Skin'n' Bones connection

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PAA
PSORIATIC ARTHROPATHY ALLIANCE
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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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The Internet:

EDITORIAL

Useful resource or Commercial scam?

When browsing the Internet for the latest developments or news about psoriatic arthritis or psoriasis, it is often difficult to distinguish truth from hype. The latter is a "disease" of our age, for which there is of course no cure.

On a recent search there were nearly 500,000 results for psoriasis and 50,000 for psoriatic arthritis. For those of us who have the patience to look at the first few pages, it is obvious that an awful lot of this material is commercial in origin and sometimes potentially misleading.
There is also a worrying addition to the raft of sites, and this is the deliberate misspelling of words, which closely match genuine websites or diseases. The objective of this is to dupe the innocent vulnerable browser into visiting and using the services provided by these sites, usually for commercial gain.

The policing of the Internet is an increasing global problem and will ultimately be the responsibility of individuals who use the web. It would be a shame if such a useful resource is discredited by the aims of a small number of cynical scheming individuals.

UP-DATE : PAA OFFICE

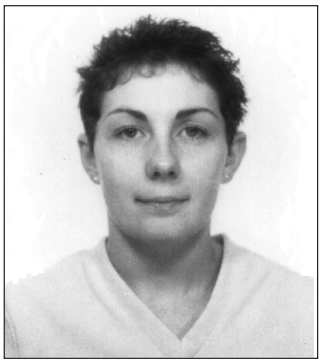
In recent years, as some of you may be aware, the PAA has struggled to keep its existing services maintained, which in some periods of time have suffered. This being said, the PAA would like to thank all of its long-standing members for sticking with us through the bad, lean times, and have continued to support us.

We are pleased to announce that we have been able to address some of the administration problems in the office, and, are now able to become a more streamlined, efficient organisation.

Please meet the team who are here to help you.

Susan

Caroline



Nichola

OFFICE HOURS
Monday 9.30 – 4.30
Tuesday 9.30 – 4.30
Wednesday 9.30 – 3.00
Thursday 9.30 – 3.00
Friday 9.30 – 12.30
Hours may vary during holiday seasons

Cover photo: Wind generators - Cornwall. David Chandler,

National Patient Safety Agency

NHS

New patient safety solutions to prevent deaths linked to Methotrexate

The National Patient Safety Agency (NPSA) recently announced a package of practical solutions to reduce errors associated with the use of the drug oral Methotrexate. The NPSA has joined forces with the three pharmaceutical companies that manufacture the drug in the UK in a unique collaboration to improve patient safety.

Oral Methotrexate is taken in tablet form by thousands of people in the UK, normally for the treatment of moderate to severe rheumatoid arthritis and severe psoriasis. It is a safe and effective medication if taken at the right frequency and in the right dose, and with appropriate monitoring. However, the NPSA has identified 25 patient deaths and 26 cases of serious harm linked to the use of oral Methotrexate in a community setting over a 10 year period in England. The NPSA has also established that the problem is well-documented in the US and Australia.

Detailed analysis by the NPSA has identified key underlying factors including: patients not sufficiently informed about how the drug should be taken, for example on a weekly, and not a daily basis; health professionals and patients not benefiting from clear packaging or eye-catching messages on packaging across the industry; and variations in patient monitoring and treatment reviews.

In its first full year of operation (2002/3), the NPSA has collaborated with health professionals, patient groups, the pharmaceutical industry and medical and pharmaceutical software suppliers, to identify and develop three national solutions:

1. A new patient treatment diary, trialled with patients and patient groups, to empower patients with information, enable them to keep their own track record, and to ensure they are monitored correctly.

2. Pfizer, Goldshield and Mayne Pharma, the three UK manufacturers of Methotrexate, are working with NPSA and MHRA to develop new packaging designs and build on patient information currently available as part of a longer term piece of work that will help to improve safety when Methotrexate is prescribed by healthcare staff and administered by patients and their carers.

3. A project to adapt IT systems in GP surgeries and community pharmacies to incorporate flagging mechanisms and default settings to support NHS staff by designing out opportunities for human error in prescribing the drug.

Each solution will be developed in collaboration with the major stakeholders, and subject to further testing and risk assessment by the NPSA.

Wendy Harris, Senior Pharmacist at the NPSA, said: "Whilst the vast majority of people who take Methotrexate receive safe and effective treatment, there are some key patient safety issues we have to tackle. Methotrexate is a powerful drug, and one of only five drugs in the country taken at a weekly dose*. This leads to mistakes, both by patients and healthcare professionals.

"As this is a complex problem, we are working on a range of solutions and consulting with all the parties involved. We are delighted that three pharmaceutical companies have decided to work with us in a shared effort to tackle this issue across the industry. There is great potential to reduce the errors associated with this drug, and to translate much of the learning both internationally and to future NPSA projects focused on reducing medication errors in the NHS."

* There are 13,000 medicines currently licensed for use in the UK. Oral Methotrexate is one of only five medicines that should be taken on a weekly basis. Note: Oral Methotrexate is taken on a more frequent basis for specific conditions, for example by cancer patients who may be prescribed the drug on a daily basis as part of their hospital care.

During 2002 the Committee on Safety of Medicines (CSM) made a recommendation on how the labelling of manufacturer's packs of Methotrexate tablets could be improved to assist in reducing the potential for error. This change has already been progressed by the Medicines and Healthcare products Regulatory Agency (MHRA) which is responsible for acting on behalf of ministers in relation to the licensing of all medicines. New labelling statements will begin to appear in pharmacies.

INNOVATIONS
IN DIAGNOSIS AND TREATMENT

DIAGNOSIS

Is it psoriatic arthritis or rheumatoid arthritis plus psoriasis?

Psoriatic arthritis is grouped with other forms of arthritis labelled "sero-negative". By this we mean that tests in the serum for rheumatoid factor are negative. There is a problem about this in that rheumatoid factor can be found in a number of other diseases, such as systemic lupus erythematosus, and even in illnesses quite unrelated to arthritis such as the tropical disease, Kala-Azar, to mention but one example.

Moreover, rheumatoid arthritis is a common disease with a prevalence of 1-2% of the population. Similarly psoriasis affects 1-2% of the population and therefore it is bound to happen from time to time that a patient has both diseases. There are some forms of psoriatic arthropathy which closely resemble rheumatoid arthritis, particularly when it presents with symmetrical joint swelling of the hands and feet.

So far the convention has been that if a patient has arthritis, psoriasis and a positive rheumatoid factor, they should not be included in a group of patients labelled as having psoriatic arthropathy. Of course from time to time patients are seen whose arthritis is so obviously that associated with psoriasis on clinical and x-ray grounds that rheumatologists feel forced to make an exception to the rule but this is never satisfactory particularly in selecting patients for drug trials or other research. Happily there is now a new investigation – anti-CCP antibodies. This new antibody test is extremely specific for rheumatoid arthritis and its sensitivity, ie, the proportion of patients with rheumatoid arthritis it picks up, is similar to that of conventional rheumatoid factor tests. It appears likely that this test will clarify the diagnosis in patients with psoriatic arthritis eliminating many of the false positive tests for rheumatoid arthritis which currently give rise to confusion.

