



Newsletter

Winter 2012



*A Merry Christmas and a Happy New Year
to all our Members and supporters*



Cyclists Wanted for RideLondon100 4th August 2013



Would you like to be part of history and join the first Olympic legacy event along with 20,000 cyclists on this new 100 mile cycle challenge?

Starting from the Queen Elizabeth Olympic Park in Stratford, you will cycle through London passing iconic landmarks before travelling out through the beautiful Surrey countryside, including the infamous Box Hill, returning to finish on the Mall.

The Ballot is now open and you can find details by visiting www.ridelondon.co.uk/Events/100. The ballot results will be

announced in early February. Alternatively we have a limited number of guaranteed Golden Bond places which you can apply for. There is a £50 registration fee and we ask you to commit to raising a minimum of £750 in sponsorship. We will be allocating our places in February, so if you think you might like to cycle for The Neuro Foundation please call **Alison on 020 8439 1234** or email her at fundraising@nfauk.org to register your interest.

The event is supported by British Cycling and takes place on closed roads. Cyclists will have nine hours within which to complete the course. Challenging but fun, so don't miss out on this fantastic opportunity to support The Neuro Foundation at the same time. Thank you!

Get running for The Neuro Foundation!

We have guaranteed places in the following events in 2013 and are looking for the brave and the bold to get fit and run for the charity.

If you are interested in knowing more or would like an application form, please contact Sarah@nfauk.org or call **020 8439 1234**.

Virgin London Marathon : Sunday 21st April ... our biggest fundraising activity of the year and we have still a few Golden Bond places left.

Virgin London Marathon : **Sunday 21st April**

BUPA London 10,000 : **Monday 27th May**

BUPA Great North Run : **Sunday 15th September**

BUPA Great Birmingham Run : **Sunday 20th October**

BUPA Great South Run : **Sunday 27th October**



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A huge thank-you to all our members and supporters on behalf of all at The Neuro Foundation

It must be an age thing! I can't believe that we are now in December. We all know that time goes more quickly as we get older but I really don't know where this year has gone.

It doesn't seem very long ago that we had to make some tough decisions regarding the finances and future of The Neuro Foundation.

Richard Taylor, the Chair of Trustees, identified the stark choices facing the Charity twelve months ago and we gave a flavour at the AGM as to how you, the members, and the office team were moving things forward and improving the fortunes of the Charity. To remind you, after seven months we had matched the income generated for the whole of the previous financial year.

The financial year has just ended at 31st October and I want to thank everyone for their help and efforts over the last twelve months. We are in a position where the income is in excess of £400,000 for the year (£240,000 in 2011).

There have been some notable achievements by you, the members and our supporters. The Virgin London Marathon 2012 team raised over £100,000 (including gift aid).

An intrepid team ran across the Sahara and you, the members, through various events raised in excess of £80,000. We have been truly overwhelmed by the wonderful support and fundraising efforts of so many people this year. The energy, inventiveness, generosity and determination is incredible and never ceases to amaze us. The Kingston team and I would like to say an enormous thank you to all those who have so kindly given up their time to help the work of the charity, supporting those affected by Neurofibromatosis.

As a consequence of the improved financial picture we have agreed to part fund another Specialist Advisor, based in Leeds, and we are looking to part fund a further two Specialist Advisors during 2013. In addition we are identifying ways to increase and improve the help and support we can offer to people living with NF.

I look forward to meeting you and to presenting the final results for 2012 at the AGM on Saturday 8th June 2013 at The Signing Tree Conference Centre formerly known as The Deaf Cultural Centre, Ladywood Road, Birmingham and to another successful year for The Neuro Foundation.

Mike Mills, Charity Manager and Finance Trustee

AGM 2013

We are delighted to advise that The Neuro Foundation's AGM 2013 has been scheduled for Saturday 8th June at The Signing Tree Conference Centre formerly known as The Deaf Cultural Centre, Ladywood Road, Birmingham, B1 6 8SZ. We will let you have further details re speakers, agenda, timings etc. in due course.



Christmas Cards 2012

We have been overwhelmed by the success of our Christmas Card sales this year. A special vote of thanks go to Tony and Pauline Holland who have done the most amazing job in administering the cards once again. The Neuro Foundation is incredibly grateful to them both for their hard work and dedication to the charity - thank you so much!

Great Christmas Present Idea or Stocking Filler

Many of you had a great time supporting Fancy Dress 4 NF on 17th May as part of World NF Awareness Day.

Carly Jim who organised the event so brilliantly, is now selling 2013 Calendars incorporating pictures of the day from around the world. They cost just £5.00 each (including UK p&p) with the proceeds being donated to The Neuro Foundation. If you would like to buy one (or more!) then please contact **Carly** by email: fancydressforNF@gmail.com

Alternatively, you can order through Carly's Just Giving page leaving a message in the text as to how many you want, and emailing your delivery address to fancydressforNF@gmail.com

<http://www.justgiving.com/Carly-Jim>



NFI Does Not Hold You Back

Megan Kerr, a pupil from Cornwallis Academy, Kent, won a national challenge set by MyKindaCrowd asking young people to identify their career icons and write a letter directly to them asking for advice and inspiration. MyKindaCrowd is an award winning social enterprise connecting young people with their futures. Megan's prize winning letter was sent to Professor Ferner in the Neurofibromatosis Unit at Guy's and St.Thomas's NHS Foundation Trust.

Megan has NFI and has been inspired by her experience of receiving excellent care from Professor Ferner and the MDT team at Guy's to give something back and not let NF hold her back.

Megan joined the team for a chat over tea and cake in October. She enjoyed talking with Professor Ferner and Dr. Leschziner about embarking on a career in medicine and was given some practical training in how to carry out a neurological examination.

We hope she will take on the challenge of neurofibromatosis in the future and encourage others to aim high and look to the future!



Left to right: Megan Kerr, Professor Rosalie Ferner and Dr Guy Leschziner

Research Update from Professor Meena Upadhyaya



Molecular mechanisms underlying malignancy in NFI - MPNSTs: Exome sequencing identifies one of the genes associated with malignancy in NFI patients

Neurofibromatosis type 1 (NFI) is a familial tumour predisposition syndrome caused by inactivating germline mutations of the NFI gene. Although most NFI patients develop multiple benign cutaneous neurofibromas, some 30-50% of patients also developing larger plexiform neurofibromas and 15% of NFI patients develop malignant peripheral nerve sheath tumours (MPNSTs). MPNSTs are aggressive tumours that pose significant diagnostic and therapeutic challenges. However, the underlying mechanisms associated with malignancy in NFI remain enigmatic.

In collaboration with BGI, Shenzhen, China, we have generated exome sequencing data on NFI-associated MPNSTs. After filtering against lymphocyte DNA, benign

tumours, the dbSNP database and 1000 Genomes Project data, mutations in a number of different genes were identified specifically in MPNSTs. The challenge has been to identify disease-causing mutations. As part of an international collaboration with Belgium, France, and the USA, we have found one gene that is somatically mutated in a number of MPNSTs not only in our own analysis but also in that of our collaborators. Further experiments are in progress to find out how somatic mutations in this gene result in malignancy in NFI patients. Currently, there is no treatment for MPNSTs. This study should improve our understanding of the underlying mechanisms associated with malignancy, highlight the pathways involved, and identify therapeutic targets and biomarkers for MPNSTs.

