May 2012

ISG E BULLETIN

Issue 23 May

Last Month

Specialised Healthcare Alliance (SHCA) Mandy Aldwin, ISG Trustee, attended the SHCA meeting on the 11th April-London. The ISG works in collaboration with SHCA www.shca.info who work hard campaigning on behalf of people with rare diseases and other complex conditions, which require specialised medical care. Attendance at such meetings is important for the ISG to keep up to date with any new developments and enables us to pass on relevant and important information to our members.

Brighton Marathon after months of training and hard work ISG member, Nancy Stevens, courageously took part in and completed the Brighton Marathon on the 15th April, helping to raise awareness and much needed funds for ichthyosis and the ISG. Well done Nancy! Please visit: www.justgiving.com/Nancy-Stevens

Surrey Lads 3 Peaks Challenge Following a 10 hour drive and a short sleep in basic digs the lads set off on the 20th April at 8am and began their ascent up Ben Nevis. Despite the awful weather conditions and most of the paths being thick with ice and snow they hit their target time and completed the first challenge. With no time to rest they jumped back into the cramped minibus and headed for Scafell Pike. Arriving at the foot of the mountain the weather looked bleak, they started their ascent at 19.45hrs and reached the summit in good time. However, the weather took a turn and the darkness closed in. The team were stranded! After 12 hours of walking the hills of Scafell Pike in the rain, snow and fog they finally reached the foot of the mountain at about 8am. The challenge was over. Despite the conditions and the exhaustion felt by all, the lads feel there is unfinished business and they are planning to complete the challenge in the near future. So far they have raised over £6,000 for charity, with 50% of this going to the ISG. Well done lads! www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads

ISG Members

The ISG welcomed 20 new members in April!

3 were from the USA, 1 from Holland, 1 Malaysia.

From the UK: 1 London, 7 NW, 1 NE, 2 Emids, 2 Anglia, 1 Wales, 1 SW

Types of ichthyosis: 6 X-linked, 2 Lamellar, 4 Vulgaris, 1 Bullous and 7 with no diagnosis.

14 were parents of children affected.

Forthcoming Events

ISG Family Day, Saturday 19th May
Please put this date in your diaries and visit our website where information regarding this event will be displayed and updated regularly www.ichthyosis.org.uk

European Conference on Rare Diseases, Brussels - 23rd - 25th May www.rare-diseases.eu/2012/6th-European-Conference-on-Rare

eni General Assembly, Brussels 26th May www.ichthyose.de/europa/
ISG Family Day 19th May has already proved to be a huge success, sponsored by the Big Lottery Fund and supported by more than 10 pharmaceutical companies and 75 families registered, our biggest event yet! The ISG looks forward to meeting all those attending on the 19th for an informative, exciting and fun filled day.

Ichthyosis vulgaris research - Dermatology & Genetic Medicine, April 2012  Filaggrin gene discovery. A research group in Dundee, Scotland, led by Professor Irwin McLean first discovered the changes in the filaggrin gene that cause ichthyosis vulgaris in 2006. Since this time we have been working hard to learn more about the filaggrin gene and how it works within the skin. For more information and to read the full article please visit our website: www.ichthyosis.org.uk/ichthyosis-vulgaris-research-update-april-2012/

Independent Parental Special Education Advice (IPSEA) Every year thousands of families struggle with the complex SEN system. Understanding the relevant legal rights and duties is crucial if a family is seeking to secure the right education for their child. For more than 25 years, IPSEA has been giving families free (and independent) legally based SEN/D advice and support. As budgets are being tightened, demand for their specialist help is higher than ever. For more information please visit: www.ipsea.org.uk

How do you access new therapies and healthcare services? In order to gather your views on these issues, Genetic Alliance would like to invite you to participate in a survey www.geneticalliance.org.uk/. The purpose of the survey is to better understand how rare disease patients are currently accessing healthcare services and specifically new therapies, their role in the healthcare system, processes for making therapies available and the obstacles encountered in trying to access care. To complete the survey please visit: www.zoomerang.com/Survey/WEB22F2B7RWB3E

The ISG Needs Your Help

’autograph Get Involved with your ISG’autograph

Do you have some time to spare? Are there any areas within the ISG you think could be improved? Maybe you have a particular interest or skill? Do you simply want to help?

My Story and Top Tips please keep sending us your ‘Top Tips’ for ichthyosis and sharing your experiences for the ISG’s website ‘My Story’ section by sending them to isg@ichthyosis.org.uk

For more information about how to get involved, please visit the ISG website ‘Get Involved’ pages: www.ichthyosis.org.uk/get-involved/
**Top Tips For Ichthyosis**

**Benefits - Have you noticed a sudden change in your benefits this month?**

Are you on benefits? Are you worried about how recent changes in the welfare system may affect you? Call Contact a Family’s freephone helpline on **0808 808 3555** to order your copy of their *Guide to future benefits* now. Written by their experts, the guide gives you up to date details of changes to the benefits system and what you can expect in the coming months. For more information please visit our website: [www.ichthyosis.org.uk/benefit-changes-get-up-to-date-information-now](http://www.ichthyosis.org.uk/benefit-changes-get-up-to-date-information-now)


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**Fundraising**

**On line Fundraising** Currently we have 16 live Justgiving pages. [www.justgiving.com/isg](http://www.justgiving.com/isg) and 1 Virgin money giving page: [www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads](http://www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads)

**Donations & Fundraising** Thank you to all who have made donations, or carried out fundraising events, during the last month.

Want to raise some money but don’t have the time?


For details of ‘Text Giving’ please visit: [www.ichthyosis.org.uk/3075/support-us-with-a-text/](http://www.ichthyosis.org.uk/3075/support-us-with-a-text/)

Without your hard work the ISG would struggle to support those affected by ichthyosis and would not be able to support ongoing medical research. Every penny counts, no matter how small.

**If you have an ISG collection box, please do not forget to empty it and send in your donations.**

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**Useful Links**

- Face it on line [www.faceitonline.org.uk/](http://www.faceitonline.org.uk/)
- Independent Parental Special Education Advice (IPSEA) [www.ipsea.org.uk/](http://www.ipsea.org.uk/)
- Changing Faces: [www.changingfaces.org.uk](http://www.changingfaces.org.uk) for psychological support

Please visit the ISG website for more useful links [www.ichthyosis.org.uk/links/](http://www.ichthyosis.org.uk/links/)