Ichthyosis:

My Story

Young people talk

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Ichthyosis Support Group

People who care about ichthyosis

The word "ichthyosis" literally means skin that is scaly like a fish. Ichthyosis includes lots of different skin conditions – but they all need treating by covering the skin with creams or ointments. In this booklet you will meet children and young people who have different kinds of ichthyosis.

During 30 years as a skin doctor I have seen lots of young people with ichthyosis. However kind their parents are, they still feel nobody really understands. It is good to know that someone shares your problem and knows what you are going through. So we have put together this collection of true stories and photos of real people with ichthyosis, so you can read about how they coped with it. You can also get to meet other people with ichthyosis through the Ichthyosis Support Group (ISG) www.ichthyosis.org.uk.

Most people with ichthyosis feel low about it sometimes. Some people feel upset about it all the time and think about it every day. Others manage to forget about it and get on with their lives. But the best thing is if you and your family can accept the ichthyosis as part of the way you are, just like the colour of your hair. Some of the people in this book have gone through bad times with their ichthyosis and they have come through it. They inspired us and we hope they will inspire you.

Professor Celia Moss

Consultant Dermatologist, Birmingham Children's Hospital

What is Ichthyosis?

Ichthyosis includes lots of different skin conditions. But some things are the same for all children with ichthyosis, whichever kind they have. Their skin can be itchy, sore and uncomfortable all the time, every day and every night. They have to keep their skin coated with ointment from head to toe, and it gets on everything – their clothes, their books and their toys. They have flakes in their hair like dandruff. They can feel embarrassed about doing ordinary things like holding hands, getting changed for PE, going for sleep-overs or interviews. Their skin looks different so people sometimes stare at them, whisper or call them names, and even if they don't they sometimes imagine that they do.

Ichthyosis is genetic, which means it can sometimes run in families. Actually the word covers 20-30 conditions, each caused by a different genetic mistake, with very different results. Mistakes in a gene called Filaggrin cause the commonest type of dry skin. By contrast, mistakes in the ABCA12 gene produce the very rare and severe harlequin ichthyosis, which can be fatal. Some ichthyosis genes also cause poor hair growth or funny nails, or rarely, problems in other organs too. Some affect boys and not girls; some mainly affect the hands and feet; some have fine white scales and some have big thick scales almost like a suit of armour. The Ichthyosis Support Group www.ichthyosis.org.uk provides lots more information.

Young children with ichthyosis at a Family Day run by the Ichthyosis Support Group at Manchester United Football Club. Separate workshops for teenagers explore young people's issues, while parents can hear talks by doctors and researchers.

Emma and Stacey

Emma (left) and Stacey celebrating at Christmas

Emma and Stacey are sisters. Emma is 19 and Stacey is 17. They live with their family in County Durham. Both girls enjoy listening to music – Eminem and Demi Lovato for Emma, Greenday for Stacey… and they both like Ed Sheeran.

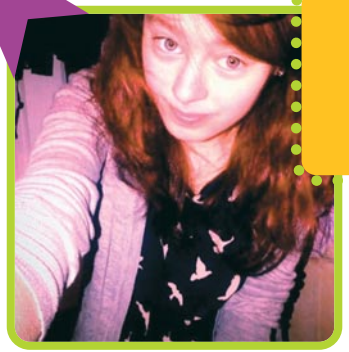
Emma and Stacey have lamellar ichthyosis. They both need to put cream on their skin twice a day. Their mum helps with this job, and sometimes they help each other. 'It's easier having someone else in the family with the same condition!' laughs Stacey. 'If your skin gets too dry, it hurts, and if you're not careful, it can crack. Then it gets rough and itchy.'

'But as long as you keep up with putting cream all over your body,' says Emma, 'you'll be okay.'

'You've just got to get on with it,' adds Stacey. 'When it's hot, our skin dries out more, and we can't sweat,' she goes on. 'We do like it a bit cooler!'

