

Skin'n' Bones

c o n n e c t i o n

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Reaching New Heights



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

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Always consult your own doctors.

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Editorial:

Summer is on us again and for those of us with psoriatic arthritis and psoriasis its decision time again. Do we 'dare to bare' and will the heat cause problems or not to our joints?

The difference the weather makes to us seems to vary enormously: for some people heat is a saviour while for others it is a burden. The torment this combination of disease can cause at this time of year is often overwhelming, even for the most level-headed of individuals.

Added to these personal problems the pressure from those around us at work, at home and within the medical system is often intolerable. This 365-day-a-year disease 'takes no prisoners' but marches relentlessly across us battle-weary foot soldiers. Although we are all loyal to the cause (that is relief from pain and suffering) we too sometimes need a rest and can only dream of the day when we are free from the problems that dog our everyday lives.

With that last thought in mind, it is amazing how committed some people affected with psoriatic arthritis and psoriasis can be, particularly in raising awareness about both conditions. It is to these individuals that we should be eternally grateful. Although facing all the problems that have been outlined above they still continue to promote and raise awareness about the disease and especially the PAA, and often unseen or unrecognised it is the work and dedication of these people whom this tired foot soldier salutes.

Thank you from all those that you have helped.

Recruits Wanted

It takes many years for treatments to develop and be available to patients. When a drug is discovered it is first tested within a laboratory. Once its initial safety has been ascertained it will then be further tested on 'healthy' volunteers. Once these trials have been completed it is necessary to ensure the drug's effectiveness for the disease it is designed for. Therefore the drug is administered within the patient group it was designed. These trials often take place in local GP surgeries or dermatology departments within hospitals.

The Skin Therapy Research Unit (STRU) is based within St. John's Institute of Dermatology; the largest dermatology centre in the United Kingdom. STRU is a dedicated dermatology clinical trials unit. The unit has considerable experience in performing clinical trials for new or existing treatments for dermatology conditions and has a particular interest in common diseases such as psoriasis, atopic dermatitis and acne. Each trial is different. For psoriasis, in the past, we have run trials for injections into the veins and muscles, tablets and a wide variety of topical treatments. The length of the trial depends on the treatment being tested and can vary from a couple of weeks to a much longer period. The longest trial we have at present is six months.

People participate in clinical trials for a number of reasons. It is an opportunity for people to feel that they are doing something to help the development of new treatments. It is also a way of gaining access to new treatments, although it must be remembered that with most trials a proportion of participants will receive a placebo (dummy drug). It also provides people with an opportunity to have regular contact with hospital staff in order to learn more about their condition and finding ways to manage it.

Prior to starting a clinical trial volunteers will be given an information sheet to read and a verbal explanation of the study. This will outline what is being tested, why it is being tested, what the volunteer will have to do and any risks that could be associated with participating in the trial.

It is important to remember that any participant in any clinical trial can withdraw at any time and does not need to give a reason although we ask volunteers to come and see us for a final visit in order to offer alternative treatment.

If you are interested in participating in clinical trials or would like further information please do not hesitate to contact us. Our address is Skin Therapy Research Unit, St. John's Institute of Dermatology, St. Thomas' Hospital, Lambeth Palace Road, London SE1 7EH. Our telephone number is 020 7928 9292 ext. 1029. We can also be reached on e-mail at kartina.jackson@kcl.ac.uk

Case History

Dear PAA,

I have always had problems with my feet and ankles, and from an early age I can remember having 'growing pains'. As that was in the war years and I was evacuated with my sister to relatives, medical check-ups were low on the list of priorities. Our younger sister died of TB in 1940, followed by our father in 1942. We returned to our family but check-ups for TB were foremost.

The visiting school doctor was not happy with my walking and I was sent to the Central Clinic in Bristol to see a foot specialist. It was decided that I needed wedges built onto the outside of my shoes to help my walking.

When I was 14 years old, I had a bony growth under the big toenail. It was very painful and I was admitted to hospital to have the top of my toe and all the nail bed removed, leaving me with an ugly stump of a toe.

From my teenage years I always had a problem with my feet and working as a sales assistant meant long hours of standing, putting more strain on my feet. I had calluses on the soles and fungi toenails, which needed treating by a chiropodist. I twice had painful ganglions removed from my left foot. My doctor prescribed Voltral for the pain in my feet and for an arthritic elbow and hands. As walking became more difficult, my doctor referred me to Southmead Hospital. They confirmed that I had arthritis in both feet and dropped arches. Also, my right shoulder joint, which was injured some years previously in a mugging, was also causing me problems. It was thought that I probably had arthritis as a child and maybe P.A. I had psoriasis on my elbows some



years ago but have been fortunate not to have skin problems now.

I have had to have orthopaedic shoes made for me and the hospital's orthotist is very helpful. I had two spells of each foot being rested in plaster and I was due to have an operation in June 1998 to fuse the bones in my feet. However, after being admitted, it was decided that my feet had deteriorated so much that the planned operation could not be performed. They kept me in overnight to have cortisone injections and then sent me home again while they re-considered the options.



In April this year the consultant prescribed Sulphasalazine tablets and I am beginning to feel positive effects from these.

