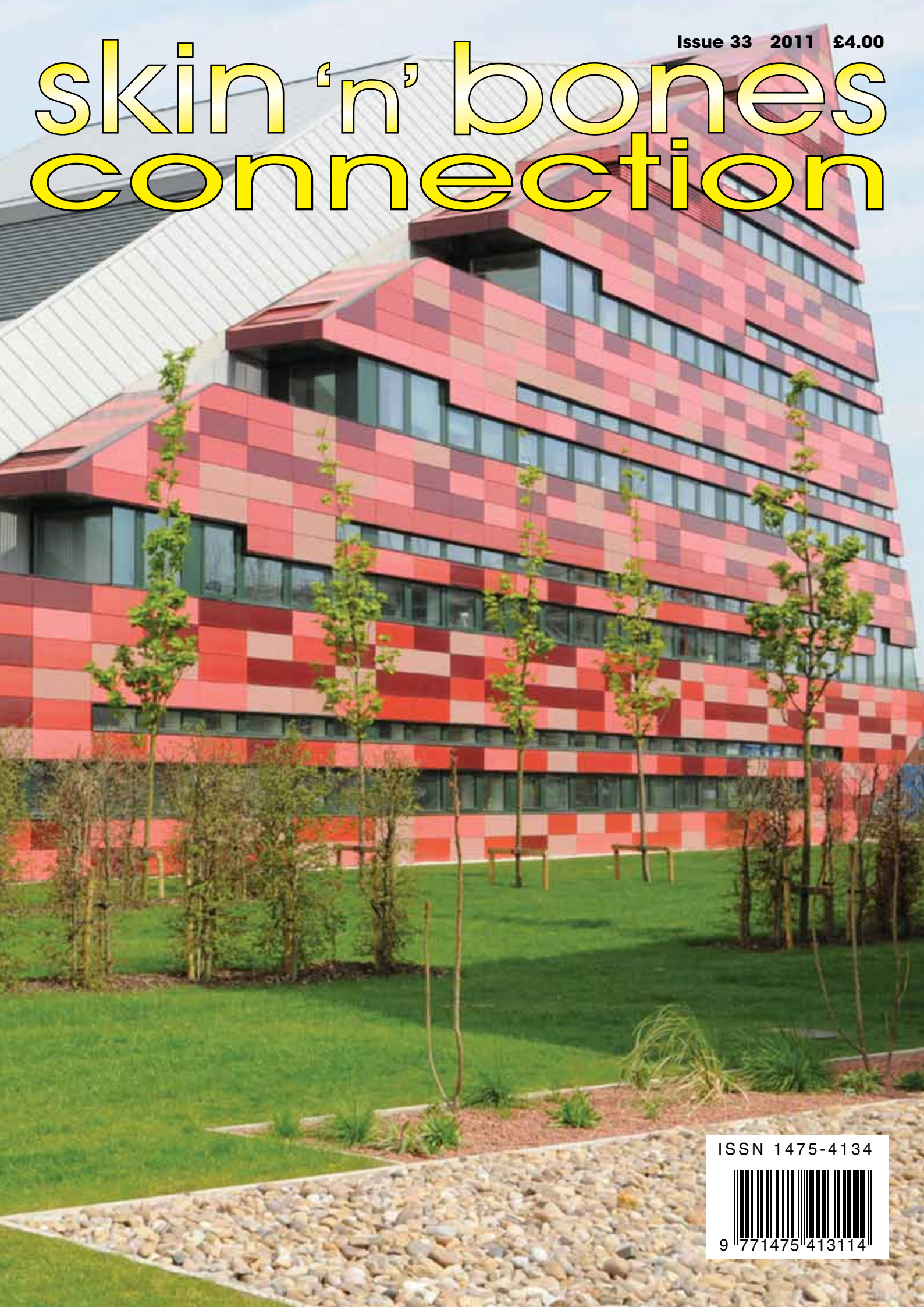
Issue 33 2011 £4.00

# skin 'n' bones connection



ISSN 1475-4134

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Correspondence Address:
PAPAA
PO Box 111
St Albans
Hertfordshire AL2 3JQ
E-mail: info@papaa.org
Web: www.papaa.org
Tel: 01923 672837
Fax: 01923 682606

Production team:
Julie Chandler
Managing Editor

Typesetting and Design
Macpro Design and Print Ltd, St Albans

Printing
Photolit Printing Ltd · St Albans

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Registered office: Acre House 11–15 William Road, London NW1 3ER

## Dear Reader

Welcome to the latest edition of Skin 'n' Bones Connection. In this issue we have highlighted some interesting activities and research studies that have taken place recently.

As you will see, we have achieved Information Standard member status (see page 3), which required us to provide evidence of our commitment to the process and also that our information is reliable and can be trusted.

On the subject of reliable evidence, we are often asked about 'miracle cures', particularly natural or herbal remedies that appear in news and media items. The best advice we can give is look for evidence, which unfortunately rarely exists. To alleviate this problem and to try and reassure consumers, new European Union legislation recently came into force called The European Traditional Herbal Medicinal Products Directive 2004/24/EC. From 30 April 2011, all over-the-counter manufactured herbal medicinal products placed on the UK market will need either a Traditional Herbal Registration (THR) or product licence; this will require the product to meet standards of safety, quality and efficacy (or effectiveness).

To know that a treatment or product works is an important aspect of living with a chronic condition. Although some clinical trial evidence does not always translate into positive outcomes in real life settings, it is vital to continue to research and test out theories in order to improve and refine the best possible care for patients and consumers.

Managing editor



**Subscription rates:**
United Kingdom - £12.00 (Renewal Rate £8.00) per annum - 2 issues
International - £24.00 (Renewal Rate £16.00) per annum - 2 issues

**Publication Dates: May and November**

**Contribution Copy Dates: 28th February and 31st August**

Skin 'n' Bones Connection is registered as a magazine ISSN: 1475-4134

**Cover Photo:**
The Jubilee Campus at Nottingham University; described in The Observer, Sunday 2 January 2011 as "… a set of wedges mottled with a psoriasis of red cladding…".

## About the Information Standard

**The Information Standard is a certification scheme for health and social care information. It is an independent scheme supported by the Department of Health. Any organisation that produces health and social care information can apply to join the scheme. If an organisation successfully meets the quality criteria of the standard and becomes certified, it can place the quality mark on its materials. The quality mark is a quick and easy way for the public to identify reliable and trustworthy sources of information. The scheme's certified members are a mix of national charities, NHS organisations, voluntary, statutory and commercial organisations. The scheme is growing as more organisations are in the process of gaining certification.**


We are pleased to announce that PAPAA has been certified as a provider of high quality health and social care information by The Information Standard scheme. We met the scheme criteria of producing safe and reliable health and social care information. PAPAA has consequently been awarded The Information Standard quality mark, which can be displayed on our literature and website illustrating to the public that the information can be trusted.

