

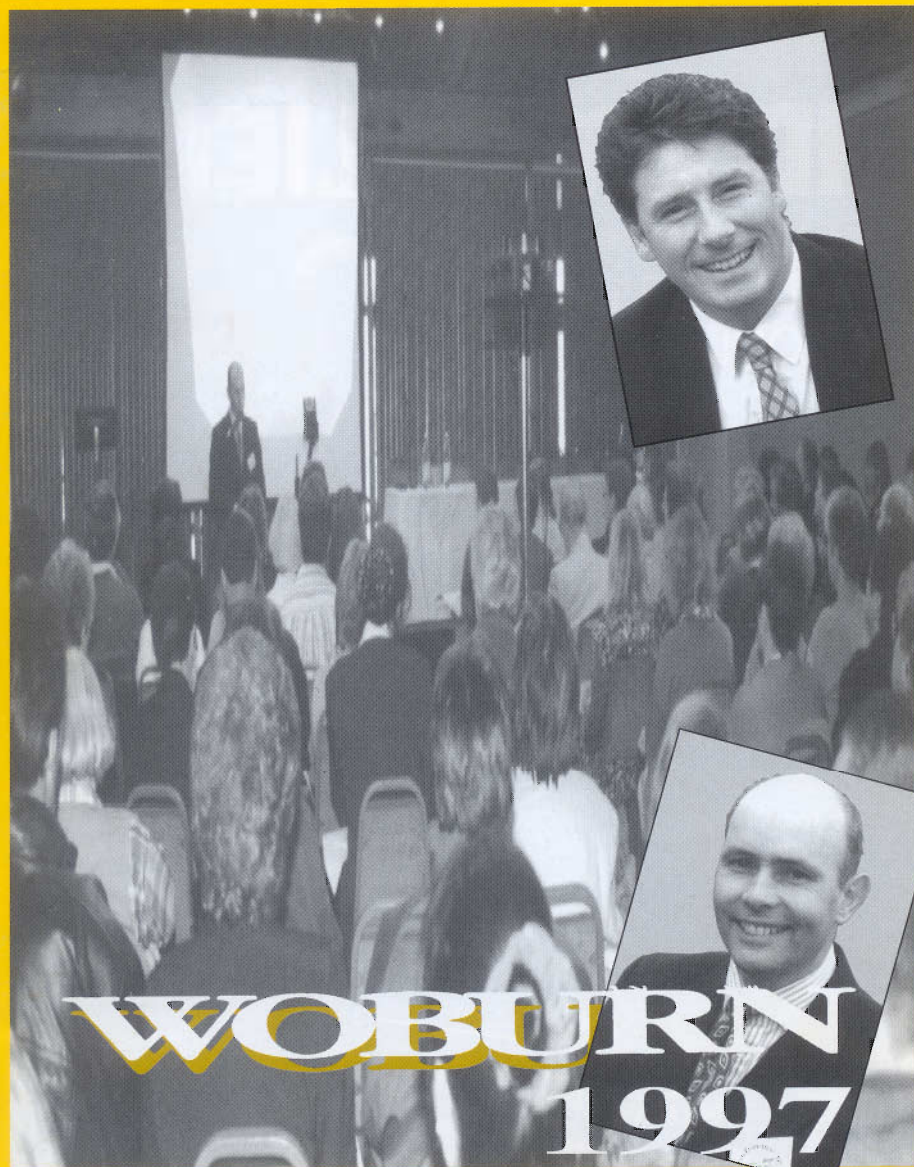
PAA

PSORIATIC ARTHROPATHY ALLIANCE

JOURNAL 9
WINTER 97

Internet address: www.paalliance.org
Registered Charity No: 1051169

Skin 'N' Bones Connection



INSIDE THIS ISSUE:

• *Recruits needed* • *Diary* • *Young PAA.* • *Book Review*

HYDROMOL CREAM

[arachis oil, isopropyl myristate, liquid paraffin, sodium pyrrolidone
carboxylate, sodium lactate]

AND EMOLLIENT

[light liquid paraffin, isopropyl myristate]

AN OASIS FOR DRY SKIN CONDITIONS



Legal Category G.S.L. Further information available from the Marketing Authorisation Holder:
Quinoderm Ltd, Manchester Rd, Hollinwood, Oldham OL8 4PB

The PAA Team

Rheumatology

Dr A Virginia Camp, FRCP, Medical Director, St Marys Hospital, Kettering, Northants.
Dr D Golding, MA, MD, FRCP, Consultant.
Dr N McHugh, FRACP, Consultant Senior Lecturer, Royal National Hospital for Rheumatic Diseases, Bath.
Dr S Jones, MRCP, Research Registrar, Royal National Hospital for Rheumatic Diseases, Bath.
Dr D Veale, Leeds General Infirmary.
Dr A G White, MBChB, FRCP, DPhysMed., Consultant, Royal Free Hospital, London.

Immunology

Ms Elizabeth Ross, Research Assistant, The Medical College of St Bartholomew's Hospital, London EC1A.

Dermatology

Professor Christopher E M Griffiths, MD, FRCP, Hope Hospital, Salford.
Ms Sherry Peters, Dermatology Specialist Sister, St Andrews Hospital, Bow, London.
Dr A Chu, Hammersmith Hospital, London

Physiotherapy

Catherine Buckley, MCSP, Physiotherapist St. Albans City Hospital.

Independent Advisers

Mr R W Martin
Mr D Edwards

Interest in P.A.A.

