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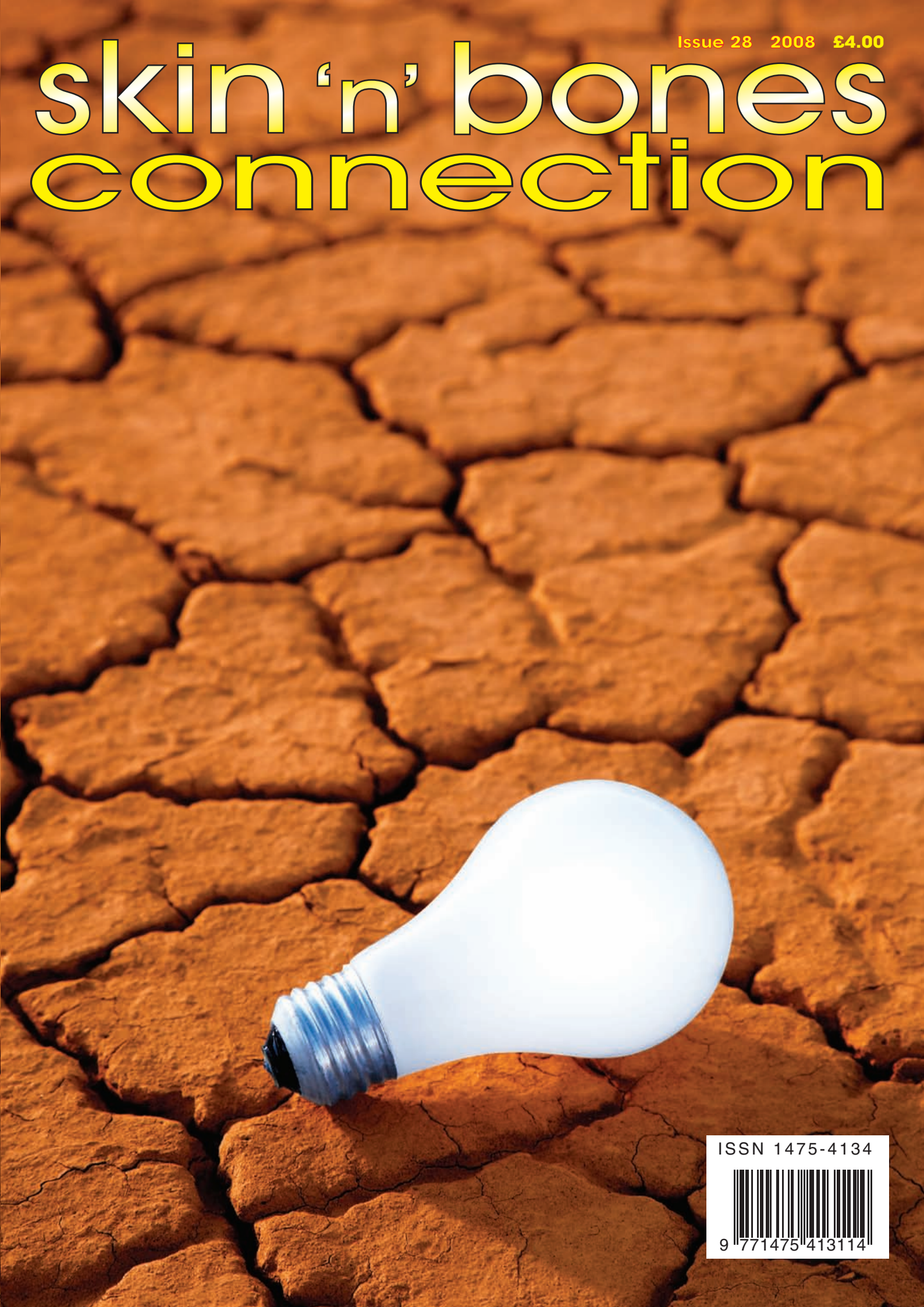
skin 'n' bones connection



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Dear Reader

For this edition we have been looking at research issues. Often it's the breakthroughs or new treatments that get the media headlines, or decisions made By NICE (see page 19), behind these headlines will be many years of dedicated work.

Events that do not get the headlines are the various meetings that are held by experts to decide where research should be focused or whether research is valid or robust enough; these meetings can often be the spark that leads to new therapies or the development of better treatment delivery, for us, the patients.

GRAPPA (The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) (see page 9), is a good example of a dedicated group of professionals who are working towards better diagnostic tools and disease criteria, which should bring earlier and better diagnosis for patients in the future. OMERACT is another collaborative group (see page 8), which brings together a wide group of professionals to look at outcome measures.

Influencing research is becoming an ever increasing important role for patients (see page 3). Your voice is important and can make a difference, which may not make media headlines, but will impact on the direction of future developments.

Managing editor

The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) is the new single identity of the Psoriatic Arthropathy Alliance and Psoriasis Support Trust The organisation is independently funded and aims to be a definitive source of information and educational material for people with psoriasis and psoriatic arthritis in the UK. To be a support to both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas. We will be looking to provide positive advice that enables people to be involved as they move through their healthcare journey in an informed way, which is appropriate for their needs and any changing circumstances.

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Research and clinical trials – Can you help?

As a charity that was founded by and includes people with psoriasis and psoriatic arthritis in its work, both on a day-to-day basis and within the management and direction of the charity, we at PAPAA understand fully the issues that face people affected by psoriasis and psoriatic arthritis.

We are aware that there are many issues and concerns that people with both psoriasis and psoriatic arthritis might have. These may be areas that would benefit from new or further research.

We want to prioritise and focus our efforts to bring real solutions to real people and make sure that when supporting research either financially or otherwise, that the benefits are patient focused and make a difference in a positive way.

The important point to remember is that research doesn't always lead to immediate changes in treatment and care, but is part of a bigger process and similar to a jigsaw puzzle, where a small piece can help to form a picture that can be understood and recognised.

As a charity we provide input into research programmes and the patient perspective. This input is becoming increasingly important and puts patients at the heart of new innovative research.

What's currently being developed?

There are ongoing clinical trials and developments of new treatments in both psoriasis and psoriatic arthritis. Large clinical trials can be expensive and are usually funded by the pharmaceutical industry and may or may not lead to a new treatment being available to the patients.

Often early publicity and media stories of "cures", "scientific breakthroughs" or "new treatment hope" are premature or misleading as the process can be full of hurdles and regulatory issues.

Other types of research can be those which investigate current treatments to see if they can be used more effectively; this can often be with drugs that have been available for some time, and where used in 'real' patients have provided benefits that were not seen in the original clinical trials.

These innovative trials still require ethical approval, but often show that what's new is not always better and that more traditional older and in some cases less aggressive treatments are just as beneficial if used in a different way. The need to research, collect data and share with other clinical professionals provides patients with a global expertise that is transferred directly in their treatment process. With patients providing feedback to their clinicians, the circle can be completed and fed back into the research so that further refinements can be made. This is where you can help.

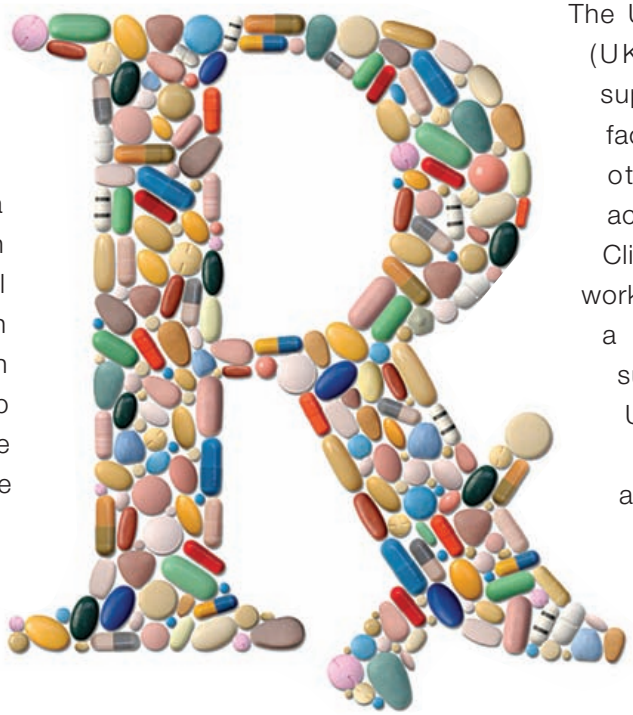
Regardless of how effective a treatment is in a controlled clinical trial setting, if, as a patient, you find it difficult to use, it has intolerable side effects, or you have other conditions which are made worse or precludes you from continuing, then the treatment is a failure (for you) although the trial data may say otherwise.

