

*Diagnosed with MGUS May 2003 followed by  
AL Amyloidosis diagnosis October 2006  
SCT at BUMC 1/5/2007  
Achieved partial response*

## **Jacqueline Mendels Birn My Amyloidosis**

**My illness started with the discovery in May 2003 of something wrong in my blood during my yearly check-up. My internist Dr. Robert Enelow, first requested a 24 hour urine specimen and then he sent me to the oncologist Dr. Seifert at Fairfax Hospital, VA. The results showed that I had Monoclonal Gammopathy of unknown significance (MGUS) and the oncologist said that there was a 5% chance that I would have one day multiple myeloma. I was terribly frightened, however I tried to be optimistic and my boss and colleagues and friends told me that 5% was a very low figure. I continued going for checkups every 6 months but nothing developed and after 2 years, I stopped going to the oncologist.**

**In September of 2006, back from my summer in Cape Cod where we have a vacation home in Chatham, I had swollen legs and ankles which I attributed to the stress of going back to work, a rather demanding and stressful job at the Foreign Service Institute of the State Department where I was training examiners in 89 different languages to assess the level of proficiency of Foreign Service Officers prior to their assignment overseas. My friend Sandra (they also have a house in Chatham) told me that during the summer I already had swollen legs.**

**I tried to have a normal schedule, I went to the National Gallery with our friends the weekend of September 15. I had to sit once in a while to relieve the pain and swelling in my legs. I went on September 18 to see my internist Dr. Robert Enelow. He did blood and urine tests. He requested a 24 hour urine analysis which I brought to Quest diagnostics on September 20.**

**On September 28, Dr. Enelow sent me to WRA in Bethesda, MD. They did a sonogram and an ultra-sound of my kidneys.**

**On October 3, Dr. Enelow sent me to the nephrologist Dr. Burka in Bethesda who immediately requested an echocardiogram, and blood and urine tests.**

**He told me that my heart was in good shape.**

**On October 5, I went back to Dr. Burka to bring him my files from Dr.**

Seifert with the MGUS results from 2003 in Fairfax hospital. On October 12, Dr. Burka ordered a renal biopsy at Sibley hospital in DC. Dr. Burka was suspecting either light chain disease or amyloidosis. He did not tell me anything. I spent the whole day at Sibley because they made a mistake about the appointment; instead of 6 am, I was due at 1 pm. I was on an empty stomach all day and very upset and tired. Dr. Burka came to the hospital in the morning and he complained about the mix-up.

On October 19, Dr. Burka confirmed the diagnostic. My husband joined me in the examination room upon request from Dr. Burka who said to both of us that I had a very serious illness: amyloidosis. My husband immediately asked if I would be cured. Dr. Burka was affirmative. He asked me to choose for treatment, either Mayo Clinic or Boston U Medical Center/amyloidosis treatment and research Unit. He called Boston Medical Center to ask for an appointment for evaluation. He recommended chemotherapy and stem cell autologous bone marrow transplant. Dr. Burka sent my file to Boston Medical Center.

On October 27, at 7 pm Dr. John Berk from Boston U. medical center called me to say that my file was incomplete. I called Dr. Burka after office hours. The slides of my renal biopsy were between Sibley hospital and Georgetown U. hospital. Finally the slides were sent by Fedex to Boston the following Thursday, November 1<sup>st</sup>. I was losing appetite and sleep, all the while continuing to work. A cousin of my husband, Dr. James Vogel, thought that I could be treated with medication and no bone marrow transplant. Not knowing that it would be an autologous bone marrow transplant, my son, my daughter, my niece, offered to give me bone marrow, if compatible.

On November 1<sup>st</sup>, I went to Dr. Enelow for my flu shot. He gave me a diuretic, Furosemide 20mg, one a day for 30 days. He called Boston to try and get me an early appointment. They put me on the priority list. I cried in the doctor's office. I was terribly upset and worried. I was scheduled for an evaluation in Boston on December 18. We went to our house in Chatham, MA for a short holiday, and to Boston to spend 3 days with our granddaughter Esperanza (Tsatsa) while her mother Anne-Emanuelle had a conference in Boston. However, I could not get an appointment at Boston Medical Center at that time because all the doctors were away at an international conference on familial amyloidosis. Back in Bethesda, on November 10, Dr Enelow gave me a potassium supplement and doubled the dose of diuretic. Nov.16, Rabbi Reiner from our synagogue, Temple Sinai, calls me and tells me about a member of the temple who was treated at Boston U for the same disease as I. He died. This was shattering news for me. The Rabbi wants to know if I want to talk to the family. I answer absolutely NO. I will never forgive the Rabbi. A

few years later, I tell him about his faux pas.

