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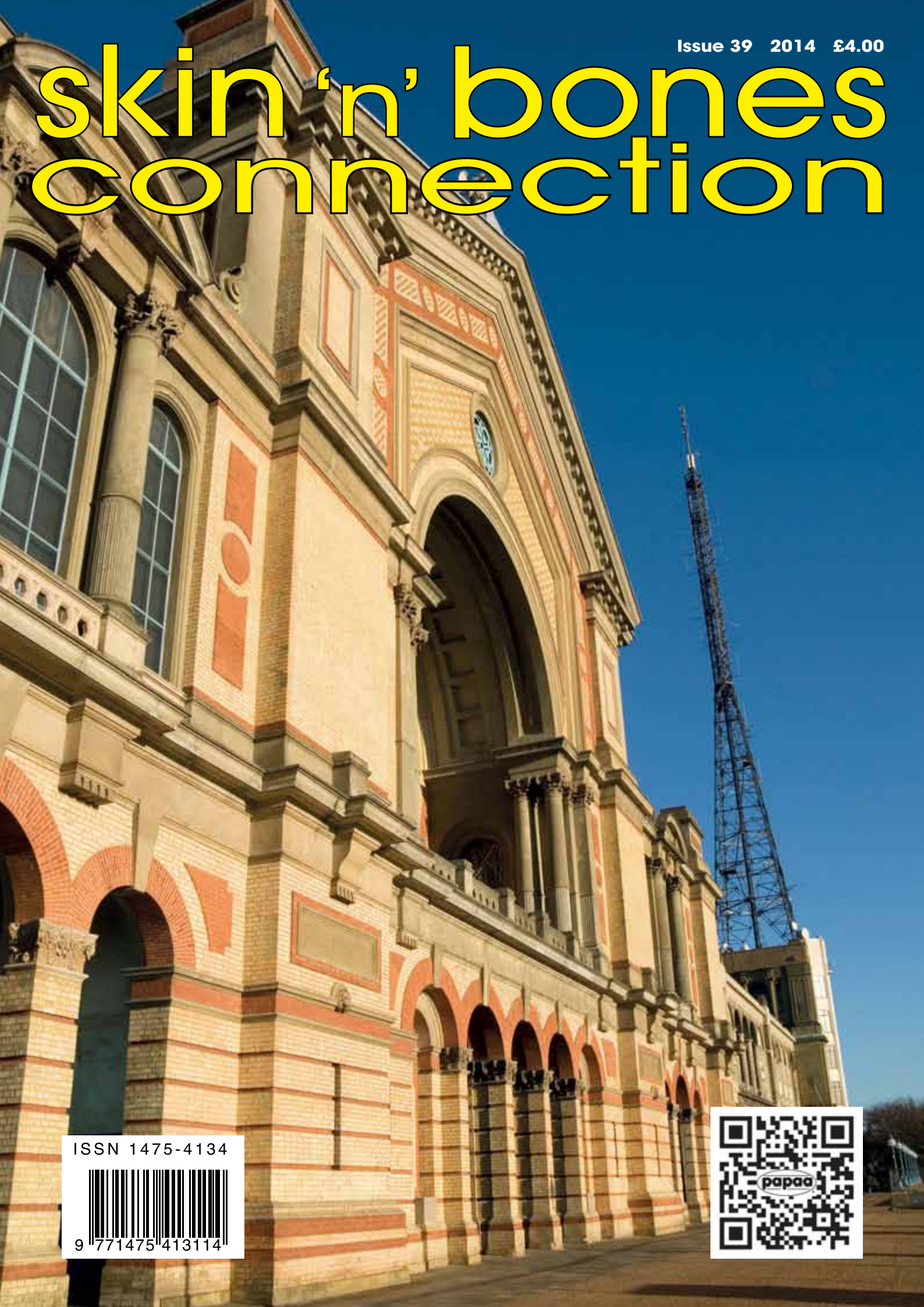
skin 'n' bones connection



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Dear Reader

The need to continue to look for ways to deal with psoriasis and psoriatic arthritis is the subject of much research and in this issue, we have highlighted some recent advances.

Research takes many forms and understanding why disease happens is the subject of an interesting epidemiology study by a group of international organisations (page 3).

Underpinning many research advancements is basic laboratory science and researchers at King's College London are looking at genetic targets as a route for therapy (page 4).

So how do people with psoriasis and psoriatic arthritis make sense of the latest research findings? The British Journal of Dermatology has come some way towards addressing this issue by trialling lay summaries of research papers aimed at the lay reader (page 5).

The advancement in research always needs to lead to better care and understanding of disease. The human benefit element has to be central to such work. We support the need for such research and have recently funded some interesting studies (page 10).

The views of the public and patients are an increasingly important part of all research. If you are interested in setting out research priorities, you can do this by giving us your views of what is important to you (page 11).

Managing editor

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

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COVER PHOTO:

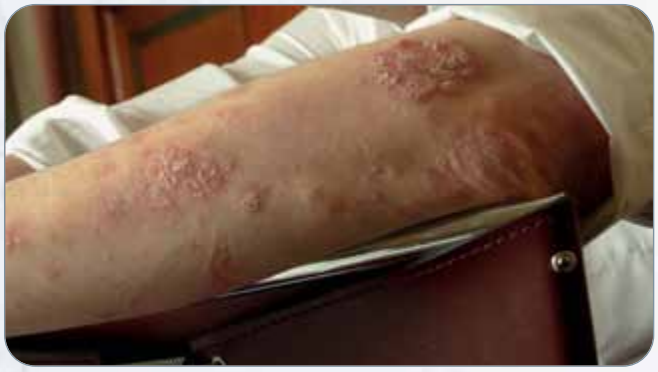
Alexandra Palace in North London, the venue for the Primary Care Expo held in February, at which PAPAA had an exhibition stand.

The International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC) have formed a partnership to develop a Global Psoriasis Atlas to fill the gaps in the understanding of the prevalence and burden of psoriasis.

While studies in recent years have contributed to an improved understanding of psoriasis, there are still significant gaps in knowledge related to the epidemiology* of trends in incidence over time.

The World Health Organisation (WHO) reported in 2013 that the worldwide prevalence of psoriasis is around 2%, but that studies in developed countries have declared prevalence rates of more than twice the global estimate at an average of 4.6%.

The project's initial task therefore will be to establish a credible and reliable database recording the prevalence of psoriasis worldwide and by country.



"By gathering data on the prevalence of psoriasis from as many countries as possible we will be able to form a clear picture of the burden of psoriasis worldwide and in so doing inform better decision making on the use of resources," says Professor Wolfram Sterry, president of the ILDS.

While gathering detailed information on prevalence, the initiative will undertake to build a framework for improved collection of data on the burden of psoriasis. In the long-term, the aim is to look at incidence over time and the burden associated with co-morbidities, as well as the economic impact of psoriasis.

"The atlas project is about driving constant improvement in the understanding of psoriasis and encouraging the ongoing collection of data and research," according to Professor Christopher Griffiths, president of the IPC.

