Skin 'n' Bones connection

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PAA
PSORIATIC ARTHROPATHY ALLIANCE
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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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Editorial:

I have had psoriasis for more than 25 years with psoriatic arthritis for more than 20 years – although for at least 10 of those years I was not given a definitive diagnosis.

Recently I was asked to give a talk entitled 'Living with psoriasis'. And asked if I was happy with the title or in fact would I like to change it.

On reflection I decided I'd like to subtitle it as 'Psoriasis, living with me'.

So why? Well in some ways psoriasis and psoriatic arthritis are like someone you don't like moving in with you, with all its baggage. Worst of all taking over your bathroom and medicine cabinet. Tablets, pills, bottles, tubes and tubs of foul smelling evil concoctions that are all supposed to be the answer to our problems. Invariably they all work to some degree but the dedication needed would try the patience of anyone.

With psoriasis and psoriatic arthritis you have to accommodate it in your life, you have to put up with its anti- social behaviour, the embarrassment it causes and the interference that in puts on your life.

Many say "its not life threatening. So what's all the fuss about?" Well the mechanics are easily described. To live with psoriasis and psoriatic arthritis is more than a clinical manifestation, it is an all-encompassing blight.

Relentless, 365 days-a-year condition that affects not only you but also partners, care givers, and other family members. It can restrict the clothing your wear, the job you do the places you go and the activities you can do.

It's can also be a lonely condition. For psoriasis, treatment has to be done twice a day in most case in a often in a busy household with children, people getting ready for work. The average person does not have the time to use the treatment correctly hence bad compliance and poor outcome. Particularly if you have arthritis in your hands or back. The physical effort can be just too much!

Some people may also comment "well if you want to get rid of it you must put in the time", not always possible, many people with psoriasis are highly motivated, but sometimes the odds are stacked against them. Even when clearance is achieved, How long will it last before the dreaded blight returns? And again the continual routine of pill taking can also be a constant reminder of burden on one's life.

For me, my life has benefited and been blighted at the same time, I had to retire from my chosen profession at 36 years of age. Physically I am now restricted by the confines of my body's inability to fight the ravages of psoriasis and psoriatic arthritis. Financially I have been denied the opportunities I previously enjoyed. Emotionally both Julie and me have been to hell and back. Although few, the benefits have been that I have had the opportunity to help others and meet warm and generous people.

There are times even for me who has access to information and experts in the field, when I feel that I can no longer put up with this relentless condition the pressure of dealing with life's normal ups-and-downs and being ill. I'm only 42 now and should be in the prime of my life. I have a loving wife, 2 beautiful daughters and hopefully a long life ahead of me, but sometimes just sometimes I wish that things could just be different not only for me but for everyone of us with this cursed condition!

David Chandler

Cover photo: Nigel Martin, Giraffes Taking the sun at Woburn Conference venue 2000 (Report Centre pages)

"Let me introduce myself"

My name is Dr Janet McDonagh and I have recently joined the PAA in the capacity as a paediatric/adolescent advisor for young people with psosiatic arthritis. I am a paediatric and adolescent rheumatologist at Great Ormond St and the Middlesex/UCLH hospitals and my special interest is the impact of chronic illnesses like psoriatic arthritis and/or psoriasis on adolescents. I have worked in paediatric rheumatology clinics in Newcastle upon Tyne (where I went to medical school!), London and Birmingham Children's Hospital as well as in Vancouver and the Children's National Medical Centre in Washington DC. I look forward to becoming involved in your organisation and hope I can be a useful resource and advocate for you.

Transitional Care Issues for Adolescents with Psoriatic Arthritis *by Dr Janet McDonagh*

Approximately 1 in 1000 children in the UK have Juvenile Idiopathic Arthritis (JIA) ie a chronic arthritis of unknown cause presenting before the age of 16. Juvenile Psoriatic Arthritis (JPSA) is one of 7 subtypes of JIA and represents 7% of cases. JIA does not always "burn out" and one third of patients continue to have active inflammation into adulthood. Up to 60% will have limitations in activities of daily living and despite average or above average educational achievement, young people with JIA are 2-3 times more likely to be unemployed. This is not related to level of disability or type of arthritis and the exact cause is unknown but concerning.

Why then is there a need to highlight the particular needs of adolescents with JPSA? It is important to remember that adolescent are NOT just small children nor are they small adults. They present with different diseases, their bodies and minds are still developing and their relationships within the family and outside the family are continuously evolving.

