PAA news

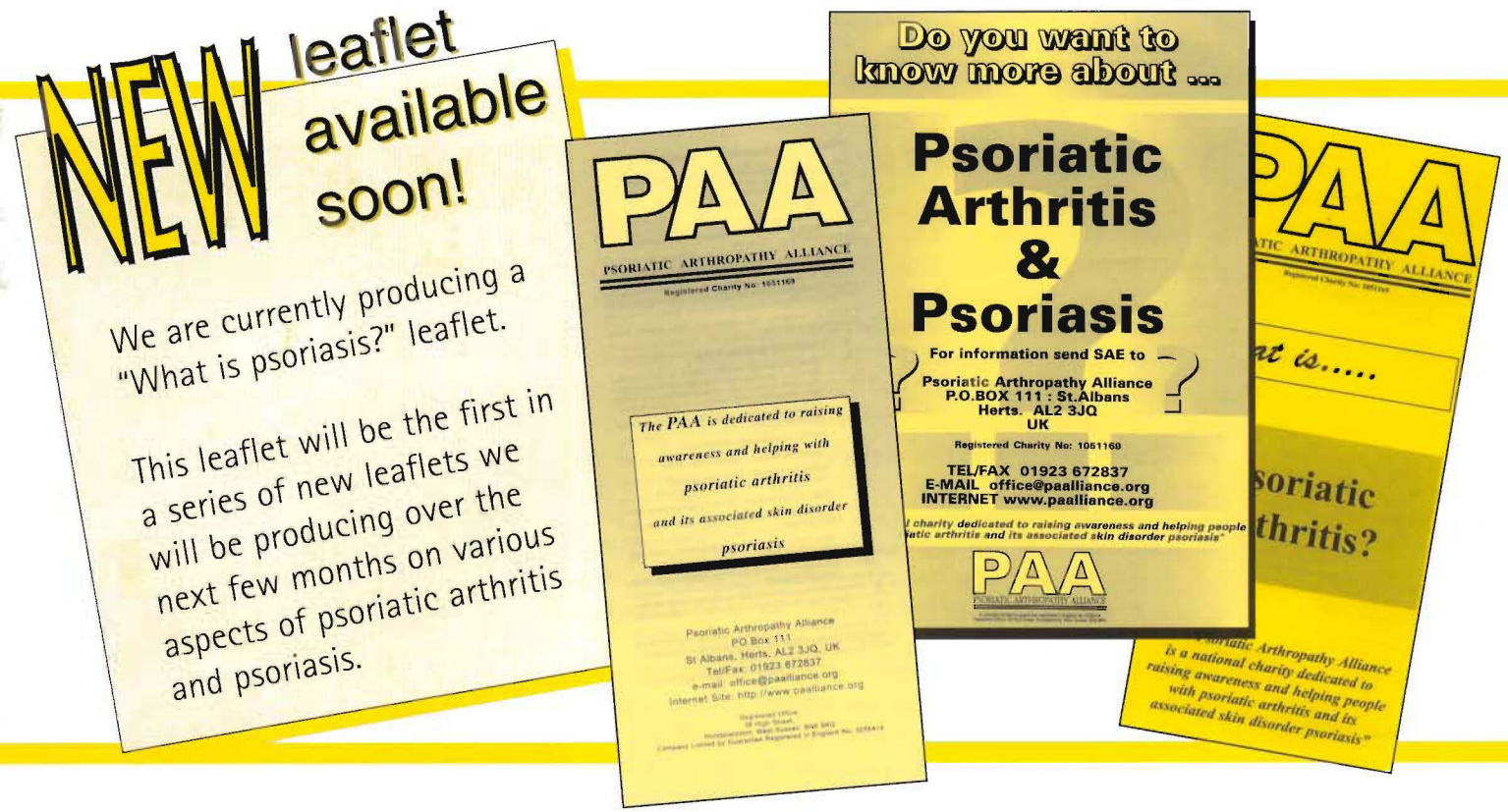
PSORIATIC ARTHROPATHY ALLIANCE

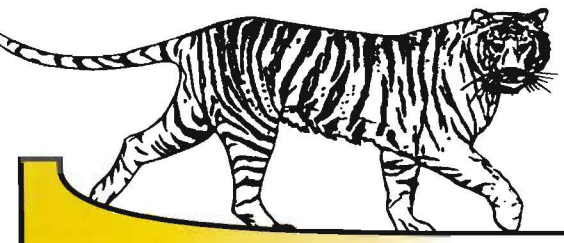
ISSUE 9 AUTUMN '97

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

LET'S SPREAD THE WORD

It is vital to continue to publicise the PAA and its work.
If anyone would like to distribute material please contact us.
We have contact posters and leaflets available.





Full details of Conference '97 on page 6

follow the footprints.

INSIDE THIS ISSUE

CASE HISTORIES • DIARY DATES • WHAT'S NEW • AND MUCH MORE

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: Aston & Co. 38 High Street, Hurstpierpoint, West Sussex BN6 9RG.

PAA, P.O Box 111, St Albans, Herts, AL2 3JQ.
Tel/Fax: 01923 672837

Comment

As part of our continual effort to update and improve our publications this issue of "News" has been expanded to eight pages and is supported by an educational grant from Evans Medical Dermatology.

This publication along with our Journal " Skin 'n' Bones Connection" relies on articles submitted for inclusion. We welcome any contribution from any source professional, lay, corporate, PR and members etc. Anyone wishing to write a piece for inclusion in any section please forward it to us at the PAA offices. We will continue to keep a balance of information relating to all aspects of the condition.

Both the "News" and " Skin 'n' Bones Connection" are circulated nationally and internationally and we are currently planning to include extracts from back issues on our Internet site when it is updated for 1998.

I would also like to take this opportunity to thank all the companies and individuals who have supported us since our formation in April 1993 without whose support both morally and financially we would not be able to continue to raise awareness about psoriatic arthritis and psoriasis.

David Chandler
Co-founder.

TRAVEL

During my quest for some form of respite, on a short holiday in Israel, I took a look at the Dead Sea area where, as no doubt you are aware, many psoriasis sufferers have found relief from their symptoms. Due to shortness of holiday time I only spent a couple of hours there, so apart from a quick dip, I was unable to assess the benefits of what was an extremely expensive location.

