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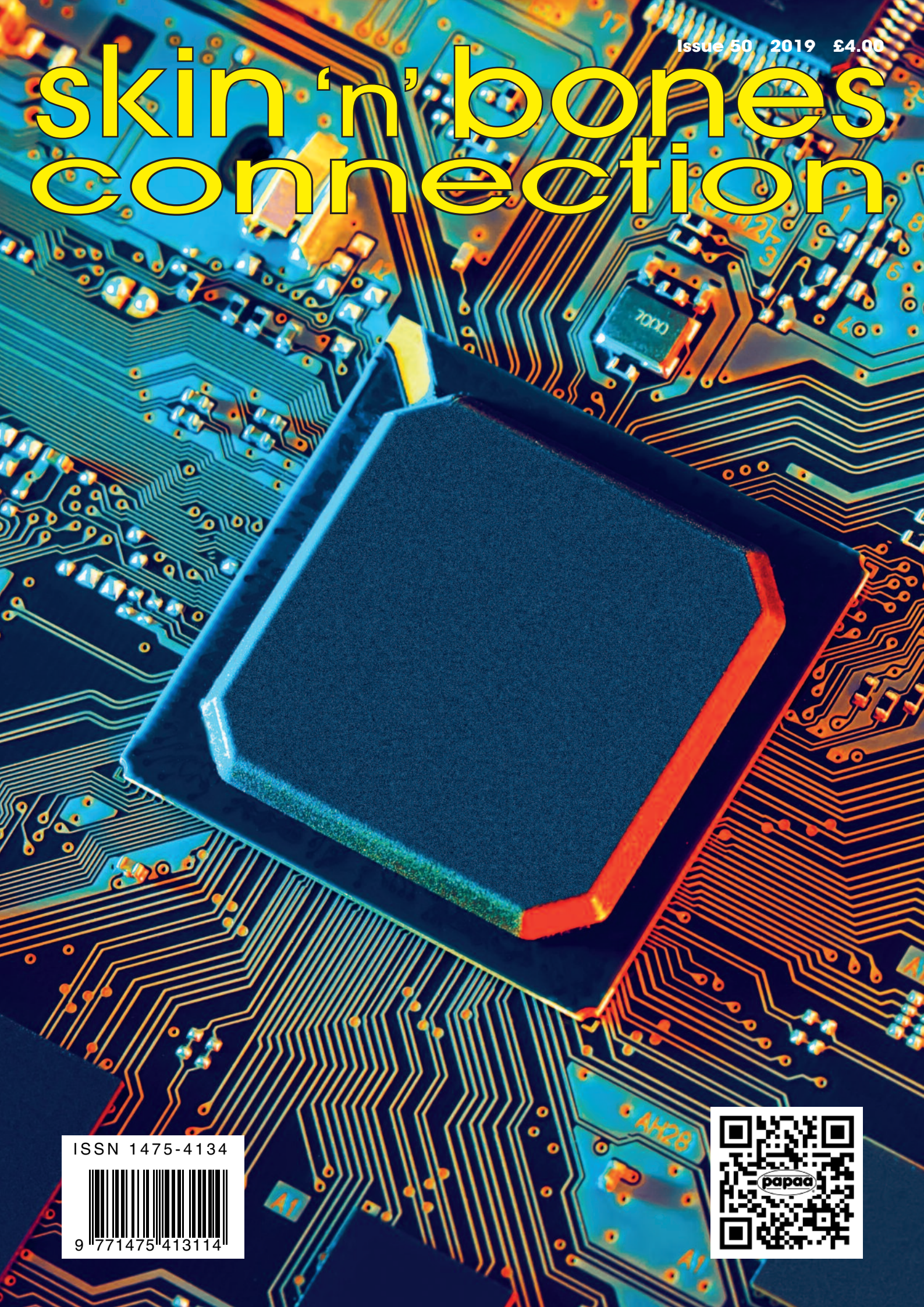
skin 'n' bones connection



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50 EDITION

papaa

Dear Reader

Since the first issue of Skin 'n' Bones Connection, published in 1993, the role of this journal has been to provide a mixture of diverse and informative articles for anyone interested in psoriasis and psoriatic arthritis.

The delivery of information may have changed (see page 3-4) to be accessible digitally, it still requires the content to be engaging and useful.

Since that first issue to this 50th edition, the themes that have emerged during that period have been consistent, including issues around diet (pages 5-9), psychological impact of psoriasis (pages 12 and 15), other peoples' experiences (page 10) and treatments (page 19).

You will also note in the article on page 4 that if you are a subscriber to this journal, you can read and download this and back issues via the subscribers' area on our new updated website.

Thank you for your continued support.

Managing editor

IN MEMORY

Dr Anthony (Tony) White
1936 - 2019

It is with sadness that we report the recent death of Dr Anthony (Tony) White; he was a long-time supporter, mentor, adviser, former trustee and most importantly friend of this organisation. He spent many hours responding to questions and queries from people who contacted us. He also provided many articles and reviewed our material regularly.

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.

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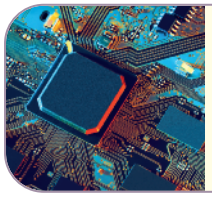

COVER PHOTO:

Electronic circuit board close up. By Raigvi

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It is hard to imagine a world when computers did not play a part in our modern lives. The internet is equally such a part of our lives. Keeping up with the changing methods of viewing content can be a challenge. The need to refresh that content to meet the changes in user habits is becoming very important and fast paced.

Tim Berners-Lee

When Tim Berners-Lee, on 6th August 1991, made the very first live web page, dedicated to information on the World Wide Web project, it must have been difficult to predict its outcome.

This was a time when it was still seen as a novelty activity for some. Even well-established organisations didn't take to an internet presence immediately, although the BBC did launch its first site on 11th May 1994, just before the newly formed Amazon on 5th July 1994, with eBay starting on 3rd September 1995. All three sites are globally recognised and dominate their sectors today.

