

Life Fest '08 a success!

By Erin Kristoff
LRG Newsletter Editor

Despite last minute cancellations, delays, complications and flash floods due to Hurricane Ike, the Life Raft Group's fourth Life Fest meeting, held September 12 through 14 at the Hyatt Regency O'Hare in Chicago, Ill. was very successful.

The Reception Dinner on Friday night was kicked off by a cocktail hour in which survivors, caregivers, doctors, pharmaceutical representatives and



Attendees listen to Donna Mazzone, at a side-effects workshop Saturday.

See LIFE FEST, Page 11

Battling gastrointestinal stromal tumor



LIFE RAFT GROUP



November 2008

In memory of Bob Spiegel, Sharla Ellingham,
Amanda Starnes, David Paulsen & Bill Roth

Vol. 9, No. 11

Plasma level testing: Why it is important and how to do it

The Life Raft Group has been speaking a lot lately about plasma level testing. Many GIST survivors and caregivers have asked questions about its relevance/importance and how to go about getting tested. In this issue, we hope to clarify this process. The following article by LRG Science Coordinator, Jerry Call will explain its relevance and discusses a presentation made by Dr. George Demetri at the 2008 Gastrointestinal Cancers Symposium.

Correlation of imatinib plasma levels in GIST patients

A higher concentration of Gleevec in the blood correlates with better clinical outcome according to George Demetri, M.D., of the Dana-Farber Cancer Institute. In an interview

See PLASMA, Page 8

GISTers in Netherlands & Belgium hold 5th annual meeting in 'Life Raft'

By Anja Long

Contactgroep GIST/Life Raft Group Netherlands/Belgium

It was suggested three years ago that the annual meeting of the Contactgroep GIST/Life Raft Group Netherlands/Belgium should be held on a boat i.e. the so-called "Life Raft". Well, for the five-year jubilee meeting of the group, held on October 4, 2008, this is exactly what happened. The boat was moored at Tolkamer on the river Rhine, right on the border with Germany, where the Rhine enters Holland.

for the meeting: patients, caregivers, speakers, committee members, representatives from Novartis (Pfizer could not attend as they had their own meeting that weekend) and last but not least, the



The Count of Bylant at Tolkamer

chairman and director of the Dutch Federation of Cancer Patient Groups (NFK), Ms. Anemone Bögels and Dr. Mrs. Els Borst-Eilers, a former Health Minister in the Netherlands.



VAN DE GRAAF

The morning consisted of a coffee reception and the speaker of the day, Prof. Dr. Winette van de Graaf, one of the leading GIST experts in the Netherlands and professor of Translational Medical Oncology at the Radboud University Nijmegen Medical

See NETHERLANDS, Page 6

NEWS

About 120 people assembled

Check out the US Presidential Candidates' stands on cancer in the healthcare plan on page 5!



New treatments for D842V mutations

By Jerry Call
LRG Science Coordinator

Effective treatments for metastatic GIST were born in 2000 when Gleevec transformed the management of GIST. Treatment with Gleevec resulted in substantial benefit for 85 percent of GIST patients, up dramatically from the historical benefit rate of about 5 percent.

The 15 percent of patients that do not respond to Gleevec are made up of several groups, including some with wild-type GIST (no detectable mutation in KIT or PDGFRA, the two genes most commonly mutated in GIST). The other major group of patients that tend to not respond to Gleevec are patients with the most common PDGFRA mutation, a PDGFRA^{D842V} mutation in exon 18. This mutation is also insensitive to treatment with Sutent. Patients with PDGFRA^{D842V} mutations make up about four to five percent of all GIST patients.

Maria Debiec-Rychter, M.D., Ph.D., of the Catholic University of Leuven, Belgium and her colleagues, have recently identified two drugs that inhibit the PDGFRA^{D842V} mutation and represent promising new treatments for patients with this mutation. Barbara Dewaele was the first author of the paper which was recently published in *Clinical Cancer Research*. Debiec-Rychter is a member of the LRG research team and this work was partially funded by the Life Raft Group.

The Leuven team found that dasatinib and IPI-504 were both effective inhibitors of PDGFRA^{D842V} mutations in labo-

ratory experiments. These experiments included tests against Ba/F3 cells (cells engineered to test specific mutations) and actual tumor cells taken from a patient with the PDGFRA^{D842V} mutation.

Dasatinib has been extremely effective for Gleevec-resistant chronic myelogenous leukemia (CML) and it is approved for that purpose in the U.S. and other countries. Dasatinib is manufactured by Bristol-Myers Squibb and the trade name in the U.S. is Sprycel; while in trials, it is/was called BMS-354825. After a slow start in phase I trials that included 18 GIST patients, there is renewed interest in dasatinib for GIST, at least in some unexplored populations. There is an open phase II trial in Switzerland for GIST patients that have never had Gleevec (first-line treatment or “Gleevec-naive”). Gleevec-resistant GIST patients are also eligible for a phase II trial of dasatinib in advanced sarcomas in the United States.

IPI-504 also effectively inhibited the PDGFRA^{D842V} mutation in the lab by a different mechanism than dasatinib. While dasatinib blocks the PDGFRA signal without damaging the PDGFRA protein, IPI-504 treatment results in the destruction of the PDGFRA protein. IPI-504 is a HSP90 inhibitor manufactured by Infinity Pharmaceuticals. It is in phase III trials for GIST patients with resistance to Gleevec and Sutent.



DEBIEC-RYCHTER

The Life Raft Group

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.).

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.