My knees are now also causing me trouble and I have had hydrotherapy sessions, which have helped a little. The physiotherapists are very helpful and have also held sessions on pain management.

At long last I have had the operation on my right foot. The bones were fused from grafts taken from my hip and three pins fitted for support and to straighten the foot. It is hoped this will ease the pain. It was quite a challenge for the surgeon and had to be carefully planned from the CT scans taken, but he is considered to be one of the best in the country and I have complete faith in him. I am so pleased that he was willing to give it a try. My foot will be in plaster for three months, followed by six weeks of non-weight bearing, but I am hopeful that it will be worthwhile in the end.

I should have accepted that I had a problem far sooner than I did and would urge others not to ignore the warning signs! My daughter who is 39 years old has also been diagnosed with P.A. and has been prescribed Methotrexate, which appears to be controlling it. I hope that early diagnosis will prevent her from having joint deformities.

I know that the most important thing is to keep a sense of humour and remain positive. I must concentrate on the things that I CAN do and not let my lack of mobility get me down. I can no longer work but this has given me more time to spend with my grandchildren.

I enjoy reading P.A.A. News and am pleased to see the research being done to treat this painful disease.

Our long hospital waiting lists do not help as things deteriorate so quickly and appointments are so far apart. However, this is not the fault of the medical teams who do a wonderful job!

Yours sincerely,

Sheila Bubb
PAA Member
(Aged 64 years)



The Role of Physiotherapy in PA

Physiotherapists are experts in the analysis and treatment of movement problems. This takes them into all aspects of the health service. As someone with PA you will probably see a physiotherapist at some time. It will most likely be due to pain, stiffness or weakness in your joints but you may also meet a physiotherapist if you have light treatment for your psoriasis, as some physiotherapy departments still run this service.

Your GP may have a physiotherapist in their practice. This physiotherapist will be a general musculoskeletal physiotherapist with skills in treating all types of joint and muscle problems. They may only have limited knowledge of PA but will be able to give you advice and appropriate exercises for any symptoms you may have at the time.

Once you have been sent to a rheumatologist you may well see a physiotherapist who has a particular interest in rheumatology. The role of the physiotherapist in the rheumatology team will vary from department to department. The following are the most common roles:

- **To help in the rheumatology clinic. Measuring your joint range and recording changes in your function. This can help the consultant decide if the medication you are on is working to control the PA.**
- **To work with the rest of the team to answer your concerns and explain what is happening with your condition.**
- **Through exercise, and some hands-on treatment the physiotherapist aims to help maintain the range and strength in your joints.**
 - Some departments can offer hydrotherapy - this is an excellent way to exercise PA joints, especially the back, hips and knees.
 - Poor posture puts strain on the joints and leads to prolonged pain and eventually damage. The physiotherapist can help teach you better posture. They can also advise you on the best way to maintain it when working, driving, etc.
 - If your PA is affecting your legs it can become an effort to get around, struggling to walk can put strain on your other joints, particularly the back - physiotherapists can help by assessing you for the most appropriate walking aid.
- **The physiotherapist will try to find ways of controlling the pain.**
 - Some departments can loan out TENS machines for pain relief.
 - Some offer alternative therapies such as acupuncture and reflexology.
 - Some will supply wrist and hand splints, collars and other types of support.
- **They will also give you advice on the best ways to help yourself.**

Catherine Buckley
Specialist Rheumatology Physiotherapist

Help the Physiotherapist help you ...

what the patient can do to gain the most from the therapy

On your first appointment with a physiotherapist you will be assessed. This can take up to one hour and involves a lot of questions and then a physical examination. The questions asked by the physiotherapist may be similar to those your doctor asks. The physiotherapist will have access to your medical notes but this is a way of checking that the information is up to date and correct.

Prepare a list of your medication and any past medical history. Try to be patient and answer questions clearly as possible. Do you know what you want from treatment?

During the first part of the assessment you are asked about your medication and past medical history. If this is difficult to remember it can be much quicker and easier to have already prepared a list to give to the therapist when they ask. It is important for the therapist to understand what your pain is like, what makes it worse and what helps it. This will give them an idea as to how it will respond to treatment. We know this can be difficult but be patient and try to answer their questions as clearly as you can. You will also be asked what you expect from treatment. This will help the

physiotherapist tailor the treatment to your needs and discuss what they think is realistic to expect. If you have thought about this before you come, you will be clearer in your views when you are asked.

Be honest with your physiotherapist!

During treatment be sure to inform the physiotherapist about changes in your condition. If you don't tell them you feel no different or you were sore after the last treatment, they won't know!

Do the exercises prescribed by your physiotherapist

The exercises will be no help if you don't do them. If you can't do them or you are worried about them, admit this to the physiotherapist as there is usually another way.

Work with your physiotherapist

In PA the best way to get the most from your physiotherapist is to work with them. You are the expert on your condition and how you feel. They have the skills and knowledge to help you get the most from your joints. Together you are more likely to achieve your goal.

