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Head and neck cancer forum

Saturday, July 21, 2018

Rene Kloeti – My personal experience

RENE KLOETI: I had to write some notes down, because as Marty said I have chemo in my brain, so I forget everything. Where's Marty? There he is. I had to make some notes. Having written these notes, I was quite amazed what a journey it has been. It's now been ten years. And I am still here.

MOST: Yay (clapping)

RENE KLOETI: And even longer ;-) thanks to lots of many, many good people and my family/friends, Marty and the support group, all the clinicians and everyone else. So, I am absolutely grateful.

My story started when - in 2007, my wife and I decided to relive our 70s, when we backpacked through central America, South America, Asia. On the road two years in Asia, two years in South America, and we said in 2007, when we did grey nomads for four months around Australia, we said "Why don't we do it again? But this time do a worthwhile trip. Why don't we make it two years?" So, we went about to find tenants, put everything in storage; got everything set up, so that we could take off and we then left Brisbane late 2007. Went a long way, via Switzerland; got caught in some snow blizzards, minus 15-degree temperatures, which made us immediately to book on our trip over to Mexico where it was going to be a bit warmer; and we then also were able to catch up and see Michael who was in Guatemala, our first son Michael. Ursula and I visited Michael in Guatemala, where he was attending a Spanish course. After a few weeks, New Year in Guatemala City, we decided we would fly on to Panama, where we intended to enrol in a Spanish course, to refresh our Spanish that had gotten a bit rusty in the last 30 years.

So there we were in Panama, enjoying our time, and one day I noticed that I had a problem swallowing food. It seemed to get stuck. We thought nothing of it. We thought, "Oh, it's just some sort of cold." Then my electric razor broke down and I said to Ursula, "I have to buy a razor. buy a new razor, shave by hand." While I was doing that, I noticed there was a lump on the right side of my throat. After a few days of thinking "it's just an infection, the glands", a mate who lived in the same apartment where we had rented, that was the days before Airbnb, we rented

a room in an apartment with some other travellers, he said, "Look, I know a doctor. I will drive you there." So he drove me there with his little Suzuki van, we went to see his doctor. She examined me. She prescribed me antibiotics and said, "No problems", patted me on the shoulder and sent me on my way. Of course, antibiotics weren't good enough.

Then having gone through the prescription, realised that I needed another lot of antibiotics. Chose not to go back to her, even though it had been really cheap, \$8 consultation but it hasn't been really a good one. So, we asked at the school, and they said to us, "There was a clinic up the street and it's called Clinica Einstein", and we thought that sounds pretty good.

In we walked and immediately a doctor said, "Antibiotics is not going to do that" - he spoke English, although our Spanish was at that stage, well enough that we could understand - and he said, "Look, why don't you come back in an hour? I will ask for an ear/nose/throat doctor to come and see you?" And we thought at that time, "Oh, well, that could be a little bit more serious," but thought nothing of it. Came back an hour later; doctor examined me and he said, "No hablo Englese", I don't speak English, only Spanish. He looked in my throat and he goes, "Oh-oh", and his face just went like that. And he said "ob-struction", meaning obstruction in English, and he said - he had a very serious face and he said, "This is not good". So that followed a scan, a CT scan in a very modern hospital. That was followed by a biopsy, where they cut a bit - 2 centimetre cut into my throat/neck, and then came a report; which came in Spanish. I took it to the school, to help me translate it. And they couldn't translate it; the face of our Spanish teacher just went like that, totally blank, and I could see that there were some pretty nasty words in there which I thought, "Well, maybe this isn't a good report."

At that stage, we rang Michael who at the moment was in Nicaragua, and came down to Panama, the three of us, we went to see the doctor and he would give us the diagnosis.

Of course, it was a huge shock. But we very, very quickly realised that - you know, you go through that stage of denial, and so on, till acceptance, and that process for us was very fast. We were in a foreign country, Panama, central America. We immediately knew we have to address it, we have to accept it. It is what it is; we have to go back and attend to this.

We had the good fortune that we had emailed our friends in Brisbane, who - our friend Marta in her walking group, has a doctor friend, who walks up to Mount Cootha, who works at the Saint Andrew's hospital and she consulted with him and by the time we got back to Brisbane, everything was kind of set up for us; and that's how we came to be with Dr Stevens, Maurice Stevens; who went straight to Saint Andrew's hospital; never had any jet-lag because that fell by the wayside. Straight into hospital. I showed him all the reports from Panama, got everything translated; and he said, "I'm not interested in any of that. We will make our own diagnosis."

Fair enough. Turned out to be a diagnosis far more severe than the one in Panama. This one turned out to be an oral pharyngeal cancer, so in the mouth and in the throat; mouth, back of the tongue and in the tonsil area; and that spreads to the lymph nodes in the throat.

