

MS Research

Newsletter

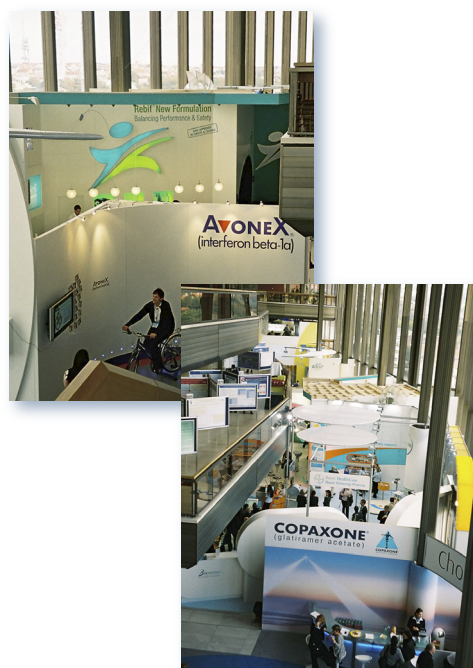
Autumn / Winter 2007

The ECTRIMS (European Committee for Treatment and Research in MS) Conference, Prague, October 2007.

Members of the Frenchay and UBHT MS Research teams attended the 23rd annual ECTRIMS Conference in the beautiful city of Prague. The very full programme covered many important developments in new drug treatments and strategies of symptom management. A full 4 day programme covered nearly all aspects of MS and was attended by approximately 5,000 delegates from all over the world. All the major drug companies were represented and many of the presentations covered exciting new and emerging treatments as well as improvements on some of the now well recognised drugs like beta interferon and Glatiramer Acetate (Copaxone).

We greatly enjoyed our stay and even managed to fit in a little sight seeing. Our hosts generously provided us with many opportunities to socialise and chat about MS treatment in some of the most interesting and beautiful venues in Prague. We look forward to the meeting in Montreal next year! Once we have moved to our new "home" at Bristol General we will set up some "information exchange" activities that will allow us to tell people about important events like this at first hand. Watch this space!

An added bonus to this meeting was an article by the MS International Federation featuring a short biography of our very own "webbie" Laurence. Laurence provides us with constant updates on research via the MSIF. Come and see how in our new home!



On the move!



The Bristol MS Research Unit at General Hospital is about to move to more suitable premises on the ground floor of the General. We are delighted with this move as it will enable us to extend our services to include a new resources centre for people who have MS and for professionals who treat it. Come and try out our comfy lounge area and new information resources! It will also provide us with more suitable space for current studies on fatigue and other aspects of MS. As part of an ongoing programme of research into fatigue we will now be able to see groups of people who wish to participate in the development of a fatigue management programme in our own Unit. Other studies on mobility and tremor will also be better accommodated. We also intend to develop a research advisory team. Do let us know if you are interested in joining in with any of these new developments-we will keep our phone number 0117 928 6332.

We have moved from our old home on Level 2 in the General and taken up temporary accommodation for about 3 weeks while refurbishment work is carried out. We hope to be in our new home well before Christmas and invite you all to a Grand Opening High-tea Party on December 10th 2007, 2.30 p.m - 5.00 p.m.

We are very grateful to UBHT for the new space and to the Above and Beyond Appeal who have provided funds to help us buy new furniture and provide better resources for people affected by MS. We wish to develop a centre that we can all be proud of! In addition the charity MS Research Training and Education continues to help us fund staff and equipment for research programmes.

This move will also mean easier collaboration with the Frenchay Neurology team and likely accommodation of some joint work both at the General and in the new BRAMS building at Frenchay when it becomes available. All in all we feel that this is a very major move forward for MS in Bristol. It brings us closer to the establishment of a single "Centre of Excellence" for MS in Bristol and enables better exchange of resources and ideas. We cannot tell yet where a single MS site will be best placed and it will be some while before that is known. Improving accommodation at both The General and at Frenchay can only be really GOOD NEWS for MS in Bristol!

Rosie Jones, MS Research Unit. October 2007.

Current research news

Studies on fatigue in MS

The MS Research Unit has started a series of studies on MS related fatigue. The current study tests the feasibility of delivering a cognitive behavioural programme to help people with MS overcome their fatigue and make better use of their time and energy. Cognitive behavioural therapies do not involve any drug treatments and are designed to enable people to take control of their own lives and manage their own symptoms. The programme we are testing here was devised by a team of psychologists and other research experts at Poole Hospital. The present phase of study involves six people undertaking six training sessions aimed at introducing them to valuable strategies of fatigue management using lifestyle evaluation and better self awareness of the factors that promote and exacerbate fatigue. This stage of the research is specifically aimed at people who have busy, physically active lives with the intention of improving quality of life and capability to cope with fatigue as a symptom of MS.

