



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

FAMILY NEWS BULLETIN

July 2011

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

In this month's edition:

- **Save the Date**
- **Donate by Text**
- **Baby News**
- **What's Up with Lorraine—Medikidz Explain NP-C**
- **Short Breaks Legislation—England**
- **Genetic Alliance UK PatientPartner**
- **Family Life—Families and Relationships**
- **A Collaborative National Transition Plan For 14 to 25 Year Olds**
- **Disabled Living UK Events**
- **Autoadapt UK Mobility Solutions**
- **ACT Launches Free Resources For Families**
- **Stop the DLA Takeaway Gathers Political Momentum**
- **Confused By All The Benefit Changes**
- **Blue Badge Announcement**
- **Activity Camps**
- **Every Disabled Child Matters (EDCM) Call For Evidence**
- **Newlife Foundation—Equipment Grants Service**
- **Baby Warming Plate**
- **Independent Parental Special Education Advice—IPSEA Now On Facebook and Twitter**

Save the Date –Conference 2011

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 last year's delegates. The Conference will be held over the weekend of 23rd-25th September. Full details are available on our website.

Donate By Text



If you live in the UK you can now donate to The Niemann-Pick Disease Group (UK) quickly and easily from your mobile phone – simply text “NPDG11” followed by the amount you'd like to donate to 70070. For example “NPDG11 £10” to 70070 (UK only). Donations are handled by our justgiving.com charitable account and go directly into our fund-raising account.

Baby News



The NPDG (UK) is delighted to announce the safe arrival of two babies; Barnaby Richard Malcolm Campbell born on 20th June 2011 weighing 7lb 10 oz—a grandson for Richard Brooks—Trustee and Treasurer of the NPDG (UK); and Harry Henshaw, born on 26th June weighing in at 10lbs 6oz, first grandson for our Clinical Nurse Specialist Jackie Imrie.

What's Up with Lorraine—Medikidz Explain NP-C



Medikidz have produced a booklet specifically aimed at children to explain the facts of living with Niemann-Pick Type C. “*What's Up With Lorraine*” which has been written by a team of doctors and reviewed by specialists does not ‘sugar coat’ the serious problems of living with NP-C, but provides your child with the knowledge to take ownership of their disease. If you feel you would like a copy of “*What's Wrong with Lorraine*”, please contact us here at Central Office on **0191 415 0693** or email **sue.npdg@tiscali.co.uk** **pdg@tiacali.co.uk**

Short Breaks Legislation—England

From April 2011, local authorities have been required to provide a short breaks service to carers of disabled children. The regulations build on the rapid expansion of short breaks services which all local authorities have achieved through the Aiming High for Disabled Children programme. The regulations require local authorities to offer a range of services for parents and publish a

statement of those services available. The advice for local authorities which accompanies these regulations has been drawn up with the help of a small group of local authorities, the Council for Disabled Children and Together for Disabled Children. Over £800 million of funding to local authorities for the provision of short breaks will be provided through the Early Intervention Grant.

Genetic Alliance UK PatientPartner



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Over the last three years Genetic Alliance UK has been working with the Dutch Genetic Alliance (VSOP), European Genetic Alliances Network (EGAN) and the European Forum for Good Clinical Practice (EFGCP) to promote the role of patient organisations in clinical trials. During the course of the

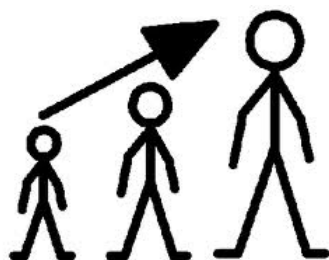
project PatientPartner has held meetings and conferences across Europe to gain further insight into how patient organisations are involved in clinical trials and how researchers engage with the patient community. They have had an enormous response and willingness from all parties to improve the dialogue and communications between all those involved in clinical trials and have developed some firm proposals as to how this can be moved forward. Following this project, two Guides have been produced: *“Patient Involvement in clinical research—a guide for Patient Organisations and Patient Representatives”* and *“Patient Involvement in clinical research A guide for sponsors and investigators”*. Copies of both guides will be available at our Conference in September, however if you would like a copy of either (or both) before then, please contact the NPDG (UK) Central Office.