The development of a Global Psoriasis Atlas is a long-term project that seeks to both drive continuous improvement in the understanding of psoriasis and uncover how it affects both the individual and society. Due to lack of evidence, among other factors, recognition of psoriasis as a serious, non-communicable, chronic disease that is widespread and represents a significant public health challenge is poor – at both local and global levels. Lars Ettarp, president of IFPA explains that,

"...building an evidence base that all stakeholders can use to advocate for improved treatment, access to care and recognition of psoriasis is a priority. Only once we truly understand the burden will we be able to command the recognition that people living with psoriasis deserve."

About the Global Psoriasis Atlas Project

The objectives of this joint project are to:

- Build an evidence base that stakeholders can use to advocate for improved treatment, access to care and recognition of psoriasis as a priority of public healthcare policy.
- Unite all stakeholders on one mutually beneficial agenda that works towards improving the lives of people with psoriasis and psoriatic arthritis.
- Encourage collection of data and research into psoriasis that could ultimately lead to better use of resources, as well as improvements in treatment and care.
- Enable benchmarking within and between countries by providing all stakeholders with local and regional evidence that is consistent and comparable.

About the partners

The International Federation of Psoriasis Associations (IFPA) is a non-profit organisation made up of psoriasis associations from around the world. www.ifpa-pso.org

The International League of Dermatological Societies (ILDS) is a non-governmental organisation in official relations with the World Health Organization. web.ilds.org

The International Psoriasis Council (IPC) www.psoriasiscouncil.org

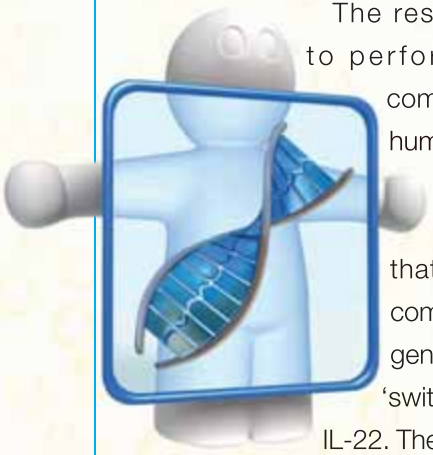
***Epidemiology is the study of how often diseases occur in different groups of people and why. Epidemiological information is used to plan and evaluate strategies to prevent illness and as a guide to the management of patients in whom disease has already developed.**

New target for psoriasis

Researchers at King's College London have identified a new gene called PIM1, which could be an effective target for groundbreaking psoriasis treatments and therapies. It is not known exactly what causes psoriasis; it is thought that certain genes such as PIM1 may play a role.

The study, published in *Science Translational Medicine* highlights for the first time the role of PIM1 and the IL-22 cytokine – a protein that sends messages between cells – in skin inflammation, such as that seen in psoriasis patients.

Scientists, led by Professor Frank Nestle from the St John's Institute of Dermatology at Guy's and St Thomas' NHS Foundation Trust and King's College London, injected IL-22 into models of normal human skin in mice*. The changes that subsequently occurred in the skin were reminiscent of psoriasis. Injecting an antibody to block the IL-22 cytokine caused these changes to reverse.



The researchers were then able to perform computer analysis, comparing the data from these human skin models with existing gene data sets (a collection of related sets of information that can be manipulated by a computer), in order to identify the gene PIM1 as one of the genes 'switched on' by the presence of IL-22. They further showed that a small molecule drug blocking PIM1 was effective in models of psoriasis. The link between the IL-22 cytokine, which causes inflammation and subsequent changes in the PIM1 gene, suggests a direct link between PIM1 and psoriasis.

It is the first time that this gene has been identified as having a specific link to the condition. The combined use of computer analysis of complex gene data sets and disease-relevant human skin models, also called integrative biology, means that research can be more easily translated to further clinical studies for patient benefit. This new type of approach will likely generate more insights into disease mechanisms but also new drugs for the treatment of psoriasis, thereby reducing the gap between discovery and the clinic.

Professor Nestle said: *"We have been able to confirm that the protein IL-22 causes inflammatory changes in human skin contributing to psoriasis. The most exciting part of the study was that detailed analysis of genes induced by IL-22 in skin allowed us to uncover a novel treatment target for this disease. We are hopeful that our research will lead to the development of new approaches for the treatment for this common and irritating skin condition."*

The authors say *"...that whilst this is a significant development, providing proof of principle in pre-clinical models of disease, further research, in the form of clinical trials, is necessary in order to test potential new treatments for effectiveness in humans. However, as the findings are easily transferable to clinical studies, the discovery of this new gene target has promise for the development of new drug therapies."*

The study was supported by the Medical Research Council, Wellcome Trust and the National Institute for Health Research Biomedical Research Centre (NIHR BRC) at Guy's and St Thomas' NHS Foundation Trust and King's College London.

Source: News release
www.kcl.ac.uk
February 2014

*An animal model is a living, non-human animal used during the research and investigation of human disease, for better understanding the disease process without the added risk of harming an actual human.

Have you found the thought of reading research reports daunting? Do you get lost in the medical jargon?

For the last few months, the British Journal of Dermatology (BJD) has been trialling a new initiative of plain language summaries of research papers which are aimed at the lay reader.

The aim is to open up important research to patients who might otherwise be deterred by medical terms and inscrutable language. It is also hoped that they will provide a useful resource for journalists wishing to publicise new breaking research.

Each summary is approximately 250 words, highlighting the key points of the research, in clear language that is easy to understand without being patronising. The summaries seek to provide a taster of the article that presents the objectives and key findings of the study, allowing people to decide if the full article will be of interest to them. Several of the studies so far have concerned psoriasis and psoriatic arthritis.

You can see the summaries (and all the previous months' summaries) in the online edition of the journal.

To access the summaries go to www.brjdermatol.org and then use the search facility by typing 'plain language summaries' and select 'in this journal' (rather than 'in this issue').

If you are a Twitter media user, you can look at the latest summaries @HealthySkin4All and scroll down to see the journal tweets.

Feedback is important and welcome – please take a minute to answer one very simple question here: https://www.surveymonkey.com/s/BJD-Summaries.

About the BJD

The British Journal of Dermatology is one of the top dermatology journals in the world, and publishes papers on all aspects of the biology and pathology of the skin. Originally the journal, founded in 1888, was devoted almost exclusively to the interests of the dermatologist in clinical practice. However, the rapid development, since the 1950s, of research on the physiology and experimental pathology of the skin has been reflected in the contents of the journal, which now provides a vehicle for the publication of both experimental and clinical ethical research and serves equally the laboratory worker and the clinician.

Source:
British Association of Dermatologists
May 2014

Emotional support

New research from University of the West of England (UWE) Bristol has found a high demand for help to cope with the social and emotional implications of inflammatory arthritis among patients. The study, which will be presented at Rheumatology 2014 this month, found that patients need more support to deal with the impact of long-term pain and tiredness.

