



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

September 2009

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

- **NPDG (UK) Regional Meetings for Families**
- **Every Disabled Child Matters Launches New Campaign**
- **Office for Disability Issues Launches "Getting a Life"**
- **Campaign to Change Benefit Rules**
- **Child Trust Fund Payments**
- **Clarification of the Health Service's Short Breaks Money**
- **David Cameron's Plans to Remove Bureaucracy for Families With Disabled Children**
- **OpenBritain—New Information Resource**
- **Staying Healthy**
- **Managing Stress for Carers**
- **Phab**
- **Local Support from Contact a Family**
- **More Support Needed for Fathers of Children With Disabilities**
- **Families Feel They are not Listened to by Professionals**
- **What to Expect When a Child Goes to Hospital—New Information Booklet**
- **A New Banking Facility Specifically for Families with Disabled Children—Your Thoughts Needed**
- **The Special Needs Handbook Would Like to Hear From You**
- **Fundraising**

NPDG (UK) Regional Meetings for Families

Many years ago the NPDG (UK) organised regional meetings for families and we are considering organising another one as we currently have 10 patients in the Greater Manchester region and 5 more in the North with relatively easy access to Manchester. The meetings are very informal gatherings usually held on a Saturday, with tea, coffee and refreshments provided.

Before going ahead, we would welcome your thoughts and comments on the possibility of organising another of these meetings— such as whether you would be interested in attending; where in the UK would suit your needs; whether you would prefer it away from a hospital; what you would like to get out of it; whether you would like to see professionals as well as NPDG (UK) staff and whether you would like to attend with your affected child/relative. We would really appreciate your feedback by phone on **0191 415 0693** or by email to **niemann-pick@zetnet.co.uk**.

Every Disabled Child Matters Launches New Campaign



Every Disabled Child Matters' (EDCM) new campaign briefing 'Disabled Children and Health' highlights the failure of the NHS to meet even the basic needs of disabled children and young people. The briefing highlights a clear disparity between central government policy and local delivery and calls on the Department of Health and Primary Care Trusts to take action to improve health services for disabled children and young people. The briefing includes recommendations for **commissioning**—PCT commissioners for child and adult health services should work together through joined-up needs assessments to identify local trends and plan for future needs of disabled young people and **transition planning**—PCT practitioners should have input into every case of multi-agency transition planning (year 9 education review) where disabled young people have a complex health need. For more information, visit **www.edcm.org.uk/health**.

Office for Disability Issues Launches “Getting a Life”

“Getting a Life” is a three-year cross-government programme that aims to identify what needs to happen to ensure that young people with learning disabilities leave education and go on to achieve paid employment and full lives. There are nine “Getting a Life” demonstration sites: Herefordshire, Manchester, Norfolk, North Tyneside, Oldham, Richmond Upon Thames, Somerset, South East Region (mainly focused on Kent and Medway) and Torbay. Each site is working with approximately 30 young people who have learning disabilities, including many with severe learning disabilities and each demonstration site has a project team that includes young people and their families working alongside senior decision makers from schools, colleges, children and adult social services in local authorities, Job Centre Plus, Connexions, Learning and Skills Council and supported employment agencies. For more information visit **www.odi.gov.uk/working/gal**

Campaign to Change Benefit Rules

The logo for Contact a Family, featuring the text 'contact a family' in white on a red background, with 'for families with disabled children' in smaller text below it.

contact a family
for families with disabled children

Contact a Family is looking for families whose children have had their Disability Living Allowance (DLA) suspended once they have been in hospital for a certain amount of time. At present, DLA regulations state that if a child under 16 is in hospital for more than 12 weeks their DLA payments are suspended. For young people aged 16 and over, the payments are suspended after only four weeks. This can impact on a parent's entitlement to continue getting Carers Allowance.

Contact a Family is gathering evidence from families about the effect of this benefits rule, to highlight the issue and push for change. Claire Pimm, Director of Policy and Communications at Contact a Family, said: "Children who have long-term health needs are often in and out of hospital and this puts tremendous pressure on their families. It is wrong that they are financially penalised at such a difficult time". If your child's DLA has been suspended after a stay in hospital, please get in touch with Contact a Family as they would like to gather as much evidence as possible to highlight this issue and encourage change in the regulations. You can get in touch with Contact a Family regarding this by calling Elaine Bennett on **020 7608 8741** or by e-mail: **elaine.bennett@cafamily.org.uk**

Child Trust Fund Payments



From 2010, the government will contribute £100 every year to the Child Trust Fund accounts of disabled children, with severely disabled children receiving £200 per year. To benefit from these payments, a child must receive Disability Living Allowance (DLA) and have been born on or after 1st September 2002. The first payments are due in April 2010 for those in receipt of DLA at any point in 2009-10. Families with disabled children face enormous financial challenges and are more likely to be living in poverty than other families. Despite this, many are not claiming the benefits they are entitled to. For further information please contact **0808 808 3555** for advice about claiming DLA and other benefits and maximising your income. We would also urge families already in receipt of DLA to have a full benefits check to ensure you are getting every penny you are entitled to.