On November 20, I saw Dr. Burka who was very positive and comforting. My appointment for evaluation was moved to December 11. While I was driving, Ms. Trafton called me from Boston U and told me that my appointment had been moved up to November 27. My last day at the office was November 22, 2006. On Thanksgiving 2006, November 23, we are packing for the long term. We leave for our house in Chatham November 24, arrive at 7:15 pm. The house is in perfect shape. Dinner, walk to Sears point, I feel extremely well, beautiful weather, good dinner at home, I practice the cello and do a French correction for Anne-Emanuelle, our daughter, professor of history of public health at the U of Toronto. Sunday November 26, we go to Boston and stay at the Newbury Guest House on Newbury Street with parking and elevator. Not bad at all, a very nice B&B. Excellent dinner at Smith & Wolensky.

Monday morning, 6:45 am, Boston Medical Center in Moakley building. I register and receive a card like a credit card with a number from the hospital. Many tests at the hospital. Verification that I have amyloidosis and they accept me at BU in the amyloidosis treatment and research unit, on the 3<sup>rd</sup> floor, same floor as treatment for cancer in the Moakley building at BU. Wednesday November 29, back in Chatham, I read all the papers from the hospital and we have dinner with our friends the Schwartz, Jerome and Sandra who are staying at their vacation home, also in Chatham. Thursday November 30, long walk.

Kate Fisher, chief nurse from the amyloid section at the hospital calls me at 1:30 pm to explain to me all details of the treatment on my hospital calendar. She gives me good advice. The big question is: do I receive 140 mg of the chemo Melphalan in one treatment or 100 mg of chemo in 2 treatments, the second one being 6 months later. Anne-Emanuelle studies the question because of my age and my state of health. I am at the age limit for the 140 mg in one treatment. I am also in excellent health, as Dr. Enelow keeps on repeating to me.

Friday December 1. We wait all day for the conference phone call from Boston. At 3:30 pm Dr Barry, Anne-Emanuelle in Toronto, and Richard and I in Chatham are on the phone to discuss the dosage.

Saturday December 2, we negotiate the rental of a small apt. in Greenhouse building: for January, \$ 4600/month, \$240 for car parking, \$153/day in December, very convenient, very close to the hospital but horribly expensive.

Beautiful weather in Chatham, I take long walks.

Iris, my sister-in-law, advises me to take vitamins and supplements, which I

buy at the health food store. Daniel offers to give me bone marrow, other people also. It won't be necessary because the treatment consists in autologous stem cell bone marrow transplant, in other words my own bone marrow.

Sunday December 3, Anne-Emanuelle announces that NK and Tsatsa will come to Chatham in December, if the doctors permit me to have them in the house near me. She also tells me that she will be my caregiver. What a wonderful daughter I have. She is taking a one month leave of absence from the university. She moves in with Richard and me in the apt. that we rented. My dates will be:

Wednesday December 13: beginning of the treatment

December 14: placing of the catheter in the jugular vein under anesthesia

December 15-16-17: I receive hormones by catheter.

December 18-19 : stem cell collection. I collect enough millions of cells in the 2 days. I don't need a 3<sup>rd</sup> day of stem cell collection.

December 21: we return to Chatham. The doctors predict that I will feel good.

Monday December 4, bad news from the Mutual of Omaha insurance, my medigap underwriter for the Foreign Service Medical Plan that covers me offers no supplementary compensation for patients under Medicare: apt. rental, trips, car rental \$ 1200/month, all add to our expenses, they probably never heard of bone marrow transplant for amyloidosis, a very rare disease.