Chronic illnesses like JPSA and/or psoriasis can potentially affect all aspects of adolescent development. Persistent active joint inflammation can affect their physical development eg delay growth and puberty. Drug side effects, pain, depression and tiredness due to persistent active disease can affect their brain (cognitive) development. Conversely, one must remember the stage of development when communicating with adolescents especially with respect to teaching them about the disease and treatment and involving them in decision-making. Chronic arthritis and/or psoriasis can also affect an adolescent's psychosocial development in terms of their relationship with their friends, their sexual identity, their self-esteem etc. Conversely, psychosocial issues such as risk-taking behaviour eg alcohol have implications to their treatment as is the case with methotrexate.

Transitional care for adolescents with a chronic illness like JPSA and/or psoriasis has been defined as a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child to adult centred care. The aims of transition are

(i): provision of co-ordinated, comprehensive, uninterrupted healthcare which is age and developmentally appropriate promotion of skills in communication, decision-making, assertiveness, self -care

(iii) enhance sense of control and independence in healthcare.
(iv) Transition is NOT a single event but a process that should start early (round age 10-11 years) and be planned. It must be remembered that as well as moving from paediatric to adult health-care young people also have to negotiate the transition from school to work or further education as well as from family to independent living.

Transfer to adult core is part of the transition process but has no fixed age or time. Ideally young people should transfer when they are in disease remission, when they are independent in their health-care and adherent with treatment and when they themselves feel ready to move on. The young person is at the centre of the transition process and plays an active and integral part in the planning and development of their transition plan. Other key players include their family, their GP, paediatric and adult multidiscipline" teams, school teachers, social services and voluntary organisations.

When young people with JIA have been asked what they want from an adolescent rheumatology service they have requested more information about their disease and treatment options. Studies have shown that unfortunately even long-term clinic attendees with JIA may have significant misunderstandings about their disease and treatment. One reason for this is that if they were diagnosed when they were young, most of the disease education and information was directed primarily at the parents. Other areas requested by adolescents with JIA include counselling particularly about relationships and sex, careers counselling and information about benefits. Studies also report that young people with JIA also want to be more involved in decision-making.

One of the big issues in adolescent rheumatology clinics is to gradually and sensitively introduce the concept of the young person being seen alone without their parents. 50% of 15 year olds in the community are actually seeing their GP on their own. Sometimes this is difficult for the adolescent as well as the parent to contemplate but it is part of the process of helping the young person becoming a good and effective self advocate. Other important aspects of self-advocacy are a full understanding of the illness, active involvement in decision-making, self-medication, making their own appointments etc.

The parents of young people with chronic arthritis may also need help becoming better advocates for their son/daughter with chronic arthritis. Such help may include: understanding adolescent development and the dynamic role of a parent; involving their son/daughter in decision-making from an early age; ensuring their son/daughter gradually becomes a good self-advocate; being aware of resources available and to help them in career exploration. Getting a job is not simply a matter of qualifications but also about the expectations of the young person and their family and teachers, their own self-esteem, their knowledge of relevant services and resources available, having work experience as well as society's attitude to chronic illnesses and disability in general.

In recognition of the needs of these young people and the deficiencies in the current service provision in the NHS, the British Paediatric Rheumatology Group, the Children's Chronic Arthritis Association and the Lady Hoare Trust for Physically disabled children have embarked on a national multi-centre 3 year study to see if a co-ordinated transitional care program can actually improve the quality of life for these young people. This is funded by the Arthritis Research Campaign and formally started in September 2000.

In summary, adolescents with JPSA and/or psoriasis have distinct needs and issues that differ from those of children and also adults. Both paediatric and adult rheumatology and dermatology teams need to be aware of these differences and support a multidisciplinary approach actively involving the young people themselves as they grow up into fulfiled and independent adults.

PsA research at Leeds

by Dr Douglas Veale

Quality of Life

The Quality of Life project funded by the Arthritis Research Campaign, started on the 1 September 1997, examining two complex diseases - psoriatic arthritis and systemic lupus erythemtosus (also known as "lupus" or SLE). The aim was to develop a questionnaire to measure the quality of life of patients suffering with both these diseases. Such a measure would help doctors and nurses to monitor the progress of patients and their response to treatment.

