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

Choice

When Julie and I founded the PAA, we had a number of aims and objectives; the main aim was to learn more about psoriatic arthritis and its relationship to psoriasis. This aim was a selfish act on our part as we had been through a tunnel of despair after my correct diagnosis some two years earlier. Although, I had problems with my skin since I was fifteen and pains in my joints since I was about twenty, a connection between the two symptoms was never made until I was well into my thirties.

At the lowest point of despair my joints were the over-riding issue that we faced, pain and fatigue dominated my daily life, affecting our life style and the way we lived. The psoriasis was an added irritation in the continuing struggle to get some answers to the mysteries that cursed us.

We had a choice, give in or fight back, I chose to give in, Julie chose to fight back. The PAA became a vehicle in which Julie could fight back at the frustration that she felt was destroying us, Why David? Why us? Why now?

Suffice to say, I was dragged into taking part in the 'campaign'. Who better to question the solutions, than someone with the condition, an idiot who asked all the wrong obvious questions? The cause gave us the opportunity to detach ourselves from the problem that we faced, we could deflect our anger towards developing solutions to the questions we asked, but didn't receive answers.

I had a choice; I made my choice – which was the easy option just give in to the over-riding forces. But sometimes in life the choices we make are selfish and not thought through, I was lucky that Julie also made a choice she chose to do what she could to help me, and ultimately help others. An unselfish act borne out of love and devotion and belief that there is an answer out there and if there isn't, provide it!

So my gratitude to Julie is beyond anything I can possibly say or write. The experience of the past ten years or so has shown me that given application, dedication and support a way forward can be achieved, sometimes we have to accept less in life than we deserve, we have to push ourselves beyond what we feel is our role.

To me the role of choice is clear, we all should have the right to make choices in life, but whatever we chose we must be fully aware of the impact and take responsibility of our actions, we can only do this if we have access to the information that is correct and unbiased, we believe that the PAA has helped to develop the process which ultimately is informed choice. I was lucky; choice gave me a second chance.

Everyone has choice; available treatment options should be based on appropriate individual need and lifestyle and not on cost, heavy promotional activity or quick fix 'cures'.

David Chandler

Cover picture: Julie Chandler - "Barnacles" Cornwall

Voluntary Worldwide Withdrawal of VIOXX® (rofecoxib)

Merck &. Co Inc, announced at the end of September 2004 a voluntary worldwide withdrawal of VIOXX® (rofecoxib), its arthritis and acute pain medication. The company's decision, which is effective immediately, is based on new, three-year data from a prospective, randomized, placebo-controlled clinical trial, the APPROVe (Adenomatous Polyp Prevention on VIOXX) trial.

The trial, which is being stopped, was designed to evaluate the efficacy of VIOXX 25 mg in preventing recurrence of colorectal polyps in patients with a history of colorectal adenomas. In this study, there was an increased relative risk for confirmed cardiovascular events, such as heart attack and stroke, beginning after 18 months of treatment in the patients taking VIOXX compared to those taking placebo. The results for the first 18 months of the APPROVe study did not show any increased risk of confirmed cardiovascular events on VIOXX, and in this respect, are similar to the results of two placebo-controlled studies described in the current U.S. labeling for VIOXX.

“We are taking this action because we believe it best serves the interests of patients,” said Raymond V. Gilmartin, chairman, president and chief executive officer of Merck. “Although we believe it would have been possible to continue to market VIOXX with labeling that would incorporate these new data, given the availability of alternative therapies, and the questions raised by the data, we concluded that a voluntary withdrawal is the responsible course to take.”

APPROVe was a multi-center, randomized, placebo-controlled, double-blind study to determine the effect of 156 weeks (three years) of treatment with VIOXX on the recurrence of neoplastic polyps of the large bowel in patients with a history of colorectal adenoma. The trial enrolled 2,600 patients and compared VIOXX 25 mg to placebo. The trial began enrollment in 2000.

Results of the VIGOR (VIOXX Gastrointestinal Outcomes Research) study, released in March 2000, demonstrated that the risk of gastrointestinal toxicity with VIOXX was less than with naproxen, but indicated an increased risk of cardiovascular events versus naproxen. However, in other studies including Merck's Phase III studies that were the basis of regulatory approval of the product, there was not an increased risk of cardiovascular events with VIOXX compared with placebo or VIOXX compared with other non-naproxen non-steroidal anti-inflammatory drugs (NSAIDs). Merck began long-term randomized clinical trials to provide an even more comprehensive picture of the cardiovascular safety profile of VIOXX.

“Merck has always believed that prospective, randomized, controlled clinical trials are the best way to evaluate the safety of medicines. APPROVe is precisely this type of study - and it has provided us with new data on the cardiovascular profile of VIOXX,” said Peter S. Kim, Ph.D., president of Merck Research Laboratories. “While the cause of these results is uncertain at this time, they suggest an increased risk of confirmed cardiovascular events beginning after 18 months of continuous therapy. While we recognize that VIOXX benefited many patients, we believe this action is appropriate.”

The results of clinical studies with one molecule in a given class are not necessarily applicable to others in the class. Therefore, the clinical significance of the APPROVe trial, if any, for the long-term use of other drugs in this class, consisting of COX-2 specific inhibitors and NSAIDs, is unknown. The company will work with regulatory authorities in the 47 countries where ARCOXIA is approved to assess whether changes to the prescribing information for this class of drugs, including ARCOXIA, are warranted.

Ensuring the safety of patients using oral methotrexate

NHS

What is oral methotrexate?
Oral methotrexate is a medicine given to patients who have moderate or severe rheumatoid arthritis - this includes patients suffering from juvenile arthritis and patients with severe uncontrolled psoriasis which hasn't responded to normal treatment. 'Oral' simply means that it is taken via the mouth. 50,000 prescriptions for oral methotrexate are issued in the NHS each year.
Note: In some cases the medicine is also prescribed to patients for leukaemia by a hospital oncology unit. This summary does not apply to these patients as they are closely monitored by hospital staff, and will receive different doses of the medicine.

What is the safety risk to patients who take oral methotrexate?
Oral methotrexate is taken by patients in their own home and is normally safe as long as it is used properly. Proper use means that the medicine is only taken weekly, that the patient fully understands how and when it should be taken and that they regularly receive check-ups to make sure that the medicine is working correctly.
The National Patient Safety Agency (NPSA) has found, however, that serious problems can occur if the proper treatment routine is not followed. Over a ten year period in England 25 patients died, with a further 26 suffering serious harm, because the medicine had either not been used or monitored properly.

How do mistakes happen?
The most common mistakes in the medicine's use are: that the patient does not understand the correct dosage, perhaps because of lost or unclear instructions; that the medicine is accidentally taken more frequently because it has been confused with other medication; that the patient is not fully aware of the warning signs associated with the medicine not working properly; that the wrong dose is given because of unclear packaging; and that confusion exists between healthcare providers as to who is responsible for the monitoring of patients.

