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Restricted choice of treatment

A fair deal needed for people with skin disease

As we all know, people with skin disease require their treatments to be tailored to meet their individual needs. For example, people with eczema and related conditions tend to have very sensitive skin, and not every product is suited to every patient. Some people will need a range of treatments for different degrees of dry skin, different body sites, different social situations, to address personal preference issues and, quite often, to avoid contact hypersensitivity or other irritant reactions. Their needs may also change over time.

This availability of a variety of preparations is also essential if we wish to improve compliance (and thus clinical outcomes) and to reduce waste, so patients with skin diseases must be given the opportunity to select the emollient or emollients that are most acceptable to them. Unlike treatments for most diseases which are generally administered orally or by injection, the majority of treatments for skin diseases are applied topically and are therefore 'worn', like make-up. For this reason, concordance and compliance are heavily dependent upon cosmetic acceptability. So, if a patient dislikes a treatment, he or she may not use it, which undermines the treatment regime, produces poor clinical outcomes and is wasteful of NHS resources.

These views are endorsed unreservedly by the British Association of Dermatologists, the British Dermatological Nursing Group and the Primary Care Dermatology Society.

An end to sampling

Therefore it was a cause of major concern to SCC members when we heard recently of a case in which a patient presented a prescription at a hospital pharmacy. The pharmacist crossed out the treatment that had been prescribed and substituted an alternative. When the patient protested, producing a sample he had been given in the dermatology department, the pharmacist said they would have to put an end to such sampling. There have also been reports of several cases in which hospital pharmacies have been restricting patient choice in respect of emollients, presumably in an effort to reduce costs. It is also worrying to consider the impact of such practices on the role of community nurses and pharmacists as they expand their responsibilities to include prescribing. Easier access to medications, particularly for repeat prescriptions, will benefit all those who have to live with a chronic condition and such restrictions are counter-productive and are damaging to patients' interests.

Supporting good practice

In order to assure patient choice, the SCC strongly supports the practice in many dermatology departments where they have available a tray or trolley with a wide range of emollients for patients to try, so that they may find those they are happy to use. We believe that all dermatology departments should do that and we hope that all pharmacists would encourage and support good practice of this sort.

These simple practices can make a major difference to the quality of life for those people who have to cope with the daily, life-long challenge of living with a skin disease.

Lynette Stone CBE
Chairman, SCC

Looking Ahead

Peter Lapsley, Chief Executive, Skin Care Campaign

New Contract for Community Pharmacy

Subject to a ballot by pharmacists, the new contract for community pharmacists in England and Wales should be implemented from 1 April this year.

Community pharmacists are seen by the government as a largely un-tapped resource. Part of the purpose of the contract is to integrate them more closely into local healthcare teams.

The new contract is focused on improving access and choice, and on helping people with long-term conditions. It will reward pharmacists for the range and quality of services they provide rather than for the volume of medicines they dispense. This gives them an incentive to offer a wider range of services – especially in supporting self-care, promoting healthy lifestyles and helping patients to get the best from their medicines.

The contract categorizes the services to be offered by pharmacists as ‘Essential’, ‘Advanced’ or ‘Enhanced’.

Essential services are those that must normally be provided by all community pharmacists. They include dispensing, repeat dispensing, disposal of medications, promotion of healthy lifestyles, sign-posting, support for self care, support for people with disabilities and clinical governance.

Advanced service are those that require accreditation of the pharmacist and/or specific requirements to be met in regard to premises.

At present, the only service under this heading is Medicines Use Review and Prescription Intervention. Under Medicines Use Review the pharmacist will periodically undertake a structured review with patients receiving medicines for long term conditions, to establish a picture of their use of the medicines – both prescribed and non-prescribed. The review will help patients to understand their therapies, and identify side-effects and changes that may be beneficial. A report of the review will be provided to the patient and to their GP.

Requirements to be met in regard to premises are designed to ensure that Medicines Use Reviews take place in confidential and suitable environments. The patient and the pharmacist must be able to sit down together; they must be able to talk at normal speaking volumes without being overheard by staff or customers; and the area must be clearly signed as a private consultation area.

Enhanced services are those which will be commissioned locally by Primary Care Trusts. Examples include minor ailment schemes, smoking cessation services, supervised administration of prescribed medication, needle and syringe exchange schemes, anticoagulant monitoring, medicines assessment and compliance support, care home support, patient group direction service, full clinical medication review and supplementary prescribing.

Where skin diseases and other long term conditions are concerned, the new contract should be good news. In addition to widening the range of services pharmacists can offer, the introduction of repeat dispensing will mean that patients will be able to get a prescription from their GP for up to a year at a time, to be dispensed in instalments agreed by the prescriber and the pharmacist.

This will benefit patients, who will no longer have to make monthly or bi-monthly repeat applications to their GP surgery for repeat prescriptions, and it should help reduce GP workloads.

Supporting Dermatology Research

The SCC’s objects are to work for the improvement of health care for people with skin disease; to educate and inform the public and others about skin diseases and their treatment; and to support other organisations in order to pursue these objectives.

Since its inception, we have taken the view that active involvement in dermatology research could become a serious distraction and a drain on our very limited resources, and that it is therefore a matter best left to others.

We have, however, been greatly impressed by the way in which the British Skin Foundation (BSF) has grown and flourished in recent years.