To donate by credit card, go to www.liferaftgroup.org/donate.htm

Donations by check can be made to The Life Raft Group and should be mailed to:

The Life Raft Group
40 Galesi Dr., Suite 19
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.



Congratulations Ashley!

On November 8, LRG member and Pediatric GISTer, Ashley Young, 23, will marry her long-time boyfriend, Mark Vincent, 21 at their home in Madison, Conn. With friends and family present. The couple have been together for three years.

Ashley is an active and vital member of the LRG; in June she helped the LRG by acting as Pediatric GIST Co-Chair for the NIH Clinic Planning Committee.

November 2008 US clinical trial update

By Jim Hughes
LRG Clinical Trials Coordinator

United States

Dasatinib Phase 2: This trial has been on-going for over a year. Initially the trial was for 12 different types of sarcoma; GIST has recently been added to the list of conditions that will be accepted for this oral drug. Dasatinib (BMS-354825) was tried in GIST in a Phase 1 trial in 2004 and 2005 for patients failing imatinib. At ASCO 2005, it

was reported that nine GIST patients entered the trial and had mixed results. Since that time recent publications indicate that Dasatinib is a potent in vitro inhibitor of several GIST mutations. These have highlighted the potential of Dasatinib as a second and third line drug especially for PDGFRA mutation GIST. Patients must have failed imatinib to enter this trial. Prior treatment with sunitinib is not required. This trial is open in 12 states and the District of Columbia.

OSI-930 Phase 1: No longer recruiting.

International

Nilotinib Phase 2: Novartis has opened a front line study of Nilotinib for GIST in Bad Saarow, Germany. Patients with unresectable GIST will be given Nilotinib instead of Glivec. Participants may not have had prior nilotinib. This trial plans to accrue 40 patients over the next year. Contact: Novartis Basel + 41 61 324 1111. NCT # 00756509. Novartis internal # CAMN107DDE06. EUDRACT- Nr. 2008-000358-11.

Imatinib + Bevacizumab

Imatinib with or without Bevacizumab in patients with metastatic/unresectable GIST

Phase: III
Conditions: GIST
Strategy: Block KIT Protein and inhibit GIST tumor blood vessel growth
NCT#: NCT00324987
Sites: Approximately 180 sites are recruiting in the US. There is no central contact info. Please check clinicaltrials.gov or cancer.gov for US trial sites
British Columbia Cancer Agency, Vancouver, BC
Charles Blanke, MD, 604-877-6098

Imatinib or Sunitinib

Safety and effectiveness of daily dosing with sunitinib or imatinib in patients with GIST

Phase: III
Conditions: GIST
Strategy: Block KIT/PDGFR protein
NCT#: NCT00372567
Contact: Pfizer
pfizercancertrials@emergingmed.com
Telephone: 1-877-369-9753
Sites: **Fox Chase Cancer Center (FCCC)**, Philadelphia, Penn.
1-800-FOX-CHASE
Monica Davey, RN
Margaret von Mehren, MD
North Shore Univ. Health System, Evanston, Ill.
Glenview, Ill.
Highland Park, Ill.
Elita Fine, RN, .847-570-2698
Bruce Brockstein, MD
New York, N.Y.

IPI-504

Study of IPI-504 in GIST patients following failure of at least imatinib and sunitinib

Phase: III
Conditions: GIST
Strategy: Destroy mutant KIT/PDGFR protein
NCT#: NCT00688766
Contact: GIST Phase 3 Team, 1-877-504-4634
RINGtrialinfo@INFI.com
Trial Website: www.ringtrial.com
Sites: **Dana Farber Cancer Institute (DFCI)**, Boston, Mass.
Tarsha Colon, RN, BSN, 617-632-5117
Massachusetts General Hospital, Boston, Mass.
Barbara Rattner, RN, 617-724-2333
Edwin Choy, MD, PhD
Oncology Specialists, S.C., Park Ridge, Ill.
Laura Magid, 847-268-8579
Pamela Kaiser, MD
New Bern Cancer Center, New Bern, N.C.
Jenifer Haggard, 252-638-0422
Richard Gorman, MD
FCCC, Philadelphia, Penn.
Monica Davey, RN
1-800-FOX-CHASE
Margaret von Mehren, MD

Nilotinib

Evaluation of Nilotinib in advanced GIST previously treated with imatinib & sunitinib

Phase: III
Conditions: GIST
Strategy: Block KIT/PDGFR protein
NCT#: Not Yet Available
Contact: **FCCC**
Telephone: 1-800-FOX-CHASE
Sites: **FCCC**, Philadelphia, Penn.
Monica Davey, RN
Margaret von Mehren, MD

BIIB021 (CNF2024)

Open-Label, 18FDG-PET pharmacodynamic assessment of effect of drug in GIST

Phase: II
Conditions: GIST
Strategy: Destroy mutant KIT/PDGFR protein
NCT#: NCT00618319
Contact: **Biogen-Idec**
oncologyclinicaltrials@biogenidec.com
Sites: Contact Biogen-Idec
Memorial Sloan-Kettering Cancer Center (MSKCC), New York, NY

Dasatinib

Trial of dasatinib in advanced sarcomas

Phase: II
Conditions: GIST
Strategy: Block KIT/PDGFR protein and related GIST tumor signal paths
NCT#: NCT00464620
Contact: There are 19 sites with contact information listed at www.clinicaltrials.gov.

