Chairman’s Welcome

With spring just around the corner and the thought of longer days and better weather to look forward to, I also look forward to another successful year for the ISG. As I write this message I think about all the positive things the ISG achieved in 2015. As we enter the spring of a new year your trustees are already working on lots of exciting initiatives for 2016.

In February we locked ourselves away for a weekend to discuss the future direction of the ISG and consider where we should focus our energies. As you can imagine this involved lots of discussion and the consumption of copious amounts of coffee and biscuits. Your board of trustees are passionate about the ISG and in providing you, our members, with the support and services you require. We came away from our discussions with a number of positive initiatives to take us forward as a group.

One of the key things we agreed upon was the appointment of a new administrator to support Liz Dale at our offices in Reading. This is a big financial commitment for the group but we believe the benefits to the membership justify this decision and will free up Liz’s time to focus on other important projects we wish to take forward.

You can of course help to support the decisions we make by getting involved in fundraising activities. As I’m sure you are aware we…

continued on page 2
Continued... from page 1

... have to generate the funds to finance everything we do. This is done by applying for grants, receiving sponsorship from pharmaceutical companies but by far the biggest contributor to our income is generated by those members who actively participate in fundraising activities. We will be focusing on promoting fundraising during the year, bringing you simple ideas you might wish to try to raise funds for the group. The more funds we can generate the more we can do to support research, raise awareness and introduce new support structures for our members.

Something I often raise is ‘getting involved’. We are always looking to bring new blood onto the ISG board. If there are any members (or family and friends of members) who would like to join our group then please do get in touch. You may have a specific skill set or you may just like to become involved in a general capacity. Someone with a legal or accounting background would complement the boards existing skill sets very well and bring additional depth to our expertise. If you or someone you know would like to know more about ‘getting involved’ then please do not hesitate to get in touch by contacting Liz Dale at head office in the first instance and I would be delighted to speak with you.

I look forward to seeing you at the family conference being held in Birmingham this coming May.

Best regards

Paul Whitehouse, ISG Chairman

Research

The ISG works closely with medical professionals and researchers with the aim of improving the lives of all affected by ichthyosis.

Currently we are aware of the following research looking for participants.

**X-linked Survey** - Researchers are looking for males with X-linked ichthyosis, or their non affected brothers, to take part in a short online survey looking at personality. To complete the survey visit our website below and follow the link to the survey.

[www.ichthyosis.org.uk/x-linked-ichthyosis-personality-survey](http://www.ichthyosis.org.uk/x-linked-ichthyosis-personality-survey)

**Emotional and Psychological effects of living with a skin condition**

Living with a skin condition is difficult, but how many people acknowledge the emotional and psychological impact it has on the person affected and their loved ones? Scott Thomas, a medical student from Kirkville College of Osteopathic Medicine – A.T. Still University, certainly does and wants to find out how many patients consider their skin condition affects them psychologically and emotionally. To complete the survey please visit the ISG website below and follow the link.

ISG Children’s Camps 2016

We are delighted to announce we have four camps planned for 2016 in the UK for children affected by ichthyosis aged 8 - 16 years. All the information about how to register is enclosed, along with a pre-paid envelope to return your registration form before the 1st May 2016.

Please read the experience of one young member below. If you would like to know more about the camps please email: sarah@ichthyosis.org.uk or liz@ichthyosis.org.uk alternatively you may telephone: 0845 602 9202

Sarah and Liz are the main ISG camp leaders and they are very nice ones too. Through the day you will be doing lots of fun activities like the giant swing, aeroball, really big zip wires, power fan and lots more. Not everyone likes the high and fast activities so we do lots of things on the ground too, like quad biking, low ropes, challenge trail and sensory trail. My favourite ones are giant swing, quad biking and zip wire.

In the evening you usually do something like challenges or quizzes. One time we did robot wars and turned Sarah into a robot blind folded, it was really funny. Later we go back to our camp rooms where we have an outside bit to play in and we do things like water balloons and races or just relax in our room before going to sleep. Sometimes we have camp fires and sing and roast marshmallows.

As well as the ISG leaders we also have a PGL staff leader who organises our day and what we do, they are very friendly and fun and they all like to sing a lot!

So I think the ISG camps are great and if you come along to one I think you will think so too.