Whilst at times I would pay almost anything to gain relief from this dreaded curse, I have heard of another location in Iceland which claims similar results to the Dead Sea. I refer to the Blue Lagoon, which is said to be very beneficial to psoriasis sufferers. It would appeal to me in the first instance because Iceland doesn't get too hot whereas Israel does and I cannot stand hot climates. Secondly, it may well be less costly than Israel which is prohibitively expensive and appears to be exploiting us poor sufferers.

I would therefore be extremely interested to hear from any members of the PAA who have any experience or, more importantly, received any benefits from visiting this Icelandic lagoon.

Ron Allsop Tel/Fax: 01604 643832.

Editor's Note:
Please send in your experiences of Iceland, Dead Sea or other health resorts here to us at the office as we hope to publish a series of travel articles soon on these spots - it would be nice to have your contributions to add to these articles.

Printed and designed by: Keith Williams Printing 01932 253838

case history

JOHN BEVAN
Location: Surrey
Age now: 55

I first noticed a small patch of what I thought was eczema on my right leg. I was not too concerned even though it did not respond to any of the normal applications. The condition seemed to come and go so it didn't affect me unduly.

When I started work assembling commercials for the cinema, I noticed that the patches became larger and started to spread to my elbows and face. I thought this may have had something to do with the emulsion on the film. The doctor diagnosed psoriasis. I was prescribed a thick zinc-based paste, this had little effect other than to soothe the itching.

The condition spread to my chest and knees. I continued to use the zinc cream with no improvement. Further patches appeared on my left leg and scalp. The treatment was extended to using Selsun shampoo and wrapping cling film over my legs and head.

