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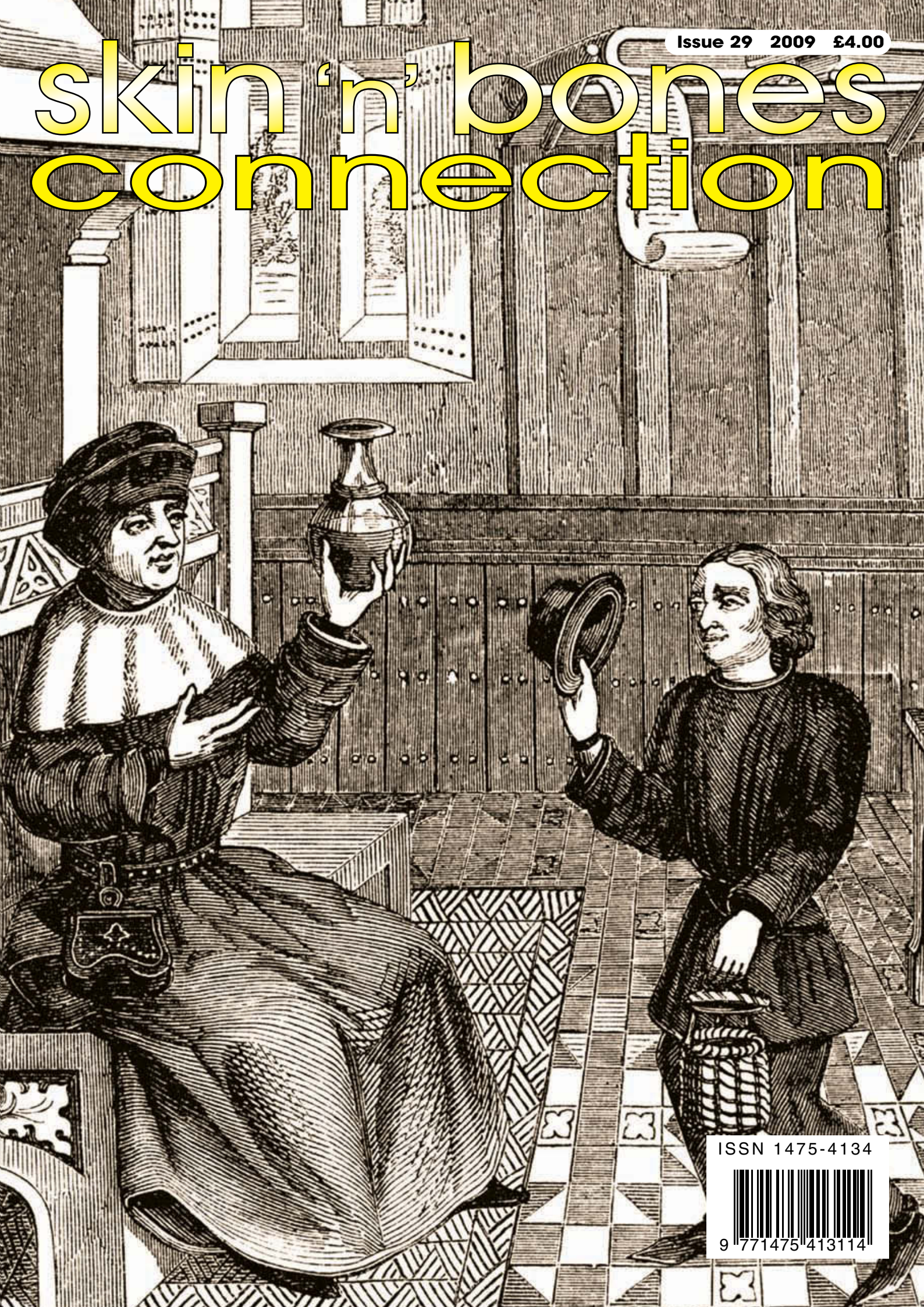
skin 'n' bones connection



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Dear Reader

The correct diagnosis of disease is a vital part of ensuring appropriate use of existing and new treatments and the development of new technologies. For doctors it is important to have tools which can accurately measure levels of disease and to show if treatments have improved the condition.

In psoriasis and psoriatic arthritis there are a number of measures used to gain this information; on pages 10 & 11 we have some of the common scoring systems explained in more detail, including PASI, HAQ etc…

For new treatments to gain a licence for use. it must have been proven to show benefit in the condition being treated. These standardised (sometimes imperfect) measures allows the benefit and effectiveness to be compared against other existing therapies or a placebo (dummy treatment).

Most clinical trials will use these recognised tools, which allow doctors to weigh up like-for-like evidence and directly compare the end point outcomes (do they work?), which will provide the proof that the therapies are better or at least as beneficial as existing treatments.

It is always worth considering the evidence when seeing a new therapy being promoted, because sometimes the difference is not always that striking.

Managing editor

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Cover Photo:
This vintage manuscript engraving depicts a doctor seated in his home holding a vial of medicine for a visiting patient. Made in the 15th century by an unknown artist it was included in 'Epistre de Othea' by Christine de Pisan, Europe's first professional woman writer. This facsimile was published in a history of science and literature of the Middle Ages in 1878 and is now in the public domain.

London Marathon

Before I showed any signs of psoriatic arthritis, I ran regularly, and I participated in races ranging from 5k to marathon. I raced at least once a month and more frequently in summer and have completed 7 marathons and numerous half-marathons. I also ran a keep-fit class for 15 years. In February 2005 I was running as well as I had done at any time in my life setting a life-time personal best for the half-marathon of 1 hour 36 minutes. I was pleased as I was due to run the London Marathon in early April and hoped another personal best was possible. With four weeks to go, I was taken ill on a running holiday in Portugal. I went from being as fit as I have ever been, to being only able to walk with the aid of crutches, and had to wait until I came home to find out what was really wrong with me.

I spent 10 days in hospital and was off work for 6 months. I returned to work initially on a part-time basis, then eventually full-time. If you are ill or injured, you can carry your place forward for 12 months as long as the race organisers are informed before the marathon starts. I told everyone I was going to do the London Marathon in 2006 so I carried my 2005 place forward for the London Marathon and walked round in 6 hours 37 minutes. I did what I set out to do – to finish.

I'd struggled at work with fatigue and have now returned to part-time working. I try to keep fit but have struggled as some days, due to the way I feel, it's not possible to do anything.

My journey towards the London Marathon 2009 started in November 2006 when I found out that I had not got into the 2007 marathon through the ballot. When I re-applied in the summer of 2007, it had never been my intention to run in 2008. As I had unsuccessfully applied the year before, I thought I might as well continue to apply as after five consecutive refusals, a guaranteed place is awarded in the sixth year. I thought I might be in better shape by then. In November 2007, I found out I was in. It was not going to happen, as I had an operation in October 2007 and was told not to exercise for a minimum of 3 months. I carried my place forward again, and therefore I knew I had 17 months to train for London 2009.

I started jogging again in late January 2008, aiming at the 'Chester Spring 5' in April. The race is 5 miles. I was very happy with the run and my time, given all that's happened to me over the past 3 years. I was also managing to get back to running with my club, Spectrum Striders Running Club.

Over the next few weeks, I carried on jogging without any problems. However, in June, I went along to a race to support my husband, John, and friends from Spectrum Striders. As the route is 2 laps in a park, I was going to jog across the park to see them at different points. On a flat path, I got a shooting pain in my ankle, and then struggled to walk. This has happened in the past, as I broke my ankle as a child, and the psoriatic arthritis has affected it.

I rested it but this didn't help. I went back to the doctor, who sent me back to the consultant, as I'd had treatment on my ankle in 2006. After a scan, there was nothing new wrong with my ankle and I was told to rest and take up a different sport. At 13, I'd been told to forget sport completely, given the damage my ankle had suffered. As you might gather, that didn't put me off. I didn't try to run for a while and was happy being able to walk our Dalmatian, Tasha.

In July 2008, I sent off my deferred place for London, with John asking me if it was a wise thing to do. I was optimistic about doing it by running and walking. I was hoping to do some of the training with Tasha, but she was taken ill and died suddenly in August. My incentive to go for a walk had gone. We both wanted to get another dog and found a puppy that would be ready to collect in late November.

With friends from Spectrum Striders, we usually go for a long weekend in the autumn and take in a race. In 2008, it was a big birthday for John and the trip was to Lake Garda to do the half-marathon. I decided to have another go at running. I would only attempt the London Marathon if I got round the Lake Garda Half without any problems. Much to my surprise, the training went well, as did the race. Apart from being very tired after the run, I was OK. On our return, we collected our new Dalmatian puppy, Pika. Three weeks later, I did a 10K race and was ok.

I then planned my training for London. The plan was very flexible as I knew there would be some days when I would try to do something. for example train, given the way I was feeling, would not have been a good idea. During the week, I was managing to go for a run and then add on a walk for Pika. At the weekend, I would do my longer run/walks, getting up to 16 or 17 miles. The only race I planned to do was Wrexham Half Marathon in mid February. This again went well.