Likely cause, HPV. We had no idea what has this HPV come from, human papilloma virus, which there will be a talk later on about that. But there it was. Things went very, very quickly. I had seven teeth taken out as a precaution, before the operation; because in the radiation, teeth get very - can get very damaged; and teeth that may be suspect, take them out. Gave me a PEG and then we waited and waited and waited, and we said, "Why did we come back - rush back from Panama so quickly? Here we are, two months down the track, and they still haven't started." They measured me a mask; the mask started to give me, uhm, kept me awake at night, to the point I had to go and see a psychologist to ask her "how do I handle this situation?" She said to me, "Rene, all you have to do is lie there. We do the rest. If you feel you may have to go to the toilet, raise your hand and we will come and rescue you, no problem. After that, I got used to that. Went through the seven-week treatment, 35 radiation sessions with chemo, which was pretty horrific. As all of you know, who have gone through that, but I came out the other end; much lighter, I lost 20 kilos, I was 78 down to 60. But I was still here.

As soon as the feeding tube was taken out, I went back to the pool and back to my beloved swimming. The first swim I had was in 29 December; I swam six laps and my mates all kind of looked at me and every one of them all sort of said, "Where's Rene? Has he not sunk yet?" and I felt so good after that and things just improved immensely.

In February - so I was finished with the treatment. That was seven weeks, end of April; so that would have been May, June, so in July. So the PEG came out in November and I swam in December. And January/February, I felt - actually, I went to a maxillofacial surgeon to say to her, "Have a look at my teeth, Caroline, am I doing the right thing by maintaining my teeth, the health of my teeth?" And she stood behind me and started to feel my neck and said, "Rene, I am a bit concerned. There is a lump there which you need to investigate, the left side."

And she said, "You will need to go and see your doctor. Tell him about that." And I did. And the doctor said, "Yeah, we knew about that. We have been watching it." "Oh, okay. You know about that. So what are we going to do about that?" "Well, it will have to come out."

So that led to what they call a neck dissection, and they took out 50 lymph nodes on my left-hand side and when I asked them - when I woke up after the operation, I said, "How did it go?" They said, "Oh, it went very well. We even took out your jugulars." "Oh, jugulars?" "Yeah, both of them." I said, "Well, how many do I

have?" "They took the internal and external jugular out; but don't worry, you have still got that one going up, with the blood supply; so you are okay."

And that was Maurice's lovely sense of humour. He said, "I opened you up like a book." I said, "Well, I hope it was a good read." But fabulous job; absolutely fabulous. Throughout this whole treatment I was looked after beautifully by all the clinicians, by the staff. There was a nurse there called Maureen Kyren, who was my darling. When I discovered her, I just latched onto her. Maureen, just when my teeth started to cut into my gums, she would put some chewing gum on, and when it was time to take the chewing gum off, she would take a pair of scissors and she would go "click, click" and get into my gums. But she did a wonderful job and she would even say to doctors, "Why have you left Rene wait so long? He's been here for an hour and a half?" And the doctors said, "Yes, Maureen," and they would immediately look after me. So she was an absolute Godsend, absolute angel.

After the neck dissection, after I recovered, I went back to the pool, swimming, and I could not lift my left arm. I wanted to freestyle and to do that with one arm, you don't go straight; you go in circles ;-).

So this arm only came up to about here, and that one to there. And I wasn't being very successful at swimming. And it was hurting, as well.

And I felt like, as I was moving my arm, I imagined a piece of steak that I couldn't eat anymore; a piece of my steak, the back of my shoulder, back and forth, across the back of my shoulder and just causing me pain. And this went on for more than a year; but I noticed the arm, I could extend it every time a little bit more; and I just kept persevering; almost telling it to behave itself and just let me swim. I persevered to the point where the muscle was restored; there was no pain anymore. Suddenly, one day, I was swimming and there was no pain. That took a good 12 months.

And then we had peace and quiet, in remission, for almost six years. Come January 2014, I had a consultation at the hospital and that was to be my final consultation and they said, "Look, Rene, you don't need to come anymore. You are finally cured. You have done very well. You have gone beyond. And we don't need to see you anymore." I said, "Well, I would still like to come and see you, because you have become more my friends." So we made an appointment for January 2015.

We went away. In those periods, those five years, three years, we kind of travelled backwards and forwards to Europe and back; had our house rented out. Did some house-sits; did some couch surfing, whatever; just travelled and lived and enjoyed.

And then we went across to Perth and did a house-sit in Perth; and when we flew over there, I noticed I started to cough. When I swam, I noticed when I lift my left arm, I felt my lung on the left side wasn't inflating properly. I thought, "Well, that's a bit odd. It's got to be the water in Perth; it is a bit different to Brisbane." Maybe there's something not quite right; but didn't feel right.