What is the National Patient Safety Agency doing to solve the problem?
Although serious harm and death is extremely rare in the use of oral methotrexate, the NPSA is working to ensure that patients receive the highest quality and safest possible care. The NPSA is:

- Sending a patient safety alert to all medical directors in England and Wales highlighting the problems with oral methotrexate and advising on how they can act to ensure that the safety of patients is protected.
- Working with the pharmaceutical industry to develop safer, patient-friendly packaging. Pfizer and Mayne Pharma have already changed the shape of the 10mg tablet to distinguish it from the 2.5mg tablet.
- Promoting guidelines and recommended content for patient information about oral methotrexate.

What should I do if I am concerned about taking oral methotrexate?
You should immediately seek medical advice from your pharmacist, GP or hospital doctor - but it is important that you do not stop taking the medicine before doing so.

More information
The full patient safety alert and patient information guidelines are available from the NPSA website at: www.npsa.nhs.uk/advice

The National Patient Safety Agency (NPSA) was established in July 2001 to improve the safety of NHS patients by promoting a culture of reporting and learning from patient safety problems. This briefing was issued on 29 July 2004

Life without psoriasis

Lifelong psoriasis for writer **John Updike** has changed his life (not surprising to those who have psoriasis) in a recent interview in the Washington Post Updike said "I might have drifted into some ordinary job but for the psoriasis," he says. He wrote about his chronic condition, in an essay titled: "At War With My Skin."He included the essay, in his memoir "Self-Consciousness."

The skin problem made his commitment to writing "more fierce," he says, because he needed as much time as possible to sit on the beach and let the sun burn the itching away.
Updike seems easy in his skin this day. He plays a little golf, and he has served as a marshal at a Ryder Cup match and the U.S. Open.

Over the years, Updike's brain has undergone a strange shift. Through constant fictional confession and the blurring of fact and myth, many of his memories have been supplanted by his memoirs. He recalls one particular trip he made to New York when he was young. His recollection is more of the story he wrote about the visit than of the visit itself. "Having written the story," he says, "totally displaces what really happened that day." If the unexamined life is not worth living, what can you say of the over-examined life? That it's worth sharing?

HANDLING PSORIASIS

There are various treatment options for people with psoriasis. These range from simple topical treatments to oral drugs with toxic side effects. But for the treatment to work, the patient has to take it and that doesn't always happen.
A new survey undertaken by researchers at The General Infirmary, Leeds, reveals that there are many reasons why patients do not stick to treatment regimes for psoriasis.

Drinking alcohol, being "fed up," forgetfulness, and being too busy were the major reasons for missing treatment.

The study involved 201 patients, average medication compliance was about 60 percent. Women, married people, employed individuals, and those who did not pay for their medication had significantly higher medication adherence rates than other patients. Medication adherence was also greater for those taking topical or combined therapy, once-daily treatment, and first-time treatment. Patients with facial disease and with more extensive disease had lower medication adherence. In addition, the perception of treatment failure also affected patient compliance.

The range of psychological, social and disease-related issues that may influence a patient's compliance with treatment can be attributed to the nature of the disease itself. Authors of the study write, "The effect of psoriasis on a patient is multidimensional, including the physical, social and psychological health of the person, and is based largely on the patient's view of his or her condition."
Psoriasis can produces significant illness and can significantly affect a person's quality of life.

SOURCE: The Archives of Dermatology, 2004;139:408-41

Vein projector guides injections

A device that projects an enhanced image of the underlying veins onto the skin could avoid botched injection attempts, scientists believe.

The gadget uses a near-infrared camera to capture a real-time video image of the patient's veins.

A projector then beams this image back onto the patient's skin to show the exact location of the veins, making them easier for medics to locate.

The University of Tennessee invention is described in New Scientist.

ONE JAB

Dr Herbert Zeman, the biomedical engineer who invented the vein contrast enhancer (VCE) device, said it could detect veins up to 8mm below the surface of the skin and map them out within 0.06mm of their correct position.

It does this thanks to near-infrared technology. The light beams sent out illuminate the skin at a wavelength of 740 nanometers. This wavelength of light is strongly absorbed by blood, and hence the veins, but is scattered by the surrounding tissue.

Dr Zeman explained: "Fat and tissue look light, veins and blood look dark." This image is fed to a PC that maps it onto a bright green background in real time.

After boosting the contrast between the tissues and the veins, the PC sends this image to a projector which beams it onto the skin in green.

This should help the person trying to pinpoint a suitable vein for an injection or drip, Dr Zeman hopes.

EMERGENCY CARE

It may be particularly useful for children, who have small veins and puppy fat that can make it hard to find a vein.

Three prototypes of the VCE device, which fit into a package the size of a shoebox, will be trialled at a hospital in Tennessee later this year.

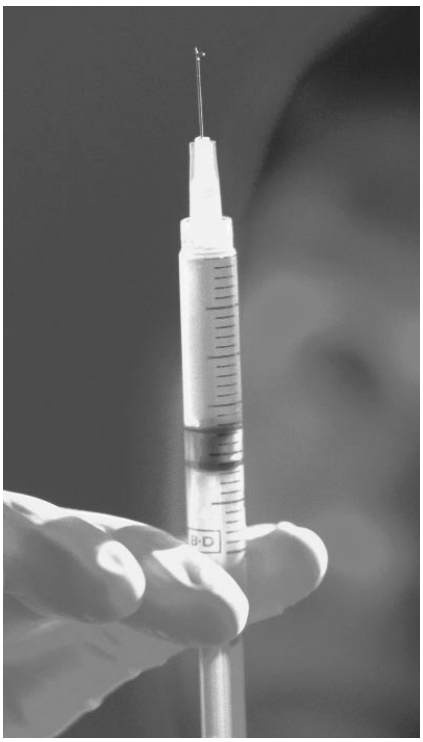
Jackie Haugh, president of the National Association of Phlebotomists, said: "If it worked, it would be an asset for every patient.

"It can be hard to find a vein in the elderly, people who are obese and especially children.

"For the six-month-old puppy fat babies, locating a vein through palpation is almost impossible."

She said it would be particularly useful for emergency situations when doctors need to find a vein to give drugs and fluid rapidly.

"When ill people are dehydrated or in shock it can be really hard to find a vein. For cannulation it would be an extra asset."



Adalimumab Improved Symptoms of Psoriatic Arthritis

Preliminary data from two studies showing encouraging results in treating psoriatic arthritis and ankylosing spondylitis with adalimumab (brand name HUMIRA) 40 mg every other week were presented at the European League Against Rheumatism (EULAR) annual congress in Berlin early this year.