December 24: Nikolai Krementsov, my son-in-law, and Tsatsa arrive in Chatham. Anne Emanuelle (AE) will come and stay with me day and night December 12 til January 16, Iris, my sister-in-law, will come January 14 til January 28 to take over, we are paying for her trip and for the care of her dogs in California. Between Jan. 14 and 16, AE will explain every detail of my treatment to Iris. Then AE will come back if necessary or Sarah or Sandra will come because they both offered to become my caregiver. Manuela, my sister, will come January 25. Richard rents a car in Hyannis when he goes back to Chatham. He won't stay with me because the doctors don't trust his cough, not contagious but still, worrisome. Richard does not feel well, sciatica and depression because he worries about me. Dr. Enelow sends me an article from the journal of Internal Medicine, an 8 year study with rate of survival. It frightens me but there is hope. Jeanne Rosenthal, my viola player and epidemiologist and Jim Vogel, Richard's cousin, an internal medicine doctor, will help me to decide the dosage of chemo, 140 mg or 100mg in 2 stages 6 months apart. Because of my age, the high dosage is not recommended, but it is still possible because I am in good health. The question is:

140mg/lb

100mg/lb + 100mg/lb in 6 months with a second bone marrow transplant.

**We wait all day on Friday December 1<sup>st</sup> for the call/conference between me, Dr. Barry and AE. Always the same question about dosage.**

**We rent the apt. in Greenhouse for 12-21 Dec and for 1<sup>st</sup>-31<sup>st</sup> January.**

**I look for medical masks and I order a wig. I go to the dentist in Chatham for a general cleaning of my teeth prior to the procedure. The dentist knows of amyloidosis, he recommends the high dosage for me.**

**AE does research the world over in Science journals for dosage of melphalan. There is a world conference in hematology at Sloan-Kettering in NY, which might help us to decide on the dosage. AE reminds me of Hippocrates' saying "First do no harm". I get ready, receive many phone calls from friends. I am confident and optimistic except once in a while when I collapse and cry. Richard is totally silent and depressed. He sleeps a lot, and I feel very much alone. We both wake up and cry. I buy 2 sweat shirts that open in the front, for easy access to the catheter, also sweat pants, very nice in yellow.**

**Monday, Dec. 11, Kate Fisher tells me that the high dosage of 140mg is quite acceptable for me. They would never have suggested it if it were too dangerous for me. What a relief. More crying, this time of joy.**

**Tuesday, Dec. 12, we leave for Boston, I drive, Richard has a bad sciatica. Stop over at the hospital garage to buy a book of tickets. We go to the apt. , 150 Huntington Ave, the Greenhouse. Small apt. but quite correct and clean, garage underground. AE arrives 5:30 we go to dinner at Bonfire and drink a good bottle of Los Vascos from Chili, my last wine until??? It is Richard's birthday, 76 years old.**

**Wednesday 12, wake up at 4 am, Richard goes back by bus to Hyannis, rents a Toyota Camry. We keep the Honda in Boston so that I won't have to take taxis full of germs. AE and I go to the hospital, all kinds of tests. I am told of the dangers of placing the catheter in the jugular vein, that is why it is done under sterile environment. I am fed oxygen through the nose and a small dose of valium and satinel, no anesthetic, I don't sleep. Nurses wonderful and so professional. It is all done in the East Newton building. Dr. Lebedis explains everything to me, asks me many questions. Afterwards I am left alone in the hallway and I start to panic. Finally I am wheeled back to my room on the 3rd floor of Moakley. Dr Seldin and Kate Fisher come and see me. I am amazed that they are so concerned with me. I start to understand that I will undergo a big deal. AE and I return to the apt, have lunch and take a walk. I feel good and optimistic but scared of hearing that I will be extremely tired afterwards. How about my job, my music, our trips? First I must get cured.**

**I sleep poorly. AE gives me 2 tylenols. I sleep poorly every night but I eat well. After the double injection of hormones in both arms to stimulate the stem**

cells, the collection starts on Dec. 19, first day, 3 millions collected between 8:30 and 2 pm. I get more injections of hormones and continue the double dose of diuretic. Next day, I collect 4 millions of stem cells. It is enough for the procedure. Dr. Emelia Benjamin, cardiologist sister of AE's friend comes for a friendly visit. We return to Chatham after a stopover at the pharmacy and spend \$330.

I arrived 49 years ago today in NY! It was December 20, 1957. I eat well, take walks, but I sleep poorly. I keep on gaining weight. I continue the diuretic twice a day. NK and Tsatsa arrive on the 24<sup>th</sup>. We take walks on the beach, Tsatsa and I have a wonderful time. We have champagne and caviar from Russia. New Year's Eve, fireworks that we see from our deck. I drink a drop of champagne with everyone.

