

Stephanie's APL Report

APL treatment May 24, 2009 – April 28, 2010

Keeping a daily journal to capture thoughts, events, symptoms, questions and notes related to doctor's meetings, list of medications, blood test results, and medical procedures and the results were important during this challenge of beating leukemia.

Sunday, May 24, 2009

Met John and Dori at Scotts for lunch. Went to Costco and Central Market. Also, shopped for running shoes and clothes at Alderwood.

Came home at 7 PM. Steph exhausted slept and felt horrible all night.

Monday, May 25, 2009

Steph woke up feeling better. Paula worked outside all day and kept on checking on Steph who wouldn't stay awake for very long.

Called Mary around 6PM and then called ER. Put call into on call doctor who never received page. Took temperature at it was 101 Called Dr. again and took her into ER with Mary.

Drew blood, lots of scans and found very low blood count.

Blood Results: WBC (White Blood Cell) 1.2 RBC (Red Blood Cell) 1.64 Hgb (Hemoglobin) 6.6 Hct (Hematocrit) 18.9 Absolute Neutrophils (ANC) .1

ER doctor temporary took Steph off saraquela, simvastatin, and donnatal. Kept her on vitamin D and calcium.

Referred to hematologist

Tuesday, May 26, 2009

Made an appointment with blood doctor and went in for blood draw.

Also went to dump.

Steph felt tired, but OK.

Wednesday, May 27, 2009

Went to blood doctor and had two-unit transfusion.

Dr. Jiang did bone marrow biopsy and thought results would be ready by the June 3.

Dr. Jiang asked to take extra bone marrow for research for Fred Hutchinson Cancer Foundation.

He also discussed possibilities for low blood count, for example, aplastic anemia, leukemia, medicines, or environmental issues. He explained red blood cells are given through transfusions, white blood cells given as injection, and platelets can be given, too. Note: if LP is on blood work results that area is really low and critical value means to contact the doctor.

Bone marrow biopsy was painful, but Steph was a trooper. Things to watch for after Steph is at home are: temperature above 99.7, oozing from hole or redness, look for red freckles on skin, little bleeding spots in the skin called petechiae, no bath or shower until tomorrow night, and do not use plastic tape.

Thursday, May 28, 2009

Good day, hung out, worked outside. Steph felt great after a little diarrhea in the am.

Friday, May 29, 2009

Perfect day today! All felt great until we got a call from doctor at the evening that preliminary tests looked like leukemia. We are to check into hospital on Monday.

Saturday, May 30, 2009

Horrible Day. Cried

Sunday, May 31, 2009

Dori, John, Mary and Mike came out. Had lunch and got ready for Monday.

Achey, achey heart.

Monday, June 1, 2009

Day 1-Induction Therapy-Session 1

Steph, Paula, Kelly, Bev (Paula's mom), and Mary met with Doctor Jiang and had good news.

The diagnosis APL (acute promyelocytic leukemia) which is better than others with a high cure rate of 85% verses 30-40% cure rate for AML (acute myeloid leukemia).

The definition of APL as cited from *MedicineNet.com* is a malignancy of the bone marrow in which there is a deficiency of mature blood cells in the myeloid line of cells and an excess of immature cells called promyelocytes. APL was first recognized as a distinct disease entity in 1957. It accounts for 5-10% of cases of acute myeloid leukemia (AML).

Dr. Jiang shared the therapy schedule:

Induction Therapy is chemo through intravenous once a day on Days 2, 4, 6, and 8

ATRA (all-trans retinoic acid) 2 times per day every day (5 pills in the am and 4 in the pm) -

4 wks from first chemo will do another bone marrow biopsy

Side effects: nausea and diarrhea (can give medicine for this), hair loss 3 weeks into chemo, watch for bleeding and infection, and watch for dry skin

Consolidation Therapy-Done at Whidbey General Hospital 4 days for one hour

Maintenance Therapy- For two years once a week a shot and take a pill every day

Moved to hospital and checked in old, dark...Dejavu

Kelly and Steph prepared a sheet *What Every Doctor and Nurse Should Know About Stephanie Haskins*

1. I had a severe brain aneurysm February 2007. I am a miracle I've been told. I have a shunt on the right side of my head. It is damaged by MRIs.
2. My doctor of choice in dealing with anything to do with my brain is Dr. Sekhar at Harborview.
3. I have had very severe diarrhea on and off the last month.
4. I have been taking blood pressure medicine to help with my shunt.
5. Sometimes I have trouble finding the right words when I am tired. Please be patient. I will get the right term eventually.

Blood Results: WBC 1.1 ANC 0.1 Platelets 20 RBC 2.35 Hgb. 9.0 Hct. 25.0

Given platelets and kept us up from 9PM all the next day. Had a brain scan, etc.

Tuesday, June 2, 2009

Day 2-Induction Therapy-Session 1

Had two units of blood, protein and platelet. Put in PIC line and got ready for first intravenous chemo.

A neutropenic diet of cooked meats and thoroughly washed fruits and veggies is the plan for now. In addition, all who enter the room must wash their hands.

Had chemotherapy about 10:30 and this was a 25 minute drip and off to sleep by 12:30

Slept until 4:30

Wednesday, June 3, 2009

Day 3-Induction Therapy-Session 1

Blood Results: WBC 0.3 ANC 0 Platelets 57 RBC 2.71 Hgb. 9.5 Hct. 27.7

Steph feels normal today. No blood transfusions Dori coming up, Paula is going home for night.

Had shower and walked.

Dori spent night-who is pragmatic and having worked from 6AM wanted to go to bed at 11.

Steph got up at 1AM-Dori was not social she wanted to sleep. Steph read the rest of the night. "How can I change those behaviors when they are not real?" Steph's response to Dori.

Thursday, June 4, 2009

Day 4-Induction Therapy-Session 1

Blood Results: WBC 0.5 ANC 0 Platelets 52 RBC 2.53 Hgb. 9.1 Hct. 25.7

Steph started watching news 6AM

Breakfast discussion at 7 a.m.

Janet nurse-discussed all the AM pills-vitamins, chemo, and diuretic

Breakfast followed with lots of bathroom time (plus Lasix in small doses to assist as a diuretic)

Lots of discussion with: P.A. Mark, Nurse Marilyn- oncology, PIC-line nurse Becky, and Day Nurse Janet

Dori spent the night

Friday, June 5, 2009

Day 5-Induction Therapy-Session 1

Blood Results: WBC 0.3 ANC 0 Platelets 45 RBC 2.42 Hgb. 8.9 Hct. 25

Steph slept well after chemotherapy from 11-5:15. Had shower and feels good.

Dr. Jiang came by-no transfusion needed. He said to expect up to 4 weeks and will depend on how well she responds to the four treatments.

Updated and added second blood pressure medicine and took her off the drip on days with no chemotherapy.

Nurse: Merri Asst: Alena

Must drink 8 glasses of H₂O

Blood pressure meds: Metroprol ½ AM ½ PM Lisiniprol AM only

Barb, Bonnie, and Mom visit

Saturday, June 6, 2009

Day 6-Induction Therapy-Session 1

Blood Results: WBC 0.6 ANC 0.1 Platelets 42 RBC 2.27 Hgb. 8.4 Hct. 23.3

Steph woke up with some fluid. Took a diuretic, peed, and felt better. Had chest x-ray, blood maintained level, no transfusion needed.

Chemotherapy went well-4 hours prior on drip and 4 hours post.

Took sleeping pill and slept at least 6 hours.

We slept and watched the Belmont-sad that our horse didn't win!

Sunday, June 7, 2009

Day 7-Induction Therapy-Session 1

Blood Results: WBC 0.3 ANC NA Platelets 35 RBC 2.32 Hgb. 8.5 Hct. 23.7

Showered, feels good! Blood count maintaining...

Dr. Jiang shared that ATRA makes the skin dry, shared that x-ray showed crackle in lungs but sound better today than yesterday.

Dr. Jiang shared usually don't find a combination of a researcher and clinician for a doctor. Steph was lucky because Dr. Jiang is both. He stated that these two combined don't usually have what the patient needs. So for a patient he recommends they not seek this combination. Steph was referring to her book and she was going to write about Dr. Jiang.

No transfusion today holding her own, Steph shared about diarrhea and doctor couldn't explain why, chemotherapy scheduled for 6 PM Monday, checked weight, and important to keep legs elevated.

Mary down all day talked and hung out until 10 PM. Some of the discussion wrapped around big picture, such as, earth, religion, since the early 1990's brain research, Madeline Hunter, and Steph's involvement with alternative education.

Monday, June 8, 2009

Day 8-Induction Therapy-Session 1

Blood Results: WBC 0.6 ANC 0.1 Platelets 25 RBC 2.37 Hgb. 8.5 Hct. 24.2

Chryo Pack-a chemical to help clotting and platelets-actual cells given time to build clotting factor. Platelets and RBC are down today. WBC almost normal

Last chemotherapy-all went well!!

Tuesday, June 9, 2009

Day 9-Induction Therapy-Session 1

Blood Results: WBC 0.3 ANC 0 Platelets 62 RBC 2.33 Hgb. 8.4 Hct. 23.6

Hung out all day. No blood transfusions or intra chemotherapy. Walked, read paper, etc.

Doc came in talked about staying until next weekend and the next 5 days are the ones to show chemotherapy signs. Just sit and wait. Home to mom's about 8PM Bought Steph 4 movies to watch.

Wednesday, June 10, 2009

Day 10-Induction Therapy-Session 1

Blood Results: WBC 0.7 ANC 0.1 Platelets 58 RBC 2.54 Hgb. 9.2 Hct. 25.7

Feeling good, no changes-had Miracle Starbucks coffee and doing fine. Doc came by chatted about process-same answers. Still feeling ok. Paula home and Dori up for evening and day tomorrow. Cath put in because pain and anxiety medicine do not allow the message to get to the bladder to empty.

Thursday, June 11, 2009

Day 11-Induction Therapy-Session 1

Blood Results: WBC 0.9 ANC 0 Platelets 31 RBC 2.35 Hgb. 8.6 Hct. 23.7

Had a transfusion. Steph started to complain about her butt hurting. She started to have a slight fever that night and was not feeling great. Mary visited until 9:30 PM and has a hard time leaving Steph. Mary got home @ 11:30 and called Steph to let her know she was safe.

Friday, June 12, 2009

Day 12-Induction Therapy-Session 1

Blood Results: WBC 0.9 ANC .3 Platelets 68 RBC 3.13 Hgb. 10.9 Hct. 30

Dr. Jiang indicated if all goes well over the weekend she could go home by Monday. Steph had a 102 fever and felt like shit. Steph made it clear her butt hurt. Probably having a reaction to IV antibiotics.

Saturday, June 13, 2009

Day 13-Induction Therapy-Session 1

Blood Results: WBC 0.8 ANC 0.1 Platelets 44 RBC 2.99 Hgb. 10.4 Hct. 28.8

CT scan of the belly. Steph's eyes tell the whole story. This was a hard experience. Dori in the AM and Mary in the PM. Mary stayed the night.

Sunday, June 14, 2009

Day 14-Induction Therapy-Session 1

Blood Results: WBC 0.6 ANC .0 Platelets 24 RBC 2.99 Hgb. 10.2 Hct. 28.6

CT scan came back with inflammation, but no abscess. Some IV antibiotics are given two times a day and some were four times a day. Had a fever and took Lomotil for bowel movement issues.

Steph took a shower and noticed a bump under her left armpit.

Steph wonder if it was worth living and felt like she was going to die. Each hour she noticed the change.

Mary and Steph talked. Mary stayed the night.

Monday, June 15, 2009

Day 15-Induction Therapy-Session 1

Blood Results: WBC 0.4 ANC .0 Platelets 15 RBC 2.89 Hgb. 10 Hct. 27.9

Rough AM. Blood pressure went down. Called in ASAP team to evaluate.

Chris, the nurse, noticed Steph's poop was clay colored and called Dr. Jiang after Chris decided to Google about the side effects of ATRA. While waiting for the phone call from Dr. Jiang, the nurse turned Steph to look at her butt and then took vitals and noted Steph's blood pressure dropped drastically and then BP dropped to 70/40. Chris called in ASAP team, which consisted of respiratory therapist and critical care nurse. She wasn't in respiratory distress; however, the critical nurse stayed until blood pressure increase to 100 and had her sit up. Steph's blood pressure improved. Mary and Paula were there during Steph's blood pressure episode. Mary stayed until about 3 PM.

Tuesday, June 16, 2009

Day 16-Induction Therapy-Session 1

Blood Results: WBC 0.7 ANC .0 Platelets 48 RBC NA Hgb. 8.5 Hct. 25.5

Steph was complaining about the pain in her rear. The nurse looked at her rear end and noticed a red sore on the outside of it. Dr. Jiang called the surgeon, who looked like Christopher Reeves, and he came and in, took one look at the sore, and said we are going for surgery tonight. He gave many reasons to Steph why the surgery needed to be done. He called it emergency surgery because she had eaten and if he waited then it would be 4 AM and who knows what could happen with the hospital schedule. Steph was glad they were doing something about it. Drained and cleaned out the abscess and packed that area with material that would eventually be absorbed and placed in a drain. Surgery at 10:30 PM Steph not feeling good!! Kelly stayed until midnight.

Wednesday, June 17, 2009

Day 17-Induction Therapy-Session 1

Blood Results: WBC 0.5 ANC .0 Platelets 47 RBC 2.64 Hgb. 6.4 Hct. 17.6

Most of the day she slept and was not eating much. Still has high fever. Added Potassium and amburylyn. The surgical PA came to remove the packing in the incision and due to lack of knowledge on the part of the PA about Steph's low platelet count and clotting caused the incision to bleed until Paula noticed it two hours later. Blood was on Steph's clothes, back of her hair, and yes, blood spreads. PA came up and re-packed the incision. Paula was pissed.

Thursday, June 18, 2009

Day 18-Induction Therapy-Session 1

Blood Results: WBC 0.5 ANC .0 Platelets 17 RBC 2.89 Hgb. 9.7 Hct. 27.1

Had headaches, felt badly, head hurts, and had fever. Platelets were given.

Friday, June 19, 2009

Day 19-Induction Therapy-Session 1

Blood Results: WBC 0.3 ANC .0 Platelets 39 RBC 2.92 Hgb. 9.7 Hct. 27.2

Heather the night nurse noticed raised red rash and said this was an allergic reaction to Vancomycin (IV antibiotic). Stopped this antibiotic and gave Steph Benadryl at 11:45 PM. Heather also discussed no change in her liver, checking for MRSA, left armpit abscess is red and hard, legs look good, bottom is not red, but hot pink. Morphine every 3 hrs and alprazolam every 6 hours and Tylenol due to 102.9 temp at 3 PM

Mary visited and watched 50 First Dates twice...

Saturday, June 20, 2009

Day 20-Induction Therapy-Session 1

Blood Results: WBC 0.5 ANC .0 Platelets 30 RBC 2.73 Hgb. 9.1 Hct. 25.6

Steph was by herself most of the day. No fever. Paula was home working in the garden. Pam visited in the afternoon, brought Steph cookies, and had a nice chat.

Sunday, June 21, 2009

Day 21-Induction Therapy-Session 1

Blood Results: WBC 0.6 ANC .0 Platelets 14 RBC 2.62 Hgb. 8.8 Hct. 24.3

Bev stayed, read, and played cards while Steph slept. The two talked. Mary came for the rest of the day. Doctor said things are on course, no fever for the past three days, discussed catheter is in due to IV antibiotics and IV fluids make you want to pee, so it is convenient to have cath in at this time, drainage out of butt looks good, it will get sensitive as your counts come up and will be tender and red as it heals, and the abscess under the arm is responding to antibiotic treatment, and increased potassium levels in IV... (Potassium level 3.3 Low)

Steph slept. Paula is at home and did various activities.

Monday, June 22, 2009

Day 22-Induction Therapy-Session 1

Blood Results: WBC 0.4 ANC .0 Platelets 8 RBC 3.14 Hgb. 10.3 Hct. 29.1

Catheter was taken out. Platelets given today. Paula came down in the AM and checked with doctor on how many days of IV antibiotics, which medications for home and the bone marrow biopsy for tomorrow. Mom at 5:00.

Tuesday, June 23, 2009

Day 23-Induction Therapy-Session 1

Blood Results: WBC 0.5 ANC .0 Platelets 36 RBC 2.47 Hgb. 8.1 Hct. 22.6

Bone marrow biopsy done at 10:30 Dr. Jiang asked Steph how she felt and thought to hold off on transfusion until tomorrow; he also suggested Paula order the oral chemotherapy pills; abscess under left arm checked by three people, PA surgeon, nurse, and the doctor and all saw improvement; rear end tube looking better and checked lungs which are okay. Then all shit broke through. Steph had diarrhea. Mary stayed the night.

Wednesday, June 24, 2009

Day 24-Induction Therapy-Session 1

Blood Results: WBC 0.7 ANC .0 Platelets 25 RBC 2.61 Hgb. 8.6 Hct. 24

Infectious disease Doctor Turell checked underarm-improving, soft around the rear end sore and predicted would be days to weeks in healing; he also shared the average is two weeks for white blood count to increase after completing chemotherapy treatment.

