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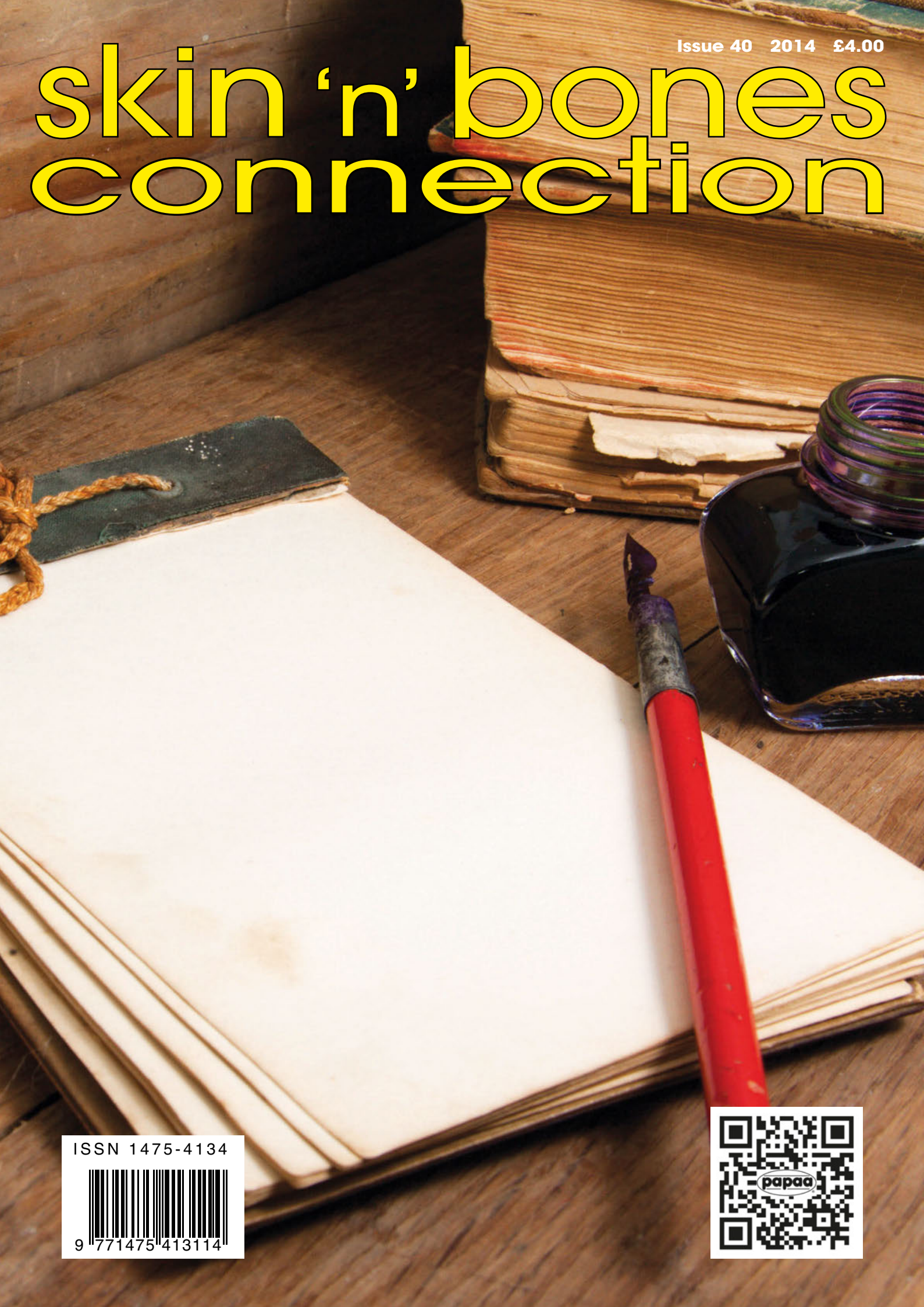
# skin 'n' bones connection



ISSN 1475-4134

## Dear Reader

It is true many people with psoriasis and or psoriatic arthritis are mildly affected, and their conditions can be well controlled with modest intervention, but for others the condition is extremely difficult to control, with risk, and benefit becoming difficult to balance.

As more research emerges, it is beginning to be apparent that the term 'being a psoriatic' encompasses a number of hidden risks which increase in line with severity of disease.

There is now the implication that body fat is a contributor to worsening psoriasis symptoms (page 3). There has also been much debate about the association with cardiovascular disease and diabetes. The International Psoriasis Council (pages 16-17) reported that there are some links now, but definitive evidence is elusive.

Research can only report what is found in a trial; this often misses important day-to-day real-life events. As a psoriatic you can help to fill in the gaps, whether sharing your story (pages 10-11) or getting involved by reporting drug allergies and side effects (pages 4-5) or contributing to treatment appraisals (page 13).

Managing health can be a challenge, but you could turn it into a useful contribution and help others along the way by getting involved.

**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:**

People often cope with their condition by communicating and learning from others, which can help to provide support.

Why not share your thoughts, views and experiences? *See pages 10-11*

# Weight and psoriasis

**Most people think of obesity as just a fat storage problem. Eat too many calories and your body will simply convert the excess energy into fat, which is then stored in specialised fat cells. However, although fat cells store energy, this is not all they do for a living. Some fascinating scientific studies over the past two decades show that fat cells do much more than simply warehousing energy supplies. We now know they are intimately involved in sophisticated signalling to the brain, muscle and other body tissues via a whole family of complex chemical/hormonal messengers. Unfortunately, it seems that fat cells also promote inflammation through the actions of a group of molecules (electrically neutral group of two or more atoms held together by chemical bonds) called adipokines.**

So today, obesity is no longer considered as simply a fat deposit problem, but as a chronic inflammatory disease, which may have an adverse impact on the body at many levels. Why does this matter to those of us with psoriasis?

Well, it turns out that psoriasis also produces an intense inflammatory response, while the combination of psoriasis and obesity further intensifies the inflammatory reaction. Perhaps unsurprisingly, studies have shown that moderate weight loss improves the symptoms of psoriasis and psoriatic arthritis. But does losing weight improve the efficacy of drug treatment? Recent evidence suggests that it does.

In a study by Di Minno et al, 138 patients taking TNF-α blockers for psoriasis were divided into two dietary groups: one group consumed fewer than 1500 kcal/day with no more than 35% fat, while the other group had an essentially free diet with minimal restrictions. Outcomes were measured as a composite score representing minimal disease activity (MDA). Results showed that patients who achieved a weight loss of equal to or more than 5% of their baseline weight were significantly more likely to achieve MDA than those whose weight loss was less than 5%. In fact, MDA was achieved by 50% of those patients with successful weight loss (equal to or more than 5%) compared with 23.1% of those who lost less than 5%. Among those who lost more than 10% of body weight, no fewer than 59.5% achieved MDA.

