Skin'n'Bones connection

ISSUE 23 2006 PRICE £3.00

ISSN 1475-4134

PAA

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

The PAA Team

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

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

Psoriatic Arthropathy Alliance is a Registered Company Limited by Guarantee No: 3055414. Registered office: Faulkner House, Victoria Street, St. Albans, Herts. AL1 3SE

Printing By Photolit Printing
Tel: St. Albans 01727 857112

Typesetting & Design By Eye for Graphics
Tel: St. Albans 01727 835968

EDITORIAL

The recent problems in a trial with healthy volunteers (see page 13) of the drug called TGN1412 made by German pharmaceutical company TeGenero makes us probably all wonder about the safety of the drugs we are taking.

The issues of rofecoxib (VIOXX) and subsequent law suits in the USA (also see page13) add to the concerns that we may have, despite a treatment being licensed and available.

The role of drug trials and the monitoring of licensed products is regulated and well controlled. In the last issue of Skin 'n' Bones Connection (issue 22) we reported the improved systems for people to report suspected side effects in a pilot scheme where Yellow Cards will be available via pharmacies, GP surgeries and other NHS outlets.

In this issue we have reproduced an article on clinical trials in psoriasis (see page 3) which will give you a view of the complexities of a trial and the various stages that have to be passed before a drug reaches the market place and can be prescribed.

With the various 'hoops and hurdles' that have to be negotiated, and the level of scares and information surrounding treatments it has to be considered as to why any researcher would want to conduct a clinical trial at all. Well I think that apart from any commercial consideration or monetary gain, there is an overwhelming view to understand disease and make outcomes for patients much better. The location cover photo of this issue is where 250 such individual researchers and patients met. It was the venue for OMERACT 8.

OMERACT stands for Outcome Measures in Rheumatology.

The acronym OMERACT was coined at the first conference held in Maastricht, the Netherlands in 1992, limited to Outcome Measures in Rheumatoid Arthritis Clinical Trials.

Since then, the OMERACT initiative has turned into an international informal network, working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies.

OMERACT strives to improve outcome measurement through a data driven, iterative consensus process.OMERACT has a 5 member Organising Committee with members from 3 continents; it has a 15 member Scientific Advisory Committee composed of international opinion leaders from 9 countries.

What does it do? To improve outcome measurement, OMERACT organises conferences that take place every two years and rotate around the globe.

For these conferences, topics of interest are prepared by self-appointed groups of experts. These topics are then prepared for the conference by literature review and specification of the points for discussion. Most topics are discussed in workshop format, where the aim is to make explicit the areas of agreement and disagreement, and to prioritise the research agenda. In several areas, the group has taken the lead in actually performing the necessary research to bring back to the conference. Recently, small group workshops have emerged alongside OMERACT conferences to speed up the work. When enough data is available, a full module is organised with the intention to come to consensus on guidelines.

At OMERACT 8 there was for the first time a psoriatic arthritis module with the objective of defining clear assessment tools for research outcome measures.

A measure is applicable when it passes the OMERACT Filter in its intended setting. The OMERACT Filter can easily be summarised in only three words: Truth, Discrimination, and Feasibility.

Each word represents a question to be answered of the measure, in each of its intended settings:

- 1. **Truth:** is the measure truthful, does it measure what it intends to measure? Is the result unbiased and relevant? The word captures the issues of face, content, construct and criterion validity.
- 2. **Discrimination:** does the measure discriminate between situations that are of interest? The situations can be states at one time (for classification or prognosis) or states at different times (to measure change). The word captures the issues of reliability and sensitivity to change.
- 3. **Feasibility:** can the measure be applied easily, given constraints of time, money, and interpretability? The word captures an essential element in the selection of measures, one that in the end may be decisive in determining a measure's success.

The inclusion of patients at OMERACT 6 held in Australia in 2002 saw a change in the mind set of the organisers, further patient involvement at OMERACT 7 2004 and the inclusion of psoriatic patients this year has led to the OMERACT Executive Committee agreeing that patient participation in an appropriate way and is seen as a necessary aspect of the development of international consensus.

Some of the 250 OMERACT 8 delegates

Cover picture: The Dragonara Resort - Malta. The venue for OMERACT 8

Clinical Trials

Introduction

When you go to the pharmacy to collect the treatment your doctor has prescribed, have you ever wondered how that treatment has been developed and how its efficacy has been proven? This article will take you on a journey on the life of a medicinal product and will also explain in detail the concept of clinical trials so that you are better informed of your rights and can make an informed decision when asked to participate.

The process of drug development is long. Did you know that most of the medicines that you buy from your pharmacist have undergone a 10-15 year testing period before they could be prescribed and sold! This may help explain why some treatments are so expensive!

When a new treatment is discovered, it is usually in the form of a chemical molecule. This molecule will initially be tested using standard laboratory tests for its effects on say inflammation or skin differentiation. If the results from these initial tests are promising the process of drug development will be initiated. Drug development may involve a number of things such as the technical aspects of a chemical scale up, analytical analysis of the material and pharmaceutical development of a dosage form and formulation. Development also refers to the entire process of taking a newly discovered compound through regulatory approval and to the point of marketing.

One of the most important decisions that a company makes, is which of its novel molecules it will develop into a medical treatment. Only 1 in 10,000 molecules makes it to the market! Therefore this is indeed a key decision which is made according to established criteria, specific for each company. When a chemical compound is found that meets these criteria then it is developed as a medicine. The compound will continue to be developed until events demonstrate that some of the criteria (especially that of safety and efficacy) cannot be met and that it is no longer likely or possible to achieve a medically and commercially viable medicine.

As a psoriasis patient you may be accustomed to using creams as opposed to tablets. These creams however, go through the same rigorous process of analysis and evaluation as an oral treatment. One must understand that a drug, be it topical or oral is a medication and will therefore have undergone all the controls and tests required by the law. People that think topically applied treatments are 'weak medications' are wrong. Topical treatments are preferred in dermatology because these will act directly on the diseased organ:- ie the skin.

The Development Plan

The development plan refers to the development of a molecule into a medical treatment. The first phase of the development plan includes pharmacology and toxicology studies. In these preliminary studies the therapeutic action is evaluated in terms of active dose, toxicity and side effects. Parallel with this, the formulation department will work on incorporating the active molecule into different types of creams and gels that will eventually be applied onto the skin. Once researchers are satisfied with the results from these initial stages will the clinical trials on humans commence. The aim of these clinical trials is to register the new treatment with the Medicines and Healthcare products Regulatory Agency (MHRA). Therefore a number of studies will be carried out, following the different phases outlined below, in order to collect information for the submission of the new drugs dossier. Thus, this is a highly controlled process in which registration will only take place if the data is sufficient, accurate and thereby acceptable by the MCA. Indeed, clinical trials have to be rigorously planned and carried out in order to ensure the utmost amount of safety for the subject trying out the molecule and the utmost amount of accuracy in testing the effects of the new treatment.

Planning Clinical Trial ?

There are certain parties involved in the planning of a clinical trial. Usually a pharmaceutical company will have a new drug to register and will therefore have a corresponding development plan to carry out. This development plan will include numerous clinical trials in order to prove the efficacy and safety of this new treatment on human subjects. Specialists from the company will be responsible for the design of the trials and for choosing an investigator (a dermatologist) for carrying out each trial. The design of these trials will correspond to the objectives for each particular study. These objectives in turn will correspond to the major and minor questions that the study is designed to answer. In all types of studies the objective should be stated as specifically as possible in the protocol. The protocol is the bible of clinical trials since it contains an accurate and complete description of the methodology of the trial, evaluations to be made during the trial, general information on the personnel involved in the trial and indeed all the reglementary sections.

- Methodology of the trial

The protocol will contain an accurate and complete description of the study methodology. This will include :

- Name and description of the new treatment
- Summary of findings of other studies already carried out
- when and how the patient should apply the treatment
- Description of the population to be studied

- An accurate description of trial design including the measures taken to avoid bias
- The expected duration of participation
- A description of the stopping rules

- Evaluations
  - Methods, timing and specification of the efficacy and safety parameters
  - Procedure for eliciting reports and reporting any side effects and inter current illnesses
  - Description of the statistical procedures to be used in analysing the data obtained during the trial

- General Information
  - Name and address of the pharmaceutical company who is carrying out the trial
  - Name and address of the investigator carrying out the trial
  - Name, address and telephone number of everybody involved in the conception , design and carrying out of the clinical trial

- Reglementary Section
  - Financing and insurance of the study
  - Data handling and record keeping procedures
  - Description of the ethical considerations relating to the trial
  - Description of quality control and quality assurance to be adopted during the trial.