The next stage of these studies will build on lessons learned and feedback from participants in the current phase and will enable us to enrol larger numbers of participants in the next research phase. If you would like to know more about this research please call the MS Research Unit on 0117 928 6332.

Welcoming two occupational therapists (OT's) to the research team.

We are very pleased that Charlie and Jen have joined us for the fatigue research programme. Both are very experienced OT's with a wealth of good experience to bring to the fatigue studies as well as to provide an OT perspective for the treatment of MS. Both have other busy jobs in addition to their research role but have given a lot of time and thought to making the research experience as enjoyable as possible for the current fatigue research participants. They work in collaboration with Angela Davies Smith, the MS Units research physiotherapist to form a comprehensive and lively team of therapy experts.

Angela Davies-Smith & Rosie Jones.

MS Research gives £20,000 to the BRAMS (Bristol & Avon MS) appeal!

The chairman of MS Research Mr Bill Tacey was delighted to be able to hand over a cheque for £20,000 towards the refurbishment of the old Glial Cell labs at Frenchay Hospital where a new MS Centre will be set up. Space in the new Unit will be occupied by one part of the Bristol MS Research team from Bristol General Hospital and the University of Bristol to carry out studies on tremor and ataxia and its treatment.

It is hoped that in due course suitable space will be found in Bristol so that the entire MS research effort of Frenchay and UBHT based researchers as well as routine MS treatment can take place in one venue. However it is well known that impending changes in the NHS in Bristol will affect both Frenchay and Bristol General Hospital. Until it is clearer where the best place for the required overall space might be, other research activities of the MS Research team at Bristol General Hospital will continue in their new location on the ground floor of the General Hospital. The additional space available there will also enable the team to run a unique resources unit where patients will be able to "drop in" and review a range of written and on line information and other research materials at their leisure. Meeting and discussion groups will also be developed.

Overall things are definitely looking better for MS in Bristol –but we all need to work together to realise our ultimate longer term goal of a state of the art, fully equipped MS Centre of Excellence at one location (and with adequate parking!).

Gill Nicholls, Editor.

Bristol Half Marathon - A big thank you to all our runners

Rachel's Run - By Rachel Miles

There is great competition for open places to run in the Bristol Half Marathon and I was very pleased for the opportunity to run on behalf of MS Research. I had run in St. Albans in June and had a goal to improve on the time I achieved then, which was a shade under two hours. Training involved roughly an hour's run every weekend and 40 minutes or so on two or three evenings during the week. It is a good way to wind down after the day's work.

The weather on the day was ideal, cool but bright, and there was a lovely atmosphere at the start. I had not run in such a huge gathering before. We were spurred on by spectators lining the whole course and shouting encouragement in the sunshine. The runners, also, were a good bunch. As we entered the tunnel under the Suspension Bridge on the Portway someone started a chant that echoed around and was passed on to those coming behind. It might not have made much sense but it felt good. We were able to shout support to the front runners who were already on the return, looking completely focussed.

There were the usual brave souls adding to the challenge by running as Superman or a banana. One guy had 'This is my stag weekend - kick me if I start walking' on his back. Seeing my parents amongst the crowd close to the half way mark and at the end gave me a huge boost. I knew that my father had calculated to the nearest minute where I should be along the route according to my target race time and so I had a good incentive to keep pace. The last couple of miles were tough and one of the most beautiful sights was the twelve mile mark. Then I knew that I would do it and in reasonable time. The last stretch is through the centre, teeming with spectators, towards Canon's Marsh, and I crossed the line with hundreds of other triumphant participants. Later we were able to access our times (logged using the chip issued at the start) on the website. I had run thirteen plus miles in one hour and fifty minutes, a personal best. The charity benefited from the generosity of my sponsors and I spent the rest of the day with a delicious glow of achievement.

Come-on the Dads! Rugby Coaches v Dads – St Bernadette’s Rugby Club Whitchurch

My son Jack is 13 years old and plays for St Bernadette’s Rugby Club in Whitchurch Bristol. They are great team and the Coaches and Managers do a great job.

Neil, better known as Moose, the Manager of the under 14s, organised the Dads V Coaches game. I did ask if I might be able to play, but they understandably thought my efforts from a wheelchair might prove to be a little dangerous.

The game was a hard one and there were a couple of minor injuries, although the match was a great fun and as usual, it rained, making it very muddy and slippery. The Dad’s did very well, although they did loose against the coaches, most of whom play for the first team.

