November 2010

ISG E Bulletin

Last Month

Jeans For Genes Day 1st October 2010  Two ISG Families were involved with the ‘Jeans For Genes’ campaign by telling their stories through various media stories, highlighting both ichthyosis and the Ichthyosis Support Group. Well done to the Whitehouse and the Ahmed families.

Genetic Alliance AGM October 19th  Maggie Aldwin, ISG Trustee & Liz Dale, ISG Administrator, attended with particular interest to the agenda point ‘Patient Support Groups Experience of Gaining NCG Funding’. Whilst at the meeting we were able to seek some good advice from Dr Colin Steward and Michaela Damin from the ‘Bath Syndrome Trust’ who have recently been awarded funding for a specialist clinical service from the National Specialised Services Team (NSS), formerly the NCG—National Commissioning Group. Josie Godfrey, from the NSS, also gave a very informative presentation and gave a brief insight into how the government ‘cuts’ may affect the process of obtaining funding for specialised services.

European Translational Research On Ichthyosis (ENTRI) on the 29th October  Geske Wher attended representing the eni at the meeting with the steering committee of ENTRI in Cologne. Details to follow.

Dermatology Clinical Assistants Meeting, 30th October in Nottingham, sponsored by Galderma  Ray Rowley, ISG Vice Chairman and Jayne Woodward, ISG Regional contact for the East Midlands attended this event making a short presentation to attendees, which included GP’s. Ray and Jayne were able to network and share information with attendees whilst manning the ISG stand. Following the Meeting Ray and Jayne were invited to stay for the formal dinner. www.medsense.co.uk/cam2010reg.php

MAB Conference call 27th October to discuss the next conference which is likely to be in London the weekend of the 18th and 19th June 2011.

Diary Dates

ISG Trustee Meeting Sunday 7th November  
Synter High Wycombe 12 pm

British Society for Paediatric Dermatology (BSPD) AGM 11th and 12th November, Cardiff
www.bspd.org/index.html

British Association of Dermatologists (BAD) Patient Support Group Meeting 11th November  
12 pm at BAD House  
4 Fitzroy Square, London, W1T 5HQ

Forthcoming Events

British Society for Paediatric Dermatology meeting in Cardiff on 11th November  
Mandy Aldwin, ISG Trustee and Gill and Theresa Davis, ISG Regional contacts for Wales and Gloucester, will be taking the ISG stand and information to help raise awareness amongst health professionals.

Delivering quality care for people with rare and complex conditions 16th November 2010 - Liz attending  
This conference in London, hosted by the Specialised Healthcare Alliance (SHCA) is aimed at a multidisciplinary audience and seeks to deliver tangible progress towards core quality standards for specialised services covering issues like diagnosis, treatment, care, commissioning and outcomes. http://www.shca.info/index.htm

eni Board of Directors Meeting 19th November, Cologne, will be attended by our very own Trustee, and President of the eni, Maggie Aldwin

Europlan UK Conference 16th November Manchester  

Training & Courses

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

If anyone would like further details for 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.
Specialised Service for Ichthyosis Professor Edel O’Toole has agreed to take the lead and move forward with submitting an outline proposal (stage 1 of the application process) to the NSS for funding into a specialised service for ichthyosis this December. It is a difficult process and may be harder to obtain funding with the new government reforms however, we are confident there is a real need for this service which will provide a holistic approach to the treatment and care of patients with ichthyosis.

Pride of Northamptonshire Award [http://www.northantset.co.uk/news/Pride-nomination-for-my-brave.6397225.jp](http://www.northantset.co.uk/news/Pride-nomination-for-my-brave.6397225.jp) Becky Jeffery, member, was nominated for her fundraising for the ISG, by organising the ‘buggy walk’ which has raised over £8,000. Becky attended the Pride in Northamptonshire Awards on Friday the 1st October and was awarded ‘Runner up’ out of the final six. Well done Becky!