This protocol will then be submitted to the local ethics committee, an independent group of people, appointed by the local health authority, which includes doctors, nurses, medical staff, lawyers and members of the public. They will decide whether the trial is ethical. In particular they check that:

- The researchers are qualified to carry out the trial
- The protocol is suitable for the needs of the trial
- The probable benefits of a new treatment outweigh the side effects
- There is enough information for participants
- The way in which people will be recruited is correct
- The local health facilities can support the trial

Once the protocol has been approved by the ethics committee, the study can commence.

Clinical Trials explained

The purpose and objectives of a study are usually related to some degree with the phase of clinical testing the study drug is in. There are four phases of clinical testing:

Phase One:

This is the initial administration in healthy human subjects. Healthy subjects are chosen for this phase since it is easier to control an unexpected adverse reaction. The main objective at this stage is to verify the dosage of treatment which is well tolerated. Hence these studies require extreme precaution and care and will be closely monitored by both doctors and research personnel. Safety evaluations are the primary and almost always the sole objectives. The doses administered are chosen after careful analysis of the results obtained in animals. Usually very small doses are used, these are then increased accordingly.

Phase Two:

These are the studies designed to evaluate efficacy in selected populations of patients for whom the drug is intended. These studies are rigorous and well controlled and are carried out in a small population of patients with similar disease characteristics. By the time the treatment reaches phase two, researchers will know quite a lot about it since only those treatments which look promising in stage one will progress to phase two. Phase one will have shown what the major side effects are and whether they are acceptable in relation to any potential benefit.

Phase Three:

These studies are conducted in patient populations for which the drug is eventually intended. These studies generate additional data on both safety and efficacy on much larger and more heterogenous groups of patients than phase two studies. Often the studies entail a comparison between the new product and a treatment already available in the shops. These studies provide much of the information that is needed for the package insert and labelling of the drug.

If you are asked to take part in a phase two or phase three study there are a number of terms which you may hear: Most of these trials will be randomised. This means that a computer will randomly allocate patients to one or other of the treatment groups in the trial. This is done so that each group has a non biased mix of patients of different ages and sex. If it were left to the researchers to decide who should get which treatment they might be influenced by what they know about their patients. Consciously or unconsciously they might put patients who were more or less likely to respond to a new treatment into that group. This would introduce bias, making the results unreliable.

Randomised trials are by definition, controlled. A 'control' is something with which to compare the treatment being tested. Usually the control will be the standard treatment or a placebo (dummy treatment). Without a control it is impossible to measure how much would have happened by chance or with the standard treatment.

If you take part in a trial of a new treatment, you may not be told which treatment group you are in. This is called a blind trial. The medicine that all the patients are given will look the same whether it is the new treatment, standard treatment, or placebo.

Some trials are double blind which means that neither you nor the doctor treating you knows which treatment you are getting. Your doctor opens a specially coded treatment pack and only the trial

organisers know which particular drug it contains. Making a trial blind or double blind is again aimed at reducing bias. If you knew which treatment you were getting it might influence how you felt. For example, knowing you were taking a new treatment might make you feel more positive or more negative, and therefore influence what you report to the researchers. Similarly, if the researchers knew you were taking a new treatment for which they had high hopes, this might affect how they judged your response to it.

Phase Four:
This phase commences after a drug has been marketed and is commercially available. These studies are used to provide additional details required to learn more about the drug's efficacy and /or safety profile.

Bearing all this in mind, it is important to be aware that before any clinical study is undertaken, careful consideration is given to the question of why the study has been proposed. Reasons for performing a study are carefully evaluated from the point of view of whether the study is truly necessary to answer the questions posed.

Clincal Trials in Psoriasis

Depending on the type of trial any of the following evaluations may be carried out on lesions:

- Erythema (redness): The investigator will assess the extent of redness on the treated areas
- Dryness: This is defined as tight sensations on the treated area due to the unusual dryness of the skin. The dermatologist will feel the treated area himself and will also ask you if you have experienced sensations of this sort during the treatment period
- Desquamation: desquamation is the abnormal shedding or peeling of the skin. The dermatologist will evaluate this parameter by looking closely at the treated area
- Burning: The dermatologist will ask you if you have experienced any prickling pain sensations at any time during the course of treatment in order to evaluate burning
- Pruritus: The dermatologist will ask you if you have experienced any itching sensations in order to evaluate this parameter
- Infiltration: This is a simple evaluation in which the hardness or firmness of the tissue around the site of the lesion will be assessed.

As you can appreciate, all the different visual characteristics of the lesions are investigated and examined in order to assess the efficacy and safety features of the new treatment. In addition to these visual factors some clinical trials also include questionnaires about the quality of life and psychological factors.

Quality of life questionnaires ?

Over the last few years, researchers have developed detailed tests and questionnaires which allow them to measure the quality of life. These allow them not only to look at the effect of a new treatment on your psoriasis but also at its much wider effects on your life as a whole, and to compare these effects with those of other forms of treatment.

Some of the questions you are asked during a trial may seem rather unnecessary and quite unrelated to your treatment. For example you may be asked questions such as:

- Over the last few weeks, how much has your skin influenced the clothes you wear ?
- Over the last few weeks, how embarrassed or self conscious have you been because of your skin ?
- Over the last few weeks, has your skin prevented you from working or studying ?

There is a good reason why you are asked such questions. The aim of any medical treatment isn't just to help you get well again. It is also geared to improving your day to day living i.e. your quality of life.

Who is in charge of the clinical trial ?

The dermatologist who asks you to take part in a clinical trial may not be the person who designed and set up the trial. However he/she should have been fully informed about the study before agreeing to become involved and should have all the information you need.

Who can participate in clinical trials ?

This depends entirely on the type of clinical trial being carried out. Each trial has certain criteria which people must adhere to in order to participate. Since clinical trials investigate the effects of new treatments, it is important not to confuse these effects with that of other treatments. Therefore, one of the most common criterion is that if you wish to participate you might have to stop your current treatment for a specified period of time. Therefore depending on your own personal characteristics, you might have a clinical trial for which you are eligible but then again there might be another trial for which you are not.

How can I find out more about clinical trials ?

The saying goes, where there is a will there is a way. This is also true for clinical trials- participation is easy if you want to participate. Your dermatologist is probably the best source of information since he/she will be most certainly implicated in clinical trials of some sort. In addition patient support groups such as the PAA might know of some trials being carried out in the UK.

What are the guarantees ?

There are both risks and benefits to consider when participating in a clinical trial. When you take part in a trial you will be monitored carefully during and after the study. You will have regular evaluations and will sometimes be asked questions about how you are feeling in general. This might mean that you will go to the hospital more regularly than usual, so you should bear this in mind when agreeing to participate.

Taking part in a clinical trial does not guarantee you better treatment, nor will you automatically get the treatment being tested. However your psoriasis will be closely monitored by a dermatologist during the clinical trial and therefore any changes, for better or for worse will be quickly picked up and acted upon.

No one should ever include you in a clinical trial without asking you. Any doctor, nurse or other researcher should always ask your permission and, if you do not give your consent, they cannot enter you into the trial.

You will however, be helping to improve our understanding of psoriasis and the best way to treat it. This does not mean that you are obliged to take part. You should only agree to help with a trial if you are entirely happy with what you are being asked to do. It is important to be aware that you can pull out at any time if you change your mind. By reading and understanding more about clinical trials now, with time to think about all the issues, we hope you will feel happier and more confident in your decision, whether or not you agree to take part.

To help you decide whether you want to take part, the researchers should tell you all about the study- what it is trying to find out, how you will be treated and what you will have to do.

Various guidelines have been drawn up for the researchers about the sort of information that people need in order to decide whether to take part in a clinical trial. But there is a lot of debate about how much people really want to know and, of course in practice this varies from person to person. The important thing is that you are satisfied you have enough information to make an informed decision. You should feel free to ask any questions which you believe are important in helping you to reach a decision. You should also feel satisfied that you have been given enough time to think about the trial and what it will mean to you before you decide.

The person who suggests that you take part in the trial should first discuss it with you and answer your immediate questions. He/she will not be able to give you a copy of the protocol since this is a scientific document containing confidential information. However, he or she should give you a leaflet or fact sheet about the trial which you can take away and read at your leisure if you wish. If you wish to take part in the trial, you will be asked to give your written consent. However, remember that even after you have given your consent you are free to withdraw at any time. It will not affect you overall care and your doctor will not hold it against you.

Questions to ask before taking part

- What is the point of the trial and how will it help people ?

  You should feel satisfied that the trial is worthwhile and that it is asking a useful question.

