

Time on fire

Dying patients can't get new drugs that could save their lives

Norman J. Scherzer
Executive Director
The Life Raft Group

In the past few months we have lost several Life Raft Group members who were not successful in obtaining drugs that were available for clinical trials. Two stories in particular stand out. Both patients are Canadians.

The first patient's GIST was resistant to Gleevec and to Pfizer's SU11248. He tried to get into a phase I clinical trial in Boston for a new drug, BMS354825, but was told that there were no available slots. With assistance from the Life Raft Group, he turned to a clinical trial in Scotland. While in the process of joining the trial — the drug was not available on a compassionate use basis — he ran out of time. He died the day he was supposed to be in Scotland to see a doctor about starting the trial.

The second patient's GIST was resistant to Gleevec and so he participated in the phase II clinical trial for SU11248. Believing that he was experiencing unacceptable side effects from the drug, he voluntarily left the trial. Later he discovered that he had been on the placebo. The "side effects" were likely symptoms of his cancer. But because he voluntarily left the trial, he could not rejoin it in order to get the actual drug.

The Life Raft Group tried to get the drug company to provide him with SU11248 on a compassionate use basis (the drug was available

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LIFE RAFT GROUP

January 2005

In memory of Ara Jelderian,
Hans Englund and Rafi Aghababian

Study: Gleevec levels decrease over time

Data raises concerns over long-term viability of lower Gleevec doses

By Jerry Call
with Norman Scherzer

One reason that side effects from Gleevec often get better over time is that levels of Gleevec tend to decrease over time in many patients, according to a new report.

This may also explain why — although there seems to be no difference in the relationship between dosage levels and initial response to Gleevec — there may be a need for higher doses over time.

Dr. Ian Judson, professor of cancer pharmacology at the Royal Marsden Hospital in London, was the lead author in this report by the European Organization for Research and Treatment of Cancer's Soft Tissue and Bone Sarcoma Group. The study, titled "Imatinib (Gleevec) pharmacokinetics in patients with gastrointestinal stromal tumor ...," looked at Gleevec blood levels from patients in the phase I and phase II trials conducted by the EORTC in patients with GISTs and other sarcomas. Patients with GIST



JUDSON

also had repeat sampling after approximately 12 months on Gleevec.

While the study is not conclusive, possibly due to a relatively small number of patients, it adds weight to a growing

concern that patients treated with lower doses of Gleevec might be at higher risk to develop resistance. The European phase III GIST study recently found a longer time to progression at 800 mg. versus 400 mg. (A smaller U.S. study has not found this). A recent Life Raft Group analysis of patient reported data showed fewer relapses at higher doses — especially when considering the actual dose delivered instead of the "intent to treat" dose.

Pharmacokinetics (PK) is the study of what the body does to a drug. Judson's study was conducted to examine the variables that affected Gleevec PK, and to determine what changes occurred over time.

Clearance (CL) is one of the primary PK parameters. Clearance describes the efficiency of elimination of a drug from the body. A higher clearance rate

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on such a basis in Boston but not Canada) but again time ran out and the patient died. His wife had died of cancer two years earlier, so their 9-year-old son was left an orphan.

In the latter case, there were two hurdles the patient and the Life Raft Group failed to navigate quickly enough: first, getting the drug company to make the drug available on a compassionate use basis and, secondly, getting the local hospital's institutional review board to approve this. The fact that this had been done by another IRB at a major hospital in the United States did not matter.

