Skin 'n' Bones connection

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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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EDITORIAL

Breakthrough or false hope?

There is an old saying which is becoming more and more relevant in this day and age of instant news and extreme reporting, which is: 'there are lies, damn lies and then there's statistics'. It is therefore becoming difficult to decipher what is truth and what is hype.

For all of us with psoriasis and/or psoriatic arthritis the cynical use of the phrase 'Scientific breakthrough' within our press along with various results of surveys and tests are beginning to dilute the worthiness of such reports.

Within this issue of Skin 'n' Bones Connection we have reported some results from surveys, which do give some interesting statistics. The first survey is from the US and highlights many issues, which we all understand, but also maybe gives us a view that is too broad and non-representative of our individual circumstances. We also have the results of the InterPSO TOPSO survey, which was conducted last year, again useful information but what does it tell us?

The use of survey results and statistics relating to psoriasis is to raise awareness about the need for better treatments and better understanding of what it is like to have a chronic disease. Too often this well meaning awareness only adds to the negative impact people with psoriasis already feel, by continuing to report stereotyped images.

So where do we go from here, raising awareness is important, but for the right reasons. Using the media and the emotions of those most in need with false hope is not useful. There is no doubt that there will be 'breakthroughs' in the treatment of psoriasis and psoriatic arthritis in the coming years, which we only can hope is publicised appropriately and beneficial to all!

David Chandler

National Institute of Clinical Excellence (NICE)

NICE are currently carrying out the following appraisals:

- New treatments for moderate to severe psoriasis the anticipated publication for the appraisal is March 2005.
- Etanercept for psoriatic arthritis the anticipated publication for the appraisal is October 2005.

Further information is available from the NICE website www.nice.org.uk. The website also contains a useful publication called A Guide to NICE which is available in a PDF format to download.

Cover photo: Camber Beach East Sussex - David Chandler,

RHEUMATOLOGY IN THE 21ST CENTURY

INTRODUCTION:

Rheumatology is a branch of general medicine which only became recognised as a specialty during the 1950s. At this time there were only a few pioneering centres in the United Kingdom, the most influential ones being at Edinburgh, Aberdeen, Glasgow, London, Manchester, Aylesbury, Bath, Slough, Leamington Spa and Buxton. Yet rheumatic diseases are the most universally complained of and spa treatments have been in existence for hundreds of years. This paper will give you a brief run through the initial development of the modern specialty and show the changes that have taken place in the last sixty years to bring us to modern day science. This is the span of my life and a brief description of my family gives an insight into this history also.

First however let us look at a timeline which illustrates treatments. The most notable discoveries prior to this century were of the effects of willow bark on rheumatic fever, discovered by a parson from Oxfordshire in the 18th.century. In those days many parsons were in fact scientists as well as classical scholars and spent their life outside their church work in studying plants, animals, geology or, in this case, folk remedies. This discovery was in fact of the salicylates which have powerful effects on fever but also pain,

We then skip over 100 years to the dying years of the 19th.century. Aspirin was first manufactured then and became the backbone of treatment for fever and pain for the next 50 years. In Victorian times laudanum (a form of morphine) was freely available and used for anything from toothache in a young child to sleeplessness. As its use increased, its addictive properties became obvious and gradually it became available only on a doctor's prescription. Aspirin was one of the few commercially manufactured drugs at this time and can really be said to be the first specific 'anti-rheumatic drug', for all its side effects. When I first went into rheumatology we had to learn how to measure the right amount of aspirin to give to patients with arthritis or rheumatic fever. This was mostly done by giving the patient toxic effects and then reducing the dose marginally. The worst toxic effect experienced was ringing in the ears and deafness although bleeding and bruising occurred and in some cases was life threatening. Now this effect of aspirin is used therapeutically to prevent heart attacks and strokes.

The first major breakthrough in the 20th.century occurred in the 1920s and was a chance discovery. At that time tuberculosis was the scourge of the world and the death rate from it was high. A Frenchmen began experimenting with the use of heavy metals (earlier arsenic and mercury had been found to help some infections) for tuberculosis. When he tried gold it did nothing for the tuberculosis but patients reported that it did wonders for their arthritis. He believed them and carried out a very careful trial which showed that gold salts did indeed help inflammatory arthritis. Gold became established as the standard treatment for arthritis quite quickly in Europe but did not move to this country until the 1940s.

This brings me to my family. My mother's mother was one of five sisters. They were born in Yorkshire of farming parents. All five suffered from crippling arthritis that began when they were about 45 years old and progressed so that by the time they were 70, they had problems walking and in personal care. As a child I remember watching my grandmother struggling to put on a coat or shirt because of her shoulders. She was an ingenious and intelligent lady and invented an aid to dressing that really worked (a coat hanger with a cup hook on the end for pulling on sleeves and pulling up zips!). She was one of the very first people in Devon to be given gold injections by her doctor, in about 1944, and always swore that it helped her. Certainly she did not become as crippled as her sisters or even her daughter. But she did have to give up playing the piano because, as a professional musician, she could not bear to have lost her facility and accuracy.

In Britain the Empire Rheumatism Council was in existence then and was responsible for research and development. This council carried out a careful study of gold using a 'placebo' (dummy) dose for comparison and showed that it worked in rheumatoid arthritis. Thereafter gold did indeed become the 'gold standard' for arthritis treatment.

The time line begins to gallop at this point. It is interesting to see why this was so. There is clear evidence that war brings about an explosion of medial advances which would only otherwise be discovered over a long period. This is partly because of the urgency of medical need in wartime but also the concentration of research money and researchers available in one place. The first world war brought mustard gas, a truly terrible weapon but the forerunner of oncology (cancer) drugs including one very familiar to many of you, methotrexate. This drug was available by the 1940s but used for cancer until in the 1970s people began using it for arthritis.

The Second World War brought two major advances, blood transfusion and antibiotics. For a blood transfusion to be safely given, some knowledge of blood groups and therefore of the immune system is required. This discovery has led to immunisations and modern immunology and genetics, both at

the forefront of modern medicine's search for a cause and cure of arthritis in all its forms. More of that later.

The antibiotic penicillin, discovered by chance by Alexander Fleming while working in a basement in London (because he refused to be evacuated with the rest of the hospital) has with others, along with immunisations and more healthy diets, been responsible for the present excellent health enjoyed by the majority of the people of the developed world and for their longevity. Antibiotics saved many of those wounded in the forces in the war. Again by chance one of the modern remedies for arthritis, sulphasalazine was developed during the war. Originally it was tried as an antibiotic but was not very effective. People felt that arthritis was an infection so all the antibiotics in turn were tried out. The idea of chronic infection in the teeth, tonsils, gall bladder, appendix and womb was also born at this time and it became the vogue for many years thereafter to subject sufferers from arthritis to unnecessary surgery to remove these 'hidden' infections. A trial of sulphasalazine was published in 1944 which conclusively showed its effects in rheumatoid arthritis. Interestingly this trial was lost for many years and sulphasalazine gained its place in the national formulary as a treatment for ulcerative colitis. Finally in the early 1970s when the toxicity of gold and steroids was clear, an enterprising group turned up the evidence for sulphasalazine, tried it out and the drug was introduced widely for all types of early arthritis. Anti-malarial drugs, also still used for some cases of arthritis, were first used for much the same reasons and found to help.

So after the war my family split up across England and the arthritis of my youngest great aunt developed apace in the damp of lowland Devon. Sadly she never benefited from any modern treatments because she distrusted science. She ended her life completely bed bound with fixed hips. The only treatment she might have accepted, hip surgery was denied her because her heart was so weak from childhood rheumatic fever. But she became my inspiration in years to come.

