

**Team FLAMES**  
will ride for a  
cure Aug. 3-4  
Last year they raised  
more than \$100,000 in  
the Pan-Mass Challenge

**T**eam FLAMES — Fast  
Legs And Minds Ending  
Sarcoma — will hit the  
road Aug. 3-4 with the  
goal of riding 192 miles across  
Massachusetts in the Pan-Mass  
Challenge.

Joan Canniff, nurse practitioner in  
the sarcoma center at Dana-Farber  
Cancer Institute and one of the dis-  
cussion leaders at the Life Raft  
Group's May meeting in Boston,  
will join 19 other FLAME team-  
mates to raise money for research  
and clinical operations at Dana-  
Farber Cancer Institute.

Team FLAMES — which last  
year raised more than \$100,000 —  
will be among 3,400 cyclists from  
across the country who aim to col-  
lect a whopping \$15 million during  
the event.

Joan pedaled in her first Chal-  
lenge last year, and has been train-  
ing long hours for her second cy-  
cling marathon. In her own words:

**See FLAMES, Page 4**

Battling GIST with Gleevec (STI571)



**LIFE RAFT  
GROUP**

July/August 2002

In memory of Todd Hendrickson

Vol. 3, No. 7

## Novartis buoys Life Raft with \$250,000 grant

CEO Vasella to Life Raft  
coordinator Scherzer:  
“I want to help you”

By **Richard Palmer**

**I**t was a most extraordinary  
offer that came at the begin-  
ning of a most extraordinary  
event, the first-ever meeting  
of the Life Raft Group.

Dr. Dan Vasella, the chairman  
and CEO of Gleevec-maker Novar-  
tis, and Life Raft coordinator Nor-  
man Scherzer were walking up the  
stairs of the Cambridge Radisson  
Hotel the evening of May 3, head-  
ing for the Fenway Ballroom  
where Life Raft Group members  
were meeting face-to-face for the

first time.

Vasella and Scherzer had just met  
face-to-face less than an hour ear-  
lier. Though they'd corresponded  
via e-mail for many months, the  
Life Raft Group meeting May 3-4,  
and Novartis' launching of a \$250  
million facility in Cambridge May  
6, had proved a serendipitous con-  
fluence that brought together the  
head of the world's 17<sup>th</sup> most valu-  
able company with a relative hand-  
ful of rare cancer patients.

Halfway up the stairs, Vasella  
turned to Scherzer, put a hand on  
his shoulder, and said: “I want to  
help you. I want to give you a  
grant.” Scherzer, surprised but not  
unprepared, told the CEO that

**See Grant, Page 2**

## A message from the Life Raft's new president

By **Stan Bunn, president**  
Life Raft Group  
Board of Directors

**T**he Life Raft Group has  
grown and evolved very  
quickly over the past  
year and a half. Our  
membership has passed the 200

mark and we are now in 13 coun-  
tries. Our membership criteria,  
which began with GIST patients in  
the early Gleevec clinical trials, has  
expanded to include all GIST pa-  
tients, regardless of clinical trial or  
treatment status. Recently we have  
seen an increasing number of pa-  
tients in trouble, who have not re-

sponded to therapy, turning to us  
for help. Many of our members  
have been pulled from the brink of  
death. Some have not made it and  
we continue to have to light too  
many candles.

We are a very diverse group and  
represent a broad spectrum of inter-

**See President's message, Page 8**

## Grant

From Page 1

would be great.

Scherzer had planted the seed a month earlier, while talking with one of his many contacts at Novartis. The Life Raft Group — once a handful of gastrointestinal stromal tumor patients on the phase II clinical trial of a drug then called STI571 — was growing. There was the need to reach patients and oncologists who hadn't heard of GIST, or Gleevec. There was talk of starting a tumor bank where the causes of resistance and relapse could be pinpointed. There was data collection, side effects management, an expanded Web site ... in all, more than volunteer patients and caregivers could handle. "We'll need help," Scherzer had told his Novartis friend.

After the Boston meeting and in the wake of much e-mail discussion, Scherzer and Gary Golnik collaborated on a list of goals and objectives that they posted to the Life Raft Group list ("LRG mission and objectives," May 31). Those goals became the grant proposal to Novartis.

And in July came Novartis' response: they would buoy the Life Raft with up to \$250,000 over two years.

Novartis agreed to give the group \$75,000 right away, and another \$75,000 if the group raises a matching sum before the end of 2002. Another \$50,000 will be given in 2003, with an additional \$50,000 if the Life Raft can match it in 2003.