- How long will the study last ?

  This very much depends on the type of the trial but could be anything from a couple of days to a number of months. Therefore if you have a holiday planned bang in the middle of a clinical trial it would be advisable not to participate!

- Can I withdraw at any time ?

  The answer here must be 'YES'

Here is a selection of practical questions you may want to ask, to which there are no 'right' or wrong answers. You just need to be sure that YOU are happy with the demands which the trial will make on you.

- How much of my time will be needed ?
- Will I need to take time off work ?
- Does the research budget cover the cost of my fares to and from the trial centre ?
- What are the possible side effects of the treatment ?
- Who can I contact if I have a problem ? Will someone be available 24 hours a day ?

SUBMITTING ARTICLES

The Skin 'n' Bones Connection does accept articles, letters and press/news releases. Articles should be sent either by post or e-mail to the Managing Editor for review.

The Editorial Team cannot guarantee insertion and reserve the right to refuse inclusion without explanation of any unsolicited material. Material that is accepted may be edited and full accreditation to contributors will be clearly displayed, unless otherwise agreed. Letters to the Editor can be signed off anonymously if preferred.

Advertisements are not currently accepted. All editorial content for products, items and suppliers of such goods is based on recommendation from readers, but are not necessarily endorsed by the charity. Inclusion is for information and educational purposes. Always consult your Doctor before undertaking any new course of therapy, treatment or activity.

PO Box 111, St Albans, Herts. AL2 3JQ. E-mail: info@psoriasis-uk.org

MOST PEOPLE WITH ARTHRITIS DON'T GET ENOUGH EXERCISE

People with arthritis don't exercise enough, and more than a third of adults with arthritis don't exercise at all, according to a study in the May issue of *American Journal of Preventive Medicine.*

"People with arthritis are not meeting physical activity recommendations made at the federal level and by experts in the arthritis field," said co-author Jennifer Hootman, Ph.D., of the Centers for Disease Control and Prevention. "That's not good, because we know that being more active is beneficial for arthritis."

While exercise has been shown to decrease their pain, delay disability and improve gait and function, people with arthritis are even more likely to be inactive than adults in the general population.

"These findings are not surprising," said Kate Lorig, a Professor at the Stanford University School of Medicine, who was not involved with the study. "What's important for people with arthritis to realize is that the most dangerous type of exercise is not to do any."

Hootman and colleagues reviewed data from the 2002 National Health Interview Survey, an ongoing household survey designed to be representative of the U.S. population. The survey included 6,829 people who had been diagnosed with arthritis and 20,676 people without arthritis.

Just 37 percent of adults with arthritis met the least stringent physical activity guidelines established by a panel of experts in arthritis, physical activity and public health in 2001 — a percentage similar to people without arthritis.

But participation rates at the more rigorous federally recommended levels of physical activity were even lower for people with arthritis — 30 percent compared with 33 percent for people without arthritis.

Twenty percent of people with arthritis reported performing some type of activity to strengthen their muscles. Both aerobic and strengthening exercises have been shown to help people with arthritis.

People with arthritis least likely to be physically active were those who had difficulty walking up ten stairs, grasping small objects, bending or kneeling, lifting ten pounds or standing for two hours.

"We can't tell from this survey which came first—the inactivity or the problems with function," said Hootman. "But we do know that getting people with arthritis active actually improves function."

The authors say that fear of pain and the misconception that exercise can harm joints are obstacles to getting people with arthritis to exercise.

Other risk factors for inactivity among people with arthritis included frequent anxiety or depression, especially among women, and severe joint pain among men.

"If we can get people with arthritis over the initial pain barrier by addressing their pain and getting them more active, they'll actually have less pain in the long term," Hootman said.

FOR MORE INFORMATION:
Health Behavior News Service
www.hbns.org.

Technology Appraisals (NICE)

NHS National Institute for Health and Clinical Excellence

The NICE Technology Appraisal process assesses the clinical and cost-effectiveness of new and existing technologies (e.g. drugs, surgical procedures, therapies) to make recommendations for their use in the NHS. Patient and carer organisations who comment on draft scopes, submit evidence on patient views, and comment on draft guidance produced by NICE. Individual patients and carers who attend committee meetings as Patient Experts.

Examples of patient input that the NICE appraisal committee has found helpful:

Patient views on the effects of treatment: in an appraisal of drugs for short-term management of insomnia, the research evidence suggested that addiction was not a particular problem for the newer drugs. This was not the experience of the patients and carers who submitted evidence. The final guidance recommended that both the newer and older drugs should not be used for long periods of time.

Patient views on the relevance of outcome measures used in research: in the appraisal of drugs for the treatment of psoriasis, in research studies, the severity of the condition was measured as the proportion of the patient's skin affected by psoriasis. However, patient and carer contributions indicated that what really influences the quality of life of patients with psoriasis is not just how much skin is affected, but where on the body the condition occurs (e.g. in skin flexures or on the face). The outcome measure used in the published research was therefore seen to be imprecise and the recommendations were modified to include measures of quality of life.

Patient views on the acceptability of new treatments: in the appraisal of a group of drugs for the treatment of advanced ovarian cancer, it became clear that although one of the new drugs was less toxic than conventional treatment, certain side-effects would outweigh the positive effects in some cases. Evidence submitted by patients and carers showed that because the drugs could cause the skin on hands and feet to flake and scale, everyday life could become so difficult for women that they might opt not to have treatment. The Appraisal Committee considered this in their deliberations.

Clinical Guidelines

Contributing to a NICE clinical guideline – a guide for patient and carer groups In April 2006, the PPIP will be publishing a *"how to"* guide on contributing to a NICE clinical guideline. Written specifically for patients and carers (organisations and individuals), the guide goes through the guideline development process step-by-step, explaining: how organisations can contribute through the stakeholder consultation process, and the role of patient and carer members of Guideline Development Groups. The guide gives tips and suggestions, including what to look for when commenting on draft guideline documents. We welcome your feedback on *"A guide for patient and carer groups"*, which will be available as a booklet and on the NICE website at www.nice.org.uk.

Public Health Guidance

NICE now has responsibility for publishing two types of public health guidance, "interventions" and "programme" guidance. The PPIP is working with NICE's public health team to ensure that patients and the public are involved in this work. **Public Health "interventions"** guidance makes recommendations on specific types of activities provided by local organisations either to reduce people's risk of ill-health or to promote or maintain healthy lifestyles. NICE "interventions" topics include:

Smoking cessation in primary care
Methods to increase physical activity

Preventing sexually transmitted infections, and preventing pregnancies in the under 18s

Three lay members have been recruited to the new **Public Health Interventions Advisory Committee (PHIAC)** involved in the production of "interventions" guidance. **Public Health "programme"** guidance deals with broader action than "interventions". It is developed by Programme Development Groups, which include patient/public members. Forthcoming topics include:

Supporting attitude & behaviour change

The optimal provision of smoking cessation services

Improving the nutrition of pregnant and breastfeeding mothers, and children

Further details on how NICE public health guidance is developed can be found at: www.publichealth.nice.org.uk/page.aspx?o=CPHEOperatingModel.

Interventional Procedures

Producing NICE guidance on Interventional Procedures

An interventional procedure is a procedure used to diagnose or treat an illness or condition, often involving surgery, the use of x-rays or other methods of investigating the inside of a patient's body. NICE guidance on interventional procedures considers how safe a procedure is, and whether it works well enough to be used routinely in the NHS. NICE Interventional Procedures guidance is produced by the **Interventional Procedures Advisory Committee (IPAC)**, which includes two lay members. Michael Davidson, lay IPAC member said: "I have found members of the committee extremely respectful of my lay position, generous in sharing information and [they have] a genuine preparedness to accept me as a contributor and not as an 'ornament'".

Consultation process

Patients and carers (organisations and individuals) can comment on draft interventional procedures guidance when it is posted on the website for consultation. Joanna Pearl, the new PPIP Project Manager, can advise on how to register an interest and comment on any piece of interventional procedures guidance.

Implementation of NICE recommendations

Dedicated teams at NICE are working with local NHS organisations and other bodies to promote the uptake of recommendations made in both clinical and public health guidance. The PPIP promotes and supports patient organisations and groups such as Patient and Public Involvement Forums and Patient Advice Liaison Services (PALS), individual patients and members of the public to help push the implementation agenda forward. For Clinical Guidelines, NICE holds a planning meeting towards the final stages of a guideline's development. Key stakeholders, including patient organisations, are invited to discuss the major implementation issues for each individual guideline. If there are significant issues relating to a particular guideline that you would like to raise at the planning meeting, please contact the relevant PPIP Project Manager.