The BSF is the only national charity dedicated to supporting research into skin disease. It works closely with patient support groups as well as with many of the country’s leading dermatology departments. It also enjoys a close relationship with the British Association of Dermatologists who provide its administration, enabling it to use its funds entirely in support of dermatology research.

At the Royal Institution’s ‘Skin Deep’ evening lecture in 2003, there was space for just two voluntary sector stands, and it seemed logical that those two should be the SCC and the BSF.

Taking Action on Dermatology Forward

Few can doubt that the Action on Dermatology Programme (AoD) has been a great success, not least because of the very inclusive way in which it has been run.

Managed by the NHS Modernisation Agency (NHS MA), the AoD programme was initiated in the summer of 2000, chiefly because dermatology was one of the four specialties with the longest waiting times. Its notably egalitarian steering group included consultant dermatologists, GPs, nurses, a pharmacist and patient representatives as well as representatives of the NHS MA.

Fifteen pilot studies, beginning in the autumn of 2001 and continuing through 2002, informed the *Action on Dermatology Good Practice Guide* and the *Dermatology Training Resource Pack*, both published early in 2003. In addition, the AoD Programme developed *Guidelines for the appointment of dermatology GPwSIs* for publication by the Department of Health, and the very useful *Ten Top Tips* for improving dermatology services.

The government has now decided that the size and role of the NHS MA should change dramatically in March this year. The MA itself is to be reduced from around 800 staff to some 150, and it is to be merged with the Leadership Centre and the NHS University to create a single NHS Institute for Learning.

An inevitable consequence of this is that the seven Action on... programmes the NHS MA has been running will be wound down. Andrew Irvine, the last full-time Associate Director of the AoD programme, left for pastures new at the end of October, being replaced until March by Claire Jones, who divides her time equally between AoD and Action on ENT, for which she has been full-time Associate Director. Come March, she, too, will leave and the AoD programme will be closed down.

Two aspects of this change are of enormous importance to people with skin diseases and to dermatology. The first is that the excellent relationship the AoD programme has helped build between stakeholders on the one hand and the Department of Health (DH) and the NHS on the other should be maintained and put onto a more permanent footing. The second is that the excellent work done by the AoD programme should not be lost.

Until the AoD programme was established, the SCC had no useful point of contact within either the DH or the NHS. True, there was a post within Disabilities Branch in Leeds which had notional responsibility for dermatology, but it was relatively junior and was also concerned with a substantial number of other specialties. Understandably, the post holder's interest in and knowledge of dermatology was superficial. With no one to talk to, the SCC had little choice but to campaign aggressively and directly to Ministers.

The AoD programme changed all that. As its first Director, Nick Evans was the first NHS manager to be required to focus all his attention on the specialty, and he was sufficiently senior to make things happen. He was an inspired choice and quickly became greatly respected by patients, health professionals and others with a common interest in skin health. In addition to managing the AoD programme most ably, he was able to provide stakeholders with sound advice about the structures and natures of the DH and NHS, about their views on policy issues and about the best ways of working with them.

When Nick was promoted to direct all the Action on... programmes, he was succeeded as Associate Director of the AoD programme by Andrew Irvine who proved similarly knowledgeable, helpful and constructive, as has Claire Jones in her brief tenure of the post.

We understand that the NHS MA is keen to sustain the benefits of this sort that accrued from the Action on... programmes, and we are glad about that. But so important is this issue that we

cannot simply place our trust in those who are reshaping this part of the NHS.

In a meeting with the Chief Medical Officer (CMO) early last summer, the All Party Parliamentary Group on Skin, the British Association of Dermatologists and the SCC made clear the very real need for dermatology to have a suitably senior point of contact within the DH. That message is being repeated at a follow-up meeting with CMO early in the new year, and we shall continue to campaign for it for as long as it takes.

At the time of writing, there is still no news as to how this issue will be taken forward – as it must be. Loss of so valuable a link would be a tragedy, both for us and, we believe, for the government.

Happily, maintenance and further development of the progress made by the AoD programme is more assured.

As has been reported in *Campaign News* previously, the (majestically named) Long Term Conditions Care Group Workforce Team Dermatology Group (the Dermatology Group) is setting out the patient pathways in dermatology and participating in the development of competency frameworks for dermatology. These are necessary precursors to enabling the LTC Care Group Workforce Team to advise the DH as to what should be the size, shape and nature of the dermatology workforce.

The pathways have drawn very heavily on the work done by the AoD programme, especially in respect of assuring rapid and reliable diagnosis; improving the interface between primary and secondary care; providing an intermediate level of care; removing much of the management of skin disease from secondary to primary care; and facilitating well supported self-management, especially of inflammatory skin diseases.

All of this, to coin a phrase, offers real 'win-win' opportunities. It should be of real benefit to patients, providing them with a significantly better service. And it should be of similar benefit to the NHS, reducing considerably the demands that dermatology places on an over-burdened system.

Even so, there is no room for complacency. Many health policy decision makers, health service managers and clinicians still fail to take dermatology seriously. The Department of Health and the NHS seem to value change for its own sake, and their interest in the specialty could easily shrink at least as rapidly as it has grown. While we may take some satisfaction from the ground we have gained recently, there can be no doubt that we shall have to continue to fight to defend it and to assure that the NHS continues to increase the attention it pays to the proper diagnosis and treatment of skin diseases.