Rheumatology:
Dr Oliver Fitzgerald, MD, FRCPL, MRCP(UK), Consultant, St Vincents Hospital, Dublin (Ireland).
Dr Dafna D Gladman, M.D., FRCPC., Consultant, Wellesley Hospital, Toronto, Canada.

Board Members

David Chandler
Julie Chandler
Patrick Parker
Chris Friend
Ann Dugdale
Kate Heath
Tricia Hobbs
Dr Virginia Camp
Dr Sharon Jones
Dr Anthony White

Managing Editor

Julie Chandler

To advertise in this journal please contact us on 01923 682606

This Skin 'n' Bones Connection is produced by the Psoriatic Arthropathy Alliance and reviewed and approved by an editorial panel drawn from the board, medical and non-medical advisers.

Contents

Page 3	- <i>Pregnancy and pa</i>
Page 5	- <i>Skin Treatment</i>
Page 6	- <i>Young PAA</i>
Page 7	- <i>Book Review</i>
Page 8	- <i>Treatments revisited</i>
Page 9	- <i>Woburn 97</i>
Page 10	- <i>Woburn 97</i>
Page 11	- <i>Spotlight on . . .</i>
Page 13	- <i>Recruits needed</i>
Page 15	- <i>L. A. Photographer</i>
Page 16	- <i>Diary</i>
Page 17	- <i>Supporters awards</i>

PAA, PO Box 111, St Albans, Herts AL2 3JQ
Tel: 01923 672837

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

Copyright 1997:
All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form whether electronically, mechanically, or otherwise without the previous written permission of the Psoriatic Arthropathy Alliance.

We also believe that at the time of printing all information is correct but we cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal. All opinions expressed herein are of the contributors and not necessarily those of the PAA. Always consult your own doctors.



PREGNANCY AND OTHER HORMONAL EVENTS AND PSORIATIC ARTHRITIS

Dr Sharon Jones



HOW THEY MAY AFFECT YOU AND YOUR TREATMENT

This article is written mostly for women with psoriatic arthritis, although their partners and men with psoriatic arthritis should read it too! In the psoriatic arthritis clinic in Bath we are frequently asked about the effects of pregnancy and other hormonal events on the disease and its treatment. This article is an attempt to clarify some of these issues, based on our own work and that of others.

Pregnancy Although a large number of women with psoriatic arthritis develop it after their family is complete, some develop it before the first pregnancy. We are frequently asked to discuss the effect the arthritis might have on both mother and foetus and changes in medication that might be necessary. It is essential that any woman with psoriatic arthritis contemplating pregnancy should discuss it with her rheumatologist or general practitioner first. All women (with psoriatic arthritis or without) should take folic acid supplement 400 micrograms per day before attempting to conceive, to reduce the risk of spina bifida.

During pregnancy, the news is very good. The peripheral joint arthritis tends to spontaneously improve. This usually starts during the first 12 weeks of pregnancy and may continue to improve throughout the pregnancy. In Ostensen's prospective study, 16 out of 19 patients had an improvement in their arthritis during the first part of the pregnancy. In our study of 64 mothers attending the psoriatic arthritis clinic in

Bath, ten mothers developed arthritis prior to the first pregnancy and four reported pregnancy-related remissions of their peripheral joint disease; no-one reported an exacerbation of their disease. However, after the pregnancy the news may not be so good, with a flare up of arthritis just when the demands of childcare are at their most. In Ostensen's study, most patients had a reappearance of their arthritis during the first ten weeks after delivery. Seven of the ten patients in our study had flare up of their arthritis within the first four months following the pregnancy. For this reason, it is advisable to book an appointment with a rheumatologist shortly after the pregnancy.

There is no evidence of any adverse effect of pregnancy on either mother or foetus, providing advice regarding medication is followed. Some drugs can be used during pregnancy without jeopardising the well-being of the foetus. There is also no contraindication to breast-feeding even if medication is taken, because only very small amounts are present in breast milk. This is summarised in the following table.

Some women develop arthritis in association with a first pregnancy. In our study in Bath, one of 63 mothers developed arthritis during her first pregnancy, and a further six developed arthritis shortly after the first pregnancy. Four of these six patients had subsequent pregnancies and all of these had pregnancy-related remissions and post-partum flare up. However, larger epidemiological studies are required to determine whether pregnancy significantly affects the risk of arthritis in mothers compared with non-mothers.

Menstruation Some women report that their arthritis is worse prior to a menstrual period. This was reported in 13 of 87 women in our study in Bath. More work is needed to confirm this association.

The Menopause The menopause may also be a vulnerable time for the development or exacerbation of arthritis. Eleven patients in our study developed arthritis and seven had flare up of joint symptoms during the

perimenopausal period. This pattern needs confirming by further study and analysis.

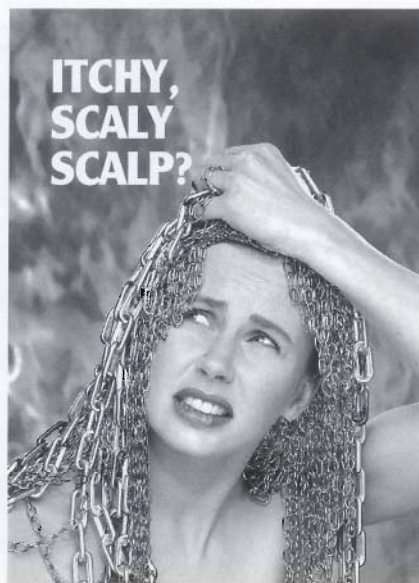
To Conclude Pregnancy, menstruation and the menopause may trigger or modify psoriatic arthritis in some women. In those who develop arthritis prior to or in association with the first pregnancy, a pattern of remissions of peripheral joint disease during subsequent pregnancies and flare up after subsequent pregnancies is likely.

