

Chairman's Update

Dear Friend

You will be aware that Charities across the Country are struggling to maintain revenue streams in this unprecedented economic climate. Where in previous years it has been possible to generate income from a broad portfolio of fundraising initiatives and activities, today this is simply not the case. The consequence being that hundreds if not thousands of Charities in the past 3 years have been forced to cease operating.

Fortunately the Neuro Foundation is not in this position however it has not been without its difficulties and has not been exempt from recessionary challenges.

In an attempt to mitigate this position we have recently increased our fundraising activities across a broad range of initiatives. These included requests to members for more financial support, the submission of many grant applications to Trusts and Foundations, approaches to wealthy individuals and the exploration of increased corporate support. Despite this our financial resources have declined and we see little likelihood of the situation improving in the foreseeable future.

It is the primary responsibility of the board of trustees to act in a way that protects the financial viability of the Charity. That requires prudent financial management and particularly in the area of expenditure control. We have consciously reduced our outgoing expenses this

year to reduce the burden on our balance sheet, furthermore we have carefully considered our long-term commitments to ensure we protect the investment we make in the core activities that deliver our charitable objectives. However these controls have not been enough to secure the stability of the Charity.

As we draw close to the end of the financial year the Charity finds itself facing a significant and unacceptable deficit and we must now take action to minimise its impact.

We have reconsidered our financial position and decided to reduce our costs further. After careful consideration and with great regret the board has decided to make the role of CEO redundant within the Charity. This personally affects Lindsey Rennard our current CEO and it is with great regret that I inform you of Lindsey's departure from the Charity effective from 17th December 2011.

Lindsey has achieved a great deal in her time at the Neuro Foundation and we are very sad to see her leave the Organisation. I would like to extend my thanks to Lindsey for all she has done and to wish her well in her future career aspirations.

The board of trustees is committed to the long-term success of the Charity and has agreed an approach which will ensure Lindsey's responsibilities are shared amongst the board.

This will include the management of the staff and office in Kingston, oversight and

Chairman's Update continued:

development of the website, ongoing financial control, production of the newsletter and most importantly communication with members, advisors and medical professionals.

Plans to hold the NF2 weekend in May 2012 and the Medical Research Update meeting in conjunction with the AGM in July remain in place and we are committed to ensuring they are the most successful ever.

The future is in our hands and we must continue to secure the services we provide to our beneficiaries. I urge you to consider how you might help us get through this difficult period.

Any suggestions you have are most welcome and of course any ideas of how we can secure income in this time of recession will be most gratefully received. Please contact me on the details below with any feedback or concerns you have, failing that you can contact any one of the trustees by requesting their contact details from the Kingston office.

My thanks to you for your continued support and please join me in securing a brighter future for all patients with Neurofibromatosis.

Kind regards

Richard Taylor, Chair of Trustees

About The Neuro Foundation**Our vision**

To improve the lives of those affected by neurofibromatosis

Our mission

Enabling people concerned about neurofibromatosis to find solutions appropriate to them

Our service

We fund a team of five specialist advisors based from Newcastle to Plymouth who provide practical, medical and emotional support, each reaching out to over 500 people a year

Website

Currently being re-developed; the current version contains a large amount of information and advice.

Telephone Helpline

Our telephone helpline is managed by our highly experienced neurofibromatosis specialist advisor Rosemary Ashton. She can give telephone consultations, practical and medical advice. Rosemary is available for consultations on Tuesday and Wednesday.

Support and Information

We provide a large range of literature for those affected by neurofibromatosis for a number of audiences, including patients, their families, medical and teaching professionals. A childrens range is currently being developed.

