Last Month

ISG New Year / Regional Contacts Meeting January 23rd 2011 The ISG committee was joined by four members of the Medical Advisory Board (MAB), two Regional Contacts, a member and her daughter, who will be co-ordinating the ISG ‘Youth Group’, and Ros Taylor, a fundraising consultant currently working voluntarily with the ISG. In all, 17 people came along to Great Ormond Street Hospital for the ISG annual meeting, which was followed by a well-earned curry.

ISG Conference Venue Ray Rowley and Claire Winter, ISG Trustees, visited the Holiday Inn Kensington Forum www.hikensingtonforumhotel.co.uk/ and the committee agreed it is a suitable venue for the ISG Family Conference in June of this year.

ISG Sub Committees Last month the new initiative of having sub committees within the ISG structure got well under way, with all the committees holding meetings and conference calls to identify the Chair of each. The ISG committee remains united but has the added bonus of working in smaller groups, to clearly define and focus on projects and the finer details of running the organisation.

Dermatology Council for England (DCE) Meeting took place on Thursday 27th January at the BAD residence and was attended by Liz Dale, ISG Administrator. There was a good turnout by the differing members, including many familiar faces from the various patient groups. On the agenda was the Proprietary Association of Great Britain (PAGB), www.pagb.co.uk/selfcare/movementforselfcareinpractice.html which represents the manufacturers of over-the-counter medicines and food supplements in the United Kingdom. The PAGB was in attendance to feedback to the DCE its involvement in the Self Care Campaign www.selfcarecampaign.org/ The second half of the meeting focused on the DCE ‘New Year’s Resolutions’ and the implementation of the DCE manifesto. The creation of a commissioning pack to assist commissioners was also discussed at the meeting.

Psychodermatology Meeting Thursday 27th January was attended by Mandy Aldwin, ISG Trustee. On the agenda were various topical discussions and presentations relating to the link between dermatology and psychiatry, and the psychological aspect of living with a skin condition. Specialists speaking on the subject were as follows:

- Dr Anthony Bewley, Dermatologist
- Dr Taylor, Psychiatrist
- Dr Richard Staughton FRCP, Consultant Dermatologist.

There were also case reports of patients with psycho-cutaneous disease sharing first hand experiences. The opportunity to meet the specialists and attendees, as well as gaining knowledge from such events, is invaluable to the ISG and enables relevant information to be filtered through to our members.

Courses & Conferences

www.cafonline.org/charitytraining
www.theclarefoundation.org/training.php
www.ncvo-vol.org.uk/training-events
www.charitycomms.org.uk/events/conferences/

Forthcoming Events

Rare Disease Day 28th February 2011
RDUK is responsible for coordinating activities in the UK. For more information please visit: www.rarediseaseday.org

RDUK Parliamentary Receptions
Rare Disease UK will be holding four Parliamentary Receptions across the UK to bring all those with an interest in rare diseases together to highlight the issue to politicians.

22nd February Scottish Parliament, 6:30pm-8:30pm scotland@raredisease.org.uk

28th February Westminster, 4pm-6pm stephen@raredisease.org.uk

3rd March Northern Ireland Assembly, 12pm-2pm stephen@raredisease.org.uk

16th March Welsh Assembly, 12pm-2pm williamsbg@cardiff.ac.uk

Register early for these events to be sure of a place!
**News**

**ISG Family Conference June 18th-19th** Keep the weekend free for this years ISG event. This year there will be a strong youth influence to the theme as well as the usual health professionals in attendance, pharmaceutical companies and organisations with an interest in ichthyosis to help support our members. Yet to be confirmed, but, the likely venue will be the Holiday Inn Kensington Forum [www.hikensingtonforumhotel.co.uk](http://www.hikensingtonforumhotel.co.uk).

**Re Structure of the ISG** The ISG is trying to move forward and improve its service and support to those affected by ichthyosis. To enable this to happen, a number of areas have been identified that need attention. The role of the regional contact has changed slightly, to make best use of resources while keeping the contact with members as paramount. The division of the committee into sub committees is underway and aims to focus the projects within the group and clearly define its outcomes. The evolution of an ISG youth run ‘sub group’ focussing on the needs of our younger members is well underway and will be led by a youth member of the ISG. These are some of the changes already underway and currently being implemented, which we hope will include much more member involvement within the ISG.

**GP’s with Special Interest (GPwSI) RCGP Dermatology Training Day, Leeds 11th-12th February** Mandy Aldwin, ISG Trustee, has been invited to attend this event to give a pre dinner speech on the Friday evening to attendees about the ISG and ichthyosis. On the Saturday Mandy will attend the full programme to help raise awareness of ichthyosis and the ISG amongst various GP’s and trainee GP’s.

