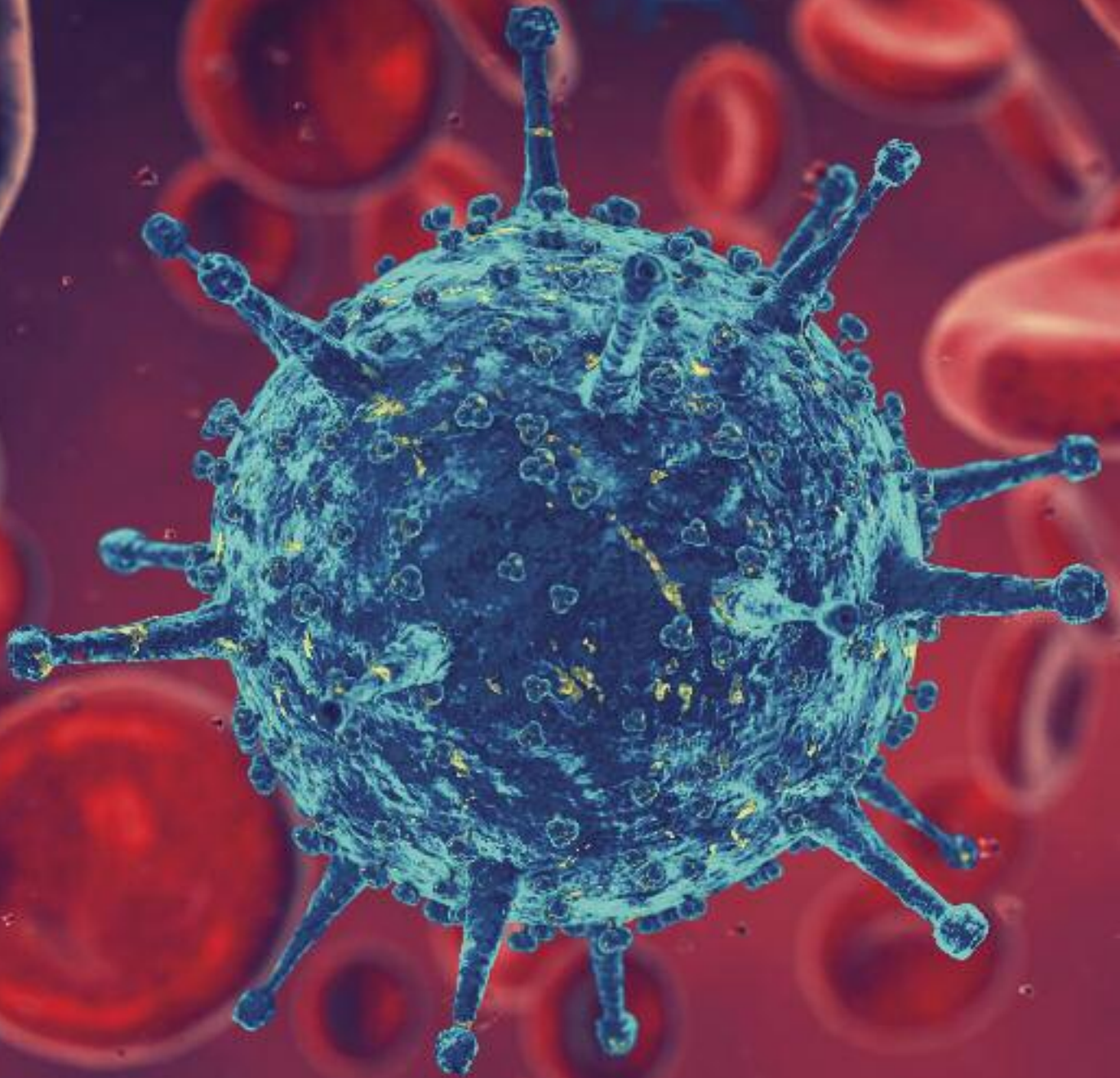


Issue 46 2017 £4.00

skin 'n' bones connection



ISSN 1475-4134



9 771475 413114



2 Contents

3 Vaccine research

4 Psoriasis report

5 Psoriasis scanner

6 Sheffield Health

7-9 Spondyloarthritis

10-12 Management of spondyloarthritis

13 Psoriatic arthritis gene

14 Biobank

15-16 Pathways

17 POM to P

18-19 Balneotherapy

20 Marketplace

Correspondence Address:
PAPAA

3 Horseshoe Business Park, Lye Lane, Bricket Wood,
St Albans, Herts. AL2 3TA

E-mail: info@papaa.org

Web: www.papaa.org

Tel: 01923 672837 Fax: 01923 682606

Production team:

Julie Chandler

Managing Editor

Artwork and Design
Macpro Design and Print Ltd., St Albans

Printing
Photolit Printing Ltd · St Albans

The Psoriasis and Psoriatic Arthritis Alliance is a Registered
Charity No:1118192 and is a Company Limited by Guarantee,
registered in England and

Wales No: 6074887

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

Copyright PAPAA 2017

All Rights Reserved. No part of the publication may be reproduced, stored in a retrieval system or transmitted in any format whether electronically, mechanically or otherwise without permission of the Psoriasis and Psoriatic Arthritis Alliance.

Disclaimer

The contents of the journal are aimed at providing information that may be of interest to people with psoriasis and/or psoriatic arthritis or those who have a specialist interest, whether in a personal or professional capacity. Some articles which will be included are of general interest and may or may not relate directly to either psoriasis or psoriatic arthritis. This material may include aspects related to health, services or products that are available.

We believe that at the time of printing all information is correct and cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal.

All opinions are of the contributors and not necessarily those of the Psoriasis and Psoriatic Arthritis Alliance. User generated contents and articles which appear in Skin 'n' Bones Connection, that are clearly a point of view of the contributor or from an external source are excluded from the Information Standard Scope.

Always consult your own doctor or medical healthcare provider.

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.

