# Skin 'n' Bones connection

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PAA

Registered charity number: 1051169
E-mail: info@psoriasis-uk.org
Website: www.psoriasis-uk.org



**PAA**
**PO Box 111**
**St Albans, Herts**
**AL2 3JQ.**
**Tel: 0870 7703212**
**Fax: 0870 7703213**

The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

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**Dear PAA**

Ten years ago I had just landed an important new job and was pleased with life. In view of being important I felt that some new suits were called for to go with my image as a young thrusting man about town and management grad type employee.

I had never been one to worry about my health greatly and the death of my fiancée, followed swiftly by eviction and losing my job made me more determined to enjoy life for the moment.

The onset of a spot of dandruff was therefore a small irritant. Before long it became a big irritant and readers will know about having to remove large areas of scales surreptitiously from smart dark suits. Cheapo anti-dandruff shampoo was followed by shelling out for real Head and Shoulders. Eventually a trip to the doctor seemed justified. I wanted to laugh when he asked me if I dyed my hair. I would have chosen a nicer colour if I had. In any case it was falling out at the front where the itching was especially bad and he told me I had psoriasis and prescribed Cocois ointment.

Although I had not heard of psoriasis, I had heard of Cocois, or rather smelt of it as my sister's dog had had it some years before for some skin complaint. Well, it was not the dog's ointment for me. The greasiness and the smell had a detrimental affect on my love life and no appreciable effect on the psoriasis. It turned out that one of my mother's friends suffered from psoriasis and recommended sunbathing, something I had never really been into. Apart from the slight nuisance of being constantly mobbed by beautiful young women this worked and the psoriasis disappeared other than from my scalp, despite having tried a skinhead haircut, much to everyone's amusement, although people no longer kicked sand in my face at the beach.

A move to the garden of England meant a change of GP, who I shall refer to as 'Dr Beazley', who prescribed Dovonex and the scalp problem disappeared too.

Life became pleasant and my fourth child arrived to make it complete, followed by a splendid summer with temperatures of 100 degrees - good for the psoriasis.

One morning I awoke early after being beaten by burglars; or at least that is what it felt like. A trip to the doctor ensued a few days later: she diagnosed psoriatic arthritis at once and described what it was. It sounded like something you watched on 'Horizon' when you wanted to feel clever; not something that ordinary people suffered from. I was sent to a consultant - the first I had ever seen who confirmed the dagnosis and prescribed a treatment of diclofenac sodium backed up with cocodomol.

This did make life much easier as with four small children and a full time job involving driving around there was not much scope for having more rest.

By 2004 there were days when I was so lame I had trouble getting to work. And work took place in a small eighteenth century shop with spiral staircase to gain access to the loo.

A transfer to the London office was worse as the psoriatic arthritis was at its worst about 6.00am, which was just when I needed to leave home to get to the railway station. I usually had to take a bus to work even though it was less than a half mile-walk. My toes had gone blue and become deformed so it was back to the doctor. I was put on methotrexate.

For three weeks I almost gave up but once the treatment set in I felt much better and now after a couple of months have only twisted toes to remind me I have psoriatic arthritis. I feel normal and can manoeuvre alright and even terrorise my children by chasing after them.

I just hope that it does not wear off and was dismayed to read Dr Camp's article in issue 19, which described it as a 'cure' in quotation marks.

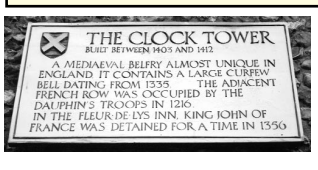
The biggest drawback so far is the instruction to drink only 'a small amount of alcohol'. How much is that? None of the literature seems to say. Perhaps the PAA can turn out one of its leaflets on Real ale and methotrexate.

I understand that both drink and methotrexate affect the liver. One of my neighbours is dying from liver failure, which puts one off risking it. Perhaps other readers can supply some wisdom through these pages and share experiences.

Two things I tried with no appreciable benefit were a copper bracelet with a magnet in it and cod liver oil capsules. I once worked with a photographer whose right index finger had seized up with inflamed joints and was cured by wearing a copper ring, but it does not seem to work for psoriatic arthritis.

Psoriatic arthritis does seem to be something of a 'Cinderella' complaint, with only the PAA banging the drum with this magazine as the main source of information. I count myself lucky that 'Dr Beazley' diagnosed what was wrong straight away, despite no one in my family having had psoriasis (and I boast 25 cousins with more than 70 children between them) that as it is supposed to be inherited. When she retires I shall have a statue of her erected by public subscription in the town. A change from a general on a horse, don't you think?

**By Quentin Williamson**




*Cover picture: St Albans Clock Tower - David Chandler*

# Woburn
## Conference report

By Chris Friend PAA Trustee

# All the Whys or Wiser the Better
### questions posed and answered at 11th PAA Conference

Some 240 people were at Woburn Safari Park on September 17th to hear Co-Founder of the PAA, David Chandler open the 11th PAA Conference. He reminded us that a key role of the organisation is to listen, support, make sense of and evaluate the maze of advice offered to us as we seek to manage psoriatic arthritis.

The PAA is fortunate to have a number of good professional advisors and of these, Consultant Physicians, Dr Anthony White, Dr Virginia Camp, Dr Tony Chu, Physiotherapist Catherine Buckley and NHS Trust non Executive Director, Patrick Parker all contributed their expertise. Furthermore we were privileged to have guest speakers Rosemary Noakes, a Phototherapy Nurse and Kathy Italiano, a Dermatology Specialist Nurse, both from Kettering General Hospital and Dr Bruce Kirkham, Consultant Rheumatologist, Guys Hospital, London.

For the first session, **'Why Not Ask'**, Dr Tony White analysed eighty questions sent to the PAA. Most concerned treatment issues, some diagnosis and others were queries about medicines.

Media stories can trigger queries about new treatments such as anti-TNF agents


for treating PA. Patients assume they are available on an NHS prescription. But, because they cost between £7000 and £14,000 per year per patient, there can be reluctance by hospital trusts to spend such amounts indefinitely when they treat rather than cure. Questions arise about the side effects of established treatments like methotrexate. Other enquiries on treatment relate to patients having been given incomplete treatment information. He cited sulphasalazine. 1 in 5 patients metabolise that drug very slowly leading to accumulation in the body (overdose). Some patients are not told that sulphasalazine takes 6 to 8 weeks to show effect and stop taking assuming it doesn't work.

Diagnosis questions are much more difficult to deal with the patient not being present Even so a benefit of being able to contact PAA with questions of diagnosis is that the specialised medical experience of the Advisors can sometimes pick up something missed by colleagues.

**Why Phototherapy**

Using sunlight to treat skin conditions is not new. Ancient Egyptians used the plant extract psoralen in conjunction with the sun's rays. So said Rosemary Noakes, Phototherapy Nurse at Kettering General Hospital in describing her work and the benefits and risks of UVB and PUVA therapy. These sources of ultra violet radiation have been developed to treat psoriasis patients using a controlled environment not reliant on sunlight.

UVB is socially acceptable, safe in pregnancy. Medication is not needed and no messy creams are involved. Patients are assessed to find out their skin type and the appropriate UVB strength for their type. Doses start low and in short duration. Lifetime levels of treatment must be limited the reason being that excess use can increase the risk of skin cancer. Assessment includes checking medications that make patients more sensitive to light including some oils used in aromatherapy that react with UVB as does the popular herbal remedy St John's Wort.

Eye protection is important due to the brightness of UVB and possible risk of developing cataracts. Also there may be a risk of cancer to male genitalia and appropriate protection is advised!

**PUVA**

UVA provides a different form of light beam from UVB. Combined with psoralen as PUVA it is a very effective treatment for patients with chronic stable plaque forms of psoriasis of the trunk and limbs. However it can cause nausea, vomiting and itching even to the point of therapy unacceptability. Erythema can be a problem and eyes may become very sensitive to light. Long-term use can induce premature ageing of the skin, freckling, and occasionally development of pre-malignant lesions.

Phototherapy requires big commitment from the patient with frequent clinic visits up to three times a week. However there is a high degree of patient satisfaction as their skin improves. Most end their treatment course feeling much better and happier.

**Why All the Blood Tests?**

Kathy Italiano, Dermatology Speciality Nurse at Kettering Hospital described blood tests necessary to ensure safety when powerful drugs such as methotrexate and cyclosporin are used. They show changes even before the patient experiences problems. When abnormalities appear treatment can be stopped before permanent damage is done. In the case of methotrexate inflammatory damage to the liver is possible with toxicity to bone marrow. Liver Function Test (LFT) results and blood cell counts give early warning in time to prevent such damage.

Cyclosporin mainly affects the kidneys. Urea, electrolyte tests and creatinine level measuring show up potential problems. Neotigosen can damage the liver and can raise cholesterol levels in the blood. LFT and serum lipid tests are done to monitor the effects of this drug.

For all patients receiving powerful drugs on going monitoring charts are used. Abnormal changes will be noted and

# Woburn
## Conference report

action taken to modify or cease therapy. Similarly new biological drugs are being monitored by blood tests so providing effective and safe treatment for psoriasis.

**Why Patient choice?**

The Government wants patients to have more choice, particularly in relation to elective surgery. Catherine Buckley, led us through the reams of 'management speak' that surround these initiatives. She specified programmes that are being implemented that will impact on patient


care. The Choose & Book system due for implementation from December 2005 is one such. This aims to eliminate waiting for elective surgery by offering patients a choice of 4 or 5 options, including private and Foundation hospitals. In theory this could reduce uncertainty for patients and use NHS resources better. This programme follows the implementation of the 'Choice at 6 Months' initiative of 2004 where patients who have waited 6 months are offered a change to another (often private) hospital. The proposals could work but need careful planning and appropriate IT systems in place in surgeries. Patrick Parker, also a Trustee of PAA then looked at some of the practical issues that may result from such 'consumerist' initiatives. He examine the type and quality of information needed to assess options; who actually makes the choice and what factors affect that decision. Information must be appropriate, accurate, current, impartial, transparent and understandable. It must cover the alternatives available. Not all patients are the same and want this type of choice. Personal circumstances and degree of illness can be a factor. The situation of partners, parents, carers can be factors as can the competence and co-operation of the primary care doctor. Patient/carer mobility considerations and after care provision are crucial. Professionally he felt these issues could hamper genuine choice and patient benefits particularly as implementation matters have not been thought through.