Raising \$75,000 by the end of this year would have been daunting — except for the amazing generosity of one Life Raft Group member.



Photo by Paul Zalewski, RavenwoodPhoto.com

**Anita and Norman Scherzer listen as Dr. Dan Vasella makes a point during the small "icebreaker" gathering just before the first Life Raft Group dinner May 3 in Boston. It was a few minutes after this photo was taken that the chairman and CEO of Novartis, maker of Gleevec, would offer to help the Life Raft Group with a grant.**

## Quote:

**"We have to raise \$15,000 this year."**

— Norman Scherzer,  
LRG coordinator, on the amount  
needed to win \$75,000 from Novartis

Stan Bunn, whose wife, Ana Marie, was just 30 when she died of GIST April 19, donated \$50,000 to the Life Raft.

The group has taken in about \$10,000 this year in donations, Scherzer said. "We have to raise \$15,000 [more] this year."

Other than the matching sums, the Novartis grant comes with no strings attached, said Scherzer. "The grant doesn't even mention the drug Gleevec," he said. "They want to support a group that deals with issues of GIST."

Preserving the group's integrity was key, he noted. The Life Raft

Group must be free to talk about unpleasant side effects of Gleevec, the failure of the drug to work on all GIST patients, and the recent cutoff of free Gleevec to U.S. patients on the phase III NCI-sponsored clinical trial.

While there may be few Life Rafter with the wherewithal to donate tens of thousands of dollars to the group, even modest donations are needed to raise the remaining \$15,000 and secure the matching Novartis grant of \$75,000.

Checks should be made payable to the Life Raft Group, Inc. and mailed to

John Poss  
Life Raft Group Treasurer  
8507 Forest Hills Blvd.  
Dallas, TX 75218

And remember, as of June 10, all donations will now be tax deductible for U.S. residents.

If the Life Raft successfully matches the Novartis grant, the group will have raised \$375,000 between now and the end of 2003.

# A GIST patient's journey to hope

Divorced with two girls, Carol Berres' struggle was just beginning

*Editor's note: Carol Berres' story was first published in April 2001 in the Milwaukee Journal Sentinel*

By Carol Berres

It's 3 a.m. on July 3, 2000, and a violent storm fells tree branches outside. But it isn't the thunder that wakes me. It's another kind of turbulence that causes me to bolt up in my bed crying out. A searing pain tears through me.

"Is this what a burst appendix feels like?" I wonder as I double over in distress. I'm paralyzed for about five minutes before the pain begins to subside.

I am recently divorced and temporarily living with my sister, Judith, and my two daughters, Caitlin, 13, and Cassi, 4. Since I share a bed with Cassi, I lie there trying not to wake her. Eventually I drift back to a fitful sleep.

When I wake the next morning, the pain, although dull, is still there. I can barely stand up. I try to call my doctor, but the storm has knocked out the phone lines.

Judith stays home from work to watch my children so I can drive myself to the urgent care facility. I learn my white cell count has skyrocketed to 17,000; 500 to 1,000 is normal. X-rays show nothing. The doctor prescribes a muscle relaxant and sends me home but asks me to return tomorrow for another blood test.



Jeffrey Phelps photo/Milwaukee Journal Sentinel

**Carol Berres, shown at her Milwaukee home, is the first Wisconsin resident to take part in the Phase III clinical trial of Gleevec.**

The next day, my white cell count is even more elevated, and there is blood in my stool.

The on-call surgeon decides I should go to St. Joseph's Hospital for a CT scan. The experience is unpleasant, but the waiting afterward is worse. Dressed in a hospital gown with a blanket draped over my knees, I wait in a cold, empty little room. As the radiologist confers with the surgeon, the radiologist's name is repeatedly called over the speaker system.

Why isn't he answering that page? It sounds important. It's my first indication something is terribly wrong with me.

## Troubling find

The scan shows a mass nearly the size of a bowling ball growing behind my stomach wall.

It doesn't matter where you are when you first hear it — in a doctor's office, over the telephone at home, or in my case, a sterile waiting area. There is a single instant that a person with cancer will never forget: It's the moment they're told

they have the disease.

What burns this memory into our minds so intensely is not just facing mortality, but the fact that whether we are by ourselves or with a loved one, we are so ultimately alone with this news. No one can feel it the same way, no matter how close they are to us. Not a beloved spouse. Not a best friend. Not a parent.

It's our moment and ours alone, and it's the beginning of the most solitary of journeys.

For someone of my small stature — I am less than 5-foot-3 and weigh (at that time) about 128 pounds — it seems bizarre that I wasn't more aware something was wrong. There were no outward signs of this tumor except some discomfort when eating. It seemed logical to blame that on stress due to starting a new job and looking for a new home.

