Acoustic Neuroma Revisted
An interview with Peter Lawrence

As many of you will remember Peter has written articles for earlier editions of the newsletter charting his experience through diagnosis, seeking out the best treatment option and undergoing Gamma Knife surgery. His story moved on this year and I met him in his beautiful garden to hear about what has been happening to him.

Peter is a zoologist who has worked for the last 40 years on genetics and his background as a scientist very much influenced his approach to the diagnosis and management of his acoustic neuroma.
He first noticed a problem in 2006 when he began to have problems with balance and vertigo. He was referred to the ENT clinic and following an MRI scan he was diagnosed with an acoustic neuroma about 1.6cm in size. As a scientist his first response was to research the condition and over the next few weeks he read numerous academic papers and became very knowledgeable about acoustic neuromas and treatment options. He followed this up by meeting specialists in all the different fields, surgery, fractionated radiotherapy and Gamma Knife before taking the decision to have Gamma Knife treatment. However, following advice from Mr Moffat (ENT surgeon and specialist with acoustic neuromas) that treatment was not advised unless the tumour was seen to be growing, he decided to 'watch and wait'. He wrote a detailed account of his information-seeking which you can find in the Spring 2007 edition of the newsletter.
http://amnet-charity.org.uk/Amnetpdfs/AMNET%20News%20issue39.pdf

However a scan a year later showed that the tumour was growing and Peter, with the consultant in Sheffield, Mr Rowe, decided to undergo gamma knife treatment. He also wrote about this along with some pictures which can be found in the Autumn 2008 edition of the newsletter.
http://amnet-charity.org.uk/Amnetpdfs/AMNET%20News44.pdf

There were no noticeable effects from the gamma knife surgery and he was feeling very well when he visited us to talk about his experiences in March 2009. A follow up MRI had showed some growth after a year (described as "swelling"); however this usually ceases and the tumour does grow any further (ca 95% of the cases are cured, as reported in the scientific literature).

The next episode of the story starts in January 2011 when his third follow up scan showed that the tumour had grown by 4mm in diameter during 2010, doubling in volume. He explained that 'after this time you would not expect the tumour to be swelling any more, but you are advised to wait until about two years after the gamma knife before worrying about any extra enlargement —but this was two and a half years, so what to do? Was it swelling or growth? Dr Jefferies, the radio-oncologist felt the tumour had actually grown and suggested Peter see Mr Moffat again, who advised surgery.

Peter wanted to know about the possibility of a second treatment with radiation and returned to the research papers. He found records of only about 10 or 20 cases of people who had been treated twice and all reported success, although some were quite recent so it was difficult to assess as there had been such limited follow up. He still wanted to avoid surgery with its possible side effects so he visited the specialist, Mr Rowe, in Sheffield again to see if there was anything else he could do. The specialist took the view that a second radiation would not be prudent because he questioned why the first one had not been effective: perhaps Peter himself or the tumour were radio-insensitive, perhaps because of effective repair mechanisms? Also it was not understood why some tumours do not respond to radiotherapy. There would need to be a good reason to try a second treatment and therefore it might be wiser to try a different method of treatment.

Mr Rowe kindly reviewed his own cases and found only three (of thousands) where Gamma Knife was carried out for a second time and these were for special reasons such as the patient being too unwell to undergo surgery. Also, as Peter's tumour had grown to 2 cm so it was reaching the upper limit for radiosurgery which is usually considered to be 2 - 2.5cm.

Following this consultation, despite his anxiety about the effects of surgery, Peter felt he had no option, so arrangements were made for the operation which was carried out in April 2011. Interestingly an MRI scan on the day of the surgery showed no further growth in the 3 months. However the evidence shows that acoustic neuromas grow intermittently, thus they can be dormant for some time before growing again. Peter hopes that Mr Moffat will keep and publish data on his case as few tumours fail the gamma knife and more information could help future patients.