Imatinib + Pegylated Interferon-a 2B

Phase II study combines targeted therapy with immunotherapy, Imatinib + Pegylated Interferon-a 2B in imatinib-naïve GIST patients

Phase: II
Conditions: GIST
Strategy: Block KIT/PDGFR protein and stimulate immune system to destroy GIST cells
NCT#: NCT00585221
Contact: **Ongoing but no longer recruiting Huntsman Cancer Institute**
University of Utah, Salt Lake City, Utah
Jessica Moehle
801-587-4438
Suzanne Dodd

Kreutz lives and works with cancer

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“I saw the pain in my wife’s eyes for me. Then I saw her mind work through how she and the boys were going to survive without me. I felt I had let them down.”

And that was just the beginning of the emotional rollercoaster for Ed Kreutz as he learned his diagnosis on July 30, 2002. Little did it matter that the sales consultant didn’t choose to have cancer. The very fact that he had cancer at all added a pinch of guilt to a large helping of anxiety.



KREUTZ

Ed’s only warning sign was that he hadn’t been feeling well for a while. “Then one night, I developed sharp stabbing pains in my abdomen,” he says. “My wife said I looked ashen. She took me to the emergency room where I was given a CT scan. It showed a tumor the size of a grapefruit.”

Ed was admitted, and surgery to remove the tumor – along with his spleen and 15 percent of his stomach – was merely the first step. His 17-day hospital stay revealed the culprit to be GIST. To make matters worse, GISTs do not respond to conventional treatments, such as radiation or traditional chemotherapy. Just two years later, another GIST turned up, and Ed needed a new strategy in his cancer fight.

“Luckily, the FDA had just fast-tracked a drug called Gleevec, an alternative form of chemotherapy that targets abnormal proteins that are fundamental to the cancer itself. In some patients, it stops the blood supply to the tumors,” Ed says. “When the tumor returned, I was put on the drug, and 60 days later the tumor receded. I was one of the lucky ones. If I had been diagnosed a year earlier, I wouldn’t be here now.”

See KREUTZ, Page 7

Pediatric GISTer tells it like it is at Teenage Cancer Trust

Rachel Gilbert was diagnosed in 2001 with GIST at the age of just 15. Since then she has bounced around from Gleevec (for seven years) to Sutent and back to Gleevec.

In that time she has grown tremendously and is now a young woman.

Recently, Rachel was invited to speak at a Teenage Cancer Trust conference under the heading “Rare and Isolated” Teenage Cancer Trust is a charity devoted to improving the lives of teenagers and young adults with cancer. Jimmy’s Teen TV was on hand to record the



event. If you would like to see Rachel speak about GIST, you can view it at www.liferaftgroup.org/library_videos.html

Arizona GISTers meet!



Arizona GISTers met on October 19 in Scottsdale. According to Local Group Coordinator, Janeen Ryan (second from right), “It was a nice turn out with old friends reuniting and new ones being made. We shared a lot of information and stories. Everyone is looking forward to the next meeting in January, we hope for even more attendees. Those present were Larry Ryan, Delle & Sarah Ferris, Ellen MacDonald, Frank Schranz, Ben & Kari Redman and Stephen & Eleanor Lewis.

GET 'EM WHILE THEY'RE HOT!

The LRG will soon be selling 2009 Entertainment Coupon books for a limited time. These books offer discounts and coupons in areas like dining, travel and shopping and cost between \$20 to \$40 dollars. Check out our website in the coming month for more information on how to get one for yourself!

Flu Shots

Cancer patients are considered high priority candidates for annual influenza immunizations and this certainly includes GIST patients. For those patients living in countries approaching winter (like the United States), this is the time to get your flu shot. In addition, you should talk to your doctor about getting a pneumococcal vaccine.



Campaign 2008

McCain vs. Obama: Looking at the candidates' health plans specific to cancer

If you live in the United States you cannot turn on the TV, radio or computer without seeing an ad, article or comedy sketch about one of the 2008 presidential candidates.

Record numbers have flocked to register in what many believe to be one of the most important elections in a generation.

Senators McCain and Obama have spent over 395 million dollars combined on campaign ads that state their take on the issues that are most important to Americans. While economy is most certainly the frontrunner, a September 19-21 CNN poll shows that healthcare is the second highest priority for voters.

So, while McCain and Obama make their "last stands" in key battleground states, we will take one last look at the candidates' healthcare plans as they relate to cancer.

Please refer to www.johnmccain.com/healthcare and www.barackobama.com/issues/healthcare for more details.

McCain




Double Federal Funding	Yes
Yes (through state/federal sponsored GAPS)	Yes
Yes	Yes
Yes	Yes
Yes	Yes
Supports translational research	Not Stated
Not Stated	Not Stated
Not Stated	Not Stated
Yes	Yes



Increased funding for research
Cancer preventative services
End pre-existing condition exclusions
Improve access to clinical trials
Increase coordination of activities
Identify health impacts of environment
Support advances personalized medicine/translational research
Support for cancer survivors and families
Supports evidence-based quality measures
Strengthen medical workforce
Supports follow-on biologics

Obama



Double Federal	Yes
Yes	Yes
Yes	Yes
Yes	Yes
Yes	Yes
Supports genomics research	Yes
Yes	Yes
Yes	Yes
Not Stated	Not Stated

NETHERLANDS

From Page 1



Over 120 people gathered for the fifth ContactgroepGIST/Life Raft Group Netherlands/Belgium meeting on October 4.

Center.

Her lecture was called “To Be a Guest Alongside GIST” and highlighted various new developments in the treatment of GIST, in particular some proposed clinical

trials in the Netherlands. She made a telling remark when she mentioned the ambivalent feelings her GIST patients often express, “Having drugs like Gleevec is wonderful, but at the same time it also feels like I am dancing on a volcano; it can erupt at any moment.”