These insights can make a difference and it is important to always tell your healthcare provider if you have stopped a treatment or you have had a reaction, this reporting helps build the picture and may change the use of a treatment or stimulate more research. At this level you are contributing a great deal to the process.

There may be other reasons why you dislike a treatment or can't use it. Arthritic fingers trying to apply cream to psoriasis plaques may be impossible and

although the treatment is clinically proven, again fails in your case. Once again reporting such issues may change the prescribing or may even make the manufacturer change the method of application. These may appear insignificant but if enough people raise the point it does make a difference.

Where else can you help? Well the charity the Arthritis Research Campaign (arc) as part of a new strategy for funding clinical trials have set up Clinical Study Groups (CSGs) in six major clinical areas, one of which is spondyloarthritis (SpA) – i.e. ankylosing spondylitis, psoriatic arthritis, the arthritis of inflammatory bowel disease, reactive arthritis and undifferentiated spondyloarthritis. No decisions on whether other forms of arthritis (e.g. SAPHO) might be within the remit and the CSG is open to suggestions on this.



The goal is to devise a strategy for clinical studies in SpA which will result in well designed clinical trials which arc will wish to fund and which can be delivered with the help of the infrastructure put in place by the UK government in the form of The UK Clinical Research Networks (UKCRN).

PAPAA has a representative on this group and would like to feed in suggestions of areas where patients feel the need for more research into psoriatic arthritis or which might benefit from further discussion.

We would like to hear what you think is important for researchers to look for. You may think that predicting disease is important or whether psoriasis severity is an indicator of future psoriatic arthritis, whatever you've wondered about your condition or asked yourself "Why do I feel tired all the time?" or "Does it make a difference if I miss a treatment dose? Then maybe you have other questions which could be answered or prioritised in future research.

At the worst the answers may have already been researched and it's an instant response or it may be something that is the missing piece of the puzzle that has not been explored. By providing feedback then you will be contributing to the process, and that could in return help you.

If you have any ideas or thoughts please let us know and we will feed these into the debate and where we have representation.

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Further details of the arc CSG can be found at:
www.arc-research.org.uk/med_director/spondarthcsg.asp

About the UKCRN

The UK Clinical Research Network (UKCRN) was established to support clinical research and to facilitate the conduct of trials and other well-designed studies across the UK. As part of the UK Clinical Research Collaboration, it works towards the development of a world-class infrastructure to support clinical research in the UK.

UKCRN is working to develop and strengthen NHS infrastructure to support the delivery of clinical research in the UK. This is being achieved through the work of Clinical Research Networks, which coordinate and support research in: cancer, dementias and neurodegenerative diseases, diabetes, medicines for children, mental health, primary care, stroke. A comprehensive clinical research network supports research in all areas of disease and clinical need.

UKCRN aims to improve patient care and allow people across the country access to the best treatment. A common theme that runs throughout its work is Patient and Public Involvement (PPI). Because UKCRN believes that active PPI is needed if it is to achieve a programme of research which directly reflects the needs and views of patients and the public.

Further information visit: www.ukcrn.org.uk

Geographic Tongue

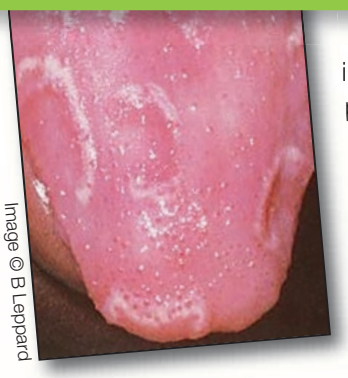


Image © B Leppard

What is geographic tongue?
Geographic tongue, otherwise known as erythema migrans, is a common condition that can affect the tongue.

Your tongue
Our tongues are sensitive muscular organs. Covering the tongue are layers of papillae and taste buds which encase our mouths with a delicate balance of flora and mucus, working to keep the environment of the tongue, mouth and gums moist and bacteria-free, fighting infections. When our mouths get infected either by having a viral/bacterial infection it is these papillae that start fighting off the infection.

What areas are affected?
The tops, sides, under surfaces of the tongue, and sometimes, the lips and inside of the cheeks can be affected. The parts affected usually develop irregular, smooth, areas which can quite often resemble a map. Next to the red patches there will probably be white wavy lines that will outline them. These patches will heal over and new ones will form in new parts of the areas affected.

Does it hurt?
In most cases geographic tongue does not hurt and just appears unslightly and does not cause any discomfort whatsoever. Unfortunately, in some affected individuals it can hurt and become very sensitive, sometimes causing a burning sensation in the mouth. This can be due to many reasons, as the red patches can be thin and raw, loss of the tiny papillae on the tongue becoming lost.

The process of geographic tongue
The normal layer of the skin on the tongue does not shed evenly, and in some cases, the skin sheds too early and in turn leaves red sore areas with white outlines around the patches. The red areas can become infected, and sore, with oral thrush (candida) often diagnosed.

Geographic tongue can also be accompanied by deep fissures (cracks) on the tongue, which again are not serious, but like geographic tongue can be seen alongside other skin conditions.

Who does it affect?
It can affect any age group (at least 1-2% of the population), including children, and it can also run in families. It is also often seen in those who have psoriasis. It is not triggered by infection or other diseases, and it affects healthy people too. It is estimated that approximately 10% of those with psoriasis have been found to have geographic tongue.

It has also been reported in studies that patients have been seen with generalised pustular psoriasis, a high proportion, of these patients will have had heavily fissured tongues, which indicated that otherwise normal healthy individuals may possess the propensity to develop generalised pustular psoriasis.

What irritates geographic tongue?
Because the red patches can be sore, eating certain foods can make the process of eating quite painful, such as acidic foods like fruits or spicy or hot foods. Some toothpastes and mouthwashes can also aggravate the condition. It should be said that eating such foods will not worsen the condition, just cause some discomfort. You will learn what foods and drinks aggravate your condition thus enabling you to avoid these or be prepared for the consequences for a while afterwards.

Smoking and alcohol can also aggravate the condition, and although not proven, it has been suggested that allergies can have some effect too. Other possible causes which should be ruled out by your doctor are vitamin deficiencies such as Vitamin B12.

Hormonal changes can also trigger flare-ups of geographic tongue, as can prolonged periods of stress.

Are there any tests to diagnose geographic tongue?
No, diagnosis is made by looking at the tongue's appearance. It is however essential that you get an expert diagnosis from your healthcare professional that it is geographic tongue and not some other condition.

How is geographic tongue treated?
There are as yet no specific treatments for geographic tongue but there are treatment options available regarding pain relief. If oral thrush has been diagnosed, then there are specific treatments for this. Episodes of geographic tongue given enough time usually settles and resolves itself within weeks or months, but has been known in some cases to take as long as a year or more, before the tongue reverts to its normal appearance.

Is geographic tongue cancerous?
No, nor will it become cancerous.

How to help yourself?
As it is a condition that can sometimes be life-long, waxing and waning in the discomfort that it can cause. Learning to accept it, recognising your own tongue's patterns and cycles will help you. Learning what triggers painful attacks, whether by episodes of stress, certain foods, drinks, ill-health will help in your understanding to deal with it in a relaxed way. If you are experiencing discomfort in your mouth, get this checked out by either your doctor or your dentist who will be able to give you advice and a correct diagnosis.

What is an Information prescription?