Another study, by Al-Mutain et al, involving 262 psoriasis patients undergoing biologic therapy (eg infliximab, etanercept etc) showed that weight loss had a strong tendency to increase the efficacy of the treatment. Major improvement in psoriasis severity as judged by the Psoriasis Area and Severity Index (PASI) score was achieved by 85.9% in the weight loss group, as compared with 59.3% in the controls.

Finally, in a study by Gelfand et al, 61 obese psoriatic patients on active treatment with cyclosporine were randomised into two groups; the first were given a low-calorie diet and the second received no dietary intervention. At week 24, the low-calorie group had lost around 7kg and showed a much greater improvement in their psoriasis symptoms than the control group.

## Conclusion

Taking together, these studies show that overweight and obese patients with psoriasis will significantly improve their symptoms by losing weight. This is true whether they are taking active drug treatment or using topical treatments only. In fact, achieving and maintaining a healthy weight should now be regarded as a fundamentally important part of the long-term management of psoriasis.

**Author:**
**Dr David Ashton, PAPAA Medical Advisor**

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Di Minno M, Peluso R, Lervolino A et al. Weight loss and achievement of minimal disease activity in patients with psoriatic arthritis starting treatment with tumour necrosis factor blockers. Ann Rheum Dis 2014; 73:1157-1162

Al-Mutairi N, Nour T. The effect of weight reduction on treatment outcomes in obese patients with psoriasis on biologic therapy: a randomized controlled prospective trial. Expert Opin Biol Ther. 2014 14:749-56.

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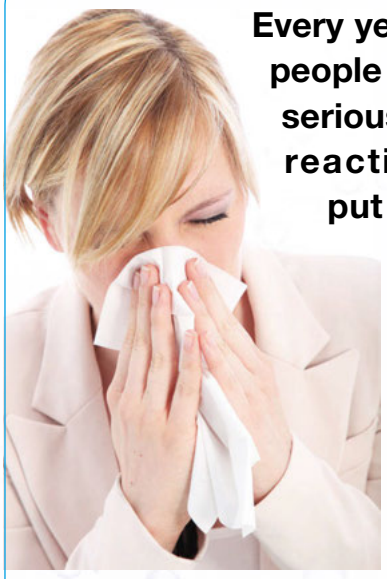
NICE National Institute for Health and Care Excellence



**Every year, around 62,000 people in England have a serious enough allergic reaction to a drug to put them in hospital. The National Institute for Health and Care Excellence (NICE) has published its first guideline on drug allergy in adults, children and young people, which aims to dispel confusion around best practice in assessment, documentation, communication and referral to specialist services.**

A recent analysis from the National Reporting and Learning System revealed that in many of the instances where people suffered harm, they had been given a drug to which they were already known to be allergic.

All drugs have the potential to cause side effects (adverse drug reactions), but not all of these side effects are considered to be allergic. An allergic reaction occurs when the body thinks the medicine is a threat and the immune system responds to it. The drugs often linked to immune responses include commonly used treatments such as antibiotics, general anaesthesia and certain painkillers (eg aspirin and ibuprofen).

Professor Mark Baker, director of the centre for clinical practice at NICE, said: "About half a million people admitted into NHS hospitals each year will have a diagnosed drug allergy. If we know that giving someone a particular drug could cause them harm, or in the worst instances may even kill them, the utmost care must be taken to ensure they are not prescribed or administered that drug.

"This new guideline encourages all healthcare professionals to be alert to the possibility of drug allergies and offers best practice on clinical management to ensure every individual is spared from serious harm."

The recommendations prioritise the thorough assessment of any person who is suspected of having a drug allergy and details what signs to look out for. These include symptoms that come on rapidly such as hives, wheezing, redness or swelling of the skin and symptoms which can take several days to show such as fever, liver dysfunction or eczema.

The guideline identified major issues in clinical documentation of drug allergy with insufficient information being recorded and shared with other healthcare professionals or people with allergies themselves. The guideline outlines a structured approach to collecting information on new drug allergies. It also makes a recommendation to redesign prescriptions (paper or electronic) issued in any setting to include information on drugs or drug classes people with a known drug allergy should avoid.

Dr Shuaib Nasser, consultant allergist, Addenbrooke's Hospital, Cambridge and chair of the guideline development group, said: "Wrongly prescribing drugs to people with known allergies puts them at serious risk of harm but we know this can be avoided. It is important that this is done, as some allergic reactions can be fatal.

"The guideline stresses the care all healthcare professionals must take when documenting new drug allergies and the importance of sharing this information with patients and other healthcare professionals. People should be provided with structured written information on drugs to avoid and be advised to check with their pharmacist before taking over-the-counter medicines. In some cases specialist investigations will be required to confirm or exclude drug allergy."

According to the guideline insufficient awareness of available services can cause considerable differences in how drug allergies are managed and access to treatment across the country.

The recommendations describe when people can have non-specialist treatment, for instance considering a different drug from the same class in those who have had a mild allergic reaction. And it also highlights the importance of referring people who have had severe reactions or need ongoing treatment, to find out what alternatives can be taken safely.

**About NICE**

**The National Institute for Health and Care Excellence (NICE) is the independent body responsible for driving improvement and excellence in the health and social care system. NICE develops guidance, standards and information on high-quality health and social care. We also advise on ways to promote healthy living and prevent ill health.**

**Website: www.nice.org.uk**

**Before a medicine is granted a licence so that it can be made available in the United Kingdom, it must pass strict tests and checks to ensure that it is acceptably safe and effective.**

All effective medicines, however, can cause side effects (also known as adverse drug reactions), which can range from being minor to being very serious. For a medicine to be granted a licence, the expected benefits of the medicine must outweigh the possible risks of the medicine causing adverse effects in patients. Sometimes, it is difficult to tell whether a possible side effect is due to a medicine or something else.

Some side effects may not yet be known, so that is why it is important for people to report to the Yellow Card Scheme. Many side effects are mild, but some can be serious and even life-threatening. Others appear after taking a medicine for a long time or even after stopping a medicine.

The Yellow Card Scheme, run by the Medicines and Healthcare Products Regulatory Agency (MHRA) and the Commission on Human Medicines, is used to collect and collate information from both health professionals and the public on suspected side effects.

It is important for people to report, as these are used to identify side effects and other problems, which might not have been known about before. If a new side effect is found, the MHRA will review the way that the medicine can be used, and the warnings that are given to people taking it to minimise risk and maximise benefit to the patient. Further information can be found on the MHRA website in the frequently asked questions (FAQ) section.

Yellow Card reports on suspected side effects are evaluated, together with additional sources of information such as clinical trial data, medical literature or data from international medicines regulators, in order to identify previously unidentified safety issues or side effects.

Information gathered from Yellow Card reports made by patients and health professionals is continually assessed at the MHRA by a team of medicine safety experts made up of doctors, pharmacists and scientists who study the benefits and risks of medicines. If a new side effect is identified, information is carefully considered in the context of the overall side effect profile for the medicine, and how the side effect profile compares with other medicines used to treat the same condition. The MHRA takes action, whenever necessary, to ensure that medicines are used in a way that minimises risk, while maximising patient benefit.

