PAA

PSORIATIC ARTHROPATHY ALLIANCE

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Internet address: www.paalliance.org

Registered Charity No: 1051169

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NEWS JOURNAL 7
DECEMBER 1996

Skin 'N' Bones Connection

David Chandler presenting David Garmon-Jones, *Dermatology Manager Merck* with his PAA Friendship and Supporters Award.

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.

Skin 'N' Bones Connection

Contents

The Swedish Psoriasis Association
Tackling Psoriatic Arthritis

Within the Swedish Psoriasis Association (known as PSO) we have long been aware of the fact that many of those who suffer from psoriasis also suffer from pains in their joints. A large number of patients have had their pains diagnosed as psoriatic arthritis, i.e. the kind of arthritic complaint that affects persons with psoriasis. Skin complaints and pains in the joints often go hand in hand, but psoriatic arthritis can occur in a person who has no psoriatic skin rash.

The dermatologists and rheumatologists we have consulted have in the past always claimed that no more than 5 - 10% of psoriasis patients also suffer from arthritic pains a figure which our experience at the PSO does not bear out. We have always had the impression that a much higher proportion of those who suffer from psoriasis are affected by disorders of the joints. The grievances our members air to us concern the low level of knowledge general practitioners show with regard to psoriatic arthritis, the insufficient extent of collaboration between dermatologists and rheumatologists, and the unnecessarily long time patients have to wait before receiving a definite diagnosis. A rapid and reliable diagnosis is vital, so that the correct treatment can be prescribed before the patient's joints are irreparably damaged.

Recent surveys carried out in Sweden confirm that psoriatic arthritis is much more common than it was previously thought to be. Specialists believe that as many as 40% or more of psoriasis sufferers also experience disorders of the joints, ligaments and tendons; many experience pain in their joints for years before a correct diagnosis is made. There are several reasons for this: many patients consult their general practitioner about their painful joints - but GPs are generally poorly informed about the connection between psoriasis and arthritic pains. A further factor is the low level of co-ordination and communication between those involved in dermatological and rheumatological care. We have heard a great many accounts of how patients have been directed around the labyrinth of the health care services yet not received the help they need. Furthermore, a person who suffers from psoriasis can experience pain in the joints due to other causes, i.e. without its being psoriatic arthritis.

The question we could not avoid asking ourselves was: What can we as an organisation for psoriasis sufferers do to help these patients. We got in touch with the Swedish Rheumatism Association, and together with them we decided that the most fruitful way to tackle the question was in the form of a project.

We formulated our objective - to increase the overall level of knowledge among doctors, others working in health care, and staff of local offices of the national social insurance authority, with regard to the joint pains that can accompany psoriasis. Naturally, our aim was also to reach directly those suffering from arthritis. The improved knowledge and awareness should then have the effect of enabling correct diagnoses to be made sooner, with the subsequent prescription of appropriate treatment and rehabilitation measures.

We applied for and were awarded grant funding to carry out the project, which is currently in progress. To date we have conducted a questionnaire survey, addressed to a large number of psoriasis sufferers in order to find out more about the extent to which they suffer from disorders of the joints, whether they have received a diagnosis, what kind of treatment they have been prescribed, and so on. This survey, although completely non-scientific, confirms without doubt that the occurrence of disorders of the joints among psoriasis sufferers is more frequent than has hitherto been believed.

We have also held six large open hearings at different locations around the country, where we have brought together general practitioners, and doctors and nurses from the areas of dermatological and rheumatological health care, and asked them to describe their experience of and work with psoriasis patients. These hearings also gave the patients the opportunity to air their views. On carrying out a follow-up we found that collaboration and co-ordination between rheumatological and dermatological clinics had improved; there has been an increase in cross-fertilisation between the different kinds of clinics. A further result of the hearings has been that seminars and conferences on psoriatic arthritis have been held in hospitals and at regional level.

The project is also backing the production of study material, and is providing advice and material for the establishment of a "patient training" programme for use in hospitals: arthritis patients will be provided with increased knowledge and support to enable them better to care for themselves and live with their disorders.

An information booklet on psoriatic arthritis will be produced in spring 1997, for the use of general practitioners. The booklet will be presented to them by dermatology and rheumatology specialists at seminars to be held in autumn 1997; and it will be translated into English.

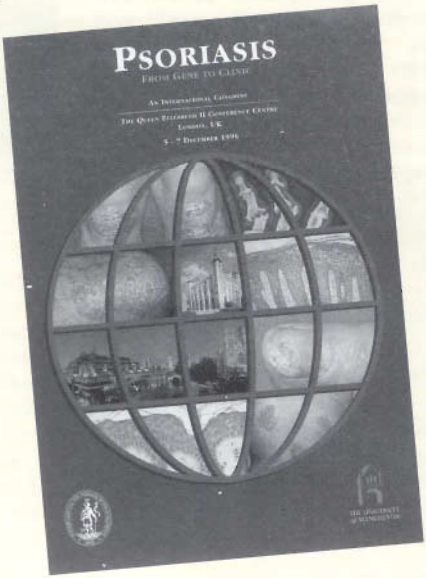
We hope that our work will lead to increased awareness of the fact that disorders of the joints are an integral part of their disease for many psoriasis sufferers, and that they may have severe, indeed disabling, consequences if appropriate treatment is not prescribed in time.