The team in the Kingston office are:

Karen Cockburn, Finance Manager, who works Monday and Tuesdays
Hazel Brannan, Marketing Assistant which includes membership and website enquiries, who works Monday, Tuesday and Wednesdays
Sarah Sinclair, Events and Fundraising, who works Tuesday and Thursdays

The Board of Trustees of the Neuro Foundation:

- Richard Taylor, Chair of Trustees
- Anne Bonnar, Vice Chair
- Mike Mills, Treasurer
- Dr Sue Huson
- Di Ollis
- Markus Gilges
- Stewart Lee

Nicole's trip to an NF Camp

The Neuro Foundation has been delighted to award several grants this year where it can be demonstrated the grant will have a significant impact on a person's personal, health or social education. One such grant was to 14 year old Nicole, who has NF1, funding her travel to an NF camp in the USA. Here is her story of the camp.

When I found out that I could go on the NF camp in Utah America I was very happy and excited because I was going to meet children my own age that had the same condition as me.

I flew to Canada with my mum and then took a flight on my own to Salt Lake City. It was the first time I had flown on my own and visited another country on my own. I felt very excited but a little bit nervous as I didn't know how to find my plane but I managed it. I was met by some of the counsellors at Salt Lake City Airport who made me feel very welcome. We drove to the camp where I was shown our cabins and we had lunch, I then met with the other children on camp.

We did lots of exciting things, like horse riding, swimming, fishing, rock climbing and we had days

out to the zoo, theatre, cinema and mini theme park. Some of the children found some of the activities difficult but they were adapted to make it easier. Everyone encouraged everyone else.

I made lots of new friends from Canada and America. It was nice to meet children with similar challenges as me, but for the week we all had a good time. Everybody understood each others difficulties and no one was horrible to anyone. It was so nice to feel I fitted in. I was very relaxed. Everyone understood each other as we all had the same condition.

We had a visit from an NF Specialist who answered our questions about NF and asked us questions about how NF affected us. He was very nice.

I would love to have a camp in the UK as I would love to have friends with NF that I could visit more often.

Nicole's mum, Vanessa, is investigating organising an NF camp in the UK on Friday 20-Sunday 22 April 2012 and would love to hear from anyone who may be interested - her email address is vanessa66@tiscali.co.uk

**The Neuro Foundation would like to invite you to:
A Residential Weekend for all those affected by NF2**

Venue: DoubleTree by Hilton Hotel at Sheffield Park, Sheffield, S8 8BW
 Date: Friday 18th - Sunday 20th May 2012.

Speakers include Mr Patrick Axon, (Consultant ENT Surgeon) speaking on "The timing of VS Surgery in NF2"; Dr Gareth Evans (Consultant Clinical Geneticist) - "Latest drugs review for NF2" and Dr Sue Huson (Consultant Clinical Geneticist) giving an overview of the NF2 service.

Fun evening events are being organised and hosted by the Entertainments Committee. For further information and a booking form, please visit our website www.nfauk.org or contact Hazel Brannan on 0208 439 1234 or hazel@nfauk.org

Learning and behaviour in NF1: An update on our research study

Annukka Lehtonen, Shruti Garg, Jonathan Green, Dorothy Trump and Sue Huson

Many of you are very well aware of the problems that children with NF1 can have with their learning and behaviour. We know from our clinic work that it can be a real challenge to get help for your children at school - as indeed many parents have written in this newsletter. We have just finished a study that looked at learning and behaviour in NF1. The previous studies in the area in the UK are Professor Ferner's study on thinking processes in adults and children with NF1 (in 1996) and Dr. Huson's study on behaviour and sleep in children with NF1 (in 2004). We wanted to do an up-to-date study that would look at both learning and behaviour.

The group of children who took part in this study were patients at the department of Genetic Medicine of St. Mary's Hospital in Manchester. This is a large department with a comprehensive coverage of the patients with NF1 within its geographical area - both patients who have only milder symptoms as well as those who experience more complications. This means that our sample could be described as population-based and gave us an excellent opportunity to look at the frequency of different learning and behaviour problems in children with a wide range of severity of NF1.

Our study aimed to define the cognitive and behavioural profile of children with NF1 in a population-based sample. We also wanted to get more information for our clinic work about how to pick out children who are likely to develop problems and how to best help these children. The study had two parts:

1. A questionnaire study focussing on behaviour in NF1 that included all children aged 4 and 16 years looked after by the Genetic Medicine department at St. Mary's.
2. A cognitive assessment study, for which we

invited 50 (randomly selected) children aged 6-16 years from the database at Genetic Medicine.

