



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

MAY 2009

Hello and welcome to the latest Niemann-Pick Disease Group (UK) Family News Bulletin.

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The Niemann-Pick Disease Group (UK) Annual Family Conference



Just a reminder that our Annual Family Conference and AGM will be held at the Holiday Inn, Ironbridge, Telford on June 19th, 20th and 21st. This venue has been chosen for its central location and excellent facilities which we are sure you will all enjoy. The hotel facilities include accessible rooms, an indoor heated swimming pool and health and leisure suite.

We hope you can join us for the Conference which provides a chance to strengthen our family network and enables families affected by NPD to meet and share their experiences. Full Conference programme details and a booking form are available on our website www.niemannpick.org.uk or you can call the Central Office on **0191 4150693** for more details.

Raising Awareness of NPD

We are always looking to raise awareness of the Niemann-Pick diseases amongst care professionals, so if you would like your child/children's school head teacher, school nurse, doctor, or any one who works with your child/children to receive a copy of the Niemann-Pick News or any information about NPD, either by post or email, then please contact us by phone **0191 415 0693**, email sue.npdg@tiscali.co.uk, or by post to the address at the end of this bulletin.

Niemann-Pick Family Directory 2009

The 2009 Family Directory has now been published and sent out to those families appearing therein. If you have yet to receive yours, or if you wish your details to appear in future directories, please contact us on **0191 415 0693** or email sue.npdg@tiscali.co.uk.

NPDG (UK) Board of Trustees

The NPDG (UK) Board of Trustees meets four times a year and is responsible for all the activities the Group undertakes. All the Trustees are volunteers, and we are continually seeking new members to join the Board. If you, or a member of your family, might be interested in joining the Board, or in attending a future Board Meeting to see what's involved, please contact Central Office for further details.

NPDG (UK) Clinical Research Nurse – Liz Jacklin

Liz Jacklin, our Clinical Research Nurse, has provided the following update of her work for the Family News Bulletin. If you have any specific research questions that you would like to see addressed in future issues, please do forward them to us at the Central Office by email at niemann-pick@zetnet.co.uk, or to Liz direct Elizabeth.Jacklin@cmft.nhs.uk (please note new email address).

Liz writes:

This continues to be an exciting and dynamic time for those of us involved with the Niemann-Pick

diseases. The field of research is very active at present, as many of you are aware. You may have heard about the recent intracranial Stem Cell Transplant that took place in India, and also of developments with the use of Cyclodextrin for NPC. I am continuing to monitor these developments closely and will report back to you as soon as I can. I am also aware that some families in the UK have started to use curcumin; I would be very interested to hear how you are getting on with this and would appreciate it if you could get in touch with me and provide some feedback.

The Medicine for Children's Network MCRN have recently collaborated with the Lysosomal Storage Disease Patient Support Groups, to form a Clinical Studies Group for Lysosomal Storage Disorders (LSDs) and Inborn Errors of Metabolism. The NPDG (UK) has been involved in the formation of this Group, which will look at research protocols in this field of medicine, and hopefully generate more interest in research into LSDs.

Recently we have had some very exciting news from Genzyme. Betsy Bogard, Associate Director, Programme Management for Genzyme announced that they have completed the Phase 1 trial of rhASM in Niemann-Pick B Patients and will now be turning their attention to a Phase 2 Trial. A full statement can be found on our website www.niemannpick.org.uk/documents/NPBupdateforpatientsUK2009-05-05.pdf. For those of you planning to attend our Annual Family Conference, Dr Robert J. Desnick, will be joining us from Mount Sinai to discuss recent Niemann-Pick Types A and B research studies.

If you would like further clarification on any of the items mentioned above, or if there is something in the research field that you have questions about, then please do get in touch, I am always very keen to hear your views and to receive your feedback. You can call me on **0161 9222967** or email me at Elizabeth.Jacklin@cmft.nhs.uk and I hope to see as many of you as possible at our Annual Family Conference in June.

