



Branch Website: www.hdahampshire.org. HDA: 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.

October 7th-9th National Family Conference and HDA AGM in Telford

Tuesday October 11th Wells Place Eastleigh from 2-5pm Public Consultation Meeting: Please try to attend an important event being organised by the H.N.A. and Southern Health. Val Cross and Paula Hull of Southern Health have worked very hard to plan this **Stakeholders and Public Consultation**. This meeting is one of several planned for different regions in Hampshire.

At these meetings the providers (Southern Health) want to hear the views of people with neurological conditions who use the health services. It is our opportunity to tell the providers what works well and where the gaps are.

The venue is in the centre of Eastleigh adjacent to the Swan Centre. There is wheelchair accessibility and disabled toilets. Parking, including disabled parking, is close to the venue. Val and the H.N.A. Committee hope that as many as possible will come to this meeting and take the opportunity to have their say about the provision for the care of people with a Long Term Neurological Condition. In order to plan the details of this meeting we would appreciate knowing how many people will be coming. Please RSVP to Val Cross at valcross@tiscali.co.uk (or phone Anne on 01329 232373) and if you have any specific needs please let us know.

Family Skittles Sunday October 23rd at The Mead End in Denmead: This will start at 1pm. The cost is £5 per head which includes a basket meal and game of skittles. Please phone Maureen (02392 593683) **by the 5th of October** if possible to let her know your choice of meal (chicken, jumbo sausage or Glamorgan sausage and chips or cheese or ham ploughmans). The address is 22 Mead End Road Denmead, Waterlooville, PO7 6PZ. Children will be paid for by the Amanda fund. We hope to see you there.

November 19th Branch meeting: Speaker from Track HD : Dr. Nayana Lahiri BSc Clinical Research Fellow with 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.

!!!! Christmas Panto: Peter Pan at the Mayflower in Southampton matinee January 14th !!!!: 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).

Next year's Branch Meetings are: 21st Jan, 24th March, 19th May, 14th July, 8th September, 1st Dec 2012

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 Meetings: We can pick you up from the ferry if you are travelling from the Isle of Wight and the Branch can pay travel expenses. **Please get in touch with Anne if you would like more details.**

Weds 2nd November at The Red Lion in Horndean at 7:30 pm.

Weds 30th November at The Cowherds in Southampton at 7:30

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*



Branch News :

Thanks to The Orchard House Care Centre for supporting us at their Summer Party 26th August which was very jolly and thanks to Annette, Becca and Co for representing us there.

The Art and cycle ride on the IOW was very much enjoyed by all, thanks to Becca and Annette for organising this.

Thanks to Eve and Dorset and Wilts RCA Ann Pathmanaban for organising the excellent Families' Day held in the New Forest on Saturday September 10th. We had a number of speakers for the day covering topics such as Speech and Language, OT input and HD and genetics counsellor Patricia Finnemore talked about options available when starting a family. There was also news from DENDRON about how to get involved in research. The event was rounded off with laughing yoga which was a roaring success and there was a carer's support group to share experiences. The afternoon ended with tea, cake and a raffle. Thanks to all those who attended and all that helped the day run smoothly; we look forward to the next one.

In August we sadly said goodbye to Andreas Wyttenbach who has been a friend and supporter of the Branch in many ways. Many members have taken advantage of his lab tours at Southampton University and he often attended Branch meetings. He made a very generous donation of over £200 to the Branch as he left. He had asked his work colleagues for donations to the HDA rather than accepting a leaving gift. We all wish him well in his home country of Switzerland where he is going to train as a teacher.

Donations: Thanks to Linda Franklin for her donation of £140 which se raised by doing a sponsored walk. Thanks to Zoe MacLaren for her further donation of £25.

Fund Raising: Annette Scivier's 'swim the solent' had to be postponed due to bad weather. The new date is set for the 24th September so hopefully she is home and dry by the time you read this!! 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/r/annette-scivier>.

Research News:

At the Family Day we had a talk from Christine Dean and Veena Agarwal from DeNDRON (the Dementia and Neurodegenerative Diseases Research Network). You can now easily get involved in HD research locally. For example there is a Physiotherapy sub-study which needs recruits at present. If you would like to get involved in this or future research please join REGISTRY. Veena can be contacted on 07787154913.

Aileen Ho at Reading University has been in touch. In mid autumn, they are starting some interesting new studies to do with speech and language. It involves listening or reading short sentences and then answering short questions about them, and also doing some talking. If anyone (patients and partners/companions) from Hampshire would like to take part and have a go at doing these interesting talking and language tasks, do get in touch (email a.k.ho@reading.ac.uk or tel Anne on 01329 232373). Aileen will arrange someone from the team to visit any volunteers at a convenient time at their home.

TV news: Shane Richie (one of our Patrons) presented a BBC Lifeline appeal which went go out on BBC One on Sunday 18th September at 16.45, it was repeated on BBC Two on Wednesday 21st September at 13.30, and is on the BBC website and YouTube. It is a 9 minute film, highlighting the work done by the HDA. The Southend branch agreed to be filmed, along side some other users of our service.

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.