Chairman’s Message

Dear Member,

As we enter the festive season and our thoughts focus on all things Christmas, I would like to reflect for a moment on all the good work carried out by the ISG throughout 2016 and take this opportunity to extend my thanks to my fellow trustees and Liz Dale our administrator for all their hard work and commitment during the past year.

Next year has special significance for the ISG as we look forward to celebrating our 20th anniversary. To mark this occasion and for our 2017 Family Conference we will be returning to London where the ISG was conceived and we look forward to seeing you there.

A very important initiative for the ISG in 2017 is that of fundraising. As you will be aware the ISG does not receive any income other than that it generates for itself, either through grant applications or from the efforts of a small number of members. Trustees do not receive any remuneration for what they do beyond reasonable expenses.

In this celebratory year we would like to set a challenge to all our members and initiate a fundraising campaign to raise as much money as we can to fill our coffers in order to support our research aims and objectives.

We will be sending you a monthly fundraising update throughout 2017 suggesting ideas you may wish to try and stories from those members who have taken on the challenge.

Continued...
To get this kick started we are suggesting the following things you may wish to participate in:

1. Something very simple and easy to start the ball rolling. We are asking all our members to Give a Gift of a one off £20 Christmas donation. Some people are already doing this instead of sending Christmas cards. You can do this in the following ways:
   - Online at www.justgiving.com/isg
   - Text ICHT16 £10 to 70070 to give a £10 donation
     (giving up to a maximum of £30 per day)
   - Call us on 0845 602 9202

2. If you think getting involved in fundraising activities may be difficult for you why not set up a regular donation and support your ISG that way. You can donate as much or as little as you want but even £5 a month will make a difference. Complete the enclosed form or go online at www.justgiving.com/isg

3. Take a look at a couple of ideas below that you could get involved with and decide which you think will work for you.
   - Unity lottery – win up to £25,000 every Saturday for just a pound a week. Visit www.unitylottery.co.uk/charity/display/Ichthysis-Support-Group
   - Easyfundraising and Give As You Live – Sign up to either and you can collect free donations for us every time you buy something online: www.easyfundraising.org.uk/causes/ichthysis
     www.ichthysis.org.uk/give-as-you-live
   - Place a collection box in your local shop or pub. Contact us for a box.

To inspire everyone, please let us have your fundraising stories so we can share these with the membership. Let us know what you have done, how you went about organising things. What you may do differently next time … Send us your photos so we can share your experience.

Arranging a fundraising event may sound daunting but it really isn’t and you will be surprised just how well your family, friends and acquaintances will support you. They are also great fun to do and very rewarding.

Take a look at our fundraising pack for further ideas www.ichthysis.org.uk/fundraising-guide-2
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Where does the money go that you raise or donate?

£100 funds 10 of our new information packs for schools and families affected by ichthyosis, helping the child to at the start of their school life, manage their condition with the support of the school.

£250 funds the provision of support, information and advice to 10 new families affected by ichthyosis.

£500 covers the average cost to the ISG of 2 families attending our Annual Conference or Family Day

£1,000 funds the cost of 5 children affected by ichthyosis attending an ISG residential camp

£5,000 helps fund projects and research related to improving the care and treatment of ichthyosis

Remember the ISG exists to support you and your family, but we cannot do what we need to do without your support. Please embrace this fundraising initiative and help us to raise the money that will help all those suffering with ichthyosis.

Thank you.
Paul Whitehouse, ISG Chairman

Members Fundraising

Irish Members Mary Kneafsey and Edel Kenny and her family represented the ISG at an ebay Strictly Come Dancing fundraising event in Dublin on the evening of Friday 18th November. The ISG was nominated to ebay by another Irish family, the Rispins, who were not able to attend.

