



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

AUGUST 2008

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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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 niemann-pick@zetnet.co.uk or to Liz direct Elizabeth.Jacklin@CMMC.nhs.uk.

Liz writes:

Clinical Trial of Miglustat (Zavesca) for NPC

The Actelion Clinical Trial of Miglustat (Zavesca) recently came to an end; however we continue to provide support for patients taking the medication on compassionate use. Actelion are presently collating data from this trial, along with information from patients who used the drug off study, so as they can re-submit an application to the European Medicines Agency at the end of September 2008. You may recall that they took the decision to withdraw their first submission in February 2008. To assist with this process, I have been asked to collate some of this data and many of you will have already received an information sheet and consent form in the post.

NPC Natural History Study

I am presently working with Dr Denny Porter from the NIH, National Institute of Health, in Bethesda, Maryland, to adapt the NPC Natural History Study Protocol that is currently underway there, so that we can establish a study here in the UK. We hope to send the draft protocol to the Ethical Committee Review Board for appraisal very soon. Once that is done and we have established funding, we will be able to start recruiting patients here in the UK. More information about this study will appear in the next issue of Niemann-Pick News.

This is a very brief overview of my work at present, if you have any questions about this or anything regarding Niemann-Pick research - please do not hesitate to contact me at **Elizabeth.jacklin@cmmc.nhs.uk** or telephone **0161 922 29667**.

Computer Needing New Home

We have recently had a computer donated to us here at Central Office. It is in full working order, and runs on Windows 98. If your family is currently without a computer and could make use of it, then please contact Toni or Sue here at the Central Office on **0191 415 0693**.

Say It With Flowers



The NPDG (UK) has recently teamed up with a company called Charity Flowers Direct based in Guernsey. Every time you order flowers through Charity Flowers Direct 15% of the total price will be donated to the NPDG (UK). So whether it's Happy Birthday, Happy Anniversary, Happy Christmas, Happy Easter, Congratulations, a present for Mother's Day or just to show you care, order from Charity Flowers Direct. Their website is **www.charityflowers.co.uk**; their Order Hotline is **08705300600** and we are listed as **The Niemann-Pick Disease Group (UK)**.

Sculpting a Voice for Genetic Disorders

This project aims to raise awareness of living with a genetic condition through the visual arts. The project will collect stories and opinions from people with genetic disorders, family members, friends and also from freely available material such as that included on the 'Telling Stories' website **www.geneticseducation.nhs.uk/tellingstories**.

To have your information included in this project, you can take a survey at www.surveymonkey.com/s.aspx?sm=zhleIN_2bAcDY1gLE9DI6v0w_3d_3d and give details about the issues which are important to, and affect, you or your family member/friend. All of this information will form the basis of an artistic response to the issues of living with a genetic condition such as care, support, public awareness and current research. The aim is to develop and exhibit a series of art installations/sculptures inspired by those affected and hold an exhibition early next year. To get involved or for more information about the project, please contact Julia Thomas by email at julia.m.thomas@talktalk.net or call her on **07711 269101**. If there is enough interest, Julia would consider holding some art workshops so that people can get more directly involved and get creative!

Care Choices

Care Choices manages the Disabilities Care Register which helps to match the care needs of adults aged 16-65. Founded in 1993, Care Choices is a leading publisher of care information and produces many of the official care directories for local authorities and councils. Other independent publications include Care Select, Progress and Care Management Matters. Through many years of care sector experience, Care Choices has developed an interactive service on their website www.carechoices.co.uk to enable those looking for care provider information with a tailor-made list of care homes matching individual needs and preferences. Care Choices provides information for care of the elderly and the specialist care of disabled adults (16 - 64) in all types of care settings from care in your own home to care homes or independent living alternatives. Whether you seek long or short term care or are simply looking for advice on topics such as paying for care, Care Choices can provide a wealth of information to assist you. More information is available on their website www.carechoices.co.uk.

Contact a Family New Image Website

Contact a Family have just launched their new image website. This new site features some of the podcasts that Louise Derbyshire of Contact a Family, who many of you will remember from our Family Conference in June this year, has been working on, including Disability Living Allowance. Further recordings of information on other benefits will be added shortly. To view the list of podcasts which are currently available go to www.cafamily.org.uk/news/podcasts.html.

Contact a Family has also increased its online support in an exciting new project, creating groups and networks for families with disabled children on MySpace, Facebook and Bebo. In addition, they have set up a virtual office on Second Life, a popular online 'virtual world'.

These can be viewed at:

Facebook: www.facebook.com/pages/Contact-a-Family/25040545213

Myspace: www.myspace.com/contactafamiy

Bebo: www.bebo.com/contactafamily

Second Life: www.secondlife.com (you need to use Aloft Island 19.40.22)

Win a Laptop, Tell Your Story and Raise Public Awareness

Contact a Family is running a national competition which aims to highlight the many issues faced by families raising a disabled child. They are calling on parents to tell their stories.



On the theme of 'Me and My Disabled Child' they are asking for short videos about the joys and challenges of caring for a disabled child. If you do not have a video camera, you could tell your story in an essay, make an audio recording or take a picture.

All entries will be considered in a category alongside those other entries using the same media, with a chance to win a digital camera and for the overall winner, a laptop. The best clips, pictures and stories will be featured on the Contact a Family website and other online channels, such as Youtube, and in their magazine, Connected.