According to a survey carried out by The Information Standard, the majority of the general public (72%) believe that they would be better able to manage their own and their family's health if they had quick and easy access to health information they could trust. The Information Standard, which is supported by the Department of Health, was launched to provide this kind of assurance.

Angela Coulter PhD, Hon FFPH, Hon FRCGP, an independent healthcare analyst who advises on the scheme, commented: "Organisations that become certified members of the scheme, and therefore display The Information Standard quality mark on their health information or social care materials, have proven that they adhere to the very highest standards of information production. The public can feel confident that if they see The Information Standard quality mark on health and social care websites or leaflets then the information can be trusted and relied upon."

**For more information:**
**www.theinformationstandard.org**

## We need your help

**As part of The Information Standard scheme we have developed a patient user group to review all written material.**
**We are grateful to those members of PAPAA who have already agreed to carry out this role.**

**If you would like to get involved in reviewing our material then please get in touch.**

**For more information about the role and specification contact:**
**Caroline Marven on 01923 672837 or email cjm@papaa.org**

# Psoriasis – evidence-based update meeting

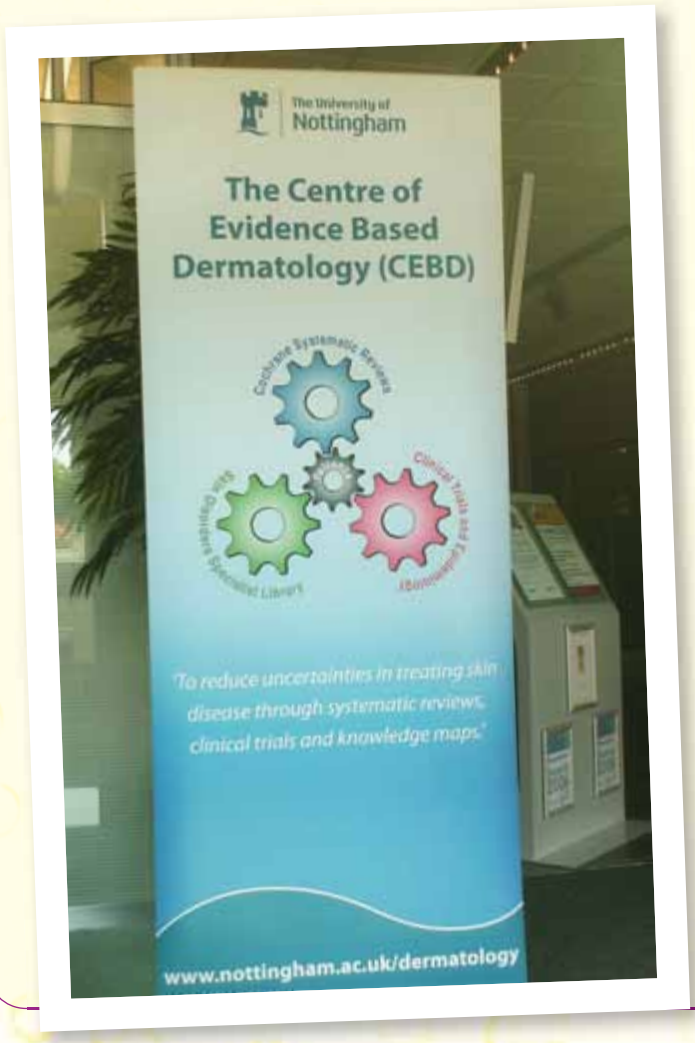
**PAPAA recently attended the psoriasis evidence based update meeting in Loughborough organised by the UK Dermatology Clinical Trials Network (UK DCTN) on behalf of the Centre of Evidence Based Dermatology (CEBD) based at the University of Nottingham.**

Each spring the CEBD holds an annual-evidence based update meeting. This year psoriasis was the chosen topic following suggestions given by delegates who attended last years' meeting.

The meeting was introduced and chaired by Professor Hywel Williams, who is also director of the Centre of Evidence Based Dermatology.


Image courtesy of K Dermatology Clinical Trials Nework, University of Nottingham

Caroline Marven (left) from PAPAA




Subjects discussed and presented at the meeting included a topical treatments for psoriasis update by Dr Anne Mason, an overview of three recent studies investigating the use of ultraviolet (UV311nm) and biologics for the treatment of psoriasis, by Prof Peter Wolf from Austria. The studies suggested that the use of biologics and UV311nm would be a promising approach and further investigation would be useful.

Dr Anna Christa de Vries from the Netherlands spoke about interventions for nail psoriasis. The presentation explored outcomes of trials of treatments following a search of published papers. The conclusion was that whilst most were single study trials, some treatments did appear to improve nails, but the quality of the studies were poor and therefore couldn't provide good recommendations. Future studies need to be more rigorous in design and allow for better comparison and validation.

Dr Adrian Tanew, also from Austria, presented a comparison study of fumaric acid ester (FAE) PUVA (psoralen plus ultraviolet A) therapy versus acitretin PUVA therapy for the treatment of pustular palmoplantar psoriasis (PPP).

PPP is notoriously difficult to treat, but the trial did suggest that the (FAE) PUVA intervention was as effective as PUVA alone.

After lunch a question and answer session took

place with the experts panel.

Once the delegates had taken a quick coffee break it was back in to hear UK Professor Jonathan Barker present genotyping psoriasis and the implications for personalised medicine. Genotyping is a process of determining which genes within an individuals' DNA are responsible for the development of particular diseases and the severity. The ultimate aim is to be able to use genetic information to personalise psoriasis care by developing prevention measures and individualised therapeutics.

The final presentation of the day was left to Professor Christopher Griffiths, who is the Foundation Professor of Dermatology and Associate Dean for Research, Faculty of Medical and Human Sciences, University of Manchester. The basis of the presentation was the dilemma of how to stop a biologic treatment and then start a different biologic drug. In some cases biologics should be stopped, such as in pregnancy or prior to an elective surgical procedure. There is some data demonstrating when etanercept can be stopped and restarted as an intermittent therapy, but further studies and long-term data needs to be collected to get a better picture. A biologic register (BAD Biologics Intervention Registry – BADBIR) of patients on biologics is being carried out and this should provide more comprehensive information for the future.