Details can be found on the guideline-specific pages of the website at www.nice.org.uk.

Gene May Help Solve Psoriasis Mystery

A common genetic variation in an immune system gene may help explain why some people are more likely to develop psoriasis than others.

Researchers say it's the first gene to be linked to the skin disease, and the discovery could lead to more effective treatments for psoriasis with fewer side effects.

Drugs used to treat psoriasis target the irregular immune system response that is thought to trigger the disease. These drugs counter this immune response but can leave the body more susceptible to infection.

By finding the specific gene that triggers the disease, researchers say more targeted psoriasis treatments could be developed.

"What we're all shooting for is trying to find out which branches of the immune system are triggering psoriasis, so you don't have to shut down the whole immune system -- only the parts that are important," says researcher James T. Elder, MD, PhD, Professor of dermatology and radiation oncology at the University of Michigan Medical School, in a news release.

Psoriasis Gene Found

In the study, published in the *American Journal of Human Genetics*, researchers isolated the gene PSORS1 (for psoriasis susceptibility 1) as a major player in psoriasis susceptibility from among a field of several genes that regulate how the immune system fights off infection.

Researchers say the gene's role in triggering psoriasis was demonstrated in 2,723 people from 678 families in which at least one family member had the skin disease.

But having the gene isn't enough to cause the disease. "For every individual with psoriasis who carries the PSORS1 gene, there are 10 other people with the gene who don't get psoriasis," says Elder.

"It's as if you are pushing a shopping cart down the aisle at the grocery store and putting genes in your cart," Elder explains. "There are several different brands of each gene on the shelf and one of them is bad for you. If you pull down enough bad ones, then you can get sick.

"But even if you get all the bad genes, you still need a trigger from the environment to develop the disease," says Elder. In some cases, that trigger may be infection, such as strep throat.

Researchers say the next step is to identify the other inherited genes that may play a role in psoriasis in order to develop better treatments for the skin disease.

SOURCES: Nair, R. American Journal of Human Genetics, May 2006; vol 78. News release, University of Michigan.

To avoid stomach upset in arthritis patients, drug combination more effective

University of California Los Angeles (UCLA) researchers found that for arthritis patients, taking a combination of two drugs may be most effective in protecting against stomach upset called dyspepsia, which is a side effect of common pain medications.

Published recently in The American Journal of Medicine, the study showed that for arthritis patients, taking an anti-inflammatory drug like naproxen with an acid-reducing drugs may prove more effective than taking a Cox-2 inhibitor like celecoxib alone for protecting against stomach upset.

According to researchers, non-steroidal anti-inflammatory drug (NSAIDS) are the most commonly used medications for these conditions, but often cause gastrointestinal discomfort known as dyspepsia.

"Dyspepsia can be a major problem for patients, causing stomach upset symptoms such as nausea, bloating, gas and belching," said Dr. Brennan M.R. Spiegel, study author and director, UCLA Center for Outcomes Research and Education (CORE). "These symptoms are far more common than more serious side effects like ulcers or bleeding."

Researchers found that compared to taking an over-the-counter anti-inflammatory by itself, a Cox-2 inhibitor taken alone reduced dyspepsia occurrence by 12 percent. An anti-inflammatory taken with an acid-reducing drug together, however, lowered incidence of dyspepsia by 66 percent.

"The drug combination was significantly more effective in reducing dyspepsia and may prove to be the preferred treatment for arthritis patients at high risk for stomach problems," said Spiegel, assistant professor of medicine, David Geffen School of Medicine at UCLA and Veterans Affairs Greater Los Angeles Healthcare System.

The study involved a systematic review of clinical trial findings in medical literature and then researchers conducted a more sensitive meta-analysis of the results.

Source www.eurekaltert.org

MOVING FROM PAPER TO ELECTRONIC PRESCRIPTIONS

Did you know that about 1.3 million paper prescriptions are issued every working day in England, with this figure set to rise by over 5% each year? And that about 70% of prescriptions are repeats?

To handle this volume more efficiently, the NHS is introducing an Electronic Prescription Service. In time, this service will allow your prescription to be sent electronically from your GP to the pharmacy of your choice. This will mean improved service, convenience and accuracy. The service is being introduced in two stages.

ADDING A BARCODE

In the first stage you will still receive a paper prescription in the way you do now. The only change will be that your prescription will have a barcode and some numbers down the right-hand side.

These provide a unique reference for your prescription but they don't hold any personal information about you. They are only there to help the pharmacist dispense the items on your prescription more easily.

The new service will be more accurate, as the prescription information won't have to be re-typed into the computer at the pharmacy.

This first stage of the Electronic Prescription Service has been designed to make sure that everything works efficiently before the introduction of a full version of the service. So, for now, the way you collect your prescriptions or medicines won't change.

We will let you know when your GP surgery or pharmacy is moving to the second stage of the service.

THE SECOND STAGE

Nominating a preferred pharmacy

Sometime between the middle of 2006 and the end of 2007, each GP surgery and pharmacy will move to the second stage of the service.

You will be able to ask your GP to send your prescription to a pharmacy of your choice electronically, so you won't need a paper prescription at all – unless you want to have one.

This may save time by reducing how often you have to visit your GP surgery simply to collect a paper prescription. In future, you will be able to go straight to the pharmacy to pick up your medicines.

As well as increased convenience for patients, this second stage of the service will also bring substantial improvements in efficiency for GPs, pharmacists and their staff.

SOME COMMON QUESTIONS

How will I obtain my prescriptions?

During the first stage, in the same way as you do now. During the second stage there will be some changes to make it easier for you. Your GP surgery will tell you about these when they happen.

Will I still be able to use any pharmacy I want?

Yes, you will always be able to use any pharmacy. You will still have the option of collecting a paper version of your prescription from your GP and taking it to any pharmacy.

Will I need to know anything about computers to use the service?

No, your GP and pharmacist will be the people using computers to provide a better service for you.

Who will see my prescription?

The same people who can see it now. Whether information is on paper or electronic, everyone involved with your prescription has a legal duty to keep information about you confidential.

Will this affect prescriptions I receive from people other than my GP?

No, not yet. We intend to include prescriptions given by other people such as dentists, nurses and hospital doctors eventually but we are concentrating on GPs and pharmacists first.

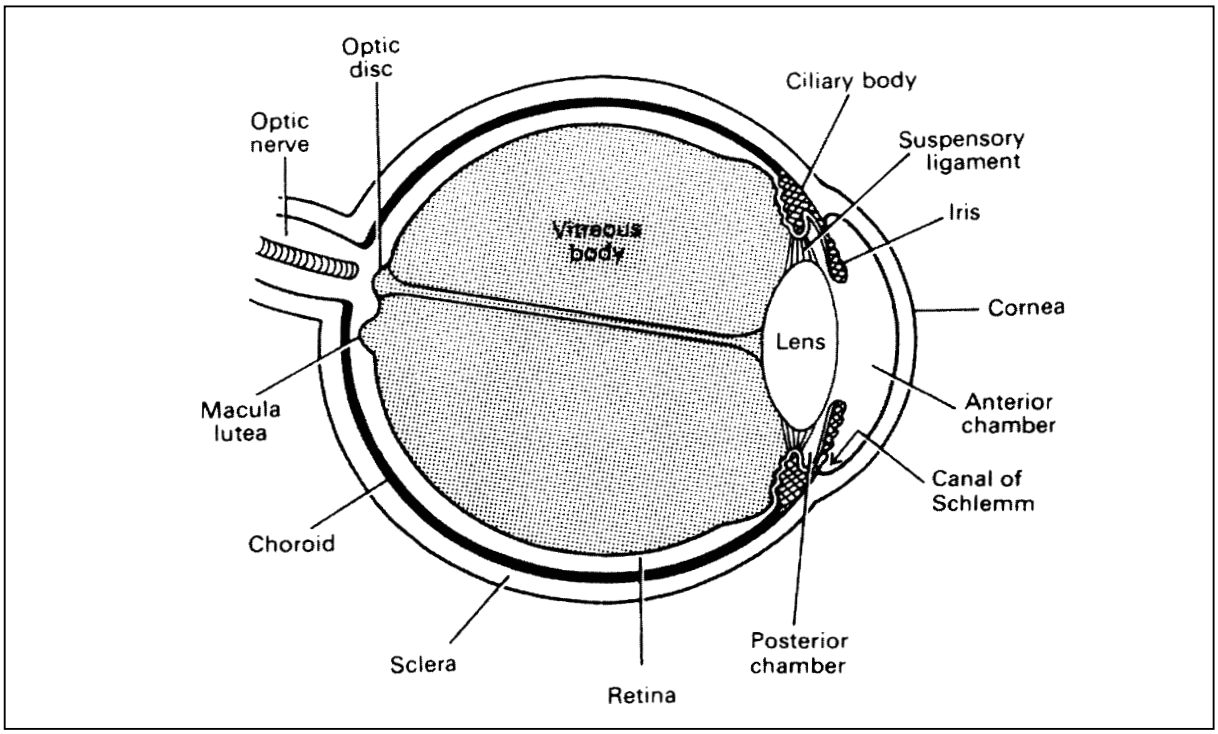
MORE INFORMATION

Is there anything else I should know?

