Skin 'n' Bones connection

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PAA
PSORIATIC ARTHROPATHY ALLIANCE
Registered charity number: 1051169
E-mail: info@paalliance.org
Internet: www.paalliance.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.

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Psoriatic Arthropathy

Seldom Suspected, Easily Missed

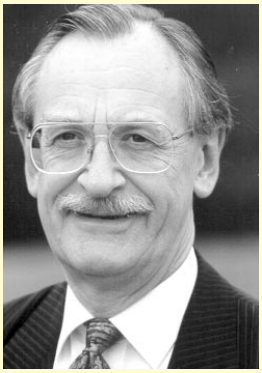
Dr Anthony White
The Psoriatic Arthritis Clinic
The Royal Free Hospital, London

Why is it that the rheumatic features of the common skin disease do not figure more prominently in the list of diagnostic possibilities when faced with a patient with an arthritis, which does not look quite right for rheumatoid arthritis or for osteoarthritis? The pattern of joints involved does not fit our mental picture of rheumatoid hand deformity, the symptoms come and go in an odd way and although the terminal joints of the fingers are affected the patient is too young for primary generalised osteoarthritis. The problem is that we expect to find psoriatic arthropathy only in patients whose psoriasis is severe. Yet whilst it is true that such cases are more prone to joint symptoms the reverse is not true - mild skin disease certainly does not exclude serious joint involvement. Hence the problem lies with ourselves and our expectations and so we fail to ask the key questions: have you had any skin disease? is there anyone in the family with psoriasis? Do you have any itchy scaly patches in your scalp? Psoriatic arthropathy can be found in patients with one small area of skin involvement in the natal cleft, the scalp or behind one ear for instance - they may not know they have psoriasis until you examine them and find it!

And then there are the nails - dystrophy of the finger and toe nails is correlated with small joint arthritis of the fingers and toes, even to some extent with the individual digits being more likely to show arthritis if their nails are dystrophic - but the nails may happen to be normal on the day you see the patient so another key Question to ask is “have you ever had any trouble with your finger nails?” Nails which readily break, nails which develop little pits in their surface and nails which show irregular margins and colour changes often yellow or brownish are all useful clues to likely nail dystrophy and female patients in particular usually recall such aspects easily when asked. Male patients are more likely to have dismissed the changes as likely to have been caused by injury or chemical exposure at work and neither may recognise any connection with mild changes in the skin even if they have discovered they have them.

Are there any other clues in the pattern of the arthritis itself? Very large but almost painless effusions of the knees are found in few other diseases and should alert one to the possibility. An arthritis which picks out individual small hand or foot joints one or two at a time in an asymmetrical pattern should arouse suspicion and particularly if whole toes swell and become pink - the cocktail sausage toe - not to be confused with gout which is much briefer in duration yet much more painful and tender. If a patient has a painful joint or two but also backache which is worse at night and is followed by severe stiffness in the mornings the patient may be describing features of psoriatic spondylosis - the combination of peripheral joint synovitis with a pattern of inflammatory back pain closely resembling ankylosing spondylitis. Many such patients share the HLA B27 tissue type with sufferers of that condition.

Because much can be done to ease the lot of these patients it is most unfortunate that they tend to fall between two stools and be seen neither by rheumatologist nor dermatologist until late on in their illness. The way to remedy this is through better teaching of medical students and doctors. The Psoriatic Arthropathy Alliance (PAA) was founded very much with this need in mind and to foster research into this sadly neglected area of medicine by bringing together the professionals involved in the specialties most able to take this forward. Already progress is being made. A greater awareness of this condition will be a vital step along the path to better treatment and, in due course, the hope of cure.



Cover photo: David Chandler, NICE The venue for the 2nd InterPSO meeting.

Learning through shared experience

by Dr. Michael O'Donnell

My enthusiasm for groups like the PAA is inherited. My father was a GP in a Yorkshire village and watching him as a child, and later working as his assistant, I realised that he'd acquired much of his understanding of medicine from his patients. True, he picked up useful knowledge from books and journals but he screened everything he read through the filter of his own and his patients' experience.

I later met lots of doctors who behaved in the same way and I came to the conclusion that the empathy they had with their patients – their ability to think themselves into the minds of others – was one of the elusive qualities that go to make a good "healer", a doctor whom patients feel better for seeing regardless of any treatment that's prescribed.

Today, of course, everyone is supporter of the notion that patients should be involved in their own care: cabinet ministers, the General Medical Council (GMC), the BMA, medical schools, and all those medical politicians who can spot a bandwagon when they see one. But it wasn't always so.

"The Good Old Days"

Some 30 years ago when I was a member of the GMC – albeit a rebel one – and suggested that medical schools should use patients not as specimens to be put on show but as actual teachers who could give talks and lectures to students I was accused of being "a traitor to my profession". And when I took part in this country's first medical phone-in, offering I might say rather pathetically generalised advice, I was reported to the GMC accused of "serious professional misconduct".

Twenty years ago I met an American woman who had suffered from diabetes since she was a child. She'd recently been admitted to a London diabetic ward and had taken with her the new American electronic device with which she monitored her blood sugar. The other patients in the ward were fascinated by it so she showed them how to use it. When the doctors and nurses discovered what had happened she was dismissed from the hospital for "unacceptable behaviour". Her crime it seemed, was not that she'd let others use the device but that she'd told them what their blood sugar levels were.

Doctors' Orders

So things have improved a lot but we mustn't be complacent. Some old medical attitudes linger on. Doctors still describe patients who dutifully follow their treatments as "showing a high level of compliance" as if doctors were born to issue Doctors' Orders which patients were born to obey. And patents who reject their doctor's treatment or advice are described as "non-compliant" as if it were a failure by the patient rather than the doctor.

Another word doctors still take in their unthinking stride, is "consent." I dislike it because, when doctors use it, it sounds as if patients have been given a choice when all they've been offered is the chance to acquiesce to what the doctors have chosen for them.

A third C word is "cooperation," use to describe the commendable behaviour of patients who make changes in their lives just to please their doctors. This treacherous trio of Cs is, of course, linked by definition: a co-operative patient is one who first consents and then complies.

Any doctor fool enough to think that seemingly co-operative patients are passively obedient should recall the memorable clinical trial in which the subjects broke the code by discovering that when they threw their tablets down the lavatory, the drug floated but the placebo sank.

To be positive, however, it's encouraging that so many doctors now accept that patients, particularly those living with a long term illness develop expertise and wisdom about their condition and want to play a part in making decisions about their own health care.

Yet those of us who are keen to enable patients to be involved in their own care need to accept that there are problems we need to resolve. Here are just a few.

Interpreting risk

Decisions about treatment often involve our attitude to risk. Doctors' perception of risk, fostered by the evidence presented in scientific journals, is mathematical; most other people's perception is non-mathematical

Imagine, for instance, the public reaction if a fully-laden jumbo jet were to crash at Heathrow Airport on four successive days killing all the passengers. There would certainly be an outcry, panic among intending passengers, and aircraft would be grounded. Yet that is the weekly British death toll attributable to cigarettes, a toll that British people accept with resignation and the British government with apparent equanimity.