This test is available already in the private sector and it is hoped that it will be adopted by NHS hospitals before long.

TREATMENT

A biological agent tailored to psoriasis?

I know from letters and e-mail enquiries passed on to me to answer that there is great interest in the use of anti-TNF alpha agents both in treating the skin and the joints. Although these agents are very effective they are at present very costly and can have the disadvantage of stirring up latent infections such as tuberculosis. Therefore new agents of a biological type, which are more specific to disease mechanisms and, we hope, therefore safer, are very welcome.

Lebwohl, Christophers and others of Mount Sinai School of Medicine, New York, USA, writing in Archives of Dermatology, June 2003, have described their results with Alefacept. This agent is involved in modifying the function to particular types of lymphocyte. The agent binds to CD2 molecules on the surface of a class of lymphocyte called activated T-cells and moreover it targets in particular cells called memory effector T-cells (CD45 RO+). More than three quarters of the T-cells in plaques of psoriasis are of this type.

Lebwohl, and his colleagues studied 507 patients with chronic plaque psoriasis in an international, randomised, double-blind, placebo controlled trial. The quality of evidence obtained by this type of study, using large numbers of patients, is particularly good. They also used both 10mg and 15mg doses of Alefacept given by intra-muscular injection, weekly for twelve weeks, comparing these groups with patients given a placebo injection, ie, one which does not contain any of the active agents. They then followed up all the cases for

three months after finishing the treatment.

The result of the study was that a greater percentage of the patients having the larger 15mg dose showed a significant reduction in their psoriasis skin score compared with placebo. Of those who took 15mg per week and achieved 75% improvement in their score at observation two weeks after the last dose, 71% maintained at least half of that improvement through the following three months of observation.

In no case was there any evidence of latent infections being rekindled. It is of note also that none of the cases who responded well had a rebound with increased psoriasis during the three months after the trial.

It is unlikely that this treatment will be available outside of trial situations in the USA in the short term and its availability in the UK will have to await the outcome of further trials here and abroad, licensing by the European equivalent of the FDA in America, our Medicines Control Agency in the UK itself and the opinion of the National Institute of Clinical Excellence, but it is a very interesting pointer to the future customisation of biological agents to much more precise disease mechanisms than has been possible before.

A G White, MB Ch B, FRCP, D Phys Med, Hon Consultant Rheumatologist, The Royal Free Hospital (Psoriatic Arthritis Clinic) Medical Adviser

MEDICAL RECORDS on the NET

A new service to let patients look at their medical records on the internet has recently started a two-year project costing £2m.

- Currently, most people have a right to see written and computerised medical records made by doctors or other health professionals.

- Patients can ask the record holder -usually their doctor or health authority - directly for their records

The service lets people view their medical records online at **www.personalmedicaladvisor.co.uk.**

- Patients can access medical records through their doctors but, if refused, can complete a form for access at the relevant practice or hospital.

- They should be given access to files within 40 days and are charged £10. But if the record has been added to in the last 40 days, access is free

- Information on a person's record can be withheld if the record holder believes it could cause the patient or another person serious harm.

- Former health secretary Alan Milburn held talks with Microsoft tycoon Bill Gates last year to discuss how IT could improve health services.

- By 2005, personal medical information on the entire population of Britain will be put on a new NHS database under Government plans.

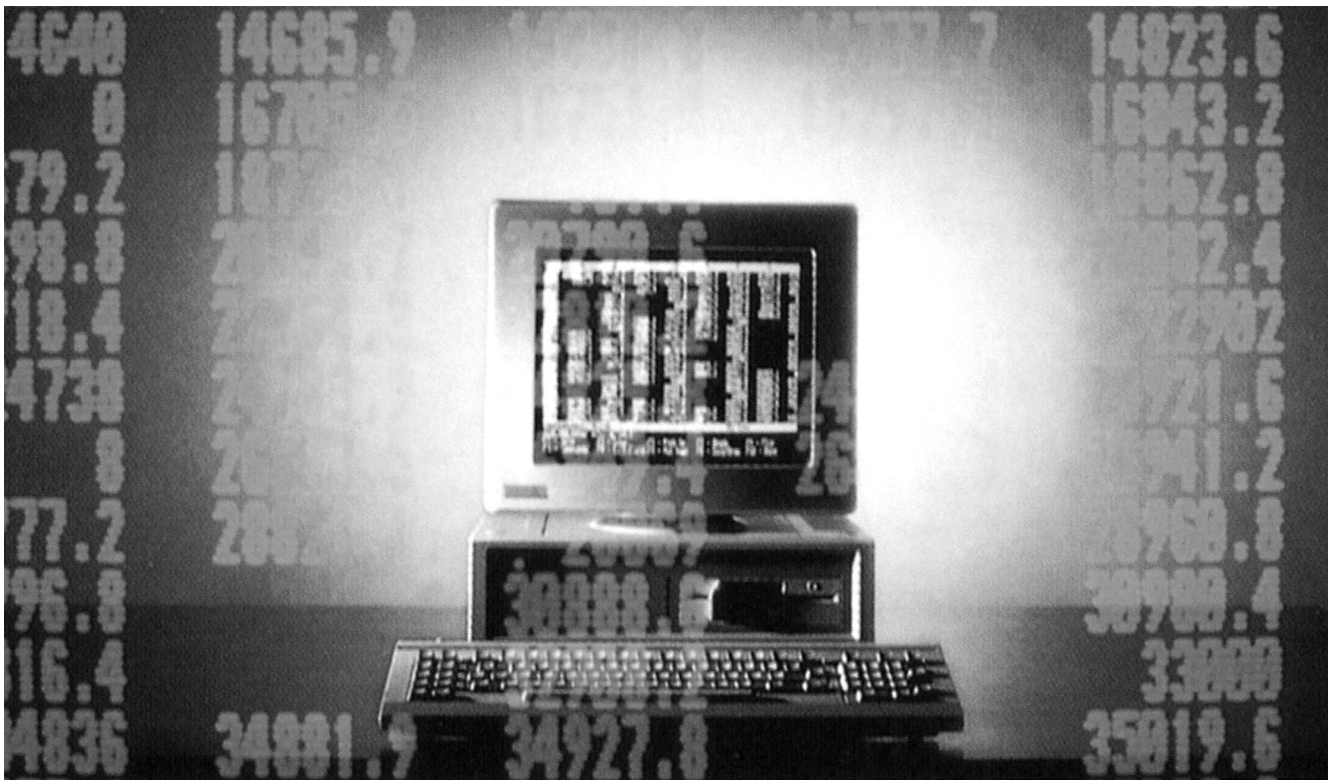
- The project will cost £2.3bn and will eliminate the problem of missing records and ensure doctors will be aware of any patient's medical history.

- Under the service, patients will be able to send blood samples for testing and the results will then be e-mailed back to them with advice.

- The service will also allow doctors in foreign countries to access patients' records if they are taken ill on holiday

- Almost half of Britons want to be able to e-mail their doctor to fix appointments, a survey by Datamonitor found last year.

- But many NHS organisations show little interest in the internet and the benefits it could bring them, according to a report by Government Computing.