Subscription rates:

United Kingdom - £12.00 (Renewal Rate £8.00) per annum - 2 issues

Publication Dates: Summer and Winter

Contribution Copy Dates: 28th February and 31st August



Dear Reader

The Researchers' interest in chronic autoimmune conditions such as psoriasis and psoriatic arthritis has increased significantly during the last two decades.

The development of injectable biologic therapies, such as the anti-TNFs, has been a significant part, or cause of that interest.

The first of these drugs for psoriasis became available in the early 'noughties', but due to the high cost they were restricted. More recently, the availability of lower cost versions (still with a significant cost) called biosimilars have been increasingly offered to patients.

Over time, although these newer drugs have become more selective and provide greater benefit, there are still people who do not respond or the treatments begin to fail. So, although they provide a solution to help manage the disease, a cure is what people still crave. Steps are being taken with some interesting research looking at producing a vaccine (page 3).

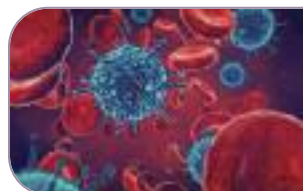
The subtleties of psoriasis and psoriatic arthritis are beginning to emerge and the work undertaken by the researchers in Manchester (page 13) has started to confirm that psoriatic arthritis is a disease in its own right, and this could lead to some exciting new therapies being developed.

Whilst all this work is happening, pathways of care (page 15) and guidelines (page 7) to help people manage and live with their conditions day-to-day are still required.

This complex work all takes time to produce and implement; the frustration people feel is understandable, which often leads to a search for an easy fix or the promise of a cure. An alert (page 6) about the way some products have been adulterated to provide solutions should be a warning to us all.

We need answers and no doubt they will come, but only slowly building on good evidence and collaboration (page 14) is the way forward in an uncertain world of change, not least, how the NHS will be able to cope with scientific breakthroughs, the high cost of new drugs and an ageing sicker population.

Managing editor



COVER PHOTO:

Viruses and red blood cells

© Shutterstock

Research from the Universities of Dundee and Oxford has shown how combining the tetanus vaccine with a viral particle that normally affects cucumbers can be used to treat psoriasis and allergies, and may even protect against Alzheimer's disease.

Scientists, led by Dundee's Dr John Foerster and Oxford's Professor Martin Bachmann, were able to take the protein coat of cucumber mosaic virus and incorporate a tetanus vaccine-derived protein structure known to stimulate the immune system, in order to create vaccines to treat multiple chronic conditions.

The vaccine showed positive results in models of psoriasis and cat allergy and was shown to raise antibody levels thought to be beneficial in Alzheimer's disease. These vaccines can be either preventative, which is the hope for Alzheimer's, but also therapeutic, meaning they can cure a conditions like psoriasis after it has already been established.

More research is required to test the efficacy of the therapeutic in a clinical setting, but the Dundee-Oxford study raises the possibility of hundreds of thousands of people being spared the ravages of chronic conditions.

Dr Foerster said, "As an academic dermatologist with special interest in the immune system, my specific attention is on vaccines to be developed against chronic skin conditions. The idea is pretty simple – for conditions such as psoriasis or eczema, the newest and most effective medicines on the market are so-called 'antibodies', which are what you and I produce against bugs in a common cold.

"For chronic conditions, these antibodies are specially made against one of the body's own proteins. By blocking

that single protein, the conditions gets better. To use the example of psoriasis, a protein called Interleukin 17 needs to be active for the conditions to progress. By creating a vaccine that stimulates the body to make antibodies against

Interleukin 17 itself we can replace the need for frequent and expensive injections and make this type of treatment much more affordable and accessible to patients who could otherwise not afford specially made antibodies.

"Our research shows that this technique works in mice and, importantly, our new vaccine technology shows that it is likely to be a more effective type of vaccine than existing ones in older people. Since many patients with chronic conditions like psoriasis are elderly this technology may work much better to obtain effective vaccines."

The paper was recently published in the journal *Nature Vaccines*. The researchers are now looking to begin clinical testing of the vaccine and have already received regulatory approval to initiate testing in humans. Present antibodies for psoriasis treatment typically need to be injected at least once a month to keep working, and cost around £10,000 per patient annually. A vaccine would offer much more affordable treatment.

In Alzheimer's, it is known that a protein called beta amyloid can cause brain damage resulting in inhibited function. Previous unsuccessful trials saw patients injected directly with antibodies against the same target but the new research suggests that starting the treatment – in the form of prophylactic vaccines – could provide a way of offering treatment even before the disease becomes clinically apparent. It is possible such a prophylactic approach may work better and this could not be done using frequent antibody injections.

Professor Bachmann, professor of vaccinology at the Jenner Institute in Oxford, said, "Alzheimer's disease usually develops in elderly people. The fact that the vaccine described here is optimised for older individuals seems therefore particularly helpful. An additional important aspect of the current work is that we developed a platform technology and are currently broadening our preclinical studies to vaccines against Parkinson's disease as well as chronic pain."



Dr John Foerster



Source:

University of Dundee

A new report by the Economist Intelligence Unit (EIU) challenges policymakers and healthcare professionals to address the burden of psoriasis.

This report benchmarks progress in Canada and countries across Europe since the 2014 World Health Organization (WHO) resolution, which called for global action to improve quality of life for people living with the condition.

The report, 'Encouraging policy action to address the psoriasis challenge', sponsored by Eli Lilly and Company, identifies psoriasis awareness, diagnosis, treatment and support as critical areas for improvement. Findings also highlight inequality in access to support and effective treatment for those living with psoriasis. The report details ways the psoriasis community can help meet this challenge and ease the burden on both patients and the healthcare system.

Based upon insights from leading experts in academia, the medical profession, patients and patient associations across France, Germany, Italy, Spain, the UK and Canada, the report concludes that more government action is needed to address the challenges of psoriasis, including the negative physical and mental health strain of the condition, as well as the growing economic impact.

Each country was benchmarked on the effectiveness of their psoriasis policies and guidelines, including adherence to WHO recommendations.