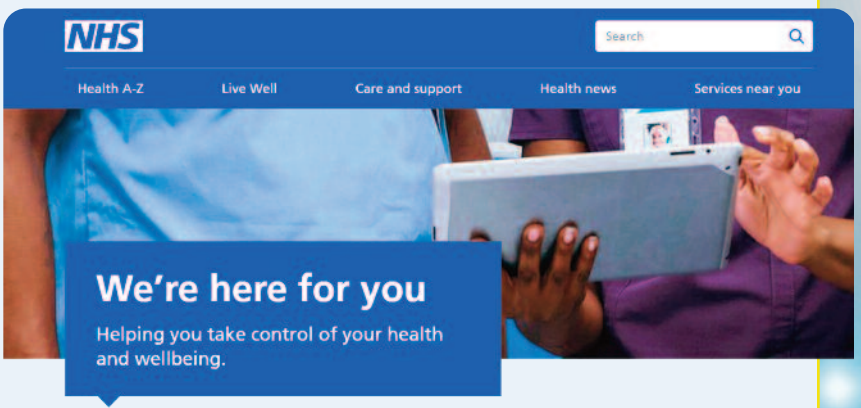
For health-related information the story is probably a little different; for many there is perhaps not a clear dominating source, although 'Dr Google' appears to be an unpredictable starting point. The Google search engine launched on 4th September 1998 and has become an overriding way people access information.

NHS Choices didn't launch until 20th June 2007 and, before it became part of the main NHS site, was a recognised brand and source of useful information. PAPAA (under PAA) as an organisation was an earlier adopter of electronic information via our first dedicated website in 1996.

Since our first presence, we have continually refreshed our sites based on changing need and user feedback.

Today, part of that changing need is to be able to access websites via a mobile device, particularly after the introduction of the Apple iPhone in 2007. Faster speed via 3G, 4G and soon 5G services, plus widespread WiFi and high-speed broadband, makes a pocket computer the 'go-to' source for information, including all that is health-related.

It is therefore vital to make sure that when someone needs accurate information and is searching via a mobile device and desktop PC, what they see is appropriate, accurate, unbiased, evidence-based and, most importantly, useful and easy to understand information.



Need to adapt

We have refreshed our online resources a number of times in the last 20-plus years to meet all those changes, and are now pleased to present our latest version.

Creating a new site has been a mammoth task. We had four separate sites running, the main website (www.papaa.org), the shop (www.psoriasis-shop.org), eTIPs, (www.etips.org.uk) and Psoriasis in Practice (www.psoriasisinpractice.org). These four sites have been brought together, to make it easier to manage and to provide a better user experience, particularly via mobile devices. Our new site is completely responsive and adaptive to different screens and devices. Data is delivered securely and the privacy of users is maintained to a high standard, fully compliant with the newly introduced EU General Data Protection Regulation (GDPR).

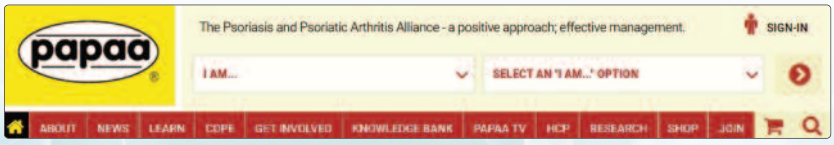
What's new?

To provide a new user experience, we surveyed people with psoriasis and psoriatic arthritis and found out what they wanted from a site and used that user intelligence as part of a discovery process that identified the type of visitor and what they needed to know and read about.

The pages and navigation process has been designed to link useful pieces of information together and along with a site search and quick entry 'I am' menu to guide users to the most relevant information.

The main sections have all the initial information that both newly diagnosed and people with a long established condition will need to know. We have also added a section called the Knowledge Bank, a comprehensive collection of enhanced information, images, educational support programmes and other content, which can also be searched with key words and category types. All this is available free via a simple login process.

A new shop section, easily accessible and with the 'about me' profile page, registered users can control their data and have easy access to the restricted enhanced full content.



Subscribers to this journal and PAPAA can now access it electronically, along with all available back issues via the subscribers' area*.

Healthcare providers also have a secure area to access a CPD-accredited training programme and dedicated news alerts. An online blog will also be available to stimulate conversation and comment on relevant topics related to psoriasis and psoriatic arthritis.

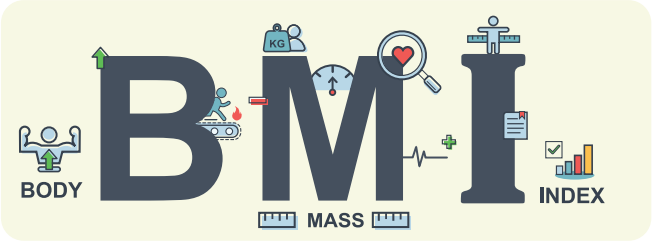
What's next?

The site is going to be continually updated and new sections will be added over time; these will include a public blog and enhanced self-help guides. We will also be expanding our awareness activity and will be making available supporters packs and promotional items. If you have any suggestions related to awareness and items that may assist, please let us know.

***To access the subscribers' area on www.papaa.org please contact us via the methods on page 2 and we'll either provide your unique access, or help you to create your own personal online account.**

There is no longer any doubt that being overweight is an important risk factor for psoriasis and psoriatic arthritis. A recent study – with data from 753,421 individuals – showed a strong, direct correlation between Body Mass Index (BMI) and the risk of psoriasis. In fact, for a 1 unit increase in BMI, there was a 9% increase in risk for psoriasis.

At the same time, there is ample scientific evidence to suggest that a reducing diet – especially if you are overweight – is likely to lead to substantial improvements in the severity of your psoriasis and psoriatic arthritis. This has been discussed in detail in a previous article, available on the PAPAA website: www.papaa.org/news/the-headlines/overweight-and-psoriasis/



But the question we are often asked is whether there is a specific reducing diet (e.g. Atkins, Paleo, South Beach, Alkaline Diet etc) which can be shown to be more effective than others for those with psoriasis and/or arthritis.

Of course, there are literally hundreds of articles and websites on the internet which make claims about this, including many seemingly convincing personal stories. However, some of the claims are not only misleading, but clearly bogus and potentially harmful. The only way to judge is by looking at the scientific evidence – and therein lies the problem.

So far as I am aware, there are no studies which have compared various diets in terms of their effect on psoriasis. The most recent and comprehensive review of its kind (Cochrane Review), which included all the relevant evidence, makes no mention whatever of specific diets in comparison with others. This conspicuous lack of evidence represents an important knowledge gap, which makes it difficult for doctors and patients to discuss.

