Last Month

BAD PSG Committee Meeting 17th May The ISG continues its close links with the British Association of Dermatologists (BAD) [www.bad.org.uk](http://www.bad.org.uk) working in collaboration to help provide better dermatology services. ISG Administrator, Liz Dale, attended the BAD Patient Support Group meeting last month where it was also decided that the BAD would fund an ISG project to help improve its IT and working efficiency as an organisation.

ISG NW Family Day 19th May Another fantastic and successful event attended by 68 families - 262 people; 134 adults; 109 children; 5 medical professionals; 6 psychology/youth workers and 10 people entertaining/providing children’s activities. This year’s event was exceptional with an exciting venue - Old Trafford - and proved a huge success made evident from feedback received. Families arrived early to ensure they gained the maximum from the day’s fully packed agenda, enjoying the formalities of the morning with a relaxed and informal afternoon, a tour of the stadium and a fun, interactive and social evening event.

BCH Paediatric Dermatology Course 24th May Paul Whitehouse, ISG Chairman, attended the 14th Annual Paediatric Dermatology Course at Birmingham Children’s Hospital. Presentations were made by 3 support groups to 38 Doctors made up of Registrars and Consultants from hospitals across the UK. This is a rare opportunity for patients and support groups to speak with Doctors and provide them with information and first hand experience of dealing with a rare condition - something they may never come across in their medical career - an excellent way of raising awareness within the medical profession.

European Network for Ichthyosis (eni) 3rd General Assembly, Brussels 26th May [www.ichthyose.eu](http://www.ichthyose.eu) was again attended by ISG trustees, Maggie & Mandy Aldwin, representing the ISG and UK. In total 8 European countries were represented by 14 members of eni, which was kindly sponsored by Eurordis [www.eurordis.org/](http://www.eurordis.org/). Maggie Aldwin was again voted in for a further 3 years as eni President.

ISG Members

The ISG welcomed 16 new members in May!

2 were from Australia, 1 from Holland, 1 USA and 1 Brazil

From the UK: 2 London, 1 NE, 1 NW 3 Wmids, 2 Emids 1 Anglia, 1 South,

Types of ichthyosis:

4 X-linked, 3 unknown, 2 Lamellar, 2 Harlequin, 1 Vulgaris, 1 Bullous, 1 CIE, 1 Netherton & 1 PPK.

Forthcoming Events

Dermatology Council for England (DCE) Meeting, 14th June, London, [www.dcf.e.org.uk](http://www.dcf.e.org.uk)

Rare and Complex Dermatology Services Engagement Event, 27th June, London


BAD 92nd & BDNG 22nd Annual Meetings 3rd - 5th July, Birmingham [www.bad.org.uk](http://www.bad.org.uk)
**ISG Member working in the Rain Forrest**

Oliver Lifely is heading off to Guyana to teach for a year in the rainforest. Oliver will be working with an organisation called Project Trust [www.projecttrust.org.uk/Country.php?c=guyana](http://www.projecttrust.org.uk/Country.php?c=guyana) an educational volunteering charity enabling people to help and work within communities with less resources than here in the UK. Suffering from ichthyosis himself Oliver is unsure how his skin will react but hopefully after he becomes acclimatised to the heat and environment the humidity will be of benefit to his skin. We will update you on Oliver’s experience and progress.

**Advances in Medicine and Treatments for Ichthyosis**

The Committee for Orphan Medicinal Products (COMP) held its 134th plenary meeting on 10th & 11th May 2012. COMP adopted 16 positive opinions recommending the following medicines for designation as orphan medicinal products to the European Commission:

- Talarozole for treatment of autosomal recessive congenital ichthyosis
- Talarozole for treatment of keratinopathic ichthyosis
- Talarozole for treatment of recessive X-linked ichthyosis

Talarozole is the current name for the molecule with the planned trade name of Rambazole. For more information please visit: [www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2012/05/news_detail_001515.jsp&mid=WC0b01ac058004d5c1](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2012/05/news_detail_001515.jsp&mid=WC0b01ac058004d5c1)

**Psychological affects of living with ichthyosis**

The Centre for Appearance Research, UWE and the Ichthyosis Support Group are looking for young people to test out in their own homes, a new 7 week online support programme called ‘YP Face It’, for young people who have worries because of a condition that affects appearance. It has 7 weekly sessions and uses interactive and learning activities, illustrations, videos, audio, photos and advice from other young people with a condition that affects appearance to help young people feel and act more positively and confidently. If you’re interested in finding out more about this study, please contact the researcher Catrin Griffiths on 0117 32 83947 or email catrin.griffiths@uwe.ac.uk

**ISG NW Day Raffle Prize Winners**

Congratulations to the following who won the BIG prizes at the ISG NW Family Day Raffle: Joe Wilkinson - ipad 3; Angela Davies - Diamond Earings; Andrew Gunter - 22” TV and Donna Taylor who won the digital photo frame! In total 28 prizes were won raising an amazing £621. Thank you to the sponsors for donating the prizes. Congratulations also to Carol Clabrough who won the ‘Survey Draw’ of which we had 42 returned - thank you to everyone who completed a survey, the information gathered is invaluable to help improve services.

**The ISG Needs Your Help**

**👍 Get Involved with your ISG 👍**

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/](http://www.ichthyosis.org.uk/get-involved/)
**Top Tips For Ichthyosis**

“We have found Aloe Vera drink is an amazing product and we have never looked back since using it and we’re delighted with the results.”

ISG Member with a child with Harlequin ichthyosis May 2012

Renown for its healing and soothing properties Aloe Vera extracts have been widely used in herbal medicine. Although there is little scientific evidence of the effectiveness of use for medicinal or cosmetic purposes many believe it is of great benefit, particularly for the skin. Some studies have shown Aloe Vera may be effective in the treatment of wounds showing that it can promote the rates of healing, if this is the case surely those with ichthyosis would benefit from its use? Please let us know your thoughts or if you have any experience of using Aloe Vera products for the treatment of ichthyosis.

The ISG does not endorse or promote such products merely passes on information from its members. We strongly advise you seek medical advice before changing or starting any new treatments, such as Aloe Vera drinks and products; it should be noted in high quantities Aloe Vera can produce toxic effects.

**Fundraising**

Thank you to all who have made donations, or carried out fundraising events, during the last month, with no Government funding you are the main reason the ISG exists. 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.

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

**Why not donate straight from your wages:**

[www.payrollgiving.co.uk/](http://www.payrollgiving.co.uk/) or [www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn.aspx](http://www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn.aspx)


or [www.ebay.co.uk/ebayforcharity/](http://www.ebay.co.uk/ebayforcharity/) or even whilst searching the Internet [www.easysearch.org.uk/](http://www.easysearch.org.uk/)

with no effort at all!

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/)

**On line Fundraising**

Currently we have 16 live Justgiving pages: [www.justgiving.com/isg](http://www.justgiving.com/isg)

1 Virgin money giving page: [www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads](http://www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads)

**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/)