

Dr D's Study Group

STI GAZETTE * Final Edition * May 2002

From the editor of the STI Gazette: Judy Orem

The STI Gazette started in November of 1999 and was sent to people on the STI Study under Dr Druker, Carolyn and then Melanie. It was to provide information and sharing but mostly to help us all continue to feel part of the whole study once we returned to our homes following our three months here at the center of it all.

As the study grew, Dr O'Dwyer and Dr Mauro, many nurses and support staff were added to help with the increased number of people participating in the trials of STI571 at OHSU. We became one big unique family thanks to Dr Druker and the staff who worked to make it so. Dr. Druker also encouraged the Gazette and Study Group.

Phase I Study people found STI571 to be safe and effective, a double plus. Phase II has been used to get approval by the FDA for Gleevec. Thanks to people like all of us, who were willing to try a new way to treat CML, Gleevec is now available by prescription.

In the first STI Gazette, Nov '99, Dr Druker said: *"Someday, when you or your family reads a textbook about this disease and see this drug mentioned, by whatever name it is eventually given, you should take great pride in knowing how much you will have helped other people with CML."* We're already seen it approved for CML and GIST and other cancer trials are underway.

in their very busy schedules to write to all of us. I always felt like I was bugging them once again but they responded gladly. Thanks to all the special support people who provided good information. Thanks to all of you for your support along the way. I couldn't have done this without your contributions. I didn't know from one month to the next if there would be enough material or what the subject matter would be, but every month you all came through. Special thanks to those who helped fold, stuff, seal and stamp the monthly mailings. Thanks for all your encouragement and support along the way. It has been fun being part of this page in medical history and helping a little along the way.

PERSONAL MESSAGE: Brian Druker, MD
Reflections on the past four years:

It is now nearly four years since we gave Gleevec to our first patient. We called it CGP57148 in those days, before its name was changed to STI571. Much has changed since then. We saw a couple of patients a month. Carolyn Blasdel joined me as our first research nurse a few months into the Phase I study. By January 1999, six months into our study, everyone was responding. As exciting as this was, I felt we had to wait for the results to be durable for this to be an important new therapy. But patients had more faith than I did. They began telling me of how their hope had been restored as their blood counts returned to normal and they regained their health. This was just a glimpse of the changes that were about to occur.

A special thanks to our doctors who made time

Supported by Leukemia & Lymphoma Society

Our program grew exponentially as the

news of the success of Gleevec spread. We were seeing upwards of 25 new patients per month. Judy started the Gazette and our patient support group to keep people connected and informed.

Gleevec captured the hearts and minds of cancer researchers, the media, and the public. A simple, cancer pill that worked and with minimal side effects. The hope for the future of all cancer therapies -- by understanding what triggers the growth of a cancer cell, that abnormality can be targeted. The most rapid FDA approval for a cancer drug came in May 2001, less than three years after the first patient had been treated. Gleevec's activity against GIST (gastrointestinal stromal tumor) was announced that same month and was FDA approved for this indication shortly thereafter. Gleevec is now the standard therapy for CML. All within the space of four years.

But change is inevitable. Following FDA approval, patients could get Gleevec from their own doctors. Despite our expertise, there were increasing pressures to stay at home, not the least of which is insurance coverage. With Gleevec being the standard of care, many insurance carriers no longer covered out of service area care. Novartis cut back on our budgets, so our only recourse was to require payment for standard treatment, such as bone marrows analyses.

Lest we forget, there are thousands of people who are alive and well due to Gleevec. The cancer research effort has a validated plan of attack. Those of you who were the early participants in these clinical trials are the true pioneers. I have and will continue to greatly value our partnership in bringing Gleevec to the forefront. Patients have been extraordinarily generous in their thanks. No award, no media appearance, and no titles, will replace the feeling of knowing that my work has made a difference to people's lives.

On a personal note, I will be getting married next month. Hard to imagine that I found the time to meet someone. Fortunately, she found her way to me and I have strived to carve out time for this wonderful woman. She and her son bring a balance to my life that was badly needed.

PERSONAL MESSAGE: Dr. Mauro

When Judy asked me to write for the final newsletter I understood that a chapter was really closing on the group and things had changed. From the standpoint of our work, our mission, and the lives of all who have been a part of our program, I however feel that most things important to us all are simply now "pivoting" around a central point: that of how to battle and best treat CML.