We asked PA, Mark, what acceptable numbers are for ANC so Steph could go home. He stated 500 or better with the range being 1,500-7,000. Hold tight is the PA's recommendation. Mary and Steph made a list about what she had already overcome: fevers of 102, mouth sores,

red raised rash, peeling lips, dry skin, constipation, swollen ankles, crackle sounds in lungs, CT scan, and dry/bloody nose. Things left to change: abscess under left armpit, healing and drain in rear end, increase of WBC and ANC.

Paula came down and hung out. Steph feeling ok and Paula stayed at moms.

Thursday, June 25, 2009

Day 25-Induction Therapy-Session 1

Blood Results: WBC 0.8 ANC .0 Platelets 25 RBC 2.5 Hgb. 8.2 Hct. 22.8

Steph shared her concern about a physician's assistance style, with Paula and mom. Mom challenged Dr. Jiang to talk to the physician's assistance about his communication style with Steph. Meg and Dessa came to visit, Steph had a blood transfusion and was given Benadryl as pre-med, and she slept. Kris came up for dinner, had an enjoyable night, and stayed until 10:30. Steph's blood pressure was high. They had a hard time getting her blood pressure 170 down besides giving her regular medication. They gave her a diuretic. Paula stayed the night and slept for four straight hours. The diuretic brought her blood pressure down to 140.

Friday, June 26, 2009

Day 26-Induction Therapy-Session 1

Blood Results: WBC 0.6 ANC .0 Platelets 29 RBC NA Hgb. NA Hct. 28

Mom came down in AM and took Steph for first walk outside. Doctor Jiang shared that numbers were low and expressed some concern about length of time the numbers have stayed flat. Then, Steph, Paula, and Bev were anxious and nervous. Steph wanted to go outside to walk. The doctor told her she needed to get up and walk around on the floor outside her hospital room to exercise. The hospital policy was patients could not go outside. Paula and Bev decided to break the rule and took Steph for a two-block walk, which was fabulous....air, the different clouds, the flowers, and that house. There was a two-story house with an attic. The house has a detached two-car garage. There were places for kids to sit, use a slippery slide, and run through the sprinkler. On the front of the house they had hoses and a porch. This is the house Steph wanted to see everyday.

Sharon came by for lunch and fun. Paula went home.

Steph was sharing about the need to get outside and breathe the air with Meg and Dessa when she was home. Meg suggested that the top floor of the hospital be for cancer patients and with a courtyard in the middle and bubble above that allows patients to get fresh air and be themselves while still inside the building. Dessa said make something that is actually outside for patients.

Saturday, June 27, 2009

Day 27-Induction Therapy-Session 1

Blood Results: WBC 1.0 ANC 0.1 Platelets 53 RBC 3.03 Hgb. 9.5 Hct. 27.1

Dori came down in the morning after spending the night with her daughter in Bellingham and

they had a great time. Steph and Dori walked around the block outside. Stayed until 5 PM Steph called around 8 PM in a panic because she was anxious. She needed Xanax and nurse to clean her. Numbers are up!

Sunday, June 28, 2009

Day 28-Induction Therapy-Session 1

Blood Results: WBC 1.2 ANC 0.1 Platelets 101 RBC 3.14 Hgb. 9.8 Hct. 28

Mom and Steph walked for two blocks outside and had a nice conversation. Steph felt good and mom stayed for four hours. Paula at home working. The numbers are up.

Monday, June 29, 2009

Day 29-Induction Therapy-session 1

Blood Results: WBC 1.6 ANC 0.4 Platelets 167 RBC NA Hgb. NA Hct. NA

Packed up in ten minutes after Dr. Jiang said it is time to go home. Discharge instructions primary illness acute promyelocytic leukemia with induction chemotherapy. Also listed the rectal abscess. Tests CBC and CMP with follow-up at Whidbey General for wound care. Home from hospital around 4 PM. Sole for dinner. Steph is happy. Animals are happy.

Tuesday, June 30, 2009

First day home. Steph slept. Paula did laundry and cleaned.

Wednesday, July 1, 2009

Blood Results: WBC 3.3 ANC - Platelets 409 RBC 3.55 Hgb. 10.8 Hct. 31.9

Doctor at 9:00 and blood draw. Take ATRA one more week. Next week, Wednesday another blood draw, stop ATRA, arrange for port, and start next round on July 20-24.

Thursday, July 2, 2009

Bark delivered.

Friday, July 3, 2009

Sean, at Color Box Freeland, did Steph's haircut to try cover missing hair and many head scars.

Saturday, July 4, 2009

Took day off and watched movies.

Sunday, July 5, 2009

Mary out working with Steph. Paula hauled bark to the garden.

Monday, July 6, 2009

Ran errands-grocery store.

Tuesday, July 7, 2009

Mary and Steph worked on Disability/Medicare. Collected information and called UMP, PPBE, Social Security, and Medicare. Paula power washed the deck and sidewalks.

Wednesday, July 8, 2009

Blood Results: WBC 10.9 ANC - Platelets 602 RBC 3.94 Hgb. 12.3 Hct. 36.1

Massage for Paula.

Blood draw and blood levels good. No ATRA until July 20. Port put in next week.

Thursday, July 9, 2009

Paula sick. Mary took Steph to Krissy Wheeler PA and to get groceries. Notes from visit with Krissy: Apply Neosporin or triple antibiotic ointment nightly to scab on left second toe. Lisinopril was not on discharge sheet. Ask Dr. Jiang about Simvastatin (for cholesterol) when on chemotherapy. (Same with Alendronate for bones) Both of these medications are for long-term health and it is ok if you need to be off them while on chemotherapy. Side effect of Lisinopril is a cough. If cough gets worse, call me (stop with Lisinopril). Aveeno lip balm. Continue current management of bottom. Armpits-no shaving until healed and use antibacterial soaps and warm compress.

Friday, July 10, 2009

Brandon here for sink.

Saturday, July 11, 2009

Organize. Paula stained the deck. Went to Mike's house on south end and dinner at Mexican restaurant.

Sunday, July 12, 2009

Organize

Monday, July 13, 2009

Paid bills and cleaned house.

Tuesday, July 14, 2009

Seattle! Aki, Kris, and shopping. Bought vacuum.

Wednesday, July 15, 2009

Luncheon with Jasmine, Kathy, Mary, Jane, Therese, and Val.
Paula made a delicious lunch of salmon broiled on the grill with wine and herb butter and she used no lemon as suggested by the guy who sold the salmon. Also had salad, bread, and great cheesecake from Central Grocery.

Thursday, July 16, 2009

Steph's port placement.

Friday, July 17, 2009

Brandon here replacing sinks. Mike and Amy here for lunch.

Saturday, July 18, 2009

Paula to Burlington with Wooley to shop for hot tub.

Sunday, July 19, 2009

Paula went to market with Rebecca. Steph home.

Induction Session 1

Chemo-Idarubicin (Idamycin brand name) (12 mg x 4 = 48 mg)

Blood Count Results Session 1

Date:	6/1 Day 1	6/5 Day 5	6/12 Day 12	6/29 Day29	7/1	7/8
WBC 5,000-11,000	1.1	0.3	0.9	1.6	3.3	10.9
ANC 1,500-7,000	0.1	0	.3	0.4	Did Not Receive	8.8
Platelets 140,000-450,000	20	45	68	167	409	602
RBC 3.7-5.4	2.35	2.42	3.13	Did Not Receive	3.55	3.94
Hemoglobin (HGB) 12-16	9.0	8.9	10.9	Did Not Receive	10.8	12.3
Hematocrit (HCT) 37-47	25	25	30	Did Not Receive	31.9	36.1

Your Questions are the Answer

Before Your Visit

Take a list of specific questions to your appointment. Familiarize yourself with your medical history, so you can convey it concisely to your doctor. Writing out a brief synopsis to give a new doctor can be helpful and save time. Keep a diary to track your symptoms and concerns. Convey these clearly to your doctor. List medications you are taking with their dosages. Tell your doctor about any medication changes. Notify your oncologist or the scheduler ahead of time if you think your questions will take an extended time to answer. This allows the staff to arrange the schedule accordingly.

During Your Visit

Tape-record your visit or bring a pencil and notebook to take notes. You also may bring a trusted friend or relative to take notes for you. Keep your discussion focused, making sure to cover your main questions and concerns, your symptoms and how they impact your life. Ask for clarification if you don't understand what you have been told or if you still have questions. Ask for explanations of treatment goals and side effects. Let your doctor know if you are seeing other doctors or health care providers. Share information about any recent medical tests. Let your doctor know how much information you want and if you have religious or cultural beliefs that affect your treatment. Stand up for yourself or have a friend or family member advocate for you if your concerns are not addressed. Balance assertiveness with friendliness and understanding.

Reference-www.ucsfhealth.org *Inclusion of this website does not imply endorsement*

July 20-23, 2009

Things to Share and Questions for Dr. Jiang from Stephanie

1. Stephanie had 48 mg of chemo during the induction therapy on day 2, 4, 6, and 8. Did she receive 12 mg per chemo session 12 mg, 24 mg, 36 mg, and 48 mg? For the consolidation therapy, she will receive 20 mg in a four-day period. Will she get 5 mg of chemo per day? With half the dose over a four-day period what does this mean for Steph? What will she receive?
2. How and when will results be reported after the first week?
3. What will be the effects the first week after chemo and ATRA?
4. What will happen the second week out?
5. What will happen the third week out?
6. What interventions can happen to help with fever, low or high blood pressure, mucositis, abscess, edema?
7. Can dexamethasone be used for side effects to ATRA therapy?
8. How long does this go on until the next session?
9. What medications does Steph take during this time?
10. When is molecular remission checked?
11. Things to check on:

July 20-23, 2009-Session 2

Summary of Meeting with Dr. Jiang

Stephanie had 48 mg of chemo during the induction therapy on day 2, 4, 6, and 8. Did she receive 12 mg per chemo session 12 mg, 24 mg, 36 mg, and 48 mg? For the consolidation therapy, she will receive 20 mg in a four-day period. Will she get 5 mg of chemo per day? With half the dose over a four-day period what does this mean for Steph? What will she receive? LPA 99 protocol (www.bloodjournal.org): Idamycin 9.3 mg X 4= 37.2 mg (chemo that kills fast growing cells (hair, mouth, stomach, etc and the least toxic to the heart) and APL cells. Formula is BSA x 5 mg= how much Idamycin is given. First applied Ethyl Chloride (numbing drug on port), collected blood samples. Will check for blood supply each day. Next gave pre-meds: Aloxi (anti-nausea) and Decadron (steroid that increases appetite and prevents nausea). Steph will have a lot of energy due to the steroid until day 6 and will come down from Decadron. Take Benadryl (anti-histamine) a half hour before bed.

How and when will results be reported after the first week?

Dr. Wung, Dr. Jiang's partner, will meet with Steph. on July 21 and review guidelines for blood pressure and Xanax.

What will be the effects the first week after chemo and ATRA?

Read about Idarubicin (Idamycin-brand name) and ATRA sheets given to you by Ann Bell, today's nurse.

A site to use: *Chemocare.com*

What will happen the second week out?

Nadir count will bottom out around day 10 and then go back up.

What will happen the third week out?

August 5 is when Dr. Jiang will meet with Steph. Labs @ 2:45 and Doctor appt. @ 3:30. This is when they will do the next blood draw and review the results.

What interventions can happen to help with fever, low or high blood pressure, Mucositis, abscess, edema?

Read about Idarubicin (Idamycin-brand name) and ATRA sheets given to you by Ann Bell, today's nurse.

What medications does Steph take during this time?

Continue with meds and finish those that are not going to be renewed.

Things to check on: **Xanax prescription, Blood pressure guidelines and did Renee, supervisor, call Dr. Sekhar regarding BP guidelines**

Monday, July 20, 2009

Day 1-Consolidation Therapy-Session 2

Blood Results: WBC 6.2 ANC 4.2 Platelets 330 RBC 3.52 Hgb. 11.0 Hct. 33.4

Vitals: 108/70 BP Started chemotherapy for consolidation therapy. Spent 3 hours at hospital, reviewed meds, and first chemotherapy put into port. Pre-meds are Ethylchloride (numbing drug on port) Aloxi (anti-nausea) and Decadron (steroid that increases appetite and prevents nausea). The chemo is 9.3 mg of Idamycin. Ann Bell was the nurse who set up Steph and shared information about LPA 99 protocol (www.bloodjournal.org) and chemotherapy information

(Chemocare.com). In addition, she said drink 8 to 10 glasses of fluids per day, rinse mouth 3 times a day using ½ tsp. of salt and ½ tsp. of baking soda added to water, wash hands with antibacterial soap, chewing gum decreases nausea and hydrates, and call triage nurse if 100.5 fever. Steph felt okay. Went to lunch at Lydia's and bought kitty litter. Had tacos for dinner.

Tuesday, July 21, 2009

Day 2-Consolidation Therapy-Session 2

Mary taking Steph for chemotherapy day 2 after 12:30 lunch. Arrived at Whidbey General Hospital at 1:20. Vitals: Blood pressure 108/70 and 98.6 temperature. Steph. discussed with Ann Bell, the nurse, the following main points: Senna laxative take two in the morning and two at night if no bowel movement and use Dicolax (if you have a very hard stool) the following night. Renee, ARNP spoke with Dr. Sekhar who said a range of 120 to 140 for blood pressure is acceptable. Remove the cath port access daily. Finished at 3:30. Nine lights put in ceiling and Woolley helping remove hot tub. Thought about New Orleans.

Wednesday, July 22, 2009

Day 3-Consolidation Therapy-Session 2

Third chemotherapy today. Looking forward to Ann Bell, but she had someone else do it. They are like a team on different days and know each other work as a team so people are individuals and aren't stuck or glued to anyone. It made me feel like I might have talked too much and she was taking a break.

Paula came with me-lots of concern about the work they were doing-tough. She was focused on the person taking over Ann Bell's job, who was slowly answering questions for me. It was touch and to go faster and not hold it.

I am going by myself tomorrow. I can do it.

Procedure, things given, ATRA-same for all four sections. This is written down.

Thursday, July 23, 2009

Day 4-Consolidation Therapy-Session 2

Same schedule for chemotherapy and it took only about an hour 1:15 PM to 2:30 or so. Same treatment of stuff I have to take.

Mike came and helped remove woods in the late afternoon. Jordan, the hot tub expert who sold us the tub, came over.

Kelly and Addie came and brought cherries from their yard. Kelly with hugs. Addie enjoyed taking off onion stems.

Ruby was uncomfortable with the measuring tape and sent her into the house.

Friday, July 24, 2009

Day 5-Consolidation Therapy-Session 2

No more medical stuff for Session 2. Take it in four days-Monday-Thursday and off Friday.

Paula worked on leaves on the ground stacking and organizing.

Two different electricians said what they would charge to put in the electricity for the hot tub.

Picked Jack, AC Electric.

Saturday, July 25, 2009

Paula did an incredible amount of work to clean up wood for burning, to take to the dump, and large numbers of leave, etc. to put at the end of the garden. Also, cleaned up things like wood, scrubbed the cement, and cleaned.

Bayview-drove downtown and walked around. Saw things people brought and we bought eggs.

Had breakfast at home of eggs, bacon, and bread. Used eggs from Bayview for egg sandwich with our great onions.

I cleaned the house by dusting and used the new vacuum cleaner- neat and nice for top floor.

Had diarrhea.

Sunday, July 26, 2009

We went to Oak Harbor and we saw Mike and his team working on his projects. We brought them ice cream bars. Bought a fan at Home Depot. While Paula was shopping at Safeway for groceries, I drove the truck up and down the rows in the parking lot.

Bought Thai food for lunch and dinner.

Monday, July 27, 2009

The company, two good guys, came by to take care of the electrical stuff for the new pool. They got here around 8:00 and were able to finish by 11:00. Looked at options for new light fixtures to put on house, especially as you come in. Also, looked for wiring we want, thinking about shifting one from the garage. Putting better lights in the house.

Mary came over and brought sandwiches, gum and vegetarian sausages for breakfast. We had a great understanding of things important for the book. Mary is fantastic.

Paula went to Oak Harbor to spend money on different lights we need to make things look better. Looks great. Fabulous pesto pasta for dinner.

Tuesday, July 28, 2009

Most amazing temperatures: Tuesday-97 degrees, Wednesday 101 degrees, Thursday 97 degrees, Friday 91 degrees, Saturday 85 degrees, back up on the weekend and then temps. go down.

Pool being put in by two guys and it is very nice and looks great.

The electricians are coming again tomorrow.

Might do fans and bring the one from the septic now in the garage but we want it with power on the house.

I'm still okay and trying hard to sustain.
Dinner was noodles and vegetables from the garden-fabulous
Cancelled tomorrow with Dori-too hot

Thursday, July 30, 2009

Paula worked on yard, moved stuff to the yard to burn, and went to dump to get rid of all the garbage from all the work.

Friday, July 31, 2009

I'm feeling pretty good. Before cleaning the house, I went to the store and bought our annual lobster. Paula worked.

Saturday, August 1, 2009

Paula went to visit family members in Mt. Vernon. David coming in this afternoon. Mary came to be with me and we talked about lots of things. She and I talked about people we knew, different things people do in their 20's to their 60's, talked about Linda who lives in Florida, and discussed money.