What did the 1950s bring to arthritis sufferers; probably the most exciting and dangerous but life saving discovery of all time-steroids or 'cortisone' as the first one was called. This was the 'take up your bed and walk' drug. In order to understand its effects you have to know something of the impact of arthritis at that time. Rheumatic fever was rampant but beginning to diminish because of the use of antibiotics and high dose aspirin. But rheumatoid arthritis and ankylosing spondylitis (psoriatic arthritis and other types of inflammatory arthritis were all called rheumatoid arthritis at that time) were only able to be treated by aspirin and gold, both with frequent toxic effects that meant that patients gave up on active treatment. The standard treatment for arthritis was bed rest and often splinting. Patients became bed bound, weak and fixed in whatever position was the most comfortable. In long stay hospitals at that time, thin stiff people of all ages were a common sight. Cortisone was found to save the lives of those with Addison's disease (the wasting disease produced by total loss of the body's production of cortisone) so it was tried in wasted arthritis sufferers with truly dramatic results. Anyone who has tried it for their arthritis will know the wonderful relief it brings to pain and stiffness. It was hailed as the cure for arthritis and everyone took it. In my family one of my great aunts tried it but it did not work because by then her arthritis had destroyed her hip and knee joints and she had osteoarthritis. My grandmother greatly benefited, as did my father by having local joint injections of cortisone. Many years later my mother had the drug for another condition; 'polymyalgia rheumatica' and did very well.

What then was wrong with this miracle drug? I think we all now know that in doses high enough to suppress the arthritis it put on weight, weakened muscles, thinned the skin, caused bowel ulcers and caused dependency so that the body could not manage without it and collapse occurred at times of crisis such as surgery. Once this was realised operations were covered by an increase of dose but the overall effects of high dose cortisone were too devastating for it to be used long term. For a time it fell into total disrepute, then its benefits were shown to be there to some extent at low doses. Then again it was overtaken by other miracle 'cures' such as methotrexate. Finally in the 1980s it was shown to have long term suppressive effects in arthritis and it is now used as a second line dug in many people at very low doses. Its latest toxic effects now measurable are on the bones. It is a potent cause of osteoporosis. Again this has caused some lessening of prescribing but for those who really benefit from the drug, any side effects are worthwhile and most can be countered by some means such as other prescriptions.

Let us now return to the 1950s because this was really the birth time of modern rheumatology. Centres for rheumatic disease were specifically set up then at Aylesbury, Edinburgh, and Slough amongst others to join the established spa centres. I have been privileged to know and work with many of these pioneers. All bar one are now dead but their work set the scene for the scientific development of the speciality which had previously been merely full of folklore and endurance as a part of life. They studied, they tried remedies and they sought for causes. In the name of science they tried remedies on themselves and I was told by one if them how he and a friend extracted joint fluid from the knees of an arthritis sufferer and injected into their own joints to see if they 'caught' arthritis! You would not find this happening today I feel! What they achieved was the evidence base for a regime of treatment that would dominate the rheumatology scene for the next 30 years. This regime was of painkillers, rest and exercise at the right time, gold or other long term agents and short courses of high dose cortisone for quick relief of inflammation. They discovered that short high doses of cortisone did

not make you dependent on the drug and that if you 'hit' the arthritis with everything you had got there was a chance that the disease would disappear for a while. They also found out that one third of all patients presenting with acute arthritis had few or no signs of it after one year no matter what you did.

The late 1950s and early 1960s were the era of the development of anti-inflammatory and pain killing drugs. Butazolidine was the first after aspirin, known now only in the animal world as 'Bute'. This is a very powerful drug but also very toxic and was at first used in far too high doses. I can vividly remember in my first visit to the rheumatology ward in Edinburgh, where I trained, a young man of 21 who was dying because the Bute had killed his bone marrow.

Indomethacin and ibuprofen (Brufen) were the next. The latter still survives and can now be bought across the counter in this country, a reflection of its weakness as an anti-inflammatory drug rather than its usefulness. But it is an excellent pain killer and useful for mild osteoarthritis. It keeps me going at any rate now!

Indomethacin is still available but seldom used. Again it was introduced while I was a medical student and became widely available after I had qualified. My memories of it are of a patient I looked after in the medical wards at Stoke Mandeville Hospital, one year after I had qualified, who only just survived acute liver failure from the drug. These individual memories of patients have a very strong influence on one's future behaviour as a doctor. I am very cautious of any new drug. However they have equally made me wish to trial new drugs for myself rather than rely on others glowing accounts. I have carefully studied and used the best methods of trying drugs, I have tried to be honest in my appraisal and I have tried not to use new drugs without this careful personal study and trial.

These three drugs were then followed by a plethora of anti-inflammatory drugs, getting on for 30 individual types in all. Some have survived, some not, all have proved a miracle drug to a few people. The newer ones are perhaps a bit safer on the stomach; all are effective for pain and inflammation. They are limited by their side effects on the stomach and kidney and by the fact that they do not influence the course of the arthritis. Nevertheless they are a major advance in the battle against arthritis because they have removed much of the burden of pain. That is not to say that arthritis sufferers do not get pain but it is certainly less burdensome than it was 40 years ago as a result of these drugs.

It was during the 1960s that psoriatic arthritis was distinguished from rheumatoid arthritis. Gout and ankylosing spondylitis had been distinguished before. Now psoriatic arthritis in its various forms and other forms of arthritis and systemic rheumatic disease were discovered. The work on psoriatic arthritis went on at Stoke Mandeville Hospital at the Oxford centre for Rheumatic Diseases and later at Leeds. I was privileged to join the team at Stoke Mandeville in 1967 as this work was published. The centre was at that time active and full of enthusiastic doctors and scientists. As a very junior doctor I was nevertheless expected to undertake a research project and publish it, as well as talk at international conferences. It was there that I first became interested in rehabilitation following a project to look at recovery of knee function and strength after surgery. I also began work on the drug penicillamine for rheumatoid arthritis which I continued for the next four years at Oxford and later as a consultant at Wycombe General Hospital. Rheumatology was a small world when I joined it; there were only 34 consultants in the UK. There are now nearly 500.

One of my principle roles in Stoke Mandeville was to prepare and look after patients with arthritis who were having surgery to their joints. This was my first experience of waiting lists! The ward for arthritis admitted patients for surgery also because of the medical complications of arthritis that make surgery a hazard. I assisted at operations which allowed me a first hand insight into the type of joint damage that active arthritis can produce. The surgeon was a pioneer and developed the first half joint replacement for the knee in this country. Joint replacement began just before this for hips. From then onwards orthopaedic surgery moved forward rapidly in this country, with joint replacements of virtually every joint in the body available somewhere. There was also a hand surgeon at Stoke Mandeville who was a plastic surgeon; his surgery was wonderful to see. He tried finger and wrist replacements as they became available. Joint replacements have revolutionised life for arthritis sufferers in much the same way as have drug therapies, particularly for those with osteoarthritis for whom there are few effective treatments. Back to my family, my mother had a very successful knee replacement in the last year of the twentieth century.

Let us now move on to the 1970s and 80s, years when I was a consultant and see where science was taking us. During these years genetics grew as a specialism. The first rheumatic disease to be specifically associated with a gene was ankylosing spondylitis (the spinal disease associated with severe stiffness and in the worst cases fusion (fixing) of the spine). The discovery of the HLA B27 gene and its association with sufferers from ankylosing spondylitis occurred more or less simultaneously on both sides of the Atlantic. Since then genes associated with many rheumatic diseases have been described although none has quite the specific association of this first gene discovery. The promise that gene therapy would lead to a cure or at least specific drugs had not been realised yet but still may be.

However the discovery of genes, the science of immunology and the simultaneous development of knowledge about the so-called

inflammatory cascade has led to significant developments in the treatment of disease- the biological drugs. For these various strands to come together in the 1990s we go first of all to the Second World War and blood transfusions. Firstly these can only be successfully used to treat people if the blood is of a compatible blood group and secondly there is a need to know about blood clotting. Both of these discoveries led to knowledge of immunology and inflammation, the development of anti-inflammatory drugs, the use of drugs such as methotrexate on the grounds of attacking the bodies own white blood cells which are said to be turning against the body (auto-immunity) and finally the present plethora of biological drugs that are attacking the inflammatory process itself and achieving miraculous 'cures' for many people.

Now that we are in the 21st.century where will we go next? Have we achieved that elusive state of being able to cure arthritis and relieve the pain and suffering endured by so many people? Sadly I fear not. Huge strides have been made but we have also discovered that we can cure many cases of childhood cancer only to find that in later life complications occur from the therapy. The latest biological treatments will take their toll although they are undoubtedly the greatest advance so far. We can relieve pain very successfully but at the expense of side effects. Suffering we understand far better and we know that in order to treat any chronic disease we must pay attention to the way each individual person responds in their mind to the diagnosis.

