



**NIEMANN-PICK DISEASE
GROUP (UK)
FAMILY NEWS BULLETIN
DECEMBER 2008**



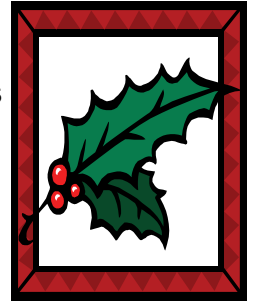
Hello and welcome to the latest Niemann-Pick Disease Group (UK)'s Family News Bulletin. In this month's edition:

- **Niemann-Pick Christmas Cards**
- **NPDG (UK) Family Directory 2009**
- **Campaign for Calum Fundraising Evening**
- **Online Shopping**
- **Liz Jacklin— Clinical Research Nurse Report**
- **Christmas Cash Bonus**
- **Families With Disabled Children Hardest Hit by Economic Crisis**
- **Working Parents Caring For Disabled Child—New Ruling**
- **New Regulations for Special Educational Needs Co-Ordinators**
- **Local Authorities to Receive Funding for Improving Standards of Transition**
- **NHS Websites Merge**
- **Listening Books**
- **New Good Practice Guide on Short Breaks**
- **Future Holiday Centre Needs Your Input**
- **Young People Invited to Take Part in “My Choices” Study**
- **New Podcast from Contact a Family**
- **Family Fund Extra**
- **Turn2Us**
- **Donation of a Laptop**
- **Fundraising**
- **..... And Finally**



Niemann-Pick Christmas Cards

We would like to thank all those who have purchased NPDG (UK) Christmas Cards this year, so far a total of almost £750.00 has been raised.



NPDG (UK) Family Directory 2009

Just a reminder, we will shortly be in the process of updating the Family Directory so could you please check your entry in the 2008 Directory and let us know if there are any changes or additions, such as email address, that need to be made. If you are not currently in the Family Directory and would like to be included, or you wish your entry to be removed, please let us know. Details of any changes should be emailed to sue.npdg@tiscali.co.uk or posted to Sue at The Central Office address, (which can be found at the end of this bulletin) by 31st December 2008.

Campaign for Calum Fundraising Evening



Carl Burdon, father to Calum (NPC) aged four has organised a fundraising evening of entertainment for the NPDG (UK) and the Campaign for Calum. The event will be held at the Lowther Pavilion, Lytham near Blackpool on **January 17th 2009**. The evening will include entertainment from three comedians, two male vocalists (including Carl), two female vocalists, a magician and a musical dance troop. The tickets will cost £15 and £13 (concessions) - there is also a limited number of VIP tickets at £20 which include an after

show buffet. You can purchase the tickets from Lowther Pavilion in Lytham by calling **01253 658666**.

Online Shopping

If like millions of others you plan to do your last minute Christmas shopping online, you can help raise money for The Niemann-Pick Disease Group (UK) at the same time. By visiting www.easyfundraising.org/uk/niemannpickdiseasegroupuk



Christmas Cash Bonus

The NPDG (UK) has welcomed the Chancellor's announcement that disabled children and their carers will receive an additional £60. The payment is on top of the annual £10 Christmas bonus given to those in receipt of Disability Living Allowance (DLA) and Carer's Allowance. In the recent pre-budget report, the chancellor announced that between January and March 2009, an extra £60 will be paid to disabled children and carers receiving the qualifying benefits. For more information about the Christmas bonus, visit Directgov at www.tinyurl.com/5tzkal.

NPDG (UK) Clinical Research Nurse – Liz Jacklin

Liz Jacklin, our Clinical Research Nurse, has kindly agreed to provide a regular 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@CMMC.nhs.uk.

Liz writes:

Lysosomal Storage Disorders - A Research Study

*As many of you are already aware, Niemann-Pick diseases are part of a group of disorders called Lysosomal Storage Disorders. This Study aims to understand the natural history, effectiveness and cost effectiveness of current and emerging treatments for those affected by a Lysosomal Storage Disorder (LSD) and their families. The Study is being funded by the Health Technology Assessment Programme, which is part of the Department of Health. The consultants at each of the NCG centres are co-investigators on the Study. Shortly, you will receive an information sheet about the Study in the post, and when you attend your clinic appointment, you will be asked to give your consent to participate in this Study. There are two parts to the Study, the first part looks at the quality of life of patients with LSDs, and the second collects clinical data on the natural history of LSDs. **You are free to decide whether or not you wish to participate in this Study; if you choose not to participate your clinical care will not be affected in any way.** You can consent to participate in the full study; if you choose to do this, you will be asked to complete a number of quality of life questionnaires. There will be no additional tests or samples required. A research nurse or analyst will be on hand to help you with the questionnaires - although she will not be able to influence your answers. The research nurse or analyst will then use your clinic notes to obtain clinical information for the natural history part of the Study. If you do not wish to participate in the full Study, you can consent to be part of the natural history Study only, in which case you will not fill out any questionnaires but the research nurse/analyst will still be able to collect clinical information from your clinic notes. The Niemann-Pick Disease Group (UK), Jackie Imrie, and myself, are in regular contact with the Study designers so please do contact us if you have any questions about the Study. At the moment, only those affected by Niemann-Pick Type C will be contacted, but we expect that the Study will soon be opened up to Niemann-Pick Type B patients.*

