Why People with ichthyosis should see a consultant dermatologist.

Many ichthyosis sufferers first contact the ISG after an appointment with a doctor. Sometimes the doctor has put the family in touch with the ISG. But all too often the patient finds the ISG for themselves, searching for the help they need after a disappointing consultation. This article is about getting the best from the NHS.

GPs know of ichthyosis, but don’t usually know much about it or the different types. They may even misdiagnose it as eczema which is much more common. They usually prescribe emollients, sometimes not the best ones, or enough. But they are after all general practitioners who need to know about all the common and serious conditions in all organs, not just the skin.

The health professional who does know about ichthyosis is the dermatology consultant or “skin specialist”. Dermatologists, like GPs, spend 5-6 years as medical students, followed by 2 “Foundation Years” in a variety of hospital departments: these posts, FY1 and FY2, were previously called Houseman and Senior House Officer. After FY2, doctors follow different career paths. Future dermatologists will undertake 2 years (ST1-2) of specialist training in hospital medicine, during which they must pass the examination for Membership of the Royal College of Physicians (MRCP). Then these “Registrars” compete for a 4 year training programme in dermatology (years ST3-6) during which they undergo numerous assessments, including a written exam, which they have to pass in order to proceed to the next stage. They all learn about different types of ichthyosis and how to diagnose and treat them. Some may take time out to undertake a research project or a specialist Fellowship. Finally, in their early to mid 30s, they compete for hospital consultant posts. Training doesn’t end there: consultants must attend regular educational sessions to keep up to date in their field, and are appraised annually.

GPs can refer patients to a consultant dermatologist, but often choose not to. GPs have to purchase hospital appointments and it is cheaper not to refer, especially chronic conditions like ichthyosis which may require long-term follow-up. The GP may not understand the value of consulting a doctor who regularly sees people with ichthyosis, and who keeps up to date in the field, and can advise authoritatively about your particular case. Many dermatologists work with specialist nurses who give valuable support to sufferers. GPs cannot prescribe retinoid drugs which are sometimes used for ichthyosis. You are entitled to see a specialist, and if necessary you should insist on being referred.

Of course some dermatologists know more about ichthyosis than others. An expert in skin cancer or psoriasis might not be the right person for you. Your dermatologist may refer you to a colleague with more expertise, and you can request that. If it is awkward to ask your dermatologist, your GP may agree to refer you elsewhere for a second opinion. If you need the name of a dermatologist who knows more about ichthyosis the ISG may be able to advise. The ISG is actively working for a national network of ichthyosis specialists to make it easier for everyone with ichthyosis to access the help they deserve. practice, but even within this specialty there are many subspecialties, of which “the genodermatoses” (which covers ichthyosis) is only one. Your GP may, unknowingly, have referred you to a dermatologist whose particular area of expertise is occupational dermatitis or skin cancer, or to a very busy general dermatologist who has not had the opportunity to develop a specialist interest. In that case the dermatologist will usually seek advice or refer you on to a colleague with an interest in ichthyosis.

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Again, you are entitled to request a second opinion. The ISG Medical Advisory Board may be able to suggest a dermatologist in your area to whom you can request a referral.

“I never get to see the consultant”
In most clinics, the work is shared out between the consultant and junior doctors. Specialist Registrars (SpRs) are consultants in training: in some cases their knowledge may be more up to date than the consultant’s! Associate Specialists and Clinical Assistants are usually GPs with a special interest in dermatology who work alongside the consultant for part of the week. They are generally very experienced. Senior House Officers are the most junior. Usually the junior doctor will discuss your case with the consultant. Certainly if you have a question they cannot answer you should ask to see the consultant. If you particularly want to see the consultant and never do, speak to the receptionist or clinic nurse as soon as you arrive. If this doesn’t work, write a letter directly to your consultant.

“My dermatologist doesn’t listen to me”
Sometimes patients leave the consultation feeling dissatisfied. You may feel that the dermatologist doesn’t understand what you are suffering, or has not helped you, or that you simply didn’t “hit it off”. I hope this is not the case with my patients, but if it is I really want to know. In the past, no-one felt able to challenge consultants who were difficult, unhelpful or downright rude. In the modern NHS such behaviour is not tolerated: consultants are appraised annually and complaints are aired and dealt with. If you are unhappy about the way you have been treated, put down your thoughts on paper and write a letter directly to your consultant. If necessary contact your hospital’s Patient Advice and Liaison Service (see below). You should also discuss the problem with your GP.

“I hate going to hospital because I am made to feel like a freak”
The doctor may ask other people to examine your skin for various reasons. Sometime this is for your benefit, the consultant may be seeking opinions and advice from colleagues. Sometimes it is for educational purposes, the consultant has a duty to teach junior doctors and medical students. But I know that patients find this experience embarrassing and humiliating. Even well-meaned sympathetic comments may feel hurtful. Children probably suffer most because they are least able to understand the reasons and express their views. Sadly, many patients feel psychologically scarred by the regular mortifying ordeal of stripping off and exposing their skin to a roomful of strangers. How can I make this better for you?

First of all, if your doctor seems insensitive to the way you or your child feels, please tell him or her we really do need this feedback from you. Either explain before the examination takes place that you find it embarrassing, or write a letter afterwards and ask for it to be placed in your file. The doctor should always ask permission, even of a child, to carry out an examination. It is perfectly acceptable to say that you prefer to be examined only by one doctor.

Secondly, make sure there is a reason for getting undressed, and if necessary ask what it is. Usually it is to judge the effect of treatment, or to look at particularly troublesome areas. If your condition is stable, and the medication has not been changed, your doctor may still need to remind him or herself of what your skin is like. But if there is no good reason, feel free to decline.

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Thirdly, I hope you will agree that we want as many doctors to know as much as possible about ichthyosis. So it might help if you can see the experience as your personal contribution to medical education. If you are somebody who feels embarrassed about your skin, take the opportunity to explain this, and how it affects your life. You are the expert. Learning from a real patient is much more effective than learning from a text-book.

“At the hospital I always have to wait for hours”
Complaints about the hospital service don’t usually come to the ISG, but I know everybody has them. Dermatology outpatient clinics are usually very busy, often overbooked, and sometimes frankly disorganised. Appointments may be changed more than once, and your records may even be unavailable when you come to clinic. These organisational problems irritate the doctors just as much as the patients. We do our best to prevent them but most are beyond our control. But please do voice your opinion. Most hospitals have a Patient Advice and Liaison Service (PALS) who will encourage you to submit a complaint. They should make public the complaints received and their response. If you are interested, key “PALS” and your hospital name into an internet search engine.

The bottom line is, if you are unhappy about something, say so. Nothing will change if you don’t. Consultants really do want to help you, and need to know if you are unhappy with the service. You may find writing a letter easier and more effective: always keep a copy in case you need to take things further. Patient choice and patient satisfaction are higher on the NHS agenda than ever before. Finally, remember that your Medical Advisory Board is here to help. Keep sending us your questions and concerns, and we will do our best to advise you.

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