The “The Count of Bylant” stayed moored for the morning session, which gave everybody plenty of chances to see and experience how busy this stretch of the river Rhine is. But after a very good lunch, and group photograph, it was anchors away and off downriver to the town of Arnhem. It was a lovely trip with beautiful views of the shores of the river. In Arnhem, we turned at the site of “A Bridge Too Far”, back towards Tolkamer. It made for a very relaxed afternoon, where there were more chances for attendees to min-

“Having drugs like Gleevec is wonderful, but at the same time it also feels like I am dancing on a volcano; it can erupt at any moment.”



ASSELBERGS

gle, interact, renew acquaintances and make new ones.

The only official bit of the afternoon was the presentation of the Committee Report, whereby Edwin van Ouwerkerk Moria, Chairman of the Meeting, outlined the challenges facing the present committee, especially since the group has grown from a small group of enthusiasts in 2003, to the official Contactgroep GIST of today.

There are about 150 members and we are still growing. But it is still a small patient group and that makes it very difficult to find enough volunteers to join the committee or do tasks such as the newsletter or organizing the annual meeting.

This problem was immediately illustrated by the fact that three of the founder committee members have decided to step down at the end of 2008. This is in addition to the already vacant post of chairman since September 2007. Fortunately a new chairman has been found; Jack Asselbergs will take over in 2009. Other committee members will hopefully be found in the next few months. The group has also engaged a professional coach, who will hopefully be able to help to en-

sure the future of the group. It has already become clear that priorities have to be set and that may mean a different way of carrying out certain tasks, such



VAN OUWERKERK MORIA

as secretarial and financial ones.

But it is not all doom and gloom for sure. All of the attendees enjoyed the meeting, which was apparent by the enthusiastic farewells to each other, promises of mail contact, meeting up and keeping in

touch. The organizers can look back on another successful annual meeting. Again it was proved that personal contact is very important to members and much appreciated.

But next year we will probably not be on a boat... Or so I think!

Global GIST Network adds new GIST representative



Global GIST-Network



Samoa
John Galuvao
leasii@gmail.com

KREUTZ

From Page 4

“I am still going through it,” he adds. “I must take this pill, which is essentially a dose of poison, every day. At some point the cancer will develop a resistance to it, and when that happens, there will hopefully be other options for me.”

In the meantime, Ed has found the Life Raft Group. “The name of the organization is appropriate because those of us who are taking Gleevec are on a ‘life raft’ while we wait for research to give us a more permanent alternative,” he says. “Being a part of their activities has meant a great deal to me and others, so while I try not to beat people over the head about contributing to it, I cannot downplay its importance either.”

Until an alternative to Gleevec is found, Ed is making the most of his time at home and at the office.

“Every day I wake up is a gift. Time with my family is precious. I try not to let cancer change me, but I have noticed intensity in emotions and how I view every day,” he says. “The most important thing I can convey here is to please get your annual physical. Get those nasty tests done. The harsh reality is that one in three women and one in two men will get cancer in their lifetime. This can happen to you.”

David Paulsen, 57

David E. Paulsen, 57, of Lakewood, Colo., passed away October 8, 2008 after a long and courageous battle with GIST. He was the beloved husband of Barbara; father of Travis (Sonja) and Adam (Anne); son of Gerald and Mary; brother of Barbara (Bill) Swanson, Laurie McCauley and Tom (Joann).

Dave was born Jan. 5, 1951 and married Barb (Bernhard) on Jan. 8, 1972. He graduated from Ft. Lewis College in 1973, and completed his MBA at Regis University in 2000.

He was a national bank examiner for 10 years and worked in the banking industry for 23 years. He coached youth football and baseball from 1984 to 1989.

TRIALS

From Page 3

Perifosine + Imatinib

Phase II study of Perifosine + Gleevec in GIST patients

Phase: II
 Conditions: GIST
 Strategy: Block KIT/PDGFRα protein and downstream signal path
 NCT#: NCT00455559
 Contact: **Online Collaborative Onc. Group**
 ocogtrials@ocog.net
 Telephone: 415-946-2410
 Sites: Los Angeles, Calif.
 Sant Chawla, Md.
 Coeur D’Alene, Idaho
 Park Ridge, Ill.
Oncology Specialists
 Kathy Tolzein, RN, 847-268-8200
 Grand Rapids, Mich.
 Sayre, Penn.
 Houston, Texas
MD Anderson Cancer Center
 800-392-1611

XL820

Phase 2 study of XL820 in advanced GIST resistant to imatinib and/or sunitinib

Phase: II
 Conditions: GIST
 Strategy: Block KIT/PDGFRα protein and inhibit GIST tumor blood vessel growth
 NCT#: NCT00570635
 Contact: **Ongoing but not recruiting patients**

Doxorubicin + Flavopiridol

Doxorubicin and Flavopiridol in treating patients with metastatic or recurrent unresectable sarcomas

Phase: I
 Conditions: GIST/Sarcoma
 Strategy: Freeze the GIST cell division cycle
 NCT#: NCT 00098579
 Contact: David D’Adamo, MD
 Telephone: 212-639-7573
 Sites: **MSKCC**, NY, N.Y.

Imatinib + Sunitinib

Imatinib & sunitinib in treating GIST patients

Phase: I
 Conditions: GIST
 Strategy: Block KIT/PDGFRα protein
 NCT#: NCT00573404
 Contact: Clinical Trials Office
 Telephone: 800-811-8480
 Sites: **Vanderbilt-Ingram CC**,
 Nashville, TN
 Jordan Berlin, MD, 615-343-4128

Sorafenib (Nexavar)

Sorafenib in treating patients with malignant GIST that progressed during or after previous treatment with imatinib and sunitinib.