Clarification of the Health Service's Short Breaks Money

The Government has written to every Primary Care Trust (PCTs) in England setting out the funding position and specific actions required from PCTs to improve the lives of disabled children.

The Care Quality Commission has also announced it will carry out a special review this year to examine the health and social care for families with disabled children and young people. The Government has clarified that 1.23% of the £27,596 million additional resources the Department of Health is making to PCTs from 2008-2011 is for disabled children's services and has set out priority areas that should benefit from this expenditure including short breaks, community equipment, wheelchairs and children's palliative care. You can view more information by visiting **www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_097376**.

David Cameron's Plans to Remove Bureaucracy for Families With Disabled Children

David Cameron, Leader of the Conservative Party, has set out his party's plans to help families with disabled children. Writing in The Independent newspaper, David Cameron made a pledge to remove the bureaucracy that families with disabled children face trying to access the support that they and their children need. The NPDG (UK) welcomes David Cameron's acknowledgement of the 'battle' that families with disabled children have in getting support and applaud his continued efforts in raising awareness of the issues for families with disabled children. We also welcome David Cameron's proposals to put more power in the hands of parents.

To read this article in full visit www.independent.co.uk:80/news/uk/politics/david-cameron-the-five-lessons-i-learned-as-father-of-disabled-child-ndash-and-intend-to-put-into-practice-1748274.html

OpenBritain—New Information Resource



Tourism for ALL UK, RADAR and the National Federation of ShopMobility have teamed up with national tourism bodies to create a new definitive guide book and website for people with disabilities and access requirements. OpenBritain will provide a recognisable brand for all types of accessible facilities. Entries in OpenBritain will either have had an access inspection, or applied for self-certification, with all members subject to random checks. The new annual guide book will replace those currently published by Tourism for All and RADAR. For more information, go to www.openbritain.net.

Staying Healthy

As a parent of a child/young adult with a disability or additional needs it is important to look after your own health and wellbeing. The Carers (Equal Opportunities) Act 2004 requires local authorities to tell carers about their right to a carer's assessment. It also makes sure that work, education and leisure issues are considered when you are being assessed. The aim of the carer's assessment is to give you a chance to tell social services about the things that could make looking after your child/young adult easier for you. This may result in getting services or direct payments to meet your assessed needs. You can contact your local social services to request an assessment.

Managing Stress for Carers


Managing Stress for Carers is a book written by Dr Ann Edworthy, a Chartered Psychologist and Principal Lecturer at Swansea Institute of Higher Education aimed at helping carers deal with stress. This book is produced by Cerebra and can be downloaded from their website www.cerebra.org.uk/parent_support/support/stress.htm or is available from their helpline **0800 328 1159**. The NPDG (UK) office also has a copy that is available to borrow.



Phab

Phab is a national charity dedicated to the integration of people with and without physical disabilities in all aspects of society. It has a network of nearly 200 clubs throughout England and Wales for all age ranges, offering various activities including arts and crafts, drama, discos, swimming, sailing, visits to theme parks, outdoor activities and holidays which members can share and enjoy together. They can be contacted on **020 866 79443** and their website is **www.phabengland.org.uk**.

Local Support from Contact a Family



Contact a Family has a team of Volunteer Parent Representatives throughout the UK who are parents or carers of disabled children and fully understand the impact of caring for a disabled child/young adult. Their team of Volunteer Parent Representatives offer someone to talk to and signposting to local sources of information and support for families. Contact a Family also has a team of experienced Family Workers covering most areas in the UK. These Family Workers can help with any of the wide range of issues that families face when caring for a disabled child/young adult, such as claiming benefits, providing information about Special Educational Needs (SEN), through to putting you in touch with local and national sources of support. To find out if there is a Family Worker or Volunteer Parent Representative in your area call Contact a Family on **0808 808 3555** or visit their website **www.cafily.org.uk/inyourarea**.

More Support Needed for Fathers of Children With Disabilities



A survey run by the Foundation of People with Learning Disabilities has found that although many fathers of children with learning disabilities would like to be more involved in the care of their child, they feel they do not have the support they need from employers and social services to do so. The report, *Recognising Fathers, a national survey of fathers who have children with learning disabilities*, found that 90% of fathers believed their involvement in their child's care had a positive impact on the child's development. Other findings included the impact on fathers' mental and physical health had been affected as a result. Four in ten fathers said they had no close friends to talk to about their situation and more than half felt they had lost touch with friends as a result of having a child with a learning disability. Lack of workplace flexibility for fathers seemed to be a problem, with half of the fathers surveyed having missed out on career opportunities or experienced a loss of income because of their caring role. Many stated that they would like to spend more time with their child but were unable to do so due to a lack of flexible working arrangements. To view the survey in its entirety go to **www.learningdisabilities.org.uk**

