

NYSTAGMUS NETWORK (UK) NETLETTER

September 2004

NYSTAGMUS TRAINING, LECTURES AND SEMINARS

These lectures and seminars are suitable for training and CPD (Continuous Professional Development) programmes for medical, educational, social work or voluntary sector staff working with people who have nystagmus.

The presentations can be adapted to the needs of individual groups anywhere in the UK. Each will focus on the effects of nystagmus on everyday life such as:

- Distance and near vision
- Null point
- Time to see
- Depth perception
- Impact on work
- Impact on education
- Social impact
- How to minimise the effects of nystagmus

The presentations can also cover:

- Causes of nystagmus
- Incidence of nystagmus
- Treatments for nystagmus
- Nystagmus research
- Nystagmus literature and websites

The presentations can be given with or without PowerPoint, OHP slides and handouts.

Previous training events, lectures and seminars given by NN Information and Development Manager Paul White and NN Vice President John Sanders include:

- Nottingham City Social Services VI team
- VISTA. The Royal Leicestershire, Rutland and Wycliffe Society for the Blind
- Sight Village, Birmingham 2004
- Albinism Fellowship in London, York and Glasgow

- Annual lectures to 3rd year optometry students, Cardiff University
- Leicester ophthalmology department
- Plymouth University Psychology Department
- Swansea Singleton Hospital ophthalmology department
- Wirral Hospital, Arrowe Park Hospital Eye Department
- Southampton University Hospital medical training
- RNIB training courses in London, Birmingham, Bristol and Cardiff
- Kent Association for the Blind (KAB)
- South Wales Association for Teachers of the Visually Impaired (SWATVI)
- Richmond VI Support Service and parents

For more information about nystagmus training, contact Paul White at info@nystagmusnet.org or phone 01636 627004

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HELP WANTED:

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 send it to Paul White at info@nystagmusnet.org.

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RESEARCH WORKSHOP

We’d also like to hear any questions you have for the International Research Workshop – entitled “Finding a Solution for Congenital Nystagmus” we are organising for September 2005. The overall objective of the workshop is “to consider what research and work must be done to create the pathways towards possible cures for the oscillations and the associated visual impairment.”

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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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CATARACTS AND NYSTAGMUS

We've had a number of questions about cataracts and nystagmus. If you've had experiences of this combination, please contact Paul.

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Contact a Family

Contact a Family have a new on-line service which puts parents of children with a disabling condition in touch with others who have the same condition anywhere in the world. It is a new new service and there are no nystagmus entries as yet. Registration is free so, if you would like to be among the first, log on to www.makingcontact.org

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Contributions

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