Skin Care Campaign Scotland

As we mentioned in the last issue of Campaign News, Skin Care Campaign Scotland (SCCS) has updated its leaflet, 'Does the health of your skin affect your life?' and we are delighted to be able to include this as an insert in this edition. If you would like further copies of the leaflet or wish to contact SCCS, you can do so via Rosemary Gierthy, SCCS Chair, 9 Bangholm Bower Avenue, Edinburgh EH5 3HS, email: rosemary.gierthy@btinternet.com.

Royal College of Nursing and British Dermatological Nursing Group Dermatology Competencies Launch

Also enclosed with this edition is an invitation to attend the Dermatology Competencies Launch at the Royal College of Nursing on 3 February. This will be an exciting launch of the work undertaken which will be helpful to all those interested in assessing and developing their expertise in dermatology across the whole spectrum of primary, secondary and tertiary settings. *Those interested in attending will wish to note the tight deadline for this event.*

Skin Care Campaign Skin Information Days – Plea for Speakers

We are always most grateful to the busy health professionals – consultant dermatologists, dermatology nurses, GPs and pharmacists – who give up time on Saturdays to speak at the Skin Care Campaign's Skin Information Days. Feed-back from those who attend the days, health professionals and members of the public alike, is that

they are very worthwhile and that the presentations given by health professionals are as least as important as the exhibitions laid on by the skin patient support groups and the SCC's corporate supporters.

Only rarely do we have any real difficulty in persuading people to help with Skin Information Days. Just occasionally, however, we find ourselves having difficulty in finding speakers locally and have therefore to cast our net wider, seeking the support of clinicians from neighbouring areas. That can be frustrating for those people who, because they have further to travel, will inevitably be giving up more time than local speakers would. We are taking this opportunity, therefore, to remind all health professionals of the value to their communities that Skin Information Days provide, and to ask them to always to support them if they possibly can.

The days planned for 2005 are:

Saturday 26 February	Tunbridge Wells
Saturday 23 April	Newport
Saturday 24 September	Blackburn
Saturday 19 November	Cambridge

and Gwen Banford (gbanford@eczema.org or tel: 020 7561 8249) will be delighted to hear from anyone able to join us and help support us by presenting sessions on eczema, psoriasis, acne, vitiligo, skin cancers, etc, at any of these events.

The All Party Parliamentary Group On Skin

With speculation rife about a General Election next May, the All Party Parliamentary Group on Skin (APPGS) has recently invited two of its parliamentary members, both health spokesmen from opposition parties, to address the Group and to set out their thoughts on the development of dermatology services.

Paul Burstow MP, Liberal Democrat Shadow Secretary of State for Health, spoke to the APPGS in October and endorsed the Group's recent recommendations on training. Head of the Liberal Democrat health team, Mr Burstow congratulated the APPGS on its 'prolific' work and noted that he had been most struck by the 'Report on The Impact of Skin Diseases on People's Lives'. He acknowledged that dermatology was sometimes overlooked by health policy makers and was broadly supportive of initiatives to modernise the management of chronic skin disease.

Mr Burstow stressed that training and audit were key factors in improving dermatology services. Echoing the findings of the APPGS's recent 'Report on Dermatology Training for Health Professionals', he noted the role of nurses and pharmacists in improving skin management and stressed the need for all GPs to be adequately trained in dermatology, not just those with a special interest in the area. Mr Burstow expressed concern regarding healthcare inequalities and highlighted that it was the Healthcare Commission's responsibility to ensure that local service provision was effectively audited.

Mr Burstow supported the Government's funding of the 'Action on Dermatology' programme and welcomed news that dermatology had recently been incorporated into chronic disease management plans. Much of the meeting was spent in question and answer with other members of the Group and Mr Burstow appeared to take a real interest in associate members' reflections on dermatology services. A number of important issues were raised including the GP contract and both undergraduate and postgraduate training. Overall, the meeting was a useful opportunity for the Group to discuss some of the principal issues in dermatology services with an opposition party spokesman,

At the APPGS's meeting on Monday 13th of December 2004, John Baron MP, Shadow Minister for Public Services for the Conservative Party, addressed the Group. A member of the Conservative health team, Mr Baron's remit includes cancer services and he has shown a particular interest in the treatment and management of skin cancers in dermatology. His presentation initiated another thought provoking and enjoyable session.

An invitation will also be issued to a Minister from the Department of Health to address the Group, it is hoped in March. Further details will be provided in the New Year. Further details about forthcoming meetings of the Group and membership can be obtained from the Secretariat, Tel: 020 7591 4833.

Jessica David

Administrative Secretary

The National Electronic Library for Health (NeLH) Skin Conditions Specialist Library

Dr Douglas Grindlay, NeLH Skin Conditions Specialist Library, Dermatology Department, University of Nottingham and Professor Hywel Williams, Dermatology Department, University of Nottingham

Spring 2005 sees the official launch of the National Electronic Library for Health Skin Conditions Specialist Library. This exciting new project is intended to act as a "one-stop shop" for NHS staff, a single web site that can be used as a portal to find quality, evidence-based information on dermatology in electronic form. The Skin Conditions Specialist Library provides an organised, easily accessible and up-to-date collection of key documents, reviewed evidence, and appraised information on skin conditions and their treatment. It also includes selected patient information resources.

The Skin Conditions Specialist Library is part of the National Electronic Library for Health (NeLH), an NHS-funded resource that aims to organise clinical knowledge and to promote evidence-based decision-making. In turn the NeLH is now part of the new National Library for Health. The NeLH brings together over 70 electronic resources such as sources of guidelines, systematic reviews and bibliographic databases in one place, so that they can be accessed at any time wherever an Internet link is available. You can find the National Library for Health, and links to these resources, at: www.library.nhs.uk.