Reason can play little part in our notion of risk – people will worry, for instance, about a risk with a drug that is 1,000th the risk they run every time they get into their cars. And our perception of risk also includes a political quality. I once heard the distinguished mathematician, Sir Hermann Bondi, describe a Swedish plan to study the Aurora Borealis by firing instrument-carrying rockets into it. When the rockets had done their job, the burnt-out remnants were due to fall over an area of Lapland so sparsely populated that the mathematical risk of anyone being hit was minute. Even so, the Swedish government felt it should offer protection to the isolated reindeer herders so it lifted them out by helicopter and lifted them back when the experiment was over.

Sir Hermann calculated that the mathematical likelihood of one of them being hit by a piece of rocket was less than one per cent of that of a helicopter accident. But let's look at the political implications. If someone had been hit – or even had had just "a bad fright" – the Interior Minister would have faced the angry accusation that he had done nothing to protect people for whom he was responsible. If, on the other hand, there had been a helicopter crash, people would have happily accepted a ministerial statement that said: "We deeply sympathise with the relatives of the victims of this tragedy. We used a well tried helicopter, flown by a well trained and experienced crew. We are appalled at what has happened but there is no other precaution we could have taken."

Not all patients want to take responsibility

Doctors soon learn there are about differences in people's attitude towards taking responsibility for decisions about their health. These differences have been measured. A recent survey of over 1,000 American women suffering from breast cancer revealed that 22 per cent wanted to select their own treatment, 44 per cent wanted to collaborate with their doctors in the decision, and 34 per cent wanted to delegate this responsibility to their doctors. As the author of a British Medical Journal editorial put it: "Most patients want to see the road map, including alternative routes, even if they don't want to take over the wheel."

Medical specialties

The narrow interests of medical specialities don't coincide with the interests of patients. Indeed the patient is sometimes the only person in a position to get specialists together. The American woman with diabetes whom I've already mentioned told me: "I spend a lot of my time as a patient trying to get one specialist to know what the other specialist is saying".

And an acquaintance of mine who suffers from psoriatic arthropathy told me recently that he is thinking of writing a survival guide on "how to get your GP and your general physician to think in harmony with your dermatologist, your rheumatologist, your orthopaedic surgeon, your physiotherapist, your district nurse and your carer."

Difficulties doctors face in encouraging patients to make choices

Not surprisingly GPs and specialists who have spent a minimum of ten years in training feel that the knowledge and experience they have acquired in that training should not be discounted

They find it hard not to intervene if patients at times select treatments that are less effective or less cost effective than the medically recommended approach. Patients with moderately raised blood pressure, for instance, value the benefits of drug treatment less than their doctors and not surprisingly are less tolerant of side effects. So encouraging patients to make choices about treatment would probably result in fewer drugs being taken which doctors know would increase the number of strokes and heart attacks in the population.

It's also been estimated that only 50 to 65 per cent of patients with chronic conditions stick to their treatment. By not taking their drugs the other patients are, of course, expressing a choice. Many doctors find it difficult to accept – not to mention encourage – such explicit disagreement with their recommendations. Hence their use of that weasel word "compliance".

The doctors' difficulty diminishes, however, when they accept that they have to treat an illness rather than a disease. The two are not synonymous. Diseases can be defined, their causes sought, organisms or mechanical defects identified; an illness is an individual event, the possession of one person whose physical condition and emotional state determine the way the disease affects that individual life.

Even with diseases where we have compelling evidence about their nature and treatment, doctors have to weigh the generality of the evidence against the particular needs of the individual and seek to understand the feelings of regret, betrayal, fear, loneliness – indeed all the perplexing emotions –that can turn the same disease into a different illness in different people. And, of course, patients are experts on their own illnesses because they are experts on their own values and priorities, their obligations, their attitude to risk, their preferences and so on.

If doctors are to treat illness as successfully as they treat disease they need to enhance their medical experience with the experience of their patients who contribute to our understanding of the world in which we all struggle to survive.

Time.

Shortage of time is the modern doctor's greatest enemy. Time not just to examine, investigate, and treat but time to explain, to listen, to understand. For some 30 years I've tried, with little success, to convince doctors that if they want patients to recall, and indeed understand, explanations and advice they deliver in consulting rooms they should give the patient a recorded tape cassette of the consultation or send a letter spelling out what they said or meant to say.

The difficulty people have in understanding what they hear is not confined to medicine. It is well-explained by the American author Sue Grafton in one of her highly successful detective novels where her private eye Kinsey Millhone explains why she always writes out her reports: "With verbal reports, much of the data gets lost in translation. Most people aren't trained to listen. Given the complexity of our mental processes, the recipient tunes out, blocks, forgets, or misinterprets eighty percent of what's been said. Take any fifteen minutes' worth of conversation and try to reconstruct it later and you'll see what I mean. If the communication has any emotional content whatever, the quality of the information retained degrades even further."

Lessons of experience

These problems should not deter doctors from seeking to improve the ways in which they involve their patients nor patients from becoming involved, if they wish, in their own care. And organisations like the PAA have big role to play in helping to solve those problems. At meetings for instance, patients, nurses, doctors, and carers get a chance to share their experience. Indeed a day such as the PAA conference is a large scale model of the ideal medical consultation in which the doctor learns through the experience of the patient and the patient learns through the experience of the doctor.

Psoriatic Arthritis & Psoriasis

Conference 2002

Saturday 14th September 2002

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*PROVISIONAL PROGRAMME		
9.00-10.30	Registration	
10.30	Welcome	David Chandler
	Keynote Speaker	TBA
	Session One **Chair - Dr Virginia Camp**	
11.00	The Basis for Future Treatment	TBA
11.45	You & Your Diet	Arleen Rowell & Shirley Talbot
	PA in the Spine & Jaw	Dr Anthony White
12.45	Lunch	
	Session Two **Chair - Chris Friend**	
1.45	Psoriasis in Children	Dr Anthony Chu
	PA in Children	Dr Janet McDonagh
	Handling Children	Janine Hackett
	Physiotherapy OT / approach	Bernie Johnson
3.00	Comfort break	
	Session Three **Chair - Patrick Parker**	
3.30	Questions & Answers	An expert panel
4.30	Close of conference	

Limited spaces available so please hurry

*Subject to change

This conference is organised by the 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 number: 1051169

Further information can be obtained by contacting:

PO Box 111
St Albans, Herts. AL2 3JQ UK
Fax: 0870 7703213. e-mail: info@paalliance.org

GALDERMA
This conference is supported via an Educational Grant from Galderma

St Thomas' Hospital *Research*

At the St. John's Institute of Dermatology within St. Thomas' Hospital, London, research has been undertaken into the possible genetic causes of a range of skin diseases for over five years. At present we are concentrating on 'late onset' psoriasis, and we need to find individuals whose psoriasis did not appear until after the age of forty. The point of this work is to try and identify any inherited material (genes) that might possibly lead to this condition, hopefully increasing our understanding of psoriasis in general.

