



**Niemann-Pick Disease Group (UK)
17th NPDG (UK) Annual Family Conference**

**10th- 12th September, 2010
The Robinson Executive Centre
Wyboston Lakes, Bedfordshire**

***“Pathway to Progress”
“A journey of a 1000 miles starts with a single step” - Lao Tzu***





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Pathway to Progress

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The Niemann-Pick Disease Group (UK) is a registered charity committed to supporting those affected by all types of Niemann-Pick disease. The main aims and objectives of the Group are; to make a positive difference to the lives of those affected by Niemann-Pick diseases (NPD), relieve sickness and any distress which may arise there from, and to advance the education and awareness of families, professionals and the general public in all matters concerning the disease, through the provision of effective support in the three main areas of **care, information and research**

The aim of our 17th Annual Family Conference is to address the needs of all those affected by Niemann-Pick diseases (NPD), their families, and the health and social care professionals involved in their care. Our theme this year is ‘Pathway to Progress’; as each Conference passes, we move a step closer to our common goal - the discovery of effective treatments for this group of diseases. This is not an easy, or a short road but increasing activity in the field of Niemann-Pick diseases brings renewed hope for our shared journey. This year, as always, we offer you the opportunity to hear the latest developments from around the world.

Presentations by experts in the field of Niemann-Pick diseases will provide an overview of the latest information regarding research, therapies and related care issues. This would not be possible without the support of our members and the ever increasing number of professionals associated with the disease. The Conference also provides an ideal opportunity to strengthen our family support network by encouraging families to share their thoughts and experiences. This will be the largest gathering of families affected by Niemann-Pick diseases in the UK; previous speakers and professional delegates have told us how much they value the opportunity to meet, network and share their skills with families and colleagues.

We aim to make the Conference an enjoyable experience, one which will be of benefit to the whole family. We hope that you will be able to join us for this exciting and informative weekend, whether you are a regular attendee or intending to join us at Conference for the first time, we look forward to welcoming you to Wyboston Lakes.

Venue

The Conference venue is the Robinson Executive Centre, Wyboston Lakes, Great North Road, Wyboston, Bedfordshire, MK44 3AL The Robinson Executive Centre is an award-winning, residential conference and training centre, that offers a tranquil and distraction-free environment. The Niemann-Pick Disease Group (UK) has secured exclusive use of the centre for the duration of the Conference. The centre has 27 meeting rooms, ample free parking and 120 bedrooms. On site leisure facilities include an 18 hole golf course and a fully equipped health and fitness centre with an indoor swimming pool.

Located on the A1 M, Cambridgeshire/Bedfordshire border, just 10 minutes from St. Neots Rail Station, one hour equidistant from Luton and Stansted Airports. More detailed Travel information will be distributed following registration. For Further information visit www.wybostonlakes.co.uk

2010 Preliminary Programme

Friday 10th September 2010

- 4.00 pm Arrival and Check in.
- 6.00 – 8.00pm Conference Registration
- 6.30 – 9.00pm Dinner
- 8.00 pm Welcome Address – Jim Green, Chair, NPDG (UK)
- 6.00 – 10.00pm Children's entertainment and social time

Saturday 11th September 2010

- 8.30 – 9.15am Registration
- 9.15 – 9.30am Welcome, Jim Green, Chair, NPDG (UK)
- 9.30 - 10.00am Professor Frances Platt
Department of Pharmacology, University of Oxford, UK
- 10.00 - 10.30am Parallel Sessions

10.00 - 10.30am
Dr Steven U. Walkley
Department of Neuroscience,
Albert Einstein College of Medicine
New York, USA

10.00 - 10.30am
Dr Ed Schuchman MPH. PhD., BS.
Professor of Genetics and Genetic Sciences
Mount Sinai School of Medicine,
New York, USA

10.30 – 11.00am Parallel Sessions

10.30 - 11.00am
Dr Daniel S. Ory M.D.
Professor, Internal Medicine, Cell Biology
and Physiology
Washington University in St Louis, USA

10.30 - 11.00am
Genzyme
Acid Sphingomyelinase Deficiency (ASMD)
Clinical Trials

11.00 - 11.30am Coffee

11.30 – 11.55am The Peter Carlton Jones Memorial Award

11.55am -1.00pm Parallel Sessions

11.55 - 12.20am
Dr Chris Hendriksz
Clinical Lead for Inherited Metabolic
Disorders, Director for Lysosomal Storage
Disorders, Birmingham Children's Hospital
NHS Foundation Trust, UK

11.55 - 12.40noon
Enzyme Replacement Therapy – A Patients
Perspective
Emily Lew
Director, Gaucher's Association.