As time went on the condition erupted more often, especially at times of stress. Then I noticed white deposits under my toenails and fingernails. At first they did not hurt, but as the nails became thicker they became really painful. The doctor told me there was no treatment for this condition. I have to cut my nails as short as possible but can only go as far as the quick, the remaining deposits feel as if I have splinters under all of my nails.

About 18 years ago I started to get pain in the cushions of my heels, I put this down to standing for long periods while film editing. The pain got worse and spread to my ankles, knees, hips, back, neck and jaw. My psoriasis also worsened and had soon spread all over my torso, hands and ears.

I mentioned the pain in my joints to my doctor who dismissed it as "getting older". However, he did send me to Frimley Park Hospital for PUVA treatment for the psoriasis. This required taking a drug which makes one susceptible to UV light. So susceptible in fact, that even after the three to ten minutes PUVA treatment I had to continue to wear goggles for protection against sunlight for the entire eight hours that the drug remained active. The treatment had little effect on my psoriasis and was discontinued.

I then pressed my doctor into sending me to a local rheumatologist. I had blood tests and x-rays on many of my joints. The blood tests and x-rays revealed nothing and I was put on a course of physiotherapy, which had no effect other than to induce pain. It was during this treatment that I noticed a fly sheet on the hospital notice board promoting the Psoriatic Arthropathy Alliance (PAA). I joined and was recommended to a specialist who diagnosed psoriatic arthritis (PA), something I had told my GP I'd been suffering from for years! I am currently attending a clinic at St Bartholomew's in London.

But just how does PA affect me? The psoriasis on my face and scalp can be embarrassing, especially when wearing a dark jacket. The flakes on my forehead often get in my eyes and cause irritation; I'm always cleaning my glasses. Flakes from my chin stick in my beard or fall onto my chest. I am constantly brushing off flakes or scratching lesions. As well as all this I have to take drugs every day to control the pain and use a multitude of skin creams and special shampoos.

I am always concerned about what may be going through the mind of a person who finds themselves opposite someone suffering from psoriasis. I usually try and mention what it is before the telltale signs of enquiry appear; it is often inappropriate to launch into an explanation when business is on the agenda, however I usually do as it makes both parties feel more comfortable. I'm sure everyone who suffers from psoriasis knows the feeling of someone desperately trying not to be rude but finding themselves staring at the scaly patches. You can almost hear them saying to themselves: "I hope whatever it is is not catching".

Beaches, swimming pools and sauna baths are places which can be uncomfortable. I have had concerned people ask me if I should be using a public place. Once again, I have to launch into a short profile of the illness to hopefully assure them, and make it a little easier for myself.

If psoriasis is a constant irritation which can be temporarily relieved by scratching, there is little that can relieve the insidious pain of the accompanying arthritis. I liken it to having toothache in all the joints. Things like walking and driving can induce searing pain in my hips, feet, back, arms and shoulders, and I often arrive at my destination in a great deal of pain.

This type of handicap has had an adverse effect on my family, the walking and camping holidays we used to enjoy have been curtailed. While on a recent holiday in America and Canada, I found myself in such a state of exhaustion that most afternoons I would have to give in and go to bed. As a result there is a feeling that one has spoilt the occasion for others. It is a rare occasion when my sleep is not interrupted by pain in my feet and hips. When I get up my joints are stiff for about an hour.

Household tasks can be arduous, picking up kitchen implements can be difficult and painful, opening plastic and cardboard milk bottles sometimes takes ages. Other activities like turning the pages of a book and counting bank notes are difficult, especially if the notes are new. Many of the other daily tasks like mowing the lawn or using a screwdriver result in my hands swelling and remaining like that for days.

Coming to terms with an incurable condition is not easy, not knowing how the artful disease will treat you. I have often been fooled by a period of remission only to be brought back to reality by a disease which lurks in the shadows like a stalker.

