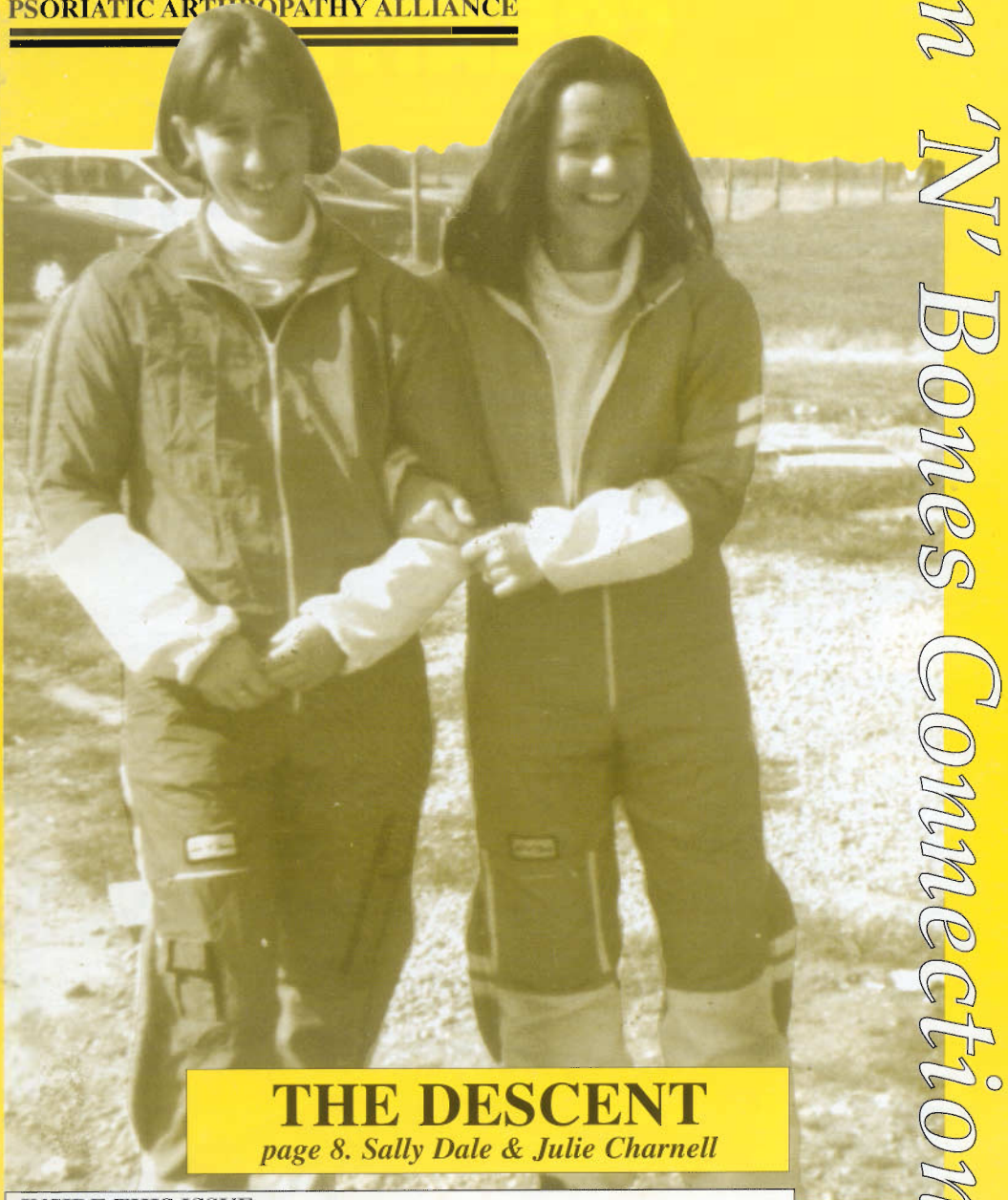
PAA

PSORIATIC ARTHROPATHY ALLIANCE

JOURNAL 8
SUMMER 97

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

Skin 'N' Bones Connection



THE DESCENT

page 8. Sally Dale & Julie Charnell

INSIDE THIS ISSUE:

HYDROMOL CREAM

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

AND EMOLLIENT

[light liquid paraffin, isopropyl myristate]

AN OASIS FOR DRY SKIN CONDITIONS

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

Contents

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

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

Psoriatic Arthropathy Alliance is a Registered Company Limited by Guarantee No: 3055414.
Registered office: Aston & Co. 38 High Street, Hurstpierpoint, West Sussex BN6 9RG.

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The PAA Team

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

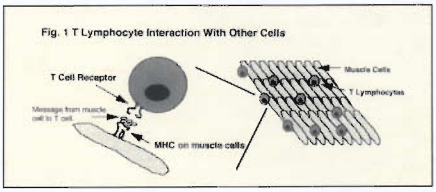
PSORIATIC ARTHRITIS AND THE IMMUNE SYSTEM
Tissue Type and MHC.