Curcumin

As many of you may be aware, the use of the naturally occurring substance Curcumin (Turmeric) is currently a hot topic of debate in NPC. Some families in America are using the substance as a drug and are treating their children with it. This has led many others to ask if they should be doing the same. There have been no clinical trials using curcumin in NPC carried out in humans. It is therefore not possible to assess the effects or side effects associated with it. As with all therapies our advice would be to look very carefully at the evidence and to discuss this with your clinician before making any decisions.

As always if you would like to discuss these or any other issues relating to Niemann-Pick Disease with me then I would be very happy to hear from you.

Families With Disabled Children Hardest Hit by Economic Crisis

Carers UK have launched new research into the financial difficulties being experienced by carers with one of the key findings of 'Carers in Crisis' is that families with disabled children have been hardest hit among carers by the credit crunch. Key findings from the report included: people caring for a disabled child under 18 are among the worst off as they are most likely to be cutting

back on food and to be in debt and carers on Income Support do worse than any other group according to all major indicators. For more information and to read the report in full visit www.carersuk.org/Policyandpractice/Research/Financialimpactofcaring/1228318101

Working Parents Caring for a Disabled Child—New Ruling

The Employment Tribunal has ruled to protect parents who combine work with caring for a disabled child against harassment and discrimination in the workplace. The ruling means that parent carers have the right to claim against employers who treat them unfairly "by association with disability". Working parents of disabled children are now protected in law against discrimination such as a refusal to offer flexible working. The decision follows a parent carer's legal victory in the European Court of Justice and has now clarified the law in England and Wales which will pave the way for parents of disabled children to make immediate claims against their employers if they are treated unfairly.

New Regulations for Special Educational Needs Co-ordinators (SENCOs)

A new requirement for SENCOs to be qualified teachers by September 2011 has been introduced. The Education (Special Educational Needs Co-ordinators) (England) Regulations 2008 (SI 2008/2945) are due to come into effect on 1st September 2009, so that schools can make any staffing adjustments. Some of the SENCO functions will still be done by other staff, including teaching assistants, who will carry on improving the achievement and well-being of pupils with SEN and disabilities. To see the regulations go to Teachernet at www.tinyurl.com/6rvudc

Local Authorities to Receive Funding for Improving the Standards of Transition

As part of the Aiming High for Disabled Children programme, the government is investing £19m to improve standards of transition in England. At the official launch last week, the Minister for Schools and Learners, Sarah McCarthy-Fry, MP, confirmed that every local authority area is to receive £10,000 to assess their current support for transition. This includes obtaining the views of young people and families and completing a self assessment questionnaire. Thirteen local authorities will receive an additional £37,500 to extend their practice in engagement with disabled young people and also their families; personalisation; joint assessment processes in children's and adult services; education, employment and training options at 16+ and strategic partnership working.

The Council for Disabled Children is to be the national transition support team and will work with local authorities to help them improve standards of transition. For more information about the Transition Support Programme visit www.transitionsupportprogramme.org.uk/

NHS Websites Merged

Previously, the NHS had two national websites - NHS Choices and NHS Direct. Now both these websites have been combined into one - NHS Choices - making online information about health and health services available from one site. The site will include popular features like 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. To view this site go to www.nhs.uk

Listening Books

Visually impaired children and young people can now benefit from the expanded content of Listening Books, an audio book charity. The Listening Books Sound Learning service includes over 650 titles - both classics and contemporary fiction. Users log onto the Listening Books website then choose which audio book they want to listen to and press play.



Their full range includes leisure and learning from Key Stage 2 to A-Level. Listening Books is currently offering a limited free trial on their website www.listening-books.org.uk

New Good Practice Guide on Short Breaks

The Social Care Institute for Excellence (SCIE), supported by the Council for Disabled Children and Aiming High Implementation Group, has published a good practice guide to short breaks, called 'Having a break: good practice in short breaks for families with children who have complex health needs and disabilities'. This is in response to the new duty on local authorities to provide short breaks for disabled children introduced in March 2008. The guide has been compiled following research with a wide range of networks and includes many examples of innovative family-friendly practice. It is aimed at commissioners and service providers for children with complex health care needs and their families.

