



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: 21st May (with speaker **Barbara Grosvenor** a local author who is writing a book about HD), July 16th, Sept 10th (as part of the family day) 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.

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 have organised horse riding for the youngsters before this. For details of the gardens go to www.furzey-gardens.org .

Monday 18th April: Skittles evening at The Crofton pub in Stubbington at 7pm. This will include a meal and costs £8:95. Please let Maureen know if you would like to attend.

May 4th 2011 @ 7:30 : Theatre trip to We Will Rock You. at the Mayflower Southampton: We have a waiting list for those who were not lucky enough to get tickets so let us know as soon as possible if you are unable to attend but have received tickets. We would hate to see them go to waste.

Next Carer's Meeting: Next meeting is in Southampton on May 11th 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 hope to organise another carers meeting in Waterlooville soon. Please get in touch with Anne if you would like more details about this.**

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 a **Garden Party at Westbury House West Meon** is in the planning stages for the **13th June.**

Saturday June 25th and July 2nd: 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.

Friday 29th- Sunday 31st 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 Day for Saturday 10th September at Brockenhurst from 11am until 4pm. 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 to 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.



Hampshire Branch AGM: March 26th 2011.

Present: Barry Blake (chair), Heather and Erin Brookmier, Debbie and Philip Gater, Tony Geary, Colin Gould, Maureen and Peter Graham, Lauren Hallum, Sarah Hands, Myra Heppenstall, Naomi and Chris Honey, Chris Hunter, Caroline Lang, Lynda Mitchell, Eve and Jacob Payler, Annette Scivier, June Slocombe, Anne Stephenson, Meg, Ben, Florence and Ellie Walters, Rachel Yorke,

Apologies: Linda and Stu Franklin, Avis and Cliff Nevatte, Hugh Marriott, Trudi Smith.

What happened: The Raffle raised £22.

Barabara McClelland: There was a minute of silence as we thought of Barbara who was one of the founder members of the Branch with her husband Andrew. A few of the Branch members attended the memorial service which was a lovely celebration of Barbara's life. Thinking of others to the last she left her brain for research and a collection was taken which went to the HDA research fund.

Chair's Report: Barry gave a summary of the year's events and thanked the committee members for their work over the year. Special thanks also went to Trecia Aspey for organising social and fund raising events and to Tony Geary for helping open up and organise the venue for the meetings.

Treasurer's Report: (Thanks to Ben for all his hard work on this)

Accounts:				
April 2010 - March 2011	General Fund	Last year	Amanda Fund	Last year
Available funds @ 1.4.10	1,972.67		2,968.71	
Fundraising	815.54	2,131.85	0.00	
Grants	0.00	4,285.00	3,000.00	3,000.00
Donations	7,466.81	1,148.81	8.21	
Raffles	0.00	99.63		
Contributions to social events	231.00	360.00		
Interest	5.06	6.52	1.21	10.31
Total income	8,518.41	8,031.81	3,009.42	3,010.31
Grants & support	(1,697.65)	(2,067.72)	(1,081.52)	(957.44)
Social events	(1,356.32)	(4,013.82)	(1,285.46)	(1,160.00)
Conference costs	(540.00)	(142.00)	(45.00)	(475.00)
Branch admin	(31.95)	(338.45)	0.00	
Equipment	(522.42)	(155.00)	0.00	
Donation to Head Office	(3,740.00)	(1,400.00)		
Total expenses	(7,888.34)	(8,116.99)	(2,411.98)	(2,592.44)
Income - expenses	630.07	(85.18)	597.44	417.87
Proposed year end donation to Head Office	(650.00)		0.00	
Available funds @ 31.03.11	1,952.74		3,566.15	

The Committee:

The Committee for 2011 is composed of the following;

Barry Blake (Chair)

Anne Stephenson (Secretary) *Proposed by Elaine Fryer and Seconded by Naomi Honey.*

Ben Walters (Treasurer)

Maureen Graham (Social Secretary)

Annette Scivier (IOW Rep)

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.



Dawn Campbell: from **The Princess Royal Trust for Carers** spoke to the Branch about the work they do in supporting carers in Hampshire. Dawn is based in East Hampshire but there are other care workers who cover other areas. Of special interest was their 48h Emergency Care. This can be put in place in a matter of hours and is a free service to support a carer who has to leave the person they care for unattended unexpectedly (e.g. due to an accident). To receive this you have to register with the charity. There are also carers' support meetings and one to one support available. Full details are available through the web site www.carercentre.com or telephone the Winchester office on 01962 842034.