Nevertheless, two other recently published reports offer some interesting and helpful insights.

Reported dietary behaviours in patients with psoriasis

In the first study of its kind, the National Psoriasis Foundation (NPF) in the US carried out a questionnaire survey of the dietary habits, preferences and perceptions of 1206 patients with psoriasis and what effect these habits had on the severity of their skin disease.

The researchers achieved a response rate of 60%, which is good enough to allow some meaningful conclusions to be drawn. The average age of the sample was 50.4 years and 73% of the survey participants were female. Here are some of the highlights from their findings:

- Compared to an age and sex-matched control group, psoriasis patients consumed significantly less sugar, wholegrain fibre, dairy and calcium, whilst consuming more fruits, vegetables and legumes
- 86% reported using dietary modification and the percentage reporting skin improvement was greatest after reducing alcohol (53.8%), gluten (53.4%), nightshades (52.1%)* and after adding fish oil/omega-3 (44.6%), vegetables (42.5%) and oral vitamin D (41%)
- Specific diets with the most patients reporting a favourable skin response were Pagano (72.2%), vegan (70%), Paleolithic (68.9%), gluten-free (52.9%), low carbohydrate-high protein diet (51.7%), Mediterranean diet (48.4%) and vegetarian diet (40.4%).

**nightshade vegetables belong to the family of plants with the Latin name Solanaceae, examples of which are potatoes, tomatoes, peppers and eggplants.*

It's very important to note that these observations do not represent scientific evidence of efficacy. This is simply a report of what people with psoriasis do

and is not a direct comparison of any of the diets.

There are, of course, many other diets such as the South Beach, Ornish, Dukan, Alkaline and Atkins diets etc – including one or two absurdities like the blood group diet. But as with those mentioned in the survey above, there is currently no scientific evidence to recommend any one of these specifically for people with psoriasis.

The available evidence suggests that the key factor in dietary modification is reduced calorie intake and weight loss – and it is the weight loss which appears to have the beneficial effects on psoriatic skin lesions by reducing inflammation. Thus, to the extent that any diet produces weight loss, it will probably have a beneficial effect on psoriasis.

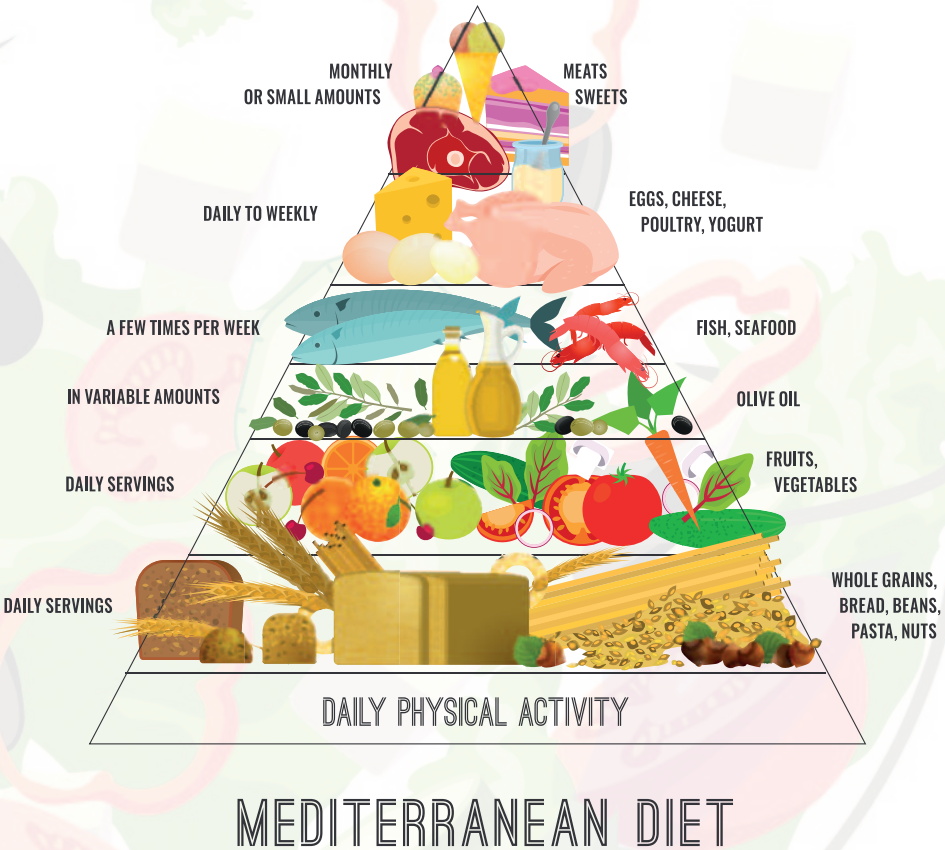
However, that is not quite the end of the story!

The Mediterranean diet

A recent report shows that a Mediterranean diet may be the best choice for patients with psoriasis.

The NutriNet-Santé program is an ongoing, observational, web-based questionnaire cohort study launched in France in May 2009. The present study was performed within the framework of the NutriNet-Santé program, with data collected and analysed between April 2017 and June 2017. Data on dietary intake (including alcohol) were gathered during the first 2 years of participation to calculate the MEDI-LITE score (ranging from 0 for no adherence to 18 for maximum adherence).

People with psoriasis were identified via a validated online self-completed questionnaire and then categorised by disease severity: severe psoriasis, non-severe psoriasis, and psoriasis-free. Of the 35,735 respondents, 3557 (10%) individuals reported having psoriasis, which was severe in 878 (24.7%) of cases. The results were analysed to estimate the risk of having severe psoriasis or non-severe psoriasis compared with being psoriasis-free.



MEDITERRANEAN DIET

The results demonstrated that adhering to the main elements of the Mediterranean diet was associated with a significantly lower risk of severe psoriasis. Accordingly, the authors suggest that the Mediterranean diet should be integrated into the routine management of patients with psoriasis.

Again, of course, this is not a comparison of the Mediterranean diet with any of the other diets mentioned previously. Nor is it a properly conducted trial to establish efficacy (there is no control group included). It simply shows that the structure of the Mediterranean diet may be helpful for patients with psoriasis. Remember too, that the Mediterranean diet is a healthy choice for almost everyone, not just those with psoriasis or arthritis.