We preferably need people who have been seen by a dermatologist, and who live in the South East of England. The research involves completing a questionnaire about your psoriasis and taking a blood sample. This once off 10 ml. (about 2 tablespoons) blood sample can be taken at Lewisham Hospital or at St. Thomas', at the same time as filling in the questionnaire. The whole visit would take approximately thirty minutes. Are you in a position to help us? We are able to offer travel expenses for those in the South East of England.

For more information please contact:

Paul Affleck
Research Nurse
The Skin Therapy Research Unit
St. John's Institute of Dermatology,
St. Thomas' Hospital, Lambeth Palace Road, London SE1 7EH

Tel. 020 7928 9292 ext. 1399 E~mail stru@kcl.ac.uk

RESEARCH STUDY

THE IMPACT OF PSORIASIS ON FAMILY MEMBERS

HOPE HOSPITAL, SALFORD.

There is currently a study being conducted at Hope Hospital, between the Dept of Behavioural Medicine and the Dermatology Departments. We have been asked to circulate some questionnaires to those who may be interested in participating.

The aim of the study: -

"As you will be aware, psoriasis appears to affect all aspects of a patient's life, including the physical, behavioural, psychological and social. Given the wide-ranging impact of psoriasis on individual's lives it would seem unlikely that psoriasis patients families, especially their partners will remain untouched.

While the psychological adjustment of patients with psoriasis is being studied extensively at present, relatively little research has focused on the psychosocial and psychological reactions of their spouses or partners. Thus our study aims to examine psychological distress in well – partners of patients with psoriasis and examine this in relation to psychological and physical factors in patients themselves."

(Damon L Mason, Research Psychologist, Hope Hospital,Salford).

Contact details:-

Dr Helen Richards
Dept of Behavioural Medicine
Hope Hospital
Stott Lane
Salford
Manchester M6 8HD.
Tel: 0161 789 7373

THE UNIVERSITY *of* MANCHESTER

INVOLVING THE PATIENT IN THE NEW NHS

Fact Fiction or Farce?

ARTICLE - Patrick Parker

It seems to me that I am always the one at conferences or meetings who gets to talk about Government plans, strategic Health Authorities, Primary Care Trusts and the like. They all make for exciting, stimulating conversations, usually about what sense, if any, can be taken from them. I jest, of course.

The truth is that this present Government has made a great deal of noise about public and patient involvement in their Health Service and their commitment to it. In reality, a lot of words have been produced but with a lack of clarity and cohesion. The resultant proposed changes enhances the view that there is less power for the patient, the routes to decision making are unclear for the public and what value will result, appears minimal.

It all started at the end of July 2001 with the publication on proposed reforms in the NHS. A section was devoted to public involvement, centred around abolishing Community Health Councils (CHC). The Councils, the public watchdog on health issues were the independent scrutiny groups on health issues in local regions, numbering 208. They provided public advocacy and links on health for 27 years, costing some £7 million to run annually. At the heart of all CHC's in England and Wales was their ability to cover, independent of any particular NHS Trust or group, all aspects of medical care and to link across Health Authorities.

The latest version of the reform package promises their demise by April 2003. Their perceived main replacement will be PALS – Patient Advocacy & Liaison Service charged with being up and running in every NHS by April 2002, PALS will be run by professionals within each Trust with a manager, co-ordinator and others to liaise with the patient, if necessary, through their own Trust, whether hospital or Primary Care. Links between Trusts and within a region are not guaranteed nor is independence a consideration.

Next up are Patients Forums. Again, envisaged for each Trust, they will be charged with reviewing the Trust's performance and will consist of non-paid professionals and the public. Exactly where and how these people will operate is unclear and how many will be genuine patients/public is also not clarified.

Thirdly, the patient is expected to become involved with the Independent Overview and Scrutiny Committee set up by each local Council to oversee the local health economy each 6 months. Viewed already as a disaster in waiting by many Councils, what real effective power they will wield is undecided.

Along with these goes a rag bag of possibility – a Transitional Advisory Board, Independent Review Group, input into CHI – the Commission for Health Improvement etc. The whole has been costed at ten times that of running to days CHC's and for what?

The Government calls for patient enforcement in the NHS on the basis of free-flowing information. Stemming from recent events at the Whittington Hospital in London, it seems a pipe dream, safer by far, to keep politicians out of health care matters.

Patrick Parker is a PAA Trustee, board member. By background, he is a pharmacologist and now is chairman of Bromley's Community Health Council.

Does homœopathy work?

The latest issue of ***Effective Health Care*** focuses on the effectiveness of one of the most established complementary disciplines - homœopathy

Homœopathy is a system of treating patients using very low dose DISSEMINATION preparations according to the principle 'like should be cured with like'.

Homœopathic remedies are often known as potencies and are prepared by a process of serial dilution with succussion (vigorous shaking). The remedies are diluted to such a degree that not even a single molecule of the starting substance is likely to be present.

It has been estimated that there are around 470,000 users of homœopathic remedies in England every year.

