



**NIEMANN-PICK DISEASE
GROUP (UK)
FAMILY NEWS BULLETIN
December 2010**



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

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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 £400.00 has been raised.

NPDG (UK) Family Directory 2011

Just a reminder, we will shortly be in the process of updating the Family Directory so could you please check your entry in the 2010 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 7th January 2011.

The Family Care and Interactive Support Project

In our spring edition of Niemann-Pick News we told you about the Family Care and Interactive Support Project, supported by a grant from the Big Lottery Reaching Communities Programme, which has given the NPDG (UK) an exciting opportunity to provide an improved and more efficient support and advice service to those affected by the Niemann-Pick diseases. The overall aim of the project is to improve outcomes for families with Niemann-Pick diseases, through the use of interactive technology that will enhance access to support and information services. Using appropriate interactive technology, such as video cameras, webcams and media links, families will have increased access to expert care and advice provided by NPDG (UK)'s Clinical Nurse Specialist for Niemann-Pick Disease, Jackie Imrie, enabling them to achieve a more timely response to their questions and concerns. The pilot scheme for this project is now underway with five families enrolled at present and three more soon to sign up. If you would like to know more about this project, or if you would be interested in participating, please contact Toni Mathieson at the NPDG (UK) Central Office by telephone 0191 415 0693 or email niemann-pick@tiscali.co.uk

Genzyme ASMD Clinical Trial



The NPDG (UK) understands that Genzyme is currently in dialogue with the US Food and Drug Administration (FDA) in regard to a Phase 2 ASMD clinical trial of recombinant human acid sphingomyelinase (rhASM). This is a formal process that Genzyme is required to undertake. There is no indication as to how long this process will take. A further update will be provided in the next Bulletin.

The NPDG (UK) Says “Goodbye to Clinical Research Nurse Liz Jacklin”

On November 17th Liz Jacklin, the NPDG (UK) Clinical Research Nurse left her post. Liz has prepared the following statement.....” *after 4 and a half years working for the Niemann-Pick Dis*

ease group (UK) I am now writing to inform you that I have been offered and have accepted a job as Clinical Research Nurse with the Medicines for Children's Research Network (MCRN) based at the Royal Manchester Children's Hospital. I have very much enjoyed the opportunities and experience I have gained whilst working for the NPDG (UK) and am very sorry to leave, however, I will not be leaving the field of NPD as I will be working part time with Actelion on the NPC registry. The registry is now all set to start in the UK and we are hoping to recruit our first patient soon. I will of course very much miss the patients and the families that I have got to know and I hope that I will still be able to attend the Annual Family Conference—I know my friends and family that have helped in the past would be keen to do this also! I wish you all the very best for the future, you will all remain in my thoughts and in my prayers; I very much hope that I will see many of you again soon. Liz”

The NPDG (UK) would like to thank Liz for her hard work and efforts over the last four years and to wish her every success in her new role.

Save the Date



Our Annual Family Conference 2011 will once again be held at the Robinson Executive Centre, Wyboston Lakes, in Cambridgeshire, a venue which proved very popular with this year's delegates. The Conference will be held over the weekend of 23rd-25th September. Full details will be given in the Spring of next year.

Returned Post



On a few occasions the NPDG (UK) has had mail returned to us marked “addressee has gone away” and we have removed the address from our mailing list. Our Autumn 2010 Newsletter has recently been posted out, if you have not received your copy this may be the reason, so please do let us know. Also please keep the NPDG (UK) informed if your address (or email) changes.

Net Buddy Top Tips



If you are looking after someone with a learning disability – whether you're a parent, carer, teacher, therapist or another professional – you'll find some great ideas at www.netbuddy.org.uk. Netbuddy is the first online resource of its kind offering hundreds of handy tips and simple yet ingenious suggestions from people with everyday experience of special needs. You can use the site in a number of different ways. Either search for a tip in a specific area, such as 'repetitive behaviour' or 'sleeping'. Or you can post a question on the interactive forum. You can also search for practical help in the information packs. Plus you'll find loads of useful links to other sites and resources.

Cerebra Grant Scheme



Cerebra has increased their budget this year to give more grants to help children who have disabilities because of a brain related condition or injury. The condition may be of a physical nature or a learning difficulty or both. The equipment or resource requested must improve the child's quality of life and not be available from statutory agencies like social services or the NHS. The child also must be aged 16 or under. Some examples of grants made are touch screen computers, holidays, approved therapies, power wheelchairs, and sensory toys.