Conclusions

What conclusions can we draw from the available evidence? I think there are four:

1. No scientific study has yet compared the impact of specific diets – South Beach, Ornish, Palaeolithic, Atkins etc – in terms of their impact on psoriasis.

2. It follows that – in terms of psoriasis – there is no basis on which to recommend one diet over another

3. The key factor appears to be weight loss and it is this which reduces inflammation and leads to improvements in skin lesions

4. A Mediterranean diet has been shown to confer important health gains for the wider population, whilst also having a significant beneficial impact on psoriasis and arthritis

So, whether you are overweight or not, we suggest the Mediterranean diet as the most suitable dietary option. If you wish to lose weight, you simply reduce the total calorie intake so that you lose around 1-2lbs per week. If you already have a healthy body weight, you can still follow the Mediterranean diet for general health.

We have covered the Mediterranean diet previously and you can view or download the leaflet on the PAPAA website: **https://www.papaa.org/learn-about-psoriasis-and-psoriatic-arthritis/further-information/**

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Let's talk gluten!

Over the past decade or so, a gluten-free diet has been promoted by celebrities for weight loss and improved health, as well as by athletes claiming improved performance. As anyone who uses the internet as a source of information will know, it has also been extensively promoted as a way of improving – or even eliminating – psoriasis. But is there any real evidence for this? Before we try to answer this question, it may be helpful to say something about gluten sensitivity and why it's important for psoriasis sufferers.

Gluten, coeliac disease and wheat allergy

Gluten is a general name for the proteins found in wheat, barley and rye.

Coeliac disease, which affects around 1% of the population, is a well-defined illness, where the body's immune system attacks itself when gluten is eaten. This causes damage to the lining of the gut and means that the body cannot properly absorb nutrients from food. Coeliac disease is not a food allergy or intolerance; like psoriasis it is an autoimmune disease.

Non-coeliac gluten sensitivity (NCGS) is when symptoms similar to coeliac disease are experienced, but it is not clear how the immune system might be involved because no antibodies are produced, and there does not appear to be damage to the gut lining. Despite claims that up to 6% of the population has NCGS, the true prevalence is unknown.

Wheat allergy, on the other hand, is a reaction to proteins found in wheat, triggered by the immune system and usually occurs within seconds or minutes of eating. Genuine wheat allergy is very uncommon and probably affects less than 1% or the population.

Gluten sensitivity – fashion fad or fact?

Research shows that up to 20% of people think they suffer from food allergy or food intolerance. However, scientific evidence suggests that the real prevalence of food allergy and intolerance is very much lower than this.

To see how many people are genuinely gluten-sensitive, researchers in Italy enrolled 392 patients who believed they had gluten sensitivity into a controlled clinical trial. All the study participants were asked to eat gluten-containing foods for two months before their initial diagnostic tests to establish whether they had coeliac disease, NCGS or a wheat allergy. All patients then followed a gluten-free diet for six months. After the six-month period, those who did not test positive for coeliac or wheat allergies were instructed to re-introduce gluten-containing foods and they were monitored for symptoms associated with gluten sensitivity.

What were the findings?

Of the 392 patients, 26 (6.63%) tested positive for coeliac disease, two (0.51%) for wheat allergy and 27 (0.88%) were found to suffer from non-coeliac gluten sensitivity. In other words, 86% of those who believed they were sensitive to gluten could tolerate it perfectly well. This study clearly shows that self-diagnosed symptoms are a very poor guide to the presence of true gluten sensitivity. Why is this important for psoriasis sufferers?

Psoriasis and coeliac disease

Psoriasis is a chronic autoimmune condition and it is well known that patients with psoriasis are more likely to have other autoimmune diseases, including diseases of the gut such as Crohn's disease, ulcerative colitis, and coeliac disease. In fact,

patients with psoriasis have around a threefold increased risk for coeliac disease. The converse is also true; patients with a diagnosis of coeliac disease have a significantly increased (75%) risk of developing psoriasis. So, it's clear that there is a very close link between the two conditions.

Given this association, it follows that if you have psoriasis and develop symptoms such as bloating, cramping, diarrhoea and lethargy you should discuss this with your doctor. If tests then show you have a gluten sensitivity, there is good evidence that you may benefit from a gluten-free diet. A 2001 study demonstrated the impact of a gluten-free diet in 33 people with psoriasis who had raised antibodies to gluten and who were therefore likely to have either coeliac disease or NCGS. After three months on a gluten-free diet, 73% of study participants saw a significant improvement in their condition, compared with none of the people without gluten antibodies. Whilst this is a small trial, it does suggest significant benefit.

Psoriasis and a gluten-free diet

But if you have psoriasis and you have no bowel symptoms of any kind, should you still consider a gluten-free diet? The short answer is no. There is no good evidence that in the absence of symptoms suggestive of gluten sensitivity, a gluten-free diet will be of any benefit. More importantly, it may well be harmful.

Whole wheat is a great source of fibre, antioxidants and multiple nutrients, which means a gluten-free diet eliminates an entire category of healthful foods. Moreover, a gluten-free diet is often higher in calories, fat, salt and sugar because of the need to enhance flavour and texture to make up for the absence of gluten. This may lead to weight gain with all the attendant health risks.

Recommendations

- If you have psoriasis and you develop bowel symptoms such as bloating, diarrhoea, and lethargy, you should discuss these symptoms with your doctor.

- If you have psoriasis and have been diagnosed by your doctor (not self-diagnosis) as having gluten sensitivity, then following a gluten-free diet will probably improve your bowel symptoms and may also help your psoriasis.
- If you have psoriasis but have no bowel symptoms suggestive of gluten-sensitivity, you should not embark on a gluten-free diet.
- A Mediterranean diet is the best choice for the vast majority of those with psoriasis.

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We have a continual process of data gathering, which we do via all the processes of joining PAPAA. This largely unpublished data gives us a view of who we represent, therefore allowing us to tailor our material to suit.

We have also been surveying people with psoriasis and psoriatic arthritis since our early origins for more than 20 years. Those rich qualitative data provide us with a real-life view and also helps us to put forward a collective consensus of what it is really like to live with psoriasis and psoriatic arthritis.

