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skin 'n' bones connection

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papaa®

Dear Reader

Coping with psoriasis and psoriatic arthritis can be a lonely experience, and people often find differing ways to cope. One way is to seek advice and develop coping skills. Our cognitive behavioural therapy programme eTIPs (page 20) is designed to help people understand what causes negative thoughts and how to deal with them.

Another way to cope is to cover up and the British Association of Skin Camouflage explains (pages 10-12) how to get the most out of skin camouflage.

The goal for many will be a cure and although not imminent, the need for more research and developing further ways to improve services is being explored by the IMPACT research team in Manchester (page. 5-6).

However you decide to manage your condition you are not alone as many others are seeking similar advice which is evident from the statistics generated by the PAPAA website (page 7).
The more informed you are, the better you will be able to cope.

Managing editor

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COVER PHOTO:

Did you guess the front cover?

It is orange medicine bottles - the research continues!

'Understanding and improving patient experience of NHS services is essential to providing a service based on patients' needs'

National Institute for Health and Care Excellence (NICE) recently published a new quality standard and guidance on patient experience in adult NHS services.

There have been a number of documents and initiatives over the past few years that have highlighted the importance of patient experience and the need to focus on improving this experience where possible. Such proposals have underlined the significance of the entire patient experience within the NHS, ensuring people are treated with compassion, dignity and respect within a clean, safe and well-managed environment.

'The quality standard and guidance echo the approach taken in the RCN's 'Principles of Nursing

To deliver the best possible experience for patients who use NHS services, high quality care should be clinically effective and safe. This quality standard and accompanying clinical guidance aim to ensure that patients have an excellent experience of care from the NHS.

The new quality standard for improving the quality of patient experience includes ensuring that patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care. It also states that patients have their physical needs (such as nutrition, hydration, personal hygiene and pain relief) and psychological concerns (such as fear and anxiety) assessed. In addition the standard states that patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.

NICE has also published accompanying clinical guidance on patient experience in adult NHS services. This guidance promotes person-centred care that takes into account a patient's needs, concerns and preferences. It acknowledges the value patients place on healthcare professionals acknowledging their individuality and the unique way in which each person experiences a condition and its impact on their life. The guidance therefore makes a number of recommendations on knowing the patient as an individual, essential requirements of care, and enabling the patient to actively participate in their care. Recommendations include:

New quality standard

Develop an understanding of the patient as an individual, including how the condition affects the person, and how the person's circumstances and experiences affect their condition and treatment.

Ensure that the patient's personal needs (for example, relating to continence, personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy

Christine Carson, programme director, Centre for Clinical Practice at NICE, said:

"Understanding and improving patient experience of NHS services is essential to providing a service based on patients' needs. Ensuring that the NHS is patient-centered is crucial; therefore NICE is pleased to be publishing both a quality standard and guidance that will aid healthcare professionals in delivering the very best experience for patients, right across the NHS."

Dr Peter Carter, RCN chief executive and general secretary, said: "The RCN welcomes the publication of this NICE quality standard and guidance. They are important and practical steps forward in ensuring that the NHS takes proper account of patients' experiences in care. The quality standard and guidance echo the approach taken in the RCN's "Principles of Nursing Practice", in supporting nurses and healthcare assistants in delivering high-quality and safe care. We look forward to seeing the NICE quality standard reflected in commissioning intentions and to links being made between them and the NHS and social care outcomes frameworks."

www.nice.org.uk

About NICE

The National Institute for Health and Care Excellence (NICE) is the independent organisation responsible for providing national guidance and standards on the promotion of good health and the prevention and treatment of ill health.

About quality standards

NICE quality standards (QS) are a set of specific, concise statements and measures that act as markers of high-quality, clinical and cost-effective patient care. They apply nationally in health and social care, and are developed from the very best available evidence, such as NICE guidance or other NHS Evidence-accredited sources. Quality standards are produced with the NHS and social care, along with their partners, service users and carers. They are a pivotal part of the new NHS Outcomes Framework, an overview of aims and objectives in improving patient outcomes in the NHS.

We previously reported on the IMPACT (Identification and Management of Psoriasis Associated ComorbidiTy) programme in Issue 33 2011. The study team, led by world-renowned dermatologist Professor Chris Griffiths, is now halfway through the five years of funding awarded by the National Institute of Health Research (NIHR). The main aim of the research programme is to apply the best possible knowledge to develop responsive services to improve care and to support the physical and psychological needs of people with psoriasis.

The two major goals within IMPACT are to:

- Develop an evidence-based, acceptable, feasible and accessible primary care-based intervention to improve self-care and coping for people with psoriasis.
- Devise evidence-based training for primary care staff to improve access to targeted services for people with psoriasis.

In order to develop the intervention, (care and support) the team is currently working across several research studies which will feed vital information into future resources developed for patients and practitioners, and training given to primary care staff.

