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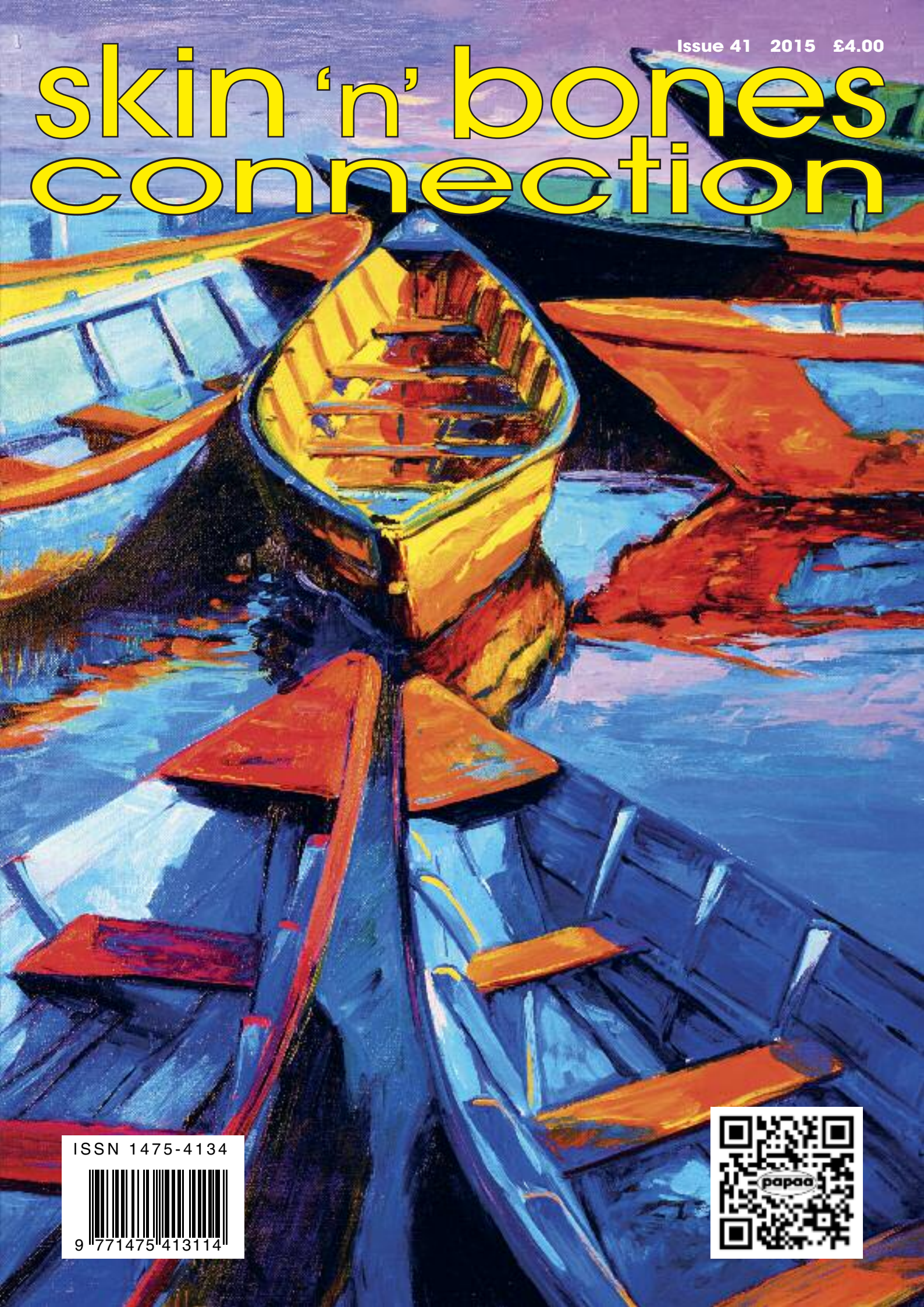
skin 'n' bones connection



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Dear Reader

Striking a balance between raising awareness and scaremongering is always a challenge. The need to alert people of potential dangers of unforeseen consequences sometimes can appear negative. The lack of knowledge of any subject often provides a vacuum that sucks in the fears and phobias.

We try to provide a positive, balanced view and allow you, the reader, to make an informed choice based on evidence and fact; sometimes the interpretations of the evidence are not reflective of our own experiences. On page 3, we explain how we are trying to bridge these two differences with the use of surveys and real-life views.

Living with a chronic condition often affects activities that others would not give a second thought about undertaking, whether in our personal lives or working day. Going on holiday or travelling can be an event that many approach with delight, but if you have to take or carry medicine it can be a daunting task. On pages 10-11 there are some ideas you may wish to consider so your planned trip runs as smoothly as possible.

Gaining knowledge and putting it into context can provide reassurance and reduce anxiety, knowing where to find information or who to ask can make living with a chronic condition easier, and knowing your rights is a good place to start (see Marketplace page 20).

Managing editor

Correspondence Address:
PAPAA
3 Horseshoe Business Park, Lye Lane, Bricket Wood,
St Albans, Herts. AL2 3TA
E-mail: info@papaa.org
Web: www.papaa.org
Tel: 01923 672837 Fax: 01923 682606

Production team:
Julie Chandler
Managing Editor

Typesetting and Design
Macpro Design and Print Ltd, St Albans

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11–15 William Road, London NW1 3ER

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

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Original Oil Painting on Canvas. Boats and sea.
Modern impressionism From ShutterStock

Quantitative v qualitative

As a charity, we have and will continue to support the need for good quality psoriasis and psoriatic arthritis research, whether it is quantitative or qualitative. The results of research can often be difficult to interpret due to the need for definitive answers.

Quantitative research gathers data in numerical form, which can be put into categories, or in rank order, or measured in units of measurement, whereas **qualitative** research gathers information that is not in numerical form. For example, diary accounts, open-ended questionnaires, unstructured interviews and unstructured observations. This qualitative research can be very powerful as it has a personal perspective; for conditions like psoriasis and psoriatic arthritis, this is very important.

It is always impressive to see the results of a clinical trial, where a new drug is trialled against a current therapy and the results demonstrating better outcomes. But what if the new treatment causes side-effects, has to be used more frequently or is administered in a hospital and therefore becomes a burden or impossible to use? It could be argued that the results are worth any potential inconvenience that might be involved in the process of getting better or avoiding disability.

What quantitative research cannot tell us is what it is like to live with a chronic condition. It can tell us how someone responds to treatments and can measure that response, and it can record the side effects and disease progression, but cannot report the emotional and psychological impact. For that, a different approach is needed and qualitative research looks to explore this.

The use of data gathered from qualitative research is becoming increasingly, in some cases, more important. The patient perspective has a vital role to play. Patient advocacy organisations such as PAPAA are continually approached from bodies such as the National Institute for Health and Care Excellence (NICE), The Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (AWMSG) to provide input in the appraisals of new drugs for use in the NHS. Our submissions are made by gathering the collective views of those who contact us. In recent submissions we have used anonymised quotes directly taken from surveys to give a connection to real people.

Those that make decisions on whether a drug is approved for use or not do so by reviewing the evidence presented; as stakeholders (those affected by decisions) we do our best to make sure that people with psoriasis and psoriatic arthritis get their voice heard. We attend the meetings, we make submissions, contribute as expert patients and comment on the decisions made. If you have ever made a comment, completed a survey or provided us with your observations, it has not been in vain; it has all been used to develop the view we take when representing patients.