It was actually Brian Rispin who works for eBay who nominated the ISG (whose nephew has ichthyosis) to be one of the beneficiaries from a fundraiser event held at the iconic Croke Park in Dublin. Employees in the eBay Dublin office competed in their very own Strictly for Charity on Friday 18th November which raised an amazing €5000 for the Ichthyosis Support Group. A massive thank you to Brian and the eBay Foundation from the Ichthyosis Support Group.
ISG School Information Pack

We are very proud to launch our School Pack – Coping with ichthyosis at Pre-School and Primary School. This Information Pack is the first of its kind in the UK for ichthyosis.

Starting school or going to a new school is a very exciting, but maybe a worrying, time for any parent and child especially where the child has ichthyosis. It’s a time when the child gains more independence and that represents an even greater challenge. This may be the first time your son or daughter has been responsible for managing their skin care routine themselves and most teachers are unlikely to have cared for a child with ichthyosis previously.

This guide is for pre-schools and primary schools and all the staff who work there. It provides information for pre-school staff, primary school teachers, teaching assistants and school nurses, with the purpose of helping to support the child, parent/carer and their families.

The aims of this guide are focused around the child, so pre-schools and primary schools can provide the support required for a child with ichthyosis, and are based around four main areas as follows:

**Information**: Information provision and advice on how to support a child with ichthyosis to have a fulfilling school life.

**Empower**: Enabling the child with ichthyosis to feel totally included and involved with every aspect of school life.

**Understand**: Helping other children (and adults in pre-/school setting) understand ichthyosis and what it means to the child and those close to them.

**Support**: Support parents in ensuring the needs of their child are met at pre-school, school or playgroup.


Should you prefer a printed copy of the School Pack to be sent to you please email us [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk)

Have you met Theo our mascot? Theo is the character running throughout the School Pack and if you would like your very own Theo you can buy him from our online shop [www.ichthyosis.org.uk/product/theo/](http://www.ichthyosis.org.uk/product/theo/)
Research

Research study in boys and young men with X-linked ichthyosis on hormones and puberty

Researchers from the University of Birmingham and the Birmingham Children’s Hospital NHS Trust have undertaken a study in boys and young men with X-linked ichthyosis (XLI) which has recently been published in a medical journal (details below). The study was greatly supported by the ISG: most of the people who volunteered to take part did so after seeing information sent out by ISG.

XLI is caused by the lack of an enzyme called steroid sulphatase (STS). The same enzyme is involved in processing male hormones (androgens). So the researchers wanted to check whether androgens function normally in people with XLI. Androgens have several functions in males, in particular during puberty, like development of the sexual organs and the growth spurt.

Volunteers with XLI were asked to attend a research clinic at the Birmingham Children’s Hospital (children below 16 years of age) and at the University Hospital Birmingham (young men older than 16 years) where they were seen by an endocrinologist (hormone doctor). For each person with XLI at least one volunteer without the condition of the same age was recruited to compare the study results (‘control group’). Each study participant was asked to provide a urine sample (collected over 24 hours) and a blood sample. The samples were sent to the research laboratory at the University of Birmingham where steroid hormones were measured with state-of-the-art mass spectrometry techniques.

The results from people with XLI were compared to those from the control group. The researchers found that some androgens are lower in people with XLI due to their lack of STS, but remarkably it does not affect their development and progression through puberty. The explanation seems to be partly that people with XLI had higher activities of a different enzyme (5alpha-reductase), which activates androgens. In other words, the body seems to be able to compensate for reduced androgen production due to deficiency of STS by finding a way to increase androgen activity. Overall, this study reveals important novel insights into the function of the STS enzyme.

Overall, this study provides important insights for patients with XLI, as the condition does not seem to affect their development during puberty and beyond. In addition, this study helps to understand how the enzyme STS works ‘in real life’ and future studies are planned to learn more about how the STS enzyme is regulated.

The research team is greatly indebted to all study participants and to the ISG for their support. In case of further questions related to this study, please email Dr Idkowiak from the University of Birmingham (j.idkowiak@bham.ac.uk).

In Mid November 2016 the ISG travelled to Glasgow, Scotland for the long awaited event for our Scottish members, the ISG’s first ever Scottish Family Day.

