Issue 55 2022 £4.00

skin 'n' bones connection

ISSN 1475-4134

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Registered office: Acre House
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Dear Reader

Welcome to issue 55 of Skin 'n' Bones Connection.

With the world emerging from the pandemic, it would be easy to hope that our health needs will revert to a pre-COVID state. Unfortunately, for many, those two years have added to their problems, not least access to care and the impact on mental health.

A dominating issue that arose during COVID for people with long-term medical conditions was whether to get a vaccination. On page 3, researchers have investigated why some people get vaccinated, whilst others do not. Interestingly, the rise in people getting tattooed shows that many psoriatics are not concerned about needles applied for body art; they may be unaware that the risks of inking are higher for people with skin conditions, as reported on page 6.

The issues around mental health and innovative interventions to manage it are explored in articles starting on pages 7 and 10. Even with these progressive ideas, there is still a need to provide conventional medicine, which patients must store safely in order to protect those around us, including our pets, as detailed on pages 17 – 19.

If you have an idea that you would like explored or included in a future issue, please let us know by using the contact details on page 2.

Managing editor

Subscription rates:
United Kingdom – £12.00 (Renewal Rate £8.00) per annum – 2 issues
Publication Dates: Summer and Winter
Contribution Copy Dates: 28th February and 31st August
Skin 'n' Bones Connection is registered as a magazine ISSN: 1475-4134

COVER PHOTO:

Communication, talk and think

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New data show treatment goals are important, but patients' and professionals' perceptions may not be aligned. Results presented at the 2022 EULAR Congress in Copenhagen show that early achievement of minimal disease activity (MDA) in psoriatic arthritis (PsA) is associated with long-term improvements in quality of life.

Although this highlights the importance of setting and achieving goals early on in the disease, further multinational data released from the UPLIFT study suggest the majority of PsA patients are not aligned with their healthcare provider on the topic of treatment goals. This emphasises the need to improve communication around treatment goals in order to optimise patient outcomes.

People with PsA experience pain and swelling in their joints and at the points where tendons and ligaments attach to the bone. MDA is a treatment target used in PsA that takes both clinical manifestations and the patient perspective into account.

Previous studies have shown that achieving MDA in the first year after diagnosis is associated with better quality of life. However, data about the long-term impact of achieving MDA within the first year have been lacking. Now, new information presented at the 2022 EULAR Congress shows that PsA patients with sustained MDA have quality of life comparable to the general population after 1, 2 and 3 years of follow-up.

However, those who did not achieve MDA in the first year after diagnosis tended to have lower quality of life compared to those with sustained MDA, and these differences persisted over time.

Overall, the research presented by Dr Selinde Snoeck Henkemans concluded: "… that failure to achieve MDA in the first year after PsA diagnosis is associated with worse quality of life outcomes that persist even despite more intensified treatment."

These insights into the significance of MDA are complemented by another study released at the Congress, looking at findings from UPLIFT, a multinational survey among adults with a diagnosis of PsA and/or psoriasis, as well as treating rheumatologists and dermatologists.

The study, presented by Professor Pascal Richette, found that rheumatologists rated disease remission or low disease activity (LDA) as the most important goals, while patients were focused on decreasing joint pain. Patients and their rheumatologists generally agreed on the top factors contributing to disease severity, treatment goals, and attributes of ideal PsA therapy. However, the majority of patients did not feel aligned with their healthcare provider on current treatment goals.

These findings suggest that development of methods to discuss treatment goals and achieve alignment in perceptions are important to improving patient outcomes.

Source:
EULAR June 2022

Perceptions about vaccinations

NIHR | Nottingham Biomedical Research Centre

Why do some people choose to be vaccinated while others do not? Researchers at the Nottingham Biomedical Research Centre have been carrying out qualitative work with patients about facilitators and barriers to vaccination and the perceptions in inflammatory conditions. The following is the lay summary of the findings:

Why did we do this study? The immune system protects the body from infection, it attacks germs and helps keep us healthy. In the UK, around one in fifty adults has a condition where the immune system is too active and mistakenly attacks parts of the body. This can cause damage to the joints, gut, skin or blood vessels. These conditions can be treated with medicines that dampen down the immune system. But this means that someone taking them has a higher chance of becoming seriously unwell if they get flu, pneumonia or COVID-19. Although the chances of this happening can be reduced with vaccines, many people on these medicines do not get vaccinated. The reasons for this are not well understood.

Our aim in this study was to find out why some people with these conditions and who take medicines that dampen their immune system choose to get vaccinated for flu, pneumonia and COVID-19, while others do not.

Who did we talk to? Between November 2021 and January 2022, we interviewed 20 people with different conditions - rheumatoid arthritis, Crohn's disease, vasculitis, lupus, ankylosing spondylitis, and psoriatic arthritis.

What did we find? We found that there are many reasons for being vaccinated or not. This varied by the type of vaccine, but not from condition to condition. The key reasons are listed here:

Reasons for being vaccinated

For all: Knowing that they had a high risk of getting seriously unwell if they caught flu, pneumonia or COVID-19. Believing that vaccines will keep them well. We found it was important to people that they could keep healthy, having been ill with their condition. Seeing that these vaccines are endorsed by charities working on behalf of these patients.

For flu and pneumonia only: Knowing that they were eligible for these vaccines. Getting a recommendation from their doctor or nurse. Getting a direct invitation to be vaccinated, by text message or letter. We found that recommendations and invitations were often given for flu, but not pneumonia. Adverts to be vaccinated for flu were also seen more often than for pneumonia.