My ISG Camp Experience - by Ellamay

I am 11 years old and I have Non-bullous ichthyosis (CIE). I have been to the Ichthyosis Support Group Camps for children at PGL and want to tell you how brilliant they are. I think the camps are a great way for people that have ichthyosis, or have a brother or sister, mum or dad with it, to meet up and make new friends with the same condition.

You or your mum and dad may be unsure about you coming to the camps (I didn’t want to go at first) but they are really great fun. All the boys share rooms and the girls sleep in rooms together. It is great fun and you get a cooked breakfast, lunch and dinner, the food is really nice.
ISG Family Conference 2016 - Birmingham

We are excited to announce this year’s ISG annual event will take place at Conference Aston in

**Birmingham, England on Saturday 7th May and Sunday 8th May**

Registration is essential to attend the event and you will find full details and how to register in the invitation enclosed. There will be the usual mix of medical professional input, member discussion groups, sharing of information and knowledge about all types of ichthyosis and related conditions. Children of all ages will have a wonderful time participating in lots of activities. Pharmaceutical companies will be giving away lots of samples for you to take away.

We look forward to seeing you soon!

#ISGFamDay16

ichthyosis.org.uk

Do you want to remain on our mailing list?

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. 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 please complete and return the enclosed form by 1st May 2016. Thank you.
MyISG Community

Join the MyISG Community

Become a MyISG member and join other members with similar conditions. Share your thoughts, join the conversation and meet like minded people. MyISG is a private community website for ISG members. You can follow other members and topics that interest you and make new friends with similar conditions. MyISG is a forum where real discussions take place and honest opinions are expressed.

Our easy-to-use site will let you instantly create private content, just for your thoughts, or create a group blog and invite others who share your interests to join in. You will also have private condition specific material available either from the ISG or from other members.

MyISG is more than just a blogging site, we’re a community. You can now submit articles to be posted and by viewing the discussion in our topics listings, you’ll be able to find and connect with members who share your interests or condition.

If you haven’t already done so please register today at www.myisg.org.uk and start posting your questions, suggestions and advice – a place where you can share information with others affected by ichthyosis.

Please note you must be an ISG member to register so you can rest assured in knowing this is a private site and not open to the general public.

Fundraising

The ISG would like to say a huge thank you to everyone who has raised money and awareness for the ISG over the last year. Your continued support is crucial to enable us to support families, like yourselves, affected by ichthyosis.

You may be aware that each year the ISG aims to raise awareness in the UK with an ‘Ichthyosis Awareness Week’. This year we have decided to extend the awareness campaign to a month, during May - ‘Ichthyosis Awareness Month’, to coincide with our friends in the USA.

We have held various events over the last 18 years but more recently we have celebrated the huge success of the ‘Ichthyocyclotron’. This event is a fundraising event which can generate a lot of interest and so raise greater awareness of ichthyosis. We ask that people cycle at least 0.1 mile for every year the ISG has been around. This year we are asking you to cycle 1.9 miles (or more if you want a challenge) for ichthyosis, asking friends, family, work colleagues or school friends to join in and to collect sponsorship money.

We are able to support any fundraising activity you organise with T-shirts, leaflets, posters, balloons and sponsor forms. For more information please email: isg@ichthyosis.org.uk
Member’s Spot

My name is Grace and I’m 15, I have Bullous Ichthyosis Erythroderma (BIE). This means that my skin is dry, fragile, and thick. My daily routine consists of waking up at 5:45am, having a shower using Sanex to wash with and I have to wash my hair every day, because it gets so greasy. After this, I put on a thick layer of 50/50 liquid paraffin and white soft paraffin, mixed through with a scented cream so it smells nice. So I don’t ruin any of my clothes, I use my pyjamas when I have all my cream on. I have to wait for the cream to sink in before getting dressed, and then I leave for school.

At school, I have a cream to use whenever I need it, and 2 cards to say I can get water whenever I need it and go to cream at any time. When I get home, I have a bath and then put on the same ointment as I did in the morning. I don’t like the fact that I have to get up so early, considering both my brother and sister go to the same school as me, and get up an hour after me. Sometimes I get skin infections because I scratch too much, so I have to go on a course of antibiotics to clear the infection.