If you are worried about a symptom you think may be a side effect: check the patient information leaflet supplied with the medicine. This lists the known side effects and advises you what to do.

MHRA
Regulating Medicines and Medical Devices


Talk to your doctor or pharmacist.

or

**Call the NHS**

NHS 111 in England and Scotland on 111 (textphone 18001 111)

NHS Direct Wales/Galw IECHYD Cymru on 0845 46 47 (textphone 0845 606 46 47)

Use the NHS symptom checker tool at http://www.nhs.uk/symptomcheckers/Pages/Symptoms.aspx

To report a side effect go to: https://yellowcard.mhra.gov.uk/

# Short films

**The sharing of other peoples' experiences can often provide a useful insight into living with a chronic disease, and help to reduce the isolation and loneliness associated with conditions such as psoriasis and psoriatic arthritis.**

PAPAA has produced a number of short films, where real people talk about their journey from diagnosis to how they manage their condition on a day-to-day basis. The films are available on PAPAA's website and YouTube channel.




Filmed as part of the Psoriasis in Practice education programme produced in conjunction with leading consultant dermatologist Professor Alex Anstey and colleagues at Aneurin Bevin Academic Dermatology, the seven films are:

- My psoriasis journey
- Psychological aspects of psoriasis
- Treating psoriasis
- Living with psoriasis & psoriatic arthritis
- Relationships and psoriasis & psoriatic arthritis
- Psoriasis at work
- Impact on lifestyle with psoriasis

The films will build into a library, and in the future we will be developing films on subjects such as explaining psoriasis and psoriatic arthritis, the treatments and how to get the maximum benefit from the NHS.

**To view the current series go to:**

**Website: www.papaa.org/self-help/short-films**

***or***

**YouTube channel: www.papaa.tv**

**Scratching an itch only makes it worse. New research from scientists at Washington University School of Medicine in St. Louis indicates that scratching causes the brain to release serotonin (a feel good chemical agent), which intensifies the itch sensation.**

Scientists have known for decades that scratching creates a mild amount of pain in the skin, according to senior investigator Zhou-Feng Chen, PhD, director of Washington University's Center for the Study of Itch. That pain can interfere with itching — at least temporarily — by getting nerve cells in the spinal cord to carry pain signals to the brain instead of itch signals.

''The problem is that when the brain gets those pain signals, it responds by producing the neurotransmitter serotonin to help control that pain,'' Chen explained. ''But as serotonin spreads from the brain into the spinal cord, we found the chemical can 'jump the tracks,' moving from pain-sensing neurons to nerve cells that influence itch intensity.''

Scientists uncovered serotonin's role in controlling pain decades ago, but this is the first time the release of the chemical messenger from the brain has been linked to itch.

**Source: Washington University Center for the Study of Itch**


**Researchers in America have linked a species of intestinal bacteria known as Prevotella copri to the onset of rheumatoid arthritis, the first demonstration in humans that the chronic inflammatory joint disease may be mediated in part by specific intestinal bacteria. The new findings by laboratory scientists and clinical researchers in rheumatology at NYU School of Medicine add to the growing evidence that the trillions of microbes in our body play an important role in regulating our health.**

Using sophisticated DNA analysis to compare gut bacteria from faecal samples of patients with rheumatoid arthritis and healthy individuals, the researchers found that P. copri was more abundant in patients newly diagnosed with rheumatoid arthritis than in healthy individuals or patients with chronic, treated rheumatoid arthritis. Moreover, the overgrowth of P. copri was associated with fewer beneficial gut bacteria belonging to the genera Bacteroides.

''At this stage, however, we cannot conclude that there is a causal link between the abundance of P. copri and the onset of rheumatoid arthritis,'' Dr Littman says. ''We are developing new tools that will hopefully allow us to ask if this is indeed the case.''

The researchers plan to validate their results in regions beyond New York, since gut flora can vary across geographical regions, and investigate whether the gut flora can be used as a biological marker to guide treatment.

''We want to know if people with certain populations of gut bacteria respond better to certain treatment than others,'' says Dr Scher. Finally, they hope to study people before they develop rheumatoid arthritis to see whether overgrowth of P. copri is a cause or result of autoimmune attacks.

**Source:**
**NYU School of Medicine media office**

# Get involved

**We have been increasingly asked how people can get involved with the work of PAPAA, support us or raise awareness about what we do. In response to this, we have developed a number of ideas that could help us and raise awareness about psoriasis and psoriatic arthritis.**

Of course, raising money is vitally important for all charities and PAPAA is no exception; we rely on the generosity of our supporters and donors to help us carry out our work. However, awareness is even more important and we will never stray from that path.

As part of our continued awareness activities, the donations we receive help to fund the distribution of free information and the production of new information. It also supports the research we fund on the impact, cause or management of psoriasis or psoriatic arthritis.

Every contribution is directed towards the core aims of the charity to help to provide a positive approach to dealing with psoriasis and psoriatic arthritis. Our philosophy and activities are explained in more detail in our recently updated ***About Us*** leaflet. If you would like a copy of the updated leaflet, please contact us (details on page 2).

## Getting involved

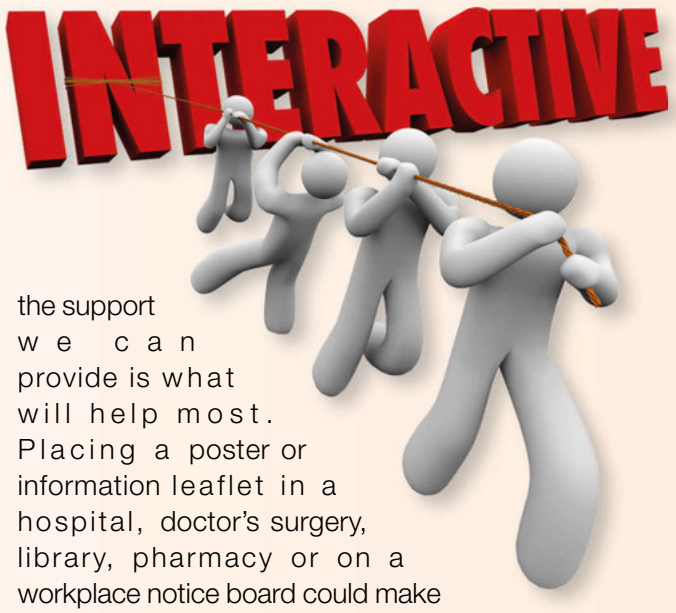
If you decide to get involved, firstly, we must say thank you. We know that there are many good causes you could help and your time is extremely precious. We never forget that, nor do those who we help, as they know that every contribution, whether through your time, monetary or in kind is because you want to help people affected by psoriasis and/or psoriatic arthritis.

## What can I do?

We value every effort, whatever it maybe. Not everyone can run a marathon or climb a mountain, and many people feel that these examples are the only ways that charities raise awareness or funds. Of course, if that is what you want to do then we will support you in your efforts, but equally if you just want to tell a friend about us, then that is great too. It can be daunting getting involved as the weight of expectation can be too much to deliver. We never set minimum limits; every effort, however large or small, helps to raise awareness and the profile of psoriasis and/or psoriatic arthritis.