The research suggested a need for psychological support from diagnosis onwards, with almost every patient wanting support (97%) and suggesting they would use psychological support services (96%). Despite this, less than a quarter (23%) had been asked about social and emotional issues by a rheumatology professional, suggesting there is a gap between the support provided and the support patients need.

Conducted with funding and support from Arthritis Research UK, the research surveyed 1,200 patients' opinions on the support currently available and their preferences for the type of services they would like to see in the future. Of those patients surveyed, only a small minority (6%) felt that social and emotional issues were irrelevant to their condition.

Inflammatory arthritis causes inflammation of the joints which leads to joint damage, stiffness and pain. These symptoms can cause patients to become depressed, fatigued, anxious and distressed. To support them in overcoming these issues, patients suggested they would like to access face-to-face support with a rheumatology specialist or a GP as needed.

If available, two thirds of patients would be interested in attending self-management or coping clinics. Other services that patients would use to help them cope with their condition included peer support groups, pain management and patient education. Patients also said they needed more support for practical aspects such as the effects of their arthritis on work, leisure and relationships. Many people with these conditions are of working age and could get back to work with help from health professionals in the rheumatology team.

Lead researcher Dr Emma Dures said,

"Patients have told us that psychological and emotional support is important and they would like help from rheumatology specialists to cope with the impact of living with arthritis. Therefore our research will now focus on supporting teams to acquire the skills and resources necessary to provide psychological and emotional support to improve quality of life for patients."

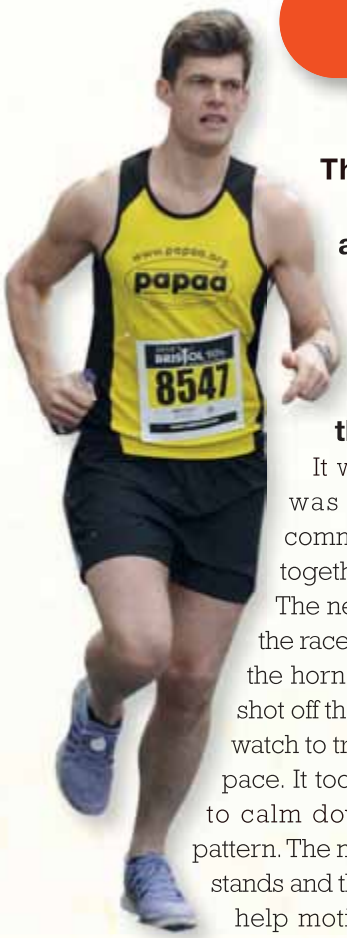
The British Society for Rheumatology's guideline for the management of rheumatoid arthritis states: "Effective care, treatment and support should be available for all patients with RA… Psychological and social support is an important aspect of management. Real and potential psychological distress should be addressed through the multi-disciplinary team and appropriate agencies."

President of the British Society for Rheumatology Dr Chris Deighton said, "It can be physically and emotionally distressing for patients who develop an inflammatory arthritis. There is clearly a huge unmet need for people with inflammatory arthritis, and more psychological support would improve the quality of their lives. All rheumatology services should provide access to professional psychological support."

The research, *Psychological support for inflammatory arthritis: what do patients get and what would they like?* from Dr Emma Dures et al will be presented as a poster abstract (number 54) at Rheumatology 2014. The research was funded and supported by Arthritis Research UK.

Source: UWE Bristol

www.uwe.ac.uk



The Bristol 10k! What a day! The weather wasn't the best and a little blustery to say the least! Spirits were extremely high as I took a short walk with my headphones on to the runners' village to get in the zone!

It was extremely busy, but everyone was so friendly and it had a great community feel with everyone coming together and supporting their charities. The nervous energy started to boil up as the race time came ever closer. 9.45am and the horn sounded for the start of the race, I shot off the start line constantly looking at my watch to try and get into the right rhythm and pace. It took me about 2km for my heart rate to calm down and get into a nice running pattern. The music was blaring from promotional stands and the public that were out were a great help motivating you along at every check point along the way.

I hit the Portway and saw my family cheering me along which was another great boost and then started to think about why I was doing this which was to prove that it can be done. I went over the halfway point and knew I was onto a good time; the race was going well but getting very busy now with all runners.

I hit around 8k and had the most uncomfortable stitch that was quite crippling so I backed off a little to let this subside. This quickly passed and I picked up the pace again and was soon approaching the finish line. I knew I was on for a personal best (PB), so gave it everything I got, darting in and out between all the other runners. I crossed the finish line, 45 minutes and 15 seconds a PB for me and what an experience it was and to raise money for something that is so personal to me, a real achievement and something I will not forget.

Thank you to all that supported me throughout this time and helped me raise money for PAPAA.

About Ben

Ben has had psoriasis all of his life and in August 2001 was diagnosed with psoriatic arthritis. At the time he was 18 years of age and didn't really know what impact it would have on his life, but has since grown up with it and found ways of dealing with the inflammation and constant dull pain. **"You cannot let it get in the way of what you want to do and with the help of new drugs and a healthy lifestyle it is possible to put the disease into remission for extended periods of time"**.

Ben considers himself to be one of the 'lucky ones' and has responded well to treatment **"I have no intention of letting this get the better of me and have decided to use my diagnosis as the impetus to try and make a small difference for those who have a daily struggle with this condition"**.

Source: Ben Smithson

Note from the Editor:

Well done Ben and thank you for supporting PAPAA. The money you have raised will help PAPAA continue its work. If you would like to follow Ben's example or raise some money for PAPAA visit our fundraising page on our website where there are ideas and suggestions of how to get involved.

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

Out and about

One of PAPAA's activities is to promote and raise awareness of the needs of people with psoriasis and psoriatic arthritis to healthcare professionals. There are numerous events that we can attend, but selecting the correct location and event can be difficult.

As an organisation, we are widely known amongst dermatology and rheumatology specialists and, in particular, those based in

hospital secondary care settings. The support we receive in the distribution of our material and awareness about the organisation is invaluable. Although attending events where we are well known is gratifying, it is not always of value or productive.

Where we have difficulty raising awareness is in the GP primary care setting, where awareness of psoriasis and psoriatic arthritis is often low. The demand on the time of GPs is very high and the pressure of meeting targets for particular conditions reduces the priority of dealing with chronic conditions such as psoriasis and psoriatic arthritis.

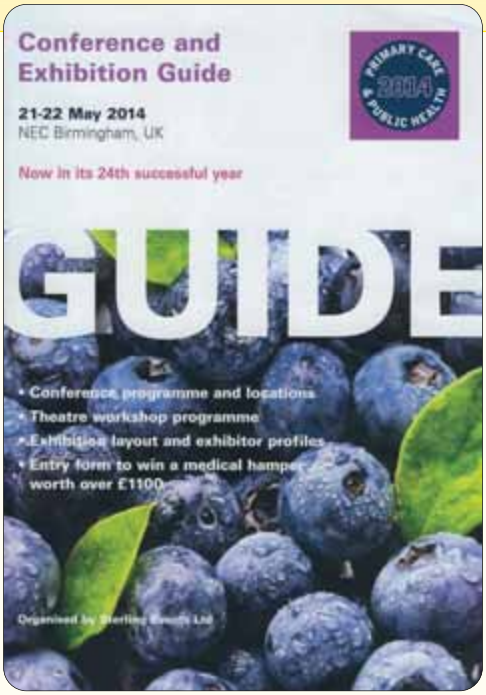
To address these issues we have developed a support programme specifically designed to help those in primary care understand and learn how people are affected by psoriasis and psoriatic arthritis.

