Last Month

**ISG Trustee meeting 8th August**  Members of the committee were joined by Mike Davies, ISG member, who is currently developing the new ISG website. Mike presented the group with the work he had done on the website so far and all agreed the ‘new look’ website was fantastic. Hopefully soon it will go live.

**Isle of Wight Beach Soccer 15th August**  An annual charity event supporting the ISG run by the husband of one of our members living in the Isle of Wight. Sophie Newman, regional contact for the South East, hosted this charity event on a sunny Appley beach one Sunday during August. The event was attended by 6 ISG families who all came to support the teams playing for the ‘Ichthyosis Charity Cup’. After many games between the 8 teams the ‘Jersey’ team won the battle of the sands 4v3. Mandy Aldwin, ISG Trustee, and Lauren, Sophie’s daughter, presented the winning team with the Cup www.iwbsa.com/events.php?EID=33.

**Charity Walk around Dinton Pastures on the 17th August**  Leila, aged 15 yrs and a cousin of Mandy Aldwin, ISG Trustee, and her friends completed the 6 km walk in Woodley near Reading. Leila wanted to do something for her cousin’s charity this year so she organised a group of friends to do a charity walk for the ISG .  www.justgiving.com/Maggie-Aldwin

**Route Maps for Rare Conditions**  Genetic Alliance UK is starting an exciting new project called Route Maps for Rare Conditions, funded by the Department of Health in England for the next three years. The pilot project will work with eight member groups of Genetic Alliance UK to develop Route Maps for their condition. The process will be facilitated by a Genetic Alliance UK Project Manager, Jessica Burke. A toolkit and written methodology that user-led groups can use to develop their own Route Maps for their condition will be one of the key outcomes of the project. The ISG applied to participate in this project but unfortunately the application was unsuccessful. However, as a result of the project a toolkit will be developed to enable support groups to develop their own Route Map.

Diary Dates

**Rare Disease UK AGM 13th September**  will take place at 09.30 in Central London (venue to be confirmed)

**Dermatology Clinical Assistants Meeting, 30th October**  in Nottingham, ISG attendees needed to give a talk, raise awareness and man the ISG stand. www.medsense.co.uk/cam2010reg.php

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

Forthcoming Events

**Changing Faces 11th September**  Explore Space Day, Glasgow 11.00 am. For more information visit www.changingfaces.org.uk or e mail michelleb@changingfaces.org.uk

**Rebecca Towers Sky Dive 17th September**  Motivated by her daughter, who has Lamellar Ichthyosis, Rebecca will leap from an aeroplane to help raise awareness of ichthyosis and much needed funds for the ISG www.justgiving.com/Rebecca-Towers

**ISG Funday Thorpe Park 19th September** This year the ISG is hosting a Funday for all its members. Please forward details of this event to any new families with Ichthyosis. For more information please contact Liz liz@ichthyosis.org.uk

**Pride of Northamptonshire Award**  http://www.northantsft.co.uk/news/Pride-nomination-for-my-brave.6397225.jp

Becky Jeffery, member, has been nominated for fundraising for the ISG, by organising the ‘buggy walk’ over the last few months.

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.
European Translational Research On Ichthyosis (ENTRI) on the 29th October  
Our very own Trustee, and President of the eni, Maggie Aldwin will be travelling to Cologne for an eni board of directors meeting. Maggie will also be attending a meeting with the steering committee of ENTRI whilst in Cologne.

Rare Disease UK  
The Patient And Client Council is a powerful, independent voice for patients, clients, carers, and communities on health and social care issues. The Council will be doing a project on rare diseases in Belfast. They are meeting with different charities and organisations in Northern Ireland to see how individuals and families are affected by rare diseases and what kind of support they are currently receiving. The ISG has asked our Irish members to try to get involved.