The project has progressed very well, first of all researchers interviewed 50 patients with each condition. Key points raised by the patients were then identified and a questionnaire prepared, which was sent out to another group of 150 patients, 100 "psoriatics" and 50 "lupus". Following this responses were received and allowed a further refined questionnaire to be made. This was then sent to a much larger group of patients, 500 "PsA" and 100 "lupus" and these responses have now been received and are currently being analysed. It is hoped the final phase will be completed by November 2000. It is a great credit to David, Julie and all the subscribers to PAA that this study has been successfully brought to this penultimate stage. Of course the hard work is only beginning for some of us, I have to sit down now with the team and derive the final instrument from the analysis I will then write a paper on this which will be submitted to Arthritis and Rheumatism Journal for publication. Many thanks for all your hard work!

New Treatments

Many of the subscribers to PAA will be aware that we have undertaken a study of Cyclosporin in combination with Methotrexate for severe PsA, in association with Novartis Pharmaceuticals and a group of Rheumatologists in Holland and Belgium. This study is just over half way to completion, volunteers in the Yorkshire region who are currently taking a stable dose of Methotrexate but whose disease is not fully controlled are still being recruited.

In addition, we are planning a new study of anti-TNF therapy in PsA which will be commenced shortly.

Pathogenesis of Arthritis

We have over the past five years undertaken several studies examining the nature of joint inflammation in PsA and in RA. We have described some unique findings relating to blood vessel growth in arthritis which may be very

important for the development of new treatments for the future. This work was originally published in the Arthritis and Rheumatism journal and it was picked up by the Financial Times also! The follow-up studies have look at the expression of specific growth factors, at the molecular level, which may be responsible for these changes. The preliminary results from these studies are about to be submitted for publication but there is a long way to go and more studies require to be done.

I would like to thank all those who have participated in this work.

So you're thinking of starting a family?

by Fiona Pringle

Will I have problems conceiving?

1 in 6 couples experience difficulty conceiving. This can be as a result of female problems, male factors or a combination of both. Common reasons for failing to conceive include tubal damage, endometriosis, ovarian failure, and low sperm count. In many couples the cause for their infertility is "unexplained". Most couples will conceive within a year, however if you are experiencing problems you should seek advice from your GP initially who can then refer you on to a Gynaecologist if necessary for further investigations and treatment.

Will my fertility be affected if I already have PA?

PA itself should not be directly responsible for fertility problems however, sometimes the treatments and drugs used to treat the condition can reduce your fertility. Often the affect of the drugs on your fertility is reversible once the drugs are stopped. If you are thinking of starting a family then you should discuss it with your GP and hospital consultants first.

Is the condition genetic?

If one parent has PA then they have a 1 in 4 chance of having a child with PA. If both parents have PA then that risk increases to approximately a 3 in 5 chance of their child developing PA.

Can I go anywhere for genetic counselling?

Before trying to get pregnant it is advisable to discuss it with both your GP, Dermatologist and Rheumatologist as they will be able to advise you about problems you may face during your pregnancy and the risks to a child of developing the disease. Most large hospitals have a consultant geneticists but it is unlikely that you would need to see them.

Will my PA become worse or improve during pregnancy?

Approximately 80% of women find that their PA improves during pregnancy. Often the symptoms re-occur 6-12 weeks following delivery. In some cases the psoriasis or arthritis presents for the first time during pregnancy. During pregnancy hormonal changes cause the ligaments to stretch to allow the pelvis to accommodate the growing baby. This together with the additional weight of the baby can also cause lower back problems in later pregnancy. It is therefore advisable to see a physiotherapist regularly. Aqua-natal classes are also widely available, your midwife should be able to advise you of the classes held in your area. These exercise classes take place in a swimming pool so that the weight of the baby is supported by water.

Will I have to stop any drug therapies prior to conceiving and during my pregnancy?

Before trying to conceive you must discuss your plans with your doctor. Several drugs used to treat PA are not safe

to take whilst pregnant and some of them even need to be stopped several months prior to conceiving as they are harmful to an unborn baby. Some of the drugs are also associated with reduced fertility.

Methotrexate-Reduces sperm count in men and causes ovulatory problems in women. The effect is reversible but should wait 6 months after stopping the drug before conceiving as is associated with fetal abnormalities.

Azathioprine-There is a possible increase in of abnormal birth defects. Small concentrations of the drug have been found in breast milk. Should only be used in pregnancy if the benefits outweigh the risks.

Non-steroidal anti-inflammatories (NSAID) These can reduce amniotic fluid and are excreted in inflammatory drugs breast milk. Therefore should be avoided in last 3 months of pregnancy or whilst breast feeding.

Gold -Safe use has not been established in pregnancy. Advise to wait 6 months from stopping treatment before trying to conceive.