An interesting item that is issued by Kettering General Hospital NHS Trust about important effects of Herbs during Surgery

HERB	RELEVANT EFFECTS	CONCERN DURING SURGERY	RECOMMENDATIONS
ECHINACEA	Activates cell - mediated immunity	Allergic reactions, reduction of effectiveness of immunosuppressive drugs, poor wound healing, increased risk of infection	Discontinue as far in advance as possible before surgery
EPHEDRA	Increases heart rate and blood pressure	Risk of Myocardial infarction and stroke, in patients anaesthetised with Halothane: Ventricular Arrhythmias	Discontinue at least 24 Hours before surgery
GARLIC	Inhibits Platelet aggregation	Increased risk of Bleeding	Discontinue at least 7 Days before surgery
GINKGO	Inhibits Platelet activating factor	Increased risk of Bleeding	Discontinue at least 36 Hours before surgery
GINSENG	Lowers Blood Glucose, Inhibits Platelet aggregation	Hypoglycaemia increased risk of bleeding could decrease anticoagu-lative effect of Warfarin	Discontinue at least 7 Days before surgery
KAVA	Sedates, reduces anxiety	Could increase sedative effect of anaesthetics	Discontinue at least 24 Hours before surgery
ST JOHN'S WORT	Inhibits Neurotransmitter Re uptake	Interaction with other drugs	Discontinue at least 5 days before surgery
VALERIAN	Sedate	Could increase sedative effect of anaesthetics, long term use could increase the amount of anaesthetic required	Reduce dose gradually over several weeks before surgery, or if patient is dependent on Valerian, take up until day of surgery

For further information please contact Drug information helpline – 01536 492587 (9.00 am to 4.00 pm)

Produced by Carole Burley and Alison Peacock - Pre-operative assessment project nurses.
In consultaion with Graham Bell, Principal Pharmacist and Dr J Luthman Consultant Anaesthetist

PRESS RELEASE

NEW WEBSITE PROVIDES DETAILS OF PHARMACEUTICAL INDUSTRY CLINICAL TRIALS INVOLVING UK PATIENTS

A new website that publishes details of clinical trials undertaken by pharmaceutical companies that involve UK patients was recently launched by the Association of the British Pharmaceutical Industry (ABPI).

The publicly-accessible website - thought to be the first of its kind in the world set up by the pharmaceutical industry - starts service with clinical trial reports already in place from major pharmaceutical companies, with more expected to join shortly.

"The pharmaceutical industry in the UK has once again taken a world lead by providing this information on clinical trials," said Dr Trevor Jones, Director General of the ABPI. It is proof positive of our commitment to greater openness and a greater flow of communication between ourselves, healthcare professionals and patients."

The launch of the website is the result of a policy announced some time ago by the ABPI under which member companies are encouraged to register voluntarily all clinical trials involving UK patients that have formed part of a licensing application. Participating companies will register the phase 3 trials within three months of receiving their first licence in a major market.

The website will provide a readily accessible list and information about which trials have been carried out and in which therapeutic areas. As well as healthcare professionals, the site will be of especial use to patient organisations and the public.

Phase 3 clinical trials are the last major stage of testing before a licence application is made to the regulatory authority, and are typically conducted in several thousand people suffering from the disease that the medicine is designed to treat. They are conducted primarily to gain information about the efficacy of the medicine, and its safety profile.

Among the information about the trials that will be included on the website are:

- Details of the company conducting the trial.
- The design and methodology being used.
- The topic, objectives and aim.
- The planned and actual sample size.
- The start and end date, plus any information about follow-up duration.
- Whether the results of the trial have been published in a learned journal and, if so, its details.
- Details of how to get further information about each trial.

"Major companies are already participating and more are close to joining, so this venture has got off to a good start," said Dr Jones. "Our aim now is to encourage more member companies to join - so that anyone can have access to the information about new medicines that have been approved for prescribing."

The website, which is hosted by CMR International, can be found at www.cmrinteract.com/clintrial.

The Association of the British Pharmaceutical Industry

The Association of the British Pharmaceutical Industry
12 Whitehall, London SW 1 A 2DY
Press Office Telephone. +44 (0)20 7747 1410 Fax: +44 (0)20 7747 1414

Conquering inflammatory diseases

New, nature-based medical treatments are on the verge of making breathtaking strides against a host of chronic diseases, such as psoriasis, arthritis and possibly even multiple sclerosis. A class of pharmaceuticals called biologic" therapies -- drugs derived from living cells instead of synthesized chemicals -- promises to change radically the treatment of diseases caused by inflammation of the body's tissues. Four new drugs either on the market or in prospect are leading the way in the field.

This development has been made possible, experts said, by painstaking progress in the fields of genetics, microbiology and bioengineering, all of which have led to the development of medicines that can interfere with inflammation at the molecular level.

"Many inflammatory diseases seem to have a genetic component, and now we see that many are triggered by other processes, some in the workings of the immune system," said Dr. Anthony Gaspari, professor of dermatology at the University of Maryland in Baltimore.

One such process, Gaspari explained, involves the malfunction of cytokines -- proteins the body uses to trigger inflammation. Sometimes, the trigger can backfire and lead to the overproduction of skin in psoriasis, the destruction of the myelin -- the cells surrounding nerve fibers -- in multiple sclerosis and the abnormal growth of connective tissue in the MS-like illness, scleroderma.

All of these chronic and progressive disorders seem to be rooted in an internal biochemical mechanism that can be addressed by an individually tailored biologic treatment, Gaspari said at a recent American Medical Association briefing on the new therapies.

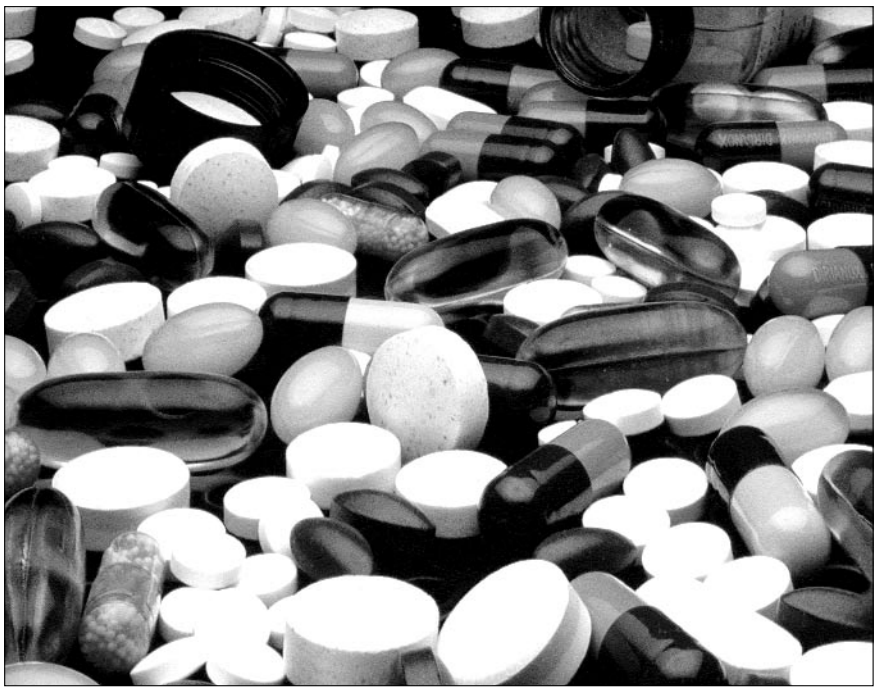
"So what is now proving so potent for rheumatoid arthritis, psoriatic arthritis and psoriasis might be leading us to new therapies for the other, apparently related disorders, like MS and scleroderma," he said.

