Last Month

Leeds Regional Dermatology Meeting Mandy Aldwin, ISG Trustee, attended this meeting on the 6th January 2012. Mandy gave a presentation to dermatology consultants and registrars, raising awareness of ichthyosis from a patients perspective, helping them to understand the issues patients face and how these impact on quality of life and daily living.

British Association of Dermatologists Strategy Day Mandy and Maggie Aldwin, ISG Trustees, attended this interactive workshop in London on the 21st January. The purpose of the day was to focus on the future of the NHS service structure and its implications for dermatology. The NHS ‘shake up’ and developments will inevitably effect commissioning at both local and national levels having an impact on dermatology services as a whole.

Psychodermatology UK Annual Meeting Liz Dale, ISG Administrator, and Mandy Aldwin, ISG Trustee attended this annual event on the 26th January hosted by Dr Anthony Bewley, ISG Medical Advisory Board Member. Psychodermatology is a newer, emerging sub speciality of dermatology and is being acknowledged more amongst health professionals. The association of the psychological effects of a visual skin condition is becoming recognised more and so treatments and management of the condition is beginning to improve. The ISG’s representation is important to raise awareness, particularly amongst health professionals, such as psychologists and psychiatrists, who may begin to see more patients suffering with ichthyosis in the future. The ISG is aware of the psychological issues associated with ichthyosis and is keen to support developments into this speciality. Currently, the British Skin Foundation is researching the psychological affects of living with a visual skin condition and is asking people if they would like to complete a short survey at: svy.mk/wyKS9w

Forthcoming Events

DCE Meeting 9th February 2.30pm
London www.dermatologyengland.org.uk

Rare Disease Day 29th February
www.rarediseaseday.org

The RCN Dermatology Nursing Conference
29th February, London www.rcn.org.uk

Rare Dermatology Service Model of Care Design Day 1st March 10-4pm, London

Please note: An ISG representative aims to attend these meetings, as they are not intended for the general public. If you have an interest in any of the above please contact the ISG at: isg@ichthyosis.org.uk

ISG Members Events

If you have an event planned, or would like support with an event, please get in touch.

For ideas on planning events please visit:
www.ichthyosis.org.uk/916/fundraising-guide/
News

New members to the ISG This month the ISG has welcomed 12 new members to the group, bringing our total number of active members to 623. Over the years, we lose members for various reasons; they may move house and forget to tell us or decide they no longer need the same level of support. We welcome and encourage new members, particularly through our website, and since the ISG was formed in 1997 we have provided support to over 800 individuals and families.

Rare Disease Day 2012 www.rarediseaseday.org The 29th February marks the fifth international Rare Disease Day coordinated by EURORDIS www.eurordis.org. On this day patient organisations from more than 40 countries worldwide are joining forces to raise awareness using the slogan “Rare but strong together”. To take part, or to find out about UK events taking place near you, please visit www.raredisease.org.uk for more information.

ISG Family Day This year’s event is still in its planning stages but is likely to take place on May 19th 2012 and be held in the North West. As soon as details are confirmed, we will be sending out information inviting and encouraging members to register for this event. Please remember places are limited so the sooner you register the more likely you are to secure your places.

My Story and Top Tips The ISG would love to hear about its members’ experiences and ideas about living with ichthyosis and be able to share these with others. Our members, particularly those new to ichthyosis often express to us the comfort and knowledge they gain from hearing how others deal with the dilemmas faced with living with ichthyosis. Please send us your story, or top tips, and we will post them on our website. Please write to isg@ichthyosis.org.uk

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?

The ISG structure consists of the following Sub Committees: Events, Fundraising, Media & Communications, Medical & Research, Youth Forum and Finances & General Purposes. If you would like to find out more about each Sub Committee, or think you may have a quality, skill or interest in any these areas, please get in touch and find out how you may be able to join the team.

If you have any ideas, or would like to volunteer, please contact the ISG by telephone: 0845 602 9202, email: isg@ichthyosis.org.uk or post: PO Box 1404, Bagshot, GU22 2LS.

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

Motivation, Encouragement and Support - Talking through problems and issues often helps and very often we gain more from talking about our problems or concerns than we expect. Reassurance and understanding are particularly important as a parent or carer and listening can offer much support to someone with ichthyosis.

If you would like to make contact with others affected by ichthyosis, of a similar age and location, please get in touch with your Regional Contacts in your area, or alternatively, you can email: isg@ichthyosis.org.uk and start sharing your experiences of ichthyosis.

Fundraising

Justgiving ISG Currently we have 16 live Justgiving pages.  www.justgiving.com/isg

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

- Tammy Smith, ISG Regional Contact
- Mr & Mrs Fairbrass
- The Patricia Ann Buller Charity
- Saeeda Rangzeb, ISG Asian Contact

Want to raise some money but don’t have the time? Why not donate straight from your wages, while you shop or even when searching the Internet - with no effort at all!

www.easyfundraising.org.uk/
www.ebay.co.uk/ebayforcharity/
www.easysearch.org.uk/
www.payrollgiving.co.uk/
www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group

For ‘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 cheques.

Links

Relevant medical publications  www.ichthyosis.org.uk/1250/publications-2/

ISG Facebook en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info

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