

NYSTAGMUS NETWORK (UK) NETLETTER

October 2004

TOP UK NYSTAGMUS RESEARCHER

Professor Richard Abadi, one of the leading nystagmus researchers in the UK, has agreed to be a guest speaker at our 2005 Open Day.

Richard has been researching nystagmus at Manchester University for more than 20 years. He is also advising NN UK on the first ever international nystagmus research workshop to be held in England next year.

At our Open Day in Birmingham next May, Richard will talk about "Research Directions in Nystagmus" and explain what we want to achieve from the international workshop later in the year.

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NYSTAGMUS IN WOKINGHAM

A member of the Nystagmus Network from Berkshire, who has a 2 year old son with nystagmus, would like to talk to others in similar circumstances. If you live in the Wokingham area, please contact Elizabeth Norwood by emailing liz@scrutchley.co.uk.

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TEACHERS' PACK LAUNCH

On October 14th, in conjunction with World Sight Day, we will be launching our new information pack for use in schools. This pioneering information pack outlines the problems caused by nystagmus and suggests practical solutions for use in the classroom.

Claire Entwistle, NN acting chairman, said: "I know from my own experience that ignorance about nystagmus often made my school days a nightmare. The information we have brought together in this pack means that children with nystagmus no longer have to suffer needlessly the way that previous generations did."

The pack was written with the help of specialist teachers of the visually impaired, Learning Support Assistants, parents, adults and, perhaps most importantly of all, children with nystagmus. It

also draws on unique research carried out by the University of Plymouth for the Nystagmus Network.

Topics covered in the Teacher Pack include:

- Starting school with nystagmus
- Good ideas from children with nystagmus
- Ways to help in the classroom
- Working with parents
- Advice for Learning Support Assistants (LSAs)

The 40 page pack will be available from mid October at a price of £15. To order a copy in advance, email Paul White at info@nystagmusnet.org

For more information about World Sight Day see www.v2020.org

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NEW LOOK NEWSLETTER

The latest issue of Focus, our quarterly newsletter, has a new layout and pictures. Articles include advice from our patron Sir James Galway OBE, an article on Blind Sports and experiences from people with nystagmus.

Focus will be sent to all NN members during October and is available in large print, on tape and disc.

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RESEARCH REQUESTS

Three research centres in the UK are looking for volunteers with current projects.

- Leicester is recruiting people willing to take part in a two months drugs trial.
- Swansea needs another dozen people to make one visit to have their null point measured. They will pay travel expenses from anywhere in the UK.
- Royal Holloway near Heathrow has asked for people willing to spend 40 minutes in an MRI scanner.

For more information, contact Paul White at info@nystagmusnet.org

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WANTED: MEMBERS OF THE PUBLIC TO BE PART OF ADVISORY GROUPS TO SHAPE MEDICAL RESEARCH

The Medical Research Council (MRC) is keen to hear from anyone who has strong views on public health and medical research issues, with the time, energy and enthusiasm to want to make a difference to medical research and the work of the MRC.

The MRC is inviting members of the public to apply to join a choice of two public involvement advisory groups. The groups will build on MRC's existing public involvement work started four years ago, with a view to further developing and expanding activities and outreach across the UK.

Members play an active role in discussing ethical issues, commenting on documents, such as patient information leaflets, and take part in consultation on topics like clinical trials, the UK Biobank and the Human Tissue Bill.

The two new groups offer an opportunity to get involved at a level and location that would suit a volunteer's interests and availability.

The two groups will both have an interest in national issues and will help make the MRC aware of and able to respond to people's interests and concerns about medical research, and advise on ways to promote public involvement in MRC research activities.

The positions on both groups are voluntary, but all expenses are covered.

MRC is looking to recruit people from a diverse range of backgrounds and life experiences who have good communication skills, plenty of enthusiasm, an interest in the aims of committee, the ability to devote time and energy to the subject, a wide network of existing contacts and a willingness to make a valuable contribution to public health in the future. Selection will take place the week beginning 11 October 2004.

Application forms are available from http://www.mrc.ac.uk/index/public-interest/public-advisory_group_public_involvement/public-new_members_agpi.htm or by emailing

fatima.deabreu@headoffice.mrc.ac.uk. Or calling Fatima De Abreu on: 0207 636 5422

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The following information was taken from e-access bulletin, a free monthly e-mail newsletter. For further information and to subscribe, please go to: <http://www.headstar.com/eab>.

First Magnifier Software Launched For Mobile Phones.

The first magnification software for mobile phones will be available by the end of this month, allowing users of compatible phones to enlarge their on-screen text by downloading the software over the web.

Various areas of a phone's screen display can be magnified, and the software can be configured to begin working as soon as the phone is switched on. Mobile Magnifier works with Nokia 3620; 3650; 3660; 6600; 6620; 7610; 7650; N Gage; N Gage QD; and Siemens SX1 handsets.

The software, whose price has not yet been decided, has been designed by Spanish programming company Code Factory (<http://fastlink.headstar.com/code1>).

EASY READ

A font designed for vision-impaired people by the American Printing House for the Blind has been improved to make it even easier to read, and is available for free download on the web. APHont now has bold and italic versions, and results from user group testing found 60 per cent of users preferred it to other fonts: <http://www.aph.org/products/aphont.html> .

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Contributions

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