

THE PSORIATIC ARTHROPATHY ALLIANCE

136, High Street, Bushey, Herts, WD2 3DJ.
Tele/Fax: 0923-672837

Sept 1994

NEWSLETTER: 3

NEWS UPDATE!!!!

What have we been up to, well quite a lot. Our Executive Committee has now been formed with us all working well together with some exciting ideas come out of the discussions. Our medical advisory team is nearly complete and in this regard Mr Jan de Vries, author of many books including, Arthritis, Rheumatism & Psoriasis, Skin Diseases and practitioner of alternative medicine has kindly agreed to join the team.

We are still on target, all being well to become a Charity early/middle of next year which brings me on to our NAME CHANGE.

As you will see it has been discussed and decided by the Executive Committee that "Support Group" was far too limiting for the work which the organisation intends to carry out in the future years and as we are going for Charity Status it was best to decide on a befitting name for our Constitution now rather than to change parts of it at a later date which would be more difficult. We all hope you like the new name "ALLIANCE" bringing both the skin, arthritis and associated conditions together where they belong.

THE SKIN CARE CAMPAIGN

This is well underway and doing well and is gradually being publicized both to the medical professionals and to the general public, with more new projects underway and in formation.

Don't forget the ALL PARTY PARLIAMENTARY GROUP FOR SKIN which has been set up. We want your views and contributions as to what you think is wrong in the treatments and quality of these, and medical care you receive, what you think could be done to improve things.

This really is your chance to have a say in your care, what you want, what you are not getting and how you would like to see changes implemented.

THANK YOU

We would like to extend a very warm thank you to Professor Ronald Marks, of The Dermatology Dept, University of Wales, Cardiff, for including the Group and its work in a small piece in his new book just out entitled "Coping with Psoriasis", priced £5.99, ISBN 0-85969-690-1, published by Sheldon Press. It's a great comfort to be recognised by a person such as himself who strongly appreciates all the good work Patient Support Groups are trying to do in attempting to co-operate and work with the medical profession to bridge the wide gap between them and the Patient.

HEAD TALK

Further to our piece on scalp problems we followed this up by approaching the hair professionals who informed us that it is part of the teaching course for hairdressers to be educated on scalp conditions and so they are not too surprised when they come across psoriasis of the scalp or any other scalp problems of which there are quite a few.

We are still trying to get a directory of hairdressers together that you have found helpful so please drop us a line. Here are a few you have let us know about.

Sally Ann Hair Fashions,
25, East Hill,
Colchester, Essex.

A friendly salon who will accept scalp conditions no matter how bad as an ordinary problem and won't make you feel uncomfortable.

HAIRS & SIRS,
65, Liverpool Road,
Burscough,
Lancs.
Tele: Burscough 896075.

Lynn and Sharon welcome any new clients. They are kind and understanding and use coal tar derivative shampoos if desired.

Helen Noble,
A CERTAIN FLAIR,
63, High Street,
Buntingford,
Herts,
SG9 9AD.
Tele: 0763 272131.

Very understanding in treating scalp conditions.

Why not give a hairdresser you fancy a call before you book and have a chat to her before you make an appointment. Sometimes this can be an easier way to find out if she/he is understanding about scalp problems.

SAMPLES TO TRY

We have the following if you fancy trying them to give away, so just let us know.

Cocois cream, Clinitar cream, Gelotar, Balneum bath oil with tar, Baltar, Capasal, Pentrax, Alphosyl 2 in 1, Neutrogena, Polytar shampoos.

TENS

Machine for loan to members.

The TENS machine that was kindly donated by N.H. Eastwood & Son Ltd., is available for loan to members for a 4 week period. Please let us know if you would like to try it. These machines are available direct from N.H. EASTWOOD & SON LTD, 118, East Barnet Road, Barnet, Herts, EN4 8RE. Tele: 081 441 9641, on a free trial 3 week period basis. If you would like more details they are a very helpful, friendly firm, just give them a call.

CASE HISTORY: 1

My Psoriasis began in my scalp in 1981, when I was 19, aggravated by my reluctance to see a GP and my persistent picking at it. When I eventually went to the doctors I was treated with various solutions, shampoos and creams, and the psoriasis eventually settled down and never really troubled me much.

In 1982, I had an infection in 3 of my toes, this infection eventually went but left one toe very painful and swollen. A local hospital did blood tests and x-rays but said there was nothing wrong.

In 1989, when I was 8 weeks pregnant and after numerous back problems, a different GP thought that my now very stiff and swollen knee was arthritis. She told me that as I had been diagnosed in 1982, (by the same hospital who had told me there was nothing wrong), as having arthritis, that it was more than likely that I also had it in my knee and spine. She was right. Being pregnant, however, stopped all the x-rays and much of the treatment except Brufen late into the pregnancy.