Elizabeth Ross, Immunology Department, Medical College of St. Bartholomew's Hospital, London, U.K.

Psoriatic arthritis is a disease intimately associated with the immune system. Many physicians are not aware that an inflammatory arthritis can be associated with psoriasis and thus obtaining a diagnosis often proves more difficult than it should be. Once diagnosed, however, there is a paucity of information that is available to either doctor or patient regarding this disease. Since its inception only a few years ago, the PAA has gone some considerable way in raising the awareness of PA and contributing to the dissemination of information.

At the Medical College of St. Bartholomew's Hospital, the immunology and rheumatology departments have joined together in an attempt to better characterise the contribution of the immune system to the pathogenesis of PA. We are greatly indebted to the members of the PAA who have contributed their time and, in some cases, quite literally, a piece of themselves to our research. Results to date have been very interesting and will aid in understanding the way in which the immune system is involved in skin and joint inflammation caused by PA.

During the PAA annual meeting there were many references to the search for a tissue type which is shared by people who suffer from PA. The relevance of this information is not obvious and some readers may benefit from an explanation. The term "tissue type" refers to a collection of markers on the surface of the cells in our bodies. These markers contribute to distinguishing one person from another and are used by the immune system as identity tags (figure 1). The directions for the production of these markers are found in the genes of the major histocompatibility complex (MHC) which are passed from one generation to the next and are, therefore, shared within families. At present, the search is on for a gene or collection of genes in the MHC which are associated with PA. Other rheumatic diseases such as rheumatoid arthritis and ankylosing spondylitis occur more frequently in individuals with particular MHC genes.



It is thought that there is a genetic predisposition to the development of psoriasis and PA but exactly which genes are involved is unknown at present. Evidence suggests that inflammation in the skin and joints is in part directed and maintained by cells of the immune system called T lymphocytes (figure 1 and 2). Under normal circumstances these cells survey the bloodstream and body tissues for signs of infection and cancer. In the event that a foreign agent, such as a virus, is found, T lymphocytes destroy the infected cells and send messages into the local area to recruit assistance in clearing the infection.

For reasons unknown, T lymphocytes are present in large numbers in the psoriatic skin and inflamed joints of people with PA (figure 2). The activity of these T lymphocytes and the messages which they produce contribute to the thickened epidermis in psoriasis and damage in the joint. Many of the stronger drugs prescribed for PA such as methotrexate, azathioprine and steroids serve to reduce the production and/or activity of the cells of the immune system, including T lymphocytes.

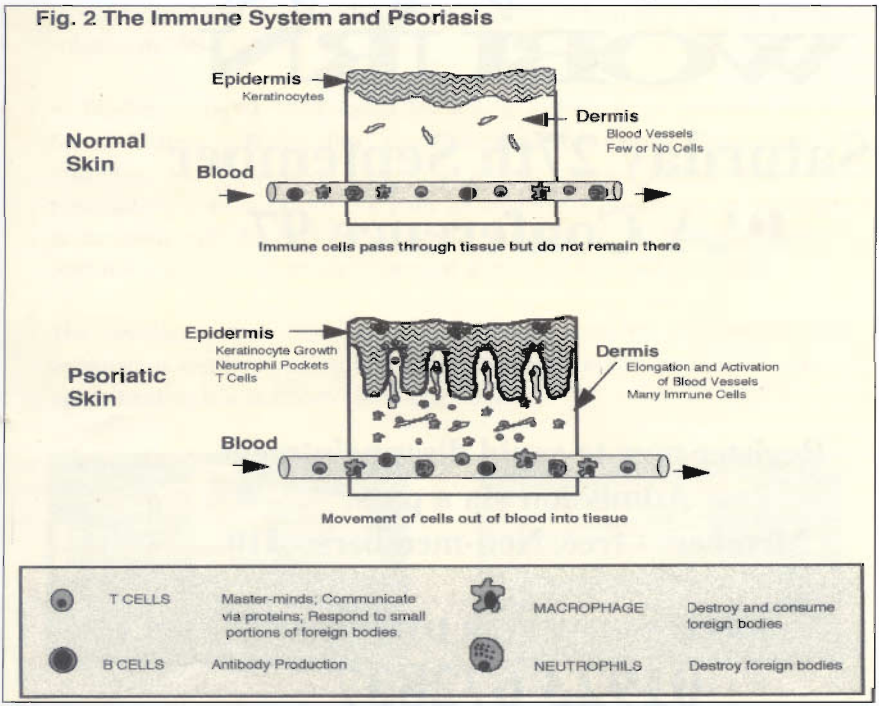
It is through tissue type markers, the products of MHC genes, that T lymphocytes communicate with the rest of the body. These markers are required for a T lymphocyte to receive information as to the identity and state of healthiness of body tissues. If a particular tissue type were found to be linked to the development of PA it would provide essential information regarding the seemingly inappropriate activity of T lymphocytes.