President of the International Federation of Psoriasis Associations IFPA Lars Ettarp said:

"We know that psoriasis management to a great

extent depends on national healthcare systems. Some countries have well-established, well-functioning healthcare systems with adequate resources to help all patients. In other countries, this might not be the case.

That is why we strongly urge national governments to prioritise their health-care system and set up a national advocacy plan on psoriasis. Steps like these are essential to start improving life quality for people with psoriasis across the world."



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

About The Economist Intelligence Unit (EIU)

The EIU is the research and analysis division of The Economist Group and the world leader in global business intelligence. Created in 1946, the EIU has 70 years' experience in helping businesses, financial firms and governments to understand how the world is changing and how that creates opportunities to be seized and risks to be managed. www.eiu.com

Source: IFPA

The report can be viewed and downloaded from the following address:
perspectives.eiu.com/healthcare/encouraging-policy-action-address-psoriasis-challenge-1

A newly developed tissue scanner offers doctors the opportunity to look under the skin of people with psoriasis. This provides clinically relevant information, such as the structure of skin layers and blood vessels, without the need for contrast agents or radiation exposure.

A team of researchers from Helmholtz Zentrum München and the Technical University of Munich (TUM) recently published the technology in the journal *Nature Biomedical Engineering*.

Currently, physicians evaluate the severity of the condition based on visual assessment of features of the skin surface, such as redness or thickness of the flaking skin.

"Unfortunately, these standards miss all parameters that lie below the surface of the skin, and may be subjective," Dr Juan Aguirre points out.

"Knowing the structure of the skin and vessels before treatment can provide the physician with useful information," explains the group leader at the Institute of Biological and Medical Imaging (IBMI) at the Helmholtz Zentrum München.

In order to provide clinicians with this information, Aguirre and his team developed a new technique that gets under the skin. It bears the name RSOM (raster-scan optoacoustic mesoscopy) and works as follows: A weak laser pulse excites the tissue of interest, which then absorbs energy and heats up minimally. This causes momentary tissue expansion, which generates ultrasound waves. The scientists measure these ultrasound signals and use this information to reconstruct a high resolution image of what lies under the skin.

While developing the method, the scientists were able to reduce the size of the scanner to a handheld device.

"This technology, which is easy to use and does not involve any radiation exposure or contrast agent, is allowing us to acquire the first new insights into the disease mechanisms. It also facilitates treatment decisions for the physicians," explains Prof Dr Vasilis Ntziachristos, director of the IBMI at the Helmholtz

HelmholtzZentrum münchen
German Research Center for Environmental Health



Zentrum München and chair of biological imaging at the Technical University of Munich.

In the recently published study, the scientists demonstrated RSOM's performance by examining cutaneous and subcutaneous tissue from psoriasis patients. RSOM allowed them to determine several

characteristics of psoriasis and inflammation, including skin thickness, capillary density, number of vessels, and total blood volume in the skin. They compiled these to define a novel clinical index for assessing psoriasis severity that may be superior to the current clinical standard because the



new index also takes into account characteristics below the skin surface.

The researchers plan to use the same imaging method to assess other diseases such as skin cancer or diabetes in the future. Patients with diabetes often suffer from damaged blood vessels that, if detected early enough, may allow earlier treatment and therefore greater efficacy.

Reference:

Aguirre, J. et al. (2017): Precision assessment of label-free psoriasis biomarkers with ultra-broadband optoacoustic mesoscopy. *Nature Biomedical Engineering*, DOI: 10.1038/s41551-017-0068

Source:

Helmholtz Zentrum München

Living with a skin condition can affect your mood; you might notice that the physical symptoms can feel burdensome, or stress might contribute to a worsening of your symptoms. Skin conditions can also have an impact on your social life, work and relationships.

Sometimes you might notice that you feel anxious, low, stressed or embarrassed, or you might have worries about the appearance of your skin condition. Because of how you are feeling you might have stopped doing things you previously enjoyed.

The Sheffield Health and Social Care Wellbeing Service is providing practical ways of overcoming stress, anxiety and low mood. To learn more about the service:

Call 0114 271 6568 or visit
www.iaptsheffield.shsc.nhs.uk



The Health Services Authority (HSA) in Singapore issued an alert on 2 November 2017 about two traditional Chinese medicinal products found to contain undeclared Western medicinal ingredients. The products have caused serious adverse reactions.

The products are called:
WAN LING REN SEM CHIN KUO PILL and **CHONG CAO DAN**

The sale of these products may be confined to the area where the alert has been issued, but given the access to products over the internet, they may have been made available elsewhere. Anyone who has purchased these products is advised to contact their doctor.

Product alert



We would encourage anyone to use the Medicines and Healthcare products Regulatory Agency (MHRA) Yellow Card scheme to report any possible reactions, providing as much information as possible, including the brand name (if it has one), the list of ingredients, a copy of package labelling, and details of the manufacturer.

Further advice on using herbal medicines can be obtained by visiting the MHRA website:
www.gov.uk/drug-safety-update/herbal-products-safety-update
or to report adverse events go to The Yellow Card Scheme;
<http://yellowcard.mhra.gov.uk>

As highlighted in the last issue, NICE Guidance on spondyloarthritis for over 16s was published earlier in this year. The NICE team have also produced 'information for the public' which explains what you should expect concerning the recognition, referral and diagnosis of spondyloarthritis. This information also explains the care that NICE has evaluated and found to work best for people who are 16 and older who have or may have spondyloarthritis (a type of inflammatory arthritis). It will help you, your family and carers know what to expect from health and care services.

The NICE advice aims to help healthcare professionals recognise the symptoms of spondyloarthritis, especially symptoms in the back such as pain and stiffness, which may be mistaken for other types of low back pain, or joint and tendon problems which may be seen as unrelated. This is important so people get the right diagnosis and treatment without delay.