By now I'd moved house and GP. When my daughter was born all the tests and x-rays were done and PA confirmed as well as ankylosing spondylitis in the spine. At this stage the PA was controlled by drugs but continual trips to the hospital were needed to remove the fluid from the knee.

In 1990, when my daughter was 5 months old, a domestic crisis forced me to move to a woman's refuge. Within weeks the psoriasis disappeared but the arthritis escalated at an alarming rate. The consultant rheumatologist had told me it would only affect one or two joints, but as I sat in his office eight joints later in floods of tears he decided to put me on steroids. This helped a bit but the illness has progressed leaving me quite badly disabled by the condition.

Today I have PA in 13 joints. I'm awaiting surgery to rebuild my right wrist and a synovial membrane scraping on my knee, although a PA consultant rheumatologist at a large hospital in London has suggested that I should try an alternative to this before I go ahead with the operation. He also thinks that my left knee joint may be damaged and in the long term needs a replacement joint. Since my local rheumatologist doesn't believe in replacement joints before the age of 40 (I'm 31) I am in the process of trying to change rheumatologists.

In the meantime the drugs have been changed, doses increased and the psoriasis has this month returned. I have also had 2 massive steroid injections into a muscle rather than a joint. They have made me more mobile but after only a couple of weeks the effects are already wearing off. If my ESR of 120 doesn't improve before my next rheumatology clinic I am told hospitalisation will be necessary.

Life as a single parent with PA is very hard, especially when some mornings you can't even get out of bed, but when I get down my daughter Catherine, gives me the strength to carry on. She's such a big help that I don't know how I'd manage without her. I know too that my GP who has been absolutely brilliant is also there if things really do get too much for me.

I do have a couple of friends with Rheumatoid arthritis, but they don't understand why they respond to the drugs they are on when my arthritis refuses to improve on exactly the same drugs. I hope that by joining the PA Support Group I will find some new friends who understand what I'm trying to say because they've been there too.

Here's looking forward to a future with new friends and new and improved joints (preferably bionic!).

Sue Johnson, Essex, member.

CASE HISTORY: 2

Psoriasis commenced 23 years ago, and I have used many creams, including Steroids. The arthritis then appeared 10 years ago. First in the metatarsals of left foot, gradually extending now throughout.

Now on the following drugs:

Arthrotec :	anti-inflammatory
Dyhracodeine:	pain
Molipaxin:	anti-depressant

Have been on:

Voltarol	Brufen	Sytotec
Lederfen	Surgam	

I am not working now, but am very good at giving advice, but not taking it myself!!

After much thought, and hating the word ACCEPTANCE I wish everyone in the Group happiness and may they and I get better not worse.

Psoriasis and attendance arthritis is a better illness than Rheumatoid arthritis – if you can believe and hold on to that life would seem good. I know there are many times when I want to do so much and hate the limitation of myself. I have to say to myself I'm lucky I still have movement, I'm not in a wheelchair.

Do some of you or all of you feel this anger? It's taken me time even to acknowledge this anger I feel – how can I direct it? I Can't even hit anything cos it will hurt me, so what do I do, shout, scream, any ideas!!

LETTER:

Dear Both,

I'm 48 years old, female, and would like to relate several factors about my psoriasis:-

1. It is best ignored.
2. Stress does aggravate it but it is difficult to avoid except by living in cottonwool or with a rich sugar daddy.
3. At various times different creams can work. People change continually.
4. Don't let it beat you. I once told someone not to worry it was only a plague, contagious and deadly!!
5. Learn to put yourself first – NOT LAST.
6. Be tender to yourself.

Yours faithfully.

Letter and Case history kindly supplied by Barbara Mason, Scotland, member

MEMBERS REVIEW

Review of articles on Psoriatic Arthropathy in Oxford Textbook of Medicine (2nd Edition) 1987
Textbook of Dermatology (4th Edition) 1986.

Arthropathic Psoriasis or Psoriatic Arthritis or Arthropathy

Definition: An association of psoriasis with a disease or disorder involving a joint considered for epidemiological or serological reasons not to be just a chance co-existence of psoriasis and rheumatoid arthritis. The basis of the association is unknown. It has only slowly gained acceptance despite 19th century reports.

Approximately 7% of patients with psoriasis develop arthritis. Conversely psoriasis is present in about 4% of all patients with inflammatory polyarthritis. There is a male predominance in the distal type of PA whereas females predominate in the other types. Prevalence of PA in the population has been estimated as 0.1%.