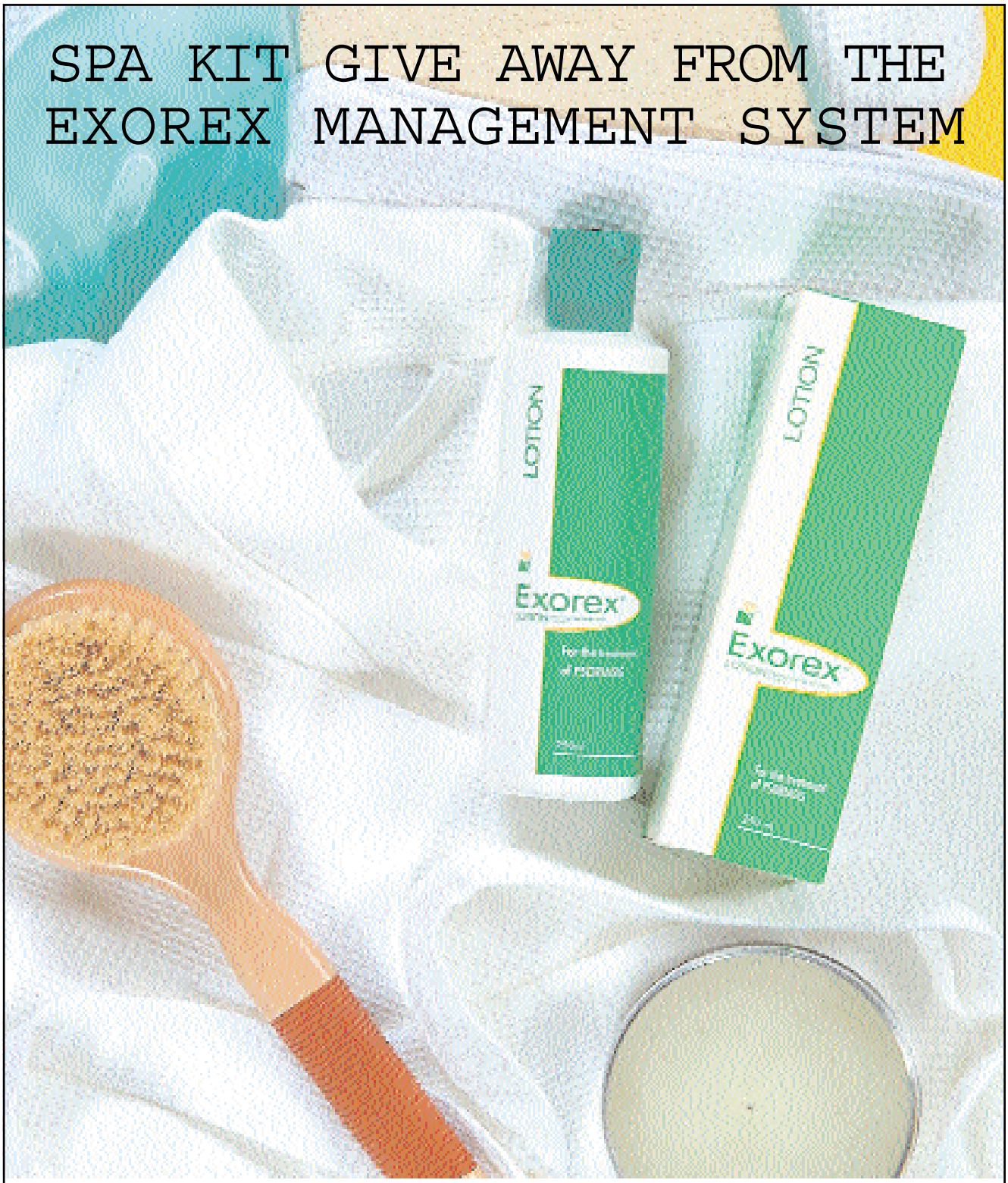
- Given the large number of users, and the availability of homœopathy within the NHS, it is important to establish the effectiveness of homœopathy as a treatment
- There is currently insufficient evidence of effectiveness to either recommend homœopathy as a treatment for any particular condition, or warrant significant changes in the current provision of homœopathy.
- The evidence base for homœopathy needs to be interpreted with caution.
- Many of the areas that have been researched are not representative of the conditions that homœopathic practitioner's usually treat.

Additionally, all conclusions about effectiveness should be considered together with the methodological inadequacies of the primary studies and some of the systematic reviews.

Further information can be obtained from Paul Wilson on 01904 433634.

University of York, York, YO10 5DD www.york.ac.uk/inst/crd

SPA KIT GIVE AWAY FROM THE EXOREX MANAGEMENT SYSTEM



Exorex Management System for mild to moderate psoriasis includes products to WASH, TREAT and MOISTURISE the condition. Exorex lotion is the most important product in the range as this is the "TREATMENT" element, containing the active ingredient of 1% coal tar. Exorex lotion is non-greasy, easy to apply and importantly for people who have Psoriasis, it is pleasant to use with no strong odour. Exorex lotion is available at pharmacies priced £14.95 for 100ml.

Exorex are giving away 5 luxurious spa kits including a white waffle robe, loofah mitt, bath pillow, candle, eye mask, body brush and wash bag, each worth £60.00.

Simply send your name and address to:

Exorex/PAA Offer
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Always Read the Label

Second meeting: Sophia-Antipolis, France 4–5 April 2002

The second meeting of InterPSO, The International Network of People with Psoriasis, took place in April 2002, and was attended by representatives of patient associations from Belgium, France, Germany and the UK. Representatives from Galderma (France) were also present.

As you may recall from the previous report on InterPSO, it provides a forum for patient groups to discuss topics of common interest and to achieve common goals. Giving patients a chance to influence the development of psoriasis treatments at an early stage, and should increase the likelihood of obtaining treatments to suit patients' lifestyles. It also gives Galderma a unique opportunity to enhance their understanding of patients' needs.

The Patient Associations

United Kingdom

David Chandler outlined the work of the Psoriatic Arthropathy Alliance (PAA).

France

The activities of the Association pour la Lutte Contre le Psoriasis (APLCP, France) were described by Michèle Corvest. The APLCP was founded in 1983 and now has more than 15,000 members in 15 regional chapters. The APLCP produces four bulletins per year and holds many regional conferences and a national congress, every 2 years.

Belgium

Eddy Swolfs summarized the work of the Vlaamse Vereniging van Psoriasis Patiënten (VVPP, Belgium), which was founded in 1982, and now has 1500 members. Association activities include a three-monthly information bulletin, two films, meetings and information sessions. The VVPP supports patients and defends their interests in various ways including organizing social events (e.g. swimming sessions) and visits, listening to patients, working with families, cooperating with physicians and pharmacists, contacts with the ministry of social affairs and supporting the creation of daycare centres. The VVPP tries to counter the taboo of a skin disease through publicity activities, and encourages research.

Germany

The work of the Deutscher Psoriasis Bund (DPB, Germany) was presented by Hans-Detlev Kunz. This national self-help group for psoriasis patients was founded in 1973 by doctors and now has more than 9000 members. DPB achievements include acceptance by the professional dermatology association as the voice of people with psoriasis, increasing the range of treatments available under statutory health insurance, supporting genetic research, producing a 3-monthly journal for members and dermatologists, producing treatment calendars and providing patient brochures for psoriasis treatment products. More than 45 local groups enable members to meet, and regular events include a psoriasis day every 2 years.

Formulation in dermatology (Laurent Fredon, Sandrine Orsoni, Alain Brzokewicz)

Members of the formulation team at Galderma discussed the principles of formulating products for topical treatment. The most important considerations are pharmaceutical requirements and 'cosmetic' acceptability to patients. Formulations for psoriasis, include solutions, shampoos or foams for the scalp, and lotions, creams, ointments, or perhaps gels for the body; the advantages and disadvantages of such formulations were considered. A better understanding of patient needs would assist the development of improved treatments.

Galenics wish list

Delegates discussed their ideas about the best topical formulations. Different formulations are needed for different lifestyle needs. Twice-daily treatment is not always practical since time is limited in the morning, and dermatologists appear to be unaware of this preference for once-daily treatment. Patients should discuss these aspects with dermatologists but there is not always time to do so. Delegates considered safety to be a priority. They noted that they are not given details of all the products available when they visit their doctors and that doctors themselves are not always aware of all the options. Some patients find alternative treatments more attractive, regardless of their effectiveness, perhaps because of their perceived lack of side-effects and ready availability.

Checklist for patients
The patient delegates were asked to think about what should be included in a checklist for patients going to their doctors. They listed questions patients should not forget to ask and suggestions of relevant information patients should tell doctors. These suggestions will be amalgamated to form a comprehensive checklist.