What did we do?

Questionnaire study

A set of questionnaires asking about children's attention, social communication skills and general behaviour was sent to all parents of children aged 4 to 16 years. The parents were asked to fill in the questionnaires and return them to us. If parents gave their permission, we also contacted the children's teachers and asked them to fill in similar questionnaires.

Cognitive assessment

We asked the children to do a series of different tasks that all had to do with different aspects of learning, such as attention, planning, memory, visuospatial skills, reading, spelling and maths. Doing the tasks took about 2.5 hours, and they were done either at the children's homes or at the hospital. We also asked 6-16-year old siblings, who did not have NF1 themselves, to take part in the study, because we wanted to compare how children with NF1 did in comparison to children who do not have NF1.

What did we find?

Questionnaire study

The parents of 109 children (53%) filled in the questionnaires. The children were on average 9 years 10 months old. The questionnaires showed that a considerable number of children displayed autistic symptoms and problems with social communication. This does not necessarily mean that these children are autistic, but that they have some of the associated symptoms. We also found that over half of the children had attention problems and more than half of the children had high rates of behavioural problems.

Fifty-three teachers (48%) returned the questionnaires. The pattern of the results was generally very similar to the parents' responses, although the teacher ratings were overall lower, suggesting that teachers perceived the children's behaviour as less problematic than parents do or, alternatively, children's problems may be more obvious in the home environment and to their parents.

Cognitive assessment

Fifty-one children with NF1 and 20 of their siblings took part in the study. The children and young people were on average 11 years old. The results show that children who have NF1 struggle with school subjects (reading, maths and spelling) more than children without NF1; almost two thirds of children with NF1 had problems with one or more academic skills, many of them with more than one area of academic performance. Children with NF1 also often had specific problems with their ability to concentrate, some aspects of their memory, visuospatial skills and learning. The two groups were equally skilled in recognising facial expressions and did equally well on a task measuring their spatial memory span.

What does this mean?

NF1 is extremely variable, and therefore not all children with NF1 have all of these problems. We do know, though, that many children and young people struggle with different aspects of learning and/or behaviour, and therefore it is extremely important to make schools aware of these problems, and for doctors treating children with NF1 to know what kinds of problems to look out for. There were quite a number of children who had problems in more areas than just one, and these children would require even more attention. It was interesting to note that oppositional behavioural problems were relatively uncommon, while inattention problems were frequent. This fits in with the clinic and parent observations suggesting that children with NF1 fail to attend

in the classroom, but do not usually disrupt the class either, so their problems are not necessarily noticed by teachers.

What is going to happen next?

We are now working with the Neuro Foundation to improve the information available for schools, colleges and universities about NF1. We are also publishing our results in medical journals to alert Paediatricians to the learning and behaviour problems in NF1.

Our research studies are continuing in two main areas. We are following up the findings from the questionnaires showing that some children with NF1 have autistic symptoms. Dr Garg, a trainee Child Psychiatrist, will be looking at this in more detail. We are also hoping to be part of a treatment trial looking at whether a drug called lovastatin helps the learning problems with NF1. We will know by Christmas if this will go ahead.

We would like to thank all the parents and children who took part in this study. None of this work could take place if families affected by NF1 were not so enthusiastic about taking part in our studies - your help is extremely valuable to us.

Cycle success

Many thanks to Clive and Sheila Owen, who organised a sponsored bike ride in memory of their son Ian. Despite awful weather conditions, 30 bike riders took part, all of whom completed the 18 miles cycle - and raised over £500 for the charity.



The Neuro Foundation is very proud of our team of specialist advisors. Here we present information on three of our team of five; information on the work of Susan Musson (Newcastle) and Carolyn Redman (Southampton) will follow in the next newsletter.