Congratulations to Dr Carly Jim who has won the Exemplary Researcher Award from the Research Institute for Health and Social Change at Manchester Metropolitan University.

The award was made in recognition of Carly's work in raising awareness of Neurofibromatosis and bringing people together to conduct research into NF.

Well done Carly, you must be thrilled.

PGL weekend camp 14th - 16th Sept 2012

Recognising the benefits of providing an opportunity for young people with Neurofibromatosis to meet up and get to know each other, Vanessa Martin took on the organisation of a PGL Camp earlier this year. With the amazing grant provided by Jeans for Genes, and supported by The Neuro Foundation, the weekend event was a terrific success. Vanessa should be proud of her amazing efforts and it is testimony to her and PGL that there was some wonderful feedback from the children and their parents who attended.

We wanted to share a selection of the lovely comments that have been written. We also wanted to share some of the fab camp photos.

Nicky Clifford was one of the Mum's who attended the event and she wrote the following story of her experience, which seems to sum up very well the parents view.

Hi, I want to try to put into words what this camp meant to me and to all of us and to thank all of you who made it possible. Honestly, where do I start?

I had the absolute privilege of being part of the NF Camp 2012 which was held this weekend for children with Neurofibromatosis. It is hard to sum up in words exactly what the camp did for the children and the parents. For one weekend to make such an impact in the lives of 31 people is an incredible achievement. Bearing in mind that many of the kids and parents had never met another person (apart from those in their own family) who have Neurofibromatosis, and if they had met others it was through hospital visits; so this weekend was truly life-changing for all of us.



- *To see our children, who are normally the ones who are left out, bullied and different, to suddenly be in a safe environment.*
- *To see our children, some of whom are nervous and anxious about new things, try activities such as zip wire or abseiling, due to the support they received from the other children, the PGL staff and the parents.*
- *To see our children (and some parents with Neurofibromatosis), some of whom have significant tumours in their legs, arms and in other areas, some of whom are in constant pain, to see them making their way up a very high pole, using metal rods as steps and actually making it to the top - there wasn't a dry eye...*
- *To see their faces as the claps and cheers and support from the group helped them to succeed.*
- *To see our children making friends.*
- *To hear the laughter, to see them relaxing.*
- *To see our children bonding together, chatting about how Neurofibromatosis affects them.*
- *To see parents eyes fill with tears as they watched their children blossom.*
- *To hear the parents' relief as they talk about their children; their fears, the hospital appointments, the stress, the fact that they don't want their children to have to go through all of this and the fact that, for this weekend, they know that they are with people who understand.*
- *To be filled with inspiration for all those on the camp who brave the daily challenges of their condition, who fight through the pain and who don't moan or complain, who don't feel sorry for themselves, who face life with a 'Can Do' attitude, whatever their challenges.*
- *To look on in amazement when my son, in response to being asked how the camp went, said 'Yeah, Good, I made lots of friends.' He never goes anywhere and makes 'lots of friends', so this one fact in itself feels life-changing.*
- *These children and us parents now have a support group thanks to all of you.*

Even reading through this email, it still doesn't adequately reflect the emotions which have touched me from being part of that one weekend and the shifts which it has brought about in all our lives. We are not coping with this medical condition on our own anymore and you cannot put a value on that.

Comments from some of the children.

This is ten year old Nathan's story "In September 2012, I went to PGL camp with Neuro Foundation. It was quite fun! I didn't like the Challenge Course, it was too muddy. The activities were fun, for example, the Giant Swing. I was happy that me and my team won at the PGL Summer Fair. Our team name was Boom. We got it from my sweatshirt"



Nicole's feedback was also very positive. "I had a great time at camp, it made me feel like a proper teenager and I made lots of new friends who I now meet up with. It was nice that I didn't have to hide or explain anything to anyone - everyone understood because we were all the same even though NF affected us all in different ways. I can't wait to do another camp. I loved all the activities and it helped me to grow in confidence as I know that even with NF there are lots of things I can still do"

Courtenay said " I really enjoyed it and hope we can have another one soon "

Cameron age 10 summed it up as "Awesome" and his sister Tyanna, aged 8 said "The most funnest thing I have ever done"

Rachel confirmed Cameron's view that "The camp was awesome! I feel I have made some friends for life! I came home feeling truly proud of the achievements made. Parts of it were hilarious. I would do it all again in a heart beat."

Rachel's brother Daniel said I really enjoyed it and meeting up with other people who have NF.

Will says it was good to meet other kids like him. His bother, twelve year old Mikey thought the camp was good and his sister Immie age eleven says she enjoyed camp and all the activities and liked meeting other kids with NF.

Fourteen year Maryam's feedback was that she really enjoyed camp as she made new friends who she will cherish for a life time.

All in all a very successful event. A huge thank-you to Vanessa for her hard work.

and hope we can have

funnest thing I have



We always love to hear about the amazing challenges people put themselves through so when we heard one of our own Neuro Foundation Specialist Advisors had agreed to take up the challenge of a 40k bike ride we were keen to know how she got on.

Here in Carolyn's own words (and pictures) is her story:

“ I decided to sign up for the 40 Kilometre Cycletta race on the spur of the moment. It was a moment of madness! I had only two weeks to prepare and one week of that without my bike as I had to get it serviced at my local bike shop.

The race began and ended at Ragley Hall, Warwickshire, the course meandered through gently undulating hills (I'll come back to that) through beautiful villages and countryside with more chocolate box thatched cottages than you could shake a stick at!

It was extremely well organised by www.cycletta.co.uk. Up to 80 % of the participants were novices - so, most people were as nervous as you at the start of the race. There were two 'Treat Stops' along the route, long tables full of drinks, fruit and best of all jelly babies, fruit pastilles, chocolates and chewy sweets. I confess to having a very sweet tooth, so, I was very happy with that.

Post race, there were free massages, helmet hair rescue hairdressers, manicures, and a goody bag crammed full of lovely things. I would highly recommend these events.

So what did I learn from this race?

1. I am not quite as unfit as I thought I was – great surprise
 2. Gently undulating hills is code for Massive Unrelenting Hills (in my book)
 3. I met a fellow Novice Cyclist, Jo O'Sullivan, and made a friend along the way. We chatted for the entire 2hrs 39 minutes which is how long it took us to complete the race. I guess we could have completed it quicker if we had saved our breath for breathing, but it was more fun this way. She is doing a coast to coast Bike ride across Cuba in November; 350 km, pretty awesome, I think. I might just be inspired to find another challenge for |
- The Neuro Foundation. Watch this space!



Macclesfield Family Event 22nd September



We heard some amazing feedback from the Manchester team who organised a Family Event in Macclesfield on 22nd September.

In total eleven families attended the event with children ranging from five to twelve. The children had great fun; most had never met anyone with NFI before.

Parents all commented on how lovely it was to see their children playing together. A team of four NFI Clinical Nurse Specialists and one administrative assistant were in attendance on the day.