Quotes: *When you retire from teaching, it changes because you learn to like yourself instead of waiting for everyone to like you.*

If you want to be comfortable with your life, you shouldn't have to think about it.

It is everything and it is nothing.

This is about you!!

Paula created a lunch option list: fried green tomatoes, zucchini-fried, BBQ, or raw, corn-raw, boiled, or BBQ, tuna, turkey, ham or veggie sandwiches, chips, 20 cherries, salmon salad, and lobster salad. We had lobster on toast along with chips.

Sunday, August 2, 2009

George came over at 8:00 AM. The goal is to finish the pool and was done at 4:00. I had lunch at 1:00. We had time to talk and had wine and pasta with our onions and garlic. Felt okay.

Monday, August 3, 2009

Today we were both tired and decided to take it easy. Have a small sore in my mouth. Today had diarrhea at the beginning of the day. Today is day 15 of the consolidation therapy. Lots of diarrhea poured out. Blood from all the pressure and this hurts. Took a pill at 1:45 to 2:00 and it seems to be stopping. Now it is 3:30 and will take another if it doesn't stop. Ten or more exits.

Tuesday, August 4, 2009

Did not have diarrhea. Paula worked and she re-stained the deck, painted the cement below and it looks good.

We went to Home Depot and met Kelly, Addie, and Meg. Kelly lectured me about being around people when my blood count is low.

Went to the grocery and couldn't get into the seafood store.

Wednesday, August 5, 2009

Blood Results: WBC 1.0 ANC - Platelets 70 RBC 2.86 Hgb. 9.3 Hct. 26.4

Slept all day on the couch and I did not want to get dressed until I had to get ready for the doctor's appointment.

Medication as of August 5, 2009

Daily Medications	Purpose	Amount and Time
Acyclovir	Protects against virus'	Twice a day 400 mg. Am pm
SMZ	Antibiotic	Thursday/Friday am and pm
Alendronate Sodium	Bone growth	Every Monday morning
Cipro- 2 hours prior to calcium.	Protects against infection	a.m.-8:00 a.m. p.m. - At least 6 hours after a.m. meds.
Calcium Citrate-at least 2 hours after Cipro	Protects bones	2 tablets daily am
Multi vitamin	Vitamin	I tablet daily am
Metoprolol Not taken if blood pressure is lower than 100	Lowers blood pressure	25 mg am 25 mg pm
Lisiniprol Not taken if blood pressure is lower than 100	Lowers blood pressure	10 mg Am only
Simvastatin	Cholesterol	Pm only
As Needed Medications	Purpose	Amount and Time
Anti diarrhea - Lomotal	Protects against diarrhea	Most likely am
Sleeping pill-timazopan	Helps you sleep	At night
Acetaminophen - Tylenol	Fever and pain	Anytime
Senna laxative	Keeps bowels regular	If bowels are hard
Clotrimazole	Cream for hand	If dry skin
Dulcolax	Anti diarrhea	If bowels are very hard

Things to share and Questions with Dr. Jiang from Stephanie

1. Do we continue w/ the three antibiotics after Stephanie's blood has recovered?
CIPRO 2x daily:
SMZ: Thursday and Friday 2x daily
Acyclovir: 2x daily

2. Based on Stephanie's last Session 1 of chemo, her low point was around days 14-18. When does day 1 of Session 2 begin?
3. Does she take ATRA for only 15 days during the next two rounds?
4. Confirmed in our medicine plan: Steph will take CIPRO as soon as she gets up. After two hours, she will take the rest of her a.m. medications. Evening meds will be at least 6 hours after her a.m. meds.
5. Blood Pressure – a.m. around 120/80. In the p.m. hovering around 100. What is causing the decrease in her blood pressure? What changes need to be made to ensure her blood pressure does not get too low?
6. Eye sight – Seems to be changing, should she make an appt. with her eye doctor or will this return when chemo is over?

The blood results were low. We were angry with things. Dr. Jiang said I should have taken antibiotics and stopped taking ATRA on the 15th day of consolidation therapy.

Dinner was scallops with side dish of fried rice made with veggies from our garden
Mary called from Alaska and talked with Paula.

Thursday, August 6, 2009

I felt very sick and slept on the couch most of the day. I didn't want to even walk around. Worst day that serves as the last in this Session 2 is last 15, 16, 17, and 18 –19. I was getting better, which started at 7:30 PM on day 18.
Talked to Mary in the afternoon and Nancy in the evening.

Friday, August 7, 2009

Paula finished painting around the hot tub and cleaning which included: bark, hot tub, painting the swing, set up and paint the fencing around the hot tub.
Meg and Dessa came out and got garden zucchini, corn, cucumber, beans, tomatoes, and two eggplants.
Went to Miriams and ate a sandwich and potato salad for lunch
Steph-that's I, read things, like the paper and Newsweek.
Felt much better, this makes this day 19-almost
Set up the answering phone and seemed normal.

Saturday, August 8, 2009

Paula worked and cleaned the garden. I read papers and worked on the book.
We spent time talking about my cancer and how to include things from the latest volume 2 in the book.

Sunday, August 9, 2009

We had a restful day. Took the cats for a walk. Read more of the book.

Paula took Ruby for a walk by the water. I waked up our driveway to get the paper and struggled somewhat walking it.

Monday, August 10, 2009

Busy Day

Feel a lot better than a few days ago. We were able to be more regular like we are when “my recovery and sessions” don’t dominate.

Paula worked on the book and she has great ideas. She also cleaned the main floor-great jobs.

Talked with Mary on the phone and discussed possibilities about how to add the leukemia section to the book. We are going to talk on Wednesday.

Made phone calls and took care of furnace cleaning, doctors, dentist, etc.

Paula was in the pool for 20 min.

I had a hamburger. We had gone to Freeland in the car. I drove with Ruby.

Wednesday, August 12, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. Do we continue w/ the three antibiotics after Stephanie’s blood has recovered?
 - CIPRO 2x daily:
 - SMZ: Thursday and Friday 2x daily-
 - Acyclovir: 2x daily
2. Based on Stephanie’s last Session of chemo, her low point was around days 14-18. When does day 1 of round 2 begin?
3. Does she take ATRA for only 15 days during the next two rounds?
4. Confirmed in our medicine plan: Steph will take CIPRO as soon as she gets up. After two hours, she will take the rest of her a.m. medications. Evening meds will be at least 6 hours after her a.m. meds.
5. Blood Pressure – a.m. around 120/80. In the p.m. hovering around 100. What is causing the decrease in her blood pressure? What changes need to be made to ensure her blood pressure does not get too low? Should one be reduced from 10 once a day back to five twice a day?
6. Eye sight – Seems to be changing, should she make an appt. with her eye doctor or will this return when chemo is over?

7. Exercise – Using treadmill, Hot Pool, Swimming, Ocean
8. Sleeping medication – Seems not be as effective. Can we get another prescription?

Summary of Meeting with Dr. Jiang

Blood Results: WBC 1.9 ANC .6 Platelets 140 RBC 3.03 Hgb. 10.1 Hct. 29.7

Vitals: 129/68 BP

Nurse asked is left foot numb. Steph mentioned better now

Discussed eyesight is blurry, skin issue on hand (returning), and mouth sores went away (no ice cream)

Do we continue w/ the three antibiotics after Stephanie's blood has recovered?

CIPRO 2x daily: **once neutrophil is above 1,500 or one more week then can discontinue**

SMZ: Thursday and Friday 2x daily-**continue**

Acyclovir: 2x daily-**continue**

Based on Stephanie's last Session of chemo, her low point was around days 14-18.

When does day 1 of Session 2 begin?

Next meeting is 8/26 with Dr. Jiang-blood work at 8:20 and appt. at 9:00

Next chemo 8/31-9/3 (Birthday is September 4-Happy Birthday Steph.)

Does she take ATRA for only 15 days during the next two sessions?

Only take ATRA for 15 days in each round.

Confirmed in our medicine plan: Steph will take CIPRO as soon as she gets up. After two hours, she will take the rest of her a.m. medications. Evening meds will be at least 6 hours after her a.m. meds.

Continue with the above plan.

Blood Pressure – a.m. around 120/80. In the p.m. hovering around 100. What is causing the decrease in her blood pressure? What changes need to be made to ensure her blood pressure does not get too low? Should one be reduced from 10 once a day back to 5 twice a day?

As of August 12, 2009 changed Lisiniprol to 5mg in the AM and 5 mg in the PM

Eye sight – Seems to be changing, should she make an appt. with her eye doctor or will this return when chemo is over?

Eyesight change is common while on chemo. Just wait until done with all rounds.

Exercise – Using treadmill, Hot Pool, Swimming, Ocean

Yes, you can walk and use the treadmill. Hold off for now on the hot pool, swimming, and the ocean.

Sleeping medication – Seems not be as effective. Can we get another prescription?

Changed Temazepam to Ambien (5 mg) start with 1 pill @ night. Renee stated if you are waking up try two pills. Ambien last longer and calms down the brain. If taking for more

than 2 weeks and not going to take any longer taper off by taking one pill every other day, then every two days, etc. Gradually go off.

Wednesday, August 26, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. What type of preventive shots should she get, i.e. flu, pneumonia, etc.?
2. What about a platelet transfusion?

Summary of Meeting with Dr. Jiang

Date:	8/26
WBC 5,000-11,000	3.6
ANC 1,500-7,000	2.6
Platelets 140,000-450,000	102
RBC 3.7-5.4	3.15
Hemoglobin (HGB) 12-16	11
Hematocrit (HCT) 37-47	32.5

Vitals: 117/68 BP 98.6 temp. 74 Pulse
After biopsy 114/69 BP 97.8 temp. 76 Pulse

Steph shared the following: Poop is frequent throughout the day and hard-not regular like when she was not on antibiotics. Could bowel movement changes be related to the antibiotics? Port is hurting-Renee checked it after the biopsy and said it is healing-no redness and no swelling. Back is hurting. Steph asked for the doctor's report from 8/5, 8/12, 8/26-still need to get. Discussed platelet numbers lower than 8/12/09, which was 140 and today 102.

Bone Marrow Biopsy: Gave Steph Ativan for anxiety before procedure one pill of .5 and ten minutes later another .5 (need to give to her earlier). Doctor took core out of bone marrow and hit the old hole (OUCH) and sample of blood to be sent to U of W. Watch for fever, bleeding from site (if still bleeding tomorrow come back to hospital), and place ice pack on sore at night to cut pain and bruising.

Chemo: Nurse went over the new chemo med-Mitoxantone (18 mg for five days) this is a push type chemo 8/31-9/4 9:30 appointments. Except Wednesday at 8:45. Drink 2-3 quarts=12 glasses of fluid per day

Medications: Start ATRA 8/31. Do not start CIPRO

Consolidation Session 2

Chemo- Idarubicin (Idamycin brand name) (9.3 x 4 = 37.2 mg)

Blood Count Results

Date:	7/20 Day 1	8/5	8/12	8/26
WBC 5,000-11,000	6.2	1.0	1.9	3.6
ANC 1,500-7,000	6.8	.2	.6	2.6
Platelets 140,000-450,000	330	70	140	102
RBC 3.7-5.4	3.52	2.86	3.02	3.15
Hemoglobin (HGB) 12-16	11.0	9.3	10.1	11.0
Hematocrit (HCT) 37-47	33.4	26.4	29.7	32.5

Monday, August 31, 2009

Day 1-Consolidation Therapy –Session 3

Blood Results: WBC 2.3 ANC 1.2 Platelets - NA RBC 3.17 Hgb. - NA Hct -NA

Friday, September 4, 2009

Day 5 of consolidation therapy-Session 3

Blood Results: WBC 4.2 ANC 3.4 Platelets 179 RBC 3.05 Hgb.10.8 Hct 32.7

Happy Birthday Steph...

Wednesday, September 9, 2009

Blood Results: WBC 0.6 ANC 0 Platelets 82 RBC 2.75 Hgb.10.0 Hct 29.7

Sue noted stopped Alendronate Sodium. Use of B. cream (samples in the bathroom)-use generously. Labs Friday, Sept. 11 @ 10 and Wed. Sept. 16 @ 9:30

Dr. Jiang says Lisiniprol and Metoprolol work independently. Give Metoprolol at least once a day OK to skip one blood pressure dose daily.

Isolation techniques: no body contact, kissing, hugging, etc.

Maintain calories; elevate feet, DB & C 94 degrees. Underarms are OK

Thursday, September 10, 2009

Sue noted 8:30 AM 98.2 temperature. 111/72-82-small stool, urine, mouth, perineum, skin
10 AM ate 100% breakfast-small stool, void, c/o vaginal irritation
10:15 AM nap/resting, "direct TV, void, small stool, side turned-right
11:30 97.2
12:00 PM sleeping
1300 sleeping face flushed; occ dry cough
1430 98.6 temp; 110/66-75; ate 100% lunch; Tylenol
1445 improved well being with Tylenol
1600 98.6 temp
6 PM 98.8
Paula noted 8 PM 98.0 temp; 126/72-mouth sores and sore tongue; 2 Tylenol and not seltzer, tomato or lemon

Friday, September 11, 2009

Blood Results: WBC .1 ANC 0 Platelets 12 RBC 2.85 Hgb. 10.5 Hct. 29

Steph woke up, felt chills, and was on the toilet when Paula found her. Paula took her temperature, and put on Steph's sweats and drove her to ER at Whidbey General Hospital. When she arrived the intake person asked questions that were already in Steph's file. Paula insisted that they get her in a room and get to the real business of helping Steph. This same ER doctor saw Steph on May 25, 2009. Steph's temperature was 103 at 4 AM. She was in a lot of pain and finally gave her pain meds and put her on fluids. Steph was feeling less pain with the happy drugs. Her vitals at 6 AM were 101.8 temperatures, 97 oxygen sat. levels, 85 heart rate, 76/49 BP on left side sitting up, and she said her pain level was 3 out of 10. Added more fluids due to BP. Steph had a chest x-ray, which showed no lung issues. Vitals at 6:30 AM 101 temp., 78 heart rate, 97 oxygen sat. levels, BP 70/45 left side sitting up, 72/46 right side lying down. Put Steph on oxygen as a precaution. Moved to ICU at 6:45 AM. Paula went home to take care of Ruby, get some clothes, pillow, and the ATRA.

Susan stayed with Steph while Paula went back to school. Steph was having fevers, felt hot, and then would get the chills. She threw up and Zofran was administered for nausea. Vancomycin (antibiotic) was given and reviewing notes from June 19 Steph developed a red rash, an allergic reaction, while on this antibiotic when she was at Providence Hospital. So Paula called the nurse and asked them to take her off this med. Steph had platelets.

Judy was the nurse (5:30 PM) who suggested Steph eat Activia and drink cranberry juice to help with yeast and ph balance issues with urine, as a precaution. Judy discussed some of the meds: Zantax (anxiety) every four hrs as needed, Zofran (nausea) every four hours as needed, Dilaudid (narcotic/pain med) every hour as needed, Tylenol was given every four hours even if she was sleeping. Paula went home and Mary stayed with Steph for the night.

Tylenol @ 6:15 PM, Pain med include with 9:30 PM meds. 450 cc of urine and medium size and soft BM, Vitals @ 10PM 102.6 temperature, 100 oxygen levels, 109/61 BP, 104 Pulse rate. Vitals @ 11:10 PM 102.3 temperature, 99/44 BP, Vitals @ 11:55 PM 102.1 temperature, Adivan given for sleep and to relax, Steph woke up, used the commode, and had another soft medium size BMs and peed. Steph's vitals were great throughout the night.

Saturday, September 12, 2009

Blood Results: WBC.1 (am) .1 (pm) ANC 0 Platelets 47 RBC NA Hgb.7.9 (am) 9.5 (pm) Hct. 22 (am) 27.9 (pm)

1:20 AM 99.3 temperature and 6:00 AM temp 102 to 103. Paula came around 7 AM and Dr. Langrock came by and was watching the game. Dr. Roof came by and shared that Vancomycin ***might*** be used to help fight her infection and most people do not have reactions and will give this med slowly and watch for any reaction. Red Blood given today and Benadryl was given before to prevent any type of reaction. Steph is sleeping most of the day. Tylenol is now only as needed. 103 temperature. down to 100.2 @ 7:15 PM

Sunday, September 13, 2009

ANC 0

Antibiotics: Imipenem cilastatan 500 mg. 3 x day every 8 hrs. ; ACY acyclovir 400 mg. 2 x day; Cipro Floxacin 500 2 x day

6:00 AM 98.8 temp 101. @ 8:30 Am chills. Steph had sip of coffee and threw up. 10:10 AM BP 136/62 Metoprolol (lower dosage of BP), Xanax, and Tylenol Steph asked for. Zofran admitted at 10:20 for nausea. Cool rag to forehead has some physiological results. 11 AM 101.4 temperature. 104/49 BP; 99/51 BP @ 1:10 PM

2:35 PM 98.5 temperature has chills added warm blankets; 3:30 PM 100.3 temperature along with chills and 161/84 BP and gave Xanax and Lisprol at 3:40 PM.

