

NYSTAGMUS NETWORK (UK) NETLETTER

February 2007

Thank you!

Many thanks to everyone who purchased NN Christmas Cards. Sales were very good and all the profit will be ploughed back into the Nystagmus Network. Our apologies to any member who did not get their order as requested; we did have to substitute a few orders as we sold out of two designs very quickly. Next year we hope to have a card with a religious theme, as requested by some members.

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One Vision - Nystagmus Network Open Day

Saturday July 7th at Queen Alexandra College in Birmingham.

This year we are working with the Albinism Fellowship and N.B.C.S to produce a range of indoor and outdoor fun activities for children of all ages leaving the adults to get together to discuss matters of interest and share common experiences.

A full day for people who have nystagmus, their friends and families to include an update on findings in Nystagmus and Albinism research.

The Annual General meetings of the Albinism Fellowship and the Nystagmus Network will take place on the day, come along and have your say.

Pre-ordered lunches will be available from the college catering service and transport to and from the railway station will be provided via executive coach.

Full programme details will be on the website shortly and in the March edition of Focus

For further information phone Paul on 01636 627004 or email info@nystagmusnet.org

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Passport Applications

Passport applications (renewal or first time applications) can now be completed on the Passport Office website <http://www.passport.gov.uk>.

It is much easier than wading through the form you get at the Post Office and there is an "RNIB Friendly" button at the top right of the application form itself that brings up a large print version. When you have completed the on line form you send it back electronically and they will check it and send it to you as a paper copy ready for signatures and photos. Easy as pie!

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Training days in Bristol and Sheffield

These events are aimed at professionals and families affected by nystagmus. They cover everything from the latest research and medical options to what it's really like to live with nystagmus. Feedback from previous events includes:

- "Very informative and a lot to think about."
- "Very good hearing from people who have the condition as we were given 'first hand' knowledge."
- "The personal accounts were invaluable. The medical background was very interesting and it will be useful to have the 'laymen' knowledge behind advice for parents."

The speakers for Bristol on March 7 are:

- Debbie Wiggins, a post-graduate vision scientist at Cardiff University who has nystagmus herself.
- Paul White, NN Information and Development Manager and father of two sons with nystagmus.
- John Sanders, NN vice-president and freelance journalist who also has nystagmus.

The Sheffield speakers on March 20 are:

- Professor Chris Harris of the University of Plymouth, a vision scientist, author of Early Onset Nystagmus and adviser to NN.
- Faith Budge, a researcher at the University of Plymouth who has carried out one of the most comprehensive surveys into the effects of nystagmus.
- Debbie Wiggins (see above).
- John Sanders (see above).

NN is working with the RNIB on these two events. For further information contact:

- about Bristol -- Gina Large at BristolTemp@rnib.org.uk
- about Sheffield -- Rachel McHale at Rachel.McHale@rnib.org.uk
- or NN's Paul White at info@nystagmusnet.org

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Seminars in Ophthalmology

A few copies of the "Seminars in Ophthalmology" supplement dedicated to nystagmus are still available (UK only, £8.80 each) from John Sanders, email eyesitejs@msn.com.

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UltraCane is now available via two easy payment options. For more information, please telephone 01423 326212, or e-mail info@soundforesight.co.uk

PhD Studentship (2006-2009) - Visual Function in Nystagmus Cardiff School of Optometry and Vision Sciences, Cardiff University

A PhD studentship is available to investigate the impact of stress on visual function in congenital nystagmus. This studentship is open to UK and other EU candidates who have obtained at least a 2.i honours degree in optometry. The successful applicant must be a member of the College of Optometrists throughout the tenure of this studentship, which provides a stipend of £16,010 per annum (to include fees and maintenance).

Informal enquiries are welcome and can be made to Dr. Jon Erichsen at ErichsenJT@cf.ac.uk. Further details at: <http://www.cardiff.ac.uk/optom/BSc/BSc.html>

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Pathways for Children

‘Working together for children who are blind and partially sighted - Every Child Matters ‘

A conference organised by North Yorkshire County Council about breaking down barriers, improving communication and interagency working. This event will be of interest to anyone working with children in the areas of health, education, social care and the voluntary sector. Key Note Speakers are Professor Alistair Fielder, City University London and Mary Bairstow, Vision 2020.

Pathways for Children is on Friday 23 March 2007 at The Pavilions, Harrogate and costs £150 (Concessions £60). Please quote code YH/06/B19.

Further details from Becky Newham, RNIB, Grosvenor House, Grosvenor Road, Leeds, LS6 2DZ Tel: 0113 2748855 Fax: 0113 2748800
Email: rnibyorkshirehumberandnortheast@rnib.org.uk

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Metropolitan Society of the Blind

John Harris has succeeded Frank Luck as the society’s Chief Executive. During 2007 they will be considering their aims and ambitions for the future. They are seeking your thoughts on:

- Their efforts to overcome loneliness and isolation by visiting people in their own homes.
- The way they help people newly diagnosed with visual impairment via links with four inner London hospital eye clinics.
- Their welfare rights advice service which helps people with visual impairment claim benefits
- Their role in delivering audio equipment on loan from the British Wireless for the Blind Fund
- Their grants to individuals and organisations working directly with blind and VI people
- Anything else you think they need to think about as they make plans for the next 5 to 10 years

You can phone them on 0207 403 0134, Email them at enquiries@msb.gb.com or Write to them MSB Lantern House, 102 Bermondsey Street, London SE1 3UB