

NYSTAGMUS NETWORK (UK) NETLETTER

April 2007

NN Open Day With A Difference

We are holding our annual Open Day in Birmingham on Saturday 7th July. And for those of you who have been before, we are trying a new format to give you a taste of something different...and for those of you who haven't, we promise you not just an interesting day, but a lot of fun.

For the grown-ups, we have excellent speakers on diagnosis, education, employment and research.

For the children we are laying on our biggest-ever programme so, whether they are affected by nystagmus or not, please do bring them along as it is going to be a fun-packed day.

For the first time we have asked other organizations to join us for some parts of the day. The other organizations who will be there are: the Albinism Foundation; the National Blind Children's Society and LOOK, the National Federation of Families with Visually Impaired Children. We work closely with all three organisations. People with albinism also have nystagmus. The NBCS supports children with partial sight, as does LOOK.

Registration starts at 1030 am, the event kicks off at 11 am, and everything will be wrapped up by 4.30pm. It is being held – as before – at Queen Alexandra College in Birmingham, and we are providing free transport from and to the Birmingham New Street Station at the beginning and end of the day.

Cost of the day: £10 per adult – children come free of charge.

The adults' day:

Guest speakers for the morning include:

- Debbie Wiggins Cardiff University- research
- Robin Spinks - Sightsavers International - employment
- Rosie Dempsey - Albinism Fellowship- education
- Chris Green- Nystagmus Network- early diagnosis

This year we are also trying to give you more time to mingle and talk informally with others, as we know from what you have told us that this is particularly important.

The Annual General Meeting of the Nystagmus Network will take place before lunch. In the afternoon, you can join in discussion groups, visit the exhibitor displays and end the day (if you wish) watching the children's talent show

The children's day:

The crèche, run by the Birmingham childcare organisation Newnest, will be open throughout the day (except lunchtime) and will cater for children aged up to 9 years.

For young people aged 9-18, LOOK is organising a range of activities in its marquee which include:

- **Sonic Youth**

Children will get the chance to move within space triggering different sounds using the latest technology creating different soundscapes which may include; jungle, sea and sounds of the city. Supported by The Touch Down Dance Company and Jeremy Haigh, Recording Engineer

- **The Talent Show**

We will invite you up to the stage to perform in front of your peers and families. Please bring any instruments, props and music you will need. Supported by LOOK volunteer mentors.

We obviously want you to book up for this as soon as you can. We are sending booking forms by a separate mailing and would urge you to look out for them in the post.

We will need to know how many of you are coming, how many lunches you need (you can pre-order) plus a cheque to cover your costs.

We believe the day will offer great value, terrific fun – but also lots of information and the chance the talk to others. We very much look forward to welcoming you for the event.

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FOCUS NEWSLETTER

Nystagmus research and studying at university are the two main themes in the March issue of our quarterly newsletter "Focus".

In an interview with NN scientific adviser Chris Harris, John Sanders traces the history of nystagmus research over the last 20 years. The first of two articles describes developments from the publication of the landmark research paper "Nystagmus in Infancy" in 1992 to the international research workshop of 2005. A second article in June's Focus will summarise progress since the workshop.

Also in the March Focus: Two students -- one in Canada, the other in the UK – write about their experiences of university so far. They talk about the help available and some of the problems you can expect to encounter.

Focus is sent four times a year to all members of NN. To find out about joining, click the link to our membership page.

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The QALYity Project

Members of the Nystagmus Network are among those invited to give their viewpoints on the subject of their quality of life to a study taking place in England and Wales.

The QALYity Project (an alliance of prestigious patient groups, medical professionals, academics, and journalists) is conducting the study in order to develop an index that can measure how effective each individual medical treatment or form of care/ support is at improving the quality of life of people with a long-term medical condition (or a disability)—as *determined by the individuals themselves, not by clinicians*. The results of the survey, and the tools that emerge from it, will be made publicly available, will be submitted for peer review, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), the government-funded body that decides which treatments and care should be paid for by the NHS [for more about the QALYity project: <http://www.patient-view.com/qalyity.htm>]

The short questionnaire can be filled out online by clicking on the following weblink:

[QUALITY OF LIFE SURVEY FOR PATIENTS](http://www.surveymonkey.com/s.asp?u=723883484804)

[<http://www.surveymonkey.com/s.asp?u=723883484804>].

For general enquiries about this study, please feel free to contact Dr Wyke at:

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Tel: 0044-(0)1547-520-965

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Email: info@patient-view.com

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Petitions to PM

There are a number of petitions on the government petitions web site of relevance to vision impaired people. It would be good if many of us could sign these to encourage greater awareness of VI issues - petitions need to get 100 signatures to get a government response. Links are as follows:

<http://petitions.pm.gov.uk/carfreepavements/>

<http://petitions.pm.gov.uk/Disability-Fuel/>

<http://petitions.pm.gov.uk/SaveBraille/>

<http://petitions.pm.gov.uk/SupportAT/>

<http://petitions.pm.gov.uk/Talking-Books/>

<http://petitions.pm.gov.uk/DLAandTheBlind/>

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