In recent years, we've gone on a trip where three Cheshire running clubs get together for a training trip to the Algarve in March. We went again this year and although training mainly on my own, I did a 20 mile run/walk (with John's help) without any reaction. Now all I had to do was stay fit until the big day.

The London Marathon weekend starts on Friday morning, 24 April 2009

- 9am – John takes our seven month old Dalmatian, Pika, for a walk while I check that I've packed everything I need for the marathon: shorts, vest, socks etc. Then I organise the food I want to take with me; bananas, jelly babies (a must!), dried apricots, homemade fruit cake, drinks …, and the kitchen sink, at least that what it seems like.
- 10.30am – John's back with Pika. A quick cup of tea, then off to the kennels with Pika, to get back in time for two friends from Spectrum Striders, who are both doing the marathon, arriving to pack the car.

London Marathon

- 12 noon – We're off
- 5pm – Eventually arrive at ExCel conference centre, London, where race registration and the marathon Expo are sited. Collected my number and chip. I'll have to do it now! We wandered round the expo, collecting race information for future races (not marathons) and looking at all of the running gear that is available. We also bumped into some other Spectrum Striders who had made their way down. We'll see them later as we're all staying in the same hotel.
- 7pm – Leave the ExCel to head across London to our hotel in Westminster.
- 8pm – Arrive at the hotel after being sat in traffic queues. Dump the bags and go out for a meal, and guess what? After a bit of a wait in the restaurant, it's pasta again.
- 11pm – Back at the hotel, unpack, then a cup of tea and off to bed.

Saturday 25 April 2009

- 8.30am – Breakfast, then back to the room. Pin my number on my vest, put the chip on my shoe and check that I've got everything with me.
- 10am – After breakfast, the Spectrum Striders group go for a slow walk up to the finish area, passing Buckingham Palace and onto The Mall. Group picture taken of the runners present. There are always a couple of debut marathon runners in the group and we show them where the seasoned marathon runners always meet at the end of the race. The instructions are "walk down past Horse Guards Parade, to Clive of India's statute, then turn right, walk into the park and meet by the duck!!" This year, three little yellow ducks were there!
- 12 noon – Lunch with the gang.
- 1pm - Wander back to the hotel to put my feet up, and write up diary.
- 5pm – Go out to watch Manchester United v Tottenham Hotspur. Spurs fan. They lost!
- 8.30pm – Off to an Italian restaurant again for some more pasta. Then back to hotel and off to bed.

Sunday 26 April 2009

- 6.30am – The alarm goes off. I get up, get dressed ready to run, say good-bye to John, pick up my bag and go to breakfast. For me, it's coffee and toast. I also wrap up some toast to take with me as the marathon does not start until 9.45am.
- After breakfast, the taxis arrive to take all the runners in our group to Charing Cross Station, where we get on the train to Blackheath (race number is your ticket on the train). The train is full of excited and nervous runners, of all ages, shapes and sizes, but all with the same goal, to finish the marathon.
- 8.15am – Arrive at the start and enter the runners' enclosure. We then find a spot to use as a base for the group and then people can wander off to the toilet queues and pick up free cups of tea and/or water. The waiting at the start of any race is always the worst time as nerves kick in. However, today I am not nervous. Instead, I am looking forward to the day.
- 9.15am – Queue up for the last time at the toilets, then go to my holding pen at the start. Then just wait for the start gun.
- 9.45am – The gun goes, but we don't move as it takes a few minutes for the crowds to move. It takes me 6 minutes to get over the start-line, and then we're off. My plan works well, running at my own pace for as far as I can, without getting carried away with the crowds. I reach halfway in 2 hours 20 mins which I am pleased with but knew I would have to walk at some point. Just after the 15 mile marker I decided to walk to the 16 mile marker, with the hope of walking a mile then jogging a mile to the finish. This worked up to 23 miles and then I decide the best thing to do was to walk to the end, apart from jogging down The Mall. I finish in 5 hours and 31 minutes. Very pleased.
- Meet John and a few others from the club in the park by the finish area and can sit down at last. All very pleased apart from one who pulled out at 20 miles having twisted his knee. We then walk the mile back to the hotel.

- A great day, enjoyed by all.
- My webpage at Justgiving.com is still open and will remain open until 26 July 2009 if you would like to sponsor me. Just put my name in 'Find a friend' and follow the instructions.

Thank you in advance for your support.

Linda Owen.

Direct link to Linda's fundraising page:
http://www.justgiving.com/lindaowen-papaa
or you can send a donation by post to the PAPAA office.

Editorial comment:

Well done Linda for completing the London Marathon. A great achievement! Congratulations from everyone at PAPAA, we think you have shown great determination. We are also extremely grateful for the funds you raised on behalf of PAPAA.

Get involved

We have had a number of people asking about holding events to support PAPAA. So in response here are a few ways in which you can help us.

You will see on page 4 and 5 that Linda Owen completed the London Marathon in April, which is a fantastic achievement, we would not expect this to be seen as the only way to get involved.

In the past we have had runners in the London Marathon, and individuals have carried out other sponsored activities, including cycle riding and abseiling.

Other events organised by individuals, where we have received donations included:

- **Raffles**
- **Grand prize draws**
- **Plant sales**
- **Garden fetes**
- **In memoriam**
- **Sales of T-shirts, pens, key rings etc**
- **Craft item sales**
- **Cake sales**
- **Coffee mornings**

If you have any ideas or want to raise funds for PAPAA we are always open to suggestions. Or if you need support, advice or promotional items please contact us:

For those of you who use the internet we have a number of sites that if used can provide us with funds at no cost to the user. These include:

eBay for Charity, an easy way for buyers and sellers on eBay.co.uk to support their favourite charities. Buyers can shop for items knowing they're supporting a good cause, be it an everyday bargain or a special auction. Sellers, whether they're individuals or businesses, can donate a percentage from any sale to a charity of their choice and add Gift Aid to their donations.

http://donations.ebay.co.uk/charity/charity.jsp

Netfundraising allows you to raise money for your favourite causes just by shopping online. Raise money whilst you save money.

http://www.netfundraising.org.uk/

Shop online and raise funds with **Easyfundfraising,** a shopping directory listing online stores including Argos, Next, Debenhams, John Lewis, Toys R Us, HMV and more than 600 others. Just use the links on the easyfundraising site whenever you shop online and, at no extra cost to you, we'll receive a free donation of up to 15% from every purchase you make.

http://www.easyfundraising.org.uk/papaa/

Easysearch; where you can now raise funds when you search the web. Use easysearch every time you search the Web and PAPAA will get 50% of the fees paid by the advertising sponsors.

http://papaa.easysearch.org.uk/

Justgiving; which lets you donate to PAPAA online, set up your own fundraising page for an event, in memoriam or any activity which you wish to promote to raise funds. It's easy, quick and tax-friendly.

http://www.justgiving.com/psoriasis

The Charities Aid Foundation is a registered charity that works to create greater value for charities and social enterprise, by transforming the way donations are made and the way charitable funds are managed. You can donate via CAF Charity Account or with a debit or credit card online

https://www.cafonline.org

Simplefundraising provides the power of the Google search engine, a shopping directory of virtually every UK retailer that has an online presence – major household names, such as Tesco, Direct Line, Amazon, HMV, Boots, Carphone Warehouse, Thomas Cook as well as a plethora of independant retailers. PAPAA will receive a free donation at no cost to you.