He warned more health care changes are on the way with a new Government White Paper on the future of the NHS imminent. We need to keep ourselves informed, involved and able to judge and influence theory versus practice.

The principle guest speaker of the day was Dr Bruce Kirkham, Consultant in Rheumatology at Guys Hospital, who has a special interest in the relatively new anti-TNF agents in the treatment of psoriatic arthritis.

Psoriatic Arthritis having been historically a 'Cinderella' disease he welcomed the recent significant progress in developing new treatments and ways of measuring their efficacy.

While the cause of the condition is still not clear its process is becoming so. Drugs have been developed that act on the process of both arthritis and psoriasis and viable health assessment tests of how the patient feels and performs daily tasks are now available.

TNF Blockers have been shown to have real effect in severe PA both in terms of health assessment and in scans but they have side effects. TNF normally helps the immune system fight infection so blocking it can increase the risk of serious infection. This limits anti-TNF agents to managing serious psoriatic arthritis. But, because they can be used to treat psoriasis too dermatologists and rheumatologists are beginning to work together better, which is good for patients..

Discussing the high cost of these new drugs he felt that as more come on stream and compete, prices would fall. Biologicals are difficult and expensive to make and research costs have to be recouped. He told the audience that once licensed these drugs are available for prescribing in the NHS and do not have to await the assessment of the National Institute for Clinical Excellence.

In the last session,'Why Clinical Trials', Dr Tony Chu, a favourite speaker at PAA conferences, described the complex and expensive process of clinical trials of new medicines.

Doctors assess the value of treatments by experience over years of clinical usage as in the case of methatrexate (which has never had formal clinical trials for psoriatic arthritis) or by Evidence Based Medicine providing proof of safety and efficacy via constructed clinical trials. This involves large numbers of patients half receiving active drug and half placebo or a comparative drug. The study must be 'blind' i.e. neither patients nor researcher know which is which.

This type of study must be done for new drugs to licensed for prescribing and were legally instituted to ensure patient safety. The process is controlled by the European Medicines Evaluation Agency, takes about 12 years and costs around £400 million.

85% of new medicines are developed by the pharmaceutical industry although universities and hospitals do important basic research. Only 4% of new products actually reach the market

The complex system comprises preclinical toxicity tests in animals then limited clinical test of human safety and absorption in normal patients. Next the

drug will be administered to a few patients who have the target disease. Phase II tests to show efficacy and the right dose for the majority follow. Then comparative tests are done in several hundred patients against placebo or an established treatment to show comparative efficacy. This should identify side effects. Phase III clinical studies are larger and last up to 3 years. At least 2 such studies are required by law and involve thousands of patients. In the UK local ethics committees must approve the process and active comparator trials are preferred to use of placebos. If all is well and a licence is granted on grounds of safety and efficacy a medicine can legally be prescribed but in due course the drug will be assessed by NICE who will decide whether the medicine offers value for money and may advise against its use.

Post marketing studies will be done to evaluate the new medicine in long-term use and special groups such as children. Lastly if used in hospitals the local formulary committee must be convinced of value for money – not an easy process.

As in previous years the Conference ended with the ever popular Questions and Answers sessions with the active participation of the audience. And nobody was eaten by lions…

# BRIGHT COLOURED FOOD

Researchers from The University of Manchester's Medical School have discovered that eating more brightly-coloured fruits and vegetables like oranges, carrots and sweetcorn may help reduce the risk of developing inflammatory disorders like rheumatoid arthritis.

Rheumatoid arthritis currently affects around 1% of adults in the UK. Previous studies have suggested that vitamin C and the pigment beta-cryptoxanthin, both of which are found in brightly-coloured fruit and veg, may act as antioxidants, and protect the body against the oxidative damage which can cause inflammation.

The Manchester team, based in the Arthritis Research Campaign's Epidemiology Unit, worked with researchers from the Institute of Public Health at the University of Cambridge to analyse health questionnaires and diet diaries by over 25000 45-74 year-olds; completed as part of the EPIC (European Prospective Investigation of Cancer) Norfolk study of diet and chronic disease in the 1990s. They then followed-up the participants over a nine year period to identify new cases of inflammatory polyarthritis (IP), including rheumatoid arthritis.

Dr Dorothy Pattison, who led the research, said: "We found that the average daily beta-cryptoxanthin intake of the 88 patients who had developed inflammatory polyarthritis was 40% lower than those who hadn't, and their intake of another carotenoid, zeaxanthin, was 20% lower.

"Those in the top third for beta-cryptoxanthin intake were only half as likely to develop IP as those in the lowest third, and vitamin C was also found to be an important factor."

The findings appear to confirm previous evidence that a modest increase in fruit and vegetables containing beta-cryptoxanthin and vitamin C, equivalent to one glass of freshly-squeezed orange juice each day, might help to protect against developing inflammatory joint diseases.

Dr Pattison has previously published research which found that both low intakes of fruit and vegetables (in particular those high in vitamin C), and high levels of red meat consumption were associated with an increased risk of developing IP.

# BENEFITS CLAIMANTS ARE NOT FRAUDSTERS

RADAR
the disability network

RADAR, the UK's leading disability rights organisation, welcomes the Government's plans for welfare reform, and is seeking to contribute to a positive debate. Over a two week period we are dispelling 8 myths about Incapacity Benefit and disabled people as part of RADAR's Prescription for a Healthy Debate - take one truth a day!

**Myth 2:** People on Incapacity Benefit are fraudsters.

**The truth of the matter.**

The House of Commons Committee of Public Accounts recently published the "Fraud and Error report in benefit expenditure" which claimed that the DWP lost an estimated £3billion out of a total of £109bn expenditure to fraud in 2003-04.

It is important that this not be automatically taken as evidence that people on Incapacity Benefit are fraudsters.
In reality, fraud among people claiming Incapacity Benefit accounts for less than 2% of the Department for Work and Pension's total expenditure on benefits. Fraud accounts for no more than £20m, with over £90m being wasted through errors that are not the fault of claimants.

It should also be noted that a crackdown on fraud in 2004 reduced the total amount of benefit fraud by £500 million, but the amount of money lost on errors increased by roughly the same amount.

Kate Nash, Chief Executive of RADAR, says, "An overhaul of Incapacity Benefit must take into account the reality that far more money is lost through error than fraud. We must not jump to conclusions that those in need of government support are fraudsters. We must instead start from a position of trust and respect."

**Tomorrow's Myth.**

*"People on Incapacity Benefit could get a job if they really wanted one."*

For further information please contact:
Erin O'Brien
RADAR
erin.obrien@radar.org.uk

# New research shows arthritis patients still denied treatments in health care lottery

Doctors have responded with concern following the publication of recently published research, which shows that patients with severe rheumatoid arthritis are still being denied access to vital treatments, despite guidance from the National Institute for Clinical Excellence (NICE) instructing health care trusts to provide them.

The new research was commissioned by the British Society for Rheumatology (BSR) and the Arthritis and Musculoskeletal Alliance (ARMA) after growing concerns from doctors and patients. The research suggests very little has changed since a similar survey in 2003.

Professor David Isenberg, a rheumatologist and President of the BSR, thought the results were 'very disappointing'. He said:

"It is immensely frustrating for doctors to have patients who clearly qualify for anti-TNFa intervention but are unable to get it. These drugs offer hope and relief to people who have severe rheumatoid arthritis, and are likely to be affected by high levels of pain and disability, making their day to day living very difficult."

Of the 148 rheumatology units across the UK which responded to the 2005 survey:

- 31% of doctors are unable to provide treatment to all qualifying patients.
- More than 50% cited lack of funding as the reason.
- Doctors estimate nearly 1700 rheumatoid arthritis patients who could benefit from anti-TNFa drugs are being denied treatment.

Doctors also said they were unable to help people with other arthritis related conditions with anti-TNFa treatments despite the clear benefits of doing so; 58% were unable to prescribe the treatments for people with ankylosing spondylitis (AS), and 53% saying they were unable to prescribe the treatments for people with psoriatic arthritis (PSA). NICE is developing guidance on these treatments, but in the meantime the lack of approval from NICE is the main barrier to treating AS and PSA with these drugs.

A similar survey carried out by ARMA in 2003 showed around 33% of doctors were unable to prescribe anti-TNFa treatments to all qualifying patients with rheumatoid arthritis, showing only a 2% improvement over two years. These results are in spite of the NICE guidance, which was introduced in 2002.

Professor Isenberg added:

"NICE guidance was developed to combat this type of inequality, but it isn't working for all of our patients. It is wrong that some people are being left with unnecessary pain and disability. The Department of Health should remind health trusts they need to take urgent and immediate action to ensure people get the treatment they are entitled to."

**Copies of 'Access to anti-TNFa treatments for adults with inflammatory arthritis – 2005' are available from the BSR on www.rheumatology.org.**

# Hope for skin

A team at Newcastle University has discovered that an ointment, dithranol, used to soothe psoriasis actually kills the cells that cause the problem.

It is believed the discovery will pave the way towards better treatments for the UK's one million sufferers.

The team was led by Professor Nick Reynolds and Dr Mark Birch-Machin, of the skin research group.

Currently the drug is only used in hospitals for severe cases of the disease because if misused can cause burning and discolouration of clothing.

Prof Reynolds and his team are now hoping that more effective ways of administering the drug will be found.

Dithranol is a compound derived from the araroba tree found in the rain forests of the Amazon.

Prof Reynolds said: "Most people suffering an episode of psoriasis that requires treatment with dithranol have to either attend hospital as an outpatient five days a week, or be admitted for a three-week period.

"In modern life, this is far from ideal. These findings represent an important step towards the development of better-designed treatments for psoriasis sufferers."

Psoriasis is a genetic condition which, when triggered by certain factors such as injury or throat infection, leads to an over-production of skin cells.