Phase: II
 Conditions: GIST
 Strategy: Block KIT/PDGFRα protein, downstream KIT/PDGFRα signal path and related GIST tumor signal paths
 NCT#: NCT00265798
 Contact: **Univ. Of Chicago Cancer Res. Center**,
 Chicago, Ill.
 Ravi Salgia, MD
 rsalgia@medicine.bsd.uchicago.edu
 Blase Polite, MD
 bpolite@medicine.bsd.uchicago.edu
 Telephone: 773-834-7424
 Sites: **City of Hope**, Duarte, Calif.
 Warren Chow, MD, 626-256-4673
USC-Norris Cancer Center,
 Los Angeles, Calif.
 Hein-Josef Lenz, MD, 323-865-3955
UC-Davis, Sacramento, Calif.
 David Gandara, MD, 916-734-3771
Decatur Memorial Hospital,
 Decatur, Ill.
 James Wade, MD, 217-876-6617
Oncology/Hematology Assoc.,
 Peoria, Ill.
 John Kugler, MD, 309-671-5180
 James Knost, MD,
 jkknost@ohaci.com
Central Illinois Hem/Onc,
 Springfield, Ill.
 Edem Agamah, MD, 217-525-2500
Univ. of Michigan, Ann Arbor, Mich.
 Scott Schuetze, MD, 734-647-8925
MSKCC, New York, N.Y.
 David D’Adamo, MD, 212-639-5720
Medical College of Wisconsin
 Milwaukee, Wis.

BEZ235

A Phase I/II multi-center, open-label study, administered orally on a continuous daily schedule in adult patients with advanced solid malignancies.

Phase: I/II
 Conditions: Adv. Solid Malignancies/ Adv. Breast Cancer
 Strategy: Block KIT/PDGFRα downstream signal path
 NCT#: NCT00620594
 Contact: Novartis
 Telephone: 862-778-8300
 Sites: **Nevada Cancer Institute**,
 Las Vegas, Nev.
 Montessa Linsangan,
 702-822-5282
Sarah Cannon Res. Institute,
 Nashville, Tenn.
 Howard Burris, MD, 615-329-7274

See TRIALS, Page 9

PLASMA

From Page 1

with Peggy Peck on the medpageTO-DAY website, Dr. Demetri said that the imatinib plasma level was not associated with age, gender, disease bulk, or body weight. “You really need to do pharmacokinetic testing to determine the level of imatinib because there are no clues,” Demetri reported at the Symposium. The

sults suggest that monitoring pharmacokinetic/ pharmacodynamic relationships may provide novel predictive markers and that exposure to adequate IM trough plasma concentrations (>1,110 ng/mL) is important for optimal clinical response.”

A video report is available on www.liferaftgroup.org/library_videos.html. In the interview, Dr. Demetri explained that “when you give Gleevec or any other kinase inhibitor to a group of patients, they will handle it very differently, some people will have high levels and some people will have low levels... The important part about that is whether we for years might be underdosing people, and whether we

Plasma levels and response rates

	Objective Response	Median Time to Progression	Objective Response Exon 11 patients
Quartile 1 <1,110 ng/ml	44%	11.3 months	55.6%
Quartile 2+3 >1,110 ng/ml - <2,040 ng/ml	67%	30.6 months	94.1%
Quartile 4) >2,040 ng/ml	74%	33.1 months	92.3%

findings suggest that “we may have been under-dosing some people,” he said.

This report is based on analysis of the pharmacokinetic data from the original phase II Gleevec trial for GIST (B2222), which started in July of 2000. Plasma levels (plasma is one component of blood) taken after 29 days of Gleevec, were available for 73 of the 147 patients enrolled in the trial. These plasma levels were grouped into quartiles according to imatinib trough (IM) plasma concentrations (the level of drug in the blood at its lowest point during the day, just before taking the daily Gleevec capsule). The plasma levels and response rates of these groups are listed in the table above.

The authors concluded that, “Exposure to adequate drug levels of imatinib appears to correlate with clinical benefit; patients with the lowest imatinib levels show lowest objective response and shortest time to progression. These re-

perhaps should develop a blood test to check the levels of this drug in people’s blood and have more certainty that there’s actually therapeutic levels in the blood.” Demetri went on to explain that “it’s possible that we could have done this analysis and found nothing at all, but in fact, we saw something that is a bit worrisome for the patients with the lowest levels of the drug.” The next step according to Demetri will be to “... talk with our colleagues, decide exactly how much this is worth pursuing, (and) decide how to mount a large trial.”

Testing How-To

Plasma level testing can be done by any of the doctors that you see, but remember that **your doctor must register** with Avantix Labs (The company that is providing the free testing) in order to do so.

This and further information can be found at www.cmlalliancebloodleveltesting.com.

Signing up:

- Complete Healthcare Provider registration form online or via fax.
- Upon approval, you will receive a unique account/User ID number via email or fax.

- Complete registration form online or via fax.

