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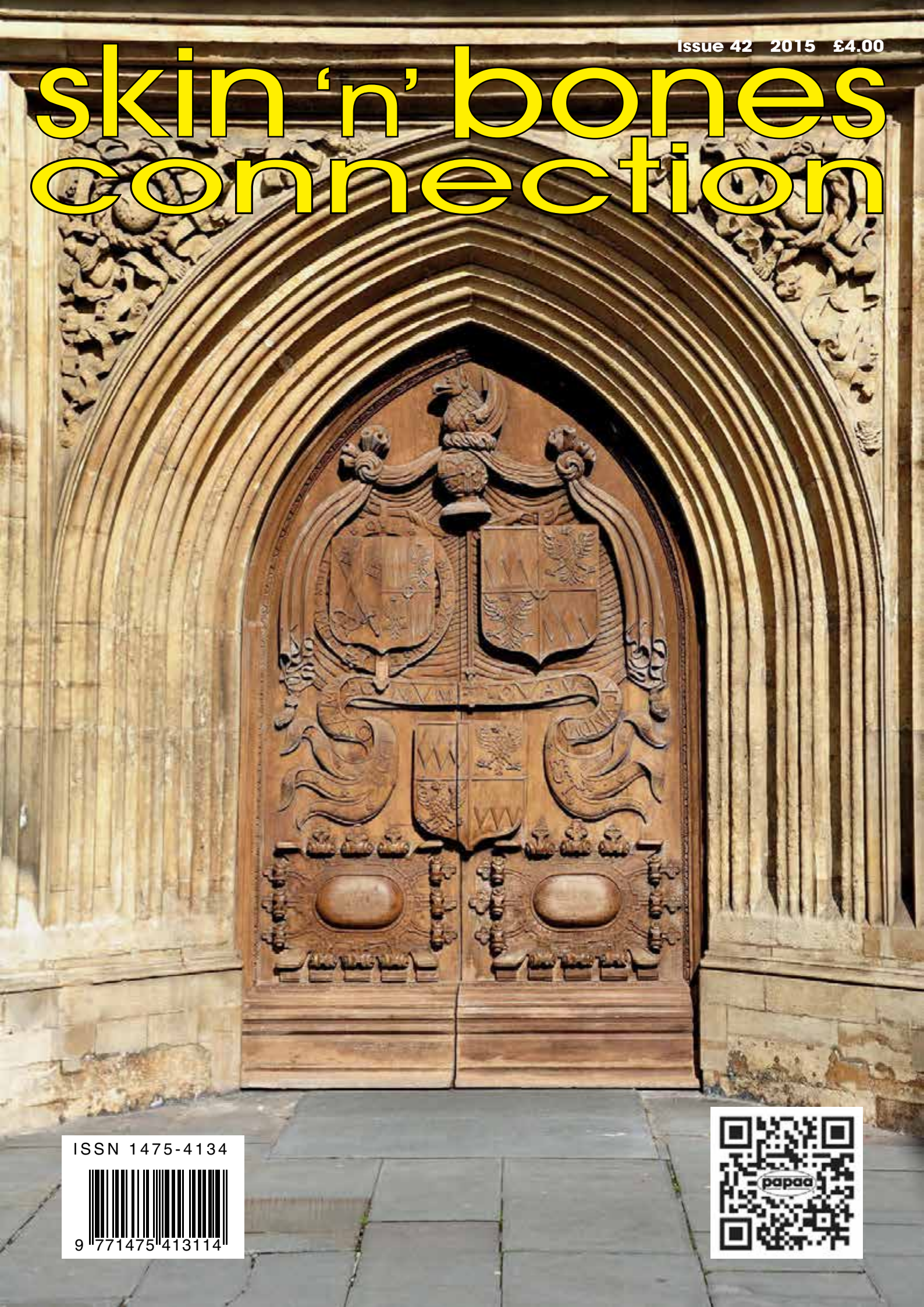
skin 'n' bones connection



ISSN 1475-4134

Dear Reader

We often hear in the news about scientific breakthroughs or the unmet needs of people living with long-term conditions, many life-threatening. The emotions experienced and imagery used can be very chilling, putting chronic conditions such as psoriasis and psoriatic arthritis in a category of less importance, which for people affected by these conditions is not the case.

The difficulty is how to express the issues without causing unintended consequences that, instead of raising awareness, just increase the myths, stigmas and stereotypes that surround both psoriasis and psoriatic arthritis.

Creating issues around the problems faced is a way, but to whom? Should the public be made or even forced to understand? Or should those with the conditions develop ways of coping or strategies to avoid embarrassment or awkward questions?

Depending on your views, experiences both past and present you will have opinions about which scenario is most appropriate. Within those scenarios everyone has a part to play, whether researchers (pages 3, 4 and 5), doctors (page 6 and 7) the regulators (pages 11, 14, 16 and 17) or indeed charities (pages 10, 12, 13 and 20). The aim should be to provide what people need to live with a chronic condition that is appropriate and useful so their lives are better and not blighted by having a less publicly emotive condition.

Managing editor

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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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COVER PHOTO:

Carved wooden oak door, Abbey Church of Saint Peter and Saint Paul in Bath, England.
The historic city of Bath is a popular travel destination.
Bath is also a centre for research into psoriatic arthritis. To learn more see page 3.

Part of the Royal United Hospitals Bath NHS Foundation Trust (Royal National Hospital for Rheumatic Diseases), the RNHRD provides a specialist service for patients with psoriatic arthritis and is highly regarded nationally and internationally as a centre of excellence for the condition – helping people to work towards a pain-free, active life through a tailored combination of therapy, drugs and exercise.

The National Institute for Health Research (NIHR) awarded the £2m grant for a five-year programme of research to improve diagnosis, referral pathways and clinical care for people with psoriatic arthritis. The RNHRD will lead on the research programme in partnership with the University of Bath, and will work with other NHS trusts and universities across the country.

