

Hello Everyone,

Where has the time gone? It seems like only yesterday I was at the AGM in Birmingham in July, and now Christmas is rapidly approaching once again.

Since the last edition of the NF2 News we have had a new addition to our family; a Cocker Spaniel puppy called Molly. She is absolutely gorgeous, as you can see from the photo, and full of fun and mischief. She has brought a lot of smiles and laughter into our home, together with a lot of natural waste products! I'm not sure whether our Christmas tree will survive the festive season this year!

I am very excited to be able to include details of the NF2 Weekend to be held in Sheffield on 18th/19th/20th May 2012. The weekend is a great way to meet other people who have been affected by NF2 in a relaxed and friendly environment. I hope to meet as many of you as possible there.

Once again I would like to thank all those people who have contributed to this edition, especially those readers who sent in replies to "Question Time"; you know who you are! If you would like to contribute to the next edition of the NF2 News please e-mail me at juliedking@tiscali.co.uk or contact me via Head Office. All contributions are gratefully received, no matter how small.

Wishing you all a Merry Christmas and a Happy, Healthy 2012.



Julie King

Ollie Cassin Raises Funds for NF2 Research



Above: Ollie Cassin at his Baptism

Once again the Cassin clan have done us proud! Justin and Catherine Cassin have made another wonderful sacrifice at the baptism of their fourth child, Ollie, on 10th July, 2011.

As with their three other children, Katie, Adam & Harry, my wonderful sister and brother-in-law didn't ask for presents for their children's baptisms, but asked for donations to NF2 research instead. The generous guests raised £235, which was amazing, and collectively Katie, Adam, Harry & Ollie have raised over £1,000, a remarkable amount of money.

On behalf of my family who have NF2, (Scott, Olivia & Zac), I would like to thank them from the bottom of our hearts for such a kind, selfless gesture and wonderful achievement.

Thanks Katie, Adam, Harry & Ollie for starting life with such a positive act.

In case you were wondering from the photo, yes Ollie is as cute as he looks! This was him on his baptism day.

Sent in by Clare Goddard

The Neuro Foundation would like to **invite you** to our residential NF2 weekend on 19/20 May 2012

Full details are in the enclosed flyer - we hope to see you there!

Introducing the Entertainment Committee by Julie King

Those of you that attended the last NF2 Weekend, back in May 2009, may remember a group of members volunteering to assist in the running of the NF2 Weekends, by organising the evening entertainment at future weekends. In September this year, with the prospect of an NF2 Weekend in May 2012, the Bennettas and Owens got together chez the Kings, and “The Entertainment

Committee” was born. Thanks to the mild September weather we were able to sit outside in our garden, with a glass or two of wine and an Indian Takeaway, and thrash out some ideas. All in all we had a very “entertaining” and productive evening. We hope that as many of you as possible will join us in Sheffield for a Weekend of fun and friendship.



Left to right: Bramwell Bennetta, Steve Owen, Julie Bennetta, Anthea Owen, Emily Owen, Sam King, Bethany King and Steve King

My Day at the AGM by Julie Bennetta

Having missed the last AGM because of a wedding, and the previous by the distance to be travelled, I was looking forward to travelling to meet up once again with members old and new.

On leaving my home town of Bridgend in South Wales, it was raining quite heavily, and I must admit I was not looking forward to a two and a quarter hour journey in those conditions. Pleased to say that an hour later it started to brighten up, and on reaching the venue in Birmingham we were in brilliant sunshine.

After the customary signing in, meet and greet, I made my way to the main hall. My first thoughts were, “Where was everybody going to sit?”, but sure enough there was enough chairs. Just shows how the amount of members attending the AGM has diminished over the years, which is disappointing.

The meeting commenced with the introductions of personnel and then the formal AGM took place. The main point of interest to those who did not attend, was that we have another Trustee who knows all about Nf2. His name is Stewart Lee, and I am sure that from the talk he gave us later in the morning, he will be a great asset to the Association.

Obviously, the financial statement to the year ending 31st October 2010 was discussed. The balance sheet is looking healthier than last year,

mainly due to legacies. As all charities, there are less monies being given to them than in previous years.

We had very informative talks from Dr. Sue Huson and Carolyn Redman, together with updates on the workings of the Association from Richard Taylor, (Chair of Trustees) and Lindsay Rennard, (CEO).

After a very enjoyable lunch, we split up into various groups to attend the ‘workshop’ that the individual was interested in. I attended the Nf2 weekend group. Basically, we discussed the format of the weekend which will take place on the 19th / 20th / 21st May 2012 at the Sheffield Park Hotel, details of which are included with this edition of the NF2 News.

The final session was a gathering of all and the main points from all the workshops were presented to everyone present. One of the workshops was Local Fundraising and Support Groups. Although I could not attend this, at least I now know what was discussed and I felt that I did not miss out that much on such an important topic.