Use of Medication in Psoriatic Arthritis before, during and after pregnancy

DISEASE MODIFYING AGENTS	BEFORE PREGNANCY	DURING PREGNANCY	BREAST-FEEDING
SULPHASALAZINE	Safe in women. Causes oligospermia, reducing fertility in men. Fully reversible on stopping	Safe	Safe
METHOTREXATE	Stop 6 months prior to attempting to conceive	Not safe May damage foetus	Unsafe
INTRAMUSCULAR GOLD	No further injections once pregnancy confirmed	Not safe	Unsafe
HYDROXYCHLOROQUINE (RARELY USED)	Safe	Safe	?Safety
PENCILLAMINE	Withdraw prior to conception	Not safe	Unsafe
AZATHIOPRINE	Safe	Safe	Unsafe
CYCLOSPORINE	?Safety	?Safety	Not recommended
CORTICOSTEROIDS			
oral	Safe	Safe	Safe
injection	Safe	Safe	Safe
NON-STEROIDAL ANTI-INFLAMMATORIES (NSAIDS)	Safe	Safe until last 4 weeks. Risk of constriction of ductus arteriosus in baby's heart	Probably safe, but keep dose to minimum
ASPIRIN	Safe	Safe until last 6 weeks. Risk of constriction of ductus arteriosus in baby's heart. Increased risk of bleeding of mother and baby at delivery	Probably safe, but keep dose to minimum
PARACETAMOL	Safe	Safe	Safe
CO-PROXAMOL	Safe	Avoid if possible. Withdrawal effects in neonate	Safe

HOW TO MAXIMISE YOUR SKIN TREATMENT

- Bathing should be used as a moisturising event. Soaps and detergents should be avoided as they tend to degrease the skin and make things worse. Use instead an emollient bath oil and/or a soap substitute such as aqueous cream or emulsifying ointment. Very hot baths should be avoided. Examples of these bath products are: E45 wash (Crookes), Balneum range (Hermal), Hydroml range (Quinoderm) and Eucerin (Beiersdorf).
- Pat the skin dry after bathing, avoiding hard rubbing. Skin may look redder after bathing - don't worry, this is normal.
- Topical steroids should be applied to freshly bathed skin or 30 minutes after moisturisers have been applied. Allowing the moisturiser to soak into the skin improves the efficacy of the steroids.
- Generously dot the skin with the preferred moisturisers and smear in a downward motion following the natural hairfall. Avoid applying in an enthusiastic, circular motion as this may irritate the skin and block up the hair follicles.
- Emollients come in a wide range and the severity of the skin disease will determine the type of moisturiser to use. Some people find that some emollients are better suited to their particular skin condition. Don't be afraid to try a variety until you find the one you like the best. E45 cream, Balneum Plus, Hydromol, Eucerin and Oilatum are just a few of the brand names you will see on the pharmacy shelves. For those of you who also find that your psoriasis itches, Hermal recently launched a product called Balneum Plus Cream which contains a product which helps to relieve the itchiness.
- Dry, cracked, scaly skin needs the occlusiveness and oiliness of an ointment such as 50% liquid paraffin in 50% white soft paraffin or grease-based emollients such as Unguentum (Hermal) or Diprobase Cream (Schering Plough).
- Skin that is less dry may require a lighter emollient such as E45 cream or Eucerin.
- To ensure the texture of the skin stays waxy and pliable, emollients should be reapplied before the skin feels dry and rough again. Apply liberally.
- Information is available regarding effective emollient therapies from many of the pharmaceutical companies that produce emollient ranges.



**ITCHY,
SCALY
SCALP?**

**There's an effective treatment
that shifts the scale**

Cocois®

COCONUT OIL COMPOUND

Further information and prescribing information
is available on request from:

Evans Medical Ltd, Regent Park, Leatherhead, KT22 7PQ

Legal Category: GSL Date of preparation: August 1997

BCOCH00

I'm Eve, I'm 17 and I've had psoriasis since I was 7 and arthritis for 3 or 4 years now. For my last two years of school I had a home tutor as I wasn't well enough to attend school. Thanks to my home tutors I managed to pass seven GCSEs! I'm now a little better than I was then and I'm able to attend college. I'm doing three A-Levels. I use crutches to get around most of the time but sometimes have to use my wheelchair. My hobbies are writing letters (I've got 20 penpals!), swimming, reading and enjoying life.

Hi! my name's Claire and I'm 19 years old. I've had PA for eight years. At the moment I am at a local college studying Business Studies. For the past two years I was at a residential college for disabled students. I like doing cross-stitch, singing and reading. I really enjoy driving and I hope to take an advanced drivers, test and become a member of the Institute of Advanced Motorists.



We feel that there isn't enough support for young people with PA and there isn't enough opportunities for them to get in touch with others who have the same condition. That's where we come in, we aim to change all of that! We want to set up a group within the PAA specifically for people up to the age of 25. We will have a page in the newsletter and journal. We would like to hear from all members of the PAA who are 25 or under, children, teenagers and young adults. We want to know what you want from this group and any ideas on how we should use our space in the newsletter and journal. What do you want from the group? Are you interested in a penpal group? Would you be interested in day trips? This group is going to be run by the young people for the young people, we want to hear your ideas.