Judith Eelloo, Clinical Nurse Specialist NFI, based at St Mary's Hospital, Manchester, who organised the day, was able to share with us feedback from parents and children.

Some of the comments from the parents about what they liked best about the day included:

- A chance to talk to people in the same situation;
- Chance to meet other families with NFI and speak to the NF team;
- Kids could play for as long as they liked and food was nice and lots of staff;
- Seeing my son get on with other children with NFI he has never had that opportunity;
- Relaxing atmosphere, friendly helpful staff and hospital team, no pressure, meeting others parents of children with NFI;
- That all the children had fun.



Francesca Hargreaves aged 11 with her sister Rebecca who kindly made Christmas mouse decorations sold in aid of The Neuro Foundation. Thanks girls.

The children also gave the team feedback on what they enjoyed the most. Some of the comments included:

- Fun day big play area;
- Meeting new friends and playing games with other children;
- Meeting other children with NFI and being able to play with them;
- Football and meeting other children with NFI and having fun;
- Everything.

The unanimous verdict was that all feedback participants would attend a similar event in the future and would even like two or three events per year. The overwhelming verdict was that all respondees would be interested in attending an NFI weekend camp as well as attending a local support group.

Key messages are that parents felt that this event provided the opportunity to meet other parents of children with NFI which was very important, as well as being able to talk to health professionals, gain information and access resources about NFI. Parents also said it was important that their children had the opportunity to meet other children with NFI.

A huge thank-you to Judith and the team who made the event such a great success.



Corporate Donors

We are delighted to share the news about several Corporate donations which we have received over the last few months up to the end of September.

Our huge thanks go to Banner Homes, Harry Fairclough Ltd, the Billington Group, the London Film and Comic Conference, Npower, Serco UK, Phoenix International, Rose & Rose Solicitors, Asda, Swift Research Ltd, Metal Spinners Group Ltd, Tresillian Midi Group and Compuware Ltd.

We are really grateful for all of these amazing donations. Thanks again.

Give A Car

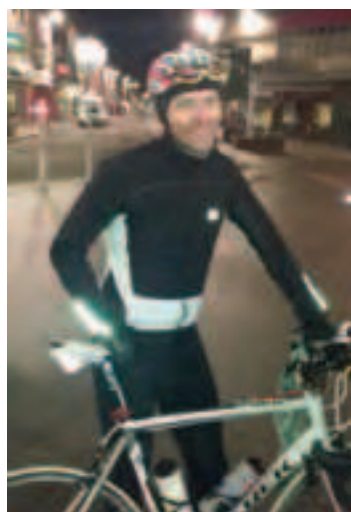
Do you have a car that you need to scrap? The Neuro Foundation is now registered with "Give a Car - Make a Difference", so you have the opportunity to donate up to 100% of the value of the car to charity.

Visit the link for full details of how the scheme works

<http://giveacar.co.uk/how-it-works>



Leicester to Skegness Bike Ride



Rob Taylor undertook the challenge to cycle 170 miles from Leicester to Skegness on 14th October. He had entered the Leicester Marathon originally, but had to withdraw due to injury, and decided on the bike ride so as not to let his sponsors down. What dedication - thanks Rob! We are very impressed.

You might like to read Rob's story below:

“ Sunday the 14th October 2012 was the day when a friend and I would ride 170 miles from Leicester to Skegness and back again.

The ride started off in the dark with the year's first frost on the ground. We rode off at a steady pace out towards Melton Mowbray. Quite hilly as Leicester itself sits in a valley. The sun rise was amazing as we rode along the winding country roads. Felt good to be alive. It was shaping up to be a great day. Also on the ride we had my Dad and two family friends following us in a camper van providing support i.e. extra water bottles, food, that kind of thing. We stopped at Tattersall Bridge picnic area for a 10 min. breather with about 65 miles done. A quick and energy bar and we were off again. The ride to Skegness from there was very quick as we had a nice tail wind.

We reached Skegness clock tower and we met the support car and had a 30 min. break. Then back on

the bikes, back to Leicester. The tail wind soon turned into a head wind and as we made our way back out of Skegness we could see the rain clouds gathering, and gather they did. By the time we got to Grantham we were a little wet and cold. We stopped in Grantham and had something to eat. We were now 158 miles in and I was starting to feel it. I was feeling tired and a little weak. We carried on and we met up with the support car in Waltham-on-the-Wolds. At this point we stopped as I felt a little sick but afterwards I felt great and was ready for the final push towards home. So we got back on our bikes and with heads down, off we went. A cycling friend met up with us, with about 30 miles to go to Leicester; in his car. He opened up his hatch back and we rode all the way back behind him which was a welcome relief. It was getting dark now and we had a bit of a convoy going on with my Dad and his two friends in the camper van following us and Tim up front drafting us. We made it back to Leicester clock tower, eleven and a half hours from when we started and it was great to be back. There was lots of back slapping, man hugs and congratulations going on. We had done it. It was and still is a great ride and one that will never be forgotten. Not just because of the achievement but because of why I did the ride - for The Neuro Foundation and also in loving memory of my Mum and my Sister. Roll on 2013 when we're going for the 200 mile target.

On behalf of The Neuro Foundation a special thank you to Rob and his friend as well as their support team. A fantastic effort.

Hello Everyone,



I just wanted to write a few words to reassure you that I have not abandoned the NF2 News! This joint December newsletter made financial sense with both newsletters due to be published around the same time, and hopefully you will agree that it is not lacking in NF2 content. The question is: should we make this a

permanent arrangement; what do you think?

Thank you to all the people who have answered my pleas and contributed towards this newsletter. As always the address to send your ideas, articles, comments, jokes, reviews, criticisms(!) is juliedking@tiscali.co.uk.

Before I go I would just like to share with you one of the best experiences of my life. On holiday in Florida this summer I went swimming with dolphins. They really are the gentlest creatures you can imagine. I was a bit apprehensive about the swimming bit, having opted to accompany my children on the deep-water experience, rather than staying in the shallows. However I needn't have worried; the ride was so smooth, we glided through the water. Seeing the delight on my children's faces as they kissed, cuddled and swam with the dolphins is something I will treasure forever.

Julie

NF2 Patient Carer Day - Cambridge Tuesday 6th November

The Neuro Foundation were delighted to have been invited to, and participate in, the first Cambridge NF2 Patient Carer day held on Tuesday 6th November. Sally Taylor, NF2 and Skull Base Nurse Practitioner, based at Addenbrookes Hospital, organised the informative and interesting day. Over thirty patients and their carers from across the region attended the day which included a range of presentations from many members of the Cambridge Multi-Disciplinary Team.

Patrick Axon, Consultant Skull Base and Hearing Implant Surgeon, provided an outline of the NF2 service and latest updates as well as later giving an update on the Avastin drug trial.

Neil Donnelly, Consultant in Otoneurological and Skull Base Surgery gave a presentation on 'Balance' and factors affecting balance in patients with NF2.

The latest updates on hearing implants was given by Zebunnisa Vanat, Clinical Lead for the Adult Hearing Implants Programme in Cambridge, covering cochlear implants and suitability to have this type of implant as well as ABI's (Auditory Brainstem Implants).