January 1<sup>st</sup>, 2007, departure, AE and I, for the procedure in Boston.

January 2<sup>nd</sup>, I am given Protonix. We go from the garage to the Moakley building by foot. We wait 30 min in the waiting room. I get saline solution through the catheter. I drink a lot, water, juice, ginger ale. I get breakfast at 11:30 and medicines against nausea. The melphalan injection starts. It is the first day of 2. I take ice cubes in my mouth with cranberry flavor. It is very painful and makes me cry. I get cramps in my legs. The melphalan injection lasts 40 minutes. I drink water and juice. It is horrible. I am given more saline solution through the catheter. Dr. Sancharawala comes and talks to me. There are 50% chances that the amyloid will be eliminated in the blood. She says that they will see next June when I come for my checkup. I have to breathe in a machine 10 times every hour to activate the lungs. We leave the hospital at 3:30 pm, go home, I am a little drowsy. We go for a walk.

Wednesday January 3, Hospital at 9 am. Cleaning of the catheter, 2 hours of saline solution before the melphalan intravenously. Very hard, I cry, take ice in my mouth. It ends at 3 pm. We go home. Another patient, Mr. Barro, is much sicker than I am. He has many side effects. Hopefully, it won't be like that for me. Dr. Berenbaum comes to see me in my hospital room. He is a psychiatrist. He asks me how I feel mentally. I tell him that I am strong. He wants to know what was my worst pain and misery in my life. I tell him about my brother's death and my survival in WWII. I cry. We talk about the war, he tells me that his cousin, Michael Berenbaum, survived Auschwitz and works at the Holocaust museum. He wants me to preserve my energy in order to get stronger. If I cry all the time, I must call him. He tells me "you are a survivor". 10 pm, I am tired, AE and I go home and go to sleep.

Thursday 4 January, I sleep until 6 am, take my medicines, go back to sleep until 10 am. Hospital. Get acquainted with Dr. Skinner, the head of amyloidosis treatment.. She explains to me that MGUS was the predecessor of

amyloidosis. I am lucky that the progression was very slow. My rate of creatinine is low. My kidneys function. The doctors do not know exactly if the amyloid will be eliminated and if I will be in remission. We meet Nikolai and Tsa who are staying at hotel Colonnade, next to our apt. in Greenhouse. We go by foot to their favorite restaurant “Atlantic fish”. They have a good dinner. I have my tea and yogurt. I am on a neutropenic diet.

Friday 5 January. I slept well. Today is a big day: transplantation of my bone marrow. Everything goes as planned. I am given all the stem cells that had been collected 3 weeks ago. My heart and all my vital organs are in good shape. Nikolai and Tsa come to get me and take me home in a wheel chair. I am tired.

Saturday 6 January. It is called Day + 1. I wake up several times but go back to sleep. I take a walk all the way to the hospital, and get treatment. Another walk in the afternoon.

Sunday 7 January. Day + 2. I sleep well, walk to the hospital, mild weather, walk back, sit in the sun on a bench. Somewhat tired, long rest in the afternoon.

Monday 8 January. Day + 3. It is raining and we drive to the hospital. A little more tired. Siesta, quiet evening.

Tuesday 9. Day + 4, same routine, hospital, medications, tired.

Wednesday 10. Day + 5. I sleep a lot, hospital at 10:30. Platelets are going down. New doctor, Dr. Oren. Apparently, everything will be worse for me for 3-4 days. Lunch at the hospital. I eat well.

Thursday 11. Day + 6. I am pale and I throw up. Hospital, incident with tube that gets loose, I am full of blood, scared, but the nurse fixes it all. Colic and throw up twice.

Friday 12. Day + 7. Everything starts well. Then, violent diarrhea, 3 times. I take 3 immodium. Quiet evening.

Saturday 13. Day + 8. Hospital. I get 2 bags of platelets, tylenol, benadryl. 4 people in the same room. I don't like it. But Janet, the nurse, is wonderful. Another one of my angels. We go home around 1 pm. I am very pale and tired but I feel well and my moral is positive. No fever, and no hospitalization. Anne-Emanuelle is saving my life and Richard says that he will be thankful to her for ever. I speak at length to Manuela and I tell her to listen without assuming but I am already planning my return to Bethesda. But, I must be patient. Around 10 pm, I have burns in my digestive tube, it must be the small peas that I did not digest.