Sample Collection:

- Order Sample Collection kit (The LRG handed these kits out at Life Fest, more are still available)
- You doctor should draw 5mL of blood in a purple vacutainer (with EDTA)
- **Blood should be drawn no more than 2 hours before the next scheduled dose of Gleevec**
- Within one hour of the collection, your doctor should centrifuge the blood sample and harvest about 2 mL of plasma and place in a 5 mL plasma polypropylene collection tube
- Place the mailing label printed from the CML Alliance website on the Test Request form before submitting sample(s) for analysis. Make sure patient and physician names are on the label
- **Shipping:**
- Place the plasma sample with the appropriate label along with the test request form in a padded envelope. The sample may be shipped at room temperature. No dry ice or cold pack is required
- Ship the sample Monday through Thursday via FedEx overnight. **Samples should not be sent on Friday or Saturday.**
- Test results showing imatinib concentration will be sent to you via email or fax
- For your records, a hard copy of the result will be sent to your mailing address via U.S. Postal Service

All of the forms mentioned can be found at the CML Alliance website listed at the beginning of the Testing How-to.

Stay Tuned! The GIST Alliance is coming at the end of November. Details to follow.

ALERT!

You can do your holiday shopping and contribute to the LRG by using Goodshop or iGive. Go to www.igive.com or www.goodshop.com to start shopping!



Did you miss the Familial GIST webcast on October 3?

Have no fear! You can find an archived recording of all of our webcasts in our LRG library. Go to www.liferaftgroup.org/library_videos.html.



TRIALS

From Page 7

AUY922

Phase I-II study to determine the MTD of AUY922 in advanced solid malignancies and efficacy in HER2+ or ER+ locally advanced or metastatic breast cancer.

Phase: I
 Conditions: Breast Cancer/Solid Malignancies
 Strategy: Destroy mutant KIT/PDGFR
 NCT#: NCT00526045
 Contact: **Novartis**
 Telephone: 800-340-6843
 Sites: **UCLA**, Los Angeles, Calif.
 Carolyn Britten, MD, 310-825-5268
DFCI, Boston, Mass.
 Tarsha Colon, RN, BSN
 617-632-2201
Washington University,
 St. Louis, Mo.
 Paella Fracasso, MD, 314-362-5654
Nevada Cancer Institute,
 Las Vegas, Nev.
 Sunil Sharma, MD, 702-822-5360
Medical College of Georgia,
 Augusta, Ga.
 Thomas Samuel, MD, 706-721-2505
Cancer Therapy and Research Center,
 San Antonio, T.X.
 Monica Mita, MD, 210-562-1797
MD Anderson Cancer Center (MDA),
 Houston, T.X.
 Vassiliki Papadimitrakopoulou, MD,
 703-792-6363

BGT226

A phase I/II study of BGT226 in patients with advanced solid malignancies including those with advanced breast cancer

Phase: I
 Conditions: Solid Tumors, Breast Cancer,
 Cowden Syndrome
 Strategy: Block KIT/PDGFR downstream signal path
 NCT#: NCT00600275
 Contact: Novartis
 Telephone: 800-340-6843
 Sites: **Nevada Cancer Institute**,
 Las Vegas, Nev.
 Sunil Sharma, MD
DFCI, Boston, Mass.
 Kathryn Josephs, 617-632-7652
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Massachusetts General Hospital,
 Boston, Mass.
 Natasha Isaac, 617-726-6225
 Steven Isakoff, M.D.
Cancer Therapy and Research Center (CTRC),
 San Antonio, T.X.
 Jerry Medina, 210-450-1789
 Francis J. Giles, MD

BIIB021 (CNF204)

Once or twice daily administration of BIIB021 to solid tumor subjects

Phase: I
 Conditions: Advanced Solid Tumors
 Strategy: Destroy mutant KIT/PDGFR
 NCT#: NCT00618735
 Contact: **Biogen-Idec**
 oncologyclinicaltrials@biogenidec.com
 Sites: **Premiere Oncology**,
 Santa Monica, Calif.
 Lee Rosen, MD, 310-633-8400
So. TX Accelerated Research Therapeutics (START),
 San Antonio, TX
 210-593-5265

GDC-0941

An open-label phase I, dose-escalation study in patients with locally advanced or metastatic solid tumors for which standard therapy is ineffective, intolerable or does not exist

Phase: I
 Conditions: Solid Tumors
 Strategy: Block KIT/PSGFR downstream signal path
 Sites: **DFCI**, Boston, Mass.
 Tarsha Colon, RN, BSN,
 617-632-5117
TGen, Scottsdale, Ariz.
 Joyce Ingold, RN, 480-323-1339

IPI-493

Phase I dose escalation study of IPI-493

Phase: I
 Conditions: Advanced malignancies
 Strategy: Destroy mutant KIT/PDGFR
 NCT#: NCT00724425
 Sites: **Premiere Onc.**, Scottsdale, Ariz.
 Patricia Shannon, RN
 480-860-5000 ext 223
 David Mendelson, MD
Premiere Onc., Santa Monica, Calif.
 Marilyn Mulay, NP, 310-633-8400
 Lee Rosen, MD
San Diego Pacific Onc. and Hem. Assoc., Encinitas, Calif.
 Karen Brady, RN, 760-752-3340
 Richard Just, M.D.
Univ. of Colorado Health Science Center,
 Aurora, Colo.
 Stacy Grolnic, RN, 720-848-0655
 Colin Weekes, MD, PhD

LBH589

Phase IA, two-arm, multi-center, dose-escalation study, by IV on two dose schedules in adult patients with advanced solid tumors and non-Hodgkins lymphoma

Phase: I
 Conditions: Adv. Solid Tumors/Lymphoma
 Strategy: Unblock GIST cell death genes
 Sites: **Nevada Cancer Inst.**, Las Vegas, Nev.
 Donna Adkins, RN, 702-822-5173
 Sunil Sharma, MD