For COVID-19 only: The focus on COVID-19 and its threat in the news, and seeing how many people were catching it. Feeling that being vaccinated would help others. The go-ahead from a doctor or nurse that the new vaccines were suitable for their condition. The mass vaccination programme, with invitations being sent to get vaccinated when required to do so and on more than one occasion. Plus, good availability of appointments. A doctor or nurse checking to see if they had been vaccinated. Seeing news reports that the vaccines were reducing how many people were getting seriously unwell from COVID-19. Hearing from people with the same condition that the vaccines did not cause it to flare up.

Reasons for not being vaccinated

For all: Their condition not being stable, because of current symptoms or taking new medicines.

Believing that a vaccine could cause a flare-up of their condition.

For flu and pneumonia only: Not knowing that they were eligible for these vaccines. No recommendation from their doctor or nurse. No direct invitation to be vaccinated.

Source:
Nottingham Biomedical Research Centre
May 2022

A survey by the Royal College of Occupational Therapists (RCOT) has found that its members have seen an 82% increase in demand for occupational-therapy-led rehabilitation services in the UK over the last six months alone.

As the country begins to 'live with COVID', already overstretched rehabilitation services have seen demand rocket over the past two years due to the pandemic and are now experiencing a further rapid increase in patients. The findings raise questions about the prospects of providing timely rehabilitation for people recovering from short- and long-term illnesses and who need urgent support to live independently.

The survey, which over 550 occupational therapists working across the UK took part in, found that:

- 84% are supporting people whose needs have become more complex due to delayed interventions arising from the pandemic
- 82% of respondents noted increased demand for occupational therapy-led rehabilitation over the previous six months
- 71% of respondents felt there were not enough occupational therapists to meet demand
- 66% of respondents reported difficulties in delivering rehabilitation services due to reduced access to facilities, suitable space and equipment
- 50% are supporting people affected by Long Covid.

Commenting on the survey, RCOT Director of Practice and Innovation Karin Orman said:

"It's clear from this survey that rehabilitation services across the UK are overloaded, with the vast majority of occupational therapists seeing a huge increase in demand and complexity of their caseload over the last six months alone. This simply isn't sustainable and there isn't a big enough workforce to currently meet demand.

"Across the UK, health and social care leaders need to invest more in rehabilitation services and drive the recruitment of more occupational therapists as a matter of urgency. Not in a few years, but now. As leaders of rehabilitation services, occupational therapists are a vital part of the solution to getting through the backlog of people needing intervention. The maths is simple – the quicker people have access to rehabilitation services, the better their chances at getting back to doing the things they need and love to do."

Layla Moran MP, Chair of the All-Party Parliamentary Group on Coronavirus, said:

"These new findings clearly show that the long-term impacts of the virus, including Long Covid, are exacerbating many of the challenges that occupational therapists are facing both in the NHS and beyond.

"Healthcare professionals are bearing the brunt of UK government inaction and as long as Ministers bury their heads in the sand and refuse to address the growing Long Covid crisis, our economy and essential services will be under even greater strain. They must commit more money for research and funding, and recognise the condition as an occupational disease."

About the Royal College of Occupational Therapists

The RCOT is the professional body for occupational therapy. It has championed the profession and the people behind it for over 80 years and today represents more than 35,000 members across the UK. The organisation also works with healthcare commissioners, political leaders and others throughout society to position occupational therapy as a solution at the heart of health and social care.

Occupational therapists see beyond diagnoses and limitations to hopes and aspirations. They look at relationships between the activities you do every day – your occupations – alongside your illness or disability and your environment to recommend adjustments. These are practical, realistic and personal to you, to help you achieve the breakthroughs you need to elevate your everyday life.

Source:

RCOT May 2022

To ink or not to ink

In 1871, Charles Darwin wrote in his publication 'The Descent of Man' *"that there was no country in the world that did not practise tattooing or some other form of permanent body decoration."* One hundred and fifty years later, in a 2021 UK survey, it was found that 35% of United Kingdom citizens aged 30-39 have tattoos, an increase on the results of a 2015 survey that reported that a fifth of all British adults were inked.

The trend for body art will no doubt continue, which potentially causes a dilemma for anyone with a skin condition such as psoriasis. To ink or not to ink is a personal choice, but one which might be influenced by how your skin will react. *Clinical, Cosmetic and Investigational Dermatology* (Rogowska et al), conducted by researchers at the Department of Dermatology, Venereology and Allergology, Faculty of Medicine, Medical University of Gdansk in Poland, concluded for psoriatics:

"...that dermatological counselling is recommended for patients considering getting a tattoo...". They further suggested that doctors should offer to "*...advise them on choosing the best time for tattooing and the safest location for the tattoo on the body...*"

There are potential risks associated with tattoos for people with active psoriasis, called Koebner's phenomenon. In some people with psoriasis, trauma to the skin – including cuts, bruises, burns, bumps, vaccinations and tattoos – can cause a flare-up of psoriasis symptoms either at the site of the injury or elsewhere.

The researchers recommended: *"... tattooists should be educated about the possible health complications connected with tattooing and on the precautions that should be followed."*

Furthermore, *"... a standardised questionnaire, inclusive query about the client's medical history and medications, could be implemented by tattooists for the benefit of the whole tattoo-society."*

It was also expressed that every patient under systemic treatment who is willing to get a tattoo should have an individual assessment of its risks performed by a doctor.

The published results on the anonymous online survey from 150 tattooed psoriatics indicated:

- Only 8% sought medical advice before getting a tattoo
- 15% were receiving systemic psoriasis treatment when undergoing the tattooing procedure, 5% methotrexate, 3% cyclosporine A, 1% acitretin and 6% biological therapy
- 9% of the participants experienced complications associated with their tattoos, among which featured the insurgence of the Koebner phenomenon on the tattoo site
- Interestingly, 50% said getting tattooed improved their self-esteem.