Family Life - families and relationships

Family Life is a new two year project working with children centres and parent groups in England to raise awareness of the relationship issues that many families face when caring for a disabled child. There will be a dedicated relationships enquiry service, training, workshops and new resources for families. For more details get in touch with Contact a Family's Relationships Information Officer at yvonne.mcgahren@cafamily.org.uk

A Collaborative National Transition Plan for 14 to 25 year-olds

The development of a number of therapies for the treatment of lysosomal storage disorders (LSDs) like Niemann-Pick disease has led to patients living longer and moving from paediatric to adult services. This transition can be a difficult time for patients. In 2010, the UK Lysosomal Storage Disease Collaborative Group was awarded a three year grant by the Advisory Group for National Specialist Services (AGNSS), the body that manages the Specialist Services for lysosomal storage disorders in England to develop a national transition plan for LSDs. Lindsey Wingate, Advocacy Support Officer for the Society of Mucopolysaccharide Diseases



(MPS) was appointed to undertake this project. Here, Lindsey outlines her plans – *I am working on a document concerning Transition for young people; a process many face when they leave behind paediatric health services and enter adult health services. This is a joint project with the Lysosomal Storage Disease Collaborative Group who's members are; Association for Glycogen Storage Disease, The Batten Disease Family Association, The Gauchers Association, The Niemann-Pick Disease Group (UK), The Save Babies Through Screening Foundation UK and the Society for Mucopolysaccharide Diseases (The MPS Society). The aim of the project is to devise a set of Transition guidelines which we hope the Department of Health will adopt and put into practice nationally. I have read copious amounts of legislation regarding the need for proactive transition plans to be created and adhered to. I have contacted every local authority I could find recorded in a governmental list of local authorities asking for any Transition information they could give me. I also contacted many agencies who work with long term medical conditions to ascertain whether they had knowledge, experience or indeed a plan. In all areas I was informed that transition plans are needed! I am currently arranging meetings with medical experts who work with patients with Lysosomal Storage Diseases all over the UK. I have developed a list of 'open' questions, and all participants will be asked the same questions to ensure the research is fair and balanced. I am also working on the development of questions for young people with Lysosomal Storage Diseases and their parents and I will speak to individuals who are before, during and after transition. I am really looking forward to learning from these experts as their experiences are going to be really valuable. Once the questions have been finalised I will contact young people in the 14-25 age range and their parents to organise venues throughout England to hold our meetings and conduct the study. It will be an exciting opportunity to shape the future for all young people with lysosomal storage diseases. For further information on this project please contact the NPDG (UK) Central Office by email niemann-pick@zetnet.co.uk or 0191 415 0693.*

Disabled Living UK Events



Disabled Living is the oldest disability charity in Manchester having worked with disabled people of all ages for over 110 years. It also has one of the largest Disabled Living Centres in the country, which amongst other services, specialises in advice, information and training on equipment for easier and independent living. Disabled Living organises the largest UK exhibitions totally dedicated to disabled children, their families and the health and social care professionals who work with them. The events specifically focus on equipment, products, and services to improve independence and quality of life. The events allow both public and professionals to try the latest equipment and products solutions and talk to the

specialists who supply them. There is always a full and varied programme of talks and discussions covering topics such as legal and education issues, new therapies, communication and ICT.

Many voluntary organisations are also on hand with information on support, funding, holidays, publications and so on. Disabled Living have organised the following events :

Kidz Up North – Thursday, 24th November 2011 – Reebok Stadium, Bolton.

Kidz in the Middle – Thursday 29th March 2012 – Ricoh Arena, Coventry.

For free tickets or more information on any of the Kidz events please contact Disabled Living on 0161 607 8200 or visit their website www.kidzupnorth.co.uk/

Autoadapt UK Mobility Solutions

Autoadapt UK offer award-winning, reliable and safety tested solutions for adapting your vehicle, to increase your independence and regain your freedom. Their products Turny, Carony and Turnout are innovative solutions for getting in and out of your vehicle. And the Carolift family of wheelchair lifts allow you to easily bring your wheelchair along. They offer a full range of high quality products for car adaptation, including Braun wheelchair lifts, hand controls, seating comfort and much more. Autoadapt has a network of highly skilled dealers across the UK and worldwide provide top class service and support. For more information go to www.autoadapt.co.uk



ACT launches free resources for families

ACT, the UK children's palliative care charity has recently produced an updated version of its popular booklet, A Family Companion to the ACT Care Pathway, which is now available free to families of children with life-limiting and life-threatening conditions, and children's palliative care professionals. Anyone can now download a copy from the ACT website – www.act.org.uk/familycompanion.



ACT has also produced two factsheets written specifically for families of children with life-limiting and life-threatening conditions, to help inform and empower them, and to support them throughout their child's care:

- **Understanding siblings' needs** which has been designed to help parents who are worried about talking to siblings about their brother or sister's life-limiting diagnosis and how it will affect them.
- **Spiritual, religious and cultural wishes** explains how spirituality, religion and cultural backgrounds can play a big part in shaping families' wishes, and aims to give parents the confidence to ask professionals to care for their child in accordance with their values or beliefs, whatever they may be.

These new factsheets complement the ACT Family Companion and the existing family factsheets, 'End of life planning' and 'Newly diagnosed'.

