



Website: www.hdahampshire.org.

Future Events:

ALL the following events are FREE to younger Branch members 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.

Branch meetings in 2011 are: March 26th AGM (with a speaker from the Princess Royal Trust for Carers), May 21st (with guest speaker author Barbara Grosvenor) July 16th, Sept 10th (TBC) and November 19th.

All Branch meetings are at 2pm at Sembal House, Handel Terrace, Southampton SO15 2FH. There is disabled access, ample parking and it is only 5 minutes from the central railway station and a bus stop. DVD player provided to entertain younger children.

Next Carer's Meeting: Next meeting is in Southampton on February 16th at The Cowherds (The Common, Southampton, SO15 7NN) **at 7:30 pm.** We can pick you up from the ferry if you are travelling from the Isle of Wight and the Branch can pay travel expenses.

February 15th Conference in Milton Keynes: This has some excellent speakers lined up including Charles Sabine who spoke at the 2009 HDA conference. He is HD positive and is a well known as a correspondent for NBC news. Other presentations include "*Huntington's Disease a Medical perspective, The Milton Keynes HD Pathway, The Role of the HDA, Expert panel Q and A*" Eve is going to this and has space in her car please contact her for more details. If you would like to go the Branch can pay your expenses.

February 26 -27th Telford: Young people's conference (for over 18s): Decisions Dilemmas and Discussions. This is organised by the HDA and was attended by 2 of our young people last year. The Branch will fund your attendance if you want to go through the Amanda Fund. Two of our Branch members went last year. See HDA website or contact Anne for more details.

Sunday 6th March: Amanda Fund Trip to Race Centre at Chandlers Ford (date TBC): **Have you ever fancied being a racing driver??!** We are booking a race event. This involves a driver's briefing and then up to 2 hours of virtual racing against each other in the comfort of a warm room. You are in charge of a virtual car going around a racing circuit. People who have already been say it was 'wicked' and 'awesome' (!!)
www.theracecentre.co.uk .This is a free Amanda fund event open to any young person in a family where one of the family members has HD but **you need to be 8 years or older**. Please contact Anne if you are interested. Places will go quickly and it is first come first served!!

Tuesday March 22nd Hampshire Neurological Alliance AGM: This is an umbrella organisation and useful lobbying group for all people in Hampshire affected by a long term neurological condition. Our Branch is a member and every is welcome to attend this meeting at Badgers Farm Community Centre Winchester from 1:30 to 3:30pm. There are 2 speakers: Dr Chris Kipps (Clinical lead Neurology RHCH Winchester) speaking on 'Neurological Conditions – The problems associated with Diagnosis' and Mr Geoff Woollan (Hampshire CC Commissioning Officer for Long Term Conditions) 'The Importance of Service User Involvement'. If you would like to attend (and I can thoroughly recommend the refreshments as I attended last year!) please contact Martin Cross (mart.cross@tiscali.co.uk or tel 023808590).

March 25th: There will be a special tour for Branch members of the **new** research labs in Southampton University to see the work of Andreas and the rest of the team who are doing research in to HD. Please contact Anne if you are interested.

March 26th Branch AGM with speaker: Dawn Campbell from **The Princess Royal Trust for Carers** is coming to speak to the Branch about the work they do in supporting carers in Hampshire (postponed from January). She has already been invaluable in supporting one of our families. Please support this meeting and find out what the Trust can offer you. If you wish to join the committee you would be sure of a warm welcome and new faces are always appreciated so don't be shy, contact Anne for details.



Sunday 10th April: Visit to Furzey Gardens/ Amanda Fund Horse Riding : We will meet at the Gardens near Minstead in the New Forest at 12:45 and will arrange to have afternoon tea together. Some of us plan to go on to have a drink at the Mill House in Lyndhurst. We also hope to organise horse riding for the youngsters before this (please ring Anne as soon as possible if you are interested in riding). For details of the gardens go to www.furzey-gardens.org.

April: Skittles A skittles evening will be arranged for April. Further details nearer the time.

May 4th 2011 @ 7:30 : Theatre trip to We Will Rock You. at the Mayflower Southampton: Please confirm your attendance with Maureen if you asked for tickets as we have a waiting list for those who were not lucky enough to get tickets and we would hate to see them go to waste if you are not able to attend.

13th to 19th June 2011 - Awareness Week

Friday 19th- Sunday 21st July at Avon Tyrell. Young People's Summer Camp –If you are interested let Eve know. We would love to see some new and not so new faces this year. Camp is free is a great opportunity to let your hair down and get stuck in. From raft building to water rides it is a full on weekend with an opportunity to be with people who share the same experiences.

Saturday 10th September : Family Day: Eve Payler and Ann Pathmanaban have arranged a Family's Day for Saturday 10th September the venue (TBC) is to be in the New forest and we have arranged a variety of speakers for the day. It is really hoped that we have a full house so please come along and make some new friends and hopefully find out a bit more about HD. Currently those who have agreed to attend are a Speech and Language therapist, a genetics nurse from Southampton, a speaker from Dendron (research team). We also hope to have a speaker too update us on the current research news and a speaker about support for carers.