In conclusion from this small study, with careful support from doctors and timing when to have a tattoo, it can be done successfully, but it's still not without risks, and perhaps careful consideration should be taken before going ahead.

Reference:

Rogowska P, Walczak P, Wrzosek-Dobrzyniecka K, Nowicki RJ, Szczerkowska-Dobosz A. Tattooing in psoriasis: A questionnaire-based analysis of 150 patients. Clin Cosmet Investig Dermatol. 2022;15:587-593. doi:10.2147/ccid.s348165

The 2022 Life Search Health, Wealth and Happiness Index shows UK citizens' overall wellbeing score is at a 10-year low. When studied in isolation, the nation's 'health' is almost back up to pre-pandemic levels, but rising cost of living has been most detrimental to peoples' mental health in the last two years, ahead of COVID restrictions and the conflict in Ukraine.

But the UK's 'wealth' is falling again after a brief uplift in 2021, with 72% expecting to be worse off this year by an average of £3,020 (£252 per month), rising to £3,859 in London.

Britons' 'happiness' is at lowest level in a decade – 45% say the pandemic has negatively impacted their mental health, rising to 52% of ethnic minority groups.

Commissioned with the Centre for Economics and Business Research (CEBR) and supported by consumer research from among 2,000 adults in the UK and further bespoke research among 502 ethnic minorities, the annual update of the combined Life Search Health, Wealth and Happiness Index reveals record lows in the decade-long series.

Looking at each of the three indices in isolation, Britons' happiness has been hit the hardest in the last year, falling to its lowest point in the last decade as the conflict in Ukraine and the rising cost of living took their toll. In comparison, the nation's health saw the largest improvement in the index.

However, while UK citizens' wealth saw strong gains in 2021, up 11% on 2020, it has since been on the decline in 2022, dropping 8% in the first three months compared to the previous period. The rising cost of living is having a detrimental effect on our mental health, too. When polled in April 2022, 74% of adults said their mental health has been negatively impacted in the last two years and of these, the ''rising cost of living'' (28%), closely followed by ''COVID restrictions'' (27%), were the top causes. And it may get worse still, as 72% of all people surveyed expect to be worse off financially this year as inflation soars, expecting to be £3,020 per year (£252 per month) out of pocket on average.

The overall health score has improved but mental health impact is significant with women, young people and ethnic minorities hit the hardest.

In fact, over half (51%) think the COVID pandemic has had a negative impact on their access to healthcare, rising to 57% of women and 62% of those aged 55+. While the figure is a little lower (49%) among all ethnic minorities, it is higher (55%) amongst those of Pakistani/Bangladeshi origins.

Added to this, almost one in two (45%) in the study believe the COVID pandemic has had a negative impact on their mental health (10% ''very negative''), rising to 50% of women and younger people. The impact is even higher (52%) among people from ethnic minority groups; rising

still among women in this community (58%) and among Pakistani/Bangladeshi ethnic groups (59%). But it is not just COVID that has impacted mental health, the rising cost of living has also been a major factor over the last two years.

Debbie Kennedy, chief executive at Life Search, said:

"While there may be a sense that after two long years the worst of the pandemic is behind us, the nation's health, wealth and happiness is still not close to being back to levels seen pre-COVID. In fact, our happiness is at a record low, mental health issues remain high and the energy crisis, inflation and conflict in Ukraine point at another chapter of uncertainty.

"At a more granular level, our study reveals the pandemic pressures and consequences faced specifically by people in ethnic minority communities, where many have been hit harder over the last two years and the ripple effect may continue much longer. Many in those communities feel they've had to work harder, dig deeper and risk more to stay afloat."

Jabeer Butt OBE, CEO of the Race Equality Foundation, commented:

"Across education, finances and general happiness, it's clear ethnic minorities are suffering. These major findings reflect our own knowledge that Black, Asian and minority ethnic communities continue to bear the brunt of the effects of the pandemic and cost of living crisis. We urgently need targeted support to take account of and effectively address these unequal impacts if we want to see a healthier, wealthier and happier Britain in the coming years."

The study also found:

- Over a third (35%) of all British parents think the pandemic has had a negative impact on their children's educational opportunities (12% "very negative"), rising to 42% of ethnic minority families and 48% among mixed race families
- Over half (51%) of people from ethnic minority groups feel the pandemic has adversely impacted their household finances, compared to just 38% of white Brits and rising to 58% of Pakistani/Bangladeshi adults
- Almost two-thirds (63%) of ethnic minorities have seen their cost of living negatively impacted by the pandemic (59% of all UK adults)
- Almost a third (29%) of people from ethnic minority groups, compared to just 15% of all Brits, think the pandemic has had an adverse effect on their position in society.

In fact, a larger proportion of ethnic minorities (26%) than white British adults (19%) felt that they were more at risk of getting COVID than the average UK citizen due to their day-to-day circumstances (e.g. job they have, where they live etc). Furthermore, 35% of people from ethnic minority groups felt that the pandemic meant that they couldn't do their job safely, rising to 44% of Black Britons. This compares to just 19% of all white British adults.

Source:
Life Search
www.lifesearch.com/hwh22

PAPAA believes that working together in a partnership between the patient and healthcare professionals (HCP) is a good way for everyone to understand the patient's needs and what is available to support those needs.

For patients, PAPAA provides information and support as a listening ear, plus printed and digital resources material along with interactive education and training.

For healthcare professionals, patient support information material is provided along with access to an online accredited course called Psoriasis in Practice (PiP). This training programme for healthcare professionals has now been reaccredited by the Royal College of Nursing (RCN) Centre for Professional Accreditation.

The programme is worth 10 study-hours, with a certificate issued on completion, and can form part of HCPs' Continuing Professional Development (CPD) portfolio.