http://www.simplefundraising.co.uk/4256/

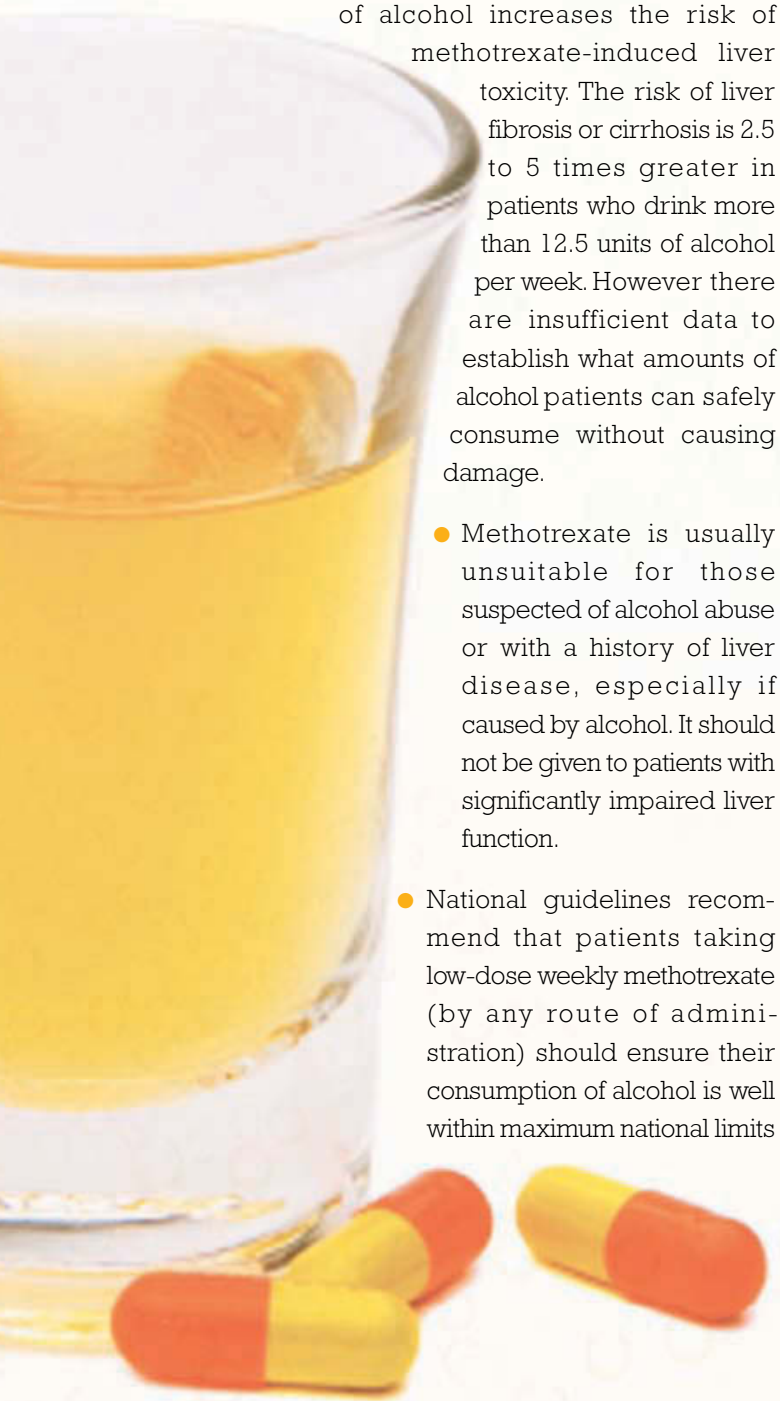
If you know of any other sites that would be useful, please let us know and we'll investigate further.

Alcohol and methotrexate

The NHS UK Medicine Information (UKMi) has recently issued a medicines Q&A called 'Can patients drink alcohol whilst taking long-term low-dose methotrexate?'[1] which looks at the risks of drinking alcohols whilst taking methotrexate.

The summary of the advice is as follows:

- Patients may drink alcohol whilst taking long-term low weekly doses of methotrexate (25mg or less), but they should limit their intake.
- Evidence suggests that consumption of alcohol increases the risk of methotrexate-induced liver toxicity. The risk of liver fibrosis or cirrhosis is 2.5 to 5 times greater in patients who drink more than 12.5 units of alcohol per week. However there are insufficient data to establish what amounts of alcohol patients can safely consume without causing damage.
- Methotrexate is usually unsuitable for those suspected of alcohol abuse or with a history of liver disease, especially if caused by alcohol. It should not be given to patients with significantly impaired liver function.
- National guidelines recommend that patients taking low-dose weekly methotrexate (by any route of administration) should ensure their consumption of alcohol is well within maximum national limits (two to three units a day for women and three to four units a day for men, with at least one or two alcohol-free days per week).
- Patients with psoriasis or psoriatic arthritis should not drink more than six units of alcohol per week because they may have a higher risk of liver toxicity than those with other inflammatory conditions.



The last bullet point is particularly relevant to readers of this journal. This is drawn from guidelines produced by the British Association of Dermatologists[2] If you do take methotrexate you are strongly advised to talk to your own doctor or health care provider to find out exactly whether this advice is suitable in your own circumstances.

The full advice can be viewed at the UK Medicine Information website:

http://www.ukmi.nhs.uk/

About UKMi

UK Medicines Information is an NHS Pharmacy based service. Its aim is to support safe, effective and efficient use of medicines by the provision of evidence based-information and advice on their therapeutic use.

The service has two broad functions:

- To support medicine management within NHS organisations.
- To support pharmaceutical care of individual patients.

Glossary

Liver toxicity: is a common side effect of many drugs.

Liver fibrosis: refers to the accumulation of tough, fibrous scar tissue in the liver.

Cirrhosis: is the result of long-standing injuries to the liver due to repeated scarring. It is most commonly seen in people, who regularly drink alcohol to excess, but there are a number other condition which cause cirrhosis including hepatitis B and C, but not hepatitis A.

Reference:

1. Can patients drink alcohol whilst taking long-term low-dose methotrexate? Medicines Q&A 241.1 Prepared by UK Medicines Information pharmacists for NHS healthcare professionals

2. Methotrexate information - **http://www.bad.org.uk/site/1121/default.aspx**

In February the Arthritis Research Campaign (arc) launched the first evidence-based report dedicated to the use of complementary medicines in arthritis using results from randomised controlled trials.

Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia is a summary of existing published studies which indicates whether or not there is scientific evidence to support the clinical effectiveness and safety of certain named products for people with arthritis.

Despite the number of complementary and alternative medicines on the market, the report found that evidence from randomised controlled trials was available for only 40 of them. There are considerable variations in the level of scientific data to support the effectiveness of such medicines. For nearly two-thirds of compounds used for rheumatoid arthritis (the most common inflammatory arthritis) the available data suggest they are not effective, while the effectiveness of glucosamine, a supplement popular with people with osteoarthritis (OA) is again called into question. Effectiveness is measured by improvements in pain, movement or general well-being. The report says:

For rheumatoid arthritis (RA):

Nearly two-thirds (13 out of 21 complementary medicines [62 per cent]) were shown to have no or little effect based on the available evidence (scoring 1 out of 5 on the effectiveness scale).

The 13 are: antler velvet; blackcurrant seed oil; collagen; eazmov herbal preparation; feverfew; flaxseed oil; green-lipped mussels; homeopathy; reumalex herbal mixture; selenium; Chinese herb tong luo kai bi; vitamins A,C and E anti-oxidant vitamins; and willow bark.

By contrast fish body oil scored 5 out of 5 for people with RA, reducing joint pain and stiffness.

For osteoarthritis (OA):

Nearly one-fifth (6 out of 27 medicines [22 per cent]) were shown to have little or no effect based on the available evidence.

Glucosamine, one of the most widely taken products, showed mixed results with glucosamine sulphate scoring 3 and glucosamine hydrochloride scoring 1.

Capsaicin gel, made from chilli peppers, proved most effective in relieving pain and joint tenderness, scoring the full 5.

For fibromyalgia:

Only four products were assessed.

None of them highly effective with three medicines scoring 2 out of 5, and the fourth an ineffective 1.

Safety:

One quarter of the compounds were given an "amber" safety classification indicating there were important side-effects which had been reported, although there is much less safety information available for complementary medicines in comparison to conventional medicines.

Only one "red" safety classification was issued: against thunder god vine for RA.

Professor Gary Macfarlane, who led the research, said it was important that people with arthritis had some guidance on the complementary medicines available. "While over 60 per cent of people with arthritis or other aches and pains use some form of complementary and alternative medicine - and find different things work for them - it is useful to also have the scientific evidence available and just as important to know how safe we think they are to use," he said "All of the evidence can now be accessed in this definitive report."

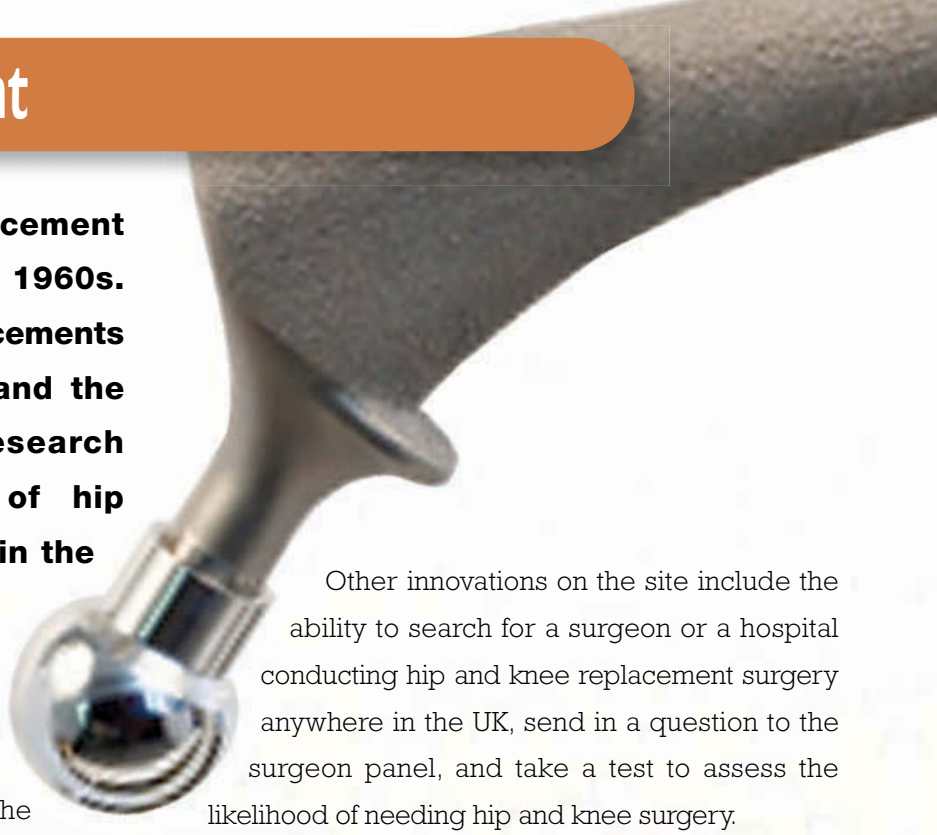
Forty-six per cent of people in the UK use complementary medicine at some point in their lives for a wide range of conditions, spending over £450 million a year on products and treatment outside conventional therapy. The report, the first of its kind dedicated to arthritis, has been produced to help people make up their minds about products for which claims have been made but in many cases are unsubstantiated by hard evidence.