After lunch Anke Hensiek, Consultant Neurologist, provided an update on the new drug trial using Sorafenib.

Christine Marriott from Cambridgeshire County Council gave an outline of the service they provide in the region to people with hearing problems.

One of our members, Jessica Cook, gave an inspirational presentation on her NF2 book project. Many of you, I know, may have offered to write your 'stories' of living with NF2 for the book. This book is going to be an amazing read. See link for more information: <http://www.nfauk.org/events/46>

Representatives from both The Neuro Foundation and Hearing Link charities outlined the service that they provide to people affected by NF2.

At the end of the day there was an opportunity to ask the panel of experts questions.

At the time of going to press we weren't able to include feedback comments but the initial verdict was that this was a most successful day and I am sure it will be the first of many. Well done Sally and her team for all their hard work organising such an informative and valuable day.

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



I am considering what to do in the future. I would like to go to university but feel unsure as I am completely deaf - I don't know if I would manage at university. Has anyone else been to university as a profoundly deafened student? If so, what was/is it like?



Here are your replies ...

"When I became profoundly deaf I was 21 and in my 2nd year at university. I became very ill due to various complications and had to leave. Two years later I decided to return to uni, starting from scratch. This time I was going back as a Deaf student. I was so worried about how I would cope in lectures and if I would make friends, but I needn't have worried. My university has been brilliant with support. I have an electronic note taker with me in every lecture; it's sort of like having live subtitles. One thing I really

benefitted from was taking a sign language class; not only did it help my communication, but it was much easier to make friends, because I didn't have to worry about trying to lip-read them.

I'm now in my 3rd year of my English degree and I love it. Going back to university was the best decision I've ever made."

Sent in by Natalie Thurston

Fred Suter, (BA (Hons) Modern Languages – University of Southampton), wrote the following article about his experience at university for a Disability Rights UK publication...

CASE STUDY

Being deaf might seem a huge hurdle and studying languages an even bigger one.

On the academic side of things, such as finding different pathways for listening exercises, it may be a bit of a challenge sometimes. However it is definitely far from impossible as many might think. With the support of my tutors and especially the disability team here, everything is done to ensure that my university experience matches the one of a hearing student.

From my Disabled Students' Allowances (DSAs) any extra equipment which I require at university, such as a printer or specific books, are paid for by Student Finance. This is important as I rely more on sources which I can read than the average student.

The greatest piece of support is Remote Captioning. Thanks to this system, I manage the biggest hurdle, which is communication. I even wish I had this service 24 hours a day! I can read from my laptop screen every word being said in the classroom, just like subtitles, milliseconds after it is said. I feel totally equal to the other students.

Of course this support doesn't just fall into my lap, what I do is work actively together; help sort out things where I can. And this also counts for other kind of support that I get.

"I feel totally equal to the other students"

I am open to discussing needs with tutors and the disability team, searching for the best equipment available and handing in signatures quickly when required. I think that way I benefit from it in the best way possible, because what goes around, comes around.

Of course university isn't all positive. It hurt to see students from my corridor in halls making friends in the first week but hardly ever knocking on my door. I kept telling myself at the beginning to stay calm and that it takes time, and I think I was right.

While others may make their friendships really quickly, I need to find the people who are worth it and who I want to go into deeper relationships with and I am surprised how quickly that actually happened. I already have my social circle built and I can't wait for my second year!

"I can absolutely recommend having the courage and taking the step towards university"

I think if you are deaf, you are much more in charge of yourself. You have to take the first steps and that can be pretty challenging because deafness no doubt causes a lack of confidence. But if you build the larger part of the bridge towards other students, work closely together with the people who want to help you, then it is worth it and I can absolutely recommend having the courage and taking the step towards university.



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Thank you to Natalie and Fred for sharing their experience of university with us.

Question Time will be back in the next edition of the newsletter. Please send in any questions you may have on living with NF2 to juliedking@tiscali.co.uk for inclusion in the next newsletter. All questions and answers can of course remain anonymous.

Almost 200 people gathered on Sunday 22nd July to celebrate the wonderful life of Joe Guglielmi at St Peter's Church, North Hill, Colchester. Joe was an inspiration to all around him, and brought joy into people's lives with his kindness, laughter and passion for living life to the full. Joe faced the adversity of his life with Neurofibromatosis Type 2 with great courage and he was always incredibly positive and fun-loving, full of energy and love for his family and friends.

Despite being completely deaf for most of the last decade, Joe never came across as deaf to many people he met. He had an amazing ability to connect with people, whether on one of his many exciting holidays, down the pub watching football or supporting other young people with NF2. Coupled with an extraordinary ability to lip-read, this meant many people didn't fully realise the extent of his condition.

One side of Joe's face was paralysed as a result of his NF2. One of the effects of this is that he usually had to drink through a straw. Over time, the drink in question graduated from Coke to Budweiser, onto Guinness and recently onto Champagne. Joe undoubtedly could have represented Britain for his ability to drain a can of Guinness through a straw. Another of Joe's passions was food; a Big Mac at McDonalds, a Simply Outrageous ice-cream sundae at Sloppy Joes, one of his dad's mixed grills, or one of his mum's cooked breakfasts.

Technology played a big part in Joe's life, particularly after he was diagnosed with NF2. He loved playing on his Wii and PlayStation 3 with his communicator guides. Facebook was also a big deal to Joe. With face-to-face communication sometimes being difficult, he loved chatting to people online, and would be genuinely thrilled when people took the time to chat to him.

Another of Joe's passions was Manchester United, of whom he was a committed supporter until the end. Some of his favourite times in recent months were spent down at Yates's or Riley's watching matches.

Joe had the loudest, most infectious laugh – and he really loved to laugh. At the Odeon in Colchester, Joe was a regular at the subtitled performances, and would invariably end up in convulsions of laughter - even at films that really weren't meant to be that funny.

Joe has proved to be an inspiration through his work with The Neuro Foundation and Hearing Concern LINK.



Over the years, he and his mum have actively supported young people and their families who had been newly-diagnosed with NF2. Many of those who Joe helped have said how he gave them hope, and how his courage and fighting spirit was a huge source of inspiration for their own futures. Last year, Joe and his Mum were invited to a garden party at Buckingham Palace, in recognition of their work.

We've had nine amazing years with Joe since he was first diagnosed with NF2, living life to the full. It is ironic that Joe has left us at one of the happiest points in his life. But in many ways, Joe is still with us – watching over us and sending us a virtual hug when we need one. He lives on in our memories and stories, and in what we have become because of him. So when you log on to Facebook, when you see Manchester United on top form, when you see someone laughing hysterically in the cinema – remember Joe, and his affection, his huge bear hugs and his laughter. Remember how courageous and stubborn he was in the face of adversity. And remember how amazingly happy and content he was, and how much joy he brought to our own lives.

Taken from a tribute to Joe, written by his brother Tom and mother, Lynda McFaull.

Joe's family have set up a fund on Just Giving, 'In memory of Joe Guglielmi', which The Neuro Foundation are using to support other youngsters with NF2. It stands at over £4000 already. Tom and Anna, Joe's sister, are running in next year's London Marathon in their brother's memory, and we all wish them the best of luck.