The programme is called Psoriasis in Practice and is a distance-learning course, which is endorsed as Continuing Professional Development (CPD) by the University of South Wales and specifically aimed at providing training to a pressured workforce, which not only helps them, but also benefits their patients.

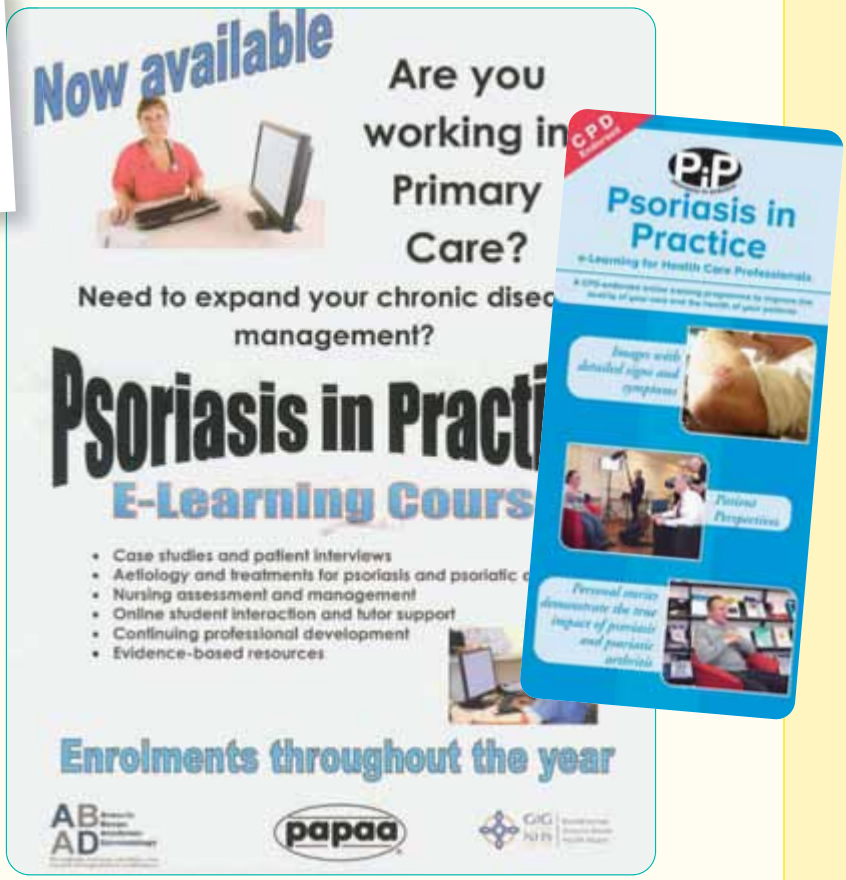
So how do we reach out to these professional allied healthcare groups? Apart from direct promotion, another way of promoting the programme and our work is to attend events and studies aimed specifically at the primary care sector. This year we have attended two events to do just that.

In February, we had a stand at the Primary Care Nursing Expo at Alexandra Palace in London. The event attracted many primary care and allied healthcare professionals, including practice nurses, health visitors, healthcare assistants, and occupational therapists, many of whom were unaware of either psoriasis or psoriatic arthritis, as depressing as this may sound. It is the ideal setting to raise awareness. Even informing just one individual could help a large number of people within their practice.

In May we attended Primary Care and Public Health 2014, held at the National Exhibition Centre in Birmingham. This event was in its 24th year and attracted large numbers of primary care healthcare professionals. Again the knowledge of some of those who attended was low, but the PAPAA stand was greeted with enthusiasm and interest.



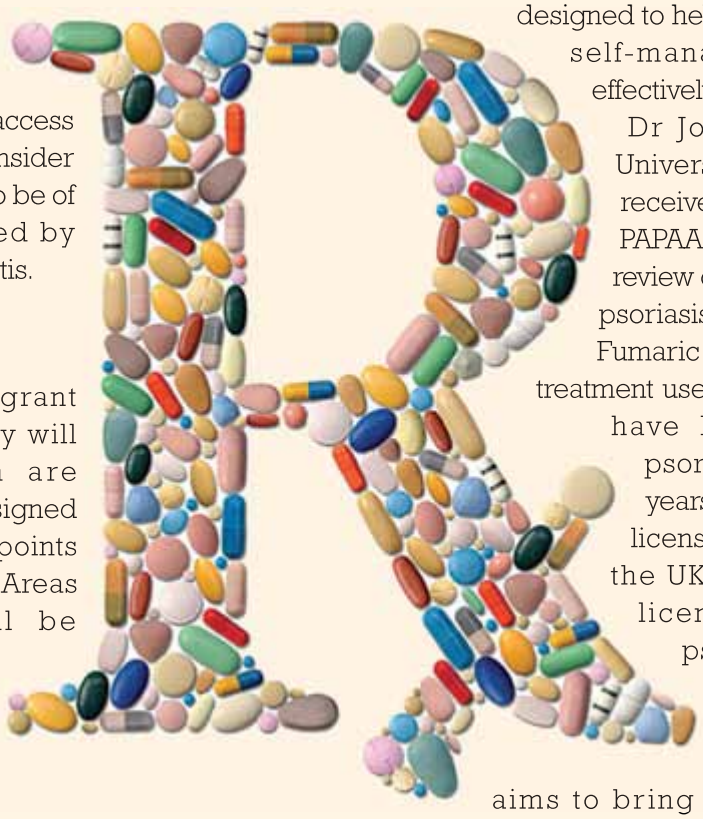
If you are aware of any events or places where our material could be displayed or we could have a stand promoting the condition please let us know.



Supporting research

As a charity, PAPAA is supportive of well-run medical research. The areas that are considered for funding are 'here and now' studies, which could lead to patient benefit in the short term.

PAPAA operates an open access funding policy, and will consider applications that are likely to be of benefit to those affected by psoriasis or psoriatic arthritis.



Type of grants

There are no specific grant schemes, but the charity will favour grants which are methodologically well-designed with clearly defined endpoints (outcomes or benefits). Areas of research that will be considered include:

- **Short-term observational studies**
- **Psoriasis in children**
- **Systematic reviews**
- **Funding of feasibility and pilot studies**
- **Small epidemiological surveys**

The above are just examples, and the charity will view all applications with equal enthusiasm.

