

## **A Personal View Of Polycythaemia Vera (Laurie male age 68) Barnet, Hertfordshire**

### **The Beginning.**

My story begins in February 1990. I worked for British Telecom at Keybridge House near Vauxhall Cross as a Commercial Officer. On Friday 23rd I arrived at the office feeling quite muzzy headed, and I had numbness of the lips and hands. I put it down to a migraine which often I suffered from in the past and waited for it to go away before beginning work.

About a quarter of an hour later I became aware that there was something wrong with my face, so I looked in the office mirror. I saw that the right side of my face had slipped downward, leaving me looking in quite a state. I immediately thought Stroke!! My wife Betty is a nurse who had told me previously of the signs to look for in stroke patients, little realising that I was soon to find out for myself. Accompanied by a first aider I got into a cab and straight on to St. Thomas' Hospital.

They diagnosed me as having a TIA at first. They kept me under observation for about an hour and took some blood samples from me in the meantime. Eventually my blood results had come back and I was requested to stay in the hospital. A while later I was sent to the Haematology clinic where a doctor awaited to do venesection procedure on me, I was told the diagnosis was Polycythaemia Vera. My blood count was off the scale; both my red blood and platelets were exceptionally high, and for that reason another stroke was quite on the cards. Incidentally, that was my introduction to the Haematology clinic on the fourth floor and all the wonderful staff there, both doctors and nurses.

It was decided to keep me in the hospital where I continued to have venesection until the blood levels stabilised. I was to spend about a week on Lambeth ward. It was there I met Dr. Tom Pearson for the first time; he put me at ease straightaway. I was put on Busulphan and aspirin.

### **The first three years of living with Polycythaemia and Stroke.**

A week later I returned home. As a result of the stroke I lost the use of my right hand for a while, which was to come back after a month, and my speech was also affected. All the family had difficulty in understanding what I was saying. I used to swear quite a lot at the sheer frustration at not being understood, but luckily they didn't understand those words either. Gradually everything came back as time went on.

I was left with the problem of not being able to type with my right hand. My brain knew what letters it wanted my hand to type, but couldn't make a connection. I had learned to touch-type when I first started with BT...alas, all lost now. Betty, my wife, got me to draw endless round circles and to fill number and hands in to form a clock. I found difficulty in signing my name at first, but this improved as time went on.

All this time I was attending the clinic at St. Tom's, every three days at first, then once a week until I graduated to once a month. In May I was admitted back to Lambeth ward suffering from a virus. I found it very hard to stop shivering and I felt very cold. Under the care of Dr Tom again I soon recovered.

In June it was back to work again. The management and staff welcomed me back and treated me with great compassion. I was the administrator and had a lot of writing to do as part of my duties. When doing reports of which there were endless, the rest of the staff helped out where necessary. For the next couple of months I was in work on a part time basis only. I had lost a lot of my former strength and the journey to and from work left me exhausted.

I was left thinking, what am I doing in this situation and where am I going? I was getting a lot of support from my colleagues. How long would that last before resentment settled in? I made an appointment to see a staff support officer, who made a comment, "Don't worry, it will sort itself out. You're not the only sick person on the staff. Let the management do the worrying." I took on board the comments of the staff support officer and continued working as before and worrying about the situation nevertheless.

All this time I continued to go to the clinic as an outpatient at first twice week, then once a week ending up at once a month. I was put on busulphen at first, but after a while Dr. Pearson changed my medicine to Hydroxurea, which stabilised my blood. I was eventually going to the clinic every three months.

In 1993 BT decided to close the Vauxhall unit down, offering the staff early voluntary retirement. So on the 1<sup>st</sup> July 1993 I was sent on three months gardening leave until the October when I became redundant.

### **1<sup>st</sup> July 1993 until the present time.**

I thought of getting a part time job but my wife disagreed. So I became a house husband, which suited me and my wife better. She was working full time as a District Nursing Sister and of course I've taken advantage of having my own nurse on hand.

Over the next seven years my condition was stable with only the occasional glitch which called for the good Dr. Pearson to alter my tablets from time to time.

In 1999 I discovered a sore spot on my cheek which my GP thought was worrying and made an appointment for me to see a consultant maxillary facial surgeon. I was diagnosed as having a BCC (Basal Cell Carcinoma) which is pre-cancerous condition.

Since that time I've had several BCC's removed from my face and one from my ear. Of late I've had radiotherapy instead of surgery because of the fragile state of my face. Lately I've had one removed from under my left cheek which was close to my eye. This necessitated my having a lead shield put over my eyeball; it was like having a contact lens inserted in my eye - but much heavier of course.

Over the last 6 years I've had the occasional TIA which necessitated me altering my tablets. The staff at St Thomas' were on hand to offer advice. I feel I owe the Professor a lot for looking out for me in the early years.

I am now under the care of Doctors Claire Harrison and Deepti Radia, and like the Professor before them I continue to be very grateful for all the care and attention they have given me over the years.

In conclusion I have to say over the last sixteen years that my general outlook has remained good. I continue to meet with my friends every week for some lively discussions. I have holidays every year. I have lots of varied interests.

I asked Professor Pearson sixteen years ago, being mindful of all scare stories which were about at the time about Polycythaemia, if he could give me a prognosis. "My advice to you," he said, "is watch out for the buses as you cross over the road in front of St. Tommy's."