Professor Alan Silman, the Arthritis Research Campaign's medical director, explained: "Complementary medicines are widely used by people with arthritis as they seek to avoid taking potentially harmful drugs, preferring natural products. However, natural does not mean they are either safe or effective. Many people spend hundreds of pounds on these products and they need to know that there is a strong chance of benefit."

The report covers medicines taken by mouth or applied to the skin, rather than therapies such as acupuncture and chiropractic. It scores medicines according to their effectiveness with 1 indicating that the available evidence suggests that the compound is not effective and 5 indicating that the compound is effective. It also grades the medicines according to safety, providing traffic light classifications for each.

A PDF of the full report can be accessed at: http://www.arc.org.uk/arthinfo/documents/6300.pdf

Hip and knee replacement



Hip replacement and knee replacement surgery started in the UK in the 1960s. About 160,000 hip and knee replacements are done each year in the UK and the figures are rising. Some recent research predicts that the numbers of hip operations will more than treble in the next 20 years.

A new website dedicated to providing independent information for patients undergoing hip and knee replacement surgery in the UK has been launched. The website boasts a panel of orthopaedic surgeons and was launched at the British Orthopaedic Association conference in Liverpool recently.

The Hip and Knee Network was part-funded by the EU and enables patients to access government data on the quality and take-up of all hip and knee implants on the market. This is the first time that this data has been presented in an easily accessible way to the public and the Hip and Knee Network has already had a lot of interest in this part of the site from patients undergoing this type of surgery.

A guiding principle of the website is that it is completely independent of the NHS, private medicine, and implant suppliers. All information on the site is produced and/or vetted by a panel of specialist orthopaedic surgeons. Therefore it is the only place on the internet dedicated to providing high quality, impartial information on hip and knee replacement surgery.

Steve Young, one of the consultant orthopaedic surgeons behind the website, explains: ''We felt that patients should be better informed; There is a lot of information out there, but it's either too fragmented or created by people with a vested interest in a particular product or service. We designed the site to present all the information in a straightforward, unbiased, ethical way, which will support and complement the work done by surgeons and physiotherapists with hip and knee replacement patients.''

Other innovations on the site include the ability to search for a surgeon or a hospital conducting hip and knee replacement surgery anywhere in the UK, send in a question to the surgeon panel, and take a test to assess the likelihood of needing hip and knee surgery.

Mr David Stock, another member of the website's surgeon panel, continues: ''This project is about creating a community for patients and surgeons involved in hip and knee replacement surgery. It's difficult for surgeons to find the time to generate the sort of presence on the internet that would help patients find the right quality of information. By combining our efforts we can do more to help them.''

The Hip and Knee Network has a secure area for orthopaedic surgeons to network and communicate with each other in private in addition to forums to enable professional debate.

Mr Jon Waite, the third member of the surgeon panel, goes on to say: ''It's important to understand that this site is not just about the panel involved so far, we are inviting all of our surgical colleagues to get involved and contribute to the debate and discussion. It should become a powerful resource and a platform for new ways of interaction between patients and surgeons.''

The founders hope that with the quality of information available on the Hip and Knee Network it is set to become the first port of call on the internet for those with an interest in hip and knee replacement surgery.

For further information visit:
www.hipandkneenetwork.co.uk

Gardening and arthritis

Living with psoriatic arthritis or any joint pain can be difficult, even at the best of times. We're told that we should exercise and try to keep fit, which may sometimes appear to be a difficult prospect. Gardening can be a good way to relax and get some gentle exercise if you take care and follow some simple advice.

The NHS change4Life campaign[1] says "…gardening for as little as an hour a week could reduce the risk of heart disease…", so it has other benefits too.

Here are some simple tips you might consider:

Planning: plan what you want to do in the garden, how long it will take you, and what help (if any) you need.

Regular comfort breaks: it is important that you pace yourself, do a little, rest a little, have a cup of tea or cold drink, sit and ponder a little then start again. Remember if it is a cool or chilly day not to get too cold or you will stiffen up!

Fewer steps; do you find yourself walking back and forth from the shed to get tools, gloves and accessories? Put all you need into a wheelbarrow or bucket and take it with you.

- Go for lower maintenance
- Use homemade or store-bought sculptures in place of plants
- Plant perennials, which will bloom year after year on their own, instead of annuals like petunias, which you have to replant every year
- Plant in containers on your patio
- Use raised beds; they are easy to reach and maintain all year round.

Music while you work: if you have an MP3 player, why not plug yourself in and indulge yourself whilst doing something positive? You are never too old to get yourself an MP3 player!

Gloves: invest in and wear a pair of good gardening gloves that are comfortable but practical to protect your hands. Many gloves currently being sold as gardening gloves often do not fit very well, and are cumbersome and uncomfortable, particularly those sold as ladies' gloves, which can also look very unattractive. There is also limited dexterity in most of the current products, resulting in a lack of feel, because often the leather used to make these gloves is industrial grade leather which tends to be fairly low in quality.

There are many brands on the market, so try a few and get advice from a good garden centre. Although some are expensive it's worth thinking about the benefit of choosing the right fit and quality if you have arthritis.

A product range that has been brought to our attention is called Gold Leaf Gloves[2], made by JAYCO (UK) Ltd., but there are many other brands that offer similar styles, designs and protection so have a look next time you visit a garden centre or nursery.

Tools: use a multi-purpose tool; use an ergonomic tool that can be adjusted up or down to ensure that you do not have to stoop; use one that has sturdy padding to prevent hurting hands.

There are a number of places where you can get an idea of what is best for you to enjoy your days in your garden. A useful place to look is the website run by Thrive[3], a small national charity that helps people with a disability to start or continue gardening. Or 'ask Fred'[4] on a website where "…all tools are carefully selected and tested by Fred Walden…", a garden writer and equipment consultant to organisations world-wide including the UK National Health Service, Charities and Universities.

Another outlet is Peta (UK) Ltd.[5], designers, manufacturers and suppliers of ergonomic tools, aids and assistive devices for people suffering with reduced grip problems. They have an entire range of Easi-Grip scissors, kitchen tools and more, all available to purchase online. They even have a special section dedicated to children.

Listen to your body: pay more attention to your body, and know when to stop. Just doing that one little extra job may lay you up, so be sensible and realistic – there is always tomorrow!

Get help: don't be afraid or too proud to ask for help when you need it, from your kids, husband, wife, partner, friends or even your neighbour. You don't have to move heavy plant containers yourself or do other heavy lifting that can help trigger painful flare-ups. You could even consider paid help every now and then to help with the major tasks of gardening. Exercise is king. If you have arthritis, moving may hurt, but if you exercise, you will feel better both physically and mentally. As long as you do everything in moderation, and stick to your comfortable limits, gardening can be an excellent form of exercise.

Sunscreen and hat: don't forget to protect your skin too from the elements. Sometimes our necks can get forgotten and yes, end up with sunburn!

If you do not have access to the internet we will be happy to supply you with other ways of contacting the organisations and services mentioned in this article.

References:

1. **www.nhs.uk/change4life**
2. **www.goldleaf-gloves.com**
3. **www.carryongardening.org.uk**
4. **www.fredshed.co.uk**
5. **www.peta-uk.com**

Analysis tools

There are a number of tools used to measure and assess the effectiveness of treatments and the improvement of symptoms. The following are some which you may come across:

The body surface area (BSA) is the measured or calculated surface of a human body. The area of a hand print is roughly 1 percent of the total BSA. In psoriasis BSA is used as a guide to assess the amount of skin affected by psoriasis. The problem with this method is that unless the psoriasis is in large connected plaques it is difficult to get an accurate total percentage calculation. There has been some debate about this method, often the palm area (not including fingers) is used as the measure and therefore could lead to an overestimation of coverage[1].

The Dermatology Life Quality Index (DLQI)[2] is a simple ten question questionnaire, which is used for more than 30 different skin conditions. It is the most frequently used questionnaire in controlled trials in dermatology.

The ten questions cover the following areas:

- Symptoms and feelings
- Daily activities
- Leisure
- Work and school
- Personal relationships
- Treatment

These are assigned a score and once added together give a total DLQI.