It has been suggested for other diseases linked to certain tissue types that the affected tissue is altered such that the immune system mistakes it for something foreign. Alternatively, an unidentified infection may result in chronic inflammation either because it resides in inflamed tissue or causes confusion in immune cells resulting in healthy tissue being mistaken for infected tissue.

The big answers to the big questions like "What causes PA and how can it be cured?" have yet to be found, but many doctors and researchers have begun to address essential smaller questions required for the understanding of PA.

Since the seminal study of Moll and Wright identified PA as a unique disease as opposed to the coincidental occurrence of psoriasis and arthritis, many groups around the world have attempted to characterise and discover better treatment for this disease. Advocacy groups such as the PAA are an essential resource for sufferers, medical professionals, the pharmaceutical industry and government. The PAA has facilitated the exchange of information between all these groups and increased the PA awareness. Long may it continue.

Fig. 2 The Immune System and Psoriasis



Guess What's Coming up? . . .

WOBURN

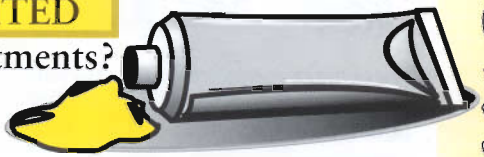
Saturday 27th September
PAA Conference 97

Register now to avoid disappointment.
Admission via a pass.
Members - free, Non-members - £10

RING NOW FOR DETAILS
01923 672837

TREATMENTS RE-VISITED

What are vitamin D treatments?



Once you have developed psoriatic arthritis, the treatment of psoriasis will probably become less important, especially the thought of applying all those creams with painful arthritic fingers may put you off.

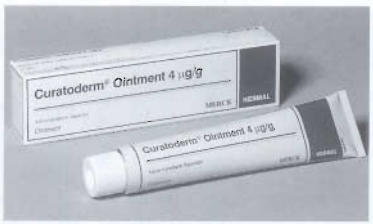
For all of those who have had psoriasis for many years, the mere thought of treatments will probably conjure up all sorts of visions of nasty foul smelling difficult to apply topical applications.

Over the years, there have been few steps forward. A major breakthrough came with the discovery of vitamin D3 analogues (i.e. substances that resemble vitamin D3 in their structure). The first generation of vitamin D3 analogues were developed in research laboratories in 1970 with the synthesis of calcitriol. In 1974 tacalcitol was identified. The second generation were developed in 1985 with the synthesis of calcipotriol.

Vitamin D3 analogues are believed to work by reducing the excessive production of the skin cells that cause the thickening and scaling of the skin. The first commercially available vitamin D3 was calcipotriol launched by Leo Pharmaceuticals in 1991 as an ointment under the brand name Dovonex, and was quickly followed by a cream version in 1993 and a scalp solution in 1994.

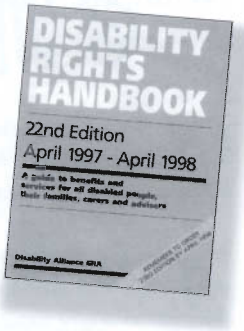
At the beginning of 1996, tacalcitol was launched as an ointment by E. Merck Pharmaceuticals called Curatoderm. Both Dovonex (twice a day treatment) and Curatoderm (once a day treatment) are only available on prescription from a doctor. As with all treatments, using the product in accordance with the doctors instructions (or those in the leaflet contained within the pack) is extremely important and could lead to better results.

The development of these more convenient treatments may mean this treatment is worth re-visiting for those people who may have possibly given up on treating this stubborn chronic condition.



BOOK REVIEW

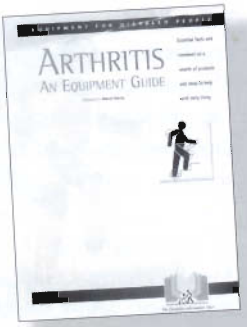
DISABILITY RIGHTS HANDBOOK
Disability Alliance ERA



22nd Edition April 1997 - April 1998
Social Security Benefits - all you need to know in one book.
Every year since 1977 the Disability Rights Handbook has provided essential information on disability benefits to thousands of disabled people, their families, carers and professional advisers in the U.K. The 22nd edition of the book, published in May 1997, brings you all the latest information on social security benefits and related services for disabled people.
All chapters in the handbook are fully updated to take account of legal changes. It is further backed up with an extensive directory - providing addresses and telephone numbers for national charities and self-help disability organisations in Great Britain and Northern Ireland.
Widely acclaimed by disabled people, their families and the many professionals who work with them, the Disability Rights Handbook is excellent value.

Price: £10.50 post free (£6.50 if you're on benefit)
ISBN 0 946336 79 2
Disability Alliance Educational and Research Association, Universal House, 88-94 Wentworth Street, London E1 7SA.