Recent findings from IMPACT

- In-depth interviews with a community sample of people with psoriasis revealed that practitioners were perceived as lacking knowledge and expertise in the management of psoriasis, resulting in some participants withdrawing from conventional health service providers and seeking alternative sources of help. Some of the findings have been published in the British Journal of Dermatology (Nelson et al., 2013) and the team wrote an editorial in British Journal of General Practice (Cordingley et al., 2012) timed specifically to coincide with the release of the revised national NICE guidelines which advises GPs, specialist doctors and nurses on the management of psoriasis.
- Evidence that psoriasis needs to be recognised and managed as a complex long-term condition, and that healthcare practitioners should aim to meet the emotional, social and physical needs of individuals, including regular review of treatments which may involve referrals to specialist care.
- We have carefully examined data from around the world to produce summary statistics which give a more accurate estimate of the number of people with psoriasis in different parts of the world. This knowledge enables healthcare organisations to plan appropriate services to meet the needs of people with psoriasis in those countries. Research findings have been published in the Journal of Investigative Dermatology (Parisi et al., 2013).

The IMPACT research team benefits greatly from a partnership developed with their Research User Group (RUG), which provides valuable advice on their

'The group includes people with psoriasis and those with an active interest in research into psoriasis'

research plans from a service user perspective. The group includes people with psoriasis and those with an active interest in research into psoriasis. The group meets every 3-4 months in central Manchester and has had a valuable input into the research programme. This has included suggestions for new wording of letters of invitation to new people who may want to take part in research as well as providing detailed feedback on our study methods from a patient perspective. Alison Littlewood, IMPACT programme manager said: "The IMPACT researchers consider the RUG as key members of the IMPACT team. They continue to provide essential advice on each stage of the research process, and we are looking forward to working together in the development of the primary care-based intervention, (care and support) to ensure it is as relevant as possible to those whom it will affect". Three patient representatives currently sit on the IMPACT Steering Committee in an advisory capacity.

IMPACT Identification and Management of Psoriasis Associated Comorbidity

More information on this research and findings so far can be found on the IMPACT website

www.impactpsoriasis.org.uk

You can also follow the team on Twitter

@impactpsoriasis

The team is not recruiting people to take part in the research as this is based in specific GP practices, but if you do have any questions or comments about the study you can contact Alison Littlewood, programme manager, by email or telephone.

Email:

alison.j.littlewood@manchester.ac.uk

Tel: 0161 275 6089

You are not alone

This rise of the internet and its impact on all aspects of life from news reports to online shopping appears to be constantly blamed and praised in equal measure for various problems faced in the UK today. Certainly, health is no exception to this good or bad effect and adding to individual's worries and concerns.

In a recent study carried out by campaign group Wholegrain Goodness it was reported that individuals are more than twice as likely to look online (51%) for information on health and nutrition than consult a doctor or nurse (22%). The use of the internet, or 'Dr Google' as it is sometimes called, is a trend, which is probably only likely to increase.

As a charity, we have adapted to meet the changing needs and demands, and in March 2012 the PAPAA website was re-launched to be more intuitive to searches. Since the re-launch, we have monitored the visits, page views and most common searches.

Last year there were more than 190,000 unique visits to the site compared to 75,000 visitors for the previous year, with more than 250,000 page views. In the most recent months, we are seeing an increase to 1,000 people a day looking at the site. A third of all visits are now via a mobile device or tablet.

Common searches that are used include information for scalp, nail and genital psoriasis along with their treatments. For psoriatic arthritis, hands, feet, exercise and pain relief are common searches.

The site has content covering every aspect of psoriasis and psoriatic arthritis, including case histories, image galleries, treatment pages, self help and a vast amount of detailed information which can be downloaded in easy-to-print format. For those who do not have access to the internet, we have a list of the content and you can order copies of the pages via an order form.

Did you know?

To accompany our main site we also have an eCommerce site, where you can order leaflets free of charge and purchase from a small selection of psoriasis or psoriatic arthritis-related books.

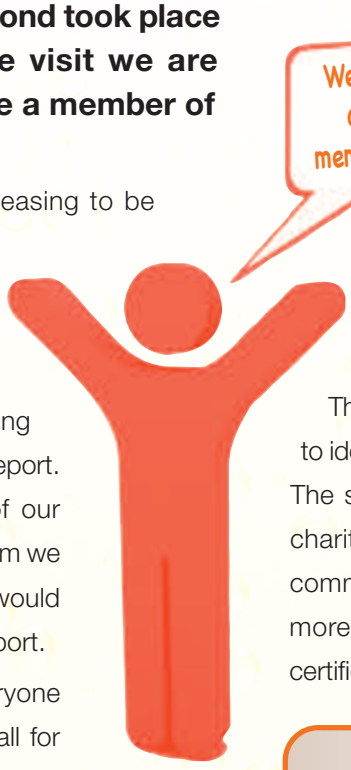
See page 20 for details.

