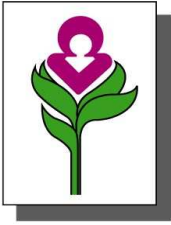

Huntington's Disease Association



Bristol Branch Newsletter—2007

Secretary: Val Marsh Tel: 0117 9860699 Email: info@hdabristol.org.uk
Head Office: Downstream Building, 1 London Bridge, 3rd Floor,
London SE1 9BG. Registered Charity Number: 296453

W elcome to this year's newsletter, my third as chairman. As you will see from the articles, we've had another busy year of fund raising and raising awareness of Huntington's Disease and we've lots planned for this year.

I would like to thank all those who have helped over the past year with the organisation of our events. A great deal of planning and preparation takes place to make each occasion such a success.

This year we say farewell to a couple of committee members; Clare, who has left us for far more important duties as a Mum and Pam, who has finally managed to retire after many years as our secretary. The good news is that Val has agreed to take over as secretary and Lesley has joined us on the branch committee.

Finally thanks to you, our readers. Without your support we would not be able to put as much into helping sufferers and their families, and seeking a cure for HD. Here's to another successful year's campaigning and fund raising.

Sadie Nicholls

Support from the Sky

L indy Foster, one of our braver supporters has agreed to do a tandem skydive to raise funds and awareness this summer. A tandem parachute jump is one where you are strapped to an instructor and you jump from the aircraft together. It is a great way to raise funds as a minimum of training is required before making the parachute jump.

Lindy will have to raise £385 in sponsorship to do the jump. The branch will receive approximately £200 of this plus any additional sponsorship above this amount.

There will soon be a web page at,

<http://www.justgiving.com/huntingtons/raisemoney>

Under Lindy's name so watch out for it. For those of you who have not used the Just Giving web site before, it is a way of donating to a particular fund raising event online. It removes all the hassle of giving for the donor and collecting for the person doing the fund raising. They even claim the 28% tax relief for eligible donations.

It's goodnight from her...

At this year's AGM, the branch said farewell to our secretary, Pam Payne. Pam joined the Bristol Support Group in 1991 (it gained branch status in 1998) and was elected secretary in February 1999. She has been our secretary ever since and has helped make the branch the success it is today.

She is a powerhouse of energy and organisation and has a fantastic memory for names and faces. She has a huge circle of friends and acquaintances and has a wonderful way of gently coercing them into helping out with all our activities.

She will be sorely missed but we wish her well in her 'retirement', although she will still be helping out behind the scenes.

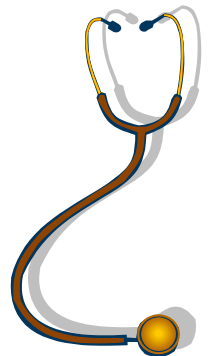


The branch presented Pam with a photo printer and a bouquet as a farewell gift.

HD Clinic Opens in Bristol

Good news for the HD families in Bristol, Bath and surrounding areas! A new specialist HD Clinic started in May at Frenchay Hospital. These will be held on a monthly basis (the second Friday of the month, in the mornings). These will be run by Dr Kasia Sieradzan, Consultant Neurologist, Dr Stefania Bruno, Consultant Neuro-Psychiatrist, Nurse Helen Lewis, a Movement Disorder Research Nurse and myself. All referrals have to be made via a GP.

The highly specialised nature of the problems presented by this rare disease demands a high degree of expertise from those who wish to help them. Many of the problems cannot be answered by conventional services. This Clinic will address the more complex issues surrounding the neurology and neuropsychiatry that HD presents.



This can only improve the awareness of HD and raise the profile of our families in the area.

Carol Dutton
Regional Care Advisor
Huntington's Disease Association

A Tale of Research

We had agreed to take part in a sleep study by the Cardiff Huntington's Disease (HD) Centre and so duly presented ourselves at the research centre at Cardiff University Hospital. The day started really easily with the doctors making us tea and toast while the paperwork was done and I tried all the switches on the reclining bed/chair.