NF2 Patient Carer Day - Manchester

A patient's perspective

This was the first Manchester NF2 day so we did not know what to expect but, from start to finish, the day was fantastic... I would like to thank all who were involved in making it happen, including speakers, facilitators and organisers.

We arrived early, (had a very good journey up the M6, no queues!), so helped set up some of the stands that were on display. There were stands from Hearing Link, The Neuro Foundation, Voice Recognition software and Children With Tumours, all of which had lots of information and people who could answer any questions that were asked.

The day officially started at 10am with registration and coffee, which gave time to chat with old friends and new. The first session was Natalie Thurston, an NF2 patient, talking about her experience of life with NF2. Her talk was very good and uplifting. Natalie showed that, without ignoring NF2, it is possible to focus on the positive aspects of life.

This was followed by workshops, one for the people who had NF2 and one for their friends/family members. Actually, there were two 'NF2 groups' – one for the young people, one for the older ones. People who had perhaps considered themselves reasonably young beforehand got a bit of a wakeup call here! These workshops were a time to feed back to the professionals any thoughts (positive and

negative) about how the NF2 service is run and how it could be improved.

Next on the agenda was lunch and chat. The afternoon began with a presentation from Professor King, Consultant Neurosurgeon from Manchester Hospitals. He gave a very good overview of the current NF2 service and how it has evolved and developed since it started, back in the 1950's.

This session was followed by an Expert Panel question and answer time. The panel consisted of a Geneticist, (our very own Gareth, no less!), a Neurosurgeon, an ENT surgeon, an NF2 nurse and an Oncologist. The panel answered our questions openly and honestly and it was a very helpful session.

Overall, it was a very positive day and a good opportunity to meet with other families who are affected by NF2. Research into treating NF2 is progressing, slowly but surely. Despite frustrations, for medics and patients alike, that there is not yet a cure for NF2, things are looking more positive.

In closing, I will borrow something from Professor King's presentation (I hope this is not plagiarism!). His final slide showed a picture of an orange. Most of us were probably thinking, "Why"?!

His explanation, "Because the future is bright..."

Sent in by Emily (and Steve) Owen

NF2 Weekend 2013



After generous sponsorship we are very pleased to announce that we will have a residential weekend for all those affected by NF2 in 2013. Dates have now been booked and will be 13th - 15th September. Once again we will go to the Double Tree by Hilton Hotel, Sheffield which provides extremely well for people affected by NF2. As soon as we have more information about speakers and our programme for the weekend we will let you know.

In the meantime if you are interested in signing up for the weekend please contact the Head Office on hazel@nfauk.org or call **020 8439 1234**.

Paralympics

What a wonderful summer – well not the weather but at least we had the Diamond Jubilee, the Olympics and Paralympics to distract us from the incessant rain.



If you were glued to the screen and watch the Paralympics you may have seen the USA wheelchair rugby team and in particular, one of its stars, Derrick Helton, who has NF2. Their team did really well beating France 70 – 44 and Japan 53 - 43 winning the bronze medal for their country. Many congratulations to Derrick Helton and the rest of the team!

Great picture Derrick - you should be very proud!

iDID & beyond... Digging deep for an adventurous streak

My name is Susanne Rees and I was diagnosed with NF2 at the age of 19 following neck pain. At the time of diagnosis, I didn't have any hearing problems or balance issues so it was a complete shock to discover that I had a genetic condition when I had grown up 'healthy'.

As with most people living with NF2, I have undergone various surgeries and have been poked and prodded every which way. The biggest impact NF2 has had on my life is when I lost my hearing. Before then, I was very adventurous and enjoyed pursuits such as rock climbing, canoeing and skydiving! After I became deaf, I became very withdrawn and I stopped taking part in anything like that. I have always been a very positive person and I became frustrated that I was beginning to feel sorry for myself; I decided I was going to start facing my fears and get my life back on track.

My first step was deciding to go to college so I could get some qualifications to head to university. At university, a friend of mine asked me if we could go climbing together. I had previously been told that I could no longer climb because I was deaf, and had accepted this as a fact. I told my friend who, in a not so polite way, didn't agree and we set a date to give it a go. It was a real pinnacle moment (excuse the pun) in my life. I began to climb regularly and found it helping my balance issues. I wanted other people who were deaf or disabled to have the same opportunity and after doing some research, it was an area in sports that was seen as massively inaccessible for people with disabilities.

After meeting some amazing people, all of whom had different disabilities, I set about with an idea for a website to show people how and where they can access sports. The website would be an information portal for professionals and individuals, and the aim was to support both sides equally, to create more opportunities and increase deaf and disabled participation.

As the idea developed, so did the services and iDID Adventure was born. iDID is a social enterprise aimed at improving physical and mental health through access and participation in adventure sports. iDID specialise in inclusive events and adventure programmes for deaf and disabled individuals in activities such as Rock Climbing, Watersports, Snowsports, Horse-Riding and Urban Sports.

iDID was established in 2011 and has been supported by the Young Foundation and University of Northampton partnership. Since launching, iDID has successfully held events in Surfing, Wakeboarding, Rock Climbing and Skiing with an indoor skydiving event coming up in January 2013.



We've even had some NF2er's involved!

As the director, I have to regularly overcome issues as a result of NF2, such as using the telephone, conducting meetings, managing my hospital appointments, fatigue and also taking part with balance difficulties. With support from access to work and a little (that's a lie, a BIG) gulp of confidence, I now am comfortable with my role and the management of it.

For all of you that are dubious about how you might take part in these activities, check out the website www.ididadventure.co.uk. Have a look around and read blogs from people with a wide range of disabilities that have taken part. It is a common misconception that these sports are for the super elite!

Having NF2 can sometimes be scary and lonely and the fear or getting out of your comfort zone can sometimes take over your life. My biggest advice to people is, if there is something you want to do, whether it is going horse riding or to the shops on your own; be brave, face your fears... if you can handle surgeries and life with NF2, you can definitely handle facing your own fear.

I am a bit of a geek and love a goof quote. One of my favourites comes from Eleanor Roosevelt:

"You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You must do the thing which you think you cannot do."

Sent in by Susanne Rees, Director of iDID.

Hearing Loss Research

Action on Hearing Loss have announced the results of research that could bring a cure for deafness a step closer.

“We are really excited to be able to tell you about a great piece of research we’re funding at the University of Sheffield. Researchers from the university have used human embryonic stem cells to restore hearing in a common form of deafness. As well as proving that stem cells can be used to repair damaged hearing, it is hoped

the breakthrough will lead to new cell-based therapies in the future for some forms of deafness. Read our press release for more details and let us know what you think!

<http://www.actiononhearingloss.org.uk/news-and-events/all-regions/press-releases>.

Once in the Press release section check out the article on the human stem cells dated 12 September 2012

Hearing Link Programmes for adults with NF2, their families and friends

We are delighted to let you know about some of the programmes Hearing Link run for families with NF2. Their friendly residential specialist programmes help people with Neurofibromatosis Type 2 and their families adapt to hearing loss and equip them with skills and information to help them cope. On the programme you will learn new skills, develop your confidence and learn to manage the emotional and practical challenges brought about by acquired profound hearing loss. Partners, children, parents and close friends will improve their understanding of hearing loss and learn ways of coping with it themselves. The programme covers: lip-reading, relaxation, coping strategies, communication techniques, family relationships, implants (cochlear/auditory brainstem), balance, tinnitus, employment, assistive equipment, and other topics relevant to the group. There is also a social event to help people to get to know each other outside of the timetabled sessions.

