



The Huntington's Disease Association

hunting for a cure - with care

HAMPSHIRE
BRANCH:
November 2009
Newsletter

Website: www.hdahampshire.org.

Any comments or questions about this edition to **Anne Stephenson** (secretstanne@aol.com or 01329 232373) 20 Alders Road, Fareham, Hants PO16 0SH.

You can contact our **Regional Care Advisor**: Eve Payler on 02380 612218 (eve_payler@hda.org.uk or by post to The Huntington's Disease Association, Neurosupport centre, Liverpool, L3 8LR).

You can contact **Barry Blake** (Chair) on 01329 286157.

Maureen Graham (social secretary) can be contacted on (02392 2593683 or m.graham11@sky.com).



Please help HD research by taking part in a Quality of Life Questionnaire:

At the Family Day in Reading we had a talk by **Aileen Ho** from the Berkshire Branch.

She explained that it is important that when people are involved in drug trials the success of their treatment can be measured. To this end Aileen has produced a questionnaire to measure the impact HD has on quality of life. She needs to collect as much data as possible from people **before** trials begin. There are two questionnaires, one for people who are gene carriers/at risk and one for carers. You should have received them with your December Newsletter from HDA Head Office (they are yellow and pink respectively). If you need another copy or have not received one please contact Anne as we have some spare copies. Aileen has an article in the newsletter (see page 10)

Future Events:

The 2010 branch meetings: At 2pm at Sembal House, Handel Terrace, Southampton SO15 2FH.

February 6th

March 27th (AGM)

May 22nd

July 17th

September 11th

November 20th

Carer's Meeting: January 11th from 7:00 p.m. at The Still and West, Portsmouth close to the Isle of Wight ferry terminal. Just turn up and look for the table with the collecting tin on it. We will refund travel expenses.

Social: Fancy a meal out with friends?? On Monday February 22nd 2010 at 7p.m. at The West Meon Hut (GU32 1JX...on the junction of the A272 and A32). Bring as many people as you can for a slap up meal and raise funds for the HDA. If you are interested please contact Maureen. The pub does 'Two for One' meals and the idea is that all meals will be paid for but the cost of the 'free' meal will be donated to the HDA. There will be at least 30 of us so we need to order the meals in advance. Please contact Maureen before the end of January to let her know you are coming if you have not done so already. We will be getting in touch about the menu etc after xmas.

Amanda Fund Paintballing: This will be taking place in Romsey. Participants must be 10 years or older. Free to Branch members. Get in touch with Anne (01329 232373 or secretstanne@aol.com) if you are interested the date is to be confirmed.

Young People's Conference 27th and 28th February Telford: This is for people of 18-25 years who are at risk or gene positive. Contact head office for details on 0151 298 3298 or email info@hda.org.uk. We can provide funding towards your costs.

Kids Summer Camp at Avon Tyrell on 6th-8th August: Contact head office on 0151 298 3298 or email info@hda.org.uk for a booking form. There are 3 summer camps at different venues next year. This is our closest and is highly recommended. Places are free.

Please note: You should have received your December Newsletter from Head office

Branch Meeting: November 21st 2009.

Who was there: Barry Blake, , Karen and Chantelle Durnall, Steve and Linda Franklin, Elaine Frier, Tony Geary, Colin Gould, Steve, Caroline and Lauren Hallam Myra and George Heppenstall, Cliff and Avis Nevatte, Jacob and Eve Payler, Pat and Robbie Richardson, Mark Robinson, Anne Stephenson, Meg, Ben, Flo and Ellie Walters, Andreas Wytttenbach

Apologies from: Brian Cady, Maureen and Peter Graham, Sarah and Eric Hands, Hugh Miller, John Seller, Trudi Smith, Meg, Ben, Flo and Ellie Walters

What happened:

Chair's Report:

Barry spoke about Pauline Willis who sadly died recently. She was John's carer and a solid member of the support group. She was always ready to help others and will be sadly missed. We held a minute silence.

There was a short report from the HDA conference which was attended by 6 branch members.

There was a short report from the Family Day in Reading, attended by Anne and Barry and some members that we hadn't made contact with before. We hope Aileen Ho will come and speak at a future meeting.

The pub social at 'The Inn by the Sea' was attended by more than 20 members and was great opportunity to chat in a relaxed atmosphere.

Donations: Thanks to Maureen Mintram for a donation of £16.18 which she collected at work (and thanks to her colleagues for their support). Thanks also to Waitrose at Portswood, Southampton for a donation of £307. We were their nominated charity of the month. **If you have a Waitrose near you please nominate us!**

Speaker: Andreas Wytttenbach gave us a comprehensive talk about news from the World Congress in Vancouver. Overall he felt that there was no 'Wow a breakthrough' type news but people are continuing to chip away at the HD problem from many different angles. There seems to be a switch in funding focus from basic research to drug trials and work like Aileen Ho's will enable us to measure the success of these drug trials more effectively.

If you would like to know more about the World Congress then you can visit:

<http://www.cmmmt.ubc.ca/news/releases/2009/09/world-congress-on-huntington-disease-event-update>

The raffle raised £20. Thanks to all who brought prizes or provided sherry, sausage rolls, mince pies etc.

Remember the branch is here to help families like yours. The branch can make a welfare grant of up to £300 per family; for example, recently we gave money towards a new wheelchair for a Branch member. There is also a grant of up to £100 available for younger branch members from the Amanda fund. If you need financial support from the branch please get in touch with Barry (01329 286157) or Anne (secretstanne@aol.com). All requests are considered by the committee in strict confidence.

Advice from Branch Members including Committee Members: advice given by Branch members is given in a lay capacity and it should **not** be treated as professional advice

**RESPITE?? : Do you need some respite but can't afford it?
Get in touch with Barry (01329 286157) and we might be able to help.
(Requests will be treated confidentially).**

Save your stamps and empty printer cartridges: Please save your used stamps (tear off with a border of envelope around it) and empty printer cartridges as they can be used to raise money. Bring them to the next meeting or send to Eve.

Do YOU use the internet? Raise money for Huntington's Disease Association just by searching the web. everyclick.com is an internet search engine with a big difference - it donates half its revenues to charity. If you use everyclick.com as your search engine every search you do can raise money for Huntington's Disease Association. Please go to <http://www.everyclick.com/uk/huntingtonsdiseaseassociation> to do all your searching. It does not cost us, or you, a penny. So please use it - and pass the message on! Find out more on the HDA website (fund raising section)

We don't want problems with finances or with transport to prevent you attending our events. We may be able to subsidise them and arrange transport for you. You can contact us confidentially to arrange this.

If you have any ideas for events or outings or Amada fund activities (ie specifically for under 18s) please contact Maureen.



<http://www.everyclick.com/uk/huntingtonsdiseaseassociation>