There is also information on the care you should expect if diagnosed with spondyloarthritis. An overview of this information and advice is provided below. You can read NICE's 'information for the public' in full online at: www.nice.org.uk/guidance/ng65/ifp/chapter/Spondyloarthritis-the-care-you-should-expect

PAPAA is working hard to help raise awareness of the NICE guideline recommendations to help reduce the delay in diagnosis of spondyloarthritis that some people experience. It is important that health professionals who you may go to see about back, joint or tendons problems, such as GPs, physiotherapists, osteopaths and chiropractors, or people you see about your skin such as dermatologists and dermatology nurse specialists, are aware of possible signs and symptoms of spondyloarthritis and when to refer onto to a rheumatologist for specialist assessment.

What is spondyloarthritis?

NICE explains that spondyloarthritis is a fairly new term given to a group of conditions involving inflammatory arthritis that have some common features and other associated conditions. Conditions that come under the term spondyloarthritis include psoriatic arthritis, ankylosing spondylitis, reactive arthritis (triggered by certain infections) and enteropathic arthritis (related to inflammatory bowel diseases - Crohn's disease and ulcerative colitis).



Some people may also have had uveitis (an acute inflammatory eye condition that causes eye pain, eye redness, sensitivity to light or blurred vision). Some people may have several conditions, or no identified condition (undifferentiated spondyloarthritis).

There are two main types of spondyloarthritis:

- **Axial spondyloarthritis (axial ~ spine) - which mainly causes pain and stiffness in the back and buttock regions**
- **Peripheral spondyloarthritis - which mainly causes pain, stiffness and swelling in joints and tendons of the hands, feet, arms and legs.**

Some people may experience both types of problems.

NICE information also explains why spondyloarthritis happens is not fully understood, but research shows that it can run in families. Some conditions increase a person's risk of developing spondyloarthritis. These include:

- **current or past psoriasis or a family history of psoriasis**
- **inflammatory bowel disease (Crohn's disease and ulcerative colitis)**
- **an acutely painful eye condition called uveitis.**
- **certain infections, such as some stomach bugs or sexually transmitted infections (STIs)**

Spondyloarthritis: the care you should expect

- having a gene called HLA-B27, although people can have this gene and never develop problems and many people with spondyloarthritis do not have this gene.

What your GP will look for:

NICE provides information on what your GP, physiotherapist or other healthcare professional will want to know about your symptoms to find out if you could have spondyloarthritis. They should ask about your signs and symptoms, and about your family and medical history.

NICE guidance provides separate recommendations for recognising and diagnosing axial and peripheral spondyloarthritis, which relate to evidence for different signs and symptoms, risk factors, investigation strategies and treatment.

If your symptoms are mostly in your back (axial)

If you have low back pain and you go to see your GP, he or she will want to know more about your symptoms to find out if you could have axial spondyloarthritis.

They will want to know how old you were when the back pain began and how long it has been going on. NICE advises that they should also ask if you have any of the following:

- back pain that started before the age of 35 years
- waking during the second half of the night because of symptoms

- buttock pain
- symptoms get better when you move around
- symptoms get better with non-steroidal anti-inflammatory drugs (known as NSAIDs, such as ibuprofen and naproxen)
- a close relative (parent, brother, sister, son or daughter) with spondyloarthritis
- any other type of arthritis or pain or swelling in your joints that was not caused by an injury
- current or past psoriasis, or a family history of psoriasis.

Your GP should refer you to a rheumatologist if:

- your back pain started when you were under the age of 45
- has lasted for longer than 3 months and
- if you have 4 or more symptoms from the list above.

If you have 3 symptoms from the list above, then NICE recommends a blood test to see if you have the HLA-B27 gene - if the test shows you have the gene, NICE recommends a referral to a rheumatologist.



If your symptoms are mostly in your hands, feet, arms and legs (peripheral)

Your GP will want to know about these symptoms or any symptoms in other parts of your body, together with your family and medical history, to find out if you could have peripheral spondyloarthritis. This will include questions about:

- pain or swelling in your joints or tendons that was not caused by an injury
- back pain
- current or past psoriasis
- a close relative with spondyloarthritis or psoriasis.
- episodes of uveitis (acute eye inflammation)
- inflammatory bowel disease (Crohn's disease and ulcerative colitis)
- infections, such as some stomach bugs or sexually transmitted infections (STIs).

Although morning stiffness is not included in the lists above, it is an important factor in the assessment of inflammatory disease. You may be asked about symptoms of morning stiffness in the affected joints and how long it lasts.

Will I see a specialist?

Doctors who specialise in treating arthritis and related problems are called rheumatologists. Your GP should refer you to a rheumatologist if your GP thinks you could have axial or peripheral spondyloarthritis.

Problems with your eyes

NICE also recommends that if your doctor thinks that you have uveitis (an acute, painful inflammatory eye condition), you should be referred to see an eye specialist, an ophthalmologist, straight away. The eye specialist should see you on the same day.



What tests might I have?

NICE advises that when you see a specialist and depending on your symptoms, they may request further tests, such as x-rays, MRI, ultrasound or blood tests. These are to check for inflammation or infection and to rule out other conditions.

Diagnosis of spondyloarthritis is not always straightforward and NICE advises that spondyloarthritis should not be ruled out solely on based on the presence or absence of any individual sign, symptom or test result.

NICE also advises not to rule out a diagnosis of spondyloarthritis solely based on a negative HLA-B27 test, or if blood tests for inflammation are normal.



Article by
Dr Carol McCrum
Consultant Physiotherapist
Physiotherapy Dept
East Sussex Healthcare
NHS Trust

NICE has provided information for the public on the management of spondyloarthritis and information on coping with symptoms for people who are diagnosed with spondyloarthritis.

Medicines

NICE emphasises that early treatment of spondyloarthritis is important to relieve symptoms and reduce joint damage. Some medicines control the disease itself, and some help to ease symptoms.

If you are diagnosed with spondyloarthritis, your healthcare team will help you to find the best treatments for you. They will talk with you about medicines you can try, based on your symptoms, needs, and any other medical conditions which need to be taken into account. You can read more information about NICE's recommendations on medicines for spondyloarthritis on their website provided in information for the public or in detail in the NICE Guidance on Spondyloarthritis for over 16s (NG65).