'You can have a good couple of months,' says Emma, 'and then it suddenly creeps up on you. Your skin gets really bad, for three or four weeks, and it's a pain. When it's worse, you need to put on extra cream.'

There are lots of ways of being different. I don't judge people on their appearance



Emma

Emma is studying art and design, and hopes to study illustration at university. Stacey is planning to do childcare qualifications. 'I've had lots of experience with our younger brothers and sisters,' she says.

Emma was a collodion baby: she was born with a shiny waxy outer layer to the skin, which she shed a couple of weeks later. Her condition is classed as a disability. Stacey, a bit younger, hasn't had that classification.

'If there was a cure, I wouldn't take it,' says Emma. 'This is how I am. I like being different. No one else has it, just us. Some people look very different, say if they use a wheelchair, but there are lots of ways of being different. I don't judge people on their appearance,' she continues, 'so I don't want them to judge me.'

'We do get upset about it sometimes,' Stacey adds, 'but you can't change it. I feel we've accepted it. What's the point of being upset about it? It doesn't have to change your life,' she continues. 'We're normal teenagers. We wear normal, fashionable clothes...'

'...and we're always dying our hair,' says Emma, currently a redhead. 'Mine is dip-dyed turquoise,' giggles Stacey.

Stacey

Louis and Eddie

Louis (9), George (8) and Eddie (6) are brothers. Louis and Eddie both have X-linked ichthyosis – but George doesn't.

Louis and Eddie have noticeable scales on the skin of their legs, arms, tummies, and occasionally on their faces. They put cream on the affected skin each evening, after a shower – and before school too, if they remember. Their skin improves in the summer, when the scales look lighter and less visible.

Eddie, Louis and George on holiday

Louis and Eddie's ichthyosis is mild, though other forms of X-linked can bring more symptoms, such as having no sense of smell. They have ichthyosis because their mum is a carrier, though she didn't know it.

I just say, 'I was born with it. It doesn't bother me'

'We have to wear shorts at school, so you can see our legs,' says Louis. 'If people ask me about it, I say I have a skin condition called ichthyosis. I say I was born with it and it doesn't bother me.'

'Sometimes I test my friends to see if they can remember the name,' Eddie chips in. 'But usually they can't!' he laughs.

Marni

Marni and his sister reading together

Five-year-old Armaan, or Marni as everyone calls him, lives in Leeds with his family. He has harlequin ichthyosis, a rare and severe type. But Marni doesn't let that stop him having fun. His favourite thing is wrestling. He loves to watch it, and he loves to do it too. 'Don't try this at home!' he warns, like they say on telly, as he launches into his moves.

Marni was born prematurely, and spent his first couple of months in hospital. He had plastic surgery at 6 weeks and again at 6 months to help his eyes and ears to work better. Since then, he has spent a lot of time in hospital. Lately though, his parents have decided only to take Marni in an emergency. 'We were there every week,' says Gulzeab, Marni's mum. 'Now the dermatology nurses have become our second family,' she laughs.

Marni goes to his local primary school, where a one-to-one carer helps him so he can join in with the other children. Marni loves school, and his reading, writing and drawing are coming on beautifully.

‘I’m proud that he’s hardly had any time off school,’ says his mum, Gulzeab. ‘He’s building up his immunity.’ She puts some of this down to natural remedies such as aloe vera drink and royal jelly.

Aleena and Zayyan, Marni’s older sister and brother help to look after him. Aleena, who is 15, reads him bedtime stories, and she massages Marni’s face, neck, fingers and feet with moisturisers, to help to keep his skin supple.

Don’t try this at home! Marni likes playing with his toy wrestlers

In life, you have to compromise and improvise

Sometimes Marni feels sad about looking different, and he asks, ‘Why is my skin poorly?’

Marni with his dad

‘That’s a hard question to answer,’ admits Gulzeab. ‘I say to him that other children have different things to deal with, like his friend who has bad eczema.’

Marni has harlequin ichthyosis because both his parents carry the ichthyosis gene. Gulzeab says, ‘Our children can have genetic counselling when they reach 16, to find out whether they are carriers too.’