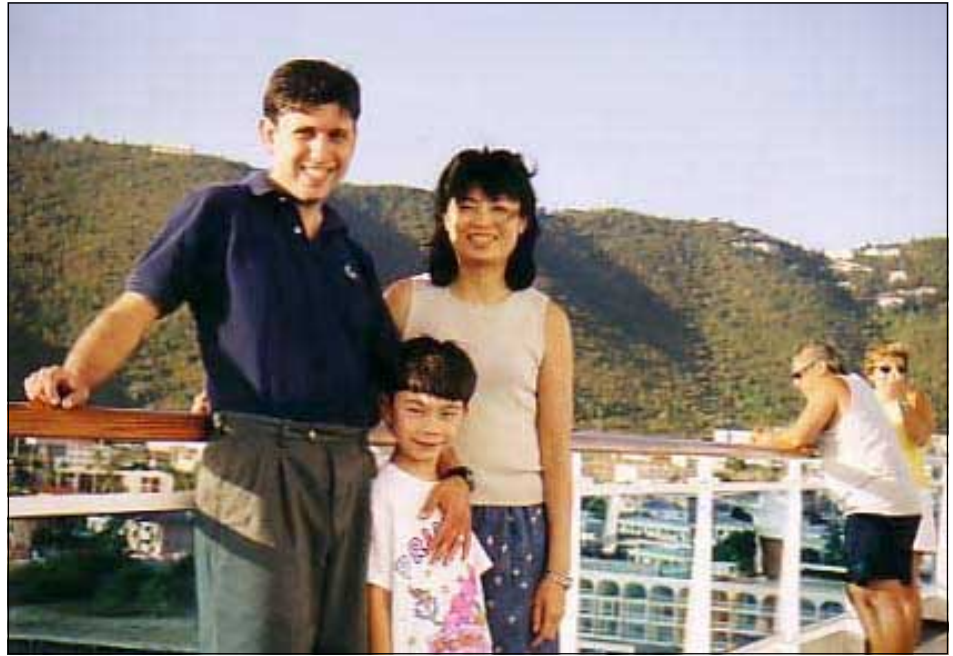
One could only imagine what would have happened if these patients had a deadly communicable disease. Picture this scenario: Two patients are dying from anthrax. A reporter discovers that there is a drug that might help save them. But both patients die before they are granted access to this drug.

The reporter also discovers that a committee of medical experts at the local hospital took three months to decide if the patients should get this drug. This institutional review board met only monthly and its top priorities were protecting patients against unsafe treatments and, of course, protecting the institution against lawsuits. The reporter also learns that these experts refused to accept the findings of another expert committee at another prestigious institution, but instead had to duplicate the process.

Imagine the fallout from the ensuing story. Politicians would decry the lack of urgency and inflexibility of the medical bureaucracy, and the absurdity of trying to protect a dying patient from a potentially unsafe treatment.

Protecting a dying patient. Now that is an interesting conundrum.

What could justify not getting a drug to a dying patient in a reasonable period of time, say a few hours or at most a few days?



The Jelderian family poses for a family portrait. Florence died of cancer in 2002; Ara died Dec. 25 of GIST while trying to get SU11248 on a compassionate use basis. Their son, Michael, is now 9.

There is certainly plenty of finger-pointing that could go on.

— The drug company has to produce enough drugs so that it could be made available on a compassionate use basis when the patient is not able to get it in a clinical trial. — Second, a physician at a particular medical facility has to decide that that patient must have this drug and initiate the process of requesting it.

— Third, the hospital's IRB has to approve use of the drug on a compassionate-use basis. The IRB must be able to convene on an emergency basis and to operate under a protocol that defined acceptable risk for terminally ill cancer patients differently than that for other drugs, such as those treating impotence. In the case of a drug like Viagra, the risk of drug side effects may far outweigh the desirability of getting an erection but rarely would that risk-benefit ratio apply to a cancer drug for dying patients.

— Fourth, the patient must be able to get to that medical facility, overcoming whatever financial obstacles might

IRBs must be able to meet on an emergency basis and define acceptable risk for dying cancer patients differently from those on drugs for other conditions, such as impotence.

exist. Here the issue of financial responsibility is a little clearer; it is the patient's. If the patient is not a citizen of the country in which the medical facility is located, that may involve tens of thousands up-front dollars.

— Fifth, and most important, every one involved needs to have a sense of urgency similar — just as if the patient had anthrax.