Aetiology:

The skin manifestations usually precede the arthritis, often by many years. The skin and joint changes frequently do not wax and wane together. The psoriasis can be in remission and the arthritis crippling. It is highly unlikely that psoriasis could be a direct complication of one type of seronegative polyarthritis. Similarly, the arthritis is unlikely to be a simple complication of the psoriatic process. Also a single common cause is equally improbable since the great majority of psoriatics never develop arthritis (and vice versa). The distribution of age onset is so dissimilar and the two only infrequently develop simultaneously.

There is a strong incidence of inherited factors playing a key role in the aetiology of PA. Psoriasis has been detected in 6% of first degree relatives of patients with seronegative polyarthritis (without psoriasis themselves). Infection, trauma and neurotrophic effects are also factors precipitating the arthritis.

Clinical Features: Five subgroups of PA are generally recognised:

1. Predominant involvement of the distal interphalangeal joints. The disease often starts in the toes. Other joints may become progressively involved.
2. Psoriatic arthritis mutilans is a severe deforming arthritis equally prevalent in males and females involving multiple small joints in the hands, feet, spine, and elsewhere. The associated psoriasis is often severe. This type of PA is uncommon.
3. Arthritis that is clinically indistinguishable from rheumatoid disease but follows a more benign course. It is more common in females. Asymmetry of joint involvement is commoner than in rheumatoid arthritis and spinal involvement more frequent.
4. Oligo (or mono) arthritis is distributed in an asymmetrical fashion affecting any synovial joint. This is the commonest form of PA.
5. Ankylosing spondylitis occurring either on its own or in association with any of the above groups, this accounts for approximately 5% of all types of PA.

Arthritis is found 10 times more commonly in patients with severe skin involvement than in those with mild involvement.

Psoriatic nail changes such as pitting and ridging are more frequently seen at the onset of the arthritis than are the skin lesions. Overall 81% of patients with PA have nail changes compared with 32% of patients with psoriasis and no arthritis.

Diagnostic difficulties can occur when patients with psoriasis display arthropathies other than PA. Gout can simulate PA both clinically and radiologically.

The most important serological feature is the complete absence of rheumatoid factor from the serum of patients with the distal and "Mutilans" type of PA. If a patient with seropositive rheumatoid arthritis later develops psoriasis, rheumatoid factor does not disappear from the serum if the arthritis remains active.

Extra-articular features are much less frequent than in rheumatoid arthritis. Eye lesions are common; conjunctivitis has been reported in 20% of patients, uveitis in 10% and scleritis in about 2%.

Treatment:

Non-steroidal anti-inflammatory drugs are used although they have been reported to have caused minor flare-ups of the psoriasis. Physical therapy is used also. Stronger drugs (methotrexate) can be used in aggressive joint disease but the side effects may preclude its prolonged use in some patients. The vitamin A derivative Etretinate has been shown to benefit the arthritis as well as the skin lesions in psoriatic patients. PUVA used for psoriasis may benefit PA and also PUVA and etretinate combination. Occasionally, in certain cases, low dose steroids may have to be used. Reduction of steroid dosage may destabilize the psoriasis. Intra-articular injection of steroid into inter-phalangeal joints of the fingers may be of value.

Prognosis:

Psoriatic Arthropathy, is often quite a mild disease notwithstanding the minority with "arthritis mutilans". A 10 year follow-up study suggested that it produced less pain and disability than rheumatoid disease. Excluding the "mutilans" group, in this study 30% lost no time off work and only 3% had more than a total of one year off work in the 10 years. Many patients showed little or no radiological deterioration.

Doreen Miles, Member,

Doreen's comment: I wonder how many PA sufferers would agree with the last statement, though everyone has their own "pain threshold". I took early retirement as I could not stand and work all day due to the arthritis in the sacro-iliac joint. I was crippled by 6.0pm!

BITS'N'BOBS

Mary Page a member from Sussex is collecting stamps for a Guide dog, so please don't throw your envelopes away without tearing the stamps off. I am sure you will agree it's for a very good cause and it takes an awful lot of stamps to get one, so please help. Send them into us and we will pass them on to Mary. Thanks.

OFFICE LIBRARY

We have been trying to build up a library of books, articles, and medical papers on Psoriasis, Psoriatic Arthritis and associated conditions for the benefit of anyone who would like to come in and have a read of all the information we have. So if you come across any newspaper, magazine cuttings etc please cut them out and send them into us, even if you just see one or two items it soon builds up.

Any donations of books on psoriasis etc. would be gratefully received.

The office is open during the week: Mon-Fri 9.0am-4.0pm; closed for lunch: 12.0 noon-1.30pm to anyone who wishes to come and see us and have a look at the info or for a chat, although we would appreciate a call first just to make sure we are there and not at a meeting. Thanks.