Until recently, only toxic drugs such as methotrexate were available for patients with moderate-to-severe psoriasis. In less severe cases, skin creams and ultraviolet light therapy often could be used successfully.

"Biologic therapies now give us a powerful means to confront this often debilitating condition," Dr. Kenneth Gordon, associate professor of dermatology at Loyola University Medical Center in Maywood, Ill., said. "So far, we haven't seen significant long-term side effects, and we will keep our eyes open for them. Biologics are our future in this field -- for the next decade and maybe beyond."

In the case of psoriasis, biologics block the inflammatory response that leads to overproduction of skin cells. The disease is characterized by various degrees of red, scaly patching of skin.

Patients receive the medications by injection -- either subcutaneous, or under the skin, or intramuscular -- once a week or every other week. This represents an improvement over the current, twice-daily applications of creams and ointments, which can be cosmetically unacceptable or



continued

INTERNATIONAL NEWS

otherwise unpleasant.

The four new biologic treatments for psoriasis are sold -- or will be sold -- under the brand names Amevive, Raptiva, Remicade and Enbrel.

Amevive, manufactured by Biogen Inc., of Cambridge, Mass., was approved by U.S. Food and Drug Administration last January. Clinical studies showed it reduced symptoms of psoriasis by at least 75 percent in 21 percent of patients after three months. Amevive inhibits the activity of the immune system's T-cells in what is called "remittance therapy." A patient receives treatment for 12 weeks and then is off for 12 weeks.

One possible problem is whether remittance therapy will cause long-term effects to the immune system, and the FDA has recommended further study to detect such adverse effects.

Raptiva, manufactured jointly by Genentech Inc., of San Francisco and Xoma of Berkeley, Calif., was submitted to the FDA for approval in December 2002. It is expected to be available later this year. Like Amevive, it inhibits T-cell activity. A trial involving 556 patients indicated weekly injections cut psoriasis symptoms by 75 percent or more in 27 percent of patients after three months of treatment and by 50 percent or more in 59 percent of patients.

Looking at both medications, Jason Kantor, a pharmaceuticals industry analyst at W.R. Hambrecht and Co. in San Francisco, said "biologic agents that block the inflammatory protein called tumor necrosis factor-alpha, or TNF-alpha, could prove more potent over time, because they do not inhibit immune system activity in any way".

One such agent, Enbrel, by Amgen Inc., of Thousand Oaks, Calif., already is approved for treating rheumatoid arthritis and psoriatic arthritis. Clinical trials indicated Enbrel injections curbed psoriasis symptoms by 75 percent or more in 49 percent of patients, and a lower dose had the same effect in 34 percent of patients. Most notable, response rates for Enbrel rose after six months of continuous treatment.

"Enbrel is likely to dominate the market," said Kantor, "simply because it has been around the longest and has the added factor of being, like insulin, an at-home injectable treatment." For some reason, however, Medicare will only reimburse for treatments given in a doctor's office, which could exclude reimbursement for Enbrel, he added.

Kantor said because Enbrel is FDA-approved for psoriatic arthritis, a closely-related condition, physicians are noting "a little bit of psoriatic arthritis" in their diagnosis and so they can be reimbursed for the $10,000-to-12,000-per-year treatments by private insurers. Enbrel is being widely-used for psoriasis in an "off-label" mode, he noted, which is how a U.S. physician can prescribe a drug for one condition even though its FDA approval was for another condition.

Kantor said although all of the biologics come with a high price tag, "the effects are so powerful that we don't see inhibitions in insurance reimbursements for those who take Amevive or Enbrel, the later with a psoriatic arthritis diagnosis involved."

Another rheumatoid arthritis agent, Remicade, by Centocor Inc., of Malvern, Pa., also is being studied for its potential use in psoriasis therapy. Remicade blocks the same inflammatory protein as Enbrel. A study of 249 patients with moderate-to-severe psoriasis showed 88 percent treated with a higher dose of Remicade achieved a 75 percent or greater improvement in symptoms after 10 weeks. Even at a lower dosage, 72 percent of the trial subjects achieved a 75 percent or greater improvement.

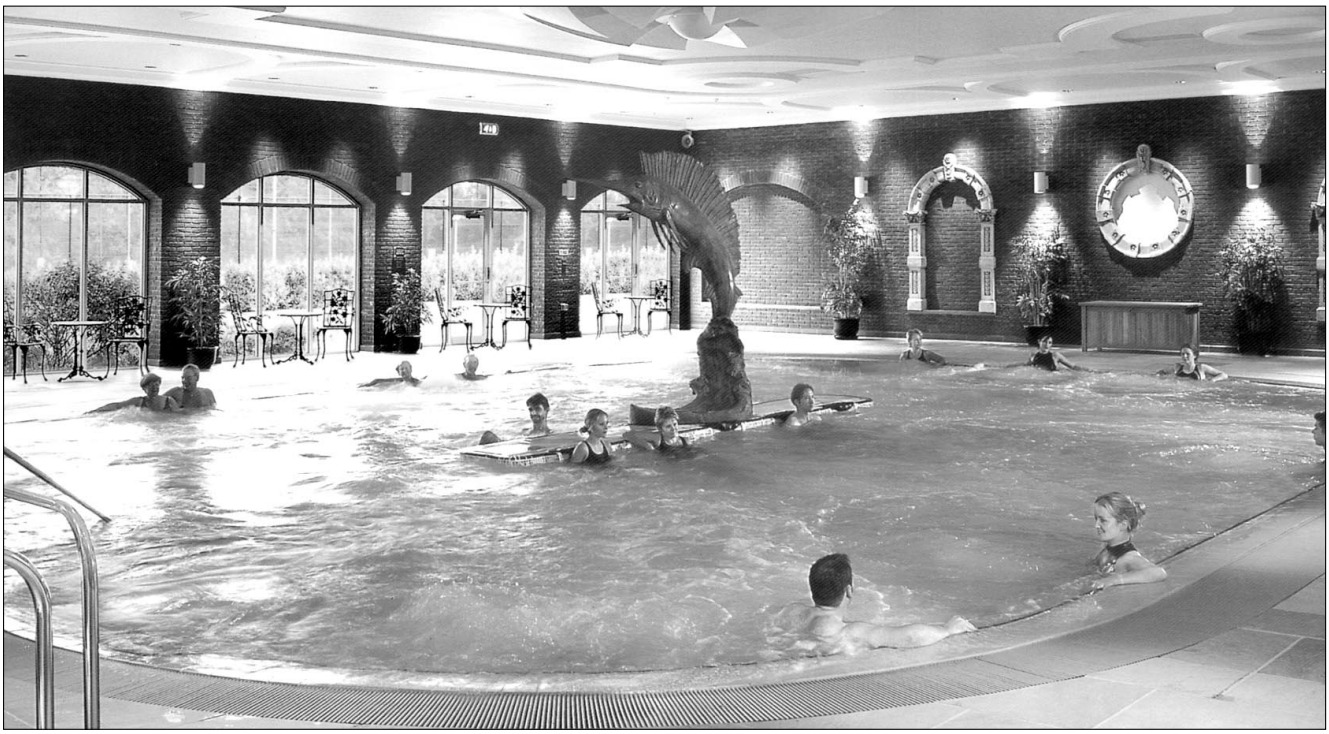
Kantor noted the annual market for biologic treatments for psoriasis in the U.S. alone could be worth $2 billion, with the market in Europe adding another $1 billion in potential sales. If biologic agents continue to show promise in treating other inflammatory conditions, he said, "then added to rheumatoid arthritic, psoriatic arthritis and psoriasis, the numbers could explode."