Physiotherapy

NICE recommends that people diagnosed with axial spondyloarthritis should be referred to a specialist physiotherapist. They should help you to create an exercise plan to help maintain your mobility and ease symptoms such as stiffness and pain. The exercise plan should include:

- stretching, strengthening, and exercises to help your posture
- deep breathing
- exercises to move and stretch the different parts of your back and neck
- aerobic exercise (exercise that makes you breathe harder than normal, for example, walking, swimming and cycling).

Your healthcare team may also discuss hydrotherapy, which is exercise with a physiotherapist in a warm-water pool.

Help with everyday activities

NICE advises that if your symptoms make it hard for you to do everyday activities – such as cooking, dressing, cleaning and doing your job – you may be referred to a specialist therapist (such as a physiotherapist, occupational therapist, podiatrist or orthotist).

The therapist can assess your needs and help you to cope with your symptoms. For example, you might see an occupational therapist if you struggle with tasks around the house or at work, or you might see a podiatrist for help with foot problems. If you see a therapist, they should find out about what you need, give you advice about equipment that might help, and arrange reviews to make sure that the therapy is still meeting your needs.

Coping with flares

Some people have times when symptoms get worse, which is called flares or flare-ups. NICE has recommended that people diagnosed with spondyloarthritis should be advised about flares and given a tailored flare management plan. This plan should include:



- how to access care during flares
- how to self-care (for example, exercises, stretching and joint protection)
- information on pain and fatigue management
- information on medicines
- how to manage the impact on daily life and ability to work.

Managing flares

Flares may be managed by your GP, rheumatologist or another member of the healthcare team, depending on the persons' needs and other medical factors. NICE advises that GPs should seek specialist advice if needed, especially where people:

- have recurrent or persistent flares
- are taking biologic medications like anti TNF or anti IL17A
- have other medical conditions that may affect the treatment or management of flares.

Follow-up checks

If you have spondyloarthritis, NICE recommends that your healthcare team should work together to make sure that your condition and medicines are monitored, and that you get specialist help when you need it, for example, to manage flares, symptoms or other health problems.

Osteoporosis risk

NICE advises that people with axial spondyloarthritis may be at risk of developing osteoporosis. This is a condition that weakens bones, making them fragile



and more prone to fractures. NICE recommends that people with axial spondyloarthritis should consult a healthcare professional if there is increased pain following a fall or physical trauma. NICE also advises that if you have axial spondyloarthritis, you might need a check-up every 2 years to look for signs of osteoporosis. Your healthcare team can give you more information.

There is more information for the public on assessment and management of osteoporosis on the NICE website: www.nice.org.uk/guidance/cg146/ifp/chapter/About-this-information

Surgery for axial spondyloarthritis

People with axial spondyloarthritis should only be referred to a complex spinal surgery service to be assessed for spinal deformity correction if the spinal deformity is significantly affecting their quality of life and is severe or progressing.

Making decisions together

NICE emphasises that you should be part of all decisions about your care so you can discuss and agree which treatments are likely to suit you best. Your healthcare team, which may include healthcare professionals such as a rheumatologist, dermatologist and other specialists, GP, specialist





nurses, physiotherapists or other therapists and pharmacists, should involve you by:

- talking and listening to you so that they understand what matters to you
- giving you all the information you need so that you can make your mind up
- explaining if they think something that is mentioned here would not work for you and why, and discussing other options you could try instead
- giving you details for someone in your healthcare team that you can contact if you have any questions.

There is more information about how you should be involved in your care on the NICE website.

Information and advice

You should get explanations and information about spondyloarthritis. Information should be relevant to your needs and condition, verbal and written, and available whenever you need it. NICE guidance also recommends that information should be given on uveitis, psoriasis and inflammatory bowel disease if a person has these conditions.

NICE advises that people diagnosed with spondyloarthritis are provided with information that is:

- available on an ongoing basis
- relevant to the stage of the person's condition
- tailored to the person's needs.

How did NICE develop this information?

NICE wrote this information from the recommendations made in the NICE guideline. The guideline and this 'information for the public' were developed with people who have been affected by spondyloarthritis and health professionals involved in the care of people with spondyloarthritis. All the decisions in the guidance and information for the public are based on the best research available. You can read the full guideline on the NICE website: www.nice.org.uk/guidance/ng65

You may also like to read NICE's information for the public on '*Patient experience in adult NHS Services*' www.nice.org.uk/guidance/cg138 This sets out what adults should be able to expect when they use the NHS.

Article by
Dr Carol McCrum
Consultant Physiotherapist
Physiotherapy Dept
East Sussex Healthcare NHS
Trust



Researchers led by the Arthritis Research UK Centre for Genetics and Genomics at The University of Manchester have identified genetic variants which are associated with psoriatic arthritis but not with psoriasis, in the largest study of psoriatic arthritis ever published.

Nearly all patients with psoriatic arthritis also have skin psoriasis and, in many cases, the skin disease is present before the arthritis develops. However, only one third of patients with psoriasis will go on to develop psoriatic arthritis.

The researchers, who are part of a European consortium, say that their work, which took three years to complete and is published in *Nature Communications*, is a breakthrough because genetic changes have been identified which increase the risk of psoriatic arthritis, but not psoriasis.

Until recently, opinion was divided as to whether psoriatic arthritis was a condition in its own right, or psoriasis combined with rheumatoid arthritis.

The findings could, in future, lead to the identification of people with psoriasis who are at risk of developing psoriatic arthritis.

Dr John Bowes, who led the analysis of the work, said:

"Our study is beginning to reveal key insights into the genetics of psoriatic arthritis that explain fundamental differences between psoriasis and psoriatic arthritis. Our findings also highlight that CD8+ cells are likely to be the key drivers of inflammation in psoriatic arthritis. This will help us to focus on how the genetic changes act in those immune cells to cause disease."

The gene identified by the research team lies on chromosome 5 and is not the first psoriatic arthritis specific gene to be identified. Patients who carry the HLA-B27 gene are also more likely to develop psoriatic arthritis.

