



finding the answer....supporting the need.

News from the Proteus Family Network UK

Reg'd charity No.,1098608

Welcome...to your new look News shot

December
2005

WELCOME TO NEW MEMBERS

Dianne Golding and Daniel
Lisa and Julian Hales – Waller
and Joel
Linda Jenkins
Jackie Wright and Isobel
Marie Weis
Tokunbo Lapido and Atinuke

News..News...News...

We hope you like our new look News Shot. This will not replace the normal Newsletter, but will complement it, by giving you up to the minute information as quickly and regularly as possible.

Drop us a line, by e-mail or snail mail and let us know what you think and what you would like to see in it - it is here for **YOU**.



New Medical Advisory Board member.....

we are pleased to welcome Miss Deborah Eastwood as a member of our Med. Board. Deborah is a Consultant in Orthopaedics at GOSH . I am sure those of you who attend the Proteus clinics at GOSH will meet her sooner or later..we are grateful for her support..thank you Deborah.

Adult Clinics

You may have seen an article in the recent Proteus Syndrome Foundation newsletter by Susan Huson, which referred to work she is doing in helping Professor Harper and Mr Monsell in furthering patient care. Susan Huson is not a member of our Med. Board. She has attended a Med Board meeting by invitation.

We can assure you that the development of adult clinics is being pursued by your Medical Advisory Board - Prof.Harper, Mr.Fergal Monsell, Dr. Deborah Eastwood, Richard Houlston- and the committee of the PFN UK. working together. It is an absolute priority for us. If you are concerned about the lack of an adult Proteus clinic in the UK, please write to the Chair, Jean Harrison, voicing your concerns. The more support we can show, the better our case...so go on, put pen to paper and start writing.



Klippel Trenaunay Members

Most of you will know that we welcome anyone as a member if they have an associated condition and no support group. We especially welcome **KT** families and individuals. We have 9 **KT** families in membership. This News Shot will be going out to the members of the previous **KT** group, with an invitation to join the group, so, watch this space - the **KT** section may be about to expand!

Fund raising and Donations

Thanks to all those who have raised or donated funds for the group over the past 12mths . A total of 5404.79 was received by the Network, with some specifically donated for the research work. And thanks also to those who donate on a monthly basis and have gift aided their donation. Join them - Make a New Years resolution and take out a monthly donation - ask friends and family - I'm sure they'd love to help - Gift Aid forms attached...thank you.

Miss D.Eastwood FRCS
Consultant in Paediatric Orthopaedics
Orthopaedics

Medical Advisory Board
Professor J.Harper MD. FRCP. FRCPCH
Consultant in Paediatric Dermatology

Mr F.Monsell MSc. FRCS (Orth).
Consultant in Paediatric



PFN UK Family Weekend 2005

The family weekend, held earlier this year in May, at Swindon, was a great success. Sixteen families stayed overnight and it was great to see so many new faces. Having time to meet socially on the Saturday evening gave us all the opportunity to exchange experiences - whilst some of us had a great time playing games with the children!

After the AGM on Sunday morning, we had presentations from Michelle Batilava, a child psychologist from Changing Faces and Professor John Harper of GOSH, who is head of our Medical Advisory Board. **Here's the view from one new family -**

We found the wk-end to be so valuable, Jacob gained so much from meeting other children with the same condition as him. Words just do not go there. The wk-end, was a god send. It was a wonderful way to share things with other people, who for the first time in my and Jacobs life could understand what we meant and where we was coming from. The wk-end was priceless, and we are looking forward to the next one.

Family News

We remembered Babs and Gordan Walker at the family weekend, who could not be with us as Grant was quite poorly in hospital. We are sad to tell you that Grant, who was 17, lost his battle with Proteus soon after and passed away peacefully. Donations of 300 in memory of Grant were made to the group. Please continue to remember Babs, Gordan and their son Craig, especially over Christmas.

KT members may remember Oliver Rocyn-Jones who with his family was involved with the original KT support group. Oliver, who was 26, passed away at the New Year, His family, friends and work colleagues wished to remember Oliver by making donations towards the research programme and presented a cheque to Prof. Harper for 2060.....

To support fundraising events, we find that we are often asked if we can supply photographs along with our fundraising material. If you have any family photographs which show not only the difficulties, but also the positive side of Proteus...and you are happy for them to be used in fundraising events, please send them to me - 31 Baswich Lane, Stafford, ST17 OBH - with a note giving permission for their use. If you can e-mail them or put on a disc, so much the better, thanks...

When a loved one's gone

**Those we love remain with us, for love itself lives on.
And cherished memories never fade because a loved ones gone...**

**Those we love can never be more than a thought apart.
For as long as there is memory they'll live on in the heart.**

*Best wishes for a **Happy Christmas** and **Healthy 2006***

Jean Harrison.