Although anyone in the UK is able to access the NeLH and its Specialist Libraries, its primary purpose is to support health professionals who care for people with skin conditions. It should be noted that, for licensing reasons, some of the resources included in the NeLH database (such as full-text journal articles) are only accessible to NHS professionals.

The scope of the NeLH Skin Conditions Specialist Library is the diagnosis, treatment, management and prevention of skin conditions. This includes aspects such as disfigurement, skin aspects of plastic surgery, wound care, leg and pressure ulcers, sexually transmitted diseases that affect the skin, alternative and complementary treatments, and consumer skin care.

For patients and the wider public, the initial source of health information is intended to be NHS Direct Online (<http://www.nhsdirect.nhs.uk/>). People who want to know more, such as those with long-lasting conditions, will be able to use the NeLH, but it must be borne in mind that the information it contains may be very technical and not necessarily written with non-specialists in mind.

What will be the content of the Skin Conditions Specialist Library?

One advantage of the Skin Conditions Specialist Library is the organisation of its content by skin topic and resource type (i.e. guidelines, evidence etc), to facilitate retrieval by users. In addition, the NeLH incorporates powerful search functions, allowing users to search just the Skin Conditions Specialist Library, or the NeLH as a whole. This search facility will be all

that many users need, especially non-specialists less familiar with the terminology and diagnostic features of skin diseases.

As with the rest of the NeLH, the initial focus on content will be NHS-branded or NHS-funded information. The Skin Conditions Specialist Library is very much a work in progress, and with time we expect it to grow to include more and more external resources, as long as they meet our quality criteria.

We see a very important role for the Skin Conditions Specialist Library in identifying gaps in the evidence and knowledge base, to help prioritise future research, reviews of the evidence and policy development. Our consultations so far have identified a need for the Library to include quality, evidence-based information on the "rarer" skin conditions, but ironically it is just this information that is most often lacking, at least in electronic form.

Another important function of the Skin Conditions Specialist Library is to provide a current awareness service, to alert our users to important new research, systematic reviews, guidelines, policy developments, news and conferences that are relevant to the Library's remit.

Finally, we hope the Library will also act as a single source for high quality patient information. While this information will then be available directly to patients and relatives using the NeLH, it will also be an important resource for dermatologists, GPs and nurses when they are looking for information to give out during consultations. As skin conditions are often chronic, disfiguring and difficult to treat, we believe very strongly in this role for the Library and the need for patients to be consulted as the Library develops.

Who is involved?

The NeLH Skin Conditions Specialist Library is based at the Centre of Evidence-Based Dermatology at the University of Nottingham (which also hosts the Cochrane Skin Group). The Clinical Lead for the Skin Conditions Specialist Library is Professor Hywel Williams and the Information Specialist is Dr Douglas Grindlay.

A wide-ranging Stakeholders Group has been set up to ensure that the needs and views of all potential users are taken into account. The Stakeholders Group includes representatives from professional organisations such as the British Association of Dermatologists, the Primary Care Dermatology Society, the British Dermatology Nursing Group, the British Association for Sexual Health and HIV, the British Association of Plastic Surgeons, and the Cochrane Skin Group. There are also representatives from the Skin Care Campaign and the larger patient support groups. Another group of stakeholders is health information providers and librarians.

In addition to the official Stakeholders Group, we consider all users (and potential users) of the Skin Conditions Specialist Library as our stakeholders. Comments and suggestions for improvement are welcome, and we hope with time to develop a community of interest in skin conditions in the UK supported by newsletters and regular updates via the web site. We will always be keen to hear about potential resources to add to the Library and will try to meet the needs of our different users.

Conclusion

The NeLH Skin Conditions Specialist Library is a project that should be of real, practical use to all health professionals who treat and manage skin conditions and provide support to the people affected. It also has the potential to help ensure that existing gaps in the evidence and knowledge base for dermatology will be addressed in the future.

Do take a look once the library goes online, via the National Library for Health home page or at:
<http://www.library.nhs.uk/skin>

New Consensus on Wound Dressing Procedures

In a step towards developing the expert opinion regarding trauma and pain, two documents have been launched over the summer expanding the evidence regarding this topic.

Molnlycke Health Care, under the Tendra wound care brand, has worked with the World Union of Wound Healing Societies and also Wounds – UK to produce two Best Practice documents which explore the issues around trauma and pain at wound dressing changes and propose actions for the nursing professional on how to minimise this.

Both these documents have been inspired by the seminal document: the European Wound Management Association position document on 'Pain at wound dressing changes'.

"It is only in recent years that the importance of pain in caring for patients with wounds has been recognised. There is now an opportunity for individuals, societies and associations to try and improve and influence the way in which practitioners deal with aspects of wound healing and one of those is pain," said Professor Keith Harding, who chaired the Molnlycke symposium at the recent World Union of Wound Healing Societies Congress in Paris.

The first document, entitled 'Principles of Best Practice: Minimising pain at wound dressing – related procedures' is a consensus document which aims to provide principles that offer flexibility in order to meet local community needs anywhere in the world. Luc Teot, at the launch of the consensus document in Paris, said, "It is impossible to guarantee that every patient will have no pain. But all patients have a right to a minimum standard of professionalism. Ignorance of modern knowledge and techniques is no defence."