The Electronic Prescription Service is being implemented gradually to give everyone time to get used to the new arrangements. Paper prescriptions are only being phased out slowly. Even when the Electronic Prescription Service is fully implemented a paper version of your prescription will continue to be available if you need one. Over time, many people will see considerable benefit from the new Electronic Prescription Service. More information is available from www.cfh.nhs.uk/eps or you can ask at your GP surgery or pharmacy.

Psoriatic Arthritis and the eyes

Fewer than 1 in 10 people with psoriatic arthritis develop a problem with the eyes called uveitis.



Uveitis

Uveitis means inflammation of the uvea. This can affect the iris (iritis), ciliary body (cyclitis) or the choroid (choroiditis). Symptoms depend on whether all or just part of the uvea is affected, but may include:

- dull, aching pain in the eye
- redness
- risk is higher if B27+?? so common in spondylitis sub groups
- it can occur whether arthritis currently active or not
- blurred or misty vision
- a muddy appearance to the coloured iris in the affected eye
- a pupil that may be smaller than on the other side and irregular in outline.

Symptoms can affect one or both eyes. Inflammation is thought to result from the immune system attacking the cells of the uvea. Treatment of uveitis is urgent to stop the inflamed iris from sticking to the lens behind. This would cause permanent damage to the eye and can also trigger glaucoma (rise in fluid pressure in the eye due to blocked drainage channels). Uveitis often returns from time to time.

Note: Children with psoriatic arthritis should have regular screening tests for uveitis as they may not develop symptoms until their eyesight has been damaged and irreversible visual impairment takes place.

Treatment

Inflammation is damped down with eye-drops containing corticosteroid drugs. In severe cases, you may also need to take steroid tablets by mouth to boost the effect of the drops. Eye-drops that relax the iris and ciliary body are also used. These make the pupil dilate and ensure that an inflamed iris does not stick to the eye lens (posterior synechia). The inflam mation is monitored by regular examination of the eye using a slit-lamp. If steroid eye drops are used for prolonged periods, the fluid pressure in the eye will also need to be checked regularly. This is because long-term use of steroid drops can cause a form of glaucoma.

Useful address

The Royal College of Ophthalmologists (eye specialists): Tel: 0207 935 0702 Fax: 0207 935 9838- 17 Cornwall Terrace, London NW1 4QW. Can provide a list of practising ophthalmologists. www.rcophth.ac.uk

This is Factsheet No. 20 from Psoriatic Care Fact File 2nd edition
ISBN 0-9547465-0-3 Published by PAA 2004

Sensitive areas in Psoriasis

Psoriasis is an acceleration of the usual replacement processes of the skin. Normally a skin cell matures in 21 to 28 days and during this time it travels to the surface, where it is lost in a constant invisible shedding of dead cells.

In patches of psoriasis the turnover of skin cells is much faster - around four days - and this means that even live cells can reach the surface and accumulate with dead cells in visible layers.

This process is the same wherever it occurs on the body.

What defines a 'sensitive' area?

Skin in some areas of the body is thinner and here it may be more sensitive to treatment. These areas might include the face and the hairline. In addition, the flexures - in skin folds, armpits, under the breasts between the buttocks and in the groin area are usually more sensitive.

How does psoriasis differ in a sensitive area'?

Psoriasis in 'sensitive areas' often does not have the typical 'plaques' or scaliness seen in other areas and appears as bright red, shiny patches of skin.

What causes psoriasis in 'sensitive areas'?

Psoriasis commonly affects sensitive areas, but it is not always easy to identify what the triggers are.

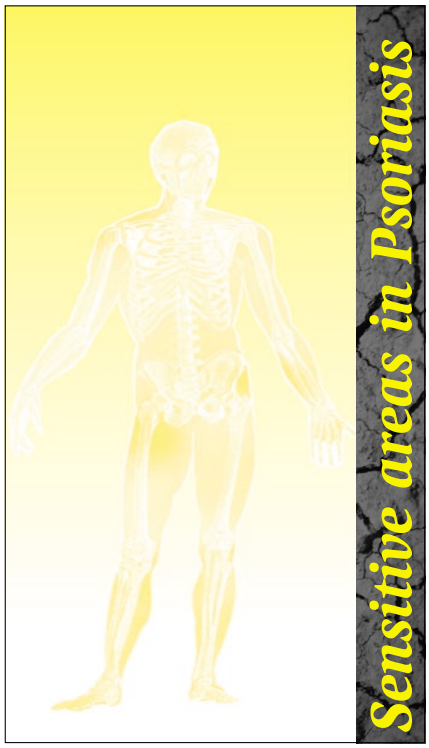
In the armpits and in the flexures and groin area it may be worsened by tight clothing rubbing the skin, by deodorants or antiperspirants, or by contraceptives - sheaths, caps and spermicides, sanitary towels or tampons, harsh toilet paper, thrush or sexual intercourse.

Should I treat my psoriasis in sensitive areas differently?

If you develop psoriasis in a sensitive area, you should discuss it with your doctor, as some products are more suitable for treating these areas.

With all psoriasis it is very important that you routinely use a moisturiser/emollient to make the skin more comfortable. In addition, there is a range of topical treatments available - creams and ointments - that your doctor can prescribe.

Topical vitamin D creams and ointments are very effective in treating psoriasis and the newer types are less likely to cause irritation, which was traditionally a problem with these products. This means you may be able to reduce the numbers of different types of treatments that you use at any one time, by using the same one at all sites.



Topical steroid creams may be recommended for sensitive areas. However, care should be taken with their use in flexures as the warm, air-free environment can increase the strength of cream and may lead to side effects such as skin thinning. It is also important that topical steroids are not used for long periods of time or without close supervision from your doctor. Treatment should never be stopped abruptly as this may trigger a rebound flare of your psoriasis.

Topical steroids may also be combined with anti-fungal and anti-bacterial agents because infections with yeasts and bacterial are more common.

If you have scalp psoriasis you may have specific treatments prescribed by your doctor. If these cause irritation around the hairline and on facial skin, you should talk to your doctor about a different type of treatment that is approved for use in sensitive areas.

Your doctor may refer you to a dermatologist if you have very extensive psoriasis or if your psoriasis has not responded to the treatments he has prescribed for you. Other types of treatment are available for the dermatologist to prescribe.

Can I use make-up to conceal the psoriasis on my hairline and face?

There are organisations that specialise in camouflage make up, including the British Red Cross Skin Camouflage Service (www.redcross.org.uk) and the Skin Camouflage Network (www.skincamouflagenetwork.org.uk).

However, make up could interfere with the efficacy of your topical psoriasis treatments and this is something that should be considered very carefully and discussed with your doctor.

Is it catching?

Psoriasis is not an infectious condition. It is not clear exactly what causes psoriasis, but it seems likely that there is some sort of genetic connection as members of the same family may often be affected.

Fortunately, many people with psoriasis go through long periods where they are free of any symptoms.

VIOXX® (rofecoxib) update

The world's largest class action lawsuit has been launched in the US by patients seeking compensation for heart damage and strokes they claim were caused by Vioxx, the Cox-2 inhibitor produced by Merck. The drug company anticipates legal action in Europe, Canada, Brazil, Australia and Israel.

Merck is hoarding $604m (£320m) to defend itself over several years, a cost which left the company's fourth quarter profits down by 21 per cent. Merck has lost over $800m due to Vioxx since it was pulled from the shelves in September 2004.

A controversial study published in The Lancet by an employee of the US Food and Drug Administration (FDA), David Graham, found that as many as 140,000 cases of heart disease and up to 56,000 deaths in the US could have been caused by the painkiller over the five years it was on the market. The study, which ran over three years at Kaiser Permanente hospital in California, was sponsored by the FDA and scheduled for publication in November 2004.

The risk of heart disease and death was substantially higher among patients taking Vioxx compared with ibuprofen, naproxen, and another Cox-2 inhibitor Pfizer's Celebrex. Graham says the FDA delayed publication until January 2005.