In the last few years I've learned to adapt and all in all I'm better off than many of the members of the PAA, but there is always the thought of ending up in a wheelchair.

ADOPT US AS YOUR CHARITY!

WHY?

What have we achieved in the last four years?

- Set up an organisation from nothing in April 1993.
- Gained full charitable status.
- Held an official charity launch at the House of Commons, where members, MPs and professionals attended.
- Raised and continues to raise awareness of the condition amongst politicians and health opinion formers.
- Member of the All Party Parliamentary Group for Skin.
- Become a strong advocacy organisation taking up the issues that affect the patient with psoriatic arthritis and psoriasis.
- Consistently produce quarterly publications for members which have been circulated to a wide audience of medical and non-medical professionals, nationally and overseas.
- Held an annual conference each year since our formation.
- Launched our own Internet site, thus continuing the awareness of psoriatic arthritis and psoriasis.
- Initiated a pilot national media awareness campaign with a spring awareness week to be on going in 1998.
- Dealt with an average of 3,000 enquiries each year.
- Constantly contributed to the debate for better healthcare for patients and the services they receive.
- Made links with similar organisations nationally and internationally.
- Developed a strong board of committed medical advisers.
- Constantly made information available.
- Produced a physiotherapy booklet for psoriatic arthritis.

All this has only been achieved with sheer hard work and dedication from those involved with the organisation to reach a single goal:

"...to protect, serve, and respect the interests and rights of people who have or might become susceptible to psoriatic arthritis".

involved

continue?

1996 1996 1997

HOW?

The PAA does not run or cannot survive on thin air - we do need your help to continue! -

Help!

Here are some ways that you could possibly help with

- Does your Company have a **charity policy**?
- Does it donate equipment and other products?
- Does your Company encourage its **employees** to fundraise actively for charity and match the proceeds raised by its employees - if so, why not **nominate** the PAA?
- Are you a **shareholder** - why not drop the companies a line and **nominate** us as a charity - many do have charity policies and may be willing to help us.
- Get local companies to help sponsor our
  - Newsletters (**advertising** space available)
  - **Skin 'n' Bones Connection** News Journal (advertising space available)
  - **Sponsorship** for educational materials, leaflets, posters, booklets, etc.
  - **Annual Conference** - would your Company be willing to sponsor various elements of it, ie. catering, promotional, venue hire, prize donations, donations in general?
  - Professional/educational training days
  - On-going **Awareness Campaign** -
    Does **your** Company do any promotional work, have **links** with radio/television/papers and would be willing to **promote** the PAA and the condition?
    Would it be prepared to **donate** some **PR** time to the PAA to help issue on-going press releases about our work.
    Can it **help** with our 5th Birthday event next year?
- Get local companies/large stores in **your area** interested in our work.
- If there are any raffles/other activities raising money for charity where you work, why not **nominate** the PAA as a **good cause.**
- Are there any local fundraising activities planned in **your** area **raising** money for charities? Why not write in and **nominate** the PAA.
- Get your local Rotary Club **involved.**
- **Do you know anyone willing to run the London Marathon for us?**
- Fundraising info sheets available from the PAA office.
- **Please help us to continue the work we are doing and to grow and expand the organisation to help meet your needs.**

good cause

donations

case history

ANITA MACAULAY
Location: Warwick
Age now: 39
Age of onset of PA: 12
Years before diagnosis: 12

I was 12 years old when I first noticed that my right knee was swollen and painful. My GP referred me to an orthopaedic specialist, who aspirated my knee and sent the fluid off for analysis; a procedure that I was to endure regularly for many months! My leg was put in a full plaster cast and soon after I was admitted to hospital for a tissue biopsy. I spent the next nine months having my knee aspirated weekly, and finally my parents were told that I had septic arthritis.