These are called keratinocytes and cause a thickening of the skin, resulting in the raised red, scaly patches of psoriasis.

**Story from BBC NEWS:**

# NEW CODE OF PRACTICE FOR PHARMACEUTICAL INDUSTRY UNVEILED

Details of the revised and updated ABPI Code of Practice that governs the UK-based pharmaceutical industry's relations with healthcare professionals and other stakeholders were published recently. The new code comes into effect on January 1, 2006.

A major review of the code and its operation has taken place, and among key changes to the code are:

- Patient safety is being further promoted by a requirement for all printed, promotional material to include prominent information about reporting adverse drug reactions.
- Further definition and restrictions are being applied on what can be provided to health professionals in the way of promotional aids, hospitality, subsistence, travel, and accommodation.
- Relationships with patient groups and the provision of information to the public are covered in greater depth.
- A reduction in the permitted number of pages of medicines advertising and an outright ban on all promotional competitions are introduced.
- Moves to speed up the process of determining complaints so that decisions can be made more quickly and sanctions imposed faster.
- Materials or activities ruled in serious breach of the code may, under certain circumstances, be suspended, even if an appeal is intended, which will reduce the time such material remains in use.
- Results of some, more serious cases will be advertised in the medical and pharmaceutical press, thus strengthening the sanctions available.

"This has been a fundamental review of the code and follows a far-reaching public consultation exercise. We have listened to all these comments and taken action accordingly," said Vincent Lawton, President of the ABPI.

"As well as the changes to the code itself, we want to ensure that more people and organisations know about it, its provisions and understand how it works. With this in mind, we are planning to create a new communications post within the Prescription Medicines Code of Practice Authority (PMCPA), which administers the code, and there will be a major campaign in the new year to ensure that the code has as high a profile as possible."

Jeremy Mean, Senior Policy Manager at the Government regulator, the Medicines and Healthcare products Regulatory Agency (MHRA), said: "The control of medicines advertising in the UK is based on a long-established system of self-regulation supported by the statutory role of the MHRA.

"The MHRA warmly welcomes the new code, which includes positive changes to enhance patient safety to ensure that the code remains robust and rigorous."

The MHRA's backing for the new code coincides with the publication of a joint memorandum of understanding between the ABPI, PMCPA and the MHRA. The memorandum sets out the arrangements for the regulation of the promotion of medicines for prescribing in the UK, and is available on both the MHRA website (www.mhra.gov.uk) and that of the PMCPA (www.pmcpa.org.uk).

The changes to the code have been agreed following a major consultation exercise with a wide variety of stakeholders, including professional bodies representing doctors, pharmacists and nurses; patient advocacy groups; and the MHRA. The process of considering complaints will be more transparent.

"The ABPI Code of Practice has been the gold standard for pharmaceutical industry regulation throughout the world for many years, and our aim was to ensure that it continued to be strong and effective as well as fully meeting all the changes and requirements that have occurred since the last review," said Andrew Hotchkiss, ABPI Board member and Managing Director of Lilly UK, who was in charge of the project.

"Self-regulation is by far the most effective means of ensuring that the industry's relationship with the NHS and others is conducted in a responsible and ethical manner. Given that branded medicines can make the difference between life and death, it is incumbent on all of us who work in the pharmaceutical industry to ensure the highest standards when dealing with healthcare professionals and other stakeholders. The revised code is a strong message of intent but, ultimately, society will judge us on our actions and behaviour."

## Key changes to the ABPI Code of Practice Safety

To emphasise the pharmaceutical industry's commitment to safety, the new code requires companies to include prominent information about adverse event reporting mechanisms on all promotional material. This comes at a time when the Government is extending the 'Yellow Card' scheme so that patients across the country can report adverse effects, and will mean that all promotional material produced by companies will have to be changed.

## Relationships with health professionals

Existing rules that cover the provision of promotional aids, hospitality, travel and accommodation have been further defined. For example, it is now specifically stated that items must not be offered for the personal benefit of health professionals or administrative staff. It remains the case that items must be inexpensive - the limit is £6, excluding VAT – and relevant to the recipients' profession.

The new code makes it clear that promotional aids are more likely to be acceptable under the code if they benefit patient care, and gives more guidance on the types of items that are both acceptable and unacceptable. It also bans the use of promotional competitions and quizzes.

As far as meetings and seminars are concerned, subsistence must be strictly limited to the main purpose of the event and be secondary to the purpose of the meeting. Companies must only offer economy air travel to delegates sponsored to attend meetings. Lavish venues must not be used and companies should avoid using venues renowned for entertainment facilities.

Further clarification is also given on the circumstances under which meetings may be appropriately held outside the UK.

## Relationships with the public and patient groups

Definitions of what information can be supplied to the public have been improved to give more guidance and to clarify how companies may respond to patients' needs for reference information on medicines. Promotion of prescription-only medicines to the public remains strictly prohibited.

There is also an important new clause concerning relationships with patient advocacy groups. While companies are permitted to work with such groups, their involvement must be made clear, and rules on arrangements for meetings are the same as those for health professionals.

Companies must make public, by means of information on their website or annual report, a list of all patient organisations to which they provide financial support, and a written agreement must be in place with every organisation spelling out exactly the terms of the relationship and funding of every significant activity or ongoing co-operation.

## Complaints and sanctions

Various moves have been put in place to speed up the process of deciding a complaint and imposing sanctions. For example, a company accepting a ruling of the Code of Practice Panel has just five working days – instead of the current ten – to stop use of the material.

In addition, if the material or activity found in breach is likely to prejudice public health or safety, or is a serious breach of the code, the company will be required suspend use of it even if an appeal is planned.

Several different sanctions are already applied to companies found in breach, but the new code gives additional sanctions to the Appeal Board and also allows for details of certain cases, considered serious, to be advertised in pharmaceutical or medical press.

Brief details of ongoing cases will in future be available on the PMCPA's website. In the past, such details have only been provided when the case is completed.

**The new ABPI Code of Practice can be accessed at www.pmcpa.org.uk.**

# Women feel pain more than men, research shows

***Women feel pain more than men despite the popular notion that the opposite is true, according to research.***

Scientists investigating gender differences in pain have found that not only do women report more pain throughout the course of their lifetime, they also experience it in more bodily areas, more often and for longer duration when compared to men.

There also seem to be differences in how men and women think and feel about their pain. For example, anxiety may affect men and women in different ways, and the strategies used to cope with pain may actually make their experience worse.

These conclusions are based on several studies into the pain response of volunteers exposed to a pain stimulus, such as a cold water bath, as well as field studies in clinics and hospitals.

"Until fairly recently it was controversial to suggest that there were any differences between males and females in the perception and experience of pain, but that is no longer the case," said Dr Ed Keogh a psychologist from the Pain Management Unit at the University of Bath.

"Research is telling us that women experience a greater number of pain episodes across their lifespan than men, in more bodily areas and with greater frequency.

"Unfortunately all too often the differences between males and females are not considered in pain research or practice, and instead are either ignored or statistically averaged."

There remains much discussion in the scientific community about why these gender differences in pain exist.

"While most explanations concentrate on biological mechanisms, such as genetic and hormonal differences, it is becoming increasingly clear that social and psychological factors are also important," said Dr Keogh.

One example of this is the different strategies men and women use to cope with pain. Whilst women tend to focus on the emotional aspects of pain they experience, men tend to focus on the sensory aspects, for example concentrating on the physical sensations they experience.

"Our research has shown that whilst the sensory-focused strategies used by men helped increase their pain threshold and tolerance of pain, it was unlikely to have any benefit for women," said Dr Keogh.

"Women who concentrate on the emotional aspects of their pain may actually experience more pain as a result, possibly because the emotions associated with pain are negative."

To carry out this research, scientists asked volunteers to place their non-dominant arm in a warm water bath (37 degrees centigrade) for two minutes before transferring the hand into an ice water bath maintained at a temperature of 1 - 2 degrees centigrade.

The cold pressor tank allows researchers to monitor the pain threshold (the point at which volunteers first notice the pain) and pain tolerance (the point at which volunteers can no longer stand the pain). An upper time limit of two minutes is used in these kinds of studies.

Other research by the Pain Management Unit has looked at the relationship between gender differences in anxiety sensitivity and pain. Anxiety sensitivity is the tendency to be fearful of anxiety-related sensations (e.g., rapidly beating heart), and seems to be important in the experience of pain sensations. In a study of 150 patients referred to a hospital clinic with chest pain, researchers discovered that the factors that predicted pain in men and women were different.

Researchers believe that it is the fear of anxiety-related sensations and an increased tendency to negatively interpret such sensations, both of which are more predominant in women than men that influences women's experiences of pain.

"Chest pain is associated with coronary heart disease, angina and heart attacks, so it is understandable that chest pain is a cause of great anxiety for patients and that anxiety has an important role in the experience of chest pain," said Dr Keogh.

"This research is also consistent with studies that suggest that men and women experience chest pain in different ways and that, compared to men, women can sometimes report more intensive pain and nausea."

Another study has shown that interdisciplinary approaches to pain management may have different effects on women than men.

Working with the Royal National Hospital for Rheumatic Diseases in Bath, researchers from the Pain Management Unit carried out assessments on 98 patients in chronic pain as they went through a pain management programme involving physiotherapy, psychological treatments and occupational therapy.

Whilst both men and women exhibited a significant reduction in pain intensity both during and immediately after the programme, three months later women reported the same levels of pain as pre-treatment, whereas men's remained the same as immediately post-treatment. Interestingly, there were improvements in disability, in both sexes, which were maintained at follow-up. This suggested that there may also be important differences in pain experiences and improvements in disability.

"Gender can be profitably examined as a potential predictor of pain experience, and in particular, pain following treatment, but it is too early to say exactly how gender-specific interventions can be tailored to address these potentially important differences," said Dr Keogh.

"However, evidence is certainly converging to suggest that accounting for greater differences may increase the overall effectiveness of treatments."

