



NIEMANN-PICK DISEASE GROUP (UK)

FAMILY NEWS BULLETIN

MAY 2008

Hello and welcome to the Niemann-Pick Disease Group (UK)'s first Family News Bulletin. This monthly news bulletin is intended to keep families up-to-date with all things Niemann-Pick in between editions of Niemann-Pick News.

We hope you find it interesting and informative.

In this month's edition:

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

Just a reminder that our Annual Family Conference and AGM will be held at the Hilton Hotel, East Midlands Airport on June 28th and 29th 2008. This venue has been chosen for its central location and excellent facilities, which we are sure you will all enjoy. The hotel facilities include: disabled rooms, a piano bar, indoor heated swimming pool, health and leisure suite. We hope you can join us for Conference which provides a chance to

strengthen our family network, allowing families affected by NPD to meet and share their experiences. Places are limited, so if you are interested in attending, please call the Central Office on **0191 4150693** to reserve your place.

Niemann-Pick Awareness Week

This year Niemann-Pick Awareness Week will be held from 14th to 20th July. So why not get involved by organising your own fundraising event? Help us to make Awareness Week 2008 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 4150693** or email **Niemann-pick@zetnet.co.uk** for a fundraising pack, information and ideas.

Hope For Hollie James Bond Ball Raises More Than £25,000 To Help Research Into Niemann-Pick Disease



Organisers of a James Bond-themed Casino Royale Ball held to raise money for Niemann-Pick Disease Group (UK) and the Hope For Hollie Fund have declared the event a complete success. More than 500 people attended the event at the stadium:mk, helping to bring the total amount raised to more than £25,000 for the Hope for Hollie campaign – a testament to the hard work of everyone involved with the campaign, including Hollie's parents Pete and Helen Carter. On the evening, guests were treated to many amazing James Bond-themed surprises. They had the opportunity to meet look-a-likes 'Sean Connery' and his arch nemesis 'Blofeld' and have photographs taken next to an Aston Martin and a Jaguar car. A champagne reception followed and then guests were treated to a three-course dinner with wine and were able to have a spin on the casino. Helen and Pete said: "We are absolutely delighted that the Casino Royale Ball has raised such an amazing sum of money for our 'Hope for Hollie' campaign. This is the first time we have staged such an event and the money raised will go towards Niemann Pick Disease Group (UK)'s vital work helping children such as Hollie. "We are so grateful to everyone who gave up so much time and put in so much effort to ensure our event was such a great success and also to all our sponsors."

Niemann-Pick Disease Group (UK) Collection Boxes

We now have a new supply of yellow plastic collection boxes. If you are interested in some to distribute amongst your friends, family or contacts, please call the Central Office on **0191 4950693**.



Channel Five Extraordinary People


Sarah Rest, Development Producer at Flame TV, is working on a series of documentaries for Channel 5's Extraordinary People series. She is looking for adults or children with rare medical conditions which have changed their lives. Often the subjects of the series are incredibly inspiring people with stories of courage and passion. If you would like to find out further information

on what would be required if you took part please contact Sarah Rest directly on **020 7713 6868**.

ACT Launches New Champions Awards Scheme

ACT, the Association for children's palliative care, have launched a new Champions Awards Scheme. They are asking children, young people, parents and carers to tell ACT about their 'Champions' so they can recognise and celebrate their role in making a difference to their quality of life. You can nominate any individual, team or organisation that has helped you, however, they must work in England. For further information of the awards and to nominate your Champion visit <http://www.act.org.uk>. In addition, ACT want to ensure that all life-limited children and their families get the highest standards of care and support. They are offering grants to support parents, carers and professionals to maintain or improve their level of knowledge and skills in children's palliative care through training, conferences, seminars and professional development. They have received support from The True Colours Trust to award small training and development grants. Further information is available on their website <http://www.act.org.uk>.

WellChild Children's Health Awards

 WellChild are inviting nominations for the 4th annual WellChild Children's Health Awards. The Awards celebrate the bravery and courage of sick children along with the many dedicated volunteers and professionals who support both them and their families. The event will take place in October at Lord's Cricket Ground in London. If you've been inspired by the bravery of a child, or the dedication of carers and healthcare professionals, take time to nominate them. You can nominate someone who has either made a real impact to your life or has touched the lives of others. Nominations can be made online at <http://www.wellchild.org.uk/awards> or email if you would like copies of the nomination form to awards@wellchild.org.uk.

New Relationships Guide For Families With Disabled Children

Research shows that parents of disabled children are more likely to experience relationship difficulties and this can have a significant impact on a child's wellbeing and behaviour. Contact a Family and the relationships experts One Plus One have published a guide for parents of disabled children and professionals working with them, to help strengthen couple and family relationships. For your free copy of the guide ring the Contact a Family helpline on **0808 808 3555**.



Help Other Parents Of Disabled Children Deal With Bullying



Contact a Family is joining forces with Parentline Plus to produce a guide for parents of disabled children to help them cope if their child is being bullied and are looking for your help. Research suggests that more than one in three disabled children have been bullied at school and many parents can feel they have nowhere to turn. Bullying can take place at school, on school transport, in playgrounds, at leisure



activities, online; bullying can take place anywhere. The guide will be a tool for parents to help them cope if their child is being bullied. As well as containing information about the action schools should be taking and the legislation around bullying, it will include the parents' perspective and their stories. If your child has been bullied or is being bullied because of their disability and you would like to share your experiences to help other parents please get in touch with Contact A Family. The information they would like to know would be: how you spotted signs of bullying, the strategies you used to deal with the bullying, whether they worked or not, how you coped with the situation and any advice you would like to give to other parents in similar situations. Your experiences will be used anonymously in the guide. If you would like to share your experiences or have any questions about the project, please contact Penny Roper on the freephone helpline **0808 808 3555** or email penny.roper@cafamily.org.uk .

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:

- Jodie O'Grady and three friends raised £580 by taking part in a parachute jump.
- Mr and Mrs Charles Lawson donated £800 from their golden wedding anniversary celebrations.
- Premier Pension Services (via Colin Stirrat) donated £849.41.
- Mr Raj Nehra donated £1000 in memory of his late wife.
- Clyst Vale Community College raised £194.05 from a staff raffle.
- Anixter Fasteners in Gloucester held a dress down day and raised £117.00
- UIA in Stevenage have held several dress down days and raised a £160.42 throughout the first few months of 2008.
- Artizan Hair in Milton Keynes raised £327.00

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 first 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 out at the beginning of June. If you require a paper copy, please let us know.