Patients with psoriatic arthritis responded to adalimumab treatment as early as two weeks after the initial dose showing significant improvement in both the signs and symptoms of the joint disease and skin manifestations with continued improvements at 12 weeks. Analysis of a separate 12-week study shows that adalimumab significantly improves spinal symptoms in patients with active ankylosing spondylitis after only one dose.

"The findings of these two studies are significant because they validate our research to assess adalimumab's potential to treat other autoimmune diseases in addition to rheumatoid arthritis," said James B. Lefkowith, M.D., divisional vice president, development, Abbott Immunology.

Adalimumab provided joint and skin improvement in psoriatic arthritis. Fifteen patients with active psoriatic arthritis were treated with adalimumab 40 mg every other week, in this open-label trial, and observed over a 12-week period to evaluate the potential therapeutic effects of the treatment. After two weeks, significant improvements were seen in the signs and symptoms of the joint disease and skin manifestations associated with disease. Further improvements in the skin and joint disease were evident at 12 weeks. Forty-two percent of patients treated with adalimumab experienced an ACR 20 response after only one dose. ACR (American College of Rheumatology) 20, 50 and 70 criteria represent percent improvement in tender and swollen joint counts and other relevant clinical measures. Also after two weeks, 77 percent of patients experienced at least 25 percent improvement in health-related quality of life as measured by the Health Assessment Questionnaire (HAQ) disability index, which is designed to capture patients' assessment of activities of daily living such as grooming, dressing and walking. Health-related quality of life questionnaires are used to measure the impact of chronic illness on a patient's life.

Further improvement was seen at 12 weeks in both the arthritic symptoms and in health-related quality of life. Sixty-six percent of patients achieved an ACR 20 response and approximately 30 percent attained ACR 50. The HAQ disability index also showed further improvement at week 12 compared to week two. Substantial improvements also were evident in the skin disease of these patients. Target lesion scores, an evaluation of the severity of a single psoriasis lesion, improved by nearly 30 percent after one dose. After 12 weeks, the target lesion score improved by more than 70 percent.

"The initial results and analysis of this study show that HUMIRA provided significant benefit to many patients with psoriatic arthritis shortly after the first dose," said Christopher T. Ritchlin, M.D., associate professor and lead investigator, University of Rochester, Rochester, New York. "While more research is necessary, these early findings are promising and support HUMIRA's potential as a treatment for psoriatic arthritis."

COMPLEMENTARY MEDICINE ON NHS

Patients could be offered complementary medicine such as acupuncture and homeopathy on the NHS under plans being considered by the Welsh Assembly Government.
The proposals have been put forward by Welsh Secretary Peter Hain, who says he has the support of both the Prime Minister and the Prince of Wales.

Mr Hain said he wants to see Wales act as a model for the UK for further development on complementary medicine.
Health Minister Jane Hutt is now considering a pilot scheme.
Around one in five adults in the UK are estimated to have used some form of complementary medicine.
Under Mr Hain's proposals, Welsh GPs may be able to refer their NHS patients to dieticians and reflexologists. Mr Hain, who uses complementary medicine himself, claims his son's asthma went after he was given advice about his diet. Cardiff GP Dr Andrew Dearden, who is the Chair of the BMA's Welsh GPs' committee, said it sounded like a good idea. "I suspect we would need a list of conditions that could be treated, and a list of people who have contracts with the NHS, so the NHS can ensure they are properly trained," he said. "I would have some difficulty prescribing a tablet or medicine I had no training with.
"I think the referral to a practising practitioner would be the way forward."

Talks are under way between the assembly government, the Department of Health and the Prince of Wales Foundation. A guide for Welsh patients on complementary treatments is also under development.

WOUND HEALERS CAUSE SKIN DISEASE

Dutch researcher Manon Franssen has shown that cells which heal the skin following an injury play an important role in the development of the skin disease psoriasis. In people with psoriasis, the skin peels much faster than normal so that it flakes and becomes inflamed.

Franssen investigated the transit amplifying cells in the uppermost layer of the skin. These cells develop from stem cells (general unspecialised cells) and specialise into skin cells when new skin cells are needed. The transit amplifying cells are involved in the healing of the skin following an injury and in the regular renewing of the skin.

Normally these cells wait until they receive a signal to develop into skin cells. Franssen discovered that in people with psoriasis, some of the transit amplifying cells divide without waiting for a signal. As a result of this, too many skin cells develop and the skin is renewed more quickly than normal. However, when Franssen cultured the transit amplifying cells from the skin of psoriasis patients, these cells grew less quickly. Exactly how the cell division of transit amplifying cells and stem cells is regulated, is not yet clear.

In the case of psoriasis, not only is there a more rapid renewal of the skin, but the number of cell layers on the surface also increases. The skin condition causes red marks that are rich in blood and often inflamed. These red marks are covered with shiny white flakes of skin and sometimes itch. Psoriasis is not infectious.

A cure for the disease is still not available and at present only the symptoms can be controlled. According to the Dutch Psoriasis Society about 300,000 people in the Netherlands suffer from a form of this disease. Stem cell therapy might be able to provide a cure for them in the future.

Stem cells currently form an important research area in medicine. Stem cell therapy – the replacement of defective or absent stem cells, tissues or organs in patients – should be able to cure many diseases in the future.

Stem cells from the uppermost layer of the skin have never been isolated. The isolation of their descendants, the transit amplifying cells, is an important step in the right direction. By culturing these cells from patients, complete pieces of skin can be reproduced. These are extremely useful in the treatment of burns, bedsores or skin cancer. The culturing of 'diseased' skin offers the possibility of thoroughly studying diseases and testing new treatments.

The research was funded by the Netherlands Organisation for Scientific Research

By Catherine Smith, Jonathan Barker and Alan Menter
ISBN 1-899541-98-5
www.fastfactsbooks.com
64 pages

"Correct diagnosis and treatment of psoriasis can be problematic – this book provides a thorough, practical account of the clinical presentations, differential diagnosis and range of modern therapies. It can be an essential resource for anyone who manages psoriasis patients in the primary care setting"
Authors

Chapters include:-

Epidemiology/pathophysiology
Clinical presentation
Differential Diagnosis
Topical Therapy
Phototherapy
Systemic Therapy
Future Trends

Please note this book was designed originally for clinicians and health professionals.

SPECIAL OFFER

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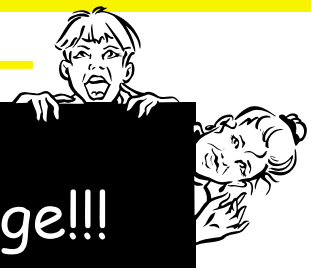
Check Publications List page 17

PAA Kids



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

DID YOU KNOW FACTS ABOUT YOUR SKIN?