Every year, Marni and his family go on holiday to Turkey. ‘The flight dries him out, but once we’re there, his skin is gorgeous,’ says Gulzeab. ‘The heat seems to suit him. We were scared at first, but the doctors encouraged us to try,’ she continues. ‘We don’t travel light – but in life, you have to compromise and improvise.’

Annabelle

Annabelle is 8. She has a form of ichthyosis called CIE. 'Only around three in a million people are diagnosed with CIE each year,' says her dad, Paul. Annabelle has been on telly to talk about it. 'So I'm a little bit famous!' she grins.

After a bath first thing in the morning, Annabelle puts cream all over her skin, and again at toast time at school, at lunchtime and again after a bath at the end of the day. 'If you don't put cream on, you get dry and itchy,' she explains. A helper at school lends a hand putting the cream on carefully, downwards in the direction of the hair follicles, otherwise it could clog the pores.

You have to look after your skin, as it works differently

Annabelle felt upset recently when a friend didn't want to touch or hold hands. It turned out the friend was worried that she might catch ichthyosis. And sometimes people can make thoughtless and hurtful comments. So Annabelle's parents came into school and explained to everyone that Annabelle has to look after her skin, because it works differently – and that ichthyosis isn't catching.

Annabelle's family does a lot of fundraising and education work for the Ichthyosis Support Group (ISG). Recently Annabelle met another girl the same age with CIE through the group. 'We look like sisters!' she laughs.

'It's important to know someone else who has the same experience,' adds Paul.

Annabelle and her older sister dressed up for Hallowe'en

But ichthyosis isn't catching

Annabelle climbing

Parents' story

Annabelle was a collodion baby: she was born inside a waxy membrane or outer skin. It took a few days until the membrane was ready to fall away. Inside, baby Annabelle couldn't yet open her eyes.

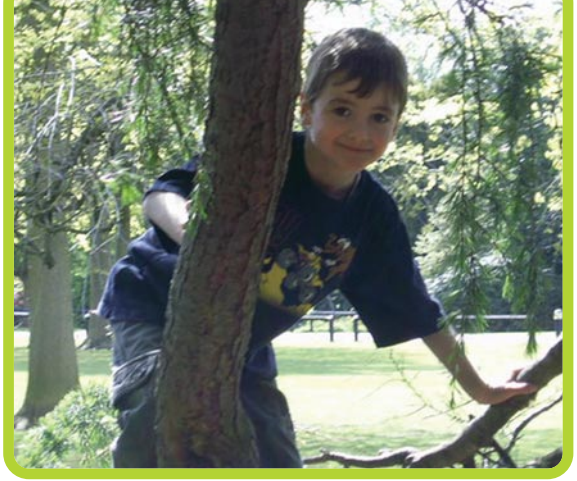
'It was very scary at the time,' admits Paul, Annabelle's dad. 'They'd never had a collodion baby at the hospital. We didn't know which kind of ichthyosis Annabelle had, and what effect it would have on her life.'

Sometimes people make critical comments, thinking Annabelle has got sunburned and her parents aren't looking after her properly. 'That makes me feel very protective,' says Paul, 'and sometimes, I admit, frustrated.'

On a recent shopping trip, Annabelle suggested her dad parked in a disabled space. 'But you're not disabled,' he said.

'I am,' said Annabelle. 'I can't tie my laces.'

Tom



Tom when he was a bit younger

Tom is 10. He likes playing with his friends at school, and on his Xbox, and building castles on Minecraft.

Tom has bullous ichthyosis. That means as well as his skin flaking off, it also gets blisters, which can become sore or infected. But Tom looks on the bright side. 'At least the blisters heal up quickly, because my skin re-grows so fast,' he says. 'And if anyone says anything about my skin, my friends all stick up for me!' Tom and his older sister made up a Skin Rap about ichthyosis, and put it on YouTube.