This present decade is the decade of the patient and of empowerment and self management. We have I believe learned that all drugs are powerful and will inevitably lead to side effects in some people. We also know that herbal remedies work but are not free of bad effects. We know that teamwork between professionals, patients, families and voluntary organisations will lead to best treatment and satisfaction for sufferers and assist them to understand and manage their disease better.

I hope that all those who strive to treat, investigate, cure or understand the rheumatic diseases will give sufferers choices and the knowledge to choose that treatment which they feel is right for them. If no treatment is chosen, then I hope that that decision is made with full knowledge. My family certainly chose where they could but was very accepting of the lack of available treatments for arthritis. They equally accepted the pain and suffering as part of life. Now we do not. We cannot get rid of pain altogether because it is a necessary physiological protection for the body but we should not accept chronic pain and disability as a fact if we have arthritis. There is an enormous amount that modern science can do for us and a lot that we can do for ourselves.

I have found my 60 years of rheumatology exciting, rewarding and sometimes painful. I went into rheumatology initially by chance, my husband and I were both ill and we decided we could not face yet another move to a job I had obtained in another hospital. I was intending at that time to be a pathologist and study diseases under the electron microscope. But after I had done a six months rheumatology post I felt that I had at last found what I wanted to do and remembered clearly the words of my great aunt when I told her I wanted to be a doctor. 'Oh good now you can find a treatment and cure for the family arthritis'! Well I haven't but in my career I have been able to give to patients the help of others and I believe we are certainly closer now to a cure than at any time in the last 60 years. I wish though that we actually knew the cause. My mother is far less crippled than either of her parents or aunts and I am better still. I hope that my children who already have some joint problems will be even better. All we really ask in life is for happiness and a degree of creature comfort. No one wants to live forever but we do want to enjoy life and be healthy right into old age so we can continue to be a plague to those around us but more particularly able to look after ourselves and continue to work at the pace we choose!

Dr. Virginia Camp
PAA 10th anniversary conference
September 2003

RESEARCH ROUND-UP

Dr A G White

In the past three years the British Society for Rheumatology has accorded psoriatic arthritis an enhanced research priority and this is beginning to bear fruit in the form of research papers in increasing numbers. At the Twentieth Annual Meeting of the British Society for Rheumatology in Manchester in April last year there was a sufficient number of papers to justify dividing them into two groups, those on genetic research and those on clinical research. The following is an attempt to summarise a selection of the papers presented.

GENETIC RESEARCH

Myers and others from the Rheumatology Department of University of Newcastle-upon-Tyne and its associated hospitals, presented interesting data on the predominance of female siblings of subjects with psoriatic arthritis. It has been known for some time that there is a disturbance in the sex ratio in the families of individuals with auto-immune disorders related to HLA types. It was known that, in those diseases which are commoner in the female sex, the greater the number of sisters in a family the more likely one of them is to have the condition. The Newcastle Group looked specifically at psoriatic arthritis, a condition where men and women are roughly equally affected. They analysed data accumulated over a period of fifteen years in which they studied eighty sets of siblings and found that even though there were more men with psoriatic arthritis overall, there was nevertheless a preponderance of sisters among their families. This suggests the parents passing on the genes for auto-immune arthritis of this kind are more likely to have female children. In a previous issue of Research Round-Up we quoted another paper on this general topic which showed that men with psoriatic arthritis are more likely to pass on their disease to the next generation than are women with the condition. The precise explanation of these interesting findings is as yet uncertain.

The same study group looked at the various tissue types which have a relationship to psoriasis and the accompanying arthritis, namely CW6, B27, B38, B39, DR4 and D7. CW6 is well known to be associated with psoriasis and B27 with the version of psoriatic arthropathy which includes spinal involvement. B38 and B39 have been shown previously in studies by Gladman in Toronto, to have some prognostic significance for peripheral-type arthritis of the hands and feet particularly. This new study suggests that the presence of the tissue HLA DR4 in a patient with psoriasis and inflammatory arthritis makes the pattern of the arthritis likely to be more closely similar to that found in rheumatoid arthritis which, bearing in mind the effect that DR4 has on the severity of rheumatoid arthritis, makes quite good sense.

Kane and others from the Department of Rheumatology, St Vincent's University Hospital, Dublin, and the Department of Genetics of Trinity College, Dublin report some very interesting studies on the variability of gene functions related to TNF-∂-308 and TNF-ß+252. They showed that individuals showing TNF-∂-308 and TNF-ß-B1 patterns showed a significant association with the age of onset of the psoriasis. Also the presence of joint erosions on x-rays, but not new bone formation, was significantly associated with the presence of TNF-∂-308 and TNF-ß-B1 and was associated with these erosions progressing more than in other individuals over the period of the study. With the accumulating evidence of the efficacy of anti-TNF biological agents in psoriatic arthropathy, these findings are of particular interest.

A combined study from the Royal National Hospital for Rheumatic Diseases, Bath, and Imperial College of Science & Medicine, London, parallels somewhat the work on TNF-∂ reported above but refers to interleukin 1 and the interleukin 1 receptor gene and its variations in individuals with psoriatic arthritis. The interleukins are the mostly inflammatory molecules which are largely under the control of TNF-∂ and the pharmaceutical industry is now marketing biological agents to suppress the effects of individual interleukins of which there are now more than a dozen discovered. Certain variations, or polymorphisms as they are termed technically, of the gene controlling interleukin 1 were found to have an association with the presence of psoriatic arthritis compared with control subjects. It is probably too early to say what therapeutic significance this may have in the long run. In another paper the same group showed that a rare TNF-∂ version was significantly more commonly detected in patients with large numbers of joints involved than in other forms of the condition. The study involved 138 psoriatic arthritis patients and 235 controls, so that the conclusions drawn may well be of clinical as well as purely statistical significance, but have no application to treatment as yet.

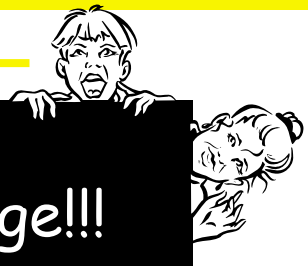
CLINICAL RESEARCH

We sometimes refer to psoriatic arthritis as "sine psoriasis", which is simply the use of Latin to say that now and again one comes across patients who have psoriatic arthritis but who do not themselves have psoriasis. This has always been a problem group because the usual definitions of psoriatic arthritis require the presence of psoriasis for the diagnosis to be secure. Scarpa & others of the Clinical Experimental Medicine, Immuno-Haematology & Dermatology Departments of the Federico II University, Naples University, studied the family backgrounds and immuno-genetics of patients with sero-negative spondarthropathy defined

according to standard European criteria and found that those with a positive family history of psoriasis in first or second degree relatives, who also showed arthritis of the end joints of the fingers and swollen "cocktail sausage toes" and who also were of the HLA CW6 tissue type best identified those with psoriatic arthritis sine psoriasis. J S Lewis & others, in a collaborative study from the Royal National Hospital for Rheumatic Diseases, Bath, the Department of Dermatology, Royal United Hospital, Bath, and Department of Medical Sciences, University of Bath, looked at 81 patients with psoriasis attending a Dermatology Outpatient Department who were thought to be free of arthritis. Roughly half of these turned out, on rheumatological full assessment, including x-rays, to have psoriatic arthropathy of some type. This does, as they comment, have implications for clinical practice and genetic studies. It would seem to me to have a particular message for rheumatologists and dermatologists that they should work in close collaboration in treating the whole patient.

Finally, in How do We Treat Psoriatic Monarthritis? – Makadsi and Harrison, Department of Rheumatology, North Manchester General Hospital, performed a postal survey on the management of patients with a single swollen, inflamed joint in the presence of psoriasis with particular reference to the treatment used. All rheumatologists in the NW Deanery of the UK were surveyed. Of the 32 replies received, 78% used disease-modifying drugs, methotrexate and sulphasalazine equally, systemic steroids were rarely, if ever, used, 50% referred patients for surgical synovectomy, usually performed through the arthroscope, 7 used the alternative with radio-active yttrium which can only be provided in centres with a nuclear medicine facility and 19% employed intra-articular methotrexate. Having advocated this on the basis of a small-scale study in 1985, using it in combination with triamcinolone hexacetonide, it would have been interesting to know whether the methotrexate was used on its own or in combination. There would appear to be an opportunity for a larger nationwide study with uniform outcome measures. The decision as to which method of treatment to use might well depend upon whether treatment was directed at the first presentation of a monarthritis or in recurrences.