Information Standard

In 2011 PAPAA was certified as a provider of high quality health and social care information by The Information Standard scheme. As part of the scheme member organisations have an annual check by an external evaluator; our second took place in April and following the visit we are delighted to continue to be a member of the scheme.

Once again It was particularly pleasing to be praised for the many compliant aspects of our processes; our use of lay reviewers was classed as beyond what most organisations had been undertaking and as 'good practice' in the final report. This is due to the enthusiasm of our valued volunteer lay reviewers, whom we must thank, as without you, we would not have achieved such a good report.

We are extremely grateful to everyone who has recently answered our call for help and we'll be sending out material for you to review very soon. Anyone interested in becoming part of our lay reviewer team, please let us know and we'll send you full details of how to take part.



About the Information Standard

The Information Standard is a certification scheme for health and social care information. It is an independent scheme supported by the Department of Health.

Any organisation that produces health and social care information can apply to join the scheme. If an organisation successfully meets the quality criteria of the standard and becomes certified, it can place the quality mark on its materials.

The quality mark is a quick and easy way for the public to identify reliable and trustworthy sources of information. The scheme's certified members are a mix of national charities, NHS organisations, voluntary, statutory and commercial organisations. The scheme is growing as more organisations are in the process of gaining certification.

For more information
www.theinformationstandard.org

We need your help

As part of The Information Standard scheme we have developed a patient user group to review all written material.
We are grateful to those members of PAPAA who have already agreed to carry out this role.

If you would like to get involved in reviewing our material then please get in touch.

For more information about the role and specification contact:
Caroline Marven on 01923 672837 or email cjm@papaa.org

Robert Field and Dr Chris Deighton

New single society for all rheumatology health professionals

The British Society for Rheumatology (BSR) and British Health Professionals in Rheumatology (BHPR) unanimously voted at their recent AGMs for the two organisations to merge.

They agreed that, just as people with rheumatic conditions need to be treated by a team of medical professionals who are knowledgeable about them and their condition, including consultant rheumatologists, physiotherapists, occupational therapists and specialist nurses, so one society should represent this team of experts.

Speaking after the meetings, Dr Chris Deighton, president of the BSR, said: "We are delighted that our close working relationship with BHPR has been formalised. Both societies exist to promote excellence in the treatment of people with rheumatic and musculoskeletal conditions. This decision by the members ratifies our integration to do this together."

Robert Field, president of BHPR, added: "The two societies have worked very closely for some time; through this integration we have an even stronger clinical voice together. The new joint society will formally represent the multidisciplinary team involved in the care of patients with these challenging conditions.''

ABOUT THE BSR

BSR is the professional organisation for rheumatology musculoskeletal medical and long-term conditions. Supporting clinicians at all levels to deliver the highest quality rheumatology care – in the UK and abroad – by providing: An authoritative voice collectively representing rheumatology in the formulation and implementation of policy at local, regional, national and international levels.

ABOUT THE BHPR

British Health Professionals in Rheumatology (BHPR) exists to unite and support members of the multidisciplinary team in delivering best quality care which meets the needs of individuals with musculoskeletal conditions.

For further details visit:
www.rheumatology.org.uk

Skin camouflage

Perhaps you may have heard of skin camouflage or might have read the information on the PAPAA website and wondered if it would be suitable for you. The British Association of Skin Camouflage (BASC) would be the first to admit that skin camouflage is not something everyone tries, or wishes to use; neither is it suitable for every non-infectious skin condition.

However, for those who have found skin camouflage to be successful – the benefits to self-esteem and overall wellbeing can be life-changing! BASC believes skin camouflage should be offered to everyone as part of his or her dermatology care package and once informed the person can decide for himself or herself. Sadly, this is not current practice and, unfortunately, not all doctors appreciate the advantages gained by using these simple products and easy application techniques.

What is skin camouflage?

Skin camouflage is a crème that is best described as being a highly pigmented ointment which is

Mix colours together on the palm

Back of hand before skin camouflage application

applied over the psoriasis and blended into the surrounding unaffected skin. The product relies on its wax and oil formula to make it waterproof, which then needs to be stabilised (set) with a loose powder. There is the hypothesis (theory) that the wax-oil can help maintain hydration by acting as an emollient. Certainly, the wax-oil preparation should not harm psoriasis and it may well prove to be more advantageous than using water-based foundations.