Rosemary Ashton - Telephone helpline



Rosemary with her new grand-daughter

I began working full time for the charity in June 1995 and was based in St Mary's Hospital Manchester. The area I covered was huge and all the towns seemed to begin with the letter "B".... Burnley, Bury, Blackburn, Beverley, Blackpool, Bodelwyddan.... This was in the days before satnav and I rushed all over the country trusting my maps, one eye on the lookout for a phone box if I had trouble finding an address (no mobiles then either!). I was always dashing here and there zooming along motorways never quite sure where I was going. I got there eventually, determined not to let someone down where I had promised to visit.

I knew very little about NF when I started and it seemed neither did anyone else, apart from the few specialist doctors I worked with in the hospital.

16 years on the situation has changed dramatically. I have worn out several cars travelling 20,000 miles a year. My hospital has been demolished and replaced with a state of the art site accommodating several major hospitals.

Manchester Foundation NHS trust has 2 NCG funded services for NF1 and NF2 and many many doctors and nurses working to support those clinics. Across the region there are a number of specialist NF1 paediatric clinics that ensure consistent care for all children with NF1. Everyone with NF can have access to specialist clinical care if this is needed. I feel the charity played a significant part in achieving these things.

In January this year I decided to take a step back from dashing around the country and now work from home 2 days a week running the Helpline for the charity and answering emails. I really miss the contact with "my" families who I have got to know so well over time, but it is good to hear familiar voices on the phone from time to time. It always surprises me to learn that children grow up so rapidly and are now working or going to college.

The Helpline gets many calls each week and they vary greatly. Some people have just had a diagnosis and are waiting for other appointments and want to know more in between times. They may have looked on the internet for information and found this upsetting and muddling. They want to talk to someone who "knows about NF" ...which I do. I get calls about children struggling at school and discuss ways to help and support them. Calls come in from parents and teachers about difficult behaviour and how to cope with this. I hear from doctors and other nhs professionals asking for advice and information. I post out or email lots of information. I speak to people who have worrying symptoms and are not sure what to do.

In between calls I am also starting to review our factsheets and writing new ones. All this information is checked by the Medical Advisory Board of the charity for accuracy and content. 2 new factsheets are now on the website and more are in the course of preparation. I am keen to ensure that people who have difficulty reading can access an "easy read" version of the NF1 information and this will appear on our website soon.

In spite of my changed role and no longer being the national team leader, I am still very much part of the charity's Specialist Advisor team. We do have occasional opportunities to meet up and hear the latest updated information and research about NF which is crucially important so we can be effective in our roles. The charity and people who support our work still need to achieve progress for patients and their families.

So what am I doing with all the extra time I now have? In one word: "Henry". I promised myself a semi-retirement present of a dog and he arrived last summer as a wriggling Vizsla puppy. My pride and joy garden has been flattened and dug up (not by me now). My furniture, cupboards and walls have all been "Henried" by teeth marks. My wardrobe has taken a downturn. Would I be without him now? Of course not! I fear I am turning into one of those people who say they don't know how they found the time to go to work!

Helen Tomkins - Devon and Cornwall



About Me

It is always a difficult task to write about oneself!! So I asked some of those whom I have been supporting what they would like to know about me so here goes:

What made you want to work with NF?

Working with NF has been a great opportunity and enables me to use my expanse of clinical skills.

I aim to be holistic in relation care provided to patients. As those of you who have NF will know it affects every one differently, everyone is unique. NF can have physical, social and psychological influences on an individual's life. I hope to be able to make a difference and help the life journey that individuals have with NF face that little bit easier. I think that the way to achieve this is to look at the individual's unique difficulties, skills and abilities with an encouraging approach towards care. Another great reason for working in this area is that I see there is a huge potential for developing things further, and increase awareness about Neurofibromatosis.

What are your qualifications?

My clinical background is that of an Occupational Therapist, I did my initial Occupational Therapy Degree at Oxford Brooks University, and then completed a Masters at Exeter University. I have completed a Post Graduate Certificate in Medical Education at the Peninsular Medical School. I also have Completed Post Graduate Training in various subjects including Family Therapy and Cognitive Behavioural Therapy. From reading this you can see that I do enjoy learning and try to keep up to date with developments in services.