Sunday 14. Day +9 I sleep rather poorly, maybe because of the film we saw on TV. Hospital at noon. Excellent news, I have 100% of oxygen in my body, the platelets enter my system. No need for transfusion. My legs continue

to be swollen. Bad weather. I would like to be back home. Anne Emanuelle has not slept for 1 week, has been watching me 24 hours a day. Impossible to imagine the care she is giving me. She dares not go to sleep because I am still in danger. And she watches me. Iris, my brother's wife, arrives tomorrow. I hope that AE can go home tomorrow night. Richard is very sad and depressed, all alone in Chatham. He does nothing but worries. Friends from Bethesda call him. I see my limits, this morning in the hospital garage, I have difficulty climbing 4 steps. Small nose bleed.

**Monday 15. Day + 10** Iris arrives. I have total insomnia. Hospital 9:30. excellent news, I created 29,000 platelets. Doctors will stop anti-virus and antibiotics. I take a mild sedative and finally I take a small siesta. Everything gets better for Richard who will drive from Boston to New Haven. Daniel will pick him up in New Haven and take over the driving when it is time to go home. I will fly back.

**Tuesday 16. Day + 11.** AE goes home, arrives safely. Hospital at 9 am. Excellent news. I have now 67,000 platelets. The doctors are extraordinarily satisfied. My state is "outstanding", no more antibiotics, no more anti-virus. Dr. Oren says that I will be fragile for 1 year. I am happy, happy. My catheter is removed. Not too painful. Small scar. Manuela organizes my trip home with her who will do a circular trip, Atlanta to Boston and back with me to Bethesda, hopefully on January 23. Richard and Donald, who came to see him to give him support, will drive to Boston in Donald's car. Richard will return the rental car, will retrieve our car and will meet Daniel in New Haven. Daniel will do the driving all the way back home to Bethesda. I will fly home with Manuela. I have a good appetite, do some exercises and take a small siesta.

**Wednesday 17. +12.** I don't go out at all, my legs are swollen and burn me. Iris puts 4 pillows under my legs. Hospital 9 am. Increase by 50% of the diuretic. I am very cold. I take a 1 hour siesta. Angry at Sandra who tells Ri that I have only 30% chances of success. Iris makes a beef bourguignon, delicious.

**Thursday 18. Day +13** I don't sleep well, despite the sedative, I sleep from 9 pm till 2 am. Up at 6 am. Hospital 8:30. Wonderful news. Officially I will leave next Tuesday. Still 10% possibility of a change in my date of departure. I am given a double dose of diuretic. We take a walk in the Prudential mall and return through the streets. It is sunny. I call Dr. Enelow and make an appointment for Friday January 26 in his office. Quiet dinner with croque-madame, apple sauce. I take a double dose of diuretic.

**Friday 19. Day +14** 9 am, hospital. I now took 103,000 platelets. Last injection of hormone for red cells. Conference with Kate Fischer: she tells me all that I am allowed to do and must not do. I have a chemo brain. I loose all

my hair. Farewell and thanks. Carol, the insurance specialist, tells me that all my appointments with Dr. Enelow will be reimbursed by Medicare. I will stay fragile for 100 days, then less fragile for 300 days. My afternoons will have to be quiet.

Saturday 20-Sunday 21, days 15 and 16 I sleep very poorly. Iris buys 2 homeopathic sleeping pills. Difficulty with digestion despite wonderful cooking of Iris. Another very bad night.

Monday 22 day + 17. Hospital at 8 am. I did not sleep at all. Dr. Oren says that my state is “outstanding”, “fantastic”, but I don’t sleep. He gives me Ambien and Ativan for sleeping.

Tuesday 23. Day + 18. Departure from the hospital. Taxi, Airport with Iris. Manuela is there, waiting for us. I am in a wheel chair with a mask on my face. Manuela warns the stewards on the plane that I am not contagious, just fragile. We arrive at Reagan National airport. Richard is there, waiting for us. I don’t sleep. Very tired, no appetite. Terrible pain in my legs.