Jan de Vries

As we mentioned Jan has kindly agreed to join us on the team and has offered to do a "Question & Answer" page for us on any questions you may have on alternative therapies and psoriasis and PA, so if you have any questions please send them in and Jan will answer them via the newsletters and journals. So come on GET MOTIVATED!!! PLEASE

NEXT JOURNAL OUT SOON.

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ALLIANCE**
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Tele/Fax: 01923-672837

FEBRUARY 1995

NEWSLETTER 4

UPDATE

Well with 1994 under our belts and a fresh New Year ahead there is even more hard work to be done.

1994 was a gruelling year for us all at the PAA and alot of groundwork covered with an enormous amount of meetings attended, some of which you already know about regarding the SKIN CARE CAMPAIGN. The other meetings will be reported in the forthcoming journals.

Ourselves and the Executive Committee regularly meet now every three months with sub meetings being held at intervals to keep things up-to-date.

You will be pleased to know that at long last (fingers crossed and funds raised) we plan to hold a meeting this year with speakers and also possibly some representatives from the Pharmaceutical Industry, to enable you all to have an opportunity of talking to them about various products. Hopefully there will be some freebies for you to take home and try if we ask them nicely!! More details on the meeting later on in the year.

It will really nice to have the opportunity to meet you in person and those of you we have spoken to over the phone lines.

In the not too distant future we hope to have an up-date on our Charity application.

We are getting ourselves in shape for 1995.

**KEY WORD for 1995 –
MOTIVATION!!**

We need your help. Please can we have your contributions to these news letters otherwise there is no point in producing them, so please put pen to paper. As said before many times if you don't want your name printed that's fine but we do need your input please. What you have to say counts in this organisation!

NEWS!! JOHN BOWIS MP.

We have been lucky enough to secure an appointment to see Mr John Bowis MP, Under Secretary of State for Health in February, wherein we will have the opportunity to discuss matters that you have raised with us over the months, the difficulties and frustrations we all face, as well as explaining the work and the need for this organisation to him. Let you know how things went in the forthcoming Journal.

CONTACT LISTS

Please don't forget these, have a go, chat or write to someone on these lists. We feel sure they would be pleased to hear from you. Nobody likes making the first move, but rest assured there is nobody added to these lists that doesn't want to be on them! These lists are a valuable way of finding out about your condition, helping each with tips and most of all MAKING FRIENDS!

You all have so much to offer each other.

I know we're nagging again!!

Talking of contacts, **Archie Toppin**, who lives in Scotland, has recently been diagnosed with PA and would love to hear from anyone who wants to talk to him so please get in touch. His number is: 0141-644-5390 (Clarkston, Glasgow).

CASE HISTORY

My Psoriasis started in 1958, at the age of 14, and I was treated with the usual coal tar ointments in addition to weekly sunray sessions at the local hospital. After the births of my daughter and my son in Hong Kong, a couple of fingers became swollen and, in the absence of any Rheumatologists in the Colony, it was decided that I should seek specialist attention in the U.K. Psoriatic Arthropathy was diagnosed and Butazolidin prescribed. Surgery to straighten a badly deformed finger followed in 1972.

Having lived overseas since 1965, I have been treated in Hong Kong, Kuwait, Thailand and latterly Indonesia where my husband is presently working. Fortunately during this period I visited Britain almost annually and received both private and NHS treatment in this Country. Although Methotrexate was suggested about five years ago, I was unwilling to take the risk without competent follow-up treatment in Thailand and, more particularly, Indonesia. Both hands are now severely deformed (Arthritis Mutilans) and my condition is such that I have frequently been a source of great interest to medical students overseas – after being asked by specialists whether I minded their students examining me. They have to learn and I had no objection.

In an effort to preserve my right wrist and left elbow from further damage, and as I have been based in the UK for the past 20 months, it was decided to start a course of Methotrexate this Summer. Although regular liver function tests are necessary, this is a minor inconvenience, and I am grateful to be able to benefit from the excellent medical facilities available in this Country. The Methotrexate seems to have had a good effect, particularly on the skin condition, and I have more or less stopped taking the NSAIDS which, after 25 years, had caused the well documented stomach problems in spite of having taken Zantac since 1988.

I am constantly being told by relatives and strangers that I should be given a "Disabled" car sticker as my condition precludes me from carrying anything by the normal hand grip – I can only manage if a bag can fit over my wrist. However, when I approached the relevant department, I was told that, although some toes are deformed, as long as I can walk a reasonable distance, I am not eligible, so it looks as if I must continue to struggle with my shopping bags to the far end of the car park!!