In the morning, Tom puts cream on his skin, and again during lunchtime at school. He goes to the staff toilet and sits down to read for 20 minutes while the cream soaks in. Then after school he has a good long soak in the bath, and puts cream on again.

If anyone says anything about my skin, my friends all stick up for me

The doctor recently suggested that Tom goes onto constant antibiotics. But mum Beccy isn't keen on that. 'I'd rather just keep on with the baths and creaming. If we put in the effort, we can get his skin back on track.'

Tom has found it helpful meeting other children and adults through the Ichthyosis Support Group. 'It's good to talk to other people who have the same thing,' he says.

Tom and his sisters

Parents' story

An hour after Tom was born, his skin had blistered all over his body. 'It was very traumatic,' says Tom's mum, Beccy. 'He looked as if he'd been burned.' Tom was taken straight into special care, where it took the doctors a while to diagnose his condition.

'Looking back, it's a bit of a blur,' Beccy continues. 'If he wasn't shiny with the cream, it was time to put more on. It was daunting at first. Even holding him made his skin blister.'

As a baby, Tom's skin needed thick grease, which can damage the washing machine as well as other clothes. But as he has grown older, it has got easier. Though Beccy worries that Tom finds it hard to put on weight. 'They reckon you lose 1200 calories each day just through shedding skin,' she says.

Nowadays, Beccy keeps in touch with other parents via ISG's Facebook page. 'It's like a little family,' she says.

Amy

Amy is 11 years old. She lives on her family's farm near Bakewell, Derbyshire, where she helps to feed the calves and lambs, especially orphan lambs. And Amy loves horse-riding.

Amy has a rare form of ichthyosis, called Netherton's syndrome. She needs to bathe and use cream all over her skin twice a day. Her skin is red and itchy, and it gets blotchy and swells up when she is anxious or tired, or even just excited. Then Amy needs to take anti-histamine pills to calm her skin. She finds it helpful to distract herself, too. 'Thinking about horses always calms me down,' she says.

Thinking about horses always calms me down

When Amy was born, it took the doctors a while to work out what her condition was, and how to treat her. She became dehydrated

Amy in the lambing shed

after a few days. Nowadays, because of Amy, doctors know how to keep Netherton's babies more comfortable.

Anything Amy wants to do, she'll find a way

Amy's condition means she has lots of allergic reactions. She's allergic to dog hair – so they have a poodle, because poodles don't moult. She is even allergic to horses, and has to be careful not to touch her eyes until she has washed her hands. She carries an EpiPen in case of a strong reaction.

Amy and her sisters

'Anything Amy wants to do, she'll find a way,' says her mum, Lisa. For instance, before she goes swimming, she puts on as much grease as a channel swimmer. 'But I go swimming!' says Amy.

'When I was 6 or 7, I thought I was the only person in the world with Netherton's,' says Amy. 'But the doctor put me in touch with another girl with Netherton's at my hospital. It's good to be in touch.'

Parents' story

Amy's mum, Lisa, says, 'You've got to be strong, as a parent. You feel fragile as a new mum, and you can see your baby is fragile.' Lisa had lots of help from their specialist nurse, who stayed beside Amy in hospital and worked out how to look after her. She still comes to visit.

'When you go out, people will comment or ask you questions. You have to prepare yourself for it, or it can throw you off track,' says Lisa. Now Lisa has had some little cards printed to hand out to people who are looking. Then they can read what's on the card and find out more if they want to. 'It's a way of educating people out there,' says Lisa.

Adults' perspectives

Amel

Amel is 34 and has EKV, a rare form of ichthyosis. Looking back, she says, 'As a teenager, it's hard to do what's best for you. I didn't want to take the time to look after my skin, or see any more dermatologists. I just wanted to forget about my skin.'

A teenager with ichthyosis will want privacy as their body is changing, and yet may still need help to care for their skin every day. 'My mum backed off at that time,' Amel remembers, 'and gave me space to work through it my own way.' And parents may struggle with guilt about the genes they have passed on – even though they didn't do it on purpose. 'Teenagers pick that up,' says Amel.