ARTHRITIS
AN EQUIPMENT GUIDE
The Disability Information Trust



Treatments for arthritis include drugs to ease symptoms and help control the disease, surgery, exercise and now other treatments are used by hospital doctors and reputable alternative practitioners. Something that should never be overlooked, however, is the acquisition and use of equipment - to help protect the joints, bones and muscles from unnecessary strain and pain and to counter the physical hindrances that are so commonly experienced. This completely new 2nd edition of Arthritis - an Equipment Guide presents invaluable information on such equipment. Examples have been chosen for inclusion through experiences of daily practice and trials and the range of items available to substitute for diminished or lost abilities may surprise many.

Price: £12.00 (UK only) £16.00 (Overseas) p&p free
The Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD.
ISBN 1 873773 14 5

Skin 'N' Bones Connection

THE DESCENT

On the morning of 4th May 1996, Julie and myself set off at 7.30am for the hour's drive to Hinton-in-the-Hedges just outside Banbury. It was a sunny, dry morning, hopefully perfect conditions for our impending parachute jumps.

We were to be included in the first two lifts of the day which we were glad about as we were both quite nervous. We had our brief training session during which we were shown what positions we needed to maintain and exactly what would happen during the plane ride and the rapidly nearing descent.

By 9.30 we were fully trained, kitted up and raring to go. However, one vital piece of equipment seemed to be missing - the pilot! Due to the regular pilot's holiday a stand in had been booked but didn't turn up. We waited, nerves getting steadily worse until at last at 2pm a pilot turned up.

I was strapped up and taken over to the plane, suddenly realising that this really was it. We took off and started circling round and gradually gathering height. As I hadn't flown before I was completely taken up with the flight. We were told at intervals what height we were at. At 5000 feet I looked out of the door (well, the hole where the door should have been!) and tried to imagine what twice that height would look like - about five minutes later I unfortunately found out. The temperature in the plane dropped to about minus 10 degrees just before we left it.

Sitting with my legs hanging out of the door of a plane at 10,000 feet I hoped I'd wake up any minute in bed after a bad dream. As a voice shouted in my ear "Are you ready to skydive?" my answer was unintelligible but obviously was taken as "yes" and although I couldn't quite believe it I was upside down and indeed 'skydiving'.

At 190mph on exit from the plane a drove chute goes up and steadies the descent to a mere 120mph! After about 25 seconds in freefall, the parachute opened up and we spent about five minutes circling around which Julie, a funfair fanatic, loved every minute of, but which sent me a bit green!

We both had a rather bumpy landing as it was a rather windy day, but we didn't have any bruises to show for it.

After I'd done my jump, the sky clouded right over and Julie didn't get to go up until 6pm, but she said it was well worth the wait.

We both had a great day which we'll remember for a long time to come - whether we'll be doing a repeat performance remains to be seen!

Editorial note: Sally Dale is 27 years old and has psoriatic arthritis. She raised nearly £1000 from sponsorship for the jump towards the work of the Psoriatic Arthropathy Alliance.

PAA awards

Some recent recipients of Friendship & Supporters Awards

Jonathan Bastow receiving an award on behalf of Leo Pharmaceuticals from PAA Board member Chris Friend.

David Chandler (centre) presenting Evans Medical with their award at a recent press conference.

Long-term supporter and adviser Bob Martin (right) from Schering HealthCare receives his award.

WELCOME NEW ADVISER

We are pleased to announce that Dr Tony Chu has agreed to join our medical advisory panel.

CURRICULUM VITAE

Dr Tony Chu was born in London, UK, in 1951. He attended Guy's Medical School where he qualified as a doctor in 1975 with MB, BS. During his time at Guy's he obtained a BSc honours degree in pathology.

In 1978 he passed as member of the Royal College of Physicians (MCRP) and in 1993 he was elected as a Fellow of the Royal College of Physicians (FRCP).

He completed his dermatology training between 1978 and 1982 at Guy's Hospital, London; Columbia Presbyterian Hospital, College of Physicians and Surgeons, New York; and St John's Hospital for Diseases of the Skin, London.

He was awarded a Wellcome Senior Research Fellowship in 1982 and was appointed as a Senior Lecturer/Honorary Consultant Dermatologist at the Royal Postgraduate Medical School, Hammersmith Hospital, London.

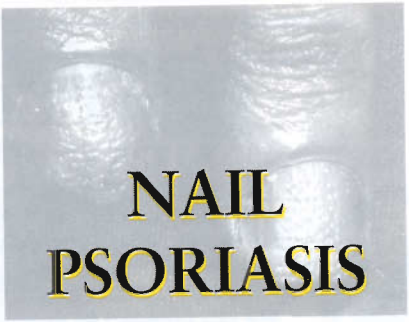
His present appointment started in 1989 as a Senior Lecturer and Consultant Dermatologist at the Royal Postgraduate Medical School, Hammersmith Hospital, London, where he has both a scientific research department and a clinical department which includes a specific acne research clinic.

Tony's main academic interest is the biology of the Langerhans cell in physiological and diseased states, specifically investigating Langerhans cell histiocytosis and skin carcinogenesis. Other research interests include allergic dermatitis and psoriasis.