The Willink Biochemical Genetics Unit is Moving

In June the Royal Manchester Children's Hospital (including the Willink) will be moving to Central Manchester—the new contact address will be Oxford Road, Manchester.

Laurel Parker Scoops Award



Laurel Parker (NPC) aged 13 was recently honoured with the Rayleigh Town Council's Junior Disabled High Achiever 11-16 years Award.

The NPDG (UK) would like to send Laurel our congratulations on achieving this award. Full details can be found on our website using the link <http://www.niemannpick.org.uk/articles/laurelparker.html>

Niemann-Pick Awareness Week

This year Niemann-Pick Awareness Week will be held from 20th to 26th July. So why not get involved by organising your own fundraising event? Help us to make Awareness Week 2009 one to remember, by increasing awareness of Niemann-Pick Disease, raising money and having fun!!!! If you would like to get involved and hold an event, big or small, please call the Central Office on

0191 4150693 or email niemann-pick@zetnet.co.uk for a fundraising pack, information and ideas.

Take Part in a Contact a Family Podcast



Contact a Family (CAF) is looking for families to take part in a podcast series on what it is like for families affected by rare disorders. Families whose children have very rare disorders often do not have access to other parents to share their experiences, so hearing the stories from other families can be a great source of support. CAF would like to interview families or affected adults about their experiences of a disorder or having a child or children with a rare disorder. A member of CAF would come to visit the family in their homes or a place that is convenient. For more information contact **Sasha Henriques** on **0207608 8714**.

Steps Towards Inclusive Play For Disabled Children

The NPDG(UK) welcomes the recently published National Play Strategy and its commitments to improve access and inclusion to play areas for disabled children. The National Play Strategy outlines the Government's long term vision for safe and accessible play for all children and makes commitments to disabled children including making play spaces fully inclusive and accessible for all disabled and young people; a Neighbourhood Play Toolkit to provide information on how authorities can include disabled children in the decision making process and 4000 play workers with training on equality and inclusion issues. For more information go to www.dcsf.gov.uk/play.

News from the Family Fund



Family Fund Increases Age Limit In England

The Family Fund is a national charity which gives grants to families with disabled children. They have recently increased the age limit of children they can help in England to include 17 year olds, providing the application is received before the young person's 18th birthday. This brings it in line with the eligibility criteria for Wales. In Northern Ireland and Scotland, the age limit of children and young people they can help is 16 years of age or under, providing the application is received before their 17th birthday. For more information go to www.familyfund.org.uk.

The Family Fund Needs Your Help

The Family Fund would like your help to understand the financial needs of families with disabled children. The Family Fund is currently conducting a survey of families and would like your input. Your help will allow them to ensure that they are meeting your needs and those of other families with disabled children. The survey should take no more than 10 to 15 minutes to complete and your response will be confidential.

For more information email financialneeds@familyfund.org.uk

Calls For Help With Administering Direct Payments

Local councils are being urged to provide better support to carers managing direct payments rather than burdening them with the unnecessary administration and worry in the Government's drive toward personalisation of care services. Research by Carers UK shows that the scheme, introduced in 1997, has been very successful for many families but highlights a number of concerns. More than half of those carers questioned (53%) reported their overall experience of the scheme was positive, with almost three quarters (73%) stating that the care they are able to purchase is better at meeting their families' needs than the previous service. However, nearly one in ten reported a negative experience of the scheme and a general complaint was the lack of support available to help manage the money which in turn caused extra stress, worry and feelings of being overwhelmed.

Carers UK's research highlights how the success of direct payments is heavily reliant on local authorities and their ability to support carers. The amount of paperwork can be "off putting" for carers and more than three quarters of those surveyed had no contingency plans in place should something go wrong. In addition, in some areas, there simply are no suitable services available for carers to purchase with direct payments. For more information go to www.carersuk.org.uk

Changes to the NHS Complaints System

On 1st April 2009, the government introduced a new process for dealing with patients' complaints about NHS healthcare. Following public feedback they are streamlining it from a three-stage to a two-stage process, to make it easier and quicker for a complainants to have their concern dealt with. All complaints about the NHS are dealt with by the Health Service Ombudsman. For further information go to <http://tinyurl.com/cwcpmt>.