PAPAA information

Closing remarks were provided by Professor Hywel Williams; the delegates were given an interesting day and much food for thought.


Time for a break and coffee

**British Association of Dermatologists Biologic Intervention Register or BADBIR is an observational, prospective study open to patients undergoing treatment for psoriasis with either a biologic drug or a standard anti-psoriatic therapy. Please speak to your dermatologist if you are interested in becoming involved as several eligibility criteria apply.**

## About the UK Dermatology Clinical Trials Network

**The UK Dermatology Clinical Trials Network (UK DCTN) was formed in February 2002, with the aim of conducting high quality, multi-centre clinical trials that answer questions of importance to clinicians and patients. It involves a collaborative network of dermatologists, dermatology nurses, health services researchers and patients throughout the UK and Southern Ireland.**

**UK DCTN is co-ordinated by a small team within the Centre of Evidence Based Dermatology.**

**Website: www.ukdctn.org**

**An unprecedented 140 delegates attended the annual GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) meeting in Miami, 10-12 December 2010. This wasn't just because of the attraction of temperatures in the 70s in December but also because Miami is only a short journey for people from Central and South America. More dermatologists, who comprised 30% of those attending. Such a large group discussion was always going to be vigorous and challenging but this was healthy and resulted in rigorous outcomes, new collaborations and a strengthening of the link between the two specialties**.

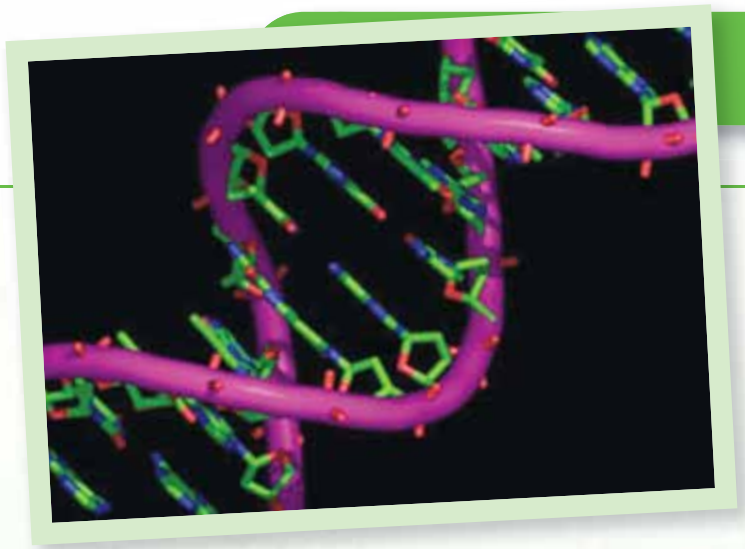
The first session, always a crucial one, concerned the development of an index to measure the effect of new therapies on psoriatic arthritis. It has become clear in recent years that psoriasis is only one aspect of the disease and there are strong advocates, particularly from Italy, who would lump all the manifestations under one umbrella, called psoriatic disease. This means that we should take into consideration much wider aspects of the disease in clinical trials. In the past drugs, such as the new biologic anti-TNF drugs, have been measured only in terms of joint or skin inflammation, and rarely together in the same trial. The new measures promise to evaluate other and more varied aspects of the disease such as enthesitis, dactylitis and involvement of the spine. The GRAPPA membership, which comprises over 350 physicians worldwide, is now collecting information on over 450 patients with psoriatic arthritis in order to develop this new composite measure of disease activity. This will mean that, in future, all facets of the disease will be taken into account when using new treatments. This may also include aspects of the disease usually neglected such as obesity, high blood pressure and high cholesterol, all of which may contribute to an increased risk of heart attack and stroke in psoriatic arthritis.

*Philip Helliwell GRAPPA*

That first full session set the agenda for the rest of the meeting. People were happier to speak up and to make their voices heard. Contributions from clinicians, epidemiologists and laboratory scientists really made an impact and the good thing is that, although many of these people were not 'big names' they were listened to and respected as part of this process. Many delegates noted this, and I think it occurs as a result of a refreshingly open and inclusive approach to the organisation.

And so to other issues. What do rheumatologists mean by musculoskeletal inflammation? This is an important question as dermatologists are often the first people to encounter psoriatic arthritis in their psoriasis patients. To have clear guidelines for recognising arthritis would help pick this condition up earlier. Rheumatologists and dermatologists are also working together to develop a screening questionnaire to detect arthritis. There was a lot of animated discussion but such symptoms as prolonged morning stiffness in the joints, warmth and swelling and improvement with anti-inflammatory drugs were thought to be helpful. The dermatologists at the meeting felt that they could, with further training, recognise the features of arthritis themselves. Of course many of the oral drugs used for arthritis and psoriasis are the same, so that both skin and joints benefit. There was also discussion of new ways of looking at the joints with ultrasound, something both dermatologists and rheumatologists could develop.

On the second day the meeting looked more at the science behind the diseases. Just recently there has been a lot of activity in genetics with large genome wide screens being performed in Europe and North America. New genes important in both the skin and the joints have been identified and are likely to lead to new treatments in due course. No doubt at some point in the near future we will be able to predict those people with psoriasis who are likely to go on to



develop arthritis. And in a similar vein we are also likely to be in a position to predict those people with psoriatic disease who are most at risk of heart disease. More and more clinics are likely to be checking your blood pressure, weight and height and cholesterol as part of the routine checkup.

The final session of the meeting was about new international collaborations. Latin America was described as a sleeping giant in this field as it has such a large population and has hitherto not really contributed to international efforts. Only this year the GRAPPA group held a satellite meeting at the Brazilian Society of Rheumatology and further meetings are planned for Argentina and Colombia. Genetically of course there is a strong link to Spain and Portugal but we heard about the fascinating genetics of the native Indians, in whom psoriasis is virtually unknown. Racial intermixing is changing that pattern of course.

There is no doubt that the GRAPPA group is growing and gaining in strength and influence. For 2011 further meetings are planned in London and Naples. For 2012 plans are already being made to have another conference with the International Federation of Psoriasis Associations (IFPA) in Stockholm – this will be the third such venture and usually attracts large numbers of patients and dermatologists from around the world. This is an exciting area in which to work at the moment as the basic science is changing fast and every year new treatments become available. This is good news for patients with the disease.