I am sure that some very bright people reading this would be able to present a rationale of why the current situation has to be — and we invite anyone who wishes to do so to respond through this newsletter. But it would



At the Life Raft's board of directors meeting are, from left, Chris Carley, Gerry Knapp, Jim Hughes, John Poss, Dr. Arnold Kwart, Stan Bunn, Bob Book, Liana Baldor, Norman Scherzer, Allan Tobes, Tricia McAleer, and Jerry Call.

Life Raft board of directors adds 12th member

Meeting Jan. 8 in Tampa, Fla., the Life Raft Group's Board of Directors (see directory on last page) unanimously approved the following actions:

- Added a 12th member of the board of directors, Chris Carley of Chicago. A GIST patient still on the first Gleevec trial, Carley also serves on the board of

the Lance Armstrong Foundation.

- Created an Executive Committee consisting of Stan Bunn, president; Allan Tobes, secretary-treasurer, and fund-raising co-chairman John Poss.

- Approved the promotion of Tricia McAleer from administrative assistant to executive assistant.

- Authorized the expansion of the science coordinator's position, held by

Jerry Call, from part time to full time.

- Made a commitment to accept a five-year, \$300,000 anonymous-challenge grant calling upon the Life Raft Group to match \$60,000 a year for the next five years.

- Acknowledged the receipt of a \$20,000 grant from AMGEN pharmaceuticals and a \$10,000 grant from the Lance Armstrong Foundation.

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take an awful lot of illumination from the candles we light when one of our members dies to make that acceptable to the families and friends of these patients.

There is a feeling of helplessness as patients and caregivers try to navigate this clinical trial/compassionate use landscape to stay alive. It is easy to believe that this system was just not designed to meet the urgent needs of dying cancer patients.

On the other hand, perhaps we need

to shine some lights on the major obstacles to survival that could be overcome with a different set of priorities.

Maybe a time clock showing how long each part of this process takes. On one side of the clock, the names of IRB members and their photographs. On the other side, a list of patients and their photographs. As the clock ticks and deliberations slowly advance, photos of the patients would wink out.

Perhaps there should be other clocks for the other parts of this process, in-

cluding expanded drug production to meet compassionate use needs, clinician time to draw up protocols and so on.

Tick-tock, tick-tock, tick-tock. Day three: John Doe has died. Tick-tock, tick-tock. Day seven: Jane Doe has died. Tick-tock. Day 17: The IRB convenes.

Dedicated to Ara Jelderian and Mike Matthews. May their heroic struggles not be in vain.

STUDY

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means that the drug is being removed from the body faster. Variations in clearance from one person to another or in the same person over time might require an adjustment in dose.

The study looked at several different PK models. In the model that produced the best fit, clearance was correlated with body weight, and granulocyte count. Patients with a lower body weight or with a higher granulocyte count, tended to “clear” Gleevec from the body slower than patients with higher body weight. In their model, a patient with 77 percent of median body weight or with 1.87 times the median granulocyte count, the apparent clearance was 6.53 liters/hour, or about 70 percent of the typical apparent clearance of 9.33 liters/hour.

What this suggests is that heavier patients might need higher doses of Gleevec in order to receive an equivalent dose when compared to a lighter patient. It may also explain why very preliminary research findings by the Life Raft Group suggest that females (lower weights?) in particular seem to respond to higher doses of Gleevec with lower relapse rates.

One of the most interesting findings to come out of this study was that clearance of Gleevec increased by 33 percent in the 12-month period studied. The increase in apparent clearance, if true, should lead to decreasing Gleevec blood levels, and the study found a 42 percent decrease in “area under the curve (AUC),” one measurement of drug blood levels, over the 12-month period.

When Gleevec is administered on an ongoing basis to GIST patients, certain parameters, such as liver function, may change significantly. This leads to a hypothesis that clearance might increase in GISTs requiring Gleevec, which usually contain liver metastasis, because liver functions may improve as a result of tumor shrinkage. A Euro-

pean study of this question has just begun, according to Dr. Jaap Verweij of Erasmus University Medical Center, Rotterdam.