The Disability Index of the Health Assessment Questionnaire (HAQ)[3] measures a patient's level of practical capabilities. Altogether there are 8 categories: dressing, eating, walking, hygiene, reaching, gripping, rising and usual activities. The responses are measured on a scale of 1 – 3.

The Nail Psoriasis Severity Index (NAPSI)[4] is a tool used for evaluating the severity of nail psoriasis. NAPSI score is determined by calculating the individual nail surface area that is affected. The total calculation is then recorded to compare the effectiveness or improvement following treatments.

The Short Form 36 Health Survey (SF-36)[5] is a survey consisting of 36 questions used to decide the cost-effectiveness of health treatment. There are eight scaled scores, with each score being turned into a 0-100 value, 100 being the best case scenario.

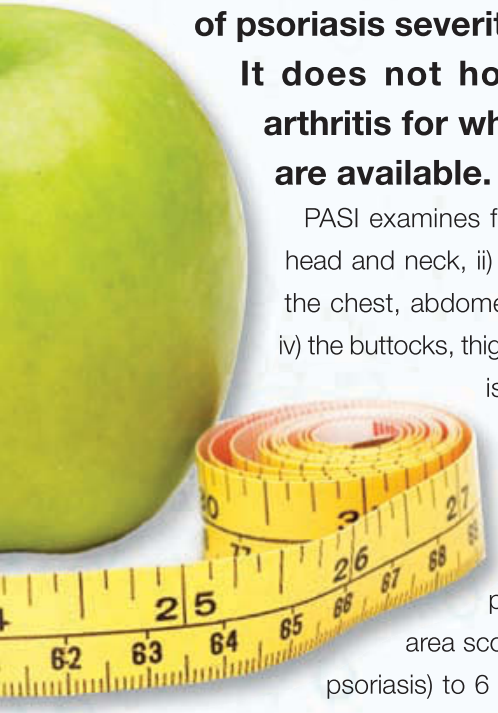
The sections are:

- vitality
- physical functioning
- bodily pain
- general health perceptions
- physical role functioning
- emotional role functioning
- social role functioning
- mental health

References:

1. Severe Psoriasis and the Rule of Tens: The British Journal of Dermatology. 2005;152(5):861-867.
2. A.Y. Finlay, G.K. Khan. Dermatology Life Quality Index (DLQI): A simple practical measure for routine clinical use. Clinical and Experimental Dermatology 1994; 19: 210-216.
3. Fries J, Spitz PW, Young DY. The dimensions of health outcomes: the health assessment questionnaire, disability and pain scales. J Rheumatol 1982;9:789–93
4. Nail Psoriasis Severity Index: a useful tool for evaluation of nail psoriasis: J Am Acad Dermatol. 2003 Aug;49(2):206-12.
5. Short Form 36 Health Survey: www.sf-36.org - Accessed online April 2009

The Psoriasis Area and Severity Index (PASI) is a score used by doctors and nurses to record psoriasis severity. It is widely used to assess the progress of people receiving treatment for psoriasis, particularly in research trials. PASI has become the most widely used measure of psoriasis severity internationally. It does not however examine arthritis for which other scores are available.



PASI examines four body regions: i) the head and neck, ii) the hands and arms, iii) the chest, abdomen and back (trunk) and iv) the buttocks, thighs and legs. Each region is given a score to show how much of the region is affected by psoriasis (area) and a score to record how bad the psoriasis is (severity). The area score can range from 0 (no psoriasis) to 6 (all of the skin affected).

The severity score for each region is reached by adding scores for redness, thickness and scale, each of which is graded from 0 to 4, giving a maximum of 12.

Some complicated arithmetic is then used to produce the final score. An area and severity score for each region is calculated by multiplying the area score by the severity score (maximum 6 x 12 = 72). The amount each region contributes to the final PASI is then weighted according to how much of the total body skin surface it represents. The head and neck contribute a tenth, the hands and arms two-tenths, the trunk three-tenths and the buttocks, thighs and legs four-tenths. The region scores are each weighted by the given amount and then added together to give the final PASI score. Thus someone with severe extensive psoriasis affecting the face and scalp might achieve a region score of 36 for the head and neck but this would contribute only 3.6 (one-tenth of 36) to the final PASI score. Although PASI can in theory be as high as 72 it is rare to get a score of more than 40. PASI scores will also vary to some degree between scorers as there are no absolute standards to indicate, for instance, how red, thick or scaly a patch of psoriasis must be to be counted as very severe (4) rather than severe (3).

PASI is used to help judge the most appropriate treatment for a person's psoriasis. A score of more than ten is generally taken to mean that the psoriasis is "moderate-to-severe" and therefore may be suitable for the more powerful forms of treatment. A PASI level of ten or more is often required for someone to be considered for a clinical trial. This is also used in helping to decide whether some of the newer treatments are appropriate for a given person with psoriasis.

In many recent clinical trials success is measured by the proportion of people receiving a treatment who achieve a PASI 75. This is shorthand for a 75% reduction of the PASI score from the start to the end of the trial. If someone starts with a PASI score of 36 then the final score should be no more than 9 for that person to achieve a PASI 75 response. The important issue to remember that PASI 75 is not clearance and although your doctor may be content to see this level of improvement you may still not be happy with your skin.

PASI is a useful way of indicating how severe psoriasis is but it is not a perfect tool and many other factors are taken into account when you and your doctor are discussing what the best treatment will be for you.

We are grateful to: Dr Robert J G Chalmers MB FRCP, consultant dermatologist, University of Manchester, for his input into this PASI explained article, which was originally published online at: www.papaa.org July 2008.

Expert Patients Programme – Wales

The Expert Patients Programme Wales (EPP) provides a range of self-management courses and workshops for people living with long-term health conditions or for those who care for someone with a long-term condition.

The original chronic disease self-management course (CDSMC) was developed in the USA by Professor Kate Lorig of Stanford University, California, in the 1970s and is now run in the UK and many other countries around the world.

In Wales, courses run are:

- the original CDSMC for people with long-term health conditions
- a course for carers
- workshops for people who want to work or regain employment
- workshops on mental health and on 'food and mood'.

Living your life

EPP is about making you an expert in living your life to the full with your condition, not about making you an expert in the specific condition you have.

A number of people who attend an EPP course go on to train as volunteer tutors to help deliver the programme locally.

All of the people who are involved with EPP in Wales, the staff and the volunteer tutors, have personal experience of either living with a long-term health condition or of caring for someone with a long-term health condition.

A few facts and figures about EPP in Wales:

EPP first started in Wales in 2002 when a pilot project was run by two local health boards: Gwynedd and Swansea.

The Welsh Assembly Government has shown commitment to the programme and announced that EPP is to be rolled out across the whole of Wales.

To date:

- 345 EPP courses have been delivered in Wales
- 2676 people have completed an EPP course
- 130 volunteer tutors have been trained
- 17 local EPP co-ordinators/trainers have been employed to help support the volunteers and to manage and arrange the courses locally

Become a volunteer tutor

Many people who attend an Expert Patients course find that they want to be involved. This means that a number volunteer to be trained to deliver the programme.

Full training is provided and volunteer tutors have access to local EPP co-ordinators for help and support and are also given ongoing training and updates.

For more information about volunteering for the EPP visit: **http://www.eppwales.org**

Scottish Intercollegiate Guidelines Network

The Scottish Intercollegiate Guidelines Network (SIGN) was formed in 1993. Its objective is to improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcome through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence.

The membership of SIGN includes all the medical specialties, nursing, pharmacy, dentistry, professions allied to medicine, patients, health service managers, social services, and researchers.

The work of SIGN is supported by an Executive based at Elliott House, Hillside Crescent in Edinburgh. Since 1 January 2005 SIGN has been part of NHS Quality Improvement Scotland.

SIGN has a programme of 113 evidence-based clinical guidelines - published, in development, or under review - covering a wide range of topics. Many of the SIGN guidelines relate to the NHS priority areas of cancer, cardiovascular disease, and mental health. Comments on any of the published guidelines are welcome and will be used to inform the review process.

Get involved

A joint meeting on the management of atopic eczema and management of psoriasis and psoriatic arthritis in adults is being held on Thursday 1 October 2009 at Our Dynamic Earth in Edinburgh.

At this meeting the guideline development groups will present their draft recommendations and will be looking for feedback. If you have been affected by any of these conditions, you are encouraged to go along, as this is your chance to make sure that the guidelines have taken account all of the matters that are important to patients and carers.

If you can't make the meetings but would still like to comment on the draft guidelines, contact the SIGN Executive, who can send you a copy.

If you are interested in attending this meeting please contact:

Lesley Forsyth at the SIGN Executive, Elliott House, 8-10 Hillside Crescent, Edinburgh EH7 5EA, Scotland. Tel: +44 (0) 131 623 4728 Fax: +44 (0) 131 623 4503 or Email lesley.forsyth@nhs.net for further information.

SIGN patient network update newsletter is available at: http://www.sign.ac.uk/pdf/pnlmarch2009.pdf

DNA 'hotspots' linked to psoriasis

Published in Nature Genetics[1] scientists at the University of Michigan Department of Dermatology, the University of Michigan School of Public Health and their collaborators have found DNA 'hotspots' that may reveal how genetic differences among individuals result in psoriasis. The findings could lead to new drug targets and tailored treatments for the disease.

