**Last Month**

**Genetic Alliance Annual General Meeting (AGM) 1st November 2011**
ISG Administrator, Liz Dale, attended the 22nd AGM in London earlier this month, which included presentations and discussions about changes to public health and nationally commissioned specialised services in the NHS. For more information please visit [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk/).

**British Society of Paediatric Dermatology Annual Meeting 11th & 12th November**
Mandy Aldwin, ISG Trustee, and Jayne Woodward, Regional Contact for the East Midlands, attended the 26th annual meeting, held this year in Nottingham. Attended by many consultant dermatologists, it proved a successful opportunity to raise awareness about ichthyosis and the ISG [www.bspd.org/](http://www.bspd.org/).

**British Association of Dermatologists (BAD) Patient Support Group (PSG) Committee Meeting, 17th November, London**
The ISG attended this meeting and continue to work closely with BAD to help improve services for people with ichthyosis. We are also pleased to announce the BAD has awarded the ISG a grant towards our next event [www.bad.org.uk/](http://www.bad.org.uk/).

**Dermatology Annual Conference for GPs, Cardiff 26th & 27th November**
On behalf of the ISG, Mandy Aldwin attended this event for GP’s wishing to continue their professional development in dermatology. Having a presence at such events helps to raise awareness of ichthyosis and the ISG, whilst allowing GP’s to keep up to date and enhance their knowledge of the condition.

**Meeting with Changing Faces 29th November, London**
Maggie & Mandy Aldwin along with Liz Dale, from the ISG, met with Shirley Rose and Carole Easton, from Changing Faces, to explore how we may work together and support each other in the future. It is likely Changing Faces will facilitate some youth sessions at our event next year, in May.

**Forthcoming Events**

- **Leeds Regional Dermatology Meeting**
  6th January 2012
  The ISG has been invited to speak to dermatology consultants and registrars.

- **Specialised Healthcare Alliance Meeting**
  11th January 2012

- **Psychodermatology UK Annual Meeting**
  26th January 2012

**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](mailto: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/](http://www.ichthyosis.org.uk/916/fundraising-guide/)
**News**

**New ISG On Line Shop** Please keep visiting for new products. We currently have seasonal items, such as Christmas cards, calendars and diaries, along with our traditional and useful items such as mouse mats, trolley coins, keyrings, T-shirts and much more. And remember buying these products helps to raise awareness!

**Advances in Medicine** Progress is underway in preparation for clinical trials to be started on a new retinoid acid metabolism blocking agent (RAMBA). It is said that these trials will be undertaken by a large and well known pharmaceutical company. The target population will be patients with Lamellar ichthyosis with the aim of using the drug to treat anyone whose condition may benefit.

**Ichthyosis in the Media** The ISG is regularly asked by various media sources for people to tell their story about living with ichthyosis. Whilst we appreciate not all journalists are sensitive to issues surrounding ichthyosis we also acknowledge the good that may come of media coverage. If this is something you would like to find out more about please contact us isg@ichthyosis.org.uk

**New members to the ISG** Last month we welcomed 12 new members to the ISG. We are currently updating our information for members and new members. Once these are complete we aim to send these out to all new and existing members. The information will be new and up to date, containing lots of useful information about living with and caring for someone with ichthyosis. If you have any ideas about what you would like included, please let us know isg@ichthyosis.org.uk

**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 with others. Please send us your story or top tips!

**The ISG Needs Your Help**

**Are you tired of writing and sending Christmas cards?** Why not send your Christmas greetings this year by email, donating the money you would have spent on cards and postage to the ISG. Help to raise awareness of ichthyosis by informing friends and family why you are not sending cards this year!

**Volunteers Needed**

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

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.

**Get Involved with your ISG**

- Surveys / research studies
- Fundraising
- The ‘Youth Forum’
- Starring in our educational DVD

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

Winter Weather and Ichthyosis - Keep warm, keep moisturised, keep covered!

Central heating often dries the skin. Try placing small bowls of water on, or near radiators to reduce dry atmospheres. This is a cost effective alternative to expensive humidifiers. Add a few drops of your favourite aromatherapy oil for a fragrant smell!

If you have any tips you would like to share, please email: liz@ichthyosis.org.uk

Fundraising

Justgiving ISG Currently we have 21 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:

- Linslade School, Leighton Buzzard, and the Pollard family
- Sasha Inglott and her 6th form students completing a Sky Dive
- LDJ Solicitors
- Tammy Smith for organising a fundraising event in the summer

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.easysponsor.org.uk/
www.easycare.org.uk/
www.penyrollgiving.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/