Observational study of compliance with topical treatments for psoriasis It was proposed that a study of the adherence of patients to topical treatments, carried out by sending out questionnaires to the patient members, would be a valuable joint venture for InterPSO. Medications are dispensed with the expectation that they will be taken exactly as prescribed, but most patients do not follow their doctors' directions. For example, 77% of patients comply with oral medication regimens when the treatment is designed to cure a disease (e.g. antibiotics for an infection) and only 50% comply when medication is to be taken over a long period. The figures for topical drugs might be worse or better depending on various factors. The reasons why patients do not comply with their treatments may be related to the nature of their disease, the medication and its side effects, and a variety of other factors. Compliance is difficult to assess since patients tend to exaggerate their own compliance or non-compliance. The proposed study would evaluate patient compliance with their topical treatments for psoriasis.

A questionnaire would be completed by psoriasis patients, aged at least 18 years, who were currently using topical treatments for psoriasis. The aim would be to obtain completed questionnaires from around 200 patients from each of the five countries currently included in InterPSO (Belgium, France, Germany, the Netherlands and the UK) questionnaires. The results would be analysed for each individual country and for all of the countries together.
The questionnaire will be short to encourage patients to complete it, and would include questions in the following categories:

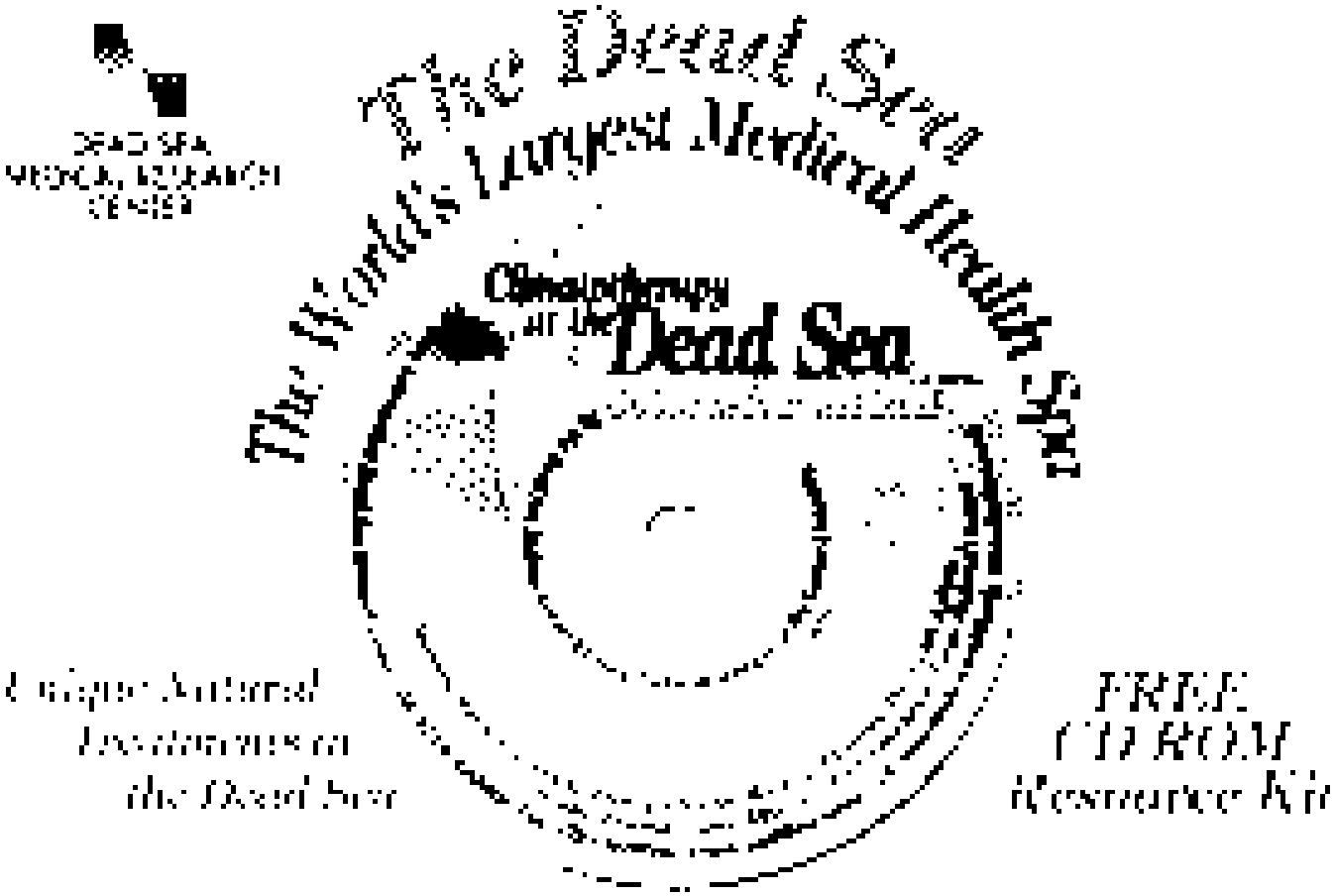
- sociodemographic characteristics
- your disease
- topical treatment characteristics
- adherence to treatment
- additional questions

It was agreed that questionnaires would be sent out in the autumn.

Galenics laboratory demonstrations and testing of formulations
Delegates saw demonstrations in the galenics laboratory of the preparation of emulsions, ointments and gels. They were asked to test these formulations, to evaluate their sensory qualities (e.g. greasiness, ease of spreading, oily effect) and to give their preferences.

Galderma research on psoriasis treatments in brief
Galderma researchers are using sophisticated up-to-date techniques to identify the many genes involved in psoriasis, each of which is a potential target for future treatment. Galderma also has other drugs in development, in addition to their new natural vitamin D drug, calcitriol (Silkis®), and are researching potential immunological treatments.

Summary
The delegates found it valuable to meet and exchange ideas, and were enthusiastic about the prospect of the joint activities. Suggested topics for the next meeting included presentations (from patient delegates) on how the healthcare systems of their countries work for psoriasis patients, together with discussions on developing future treatments for psoriasis and psoriatic arthritis.



The Dead Sea region is renowned worldwide as a healthy environment, blessed with a rare combination of natural resources: filtered solar radiation; the saltiest, mineral-rich sea on earth; thermo-mineral water dominated by sulphur; medicinal black mud along the shoreline; high barometric pressure which creates a high concentration of partial oxygen, dry air that is pollen-free; and a consistently moderate temperature throughout the year.

This unique natural environment has led to the development of Dead Sea Climatotherapy .

The Dead Sea Marketing Board promotes Dead Sea Climatotherapy as a natural alternative treatment for skin diseases such as psoriasis, atopic dermatitis, vitiligo and mycosis fungoides in its early stages; rheumatic diseases such as psoriatic arthritis and osteo-arthritis; chest diseases such as cystic fibrosis and asthma; heart disease, coronary function and hypertension; and eye disease such as uveitis.

Over the past decades, extensive clinical work and research has been conducted by leading local researchers and doctors in the field, including co-research with institutes, mainly in Europe. The purpose of this research is to assess the overall therapeutic efficacy of Climatotherapy at the Dead Sea and to ascertain the added value of each resource. To access this information and research, The Dead Sea Research Centre (established 1992) has developed an up-to-date CD that will allow doctors virtually direct access to this most recent information available for treating patients.

