Last Month

Rare Dermatology Service Design Day The National Specialised Commissioning Team (NSCT) held a model of care design day on the 1st March at the British Association of Dermatologists House in London, to explore proposals for a Rare Dermatology Service. Mandy Aldwin, ISG Trustee, and Liz Dale, ISG Administrator, attended this meeting highlighting the needs of patients with ichthyosis, demonstrating how these differ from other dermatological conditions. The day was well attended by clinicians, specialist nurses, patient groups and other interested parties, all interested in developing a model of care for people with rare skin disorders.

National Council for Voluntary Organisations (NCVO) Annual Conference, 5th March Andy Corbett, ISG Trustee, attended this annual event supporting voluntary organisations with practical skills and resources to continue moving forward as an organisation. There was a great opportunity for networking and exchanging organisational practices and ideas, essential for small voluntary organisations, such as the ISG, to run effectively.

Andover College Change of Tune Festival, Friday 16th March. The Ichthyosis Support Group was invited to attend this event which celebrated local artists and raised awareness of the many charities working tirelessly to support local communities. The aim was to communicate a message of social equality and a commitment to community inclusion. ISG Trustee and Regional Contact Coordinator, Yvonne Peet, attended this event to raise awareness of ichthyosis amongst the local and college community meeting and educating a steady flow of interested students and community residents about ichthyosis. To watch Yvonne in action please visit: www.youtube.com/watch?v=052Z7uMH8w

ISG Members

46 new members since January 2012 to date

Types of ichthyosis included: 15 undiagnosed; 14 vulgaris; 6 X-linked; 4 Bullous; 2 Harlequin; 1 EKV; 1 Collodion baby

• 33 from the UK & Eire
• 2 from Europe
• 11 from the rest of the world

• 23 were parents of affected children
• 17 do not attend hospital or see a consultant
• 34 found the ISG by searching the Internet.

Forthcoming Events

3 Peaks 24 hr Challenge 21st April
ISG member John Dale, will be joining a team of 14 lads from Surrey to undertake the 3 Peaks Challenge in 24 hrs to help raise money for the ISG.

For more information please visit: www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads

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
ISG Family Day 19th May is proving to be very popular with more than 60 families already registered for what looks like a very informative, interesting and fun filled event. If you have not already returned your registration form please do so as soon as possible to ensure your attendance, please remember spaces are limited so don’t miss out.

ISG Annual Conference Meeting will take place during the NW Family Day on the 19th May. If you have any questions regarding the last chairman or financial report and accounts, or would like to elect a representative to become an ISG corporate member, please email ISG trustee Maggie Aldwin: maggie@ichthyosis.org.uk

Ichthyosis in the media ISG Member and NE Regional Contact, Tammy Smith, appeared last month, with her two sons, in Pick Me Up magazine on the 29th March, sharing their story of how ichthyosis has affected them as a family. In addition, ISG member Nelly Shaheen, appeared in ‘New’ magazine where she talks about her experiences of living with harlequin ichthyosis and will be appearing on the new Channel 4 series ‘Beauty and the Beast: The Ugly Face of Prejudice’.

National Plan for Rare Diseases is announced in a launch of proposals by the UK’s health departments. Following public consultation by the health departments there are plans to improve service for patients with rare diseases and to facilitate research. www.dh.gov.uk/health/category/latest-publications/consultations/

Centre for Children’s Rare Disease Research Great Ormond Street Hospital (GOSH) charity announced its plans to raise money to build a centre for research into rare disease’s for children. The centre is estimated to cost £66 million and will bring together clinical and research expertise from GOSH and UCL’s Institute of Child Health. Such a centre will help to improve diagnosis and improve treatments for all rare diseases in children.

Pharmaceutical, Medical and Health Companies The ISG continues to seek support and work with various relevant organisations in our attempt to improve the lives of all those affected by ichthyosis. The following organisations are currently supporting the ISG NW Family Day in May: Dermal Laboratories; Mölnlycke Health Care Ltd; Galderma UK Ltd; LaCornium Health UK; Synergy Health Plc. The ISG would like to thank them for their support and interest in the ISG and ichthyosis.

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/
Top Tips For Ichthyosis

Hair & scalp care - Trying to treat the scalp, remove the scales and have fresh grease free hair?

- Moisturise the scalp using your normal emollient or olive oil, for example, and leave over night if necessary covering with a scarf or towel to keep the moisture in.
- Remove the scales by gently combing through the hair with a fine toothed comb before washing.
- Try using a medicated shampoo to help reduce itching and the build up of scaling.
- Repeat this process 2 or 3 times a week to treat the scalp and help prevent scaling.
- Constant application of cream often gets absorbed into the hair, particularly if it is not short, try using a dry spray in shampoo to keep hair looking fresh and grease free.

Fundraising

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

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

- Mr Baker
- Mrs Stansfield
- The Lark Family
- Jenny Davies

Want to raise some money but don’t have the time?
Why not donate straight from your wages: www.payrollgiving.co.uk/ or www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn.aspx?, as you shop; www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group www.easyfundraising.org.uk/ or www.ebay.co.uk/ebayforcharity/ or even whilst searching the Internet 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/

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.

Useful Links

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

Please visit the ISG website for more useful links www.ichthyosis.org.uk/links/