A recent award was made to University of Hull investigators Dr Henning Holle and Dr Fiona Cowdell, who are carrying out an online research study called *Auditory modulation of itch in people with psoriasis: an online study*. Their aim is to develop new treatments for psoriatic itch, and this study will allow them to find out more about whether their approach is helpful.

In the study, participants will be asked to listen to a number of scratching and rubbing sounds on a computer (using headphones, if possible). They will then rate how itchy they feel while listening to these sounds. This study takes approximately 1 hour and can be completed in sections. Although there are many therapies for itch, few are effective in reducing psoriatic itch. There is a need to develop new approaches to relieve this unpleasant condition. The study has fully recruited participants.

Another award went to Dr Rod Tucker, who is studying the feasibility of whether a community pharmacist can deliver an educational programme designed to help people with psoriasis self-manage their condition effectively.

Dr John Ingram from the University of Cardiff has also received a research grant from PAPAA to carry out a Cochrane review of Fumaric Acid Esters in psoriasis.

Fumaric Acid Esters (FAE) are a treatment used to treat psoriasis, and have been used to treat psoriasis for more than 30 years. They are not currently licensed to treat psoriasis in the UK, but are a popular licensed oral treatment for psoriasis in Germany. A number of trials have been undertaken and the Cochrane review aims to bring these together systematically to compare effectiveness and any side effects, to be able to provide some guidance on the role of FAE in psoriasis.

In future editions we will publish reports of the results of the studies currently being funded by PAPAA. For more information about our funding policy and current portfolio **visit : www.papaa.org/research**

About Cochrane

The Cochrane Collaboration is a global independent network of health practitioners, researchers, patient advocates and others, responding to the challenge of making the vast amounts of evidence generated through research useful for informing decisions about health. A not-for-profit organisation with collaborators from more than 120 countries working together to produce credible, accessible health information that is free from commercial sponsorship and other conflicts of interest.

Visit: www.cochrane.org

Would you like to help with research? Do you have psoriasis and/or psoriatic arthritis? Do you want to have your say about what is important to you?

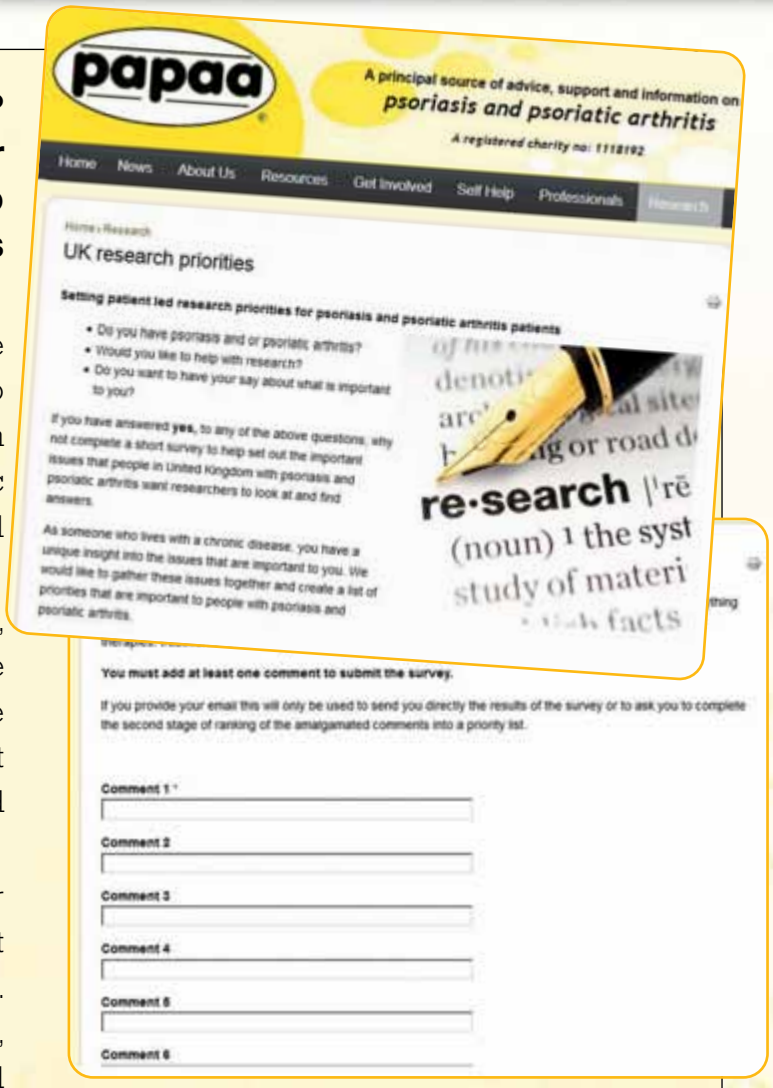
If you have answered yes to any of the above questions, why not complete a short survey to help set out the important issues that people in the United Kingdom with psoriasis and psoriatic arthritis want researchers to look at and find answers.

As someone who lives with a chronic disease, you have a unique insight into the issues that are important to you. We would like to collate these issues together and create a list of priorities that are important to people with psoriasis and psoriatic arthritis.

The survey is available online or as a paper version (enclosed with this journal). The first phase is for you to say what is important to you. Once we have gathered sufficient suggestions, they will be grouped together by experienced researchers in psoriasis and psoriatic arthritis as questions that could be answered by a research programme.

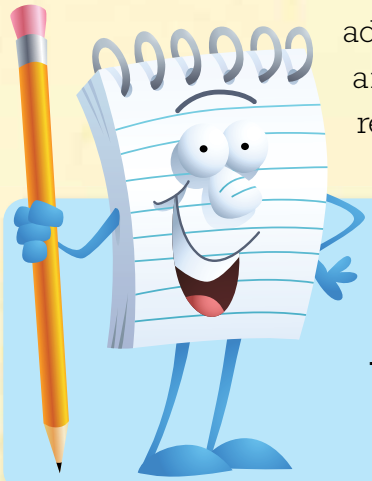
The second stage will be to ask people to rank these questions in order of priority with the view of getting them made into patient-led questions that need answers from research.

Whether you choose the online or paper version, all we ask is that you complete as many of the text boxes as you can (there are 10) with issues, worries, questions, concerns or anything you think would help you cope, manage or understand the conditions you live with better. This could include therapies, treatments, doctors, appointments, hospitals etc (feel free to provide any suggestions).



By helping with this survey, you will be directly influencing the research agenda and raising real issues that are important to people with psoriasis and psoriatic arthritis.

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
Email: info@papaa.org

Hospital experiences

People are generally having a better experience in hospital than a year ago but the quality of their stays can vary, according to a national survey from the Care Quality Commission (CQC).

Around one in four people rated their overall experience in hospital as 10 out of 10, reveals the survey, which gathered the views of over 62,400 people who had stayed in hospital for at least one night last year.

The survey asked people to give their opinions on the care they received, including:

- **the information provided by staff**
- **whether they were given enough privacy**
- **the cleanliness of their wards**
- **their discharge arrangements**

On a national level, people were more positive about their stays in hospitals, with most responses in the survey having improved or stayed the same since it was last carried out in 2012.