We intend to continue to gather real peoples' views and take these forward to influence the important areas of need. We have a number of surveys you can complete which can be found on our website.

Psoriasis quality of life survey: www.papaa.org/quality-life-psoriasis-survey

Psoriatic arthritis quality of life survey: www.papaa.org/quality-life-psoriatic-arthritis-survey

Research priorities survey: www.papaa.org/surveys/uk-research-priorities

For those of you who do not have access to the internet, paper versions of all our surveys are available upon request.

Last year you responded and provided your views on what people would see as priority areas of research and so far, we have received close to 1,000 suggestions. The suggestions are now being refined into areas of interest and need and we will be seeking further views once we have the data analysed. You can continue to provide your views as we will be checking that the priorities continue to reflect what is important to patients.

Special-order medication

Whether your psoriasis is newly diagnosed or you have had it for many years, there may be occasions when your doctor might consider offering you a different form of treatment, particularly if you have not seen any improvement or have been affected by an adverse reaction.

There are myriad of treatments, and most people at some stage will have tried or been offered a topical application, such as a cream or ointment. These products, whether available on prescription or over-the-counter from a pharmacy, are likely to be a 'licensed' branded product or a licensed generic equivalent in a container and packaging that has been manufactured by a pharmaceutical manufacturing company.

There is also a group of products, which your doctor might consider prescribing, where the contents are made to a formulation which is considered more useful for your personal circumstances. These products are considered to be unlicensed medicines and are available from 'special-order' manufacturers and specialist-importing companies.

The Association of Pharmaceutical Specials Manufacturers' website describe these products as:

"A Special is an unlicensed medicine prescribed to meet the individual clinical need of a patient when a suitable licensed medicine is not available. 'Specials' account for approximately 1% of all prescriptions in the UK, but account for more than 75,000 different formulations. Most Specials are produced by a small number of pharmaceutical companies who dedicate their resource and expertise to this very specialist area of medicines manufacture. In the UK, these companies are represented by the APSM – Association of Pharmaceutical Specials Manufacturers."

The Medicines and Healthcare Products Regulatory Agency (MHRA) recommends that an unlicensed medicine should only be used when a patient has special requirements that cannot be met by use of a licensed medicine.

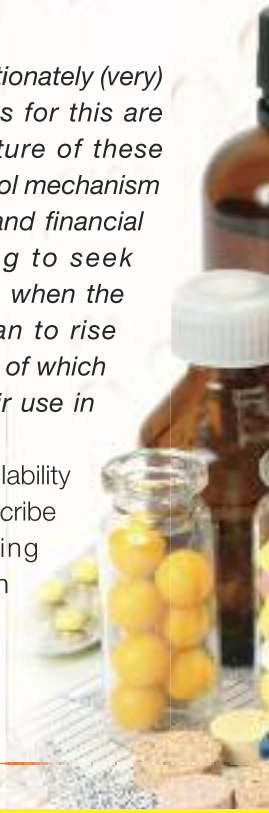
Given the potential number of different formulations that could be used, The British Association for Dermatologists (BAD) has recently produced a guide to help rationalise the different products to a more accessible 39 combinations in a publication called ***Specials Recommended by the British Association of Dermatologists for Skin Disease 2014*** **www.bad.org.uk/specials**. The aim of this is to reduce minor variations in prescribing, which will allow the most effective and popular specials to be more readily available to patients, and provide prescribing guidelines for non-specialists.

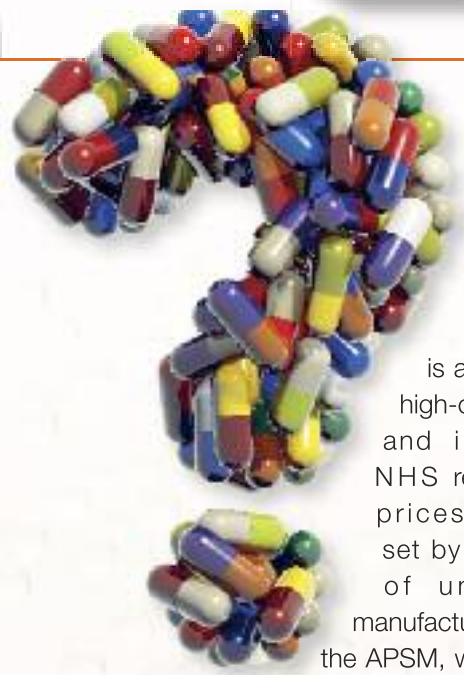
In the document, the BAD says:

"... unlicensed medicines are disproportionately (very) expensive in primary care. The reasons for this are complex but include the bespoke nature of these medicines, the absence of any legal control mechanism on manufacturing and dispensing fees and financial incentives in community dispensing to seek preparations at higher cost... until 2008 when the cost of Specials in primary care began to rise sharply (to £120m in England in 2009/10, of which up to £30m was topical medicines) their use in primary care attracted little attention."

For many people with psoriasis the availability and flexibility of a doctor being able to prescribe potentially beneficial therapies is being hampered by the high cost and acquisition process of these products.

In November 2011, the Department of Health (DoH) introduced a





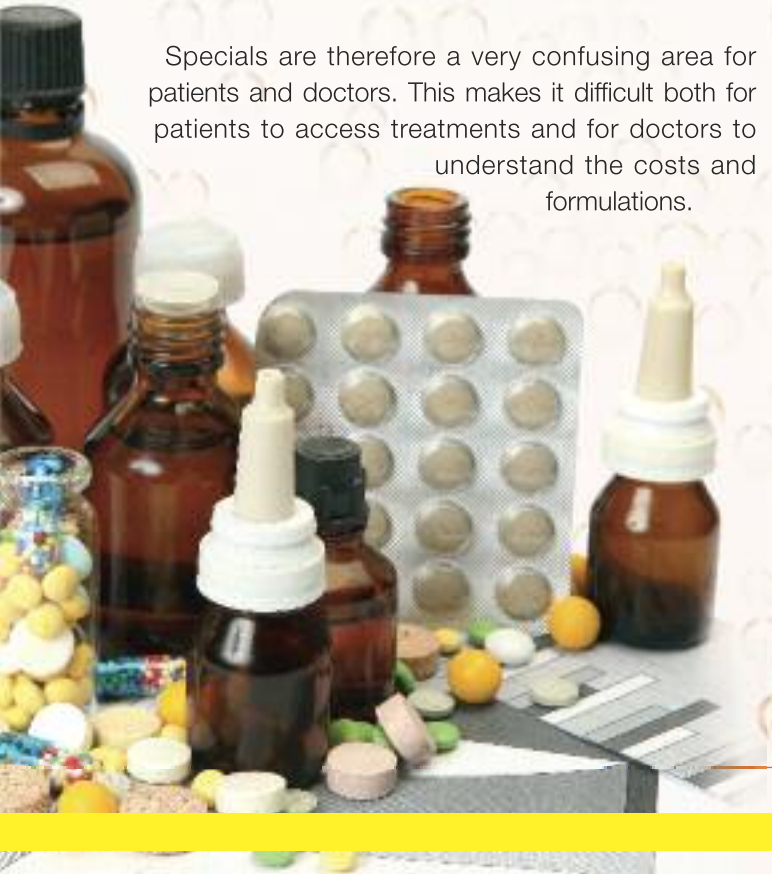
Specials Drug Tariff, which involved changes to arrangements relating to the reimbursement of Specials.