PAA Kids



Calling all kids with psoriasis and psoriatic arthritis - this is your page!!!

CHILDREN AND PSORIASIS - DID YOU KNOW

- Psoriasis affects more girls than boys as youngsters but strangely it becomes equal when both sexes reach adulthood.
- It is estimated that approximately 80 million people world-wide suffer from psoriasis, with 25% having moderate to severe psoriasis.
- It is estimated that out of the total affected patients, 10-15% of these will be children under 10 years of age.
- It is estimated that 5 million people a year will seek help for their condition, with 15% being in the Paediatric (childrens') age group.
- Psoriasis is commonly compared to a snake, always shredding its skin to reveal a new one.
- The most common form of psoriasis in kids is "guttate" which is usually triggered off by a chest infection or the bugs called streptococcal, which cause sore throats.
- Scalp psoriasis is more common in kids, as is, seborrhoecic psoriasis
- Babies can get a form of psoriasis too called "nappy" or "napkin" psoriasis.
- Strange but true, in some cases, psoriasis has been known to completely disappear, never to return!! Spooky. Nobody knows why.
- A lot of the medical textbooks on psoriasis maintain it does not itch – but hey, we all know it does!
- You can use cover-up, concealing, camouflage creams to help make your skin look better.
- If you have to have an immunisation, don't worry or be surprised if a small patch of psoriasis develops around the jab site – it's common.
- If you go into hospital for any operation, you may develop patches around your incision/injury/scar site – don't worry – its common. TIP: Try not to go to hospital too often for other such treatments!!
- *Why do I get Psoriasis?*

Well, the chances are it may run within the generations of your family. Maybe someone unknown to you back in the history of your family had it, or one or both of your parents, brother, sister, aunt, uncles may have had or have it. So the chances are you may be prone to it yourself, keeping up the family tradition – there's nothing wrong with that!!

- *Why couldn't my doctor tell the difference between eczema and psoriasis?*

This happens because they both do look similar in appearance, both conditions being caused by the body's immune system function not working as well as it should. Saying this though, both eczema and psoriasis do have differing characteristics in their appearance, and it may mean that your doctor is not as well informed as he should be. GP's have to have a lot of knowledge about almost everything medical and sometimes they can get alittle confused in their findings.

Don't be too hard on him, if you are not sure of his diagnosis, always ask him nicely to refer you onto a dermatologist at your local hospital for a second opinion. You are entitled to be referred on if you are not happy.

PAA Kids just remember, be positive, be active, and be part of your treatment options – ask questions, SAY NO if you feel a treatment is not right for you – get your doctor working and talking with you about you, what you want and how you want to achieve good result in your treatment outcomes.

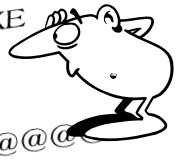
One day you will be an adult taking on these decisions yourself, so you might as well get into practise now for life!! Get the medical team around you that you want, you need, to help you achieve good outcomes and management of your condition.

REMEMBER
We want you input, case histories, puzzles, jokes, fundraising ideas, help us to help you get motivated, lets get PAA Kids rolling in 2004 and beyond.

PAA Kids

Skin'n'Bones Connection

OLD MR KELLY
HAD A PIMPLE ON HIS BELLY
HIS WIFE CUT IT OFF
AND IT TASTED LIKE
JELLY!!!!!!!!



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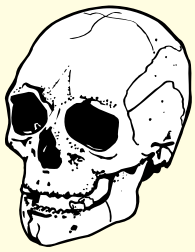
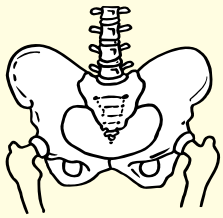
What's the time
Ten to Nine
Hang your knickers on the line
When the're dry
Bring them in
Put them in the biscuit tin
Eat a biscuit
Eat a cake
Eat your knickers by mistake
@@@@@@@@@@@@@@@

If you have got any good limericks or rhymes, go on send them in.....please

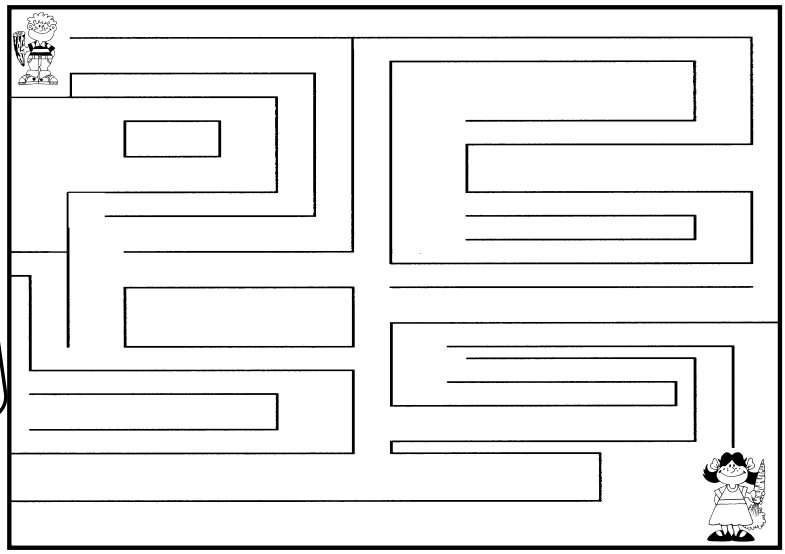
STICKS
MAY
BONES
BUT
STONES
WORDS
HURT



BREAK
ME
WILL
AND
HURT
NEVER
MY



CAN YOU REARRANGE THE WORDS TO MAKE A WELL-KNOWN PROVERB? *(Answer at the bottom of the page)*



WORDSEARCH

Find the hidden words

S	U	N	S	H	I	N	E	P
O	H	G	D	Z	W	O	R	M
J	S	S	P	R	I	N	G	U
S	U	S	J	O	N	V	X	E
W	M	Y	H	L	T	Q	E	T
O	M	E	H	C	E	I	C	R
R	E	U	A	I	R	C	I	O
R	R	A	I	N	K	O	E	S
A	N	O	L	P	L	L	E	T
P	X	T	H	U	N	D	E	R
S	E	R	O	B	I	N	P	T

ROBIN
SUMMER
ICE
THUNDER
HAIL
WORM
COLD
SPRING
RAIN
SUNSHINE
FROST
SPARROWS

Aims for you and your treatment!!

GETTING MOTIVATED IS THE KEY!!

- ✔ **Yes,** I will try to see through my skin treatments – **REMEMBER**, sticking to the treatment gets results….
- ✔ **Yes,** I will go to the hospital/ doctors willingly, without winging, upsetting my mum or dad.
- ✔ **Yes,** I will be positive about myself, and the way I feel and look
- ✔ **Yes,** I will carry on doing the things I love to do without feeling I shouldn't because of my skin
- ✔ **Yes,** I will take things in moderation, and enjoy them, without making my joints feel more worse
- ✔ **Yes,** I will stop giving my mum and dad a hard time because I've got psoriasis
- ✔ **Yes**, I will learn to jump over the obstacles in my way to achieve all the things I want to, despite feeling low sometimes – ***I will pick myself up and get going again!!***
- ✔ I will control the psoriasis/and or arthritis, instead of it controlling me!!

THE CONDITION WILL LEARN TO LIVE WITH ME MY WAY!

ASK ABOUT MEDICINES

Almost everyone takes medicines at some point in their lives and they have an enormous potential to affect our health and wellbeing. A new, uniquely broad-based initiative called Ask About Medicines, aims to increase people's understanding of their medicines – by creating more opportunities to discuss their views and concerns about medicines with a range of health professionals, including pharmacists, doctors and nurses.

To find out how people regard medicines and information about medicines, a survey of more than 2,000 adults in the UK was conducted by MORI especially for Ask About Medicines Week held last October. A separate MORI poll was conducted among health professionals including GPs, pharmacists and practice nurses.

