



**NYSTAGMUS NETWORK (UK) NETLETTER**  
December 2004/January 2005



**Seasons Greetings to all readers**

## **NEW RESEARCH REQUESTS**

### **LONDON: GREAT ORMOND STREET HOSPITAL in co-operation with the INSTITUTE OF CHILD HEALTH**

NN scientific adviser Richard Clement and Maria Theodorou are looking for young child volunteers (6 months-4 years), to assess eye movements. It will involve a 30-60 minute visit to Great Ormond Street Hospital for non-invasive eye movement recording. If anyone is interested, and lives in or near London, please contact [m.theodorou@ich.ucl.ac.uk](mailto:m.theodorou@ich.ucl.ac.uk) or [r.clement@ich.ucl.ac.uk](mailto:r.clement@ich.ucl.ac.uk).

Maria is an ophthalmologist who has recently joined David Taylor and Richard Clement at the Institute of Child Health. They are researching a new approach to congenital nystagmus which may lead to a new treatment to improve the visual acuity of children. At present they are looking at the nystagmus waveforms of nystagmus patients (mainly those with congenital idiopathic nystagmus and ocular/oculo-cutaneous albinism).

### **PLYMOUTH -- MS AND NYSTAGMUS**

NN scientific adviser Professor Chris Harris is planning some research which may help people who have nystagmus as a result of MS (Multiple Sclerosis). If you have MS and nystagmus and would like to find out more from Chris about possibly taking part, please phone him on 01752 233150 or email [C.M.Harris@plymouth.ac.uk](mailto:C.M.Harris@plymouth.ac.uk)

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### **ONGOING RESEARCH – VOLUNTEERS WANTED**

Here's a reminder of three research centres currently looking for volunteers:

- Leicester is recruiting people willing to take part in a two months drugs trial. Phone 0116 2586291 for further information.

- Swansea needs more people to make one visit to have their null point measured. They will pay travel expenses from anywhere in the UK. Phone 01792 205666 for details.
- Royal Holloway near Heathrow has asked for people willing to spend 40 minutes in an MRI scanner. Details from:  
Tony, 01784 413 520 [a.morland@rhul.ac.uk](mailto:a.morland@rhul.ac.uk)  
Gavin 01784 414 415 [gavin.houston@rhul.ac.uk](mailto:gavin.houston@rhul.ac.uk)  
Elisabeth 01784 414 415  
[elisabeth.vondemhagen@rhul.ac.uk](mailto:elisabeth.vondemhagen@rhul.ac.uk)

For more information about any of the above research, contact Paul White at [info@nystagmusnet.org](mailto:info@nystagmusnet.org)

You don't need to be a member of NN to participate in the above projects. But do remember that the more members we have, the more research gets done.

This is partly because more members for NN means more income and therefore we can help to fund more projects. Also, it's easier for us to find volunteers, by email for example, at short notice. In addition, the more supporters we have, the more likely we are to attract funding from other organisations.

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## **NAMING NYSTAGMUS**

A couple of years ago, some US doctors and researchers got together to talk about the words used to describe nystagmus and other abnormal eye movements. If you think nystagmus is simple, then take a look at their conclusions at [http://www.nei.nih.gov/order/pub\\_sorted\\_by\\_title.asp](http://www.nei.nih.gov/order/pub_sorted_by_title.asp) and click on the heading about classifying eye movement abnormalities.

Here's a short out-take from that document listing the words used to describe various forms of nystagmus:

### **General, descriptive terminology (many types of nystagmus and oscillations):**

Pendular, Jerk, Horizontal, Vertical, Torsional, Cyclohorizontal, Cyclovertical, Diagonal, Elliptical, Upbeat, Downbeat, Rightbeat,

Leftbeat, Clockwise, Counterclockwise, See-Saw, Periodic Alternating, Asymmetric (a)Periodic Alternating, Alternating Windmill, Centripetal, Centrifugal, Induced, Muscle-Paretic, Pursuit-After, Spontaneous, Uniocular, Gaze-Evoked, Convergence-Evoked, Intermittent, Drug-Induced, Perverted, Stepping-Around, Epileptic, Ictal, Cervical, Neck-Torsion, Vertibral-Basilar Artery Insufficiency, Bow-Tie.

We at the Nystagmus Network tend to steer clear of getting involved in talking about the details of an individual diagnosis. Hopefully, after reading the above, you can understand why we've taken that decision.

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### **Everyone`s a winner with the new Weather Lottery!**

We invite everyone to help us raise money for NN with our new fundraising lottery. Players have the chance to win £10,000 every weekday for just £1 a week. At the same time, our members and supporters know they are contributing to a worthy cause of their choice. The Great Weather Lottery game, which has created twenty-two £10,000 winners, is based on the Fahrenheit temperatures in six locations as published in the Daily Telegraph from Monday to Friday. The system has already raised £1,250,000 for good causes and NN has now joined them.

The Nystagmus Network will benefit directly from the revenue generated, with 80% of funds being used for prizes and NN`s own use. There are three main benefits to this unique fundraising tool; the system is supplied free of charge, the fundraising has perennial growth and all the administration is carried out by the Great Weather Lottery. Unlike the National Lottery, players know exactly where the proceeds will be spent.

The Great Weather Lottery, based in Leeds, has been established for four years and is a major source of income for a wide range of sports clubs, charities, schools and other organisations. Help us raise more for NN!

For more information and an application form, **please call Chris Abberley, Fundraising Coordinator on 01273 711696 or email him at: [c.abberley@btinternet.com](mailto:c.abberley@btinternet.com)**

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**A date for your diary**

Nystagmus Network Open Day Saturday 14<sup>th</sup> May 2005.

After a number of years in London this year's open day is to take place in BIRMINGHAM at Queen Alexander College. Full details of the programme will be published in the March issue of Focus and on the NN website. For the moment I can tell you that the programme will include the chance to talk about low vision aids and issues surrounding work and visual impairment. There will also be a thorough update on state of the art research in the field of nystagmus. The day is OPEN to members and non-members alike and we welcome delegates from all areas who have an interest in nystagmus. Please contact me by phone 01636 627004 or by email [info@nystagmusnet.org](mailto:info@nystagmusnet.org) if you have any questions regarding this event.

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**NN FOCUS NEWSLETTER**

Driving with nystagmus, a first hand account of fMRI scans and support at school are some of the topics covered in the December issue (number 65) of our Focus newsletter.

There's also an update on nystagmus research from Cardiff University, the latest on disability legislation and a new Northwick story.

Focus is sent free to all NN members and is available in print, on tape and disc. *For details of how to join NN, click [here](#).*

John Sanders, NN vice president

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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)