Key highlights include:

Overall experience

71% rated their overall experience as 8 or above and 27% as 10 out of 10; up from 69% and 25% in 2012.

Dignity and respect

91% of people felt they were always treated with dignity and respect; up from 80% in 2012.

Discharge arrangements

54% felt that they were "definitely" involved in decisions about their discharge from hospital; an increase from 53% in 2012, but this still leaves 46% who did not feel fully involved.

Also, 41% of those surveyed said that their discharge from hospital was delayed, representing no change from last year.

The delay was for longer than four hours for around 1 in 4 (24%) of these people. Waiting for medicines was the most common reason.

Providing information to patients

3 out of 4 (75%) said that they were given the "right amount" of information about their condition or treatment by staff when they went through A&E and 80% said the same about their hospital ward; up from 74% and 79% in 2012. However, almost two fifths (39%) felt they were not given sufficient information about the side effects of their medication before being sent home.

Alongside the national improvements, some of the responses in the survey show a wide range in performance between NHS trusts. For example, there were large variations in responses to questions about patients being told how to make complaints about their care, whether they received copies of letters sent between their hospital doctors and GPs, and whether staff told them about any danger signals

they should watch out for after being discharged. Also, variations were reported in people being given printed information about what they should do or avoid doing after leaving hospital, and whether they had someone from the hospital to talk to about their worries and fears.

Areas where there was the least variation between NHS trusts include whether respondents felt threatened during their hospital stay by other patients or visitors, whether they were given enough privacy when being examined or treated on the hospital ward, and whether hand-wash gels were available to use. Also, there was little variation in whether people trusted and had confidence in their doctors. Overall, NHS trusts scored well in all of these areas.

As well as a report of the national findings, CQC has published the results for each of the 156 acute and specialist NHS trusts that took part, so that people can see how their local services performed.

Professor Sir Mike Richards, chief inspector of hospitals, said:

"It is encouraging that the results for many of the questions in the survey show improvements, with areas such as information provision, cleanliness and privacy all performing better than last year. However, scope for continued improvement remains, including with how patients are involved in their discharge arrangements.

"I would like NHS trusts to reflect on their survey results to understand what their patients really think about the care and treatment they provide. This will help them to identify what they need to change.

"Gathering feedback from people who use services is at the heart of our new approach to regulation.

We will use information from the survey as part of our wider monitoring of hospitals, to help us determine what we should inspect and when."

About the Care Quality Commission

The Care Quality Commission (CQC) is the independent regulator of health and social care in England.

They make sure health and social care services provide people with safe, effective, compassionate, high-quality care and encourage care services to improve.

They monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and publish what they find to help people choose care.

For further information
The Care Quality Commission visit:
www.cqc.org.uk

Source:
Care Quality Commission April 2014

In a move to help people buy and use safe herbal medicines that meet acceptable standards of safety and quality, the Medicines and Healthcare products Regulatory Agency (MHRA) announced that from 30 April 2014 all manufactured herbal medicines will have to be authorised in order to be sold and supplied lawfully in the UK.

This means that after this date herbal retailers will no longer be able to sell unlicensed herbal medicines that are not registered under the Traditional Herbal Registration (THR) scheme in the UK.

Products registered under the THR scheme meet safety and quality standards and are accompanied by patient information about the product and how it should be used. Registered products can be identified by the THR logo and a THR number on their label.

Dr Linda Anderson, MHRA Licensing Division, said:

"Natural doesn't always mean safe and some unlicensed herbal products can be harmful and some may have serious side-effects.

"We know that people buy and use herbal medicines, so it's only right that they have access to products that are safe and meet good quality standards. And that's where we come in – our THR scheme can help assure you that these products meet these standards.

"It is now nearly ten years since the implementation of the European Directive on herbal medicines. Companies have had this time to bring products up to appropriate standards and apply for a THR registration."

The requirements for the THR scheme are set out in the Traditional Herbal Medicinal Products Directive (THMPD) which was introduced in 2004 and came into effect on 30 April 2011.

For those herbal medicines that were on the UK market before April 2011, the MHRA allowed retailers to 'sell through' their stock because it was anticipated that they would be sold within an 18-24 month period - the average shelf-life of these products. This transitional protection also allowed manufacturers to bring their production up to the required standards to meet the directive.

However, these unlicensed herbal medicines are still being sold and in July 2013, the MHRA launched a consultation to seek views about ending the sell-through period. The responses have now been considered and 30 April 2014 was the deadline for retailers to stop selling these products.

About the MHRA

The MHRA is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe.
The MHRA has been providing help and advice to the herbal industry since the introduction of the herbals directive about manufacturing and quality standards. Herbal manufacturers have had seven years to bring their products up to the required safety standards and the MHRA have had continual dialogue with the herbal industry to help them ensure that they meet the required manufacturing and quality standards.

For more information visit: www.mhra.gov.uk

Source:
MHRA press office

More than seven million patients across the country will benefit from innovative pilot schemes trialling improvements to GP access, funded by the £50m Prime Minister's Challenge Fund.

Twenty GP collaborations were successful in their bids to the fund and have been awarded investment to run pilots for a year.

The Challenge Fund has created great interest amongst practices in adopting new ways of working, attracting more than 250 expressions of interest.

The successful schemes were awarded sums from £400k to £5m, including three pilots across London which cover half of London's population.

A wide variety of ideas are to be trialled, including 8am-8pm working, better use of telecare and health apps, access to appointments through email and video consultations and greater flexibility with face-to-face access.

Mike Bewick, NHS England's deputy medical director, said:

"We were very pleased so many practices came together to look at delivering innovative services at scale and we will await the outcomes of the pilot schemes eagerly.

"This fund is about helping those people who struggle to find a GP appointment to fit in with family and work-life and making the most of new technologies. We need to create an environment that enables GPs to play a much stronger role, as part of a more integrated system of out-of-hospital care."

In October 2013, the prime minister announced the Challenge Fund to improve access to general practice and NHS England was asked to lead on the selection and management of the pilot schemes.

GP practices were invited to submit their expressions of interest (EOIs) in December and NHS England's area teams considered them before a national assessment panel made the final decision.

The panel had representatives from NHS England, the Department of Health and patient groups.

Charles Alessi, chairman National Association of Primary Care, said:

"The National Association of Primary Care commends those practices that bid for the Prime Minister's Challenge Fund, and I am not surprised by the overwhelming response.