NHS Websites Merge

Previously, the NHS had two national websites—NHS Choices and NHS Direct. These websites have now been combined into one—NHS Choices—making online information about health and health services available from one site. The site will include popular features such as the self help guide, a health encyclopaedia and the online enquiry service. There will be directories of services, comparative hospital performance data and guides to common long-term conditions, with translations available. The new combined site is available at www.nhs.uk

Kidz Exhibition Dates Announced

Two further Kidz exhibitions have been organised for 2009. The Kidz exhibitions are free to attend, allow disabled children and their families and professionals to try the latest disability equipment and products, and to talk to specialist who supply them. There is also a full programme of



talks covering topics such as legal and educational issues, new therapies, communication and ICT. Many voluntary organisations are on hand with information on support, funding, holidays, publications and benefits. Kidz South will be held on 18th June at Rivermead Leisure Complex in Reading and Kidz Up North will be held on 26th Novem-



ber at the Reebok Stadium in Bolton. For free tickets or more information, contact Disabled Living on **0161 214 5962** or **info@disabledliving.co.uk**.

You can also visit **www.kidzupnorth.co.uk** and **www.kidzsouth.co.uk** for more information.

Take Action

The Every Disabled Child Matters (EDCM) campaign is calling on families to take action by emailing their local authority to ask how they are planning their short breaks services now and beyond 2011. The Children and Young Person's Act 2008 introduces a new duty on local authorities to provide short breaks services and will come into force in 2011. EDCM would like to monitor the activity of local authorities in planning their short breaks to ensure that families get the best services to meet their needs and has drafted a template letter which you can email to your local authority directly. Visit **www.edcm.org.uk** for further details.

Free Booklets from Advisory Centre for Education



ACE is a national charity that provides independent advice for parents and carers of children aged 5 to 16 in state-funded education. They offer free advice on many subjects, such as exclusion from school, bullying, special educational needs and school admission appeals. All advice booklets from the Advisory Centre for Education (ACE) are free for families. Booklets can be downloaded for the ACE website at **www.ace-ed.org.uk**

Peace of Mind Care Trust Fund

Peace of Mind Care is a charity which was set up in memory of Brandon Perrin (NPC 02/11/1995-12/01/2006) to raise money for children and young people who have a terminal illness, substantial disabilities, young carers and vulnerable children and young adults in the UK and abroad. They also work with children and young people who are at a disadvantage due to poverty, have been victims of bullying and abuse or who are at risk of depression, homelessness, alcohol/drug abuse. The Charity tries to bring happiness and support to those they help. The Charity believes that every child and young person should be given the same opportunities to succeed, increase their self confidence, self esteem and reach their full potential and have fun regardless of their age, abilities, gender, size, race, religious beliefs, social background and family financial status. For further details visit **www.peaceofmindcare.co.uk**

Have Your Say About Special Educational Needs in SEN Magazine

Are you a parent of a child with a special educational need? Do you have something you'd like to shout about? Maybe you would like to praise your child's school, or you would like to raise an issue about special educational needs so professionals can read your views and take note. Whatever your view, SEN Magazine would like to hear from you. They are looking for one-off contributors for the new Point of View section which features two short articles written by a parent or guardian and a teacher or SENCO. If you have something you would like to shout about

(good or bad!), please get in touch with Annie Makoff, the editor for SEN Magazine, by telephone on 01200 409801 or by email annie@senmagazine.co.uk.

Rare Disease UK Need Your Comments

Rare Disease UK are looking for some personal/real stories that can be used in their business plan. They would like to include some quotes from patients and need your help in answering the following questions:

- Thinking back to the original diagnosis, can you give an example of how this process could have been improved if the healthcare professional you met along the way had heard/knew about Niemann-Pick Disease.
- Can you give an example of a situation which has occurred since the diagnosis where you have faced difficulty due to a lack of knowledge and understanding of Niemann-Pick Disease by a healthcare professional dealing with your family.