Sadly, both my daughter (27) and my son (23) have both inherited Psoriasis and my daughter is on NSAIDs for joint inflammation, but I am hopeful that medical research will ensure a better future for them.

Jacqueline V. Harvie.

For those of you who have a tele contact list there was an error in Jacqueline's telephone number for which many apologies, her number should read 015.

A REVIEW OF ARTICLES ON PSORIASIS PUBLISHED

IN:-

The Pharmaceutical Journal	September 23 1989
Chemist & Druggist	January 11 1992
The Practitioner	March 1991 Vol 235
BMJ	October 5 1991 Vol 303
BMJ	February 20 1988 Vol 296

Psoriasis is a common skin disorder affecting about 2% of adults in the UK. at some stage in their lives. It is equally common in both sexes. A family history of the disease increases the likelihood of psoriasis to 30%. Strangely, the disease is more common in butchers and those dealing with skins. It can start at any age, but most commonly develops between the ages of 5 and 25 with increased incidence in the 25-45 age group. It is less common in darker skinned races and among white populations living in Southern Countries.

The degree of psychological and social morbidity that accompanies psoriasis is commonly underestimated by the medical profession (B.M.J. vol 303 5 Oct 1991). However, guidelines HAVE been produced for managing patients with psoriasis. Recognition and acceptance of the life-long difficulties and uncertainties of psoriasis by the doctor help to foster a relationship of trust between the doctor and a patient suffering from a condition with no guaranteed cure. As it is not known what causes psoriasis, treatments aim at suppressing the disease, inducing prolonged remission and making the amount of psoriasis present that which can be tolerated by the patient.

There are several forms of psoriasis and a person may, during a life-time, move from one type to another. The body surface area affected can range from a small area to almost total coverage. The degree of disability experienced by different people with the same amount of psoriasis varies greatly, people having different opinions of the most upsetting aspect of the condition. Reassurance is necessary that the disease is neither infectious or malignant.

SYMPTOMS

The characteristic sign of psoriasis is patches of red scaly skin, slightly raised. Silvery white scales are pronounced. The usual sites affected are elbows, knees, scalp, lower back, chest, face, abdomen and genitalia. Itching is not a frequent feature but may occur, particularly where the condition occurs in skin folds. The redness is due to a proliferation of small blood vessels which occur nearer the skin's surface than normal. If scales are scratched off they may leave small bleeding points. The lesions arise because of a rapid turnover of epidermal cells. In normal skin the time from when cells develop in the basal layer to when they are shed is 25-30 days. In psoriasis this is shortened to 3 or 4 days. As a result the cells are poorly formed and remain clumped together appearing as scales.

TYPES OF PSORIASIS

1) Common Chronic Plaque Psoriasis

Individual lesions are clearly demarcated, red and scaly, occurring first on the elbows and knees.

2) Flexural Psoriasis

Flexural involvement is common in plaque psoriasis but some patients have exclusively flexural disease. Flexural plaques are red and moist rather than scaly.

3) Acute Guttate Psoriasis

Acute attacks of psoriasis may occur in children (after throat infections especially). It occurs

as small evenly scattered, discoid lesions on the trunk and limbs. It clears spontaneously.

4) Pustular Psoriasis

- a) Acute generalised pustular psoriasis is very uncommon. In this condition there is profound constitutional upset associated with fiery erythema of the skin and sheets of superficial sterile pustules. The patient requires hospital treatment.
- b) A localised pustular skin disease of the palms and soles can also occur and may be accompanied by painful cracks and fissures over skin creases. Sterile pustules may occur.

5. Scalp Psoriasis

This may be mistaken for severe dandruff.

6. Nail Psoriasis

Small thimble-like pits occur in the nail together with thickening, ridging and separation from the nail bed.

7. Psoriatic Arthritis

This occurs in 6–7% of patients with psoriasis. Joint pain occurs commonly in the terminal fingers and toe joints and sometimes in the lumbar joints.

Trigger Factors

Predisposition is genetically determined. The risk of the condition developing in a child with one affected parent is 25%.

Attacks of psoriasis may be precipitated by infections, sunlight and hormonal changes such as occur in puberty, pregnancy and at the menopause.

Drugs thought to precipitate or worsen psoriasis include alcohol and in some patients Beta-blockers, nonsteroidal anti-inflammatory agents (Only minor flare-ups recorded), lithium and chloroquine. Although antimalarials can exacerbate the condition, they should always be taken by patients travelling to malarious areas, having sought specialist advice first as to a suitable kind.

Nervous stress and strain are also factors exacerbating established psoriasis.

Treatments

Emollients: For mild conditions and the self-limiting guttae psoriasis, petroleum jelly or emollients such as emulsifying ointment or aqueous cream (all of which can be purchased by the patient) to relieve cracking, soften the skin and may be all that is required. They require frequent application but are side-effect free and economical.