"This discovery highlights the role of several genes in mediating the immune responses that result in psoriasis," says Goncalo Abecasis, PhD., co-principal investigator on the project, and associate professor of biostatistics in the School of Public Health.

"Some of the highlighted genes, like those in the IL-23 pathway, are already targeted by effective psoriasis therapies. Others, like TNFAIP3 and TNIP1, may become targets for the psoriasis treatments of the future."

Psoriasis has a strong genetic component; a child with two affected parents has a 50 per cent chance of developing it; siblings have a three- to six-fold risk. But the genes responsible for psoriasis haven't yet been completely understood.

In this large, multi-centre study, researchers used cutting-edge genomic technology to identify subtle genetic signals influencing the risk of psoriasis. They scanned millions of DNA variations in the genome to find those that occur significantly more often in psoriasis patients than unaffected people.

The study was led by James Elder, MD, PhD, a professor in the Department of Dermatology.

Within the past 18 months, researchers have increased the number of independent genetic 'hotspots', or loci, confidently associated with psoriasis from one in 2006 – to ten in 2008. Four of these have been identified for the first time by this study, and two more have since been confirmed by these researchers.

Once the full catalogue of psoriasis genes has been identified, it may be possible to generate a 'psoriasis gene profile' that can accurately predict one's risk of developing the disease. Such work may one day help assess risk of heart attack and stroke, since psoriasis carries an increased risk of coronary artery disease.

PAPAA produces a free leaflet 'Psoriasis and the Heart' which is available free - please contact PAPAA for a copy. Tel: 0870 7703212 or info@papaa.org

Reference:
1. Nature Genetics, volume 41, no. 2, p. 199-204

Psoriasis and obesity

Patients with psoriasis may have higher levels of an obesity-related hormone.

Associations have been made between psoriasis and obesity, hypertension, cardiovascular disease, diabetes mellitus and metabolic syndrome. A recent study done by researchers at Taichung General Hospital and National Chung Hsing University in Taiwan provides new insight into the obesity and psoriasis link.

Researchers studied 77 patients with psoriasis and 81 individuals who were the same age and sex but did not have
psoriasis. Patients with psoriasis were found to have higher levels of leptin, a hormone produced by fat cells that may contribute to obesity, than individuals who did not have psoriasis.

Study authors point out high circulating leptin levels in individuals with psoriasis may derive not only from fat tissue but also from inflammation. They also added there are measures that can be taken to reduce leptin levels. "Body weight loss has been reported to significantly decrease leptin levels and improve insulin sensitivity and may reduce the likelihood of developing metabolic syndrome and adverse cardiovascular diseases," study authors were quoted as saying.

Further articles related to this subject are available from the PAPAA website: www.papaa.org or we can provide you with a list of the articles.

Source:
Archives of Dermatology, 2008;144:1571-1575

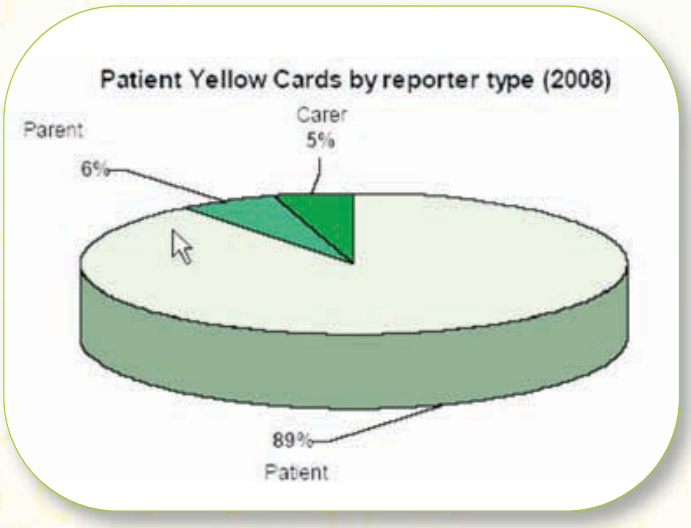
Yellow Card Scheme

MHRA

In February 2009 the Medicines and Healthcare products Regulatory Agency (MHRA) celebrated its first anniversary of establishing patient reporting as a recognised part of the Yellow Card (YC) Scheme. It also marks the first year of a new online reporting form. The YC Scheme is vital as a foundation for the Agency's work in drug safety monitoring.

The information collected from the YC Scheme over the past year has contributed to the Agency's advice on issues like Varenicline (Champix) and adverse psychiatric reactions associated with Rimonabant (Acomplia) and the withdrawal of its licence due to psychiatric risks.

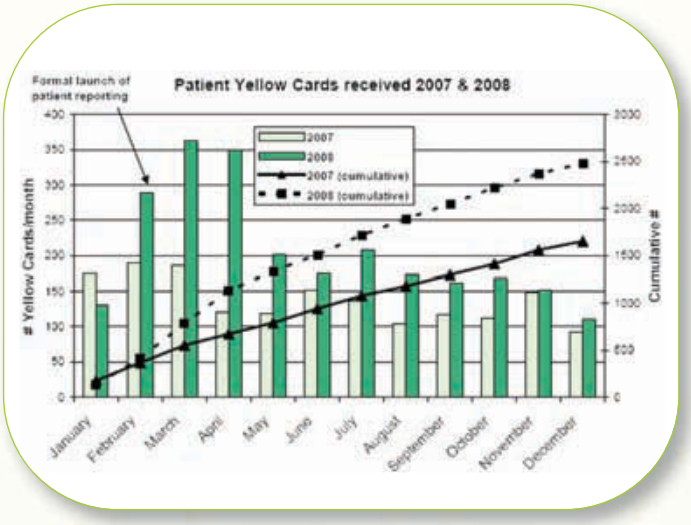
In the past year more than 2,500 Yellow Cards were lodged by patients or carers, bringing the total number of patient reports to almost 9,000. The Agency has also seen double the number of reports submitted online.



MHRA director of vigilance and risk management of medicines, Dr June Raine said: "We are grateful that the public is hearing our message that no medicine is risk-free and has taken an active role in reporting side-effects to us. Medicines have important benefits; however, they may also have side-effects.

"The main trends which have emerged from the YC Scheme in the past year are: a 17 per cent increase overall for all reports to 25,000; including an increase of 50 per cent reporting from the public.

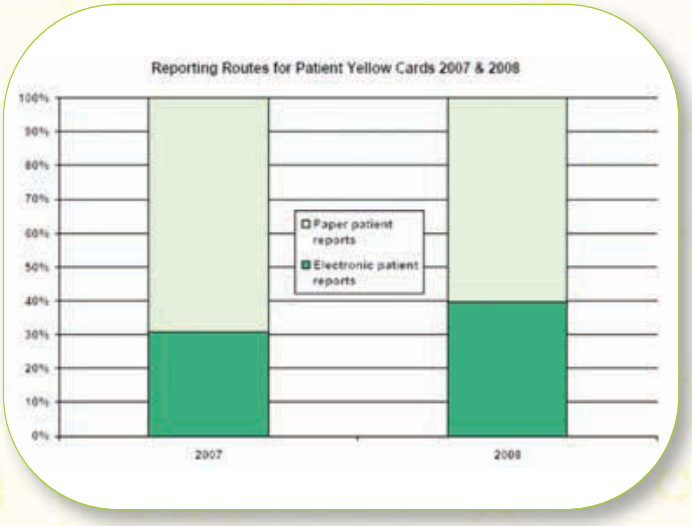
"The more reports the MHRA receives about suspected adverse drug reactions, the sooner we can relay important safety messages to the public and healthcare professionals – everyone benefits from better information.



"If you suspect that you have had a side-effect to your medicine, please tell us about it via the Yellow Card Scheme. Ask your pharmacist for a Yellow Card or better still report online at www.yellowcard.gov.uk ".

The monthly MHRA Drug Safety update was launched in August 2007. It provides the latest official safety news about medicines to healthcare professionals. A survey on the bulletin found that 147 (89 per cent) of 165 healthcare professionals said Drug Safety Update is useful or very useful for keeping up to date.

For the latest drug safety update visit: http://www.mhra.gov.uk/Publications/Safetyguidance/DrugSafetyUpdate/index.htm



Anti-TNF drugs increase the risk of psoriasis

A new study published in the Annals of the Rheumatic Diseases[1] recently by researchers from the Arthritis Research Campaign epidemiology unit at the University of Manchester showed evidence that the risk of psoriasis is increased in rheumatoid arthritis (RA) patients being treated with anti-TNF therapies.

The study looked at three anti-TNF therapies licensed for RA in the UK (adalimumab, etanercept and infliximab). The study included 12000 patients with severe RA, with 2880 of these only using conventional disease-modifying anti-rheumatic drugs. A total of 25 individuals who were using anti-TNF drugs developed psoriasis whilst no incidence of psoriasis was reported in those treated with conventional medicine.