Part VIIIB of the drug tariff is a tariff of high volume and high-cost unlicensed specials and imports, with set NHS reimbursement prices. The prices on the tariff are set by analysis of a selection of unlicensed specials manufacturers' prices submitted by the APSM, with a margin included for pharmacy purchase profit. For all other products not listed in Part VIIIB, the pharmacy can claim back the full amount they paid for the special (even when it is thousands of pounds) plus £20 for acquisition costs. The tariff is designed to limit the latter practice, which is associated with very high costs, as the pharmacist had no incentive to purchase a special cheaply.

In June 2013 The Daily Telegraph reported:

"... it has today been disclosed that a complicated system of backhanders and discounts means that pharmacists and manufacturers can reap enormous profits from the NHS. In 2012 the cost to the NHS of buying "specials" exceeded £100 million, with about 800,000 medicines prescribed by doctors."

Specials are therefore a very confusing area for patients and doctors. This makes it difficult both for patients to access treatments and for doctors to understand the costs and formulations.



We are keen to understand what specials mean to people with psoriasis and would like to hear your experiences.

- **Have you been offered a special?**
- **Who offered you a special?**
- **Tell us what your experience of a special is?**
- **Do you know how much they cost?**
- **Have you had difficulty getting your special?**
- **Do you have any other issues related to specials to share?**

You can tell us your experience by visiting our website and submitting your anonymous comments at: **www.papaa.org/your-views**

Alternatively you can

email: info@papaa.org

telephone us on 01923 672837

or write to:

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

Reference and source material:

- The Association of Pharmaceutical Specials Manufacturers www.apsm-uk.com
- The Medicines and Healthcare Products Regulatory Agency (MHRA) www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency
- The British Association of Dermatologists Specials Recommended by the British Association of Dermatologists for Skin Disease 2014 www.bad.org.uk
- The Daily Telegraph. Article: Pharmaceutical scandal specials unlicensed medicines outside NHS tariffs can reap huge profits; 20 June 2013
- To report a side effect go to: https://yellowcard.mhra.gov.uk/

Skin services failing

A report by The King's Fund into a major NHS speciality - dermatology - has identified staff shortages, poor training, inconsistent quality in diagnosis and treatment and large variations in access to specialist care, affecting millions of patients across the UK each year.

Dermatology represents an important part of NHS provision. Each year, approximately 24% of the population will visit their GP with a skin complaint, making skin conditions the most frequent reason for people to consult their doctor with a new problem.

The independent report by The King's Fund, commissioned by the British Association of Dermatologists and released recently, reveals a number of worrying challenges facing dermatology services and identifies opportunities for improvement, which may also be applied to other health specialties. The report looked at a range of issues, including workforce (staffing), training, use of temporary or locum staff, technology and the role of pharmacy, making a number of observations and recommendations.

The authors, Nigel Edwards and Candace Imison, summarise:

"Dermatology represents an important part of NHS provision. There are approximately 13 million GP consultations for skin conditions a year and 716,830 new referrals and yet this important area is poorly understood and has received comparatively little attention. Commissioning has often been poor. Inadequate planning has left gaps in the workforce. The 40,000 GPs managing this workload have received little training in dermatology and there are only 650 consultants to advise them and provide the more specialist care."

These include the following two key recommended objectives:

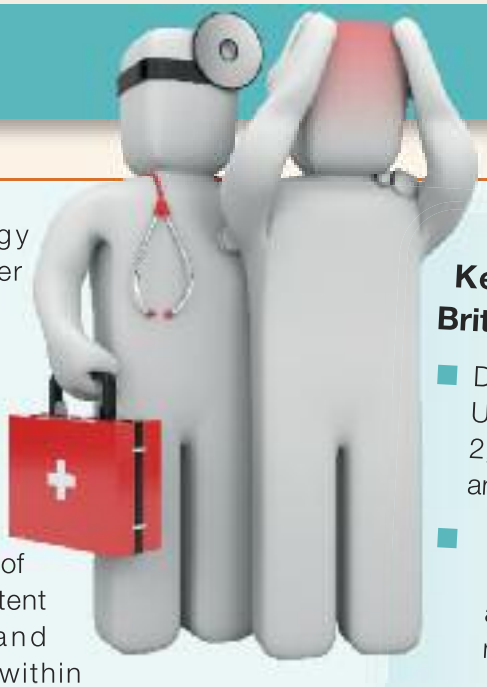
1. To urgently improve quality of dermatology knowledge in primary care.

The report outlines: "GP dermatology teaching averages approximately only six days and most GP training schemes have no dermatology attachment…. Dermatology undergraduate training averages a couple of weeks at most, is variable in terms of quality as well as syllabus, and it is not compulsory." As well as improved education and training and targeted continuing professional development, other solutions might include the development of experts in larger GP practices, and the use of peer review and decision-support."

2. To improve commissioning

The report states: "Our work exposed major concerns about the current quality of commissioning for dermatology services and the lack of specialist knowledge among commissioners… Commissioning should not be driven by short-term tactical decisions designed to minimise the price paid rather than to improve value for patients; there is a danger of service fragmentation and of models of care that make false economies … or in the worst case threaten the quality of care. We saw a number of examples of this."

The British Association of Dermatologists (BAD) asked The King's Fund to explore the current challenges facing dermatology services and identify opportunities for the future. The King's Fund engaged a wide range of stakeholders from within and outside dermatology to help address this question. This engagement activity included a survey, stakeholder interviews with patients and with clinicians from both primary and secondary care, interviews with the independent sector and commissioners, visits to



specialist dermatology services, and stakeholder workshops.

"There are opportunities to improve these services but also an increasingly urgent need to respond to: growing demand and expectations; rising costs of new treatments; inconsistent quality in diagnosis and treatment (particularly within primary care); large variations in access to specialist care; issues with patient experience; and shortages, and an uneven distribution, of senior medical and nursing staff. There is a challenge for primary care where there are some of the greatest opportunities for improving the quality of care for people with skin conditions. This report looks at these issues and the options for addressing them.

"Dermatology is a useful case study that can shed light on thinking for other outpatient-based services and how these can develop new delivery models that make better use of limited specialist skills."

Dr David Eedy, president of the British Association of Dermatologists said:

"This independent report confirms our suspicions about many of the problems currently facing dermatology, while suggesting some interesting solutions. Workforce and GP education are already top of our agenda, yet seem to be ignored by the powers that be. Given that as much as 20-25% of GP workload involves skin disease, the added pressure on GPs will not be alleviated by cutting further consultant dermatologists who help them with some of their most numerous, time-consuming clinical problems. And yet the shortfall in consultant numbers is not being addressed by creating further trainee posts in dermatology, which would seem like a logical step. Furthermore, it is widely acknowledged that there is a lack of knowledge about skin disease in general practice as a result of poor undergraduate and postgraduate teaching which leaves most GPs lacking the skills to manage dermatology and results in more patients being referred to consultants. This is not the fault of the GPs but of the education they are offered."

