doi: 10.3325/cmj.2010.51.361

If the Stars Were Mine…

By Vesna Andrijević-Matovac
vesna.andrijevic-matovac@zg.t-com.hr

MAY 23, 2006

It was exam time. My Faculty was crawling with students. They had suddenly woken up and were now coming for consultations in large numbers. I was sitting in the waiting room at Dubrava Hospital, impatiently waiting for the nurse to call me. I was in a hurry because I was already late to the faculty. This was one of my three monthly checkups – in a week my last Herceptin and one-year of therapy and therefore my second two years of treatment would be over. I was lying there, ready to be examined, thinking about all the things still waiting for me that day. My Prof. Brkljačić was busy with another patient, so two young lady doctors came over to me, introduced themselves as residents, and asked my permission to examine me. I was often examined by students and residents and in principle did not object if my physician finished his examination. Then I was glad to act as a model for them to spread some gel on and practice their diagnosis. How else could they learn? But this time, before my examination, I didn't like it at all because it just enhanced my subconscious worries. The examination took ages, and I was already a little angry. My neck was next. The young doctor passed a probe over the supraclavicular area.

"This node doesn't look normal to me!?" they said to each other, as though I didn't exist. They were getting on my nerves, I would really like to send them to hell.

"You mean this one? No! This one lower down." They are only residents, they have no idea, I think to myself. What is it that doesn't seem normal to them now?

"This node is suspect, I would puncture it," now energetically and self-confidently the young doctor finally turned to me.

At the mention of a cytopuncture, I broke out in a sweat from head to toe in a second.

"I feel sick… Please call Prof. Brkljačić."

Prof. Brkljačić, my dear Boris, came in a flash, took the probe and in less than a minute called the cytology lab. No… No… No… I don't believe it is ALL happening again. Boris called Prof. Virag and together they discussed possible surgery on the node.

Prof. Virag, self-effacing, a man of few words: "I'm not going to operate if the illness has already spread elsewhere! The best thing is to do a positron emission tomography-computed tomography (PET-CT). If only that node is involved, we will go to surgery."

I was psychologically "on my knees." I asked my husband to tell our daughter that it was happening again. I still found it hard to look her in the eye. I don't know where that feeling came from and why, but I had begun to feel guilty about my illness. I know it sounds odd, but it was as though I had failed in my duty as a mother, who was having relapses all the time. I needed time to come to terms with that irrational guilt.

I went with my husband to Klagenfurt, Austria. At that time there wasn't a PET-CT in Croatia, except at Rebro Hospital, but only for indications other than breasts cancer. Doctors very rarely refer their patients with that kind of diagnosis for treatment abroad, and the patient needs to submit an application to the Croatian Institute for Health Insurance – and usually the patients have never heard about that kind of test. Doctors most often never tell their patients about this possibility, because the application requires their recommendation, which they only reluctantly write.

The finding of the PET-CT on May 28, 2006 showed increased metabolic activity only in that lymph node, 9 mm in size. Already on May 30, I am the first on the list for surgery.

I woke up after surgery. There was a drain in my neck and a bottle from which all kinds of stuff dripped away slowly. My voice was hoarse. I would rather not remember the next few days. The draining of the surgical area would just never stop. Lymph flowed for several days. Prof. Virag had gone off on a holiday. The young doctors came and went on their rounds, thinking about another operation. I was worried. On the fifth or sixth day, an older red-headed nurse, probably close to retirement age, took a look at my wound in the bandaging room and said to the young doctor, "You know, sir, this is like that because there is a vacuum created somewhere, which is draining the fluids out. It will never stop. I'm taking it out," and before the doctor realized what was going on, the drain was out. "So, now we will see what will collect in there."

And to my joy, the drainage ceased. The pathohistological finding was the same as before. I asked my husband to take our daughter on a holiday and I stayed with my mother in Zagreb. We went on a weekend course on macrobiotics. I started eating only macrobiotic food. Miso soup, rice sprinkled with gomassio for breakfast, for lunch again some combination of cereals, plus boiled vegetables in various ways, wakame, nori, kombu, black soya, azuki beans, mainly a lot of food that does not grow in this part of the world. I knew that food is important in the treatment of malignant tumors, I also knew that Western medicine confirmed that fact long ago, in relation to preventing angiogenesis. I read, together with my mother, a pile of books on nutrition, which recommended various forms of diet, but in that whole forest of information, I failed to find my own way. I kept thinking about the old people from the villages, who ate animal fats and various forms of "unhealthy foods" and lived to a great old age. There was something untrue in all those theories. I have to admit that the macrobiotic food, which we spend hours preparing, was very tasty, but I only managed to keep going like that for three months. I was so depressed eating that way, but we decided to wait weeks for my consultation with Mr. Pejić from Makranova, the best known consultant on macrobiotic food in the former Yugoslavia. After the consultation I came away with a huge list of various nutritional supplements, which you can buy in his Biovega shop. I have nothing against Mr. Pejić, and I still buy quite a lot of food in Biovega, to use in my diet. But then I realized that this was not my way, that the problem of food like that was in my head, that macrobiotics is not just about food, but a life style, imported from distant Japan. In my soul I was in fact what my dear friend Nada called an "organized anarchist." Nothing could convince me in the long-term that, for example, azuki beans, grown who knows where, were actually so much more healthy that any other beans from this part of the world. I actually realized that I cannot stand any form of force, and not being allowed to eat a piece of home-grown pumpkin or a thin slice of cured ham was for me an attempt to squeeze me into a mould, which an "organized anarchist" cannot stand.

