



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

FAMILY NEWS BULLETIN

December 2011



Hello and welcome to the latest Niemann-Pick Disease Group (UK)'s Family News Bulletin. We hope you find it interesting and informative. In this month's edition:

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Jackie Imrie - NPDG (UK) Clinical Nurse Specialist

At the end of this year, our much loved, respected and relied upon Clinical Nurse Specialist, Jackie Imrie will retire. The NPDG (UK) is happy to confirm that Jackie has kindly agreed to continue working with us until such time as a new post holder is in place. Therefore, Jackie will still be available, on a part-time basis, to provide you with support and advice as needed. At present we are finalising new contact details for Jackie and these will be distributed very soon. If you have any questions at all, please do contact Sue or Toni at the NPDG (UK) Central Office, by telephone **0191 415 0693** or email **niemann-pick@zetnet.co.uk**<



Save The Date

Following positive feedback from our 2011 attendees, we are pleased to confirm that The NPDG (UK) Annual Family Conference will once again take place at Wyboston Lakes, Bedfordshire. Please save the date - 21st - 23rd September 2012.

New Office Premises for the NPDG (UK)



After several years of working from a small home office in our Executive Director's house, and completely taking over her dining room, kitchen, lounge and garage, we are very pleased to report that on the 1st December the Niemann-Pick Disease Group (UK) took possession of keys to our new office. As of January 1st 2012, our Central Office address will be Suite 2, Vermont House, Concord, Washington, Tyne & Wear NE37 2SQ.

Our telephone number remains the same, however we will be changing our email addresses in due course and will ensure the new details are circulated as soon as possible. In the meantime, the Trustees of the NPDG (UK) would like to thank Toni and Stewart for being so accommodating over the past six years.

News From Our Families Officer, Elizabeth Davenport

Elizabeth Davenport, the NPDG (UK) Families Officer writes:

"Some of our members have mentioned that they would be interested in attending self assertiveness and confidence building courses in their local areas. I am currently in contact with some parent participation groups and 'Contact a Family' to find out about courses running around the UK. If you would like me to search for a course near you then please get in touch.

I am also trying to find out if families are receiving the correct level of benefits such as direct payments, disability living allowance and carers allowance etc. If you would like to contact me I can arrange a benefits check for you.

Some of you may be asked to attend an interview at your local job centre to discuss finding work. If you have been asked to attend such an interview or have received a decision about looking for work or attending training—please do call me as I can offer support, if needed.

If you have a child who is nearing 14yrs or older, then it is time to think about the transition from Children's Services to Adult Social Care. This is an important process and one which I feel must be started sooner rather than later so all health and social care agencies can be involved. Please contact me for more information and I will be glad to speak to agencies on your behalf and get the process started. Finally I would like to wish everyone a peaceful and happy Christmas and I look forward to working with you all in the New Year.” If you would like to contact Elizabeth regarding any of the above you can do so by email at **elizabethnpg@aol.co.uk** or telephone on **07896 197576**



John Lewis Charitable Giving - Please support NPDG (UK)

Every month John Lewis will be donating £1,000 across three chosen charities. All you have to do to nominate the NPDG (UK) is send an email to facebook@johnlewis.co.uk. Then, if chosen, the Group would be one of three charities that facebook users can vote for. At the end of the month they will split the donation, relative to the number of votes each charity receives. Their Facebook team will be supporting three new charities each month.

The link to their Facebook page is http://www.facebook.com/JohnLewisRetail?sk=wall#!/JohnLewisRetail?sk=app_160436757357028. For further information please contact them at facebook@johnlewis.co.uk.

Can You Help the University of Notre Dame to Better Understand the Natural History of NP-C?

The University of Notre Dame is seeking to understand more about the natural history (or the progression) of NP-C disease. Improving knowledge in this area would assist in the development of new drugs and therapies, and provide valuable information that could tell researchers whether a new drug is working effectively. Undergraduates at the University who are preparing to go to medical school now have the opportunity to attend a class where they can be trained in the clinical diagnosis of rare diseases such as NP-C. They will transform clinical data from patient medical records into digital information, allowing a rapid analysis of the records plus the development of natural histories that will assist in diagnosing and treatment.