Kristina Soderlind
The Swedish Psoriasis Association
Rokerigatan 19
S-121 62 JOHANNESHOV
Sweden

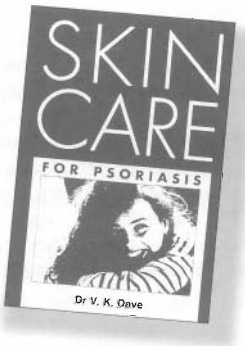
Professional Diary

'From Gene to Clinic'

5-7 December 1996
An International Congress
The Queen Elizabeth II Conference Centre
London



BOOK REVIEW

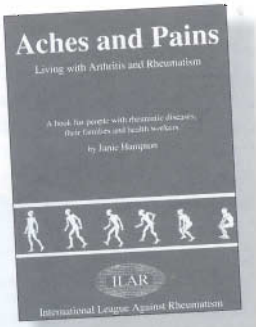


SKIN CARE FOR PSORIASIS
Dr. V. K. Dave FRCP
Honourary Consultant Dermatologist, at the Dermatology Centre Hope Hospital, Salford, Manchester.

An easy to follow self-help guide in the care of Psoriasis. The book offers practical advice on control of stress and psoriasis, looks at lifestyle and offers some self care routines.
Price: £7.95
ISBN1 872362 63 X
Publishers: Class Publishing, Barb House, Barb Mews
London W6 7PA

THE PSORIASIS HANDBOOK
Jenny Lewis
An established self-help author

The Psoriasis Handbook seeks to inform and offer help to those with Psoriasis of all age groups. The book contains case histories and explains some of the treatments available.
Price £ 8.99
ISBN 0-09- 180985
Publishers: Vermilion

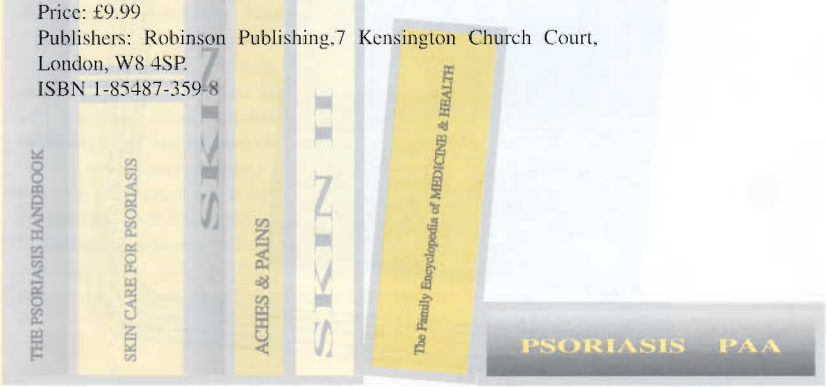


ACHES & PAINS
Living with Arthritis and Rheumatism.
Janie Hampton

A 72 page paperback for people with rheumatic diseases their families and health workers. Gives practical guidance on themost common rheumatic diseases.
Price: £2.00 including P & P.
Available from TALC, P.O.Box 49, St.Albans, Herts, AL1 4AX

The Family Encyclopedia of MEDICINE & HEALTH

Approximately 1000 pages, this book contains both common and unusual medical terms, problems, symptoms and treatments. Easy to read, helpful illustrations.
Price: £9.99
Publishers: Robinson Publishing,7 Kensington Church Court, London, W8 4SP.
ISBN 1-85487-359-8



From 9th Symposium of European Legue Against Rheumatism Madrid October 1996

Roving Report 1

Four hundred and fifty-seven abstracts were accepted for publication in the Conference Abstract Book. Of these, there were eight on Psoriatic Arthropathy, of which three were from Italy, two from Russia and one each from Portugal, Hungary and Croatia. There were no contributions from the United Kingdom on this subject.

A study by Taccari, Riccieri and others of Rome presented up-to-date information on the significance of tissue types in relation to the various forms of psoriatic arthropathy showing, as expected, an increase in B27 among those with spinal and sacro-iliac joint involvement. Those with more severe involvement of the small joints of the hands and feet showed more commonly the B39 tissue type, 14% of such cases being positive compared with 2% of controls and only 5% of those with psoriasis of the skin alone. DR7 also showed an increase in such subjects, 45% of those with psoriatic arthritis, compared with 26% of controls and 18% of those with psoriasis of the skin alone. These findings on a small group of 22 patients with psoriatic arthritis conform very closely to the studies of Gladman in Toronto on a considerably larger series of patients,in excess of 300.