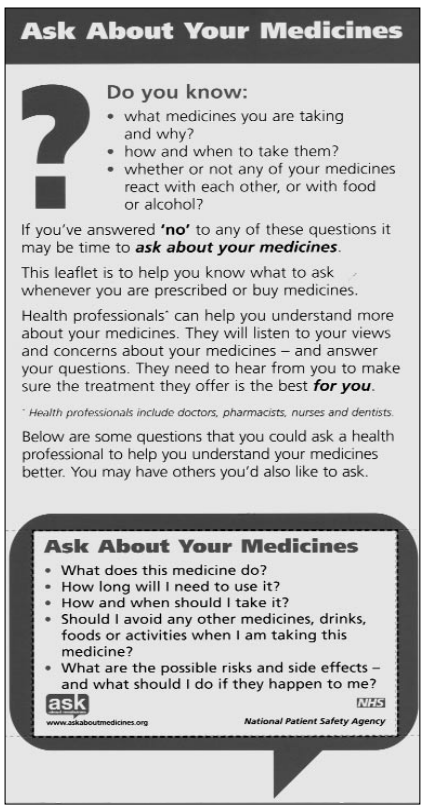
Findings from the surveys include:

- 55% of people prescribed a new medicine in the last twelve months felt that they did not know enough about other possible medicines or treatments
- Almost one in three medicine takers felt they did not know enough about the potential side effects of medicines
- Six out of ten patients said that the benefits of medicines outweighed the risks
- Four out of five people (81%) said that it was valuable to have different types of information about medicines from different sources (eg patient leaflets and Internet sites)
- One in five people want to make more use of the Internet in future as a source of medicines information
- The most popular source of information remains advice from health professionals
- Health professionals are ready for partnership. Over half of the GPs, practice nurses and pharmacists surveyed believe that most patients want to be treated as partners in decisions about medicine taking. Only one in ten doctors said that patients would want the prescriber to decide for them

"Research shows that up to 50% of people do not take their medicines as prescribed[1] and that people's experiences, beliefs and views about medicines influence if, when and how they take their medicines more strongly than any other factor[2]," says Joanne Shaw, Director of the Task Force on Medicines Partnership and co-chair of the AAMW Executive. "The survey shows us that one in three people believe the benefits of taking medicines don't outweigh the risks"

Knowing what questions to ask is key to prompting discussion, and to help facilitate this process an Ask About Medicines Question Card has been specially developed with the National Patient Safety Agency (NPSA). The card features five key questions and five top tips for asking questions about medicines. The cards have been made available in pharmacies and a range of other healthcare settings across England, Wales and Scotland.

Wendy Harris, Senior Pharmacist at the NPSA says: "The NPSA is delighted to be sponsoring the AAMW Question Card in a shared effort to encourage patients and health professionals to discuss medication use. Involving patients and their carers in decisions about their medicines and informing them to take or use their medicines safely will, we believe, help ensure that they obtain the greatest benefit from their medicines in the safest possible way."



There is an enormous amount of information about health available from a large number of different sources, but it is not always easy to know how and where to start looking for it. The Health and Medicines Information Guide and Directory provides guidance on how to find health information and how to judge if it meets people's own particular needs. The booklet includes a Directory listing information resources, helpline numbers and Internet-based links that will help people get started. The booklet will be available to download from www.askaboutmedicines.org. Printed copies can be ordered from www.abpi.org.uk.

"Research shows that most medicine takers see their health professional as the best person to advise on medicine taking, but often during consultations they do not ask the questions that most concern them," says Kristin McCarthy, Director of the Doctor Patient Partnership and member of the AAMW Executive Group. "Encouraging more open discussion about medicines helps people to be actively involved in decisions about their treatment and ultimately leads to safer and more effective medicine taking."

REFERENCES:

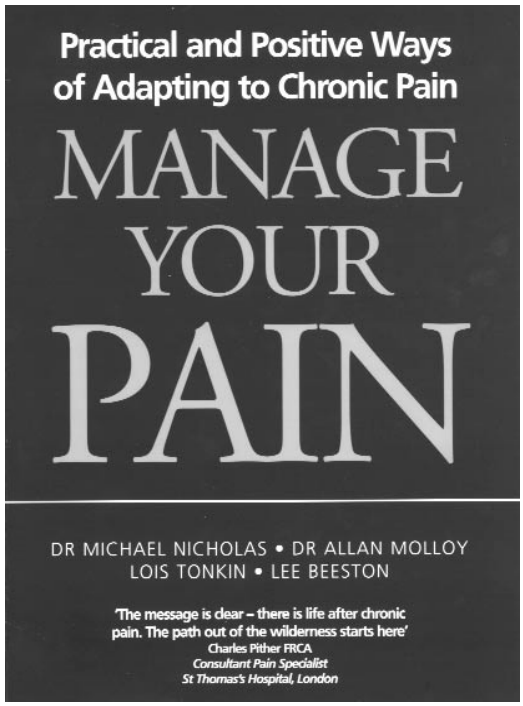
1. **'From Compliance to Concordance',** Royal Pharmaceutical Society of Great Britain, 1997

2. Horne R & Weinman J (1999) Patients' beliefs about prescribed medicines & their role in adherence to treatment in chronic illness. Journal of Psychosomatic Research 47(6): 555-567

books

MANAGE YOU PAIN -

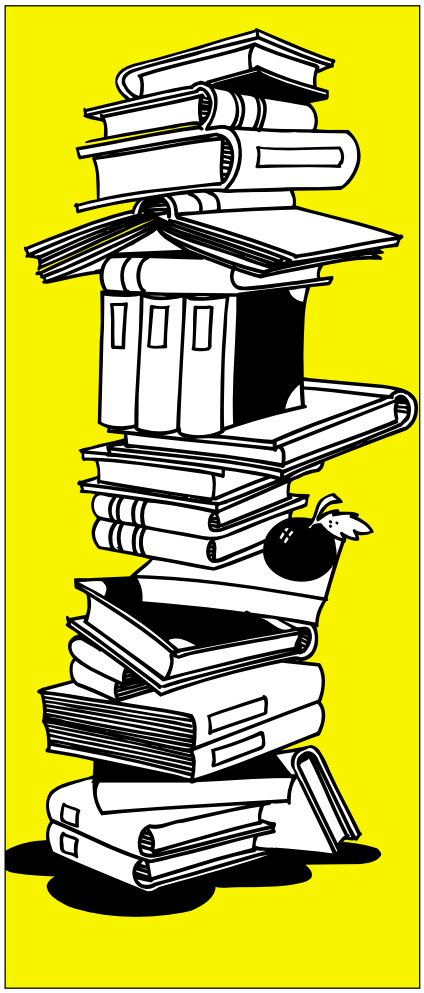
Dr M Nicholas, Dr A Molloy, L Tonkin, L Beeston.



Does pain interfere with your sleep, work or social life? Do you ever need to rest during the day because of pain? Are you concerned that your doctor has missed something? Then maybe this new book is for you.

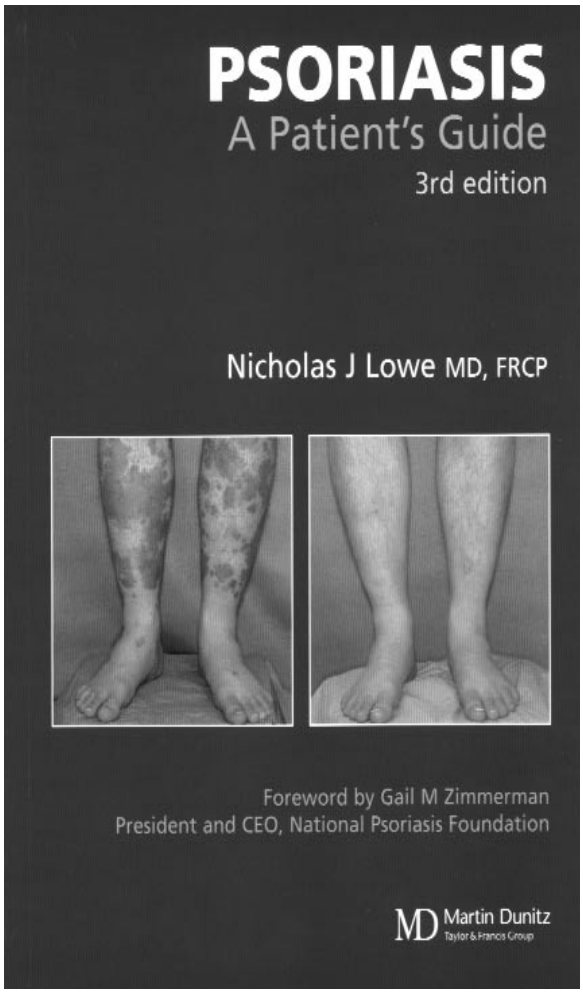
Drawing on the latest research and the authors' extensive medical experience this book explains the practical and positives ways in which you can adapt to chronic pain and manage it so that you can again lead your life.

