



## **Niemann-Pick Disease Group (UK)**

### **Interactive Workshop on Niemann-Pick Diseases & 17<sup>th</sup> NPDG (UK) Annual Family Conference**

**Friday 10th September, 2010  
Wyboston Lakes, Bedfordshire**

On Friday September 10<sup>th</sup> 2010, the Niemann-Pick Disease Group (UK) will host their first event specifically for professionals. This one day event will feature both clinical and scientific presentations, providing an opportunity for both UK and International professionals to share current information regarding all aspects of Niemann-Pick diseases, including clinical management, research and potential therapies.

**Who should attend?**

The meeting is for all professionals with an interest in this group of diseases.

#### **Call for Posters**

Included within this specialised workshop there will be a dedicated session consisting entirely of contributed abstracts, which will be for display as posters only. The presenting author will be expected to be available at the poster at a pre-determined time during the Workshop to answer questions. Posters must be available for the whole of the Workshop, please see below for details of how to submit an abstract.

#### **17<sup>th</sup> NPDG (UK) Annual Family Conference**

The 17<sup>th</sup> NPDG (UK) Annual Family Conference will follow the Interactive Workshop, on Saturday 11<sup>th</sup> and Sunday 12<sup>th</sup> September. The Conference aims to address the needs of all those affected by Niemann-Pick diseases, their families, and the health and social care professionals involved in their care. As well as highlighting the most recent advances in research, the Conference provides an ideal opportunity to strengthen our family support network by encouraging families to share their thoughts and experiences with others in a similar situation.

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.

If you would be interested in attending this Conference, or would like to receive further information, please contact the Niemann-Pick Disease Group (UK)

## **Preliminary Programme - Interactive Workshop on Niemann-Pick Diseases**

**Friday 10<sup>th</sup> September 2010**

- 10.00 am      **Welcome and Introduction**  
Professor Frances Platt, Department of Pharmacology, University of Oxford
- 10.15 am      **Understanding ASMD Niemann-Pick Type A/B Disease**
- 10.45 am      **Understanding Niemann-Pick Type C Disease**
- 11.15 am      **Extended Discussion**
- 11.45 am      **COFFEE BREAK and POSTERS**

## **Clinical Management of Niemann-Pick Diseases**

- 12.10 pm      **Early Recognition and Diagnosis of Niemann-Pick Disease**
- 12.30 pm      **The Importance of Optimal Care and Non-drug Aspects of Management of NPC**
- 1.00 pm        **LUNCH and POSTERS**

## **Research and Potential Therapies**

- 2.00 pm        **Biomarker Discovery/Evaluation**
- 2.30 pm        **Emerging Disease Modifying Therapies**
- 3.00 pm        **COFFEE BREAK and POSTERS**
- 3.45 pm        **Challenges of Translating Laboratory Advances into Clinical Trials in NPD and Other Rare Diseases**
- 4.15 pm        **ERT for ASMD Niemann-Pick Disease, Where Are We Now?**
- 4.45 pm        **Future of Clinical Trials/Biomarker Validation for NPC**
- 5.15 pm        **General Discussion**
- 6.00pm        **Drinks Reception**
- 7.00pm        **DINNER**

## Venue

Wyboston Lakes, Great North Road, Wyboston, Bedfordshire, MK44 3AL  
[www.wybostonlakes.co.uk](http://www.wybostonlakes.co.uk)

Location: Cambridgeshire/Bedfordshire border 10 minutes from St. Neots Rail Station, one hour equidistant from Luton and Stansted Airports.

Further Travel information will be distributed following registration.

## Submit an Abstract

Included within this specialised workshop there will be a dedicated session consisting entirely of contributed abstracts, which will be for display as posters only. The presenting author will be expected to be available at the poster at a pre-determined time during the Workshop to discuss their work and receive feedback.

Abstracts for posters should be submitted no later than Friday 30<sup>th</sup> July. All abstracts must be original work and should be no more than 250 words, submitted electronically, in Microsoft Word format, to: [niemann-pick@zetnet.co.uk](mailto:niemann-pick@zetnet.co.uk). A selection committee will review the abstracts. The Committee reserves the right to accept or reject abstracts for inclusion in the programme. All authors will receive notification of outcome of their submission by 13<sup>th</sup> August 2010.

Presenting authors are not exempt from registration fees, which must be received by 27<sup>th</sup> August 2010. Please note: posters should be no larger than 1m x 1.5m.

Posters will be displayed on Friday 10<sup>th</sup> September. If the presenter is also attending the NPDG (UK) Annual Family Conference, the work will also be displayed throughout this Conference.

The Workshop organisers will not be held responsible for submission errors caused by internet service outages, hardware, or software delays, power shortages or unforeseen events. Responsibility of abstracts rests with the author.

### Key Dates:

Abstract submission deadline	Friday 30 <sup>th</sup> July 2010
Conference Registration	Friday 27 <sup>th</sup> August 2010

### Early Bird Rates:

10% discount for bookings received and paid in full by Friday 30<sup>th</sup> July 2010

**The NPDG (UK) looks forward to welcoming you to what should be an interesting and informative meeting.**

## Registration Fees

Interactive Workshop on Niemann-Pick Diseases - Friday 10 <sup>th</sup> September	
<b>Workshop Residential Rate: £110.00</b>	Includes refreshments**, lunch, dinner and overnight accommodation on either <b>Thursday 9<sup>th</sup> or Friday 10<sup>th</sup> September</b>
<b>Workshop only: £75.00</b>	Includes lunch, refreshments** and dinner on Friday 10 <sup>th</sup> September
<b>Workshop &amp; Family Conference: £250.00</b>	Includes Workshop and Family Conference Two Night Residential Rate* as detailed below
NPDG (UK) Annual Family Conference Saturday 11 <sup>th</sup> / Sunday 12 <sup>th</sup> September	
<b>*Family Conference Two Night Residential Rate: £195.00</b>	Includes dinner and accommodation on <b>Friday 10<sup>th</sup> September</b> , breakfast, refreshments**, lunch, dinner and accommodation <b>Saturday 11<sup>th</sup></b> , and breakfast, refreshments** and lunch on Sunday 12 <sup>th</sup> September
<b>Family Conference One Night Residential Rate: £145.00</b>	Includes refreshments**, lunch, dinner and overnight accommodation <b>Saturday 11<sup>th</sup> September</b> and breakfast, refreshments** and lunch on Sunday 12 <sup>th</sup> September
<b>Conference Only (both days): £75.00</b>	Includes refreshments** and lunch, does not include gala dinner on Saturday 11 <sup>th</sup> September
<b>Conference Only (one day): £45.00</b>	Includes refreshments** and lunch, does not include gala dinner on Saturday 11 <sup>th</sup> September
<b>Conference Only (half day): £25.00</b>	Includes lunch and refreshments** on day of choice
Interactive Workshop on Niemann-Pick Diseases and NPDG (UK) Annual Family Conference – Three Night Package	
<b>Three Night Residential Rate: £295.00</b>	Includes Interactive Workshop, Family Conference, overnight accommodation <b>Thursday 9<sup>th</sup>- Saturday 11<sup>th</sup> September</b> , plus meals and refreshments**

*\*\*Please note refreshments consist of tea and coffee. Alcoholic beverages are not included.*

**Registration deadline - 27<sup>th</sup> August 2010**

**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

Email: [niemann-pick@zetnet.co.uk](mailto:niemann-pick@zetnet.co.uk) Website: [www.niemannpick.org.uk](http://www.niemannpick.org.uk)