



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

September 2011

Hello and welcome to the latest Niemann-Pick Disease Group (UK)'s Family News Bulletin. We hope you find it interesting and informative.

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Final Call—Join Us for Conference 2011—23rd-25th September



Just a reminder, the Annual Family Conference is being held over the weekend of 23rd September this year, at the Robinson Executive Centre, Wyboston Lakes on the Cambridge-Bedfordshire border. If you wish to join us, please send your registration forms to us by Friday 9th September. Alternatively, give us a call, **0191 415 0693**, and we can complete them for you. Full details and booking forms can be found on our website www.niemannpick.org.uk

The NPDG (UK) Funds Research Project



Following a presentation made to the NPDG (UK) Board of Trustees by Professor Fran Platt, University of Oxford, it was agreed that the NPDG (UK) would provide funding for the following project, which will contribute to the collection of data for the proposed NIH clinical trial of Cyclodextrin for NP-C, planned to start in 2012. Fran Platt explains: *“We have been evaluating expansion of the lysosomal compartment in response to lipid storage as a potential biomarker for NPC using a probe called LysoTracker. During the course of these studies we have monitored blood cells (B cells)*

from patients who began intravenous cyclodextrin (CD) therapy on a compassionate use basis. We observed a dramatic increase in LysoTracker following CD therapy in these patients (but not in non-CD treated NPC patients) that was B cell specific. To gain insights into the mechanisms underlying this observation we will conduct a 6-month study to investigate the biochemical basis for this change and determine whether it adversely affects B cell function. These studies will shed light on the mechanisms of action of CD and help inform the most appropriate route of CD administration.”

The NPDG (UK) continues to support and encourage requests to support research projects that will facilitate progress towards therapeutic interventions. The above project is funded in addition to support provided earlier this year to Cardiff University, enabling the completion of research work into the belief that stimulation of acid sphingomyelinase activity could clear the remaining sphingomyelin and cholesterol storage in NP-C cells.

Elizabeth Davenport, NPDG (UK) Families Officer writes for the Family Bulletin



Newly appointed Families Officer, Elizabeth Davenport, will be making regular contributions to our Family Bulletins. Elizabeth writes: *Following on from our picnic at Lotherton Hall, I have been thinking about ways in which we could organise activities throughout the year for our families. I have had a few ideas and would love to hear your thoughts on the following activities:*

As Christmas is just around the corner I would really like to organise some Christmas ‘get togethers’ around the country. So if any of you would like to email me I will try and organise a ‘do’ in your area.

Some of our mums would like the opportunity to meet informally over coffee and cake to gain support from other mums in their area. If you would like to know more then please contact me. If any dads or siblings would like a similar group then just get in touch.

We are also hoping to run a group for all families who have suffered bereavement. Each group will have opportunities for families to gain support, and, if you wish, share feelings. We will have craft activities for children, and a therapist offering relaxation techniques such as massage, reflexology and Indian head massage throughout the session for parents.

We hope that the first group will run in October in Leeds, but we aim for the group to run throughout the country. Letters will be going out to you all but please contact me if you have any questions in the meantime.

*If you have any other ideas then I would love to have a chat with you about them. As always I am available to support families with information about housing, benefits, education and employment.” Elizabeth can be contacted by phone on **07896197576** or by email **elizabeth-npdg@aol.co.uk***

Calling All Knitters



At Conference this year we plan to include knitted Christmas tree decorations on our craft stall to raise funds for the Group. So if there are any keen knitters out there, or you know someone who is, we would love to hear from you. All (small) knitted items should be sent, along with the name and address of the knitter, to NPDG (UK) Central Office, 11 Greenwood Close, Fatfield, Washington, Tyne and Wear NE38 8PD to arrive before Monday 19th September. Alternatively, if you are attending Conference this year, you could bring them along with you.!

Join Us on Facebook



The NPDG (UK) has set up a facebook page where you can keep up to date with what's happening with all things Niemann-Pick, as well as keeping in touch with families affected by NPD worldwide. To join us go to **www.facebook.com/group.php?gid=125434951250**.

Disabled Travel Guide

The Disabled Travel Guide is a useful publication which covers common worries and frequently asked questions when travelling, including: what happens at security and customs; general airport assistance; advice before travelling; travelling with medication; wheelchair advice and other useful tips and advice.

The guide is available to download in in text format by going to **www.parkat.co.uk/disabled/**

Department of Health Funding for Contact a Family to Support Parent/Carer Forums

Contact a Family has recently been successful in applying for funding from the Department of Health (DH) to support the involvement of parent carers in shaping health services at local and national level. This work will link in with changes being implemented as part of the NHS White Paper which include making GP consortiums working with other clinicians responsible for commissioning local hospital and community services. New structures will be created to support local user involvement; more details about this will be available soon.

Contact a Family Special Educational Needs & Disability (SEND) Project



contact a family
for families with disabled children

Contact a Family have received funding from the Department of Education to work in partnership with SENCOs, Parent Partnership Service and parent networks to develop good practice around information given to parents through schools. The project recognises that SENCOs are a key point of contact and support for families. Contact a Family would like to work closely with parent forums, some of whom are already linking in with SENCOs, either through schools or local SENCO forums.