**Rare Disease Day 28th February 2011 - Get Involved** As part of Rare Disease UK, the ISG would like to encourage you to support this annual day [www.rarediseaseday.org/article/get-involved](http://www.rarediseaseday.org/article/get-involved). To help raise awareness of rare diseases there are many things that can be done to support this event. People affected by rare diseases can act as media case studies or write to their local politician using the template supplied. Individuals, patients, patient organisations, researchers, drug developers, public health authorities, health professionals etc can all get involved and make a difference.

**New ISG Website Soon to be Launched** Finally, the time has nearly arrived to launch the ISG new website. We are aiming to go live with the new website by the end of February so please keep visiting, as there will be lots of new links and information to view [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk).

**Redirection of post to the new PO Box address has expired** Please note our new address is PO Box 1404, Bagshot GU22 2LS. The six month crossover period has now ended and we are unable to further extend the redirection service. Any mail posted to the old address will no longer be forwarded to the new ISG address.

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**Useful Links**

**Easy Fundraising & Easy Search** To help raise money for the ISG register at to shop online with over 2,000 well known retailers [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk). Also go to easy search [www.easysearch.org.uk](http://www.easysearch.org.uk) and select the Ichthyosis Support Group. Both are free to use.


**Ebay For Charity**—Donate a % to the ISG from your online sales [www.ebay.co.uk/ebayforcharity](http://www.ebay.co.uk/ebayforcharity).


**Payroll Giving**—another easy way to donate to charity direct from your pay [www.payrollgiving.co.uk](http://www.payrollgiving.co.uk).
Members and Fundraising

Justgiving ISG Currently we have 14 live justgiving pages:

- Celia Moss - Supporting the ISG www.justgiving.com/Robin-Ferner
- Sharon Beattie - Fundraising for her son Harry www.justgiving.com/Sharon-Beattie/
- Amy Moxham - Poker www.justgiving.com/Mekhi-Barbour-Poker
- Amy Moxham - Speed Dating www.justgiving.com/Mekhi-Barbour-SpeedDating
- Laura Levy - Fundraising for her son Mekhi Barbour www.justgiving.com/Laura-Levy-
- Eggbuckland Community College www.justgiving.com/Eggbuckland-ISG
- Rebecca Jeffery - Buggy Walk www.justgiving.com/baby-Freddie
- David Roberts 2000 Mile cycle Ride www.justgiving.com/Wheresthepoint
- Richard Peet - 30 mile Cycle Ride- www.justgiving.com/Yvonne0
- Emma Picken - Ichthyosis Camp www.justgiving.com/Emma-Picken
- Serena Gibson - General Fundraising http://www.justgiving.com/serena-gibson

Donations & Fundraising

Thank you to the following donors and fundraisers who have all made donations or carried out fundraising events in the last month:

- Ann Hodgkin - Donation made in lieu of sending Christmas Cards.
- Ralph Oldacres - Raising funds by playing music for small local organisations.
- Chipping Hill School - Christmas collection for pupil Lilly Robinson, affected by ichthyosis.
- Charlie Cole - A generous donation.
- The Patricia Ann Buller Charity - A donation towards the organisational costs of the ISG.
- Staff at the George Elliot Hospital Outpatients Department - Donations made in lieu of sending Christmas cards.

The ISG Needs Your Help

British Skin Foundation (BSF) Online Survey has been set up to try to highlight how skin disease affects people not only physically and medically but also to identify the psychological and social impact of skin disease that so often goes unrecognised. Skin disease has a huge impact on a persons life. It may affect relationships, encourage bullying and a lack of social interaction may be apparent. If you are a sufferer of skin disease, or know of anyone who would be interested in taking part in this brief survey, please go to the link www.surveymonkey.com/s/surveyautumn2010

X Linked Study Birmingham - participants wanted! The University of Birmingham and Birmingham Children’s Hospital have jointly set up a research study with boys and men aged from 6 to 30 years, with X-linked recessive ichthyosis (XLI). If you know of any members who fall into this category, and may like to take part, please ask them to contact Dr Jan Idkowiak j.idkowiak@bham.ac.uk

X Linked Study Wales - request for participants Dr William Davies, at Cardiff University, is carrying out a study looking at people in the Cardiff area affected by X-linked ichthyosis - compared to their non affected male siblings. If you know of any members who may be willing to participate, please ask them to contact William Davies daviesw4@cardiff.ac.uk