keohan. Elsie stayed several months in New York, and then returned quarterly until the trial closed.

Last July she got her last consignment of Glivec in New York, and we were left to scramble for a new source. Like most people we cannot afford to buy the medication over the counter.

In Costa Rica there is a national health system (the CCSS), and we applied to have it provide Glivec, only to be turned down. The CCSS has a limited budget and their administrators find excuses to reject expensive therapies.

So we applied, via the Web, to the Max Foundation, and received a positive response just as Elsie's Glivec reserve was running out.



Elsie Hernandez, pictured with her husband, Michael Josephy, was able to get Glivec through the Max Foundation. The foundation aids GIST patients outside North American who need Glivec but don't have insurance.

At this writing they have provided her with a month's supply (at 800 mg daily), and we hope they will continue to do so. The physician in the local Novartis office has been a great help in our application, and we're glad she has taken a personal interest.

Others who may need this resource should look up the foundation's Web site at http://www.themaxfoundation.org/ or The Max Foundation, 110 W Dayton, Suite 205, Edmonds, WA 98020, U.S.A., phone 425-778-8660, toll free: 1-888-462-9368, fax: 425-778-8760. They will only cover GIST (or CML) patients outside the U.S.A. who have no insurance coverage for Glivec.

First of all, the patient's hospital must fill in an application to be a recognized clinic, and then the physician must apply for each individual patient on their behalf. One must report one's medical history, diagnosis, insurance coverage (if any) and salary. All the relevant forms can be found on the foundation's Web site.

Shaulis

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Jan.11, 1998.

Last March, Nora was diagnosed with cancer. After battling her disease with courage and faith, Nora died Monday, Nov. 4, 2002. A memorial service was held Nov. 6 at Washington Cathedral in Redmond, Wash. Nora had the opportunity to say what she wanted said and sung. Her surviving loved ones related the words for her.

First, Nora wanted to say, "Life is more precious than you realize." When you lose life, you see more powerfully how wonderful life is. Nora would say, "live life to the full." Life is not about work or money or stuff. Life is about God, people and relationships. Keep the main thing the main thing.

Second, Nora wanted to say, "Heaven is sweeter than you can imagine." The Bible uses human concepts and words to describe heaven. The Bible tells us that heaven has gates of pearl, streets of gold, walls of jasper. Nora would want everyone to know that heaven is simply where God is.

Therefore, don't get too attached to this world. Set your heart and affections on things that are above

Third, Nora wanted to say, "God is far greater than you know." God is always careful to not overwhelm us with his greatness. But now that Nora is no longer confined by human limitations, she is beholding the full glory of God. She is basking in the power and embrace of God's presence. Nora wanted to say, "It can't be overstated how worthy God is to receive your whole-hearted worship and praise."

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), most of whom 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 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, U.S.A., as a 501-c-3 nonprofit organization, are tax deductible in

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