

doi: 10.3325/cmj.2010.51.472

It Is October Again, One More

SEPTEMBER, 2007

A little bit more and the third line of chemotherapy would be over, and so one more year of adjuvant therapy with Herceptin. A PET-CT follow-up scan was planned, this time in Graz, because Klagenfurt was overbooked and was not taking patients from outside Austria. I arranged an examination in Graz. I was completely sure that everything was OK, there were no visible signs of disease. But still I felt butterflies in my stomach like I used to long ago, before taking an exam at the university, and my knees shook as I climbed the stairs to the LKH – Graz State Hospital, looking for the department of nuclear medicine. The usual procedure – FDG contrast, etc; I knew I was radioactive again but who cared about that any more as I lay in a separate booth, separated by a screen from a patient I knew, also from Croatia. Unfortunately it was recommended that we did not talk, so that all muscles would be as relaxed as possible for better accumulation of the contrast medium. So we lay in silence, each with her own thoughts but still conscious that we shared the same fears and the same hope. Long ago I refused to be given the iodine contrast because it made me feel sick, so each time I asked for a native CT. The imaging finished. I left with my husband for lunch in a nearby restaurant, but every mouthful stuck in my throat. I drank my sedative. I returned to the ward. I waited. Here, in contrast to Klagenfurt, where I was already at home, I didn't know a single doctor, so I didn't know who was going to give me the good or bad news. The lady from Zagreb was also waiting for her results, while her husband stroked her bald head, seriously and deep in thought. Suddenly a tall bearded man came out into the waiting room in the hall, wearing a black suit and a bow tie, no white coat, the image of a magician. He only needed a black top hat and a magician's wand. He called out both our names. I got up, and to my astonishment he saluted me theatrically, like an Austro-Hungarian soldier, and handed me the printout of the results of my PET-CT. It described my findings: three positive lymph nodes, in the mediastinum. At my attempt to get him to explain to me, as a lay person, the precise location of those nodes, he simply mumbled briefly, "See your oncologist," saluted again, swung around on his heels and, like David Copperfield, disappeared be-

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hind a screen. Three nodes in the mediastinum seemed like a piece of cake to me, but returning to Zagreb was a real nightmare. All the way I spent on the phone, arranging appointments with Prof. Boris Brkljačić and Assistant Professor Dražen Huić, who were always ready to help. My husband was already at the end of his tether, I could see the pain on his face. I know the feeling when he can't even comfort himself, let alone me, so he just gets edgy.

"What on earth do you want from those people now; you've already driven God and the devil insane. It's not the cancer that'll kill you but your head, spinning all the time!!!"

"What do I want? Didn't you hear that doctor? I want Boris to look at the CT, because that is his field as a radiologist, and Dražen to see the PET because he is in nuclear medicine. Do you get the difference between those two specialties?"

"I don't understand anything, I am stupid!" The ride to Zagreb passed in a "pleasant" atmosphere.

At the border post, the customs officer looked at my passport, and looked at me suspiciously, because I had much longer hair than in my passport picture, where I had only about 2 mm of hair after a round of chemotherapy. "Why are you staring at me," I thought to myself, "Give me my passport back, I want to go home."

"Have you been for a medical examination? I can measure your radioactivity."

"Yes, my wife was in Graz for a PET-CT examination."

"Oh, OK, OK, it's alright. Have a safe trip!" he said and gave back the passports.

"Yes, you idiot, it's not alright, and it's not a good trip!" I thought to myself. But at the same time I was overtaken by shame and a feeling of guilt. It's not that guy's fault that I have cancer that has started moving around the mediastinum of my body, without my permission, and without "customs control."

I went on to Prof. Brkljačić's right next morning. After carefully studying the CT image of my thorax for quite a long time, he only saw one possibly suspect lymph node, while he believed the other two were not malignant, and even said that one was not even a node, but a blood vessel!!? Hope began to stir in me that there were at least fewer of them. I went to Rebro Hospital, to see Assistant Professor Dražen Huić. And Dražen also saw only one node on the PET, right by the arch of the aorta, which was quite active metabolically, and therefore very suspect. But he was so calm he managed to comfort me. Perhaps that character from Graz wasn't a doctor after all, but really some performer.