I am about to begin my education in complicated medical terms. "Possibly lymphoma, leiomyosarcoma, pancreatic cancer." I hear these terms but can't comprehend them.

## Another scan

A gastroenterologist is called in July 6.

"It's not a typical-looking tumor," the doctor says. "Looks like there are air bubbles in the middle. Not likely, but could be an abscess or infection, but more likely the tumor is beginning necrosis, outgrowing its own blood supply." That could be responsible for the infection. Another CT scan is ordered.

On July 7, I am released from the



## FLAMES

From Page 1

“Why did Joan — the woman afraid of sweat and dirt — pedal 192 miles, 90 percent of which was spent in the pouring rain and thunder and lightning? The answer is simple; I had no idea what I was getting myself into!

“So why then am I doing it again this year? Because I know exactly what I am getting myself into.”

Riders participating in the two-day PMC rides pledge a minimum of \$2,000, while those participating in one-day PMC rides pledge a minimum of \$1,000. The rigorous and scenic routes take riders through 43 Massachusetts towns.

Riders, some of whom are cancer



**Life Rafter Gary Golnik presents Joan Canniff with a special recognition award during the Life Raft Group meeting May 4 in Boston. Canniff will be part of the 20-member Team FLAMES riding nearly 200 miles Aug 3-4 to raise money for sarcoma research.**

Photo by Linda Palmer

survivors or riding for a family member fighting the disease, range in age from 15 to 78 years old. The average PMC cyclist is 41 years old, trains for three months, solicits

40 sponsors and raises \$4,000. During the PMC weekend, more than 1,800 volunteers donate their time while 200 corporations provide various levels of support.

## Berres: Hoping for the best, planning for the worst

From Page 3

hospital to “get things in order” before surgery, which is scheduled for the 12th. Still no results from the scan. It appears I won’t know what it is until I wake up from the anesthesia. I spend the weekend planning for the worst, calling on stunned friends to witness my signature on a will and power of attorney.

### Surgery day

I arrive at the hospital for my surgery, and the nurse hands me a gown and tells me to change.

“I think I’ll change into someone else,” I tell Judith as I step into a small room.

The surgery lasts 5 1/2 hours. When I awake, I still have two-thirds of my stomach and all but the tail of my pancreas, but no spleen. I am in the hospital for two

weeks, during most of which I can’t eat.

Leiomyosarcoma. It sounds like it should be served at a luau. But instead it was living in me. The surgeon says all the cancer has been removed. It was a large mass of 15 cm. by 15 cm. by 10 cm. As a reward for having the largest tumor on the surgical floor, I get to cart around the largest IV, too.

I meet the oncologist in my HMO plan — the only one in my plan. He tells me I have a rare cancer, one in the family of soft-tissue sarcomas. These sarcomas make up only 1 percent of all diagnosed cancers, and the leiomyosarcomas are only a hundredth of those. It’s rare and very aggressive.

Odds are, especially with such a large tumor, that it may recur. I learn that because it’s uncommon,

there have been no large studies of the effectiveness of treatments. I learn the odds are slightly better with chemotherapy. Radiation, I’m told, is not a good option because of the toxicity to organs. Regardless of the treatment, I must have CT scans every three months to monitor any return of tumors. The oncologist wants to start chemotherapy treatment soon. My head is spinning with all the information.

### A time to heal

Recovery is slow, and the shock of what has happened begins to sink in. I can barely eat and have lost a lot of weight. I see my wound for the first time when I change the dressing, and I cry when I see the 9-inch L-shaped gash across my middle.

**See More Berres, Page 6**

# Todd Hendrickson, clinical trial patient No. 1 at OHSU

**T**odd Arthur Hendrickson, 44, of Wayzata, Minn., U.S.A., died peacefully in his home June 29, 2002.

The Life Raft Group knew Todd as the first GIST patient on the clinical trial at Oregon Health Sciences University, Portland, taking a drug then known as STI571. He and his wife, Janet, were among the first members of the Life Raft Group, and Janet served as the group's first medical librarian.

