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**MAUREEN’S STORY**

A friend of mine recently told me that I was indestructible, and I suppose in a way, I am. I have realized that I get this determination and survival instinct from my mother, who had nursed her mother through breast cancer, though in those days there was not much help or hope with this disease.

Apart from my two previous breast cancer scares, the 1st in 1990, then again 2002, where I had to have a double mastectomy, I now find myself having to go through breast cancer again, as it was diagnosed in 2012.

Luckily, I was prescribed a pill called Letrazol, Within a couple of weeks, the rash/tumors had disappeared. which I tried taking for two years, but I was putting on weight , plus it was knocking me out, I asked to be put on Tamoxifen and I find it suits me better, I have been told I will have to take it for the rest of my life, which I think is a plus, considering what could have been. Within a couple of weeks, the rash/tumors disappeared.

The real reason I want to write this, is that this last type of breast cancer I had is very rare, in fact, so rare that two breast cancer consultants told me that they had never seen this type before.

It started with having a kind of rash all over both my breasts, but with little lumps. When I went to my GP, I was told that I should see a Dermatologist just to be sure, I was offered an appointment for 3 months’ time on the NHS.

I decided to go private because of my history with cancer, and was seen within a week,(money talks! but it shouldn’t,) but that would be another story.

I saw a lovely lady dermatologist who also said she didn’t think it was breast cancer related, but she did take a biopsy, Thank God! I went back to my GP, I think within a week I had the results, and yes! It was back, albeit, in a different form, she also noticed I had some other skin marks on my arms and legs, which later on proved to be pre cancer as, and was removed at a later date.

You can imagine how shocked I was, especially after being told it was NOT cancer related, but even more unbelievably, I’d had a double mastectomy nine years previously and for some reason was totally convinced that I would not get breast cancer anymore.

Nobody had told me you could STILL get breast cancer after such a major operation. This is the main reason I’m writing this, it’s to get this across to other woman who should they have the same, or similar, will hopefully have much more knowledge than me.

I want to say at this point, that I’m not in any way being negative or running down any of the consultants that have treated me over the last 25 years, I know, I don’t think I would be still here if it wasn’t for them. All I would like is more understanding as to why this has happened to me and if it had happened to anyone else..

I read in the newspaper last year that Angelina Jolie had had a double mastectomy after finding out she had the cancer gene, I just wonder if she was aware that, although very rare, she could still get breast cancer?

I was also going to have the gene test when I was first diagnosed in 2011, my grandmother and also my niece had had breast cancer, however, when I learnt that they could also tell whether or not, that there could be a chance of also getting ovarian cancer if you had this gene, I opted out of knowing, feeling I had been through enough.

I have since asked my breast consultant where inside my breasts had the tumor grown , although he wasn’t really sure at that point, however, he did say that wherever the tumors had grown, they had travelled to my skin, which was why they looked like a rash on my breasts.

I had in fact gone back to see my original consultant even though I had moved to a different area, I could no longer be a patient in that hospital, but because he had been with me for 22 years, seeing me through the ups and down of my illness, plus we had a good rapport, so when he examined me, he said that what I had was extremely rare.

He is a much respected breast surgeon with many years’ experience, so I was totally shocked and confused, after all, I had always had so much faith in him and still do, even though due to my moving to a different area, I don’t get to see him anymore.

Fortunately, when I attended my 1st appointment at my local hospital, the consultant started me on Letrazol, a hormone pill that takes away oestrogen as cancer cells feed off this, as soon as I started taking it, the lumps /rash went away. Unfortunately, the side effects of this pill made me put on quite a lot of weight; I am now taking Tamoxifen which suits me much better.

I want to explain my operation as it could be important in trying to establish how I did get this disease again.

It’s called latissimus dorsis flap reconstruction on both breasts. In layman’s terms, this means because I preferred not to have implants inside me, my surgeon used the muscles from my back, I had this done at the same time as having the tumor removed. It was a long operation, 7 hours in theatre, and 2 weeks in hospital. I think there were 9 lymph nodes in my right breast which were removed.

Although I’d had a double mastectomy in 2002, I only had cancer in my right breast, but because I’d had cancer in both breasts in 1990, I chose to have a double mastectomy, although my surgeon tried to talk me out of it, I just felt, let’s get it all over and done with in one go.

Part of the reason I am writing this is to include the help I had received from Macmillan in the past and also the present, is that when I first discovered I had breast cancer in 1990, a friend of mine got in touch with them on my behalf.

I remember they were so helpful to me emotionally and financially, I was a single parent and having to give up my full time job because of all the treatment I was having. I had to cut my hours down to part time.

They helped me financially, and even paid for me to go away for a holiday; they also gave me a visit at home one evening when I was feeling pretty rough. They really did see me through that bad time, and I will always be thankful to them for that.

The main reason I am writing this, is for someone to maybe has heard of this particular breast cancer and show some light on it, or possibly someone has had the same as this, also could there be someone with more knowledge then I have ? Surely I can’t be the only person in the world to have had this type of breast cancer.

It’s been a long bumpy journey, with lots of highs and lows, however, I’m extremely grateful I’m still here to tell the tale as it were, and I’m just hoping to God that I will have a clean bill of health for the rest of my days.