I really enjoyed the day, it was very informative, and it was the first time in all the years that I have attended these AGM’s that Nf2 was given so much prominence. The Trustees were very professional in the presentations and I am already looking forward to next years AGM.

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Memories of Janet Burt

I was very sad to hear that Janet Burt, who I knew through attending the NF2 Weekends, had passed away over the summer. I remember Janet as always taking an interest in other people and being eager to help out. She was a lovely person to know and had many friends. Here are some more memories of Janet

On Monday, 25th July 2011, over 250 people gathered at Acton Parish Church for the funeral of Janet Burt. As the Vicar said during the funeral service, Janet was an inspiration. Despite not being in the best of health, particularly towards the end of her life, Janet always displayed courage and dignity. Janet was a good friend to many of us. She was always cheerful and loved to chat. People felt better after spending time with Janet. The number of people who attended her funeral, plus those who were unable to be there, is a testimony to how many lives Janet touched. Janet was a special person and she will be much missed.

By Emily Owen

Janet Burt was one of my dearest friends. No matter what was happening in her life, she was always concerned for others; she never complained or felt sorry for herself. She was determined to make the most of her life and enjoy it to the full. She frequently wrote articles called 'Going it alone' for

the Nf2 News about her latest adventure. Despite being totally deaf, with severe balance problems and suffering with frequent seizures, in the summer of 2006 Janet came to visit me on the north east Kent coast, travelling over 250 miles, alone, from her home in Cheshire, Janet wrote...

"Again I have been gallivanting! I went to Karen's house in Broadstairs, which meant two train journeys plus a taxi across London! Such a shame I am deaf, as the taxi driver gave me a sightseeing tour and running commentary from Euston to Victoria! We had a lovely time, we caught the bus to Canterbury one day, had a wander around the beautiful Cathedral. Next day we went into quaint Broadstairs, cream teas both days. Then Karen's husband John took us to Dover. We walked along the 'White cliffs and could see France in the distance across the English Channel. On Friday I returned to London by train and stayed with Jane Hill, another Nf2 friend. This is where it got hectic! Day 1 Hoxton market for pie and mash, then Covent Garden. Day 2 The British Museum, where we met some mummies. Day 3 Fortnum and Masons - £10 for 2 coffees but what the heck! Back home I flopped big time but I feel such a sense of achievement by doing all this"...

Janet was an inspiration to all who met her.

By Karen Over



Karen Over and Janet Burt (right) in Dover

Question Time

In the last issue a reader asked the following question.....

"I had an ABI implanted 10 years ago, which involves having a magnet in my head. Since then, due to the magnetic forces involved with MRI scanning, I have not had an MRI scan. At my last consultation with my Drs, in April 2011, I was advised that it would be a good idea to have an MRI scan. This would involve having a bandage tightly wrapped around my head to prevent the magnet from flying out during the scan. This technique has been mentioned to me a few times over the years and each time I have resisted. This time, though, I was persuaded to say I'll give it a go. I am slightly nervous about it, though, and wonder if you have had a scan in this way? If so, what is it like? Does it hurt? It you could share your experiences with me, I'd be really grateful – Thanks."

Here are your replies

"I have had one MRI with my head bandaged and it was a painful 45 minutes. The spinal scan was worse than the head scan. I think it is like giving birth although a lot quicker, because afterwards you think, 'I am never going to do that again,' and then the next day you think, 'That wasn't so bad after all.' I would have another tomorrow if I needed to. It did feel like your head was on fire and the magnet was being ripped out, but five minutes after you get out of the magnetic field you feel back to normal. I was really anxious about the first one, but now I know it won't kill me, I will be a lot less anxious for the next."

"I had my first MRI scan with my head bandaged a few months ago. The scan was quite painful but not as bad as I had feared. The Doctor bandaged my head firmly, but not too tightly, and then I went into the scanner. The process of entering the scanner was done very slowly, so as to prevent any dislodging of the magnet. I had been warned that this bit especially would hurt, so I was prepared! The spinal scan hurt my head more than the brain scan; maybe because I was further into the scanner for the spinal one. I have since had an appointment in clinic, and the Doctors suggested that next time I need an MRI scan, I could have some local anaesthetic injected into the area around the magnet in my head beforehand, which would mean that the scan would not hurt at all. I have to say, I did wonder why they hadn't suggested this before I had my scan (!). Anyway, I'm glad to know it is an option for next time. "

I have had the following question sent in by a reader asking for our help

"I have recently been told about an organisation called LINK that runs courses for people who have lost their hearing. My Doctor has suggested that I go, but I am really nervous about it. I don't know what to expect. Can anyone who has been tell me anything about it? Was it a helpful course? Are you glad you went?"