ISBN: 0-285-63679-0
Price £12.99
Souvenir Press.



NEW BOOK – PSORIASIS A PATIENTS GUIDE

by Nicholas J Lowe MD FRCP



Psoriasis has been documented for centuries - its earliest description can be traced to Celsus in 35 to 40 A.D., and the term itself dates back to Galen, the famous Roman physician, in the second century A.D.

As a condition, it occurs in all races and in all parts of the world, affecting nearly one and a half million people in the UK alone. It can range in severity from mildly irritating patches to painful, near total skin coverage, and has a drastic affect on the lives of all sufferers, often leading to extreme physical discomfort and depression.

Now in its third edition,' Nicholas J Lowe's best-selling guide to psoriasis is crucial reading for anyone with psoriasis. Answering all your questions about the disorder, and completely updated and revised to take into account improvements in technology and research and new treatments, it provides a jargon-free, practical guide to the disorder.

Dr Lowe believes that people with psoriasis and their families need to have the very latest information and encouragement about recent medical advances if they are to have a chance to beat - or at least control - psoriasis. With this in mind, he has produced his bestselling guide to ensure patients can find everything they need to know in one short, accessible, and easy-to-read volume.

Published by Martin Dunitz: £14.95 ISBN:1-84184-309-1:

Skin'n'Bones Connection

BIOLOGICAL THERAPIES

What treatments are available for psoriasis?

At present there are three main ways to treat psoriasis

- with topical treatment (where the treatment is applied directly to the skin)
- with light treatments (using either UVB or UVA light usually in hospital) or
- with drugs (which can be taken either by mouth as tablets/medicine or by injection)

All these treatment options have side-effects. Also, some treatments may not help all patients and sometimes psoriasis can be so severe that even the strongest treatments do not work. For these reasons doctors have been trying to develop new, better, treatments for psoriasis which have very few side-effects and are safe for patients to take in the long term.

What are biological agents?

There are many new drugs for psoriasis currently being developed. This is good news for psoriasis treatment and is thanks to an enormous amount of research work and to new techniques available to drug companies for drug development. These new drugs are referred to as "biological agents", or "biologics" in the USA, as they have been carefully designed to resemble human chemicals or proteins and to interrupt important steps in the development of psoriasis. These selective features also help reduce side-effects and increase safety.

What new biological therapies are available?

Biological therapies are not widely available yet and many treatments are still at the clinical trial stage. However they are an exciting new advance in the therapy of psoriasis and likely have a big impact on future psoriasis treatment. Examples of some of the new biological therapies include:

- Alefacept: is effective in psoriasis when given once weekly by injection and has produced excellent improvement in psoriasis in approximately one third of patients in clinical trials.
- Eflalizumab: is given by injection. In trials half the patients treated achieved good clinical improvement and a quarter achieved excellent improvement.
- Etanercept and infliximab: are effective treatments for many immune-mediated diseases including rheumatoid arthritis and psoriasis. They work by blocking a chemical called TNF-a which is an important stimulant of skin inflammation. TNF-a is increased in psoriasis. In a trial of patients with severe psoriasis infliximab (given as an intravenous infusion) was highly effective in >80% of patients and etanercept (given as an injection into the skin) produced excellent improvement in a quarter of patients.

There are a number of biological therapies in development. It is likely that they will change the way psoriasis is managed. The main potential drawback is cost to the NHS.

Dear PAA

I'm in my late twenties and have suffered with severe psoriasis since the age of seven. I tried most creams and treatments but all to no avail, I stopped all treatments at the age of sixteen and learnt to cope with it.

Over the last two years I started to suffer with a pain in my lower back and pelvis, as I am a young woman doctors assumed it must be an gynaecological problem. After two separate stays in hospital I was discharge and told it was definitely not a gynaecological problem, but they didn't know what it was.

After many trips to my GP they sent me to see a physiotherapist on my first visit the physiotherapist mentioned psoriatic arthritis I had never heard of this before. I have recently seen a rheumatologist who told me I have got psoriatic spondylitis. The pain has now spread to my neck hands arms legs and feet.

I would like to get in touch with other people who have got this condition who could contact me and help me learn and understand this condition to stop me thinking I am going insane and let me get on with living my life again.

Yours faithfully
Donna Storrs

Note from the Editor: *if anyone would like to get in contact with Donna please send you letters to the PAA office and we'll forward them on.*

Remedial camouflage make-up course

A new OCN accredited course over 11 weeks with Helen West. This course is ideal for anyone who wants to learn, assist a person with, or indeed has themselves a scar, birthmarks, disfigurement or unwanted tattoos. This course also complements the skills of make-up artists/beauticians who regularly meet people with these needs. All materials are provided.

Course date: Friday 23rd April to 9th July 09.30-12.30

Further information contact Peter Symmonds Adult Continuing Education or e-mail Helen@madeup.co.uk

US PATIENT STUDY RESULTS

A recent survey of people with moderate-to-severe psoriasis published in the USA showed that people with psoriasis experience a crisis in self-confidence so severe it can darken almost every aspect of life, from the quality of a person's love life to performance on the job and day-to-day social interactions. People report feeling like social outcasts and being misunderstood by the public.

The survey is the most comprehensive study in the US to date to specifically examine the social and emotional effects of psoriasis. It also illustrates the need for a public education and support program for people with psoriasis. The Person Behind the Patient, is a unique collaboration of health providers, advocates and people with psoriasis including the National Psoriasis Foundation and the Dermatology Nurses Association (DNA). The new program was launched at the 62nd Annual Meeting of the American Academy of Dermatology (AAD).

"Comprehensive care of psoriasis goes beyond treating the symptoms. This survey validates the need for an understanding about how psoriasis can impact a patient's social life and emotional and physical well-being," said Alan Menter, MD, Chief of the Division of Dermatology at Baylor University Medical Center and a member of the Beyond Psoriasis Advisory Board. "I am committed to this program and its objectives to provide education, sensitivity and support to these individuals similar to what is available for other chronic diseases like heart disease or arthritis. Otherwise, the patient's psoriasis is not fully managed."

Conducted in December 2003 by the NFO, a leading market research firm, the survey sampled 502 people with moderate-to-severe psoriasis to determine the effect the disease has on four crucial aspects of life: self-esteem, work/school, relationships (including sex life and intimacy) and social interactions. Most strikingly, three-quarters (73%) of people with severe psoriasis and about half (48%) of people with moderate psoriasis reported low self-confidence serious enough to affect virtually all aspects of life. Further, the survey found that one of the driving forces behind these feelings is a perceived lack of understanding among the general public. Less than one in ten people surveyed (8%) feel that society understands the disease. Sixty-seven percent say the public is ignorant about psoriasis, 64% say the public is afraid that the disease may be contagious, 56% say the public is disgusted by psoriasis and 45% say that people with psoriasis are often the "object of ridicule."

Findings of an Omnibus Survey of 1,000 adult Americans, conducted by Opinion Research Corporation International (ORC) in December 2003, found that the vast majority of respondents (88%) have heard of psoriasis and that almost half (46%) knew someone with psoriasis. The findings showed that although the public is not aware of the prevalence of the disease (93% were not aware that 4.5 million Americans have psoriasis), 86% of the respondents did know that psoriasis is not contagious and 52% were aware that psoriasis is more emotionally crippling than physically disabling.

"I'm really surprised that so many people know that psoriasis is not contagious. I have psoriasis, and when I have a flare up, I am really self-conscious. I know that people stare and stay away from me because they think I am contagious," said Mike Frisbie, a member of the Beyond Psoriasis Advisory Board and psoriasis patient. "Part of what we want to do with this program is to help people with psoriasis feel more comfortable with discussing the disease and to learn ways to cope with the self-defeating attitudes that can cast a shadow over many aspects of our lives. We want to help empower others to speak up about their disease with their doctor, their friends, acquaintances and loved ones, and in doing so, help them continue their lives in a positive way."