"The GP Challenge Fund will give colleagues the time and ability to work innovatively to ensure better patient outcomes in an out-of-hospital environment"

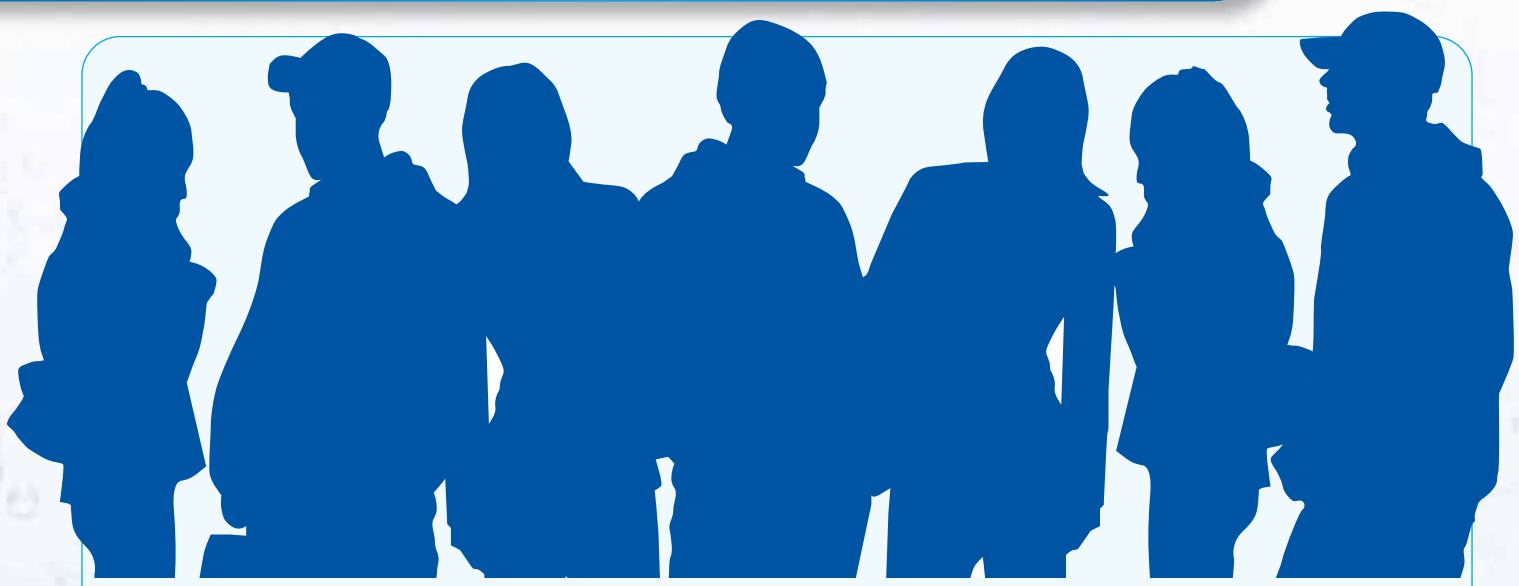
NHS England will now oversee the pilots that will be part of a 12-month national development and evaluation programme.

NHS England wishes to build on the momentum created by the bid process and, alongside the pilots, is looking to establish a number of associate networks to the Challenge Fund to link a number of the other innovative bids within their region and nationally to share learning.

For more information visit: www.england.nhs.uk

Source: NHS England April 2014

Young arthritis



New research suggests that younger people with arthritis make treatment decisions based on how the treatment will affect their appearance, their social life and their physical and mental wellbeing. The research, which was presented at the British Society for Rheumatology's conference, Rheumatology 2014, suggested that young people are concerned about whether treatments, could threaten their day-to-day life.

Inflammatory arthritis, a group of conditions including juvenile idiopathic (unknown cause) arthritis, rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis, can need aggressive treatment, including the use of biologic therapies. For young people, making these crucial treatment decisions comes at a difficult time in their personal and disease development. It is vital that the right decision is made because these decisions can have profound consequences.

The research, which included interviews with twenty-five 16-25 year olds with inflammatory arthritis, suggested that young people judge biologic treatments on their potential to help them to lead a normal life. While they understand the potential long-term risks of these therapies, they feel bound to accept these risks in order to improve their life for the near future.

The research also suggests that the emotional, social and vocational consequences of side-effects of treatment can be central for young people. Generally, patients value treatments that help them to live a normal life. However, perceptions of a 'normal life' are different depending on age, condition and their treatment.

The researchers conclude that:

"Young people need support and encouragement to explain how treatments help or hinder normal life, so regimens can be clarified and/or adjusted in order not to be unnecessarily restrictive."

Ruth Hart, researcher at Newcastle University, said:

"For many young people with arthritis, keeping on top of treatment is a struggle, but if not properly managed, the condition can have very serious consequences. So helping young people identify the challenges and opportunities of different treatment options is a key step in enabling them to make decisions about treatment that they can see through."

Chris Deighton, president of the British Society for Rheumatology, said:

"People with inflammatory rheumatic diseases need as much information on drug regimens as possible so that they can make informed decisions on the best strategies, weighing up the pros and cons, and short and long-term considerations. This applies to all patients, but especially young people with their whole lives in front of them."

Source:
British Society of Rheumatology

Decisions on ustekinumab

Ustekinumab is a biological therapy* designed to recognise and attach to specific proteins on the surface of cells. It acts as as blocker of molecular messages by targeting a particular protein called interleukin-12 (IL-12) and interleukin-23 (IL-23). Interleukins are reproduced by white blood cells for regulating immune responses in psoriatic arthritis.

Ustekinumab is licensed for psoriasis and psoriatic arthritis, but in recent guidance there were different outcomes following appraisals of the drug.

The National Institute for Health and Care Excellence (NICE) published guidance not to recommend ustekinumab for psoriatic arthritis, although the drug is recommended by NICE for the treatment of psoriasis.

The Independent Appraisal Committee examined the clinical and cost-effectiveness of using ustekinumab alone or in combination with methotrexate for treating active psoriatic arthritis in adults when the response to previous non-biological disease-modifying anti-rheumatic drug (DMARD) therapy has been inadequate. The guidance does not mean that people currently taking ustekinumab will stop receiving it. They have the option to continue treatment until they and their clinicians consider it appropriate to stop.

Commenting on the guidance, Sir Andrew Dillon, NICE chief executive, said:

"The independent advisory committee reviewed the evidence on ustekinumab, including evidence on the nature of psoriatic arthritis, the views of people with the condition, those who represent them, and clinical specialists. The Committee understood that psoriatic arthritis is a chronic condition that can have a significant physical and psychological impact on an individual's life, employment and social activities.

"The Committee accepted that ustekinumab is clinically effective compared with conventional DMARD treatment, but the Committee concluded that ustekinumab appeared less effective than TNF alpha inhibitors. The Committee also noted that the economic analyses found that ustekinumab was not a cost-effective option. Whilst recognising the severity of the disease, the Committee concluded that ustekinumab could not be considered a good use of NHS resources. NICE currently recommends golimumab, adalimumab, etanercept and infliximab for treating active and progressive psoriatic arthritis in adults (technology appraisal guidance 220 and 199)."

The decision in Scotland by the Scottish Medicine Consortium (SMC) was to recommend that ustekinumab is accepted for restricted use within NHS Scotland. Alone or in combination with methotrexate, for the treatment of active psoriatic arthritis in adult patients when the response to previous non-biological, disease-modifying, anti-rheumatic drug therapy has been inadequate, or for use in patients with active psoriatic arthritis who have failed on, or are unsuitable for, treatment with a biological anti-TNF drug.