I know there are a lot of people out there that have benefited hugely from LINK courses, so please could you share your experience with our reader. Any responses or questions should be e-mailed to me juliedking@tiscali.co.uk and they will be included in the next newsletter.

My Story by Anna Lickley

It all started for me in my mid teens; I noticed a few lumps and bumps that hadn't been there before. I then began losing the hearing in my right ear, and these things together prompted my GP to send me for an MRI scan, which showed two large acoustic neuromas (I have later found that the one on my right-side was the largest the treating team in Manchester have seen).

I was referred to Manchester very quickly and saw Professor Ramsden and his team of very expert surgeons and was admitted for surgery. It was all very sudden and hugely derailing for all of my family. It took me several years though to learn about NF2 and adjust to having it (well, I still am really!). I remember early on feeling like my life would just carry on in the same way as before, but in the twenty odd years since then, I realise being able to adapt and allow for changes all the time is vital!

The surgery was incredibly long (18 hours) and they didn't remove all of the massive thing, so it grew back fairly quickly and I needed more surgery.

Just before I went to university (in Sheffield), I had the gamma knife on the left-side. There was a bit of reluctance because, again, the acoustic was large and the team weren't sure the treatment would be effective to it. The hope was that it would kill off the core of the neuroma and stop the growth, ideally preserving the hearing on that side.

It worked for a while, but during my time at university, I was going gradually more and more deaf, and was profoundly deaf by the end of my second year. I found the whole experience of going deaf very odd, because a lot of the time I didn't link the fact that I was struggling in social groups with the fact that I couldn't hear, but felt somehow like my social confidence was suddenly blown away. I learnt about lip-reading and also went to BSL classes, both of which started to help my communication again and gave me some confidence back. Signing has been something I am so pleased to have learnt.

When I finished university, my intention was to teach, but my degree had been in French and so teaching French as a deaf person was a tad tricky. Needless to say, I changed my career plan!! I ended up working at Bristol University supporting disabled students and eventually set up my own business, training people about disability equality and also teaching BSL (having learnt it, I got to teach after all and thoroughly love doing so). So, I had several years of relative reprieve and was able to work with great support from Access to Work.

This year has been an incredibly tumultuous year in health terms. I had the gamma knife again on the remaining bit of the left-sided neuromas, (to preserve some facial movement), but 5 other head tumours were seen in the scans and so the team also treated those. I had the treatment twice with the result that my tumours swelled up in reaction and started causing many symptoms. My balance is, well, 'staggering'! I can barely stand without holding onto something these days. I also damaged the cornea on my one good eye, (the other has had a cataract from birth), and so my vision is poor, which doesn't help my mobility.

My adaptation skills are being tested at the moment! I have also 'retired' from work with tiredness, sight loss etc. I am enjoying the quiet pace and have got some fantastic support. I am keeping up my teaching from home, more on a voluntary basis, which works very well, as I need people to support me when I go out. I've found that people love to learn and practice signing in exchange for taking me out for coffee and cakes!

I have also started a blog about NF2 and Disability and am greatly enjoying writing. There are days when I just feel exhausted, but I am also learning that these are inevitable and just to go along with them. I think none of us would choose to have NF2 but we can't change it.

You can see my blog, which is about living with NF2 at <http://inthegenes-genesandjumpers.blogspot.com/>

My Role in the NF2 Service by Mary Perry

I have been in post as an NF2 Clinical Nurse Specialist in Manchester since January. I have, however, been involved in the care of NF2 families for some years in my previous role as a Genetic Counsellor. The team in Manchester have been passionate about developing the NF2 service, and it was a great relief to learn last year that NF2 was to receive Government funding and become a Nationally Commissioned (NCG) service. NCG funding ensures that rare conditions like NF2 are managed by health professionals who have a high level of expertise and who are familiar with the condition.

One of the challenges and most exiting aspects of my job along with the NF2 team is to develop and evolve services for those affected by NF2.

As you are aware NF2 is a complex and variable condition and the Nf2 service reflects this.

There are 4 main centres that co-ordinate NF2 care for the whole of England: Manchester; Oxford; Cambridge and Guys hospital in London. Each centre has an Nf2 multidisciplinary team. While each centre is organised slightly differently the core aspect is the same. In addition to these centres Sheffield is the designated centre of expertise for stereotactic radiosurgery treatment.

The NF2 team is made up of Specialist Neurosurgeons, ENT skull base surgeons, Geneticists, Neurologists and Specialist Nurses. These are the health professionals who you will most often meet in clinic who oversee and manage your care. This team is supported by and linked to many other services.

The NF2 nurses are a first line of contact if you have any concerns or questions about NF2 or if you need an appointment or any additional support. We can act as a link and make referrals to other services. We hopefully compliment the service provided by the NF Specialist Advisors.