Parents and carers can request an application form by calling **01267 244200**, download one from their website at **www.cerebra.org.uk** or by e-mail: **debbieg@cerebra.org.uk** Applications are accepted throughout the year but allow 4-6 weeks for a decision.

New Topics to Discuss on the 'Hope for Hollie' Forum



Four new topics have recently been added to the 'Hope for Hollie' Campaign e-forum which 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 affected families, carers, experts, and also discussion about fundraising activities. To join, visit **www.hopeforhollie.co.uk** or follow the link on the NPDG (UK) Website.

Ready-Made Meals to your Door



Wiltshire Farm Foods
delicious meals to your door

Wiltshire Farm Foods is the UK's leading meals delivery service. Their meals are prepared in Trowbridge, Wiltshire, frozen the moment they are cooked, and delivered across the UK & Northern Ireland through a network of local outlets. They also offer a range of soft and pureed food. For more information go to **www.wiltshirefarmfoods.com/frozen-ready-meals/soft-and-pur%C3%A9ed-ready-meals**

Special Educational Needs – A Parent's Guide

According to the latest figures, around a fifth of all children have been diagnosed with special educational needs: 1.7 million out of a school total of 8.5 million. But how can you be sure that your child is getting the right support? **Special Educational Needs – A Parent's Guide**, originally released in 2008, has been extensively revised and updated. Published 1st September, the revised edition brings together the facts on special educational needs, looking in detail at the different types of additional needs and how parents and carers can cope with them in daily life. The guide describes which professionals can help, how to get through the 'system' and gain support, how to handle behavioural difficulties at home and school, and how to get the best education for your child with special needs. Practical issues such as sleep deprivation and finance are also an integral part of the book. This Guide is not just for parents; it is for all those who are concerned about a child's development, including other family members and professionals working with children.

It arms the reader with all the facts and resources they need to help a child with special educational needs. Published by Need2Know – **Special Educational Needs – A Parent's Guide** priced £9.99 is available now from their website www.need2knowbooks.co.uk, by calling **01733 898103**. It can also be found in all good bookshops.

Whizz-Kidz Ambassador Network



As well as making new friends and trying out sports and leisure activities, young disabled children will be able to take part in life skills training. There are also sessions available on communication skills, media training, public speaking and preparing a CV. As a key part of their life skills programme, Whizz-kidz offers young people aged 14 or over the opportunity to do a work placement. Working in partnership with companies all over the country, young disabled people will learn new skills and get their first insight into the work place. Whizz-Kidz Young Ambassador Clubs take place during school holidays or at weekends around the country. For more information, call **0800 151 3350** or check out the website www.kidz-unlimited.org.uk

Free Transition Magazines

My Future Choices from the Transition Information Network (TIN) provides information about the transition process—for more information go to www.transitioninfonetwork.org.uk. **Progress Magazine** is aimed at parents, carers and young people—visit www.progressmagazine.co.uk. **Transitions Magazine** emerged out of KIDS Young People's Including Network (YP-in) and is aimed at and written by young disabled people. Every issue covers 3 main themes—Relationships, Identity and Independence. You can download a copy from www.kids.org.uk or email pip@kids.org.uk or call **020 7359 3073** for a free hard copy. Finally, Contact a Family has published two guides, **Preparing for adult life and transition** and **Money at 16**. For free copies and advice on any issue around disabled young people's transition to adulthood, phone the Contact a Family freephone helpline on **0808 808 3555**.

The Sand Rose Project



The Sand Rose Project is a charity which aims to provide a break to bereaved families, particularly those with a young family. They aim to help such families adjust and become more able to cope with their loss. They have three adjoining cottages of varying sizes, with sea views and a large walled garden which offer a unique place to help establish a new normal. There is also a games room and a quiet room where you have a wonderful view of the bay and St Michaels Mount. Although the charity is based in Cornwall, the project extends to all local authority areas in England and Wales. They do not offer a therapeutic or counselling programme but simply a venue for a break. For more information go to www.sandrose.org.uk

Enjoy Jersey with Carefree Holidays for the Disabled

The Maison des Landes is a holiday hotel catering exclusively for disabled guests and their families or carers, in accommodation which has been specially designed to meet their needs. It features an indoor heated pool with ramps and hoists, en-suite facilities which include walk-in showers, extensive gardens with magnificent views and daily island tours in their specially adapted minibuses. For more information visit www.maisondeslandes.co.uk or call **01534481683**.

