

NYSTAGMUS NETWORK (UK) NETLETTER
July/August 2004

UK RESEARCH REQUESTS

Volunteers are wanted to help with two projects, one in Surrey, the other in Leicester. The Royal Holloway is a repeat request and the team there would like to thank those who have already taken part.

The Leicester research is a new project being conducted by Professor Irene Gottlob, one of the Nystagmus Network's Medical Advisers. We have called for volunteers before, but the project is about to start soon and more volunteers are needed.

Request for volunteers from the Vision Research team at Royal Holloway, University of London:

Our group has several active research projects examining the routing of visual information from the eyes to the brain and the brain activity involved with processing visual information. Certain patient groups, such as those with albinism, have both atypical organisation of the visual pathways and uncharacteristic brain activity patterns when shown patterns. The processes that govern such diversity are poorly understood and we're interested in determining the contribution of nystagmus to such patterns and help us understand better the development of the human visual system.

What would you do if you wanted to take part?

We ask you to lie in a magnetic resonance imaging scanner (MRI) for approximately 40 minutes and look at visual patterns. During this time, the scanner takes pictures of your brain, which are used to produce the brain activity maps.

Is it safe & does the study have ethical approval?

There are no known harmful effects from the scan. As a strong magnetic field is used, individuals who have pacemakers, for example, won't be able to participate.

The study is approved by the ethics committee of the Psychology Department at Royal Holloway. Volunteers are free to withdraw from the study, at any time.

Where does the research take place?

At Royal Holloway University in Egham, about 8 miles from Heathrow.

What do the participants get?

We cover travel expenses from within the UK and a gratuity of £20 together with a picture of your brain if you want one.

Contact:

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LEICESTER RESEARCH

“Treatment of congenital nystagmus with medication”

By Professor Irene Gottlob (a medical adviser to the Nystagmus Network)

Ophthalmology, University of Leicester

CALL FOR VOLUNTEERS

We have found that medication can improve the vision in some people with nystagmus. We are conducting a study to compare the effect of two different drugs in congenital nystagmus. We would also like to compare these drugs with a placebo (pills that contain no active drugs).

Further details can be found in the Research section of our website.

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ASK A QUESTION

We are planning a major update of our book “Early Onset Nystagmus” with the help of our Scientific Adviser Chris Harris. The book is largely in question and answer format. We’ll be adding to this with some new sections plus some additional Q&As. If you have a question about nystagmus which is not in the current edition of the book, please email it to eyesitejs@msn.com.

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HEAD POSTURE RESEARCH IN SWANSEA, UK

The research project below is being carried out by staff in the eye department of Singleton Hospital, Sketty Lane, Swansea, SA2 8QA, telephone 01792 205666. The Nystagmus Network has already provided a number of participants for this project, but the hospital would like to see about a dozen more to complete their work.

Further details can be found in the Research section of our website.

The following articles were taken from the E-Access Bulletin for more information please visit: <http://www.headstar.com/eab>

EUROPE LAUNCHES MAJOR ACCESS PROGRAMME.

The European Commission has launched a major new programme of research into accessibility policies across EU member states, paving the way for a set of accessibility guidelines to improve access to digital services and technologies for disabled users across the continent.

The eInclusion@eu project (<http://www.einclusion-eu.org>) will examine national and regional policies on access to employment, public sector technology procurement, and access to online public services such as e-government, e-health and e-learning. As part of its work the 30-month project aims to build an EU-wide picture of accessibility requirements for government web sites, including which accessibility standards are used, if compliance is voluntary or mandatory, and whether feedback from users is collected and acted on.

BANKS NAMED AND SHAMED OVER CARD PROBLEMS.

UK banks who fared poorly in a 'mystery shopping' exercise to test the accessibility of new-style credit and debit cards are to be "named and shamed" by the RNIB.

The cards tested use a new so-called 'Chip and PIN' system designed to combat fraud by requiring users to key in a security PIN number whenever a purchase is made. Banks are supposed to offer and explain an alternative to Chip and PIN called 'Chip and signature', which is easier for some people with impaired vision

since they may find keypads hard to use. However, the survey found that many were not doing so.

Results of the mystery shopping experiment will be published towards the end of August and will include full details of which card issuers were contacted along with a breakdown of the results.

For more information visit

http://www.rnib.org.uk/xpedio/groups/public/documents/publicwebs/ite/public_mysteryshopping.hcsp

GUIDELINES FOR LOCAL GOVERNMENT CHIEFS.

The RNIB has published guidelines for senior managers and policy-makers in local government on how to make new technologies, from smart cards to tactile displays, more usable by people with disabilities.

Written by Dr John Gill, chief scientist at the RNIB, the 'Accessibility' booklet (<http://www.tiresias.org/guidelines/access-ability/>) provides an overview of design considerations to be taken into account when developing new services. From transport and financial transactions to telecommunications and computing, the publication outlines common problems experienced by the elderly and disabled and offers suggestions for addressing them.

The guidelines were developed in collaboration with Comité Européen de Normalisation (CEN - <http://www.cenorm.be>), the European technology standards body.

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Contributions

Please send contributions, ideas or links for the NetLetter to Gill Taylor at gill@taylors.uk.com