Shortly afterwards my GP recommended that I should go to London for a second opinion. I was duly taken to visit another specialist, who threw away my plaster cast, strapped my leg up and gave me intensive physiotherapy to help build up my wasted thigh muscles. I learnt, only last year, that the reason for this speedy second opinion was because the orthopaedic specialist had informed my GP that he was planning to amputate my right leg above the knee! He had apparently identified bacteria in my leg which would lead to gangrene. My GP (to whom I will be eternally grateful) thought this was appalling, hence the referral. The opinion now is that the bacteria that had been isolated was either hospital contamination or skin surface bacteria!

Within weeks my knee had settled down and I was to get no further trouble for about ten years, when all of a sudden it became swollen again. This time I saw a different orthopaedic specialist who diagnosed joint inflammation and performed an operation to remove the membrane surrounding my knee joint. I made a poor recovery from surgery. I think the specialist thought my problems were 'all in the mind', but when it became apparent that I could not move my leg (as opposed to would not) I was put into plaster and sent home on crutches. Within days my arms began to ache, which was put down to my use of crutches.

Over the next three months I felt increasingly unwell, and I became lethargic and suffered generalised pain in my joints. I was finally admitted to hospital for tests. During my stay I noticed that my fingernails had become pitted and had started to lift off from the nail beds. I worked in a medical laboratory at the time and thought that I had contracted a fungal infection. I was seen by a dermatologist who looked at my nails and asked what was to become the 64 million dollar question: "Does anyone in your family have psoriasis?" I replied that my sister was covered in it. The dermatologist then told me that he was sure I had psoriatic arthropathy (PA).

At last after 12 years I had a diagnosis, but where did I go from there? I was very ill and still in hospital. I began a course of gold injections which were soon stopped when I had a severe reaction to them. I was allowed home on Christmas Eve armed with medication and hopeful that now I had a label and some treatment I would get better and stay that way - this turned out to be wishful thinking!

Over the next few years I knew I had to be careful with my knees but apart from that I was generally well and worked full time, firstly as Company Microbiologist for a national food manufacturer and then as Group Technical Manager for a large bakery chain. I also took a maternity break and while I was pregnant there was, if anything, an improvement in my health and no sign at all of any arthritic problems.

In 1991 I had a minor car accident during which I hit my knees and jarred my elbow. That night I awoke with excruciating pain in my right elbow. Over the next six months my GP prescribed various anti-inflammatory treatments, none of which seemed to give much relief. I began to feel generally unwell again and was referred to a specialist. I was lucky! Two weeks later I saw a rheumatologist who knew a lot about PA. He recommended steroid injections into my elbows, which by then were seizing up and causing me extreme pain. Sadly the injections had no effect. Shortly afterwards I was so ill that I was admitted to hospital for further treatment. I endured steroid injections into most of my joints and the rheumatologist prescribed a drug therapy regime which included a 'cocktail' of non-steroidal anti-inflammatory drugs (NSAIDs), steroids and sulphasalazine. Eventually I returned home, still sick but at last feeling that I was in the hands of someone who knew the condition and would do all he could to keep it under control.

So what is happening now? I left my job as Group Technical Manager for the bakery as it was a physical job which entailed a lot of standing and walking and climbing over machinery as well as mental exertion, which I just could not endure. I realised in the weeks and months after my big 'flare-up' that my life would have to change. I obtained a sedentary job in a totally different field - now I work in the voluntary sector as Director of a charity for a physical disability.

I have obtained various minor aids in my home which have helped me to remain as independent as possible. My rheumatologist does his best to avoid admitting me to hospital for treatment, as he knows that I am a single parent with a five - year-old son. I continue with various drug 'cocktails' and my arthritic problems vary throughout the year - I always feel better when the warm weather is here. I have permanent bone damage in my elbows, right wrist and knees and my mobility is quite badly impaired now. I find my specially adapted car and voice-activated computer a godsend. I have had problems 'coming to terms' with my illness, although I have finally recognised that this disease is a disability and it is not going to go away. I realise that it is up to me to adapt my life to cope with my limitations, much as I object to this!