Although the answers to these questions could be lengthy, Rare Disease UK need just a short note that can bring to life their aims and highlight the issues families affected by rare disorders face. This information will then go to new members, policy makers, MPs and other stakeholders. To have your quotes included contact Melissa Hillier by email on Melissa@raredisease.org.uk.

Fundraising

During the months of March, April and May 2009, the NPDG (UK) received over £13,000 from donations, collection boxes and fundraising events organised by families and friends and we would like to thank all those involved.



Recent fundraising events were organised by The Royal Oak Public House; friends and family of Jackie Humphries; Tim Owen, Leigh Price, the Elliott Family, Hannah Bishop and the staff and pupils of Hallaton C/E Primary School, Rose, Val and the Residents of Astral House and South Hylton Working Men's Club. As well as the Institute of Chartered Accountants, Ducklings Preschool and Leapfrog Nursery, in conjunction with the Hope for Hollie Campaign.

We also received donations "in loving memory" of Corrinne Berg, Anthony O'Hara, Ivy Porter and Chris Thomson.

General donations were received from Ruth Berman, Andy Brooks and Accenture.

Ann and Michael, Billy and Denise, South Hylton Working Men's Club, Michelle McGuire, Tony Mundell, Bill Owen, ANP Stores, The Three Horse Shoes, John and Blaikie and Brenda Clarke all donated the contents of their NPDG (UK) collection boxes.



We would like to say a huge thank you, and congratulations to Claire Perkins (NPC) (pictured here with mum, Paula, dad, Mark and brother, Jamie) who recently celebrated her 18th birthday. Claire requested that instead of presents, donations be made to the NPDG(UK) - this raised a staggering £1080. Many thanks to Claire and her family.

Do you have a NPDG (UK) Collection Box?



Recently, one of our Charity collection buckets was stolen from its designated venue during a robbery. Luckily, as all of our boxes are numbered and traceable, the police contacted us immediately and in turn we were able to contact the person responsible for this box to inform them of the incident. Unfortunately, the bucket was empty by the time the police discovered it.

In light of this incident, we would like remind everyone of the following guidelines that will assist you in ensuring the safety of your collection box:

- NPDG (UK) collection boxes/buckets (both cardboard and plastic) are only to be used for their intended purpose - to raise funds for the NPDG (UK).
- It is illegal to collect money in a public highway or street, or on a house-to-house basis, without a valid licence from your local authority. The NPDG (UK) does not hold a national collection licence and therefore it is not authorised to allow individuals to conduct street collections on its behalf.
- Plastic collection boxes/buckets are numbered and traceable, if you place a box with a local business or another venue other than your home, please do let us know.
- Cardboard collection boxes are intended for home use, or use at a single fundraising event.
- Boxes should be emptied frequently, the contents checked by two people, the amount raised recorded (forms are available to assist you with this process), and a cheque forwarded to the NPDG (UK) as soon as possible.
- We advise that collection boxes/buckets are locked safely away at night, to reduce the risk of theft.
- The boxes are issued on a trust basis and remain the property of the NPDG (UK) at all times, we reserve the right to recall a box if we feel it is not being used appropriately.

Finally collection boxes are a great help to the Charity – not only do they generate much needed income, they raise awareness of Niemann-Pick diseases and the work of the Charity. Thank you to all of you who have successfully raised £1645.00 in the past year using our boxes – your efforts are very much appreciated! If you have any questions about collection boxes, would like a supply of collection forms/stickers, or would like to inform us of any changes, please contact the Central Office on **0191 415 0693** or email **niemann-pick@zetnet.co.uk**

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, please send them to **Sue Lowe, 11 Greenwood Close, The Pastures, Fatfield, Washington NE38 8LR** or email **sue.npdg@tiscali.co.uk**.

If you have received this Bulletin through the post and would now like to receive it by email please let Sue know at the above address or email her at **sue.npdg@tiscali.co.uk**.