At present, Gaspari said, "There is no cure for any of the inflammatory diseases. As we unravel the mysteries of the immune system and identify genes that are passed on in families, we may be able to develop therapies that can cure these awful diseases. For now, the biologics are the advance guard of what we have to offer patients and their use appears to be growing to include many if not most of the major inflammatory diseases."

nirvana
SPA

Taking the Waters at Nirvana Spa

A Dead Sea Experience



First it was Floatation tanks now it's the turn of Floatation pools to transform stressed individuals into relaxed and revived human beings without the restriction of an enclosed environment.

Nirvana Spa, the luxury destination spa in Wokingham, Berkshire has recreated the Dead Sea experience by launching the UK's first floatation pools: the Celestial Room and Ocean Room.

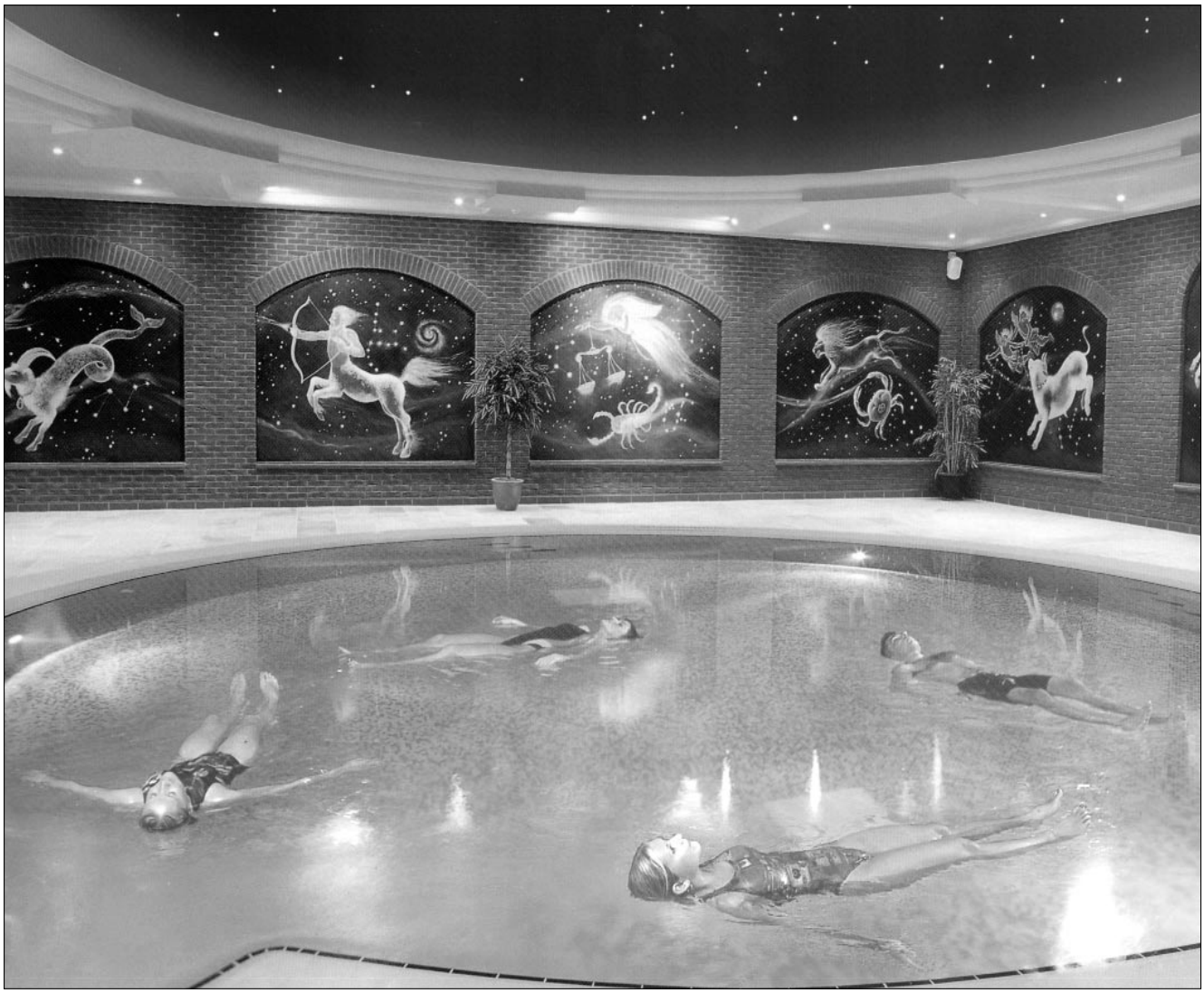
The Celestial Room, featuring a star domed ceiling and zodiac murals, offers the ultimate floatation experience and immerses the user in a sensory heaven. Its large circular pool holds up to six people at a time and the water is kept at a comfortable 35^{0}C. A gentle current, dimmed lighting and ambient music enhance the therapeutic relaxation process. Floatation sessions last 45 minutes.

The Ocean Room offers a more social environment. It is of particular benefit to those people seeking the curative properties of the Dead Sea salts for pain relief and healthier skin as well as relaxation. It is great fun too! Anyone who has ever wanted to know how an astronaut feels in space can find out in the Ocean Room as they propel themselves upright through the water or lie back and read a book.

FLOATATION POOLS

Nirvana Spa's team of experienced spa therapists is on hand to provide consultations and to ensure users gain maximum benefits from their floatation sessions.

Nirvana Spa has spent two years researching and developing the floatation pools including sending its chief medical adviser to the dead Sea to study specific treatment programmes. Nirvana



has imported over 100 tonnes of original Dead Sea salts containing 21 different minerals beneficial to the skin. These mineral salts are mixed with Nirvana Spa's own pure natural source of water from beneath its building.

Simon Brown, Nirvana Spa's deputy chairman, said: *"People travel from all over the world to experience the benefits of the Dead Sea. Now there is no need to travel. Our large salt pools are recreations of the Dead Sea and offer one of the purest forms of relaxation and skin therapy available. For Nirvana Spa, these pools represent a revolutionary step forward and for our members and day spa clients it is an opportunity to enter a higher level of relaxation and enhanced quality of life."*

Nirvana Spa is an adults only destination spa dedicated to relaxation. It offers a selection of natural spring-fed pools with water clean enough to drink and a range of spa therapy treatments to soothe and restore both body and mind.