## Raising awareness

Here are a few ideas that might give you some inspiration. Getting the message out about




the support we can provide is what will help most. Placing a poster or information leaflet in a hospital, doctor's surgery, library, pharmacy or on a workplace notice board could make all the difference to someone affected by psoriasis or psoriatic arthritis.

### *We can provide:*

- **Posters**
- **Contact cards**
- **Leaflets**
- **Promotional items**
- **T-shirts**
- **Hats**
- **Pens**
- **Pencils**
- **Pads**

Let us know what you want to do and we will try to support your activity.

## Fundraising

Raising funds for charities can sometimes be a complicated process. Street collections and asking for money in a public place will often need a licence and most of all, permission from the charity involved. Running raffles, lotteries and prize draws (depending on the prizes) will also need to be done under licence and comply with relevant laws and regulations.

This level of activity can be time-consuming and in some instances bureaucratic and you may say "I don't have the time". But not all fundraising has to be that challenging and in some instances you will not even know that you are raising money.

Gift Aid is a good example. If you're a taxpayer making a donation, all you need is to indicate that you want to Gift Aid it. Then the government adds 25% at no cost to you. So a £10 donation immediately becomes a £12.50 donation. We can provide Gift Aid forms for single or recurring donations.

There are also many very simple ways to donate and Gift Aid at the same time. Justgiving lets you donate to PAPAA online, set up your own fundraising page for an event, in memoriam or any activity, which you wish to promote to raise funds. It's easy, quick and tax-friendly. www.justgiving.com/psoriasis/donate/

## Internet donations

Buying goods on the internet via certain sites can also provide PAPAA with funds. Try, eBay for Charity and Easyfundraising. See PAPAA website for more details.

If you are not buying goods then using search engines


such as Easysearch or, Everyclick can also provide PAPAA with funds just for nominating us when using those sites.

## More involved

You may say that it is all very well raising money and circulating posters, but can I get more involved in PAPAA's work? Well the answer is yes. As a patient-centred charity PAPAA consults with people affected by both conditions and as part of that process has developed a lay user group, which along with its medical advisory panel helps to provide positive solutions to manage psoriasis and psoriatic arthritis. For more information, see the advert below.

***If you have any ideas or want to know more about getting involved, contact us or visit our website: www.papaa.org/get-involved***

# 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**

# Share your story


**Since July, we have been inviting people to share their experiences and stories via our website. Here are a couple of stories recently submitted**

## Story 1

I started getting psoriasis in my late teens. My scalp was a mess and I underwent the usual multitude of skin scrapes, lotions and potions before getting a definitive diagnosis.

What I now know is the arthritis began in my feet; the job I had meant standing for 8-10 hours a day and the burning agony would leave me sweaty, breathless and distracted after only an hour or so at work. It went undiagnosed, X-rays revealed nothing, life was hard but when I stopped work and returned to study things calmed down. Things were ok, just scaly skin for a couple of years, then I got pregnant. Hell like I had never experienced was unleashed on my joints. I was still undiagnosed, my GP would get exasperated at my description of the pain and remind me that being pregnant was natural, that I needed to deal with it. How does one deal with crying in pain while your hubby tries to roll you over during the night, your hips and pelvis feeling like they are being ripped in two, so much that everything within you demands that you cease trying to move! I am so thankful we didn't have neighbours during that time - I'm sure they would have called the police from all the screaming :-)

After an assisted birth, as the joint pain was excruciating, even over the contractions, the pain died down a little and was manageable for a few months and, finally, I saw a physician who diagnosed me with psoriatic arthritis.

Over the last 20 years it's had its moments. I occasionally have massive flares that mean I need help with basic functions like eating and toileting but most of the time it is a grumbling beast that gives me moderate pain and fatigue every day. I cannot remember a day without pain; I long for a day where I feel on top of the world! The pain I find hardest to bear is the costochondritis, it seeps into my very being and I cannot focus, think or even be distracted.

I hate being 'a burden' as I see my hubby put on yet another load of washing or do the vacuuming again, after working all day as a teacher. The frustration is huge; some days I wonder why he stays, and then things settle for a bit and I'm more capable with the day to day things and my morale is boosted a little. He loves me regardless, he understands most of the time and he is my rock.

It is so encouraging to read others stories, it reminds me I am not alone in my journey, others understand the daily struggle too.

Thank you all for sharing.

*From a 40 year old female living outside the UK*

## Story 2

I first had psoriasis when I was about 12 years old; it appeared under my eyes and on my elbows.

It didn't worry me much as it came and went and was quite faint. During my teens it appeared in a few more places: knees, back and buttocks. I have forgotten how many different treatments I tried both from GP and "old wives' tales" but nothing worked. It became worse through my teens and 20s.

When I became pregnant with my first child I was told it would be better during pregnancy but instead it flared terribly until my skin was about 50% covered with plaques and inverse psoriasis started in intimate areas and under my breasts. From then on my skin just got worse, the flaking used to embarrass me so much I would wear 2 long sleeved shirts, I would put elastic bands around the wrists of the bottom shirt to prevent dropping flakes of skin after my husband used to remark how "off-putting" it was.

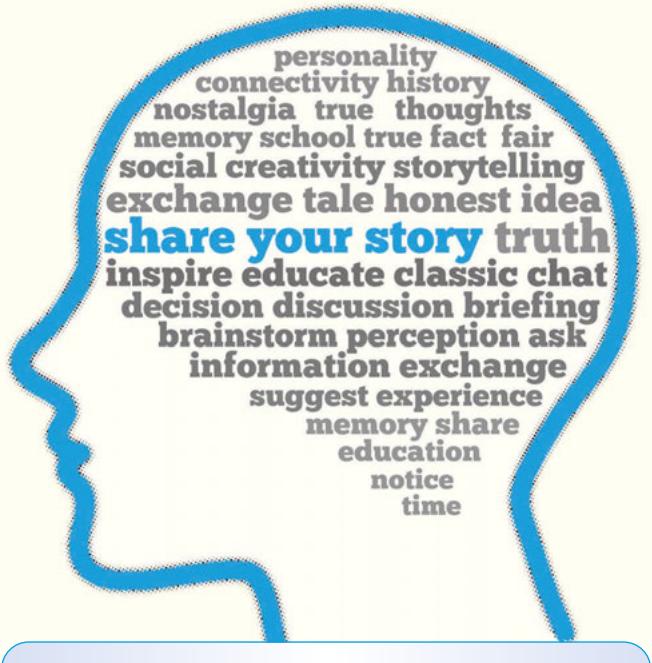
I found that words would really hurt me and I no longer did the things I loved because of my skin. No swimming in my late teens after I was asked to get out of a local pool as parents had complained that I shouldn't be in the water with their children. Once a mother pull her child away from sitting on a bus seat next to me and hissed at her child "you might catch it". These experiences affected me deeply and I did all I could to hide as much of myself as possible. By the time I was in my 30s my back, buttocks, belly, thighs, upper arms, elbows, breasts, knees and shins were completely covered with psoriasis, which would crack and split.