Murgia,Cacace and others from Cagliari studied psoriatic arthritis patients by thermal imaging, x-rays and isotope bone scans, examining 165 patients but they emphasised that 9% of those examined showed isolated inflammation of the sacro-iliac joints often with minimal symptoms and that this was commoner in males. The third Italian paper by Spadaro, Taccari and others, from the same source as the first paper, evaluated interleukin-2 receptor and interleukin-6 levels in patients treated with Cyclosporin and methotrexate. Whilst both drugs produced reductions in the interleukin measurements, they did not correlate at all well with traditional clinical measurements or the older methods of biochemical assessment such as C-reactive protein.

The Russian contribution was essentially clinical in the first instance with a paper which essentially listed the distribution of destructive bone lesions within joints. They postulated disturbance in the micro-circulation but did not present evidence for this. V V Badocin was the principal author of this paper and another from Moscow, and the second paper suggested that dissolution of bone was related to the activity of the inflammatory process and again to the involvement of blood vessels. These papers were essentially descriptive. Luis Mauricio Santos and others from Lisbon produced evidence for subluxations of the cervical spine between the first and second cervical vertebrae, a feature which has been previously described rarely and they confirmed this, finding only one case among fifty patients studied. The patient had a long standing and very widespread involvement of other joints.

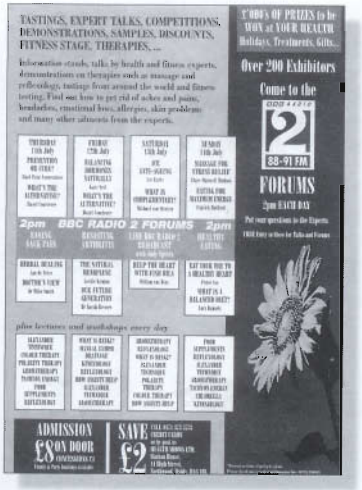
Koo Sesztak and others from Budapest examined the effect of non-steroidal anti inflammatory drugs in provoking deterioration in the skin, and concluded that 26 of 422 psoriatic patients who used such medicines showed exacerbation of their skin disease, most frequently with ibuprofen and indomethacin as well as phenylbutazone (this drug is not used in the UK except rarely for ankylosing spondylitis). They concluded that the safest drugs were diclofenac and piroxicam from the point of view of provoking relapse of psoriasis from among this group of drugs.

There were no new fundamental insights into the disease process, or significant breakthroughs in treatment reported in this small number of papers.

Dr.A.G.White
Consultant Rheuamtologist
Royal Free Hospital
Psoriatic Arthritis Clinic.

Roving Report 2

Your Health Show Review
Olympia 11-14th July 1996



David pictured with Jackie Harvie, a member from Worcester, who came to the show to give us support.

Judy Spiers a Radio 2 presenter, talking to David prior to interviewing him for 5 minutes on her national show.

Carly Chaytow Organiser behind the scenes at Olympia

Over 25 000 people visited the show during the 4 days and many stopped at the PAA stand

FOOD & ARTHRITIS

Roving Report 3

An Illustrated Talk on "FOOD & ARTHRITIS" presented by Dr Gail Darlington. 23rd October 1996 at 7.30pm.

The PAA was kindly asked by Dr. G.R. Clarke, rheumatologist at Harold Wood Hospital, Essex, if we would advise some of our members locally of the above talk he was arranging, which we were very pleased to do.
Here's a brief summary of that presentation from a member who went along . . . Take it away Alison.

Dr Darlington's interest had been provoked many years ago by the success of dietary treatment in a child who had not responded to any conventional treatment for rheumatoid arthritis. Since then, Dr Darlington has moved from considerable scepticism to a belief that diet can assist in up to 40% of rheumatoid sufferers. The majority of research has been conducted on rheumatoid arthritis patients but she believes that the research has relevance for other types of arthritis.

Dr Darlington's own research started in 1983 and required patients to have a one week elimination diet that consisted of fish, pears, mineral water, carrots and sea salt. After one week, different foods were introduced, one at a time over a period of 6 weeks. The patients also had to come of all drugs. Although Dr Darlington didn't go into great detail, she told us that 4 of the worst culprits for food intolerance were cereals such as corn and wheat. Dr Darlington stressed that no one should attempt to carry out this elimination process without medical supervision but should talk to their doctor about it. Dr Darlington also suggested that there was little point in reading the various books on diets for arthritis as they all gave conflicting advice.

Dr Darlington's research found that of the 140 patients involved, 36% (50 patients) continued to control their arthritis purely through diet and no medication for anything between 6 months and 9 years, depending on when they first joined the research programme. Additional patients may have shown improvements but could not be counted if they took even the mildest of medication.

During the question and answer session that followed, Dr Darlington recommended the following supplements and foods for healthy living; research exists to show that they can variously assist in preventing heart disease, cancer of the colon, arthritis and possibly Alzheimer's:

Omega 3 Fish Oils, Evening Primrose Oil, Olive Oil, Sunflower Oil, fruit and vegetables but especially red, orange and yellow; garlic and onions; chocolate; tea; dates and strawberries; hard water for calcium (the scum in the cup is a good sign of calcium), oily fish such as salmon and mackerel; carrots were strongly recommended, preferably raw and all foods should be undercooked.