Researchers were quoted as saying: "Results from this study suggest that the incidence of psoriasis is increased in patients treated with anti-TNF therapy. Our findings also suggest that the incidence may be higher in patients treated with adalimumab."

Reference:

1. First published online: 2 April 2008. doi:10.1136/ard.2007.087288 Annals of the Rheumatic Diseases 2009;68:209-215

Efalizumab withdrawn

On 19 February 2009 The European Medicine Agency Committee for Medicinal Products for Human Use (CHMP) has recommended the suspension of the marketing authorisation for efalizumab from Serono. CHMP has concluded that the benefits of efalizumab no longer outweigh its risks, because of safety concerns, including the occurrence of progressive multifocal leukoencephalopathy (PML) in patients taking the medicine.

Efalizumab is known commercially as Raptiva and was marketed in the UK by Serono.

Elsewhere, Genentech, a biotechnology company, has initiated a phased voluntary withdrawal of efalizumab from the US market.

Full EMEA press release can be viewed at:

http://www.emea.europa.eu/humandocs/PDFs/EPAR/raptiva/2085709en.pdf

A link is available from the PAPAA website articles section.

Letters

Dear PAPAA,

I was very interested in reading the information on your website. My GP has never admitted that there was any connection between my psoriasis and my arthritis but the hospital doctor diagnosed me as having psoriatic arthritis. My GP seems to be paying more attention to the psoriasis than the arthritis. It may be unsightly but it is not painful or itchy or anything. The pain of the arthritis is excruciating. Sometimes I wake up screaming in the night with it. The right knee is the main joint affected although pains come and go in the others. There also seems to be a slight overall swelling in my hands so that I am clumsy and drop everything.

I am completely crippled by the pain in that knee and drag myself around with a Zimmer frame. I have been like this for 3 years now and think it is a poor do at just 54. My psoriasis is of the pustular variety although they run together into patches here and there. I feel very much out on a limb in this back water with a GP who doesn't seem to understand and couldn't care less and I am very grateful for all the information you have sent to me.

AM

Q **Dear PAPAA,**

My husband and brother-in-law suffer badly from psoriasis. I would be grateful for any literature you could send me on the disease. I would also like to know about the risks of the disease being passed on to my children.

RM

A **Dear RM,**

It is estimated that if 1 parent has psoriasis that there is a 15% chance that a child will develop the condition. If both parents have psoriasis this increases to about 75%. Interestingly, if a child develops psoriasis and neither parent is affected there is a 20% chance that a brother or sister will also get psoriasis. This is because the condition is known to skip generations but somewhere there will be a familial link to a relative via either or both parents.

PAPAA

Q **Dear PAPAA,**

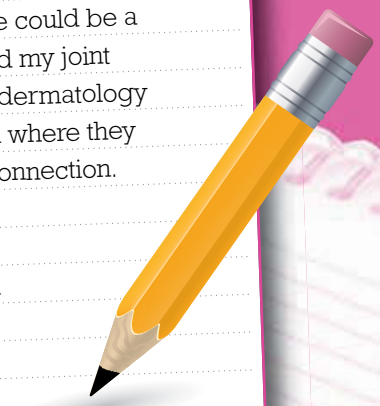
I would be grateful if you would send me information with regard to palmoplantar pustulosis [PPP] as I have recently been diagnosed as having this.

My problems started 3 years ago when I was woken in the middle of the night with a violent pain in my left shoulder, after which I have been unable to move my arm properly. I have undergone two operations to try to correct this, which have been unsuccessful. Six months after the attack on my shoulder I started to suffer from joint pains in my wrists and hands. I have been to the hospital many times to try to discover the cause of my shoulder and joint problems – all to no avail.

In December, I developed PPP on my hands and my dermatologist said there could be a connection between the PPP and my joint problems. I was referred to the dermatology department at my local hospital where they seemed to think there was no connection. I am now to be referred to the rheumatologist for blood tests.

Even before I was diagnosed with PPP I was certain that the rash and the joint pains were connected.

PR



A **Dear PR,**

PPP is normally recognisable by large yellow pustules up to 5cms in diameter, in fleshy areas of hands and feet, such as the base of the thumb and the sides of the heels. They then turn brown and drop off or peel. PPP is usually cyclical with new crops of pustules followed by periods of low activity. This form of psoriasis affects approximately 5% of people with psoriasis.

PAPAA

Q Dear PAPAA,

Could you send me some information about psoriasis as my 5 year old daughter has recently been diagnosed with this condition? Two people have recommended to me that the Dead Sea bath salts are good to use for psoriasis. I can't find expert advice on this so I haven't tried them yet which is why I am writing to you. My local library is useless. I was also wondering if diet can aggravate psoriasis in the same way that it sometimes can in eczema. *RJ*

A Dear RJ

A number of studies have suggested that Dead Sea Climatotherapy (DSC) may be an effective intervention for psoriasis. However, the quality of the studies is highly variable, most often due to lack of control groups and inadequate follow-up. However, some more recent studies have been of better quality and do suggest benefit, although whether this translates into bath salts has not been proven. There is little evidence to suggest that diet aggravates psoriasis, although if you think it does it's worth talking to your daughter's doctor about it. *PAPAA*

Dear PAPAA,

I read with interest about the link between psoriasis and arthritis.

Our daughter, who is now 15, has had psoriasis from the age of 7. At that point she was covered entirely except for her face for several months. Since then the only place she has continued to have it quite badly is her scalp, behind and inside her ears. Treatment has consisted of different types of steroids since the age of 7 with the result that these treatments keep it dampened down but her hair is like straw and it breaks and falls out, occasionally in handfuls. Over the last 4 years she has complained on and off about pain in her toes, neck, hip and hands. I've always thought personally that these joint pains were possibly connected with psoriasis and the pains are becoming worse this last year. I finally saw my GP who just said they were growing pains and there was not a link between the two. Understandably I was upset but for my daughter's sake, as PE at school is sometimes out for her. I could go on, but I can't tell you how relieved I was to see your information leaflets linking the two together. Personally I would like to have my daughter seen by someone who does believe there is a link, as understandably she could get worse over the years and I feel helpless and frustrated at not being able to do more for her. *YF*

Dear PAPAA,

I wrote this poem in the middle of the night during a bad flare-up – we must keep going even when in a lot of pain. I have been a member for many years and enjoy the magazine.

CT

PRECIOUS THINGS

What is this thing called pain? Psoriatic arthropathy is its name.

It has haunted me for over sixty tiresome years, and has brought with it many tears.

The tiredness, pain is beyond belief. The drugs do bring some relief.

Flare-ups cause a downwards twist, to ankles toes and even wrists.

You think it will never end and suddenly you have turned the bend.

If I look wizened old and thin, some sympathy would come flowing in.

My face is full, my toes are fat, the drugs I have to thank for that.

My answer is to have a chat, a laugh, a smile, will help with that, so painful joints will carry on the best they can.

There is always someone worse than you.

Do not give up – pick up the phone and call a friend, you are already on the mend.

The adrenalin flows. The pain abates.

The joy of living is all around. The birds, the flowers, the sky so blue. These are precious things, given to you.

Accept this and YOU will pull through.

Please note: letters and e-mails have been edited and names withheld for privacy

Golimumab for PsA shows promise

A new phase III clinical trial[1], called GO-REVEAL (Golimumab-Randomized Evaluation of Safety and Efficacy in Subjects with Psoriatic Arthritis using a Human Anti-TNF Monoclonal Antibody), which was the largest of its kind to be completed with a biologic agent to treat psoriatic arthritis and the first placebo-controlled study evaluating the effect of a TNF inhibitor on nail psoriasis, found that golimumab significantly improved active psoriatic arthritis and associated skin and nail psoriasis.

The trial was a multicentred, randomised, double-blind, placebo-controlled trial, led by Arthur Kavanaugh of the University of California San Diego in La Jolla.

Included in ten trials were 405 patients with active psoriatic arthritis even after having taken other disease-modifying anti-rheumatic drugs or non-steroidal anti-inflammatory drugs.

The results showed that golimumab was efficacious and generally well tolerated as measured using the American College of Rheumatology 20 per cent improvement criteria. Those who initially showed little improvement and switched from placebo to golimumab or increased their dosage also showed improvement.

This was also the first placebo-controlled study evaluating the effect of an anti-TNFα on nail psoriasis. Significant improvements in nail symptoms were seen in those treated with golimumab as early as week 14 and were maintained or improved through the end of the study period.

Other efficacy assessments included:

- Psoriasis Area and Severity Index (PASI) in patients in whom at least 3% body surface area (BSA) was affected by psoriasis at baseline
- Short Form 36 Health Survey (SF-36)
- Disability Index of the Health Assessment Questionnaire (HAQ)
- Nail Psoriasis Severity Index (NAPSI)
- Physician's global assessment of psoriatic nail disease, and enthesitis

Golimumab is given as a subcutaneous injection. The researchers are hoping that longer-term data on golimumab's efficacy and safety will be reported in the future.

Golimumab does not have a marketing authorisation for the treatment of psoriatic arthritis in the UK, but a marketing authorisation application was submitted to the European Medicines Agency for the approval of golimumab as a monthly subcutaneous treatment for adults with rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis in March 2008.