Thursday 25. Dr. Enelow, complete exam, I have very little feeling in my toes. Nerves are damaged. Dr. E. says that all the steroids that I took prevent me from sleeping. He prescribes Valium to sleep and Gabapentin for the nerves and the pain. I sleep in the armchair.

Saturday, Sunday Monday, I feel much better, take half dose of Valium and 2 gabapentin. I sleep at first in bed, then in the leather armchair, sitting up. Difficult digestion, diarrhea. I take one Gabapentin at 5 pm and one at 9 pm. + ¼ valium. Manuela goes home, because I am strong enough, or so I believe.

Sunday 4<sup>th</sup> February. Terrible pain in the left muscle of my buttocks. I take 2 tylenol, twice. Dr. Enelow wants to see me, but I am not strong enough.

Tuesday 6 Feb. I go to Dr.E. He says that I don’t have enough strength. He tells me to stop Lasix. I take Magnesium and calcium recommended by Iris. I try and exercise my arms. I start to play a little cello for the first time.

Friday 9 Feb. Call from Boston. The doctors want me to take Lasix again, 40 mg. I take 1 Gabapentin and ¼ valium.

Sunday 11 Feb. email from Dr. E. he wants me to take 80 mg of Lasix and 2 Gabapentin.

Monday 12 Feb. 80 mg Lasix and potassium.

Tuesday-Friday, snow and ice. I don’t go out.

Friday through Tuesday, Tsatsa comes for a visit, with her mama, wonderful for me. We have so much fun. I start to use my stationary bicycle.

Wednesday 21 Feb. Visit with Dr. Enelow. He watches me very closely. I am able to take a walk alone in the park in front of our condo.

Thursday 22 Feb. We go to the movies, matinee. I wear a mask. I take ½

**Diovan, 1 Lasix and 1 potassium. I sleep well every night and I take a siesta every afternoon. Vitamin D every day for 1 week. A friend comes for a short visit. A neighbor comes the next day. I feel better and better. I start to have friends over and I prepare lunch.**

**March 7, I fall down on my left shoulder, terrible pain.**

**March 8, Dr. Enelow shows me 3 exercises for my shoulder. He is very satisfied with my state of health. I take longer walks. I don't eat much meat, don't feel like it.**

**March 23, I go to my office. Not much of a welcome. I am disappointed.**

**March 27. I receive an email from my supervisor telling me that my job has been eliminated. It is a terrible shock for me. I was looking forward to go back to work in April. I am very depressed. I try to go out with friends, museums, dinners.**

**May 3<sup>rd</sup>. Jessica advises me to go to a social worker. I go to see Susan Abrams , psychotherapist, who tells me the difference between "Being and Doing".**

**June 6<sup>th</sup>. We drive to Toronto and stay for 6 days, I take Tsa to school, I pick her up. Always wonderful. We visit the new Ontario museum, have dinner in restaurant.**

**June 12<sup>th</sup>, we leave for Delmar, long trip. June 13 we leave for Chatham.**

**June 18<sup>th</sup>, checkup at Boston U, we sleep over at Newbury guest house, next day appointment with Dr. Barry. I go through all the tests. We return to Chatham.**

**June 22<sup>nd</sup>, phone call from Dr. Barry. Very satisfied. Email from Dr. Skinner, very positive. I play at Sandra's. I faint. Ambulance. Hospital; they keep me overnight. I continue to take lorazepam upon advice from Jessica. I don't sleep, very depressed. Manuela is with us, helps me, we walk together. I start to sleep again.**

**July 18 Dr Roth, I stop diovan, lasix and potassium. Very frequent episodes of weakness. Panic attacks. Sometimes very cold ocean water helps me. Extremely tired and depressed. I take ativan and valerian. I feel heavy, dizzy, drowsy. I take melatonin every day.**

**August 14, Dr. Roth for sore throat and cough. I feel weak and faint on chair on my way out. Diarrhea. I take robitussin and ½ ativan and 1 ½ melatonin**

**August 15, go to otorhyno Dr. for Richard. Dr. speaks of cancer. I faint in Dr.'s office. Manuela comes back. I don't sleep, even with ativan and melatonin.**

**Jessica + Todd + Kady arrive. Jessica tries to help me, talks to me a lot. Return to Bethesda August 31.**

**Sept. 5, Dr. Enelow, 25 mg Zoloft and gabapentin to sleep. It gives me vertigo.**  
**Sept. 6, trazodone, 2 tablets to sleep.**