You can be part of that process and also know that whatever you say will be confidential and anonymous. Taking part is up to you, but it does help us to improve our services for you.

We have now developed the PAPAA survey, which aims to build upon and add to those previous data results.

So, what have you told us?

Well, we know that people live in all parts of the UK, which is our area of operation, we therefore input and monitor closely what happens in England, Scotland, Northern Ireland and Wales. We have found that there are universal issues that affect everyone.

Working life

The impact of both psoriasis and psoriatic arthritis are profound, but many people carry on regardless.

"I work full-time as I cannot afford to go part-time, struggle daily with work, no hobbies now and very little social life, find it difficult to communicate with others and focus after work. Days off spent catching up with sleep etc."

"I don't take time off work at all but I can experience extreme tiredness and pain in joints, but fight through as don't want it used against me in current financial climate.

Relationships

People also reported the difficulty they have with their relationships.

"Husband struggles to understand what it's like for me when I have flare-ups."

"I am not my happy self when it's bad and it massively affects all my relationships. I am depressed and push people away as I don't like them to see me like this."

"Fatigue means I don't have any enthusiasm and as partners can't see the illness they don't always understand."

Other conditions

We find that often people have a number of other conditions that also plays part in their daily lives, including: anxiety, asthma, atrial fibrillation, bradycardia, chronic fatigue syndrome, depression, diabetes, migraines, endometriosis, GERD, Graves' disease, high blood pressure, hypothyroidism IBD, IBS, migraine, osteoarthritis, Raynaud's syndrome, Sjögren's syndrome and oesophageal reflux to name just a few.

People report a huge problem of juggling appointments and keeping up with treatments, which causes stress and further anxiety, both of which are unhelpful for those with psoriasis.

Social life

The way psoriasis and psoriatic arthritis and all aspects of peoples' lives is reflected in how social lives are affected.

"I don't have the confidence to go out, I panic and I'm tired and too emotional to interact with people. I get brain fog a lot and I find it very

embarrassing, I just feel stupid, it's safer being alone."

"I barely have a social life. My work and family life take all my energy, I don't have much to give after that."

"I don't like going out unless I really have to."

On reflection

In free text comments we receive a number of responses that not only show frustration with the conditions but also the care that is offered.

"Doctors look at symptoms individually instead of putting all the pieces together. I am suffering just on naproxen and I'm losing function in hands. I have decided to retire early from my job because I can no longer cope."

"I remember a school nurse telling me my immune system was really good. My psoriasis was misdiagnosed as eczema. I'd really like early diagnosis of the illness and perhaps something preventing the progression to psoriatic arthritis."

"Psoriasis took away a carefree youth. Constantly requiring attention. Never missing a day with creams etc, otherwise back to square one. Bullying. The arthritis took away my career. My job as a veterinary nurse, which I loved. And it looks like doing so again. I am working minimal hours. In jobs I don't like to get by. It's only because my husband is working that I can do this. I do not receive any financial help. I have not had any children because I don't want to pass this on. Sorry if this sounds harsh but it's how I feel."

The future

We also asked where research should be concentrated; predominantly, the call is for a cure, but other comments included wanting to see better diagnosis, management and pain control.

There was a call for honesty when given a diagnosis and people wanted to see investigations to see if diet and the environment make any difference to developing the conditions and their long-term outcomes.

These few quotes and comments are just a small sample of the thousands of survey results and data we hold, but reflect constant themes. We are extremely grateful to all those who complete our surveys, and we do use those results and comments to influence our work.

We use the quotes in our submissions to National Institute for Health and Care Excellence (NICE) and the Scottish Medicine Consortium (SMC), to raise awareness for new therapies and to reflect what real people need to overcome, as expressed in their own words.

The PAPAA survey is an ongoing project; the more data we gather the greater the impact, as it will reinforce what we already have learnt, and what work we need to do next for your benefit.

If you would like to complete our survey you can online at www.papaa.org/get-involved/the-papaa-survey/

Nine out of ten dermatologists agree that not enough importance is placed on the psychological effects resulting from skin conditions, according to a recent survey undertaken by the British Skin Foundation.

Dr Andrew Thompson*, reader in clinical psychology and practitioner clinical psychologist, University of Sheffield and Sheffield Health and Social Care NHS Foundation Trust, comments,

"This survey demonstrates that dermatologists recognise some patients experience psychological distress associated with their skin condition. It also indicates that whilst dermatology is making great advances in treating the medical aspects of skin disease, perhaps not enough is being done to address the accompanying psychological effects. Clearly, we need more research that looks to develop effective psychological treatments or support for both children and adults living with skin conditions."

Additionally, 87% of dermatologists agree that people with skin conditions in the UK do not have sufficient access to psychological support.

Dr Alexandra Mizara, consultant psychologist and British Skin Foundation spokesperson, says,

"It's not surprising that the majority of dermatologists report that the psychological care of skin patients is poor and understated. Skin patients often experience that they are not listened to or understood by their healthcare providers. The occasions that they are listened to and understood are rare and extraordinary. If you suffer with a skin condition that has impacted adversely on your life, talk openly about it to your doctor and ask them to refer you to see a psychologist."

Dr Thompson's tips for seeking psychological help for your skin condition: Although there are few specialist psychological services for people with skin conditions, it's definitely worth checking your local area as some do exist. Talk to your GP, dermatologist or dermatology nurse, who will be able help. Even if there is no skin disease-specific wellbeing service in your area, 'talking based therapies' are readily available and can greatly reduce feelings of low mood or anxiety. Look online for charities, support groups, online forums and specific self-help websites.

*You may be interested to know that PAPAA funded research by Dr Andrew Thompson and colleagues at the University of Sheffield, entitled *Examining the association between parental mindfulness in parental and child wellbeing in childhood psoriasis: Should we test mindful parenting as an intervention.* We will report the findings in a future edition of this journal.

To see what else we have funded, visit www.papaa.org/research/current-research/

Source:
www.britishskinfoundation.org.uk

In the UK we often accept that access to healthcare, although sometimes difficult, will eventually provide solutions or at least there will be information to help make a choice. This is not always the case elsewhere in the world. But there are many people and organisations who are trying to support and provide what is seen as a 'given' in the Western world.