As large studies close and some of the energy of past trials using STI571 alone diffuses, it will resurface and refocus in other (some small, some large) trials where we learn how to fine tune combination therapies, demanding more from front-line therapy and seek ways to recapture response. The medical community at large is now more familiar with STI571 and many of you will need to continue to be your own advocates as you redirect your own shared care or switch care entirely to closer to home. As I mentioned earlier the new combined Leukemia / BMT clinic was realized to channel the experience from CML and combine efforts with our colleagues in order to ensure and realize the vision of our future as a broad program for all hematologic malignancies. We will sorely miss Michael O'Dwyer, however, his return to Ireland is also based in sensibility and vision for the future and we look forward to ongoing collaborations and dialogue across oceans.

We will never forget the energy, the effort, and the power of the work that went on here at OHSU; I am forever proud to have been a part of it and will focus my efforts in clinical work to continue our mission and "push the envelope" in CML therapy and with my colleagues in all hematologic malignancies. The best way to sum up these efforts is to say thank you- to you, the heroes, the brave souls-- who were "pioneers" in historical trials that redefined treatment of an illness.

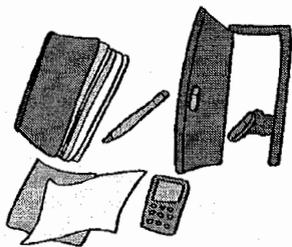
And to say that we likely will never stop calling it STI571. And I think that's ok.

PORTLAND 2002 ROSE FESTIVAL GRAND MARSHALL will be Dr. Druker. This will be announced on his Birthday April 30th.

PERSONAL MESSAGE

To Dr O'Dwyer:

We will miss you but send best wishes with you and your wife as you return to Ireland.



EXTRA: All the STI Gazettes are available at: <http://groups.yahoo.com/group/STIGazette/> If you want to join the STIGazette yahoo group send me email as it is a secure site. The files are in pdf format. You will need acrobat reader to open the file. Acrobat reader is a free download from www.adobe.com. All the STI Gazettes are there or I can email them to you as word perfect files or pdfs.

Judy at: jorem@flash.net

NEWS FROM THE GROUP: From the first person willing to try this drug to those who followed:

Bud: What a privilege it was to be chosen for the first phase of the "miracle drug" STI571. As the **number one** recipient, my main thought was the hope for more time with family and friends, but, if it didn't work for me, maybe someone down the road would benefit.

The article in the Oregonian of May 1, 1996 "New drug may fight common leukemia" with a picture of Dr Druker started me on my quest.

It is with sadness I see the end of the STI Gazette. It had a wealth of information that reached so many of us. Judy, you and your volunteers have done a super job. Thank you very much.

There is not enough "thanks" that can be given to Dr Druker and his staff for what they have done for all of us. Best of luck to everyone.

Dori: Can you believe it? The Phase I study closed and the last issue of the Gazette is at hand. As #006, I am one of the longest participant in the study. My path to Dr. Druker and Gleevec was similar to most of yours. I still pinch myself to

realize it all really happened. As the Grateful Dead said "What a long strange trip it's been" or it should be "What a long GREAT trip it's been".

I was diagnosed with CML in Nov 91 at age 54, my first grandchild due in a month. Like the rest of you, I went through various treatment experiments, -mine being HHT, interferon, a bone marrow harvest in preparation for an autologous bone marrow transplant. In 96, after exhausting all there was available, including a jaunt to Mexico, I was in Portland for another consult for an allogenic bmt. At that consult I heard of Dr. Druker and his experiments. At that time, animal studies were about to begin and a spark of hope was rekindled. During the next two years, I called Dr. Druker frequently checking on the progress of this new drug. He was always encouraging and responsive to my questions. Finally, wonder of wonders, animal studies were completed. In Nov 98 I started on STI 571 in Portland. No one, so far, had shown any side effects and the drug seemed to making some effect. I began at 200, and began that unknown trail - being one of the first that noted peri-orbital edema, muscle cramps, nausea: "I just have to eat some crackers with it". I stayed on 200 for two years, then moved up to 400. I am now at 36% abnormal and a PCR of 1.9. I may increase the dose to 600 depending on this last biopsy. Amazing!! To have ten and one half years of CML under my belt - skiing, hiking, canoeing, enjoying grandkids, planning on hiking over 15,000 ft passes to Macchu Picchu in Peru. Truly, what a great trip it's been. Thank you Dr Druker, and good luck to everyone.