# Study of impact of psoriasis/psoriatic arthritis on lifestyle choices (SIPPA)

March – July 2005, J E Chandler

## Aims and purpose of the research.

SIPPA, was designed to look at the perceptions held by people with either/or both aspects of the disease particularly on lifestyle choices that were made because of their condition simultaneously and look at how both psoriasis and psoriatic arthritis effect lifestyle choices. There have been studies [1-9] previously but these have looked at psoriasis alone, although a large Nordic country study [10] showed that consideration of arthritis needed to be included in treatment of psoriasis.

SIPPA, looked at some individual case history studies that were submitted together with survey returns,that illustrated the reality of living with a disease, as assessed by the individuals and to see the perceptions held about the condition.

SIPPA is an independent study, (solely funded by the PAA with no funding from the pharmaceutical industry or other sources). It's initial aims were not to compare at the present time, its findings to previous studies. This may of course be done at a later stage, when more evidence is added to the statistical information gathered after the cut off date. This is due to the time restraints imposed by this project at the present time.

## METHODOLOGY

Three groups of psoriatic patients were identified and consisted of:-
Group A: PAA subscribers database, active or non-active in seeking professional help for their condition;
Group B: Psoriatic patients attending a dermatology clinic – this provided a snapshot view of a limited number of patients, who were actively seeking treatment for their condition;
Group C: Unknown recruitment base from an advert placed in a national newspaper – this was to make the survey balanced in its approach to groupings of respondents.

The study took the form of a postal survey and was mailed out with reply envelopes to 1500 individuals selected as above.

## Statement of results

The heart of the report consists of tables, grids, charts and individual case histories, the latter have been extracted from the returned surveys with selection criteria based on more detail given on individual circumstance expressed in free text answers.

## Psoriatic arthritis questionnaires

- 432 people completed the psoriatic arthritis study
- Female = 274
- Male =124
- Non stated = 34

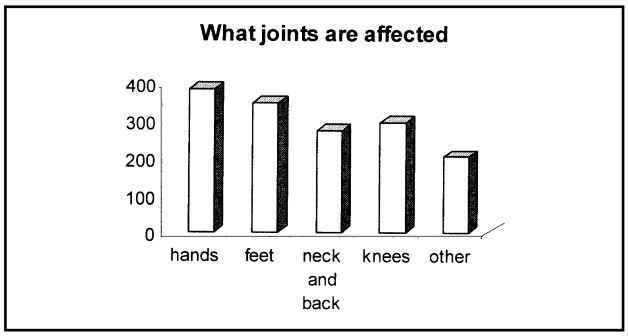
➢ 353 respondents gave their age. Average age is 52 years

➢ 392 respondents answered the question "how long have they had psoriatic arthritis". Average time was 15 years

➢ 408 respondents answered the question "what age was your psoriatic arthritis diagnosed". Average age was 39 years

➢ 354 respondents answered the question "how long did you have psoriatic arthritis before it was diagnosed". Average time was 3 ½ years.

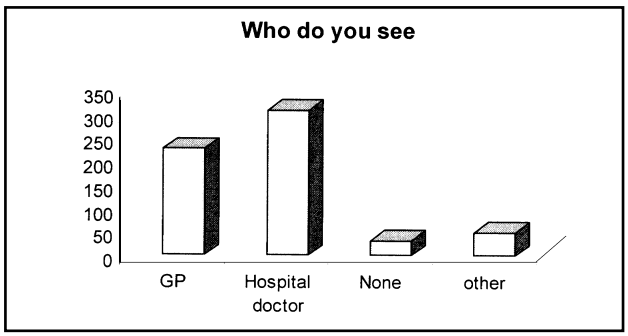
**Fig1**




(hands 26%, feet 23%, neck and back 18%, knees 20% and other 13%)

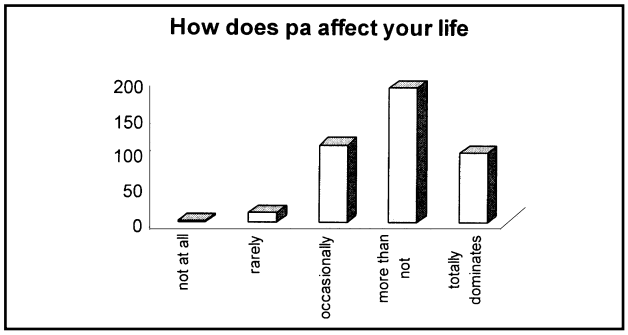
94% of respondents also have psoriasis

**Fig 2**




(GP 37%, Hospital doctor 50%, none 5% and other 8%) [fig 2].

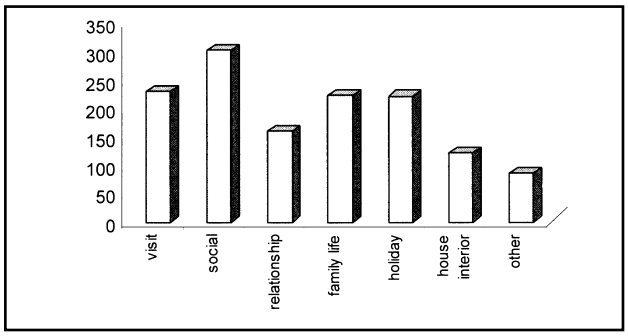
**Fig 3**




354 (85%) of respondents said their day to day life is affected and 63 (15%) said it was not [fig 3]

(Not at all 0.5%, Rarely 3%, Occasionally 26.5%, more than not 46% and totally dominates 24%)

Fig 4




Places they visit 17%, social activities 23%, relationships 12%, impact on family 17%, choice of holiday 16%, Choice of house interior 9% and other 6%) [fig 4]

108 respondents conceal their psoriatic arthritis. 304 respondents do not. Of the 304 who do not hide it 66% of them talk openly.

## The psoriasis survey

- 444 people completed the psoriasis study

**126 male, 281 female and 37 didn't state**

- ➢ Respondents average age 52 years.
- ➢ How long have you had psoriasis?
- ➢ Average length of time 26 years,
- ➢ Average age when diagnosed 28 years,
- ➢ Average length of time before diagnosed 3 years,
- ➢ Average % of body covered by psoriasis 23% (by self assessment)
- ➢ 92% of respondents also had psoriatic arthritis
- ➢ 63% of respondents say psoriasis affects their life. [fig 7]
- ➢ 45% of people hid their psoriasis. Of those that did not hide it 74% talk openly about it.
- ➢ 58% have their self esteem affected
- ➢ 60% have their self confidence affected.
- ➢ 128 of the respondents would try anything to get rid of their psoriasis
- ➢ 52% of respondents would do the same activities if they didn't have psoriasis
- ➢ 86% would like to see more information on psoriasis