WE NEED A NAME FOR OUR GROUP ! ! ! We want to hear from anyone who has an exciting name for our group. It needs to say that we're a young group with PA.

BOOK REVIEW

THE HEALTH ADDRESS BOOK

Please contact:
Peter White
Financial Times Healthcare
Maple House
149 Tottenham Court Road
London W1P 9LL
Tel: 0171 896 2405
Fax: 0171 896 2449
Http://www.fthealthcare.com
Please add £3.00 per book p/p.



IF ONLY I'D KNOWN THAT A YEAR AGO!

A revised guide to services for newly disabled people, their friends and families, produced by RADAR is available now. The guide provides an overview of services and facilities with a contacts listing. Topics covered vary from accommodation, aids, equipment, benefits, education, employment, health and care.

Available priced £2.50 (inc. p/p)
from: RADAR, 12 City Forum, 250 City Road,
London EC1U 8AF.
Tel: 0171 250 3222

DISABLED
Living
FOUNDATION

HELPLINE

For all your advice and information needs on equipment large and small - from bath seats and wheelchairs to jar openers and tap turners

0870 603 9177

(Calls are charged at 8p per minute)

Minicom: 0870 603 9176

Open Monday to Friday 10am to 4pm

Registered Charity No: 290069

DISABLED
Living
FOUNDATION

HELPLINE

- ☛ Do you have difficulty getting out of the bath?
- ☛ Are you having problems cooking?
- ☛ Is your arthritis making it difficult to hold cutlery?
- ☛ Are you worried about falling on the stairs?
- ☛ Do you find it difficult to hold your book or paper?

Do you know anyone who is having any of these difficulties?

If you have a disability or are generally slowing down as you get older, we can tell you about some of the thousands of useful gadgets and adaptations that are available. Alternatively, we may be able to suggest easier ways of carrying out everyday tasks. We also have information on other charities, self-help groups and equipment suppliers.

Please ring us on:

0870 603 9177

Minicom: 0870 603 9176

Open Monday to Friday 10am to 4pm

(Calls are charged at 8p per minute)

If your first language is not English, please write to us in your own language and we will reply in that language.

Registered Charity No 290069

TREATMENTS RE-VISITED

EMOLLIENTS

Under-rated and under-used but play a vital part in dry skin conditions.

Our skin is the largest organ of the human body, and has the greatest contact with the elements around us, the wind, rain, cold and our environment. As the skin is exposed to chemicals, detergents and pollution it takes a huge battering each day of our lives, but which is often neglected by most people and taken for granted.

But for those of us who have a skin condition, we are constantly reminded of our skin problems and how to tackle the discomfort we experience every day.

Emollients can play a valuable part in all of our skin routines and, in some cases, give us some relief from itching, flaking and other discomforts. The problem is while most of us rigorously apply our daily skin treatments and topical applications to our discontented skin, most of us forget about the use of emollients - probably because we are not told of their existence, their benefits, or even where to get hold of them to try. Doctors to some extent even forget the role they can play in complementing prescribed treatments.

How can emollients help those of us with a dry skin condition such as psoriasis? They are used mainly for their moisturising effect on the skin, working hard to reduce the flakiness, itching and roughness, producing a protective discreet film on the skin. This protective film helps to prevent the moisture

evaporating from the skin, thus helping to keep dehydration to a minimum, keeping the skin from drying out.

Some emollients can even be used as pleasant additives to the bath, but most are best applied directly to the skin immediately after bathing and patting your skin dry.

How do emollients work in conjunction with steroids and/or other topical preparations?

Some emollients are very well suited to mixing with other topical treatments because they are prepared with non-ionic emulsifiers and have an appropriate pH balance, which means they dilute well with other ingredients. Coal tar for example and similar difficult compounds can also work well with most emollients for safe effect.

It has been said that for some patients who use steroid applications, by using an emollient regularly the patient can actually reduce the treatment applications of the steroid preparations in their regime.

Why not explore the emollients available to you with the help of your doctor, chemist or other healthcare professional. There are some good ranges available now which are really quite pleasant to use but ALWAYS READ the instructions and information on the product. IF IN DOUBT always consult your practice nurse, dermatologist or GP.

PSORIATIC ARTHROPATHY CALLS FOR INCRE



Speakers at the recent 1997 Psoriatic Arthropathy Alliance Conference highlighted the difficulties of diagnosing patients who suffer from both psoriasis and arthritis, and called for better training in this area for medical students.

Mis-diagnosis frequently occurs, however, because psoriatic lesions and the pains associated with arthritis are not always present at the same time. In 20% of cases, the psoriasis is not visible, usually leading to a simplified diagnosis of arthritis. Making the connection between the two, whilst understanding and recognising the symptoms, is considered by the Alliance to be essential in order to achieve improvements in overall standards of patient care.

At the conference, Dr Tony Chu, from the Unit of Dermatology, Imperial College of Science, Technology and Medicine, Hammersmith, highlighted the problems associated with diagnosis by illustrating the close similarity between psoriasis and other skin conditions. Dr Chu went

on to point out that medical students only receive two weeks' dermatology training during their five years of study, and emphasised the need for better student training, better and enforced training for GPs, better understanding of the impact of the condition on patients' lives and better understanding of the drugs available for treatment. He said that pressure should be placed on the government, medical schools and medical organisations to achieve these aims, with demand being spearheaded by the patients themselves.