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Peter hopes that with the development of a number of lab-designed antibody treatments for specific tumours, research may eventually provide one for acoustic neuromas. The acoustic neuroma is a special kind of tumour, it is made by cells that lack a normal copy of the NF2 gene. Most people have two normal copies of the NF2 gene so if a cell loses one copy it can rely on the other. However some people have, at birth, only one normal copy of NF2 which makes them very likely to have these tumours —because their cells occasionally lose the only copy they have. These people almost invariably have acoustic neuromas on both sides, as well as neuromas elsewhere. For some unknown reason loss of copies of the NF2 gene occurs particularly often in Schwann cells associated with the vestibular nerve (which is why acoustic tumours should be known as vestibular schwannomas). Why cells in the vestibular nerve are most sensitive is one of the many important mysteries about these tumours. It would certainly help understanding if more studies of the tumour DNA were undertaken.

One of the contra-indications for Gamma Knife has been that surgeons believe it is more difficult to remove the tumour following radiosurgery. But the literature on the difficulty of further surgery is very mixed, some papers reporting surgery is more difficult after radiosurgery, others reporting that this is not so. But the surgeons in Addenbrookes have an unusually rich experience as they have undertaken more than 1000 operations so Peter believes their opinion is most likely correct. Peter asked Mr MacFarlane (Neurosurgeon) about this and was told that while it is helpful that the tumour is less vascularised (with a poor blood supply), the tumour does become more adherent to the structures around it which can present problems. In Peter's case Mr Macfarlane and Mr Moffat did have to leave a small part of the capsule of the tumour because it was attached to the brain stem. However they think that the capsule is unlikely to grow because there is so little left and the radiosurgery may have killed those cells anyway. Nevertheless, he will need another follow up MRI in about a year, so that will be something to worry about.

Following surgery Peter was in hospital for 7 days and although he had no facial weakness he did suffer double vision, nausea and balance problems. Apart from these horrid symptoms he felt he was well looked after in the hospital and the two surgeons were very clever and very kind. The sterility of the operating theatres is put through a big trial with these long operations and had passed the test superbly. When I interviewed him, about 6 weeks after his operation, he was feeling much better and beginning to resume his normal activities. *(Continued on next page)*

We talked about the decisions he had made through the process and he believes that watch and wait and then radiosurgery were his best options when the tumour was first diagnosed and began to grow. Despite the fact that he was one of the few people who are unlucky enough to require surgery after Gamma Knife, he has no regrets and believes he did make the right decisions at the time and in the circumstances. From his research and experience Peter still believes that if the tumour is less than 2cm then radiosurgery is the best choice of treatment although there are many factors that might influence that decision, such as the age of the patient for example.

Peter believes that in 2006, when he was first diagnosed, the official consensus was to go for surgery but by 2010 this had changed and even the surgeons have altered their opinions and are often recommending radio surgery rather than surgery.

June 2011

Condition update from Stephen West.

For those of you that are new readers of the AMNET newsletter. I live in Hitchin, Hertfordshire.I was diagnosed as having an acoustic neuroma towards the end of 2005. At the time I was 43 and this was the first time I had ever been told that I was suffering from any sort of major illness.

The term acoustic neuroma was something that I had never heard of before. I was told quite a lot of information by the hospital staff; however, the thought of me being diagnosed as having a tumour inside my head was really quite worrying.

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I contacted AMNET as it was one of the contacts I had been given in the leaflet I was given at Addenbrooke’s. I spoke to Alison Frank who was very helpful and invited me to attend the next meeting of the group which was just what I wanted so that I could meet other people with the same condition as me. As many of you will know, I had been given radiotherapy (FSR) and surgery as two possible treatment options, both with pros and cons to them but what I wanted most was to understand exactly what each of these would mean for “me.”

The first AMNET meeting I attended was in April 2006.and it was after this meeting that I decided on Fractionated Stereotactic Radiotherapy as my choice of treatment. I joined AMNET at that meeting and I completed my radiotherapy treatment in July 2006. Since then, I have been for several follow up MRI scans at Addenbrookes to monitor the tumour, so far all the indications show that the FSR treatment has been successful because the nucleus of the tumour is no longer growing. This is very reassuring to know. I still have the same symptoms that caused me to first seek help from the doctors back on 2005 (Impaired balance, Tinnitus & one sided hearing reduction) they are no worse than when I started the treatment.

After my recent successful scan, I have to wait for several years before my next one. In the meantime, I am still employed as a railway controller in London and coping with the day to day pressures of family life at home.

AMNET and the support of its members have been very reassuring as everyone has been helpful and willing to share their experiences with me.

Having a guest speaker at the meetings is also another valuable source of information.

With thanks from Stephen West