In 1990, Tony started the Acne Support Group, which remains the only world charity for the acne and rosacea sufferer. He remains the Chairman of the Acne Support Group and maintains an active interest in the activities of the charity.

Hobbies include gardening, painting, hang gliding and bungee jumping.

SPOTLIGHT ON...



NAIL PSORIASIS

Psoriasis can affect any part of the skin including the scalp and the nails. When psoriasis affects the nails they can become very deformed which can lead to enormous embarrassment.

What change do you see in nail psoriasis?

A number of changes occur in nail psoriasis, the most common of which are:

1. Pitting of the nails - the surface of the nail develops small pits looking rather like the surface of a thimble. The number of pits is variable from one to dozens.

2. Onycholysis - this is where the nail becomes detached from the underlying nail bed and a gap develops under the nail. This starts off looking like a white or yellowish patch at the tip of the nail but the patch can then extend down to the cuticle. The gap between the nail and the nail bed can become colonised by a particular bacteria which can then produce a black pigment. These bacteria are called Pseudomonas. This causes discoloration of the nail and can cause considerable alarm when mistaken for melanoma under the nail.

3. Sub-ungual hyperkeratosis - this is where you develop an accumulation of chalky material under the nail. The nail becomes raised up and can become tender especially when the surface of the nail is pressed. This can become particularly troublesome on toe nails where the nail may be pressed by shoes to cause considerable discomfort.

In addition to these changes you may get longitudinal ridging of the nails and reddish marks under the nails called splinter haemorrhages due to tiny burst blood vessels under the nails.

What causes nail psoriasis?

Nails grow from the nail plate which is just under the cuticle. In patients who develop psoriasis of the nails it is involvement of the nail plate that causes pitting and ridging of the nails. Onycholysis, sub-ungual hyperkeratosis and splinter haemorrhages are due to disease of the nail bed. The nail itself is totally inert, being composed of modified dead skin cells, and therefore any treatment must be directed to the nail plate itself or in the onycholytic nail to the nail bed.

The severity of nail involvement does not follow the severity of psoriasis elsewhere in the body. Rarely, the nails can be the only site of the body affected. More usually the nails are involved with scalp psoriasis or psoriasis elsewhere on the body. You can however develop severe nail changes with only minimal psoriasis elsewhere on the body. Nail psoriasis is particularly common with psoriatic arthropathy.

What treatment is there for nail psoriasis?

Nail psoriasis is perhaps the most difficult part of psoriasis to treat. We have tried a large number of different treatments in the past, none of which have given particularly good results. These include:

a. Injections of steroids under the nail - these are extremely painful and generally do not work.

b. Removal of the nail - nails can be removed quite painlessly using a high concentration of urea applied under polythene occlusion to the nail. The nail becomes rather jelly-like and can be peeled off. Nails can also be surgically removed or removed by X-ray therapy. In general the nails tend to grow back abnormally.

c. The use of topical steroids rubbed into the cuticle - the nail plate is under the cuticle and by massaging steroid creams into the nail plate you can induce some improvement in nail psoriasis. This is not consistent, however, and there is the risk that the cuticle can become thinned with thread veins over the surface.

In Germany many patients derive benefit from colloidal silica gel. This is taken by mouth mixed with orange juice. Over a period of two to three months improvement of the nails can be seen.

In Germany, colloidal silica gel is used for dry skin and brittle nails and is a product that can be bought over the counter. It is available in the UK marketed by a company called Saguna but it can be very difficult to obtain. There have been some very limited trials looking at the efficacy of this preparation and these have shown reasonable results.

Anecdotally a number of dermatologists noticed that psoriasis of the nails improved when patients were using vitamin D preparations for psoriasis of their skin. This led to a more focused study of vitamin D creams and ointments rubbed into the cuticle in the treatment of nail psoriasis.

Experience from around the world has shown that this is an effective line of treatment and should be regarded as the first-line treatment of choice. The vitamin D cream or ointment should be massaged into the cuticle for about five minutes twice a day. When onycholysis is present, calcipotriol scalp solution can be dripped under the nail and massaged in, which is effective.

Remember that nails grow extremely slowly and what you are influencing is not the existing nail but new nail that is developing from the nail plate. It may, therefore, take up to a year for finger nails and two years for toe nails to grow out normally so you must be patient with the treatment.

Is there anything else I can do for my nail psoriasis?

Nail psoriasis is predominantly a cosmetic problem. The nails are distorted and this is extremely embarrassing. Nail varnish can obviously be used by women to conceal the pitting and onycholysis seen in psoriasis of the nails. No cosmetic camouflage, however, is available for men.

If sub-ungal hyperkeratosis becomes uncomfortable a chiropodist can pare down the nail to remove the pressure from the wearing of shoes.

Dr Tony Chu
Senior Lecturer and Consultant Dermatologist at the Royal Postgraduate Medical School, Hammersmith Hospital, London.