I get extremely tired, irritable and endure great pain. I try very hard to cope with daily living by myself but it is hard at times. It is especially hard to ask for help, both for people to do the practical things I can no longer do and also to ask for medical help when it all gets too much. I get so exhausted that some days it is an effort even to talk. I live in hope that my rheumatologist can at least make the rest of my life 'bearable' - I'm not looking for a miracle anymore. I am sure that an early diagnosis of PA is vital to prevent or delay permanent bone damage and maintain mobility for as long as possible. In my case I nearly lost a leg through the wrong diagnosis being made!

UPDATE

Awareness Campaign

It has been six months since we initiated our first awareness week (21-25 April). The coverage during the week generated a number of enquiries, particularly following the activity on local radio stations and in regional newspapers. We have also had articles in women's magazines, teletext and professional medical journals.

This year's activities have given us a good insight and has been a useful pilot for next year's awareness week and on-going awareness campaign. If anyone has any contacts or ideas to raise awareness or gain media attention please let us know.

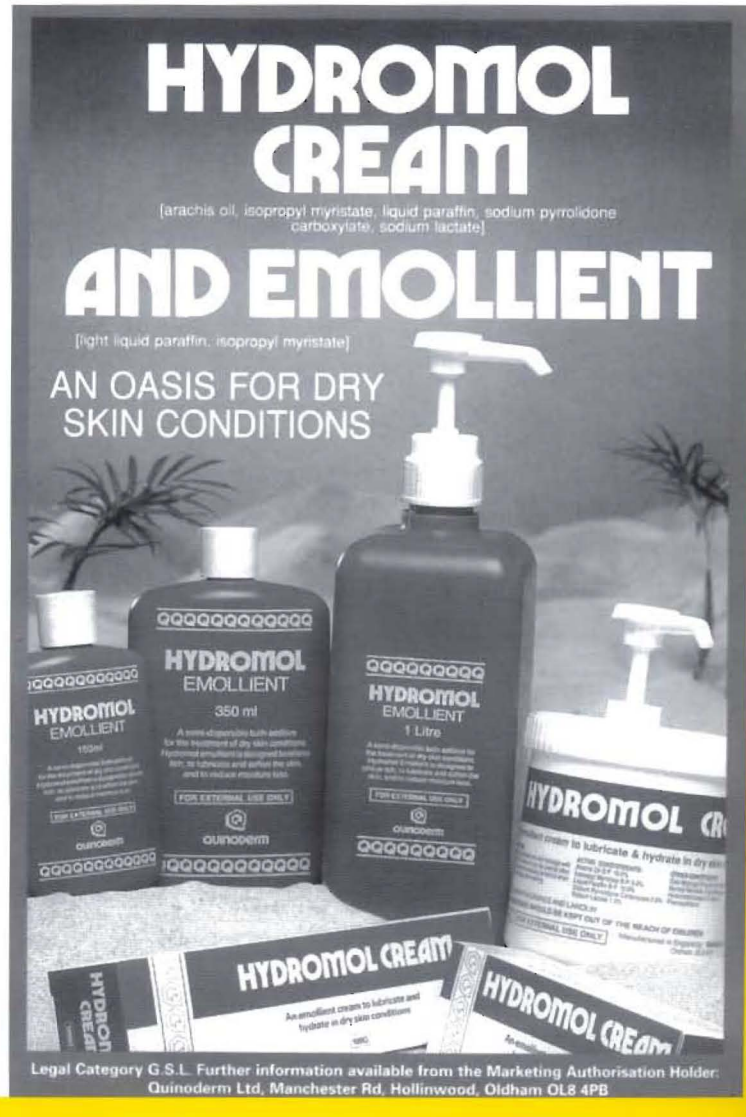
We would like to give a big thank you to the following members who helped with interviews, case histories, press releases and general awareness activity during the campaign: John Bevan, Brenda Boyce, Hilary Burrage, Geoff Buckley, Paula Carter, Sally Dale, Irene Deighton, Mike Elliott, Jackie Harvie, Janice Johnson, Sue Johnson, Gillian Lanfear, Anita MaCaulay, Anita Shapiro, Michael Sullivan, Chris Van-Hilton, and all the other members who independently raised awareness, to you, we are extremely grateful.