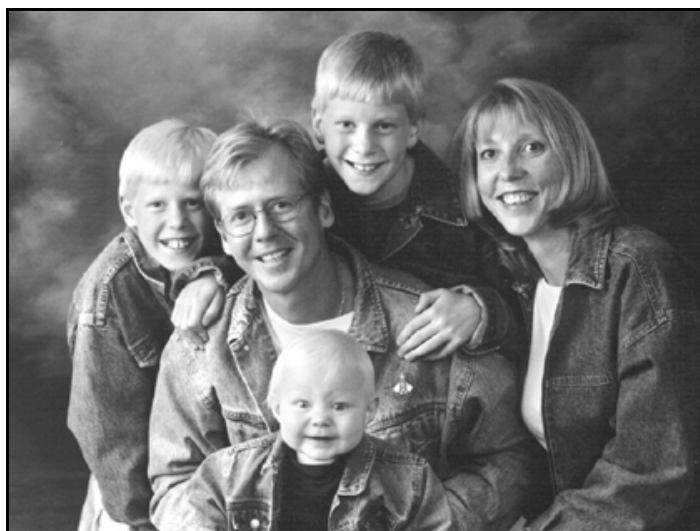
Todd was born July 3, 1957, in Fargo, North Dakota, to Arthur and Georgene Hendrickson. He moved to the Twin Cities in 1980 after graduating from the University of North Dakota. Todd was an investment banker for Miller and Schroeder Financial for most of that time. He loved to golf and was a member of Wayzata Country Club.

One of Todd's greatest loves outside of his family and friends was his airplane and his love of flight. Todd had an incredible gift of bringing out the best in others. He will be deeply missed by his family and many friends who are left with the fondest memories of his life.

He is survived by his loving wife, Janet, and his beloved children, Max, Tyler and T.J.; a brother and sister-in-law, Jay and Heidi Hendrickson and their children, Jon and Jennifer of Bloomington, Minn.

A memorial service was held July 3 at Minnetonka Lutheran Church. The program for the service included the following tribute written by Janet:

“The hardest thing of all,  
you know  
Was to hold your hand then  
let you go



**The Hendrickson family, pictured in the fall of 1999. Todd and Janet are shown with their sons Tyler, left; Max, in the middle, and T.J. in front.**

We cherished you beyond all measure

You gave those around you so much pleasure

“A life lived well is what you had  
A friend, my husband and our dad

Your presence here will be replaced

With memories of your smiling face

“Goodbye is not the thing to say  
We'll meet again another day  
You're free from pain and sickness, Todd

We've left you in the arms of God”

## In Memoriam

There have been 18 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, 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.

## More Berres

From Page 4

I'm feeling well enough now to research the disease. It's true, there isn't much information, not even on the Web, and what I find is grim. But I stumble upon a posting on a cancer Web site from a woman named Louise, who also has leiomyosarcoma.

I send her e-mail, and we discover we have more in common than this strange malady. We're both writers, we share a desire to know more about our disease, and we both have strong wills to fight it. Most importantly, we both have a sense of humor.

Louise opted not to have any chemotherapy or radiation, and I wonder what is best for me.

I get a second opinion. This oncologist agrees leiomyosarcoma is difficult to treat, and there is not a good large study on treatments. Still, she recommends chemotherapy, saying, "I would do it if it were me." She also suggests I have a post-operative CT scan and have the pathology of the tumor re-viewed because "results are very subjective."

I'm not sure what this means. Could it be something other than leiomyosarcoma?

### Cruel therapy

I start chemotherapy on Sept. 6., and see the radiation oncologist at St. Joseph's Hospital, who concurs that radiation is probably not a good option for me. One important thing that comes from this appointment, however, is that he tells me a new term for my disease: gastrointestinal stromal tumor, or GIST.

I have no idea just how significant that information will be. I start to

research GIST and discover it's just as rare as and even more persistent than leiomyosarcoma. I find my research is too depressing and have to stop for a while.

The good news is that the CT scan shows all the tumor was removed, and there are no signs of new growth. The bad news is the chemotherapy makes me tired and nauseous. I am told my hair will fall out.

### The other shoe drops

I finish treatments on Dec. 22 and tell myself it's the best Christmas present my children and I could ask for. My next CT scan is Jan. 22, and I'll see the doctor on the 29th. I'm finally feeling stronger, so I'm confident the scan will be fine. I'm so confident, and I go to the doctor's appointment alone.

I'm wrong. The cancer is back.

This time it has metastasized to my liver. The doctor says the surgeon will review the scans and be in touch. I walk out of the office in a haze, feeling lost and confused. I'm angry at having gone through chemotherapy for nothing, but most of all, I am terrified.

I know I must have surgery, but I have no confidence in my medical "team." I need to find some new players. I go online and look for cancer centers in Wisconsin.

Only one comes up: The University of Wisconsin Comprehensive Cancer Center in Madison. I see the center's director, John Niederhuber, a renowned surgeon. I feel the first stirrings of hope in nearly seven months.