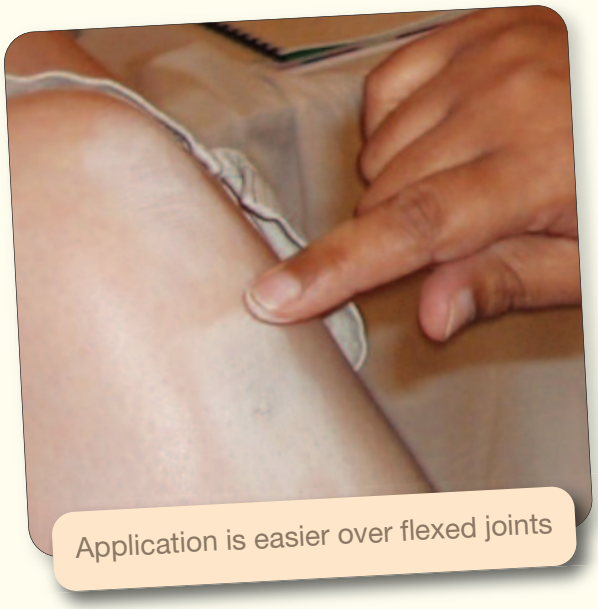
The setting powder helps to prevent the crème from smudging and it also absorbs moisture from the crème and your skin, but at the same time it will create a matte finish. Should this be inappropriate and make the camouflage obvious, then using a fixing spray will give the skin a slight, natural sheen. The fixing spray will also help prevent any natural desquamation (flaking off) during the day. Skin camouflage will last longer and look better when the lesion is flat to the surrounding, unaffected skin.

Skin camouflage cannot correct the skin's structure and function, the intention is to mask the silver-white scales and erythema (redness) with your natural skin colour, which can make the condition less noticeable.

Five brands of crème are currently available, at your doctor's discretion on NHS prescription, offering a

choice of over 300 crème colours and 10 tinted powders. These brands are also available off-prescription via the internet or order from your local chemist. Most cosmetic companies will have a range of products on sale, some of which may be suitable for camouflage.

The trick is to find the product best suited to your lifestyle – for example some brands last longer in humidity and some will give a more dense coverage than others. Once the products have been chosen you then need to achieve an acceptable skin colour match.



Application is easier over flexed joints

Consultation

Although you can purchase small 'do it yourself' kits, the skin camouflage consultant will have a wider range of brands and colours. Ideally you need a consultation with someone trained in the principles and art of paramedical skin camouflage who will select the brand best suited to your needs and help you decide an acceptable skin match. This process can take a few attempts; the 'trial and error' needs to be done on skin adjacent to the psoriasis otherwise unacceptable colours will embed between the plaques and interfere with the colour selection.

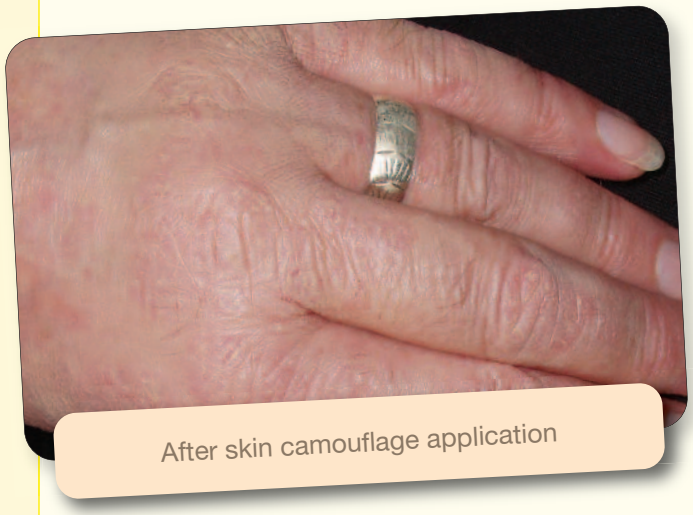
Application

Crèmes can be mixed together, when necessary, to create an acceptable colour match, although BASC would not recommend mixing more than two together because of the time this might take and the cost implication. However, it will probably be necessary for you to have a 'summer' and a 'winter' set of colours – indeed these may be identical but the consultant will show you how to mix the 'summer-darker' with the 'winter-paler' to mirror seasonal changes to your skin. This mixing principle can also apply to areas of skin that are affected by being frequently exposed to the sun, an example being the back of your arm.

You can mix different brands together, if required, with no adverse affect.

Cosmetic houses like to sell a green complementary colour to apply over erythema (redness) – this is not required for psoriatic plaques; should the skin camouflage not give the required coverage, then a pale yellow (for skin groups 1-3 based on the Fitzpatrick skin classification scale) and pale orange (for skin groups 4-6) should solve the problem.

Once an acceptable skin match has been agreed, the camouflage technician will then agree the easiest method of application. You will also be advised on how to maintain the camouflage during wear and



After skin camouflage application

effective, simple methods of removal.

Application

Emollients (moisturisers), sun protection and topical medication can be applied before (and under) the camouflage crème. You will need to allow time, up to ten minutes, for this to be absorbed – blot off any excess with a tissue – then apply the camouflage.