Negative effects were most dramatically experienced by people with psoriasis who are 18-24 years old – a population just beginning to develop their self-esteem and interpersonal relationships that will influence the rest of their lives. Women, single people and those who have visible psoriasis (usually on their face and/or scalp) were most impacted.

· More than half (58%) of women compared with 45% of men experienced lower self-confidence because of their psoriasis

· Self confidence of young adults (68%), people with early childhood onset psoriasis (58%), and people with visible psoriasis (58%) were also more dramatically affected

Relationships

Many people with psoriasis had problems with sex and intimacy. In fact, four in ten people with psoriasis (38%) agreed that the disease affects their sex life/intimacy. The problems are more prevalent for those who are single. Feelings of worry are common.

· More than half (53%) of those single admitted to having problems with their sex life (versus 30% of married people with psoriasis)

· Half (49%) of young adults (ages 18-24) are also more likely to experience angst in intimate situations (versus 36% of 25-35 year olds)

· Half (52%) turn off the lights when they are intimate with their partner; 48% worry that their partner is embarrassed by their psoriasis; 26% say psoriasis interferes with their ability to getting emotionally close to their partner.

In general, the people surveyed felt that their family and friends understand their psoriasis and are supportive. Understanding of family could be driven by genetics: almost half (45%) of the people surveyed have at least one family member with psoriasis. Of those, the majority (62%) has at least one parent who has psoriasis. 81% are worried and 76% feel guilty that they might pass psoriasis on to their children.

Most people with psoriasis avoid public interaction, dress to hide their condition and feel like outcasts (64%). Psoriasis affects daily interactions for four in ten (38%) respondents. For those with severe psoriasis, this increases to 57%.

· Three fourths (74%) do not like to be in public when their psoriasis flares up

· 64% hide their condition with long sleeved shirts and long trousers

Work and school can be particularly problematic for people with psoriasis. One-third (37%) of all people with psoriasis agree that the disease affects work/school.

· Those people with severe psoriasis, visible psoriasis (face and/or scalp), early childhood onset and young adults (18-24) were more likely to agree (55%, 40%, 48%, 41% respectively).

Gail Zimmerman, President and Chief Executive Officer of the National Psoriasis Foundation said. "With support from healthcare professionals and others with the disease, people with psoriasis can help to build widespread public awareness and at the same time become more confident spokespersons about their disease. That public awareness, in turn, will lessen the social pressures, completing the circle of positive communication and support."

Best Value Disability Products

Free services products website launched

A new website called 'BestValueDisabilityProducts.com' was launched earlier this year. The site provides the following to the elderly, people with disabilities and long-term health problems and to their families and carers, as well as to Social Services staff and owners of care homes, both in the U.K. and worldwide:

1. Advice from an experienced Occupational Therapist on the vast variety of different products, which can help to improve independence, and on the advantages and disadvantages of each type. This is ideal if customers are not sure what products are available, or can't decide which products are right for them.

2. Details of the Lowest Price currently charged for each type of product in the UK. They have searched all national disability-products suppliers to find which is charging the best price for each type of product, saving the customer hours of phoning around, searching websites or visiting individual product showrooms!

3. Details of alternatives to these 'lowest-priced' products, which cost a little more, but are particularly well designed, either in terms of their looks or function, ideal for those who are not on a tight budget or have particularly high standards!

Visitors can either use the website and its free advice service solely to obtain information or they can ask BestValueDisabilityProducts.com to order their chosen products for them, at no extra cost, in which case help is given with completing order forms and claiming VAT exemption and the customer receives a 'Price Promise', which offers to refund the difference if the customer later finds their choice of products for less money elsewhere.

The products featured on the website fall into the following categories: Access, Bedroom, Bathing, Chair & Seating, Dressing, Drinking & Eating, Household, Kitchen, Leisure, Mobility, Moving & Handling, Personal Care, Showering, Stairs, Toilet, Washing & Drying and Miscellaneous. Prices are checked regularly to ensure that information provided on the website is accurate and up to date.

Another interesting feature of the website is that it features an 'Invent Me!' page, which allows customers to send in details of the particular problems that they are having which are not solved by the current range of disability products which are on the market. The website then challenges manufacturers and suppliers (as well as budding inventors in their own homes) to come up with a product that fits the bill! The website then tracks the progress of these new products through their design and manufacture, right up to the stage when they are actually available to buy on the market.

Further information:

www. BestValueDisabilityProducts.com

PAA Publications order form

(for free publications enclose a 6" x 9" SAE) to:
PAA Publications PO Box 111 St Albans Herts AL2 3JQ
All payments should be made payable to the PSORIATIC ARTHROPATHY ALLIANCE

Publication title	Issue no.	Publication Date	Unit Cost	Qty. Required	Sub total
Newsletter	7	September 1996	50p ~~£3.00~~		
Skin 'n' Bones Connection	7	December 1996	50p ~~£3.00~~		
Newsletter	8	March 1997	50p ~~£3.00~~		
Skin 'n' Bones Connection	8	Summer '97	50p ~~£3.00~~		
PAA News	9	Autumn '97	50p ~~£3.00~~		
Skin 'n' Bones Connection	9	Winter '97	50p ~~£3.00~~		
PAA News	10	Spring '98	50p ~~£3.00~~		
Skin 'n' Bones Connection	10	Summer '98	50p ~~£3.00~~		
PAA News	11	Autumn '98	50p ~~£3.00~~		
Skin 'n' Bones Connection	11	Winter '98/99	50p ~~£3.00~~		
PAA News	12	Spring '99	50p ~~£3.00~~		
Skin'n'Bones Connection	13	Winter 2000	50p ~~£3.00~~		
Skin'n'Bones Connection	14	2001	50p ~~£3.00~~		
Skin'n'Bones Connection	15	2001	£3.00		
Skin'n'Bones Connection	16	2002	£3.00		
Skin'n'Bones Connection	17	2003	£3.00		
Skin'n'Bones Connection	18	2003	£3.00		
Skin'n'Bones Connection	19	2004	£3.00		
What is Psoriasis? leaflet	-	2001	Free		
Occupational Therapy & Joint Protection	-	2003	Free		
Physiotherapy and Exercise Booklet	2nd edition	2003	Free		
Psoriatic Arthritis - The Feet leaflet	-	2003	Free		
What is Psoriatic Arthritis? leaflet	-	2002	Free		
PAA subscription form leaflet	-	2001	Free		
Clinical Trials booklet	-	2001	Free		
Nails Psoriasis leaflet	-	2001	Free		
PAA contact poster A4	-	-	Free		
Psoriatic Care Fact File- 26 fact sheets	1st edition	1998	£7.50		
Psoriasis - A Guide To Emollients	-	1999	Free		
PAA -The Birth of a Charity A4 pamphlet	1st edition	1996	50p		

The follow non-PAA publications are also available by sending a 6"X 9" SAE.

Key facts about psoriasis booklet	-	-	£1.50		
So You've Got Psoriasis booklet	-	-	£3.50		

+ suggested postage donation	**£ 1.00**
TOTAL COST £	

Name _____ Title _____ Telephone _____

Address _____

Postcode _____ Country _____

Please allow 28 days for delivery. Thank you.

This information is supplied by the Psoriatic Arthropathy Alliance. A national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder, psoriasis. Registered charity no 1051169.
Further information can be obtained by contacting:
PAA PO Box 111 St Albans Herts AL2 3JQ . Tel: 0870 7703212 Fax: 0870 7703213. E-mail info@paalliance.org
A Company limited by guarantee registered in England no: 3055414.
Registered office: Faulkner House Victoria Street St. Albans Herts AL1 3SE.

TO REGISTER OR SUBSCRIBE TO SKIN 'N' BONES CONNECTION

PLEASE FILL IN AND RETUREN TO PAA

SUBSCRIPTION FORM

Please complete the following clearly:-

SECTION 1 & SECTION 2 (optional)

SECTION 1

First Name(s) .....

Last Name .....

Title (Miss, Ms, Mrs., Other) .....

D.o.B .....

Address .....

.....

..... Postcode .....

.....

.....

Country .....

Telephone .....

Fax .....

E-mail .....

Mobile .....

I would like to be added to the PAA Register (Free) ☐

I would like to subscribe to Skin 'n' Bones Connection

UK - £12.50 (including postage and packing) ☐

Overseas: £20.00 (including Air postage and packing) ☐

I enclosed my annual subscription fee of: £ .....