I arranged another trip to Barcelona by e-mail, to see Prof. Baselga. Just as I was boarding the plane I met our well-known oncologist, Prof. Vrdoljak. Although I tried my best to have a polite conversation with him, I had never been able to do so since the time of my initial diagnosis. I felt as though he could not stand patients like me, who asked a lot and wanted to know everything, especially if they were not doctors, meaning they were a lower caste, with whom he had nothing much to discuss. Climbing up the stairs of the little plane, I still tried to be nice, because as an expert Prof. Vrdoljak was up to date with everything going on in the world in the field of breast carcinoma.

"Prof. Vrdoljak, I'm going to Barcelona now to see Prof. Baselga, but when I come back I would really like to talk to you. Could you give me your cell phone number again, which you gave me a few years ago? Unfortunately I've changed my phone and some of the numbers I had, including your number, got lost."

"No, Mrs Andrijević-Matovac, I can't give you my number, it's your own fault if you lost it!"

I was not disappointed by this rejection; I did understand that he didn't want to give his private number to patients any more. But I was disappointed by his dismissive tone and the way he refused me. We boarded the plane.

"You know, Prof. Baselga is not God," he added in the voice of an actor playing Shakespeare, as we looked for our seats in the plane.

"No, Prof. Baselga truly is not God, but he is a doctor whom I trust completely, and for the optimism he instills in me, I am willing to travel to the end of the world to see him."

I felt miserable for the entire flight. We have such a great expert in oncology, a man educated in the US, who unfortunately communicates so badly with patients. But well, perhaps I get on his nerves, since at one time I refused to join the HERA study he was running, whatever... it doesn't matter. I could hardly wait to meet with Prof. Baselga, and his first question, as always, with his broad smile, "Vesna, how are you?" and his hug and kiss. Catalonians kiss each other each time they meet. Baselga really is not God, but he is a God-man, God-doctor, and God-humanist, and many Croatian doctors are also like that, approachable and open to their patients. But that is impossible to learn, it is something you have to have inside you... and if alongside his expertise a doctor manages to preserve that love for his vocation which can always be clearly seen in his communication with patients, then he may be called an excellent doctor. Sometimes a warm word and the feeling that your doctor understands us mean more to us patients than hectoliters of cytostatics.

"Vesna, how are you?" my Jose Baslega began. We did a new PET-CT there in the hospital, which was included as a part of Professor's project.

"Yes this node by the arch of the aorta is really very suspect, but my experience with PET-CT is such that it may be, but may not be... I suggest that we do another PET-CT at the end of November. If the metabolic activity is the same, we shall see what to do next." Then we went on to talk about other topics, including the patients I had sent to him from Croatia.

I returned to Zagreb. Prof. Brkljačić introduced me to Prof. Hedi Hricak, head of radiological diagnostics at the Memorial Sloan-Kettering Cancer Center. She suggested that we do the next PET-CT in Munich with Prof. Schweiger at the Rechts der Isaar Clinic.

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Munich, Rechts der Isaar Clinic, Nuclear Medicine Department. In a nearby cafe, I was passing the time with my sister while waiting for my results. I was completely calm. My sister was amazed.

"Look, in the past three months I have been completely happy to accept the fact that my cancer is after all a metastatic disease and not just a local problem. At this moment all I want to do is go and get my results as soon as possible and then go shopping in the city center.

It's all already decorated for Christmas. I want to breathe in the smell of cinnamon, cloves, and mulled wine on Marienplatz – as soon as possible."

"O my God, after six years, your attitude has really progressed!" says my Bilja, as I have affectionately called her since childhood, with visible relief. She is five years younger than me but in our relationship she has always been older, more serious, somehow more down to earth and rational. She is always with me, my constant support.

Prof. Kraus called me into a room with a large number of screens, on which my previous PET-CT scans were already displayed. He also called Prof. Michael Molls from the radiotherapy ward, whom I met for the first time. It was obvious that the lymph node by the cardiac aorta was highly metabolically active. I did not even blink. I was only thinking of the shopping ahead. In the course of the conversation I learned that Prof. Molls' wife was from Zagreb, and that he himself has many colleagues and friends from Zagreb.

"How long are you staying in Munich?"

"Until tomorrow evening."

"Come to my radiotherapy department tomorrow."

"But tomorrow is Saturday," I reminded him, thinking that he had perhaps got the days confused.

