ISG Funday at Thorpe Park 19th September went well with a fantastic turnout of around 37 families, amounting to 116 adults and 38 children, along with three pharmaceutical representatives from Galderma and a children’s entertainer.

At 09.30 families started to arrive and register at Lake View, situated within Thorpe Park. Keen to get out on the rides, people said a quick hello and went off for the morning. By 12.30, hungry families began to arrive back at Lake View for a well earned lunch and social interaction with other families. After lunch, the ISG AGM took place and most stayed for this opportunity to learn more about what the ISG can do for its members but some could not wait to get back out there and soak up the thrill of the rides. By 17.30 people (some very wet from the rides!) started to leave the park and returned back to Lake View to say their goodbyes. Feedback from some of those who attended on the day is very positive stating - a fantastic time was had.

DVD Filming Underway Rob Walters attended the Funday at Thorpe Park to begin filming for the ISG Educational DVD. Rob introduced himself to families as they arrived, informing them he would be filming and seeking willing participants. Many people were keen to be involved and throughout the day Rob kept appearing from nowhere to capture the moments of the day.

Rebecca Towers Sky Dive 17th September Rebecca jumped from an aeroplane to help raise awareness of ichthyosis and much needed funds for the ISG. Rebecca’s daughter, Reanna, has Lamellar ichthyosis and lost an eye to this condition 4 years ago. Rebecca has raised nearly £400 for the ISG by completing her ‘Sky Dive’. Well done Rebecca!

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Training & Courses

www.cafonline.org/charitytraining


www.theclarefoundation.org/training.php

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.
Ichthyosis in the media  The ISG has been supporting this year’s J4G campaign and a few of our members have appeared in the media this week. Please see links below.
www.jeansforgenesday.com/register/check2.aspx

Paul Whitehouse, ISG Chairman, and family have been in various papers and online this week, as well as being invited to appear on BBC West Midlands on the 1st of October.
http://www.daily-mail.co.uk/health/article-1315396/Girl-5-rare-condition-sheds-skin-day.html
http://www.metro.co.uk/news/842128-5yr-old-dancer-whose-skin-falls-off-14-times-a-day

The Ahmed family from Leeds has also appeared in the spotlight this week supporting the J4G Campaign
http://www.yorkshireeveningpost.co.uk/news/Leeds-tot39s-rare-skin-torment.6549784.jp

Pride of Northamptonshire Award  http://www.northantset.co.uk/news/Pride-nomination-for-my-brave.6397225.jp
Becky Jeffery, member, was nominated for fundraising for the ISG, by organising the ‘buggy walk’ which has raised over £8,000. Becky is through to the final six for the Pride in Northamptonshire Awards and will be attending the awards on Friday the 1st October

European Translational Research On Ichthyosis (ENTRI) on the 29th October Geske Wher will be representing the eni at a meeting with the steering committee of ENTRI in Cologne.

Dermatology Clinical Assistants Meeting, 30th October in Nottingham, www.medsense.co.uk/cam2010reg.php. ISG Vice Chairman, Ray Rowley and ISG Regional Contact for East Midlands, Jayne Woodward, will be attending on behalf of the ISG to give a talk and be available with information to distribute.

eni Board of Directors Meeting on the 19th November, Cologne, will be attended by our very own Trustee, and President of the eni, Maggie Aldwin. This was previously scheduled to coincide with the ENTRI meeting on the 29th October but had to be postponed until November.

New ISG Website Soon to be Launched  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.

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 until 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 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:

- Rebecca Jeffery — Buggy Walk 19th June 2010
- Ellamay Dale — Buggy Walk 19th June 2010
- David Roberts — 2000 mile cycle ride during May 2010
- Rebecca Towers — Sky Dive 17th September 2010
- John Dale — 30 mile cycle ride during Ichthyosis Awareness Week
- 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

Donations & Fundraising

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

- Edel Kenny presented a cheque for £8,205 at the Thorpe Park Funday which was the result of all her fundraising in the last 12 months.
- Sophie Newman, Regional Contact for the South raised £543.88 at the Beach Soccer event in August.
- The final figure for the Buggy walk, organised by Becky Jeffery, is just over £8,000.

Thank you to:

Normanby Methodist Wives Club
Mr R Oldacres
Tim O’Sullivan
The Oldacres family

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

The ISG Needs Your Help

Recommendations to Develop a Strategy for Rare Diseases For the past year, Rare Disease UK, with the guidance of its five working groups, has been working on a report looking at developing recommendations on what should be included in a strategy for rare diseases. The final report will be launched at four parliamentary receptions to coincide with ‘Rare Disease Day 2011’ (February 28th 2011). Rare Disease UK is asking for feedback on its findings and your evidence to inform the final report. For more information or to give your views, please visit: www.raredisease.org.uk/documents/consultation_rduk.pdf

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 may like to take part, and fall into this category, 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 please ask them to contact William 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