Dr. Langrock states Steph has Alpha-hemolytic streptococci, which is bacteria and found in the blood, not septic. This is based upon clinical findings: urine output, fever (chills probably due to bacteria), mental state, and all of this is improving so he feels his conclusion of bacterial verses septic is correct. Some questions asked of Dr. Langrock were- if the following antibiotics could cause neutropenia: Imipenem Cilastatioan, ACY, or CIPRO- he didn't think so. Patient has had prolonged neutropenia. Vancomycin has reversible neutropenia has been reported what about this? He is not aware of this and good question to ask Dr. Jaing. Will call Dr. Jiang regarding platelets and transfusion. Also, plan to talk to Dr. Diaz. Dr. Oakland, B. Fisher PA, and Dr. Gonzales will be the team of doctors working with Steph.

Blood culture sent out again looking for typing, identification of infection, and resistance to which antibiotic.

4 PM 102.9 temp and gave Zofran before Dilaudid pain med in IV. Gave Tylenol too because some chills and a lot of discomfort and some confusion.

4:55 PM 101.5 temperature. 98-oxygen level, and 95-97 with oxygen support, 130/66 BP

6:40 PM 100 temperature. 94-oxygen saturation level, 121/53 BP

Monday, September 14, 2009

Blood Results: WBC .2 ANC NA Platelets NA RBC NA Hgb. 8.5 Hct. NA

Sue noted 8 AM 101.4 temperature; 8:40 AM chest x-ray; Blood draws taken AM and PM from arm and vein (port). 9:10 AM given platelet transfusion x 2 bags. Jan M. in to visit. 9:30 99.2 temperature. Red blood needed if lower than 8. B. Fisher PA ordered nupigen (WBC booster) before consulting Dr. Jiang or his staff. 10:15 B. Fisher to contact Dr. Diaz, Infectious Disease doctor from Everett to find out about her reaction to vacomycin. Chest x-ray shows pneumonia

in right lower lobe. Started vancomycin, gave Prilosec (acidity in stomach helps with this). Finished Tretinoin 10 mg (ATRA) didn't take the PM dose. Stopped use of CIPRO and gave nupigen 1 dose 480 micrograms. Jennifer, nurse, gave Lisinprol 5mg, Tylenol 650 mg. @ 6 PM. Dr. Bantastian, colleague of Dr. Jiang, agreed to giving nupigen to boost WBC. ANC needs to be 1.0

Chills in the PM and fever so recorded meds for the next three days to look for a trend:

12:30 Vancomycin, 4:45 Ondansetron and Dilaudid, 6:00 Lisinopril, 7:00 Potassium Phosphate. 5 PM temp 102.3 BP 153/80 HR 124; pain meds given and Lisinprol. Sleeping. 5:45 PM 140/69 BP 120 heart rate 32 respirations, oxygen saturation levels start at 77 and slowly move to 93. Jennifer gave Steph some oxygen. 5:55 PM blood culture check to see what is causing the fevers-blood draws from port and vein-takes a couple days to grow.

6 PM Jennifer mention about Lisinprol 5mg to help get BP down. Tylenol 650 mg given due to 103.2 temperature. Gave pain meds and Tylenol by 9 PM and was "loopy, happy, and comfortable" seems to do the trick. Upped her blood pressure meds because her blood pressure was too high. Paula gave her a bath, checked her rear end, applied A & D ointment, and cleaned it well. Looked red and some sores right by the rear end. Had a good night.

Tuesday, September 15, 2009

Blood Results: WBC.2 ANC 0 Platelets 44 RBC NA Hgb.8.0 Hct. 23

Sue notes ate 80% of breakfast of French toast and yogurt. Steph is talkative and figuring out how many days of treatment. 10 AM 98.3 temp 129/70 BP on commode and soft stool. Renee Yanke, head of MAC lab, mentioned adding a new IV drug Caspofungin, anti-fungal, once a day; continue with potassium replacement; will order a physiotherapy consult, may be done in the room; Nupigen once a day. Mary called @ 11:45 sleeping with a 99.9 temperature. At 12:30 99.7 temperature BP144/78 with oxygen saturation @ 96%. 1430 temporary 100.2 took two tablets of Tylenol and has a headache and Steph says "don't feel good". 1450 BP 167/95 Heart rate 112 and temperature. 100.4. Gave Clonidine 0.1 for high blood pressure. 1500 phone call to Paula and twenty minutes later gave Dilaudid and will give Zofran. Steph was coughing up small amount of thick white mucous. 1530 Blood pressure has gone down to 143/79 and heart rate is 102. Steph is resting comfortably.

Meds in the afternoon: 2:15 Vancomycin, 3 PM Ondansetron, Dilaudid, and Clonidine, 6 PM Magnesium Sulfate

Wednesday, September 16, 2009

Blood Results: WBC .2 ANC NA Platelets Na RBC NA Hgb. 7.3 Hct. 21

7 AM clear and having coffee and sitting in the chair, Paula mentions.

Sue noted the main IV was discontinued and given Lasix (diuretic) IV; continues potassium replacement. Questioning if the porta cath. is source of infection and continuing T's.

Physiotherapy in for strengthening exercises. Temp. is 97 at 10 AM. Steph is sleeping at 11 AM and has had huge urine output since Lasix. Waiting for Dr. Jiang. Paula and Mary call at noon. Temporary 100 BP 148/76 and oxygen saturation levels are 97%. 1300 Dr. Jiang states "No change in treatment plan." Perineal/rectal area looks okay and he states another seven days in the hospital. 1320 first unit of PRBC up and watching 50 First Dates and looks good. 1445

temperature is 99.6 and BP is 130/74.

Sitting up for around three hours and went to bed with chills and a temperature. 100. Along with red blood cell replacement Vancomycin was given before this episode. Fever is up to 101.2 at 7 PM gave pain meds. along with Tylenol. BP 164/96. Peggy, the nurse, is looking for Cloridine. Steph is sleeping at 7:45 for about a half hour. She ate a huge dinner. Steph is druggie and feeling better and Paula can hear her breathing and sounds wheezy around 8:20 PM. Mary stayed until midnight and then Steph slept.

Meds for the afternoon: 3:00 PM Primaxin-antibiotic 3:45 PRBC #2, 5 PM Calcium, 6 PM Vancomycin, mouthwash, and potassium, and 7:45 Ondansetron and Dilaudid

Thursday, September 17, 2009

Blood Results: WBC .2 ANC 0 Platelets 9 RBC 2.98 Hgb. 7.3 Hct. 28.2

Paula notes Steph is probably tired today and her temperature. seems to spike at night. Dr. says she can get up and start walking around with Sue... only if she feels like it. Also, Paula asked Sue to help Steph with a shower today.

Sue noted Terri is the nurse with Steph this morning. Steph is sleeping with somewhat labored respirations at 8 AM. Around 10:15, she ate two pancakes, OJ, decaf coffee and is sitting in the recliner. Her temperature. is 98.4, BP 135/74 with 96% oxygen sats. Brita Fisher PA comes by at 10:30 and mentions Steph will receive platelets and Nupigen today. Sue notes that Steph "looks better." Around 11 AM coughing up small amounts of thick yellow sputum, urine output okay, and small soft stool. Had Zofran and Dilaudid prior to Nupigen at 11:45 AM. 1330 Erin, dietician, came by to consult. Steph ate a bowl of noodle stroganoff for lunch. Steph can now select her meals from the cafeteria menu. Steph walked the hallway, brushed teeth, and takes fluids around 1400. Around twenty minutes later temp 37.6 c BP 154/90, heart rate 100, and first unit of platelets. Steph is coughing up thick white sputum with a temperature. of 99.7 around 1545. Around 9:40 PM 139/80 BP with 94 oxygen sats., 94 heart rate, and 98.5 temperature. 1AM blood pressure is up to 180 and heart rate is 140. Chest x-ray and Lasix 1.5 hrs. from 2 AM on

Friday, September 18, 2009

Blood Results: WBC .3 ANC 0 Platelets 31 RBC 2.98 Hgb. 9.7 Hct. 28.7

Sue notes Paula is here and Steph is sitting up, eating waffles, and drinking OJ. Around 10 AM, temperature is 99.1 BP 134/70 and oxygen sats 97% on 2L of oxygen and she is feeling sleepy. Steph ate all her breakfast. 1415 BP 129/72; heart rate 86, and oxygen sats are 96%. Had clam chowder for lunch; slept ½ hour outside in a wheelchair; walked about 100 feet. Has been of oxygen and managing well. Steph's feet still slightly puffy. Best day so far. Nursing staff reluctant to share lab values with Sue, Paula aware.

1515 Dr. Roof in and the blood cultures are back (type not disclosed) but present IV antibiotic course will cover it. Will stop Caspofungin tomorrow and will continue with potassium and magnesium replacement. Dr. Roof feels we are on the right course and waiting for blood numbers to start going up.

Saturday, September 19, 2009

Blood Results: WBC .2 ANC 0 Platelets 18 RBC 2.93 Hgb. 9.5 Hct. 28.0

Sarah, the nurse, changed the port. Huskies won!!! Cougs won, too!! Steph sat up quite a few hours.

Sunday, September 20, 2009

Blood Results: WBC .3 ANC NA Platelets 49 RBC 26 Hgb. 8.5 Hct. 24.8

Paula got a phone call from Steph because they were going to move her and Paula wasn't there. Moved to room 25 from ICU. AM nurses are Jolene and Nancy. Blood pressure went up @ night and used a diuretic.

Monday, September 21, 2009

Blood Results: WBC .3 ANC 0 Platelets 26 RBC 3.36 Hgb.10.5 Hct. NA 139 K 3.6

Sue writes Janet is the nurse. Wow!! Out of the cell, private room 25. Eating all food, hungry looks great. Temp. 98.7 BP 148/70. Making plans for discharge later in week. 10 AM Visit from Anne-Marie "cheerful". Had rectal swab of 9/18 which equals Vancomycin resist enterococcus (VRE). Sleeping around 11 AM. Mary called to ask how Steph is doing and if the lab results from 9/20 were there. 2 PM BP 153/89, 101 temp. , face flushed. Gave Tylenol and blood culture taken from port and vein. 3:45 PM 37.6 c temp. 159/89 BP and 94% oxygen sats. 4 PM Shannon from infection control stopped by and then Dr. Mall, first day at Whidbey General Hospital, came by.

Paula asked for copy of blood results from 9/13-9/21 and the results still not received by 7 PM. Questions for the doctors: What is antibiotic schedule at this point? What is plan for new antibiotic? Blood pressure needs to be below 140.

Tuesday, September 22, 2009

Blood Results: WBC .3 ANC 0 Platelets 15 RBC3.45 Hgb. 10.8 Hct. 31.9

Paula noted busy night last night... Steph was fine but Dr. Mall had difficulty talking with us due to her time constraints. I put a call in MAC lab for consult as Steph is VRE-Dr. Mall would like to continue with Vancomycin. Steph refused it this at 7 AM. The nurse charted it and they are forced to change antibiotic. Mall thinks possible shunt or port infection. I don't think it's the shunt. Gave her the neurosurgeon's phone numbers at Harborview and Dr. Jiang's for consult. She is feeling better and had a good night. Call and let me know what transpires throughout the day. I think some would like to kick me out of here....

Sue noted 8 AM early consult with Dr. Roof, Dr. Mall, Paula, and Steph regarding Vancomycin and hospital plan. Weight is 83.9, temporary 97, and BP 135/81. CXR checked and small stool. Appetite good. Renee Yankee came in for lengthy consultation. She emphasized more ambulatory, fluids, and DB & C. Steph is sleeping around noon. Ate lunch in chair and had temperature. of 36.9 and BP 116/72. Also, went outside for 30 minutes. Steph mentioned, "I think I am better." Incentive spirometer to 1350/1500

Wednesday, September 23, 2009

Blood Results: WBC .3 ANC 0 Platelets 8 RBC 3.23 Hgb. 10.1 Hct 29.6

Paula notes had a good night. Apparently, I have a meeting with Dr. Jiang at 4:15 today. She asked Sue if she could confirm that. The AM or night nurse said it was written in her chart to transfer today. I had the night nurse put down that it was NOT the case. We will notify Dr. Jiang today. If he comes by and decided to move her, I am hoping that can be tomorrow not today I can take the day off and go with her. I have meetings from 8-10 AM... will call after that! Dr. Mall had orders for helicopter to transfer Steph to Providence. Paula stopped that. Renee from the MAC lab suggested keeping using the breathing machine, getting up and moving, and using the mouthwash.

Sue noted sleeping soundly at 8 AM. Dr. Roof was in and will return later to give six units of platelets today. 1300 Platelets in and sleepy after Benadryl given before platelets. BP 100/66. Note to take home Activia because live bacteria are not okay. Different opinion from the ICU nurse who recommended Activa. Around 1500 awake and cheerful. Dr. Roof returned and Renee Yanke came by, too. Waiting for Dr. Jiang Vitals at 4:35 PM 120/78 BP, 78 Pulse, 36.5 temperature, 99 oxygen sats. gurgling in stomach good sign, large poop, no crackling in lungs. Steph stated she feels better today verses last Wednesday when she met with Dr. Jiang. Dr. Jiang explained that this recovery is slower because she has had more chemo in her verses when she was recovering at Providence in June. Dr. Jiang asked how is your eating and Steph offered him a dinner on her. No mouth sores, no belly cramps, poop twice a day with no pain, no vaginal problems. Dr. Jiang stated stay the course with the current meds. He stated discontinue nitro. He projected a week from now Steph would be home.

Thursday, September 24, 2009

Blood Results: WBC .5 ANC 0.1 Platelets 42 RBC 3.22 Hgb. 10.1 Hct. 29.6

Sue notes good day. No fever and appetite is good. Dr. Roof and Renee Yanke are in. Lab work shows slight improvement. Slept past lunch, cheeks are red, bit of a snuffle nose, and still has dry cough. Anxious regarding sister's visit. Need moisture and newspaper.

Friday, September 25, 2009

Blood Results: WBC .6 ANC .4 Platelets 33 RBC 3.30 Hgb. 10.3 Hct. 30.4

Paula notes clean clothes in white bag and money in Steph's purse. Had a good night-little sniffy don't know if she has a cold? No going outside, but can walk around the hospital. Will call around 12:45.

Sue notes best day. Blood work slowly going up. Renee Yanke says neutrophils have to be .5 before discharge. May need platelets over weekend. Small clear nasal discharge inside today.

Saturday, September 26, 2009

Blood Results: WBC 0.8 ANC 0.1 Platelets 22 RBC 3.23 Hgb. 10.2 Hct. 29.3

"Here we go again... I'm inclined to go to what is in my body APL chromosome 15 & 17. They don't get along; make sure not to encourage doing that. Never heard of APL don't call cancer. Why is leukemia different than cancer?"

The chemo given to me is a nightmare. Waiting to get out of here (Whidbey General Hospital). Almost like it wasn't me. Like my body was taken out of here and worked on. Depends on who does what and how they go. Who is going to find out so we can have people do what they suppose to?

My whole history to find out what is going wrong with me. I can't tell how anything relates to something else. I didn't understand why I was moved here." (Steph spoke about getting sick and how it relates to her brain.)

"You are not going to have a chance because you didn't know you were going to have this. You don't know what to do. I was getting sicker and sicker." Steph shares her thoughts about APL. "We don't know what to look at. Some people are more susceptible to cancer."

Sunday, September 27, 2009

Blood Results: WBC 0.9 ANC 0.2 Platelets 20 RBC 3.09 Hgb. 9.7 Hct. 28.53

Monday, September 28, 2009

Blood Results: WBC 1.0 ANC 0.3 Platelets 64 RBC 2.99 Hgb. 9.3 Hct. 26.8

Checking out of this place.

Friday, October 2, 2009

Blood Results: WBC 1.5 ANC .7 Platelets 30 RBC 3.32 Hgb. 10 Hct. 30.4

Sunday, October 4, 2009

WBC 1.7 ANC 1.0 Platelets 34 RBC 3.44 Hgb. 10.6 Hct. 30.9

Called for an ambulance after eating some peanuts and having difficult time breathing and chest pain. Chris was one of the paramedics who brought Steph to the hospital. Paula shared the list of meds: Acyclovir 400 mg 2 x a day; Calicum 2 tablets, Multivitamin, Metoprolol 25 mg AM and 25 mg PM; Lisiniprol 10 mg AM, CIPRO 500 2 x a day; Simvastatin PM only and finished Zitchromax 6 pills. Dr. Nicholas Perera, ER doctor, graduated in 1996 listened to Steph describe the feeling in her throat/esophagus and the rash on her abdomen. He prescribed Lydoecane to numb her throat. Based upon her blood results and a chest x-ray that showed nothing the ER doc sends Steph home.

Heather, the nurse, shares about her boyfriend's brother who has been recently diagnosed with leukemia. Steph shared with Heather how she is willing to talk with her boyfriend's brother. Heather was reassured because Steph looked great and was doing so well.

Tuesday, October 6, 2009

Medication

Daily Medication	Purpose	Amount and Time
Acyclovir –large white pill	Protects against virus'	Twice a day 400 mg. AM PM
Calcium Citrate- at least 2 hours before CIPRO	Protects bones	2 tablets daily
Lisiniprol Not taken if blood pressure is lower than 100	Lowers blood pressure	5 mg AM (prescription says 10 1 x a day)
Metoprolol Not taken if blood pressure is lower than 100	Lowers blood pressure	½ tablet twice a day 500 mg
Multi Vitamin	Vitamin	1 tablet daily AM
SMZ	Antibiotic	Thursday and Friday AM and PM
Simvastatin	Cholesterol	PM only
Alendronate Sodium	Bone Growth	Every Monday morning when to start?