What did you do before?

I am lucky to have a wide range of experience. Being an Occupational Therapist had enabled me to work in both Health and Social Care Settings with both Physical and Psychological illnesses. For the majority of my working life I have worked in the UK but I also spent two years working in the USA - this was a great opportunity but I could write for a long time about my experiences. Please do ask me if you want more details....

Could you tell me a bit about you and your family? When I am not working, I enjoy spending time with my family. I have two young children who are very active! I also have a number of pets including 6 Chickens (relatively new addition's to the family), 2 dogs and not forgetting "Nemo" the Goldfish.

Where are you based?

I have an office at Derriford Hospital. This enables me to work closely with the other Health Care Professionals who maybe involved in an individuals care.

How are you finding working with NF?

I am really enjoying working with individuals who have NF, I have met some wonderful, inspiring people since starting this job and am looking forward to the prospect of continuing to develop the service further.

What would you like to see happen in the future?

I would like to develop the support networks available for individuals. Increase awareness of NF. Help improve the lives in any way that I am able by assisting those who need support from a NF advisor.

What I Can Do For You.

Support you if you have a diagnosis of NF1 and NF2 in the Devon and Cornwall Region

Support you when your symptoms are being investigated as possibly being NF related

- Home Visits
- School Visits
- Accompany you as relevant to clinic appointments
- Talk to Health and Social Care professionals about your care and support needs
- Assist in relation to following up on test results and clinical investigations
- When appropriate I will help co-ordinate your clinic appointments
- I am a contact point for Health Professionals and others who require additional information about NF
- Help you explore social support and activities that are running in your local area

Please note: I will of course try and help support individuals who contact me from other areas. This will be telephone support and where possible I will link you in with an advisor or other support in your local area.

Carolyn Smyth - Birmingham



Hello! I am based in Birmingham, My background is Nursing, before I started working for the Neuro - Foundation I worked as a Research Nurse trying to find genes for Type 1 Diabetes. Before that I worked in too many specialities to mention but here are a few - Community Nurse, Poisons Unit, and Genito - urinary Medicine. I also worked as a Nanny in Paris and New York shortly after qualifying as a nurse.... That seems like a life time ago now!

I cover the West Midlands Region. This is an area of six counties, Staffordshire, Shropshire, West Midlands Warwickshire, Herefordshire and Worcester. I work part time 25 hours a week and I have been in post for ten years now, I cannot believe how quickly the time has passed! My role is so varied from day to day but I hope the following information will give you an idea of what I do.

A large part of my work involves visiting schools. Talking to teachers, and/or SENCO's (Special Educational needs co-ordinators) LSA's (Learning support assistants) Liaising with Educational Psychologists, attending TAC or Team around the Child meetings.

These visits are particularly helpful for Teachers and Parents but most importantly for the child. Some children with NF have a difficult time at school but with the right sort of help and support they are better able to reach their full potential and gain confidence. Providing information about (Neurofibromatosis) NF1 helps to promote a greater understanding of NF1. When these problems relate to issues such as concentration and short-term memory, such difficulties can easily be

misconstrued as a child being naughty or lazy when in fact they are trying their very best.

I see patients in NF1 or 2 clinics throughout the various counties. Home visits are invaluable and can help a family or individual to come to terms with a diagnosis. I also organise family 'get together' usually every year for people who would like to meet others with the same condition.

I have acted as an advocate if one of my clients needs to appeal against a decision with regard to Benefits. I have also represented parents when the Local Education Authority has refused to grant a statement of educational needs. Whenever possible I try to obtain money from charities to help improve the lives of those with NF, this might be for equipment such as software for a computer, to help with visual impairment; or obtaining funds for the basics such as clothing for those in need. Obtaining money from Charities is becoming increasingly more difficult (some might say impossible) The economic climate is so bad at the moment that things are changing all the time and many of the small charities are no longer in existence.