You will find it easier to apply your skin match crème camouflage with clean fingertips. This is because the crème needs to be gently massaged into the plaques; you will achieve an even application if you flex (bend) knees, elbows and fingers joints. A small amount of product covers a large area of skin! If necessary build up the application, ensuring that any cracks between the plaques are equally covered.

The next step is to apply the setting powder in a pressing-rolling motion over the camouflage crème. A velour make-up powder puff is the tool to use as it is difficult to achieve sufficient setting with a powder brush.

If you over-powder you can create a caked appearance, which is simply rectified by blotting the area with a slightly dampened cotton pad.

Should the camouflaged area appear too matte, then (following manufacturer's instructions) apply the fixing spray.

Obtaining the camouflage

Five brands of skin camouflage are currently available, at Doctor's discretion, on NHS Prescription.

These are Covermark, Dermablend, Dermacolor, Keromask and Veil. These can also be ordered without a prescription at any chemist (pharmacy counter), from the internet and directly from the UK distributor.

Over the counter cosmetic brands are available in department stores, chemists and online.

Camouflage consultants

You normally require your dermatologist, GP or healthcare advisor to refer you to a free NHS clinic. Private practice requires no medical referral for psoriasis, and a consultation is usually within a few days, however a fee might apply. For your nearest consultant, please contact:

- The British Association of Skin Camouflage provides both NHS and private practice and is acknowledged as the major training provider for this specialism.
  www.skin-camouflage.net

- The British Red Cross Cosmetic Camouflage Service is now under the wing of Changing Faces.
  www.changingfaces.org.uk

- The Skin Camouflage Network provides both NHS and private practice.
  www.skincamouflagenetwork.org.uk

Source:
Elizabeth Allen
The British Association of Skin Camouflage

> 'the NIHR is calling upon individual researchers and research groups to show that they back the drive to empower patients in clinical research.'

The National Institute for Health Research (NIHR) has launched a new campaign to empower patients and encourage engagement in clinical research – and are calling on all NIHR-funded researchers to take part.

The **It's OK to ask** campaign launched on International Clinical Trials Day in May and is aimed at encouraging patients and their carers to ask their doctors about clinical research and whether it is right for them.

At present, patients are often unaware of clinical research opportunities unless they are asked to take part by a clinician. Whilst the clinician-initiated approach to recruitment has been very successful, the NIHR also wants to empower patients to start conversations about research if they want to. This could have a positive impact on the speed of recruitment to studies and the general research culture across healthcare providers, which would be beneficial to researchers.

Whilst the main part of the campaign will be patient-focused, the NIHR is calling upon individual researchers and research groups to show that they back the drive to empower patients in clinical research.

About NIHR

The National Institute for Health Research (NIHR) is funded by the Department of Health to improve the health and wealth of the nation through research. Since its establishment in April 2006, the NIHR has transformed research in the NHS. It has increased the volume of applied health research for the benefit of patients and the public, driven faster translation of basic science discoveries into tangible benefits for patients and the economy, and developed and supported the people who conduct and contribute to applied health research. The NIHR plays a key role in the government's strategy for economic growth, attracting investment by the life sciences industries through its world-class infrastructure for health research. Together, the NIHR people, programmes, centres of excellence and systems represent the most integrated health research system in the world.

SOURCE:
The NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
News release

For further information, visit the NIHR website:
www.nihr.ac.uk
To find out more about the It's *OK to ask* campaign go to:
www.crncc.nihr.ac.uk/oktoask

Future models of care

ROYAL PHARMACEUTICAL SOCIETY

Current NHS reforms, along with an unprecedented era of economic, demographic and technological change, present both challenges and opportunities for the pharmacy profession. There are various visions for pharmacy and new models of practice in circulation, but nothing that knits them together in a coherent narrative for the profession's role in the reformed NHS in England.

With this in mind, the Royal Pharmaceutical Society has set up a Commission on Future Models of Care, chaired by Dr Judith Smith (pictured), director of policy at the independent charitable research foundation the Nuffield Trust.

The Commission will bring together expertise from across pharmacy, the wider healthcare sector, and patients and the public to develop practical ideas about how future models of care can be delivered through pharmacy.

The report of the Commission – to be made in autumn 2013 – will suggest how policy makers, commissioners and the pharmacy profession can put into practice such new models of care.

The Commission's terms of reference are to:

- make the case for change in relation to the role that pharmacy can play in the delivery of care
- articulate the benefits to patients of involving pharmacists in the delivery of a wider range of services
- identify the range of models of care involving pharmacy that are starting to emerge in the UK and overseas
- examine what has helped or hindered the development of such models of care
- identify what needs to be done to enable and support the spread of such models of care
- consider the implications of the Commission's findings for policy and practice in the English NHS and more widely.

