

Dr. Brian Druker

Battling the Dragon

Monthly Newsletter of the Life Raft Group



*The new name for
STI-571*

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**Dr. Demetri says:
"Flu shots are a
Good Thing!"
Check with your
Doc today; flu is
expected by
January.**

▶ In a briefing to the "First Annual CSFB European Large Cap Pharmaceutical Conference", Novartis CEO Daniel Vasella announced that Glivec would be the new name for STI-571. As is typical, the announcement seems to have been made first to the financial community. Inside this issue I'll comment on other news from Novartis that appeared in Vasella's briefing.

▶ The American Society for Hematology conference the first week of December has a number of papers on CML and STI-571. News will be forthcoming as we get it.

▶ Next month's issue may have an article written by the Doctors/nurses from OHSU (I'll keep you posted).

▶ We have four new members this month, bringing the total to 24. Forgive me if I missed anyone in the list below. If any of you run into anyone else on the study, please remind them that we exist and can communicate with them by email or by the newsletter. We also have 4 people on the newsletter-only list who are trying to get into one of the studies.

▶ The first version of the symptom survey is included in this issue, along with the usual member news.

▶ I didn't have room for a joke of the month; maybe next month if it's a slow news month. So long, and keep fighting.

Gary

Welcome to Life Raft Members Joining In December

In no particular order:

Rick H.

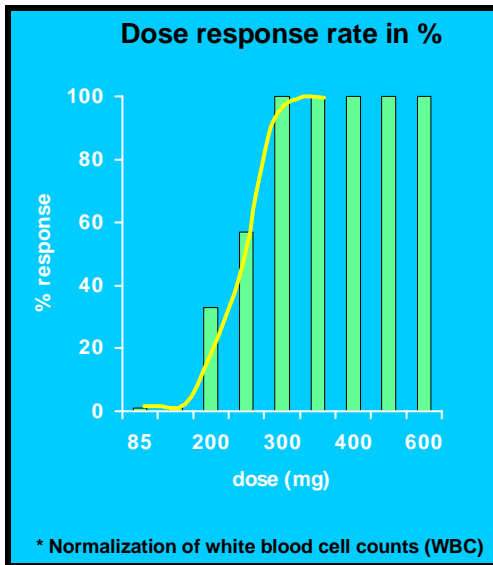
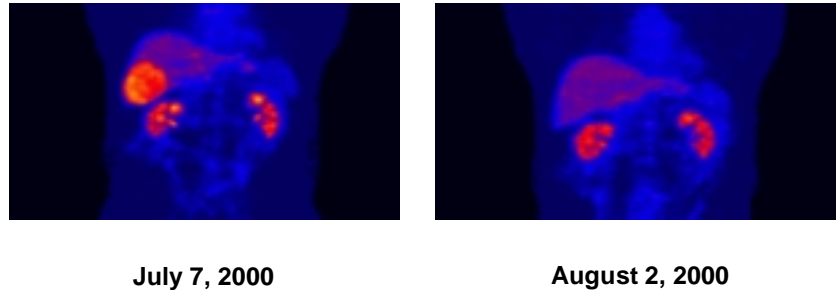
Gary K.

Linda O.

Cordelia S.

The three pictures on this page are from the Vasella presentation to investors. I have presumed that Novartis intends all of this for open distribution, since they placed it on their web site without restriction. The picture at top right shows one of us (or at least some one from the study) with a large liver tumor. The left portion shows the initial PET scan. The right portion clearly shows a “cold” tumor a month later. Without a CT, shrinkage can’t be seen.

**GIST Patient on Glivec™ –
 FDG-PET Before and After 4-Week Treatment**

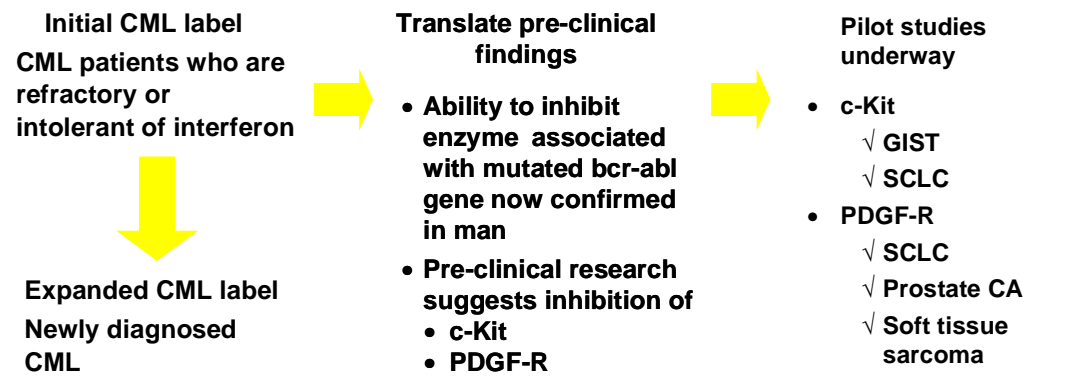


The graph at left shows a dosage study from the CML group. The lower axis is non-linear (I guess that doesn’t matter to investors). This partially suggests why the dosages in our study may have been chosen: 300 mg is the lowest for full response. 400 mg thus provides a cushion on the low end.

The chart below is the “things to come” side of the presentation. The part that says “Pilot studies underway” is the most interesting. There are two main areas: c-Kit (us), and platelet derived growth factor (I don’t know what the R stands for). I presume that SCLC is small cell lung cancer, which we’ve seen mentioned before. Other soft tissue sarcomas and prostate cancer also seem to be on the list. Perhaps LMS might be affected after all (through the PDGF route)?