The CD includes the following:

1. **A short video presentation** on "Dead Sea Climatotherapy," highlighting clinical findings and including interviews with doctors and patients, as well as references that support climatotherapy's efficacy.
2. **Direct link with an informative web site** on medical facilities at the Dead Sea, through which, among other functions, enables contact to be made with a dermatologist, to gain further information and responses to professional questions: **www.deadsea-health.org**
3. **Direct link with the "Guide to the Dead Sea" web site**, which includes information on medical centres at the Dead Sea, hotels and other tourism information: **www.deadsea.co.il**

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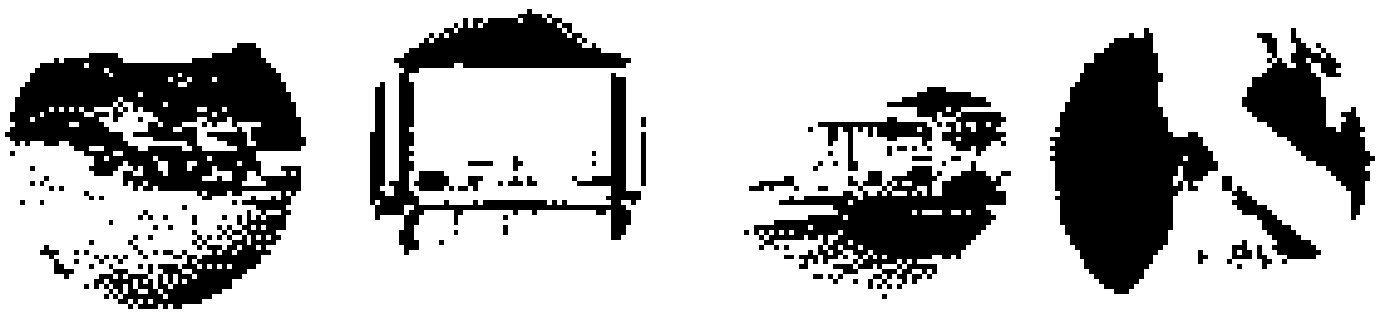

In addition, the kit contains a brief guide on the treatment of psoriasis at the Dead Sea, presented in a clear and simple format for use also by patients. We believe this material will enable you, the medical health professional, to broaden your knowledge on all aspects of climatotherapy, thereby helping you reach the best and most appropriate professional decisions for your patients.

All you need to do is to contact the Dead Sea representation bureau in London as follows, and we will send you the CD kit.

Tel: 020 8741 5566
Fax: 020 8741 6107
E-mail: deadsea@iiuk.uk
Mail: DSMB, 48 Glentham Road, Barnes, London SW13 9JJ

Quote reference: Dead Sea Medical MK1

We will also gladly answer any further question you may have.
Please contact Kevin Harris, DSMB UK Manager, Tel: 020- 8741- 5566 or e-mail: deadsea@iiuk.co.uk

We look forward to hearing from you and assisting you in informing other UK professionals as well as patients, about the unique natural benefits of Dead Sea Therapies.

Yours sincerely,

Kevin Harris

Kevin Harris
DSMB UK Manager

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Fax back to: the Dead Sea Marketing Board: 020 8741 6107

Please send a CD mailing kit to:

Name: ..... Title: .....

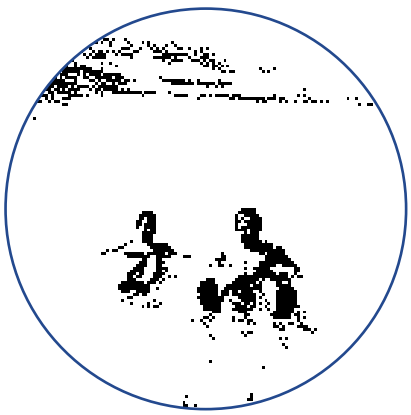
Email: .....

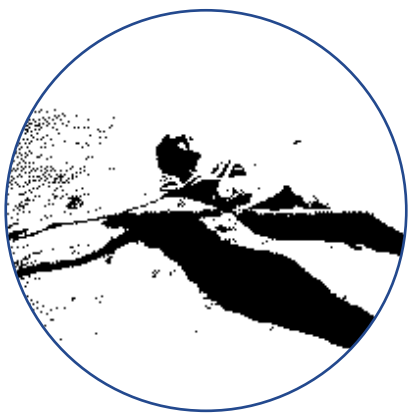
Address: .....

We require further information regarding the CD mailing. Please contact us:

Name: ..... Title: .....

Email: ..... Telephone: .....





books

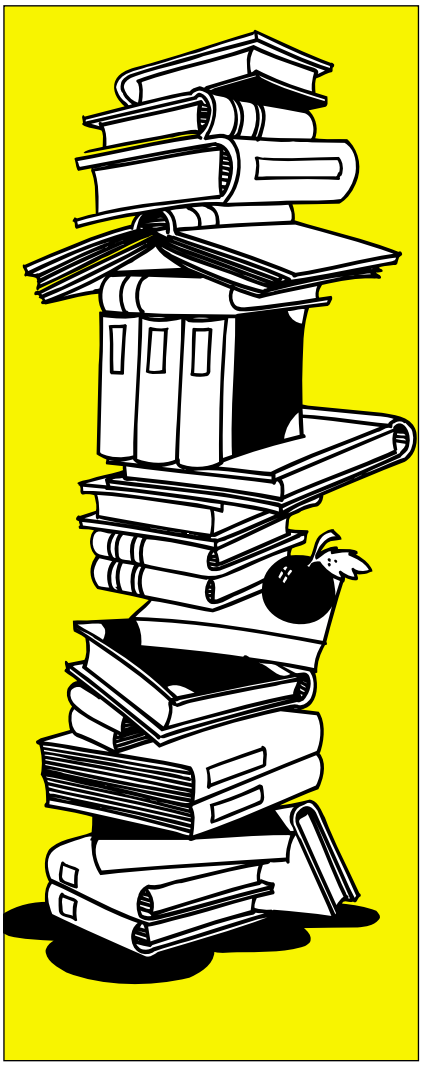
After the Doctors... What Can You Do?

By **Ron Garner, BEs, MSc**, is a superbly written book that will give you a simplified, yet clear understanding of health and disease and what you can do to improve your health.

When you finish reading this book you will know:

- What health is, how we can regain it, and how we can stay free of degenerative disease.
- How diseases like diabetes, arthritis, heart disease and even cancer are actually our body's effort to keep us alive longer.
- How drugs work and what they do to our body.
- What the natural chemistry of our body needs to be to keep us healthy, and that when it gets out of balance, how this leads to disease.
- What we must do to reverse the disease process and become healthy.
- Which supplements can help the body and which ones just place extra burdens on it.