Dithranol: This is a satisfactory treatment for the majority of patients with chronic plaque psoriasis. It works by reducing the rate of cell turnover. It is most satisfactory when there are large plaques and fewer in number as then there is less likelihood of a large amount of unaffected skin being accidentally burned by the drug. Improved formulations and short regimes have made treatment with dithranol more acceptable.

Coal Tar: This is an alternative for patients who are intolerant of the burning effect of dithranol. Ointments containing coal tar are cosmetically more acceptable but less effective. It is used in shampoos for psoriasis of the scalp. Also used in bath additives.

Steroids: Applied topically there have vaso-constrictor and anti-inflammatory effects. There is rapid clearance of lesions but side-effects prohibit prolonged use.

Ultraviolet light: Many psoriasis sufferers find their condition improves on exposure to sunlight but about 5% have photosensitive psoriasis and should avoid the sun.

The use of commercially available sun beds is not recommended.

PUVA: This treatment is only available in dermatology departments and is used for severe psoriasis. There are some side-effects.

Retinoids: These are vitamin A derivatives which reduce cell proliferation. Side-effects include hair loss and dryness and thinning of the skin.

Cyclosporin A: Reserved for patients unresponsive to conventional care.

Cytotoxics: Their use is restricted to patients with extensive psoriasis resistant to other safer forms of treatment.

Steps should be taken by the doctor to reduce stress if this is a trigger factor.

Severe and disabling forms of psoriasis do exist but they are rare. The main damage done by the disease is psychological. It is difficult to exaggerate the hurt and humiliation that an incurable and easily visible skin complaint can cause. A sufferer's social life and sporting activities such as swimming represent major obstacles. Various support groups exist throughout the world whose aims are mutual support, education and the development of coping techniques. They now also support research and aim to increase public acceptance and understanding of the disease. The latter, with support from doctors, would go a long way in helping sufferers cope and relieve some of the stress that living with the condition causes.

The article written in the "Chemist & Druggist" was entitled "Balancing the Scales". A very appropriate title don't you think?

Article written by Mrs Doreen Miles, Member, Essex.

Thank you Doreen for putting so much time, work and research into this and the previous article in Newsletter 3 on PA. The two articles are both interesting and informative.

POEMS POEMS POEMS POEMS.....

PSORIASIS & PA - The Brothers Grim!

Infinite layers peeling, scaling, flaking, over and over again
Greasey, slimey, oily creamers envelope in a red raw gloss
Aching, burning and stinging in my wrapping, if only they knew
Swelling, tender, throbbing pain muffled by pale "love-hearts", twice daily to be sure,
no more, no less
Festering within, biding time, waiting for a trigger to shoot a bullet of poisoned pain, quitting
after a spell, leaving in its wake an ugly trail of rigid digits
The Brother Grim, a sickening duo, dastardly and cruel, no point sobbing
Their time will come rejoice we will.

AND KNOW THAT

Victory comes with patience
Relief with affliction
and
Ease with hardship

Sent in by Ricky Ahmed, Member, London.

CONGRATULATIONS NEW MUM!!

We are pleased to announce that Dr.Sharon Jones,one of our medical advisors in Bath, safely gave birth to a lovely baby daughter just before Christmas. Well done and lots of best wishes.

THANKS

Thanks to everyone that sent in stamps for Mary Page,who is collecting for the Guide dogs, they were very much appreciated.Please keep them coming.

Thank you to everyone that has sent in a little extra either in donations or stamps with your subscription fees and renewal slips. It really is appreciated and does help us to keep going.

DOVENOX

A lot of you already use Dovenox ointment for the treatment of your body psoriasis but did you know you can get it in a cream formulation now on prescription from your doctor.Leo have also produced Dovenox lotion for the treatment of your scalp psoriasis too.

DON'T FORGET!!

If there is an emollient that you like using why not ask your doctor next time you see him if he would kindly add it to your prescription. These items can work out cheaper this way,although ask your chemist first the price of the item off prescription to check if it is worthwhile.

AVEENO PRODUCT RANGE

*Some of you may be pleased to learn that Bioglan who produce the Aveeno range now operate a **Mail order** service for your convenience.*

GREEN LINE - Dry Skins:

Emulave Fluid (liquid soap)	£ 7.50
Emulave Cleansing bar	£ 2.47
Oilated bath additives	£ 9.69

BLUE LINE - Sensitive/Normal Skins

Regular bath additives	£9.96
Aveenocream (moisturiser)	£4.92
Aveeno bath oil	£5.99
Aveeno cleansing bar	£2.47

For orders up to £25.00 add £1.00 per item for postage & packing

For orders over £25.00 postage & packing free.