Catherine Buckley
Specialist Rheumatology
Physiotherapist

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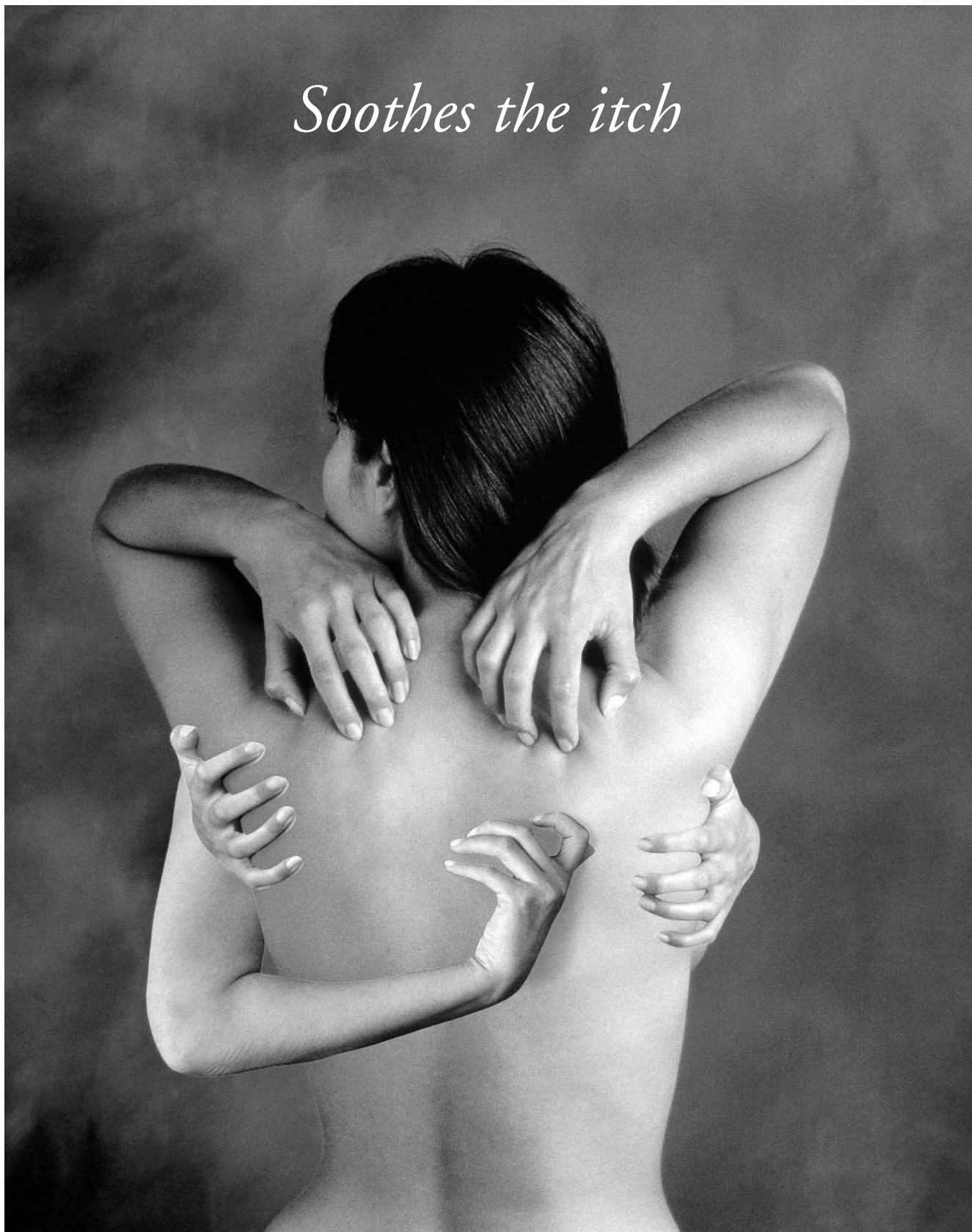
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NEW REPORT 1

THE EXPERT PATIENT

Which looks at how the Government's Healthy Citizens programme could impact on public health in the UK. Commissioned by the ABPI, it was written by John Illman, former medical correspondent on the *Observer*. The report contains a range of views expressed by people who are deeply committed to ensuring that patients become better informed and therefore more 'expert'. *The Expert Patient* also includes *The Patient's Code* - some suggestions on how the doctor / patient

relationship can be improved so that it runs as smoothly as possible.

Some of the comments made in *The Expert Patient*:

- If we become a nation of expert or even just better informed patients, we may reduce the incidence of chronic disease and promote preventive medicine. There would be a better chance of patients getting the treatment that is really the best for them.
- Patients need new skills for a new age. Information and communication skills are the prerequisites for the informed patient of the 21st century. Patients who do not develop

these skills could become the new underclass in a two-tier health system.

- We are now living with a global medium - the internet - which does not recognise national rules. UK citizens have access to US websites which communicate information to 'US citizens only' and to thousands of medical sites offering contradictory and misleading information.

A survey commissioned by the ABPI and set out on page 10 of *The Expert Patient* shows that doctors are not particularly supportive of the Government's proposals and foresee not only an increase in their workload but also a deterioration in the relationship with their patients.