Our skin is probably the most taken for granted organ on our bodies – it takes a huge battering from the weather, environmental factors such as central heating, air conditioning, pollution, all modern day factors.

- Did you know that the skin of an average adult covers 2sq.m.
- Your skin controls body temperature, keeping you warm, or cold.
- Your skin acts as a waterproof for your body.
- It protects you from the sun's harmful ultra-violet rays.
- Your skin contains nerve endings, that enables you to touch and feel.
- Your skin builds up essential Vitamin D, helping your bones to grow stronger.
- Your skin stores fat.
- It absorbs oxygen and releases carbon dioxide.
- Everyone's foot and handprints are unique to them, nobody will ever have the same patterns or grooves.
- Your skin breathes through tiny openings called "pores".
- Hairs grow all over your body except on the soles of your feet!
- Did you realize that the skin on your elbows is loose and wrinkly, allowing them to bend, but the skin on your feet is tight to stop you slipping around!
- Did you know that your skin varies in thickness around your body? The average skin on your body measures approx 1.5mm thick, your eyelids about 0.5mm thick and the skin on the soles of our feet may be up to 6mm thick!
- Your skin is divided in to three layers; the epidermis, the dermis, and a fatty layer called the hypodermis.

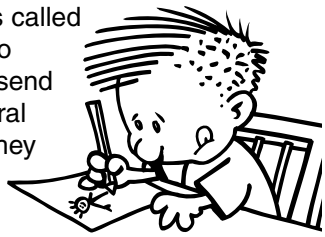
The Epidermis:-

- This is the top layer of your skin that you can see. It protects the inside of your body from infections, it's waterproof and stops your body from drying out.
- The top layer of the epidermis is made up of dry flat dead cells, which are constantly being rubbed off yourself, or clothes next to your skin.
- Most house dust is made up of dead skin cells!
- Your epidermis is constantly working to produce new cells to make new skin.
- It is contains the pigment that colours our skin.

The Dermis and the Hypodermis:-

The Dermis lies below the Epidermis. And this is what gives your skin its stretchiness, because it is made up of elastic fibres, helping your skin to expand and contact.

Your Dermis contains loads of blood vessels, keeping your skin fed with food and oxygen. The dermis also has loads of nerve endings called "receptors" that allow you to feel. These nerve endings send the messages to your central nervous system because they are sensitive to pain, hot and cold.



Under the dermis you have the third layer, called the Hypodermis, which contains fat, helping you to keep warm. The hypodermis stores the energy you need, and also connects your skin to your bones and your muscles!

Did you know that the dermis contains hair follicles that produce the hairs on your skin, but that they all have tiny muscles that can make them stand or lie flat.

Do you know why sometimes when you sweat, it tastes salty? This is because the sebaceous glands producing the oil that keeps your skin supple, produces a salty sweat to cool down the surface of your skin.

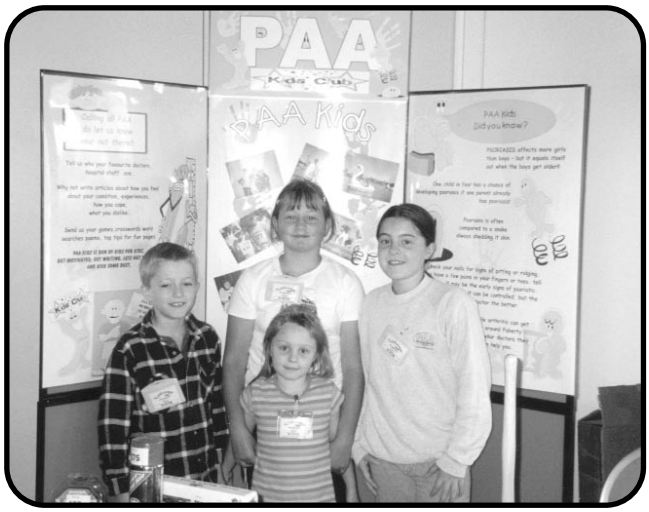
Skin 'n' Bones Connection

PAA Kids

THE SUN AND YOUR SKIN?

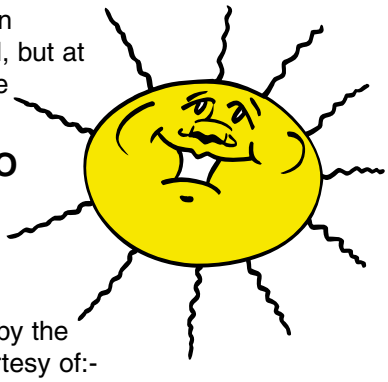
The sun is good for all of us BUT in moderation and with proper preventative measures to protect us, such as sun creams and moisturizers.

In our skin, we have what is called a substance known as melanin, which again protects our skin and gives it it's colour. How much melanin we have depends on our skin colour – if you are fair you have a small amount or if you are dark in colour you will probably have a lot. The more melanin you have in your body the more suntan you will develop!



PAA Kids team at Woburn 2004

The sunshine helps our skin and body develop Vitamin D for us which is good – but without proper moderation and prevention in the sun can be dangerous, causing skin cancers – so be careful, but at the same time enjoy the sunshine.