Medications to be determined

As Needed Medication	Purpose	Amount and Time
ATRA	Oral chemo	50 mg AM-5 brown pills 40 mg PM-4 brown pills
CIPRO	Antibiotic	500 mg every 12 hours for five days 9/30-10/5
Zithromax	Antibiotic	500 mg first day 250 mg the next four days 9/30-10/4
Alendronate Sodium	Bone Growth	Every Monday morning
Alprazolam	Anxiety	25 mg
Lonox	Diarrhea	1 tablet up to 8 in 24 hours
Anti diarrhea-Lomotil	Protects against diarrhea	Most likely am
Sleeping pill-Ambien	Helps you sleep	At night
Tylenol	Fever and pain	At night
Senna laxative	Keeps bowels regular	If bowels are hard
Clotrimazole	Cream for hand	If dry skin
Dulcolax	Anti diarrhea	If bowels are very hard
Prochlorperazine	Anti nausea	10 mg.

Wednesday, October 7, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. Stephanie has no fever.
2. Stephanie's blood pressure was low on Sunday, Oct. 4 more information to discuss.
3. There is a rash on Steph's abdomen. What is causing the rash?
4. A trip to the ER on Sunday, Oct. 4 was included. More information
5. Soft, frequent stools four to five times a day-current.
6. Vaginal infection started on Sunday and noticed on Tuesday, Oct. 6.
7. What about getting a flu shot? When can this happen?
8. When is this section over and what are the expectations?
9. When is the final section 4 done?
10. When can we set up the maintenance section?
11. Can we make sure that the last round of chemo is done and time to recover before December 19?

Summary of meeting with Dr. Jiang

Did not have written notes from this meeting.

Wednesday, October 14, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. Stephanie's rash has dissipated.
2. What are the results of the stools specimen submitted turned in on Wednesday October 7, 2009 and Thursday October 8, 2009?
3. Soft, frequent stools, three to five times a day. I do not force a bowel movement in an effort to avoid any damage to bowel. The stools are a medium size, color, two to three on each, and are solid not needing treatment on unsolid stools. When is it to be normal with one or two movements during 24 hours?

4. Vaginal infection that has been treated and is currently resolved.
5. What are the results of the blood evaluation today available to look at against October 7th results?
6. Flu shots. There are two – H1N1 and regular flu shot. I would like to discuss both of them briefly again about the very best dates to schedule taking them considering the beginning of the last week in October scheduled to start the last Chemotherapy.
7. Blood Pressure: While in the hospital, my blood pressure was high and I was given medication to lower it. While at home, it tends to run in the 110/60 -- 70 in the a.m. and then below 120 in the p.m. What should we do to make it come in at 120 -130 all day long? What about taking the meds at night to carry us through the day?
 - a. Lisiniprol 1x a day 10. Should this be am or pm?
 - b. We are taking 25mg. of Metroprol regardless of BP.
 - c. Can we take as needed or does it need to be daily dose?
8. Once a week bone pill *Alendronate Sodium*– when should we begin this?
9. Acyclovir – 400 mg. 2x a day – for how long?
8. Based upon this meeting can we confirm the following:
 - i. Final Chemotherapy completed week of October 28, 2009.
Please schedule around 3 pm so Paula can attend.
 - ii. Is this just one day of chemo?
 - a. Do we begin taking the oral chemo *ATRA* again for 15 days?
 - b. Cipro – when do we begin taking this?
 - iii. Bone marrow biopsy – will this be before or after the next round?
 - b. Recovery during November – what does that look like? Are you projecting that I will spend time in the hospital?
 - c. Maintenance will begin December 2, 2009-*Is molecular remission checked? When and Why?*
 - d. Trip to Maui starting Dec. 19, 2009 – how do we do the shots?
9. What are the amounts and names of each Session?

First Session 12 mg for each of four dosages = 48 total

Second Session 9 mg for each of four dosages = 36 total
 Third Session 18 mg for each of five sessions = 90 total
 anticipated
 Fourth Session 12 mg for one session = 12 total

Other Questions / Comments:

Summary of meeting with Dr. Jiang

Date:	10/14
WBC 5,000-11,000	2.4
ANC 1,500-7,000	1.2
Platelets 140,000-450,000	115
RBC 3.7-5.4	2.9
Hemoglobin (HGB) 12-16	9.2
Hematocrit (HCT) 37-47	26.5

Vitals: 100/62 BP 85 Pulse 36.9 temp.

Information: Continue with the neutropenic diet. Small dose of Imodium in the AM if frequent stools are bothersome. Wait two more weeks to schedule flu shots. Can exercise (not too strenuous), take walks, eat out and does not need to wear the mask. Remember to wash hands. Napping, no pain, no constipation, frequent small soft stools, no swelling, rash gone, probably due to antibiotics, dry skin on abdomen.

Medications: Lisiniprol .5 in the AM and Metoprolol twice a day .25. Begin Alendronate Sodium next week October 17. Take Acyclovir for one more week
 Do not take ATRA or CIPRO for now.

Maintenance- one shot a week Methotrexate and 6 MP pill once a day

Wednesday, October 21, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. What are the results of the blood evaluation today compared to October 14, 2009 of Session 3?

Takes to Day 45- Session 3 -Well below 2 & 1 on WB, Well below of 2 & 1 on ANC

Session 1 & Session 2 - Days 38 - Both succeed significantly over Session 3 on fewer days.

2. Can the final Session be moved from October 28, 2009 to November 4, 2009 or November 11, 2009?
3. If it was moved to further dates, the latest be November 11, the time to recover would extend by two weeks. Instead of the maintenance starting on December 1, 2009, it would start on the 16th.
We are leaving on the 19th to go to Maui. Is it possible to start the maintenance program when I return to Whidbey on January 2, 2010 or start the oral medicine on the trip and then do the weekly shot when I return?
4. The maintenance is using Chemo-Idamycin, inserting at a rate of 12 mg of one dosage like the Induction Session 1, or 9mg if it is one dosage like the Second Session. What are the expected outcomes of recovering from this?
5. I have had one brief involvement of diarrhea on Sunday and Monday. It is very runny and gives no warning. Is there something I am taking that causes this? If there is something that causes this is there something that can be used to limit this?
6. What are the medicines such as Cipro scheduled according to what we are scheduling and doing for maintenance?
7. Have not scheduled Flu shots yet. You said two weeks so you are suggesting the week of October 26, 2009.
8. Bone pill is delayed until after I have dealt with the final session.
9. Other???

Summary of meeting with Dr. Jiang

Date:	10/21
WBC 5,000-11,000	3.3
ANC 1,500-7,000	1.7
Platelets 140,000- 450,000	151
RBC 3.7-5.4	2.86
Hemoglobin (HGB) 12-16	9.0
Hematocrit (HCT) 37-47	26.8

Vitals: 117/65 BP and 36.5 temp.

Information: Renee discussed neutropenic diet. Eat well-cooked meat. Do not eat raw meat. Okay to eat hard-boiled eggs, bananas, oranges, and cook fresh vegetables. When blood count is low there is a concern about eating yogurt that has live cultures (make sure it is pasteurized)

Blood Counts are good stated Dr. Jiang. Steph is considered a low risk patient based upon her blood count

October 28 at 3:30 for blood draw and next Session 4 with Idarubicin 12 mg. Dr. Jiang said give 6 weeks/42 days to build blood counts up after Session 4. This is accumulative process due to chemo from Sessions 1, 2, and 3.

Maintenance will begin in January with the once a week shot and pill

Get seasonal flu shot this week before Session 4

Bone marrow biopsy done today-gave Ativan 2 doses into port (anxiety med) before the procedure

Dr. Jiang did the bone marrow biopsy at Whidbey General Hospital. Results show complete molecular remission (CMR). PCR-a sensitive test that can detect remaining cancer cells which was sent to U of W shows zero cancer cells out of a million cells.

Medications:

Acyclovir-protects against virus 800 mg 2 times a day-Oct. 28

Continue with all other meds.

CIPRO-Begin November 2 (five days after Session 4)

ATRA is after Session 4-due to low risk do not need this –Ask Dr. Jiang

Waiting until after Session 4 to take Alendronate Sodium-bone growth pill

Dr. Jiang wrote a prescription for Lonox-diarrhea meds.

Danger: Remember Zithromax caused Steph to throw up. This antibiotic came in a six-pack (two pills for day one and then one each day after for a total of five days).

Consolidation Session 3

Chemo-Mitoxantrone (18 mg x 5 = 90 mg)

Blood Count Results

Date:	8/31 Day 1	9/4 Day 5	9/11	9/28	10/2	10/4	10/7	10/14	10/21
WBC 5,000-11,000	2.3	4.2	.1	1.0	1.5	1.7	1.7	2.4	3.3
ANC 1,500-7,000	1.2	3.4	0	0.3	.7	1.0	.70	1.2	1.7
Platelets 140,000 -450,000	Did Not Receive	179	12	64	30	34	52	115	151
RBC 3.7-5.4	3.17	3.05	2.85	2.99	3.32	3.44	3.20	2.9	2.86
Hemoglobin (HGB) 12-16	Did Not Receive	10.8	10.0	9.3	10	10.6	9.7	9.2	9.0
Hematocrit (HCT) 37-47	Did Not Receive	32.7	29.7	26.8	30.4	30.9	28.8	26.5	26.8

Wednesday, October 28, 2009

Summary of Meeting with Dr. Jiang

Date:	10/28 Day 1 Session 3
WBC 5,000-11,000	4.4
ANC 1,500-7,000	3.4
Platelets 140,000- 450,000	153
RBC 3.7-5.4	2.98
Hemoglobin (HGB) 12-16	9.8
Hematocrit (HCT) 37-47	28.6

Pre-meds- Aloxi (anti-nausea) and Decadron (steroid that increases appetite and prevents nausea). Take Benadryl (anti-histamine).

Chemo- Idarubicin (Idamycin brand name) (22 mg x 1 day) Idamycin was divided into two syringes and a slow push into the tubing into the port. Dr. Jiang states this session 4 should be the easiest one because this is the lowest dose; blood counts will probably increase by day 35, and NO going to the hospital. He also projected that the ANC will not go as low as it has. The mind controls the body was another thought he shared. The nurse shared that 10-20% of the people taking Idarubicin lose their hair. She also stated that even with Steph in Complete Molecular Remission she wouldn't want take the chance without taking this last dose of Idarubicin.

Bone marrow biopsy- results from October 21, 2009 show complete molecular remission (CMR), which is excellent stated Dr. Jiang. PCR-a sensitive test that can detect remaining cancer cells, which was done at the U of W shows **ZERO** cancer cells out of million cells. Two page results were given to Steph.

Port-The port needs to be flushed every 6 weeks. For each blood draw the port is flushed. In addition, if the port is accessed for 7 days then need to change the needle, just like was done while Steph was at Whidbey General for the 21 days.

Next appt. November 4th: Blood draw at 2:45 and Dr. Jiang appt. at 3:30

Medications: Discussed Reclast- the once year bone growth shot given at the MAC unit. Take ATRA for two weeks October 28-November 11.

Wednesday, November 4, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. Hemoglobin at 12-16 and Hematocrit at 37-47 have not been reached. What is the impact of these on function and how much longer when the Consolidation Session 4 is over does it take? What about issues on anemic?
2. I have had two days of diarrhea, Saturday and Sunday, and used the pill to slow it down. Today, Monday it didn't happen. Is there anything special I should pay attention to through this process?
3. What is the dosage and how many times a day for CIPRO? How long should CIPRO be taken?
4. What could cause low blood pressure and what should be done about this?
5. What is the name of the once a week injection during maintenance? What are the side effects and what should we be watching for?
6. What do we to watch for and what are the side effects for the pill 6 MP (Mercaptopurine) which is taken during maintenance? How many times per day and what is the dosage?

Summary of Meeting with Dr. Jiang

Date:	11/4
WBC 5,000-11,000	2.4
ANC 1,500-7,000	1.5
Platelets 140,000-450,000	109
RBC 3.7-5.4	2.76
Hemoglobin (HGB) 12-16	9.2
Hematocrit (HCT) 37-47	26.5

Vitals: 104/56 BP 80 Pulse 36.8 temp.

Information: normal appetite, no sores in mouth, no nausea or vomiting, diarrhea on Sat. and Sun., but since beginning CIPRO bowel movements are normal, no shortness of breath, no swelling of feet, palms have dry skin-which happens when body is back on track, skin is dry and Dr. Jiang suggests drinking more fluids

Red Blood Count (RBC) normally is the slowest to recover and will take a few months due to the chemo treatments. There are no anemic issues. Avoid taking iron supplements because when you need a blood transfusion that will overload the body with iron.

Diarrhea: Dr. Jiang shared not a big concern just continue to take the Lonox- diarrhea medication when needed.

H1N1 shot-Dr. Jiang stated blood counts are decent so could wait. Went to Dr. Roof's office, received a prescription for H1N1 shot, and will go to Oak Harbor at the Elks Club, Thursday, Nov. 5 to get this flu shot.

Next appt November 11, 2009: Blood draw 9:45 and Dr. Jiang appt. at 10:30

Wednesday, November 11, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. I am going to Hawaii and can I eat sushi, raw oysters, raw fish, and medium rare meat?
2. What is the difference between acute and chronic leukemia?
3. When do you stop the Acyclovir?
4. When do you stop CIPRO?
5. We are stopping ATRA as of today.
6. Are you familiar with television show, "Brothers and Sisters" where the young woman who is her forties has lymphoma and she has stopped chemo and looking into the option of natural medicine? What do you know about this and what do think about this?
7. APL was discovered in 1959. Are there any studies that show the results of patients on the both the original six months and the maintenance?
8. Have you heard about Kareem Abdul-Jabbar has chronic myeloid leukemia and announced this on November 10, 2009? Michael J. Fox is a wonderful actor and a fabulous advocate for Parkinson disease and is affecting people's lives. Do you think Kareem Abdul-Jabbar can do something similar for leukemia or do you know of someone else?

Summary of Meeting with Dr. Jiang

Date:	11/11
WBC 5,000-11,000	0.7
ANC 1,500-7,000	
Platelets 140,000- 450,000	33
RBC 3.7-5.4	2.60
Hemoglobin (HGB) 12-16	8.7
Hematocrit (HCT) 37-47	25.5

Vitals: 114/70 BP 80 Pulse 36.7/98.2 temp.

Information: normal appetite, no sores in mouth, no nausea or vomiting, no shortness of breath, no swelling of feet, dry lips-used Vaseline, "TIRED", active last Sunday, checked port no redness or swelling-talk to Jackie about accessing port

Hawaii: Wait until December 16 blood count results for eating sushi, raw oysters, raw fish, and medium rare meat.

Blood Counts-low point is now and in the next two weeks should feel better. Thanksgiving dinner should be good-eat less spicy food

Maintenance- There have been many trials done on induction and consolidation therapy. In addition, there have been trials with patients with maintenance and without maintenance therapy. The trials with patients using maintenance therapy found those patients did not have a relapse. The therapy consists of the 6 MP pill (Mercaptopurine) and Methotrexate. Methotrexate is given as injection, through the vein (port), or in a pill form. The pill absorption rate and dose are not worked out, but Dr. Jiang is considering the pill form for Steph. It is possible for a 6-month trial and for the last year of the maintenance therapy.

People on maintenance work full-time and may have lower blood counts, but not to the degree when on chemo.

Next appt November 18, 2009: Blood draw 3:00 and Dr. Jiang appt. at 3:45

Medications:

- CIPRO-continue until counts recover
- Acyclovir-continue and will stay on this even after counts recover
- Metoprolol-continue
- New prescription-Numbing cream put on a hour before blood draw
- DONE-ATRA as of November 11, 2009

Wednesday, November 18, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. I am now at day 22, which means recovery. Where am I relative to that? When can I have my teeth cleaned?
2. I have been very, very tired the last couple of days, when can I expect I will improve having energy?
3. Is a blood transfusion affected by my chemotherapy? Yes or No? If yes, how? How long is Idarubicin in my body?
4. We really appreciated looking at Francis Collins and the human genome project. Does this have anything to do with creating preventative items that prevent people from getting cancer?
5. We got data from the American Cancer Society. What is the difference between Observed Survival Rates and Relative Survival Rates?
6. Cancer sites were listed as Female Breast, Uterine Cervix, Colon and Rectum, Uterine Corpus, Leukemia, Lung and Bronchus, Melanoma of the Skin, Non-Hodgkin Lymphoma, Prostate, and Urinary Bladder. (Rounds to the nearest 10. Excludes basal and squamous cell skin cancers and in situ carcinomas except urinary bladder). The All Sites for Alabama is 24,090 and when you add the cases it is a discrepancy of 16,420. People need to know if their cancer is curable, what are the numbers, and what is the survival rate? Is there information on a site that gives us this information?