Further details can be found at www.scie.org.uk/publications/resourceguides/rg14/index.asp

Future Holiday Centre Needs Your Input



Ellie's Haven, a charity in Cornwall, needs help from families to ensure it delivers the best type of holiday for them and their disabled child and is calling on families to provide input by completing a short online questionnaire. Ellie's Haven was launched in November 2007 by a couple in Cornwall whose little girl, Ellie, has a life-limiting medical condition. The charity plans to build a special centre on the outskirts of Looe to offer short breaks and holidays to families with disabled children. In its first year, Ellie's Haven has raised more than £100,000 and has acquired some land. The next step is designing the facility and Ellie's Haven needs input from families to make sure it's built to suit their needs.

To learn more about the charity, visit www.ellieshaven.org.uk and to complete their survey visit www.surveymonkey.com/s.aspx?sm=NnQ_2fcA2zQiUgYWsGRcvjqg_3d_3d

Young People Invited to Take Part in 'My Choices' Study

The Welsh Assembly Government has made palliative care and support to families a priority. Current provision is known to be fragmented and children frequently have few choices with very little known about the experiences of children with palliative care needs and their families. The 'My Choices' study has been planned in collaboration with The Association for Children's Palliative Care (ACT), Children's Hospices UK and Contact a Family, along with colleagues from the 'Lifetime Service' in Bath. If you are a young person aged 16-21 years with complex health needs, or a parent (over 16 years) of a child with complex health needs you can help by filling in an online booklet about the type of services and care you prefer, and where you would like to be looked after in different situations. The results will be used to write a report and they will use published information on costs to build up a complete picture. The study is funded by the Welsh Assembly Government with permission from the North West Wales Research Ethics Committee.

For further information call **01248 383150** or email n.d.hulme@bangor.ac.uk or visit www.bangor.ac.uk/healthcaresciences//research/mychoices

New Podcast From Contact a Family

Contact a Family has produced a podcast on Carer's Allowance which explains the main criteria for claiming Carer's Allowance, how to claim it and where to get further support in claiming this benefit. Other podcasts include income support and jobseekers allowance, money when your child reaches 16. To listen to the podcasts visit www.cafamily.org.uk/news_podcasts.html

Family Fund Extra

The Family Fund understands how expensive caring for a disabled child can be and try to help as many families financially as they can each year. Family Fund Extra is their way of finding new ways to support and make a difference to all families that care for a disabled child or young person. Family Fund Extra offers a variety of services such as electrical products and holidays. For more information visit www.familyfundextra.org.uk



Turn2Us

Turn2us is a new independent charity that helps people access the money available to them – through welfare benefits, grants and other help. Their free, accessible website is a comprehensive and invaluable resource that helps you find sources of financial support, quickly and easily, based on your particular needs and circumstances. In some cases, you can make online enquiries to grant-giving charities listed on the site. Sign up to their newsletter for regular updates on their many activities at www.turn2us.org.uk



Donation of Laptop

The Niemann-Pick Disease Group would like to thank Andy Bramley of Bramatt Computer Ltd for the very kind donation of a laptop for use by the Group. We would

also like to thank Amanda and Roger Peacock for organising this generous gift.

Fundraising



The total amount of funds raised since our last newsletter is £1601.34 which is made up from general donations from Bill Owen, Mary and Phil Winetroube, Staff and Customers of The Three Horse Shoes and The Barge Inn, Brenda Clark, Steve of Uplands Bowls Club, Janet Tungate, Sally Tungate and Steve Keeble; the sale of our wristbands by Susan Wright; Ian Brown (birthday party donation), Philip Hurst (60th Birthday celebration), Amanda Lewis competing in the London Royal Parks Half Marathon, raffles held by Ron and Rose Thompson and Ann and Mike Lidle and also a donation in memory of Carl Symes on the anniversary of his death.

The Niemann-Pick Disease Group (UK) would like to thank all our families and friends who have worked so hard to raise money for the Group throughout 2008. Remember, it doesn't matter how small or large the donation, every penny helps the NPDG (UK) to make a positive difference to the lives of those affected by Niemann-Pick disease.

If you would like information about holding a fundraising event, please contact Sue or Toni at the Central Office on **0191 4150693** or email **niemann-pick@zetnet.co.uk**

And Finally



On a final note, from the Trustees and Staff of the Niemann-Pick Disease Group (UK), we would like to send you our warmest wishes for a very Happy Christmas and a good New Year.



PLEASE NOTE: The NPDG (UK) Office will be closed from Monday 22nd December to Monday 5th January 2009. The answerphone will be on and we will check for messages on a daily basis—so if you do need to speak to someone urgently, please be sure to leave a message and we will get back to you as soon as possible.

We hope you enjoyed reading this edition of the Family News Bulletin. If you have any articles, suggestions, announcements or comments for future issues of the Family News Bulletin which you would like included, please send them to **Sue Lowe, 11 Greenwood Close, The Pastures, Fatfield, Washington NE38 8PD** or by email to **sue.npdg@tiscali.co.uk**.