Research Programme Partners

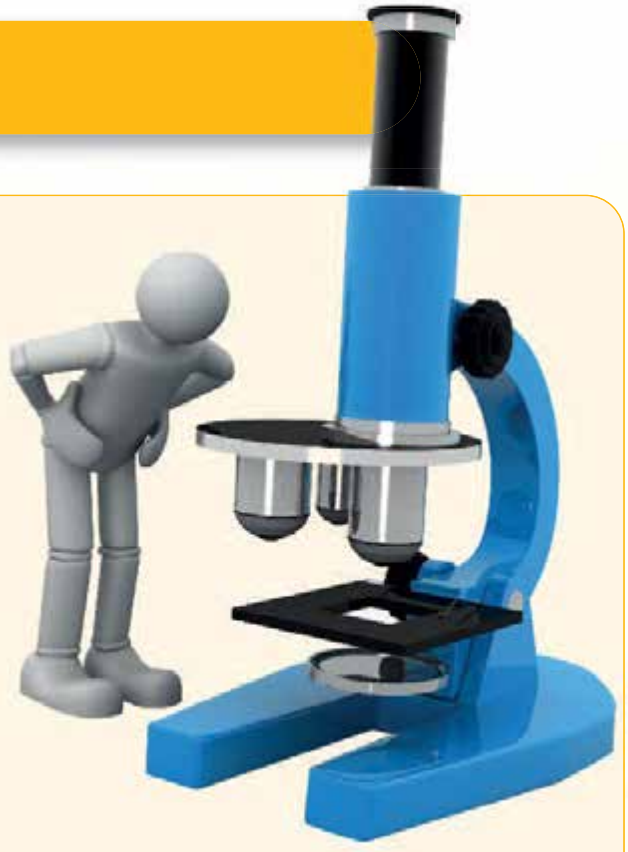
- Bath and North East Somerset Clinical Commissioning Group
- Guy's and St Thomas' NHS Foundation Trust
- Keele University
- King's College London
- Leeds Teaching Hospital NHS Trust
- University of Bath
- University College Dublin
- University of Leeds
- University of Manchester
- University of the West of England, Bristol
- University of York
- University Hospital of North Staffordshire NHS Trust

There is currently no specific test for psoriatic arthritis but emerging evidence suggests that earlier diagnosis and treatment can help reduce the effects of this disease.

Professor Neil McHugh, consultant rheumatologist at the RNHRD and professor of pharmacoepidemiology at the University of Bath, will lead the research project said:

"I am delighted that we have received this significant amount of funding, this represents one of the largest awards ever granted to the RNHRD. I am looking forward to working with my colleagues across the country to make further progress in identifying and tackling this long term condition.

"Working with the University of Bath and drawing on expertise across the NHS will allow us to deliver evidence-based, practical recommendations for tests that can look for the disease in its early stage, leading to quicker referrals for those with psoriatic arthritis.



"This research will also help us understand the best way to care for people with this condition as well as how to develop educational material and guidelines to provide support to patients, carers and the healthcare community."

Professor McHugh added:

"Understanding patients' experience of this disease will be at the heart of this research. If we want to measure whether treatment for psoriatic arthritis is effective, we need to identify what matters to patients – looking not just at physical aspects, such as fatigue and pain, but also mental health and wellbeing and broader quality of life measures such as the ability to work or socialise."

Research and development continues to underpin the high quality, evidence-based care delivered both at the RNHRD and the RUH. The recent affiliation of both research teams has served to create a powerhouse for health research in the City of Bath, strengthened further by its links to other renowned local research institutions such as the University of Bath.

About Professor McHugh

Professor McHugh graduated from Otago University Medical School, New Zealand, completed physician training before specialising in the sub-specialty of rheumatology and has had research fellowships at the Walter Elisa Hall in Melbourne (1985), Yale University Medical School (1990-1991) and the National Heart and Lung Institute (2002-2004). He has been a consultant rheumatologist at the RNHRD since 1991.

About The National Institute for Health Research (NIHR)

The National Institute for Health Research (NIHR) is funded by the Department of Health to improve the health and wealth of the nation through research. Since its establishment in April 2006, the NIHR has transformed research in the NHS. It has increased the volume of applied health research for the benefit of patients and the public, driven faster translation of basic science discoveries into tangible benefits for patients and the economy, and developed and supported the people who conduct and contribute to applied health research.

The NIHR plays a key role in the government's strategy for economic growth, attracting investment by the life sciences industries through its world-class infrastructure for health research. Together, the NIHR people, programmes, centres of excellence and systems represent the most integrated health research system in the world. For further information, visit the NIHR website.

NIHR research programmes fund research using a wide range of study designs including, but not only, evidence synthesis, pilot and feasibility studies, randomised controlled trials and both quantitative and qualitative.

The scale of funding ranges from a project – or an individual study – to a programme of linked studies that are funded together as a programme of research.

For more information about the
National Institute for Health Research
Website: www.nihr.ac.uk

Source:
Media release
Royal United Hospitals Bath
www.rnhrd.nhs.uk
July 2015

The British Journal of Dermatology (BJD) has published online the results of an International Psoriasis Council (IPC) survey identifying 21 psoriasis research priorities. The results will also appear in a print edition of the journal.

The article, ''Prioritising the global research agenda in psoriasis: An International Psoriasis Council Delphi consensus exercise'', identifies priorities that will guide future research into the autoimmune disease.

The council, a global non-profit organisation focused on psoriasis research, launched the survey because gaps exist in the understanding of psoriasis, according to Dr Bruce Strober, interim chair of the department of dermatology at the University of Connecticut, an IPC board member, and the article's lead author.

The priorities encompass a range of issues, including how the disease begins, the genetics of psoriasis, optimal treatment use, and psoriasis in children. The survey's top three priorities were:

- Determining whether early, aggressive intervention can affect the disease's progression
- Identifying biomarkers that correlate with psoriasis
- Creating a ''map'' that identifies genes that confer susceptibility to developing psoriasis.

To determine these key research needs, the IPC used the Delphi method*, a survey technique that uses a series of anonymous interspersed discussions and rounds of voting to collect data from a panel of experts, eventually reaching a consensus. For this study, the IPC surveyed psoriasis experts from around the world who belong to the council. After repeated voting online, these specialists reached consensus on the 21 priorities.

''The Delphi method has generated a more data-driven, unbiased prioritisation of topics important for study,'' Strober said. ''This list will provide both institutions and individuals a better sense of the pressing and relevant research needs in psoriasis.''

Find the 21 priorities and abstracts at www.psoriasiscouncil.org/Delphi2014

About IPC

Founded in 2004, the International Psoriasis Council (IPC) is a dermatology-led, voluntary, global non-profit organisation dedicated to innovation across the full spectrum of psoriasis through research, education and patient care.

IPC was established as an international organisation of global psoriasis experts working on the advancement of psoriasis. IPC provides expert opinion on current psoriasis issues, both therapeutic and research-related, convenes roundtable conferences, contributes manuscripts to top-tier medical journals, and presents at important congresses around the world.

Learn more about the International Psoriasis Council at www.psoriasiscouncil.org.

You can also follow the IPC on Facebook and Twitter.