Alcohol, colas and diet colas, coffee and smoked foods are not good for any of us. Decaffeinated coffee is all right in moderation (4 cups max. daily); anti-oxidants in pill form contain Beta-Carotene which isn't good.

The final surprise was the strongly expressed statement that there is nothing wrong with citrus fruits unless we happen to believe already that we are affected by them.

The whole talk was most interesting, well presented and informative. The research is continuing and I would strongly recommend Dr Darlington as a future speaker at an PAA AGM.

Alison Shuttleworth, member Essex.

Packed House

PAA in motion!
Members participating during Catherine Dyce's physiotherapy demonstration

Dr Virgina Camp with the new PAA pre-launch physiotherapy booklet - out early next year.

Mr & Mrs G. Mean.
Members.
Win 1st prize in the Raffle.

WOB

The PAA Medical Team - at your mercy.

Fun for all!

Merck Dermatology

After the event Lord Tavistock of Woburn came to
things went so we graped him for a last photocall!
We would like to take this opportunity to thank
Crawford, catering manager and his team of th
Lodge for looking after us and all the arrangemen
day. They really did do a great job.
From l. to r. Alastair Crawford, Virgina Camp, Lord T
Tricia Hobbs, David Chandler, Julie Chandler, Tor
Patrick Parker.
Spot the gremlin!

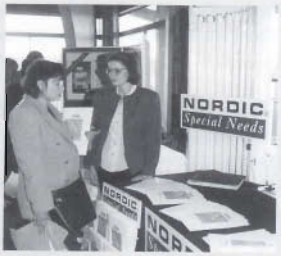
BURN

Dr. Veale - mingling with the crowd and answering your questions.

Yoni International

Leo Pharmaceuticals

Neutrogena



Nordic

PAA AWARDS
Friendship & Supporters

The PAA in recognition and appreciation of the work done and support given to it over the year by some of our members and industry have decided to initiate an award scheme each year, whereby a limited number of awards will be presented to those who have helped forward the PAA's work in some way.

The first of such awards were presented this year at our Conference:-

Mrs Jackie Harvie, Miss Sue Johnson, Miss Sally Dale, Mrs Janice Johnson (unable to attend event).

Awards to those in the industry:-

Mr Jon Stratton, Product Manager, Quinoderm Limited. He has supported and encouraged us from our early days.

Mr David Edwards, again he has encouraged us from our early days, where he was Dermatology Business Unit Manager at Roche. He has now left Roche to work for PA Consulting and has also joined us on the PAA Team as Pharmaceutical advisor.

Jackie Harvie

Jon Stratton

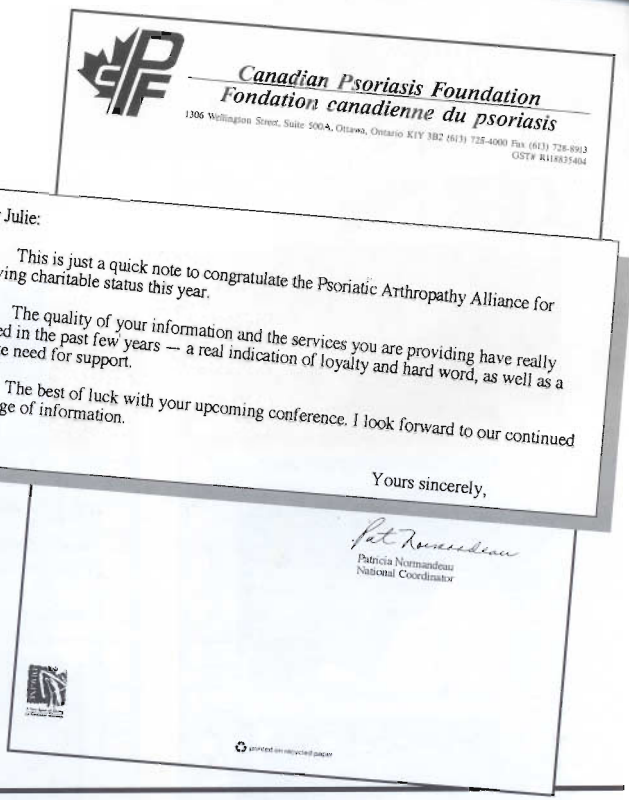
Sue Johnson

David Edwards

Sally Dale

NEWS FROM OUR FRIENDS OVERSEAS

"We received this wonderful letter from Canada."



Canadian Psoriasis Foundation
Fondation canadienne du psoriasis
1306 Wellington Street, Suite 500A, Ottawa, Ontario K1Y 3B2 (613) 725-4000 Fax (613) 728-8913
GST# R118835404

Dear Julie:

This is just a quick note to congratulate the Psoriatic Arthropathy Alliance for receiving charitable status this year.

The quality of your information and the services you are providing have really evolved in the past few years — a real indication of loyalty and hard word, as well as a definite need for support.

