

NMO Patient Meetings
Friday 7th and Saturday 8th June 2013
Venue – BVSC, Digbeth Street
Birmingham B5 6DR

We would like to cordially invite you to the 2013 NMO Annual Patient day.

Enclosed is a draft of the programme, including for the first time an option to come down to Birmingham the night before and meet up with other patients and their families!

We would be very grateful if you would get back to us at your earliest opportunity to let us know that you are coming. Details on how to do this are on the last attached page!

If you are unable to attend the meetings, but have a burning question for the experts, please feel free to email, call or send to us (using the response form attached) as we are hoping to film the day for those who can't get there.

Programme for Saturday 8th June – NMO Patient day

9.30 – 10.00	Registration and Coffee	
10.00 – 10.10	Introduction - Dr Jackie Palace	
10.10 – 10.30	Research Progress at John Radcliffe - Dr Jo Kitley	
10.30 – 10.50	Research Update from Walton Centre - Dr Liene Elson	
10.50 – 11.25	Ask the Experts Clinical Panel 1 - Dr Jackie Palace; Dr Paddy Walters; Dr Liene Elson ; Kerry Mutch; Kate	
11.25 – 12.00	Ask the Experts Clinical Panel 2 - Dr Anu Jacob; Dr Isabelle Leite; Dr Jo Kitley; Jon Revis; Emily Gerrans; Abi Methley	
12.00 – 13.00	Lunch	
13.00 – 14.00	Breakout sessions 1, 2, 3, 4	
14.00 – 15.00	Breakout sessions 1, 2, 5, 6	
15.00 – 15.30	Comfort Break	
15.30 – 16.30	Breakout sessions 3, 4, 5, 6	
16.30 – 16.45	Summary of Fri pm Networking Session	Kath Beller
16.45 – 17.00	Summary of Day, Moving Forwards	Dr Anu Jacob



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Afternoon Workshop Sessions.

1) **Introduction to NMO** – Dr Anu Jacob, Dr Paddy Walters.

An excellent overview of NMO especially applicable to patients recently diagnosed wishing to gain more understanding of NMO.

2) **Making the Most of what you've got** – Physiotherapist Emily Gerrans , Kate

The saying is 'if you don't use it you lose it' Exercise of any kind releases endorphins to make you feel good. We hope to have representation from Sportability whom believe being disabled represents challenges and opportunities.

3) **Adjustment to Chronic Disease and experience of others** - Abi and Kerry

Using results from 15 patient interviews and support from Literature, we explore the journey of living with NMO.

4) **Living well and dietary needs** Dr Isabelle Leite

This session will explore the necessity and benefits of steroids AND their side-effects; Dietary advice will also be available on healthy eating. We hope to have representation from Slimming World.

5) **Coping with changes in vision** TBC

This session will explain how vision is affected in NMO such as peripheral, field and depth, colour. An explanation of the visual tests and reasons for testing.

We hope to have representative from RNIB to give advice on practical advice on living with visual loss.

6) **Fatigue and energy levels** – Kay

This session will explain the different types of fatigue , causes and how some suggestions on managing fatigue.



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Friday June 7 19.30-21.00

NMO Group Meeting

We acknowledge coming to Birmingham for ONE day is long and tiring. We also recognise that NMO is a rare condition and many of you may feel isolated, not having the opportunity to meet others and relate to the underlying worry of when the next relapse may happen.

This year we have reserved 20 rooms including 4 level access for Friday 7 June At IBIS Hotel Birmingham City, Ladywell Walk, Birmingham. B5 4ST, only a few hundred metres from the patient day on the Saturday.



The rooms are reserved until 10th May.

The cost is £49 B+B single person, £55 B+B double or twin. To book your room Please phone Sarah or Luiana on 0121 622 6010 quoting reference code: **686693**

We have also booked a meeting room and buffet dinner at the IBIS hotel 19.30 in the “James Watt” Room on the ground floor.

This is your opportunity to network and meet others going through similar experience, make new friends and to initiate and establish NMO Charity and support group moving forwards.



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Response form

Please complete details on this form to help us organise the NMO day.

Name:

Guest Names (if appropriate):

I/We would like to: (please circle below as appropriate)

Attend Friday 7th June: patient meeting 19.30

Attend Saturday 8th June: patient day 09.30

Ask a question (space overleaf for your questions)

Breakout Sessions: you will have the opportunity to attend 3 sessions, please tick your choices.

- | | |
|--------------------------|--|
| <input type="checkbox"/> | 1. Introduction to NMO. |
| <input type="checkbox"/> | 2. Making most of what you've got. |
| <input type="checkbox"/> | 3. Adjustment to chronic disease. |
| <input type="checkbox"/> | 4. Living well and dietary needs. |
| <input type="checkbox"/> | 5. Coping with visual change. |
| <input type="checkbox"/> | 6. Managing Fatigue and energy levels. |

Please return form by post or email

nmo.advice@thewaltoncentre.nhs.uk

Stephanie Edwards NMO Co-ordinator NMO Service,
Walton Centre Foundation Trust, Lower Lane, L9 7LJ

Tel 0151 529 8357

by 20 may 2013.

Many thanks

The NMO teams at Oxford and Liverpool



www.nmouk.nhs.uk

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Please could you let us know if there any questions that you will be asking/would like to be asked to the expert panels in the morning sessions on the space below

Please ask anything - as if you have thought about it – you can be sure others have thought the same!

Many thanks and look forward to seeing you at the meetings

NMO Teams at Liverpool and Oxford



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