Novartis also mentions a more generalized development approach aimed at the kinases, of which 500 are known, and up to 1000 more may be found as a result of genome research. I’ll continue to monitor the Novartis sites to see if anything else appears.

Glivec™ – Promise Beyond CML?



Member Symptom Survey

Interesting Web Sites

For those who have access to the Web, here are some interesting, useful, or otherwise related web sites.

Jerry Mayfield's CML/STI site:

www.newcmldrug.com

Dr. Demetri's web site:

www.sarcoma.net

The National Cancer Institute's CancerNet:

www.cancernet.nci.nih.gov

National Library of Medicine Literature search:

www.ncbi.nlm.nih.gov/PubMed

Member News in Brief

Candace is "officially" in remission according to Dr. Blanke!

Dr. B. also had good news for Trudy: major shrinkage, cold tumors in the PET scan.

Cordelia's tumors are shrinking and PET activity is down.

Anita had another good scan, with slightly slower progress (but last month was so dramatic!).

Bob's tumors have shrunk as well.

Sandi's have too (I love good news!).

Cynthia had 30% reduction in size after 4 weeks (despite being off for 10 days to allow her body to recover).

Tom and Trudy both had RDW increases. No news yet on why.

Joan had to come off Glivec temporarily due to liver enzyme and neutrophil problems.

Stephanie started on 600 mg!!!

Todd had major reductions in pain as well as shrinkage.

Jim had some further problems with kidney functions.

Jeff is hoping to return to the trial as his liver func-

Symptom	% of total	
	Yes	No
Nausea	40.0%	60.0%
Vomiting	7.1%	92.9%
Diarrhea	60.0%	40.0%
Chills	50.0%	50.0%
Mild Rash	26.7%	73.3%
Severe Rash	7.1%	92.9%
Headache	14.3%	85.7%
Insomnia	14.3%	85.7%
Swelling / fluid retention	40.0%	60.0%
Puffy eyes	42.9%	57.1%
Low blood counts	50.0%	50.0%
Fatigue	40.0%	60.0%
Reduced PET activity	100.0%	0.0%
Shrinkage	80.0%	20.0%
Liquefaction	77.8%	22.2%
Low neutrophils	25.0%	75.0%
Electrolyte imbalance	14.3%	85.7%
Renal problems	6.7%	93.3%
Liver toxicity	7.1%	92.9%
GI bleeding	7.1%	92.9%
Reduced white blood count	42.9%	57.1%
Reduced pain	63.6%	36.4%
Better appetite	46.7%	53.3%
Poorer appetite	7.1%	92.9%
Metallic taste	28.6%	71.4%
Heartburn / Acid reflux	42.9%	57.1%
Aches	14.3%	85.7%
Muscle cramps	60.0%	40.0%
Nose bleeds	6.7%	93.3%
Elevated creatinine & uric acid	6.7%	93.3%
Bloating or gas	46.7%	53.3%
Foggy thinking	35.7%	64.3%

Percentages are based on the number responding to a particular category (14 or 15 for most).

tions continue to improve.

Michael's cancer is "99% gone"!!!!

Marina has improved but has been having trouble with burning sensations of the skin.

The Life Raft Group

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Who are we and what do we do? We are a group of patients and caregivers (spouses and others) in the STI-571 (Glivec) GIST trials who have come together to share our experiences and to provide each other with support. Persons not in the trial are encouraged to seek support from the broader LMS community. We try to emphasize side effects, symptoms, and other drug-related issues. Members are encouraged to correspond privately to each other or to the wider group as appropriate to the specific issue.

Privacy: Privacy is of paramount concern. We have all pledged to respect the privacy of members of our group, and agreed not to send information that might be considered private to anyone outside of the group. We try to err on the side of privacy. To assist in that goal, we do not include in the group professional members of the various study sites.

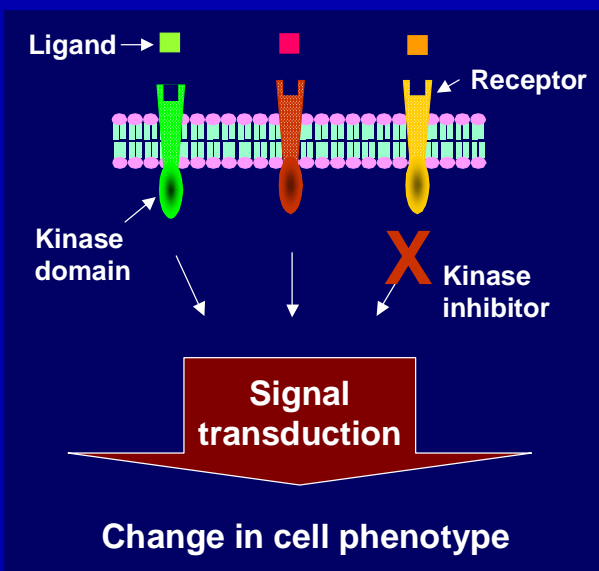
Method: Our primary means of communication is through an email group maintained by each member on their own computer. Occasional updates of general interest are provided to all members.

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! Errors are entirely my fault, but let me know and I'll fix them. Gary

Novartis Targets the Future

Kinases – A Rich Source of New Drug Targets



- Kinases are enzymes that activate other proteins, driving a wide variety of cellular responses and functions
- Specific kinases may play a key role in many diseases
- 500 kinases are known
- 1 000 or more may be revealed when the genome is complete

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