HIFA (Healthcare Information For All) is a global social movement to improve the availability and use of healthcare information in low- and middle-income countries. It has more than 19,000 members (health workers, librarians, publishers, researchers, policymakers...) committed to the progressive realisation of a world where every person has access to the healthcare information.

The HIFA Vision and Strategy

The HIFA Vision: "Every person and every health worker will have access to the healthcare information they need to protect their own health and the health of others."

The HIFA Strategy accelerates progress towards the HIFA Vision by promoting communication, understanding and advocacy among all stakeholders in the production, exchange and use of healthcare information, thereby helping to strengthen the Global Healthcare Information System.

For more information: www.hifa.org

Another group that is working globally is The International Alliance of Patients' Organizations (IAPO), which is a unique global alliance representing patients of all nations across all disease areas.

Patient-centred healthcare

IAPO works to promote patient-centred healthcare around the world. It has 276 member organisations from 71 countries representing 50 disease areas.

The vision is to see patients placed at the centre of healthcare, with a mission to help build patient-centred healthcare worldwide.

IAPO work with their members to get patients' voices heard by everyone involved in healthcare.

Policy and advocacy

IAPO forms clear positions on relevant healthcare policies and processes, then advocates for change with a strong patients' voice at international, regional and national level.

Capacity building

It provides resources and training to members, based on consultation with them about their needs, to help them thrive in their own fields.

IAPO also supports members to work with others to further the agenda of patient-centred healthcare. This includes organising events, such as regular regional meetings and a biennial Global Patients' Congress, where organisations can share best practice, gain insights, and speak out on behalf of patients.

To learn more visit www.iapo.org.uk

The Journal of the European Academy of Dermatology and Venereology recently published an article by C Grodner et al called 'Tattoo complications in treated and non–treated psoriatic patients', which reported the results of the group's research study.

The aim of the study was to evaluate the frequency of tattoo complications in patients with psoriasis and determine whether the occurrence of complications was associated with psoriasis status and treatments received at the time of tattooing.

Tattooing has become so common in recent years with the study paper reporting that 10-20% of the Western population now has a tattoo.

The recommendation for people with psoriasis is: *avoid having a tattoo if the disease is active and the individual is receiving immunosuppressive treatments*. Although further to this scientific data supporting these recommendations are lacking, with dermatologists often reluctant to advocate tattooing in psoriasis patients at all. The Koebner phenomenon may also contribute to the decision; this is when psoriasis starts after injury or damage to an area of skin which is previously unaffected by psoriasis.

The researchers studied 2053 people with psoriasis, of which around 20% had a tattoo. In the non-tattooed group 15% wanted a tattoo but had resisted because of their psoriasis.

The conclusion of the researchers was:

"The rate of tattoo complications in psoriasis patients was low. Although the risk of complications was highest amongst patients with psoriasis requiring treatment at the time of tattooing, all the complications observed were benign."

If you are contemplating having a tattoo and have psoriasis, then it is probably still a good idea to talk to your healthcare provider, and of course make sure you seek out a reputable tattooist.

Source reference:

Tattoo complications in treated and non–treated psoriatic patients

- C. Grodner A. Beauchet A.–C. Fougerousse N. Quiles–Tsimaratos J.–L. Perrot H. Barthelemy J. Parier F. Maccari N. Beneton D. Bouilly–Auvray … See all authors

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https://doi.org/10.1111/jdv.15975

In research conducted at Durham University, a study was undertaken of adult participants with a visible difference and their experience of working (or seeking work) in the UK.

The aim of the research was to:

- understand better the experiences of people with a visible difference in relation to the job market and workplace in the UK
- analyse whether the law goes far enough to promote equality for people with a visible difference
- suggest how, if needed, the equality rights of people with a visible difference can be better upheld.

Summary of the results

Seventeen interviews with volunteer participants were included within the project analysis, and five key themes were identified.

Theme 1: Me and visible difference – a complex equation of how I feel

Almost everyone expressed feelings of low confidence and / or self-consciousness related to visible difference at different times of their life. But there are various factors which some people believed impacted on the way they felt - such as fluctuations in the severity of their condition, self-acceptance, gender, age and level of job experience. There was not one unified picture of 'what helps' and 'what hinders'. What the accounts did suggest, though, is that visible difference cannot be understood as an isolated, sole determinant of people's experiences; the importance of other aspects of life – such as friends and family, pride in one's job and in one's own skills, or a role helping others – are also integral to the experiences recounted.

Theme 2: Me, you and visible difference – balancing coping and explaining against privacy

This theme relates to how people cope with having a visible difference in their daily lives. People talked about a variety of proactive and reactive coping strategies – such as explaining, hiding one's difference or insecurity, and taking support from relevant charities and others in a similar position. Sometimes coping strategies seemed to focus more on self-protection - such as applying for manageable roles. While explaining is a common strategy, it wasn't always simple; people often factor in various different things when deciding whether to 'explain' their condition to others. Some people seemed to feel a conflict between a desire to explain and a resentment about having to.

Theme 3: Me, visible difference and work – my health needs and my job in conflict

This theme relates to the tension between what people felt was good for their health, and what they felt was required for their jobs. People often felt conflicted between the two, or forced to prioritise one over the other.

Theme 4: Me, visible difference and society – feeling that I fall between the cracks

Many participants seemed to feel that their condition made them fall between the cracks. Legally, not everyone was aware of the law, and people often did not self-identify as disabled. This created a dilemma for many people on whether to disclose a condition during recruitment. Some wanted employers to have a more flexible approach to health, rather than a tick box 'disabled or not' approach which exacerbates this dilemma.

In health terms, the feeling of falling between the cracks related to both a lack of understanding about some conditions and, for some, a need to battle for treatment because their condition is seen as 'cosmetic' or given low priority for care.

Socially, many people had, at some stage in their lives, felt that visible difference prevented them from fitting in; some felt overlooked, harassed or targeted in the workplace. A feeling of their condition being misunderstood or underestimated by colleagues was also commonly cited. However, there were also very many positive stories of inclusion at work; people with good friends and supportive colleagues, many of whom enjoy their job.