Hampshire Neurological Alliance AGM: Annette represented the Branch at this meeting and spoke briefly about the work of the HNA. Dr Kipps (who has worked with several Branch members was one of the speakers and he described the difficulty of diagnosing people with long term neurological conditions.

Track HD: Lynda talked about Track HD. A research project at the National Hospital for Neurology in Queen's Sq London in which she and Mick have taken part. This is designed to identify biomarkers which will enable the onset of HD symptoms to be identified and therefore may be useful in the future to determine when medication is required and to enable doctors to track the progression of the disease. Lynda described how the tests were tiring but that taking part in research was a rewarding experience and offered hope to the next generation.

Lab Visit: Naomi and Chris spoke about how much they had enjoyed the lab visit at Southampton University and what a warm welcome they had received. Thanks to Andreas Wytenbach and his team for this.

Donations: Thanks to The Royal Lymington Yacht Club Scow Division who made a generous donation of £313 after a talk by Hugh Marriott. Thanks also to Trudi Smith for her kind donation.

Books available to borrow: The Branch has purchased a number of books which people are welcome to borrow (and return!). They will be brought to Branch meetings and carer's meetings but are also available by post. 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.

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



Other news:



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

Carers Together:

Do you care for or provide support for a relative or friend?

Do you need advice & help from other carers who could support you ? We have received the following information from Carers Together:

Carers Together provides a voice for relatives, friends, neighbours, who are caring for or arranging care for someone else. It represents carers' views & needs at local & county level. It is an independent organisation run by carers for carers. There are a number of Carers Cafes which meet monthly for mutual support and to hear from a speaker, or you might like to try our healthy activities, Friday Munch Club Lunch Bunch, Pilates or summer outings, which are open to the carer and the person they care for. All of our groups are friendly informal groups who share support, experiences, concerns & information

Caring Active Listening Line - 08000 3 23456 available 9am -11pm 365 days a year. The service provides an independent non-judgemental listening ear for carers

If you would like any further info on the wide range of services

Carers Together provides contact Pilar, Wendy or Susie at: Carers Together, Unit 12, 9-19 Rose Road, Southampton, SO14 6TE Tel 023 8020 2623 or email pilar.callaby@carerstgether.org.uk or wendy.stratford@carerstgether.org.uk or visit www.carerstgether.org.uk

The West Surrey Branch share the following information...

RICABILITY - You might like to take a look at www.ricability.org.uk which is the website of an independent consumer research charity aimed at providing free, practical and unbiased reports for older and disabled people. The consumer reports give clear, factual and user-focused guides and are based on user tests by the disabled and the elderly. The reports and guides cover a wide range and include:

-Getting around – a guide on wheeled walking frames, powered wheelchairs and scooters; choosing a car and gives measurement data on over 500 cars for getting in and out and stowing wheelchairs.

-At home – how to choose domestic appliances, radios and digital TV equipment (including information about newer devices); making your kitchen easier to use and a guide to buying central heating controls if you have a visual impairment.

-Personal care – a guide to pill boxes, dispensers and reminders; bathing including general advice on using hoists, bath boards and seats; tips on choosing products for bladder and bowel control and where to get further help and advice. You can also get more information on 020 7427 2460.

Accessible Property Register launches personalised property alerts



Disabled and older people looking for wheelchair accessible accommodation can opt to receive e-mail alerts when wheelchair accessible property becomes available.

Specialist website, Accessible Property Register www.accessible-property.org.uk has launched the new feature allowing our website users to opt for automated e-mail alerts whenever new property adverts are posted. Site users can set up their own individual alert and select from a number of criteria including area (includes postal areas), property type, buy or rent, price/maximum weekly rent, and the combination of access features required.

Once a new advert for a property that matches selected criteria is posted on the APR website, an automated e-mail alert (including a link to the advert on the APR website) is sent within one hour. Anyone wishing to set up a property alert can do so free of charge by registering on the Accessible Property Register website at www.accessible-property.org.uk and following the links.

Improving mobile phone advice for disabled users

A new website has been launched to help consumers search for and compare the accessibility features of thousands of mobile handsets.

The mobile accessibility website (<http://www.mobileaccessibility.info/>) is part of an initiative designed to help disabled and elderly people identify mobile phones that have the features they need.