On a damp and drizzly day we welcomed 26 families and 15 medical professionals and speakers, including 20 children, to The Grand Central Hotel, Glasgow. Of the 26 families two thirds were new to the ISG! We were delighted with the support from various Medical professionals, including two of our MAB, Dr Zamiri and Professor Sara Brown, and their colleagues from all over Scotland including another Professor of Dermatology, Senior Charge Nurse, Ophthalmologist, ENT Surgeon, Clinical Geneticist and two Consultant Dermatologists.

The children were looked after while the parents listened to various talks and presentations and took part in discussion groups. They all had great fun with games, crafts, balloon modelling and the general excitement of making new friends. Two young lads developed an immediate friendship and have since kept in touch. A young lady formed a costume of sorts from of dozens of modelling balloons attached to herself, it was a cross between a massive skirt, sea creature and a very colourful firework!

Whilst the children were being entertained the adults were able to meet other individuals and families affected by ichthyosis, sharing experiences and giving support to one another. Two families with a very rare type of ichthyosis met someone else with their condition for the first time during this event.

Overall the feedback on the day from those attending and afterwards has been very positive for both the conference and the care the children received. Everyone appeared to have had a wonderful day and there were many requests for us to do it all again.

“Thanks for arranging such a wonderful event today. We found it really interesting. Our children had a wonderful time, thank you to everyone who cared for them during the day.”

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Zerocream® Emollient Survey Report

You may remember at the end of 2015 the ISG, in partnership with Thornton & Ross Dermatology, invited our members to try a product, Zerocream®. This seemed to have been a welcome invitation as we received 250 request for the product to try (about a third of those we sent the information to). Those sent the samples were then asked to complete a short survey. The aim was to learn more about the management of ichthyosis and the use of Zerocream® emollient.

141 members of the ISG responded to the survey. The key findings are shown below.

**Key Findings**

- Respondents included a wide range of ages. 33% were under the age of 16 and the survey was completed by a parent or carer on their behalf.
- Slightly more males responded than females, with 52% males completing the survey compared to 47% females and 1% preferring not to say.
- The majority of respondents have had ichthyosis for over a decade. 73% stated they have had ichthyosis for 11+ years and 49% of respondents have had ichthyosis for 30+ years.
- 92% of respondents regularly use emollients, with 7% using them “sometimes” and only 1% not using emollients at all.
- Many respondents have had little or no education about ichthyosis treatment. 77% had never had a demonstration of how to correctly apply an emollient. 70% had never received advice on how much emollient to use. 67% had never received a selection of samples to try and 54% had never been given a choice of which emollient to use.
- 85% of respondents liked Zerocream.
- 74% of respondents stated that it is as good as, if not better than, their current emollient.
- 68% stated they would continue to use Zerocream.
- 47% of respondents saw an improvement and 29% were unsure, only 25% didn’t see any improvement in symptoms.
- Of the respondents who noticed an improvement, 69% saw a decrease in dryness, 29% saw a decrease in scaling and 24% of respondents saw a reduction in the need for other creams/emollients.
- 49% of respondents said that their skin felt less dry after using Zerocream, 41% of respondents said that their skin felt comfortable and 30% said their skin felt smooth after using Zerocream, 11% of respondents also said that their skin felt moisturised all day following use of Zerocream.
Win a Samsung Tab A

Enclosed with this Newsletter is a form and pre paid envelope. We are asking that you complete this form and return to the ISG if you wish to remain on our mailing list. All fully completed forms will be entered into a draw and the lucky winner will receive a Samsung Galaxy Tab A.

We use a variety of methods to communicate including email, post and website. To provide the best support to our members it is important we hold the correct and relevant information.

If you would like to remain on our mailing list, and for a chance to win the Samsung Galaxy Tab A, please complete and return the enclosed form by 1st February 2016.

Thank you.

This Newsletter was supported by a donation from Epaderm™