The second document, entitled 'Best Practice Statement – Minimising Trauma and Pain in Wound Management' was produced by Wounds – UK and endorsed by the Tissue Viability Nurses' Association. In the opening statement in this document, Alison Coull (formerly Finnie), Vice-chair of the TVNA, states that "It guides clinicians in a practical and helpful way through preparation before and during dressing changes. Specific guidance is offered for particularly challenging and painful arenas of wound care."

For further information visit the Tendra UK website at www.tendra.com.

Art Competition Launched to Help Banish Stigma of Psoriasis

A national art competition, launched this month, is aiming to tackle the stigma and misunderstanding surrounding psoriasis. The *Inside Out* competition, sponsored by Wyeth and in collaboration with the Psoriasis Association, encourages those affected by the disease to express the personal impact of the condition via artwork.

The competition is exclusively for people with psoriasis, their families, friends and carers. Entries can be submitted in a variety of formats from painting to collage and photography. The competition theme *Inside Out* – represents the dual impact of skin diseases; both the physical effect on the *outside* of the

body and the impact on how people feel about themselves on the *inside*.

Twelve short-listed entrants will have their work displayed at an exhibition in London and will have the chance to win a cash prize and a place on a weekend art course. The prizes will be presented by *Changing Rooms* designer Anna Ryder Richardson at a ceremony in 2005.

For more information and details of how to enter please visit www.insideoutartcompetition.co.uk or telephone 020 8392 8040 for an entry form.

Hypomelanosis of Ito Syndrome

Hypomelanosis of Ito Genetics Research

Dr Celia Moss and Dr Saleem Taibjee from Birmingham Children's Hospital in conjunction with the Skin Laboratory at University Hospital Birmingham have recently set up a research project looking into the genetics of hypomelanosis of Ito. They are trying to find out if the diagnosis of the condition can be improved by taking skin biopsies and looking at skin cells called keratinocytes. The hope is that they can help families find out what is the precise genetic abnormality (mosaic) in their child. This research may also help us to understand which pigment genes are disrupted, causing the characteristic lightening and darkening of the skin in this condition.

Hypomelanosis of Ito is a very rare condition in which there is patchy skin discolouration.

Information

For further information relating to HI, HITS (UK), or to take part in/request more information regarding this research project please e-mail: tgrant@hitsuk.freemove.co.uk or call 07940 114943.

WHAT IS HI?

The definition of HI is: A neurocutaneous syndrome of streaky, patchy, whorl-like, or linear macular hypopigmentation of the skin, often associated with seizures, developmental and intellectual retardation and other anomalies.

The symptoms of HI can include:

Asymmetry of the body, patchy pigmentation which can occur on any part of the body, but not normally the palms, scalp or soles of the feet. Gross motor and psychomotor retardation, epilepsy, scoliosis, dental and bone anomalies, unusual ophthalmic features and kidney problems, amongst others.

Diagnosis of HI

HI is a manifestation of an etiologically heterogeneous group of disorders, some of which are associated with genetically distinct cell lines.

WHAT IS HITS (UK)?

HITS (UK) is a family support network which was specifically set up by families to support other families with this syndrome because no other support group existed anywhere else in the world.

HITS (UK) aims to support families by letter, e-mail, telephone, internet discussion board and monthly "live chats" and by bringing families together at events to reduce the sense of isolation often felt.

The Family Support Network's aim is:

To enrich the lives of families and children affected by Hypomelanosis of Ito by facilitating and encouraging communication and linking families together, and by being a focal point offering verbal and written support :

- To put families who have a common situation or difficulty in touch with each other to enable them to gain mutual support and friendship.
- To reduce the sense of isolation families and children with disabilities or special needs often feel.
- To liaise with the medical profession to communicate the group's existence and to share medical information available to us.
- To have quarterly conference calls and to produce a quarterly Newsletter.
- To organise an Annual or Bi-Annual Family Event.
- To promote the importance of the group and the need for communication.
- Our future aim is to organise medical training awareness days in an attempt to gain earlier diagnosis.

Ignorance creates disillusion – Awareness ends confusion!

Family Day

HITS (UK) will be holding its 2005 Family Day in North London on July 2nd.

Membership

Membership is open to all families in the UK and throughout the world affected by HI.

Please contact Terri Grant at tgrant@hitsuk.freemove.co.uk or call 07940 114943 for more information.

We currently support families in the UK, India, Ireland, Italy, France, the USA, New Zealand, Canada, Cyprus, Brazil, Malta, Spain, Sweden, Turkey and Australia.

**Terri Grant,
Chair.**

News Round Up

Acne Support Group Acne and Rosacea Training Day

The Acne Support Group will be holding an Acne and Rosacea Training day at the British Association of Dermatologists' offices, London, on 25th February called 'Practical Management of Acne and Rosacea'. This event is aimed at primary healthcare specialists and beauty therapists who wish to have greater confidence helping patients and clients affected by either conditions. To reserve a place, please call the ASG on 01637 881195. An ASG certificate of attendance will be given to each delegate. We are asking for a donation for attendance of £50 or £25 for NHS employees which will help pay for the day. Any profits will go to the ASG. The day runs from 10 until 3pm.

Contact a Family Free Minicom Service

Contact a Family now has a free number for their minicom service: 0808 808 3556. In addition, they produce a free rare disorders e-mail bulletin giving information about rare conditions, including conferences and research. If you would like receive an e-mail bulletin or know of a family who would like to start a group, please e-mail Contact a Family's rare disorders groups worker, Liz Ranger, on liz.ranger@cafamily.org.uk or telephone 0207 608 8715.