Volume of distribution (V) is the second major PK parameter. It is a little more complex than clearance. For starters, it is not a real “volume.” It is the concentration of a drug in the plasma (the fluid non-cellular, portion of blood) in relation to the total amount of the drug in the body. Volume of distribution is an imaginary volume; the major determinant is the relative strength of binding of the drug to tissue components as compared to plasma proteins. Volume of distribution will be higher where most of the drug is distributed to tissues and less of the drug to plasma. Conversely, volume of distribution will be lower in drugs where most of the drug is held in plasma and less drug is distributed to tissues.

In this study, hemoglobin levels affected the volume of distribution of Gleevec. Low hemoglobin levels correlated with low volume of distribution. For a patient with 84 percent of the typical hemoglobin level, the volume of distribution was about 70 percent of the typical volume of distribution. In simpler terms, this suggests that higher hemoglobin levels helps the Gleevec leave the blood and get into tissues, including tumors.

This finding is supported by a EORTC presentation given at the November meeting of the Connective Tissue Oncology Society (CTOS). This presentation, given by Martine Van Glabbeke, reported low hemoglobin levels as a significant prognostic factor in initial resistance to Gleevec (progression within three months).

While the study investigators noted



VERWEIJ

that alpha-1-acid glycoprotein levels were considered to be potentially important, they were not measured for this study.

The study raises practical questions:

— Would phasing-in higher doses of Gleevec improve compliance and response rates? There is a study in the planning stage that is designed to answer the question of compliance, according to Verweij, but the study can only be done if financial support can be obtained. “The protocol as it currently is foresees a start at 400 mg. and then a stepwise increase to 800 mg. over a period of two months [time still under discussion],” Verweij said. “The protocol objectives are to try and increase the percentage of patients that tolerate 800 mg. in the long term.”

— Is there the need for an expanded role for clinical interventions to raise hemoglobin levels, such as epoetin alfa (Procrit) or transfusions? “There is still a lot of uncertainty” said Verweij. “It is far too early to draw any scientific conclusion at this point. One could not yet justify this approach.”

— Can certain variables, such as body weight, granulocyte count, hemoglobin levels, drug-related side effects, and response be used to adjust Gleevec dosage levels? Dr. Ian Judson, Royal Marsden Hospital, London, responded to this question for us. “What we cannot do is use these limited PK data to suggest modifications in imatinib (Gleevec) dose according to haemoglobin, WBC, or liver function, etc. The trend to increased clearance over time may contribute to improved drug tolerance but acquired resistance is due to new mutations and a substantial dose increase may then be effective in a percentage of patients, as reported.”

The study’s conclusion noted “Given the large interpatient variability in

Rafi Aghababaiian, 38, fought GIST for two years

Despite several surgeries, clinical trial drugs and best efforts of doctors, Rafi Azad Aghababian, 38, of Calabasas, California, lost his two-year battle to GIST on Jan. 22, 2005.

Rafi was born April 13, 1966, and grew up in northern New Jersey, obtaining his undergraduate degree at Manhattan College and earning his master's in finance from Rutgers University in 1990. He moved to California in January 1991 and finally settled in Calabasas. His entrepreneurial spirit led him to start two bagel stores. After they closed, he went into integrated technology consulting, working for several years at Big Five consulting firms until the collapse of Arthur Andersen when he found a happy home as practice director for a smaller IT consulting firm, the Nakoma Group.

He married Michelle Schardt in December 1995 in Half Moon Bay, Calif. Their two daughters attend Bay Laurel Elementary in Calabasas.

Rafi loved to travel, especially to Cabo San Lucas in Mexico, Hawaii and the seaside village of Cambria, Calif. He loved heavy metal and classic rock music since childhood, as well as science fiction and horror movies. "The Lord of the Rings" was one of his favorites.



Rafi Aghababaiian and his wife, Michelle, and their daughters Seta and Sidra are seen last August along Moonstone Beach in the town of Cambria, California.

He loved all his cats and his special cat, Nala, never left his side while he was ill. He taught his daughters to always give a portion of their money to the animal shelter, and to love animals and respect them.

