

Eyewitness Account of Rita's Operation by Lyn Rothman

Yesterday I had a life changing experience. I witnessed a miracle.

Some years ago my husband Mo, a brilliant and energetic man, a powerhouse who had been Executive Vice President of Columbia Pictures, was diagnosed with Parkinson's Disease. We were both shocked and frightened - what would our exciting life become? He was immediately given L-dopa, which alleviated the symptoms somewhat. I found it difficult not to project years to come - should we move flats, as stairs were becoming a problem, dressing himself was also becoming difficult, pouring himself a glass of wine - small things we had taken for granted were now a struggle. We were so grateful for the extraordinary and fulfilling life we have shared together.

We were lucky enough to be recommended to an excellent neurologist, Professor Richard Frackowiak, at University College Hospital. Mo, as he always does, made him an instant friend.

A couple of years after Mo's diagnosis I read a moving account in the Financial Times by Michael Holman, the Africa Desk Editor, entitled 'Listening to my Brain'. He had had an operation in Grenoble, France, called Deep Brain Stimulation (DBS). This operation was pioneered by two Frenchmen, Professors Benabid and Pollak. Michael was awake during surgery while Prof. Pollak inserted an electrode into his brain and stimulated the faulty cells, not unlike tuning up an engine. The next stage of the operation was to insert a small stimulator (similar to a heart pacemaker), under the collarbone and to run wires under the skin to connect with the electrode. Michael, who could not even shave himself because he shook so much, was back at work within weeks and leading a normal life once again.

I showed the article to Mo and the next time he had a check-up, out of the blue, he asked Professor Frackowiak if he could have the operation. I burst into tears at the thought of Mo giving himself to something still experimental. In fact, he was told that he was not a candidate as he had other medical problems.

My darling man did not give up - he was desperate. 'Do you do this operation here?' he asked. 'No' was the reply. The reason being, that funding was needed to encourage one of the world's leaders in this surgery to relocate from Sweden, and two more doctors, one from the pioneering team in Grenoble, and the third already in England. Professor Marwan Hariz was being courted by many centres in Canada and America, including Harvard, and the funding was just not there.

'How much do you need?' said Mo. 'Three and a half million pounds.' Mo replied, 'I will help you get it off the ground and my wife is a professional fundraiser - she will help too.'

My heart sank - how could I embark on an appeal of this nature single-handed and look after my husband. Also, I had been fundraising for Aids for many years and felt I had used up the goodwill of many of my friends.

I understood Mo's reasoning, that by helping in this way the professor would reconsider his request, but this was not to be. I thought hard and long before agreeing to give it a try - I wanted him to have the best possible treatment, even if this was not DBS. If we helped them they would help us.

I started by writing to friends who I knew had a special interest in Parkinson's, and managed at the end of six months to raise £2 million, enough to secure the

services of our now beloved Professor Marwan Hariz, and his team, Patricia Limousin and Marjan Jahanshahi.

Yesterday I was in the theatre to see at first hand this modest maestro at work.

I arrived at the hospital Imaging Department at 7.30am - the operation was to start at 8.00am. I was so afraid of being late and keeping them waiting! I found a kind porter who took me to the Imaging Department. On my way I met 'Prof', as he is lovingly referred to by all at the hospital. He seemed thrilled that I was interested in witnessing him at work. He was pulling a little trolley, on which were several black suitcases. "I keep these locked in my office, and do not leave your handbag unattended." We went through the swing doors where nurses were beginning to arrive in 'mufti'. He asked one of them to take me into the women's changing room while he changed into his hospital gown. I was shown piles of cotton tops and trousers on three shelves - small, medium, large and shelves of non-static backless shoes. I came out to find 'Prof' waiting for me. He handed me a cotton surgical cap, to make me look more the part he said. We walked together to what looked like a small operating theatre. There were three computer screens showing the skull and a great deal of other equipment besides. Behind the computers was a glass wall, through which I could see a 'state of the art' bed, at the far end of which was something that looked not unlike half of an MRI scanner, with enough room for the head to be placed in it.

I was introduced to Rosemary from Australia and then to two Filipino nurses and several other people who came in and out. Professor Hariz took the time to tell me that this operation was going to be particularly complicated and that if the electrode did not hit the spot after the second attempt he would have to give up. "You cannot make the brain into a sieve," he said. He told me that the patient had understood this, but as her life was unliveable, she wanted to go ahead.

The professor went through a door in the glass wall and opened one of his black briefcases. Inside it looked like a tool kit. Indeed it was - spanners, drills and the like. He also had inside the stereotactic frame which keeps the patient's head completely immobile, not only while complex measurements are being taken, but while the operation is being performed. Putting the frame together was complicated and took a good twenty minutes.