Ectodermal Dysplasia Society

The Ectodermal Dysplasia Society will be holding its Regional Family Conference and Annual General Meeting at the London Zoo Conference Centre, Regents Park, London, on Monday, 4th April 2005 from 11.00 am - 4.00 pm.

Registration forms can be obtained from Diana Perry, Ectodermal Dysplasia Society, 108 Charlton Lane, Cheltenham, Glos. GL53 9EA, or by emailing: diana@ectodermaldysplasia.org or by visiting the website: www.ectodermaldysplasia.org

This conference will be an opportunity to gain more knowledge of Ectodermal Dysplasia, to meet other families who experience this condition and to meet members of the Ectodermal Dysplasia Society Medical Advisory Board.

Herpes Viruses Association

Why get involved with Cochrane? The HVA goes to the Cochrane Skin Group Annual Meeting

Last September the Annual Meeting of the Cochrane Skin Group was held at the offices of the British Association of Dermatology in London. The UK location provided the opportunity for members of the Skin Care Campaign to attend and find out more about how Cochrane works.

(For those who do not know, the Cochrane Collaboration is an international non-profit and independent organisation, dedicated to making up-to-date, accurate information about the effects of healthcare readily available worldwide. It produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. The Cochrane Collaboration was founded in 1993 and named after the British epidemiologist, Archie Cochrane. The Cochrane Skin Group is administered in the UK at Nottingham and currently lists 17 completed reviews, 34 protocols on the way to becoming reviews and 39 protocols under development.)

Protocols being worked on at the moment include one on the use of antihistamines for atopic eczema, one on complementary therapies for acne and one on interventions for vitiligo. Of particular interest to the HVA is a protocol under development on interventions for prevention of cold sores.

The Cochrane Skin Group is always looking for new people who would like to get involved. Interested members of skin charities can become reviewers or can join the teams drawing up new protocols.

Completed Cochrane reviews are increasingly being referred to by health authorities around the world. As cost of medical treatment creeps upwards, practitioners need to be as sure as they can be that treatments are effective and if there is a choice, that the chosen treatment is the most effective one. In the UK, organisations like PRODIGY and NICE often base prescribing recommendations on the results of Cochrane reviews.

Nigel Scott

National Eczema Society

International Survey Reveals Devastating Human Cost of Eczema

An international study¹ backed by the National Eczema Society and global patient support groups, has revealed that more than a quarter of patients with atopic eczema have been bullied or teased because of their skin condition.

The results of the ISOLATE (International Study Of Life with ATopic Eczema), released today at the European Academy of Dermatology and Venereology congress in Florence, Italy, show that eczema patients face a lifetime of isolation, bullying, discrimination and under-performance at school and work.

As the largest and most comprehensive study of its kind ever conducted and supported by international patient associations and physicians, ISOLATE reveals for the first time the extent of the emotional suffering caused by atopic eczema. Two thousand people from eight countries (France, Germany, Spain, Mexico, the Netherlands, Poland, UK and US) with moderate to severe atopic eczema were interviewed for the study.

Atopic eczema is a chronic, persistent allergic disease affecting as many as 20% of children and 4% of adults². It makes the skin red, dry and itchy and scratching leads to broken, oozing and bleeding skin. Apart from the intense physical discomfort, patients are often acutely aware of the appearance of their skin, which may become inflamed, flaking and blotchy when the disease periodically flares up.

Bullying and discrimination

One effect of these highly visible symptoms is that no less than 27% of patients have been bullied or teased because of their eczema. Around 10% of adult patients believe they have suffered discrimination at work including being stared at, not being accepted or having comments made behind their back, with many outsiders wrongly assuming that the condition is contagious.

Furthermore, one in seven adult patients believe their career progression has been hindered by eczema, with the disease affecting job interviews and restricting their choice of careers. Bearing in mind the widespread prevalence of the disease, this equates to more than 115,000 people in a country such as France, over 170,000 in Germany and nearly 300,000 in the UK.

Margaret Cox, Chief Executive of the National Eczema Society, the only UK charity dedicated to the needs of eczema sufferers and their carers, said: "Eczema is sometimes dismissed as a minor irritation, but this survey clearly demonstrates the suffering experienced by millions of people in all aspects of their everyday lives. It is hard to appreciate the misery that eczema can cause unless you, or a member of your family, have the disease. Even doctors may not fully appreciate the psychological

and emotional burden faced by patients who have to live with this distressing condition."

Reflecting the desperation felt by many patients, the survey found that no less than 75% of those interviewed said that being able to control their eczema effectively would be the single most important improvement to their quality of life.

Isolation from the outside world

The survey shows that atopic eczema can also have a serious impact on patients' relationships, with many reporting that eczema prevents them from making friends and 20% of teenagers and adults believing the disease has made it harder for them to find a partner. Once again, this figure equate to hundreds of thousands of individuals in many countries.

Even in established relationships many couples have problems caused by eczema, with 43% of adult patients feeling awkward about a partner touching or seeing their body when their symptoms flare up. A similar number of patients are concerned about being seen in public during a flare-up.

The survey included focus group discussions with patients, one of whom described the way his life had been blighted by eczema: "It prevented me from getting married, because it was on my body, face, my scalp. I always feared that if I got married and had children they would have those genes as well, so I thought rather than making several people unhappy it was better to be unhappy on my own."