Families Feel They are not Listened to by Professionals

What Makes My Family Stronger, published by Contact a Family, details the results of a recent survey asking families of disabled children what makes them stronger practically, socially and emotionally. 615 families responded, with results indicating that negative attitudes towards disability, a lack of services and a lack of support from professionals are the main barriers preventing families with disabled children from living normal lives. Following on from this survey, Contact a Family are making several recommendations to Government, including a call for investment in a UK-wide campaign to raise awareness of the needs of families with disabled children. You can read the full results of this survey by going to www.cafamily.org.uk/pdfs/wmmfs.pdf

What to Expect When a Child Goes to Hospital—New Information Booklet



It can be a worrying time when a child or young person is ill and it is not always easy to find all the information needed. Action for Sick Children (Scotland) can help by giving families information which shows where to access advice and support when a child is ill and what they can expect from health service providers. Their new booklet, *What to Expect When a Child Goes to Hospital* is designed to answer some of the questions parents/carers may have when a child goes to hospital. To request a copy of this booklet, which is free of charge to parents and carers, contact Action for Sick Children (Scotland) by calling **0131 553 6553**. You can also request a copy by sending an email to enquiries@ascscotland.org.uk. For more information visit their website www.ascscotland.org.uk.

A New Banking Facility Specifically for Families with Disabled Children—Your Thoughts Needed



The Family Fund is a charity that helps families with severely disabled children to have choices and the opportunity to enjoy ordinary life. They are considering whether it would be feasible to set up a new banking facility that would provide financial products and services designed specifically to meet the needs of families with disabled children. They are conducting a survey to help them understand your financial needs. The survey should take no more than 15-20 minutes to complete and your response will be confidential. To learn about the Family Fund visit: <http://www.familyfund.org.uk/> and to complete the survey, which closes on 27th September, go to http://www.surveymonkey.com/s.aspx?sm=Ata6pvlrEoh4mvWFq1aHTw_3d_3d

The Special Needs Handbook Would Like to Hear From You

The Special Needs Handbook are compiling a unique new publication which will be useful to parents and professionals alike. The Special Needs Handbook will be full of handy, helpful tips, ideas and solutions for day to day problems encountered by people living with or supporting a child or adult with special needs. Once compiled, the Special Needs Handbook will be made available free over the internet. Internet users will be able to print off and copy any of the mate-

rial, to use either personally or to disseminate freely to others e.g. support groups, schools, therapists, etc. The handbook may also be published (not for profit) and made available through shops. Examples of useful tips: *Tooth brushing*—Use an electric toothbrush. The vibrations can be a sensory aid; *Dressing*—Crawling: use goal-keeper trousers which are already padded at the knees and hips; *Toys*— pet shops sell great sensory toys. If you have any practical tips that you would like to share, please email them to mail@specialneedshandbook.com. All contributors will be acknowledged - so remember to include your name and address along with the tips you send in.

Fundraising



During the months of August and September 2009, the NPDG (UK) received just under £15,000 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 The Hope for Hannah Campaign, Gemma Salisbury, The Scott Family, Jamie Perkins, Team HML, Sheila Simpson and friends, Stephen Davidson, 24/7 Drug and Alcohol Team, Mrs Dodd and her daughter, The Elliott Family, Matthew Jellings and friends, Ron and Gill Plant, Springhill High School, the Residents of Astral House and SSP in Halifax. Fossil (UK) held a Formula One Charity Day to raise funds for the NPDG (UK) and Hope for Hollie Campaign. Full details of these fundraising events will be featured in the next edition of Niemann-Pick News which will be distributed by the end of October.

General donations were received from Gemma Gibbs, Betty Harris, Julie Milligan, Ingar Smale, Mrs Greevy, Lorraine Bishop, Penny Shopland, Pat O'Neil, Mr and Mrs Hulme, Andy Cudlip, Mrs Moncrief, Brian Beedham, Wendy Peart, Bill and Jane Owen, Zehra Zakiuddin, Mr and Mrs White, Mr and Mrs Martin, Mr and Mrs Buckingham, Mr and Mrs Peacock and Kait Pyne.

ANP Stores, Bill and Jane Owen, Christine and Joe Scott, Kait and Norman Pyne, Jackie Colquhoun, The Three Horse Shoes Inn and John and Blaikie all donated the contents of their NPDG (UK) collection boxes.

We have also received a generous donation "in loving memory" of Mrs Nehra and received a very generous bequest from the Late Mrs Cicely King-Lewis.

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, please send them to **Sue Lowe, 11 Greenwood Close, The Pastures, Fatfield, Washington NE38 8LR** or email sue.npdg@tiscali.co.uk.

If you have received this Bulletin through the post and would now like to receive it by email please let Sue know by email at sue.npdg@tiscali.co.uk, or post to the usual address.

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.