Fig 5

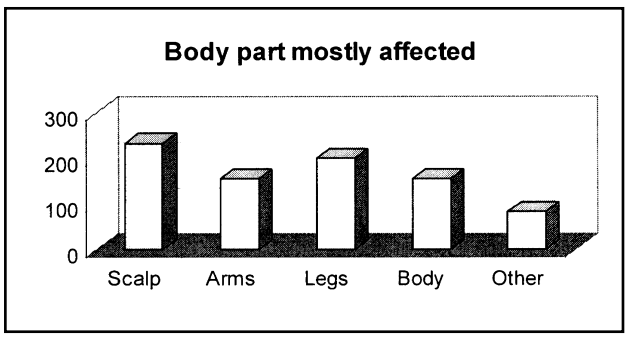



Fig 6

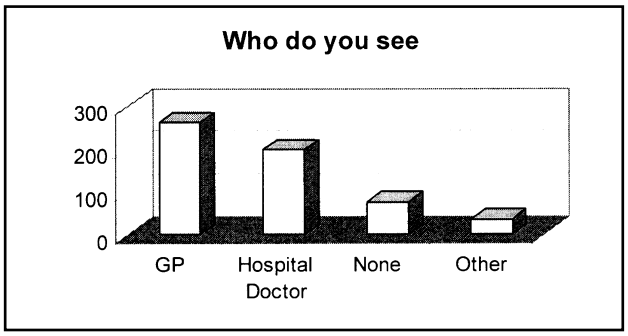



Fig 7

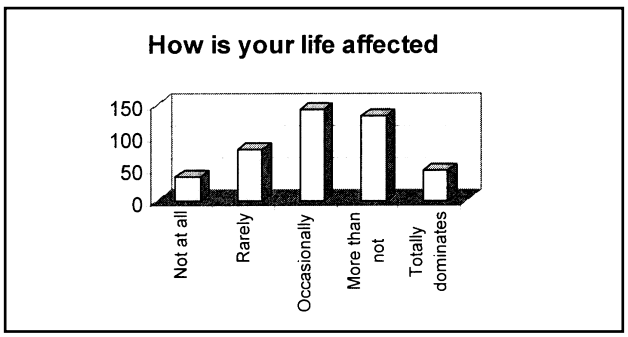



Fig 8

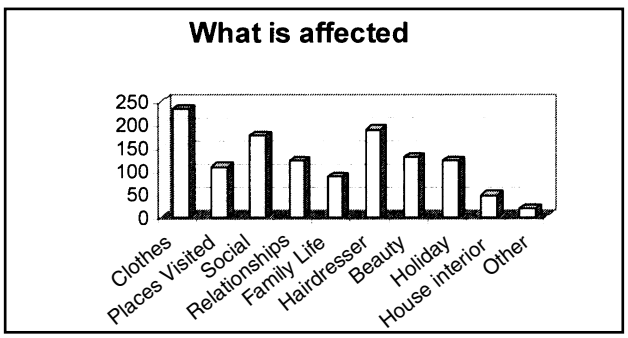



Fig 9

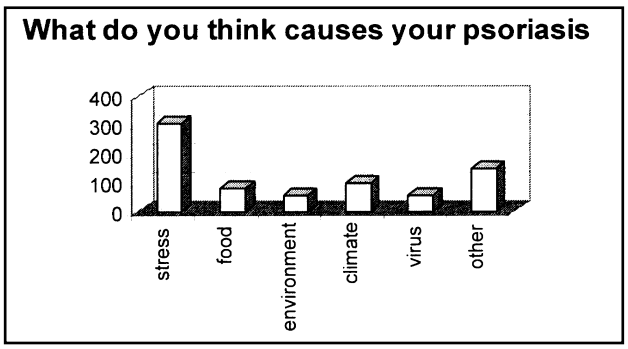



Fig 10

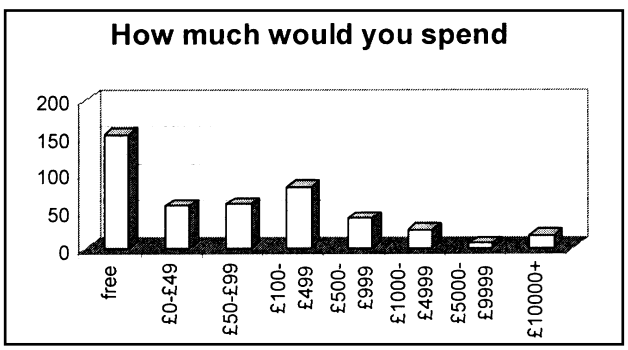
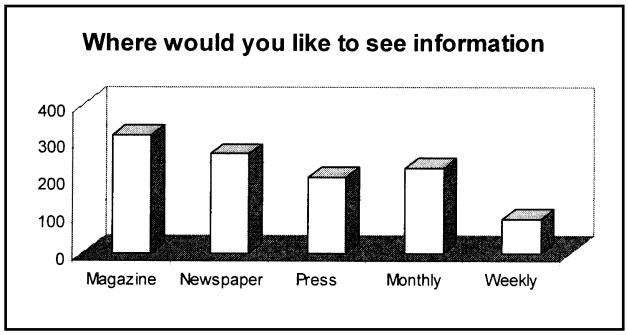


**Fig 11**

| | Yes | No | Don't Know |
|---|---|---|---|
| **General Public** | 63 (14%) | 329 (76%) | 43 (10%) |
| **Doctors** | 204 (47%) | 183 (42%) | 47 (11%) |
| **Nurses** | 164 (38%) | 179 (42%) | 87 (20%) |
| **Newspapers** | 60 (14%) | 288 (67%) | 83 (19%) |
| **Television** | 47 (11%) | 304 (71%) | 80 (18%) |

**Fig 12**




## Perspective of the impact of psoriasis and/or psoriatic arthritis:

Psoriasis and psoriatic arthritis are not discriminatory, affecting both men, women, children, appearing at any age and in varying degrees. However, you have to have a predisposition to psoriasis - i.e. it may run in your close family unit or way back in past generations. Having this predisposition to psoriasis also increases your chance, if you have psoriasis, of developing psoriatic arthritis too.

Over the years psoriasis has had myths built up around it, dating back to the days of leprosy! Many myths are alive today. Many people think Psoriasis is contagious, or people are dirty, their personal hygiene to blame – this is not the case[22]. You will see from some of the information that is to follow, that there is a common thread that runs through many of the case histories, whether it be the misconceptions that psoriasis is contagious, or stress, environmental factors, food intolerances are all major causes of the condition, which can all build up the guilt within a patient. For example, they drink, smoke, eat too much which has brought all this on themselves, which is just not the case, but all contribute to their lifestyle, perceptions of themselves and their self-esteem.

Those living with psoriasis have more than just a skin condition to live with and manage. They have relationships to forge and maintain. There are financial costs involved on a monthly basis regarding prescriptions charges for the amount of topical treatments they have to use.

Family units are affected, children wanting to do everyday things with their affected parent, but are unable to due to the parent's unwillingness to show their skin in public i.e. swimming pools, changing rooms etc.

Normal everyday things can be a challenge down to the colour of clothes they wear – will it show all the shredding skin flakes i.e. black or do they stick to beige. [fig 4]

Discrimination occurs regarding employment issues – denied employment opportunities i.e. restricted from opportunities in the food industry or being a lifeguard. Employment in the leisure industry may be difficult because they have to wear shorts, t-shirts etc.

Children are being bullied at school by kids, encouraged by parental attitudes because they look different.

Normal day-to-day things we all take for granted can be a major challenge for some.

## CASE HISTORIES:-

### Case History Respondent #008

A 45 year old female has had psoriasis since the age of 10 with most of the body being affected also has had psoriatic arthritis since age 25 with the hands feet and neck being affected. In this case the psoriasis is the dominating element of the disease with it affecting lifestyle more than not, the psoriatic arthritis occasionally affecting social activities. Both conditions affect the daily life style of this individual and her self esteem which has been affected by psoriasis.

Her choice of clothes, social activities, relationships, visits to the hairdressers and beauty therapies were affected by having psoriasis. Her choice of social activity was affected by psoriatic arthritis to due to her limited range of mobility, this person said they would swim and go to the gym if they didn't have psoriasis.

This individual believes that their psoriasis is caused by stress, food, and environment, with psoriatic arthritis being caused by a virus.

When asked about messages that needed to be promoted in the media the respondent said the following "that this is not a disease, not catching not dirty"

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis?":

"Anything - I now realise how much it has influenced my life choice/self-esteem and relationships in a very negative way. I feel depressed about it, and very worried about the future as it is getting worse. Doctors' don't seem interested at all and never ever ask about it at all. Psychological help is needed as well as creams"

### Case History Respondent #060

A 50 year old female has had psoriasis since the age of 14 and psoriatic arthritis since age of 49. The psoriasis affects mainly nails but most recently has had pustular psoriasis of the face. The psoriatic arthritis affects hands, feet, neck and back, knees. Both conditions affect more than not with flare-ups of psoriatic arthritis totally dominating her life.

Places visited, social activities, relationships and house interior were affected by psoriasis, whilst choice of social activity and choice of motor vehicle was affected by psoriatic arthritis. This person said they would do more exercise, go on long walks, swim and gardening if they didn't have psoriasis and psoriatic arthritis.

This individual believes that the psoriasis is caused by genes, with psoriatic arthritis being caused by a stress, environment and virus.

When asked about messages that needed to be promoted in the media the respondent said the following:

"a more positive approach as opposed to related to death of playwright Dennis Potter" [20]

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis"?:

"…I do not feel enough has been asked about the state of mind

of the sufferer; from deep depression, anxiety, inability to get complete nights of sleep and ability or otherwise to cope with chronic pain" .

## Case History Respondent #081

A 56 year old female has had psoriasis since the age of 12 with most of the body being affected also has had psoriatic arthritis since age 45 with the hands feet and neck being affected. In this case the psoriasis does not affect her life at all only occasionally, but psoriatic arthritis does have an impact on family life daily. including most manual tasks such as cooking, cleaning, bathing and writing life. This individual's self esteem has not been affected by psoriasis or psoriatic arthritis.
This individual, however, believes that the psoriasis and psoriatic arthritis are caused by a heredity predisposition to the disease that could be exacerbated by stress, food, environment and climate.

When asked about messages that needed to be promoted in the media the respondent said the following "basic facts with emphasis that it is not contagious"

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis?":

"Live in the sun"

And to the same question regarding psoriatic arthritis "Anything if it could be cured, but this would depend on what was involved… I'd rather not have the condition, of course, if only for the long term hassle and possible consequences of taking a cocktail of strong drugs"

## Case History Respondent #094

A 68 year old female has had psoriasis since the age of 13 with most of the body being affected with only nails currently being affected also has had psoriatic arthritis since age 54. In this case the psoriasis does not affect her life, but in the past it has had an impact on the choice of clothing worn.

The psoriatic arthritis rarely affects but is present in hands and feet, but does have an impact on choice of social activities.

Again, this individual believes that the psoriasis is caused by stress, virus and genetics, but does not have a view on what causes psoriatic arthritis.

When asked about messages that needed to be promoted in the media the respondent said the following "that it can be alleviated, so keep on until your GP sends you to see a specialist".

In response to the question "what would you do if you didn't psoriatic arthritis?" the reply was "tap dancing".

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis?":

"I'm fortunate, to me it was an annoyance but not life threatening, so I lived with it. It was short hair washed daily, long sleeves, nail varnish but methtotrexate has cleared the lot. I always felt that I was behind the ugliness looking out. So it didn't affect me – in fact it was an excuse to wear extreme clothing styles and bright nail varnish"

In response to the same question for psoriatic arthritis the respondent wrote the following:

"Before methotrexate [disease modifying drug DMARD], I couldn't go for a walk, knit, peel vegetables, take the handbrake off the car, make pastry, carry a book – though in costume on stage I could forget the pain. Since treatment I can do virtually everything again (though tap dancing hurts!) and as a bonus my skin is clear for the first time since I was 13".

Clearly from the responses given to the above, demonstrates that the respondent has over the years, despite much pain, developed coping mechanisms that have built up her self-esteem and confidence, enabling her to live with a chronic long-term condition, and regain and sustain, with the help of appropriate drug management for her, some quality of life

## Case History Respondent #101

A 37 year old female has had psoriasis since the age of 4 with most of the body being affected (90% self-assessed). She has had psoriatic arthritis since age 21. The psoriatic arthritis only affected fingers and toes until the age of 34 when it became totally debilitating and dominating of her life.

"Because of my arthritis I couldn't care less about my looks anymore – got past caring, just pain and lack of mobility which doesn't help when I have three kids 14, 11 and 7".

This individual believes that the psoriasis and psoriatic arthritis are caused by stress and genetics.

In response to "what would you do if things were different?" this individual wrote "walk round shops, walk into school to meet teachers rather than sit in the car all the time, visit places and take the kids out more"

When asked about messages that needed to be promoted in the media the respondent said the following "positive outcomes, causes and treatments"

Clearly, self esteem and self confidence, restrictive mobility have affected this person a lot, with the impact of both aspects of the disease not only affecting the choices she makes but also those that affect her activities with her family, which could have a long term impact on her children. There may be more responsibilities on the children as "carers" for her and so-forth depending on the severity of the respondent's illness.