Golimumab is currently included to a Multiple Technology Appraisal (MTA) by The National Institute for Health and Clinical Excellence (NICE)[2]. Other biological therapies for psoriatic arthritis include: adalimumab etanercept and infliximab.

References:

1. **Published in Arthritis & Rheumatism, April 2009; 60: 976-986.**
2. **www.nice.org.uk**

Etanercept approved for children with severe psoriasis

Etanercept, a tumour necrosis factor (TNF) blocker, has been approved for the treatment of children with severe plaque psoriasis. Etanercept is the only biologic treatment approved for chronic severe plaque psoriasis in children and adolescents aged 8 years and above[1]. Paediatric patients who have taken etanercept experienced significant improvement in their signs and symptoms of psoriasis[2].

''The efficacy and safety profile of etanercept is supported by extensive clinical evidence and its availability for children represents a significant milestone in the treatment of childhood psoriasis'' said Dr Ruth Murphy, consultant dermatologist at Queen's Medical Centre, Nottingham.

According to the results of a 48week study that involved 211 patients with moderate-to-severe psoriasis between the ages of 4 and 17 years[2], etanercept is an effective treatment for children with severe plaque psoriasis.

Etanercept is also approved for the treatment of adults with moderate to severe plaque psoriasis. It has been used in adults since 2004.

Etanercept can only be prescribed (POM) by a hospital consultant when other treatments have failed. Other biological agents licensed and used in adults with psoriasis are adalimumab, infliximab and ustekinumab.

Etanercept is known commercially as Enbrel and is marketed by Wyeth Pharmaceuticals Ltd in the UK.

References

1. **Enbrel Summary of Product Characteristics (SPC), December 2008.**
2. **Paller AS et al. Etanercept treatment for children and adolescents with plaque psoriasis. N Engl J Med 2008;358:241-51**

Ustekinumab approved for psoriasis

It was announced in January that ustekinumab, the first in a new class of biologics, had been approved by the European Commission for use across Europe. The approved indication of ustekinumab is for the treatment of moderate to severe plaque psoriasis in adults who failed to respond to, or who have a contraindication to, or are intolerant to other systemic therapies including ciclosporin, methotrexate and PUVA (psoralen plus ultraviolet A light).

In clinical studies, treatment with ustekinumab demonstrated significant improvements in patients' psoriasis and quality of life, which were sustained with as few as four injections a year (every twelve weeks) following two starter doses at weeks 0 and 4. The approval of ustekinumab offers adults living with moderate-to-severe plaque psoriasis a new therapy which has the potential to make a considerable impact on their daily lives.

The approval is based on data from two large studies[1,2], which included 2,000 patients in whom the efficacy and safety of ustekinumab in the treatment of moderate-to-severe plaque psoriasis were evaluated. Two-thirds or more of patients achieved the primary endpoint of each trial, as measured by using the Psoriasis Area and Severity Index.

The most common adverse reactions in clinical trials were arthralgia, cough, headache, injection site erythema, nasopharyngitis and upper respiratory tract infection. Most were considered to be mild and did not necessitate discontinuation of therapy.

The National Institute for Health and Clinical Excellence (NICE)[3] is currently appraising ustekinumab for the treatment of moderate to severe psoriasis. The Final Appraisal Document (FAD) is expected to be issued in September 2009.

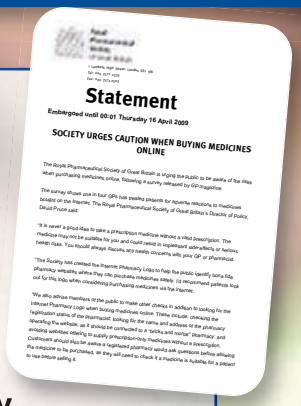
Ustekinumab can only be prescribed (POM) by a hospital consultant when other treatments have failed. Other biological agents licensed and used in psoriasis are adalimumab, etanercept and infliximab.

Ustekinumab is known commercially as Stelara and is marketed in the UK by Janssen-Cilag Ltd.

References:

1. PHOENIX 1. The Lancet. 2008;371:1665-74
2. PHOENIX 2. The Lancet. 2008;371:1675-84
3. http://www.nice.org.uk/Guidance/TA/Wave18/20

Caution online


Statement

Embargoed until 00:01 Thursday 16 April 2009

SOCIETY URGES CAUTION WHEN BUYING MEDICINES ONLINE

The Royal Pharmaceutical Society of Great Britain is urging the public to be aware of the risks when purchasing medicines online, following a survey released by GP magazine.

The survey shows one in four GPs has treated patients for adverse reactions to medicines bought on the Internet. The Royal Pharmaceutical Society of Great Britain's director of policy, David Pruce said:

"It is never a good idea to take a prescription medicine without a valid prescription. The medicine may not be suitable for you and could result in unpleasant side-effects or serious health risks. You should always discuss any health concerns with your GP or pharmacist.

"The Society has created the Internet Pharmacy Logo to help the public identify bona fide pharmacy websites where they can purchase medicines safely. I'd recommend patients look out for this logo when considering purchasing medicines via the internet.

"We also advise members of the public to make other checks in addition to looking for the Internet Pharmacy Logo when buying medicines online."

These include: checking the registration status of the pharmacist; looking for the name and address of the pharmacy operating the website, as it should be connected to a 'bricks and mortar' pharmacy; and avoiding websites offering to supply prescription-only medicines without a prescription.

Customers should also be aware a registered pharmacy would ask questions before allowing the medicine to be purchased, as they will need to check if a medicine is suitable for a patient to use before selling it.

For further information, visit www.rpsgb.org.

A document listing websites displaying the internet pharmacy logo can be accessed at:
http://www.rpsgb.org.uk/pdfs/iplpharmacywebsites.pdf

Market Place

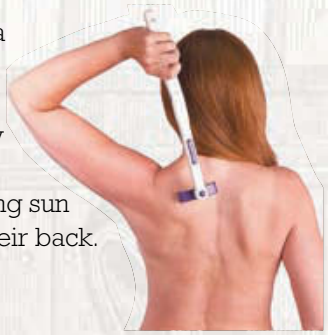
Here are a few items that have been brought to our attention by our readers. These are for your interest and in no way are we endorsing or recommending these products.

We've been sent some interesting items for this edition, so thank you if you have provided suggestions.

From **Viva** a long-handled brush and comb set that may help tidy your hair without raising your hand above shoulder height. If restricted arm movement stops you from brushing or combing your hair, this innovative long-handled set could restore your independence and confidence.

Code:1458098. **Price £10.95**

Another product from **Viva** is a long-reach roller for lotions and creams. A problem solver so simple you will wonder why no-one's thought of it before! Everybody has trouble applying sun lotion and moisturisers onto their back.



Code: 1076448. **Price £16.95**

As a follow-on from our gardening article on page 9, how about this garden paving scraper from **Easylife Lifestyle Solutions**. It contains 2 different attachments for quick and easy removal of dirt.

Code: 2754. **Price £12.99**

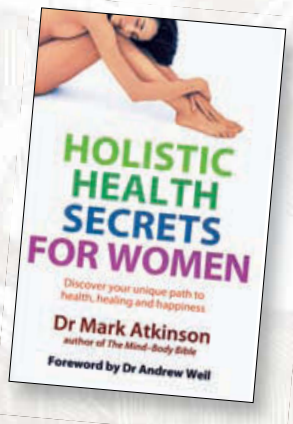
A reader has recently told us about **Youreable Shop** which offers an extensive range of disability aids to help make your life easier. You can browse through the extensive products via the categories sections. The website says that "Youreableshop.co.uk is one of the UK's leading disability retailers. At Youreableshop.co.uk we aim to help you stay mobile by offering over 13,000 disability products at highly competitive prices…" They also claim that "most products are at wholesale prices".

TENS (Transcutaneous Electrical Nerve Stimulation) has successfully been used for many years by medical professionals and patients worldwide as a form of drug free pain relief. **Pain Doctor** is a new clinically tested class IIa CE-certified medical device to target pain whenever required. Comes complete with 60ml conductive gel; replacement gel can be bought separately. Requires 2 AA batteries, which are supplied.

Prices from £47.99*

New book:

Holistic Health Secrets for Women: Dr Mark Atkinson: A comprehensive holistic guide to female health specifically designed for women. The book is an easy to follow, integrated medical approach for addressing the most common health and life challenges that women face today.
ISBN: 978-0-7499-2824-7:
Published by Piatkus Books. 2009.
Paperback.
Price £8.44* (UK cover price £12.99)



Contact details for the above products:

Viva
0844 482 1616 **www.vivadirect.co.uk**

Easylife Lifestyle Solutions
0871 855 2000 **www.easylifegroup.com**

Youreable Shop
0844 888 1337 **www.youreableshop.co.uk**

***Amazon**
(Online only) **www.amazon.co.uk**

If you come across products or items that you have found useful or you think others will find of interest please let us know. There may be similar products on the market made by other manufacturers that are as useful so keep your eyes open