PX866

Phase I trial of oral PX866

Phase: I
 Conditions: Advanced Solid Tumors
 Strategy: Block KIT/PDGFR downstream signal path
 NCT#: NCT00726583
 Sites: **Univ. of Colorado Health Sciences Center**,
 Aurora, Colo.
 Sharon Hecker, 720-848-0667
 Antonio Jimeno,
MDA, Houston, T.X.
 Rhonda Clement, 713-563-3559
 Roy Herbst, MD

SF1126

Phase I open label, safety, pharmacokinetic & pharmacodynamic dose escalation study of SF1126 given twice weekly by IV to patients with advanced or metastatic tumors

Phase: I
 Conditions: Solid Tumors
 Strategy: Block KIT/PDGFR downstream signal path
 Contact: **Semaphore Pharmaceuticals**
 Telephone: Ulrich Schwertschlag, 978-257-1926
 Sites: **Arizona Cancer Center**, Tucson, Ariz.
 Daruka Mahadevan, MD, 530-626-0191
Indiana University, Indianapolis, Ind.
 Elena Chiorean, MD, 317-278-6942

SNX5422

Safety and pharmacology in patients with refractory solid tumor malignancies

Phase: I
 Conditions: Solid Tumor Malignancy
 Strategy: Destroy mutant KIT/PDGFR
 NCT#: NCT00506805
 Contact: Pfizer Onc. Clinical Trial Information
 Telephone: 1-877-369-9753
 Sites: **TGen Clinical Res. Services**,
 Scottsdale, Ariz.
 Joyce Ingold, RN, 480-323-1339
 Ramesh Ramanathan, MD
Sarah Cannon Res. Institute,
 Nashville, Tenn.
 Howard Burreis III, MD

STA-9090

Once-weekly study in solid tumor patients

Phase: I
 Conditions: Solid Tumors
 Strategy: Destroy mutant KIT/PDGFR
 NCT: NCT00687934
 Sites: **DFCI**, Boston, Mass.
 Pilar De La Roche Mur, 617-632-5841
 Geoffrey Shapiro, MD, 617-632-4942
Karmanos Cancer Inst. (KCI), Detroit, Mich.
 Pat LoRusso, MD, 315-576-8716
 (# for all sites)
Mass. Gen., Boston, Mass.
 Boston, Mass.
 Pilar De La Roche Mur
Beth Israel Deaconess Med. Center (BIDMC),
 Boston, Mass.
 Pilar De La Roche Mur

TRIALS

From Page 9

STA-9090

Administered twice-weekly in solid tumor patients

Phase: I
 Conditions: Solid Tumors
 Strategy: Destroy mutant KIT/PDGFR
 Sites: **Premiere Oncology**,
 Santa Monica, Calif.
 Lee Rosen, MD, 310-633-8400
US Onc. Dayton Onc. & Hem., P.A
 Kettering, Ohio
 Robert Raju, MD

XL147

Study of safety and pharmacokinetics of XL147 in adults with solid tumors

Phase: I
 Conditions: Cancer
 Strategy: Block KIT/PDGFR downstream signal path
 NCT#: NCT00486135
 Sites: **DFCI**, Boston, Mass.
 Tarsha Colon, RN, 617-632-5117
Mary Crowley Med. Res. Ctr.,
 Dallas, Texas
 J. R. Dolan, 214-658-1943
 Gerard Edelman, MD

XL765

Study of safety and pharmacokinetics of XL765 in adults with solid tumors

Phase: I
 Conditions: Cancer
 Strategy: Block KIT/PDGFR downstream signal path
 NCT#: NCT00485719
 Sites: **KCI**, Detroit, Mich.
 Theresa Laeder, 313-576-9386
 Pat LoRusso, DO
START, San Antonio, Texas
 Gina Mangold, 210-413-3594
 Kyriakos Papadopoulos, MD

OSI-930

Dose escalation study of daily oral OSI-930 in patients with advanced solid tumors

Phase: I
 Conditions: Solid Tumors/Sarcoma
 Strategy: Block mutant KIT/PDGFR
 NCT#: NCT00513851
 Contact: **Ongoing but not recruiting**

CNF2024

Oral CNF2024 in advanced solid tumors

Phase: I
 Conditions: Tumors/Lymphoma
 Strategy: Destroy mutant KIT/PDGFR
 NCT#: NCT00345189
 Contact: **Active, not recruiting**

Mayer's art on 'Oncology on Canvas' tour

By **Erin Kristoff**
 LRG Newsletter Editor

LRG member and GIST survivor, Ellen Mayer is showcasing her artwork once again, this time in the Lilly "Oncology on Canvas" World Tour. Not only did Ellen showcase her work at the October 22 US Grand Finale & Awards presentation hosted by Regis & Joy Philbin, she showcased GIST, spreading awareness to Regis, Joy, Anita Chernenwski, the event coordinator and Richard Gaynor, the Chairman of Lilly Oncology.

The tour will now travel on to over 40 destinations in the US alone, such as Jefferson Hospital in Metairie, La., the Capital Region Cancer Center in Jefferson City, Mo. and the Cape Cod Hospital in Hyannis, Mass (A full 2008 calendar can be found at www.lillyoncologyoncanvas.com/common_pages/tour_calendar.jsp).



Ellen talks about GIST and her work with Richard Gaynor, the Chairman of Lilly at the U.S. Grand Finale hosted by Regis & Joy Philbin.

calendar.jsp).

Here is an excerpt from Mayer's description of "Always in My Head".

"My Goal in life is to tell as many people as I can what GIST is, and raise awareness in the medical field because many doctors never heard of GIST.