"Yes, I know. I will be at the Clinic, I have a symposium, but come at 8 in the morning and I will suggest a method for stereotaxic radiation of that node."

"And what is that, what kind of method?" I want to know immediately.

"Come tomorrow, we will sit down in peace and I will explain it all to you. We will settle it all then."

The next day, Prof. Molls explained the stereotaxic method in detail, whereby the node by the aorta would be radiated, along with the entire area of the mediastinum. I agreed, but only after Prof. Baselga gave his blessing. Again, a few days before Christmas of 2007 I traveled to Barcelona. This time with my husband. Prof. Baselga in no way agreed to the radiation of the entire mediastinum. He asked me if I had Prof. Molls' private cell phone number. Yes, I did. He promised that he would call him and that the two of them would agree on the further steps. When I was

leaving, his secretary told me that I didn't need to pay the usual consultation fee of € 250. I thanked Prof. Baselga, and he just smiled and waved his hand in passing.

"Vesna, it's Christmas time, a time for giving. You will pay next time. I will let you know what I arrange with my colleague Molls."

Yay!! I had enough time to go shopping in my favorite store, Massimo Duty. During the day, somewhere on La Rambla, my phone rang. A call from Baselga's Oncological Institute with the news that immediately after New Year only the node by the aorta would be treated by the stereotaxic method, sparing the rest of the mediastinum. I returned home the day before Christmas Eve. Our custom is that the entire family gathers every year at my house. Each one brings a part of the menu. This time they wanted to spare me, but that was like a punishment for me. So, that Christmas Eve in 2007, there were 14 members of the family at my house. There was no up-coming treatment that could spoil the joy of Christmas and the family gathering. The scent of the Christmas tree, fish soup, vanilla biscuits, mum's baklava that she made by hand, the wreath on the front door, which I made specially every Christmas, and the bright colored heap of presents under the tree, which was most interesting to our Maltese dog... For years now she has known that in that colored heap there is always something for her ... at least a bone, a toy, or a dog treat.

In January 2008, I underwent stereotaxic radiation for five days, with maximum care taken to avoid the surrounding tissue, which was particularly important due to the proximity of the aorta. The hardest thing was to lie motionless for more than 50 minutes, wrapped in some kind of cellophane foil in a specially prepared bath, which is actually there to catch all the excess fluids created during the planned radiation. I felt like a ready-to-cook chicken in the store, wrapped in transparent foil. In May at my next check-up in Munich all they could see were fibrotic post-radiation changes. Since it was impossible to undergo the stereotaxic therapy in Croatia, at my request and after I submitted immense documentation and all other "second opinions" from abroad, my expenses were covered in full by the Croatian Institute for Health Insurance. I continued with Herceptin monotherapy, for the fourth consecutive year.

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Since June, Prof. Baselga is no longer in Barcelona. His institute is working, but he has moved with his family to Bos-

ton. Now he is the Chief of the Hematology/Oncology Division and Associate Director of the Massachusetts General Hospital Cancer Center in Boston, where he is also Professor of Medicine at Harvard Medical School. In July, while I was undergoing radiation of my left pleura in Munich, he sent me an e-mail:

"Vesna,

We have the results back from your mutation and your tumor has a PI3K mutation which would make you potentially a candidate for an agent from Novartis that is called BEZ235 and that we have seen some responses in patients that had progressed to prior therapy with herceptin and other combinations. I would strongly consider this as a good option. As you know, I am now in Boston and I am expecting to be back in Barcelona on the week of September 27th. I would be very happy to discuss this further with you.

Please receive my best regards.
Jose Baselga"

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I had a consultation arranged to see how to continue with my systemic therapy after radiation of the pleura and in view of the now proven P13K mutation (found in about 25% of HER2-positive women). I used the trip to Barcelona to record another interview with him, which I had arranged in the spring, as part of a project to make a film about oncology patients in Croatia. So this time there was a film crew there with me: Zdenko, Marko, Paula, and Goran. Apart from the interview, conducted with him by the script-writer Paula, the professor gave permission to film my consultation too. What a coincidence! I remember my first meeting with him in February 2005. Then he had asked my permission for Spanish journalists to be present and film my examination and consultation with him. Today I was asking him if Croatian journalists could attend my consultation and interview him.