The best of luck with your upcoming conference. I look forward to our continued exchange of information.

Yours sincerely,

Patricia Normandeau
National Coordinator

printed on recycled paper

NEW LINKS ! ! !

In August this year we were honoured to be invited to become members of the International Federation of Psoriasis Associations which we gratefully accepted. So far we appear to be the first UK representative. We very much look forward to working with the IFPA member groups in the months and years to come.

International Federation of Psoriasis Association
6600 SW 92nd Avenue, Suite 300
Portland, OR 97223-7195, U.S.A.
Tel: 503.244.7404
Fax: 503.245.0626
E-mail: 76315.2746@compuserve.com
Web Site: http://www.psoriasis.org

ARGENTINA
Contacto Psoriasis

AUSTRALIA
Psoriasis Association of NSW, Inc.
Psoriasis Association of Victoria

CANADA
Canadian Psoriasis Foundation

CZECH REPUBLIC
Spolecnost Psoriatiiu a
Atopickych Ekzematiku

DENMARK
Danmarks Psoriasis Forening

FINLAND
The Finnish Psoriasis Association

FRANCE
Association Pour La Lutte Contre
Le Psoriasis

ICELAND
Samtök Psoriasis

ITALY
Associazione per La Difesa
Degli Psoriasici
Associazione Salute Nature

IFPA

LITHUANIA
Lithuanian Psoriasis Society

NEW ZEALAND
Psoriasis Association of NZ, Inc.

NORWAY
Norsk Psoriasisforbund

SINGAPORE
Psoriasis Association of Singapore

SLOVAK REPUBLIC
Slovak Association of Psoriasis

SOUTH AFRICA
South African Psoriasis Association

SPAIN
ACCIO Psoriasi

SWEDEN
Svenska Psoriasisforbundet

UNITED STATES
The National Psoriasis Foundation

Help I need someone

The word counselling or therapy is continually appearing in the press and yet few people know about it. Others feel that it would help them but are embarrassed to seek help because they see it as a sign of weakness or failure. However short term counselling in stressful situations can be enormously helpful both for the client and their family.

Counselling owes much to the so called third force of therapy, the first being Freudian psychoanalysis and the second based on the work of Pavlov using behaviour techniques. The final thread uses humanistic techniques and covers a wide range of counselling methods which are suitable for treating those with long term medical conditions and their families.

Once you have decided that counselling would help you either because you have PA or you are caring for someone that does, you then need to go about trying to find a counsellor. The first step is to visit your GP. Many practices today have their own counsellor and your GP could decide that you should see them. You will then have an assessment and you will agree between you a 'contract' which will decide how many sessions you will have. Most NHS counsellors usually agree approximately 6 sessions of half hours or 50 minutes. Long term work is rare and they will usually refer you onto a local hospital if they feel that this is needed.

However NHS resources are rare and you might decide that you wish to go privately and need to find your own counsellor. Again your GP maybe able to help and know someone who you can see. Alternatively you can phone the British Association of Counselling on 01788 578328 for a list.

After you have spoken to the counsellor on the phone, you will agree an assessment session similar to NHS practice. This is an initial session and do not feel embarrassed if at the end you do not feel you can work together. There are very few counsellors that specialise or are aware of the needs of those suffering from PA or their carers. So it may be that it takes a couple of assessment sessions before you find the right person. However you will be charged, and so it is worthwhile finding out basic information over the phone before you make an appointment. The contract, either written or verbal will also cover missed sessions,lateness and fees. Most counsellors will charge between £15 to £25 for a 50 minute or I hour session.

When looking for a counsellor it is important to ensure that they are a member of the BAC although they may still be working towards accreditation. Some psychotherapists belong to the UKCP and again they may not be full members. Trainees should inform you that they are still working towards full registration and should charge accordingly. They should all have appropriate insurance.

People with PA and their carers do not often need long term work but just some help over a particular stressful time when depression can be a problem or the family dynamics seem to be overtaken by the condition. Please take that first step by going to see your GP.

Bernice Green BA (Hons)
Advance Psychotherapy Trainee
Whittington Hospital
BAC member

Q&A

Q. Have you managed to find any similar symptoms for PA? All cases seem to be so different?

A. *Although it seems that all patients seem to be different in some respects, and individuals differ widely in the pattern and the intensity of their arthritis, there are certain common patterns where the symptoms are similar from one person to another, for instance, the tendency for the end joints of the fingers to be picked out in one group, spondylitis, inflammation of the spine, to be common to another group, and an intermittent pattern, where the disease comes and goes in a rather random fashion, affecting different joints in different attacks in yet a third type, and there are other recognised patterns too.*

Q. Arthrotec wasn't working for me - does the action of the pill change with body changes?

A. *Arthrotec is a combination of two medicines, one which is fairly successful as a symptomatic drug to reduce inflammation in all kinds of arthritis, and another drug to stop it upsetting the stomach lining. The range of dose which can be given with this drug is quite small so that some patients are not able to be given a dose which reaches the level of providing adequate relief and the only solution is to try something different.*