Another speaker at the conference, Professor Chris Griffiths (right) from the Department of Dermatology of Hope Hospital, Manchester, stressed that consultants, nurses and psychologists all have a part to play in managing a patient's condition.



Professor Griffiths added emphasis to the cross-disciplinary message

Y ALLIANCE CONFERENCE BASED GP TRAINING



by advocating that consultants, nurses and psychologists all have a part to play in managing a patient's condition, while Dr Douglas Veale (right) from the Rheumatology Department at Leeds General Infirmary stressed the importance of medical, paramedical groups and the PAA working together to broaden clinical knowledge.



Dr Tony White, (right) Consultant Rheumatologist at the Royal Free Hospital, London, talked about how patients and doctors can work together. Dr White explained how important it is for doctors to tell patients what to expect during a clinic appointment, such as why certain tests will be performed and what these involve. In turn, patients can help the doctor by having a mental list of their medical history and what treatments they have received. He took the view that hospital



consultants owe their patients honest explanations of the causes of delay in outpatients and in scheduled admissions to hospital, and, as with information about drugs and their side effects, leaflets help. They should particularly take into account a patient's work and home circumstances in coming to decisions about when to offer surgery. Dr Veale cited research which suggests that doctors should give their patients more information about psoriatic arthropathy on the basis that knowledge helps to eradicate their fear and anxiety.



Skin 'N' Bones Connection



ON...



ARTHRITIS: STANDARDS OF CARE

Over the past 18 months, the British League Against Rheumatism (BLAR) has been managing a project to establish the first-ever nationally agreed standards of care for people with arthritis, and November 13 saw the launch of the report of the project entitled Standards of Care: Towards Meeting People's Needs. This report forms one part of Arthritis: Getting it Right: A Guide for Planners. The guide contains two other reports, Understanding People's Everyday Needs by Arthritis Care and Working in Partnership, also by BLAR. The guide was launched at a House of Commons reception hosted by Tessa Jowell MP, the Minister for Public Health, which was supported by Novartis Pharmaceuticals.

The need for standards of care for people with arthritis was identified in the 1994 BLAR report, Disability and Arthritis. It was noted that although standards of care existed for a wide variety of medical conditions, no such guidelines were available for arthritis at the time, despite the fact that 8 million people in the UK are directly affected by the disabling disease. Therefore with funding from the Department of Health, BLAR set out to change the situation.

The standards were set by a multi-disciplinary advisory group, comprising nine representatives from eight organisations whose area of interest lay in each of the categories that the standards would cover. These organisations were Arthritis Care, British Health Professionals

in Rheumatology, British Orthopaedic Association, British Society for Rehabilitation Medicine, British Society for Rheumatology, Disability Living Allowance Advisory Board, Primary Care Rheumatology Society and the Royal College of Nursing Rheumatology Nursing Forum.

The resulting standards cover two types of arthritis: osteoarthritis and rheumatoid arthritis. They are concerned with primary care, rheumatology secondary care, orthopaedic secondary care, X-ray services, hospital in-patient care (both rheumatology and orthopaedic), local and hospital pharmacy services, physical access and hospital transport. Most of the standards emphasise the importance of education and awareness of treatments and services, rather than stating how arthritis should be managed medically or what levels of manpower should be available. There are 'essential' standards and 'desirable' standards, the former representing the minimum service provision whilst the latter represent a level of ideal provision, with recognition that the standards covered under this heading are not considered by BLAR to be as important as the 'essential' standards.

In addition to defining the standards, the project also aimed to discover how well care for people with arthritis in the UK measures up to the agreed standards. Following a nation-wide audit involving 18 UK regions and over 1000 people with

arthritis, it was hoped to both highlight examples of good practice in terms of the standards already being met as well as identifying those aspects of care and service provision which require improvement.

The results of the audit generally appear promising, but not entirely satisfactory. In brief, the main findings were:

Both primary and secondary health care services seem to be relatively good at providing explanations of pharmacological treatments, but fare less well in providing explanations for treatments and services focusing on other areas.

- Provision of written information in primary and secondary health care fell below the standards recommended by BLAR.
- Orthopaedic care seemed to be very effective in providing verbal explanations in all the recommended areas, but again the provision of written information does not meet the recommended standards.
- Few pharmacies offered people the choice of not having child-resistant medication containers.
- The standards covering the care of in-patients, including orthopaedic in-patients, were met in almost all the cases in the audit.
- Few of those eligible for employment were given information about the relevant issues.
- Respondents reported that their homes were the main locations where they encountered physical access problems. Additionally, physical access was often a problem in other areas including hospitals and public transport.

The standards should be considered as a challenge to the services involved rather than as a threat. The purpose of the audit was not to criticise services or commissioners, but to highlight areas

where improvements could and should be made. Similarly in areas where standards appear to have been met, this should not justify complacency, and efforts to uphold the standards should be maintained.

The league believes the way forward in the care of individuals with arthritis is for health authorities/commissioners to support and incorporate the BLAR standards into their contract or service specifications for rheumatology services. Whilst BLAR has no specific evidence that meeting these standards will improve the medical position of people with arthritis, there is an increasing body of evidence to suggest that information about, and greater understanding of, chronic illness can improve outcome. Most of the standards of care outlined in the report reflect this philosophy of supporting people with arthritis through education and awareness, and the league believes that through meeting the standards, the lives of people with arthritis will be improved irrespective of medical advances.

For full details of the Standards of Care report, please contact:

**Kevin Rowan, Audit Project Manager,
BLAR, 41 Eagle Street, London
WC1R 4AR.
Tel: 0171 242 3313.**

Details of the BLAR Working in Partnership report can also be obtained from the above address. This report provides details of the work of BLAR and its 23 membership organisations.