Prices start from £55 for the Floatation Evening Spa package, which includes use of facilities, a light dinner, robes, towels and a 40 minute Floatation Session.

For further information on Nirvana Spa telephone 0118 989 7575 or visit the website www.nirvanaspa.co.uk.

PAA Kids

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

GET MOTIVATED - this is your chance to have your say!!!

ARTICLES • PICTURES • PUZZLES • POEMS

TRY OUR WORD SEARCHES PUZZLES, CROSSWORDS, and, don't forget to send us your games for the fun page - so get cracking, get those fun things coming into to us soon.

TELL US WHAT YOU WANT FROM THIS PAGE

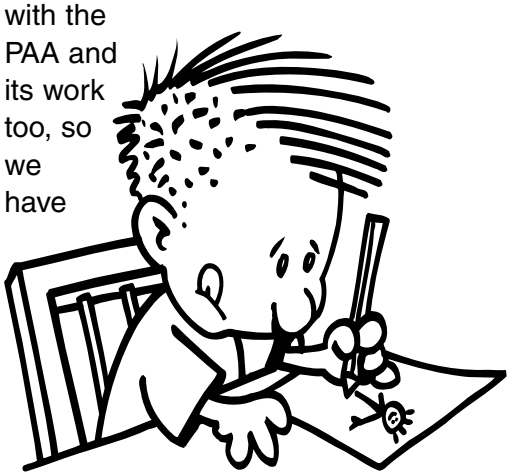
WHY NOT WRITE AN ARTICLE ABOUT HOW YOU FEEL LIVING WITH PSORIATIC ARTHRITIS

TELL US WHO YOUR FAVOURITE DOCTORS ARE AND WHY?

COME ON LET US KNOW YOU'RE OUT THERE!!

PAA KIDS is run by kids for kids and will operate in future issues of Skin'N'Bones Connection if we all make it work by getting motivated, contributing and growing!! so come on GET WRITING!

Let's introduce ourselves to you - my name's Hannah, I am 9, with a sister, Amy whose 4. We haven't got psoriasis, but our dad has, so we know what its like. Besides living with it, we have grown up with the PAA and its work too, so we have met many people with it.

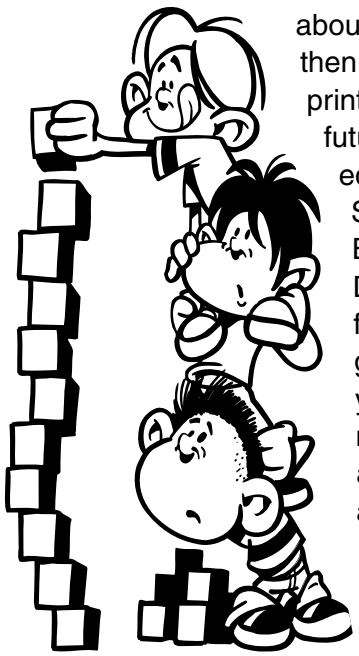


Next on the team is Aiden, he's 9, and Camilla, who is 9.5. They do not have the condition, but support all the efforts of the PAA, and help out each year at the PAA conference at Woburn Safari Park. Last year we all did a Tombola and guess the Woburn reindeer game - all without adults help - it was great fun.

Hope we will all get to meet you at future conferences and make some new friends.

DO YOU WANT A PEN PAL?

Here's your chance to get in touch with others. Just write in to us with a few details about yourself, then we will print it in future editions of Skin'N' Bones. Don't forget to give us your name, address, and please don't forget to get permission from your parents that it's OK to seek a pen pal.



Skin'n'Bones Connection

Skin'n'Bones Connection

PAA Kids YONGER PERSPECTIVE - kids need help too.

DID YOU KNOW?

FIRST THINGS FIRST - Psoriasis is not catching!!

Don't give up with your doctor or hospital – Psoriasis and treatments need to be found that suit you – this may take a little bit of time, and experimentation – so hang in there.

If you are lucky enough to see a specialist nurse dealing with your skin problem, don't be afraid to ask her questions – she will gladly explain or allay your fears. Sometimes your parents don't always have the answers, especially as to why things don't work with your treatments, so your doctor or nurse is the best person to get to know and talk to, especially to prescribe the treatments suited to you and your lifestyle!!

WHAT TRIGGERS YOUR PSORIASIS OR SOMETIMES MAKES IT WORSE?

Nobody really knows for sure, however if you are under pressure and stressed with exams, schoolwork, relationships, anything that really worries you, stress can make things worse, and you feel ten times worse – so get chilled out.

DON'T GET STRESSED OUT!

You can and probably will feel angry at times – "why me". Don't worry this is normal. You are bound to feel like this sometimes, fed-up with your treatments, doing them, not seeing any results from all that effort – going backwards and forwards to the doctors, wondering and worrying if the condition is getting worse or better – this is normal, you are normal for thinking like this. All these emotions will help you to cope better with your condition, throughout your life – so chill.

You will feel sometimes that the condition is "larger than life", a bit like a boil/spot on the end of your nose, that hurts and festers, and you think it stands out bigger than you are, when actually, nobody really notices that small redish mark on the end of your nose!! Then there will be other times when you totally forget you have a skin problem to treat, either its being good, cleared up, or there are other good things going in you life to take your mind off all your negative feelings. THIS IS NORMAL!!

HOW DO I DEAL WITH WHAT I'VE GOT?

Coming to terms with your skin and/or arthritis is the first step to managing your problem, then to deal with it and look after yourself – so little by little, accept that you have a problem but that's not your fault. Lots of other people have problems too, sometimes you just can't see them. Then get to know and feel comfortable with your medical condition.

SUMMER TIME

Be careful of the sun – don't get sunburnt and always use a good sun protection cream, especially if you are fair skinned.

SWIMMING:

Swimming is great and fun too, so don't get hung up about going – once you get a grip of yourself and go, you'll love it. However, your skin may become irritated by the chlorine in the water which varies in level from pool to pool. To combat this try to protect your skin by good moisturising, and if you can get a barrier cream to apply before you go into the water, this may help too.

MOISTURISING:

Don't forget this is really important to learn early on, and to make part of your daily skin routine.

WHY MOISTURISE?

Moisturising keeps skin hydrated, flexible and healthy and best of all it prevents worsening of the psoriasis, and can reduce irritation and itching. It helps in the winter months, when our skin does not get the opportunity to breath, being covered up in all our heavy, warm clothing.

HOW DO I DO THIS?

You can moisturise without too much trouble at all, for instance, in the bath. There are emollient products that you can add to the bath that do the job well, without you making any efforts at all, apart from enjoying your bath time!!

Then there are products that you can apply after your bath, or during the course of the day.

So, go on, give it a try.

MAKE YOUR TREATMENT TIMES FUN!

(Now you won't take us seriously, but honestly we are not MAD!!)

Invent games with your nurse, doctors and parents to make applying your treatments fun.

Example: Creaming speed record

Reward system: each time you go to the doctors/nurse or hospital, give yourself a treat, or ask your parents to give you one.

Give yourself a treat for each completed month of treatment, again ask your parents to let you have something special, so that it gives you an incentive to work for.