**The Delphi method is a structured communication technique or method, originally developed as a systematic, interactive forecasting method, which relies on a panel of experts. The experts answer questionnaires in two or more rounds.*

Source:
International Psoriasis Council
www.psoriasiscouncil.org

Spotlight on the Royal Free

Getting access to the care and treatment you need to manage your psoriasis is sometimes difficult or hard to find.

The psoriasis clinic based in the Royal Free dermatology department in London not only aims to treat your psoriasis, but help you lead the life you want to. They work on the principle that every patient is an individual with individual needs and wishes. New patient clinics are run on a Tuesday afternoon and the aim is that all new patients are seen by one of the lead psoriasis consultants.

People may be asked to have some fasting blood tests performed before their appointment and also to fill in several questionnaires. The appointment will be up to 30 minutes in duration. The clinic nurse will record weight, blood pressure and test urine prior to the individual seeing the doctor. The doctor will ask the patient questions about their psoriasis, medical history and examine their skin.

In particular, the team is interested in how psoriasis is affecting an individual's life, what they would like to change in their life by having effective treatment and also about treatments they feel would be most suitable. The aim is to formulate a management plan including treatment and follow-up. Treatment may also include psychological intervention if appropriate.

If a prescription is issued, this will need to be taken to the Royal Free Hospital pharmacy. The prescription is not valid in pharmacies outside the Royal Free Hospital.

Psoriasis step down clinic

The psoriasis step down clinic is for people whose psoriasis is stable on medication or who are being initiated onto new medication. It is held in the dermatology clinic at the Royal Free Hospital, opposite clinic 6 on the first floor. The clinic is a GP-led clinic and is supervised by dermatology consultants.

People may move between the psoriasis clinic and psoriasis step down clinic according to individual need. Throughout care patients remain under the eye of the psoriasis consultant.

Biologics clinic

The biologics clinic is for people prescribed biological medications. This clinic runs alongside the psoriasis clinic on a Tuesday morning.

Nurse-led psoriasis clinic

The nurse-led psoriasis clinic is run by a specialist nurse. This clinic is for patient education, topical treatments (such as creams and ointments) and monitoring of medications.

Psychodermatology clinics

If appropriate there is an opportunity to discuss a referral to see a member of the psychology team. There may be an offer of psychological intervention as an additional treatment option. The psychodermatology clinic is run within the dermatology clinic. People are initially offered an assessment appointment with a psychologist and if both the individual and the psychologist think that psychological therapy would be appropriate then a course of treatment is offered.

Telephone clinic

There is a weekly telephone clinic on a Tuesday afternoon that is used for monitoring tablet treatment and was set up in order to reduce the amount of time people need to spend travelling to and from the hospital.

Patients are telephoned by a member of the psoriasis team on the afternoon of their appointment – this could be a doctor or a nurse. There may be a request to have blood tests performed prior to the telephone clinic appointment.

If a prescription is issued during the telephone consultation, it will be taken to the Royal Free Hospital pharmacy and available for pick-up from the pharmacy from Thursday onwards. The prescription needs to be collected within two weeks.

If a patient has phoned the psoriasis patient co-ordinator team they may be offered a telephone clinic appointment in order for the team to answer any queries.

Joint psoriasis and psoriatic arthritis clinic

The joint psoriasis and psoriatic arthritis clinic runs once a month on the third Monday morning of each month. Consultant rheumatologists and consultant dermatologists see patients who have both psoriasis and psoriatic arthritis together. This clinic is for patients with complex problems who need treatment for both their skin and joints. It is used to make treatment decisions and is not for long-term follow up.

Psoriatic arthritis clinic

This clinic runs every week on a Monday afternoon. A consultant rheumatologist sees both new and follow-up patients for assessment and treatment. There is close communication between the consultant and the rest of the psoriasis team.

Source:
The Royal Free website
www.royalfree.nhs.uk
November 2015

European League Against Rheumatism

The European League Against Rheumatism (EULAR) is the organisation which represents the people with arthritis/ rheumatism, health professionals and scientific societies of rheumatology of all the European nations.

The aims of EULAR are to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases.

To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with musculoskeletal diseases by the governing bodies in Europe.

EULAR holds an annual congress, which aims to provide a forum of the highest standard for scientific (both clinical and basic), educational and social exchange between professionals involved in rheumatology, liaising with patient organisations.

The 2015 congress was held in Rome, Italy. Amongst the presentations at the congress were a number of interesting developments for people affected by rheumatic conditions.

One presentation showed an increased risk of developing psoriatic arthritis among people with psoriasis exposed to physical trauma, particularly when the trauma involved bone and/or joints.

''This is the first sizable population-based cohort (a group of people with a shared characteristic) study to determine the risk of psoriatic arthritis following trauma in psoriasis patients,'' said Dr Thorvardur Love, senior author from Landspitali University Hospital, Iceland.

''Our findings highlight the importance of further study into the complex factors that lead to arthritis in psoriasis patients, as we may find ways to modify the risk once we fully understand it,'' he added.

Trauma had previously been found to be associated with psoriatic arthritis in smaller studies, which in turn had led to the idea of a ''deep Koebner'' phenomenon playing a role in psoriatic arthritis, mirroring the superficial Koebner phenomenon seen in skin psoriasis.

Koebner found that when an area of skin in people with psoriasis became traumatised following injury, a psoriatic lesion often appeared in the same location. A deep Koebner's phenomenon works on

the same principle, but involves deeper tissues, including bones and joints.

Using data collected between 1995 and 2013, 15,416 psoriasis patients exposed to trauma and 55,230 unexposed controls were identified and followed up for a total of 425,120 person-years during which 1,010 incident psoriatic arthritis cases were recorded.

The incidence rate of psoriatic arthritis among psoriasis patients not exposed to trauma was 22 per 10,000 person-years compared to 30 per 10,000 person-years in the exposed group.

Fertility and NSAIDs

In another interesting presentation, a study showed that diclofenac, naproxen and etoricoxib significantly inhibit ovulation in women with mild musculoskeletal pain. Of the women receiving NSAIDs, only 6.3 per cent (diclofenac), 25 per cent (naproxen) and 27.3 per cent (etoricoxib) ovulated, compared with 100 per cent of the control group.

These findings suggest that readily available non-steroidal anti-inflammatory drugs (NSAIDs) could have a harmful effect on fertility, and should be used with caution in women wishing to start a family.

''After just ten days of treatment we saw a significant decrease in progesterone, a hormone essential for ovulation, across all treatment groups, as well as functional cysts in one third of patients,'' said study investigator Professor Sami Salman, department of rheumatology, University of Baghdad.