I also attend NF2 Clinics, both Adult and Paediatric. I aim to provide practical help and advice and a point of contact for any concerns or questions there have been huge changes recently with the introduction of the NCG funded specialist clinics. We now have dedicated NF1 and NF2 Nurses. It is wonderful that people with NF are now getting treatment in a multi disciplinary setting; this means that they can be seen by different specialists in one visit. Thus reducing the need to attend hospital so frequently. This has been a major breakthrough and only came about as a result of the hard work of NF Doctors who have worked very closely with the Neuro Foundation for many years to get this service running.

Over the years I have been inspired, humbled and amazed by so many of the people I have met with both NF1 and 2. It might not be the kind of job you

can leave behind when you leave the office but I can honestly say that I love my job and feel very privileged to have met so many courageous people in the course of my work.

Fundraising News

Thanks to the North East Ladies Day who held a lunch in aid of three charities on 5 October, including the Neuro Foundation. Lindsey Rennard was asked to speak about the charity; specialist advisors Rosemary Ashton and Gayle Seymour (now retired from her post in Newcastle) also attended.



The NELD Committee

Many thanks to Simon Moore, who raised £2964 for the Neuro Foundation, cycling 100 miles from Manchester to Nuneaton. His 11 year old daughter, Ellie, has NF1. Thank you also to mum Cheryl, who raised £1000 by asking for donations to the charity instead of birthday presents.



Simon and Ellie

Dr Carly Jim writes about her research projects, inspired by her daughter



Hello! My name is Carly Jim and my little girl Ellie has NF1. I would like to tell you a little bit about this wonderful little girl and why I am committed to "improving the lives of those affected by neurofibromatosis".

My wonderful Ellie was born on the 30th June 2010 by elective C-section, I say elective, I elected for her to be born on the 5th of July, however she decided that she wanted to be a June baby and that was that. Looking back I can see that she came into this world a spunky and determined little thing and I have no doubt if anyone can cope with having NF1 it's her.

For the first few weeks Ellie was developing well although the top right eye lid was puffy and drooping (ptosis). We managed to get an appointment for an ophthalmologist whilst we were waiting we noticed the café au lait marks appear. I wasn't concerned at all I just thought they were birthmarks (John, her Dad was a little more suspicious), so I was surprised at her 6 week check when her GP said the marks were worrying. Once I realised the café au lait marks were significant I decided to look on the internet, and not surprisingly I found neurofibromatosis. I was 100% convinced at this point that she had NF1. The phrase "if it walks like a duck and quacks like a

duck it's probably a duck" kept ringing in my head. Thankfully the ophthalmologist said her eyes looked healthy and her vision was developing normally. He said there was no obvious sign of a tumour but that she would need regular monitoring. We mentioned to him our concerns regarding the café au lait marks and the possibility of her having NF1. He looked at the marks, and said he would refer us to Dr Huson. On 23rd of November 2010 Dr Huson confirmed the diagnosis of NF1 based on her multiple café au lait marks; auxiliary freckling; a probable plexiform neurofibroma on her lower left leg; small stature; sunken chest (pectus excavatum) and ptosis. The diagnosis was harder on John than it was on me as until this point he had convinced himself that I was just being paranoid.



I asked Dr Huson how Ellie could possibly have an illness that neither myself (a health psychologist), nor my husband (a former geneticist) could have heard of. She told me that "many people are only mildly affected and so it hasn't become a household name". I did take some comfort in that, but when I then asked at what point can we rule out complications and she said "never" - that's when it really hit home. In that instant I promised my little girl that I would do everything in my power to minimise the impact of the condition and to commit my professional skills and knowledge to researching the neurofibromatoses.



In collaboration with professors at Manchester Metropolitan University; the Neuro foundation; the NF1 nurses; Dr Huson and other colleagues I have designed two projects. The full summaries can be downloaded from <http://mmu.academia.edu/CarlyJim>.

Project 1 - The NeuroFile©.