Cheques payable to "Bioglan Laboratories Ltd. Allow 14 days for delivery.

Send to: Bioglan Laboratories Ltd., Freepost,Hitchin,Herts,SG4 0YD.

ARE WE GETTING THINGS RIGHT?

If you have any moans and complaints about the services we are or not providing please let us know so we can improve things. YOUR OPINIONS count. Thanks.

RENEWALS due 1994

Please can we ask all those of you who have been sent renewal forms and have forgotten about them and still would like to stick with us to receive the usual newsletters,journals etc, please send your forms back. Due to increasing costs although we would like to keep sending you these free unfortunately we have to stick within our limited budget,so the mailing list will be up-dated shortly and all those who have not renewed will be removed. Sorry but our funding is so limited we have no choice.

Thanks

PSORIATIC ARTHROPATHY ALLIANCE

P.O.Box 111, St. Albans, Herts, AL2 3JQ.

Tele/Fax: 01923 - 672837

NEWSLETTER 5.

SEPTEMBER 1995.

CHANGE OF ADDRESS:

Please make a note of our new address above. Sadly we have had to say a fond farewell to 136, High Street, Bushey, which has been our free office base for the last 2½ years. The landlord plans to redevelop the site. As our funding is very limited we feel that alternative accommodation may be out of the question at the present time but if the position changes we will keep you advised of any other address.

WHAT'S BEEN GOING ON ???

It's been a hectic time since our last newsletter. Here's a quick up-date.

We are pleased to welcome to our Medical Advisory Team, Professor Christopher Griffiths, Dermatologist, who has had a longstanding interest in Psoriasis and has carried out considerable and extensive research work in the field of Psoriasis. He has just set up a weekly Psoriasis specialty clinic at the Skin Hospital in Manchester, and also hopes along with some other colleagues to put together a study on genetics of Psoriatic Arthritis. Hopefully plane flights allowing, Professor Griffiths hopes to come along to introduce himself to you all and give a short talk, as well as answer any questions you may have before he flies off to a conference in Vienna.

Sherry Ross, a specialist Dermatology Sister, at St. Andrews Hospital, London, has joined us. Sherry herself has Psoriasis so understands the problems we have only too well and is eager to set to work with various projects the PAA hopes to commence shortly.

Again she will be at the Meeting, so any questions you have or just want a chat, she is looking forward to seeing you all there.

Rheumatology Nurse for the Medical Advisory Team

We feel it would be beneficial to have a Rheumatology Nurse working with us and plans are afoot hopefully to persuade one to join us!

DAVID!!!

Sadly after 20 years, being self-employed, doing the same physical job, due to progressive ill health he has finally had to hang up his welding gloves, spray guns and green boiler suit

for good (well I'm trying to talk him round to doing the rust spots on my car when he feels up to it, but he's a tough cookie to crack sometimes!). BUT fear not he has gone on to do something more positive with his time. As from 1st May 1995, he took on the role as full-time Co-Ordinator for the Skin Care Campaign, based at the National Eczema Society in London, whilst I have taken on more full-time day-to-day duties in the running of the PAA. David and myself still continue to represent the PAA together at various meetings that need to be attended. David's input into the PAA will be the same if not more as he spreads his wings. It will enable the PAA to be represented on a much broader scale, which will be a good thing for raising awareness of the condition.

I'm sure along with myself that we all wish him well in his work.

HAIR DIRECTORY

As you know last year we asked you to send in your nominations for hairdressers that you have found sympathetic and understanding to scalp psoriasis, and did not make you feel awkward about it. PLEASE keep these coming in as response has been a little slow with this project, and we really do think it would be a good idea to compile a NATIONWIDE DIRECTORY of this nature.

"WHICH Way to Health" kindly included a piece on this project for us in the August issue of their publication, so please let's have some more interest. Thank you!

GENETIC INTEREST GROUP (GIG)

Julie has also taken up a new role too as a Trustee on the Management Board of GIG, whilst also representing the PAA in this Organisation. In the months to come she will endeavour to keep you informed of what's going on in this vast field, which I am sure will be an interesting period now that the Science & Technology Committee Report on Human Genetics has been released, along with on going debates on the Disability Discrimination bill. These beg extensive discussions in themselves.

PAA

Inaugural Meeting Zoological Gardens

London: MEETING ROOMS

23rd September 1995: 9.30am – 3.0pm

Please let's make this a good day. A lot of thought, time, effort and though I hate to say it, money has gone into arranging this day for you all, so that you can actually have an opportunity of meeting our Medical team, ourselves and all those involved. It will enable you to get answers to all the questions and queries that you may have about PA and psoriasis. It also gives you the chance to become involved, participate and get to know us all. Even though we are steadily growing we want to keep in touch with you and not become so distant as is the case with some Organisations. We are working for you.