He was giving and unselfish, and in his last two years of life signed up with Big Brothers of America to be a Big Brother because he wanted to give more and make a difference. His dream was to go to law school to be a patient advocate before the insurance

companies that had caused him so much grief over his medical bills.

He is survived by his wife and best friend of nine years, Michelle; his daughters, Seta, 7, and Sidra, 6, and his parents, Wahab Aghababian and Madeleine Hilton.

Services were held Jan. 29 at St. Peter's Armenian Church in Van Nuys, Calif. Donations are preferred to either the GIST Cancer Research Fund, www.gistinfo.org, or Valley Cats, www.valleycatsinc.org

MORE STUDY

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clearance and AUC, it is currently not possible to determine whether or not PK factors might play a role in the development of resistance to imatinib. Mutations affecting the KIT binding site and activation of alternative proliferative pathways offer more likely explanations. However, stabilization of progressive disease following an increase in imatinib dosage has been described Increasingly, knowledge

of mutation type can be used to predict the response of GIST to imatinib. Further work is required to determine whether or not a late increase in imatinib clearance truly does occur in GIST patients and the extent to which this contributes to alterations in response and disease control."

This study gives additional insight to some practical concerns in the treatment of GIST patients. While the re-

sults of this study are not definitive, GIST patients and their doctors must often make many decisions based on incomplete or immature data. This study gives GIST patients a little more information with which they can make these difficult decisions.

Jerry Call is science coordinator of the Life Raft Group. Norman Scherzer is the group's executive director.

Fletcher gives Axelrad lecture at CTOS

By David Josephy,
Science Advisor
Life Raft Group

One of the world's leading GIST pathologists, Dr. Jonathan Fletcher of Brigham and Women's Hospital in Boston, was chosen this year to give the prestigious Nina Axel Lecture at the annual meeting of the Connective Tissue Oncology Society.

The CTOS conference was held Nov. 11-13 in Montreal, Quebec, Canada. The Axelrad lecture is named in memory of a sarcoma patient whose family endowed the lecture. Its presentation to Fletcher was a mark of the esteem in which his peers hold him.

Fletcher's hour-long talk Nov. 13 was titled "Cytogenetic insights in mesenchymal tumours." Fletcher speaks very well, with a modest and understated presentation. Deliberately, the focus for the first half of his talk was not on GIST, which had already received a lot of discussion. Instead, he described his group's notable discoveries on the specific gene that is mutated in "ABC" (aneurysmal bone cysts).

Cytogenetics is the study of chromosomes in cells. In his introduction, drawing on his cytogenetic approach to cancer research, he explained how difficult and unpredictable it is to re-



Dr. Jonathan Fletcher shows off a new Life Raft Group T-shirt he was given at the Connective Tissue Oncology Society meeting in Montreal. He's flanked by, from left, Life Rafter Jim Hughes, Jerry Call, Norman Scherzer, and David Josephy, Ph.D.

trieve and culture viable cell lines from tumor samples, and the degree of art and luck involved in doing so. He cautioned that these studies may be limited or biased by the fact that many tumor samples, for whatever reasons, do not yield cell cultures which can be studied by cytogenetic approaches.

In the second half of his address, Fletcher turned to a discussion of smooth muscle tumors — leiomyosarcoma (LMS) and GIST. This was a science talk, so its impact on therapy is indirect, but the science was fascinating. He said that we still have a lot to learn about the true cellular origins of sarcomas. He believes that they usually originate not from well-differentiated mesenchymal cells, but from more primitive precursor cells.

Thus, GIST should probably be viewed not as derived from the interstitial cell of Cajal itself, but probably from a less-differentiated progenitor of those cells.

He contrasted leiomyoma and LMS, as being different at the chromosome-analysis level. Leiomyoma cells typically display a karyotype (chromosome pattern) which is "simple," that is, only slightly different from normal cells. One specific chromosome translocation from chromosome 12 to chromosome 14 is common in leiomyoma, but the other chromosomes appear normal. In contrast, LMS cells show a wildly complex and abnormal karyotype, with a great excess number of chromosomes and many abnormalities.