The psychological burden

More than half of those in the survey described the often unrecognised psychological burden of eczema, including frequent bouts of depression. In addition many suffered from loss of self-confidence when their symptoms flared up. Anger, frustration and embarrassment were listed as common feelings among respondents. The survey showed that according to patients, their physicians are largely ignoring the emotional impact of eczema, with only 26% of doctors discussing this aspect of the disease with their patients.

Other caregivers described the trauma of seeing their children's symptoms and being unable to help. One parent said: "It causes a lot of sorrow, as my son's eczema is so severe now that it leaves scars, and those scars will never go."

Even when free from symptoms, more than half of patients and carers worry about the next time their disease will flare up. In the words of one patient: "Even if you don't flare up, you are nervous and you panic because you know it's going to happen again, you just don't know when... It's really an emotional thing."

Underperformance at work and school

During a flare-up, when the physical symptoms are at their most unbearable, patients estimate that on average they under-

perform for 10% of the time they are at work or school. As moderate patients spend more than three months of each year in 'flare' and severe patients more than five months, the impact is considerable.

In a typical year, patients miss an average of three days at work or school due to eczema. Sleep is affected for an average of seven nights during every flare, leaving patients tired and irritable. Given that even patients with moderate disease experience at least seven flares a year, this equates to 49 sleep-affected nights each year.

The need for long term control of eczema

The survey also examines patients' concerns about their current medication and their desire for a safe and effective therapy that can be used long-term to prevent the progression of sudden flares-ups. Results show that 58% of patients restrict their use of topical steroids because of their concern about side effects such as skin-thinning, and 66% use them only as a last resort.

A significant majority of those who took part in the study identified the need for an effective treatment that would give them long-term control of their eczema and a much-needed improvement to their quality of life.

Prof Jan Simon, Professor and Chairman, Department of Dermatology, Venereology and Allergology of the University Medical Center Leipzig, Germany, who presented the results at EADV, said: "This study has revealed for the first time the true extent of the suffering caused by atopic eczema, not just physically but also at a deeper emotional level due to the isolation and withdrawal that it imposes on many patients.

"In general, doctors and other healthcare professionals must recognise that they are not doing enough to address the psychological challenges faced by their patients as a result of this disease. We should also be aware that controlling atopic eczema more effectively in the long-term using newer treatment options can make a radical improvement to patient's quality of life."

For further information please contact Margaret Cox, Chief Executive, National Eczema Society on tel: 020 7561 8239 or email: mcox@eczema.org.

References

1. International Study of Life with Atopic Eczema. Date on file.
2. Mattson Jacks Epidemiology Database
3. Estimate based on Journal of World Allergy Org, Nov 2001
5. Br J Dermatol. 2002 Oct;147(4):716-24
6. Data on file
7. An Esp Pediatr. 1999 Oct;51(4):369-76

Tuberous Sclerosis Association Complex Multi-Disciplinary Study Days

Organised by the Tuberous Sclerosis Association, these study days are open to anyone in the medical, health or caring professions. They look at the diagnosis, treatment and management of tuberous sclerosis, including neurological complications, psychiatric disorder, clinical guidelines for care and genetics.

TITLE: The Child with Tuberous Sclerosis – from Diagnosis to Adulthood

VENUE: The Lecture Theatre, Postgraduate Medical Centre, Queen Elizabeth Hospital, Metchley Park Road, Edgbaston, Birmingham B15 2TQ

DATE: Thursday 17th March 2005

TITLE: Tuberous Sclerosis – The Adult Perspective

VENUE: The Lecture Theatre, Postgraduate Medical Centre, Queen Elizabeth Hospital, Metchley Park Road, Edgbaston, Birmingham B15 2TQ

DATE: Thursday 14th April 2005

COST: £60 per person

Further details and an application form can be obtained by contacting: Mrs Janet Medcalf, Head of Support Services, TSA, PO Box 9644, Bromsgrove, Worcs B61 0FP (tel: 01527 871898), email address support@tuberous-sclerosis.org or via our website www.tuberous-sclerosis.org

Vitiligo Society

The First International Meeting of Vitiligo Patient Societies

Florence, 20th November 2004

Early this year the Vitiligo Society received the news that Professor Torello Lotti, President of the Conference of the European Association of Dermatology and Venereology had offered facilities free of charge on the last day of the conference for vitiligo patient groups to hold a meeting. This seemed like the perfect opportunity to form an alliance of vitiligo patient associations. Besides, it was a great excuse to visit that wonderful city of Florence where the conference was to be held.

The meeting was organised by Alida de Pase whose rehabilitative cosmetics are used by many to disguise the vitiligo patches. She is an Italian who is also a long standing member of the Society and has had vitiligo for over 50 years. She spread the word among her patients and health professionals which not only raised the profile of vitiligo but increased the number of attendees at the meeting. These included many dermatologists as well as representatives of patient groups including the French, two Spanish Groups, and Italian group which forms part of a

larger organisation for psoriasis patients as well, the Vitiligo Society and the American Vitiligo Research Foundation (AVRF). Altogether there were nearly 100 delegates and many who could not attend sent their apologies and best wishes for a successful meeting.

A video made especially for the meeting by Professor Richard Spritz, a geneticist who is conducting research to find the genes responsible for vitiligo was shown. In it he expressed his regret at not being able to attend and gave us his support. He also spoke about his research, acknowledging the invaluable help his team had received from vitiligo patients all over the world. A slide presentation with music by the AVRF was also shown. It contained some wonderful pictures of children with vitiligo.