Q. Could you tell me more about neck involvement in PA? Can anything be done?

A. *It is true that sometimes the neck is involved in psoriatic arthropathy with inflammation of the small sliding facet joints, and this can be painful.*

Neck involvement is also seen in those patients with psoriatic spondylitis and here stiffening of the neck may occur gradually over time. In either case the combination of anti-inflammatory drugs and painkillers, together with gentle mobilisation of the neck, best undertaken by a physiotherapist familiar with the condition, is the best treatment in the early stages. If the pain is very acute, the temporary use of a collar may provide relief, even if it is only worn for a few hours in the day when pain is troublesome, or at night to stop getting into a painful position during sleep. The more powerful drugs which modify the underlying disease process in other joints are often quite often successful in improving matters in the neck too.

Q. What happens to the tissue when affected? Is scar tissue built up?

A. *When the tissues of the joint are inflamed, what happens depends very much on how long the inflammation lasts. In those people in whom attacks in any one joint are brief, there may be complete recovery and a return of the joint to normal function, whereas when a particular joint is affected severely for a very long time, there may be great damage to the lining of the joint and occasionally erosion of the underlying bone. Scar tissue does not build up as a rule, although there are very occasional patients where the reaction of the tissues is unusual and leads to an increase in the fibrous tissue which is a kind of scarring and leads to stiffening of the joint, but this is a very small minority of patients with psoriatic arthritis.*

SPOTLIGHT ON...

HOLIDAY CARE SERVICE

How we can help you

The Holiday Care Service, a national charity founded in 1981, is the UK's central source of holiday and travel information and support for disabled and disadvantaged people.

Each year 40 per cent of the UK population do not take a holiday away from home, often because a disability or financial circumstances seem too great a burden.

At Holiday Care Service we believe that everyone deserves an annual holiday, whatever their age, disability or circumstances. At our offices in Horley, Surrey we hold a computerised database, comprising 170 different fields of data on all aspects of accessible tourism and travel. And each year we answer over 27,000 enquiries from disabled and disadvantaged people, giving them both the information and the confidence to take a break they may not previously have believed possible.

In particular we can help with information on:

Accessible accommodation (both serviced and self-catering)

Accessible visitor attractions

Accessible transport

Low cost holidays

Children's holidays

Holidays for one-parent families

Holidays for carers / Respite care

Sources of holiday funding for those on low income

If you are an older person or carer, if you have a physical, sensory or learning disability or if your income is limited, do contact us and we'll be pleased to help you find the holiday that's right for you.

And if you are a social worker, health visitor or tourism professional, we'll be happy to advise you on holiday arrangements for disabled or disadvantaged people.

How we work with the tourism industry

Apart from providing a unique holiday and travel information service to disabled and disadvantaged people Holiday Care Service also works closely with operators in all sectors of the tourism industry, to stimulate improved access provision.

This we do by offering a range of consultancy services, covering access audits, inspections and disability awareness training for staff. Along with the national tourist boards, Holiday Care Service is an agency accredited to inspect against the National Accessible Scheme for tourist accommodation. We are also able to advise on the accessibility of conference facilities and visitor attractions.

Holiday Care Service works under the auspices of the TOURISM FOR ALL campaign, which aspires to create a mainstream tourism environment accessible to everyone - regardless of age, disability or disadvantage.

Contact our information office on:

Telephone: 01293 774535
Minicom: 01293 776943
Fax: 01293 784647

or write to:

Holiday Care Service
2nd Floor
Imperial Buildings
Victoria Road
Horley, Surrey RH6 7PZ

SOO COVERS

Sooshoos and Soomitts were originally produced in South Africa to be used over a skin nourishing cream to increase its absorption by the skin, leaving it soft and supple. It is estimated that the skin's ability to absorb this cream is enhanced by up to 10 times through the use of the waterproof/cotton covers. The covers are made from a warp knitted nylon tricot laminated with polyurethane and covered by a pure cotton knit external layer.

Very rapidly the manufacturers of these covers were receiving requests for their products from people suffering from skin conditions, like eczema and psoriasis, who were finding the shoes and gloves both beneficial and comfortable to wear. Wearing the covers seems to increase the efficacy of the dermatological creams as well as give the patient the convenience and comfort of having the area covered. In addition the covers protected carpets, bedding and clothing from the creams used. Elbow and knee covers were added to our product range at this stage at the request of our customers.

Prompted by various requests from the UK, Soo Covers are now available here. Trials have been undertaken at hospital dermatology units in the UK to test the benefits that had been reported by our customers in South Africa, and we are pleased to say that the provisional results have been most promising, with many patients involved in the trials now ordering additional items.

We will be conducting further trials for our new products, neck and head covers, shortly and would be interested in hearing from you if you would like to participate (write or phone as below).

If you would like to know more about SOO COVERS, please feel free to contact me at the following address.