Sulphasalazine -No data on safety in pregnancy available. Lowers sperm count but this is reversible once drug stopped.

Calcipotriol -Safe use in pregnancy has not been established therefore avoid unless no other alternative available.

Voitarol -Prostaglandin inhibitor, therefore prolonged use of high doses can affect ovulation. Avoid in pregnancy unless no alternative available.

Will my midwife know anything about my condition?

Your community midwife may not know much about PA so expect to be teaching her! However most large hospital have a specialist unit that cares for women antenatally that have additional medical problems and they should be able to advise you on your pregnancy, delivery and post-natal period.

Fiona Pringle

Useful addresses:

CHILD
(The National Infertility Support Network)
Charter House 43 St Leonards Road
Bexhill On Sea East Sussex TN40 I JA
Tel: 01424 732361

ISSUE
(The National Fertility Association)
114 Lichfield Street, Walsall WS11 SZ
Tel: 01922 722888

Miscarriage Association
c/o Clayton Hospital Northgate Wakefield W.Yorks WF1 3JS
Tel: 01924 200799

HFEA
(Human Fertilisation and Embryology Authority)
Paxton House, 30 Artillery Lane, London El 7LS
Tel: 020 7377 5077

National Childbirth Trust (NCT)
Alexandra House, Oldham Terrace, London W3 6NH
Tel: 020 8992 8637

National Endometriosis Society
50 Westminster Palace Gardens
Artillery Row, London SWIP IRL
Tel: 020 7222 2776

Psoriatic Arthritis & Psoriasis

Conference 2001

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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
Tel/Fax: +44 (0) 1923 672837. e-mail: info@paalliance.org

CONFERENCE

A really special day at the PAA Conference in September 2000 everybody had a great time and we even found out a lot of new things

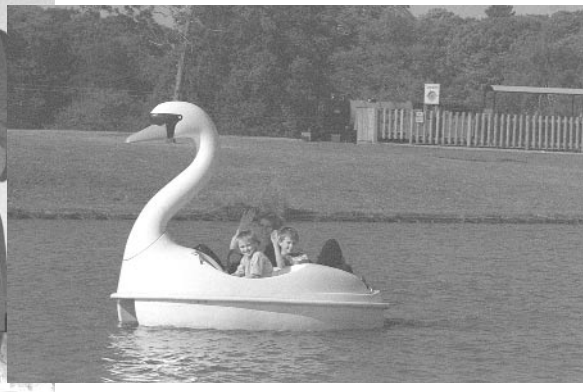
The Grand Draw taking place - Sylvia Adames and a willing helper.

Smile - David Chandler taking a break

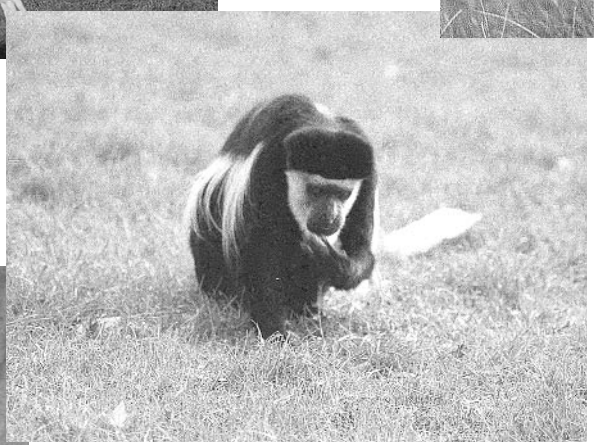
The Grand Draw in full swing

Even children enjoy themselves at a PAA conference

REPORT *in pictures*



☜ *Pamela Hardy demonstrating techniques of a Chiropractor. See page 12 for full report.*



☜ *Benefits isn't monkey business when explained by Brendan Spilane from the Benefits Agency*

Pamela Hardy's daughter Fiona taking a well earned rest ☞

CHIROPRACTIC & PSORIATIC ARTHRITIS

Pamela Hardy

Pamela is a chiropractor who practices with her daughter, Fiona and several other complementary practitioners in Lymington, Hants.