''These findings show that even short-term use of these popular, over-the-counter drugs could have a significant impact on a woman's ability to have children. This needs to be better communicated to patients with rheumatic diseases, who may take these drugs on a regular basis with little awareness of the impact.''

NSAIDs are among the most commonly used drugs worldwide, and are taken by more than 30 million people every day. Available without prescription, NSAIDS are largely used for the treatment of pain, inflammation and fever – all common features of rheumatic conditions.

Thirty-nine women of childbearing age who suffer from back pain took part in the study, and received diclofenac (100mg once daily), naproxen (500mg twice daily) and etoricoxib (90mg once daily) or placebo. Treatment was given for ten days from day ten of the onset of the menstrual cycle; hormonal analysis (progesterone level) and follicle diameter were conducted via blood sample and ultra sonography respectively.

At the end of the NSAID treatment period, the dominant follicle remained unruptured in 75 per cent, 25 per cent and 33 per cent of patients receiving diclofenac, naproxen and etoricoxib respectively. Rupturing of the dominant follicle, and subsequent release of an oocyte (unfertilised egg), is essential for ovulation to occur.

''These findings highlight the potential effects NSAIDs may have on fertility, and could open the door for research into a new emergency contraception with a more favourable safety profile than those currently in use,'' concluded Professor Sami Salman.

Source:
EULAR 2015
Press release
www.congress.eular.org

Psoriasis in Practice

Over the years as an organisation a complaint PAPAA often hears from people with psoriasis is that they feel there is a lack of knowledge about psoriasis and psoriatic arthritis at primary care level. Equally, we hear that some GP-led practices provide excellent service and support. It would be good if this could be replicated across the UK. As an organisation, we decided to try to help patients by providing those in the primary care setting with a simple course that could highlight the needs of people with psoriasis.

This need for a broadening of knowledge coincides with the revalidation process that comes into force from April 2016,when nurses will need to revalidate to maintain their registration with the Nursing and Midwifery Council (NMC). Gaining enough CPD (continuing professional development) study hours will be essential. A new online course, launched on 9th November 2015, will award nurses 10 study hours and a wealth of information on a common yet often overlooked disease.

Psoriasis in Practice (PiP) is a training programme created by registered charity PAPAA, the Psoriasis and Psoriatic Arthritis Alliance. Nurses and other healthcare professionals can enrol at any time of year they like, and will have up to six weeks to complete the course.

Accredited by the Royal College of Nursing, the programme is hosted entirely online for maximum flexibility and convenience, and learning outcomes that enhance patient care and professional competence. On successful completion, participants will receive RCN-approved study hours and a certificate to add to their revalidation portfolio.

The programme features evidence-based (based on published research trial data) content, focusing on patient perspectives, aetiology (the study of causation or origination) and treatments for psoriasis and psoriatic arthritis, and nursing assessment and management. Psoriasis is a common scaly skin condition which affects 2-3 per cent of the UK population. So in an average GP practice of 4,000, there could be as many as 120 people living with this chronic condition. Up to 20 per cent of those affected will also have potentially disabling psoriatic arthritis, which is often undiagnosed or misdiagnosed.

As well as the various physical symptoms of the different forms of psoriasis and psoriatic arthritis, the mental and emotional toll can be extremely damaging. Among those severely affected, there is a high incidence of depression, anxiety and even suicidal tendencies. The PiP e-learning course aims to help participants to identify, manage and support patients, using evidence-based resources, case studies, patient interviews, the latest guidelines and descriptions of treatments.

Further information about the Psoriasis in Practice course can be found at: www.psoriasisinpractice.org

Source: PAPAA press release

What is revalidation and why is it important?

All nurses and midwives will have to revalidate to maintain their registration with the Nursing and Midwifery Council (NMC).

Revalidation is straightforward and will help nurses and midwives demonstrate that they practise safely and effectively. The new process replaces the current post-registration education and practice (Prep) requirements and nurses and midwives will have to revalidate every three years when they renew their place on the register.

Revalidation builds on existing renewal requirements by introducing new elements which encourage nurses and midwives to reflect on the role of the code in their practice and demonstrate that they are 'living' the standards set out within it.

The requirements for revalidation include:

- **450 practice hours or 900 if revalidating as both a nurse and midwife**
- **35 hours CPD including 20 hours participatory learning**
- **Five pieces of practice related feedback**
- **Five written reflective accounts**
- **Reflective discussion**
- **Health and character declaration**
- **Professional indemnity arrangements**
- **Confirmation.**

Revalidation will help to encourage a culture of sharing, reflection and improvement amongst nurses and midwives and will be a continuous process that nurses and midwives will have to engage with throughout their career. It will allow nurses and midwives to demonstrate that they practise safely and effectively, strengthening public confidence in their professions.

Revalidation is about promoting good practice across the whole population of nurses and midwives. It's not an assessment of a nurse or midwife's fitness to practice.

About the NMC

The NMC regulates nurses and midwives in England, Wales, Scotland and Northern Ireland. It exists to protect the public, set standards of education, training, conduct and performance so that nurses and midwives can deliver high quality healthcare throughout their careers.

Source:
www.nmc.org.uk

The British Association of Dermatologists (BAD) has recently launched Skin Support, a Department of Health-funded website providing psychological support for people with skin conditions.

The website brings together, and links to, patient information leaflets, support groups, self-help materials and help lines.

Prior to the Skin Support website, support materials and services directed specifically at skin disease patients were sporadic and disparate, and those that did exist were not always easy to find or access. While there are both patient support groups, centred on individual skin conditions, and also mental health charities, until now there has been no centralised hub that provides co-ordinated resources appropriate to people with problems that go beyond their skin and are psychological or psychiatric – this is the role that Skin Support fills.