I found the only way to manage it so I was fairly comfortable was to bath every other day, rub all the skin flakes off gently after soaking for an hour or so, then plaster myself with aqueous cream as often as practical. In 2010 I plucked up enough courage to get more treatment and was referred to a dermatologist for the first time ever. I received UVB treatment with a steroid cream and in 10 weeks I was cleared completely. It is returning slowly and I've been referred back to the dermatologist, so fingers crossed.

I've had tendon pain in my wrists and ankles since my eldest son was born, and grew lumps on my wrists over the years and was diagnosed with tenosynovitis. It didn't trouble me too much and would improve with ibuprofen after a few months. In 2005 my pain increased to different areas; especially in my sternum area. I was prescribed anti inflammatory meds, which did help.

All blood tests came back clear with no rise in the inflammation markers. In 2010 I saw a rheumatologist who diagnosed psoriatic arthritis and started me on oral methotrexate (MTX); that was changed to subcutaneous injections after problems with nausea. I tolerate this much better. The pain of my condition doesn't usually get me down but the grinding fatigue does; often I'm too tired to even climb the stairs during a flare and I'm now being investigated for secondary fibromyalgia. I've learnt to enjoy every day that I'm well enough to get out and about, and to be gentle with myself when I can't get going.

*From a 51 year old female living in England*




- **Can you identify with these stories?**
- **Do you have a story to tell about your psoriasis or psoriatic arthritis?**
- **Share your coping strategies?**
- **Would you like others to know how your life has been affected?**

**Your experiences count!**

This is your opportunity to let others know what it is like to live with these conditions. The negative and the positive effects.

Share your thoughts and let others see the impact. It is up to you; if you just want to get something off your chest, here is your chance. You can submit anonymously or share your name.

By sharing your story, you will help to build a picture of the extent these conditions have on real people and their lives.

**Please note:** We will not publish your name and may edit your story to protect the privacy of others mentioned.

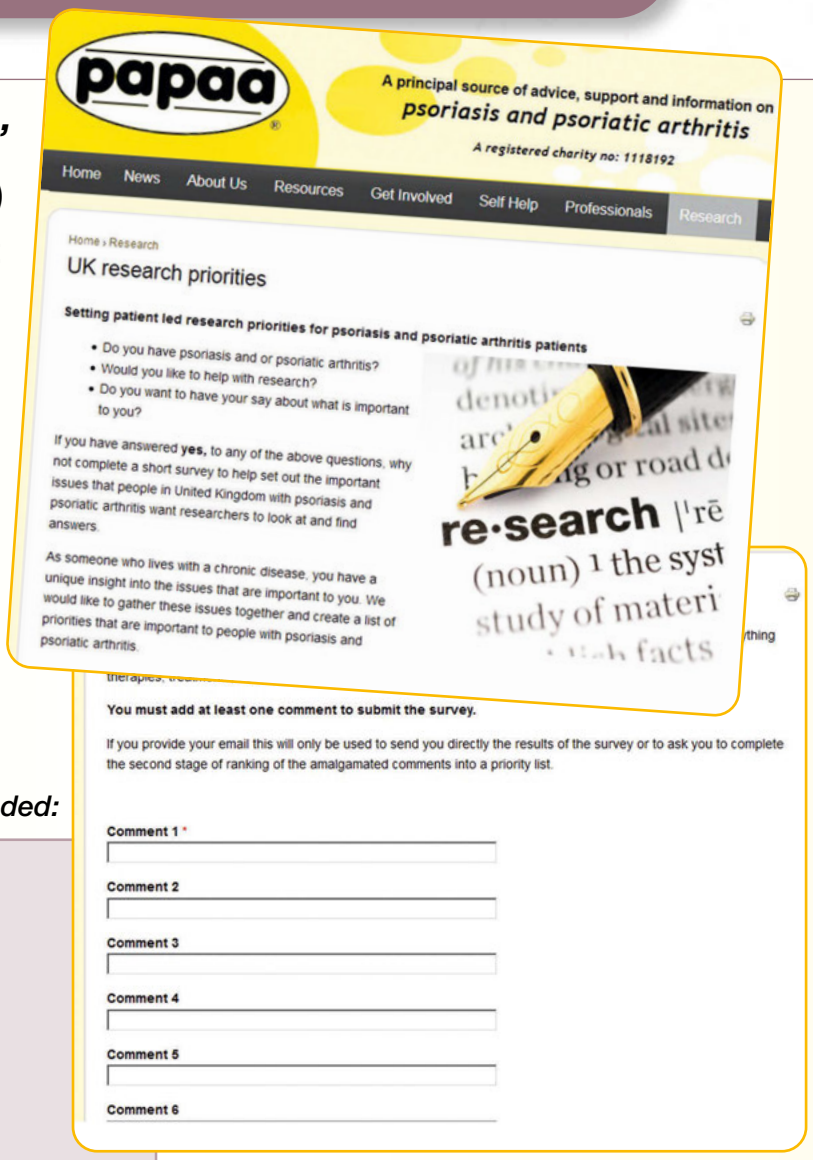
**To read other stories already submitted go to:**

**http://www.papaa.org/self-help/case-stories**

# Research priorities

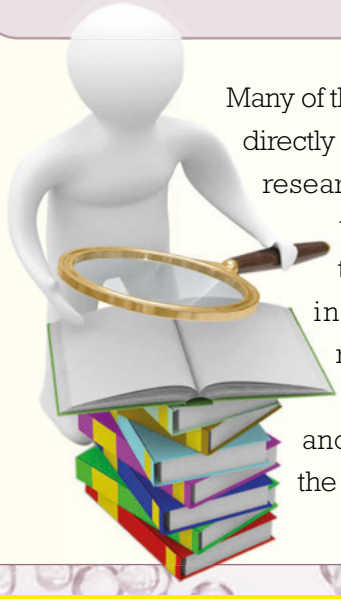
**In the last issue of *Skin 'n' Bones Connection* (issue 39) we asked people to suggest areas where research should be prioritised for psoriasis and psoriatic arthritis.**

We are grateful to those who completed the survey both online and on paper. We received many useful ideas with more than 700 suggestions, which we have begun the task of collating.




***The areas from the initial results included:***

- Genetics
- Pain management
- Flares
- Fatigue
- Diagnostic tests
- Drug side effects
- Managing depression
- Healthcare provision



Many of the suggestions may not directly lead to a direct piece of research, but some will and the quality and depth of the responses will influence how PAPAA represents the needs of people with psoriasis and psoriatic arthritis in the future.

We had originally intended to close the survey once we had reached our target number of returns, but have decided to keep the survey open and continue to monitor peoples' views and comments.

You can submit your comments anonymously, but if you do provide an email or address we will send you the results and the opportunity to rank the research questions when compiled. The choice is yours.