The course has been available since 2012. Over time, its content has been comprehensively revised and improved and is now in version 8. Many of the revisions have been to keep up to date with changing practices and new patient needs, particularly post-COVID.

Learning Outcomes:

- Understanding what psoriasis and psoriatic arthritis means to people and how their quality of life may be compromised
- Recognising that psoriasis and psoriatic arthritis are more than skin and joint conditions
- Being able to advise people with psoriasis and psoriatic arthritis on managing their condition effectively
- Knowing when patients need more help and when to refer to specialist services.

PAPAA originally developed the course with Professor Alex Anstey and colleagues at the Aneurin Bevan Health Board in Newport, South Wales. The main reviewers of the content are Julie Van Onselen, dermatology nurse specialist and independent clinical and educational adviser and medical writer, and Professor Philip Helliwell, associate professor in rheumatology at the University of Leeds, UK, and honorary consultant rheumatologist for the Leeds Teaching Hospitals and Bradford Teaching Hospitals NHS Trust.

The content of the course includes: evidence-based content, latest NICE and SMC guidance, images, signs, symptoms, patients' perspectives and personal stories, video interviews, treatment options and virtual consultations.

To learn more about how PAPAA supports healthcare professionals, visit www.papaa.org/hcp

Mindfulness and museums

Can a museum visit improve your mental health? The arts and culture sector has recently begun to gain backing from medical professionals as a method of improving a patient's mental health and wellbeing, tackling issues such as anxiety and depression. For many, visiting a museum, gallery or another cultural institution may be an unusual activity, but it is because such an activity is isolated and distanced from our everyday routine that it has the potential to remove one from the environment that causes so much stress and anxiety, into a space that is free from negativity and the anxiety triggers of everyday life. Visiting arts and cultural organisations includes active and passive participation and can include a variety of activities such as performing arts, visual arts, literature, culture and online arts to improve mental health.[1] Does the experience require the validation of a medical professional to be considered worthwhile?

During the coronavirus pandemic, lockdowns and long periods of isolation increased loneliness and vulnerabilities from the lack of socialisation in many individuals. The increased chance of psychological and mental turmoil from isolation can trigger anxiety and depression among individuals, and these stressful events impact our physical and psychological wellbeing. In some cases, having conditions like psoriasis and psoriatic arthritis can have an emotional impact as "physical appearance means low self-esteem and anxiety are common among people with the condition. This can lead to depression, especially if the psoriasis gets worse".[2] External factors such as stress, in some cases, cause a physical response from the body in ways such as immune response and flare-ups; these triggers can impact an individual's self-esteem and be factors for not wanting to engage in outdoor social activities. This, therefore, creates a perpetual cycle of anxiety and depression from self-imposed isolation.

Furthermore, attending social events with the backdrop of cultural organisations such as museums and galleries brings like-minded people together who also feel their mental and physical health requires support. These cultural events can create a sense of bonding and the opportunity to break down the barriers to leaving the comfort of their homes and entering an environment disconnected from their mundane routine. These sessions also encourage people to visit places which distract them from the ordinary routine of everyday lives. Many cultural organisations are well equipped to offer accessibility support to make visits easier and stress-free.

The NHS released The NHS Long Term Plan in January 2019, outlining its aims and objectives for the next five years. In this report, the NHS outlined its 'top tips' for general practice in development by young carers, including policies on accessible preventative health, social prescribing and early referral to local support services.[3] This report also plans that, within five years, over 2.5 million more people will have the opportunity to benefit from the policy of social prescribing, a personal health budget and a new support network for self-management of health in collaboration with patients' groups and the voluntary sector. The creative health inquiry report of 2017 by the All-Party Parliamentary Group on Arts, Health and Wellbeing outlined the types of activities covered by social prescribing practice, including sessions combining "activities such as gallery talks and tours, discussions, museum object handling and collections-inspired creative activities".[4] These activities explore the value of cultural heritage in overcoming social isolation through "touch and wellbeing mediated by cultural artefacts". The historical objects and heritage sites used to focus these sessions form a way to discuss thoughts and feelings in a social and open setting that attempts to remove barriers that can increase isolation, while the main focus of these activities appears to be on socialisation and how this social aspect is integral to creating a positive psychological impact on wellbeing. The use of historical objects and settings can spark conversations and forms of storytelling that bring people together through a sense of unity.

The concept of medical professionals prescribing museum visits for patients who struggle with their mental health took shape and momentum in Brussels, Belgium, in 2021. This concept is part of a three-month project that aimed to "rebuild mental health amid the COVID-19 pandemic" and gave doctors the authority to prescribe museum visits as an appropriate treatment.[5]

The programme allows patients who are treated for stress at Brugmann hospital in Belgian to be "offered free visits to five public museums" to improve their mental state.[5] This project was inspired by a similar scheme in Quebec, Canada, where doctors can prescribe up to 50 museum visits a year to patients, and Delphine Houba,

responsible for culture in Brussels, emphasised that it "has been shown that art can be beneficial for health, both mental and physical".[5]

The prescription of museum visits has also gained momentum in the UK, for example, a charity based in Cambridgeshire called Arts and Mind and its project Arts on Prescription. The charity aims to use heritage to improve the health and wellbeing of people experiencing anxiety and depression through weekly art sessions facilitated by professional artists with support from counsellors.[6] Other programmes include, but are not limited to, the Dulwich Picture Gallery in London, which has held a programme since 2005 entitled Good Times: art for older people that accepts GP referrals of "frail, depressed or lonely people"; it aims to make a conscious effort to engage with older people, in particular men, with socialising and creative workshops, tours and other activities.[4] The NHS Central and North West London (CNWL) programme called Arts in Health aims to "promote any possibility where art increases health and wellbeing" through collaborative partnerships, including the British Museum, Brent Museum and Archives, and the Wellcome Art and Health Collection, since 2017.[7] Research is still ongoing to evaluate how much these programmes impact and improve quality of life for those experiencing anxiety, loneliness and depression. The current research suggests that "taking part in creative activities has a positive effect on physical, emotional and mental wellbeing" by improving quality of life, personal independence, increased self-esteem and confidence, providing opportunities for self-expression and social engagement.[7]