**Source:**

*We are grateful to Dr Philip Helliwell for supplying this article.*

**Glossary:**

**Enthesitis** is inflammation of the point where tendons or ligaments insert into the bone.

**Dactylitis or sausage digit** is inflammation of an entire a finger or toe.

**About GRAPPA:**

GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) is organised exclusively for non-profit, educational, and scientific purposes, specifically to facilitate sharing of information related to psoriasis and psoriatic arthritis, networking among different medical disciplines that see psoriasis and psoriatic arthritis patients and to enhance research, diagnosis and treatment of psoriasis and psoriatic arthritis.

## About the author:

Philip Helliwell is currently Senior Lecturer in Rheumatology at the University of Leeds, in the UK, and Honorary Consultant Rheumatologist for the Bradford Hospitals NHS Trust.

Previous appointments include: Member of NHS R&D Research Committee on Physical and Complex Disabilities, Member of the Executive Council, Centre for Biomechanics and Medical Engineering; Treasurer and Member of Executive Committee, Society for Back Pain Research; Member of Education Committee, Arthritis Research Campaign; and Editor for the ARC Patient Information Leaflets and Convener Publications Working Group. His main research interest is in clinical features and classification of psoriatic arthritis. He was a founding member of the GRAPPA group in 2003 and served on the Executive Committee until 2008. He was the PI of the CASPAR study and is now leading the GRAPPA composite measure exercise.

Between 1997 and 2000, Dr Helliwell was a Member of the Heberden Committee at the British Society for Rheumatology, where he was involved in research, training and educational matters. He was also a Member of Council at the British Society for Rheumatology.

Dr Helliwell is also a referee for MRC, EPSRC, ARC and several European and North American Journals.

# Ichthyotherapy for psoriasis

**In response to recent enquiries to our helpline we are gathering data about the use of the 'Doctor Fish of Kangal', or ichthyotherapy, which can be defined as the use of fresh water or marine organisms, or fish, as agents of skin wound or condition cleansing.**

## Background

The 'Doctor Fish of Kangal' are Garra rufa or red barb fish and belong to the carp family and are found in the Kangal Springs in Sivas, Turkey. The springs were a kind of reed-bed until 1917, when by chance a shepherd who was wounded on his foot saw his wound healed by the water of the spring.

This fact got the attention of the public and primitive pools were built in the late 1950s. In 1960s the springs were taken over by the local administration of Sivas and several lodgings facilities were built.

The springs were put out to tender in 1996 by the local administration for a long-term operation contract. The area is now a modern therapy centre for psoriasis.

## UK walk-in pedicure therapy

In the UK there has been recent publicity about the use of fish that nibble the feet in a health spa setting; these are often located within shopping centres. The benefits claimed by some of the outlets include the treatment of psoriasis.

As an organisation that is evidence driven we have been searching for robust data that backs up these claims in order that you as a person with psoriasis can make an informed choice regarding the validity and safety of using such therapies.

## Expert comments

After speaking to various experts, the only research that appears to have been published is an article called Ichthyotherapy as Alternative Treatment for Patients with Psoriasis: A Pilot Study (reference 1). The following statement has been put together to assist you with regard to the research of psoriasis and Garra rufa fish:

''We have reviewed the trial published and whilst the results appear to be promising, these should be interpreted with caution. This was an open, retrospective evaluation of the treatment so there is no control group - i.e. it is difficult to be certain that the beneficial effect is due to the treatment, or whether it is a so-called placebo response, or just spontaneous resolution. Secondly, the fish treatment is given with UVA -

which may also be contributing to the therapeutic effect. Finally, the data on outcome was retrospectively documented, which automatically introduces potential bias (e.g. it is possible that only those patients finding it helpful continued, and therefore these were the only patients on whom data was available to report on).

In summary, this paper may indicate promise but there are significant methodological limitations to the study that make it difficult to reach firm conclusions on efficacy or safety.''

The last point in this statement should be specifically considered as safety has not been established, therefore you should proceed with caution as one expert we consulted did have concerns about potential infections that may arise from contaminated water or less than hygenic premises.

## Latest update

There have been reports from various media outlets including the BBC, The Press Association and Reuters about the safety of fish spa treatments and the following appeared on Reuters website on 1 March 2011:

''...Officials at Britain's Health Protection Agency (HPA) said they were launching an investigation into possible infection risks associated with the exfoliation treatment after receiving enquiries from local environmental health officers.

The HPA said it would assess all of the latest evidence on risks before issuing guidelines for the spa treatment.

''The HPA and Health Protection Scotland is currently unaware of any cases of infection associated with the use of the fish spas pedicures in the UK,'' a spokesman said.

Fish spa pedicures have already been banned in some U.S. states for health and safety reasons...

**Your help needed**

- **Have you used fish therapy?**
- **What was your experience?**
- **What were you told about the therapy?**
- **Was the experience good or bad?**

**Let us know your experience, views or any information you have by emailing us at: info@papaa.org, sending a letter or visit our website at: www.papaa.org**

**Notes and references:**

Reference 1 eCAM 2006;3(4) 483-488 doi:10.1093/ecam/ne1033 Ichthyotherapy as alternative treatment for psoriasis: A pilot study.

M. Grassberger & W. Hoch - Medical University of Vienna, Austria

The background data for this article was previously published in Skin 'n' Bones Connection 2001; issue 15; page 15. (ISSN:1457-4134), which in turn was an abridged version of an article by Dr Levent Undar.

### About the Health Protection Agency

The Health Protection Agency is an independent UK organisation that was set up by the government in 2003 to protect the public from threats to their health from infectious diseases and environmental hazards. It does this by providing advice and information to the general public, to health professionals such as doctors and nurses, and to national and local government.

**Website: www.hpa.org.uk**

# Treating psoriasis effectively


**For any treatment to have the best chance of success, you need to follow your doctor's instructions as exactly as possible. Unfortunately, the treatments for many skin diseases can be rather time-consuming and laborious. Applying creams to large areas of skin is much more inconvenient than swallowing a tablet.**

Despite this, it is vital to be self-disciplined and almost obsessional about using your medicines according to the instructions. If you are not exactly clear how any of your medicines should be used go back to your doctor and get full instructions.

The way to get the best out of your treatments is to use them correctly.

### Tips to help you use your treatments correctly

- Try to take or use your treatment regularly, at the same time every day, so you get into a routine
- Keep your tablets or creams somewhere you can remember them easily, such as with your toothpaste (but make sure they are out of the reach of children). If you have an alarm clock, set it for the time your next treatment is due
- Make sure you get your next prescription in plenty of time so you don't run out
- If you are going away, take enough tablets or creams with you to last the whole time
- Read and keep the information leaflet that comes with your medication
- If in doubt about any part of your treatment, ask your pharmacist, practice nurse or doctor for advice
- Keep a record of treatments you have tried in the past and let your doctor know if they caused you any problems
- Remember to store your medications correctly according to the instructions given – this will usually be in a cool, dry place away from the sight of children

- If the cost of your treatment is stopping you from using some or all of the medications advised, talk to your pharmacist about ways of reducing your prescription charges.