There is a wealth of further information on their website pages - here are some of the relevant links:

- General information page about the NF2 programme: www.hearinglink.org/nf2programmes
- Frequently asked questions about the programme: www.hearinglink.org/nf2programmes/faq
- Communicating in a group: www.hearinglink.org/communicationgroups
- Apply for a programme: www.hearinglink.org/intensiveprogrammes/apply
- Find out what previous participants have said about their time on the programmes via their new Facebook group: www.facebook.com/hearingLinkIntensiveRehabilitationProgramme

Their home page changes theme on a weekly basis. www.hearinglink.org

Useful Smartphone and other Platform Apps



For all of you Smartphone, tablets and PC users out there, one of our Specialist Advisor's, Helen Tomkins, has made us aware of a couple of useful apps which may be of interest.

The first is '**Tango**' which is free to download and it is similar to Skype but for mobiles i.e. free video calls if you have a wifi connection. This could be a useful communication tool and an aid for sign language perhaps.

The other app is called '**Whatsapp**' and is available for 69p to download. This app provides a quick way of communicating back and forth via typed messages and photos.

If you have any other tips or useful apps to share with our readers please contact info@nfauk.org or call **020 8439 1234**.

The Ellie Bracelet

Isn't this a cute bracelet?

It has been created by Vikki at Blingery in honour of Carly Jim's daughter, Ellie who has been diagnosed with NF1.

They cost £5.00 each plus p&p and here's the good bit - £2.00 from every sale will be donated to The Neuro Foundation. www.blingery.co.uk



Many of our newer members may not have seen some of Doctor Sue Huson's Question and Answer information that we used to publish in our Newsletter. We have a selection of some of the Q&A's based on typical questions we often get asked at the Head Office.

Is epilepsy common in NF1? Are there special precautions which should be taken?

Epilepsy and seizures are relatively common medical problems in the general population; all of us have a risk of just under 2% of developing epilepsy by the age of 40 years. In NF1 there is a slight increase of this risk to around 4%; this is for seizures with no obvious cause. Sometimes people with NF1 will develop seizures secondary to another NF1 complication such as a brain tumour or aqueduct stenosis. Both of these are rare complications.

Very young children with NF1 are also at risk of developing a specific kind of seizure called hypsarrhythmia- the risk is probably no more than 1%. As this often develops in the first year of life it can be the way the NF1 diagnosis comes to light.

There are no special precautions people with NF1 need to take with regard to seizures. There is no contraindication to the routine childhood vaccinations just because you have NF1; however, if your child has had seizures or any other neurological problem you need to ask their Doctor for advice.

Is it safe for a child with NF1/NF2 to have the usual childhood vaccinations?

This is straightforward. There are no special rules that need to be considered for a child with any form of NF when vaccination is being considered. In other words, there is nothing about NF which would preclude a child from having a vaccination.

What should I do if I don't feel my Doctor is taking my NF1 seriously?

This is a question people often ask me in clinic or when I talk to family groups. When I first started working on NF (over 25 years ago) we were very cautious when talking to families about the severe aspects of NF1 and NF2.

As the years have passed things have changed, Doctors are less paternalistic, and lots of people have access to information on the internet and through charities like the

Neuro Foundation. I have become convinced that people with NF should have as much information as they want about their diagnosis. A common situation now is for people to know more about NF than their local doctor. A good doctor will always take what you are saying seriously but some will still ignore the significance of the NF background when assessing particular symptoms.

For those of you under an NF clinic it is straightforward: your clinic doctor will want you to contact them directly. If you are asking your GP and you don't feel they really understand about NF, then it is good to check out your worries with the Helpline or one of the Specialist Advisors. They will be able to help you take things forward.

What are the current recommendations for eye checks in NF1?

Five per cent of children with NF1 at most will develop visual problems due to an NF1 related tumour called an optic nerve glioma. The usual problems they cause are decreased vision, a loss of colour vision, a squint or one eye being more prominent than the other. They most frequently cause problems up to the age of seven - exactly the age when we can't rely on children to complain of visual problems.

For this reason we recommend all children with NF1 have an annual check with a Paediatric Ophthalmologist until they are past their seventh birthday. After this their vision can be checked as part of their annual NF check.

If anyone with NF1 develops visual problems it is always important to mention the NF1 to the Doctor you are seeing.

The most common eye features of NF1 are the Lisch nodules - small brown coloured swellings on the iris (coloured part of the eye) - these never cause symptoms.

Is it safe for girls with NF1 and NF2 to have the new vaccine for cervical cancer?

The short answer to this is YES. People with any form of NF can have any kind of vaccine providing they are well otherwise.

*Dr Sue Huson,
St Mary's Hospital, Manchester.*

Some of our recent fundraising and awareness events

Once again we have been amazed by all of your fantastic fundraising efforts.

We would like to say an enormous thank you to all those who have so kindly given up their time to help the work of the charity, supporting those affected by Neurofibromatosis. Thank you!

Here are just a few of those events.

JULY

Idle Trail Race

The 10 km Idle Trail Race took place on July 29th 2012 along the Leeds Liverpool Canal in Bradford and was a great success. This was a scenic race along towpaths, bridleways and private road. The Neuro Foundation would like to say a BIG thank you to Dixie from Real Radio, Yorkshire for coming along to present the prizes. The picture shows Davina Smith, one of the Trustees of The Neuro Foundation with Dixie and Julie Parker-Heys.



Awareness Day in Ayr

Yvonne Keirs Don, together with family and friends spent the 15th July bag packing and raising awareness about NF at Asda in Ayr, Scotland. Thanks Yvonne. Hope you enjoyed the day.

Birchwood NF Group

Where do we start with all of the fundraising activities organised by Sue Harrison and the Birchwood NF Group? Sue's fundraisers have included climbing Snowdon, raffles, a zumba party, sponsored walk, musical evening etc.. On behalf of The Neuro Foundation we would like to thank you very much for all of your amazing efforts.

Golden Sands Charity Garden Party

Another one of our amazing fundraisers is Patricia Nicholas and the Golden Sands Charity. We heard that the garden party held in memoriam of Bill Goode was a terrific success raising an amazing amount of money for The Neuro Foundation. We are enormously grateful to all involved. Your support of the charity is much appreciated.

Cumbria and District NF Group

Hannah and her family are longstanding supporters and fundraisers for the charity. Check out the lovely photo of Hannah Tucker presenting a cheque to Richard Taylor, Chair of The Neuro Foundation at the AGM and Open Day on Saturday 7th July. Thanks from all the staff on behalf of the charity.



Corpus Christi Catholic Sports College

Jonathan Renwick raised an amazing amount of money by selling decorated notepads at his school, Corpus Christi Catholic Sports College and the school donated some additional funds.

A huge thank you to Jonathan and his school. We are most grateful.