"My painting, called 'Always in My Head', tells the story in the faces I paint. I have Cancer, emotions of BEWILDERMENT, FEAR, DEATH, HOPE, UPS, DOWNS, TESTS, SURGERY, RECOVERY, QUESTIONS OF WHAT THE FUTURE WILL BE, and the STRENGTH to fight. Learning to have patience and how to have inner peace, and to live life with having Cancer.

*"I am an artist, I am not Cancer.
 Fear, Laughter, Dread,
 Happy, sad,
 Going on with life
 But, never leaving my head."*

To listen to an October 27 radio interview in which Mayer talks about GIST and her art, you can go to her website at www.mayergalleryart.com

Congratulations Ellen!



Ellen Mayer poses with her painting, "Always in My Head".

Pennsylvania GISTers meet

Pennsylvania local group coordinator, Kim Trout met with Judy and Matthew Galbo of Hanover. They shared stories, experiences with doctors and medications and coping mechanisms. "It was a beautiful day and it was great to meet new people who understand what each other is going through," said Kim. Another meeting is planned for Saturday, February 21, 2009.

A True 'Ironman'

Steven Eldred raised money for the LRG by entering in his first Ironman competition, July 19 in Lake Placid, NY. The money was raised in honor of his father-in-law, Erwin Johnson, an LRG member.

The LRG would like to congratulate Steven on completing the grueling two mile swim, 112 mile bike ride and 26 mile run. **Thanks Steven!**



Sharla Ellingham, wife, mother, grandmother, passes at 76

Sharla Bea Ellingham, age 76, of Polson, Mont., passed away at her home Friday, Oct. 17, 2008, from natural causes. She was born Oct. 15, 1932, in Hoopston, Ill., to Charlie and Olive (Sloan) Holmes. She attended schools there and graduated from Hoopston High School. Sharla worked in marketing and research while living in Illinois. She and Robert Elling-

ham married in Las Vegas in 1960. After leaving Las Vegas, they settled in the Bitterroot area in Montana, namely Connor. They moved to Polson 13 years ago to live in their home on Kings Point. Sharla was a member of the Polson Foursquare Church. Art and reading were her hobbies. She was preceded in death by her parents. Sharla is survived by her husband, Robert Ellingham of

Polson; and a son, Thomas (Cindy) Ellingham of Connor, Mont.; along with two grandchildren; and three great-grandchildren. Condolences to the family can be made at www.groganfuneralhome.com.



ELLINGHAM

LIFE FEST

From Page 1

guests met and made friends, many for the first time.

Amid shouts of, "I'm so glad to finally meet you!" and "Good to see you again!" were offers of "Let me introduce you to so-and-so," as

members introduced each other to family and other local members. The attendees then moved inside for a wonderful dinner, followed by speeches and the presentation of awards.

Dick Kinzig, Chicago-area Coordinator welcomed everyone and spoke about why he joined the LRG and how he founded the first local chapter. LRG Board President, Jerry Cudzil, delivered his first address as President. He honored former president, Stan Bunn and expressed his hopes for the future of the group. Executive Director, Norman Scherzer followed with a heartfelt speech about what keeps him fighting. Then it was on to the awards!

The Association of Online Cancer Resources (ACOR) received a Certificate



HELMAN

of Appreciation, graciously accepted by President, Gilles Frydman. Steve Rigg, who helped create the LRG Patient Registry, received an Allan Tobes Volunteer Award. Kendra Tobes presented the award after a touching speech about her late husband who acted as Chief Financial Officer, board member and local area coordinator

for the LRG. In a surprise twist, the Master of Ceremonies himself, Dick Kinzig, was also presented with a Volunteer Award. Finally, the Humanitarian of the Year Award was presented to Dr. Lee Helman, by Board Member, Ray Montague, for his role in the creation of the National Institutes of Health (NIH) Pediatric GIST clinic.

Saturday and Sunday's general sessions and workshops proved to be very informative. Special thanks must go out to Dr. Bruce Brockstein of Evanston Hospital and Donna Mazzone, RN of Lutheran General Hospital who filled in at the last minute for Dr. Jonathan Trent and Pat Neal, RN, respectively, both of MD Anderson in Houston, Texas.

Attendees were offered sessions on topics like GIST 101, an LRG Research Team update, GIST survival strategies, nutrition, drug development, coping, side-effects and building a personal survival plan.

A bonus for the weekend was a spectacular Saturday night dinner, planned by LRG member, Phil Vettel. Anyone who wished to attend, enjoyed a fantastic dinner at Tavern at the Park, followed by a trip to Millennium Park. Although it was a little wet, everyone had a great time, especially the interactive Crown



Survivors, caregivers and many others got to know each other at Friday night dinner.

Fountain. Very special thanks to Michael O'Connor for providing a bus and Pete DeCastro of Tavern at the Park for going above and beyond charitable.

Other thanks include Jennifer Sisson and the staff of the Hyatt Regency O'Hare for their great support during the weekend; the Chicago-area local chapter members who volunteered to aid LRG staff and help their fellow members. Of course, a big thanks to everyone who attended for making the event such a success.

Please go to www.liferaftgroup.org/members_lifest.html if you would like to view:

- Life Fest Presentations
- Videos from the Reception Dinner
- A photo slideshow of the weekend or
- Life Fest 2008 agenda



"It is wonderful to see people from all over...interacting. I particularly like to see new GISTers seeking advice from 'old' GISTers," said one member.

Mark your calendars!

- Rhode Island GISTers will be meeting on **November 22**. Please contact Susan Farmer at sfarmer10@cox.net for more information.



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