Fletcher tells Life Rafter of new type of trial

By Jerry Call
Science Coordinator
Life Raft Group

Dr. Jonathan Fletcher met with Life Raft Group representatives after the CTOS meeting. Fletcher is one of the top researchers in the field of molecular biology of GIST. He is a

wonderful speaker and his opinions are always highly sought in meetings like CTOS. In addition to being a top GIST researcher, Fletcher is a medical oncologist who spent the first part of his career working in pediatric oncology.

One of the items discussed was a GIST tumor bank. Fletcher told us of a few of the problems with setting up a tumor tissue bank and made a few sug-

gestions.

On another topic, Gleevec-resistant patients and tissues are the focus of the majority of GIST research work, and they should be. We wanted to talk to Fletcher about efforts being made to obtain and analyze tissue from patients other than those resistant to Gleevec. Specifically, we asked about tissue

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Pediatric GIST families mobilize

NYC gathering of young GIST patients, parents is planned May 21-22

By **Tricia McAleer**
Executive Assistant
The Life Raft Group

The first meeting of the Pediatric GIST Family Committee was held Dec. 21. Attending were Brian and Dorothy McBride, Raymond and Sheila Montague, Gordon Simmons and Life Raft staffers Tricia McAleer and Norman Scherzer with his wife and GIST patient, Anita.

The Montagues' son, Jonathon, 23, died of GIST in 2002. Since then, the Montagues have created the Arbor Foundation in his honor. This foundation helps support the advancement of the Life Raft Group pediatric GIST database with an annual grant.

The McBrides have raised more than \$10,000 for pediatric GIST research with the help of the Saint John Villa Academy High School. Their 16-year-old daughter, Malorie, bravely revealed herself as a cancer patient to everyone in her school in order to reinforce the fund-raiser. Since then she has been surrounded by supportive friends and faculty.

The Life Raft Group will host a first-ever pediatric GIST family gathering planned for the weekend of May 21-22 in the New York area. Families and key experts will be invited to join.



At the first meeting of the Pediatric GIST Family Committee are, from left, Brian and Dorothy McBride, LRG staffers Trish McAleer and Norman Scherzer, and Ray and Sheila Montague.

This ground-breaking meeting will encourage pediatric GIST families to interact with key medical professionals who are committed to supporting research of this rare cancer. This will also give families the opportunity to forge a support network tailored specifically to their needs.

Sheila Montague and Dorothy McBride volunteered to maintain the Life Raft Group pediatric GIST database. They will both receive training from the Life Raft Group to accurately manage complex medical records.

Dorothy also volunteered to focus on fund-raising for pediatric GIST. The goal is to support a part-time young investigator, someone who will focus on the pathology of pediatric GIST.

Dr. Cristina Antonescu of Memorial Sloan-Kettering Cancer Center in New York has offered to supervise this investigator at her lab.

The group adopted a working definition of pediatric GIST to include young adults up to age 25 verified by genetic testing. The committee will also attend a follow-up meeting this February to continue establishing a Center of Clinical Excellence for pediatric GIST at Memorial Sloan-Kettering.

For more information regarding the Pediatric GIST family gathering, please contact the Life Raft Group office, 40 Galesi Dr., Wayne, NJ, 07470, phone (973) 837-9092, e-mail liferaft@liferaftgroup.

FLETCHER

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from patients who were stable but have not had significant shrinkage to Gleevec, and about residual viable tumor cells from patients that were responding well to Gleevec. While sta-

bility is generally considered to be a major victory by both patients and doctors, there are a small number of GIST patients that have very large tumor burdens for whom stability is not

enough. Fletcher told us that a significant amount of work had been or was being done in this area.

Gleevec often kills most GIST tumor

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U.S. agency puts AMG 706 on fast track

FDA designation speeds development of drug

By Erin Kristoff

Administrative Assistant
Life Raft Group

Amgem's experimental drug AMG 706 has been granted "fast-track" designation in the United States. "AMG 706, Amgen's first investigational oral cancer therapy, may hold promise for various tumor types and is currently in phase II trials for the treat-

ment of [GIST], a fatal cancer," said Dr. Beth Seidenberg, chief medical officer and senior vice president of global development at Amgen. "Fast-track designation represents an important step for [AMG 706] and will help to streamline development."