To find out more or to order this book online, visit the web site at www.hopeforhealth.com.



books Continued

ADVISORY CENTRE FOR EDUCATION (ACE)

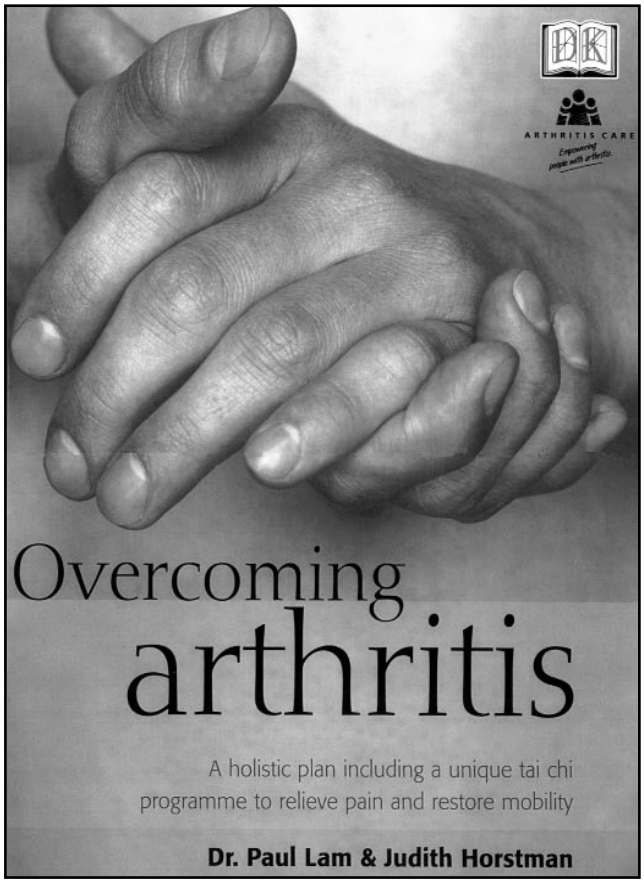
ACE SPECIAL EDUCATION HANDBOOK

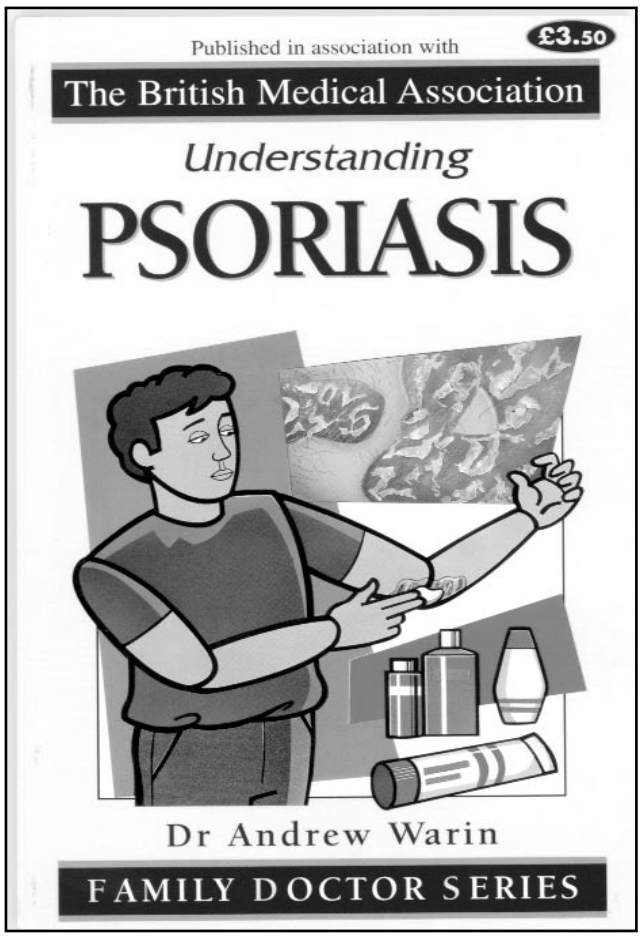
The Advisory Centre for Education has just published the eighth edition of it's well known handbook on the law of special education for parents. It costs £12 plus £2 p&p. The handbook has been published to coincide with the changes to legislation and the new Code of Practice.

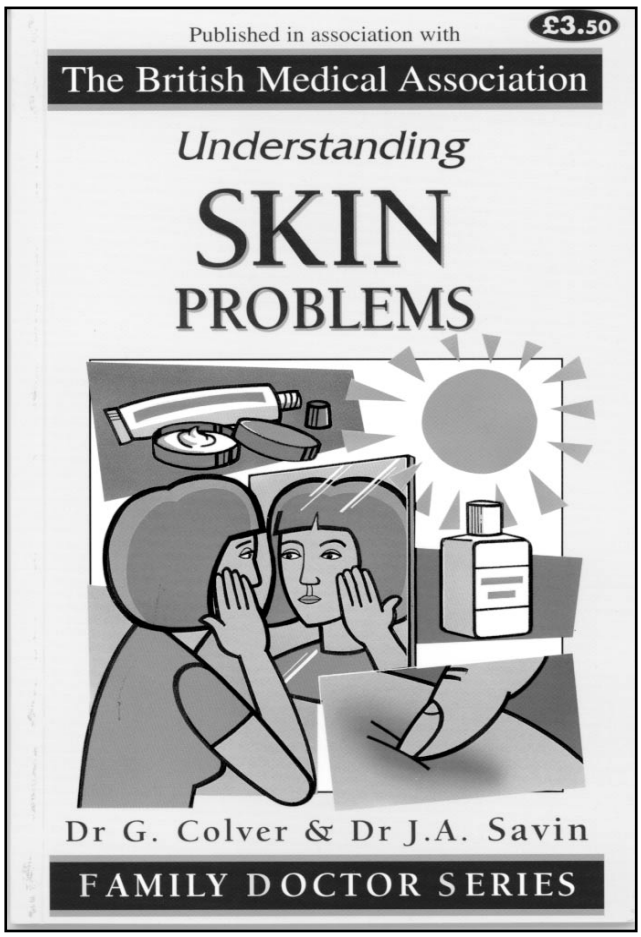
The handbook is particularly relevant to parents going through assessments and the Statementing process. The handbook:

- is clear about what is a legal requirement and what is good practice;
- describes in detail parents' rights
- gives practical advice to parents on meetings with schools, examining a statement, choosing a school and taking an appeal or complaint through the system

Advice Line 0808 800 5793
E-mail enquiries@ace.dialnet.com
1c Aberdeen Studios. 22 Highbury Grove
London N5 2DQ







Skin'n'Bones Connection

PATIENTS OFFERED ELECTRONIC PRESCRIPTIONS
IN NATIONAL PILOT STARTING IN NORTHAMPTON

At the end of March, the Pharmacy2U Consortium launched the first of three NHS pilots to test the feasibility of Electronic Transmission of Prescriptions (ETP) between GP, Pharmacist, and the Prescriptions Pricing Authority (PPA). Initially launched in the King Edward Road Surgery in Northampton, the pilot is subsequently rolling out to approximately 40 GP surgeries and 22 pharmacies. The pharmacies are owned by Co-op Healthcare Ltd and Pharmacy2U Ltd.

The pilots will all be evaluated by an NHS appointed evaluation team.

