



The Huntington's Disease Association

hunting for a cure - with care

HAMPSHIRE
BRANCH:
February 2010
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).

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

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

March 27th (AGM): There are vacancies for secretary and for general committee members. If you would like to help the Branch by being a committee member then please get in touch with Anne or Barry or just come along to the meeting. Any necessary voting will take place. Please attend if you can, give your input and show your support.

Other Branch meeting dates in 2010:

May 22nd,

July 17th,

September 11th,

November 20th

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.

Next Carer's Meeting: March 2nd 7:30 p.m. at The Red Lion Southampton 55 High Street, City Centre, Southampton, SO14 2NS. 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.

HDA Awareness Week 14th-20th June 2010

19th and 20th June is the weekend of the balloon and kite festival at Southampton common. We plan to be part of this event in some capacity. We will need a team of volunteers for the event. Please let Maureen know as soon as possible if you can be involved even for a short time as we will need a rota of people to cover the stall etc. More details coming soon.

You also may like to do your own event to mark Awareness Week. Let us know if you need any support/balloons/leaflets etc.

We also hope to go gliding with the Oxford Branch if they are running their usual Awareness Week event.

This will probably be on the **12th June.**

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.**

Social events over the page.....Social events over the page.....

Future Social Events:

ALL the following events are FREE to children thanks to the 'Amanda fund'

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

'Chicago' at The Mayflower, Southampton 27th Feb (matinee 5pm) We have just managed to get a limited number of special tickets for this at only £5 to Branch members. Contact Maureen (first come first served!).

March 15th Skittles: At 'The Crofton' in Stubbington from 7p.m. Branch members will only pay £3 and this includes supper (£7.25 to non-members). Please book your place through Maureen.

April: London Theatre trip to 'The Lion King': Exact date to be confirmed but we plan a heavily subsidised trip to this amazing show. These tickets will be available on a first come first served basis, so let Maureen know if you are interested as soon as possible.

May: Exbury Gardens: Date to be confirmed but probably May 9th. More details in the March newsletter

26th May: 'Hairspray' at The Mayflower Southampton We have booked some tickets for this evening performance. Please contact Maureen asap if you would like to go.

June 12th and 19th and 20th Awareness week events ...see front page

July 4th: Isle of Wight Excursion: To Waltzing Waters and then Flamingo Park

September 4th 'Les Miserables' If you are interested in this production then let Maureen know asap as limited tickets are available.

September 19th: Marwell Zoo

October 30th: Pub Social at The Mill House in Lyndhurst

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 secretanne@aol.com) if you are interested. The date is to be confirmed.

Help Needed?: Do you need help with gardening, decorating or some other DIY type project? We might know some people who can help in exchange for tea and cake!
Get in touch with Barry or Anne for more info.

Help wanted:

From Huntington's disease carers to give your opinion on respite provision see <http://www.hda.org.uk/research/2009/2009-11.php>

Participants needed for HD research: Treatment & prevention - Research into siblings with Huntington's disease. See <http://www.hda.org.uk/research/2009/2009-08-02.php>

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)

News:

From Annette: This was gleaned from a workshop run in 2009 by the Royal College of GPs, with support from the **Princess Royal Trust for Carers**.

Did you know ...

- 1 in 7 households have a carer
- 175,000 carers are under 18
- 18% of carers look after more than one person
- Carers save Health + Social care £57 billion per year
- 1.2 million carers care for more than 50 hours per week

Carers need support to continue in their role and they should ask for, or demand, support from any of the available agencies. Here are some useful organisations to contact, with links. Although some of these organisations are for 'professionals' it is important that carers have this information so they know what to ask for. We all know that accessing support can depend on how good your social worker is and how much they know. This information should help you know what you are entitled to. We are hoping to get a speaker from the Princess Royal Trust to come to a Branch meeting.