Professor Anne Barton, a rheumatologist and senior author on the study, explained:

"By identifying genes that predispose people to psoriatic arthritis but not psoriasis, we hope in the future to be able to test patients with psoriasis to find those at high risk of developing psoriatic arthritis. Excitingly, it raises the possibility of introducing treatments to prevent the development of psoriatic arthritis in those individuals in the future."

Dr Stephen Simpson, director of research at Arthritis Research UK, added: "This is a significant finding. Not only does it help establish psoriatic arthritis as a condition in its own right, but it could have major implications in the way that patients with this condition are treated and lead to the development of drugs specifically developed for psoriatic arthritis, which are greatly needed."

The research was funded by the National Institute for Health Research Manchester Musculoskeletal Biomedical Research Unit.



Professor Anne Barton

Source:

The University of Manchester

A consortium led by the University of Glasgow has been awarded a £1.7 million grant to create the world's largest immune-mediated inflammatory disease (IMID) biobank.

The Medical Research Council (MRC) funded project will be delivered by the IMIDBio-UK consortium, which brings together researchers from the University of Glasgow, Newcastle University, the University of Cambridge, Queen Mary University of London and the University of Manchester.

Immune-mediated inflammatory diseases are common medical conditions that cause substantial pain, distress, loss of function and early death. They include rheumatoid arthritis (RA), psoriasis, systemic lupus erythematosus (SLE), Sjogren's syndrome and autoimmune liver diseases such as primary biliary cholangitis.

Led by Professor Iain McInnes, director of the University of Glasgow's Institute of Infection, Immunity and Inflammation, the IMIDBio-UK project will incorporate MRC, National Institute for Health Research and Scottish Government Chief Scientist funded biobanks and clinical datasets into one single, searchable and analysable 'superhighway', allowing unprecedented access to information about IMIDs across the UK.

This superhighway of information will provide the kind of large-scale data needed to apply a precision medicine approach to these health conditions. Researchers hope that it will soon be possible to create a 'molecular map' of a patient, which would ultimately allow doctors to be able to prescribe more effective, less toxic drugs to patients, based on their individual condition.

Professor Iain McInnes, Muirhead chair of medicine, said: *"IMIDBio-UK is a unique opportunity to bring together the strengths of inflammation medicine from across the United Kingdom.*

"By working together we will learn from cohorts (a group of people with a shared characteristic) of patients

with seemingly different conditions, such as psoriasis, arthritis, kidney and liver disease, and bring them together to shed new light on the specific causes of each condition individually, but also we hope to find common pathways that drive them collectively.

"Using this knowledge in future we will be able to seek new medicines, and importantly, by applying the principles of precision medicine, we will be able to use these new medicines in the right person, at the right time, and at the right dose."

The IMIDs are clinically diverse, variously targeting the skin, joints or kidneys, but share some common genetic features, environmental triggers and inflammatory mechanisms. Since the 1990s, drugs and improved treatment strategies have revolutionised the treatment of a significant proportion of people with some IMIDs. However some IMIDs have not really progressed and even in those in which advances are notable, many patients do not yet respond to treatment or lose their responses over time.

Until now, most IMID collections of data have been specific to only one disease, leading to a narrow approach to the broader inflammation medicine field.

Researchers hope that this project will enable wider, safer use of biologics and new medicines across the IMID spectrum. By bringing together samples and comparing data and clinical practice, it will optimise clinical pathways for common IMIDs, and provide much needed insight into biologic use in rarer or poorly characterised IMIDs, ultimately delivering patient benefit and healthcare savings.



Professor Iain McInnes

Source:
University of Glasgow



British Society for Rheumatology (BSR) and the Royal College of General Practitioners (RCGP) recently launched a joint quality improvement project to improve care for people living with inflammatory arthritis.

The joint project will deliver a suite of online resources to help improve pathways between primary and secondary care, with a focus on reducing delays to diagnosis and creating standardised shared care agreements. The recent National Clinical Audit for rheumatoid and early inflammatory arthritis revealed delays in referral from primary care to specialist treatment for people with suspected inflammatory arthritis, with only 17% of cases being referred within the three days recommended by NICE. Early diagnosis and treatment is crucial to prevent joint and organ damage and reduce potential disability.

Furthermore, once people are established on a treatment plan, their care is shared between primary and specialist care through joint agreements on prescribing and monitoring of high-risk drugs such as methotrexate. These shared care agreements are numerous and



vary from locality to locality; there is therefore an opportunity to reduce risk by standardising and streamlining these agreements.

This one-year initiative will be led by the newly appointed RCGP clinical champion for inflammatory arthritis, Dr Danny

Murphy, a GP principal in Devon with a special interest in rheumatology, who also works as a part-time staff-grade rheumatologist at the Royal Devon and Exeter Hospital. In addition to various research projects in rheumatology, Danny has also advised on the development of the recent BSR guideline on Biologics for the Treatment of Axial Spondyloarthritis.



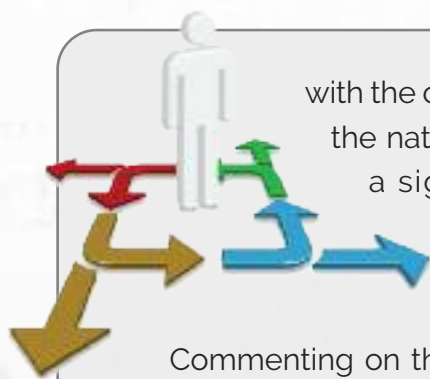
Dr Danny Murphy

Inflammatory arthritis affects close to a million people in the UK and includes conditions such as rheumatoid arthritis, axial spondyloarthritis and psoriatic arthritis. This project, in conjunction



Dr Peter Lanyon





with the ongoing work through the national audit, will make a significant impact on care for people living with these conditions.

Commenting on the collaboration, BSR president Dr Peter Lanyon said:

"This new collaboration between BSR and the RCGP is a really important strategic initiative, aiming to improve the care pathways for people who live with inflammatory arthritis. We greatly welcome the appointment of Dr Murphy as the first ever RCGP clinical champion for inflammatory arthritis. This will undoubtedly raise awareness of these conditions across the RCGP membership and beyond. It's a great opportunity for clinicians in primary and secondary care to work more closely together to develop national solutions to help reduce delays to diagnosis and deliver better co-ordinated care."