All prescribers in the pilot be able to send 'e-scripts' using their EMIS® clinical systems. Patients of practices involved in the pilot have the choice to sign up for the service by filling in a recruitment leaflet and returning it to the project managers.

The main expected benefits of the new service are:

- Saving money by releasing GP and pharmacist time
- Increased accuracy of prescribing and dispensing;
- Reduced fraud;

Pharmacy2U Consortium
Delivering ETP

- All patients using Pharmacy2U will be able to order their repeat medication from the Pharmacist by telephone, from a website (www.pharmacy2u.co.uk), by fax, or by post rather than by visiting the surgery. 80% of all prescriptions in the UK are for repeat medication.
- All patients using Pharmacy2U benefit from free delivery of their medicines to their home, work, or carer free of charge by secure, recorded delivery.

The pilots were a key announcement in the NHS Plan announced by the Prime Minister in Summer 2000 as the blueprint for the modernisation of the NHS over the next 10 years. It is anticipated that by 2004, electronic prescriptions will be routine in the community. Transfer of prescription data between GPs, pharmacies and the Prescription Pricing Authority will be carried out electronically in the majority of cases by 2008, or even earlier.

Commenting, Dr Andrew Willis, IT lead at the King Edward Road Surgery, said:

"The project is perhaps the best example so far of joined-up information management and technology in the NHS. Almost everyone wins. It brings real benefits to patients using for the first time secure, encrypted data transfers and electronic signatures across the NHS Network.

"It makes life easier for patients, receptionists, doctors, and pharmacist. It is far more than just the electronic transfer of prescriptions. It is a real advance in helping the patient, pharmacist and practice work together to deliver high quality chronic disease management."

Dr Julian Harrison, Project Leader of the Pharmacy2U ETP Consortium, said:

"This pilot will offer NHS patients a new level of convenient, efficient pharmacy service. This pilot will help those patients on repeat medication who do not have time to go to the surgery and the pharmacy each month to collect their prescriptions. It will also help those patients who are housebound or elderly."

PAA Publications order form

Copies of current and back issues of PAA publications are available at the costs set out below. PLEASE indicate which publication(s) you require, and return this form with your remittance. **Postage** is free on chargeable items but a suggested donation of **£1.00** would be gratefully accepted (**for free publications enclose a 6" x 9" SAE**) to:

PAA Publications PO Box 111 St Albans Herts AL2 3JQ
All payments should be made payable to the
PSORIATIC ARTHROPATHY ALLIANCE

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

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

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

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

Name _____ Title _____ Telephone _____

Address _____

Postcode _____ Country _____

Please allow 28 days for delivery. Thank you.

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

TO REGISTER OR SUBSCRIBE TO SKIN 'N' BONES CONNECTION

PLEASE FILL IN AND RETUREN TO PAA

SUBSCRIPTION FORM

Please complete the following clearly:-

SECTION 1 & SECTION 2 (optional)

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First Name(s) .....

Last Name .....

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

D.o.B .....

Address .....

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..... Postcode .....

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Country .....

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E-mail .....

Mobile .....

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

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

UK - £12.50 (including postage and packing) ☐

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

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

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

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

Signed: .....

Date .....

QUESTIONNAIRE

(Completion optional and confidential)

SECTION 2

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

.....

Occasionally we are supplied with product information and samples, as a would you like to receive these in the future? YES/NO

Would you be willing to enter into confidential surveys relating to psoriatic arthritis and/or psoriasis? YES/NO

How long have you had PA? .....

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

Areas/joints affected? .....

Medication tried (please list) .....

.....

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

.....

Any family history of PA or psoriasis in your family? .....

Other information:
Are there any websites or publications you think would be of interest to our readers? (please list)

.....

.....

.....

Signed .....

Date .....

All information given on this questionnaire is treated with the strictest confidence and will not be given out without the prior permission of yourself.

Thank you for your time and co-operation in the completion of this form.

What do I get if I Register?

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

What do I get if I subscribe?

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

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

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

DOCTORS APPLAUD NICE APPROVAL OF ARTHRITIS DRUGS

The decision by the National Institute for Clinical Excellence (NICE) to approve new and highly effective drug treatments, known as Anti-TNFs, for people with severe rheumatoid arthritis (RA) has been strongly welcomed by the British Society for Rheumatology (BSR).

"The decision by NICE to recommend the use of Anti-TNF drugs is great news for the whole arthritis community and will have a massive impact on arthritis services," said Dr Peter Prouse, a consultant rheumatologist and Honorary Secretary of the BSR. "The evidence supporting the effectiveness of Anti-TNFs is striking," he continued "and they offer hope for those with the most severe forms of rheumatoid arthritis who have failed to respond to conventional treatments."

Rheumatoid arthritis is an extremely painful and debilitating condition affecting around 370,000 adults in the UK and around 10% of this number have severe RA. For those with the severest form of RA who have failed existing therapies, prognosis has been very poor, with severe disability and a significantly shortened life expectancy. Anti-TNF is the only effective treatment for these people. Although the treatment appears expensive, at a cost per patient of £8 -10,000 per year, this is offset by the benefits to the health service in reduced costs of conventional drugs, joint replacement surgery and time in hospital. Moreover, treatment with Anti-TNFs can offer those with severe RA the opportunity to continue working, support themselves and their families and live independent lives.

Recognising the need to monitor this group of drugs, the BSR has already established a register gathering detailed information from all patients treated with Anti-TNFs.

NICE have also approved anti-TNF therapy for children and young people with a similar condition known as juvenile idiopathic arthritis (JIA). This condition affects around 14,500 children and young people in the UK and can be extremely debilitating. AntiTNFs offer a lifeline to those children with JIA who have failed other treatments.

The BSR worked closely with patient support groups and other health professionals in collating the clinical, economic and social proof supporting Anti-TNFs. "The submission to NICE was truly a collaborative effort involving both health professionals and people with arthritis," concluded Dr Prouse. NICE have accepted the overwhelming evidence in favour of Anti-TNFs and we are all delighted that they have approved their use."

Whats New

For more information call Home Free 0870 908 7030 www.homefree.co.uk

'Improving Clinical Outcomes In Psoriasis' Symposium-26th April, 2002 Cannes, France

This meeting was held in Cannes in preparation for the UK launch of Calcitriol (Silkis), the newest addition to the family of topical vitamin D treatments for Psoriasis. The meeting brought together UK Dermatologists and some GPs with an interest in psoriasis.

Stimulating and thought provoking discussions were held with a primary focus on the understanding of the quality of life issues and psychological disabilities that are faced by patients. The roles of both GPs and Dermatologists were re-examined in order to bring a more personal interaction and interface with patients. The role of calcitriol (Silkis) within the overall context of treatment strategies for psoriasis was also discussed in preparation for the UK launch in May 2002.

The participants also visited the impressive research facilities organised by the sponsors of the meeting, Galderma. This site is dedicated to the research and understanding of skin disorders.

GALDERMA

DIARY DATES

PAA Conference 2002

14th September
Woburn Safari Park
Bedfordshire
9.00am 4.30pm