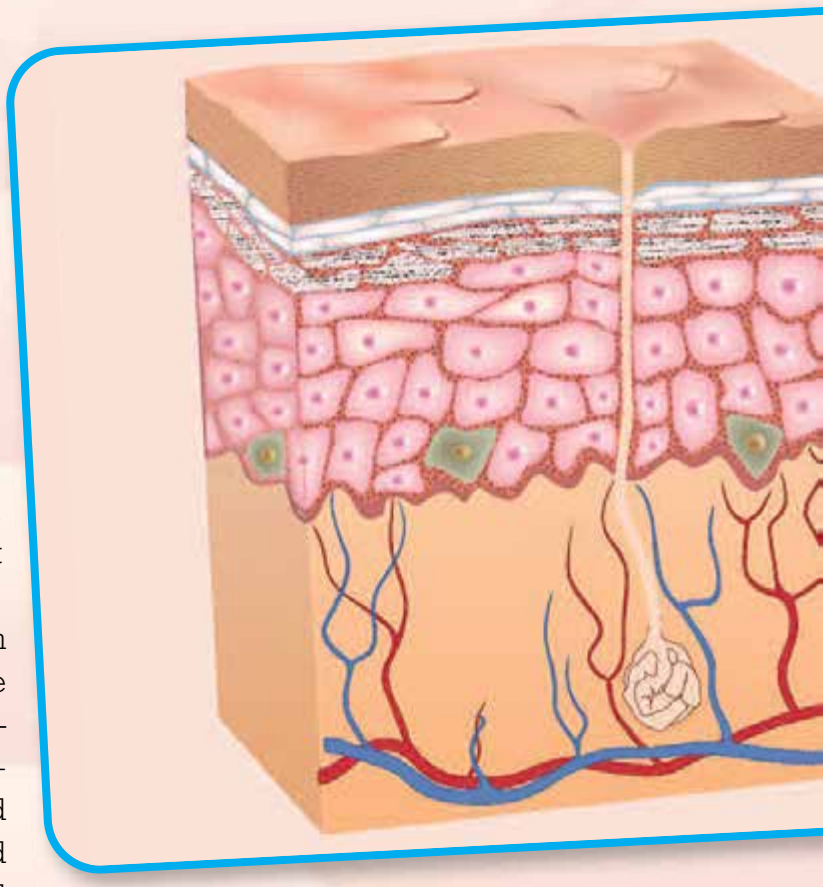
Skin conditions are the most frequent reason for people to consult their GP. It is not just the physical symptoms that affect peoples lives – conditions that are visible, disfiguring or long-term can carry a multitude of psychological and social effects, including isolation and depression. In the UK, psoriasis alone is linked to 300 suicide attempts annually.

A British Association of Dermatologists', survey in 2011 revealed that 85 per cent of patients indicated to their dermatologist that the psycho-social aspects of their skin condition were a major component of their illness.

Furthermore, stress, as well as being a frequent side effect of skin conditions, is also known to actually cause and exacerbate (make worse) a skin condition. Therefore psychological and self-help interventions can be crucial not only for easing mental distress but also for improving many of the physical symptoms of the skin disorder.

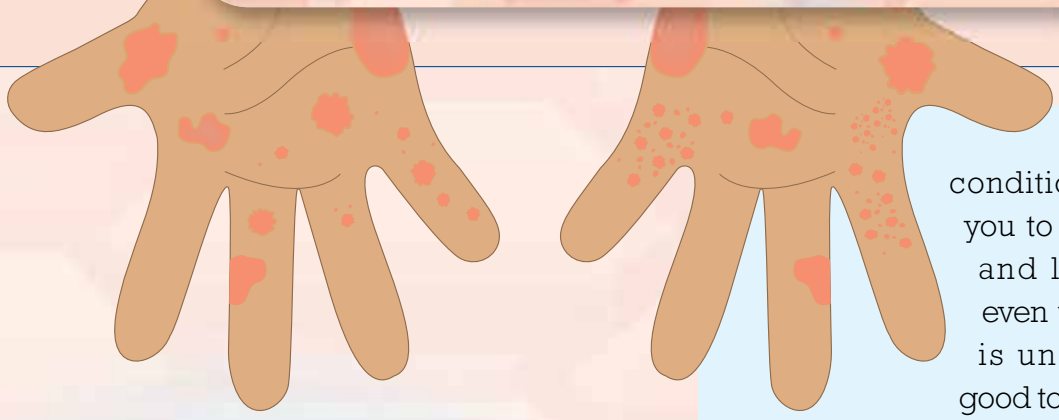
Dr David Eedy, president of the British Association of Dermatologists, said:

"A skin condition can have a devastating impact on people's mental and emotional wellbeing, and the benefits of support on both mental health and physical symptoms are well known in medical circles. However, few dermatology departments have access to local



liaison psychiatrists and their associated services, so self-help can be a vital tool for patients. The problem is that finding self-help materials can be difficult – patients don't know where to look and resources are available across so many different websites. The beauty of the Skin Support website is that it brings together lots of content in one easy to navigate place, and it tailors the materials to people's individual skin condition and any physical impairment this may involve.

"A report produced by the All Party



Parliamentary Group on Skin in 2013 showed that there is under-provision of psychodermatology services. Whilst a website can in no way replace this kind of specialist care, it is a good starting point and will be of enormous benefit to clinicians as well as patients.''

Dr Andrew Thompson is reader in clinical psychology at The University of Sheffield and a practising NHS clinical psychologist, and he was a member of the advisory panel associated with the development of the website. He said: ''Skin conditions can have a significant psychological impact on people and it is well acknowledged that access to psychological intervention and even to good quality evidence-based self-help is limited. Consequently the Skin Support project is an important development as it is unique in providing people with skin conditions with information about emotional and social issues associated with dermatological conditions. People visiting the site can also download self-help materials that have been written by qualified clinicians, such as myself, and have been either tested in the NHS or in research. We also hope that the site will encourage people to seek further help from their GP or dermatologist if needed''

Members of the public with skin conditions have also provided testimonials for the website:

''Enduring skin conditions tend to cause you to be self-conscious, and lack confidence, even when the condition is under control. It is good to know that there are different, recognised methods which can be used to overcome this.''

Susan Welch, 62, Surrey

''Emotional support is something that was really missing for me, my condition caused me to have a lot of dark days. It's good to think beyond just physically managing my skin.''

Sally Hooker, 52, Essex

''The blotchy skin I have with mast cell disease can be embarrassing but being able to share my problems with other sufferers has been a great help.''

Gerry Newnham, 68, Hertfordshire

The Department of Health Innovation, Excellence & Strategic Development Fund awarded the British Association of Dermatologists (BAD) a three-year grant to enable them to develop an online hub for psychological support specifically targeted at skin disease patients.

The British Association of Dermatologists is the central association of practising UK dermatologists, which aims to continually improve the treatment and understanding of skin disease.

To access the site go to:
www.skinsupport.org.uk

Source:
www.bad.org.uk

Yellow Card APP

- ***Have you ever had a side effect from a medicine that you have bought or been prescribed by a doctor?***

- ***Did you know that you could report any adverse event directly to the Medicines and Healthcare Products Regulatory Agency (MHRA) via a scheme called Yellow Card?***

The scheme was born from one of the biggest healthcare scandals of our time to protect public health and was introduced by Sir Derrick Dunlop, chair of the committee on the safety of drugs, in the wake of the thalidomide disaster in 1964. The aim was to monitor the safety of UK medicines and act as an early warning system to identify potential side effects and adverse reactions. Last year saw its 50th anniversary and with that has dawned a new age with the development of mobile application for iOS and Android.