INTRODUCTION:

First a little history to put you in the picture. We know from ancient documents that manipulation has been practised for thousands of years, for example by the Incas and the ancient Greeks. The founder of modern chiropractic was an American healer called Daniel David Palmer. Since its inception in 1895, it has grown to be the third largest healing profession in the world after medicine and dentistry. About 4 years ago an Act of Parliament was passed, which precludes anyone calling themselves a chiropractor who is not suitably qualified to the standard that the government has laid down. To become a member of the British Chiropractic Association, to which I belong, requires a full-time five year degree course and then on-going training. We also have a statutory obligation to belong to the College of Chiropractors and undergo postgraduate learning. Our educational standards and professional responsibilities are the same as you would expect from your general practitioner or hospital consultant.

The chiropractic profession specialises in the diagnosis and treatment of nerve, muscle and joint disorders. It is therefore familiar with the mechanical aspects of psoriatic arthritis. By mechanical I mean the joint pain and stiffness that sometimes accompanies the skin condition. With all forms of inflammatory arthritis, such as psoriatic arthritis, there are periods of time when the inflammation is active and aggressive and then episodes of remission when the inflammation in the joint has subsided leaving reduced symptoms. Chiropractic may be an option that could give you some symptomatic relief by caring for your joints and so allowing you to enjoy the very best quality of life possible.

To enable you to do this we will look at three main topics:

1. ***What chiropractors do?***
2. ***Where and why chiropractic could fit into your programme of care?***
3. ***How do chiropractors treat patients with psoriatic arthritis?***

What do Chiropractors do?

Chiropractors specialise in the diagnosis and treatment of conditions that are the result of mechanical joint dysfunction and the effects these dysfunctions have on nerves and muscles. It is most commonly spine or joint pain that bring people into our offices. We may actually diagnose your arthritis initially. If I suspect that someone has psoriatic or another inflammatory arthritis I will immediately refer that person back to their general practitioner. I do not treat as many people with psoriatic arthritis as I could because unfortunately after they return to their doctor I rarely see them again. However, from my experience, chiropractic care can actually complement the other treatments. I would recommend both sufferers and

their doctors to consider it seriously as a form of care.

Chiropractors always look for the reasons for pain. We are not just interested in your symptoms. The problem is often a long way away from where the symptoms are. We will endeavour to find out which structures in your body are causing your pain, Then we treat the causes very specifically if we are able to.

When and why should chiropractic fit into your programme of care?

The when is very simple. As soon as an inflammatory episode has subsided a chiropractor may be able to help. The manual techniques that chiropractors use are contraindicated during inflammatory flare-ups and should not he carried out then. The reasons that chiropractic may help between flare-ups are;

* It helps to reduce pain and stiffness. It is the joints between the bones that allow our bodies to move. During psoriatic flare-ups it is not only the joints but also the ligaments that are attached to them that become inflamed. As long as the inflammation persists, the patient is unable to use the joint properly. Even when the flare-up is over, the joint may remain stiff and painful. This can be due to some cartilage damage within the joint and that cannot be healed. But some of this stiffness and pain is due to muscle and ligament dysfunction and chiropractic can help.

* It helps to remove muscle tenderness and spasm. This spasm causes muscles to be weaker than normal. This makes limbs feel weak and joints are even more unstable. Muscles provide vital protection to the joints. Correspondingly well functioning joints enable muscles to have proper tone and strength. Chiropractic helps to prevent a vicious cycle of weakness and stiffness.

* Chiropractic may assist in reducing degenerative joint changes. Persistent joint inflammation may cause cartilage and underlying bone erosion. Where chiropractic care may help is in reducing the speed at which degenerative changes continue in people suffering with arthritis. We believe this to be due to avoiding continuing stresses on joints by encouraging, more quickly, the joints to function as normally as possible.

How do chiropractors treat patients with psoriatic arthritis?

* Assessment: First we assess joint movement both individually and in the way you move, stand and sit. We do this by looking at the active range of movements to see the amount of joint and soft tissue damage. We look at the way you walk, how you move your back and at the strength and function of muscles. This will draw our attention to dysfunctioning joints which need the most help.

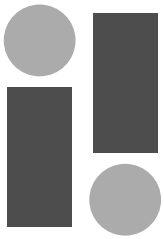
* Then we gently traction each joint and mobilise it

* We often use massage and ultrasound therapy on muscles to relieve tenderness and spasm. We also use this therapy to relieve pain and stiffness so as to reduce wear and tear on joint surfaces

* We are very keen on rehabilitation and preventative care. We teach patients simple exercise programmes to do at home and provide ergonomic advice. We do our best to help patients to help themselves.

Summary:

I hope that this information is interesting and useful. It may give you encouragement to know that chiropractic care is a further option for treatment for your arthritis.