In conclusion, art and cultural activities have the opportunity to improve mental health by removing an individual from an unconstructive environment into a space that is distanced and isolated from the triggers of their everyday routine. Furthermore, prescribing visits to museums to relieve stress is only one factor to improving mental health; another contributing factor is tackling the stigma and wider representation of mental health in a broader context. Mental health needs a positive portrayal in film, television and theatre performances to help reduce undesirable representation and avoid stereotypes, and increase wider understanding of the illness and associated conditions.[1]

The patient also needs to attend these cultural visits, events and activities with an open mind and approach if they are to gain the desired impact. Of course, these visits are not a cure, but could increase social connections, give purpose, and build self-esteem and confidence. The potential for positive benefit and impact these activities and visits have on the general public of all ages and diversity is high. This is one way for museums, galleries and other cultural institutions to encourage untypical visitors to engage in activities that have a positive psychological impact.

For this type of programme to be successful, the activities should be designed in collaboration with creative and medical professionals and the target communities. The arts and culture sector has the opportunity to connect people to objects, places, people and ideas that improve our quality of life and broaden our outlook of the society we live in and operate.

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Innovative Medicines Fund

Up to £340 million has been made available through the Innovative Medicines Fund to purchase the most promising medicines and fast-track them to patients, to give adults and children the best chances of survival, recovery or a healthier, longer life.

The fund, which meets a government manifesto commitment, will further support NHS England in offering patients potentially transformative new drugs while further real-world evidence is collected to inform a final decision by the National Institute for Health and Care Excellence (NICE) on whether the treatment is clinically and cost effective and a good use of taxpayer money in the long-term, reducing delays and boosting patient outcomes in the interim.

Examples of previous medicines which patients have accessed in a similar way through managed access agreements include a treatment for children with spinal muscular atrophy and a treatment to slow the progression of a life-limiting metabolic disorder.

It builds on the success of the reformed Cancer Drugs Fund which, in the past five years, has provided more than 80,000 people access to life-extending or potentially life-saving drugs which might otherwise not have been available for years.

The health and social care secretary, Sajid Javid, said:

"I want NHS patients to be the first in the world to access the most promising and revolutionary treatments that could extend or save their lives. The launch of the Innovative Medicines Fund delivers another manifesto pledge and will fast-track cutting-edge medicines to adults and children to give people renewed hope for a better future. A total of £680 million has been ringfenced for the Innovative Medicines Fund and Cancer Drugs Fund - £340 million each - to fast-track medicines to NHS patients."

An estimated one in 17 people in England will be affected by a rare disease in their lifetime. The Innovative Medicines Fund will provide quick access to novel treatments, including potentially lifesaving gene therapies for serious conditions with few treatment options. It often takes longer for pharmaceutical companies to collect data on a medicine's clinical and cost effectiveness for rare diseases due to the smaller patient cohort. Rather than making patients wait until this date is available, this

new scheme will allow access while this important process takes place, with support from NHSE and NICE.

NHS commercial medicines director Blake Dark said:

"The NHS continues to be a pioneer in striking deals and rolling out the latest cutting-edge drugs and treatments. This new Innovative Medicines Fund will build on the success of the Cancer Drugs Fund, enabling more patients to benefit from early access to the most promising cancer and non-cancer medicines.

"The NHS Long Term Plan shows we are committed to adopting NICE-approved treatments at the earliest opportunity and £680 million of ringfenced funding will help provide faster access to promising new drugs and ensure the NHS remains at the forefront of securing the best revolutionary treatments for patients.

"It is hoped improving access to treatment for those patients most in need will help alleviate pressure on the NHS, supporting wider efforts to tackle the Covid backlog.

"All medicines deployed through the Innovative Medicines Fund and Cancer Drugs Fund will have been approved by the Medicines and Healthcare products Regulatory Agency (MHRA) after meeting high standards of safety and quality and will have been recommended as suitable for the IMF by NICE."

Chief executive of NICE Dr Samantha Roberts said:

"I am delighted that NICE has been able to play a key role, alongside NHS England and NHS Improvement, to create this important new initiative to give people earlier and faster access to promising new innovations in treatment.

"This fund, like the Cancer Drugs Fund, will help us more quickly identify and make available transformational new treatments that will bring real benefits to thousands of people and offer high value to the NHS."

The Innovative Medicines Fund supports the government's Rare Diseases Action Plan to ensure people living with rare conditions benefit from faster diagnosis, treatments and support to manage their conditions.

Following a public call for evidence, the government is also developing a 10-Year Cancer Plan to make England a world-leader in cancer care, with renewed attention paid to innovative treatment and early diagnosis to improve outcomes for patients.