An e-mail arrives from Louise with some information about a new drug for GISTs that began as a treatment for a form of leukemia.

"Using only non-operable subjects now, since they need a tumor

to watch and measure . . . Thankfully, we don't qualify," she writes, adding that it's good information to have.

Niederhuber agrees surgery is necessary, but mentions a new drug and the word "options," which up until now no one has uttered. I feel better about my chances already.

Feb. 12 at the University of Wisconsin Hospital and Clinics, Niederhuber and his team remove more of my stomach, more of my pancreas and some of my colon. The bad news is that Niederhuber believes some cancerous cells remain, and he decided not to remove the tumors in my liver. There were too many.

I wait impatiently to see whether I'm eligible to take part in the study of this new drug, STI571. Eventually, I am told the pathology confirms GIST, and Madison will indeed be one of the test sites.

I meet James Thomas, an oncologist with the UWCCC on March 6. I will be working with Thomas and Deb Warren, an RN who is the manager of clinical trials. I begin the new treatment March 13.

Hope is back in my vocabulary.

*Postscript: Carol and her girls are settled into the home they bought a week before Carol learned she had cancer. "Every day, I really am thankful for the breath I take and everything that goes with it," Carol writes. "Like so many Life Rafters who found Gleevec, I am blessed with that new life after all and I certainly appreciate it more than I ever could have before." Daughter Caitlin "graduated" from eighth grade this year and Cassi, age 5, learned to read this year. As of this month (July), Carol's scans showed her GIST is stable.*



# KIT remains the primary target of GIST therapy

But a question arises:  
Did Gleevec inhibit KIT  
signaling in patients  
who didn't respond?

By **Angela Riepel and Jerry Call**  
Life Raft Group Science Team

**P**eople get cancer, the theory goes, after a series of molecular missteps within their own cells.

Researchers have therefore wondered if a therapy that targets just one molecular misstep in the series would work. The success of Gleevec against chronic myelogenous leukemia (CML), and gastrointestinal stromal tumors (GIST) shows that molecularly targeted therapy can work against these cancers.

The c-Kit gene provides the genetic code for creating the KIT receptor. The KIT receptor belongs to a class of cellular receptors called tyrosine kinase receptors. Mutations in the c-Kit gene (which occurs in most GIST tumors) result in defective KIT receptors in GIST tumors. This results in continuous activation of the KIT receptor (called "constitutive activation"). This activated KIT signaling pathway sends both a proliferation and a survival signal to the GIST tumors through various downstream pathways.

Two recent research papers emphasize the key role the receptor "KIT" plays in sending the signals that trigger GIST tumor growth, and underscore the importance of Gleevec in treating GIST. Gleevec is able to inhibit KIT signaling in GIST, and in doing so, inhibits new

cell growth and causes GIST cancer cells to die.

Brian Rubin and colleagues, reporting in "KIT Activation Is a Ubiquitous Feature of Gastrointestinal Stromal Tumors," that KIT mutations are more common than previously thought, occurring in 92 percent of the tumors examined. Mutations were found in exons 9, 11, 13, and 17 of the KIT gene

## Quote:

**For those patients who fail to respond to Gleevec, it is likely that, in the future, an agent or agents will be added to Gleevec to increase its effectiveness.**

(exons describe the general location in the gene). Contrary to earlier reports, KIT mutations were also found in each of 10 benign GISTs as well as in borderline and malignant GISTs. This may be because prior studies did not examine as many exons or used different criteria to grade GISTs. Regardless of whether the KIT gene was mutated or not, KIT phosphorylation (indicating activated KIT signaling) was always present. There was no correlation between the mutation's location and KIT activation. The authors' conclusion is that KIT activation is a central event in the behavior of GISTs.

In a second paper, "Gastrointestinal Stromal Tumors with KIT Mutations Exhibit a Remarkably

Homogeneous Gene Expression Profile" by Susanne Allander and colleagues, 13 KIT-mutant GIST tumors were analyzed using microarray technology. When a gene is "expressed," it means that it has been activated and is in use by the cell that expresses it. Microarray technology looks at the expression of a large number of genes at the same time. The results showed a remarkably distinct and uniform gene expression profile for all of the GISTs. KIT was found to be the most highly ranked gene on the "discriminator list." Genes that would be expected to be activated by KIT signaling were also highly expressed.

The striking observation of the microarray study was the remarkable consistency of the gene expression pattern within the GIST tumors (they consistently express the same genes). This high correlation of gene expression is in contrast to that observed in the more common cancers, which show extremely diverse gene expression between tumors.