### Tips on when to stop a treatment

Different types of treatment take different lengths of times to show a good effect. For example:

- Treatment applied directly to the skin (called a topical treatment) will usually show a good effect within three to six weeks but may be tried for up to three months to see if it works. Feel the treated area with your fingers and continue topical treatment until the skin feels entirely smooth and normal.
- A disease-modifying drug such as methotrexate tablets should start to make a difference within two or three months. Cyclosporin will show an effect within one month. If you do not think your treatment is helping, don't just stop using or taking it. Go back to your doctor for advice. You may need to use the treatment more often, take a higher dose, change to a stronger product or see a specialist. Never stop taking an oral corticosteroid drug, other than on medical advice, as this may be dangerous.

### Tell your doctor straight away if:

- a product burns or irritates your skin or makes your symptoms worse
- you think you have developed an unwanted effect of treatment
- you think you may be pregnant.

Professor Alex Anstey

# Dermatology:

## Training, Education and Research through Patient Involvement

**The Academic Dermatology Unit based at the Royal Gwent Hospital, Aneurin Bevan Health Board in Newport, consists of a team of multi-professional staff headed by consultant dermatologist, Professor Alex Anstey. Their philosophy is "Dermatology Training, Education and Research Through Patient Involvement" and, in collaboration with PAPAA, Academic Dermatology are developing a patient-centred, web-based course in psoriasis and psoriatic arthritis aimed at primary care nurses.**

Professor Alex Anstey has been a consultant dermatologist at the Royal Gwent Hospital for nearly twenty years. He has a long-standing interest in the treatment of psoriasis, and is acknowledged as an international expert in the treatment of difficult psoriasis. Professor Anstey is particularly keen to develop models of care for patients with psoriasis focused on the primary care team.

Many patients with psoriasis have significant problems due to their skin disease. Unfortunately, few general practitioners are experts in the management of this common condition, and only patients with severe psoriasis tend to be referred for specialist care. This means that many patients with problem psoriasis do not receive optimum treatment.

In order to address the gap in service provision for patients with psoriasis, Professor Anstey has instigated a number of projects. These include introducing a home phototherapy service in Wales over the next two years as well as piloting the provision of phototherapy for general practice surgeries in isolated locations. He is also involved in championing patient advocacy by establishing patient panels across Wales to ensure the views of patients are represented and not overlooked.

**'Psoriasis in Practice'** will be offered as a continuing professional development course for primary care nurses who are interested in expanding their chronic disease management knowledge to include psoriasis and psoriatic arthritis. The course will include case studies and patient interviews, which are currently being filmed. Professor Alex Anstey explained: "This is a really exciting and unique project, and the first time anyone has developed this kind of online educational project for GP practice nurses. The narratives and experiences of a number of patients will be used to inform part of the course which, when completed, will be accessed across the UK."

**For more information visit:**
**www.psoriasisinpractice.org**

# Obese children and psoriasis

**Children who are overweight or obese have a significantly higher prevalence of psoriasis, and teens with psoriasis, regardless of their body weight, have higher cholesterol levels, according to a Kaiser Permanente study published online in the Journal of Paediatrics.**

The study findings suggest that higher heart disease risk for patients with psoriasis starts in childhood in the form of higher cholesterol levels.

"This study suggests a link between obesity and psoriasis in children," said study lead author Corinna Koebnick PhD, a research scientist at the Kaiser Permanente Southern California's Department of Research & Evaluation.

"But our study findings also suggest that the higher heart disease risk for patients with psoriasis starts in childhood in the form of higher cholesterol levels. We may need to monitor youths with psoriasis more closely for cardiovascular risk factors, especially if they are obese."

Researchers used electronic health records to study 710,949 racially and ethnically diverse children and found that obese children were almost 40 per cent more likely to have psoriasis than children of normal weight.

Extremely obese children were almost 80 per cent more likely to have psoriasis than normal weight children. Additionally, among youths with psoriasis, it was four times more likely that the psoriasis would be severe or more widespread in obese youth than was seen in normal weight children. Additionally, teens with psoriasis had 4 per cent to 16 per cent higher cholesterol levels and liver enzymes, regardless of their weight, than youths without this condition.

"Very little is known about psoriasis in children where the disease is mostly viewed and treated as a burdensome skin condition and less considered a metabolic disease," adds Dr Koebnick.

"Psoriasis may also put children at risk for metabolic disease, as seen in adults, so studies such as these are extremely important in helping primary care providers learn the best way to care for these children," notes co-author Dr Amy Porter.

Epidemiologic studies in adults have shown that patients with psoriasis are at a higher risk of developing metabolic conditions such as diabetes, hypertension, heart attack and stroke. In adults, obesity has also been linked to a higher risk of developing psoriasis, and obesity, like psoriasis, is also associated with an increased risk of cardiovascular disease, metabolic syndrome and diabetes.

"Both conditions are characterised by a chronic, low-level inflammation," notes Dr Koebnick. "Yet we know little to nothing about the metabolic risk of psoriasis, especially when combined with obesity in children." Psoriasis in children may increase blood cholesterol levels, and this may additionally be triggered by the presence of obesity. While the present study has limitations due to its cross-sectional design, where both body weight and information on psoriasis were assessed at the same time, future studies based on this cohort will address these issues.

"It has been well described that adults with psoriasis have increased cardiovascular risk factors, but we have now examined these issues in children. As we follow these patients over 30 to 40 years, we will be able to determine if these increased cardiovascular risk factors in turn increase the risk for major adverse cardiac events, "said study senior author, Dr Jashin J Wu.

This study is part of the Kaiser Permanente Southern California Children's Health Study, Kaiser Permanente's ongoing work to identify and treat childhood obesity through research and community programs.

**Source of article:**
**www.kp.org/newscenter**
**Accessed: 18 May 2011**


**A £2 million study has been launched at The University of Manchester aiming to improve the care of people with psoriasis.**

The five-year IMPACT Programme (Identification and Management of Psoriasis Associated ComorbidiTy) has received a National Institute of Health Research (NIHR) grant to fund research into the physical and psychological needs of psoriasis patients.