The NeuroFile© is small ring binder which has information about NF1 and about the individual child. The NeuroFile© can be given to the teacher and it is small enough that the child can carry the NeuroFile© in their school bag. The ring binder will have extra copies of key pages which can be given to relevant people. In the project, an NF1 nurse will visit a family and spend a day with them making a NeuroFile© for the child. One month after the

child has been given the NeuroFile© we will ask the family to tell us if it has been helpful. We will ask the family again a year later. If the families do not want to answer questions or do not want to use the NeuroFile© that is ok as they can stop being in the project at any time. If the project shows that the NeuroFile© is good then we will put a template for NeuroFile© on the Neurofoundation's website so that any family who wants one will be able to make one. In the future it is hoped there will be an electronic version of the NeuroFile©, such as a phone 'app'.

Project 2 - Experiences of NF1

The aim of this project is to find out about people's experiences of having NF1, with a particular interest in the medical care that they have received. In the project I will interview people with NF1 about their experiences. The interviews will be analysed see if there are areas that a lot of people have in common, or whether the experiences are specific to the individual. People who take part in the interviews will have the opportunity for their experiences to be shared with other people by the use of an award winning website called health talk online (www.healthtalkonline.org) and to have a chapter in a book on NF1 dedicated to their story. It is hoped that this project will provide an opportunity for people to tell their story; for improvements to be made in the NHS as a result of the information given; and to raise awareness of NF1 amongst patients, medical professionals and the general public.

If you would like to give me some feedback on my ideas or register interest in taking part in one of the projects I would be delighted to hear from you. Thank you for reading this article, I look forward to meeting you all in the future.

Dr Carly Jim, Research Associate, RIHSC (Research Institute for Health and Social Change), Manchester Metropolitan University (MMU), Hathersage Road, Manchester M13-0JA, **E-mail c.jim@mmu.ac.uk**

Regional Fundraising Champions

The Neuro Foundation is delighted to announce the formation of several regional support groups. Many members have said they would like a local group, so please let us know if you would be able to help with a new group in your area.

- **Newcastle** - Ruth Bond is co-ordinating this group, which met for the first time in early October. She would love to hear from anyone who would like to attend the next meeting, planned for late January - her email address is ruthbond@mglabs.co.uk.s
- **Plymouth** - Mandy Debarring is launching a local group. The first meeting will be on Saturday 17 March 2012 at The Guild Hall, Bradninch. This event will be an afternoon tea with a raffle, tombola, tea, coffee, cakes,

squash and fizzy drinks for the children. This will be open to all giving us an opportunity to start to make people NF aware and to raise some much needed funding for our group. Plans for other events such as a disco for the children can be arranged. A fully licensed bar will be available for adults to enjoy. Mandy is planning to hold regular meetings, with talks by medical professionals.

Mandy can be contacted on
benfawarecarepleasedontstare@hotmail.co.uk

- **Cumbria** - Elizabeth Samson has been fundraising for the Neuro Foundation for many years, and is always delighted to hear from others who would like to start fundraising or get in touch.

Thank you so much to all of you who have supported the Neuro Foundation

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:

£22 (Family member) or £15 (individual) (Please tick as appropriate)

I have enclosed a cheque for the sum of £ made payable to the Neurofibromatosis Association.

Please debit my card number / / Issue No.

Start Date: Expiry Date: Security Code: Date:

Name: Address:

I WOULD LIKE TO RECEIVE INFORMATION ON:

- | | | | |
|--|--------------------------|----------------------------------|--------------------------|
| How the charity can help me | <input type="checkbox"/> | Setting up a local support group | <input type="checkbox"/> |
| Raising funds for The Neuro Foundation | <input type="checkbox"/> | The 2012 London Marathon | <input type="checkbox"/> |
| Membership of The Neuro Foundation | <input type="checkbox"/> | Leaving a Legacy | <input type="checkbox"/> |

Please return to :

The Neuro Foundation, Quayside House, 38 High Street, Kingston upon Thames, Surrey KT1 1HL

Gift Aid

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

**Still a few places left at time of going to press!
 Call 0208 4391234 for details**