Theme 5: Me, visible difference and rights – moral duties to be wary of

In generic terms, rights were seen almost as a moral duty: something that should be enforced if needed, to stand up for myself or to prevent the same thing from happening to others. However, people were wary about the reality of enforcing rights – both in terms of challenging discrimination, or having reasonable adjustments made (if appropriate). There was also a strong sense in some interviews that rights are only positive if handled in a certain way - there is the potential for them to become 'wrongs' if dealt with inappropriately by others.

What happens now with the research?

The interviews are part of a wider research project and provide an important contribution to evaluating whether the law is working properly. The research suggests that there may be some problems with the way the law works, and that some legal changes would be beneficial, including amended definitions and increased guidance. The researcher hopes that these findings will open a debate about these important issues.

Let PAPAA know your view

Why not tell us how you feel about your psoriasis and or psoriatic arthritis? Complete our online survey and/or share your story.

Survey: www.papaa.org/get-involved/the-papaa-survey/

Your story: www.papaa.org/coping/share-your-personal-journey

Researcher report by:
Hannah Saunders, FHEA

What is a visible difference?

The charity Changing Faces which supports people with visible differences says:

". . . We describe this as a scar, mark or condition affecting appearance.

For example:

- A condition that changes the shape, size, feel or look of the face or body, or how it functions
- A birthmark, an area of skin or a part of the body that varies in appearance, texture or colour, or it is different to other parts of the face or body…"

"When appropriate, Changing Faces also uses the term 'disfigurement', usually in a more legal or professional medical setting. 'Disfigurement' is used in the UK's Equality Act 2010 to protect people from discrimination. However, we recognise that 'disfigurement' is not a term preferred by many people who are affected. The words you use are up to you and depend on what you feel comfortable with."

What does the law say?

Under Equality Act 2010, the types of discrimination ('protected characteristics') are listed and it is against the law to discriminate against anyone because of:

- age
- ender reassignment
- being married or in a civil partnership
- being pregnant or on maternity leave
- disability
- race including colour, nationality, ethnic or national origin
- religion or belief
- sex
- sexual orientation

These are called 'protected characteristics'.

You're protected from discrimination:

- at work
- in education
- as a consumer
- when using public services
- when buying or renting property
- as a member or guest of a private club or association

You're legally protected from discrimination by the Equality Act 2010.

You're also protected from discrimination if:

- you're associated with someone who has a protected characteristic, for example a family member or friend
- you've complained about discrimination or supported someone else's claim
- Action against discrimination
- You can do something voluntarily to help people with a protected characteristic. This is called 'positive action'.

References:

https://www.changingfaces.org.uk/adviceandsupport/self-help/adults/visible-difference

https://www.gov.uk/guidance/equality-act-2010-guidance

The MHRA (Medicines and Healthcare products Regulatory Agency) has issued alerts to healthcare professionals and retailers, as Perrigo Company plc is recalling all unexpired stock of certain batches of ranitidine medicines used to treat conditions such as heartburn and stomach ulcers. This alert is relevant to people with psoriatic arthritis as ranitidine is often prescribed alongside non-steroidal anti-inflammatory drugs (NSAIDs) to protect the stomach lining.

The alert has been issued to healthcare professionals to recall one prescription-only product; Ranitidine 150mg/10ml Oral Solution produced by the company.

A second alert has been issued for medicines available for both over-the-counter and on general sale under the branding of Zantac, Galpharm, Boots, Kirkland, and Morrisons.

In both alerts, healthcare professionals and retailers have been told to stop supplying the products immediately. All remaining stock should be quarantined and returned without delay to the supplier. Patients should not stop taking their medication, and a treatment review is not necessary until the next routine appointment.

The Perrigo recall is a precautionary measure due to possible contamination of the active substance in Zantac, ranitidine, with an impurity called NDMA (N-nitrosodimethylamine) which has been identified as a risk factor in the development of certain cancers.

The MHRA is actively involved with the European Medicines Agency and other medicines regulators to determine the impact of what is an ongoing, global issue. On 8 October and 17 October, MHRA drug alerts were also issued regarding the withdrawal of other, prescription-only ranitidine medicines.

An investigation into other potentially impacted products is continuing and further updates will be provided as the investigation progresses. Other ranitidine products have been quarantined, and the Department of Health and Social Care issued an alert on 15 October regarding shortages of the medicine and advice to healthcare professionals on alternative treatments. The DHSC has also added ranitidine to a list of medicines subject to export restrictions.

Dr Andrew Gray, MHRA deputy director of inspections, enforcement & standards, comments:

''Whilst this action is precautionary, the MHRA takes patient safety very seriously.

''Patients should keep taking their current medicines but should speak to their doctor or pharmacist if they are concerned and should seek their doctor's advice before stopping any prescribed medicines.

''We have asked companies to quarantine batches of potentially affected medicines whilst we investigate and we will take action as necessary, including product recalls where appropriate.

''We have also requested risk assessments from the relevant companies which will include the testing of potentially affected batches.

''Currently, there is no evidence that medicines containing nitrosamines have caused any harm to patients, but the agency is closely monitoring the situation, and working with other regulatory agencies around the world.''

About MHRA

Medicines and Healthcare products Regulatory Agency is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. The work of the MHRA is underpinned by robust and fact-based judgements to ensure that the benefits justify any risks.