12.20 – 12.40pm
NP-C Patient Survey Outcomes
Kristen Cardinal, Actelion Pharmaceuticals,
Medical Science Liaison Manager, Zavesca

12.40 – 1.00pm Family Voices
Niemann-Pick Type C

12 40 – 1.00pm Family Voices
ASMD Niemann-Pick Types A & B

1.00 – 2.00pm Lunch

2.00 – 2.30pm Optional Session – Rev K. Johnson

2.30 – 2.50pm NPDG (UK) Big Lottery Project – Providing Interactive Care and Support
David Roberts, Trustee, NPDG (UK),
Jacqueline Imrie, Clinical Nurse Specialist Niemann-Pick Diseases
Toni Mathieson, Executive Director, NPDG (UK)

3.00 - 4.15pm Parallel Sessions

3.00 – 3.45pm
Type C Discussion Forum
Dr Marc C. Patterson M.D. FRACP
Department of Medical Genetics, Paediatrics
and Neurology
Mayo Clinic, Rochester, Minnesota, USA

3.00 – 3.45pm
ASMD Niemann-Pick Types A & B Family
Discussion Forum – How can the NPDG (UK)
support you?

3.45 – 4.15pm
Dietary Advice for patients on Zavesca
Helena Champion
Nutrition and Dietetic Department,
Addenbrooke's Hospital, Cambridge, UK

3.45 – 4.15pm
ASMD Niemann-Pick Types A & B Research –
The Way Forward

4.15 – 5.00pm Panel Session

Throughout the course of the day you will have the opportunity to write down your comments and questions for discussion during this Session. Look out for the boxes situated around the Conference venue, pop your question or comment on the cards provided and drop it into the box.

5.00 pm CLOSE
6.45 pm Dinner
8.15 pm Family Entertainment
11.30 pm CLOSE

Sunday 12th September 2010

9.15 – 9.35am NPDG (UK) Annual General Meeting

9.35 – 9.40am Welcome

9.40 – 10.20am First Breakout Sessions

10.20 - 11.00am	Second Breakout Sessions
11.00 –11.30am	Coffee and Check Out
11.30 - 12.00pm	David Begley BSc PhD King's College London, UK.
12.00 – 12.25pm	Helena Prady Medicines for Children Research Network
12.25 – 12.40am	NPDG (UK) Clinical Research Nurse Report – Liz Jacklin
12.40 – 12.55am	NPDG (UK) Clinical Nurse Specialist Report – Jackie Imrie
1.00 – 2.00 pm	Lunch and CLOSE

Children and Young Adults' Activity Programme

To enable parents and carers to be fully involved in the main Conference Programme, the NPDG (UK) will once again be running a comprehensive Activity Programme for children and young adults throughout the Conference weekend. Co-ordinating the Programme for the third year will be Liz Jacklin, Alison Hitchens and Ged Rowles, with their team of carefully selected volunteers (all of whom undergo the required level of CRB checks and receive appropriate training).

The aim of the programme is to provide a safe environment and appropriate activities that are suitable to all levels of ability. The programme is open to children aged 3 years and above. If you have a child younger than this, and you would like to participate in the Conference, please let us know, crèche facilities can be arranged.

As places on the programme are limited, please book as early as possible.

The Children and Young Adults' activity Programme is supported by a generous donation from Dr Heti Davies

Key Dates:

Conference registration deadline: Friday 27th August 2010

Early Bird Accommodation Rates:

10% discount for bookings received and paid in full by Friday 30th July 2010
(applies to accommodation only)

To book please complete the attached Registration Form and return it, with payment, to:

Niemann-Pick Disease Group (UK)
11 Greenwood Close, Fatfield, Washington, Tyne and Wear, UK, NE38 8LR
Telephone: 0191 415 0693
Email: niemann-pick@zetnet.co.uk Website: www.niemannpick.org.uk

**We look forward to welcoming you to our
17th Annual Family Conference!**