AUGUST 2006

Together with my sister I travelled once more to Prof. Baselga in Barcelona. Prof. Baselga had a theory that, in view of the earlier irradiation of my supraclavicular region where the fibrotic tissue certainly originated, Herceptin, as a large molecule, could not work well. His recommendation was for a further 6 months of Navelbin every week in combination with Herceptin, and then another six months of Herceptin as a three-weekly mono-therapy. Prof. Baselga was still very optimistic. Unfortunately Navelbin was not even registered as a drug in Croatia. Once again I had to buy the drug myself. Moreover, at the hospital there were no clearly defined regulations and, according to the legal regulations of the Ministry of Health, a drug that is not registered in Croatia should not be administered in a hospital. But still there were a few of us patients who, through the sincere understanding of our doctors, did receive chemotherapy which we humbly brought to them in little homemade ice boxes. I know that in treating us, the doctors themselves were committing a petty crime. This problem is still not resolved to the benefit of the patients, and at Rebro Hospital some internal rule book now actually completely prohibits the use of such drugs. I think this is completely wrong. If a patient is able to buy a drug that is not registered in Croatia, but in the world it may be the "gold standard" for treatment of his or her illness and could help, I think that he or she must be able to receive it in the hospital in the home country.

I spent every Thursday from the autumn of 2006 to January 2007 at the day-hospital in the basement of Rebro Hospital, receiving treatment with Navelbin and Herceptin. On Mondays and Tuesdays, I taught at the Faculty. At my first lecture, I noticed that I could hardly breathe whilst giving the lecture. Very soon, Prof. Večerina established that as a result of the operation, or later compression to stop the lymphorea, my left vocal cord had been paralyzed. I asked for a lecture theatre with a microphone and asked my students to bear with my slow and breathless speech. I stopped walking about while I was talking, because that made me even more tired, although sitting down did not agree with my temperament. That year, my teaching and communication with students were more important to me than ever. But still I could not find a way to come out of depression. As soon as my father's car (he was usually the "duty driver") stopped in front of the Clinic every Thursday, I felt a lump in my throat. The problem was no longer the leukocytes, which were falling because of Navelbin, so the dose had to be reduced, nor the purple lines of my veins for which

Navelbin was truly toxic, so they were constantly sour and painful, nor the breathlessness after Herceptin. The problem became my floods of tears. All the patients knew me for my tears, which did not fall quietly and secretly, they fell like Niagara Falls. I was no longer able to look at all of us together in the same room. On one bed they were draining ascites from a patient and despite the improvised screen you could see everything. I couldn't take the poor patient who had been given a thoracotomy and was constantly throwing out phlegm through that little hole, making my stomach turn; I could not watch a patient who was constantly throwing up. I got into a cycle of self-pity, from which I could no longer see any way out. Shouldn't this all be more humane, better? Shouldn't women with breast cancer be separate, on a special ward, and patients with lighter therapy be separated from the more serious cases? At the other end of the same hallway was the psychiatric ward, but no one from there ever came to see us. Psycho-oncology, as a sub-specialization of psychiatry, does not exist in Croatia. There are probably some scientific papers and books in that field.

At moments like that, the only psychiatrist and the best psychiatric treatment was to be found at nurse Emica's day-hospital. "Girls, please make some coffee, Vesna is feeling down in the dumps again today…" she ordered the younger nurses. Soon the smell of alcohol and cytostatics was replaced by coffee, which was given to all patients. There was nowhere in Zagreb where you could drink coffee that tasted and smelt like nurse Emica's, nowhere in the world, because just at that moment it was for me a personalized therapy. It contained all her love and empathy, which could not be cooked up by any recipe or prescription. There was always a little biscuit or something similar served up with coffee. Yes, I knew that tumors feed on glucose but at moments like that I comforted myself that I really didn't care if I was also feeding that animal in me. After Emica's coffee, my tears would dry up, and I would think, with my eyes wide open, about the fact that I had to find a way for psychologists and psychiatrists to be included in work with oncology patients. I was not yet considering to organize an association of patients with breast cancer, but I thought frantically about how to help myself and others, those who were also weeping silently.

I was in my office. The telephone rang. It was Prof. Jakić-Razumović, a pathologist from Rebro. She is the president of the non-governmental organization Nada (Hope) and she was launching a campaign entitled They Are Not Alone. "Vesna, you mentioned that you know Prof. Đikić. What do you think, would he agree to have his picture taken with you? You see, we are running a campaign like the one run by the English photographer Rankin, who has taken a whole series of pictures, you know, what we wanted you to do in London in the spring with Goran Višnjić. So then Croatia would be part of the "Breast Friends" project. But since Višnjić couldn't come over from Los Angeles for the shoot with you, his picture was taken for Redkin's book alone. The idea is to take a picture of a famous person who supports women with breast cancer, and now Croatian photographer Hoyka is going to take maybe 5-6 pictures, so we can include them in Redkin's exhibition, which is coming to Croatia in December."