About the Royal Pharmaceutical Society:

The Royal Pharmaceutical Society is the dedicated professional body for pharmacists. It was originally founded as The Pharmaceutical Society of Great Britain on April 15th 1841 by a group of leading London chemists and druggists. In 1988 The Queen agreed that the title 'Royal' should be granted to the Pharmaceutical Society. In 2010 it shed its regulatory function to become the new professional leadership body for pharmacists in England, Scotland and Wales.

NHS Scotland staff alert line

A free, confidential phone line for NHS Scotland staff who wish to raise any concerns about practices in NHS Scotland has received 34 calls from Scotland since it was launched.

The National Confidential Alert Line for NHS employees went live in April this year and provides an additional level of support and advice for staff.

23 calls anonymously raised concerns about NHS practices while 11 calls related to personnel or contractual matters. As well as this, 19 calls were received from health workers in other parts of the UK excluding Scotland.

All of the concerns that employees raised were passed on to the relevant authority for further investigation.

Health secretary Alex Neil said:

"It is vitally important that all NHS workers feel that they can raise any concerns they may have about patient safety and malpractice because it helps to improve our health service.

"We have created a way that staff can speak to an independent organisation, anonymously , safely and confidentially. I have also been clear that any areas of concern have to be investigated so that lessons will be learned.

"Over the month of March, 158,000 fliers and 5,000 posters were distributed to NHS Scotland staff and this publicity drive is set to continue to make sure that everyone who needs it knows about this service.

"While the Francis Inquiry focused on NHS England, we can still learn lessons about our NHS, by listening to staff and patients and learning from mistakes."

The contract to provide the alert line was awarded to Public Concern at Work, which will also support callers to pursue their case with the appropriate regulator when they consider this to be the most suitable course of action.

Figures on the alert line will be published quarterly on the Scottish government website. The levels of calls over the first three months will be used to set a baseline figure on which to measure future calls.

In June 2010 the government asked Robert Francis QC to undertake a public inquiry into the role that commissioning, supervisory and regulatory bodies played in monitoring the work of Mid Staffordshire NHS Foundation Trust. The request followed his earlier independent inquiry into the care provided by the hospital trust.

Source:

www.scotland.gov.uk

For more information about **Public Concern at Work**, the whistleblowing charity visit:

www.pcaw.org.uk

Regular readers of Skin 'n' Bones Connection often contact the editor about items reported in previous issues and want to know how the events or activities have progressed.

In order to update readers we have revisited some selected items of interest and the following is brief update.

In 2008 (Issue 27 P13) we reported on the research work being undertaken at the Royal National Hospital for Rheumatic Diseases in Bath (RNHRD) by Professor Neil McHugh and colleagues. One study was the MIPA trial (methotrexate in Psoriatic Arthritis). This was a multi-centred trial to look at the value of methotrexate (MTX) in the treatment of synovitis in psoriatic arthritis (PsA), which is widely used but without any trial evidence.

The results of the trial were first published online in the journal called Rheumatology in February 2012.

The trial recruited patients from January 2003 and, after screening, 221 patients were enrolled into the trial. 109 received MTX, whilst the remaining 112 participants were given a placebo. The trial headline conclusion said: ''This trial of active PsA found no evidence for MTX improving synovitis and consequently raises questions about its classification as a disease-modifying drug in PsA''.

The trial took 10 years from original inception to completion and reported that ''Many specialists were unwilling to participate because they believed that the efficacy of MTX was established and believed a placebo-controlled trial was unwarranted.''

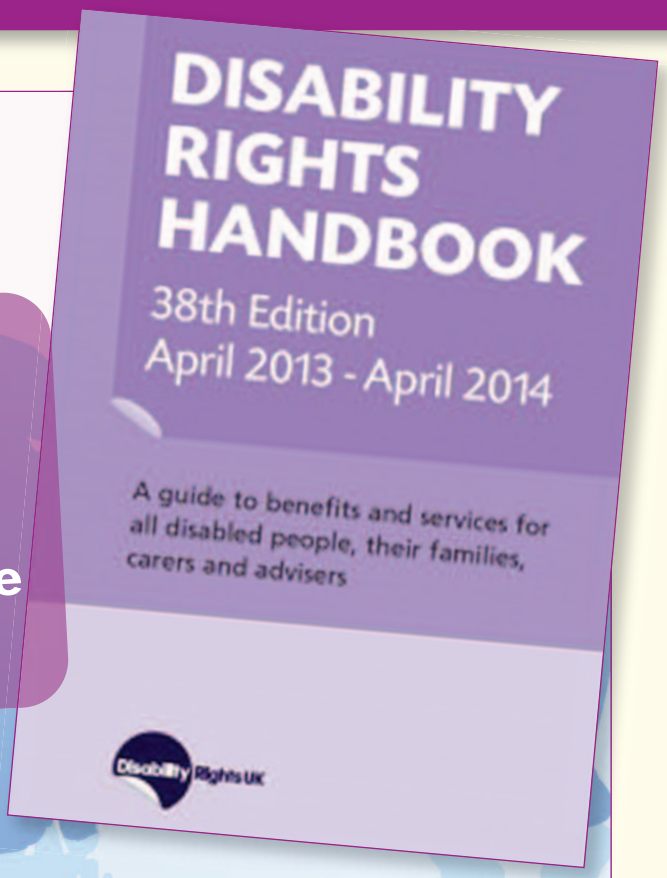
The authors of the trial paper suggested that although MTX was seen to be ineffective in PsA, that it was a complex condition and psoriasis responds well to MTX. It was also noted that patients with rheumatoid-like pattern of disease may respond to MTX, which means as a consequence ''... there are justifiable reasons for treating some patients with PsA with MTX''.

