Last Month

BDNG Paediatric Dermatology Nurses Meeting Liverpool. ISG Trustee, Mandy Aldwin, attended this meeting giving a presentation on Nethertons Syndrome on behalf of the ISG. Attendance at such meetings and training days offers the opportunity for nurses to learn first hand what it’s like living with ichthyosis, raising the profile of the condition and of the ISG. For more information visit: www.bdng.org.uk/

Ichthyosis Support Group Beach Soccer Charity Cup Once again the ‘Isle of Wight Beach Soccer Association’ (IWBSA) supported the ISG by holding a charity cup event on Appley Beach, Ryde, Isle of Wight. ISG member and Regional Contact, Sophie Newman, supported this event in aid of ichthyosis www.iwbsa.com/news.html#name139 where the ‘Wight Stripes’ won the cup and brought the beach soccer season to an end.

ISG Attends the All Party Parliamentary Group on Skin (APPGS) Expert Group Meeting
ISG Trustee, Mandy Aldwin, joined an expert group to take part in reviewing and discussing the report from the 2003 ‘Enquiry Into The Impact Of Skin Diseases On People’s Lives’. The expert group consisted of patient organisation representatives, dermatology consultants, a dermatology nurse and other parties with an interest in the psychological wellbeing of dermatology patients. The group will work to establish if improvements have been made in how the psychological effects of skin disease are monitored, treated and viewed. A new report will be produced and an oral hearing will be held in the House of Commons.

Annual Ladies Night at the Liverpool One Bridewell Pub ISG Member, Faye Calvey, recommended the ISG as the chosen charity for this year’s event at her local pub in Liverpool. Supported by the ISG, a fun night was had by all, both raising awareness of ichthyosis and a staggering £1,300 for the Ichthyosis Support Group.

ISG Members

Last month the ISG welcomed 18 new members.

As a support group the ISG welcomes your views, comments and suggestions!

• Is the ISG meeting your expectations?
• Is there anything else we could be doing?
• Do you have any suggestions on how we can improve our services?

Contact the ISG: isg@ichthyosis.org.uk

Forthcoming Events

Coming Soon -
The ISG Christmas Online Shop
Please keep checking out our online shop for new seasonal merchandise
www.ichthyosis.org.uk/shop/

French Support Group for ichthyosis -
General Assembly 29th & 30th September
www.anips.net

European Network for Ichthyosis (eni) -
Board Meeting, London, October (not for public)
www.ichthyose.eu
Social and Psychological Affects of Skin Diseases We are pleased to announce that the All Party Parliamentary Group on Skin (APPGS) has launched its inquiry into the social and psychological effects of skin diseases. As part of the review of the 2003 Enquiry Into The Impact Of Skin Diseases On People’s Lives, the APPGS has issued a call for evidence to compare the responses to those received in 2003. The aim is to find out if there have been improvements in the acknowledgement and management of the psychological effect of skin diseases. As part of this evidence, they are encouraging patients, families and health professionals to complete a short questionnaire and are accepting submissions until Friday 19th October.

Download the questionnaires here:

Patients: www.appgs.co.uk/wp-content/uploads/2012/09/WrittenCallForEvidencePatients.doc
Professionals: www.appgs.co.uk/wp-content/uploads/2012/09/WrittenCallForEvidenceHealthProfessionals.doc

Please send completed questionnaires to: mark.johnson@appgs.co.uk visit www.appgs.co.uk/newsarticles/

Genetic Conditions and Insurance Genetic Alliance UK has published the booklet ‘Genetics and Insurance: what you need to know, what you need to tell’ available here: www.geneticalliance.org.uk/docs/genetics-and-insurance.pdf to help people access appropriate or affordable insurance. The booklet covers - Life Insurance, Income Protection Insurance and Critical Illness Insurance. Insurance can often be a problem for people with medical conditions, and this booklet may help to answer questions relating to obtaining the right insurance for you.

Changing Faces - ‘Look at Me’ Campaign We recently asked you to take part in a short survey on behalf of the Look at Me campaign in relation to skin conditions. Changing Faces is gathering evidence and support for the identified need that people with skin diseases should receive high quality information and appropriate psycho-social care. Changing Faces has recently published their Look at Me Preliminary Report 2012 and the full report will be available in 2013. To view the report please visit: www.ichthyosis.org.uk/changing-faces-look-at-me-campaign/ where you will be able to download the full report.

Benefits and Financial Advice for Families In light of recent government changes, we are increasingly hearing from families being directly affected by benefit cuts. For many this is sudden and is having a dramatic effect on how they care for their child(ren) with ichthyosis. Contact a Family has recently published the following document that may help families in need of benefit and financial advice www.cafamily.org.uk/media/447565/benefitscurrentlastupdatedaugust2012.pdf.

Your Ichthyosis Support Group

Your experiences of living with ichthyosis - My story
We have learnt from our members over the years that hearing other people's experiences of living with ichthyosis really does help, particularly for new parents entering the unknown. www.ichthyosis.org.uk/category/my-story/ If you would like to share ‘your story’ please email us isg@ichthyosis.org.uk

Get Involved
Do you have a particular skill or area of expertise that may help the ISG and its members? If so please let us know and we would welcome any ideas you may have. Please call us on 0845 602 9202 or email: isg@ichthyosis.org.uk
Psychological Effects of Living with Ichthyosis

YP Face it - aged 13 to 17 years? Worried about ichthyosis and the way you look?
The Centre for Appearance Research, University of the West of England and the Ichthyosis Support Group have teamed up and are looking for young people to test out in their own homes, a new 7 week online support programme. Called ‘YP Face It’, it’s for young people who have worries because of a condition that affects appearance. It has 7 weekly sessions and uses interactive and learning activities, illustrations, videos, audio, photos and advice from other young people with a condition that affects appearance. The aim is to help young people feel and act more positively and confidently. If you’re interested in finding out more about this study, please contact the researcher Catrin Griffiths on Tel: 0117 328 3947 or email catrin.griffiths@uwe.ac.uk

Fundraising

Thank you to those who have made donations or carried out fundraising events recently:

• Karl Gates • Mary Kneafsey • Edel Kenny • H5 Club • Mr & Mrs West • Normanby Methodist Wives Club

Without government funding you are the main reason the ISG exists.
Without your hard work the ISG would struggle to support those affected by ichthyosis.
Without you we would not be able to support ongoing medical research.

Remember every penny counts, no matter how small.

7:30pm Wednesday 3rd October

The Ichthyosis Support Group (ISG) is registered and would like to invite you to take part!
So why not invite your friends, family and colleagues to join your team and play helping to raise money for the ISG from the comfort of your own home?

Each team will pay a £10 registration fee to the Big Give and a £10 participation fee for each team member. Every supporter who takes part will then receive a £10 voucher to donate to the Ichthyosis Support Group (ISG) meaning 100% of each supporter’s participation fee goes to the ISG! The winning team will receive a further £250 voucher to give to the ISG, and, in addition to all of this, the winning team will also pick up a £250 cash prize! Register now!

www.thebiggive.org.uk/

Research

Despite the rarity of ichthyosis and the lack of funding, the ISG is aware of current research into the condition in the UK and is indeed about to award some funding towards this research (details to follow). Some of the current studies include:

• Bullous (EHK) • Harlequin • KID Syndrome • X - linked • Psychological impact of ichthyosis • Vulgaris

For information and details about research, please visit our website: www.ichthyosis.org.uk/category/research/