



## *NIEMANN-PICK DISEASE GROUP (UK)*

### *FAMILY NEWS BULLETIN*

*JUNE 2008*

Hello and welcome to the Niemann-Pick Disease Group (UK)'s Family News Bulletin. This monthly news bulletin is intended to keep families up-to-date with all things Niemann-Pick in between editions of Niemann-Pick News. We hope you find it interesting and informative.

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#### **Niemann-Pick Disease Group (UK) Annual Family Conference and AGM**

A final reminder that our Annual Family Conference and AGM will be held at the Hilton Hotel, East Midlands Airport on June 28th and 29th 2008. We hope you can join us at Conference which provides a chance to strengthen our family network, allowing families affected by NPD to meet and share their experiences. Places are limited, so if you are interested in attending, please call the Central Office on **0191 4150693** to reserve your place.

## Baby Congratulations

The NPDG (UK) would like to offer congratulations to Janice Brooks, one of our Trustees, on the safe arrival of her third grandson. Janice's daughter Gabrielle gave birth to Bertie on Wednesday 14th May weighing 7lbs 3oz - we all look forward to meeting him at Conference this year.



## Annie is Granted Her Lion King Wish

A big wish has come true for 12 year old Annie Pyne, who was diagnosed with NP Type C in 2005, thanks to Starlight Children's Foundation. Starlight organised a fun-filled few days in London with her mum, dad and brother Robert, where she saw the sights, went shopping and went to see the stage production of Disney's The Lion King.

Starlight grants once-in-a-lifetime wishes for seriously and terminally ill children. For further information visit their website [www.starlight.org.uk](http://www.starlight.org.uk) or call **020 72622881**.

## How Social Networking Sites Can Help You

Have you heard of Social Networking Sites like Facebook, MySpace, and Bebo but are not sure what they are and how people use them? Do you think you could be using social networking sites like these but just not sure how to start? Do you feel nervous using the internet and technology in general? Would you like the opportunity to meet up and network with national and local support groups? If so, you might be interested in a workshop which has been organised by Contact a Family on **Saturday, 21st June between 10.30 am and 2.30pm** at their offices 209-211 City Road London, EC1V 1JN.

Using practical examples and demonstrations, you will learn how to use FREE social networking sites to promote your events and meetings and talk to other parents. The Contact a Family Media Adviser can give you follow up support afterwards to give you the confidence and skills to implement any of these ideas into your own activities. No prior knowledge or experience is required and this workshop is for any parent of a disabled child or member of a local or national support group. The event is free of charge and lunch is included. Contact a Family are willing to offer a contribution towards travel and childcare costs on a first come, first served basis. If you have any questions or would like to request a booking form, please telephone Louise Derbyshire on **020 7608 8715** or email [louise.derbyshire@cafamily.org.uk](mailto:louise.derbyshire@cafamily.org.uk).

## Counting The Costs

Finances can be a major concern for families with disabled children. It costs almost £7000 a year more to raise a disabled child due to direct costs such as special aids and adaptations, transport, heating and childcare. With rising living costs affecting all families, Contact a Family wants to find out the effects on families caring for children with disabilities, serious health conditions, rare

conditions living in the UK. This research will be used in future campaigning work.

If you would like to help Contact a Family, you can complete their survey on line at [www.cafamily.org.uk/quiz.html](http://www.cafamily.org.uk/quiz.html). If you would prefer a hard copy of the survey, please call their Freephone Helpline on **0808 808 3555** and request a copy of the Counting the Cost Survey.

## Break Charity Holidays



Break Charity has been supporting children, adults and families with special care needs since 1968. Their range of services include supported holidays, short breaks, respite care and day care support for people with learning disabilities; self catering holiday chalets, homes for children. and assessments for families in crisis.

For more information on their holiday homes or services in general, visit their webpage [www.break-charity.org](http://www.break-charity.org) or call **01263 822161**.

## Help Other Parents of Disabled Children Deal With Bullying

Contact a Family needs your help to produce a parent guide about bullying. Research suggests that more than one in three disabled children have been bullied at school and many parents feel they have nowhere to turn. Working with **Parentline Plus**, Contact a Family are producing a guide for parents of disabled children to help them cope when their child is being bullied. As well as containing information about the action schools should be taking and the legislation around bullying, it will include parents' experiences. If your child is being, or has been, bullied because of their disability and you would like to share your experiences to help other parents, please contact Penny Roper on **0808 808 3555** or email [penny.roper@cafamily.org.uk](mailto:penny.roper@cafamily.org.uk)

## New Guide to Support the Inclusion of Disabled Children

The Council for Disabled Children (CDC) has launched a new guide aimed at supporting the inclusion of disabled children in children's centres and extended schools. The guide is designed to be a helpful tool for children's centres, schools and other practitioners to ensure that disabled children have full and equal access to services and activities. To find out more and to download a copy, go to [www.ncb.org.uk/extendinginclusion](http://www.ncb.org.uk/extendinginclusion).

## Norman Raises £7,629

As you may remember, Norman Pyne and friends took part in a sponsored bike ride from Land's End to John O'Groats in April 2007. Sponsorship money for this ride has been coming in over the last year, with the final cheque being received this week. The total raised was £7,629 and the NPDG (UK) would like to thank Norman and his friends for making the journey and everyone who sponsored them so generously.



## Niemann-Pick Awareness Week

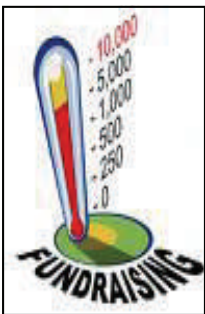
This year Niemann-Pick Awareness Week will be held from 14th to 20th July. Help us to make Awareness Week 2008 one to remember, by increasing awareness of Niemann-Pick Disease, raising money and having fun by organising a quiz night, a "Niemann-Pick-Nic", a bring and buy sale or another fund raising event. 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.

## Niemann-Pick Disease Group (UK) Collection Boxes

Just to remind you we now have a new supply of yellow plastic collection boxes. If you are interested in some to distribute amongst your friends, family or contacts, please call Toni or Sue at the Central Office on **0191 4950693** or email **Niemann-pick@zetnet.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:



The amount of £1,110 was received in loving memory of Tony Brooks.

Irene Cresswell donated £200 and Miss A McDonald donated £100, both via the Hope For Hollie Fund

Mr and Mrs Richardson donated £320 which was generously donated in lieu of gifts at their daughter's christening. (Again via the Hope for Hollie Fund).

The Clan Colquhoun Society of the United Kingdom kindly raised £100.00.

Thanks to all at The Cheltenham and Gloucester Nuffield Hospital, who made the NPDG (UK) one of their supported charities during 2007/08 and raised £500.00.

Amelia Grigg and the staff and customers of The One-Six-One Bar in Cheshire raised £50.00.

Hindley Library Ladies Circle donated £30.00. Mr and Mrs Toft donated £50.00.

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 and would welcome your comments. 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 this news bulletin will be sent out via email out at the beginning of July. If you require a paper copy, please let us know.