Other events: We have more ideas for events in the coming year but would like to hear from you too. If you would like to see us run a particular event or if you would like us to use a venue near you please get in touch.

Other news:



New website: Have a look at this great new site written by scientists with news about HD research in plain terms at <http://hdbuzz.net>

Head Office news- The latest news can be accessed on the HDA website – www.hda.org.uk. In particular, assistance is still required with the research study called RESULT (Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions). Also, the BBC is making a documentary about the issues surrounding inherited genetic conditions to be shown next year and there are details of how you can be involved if you so wish.

Holiday Help? The Accessible Property Register www.accessible-property.org.uk has details of how to arrange care support if you are on holiday with someone who is disabled. It also has information about wheelchair accessible holiday accommodation and wheelchair accessible residential property for sale or for rent.

How do I get help? Home Care Assessments

Carers UK have produced a fact sheet with the above-mentioned title. It explains the help and support that can result from carrying out an assessment for either carers or disabled adults and children. Details are given about how to obtain an assessment and the kind of questions that will be asked. You can get a copy by ringing 0845 241 0963 or by sending an email to publications@carersuk.org.

Tripmobility: This company can provide equipment such as hoists, profile beds, wheelchairs, commodes and many other items throughout the UK for a single day or long term hire. The service is especially useful if you are going on holiday, or do not want to have problems associated with getting equipment into your vehicle, or if you wish to offer a disabled guest appropriate facilities whilst staying with you. Ring 01977 618043 or visit www.Tripmobility.com



Hampshire Branch Meeting: January 2011.

Present: Barry Blake (chair), Ann, Dave and Lorraine Docwra, Linda and Stu Franklin, Elaine Frier, Debbie and Philip Gater, Dave Geary, Tony Geary, Colin Gould, Maureen Graham, Naomi Honey, Stuart Kneller, Tabitha Leishman, Avis and Cliff Nevatte, Eve Payler, Meg, Ben, Florence and Ellie Walters,
Apologies: Myra Heppenstall, Caroline Lang, Hugh Marriott, Pat and Robbie Richardson, John Seller, Annette Scivier, June Slocombe, Trudi Smith,

What happened: The Raffle raised £18thanks to Flo and Ellie for their help.

George Heppenstall: There was a minute of silence as we thought of George who attended meetings for many years with his wife Myra. A few of the branch members attended the funeral and were touched by the turn out and kind words that were shared about George and his life.

Eve Payler: Eve, the Regional Care Advisor Hampshire/Berkshire and Isle of Wight talked briefly about her role. Eve has been in post for 3.5 years now. She currently works 4 days a week (not Fridays) and is available to all whose lives have been touched by HD to talk formally or informally about the challenges that HD can throw at you and offer practical support and advice. From benefits and care options to end of life issues and advance directives. Eve is also available to provide training to carers, care homes and other professionals. In the past 3.5 years Eve has had approximately 130 new referrals to the service and continues to find the role stimulating and rewarding. If you wish to contact Eve you can e mail her or call. See the contact details at bottom of first page.

Funding Surveys: Hampshire county council and Southampton city council have sent round a questionnaire regarding funding for care. Those who attend the meeting completed the survey. If you wish to take part please let Eve know and she can get the survey sent out to you. (It will be sent as an attachment if you receive the newsletter by email).

Treasurer's Report: Ben informed the group that the branch funds and Amanda funds remain exceptionally healthy. We have to consider what to do with the funds before the end of the financial year. Anything over £2K goes to head office core funds. The committee have discussed further funding of Eve's hours till September 2011 as the work of the RCA is vital life line to families in need. Don't forget the Branch can make grants in the case of hardship of up to £300, please get in touch if you need support or know of someone else who needs it.

Young People Networking: We discussed the need for the younger Branch members to be able to get together. We want to give younger members the opportunity to get the support they need both from each other and from Eve and the HDA itself. It is hoped that the Amanda fund social events will provide a forum for this and that ideas generated by the people participating in these events will be the spring board for more events in the future. We also discussed the idea of a Young Person's day. It could be something similar to a Family Day but specifically for younger people. If you have any suggestions, ideas or thoughts please share them with the committee as we want to offer the younger members an opportunity to network and find their own means of support. Please contact Anne or let us know at the next meeting.

Donations: Congratulations and thanks to Tony and Avis Nevatte's mother, Joan who celebrated her 90th birthday on 8th January. She very kindly asked for donations to be made to the HDA in lieu of birthday presents and so far has raised £185 towards branch funds.

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

CONTACT DETAILS: Website: www.hdahampshire.org.

Any comments or questions about this edition to:

Anne Stephenson (secretary) (secretstanne@aol.com or 01329 232373 Or 07748 631 876)
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 is on 02392 593683 or email m.graham11@sky.com