We would also like to thank the following pharmaceutical companies who sponsored the public relations time: Evans Medical Dermatology, Leo Pharmaceuticals, Merck Dermatology, Novartis Pharmaceuticals UK Ltd, Roche Products Ltd and Quinoderm Ltd.

NEW

Evans Medical has acquired Cocois, the coconut oil compound for the treatment of scaly scalp disorders from Bioglan Laboratories.

Cocois is a modern, reformulated version of Unguentum Cocois Co.. the hospital-developed compound for treatment of inflamed and itchy scaly scalp. Like the original, it works because the salicylic acid (2%) removes the scale to allow the coal tar (12%), sulphur (4%) and coconut oil constituents to reach the scalp. Unlike other formulations Cocois requires only one hour of contact to get results, and is formulated for stability and ease of use in scaly scalp disorders such as psoriasis, eczema, dermatitis and dandruff. Cocois is available on prescription and also available from pharmacies as it is a General Sales Licensed Product (GSL). Further information can be obtained from Evans Medical Ltd, Evans House, Regent Park, Kingston Road, Leatherhead, KT22 7RQ.



PSORIATIC ARTHRITIS? COME AND FIND OUT MORE...

PAA

PSORIATIC ARTHROPATHY ALLIANCE

Registered Charity No: 1051169

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.

CONFERENCE '97

Being held this year at

WOBURN

PROGRAMME

9.00am	Early Registration, Tea/Coffee	
10.00am	Welcome/Introduction	David Chandler
	Session One	**Chair - David Chandler**
	Research - 1 hour	
	Research Studies Psoriasis - Manchester	Prof Chris Griffiths
	Research Studies Psoriatic Arthritis - Leeds	Dr Douglas Veale
	Research Studies Psoriatic Arthritis - London	Elizabeth Ross
11.15am	**Tea Break**	
11.45am	**Session Two**	**Chair - David Chandler**
	Demonstrations - 1 hour	
	Maximise your Skin Treatments	Nurse Fiona Pringle
	Cosmetic Camouflage	British Red Cross
12.45pm	**Lunch Break**	
1.45pm	**Session Three**	**Chair - Patrick Parker**
	1 hour 15 mins	
	Acupuncture - the Truth	Dr Virginia Camp
	The Next Generation	Dr Tony Chu
	Working Together - You and Me (Patient Participation)	Dr Tony White
3.00pm	**Afternoon Break**	
3.30pm	**Session Four**	**Chair - Patrick Parker**
	1 hour	
	Questions and Answers	Medical Advisers
	End of conference	David Chandler
4.30pm		

Programme subject to change

SAFARI LODGE
WOBURN SAFARI PARK
BEDFORDSHIRE

Saturday 27 September 1997
Come along, it's going to be a good day, let's see you all there.
Kick-off time 9.00am
Your chance to talk to the experts, they're friendly, and they don't *bite!*

Registration Desk & Exhibition open at 9.00am

EXHIBITORS

British Red Cross Cosmetic Camouflage Service, Crookes Healthcare, Evans Medical, Leo Pharmaceuticals, Merck Dermatology, Nordic Saunas, Quinoderm Ltd, Stafford-Miller Ltd, Stiefel Laboratories (UK) Ltd, & others to be confirmed.

