Last Month

ISG Trustee Conference Call December 5th 2010 The committee were joined by Jenni Robertson, who will lead the project of setting up an ISG Youth Forum, to discuss the progression of the project so far and Yvonne Peet who was formally elected the new Regional Contact Coordinator. Venues for the 2011 ‘ISG Family Conference’ are still being viewed with the hope of a confirmed venue being agreed early into the New Year.

Alliance Pharmaceuticals Paul Whitehouse, ISG Chairman, and Mandy Aldwin, ISG Trustee, met with Peter Butterfield from Alliance last month to discuss the various ways in which the ISG and Alliance can work together in 2011.

Christmas Cards from the ISG As much as we all love to uphold Christmas traditions we felt this year, being a small charity, we should try to conserve the hard earned funds of our members by sending an Email of ‘Christmas Greetings’ rather than undertaking the costly exercise of sending Christmas cards. We hope you all received our Email to wish you all a Merry Christmas and were not disappointed by the lack of a Christmas card this year!

Diary Dates

23rd January Regional contacts meeting, Great Ormond Street Hospital 12-4pm.

27th January Psychodermatology UK Annual General Meeting, London

Forthcoming Events 2011

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!

Training & Courses

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

If anyone would like further details of any of the training or would like to attend, please contact Liz liz@ichthyosis.org.uk. Not all training courses are free and will have to be agreed by the trustees prior to booking.

Happy New Year
Regional Contacts Meeting January 23rd 2011 This annual ISG meeting, to be held this year at Great Ormond Street Hospital, is a great opportunity for the Regional Contacts to meet the Committee and Medical Advisory Board (MAB), Share views and ideas and have a direct impact on how the ISG can help its members. Following the meeting will be an opportunity to socialise and get to know one another a little better at one of the local restaurants.

Specialised Service for Ichthyosis The deadline for submitting an outline proposal for national commissioning for this service was December 2010. Unfortunately the team leading the application, who will be responsible for the running of the service if nationally commissioned, felt there were too many discrepancies at the time of the submission deadline that needed more thought and time put into. As a result the application will be postponed until the next deadline, December 2011 allowing more time to be focused on the finer details of the service. It is very disappointing that the application process will be delayed a year, but, it was felt by all parties involved that better a late application than an unrealistic one. The ISG has also been very supportive of this process and application and will continue to do so during the year ahead.

Romantic Relationships Survey - Centre for Appearance Research (CAR) The ISG supported this survey by posting a link on our website and facebook page. The results have now been collated and a feedback summary is available. If you would like a copy please contact either Liz via email: liz@ichthyosis.org.uk or CAR direct CAR@uwe.ac.uk who will be able to provide a copy of the summary of feedback from the surveys completed.

The Allergy Gene by W.H. Irwin McLean The full article is online at The Scientist, Magazine of the Life Sciences http://www.the-scientist.com/article/display/57833/ This article is very interesting to read and it does refer to the identification of the Ichthyosis Vulgaris gene in 2005. The article is discussing how a mutation in a skin protein revealed a link between asthma and eczema and the question of preventing genetic related allergies, common in Ichthyosis Vulgaris and Netherton’s syndrome as well as some other forms of ichthyosis, is quite relevant and interesting.

New ISG Website Soon to be Launched Mike Davies, member of the ISG and father of an affected adult, has been assisting the ISG to set up and re design the website. Although this is taking time, progress is being made and soon our new look website www.ichthyosis.org.uk will go live. Please keep visiting the site and soon you may see some changes.

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.

Useful Links

Easy Fundraising & Easy Search To help raise money for the ISG register at http://www.easyfundraising.org.uk to shop online with over 2000 well known retailers. Also go to http://www.easysearch.org.uk search engine and select the Ichthyosis Support Group. Both are free to use.

Facebook Remember to help raise awareness, publicise events and meet new members by registering with and using the ISG facebook http://en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info

Ebay for charity—donate a % to the ISG from your online sales.

Give as you earn—Why not complete the following form and donate straight from your wages http://www.cafonline.org/pdf/GAYE_0971B_DIF_180609.pdf.
Members and Fundraising

Justgiving Currently we have 13 live justgiving pages:

- [http://www.justgiving.com/Mekhi-Barbour-Poker](http://www.justgiving.com/Mekhi-Barbour-Poker) Amy Moxham
- [http://www.justgiving.com/Mekhi-Barbour-SpeedDating](http://www.justgiving.com/Mekhi-Barbour-SpeedDating) Amy Moxham
- [http://www.justgiving.com/Yvonne](http://www.justgiving.com/Yvonne) Richard Peet — 30 mile cycle ride during Ichthyosis Awareness Week
- [http://www.justgiving.com/Emma-Picken](http://www.justgiving.com/Emma-Picken) Emma Picken — Ichthyosis Camp
- [http://www.justgiving.com/Maggie-Aldwin](http://www.justgiving.com/Maggie-Aldwin) Maggie Aldwin — Leila’s 6km walk 17th August 2010

Donations & Fundraising

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

- Peter Casasola, brother-in-law to ISG Chairman Paul Whitehouse, who completed the Great Midlands Fun Run.
- Yvonne and Angie Barry who decided not to send Christmas cards last year but donate the money they would have spent to the ISG.
- Barclays Coventry Contact Centre for holding a samosa sale and raffle and donating the proceeds to the ISG.

The ISG Needs Your Help

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

What Matters to Patients Project
A study, commissioned by the Department of Health and the NHS Institute for Innovation & Improvement, aims to strengthen the evidence base for understanding and improving patient experience. The study is being conducted, over a nine-month period, by researchers from the National Nursing Research Unit, King’s College, London and the Point of Care Programme at The King’s Fund. For more information, or to take part in this survey, please contact Dr Glenn Robert glenn.robert@kcl.ac.uk or Jocelyn Cornwell j.cornwell@kingsfund.org.uk This Project finishes January 2011