She finds social media a great help, as it allows young people with ichthyosis to keep in touch with others. 'You don't feel you're alone with it.'

And relationships? Amel describes her skin as her "bull***t detector". 'It weeds out anyone who's only interested in superficial issues,' she laughs. 'None of

Amel on holiday

the men I've been involved with have been bothered about my skin!'

Amel describes herself as a happy, well-adjusted adult. Even so, she says, it's a big decision whether to have children, knowing that you may pass on your genes. 'We discuss this at ISG, and we follow all the latest scientific developments in genetics and treatment. They are making new discoveries all the time.'

Nelly

Nelly as an Olympic Ambassador for Coventry in 2012

Nusrit, or Nelly as she is known, is 29. Like Marni, she has the rare harlequin ichthyosis. 'It's not an easy thing to live with,' she says, 'but I have good support from my family. We're very close.'

Growing up, Nelly found it hard when she started to notice people's ignorant comments and staring. 'It annoyed me, and it made me feel insecure,' she says. 'But it would be boring if we all looked the same! Now I do my best to ignore it, and I don't let it stop me from doing things I want to do.'

Nelly is involved with disability campaigning and has spoken on television to raise awareness about ichthyosis. This in turn has helped to build her own confidence. 'People remember me from the telly,' she says, 'and they ask how I'm doing. I prefer it when someone asks me a direct question, rather than talking behind my back!'

Ichthyosis Support Group (ISG)

The Ichthyosis Support Group (ISG) is a network of people with ichthyosis, parents and medics. ISG was set up in 1997, and is run by a voluntary committee of eight people with ichthyosis and their relatives, and a part-time administrator.

Maggie (right) and her daughter Mandy Aldwin, two of ISG's founding members who are still on the committee

ISG treasurer Maggie Aldwin writes: My daughter Mandy is all grown up now, but I remember her frustrations when she was younger. She grew fed up with the daily routine of lengthy baths and having to smother herself with creams. She didn't want others to look at her skin, not even her dermatologist. Even today she doesn't like anyone else looking at her skin when it's not at its best. She would love to take a day off from her skin routine – but knows that she can't.

Many children go through this stage. They may find it hard when they realise that they are the only one who has 'peely' skin in their school.

I hope other young people with ichthyosis, and their families, will find strength and inspiration from reading how these young people have coped. I hope it may encourage you to get in touch with the Ichthyosis Support Group, or even come along to an ISG event where you can meet other children and adults who have ichthyosis. It can be daunting when you first see others who look like you. But realising you're not alone and talking to others who know exactly what ichthyosis is all about, can help you feel better. And then maybe one day you will be able to help others feel better about themselves, too.

Resources

Ichthyosis Support Group (ISG) runs family events and offers lots of support and information.
Email sarah@ichthyosis.org.uk about ISG's UK youth forum. Phone 0845 602 9202 www.ichthyosis.org.uk or see ISG's Facebook page

Changing Faces offers support to people and families affected by looking different.
Phone 0845 4500 275 or 0207 391 9270 www.changingfaces.org.uk

Childline offers advice and support to children. Freephone 0800 1111 www.childline.org.uk

Contact a Family supports families of disabled children, whatever their condition or disability.
Free phone helpline 0808 808 3555 www.cafamily.org.uk

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Young people talk

Young people with ichthyosis can feel very alone. It is good to know that someone else shares your experience and understands. This booklet is a collection of true stories and photos of real people with ichthyosis, so you can read about how they cope with it.

Introduction by Professor Celia Moss, Birmingham Children's Hospital

Written by Mandy Ross Designed by Heather Blackham

Original series conceived by Celia Moss and Mandy Ross, developed by Birmingham Children's Hospital Charities, and designed by Anne Matthews

If you would like a copy of this booklet, please order online at www.ichthyosis.org.uk or write to Ichthyosis Support Group, PO Box 1404, Bagshot GU22 2LS

Professionals can obtain copies (minimum 25) from bch.charities@bch.nhs.uk
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