The authors interpret this observation to suggest that GISTs arise from cells with mutant KIT genes and that the progression from a single cell with a KIT mutation to cancer appears to involve only a limited number of other molecular missteps.

Taken together, the recent literature on GIST underscores the importance of inhibiting KIT signaling when treating GISTs. Even in GISTs where the KIT gene is not mutated (called "wild-type" c-Kit) signaling occurs via the KIT path-

## President's message: Transitions made, more ahead

From Page 1

ests, needs and backgrounds. Some view our listserve as the major reason for the Life Raft Group, and need and enjoy the constantly growing number of e-mails and persons who post them. Others view this aspect of the Life Raft Group quite differently and find the volume and the chatter overwhelming. Some choose to express their point of view frequently, and sometimes forcefully. Others choose to participate far less, if at all, and some choose to share most of their

comments privately. Some like to listen to others. A very few like to listen to themselves.

Despite all these differences we have almost no turnover and we seem to be able to work most things out.

The Life Raft Group has gone through a number of transitions in its short life span, a few with difference of opinion. There are many aspects to our new non-profit organization, only a few of them clearly visible — the general list,

the newsletter and the Web site.

Although our list seems to command the greatest attention of many, and although we are committed to maintain it and navigate it through continuous and more complex growth, it represents only a very small portion of where we are heading as an organization. We urgently need to reach those GIST patients who have not yet been correctly diagnosed and link them to

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## KIT: GIST is a model of study for resistance, signaling

From Page 7

way and this may promote proliferation and survival of the cancer cells.

This is supported by the fact that in the phase II trials, more than 50 percent of patients with wild-type c-Kit had either a partial response or stable disease, indicating that inhibiting KIT signaling with Gleevec was important even if the c-Kit gene is not mutated.

In CML patients, treatment failure with Gleevec is associated with failure to inhibit bcr/abl signaling (Gleevec targets bcr/abl signaling, in CML). This leaves us with an interesting question about GIST and Gleevec.

- Was Gleevec able to inhibit KIT signaling in GIST patients who did not respond to Gleevec?

Gleevec will probably remain important for almost all GIST patients (except possibly for those where surgery removed all visible tumors) in the foreseeable future.

For those patients who fail to respond to Gleevec, it is likely that,

in the future, another agent or agents will be added to Gleevec to increase its effectiveness. Other drugs might enhance Gleevec's ability to inhibit KIT activity, inhibit a component of KIT activity such as a downstream pathway, or take advantage of KIT's inhibition to sensitize tumors to other treatments. Studies examining the expression pattern of genes in GISTs may be used to determine what other molecules those drugs might target.

Another possibility is that other KIT inhibitors may be developed. One such drug in Phase I trials for GIST patients who have failed or are intolerant to Gleevec therapy is Sugent's SU011248.

The relatively consistent pattern of genes expressed in GISTs suggests that what works for one patient is likely to work for many others. It also presents an opportunity for further study. Since GIST is relatively simple compared to other more complex cancers, it may pre-

sent a model for study of resistance mechanisms in GIST and other cancers. It also may present a model for studying signaling pathways downstream from KIT. These downstream pathways are likely to be used in other cancers as well, and the relative simplicity of GIST may make them easier to study and develop drugs to affect these downstream targets.

*Authors' note: We are a patient and a caregiver, not doctors. This is offered as well-researched food for thought, and is not a substitute for careful discussion with your doctor.*

Sources: "Kit Activation Is a Ubiquitous Feature of Gastrointestinal Stromal Tumors" by Brain P. Rubin, Samuel Singer, Connie Tsao, Anette Duensing, Marcia L. Lux, Robert Ruiz, Michele K. Hibbard, Chang-Jie Chen, Sheng Xiao, David A. Tuveson, George D. Demetri, Christopher D. M. Fletcher, and Jonathan A. Fletcher.

"Gastrointestinal Stromal Tumors with KIT mutations Exhibit a Remarkably Homogeneous Gene Expression Profile" by Susanne V. Allander, Nina N. Nupponen, Markus Ringner, Galen Hostetter, Greg W. Maher, Natalie Goldberger, Yidong Chen, John Carpten, Abdel G. Elkahoul, and Paul S. Meltzer.



## Message

From Page 8

treatments like Gleevec. It is a shame to have any GIST patient die from this terrible disease who could have been easily saved by the timely administration of drugs like Gleevec. We also urgently need to uncover the reasons why some patients fail to respond to Gleevec or subsequently relapse.