* The Princess Royal Trust for Carers Professionals website: www.carers.org/professionals

Materials developed by the Partnership between the Princess Royal Trust for Carers and Royal College of General Practitioners include:

- Supporting Carers: An action guide for general practitioners and their teams
<http://www.carers.org/press/a-guide-is-launched-to-help-gps-support-unpaid-family-carers,4081,NW.html>
- Carers in Practice Leaflet <http://www.carers.org/data/files/carers-in-practice-lft-1828.pdf>
- Carers as Partners Leaflet <http://www.carers.org/data/files/carers-as-partners-lft-1827.pdf>

* National Carers' Advice Line (provides information and access to other services): www.nhs.uk/carersdirect

* NHS Choices www.nhs.uk

* Partners in Care www.partnersincareny.org

* New Deal for Carers <http://www.dh.gov.uk/en/SocialCare/Carers/index.htm>

Aimed at health professionals, this website contains information on Government guidance and regulations affecting carers, details of the current carers grant and other relevant information on carers' policy Department of Health

* Caring with Confidence: <http://www.caringwithconfidence.net/>

A knowledge and skills based programme which aims to help carers make a positive difference to their life and that of the person they care for.

From Anne: From 'The News' on 1st January 2010. **Carers in Portsmouth are being offered free emotional support from dedicated counsellors.** Up to 5 sessions are available through the joint forces of the NHS and Relate. People can go to the centre in Orchard Road, Southsea or can be visited in their home. Young carers can take someone for support. "Carers have to adapt to a new relationship with their partner, parent, sibling or friend and this often leaves them over looking their own wellbeing. There can be feelings of isolation, guilt and confusion over the future of relationships" Certainly sounds familiar!

Call 023 9285 1864 for more details

RESPITE?? : Do you need some respite but can't afford it? Get in touch with Barry and see if we can help. (Requests will be treated confidentially).



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Branch Meeting: February 6th 2010.

Who was there: Barry Blake, Elaine Frier, Sarah Hands, Dave Geary, Tony Geary, Colin Gould, Myra and George Heppenstall, Cliff and Avis Nevatte, Mark Robinson, June Slocombe, Anne Stephenson, Meg, Ben, Flo and Ellie Walters,

Apologies from: Brian Cady, Karen and Chantelle Durnall, Maureen and Peter Graham, Hugh Marriott, Barbara and Andrew McClelland, Annette Scivier,

What happened:

Chair's Report:

Barry briefly outlined the activities since the last meeting which had included a carers meeting in Portsmouth and the xmas outing to Osborne House on the Isle of Wight.

Treasurer's Report: Ben reported that branch finances were in a good state and that we had been able to meet several requests from members for financial assistance over the xmas period both from Branch funds and The Amanda fund. More details of Branch funds are available on request and a full report will be given at the AGM and will accompany the next newsletter.

Proposed outings: were discussed and dates agreed. Final arrangements were made regarding the social at the **Meon Hut on February 22nd**.

Donations:

Abbots Barton Nursing Home: Chantelle and Barry will be representing the Branch on the 18th February when a cheque will be presented from Abbots Barton Nursing Home, Winchester, to be shared between the Hampshire and Berkshire Branches. This is the result of several fund raising events including the Christmas fair where we had a stall and which several members attended. Thanks to Abbots Barton staff and residents for their support and their excellent care of one of our members. *Radio Solent featured a piece about this event and Chantelle on the Breakfast show on the 18th February.*

Langdale Nursing Home: Chantelle represented the Branch on February 12th at Langdale Nursing Home, Gosport and received a cheque for £107 on our behalf. This was raised during an HD awareness day and the activities included a Red Raffle. Thanks to Langdale staff and residents for their support and their excellent care of two of our members.

Amanda Fund: Thanks to the Peter Barker-Mill Memorial Charity for renewing their commitment to the Amanda Fund. Their decision to renew their donation was largely due to the letters sent by the many families who have benefitted directly from the fund describing how they had been supported.

The raffle prizes were donated to support the Red Raffle at Langdale Nursing Home. Thanks to all who brought prizes and bought tickets (raising £19).

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 much needed break for a young family. 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

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