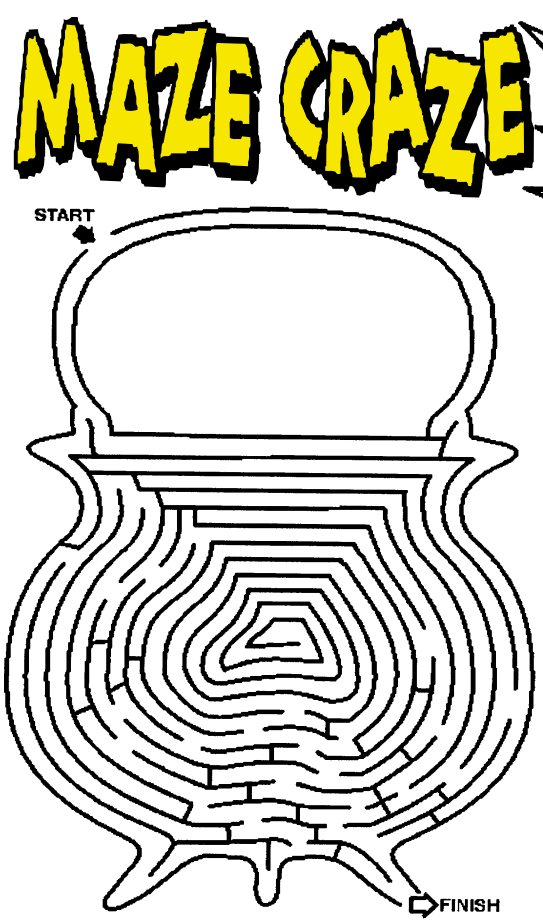


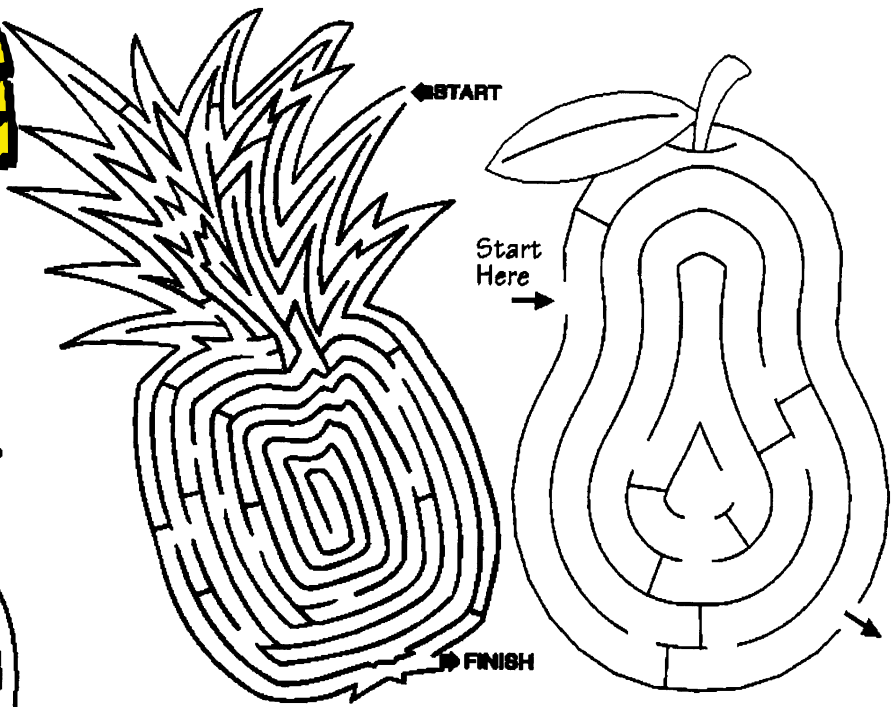
THERE'S MORE TO YOUR SKIN THAN YOU FIRST THOUGHT!!!

Sourced and abridged by the PAA for PAA KIDS courtesy of:-

How My Body Works: The Skin
An Orbis Play and Learn Collection

MAZE CRAZE





REMEMBER
We want you input, case histories, puzzles, jokes, fundraising ideas, help us to help you get motivated, lets get PAA Kids rolling in 2005 and beyond.

Efalizumab
recommended for approval by the European Medicines Agency (EMEA)

The first in a new class of biological treatments for psoriasis has been recommended for approval by the European Medicines Agency (EMEA). Efalizumab is self administered treatment indicated for psoriasis via once a week injection. Trials for the use of efalizumab in psoriatic arthritis were stopped earlier this year because of lack of efficacy.

Efalizumab is not the only biological therapy on or near the market, at least in the US. There, alefacept, another T cell-targetting therapy that acts by destroying the lymphocytes associated with the disease.

Meanwhile, etanercept was also recommended for approval in psoriasis earlier this year, and is on course to be the first anti-TNF drug cleared for this indication. Alefacept was turned down by the EMEA last year, despite being cleared in the US. The agency is demanding head-to-head trials with approved therapies - such as cyclosporine, methotrexate or oral retinoids – before it will back the drug.

Biologicals have emerged as alternatives to systemic therapy that offer not only much more convenient treatment – a single weekly injection in the case of Efalizumab – but also improved efficacy and fewer side effects.

Competitive position

But despite its promise, efalizumab and other biologicals cannot help every patient. For example, around 25 per cent of patients in the CLEAR study had no response at all to efalizumab, and manufacturer Serono now has a pharmacogenetic programme ongoing trying to determine the genetic profile of responders versus non-responders.

It is estimated that at least six genes are involved in the disease, with the disease occurring once a patient is immunologically primed and a trigger event – such as an infection – takes place. Once it emerges, patients have psoriasis for life.

Looking further back in the pipeline, Serono is continuing to conduct basic research in psoriasis, and one focus is on the use of agents that bind DNA and switch off the disease.

Finally, there is the difficult issue of cost. In the US, efalizumab is priced at around $14,000 a year, so its use is likely to be reserved for those patients whose lives are significantly and severely impacted by the disease. A study published last year by Steven Feldman, a professor of dermatology at Wake Forest University School of Medicine, found that methotrexate costs about $1,600 a year and phototherapy from $3,600 to $4,600, with cyclosporine coming in a little higher. In contrast, biologics range from $16,000 to $33,000 a year.

This has been reflected in the sales of the drug in the US. At one point tipped as a potential billion dollar drug, analysts have scaled back their expectations to the $300-$500 million range, at least in the short-term, as they believe it is likely to be used after the more established therapies. This pattern is likely to be the same for all biologics.

Efalizumab has seen somewhat slow take-up in the US – expected as doctors get accustomed to using the new drug - but it still brought in revenues of just under $20 million in the first half of the year in the US alone.

How does it work?
Efalizumab works by blocking the activation of certain immune cells, called "T cells," and the migration of those cells into the skin. T cells are a type of white blood cell in the body that normally help us ward off foreign invaders and fight infection. In psoriasis, however, these T cells are mistakenly activated and there are too many of them in the skin. This triggers other immune responses that fuel the development of psoriasis lesions. By blocking T-cell activation and the movement of these cells into the skin, efalizumab interrupts the cycle of psoriasis, this can lead to improvement in signs and symptoms. In clinical trials efalizumab has not shown any significant improvement in psoriatic arthritis

Who can get it?
It is prescribed for adults with moderate to severe plaque psoriasis. The exclusions are people taking vaccines or with active serious infections. Caution is advised for the elderly, due to the already increased risk of infection for this age group. There is no data regarding use in pregnant woman or nursing mothers. Doctors will make a decision on clinical need. It is not licensed for use in children.

How is it used?
Patients take efalizumab at home once per week by giving themselves an injection under the skin, similar to diabetes patients who give themselves insulin injections. Dosing is determined by body weight; a smaller dose is given for the first injection to help the body become accustomed to the medication. The course of treatment will be determined by your doctor (usually 12 weeks).

What are the side effects?
The most frequent side effects reported in clinical studies were:

- headache
- infections (usually upper respiratory infections)
- chills
- nausea
- flu syndrome
- fever
- back pain
- acne

These events happened most often after the first dose of efalizumab and may decrease after additional doses. These side effects are generally mild and did not cause most patients to stop taking efalizumab.
Efalizumab does suppress the immune system, which means it has the potential to increase the risk of infection. The most serious side effects were very rare, but included psoriasis relapse, serious infections and thrombocytopenia (low platelet counts).