When I started to cough, I brought up a bit of blood; and that's when I started to get a bit worried. And we went to a haematologist, to have a look at our blood. He just wasn't concerned. My wife said, "What about my husband's cough?" He said, "Oh, don't worry about that. It will be alright. Go to Switzerland for three/four months, have yourself checked up when you come back."

So off we went. A week after arriving in Switzerland, the cough had gotten worse. Ursula said, "No, I want you to go and see this GP" in this little village where Ursula had grown up. And we knew the doctor who also treated her mum, many, many years ago. So he's a well-experienced GP. The first thing he did was took a blood test; and then he said, "Mr Kloeti, you have very high inflammation markers. I am very, very concerned." He knew that I had had cancer. "Let's do an X-ray." In Switzerland, GPs have all that equipment in-house. So he did an X-ray. The result was transmitted onto his screen/computer, and he showed me and there was a great big shadow on the left lung.

I said, "Gee, I hope it is not cancer, but it looks pretty much like it." He said, "Well, it might be. Let's do a CT scan." So two days later I had a CT scan in the local village and with a report back, it was confirmed it was lung cancer; it was a pretty sizable cancer; it was about the size of a grapefruit, sitting on my left lung; and that was what had caused me trouble breathing.

So, once again, we are overseas; cancer diagnosis; and I can't say the word that I thought then, but we knew we had to come back. So we came back to Brisbane, and underwent radiation for five weeks. By that stage, radiation had become much more accurate; so it was targeted just onto my lung and on the side and on the back. I had a big burn on my chest, but the cancer shrunk from 11 centimetres down to about 3/4, which was phenomenal.

And then they offered me chemotherapy. When I said, "What extended life is that going to give me?" They said, "Well, possibly a few months." I was thinking, "Well, having gone through chemo six/seven years earlier, I don't think I will bother. I will just see what goes on. I'm okay." And having gone through that whole period, having put everything in order, death didn't seem to be so scary anymore because you accept things as they are. I thought, "Well, I don't think I will bother with chemo. I will just let it be."

Then late 2014, doing my diary for 2015, I noticed I had this appointment over at Royal Brisbane, January 2015. So I said to Ursula, "I think I might go, just in case. Let's see if they know that I have had this radiation treatment at the Wesley

Hospital." And they knew about it. And they said, "Look, what do you want to do? Do you want a scan?" I said, "Well, I don't really need to. I know it's not really good. I know it has spread to my abdomen. I don't think I will bother. If it's gotten worse, I probably won't feel very happy. It's alright." So they said, "Just come back in six months' time and we will see if we need to give you any help in terms of pain management and then we will take things from there."

July 2015, I had a good talk with one of the doctors and just as I was leaving the surgery, just opened the door and said, "Oh, by the way, if you ever hear anything about immunotherapy, would you let me know", because immunotherapy, I had known about that for a number of years; because in Europe, that had already been on the market and been practised. I thought immunotherapy would be the thing for me. So I was really skinny at the time and they said, "Look, I will just set you up for an appointment." Two and half weeks later, I went to see Brett, the medical oncologist; and I said to Brett, "You have given me chemo six years earlier and that was for head and neck. My problem is now in my lung." And he said, "Well, guess what? I am actually an expert in lungs." So we talked about various issues. He said, "The first thing I need to do is do a scan, to see where you're at." When the report came back, he said, "Well, if you do nothing, you have got six months. If you do chemo, 10 per cent chance of 12 months." I thought, "Well, that's not real good. I can accept it under the circumstances." And then he said, "But wait, there's more. There's a trial that we are running and it's for immunotherapy and I just went, "Bing." I have actually come across this opportunity. I said, "That's wonderful. What does it involve?" He said, "Well, you didn't want chemo last year and because you didn't have chemo in 2014, you are now actually eligible for this trial which involves chemotherapy with immunotherapy. You are an ideal candidate. The trial is exactly for your cancer. Non-small squamous cell, lung cancer stage 4", that was the trial. And here I was, virtually an ideal candidate.

And coming from Switzerland, the pharmaceutical company that offered that was a Swiss company. So I thought, "Well, how lucky is that, to be coming across that opportunity?"

So I was accepted into the program after a few tests. And enrolled in this program and I am still in the program. I have had 49 fusions, every three weeks. Initially, I had four sets of chemo. After the fourth set, I couldn't continue anymore; but now I am on what they call "maintenance period immunotherapy". The cancer is stable. I swim every morning. I love life. I live life to the fullest. I enjoy my time. I come to these meetings. See Marty. I also go to the Lung Cancer Support Group people. So I have two support groups, that I go to now And I am absolutely grateful. Grateful to be alive, to be here, to be talking to you, my friends. And I can't express my thanks to Ursula and Michael, Marty, Judy, the whole team; all my friends who I have made through this group, it is absolutely fantastic; and I am so joyed to be here and I thank you very much. I wish you all a good life!