



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

JULY 2008

Hello and welcome to the latest edition of the Niemann-Pick Disease Group (UK)'s Family News Bulletin

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

Our Annual Family Conference and AGM was recently held at the Hilton Hotel, East Midlands Airport. We welcomed several new families to the Conference and were re-united with many old friends; we were also joined by delegates from France, Germany and the USA. We are very grateful to those families who shared their experiences of Niemann-Pick with us and of course to the professionals who gave up their time to share their knowledge and expertise. The Children's Programme was once again a great success, with an outing to "Conkers" an all weather adventure park on the Saturday.

We hope all the families who attended the Conference this year found the weekend enjoyable and beneficial—especially those who joined us for the first time—we hope to see you all again next year!!!

The Annual General Meeting of the NPDG (UK) took place at the Conference, with members of the Group choosing to re-elect the current serving Trustees, as well as new Trustees, Coral and Andy McLean, to serve on the Board. If you would like to know more about our Trustees, further information is available on our website.

We are now in the process of organising next year's Family Conference. It will be held at the Holiday Inn, Telford from 19th to 21st June and we would welcome any suggestions on how we can tailor Conference 2009 to meet your needs. You can get in touch by emailing us at the Central Office on niemann-pick@zetnet.com or by calling **0191 4150693**.

Niemann-Pick Disease Group (UK) Website Launch

The NPDG (UK) launched their new look website at Conference 2008. We hope you will find it very user-friendly and informative. If you would like to promote a fundraising event on the site, please forward your details to Sue Lowe at sue.npdg@tiscali.co.uk. We would also welcome your comments/thoughts on the website, and these can also be emailed to Sue. We would like to thank Paul Cartwright who worked very hard in designing the site. You can view the website at www.niemannpick.org.uk.

Charity Concert



Once again, Tony Jellings, a former NPDG (UK) Trustee, has organised a charity concert to benefit the Group. The concert will be sponsored by Raj Nehra and feature one of our Patrons, award-winning international cellist, Guy Johnston. The concert, which is being held in memory of Raji Nehra, will take place at St George's Church, Kemp Town on Thursday 14th August.

The programme will include the music of Shostakovitch, Stravinsky, Schumann and Chopin; tickets are on sale now at £15 each (£12 concessions). For further information and to purchase tickets, contact the Dome Box Office, Brighton on **01273 709709**.

We would like to thank Tony for his continuing efforts to support the work of the Group.

Research Study—Niemann-Pick Disease Type C

Karen Quandt will be conducting a research study at the University of Washington on Neurodegenerative Diseases in Family Members of Patients with Niemann-Pick Disease Type C.

Karen is a University of Washington Graduate of the Master Nursing Program and Mom to Ty, 10 years old with NPC. In 2007, as part of her graduate work, Karen conducted a Health History survey of twenty five Niemann-Pick Type C patients. She found that some family members of those patients had other neuro-degenerative diseases, besides NPC. Karen now wishes to conduct a larger survey of NPC families to see if family members have neuro-degenerative diseases in a higher percentage than the general population. The NPDG (UK), along with the National Niemann-Pick Disease Foundation in the USA, has agreed to support Karen by informing our families and members of this research project. Taking part in this study is voluntary and you may not directly benefit from taking part.

If you choose to take part in this study, you can complete the survey in either of two ways – you

can complete and return the form on a computer, or a copy of the survey can be posted to you. The responses you give are anonymous, you do not have to answer every question and you can stop at any time.

You can access the survey by visiting the following website: **www.surveymonkey.com:80/s.aspx?sm=EiRuYuQECqE3Ui95fq3DXQ_3d_3d**. Alternatively, if you would like a copy mailed to you, or you have any questions, please contact Toni Mathieson at the Central Office on **0191 415 0693** or email **niemann-pick@zetnet.co.uk** or you can contact Karen direct at **kquandt@u.washington.edu**.

Government Commits to Overhaul Care and Support

The government has launched a six month consultation paper to ask the public for their views on improving the system of care and support for adults and older people in England. Although the focus of the work is on support for adults and older people, you can also put your views on the transition to adulthood for disabled young people. The six month consultation period is taking place between May and November 2008, with the findings being used to inform a Green Paper on the reform options which is expected in 2009. Responses can be emailed to **careandsupport@dh.gsi.gov.uk** or posted to The Care and Support Team, Room 543, Richmond House, 79 Whitehall, London SW1A 2NS.

For more information go to **www.careandsupport.direct.gov.uk**.

Dads' Website and Information Service Launched



The Dad Info website covers all aspects of pregnancy, birth and new parenthood from a dad's perspective, including the most important health issues for their partner and baby. There is information for fathers with disabled children, paternity leave, fathers' legal rights and financial help, as well as entertainment features. For more information visit **www.dad.info**.

Put Parents in Control of Special Educational Needs Policy/Text AskACE

A new report on special educational needs (SEN) entitled "Learning the Hard Way" sets out a number of measures to ensure that in future SEN policy is driven by parental choice, rather than 'expert' opinion. It recommends turning 'statements' for children with the most severe learning difficulties into 'personal budgets' for their parents to manage, together with schools, and reforming the statementing process. You can read the full report on the internet by going to **www.policyexchange.org.uk/libimages/385.pdf**.

And whilst on the subject of SEN; a free text advice service has been launched from the Advisory Centre for Education (ACE). Just text the phrase AskACE to 68808 for advice on issues such as getting extra help for your child with a special educational need at school, getting a statement for your child, disability discrimination and SEN related exclusion issues. For further information on ACE, please see their website **www.ace-ed.org.uk**.

New and Updated Guides from Contact a Family

The following Contact a Family publications have recently been updated and are available to download from their website, www.cafamily.org.uk or by calling their helpline **0808 808 3555**

- Guide to Claiming DLA for children
- Preparing for adult life and transition—England and Wales
- Preparing for adult life and transition—Scotland
- Special Educational Needs—England

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 during June and July:

Artizan Hair (Milton Keynes) and Chrissie Downing raised £152.00 (Hope for Hollie Fund) by holding a Tarot Card reading.

Jon Chiles and colleagues at Stockport Metropolitan Borough Council ITC Department raised £60.00.

Andy Cudlip donated £20.00 from a collection box.

Neil Hopwood took part in the Bristol 10k Run and raised £140.00 through sponsorship.

Eileen Horton attended a Unison conference recently and nominated the NPDG (UK) for their "annual charity bucket collection". The Group was chosen and we received £805.36

The NPDG (UK) 3rd annual golf day was held at the Ramside Hall Golf Club and raised over £5000. Special thanks go to Craig Mathieson and the team for organising it.

Springhill High School in Rochdale held a non-uniform day and raised £389.00

Gill Walker raised £100 by organising a collection box and a producing Nature Walk booklet to sell at the farm shop where she works.

UIA Insurance in Stevenage, Herts, held another dress down day and raised £73.00.

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 in August. If you require a paper copy, please let us know.