GliaxsoSmithKline IMPACT Awards  
The IMPACT Awards have been running since 1997 and are designed to recognise and reward charities that are doing excellent work to improve people’s health. They are funded by GlaxoSmithKline and managed in partnership with The King’s Fund. The awards are open to registered charities that are at least three years old, working in a health-related field in the UK, with a total annual income between £10,000 and £1.5 million. The ISG has decided to apply for this award and the application will be submitted at the beginning of September.

The Royal College of Physicians (RCP) London holds an annual public open day for members of the public to find out more about what physicians do, how they are trained and the role of the College. (Saturday 18th September, 11am - 4pm, FREE ADMISSION) The BAD has been invited to have a stall there which will display ISG literature and merchandise.

National Institute for Clinical Excellence (NICE) - 
The ISG will be working with NICE following a workshop invitation to attend the Third Sector Engagement with NICE on the 22nd September. The workshop will address issues that arise from how NICE engages with national charities and voluntary organisations.

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 6 month crossover period where mail will be redirected until the end of December 2010.

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.

Pharmaceutical Companies 
Crawford Healthcare Ltd and Beiersdorf have each pledged some money towards the ISG Funday at Thorpe Park on the 19th September 2010. Crawford Healthcare Ltd has donated £250 and Beiersdorf £100. Thank you to both for their donation.

DVD for Ichthyosis Awareness  
The ISG is in the process of creating a DVD for educational and awareness raising purposes. Filming is soon to begin and will also take place at this year’s ISG Funday at Thorpe Park on the 19th September.

ISG Newsletter Summer 2010 was distributed at the end of July. It included a Thorpe Park Funday Invite. If anyone would like a copy of the Newsletter please contact Liz on 0845 602 9202 or liz@ichthyosis.org.uk

The ISG Needs Your Help

TV Documentary, request for people to participate  
For more information please contact hannah.runham@mentorn.com or visit http://www.mentorn.tv

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
Members and Fundraising

Justgiving Currently we have 11 live justgiving pages:

- Rebecca Jeffery — Buggy Walk 19th June 2010 — Raised so far £4,498.82
- Ellamay Dale — Buggy walk 19th June 2010 — Raised so far £165.00
- David Roberts — 2000 mile cycle ride during May 2010 — Raised so far £1,350.00
- Rebecca Towers — Sky Dive 17th September 2010 — Raised so far £175.00
- John Dale — 30 mile cycle ride during Ichthyosis Awareness Week — Raised so far £85.00
- Richard Peet — 30 mile cycle ride during Ichthyosis Awareness Week — Raised so far £35.00
- Matt Jeffries — Nethertons 10K walk — Raised so far £940.00
- Matt Jeffries — Nethertons Research Group — Raised so far £126.00
- Matt Jeffries — Nethertons Research Group Sky Dive — Raised so far £240.00
- Emma Picken — Ichthyosis Camp — Raised so far £0.00
- Maggie Aldwin — Leila's 6km walk 17th August — Raised so far £249.00

Donations & Fundraising

- Mr Colin Taylor, member, donated £25.00 towards the cost of newsletter distribution.
- Annette Hobbs, Friend of the Sullivan family, sent in a cheque for £70.00 raised at work by eating cakes made by another member of staff.
- Danny Oldacres, member, sent in a cheque for £150.00 raised at Nuneaton Carnival to go towards research into Netherton Syndrome.
- The Pollard family sent in 2 cheques donated by work colleagues. £100.00 was donated out of the winnings of Mr Langeroodi who won the works Lottery. £170.00 was donated by B/E Aerospace Sports and Social Club, which held a fundraising event.
- Ellamay Dale collected the rest of her ‘Buggy Walk' sponsorship money and sent in £80 to add to the £165.00 she raised on Justgiving.
- Becky Jeffery sent in another cheque for £20.00 in collected sponsorship money for the ‘Buggy Walk'.
- Joe Wilkinson, whose daughter has ichthyosis, sent in a cheque for £210.00 raised in memory of her late uncle who passed away in June this year.

A further sum of £615.00 has also been raised from Funday Registrations so far. This money will help towards the costs of this year’s Funday event.

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.