Another trial reported in the same issue of Skin 'n' Bones Connection also carried out at the RNHRD looked at using a topical methotrexate cream for nail psoriasis, unfortunately the treatment did not show enough benefit for the trial to be explored further.

Acknowledgement:

We are grateful to Professor Neil McHugh for providing trial updates and references.

To see the full trial paper of the MIPA study free you can visit: http://rheumatology.oxfordjournals.org/content/51/8/1368



'April 2013 saw the biggest changes to the benefit system since the introduction of the welfare state'

Disability Rights Handbook

The biggest changes to benefits since the introduction of the welfare state explained in the Disability Rights Handbook 38th Edition (April 2013-2014)

The new edition of the Disability Rights Handbook is a must-buy if you need advice or provide it.

April 2013 saw the biggest changes to the benefit system since the introduction of the welfare state and will affect more than 2 million disabled people. Council tax benefit will go, as will much of the social fund, to be replaced by local schemes run by local authorities.

Disability living allowance will be replaced by a new benefit for people of working age (16-64), the personal independence payment (PIP). The handbook focuses on the new PIP and explains how it works and how to claim it.

The new edition of Disability Rights Handbook provides in-depth information on the entire benefits system and comprehensive guidance on these critical changes.

The Disability Rights Handbook is written by benefits specialists and provides information and guidance on benefits and services to advisors, disability organisations and disabled people.

Disability Rights Handbook 38th Edition

is available from £15 to those receiving benefits (RRP £29.99)

To find out more visit:

www.disabilityrightsuk.org

Letters

Dear PAPAA,

I am the second eldest of thirteen children, my father has psoriasis my brother has psoriasis my sister has psoriasis and my youngest daughter may have psoriasis. Several people at work also have psoriasis and it is just accepted.

I heard about PAPAA, through my good friend, she brought me an article from a magazine, which is why I wrote to you. I will phone you when I get my results and let you know the treatment prescribed and will be happy to support your efforts; sometimes it helps to talk and offload on someone who knows the score.

Q Dear PAPAA,

Dear PAPAA

I have PsA and type 1 diabetes. I'm going onto methotrexate, but I'm concerned about any potentially issues that might occur in relation to the diabetes and whether there is likely to be any other complication or tolerance issues.

Yours KR

A Dear KR,

We asked one of our medical advisors and the response is as follows: "... I am unaware of any problems with methotrexate and diabetes. Methotrexate can make you sick, and that may affect diabetes control, but that is the only link I can think of. Not even any interaction between drugs..."

Yours PAPAA

Q Dear PAPAA,

About 3 years past I was diagnosed as suffering from psoriatic arthritis and have been on treatment for the complaint since then.

I am affected badly in the knee, wrist and shoulder joints, and recently find that it is spreading to the toe joints.

Past treatment has included injections directly into the affected joints and anti-inflammatory pills. About 3 months ago I started a course of disease-modifying tablets and these seem to have helped the condition slightly.

I am grateful for the information you have provided on the condition and found your website invaluable.

There is history of psoriasis in my family although none are in relation to the arthritic problems with joints. I am a 51 year old man and otherwise enjoy excellent health.

Yours EC

Q Dear PAPAA,

I was wondering if you could help. I am a nurse and look after many patients with psoriasis as I give biologic injections in the community. I have heard that bathing in the Dead Sea in Israel has been known to be hugely beneficial to psoriasis suffers and wondered if you had any information. I actually live in a town called Droitwich Spa, which is historically famous for its brine baths. The concentration of the salt brine is meant to be the equivalent if not slightly greater than that of the Dead Sea. Sadly the brine baths were closed a few years ago but I sit on a committee dedicated to reopening them. Naturally, I am wondering if the brine would be of benefit to psoriasis patients. It is known to be of great benefit to patients with locomotor disorders but I am hoping its benefits extend to psoriasis patients too. If so this could help raise our profile for helping psoriasis patients as well as campaigning to reopen such a valuable resource. If you have any information or suggestions to raise our profile, I would be so grateful and hope that if this resource could help; maybe suffers would not have to travel as far as Israel.