This is a view echoed by Professor Helen Stokes-Lampard, chair of the RCGP, who stated:

"We're delighted that the college is partnering with the BSR to raise awareness of this important clinical area in general practice. This collaborative project aims to support our members and their practice teams in the identification and appropriate management for patients living with inflammatory arthritis throughout the UK. I look forward to being involved in this project, and following its progress and the impact it has on GPs, our teams and our patients."

Expressing his honour at being appointed, Dr Danny Murphy, the new clinical champion remarked, "I am very proud to be the RCGP's first clinical champion for inflammatory arthritis, and am looking forward to working closely with the RCGP and BSR over the next year. Our aim

for this project is to empower primary care practitioners to deliver the best possible care to patients with inflammatory arthritis, by focusing on eLearning, curriculum updates and engagement with commissioners."



About British Society for Rheumatology:

The society exists to promote excellence in the treatment of people with arthritis and musculoskeletal conditions and to support those delivering it.

It is the leading UK specialist medical society for rheumatology and musculoskeletal care professionals, representing the whole multidisciplinary team: consultant rheumatologists, trainees, specialised nurses, physiotherapists, occupational therapists, psychologists and GPs with special interest in rheumatology.

The society aims to improve standards of care in rheumatology and secure a high priority for rheumatology services.



About the Royal College of General Practitioners:

The college is a professional membership body and guardian of standards for family doctors in the UK, working to promote excellence in primary healthcare. It represents and supports GPs on key issues including licensing, education, training, research and clinical standards. It is the largest of the medical royal colleges, with more than 50,000 members

Source:

BSR media release

In August the Medicines and Healthcare products Regulatory Agency (MHRA) announced the approval of Dovonex Psoriasis 50 microgram/g ointment would be made available through pharmacies without prescription. This treatment can be used for up to 12-weeks after which people will be advised to see their doctor about ongoing treatment. The product contains calcipotriol, a vitamin D analogue, and the medication is supplied as ointment in a 60g tube, and is suitable for adults aged over 18, with mild to moderate plaque psoriasis.

Previously the product was available as a prescription-only medication (POM) and only available following a consultation with a doctor. The change to a pharmacy product (classified as P) is seen as a way for patients to access treatment when the condition flares or they are unable to see their GP.

Purchasing the product at a pharmacist will still require some professional involvement and should only be offered to an individual who has a previous diagnosis of psoriasis. Pharmacists and their staff will be able to provide suitable advice to the patient to ensure that the product is suitable for them. The outer packaging and the patient information leaflet also include an image of plaque psoriasis, which will help both pharmacists and patients in this respect.

During the consultation process, people with psoriasis along with clinical experts, were involved in helping to guide the decision to change the licence from POM to P.

Dr Sarah Branch, MHRA's deputy director of VRMM, said:

"Psoriasis is a chronic disease which can have a major impact on people's quality of life. By making this medicine more widely available, patients will be able to treat flare-ups quickly without the need for a prescription."

Ash Soni, the RPS president said:

"Widening access to medicine is great news for

patients. Pharmacists are experts in medicines and are well trained to ensure safe supply of medicines to the public. Pharmacists are already able to sell products for the treatment of psoriasis with appropriate advice on management, application and side effects. We welcome the addition of Dovonex Psoriasis ointment to the range of products available.

"Pharmacists are more easily accessible than doctors and trained to give advice on medicine use, make sure the chosen medicine is appropriate and check if a person needs to see another health



professional. This is an important patient benefit and we would like to see more medicine available through pharmacy in future."

About the MHRA

The Medicines and Healthcare products Regulatory Agency (MHRA) is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. Their work is underpinned by robust and fact-based judgements to ensure that the benefits justify any risks. MHRA is a centre of the Medicines and Healthcare products Regulatory Agency, which also includes the National Institute for Biological Standards and Control (NIBSC) and the Clinical Practice Research Datalink (CPRD). The Medicines and Healthcare products Regulatory Agency is an executive agency of the Department of Health.

Source:

**Medicines and Healthcare products
Regulatory Agency**

The use of water-based therapies (balneotherapy – bathing in water containing minerals), for conditions such as psoriasis and arthritis has long been promoted as being effective. Unfortunately, there is not enough scientific evidence to say that complementary therapies such as these work in treating either psoriasis or psoriatic arthritis.

Regardless of the lack of evidence, many people report that they find such activities a relaxing and useful pursuit. Throughout the world there are a number of places where people in the past have found solace in a spa environment, not least the ancient Roman waters in Bath.

The Roman Baths, at the heart of the City of Bath World Heritage Site, consist of the remarkably preserved remains of one of the greatest religious spas of the ancient world. The city's unique thermal springs rise in the site and the Baths still flow with natural hot water.

The tradition of the thermal waters has been taken into the 21st century with the development of a collection of buildings known as the Thermae Bath Spa. The restoration of five historic buildings and the design and creation of one new contemporary building, to provide The New Royal Bath.

Until the restoration of the spa, which was completed in 2006, the natural waters ended up draining into the River Avon. Today, an astonishing 1 million litres plus flow from the natural springs from the Avon Valley is captured and fully used in the Thermae Bath Spa.

The thermal waters at the Thermae Spa contain over 42 different minerals, the most concentrated being sulphate, calcium and chloride. In all four of the baths the optimum bathing temperature is approximately 33.5 C (92F) with a depth of 1.35m.

People who visit the spa will find four natural thermal baths – one in the Cross Bath, a separate building, which can be used by individuals or small groups (up to 12 people). It is available to individuals on a 1.5 hr spa basis, including towel, robe and slippers.

New Royal Bath, (the main Spa), houses an open air rooftop pool overlooking the skyline of Bath city centre, the Hot Bath (used for Watsu treatments) and the Minerva pool, the largest of the thermal baths. The thermal waters are complemented by a massage jet, whirlpool and lazy river.