Entries must be submitted by 30 November 2008. Video and audio entries should be no longer than three minutes and written stories no longer than 2,000 words. Videos, podcasts, word documents and digital photos can be submitted by e-mail to new.media@cafamily.org.uk with Competition in the subject header. They can be submitted either as an attachment or a link. All printed stories, photographs, tapes, DVDs can be posted to: Competition, Contact a Family, Freepost Lon8801, London EC1B 1EE. Email entries larger than 4mb should be submitted by post on DVD or tape format.

Sibs Conferences and Workshops

Sibs is the UK charity for people who grow up with a disabled brother or sister. They support siblings who are growing up with, or who have grown up with, a brother or sister with any disability, long term chronic illness or life limiting condition. There are over half a million young siblings and over a million adult siblings in the UK. Siblings have specific needs that require attention at different stages of their lives, including relief of isolation, information and strategies for coping with the situations they find themselves in. Sibs run a wide range of conferences and workshops around the UK. For full details of these events and dates, visit their website at www.sibs.org.uk.

Better at Home—The Family Story

Better at Home is a new campaign being run jointly by national children's charity, WellChild and the Royal College of Nursing (RCN). The main aim of the campaign is to try to reduce the need for children and young people with long term complex health care needs to stay in hospital for months and in some cases years. This can have a huge impact on families practically, emotionally and financially and so there is an urgent need to reduce these additional stresses on families and improve their quality of life and the overall care of their children.



The idea for the campaign came from reports of families staying on Intensive Care and High Care Units for long periods of time when, with the right community support, the care of their child could have been continued at home. It became apparent that, with more specialist community children's nurses making sure that the right care packages were in place, many of these children could be discharged earlier. WellChild is already trying to make an impact by funding children's nurses in some areas of the UK,

however this is just the tip of the iceberg and more community children's nurses are urgently needed.

The first stage of the campaign is to try to find out exactly how many children and young people stay in hospital long term and what would be needed to help them get home. They already have considerable parliamentary support for the campaign as well as from professionals working in this field. However the experience of families is the most important part of this campaign and they would love to hear from any parent or carer willing to share their story with them.

Alternatively, if you want to know more about the campaign and how you can get involved, call **0808 801 0330** and speak in confidence to one of the nurses working on their free Helpline on children's health, or email your story to **campaign@wellchild.org.uk**. If you would like to keep up to date with developments, then please visit **www.wellchild.org.uk**.

Register For a New Service from Family Fund

The Family Fund is launching 'Family Fund Extra' during October and is calling on families with disabled children to register their interest. Family Fund Extra is a separate scheme from their grant making programme and aims to help families make their money go further. It will offer a variety of discounted goods and services, like electrical products and holidays. It will also allow supporters of Family Fund to make a difference to disabled children through donations and 'donate as you shop' opportunities. If you care for a child or young person up to the age of 25 years old and would like to benefit from the discount and services Family Fund Extra will offer, register now at **www.familyfundextra.co.uk**.

Seven Million Households To Qualify For Help To Go Digital



The Help Scheme has been set up to help households where there is a child or adult entitled to Disability Living Allowance and/or are registered blind or partially sighted. The scheme will help households to make the switchover to digital TV, including providing them with easy-to-use equipment and help to install it.

People should be contacted well ahead of switchover in their region with details of how the scheme works and the digital options available.

For more information go to **www. Digitalul.co.uk/en/how/help-scheme.html**.

New Organisation To Help Find Care Workers For Disabled Children

Cool2Care is a new social enterprise organisation (a business that gives its profits to charity or reinvests them for community benefit) that brings together families of disabled children with people who want to care for them. If you are a parent or guardian of a disabled child or young adult and would like to employ a trained care worker, or personal assistant, Cool2Care can help you find the right care worker for you and your child. If you are thinking of working with disabled children and young adults, then Cool2Care can help too. For further details go to **www.cool2care.co.uk**.

Fundraising Events

The Niemann-Pick Disease Group (UK) would like to thank the following families and friends who have recently raised funds for the Group:



Luke Peacock raised £168 from the sale of wristbands.

Hallaton C/E Primary School held an afternoon tea and raised £278.00.

Mark Stonier held a breakfast meeting and raised £96.00.

UIA in Stevenage held a dress down day which raised £82.38.

Sam Wise held a coffee morning which raised £389.00.

Mary and Phil Winetroube raised £655.03 by holding a 'Niemann Pick-Nic'.

Jane Hickman took part in the Market Bosworth Sprint Triathlon and raised £500 through sponsorship.

Generous donations totalling £450.00 were received from Gary and Lynn Archbold; Shabbir Akooji; Clare Botham; Mrs Driver; Jane Pyne; Uplands Short Mat Bowls Club and Mrs Tungate.

We have also received a total of £108.41 from various collection boxes; including Café Nero in Market Harborough; Lawrie Brown; Roy Green; The Barge Inn and Larry. We have plenty of collection boxes here at the Central Office, if you would like one (or more), please contact Toni or Sue on **0191 415 0693**.



.Carl Hitchens, dad to Harry, NP Type C, (pictured on the left) will be running the New York Marathon on behalf of Martin House Children's Hospice and the NPDG (UK). If you would like to sponsor Carl, please contact use here at the Central Office.

We have received news of an unusual fundraising idea from Louise Moore. Louise is a friend of Jodie O'Grady, mum to two year old Joshua Cullip who has NP Type C. She is trying to raise £2000 for the NPDG (UK) and says when she does she is going to get a life-size tattoo of a jar of marmite!!!!!! You can read more at justgiving.com/npc-joshua.

We are very grateful to all the above and all who continue to so generously support the work of the Group.

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

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.

The next edition of the Family News Bulletin will be out in October, however, you will be receiving your copy of the latest edition Niemann-Pick News by mid-September.