**To complete the survey go to:**

**www.papaa.org/surveys/uk-research-priorities**

**To request a copy by post or email:**

**Telephone 01923 672837 *or***

**Email: info@papaa.org**


**The All Wales Medicines Strategy Group (AWMSG) was established in 2002, as a statutory advisory Welsh Assembly-sponsored public body under the 1977 NHS Act, to provide advice on medicines management and prescribing to the Welsh government's Minister for Health and Social Services in an effective, efficient and transparent manner.**

AWMSG brings together NHS clinicians, pharmacists, healthcare professionals, academics, health economists, industry representatives and patient advocates. AWMSG, acting in a strategic and advisory capacity, is an authoritative and expert channel through which consensus can be reached on the use of medicines within both primary and secondary care.

AWMSG works to develop innovative partnerships that benefit patients and achieve the best outcomes from the use of medicines in Wales. All involved with prescribing and medicines management will work together to ensure equity of access to the most clinically appropriate and cost-effective medicines for the people of Wales.

***The group's main functions are to:***

- Advise the Welsh government of future developments in healthcare to assist in its strategic planning.
- Advise the Welsh government on the development and implementation of a prescribing strategy for Wales.
- Develop timely, independent and authoritative advice on new medicines.

The work of AWMSG is planned via the AWMSG Steering Committee. This committee prioritises the work programme of the parent committee to ensure the efficient use of AWMSG resources.

## Do you want an opportunity to ensure your views are heard by the AWMSG?

You can have a voice in processes, which could impact on patients and carers living in Wales.

Whether you are an individual, a small group or a large organisation, AWMSG wants to know your views.

AWMSG produces advice on new medicines and medicines management, and welcomes your input if:

- you have experience of the condition, or,
- you have experience of the treatment, or,
- you care for someone with the condition, or,
- you are a representative for a patient organisation concerned with the condition.

Your experience of the disease/ condition/ treatment in question will help AWMSG understand how these health problems affect patients and/or carers. Patients/carers/patient organisations are often able to provide additional insight, which is invaluable in the work they do and the advice that they give to NHS Wales.

## New medicines

AWMSG advises the Welsh government whether new medicines should be available for use in NHS Wales. New medicines are appraised (evaluated) against currently available medicines to compare:

- how well they work
- how cost-effective they are
- which patients they would benefit the most.

Your input will have an effect on which medicines are available within NHS Wales.

**For more information go to:**

**www.awmsg.org**

# Scotland accepts certolizumab pegol for PsA

**Certolizumab pegol is a treatment for psoriatic arthritis, a medicine that blocks a protein called tumour necrosis factor alpha (TNF-a) and helps to reduce swelling and pain. It is given as an injection under the skin at weeks 0, 2 and 4, followed by a maintenance dose every 2 or 4 weeks thereafter.**

The Scottish Medicines Consortium (SMC) previously accepted certolizumab pegol for the treatment of severe, active axial spondyloarthritis, comprising ankylosing spondyloarthritis and non-radiographic axial spondyloarthritis.

The advice SMC has given is that certolizumab pegol can be offered for restricted use in combination with methotrexate, for the treatment of active psoriatic arthritis in adults when the response to previous disease-modifying anti-rheumatic drug (DMARD) therapy has been inadequate.

Certolizumab pegol can be given as monotherapy (the use of a single medication) in case of intolerance to methotrexate or when continued treatment with methotrexate is inappropriate. It is restricted to use in patients whose disease has not responded to adequate trials of at least two standard DMARDs either individually or in combination.

A study showed that compared with placebo (a dummy medicine containing no active treatment), certolizumab pegol improves symptoms of psoriatic arthritis.

This SMC advice takes account of the benefits of a patient access scheme (PAS). A PAS is a scheme proposed by a pharmaceutical company in order to improve the cost-effectiveness of a medicine and thus enable patients to receive access to new medicines that may otherwise not have been judged to be a cost-effective use of NHS resources. The proposed PAS gives a discount on the price of the medicine. An economic analysis compared certolizumab pegol with other medicines used for the treatment of psoriatic arthritis, and showed that certolizumab pegol was as effective and could lead to cost savings when the PAS was taken into account.

SMC accepted certolizumab pegol for restricted use in Scotland because the balance of costs and benefits meant that it was considered to offer value for money. This SMC advice depends upon the continuing availability of the PAS or an equivalent or lower list price in NHS Scotland.

The advice follows recent similar guidance given by the National Institute for Health and Care Excellence (NICE) under the title of evidence summaries: new medicines (ESNMs), which are considered if a NICE technology appraisal (TA) is not planned or in progress, or unless the technology appraisal programme will not publish an appraisal consultation document (ACD) within 6 months of the medicine's launch.

A NICE technology appraisal was not considered appropriate for certolizumab pegol for psoriatic arthritis.

Certolizumab pegol, also known by its brand name Cimzia, is an anti-TNF biologic drug and is in the same class as adalimumab (Humira) etanercept (Enbrel), golimumab (Simponi) and infliximab (Remicade).

**Source:**

**SMC: www.scottishmedicines.org.uk**

**NICE: www.nice.org.uk**

## PSORIASIS TREATMENTS

| GENERIC NAME | BRAND NAME | DOSAGE | LICENSED INDICATIONS | MODE |
|---|---|---|---|---|
| Adalimumab | Humira | Every other week | Moderate to severe chronic plaque psoriasis | Subcutaneous injection |
| Etanercept | Enbrel | Twice every week | Moderate to severe plaque psoriasis | Subcutaneous injection |
| Infliximab | Remicade | Every eight weeks after initial doses | Very severe psoriasis | Intravenous injection (at clinic) over 2 hours |
| Ustekinumab | Stelara | Injection every four weeks | Severe plaque psoriasis | Subcutaneous injection |

## PSORIASIS TREATMENTS UNDER REVIEW

| | | | | |
|---|---|---|---|---|
| Apremilast | Otezla | Twice a day | Moderate to severe plaque psoriasis | Oral tablet |
| Brodalumab | Unknown | Every two weeks | Moderate to severe plaque psoriasis | Subcutaneous injection |
| Secukinumab | Cosentyx | Once a month | Moderate to severe plaque psoriasis | Subcutaneous injection |

## PSORIATIC ARTHRITIS TREATMENTS

| | | | | |
|---|---|---|---|---|
| Adalimumab | Humira | Every other week | Psoriatic arthritis | Subcutaneous injection |
| Certolizumab pegol | Cimzia | Every other week | Psoriatic arthritis | Subcutaneous injection |
| Etanercept | Enbrel | Twice every week | Psoriatic arthritis | Subcutaneous injection |
| Golimumab | Simponi | Once a month | Psoriatic arthritis | Subcutaneous injection |
| Infliximab | Remicade | Every eight weeks after initial doses | Psoriatic arthritis | Intravenous injection (at clinic) over 2 hours |
| Ustekinumab | Stelara | Every four weeks | Psoriatic arthritis | Subcutaneous injection |