I would like to make a donation of: £ .....

PLEASE MAKE CHEQUES PAYABLE TO:
"PSORIATIC ARTHROPATHY ALLIANCE" Thank you.

Signed: .....

Date .....

QUESTIONNAIRE

(Completion optional and confidential)

SECTION 2

Where did you hear about the PAA? .....

.....

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.

What do I get if I Register?

- Opportunity to take part in patient focus group meetings
- Receive relevant mailings via PAA (such as surveys, new product information etc.)

What do I get if I subscribe?

Benefits of becoming a subscriber to Skin 'n' Bones Connection are:

- Two issues per year (two back issues immediately)
- Other mailings during the year about PAA activities and events.
- Free new information leaflets when produced
- Publications list
- Automatic inclusion to the PAA Register

PLEASE RETURN TO:
Subscriptions
Psoriatic Arthropathy Alliance
PO Box 111
St Albans Hertfordshire
AL2 3JQ UK

InterPSO TOPSO Study

Psoriasis, the chronically relapsing disorder of the skin, affects 1.5% of the population of Europe and possibly 2.6% of the United States. Though not contagious, it is physically and psychologically very distressing. The condition is generally treatable with topical preparations, but compliance rates are known to be quite low.

InterPSO (a joint collaborative project between the Psoriatic Arthropathy Alliance (UK) and Galderma International (France). Brought together a European patient focus group, with participants from United Kingdom, France, Belgium, Germany and the Netherlands to initiate a topical treatments patient compliance study.

These patients responded that complying with topical treatment was difficult, more so than any previous research has suggested and that, though their treatments generally worked, patients badly need preparations that are easier to use and that are less unpleasant than they are now.

1,281 adult patients responded, nearly evenly among the five countries. The average age was 51.86 years, the French tending to be slightly older and the Germans slightly younger. The sex ratio, as it is in psoriasis generally, was nearly balanced, except for the UK, where men were only a third of the respondents. Most lived with other adults, most had children, and half considered themselves their children's primary carers. On average, a third of the respondents had university educations, but variability among countries was high. It corresponded roughly with self-assessment of the severity of condition: lower education generally meant harsher assessment.

Most patients had trouble with psoriasis on their scalps, elbows, and knees. Ears, nails, and backs were also common. Germans, for some reason, were 5 times less likely than any other population to report psoriasis on the backs of the pinnae of their ears. UK patients were more likely to have it on their nails than French or Belgian patients were. Each patient tended to have suffered psoriasis for about 25 years, and about 25% of cases were generalised or severe.

Most patients were prescribed corticosteroids, calcipotriol, or salicylic acid. Nearly negligible were retinoids, calcitriol, and tacalcitol. People on topical treatments who also chose alternative therapies tried sun-sea stays or baths about half the time, and oral remedies 38% of the time. About a third also tried phototherapy, and 36% tried complementary medicine, including vitamins, homœopathic cures, acupuncture, and traditional Chinese medicine. Dermatologists did two-thirds of the prescribing of topical treatments overall, except in Britain, where GP's wrote 60% of them.

Amazingly, 13% of survey patients used an alternative therapy instead of their topical prescriptions, and another 18% used no therapy of any kind. Without even considering patients who tried their prescribed therapy and refused to continue with it, this constitutes a startlingly enormous failure to comply.

Why? We know that treatment takes a lot of time, money, and physical assistance. Three out of four patients say they need help from another person to carry out their treatment, and that that person is not available to help about a fifth of the time. Daily therapy, though it usually means only one application of topical preparation, appears to require 17 minutes a day overall, though this varies widely by country (25 minutes in Germany, 12 in Holland). It is not cheap, either. German patients spend on average 35 euros a month on their local therapies for psoriasis, and British patients, at the other end of the scale, spend nearly 9 euros; the overall mean is 21.97 euros.

In practice, most patients finally did not comply with their prescriptions completely: only about 27% stayed the whole course. It was a little better in Germany, a little worse in France and Belgium, but the variation among countries was not significant. There was slight variation among users of the usual six topical substances. Oddly, there is no sign in any patient group that compliance worsened over time.

What did patients say about their treatments? 27% said their treatments didn't work well. Far more common, at 51%, were answers that had to do with convenience: 26% felt their treatment took too long to rub in, 17% thought the process was too complicated or difficult, and 8% found the treatment 'too restricting'. And outweighing even these were the 73% of answers about unpleasantness, which contained the biggest single point of agreement of all: 29% disliked the stickiness enough to discontinue at least some applications; another 15% found the preparation irritating, another 15% said it had 'side effects', 8% disliked the smell, and 6% disliked the texture. 7% responded spontaneously, in free-text answers, that they only applied their medication when they thought they needed it.

The problem of compliance, that ought to be a straightforward function of whether or not a given treatment works, is actually a matter of agreeableness and time required. It was very useful, and our study was novel in this respect, to focus directly on the patient's point-of-view.

We now know what to tell doctors, what direction pharmaceutical research should take, and what broader and more detailed studies deserve to be commissioned for the future.

The study was conducted during May 2003.

REGULATION OF HERBAL MEDICINE AND ACUPUNCTURE PROPOSALS FOR STATUTORY REGULATION

The Department of Health has launched a consultation document on the statutory regulation of herbal medicine and acupuncture practitioners. This paper seeks views on the statutory professional self-regulation of the herbal medicine and acupuncture professions.

This document follows the recommendation made by the House of Lords Select Committee on Science and Technology that it would be in the interests of patients and practitioners for the herbal medicine and acupuncture professions to strive for statutory regulation.

The Department of Health has carefully considered and built on the recommendations of two independent regulatory working groups in developing its proposals for the statutory regulation of herbal medicine and acupuncture.

The Medicines and Healthcare products Regulatory Agency (MHRA) has published a linked consultation document on the regulation of unlicensed herbal remedies made up to meet the needs of the individual patients.

The formal consultation period will run from 2 March until 7 June 2004. If you have comments on the proposals or responses to the specific consultation questions, you can send them to:

Herbal Medicine and Acupuncture Consultation
Department of Health
Room 2N35B, Quarry House, Quarry Hill
Leeds, LS7 2UE
E-mail: HM-AC-Cons@doh.gsi.gov.uk

A better life for people with chronic disease

Health Secretary John Reid recently set out his vision for a new deal for people suffering from long-term chronic diseases like asthma and diabetes.

Mr Reid announced plans to ensure that people in England with chronic disease receive the support they need.

Under Mr Reid's plans, specialist teams across the country will provide advice, care and treatment for chronic disease - often cutting out the need for visits to GPs and hospitals.

Mr Reid announced the launch of a programme for 2004/05 to establish case-management demonstration sites within each of the 28 Strategic Health Authorities. In the UK, there are some 17.5 million people living with chronic conditions like diabetes and asthma. The World Health Organisation estimates that by 2030 the incidence of chronic disease in the over 65s will have doubled.

People with chronic diseases account for up to 80% of GP consultations - around 180 million visits a year.

Existing chronic disease management schemes in the US have cut hospital admissions among the target group of patients by up to 50%. These approaches are currently being tested by the NHS.

Speaking at a Guardian conference 'Managing new realities - integrating the care landscape' in Birmingham, Mr Reid said:

"The whole point of an effective health system must be to reduce the numbers of people who have to go to hospital. Acute care will not solve the pain and distress of those 17.5 million people. Older people and those with long term chronic disease suffer particularly where services are fragmented.

"Chronic disease has a huge impact on people's quality of life and on their families, and it consumes a large proportion of health and social care resources. There is a lot happening already, both nationally and locally to introduce better chronic disease management. But this needs to spread. That is why we are launching a programme to establish case management demonstrator sites within each Strategic Health Authority, building on PCTs' existing experience of developing and implementing these approaches.

"The demonstrator sites will introduce active management of high risk patients. They will provide co-ordinated patient centred care within a whole systems approach to keep patients with the greatest burden of illness healthy for longer."

The sites, which are now being selected, will:

- maintain health and promote well-being;
- detect early changes in condition and prevent unnecessary admissions;
- when admissions do occur, facilitate safe, early discharge;
- have access to advice and support on applying and developing tools and techniques to extract and analyse data that will enable them to identify their target populations.

DIARY DATES

PAA Conference 2004

11th September
Woburn Safari Park
Bedfordshire
9.00am 4.30pm