From 2008, everyone who has a long-term condition or social care need will be offered an 'information prescription' (IP), in consultation with a health or social care professional. IPs will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.

This includes helpful and relevant information, for example about conditions and treatments, care services, benefits, and support groups. IPs will also contain links or signposts to sources of information about local health, social care, and other services - usually phone numbers, websites etc.

IPs can take very many forms, with many different types of information, and be issued by a wide range of different professionals and clinicians.

The Department of Health has funded the development of an online resource. Also available is a short flyer promoting this online resource. Please feel free to download the flyer and share the link with colleagues so they can see at a glance what the online resource offers and how it can help and support your organisation to introduce information prescriptions locally.

The resource contains ideas on how to get started and things you need to think about throughout the process. It also has many rich examples of information templates, prescribing procedures, patient leaflets, and so on, developed by the pilot sites.

Who is this resource for?

If you are a social carer, GP, consultant, specialist nurse, community care practitioner, a member of staff at a hospital, clinic or pharmacy, a district nurse or any other professional, clinician, volunteer, patient or carer – with an interest in IPs – this resource is designed for you. It is designed to help you understand what IPs are and help you play your part in making a case for IPs in your own organisation, drawing on the experience of the 20 pilots planning the first essential steps:

a) engaging users and carers in determining what information needs there are; b) gaining the active and enthusiastic participation of professionals and partner organisations; and c) sourcing and/or collecting and quality-assuring the information that will be included in your IPs, undertaking the necessary project planning, encouraging small beginnings and growing on success promoting IPs internally and externally, to raise awareness and encourage staff and users alike to participate in the process getting an effective and comprehensive IP system working in your local area, and then monitoring, evaluating and improving it through the evidence and experience you gain along the way.

The resource also includes examples of models and templates for IPs, good practice examples, hot tips and checklists.

To order an overview hardcopy contact:
Department of Health order line, quoting the code 288509.
www.orderline.dh.gov.uk
phone 0300 123 1002
email: dh@prolog.uk.com

Koebner's phenomenon

Koebner's phenomenon or Koebnerisation is named after the German dermatologist Heinrich Koebner who found that people with psoriasis whose skin had become traumatised following an injury often developed a psoriatic lesion in the area, but where psoriasis had not previously be seen, including cuts, bruises, burns, bumps, vaccinations, tattoos and other skin conditions. There has been a hypothesis of a 'deep Koebner phenomenon' which might trigger psoriatic arthritis.

A recent study at the University of Manchester looked at environmental risk factors for the development of psoriatic arthritis[1], with the objective to identify potential risk factors for the onset of inflammatory arthritis (IA) in a large group of patients with psoriatic arthritis (PsA).

Patients recruited into the trial needed to have psoriasis and developed IA within the previous five years. The results of the study (98 cases and 163 control cases) showed a positive association with a previous trauma; these included rubella vaccination, injury sufficient to require a medical consultation, recurrent oral ulcers and moving house. Cases were also more likely to have experienced a fractured bone requiring hospital admission.

The study author's concluded that "…[there were] a number of environmental exposures associated with the onset of IA in subjects with psoriasis. The strongest associations were with trauma thereby adding to the hypothesis of a 'deep Koebner phenomenon'…" and "…in PsA our data also suggest that exposure of the immune system to certain infection related triggers may also be of relevance…"

The researchers reported that further studies are needed to verify the observations and to examine potential immunological mechanisms that underlie them.

The article was published in the Annals of the Rheumatic Diseases (ARD) in May 2008 an abstract is available by visiting the website: http://ard. bmj.com

Reference:
1 - Ann Rheum Dis. 2008 May;67(5):672-6. Epub 2007 Sep 6. Environmental risk factors for the development of psoriatic arthritis: results from a case-control study. Pattison E, Harrison BJ, Griffiths CE, Silman AJ, Bruce IN.

Opportunistic fungal infections

In the USA the Food and Drug Adminstration (FDA) issued a report regarding the risk of fungal infections in patients taking TNF alpha blockers. The report indicated that there had been deaths in patients taking these drugs. The FDA suggested that doctors were failing to recognise histoplasmas and other invasive fungal infections, therefore leading to treatment delays.

PAPAA, given our constituent group are increasingly being prescribed anti TNF alpha blockers, we contacted the UK Medicines and Healthcare products Regulatory Agency (MHRA) to find out if there are any issues that UK patients and doctors should be aware.

The response we received is as follows:

"…the MHRA is aware of this issue and there have been discussions in the European setting. The issue is mainly a USA issue regarding opportunistic fungal infections in patients receiving treatment with TNF alpha inhibitors in areas of the USA where invasive fungal infections such as histioplasmosis are endemic. We have very few of these case reports in the UK and the product information for all three TNF alpha inhibitors has warnings about the possibility of patients developing opportunistic infections during treatment with TNF alpha inhibitors. Following discussions with colleagues in the European Medicines Agency (EMEA) we have decided that the warnings in the product information for etanercept (Enbrel) could be further strengthened to include more specific information about the different types of fungal infections.

The overall message is that the recent regulatory action in the USA does not impact the positive risk/benefit balance for TNF alpha inhibitors in the UK setting because these infections are very rarely seen in UK patients. Prescribers should continue to heed the warnings about the potential for patients receiving Anti-TNF alpha treatment to develop opportunistic infections (including fungal infections) and take appropriate action if infection occurs…"

Progressive multifocal leukoencephalopathy (PML)

Merck Serono, in agreement with European authorities, has issued a 'Dear Healthcare Professional' letter highlighting the association of progressive multifocal leukoencephalopathy (PML) with efalizumab (Raptiva).

The letter discusses one confirmed case of PML and one case with symptoms suggestive of PML. It recommends that if a patient develops PML, then efalizumab must be permanently discontinued and a yellow card report must be submitted to the MHRA.

Patients must be regularly monitored for any new or progressive neurological symptoms that may be suggestive of PML (impaired cognition, visual disturbances, hemiparesis, altered mental state, or behavioural changes. If PML is suspected, further dosing should be withheld until PML has been excluded.

Sources: National Electronic Library for Medicines: www.library.nhs.uk
Medicines and Healthcare products Regulatory Agency (MHRA): www.mhra.gov.uk
Food and Drug Adminstration: www.fda.gov

OMERACT 9

Opinion leaders, clinicians, patients, and researchers came together for OMERACT 9, which was held in May 2008, in Kananaskis, Canada, to discuss a myriad of conditions and methods that relate to Outcomes Measures in Rheumatology.

Twelve different research groups presented their findings and in the true spirit of OMERACT strove to improve endpoint outcome measurement through a data driven, iterative alignment process. OMERACT was once again characterised by a commitment to the interactive development of a majority alignment across relevant stakeholder groups on determining relevant health outcome domains and endorsing valid, responsive, feasible health outcome measures/scales in patients with musculoskeletal conditions.

A total of 215 participants from a wide range of disciplines, including rheumatologists, allied health professionals, psychologists, and biostatisticians, attended OMERACT 9. In addition to the clinicians and researchers in these fields, we also had a valuable contingent of patient participants representing three continents with diseases including fibromyalgia, gout, psoriatic arthritis, vasculitis, and rheumatoid arthritis.

The Fellows Program was once again a rousing success and we look forward to the future research these bright young researchers will undertake. Input from all these stakeholder groups into the wide range of topics that were discussed was invaluable.

Topics included both disease-specific issues, such as fibromyalgia, gout, and vasculitis, as well as methods-specific issues such as the patients perspective, worker productivity, soluble biomarkers, single joint response, ultrasound, synovial tissue, flares in rheumatoid arthritis, and MRI in inflammatory arthritis. The proceedings of this consensus conference will be published in the Journal of Rheumatology in early 2009.

The results from the consensus voting will also be used to inform future outcomes measures and research agendas.

OMERACT is a group of more than six hundred researchers, patients and clinicians from the non-profit, business, and academic communities around the world who are interested in outcome measures in rheumatology.