In order for this class to be successful, the University needs as many NP-C patient medical records as possible – and this is where you can help. If you would like to assist with this request, you will need to obtain a copy of your/your child's records from your local Health Authority. For more information about how to do this, please contact the NPDG (UK) Central Office or visit the NHS Choices website:

<http://www.nhs.uk/chq/pages/1309.aspx?categoryid=68&subcategoryid=160> You may have

to pay a fee to obtain a copy of your records. The maximum charge for this is £10, and this will be fully refunded to you by the University of Notre Dame/The Niemann-Pick Disease Group (UK).

If you are interested in learning more about this study, please contact Dr Kasturi Haldar, Director, Centre for Rare and Neglected Diseases, University of Notre Dame khaldar@nd.edu or Toni Mathieson at the NPDG (UK) Central Office, telephone **0191 415 0693** or email niemann-pick@zetnet.co.uk

New Face Book and Twitter Pages



The NPDG (UK) has recently updated and moved its Facebook Page—if you would like to join this page for regular updates and to make contact with other families worldwide, please “like” us by following this link <http://www.facebook.com/#!/pages/Niemann-Pick-Disease-Group-UK/111042605677023?sk=wall&filter=1>. You



can also follow us on Twitter by going to <https://twitter.com/#!/NPDGUK/>

NPDG (UK) Annual Report and Accounts

Our 2010/2011 Annual Report and Accounts are now available to view on our website www.niemannpick.org.uk/about_us/annualreports.

NPDG (UK) Family Directory - Its Future is in Your Hands

What do you think about the NPDG (UK) Family Directory? Is it useful to you and would you like us to continue producing it? During our discussions at our Annual Family Conference in September, families told us that they preferred to contact each other via social networking sites such as Twitter and Facebook. The Niemann-Pick Disease Group (UK) Trustees will be holding a Board Meeting at the end of January and the future of our Family Directory will be on the agenda. Before this meeting takes place we would like to hear your views on the Directory. Also, please let us know your thoughts and ideas on how would you like to meet and stay in touch with other families. Your suggestions can be emailed to sue.npdg@tiscali.co.uk or posted to Sue Lowe at The Central Office's new address Suite 2, Vermont House, Concord, Washington, Tyne and Wear NE37 2SQ.

Hope for Hollie Campaign New Website



Back in November the Hope for Hollie Campaign launched their new website, which you can find at the same website address www.hopeforhollie.co.uk. At the time of the website redesign, the Hope for Hollie Team took the decision not to continue with the Hope for Hollie Family Forum. It was felt that this was an appropriate time, in light of work taking place to upgrade the NPDG (UK) website, to relocate the forum to the NPDG (UK). We are very grateful to the Hope for Hollie Team for providing this valuable service, which has been of

great support and benefit to the many families who have participated over the years, enabling them to share their thoughts and experiences regarding all aspects of Niemann-Pick disease. The Hope for Hollie Team, and the NPDG (UK), would like to apologise for the gap in this service whilst work is taking place to upgrade the NPDG (UK) website. On completion early in the New Year, the new look NPDG (UK) website will provide an interactive environment, including several different forums and a live chat facility. Please do get in touch at sue.npdg@tiscali.co.uk if you have any comments or questions regarding the Hope for Hollie Forum or work taking place on the NPDG (UK) website.

Information Packs



We have recently produced new information packs which we are sending out to all healthcare professionals and organisations. If you would like a pack sent out to your healthcare professional, school or anyone else, please email me sue.npdg@tiscali.co.uk with their contact details. Alternatively, if you would like to hand these out yourself, please let me know how many packs you need.

New Special Educational Needs National Advice Service

Contact a Family have been awarded the Department for Education contract to include a Special Educational Needs (SEN) advisory service within their existing range of services for families. The new SEN National Advice Service will be part of their integrated Helpline/Online service for families. It will be staffed by experienced SEN advisers. It will be a one stop shop for parents and other family members caring for a child with SEN, on all education issues, including: Early years/portage, School Action and Action Plus, Individual Education Plans (IEPs), Statutory Assessments, Statements, Transition Planning, 139A assessments and post-16 provision, home education, bullying, exclusions, school transport, 16–19 Bursary Fund.

For more information contact their telephone **0808 808 3555** or email helpline@cafamily.org.uk or visit their website www.cafamily.org.uk.

On a Low Income? Check Now With Your Energy Supplier for a Possible Rebate

If you are a family with a disabled child and on a low income, it's important that you call your energy supplier to see whether you qualify for a discount or a rebate worth up to £120 under the government's new Warm Home Discount Scheme.