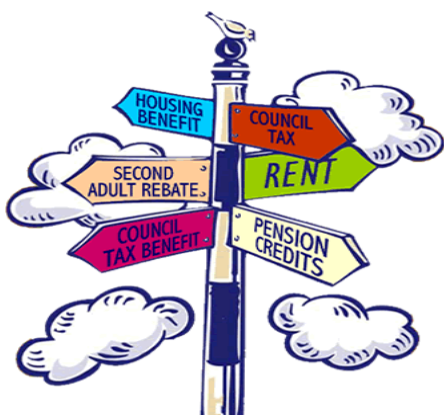
All ACT family resources, including the two new factsheets are available free to download from the ACT website www.act.org.uk/families and printed copies are available by calling ACT on 0117 916 6422 or emailing susannah@act.org.uk

Stop the DLA Takeaway Gathers Political Momentum

Contact a Family and The Children's Trust are continuing to campaign to stop the DLA Takeaway and now have several supportive MPs on board. Currently a child's Disability Living Allowance (DLA) is stopped after 84 days in hospital and subsequently the parents' Carer's Allowance is

suspended. The regulations are penalising vulnerable families at one of the most distressing times of their life and Contact a Family and The Children's Trust are calling for them to be scrapped. Graeme Morrice, MP for Livingston, has tabled an Early Day Motion (EDM) in support of the campaign and to raise awareness of the issue politically. If you think these rules are unfair, or wish to find out how to encourage your local MP to support this campaign, go to www.cafamily.org.uk/index.php?action=view&id=631&module=newsmodule&src=%40ranom4864ff40710ee&utm

Confused By All The Benefit Changes?



To help parents make sense of the recent welfare reforms announced by the Coalition Government and what the changes will mean for them, Contact a Family has produced a free guide to Future Benefit Changes. The guide is available from the Contact a Family Freephone helpline on **0808 808 3555**. The changes will impact on all families with a disabled child. While some of the changes will not take effect for a year or two, others will have already started to have an impact - including changes in housing benefit for many private tenants, and a number of tax credit cuts including reduced help with childcare costs. While many of the changes proposed will mean cuts in financial help – there is some good news. One of the changes made in April will allow children

aged 3 or above who have a severe visual impairment to start qualifying for the high rate of the DLA mobility component.

Blue Badge Announcement



On 14 February 2011, the Minister for Transport, Norman Baker MP, announced the long awaited programme of reforms to modernise the Blue Badge scheme (set out by the previous Government in 2008). This largely focused on reducing fraud and abuse such as introducing a new badge design and giving local authorities improved enforcement powers. The reforms also look at operational savings and improved customer services for badge holders. The NPDG (UK) was pleased to see that, amongst other changes, the eligibility was extended to more disabled children under the age of 3 with specific medical conditions from May 2011 (subject to secondary legislation). For more information see Department for

Transport **website** www.dft.gov.uk/topics/access/blue-badge/

Activity Camps



Over The Wall is a charity offering week long residential activity camps to children and young people aged 8 to 17 years who are affected by serious and life-limiting illnesses. There are a number of dates available during summer 2011. For full details of the criteria for applications and terms and conditions contact Over the Wall www.otw.org.uk

Every Disabled Child Matters (EDCM) Call For Evidence



EDCM is gathering as much evidence as possible from parents and carers about cuts to disabled children's services in their local areas. They have created a 'tell us your story' form to enable parents and carers to provide information to help inform their work which can be accessed by going to www.ncb.org.uk/edcm/get_involved/whats_your_story.aspx

Newlife Foundation - Equipment Grants Service

The Newlife Foundation provide grants, which are not means tested, to help families purchase equipment including mobility equipment, care equipment, communication aids, comfort and therapy equipment and more. grants are available for children aged 18 and under who have a significant disability and are permanent residents in the UK. Application forms can be downloaded from their website www.newlifecharity.co.uk/docs/services/equipment_grant_services.shtml



Baby Warming Plate



The mOmma Developmental Meal Set has been designed by Tomy and is a revolutionary range of stylish developmental feeding products that have been specially designed to keep food warm during meal times. The fork has been designed for easy and natural transition for feeding development and the protective cover to place over the spoon ensures maximum hygiene when not in use and can be placed on the base of the spoon to extend the handle making feeding easier. The mOmma range can be purchased from www.amazon.co.uk.

Independent Parental Special Education Advice - IPSEA Now On Facebook and Twitter



IPSEA is using Twitter and Facebook pages to Broadcast changes to legislation and case law; highlight resources on their website; encourage participation in surveys and let people know how they can support them. If you are on Facebook, you can help IPSEA by "liking" it and "sharing" it with all your friends.

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.