For more information visit www.omeract.org

International research

The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) is a global collaboration of more than 300 thought-leaders including rheumatologists, dermatologists, radiologists, geneticists, methodologists, epidemiologists, representatives from patient associations and biopharmaceutical representatives.

The inaugural meeting of GRAPPA was held in August 2003, where a consensus exercise started the group towards prioritising key areas or domains of inquiry in psoriatic arthritis and psoriasis. Subsequent meetings focused on identifying and initiating research projects, advancing standardised criteria for psoriatic arthritis registries and developing treatment guidelines for PsA.

A goal for GRAPPA is to provide a forum for networking and communication between international researchers in rheumatology and dermatology, industry, patient associations and regulatory agencies. To become member of GRAPPA a membership form must be submitted and include support from two current GRAPPA members. There are no fees involved.

Members of GRAPPA are kept apprised of current research and data relating to diagnosis, treatment and aetiopathogenesis of psoriasis and psoriatic arthritis.

Members are asked to contribute to research in these areas. Members are also available to participate in meetings held adjacent to rheumatology and dermatology meetings.

The president of GRAPPA is Dr Dafna Gladman, professor of medicine and director of psoriatic arthritis program at the University of Toronto, vice president is Dr Philip Mease, clinical professor at the University of Washington School of Medicine in Seattle and chief of rheumatology clinical research at the Swedish Hospital Medical Centre.

Gladman and Mease are both internationally recognised as experts in their field.

GRAPPA 2008: Rheumatology and Dermatology Conference

This meeting was held in September in Leeds over 2 days. The meeting chair was Dr Philip Helliwell, senior lecturer in Rheumatology, University of Leeds.

The meeting had plenary sessions on imaging, composite measures in psoriatic arthritis and biomarkers. Members heard presentations on each topic and separate discussion groups debated issues relating to the presentations. At the end of the session, members voted on the points raised. These consensus decisions influence the future research agenda and make for rounded debate.

Although groups such as GRAPPA may not be well known amongst the wider public, the decisions and outcomes of such meeting are widely acknowledged.

What is cognitive-behavioural therapy (CBT)?

Cognitive–behavioural therapy and psoriasis

CBT is a therapy which aims to change how you think and what you do.

CBT can help you to change how you think; this is the cognitive part and what you do, the behaviour element. By changing the way you think about a situation, you can learn how to change your reactions or behaviour; this can help to change physical symptoms, such as stress or tension, which can change how you feel.

By exploring thinking styles and identifying the negative thoughts that affect our actions, CBT can teach us how to change these thought patterns and the behaviour that follows.

An example of negative thinking could be that you are invited into a situation where you think everyone will stare at you. This will make you behave cautiously, withdrawn and avoiding eye contact. Physical tension may develop palpitations, you start sweating or feel hot. You may become frustrated and low and become withdrawn.

A vicious circle can be established, and in turn keeps stress and anxiety going and makes this circle difficult to break. CBT aims to break this cycle by changing thinking styles.

Why do people with psoriasis need psychological support?

Psoriasis affects 2-3% of people in the UK and can create physical and psychological distress. Psychological discomfort is made worse by the visible nature of the condition. Many people may feel reluctant to expose parts of their body affected with psoriasis, and therefore tend to cover up with long sleeves, trousers, polo necks etc. even during hot weather spells.

It is well known some people avoid social interactions and activities they once enjoyed (eg. swimming). This can all lead to more psychological distress – feeling down, anxiety, stress, worry, negative thinking, low self esteem, and difficulties with coping. Although, not everyone feels the same.

It can be difficult to tackle these feelings alone, and generally services for people with psoriasis do

not include emotional or psychological support. The University of Manchester (departments of clinical psychology and dermatology) have embarked on a PAPAA funded study to help people manage psoriasis better. They have designed a programme, known as e-TIPS (electronic-Targeted Intervention for Psoriasis), which will provide a web-based Cognitive Behaviour Therapy (CBT) programme for people with psoriasis. CBT is a widely used approach in psychology and aims to help us understand that the way we think about a situation (the cognitive element in CBT) can affect the way we feel and the way we behave.

About eTIPs

This study which begins recruiting people in the autumn 2008, will run until December 2009. It aims to reduce psychological distress and improve psoriasis, help with coping and managing psoriasis better, improve quality of life, and increase feelings of confidence and positive thinking.

It will be delivered online so that it is widely available, and can reach out to individuals who may not wish to discuss psychological complaints face-to-face. Another benefit of using the internet is that participants can take part at their own convenience and in the privacy of their own home, and can also work at their own pace.

Participants will complete the web-based therapy over a six-week period and will be required to complete questionnaires at 3 or 4 different time points (including a six month follow-up). Participation is voluntary and available to all eligible people as long as individuals have been diagnosed with plaque psoriasis, are 16 years old or over, have working knowledge of the English language, and have internet access.

Research team: Professor Christopher Griffiths, Professor Nicholas Tarrier, Dr Christine Bundy, Ms Binder Kaur, Dr Sandra Bucci.

Recruits needed!

Please contact us if you wish to be considered to take part in the trial, We cannot guarantee that everyone will be included immediately, as allocation will be randomised.

For further information please

Email: info@papaa.org

Better support in Wales

New plans to provide better services for the thousands of people in Wales who suffer from chronically painful conditions such as arthritis and serious back pain were issued in June by the Welsh Assembly Government Health Minister, Edwina Hart.

Such conditions – termed chronic non-malignant pain (CNMP) – can affect anyone at any age and from any social background, with evidence suggesting that some forms of chronic pain are more prevalent in poorer areas.

One in four people with chronic pain report losing a job due to the barriers presented by their condition, one in five say their pain is so bad they want to die and a quarter have been diagnosed with depression because of their condition.

If even 10 per cent of the population had such pain every day there would be over two billion days of suffering in the UK – 30-40 days of pain for everyone. In 2002, over 4 per cent of the working population in the UK was on incapacity benefit, at a cost of £6.7bn. It is estimated that around one quarter of those were provided with incapacity benefit due to chronic pain conditions, mainly of the musculoskeletal system, including severe back pain.

Living with CNMP can affect individuals in a number of ways. As well as coping with physical pain, the pain experience can have a dramatic impact on self-esteem, social relationships, employment opportunities and personal finances.

The new plans will mean:

- earlier assessment, diagnosis and management of painful conditions
- more patient-centred services – planning and delivering services around the needs of the patient
- individuals will be supported to fully understand and cope more effectively with their conditions to help them get on with their daily lives and routines, and where appropriate return to work
- pain will be managed more effectively in community and primary care settings to help ensure that services are provided closer to people's homes
- fully engaging the skills and experiences of a wide range of appropriate health and social care professionals to ensure the individual's journey through the care system is clearly mapped out and actively supported.

The Minster for Health and Social Services, Mrs Edwina Hart, said:

"Chronic pain conditions such as back pain and arthritis are some of the most common and most debilitating conditions affecting people in Wales, impacting upon the everyday lives of individuals in devastating ways…

…The Welsh Assembly Government is committed to ensuring that services are more patient-centred and delivered closer to people's homes wherever appropriate, enabling individuals to live their daily lives more easily…

…This plan will help to ensure that pain services are improved across Wales, enabling people living with chronic pain to positively manage their pain experience, return to work wherever possible and live more independently, while also helping to reduce the wider economic costs to society…"

Scotland accepts steroid based shampoo

The Scottish Medicines Consortium (SMC) in August accepted clobetasol propionate 0.05% shampoo for use within NHS Scotland for the topical treatment of moderate scalp psoriasis in adults, as a short course treatment of steroid-responsive dermatoses of the scalp such as psoriasis, which do not respond satisfactorily to less active steroids.

The decision follows a previous rejection in February, when clinical equivalence to existing topical formulations of clobetasol propionate had not been demonstrated. The drug advice notes now show that a comparison of clobetasol propionate 0.05% shampoo to another clobetasol formulation demonstrated non-inferiority and costs are similar.