Under the U.S. Food and Drug Modernization Act of 1997, the fast-track programs are designed to expedite the review of new drugs that are intended to treat serious or life-threatening conditions and that demonstrate the potential to address unmet medical needs.

Early clinical data on AMG 706

show signs of solid tumor regression with promising initial safety data. The fast-track designation came Dec. 6.

AMG 706 is in phase two trials for GIST at an expanding number of locations in the United States and abroad. Two phase one clinical trials have been expanded to include GIST patients for whom the experimental Pfizer drug SU11248 failed. Information can be found at the Life Raft Web site, www.liferaftgroup.org

These trials do not have a placebo, ensuring that all GIST patients will receive the actual drug.

FLETCHER II

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cells, but seldom kills them all. This is why GIST patients must continue to take Gleevec as long as it continues to work for them. Over time, most GIST patients become resistant to Gleevec. It therefore makes sense to try to find out what is stopping those Gleevec-resistant cells from dying. Fletcher said that some work was ongoing to analyze these residual viable cells.

We also asked Fletcher about the concept of earlier "combination treatment" clinical trials, the theory being that the addition of a second agent to Gleevec might be more effective while cells were still sensitive to Gleevec. Fletcher seemed generally supportive of this concept. While we generally did not discuss details of this concept, we did discuss one very interesting specific. Fletcher told us of a different kind of clinical trial concept called an "investigational window." In theory, this innovative clinical trial concept could be used to investigate whether a particular drug had at least some signs of activity in GIST during the initial stages of drug treatment, before Gleevec, and before a patient became resistant to Gleevec.

Gleevec-resistant GIST is much harder to treat than Gleevec-sensitive GIST. The question that arises is whether a second drug, given at an earlier time when tumors are still sensitive to the effects of Gleevec, might be more effective than at a later time when cells are becoming resistant to Gleevec.

The concept of an investigational window, as we understood it, is that a newly diagnosed patient with metastatic GIST might be able to receive a candidate drug for a short time while he or she is not in danger. The theory being that some patients probably had a "window" of time, perhaps two weeks or so, that they could afford to take a chance to see if a new drug/treatment showed immediate initial benefit (perhaps an early indicator might be PET scans).

The benefit of an investigational window-type trial would seem to be the possibility of identifying a drug that might have benefit in combination with Gleevec in the early phases of treatment when this same drug might have little or no benefit in Gleevec-resistant GIST. The possibility of reduced time to identify these drug combinations would seem to be another potential benefit.

The potential drawback to an investi-

gation window-type trial would seem to be in getting patients to agree to take a chance on an unapproved drug when a "wonder drug" like Gleevec is approved and waiting on the shelf. It would take special patients to appreciate the potential long-term benefit. Newly diagnosed patients are typically in shock from being diagnosed with cancer. Patients who had a primary tumor removed, then had a recurrence perhaps a year or two later might be better equipped to appreciate the potential for long-term benefit. These patients are typically over their initial shock and have often become quite educated thanks in part to support groups like the Life Raft Group.

The possibility of extending the investigational window concept to stable patients should also be considered. These patients might just need a little something added to Gleevec to nudge Gleevec-sensitive cells into apoptosis (cell death).

Another question that we had for Fletcher was whether he still considered GIST to be a role model for other cancers. He replied that GIST was the model for every other molecularly-targeted cancer therapy in solid tumors. He said that chronic myelogenous leukemia was also a role model for targeted therapies.

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Who are we, what do we do?

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

How to join

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

Privacy

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

How to help

Donations to The Life Raft Group, incorporated in New Jersey, U.S.A., as a 501(c)(3) nonprofit organization, are tax deductible in the United States.

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

The Life Raft Group
 40 Galesi Dr.
 Wayne, NJ 07470

Disclaimer

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