Available on the App Store

ANDROID APP ON Google play

The MHRA, collates and reviews reports of suspected adverse drug reactions on all licensed and unlicensed medicines and vaccines. It includes those issued on prescription as well as those bought over the counter from a pharmacist or supermarket.

Yellow Cards are used alongside other scientific safety information to help MHRA make changes, if necessary, to the warnings given to people taking a medicine or vaccine, or to the way they are used, to minimise potential risks.

The new Yellow Card smartphone app supplements an existing one-stop website and is the only app that allows patients, carers and healthcare professionals to report side effects directly to the Yellow Card Scheme to help MHRA ensure they are acceptably safe for patients.

Users can select specific medicines or vaccines to track and receive news and alerts about them.

The app has been created in collaboration with the Innovative Medicines Initiative WEB-RADR project, a large-scale public-private partnership between the European Commission, national regulatory authorities, academia, small and medium sized enterprises and the European Federation of Pharmaceutical Industry Associations (EFPIA) that aims to boost biopharmaceutical innovation.

The key features can be used by patients, carers and healthcare professionals and provide a convenient alternative to using paper Yellow Card forms or the Yellow Card website. The app is free to use for everyone on iOS and Android and is easy to use for reporting side effects directly to the Yellow Card Scheme. It also enables users to create a 'watch list' of medications in order to receive official news and alerts.

Users can see an immediate response that shows Yellow Card has been accepted, submit updates to Yellow Cards already submitted and view previous Yellow Cards submitted through the app.

The app can be downloaded from the iTunes App Store and Google Play for your iOS or Android device for free.

Source:
MHRA media release

Scientists now report a new way to assess cholesterol that shows promise for evaluating the increased heart attack risk observed in patients with psoriasis.

The new technique measures the function of high-density lipoprotein (HDL), known as good cholesterol, rather than HDL cholesterol concentration. The study, conducted by researchers from the National Heart Lung and Blood Institute (NHLBI) at the National Institutes of Health (NIH) in the USA, could broaden the use of the technique. The study appears in the online issue of the European Heart Journal.

Research has shown psoriasis to be a risk factor for developing atherosclerosis, or hardening of the arteries, which is the major cause of heart attacks. Recent studies indicate that the level or concentration of HDL may not adequately predict heart disease risk. A better understanding of how HDL may be involved in atherosclerosis is needed, scientists say.

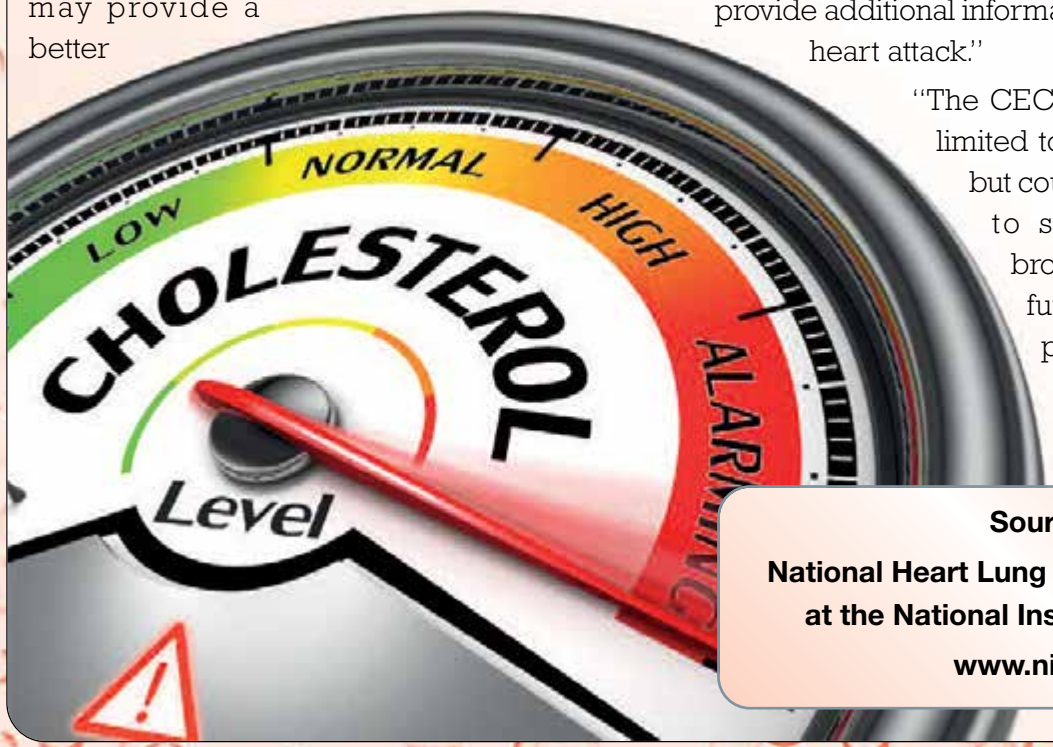
An emerging technique called HDL-cholesterol efflux capacity (CEC) measures the activity or function of HDL rather than its concentration and may provide a better assessment of a patient's HDL. CEC measures the ability of HDL to remove cholesterol from the arterial wall and excrete it from the body.

In the new study, a research group led by NHLBI's Dr Nehal N Mehta studied 101 patients enrolled in a psoriasis study at the Clinical Center of the National Institutes of Health. Using sophisticated imaging techniques, scientists took detailed pictures of the patients' coronary arteries and characterised the type of atherosclerotic plaque, a fatty substance that builds up inside the arteries that can lead to heart attacks.

By analysing the patients' blood samples, the scientists found that psoriasis patients with poor HDL function, as measured by lower CEC, had higher levels of coronary plaque. Additionally, this lower CEC was strongly associated with the presence of early, fat-rich coronary plaques which are most often the cause for heart attacks. Patients with better HDL function measured by higher CEC had lower levels of coronary plaque.

''These findings suggest that HDL function plays an important role in early atherosclerosis and may provide additional information about future risk of heart attack.''

''The CEC technique is currently limited to experimental settings but could provide a useful way to study cholesterol in broader populations in the future, not just psoriasis patients'', Dr Mehta said.