Many of you will have been asked to fill in a Quality of Life questionnaire when you attend the NF2 clinic (QOL). In a way it is a key starting point. How does NF2 affect you on a day to day basis, and what resources do you need to enable and empower you to live life as fully as you can?

You will all be at different stages of your NF2 journey and have different needs along the way. The ethos of the NF2

service is to provide individualised care. Discussions about your management take place at our multidisciplinary team meeting, where your scans are carefully reviewed along with the Neuroradiologist. Decisions and a plan of care are made in discussion with you and your family, taking into account any symptoms you have.

There are times, hopefully, when NF2 can take backstage and times when intervention is needed. If your tumours are growing it is important that all the treatment options are considered.

If you have a growing Vestibular Schwannoma (VS), the size and growth rate, and the degree of hearing you have are all influencing factors. Surgery with or without hearing rehabilitation in the form of a cochlear implant or auditory brainstem implant has traditionally been the mainstay of treatment in Manchester. However stereotactic radiosurgery is also sometimes an option. Over the last year we have seen the advent of the first drug treatment for NF2 in the UK. The NCG has funded Avastin (bevacizumab) under strict criteria for the treatment of rapidly growing VS.

The advantage of my post is that I can work across hospital, clinic community and home settings. This means I can be visiting someone after their surgery one day and the next day I might be in Cumbria at a home visit assessing what additional support or equipment is needed in the home to help with day to day living or helping with a DLA application.

Hearing loss or contemplating hearing loss is a concern for everyone with NF2 at some stage and the nurses are acutely aware of this. Most of us have now attended the Hearing Link intensive programme weeks, which are specially organised for NF2 families. Hearing Link is an organisation that supports people with acquired hearing loss. Their programmes offer very practical advice on coping with day to day aspects of communication. The NCG service will provide funding for NF2 families who wish to attend.

This is a very brief overview to give a flavour of the NF2 service. Please do contact the nurses if you would like further information about services that can be accessed and we will keep giving you updates through the Neuro Foundation.

Mary Perry
Clinical Nurse Specialist NF2

Wording for Neuro Foundation UK and Advocure NF2 websites for Sorafenib in NF2 study

Adults who have Neurofibromatosis 2 (NF2) and skin tumours (schwannomas) are invited to participate in a research study being undertaken in Plymouth and Manchester; Professor C. Oliver Hanemann, a consultant neurologist at the Peninsula College of Medicine and Dentistry in Plymouth is the Chief Investigator.

Although needed there is currently no drug treatment for tumours in patients with NF2. Many NF2 patients have multiple tumours which are genetically well defined. As the tumours have the same gene defect, one of these tumours, schwannomas (at nerve endings in the skin), can be used as a model for all NF2 tumours. This has allowed Oliver Hanemann's research group to successfully identify and characterise a new molecular drug target. In a human cell culture model Oliver showed that this new target can be effectively inhibited by a drug which led to reduction of the tumour's growth.

The availability of 'nerve tumours in the skin' has also allowed the development of an innovative clinical trial design to test whether the drug gets into the tumour and does its job in the tumour. To determine whether this happens, skin nerve tumour biopsies have to be analysed before and after therapy.

This is a very short trial in a limited number of patients which will quickly indicate whether drug candidates for NF2 related tumours should be tested in a large multi centre randomised trial. The trial design also allows the evaluation of substitute markers (biomarkers) which are of great value in subsequent clinical trials.

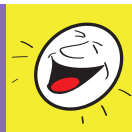
If you would like to help this research by taking part in the study, you will have to meet certain eligibility criteria related to your current medical condition and medications, and you will need to attend one of the research sites (Plymouth or Manchester) for clinical assessments and blood tests on five occasions. The duration of the study for each eligible participant is approximately eight weeks from the pre study visit (to assess eligibility) to the end of study follow up visit. Samples of skin nerve tumours will be taken before and after treatment with the study drug. Your General Practitioner will be informed of your participation.

This advertisement and study has been approved by the London Bloomsbury Research Ethics Committee. If you would like more information about taking part in the trial please contact Oliver Hanemann. We will be keeping a record of responses to this advertisement, but please be assured that this does not place you under any obligation.

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And Finally.....



A man was sitting in a bar and noticed a group of people using sign language. He also noticed that the bartender was using sign language to speak to them.

When the bartender turned to him, the man asked how he had learned to use sign language. The bartender explained that these were regular customers and had taught him to speak in sign. The man thought that was great.

A few minutes later the man noticed that the group were waving their hands around very wildly. The bartender looked over and said, 'Now cut that out! I warned you!' and promptly threw the group out.

The man asked why he had done that and the bartender said, 'If I've told them once, I've told them a hundred times; "NO SINGING IN THE BAR!"

Please can you send in your jokes or funny stories; this one was sent in by me!