## Case History Respondent #338

A 63 year old female has had psoriatic arthritis since the age of 15 with neck, hands and jaw affected, currently she does not have any psoriasis but has had patches previously. She is more affected than not by her arthritis "I think carefully about the task I carry out with my hands daily and avoid overuse where possible. I conceal my psoriasis from those who believe that limited hand use would prevent me carrying out work properly and effectively"

Her psoriatic arthritis affects her self confidence "I'm conscious of malformations of my hands when on show. I'm a practising Architect. It is important to me to continue my work, as well as I'm able, as this is of value to my self-esteem. My hands are obviously of prime importance to my work, hence my preoccupation with rationing of hand use"

This individual believes that the psoriasis is caused by stress and climate

In response to the question what would you do if you didn't have psoriatic arthritis the reply was "more craft work and sewing".

When asked about messages that needed to be promoted in the media the respondent said the following "how psoriatic arthritis

affects sufferers, but emphasis on the fact that these are ordinary people not invalids"

Clearly this condition has a huge impact on the respondent's lifestyle; what she does in her leisure time could seriously have an impact on her working life, as she relies on the use of her hands as her financial income, so employment and discriminatory issues arise too.

## Case History Respondent #387

A 23 year old female has had psoriasis since the age of 7 with scalp being affected, who also has had psoriatic arthritis since age 21 with the hands, feet, neck, back and knees affected.

This individual doesn't feel that her psoriasis or psoriatic arthritis has an impact on day-to-day life and does talk openly about the condition. She believes that the psoriasis is caused by stress and food, with psoriatic arthritis being caused by stress, food, environment and climate.

In free text the following was written in reply to the question "what would you do to get rid of your psoriatic arthritis?":

"I'm now using Humira (adalimumab an anti-TNF drug produced by Abbott Pharmaceuticals) and to be honest have tried to blank out how bleak and desperate things were when things were unbearable. I attempted suicide – that's what I tried to get rid of my psoriatic arthritis"

The last statement clearly reflects this individuals desperation and mental torment she has experienced in learning to deal with her condition, reflecting the impact the illness has had on her. Perhaps in this case, more could have been done by her medical team to spot the signs for more help in helping her to cope.

## Case History Respondent #448

A 51 year old male has had psoriasis since the age of 4 with most of the body being affected at some stage, also has had psoriatic arthritis since age 20 with the hands, feet, neck and back being affected.

In this case both the psoriasis and psoriatic arthritis affected lifestyle more than not.

Both conditions have impacted on self esteem and self confidence with choice of clothes, social activities, relationships, family life, going to the barber and holiday destination being affected by psoriasis, whilst relationships, family life, holiday destination have been affected by psoriatic arthritis "It has affected my life choices, employment, hobbies (playing guitar), sport and fitness"

This individual believes that the psoriasis and psoriatic arthritis can be affected by stress, food, environment, climate and virus but that they are caused by something else.

When asked about messages that needed to be promoted in the media the respondent said the following "positive messages of how people live with the disease, and that people can live good lives"

In free text the following was written in reply to the question "what would you do to get rid of your psoriatic arthritis?":

"I feel it is too late, the damage is done. Still have awful problems with my nails which hare unsightly and problematic. Would consider corrective surgery for cosmetic reasons (fingers straightened so guitar playing would be more accessible). Not keen on drugs – have tried most treatment and felt worse. Also tried diet change, exercise and relaxation"

From this statement, clearly the respondent has tried much to overcome the condition or indeed improve it, and, this statement is tinged perhaps with resignation and accepting of what he has to live with, but again shows the impact the condition has had on his wellbeing.

## Analysis and discussion

The results and analysis of this study need to be placed in context. Charities are often set-up to fulfil a need, usually because the system has failed. In this case the National Health Service which has failed to help or support those with the condition or to support individuals or raise awareness about the cause. In the case of psoriasis awareness is relatively low amongst the general public and where awareness exists it us usually negative and often stigmatising. In the case of psoriatic arthritis lack of awareness amongst people with psoriasis is low and virtually non existent in wider context.
The response to the survey was high. Total after the analysis cut-off date was 29% (464) returned psoriatic arthritis surveys and 32% (497) returned psoriasis surveys.

The gender spilt is typical of the database and it was expected that more females would respond, interestingly more females wrote free text answers than males and this is reflected in the selected case histories. The survey aimed to find out about life styles choice was partly fulfilled, but encouragingly enough many were not deeply affected by the condition with only 24% expressing that psoriatic arthritis dominated their life with only 12% of those with psoriasis expressing the same view. It is a well known view that self esteem is affected, but again although it would be expected that those who are members of a self-help charity may be more severe many did not feel that this aspect was affected. It therefore could be argued that either they have benefited from the work of the organisations or have become resigned to the condition and no longer care about what others felt this reflected in case history#101 whose psoriatic arthritis has become so debilitating that she has "got past caring"

The ability of some individuals to cope and not be affected on a daily basis although having extensive disease could be explained again by attaining a certain level of knowledge, education or awareness about the condition although this contradicts the issues as reported in the media with only 8% believing that news stories were positive about psoriasis and only 2% about psoriatic arthritis. This is reflected in the frustration with many free text comments wanting to see more positive messages and better awareness about the disease this was reflected in case history #448

## Conclusion

It is clear that psoriasis and psoriatic arthritis have a major impact on the lifestyles of those who responded to this survey. Other studies have also shown impact on quality of life.

Although, it would be safe to assume that those who are motivated to complete a survey, contact a support organisation or belong to a charity may be at the more severe end of the disease spectrum, these results also included answers from individuals who are not as physically affected but have some form of psychological impact.

- Early diagnosis and appropriate interventions must still be a key to long term positive outcomes

- Education of healthcare providers is still perceived to be low
- Awareness should be more visible but positive
- Encouragingly many people cope well and do not let the conditions affect their lifestyle choices
- Psychological impact should not be underestimated, physical disease severity is only one aspect

Given the range of needs and the way psoriatics cope and manage disease and the way in which it is portrayed within the media, providing positive management and coping mechanisms for individuals that allow individuals to feel comfortable and less stigmatised by disease appears to be a positive approach.

It may be more effective to help individuals than try to change general population attitudes; the medical professional and healthcare providers must play a key role in developing a good communication and management with greater involvement of the patient. The survey also included people who were not being seen by anyone for disease management, given that both diseases are chronic and life long and in the case of psoriatic arthritis potentially disabling, careful consideration needs to be given to helping these individuals to be able to gain access to care as and when needed.

## Contributors and collaborators

J E Chandler, General Manager/co-Founder of the Psoriatic Arthropathy Alliance (PAA), Psoriatic Arthropathy Alliance, St Albans,

D A Chandler, Patient, Director Co-Founder of the Psoriatic Arthropathy Alliance (PAA), Psoriatic Arthropathy Alliance, St.Albans, ,

C J Marven, for data analysis, Teaching-aids At Low Cost (TALC), St Albans

Dr A.G. White, Trustee/Advisor to the PAA and Consultant Rheumatologist, Dermatology Department, Royal Free Hospital, London

Dr S.McBride, Medical Advisor to the PAA and Consultant Dermatologist, Dermatology Department, Royal Free Hospital, London…..

## References. and resources


1. Gupta MA, Gupta AK,Quality of Life of psoriasis patients, JEADV 2000, Finlay AY, Coles EC (19950 The effect of severe psoriasis on the quality of life of 369 patients,
2. Fried RG et al (1995) Trivial or terrible? The psychological impact of psoriasis. International Journal of Dermatology. 34,2,236-244.
3. Jennifer Warer et al (2004) Psoriasis shows people with psoriasis feel misunderstood,
4. Mary Shomon (2005)New survey documents concerns of people with psoriasis.
5. Finlay, A,2003, What do quality of life scores really mean?, JEADV 17(3):58
6. Myon, E., Finlay, A.,Dreno, B., Corvest, M., Lefrancois, P., and Taieb, C., 2003, A national survey of quality of life in patients with psoriasis, JEADV 17 (3):59
7. Myon, E., Finlay, A., Lefrancois, P., and Taieb, C., 2003, Duration of psoriasis and quality of life, JEADV 17 (3): 376.
8. Myon, E., Finlay, A., Lefrancois, P., and Taieb, C., 2003, Psoriasis: Quality of life according to gender, JEADV 17 (3): 375.
9. Finlay AY, Coles EC. The effect of severe psoriasis on the quality of life of 369 patients. Br J Dermatol, 1995; 132: 236-244.
10. Quality of life and prevalence of arthritis reported by 5,795 memebrs of the Nordic Psoriasis Associations H Zachariae; R T Zachariae; K Blonqvist; S Davidson; L Molin; C Mork; B Sigurgeirsson; Acta Derm Venerol 2002;82:108-113
11. British Association of Dermatologists Guidelines for Use of Biological Interventions in Psoriasis 2005
CH Smith, A V Anstey, JNWN Barker, AD Burden, RJG Chalmers, D Chandler, AY Finlay, CEM Grifitths, K Jackson, NJ McHugh, KE McKenna, NJ Reynolds, AD Ormerod
12. Martyn Denscombe (1998, 1999,2000) The Good Research Guide, (3rd edition) Open University Press, Buckingham. ISBN 0-335-19805-8
13. Judith Bell, (2000), Doing Your Research Project, (3rd edition), Open University Press, Buckingham. ISBN 0-335-20388-4
14. C.Inglis, Research Methods, (1997), Units 1,2,3,4,5 @ Level One , Certificate in Higher Education, Centre for Educational Development, University of Wales, Lampeter.
15. C.Inglis, Research in Practice, (1997) Certificate in Higher Education, Unit One, Centre for Educational Development, University of Wales, Lampeter.
16. The Art of Interviewing: chapter III.II, Jacquelin Burgess, (further reading supplied by Centre for Educational Development, University of Wales, Lampeter, with Research Methods, Unit Five, Level One, Certificate in Higher Educations).
17. Questionnaire Surveys: chapter III.10, Gary Bridge, (further reading supplied by Centre for Educational Development, University of Wales, Lampeter, with Research Methods, Unit Five, Level One, Certificate in Higher Education).
18. Psoriatic Care, The Psoriatic Arthropathy Alliance (PAA), 2nd edition, 2004, PO Box 111, St. Albans, Herts, AL2 3PX.
19. Oxford Pocket School Dictionary, Oxford University Press, Oxford, OX2 6DP, Third Edition 2002, ISBN: 0-19-910901-X.
20. C.Inglis, (1999), Research in Practice, Unit One, Level Two, Centre for Educational Development, University of Wales, Lampeter.
21. "The Singing Detective", (1986) Dennis Potter, Play, Broadcast by the BBC, London.
22. Jennifer Warer et al (2004) Psoriasis shows people with psoriasis feel misunderstood. WebMD Medical News.
(http://my.webmd.com/content/article/82/97078.htm
23. Mary Shomon (2005),New survey documents concerns of people with psoriasis. http://www.thyroid-info.com/articles/psoriasis.htm
24. Jarvis, Sarah Dr, GP, GP Trainer, Fellow of the Royal College of General Practitioners, Psoriasis: More than skin deep, 2003, produced and published by Red Door Communications Ltd., London.
25. Martyn Denscombe (1998, 1999,2000) The Good Research Guide, (3rd edition) Open University Press, Buckingham. ISBN 0-335-19805-8
26. Doing your Research Third Edition Judith Bell Open University Press ISBN 0335 20388 4 (pb)1999

# Drug breakthrough for psoriasis sufferers

An international team led by a dermatologist at The University of Manchester has found that treatment with the emerging drug infliximab, marketed as Remicade, can quickly and significantly improve psoriasis symptoms.