Source:

National Heart Lung and Blood Institute at the National Institutes of Health

www.nih.gov

The National Institute for Health and Care Excellence (NICE) has published guidance for secukinumab for treating moderate to severe plaque psoriasis in England and Wales. Under the guidance, secukinumab is:

"... recommended, within its marketing authorisation, as an option for treating adults with plaque psoriasis only when: the disease is severe, as defined by a total Psoriasis Area Severity Index (PASI) of 10 or more, and a Dermatology Life Quality Index (DLQI) of more than 10; the disease has failed to respond to standard systemic therapies, for example, ciclosporin, methotrexate and PUVA (psoralen and long-wave ultraviolet radiation) or these treatments are contraindicated or the person cannot tolerate them; and the company provides secukinumab with the discount agreed in the patient access scheme."

Secukinumab is in a group of drugs known as biologic agents and is similar to others already recommended by NICE. This class of drug offers targeted therapy and secukinumab neutralises interleukin-17A, which is thought to be involved in the body's autoimmune response in diseases such as psoriasis.

Secukinumab has a marketing authorisation for the treatment of moderate to severe plaque psoriasis in adults who are candidates for systemic therapy.

The drug is sub-cutaneously self-injected at a dose of 300mg every 4 weeks after initial weekly dose in the first month of therapy.

In the model data presented for appraisal of the trial, the Psoriasis Area Severity Index (PASI) showed that more than half (55.4 per cent) of those treated reached a PASI 90, which is a 90 per cent improvement in the scales, thickness and redness of the affected skin.

However, the summary of product characteristics includes the following adverse reactions for secukinumab: upper respiratory tract infections (most frequently nasopharyngitis, rhinitis), oral herpes simplex, rhinorrhoea, diarrhoea and urticaria; so risk and benefit needs to be considered.

Under regulations, the drug must be made available in line with the recommendations in the appraisal within 3 months of its date of publication.

Secukinumab was also accepted for the treatment of plaque psoriasis by the Scottish Medicines Consortium (SMC) in June. A patient group submission stated that patients often consider biologic agents to be the most effective treatment currently available for this condition. As secukinumab targets a different part of the immune system to existing biologic agents, it may also benefit those who have responded poorly to existing treatments.

Secukinumab is commercially known under the brand name of Cosentyx and manufactured by Novartis.

NICE has also recommended ustekinumab (Stelara) for psoriatic arthritis. We reported in a previous *Skin 'n' Bones Connection* (issue 39, 2014) that in May 2014 NICE issued technology appraisal guidance 313, which did not recommend using ustekinumab alone or in combination with methotrexate, for treating active psoriatic arthritis in adults when the response to previous non-biological disease-modifying antirheumatic drug (DMARD) therapy has been inadequate.

In a rapid review of TA313, updated guidance from NICE now recommends ustekinumab in specific circumstances following the introduction of a patient access scheme which the company that manufactures ustekinumab has agreed with the Department of Health.

Professor Carole Longson, director of the health technology evaluation centre at NICE, said: "Psoriatic arthritis is a chronic condition that can have a significant physical and psychological impact on an individual's day-

to-day life. NICE has already recommended a range of treatments (referred to as TNF-alpha inhibitors) – golimumab, adalimumab, etanercept and infliximab – to help manage active and progressive psoriatic arthritis in adults.

"This guidance resulting from the rapid review of TA313 now recommends that ustekinumab could be a treatment option for people who are unable to use the drugs that NICE has already recommended, or who have already had treatment with one or more of those drugs. This applies if the company provides the drug as agreed in the patient access scheme."

Another treatment that has been appraised for use in psoriasis and psoriatic arthritis in England, Wales and Scotland is apremilast.

Apremilast is the first in a new class of medicine for the treatment of plaque psoriasis and is also indicated for psoriatic arthritis. The treatment is oral (tablets) and taken twice a day. It has been suggested that apremilast is more convenient for patients than many other treatments used at this stage of therapy and may also mean fewer appointments at outpatient clinics.

The SMC approved the use in Scotland of apremilast as a psoriasis treatment for patients who cannot tolerate or do not respond to the main therapies used currently, including disease-modifying drugs or ultra-violet light therapy. It was also approved for psoriatic arthritis for use in adult patients with active psoriatic arthritis who have had an inadequate response with at least two prior DMARD therapies or who are intolerant to such therapies.

The decisions for England and Wales from NICE were very different, and treatment was not recommended.

In press statements, Professor Carole Longson, director of the health technology evaluation centre at NICE, said

"The committee considered the evidence on the use of apremilast both before and after TNF-alpha inhibitors and for people who aren't able to take TNF-alpha inhibitors. The committee concluded that apremilast is clinically effective compared with no other treatment. However, compared with TNF-alpha inhibitors, apremilast was the least clinically effective for treating psoriatic arthritis, although some costs were saved by its use. Importantly, there was not enough robust evidence demonstrating that apremilast slows progression of the disease compared to TNF-alpha inhibitors. The committee concluded that they were unable to recommend apremilast for treating active psoriatic arthritis because the costs saved were not sufficient to justify the health losses."

For use in psoriasis NICE issued a final appraisal determination (FAD) issued in June, which said:

"Apremilast is not recommended within its marketing authorisation for treating psoriasis, that is, for treating adults with moderate to severe chronic plaque psoriasis that has not responded to systemic therapy, or systemic therapy is contraindicated or not tolerated".

Ampremilast is commercially known under the brand name of Otezla and manufactured by Celgene Corp.

Glossary of terms:

PASI (Psoriasis Area and Severity Index) is the most widely used tool for the measurement of severity of psoriasis. PASI combines the assessment of the severity of lesions and the area affected into a single score in the range 0 (no disease) to 72 (maximal disease).

DLQI (Dermatology Life Quality Index), developed in 1994, was the first dermatology-specific Quality of Life instrument. It is a simple 10-question validated questionnaire that has been used in over 40 different skin conditions in over 80 countries and is available in over 90 languages. Its use has been described in over 1000 publications, including many multinational studies. The DLQI is the most frequently used instrument in studies of randomised controlled trials in dermatology.

Patient access scheme are special ways pharmaceutical companies can propose to enable patients to gain access to high cost drugs. Usually in the form of a discount off the price the NHS pays.

Full details of both sets of guidance are available at:

NICE website: www.nice.org.uk
SMC website: www.scottishmedicines.org.uk

Source:
NICE and SMC media releases

PAPAA post

Your website has cheered me up. I am a retired nurse (1 year). I have been so unhappy of late, as my health has been deteriorating so that I am constantly visiting my GP. I have managed hypothyroidism and arthritis for 25 years. However, I have this year suffered so much though with joint pain exhaustion, fatigue, sciatica, uti cellulitis and now psoriasis. I am constantly prescribed medications and finally had a state of collapse, resulting in paramedics taking me to hospital whereby a neurologist took me off all medications, prescribing a different lot. I went home, started new medications and had a massive drug adversity and acute withdrawal of prescribed medications all in one go.