Further copies of *The Expert Patient* are available free of charge from Mrs Margaret Fleming in our Publications Department:

Tel: 020 7930 3477, ext. 1446;
Fax: 020 7747 1411;
E-mail: mfleming@abpi.org.uk.

FOR CARERS TO MEET THE CHALLENGES OF ARTHRITIS

Arthritis - literally - has a crippling effect on the lives of British people. It is the number one physical disability in the UK. Nine out of ten people have the disease by the time they reach 60. One in four visits to a GP are about arthritis or rheumatic pain.

Yet, contrary to the Press, which often depicts arthritis as being trivial or something terrible that leaves you in a wheelchair, the majority of arthritis sufferers can lead a full and independent life.

Caring for Someone with Arthritis, a new guide published today by Age Concern, provides a vital role in promoting independent living. It is full of practical advice and guidance, and takes an honest look at the challenge of arthritis from the point of view of the would-be family or informal carer.

Caring for Someone with Arthritis gives basic information about the most common forms of arthritis and how they can, be treated, from drugs and exercise to complementary therapy and diet. It examines the types of care and help people with arthritis want and who can provide it - whether it is social services, doctors and other professionals, or the carers themselves. It also features many personal experiences of people with arthritis and their carers.

Topics include:

- the different types of arthritis and the problems it causes;
- how to treat arthritis;
- what it means to be a carer;
- carers' rights to obtain help from social services;
- services available to arthritis sufferers - health and social services professionals,

voluntary organisations and the family;

- planning for change - the practical aspects of acting on decisions to improve everyday life for the arthritis sufferer.

Caring for Someone with Arthritis (price £6.99 plus £1.95 p+p) ISBN:0862422663 is the latest addition to Age Concern's popular Carers' Handbook Series. It is available from Age Concern England's mail order department on 020 8765 7203, or people can send a cheque to Age Concern England at **Mail Order Department, Astral House, 1268 London Road, London, SW16 4ER.**

It can also be ordered from local Age Concern organisations and good bookshops around the country.



Skin'n'Bones Connection

ISRAEL has often been called the Land Of Miracles. However, having tried so many 'miracle cures' for my psoriasis I could be forgiven for feeling a little sceptical when departing for the Dead Sea on April 29 this year.

Over the 27 years that I have been a sufferer I have been drawn into the trap of trying all forms of miracle cures, all with very little success. I've spent hundreds of pounds on 'exciting new discoveries', all promising to cure my psoriasis but, alas, the only treatment that had any real effect was the steroid creams that we all know and love so well.

Around May/June last year I suffered the worst spate of psoriasis that I have ever had in my years of suffering. This was a delayed reaction to a very stressful period during the first two months of 1999. By October I was desperate and telephoned All Abroad to try and get out to the Dead Sea. Unfortunately I was too late as the last group had just left and there wasn't any more groups for that year. I asked Kathy White of All Abroad to ensure that I was included on the very first group for 2000 and this left on April 29.

My trip was for three weeks during which time I really did experience a miracle. Psoriasis patches that had been resistant to treatment for 27 years disappeared, my scalp cleared completely as did most of my body. The only blemishes left are scarring mainly caused by the massive amounts of harsh steroid creams that I have used over many years.

Group v Sole Travel

I decided to travel in a group as I understand going it solo can be a very lonely experience. The Ein Bokek area of the Dead Sea is mainly visited by Germans, French and Scandinavians with very few

Brits. Being in a strange land you really do need fellow country folk with you for the camaraderie. We stayed at the Ceasar Premier Hotel which was excellent in all respects and, as I have already stated, I booked through All Abroad who did an excellent job. The MD is David Kirsch who is a psoriatic. David joined us and was with us for the first two weeks. He was very attentive and made a special effort to involve himself with all members of the group. He dined with most of the group and was usually the first to put his hand in his pocket to buy drinks and wine.

David really does believe in the 'hands-on' approach. He's not the type who leaves the group to fend for themselves and I can't recall any day when he didn't ask members of the group how their skin was progressing. His 'hands on' and very attentive manner is quite unique. He even hosted two parties for members of the group who had birthdays, including providing champagne and birthday cake.

The Treatment

The treatment consists of the three S's: Sun and Sea Salt (sorry about the last one). Being a first timer I opted for the Dead Sea Mor Clinic consultations and was under the care of their Dr M Harari. He provided me with various creams and oils together with a schedule which gave very precise instructions as to how much time I had to spend in the Dead Sea and how much sunbathing I should do. followed the instructions and achieved miraculous results. Just three weeks in the sea and sun and my skin, for the first time in 27 years, is 95 percent clear. Even the very stubborn five percent that didn't clear is very much improved and that's without a single drop of steroid - just sun, sea salt and moisturiser.

I understand from other members of the group who are regular visitors to the area that the cure is

not permanent and that the psoriasis always returns following a good remission period. However, without exception, all agreed that the benefits of the Dead Sea are accumulative in that the remission periods get longer each year and, although the psoriasis returns, it is always less severe than the time before. I cannot recall a time when my skin looked so clear and healthy, and even if it doesn't last I won't hesitate in returning to the Dead Sea next year to repeat the miracle.