Mary Crocker, 3 Kelso Close, Worthing, West Sussex BN13 1PL. Tel: 01903245116

The following items are now available for order/purchase (prices include postage):

Product	*Description*	*Sizes*	*Prices*
Sooshoos	*Shoes*	*S- 4-5* *M -6-7* *L - 8-9*	*£4.00*
Soomitts	*Gloves*	*S - 6-6.5* *M - 7-7.5* *L- 8-9.5*	*£4.50*
Sookysox	*Children's shoes*	*S, M, L*	*£3.00*
Sookymitts	*Children's mittens*	*S, M, L*	*£2.50*
Sookygloves	*Children's gloves*	*S, M, L*	*£3.50*
Elbow covers	*Elbow covers (single)*	*S, M, L*	*£2.50*
Knee covers	*Knee covers (single)*	*S, M, L*	*£3.00*

The covers should be washed regularly either by hand or in the washing machine.
NB: Allergy tests on all these products have been conducted.

PSORIATIC ARTHRITIS CLINIC

News from Leeds

I am writing to you with a proposed new Psoriatic Arthritis Clinic which we have established in the Leeds General Infirmary for the North Yorkshire Region. We would be glad to see any patients with psoriatic arthritis in this area. Many of the original studies defining this condition were carried out and published from LGI by Professor V Wright and colleagues. We are hoping not only to continue this tradition but also develop it. In parallel with the clinical commitment to the management of patients with this condition, we are dedicated to develop research in this area.

We are considering a number of research proposals including clinical studies, novel techniques of investigation, treatment and also studies of the genetics of psoriatic arthritis. I do know that in the 1970's there was an extensive survey of family members of patients suffering from psoriatic arthritis undertaken in the Leeds area. Whilst we have many of the case notes, the family members are not easily identifiable from these files and I was hoping to avail of your help in this respect. If you know any persons or indeed any large families with a number of members suffering from psoriatic arthritis in the Yorkshire area, I would be very grateful if the PAA could put them in touch with us. If so, you could contact them directly, by highlighting our clinic in your newsletter or by identifying them and allowing us to contact them locally.

We held a symposium on psoriatic arthritis for the Northern and Yorkshire Region in January which was very successful and we see this has an area to which we are committed to develop not only regionally but nationally and indeed internationally.

There is a long tradition of clinical and research interest in psoriatic arthritis (PA) at Leeds. Indeed, the original descriptions of the different forms of arthritis in the UK came from Professor Wright and Dr Moll in this unit in the early 1970's. In order to maintain and develop this interest we have recently started a psoriatic arthritis initiative in the region. The first step in this is to provide a specialised clinic for patients with psoriatic arthritis in the Leeds area, which is now underway. Some may be aware that there appears to be a genetic link in PA and to study this more closely, we need to identify families in which more than one member has psoriatic arthritis, it may be a brother, sister, cousin, aunt, uncle or indeed grandparent! The relationship is not so important, if there are several members in one family with PA then this may be even more interesting.

Thank you for your anticipated co-operation.

Yours sincerely
Dr Douglas Veale
Consultant
Rheumatologist

Recruits still needed

Dr Veale can be contacted on 0113 292 3956

What's new on the Net
No.1 in a series of occasional articles by David Edwards

The Internet is hot news these days. It may not always be good news, but not a day goes past without some reference in the media to the way it does or will pervade our lives.

To those of you who may be computer - literate, the Internet might be seen as your gateway to the biggest reference library in the world, or to confer the ability to communicate electronically, on a global basis, with anyone who has an appropriately wired terminal, for the price of a local call. To those of you who are not, it is at worst, as clear as mud, at best, a haven for pornography, filth, and detailed descriptions of how to make atom bombs for terrorist use, (both of which are readily available to those that seek such information). The truth is that both descriptions are accurate.

What the Internet is all about is information and communication. it was originally conceived in the late 1970's as a US military means of storing information on computer and accessible by a large number of terminals anywhere in the country, to prevent destruction in the event of nuclear war. It was taken up by academia, (Universities), in the 1980's as a means of sharing research data and remained the preserve of 'tecchies' until the early 1990's, when the PC, (personal computer), revolution bought it into the reach of 'Joe Public'. From this stage all sorts of organisations and private individuals started using it for business, communication and information. The bulk of this has been in the USA, but the 'net' is now global, with the language being primarily English.

It is capable of 'on- line', that is real time, communication, pictures, video, audio, etc. and has amongst its key features three main areas of use, these being as follows:

• The World Wide Web (www) - each organisation, group, or individual can have their own individual page(s), which gives details of them, their organisations, or their products, which may advertise, talk about special interests, or just general information. They vary considerably in their complexity and presentation, but virtually all carry 'links' to other related pages, which can be accessed by 'clicking' on an icon which appears on the screen. By this method, the user can skip or 'surf' from page to page as desirable. Hence the expression that has come into modern day parlance, 'Surfing the Net'.

Each page has a unique address, or URL, (Uniform Resource Locator), but because there are now literally millions of pages on every subject under the sun, unless you know the exact address, to find information on a particular topic would be akin to the proverbial 'needle in a haystack'!