Key facts about skin disease from the British Association of Dermatologists:

- Dermatology comprises a vast proportion of the total UK health burden. Dermatologists manage over 2,000 diseases of the skin, hair and nails in adults and children.
- Each year 54% of the population is affected by skin disease, and 23 to 33% of the population at any one time has a disease that would benefit from medical care.
- Approximately 13,000 melanomas and around 500,000 non-melanoma skin cancers are diagnosed a year. The number of just one type of skin cancer, basal cell carcinoma, equals all other cancers combined, and increased by 133% between 1980 and 2000. Melanoma incidence increased by 50% over just 13 years. Actually the true figure is not known because the government does not collect the numbers!
- Approximately 4,000 deaths occur in the UK annually due to skin disease, most often from malignant melanoma.
- Skin diseases represent 34% of disease in children, with atopic eczema affecting 20% of infants.
- Skin cancer is the most common cancer and the second most common cancer causing death in young adults.
- Hand eczema is one of the most common reasons for disablement benefit in the UK.

The King's Fund is an independent charity working to improve health and health care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible care is available to all.

Source:
British Association of Dermatologists

Tattoos and body piercing

Tattoos

A tattoo is when a permanent mark is made on the skin by using a needle or similar device to insert a coloured ink or dye, in order to create a decorative pattern on human skin. In animals tattoos are used as a permanent form of identification, this is referred to as branding.

Tattooing has been practised in many cultures throughout the world and in some cases used for religious or ceremonial reasons.

The first electric tattoo machine was produced in the late 19th century, although this made tattoos more popular, the trend was more likely to be taken up by sailors or those considered to be of dubious character.

Henna tattoos or mehndi tattoos are painted on or applied from a tube. Mehndi is an ancient art form, where a powder made from dried lawsonia inermis leaves is dissolved in hot water. The design is then applied to the skin and left to dry for 30-40 minutes, washed off leaving a temporary 'tattoo'. There have been reported cases of contact dermatitis where chemical colouring agents have been added; this is sometimes called 'black henna'. The eruption causes intense itching and burning at the application site. Treatment with systemic steroids and topical antibiotics may be needed in extreme cases.

Body piercing

This is where a hole is made in the skin in order that a ring or other piece of jewellery can be inserted. The most common site would be the earlobe. There are many reasons why piercings are done. It was believed by sailors that pierced ears improved eyesight, and in some countries ear piercing is seen as an entering puberty ritual.

Psoriasis, tattoos and body piercing

In some people psoriasis can be caused by a trauma to the skin, including cuts, bruises, burns, bumps, vaccinations, tattoos, piercings and other skin conditions. These traumas can cause a flare-up of psoriasis symptoms either at the site of the injury or elsewhere. This condition is called Koebner's phenomenon.

Koebner's phenomenon or Koebnerisation, (named after German dermatologist Heinrick Koebner) is where skin has become traumatised following injury. Psoriatic lesions can develop at the injury site where psoriasis has not been previously seen; including cuts, bruises, burns, bumps, vaccinations, tattoos and other skin conditions. For this reason if you have psoriasis or a family history of psoriasis you may want to think seriously about undertaking such procedures.

If you still want to have a tattoo or body piercing make sure you discuss this with your doctor or healthcare provider, in order to get the facts about how these procedures may affect you.

Remember, it is illegal for anyone to tattoo or body pierce anyone under the age of 16, it is also illegal to tattoo or body pierce anyone under the age of 18 without the permission of a parent or guardian.

Other risks to consider

Dirty equipment: piercing of the skin with a needle or injecting a dye into it, involve some risk of infection – because it means breaking the protective layer on the skin. Instruments used during the process may not be clean, or bacteria/viruses already on your skin may penetrate the immune system. Possible infections you might get if you're unlucky include serious diseases such as hepatitis B, hepatitis C, herpes and even HIV.

Ask about hygiene procedures.

If you are considering any of these procedures, make sure those practitioners have established reputations and are registered tattoo studios. Ask to see a certificate from environmental health.

Untested dyes: many of the dyes used in tattoos are untested and not necessarily designed for the purpose of injecting them into the skin.

Other skin reactions: apart from psoriasis, some people have skin reactions to tattoos, such as swelling, scaling, ulcers or the forming of large scars called 'keloids'. Body piercing can trigger rashes or blisters which may be caused by allergic reactions to the metals contained in jewellery. If you have diabetes, problems with your immune system or if you have chemical sensitivities you should also be careful and consult your doctor.

Negative attitudes: some employers may have prejudices that could make it difficult getting the job you want when you leave education or seeking different employment, this could also cause you problems in later life.

If you are still determined to have a tattoo or body piercing, you need to consider that getting a piercing or tattoo is a permanent commitment. You can remove tattoos with laser treatment but it's very expensive and there are no guarantees – it can leave scarring, a shadow or discoloured skin. Piercing does tend to heal over but may sometimes leave a small scar. If the piercing has been in for a while you may be left with a permanent hole. Psoriasis can also occur at scar/injury sites.

Scientific research

In 2003 the European Commission undertook a study called *'Risks and Health Effects from Tattoos, Body Piercing and Related Practices.'* Which concluded:

The health impacts and risks associated with tattooing and piercing as reported casually in the medical literature shows that a systematic observation and registration of health impacts is widely missing.

The origin and chemical structure of colouring agents used for tattooing are hardly known.

Pigments are mainly industrial organic pigments with

high microbiological and impurities and a load of metals such as cobalt and mercury.

The observed health effects, which are potentially associated with tattooing and piercing, include:

- **viral infections such as hepatitis, AIDS, and cutaneaous infections**
- **bacterial infections such as impetigo, toxic shock syndrome, tetanus, chancroid, tuberculosis and leprosy**
- **fungal infections such as sporotrichosis and zygomycosis**
- **allergic reactions such as cutaneous irritation and urticaria**
- **granulomatous/lichenoid reactions**
- **pseudo-lymphomas**
- **lymphadenopathy**
- **sarcoidosis**
- **malignant lesions such as melanoma and skin cancer**
- **behavioural changes**
- **psoriasis, photosensitisation, phototoxicity and photogenotoxicity**
- **nickel allergy**

Little is known with respect to the transport and metabolism of the colouring agents in the body both with respect to tattooing and removal of tattoos by laser treatment.

Risk assessment studies for these substances are only emerging. At present, existing knowledge is insufficient to quantify the administered dose of harmful substances.

The scientific evidence reported leads to the following recommendations:

- Adverse health effects associated to tattooing and piercing should be avoided by applying only substances and materials ("positive list"), which are not harmful, do not dissolve in the blood stream, do not contain heavy metals and are compatible with the skin and blood vessels. Ingredients of colours and materials should be properly labelled. It should be obligatory to have licensed colours and materials to be used in tattoo and piercer studios.
- The hygienic conditions of tattoo and piercing studios should be standardised and regularly controlled. Minimal hygiene rules should be made obligatory.
- Regular training courses on the potential health impacts should be performed for tattooist and piercers.
- An accreditation bureau/laboratory should be established for education of tattooist and piercers and supervision of their studios.
- Surveillance of occupational diseases of tattooers and piercer mandatory.
- Harmonised schemes should be developed at the European level.
- There is a need for epidemiological studies on the prevalence and causal association of tattoo and piercing-related adverse effects.
- The debate on epidemiological studies of tattoo and piercing-related viral hepatitis needs to be clarified.