Sandy: The final potluck makes me remember my friends that I met in the 2 months I was at Portland in '99 and how lucky I have been..... I am now only 0.053% positive for bcr/abl and I am one of the small number of accelerated patients in the world to have had such a spectacular response to Glivec therapy. You mentioned that this lunch would help you as with 'closure'this is a difficult aspect I think for all of us touched by this disease and the story of STI/GLIVEC...(euro sp.) I too am trying to live a 'new' life now and have almost completed the first year of my 2 year part time post-graduate studies (MA) in Art and Visual Design at

University in London..... I rarely tell people the story of my fight with CML but the memory of the last 4 years has affected me I believe forever and is evident in the work (ceramic based) i now produce..... I wonder if it is possible to ever have 'closure' and indeed if that is really desirable. cml and my fight to live has changed my attitude and how I respond to the old old questions 'what is the meaning of life?' and 'what does it mean to be human?'..... One day I will visit Portland again and hopefully see some of the lovely people I met there.....I wish you all well at your lunch and please give my love to all those what remember me. Love and a peaceful life, o)))))))))

Max & Alta: We have looked forward to the Gazette every month and all the news in them. We have given several of them to Max's cancer Dr. in Iowa City. We also enjoyed the meetings when we were able to be there. The very first one we went to was the very first appointment Max had out there. We had to be there for 2 months and everything was so new to us and we went to that meeting and felt so good when we came out. What a group of people. Everyone was just so up. And so friendly. So we never missed one when we were there. Without Leslie's help I think we would have been lost. She has been just a great, great person.

LaDonna: I'm feeling sad that the STI Gazette will be no more. It has been one of my comforters during the healing process. You've been a wonderful editor. Thank you for all your hard work. I also miss our support group.

I want to thank Dr Druker and Novartis for my extended life. My family and I are grateful to you. Goodbye, Dr O'Dwyer you'll be missed. God bless my fellow STI brothers and sisters. I love you.

Norma: First of all I want to thank Dr. Druker from the depths of my heart! I also want to wish nothing but happiness for his future. I also want to thank Norvatis for taking the chance by taking on Gleevec. The Phase One Trial was an experience of a lifetime. Not only were we able to participate in a new promising drug, but all the

wonderful times we had as a group were beyond words. Even going to our doctors visits were just a treat! How often can you say that? I was at the first OHSU gathering, one in the middle, and the last one. I was also privileged to be able to present Dr. Druker, at his birthday party, with the "up coming" albums that so many CML people participated in. How is that for someone that comes from Chicago?

I must thank all the wonderful people I have met along this path. A special thanks to Judy for all the time and effort she has put forth on so many different projects. She started the group meetings, and without her we would not be writing our good-byes in this newsletter.

How different all of this has changed my life! When I was dx and given the three to five years to live, I was praying to live to be 60. Now soon to be 57, I am hoping for 80. I just returned from Florida, where I met up with others with CML, from the Yahoo list. What a grand time we had! We will move into a new home in June, our youngest daughter getting married in Aug. and back to Florida in Sept. Wow, I would have never even dared to dream all this adventure back in Aug of 1999. And this too must come to an end, but never forgotten!! Love to all

Bonnie: Leaving for Portland on April 18, 2000 with mixed emotions on being away from my family and friends for two months only in hopes of a new lease on life. I found my second home. Portland is a beautiful city with its snow capped mountains, greener than green, and its richness in food and retail. Ok, we all know I love to shop! But what has made me truly love this city is the people. Doctor Druker and his staff are a top-notch team devoted to the CML community. There is not a day that goes by that I do not mention his name with much respect and thanks for his devotion to "making a difference". I wish to thank all of you from the bottom of my heart for making a difference in my life. Thanks for the memories!

Thelma: First, I would like to thank all who had anything to do with getting STI/Gleevec pills approved and for the STI Study. If not for

Gleevec, I don't think I would be alive today. I have had two and a half years of better living. I have enjoyed every trip to Portland for the STI Study. I also have met a lot of good and nice people, doctors and nurses. I really hate to hear that the STI Gazette is coming to an end. I really looked forward to reading it. It was very uplifting. Also I would like to say thanks to everyone and also good luck to Dr O'Dwyer as he goes back. Sorry to see him leave. Good luck to everyone.

(#7) Mark: My last PCR showed 0% Ph+.