Source:
Department of Health and Social Care and The Rt Hon Sajid Javid MP
June 2022


papaa < Pso Pscience >
April 2022: Issue 1
A bi-annual review digest of research associated with psoriasis and psoriatic arthritis
Welcome to the first Pso Pscience of 2022 from PAPAA!
Over the past two-decades there has been a revolution in our understanding of psoriasis and psoriatic arthritis, both in terms of basic immunology, disease mechanisms and therapeutics.
This newsletter is designed to provide a summary of recently published research.
Of course, it's never a good time to have psoriasis or psoriatic arthritis, but if you have to have it, there has never been a better time!
Air pollution may trigger psoriasis flares
Psoriasis flares are known to be triggered by environmental factors, including infections, stressful life events, smoking, alcohol and drugs.
In this study, investigators studied the relationship between environmental air pollution and the risk of psoriasis flares in around 1,000 patients with chronic plaque psoriasis. Concentrations of several pollutants (carbon monoxide, nitrogen dioxide, other nitrogen oxides, benzene, coarse particulate matter) were measured and recorded in control visits and in the 60 days preceding the psoriasis flare. In all, more than 15,000 measurements were included in the analysis.
Results showed that concentrations of all pollutants were significantly higher in the 60 days before psoriasis flare compared with the control visits. These findings strongly suggest that high levels of air pollutants may be a trigger factor for psoriasis flares.
Comment:
This is an interesting finding, which is perhaps not entirely surprising, given that worsening of other diseases that share common inflammatory pathways with psoriasis - such as atopic dermatitis - have been associated with exposure to air pollution. Presumably it is due to the fact that inhalation of pollutants can lead to oxidative damage to cells and an increased inflammatory reaction. It may also be due to direct contact with the skin. More research is needed!
Reference:
Bellinato F, et al. Association Between Short-term Exposure to Environmental Air Pollution and Psoriasis Flare. JAMA Dermatol. Published online February 16, 2022.doi:10.1001/jamadermatol.2021.6019

Over the past two decades there has been a revolution in our understanding of psoriasis and psoriatic arthritis, in terms of basic immunology, disease mechanisms and therapeutics.

This section is taken from our new online newsletter, and is designed to provide a summary of recently published research.

We will produce two issues a year: April and October.

Air pollution may trigger psoriasis flares

Psoriasis flares are known to be triggered by environmental factors, including infections, stressful life events, smoking, alcohol and drugs.

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A new topical

One of the problems with topical treatments (those applied directly to the skin) is that they often have adverse side effects. This is especially true of steroids, which are associated with skin discolouration and atrophy. Now a novel, topical treatment, which avoids many of these unwanted effects, is currently under development.

Tapinarof (Dermavant Sciences) works by activating the aryl hydrocarbon receptor (AhR) in the skin and thus modulates the activity of inflammatory molecules - specifically interleukin-17. Two clinical trials have demonstrated significant improvements in severity of plaque psoriasis, in patients treated with 1% tapinarof cream (once daily), from as early as the second week of treatment. Around 40% of trial subjects achieved complete skin clearance.

In addition:

- 82% of patients preferred tapinarof to previous topical treatments and considered it more effective
- Over 85% either strongly agreed or agreed they could easily manage their psoriasis with tapinarof
- Some 83% stated that they would use tapinarof again or continue using it if available

Comment:

Tapinarof offers a new and effective topical treatment, with high levels of patient satisfaction. It is expected to be approved for use in the US later this year (2022).

In the UK, an application for approval of tapinarof has been submitted to the National Institute for Health and Care Excellence (NICE). Watch this space!

References:

Bissonette R, Tapinarof in the treatment of psoriasis: A review of the unique mechanism of action of a novel therapeutic aryl hydrocarbon receptor-modulating agent. J Am Acad Dermatol 2021; 84: 1059-1067. Lebwhol MG, Stein Gold L, Strober B, et al. Phase 3 Trials of Tapinarof cream for Plaque Psoriasis. N Engl J Med 2021; 385 :2219-2229.

Fish oils and vitamin D

Both vitamin D and omega-3 fatty acids derived from seafood are known to have a beneficial effect on inflammation and immunity. However, until now, no scientific trials have been carried out to establish whether taking these supplements can lower the risk of psoriasis and other autoimmune problems, such as rheumatoid arthritis. This study did just that.

Some 26,000 US adults (average age 67 years) provided information regarding age, ethnicity, region of residence, income, education, lifestyle, weight, medical history, diet and supplement use. Blood levels of vitamin D and omega-3 fatty acids were also measured.

Participants were then randomly allocated to receive vitamin D (2,000 IU/day) or matched placebo, and omega-3 fatty acids (1,000mg/day) or matched placebo, and were asked to report any diagnosed autoimmune disease – including psoriasis and rheumatoid arthritis - over an average five-year period.

Over the full duration of the trial, vitamin D and omega-3 supplements reduced the incidence of autoimmune disease by 22% and 18% respectively. There was, however, a stronger effect the longer

supplements were taken. When the last three years of the trial were considered, vitamin D and omega-3 supplements together decreased autoimmune disease by 30%.

Comment:

This was a large and well conducted study in a diverse, although older population. We don't know whether these findings would apply to younger individuals or what the impact of other doses and formulations of supplements might be. Moreover, the impact on psoriasis specifically is not known. Still, this is an important milestone, because this is the first direct evidence that long-term, daily supplementation with vitamin D and omega-3 fatty acids significantly reduces the risk of autoimmune disease.

If you have psoriasis and or psoriatic arthritis, it might be well worth discussing supplements with your GP.

Reference:

Hahn, J, et al. (2022) Vitamin D and marine omega 3 fatty acid supplementation and incident autoimmune disease: VITAL randomized controlled trial. The BMJ. doi.org/10.1136/bmj-2021-066452.

Being overweight increases the risk of psoriatic arthritis

The vast majority of patients developing psoriatic arthritis (PsA), have pre-existing psoriasis. While studies have suggested that smoking, obesity, and heavy alcohol consumption may make existing psoriasis worse, their relationship to PsA is unclear.

This large study examined whether these factors may increase the risk of psoriatic arthritis in a large population of patients with pre-existing psoriasis.