Dr Virginia Camp

Q&A

Q. Can acupuncture help with easing the pain of psoriatic arthritis? If so, where do I go, or how can I find out the best place/practitioner to consult? Is it available on the NHS?

A. Acupuncture may help to ease the pain of any type of arthritis and psoriatic arthritis is no exception. Its effect is not very predictable and overall only about 60% of people can expect any lasting help. If your arthritis is very 'active' and even if you have done well with acupuncture in the past, you may only get a few days' relief. It is always worth trying if you don't mind needles.

Acupuncture is far more widely available on the NHS than people realise. Many general practitioners practise it and so do some physiotherapists. Your local pain specialist may well be able to provide treatment in the hospital clinic. The first port of call is always your own GP who will advise you.

Q. Do you know the benefits of hydrotherapy?

A. Hydrotherapy is stretching and exercise treatment in water supervised by a specially trained physiotherapist. It can be particularly helpful to arthritis sufferers whose joints may be stiff and muscles weak, because the buoyancy and warmth of the water make movement easier. .

Q. (a) I would very much like to know whether diet can cure psoriatic arthropathy or whether sunshine is the greater factor.

(b) What foods/drinks other than tomatoes and strawberries are best to avoid?

A. First of all it is important to say that neither diet nor sunshine will cure psoriatic arthropathy because, sadly, there is no cure, neither may they even affect the symptoms. The two factors cannot be compared. Sunshine may help by warming stiff muscles and joints and in some people may relieve psoriasis. Tomatoes and strawberries do not necessarily worsen arthritis. There are three types of dietary manipulation that need consideration. The first is food elimination, where certain foods are cut out of the diet to see if joints get better. They are then added in one at a time to see if the joints become inflamed. Some people do find that certain foods make their joints worse but every person is different. However, elimination of these foods will merely dampen and not remove the symptoms.

The second "diet" tried is where certain things are added - either because there is a belief that the sufferer is deficient in one thing, e.g. a vitamin, or because it is thought that food balance has been upset. Extra vitamins, cod liver oil and amino acids are examples of this type of food change. Again there are no more than individual stories that this might help psoriatic arthritis and few trials have been published.

The third type of diet, which has even less evidence that it works, is one where the way in which food is prepared or the time at which it is given is altered.

The problem with all diets is that there is no firm evidence that they work, they are often pushed as universal cures for all types of arthritis and there is a great need for proper scientific evaluation. Judgement that diet plays any part or a great part in the treatment of psoriatic arthritis, cannot be made at this time.

Q. (a) How can physiotherapy help with joint mobility and reduction in permanent joint damage?

(b) Are there any positive treatments for my joints - shoulders, elbows, hands, wrists?

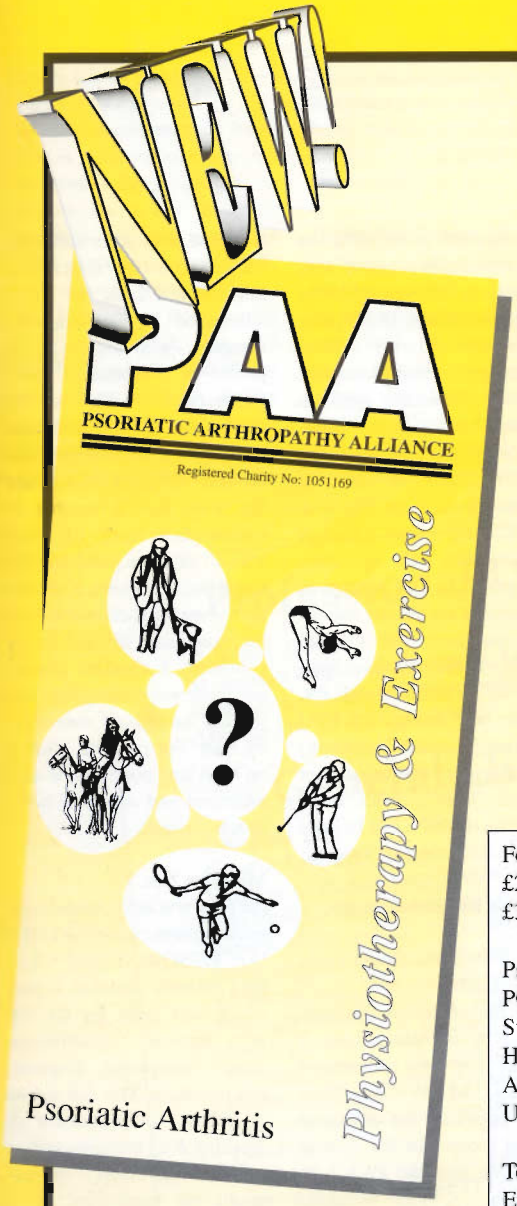
(c) Exercise routines - any comments?

A. These are frequently asked questions and very important ones to answer because arthritis will not only damage and stiffen joints, it will also lead to muscle weakness and wasting so that walking is made doubly difficult. Although it is not possible to prevent this happening entirely and joint damage will continue by way of inflammation, there is a lot that you can do to keep mobile and prevent the disability becoming any worse.