A warning should be given to clients informing them of the potential adverse health effects in vulnerable individuals, which includes:

- **pregnant women**
- **children and infants**
- **atopic individuals**
- **individuals with heart diseases**
- **behaviourial issues**
- **individuals with dermatous diseases**
- **individuals exposed occupationally to heavy metals, VOCs, PAHs, UV.**

Reference:
***Risks and Health Effects from Tattoos, Body Piercing and Related Practices*, May 2003 D Papameletiou, A Zenie, D Schwela, W Bäumler – Final draft Ispra May 2003 available on the web at: www.gesundheit-nds.de**

Medicine and travel

When booking a holiday it may be the last thing on your mind, but what and how you travel with your medication needs to be given careful consideration.

Some countries have different rules about what and how you can and cannot transporting medicine with you. It is worth checking the rules that apply to the specific country you are visiting, this will also apply to countries you may be passing through. So check the rules on:

- **the type of medicine allowed in the countries you visit**
- **the maximum quantities allowed**
- **also check as some over-the-counter UK medicine may be controlled in other countries and vice versa.**

For example, Turkey, Pakistan and India have lists of medicines that they will not allow in to the country. Do not solely rely on hearsay or friends for advice, always contact the relevant country's embassy to get a definitive list. A good place to find information is on the government website and searching for 'foreign travel advice' as this will give you links to useful information.

You also might consider asking the carrier such as the airline, train, ferry or cruise operators as their rules may be more or less restrictive than the country you visit. What you can take in your hand luggage on a plane may be restricted and you will need to place items in the main hold; this can cause problems as the temperature might affect the medicine. Read the patient information leaflet (PIL) which comes with your medicine as this will tell you how to store it and at what temperature. All PILs can be viewed at the electronic medicines compendium.

The best advice is plan well ahead; make sure you have enough medication for your complete trip. If you need prescribed medication for your health condition, talk to your GP or practice nurse about your travel plans at least two months before your departure date. They can tell you if you need to make any special arrangements, including any recommended immunisations. Remember injury sites can trigger psoriasis (Koebner phenomenon - as we referred to in page 8 tattoo article). Consult your doctor about any immunisations you may require as these may have immune system reactions or interfere with your current medication. Always remember to inform those carrying out your immunisations that you have psoriasis / psoriatic arthritis.

The advice that is given by the NHS is to:

"always carry medicines and medical equipment (needles, syringes and so on) each in their original, correctly labelled

packages. Carry your medication in your hand luggage (airline regulations permitting – check these prior to travel) with a copy of your prescription.

"Pack a spare supply of medication in your suitcase or hold luggage (along with another copy of your prescription) in case you lose your hand luggage. Check that the expiry dates of your medicines will be valid for the duration of your visit abroad."

Carrying a copy of your prescription or a letter from your doctor may also help you to avoid issues at customs and security. Having a translation into the local language of the country you are visiting can also aid you. This might also apply to any allergies you may have and provide a simple solution when buying products or dining out.

If you are taking a controlled drug as described under the misuse of drugs legislation in the UK, you may need to consider that extra legal controls apply to these medicines. It is advisable to talk to your GP as you may need a personal licence to take controlled medicines abroad.

Once you get to your destination, consider how and where you will store your medicine. If you are visiting a country, with a hot climate and particularly if you need to keep your medication at UK room temperature (below 25°C) then you may wish to take with you a vacuum flask (also known as a Dewar flask, Dewar bottle or Thermos) or a similar insulating storage vessel. A cool bag, ice pack or block may also provide a useful solution.

Finally, don't forget to make sure you have adequate holiday insurance to cover you and your family in the event of an emergency. Also remember to get your EHIC - European Health Insurance Card (formerly E111). The EHIC is free of charge and you can apply or renew a card via the official EHIC online application form, which can be accessed via the NHS website. Beware of unofficial websites, which may charge if you apply through them.

With good planning and thinking ahead booking, a holiday or trip can be just "what the doctor ordered".

Information for this article sourced from the following useful websites:

UK government: www.gov.uk

National Health Service: www.nhs.uk

Electronic Medicines Compendium: www.medicines.org.uk/emc

Sunscreens

In a recently published report by *Which?*, the consumer champion tested 13 of the most popular brands of sun creams, including Nivea and Piz Buin, as well as own-brand products from supermarkets including Asda, Morrisons, Sainsbury's and Tesco. They all claim to provide SPF (sun protection factor) of 30.

SPF 30 means that 1/30th of the burning radiation will reach the skin, assuming sunscreen is applied evenly at a thick dosage of 2 milligrams per square centimetre (mg/cm2). So it is important that the information given to consumers on the product matches performance.

In the *Which?* test two products twice failed their SPF tests: Boots Soltan Protect & Moisturise Lotion SPF30 (200ml) and Hawaiian Tropic Silk Hydration Lotion SPF30 (180ml).

Which? report that they used strict British Standard tests to assess whether the sun creams offer the SPF claimed on the label, as well as the protection provided against UVA.

Where a product failed either of these tests, *Which?* then retested a second batch. Boots Soltan Protect & Moisturise Lotion SPF30 (200ml) and Hawaiian Tropic Silk Hydration Lotion SPF30 (180ml) both twice failed the *Which?* SPF tests, offering just two-thirds of the SPF they claimed.

Which? contacted both Boots and Hawaiian Tropic about the results. Both manufacturers said they conduct their own testing of their products and they stand by the products' SPF claims.

Which? executive director Richard Lloyd said 'Consumers must be able to trust and rely on the information provided by manufacturers so it's disappointing to see well-known brands falling short. We want them to take action to ensure their products deliver the promised protection.'

The use and importance of sunscreens has been widely reported and is key in the challenge of preventing skin cancer.

In response to the *Which?* findings, Cancer Research UK's health information manager Dr. Claire Knight said:

'In the UK more than eight in 10 skin cancers could be prevented by enjoying the sun safely and not getting sunburnt.'

'The SPF and star rating are the two most important things to look out for when choosing sunscreen so, whichever brand you choose, it's vital you can trust the information given on the bottle.

'Using sunscreen isn't the only way to protect your skin from strong sun. Covering up with a shirt, hat and sunglasses and spending time in the shade are the best ways to reduce the risk of sunburn and skin cancer.'

The full test report can be found online at the *Which?* website **www.which.co.uk**

Further information about taking care in the sun is available from the

www.papaa.org/further-information/psoriasis-and-sun

British Association of Dermatologists Sun Awareness Campaign webpages, which can be accessed at www.bad.org.uk

Main source for this article: www.which.co.uk

In September 2014, Pharmacy Voice joined NHS England's Sign up to Safety campaign, making a commitment to keep a focus on patient safety through its work streams and at the forefront of all its responses.

Further developing this commitment, Pharmacy Voice has launched a patient safety group for community pharmacy MSOs (Medication Safety Officer). Pharmacy Voice's new group will build upon the Sign up to Safety commitment to keep pharmacy staff informed, ensuring they remain up to date on topics and developments that could impact on patient safety.

Each MSO is a member of the recently created National Medication Safety Network, and acts as the main point of contact for their organisation with NHS England and the Medicines & Healthcare products Regulatory Agency (MHRA) on medication safety matters. All community pharmacies with over 50 branches must appoint their own MSO, typically the superintendent pharmacist or a member of their team. At the request of NHS England, Pharmacy Voice founding member, the National Pharmacy Association, is acting as the MSO to the independent sector for pharmacies with fewer than 50 branches.