Summary of Meeting with Dr. Jiang

Date:	11/18
WBC 5,000-11,000	2.9
ANC 1,500-7,000	1.8
Platelets 140,000- 450,000	39
RBC 3.7-5.4	2.57
Hemoglobin (HGB) 12-16	8.9
Hematocrit (HCT) 37-47	25.8

Dentist-Okay to get teeth cleaned.

Energy- Energy should be back in two weeks.

Blood Transfusion and Chemotherapy- The chemo is out of the body in a week. The effects of the chemo stay with you.

Next appt November 25, 2009: Blood draw 11:30 and Dr. Jiang appt. at 12:15

Medications:

- CIPRO-finish the four days that are left. Then done due to the good blood results.

Wednesday, November 25, 2009

Things to share and Questions with Dr. Jiang from Stephanie

(One day from Thanksgiving)

1. What are the differences on two different help with diarrhea medicines?
 - a. Diphenoxylate – was given to me 10/21/09
 - b. Lonox – was given to me 6/29/09

I had a mild diarrhea Sunday and Monday coupled with fairly regular bowel movements earlier in the morning each day. Is this how it works for most people in recovery or is there something I should do to prevent diarrhea?

2. Acyclovir – When do we stop it?
3. Thursday/Friday pills – When do we stop them on morning and evenings Thursday and Friday?
4. We stopped Cipro on 11/24. Is there anything more we need to know about that?
5. What do you think of the donation given to Fred Hutchinson Cancer Research (article in your folder) from Jackie and Mike Bezos?
6. We are going to meet on December 2, 2009. I like doing the blood evaluations on those Wednesday meetings. Is there any information I need to look at in order to pursue the goal I have which is to use pills and not use weekly shots in order to have a successful two year Maintenance Therapy?
7. Alendronate Sodium Tablets USP – I haven't taken them for a while but would like to start again next Monday. It is to treat osteoporosis in postmenopausal women. I think you said yes, is that correct?

P.S. I wish you a very Happy Thanksgiving to eat what you love on that day. It is my favorite of all of the holidays because it is about spending quality time with our loved ones here in this life.

Summary of Meeting with Dr. Jiang

Date:	11/25
WBC 5,000-11,000	1.7
ANC 1,500-7,000	0.7
Platelets 140,000- 450,000	33
RBC 3.7-5.4	2.3
Hemoglobin (HGB) 12-16	8.1
Hematocrit (HCT) 37-47	23.7

Next appt December 2, 2009: Blood draw 3:15 and Dr. Jiang appt. at 3:45

Medications:

- Diphenoxylate (diarrhea medication) given as of 10/21/09 take two if needed
- Lonox (diarrhea medication) given as of 6/29/09 did not get a renewed prescription
- Acyclovir (protects against virus)-continue two more months
- SMZ (antibiotic)-Take these Thursday and Friday pills for one more month
- CIPRO (antibiotic)-done as of 11/24/09
- Alendronate Sodium Tablets USP (treats postmenopausal women for osteoporosis)
– hasn't taken these for a while but would like to start again Monday, November 30-okay to take if stomach can handle it.

Wednesday, December 2, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. We are going to meet on December 2, 2009. I like doing the blood evaluations on those Wednesday meetings. Is there any information I need to look at in order to pursue the goal I have which is to use pills and not use weekly shots in order to have a successful two year Maintenance Therapy? I prefer using pills and limited or no shots.
2. What is the date to begin maintenance?
3. Is blood evaluation and meetings with you continuing on December 9 and December 16? I would like to know exactly where my blood is before we leave for Maui on December 19, 2009.
4. I had no diarrhea incidents this past week. One, JUST ONE, very normal looking bowel movement each morning. I did not have three to five movements through the day or odd-looking movements as I have since this all started.

5. Alendronate Sodium Tables USP – I began using Monday, November 30, 2009 – No problems. I’ve set up an appointment with Dr. Johnson in January.
6. No problems at all this past week. Actually, I felt better this past week than I have on everything since we started this event on June 1, 2009.
7. What organization gives you the most resources? Which ones do you want to see supported the most?

Summary of Meeting Dr. Jiang

Date:	12/2
WBC 5,000-11,000	1.1
ANC 1,500-7,000	0.3
Platelets 140,000- 450,000	33
RBC 3.7-5.4	2.22
Hemoglobin (HGB) 12-16	8.1
Hematocrit (HCT) 3 7-47	23.6

Vitals: 113/71 Blood Pressure, 101 Pulse, and 36.8 temp.

Blood Counts: Stem cells exhausted after chemo so will take longer for blood counts to come back. One dip is okay. Good energy level, walking more, no diarrhea, normal stool, no stomachache, felt normal, slept well, appetite good, no fever, and no chills. There are variables that can change the count, for example: dehydration or hydration. Dr. Jiang does not recommend a blood transfusion, especially with energy so good.

Maintenance: The shot (Methotrexate) has been tested where the pill’s absorption rate is not as clear. Dr. Jiang suggests one year with the shot and then the following year using the pill form. Sue can give the shot at home, but Medicare does not pay for injections done at home. Look into the out of pocket expense for the injection. The date to begin maintenance was not finalized.

Next appt December 9, 2009: Blood draw 1:00 and Dr. Jiang appt. at 2:00

Medications:

- Acyclovir (protects against virus)-continue two more months
- CIPRO (antibiotic)-begin again as of 12/2/09 –12/16/09-take for two weeks
- Alendronate Sodium Tablets USP (treats postmenopausal women for osteoporosis) – started again as of 11/30/09
- Calcium
- Metoprolol (lowers blood pressure)
- Multi-Vitamin
- Simvastatin (cholesterol)
- *SMZ (antibiotic)-Stop this pill as of 12/2/09*

Wednesday, December 9, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. I have a cold. First, one I have had in many years. I have been as careful on Session 4 as the other three. Here is what is happening: I have a runny nose, dry cough, no fever, and diarrhea. I started not feeling well on Saturday as well as the week before.

To cope with this I'm taking Mucinex DM to thin and loosen mucus and controls cough, Tylenol, Halls Plus cough suppressant. We also purchased Robitussin DM and Vicks for cough and chest congestion and don't currently need them and hope not to.

Is there anything else for my cold? Are there any other antibiotics I should take?

2. Last night after a diarrhea session, I could not urinate. Paula thought that it might mean an UTI. Today, however, I have had no trouble urinating. So, should we address yesterday's issue?
3. You prescribed Diphenoxylate as of 10/21/09 it does not work as does Lonox. I would like to get a prescription for Lonox today.
4. Depending on the blood count results, if I should have a blood transfusion I would have to do it Thursday morning or Friday morning.
5. CIPRO was prescribed from 12/2/09 to 12/16/09. Will this continue after 12/16/09?

Summary of Meeting with Dr. Jiang

Date:	12/9
WBC 5,000-11,000	1.6
ANC 1,500-7,000	0.1
Platelets 140,000- 450,000	36
RBC 3.7-5.4	2.29
Hemoglobin (HGB) 12-16	8.5
Hematocrit (HCT) 37-47	24.8

Vitals: 122/66 Blood Pressure, 76 Pulse, and 36.6 or 97.9 temp.

Blood Draw: Ginny, nurse who did the blood draw, had you tilt back in the chair and put up your feet. She applied the gel in the tube and numbing spray. You also applied Lidocaine (numbing cream) to the port before you went.

Information: Started not feeling well on Saturday, December 5 compared to the week before. Had a runny nose, dry cough, no fever, and diarrhea. Had diarrhea Tuesday night and today two to three times. Currently taking Mucinex DM to thin and loosen mucus and control cough, Tylenol, and Halls Plus cough drops. Purchased Robitussin DM and Vicks and is not currently taking these two.

Cold: Infection has been in the body for the last couple of weeks and the symptoms have now shown up. The body is fighting the infection and since the white blood count has fewer numbers at this time your numbers will be lower. Dr. Jiang states that things should be okay next week. Continue to wash hands and if you get a temperature of 100.5 come to the hospital; don't want a secondary infection. Breathe into the incentive spirometer-breathing device).

Next appt December 16, 2009: Blood draw 1:30 and Dr. Jiang appt. at 2:15

Medications:

- SMZ (antibiotic)-Start this pill again as of 12/9/09

Wednesday, December 16, 2009

Things to share and Questions with Dr. Jiang from Stephanie

1. We are leaving on Saturday for Maui. What other precautions can you suggest besides taking the three antibiotics, washing hands, not eating or drinking anything from the airline, wiping all surfaces with disinfecting wipes, preferential seating on the plane, and not eating raw fish?
 - Mask, Airborne, gloves, vitamin C
2. Can we have a doctor's note for the airline?
3. After the blood count results let's discuss medication.
 - Do we continue with CIPRO? How does CIPRO interact with the Alendronate Sodium tables (bone pill) and when should it be taken?
 - Do we begin the maintenance pill and A

Summary of Meeting with Dr. Jiang

Date:	12/16
WBC 5,000-11,000	2.9
ANC 1,500-7,000	1.6
Platelets 140,000- 450,000	44
RBC 3.7-5.4	2.25
Hemoglobin (HGB) 12-16	8.8
Hematocrit (HCT) 37-47	25.3

Vitals: 119/62 Blood Pressure, 78 Pulse, and 98.4 temp.

Information: Had diarrhea 4-5 times over the last 24 hours. Took 2 Lonox. **Precautions:** Good to go to Maui. Wash hands and take usual precautions. No need to wear a mask or gloves. Bring CIPRO to Maui and only take if there is a fever. No need for blood transfusion. No need for a doctor's note.

Items to bring on trip: Bring 12/16/09 blood results, Dr. Jiang's summary report dated 11/18/09, and the blood count results for sessions 1-4

Next appt January 6, 2010: Blood draw 2:30 and Dr. Jiang appt. at 3:15

Will discuss when to take the maintenance pill, shot, and ATRA-based upon blood count results.

Medications:

- Acyclovir (protects against virus)-continue two more months
- CIPRO (antibiotic-fights bacterial infections)-begin again as of 12/2/09 –12/16/09 bring to Maui and only take if there is a fever
- Alendronate Sodium Tablets USP (treats postmenopausal women for osteoporosis) – okay to take
- Calcium
- Metoprolol (lowers blood pressure)
- Multi-Vitamin
- Simvastatin (cholesterol)
- SMZ (antibiotic)-Start this pill again as of 12/9/09
- Lonox (takes only when having diarrhea)

Wednesday, January 6, 2010

Things to share and Questions with Dr. Jiang from Stephanie

1. What does my blood look like now? Last time was December 16, 2009.
2. What do the maintenance sessions look like? What day each week? Will I see you on that day?
3. What, if any, are the side effects?
4. How does a shot affect the cancer? I want to review that approach in order to understand its advantage.
5. When do we start the ATRA? Is it fifteen days as before and the same nine pills each of those days?
6. Do any of my pills change?
7. CBS talks about treatment for leukemia to stop the disease from returning following chemotherapy treatment. It is going to be tested in the United Kingdom. Are we doing this here?

8. Does anything I've taken provide influence or prevention to any other possible cancer?
9. Did they get your holiday present from us to you there December 23, 2009?

Summary of Meeting with Dr. Jiang

Date:	1/6
WBC 5,000-11,000	3.0
ANC 1,500-7,000	1.5
Platelets 140,000- 450,000	70
RBC 3.7-5.4	2.32
Hemoglobin (HGB) 12-16	9.6
Hematocrit (HCT) 37-47	27.7

Vitals: 113/64 Blood Pressure, 72 Pulse, and 98.6 temp.

Information: Had diarrhea and a cough occasionally. Feeling fine.

Blood Results: Harder for the bone marrow to recover after all the chemo. There are not as much reserves as before the chemotherapy. Dr. Jiang states Steph's numbers are good. This is the trend after having chemo.

Maintenance: First have a bone marrow biopsy on Friday, January 8 and meet with Dr. Jiang Wednesday, January 13 and the decision will be made. Maintenance will include two tablets by mouth everyday of 6 MP (50mg) (This pill is treatment for patients with breast cancer) and every Wednesday come to the MAC unit to have blood draw and shot given. The shot can be injected in the arm or the butt. The injection site can be sore and other side effects might be constipation and cramps in the stomach. Hair will NOT fall out. The shot stays in the system longer, is slower in your metabolism, and last longer so blood count will be more like it is currently. ATRA is for 15 days (5 am pills and 4 pm pills) every three months. This will begin after next week's results from the bone marrow biopsy and blood results. The dose for the pill and shot will be adjusted so to stabilize the current blood count results.

Blood pressure/temperature: take your temperature once a day, check blood pressure once a day, and if it is consistent then take blood pressure once a week. The vitals will be taken every Wednesday.

Next appt January 13, 2010: Blood draw (fast to get cholesterol count) and Dr. Jiang appt. at 4:15

Will discuss when to take the maintenance pill, shot, and ATRA-based upon blood count results and bone marrow biopsy results. **Bring in all medicines for the January 13 appointment. Fast for blood draw, so go in earlier, because need cholesterol results.**

Wednesday, January 13, 2010

Questions and Information to Share with Dr. Jiang

Bowel Movements – Over the past three days, after the stuff from the Friday event had passed, I started to have normal movements, Sunday, Monday, and Tuesday. The more I read the information on **Methotrexate Sodium** and **Mercaptopurine** that are our next places I wound up getting diarrhea, which is my reaction when I am upset. As a result, I want to clearly understand the following about these two:

Methotrexate Sodium

- a. What is listed in Chemocare.com states this one is used for breast, head and neck, lung, stomach, and esophagus cancers? You have subscribed this to deal with my APL. Does this drug generalize and be applied to other possible cancers at various places on the body? Is that good? Is anyone, anywhere, using drugs that our specific to one place?
- b. The write-up about this talks about some significant issues with it: kidney toxicity, skin rash, diarrhea, hair loss, eye irritation, darkening skin etc. What do you believe will affect me?
- c. What does Methotrexate intrathecally mean? It doesn't seem to apply to me but I would like to understand it.
- d. It appears the affects on how much is used have a great deal to do with what happens? What exactly does my weight have to do with how much is given to me? What/where is that chart on this? Does less weight decrease the amount of impact on your body? Would it be good if I tried to lose 25 pounds in the next few months?
- e. Chemocare.com states on Side Effects ... "There are many options to help minimize or prevent side effects." What are the options?
- f. Having to deal with this for two years seems awful. You said something about five years. I am 62. My brain aneurism started when I was 59. This is now a total of three years as of February 10, 2010 with two minimum more years coming. How do people do this, have it work? You made a remark to me about how this was only six months and then I would have a life and a future. I don't understand that with what appears will be happening to me.
- g. I am to go once a week for a shot and to check my blood. Do we check the blood first and depending on what it is controls how much is put into me? What is an example of that? Are there any side effects that would control the amount I would be given...or not given at all one week because of my condition?

- h. I want to get my annual physical and breast exam. I also have a dental cleaning in February. Will these make sense and work if I am doing the treatment for cancer.
- i. Does this drug conflict with anything else I take?

Mercaptopurine

1. They say to take it one hour before eating or two hours after meals. Why?
2. Why two 50mg a day?
3. Side effects listed are Nausea, vomiting, poor appetite, diarrhea, mouth sore they say they happen with higher doses. What is considered a higher or high dose? What is an example of a cancer that has higher doses? How high?
4. Amount based on general health, height, weight, and type of cancer. Could it be 75mg instead of 100mg for this daily for me?
5. It says Side Effects are almost always reversible and will go away from treatment. Will I have any Side Effects that will last for two years?
6. They say there are many options to help minimize or prevent Side Effects. What are they for this drug?
7. Does this drug conflict with anything else I take?
8. This talks about electric razors and soft toothbrush to minimize bleeding, not drinking alcohol, small frequent meals, avoid sun. Is this sort of thing in higher doses?
9. If I don't have any cancer – why is a drug that is aimed towards tumors and cancer cells useful?
10. Is there a study available on APL that talks about people who went through the Sessions, Maintenance, and now are free of all of this as well as people who refused to do the Maintenance? I'd like to see any study(s) you recommend.

Summary of Meeting with Dr. Jiang

Date:	1/13
WBC 5,000-11,000	3.2
ANC 1,500-7,000	1.8
Platelets 140,000- 450,000	68
RBC 3.7-5.4	2.49
Hemoglobin (HGB) 12-16	10.1
Hematocrit (HCT) 37-47	29.6

Vitals: 104/60 Blood Pressure, 74 Pulse, and 98.2 temp.

Information: Energy level fine the past three days. Sleeping well without medication, appetite is good, no nausea, no bloody gums, etc., no swelling feet, no changes in medications, urination is fine. Diarrhea on Friday and took two Lonox before bone marrow biopsy. Steph mentioned that the Lonox blocked her bowels but by Sunday, all hell broke loose. By Sunday, the pain from the biopsy was 9 out of 10 and took Tylenol for pain. Dr. Al, the pathologist, will not do biopsies on Steph... Can make appointments for physical and breast exam along with February dentist appointment for cleaning.

Methotrexate Sodium (shot): Chemocare.com states this one is used for breast, head and neck, lung, stomach, and esophagus cancers. Since Steph's dose is 28 mg x 104 doses over a two-year period and this is a low dose and would not apply to the cancers listed above. Doses of 6,000 mg are considered high. This medication is used for people with rheumatoid arthritis. The arm has a small muscle and the injection could miss it so give it the butt-bigger muscle.