## PSORIATIC ARTHRITIS TREATMENTS UNDER REVIEW

| | | | | |
|---|---|---|---|---|
| Apremilast | Otezla | Twice a day | Psoriatic arthritis | Oral tablet |
| Brodalumab | Unknown | Every two weeks | Psoriatic arthritis | Subcutaneous injection |
| Secukinumab | Cosentyx | Once a month | Psoriatic arthritis | Subcutaneous injection |

**Please note that your doctor may offer you different instructions and this table is only for interest and not a replacement for the advice given to you by your healthcare provider.**

**To get full profiles (Summary of product characteristics - SPC) of these drugs and all other licensed products, visit: www.mhra.gov.uk/Safetyinformation/Medicinesinformation/SPCandPILs/**

**Mounting evidence that patients with psoriasis are at an increased risk of developing cardiovascular diseases and metabolic diseases (cardiometabolic diseases) is the subject of an article to be published in the December 2014 issue of the American Journal of Medicine.**

The article, titled "Accumulating Evidence for the Association and Shared Pathogenic Mechanisms between Psoriasis and Cardiometabolic Diseases," was written by seven councillors of the International Psoriasis Council (IPC), a global nonprofit focused on psoriasis research, treatment and education. The article is a summary of the November 2013 meeting of the IPC Think Tank, an annual gathering of global psoriasis experts to discuss the most pressing issues facing the understanding and treatment of the disease.

At the meeting, a panel of dermatology, immunology and cardiovascular specialists from around the world discussed the status of research investigating the potential association of psoriasis with various cardiometabolic-related comorbidities.

Summarising these discussions, the American Journal of Medicine article explores the potential shared pathogenic mechanisms (causing or capable of causing disease), genetic connectivity and inflammatory links between psoriasis and various cardiometabolic diseases such as heart disease, obesity and diabetes.

"It is highly unique to have expert perspectives from a multitude of disciplines at once. These types of interactions accelerate our understanding of the association between various cardiometabolic conditions and psoriasis," said Dr Nehal N Mehta, an expert in cardiometabolic diseases who led the Think Tank discussion and is a co-author of the article.

"Based on the evidence presented and outlined at this symposium, the link between psoriasis and cardiometabolic diseases demonstrates strong mechanistic ties, however definitive evidence

still is elusive. More studies are needed to better understand this association."

Among the conclusions made by the Think Tank panel and identified in the manuscript:

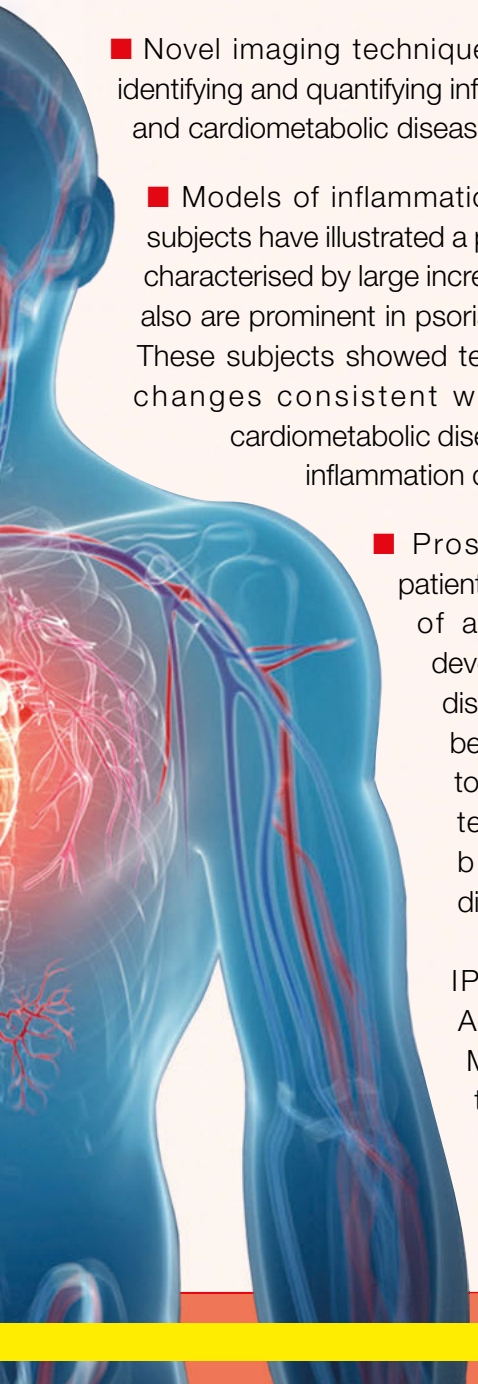
- There is a need to elucidate the link between psoriasis and cardiometabolic pathophysiologic (the physiology of disordered function) mechanisms in order to better manage the psoriasis patient.

- Identification of shared pathways through transcriptome studies (studying RNA) and genome-wide association studies (GWAS) is shifting the psoriasis model to one that is analogous to other systemic pro-inflammatory states, such as atherosclerosis and metabolic syndrome.

- Novel imaging techniques may be pivotal in identifying and quantifying inflammation in psoriasis and cardiometabolic disease.

- Models of inflammation in healthy human subjects have illustrated a pro-inflammatory state characterised by large increases of cytokines that also are prominent in psoriasis, including TNF-α. These subjects showed temporary biochemical changes consistent with those found in cardiometabolic diseases, suggesting that inflammation does precede disease.

- Prospective studies in patients starting at 30 years of age to monitor the development of metabolic diseases in psoriasis may be the only definitive way to better understand the temporal relationships between these two diseases.



"The acceptance of IPC's article by the American Journal of Medicine underscores the work the organisation is doing to educate healthcare professionals involved in the treatment of psoriasis and its associated comorbidities, and, ultimately, to enhance patient care," said IPC CEO Steve O'Dell.

"IPC is dedicated to advancing psoriasis research and treatment. Publication in this highly regarded medical journal means that these important data will reach physicians who generally do not receive much information about psoriasis and diseases associated with it."

"The Think Tank meeting, resulting in the American Journal of Medicine article, exemplifies IPC's mission to bring together thought leaders in psoriasis research, education and treatment, thereby advancing our understanding of this disease," said Dr Christopher Griffiths, foundation professor of dermatology at the University of Manchester, United Kingdom, and IPC board president.

## About IPC

Founded in September 2004, the International Psoriasis Council (IPC) is the premier global professional, dermatology-led nonprofit organisation dedicated to innovation across the full spectrum of psoriasis research, education and patient care. IPC was established as an international organisation of global psoriasis experts working on the advancement of psoriasis understanding. 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. IPC's work provides dermatologists with the most up-to-date knowledge with respect to psoriasis; identifies key needs for research and activities in the field of psoriasis; and collaborates with global, national, and international organisations.