For details of the Understanding People's Everyday Needs report, please contact:
**Arthritis Care, 18 Stephenson Way,
London NW1 2HD.
Tel: 0171 916 1500**

**Novartis Pharmaceuticals UK Ltd
Frimley Business Park, Camberley, Surrey
GU16 5SG
Tel: 01276 692 255.**



Recruits needed!



PSORIATIC ARTHROPATHY RESEARCH IN LEEDS

The Leeds Unit has developed a broad spectrum of research into psoriatic arthropathy over the past two years, co-ordinating an approach with the dermatologists and with other rheumatologists from around the UK. The unit is involved in clinical and basic science research in the following areas:

- 1) Clinical patterns of psoriatic arthritis
- 2) Patient education and knowledge in psoriatic arthritis and spondylitis
- 3) Arthroscopic appearances of psoriatic arthritis
- 4) Cellular mechanisms of inflammation in psoriatic arthritis
- 5) Molecular mechanisms of signal transduction in psoriatic arthritis
- 6) Family/genetic study in families with psoriatic arthritis.

The clinical emphasis of our studies is on the patterns of disease and examining prognostic factors over time, which may allow us in the future to predict those patients who will develop severe disease and can therefore be given more powerful therapy at an earlier stage. The clinical aspects also concentrate on the efforts in patient education and increasing knowledge among patients which plays a crucial role in the overall management of the disease through reducing fears and anxieties that may exist. The arthroscopic studies allow us to examine directly the inflamed lining of the joints in patients with psoriatic arthritis. This involves examining the joints with a fiberoptic-camera system under local anaesthetic, enabling us to directly see the inflamed lining of the joints and to assess the characteristics of this inflammation using video recordings. Furthermore it is possible to take small samples of the lining of the joints (biopsies), so that in the laboratory we are able to study the mechanisms of cellular infiltration and the molecular changes in the tissue which will allow us to identify the mechanism of disease in the future.

Finally the genetic family studies are based on original surveys in Leeds in the 1970s which identified a number of families in whom more than one member of the family was involved with psoriatic arthritis. Although this is not common it does point to a genetic factor in the cause of this condition. By studying blood samples from these families we may be able to examine what are the genetic factors responsible.

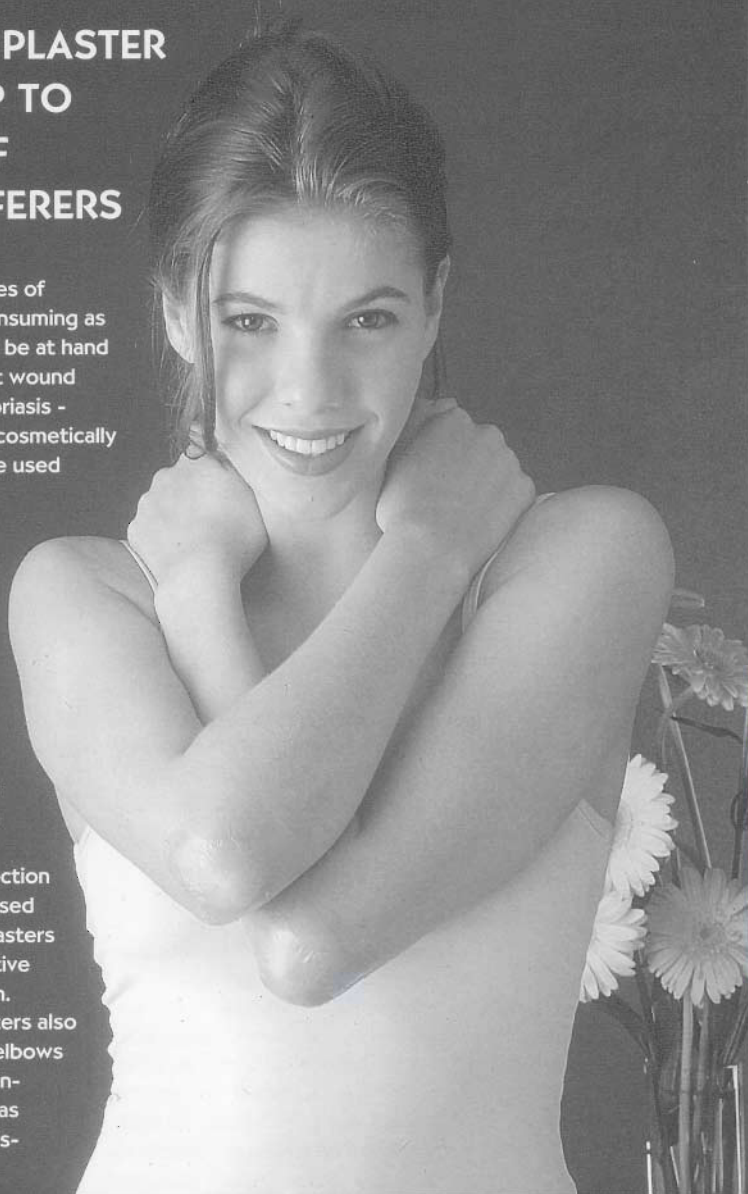
Dr Doug Veale
SENIOR LECTURER/HONORARY CONSULTANT

For more information Dr Veale can be contacted on 0113 292 3956 or
Fax: 0113 292 3804.