Meanwhile, a flurry of papers on the safety of Cox-2 inhibitors has been published, including a University of Connecticut School of Medicine study led by William White. His team report in the Archives of Internal Medicine that Vioxx treatment increased blood pressure significantly in patients with type two diabetes, hypertension or osteoarthritis. This was not the case for Celebrex or naproxen in the same patient group. Elsewhere, the jury is still out on Celebrex. Researchers at the US National Institutes of Health found no increased cardiovascular risk for elderly patients, but a US National Cancer Institute trial on cancer patients measured a more than doubled risk of cardiovascular problems and suspended the drug. Also, an unpublished study, coauthored by Graham, links high doses of Celebrex to heart problems.

Despite this uncertainty, experts seem to agree on one thing: sales of the Cox-2 class of drugs will be slashed in the wake of the high-profile Vioxx trials.

Source: Royal Society of Chemistry

LATEST FINDINGS
on Clinical Trial suspension

MHRA

The MHRA has today released its interim report into the adverse incidents which occurred on 13th March 2006 during the clinical trials of TGN1412 (see report below).

It has found no evidence to suggest that there was any problem with the manufacturing of the product which was given to the trial volunteers – it appears not to have been contaminated, or to have contained anything other than the correct ingredients. Neither have we found anything in the way the trial was run which contributed to the adverse reactions experienced by the volunteers – it was run according to the agreed protocol, and the correct dose of the product was given to the patients.

"There are still further tests planned and until these are complete we cannot be firm about our conclusions. However, if these findings were to be confirmed, it would indicate that this product showed a pharmacological effect in man which was not seen in pre-clinical tests in animals at much higher doses. The Secretary of State for Health has therefore agreed to establish a group of leading international experts in the field to examine the issue further. The Group will need to review the evidence from the TGN1412 case and consider what necessary changes to clinical trials may be required", says MHRA Chief Executive Professor Kent Woods. **www.mhra.gov.uk**

Skin'n'Bones Connection

The EHIC: free or reduced cost treatment

A European Health Insurance Card (EHIC) entitles you to reduced-cost, sometimes free, medical treatment that becomes necessary while you're in a European Economic Area (EEA) country or Switzerland.

The EEA consists of the European Union (EU) countries plus Iceland, Liechtenstein and Norway. Switzerland applies the EHIC arrangements through an agreement with the EU. The EHIC is valid in:

Austria	**Greece**	**Netherlands**
Belgium	**Hungary**	**Norway**
Cyprus (but not Northern Cyprus)	**Iceland**	**Poland**
	Ireland	**Portugal**
Czech Republic	**Italy**	**Slovakia**
Denmark	**Latvia**	**Slovenia**
Estonia	**Liechtenstein**	**Spain**
Finland	**Lithuania**	**Sweden**
France	**Luxembourg**	**Switzerland**
Germany	**Malta**	

Important changes to healthcare cover in Europe

The EHIC has replaced the old E111. From 1 January 2006, E111s are no longer valid. The quickest and easiest way to get an EHIC is to apply online.

What does the EHIC cover?

The EHIC is normally valid for three to five years and covers any medical treatment that becomes necessary during your trip, because of either illness or an accident. The card gives access to state-provided medical treatment only, and you'll be treated on the same basis as an 'insured' person living in the country you're visiting. Remember, this might not cover all the things you'd expect to get free of charge from the NHS in the UK. You may have to make a contribution to the cost of your care.

The EHIC also covers any treatment you need for a chronic disease or pre-existing illness. You need to make arrangements in advance for kidney dialysis and oxygen therapy. To arrange for kidney dialysis while you're away, contact your NHS renal unit in the UK before you travel. For limited information on oxygen supply services in the EEA countries and Switzerland, call the Department of Health's Customer Service Centre on 020 7210 4850.

Remember that the EHIC won't cover you if getting medical treatment is the main purpose of your trip. You are advised to take out comprehensive private insurance for visits to all countries, regardless of whether you are covered by your EHIC.

Your EHIC should cover you for routine maternity care while you are away. However, if you are going to an EEA country or Switzerland specifically to have your baby, you will need an E112 form - see the 'Non-emergency treatment section' for more information.

Who is eligible for an EHIC?

People who are ordinarily resident in the UK are entitled to a UK-issued EHIC. It is not valid for people who are going to live abroad. There are some restrictions, depending on your nationality:

- **UK and other EU nationals, stateless persons and refugees** are covered in all EEA countries and Switzerland. However, if you are a national of Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia, your EHIC is not valid in Switzerland.
- **nationals of Iceland, Liechtenstein and Norway** are covered in all EEA countries but not in Switzerland.
- **people who do not have UK, EU, EEA or Swiss nationality** are covered in all EU countries but not in Denmark, Norway, Liechtenstein or Switzerland. In Iceland, these people are covered for emergency treatment only.
- **Swiss nationals** are covered in all EU countries but not in Iceland, Liechtenstein or Norway.
- **dependants of EEA nationals** who are ordinarily resident in the UK are covered in all EEA countries and Switzerland, irrespective of their own nationality.

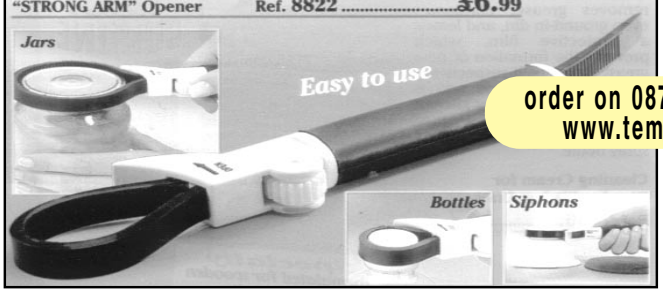
www.ehic.org.uk

GISMOS & GADGETS

Jars give way to the 'STRONG ARM' treatment!

No more struggling with stubborn jars, tight bottle caps, or blocked siphons you cannot open! Fit the non-slip strap around the top, tighten by turning the wheel with your thumb, and press the handle. That is all there is to it! Suitable for all diameters from 20 to 100 mm; takes the place of several tools, does the job quickly and without hurting your hands! Ideal when you need a "strong arm" around the house! 17 cm long.

"STRONG ARM" Opener Ref. 8822 ..... £6.99



order on 0870 404 5678
www.tempsl.com

Opens ring pull tins, jars and bottle caps effortlessly

This new gadget will make your life easier: with your SMART FISH, you can open ring pull tins without hurting your hands and spilling a drop. You can use the knob on the back to lift the lids of jars so you can unscrew them easily ; you can also use the serrated shape on the other side to unscrew bottle caps effortlessly (up to 55 mm). Manufactured from very strong plastic. Try it now!

SMART FISH
Ref. 5440 ..... £6.99

Scoop and slice

Thanks to their curved shape and three different sizes, these scoops make it easy to hollow out and slice fruits and vegetables. The blades cut the flesh (spiral or straight) without tearing the skin. They allow you to quickly and easily remove seeds from tomatoes, peppers, melons, watermelon, kiwis, etc. They're also handy for avocados and potatoes. Dishwasher safe. Food-grade plastic. Set of 3, diameters: approx. 8.5, 5.5, 4 cm. Length of stainless steel handles: approx.12 cm.

order on 0870 404 5678
www.tempsl.com

Set of 3 fruit/vegetable scoops Ref. 5234 ..... £6.50

order on 0870 600 3366
www.stowgrange.co.uk

A Rophi Knee Cushion

Knee cushions are the best way to ease back pain and aching legs, but they do tend to slip when you turn over during the night. This knee cushion comes attached to an anti-slip stocking, so it will stay in place however restlessly you sleep. The comfortable polyester fibre-filled pad prevents perspiration and is covered with a 60% polyester/ 40% cotton fabric and is clinically proven to improve your posture by ergonomically correcting the position of your pelvis and spine. Pad measures 3½" x 7" x 6½" and weighs under 4oz. The entire pad and stocking can be machine washed and tumble dried. ***Buy 2 and SAVE £2.***

26042 Rophi Knee Cushion **£14.95**
29467 Rophi Knee Cushion (2) **£27.90**

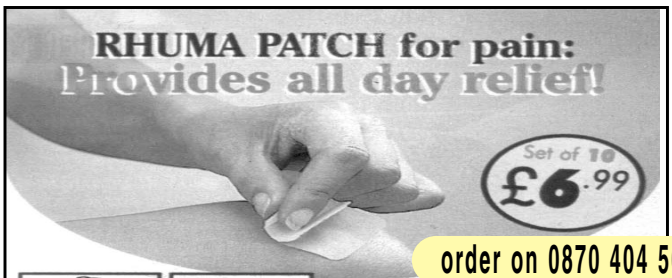
www.stowgrange.co.uk

Protect Sensitive Feet

Our Foot Elevator will provide you with relief and support, ideal if you suffer from arthritic legs or sensitive feet. Extremely comfortable to wear and will keep the pressure from bed covers off your legs. Made from foam and fastens with an adjustable touch fastening strap.

