



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

July 2010

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

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The NPDG (UK) Annual Family Conference 2010



You should by now have received full details and a booking form for the NPDG (UK) Annual Family Conference which is being held at The Robinson Executive Centre, Wyboston Lakes on the Bedfordshire/Cambridgeshire border over the weekend of 10-12th September. Full details are now on our website at www.niemannpick.org. We hope to see you there !!!!!

Would You Like to be a Family Voice at our Annual Family Conference?



Each year the Conference has a special section called “Family Voices” which gives the chance for families to share their experiences of living with Niemann-Pick disease. If you would like to share your story and experiences during the Family Voice session, or would like more information, please contact us at the Central Office **0191 4150693** or email sue.npdg@tiscali.co.uk (As a contributor to the Conference your the fees, accommodation and travel costs would be complimentary.)

Niemann-Pick News



We will shortly be producing the Autumn edition of Niemann-Pick News. If you would like your child/children’s school head teacher, nurse, doctor, or any one who supports your family, to receive a copy of the Niemann-Pick News either by post or email, then please let us know by emailing their details to sue.npdg@tiscali.co.uk.

NPDG (UK) Board of Trustees

The NPDG (UK) Board of Trustees meets four times a year and is responsible for all the activities the Group undertakes. All of our Trustees are volunteers, and we are continually seeking new members to join the Board. If you, or a member of your family, might be interested in joining the Board, or in attending a future Board Meeting to see what’s involved, please contact Central Office for further details.

Contact a Family Directory



The 2010 edition of Contact a Family’s Directory—The essential guide to medical conditions, disabilities and support—is now available. This useful guide contains patient friendly information for children and adults with disabilities, serious health conditions and rare disorders. The Directory is available in paperback, priced £40, and online. An annual subscription to the online version costs £15 + VAT per user and gives unlimited access for professionals—families can view a maximum of five different conditions over a six month period free of charge. To order your copy visit the Contact a Family online shop at www.cafamily.org.uk/shop.html or call **020 7608 8700**

Flora London Marathon 2011



At the NPDG (UK) Board of Trustees meeting held on 19th June, the ballot for Niemann-Pick Disease Group (UK)'s place on the London Marathon 2011 was drawn by Chairman, Jim Green. We are delighted to report that Alison Brooks will be representing the Group in this marathon. Alison has very kindly agreed to keep us informed with her training progress. Many thanks to all those who applied.

Cool2Care

Could the lives of you and your family be enriched by employing a care worker to help out at the busy times of your day, or during school holidays? Would you like to employ a care worker to care for your child or be a buddy for your teenager? If so, Cool2Care can help. Cool2Care take referrals and enquiries from families and their service is accessible to any family with a disabled child or teenager. They recruit, train and place skilled care workers and PAs with families, to help look after and work with disabled children and young adults. The family's requirements are considered throughout; they are supported and in control of the employment process. Cool2Care is compatible with Direct Payments and Individual Budgets, or families can use their benefits and private income to pay for care. For more information on employing or becoming a care worker visit www.cool2care.co.uk or telephone **07850 709446**.



Genetic Alliance UK

The Genetic Interest Group has changed its name to the Genetic Alliance UK and has a new logo. The Alliance felt that the new identity better represents the increasingly diverse work of the organisation. The Genetic Alliance UK carries out a wide variety of work, representing all genetic conditions, both rare and common. They work on policy campaigns with policymakers to ensure that legislation supports the needs of families. They also take part in research projects tackling issues important to members, such as the lack of good quality information available to patients, improving access to insurance and developing networks of experts to improve services for patients. For further information visit www.geneticalliance.org.uk or call **01036514805**

Holiday Accommodation

We know that many families caring for a disabled child or adult have difficulties finding suitable holiday accommodation; details of holiday accommodation that caters for families caring for a disabled child or relative are available to view on the NPIDG (UK) website—www.niemannpick.org.uk/care_and_support/holidaysspecialtreats.html.



Several years ago Wendy Butterfield, a registered childminder with 22 years' experience and her husband, a builder, embarked on a project to build a holiday let specifically with families with children, or a relative, with additional needs in mind. This project has now been completed and their next project is an indoor heated swimming pool and jacuzzi.

For further information telephone **01872 573182** or visit their website: www.poolhousecornwall.com.

Important Changes to the Family Fund

The Family Fund has changed its criteria and the way it looks at family income. They will now look at the total money coming into the household. This includes earnings through work, tax credits, benefits and other income like rental income, maintenance payments, occupational pensions or interest from savings. Some benefits will not be counted such as Disability Living Allowance (DLA), Attendance Allowance (AA) and Child Benefit—and they have also removed the savings limit. The Family Fund has introduced this change in order to make the distribution of grants to families fairer. The old system penalised working families in favour of those on benefit and meant the Fund couldn't help some of the poorest families with disabled children. For more information visit www.famiyfund.org.uk or call **0845 130 45 42**



Equity Bill Receives Royal Assent

The Equality Bill received Royal Assent at the beginning of April 2010, prior to the dissolution of Parliament. This historic piece of legislation combines existing anti discriminatory legislation into a single equality act and contains a range of new rights, powers and obligations to create a more equal society. The Equality Act will become effective from October 2010 and will replace the Disability Discrimination Act (DDA). It clarifies and improves the definition of disability discrimination, so that it is simpler for everyone, including service providers, employers and disabled people to understand. This should make it easier for individuals to challenge disability discrimination when it occurs. In addition, the Act strengthens the duty of all service providers, including schools and public sector organisations, to offer reasonable adjustments enabling disabled people to access their services. For example, schools will have to provide auxiliary aids and services, like special equipment and large print books, for disabled pupils. Organisations will also be obliged to make their information available in a range of accessible formats. Other measures in the Act include giving disabled people who live in rented accommodation the right to have adjustments made to communal areas, enabling local authorities to license more accessible taxis and extending discrimination protection to include people who are caring for a disabled child or relative. For more information visit www.equalityhumanrights.com or call the Equality and Human Rights Commission on **0845 604 5510**.