Patient assessment of platelet counts is recommended. It is unknown at this time whether long-term use of efalizumab will result in an increased chance of developing malignancies. All patients should be given detailed information before they start to use efalizumab.

How do I get efalizumab?
Efalizumab is only prescribed by hospital doctors (Dermatologist). Certain criteria will need to be met in order to qualify, this may include failure or lack of efficacy of other treatments or therapies. The cost of efalizumab may have an impact on how efalizumab is prescribed.

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

This information has been prepared by the Psoriatic Arthropathy Alliance and should not be used as a replacement for advice from your doctor.

Always consult your doctor.

Dear PAA,

For nearly eight years I suffered from severe psoriatic arthritis (PA) - from the age of 27 through to 35. During this time I had difficulty walking up a flight of stairs, couldn't squeeze a stapler hard enough to staple two sheets of paper, and was in pain and discomfort for much of the time despite ingesting large quantities of anti-inflamatories. This wasn't even the worst part - the biggest challenge I faced was a mental one. Having been a relatively active individual, my life changed when I started to develop PA and I had a very difficult time learning to adapt to the 'new' me that wasn't able to play squash, run for an hour on a soccer/football pitch or ski as I used to.

This mental anguish led to serious bouts of depression and anxiety. "Would I continue to deteriorate to the point where I couldn't walk?" In the early days my response was to fight back - ride a bike for an hour, go to the gym, etc. Of course, this probably did more harm than good, but it helped me deal with the mental/emotional side of the disease that we hear far too little about.

After this long introduction, I'm very happy to say that I have found my own personal cure for PA and I've been virtually arthritis free for three years now! For me the cure was so simple it is embarassing to even admit to! It has to do with dairy products - which I have completely removed from my diet.

My road to recovery started in a very innocent way - a pledge to purge myself of a Cafe Latte addiction! Yes, I can blame Starbucks for contributing to my disease - along with the dairy industry in general. It seems, that at least in my case, I had developed some sort of allergy to dairy products which was causing scar tissue to form in my joints thereby resulting in my arthritis.

Since dropping all dairy products I have not only solved my arthritis, I have lost almost 30 pounds and have been able to get back into shape. Perhaps because of the suffering I experienced, the 'new, new' me is now much more active than I was before coming down with this disease. I ran my first ever marathon this past Spring and have taken up triathlons with a vengeance. In fact, next year I hope to compete in my first Ironman race.

As I've never met anyone with PA before, I thought I might be able to pass my story along to some of your readers/subscribers in the hope that, on a rare chance, someone might have the same cause of their infliction that I had.

Yours truly,

Ian Smith
(Hong Kong)

Dear PAA

About four years ago you published my story about how I coped with psoriasis from a very early age and the onset of arthritis connected with it later in life.

I have been using Herbalife nutritional supplements and skin care products over the last two years with amazing results. As I know these products CAN be effective in helping people with the same problems as myself I would like to know if it is possible to either advertise the products by means of a written article by myself or provide a link such as the alternative therapy link you show at present.

My website is www.healthybodyandmind.com for further information.

My own doctor is quite happy with me taking the products and the company itself has many people in the medical profession also associated with the products.

I look forward to your reply.

Yours sincerely

Monica Mottram

Psoriatic Care FACT FILE

A UNIQUE RESOURCE FOR PSORIATIC PATIENTS IS HERE

A completely updated and extended second edition of this popular fact file. It provides instant access to 32 information sheets and additional material written in a simple easy to read style.

This is a book which can act as an essential and practical guide for those with psoriasis, by offering comprehensive useful advice along with contact information for other useful organisations.

Topics include:

PSORIASIS

- *What is Psoriasis?*
- *Psoriasis & the Young Adult*
- *Genital Psoriasis*
- *Importance of Patient Compliance & Treatments*
- *Benefits; signposting leaflet*

PSORIATIC ARTHRITIS

- *What is Psoriatic Arthritis?*
- *Psoriatic Arthritis & Exercise*
- *Psoriatic Arthritis & the Neck*
- *Psoriatic Arthritis & Fatigue*
- *Psoriatic Arthritis & Pregnancy*

The Fact File is also available on a multi-media CD-ROM in a format that is easy to understand, instant access and easy to print out covering BOTH PSORIASIS and PSORIATIC ARTHROPATHY all on one CD.

FACT FILE: ISBN: 0-9547465-0-3
48 pages + illustrations £ 9.50

CD-ROM: ISBN: 0-9547465-1-1
Card slip cover £ 9.50

2nd Edition

BLUE LAGOON

New BLUE LAGOON - Dermatology Clinic, which will open in spring 2005, has already received a significant attention from local and international psoriasis patients.

The increased interest can be contributed to a greater demand for psoriasis treatment without side effects. BLUE LAGOON - Dermatology Clinic is one of the few places worldwide offering that option.

The clinic will soon be equipped with a photo studio that allows us to attain better before and after pictures of treatment guests.

The pictures are important tool in confirming treatment results. This also allows our guests to provide their dermatologists with pictures that will help them evaluate the treatment.

Priority Medicines Project

International Alliance of Patients' Organizations

A global voice for patients

The International Alliance of Patients' Organizations (IAPO) has urged the Dutch Government, in its Presidency of the European Union, to act upon its commitment to involve patients in research prioritization and to install concrete mechanisms for comprehensive patient involvement. In addition, IAPO challenges Luxembourg and the United Kingdom, in their role taking the Presidency in 2005, to ensure that these mechanisms are implemented and adhered to.

This request is made in response to the outcomes of a meeting in The Hague recently where the Dutch Government presented an agenda for the research and development of medicines, vaccines and biologicals. We congratulate the Dutch Government for focusing attention on this issue because, at present, too many patients do not have access to safe and effective medications to treat their conditions. It was important to see patients' organizations at this event along with industry, governmental and health professional representatives. However, while industry and academic research and governmental viewpoints were represented during presentations and a panel discussion, the patients' view was conspicuously absent, relegated to the short questions and answers session. Considering that there was an overwhelming consensus that patients must be involved in all discussions of research priorities and the innovation process – not just at the end but from the very beginning – we call on all stakeholders to make this a reality.

The recommendations presented during the Conference are from the Priority Medicines for Europe and the World Report, investigated by the World Health Organization. IAPO welcomes the report as an important step forward in attempting to address the medication needs of people around the world. The report's value lies in outlining a method of prioritization to address the gaps in the development of pharmaceuticals, for example for neglected diseases. Its focus on developing countries recognized the important responsibility of the European Union to the rest of the world. Its public health perspective provides a useful method to attain the greatest help to the greatest number of people. However, it is essential that a method for prioritization is developed which does not neglect those with rare diseases. Rare diseases, as their name suggests, only affect a small number of people and they are therefore not addressed by a public health perspective or by an industry that needs to develop products for a large enough potential market to offset the enormous cost of pharmaceutical development.