Co-investigator Dr Lis Cordingley, who is based in the university's School of Community-Based Medicine, said: "The award recognises the wide-ranging impact that psoriasis and associated co-morbidities have upon the lives of people with this condition".

World-renowned dermatologist Professor Chris Griffiths, based in the university's School of Translational Medicine, is leading the research. He said: "Psoriasis can be very distressing for patients and can have a major impact upon their quality of life.

Furthermore, it appears that many psoriasis patients may be at increased risk of developing other conditions, including depression and cardiovascular disease.

"The award of this grant will allow us to ascertain the true association between psoriasis and these conditions and will enable us to design community-based services that will be of direct benefit to this overlooked group of people."

Along with a strong multidisciplinary team of academics and clinicians, patient representatives have been involved in the planning and design of the project.

A celebration of Manchester's clinical research in psoriasis was held at The University of Manchester to mark the launch of the project. The series of presentations ranged from basic science to applied research, and gave PhD students a platform alongside more experienced researchers.

### About the NIHR

The Department of Health established the National Institute for Health Research (NIHR) to provide the framework for publicly funded health research in England. Programme Grants for Applied Research are prestigious awards of up to £2m over a period of three to five years, directed towards leading researchers who can demonstrate an impressive track record of achievement in applied health research. Each programme will fund a series of related projects which form a coherent theme in an area of priority or need for the NHS.

**Collaborating primary care trusts:**

- Ashton Leigh and Wigan PCT;
- East Lancs PCT

**Collaborating hospital trusts:**

- Salford Royal NHS Foundation Trust

**For further information about the study contact:**
**Alison Littlewood - programme manager.**
**Email: alison.j. littlewood@manchester.ac.uk**
**Tel: 0161 275 7314/6089**

**Source:**
**The University of Manchester**

University of the West of England, Bristol


# Romantic experiences

## Have you ever found that your psoriasis or psoriatic arthritis has affected your romantic relationships?

Romantic experiences typically increase in frequency and intensity during adolescence, as young people progress towards adulthood. Positive romantic experiences can make valuable contributions towards healthy development, in that they improve self-esteem, help in the development of self identify, are a source of emotional support and increase the ability to develop committed relationships in adulthood.

A recent study by the Centre for Appearance Research at the University of the West of England, Bristol, has explored the romantic experiences of young people aged between 13 and 20 whose appearance has been affected by a skin condition, scarring, or cleft lip, also known as 'visible differences' (Griffiths, Williamson & Rumsey, in preparation).

Forty young people, 22 males and 18 females, completed an online survey which allowed them to discuss their experiences frankly and anonymously.

A number of common issues and concerns were revealed. Participants believed that appearance is very important in our society and experienced pressure to 'look perfect'. As a result many were concerned that their appearance was unusual and felt their condition made them unattractive. These feelings were so strong in some that they were discouraged from even contemplating the possibility of becoming romantically involved, or from taking steps towards instigating a relationship.

For those currently in a relationship, these feelings led to appearance anxiety. Many were preoccupied with concealing or camouflaging perceived differences with clothes and makeup. Some avoided certain social activities, (such as swimming), and intimacy for fear of exposing their condition or visible difference to their boy or girl friend. Concealing a visible difference was considered helpful in the early stages of a relationship, for example, when meeting a new boy or girl friend, but for some, this became problematic, when romantic relationships developed. One of the most frequent and significant concerns was how and when to discuss the issue and reveal their difference to their boy or girlfriend.

Not all of the participants spoke of negative experiences. Those less troubled by their visible difference spoke of positive past or current relationships and revealed how certain attitudes and behaviours can protect them from experiencing difficulties. For example, they believed that their romantic concerns were not different to those of the average teenager - this put their worries into perspective.

Social support was particularly important. Being able to talk openly to friends, family and boy or girl friends about their visible difference helped them to cope and provided an opportunity to receive positive reassurance. These young people accepted that their difference was part of their identity and was not something to be ashamed of. They boosted their self-esteem by focusing on other positive aspects of themselves such as their personality, intelligence, humour or kind nature and other interests and skills such as sport or music. They felt that potential partners should like them for who they are, 'it's what's in the inside that counts', and felt 'if boy or girl friends are too shallow to accept you for what you are and how you look, then they don't deserve you!'

Participants also suggested what type of support would be useful for young people with romantic concerns relating to their visible difference. They recommended online support from a young person or adult with a visible difference or a psychologist/counsellor. They preferred online support to face to face sessions because young people could look up information and post questions anonymously, in their own time. They felt that other people with a visible difference would be more understanding of their experiences and young adults would be able to offer more relevant advice, because they would already have 'been through it'.

The findings from this study have helped researchers to develop YP Face IT, an online support programme for young people who are finding it difficult to cope with their visible difference, which includes advice about romantic relationships.

*Authors: Catrin Griffiths, Heidi Williamson and Professor Nichola Rumsey from the Centre for Appearance Research, based in the University of the West of England, Bristol.*

If you would like to find out more about this project or any of the other projects that the Centre for Appearance Research (CAR) is developing. Please contact CAR@uwe.ac.uk

**Or visit the CAR website: http://hls.uwe.ac.uk/research/car.aspx**

# NICE recommends golimumab for the treatment of psoriatic arthritis

**The National Institute for Health and Clinical Excellence (NICE) recently issued final guidance recommending golimumab (Simponi) for the treatment of psoriatic arthritis.**

Golimumab joins a list of treatment options already recommended by NICE for this condition. The guidance recommends golimumab as an option for treating active and progressive psoriatic arthritis in adults if it is used, as described, for the other tumour necrosis factor (TNF) inhibitor treatments – etanercept, infliximab and adalimumab – covered by NICE technology appraisal 199.

The recommendation of golimumab is also on the condition that the manufacturer provides the 100 mg dose of golimumab to the NHS at the cost of the 50 mg dose, as agreed by the manufacturer and the Department of Health as part of a patient access scheme.

Dr Carole Longson, Health Technology Evaluation Centre director at NICE, said:

"We're pleased to recommend golimumab as another option for treating psoriatic arthritis, a condition that can cause significant distress and psychological impact on an individual's life, employment and social activities. We recognise that patients may welcome the option of a self-injectable treatment administered once a month.

We have already recommended three TNF inhibitor treatments for psoriatic arthritis that has not responded to first-line treatment, and golimumab is a welcome addition."