Brotherwood Wheelchair Cars



If a member of your family uses a wheelchair or you are finding transportation a difficulty, then you may be interested in contacting Brotherwood Wheelchair Cars. This company, formally known as Invatravel, converts vehicles to allow wheelchair passengers to travel seated in their wheelchairs. For more information go to www.botherwood.com or call **01704 506608**.

Free Attraction Tickets from Merlin's Magic Wand



The Merlin Entertainments Group has launched its own charity called “*Merlin's Magic Wand*”, which provides magical experiences for children who are seriously ill, disabled or disadvantaged and who might not otherwise be able to attend any of its attractions worldwide, which include UK based Alton Towers, the London Eye, Legoland, Sealife and Madame Tussauds. The Charity makes grants towards the cost of travel and accommodation if needed, in addition to providing entrance passes to the attraction or experience in question. Applications for awards can come from individuals or from groups working with seriously ill, disabled or disadvantaged children. If you would like an application form email HilaryBirkinshaw@merlinentertainment.biz or visit their website www.merlinsmagicwand.org

Fundraising

Since our last e-bulletin in July the NPDG (UK) has received just under £40,000 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 Tanya Lambert, Sarah Gale, Simon, Long Meadow School and Special Occasions (Hope for Hollie Campaign); a Golf Day (Campaign for Calum); Manchester to Blackpool Bike Ride by Greater Manchester Police Force Robbery Squad (Hope for Hannah); Leslie and Tony Titford; Carl Gomes; Joanne Gresty; Helen Rogerson; Tameside South and District Scouts; John Pyne; The Stallard Family in Australia; Croft and District Agricultural Discussion Society; Jim and Susan Green; Stephanie O'Hara; the Dodd Family; Dafydd and Ben Taylor; Sheila Simpson and Margaret Bradley; Dr and Mr Pinsett; Deborah Booth; Steph

Back; Hindley and District History Society; Wantage and District Ladies Darts League; The Residents of Astral, Solar and Planet House; Anne Franklin and Cathy Beach and Gwen Clark.

General donations were received from David Ramsden; Mr and Mrs Peacock; Mary, Phil and Joe Weintroube; Mr and Mrs Chalk; The Rigby Family; Bhurat Getal; A W Davidson; Mr and Mrs Poppett; Rockwell Automation; Liz Partidge and Alan Rees; A W Lingard; Friends of Rose Thompson; Reverend and Mrs Godfrey; Yvonne Cassidy; Mr and Mrs Davidson; JLT Premier Pension Services; Bill and Jane Owen; St Dionysius Church Choir; Thorpe Willoughby Community Primary School; Patricia O'Neill; Shirley Wheatley; Ian Robson; Mr and Mrs Connell; Sheila Dolan; Kevin MacGillivray; Elizabeth Sumner; Mr and Mrs Buckingham; Ron Thompson; Joan Geisinger and Ken and Connie Taylor.

We also received generous donations in loving memory of Cassie Stallard, Roger Franklin, Mrs Davidson and Gemma Wood.

The Barge Inn; Anne Franklin; Sharon Whitworth; The Perkins Family; Gwen Clark; Wendy Wynne; Mr and Mrs Coard; Langport Motors and The Colquhoun Family emptied the contents of their collection boxes.

Information about holding a fundraising event on behalf of the NPDG (UK) can be found on our website www.niemannpick.org.uk/get_involved/get_involved.html. You can also contact either Sue or Toni at the Central Office for more details or a fundraising pack.



And Finallyfrom the Trustees and Staff of the Niemann-Pick Disease Group (UK), we would like to send you our warmest wishes for a very Merry Christmas and a Happy New Year.



PLEASE NOTE: The NPDG (UK) Office will be closed from Wednesday 22nd December to Tuesday 4th January 2011, however we are still available to help. If you need to speak to one of us during this time, please do leave a message on the answerphone and we will call you back as soon as possible. If your enquiry is urgent, please call Toni Mathieson on 07816 398591.

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.