**Sept 17, 2 zoloft in the morning, 2 trazodone in the evening.**

**Sept. 21 Dr. Enelow, I must take vitamin D. I lost 20 lbs. I start to eat again. No more panic attacks. I walk every day around our neighborhood. I will not go to Jessica and Todd's wedding. Too big a trip for me. But I will go to Toronto for Tsa's birthday, Sept. 26-30. I take a wheelchair at the airport.**

**October 7, phone call from Sam Leavitt: I must see a psychiatrist.**

**Manuela told him how I am, no sleep, depression.**

**October 9, wedding of Jessica and Todd.**

**October 10, 7 am appointment at Dr. Larry Horn, psychiatrist, recommended by Susan Abrams. Richard comes with me. I talk and explain how I feel. He prescribes Nortriptyline, and sleeping pill Rozerem that I take while continuing to take Zoloft for 6 days. 2 days later, I feel better. I sleep.**

**October: Vaccination against flu.**

**October 23. Dr. Horn. I feel very good. I continue nortriptyline and Rozerem. I start to drive myself. I sleep every night.**

**November 1<sup>st</sup>, Manuela comes for a visit. We go to museum, exhibit of Hopper's paintings.**

**November 3<sup>rd</sup>, evening at Mopsik, in-laws of Steve and Dena Isaac. I feel very, very well. Manuela leaves November 6.**

**November 26, cataract operation. I have many activities, music, meetings, classes.**

**Nov. 30-Dec.2, AE and Tsa come for a visit. Excellent weekend, Air and Space Museum with Tsa and then we go to see Roosevelt memorial.**

**December 13, departure for Boston. Stopover at Judy and Willie in New Haven.**

**December 14, Chatham.**

**December 17-18-19 Boston U Medical center. Complete checkup with bone marrow biopsy, etc.**

**December 21, phone call with results: partial response to treatment.**

**December 22. Departure for Toronto, sleepover in Gloversville.**

**December 23 arrive in Toronto for 1 week. Always wonderful with the Kremontsov.**

**December 30 back in Bethesda.**

**December 31, lunch in Alexandria with our friends Nowak and Borgeaud.**

**2008, one year after the bone marrow transplant...**

**All of January, I am very busy. Dr. Enelow: all vaccinations that are needed**

after I lost them with bone marrow transplant.

Feb. 6, vaccination against polio. We plan a trip to Paris to join the children who are on a sabbatical. We stay in their apt. for 5 weeks. First 2 weeks excellent. Suddenly I feel weak and I faint 3 times. AE calls Dr. Enelow long distance. Stop Diovan. Ambulance. Hospital Lariboisière. They keep me 6 days, they never heard of amyloidosis. They run all sorts of tests. Finally I go home. Manuela arrives, we celebrate our 50 year wedding anniversary. Ma and I walk, I give her my arm and we go out a lot. Return to Washington April 24. I have high blood pressure, I take Diovan 80 mg twice a day. I am better and I stop the antidepressive Nortriptyline end of May. I start Lexapro 1 a day, valium, 5 mg, then 2.5mg, then 1.25mg. Continue Lexapro, Ativan. I faint twice, 5/21 and 6/3.

**2010**

Several fainting episodes.

We take a cruise with Holland-America Line. Very disappointing for me. Passengers not interesting. Dinner companions not interesting. Stop overs not what I expected. I get very depressed, I loose my appetite. We get off the ship in Istanbul. After 4 days, and an eruption of volcano in Iceland, we are stuck but finally we can leave on first plane to Geneva to be with the children. I faint in the Hilton lobby. Nothing serious. Back in Washington. I go to the psychiatrist Dr. Horn. He prescribes Nortriptyline like 2 years ago with Rozerem. No relief. I am in constant touch with him by phone while in Chatham in the summer, still very depressed and panicked. He tries several anti depressives. Nothing works. Finally he gives me bupropion, tells me it will take up to 6 weeks for full effect. In fact after 4 weeks I start to feel good. I continue to see Dr. Horn every 6 months and I continue taking Bupropion.

**2011**

June check up: still partial remission

**2012**

June check up at BU: some abnormality: 10% lambda plasma cells. Dr. Seldin talks to me on the phone. BU wants to see me for a check up in December. Still in partial remission

**2013**

June check up.