Side Effects: Some significant issues using Methotrexate Sodium are kidney toxicity, skin rash, diarrhea, hair loss, eye irritation, darkening skin, etc. Kidney toxicity is due to crystallization in the kidneys. Dr. Jiang stated this does not apply to Steph because her dosage is low 28 mg. compared to 6,000 mg. Chemocare.com states side effects... "There are many options to help minimize or prevent side effects." Dr. Jiang stated that people continue to work fulltime while on this medication. The blood count will drop and as we grow older, our bone marrow is not as resilient and might have to lower the dose due to blood results. This medication does not conflict with any of the other medications Steph takes.

Methotrexate intrathecally means to put into the brain because the person has brain leukemia. A lumbar puncture procedure is done to drain the fluid out and put in the chemo. This is a temporary solution for those with brain leukemia.

Weight: Try not to gain weight and do not plan to lose a large amount of weight.

Mercaptopurine (6MP pill): You take it one hour before eating or two hours after meals because it absorbs better when there is not food in your stomach. Take the two 50mg before going to bed. Steph's dosage is 94mg, but will round up to 100mg. The blood count will change before you feel any side effects. Could eventually lower the dose due to blood count results.

This drug is aimed towards tumors and cancer cells and the reason this is used even though Steph does not have cancer is for those seeds that are not detected that could grow. In addition, based upon experience a two-year maintenance plan worked. Good idea to practice hand washing and using soft toothbrush to minimize bleeding, but not applicable are electric razors, not drinking alcohol, small frequent meals, etc.

Side Effects: Nausea, vomiting, poor appetite, diarrhea, mouth sores are listed as side effects. A high dose is 600mg and Dr. Jiang stated that the low dose Steph is on should not cause side effects. This drug does not conflict with any other medications being taken by Steph.

Studies: Dr. Jiang did not cite any studies. He did share how a farmer who lives in China would sell cows to raise money for cancer treatment. Once in the city pickpockets would steal the money. Most do not pursue treatment.

Next appt January 20, 2010

Medications: No changes

Consolidation Session 4

Chemo- Idarubicin (Idamycin brand name) (22 mg x 1 day)

Blood Count Results

Date:	10/28 Day 1	11/4	11/11	11/18	11/25	12/2	12/9	12/16	1/6/10	1/8	1/13
WBC 5,000-11,000	4.4	2.4	0.7	2.9	1.7	1.1	1.6	2.9	3.0	3.2	3.0
ANC 1,500-7,000	3.4	1.5	.1	1.8	0.7	0.3	0.1	1.6	1.5	Did Not Receive	1.8
Platelets 140,000-450,000	153	109	33	39	33	33	36	44	70	63	68
RBC 3.7-5.4	2.98	2.76	2.60	2.57	2.3	2.22	2.29	2.25	2.32	2.25	2.49
Hemoglobin (HGB) 12-16	9.8	9.2	8.7	8.9	8.1	8.1	8.5	8.8	9.6	9.2	10.1
Hematocrit (HCT) 37-47	28.6	26.5	25.5	25.8	23.7	23.6	24.8	25.3	27.7	26.7	29.6

Wednesday, January 20, 2010

Things to share and Questions with Dr. Jiang from Stephanie

GOAL: To be able to function each day –including plans to leave the house and do things away from it.

PROBLEM: DIARRHEA IS UNDPRETICITABLE AND PERSISTANT.

LONOX –

It doesn't work perfectly and we haven't been able to get it again.

DIPHENOXYLATE/ATROPINE

This is a brand version replacing of LONOX. When I tried, it didn't work. Says it may cause blurred vision.

Days with Diarrhea- Total 8 days – 5 days of diarrhea – 3 without diarrhea

Wednesday No diarrhea -Shot at hospital

Thursday No diarrhea

Friday Diarrhea

Saturday Diarrhea

Sunday Diarrhea

Monday No Diarrhea

Tuesday Diarrhea

Wednesday Diarrhea

Having massive diarrhea that is not predictable does not make me be able to go outside of my home. I would like to know what kind of damage to my body would be done by this over time.

SOLUTIONS

1. Use some sort of pill daily that will prevent diarrhea
2. Use less of Methotrexite
3. Use Methotrexite as a pill instead of a shot
4. Use less Mercaptopurine – example, 25mg instead of 50mg
5. Other ?

Summary of Meeting with Dr. Jiang

Date:	1/20 Day 1
WBC 5,000-11,000	3.5
ANC 1,500-7,000	1.8
Platelets 140,000- 450,000	80
RBC 3.7-5.4	2.62
Hemoglobin (HGB) 12-16	10.5
Hematocrit (HCT) 37-47	31.0

Information: Flow cytometry from the U of W Medical Center shows NO abnormal myeloid blast. Dr. Jiang says there is no leukemia. Still waiting for the results from the RT-PCR from the U of W Medical Center. Dr. Jiang shared the Pathology report showed four out of twenty cells

were examined had a translocation between chromosome 6 and 12.46,XX t(6;12)(q13;p11.2) [4]/46,XX[16] The treatment is still the same and every three months will have a bone marrow biopsy. Dr. Jiang did a literature search and could not find any information on these chromosomes.

Bone Marrow Biopsy: Every three months there will be a bone marrow biopsy; the next one is April and then July. Then one every six months depends on the results. Steph mentioned her back has hurt this last week and Dr. Jiang asked her if it is at the site bone marrow biopsy site.

Methotrexate Sodium (shot 30 mgs. Given in the right buttocks with numbing spray applied first and Steph put her right foot on a stool to straighten her leg before the injection. The size of the needle's diameter is based upon the thickness of the medicine.

Side Effects: Low blood count, anemia, and possible diarrhea. No hair loss due to low dosage.

Weight: Dr. Jiang said it is okay to lose 15 to 20 lbs. but do it slowly and with exercise. Each Wednesday Steph's weight will be taken and that will determine the dosage-about every ten pound, loss could change the dosage.

Maintenance: Dr. Jiang shared studies about the maintenance schedule. He has changed his mind and Steph might do a year of the maintenance therapy compared to the two-year schedule. He cited because she is in the APL low risk group she does not need the longer therapy schedule. Dr. Jiang will see Steph next week and then once a month.

Next appt January 27, 2010: Blood draw 3:15 and Dr. Jiang appt. at 4:00.

Medications: No changes

Wednesday – January 20, 2010

Met with Dr. Jiang (he discussed that Side Effects could be low blood count, anemia and possible diarrhea.

ATRA (took 5 in the morning – 4 in the evening)

METHOTREXATE SODIUM (Given Right Buttocks hospital afternoon)

MERCAPTOPYRINE – took 2 at night time

No diarrhea

Thursday, January 21, 2010

ATRA (took 5 in the morning – 4 in the evening)

MERCAPTOPYRINE – took 2 at night time

No diarrhea

Friday, January 22, 2010

ATRA (took 5 in the morning – 4 in the evening)

MERCAPTOPYRINE – took 2 at night time

Took no Lonox - wanted to clear my system

5 Major Incidents of Diarrhea

1 full cup -started at 1:00

1 full cup -next 1:20

½ cup - next 1:40

¼ cup -next 2:10

Barely, then quit 2:30

Went to bed about 10:30PM

Saturday, January 23, 2010

ATRA (took 5 in the morning – 4 in the evening) planned at home and 4 at hotel
MERCAPTOPURINE – took 2 at night time - plan to take them at night at hotel
Got up 6:30AM – drank some coffee

Bowel Movements

- 1 – Regular bowel movement before breakfast – around 7:14am
- 2 – Bowel lose but still okay ...7:40am
- 3 – Bowel – watery in light color – small stools -7:55
- 4 - Bowel - watery in light color – no stools -8:05
- 5 - Bowel – just water in light color –no stools - 8:20

Felt like it had emptied out...

Took AM Pills and ATRA

Showered

Took 2 Lonox – around 8:45am

Drove to SeaTac – registered and got something to eat - for lunch –

Took 1 Lonox – around noon

Landed in Las Vegas at 5:15 were able to get to the hotel and checked in by 6:30pm

Ate one piece of cheese/mushroom – went to Bette Midler show – 7:30pm – 9:45pm

Urine feels like I have to ...but doesn't give much - drank some orange juice

Went to bed – took night pills -slept until 6:30am

Steph's Current Medication as of January 23, 201

Daily Medication	Purpose	Amount and Time
Calcium Citrate-	Protects bones	2 tablets daily
Metoprolol Not taken if blood pressure is lower than 100	Lowers blood pressure	½ tablet twice a day 500 mg
Multi Vitamin	Vitamin	1 tablet daily AM
Simvastatin	Cholesterol	PM only
Alendronate Sodium	Bone Growth	Every Monday morning
ATRA	Oral chemo	50 mg AM-5 brown pills 40 mg PM-4 brown pills
Mercaptopurine	Stops leukemia growth	50 mg at night
Methotrexite	Shot in butt – stops leukemia growth	28 mg. weekly

Medications to be determined

As Needed Medication	Purpose	Amount and Time
Lonox	Diarrhea	1 tablet up to 8 in 24 hours
Tylenol	Fever and pain	At night

Sunday, January 24, 2010

Got up 6:30AM – drank some coffee

Bowel Movements

- 1 – Regular bowel movement –light color – around 6:45am

2 – Bowel movement – total liquid – dark color -7:15am

3 – Bowel – watery in light color – 7:45

Took 2 Lonox at hotel

4- Bowel – total water

Ate breakfast ordered. Got to plane at LV - took Lenox – took another plane to LA. LA had to wait for two hours for plane to Seattle – got fish lunch -

5 - Bowel – went to bathroom – had to have running bowels – twice at LA –waiting

Took 1 more Lonox

6 - Bowel – on LA to Seattle plane had to go to bathroom – three times – thought I might lose it on my pants and not making it to the bathroom –

Took 2 more Lonox

Took 5 total LONOX total

Monday, January 25, 2010

ATRA (took 5 in the morning – 4 in the evening)

MERCAPTOPYRINE – took two at nighttime -

Had no diarrhea all day, took two bowels first thing in the morning. Took no LONOX.

Tuesday, January 26, 2010

ATRA (took 5 in the morning – 4 in the evening)

MERCAPTOPYRINE – took 2 at nighttime -

ALENDRONATE SODIUM –Once a week on Tuesday

Bowel – Had a regular bowel – light color but appropriate shapes – two movements about twenty minutes in the morning after up for awhile....

Diarrhea started at about 1:00pm...three mostly water about every 15 to 20 minutes...

Wednesday, January 27, 2010

Summary of Meeting with Dr. Jiang

Date:	1/27
WBC 5,000-11,000	3.8
ANC 1,500-7,000	2.0
Platelets 140,000- 450,000	82
RBC 3.7-5.4	2.65
Hemoglobin (HGB) 12-16	10.8
Hematocrit (HCT) 37-47	31.6

Information: Steph shared **Goal:** to be able to function each day including plans to leave the house and do things away from it. **Problem:** Diarrhea is unpredictable and persistent. Dr. Jiang suspects the medication is the cause since there are new medications in Steph's body. Her bowels have high mobility. He asked about what she eats, discussed her dry lips and hands (lotion has been used), she is not in pain, not tired, but has diarrhea 5 days out of 8. Lonox (GG-6 is written on the pill) doesn't work perfectly and we haven't been able to get it again. Diphenoxylate/Atropine (M-15 is written on the pill) doesn't work when Steph tried this.

Changes to try to stop diarrhea: Stop ATRA for the next week and begin this again in three months. Stop taking Alendronate Sodium as of February 2. Take Metamucil, powder form, in the morning to see if this can help absorb the liquid in the bowel. Also, take two Diphenoxylate/atropine in the morning. Then, take one tablet of Diphenoxylate/atropine each time there is diarrhea-up to 8 to 10 pills a day. Discussed taking two Imodium and one pill each time there was diarrhea, but decided to go with Diphenoxylate/atropine. Will try this for one week and revisit with Dr. Jiang about the results.

Bone Marrow Biopsy: RT-PCR results showing complete remission with negative PCR for 15/17 translocation, indicating molecular remission.

Methotrexate Sodium (shot 28 mgs. Given in the left buttocks with numbing spray applied first and use of a stool to place left leg on.

Maintenance: Dr. Jiang restated that one year of maintenance. Then done with ATRA, Mercaptopurine (6MP), and Methotrexate Sodium. In addition, the two other patients who had APL, one man and one woman, did not have diarrhea, but had cramps and pain.

Next appt February 3, 2010: Blood draw 2:45 and Dr. Jiang appt. at 3:30.

Medications: Calcium Citrate (protects bones) 2 tablets daily

- Metoprolol (lowers blood pressure) ½ tablet twice a day 500 mg
- Multi-Vitamin 1 tablet daily AM
- Simvastatin (cholesterol) PM only
- Mercaptopurine (6 MP) Take 50 mg before bed
- Methotrexate (shot) once a week 28 mg.
- Diphenoxylate/atropine (to stop diarrhea) Take 2 pills in the morning and one pill after each diarrhea episode
- Metamucil Take the powder form in the morning
- Lonox (to stop diarrhea) have only three pills left as of today
- **Stop:** ATRA 1/27/10 a week earlier to see if this is a cause of the diarrhea
- Begin Mercaptopurine (6MP pill 2 X 50 mg before bedtime)
- **Stop:** Alendronate Sodium Tablets USP 2/2/10 (treats postmenopausal women for osteoporosis) to see if this a cause of the diarrhea
- **Stop** SMZ (antibiotic)- as 1/6/10
- **Stop** Acyclovir (protects against virus)- as 1/6/10
- **Stop** CIPRO (antibiotic-fights bacterial infections)-begin again as of 12/2/09 -12/16/09

Wednesday, February 3, 2010

Things to share and Questions with Dr. Jiang from Stephanie

Summary of Diarrhea

1/27/10 -Did not take ATRA 4 pills at night (took Lonox) (took 2 Mercaptopurine at bed time)
1/28/10 - Did not take ATRA 5 pills am and pills 4 pm – (took Lonox) (took 2 Mercaptopurine at bedtime)
1/29/10 - Did not take ATRA 5 pills am and pills 4 pm – (took Lonox) (took 2 Mercaptopurine at bedtime)
1/30/10 - Did not take ATRA 5 pills am and pills 4 pm (took Lonox) (took 2 Mercaptopurine at bed time)
1/31/10 – Did not take ATRA 5 pills am and pills 4 pm – did not take Lonox – did not have diarrhea - (took 2 Mercaptopurine at bed time)
2/1/10 – Did not take ATRA 5 pills am and pills 4 pm – did not take Lonox – did not have diarrhea - (took 2 Mercaptopurine at bed time)
2/2/10 – Did not take ATRA 5 pills am and pills 4pm – did not take Lonox – had no diarrhea in the morning – afternoon had some diarrhea – four toilet trips – got less and less – took some Metamucil --(took 2 Mercaptopurine at bed time)
2/3/10 – Did not take ATRA 5 pills am – did not take Lonox – took Metamucil with breakfast – had three bowels with stools shaped

Summary –

I don't feel good on a daily basis the way I used to before this APL. I am still working on having a normal daily bowel movement and eliminating diarrhea. It appears that working on this continues until it is resolved.

I have appointments with two doctors next week, Dr. Roof for an annual exam and Dr. Johnson for evaluation of skin for cancer.

Summary of Meeting with Dr. Jiang

Date:	2/3
WBC 5,000-11,000	3.8
ANC 1,500-7,000	2.0
Platelets 140,000- 450,000	62
RBC 3.7-5.4	2.65
Hemoglobin (HGB) 12-16	10.9
Hematocrit (HCT) 37-47	32.3

Vitals: 114/68 BP 70 Pulse 36.8 Temp.

Information: Did not take ATRA from 1/27/10 to 2/2/10. Took Lonox 1/27 to 1/30/10. Took two Mercaptopurine at bedtime during this period. Did not have diarrhea 1/31, 2/1, and 2/3. Had no diarrhea in the morning of 2/2 but had gone to the toilet four times in the afternoon and took some Metamucil. Also, took Metamucil with breakfast and had three stools with shape

on 2/3. Steph shared that she used to use Metamucil and her bowels are better so much better. Steph shared a patch of red slightly above the left eye and Dr. Jiang checked it and said it is fine. **Review of medicines and diarrhea:** Will not take ATRA for two months. Dr. Jiang mentioned that ATRA taken alone does not work; however chemo take alone can work, but when ATRA and chemo are taken together it works. Can go back on bone growth medicine (Alendronate Sodium) after visiting with Dr. Jiang next week. Dr. Jiang mentioned that when Steph goes to Dr. Roof, ask for documentation about osteoporosis. If there needs to be a change in medication for the current bone growth pill the insurance company will pay for a change if there is a diagnosis of osteoporosis. Reclast is a once a year intravenous (IV) medication that is given at the MAC lab at Whidbey General.

Blood Results: Dr. Jiang said the blood results are great. It is the chemotherapy from the 6MP and the shot that suppress the blood. The platelets are 62 today and he mentioned that is fine. It is when they get below 50 he will cut down on the 6MP pill to 1 ½ each night. When the platelets get below 10 then there is a need for a transfusion.

Shot: The shot was given in the right buttocks and not so close to the crack. See if this helps with the pain.