The active agent in clobetasol shampoo belongs to a group of medicines called topical (meaning applied to the skin) corticosteroids. It reduces the redness, itchiness and inflammation of scalp psoriasis.

A study has shown that clobetasol shampoo worked almost as well as another product containing clobetasol (clobetasol gel). Clobetasol shampoo was not compared with commonly used clobetasol products so it is not known if the shampoo works as well as these other treatments. There is some evidence that clobetasol shampoo is safer than other clobetasol products.

SMC accepted clobetasol shampoo for use within NHS Scotland because it extends the choice of treatment for this condition and costs about the same as existing treatments, which include traditional tar based products, steroid lotions and vitamin D scalp applications

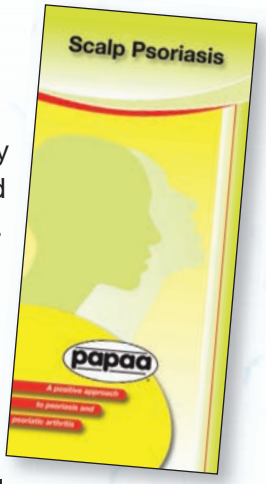
The shampoo is marketed in the UK by Galderma (UK) Ltd. under the brand name Etrivex and is only available on prescription from your doctor.

New treatment for scalp psoriasis approved in Europe

Another new treatment for scalp psoriasis has been approved in 16 European countries. The product is a once-daily topical suspension containing a combination of calcipotriol and betamethasone dipropionate (a steroid) for the treatment of moderate to severe psoriasis vulgaris of the scalp in adults. The product is made by LEO Pharma and is marketed under the brand name Xamiol®. It will be available as a prescription-only medicine (POM) from a doctor.

According to the press release from LEO Pharma, the UK will be the first country to market Xamiol® at the end of 2008. The company already markets another scalp psoriasis product called Dovonex Scalp Lotion, which contains calcipotriol.

New scalp psoriasis booklet



Scalp psoriasis is consistently one of the most searched items on the PAPAA website. As part of our process to be inclusive of those who may not be able to access the internet, we have produced a new booklet called Scalp Psoriasis based on the website text, which is available free of charge, via healthcare professionals or by directly contacting us. The booklet has sections on treatments and tips to try and alleviate this annoying aspect of psoriasis.

For those of you who can access the internet, an easy print version is available at www.papaa.org

We also have a list of all items which are on our website, and these can be ordered from us as hard copies. Contact us and we'll be pleased to send you the list.

Books (available from PAPAA)

Psoriatic arthritis - the facts

D Gladman, V Chandran

In Psoriatic Arthritis: The Facts, the authors draw on their experience from one of the largest clinics in the world dedicated to understanding and managing patients with psoriatic arthritis. Highlights include what is known about the causes of psoriatic arthritis and clinical features, along with the emotional impact that this condition has on patients' lives and how to successfully manage the condition.

Price: £12.99 (Paperback)

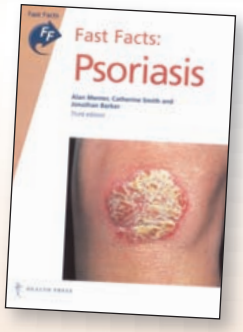
ISBN-13: 978-0-19-923122-5

Published by: Oxford University Press

Readers' offer: For a 20% discount available on this title visit: http://www.oup.co.uk/sale/webpapaa

Fast Facts: Psoriasis 3rd Edition – 2008

A Mentor, C Smith and J Barker



This book is aimed at the whole primary care team, trainee dermatologists, and established dermatologists and rheumatologists who need a quick refresher.

It provides the busy practitioner with 108 pages of practical information on all aspects of this increasingly treatable disease. Now in its third edition, this comprehensive handbook embraces the full spectrum of the disease, from localised plaques to generalised disease and psoriatic arthritis.

Highlights include:

- a well-illustrated guide to clinical presentation and differential diagnosis
- fully updated treatment chapters, covering the wide array of current and emerging therapeutic agents
- a commonsense approach to management by rotating and combining therapies
- discussion of the co-morbid conditions so often overlooked
- a concise review of the immunologic and genetic aspects of the disease
- a clear summary of the new classification scheme for psoriatic arthritis

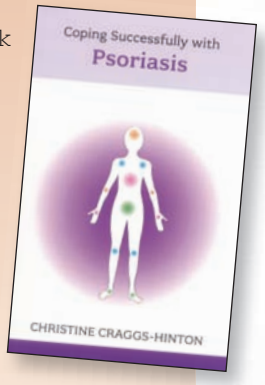
Special readers' offer: £6.00 (RRP £10.00). Visit www.fastfacts.com and enter coupon code SP6 at the checkout to receive the discount.

ISBN: 978-1-90373-403-2

Published by: Health Press Limited

Coping Successfully with Psoriasis – New - 2008

C Craggs-Hinton



Written by Christian Craggs-Hinton, who took up writing for therapeutic reasons following the development of fibromyalgia. During the past few years Christine has written more than a dozen health related books.

This paperback book runs to more than 140 pages with most elements of psoriasis covered in an easy reading style. The section headings include: types of psoriasis, creams and lotions, pills and injections, phototherapy, and complementary therapy. There is also a useful addresses section and further reading list.

Price: £7.99

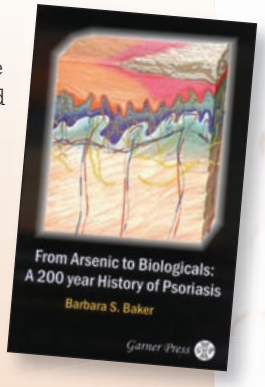
ISBN: 978-1-84709-047-8

Published by: Sheldon Press

From Arsenic to Biologics: A 200 year History of Psoriasis - New - 2008

B S Baker

This is a chronological description of how the unravelling of the mechanisms underlying psoriasis have led to a change from the empirical "try it and see" treatments of the 19th and early 20th centuries to the evidence-based treatments of the present day.



The book describes the various theories proposed to explain psoriasis and the introduction of new treatments, decade by decade, throughout the 20th century. These range from the belief that psoriasis resulted from an internal metabolic disturbance in the 19th century, when arsenic was the systemic treatment of choice, through to the 21st century when the recognition that psoriasis was a disease of the immune system enabled the development and use of therapeutic biological agents.

This book would be of interest to individuals with psoriasis, dermatologists or skin researchers, or anyone studying the history of medicine.

Price: £15.99

ISBN: 978-0-955-16032-5

Published by: Garner Press

For full list of publications to purchase visit: www.papaa.org or contact us.

Independent living in Scotland

A new long-term approach to help improve the daily lives of disabled people, backed by £600,000 from the Scottish Government, was announced today.

Communities Minister Stewart Maxwell promised to ensure that disabled people would feel valued as individuals and have the same choice, control and freedom as any citizen.

''The Scottish Government believes that disabled people should be valued as individuals, be able to fulfil their potential as active citizens, and have control over their lives and decisions.

''We have already made a great deal of progress in enabling more disabled people to participate and engage fully in society.

''We recognise that independent living, in its fullest sense, is still out of reach for some. Working in partnership with disabled people and other public bodies, the approach I am setting out today will help us to determine what we need to do to deliver long-term change for disabled people across Scotland.''

The Government and public sector bodies would work together to identify ways to break down the barriers which stop disabled people fulfilling their full potential in areas such as housing, transport, employment and education.

Morag Alexander, Scotland Commissioner, Equality and Human Rights Commission, said:

''This marks a step change in ensuring that all disabled people are afforded the opportunity to make real choices in how they live their lives.

''We recognise that it may take years to remove all of the barriers which currently prevent disabled people from fulfilling their social and economic potential.

''The Government's announcement is an encouraging statement of purpose towards increasing disabled people autonomy.''

Bill Campbell, project manager of Inclusion Scotland, said:

''As a national organisation of disabled people, whose aims and objectives are firmly rooted in the social model of disability and the principles of independent living, we welcome the Minister's announcement.

