



Branch Website: [www.hdahampshire.org](http://www.hdahampshire.org). HDA: [www.hda.org.uk](http://www.hda.org.uk) Research news: <http://hdbuzz.net>

### 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.*

**!!!! Christmas Panto: Peter Pan at the Mayflower in Southampton matinee January 14<sup>th</sup> !!!!:** Please get in touch with Maureen **as soon as possible** if you are interested. Tickets are subsidised and will cost £12 (free to members of the Amanda fund).

**Branch meetings in 2011** are: July 16<sup>th</sup>, Sept 10<sup>th</sup> (as part of the family day) and November 19<sup>th</sup> (with speaker from TRACK HD).

**All Branch meetings** (except for the one on Sept 10<sup>th</sup>) **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 date TBA 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. **We have a carer's meeting in the Red Lion in Horndean on 8<sup>th</sup> June but this may have happened before you receive this newsletter. Please get in touch with Anne if you would like more details about carer's meetings.**

**13th to 19th June 2011 - Awareness Week:** The HDA is hoping people will do something to mark awareness week. They are suggesting people hold a garden party and packs of ideas are available free of charge from the HDA. We are hoping to run a stall at QA hospital in Portsmouth and Eve is running a professionals day at **Westbury House, West Meon.** Our members on the IOW are having a Garden Party with Cream Teas at **Christchurch Vicarage, Totland, IOW 2.30-4.30 Friday June 17<sup>th</sup>;** contact Annette on 01983 754427 if you would like more details of this. We are also having a stall at a garden party at **Shelley Park Nursing Home, Boscombe at 2pm on 18<sup>th</sup> June.** All branch members are invited to attend Shelley Park; please get in touch with Maureen if you can help on the stall or for more details.

**Saturday June 25<sup>th</sup> and July 2<sup>nd</sup>:** The Oxford Branch welcome anyone who would like to go gliding from 4pm until late (BBQ available-take your own food) at Shenington gliding club. Unfortunately we cannot subsidise this event this year but you will be made very welcome by the Oxford branch of the HDA. Flights cost £20. Please get in touch with Anne if you would like more details.

**Wednesday 6<sup>th</sup> July Meal at 7:00pm the Coach and Horses Gosport Road Fareham:** Please contact Maureen to book your meal (cost is about £6 per head)

**Sunday July 10<sup>th</sup> Family Outing and BBQ at Yarmouth Isle of Wight.** 'Mainlanders' should catch the 10.45 ferry from Lymington. The Amanda Fund will cover kid's ferry fares + BBQ, (adults £12.30 day rtn, BBQ £2). **Please e-mail ([a.scivier@btinternet.com](mailto:a.scivier@btinternet.com)) or phone 01983 754427 to give Annette numbers for the BBQ and to discuss access or other details.** We will supply crabbing equipment and there will be a BBQ and plenty of social time on the beach (sorry BBQ area is probably **not wheelchair friendly**). There are cafes, shops and the pier to explore in Yarmouth for those who are less mobile.

**Details of Family day and November Meeting on next page.....**

The Committee are happy to support others who would like to organise events or get involved in other ways. Please get in touch if you have any ideas.



**A message from Eve :** Please register with the national HDA if you haven't done so already as we need to make sure as many families as possible are counted in the national statistics as this will inform care provision and support for families in the future.

**Hampshire Branch Meeting: May 21st 2011.**

*Present:* Barry Blake (chair), Lorraine Docwa with Edwin, Dave Geary, Tony Geary, Barbara Grosvenor, Linda and Stu Franklin, Maureen Graham, Myra Heppenstall, Mark Howard, Hugh Marriott, Andy and Hollie McGinty, Shelley Pattenden, John Seller, Anne Stephenson, Meg, Ben, Florence and Ellie Walters,

*Apologies:* Debbie and Philip Gater, Sarah Hands, Avis and Cliff Nevatte, Hugh Marriott, Annette Scivier, June Slocombe, Trudi Smith, Andreas Wyttenbach

**What happened:** The Raffle raised £14 thanks to Maureen and Eli and Flo and £20 donations were made towards goods for the stall at Shelley Park.