If you would like more information please contact your local SEND Development Officer:
London & the South East -Claire Harding—Claire.harding@cafamily.org.uk

West England— Carolyn Deveney—Carolyn.deveney@cafamily.org.uk

North East England—Siobhan.O'Connor—siobhan.oconnor@cafamily.org.uk

South West England—Cathy Hunte—Cathy.Hunte@cafamily.org.uk

Midlands & East England—Liz Reynolds—Elizabeth.reynolds@cafamily.org.uk

Tesco Mum of the Year



TESCO

Do you know an amazing mum? The Tesco Mum of the Year awards is celebrating its seventh year and they are looking for incredible women to honour at the ceremony next year. They are looking for mums who have made a difference; done something incredible for their community; raised money for a good cause; inspired kids to achieve through sport; or just deserve special recognition. Nominations close on 23rd September 2011. For more information visit tesco.com/living

ACT Family Companion Film



ACT

Many of you will be familiar with, or maybe have a your own copy of, the ACT Family Companion booklet, which helps explain what happens throughout your loved one's care. ACT has now launched a companion to this booklet, *The Family Companion Film*, which aims to reach out to more families who may not have time to read the booklet, or who just can't face reading lots of information.

The film tells the stories of three different families who are living with some of the issues covered in A Family Companion. They talk about the hurdles they have faced, what support they receive, and how they have dealt with difficult and emotional situations throughout their child's life. It is hoped that by watching families talk about their experiences, other families in similar situations will relate to this, and won't feel alone in the problems they have.

By producing this film, ACT wanted to empower families to talk to professionals working with their loved one, to ensure their whole family is getting access to the services that they are entitled to, and to enable them to exercise real choice surrounding their child's care, where possible. The film covers all kinds of issues such as diagnosis, care plans, key workers, caring for you child at home, learning to use medical equipment at home and respite and short breaks. The Family Companion film is available to watch on the ACT website www.act.org.uk/familyfilm

Local Square Table Learning and Evaluation Report



ACT and Children's Hospices UK have published a report that summarises the key learning from the Local Square Table Programme. This programme consisted of a series 37 local 'Square Tables' which took place in Spring



2011 across England. Funded by the Department of Health within their £30 million Children's Palliative Care Funding Programme, the events were designed to deepen the level of understanding of children's palliative care in a particular community. Each Square Table brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals and providers from the voluntary and statutory sectors, commissioners as well as other representatives from respective communities including faith and business leaders. The events were called 'Square Tables' to symbolise the equal weight and importance of all participants' views. The report summarises the learning from all 37 events. It captures the open and honest discussions between those who provide children's palliative care, those who use the services and those who play a wider part in supporting children, young people and families. You can download a copy by visiting: www.act.org.uk/core/core_picker/download.asp?id=636

New Contact a Family Survey – Isolation 2011



Families sometimes report that they feel isolated and alone when they find out their child has a disability. There may be other reasons or situations when families with disabled children are affected by isolation. Isolation can impact on all areas of life. But with the growth of the internet, social networks and the establishment of an increasing number of parent support groups and forums, there are more and more ways of connecting with others and making links and friendships. But is this enough? Contact a Family wants to find out what the emotional situation is for you and your family in 2011 and if isolation impacts on your family life.

The survey will take just five minutes to complete and the findings will help highlight this issue through a media story. You can take the survey, which closes on 23rd September by going to <http://www.surveymonkey.com/s/ContactaFamilyIsolation2011>

Have You Joined the 'Hope for Hollie' Forum?



The 'Hope for Hollie' Campaign e-forum enables families affected by NPD to share their thoughts and experiences of living with Niemann-Pick disease. All aspects of the disease can be discussed, with contributions from families of people affected, carers, experts, and also discussion about fundraising activities. New discussion topics have recently been added—so why not sign up and join the debate about research, aids and adaptations, fundraising and much more. If you would like to add any topics, please let us know.

To join, visit www.hopeforhollie.co.uk or follow the link on the NPDG (UK) Website – www.niemannpick.org.uk,

NPDG (UK) Wristbands Back in Stock



We now have a limited stock of NPDG(UK) wristbands. If you have recently requested a supply, they will be sent out shortly. Wristbands are available from the Central Office for a recommended donation of £1.00.

We hope you have enjoyed reading this edition of the Family News Bulletin. If you have any articles, suggestions or comments for future editions of the Bulletin, or have received this e-bulletin by post and would now like it by email, please contact **Sue Lowe, 11 Greenwood Close, Fatfield, Washington, Tyne and Wear NE38 8LR**, or email at sue.npdg@tiscali.co.uk.

Disclaimer: Information which appears in this Bulletin is for the express purpose of raising awareness and does not necessarily reflect the views of the NPDG (UK). All medical information should be reviewed with your doctor before being acted upon.