Give yourself targets to meet with your treatments goals.

Come on use your imagination, invent some games – Don't forget to tell us if they work too!!

LUXURY BATH TOWEL SETS TO GIVEAWAY FROM THE EXOREX MANAGEMENT SYSTEM

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 of 1% prepared coal tar. Exorex Lotion is easy to apply and pleasant to use with no strong odour. Exorex lotion is available for purchase over-the counter from independent chemists and includes:

WASH Exorex Hair and Body Shampoo
(*rsp* £6.49 *for* 250*ml*)

TREAT Exorex Lotion
(*rsp* £14.95 *for* 100*ml and* £29.95 *for* 250*ml*)

MOISTURISE Exorex Moisturising Cream
(*rsp* £6.49 *for* 100*g and* £12.99 *for* 250*g*)

Exorex Scalp Moisturiser
(*rsp* £12.99 *for* 250*ml*)

Exorex are giving away 5 luxurious bath towel sets from The White Company. Each prize, worth £53, includes two bath towels, two hand towels and two face cloths. Simply send your name and address to:

Exorex Offer/PAA
P.O.Box 97 Rickmansworth, HERTS WD3 1YX

Always Read the Label

health & comfort

In association with HealthyDirect

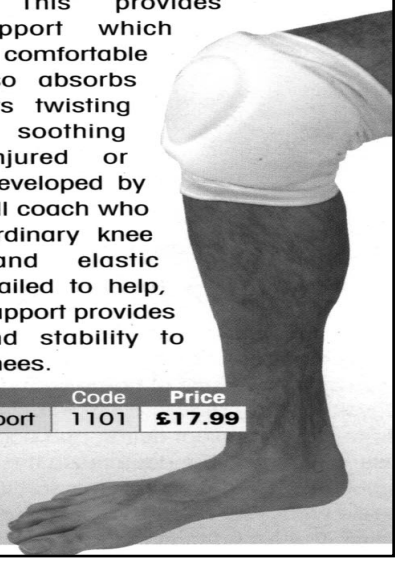
Arm Extender saves your back and neck

When you need to get to those out-of-reach items or want to retrieve items from the floor without bending down then you can use our Arm Extender. This is just the job for reaching high-up objects without risking injury or straining your neck. In addition the Arm Extender also helps you to prevent backache or back pain caused by bending down to pick up things from the ground. It is easy to use and lightweight. Save your back and neck with an Arm Extender.

Item	Code	Price
Arm Extender	1088	£4.99

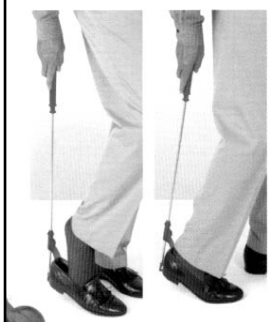
Knee Support for instant pain relief

Relieve aching or painful knees by supporting them with Health & Comfort's knee support. If you experience shooting pains, twinges or pain every time you take a step then your knee is crying out for support. This provides lightweight support which means that it is comfortable to wear. It also absorbs shocks, prevents twisting and provides soothing warmth to injured or painful joints. Developed by a veteran football coach who found that ordinary knee supports and elastic bandages failed to help, this knee support provides strength and stability to problem knees.



Item	Code	Price
Knee Support	1101	£17.99

Struggle to put on your shoes? Try our Super Length Shoe Horn.



The Super Length Shoe Horn is invaluable to all of us who have difficulty in bending over to slip on our shoes. Measuring 28" (70cm) long, it grips the shoe at arms length and moves it into position for you to glide the shoe horn easily into place, allowing your foot to fit smoothly into the heel without damaging the back of your shoe. As a special offer, we are giving away a **FREE Telescopic Magnet with every order**. The size of a ballpoint pen when retracted and approximately 24" (60cm) long when extended, it is powerful enough to pick up most metal objects without you having to bend down. **FREE** with every Super Length Shoe Horn ordered!

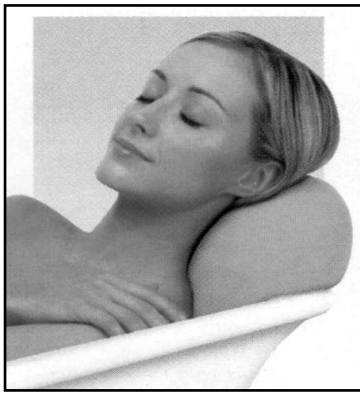
Item	Code	Price
Super Length Shoe Horn	1008	£4.99
Telescopic Magnet	1009	FREE

Reusable Heat Pad

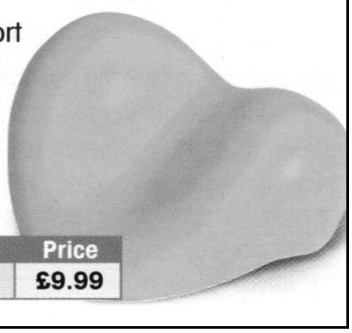
Instantly warm up your cold hands with Health & Comfort's Heat Pad. Take it with you wherever you go. You can warm your hands after gardening, playing golf or walking. Just press the small disc inside the pad that triggers the heat action. Hold the heated pad in the palm of your hand for instant warmth. Perfect for outdoor sports and work. Re-usable up to 1,000 times by simply placing in boiling water. When you want to use the pad, just push the disc for heat.

Item	Code	Price
Heat Pad	1093	£2.99

Relax in the bath - with no neck pain!



The Bath Pillow will cradle your neck and support your head whilst lying in the bath. It is made of water resistant foam and designed with contours that are shaped to support the back of your head and neck. So treat yourself and stay that little bit longer in the bath without any fear of having a stiff neck when you get out!



Item	Code	Price
Bath Pillow	1002	£9.99

TELEPHONE ORDERS:
8.30am - 9pm, 7 days a week
0870 054 66 55

PAA Publications order form

Copies of current and back issues of PAA publications are available at the costs set out below. PLEASE indicate which publication(s) you require, and return this form with your remittance. **Postage** is free on chargeable items but a suggested donation of **£1.00** would be gratefully accepted (**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	£3.00		
Skin 'n' Bones Connection	7	December 1996	£3.00		
Newsletter	8	March 1997	£3.00		
Skin 'n' Bones Connection	8	Summer '97	£3.00		
PAA News	9	Autumn '97	£3.00		
Skin 'n' Bones Connection	9	Winter '97	£3.00		
PAA News	10	Spring '98	£3.00		
Skin 'n' Bones Connection	10	Summer '98	£3.00		
PAA News	11	Autumn '98	£3.00		
Skin 'n' Bones Connection	11	Winter '98/99	£3.00		
PAA News	12	Spring '99	£3.00		
Skin'n'Bones Connection	13	Winter 2000	£3.00		
Skin'n'Bones Connection	14	2001	£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		
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.

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

Dear PAA

While surfing on the internet, we had a look at your web site, congratulations for the good work wishing your great and outstanding efforts will be more and more in help to all people suffering from Psoriasis.