**Speaker: Barbara Grosvenor** is a local author who is writing a novel where the main characters are dealing with HD in their family. Barbara has experience of nursing people in the latter stages of HD. She read excerpts from her book and asked for feedback. We look forward to seeing this book in print in the near future!

**Chair's Report:** Barry gave a summary of recent activities: Furzey Gardens and horse riding was a lovely day; Skittles evening was fun and well attended and 'We Will Rock You' was 'Awesome!' 12 people attended the last Carer's meeting.

**Treasurer's Report:** We have been able to support several requests from the hardship fund and continue to pay for Eve's extra hours until October 2011. Thanks to Trecia for raising £94 on the skittles night. We need to continue to raise funds to meet requests and support our activities; if you can help in anyway (eg sponsored events or by contacting your local Waitrose etc) then please do!

**Donations:** Many thanks to the **McClelland family** for their generous donation of a special support chair to the Branch. This is being passed on to a family who have need of it.

**Fund Raising: Annette Scivier** is taking part in the 'swim the solent' event on 8<sup>th</sup> September. She will be splitting any money she raises between the Hampshire HDA and the West Wight Sports Centre. If you can't do a fund raising event yourself please support Annette by sponsoring her and getting your friends to do the same. You can sponsor Annette and find out more at <http://www.solent-swim.co.uk/t/annette-scivier>

**Saturday 10<sup>th</sup> September : Family Day:** Eve Payler and Ann Pathmanaban have arranged a Family Day for Saturday 10<sup>th</sup> September at Brockenhurst from 11am until 4pm. Look out for a separate letter which will be sent out to advertise this event. They 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 to update us on the current research news and a speaker about support for carers.

**November 19<sup>th</sup> Branch meeting: Speaker from Track HD :** Dr. Nayana Lahiri BSc Clinical Research Fellow, TRACK-HD (who has been working with Lynda and Mick from our branch) is coming to talk about the progress of this research. She will also update us with news from the World Congress in Melbourne in September which she is attending.

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**The Huntington's Disease Association**

hunting for a cure - with care

HAMPSHIRE BRANCH:  
May/June 2011

**Amanda Fund:** The Amanda fund is to support youngsters of families in Hampshire affected by HD. It is funded by a grant from the Peter –Barker Mill Charity. At the last committee meeting we discussed the events supported by the Amanda fund as we are concerned that we need to be left with sufficient funds to meet requests for support as we feel it is important that the Amanda fund isn't only used to benefit those families which take part in events as some children do not join events but they need assistance in other ways.

We suggest the following guidelines:

1. **There is usually a ceiling of £20 per person for each social event** ( but special application can be made to the committee if family funds prevented a person taking part).
2. **Youngsters out of county** (who are linked to a Hampshire family) will be able to join Amanda fund events if their presence isn't preventing the attendance of someone from Hampshire. They should ask their own Branch to pay for their attendance or in a situation where this isn't possible we may support them up to £10 or half the cost of their participation whichever is the smaller amount.

**Books available to borrow:** The Branch has purchased a number of books which people are welcome to borrow (please return at or before the next meeting). The books will be brought to Branch meetings and carer's meetings but are also available by post (phone Anne). The following titles are available:

**Hurry Up and Wait** (Jimmy Pollard); **Huntington's Disease A Nursing Guide** (Steve Smith); **The Selfish Pig's Guide to Caring** (Hugh Marriott); **Huntington's Disease in the Family** (for young children, from the HDA); **Huntington's and Me- A Guide for Young People** (Alison Gray); **The Woman Who Walked in to the Sea** (Nancy Wexler); **Huntington's Disease- The Facts** (Oliver Quarrell); **Understanding Behaviour** (HDA); **Learning to live with Huntington's Disease- One Family's Story** (Sandy Sulaiman); **On a High Wire Without a Net – Living with Huntington's Disease** (Susan Lawrence); **Genes and Generations – Living with HD** (Alison Gray).

**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](http://www.hdahampshire.org).**

*Any comments or questions about this edition to:*

**Anne Stephenson** (secretary) ([secretstanne@aol.com](mailto: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](mailto: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](mailto:m.graham11@sky.com)