After the match, we went back to the club-house, although I didn’t play I did do a lot of shouting and joined the others in a well earned drink. An auction then began, there were some great items, among them, bottles of wine, club T shirts and sweatshirts, a dinner for two at a local restaurant and one slightly unusual item, an ice making machine, normally used in pubs and restaurants. One of the Dads donated this from his company and it encouraged a great deal of bidding. The highest bid was eventually made by Moose who then very generously put it back in to be auctioned again.

After the auction, there were welcome refreshments which included hot dogs and burgers, profits from this also went towards the total amount raised, which was £660.

A BIG thank you to all the organisers and supporters of St Bernadette’s who attended and those who played the match on a very rainy day.

Shaun McCarthy - Jack’s dad and Trustee of the MS Research Charity.

How you can help us

Events- Run for research! Ride for research!

Read in this edition how Rugby, Bristol half marathon and other events have raised funds for us. Perhaps your family could take part in a sports event? Ask for our sports and leisure fundraising pack! Or perhaps you, your firm or organisation could hold a social event for us? For more ideas of how to help by organising your own event, please contact our Fundraising Co-ordinator John Nickolls on 0117 977 2332 or fundraising@ms-research.org.uk

Information displays/collections

Can you help out for a few hours occasionally to help man Information Displays/Collections for the MSR Charity? If so, please call Brian on 07776 341601

Website

Our website offers a wealth of information of how you can help us via the Internet.

We are proud to announce the launch of a new design for our website, <http://www.ms-research.org.uk>. We found a free design by D Carter and adapted it to our needs.

Shopping on Line? If so, all you need to do is log on to the easyfundraising site <http://www.easyfundraising.org.uk/msresearch> and use the retail links provided (e.g. NEXT, Debenhams, or Tesco) whenever you shop on line, and at no extra cost to you, we will receive up to 15% of every purchase you make. Many retailers also give exclusive discounts, special offers and even e-vouchers when you shop through this site.

Search Engines – You can also help us by logging onto <http://msresearch.easysearch.org.uk> and each time you search the web 1p will be donated to our charity.

Everyclick .com is another search engine as it donates half its revenues to charity! Just make <http://www.everyclick.com/uk/msresearchtrainingandeducation> your home page and make sure you use it whenever you search the web! It does not cost us or you a penny so please use it to support MS Research Training and Education.

Please visit our website for further information.

Laurence Robb ‘Webbie’

Basingstoke skittles tournament

Our sincere thanks to Barry and fellow Skittles Team Members from Basingstoke, who organised a Skittles Tournament and raised £715 for the MS Research Charity. Barry said that it was an excellent event and the team had a great time taking part.

Would your team like to organise an event? For help with fundraising please contact:
John Nickolls – fundraising@ms-research.org.uk

Arms that won't do what you want them to!

Our previous EU funded studies have shown that a lightweight linkage system can successfully record a range of useful measurements of arm movement and tremor. Some of you will have participated in this study. Although very informative, this system did not allow for all the normal ranges of upper limb movement to be tested. Also it was cumbersome and not very cosmetically appealing! However it did enable us to evaluate the likelihood of being able to measure very large movements like reaching out or placing the finger on the tip of the nose alongside much smaller movements experienced as tremor – and all the combinations in between.

In a new study the Xbus-plus measurement system will be used to measure tremor in patients with a range of tremor severity and loss of upper limb co-ordination. The new measurement system is a state-of-the-art wireless device recently developed in the Netherlands and it's purchase for our research was generously funded by CHK Charities-a big thank-you to them! The measurement system will be used by doctors and physiotherapists to support existing clinical measurements and, most importantly, to lay down the basis for the design of systems to control tremor. We will shortly be asking for people who have an interest in tremor to come and offer us their opinion about how to tackle this difficult symptom. If you would like to be included in this discussion please contact us on 0117 928 6332 or by email to rosie.jones@ubht.nhs.uk.

WHO'S WHO

Trustees

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Fred Carpenter MBE - Trustee
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Reg Charity number 1043280 Co. Number 3005230.

Thanks to the Above and Beyond appeal

The MS Research Unit is very grateful to the UBHT "Above and Beyond Appeal" for the donation of funds to set up a patient area for information and discussion in the new MS Unit, and also to MS RTE for their continued support.



WANTED-Urgently!

Round coffee table (approx 3ft in diameter) must have legs rather than central column to ensure stability. If you track one down please let us know!



With all good wishes for a Peaceful and Happy Christmas and New Year



Please note:

The registered business address of the charity is
10, Oakwood Road, Henleaze,
Bristol, BS9 4NR

For all correspondence regarding fundraising please contact
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