Using the U.K. Clinical Practice Research Datalink between 1998 and 2014, researchers identified 90,189 cases of psoriasis, 1409 of whom subsequently developed PsA. They then examined the association between changes in body mass index (BMI), smoking habits and reported alcohol consumption in relation to the risk of developing PsA.

Results showed that being overweight or obese significantly increased the risk of developing PsA. Indeed, those with a BMI ≥35·0 kg m-2 were 2.5 times more likely to develop PsA than those with a normal body weight. Importantly, reducing BMI over a 10-year period was associated with a reduction in the risk of developing PsA compared with weight remaining constant over the same period. There was an increased risk with moderate alcohol consumption but not with heavy consumption, and no association with smoking.

Comment:

What's impressive about this study is not simply the demonstrated association between body weight and risk of PsA; many other studies have already suggested this. The key observation here is that reducing body weight is associated with a reduction in the risk of PsA. The lack of any association with smoking was perhaps surprising.

Reference:

Green A, Shaddick G, Charlton R et al. Modifiable risk factors and the development of psoriatic arthritis in people with psoriasis. Br J Dermatol 2020, 182: 714-720

Pso Science is researched and written by **Dr W.D. Ashton MD PhD.**

To download a copy, go to: **www.papaa.org/PP**

Most of us each day are on automatic pilot, doing things without even thinking and that can be a problem! Many of us are dog and cat owners, therapy dog owners, have house rabbits and other pets that roam our homes. Some of us will have disability issues or other ailments that require us to take medications in some form; usually pills, topical treatments, liquid formulations, injections or patches.

We take our medication routinely and don't give it a second thought, but sometimes accidents happen. If you use blister packs for example, how often has one pill popped out before you can catch it falling to the floor and bouncing beneath some piece of furniture or appliance? Perhaps you simply can't bend down to see where they went or indeed pick them up with aching fingers! How often have we left medicines on a table or within low reach, got distracted and left them to answer the phone or door, or just to do something else while planning to put them back in the cupboard later? Packaging of medications can be a nightmare for those of us suffering with arthritis or reduced dexterity. Blister pack packaging, childproof caps, squeezing hard tubes to get ointment out can all be frustrating in themselves, let alone if you drop some medication or forget to put it back in the cupboard.

If you have a pet or know someone who does, this information will be vital reading in understanding what to do in the event that your pet eats discarded medication - especially curious puppies! Failing to pick medication up just once can be enough to cause serious problems. And let's not forget that cats and even some dogs love to counter surf and get into mischief too.

Just think, you've gone shopping, leaving your pet sleeping, supposedly being good… It gets bored or hungry and goes on the prowl. Hmm, your pet smells something sugar-coated under the radiator gap, by the fridge door or under the sofa; it could be dropped chocolate, dried-up grapes, raisins, sultanas, mouldy food, even food that had contained onions, leeks or garlic perhaps. Lots of sugar-free foods today contain Xylitol, so certain sweets, chewing gum and biscuits can be fatal to dogs. They go sniffing in a bin bag that you were going to dispose of but forgot, and find some painkiller patches. That's fun, ripping them to pieces and swallowing some of their new-found treasure. Maybe they'll find old packets of pills or small batteries. They might even decide to chew through the cap of some half-empty cough medicine bottle.

Did you know that topical ointments and gels that you use to treat your psoriasis can also be problematic for your pets? Some topical products can be extremely toxic if your pet licks your hands, legs or any area of skin treated with topical products. Careless disposal of medications at home can enter our domestic waste systems harming river and sea life as well as ourselves if commercial filtration systems become faulty due to lack of maintenance.

What to do in case of emergency and signs to look for in suspected drug accidents

If you think your pet has swallowed paracetamol, for example; the signs to look for are:

- Panting
- Difficulty breathing
- Swollen face
- Discoloured gums
- Lethargy
- Distress
- Vomiting
- Liver damage

Do not try and make the pet sick.

Never give an animal salt water to drink.

Contact the Animal POISONLine immediately for instant advice as to what to do next.

If your pet needs to visit the vet, they may be prescribed the antidote, acetylcysteine, administered via mouth or vein and this treatment will need to continue for several days. Other medications may be given to protect the liver and reduce methaemoglobin. Blood samples will also be taken to ascertain injury to your pet's red blood cells and

liver. In severe cases, a blood transfusion may be required.

Paracetamol interferes with the animal's body and targets the red blood cells where haemoglobin is changed to methaemoglobin. As a result, the blood is less effective at carrying oxygen to the tissues of the body. It also causes liver injury, which occurs several days after ingestion. However, the outcome of paracetamol poisoning in dogs is good only if identified early.

Ibuprofen is also a health risk for animals.

The signs to look for if your pet has swallowed ibuprofen are similar to paracetamol, but also include:

- **Vomiting (may be bloody)**
- **Diarrhoea**
- **Black tarry stools**
- **Abdominal pain**
- **Weakness**
- **Convulsions.**

Contact the Animal PoisonLine immediately for instant advice. Don't panic. Whether you need an emergency trip to the vet will depend on the quantity swallowed and your pet's weight – this will determine if a toxic dose has been taken. If there has been enough of a toxic dose, treatment may include intravenous fluid therapy and monitoring of your pet's kidney function. They may be prescribed drugs to control any vomiting and drugs to protect the gut and reduce any risk of ulceration which may have occurred, and also ulcer-healing drugs.

Top tip for avoiding unwanted disaster to your pets and children:

Make sure, if you can, to identify the name of the possible drug(s) consumed, e.g. methotrexate.