The programme included three presentations by Alida de Pase, Maxine Whitton and Dr Luigi Naldi. His interesting talk, "Vitiligo: it is not all black and white: *some reflections on clinical research in a rather elusive disorder*" highlighted the dilemmas faced by both clinicians and patients in the treatment of vitiligo and in researching it. He pointed out that treatments were based on only limited evidence and suggested that underplaying the importance of the psychosocial impact of vitiligo could affect both the clinician's perception and the patient's expectations. He examined concepts such as disease, illness and sickness, and the subtle differences between them. He also spoke of the enormous stigma attached to vitiligo and the importance of educating society at large to accept vitiligo, thus removing some of the taboos surrounding it. The paucity of research in vitiligo, the fact that there is no strategy to develop clinical research reflects the lack of investment from pharmaceutical companies. He concludes that "new discoveries in experimental models should be moved forward to a clinical and pre-clinical stage in a systematic way."

Alida de Pase, whose talk was entitled "In the 3rd millennium vitiligo still keeps many of its secrets" suggested that enlightened dermatologists could use a holistic approach to the treatment of vitiligo because it takes into account not only treatments based on scientific knowledge about the disease, but also includes the use of camouflage to disguise patches and psychotherapy to give confidence and improve self esteem. She ended her presentation with the words "united we will win but divided we may fail".

Maxine Whitton spoke of the value of patient collaboration. People with vitiligo, despite cultural differences, have similar problems and concerns. An alliance would increase our knowledge and understanding, give us a larger platform from which to campaign on behalf of people with vitiligo, give us a stronger voice in raising awareness and attracting funding for supporting people with vitiligo and influencing research. An alliance can put vitiligo on the agenda scientifically, medically and politically. "A collective voice is a strong voice – patient collaboration CAN make a difference".

Representatives from all the groups present spoke about the work of their organisations. It was apparent that although some of the groups were very new and lacked resources we shared common goals and the desire to work together was strong. An understanding of our different organisations, in terms of resources and setting is crucial to the success of an alliance. We continued to get to know each other over a wonderful Florentine supper where in spite of the language constraints everyone was able to speak to someone. This meeting was a start in the process of working together for the benefit of people with vitiligo.

Maxine Whitton

Forthcoming Events – 2005

XP Support Group	Owl Patrol (annual night-time weekend camp for patients and their families) St Katharine's Parmoor, Nr Frieth, Bucks*	11-14 February
PCDS	North & Midlands Meeting, Chester ⁰⁰	11 February
Raynaud's & Scleroderma Association	4th Scleroderma Family Weekend, Chester ⁺⁺	18-20 February
BASC	Training Initiative, Chester ^{**}	18-21 February
Skin Care Campaign	Tunbridge Wells Skin Information Day ⁺	26 February
PCDS	Irish Meeting, Killarney, Co Kerry ⁰⁰	4-5 March
Tuberous Sclerosis Association	Study Day for Professionals "The Child with Tuberous Sclerosis – from diagnosis to adulthood". Postgraduate Medical Centre, Queen Elizabeth Hospital, Birmingham	17 March

BASC	Refresh Your Camouflage Skills One-day seminar	18 March
Ectodermal Dysplasia Society	Regional Family Conference and ^o Annual General Meeting, London Zoo Conference Centre, Regents Park, London. 11am-4pm	4 April
Tuberous Sclerosis Association	Study Day for Professionals "Tuberous Sclerosis – the Adult Perspective". Postgraduate Medical Centre, Queen Elizabeth Hospital, Birmingham	14 April
PCDS	(GPSI) Plastic Surgery & Minor Ops, Durham ^{oo}	22-23 April
Skin Care Campaign	Newport Skin Information Day ⁺	23 April
PCDS	South & East/AGM, Cambridge ^{oo}	11-12 June
BASC	Training Initiative, Chester ^{**}	26-29 August
Skin Care Campaign	Blackburn Skin Information Day ⁺	24 September
PCDS	South & West Meeting, Chepstow ^{oo}	7 October
PCDS	Scottish Meeting, Peebles ^{oo}	12-13 November
Skin Care Campaign	Cambridge Skin Information Day ⁺	19 November

* For further information please contact Sandra Webb, XP Support Group, tel: 01494 890981, fax: 01494 864439, email: info@xpsupportgroup.org.uk

** Further details, including booking forms can be obtained from Mary Thorp, BASC Secretariat, on 01625 871 129, or by writing to BASC, PO Box 202, Macclesfield, Cheshire SK11 6FP, or by emailing: basc9@hotmail.com

+ For details on Skin Information Days please contact Gwen Banford, e-mail: gbanford@eczema.org; tel: 020 7561 8249

** For more information and an application form, please contact the Raynaud's & Scleroderma Association on: (01270) 872776 or email info@raynauds.org.uk

^o Registration forms can be obtained from Diana Perry, Ectodermal Dysplasia Society, 108 Charlton Lane, Cheltenham, Glos. GL53 9EA, or by emailing: diana@ectodermaldysplasia.org or by visiting website: www.ectodermaldysplasia.org

^{oo} Contact details are: 01923 711678 carol@pcds.org.uk

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Copy date for the next issue is **Friday 18th March 2005** .

Please send news/articles/details of forthcoming events to

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The Skin Care Campaign is an umbrella organisation representing the interests of all people with skin diseases in the UK.

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