Dead Sea 2000 - International Dermatology Congress
"New research highlights the medical benefits of the Dead Sea"

The first Annual Dermatology Congress, "Dead Sea 2000", took place in Israel in September last year presenting radical new treatments and research into psoriasis to the international dermatological community. Hosted by the Dead Sea region between the 7th and 9th September delegates included over 60 dermatologists from Europe and from the U.S., some of whom are leading world experts in the treatment of psoriasis, and 25 chairmen and representatives of psoriasis associations from 13 countries.

The world experts contributed by outlining innovative psoriasis treatment procedures, with a special focus on the unveiling of new research on psoriasis developed in conjunction with the Dead Sea. This new research was presented for the first time to an international forum by Prof. Michael David and uncovered the potential of climatic treatment in the Dead Sea for skin diseases in general and psoriasis in particular. Prof. Michael David is Chairman of the Dermatological Society of Israel and Head of the Dermatology Department at Beilinson Hospital

Dr. Marian Amir (Ben Gurion University) presented a new paper showing the significant improvement in the quality of life of psoriasis patients treated at the Dead Sea in four parameters: body pains, mental health, general health and vitality. It should be noted that the influence of the quality of life parameters in different treatments or in the use of drugs, lately proved a decisive factor in the decisions made by the treating physician.

Another paper presented the comparison between treatment costs in the Dead Sea compared to treatment in a Swiss hospital. It has been found that climatic Dead Sea treatment is cheaper by as far as 31 to 55 percent from conventional treatment in Switzerland. The immediate result of such a successful congress is to raise the level of awareness for the climatic Dead Sea treatment to the same level as other conventional treatments used by the international medical community. Furthermore, the region plans to encourage the medical community all over the world to deepen their research into the natural characteristics of the Dead Sea climatic treatment.

Among the international participants were 60 dermatologists from Europe and the U.S and 110 physicians from Israel, including most of the heads of dermatology departments from local hospitals. The 25 chairmen and representatives of psoriasis associations from 13 countries, included members of IFPA. During the congress, a meeting took place between members of IFPA and the region's tourism organisations: the Dead Sea Hotel Association (DSHA)and the local Tamar Regional Council (TRC) to discuss possibilities of strengthening ties with the psoriasis associations in different countries. The DSHA and TRC, presented the Dead Sea climatic treatment and its results to the 13 chairmen, who represent hundreds of thousands of psoriasis patients. The majority of the Chairmen, most of whom were on their first visit to the Dead Sea, agreed that discussions should continue to help jointly promote incoming health tourism for psoriasis members of their associations.

Other findings from the conference include those of Prof. Gotlieb, who presenting from a research institute in New Jersey, U.S., revealed a correlation between the disappearance of rash with psoriasis patients and the disappearance of pathological and inner cells symptoms.
The conference was held under the auspices of the International Federation of Psoriasis Associations (IFPA) at the Hyatt Regency Hotel, Ein Bokek

Additional Notes:

The unique natural elements of the Dead Sea are:

Fire(Sun) where 420 metres of three natural layers (atmospheric, evaporation and ozone) in the atmosphere allow only the UVB rays to filter through which are almost harmless to the skin, to burns and skin cancer.

Wind(Air) which contains high concentrations of minerals and has approximately 8% more oxygen than anywhere else in the world due to the high barometric pressure.

Water (Dead Sea) containing 21 minerals, 12 of which cannot be found in any other waters, and 1 0 times more salts and minerals than the Mediterranean Sea.

Earth (Mud) which is a homogeneous mixture of Dead Sea minerals and organic elements from the shoreline.

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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 £	

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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

Letters

Dear PAA
If someone wants to know all about the research on psoriasis and psoriatic arthritis that is going on all over the world, all they need to do in enter "www.google.com" on the internet and type in "psoriasis" and hit search. You will find 172,000 entries.

I have personally had psoriasis for over 50 years and psoriatic arthritis for the past 15 years, and have been able to keep it under control for the past 17 years by utilizing a therapy given to me by a dermatologist that I was going to. It consists of an injection of 40 mg kenalog followed by 40 mg prednisone for the next four days and then four additional doses of prednisone every other day for four times. The psoriasis lesions completely clear up and usually lasts for six to eight weeks. I go through this routine every two months and have been extremely happy with the results. Even considering the side effects of steroids I suffered for years with long sleeve clothes and trying to hide the scales in my hair, on my hands and face. Finally, I found a way out of that mess and heartache. Probably won't work for everyone and I won't recommend it, but it is food for thought.