Next appt February 10, 2010: Blood draw 3:00 and Dr. Jiang appt. at 3:45.

Medications: No changes

Wednesday, February 10, 2010

Things to share and Questions with Dr. Jiang from Stephanie

Went to Dr. Lee Roof for annual physical February 8, 2010 and reported the following:

Colon Exam – Should be done 2011

Mammogram – Needs to be done this month

Pneumonia Vaccine – Dr. Roof will check with Dr. Jiang

Bone Density Needs to be Checked – Then decide on Meds

Special Tests –

3 Month Sugar Test - Normal

CHOL - 128 - Good

HDL - 56 - OK

LDL - 63 - Great

All three “very good”

Continue Simvastatin as now for Cholesterol

For now – No Alendronate

Take Bone Density Test

OK – No new medicine

Not OK - Ask about once-a-year medicine

Diarrhea Issue

It seems to be settled down as it almost feels like normal days now. That’s good. I still take one pill of the Lonox if I am going somewhere because I’m not sure I can trust myself not to have diarrhea when I am away from my house. I think the week coming up from the 10th to the 17th will be calm so I cannot use Lonox and get an accurate sense of each day and the entire week.

Summary of Meeting with Dr. Jiang

Date:	2/10
WBC 5,000-11,000	4.6
ANC 1,500-7,000	2.2
Platelets 140,000- 450,000	65
RBC 3.7-5.4	2.75
Hemoglobin (HGB) 12-16	11.3
Hematocrit (HCT) 37-47	33.1

Information: Dr. Jiang stated go get the pneumonia shot and okay to go to the dentist. He checked Steph's pulse and ankles. In addition, he asked about how much walking Steph is doing. Cleaning around the house, using the treadmill, and walking around is what Steph mentioned. Dr. Jiang stated that he would see Steph on February 24 and February 17 would be a blood draw and shot.

Review of medicines and diarrhea: Go back on bone growth medicine (Alendronate Sodium) and see what it does. Dr. Jiang mentioned ask for documentation about osteoporosis. If you can't tolerate Alendronate Sodium, the insurance company will pay for a change if there is a diagnosis of osteoporosis. Reclast is a once a year intravenous (IV) medication that is given at the MAC lab at Whidbey General. The cost for one shot is \$1,000.

Shot: The shot was given in the left buttocks. Jackie gave the shot again, but Ann Bell will give the shot next week. Ann was there today to watch the administrating of the shot.

Next appt February 17, 2010: Blood draw 3:00 and shot given at 3:45

Wednesday, February 17, 2010

Things to share and Questions with Dr. Jiang from Stephanie

Diarrhea Summary –

I have felt lousy every day. I can't really go anywhere because I might have diarrhea. If I take the pill, I feel bloated and like my bowel is stuffed and strained. It aches and I feel bad overall. If I don't take a pill, I have total water with brown color rush through my bowel five or six sessions. I cannot control it and I can't get to the bathroom fast enough to keep it off my clothes.

This is not working for me. Maybe it has gotten worse because I now have more of the medicine into my body. The solution of putting anti diarrhea pill into my body feels horrible and not stopping the diarrhea is horrible, too.

As of February 10, 2010

It seems to be settled down as it almost feels like normal days now. That's good. I still take one pill of the Lonox if I am going somewhere because I'm not sure I can trust myself not to have diarrhea when I

am away from my house. I think the week coming up from the 10th to the 17th will be calm so I cannot use Lonox and get an accurate sense of each day and the entire week. I have had diarrhea every day starting February 10 at night. It became running and total water by 9:00pm. It finally quit after five or six runs into the toilet.

February 11, 2010

I had diarrhea starting in the morning. After six or seven around 10:00 AM and then it stopped. It then started again around 4:00pm and went for four trips of first stools and then by the fourth and fifth, water.

February 12, 2010

I had diarrhea in the morning, several as in four or five trips with water by the end. I took a pill because we had to take a trip. Left from the house around noon and got back around 3:00pm. Had more diarrhea later that afternoon. This diarrhea had some light colored stools that were small.

February 13, 2010

I had diarrhea in the morning. I had four to five to the toilet. Was not water only but small light colored stools, very small, wet. I took a pill.

February 14, 2010

I had a more regular diarrhea in the morning. I had two of the closest to normal since February 10, 2010. Then it hit around 1:00 and I smeared my pants because I couldn't get to the bathroom fast enough. I then had six more with dark water. I took another pill.

February 15, 2010

I had diarrhea up to five trips to the bathroom. I was going to the dentist so I took one pill at around 9:00am. I didn't have to go to the bathroom but I had an appointment so I took another one at 11:30am. I went to the 1:00 dentist work and then back at home. I don't feel well and have gas but I went until evening and went to bed at 9:00pm.

February 16, 2010

When I woke up in the morning, I went to the bathroom about 7:00am. Lots of stools, light color, soft. I took another pill and Metamucil. Now my anus and bowel hurts but I have not had diarrhea. It is 12:15 pm. The balance of the day I did not have diarrhea. I feel like my bowel, lower area is full of gas. I had amazing farts..often and loud with lots of air coming out. Went to bed and felt stuffed in my lower area. Finally, went to sleep.

February 17, 2010

I drank coffee when I first got up at 6:30am. I had to go to the bathroom in about an hour. It filled the toilet with dark brown stools. I took the diarrhea pill and Metamucil. I have not had diarrhea but feel like it's right on the edge when I am walking around. I feel better yesterday and today then how I felt, pretty bad, from afternoon on February 10 until February 15. Platelets were found below 50. Did not get a Methotrexate shot on the 17th. I did not get diarrhea after I went home from the hospital

as I did last week. I did not have stuffed and gas and there wasn't any pain. I used Municipal for one tsp in the morning of that day when I took one Lomax. When I went to bed, I swallowed 75mg, cutting one of them in two parts and eating only one half.

Summary of Meeting with Dr. Jiang

Date:	2/17
WBC 5,000-11,000	3.4
ANC 1,500-7,000	1.6
Platelets 140,000-450,000	45
RBC 3.7-5.4	2.64
Hemoglobin (HGB) 12-16	10.9
Hematocrit (HCT) 37-47	31.5

Shots: four complete

Medications: Change Mercaptopurine (6 MP) Take 1 ½ pills before bedtime

Shot: The shot was not given today due to the blood count results.

Next appt February 24, 2010 Blood draw 3:00 and doctor's appt. is at 3:45

Wednesday, February 24, 2010

Things to share and Questions with Dr. Jiang from Stephanie

February 18, 2010

When I woke up this morning, it was normal. I had a bowel movement that was normal at 7:00am. The most normal in the last 8 days. I haven't had any other bowel movements and it is now 1:00pm. I did not use Municipal today. I have had no gas and I'm not in any pain. I am even going to take the cats out for a walk because I feel better, not very much energy but I don't feel bad.

February 19 – February 24

On these days I was normal...four days. I am not having to use diarrhea pills or Metamucil. I have two bowel movements a half hour to hour a part, first is perfect – second is just a little lighter but correct shape and most of all I feel ok – and normal. Feel normal. Do not have diarrhea.

On Sunday, we went to Coupeville with family, ate lunch, and walked around. I was truly feeling great. Had another bowel movement in the afternoon but normal.

Looking Forward

1. Reduce the shot.
2. Do the shot every other week so I can feel normal every other week.
3. Take the shot in pills instead of a shot.

Summary of Meeting with Dr. Jiang

Date:	2/24
WBC 5,000-11,000	2.7
ANC 1,500-7,000	
Platelets 140,000- 450,000	39
RBC 3.7-5.4	2.71
Hemoglobin (HGB) 12-16	10.9
Hematocrit (HCT) 37-47	32.4

Information: Lost two pounds. Steph mentioned she felt better and was moving around. Took Alendronate Sodium Tablets (bone growth pill) and did not have diarrhea.

Steph shared Summary of February 10-24, 2010: Overview: I have felt lousy every day. I can't really go anywhere because I might have diarrhea. If I take the pill, I feel bloated and like my bowel is stuffed and strained. It aches and I feel bad overall. If I don't take a pill, I have total water with brown color rush through my bowel five or six sessions. I cannot control it and I can't get to the bathroom fast enough to keep it off my clothes. Not having the shot on the 17th made all the difference. I have been normal from the 18th taking .75 of the pill at night.

Blood Results: The white blood count is down due to the combination of the shot and pill. WBC is the part of the blood that reacts to the chemo first. The red blood count takes longer to react. Due to the blood count results no shot (Methotrexite) and no Mercaptopurine (6 MP) pills for this week. Probably the blood results will go down next week and will take time to go back up.

Maintenance: Steph mentioned that 25% of people who had APL have it reoccur and 75% of those who had APL never had it again. Dr. Jiang mentioned that there is no information to show why certain people have relapses of APL and those who do not. He mentioned that Steph is in the good group but not 100% sure and the maintenance routine is an insurance policy. What about using Methotrexite in pill form? Dr. Jiang said there is not enough information. He also mentioned that intravenous infusions of arsenic trioxide is used for those in the consolidation therapy and those with those with relapses of APL, but not much information with regard to the maintenance therapy. Quote from Dr. Jiang: "Balance of Life"

U of W Medical Center: Dr. Jiang recommended going to a U of W hematologist and ask the following questions:

1. With a low blood count, what do we do with this during maintenance?
2. Is arsenic trioxide any good for maintenance purposes? What are the facts and benefits?
3. What about the four of twenty cells examined had translocation between the long arm of chromosome 6 and the short arm of chromosome 12. The presences of this abnormality in several cells indicate clonal growth?
4. Maintenance for two years, one year, or not at all?

Next appt March 10, 2010: Blood draw 9:15 and Dr. Jiang appt. is at 10:00

Medications: No changes

Wednesday, March 10, 2010

Summary of Meeting with Dr. Jiang

Date:	3/10
WBC 5,000-11,000	3.0
ANC 1,500-7,000	1.4
Platelets 140,000- 450,000	37
RBC 3.7-5.4	2.76
Hemoglobin (HGB) 12-16	11.1
Hematocrit (HCT) 37-47	32.1

Information: 109/61 BP 74 pulse 98.6 temp

Dr. Estey's Meeting: Steph mentioned what a good idea it was for Dr. Jiang to refer her to Dr. Estey for consultation. Discussed the 15% of people who have relapses and the recommended treatment is ATO (arsenic) and ATRA. Also, discussed the chromosomes 6; 12. Dr. Estey's presented two approaches (ATO and ATRA or no treatment) and he recommended for Steph no treatment. Dr. Jiang had a phone conversation with Dr. Estey. Steph is in a good group, low white count (over 10, 000 can be an issue), no bleeding, and did well during induction so the recommendation of no maintenance makes sense states Dr. Jiang.

Monitoring: Keep the ATRA, Dr. Jiang mentioned might take it later, but Steph brought up the point that Dr. Estey recommends no treatment so not to "muddy the waters". Bone marrow biopsy sometime in April in either Everett or Seattle. Once a month blood results here at Whidbey MAC lab and it will take longer for the blood counts to go up due to the accumulation of the chemo.

Next appt. March 31, 2010

Medications: No change

Wednesday, April 28, 2010

Things to share and Questions with Dr. Jiang from Stephanie

1. How are you?
2. Have generally been feeling well and am enjoying that and I am not having any problems.
3. What are the results on my blood taken today?

4. Platelets range is 140,000-450,000. Does that mean that the numbers that are like 65, 45, 39, are actually 65,000, 45,000, and 39,000? As I understood it when we were doing maintenance, you said we would have to adjust if mine went lower than 50 or 50,000. What can be negatively created if platelets are low? How can the body function safely if platelets are down by two thirds of the lowest platelets range standard, 140,000?
5. Pathology Report – I would like to get definitions under Final Diagnosis on items A-D in lay language. For example, C. states iron stores. What does that mean?
6. Do you have any thoughts regarding Arsenic/ATRA and or Arsenic trioxide?
7. PCR may not pick up the possibility of cancer cells in a timely way. Is it possible for me to have a monthly Wednesday meeting with you and my blood taken and reviewed? Since it would be only once a month could we get both the Hematology and Chemistry.
8. Mitoxantrone given in Session 3. Chemocare.com put out information, which included the following statement: “There is a slight risk of developing a blood cancer such as leukemia years after taking Mitoxantrone. Talk to your doctor about the risk.”
9. Idarubicin given in Induction Therapy, Session 2, and Session 4. Dr. Estey was talking about options and said, “So arsenic is a better drug between ATO than ATRA there is no doubt about it. You could combine them. Probably Mylotarg®, which is another chemotherapy drug, it is probably easier to use than Idarubicin and it is a better drug than Idarubicin. What are your thoughts on this?
9. Chemocare.com describes Arsenic Trioxide. What are your thoughts on this?

Summary of Meeting with Dr. Jiang

Date:	4/28
WBC 5,000-11,000	4.0
ANC 1,500-7,000	2.4
Platelets 140,000- 450,000	83
RBC 3.7-5.4	2.73
Hemoglobin (HGB) 12-16	10.7
Hematocrit (HCT) 37-47	32.7

Vitals: BP 110/69 70 Pulse 98.6 (37) temp.

Bone Marrow Biopsy: Results from the April 21, 2010 bone marrow negative for PML/RARA fusion transcripts, which are the molecular result of the t (15; 17) translocation, associated with the majority of APL cases, a distinct AML subset with M3 cytomorphology.

Next appt May 26, 2010: Blood draw 3:00 Dr. Jiang appt. 3:45

Medications: No changes

Induction Therapy-Session 1	49 days	June 1-July19, 2009
Consolidation Therapy-Session 2	42 days	July 20-August 30, 2009
Consolidation Therapy-Session 3	58 days	August 31-October 27, 2009
Consolidation Therapy-Session 4	84 days	October 28, 2009-January 19, 2010
Maintenance Therapy-Session 5	98 days	January 20-April 28, 2010
Total Days	331 days	10 months and 27 days

Blood Counts

White Blood Cells (WBCs)

WBCs help your body fight infection by protecting against foreign invaders such as bacteria and viruses. WBCs form a key part of your natural defenses, which are provided by your immune system. Neutrophils (NEW-truh-fils), a specific type of WBC, help protect against and fight infection. If your absolute neutrophil count (ANC) falls below normal, you have neutropenia. ANC is the typical measure of your body's ability to fight infection.

Red Blood Cells (RBCs)

RBCs carry oxygen throughout your body, giving you energy and keeping your organs and tissues healthy. Hemoglobin (HEE-moh-glow-bin), also known as HGB, is the protein that makes blood red. It contains iron and carries oxygen in your body. Hematocrit (hee-MAT-oh-crit), or Hct, is the percentage of red blood cells in the bloodstream. If your HGB or Hct level is too low, you may have anemia (ah-NEE-mee-ah), in which case you may feel tired and fatigued.

Platelets (Plts)

Platelets help your body stop bleeding by working with other blood factors to form a clot. A low platelet count, called thrombocytopenia (throm-boh-sy-toh-PEE-nee-ah), may lead to excessive bleeding or bruising.

Reference-www.neulasta.com *Inclusion of this website does not imply endorsement*

Maintenance Session 5

Methotrexate Sodium (injection 30 mg once a week)

Mercaptopurine (6MP 2x 50 mg once a day before bed)

Stopped maintenance-Monitoring

Date:	1/20 Day 1	1/27 Day 7	2/3	2/10	2/17	2/24	3/3	3/10	3/31	4/21	4/28
WBC 5,000-11,000	3.5	3.8	3.8	4.6	3.4	2.7	No	3.0	3.0	4.0	4.0
ANC 1,500-7,000	1.8	2.0	2.0	2.2	1.6	1.5	Blood	1.4	1.8	3.0	2.4
Platelets 140,000- 450,000	80	82	62	65	45	39	Draw	37	58	70	83
RBC 3.7-5.4	2.62	2.65	2.65	2.75	2.64	2.71	Taken	2.76	2.72	2.80	2.73
Hemoglobin (HGB) 12-16	10.5	10.8	10.9	11.3	10.9	10.9	This	11.1	10.9	11.6	10.7
Hematocrit (HCT) 3 7-47	31.0	31.6	32.3	33.1	31.5	32.4	Week	32.1	32.3	32.5	32.7

Monitoring Blood Counts

Date:	5/26	6/23	7/22	8/18	9/23	10/14	11/18	12/15	1/12	2/2	3/2	4/13	5/25
WBC 5,000-11,000	3.8	3.5	3.3	3.5	6.9	3.7	4.1	5.8	4.4	4.71	4.2	4.5	4.9
ANC 1,500-7,000	1.5	2.0	1.9	1.6	5.0	1.7		4.1	2.8	3.01	2.5	3.1	3.3
Platelets 140,000- 450,000	79	81	83	86	94	80	85	95	105	82	107	112	117
RBC 3.7-5.4	2.8	2.84	2.99	2.94	2.97	2.95	2.95	2.95	3.11	3.19	3.09	3.15	3.27
Hemoglobin (HGB) 12-16	11.6	11.4	11.9	11.6	12.1	11.7	11.7	11.7	11.8	12.1	11.9	12.0	12.6
Hematocrit (HCT) 3 7-47	33.4	33.2	34.8	33.9	33.3	33.4	32.4	33.9	34.6	35	34.1	34.8	35.7