**Learn more about the International Psoriasis Council: www.psoriasiscouncil.org**

**Source:**
**IPC press release**

# Writings on the wall

**On one of our regular Facebook postings we asked the following questions: Can you tell us about your experience with your GP?**

- **How were you treated?**
- **Could it be improved?**
- **Did you get a diagnosis?**
- **Were you referred to a specialist?**

**So, maybe not surprisingly, this provoked a big response. *The following are an edited selection:***

'I have had an excellent service. I went undiagnosed with my GP for over 10 years! However, once I first saw the specialists ... they were excellent. After 10 years, my life was in complete ruins and always suffered. Now I will always be under the umbrella of the clinic and I have a nurse, occupational nurse plus my consultant. I am moving forward and starting to gain a new life. I have full support as well for looking for work. My life is changing for the better. My GP however isn't a specialist so I would not expect them to know what is the right meds or not. That's what the clinic is for...'

'Psoriasis mysteriously appeared when I was 30 (20 years ago). It progressed rapidly & my dermatologist treated it with mixed resulted. 3 years later, I began having an eye problem that grew progressively worse; redness, pain, constant tearing. After 5 months, I changed to a new ophthalmologist. After one month of treatment with steroids, he referred me to a rheumatologist who diagnosed me with PsA. My dermatologist knew nothing of PsA; actually doubted its true existence! With treatment, I regained my life...'

'I went to my GP aged 26 with pain/stiff joints. I had psoriasis since a teen but wasn't too bad to be fair in comparison with many. I spent 2 years being told there was nothing wrong with me! After such time I visited the new GP. He referred me to rheumatology following bloods and x-ray who instantly diagnosed psoriatic arthritis. I was then transferred to another consultant that spent the next 18-mths telling me the only drug available was methotrexate as sulphasalizine didn't work alone. I had read about it and really didn't want it and so requested a 2nd opinion in London. I've never looked back and have an amazing consultant. I now have injections! My psoriasis has gone and its few and far between I experience any pain. I've lost all the weight steroids helped me gain and am now signed up to walk the London to Brighton challenge next year. 62miles, 2yrs ago I spent the day before my wedding on steroid drip to be able to walk down the aisle. Never give up, what doesn't kill can only make you stronger!'

'I still can't get a diagnosis! Nails have been tested and are not fungal but GP insisted I went on anti fungal tablets I didn't take them! I have had numerous acute episodes of joint pain and aches resulting in no movement or mobility but was told unless the area swells and my inflammatory blood markers rise no treatment no referral to dermatologist or rheumatology'

'I had psoriasis at age ten but haven't had a bad flare for over ten years odd patch here and there. Three years ago I was struggling with swollen hands, knees and ankles saw GP spent two years going back and forth as they were looking for RA, it wasn't until one day visiting GP unable even to screw up a piece of paper that a GP referred me. Once with rheumatologist he went through history sent for scans etc. after a year with no improvement I was placed on methotrexate still struggling and inflammatory markers sky high and methotrexate is upped and now hydroxychloroquine added to it but now damage in my hands is so bad I can no longer cook, major issue with my achilles tendon walking is a issue and feeling rather fed up xx'

'My current GP is awesome and so understanding of both my psoriasis and PsA. He was the one that told me about the PAPAA website. My rheumatologist is the complete opposite!'

# Writings on the wall

'I was diagnosed by my mums friend at age 9 when she came to perm my hair. The perm still went ahead despite the pain! I was properly diagnosed at hospital where I spent 4 weeks as a patient. It was horrendous! After cream was put on scalp overnight, it was washed off with tar shampoo, leaving it matted then, they used a steel nit comb to drag the scabs off! I also spent a week there on my 16th birthday, which was not celebrated in any special way. I was released early due to my highly emotional state.'

'I've had psoriasis since 1999 and only ever been given aquious cream. I got it on my eyes (eyelashes on both eyes) and was told to wash my eyes with baby shampoo.... that's all I've had! Going to see my GP on Tuesday as after joining a few groups on FB this week I now think I should be referred to see a specialist and I think I have psoriatic arthritis.'

'It will be 10 years from the first symptom and 3 years of being diagnosed with PsA. I have had no psoriasis on my skin so far. Three years ago, when I could barely walk, I visited my GP and she referred me to orthopaedics and rheumatology, I was put on methotrexate and meloxicam. I see no effects and it's getting worse, now trying some herbal supplements, vitamins and probiotics.'

'At first I was treated poorly, like I was making it up, about all the pain I was in. And for my skin tried all kinds of creams, switched Drs, Until one day my fingers started deforming then I was finally sent to a rheumatologist and was diagnosed with PsA & fibromyalgia. I had years of torment swelling in my legs then being told I just needed to walk more to pump the fluid through my body, that only made it worse!!! I had all the signs and symptoms...just the wrong diagnosis....'

'I had a fantastic service from my GP and was referred to the hospital as soon as I was diagnosed with PsA. Only problem is sometimes getting an appointment and initially getting my repeat prescriptions but otherwise they have been wonderful. The hospital is just fantastic and I love my rheumatology nurse who even has my mobile number saved on her work mobile so she knows who I am when I call. Can't fault them at all. Lucky to have the NHS.'

'I've had a bad time too. Psoriasis was misdiagnosed as childhood eczema, then diagnosed by an emergency doctor when I was 17. Have had no end of creams, ointments, etc over past 20-odd years, and my GP sent me to another GP in the surgery with an interest in Dermatology, as an alternative to referral. Finally last year I demanded referral to a dermatologist and got new ointments which have helped, and a course of full body UVB treatment which really flattened the plaques down...'

**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

# Marketplace

One of our core activities is developing patient educational information and in the last issue of ***Skin 'n' Bones Connection*** (issue 39) we reported our continued commitment to The Information Standard (TIS) scheme and our rolling review and updating process under the scheme rules. Although, the internet is now where most people read our material, there is still a huge demand for leaflets in print form, particularly for those who do not have access to the internet. We produce the most commonly viewed subjects as printed copies, and also provide a one-off print service for other material, which would not warrant the traditional printed version.

Health & care information you can trust
The Information Standard Certified Member


Currently we have eighteen leaflets available with a nineteenth just added to the range called, ***Genital Psoriasis***. This subject is the most commonly searched subject on our website and therefore deserves recognition. The material has been reviewed and revised by Dr Ruth Murphy a consultant dermatologist at Nottingham University Teaching Hospitals. The material includes, the affected sites, causes, treatments and coping.

We have also updated two of our other popular leaflets ***Physiotherapy & Exercise: Psoriatic Arthritis*** was reviewed by Diane Ellis rheumatology clinical specialist at St Albans City Hospital.

***Occupational Therapy & Psoriatic Arthritis,*** was reviewed and revised by Lucy Swift senior occupational therapist at Royal National Orthopaedic Hospital Stanmore. A peer review was carried out by Lucy Blenkiron,clinical specialist and lead occupational therapist at Avon Orthopaedic centre Southmead Hospital Bristol.


If you would like a copies of these leaflets you can order by calling **01923 672837 or by emailing info@papaa.org**

The material is also available online to read or download or can be ordered free of charge from **www.psoriasis-shop.org**

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## 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.