By Ron Allsop PAA Member

ALL ABROAD CAN BE CONTACTED ON:

Tel: 020 8905 5024
Fax: 020 8458 3234

Other useful addresses:

VIP HEALTH HOLIDAYS,
2nd Floor, Sovereign House
11 - 19 Ballards Lane,
London N3 1UX
Tel/Fax: 01923 850 820
specialise in Dead Sea trips.

THERMALIA TRAVEL
12 New College Parade
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Tel: 020 7586 7725/020 7483 1898.
arrange trips to the Dead Sea and Turkey as well as other spa resorts.

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Fax: 07-6584606

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Dead Sea Post 86930

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Dead Sea Post 86930

Tel: 07-6584626 Fax: 07-6584620

208 rooms

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- * swimming pool, clinic, spa facilities including indoor seawater pool and thermo-mineral water pools
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Tel: 07-6584121 Fax: 07-6584666

160 rooms

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- * private beach, tennis court
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FOR FURTHER INFORMATION DEAD SEA REGIONAL TOURIST ORGANIZATION:

Tel: 07-6594408 Fax: 07-6584527

Tel: 02-9943222 Fax: 02-9943223.

DEAD SEA MEDICAL RESEARCH DEVELOPMENT CENTRE:

Tel: 07-659440617

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I.P.T.C. CLINIC, EIN BOKEK (CENTRAL SOLARIUM)

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DPAZ CLINIC, CARLTON (GALEI ZOHAR) HOTEL

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DMZ CLINIC, LOT HOTEL

Tel: 07-6584558 Fax: 07-6584430.

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Tel: 02-9945117 Fax: 02-9945122

HOLIDAY CARE

ACCESSIBLE BALEARIC GUIDES

Newly updated information packs on access in the Balearic Islands are available from the UK's central source of holiday information for disabled people and their carers.

The charity, Holiday Care, has a wide range of information on accessible accommodation abroad, and their three individual sheets on the Balearic Islands have proved to be among the most popular.

The new sheets feature information on access on Ibiza, Menorca and Majorca as well as a selection of information including transport, equipment hire, attractions and mainstream and specialist tour operators.

ACCESSIBLE AMERICAN GUIDES

Three newly updated information packs on access in the United States are available from the UK's central source of holiday information for disabled people and their carers.

The charity, Holiday Care Service, has a wide range of information on accessible accommodation abroad, and their three packs on the USA have proved to be among the most popular.

These new sheets feature three regions of the States - the Western States (including Las Vegas, the Grand Canyon and skiing in Colorado), the Eastern States (including New York City, New England & Washington) and Central Florida (Orlando & Coast). Equipment hire, attractions, travel specialists.

Each sheet costs 50 pence (incl. p&p) payable in stamps, and is available from:

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2nd Floor Imperial Buildings
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Surrey RH6 7PZ**

**Telephone: 01293 774535
Fax: 01293 784647
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HOLIDAY CARE

PSORIATIC ARTHRITIS: WHAT DO YOU KNOW?

RHEUMATOLOGY RESEARCH UNIT, UNIVERSITY OF LEEDS

Knowledge Questionnaire

This questionnaire has been devised to help you to find out what you know about psoriatic arthritis.

Most of these questions have been collected from the ARC booklet for Psoriatic Arthritis. (Answers page 12)

1. Can you choose the two true statements from the following list?

Psoriasis:

- a. often runs in families
- b. is caused by cold, damp weather
- c. the cause is not known
- d. is maybe triggered by food, drugs, pollution
- e. don't know

2. Can you choose the two true statements from the following list?

Psoriasis:

- a. is helped by sunshine
- b. involves fingernails
- c. can cause Psoriatic Arthritis
- d. starts before the joint has been damaged
- e. don't know

3. Can you choose the three true statements from the following list?

Psoriatic Arthritis:

- a. affects the joints and sometimes the back or neck joints
- b. gets worse in the cold weather
- c. is a treatable joint disease
- d. can sometimes be severe
- e. is most common in old age
- f. don't know

4. Can you choose the two symptoms which can be caused by Psoriatic Arthritis?

- a. anaemia
- b. nodules
- c. overweight
- d. back pain
- e. swollen fingers (sausage digit)
- f. don't know

5. Can you choose the two blood tests which are used to assess how active your arthritis is?

- a. cholesterol level (CL)
- b. ESR (Erythrocyte Sedimentation Rate)
- c. full blood count
- d. CRP (C Reactive Protein)
- e. don't know

6. Can you choose the two true statements about non-steroidal anti-inflammatory drugs?

- a. they stop the disease from progressing
- b. they take many weeks to start working
- c. they reduce pain, swelling and stiffness
- d. they need only be taken when the pain is bad
- e. they should be taken with food
- f. don't know

7. Can you choose the one most common side-effect that non-steroidal anti-inflammatory tablets can cause?

- a. itching of the skin
- b. indigestion
- c. bruising
- d. dry mouth
- e. loss of taste
- f. don't know

8. Can you choose the two "long-term drugs" which can put the disease into remission?

- a. Methotrexate
- b. Diclofenac
- c. Indomethacin
- d. Sulphasalazine
- e. Ibuprofen
- f. don't know

