

# NYSTAGMUS NETWORK (UK) NETLETTER

## November 2005

### PATIENT'S RIGHTS

Some of our members have reported that they are being refused referrals (probably for funding reasons) to eye specialists with knowledge and experience of nystagmus who are outside their own PCT (Primary Care Trust) catchment area. We feel very strongly that people who have nystagmus should be able to choose which consultant they wish to see. If you have been refused a visit to your chosen eye clinic or consultant please let us know by email to [info@nystagmusnet.org](mailto:info@nystagmusnet.org).

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### A GENETIC STUDY TO LOOK FOR GENES FOR CONGENITAL NYSTAGMUS

UK volunteers request from Southampton University Human Genetics Division and Southampton General Hospital Eye department

#### What is the purpose of the study?

Nystagmus can occur secondary to other eye diseases, or a number of medical conditions. However, in many cases it occurs from birth with no other medical problems (Congenital Idiopathic Nystagmus). In some cases many people from the same family may be affected and by comparing the DNA that these people share (and also sporadic cases) the causative gene faults can be identified.

We plan to locate, identify and discover the function of these genes and understand how they cause nystagmus.

#### Am I able to help?

Yes, if you have Congenital Idiopathic Nystagmus (not secondary to another problem).

#### What do you want from me!?

- A DNA sample from a painless spit sample (or cheek swab for infants)
- Information about which, if any, relatives have nystagmus

#### Will I need to travel to provide the sample?

**NO.** We can send the information packs, consent forms and DNA sample kits to you for minimum hassle.

For further information, email Mr Jay Self at [jes3@soton.ac.uk](mailto:jes3@soton.ac.uk)

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## Technology Awareness

An RNIB event called techshare 2005 is being held on November 17-18, details at [www.rnib.org.uk/techshare](http://www.rnib.org.uk/techshare).

[www.revealweb.org.uk](http://www.revealweb.org.uk) is all about finding information in accessible formats.

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**CINEMA EXHIBITORS ASSOCIATION CARD.** (from Contact-a-family Newsletter October2005)

Holders of this card are entitled to one free ticket for a person to accompany them to the cinema. The card is for the person who needs accompanying and is valid for three years. To apply for the card, you need to meet one or more of the following criteria:

- be in receipt of the disability living allowance or attendance allowance;
- be a registered blind person;
- be a holder of a disabled person's rail card.

There is a processing fee of five pounds per card. The application form can be obtained from the website at <http://www.ceacard.co.uk>, from participating cinemas (these are listed on the website) or by calling 0151 348 8020.

## Accessible Victoria & Albert Museum

Information about monthly events for the visually impaired at the V&A is available from [http://www.vam.ac.uk/activ\\_events/disabilities/v\\_impaired/index.html](http://www.vam.ac.uk/activ_events/disabilities/v_impaired/index.html)

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

**Digital Guide:** A handheld computer for outdoor navigation has been developed by assistive technology company Bones GmbH with two Swiss national blindness organisations. The 'Personal assistant for visually impaired people' (PAVIP) provides audible prompts for directions, locations of key landmarks and public transport information: [http://www.bones.ch/english\\_version/pavip/](http://www.bones.ch/english_version/pavip/) .

## Contributions

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