The general principles are:

- *Seek the advice of a specialist physiotherapist as to what you should or should not do.*
- *Little and often is better than short and sharp.*
- *Exercises should treat and prevent joint contracture and stiffness, and give strength and stamina to weak muscles.*
- *A regular routine is a good idea but if a joint is very hot and swollen some exercises should be avoided.*

The alliance considers these questions so important that it has commissioned a special leaflet on physiotherapy and psoriatic arthritis, which should return from the printers very soon.



16 Page Physiotherapy & Exercise booklet

Produced by the Psoriatic Arthropathy Alliance especially for people with psoriatic arthritis.

This book contains useful advice and includes simple diagrams and explanations of different types of exercise.

For a copy of the booklet please send
£2.00 for UK
£3.00 (sterling) for overseas to the:

Psoriatic Arthropathy Alliance
PO Box 111
St Albans
Herts
AL2 3JQ
UK

Tel/Fax: 01923 672837
Email: office@paalliance.org
Website:www.paalliance.org

The Psoriatic Arthropathy Alliance is a registered charity no: 1051169
A company limited by guarantee registered in England no: 3055414
Registered office 38 High Street Hurstpierpoint West Sussex BN6 9RG

What's new on the Net

No.2 in a series of occasional articles by David Edwards

Following on from my last missive covering what the Net was all about, this article is the result of a trawl through some of the stuff I have found on it which might be of interest to members of PAA, especially those without access to a computer!

National Psoriasis Foundation.
(http://www.psoriasis.org)
US based patient support group with a huge amount of material on every aspect of psoriasis, including a large chunk on psoriatic arthropathy. A superficial glance at some of the material revealed a page of statistics (US) about psoriasis - useful if you want to get some facts together. A review of an interesting study on Kentucky families with the disease who have lived in the state for generations. The theory is to try to trace the gene pattern backwards, in order to find out how it is passed on. A warning for people with psoriasis on anti - malarial therapy; apparently chloroquine may exacerbate the condition. If in doubt, check with your doctor. A page of common Q & A's regarding the problem. A page of photo's of every different type of psoriasis together with descriptions of scientifically proven treatments. This is pretty comprehensive and covers topicals, phototherapy, internal medication, and how physicians approach treatment, (the 'treatment ladder' http://www.psoriasis.org/treatsci.html). There is also an excellent section on PA with photos and case studies available. The NPF also offer descriptions of treatment programmes for PA and request for volunteers for clinical studies. There are e - mail addresses of patients with PA, and the NPF maintain a FAQ (frequently asked question) page, together with the relevant answers. There's loads more stuff from the NPF, but I'll save some of it for the next article.

Psoriasis Resources on the Web.
(http://www.icelandic.com/sd/psoriasis.html)
I think this one originates from Iceland of all places, but I presume they have sufferers of psoriasis and PA also. They have compiled a list of patient support groups for the disease worldwide (no, the PAA isn't listed amongst them - I'll make sure they know about us though!). This is especially useful as they maintain an archive of past discussions which have arisen from the UseNet, or discussion groups. Two are monitored: alt.support.skin diseases and alt.support.skin-diseases.psoriasis

Socialise with other sufferers.
(http://shani.co.il/~skincare/socialize.htm) I think this one is sponsored by an American company who are trying to push a product called Psoderma, which is not available in the UK. It contains vitamin D3, evening primrose oil and marigold extract, and the page has a number of testimonials from US users who all say how wonderful it is (surprise!). However, it also has an e - mail list of people with the condition, divided up by continent. I checked Europe, and there was nothing there, but the US list is well maintained by state. For instance, clicking on Maryland got me the e- mail addresses and names of half a dozen contacts.

Medicine Net.
(http://www.medicinenet.com/mainmenu/encyclop/ARTICLE/Art_P/PSORIAT.htm) This long address revealed a page which was great for PA info with statistics, descriptions, causes, symptoms, diagnoses and treatment. This last section is pretty comprehensive in detailing drug therapies such as non - steroidals, disease modifying medicines, (gold, plaquenil. methotrexate and steroids), and a review of potential future treatments such as vitamin D derivatives. It contains links to the NPF page for PAA at http://www.psoriasis.org/psortypes/arthritis.html, with again lots of photos and descriptions.

Bruce Gieses page.
(http://www.tiac.net/users/giesepm/pafaq1.html) This is a PA sufferer who has compiled a FAQ page on the disease. He is not medically qualified, but has assembled Q&A's from people with PA, and answers from clinicians and other gurus from around the world (well, the US mainly...), what's worked for them, what problems they've experienced, how the disease has progressed. He also gives a list of PA organisations (not the PAA!) and mentions an arthritis discussion group with the address being misc.health.arthritis.group. I will of course inform him of our existence.

