

## **NYSTAGMUS NETWORK (UK) NETLETTER**

### **July/August 2005**

#### **RESEARCH FIRST**

September sees our research workshop taking place in the UK. It's hard to exaggerate the potential importance of this event. The workshop:

- is the first ever research meeting dedicated to nystagmus
- brings together more than 25 experts from around the world
- will result in a new book on nystagmus
- is the biggest single investment NN has ever made
- is supported by the Esmée Fairbairn Trust

The overall objective is to consider what research and work must be done to create the pathways towards possible cures for the involuntary movement of the eyes caused by nystagmus and the associated visual impairment.

Vivien Hepworth, NN's honorary president, said: "Because it is so complex, nystagmus has been described as a graveyard of ambition for anyone seeking to treat or cure it. We want to change that negative attitude and demonstrate firstly that we can improve our understanding of this condition and secondly, from there, move towards possible treatments and/or cures."

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#### **Volunteers Wanted**

The research team at Leicester University has almost finished its assessment of a possible drug therapy for Congenital Nystagmus. However, they need six more people with idiopathic nystagmus (i.e. where there is no known cause for the nystagmus) and one person who does know the cause of his or her nystagmus. If you are not sure what kind of nystagmus you have the Leicester team will be happy to examine you to find out.

For further information click here. (Andrew the link is to <http://www.nystagmusnet.org/Research.htm>)

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## **Sight Village Exhibition**

Don't forget to visit the **Sight Village Exhibition** at **The Clarendon Suites, Hagley Road, Edgbaston** Tuesday 19th July to Thursday 21st July. The Nystagmus Network will be exhibiting in Hall A on the mezzanine floor. For full details of the event, including symposiums and seminars visit [www.qac.ac.uk/sightvillage](http://www.qac.ac.uk/sightvillage)

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## **Accessible Mobile Phones**

The RNIB has a fact sheet regarding mobile phones that are accessible to visually impaired people – especially people who are unable to use the screen display. Contact the RNIB Helpline Tel: 0845 766 9999 (local rate calls) or Email: [Helpline@rnib.org.uk](mailto:Helpline@rnib.org.uk).

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## **Working Group on Accessible Biometrics**

*The following information was taken from e-access bulletin., To subscribe to this free monthly bulletin: email [eabsubs@headstar.com](mailto:eabsubs@headstar.com) with 'subscribe eab' in the subject header. For further information, please go to <http://www.headstar.com/eab>.*

A European group has been set up to research the potential of biometrics - the use of a body part to identify individuals and access their personal data - for people with a disability.

The Social and Environmental special interest group of the European Biometrics Forum (EBF - <http://www.eubiometricforum.com/>), which will also look at ethical and usability issues, will have its first meeting this Summer. Its creation was announced at a recent London conference on accessible biometrics ( <http://fastlink.headstar.com/bio4> ). "There's a huge amount of work that needs to be done on how biometrics could help disabled people," said Will McMeechan, head of business futures at Nationwide building society and chair of the new group. "I want to try and show biometrics could be useful for people with a disability. It could be seen very much as an enabling technology."

The group will also produce best practice guides for creating accessible biometric systems, covering areas such as interface design.

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### **New research poster on Nystagmus**

Chris Harris has just added a new research poster on nystagmus to his website. The link is

<http://www.harrislab.com/lab/DistalCNmodels.htm>

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### **A date for your diary**

Friday 18th - Sunday 20th November 2005

"REAL LIVES" Europe's leading event for people with a personal or professional interest in Albinism at the Radisson SAS Hotel, Edinburgh.

For more information go to [www.albinism.org.uk](http://www.albinism.org.uk)

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### **Contributions**

Please send contributions, ideas or links for the NetLetter to Gill Taylor at [gill@taylors.uk.com](mailto:gill@taylors.uk.com).