August 2010

ISG E BULLETIN

Issue 3 August 1st 2010

Last Month

British Association of Dermatologists Conference (BAD) Birmingham was held over 3 days, 6th-8th July. Mandy Aldwin and Clive Bowen (ISG Trustees) attended on behalf of the ISG. Clive Bowen has been attending the conference for the past 10 years and Mandy has joined him for the past 3. It’s the biggest annual dermatology meeting in the UK and continues to be a fantastic opportunity to raise awareness of ichthyosis and the ISG amongst healthcare professionals and the pharmaceutical industry.

Council of European Rare Disease Federations Geske Wehr, from Germany, currently managing the European Network for Ichthyosis eni@ittiosi.it (eni), attended the 3rd Workshop in Paris on 1st & 2nd July representing eni www.ichthyose.eu. Details to follow.

Clinical Service for Ichthyosis Mandy Aldwin and Liz Dale, along with Prof Edel O’Toole (MAB), Dr David Paige (MAB) and Prof David Kelsel, met with Dr Martin Ashton-Key, medical advisor for the National Commissioning Group (NCG), on the 16th July. They discussed submitting an application hopefully to obtain funding into a specialist clinical service for ichthyosis sufferers. This meeting was very positive and we should be progressing with an application in the near future.

Funding and Grants for the ISG Liz (ISG Administrator), Mandy and Maggie Aldwin (Trustees) met with Ros Taylor, a fundraising consultant last month to discuss possibly contracting her professional help. Ros will hopefully be able to provide us with the knowledge and skills to successfully apply for funding and grants.

Incorporation of the ISG The process for incorporating the ISG has begun and Rex Codling (ISG Treasurer) met with Paul Whitehouse (ISG Chairman) and Maggie Aldwin (Trustee) in Sutton Coldfield on the 21st July to discuss the new governing document.

Diary Dates

ISG Trustee meeting 8th August BMW Sytner, High Wycombe 12—4pm. Members of the committee will also be joined by Mike Davies (member) who is currently developing the new ISG website and Andy Corbett (husband to the ISG’s secretary Sue Corbett).

Dermatology Clinical Assistants Meeting, 30th October 2010 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

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. http://www.iwbsa.com/events.php?EID=33

Changing Faces 11th September Explore Space Day, Glasgow 11.00 am. Aimed at children and adults who have a condition affecting their appearance. The day will focus on confidence building, other people’s reactions, meeting others and having fun. For more information visit www.changingfaces.org.uk or e mail michelleb@changingfaces.org.uk

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

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.
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.

New Regional Contacts We have a new Regional Contact on board. Tammy Smith will take on the role of Regional Contact for the North East.

ENI based in Germany Geske Wehr, representing the eni www.ichthyose.eu, attended a European Translational Research on Ichthyosis (ENTRI) meeting in Maastricht at the beginning of June. Details of this to follow soon.

Medical Devices Company Mölnlycke Health Care Ltd are continuing to work closely with the ISG and have sponsored our latest newsletter, distributed at the end of July. The ISG will also be featured in their next internal newsletter.

Pride of Northamptonshire Award http://www.northantset.co.uk/news/Pride-nomination-for-my-brave.6397225.jp Becky Jeffery, member, will find out in September if her nomination for this award has been successful. She has been nominated for fundraising for the ISG, by organising the ‘buggy walk’ over the last few months

In the Media Nusrit Shaheen, a 26 year old lady with Harlequin Ichthyosis, from Coventry, is talking to Mentorn Media about appearing on a Channel 4 programme. Mentorn produced the documentary called ‘Katie: My Beautiful Face’ for Channel 4 which told the story of Katie Piper, a former model and television presenter who was a victim of an acid attack in March 2008.

Pharmaceutical Companies Galderma and Alliance Pharma have each pledged £250 towards the ISG Funday at Thorpe Park on the 19th September 2010. Thank you to both for their donation.

Retail Store New Look has agreed to loan some clothes for ISG fashion shows. A couple of teenagers from member families are interested in fundraising for the ISG. The idea of hosting various fashion shows could be a great way of raising awareness for ichthyosis. If you know anyone who may be interested in organising or taking part in such an event please contact Maggie Aldwin maggie@ichthyosis.org.uk

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 years event, the ISG Funday at Thorpe Park on the 19th September 2010.

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 £3,184.82
- Ellamay Dale — Buggy walk 19th June 2010 — Raised so far £165.00
- David Roberts — 2000 mile cycle ride during May 2010 — Raised so far £1,340.00
- Rebecca Towers — Sky Dive 17th September 2010 — Raised so far £140.00
- John Dale — 30 mile cycle ride during Ichthyosis Awareness Week — Raised so far £85.00
- Melanie Bradley — Walk for Skin 23rd May — Raised so far £40.00
- Richard Peet — 30 mile cycle ride during Ichthyosis Awareness Week — Raised so far £35.00
- Matt Jeffries — Nethertons 10K walk — Raised so far £392.00
- Matt Jeffries — Nethertons Research Group — Raised so far £76.00
- Matt Jeffries — Nethertons Research Group Sky Dive — Raised so far £230.00
- Emma Picken — Ichthyosis Camp — Raised so far £0.00

Donations & Fundraising

- Royal British Legion Norbury sent in a cheque for £205.00 from fundraising at the club by Del Thorne.
- Gill and Theresa Davis sent in a cheque for £500.00 raised by creating their own fundraising walk in Wales.
- A cheque was received on behalf of Paul Anderson who shaved his head for charity in March to support the ISG.
- Isle of Wight Beach Soccer on behalf of Sophie Newman (I.O.W Regional Contact) sent in a cheque for £105.00 raised at the Ichthyosis awareness week coffee morning in Ryde, Isle of Wight.
- Ratcliffe’s Charitable Trust and Hevey Building supplies sent in cheques for £250.00 and £50.00, respectively, for money raised for the Buggy Walk, organised by Rebecca Jeffery.
- Lydia Whitehouse and Darci Holcroft, both aged 8 yrs, decided they wanted to try and raise money for the ISG. Their school, Moor Hall Primary School in Four Oaks Sutton Coldfield, supported their efforts. They collected a big jar of sweets and the school children were invited to try a guess of how many sweets where in the jar, for 50p a go. They raised the grand sum of £37.24 (one little boy had spent most of his pocket money so the girls felt sorry for him and gave him a discount!). They were very pleased with their efforts and so was Amy Willetts who won the sweets!
- Geoff Holmes’ department at Stiefel Laboratories Inc had been collecting unused foreign currency which converted £166.58. Geoff presented the cash to Mandy Aldwin (Trustee) as a donation for the ISG at the BAD conference.
- Dave Roberts presented Mandy Aldwin (Trustee) with cheques amounting to £1080 which was in addition to £260 raised through Justgiving for his 2000 plus miles sponsored cycle ride around the UK.
- A family friend of the Bowen’s (ISG members), Sue Hall, raised £200 doing a 10k BUPA run on 31st March 2010.
- Trustee Clive Bowen’s Dad donated £50, payment for a job he did for a friend.
- Shelly Batt (ISG founder Trustee and Secretary of the ISG for a number of years) donated £107 which was raised in memoriam of her grandmother. She also emptied her grandmother’s collection box and sent in £27.32.
- Mandy Aldwin’s cousin is organising her own fundraising walk in August and hopes to have recruited about 20 walkers. Details to follow.

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.