We own and manage a resort in Safaga - Red Sea in Egypt , named (Menaville), where we lead a unique operation concerning Climatotherapy for treatment of both psoriasis & rheumatoid arthritis, which is known since the year 1993 worldwide and scientifically proved and published in the most respectable organizations and conferences for curative tourism.

Springing out of our mission which is to help people with psoriasis worldwide, we were wondering if it is possible to add a link about us on your web site as we believe this will be in great interest to all people suffering from psoriasis in United Kingdom.

If it is possible, could you please advise us how to add this link on your web site and what are the conditions and it should be mentioned that our Climatotherapy resort is well - known to the National Psoriasis Foundation in the United States and they had added us among their most updated guide dedicated for the alternative medicine, this guide called (Alternative Approaches) and in the chapter concerning Sun and Water, they mentioned Safaga - Red Sea as an ideal place for curative tourism due to its therapeutic application possibilities also, PSO aktuell which is German specialized magazine in Psoriasis, had added a link of our web site on its web site.

For further information, if you would care to visit our web site at www.menaville.com and have a look at the link Health Care at the home page, where you will find all information needed.

Best regards, Respectfully yours
Menaville Management
Mena for Resorts & Hotels (Menaville)
Head Office : 5A Mathaf El Manial St.
P.O.Box 6 Manial El Roda , Cairo - Egypt
Tel : 3620651 - 3629099 Direct Sales : 3648399 Fax :3630431 - 3628090
Email : menaville@link.net Web Site : www.menaville.com

The Climatic Therapy at Menaville - Safaga - Red Sea

A hint on the project's background

It was observed that some guests of Menaville, suffering from rheumatoid, rheumatism, or psoriasis, were healed during their short stay at Menaville resort in Safaga.

The steering committee of Menaville took an immediate action to study this phenomenon on scientific basis and contacted the Ministry of Scientific Research, which delegated the National Research Center to study the extraordinary phenomena.

The NRC prepared teamwork consisting of selective doctors and specialists in rheumatoid and psoriasis.

A study named 'Field and Clinical Survey of climatic effects of Safaga on skin diseases and arthropathy' was accomplished through several steps:-

First Step; 'Field Survey' which resulted in the following:

1) The affection rate of rheumatoid is only 0.014 % compared with the international rate that reached 1%, i.e., Rheumatoid rarely exists in this area.

2) The affection rate of Psoriasis in this area is 0.008% compared with the International rate that varies between (1-3 %)

Remaining Steps; 'Clinical Survey':

Two groups of patients suffering from rheumatoid & psoriasis were selected, after evaluating their cases, to be cured in Safaga in successive subgroups. They spent there, four weeks under medical supervision.

The main results were:

1) Chronic rheumatoid arthritis (109 cases)

* The results show enormous clinical improvement in 84% of the cases.14% were completely cured, and after 6 months, following up in 46% of the cases led to continuous improvement.
* The rheumatoid coefficient in 36% of the cases.
* After 6 months the blood sedimentation rate decreased in 57% of the cases.
* As a conclusion the climatic therapy is not only a kind of the natural curing, but its effect on the blood sedimentation rate and rheumatoid coefficient indicates an affection on the disturbed immunity system.

2) Psoriasis (80 cases)

After four weeks of curing, followed by 12 weeks of following up the final results show an excellent improvement in 90 % of the cases. These results are considered as a great achievement compared with curing using drugs, with its dangerous side effects.

Last Step; 'An International Press Conference':

The National Research Center, in collaboration with the USAID and foreign doctors, held an international Press Conference in Menaville - Safaga on 22/06/1995. Mrs. Mubarak sponsored the conference and it was attended by Minister of Scientific Research; Minister of Health; scientists; Egyptian and foreigner corespondents.

In this conference doctors announced that; after two years of hard efforts to prove the ability of this area to cure the patients suffering from psoriasis & rheumatoid arthritis; Safaga is an ideal Resort for Climatotherapy & Health Tourism.

NHS NICE press release

NICE launches new clinical guideline on preoperative tests to improve patient care

The National Institute for Clinical Excellence (NICE) has issued its latest clinical guideline, on the use of routine preoperative tests in elective (pre-planned) surgery for children and adults. Every year around 5 million elective surgical procedures are performed by the NHS in England. For many years it has been usual practice in many hospitals to test patients preoperatively for unsuspected conditions that might affect their treatment. However, the number and type of tests that are given before surgery vary considerably across the country. Carrying out lots of preoperative tests can lead to unnecessary delays or cancellation of operations as well as inconvenience and discomfort to patients because of 'false positive' test results. The NICE guideline will ensure that no matter where people live in England and Wales, they can be confident that the health professionals caring for them have clear recommendations about the tests that should and should not be carried out.

The guideline makes recommendations about the appropriateness of carrying out the following tests:

- Plain chest X-ray (radiograph)
- Resting electrocardiogram (ECG)
- Full blood count (for example to test for anaemia)
- Haemostasis (to test how well the blood clots)
- Renal function
- Random blood glucose (to test for diabetes)
- Urine analysis (for example to test for urinary infections or kidney problems)
- Blood gases (to test for cardiovascular or lung problems)
- Lung function
- Pregnancy
- Sickle cell anaemia

The appropriateness of testing depends on the characteristics of patients, for example their age, other illnesses they may have and the type of surgery that is planned. Therefore the recommendations are set out in 'look-up' tables, cross-referenced by the type of surgery, common chronic illnesses and age.

The guideline is accompanied by an information leaflet for the public which clearly explains what the tests are for and what to do if they want more information.

The National Collaborating Centre (NCC) for Acute Care has developed the guideline. The NCC is a group of health professional and patient/carer organisations who manage the development of clinical guidelines for NICE. The NCC's follow the Institute's standards of guideline development. They established a guideline development group consisting of service users and carers, health professionals and academics who reviewed the worldwide data and expert opinion, alongside current clinical practice, the experience of service users and the feedback they received from two rounds of widespread consultation.

Andrea Sutcliffe, Planning and Resources Director and Executive Lead for this guideline, said: "This guideline is good news for patients and health professionals. It will help to ensure that all NHS Trusts operate to the same high standards in their provision of preoperative tests for elective surgery. We hope that the information for the public which accompanies the guideline will help inform people about this important aspect their care."

Jacqueline Dutchak, Director of the NCC for Acute Care, said "This is the second guideline produced by the NCC for Acute Care on behalf of NICE. It has been developed following a collaborative and consultative approach, using the best available evidence and will help the NHS provide the highest standards of care for people undergoing elective surgery. The guideline should enable healthcare professionals to feel confident that when implementing this guidance they will be providing their patients with the best standards of care."

Antony Fisher, Consultant Anaesthetist and Clinical Director, Critical and Surgical Care Group, King's College Hospital NHS Trust says "The dearth of evidence to prove a positive relationship between performance of routine preoperative investigations and better clinical outcomes of anaesthetic and surgical interventions has historically left this area of practice open to uncertainty and thus wide variations in both practice and teaching, with a tendency to lean to over investigation as a defence against potential criticism of lack of thoroughness. The advent of these guidelines means that this uncertainty about what will be perceived as good practice is now removed and the rationalisation of preoperative investigation practice, which many institutions, including King's, have attempted previously, may now proceed confidently with the impetus and authority that these guidelines bring."

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