NEW COMPEED PLASTER COULD HELP UP TO 65 PER CENT OF PSORIASIS SUFFERERS

Treating mild to moderate cases of psoriasis can often be time consuming as well as impractical. Help could be at hand with a revolutionary new moist wound healing plaster - Compeed Psoriasis - which offers an effective and cosmetically attractive solution - and can be used with a cream treatment, if required.

Clinical studies show that Compeed Psoriasis establishes and retains a natural level of moisture, creating ideal healing conditions to make the skin soft and supple again. The 'greenhouse' environment created under the plaster also eases itching and ensures maximum protection from infection for the affected area. When used with a cream treatment the plasters extend the life span of the active ingredients by keeping them in. Anatomically shaped, the plasters also allow optimum movement on elbows and knees and the discreet skin-toned colour conceals as well as protects the sensitive psoriasis-affected skin.



Compeed®

THE *FASTER* PLASTER

FOR A FREE SAMPLE TELEPHONE COLOPLAST LIMITED ON
FREEPHONE 0800 374 655

Los Angeles photographer learns to live with psoriatic



SOME PEOPLE SEEM TO LEAD CHARMED LIVES. Danny Feld, a Los Angeles photographer, spends his days in a job that many would envy—shooting publicity stills of the stars of TV shows such as “E.R.,” “Friends,” “Star Trek” and “Mad About You.” He gravitated to that glamorous career naturally after a “wonderful, normal childhood” as the second son of two Hollywood actors. His father was Fritz Feld, whose career spanned 70 years and 400 motion pictures, and his mother was Virginia Christine, a talented character actress best known as “Mrs. Olson” of Folger’s Coffee commercial fame. To top it off, Feld has been happily married for a year to an Associated Press photographer who shares his love of travelling.

But about five years ago, life handed Feld a lemon: a suspicious pain in the joint of his right thumb. It turned out to be a fast-moving case of psoriatic arthritis (PA). “Soon I was awfully sore; it went from one joint to all over my body,” he said.

Where did this come from?

The diagnosis of PA was disturbing and somewhat mysterious. Feld had never even had a substantial outbreak of skin psoriasis—just a few barely noticeable spots. Since the only other family member with psoriasis was a distant cousin, “It seemed to come out of left field,” he said. Feld was panicked he would not be able to sustain his active career, which had him out at the crack of dawn each day hauling equipment from set to set—often for 12 hours at a time. “I had no place to turn initially,” he said. “It (PA) involves such a small group of people compared to other illnesses.” Feld found the NPF’s educational materials very helpful. “Information is the key to all things,” he

said. “It’s so difficult when you have such an obscure disease—nobody with it even wants to explain it to people unless others are really curious. Most just say it’s arthritis and leave it at that.”

Staying healthy

Feld’s physician started him on a prescription of prednisone, and he responded immediately—but he couldn’t stay on such large doses for long. When the doctor suggested methotrexate, a systemic medication originally prescribed for cancer, Feld was “quite frightened” but he eventually consented.

In psoriatic arthritis, methotrexate is used to decrease inflammation and pain, and increase flexibility. “The methotrexate has helped me a great deal,” he said. Now Feld takes a maintenance dose of prednisone with methotrexate once a week. “This keeps me pretty healthy,” he added. Feld recommends regular exercise to keep PA at bay, even though he admits he doesn’t always get as much as he should. He has been to physical therapists to get special exercises to help him with taut muscles since psoriatic arthritis also can inflame the soft tissue connecting the joints. “I think swimming is one of the very best exercises, and walking and general exercise are very helpful,” he said.

Attitude vs. pain

Along with education, medication and exercise, a person needs a positive attitude to deal with PA. “Fortunately, so far I’ve been able to continue my work, which is extremely important to me,” said Feld.

"My life is so full and my schedule is so enormous, the distraction is helpful. But the long hours are not good, so it cuts both ways." Psoriatic arthritis can be a daily battle with pain—especially for a self employed person who must stand in rigid positions on hard floors for long periods of time and haul around heavy cameras and lights. "I've learned about the wonders of wheels," Feld said. "I now use a dolly to carry heavy equipment and I carry a chair along, which is helpful." On the flip side, Feld is thankful he doesn't have a desk job. "I get to move around a lot, and I'm sometimes out on location in the sunlight which is good for my arthritis," he said.

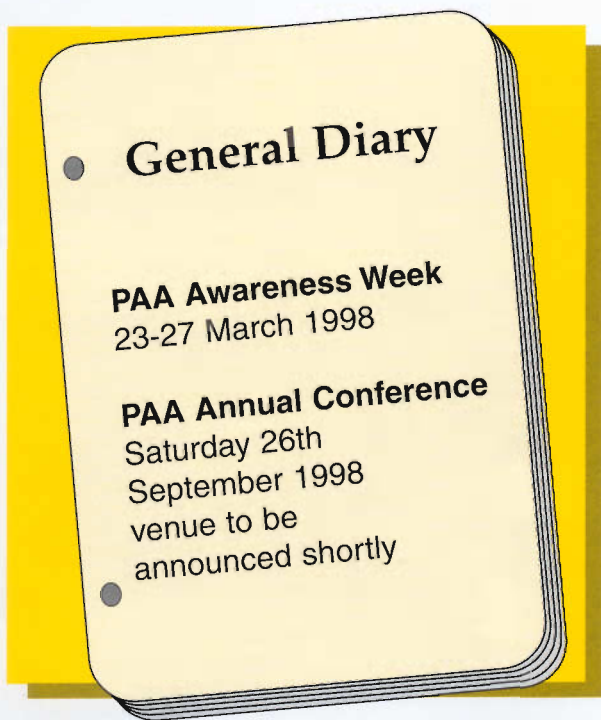
Keeping perspective

Feld said it helps him to keep in mind that other people are worse off than he is. "Sometimes I get in a rut, but for the most part I know the degree of what I have is not that bad—I shouldn't be complaining," he said. "I told my wife that if I start to complain too much, she should tell me to "forget it." His wife Rene supports him

and gives him shoulder and neck massages. "Fortunately, she's a wonderful masseuse," he said. Feld advises others with PA to keep up with their care and find a physician who is a good listener. "It takes a special kind of doctor to be involved with this disease—because it's chronic, it's tiresome for everybody."