We talked, as always, just as though the two cameras pointing at us did not exist. I was worried about why the last clinical trial I was included in had not given the expected results. Patiently, he drew the structure of a cell and explained it all to me. We agreed that I repeat the PET-CT in two months and, if the disease was progressing, to immediately join the trial. I was worried about the finances, because I would have to travel to Barcelona every three weeks. He promised that he would try to cover at least some of the cost of the plane tickets as part of the project. But I did not want to think

about that yet. I was a bit sad that he would no longer be in Barcelona all the time. I told him so.

"Professor, one of our oncologists once said to me that you are not God, but I have great faith in you. In these 6 years in which you have gone through all my relapses with me, your optimism has meant a great deal to me. How will I get in contact with you in future, not just for myself, but also for the other Croatian patients who contact our association? I am already thinking about the fact that we have several women under 40 for whom it would be worth testing this mutation."

"No, I really am not God. Your Croatian scientist Dejan Jurić works with me in Boston. For me he is a great hope for world oncology. You can always write to him if it is something urgent or to Dr Saura here in Barcelona. All my colleagues are in constant contact with me when my patients are concerned. And for those young women, send us their histopathology paraffin cubes and we will test them to see if they also have the PI3K mutation."

A firm hug as always, this time with a lump in my throat.

"Although I know most of your colleagues, if something serious happens, I will come to see you in Boston."

"It would be an honor."

We had to stay two more days because Almeni, my vice-chair of the association, did not have her appointment until Wednesday. And on Wednesday, the whole of Spain was paralyzed by a general strike. Nothing was working. There were no taxis, no buses, no underground service. You couldn't buy a slice of bread, have a drink anywhere, nothing. We were lucky that the department store El Corte Ingles was open, with tight security, and we went there to have breakfast on the 9th floor. I looked over at Montjuic, the Sagrada Familia in the distance, the balconies of the buildings full of flowers, the blue of the sea. I remembered my first visit to this eternal city, which lives 24 hours on the street. It was a special family millennium trip.

"Why are they on strike anyway?" Almeni asked me.

"They have low wages, a high level of unemployment, the banking system is in ruins. When Croatia reaches this critical mass of unity, something will begin to change there too. If all that money stolen by Croatian tycoons, who until yesterday were receiving awards and were pro-

claimed "manager of the year" but today are under investigation or are already in prison, had been used for things such as quality reform of the health system, fund for expensive drugs, clinical research, building institutions for palliative care, buying radiation treatment instruments for which you usually have to wait an average of 2 months ..."

"Vesna, how are we going to get to Quiron this afternoon for my consultation, if this doesn't calm down?"

"Don't worry, we'll find a way," and we did. Getting back wasn't so simple. The taxi which dared to drive us couldn't get anywhere near the Piazza Catalunya, near our hotel. So we walked 2 km to break through the lines of protestors, the police cordon, with burning rubbish on all sides, and some brave tourists taking pictures. I choked on the smoke from the burning trash. Finally we literally ran into our hotel, opposite the Cathedral.

The next morning, everything was fine, as though we had dreamed the previous day. I just went back to La Rambla briefly, to light a candle in my little church, Betlehem, which I never fail to do. I sat on a bench next to the Farggi patisserie. Two years before I had had my last coffee there with Goga, who was also a patient of Prof. Baselga. In my last telephone conversation with her, she asked me to send her a text message. I asked her, "What do you want me to write? and why not an e-mail?"

"Not e-mail, because then I am dependent on someone else, write to me, what the weather is like outside, write what you're doing, and don't cry, just write to me, we are brave girls," she whispered quietly.

"Vesna, when will we go back to Barcelona?"

"In spring, my dear, I promise you, we will go there again together."

That evening I asked everyone I knew, and some people I didn't know, to send her a text message. I wasn't able to keep my promise of a trip to Barcelona. She died the next day, in her own home, in January this year.

Will this sadness of mine and many people I know, sadness that is so hard to carry for years, ever end? How is it possible that no one I know sees me as a sad person? Which defense mechanisms make it so invisible? Perhaps the same ones that helped me "celebrate" nine years of treatment on October 15 this year. Yes, nine years of life given as a gift. It is October again, one more. Walk through the parks and listen to the rustling leaves. Just listen. They will tell you all kinds of interesting things ...