Yours MC

A Dear MS,

It's a difficult question; as you know, the only way to find out, will be to conduct a trial and given that it would be obvious who is in salt water and who is not, the data would not be very useful. There have been some trials papers on the Dead Sea and many anecdotal reports of the benefits, but this again is difficult to assess as other factors come into play, such as being on holiday, hot climate, having a rest and the placebo effect of faith in the Dead Sea as 'curative' treatment.

Yours PAPAA

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

Did you know? Genetics of PsA

Genetic factors play a role in PsA. People with PsA often have a first-degree relative (parents or siblings) with either psoriasis or PsA, and occasionally uveitis (inflammatory eye condition), Crohn's disease or ulcerative colitis (inflammatory bowel disease) Despite this, the children of people with PsA usually do not develop PsA, because PsA is thought to occur when a genetically susceptible individual is exposed to some sort of environmental trigger (eg a virus, trauma, toxin, hormones etc).

Comments:

"... I have PsA and my son has psoriasis and has recently developed an inflamed eye that the GP thinks may be uveitis , am praying it isn't..."

"... me, my brother and my dad all have psoriasis, and I was diagnosed with PsA a few years ago. I do have a borderline under active thyroid too so maybe this was my environmental trigger...? Very interesting to ponder, nonetheless..."

A selection taken from our Facebook page at www.facebook.com/papaa.org

"...Hello, I am hoping someone on here can help me. I have various symptoms and I think I may have psoriatic arthritis. I have had psoriasis on scalp, forehead and ears since 25 years old and I am now 38. Here is a list of my symptoms, itchy ears, sore sole on left foot, pelvic pain, conjunctivitis now cleared up, severe fatigue, pain in my lower spine just above my buttocks, sore hips, sore neck and shoulder blades. I also have problems with my hands, they are very sore and they tend to swell up and I lose my dexterity, i am due to go see a rheumatologist and I am waiting on an appointment. do any of you who have been diagnosed with psoriatic arthritis have these symptoms..."

Comments:

"...Certainly it sounds as though you have many symptoms that are associated with psoriasis and psoriasis arthritis, but it is important to get a correct diagnosis and seeing a rheumatologist is the best thing to do at this stage. .."

People with psoriasis often face a dilemma – they have heard that the sun is good for their condition, yet are loathed to reveal any more of their skin than they are absolutely obliged to. You aren't alone if you are one of those who wear polo necks, long sleeves and trousers or leggings even on the hottest summer days and never sunbathe.

Comments:

"... Sun always makes my skin worse and me really ill hated it !! the only thing that got rid of my psoriasis was salt water / sea swimming and a lot of tlc with aftercare..."

"... Hate the summer because of my skin!!!..."

"... Sun makes mine a lot worse,bought a cardigan in every colour n even had to wear flesh coloured gloves last year on methotrexate now, hands clear but not with the rest yet so another year of covering up !..."

"... to be honest guys and gals I dont care I just get my skin out and ... the people who wanna judge can just get on with it..."

"... Worse, worse, worse..."

"... I find the sun is the best treatment for my psoriasis, as long as you are sensible about it of course my UV treatment was the best thing I ever did - my psoriasis has been much better since the 6 months of treatment about 6 years ago. Now I just maintain it with regular sun exposure and people always comment that I have beautiful skin - never thought I'd hear that!..."

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

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

To date people have been discussing tiredness, diet and disability claims amongst other topics.

We post interesting news items and links to fuller articles on our website.

We also have a Twitter page linked to our Facebook page so if you prefer the micro-blogging site then you can follow us by clicking the link, which is also located on our home page.

Marketplace

FREE

eTips
learn how to cope with psoriasis

A simple online interactive, multimedia programme using Cognitive Behavioural Therapy (CBT)

A safe therapy that helps you to change the way you think and react to certain situations that may affect your outlook and moods associated with your psoriasis

- Easy to use
- Online
- At home
- In your own time
- Hassle free

Access is easy; all you need is a valid email address and a password will be sent to you.

For more information go to:
www.etips.org.uk

papaa

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
- Training programmes.

Getting the best prices online:

Price comparison sites - enter the search phrase 'compare prices' into a search engine and then access the sites directly.

Remember to check availability of products, cost of delivery and most of all whether the site is secured for ecommerce transactions.

- **www.dealtime.co.uk**
- **www.comparestoreprices.co.uk**
- **www.kelkoo.co.uk**
- **www.google.co.uk/products**

Secure sites will have a certificate on the site, such as **GoDaddy, DigiCert, VeriSign, Thawte** and **Comodo**. These certificates will allow you to check site validity, if you are suspicious.

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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.