Discussion Groups.
Nothing much going on at present apart from a conversation about flare - ups and food or alcohol. One person says he can predict that exactly three days after eating one slice of bacon, his psoriasis will flare. Two other discussions to note, one on the relative benefits of tea tree oil, whatever that is, and another on squalene, as extracted from shark liver oil (first catch your shark -Ed.)

There's loads more, but I'll save it for another day.

Happy surfing!

David Edwards
(101703.3373@compuserve.com)

Professional Diary

25th June 1997
St. James's University Hospital, Leeds
International Psoriatic Arthropathy Symposium
Arranged by Dr Douglas Veale.

General Diary

26th June 1997
Genetic Interest Group
Working in Partnership Interface Meeting
It is vital for individuals and families affected by genetic disorders to have their healthcare and other support needs dealt with in a positive, co-ordinated way. This interface meeting looks at how this can be carried out and the developments taking place in multidisciplinary ways.
Meeting open to all interested: Further details please contact GIG, Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB. Tel: 0171-430-0090.

SATURDAY 27TH SEPTEMBER 1997
PAA 3RD ANNUAL CONFERENCE
Please register now as entry is via pass only. Entry free to members and their guests. Non members £10

COPY DATES

Autumn News - July 31st
Winter Journal - October 31st

ALL PARTY PARLIAMENTARY GROUP ON SKIN

APG on Skin goes from Strength to Strength

The Parliamentary All Party Group on Skin was established in 1994 to raise awareness in Parliament of skin disease.

Since it was established, the Group has gained support in membership from some 40 MPs and Peers from all parties. In addition, nearly 100 other organisations and individuals have taken out membership of the Group representing all aspects of skin disease from patient groups such as PAA (a founding member), individual dermatology clinics and clinicians and pharmaceutical companies. The Group rapidly became one of the most successful of its type in the last Parliament.

The Group, along with other similar Groups, was suspended when Parliament was dissolved on 8th April. Following the swearing-in and State Opening of the new Parliament, it is now necessary to re-establish the Group. Assuming that there is sufficient Parliamentary support, it is the Officers' intention to do this quickly. This will require the support of at least twenty Parliamentarians, more than half of whom must represent the Governing Party.

Over the last three years, the APG on Skin (as it is known for convenience) has been successful in achieving its aims of raising the profile amongst Parliamentarians of skin and the various diseases associated with it. A core group of about ten MPs and Peers regularly supports its meetings - a good number for groups of this type.

The Group publishes newsletters which report on its activities and on the issues which it is seeking to push. It also produces factsheets on the various diseases which affect the skin. It has been keen from the start to establish close ties with the various patient groups which exist to help patients cope with their diseases and maintains very regular contact both with individual patient groups and with the Skin Care Campaign, which is its largest single funder.

In short, it uses all the means at its disposal to push various skin-related issues in Parliament.

One such device is to table questions to glean more information on government thinking about an issue, about levels of funding, research plans and so on. If a number of questions are tabled on the same subject from different MPs (especially if they are cross-party) this indicates significant Parliamentary interest in the subject and should have the effect of concentrating Government thinking on the area. The Group would welcome suggestions for questions from PAA members where an issue might benefit from an answer from Government. The Group's officers will always give careful consideration to sensible suggestions for questions.

In this Parliament, the Group hopes to push forward issues raised in its recently published report on skin service provision in the UK. The report has dozens of suggestions, large and small, as to how skin treatment could be delivered better. It highlights the poor level of basic knowledge and training amongst GPs and calls for a moderate increase in numbers of dermatology consultants and nurse specialists. It also suggests the wider use of open-access clinics. A copy of the report is available from the APG's secretariat on 0181 789 2798.

The Group has been grateful for the support of organisations such as the PAA over the past few years. We look forward to achieving even greater success together in Parliament.

Berkeley Greenwood

Action for Victims of Medical Accidents

If you have suffered injury or harm as a result of:

- Inadequate or negligent care
- Inappropriate treatment
- Misdiagnosis
- Failure to provide treatment
- Lack of informed consent

AVMA can provide free professional guidance and support

Confidential advice and support for medical accident victims

A specialist advisory service for patients

Action for Victims of Medical Accidents
Bank Chambers
1 London Road
Forest Hill
London SE23 3TP

Tel: 0181 291 2793
Fax: 0181 699 0632

and finally . . .

NEW BOOKLET AVAILABLE
'How do I make a complaint?'
An easy-to-follow guide describing the procedures involved for making a complaint against the NHS and private medical providers, as well as basic facts about litigation.
Available from the Patients' Association, 8 Guildford Street, London WC1N 1DT. Price: £4.95. Cheques made payable to "Patients' Association".

An Information Sheet and Policy Statement are now AVAILABLE from the Association of British Insurers on LIFE INSURANCE AND GENETICS.
Available from Member Services Unit, Association of British Insurers, 51 Gresham Street, London EC2V 7HQ.

The PAA would like to thank all its friends, supporters and contributors for making this publication possible.

MERCK Dermatology

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