9. Can you choose the two true statements about pain killer tablets?

Pain killers:

- a. are not addictive
- b. should only be taken when pain is severe
- c. should be taken before carrying out an activity which you know causes you pain
- d. should be taken when pain starts to build up
- e. should be taken with food
- f. don't know

10. Can you choose the three correct answers about exercise treatment for Psoriatic Arthritis?

- a. exercise is an important part of treatment for Psoriatic Arthritis
- b. exercise will cure Psoriatic Arthritis
- c. exercise weakens damaged joints
- d. move your joint to the point of pain and then a bit further
- e. exercise can reduce the chance of a joint deforming
- f. don't know

11. Can you choose the two most suitable ways for someone with Psoriatic Arthritis to take regular exercise?

- a. muscle-strengthening exercises
- b. swimming
- c. walking
- d. running
- e. shopping trips
- f. don't know

12. Can you choose one activity which you should carry out when all your joints are painful and stiff?

- a. refrain from all exercise
- b. rest in bed for most of the day
- c. carry out a range of movement exercises within your pain-free limits
- d. exercise quite vigorously
- e. don't know

questionnaire continued

13. Can you choose the three treatments which would be most suitable if your wrists are more painful, swollen and stiff than usual?

- a. rest them by putting on wrist splints
- b. reduce the stiffness by vigorous exercise
- c. use them as much as possible
- d. avoid movement by keeping them in one position as much as possible
- e. put the joints through a full range of movement several times a day
- f. use of cold/ice packs
- g. don't know

14. Can you choose the two correct sentences from this list?

The most practical way to protect your joints from strain is to:

- a. use them quickly
- b. use the larger joints rather than the smaller ones where possible
- c. slide objects rather than lift them
- d. do as little as possible
- e. carry on as though you did not have arthritis
- f. don't know

15. Can you choose the one most suitable activity when you have a busy day planned but realize you are feeling tired?

- a. take the day off and do more tomorrow
- b. do everything you had planned to do
- c. take a short rest and then do all the things you had planned
- d. do essentials and leave the rest
- e. spend the day resting in bed
- f. don't know

16. Can you choose two suitable methods of conserving your energy?

- a. sit down whilst ironing
- b. plan activities to balance work and rest periods
- c. wear splints
- d. use both hands to carry objects such as full saucepans
- e. don't know

CORRECT ANSWERS,

1. a. & c. - 2. a. & b. - 3. a. & d. - 4. d. & e. - 5. b. & d. - 6. a. & e. - 7. e. - 8. a. & d. - 9. a. & b. - 10. a. & d. - 11. a. & b. - 12. c. - 13. a. c. & d. - 14. b. & c. - 15. d. - 16. a. & d.

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books

The Psoriasis Handbook:

A Self-Help Guide

Muriel K Macfarlane

Published November 1995

United Research Publishers

Paperback

Amazon.co.uk. Price: £7.06

Cyclosporin in Severe Psoriasis

Finzi/Karger. Paperback

Amazon.co.uk. Price: £10.70

(special order)

Key Advances in the Effective Management of Psoriasis

Jonathan Barker,

Christopher Griffiths

Royal Society of Medicine

Books. Paperback

Amazon.co.uk Price: £12.95

(special order)

Recent Advances in Psoriasis

Barbara S Baker

World Scientific Publishing

Hardcover. Amazon.co.uk

Price: £19.00 (special order)

The Arthritis Bible:

A Comprehensive Guide to Alternative Therapies and Conventional Therapies and Conventional Treatments for Arthritic Diseases

Leonid Gordin et al

Paperback, price unknown

250 Tips for Making Life with Arthritis Easier

Shelley Peterman Schwarz

Published May 1997

Longstreet. Paperback

Amazon.co.uk. Price: £5.43



Skin'n'Bones Connection

Psoriatic Arthritis & Psoriasis



Conference 2000

Saturday 23rd September 2000
WOBURN SAFARI PARK
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PROGRAMME (subject to change)		
9.00am - 4.00pm		
9.30 - 10.30am	Registration - Tea/Coffee	
10.30am	Welcome/Opening address	
	Special Guest Speaker	
Session One		
	Chair - Dr Virginia Camp	
Time	Title	Speaker
11.00am	Prescribing Dilemma -	Dr T White
11.30am	Research at Leeds update	Dr D Veale
12.00 noon	Q & A's	
12.30	Lunch	
Session Two		
	Chair - P Parker	
1.30pm	Innovation and pharmaceutical research	
	TBA	
2.00pm	Difficult to treat psoriasis	Dr T Chu
2.30pm	Counselling & you	Lyn Clark
3.00pm	Chiropractor/Alternative therapies	
	Pamela Hardy	
3.30pm	Q & A's	
4.00pm	End of conference	

Limited
spaces
available
so please
hurry

Buffet lunch

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:

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St Albans, Herts. AL2 3JQ UK
Tel/Fax: +44 (0) 1923 672837. e-mail: info@paalliance.org
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Ways to Cope with Arthritis

(Medical Book of Remedies)

Diana L Anderson, Paul Katz

Published September 1996

Publications International

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Price: £2.72

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Letters

Dear Editor,

I wonder if you would be willing to print this plea for help. I'm sure your members have a wealth of experience between them and there may be someone out there who has been through a similar experience and can offer us advice.