After our blood and saliva samples were taken it started to get more interesting. Electrodes were stuck to our heads with super-glue and connected to a recorder attached to a belt around our waist (about the size and weight of a bag of sugar). After more samples we left for home with lots of instructions about filling in our sleep diaries and collecting our saliva - 8 in the morning and 8 in the evening, no food for an hour before and only water to drink. As well as the EEG recorder and the saliva samples we also had to wear an activity monitor (looks like a chunky wristwatch), and keep a sleep diary for a week.

Well, I was very surprised at how easily I adapted to sleeping with a bag of sugar strapped to my waist. Whenever I changed position (which was often) I seem to be alert enough to know that I had to make sure the recorder and bundle of wires were okay before I dropped off again. Not the best night's sleep I've ever had but not the worst either.

However we were very pleased when one of the researchers turned up next day to retrieve the EEG recorders. Solvent is very good at removing super glue but I

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...and it's Good Evening from her



My association with Huntington's Disease goes back to the 1980's when I was living in Cornwall and my first husband was diagnosed with the illness. I received information from the Huntington's Disease Association (known then as "Combat") and met up with others in a similar situation when I attended a meeting of the South-West Branch of the organisation in Devon. I was instrumental in setting up the first Branch of the HDA in Cornwall and was their first Chairman, later taking on the role of Secretary.

My husband died in 1993 and in 1996 I moved to Bristol to take up a post with Hope UK – a Christian Drug Education Charity. In 1997, I was, again, instrumental in setting

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up another branch of the HDA – the Bristol Branch. It was there that I first met Sadie and Wendy and I am pleased that they are still involved with this very important work. I took on the role of Chairman and continued with this until 2001, when work commitments (I was then Personal Assistant to the Principal of Wesley College) and my own health, made me take a step back.

I remarried in May 2003 and now live in Keynsham with my husband Vernon. I have three sons – two who live in Cornwall and one in London – and three grandchildren. My middle son, Mark, has recently been diagnosed as having Huntington's Disease and is still struggling to come to terms with it. Vernon has a daughter living in Chippenham (his son died four years ago). He has four grandchildren. We are now both retired and seem to find plenty to fill our time. We are both Christians and attend Keynsham Methodist Church.

I look forward to getting to know you all, either at our meetings or in conversation on the telephone.

Past Events

Annual Meal 16th April 2007

After a quick change of location due to the fire at the Huntsman, we arrived at the Riverside Inn at Saltford on the Monday evening. Everyone enjoyed the meal and the location next to the river and marina was very relaxing. The food was good and the staff were helpful and friendly as the choice of evening meant it was not too busy. Thanks to Pam for arranging the change of venue at such short notice.



Barn Dance 23rd March 2007

This year the Barn Dance was held at Bitton Recreation and Sports Club, with music supplied by the Free Spirit Band. If you've never been to a Barn Dance, it's a unique dance event as you don't need any skill, just listen to the caller and try to keep up with the rest of your set. Even men seem to enjoy it, although this year we did miss Justin's distinctive brand of customised dancing!

Many thanks to the band, everyone who helped arrange the event and all those

who came along and made it such a great night. The final sum raised at the event was £818.27.

Quiz Night 3rd November 2006

Twenty four teams joined us at St John's Church Hall, Keynsham for our annual quiz.

Honours went to "The Try Hards", while the wooden spoon was won by "The Egghead's Cousins". Many thanks to all who helped organise the event especially our quizmaster, Nigel and to Norman, who auctioned the chocolate cake and teddy bear in such a professional way. The event raised £765.50 for the branch.

Sponsored Walk 1st October 2006

Our usual good luck with the weather finally ran out this year! The rain really was torrential, we didn't even stop for our usual pre-walk photograph.

Luckily the sun did appear about half way through the walk, which cheered us up considerably although some of the tracks were definitely a bit on the squelchy side.



Many thanks to all those who sponsored us and to the landlord and staff of the Cross House Inn at Doynton for making us feel so welcome after the walk. The walk raised the fantastic sum of £2,109.52.