We are fortunate to have an exceptional leader who has agreed to serve as our new executive director. Norman Scherzer is a former disease management specialist for the Centers for Disease Control and a former assistant commissioner of health for New York City. In addition, Norman has five years experience running a large non-profit. He has also served as a consultant to a number of major organizations, including Harvard University. He has shown great vision and leadership in guiding the Life Raft Group to its current status and in laying out a sound vision for its future. It is Norman who is responsible for the recent \$250,000 Novartis grant.

You should know what others think of him. Let me quote just a few statements:

“The new research model pioneered by the Life Raft group is making it possible for patients and family members to contribute to clinical research for their diseases in unprecedented ways,” says Dr. George Demetri, medical director of the Center for Sarcoma and Bone Oncology at Dana-Farber Cancer Institute in Boston, Mass., where he conducts clinical trials with GIST patients. “I predict that we’ll be seeing a lot more of this sort of thing in the years to come.”

“The man many consider the



**“It is a shame to have any GIST patient die from this terrible disease who could have been easily saved by the timely administration of drugs like Gleevec,” says Stan Bunn, recently chosen president of the Life Raft Group board of directors, shown here with his son William.**

George Washington of e-patient-directed medical research is (Life Raft Group leader) Norman Scherzer ... who until recently worked with the Centers for Disease Control and the New York City Department of Health,” said Dr. Tom Ferguson, author of the Ferguson Report (Fergusonreport.com) in a draft white paper to the Robert Wood Johnson Foundation.

“Cyberspace has spawned a powerful breed of ... advocates .... Consider the case of Gleevec. Members of an (Internet group) ... spread the word about Gleevec, bringing scores of patients into new clinical trials ... Then they went one step further, creating a group called Life Raft, where participants in one trial could share information about the drug’s efficacy. Its side effects and their interactions with doctors. Conservative clinical oncologists cringed. Life Raft represented a major break with medical precedence ...

“Better-informed people are more willing to participate in the advancement of science,” says Gilles Frydman, founder of the Association of Cancer Online Resources.

“Those patients taking Gleevec do not consider themselves guinea pigs. They are the recipients of experimental medicine.” — Wired Magazine, September 2001.

It is our intention that our full-time executive director be paid a modest salary (\$25,000 this year, our start up year) and \$60,000 in 2003) and I have committed to raise that expense on my own. It is also our intention to compensate any of our volunteers who need to take time off from their regular jobs to get the work of the Life Raft accomplished. Finally, it is also our intention to pay for a small staff (starting with a part time administrative assistant) and consultants as needed.

Please join me in giving Norman your full support.

On the next page you’ll find the report of our first Town Hall Meeting and a summary of the Life Raft Group’s progress. Should you have any comments or questions, please contact me privately.

**Stan Bunn**, president  
For the Board of Directors,  
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# The Life Raft changes, looks to the future

*A lot* has happened since the group's first meeting in Boston

It's an understatement to say a lot has happened with the Life Raft Group since its first gathering May 3-4 in Boston, Mass., U.S.A.

No longer a loosely organized, all-volunteer group of cancer patients and caregivers, the Life Raft Group has been incorporated in the state of New Jersey, U.S.A., as a non-profit organization.

To do so, the Life Raft joined the New Jersey Center for Non-Profit Corporations and received their start-up package, hired an attorney as part of the package, and formed an interim board of four members (the legal minimum) consisting of Stan Bunn of Tampa, Florida, president; Bernie Kaplan, New York City, secretary-treasurer; Mike Matthews, Halifax, Nova Scotia, Canada, and Gary Golnik, Boston, U.S.A. Life Raft Group Coordinator Norman Scherzer, New York City, was named interim executive director.

Scherzer is in the process of renting a small office space, hiring a part-time administrative assistant and finding an information technology consultant.

Board members held their first teleconference July 10, and is scheduled to hold their first in-person meeting Aug. 24-25 in New Jersey.

The Life Raft Group also held its first "Town Hall Meeting" July 21 via the Internet and conference call using software and telecommunications time donated by Stan Bunn.

Eleven Life Rafterers spent two

hours talking about the mission, objectives and organization. The software enabled Life Rafterers to go online and follow the slides of the presenters, while hooked up to an international conference call.

The purpose of the meeting was to discuss issues too complex or too focused for the general list.

The meeting was limited to 25 participants due to system licensing requirements. As expected there were a few glitches and not everyone was able to get online.

Invited were all those who asked to participate following an earlier discussion on the listserve. In addition, all board members were invited along with key volunteers and anyone else who had expressed strong opinions on these issues in the past. "Every attempt was made to create a diversified and balanced group," said Scherzer.