Six years ago I met my partner Karen. A month after meeting her my father died of a brain tumour and three months after that I developed psoriasis. I was at the time in a very stressful job, which I felt was aggravating my skin, and decided to leave my job and use my inheritance to fulfil a long-held dream - to own my own little café.

Karen was also being made redundant at the time, so we combined our fortunes and set up our catering business. We knew it would be hard work but it was what we both wanted to have a go at. During the time that we were working on planning and preparing the shop, Karen experienced some strange health symptoms and, unfortunately, a few days before we were due to open, was diagnosed with multiple sclerosis. There was no turning back on the project - we had signed up for a five year lease and all our money had gone into backing the business. We simply could do nothing but proceed.

For the first two weeks of the shop's opening, Karen was in hospital having intensive treatment, and when she came out she was still unable to work. Through these weeks I struggled on doing the best I could. Eventually Karen returned to the shop and we were somehow able to carry the business along. My skin would flare up from time to time and she was often ill, but service continued much as usual and we even earned some rave reviews in the national press!

We had been running the shop for about five months when my mother was struck down by a fatal heart attack. Shortly afterwards, her sister, my aunt, died and then shortly after that my uncle died too. I found it an incredibly sad and distressing time. I would go into work and stand at the sink racked

with grief and tears streaming down my face - but we never closed the shop. The show must go on, we said (and we couldn't afford to close the shop, anyway).

Not surprisingly, two months after my mum had died I developed tremendous pain and swelling in my right foot. I could barely walk and after extensive tests I was diagnosed with psoriatic arthropathy. A series of Inter-ferential sessions at the physio and anti-inflammatory drugs gradually helped the swelling to go down so that I could walk with a stick. Karen continued to have spells of tremendous fatigue and numbness in her arm, but somehow we helped each other along. Karen also found that having MS meant that she could receive free treatments from various organisations (something to do with funding restrictions) and these helped her tremendously. We managed like that for a while but last spring I developed more problems in my joints. This time it has been my fingers, wrists and arm that cause me the most pain. I do still have a sore foot and ankle from time to time but it is my hands and left elbow that really limit me now. I am unable to lift things, turn levers and knobs, open cans and lids, prepare vegetables, etc. etc. I have been on numerous drugs and none seems to take away the swelling, stiffness or pain to any great degree. My skin has flared up badly too which doesn't aid my state of mind. Karen is doing her best now to cover for me at work - a reversal of roles now - but it can't go on for long. She is tired and so am I.

I think we thought that being self-employed would be less stressful than our previous jobs, but apart from the tremendous hours we have to put in, we hadn't taken into account the stress factor of running a shop on a main high street where we have been subjected to many, many acts of crime - our windows have been smashed in twice, our flower tubs kicked to pieces and stolen, people have tried to get behind the till, our charity collection box was stolen, customers have left without paying, our car has been broken into and ransacked whilst parked at the back of the shop, Karen has had a drink thrown all over her by some yobs the list goes on. It all takes its toll on our health and our spirits.

In truth I am unable to do my job properly any more. With the loss of my dexterity, any work around the restaurant is hopeless. We're losing customers because we have had to limit our menu and our opening hours, but we cannot give up the shop because we are tied to the lease. Obviously our income is becoming less and less, and yet with added costs of medicines and treatments our expenses increase. We both applied for DLA last year but were turned down. I am appealing the decision.

We have put the business up for sale, but the market is slow and we haven't had any luck there. And anyway I wonder what on earth I could do in its stead. I couldn't manage any work that involves the hands or work that involves a great deal of walking. I seem to get exhausted by the least activity (which upsets me so, because I was once an extremely active and creative person). I approached a local organisation that deals with employment advice for disabled people, but was told that they could only see me if I was unemployed, that they don't offer time to people who are working (because of the nature of their funding). So both Karen and I feel that everywhere we turn we hit a brick wall. It's as if we are sinking into a dark abyss with no way of getting out.

In spite of all this, I do try to hang on to some positivity and look on the bright side. We don't like to see ourselves as 'sick', but just unable to do the things we used to. However, there are some days when I feel like just closing down the shop straight away - but how would we live? I have a mortgage to pay, a teenage daughter to support and pets to look after, as well as all the usual expenses of daily life - and we would still have to pay the rent etc. on the shop until the end of the lease whether we are operating the business or not. When you're self-employed you lose all the perks such as paid sick leave or retirement on ill-health grounds. Those options are not there for us.

It's all such a worry and I'm sure that there must be one or two PAA members who can offer us some advice. It would be really useful to hear from someone who is standing outside of our situation, who perhaps can see things clearly where all we see is fog. We are really truly grateful for any input. What we really need is to know and believe that there is a way forward.

Sheree Bell
Telephone 020 8761 0246
21 St Louis Road
West Norwood
London SE27 9QN

I have sent you this article on the benefits I have received concerning my psoriatic arthritis since I was introduced to magnotherapy. I don't know if it can have the same effect on everyone but my personal results were so good that I feel I have to tell other people who are suffering the same.