The guidance golimumab for the treatment of psoriatic arthritis is available at:
**http://guidance.nice.org.uk/TA220**

**Source:**
**NICE press release, May 2011**

# Call to clarify medicine labelling

**Experts are recommending changes to make it easier for people to understand medicine labels. Officials at the British National Formulary (BNF), which is used by doctors, nurses and pharmacists for information on drugs, believe current labelling is unclear.**

Research commissioned by the BNF suggests people are unsure what some instructions mean. It found "avoid alcoholic drink" could be open to misinterpretation, and now recommends labels read "do not drink alcohol while taking this medicine".


The word drowsiness is "not always readily understood" and should now be improved to say "this medicine may make you sleepy".

The research was carried out by Theo Raynor, professor of pharmacy practice at the University of Leeds, and colleagues. He said: "Most medicines do contain leaflets which provide detailed information for patients. "However, the leaflet may get lost, which means that the label on the medicine plays a very important part in guiding people's behaviour.

"It is vital therefore that wordings on labels are simple and straightforward." Duncan Enright, publishing director at BNF publications, said: "It has never been easier to change labels on medicines, given current computerised systems and therefore we hope that the large pharmacy chains and independent pharmacies will adopt these recommendations."

***Source:***
**© The Press Association**

# Letters

**Q Dear PAPAA,**

Can you tell me if having a piercing or tattoo would affect my psoriasis?

*TC*

**A Dear TC,**

In some people psoriasis can be caused by a trauma to the skin, including cuts, bruises, burns, surgical procedures, bumps, vaccinations, tattoos, piercing and other skin conditions. These traumas can cause a flare-up of psoriasis symptoms either at the site of the injury or elsewhere. This condition is called Koebner's phenomenon. For this reason, if you have psoriasis or a family history of psoriasis you may want to think seriously about undertaking such procedures.

If you still want to have a tattoo or body piercing, make sure you discuss this with your doctor or healthcare provider, in order to get the facts about how these procedures may affect you.

*PAPAA*

**Dear PAPAA,**

I found your address on an information pamphlet in a chemist. I thought I would write and tell you about my experiences of living with psoriasis and psoriatic arthritis.

I first had signs of psoriasis in 1996 where it developed to the extent I went into hospital for 8 days, for UVA treatment. My more recent visit for light treatment used UVB over a longer period of time.

Originally, it started as one small patch at the back of my head in the hair. But there are times when it covers my face and whole body.

I continually look for new methods of treatment, homeopathy etc but I feel no one really treats the cause only the symptoms. When you are particularly down, because of how you look to others, your level of motivation and optimism becomes really threatened.

I developed psoriatic arthritis two years ago, which mainly affected my hands and toes. I know many suffer far more than I do, although I always seem to let the condition control me, rather than the other way around.

It was nice to discover your pamphlet in a local chemist and as they say knowledge is power. I have now looked at your website and feel much more informed.

Thank you for taking the time to read this letter and for providing such a comprehensive website.

Summer is a nice time for us all, so hopefully my skin will improve over the next few months, before the dreaded cold weather makes my joints hurt.

*Yours PC*

**Q Dear PAPAA,**

I am 26 years old and have suffered from pain and stiffness in my joints since I was around 9 years of age. When I reached the age of 13, I developed psoriasis.

It was not until last year that I was diagnosed as having psoriatic arthritis and began receiving treatment. I'm currently taking a DMARD, which helps me a lot, though my psoriasis flares up quite often.

I got your address from a magazine which had an article on psoriatic arthritis. I was very pleased to see this article, because before I was diagnosed I had never even heard of it and this was the first I ever heard or read of it since being diagnosed.

The article stated that around 40,000 people in Britain suffer from this disorder. Reading this made me feel relieved that I was not alone, that there are other people who have heard of what I have too.

*WM*

**A Dear WM,**

Thank you for contacting PAPAA. The number quoted for people affected by psoriatic arthritis varies, but it is generally accepted that 2% of the UK population have psoriasis, with about 10%-20% developing psoriatic arthritis, so this could give a figure of nearly 250,000 people have psoriatic arthritis.

*PAPAA*

**Q Dear PAPAA,**

I recently saw reference to a test that is used before being given a biological treatment; it's called the Mantoux test. Can you tell me what it is?

*HR*

**A Dear HR,**

The Mantoux test (or Mantoux screening test or Heaf test ) is a skin test for tuberculosis. Which was used until 2005 to determine if the Bacillus of Calmette and Guérin (BCG) vaccine was needed. Patients who exhibit a negative reaction to the test may be offered BCG vaccination.

Patients being offered biological treatments for psoriasis are recommended to have a Mantoux test if they fall within an 'at risk' group, such as: People who have been in close contact with someone known to have TB or healthcare workers who are likely to be exposed to TB.

TB symptoms include an ongoing cough, night sweats, and weight loss for no reason or people who have had an abnormal chest X-ray.

*PAPAA*

**Please note: letters and emails have been edited and names withheld for privacy**

**Q:** ***Can nail psoriasis be mistaken for fungal infection?***

**A:** Onychomycosis is a fungal infection that can cause thickening of the nails. This could be present alongside nail psoriasis, and can be confused in diagnosis. If this is present and diagnosed correctly it can be treated with systemic anti-fungal medication. It is estimated that approximately 35% of people who have nail psoriasis involvement may also have a fungal infection that could cause or worsen their psoriasis.

**Q:** ***Is there a connection between blepharitis and psoriasis?***

**A:** Blepharitis is a crusty scaling of the eyelid which can be fairly common in children; you are more likely to have this condition if you have skin conditions such as rosacea and psoriasis.

**Q:** ***Are TENS machines good for psoriasis arthritis?***

**A:** TENS (Transcutaneous Electrical Nerve Stimulation) is a simple, non-invasive technique in which electrical currents, generated by a portable stimulating unit powered by a small 9 volt battery, are passed through the surface of the skin to activate underlying nerves via two or four electrodes. TENS has many advantages over conventional treatment for pain. It does not require surgical intervention, and unlike analgesic drugs, has no serious adverse affects. It can be used long term and can, if necessary, be used in conjunction with other analgesics, such as drugs. Not every person responds to TENS treatment; the efficacy is approximately 60%. The reason for non-response to TENS by the other 40% is unknown at this point in time.

**Q:** ***Can you tell me what Telangiectasia??***

**A:** Telangiectasia is an increase in the size of blood vessels beneath the skin, causing redness and an appearance of broken veins. Most commonly found on the nose and cheeks.

**Q:** ***What is a Baker's cyst?***

**A:** This is a swelling (inflammation) behind the knee which contains fluid, common in osteoarthritis and rheumatoid arthritis, and sometimes psoriatic arthritis.