The complex is over three floors, houses 24 treatment rooms offering over 40 complementary therapies, the Springs Restaurant and the Wellness Suite consisting of spa experiences on the second floor. Visitors can explore the Roman Steam Room, Georgian Steam Room, Infrared Room, Ice Chamber, Celestial Relaxation Room and the Experience Showers. There is a spa shop (No.8) and a spa visitor centre.

So, is this new 21st century spa useful or worth

exploring? Here is a road test and personal experience from a reader:

"I have visited Thermae New Royal Bath Spa on two occasions this year and had two very differing experiences. The first time I went was in September, early morning. The first visit can be a little disorienting until you find your feet with the layout. The changing room can be a challenge as it is very large and like a maze in its design, but if you remember your locker number and where its situated for your return you are ok. The spa was quiet, so you could explore in a relaxed way, trying out the different things in the Wellness Centre, spending time in the rooftop pool, which was nice and different, warm and relaxing, then back down to the Minerva pool downstairs. The only thing I have to say, like others have said on their visit whilst I was there, it was quite a while in between when the various whirlpool and jets start-up. It is supposed to be five minutes between start ups but it is much longer than that. If you are on a time limit this can be frustrating if you want to get the best out of your session.

As I left around midday, the spa was getting busier but not so uncomfortable for that time of day. So all in all it was a pleasant session to do something different, try the warm waters and unwind.

However, the second visit was so much different and if I had done this session first I would never have considered returning.

Yes, I visited in the October half-term week! I know I should have known better! "What do you expect?" I hear you say; well someone's gotta do it, so I took one for the team!

The car parks in Bath, by the way, were horrendous too, with queues for parking tickets really long, and if you were paying by card, complicated - so allow plenty of time if you are visiting pre-booked timed events anywhere in the town.

I arrived at the spa around 12.30, and luckily, I was on a pre-booked Thermea Harmony package, which was a good package, consisting of a treatment (choice of three), 2 course meal in the restaurant, access to the spa for four hours, towel, bath robe and slippers. This meant



I could bypass the long, long queue outside, go straight to reception and then into the spa. I thought I'd be strategic and start at the rooftop pool before it got too busy. When I got to the top I was greeted with a very busy pool, so I got a space in a corner of the pool and laid claim to it and waited for the bubbles to start. It did not take too long for more people to pour in, obviously having the same plan as me! It was not long at all for it to become 'like sardines in a tin', standing room only, literally!

What made things worse was people waiting for the various jets to start, so they could enjoy it and then move on. As mentioned, this was time consuming and not at five-minute intervals. When I could bear it no longer, I ventured down to the Wellness Suite, where I was sure it would be more serene. Wrong! there were queues for each steam room and shower experience. Not a pleasant experience, so I decided to go to the Minerva Pool, thinking that everyone was up top. Wrong, this was just as busy, standing room only in the whirlpool, people frustrated waiting for it to start. The pool just got busier and noisier, although a fast track supplement is available, to avoid the queues (2 hours on the day I visited)

Was there no end to my dismay? Fortunately there was for 50 minutes at least. I had chosen for my treatment (included in the package), one of the spa's signature treatments, 'Watsu'.

This took place in the Hot Bath, located in the treatment area adjacent to the Minerva Pool, only accessible to those who have booked treatment packages. After filling in a short form I was introduced to my therapist. She led me through to the hot bath, a private enclosed pool, and immediately put my apprehensive self at ease about the treatment, what was involved and what was expected in my participation. My therapist also assured me that I was not going to drown either, and would be with me at all times, which helped the proceedings. Was not totally sure what to expect or how I would react to having water in my ears, or someone being in complete control of my body. Tip, if you let go and trust your therapist, let her/him guide your body through the movements without



resistance you will indeed get the best out of it and your therapist. With this in mind, I did just that.

Individuals will, during and after the treatment, have their own views on how it was for them; some can experience reactions of really letting go, release, emotions, things that may take them by surprise. It is a unique experience. I have a serious problem with tension and stress, and can be really sceptical of treatments anyway, so quite a hard person to convince.

I have to say it was an unusual 50 minutes. It was enjoyable, relaxing, as though you were flying through the air at times, weightless, free flowing. It was not at all stressful on the body or your aching bits (of which I have many!); you could actually feel your body being worked on, the trigger points releasing tension, and the gentle stretching movements really enjoyable, and pain-free too.

When the session was finished, I have to say, I actually did feel very dopey (more than usual!) in a relaxed way. Then it was back to reality and the chaos of Bath at half-term and the 3-hour journey back home. I thought that all that had been done to relax me would have surely been undone. I was wrong. My body felt more relaxed then it had in a long time, my neck and tension in my shoulders seemed to have disappeared. I had forgotten how normal could feel like, it was great. I had the best night's sleep I have had in ages, and the next day my body was still feeling the benefits of the Watsu treatment. A real surprise.

Yes, I would, if you have the chance, try it, either at the Thermae Spa or find a therapist near you that offers this treatment. From what I can see, therapists that offer this are few in the UK at the moment, but it is worth trying to locate one."

Note from editor: This is a personal view and PAPAA does not support or endorse any information contained in this article. From this report it appears that relaxation can take many forms. We will be exploring the use of medically supervised hydrotherapy in a future edition.

References:

www.romanbaths.co.uk
www.thermaebathspa.com



If you want to show your support of PAPAA, we have a number of PAPAA psoriasis and psoriatic arthritis awareness-related merchandise, which you can order from our shop; below are some of the current items we have available. Explore the full range of merchandise and other products by visiting our psoriasis shop.



Visit the PAPAA shop www.psoriasis-shop.org

- Order free information
- Join and pay for your subscription
- Renew your subscription
- Make a donation
- Purchase from a selection of books
- Informative training programmes.



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.



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

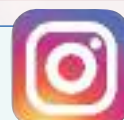
Visit the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website home page.

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 you can follow us by clicking the link, which is also located on our home page: www.twitter.com/PsoriasisInfo



Follow us on Facebook