AUGUST

Fourth Annual Charity Bike Ride Port Talbot

The Fourth Annual Charity Bike Ride at Afan Argoed on 4th August was a great success. Sheila And Clive Owen, who organised the event, tell us that they had their best ever attendance with 54 riders ranging in age from six to sixty three and everyone completed the sixteen mile course.



The ride incorporated two routes, depending on experience, and started from The Cwmavon Community Centre and was a big success. Thanks to Sheila Owen for organising the event. What an amazing day.

Odiham Jazz Weekend

The Odiham Jazz Weekend was held on 25th & 26th August at Odiham Chalk Pit. There was a Jazz Party & Picnic on Saturday evening and then Jazz & BBQ on Sunday lunchtime. The event was a huge success. Many thanks once again to the amazing organisers.



Rock the Rovers

Rock the Rovers at Kitty's and Kandy, in Kircaldy was held on Sunday 26th August. Organised by Raith Rovers FC supporters,

this one-day event saw twenty bands playing across two stages, under one roof over 12 hours. Money raised went to support various charities, including The Neuro Foundation this year. Many thanks to the organisers on behalf of The Neuro Foundation.

Waitrose

A big thank you to all of the shoppers at Waitrose in New Malden, Surrey who selected The Neuro Foundation as the charity of the month. We are very grateful.



Another Lands End to John O'Groats Challenge

Jeff Davis and Ian McKay set off from Lands' End on 18th August for their journey by bike to John O'Groats. After ten days on the road and with almost 1,000 miles behind them, they made it!

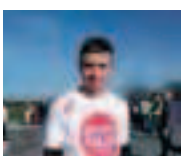
Many, many congratulations to Jeff & Ian and huge thanks to Robin for the daily weather and traffic updates from base camp, and also to Joy, Julie, Jill & Jo who sounded like an ace support team! You should all be feeling very proud of yourselves. A big vote of thanks from The Neuro Foundation!

SEPTEMBER

Thames Path Challenge

The Thames Path Challenge on 29th-30th September really does live up to its name! Participants are challenged to walk either 50k in 12 hours or 100k in 24 hours and Clair Nicholls decided to enter the 100k walk to raise funds for The Neuro Foundation - thank you Clair!

Even knowing the organisers said "The Thames Path Challenge is an iconic route along one of London's most scenic geographical features but it will take a feat of endurance, stamina and determination to push yourself across the finish line and complete the challenge", Clair still took up the challenge! This is what she posted just after finishing "Finally crossed the finish line! Wailing like a baby from the second I saw the finish line! 24 hours, 48 minutes!!" Wow. Well done Clair, you should be VERY proud of your achievement.

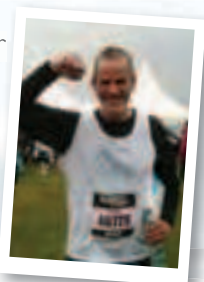


Robin Hood Half Marathon

Thank you to Daniel Taylor who ran in the Robin Hood Half Marathon. What a fantastic achievement.

The Great North Run

Huge congratulations to the amazing people who ran The Great North Run for The Neuro Foundation on Sunday 16th September - well done and thank you everyone; you are an inspiration to us all! Also many thanks to everyone who went along to watch and cheer - your support for The Neuro Foundation is invaluable.



Coleg Gwent Fundraiser

David Roberts, CBE and Paralympian Gold Medallist, recently visited Coleg Gwent in Newport to accept a cheque on behalf of The Neuro Foundation. David, who has won eleven Gold Medals for swimming at three Paralympics, in Athens, Sydney and Beijing answered questions from students and brought along the Paralympic torch that he had carried over London Bridge this year, as part of the London Games.



Students and staff had organised a host of events as a fundraiser for The Neuro Foundation, a charity that they had studied during the year. David said that he was

particularly delighted to be able to represent The Neuro Foundation as he has a close friend with the condition.

Congratulations to Victoria and all those involved in the fundraising and thanks to David for being our ambassador on the day.

Swansea 10k

A team of eleven friends from Bridgend ran the Admiral Swansea Bay 10k race on Sunday 23rd

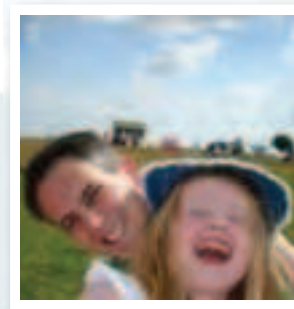


September. Aaron, Becky, Caroline, Chris, Eluned, Fred, Jack, Luke, Matt, Matthew & Mike ran in support of their friend, Jonathan Bennetta who has NF2. We are delighted that the money raised by his friends in the race will go to Jonathan's chosen charity, The Neuro Foundation.

Despite truly awful weather conditions they did it. Jonathan said after the race "It was fantastic to see everyone do so well on Sunday. Everybody gave it their all and I'm really proud of their efforts." Thanks to the fab team and to Jonathan on behalf of The Neuro Foundation.

Berlin Marathon

Congratulations to Andy Case who completed the Berlin Marathon on Sunday 30th September in a fantastic time of 3:58:19 - well done and thank you so much



for supporting The Neuro Foundation! Check out Andy's page to see why he decided to set himself this challenge <http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserProfilePage.action?userUrl=BerlinMarathon2012>

Some of our recent fundraising and awareness events

OCTOBER

Jeans for Genes Day 2012

We were amazed just how many of our members and supporters joined in Jeans for Genes day on Friday 5th October.



The Neuro Foundation is delighted to have been chosen as one of the charities to receive a grant from Jeans for Genes this year which will go towards running our very valuable telephone helpline, so your support on the day was terrific.



Adam Pearson, who many of you will know, is a Patron of Jeans for Genes this year, and in that capacity spoke to students at Fairfield High School in Horfield near Bristol recently.

Above we have a great photo of Joseph and Katie Smith - they made crispy and cornflake cakes as part of Jeans for Genes Day at Idle Primary School.

Jeans for Genes Day was F-A-B-U-L-O-U-S! Thank-you.

Sponsored silence

Amelia and Kian had a big challenge ahead of them on 5th October - a sponsored silence! Did they succeed? Judging from the giggles in this photo we thought it just might be a little difficult. But they did it. Well done to Amelia and Kian who completed their silence and raised an amazing amount of money for The Neuro Foundation.



Check out the link to see why they, and Mum, Jade Kinsey are supporting The Neuro Foundation; <http://www.justgiving.com/Jade-Kinsey>

Fun night at Meadhurst Leisure Centre, Sunbury

Clare Schauerman organised a Fun Night at Meadhurst Leisure Centre in Sunbury as a fundraiser for The Neuro Foundation.

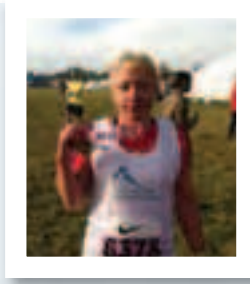
There was music, a raffle, balloon release and most alarmingly for those concerned, sponsored mens waxing!

The girls in the office thought this was a fantastic fundraising idea. Thanks Clare.



Windsor Half Marathon

If organising the Sunbury Leisure Centre day wasn't enough, Clare also took on the challenge of running the Windsor Half Marathon on 7th October. Well done Clare - your fundraising efforts are very much appreciated.