My GP came out to me after 5 days and sorted a better regime and choice of medication. At no time has any medic explained what my diagnosis is, negotiated a care plan, or really had time to listen and assess.

So quick are medics to prescribe I now have psoriasis and after reading the forum on this site I believe this is the underlying condition.

I thank all your readers/their stories and you for this site. What medics need to do is stop over-prescribing and listen to patients! Get a diagnosis first. Thank goodness for sites like this.

I will take control of my situation as never before, in the knowledge that others share and we all care!

Well done and thank you.

Yours

Anon

Mocked for having psoriasis

In an article widely reported in the news that a woman was mocked on facebook after visiting a shop by a sales assistant because of her psoriasis. Although an apology was issued, the damage had already been done.

Have you ever experienced the same? What would you do in the same situation? Below are some comments received via our social media pages.

"Absolutely awful. Poor poor lady, she's lovely looking. The only good thing to come out of this is perhaps a bit more awareness of this awful condition. Fortunately, I do not suffer from it but my husband has for 20 years and has had to endure very unkind comments. I wish her all the best"

"The apology is a sham! The ignorant shop worker should be ashamed of herself. The shop should be offering a FREE outfit! I wish her and her family all the best for the future"

"That's so sad, it's probably been one of the hardest things for me to come to terms with as a young person at school and even as an adult now"

"Dreadful way to treat another human being who just happens to have a life long condition that is debilitating. Didn't the same thing happen at another store some years ago? The apology if you read it was most likely written by a legal person".

"Outrageous some people are just pig ignorant I've had people stare at my skin and drop change into my hand like they'll catch it. I think she/we are all very brave and I hope her big day is wonderful"

"I am a sufferer and especially in the summer when not wearing long sleeve tops I get people staring especially at my elbows I agree with others some people are pig ignorant you cannot catch psoriasis"

"The apology has been written by HQ its too business like, what a sham. I also am a sufferer and yes we suffer all the negative comments the looks and so on. I am on methorexate for my psoriasis and it has worked wonders"

"When I have been asked if it is catching, stared at, or generally treated horribly, my reaction is always the same, I turn, look at the person and whilst touching them with my "horrible skin" smile and say, yes it is, and unfortunately there is no cure, then walk away"

"When I was a kid my reaction to teasing was to touch the person with my psoriasis (usually on my elbows) and tell them that now they were going to catch it. It worked wonders as of course they didn't catch it and it took the mystery out of it for them. If an adult did the same thing to me now, I'd probably do the same thing I did then".

"There is still so much discrimination towards people with disabilities"

"From the pharmacy to the bank to the shopping centre ... Its always the same thing ... Grown people act like I am going to give them a deadly disease by standing close to me. Pulling their children in close. Even had one clerk refuse to take the money from my hand !!! I feel her pain bless her heart !!!"

The following are recent posts and discussion by users on our facebook page.

Dithranol

Would you miss tar or dithranol for psoriasis if it were no longer available? Special formulations are becoming more difficult to obtain as raw materials are becoming harder to source. What impact would that have on you and how you manage your psoriasis?

"OMG I hate these substances, and the bandages you have to wear. I have suffered from psoriasis since I was about 7 years old, I am now 61. I have tried so many treatments I cannot recall. Many of which, left scarring when treating the psoriasis. I was recently introduced to propolis cream which has significantly reduced the scaling on my arms and jojoba shampoo and conditioner which has also had a significant positive effect. I have psoriatic arthritis so I am also drinking aloe gel which helps joints and with the auto immune system, which as you probably know is adversely affected by psoriasis".

''It's the only effective product for me and that's after 46 years of having psoriasis, I dread to think what I'll do if it's no longer available''

''After spending most of my childhood/early teens in tubi bandages I hate dithranol ...''

Do you have a computer or smartphone? Do you want to share your experiences?

Visit the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website home page.

To-date people have been discussing tiredness, diet and disability claims, amongst other topics.

We post interesting news items and links to fuller articles on our website **www.facebook.com/papaa.org**

We also have a Twitter page linked to our Facebook page so if you prefer the micro-blogging site then you can follow us by clicking the link, which is also located on our home page **www.twitter.com/PsoriasisInfo**

Follow us on Facebook

PAPAA research

PAPAA research grants

PAPAA has developed a small research grant-giving process and during recent years has supported some interesting projects.

Dr John Ingram at the University of Cardiff was awarded a grant to: *undertake Cochrane review of fumaric acid esters in psoriasis.*

Fumaric acid esters (FAE) are sometimes used in the UK, but are not licensed for psoriasis. They are widely used in other countries, most notably Germany. The aim of the review question was to see what is the available evidence for the benefits and risks of using FAE for treating psoriasis.

The review has now been completed and published and can be viewed at: http://www.cochrane.org/CD010497/SKIN_oral-fumaric-acid-esters-treatment-psoriasis

Dr Henning Holle & Dr Fiona Cowdell at the University of Hull received funding for a study called: *Auditory modulation of itch in psoriasis patients.* The project was to develop new treatments for psoriatic itch. In the study, the participant was asked to listen to a number of scratching and rubbing sounds on a computer using headphones, and then rate how itchy they feel while listening to these sounds.

The project has completed with the results submitted and is awaiting publication.

In Dr Rod Tucker's study the Hull-based team received a grant called: *is it feasible for community pharmacists to deliver an educational programme designed to help people with psoriasis self-manage as effectively as possible?* The project is due to complete by the end of 2015.

PAPAA's aim is to support well-run medical research and does this via the following:

- Supporting research by providing research grants
- Promoting research programmes
- Publicising results of research
- Helping to recruit into research.

PAPAA is open to applications for funds via the grant-giving process. Full details can be found at: **www.papaa.org/research/grants**

NIHR Partner Organisation status

PAPAA meets the criteria for NIHR Partner Organisation status for its research grants funding stream.

PAPAA is an NIHR Partner Organisation in respect of its Research Grants funding stream. Studies funded through this funding stream are eligible for inclusion in the NIHR Clinical Research Network Portfolio and therefore able to access NHS support via the NIHR Clinical Research Network infrastructure.

You can find further information about the NIHR Clinical Research Network Portfolio at: **www.crn.nihr.ac.uk**

PAPAA's position on pharmaceutical funding

PAPAA does not receive funds (either directly or in kind) from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions, charitable grants, legacies or other income generation. We believe that this allows us to act in an open, non-biased way and free from any perceived influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe it is beneficial to our constituent group.