The Conference garnered momentum to discussion of how to improve research prioritization and the pharmaceutical innovation process. This momentum must be harnessed and the recommendations developed to the benefit of patients, industry, research and governments. The subsequent developments of this initiative must ensure that the commitment made at the Conference yesterday is not forgotten. Patients with long term chronic conditions and the organizations that effectively represent them – patients' organizations – must be involved in every step of the process – not just in treatment guidelines but in all health policy including regulatory processes, because ultimately the decisions that will be made will affect patients' lives.

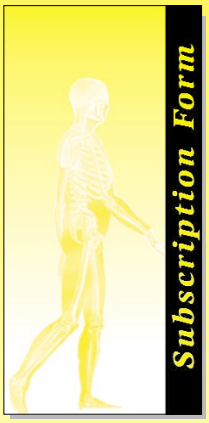
CHECK YOUR LOCALITY!

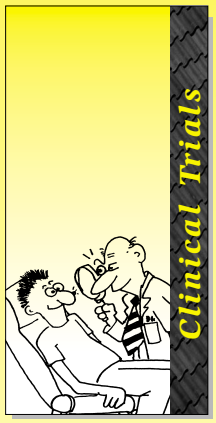
A new website, www.yourlevelbest.com lists pubs and restaurants with disabled facilities (including toilet)

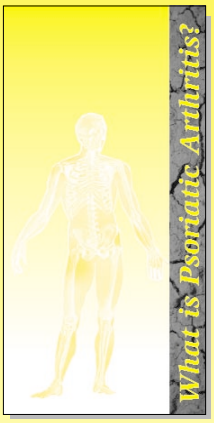
it is free to both user and the listee and has 4000 venues throughout the UK although the founder, wheelchair-user Mary Dixon wants more suggestions from local people like you. Phone 0208 355 4328, email info@yourlevelbest.com

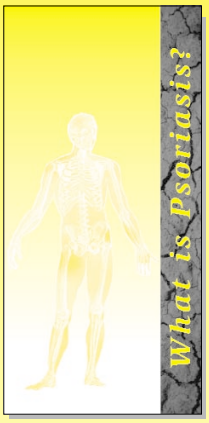
It is now possible to choose the most disabled-friendly areas in the UK.

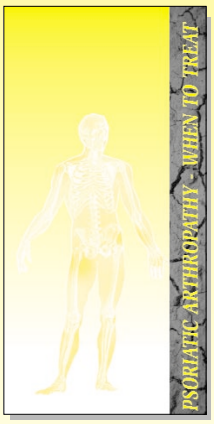
PUBLICATIONS

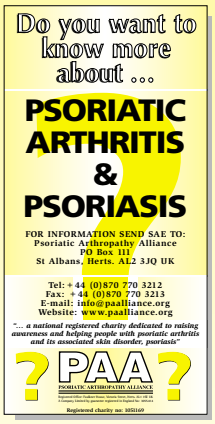


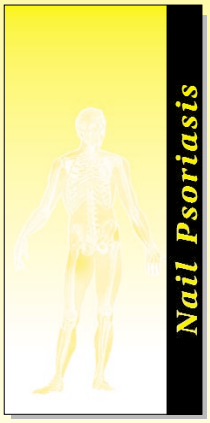


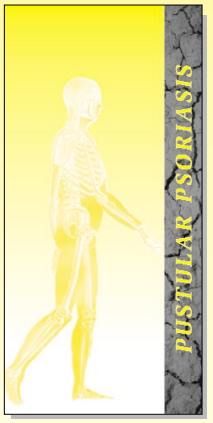


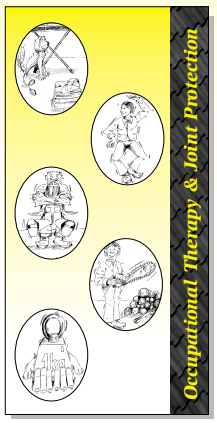


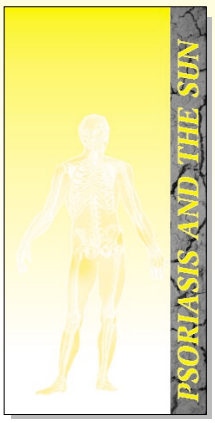


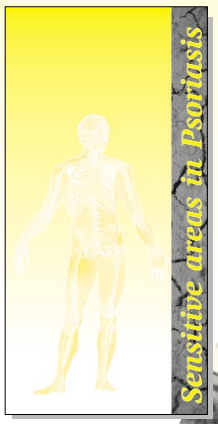


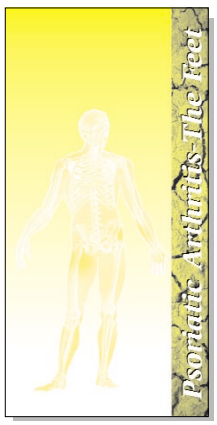


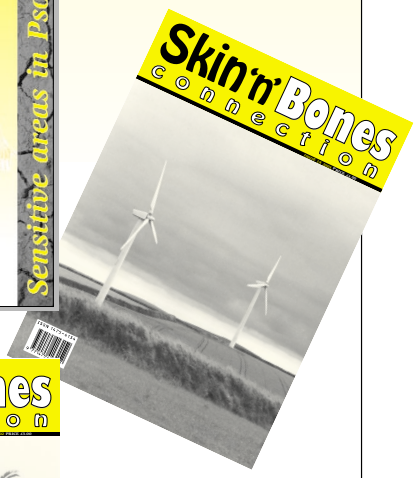












PAA Publications
order form

(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~~		
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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		
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Skin'n'Bones Connection	18	2003	£3.00		
Skin'n'Bones Connection	19	2004	£3.00		
Skin'n'Bones Connection	20	2004	£3.00		
What is Psoriasis? leaflet	-	2001	Free		
Occupational Therapy & Joint Protection	-	2003	Free		
Physiotherapy and Exercise Booklet	2nd edition	2003	Free		
What is Psoriatic Arthritis? leaflet	-	2002	Free		
Did you know? leaflet	-	2002	Free		
Psoriatic Arthropathy-When to treat, leaflet	-	2002	Free		
Pustular Psoriasis leaflet	-	2003	Free		
Sensitive Areas in Psoriasis leaflet	-	2003	Free		
Retinoids and Psoriasis leaflet	-	2003	Free		
Psoriasis and the Sun leaflet	-	2003	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- 32 fact sheets Book	2nd edition	2004	£9.50		
Psoriatic Care Fact File- 32 fact sheets CD-ROM	2nd edition	2004	£9.50		
Psoriasis - A Guide To Emollients leaflet	-	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	-	-	Free		
So You've Got Psoriasis booklet	-	-	£3.50		
Psoriasis Fast Facts	-	-	£4.50		

+ postage	**£ 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.