I have very recently started taking Isotretinoin tablets, which is usually taken to treat severe acne, but I was advised to take them to see if it helps reduce the thickness of my skin.

My dad also has ichthyosis, so we have 2 washing machines – one for greasy clothes, and one for regular clothes. The greasy machine has a special grease-proof seal. I also have to hoover my room every day because of the skin.

Having ichthyosis is a challenge in school, as I have been picked on for my skin quite a few times, but at the end of the day I can’t change it so it doesn’t faze me.

Last year I attended the ISG weekend camp in Surrey, which was great and the group participated in many activities such as abseiling, rope climbing and quad biking. It gave me confidence to try new experiences and broaden my horizons.

I like being a member of the Ichthyosis Support Group because it means I can keep in contact with people my age with the skin condition. It also means I can meet new people, share my experiences and learn from others. I find that the ISG helps with different issues, however big or small, and gives advice and tips on what to use to make your skin better or just to try new things.

Grace, ISG Member

If you would like to write something for the ‘Member’s Spot’ section of the Newsletter, maybe from an adult’s perspective, please email: isg@ichthyosis.org.uk.
Meet a Trustee

Name: Sarah Griffiths-Little
Role within the ISG: Director/Volunteer/Children’s Co-ordinator
Age: 36
Where do you live?: A little town called Nantyffylon – it’s almost as hard to say as ichthyosis if your not welsh!
What’s your favourite film?: I have lots, my overall favourite is ‘Stand by Me’, however I love…. ‘P.S I Love You’, ‘How Green Was My Valley’, ‘Who Will Love My Children’, ‘Guardians of the Galaxy’ to name but a few!
What’s your favourite book?: I love a good romance novel - I’m a true romantic! I love anything by Catherine Cookson, Iris Gower and old fashioned stories are the best! My favourite book of all time is ‘The Cold Moons’ by Aeron Clement. I first read it when I was in school, it’s about Badgers, I cried all the way through it!

What’s your favourite past time?: I love spending time with my family and friends – they are my pillars of strength in life. I have a passion for music and love all music including Country (Tim Mcgraw is my favourite along with the oldies such as Don Williams and of course Kenny Rogers!!) I do not let anything hold me back and believe in enjoying my life to the full- this can be evidenced in my Facebook page.

What’s your favourite holiday?: I am very lucky to have travelled to some fantastic places and I plan to see a lot more! I have 4 favourite holiday’s in no particular order…. New York, Aiya Napa, Florida and Jamaica. All of these are my favourite for different reasons but mostly because some fantastic memories were made.

What do you enjoy most about volunteering for the ISG?: So many things!! I have met so many amazing people since joining the ISG, people with the condition, people who fundraise for the ISG, people who want to support the ISG in other ways and people who want to see the ISG go from strength to strength. All these people give me motivation to volunteer for a fantastic cause.

Camps - I’m so proud of the ISG camps and what the children get out of them. I love seeing children gain confidence, make friends and leave walking a few inches taller.

Overall I enjoy helping and supporting people with the condition, whether that might be helping them by sending an email, having a phone call, organising Camps/Family Day. Just knowing that in some small way I am helping makes me happy.
Meet Annabelle

Ichthyosis is a condition that can take over your life, but not when you look after it. I'm 11 years old and when I was younger my skin was really bad, especially when I was first born. Although it can be a hassle with the Tubifast bandages, (which I wear at night when I am covered in cream) at the end of the day it's all worth it.

Personally my favourite creams are Epaderm and Zerobase because whenever I have those creams on I feel really cosy and I have no idea why!

When I am on holiday my skin reacts really horribly when it's in the sun and the hot weather. It's a total train wreck when I am anywhere near the sea because the salt gives me a horrible, horrible stinging feeling. I hate walking on the sand because when I have my cream on the sand sticks to my feet arms and legs it's SO annoying because I always look like a sand sculpture. I really enjoy my holidays and even though I can't swim in the sea I have a great time swimming in the proper swimming pools.

To conclude, ichthyosis can be hard and I know not everyone has the same type of ichthyosis as me so this article might not be useful to you but I hoped you enjoyed reading it.

Annabelle Whitehouse

If you would like to write something for the ‘Younger ISG’ section of the Newsletter please email isg@ichthyosis.org.uk