Source:
Media release 25 October 2019

Yellow card

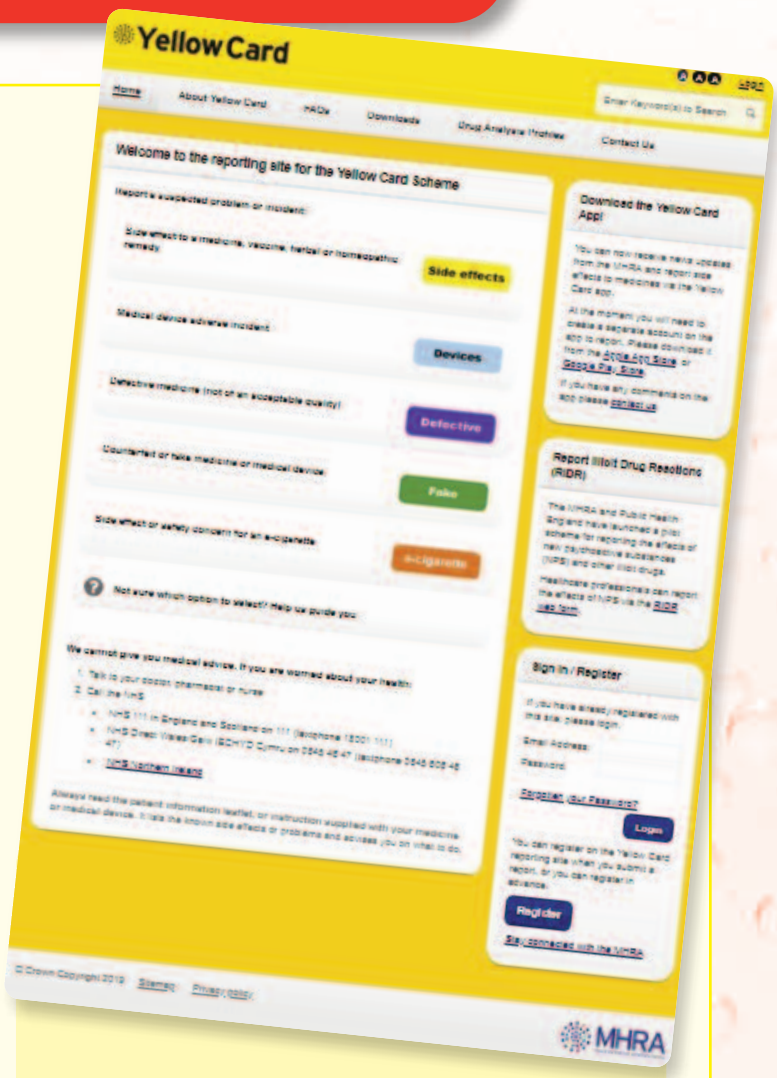
In this instance the warning and recall has been instigated by the manufacturer, with the MHRA taking up the issue and investigating.

You can also be a part of the process by reporting anything that you feel is untoward about either medicine you are taking or have seen being advertised.

You can use The Yellow Card scheme to report a problem with a medicine or medical device the following is what you can do:

Report a suspected problem ('adverse incident') with a medicine or medical device using the Yellow Card Scheme as soon as possible, for example if:

- **a medicine causes side effects**
- **someone's injured (or almost injured) by a medical device, either because its labelling or instructions aren't clear, it's broken or has been misused**
- **a patient's treatment is interrupted because of a faulty device**
- **someone receives the wrong diagnosis because of a medical device**
- **a medicine doesn't work properly**
- **a medicine is of a poor quality**
- **you think a medicine or medical device is fake or counterfeit.**



Anyone can report a problem, it is easy and quick and the MHRA will take your report seriously. To learn more you can visit **www.gov.uk/report-problem-medicine-medical-device#before-you-start or you can go direct to https://yellowcard.mhra.gov.uk/**

You may also be interested to know that an App exists too, which can be downloaded to your smart phone. Visit your operating system App device store to get a free copy.

New treatments approved

Two new therapies have been approved recently by The National Institute for Health and Care Excellence (NICE) and the Scottish Medicine Consortium (SMC). Risankizumab (Skyrizi®) and Tildrakizumab (Ilumetri®) are both indicated for treating moderate to severe plaque psoriasis.

The treatments were approved and can be prescribed, subject to certain criteria where the psoriasis has not improved with other treatments, for example, ciclosporin, methotrexate and phototherapy, or these can't be taken.

What is risankizumab?

It is a biologic agent that is administered by self-injection; it works by binding and blocking a protein called Interleukin-23 (IL-23). IL-23 is involved in the immune system and is overactive in people with plaque psoriasis, causing the overproduction of skin, typically seen in psoriasis; binding and blocking IL-23 decreases the amount of inflammation and symptoms of plaque psoriasis.

Dosage for adults: initially 150 mg, then 150 mg after 4 weeks, then maintenance 150 mg every 12 weeks, consider discontinuation if no response after 16 weeks.(Source BNF*)

What is tildrakizumab?

Similar to risankizumab, tildrakizumab is a self-administered biologic agent designed to block interleukin-23.

Dosage for adults: initially 100 mg, then 100 mg after 4 weeks, then maintenance 100 mg every 12 weeks, consider discontinuation if no response after 28 weeks, in patients with a high disease burden, or with a body weight ≥ 90kg, a dose of 200 mg may provide greater efficacy. (Source BNF*)

*BNF (British National Formulary) publications use the following sources:

NICE
National Institute for Health and Care Excellence

Healthcare Improvement Scotland | Scottish Medicines Consortium

What is the BNF?

The BNF is a joint publication of the British Medical Association and the Royal Pharmaceutical Society. It is published under the authority of a Joint Formulary Committee which comprises representatives of the two professional bodies, the UK Health Departments, the Medicines and Healthcare products Regulatory Agency, and a national guideline producer. The BNF is accessible as a printed book or online to anyone. It is the definitive source of prescribing information used by doctors in the UK.

Useful links:
www.nice.org.uk
www.scottishmedicines.org.uk
www.bnf.org

If you would like to see what other people think about these or other treatments, go to **https://www.iwantgreatcare.org/** where you will be able to read reviews and comments.

Marketplace

Promotional material

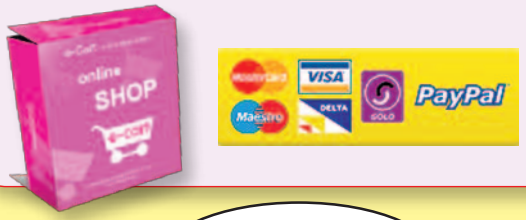
If you are thinking about supporting PAPAA or raising awareness on behalf of PAPAA about psoriasis and or psoriatic arthritis.

Why not check out some of the merchandise we have available?

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.

Join the conversations

If you have a social media presence, then why not follow us and join the conversation to see what others have to say?

The following are the links to our pages:

Facebook:	**www.facebook.com/papaa.org**
Twitter:	**@PsoriasisInfo**
Pinterest:	**www.pinterest.co.uk/psoriasisuk**
Instagram:	**www.instagram.com/the_papaa_eye**
LinkedIn:	**www.linkedin.com/company/papaa/**