- Make sure medication is stored at a safe distance away from animals and children
- Dispose of medicines, batteries, waste, empty plastic bottles, nappies etc in a secure way
- Ideally return all unwanted medicines to your locally pharmacy for safe disposal
- Never dissolve medicines and flush them down the toilet or sink. These will enter the water system and rivers and have an effect on local wildlife
- Never leave medicines and topical products lying around within reach of children or pets
- Never leave chocolate, food and sweets within easy reach
- Dispose of dead flowers and houseplants safely as some can be poisonous to pets
- If you have medicines in your handbag, make sure your pet cannot get into it and remember to zip it up if your handbag has one - especially if your handbag is regularly placed on a chair or on the floor

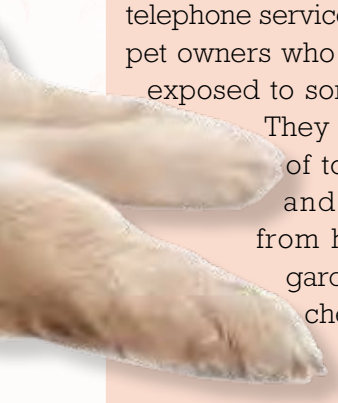
- Never leave household waste bags on the floor or in easy reach of your pets; always place them in the relevant secure bins for collection on bin day
- For the disposal of painkiller patches: Fold the used painkiller patch firmly in half so that the sticky sides stick to themselves. Place back in the wrapper, then place securely in the household waste bin or, if there are many, return them to your pharmacist for disposal
- Dispose of cigarettes and e-cigarettes (and their refills) securely
- Be aware of safe storage of cleaning/decorating materials used regularly around the house
- Be aware of pot pourri in reachable bowls
- Keep all garden chemicals etc secure
- Make sure that if you use mouse and rat bait that your pets can not eat it. Ideally, bait boxes in the

garden should be used with blocks securely fastened in the bait box or bait covered securely so that your pets cannot get it – think about preventing access by hedgehogs too

- Do not leave watering cans or bowls in easy reach of your pets if they have been used for plant food or other chemicals
- Be vigilant about care of your medications
- Have the knowledge to help if you or someone you know has a pet that suddenly becomes unwell from swallowing discarded medication.

About

Animal PoisonLine is self-funded and run by the Veterinary Poisons Information Service (VPIS) and is the only **24-hour specialised** emergency telephone service in the UK dedicated to helping pet owners who think their pet may have been exposed to something harmful or poisonous. They have experience of thousands of toxic substances in all animals and can advise on everything from human drugs, household and garden products, plants, agricultural chemicals to venomous bites and stings.



All staff are veterinary-trained, dedicated and passionate about what they do, with each animal's health a priority. They have extensive knowledge and data on poisons and also plant-based poisons. Animal PoisonLine **may** charge a fee, but this is cheaper than a vet consultation, and it is instant and thorough. It could save your pet from having unnecessary invasive tests and treatments that may not be suitable and cause them more distress.

Important information to have before you call the PoisonLine:

1. Your pet's details: name, age, breed and weight.
2. What your pet has eaten or been exposed to, e.g. the drug or product/brand name.
3. How has your pet absorbed the potential toxin? e.g. Have they eaten, inhaled or has it been on their skin?
4. How long ago was your pet exposed to the potential toxin? e.g. estimated minutes, hours.
5. How much of the potential toxin have they been exposed to? e.g. unit of measure and estimated amount
6. Is this the first time your pet has been exposed to this toxin? If this has happened in the past, when?

If you are advised to contact your vet, do tell your vet that you rang the Animal PoisonLine and advised to seek veterinary assistance. If they require detailed treatment advice about the particular substance your pet has been exposed to, they can call their professional service, the Veterinary Poisons Information Service (VPIS).

Approximately 80% of vets are members of the VPIS and use it regularly for specialist advice on the management of poisoning in animals. Please be aware that if your pet does require veterinary attention, your vet may charge a fee for calling VPIS; they will in turn refund you for your call cost made to Animal PoisonLine.

Fees for full consultation are payable. £35 is charged 8am to 8pm Monday to Friday. £45 is charged at all other times, including bank holidays. **Refundable** if you need the vet. (correct at time of press)

Available materials from Animal PoisonLine

- Ibuprofen poisoning in cats and dogs
- Advice for owners
- Paracetamol poisoning in dogs
- Prevention of poisoning and emergency advice
- Summer hazards
- Spring hazards
- Adder bites
- Rat and mouse poison
- Poisoning in dogs
- Xylitol poisoning in dogs
- Harmful foods
- Chocolate poisoning
- Poisoning from grapes and their dried fruits.

Source:

www.animalpoisonline.co.uk

Tel: 01202 509000

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?

www.psoriasis-shop.org

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.

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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.

Supporting PAPAA

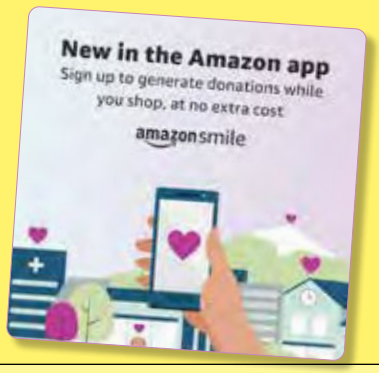
As a charity, in order to continue our work, we need to raise funds. Apart from direct donations, there are other ways to help us too.

AmazonSmile is particularly easy – and free to you. AmazonSmile donates 0.5% of your total purchase to us as a charitable donation. So, it doesn't cost you anything.

You may also be interested in other ways to support us online, such as JustGiving, The Charities Aid Foundation (CAF),

Total Giving, PayPal Giving Fund, Give a car, Easyfundraising, Easysearch and Everyclick. Links to these sites can also be found at:

https://www.papaa.org/donate/ways-to-support-papaa/



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/**