The European Infliximab for Psoriasis Efficacy and Safety Study (EXPRESS) was a placebo-controlled trial on 378 patients with moderate to severe psoriasis, to test the efficacy and safety of the drug. The findings, published in the 15 October issue of The Lancet, show that 80% of patients achieved at least a 75% improvement in symptoms after ten weeks treatment with the drug, as opposed to just 3% of those receiving a placebo.

Psoriasis is a chronic condition which results when skin cells over-produce and accumulate on the surface of the skin, producing red, scaly 'plaques' which may itch and bleed. It is thought to be genetic in origin and is a consequence of an abnormal inflammatory response in the skin. Around 2% of the population suffer from the disease, with about 30% of cases considered moderate to severe, but until now treatment options have been limited.

Infliximab blocks the activity of 'tumour necrosis factor alpha' (TNF-alpha), a protein involved in inflammation, and the vast majority of the trial subjects treated with the drug achieved clinically-significant levels of skin clearance. Nearly 60% experienced at least a 90% improvement in symptoms - or near-complete skin clearance - after ten weeks, versus 1% receiving the placebo, whilst 26% achieved complete skin clearance (versus 0% receiving the placebo). The improvements continued throughout the 50-week study.

Professor Christopher Griffiths, the University academic leading the trial from the Dermatology Centre at Hope Hospital, Salford, said: "These results indicate that infliximab is a very effective therapy among the newer biological treatments for psoriasis. As a dermatologist, I am very encouraged by the data, which show that patients with moderate to severe psoriasis can rapidly achieve skin clearance and that these results can be maintained."

Patients receiving infliximab also experienced a good response in nail psoriasis, which is present in 20 - 50% of psoriasis patients and often thought of as a treatment-resistant disease. By week 24 of the trial, those receiving the drug were experiencing a 56% average decrease in this condition, and again this response was maintained throughout the trial.

"Physicians' assessments of the patients' conditions backed up our findings," confirmed Professor Griffiths, "with 83% of those receiving the drug assessed as having minimal or cleared symptoms by week 10 of the trial as opposed to just 4% of those receiving the placebo."

# Improved system for people to report suspected side effects

Improved system for people to report suspected side effects from their medicines to UK health watchdog

The Medicines and Healthcare products Regulatory Agency (MHRA) recently launched a new UK-wide pilot to enable people to directly report their experiences of suspected side effects from medicines through its reporting system - the Yellow Card Scheme.

The improved system will see patient Yellow Card reporting forms being made available in pharmacies, GP surgeries and other NHS outlets across the UK from November 2005. Reports on suspected side effects can also be made on the Yellow Card website at www.yellowcard.gov.uk or by freephone to the Yellow Card hotline on 0808 100 3352.

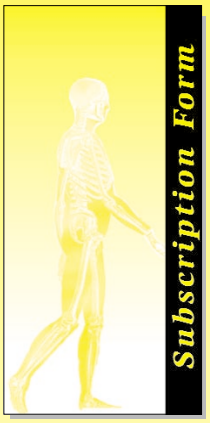
The UK-wide pilot builds on the successful patient reporting pilot run from January which was restricted to certain parts of the UK, and the wide range of feedback provided from patients and carers in the development of mechanisms for reporting suspected side effects.

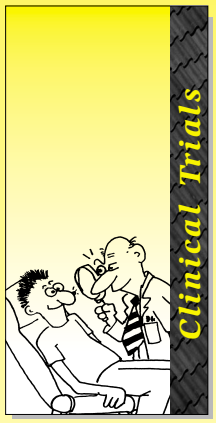
Professor Kent Woods, Chief Executive at the MHRA said, "I welcome the launch of this UK-wide pilot enabling people to report their suspected side effects to us. By inviting people to report their experiences, not only are we able to gain better insights into the safety of medicines, but we can more directly involve people in medicines regulation."

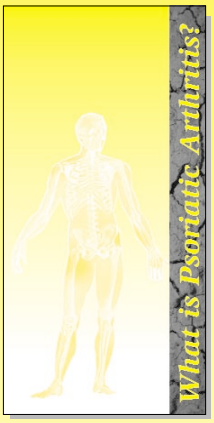
Chairman of the Committee on Safety of Medicines (CSM), Professor Gordon Duff said, "The benefits of encouraging patients to complete Yellow Card reports are becoming evident. Patients provide a different and extremely useful insight into suspected side effects that we cannot easily get from Yellow Card reports from health professionals. The Yellow Card Scheme is vital in monitoring the safety of medicines in the UK, and the incorporation of patient reporting into the Yellow Card Scheme will have significant benefits, especially as the scheme evolves and patients become familiar with it. The contributions of the Committee on Safety of Medicines' Patient Reporting Working Group have been extremely beneficial in helping to develop systems for patient reporting."

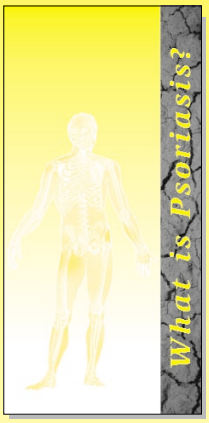
Dr Patricia Wilkie, Chairman of the CSM's Working Group on Patient Reporting said, "Patient reporting through the Yellow Card Scheme helps the MHRA to collect information on suspected side effects that patients have experienced, from the patient's own perspective. The incorporation of the patient experience in the Yellow Card Scheme is essential for medicines safety monitoring, and will be important for the development of information for patients about their medicines. The launch of the UK-wide pilot is a major step forward in achieving real patient involvement".

# PUBLICATIONS

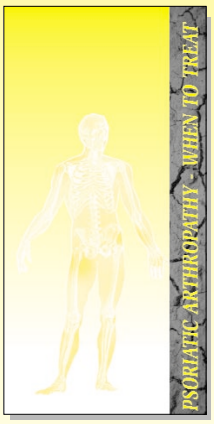


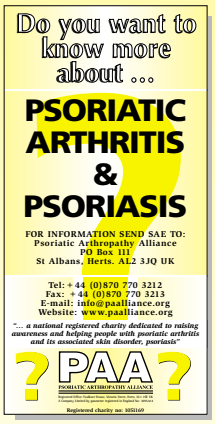



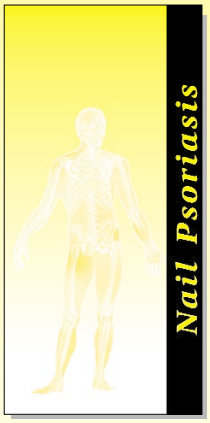



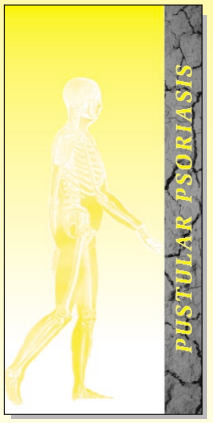




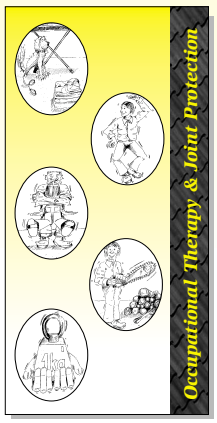


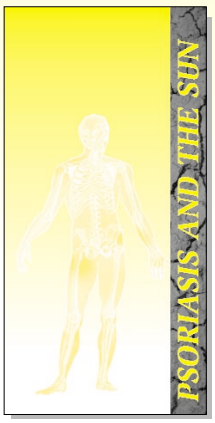


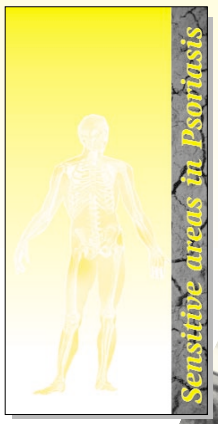



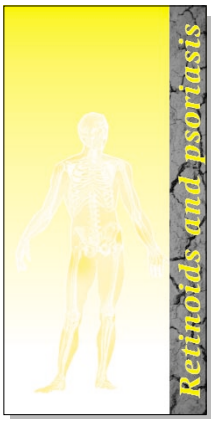



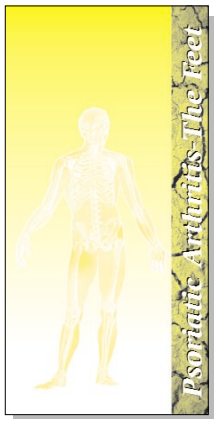




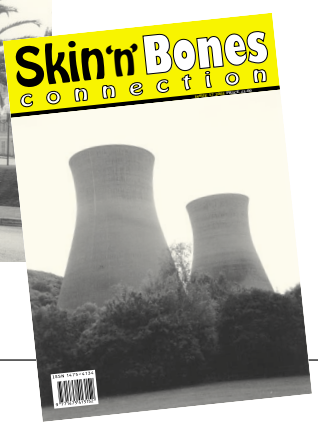









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| Publication title | Issue no. | Publication Date | Unit Cost | Qty. Required | Sub total |
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Further information can be obtained by contacting:
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Where did you hear about the PAA? .....