**Q:** ***Can psoriasis affect your heart?***

**A:** Overall, people with psoriasis have a much greater risk of heart disease than people without psoriasis. In young men and women with severe psoriasis, this risk is most noticeable, where they may be up to 3 times more likely to have a heart attack than those of the same age who do not have psoriasis.

Salford Royal NHS Foundation Trust

# New combined clinic a hit with patients

**In May 2010 Dr Hector Chinoy (rheumatologist) and Dr Richard Warren (dermatologist) established a new combined clinic for patients who suffer from psoriasis and psoriatic arthritis at Salford Royal NHS Foundation Trust. This initiative came about as both consultants appreciated that the level of care for patients with both conditions was compromised; for example with therapeutic decisions being delayed and/or not being suitable for the treatment of both conditions when a patient is attending two separate outpatient appointments. Salford Royal NHS Foundation Trust has a world-renowned psoriasis clinic, established by Professor Chris Griffiths and Dr Robert Chalmers; the addition of this new clinic has enhanced the comprehensive care for patients affected by these conditions in the Manchester region.**

Dr Hector Chinoy

Dr Richard Warren

Now coming up to the first anniversary since the clinic opened, an audit of patient feedback about the clinic has been performed. The feedback has been exceptional, demonstrating a clear patient preference for the combined clinic, as opposed to two separate services.

Drs Warren and Chinoy are also senior lecturers at The University of Manchester and, by working together on this combined clinic, has allowed them to become involved in research around both conditions, from screening for psoriatic arthritis to understanding more about the genetic basis of both conditions. As well as collaborators from across the UK. Furthermore, they now have a PhD student in the clinic to facilitate further research and regularly educate specialist trainees from both rheumatology and dermatology to improve the future care of patients with psoriasis and psoriatic arthritis.

At this stage the clinic is accepting referrals from other consultant dermatologists and rheumatologists in the North West. It is hoped that the success of this clinic, in addition to the research output generated from it, will improve the opportunities for similar services in other parts of the UK.

## About the hospital

Salford Royal NHS Foundation Trust is a large teaching trust with approximately 850 in patient beds, employing over 4,600 staff and treating in the region of 400,000 patients per year.

The hospital provides a comprehensive range of services to the 220,000 population of Salford as well as a wider range of services across Greater Manchester, the North West and nationally.

The hospital has been recognised as one of the best hospitals in the NHS and has clear plans to become the safest. With an aim to provide safe, clean and personal care, to every patient, every time, the hospital has an excellent track record; having the highest consistent rating for service quality coupled with one of the highest sets of patient and staff satisfaction scores.

**Source:**
**With thanks to Dr Chinoy and Dr Warren for supplying this article**

**Your views:**

**Do you attend a combined clinic?**

**What is your experience of care for your psoriasis and psoriatic arthritis?**

***Let us know your views and we will report them in the next issue.***

# Scotland will wait no longer

Nicola Sturgeon

**Patients across Scotland will wait no longer than 18 weeks from GP referral to treatment by December.**

That was the pledge made recently by cabinet secretary for health Nicola Sturgeon, during her first visit to a hospital since reappointment.

The first statistics measuring progress to 18 weeks referral for treatment (RTT) were also published and show that in the last quarter 85 per cent of patients who will be covered by the new waiting times target are already having their treatment within the timeframe.

In addition figures measuring current targets show that 99.9 per cent of patients are waiting 12 weeks or fewer for their first outpatient appointment and 99.7 per cent are waiting fewer than nine weeks for inpatient/day case surgery.

In addition 97.6 per cent of patients are waiting six weeks or fewer for one of the eight key diagnostic tests; this compares with 93.6 per cent in December last year.

At Edinburgh Royal Infirmary Ms Sturgeon said:

"As the recently reappointed health secretary I want to give my assurance today that there will be no let-up in this government's bid to drive down waiting times.

"Patients continue to tell me that prompt access to treatment, delivered as locally as possible, is one of their top priorities and that is why we are continuing to put such an emphasis on cutting waiting times.

"The delivery of the 18 weeks target is the next big challenge for our NHS, but it is the right challenge and I want to be 100 per cent clear that this remains one of my key commitments.

"Not only is this in patients' best interest, having even lower waiting times is a more efficient way of using NHS resources.

"I look forward to working with Boards to deliver on this ambitious target for the benefit of patients across the country. I expect that they will now be planning for sustained action to ensure that this pledge is delivered and will closely monitor progress over the coming months."

NHS Scotland is currently working towards a referral to treatment waiting time target of 18 weeks from GP referral to treatment. This was announced by the health secretary in June 2007 and is due to be delivered by December 2011.

New ways of defining and measuring waiting times came into effect on January 1 2008 when availability status codes – the practice of hidden waiting lists - were abolished.

**Source:**
**Press release: The Scottish Government**

# Marketplace

These items have been brought to our attention by our readers for your interest. We do not, however, endorse or recommend these products but please keep these coming in if they are of interest!

**Dear PAPAA,**

The Portsmouth rheumatology department is collecting the **Tesco Vouchers for Schools and Clubs**; over the past three years the department have exchanged the vouchers to obtain equipment for the children's hydrotherapy group and the newly formed Rheumatology Education and Children's Hospitality (REACH Project).

I would be grateful if you would consider asking your members to send any 2011 Tesco vouchers to: Valerie Robins, c/o Rheumatology Department, Queen Alexandra Hospital, Cosham PO6 3LY

I would like to thank you and your members in anticipation of your support.

Yours sincerely

**Colin Beevor, Matron and Clinical Nurse Specialist, Department of Rheumatology, Portsmouth Hospitals NHS Trust**

## Are you on Facebook or Twitter?

If so why not help us to develop our profile?

To get to our pages click the link from the **'About us'** page on our main website **www.papaa.org** or you can just search for us on Facebook, or on Twitter @PsoriasisInfo and then follow us.


## Psoriasis Shop

**www.psoriasis-shop.org**

- Order free information
- Join and pay for your subscription
- Renew your subscription
- Make a donation
- Purchase from a selection of books
- Training programmes (tba).

## Getting the best prices online:

Price comparison sites - enter the search phrase 'compare prices' into a search engine and then access the sites directly.

Remember to check availability of products, cost of delivery and most of all whether the site is secured for ecommerce transactions.

- **www.dealtime.co.uk**
- **www.comparestoreprices.co.uk**
- **www.kelkoo.co.uk**
- **www.google.co.uk/products**

Secure sites will have a certificate on the site, such as **GoDaddy, DigiCert, VeriSign, Thawte** and **Comodo**. These certificates will allow you to check site validity, if you are suspicious.

**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.**