Janice Perkins, Pharmacy Voice board member and superintendent of Well (formerly The Co-operative Pharmacy) said:

"Since pledging our support to NHS England's Sign up to Safety campaign last year, Pharmacy Voice has been working to expand and develop this idea by creating a specific community pharmacy group. Patient safety is the most important consideration for all front-line health professionals, and it is vital that pharmacy teams are given guidance and share knowledge around how they can improve patient outcomes in a variety of circumstances. What is really special about the group is that although our businesses are all competitors in many regards, we are working together here for the benefit of patients and the public. We are collaborating because we are passionate about driving the patient safety agenda and developing practical solutions to issues that impact us all in our working practice."

The primary aim of the Pharmacy Voice Patient Safety Group is to influence the patient safety culture across community pharmacy. Key priorities are:

- understanding the culture that underpins safe practice and in particular the human factors impacting the dispensing process;
- learning from other industries with expertise in managing safety and risk, eg the aviation industry;
- undertaking a proactive programme of research and audit, building on Pharmacy Voice's previous work;
- collaborating with other healthcare providers and in particular secondary care MSO contacts;
- understanding the impact of dispensary organisation and changes in practice on patient safety; and,
- developing patient safety best practice. Pharmacy Voice will issue a patient safety bulletin twice yearly to update on the patient safety group's progress. The first bulletin was released in June 2015.

About Pharmacy Voice

The three largest community pharmacy associations formed Pharmacy Voice in 2010 to create a stronger, unified voice for their independent & multiple members.

The members of Pharmacy Voice are the Association of Independent Multiple Pharmacies (AIMp), the Company Chemists' Association (CCA) and the National Pharmacy Association (NPA). Together we are a stronger, unified voice for community pharmacy.

Source:
www.pharmacyvoice.com

Diclofenac

People will no longer be able to purchase diclofenac tablets, used to treat pain and inflammation, from pharmacies without a prescription from their doctor due to the small risk of heart problems, the Medicines and Healthcare products Regulatory Agency (MHRA) announced in January. Topical products such as gels will remain available for purchase from pharmacies.

Dr Sarah Branch, MHRA vigilance and risk management of medicines deputy director, said:

"Diclofenac is associated with a small but increased risk of serious cardiac side effects in some patients, particularly if used at high doses and for long-term treatment. Because of this the Commission on Human Medicines (CHM) has advised that patients need to have a medical review before taking oral diclofenac to make sure it is suitable for them.

"If patients have recently bought diclofenac tablets from their pharmacy and continue to need pain relief they should talk to their pharmacist about suitable alternative treatments. However, there is not a problem if they wish to stop taking diclofenac in the meantime.

"People who have been prescribed diclofenac from their doctor should continue to take their medicine as instructed as their medical history and any tests will already have been assessed. If you have any questions about your treatment you should discuss this with your doctor at the next visit.

"If you have experienced any side effects to this medicine then you can report these to us at: YellowCard".

You can report by using the online Yellow Card form at: **www.mhra.gov.uk/yellowcard**

In August 2013 the MHRA consulted on the continued availability of oral diclofenac as a pharmacy medicine in the UK following a European review that found there was a small but significant increased risk of cardiovascular side effects associated with diclofenac. The product information for diclofenac was updated to reflect this new information.

However, this evidence has been looked at by the Commission on Human Medicines (CHM), which concluded that these side effects cannot be ruled out, even when the medicine is taken for a short time or at a lower dose. Therefore in the interests of patient safety the product is being reclassified to prescription-only medicine (POM).

A recall to pharmacy level only has been issued because this product should no longer be sold over the counter in pharmacies.

Oral diclofenac will now only be available as a POM with effect from 15th January 2015.

Source:
MHRA press release
January 2015

NICE (The National Institute for Health and Care Excellence) has published final guidance recommending ustekinumab (brand name Stelara) as a treatment option for psoriatic arthritis in certain circumstances.

In May 2014, NICE issued technology appraisal guidance TA313, which did not recommend using ustekinumab alone or in combination with methotrexate, for treating active psoriatic arthritis in adults when the response to previous non-biological disease-modifying antirheumatic drug (DMARD) therapy has been inadequate.

This updated guidance – which now recommends ustekinumab in specific circumstances – is a rapid review of TA313 following the introduction of a patient access scheme, which the company that manufactures ustekinumab, has agreed with the Department of Health.

Professor Carole Longson, Director of the Health Technology Evaluation Centre at NICE, said: **"Psoriatic arthritis is a chronic condition that can have a significant physical and psychological impact on an individual's day-to-day life. NICE has already recommended a range of treatments (referred to as TNF-alpha inhibitors) – golimumab, adalimumab, etanercept and infliximab – to help manage active and progressive psoriatic arthritis in adults.**

"This guidance resulting from the rapid review of TA313 now recommends that ustekinumab could be a treatment option for people who are unable to use the drugs that NICE has already recommended, or who have already had treatment with one or more of those drugs. This applies if the company provides the drug as agreed in the patient access scheme."

The guidance is available on the NICE website at: www.nice.org.uk/guidance/ta340

Source:

NICE press release

Important update

In the last issue of Skin 'n' Bones Connection (issue 40) in an article called 'Know your biologics', we reported on the biologic drugs, which are under review for psoriasis and psoriatic arthritis.

One of the drugs, brodalumab, an IL-17 inhibitor given as a subcutaneous injection every two weeks and in phase three trial for both conditions, has been the subject of an announcement by developer Amgen about their commenced termination of its participation in the co-development and commercialisation of brodalumab with AstraZeneca.

Brodalumab is for patients with moderate to severe plaque psoriasis, psoriatic arthritis, and axial spondyloarthritis. The decision was based on events of suicidal ideation and behaviour in the brodalumab programme, which Amgen believes likely would necessitate restrictive labeling.

After Amgen transitions the programme to AstraZeneca, future decisions on the clinical development and submission of marketing applications for brodalumab will be at the sole discretion of AstraZeneca for all territories, except for certain Asian territories, including Japan, where Kyowa Hakko Kirin has rights to brodalumab. It will be interesting to see how this drug progresses in further trials.

Source:

PR Newswire

Risk of tuberculosis TNF-alpha inhibitors

What are TNF-alpha inhibitors?

Tumour necrosis factor alpha (TNF-alpha) inhibitors are a type of medicine used to treat conditions that involve inflammation and problems with the immune system. These include psoriasis and psoriatic arthritis. TNF-alpha inhibitors are given as an injection every few weeks. When used to treat psoriasis or psoriatic arthritis they are prescribed by dermatologists and rheumatologists, usually after other medicines have been tried and have not worked well enough.

There are five TNF-alpha inhibitors licensed in the UK. These are adalimumab, certolizumab pegol, etanercept, golimumab and infliximab.

What are the risks of treatment with TNF-alpha inhibitors?