To see the full guidance go to:
The National Institute for Health and Care Excellence
www.nice.org.uk

The Scottish Medicine Consortium:
www.scottishmedicines.org.uk

Ustekinumab is known by the brand name of Stelara®

*Biological therapy is treatment designed to stimulate or restore the ability of the body's immune (natural internal defence) system to fight infection and disease. Biological therapy is also called biotherapy or immunotherapy.

Letters

Q Dear PAPAA,

I wonder if you can help me at all. I have been diagnosed with psoriatic arthropathy for the last 24 years. I am now 46 years old. During that time I have had both hips replaced, one hip revised, correctional surgery to one hip following three dislocations, both knees replaced, both elbows replaced, one shoulder replaced and one of my wrists fused. Airports are interesting!! I am in general good health and deal with life and pain as normally as I am able. I am stable on my medication. However, I have had problems with one of my ankles for over 2 years and have finally made the decision, with my surgeon, to have my ankle fused. This will be like no other operation for me as I will have to have a cast for 14 weeks, with the first 6 weeks non-weight bearing. This is not something I have been through before and means that I have to make some modifications at home. I am not registered disabled and draw no disability allowance from any source. I just wanted to ask if there is anyone, anywhere, who might be able to assist with some funding as I will need to make major alterations to my bathroom to cope during this recovery period and into the future beyond my recovery. Any help or advice that you could give me would be greatly appreciated.

Thanks in advance LK

A Dear LK

Occupational therapists (OT) often are involved in the adaptation of facilities and help with applying for grants. It may be worth talking to your GP or consultant for a referral to an OT who would then be able to advise you about what is available. The best source of information, guidance and services is the government website www.gov.uk that provides links to relevant departments and agencies.

Yours
PAPAA

Q Dear PAPAA,

Having suffered from psoriasis for about 38 years and the arthritis associated with it for about 15 years, I was thrilled to find there is help and support available. It's hard to describe living with this condition – the element of disbelief amongst friends and relations is unbelievable. Because of the remissions in the condition, I am sure they half believe I am putting it on.

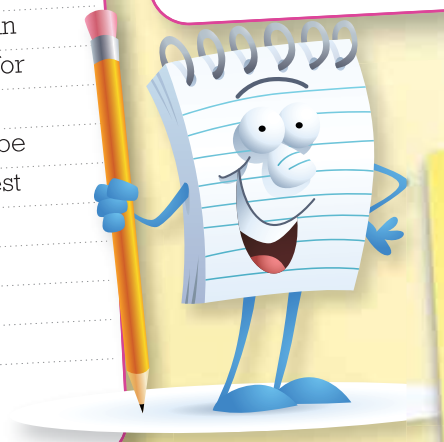
I can see for myself how odd it must seem to be able to open jars, peel vegetables, walk miles etc one week and the following week being unable to do any of these things. I would be pleased if you could send me any information tips etc also how to join the group. I carry a few bits of information on psoriasis and psoriatic arthritis to show people who have never heard of this condition, so would be very grateful for any more information, not only for myself but to educate others.

Yours CV

A Dear CV

Thank you, it is often the case that given the fluctuant nature of the condition sometimes people do not always fully understand the effect it can have. We will send you some more information. You may also find it useful to point people towards our website www.papaa.org which has information on all aspects of psoriasis and psoriatic arthritis.

Yours
PAPAA



Keep your letters and emails coming or share your experiences.
www.papaa.org/share-your-story

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

Q Dear PAPAA,

I have been taking naproxen twice a day for quite a long time but recently had to stop because I was getting abdominal pain. While I stopped taking it my joints were very painful. I saw the doctor and he gave me omeprazole [a medication that reduces the amount of acid produced in the stomach], so I have started taking them again. While I was off the naproxen my psoriasis seemed to improve, now I am taking it the psoriasis has flared up again. My question is: do you know if this is a side-effect of the naproxen?

Thank you AW

A *Dear AW*

Thank you for your email. It is an interesting question as the list of adverse events for naproxen is huge according to the NHS website. Although psoriasis is not listed, the nature of psoriasis as a waxing and waning disease might make people think that an improvement or flare-up is just part of the process and not linked to medication.

Maybe it would be a good idea to report this to the MHRA via the Yellow Card scheme, as if they get enough reports they will start to look into it further https://yellowcard.mhra.gov.uk/ and if it is widely reported, add or create a warning.

Yours

PAPAA

Dear PAPAA,

I had psoriasis for about 10 yrs. Then one day I could not kneel down. My left knee swelled up and I could barely walk. I also had scales on the back of my ears and developing in other places. I went to see a dermatologist and she suspected I had psoriatic arthritis. I then went to see an arthritis doctor and, sure enough, I have both.

My nails look terribly pitted so I started getting my nails done with shellac polish at the nail salon. This has made my nails stronger and look so pretty. Just makes me feel better about my disease. I never had nice nails as a young girl so I must have had psoriasis all along, just not that bad until I got in my 50s. I have scales on my back, legs and scalp. Cannot wear black clothes. I am on biological treatment for the past year and I have seen improvements and at least I can walk and do pretty much what I want now. The worst part of my psoriatic arthritis is the pain at night. I guess I should not complain; there are people who are 1000 times worse off than me. I guess I am just venting, so thank you for listening.

Yours GG

Follow us on Facebook

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**

Marketplace

Over the last three years we have been updating our range of patient information under the Information Standard scheme. Our commitment to the scheme continues.

We have now completed the update of our whole range under the scheme, and have begun the review procedure again, which is an important part of the scheme. We decided at the outset that our material reviews should be every two years after publication. This, we believe, gives confidence the material is still relevant and up-to-date.

One of our core leaflets, ***What is Psoriatic Arthritis?***, was subject to a two-year review recently by Dr William Tillett, research registrar at the Royal National Hospital for Rheumatic Diseases in Bath. Professor Neil McHugh, consultant rheumatologist also at Bath, wrote the original text. We are grateful to both Dr Tillett and Professor McHugh for their support.

Emollients and Psoriasis has always been one our most popular leaflets. Jill Peters, dermatology nurse practitioner and lead for intermediate dermatology services from Suffolk Community Healthcare Serco Ipswich UK and The Ipswich Hospital NHS Trust, thoroughly reviewed the material with additional updated evidence-based references. The use of references to back up statements made in healthcare information is a key part of being a member of the Information Standard scheme.

Another of our core leaflets, ***What is Psoriasis?***, has also been the subject of a thorough review. The latest review was carried out by Dr Ruth Lamb, clinical fellow in medical dermatology at St John's Institute of Dermatology in London. Although the changes may not be obvious to the lay reader, the updated reference searches and new source reference material give us confidence that we are producing the best possible material we can.

Along with the clinical expert input, part of the process includes the need for users of the material as well to have input. We are continually grateful to our lay review group, who provide valuable feedback and input into the material. If you would like to become a reviewer, see the notice about how to get involved on page 7.

Visit the PAPAA shop

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.