



Branch and Support Group News

An update from the HDA

Issue 1

22nd July 2009

Special points of interest:

- New & updated factsheets available to download
- Updated Standards of Care & Physician's Guide available
- New HDA wristbands for sale
- Awareness Week dates for 2010

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Black Tie Dinner – 30th October 2009

We are pleased to confirm that the black tie dinner planned for Friday 30th October 2009 will be taking place at the Crowne Plaza hotel on the waterfront in Liverpool from 7.30pm until late.

I have attached a temporary flyer and booking form (including information on nearby hotels for accommodation), which you can share with your branch/support group members.



We are in the process of having a professional flyer and tickets designed and printed for the event and we will send the final flyer out to you as soon as it is available.

Tickets cost £60 each or £550 for a table of 10 people. The evening includes a three course dinner, a solo performance by Tony Hadley, an auction and a disco.

We advise people to book early to avoid disappointment as the number of tickets available are limited.

We hope to see you on the night!

Southend Branch play: Dustbowl Refugee

The Southend Branch are putting on a musical drama regarding the life of Woodie Guthrie. Dustbowl Refugee will be on at the The Theatre at Shoeburyness Technical College in Shoeburyness, Essex on 23rd and 24th September.

I have attached a flyer for the event, should your members be interested in attending (attached with this e-mail). All enquiries regarding the event should be directed to Lee Pankhurst on 07986 733369 or email: leepankhurst@hotmail.com.

Big Fun Run



This is just a reminder that the Big Fun Run (5km) will be taking place at venues across England and Wales during August, September and October: Derby, Liverpool, Leicester, Coventry, Sheffield, Leeds, Cardiff and Milton Keynes.

We are a charity partner of the Big Fun Run and entry into each event is simple: please visit www.bigfunrun.com, select the date and venue and remember to select the HDA as your chosen charity.

Alternatively, entry forms are available from Head Office or can be downloaded from our website: <http://www.hda.org.uk/download/events/HDA-Big-Fun-Run.pdf>.



South Wales Branch Chair to run the New York Marathon!

and he is now set to run the New York Marathon in November this year!

Peter has secured his place, with a little help from the Huntington's Disease Society of America, and will be splitting his fundraising between their Society (\$1000) and the rest will come to the HDA.

You may remember that Peter Morse ran the Flora London Marathon for the HDA last year

If you would like to sponsor Peter, please visit his Just Giving page online:

<http://www.justgiving.com/Peter-Morse>

HDA T-shirts

We are pleased to let you know that we now have our pink HDA t-shirts available in all sizes (small, medium, large and extra large).

Unfortunately, due to an increase in printing costs, we have had to

increase the price of our t-shirts to branches and the public.

The cost to branches will be £9.50 each (cost price) and they will be sold to the public for £10.50 each.



New HDA Wristbands available

Courtesy of the Southend Branch having ordered some new wristbands, the HDA now has these for sale again at Head Office.

We have them in both adult and children's sizes and they are available for £1 each. The bands are green with white text printed on them.

Please contact Head Office to place your order.

New Factsheets, Standards of Care and Physician's Guide

We have some new and some updated factsheets available to download from our website (hard copies available from Head Office), including HD and the Law, and a Carers factsheet.

Please do check our new website page: <http://www.hda.org.uk/hda/fact-sheets.php> for more information.

We have also updated our Standards of Care document, which is available to download from the same webpage as our factsheets.. Our Physician's Guide has also been revised and hard copies are available from Head Office.

Who Sees What Project

The New Economics Foundation (NEF) is running a project to help members of organisations learn about the new systems of electronic patient records in the NHS, and contribute to the debate.

Stephen Whitehead, the Project Manager from NEF has asked if anyone from the HDA would like to be involved. If anyone is interested, they will provide you with the training and materials to run your own

discussion events for members, and free optional training sessions will run throughout the summer and autumn, so that discussions will take place between September 2009 and January 2010.

The new electronic patient records systems have the potential to profoundly change the way that some patients experience the NHS:

- Patients receiving care from lots of different

providers could have access to a single joined-up service

- Patients with chronic conditions could access their record and manage their own health online
- In the long term all patients could benefit from making it easier and cheaper to re-search new drugs.

As well as the potential benefits, there are also risks.

I am informed that the

discussions take around an hour and a half to complete and then you would be required to send an e-mail to feed back to the project.

For more information about the project, please visit their website: www.whoseeswhat.org.uk.

If you would like to get involved, please contact me as soon as possible so that I can forward your details on to Stephen Whitehead.

Accessible Property Register launches new UK 'Property Wanted'

The HDA have been made aware of the following information. Other than the information provided below, we don't know anything about this company so we are not endorsing or recommending their services to you. However, we realise that this service may be of interest to you, and are therefore forwarding the information on:

Specialist property website, the Accessible Property Register, www.accessible-property.org.uk has launched a new service designed to help anyone searching for property for sale or rent.

Property to You www.propertytoyou.co.uk is the first dedicated UK 'property wanted' website – and it's free to use!

Anyone looking for property for sale or rent anywhere in the UK can post a listing describing in detail exactly what they are looking for. Sellers, agents, landlords, or social housing organisations with property available can reply via secure e-mail. And Property to You undertakes a full UK search for available property matching your requirements.

Property to You is a mainstream website, but includes options to specify wheelchair accessible property, retirement property, and supported living.

Property to You features:

Place free 'Property Wanted' listings and bring your ideal property to your desktop!

- Let sellers, estate agents and landlords know what you are looking for even **before** property is advertised.
 - We undertake a full search for matching property and e-mail a link to the results.
 - Stay in control - contact details are not visible on the listing and responses come via secure e-mail.
 - Make direct contact with the sellers, agents and landlords, speeding up the process and saving fees.
- We inform local estate agents, landlords, and private individuals registered with us when new listings are posted.

For more information about this service, please visit www.propertytoyou.co.uk.



The new 2009 Webb Ivory catalogues are available from www.webbivory.co.uk.

If you signed up to Webb Ivory last year you should by now have received this year's catalogue.

If you are interested in signing up this year, please visit their website above, or call their Careline on 0871 376 9977.

Awareness Week 2010

Awareness Week next year will take place from:

14th June to 20th June 2010

We will shortly be discussing next year's theme and activities and will share these with you as soon as possible.

In the meantime, if you have any ideas on a theme for next year's Awareness Week, please do get in touch with Becky Davis: becky_davis@hda.org.uk.

Our First Regional Branch Meeting

“Awareness Week 2010 will take place from 14th to 20th June”



Our First Regional Branch Meeting took place in Newcastle Upon Tyne for the north of England Branches on Saturday 4th July 2009.

There were 23 people in attendance representing the following Branches:

- Newcastle
- Easington District
- County Durham
- Cumbria
- Merseyside.

The agenda items were set at our planning meeting in January: Fundraising, Branches website, Raising Awareness of HD.

The meeting ran from 10am until 1pm, and some excellent ideas were shared amongst the group.

Each Branch left the meeting with some new fundraising and awareness raising tips to try with their own branch, plus a website is going to be developed which all of the northern branches can tap into to advertise and report on their local events and activities.

Watch this space for information on our next Regional Branch Meeting!

Please share the enclosed information and attachments with your Branch/Support Group members.

If you have any queries regarding the contents of this Branch and Support Groups newsletter, please do not hesitate to contact me: **Becky Davis, Branch & Events Co-ordinator, Tel: 01743 369107, E-mail: becky_davis@hda.org.uk**.

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