Street Collection, Keynsham Friday 30th June and Saturday 1st July 2006

This was a great chance to raise funds and spread the word about HD. Many thanks to Pam for organising this year's collection and especially to all those who stood there rattling their collection tins. Also a big thank you to the generous people of Keynsham, who helped us raise £543.62 over the two days.

Help Required

This year's street collection will take place on Friday the 7th and Saturday the 8th of September in Keynsham. If you would like to help out by rattling a can at passers-by for an hour or two, then please contact Val on 0117 9860699.

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was finding lumps of the stuff in my hair for days afterwards. I suspect that my workmates thought I had nits!

We continued with our samples for the rest of the week. The hardest part was remembering not to eat for the hour before the saliva sample collection. The kids found it disgusting wandering into the kitchen to find their parents dribbling into test tubes! And the chap who came to the door to enquire about my electricity supplier deserves a bonus from his employer for the way he completely ignored the wires attached to my head!

We're involved in several research projects at Cardiff and it's a bit like meeting old friends when we arrive. The research team are always grateful to us for taking part but I think we're more grateful that this bunch of clever people (and hundreds of other academics around the world) are interested enough in our disease to try and do something about it.



Almost anyone can get involved in HD research, obviously those with a positive predictive test but also people with a negative result and people who have not had a test. People without HD, ie carers, are also useful as control subjects. The research authorities are fanatical about protecting our personal details (and it's a legal requirement) and they pay expenses for travel, bridge tolls, meals, etc. As a location Cardiff is great because it's straightforward to get to and parking is easy (there is a multi-storey car park just inside the hospital grounds).

For further details of research projects, please see,
<http://www.hdcentrecardiff.org.uk/index.html>
<http://www.ukhdn.net>
<http://www.euro-hd.net>

To find out more about local or national research activities, please contact
Dr Olivia Handley or Dr Jenny Naji
Research Coordinators for UK and European HD Research Networks
The Brain Repair Group
School of Biosciences
Cardiff University
Cardiff
CF10 3US
Email: HandleyO@cf.ac.uk or NajiJJ@cf.ac.uk
Tel: 029 2087 5197

Events for 2007

(Please cut out and stick on your fridge)

- | | |
|--------------------------------|--|
| 11th June | Monthly Meeting (Keynsham) 7:30 - 9:30pm |
| 1st July | Walk at Weston-Super-Mare
A walk and "bucket collection" will take place along the promenade at Weston-Super-Mare. Due to the location this event will be suitable for wheelchairs. We plan to meet just before 11:00am at Royal Sands at the southern end of the sea front (furthest from the town centre) and walk to Knightstone and back. |
| 9th July | Monthly Meeting (Keynsham) 7:30 - 9:30pm |
| 13th August | Monthly Meeting (Keynsham) 7:30 - 9:30pm |
| 7/8 th
September | Street Collection, Keynsham |
| 10 th
September | Monthly Meeting (Stapleton) 7:30 - 9:30pm |
| 22nd
September | Sponsored Walk |
| 8th October | Monthly Meeting (Keynsham) 7:30 - 9:30pm |
| 12 th
November | Monthly Meeting (Keynsham) 7:30 - 9:30pm |
| November | Quiz
Date and location to be finalised |
| 10 th
December | Monthly Meeting (Stapleton) 7:30 - 9:30pm
This meeting will include the Christmas Buffet. |

Regular Monthly Meetings

These usually take place on the second Monday of each month (allowing for bank holidays). The meetings are informal so please come along for a cup of tea, a chat and news of any upcoming events.

The meetings are currently held at one of two locations:

Keynsham

Room 3
Keynsham Baptist Church
High Street
Keynsham
BS31 1DP

There is plenty of free parking nearby.

Stapleton

The Priory Hospital Bristol
Heath House Lane
Off Bell Hill
Bristol
BS16 1EQ

It's a bit tricky to find - cross the motorway, drive right up to the barrier and, if closed, it will lift, continue past the first building and go round the second building to the parking area. The front door may be open or you may have to enter the side door using the door entry system. Don't forget to get a barrier exit token from staff before leaving.