55107 Foot Elevator £9.95

RHUMA PATCH for pain: Provides all day relief!



order on 0870 404 5678 www.tempsl.com

Joint pain, muscle spasm, stiffness: apply a RHUMA PATCH to the painful area. Its 100% natural formula, containing extracts of Solomon's seal, meadowsweet, devil's claw and arnica, famous for their soothing qualities, for joints and stiffness, reinforced with essential oils of mint and juniper, is diffused evenly and continuously through the epidermis and remains active for 8 to 12 hours. The active principles incorporated directly into the patch ensure maximum efficiency. Hypoallergenic and with no side effects, patches can be applied to all parts of the body (except mucous membranes). They are waterproof and perspiration resistant. A big step forwards in pain relief! Pad of 10 patches. Size: 4 x 4 cm.

Set of 10 Pain Relief Patches
Ref. 8516 ..... £6.99

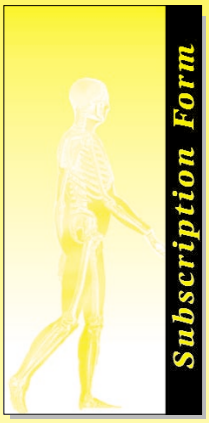
Carry and pour easily

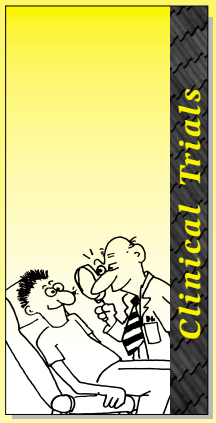
With the Handibrik® handle, you'll be able to hold and pour clumsy flat-top juice and milk cartons without spilling a drop. It easily snaps onto flat-top cartons and is easy to hold. Ready to use, simply click on. Hygienic, simple and efficient. Polypropylene. Dishwasher safe. Red, set of two. Dimensions: approx. 12 x 10 x 7 cm.

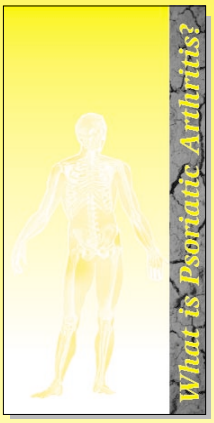
2 Handibrik® handles Ref. 5248 ..... £5.50

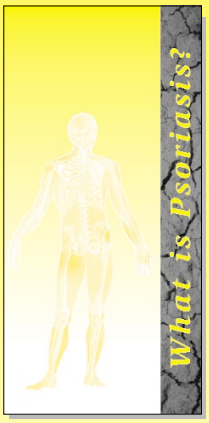
Skin'n'Bones Connection

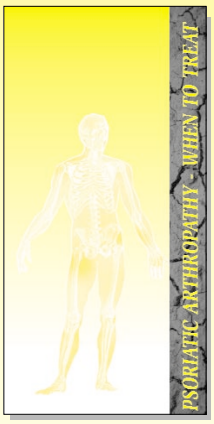
PUBLICATIONS

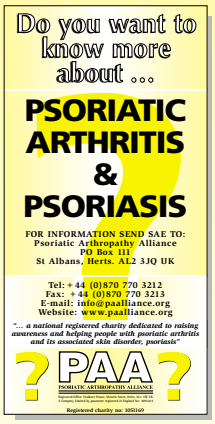


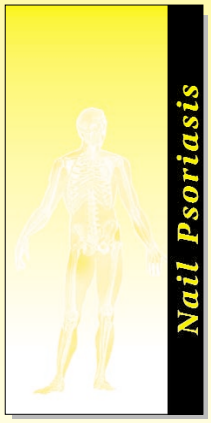


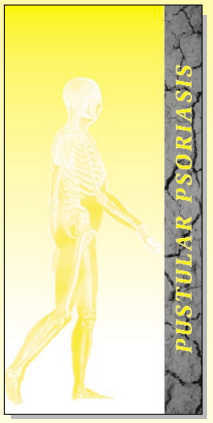


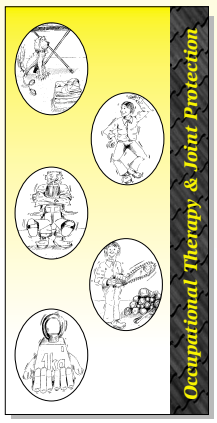


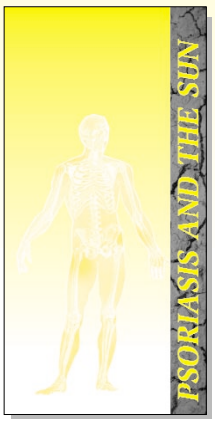


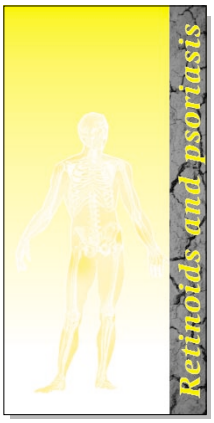


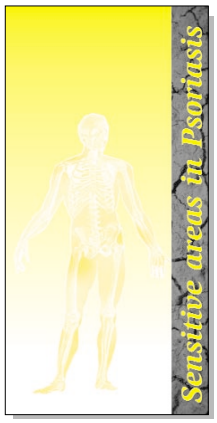












PAA Publications
order form

(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 1997	50p ~~£3.00~~		
PAA News	9	Autumn 1997	50p ~~£3.00~~		
Skin 'n' Bones Connection	9	Winter 1997	50p ~~£3.00~~		
PAA News	10	Spring 1998	50p ~~£3.00~~		
Skin 'n' Bones Connection	10	Summer 1998	50p ~~£3.00~~		
PAA News	11	Autumn 1998	50p ~~£3.00~~		
Skin 'n' Bones Connection	11	Winter 1998/99	50p ~~£3.00~~		
PAA News	12	Spring 1999	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	50p ~~£3.00~~		
Skin'n'Bones Connection	16	2002	£3.00	Out of stock	
Skin'n'Bones Connection	17	2003	£3.00	Out of stock	
Skin'n'Bones Connection	18	2003	£3.00		
Skin'n'Bones Connection	19	2004	£3.00		
Skin'n'Bones Connection	20	2004	£3.00		
Skin'n'Bones Connection	21	2005	£3.00		
Skin'n'Bones Connection	22	2005	£3.00		
Skin'n'Bones Connection	23	2006	£3.00		
What is Psoriasis? leaflet	-	2004	Free		
Occupational Therapy & Joint Protection Booklet	-	2003	Free		
Physiotherapy and Exercise Booklet	2nd edition	2004	Free		
What is Psoriatic Arthritis? leaflet	-	2004	Free		
PsA Did you know? leaflet	-	2004	Free		
Psoriatic Arthropathy-When to treat, leaflet	-	2004	Free		
Pustular Psoriasis leaflet	-	2004	Free		
Sensitive Areas in Psoriasis leaflet	-	2004	Free		
Retinoids and Psoriasis leaflet	-	2004	Free		
Psoriasis and the Sun leaflet	-	2004	Free		
PAA subscription form leaflet	-	2004	Free		
Clinical Trials booklet	-	2001	Free		
Nail 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		
Emollients and Psoriasis leaflet	-	2004	Free		
PAA -The Birth of a Charity A4 pamphlet	1st edition	1996	50p		

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

Key Facts about psoriasis booklet	-	-	£1.50		
Psoriasis Fast Facts	-	-	£4.50		
Rosie's Armchair Exercises	-	-	£4.99		

+ 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@thepaa.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 RETURN TO PAA

SUBSCRIPTION FORM

Please complete the following clearly:-

SECTION 1 and SECTION 2 (optional)

SECTION 1

First Name(s) .....

Last Name .....

Title (Miss, Ms, Mrs, Mr., 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, 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 PsA? .....

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

Areas/joints affected? .....

Medication tried (please list) .....

.....

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

.....

Any family history of PsA 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

Letters

Dear PAA

I just wanted to thank you for all the details you have listed on your website. My Gran cut out your article in the Mail on Sunday. I was close to tears just reading it. It might sound extreme but for the past year I have discovered I have PsA.