Vodafone World Of Difference UK Programme Vodafone are currently looking for people to donate themselves to their local communities for a two month placement in a chosen charity whereby Vodafone will pay their wages. The placements start in March 2011 and the deadline for applicants is 23rd November 2010. For more information visit [http://worldofdifference.vodafone.co.uk/default.aspx](http://worldofdifference.vodafone.co.uk/default.aspx) If you know of anyone who may be interested please ask them to contact Liz on 0845 602 9202 or liz@ichthyosis.org.uk.

ISG in the Media The Whitehouse family were filmed on the 16th October by NBC for the Today show in the US. NBC sent a reporter from the USA, who went along with a cameraman and producer, who came up from London to spend the day with the family and filmed them at Annabelle’s ballet lesson, out horse riding and at home. The Whitehouse family will also appear on the This Morning Show on the 16th November 2010.


ISG National Conference, London Following discussion and the availability of Trustees and MAB it is likely that the next ISG National conference will be the weekend of the 18th & 19th June. In October, Maggie Aldwin, ISG Trustee and Liz Dale, ISG Administrator, visited the Museum of London and Docklands Museum, to look at their suitability as a venue for the conference. Both were great places to hold the next conference, a little different from previous years, and a fun environment for the kids!

ISG Youth Forum At the next trustee meeting on 7th November we’ve invited Jenni Robertson, ISG Member, and her teenage daughter Lauren to join us for a discussion on the setting up of an ISG ‘Youth Forum’. Jenni works for ASDAN, a development organisation and internationally recognised awarding body, that offers awards and qualifications in volunteering [http://www.asdan.org.uk/Award_Programmes/Volunteering_SC](http://www.asdan.org.uk/Award_Programmes/Volunteering_SC).

New ISG Website Soon to be Launched Progress is being made and soon our new look website [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk) will go live. Please keep visiting the site and soon you may see some changes.

PO Box address has changed Please note our new address is PO Box 1404, Bagshot GU22 2LS. Please be aware the literature you have may have the old address on it. There will be a six month crossover period where mail will be redirected, which expires at the end of December 2010.

Useful Links

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


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](http://www.cafonline.org/pdf/GAYE_0971B_DIF_180609.pdf).
Members and Fundraising

Justgiving Currently we have 11 live justgiving pages:

- Rebecca Jeffery — Buggy Walk 19th June 2010
- David Roberts — 2000 mile cycle ride during May 2010
- Rebecca Towers — Sky Dive 17th September 2010
- Richard Peet — 30 mile cycle ride during Ichthyosis Awareness Week
- Matt Jeffries — Nethertons 10K Walk
- Matt Jeffries — Nethertons Research Group
- Matt Jeffries — Nethertons Research Group Sky Dive
- Emma Picken — Ichthyosis Camp
- Maggie Aldwin — Leila’s 6km walk 17th August 2010
- Emma Phipps — Parachute Jump 20th October 2010
- Serena Gibson — General fundraising

Donations & Fundraising

Thank you to the following donations and fundraisers from last month:

Kerry Robinson, a friend of the ISG family Pollard, who raised a staggering £1,105.00 through Colart Fine Arts by selling off excess stock and running raffles.

Thank you to:

Ralph Oldacres
Lloyds TSB and Steve Potkins
Janette King and Pampered Chef

Who have all made donations or carried out fundraising events last month

The ISG Needs Your Help

Media volunteers needed! Launch of RDUK publication: "Experiences of Rare Diseases: An insight from patients and families" To accompany the launch RDUK is hoping to get media coverage to raise awareness of rare diseases and some of the issues faced by patients and families, such as: accessing a correct and timely diagnosis, the availability of information about the condition, accessing the range of support needed, accessing treatment coordination of care, the availability of information and the ability to participate in research.

If you, or anyone you know, is interested in raising awareness of the need to create a strategy for rare diseases please download and complete the form Download the form (Word doc.) and return it to stephen@raredisease.org.uk at RDUK. Please note – anyone submitting this form must be happy to be interviewed by the media and the possible publication of their story appearing in the press.

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