DON'T FORGET TO REGISTER NOW - ENTRY VIA PASS ONLY
Members and their guests FREE, Non-members £10.00
For more information contact: PAA, P.O Box 111, St Albans, Herts, AL2 3JQ. Tel/Fax: 01923 672837

DIARY DATES

The Skin in your Practice
1-2 October 1997
Chelsea & Westminster Hospital
Postgraduate Medical Centre
369 Fulham Road
London SW10 9NH
Tel: 0181 746 8310/5590

Biology and Therapy of Inflammatory Skin Diseases
2-6 November 1997
Secretariat: Orta Ltd
PO Box 50432
Tel Aviv
Israel
Tel: 972 3 5177888

RheumaDerm'97
3-7 December 1997
Westin Dragonara Resort
Ms Josepha Cremona
University of Malta Medical School
Department of Dermatology
Boffa Hospital
Floriana
Malta

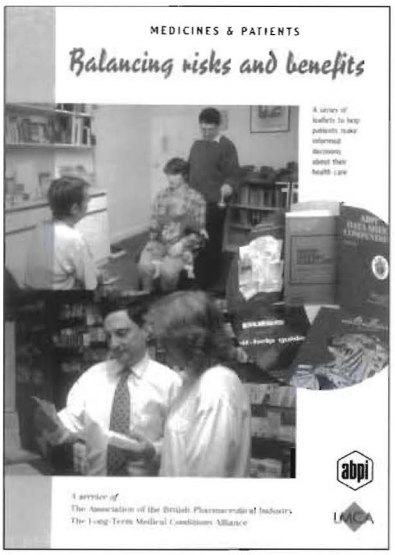
Singapore '98
18-20 June 1998
Organising Secretariat
Clinical Dermatology 2000
Singapore
CCT Healthcare Communications Limited
50-52 Union Street
London SE1 1TD
UK

NEWS IN BRIEF

LEAFLET SPELLS OUT BENEFITS AND RISKS OF MEDICINES

Information about the benefits of medicines and their risks - and how to balance the two.

Balancing Risks and Benefits is available free, from the Publications Department, ABPI, 12 Whitehall, London SW1A 2DY. It is the second in a series of similar leaflets designed to help people make informed decisions about their healthcare.



The Association of the British Pharmaceutical Industry
12 Whitehall, London SW1A 2DY
Press Office Tel: +44(0)171 747 1410
Fax: +44(0)171 747 1414

PAA

COPY DATES FOR PUBLICATIONS

PUBLICATION	COPY DATE
Winter (December) 1997 Journal	31 October 1997
Spring (March) 1998 News	31 January 1998
Summer (June) 1998 Journal	30 April 1998
Autumn (September) 1998 News	31 July 1998
Winter (December) 1998 Journal	31 October 1998

WHAT'S NEW?

WOLSEY SOFT GRIP
THE ULTIMATE NO-ELASTIC SOCK

Circulation problems and itchy skin affect many people, both young and old, and these can often be aggravated by wearing too-tightly elasticated socks. One solution to these common complaints is provided by Wolsey's Soft Grip range of socks which are uniquely designed with natural ribbing to ensure that they remain comfortable all day yet stay in position.

Wolsey Soft Grip socks retail from approx. £4.30 a pair and can be found in leading shops and stores nationwide.

PAA

HOLIDAY CARE SERVICE

INCORPORATING THE LONDON HOTEL FOR DISABLED PEOPLE

PRESS RELEASE
Newly updated holiday sheets available for disabled travellers

Holiday Care Service, the UK's central source of information and support for disabled and disadvantaged people wishing to take a holiday break, has recently updated several of its most requested information sheets.

Updated sheets include Accessible Accommodation in Israel, Majorca, Greece & Islands' and the three comprehensive sheets on the United States. Popular sheets on inclusive holidays in the UK and abroad have also been completed, as has a sheet on hiring equipment.

For further information contact:
Derek Moore, Manager, Holiday Care Service, 2nd Floor, Imperial Buildings, Victoria Road, Horley, Surrey RH6 7PZ.
Tel: 01293 774535 Fax: 01293 784647
Minicom: 01293 776943

PAA

USEFUL CONTACT CARDS

PAA

SAD FAREWELL

Mary Page - Some of you may remember Mary Page from East Sussex, a very early long-standing member, who used to collect stamps for the guide dogs.

Sadly we were told she died earlier this year.

This publication was provided with the aid of an Educational Grant from:
EVANS MEDICAL DERMATOLOGY