TNF-alpha inhibitors are effective treatments for the symptoms of psoriasis and psoriatic arthritis, but as with all medicines it is possible that there may be unwanted side effects, although not everybody gets them. One of the important risks associated with TNF-alpha inhibitors is that you may get infections more easily. These include common infections like coughs and colds, as well as more serious infections. The full list of possible side effects can be found in the patient information leaflet (PIL) supplied with the medicine. Copies of the patient information leaflets are also available online: http://www.medicines.org.uk/emc

TNF-alpha inhibitors and the risk of tuberculosis

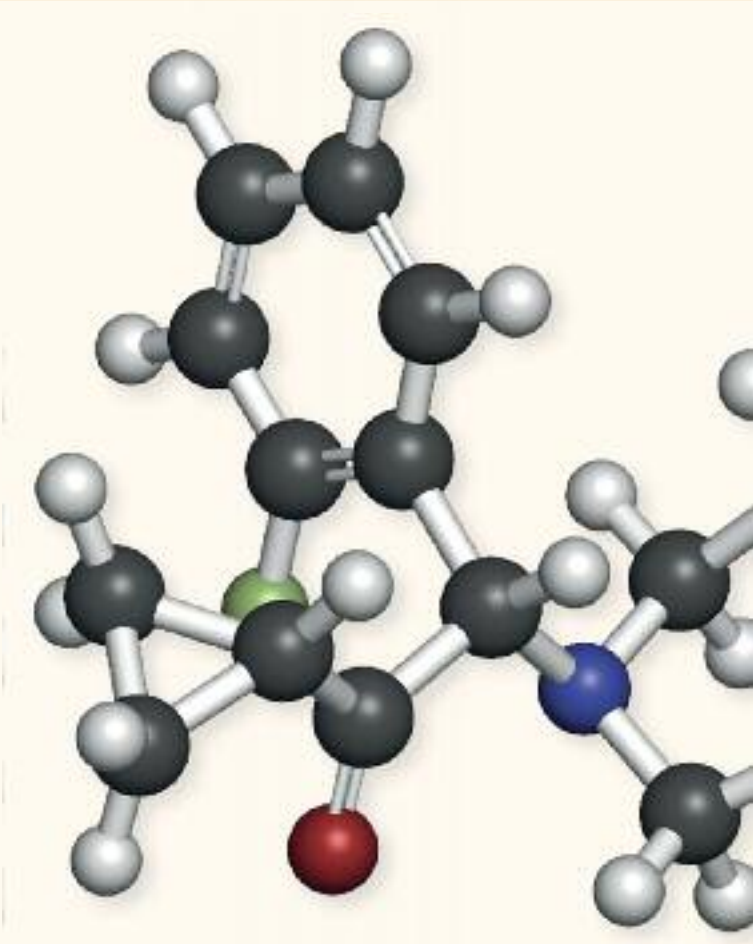
One of the serious infections that people taking a TNF-alpha inhibitor are more likely to get is tuberculosis (TB). If you have been exposed to TB in the past it can remain in the body in an inactive state, not causing any symptoms. Being treated with a TNF-alpha inhibitor also increases the risk of inactive TB becoming active again and making you ill.

Although the chance of getting TB is higher in people who are treated with TNF-alpha inhibitors, TB is not common in the UK. The World Health Organisation estimated that 15 out of every 100,000 people developed TB in the UK in 2012. TB can be treated with antibiotics, but it is still a serious illness and can even be life-threatening, especially if it is not treated.

What can be done to reduce the risk of tuberculosis?

The following steps help to reduce the risk of developing an active TB infection when you are treated with a TNF-alpha inhibitor.

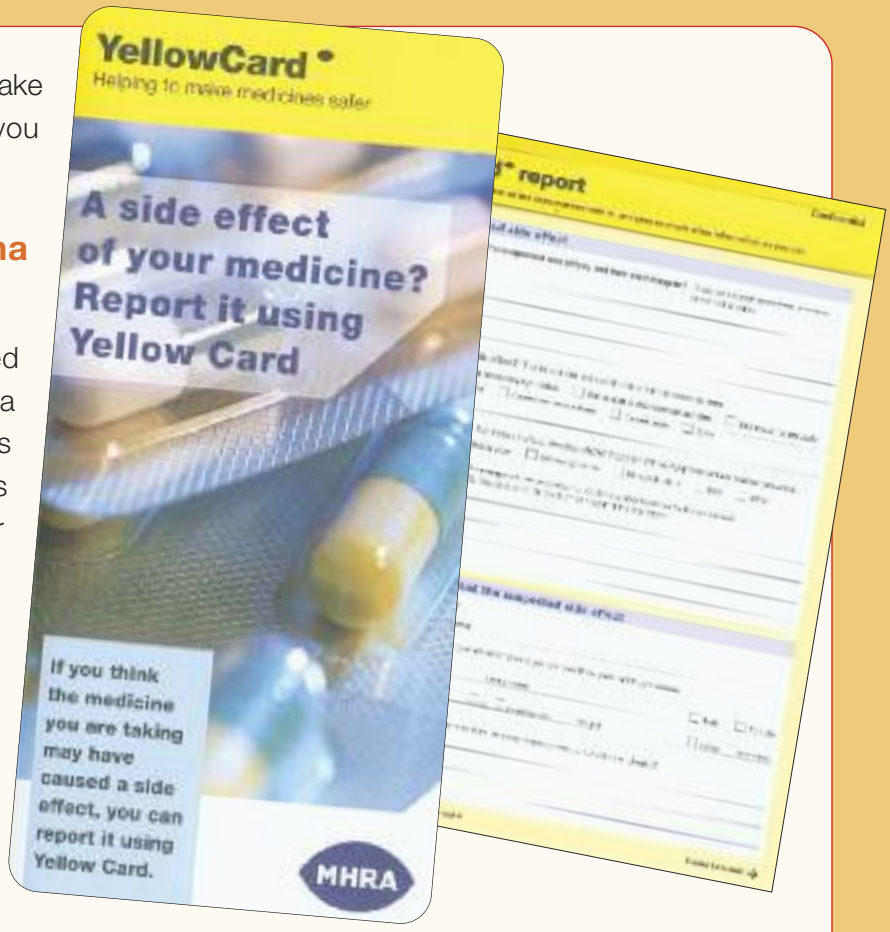
- Before starting treatment you should tell your doctor if you have ever had TB, or have been in close contact with someone else who has.



- Your doctor should test you for TB to make sure that you are not infected before you start treatment.

Patient alert cards for TNF-alpha inhibitors

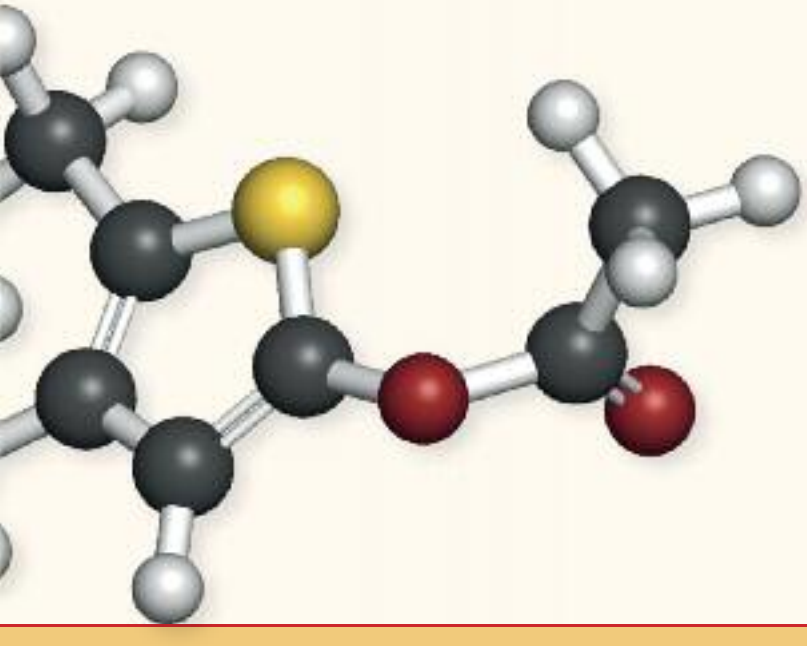
- You should be given a credit card-sized alert card when you start treatment with a TNF-alpha inhibitor. The alert card has information about some of the risks associated with TNF-alpha inhibitor treatment. The card can be used to record the results of your tests for TB. You should show the card when you visit a GP or other healthcare professional, so that he or she knows that you are using a TNF-alpha inhibitor.