Fledglings



Fledglings is a national charity which supports parents and carers of children with special needs by finding affordable solutions to everyday practical problems. They offer a free of charge bespoke information service which addresses the individual needs of each child and family. For more information, visit their website: www.fledglings.org.uk

£20m from Child Trust Funds for Disabled Children to be Redirected to Short Breaks

On 25th May 2010 the new coalition government announced that Child Trust Funds would be scrapped and £20 million would be redirected to fund “additional respite breaks” for families with disabled children. The NPDG (UK) welcomes the focus on families with disabled children from the new government and believe that the £20 million announced is additional to funding already allocated for short breaks next year.

It is important that in this announcement the government has recognised the pressures that families with disabled children face and any additional funding for respite care is welcome. The NPDG (UK) look forward to seeing the details from the announcement and how this relates to the coalition government’s overall plans for families with disabled children.

Changes in Carers Benefits Rules will help Families with Disabled Children



From 12th April 2010 Carer’s Allowance, the only state benefit specifically aimed at carers, will be made available to a greater number of those who are working. Carer’s Allowance cannot be paid to a carer if they work and earn more than a set amount. The government has announced that the earnings limit will be raised from £95 to £100 after tax deductions - the first time it has been changed since 2007.

For working families caring for a disabled child, the Carer’s Allowance rules allow certain childcare costs to be deducted from earnings, so some may qualify even though they are earning slightly more than £100 per week. Contact a Family’s free Helpline can advise families with disabled children who want to know if the change in the rules will help them claim Carer’s Allowance. Call **0808 808 3555**.

Community Care Grants

This new parent guide, produced by Contact a Family, is intended for families caring for a disabled child who are considering applying for a Community Care Grant (CCG), a form of payment from the Social Fund. Community Care Grants are designed to help people on low incomes with specific costs including clothing, household items such as bedding or a washing machine. You can download this guide www.cafamily.org.uk/pdfs/CommunityCareGrants.pdf.

Walks With Wheelchairs



For descriptions and maps of leisure routes in Britain that are accessible to wheelchairs/buggies visit www.walkswithwheelchairs.com and www.walkswithbuggies.com. Other useful information can also be found on these sites, such as whether dogs are allowed on the routes and what facilities are available.

Tips / Ideas / Recipes—Can You Help???



Following several requests from our Niemann-Pick families, we are looking to set up a page on our website for families to pass on recipes, particularly ones that liquidise well, useful tips and ideas that may help others living with Niemann-Pick disease. So, if you have any ideas, tips or recipes, please do pass them on to sue.npdg@tiscali.co.uk.

ACT Family Companion

An invaluable booklet, "A Family Companion to the ACT Care Pathway for Children with life limiting and life threatening conditions" is now available **free** to families. You can order this direct from the ACT website www.act.org.uk or by calling **0117 916 6422** or emailing Susannah@act.org.uk.

Fundraising Information

Niemann-Pick Awareness Week



This year Niemann-Pick Awareness Week will be held from 19th-25th July. So why not get involved by organising your own fundraising event? Help us to make Awareness Week 2010 one to remember by increasing awareness of Niemann-Pick disease, raising money and having fun!!! If you would like to get involved and hold an event, big or small, please call the Central Office on 0191 415 0693 or email sue.npdg@tiscali.co.uk for a fundraising pack, ideas and information.

Alternatively, you can download all the information you need by visiting www.niemannpick.org.uk/get_involved/get_involved.html

Say It with Flowers

The NPDG (UK) has teamed up with a company called Charity Flowers Direct based in Guernsey. Every time you order flowers through Charity Flowers Direct, 15% of the total price will be donated to the NPDG (UK). So, whether its Happy Birthday, Happy Anniversary, Happy Christmas, Congratulations, or just to show someone you care, order from Charity Flowers Direct. Their website is www.charityflowers.co.uk and their order hotline is **08705300600**; we are listed as The Niemann-Pick Disease Group (UK).



Hope for Hollie 2010 Halloween Ball



The third "Hope for Hollie" charity ball will take place at the Doubletree Hilton Hotel, StadiumMK on Saturday 23rd October. If you wish to be placed on the mailing list for this event, or for further information, please email info@hopeforhollie.co.uk

Fundraising/Donations



Since our last e-bulletin in May the NPDG (UK) has received just under £24,000 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 Santander in Milton Keynes (Hope for Hollie Campaign); Georgina's Gang in Guernsey; Campaign for Calum; Leslie and Tony Tifford; Carl Gomes; Ian Settle; Croft and District Agricultural Discussion Society; Stephanie O'Hara; Jim and Susan Green; the Dodd Family and Joe and Christine Scott.

General donations were received from Mr and Mrs Davidson; JLT Premier Pension Services; Bill and Jane Owen; St Dionysius Church Choir; Thorpe Willoughby Community Primary School; Brian Beedham; Lodge of Harmony 372; Mr and Mrs Buckingham; Mr and Mrs Zakiudin; Ian Robson; Mr and Mrs Connell; Shirley Wheatly and Patricia O'Neil.

We also received generous donations in remembrance of Sarah Forrester and in loving memory of Hayley Edwards.

The Barge Inn; Brenda Clark; Bill and Jane Owen; The Three Horse Shoes; ANP Stores; Roy Green; Rose Thompson; Billy Ross; Lawrie Brown; Peter Scott and John Imrie and Blaikie emptied the contents of their Niemann-Pick 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.

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.