Lisa Curtice, from the Scottish Consortium for Learning Disability, said:

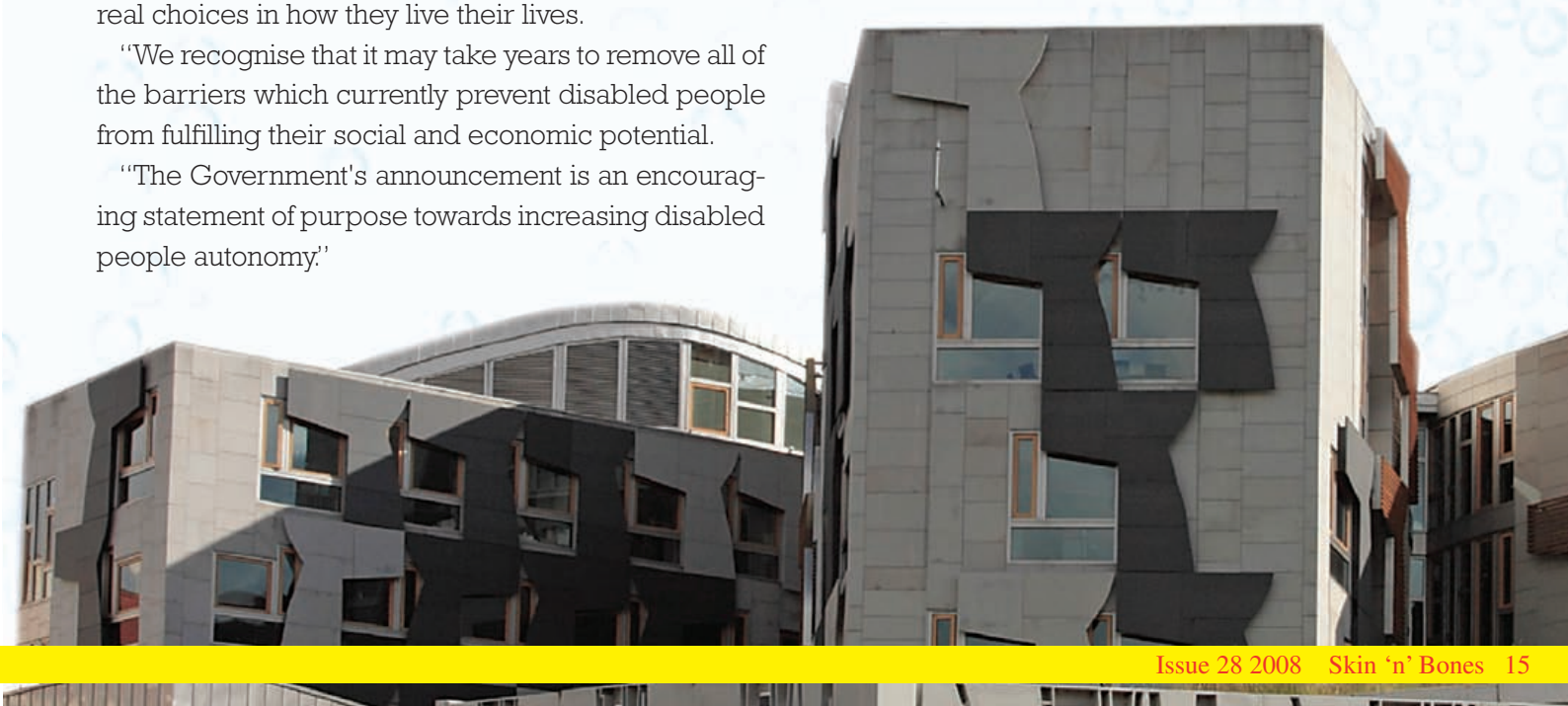
''The Scottish Consortium for Learning Disability is delighted that the Scottish Government sees independent living as a priority. People with learning disabilities want control over their lives. As equal citizens, they should have access to the support they need to play a full part in the life of their community.''

Etienne d'Aboville, chief executive of the Glasgow Centre for Inclusive Living, said:

"Glasgow Centre for Inclusive Living welcomes the Minister's announcement that the Scottish Government will be working with key agencies and, crucially, with disabled people, our organisations and our allies, to develop Independent Living in Scotland.

''Independent Living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. This initiative presents an unprecedented opportunity to address the barriers to Independent Living and to finally make it a reality for disabled people in Scotland.''

Source: www.scotland.gov.uk



Letters

Q Dear PAPAA,

Thank you for the leaflets and info on psoriasis.

I have recently developed what I think is psoriasis of the nails. I have always suffered from psoriasis of the scalp, but the prolem with the nails is new.

I wonder if you are able to advise me as to where I can obtain Vitamin D cream. I have tried various chemists, who tell me that I need a Doctor's prescription - is that really necessary.

Look forward to your reply

Many thanks

C

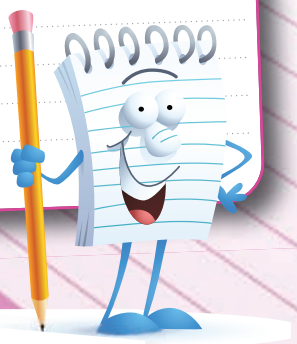
A Dear C,

Vitamin D analogue creams are only available on prescription. Calcipotriol (Dovonex) is the most commonly prescribe but there are other products Calcitriol (Silkis) and Tacalcitol (Curatoderm). The problem with nails is that once they are visible there is little that can be done apart from cosmetic camouflage such as nail varnish. The research on the use of vitamin D creams on nail has concentrated on applying the cream to the cuticle or below the area where the nail starts to grow.

There should be no reason why your doctor would not give you a prescription unless there are other circumstances that exclude you. Consult your doctor for further advice.

We do produce a leaflet on nail psoriasis which is available from us or can be downloaded from our website.

Papaa



Q Dear PAPAA,

Just wondered if you'd be able to give me a bit of advice really. I was diagnosed with psoriatic arthritis a couple of years ago. Early part of last year I was put on methotrexate. For the past 2 months my liver count has gone quite high (113 at one point), so 3 weeks ago I was taken off methotrexate and my bloods have started to get back down (75 last week).

I really don't want to go back on the methotrexate as I feel a lot better in myself and it appears obvious that it wasn't doing my liver any good.

I understand that I may have to go on different tablets but I just wondered what ones you would recommend or if you could give me any advice please before I go to see the consultant. Thank you,

CS

A Dear CS,

We are not in a position to give advice or recommend any particular treatment, as your doctor will be in the best position to know your individual circumstance. Methotrexate can take some time to get to a dosage that is tolerated and effective. Liver function does usually return to normal once treatment is stopped. Methotrexate is classed as a second line therapy of which there are others, such as ciclosporin and sulphasalizine, but again your doctor will need to assess your suitability and any other factors that may impact on such treatments, these could include other treatments or conditions you may have.

Treatment usually follows a guideline table and doctors will step through the treatments and change therapy based on results or adverse reactions, but this should be done in agreement with patients.

The best advice we can give is to find out as much as you can about the available treatments, ask your doctor why he/she has decided on the current course. What are the potential risk/benefit of using treatments in your circumstance and what are the alternatives you can have, if you find the side effects of your current therapy unacceptable.

We do have a list of available treatments on our website, or we can send you printed copies of this information.

Best wishes

Papaa

Complementary therapies explored - NMT

Readers were enquiring about the the Gaynor Hughes article (Skin 'n' Bones - issue 27, page 12) web addresses:

www.positive-healing.co.uk
www.therapynetworkonline.co.uk

Q Dear PAPAA,

I suffer from pustular psoriasis and psoriatic arthritis which flares up as the weather warms up. I have recently taken up water aerobics to lose weight and generally feel better in myself. Alas, my psoriasis is out of control; can you recommend anything to help guard my skin from the water?