Those who participated included board members Bunn, Kaplan, Matthews, Golnik, John Poss, Beverly Shirts, Renee Greenley, Vince Luce, Lee Cousins, Norman and Anita Scherzer and Penny Duke.

Bunn presented a summary of all that had happened since the May 3-4 meeting. In addition to the above mention events, other items of note included:

— An agreement in principle has been reached with Dr. George Demetri, Dana-Farber Cancer Institute in Boston and Dr. Alan van Oosterom/Universitaire Ziekenhuis Gasthuisberg in Belgium to establish tumor banks. Demetri has also agreed in principle to provide medical expertise content for the Life Raft Group Web site.

— Scherzer has negotiated a revision in the Novartis-sponsored

phase II clinical trial protocol regarding the frequency and site for visits at the two-year mark, and is negotiating changes in the NCI-sponsored phase III protocol regarding the provision of Gleevec at the one-year mark.

— Scherzer represented the Life Raft at the first-ever State of the Science Meeting for Soft Tissue Sarcoma, sponsored by the National Cancer Institute, held June 17-18 in Bethesda, Maryland, and represented the group at a May 6 press conference for the new Novartis Research Center in Cambridge.

Scherzer followed with an overview of the Life Raft Group's mission and objectives, portraying the Life Raft as an iceberg with three visible tips:

The first are the two listserves which the group runs — one for the general membership and one for the science team. These lists will continue as usual, although as the size and complexity of the membership continues to grow, the lists will need to adapt.

The second is the newsletter which will also continue but with a dramatically increased circulation and an expanded content, particularly medical.

The third is the Web site, which will also continue but with a greatly strengthened interactive component that will allow new members to apply online and current members to submit medical updates online, all in a secure environment. Medical content will also be greatly increased, both for laypersons and for medical professionals.

Given those tips of the iceberg,

## THE LIFE RAFT GROUP

<http://www.liferaftgroup.org>

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**Who are we and what do we do?** We started in July 2000 as GIST patients and caregivers in the Gleevec (STI571) clinical trials, and later extended membership to all GIST patients. We became a nonprofit group (501-c-3) as of June 10, 2002.

We share our experiences and support, focusing on symptoms, side effects and drug-related issues. Members correspond privately to each other and to the group as appropriate. To join, contact membership coordinator Penny Duke at liferaft@cfl.rr.com, or download an application at [www.liferaftgroup.org](http://www.liferaftgroup.org).

**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. To assist in that goal, the secure e-mail listserv does not include medical professionals. How-

ever, this newsletter serves as an outreach and is widely distributed. Hence, all items in the newsletter are edited to maintain the anonymity of members unless they have granted publication of more detailed information.

**Method:** Our primary means of communication is through a confidential, secure listserv operated by the Association of Cancer Online Resources, ACOR ([www.acor.org](http://www.acor.org)).

**Disclaimer:** We are patients and caregivers, not doctors. Any information shared among the group should be used with caution, and is not a substitute for careful discussion with your doctor.

**Newsletter note:** 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 you may find.

## Happenings

From Page 10

less visible are the plans to improve the quality of patient and caregiver support, to maintain and enhance the database and to begin to provide medical professional support.

These efforts will include:

- Continue to influence the conduct of the clinical trials in the areas of patient access to drugs and travel;

- Work to reform Medicare to cover oral cancer drugs like Gleevec,

- Develop a more robust way of maintaining the growing patient database,

- Do more monitoring of research and more networking to identify existing drugs that have the potential of helping GIST patients;

- Develop greatly expanded medical content for laypersons and medical professionals;

- Develop an organizational structure to sustain this effort over time and beyond the capacity of individual volunteers.

At the conclusion of this presentation, members spent about an hour and a half asking questions and making suggestions.

Participants agreed that although membership donations will be sought, no person will ever be denied membership in the Life Raft Group because of an inability or unwillingness to donate money.

Participants took note of the fact that our interim four-person board will be expanded to seven members, with a serious effort to include any groups not represented, but with the continued priority of appointing those committed to pro-

viding support to the organization, including the raising of money.

There were a lot of questions about our organizational structure, including by-laws (an interim set is available, contact Norman Scherzer), the budget (under development); broader diversity of board members (of the four there is one Canadian and three Americans; two are patients and two are caregivers) and a concern that the group may be too slanted to Dr. Demetri (guilty) and need to bring in other doctors (agreed).

Several other members focused upon fund-raising and other areas where members may help. Secretary-Treasurer Bernie Kaplan noted that fiscal accountability demands an annual audit. One member had e-mailed a suggestion that we consider holding regional meetings, an idea the group can work on.