I would very much appreciate it if you could print my letter and if at least one person ends up getting the same relief and quality of life that I have, then it will be worth the time I have spent typing this out and when you type one fingered like I do then you can imagine how long it has taken. Thank you and I look forward to reading it in your magazine.

Dear sufferers,

After just reading the letter from Mr B Johnson who told us how well he had got on with his herbal treatment, I felt that I should write and tell fellow sufferers of my success. I was diagnosed as having PA, and was put on steroids for two years which did nothing for me except put on weight, which only makes you feel even worse. I was eventually put on methotrexate which I did find relieved the pain quite considerably but was still only making life bearable. Things got worse when I was then told that because of the side effects of methotrexate I would have to have a liver biopsy and then have regular biopsies afterwards. I really didn't fancy the biopsies but, more so, it made me realise that I didn't want to be on methotrexate any longer than I needed. I then decided to try alternative medicines from homeopaths to acupuncture and a lot of other things in between but with no success. I was then one day walking around a market when I came across a stall selling magnetic bracelets which were supposedly good for general health but they stressed it was good for arthritis. I admit I thought it a load of rubbish, and what can putting a magnet on your body do? but after talking to the lady selling them I discovered that they gave a 90 - day money back guarantee, so after discussing it with my girlfriend I decided that after all that I had tried and spent out I had nothing to lose. I didn't think it would work and so would end up getting my money back but

how wrong I was. I couldn't imagine not wearing it now as the relief I have had is unbelievable- so much so I am even back to playing squash. I'm certainly not cured but I have a far greater standard of life. I now believe in magnotherapy so much I have even started to distribute them to friends, so it's even getting me back to work in a way. I would recommend these to anyone, for as I have said you've nothing to lose. If anyone is interested in trying one and you cannot find anywhere to get one in your area, or indeed if you

would just like to chat about what it has done for me, then I would be more than happy for you to contact me. If you have access to a computer then you can E-mail me on stocksy99@aol.com or even telephone me on 07970719461. I would like to think I might have helped someone but even if this is not for you, don't give up and keep trying things. There is a cure out there.

Yours sincerely,

MARK STOCKS

We have a young member of 30 years old who sadly is suffering from endometriosis. She would like to hear from anyone who is experiencing the same condition or who has both psoriatic arthropathy and endometriosis.

She is trying for a family and wonders whether any of you out there are having similar problems, especially those of you who have had problems due to previous medications taken over the years.

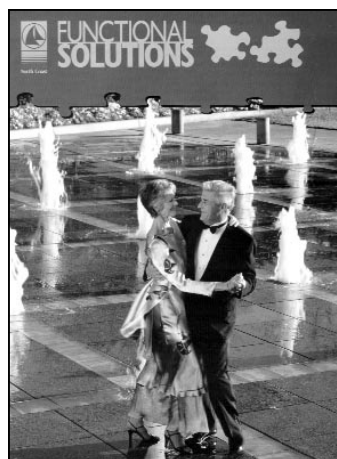
The PAA will pass on any welcomed letters to her with a guaranteed reply back!

**Thanks,
Editor**



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DIARY DATES

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GRAND DRAW 2000

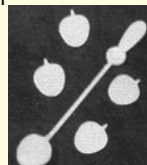
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Tel: 01977 61915

Still Blazing a Trail

The Group for Solicitors with Disabilities is now in its tenth year. It was founded in the Law Society in order to promote the issues facing practitioners with disabilities. Since its inception, it has evolved to become an essential part of the Law Society machinery. As such it is relied upon to be the collective voice of disabled professionals at every stage of their careers from gaining qualification to retirement. It advises members of the Law Society on matters of disability in general and so is a valuable resource for matters of disability awareness and etiquette. In addition it acts in a wider context, monitoring relevant legislation both in the UK and in Europe. If you have interests in both the legal world and disability, do not hesitate to make contact with us.

In order to find out more about this dynamic group, please contact Judith McDermott at: The Law Society, 113 Chancery Lane, London, WC2A IPL. Tel: 020 7242 1222

The directory for disabled travellers

IT'S 'ALL GO!' FOR EVERYONE Big Publishing Limited
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With the disabled community comprising 50 million people within the EU - 36 million of whom are able to travel - MasterCard is launching 'All Go!', the first region-by-region guide to UK hotel access for everyone. 'All Go!' has been compiled using the 'mystery shopper' technique of telephone conversations with personnel from every hotel in the country. The directory only profiles hotels and hotel restaurants (not B&B's, inns, etc.) which can provide rooms for those with disabilities, even at short notice. It is the only directory of its kind to be compiled by a wheelchair user - disability consultant Jonathan Kaye - who has spent the last two years devising and developing the project.

'All Go!' comprises hotel brands such as the Alton Towers Hotel, Travel Inns and Thistle Hotels from Lands End to John O'Groats. It does not profile those hotels owned by charities that cater exclusively for guests with disabilities. Where applicable, it highlights those hotels and restaurants that have achieved the 'Tourism for All' status.

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