Bob Bilbruck
Corona, CA USA

Dear PAA,
I am writing to let you know that I have successfully appealed against the Benefit Agency's refusal of my application for the Higher Mobility Component of the Disability Living Allowance (DLA). The Tribunal's decision was unanimous that I do qualify for DLA by virtue of being "Virtually unable to walk". It was also backdated to 9th February last year, when I was examined by the DSS doctor. I was represented by the Citizen's Advice Bureau's (CAB) Disability Information Service. I was very apprehensive about going to the appeal, but found that the tribunal, which consisted of a lawyer, a doctor and a care worker were very kind and sympathetic. They asked questions for about half an hour, then we left the room for 5 minutes whilst they made their decision. My representative said that unfortunately only about 1 in 10 people appeal against DLA refusals and that more people should appeal, using the free representation offered by the CAB. These people know the ropes and procedures, and make it a painless process for the applicant. Also, I have complained to North Yorkshire Social Services because a few months ago, they wrongly refused to give me a Blue Badge application form, saying I could only have a blue badge if in receipt of DLA. This was despite my GP sending me there for a form because of my severe walking difficulties due to the PA! Again, the CAB came to the rescue, phoned the Social Services manager and told them they were out of order by refusing me a parking badge application form. This is not just a one-off, it appears to be the policy of North Yorkshire Social Services as several others have gone to the CAB for help with the same problem. Again what is unfortunate is the number of people who just go away and don't query the incorrect information which government officials are telling them. I am pleased to say that I duly received my blue parking badge and that life has become considerably easier now I can go out and about a little more. Perhaps it may be worth letting others know of my recent experiences, that the CAB are there to help us all, and that most important, don't take what the bureaucrats tell you at face value. If you do have walking difficulties due to PA and are rebuffed by government departments, go to the CAB and ask for representation to appeal. They will only represent you if they think you have a good case, so there is nothing to lose, and after all we all pay for the benefits and the wages of the bureaucrats who seek to avoid helping people who become disabled through no fault of their own. Finally, the government's recognition that I have a disability means I qualify under the Disability Discrimination Act (DDA), and should go a long way to helping me get justice in my Employment Tribunal application against my employer for discrimination, victimisation and failing to make 'reasonable adjustments' as defined in the DDA. I will keep you posted of developments in this matter. If you want to print any of the above in Skin 'n' Bones you have my permission, I hope it will encourage others to stand up for their rights and fight against the discrimination which is endemic in society and in the very government departments which are supposed to help us!.

Best Regards,

Paul Tiffany.

Dear PAA
I am a lecturer in University of Cumhuriyet, School of Medicine, Sivas, Turkey. As you probably know, there is a place in Sivas called as Cermik with Fish (Balikli Cermik). This place is famous because of little fishes in natural warm water these are effective on the treatment of psoriasis (scientificly proved by previous studies performed with a limited number of patients. Please visit our university's web page www.cumhuriyet.edu.tr).

I am planning to organize health tours to Balikli Cermik which also going to be used for investigating the effectiveness of Cermik on the treatment of psoriasis. All patients will be examined by dermatologists before, during and after the treatment period (21 days) and take a part of scientific study.

This health tour programme was not planned only for commercial purposes, but also for scientific purposes. As you can imagine that if we cannot reach scientificly significant number of patients, the results may not be significant. In any case, I am sending you the full details of our programme with total prices.

Our responsibility for the tour will start from Istanbul International Airport. Patients will come to Istanbul on their own or with an international tourism organizations with those we have already contacted.

Total price is $1,950. Price for 21 day cure includes: - Flight from Istanbul to Sivas (return) - 21 days full board accommodation in 4 stars hotel (Sivas Buyuk Otel) - Entrance fee for Cermik with fish - Transports (from and to airports, from and to Cermik with fish everyday) Cermik with fish is 110km away from Sivas and everyday patients will be transported by air-conditioned coach. - Guidance
- Physical examination by academic dermatologist before, midterm and after the cure.
- Blood tests for HIV, Hepatitis A, B, and C before the cure
City tours
Turkish night at the end with a small, but, local originated presents

Optional: Private tours for other parts of Turkey as touristic purposes by professional tour organisers.
If you are interested in, please do not hesitate for further information

Yours sincerely,

A. Serdar Soydan, M.D., PhD,
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DIARY DATES

British Society for Rheumatology
A.G.M. & SPRING MEETING
24th - 27th April 2001
Edinburgh, Scotland