Thank you

JM

A Dear JM,

This is an interesting question; you could ask your instructor about what can be used on the skin in the pool as there may restrictions or rules that apply. It might also be worth finding out which chemicals are being used in the pool, as these may be affecting your skin. Some spas and leisure centres use alternate water treatments, other than chlorine. You may be interested to look at the Pool Water Treatment Advisory Group's website, which has some interesting information. www.pwtag.org

Papaa

Q Dear PAPAA,

I have just discovered your website and would like to know whether I can be of help? I was diagnosed with what they thought was rheumatoid arthritis at 25 after the birth of my first child. I was later re diagnosed with psoriatic arthritis 10 years later when I discovered a proper rheumatology hospital! This made more sense as my father has very severe psoriasis; however, we never made the connection as I had never heard of the arthritis connection. Luckily I have managed to avoid the psoriasis skin condition and only have severe arthritis, which may sound odd but in our situations you take any blessings you can get. So far I have had my knee replaced and am on the road to having the other one done. Both my father and I seem to have tried every drug known to man and would obviously like to help in any way we can with regard to research etc.

Many thanks

ED

A Dear ED,

As you will see [page 10] that we are currently funding research at the University of Manchester. We are also currently looking at other areas where we can support research or involve those in contact with PAPAA. We'll post details on the website and in future journals. *Papaa*

Q Dear PAPAA,

I recently joined PAPAA. I have had psoriatic arthritis for about 18 years; it affects both elbows, knees, ankles and left hip. My joints are permanently swollen and quite stiff in the mornings, but not too painful apart from the occasional painful flare-ups of my hip and knees. These occur very suddenly and can go again as quickly (e.g whilst out walking, I can suffer extreme pain in my hip but, after 15 mins rest, the pain will pass). At other times, the pain can take a few days to go.

I have taken NSAIDs when the joints flare up and have had several corticosteroid injections into my knees/elbows. My rheumatologist is very keen for me to go onto sulphasalazines, as she is worried about the joint damage that is occurring and how crippled I may be in the future (I am 47 now). I am concerned about the potential side effects of the drug and its percentage chance of helping.

Could you give me any advice/personal experience of the drug and whether it would be a good idea to consider this drug? Just recently, I have had a lot of pain in my hip for 4 weeks and it is not responding well to NSAIDs.

Could you tell me the common course of the disease and whether it is usual to have flare ups that go on for so long? Should NSAIDs always help?

Thank you *AS* By e-mail

A Dear AS,

Thank you for your e-mail. It is a common pattern with psoriatic arthritis for it to flare and then wane; the unpredictability is an annoying issue and can last for days. Most people with PsA will recognise this problem.

Sulphasalazine is used as a second line therapy and has a slower but more lasting effect on the disease than NSAIDs, although like all treatments, it may not work in everyone. Other second line treatments include methotrexate and ciclosporin which suppress the immune system. Your doctor will have considered your circumstances and decided on which is the best course for you, but if you are unsure ask for more information or a potential alternative that would suit you. There may be other combinations that you may feel happier to try.

NSAIDs are a standard treatment, but don't always appear to work, although there are a number of different types and a change may make a difference. Ask you doctor if you can try a different version or whether the dose is sufficient. You may consider asking to be referred for pain management or physiotherapy, these can provide ways of developing coping and management strategies.

If you need further information please contact us again, we do have a medical advisory panel who will answer more complicated questions.

Papaa

Please note: letters and e-mails have been edited and names withheld for privacy

Turmeric no better than placebo

Anecdotal evidence touting the healing power of the Indian spice turmeric for psoriasis received a setback in a prospective study published recently by a leading dermatology journal stating that the low response rate of patients who ingested the active ingredient of the exotic spice was probably a result of the placebo effect.

Researchers at the University of Pennsylvania School of Medicine found that despite strong scientific evidence in the laboratory demonstrating the ability of curcumin (the active ingredient in the spice turmeric) to inhibit a critical pathway of psoriasis, the positive response in patients was so low that scientists suggest the placebo effect or the disease's natural remission might be the reason. The study was published in the Journal of the American Academy of Dermatology.

"Alternative and complementary websites and newspapers publish anecdotal reports that the Indian spice has been successfully used to treat psoriasis," says Joel M. Gelfand, MD, MSCE, of The University of Pennsylvania School of Medicine. "However, spontaneous improvements in psoriasis are common, and based on our study, until larger, placebo-controlled trials are conducted, oral curcumin should not be recommended for the treatment of psoriasis given lack of proven efficacy."

But the researchers do not discount entirely the potential of curmumin as a treatment for psoriasis.

They recognise that current traditional pharmacologic approaches in the treatment of psoriasis are costly and have their limitations, including the risk of infections and possibly malignancies with long-term use resulting in many patients with the disease unable to achieve effective long-term control. Turning to complementary and alternative therapies is understandable, they say. In fact, of the estimated 7 million diagnosed with psoriasis, it is estimated that 51% use complementary and alternative medicine therapies to treat their skin.

The excellent responses that were observed in two of the 12 patients in the study suggest that curcumin may have promise for a small subset of patients with psoriasis. Large, placebo-controlled trials are necessary to definitively prove or disprove oral curcumin as a potential therapeutic agent for psoriasis. "What is needed is scientific data to assess the safety and efficacy of these treatments so that we may more rationally inform patients of their treatment options," says Gelfand.

Source: www.eurekalert.org

New public medicines info website launch

The Medicines and Healthcare products Regulatory Agency (MHRA) and the Association of the British Pharmaceutical Industry (ABPI) have launched a new website to provide authoritative information on medicines to the public.

The site, at www.mhra.gov.uk/mymedicine, provides a guide to the lifecycle of new medicines, from first discovery through to licensing and ongoing monitoring. It shows how scientists pinpoint diseases and set about finding compounds which can combat specific illnesses, and describes the clinical trials and licensing processes through to post-approval monitoring for safety.

Karen Miller, a director at the ABPI, points out that more and more people are going online to find out about health-related issues, and that while the internet is "a superb resource," it contains a lot of disinformation. ''With the MHRA, we wanted to create a website which provides an authoritative and reliable source of information which explains the time and effort invested into medicines before they arrive in the medicine cabinet,'' she said.

''Medicines can bring big benefits, but as with any medical treatment, no medicine is risk-free. By making as much information as possible publicly available, we can help people make informed choices about the medicines they take,'' added the MHRA's chief executive, Professor Kent Woods. ''We want to make sure people understand the relationship between the risks and the benefits and we encourage people to tell us about any problems they have with a medicine, so that we can investigate and help make medicines safer,'' he noted.

Anne Joshua, associate director of pharmacy at the National Health Service (NHS) online and telephone advice service NHS Direct, welcomed the new resource. NHS Direct regularly receives calls from people about new treatments and their availability on the NHS, she said. Typically, they may have heard about the treatment in the media and want to know about the benefits and risks for treating their particular condition or, as a carer, if it is available for an elderly relative with more than one long-term condition.

''If the medicine is still undergoing investigation they may want to know how they can join a clinical trial or if a clinical specialist can prescribe it for them anyway,'' said Ms Joshua, adding: ''this new web resource will provide the necessary reassurance to patients and their families about how new medicines are rigorously tested before they are available to the public and what measures are taken to ensure the safety of newly licensed medicines as they are used across the range of conditions that they treat.''

www.mhra.gov.uk/mymedicine

NICE issues guidance on the use of adalimumab

The National Institute for Health and Clinical Excellence (NICE) published guidance in June on the use of adalimumab for the treatment of psoriasis in adults.

Adalimumab is recommended as a possible treatment for adults with plaque psoriasis only if:

- their condition is severe and
- their condition has not improved with other treatments such as ciclosporin, methotrexate and PUVA (psoralen and long-wave ultraviolet radiation), or they have had side effects with these in the past or there is a medical reason why they should not be given these treatments. Adalimumab treatment should be continued beyond 16 weeks only if the psoriasis has clearly improved within this time.

The severity of a person's psoriasis before and during treatment should be assessed by considering the redness, thickness and scaliness of the plaques, the area of the body involved, and how the condition affects the person's quality of life.

When assessing a person's psoriasis, healthcare professionals should take into account any disabilities or difficulties in communicating the person might have, which might mean that standard assessments do not provide accurate information about their condition.