No worries! There exists a device, (several, in fact), called a 'search engine'. These are electronic librarians, which when given key search words, will produce details of all the references available on the subject. Obviously, the less specific the search term, the more references will be produced. Some of the more popular search engines go under the names of Yahoo!, AltaVista, Webcrawler, Lycos, and many more.

Pages have address names such as http:// www.moviesounds.com, where http stands for hypertext transfer protocol, (you don't have to remember that!). This particular page is a collection of audio clips from films, which you can download onto your computer.

• Electronic mail, or e-mail, the ability to type a message on your computer, affix an electronic address for the recipient(s), hit a button, and send it down the telephone line at the price of a local call to your service provider, and then on to anywhere in the world. The beauty of it is that it is virtually instantaneous with guaranteed delivery, (no need to worry about delays with the post, - sneeringly referred to as 'snail mail' by regular e-mail users), or postmen on strike. Messages can be sent to any number of recipients at once, and attachments such as graphs, graphics, or sounds can be added. The recipient can then begin work on or reply to the document without having to retype it or print it. Every e-mail user has an Internet address such as john.smith@joebloggs.com.

Joe Bloggs being the name of their organisation or service provider.

• UseNet, or discussion groups. It is a natural tendency of like - minded people to form together in clubs and groups. The Internet provides an ideal forum for this, on a global basis, without ever having to leave your own house or office. This could be regarded as somewhat anti - social, but that is the nature of the beast, and sometimes these people do get together - witness the Star Trek conventions; there are a number of discussion groups devoted to this 'fascinating' subject, even to the extent of offering tutorials in speaking Klingon! Again, as for the web, there are discussion groups on every imaginable topic, currently around 15000, from last night's football to last nights nuclear physics. Each has its own title such as alt.support.skin diseases.psoriasis. One can join in the discussions or just browse, known as lurking.

The Net has spawned a whole new vocabulary and etiquette, ('Netiquette'). Some samples as follows:
Threads -
discussion themes
FAQ's -
Frequently Asked Questions
To send unrequited junk mail -
'spamming'
To insult someone or make derogatory remarks -
'flaming'
To write in capitals -
'shouting'
To express happy feelings :-) sad :-(an aside:-^ wink ;-), known as emoticons
Newbie -
newcomer

All that is required to access the Net is a computer with a modem and a service provider. The latter are companies which are central terminals for manipulating the huge amounts of data flowing round the Net, and usually provide access, and electronic mail, (e-mail), for the price of a local call, plus a monthly fee. The number of providers has mushroomed over recent years, but some of the bigger ones include Compuserve, Demon, AOL and Microsoft Network. Many of these provide their own additional services, such as chatlines, financial advice, live conferences and on - line shopping as well, (virtual shopping malls with most of the major shops on - line). Just provide credit card details and your purchase is delivered to your door!

So that's a brief synopsis of it all. You may now ask why do I need to know this, and why is it appearing in a PAA newsletter? The simple answer is that the discussion groups, web pages, etc. provide an ideal forum for Patient support groups, and sufferers to meet and talk to each other, swap experiences, talk about therapies they have tried, and new therapies being tested, talk to pharmaceutical companies and expert clinicians, moan, complain, cheer each other up, learn about forthcoming conferences, etc. The list is endless.

Having read the above, you will not be surprised to learn that psoriasis and indeed psoriatic arthropathy is well represented on the Net, and has a number of active pages and discussion groups from all over the world. My mission, Jim, (and I have decided to accept it), is to keep you informed of what' s new, hot, and interesting with respect to the readers of this newsletter.

Surfs up!

David Edwards
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The PAA would like to thank all our members, supporters and friends and wish them a Merry Christmas and a healthy New Year

NEXT NEWSLETTER - MARCH 1997
NEXT JOURNAL - JUNE 1997

Round Up 1996 It's been another busy year!

ROADSHOWS:
PLYMOUTH JUNE 96
READING OCTOBER 96
MANCHESTER NOVEMBER 96

CARLTON TV
RADIO 2

EDINBURGH APRIL 96

PSORIATIC ARTHRITIS?
COME AND FIND OUT MORE . . .

PAA

CONFERENCE
Being held this year at WOBURN

WOBURN SAFARI PARK
BEDFORDSHIRE
Saturday 21st September 1996

CHARITY LAUNCH

New & old friends

Janice Johnson
Barbara Bone

Kristina Sonderlind
Director
Swedish PA

Sally Dale &
Julie Charnelle.
Fundraising jump
May

BRITISH ASSOCIATION OF DERMATOLOGISTS (BAD)
BRITISH SOCIETY FOR RHEUMATOLOGISTS (BSR)

CONFERENCES
BOURNEMOUTH JULY 96
BRIGHTON MAY 96

HEALTH SHOW JULY 96

CHARITY LAUNCH APRIL 96

IFPA

COLOUR-BOX miniatures

Youngest PAA recrui
Hannah 2½, office jun

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