He also believes in keeping up with the latest treatment information and research on psoriasis and PA. "The more informed the patient, the more the doctor can be of help," he said. "I often go to my doctor with questions I get from the Bulletin." The NPF booklets, "Psoriatic Arthritis" and "Methotrexate," are available by calling 1-503-244-7404. Reprints of recent Bulletin articles on psoriatic arthritis and exercise are available as well.

Editor's Note: This article has been reproduced by kind permission of the National Psoriasis Foundation of America and first appeared in National Psoriasis Foundation Bulletin, Number 3, Volume 28, May/June 1997.



Supporters Awards

Charles Harvie (pictured bellow receiving his supporters award from David Edwards at our conference in September) raised £1200 towards the work of the PAA by walking the 62-mile Donnington Way, which passes through Gloucestershire (almost 90%), Worcestershire, Warwickshire and Oxfordshire.

The walk is a delight for ramblers who thrive on well-kept countryside and hidden villages. The Donnington Brewery brews real ale in the heart of the Cotswolds and maintains 15 public houses along the Way - all of which Charles visited (allegedly) during his walk.

Charles has proved to be a successful fund-raiser who has previously raised £3000 for Raleigh International in order to visit Botswana as a charity worker and in Worcestershire raised over £500 for Scope - the single highest amount by an individual to date in the area.



Charles Harvie receives his Supporters Award from PAA adviser David Edwards.



Dave Thompson and Sally Pryce-Jones, pictured, receiving their award from David

Some days he really suffers from his psoriasis



But every day he benefits from E45 Complete Emollient Therapy

His psoriasis can be worse on some days than others, so he uses E45 Cream whenever he needs to soothe and relieve dry, scaly patches of skin. But leading dermatologists now recognise that daily emollient use can help other treatments work more effectively. So by using E45 Cream, combined with E45 Bath - a non-perfumed bath oil, and E45 Wash - a non-drying soap substitute, he can trust E45 Complete Emollient Therapy to help keep his skin soft and flexible - day after day.



DERMATOLOGICAL
E45 Complete
Emollient Therapy™

Always read the label
Further information is available on request from Crookes Healthcare Ltd, Nottingham, NG2 3AA.

and finally . . .

Skin-Cap Spray

There has been substantial activity (particularly via the Internet) surrounding the availability of Skin-Cap Spray. The Department of Health Medicine Control Agency released the following Product Information Notice in September:

Cheminova (UK) Ltd: Skin-Cap Spray

Cheminova (UK) Ltd has recalled all batches of Skin-Cap Spray, because the agency has tested the product and found it to contain an undisclosed steroid, clobetasol propionate.

The product is presented as a treatment for itching, redness, flaking and scaling associated with skin conditions, particularly psoriasis and seborrhea. It is not a licensed medicinal product, but the agency understands that it has been prescribed by GPs. Individuals currently using this product are advised to immediately contact their doctor.

For further information please contact: Cheminova (UK) Ltd, 94A The Broadway, Wimbledon, London SW19 1RH. Telephone 0181 543 6803. Fax 0181 944 7795.

New Health Authorities are asked to bring this information to the attention of Community Pharmacists and General Practitioners.

Similar notices have been issued in other countries throughout the world. In a future issue of this publication we will be including an article on the licensing of medicinal products and the reasons such licences need to be applied for.

A word for our sponsors.

We would like to thank the Trustees of Marchday Charitable Trust for their generous financial support of our conference without whom we would probably have been unable to hold the event - this is the second year Marchday have supported our conference.

We would also like to thank the following companies and associations:

Leo Pharmaceuticals, Crookes Healthcare, Evans Medical Dermatology, Nordic Saunas, Merck Dermatology, Quinoderm Ltd, Stafford-Miller Ltd and Stiefel Laboratories (UK) Ltd for taking exhibition space;

Novartis Pharmaceuticals (UK) Ltd for publicity and PR;

British Society for Rheumatology for poster distribution;

British Health Professionals in Rheumatology for poster distribution;

and Leo Pharmaceuticals for conference programmes and carrier bags.

And the following individuals and companies for providing raffle prizes:

Tricia Hobbs • Kate Heath • Julie Chandler • David Chandler • British Gas -Harlow • Sundae Shoes - Moulton • Mrs Kay Ives - Harlow • Shipleys Amusements - Harlow • Gwendolin Riley - Leicester • Hello Dolly Ltd - Harlow • Virgin Atlantic • The Body Shop - Harlow branch • Stone Cross Pharmacy - Harlow • Elliotts Ltd - Harlow • Marks & Spencer - Harlow • Direct Line Insurance • and Member Sue Johnson from Harlow for organising the raffle.

This publication was provided
with the aid
of an Educational Grant from
Crookes Healthcare