Professor Peter Littlejohns, NICE clinical and public health director and executive lead for this guidance said:

"Psoriasis is an extremely debilitating disorder that is estimated to affect 2% of the population. A UK study of people with severe psoriasis found that 60% had taken time off work as a direct result of their condition, many requiring hospitalisations. Today's guidance recommending the use of adalimumab will ensure adults with severe psoriasis are able to access a treatment of proven benefit."

About adalimumab

Adalimumab improves psoriasis by interfering with a substance in the body (TNF alpha) that is involved in the development of inflammation. Adalimumab is prescribed by a specialist and is injected under the skin. Once specialist training has been given, adalimumab can be self-injected. Repeated doses are given 1 week after the first dose and then every 2 weeks.

What does this mean for me?

When NICE recommends a treatment, the NHS must ensure it is available to those people it could help, normally within 3 months of the guidance being issued. So, if you have plaque psoriasis, and your doctor thinks that adalimumab is the right treatment for you, you should be able to have the treatment on the NHS.

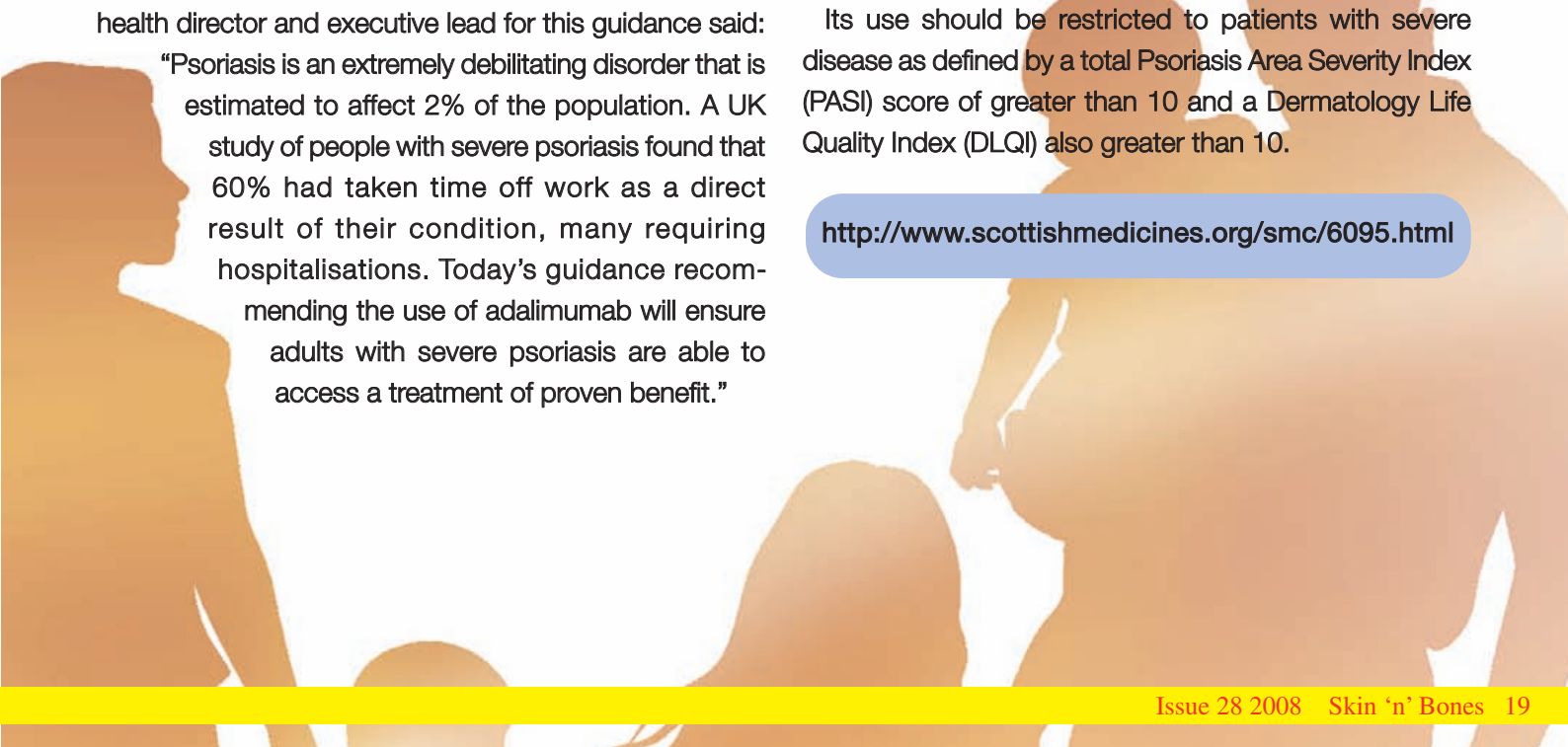
Please see www.nice.org.uk/aboutguidance if you appear to be eligible for the treatment but it is not available.

The Scottish Medicines Consortium (SMC) has completed its assessment of the adalimumab and advised NHS Boards and Area Drug and Therapeutic Committees (ADTCs) on its use in NHS Scotland. The advice is summarised as follows:

For the treatment of chronic plaque psoriasis in adult patients who failed to respond to or have a contraindication to, or are intolerant to other systemic therapy including ciclosporin, methotrexate or PUVA.

Its use should be restricted to patients with severe disease as defined by a total Psoriasis Area Severity Index (PASI) score of greater than 10 and a Dermatology Life Quality Index (DLQI) also greater than 10.

http://www.scottishmedicines.org/smc/6095.html



MARKET PLACE

Here are a few items that have been brought to our attention by our readers. These are for your interest and in no way are we endorsing or recommending these products.

We've been sent some interesting items for this edition, so thank you if you have provided suggestions.

From ***Easylife Lifestyle Solutions***, a gel ball-of-the-foot cushion. This item is designed to relieve friction pain and discomfort for sore feet. Supplied in individual packs (one for each foot) the product is odourless, washable and re-useable.

Code: 1104. **Price £9.99**

Solutions from ***Renwoods*** have a one-touch electric **peppermill**, which operates by a simple touch of a button.
(4 x AA batteries not supplied)

Code: 102 4457.
Price £15.95

Also from ***Renwoods*** a device to help pull out a standard electric plug. Supplied in a pack of ten.

Code: 108 5170.
Price £8.95.

For cat lovers, how about a spectacle holder from ***The Cat Gallery***, which pins onto your lapel giving a safe place to secure your glasses.

Code 16847
Price £6.50

An interesting product which has been suggested is the ***Electro-Reflexologist***, developed by doctors and electronic engineers. Uses safe low-frequency electro-waves to stimulate reflex zones, acupoints, nerves, muscles and capillaries. Comes with 6 electrode pads with cables, allowing TENS-style pain relief on all parts of the body Class 2A Medical Device, which is mains powered. Available from a number of outlets including *Viva Direct* and *Amazon*. Model number ER-839S

Prices vary but range between £160-£200.

PainWave X4000

The PainWave is a pulsed electromagnetic wave therapy system delivering fast and effective non-drug pain management.
The Pioneering Class 2A Medical Device has taken years of research, matching well known scientifc methods with modern technology and is designed to help relieve the chronic pain assocation with many conditions.

From Altwood Pharmacy Price £139

Contact details for the above products:

Easylife lifestyle solutions
0871 855 2000 www.easylifegroup.com

Renwoods
0844 482 1555 www.renwoods.com

The Cat Gallery
01904 413000 www.thecatgallery.co.uk

Viva Direct
0844 482 1616 www.vivadirect.co.uk

Redland Healthcare
0118 956 0800 www.redlandhealthcare.co.uk

Amazon
(Online only) www.amazon.co.uk

Altwood Pharmacy
01628 500 977 www.altwoodpharmacy.com

If you come across products or items that you have found useful or you think others will find of interest please let us know. There may be similar products on the market made by other manufacturers that are as useful so keep your eyes open as this page is designed to offer some useful gadgets.