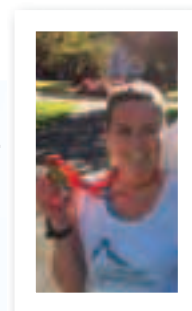
Cardiff to Kings Lynn Bike Ride

Mick and four friends set off from Cardiff to cycle to Kings Lynn on 9th October taking four days to complete the ride. The Neuro Foundation is one of five charities that will benefit from their challenge - thanks guys!

Cardiff Half Marathon

Congratulations to Ellie Jones who ran the Cardiff Half Marathon on 14th October for The Neuro Foundation. Ellie managed a personal best time too!

Check out Ellie's page <http://www.justgiving.com/Elinor-Jones2>. A big thank you from The Neuro Foundation.



Peterborough Family Fun Day



On 20 October the Orton Goldhay Community Centre was the venue for A Family Fun Day. There was a lovely selection of stalls, together with a raffle, tombola and bouncy castle not to mention delicious refreshments - sounded like a good afternoon! Plus, we are delighted to hear that The Neuro Foundation and Papworth Hospital were both beneficiaries of the day.

BUPA Great South Run

Anthony Bridgeford, and other members of the 68th Portsmouth Scout Group ran in the BUPA Junior Great South Run on Saturday 27th October. Many congratulations and thanks guys! Fab photo of Anthony wearing his medal - and his Neuro Foundation t-shirt, of course!



Neurofibromatosis Well-being Research Group - 15th February 2013

Research Institute for Health and Social Change

Elizabeth Gaskell Campus, Manchester Metropolitan University, Manchester, UK

The Neurofibromatosis Well-being research group at Manchester Metropolitan University is proud to present a one day knowledge exchange event on the genetic condition Neurofibromatosis. This event is on the 15th February 2013 at MMU, Elizabeth Gaskell Campus.

This is a free event open to anyone with an interest in Neurofibromatosis and is particularly suitable for GPs, community paediatricians, health visitors, nurses, teachers and all allied health professionals.

People with Neurofibromatosis are also warmly invited to attend. Please note this event is not suitable for children.

This one day event is presented in two halves with the morning sessions being more medically orientated and the afternoon sessions presenting the experiences of people with Neurofibromatosis and talks from Neurofibromatosis charities. The hall will also be open throughout the event with visual displays and information stands.

It is essential to register for this event. Registration is through an online booking system which can be found at the following web address

<http://nfwellbeing.eventbrite.co.uk>

When registering for the event please indicate if you are registering for the morning, afternoon or full day.

The programme of activities is as follows –

9.00	Registration opens for morning and full day delegates
10.00 - 10.30	Dr Carly Jim welcome and lay background to Neurofibromatosis
10.30 - 11.10	Dr Sue Huson Neurofibromatosis 1 (NF1)
11.10 - 11.40	Professor Gareth Evans Neurofibromatosis 2 (NF2) and Schwannomatosis
11.40 - 12.00	Coffee Break
12.00 - 1.00	Neurofibromatosis research update (short presentations)
1.00 - 2.00	Lunch Break
1pm – Registration opens for afternoon delegates	
2.00 - 3.00	Talks from people with Neurofibromatosis and Q and A session on their experiences
3.00 - 3.20	The Neuro Foundation Charity and their Specialist Advisors
3.20 - 3.40	The Children with Tumours Charity
3.40 - 4.00	Coffee Break
4.00 - 4.40	Ask the Doc Neurofibromatosis Q and A session with Dr Sue Huson
4.40 - 5.00	Dr Carly Jim thanks and conference close

New Website



We are delighted to let our members know that, thanks to the very kind donation of her time and expertise, one of our members, Carole Broster, working in collaboration with Optima Graphic Design Consultants Limited, has been instrumental in helping us to prepare to launch a brand new website. We are very excited by this new development. We

will be making an announcement early 2013 on our Facebook site and website to let you know the launch date.

We would very much like to include a section/page on our brand new website on gizmos and gadgets that our members have found useful and would like to recommend to someone else who may benefit from them. One brilliant example we heard about was The Boogie Board LCD Writing Tablet – basically the modern day 'Etch-a-Sketch' with a practical twist which has proved extremely helpful for people with NF2 who are affected by hearing problems. We told you all about it in the last NF2 Newsletter and now our Specialist Advisors are all equipped with them for visits to patients affected by NF2.

If you have any tips, recommendations or ideas of new gadgets we would love to share them. Please send by email to info@nfauk.org or call the office on **020 8439 1234**.

We look forward to hearing from you.



Christmas Appeal

In our efforts to increase the support and help we can offer to people with Neurofibromatosis, our aim for the future is to expand our network of Specialist Advisors. Each advisor supports up to 500 patients a year. Their extra-ordinary support ensures that the experience of living with NF is less isolating and stressful and enables children, young people and adults to take control and make the most of their lives.

Their day to day roles include:

- Emotional support for all those affected by the condition
- Provision of accurate and up-to-date information for individuals, families and professionals
- Liaising with health, education and social services to ensure the best practical help and support is available to a person living with NF
- Provide guidance on problems with education and advise teachers about the difficulties facing a child with NF and how best to overcome them
- They can also help people to make informed choices regarding difficult decisions about treatment, such as whether to undergo risky surgery to remove a tumour which is causing major health problems
- Sign-posting individuals to other organisations that can assist with specific issues
- They are an on-going point of contact for people as they deal with the day to day realities of living with NF.

We rely on the generous support of our members and supporters to help us in our mission to maintain the current network of advisors and hopefully be able to recruit more around the country to continue their amazing work.

Your kind donation will help us make a difference.

If you would like make a donation please complete the tear-off section and send to the address below.



I WOULD LIKE TO HELP THE NEURO FOUNDATION BY DONATING THE SUM OF £

I would like to become a member of The Neuro Foundation and enclose payment of:

Family membership £ 22 Individual Membership £ 15 Other membership types are available on request including Life Membership

You can forward a cheque made payable to The Neurofibromatosis Association or alternatively we can accept payment by credit/debit card:

Please debit my card number: _ _ _ _ / _ _ _ _ / _ _ _ _ / _ _ _ _ Issue Number _ _ _ _ _ Start Date _ _ / _ / _

Expiry Date _ _ / _ / _ Security Code _ _ _ _ Date _ _ / _ _ / _ _

First name Surname

Address

..... Post Code

Tel no.

Email



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If you are a UK taxpayer, under the Government's Gift Aid scheme The Neuro Foundation can claim the tax you have already paid on your gift. This means that your donation can increase in value by at least 25% at no extra cost to you. You must pay UK income tax or capital gains tax equal to the tax we can claim on your donations.

Signed

Date

CONTACT DETAILS

Quayside House, 38 High Street, Kingston Upon Thames, Surrey, KT1 1HL

Tel: 020 8439 1234 Fax: 020 8439 1200

Email: Info@nfauk.org (use for general enquiries) fundraising@nfauk.org (use for all Fundraising enquiries).

Website: www.nfauk.org

With heartfelt thanks to all of you who have donated to The Neuro Foundation