"Well, I don't know what to say, I don't really know him that well, but I could write him an e-mail…" I agreed to her invitation, confused as I was.

I had met Prof. Đikić in 2002. I saw an article in a national daily where he talked about his discoveries related to HER2 tumors. That was the first time I wrote to him. I wanted to know all about the way Herceptin works. He suggested we could talk about it in Zagreb, since he was coming there soon. We met for the first time in October 2002. I was pleasantly surprised by his readiness to talk to me as a patient about everything that interested me. I wrote to him again in the summer of 2006 after the lymph node surgery. Although he was a basic researcher, he was prepared to answer all my questions about HER2 receptors, as well as the news related to HER2 therapy, which was about to come into clinical use. He would from time to time send me an interesting article, which he thought I as a layperson could understand. But for me to send him a mail asking him to have his picture taken with me… at the weekend, to come from Germany… and to pay for it himself? I spent an hour in my office wondering what to do.

The answer came that same evening: "Dear Vesna, since we have known each other for a long time, and you are fighting a persistent battle, the amount of effort you have put into consultations around the world, the number of different forms of therapy you have been through, it would be my personal honor to have my picture taken with you, because I often mention you as an exemplary patient. Do not worry about the expense, I will take care of that myself."

NOVEMBER 25, 2006

An evening photo session by the well-known Croatian photographer Damir Hoyka. I thought that it would be like having your passport or identity card picture taken, from the waist up, one photograph and that's it. I had no idea that we would have to jump and hop about, waving pink ribbons all over the place. I kept blinking.

"Hey, your microbes aren't over there, they are here, in my lens, look here!" he said to Prof. Đikić. Microbes or tumor cells, it was all the same to our Hoyka.

"And you, record-breaking blinker! Give us a smile," he would say again and again to me. "I need your smile."

"How can I smile when I am ashamed of my big teeth?"

"Who is asking about your teeth? You have a beautiful smile. SMILE! I need your smile."

He hadn't told us that we needed to wear white trousers, so a problem arose. In the end he brought us two pairs of white trousers, one from his wife, one from a neighbor, and told us to put them on. I was already embarrassed because of Prof. Đikić, but at one point he said spontaneously, "Vesna, relax, it's OK, I'm having fun! After working in a laboratory, this is a new experience."

It was a real complete evening photo session, in which Prof. Đikić proved to be very simple, humble, and a real humanist, and I, finally, after several months of deep depression, once again had a really good laugh.

The exhibition was a part of a major charity campaign, and it opened in December in the presence of the highest ranking state officials. In spring 2007, Herceptin was finally accepted onto the list of the Croatian National Insurance Institute for adjuvant use in all HER2 positive women. Hoyka's photograph is still in my office today, and also at the Center for Psychological Support of our association "SVE za NJU!" (Everything for Her). Just one look at it can always improve my mood, reminding me that even in moments of the greatest suffering, one can turn defeat into victory, sorrow into laughter, and do something for the general good, and in that way help yourself too.

JULY 2010

My Munich odyssey of irradiating my pleura ends in two days. Actually, one more round of radiation of the pleura and I am done! The control CT today, according to my doctor Dr. Andratschke, is "really good." The left lung is completely expanded, there is no pleural effusion. I think they are themselves very happy with the results of the therapy. The catheter will remain in for the time being, until my next check-up. There are two more lesions visible on the pleura. After the check-up by PET-CT in about a month they will decide whether they will irradiate that too using the stereotaxic method. Yesterday, as part of a project of our association I managed to organize more filming here in Munich of a full-length documentary film on oncological patients in Croatia. We want, amongst other things, to show the Croatian public what methods of treatment are available abroad. Above all, we want to show this to the patients, because they need to know. In the meantime I began consultations with the Oncological Institute in Ljubljana on the possibility of joining a new clinical study. These days, a small group workshop was held in the premises of our Center for Psychological Support of "Everything for Her" for women suffering from cancer. Of the ten women registered nine came. We worked for two hours with two psychologists. These are just the first steps by our Center. This is what I dreamt about in my flood of tears and Emica's coffee, four years ago in 2006.

I spent the last 7 days in Munich in the Advokat Hotel, not far from the hospital. This evening Germany beat England by as much as 4:1 in the World Cup. Below my hotel window the atmosphere is euphoric. But it cannot drown out the sound of the gentle song by Melody Gardot, "If the stars were mine…" which quietly and gently floats through my room from the computer, I don't know how many times… bringing me a feeling of bliss and peace…............ mpompopparaaa......ppamparamprei......parappmpomperi....

If the stars were really mine, I would make each one of them come down to a person suffering from cancer, carrying as a gift the only thing we patients really want, in our dreams and our reality.....mpompopparaaa...ppamparamprei...parappmpomperi....