It started a few years ago (I have had psoriasis since I was about 6) It was so bad that on some days it was difficult to hold anything from a bag to a cup. When I was getting ready for work I found it hard to walk around for the first few hours.

The only way I described this to the Doctor was that it was like "Walking on cobbles". I became unable to open bottle tops and jars and my wrists and fingers became weak. I ended up last year having 3 months off work. I work in a call centre and the typing was crippling me, although this was only on my rest days, It was as if while I was busy working I would forget then on my rest days I would be crippled by the pain.

I went for various tests and waited to see a specialist and came out disheartened. He gave me Arcoxia tablets I felt like I had been fobbed off, then 3 weeks later I felt so much better. I was told this was a short term medication and practically begged the doctor to allow me to continue with them.

It has been 6 months now and the pain has returned as my body was getting used to the medication.

I returned to a different specialist and they explained in more detail PsA. I had more blood tests and x-rays. I was then given Sulphasazine 500mg. I started taking 1 a day and then increasing this to 4. I have been taking these for 2 months and I don't like them they make my stomach hurt and I sometimes feel sick. I have to have blood tests every 2 weeks for 3 months and I am due to see the specialist in a month. They did tell me it would take 3 months before they work. Am I wrong to stop taking them?

My Doctor is not very good and I was scared by what I was told about these tablets by the specialist.

My fingers hurt and although my feet no longer hurt my ankle is swollen and my small toe is enlarged. The pain in my hands is sometime unbearable I feel like I will have to give up my job. I know my health is paramount but can't imagine what I can do to earn my income.

I am 34 yrs old and the reason I was close to tears is that for so long I have been worried that I was being fobbed off and it was encouraging to read that someone like you actually had the same issues like me.

My partner is supportive we have been together 12 years but nobody can understand unless you go through the same.

I will join up with your charity I just need to get the request printed off at my aunts as I don't yet have a printer. I have found the information on your website very informative.

If I have to give up work what would I need to do in relation to finances?

As time goes on I know I feel like I cant keep putting my hands through the daily agony of having to meet targets such as only having so long to type after each call which is sometimes difficult and also having to wait for a wrist rest and signing a disclaimer for the wrist rest. One day when I was in so much agony I could not take calls because my hands were so sore.

I work for a well known telecoms company and they were ok when I was off sick but now I am back it's like they don't want to know.

Anyway keep up the good work and I am sorry I have gone on but I was pleased to see that there is light at the end of the tunnel.

Kind regards

This letter has been edited and the writer's name withheld.

Dear PAA

I was diagnosed with PsA after 2 years of pain and was initially told it was all in my mind. My GP was advised to refer me to someone as my problem was physical not psychological.

Waking in the morning as if my ankles were broke my mother then decided to pay for me to see a rheumatologist. In May 2002 I was diagnosed with PsA. I had no skin lesions it was only on my scalp and knee.

I had blood tests every 3 months up to August 2005 and still no sign of problems with blood tests except raised liver enzymes which then suggested I was having drink problem this was then proved wrong as I was tea total. My condition has become so bad I can't leave the house, drive my car or can hardly walk.

My Rheumatologist sadly become ill in August 2005 and I am left alone with my disease crippling me. There is no other rheumatologist to take his place. I don't bother going to our local hospital as they say I am a specialised subject and can't help me. Inflammation was so bad recently I rang my doctor to help me with my pain but he would not come and see me just said "take more Ibrobrufen or pay and get a second opinion".

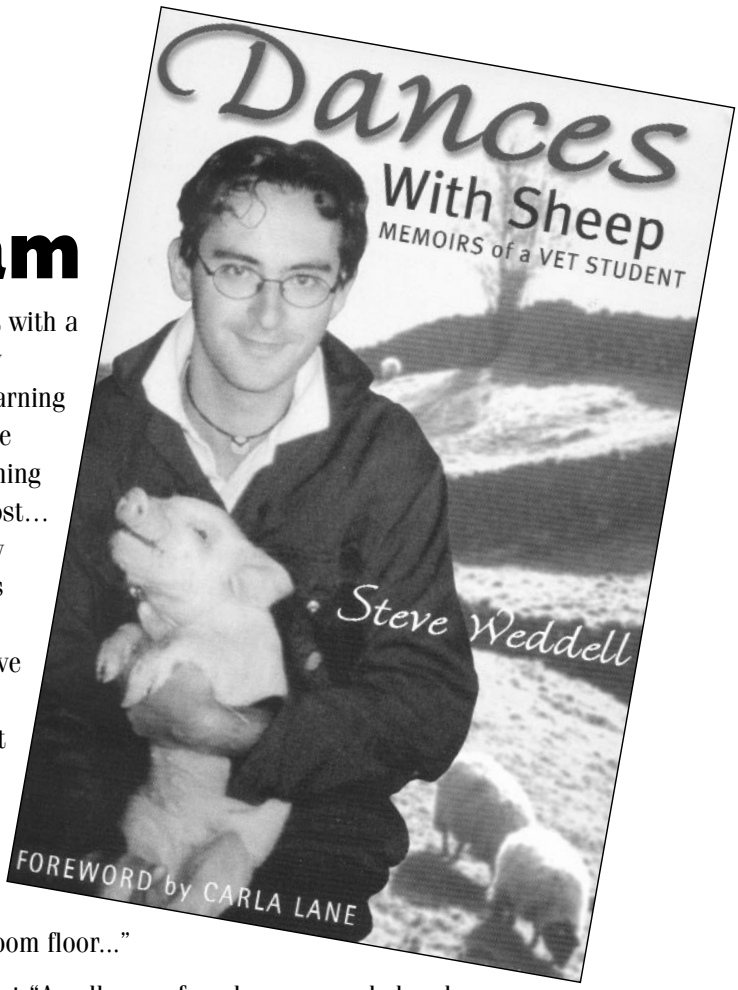
My pain tolerance levels are so high I think its ok to be crippled but can't handle it any more all over my body. If I were an animal my owners would probably be prosecuted for neglect.

I wanted to write maybe it will help another human being from suffering like I am.

Yours

This letter has been edited and the writer's name withheld.

Overcoming psoriatic arthritis to achieve a dream



Steve Weddell was a thirty-year old zoology student with a season ticket at Anfield when he went to veterinary school. He and his fellow students faced a steep learning curve and a long hard slog, combining studies in the classroom with hands-on practical work and cramming for exams. But it was tougher for Steve than for most… not only was he a mature student, coming relatively late to veterinary ambition, he had also spent years battling the painful symptoms of psoriatic arthritis. Recently on BBC Radio 4 Mid-week programme Steve recounted how he had tried to treat himself "…by filling his pockets with aspirin and take them whilst no one was looking"

Steve battled on and in an article which appeared in the Edinburgh News Steve wrote. "On bad days, rising from bed could be utter agony, requiring six aspirin to even see me make contact with the bedroom floor..."

Eventually, after collapsing on the university precinct "A colleague found me, crumpled and incoherent, and I finally owned up; confessing as much to myself as anyone else. With my shame finally revealed it became apparent I'd reached a watershed in my life. If I didn't seek the appropriate help this condition would get the better of me". "Supported by my sympathetic friend, I visited the university doctor and sought referral to a rheumatology specialist".

In 2004, Steve finally achieved his long-cherished dream of qualifying as a vet. Steve's account is in his book Dances with Sheep which is an unflinching, bittersweet and above all humorous account of his life at Liverpool vet school. It encompasses everything from sitting through early lectures to performing surgery for the first time, from dating girls to delivering lambs in the middle of the night, and from drunken evenings on the town to the worry that it might all have been in vain. Dances with Sheep will appeal to anyone with a love of animals, anyone involved with veterinary school… and everyone interested in hearing about people fighting the odds to pursue their dreams.

Dances with Sheep by Steve Weddell is published by Book Guild Publishing priced £16.99; ISBN 1-85776-999-6.

The PAA: Plans and philosophy

The Psoriatic Arthropathy Alliance (PAA) is continually reviewing its activities and consulting with other organisations in order to provide services and activities that will be appropriate for the changing needs of patients in the 21st century. The needs of people with psoriasis and psoriatic arthritis, is and will continue to be the thrust of all future activities the organisation delivers. These activities will be delivered in an appropriate way that is based on good evidence and input from patients, carers and healthcare professionals.

The PAA does not currently receive funds from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions or charitable grants. We believe that this allows us to act in a non-biased way and free from any influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe that it is beneficial to our constituent group.

We do not endorse products or make recommendations, we provide information that has been approved by healthcare professionals or has published evidence. We provide a signposting service to help people with psoriasis and psoriatic arthritis to make an informed choice and understand how to deal with their condition.