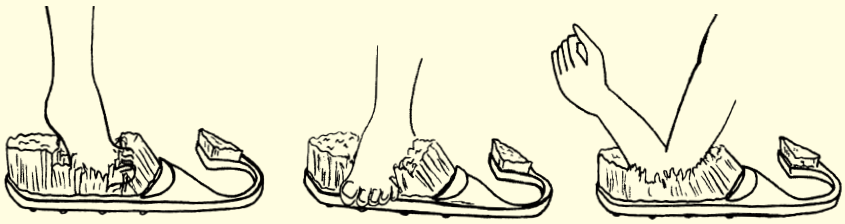
PAA CONFERENCE
Southern Region
5TH MAY 2001
BOSCOMBE, DORSET

PAA Conference 2001
29th September
Woburn Safari Park Beds.
9.00am 4.30pm

What's New!

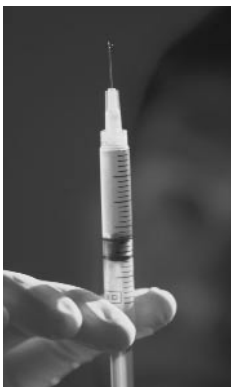
BodyRub-a brush for personal care.

To have a massage & increase the circulation of the blood in aching, swollen, tingling & tired feet is something everyone needs now & then. With this in mind ITZA-Produkter have developed an everyday aid for personal care, designed for everybody but especially for functionally disabled, diabetics, rheumatics & people with psoriasis. BodyRub is a brush that is very practical & gives you the possibility to take good care of your personal hygiene & provides you with professional foot care.
www.itza-produkter.com E-mail: itza@itza-produkter.com



Vaccine 'switches off' psoriasis

Vaccine could offer hope for patients with psoriasis. A vaccine which "switches off" part of the immune system could provide a treatment for a debilitating skin condition. In tests, psoriasis disappeared in a quarter of cases and half saw an improvement. Benefits lasted for 18 months. Psoriasis is a disfiguring genetic condition, which affects at least one in 50 people in the UK, making it as common as rheumatoid arthritis and diabetes. It is thought to be caused by a malfunctioning of the immune system, which causes accelerated growth of skin cells. These cells pile up on the surface of the skin when the body cannot shed them fast enough, leading to unsightly patches of raised red skin covered by a flaky white build-up. The condition tends to affect people first in their twenties, though people can carry the gene and not suffer from the condition. Treatment can currently either be with a drugs or with a cream. Psoriasis is rarely fatal, but the psychological damage people can suffer because of the disfigurement can have a devastating effect on their lives.It can flare up because of stress or severe throat infections.



VACCINE HOPE

The vaccine, developed in New Zealand appears to "turn off" part of the immune system. The researchers say that a single shot can offer long-lasting protection.

The vaccine was tested on 24 patients with psoriasis. Larger trials are now being carried out. Researchers carried out the trial after tests of an anti-leprosy virus in India had failed to cure leprosy, but had cleared up one patient's psoriasis. That vaccine contained microscopic organisms called Myobacterium vaccae which had been killed using heat treatment. The New Zealand team used the same preparation in their vaccine. Dr James Watson, the Auckland researcher who led the trial, said most research concentrated on trying to find the proteins which trigger the disease. Instead his team had concentrated on changing the response of the immune system. Somehow the vaccine reprograms the immune system, turning off cells that attack the skin.

Dr James Watson Lead researcher said though the vaccine worked, they did not know why it had been successful in treating psoriasis.

"Somehow the vaccine reprograms the immune system, turning off cells that attack the skin."

He added that trials on animals had shown that the vaccine could be modified to be effective against other autoimmune diseases such as cardiovascular disease and diabetes.

'BENEFIT TO PATIENTS'

Christopher Griffiths, professor of dermatology at Hope Hospital, Salford in Greater Manchester said a vaccine would benefit psoriasis patients.

He said: "The treatments we have for severe psoriasis sufferers sometimes have quite significant side effects and have to be given on a regular long-term basis.

"If this is given once and it lasts for a year, year and a half, it's probably going to be an advantage."

He predicted that psoriasis may be shown to be several similar conditions, with different treatments suiting the various forms.

The study is published in New Scientist

STOP PRESS

Out Soon, 2 new leaflets available from the PAA. Nail psoriasis and a booklet on Clinical Trials. If you would like a copy please send a SAE to: PAA, PO Box 111, St Albans, Herts. AL2 3JQ.