Dennis: When I got on the Phase II of the Leukemia Program, in Portland Oregon, I had given up because the "Interferon" I was on was too "sever" for my system. I have had a complete "turn around" in my life since I got on the drug - STI571/Gleevec! It has saved my "life" and I feel "great" except for some "spleen" pain and "tiredness"! I have gained my wright back and am able to "enjoy" each and every new day! Dr Druker, Dr O'Dwyer, Carolyn Blasdel, Dr Maruo, Sue Ann, Leslie, and "all" the others working in this "program" who have help me, Novartis for all the work in keeping the program going as long as they have are to be commended greatly! for all their "hard work" and "caring". I will greatly miss the STI Gazette as I have personally passed it on to others and I also enjoy hearing of others, who have definitely benefitted by the drug STI571 /Gleevec. As good things are coming to a close, I especially would like to "Thank" Judy Orem for getting the Gazette out and all the hard work. Its people like her who makes life worth while! Good Luck and God Bless.

Milt: After being diagnosed with CML in April of 2000, I was accepted into Study II at OHSU. I started STI571 on Sept 8th. At that time my Philadelphia Chromosome count was 94%. In February of 2001 my blood counts and bone marrow showed I was in remission and remain so. I'm back to hunting, fishing, golf, and working in my workshop.

Dr Mauro is my physician and I have the utmost respect for both him and Dr Druker. Whenever we return to OHSU we are welcomed like family.

I'm sure the dedication of the doctors and their staff will continue to help many in the future.

Doug & Di: We wanted to write and thank you for your faithful publishing of the STI Gazette. It has been a great tool of encouragement for us as we heard different stories and the latest research news.

It is sad to think it will end and yet we know everything in life has a "season". We are grateful to the Lord that He allowed us to be part of this great research group.

Knute & Liz : Whatever happens we were all part of an amazing piece of medical history and I am sad to see it (and the staff) disbanded but life moves on. All the best.

Rose: I will miss the monthly news letter, however my life is very busy again, thanks to Dr. Druker and our new lease on life. I am studying Spanish 4 days a week, taking sewing and internet classes. I still play bridge three days a week. I just got my of my favorite recipes published in QVC Best of the Best Cook Book. I am expecting my 5th Granddaughter in May. Just to think I would have missed all this fun without STI571. Thank you Carolyn & Dr. Druker.

Dan: "A handful of thanks"

Thank you Judy for all of your effort in creating and publishing the STI Gazette; I know I speak for many when I say that I will miss the regular updates. Thank you to all of you who participated in the clinical trials and who took a brave step forward on behalf of CML'ers and other cancer patients. Thank you to the doctors, nurses and staffers at OHSU. Thank you Brian Druker for your tireless work over the past few years and the major positive impact that you have had on our lives.

Gail: I am the first patient in the study for newly diagnosed untreated patients using Gleevec in combination with ARA-C. I was diagnosed in March, 2001 at the age of 60 during yearly routine blood work. We began the search for Gleevec (then STI571) immediately. Every study we tried was closed. Then, with the Alpha - Interferon shots

sitting in my refrigerator, I received a call and was directed me to Drs. Druker and Mauro at OHSU. As long as I had received no treatment, I was eligible for the study. Six months into the study I had molecular and cytogenetic remission. I will return the end of April for the final bone marrow and blood tests and hope my PCR, which is presently .0014, will be .0000! Regardless, I feel blessed to have been directed to Portland and receive the treatment they offered. I feel blessed to have the quality of life I have had during this treatment, and I know the gift I have been given of remission is priceless.

My goal now is to enlist everyone I know in helping to get approval of oral cancer drugs for Medicare. None of us knows for sure what lies ahead in the years to come, except that we are writing medical history for future patients who are diagnosed with this once uniformly fatal disease.

Pat: Thanks and thanks again for all the hard work and long hours put into the STI Gazette!!!!!!!!!!!! It has truly been a lifesaver for me. I'm up in the Siskiyou mountains, 50 miles from my doctors. At times, during the study, I felt like I was dangling by a thread and not connected to anything. It helped me keep connected, since I couldn't make the meetings every month.

I was diagnosed seven years ago with granulocytic leukemia. For 4½ years I was on hydreia or interferon. But it was beginning not to work and the leukemia was beginning to progress rapidly. When I started STI571, Dr. Druker told me I had 3 mos. to POSSIBLY two years to live. I started out at 600 mg. a day. My platelets and other counts dropped, at one time my platelets were down to 2,000, so they dropped my dosage to 400 mg. a day. With my counts so low, I was getting transfusions at least once a week and sometimes twice for three months. When the dosage was dropped my counts gradually came up. They finally reached the point where I was able to have cataract surgery on my right eye. Then August 11, 2001 I had gallbladder surgery, 52 stones and gallbladder out. Five days later went back to surgery, had my spleen taken out and a hole in an artery repaired. I came through all these with flying colors. Praise God. I'm still getting my

strength back, but feel very good. My last biopsy in January came back TOTALLY negative which I praise God for also.