You should seek medical advice if you get symptoms of TB during or after treatment with a TNF-alpha inhibitor. Symptoms of TB can include persistent coughing, shortness of breath, flu-like symptoms, weight loss, persistent tiredness, fever, and night sweats.

Reporting side effects

If you have any concerns about your treatment, or notice any symptoms which you think may be a side effect, you should talk to your doctor, pharmacist or nurse.



You can report side effects directly to the Yellow Card Scheme (operated by MHRA). This helps to provide more information on the safety of medicines.

You can report by using the online Yellow Card form at: **www.mhra.gov.uk/yellowcard**

- **Paper Yellow Card forms can be obtained by calling the Yellow Card hotline on freephone 0808 100 3352 (available weekdays 10am-2pm).**
- **May be found at some pharmacies and GP surgeries.**
- **Forms can also be downloaded (the form should be returned to the address on the bottom of the form - no stamp is needed).**
- **Make a report by telephone to the Yellow Card hotline.**

Please note the Yellow Card Scheme does not provide medical advice in individual cases.

We are grateful to the MHRA for providing this information.

PAPAA post

Q Dear PAPAA

I was wondering if you could help answer a question for me. I suffer from mild psoriasis, both plaque and inverse. I had a big flare-up last year before my wedding and changing jobs.

In your experience do you think that psoriasis gets worse with age? I realise that everyone is different but trying to get a general opinion on this.

Thank you.

DF

A Dear DF

Thank you for your email. As you suggest it is very variable. We do have a page on our website, which you might find interesting: www.papaa.org/further-information/psoriasis-older-people

The problem with having psoriasis for a long time is the treatments which were once effective often no longer work as well as they did when someone was younger, so that might give the impression that the psoriasis is getting worse. There are other changes as we age such as other conditions, which may require drug therapy that could also make psoriasis worse. There is also late first onset of psoriasis in people in their 60s.

Anything that can impact on the immune system response could trigger psoriasis to flare, so as we age or face emotional changes and stressful situations these could appear to make the psoriasis worse. It is also known that many people stop or do not treat their psoriasis as effectively after having it for many years, so again it could appear worse.

Yours

PAPAA

Q Dear PAPAA

I was diagnosed with psoriatic arthritis about 18 months ago and have failed to respond to anti-inflammatory drugs, steroids, methotrexate (which made me very ill), leflunomide and have just completed a 12 week trial with adalimumab which has also failed to have any effect on my symptoms.

I was devastated to be told by my rheumatology team today that the NHS (following NICE guidelines) will not fund a further biologic treatment such as etanercept, and they are now suggesting the best they can offer is palliative care, although they are considering whether to replace leflunomide with sulfasalazine.

At only 50 years old and with this disease already badly affecting my quality of life I feel that I've been 'thrown away'. I'm self-employed and now face having to close my business down as I can't manage the work any more as well as all the many, many other ways the joint pain/limitation is affecting my life.

Do you have any advice on how best to approach/champion for a trial with etanercept? Is it a case of having to pay thousands of pounds for a private prescription?

Any advice would be very gratefully received.

With thanks.

JG

A Dear JG

Not sure that is strictly true, as we hear from many people that they are offered a second biologic agent following failure. A view might be that a drug that targets the same part of the immune system may also not work, but a drug with a different action could.

You might like to point your rheumatologist towards the published guidance from the British Society of Rheumatology (BSR). In the 2012 BSR and BHPR guideline for the treatment of psoriatic arthritis with biologics a section said:

"..What to do if anti-TNF fails?

(i) In the case of failure of an anti-TNF treatment either due to inefficacy or adverse events, an alternative anti-TNF therapy should be considered and response to treatment assessed as for the first anti-TNF agent. Consideration of the possible consequences for control of skin disease should be given and shared care with a dermatologist when appropriate..."

Yours

PAPAA

Q Dear PAPAA

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

AW

A Dear AW

Thank you for your email. It's an interesting question as the list of adverse events for naproxen is huge.

Although psoriasis is not listed, it makes one wonder whether it has ever been reported as a side effect, as the nature of psoriasis as a waxing and waning disease might make people think it is just part of the process and not linked to medication, therefore, there may be a link but has not been investigated. Anecdotally we've heard from people that think their psoriasis has flared following the use of NSAIDs.

Maybe it would be a good idea to report this via the Yellow Card scheme (operated by MHRA - see pages 17) , as if they get enough reports they will start to look into it further https://yellowcard.mhra.gov.uk/ and if it is widely reported add or create a warning.

Yours

PAPAA

Q Dear PAPAA

I am writing to enquire whether you can tell me if the symptom I will describe is known to be psoriatic arthritis.

For 10 years I told my doctor I had arthritis before I was diagnosed. A symptom which was rare to begin with is becoming common and is often unsettling.

It begins as a sudden wave of heat and debility leading to increased heart rate and sweating, often with some panic as it stops me in my tracks and I feel as though I am about to collapse.

Originally it was associated with numb sensations, at the base of the spine and happened about once a year. Now, though I work part-time, it feels as though this is under threat as these 'turns' can occur six or more times a day, leaving me feeling unable to cope with physical tasks at all. I would be glad for any comments about this.

Thank you.

RC

A Dear RC

Thank you for your email submission via our website. Your symptoms don't particularly sound like those commonly associated with psoriatic arthritis, although tiredness and fatigue are often reported. We would strongly advise you to talk to your healthcare provider, as there may be a simple explanation for your symptoms that can reassure you of the cause.

Yours

PAPAA

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

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

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

We post interesting news items and links to fuller articles on our website www.facebook.com/papaa.org

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

Follow us on Facebook

Marketplace

From April this year, there have been major changes to the way care and support for disabled and older people is provided and paid for. The new Care Act came into force and for many comes on top of losses they have already seen to their social care support.

To help guide people through the changes, the new edition of the Disability Rights Handbook 2015-2016 (Edition 40) is available, priced at £33.50 including P&P (£18 concession price for those in receipt of benefits).

The handbook provides in-depth information on the benefits system and social care services and includes invaluable guidance on all the critical changes.

The handbook can be bought from the charity

Disability Rights UK.

Telephone: 020 7250 8191

Email: shop@disabilityrightsuk.org

Website: www.disabilityrightsuk.org

Other publications available: **Taking Charge, A New Guide to Independent Living** which complements the handbook. It includes a section on planning and managing your life following a diagnosis or as your health changes, details on rights, what to expect from services, education and employment.

Why Are You Pretending to be Normal by Dr. Phil Friend containing view points, tools and techniques for pro-actively managing disability instead of simply coping with it.

Spreading the word

Want to spread the word about psoriasis and psoriatic arthritis? We have a small selection of promotional items available, which includes pens, pads and t-shirts.

For more information visit our psoriasis shop (address on top right of this page).

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.

papaa

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.