Set up by government to ensure that energy companies offer discounted rates to vulnerable, low income groups the Warm Home Discount Scheme, replaces the 'social tariffs' offered by energy companies. Some of the energy companies have included families with disabled children on a low income among the groups to benefit. For more information please go to http://www.direct.gov.uk/en/Pensionsandretirementplanning/Benefits/BenefitsInRetirement/DG_185940

Sign up to Support the Finished at School Campaign!

Ambitious about Autism have just launched a campaign called Finished at School which aims to secure more and better educational options for all young disabled people once they finish school, to enable them to develop skills, gain employment, live more independently and ultimately to live

the life they choose. For more information about this Campaign, visit www.ambitiousaboutautism.org.uk

Get Outside and Play



Savlon and Play England, in conjunction with Natural England, have launched an interactive map to help families find great places to play outdoors where they live. Featuring the best places for children to engage with nature, including playgrounds and green spaces across England, this map encourages families to explore new local territory and play freely outdoors. For more information go to cafamily.org.uk.

New Website for Early Years Professionals

Children and the Early Years Strategic Partnership have launched the professionals section of the Families in the Foundation Years. The site offers professionals who work in the Foundation Years a 'one stop shop' for all the information and support they need to achieve the best outcomes for children and their families. More information can be found by going to www.foundationyears.org.uk

New Website for Disabled Job Seekers

Evenbreak is a new website for disabled job seekers and inclusive employers. The website aims to attract inclusive employers advertising jobs on the site, who can be confident of attracting more disabled candidates. Disabled job seekers can use the website confident that employers who choose to advertise on the site are more likely to take their application seriously, looking beyond their disabilities at the skills and talents they have to offer. Candidates can register on the site, upload their CVs and search for jobs free of charge. You can find out more about this website by visiting www.evenbreak.co.uk

Live in Northern Ireland? Rare Disease UK Needs Your Help!



RARE
DISEASE
UK

Rare Disease UK has been actively involved with the Northern Ireland Rare Disease Partnership. The Partnership, with the support of the Patient and Client Council has launched a survey which aims to capture experiences of obtaining a diagnosis of a rare disease in Northern Ireland. The survey will form a new publication which will be launched on Rare Disease Day 2012 (29th February). This publication will be instrumental in informing RDUK's and the Northern Ireland Rare Disease Partnership's future campaigning work. The survey can be filled out by a patient affected by a rare disease or a carer, but remember they are looking for responses from Northern Ireland only. The survey is available online by visiting the following link: <https://www.surveymonkey.com/s/raredisease>. If you would prefer a hard copy of the survey, or if you need any further assistance in completing the survey, please contact Sarah McCandless or Richard Dixon at the Patient and Client Council - **0800 917 0222**. The deadline for completing the survey is the 16th December.

Cinema Exhibitors Association (CEA) Card



The CEA Card is issued by The Card Network. The card entitles the card holder to one free ticket for a person accompanying them to the cinema, provided a full price ticket is purchased for the card holder. You can apply for the card if you receive Disability Living Allowance or Attendance Allowance or registered as a blind person. The card is issued to the person who requires assistance to enjoy the cinema. In this way, there is no restriction on the accompanying person, family friend, care worker etc. as long as they are capable of offering the required assistance and are aged 16 or over. The card costs £5.50. For an application form ring **0845 1231292** or visit **www.ceacard.co.uk**

Netbuddy

Netbuddy—www.netbuddy.org.uk—is an award-winning website for parents, carers and learning disability professionals. It is a space to hunt for ideas, swap tips and access information about everything from brushing teeth to challenging behaviour. All the information on the site is submitted by people with first-hand experience of learning disability, and is organised under quick searches such as 'Dressing and Undressing', 'Out and About', 'Behaviour' and 'Routines'. There are also practical information packs on subjects like financial help and jobs and training, plus a friendly interactive forum. For more information go to **www.netbuddy.org.uk**



And Finallyfrom the Trustees and Staff of the Niemann-Pick Disease Group (UK), we would like to send you our warmest wishes for a very Merry Christmas and a Happy New Year.



PLEASE NOTE: The NPDG (UK) Office will be closed from Thursday 22nd December to Tuesday 3rd January 2012, however we are still available to help. During the Christmas break, the NPDG (UK) will be moving into our new office; therefore we may experience disruptions to our online and telephone services. If you need to speak to one of us during this time, please call Toni Mathieson on 07816 398591 or NPDG (UK)'s Families Officer, Elizabeth Davenport, on 07896197576.

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, Suite 2, Vermont House, Concord, Washington, Tyne and Wear NE37 2SQ** 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.