I, in the meantime, was talking to Rosemary, who I found out was in charge of the computer measurements, and the others who came in and out. No one seemed to know anything about the patient. Up until now I had assumed that the operation would take place in this theatre, but no, this was just for taking the many complex measurements. At 9.15am the patient was wheeled in. Her name was Rita and she was shaking terribly. Although I could not hear anything I could see her smiling and chatting to the nurses - I was already full of admiration for her courage.

The first stage consisted of Professor Hariz shaving off all her hair while she sat in a chair - I would have found even this difficult.

The second stage, and the most painful, was attaching the frame to her skull. The professor took a felt tip pen and a ruler and drew lines on her face and then, with the help of two nurses and a 'cats cradle' of cotton thread, he lowered the frame over her head.

She was then given a local anaesthetic in the four places just under the skin where the screws were to be pushed into her skull. This brave woman chatted

throughout. One by one he pushed the screws in. The skin balloons around each screw, then returns to normal after about five minutes. She did not whimper.

She then lay on the hydraulic bed, which had been lowered for her. She was covered in a blanket. The bed rose, and then moved backwards so that her head was under the scanner.

Everyone - there must have been five people, all with their different tasks to perform - left the room and she was alone. I can only imagine what must have been going through her mind. They then joined me and the technical work started.

Professor Hariz showed me on the screen the tiny pinprick that he had to find with the electrode. I cannot explain the significance of what I was watching. I understood that they were taking measurements. Rosemary was in charge of the pictures that the professor needed and at his command, changed the computer image.

This complete, the patient was taken - still wearing the frame, which is extremely heavy - to the recovery room, while the team, including Dr. Patricia Limousin, went into what I can only call a computer room. I was told their work in there would take about one hour. By now it was about 9.30am

At this point, with so many people anxiously working on figures in such a small space, I felt I would be in the way, so I suggested that I could go and talk to the patient. I was taken to the recovery room, where I was introduced to Rita.

Rita is an extraordinary woman. I asked her if she minded my being with her or if she would like to rest. She asked me to stay. We talked for almost an hour. She has fostered 35 children as well as three of her own, none of whom she had told she was having this operation. "We are too close and they would have worried too much." She also told me that both her parents suffered from this horrendous illness and she had looked after them until they died. "I don't want that for my children. I never want to be a burden on them and when this opportunity came up I was overjoyed." I asked her if she was nervous and she said she was a little, but she had no choice,

I reassured her that Professor Hariz is the world's leader in this field and she could not be in better hands. I also told her how his post at the hospital came about and how he was wanted all over America. She told me how kind and thoughtful the team had been throughout her ordeal.

We chatted about her children, my children, Christmas shopping for 35, grandchildren, and many other things. Suddenly, they came to take her to the theatre - it was about 10.15am.

There is the 'Prof' with his black briefcases. This time they contain another part for the frame, more spanners, etc., in another his instruments, and in the last case the thinnest of electrodes, all wrapped up.

I am given a facemask. There is a great deal of to-ing and fro-ing. I gather some people in the theatre are doing research, while others may be students. There are probably ten people in all. Rita lies on the bed while she is told how the operation will progress. "The moment you feel any pain, you tell us and we will stop." They are all extremely kind and gentle.

Firstly, she has her head scrubbed and disinfected with orange liquid. They then cover it with blue paper-like material, leaving a small square where the insertion will take place.

Rita is then told that they will soon be drilling a hole through her skull and there will be a loud noise. She is given another local anaesthetic, after which they make an incision and lift a flap of skin.

Professor Hariz is quite short and needs two steps to be able to look down into Rita's brain. First he drills a hole. I am horrified, it is a real drill and extremely noisy. As the drill penetrates her skull, her body convulses in spasm. Rita is stoic.

Now we see the genius at work. In goes this fine, very long electrode. 'Prof's' concentration is absolute. The nurses are on hand spraying water with what looks like a plastic baster whenever required.

The tension in the theatre is indescribable. I am relieved that I know enough about the operation to be confident that the patient feels nothing. One wonderful male nurse tells Rita what is happening.

After about 15-20 minutes the Prof. asks Rita to raise her arm - it shakes. "Put your hand to your chin." It shakes uncontrollably.

A few minutes later this is repeated. She still shakes.

A third time she is asked to lift her arm - it is completely still. She puts her hand to her chin - it is still.

Tears pour down my face, I look at the others present and sense that they also feel that we are in the presence of a genius and have collectively experienced a miracle. "Rita," he says, "are you alright?" "How could I not be with you Professor?" "Oh!", he said, "I thought you may be dead!"

It is 11.15. The Prof comes and puts his arm around me and takes me to the nurse's coffee room. I am still very emotional. He thanks me for being there!

I will never forget this morning as long as I live. This kind, generous and dedicated man has just given a woman and her extended family back their dignity and her life.

Lyn Rothman