MJ: My counts continue to be very low but the overall situation looks quite good. Hope the FISH will continue to see a decrease. Hello to everyone!!

Brenda: I just want to thank you, the Leukemia and Lymphoma Society and everyone involved in doing the newsletters the last couple years. It was such a help talking to and hearing everyone involved in the program, I could have read it everyday!!!! I know things must change, but, I am really going to miss feeling so close to everyone!! I am going to feel very cut-off. Thank you so much.

Doug: About all I can add to the wonderful stories that I have seen over the last 3-4 years is just the fact that I am still here to see those wonderful stories. In the last three years I have had the great honor being in two weddings (both sons) and adding two wonderful daughters in law as well as a new (and wonderful) Granddaughter.

I have been able to travel to places like New York and Boston as well as take my 16 year old Granddaughter to Guatemala on a short team mission trip. I am working now part time in an assisted living facility in Hood River and in general enjoying life to it's fullest.

Thank so much to Dr. D and his staff at OHSU, as well as Norvatis, for all of the wonderful care and concern for me and for all of their patients.

Ginny: Just wanted to take this opportunity to once again thank all the doctors and staff at OHSU for the excellent care they have given us. Words cannot adequately express my thanks to Dr Druker for his years of effort in bringing STI to us. The STI trials have been a time filled with hope and excitement. This Gazette and the support group have given us so much information and encouragement. For these and for her friendship, I truly thank Judy. Without you, the experience would have been much different. I also am thankful for so many of you CML patients that I have been privileged to meet. It has been sort of a family experience.

For me personally, Gleevec has given me two pain-free years with hope for more. For this I am so grateful. There have been highs and lows, as CML constantly seems to present us with, but the concern, careful decisions, and support has been the best. I thank God for the entire experience and my prayer is that He will watch over and direct each one of us as we continue our CML journey.

Suzan: I would like to take this opportunity to say goodbye and thanks to everyone at OHSU, as I will no longer be on the trial. I also want to thank you Judy, for your support and for allowing us to keep in touch with the CML community every month. It's been an incredible journey that keeps on unfolding. All of us came together and helped one another through support, hard work and lots of hugs. We are an incredible community that will continue to "be there" for one another in some way.

I will miss Portland, the staff at OHSU and the Gazette, but they will never be forgotten, I will forever cherish these wonderful memories. THANK YOU EVERYONE!

SPECIAL THANKS TO THE OREGON CHAPTER OF THE LEUKEMIA AND LYMPHOMA SOCIETY for printing and mailing the 28 STI Gazettes. We wouldn't have had them without their financial assistance which have amounted to over \$3,000 for paper, printing, and stamps.

Those wishing to make a contribution to the Oregon Chapter of the LLS to help off set this expense should mark it for: *office supplies*. Their address is: Oregon Chapter of the LLS 6501 SW Macadam Ave. Portland, OR 97201

This is a suggestion from me and not from the LLS, who have never asked for help with covering our Gazette expense. They just make their supplies and equipment available each month and give a warm welcome to any who come to help mail it. Unless specified donations to the LLS go to research. But I know the office supply budget is tight as most monies go to research.

FREE Conference for Cancer Survivors, their families and health care professional at the Casey Eye Auditorium at OHSU on Saturday June 1st from 9:00 am to 3:30 pm.

Module 1: Communication and Fighting Fatigue

Module 2: Living With, Through and Beyond Cancer: Strategies for Self-Empowerment and Self Care.

Module 3: What Cancer Survivors Need to Know About Health Insurance

Module 4: Working It Out: Your Employment Rights As A Cancer Survivor

Registration Required: Contact Sue Sumpter LLS at 503-345-9866 or sumpters@leukemia-lymphoma.org.

Complementary refreshments provided

In December, the LLS is sponsoring a Webcast featuring Dr Druker: *CML and Gleevec*. It will be broadcast live, from the Old Library Auditorium at OHSU, as a teleconference and be available afterwards for people to access.

We will need an AUDIENCE to place bottoms on every seat while he's talking. Those of you in the area will get a post card about this close to the date to invite you to attend.

LLS TEAM in TRAINING: Dr. Druker will run with the LLS Team in Training in the Suzuki Rock 'n' Roll San Diego Marathon to raise money for the Leukemia and Lymphoma Society. See the next page for how you can help him achieve his goal of \$100,000 and follow his weekly training diary at www.teamintraining.org/druker

Thanks.
Enjoy life
Judy 