Skin'n'Bones Connection

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

ADVERTORIAL

Are You Changing Your Coal Tar Treatment?

As you may already know, Alphosyl® Lotion and Alphosyl® Cream (5% coal tar) has recently been discontinued by the manufacturers. However, there is another coal tar lotion available called Exorex® Lotion which you can change to. Below the manufacturers of Exorex address some common questions asked about changing to Exorex Lotion:

What exactly is Exorex Lotion?
Exorex Lotion contains just 1 % **prepared** coal tar (Alphosyl Lotion and Cream contained 5% coal tar). It is easy to apply, has a non-greasy formulation with no strong odour and is suitable for both children and adults. It also does not harm psoriasis-free skin if accidentally applied to those areas.

Alphosyl Lotion really worked for me - is Exorex Lotion as effective?
Interestingly a recent study which compared Exorex Lotion (1 % prepared coal tar) with Alphosyl (5% coal tar) showed that Exorex Lotion is more effective in the treatment of mild in mild to moderate plaque psoriasis'. Dr Mark Goodfield, Consultant Dermatologist at Leeds General Infirmary and principal investigator, said investigators and patients exhibited a preference for Exorex Lotion. Exorex Lotion was well-tolerated and produced fewer application-site reactions than conventional coal tar lotion."

Are there any other Exorex products other than Exorex Lotion that can help my psoriasis?
The Exorex Management System for psoriasis includes products to **WASH, TREAT** and **MOISTURISE** the skin. Exorex Lotion is the most important product in the range as this is the **"TREATMENT"** element, containing the active ingredient, 1% prepared coal tar.

Do I still need to moisturise my skin?
Yes. For maximum results and to allow the coal tar to absorb into the skin, Exorex Moisturising Cream is recommended after treatment with Exorex

Lotion. Similarly, Exorex Scalp Moisturiser has been formulated for use with

Exorex Lotion to help scalp psoriasis. It is recommended that after treatment with Exorex Lotion on the scalp, a non-irritant moisturiser such as Exorex Scalp Moisturiser is used.

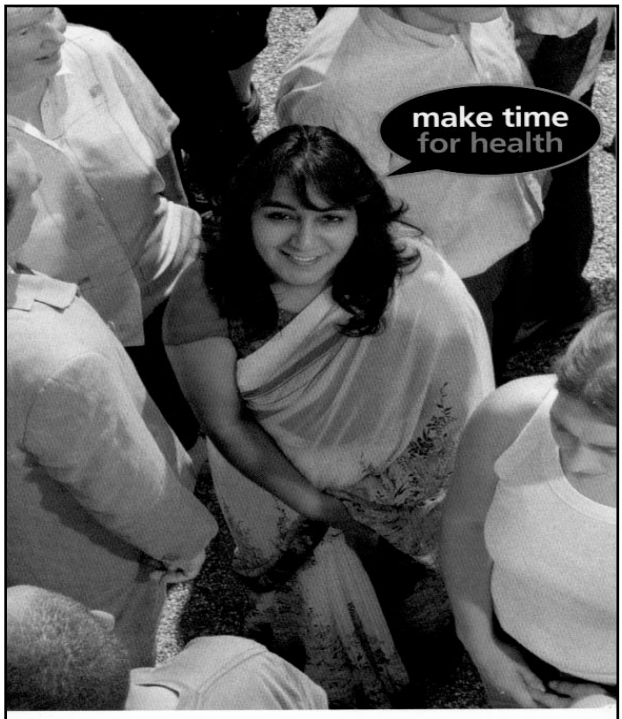
Exorex Moisturising Cream and Exorex Scalp Moisturiser are colourless and odourless once dry, and therefore can be used as often as necessary.

For further information visit www.exorex.co.uk

Reference

1. Double-blind, randomised, multicentre, parallel group study comparing a 1% coal tar preparation (Exorex) with a 5% coal tar preparation (Alphosyl) in chronic plaque psoriasis. Journal of Dermatological Treatment (2004) 14,1-9

Exorex Lotion Abbreviated Prescribing Information. Presentation: Lotion containing Prepared Coal Tar 1% w/w in an emollient base containing a complex of esterified essential fatty acids. **Indications:** Treatment of psoriasis of the skin and scalp. **Dosage:** Apply two or three times a day to affected areas as a thin layer. Massage gently and leave to dry. May be diluted with water for use in children under 12 years and the elderly. **Contra-indications:** Sensitivity to coal tar or any of the ingredients. Presence of folliculitis and acne vulgaris. Photosensitive conditions. Inflamed or broken skin. **Warnings and Precautions:** Discontinue use if irritation occurs. Avoid exposure to direct sunlight after application. Apply with caution to the face and use with care near eyes and mucous membranes. Do not apply to genital or rectal areas. Use with care in pregnancy and lactation. **Undesirable effects:** Skin irritation and photosensitivity may occur. **Legal Category:** GSL. **Basic NHS Cost and Packaging Quantities:** 100mi £8.65, 250mi £17.33. **Marketing Authorisation Number:** PL 0616610001. **Marketing Authorisation Holder:** Forest Tosara Ltd., Baldoyle Industrial Estate, Grange Road, Dublin 13, Ireland. Further information is available on request from Forest Laboratories UK Ltd, Bexley, Kent DA5 1 NX **Date of Preparation:** June 2004.



Be a voice for health

Commission for Patient and Public Involvement in Health

make time for health

Patient and Public Involvement (PPI) Forum members will be champions for health and make the views of patients and the public heard.

That's why we need people like you - people who know their communities and will give their time to make a real difference.

Can you help to bring better health to your community?

Please call **0845 120 7115** or visit **www.maketimeforhealth.org** for more information and an application pack.

Or write to
Make Time for Health
PO Box 11442
Birmingham
B2 4WP

General enquiries **0845 120 7111**

PPI Forum Membership Recruitment Line

0845 120 7115

Lines are open
8am to 10pm Monday to Friday
9am to 5pm Saturday and Sunday

Minicom 0845 120 7113

NHS
Information Authority

Now you only need to look in one place for your NHS services

www.nhs.uk

What is this website all about?

www.nhs.uk holds information about what the NHS has to offer and how you can get access to these services. This can help you make well-informed decisions.

As part of the Government's plan to deliver public services electronically by 2005, **www.nhs.uk** brings together and provides information about the NHS in a way that is useful to everyone.

If you need to find out more about NHS services, **www.nhs.uk** is the official NHS website that can help you.

www.nhs.uk provides free, basic information such as addresses, maps and contacts for NHS organisations in a layout that is clear and easy to understand.

This means that everyone, no matter where they live, can access the same information about NHS services in England.

DIARY DATES

PAA Conference 2005

17th September
Woburn Safari Park, Beds
9.00am 4.30pm