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Occasionally we are supplied with product information and samples, as a would you like to receive these in the future? YES/NO

Would you be willing to enter into confidential surveys relating to psoriatic arthritis and/or psoriasis? YES/NO

How long have you had PA? .....

How long have you had Psoriasis? .....

Areas/joints affected? .....

Medication tried (please list) .....

.....

Current Medication taken? (please list) .....

.....

Any family history of PA or psoriasis in your family? .....

Other information:
Are there any websites or publications you think would be of interest to our readers? (please list)

.....

.....

.....

Signed .....

Date .....

All information given on this questionnaire is treated with the strictest confidence and will not be given out without the prior permission of yourself.

**Thank you for your time and co-operation in the completion of this form.**

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- Opportunity to take part in patient focus group meetings
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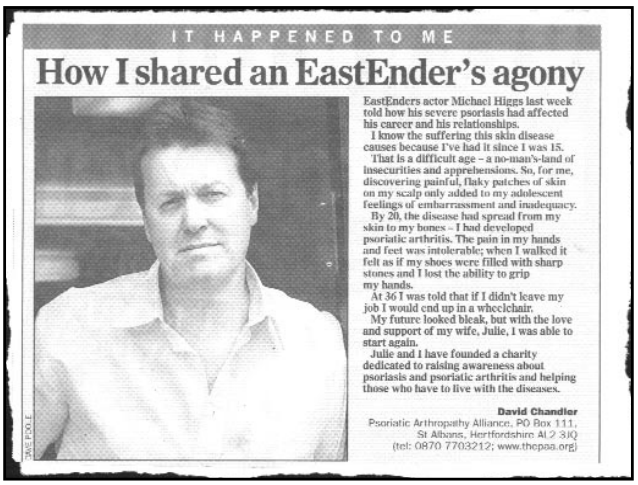
# Letters



IT HAPPENED TO ME

## How I shared an EastEnder's agony

EastEnders actor Michael Higgs last week told how his severe psoriasis had affected his career and his relationships.

I know the suffering this skin disease causes because I've had it since I was 15.

That is a difficult age – a no-man's-land of insecurities and apprehensions. So, for me, discovering painful, flaky patches of skin on my scalp only added to my adolescent feelings of embarrassment and inadequacy.

By 20, the disease had spread from my skin to my bones – I had developed psoriatic arthritis. The pain in my hands and feet was intolerable; when I walked it felt as if my shoes were filled with sharp stones and I lost the ability to grip my hands.

At 36 I was told that if I didn't leave my job I would end up in a wheelchair.

My future looked bleak, but with the love and support of my wife, Julie, I was able to start again.

Julie and I have founded a charity dedicated to raising awareness about psoriasis and psoriatic arthritis and helping those who have to live with the diseases.

**David Chandler**

Psoriatic Arthropathy Alliance, PO Box 111, St Albans, Hertfordshire AL2 3JQ (tel: 0870 7703212; www.thepaa.org)

**Dear David,**

What a relief it was to read your letter, I had no idea there was an organisation dedicated to sufferers of psoriatic arthritis, and I've been a 'victim' of this horribly debilitating condition for over fifteen years!!!

The psoriatic skin condition is relatively under control - I have a number of patches but they are all confined to the area of my buttocks - and so are not on view! I used to have a badly affected scalp but as is one of the infuriating aspects of this condition, that disappeared almost over night, and hasn't returned.

The arthritic side of things is a different matter; I suppose in medical terms you might say its status is 'chronic'.

My hands are by now, pretty badly deformed and I need to wear finger splints in order to prevent sudden joint dislocation, most of my fingers are largely useless and a number of everyday tasks are now beyond me. My feet were pretty bad too, but last year I underwent simultaneous surgery on both feet to have the 'knuckle' joints removed which; now the surgery trauma has subsided, has much improved my mobility.

I have a theory about this condition: If you accept the generally held medical opinion that stress is a major factor in triggering and prolonging the condition, it follows that people in stressful or high powered occupations are more likely candidates, and they're the ones most likely to find it the most difficult to reduce their stress levels and adapt to lesser or even no employment. They stress about this and their condition worsens - thus begins the vicious circle that the desease thrives on.

Anything I can do to help, please contact me.

Yours Sincerely,
**Mr S. W.**

**This email is in response to David Chandler's letter in The Mail on Sunday---10th July 2005.**

I was very touched by David's words' as our family are experiencing his pain through our beautiful 20 year old daughter.

Up until the spring of last year our daughter was an active [gym member---regular swimmer---dog walker] normal 19 yr old.

One day she came back from the gym and said she was experiencing muscle pain in the left thigh. over the next few days this pain moved to her pelvis / hip.

She sought help from our GP who thought it was muscle strain--sent her home with muscle rub + pain killers and told to take it easy exercising.

She suffered this pain for approx. 1 month, then went back to the doctors. They fobbed her off again ---and said come back in 2 weeks if pain is still bad.

The pain did get worse---it went to her feet. On producing a foot twice its normal size to the doctor [ the toe end of her foot had swollen so much she thought it was going to burst and the pain was excruciating.the GP she saw this time [ you never see the same one twice in modern Drs. Medical centres } suggested a blood test. The blood test showed signs of arthritis -although not rheumatoid.

The GP finally referred us to the local Head of Rheumatology . We paid privately for the first consultation for quickness.

The Specialist was wonderful. We explained that we would not be able to afford complete private treatment and he said he understood.

My daughter, after a weeks stay in hospital, MRI scan and lots of tests was finally diagnosed with psoriatic arthritis late last year. The Specialist believes there is a chance that it is hereditary [ as my late Mother in law suffered in her later years with psoriasis and almost at the same time as she was diagnosed my brother in law was also diagnosed--although he has the psoriasis and the arthritis has affected his hands ].

My daughter has not had any symptoms of psoriasis only the arthritis. She has also [ this January ] developed iritis in her left eye. She also has spondolitis in the base of her spine.

We are trying everything we can to try and make her life easier. She has just completed her 2nd year of a degree in retail management and has just started her 'business placement' year working as a Trainee Head Office Manager for a national chain store. This is approx 150 miles from our home. She has relocated [10 minutes drive from her work] She is so brave as she is in almost permanent pain. She is only taking paracetemol at the moment. We have tried ---Chinese herbal medicine---acupuncture--Homeopathy---personal training---diet.Shortly after she was diagnosed , The Specialist prescribed Sulphersalazine which she took for 3 weeks ---then one morning she woke up with an extreme allergic reaction --we didn't know what the cause was---her lips swelled her face swelled up and she had a red rash on her body from head to toe. She was fetched off the drug at once, it is thought that she is allergic to sulphur.

Our next plan is hypnotherapy. She has seen a hypnotherypist before for stress --which has helped her a lot.

My husband and I are convinced that her joint problems were 'sparked' off by stress. Two hard A level years. Going to University. Being jury foreperson at a Murder trial ---where the Defendant was found guilty ---and she had to announce this.

I do not know if this email will be read by David or his wife---as we would love to know what has kept him going and what stage is he at now after so many years.

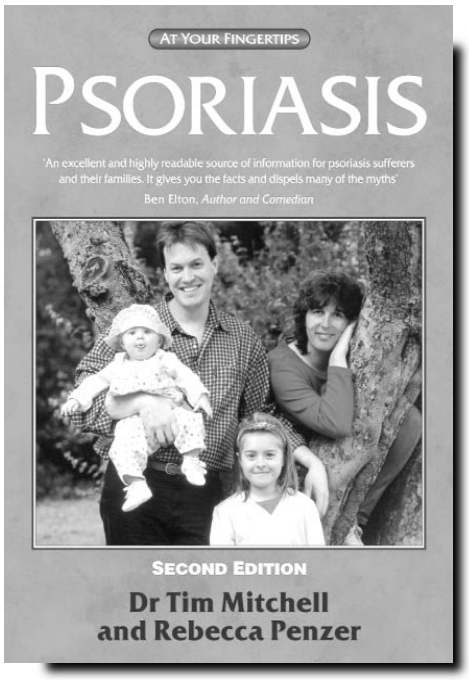
Many thanks for reading this ---I think it is wonderful that this charity has been founded to help sufferers and their families. A big thanks to The Mail On Sunday for publishing the letter ---as I would never of known of your existence.!!!!

I shall be sending for your information leaflets.

Kind regards,

**Mrs R. B.**

## Psoriasis - the 'at your fingertips' guide, new 2nd edition OUT NOW!!




The more you know about your psoriasis, the better you can deal with it.

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# Psoriasis in Art

Jean-claude Salgueira creates his own universe in pictures and objects using acrylic paint, dots, blots, grids and streams. They are eruptions of colour and energy. Repetitions and structure are important elements in his work. Always accompanied however by flowing chaos. Though the paint drips off the panels and glistens in the light, the image is never polished. Jean-

claude' s work is always about layers . Literally, in the end the images are what they are, meditations in paint. Besides his paintings, Jean-claude is also working on digital images that clearly reveal the origins of his work: his skin. **Visit: www.sagueira.com**

### THE PSORIATIC REVOLUTIONARIES

It all ended for Abimael Guzmán, aka Presidente Gonzalo, on September 12, 1992. On that day, the leader of the Shining Path, a guerilla organization that hoped to replace Peru's "bourgeois institutions" with a communist regime, was captured by members of Peru's special forces. At the time of his capture, Guzmán had come out of his jungle hideout to seek treatment for his psoriasis in Lima.

There are other revolutionaries reputed to have suffered from psoriasis:

Robert the Bruce (1274–1329),
Jean Paul Marat (1743–1793),
Josef Stalin (1879–1953).
***Source: Med Headhunters.***

# DIARY DATES