Apart from being an informative day, it's a nice venue, walk round the Zoo or take a walk round Regents Park, bring the kids, family/partners. We are setting up a small supervised games room for the kids too. Help us make our 1st Meeting a success. We don't mean to be negative but if there is not much interest in coming to these meetings then there is no point in arranging them, and let's face it, it's not often you get the chance to talk informally to so many health professionals under one roof, especially ones who are willing to listen to you.

Please can you return the enclosed attendance forms as soon as possible for us to get firm numbers of attendees. Thanks.

Should you like to use the reserved car park allocated for the meeting, tickets need to be obtained before the day from the PAA at a cost of £3.50 per car, otherwise the charge is £10.00 per vehicle on the day.

We look forward to meeting as many of you as possible.

HELLO AUSTRALIA:

PSORIASIS ASSOCIATION OF NEW SOUTH WALES AUSTRALIA, and PSORIASIS ASSOCIATION, Spring Hills, Queensland.

The PAA would like to say a warm welcome to our new friends in Australia who have also become members of the Alliance. We look forward to working more closely with them in the near future.

A PLEA FOR MORE HELPING HANDS!

REGIONAL DEVELOPMENT OFFICER/FUNDRAISER?

Are there any of you, your friends or relatives with time on your hands that would be willing to take on a mammoth challenge for the PAA?

The PAA wants to expand around the Country but to do this we need more voluntary staff to help us achieve this objective.

Initially the job will be two-fold, developing regional groups around nationally, and secondly fundraising. This would involve approaching Industry, locally and nationally for sponsorship, organising fundraising events, again both locally and nationally, and organising the Research Appeal Fund for Psoriatic Arthritis that we hope to put into action shortly.

Depending on how many of you volunteer the job could be spread between a team of you or it could be managed on an individual basis, with the help of regional organisers.

If you think you can do the job, work on your own initiative at times and want to have a go please get in touch with us or if you are coming to the Meeting in September have a word with us then.

JOB OPPORTUNITY

PUBLIC RELATIONS CO-ORDINATOR!!

Again we need someone with time on their hands, energy and drive to develop this post in the Organisation.

It will involve dealing with the media, medical/non medical persons/organisations, general public, Industry and Commerce to promote the Organisation, its work, the illness, and projects. The person who takes on the position will be expected to work on their own as well as in a team, and alongside the Development/Fundraiser Co-Ordinator in this field of work.

These posts initially will be voluntary, but reasonable out-of-pocket expenses will be met.

PLEASE GET IN TOUCH.

MESSAGE FROM A GRATEFUL MEMBER:

Mary Page, Member from East Sussex, has asked us to pass on her grateful thanks to all those of you who have been sending in used stamps so as to help her collect for the guide dogs. She is really pleased. Keep sending them in.

FUNDRAISING:

Due to lack of space recently in the newsjournals/letters, we would just like to say a big thank you to Sue Johnson for her fundraising contribution late last year wherein she raised £250 for the PAA.

Mrs E.Wright and everyone in the Psoriasis group at the Hartlepool & South Easington General Hospital, who raised £100.00.

Also thanks go to Kate Heath,who also raised some funds by selling some craft work that she had produced.

Thank you to all of you who also send in alittle extra with your "Subs". It really does help us as funding is so limited and we are not in a position as yet to engage the services of a paid member of staff,namely a professional fundraiser.

IT'S YOUR OWN FAULT!!

Or so it seems from the advice I have been given by so many well meaning friends and acquaintances. There doesn't appear to be a single form of arthritis that can't be cured by some simple and usually very peculiar remedy.

I was diagnosed as a Psoriatic Arthritis sufferer just two years ago. From an initial very painful bout of Tennis Elbow,in June 1992 the disease developed to a full blown polysymmetric distribution by the year end.

In January 1993,the diagnosis was confirmed. Since then,I've spent 12 days in my hospital rheumatology ward. Medication has progressed from NSAID's to include suphasalzone...stopped because it produced horrendous headaches and nausea.. Auranofin, (Gold in tablet form),again stopped because that produced the most antisocial flatulence,diarrhoea and griping abdominal pains!

I am now in the throws of gold therapy by intramuscular injection. A weekly jab in the bum,and all the concurrent tests. So far...so good.

Against such a background of pain and anguish,shared by many of us I am sure,who among us wouldn't prefer an easier option?

So WHAT'S ON OFFER??

Well,it deserves to be known that for the seven years prior to being "stuck",my wife and I had the good fortune to be working abroad as Resident couriers for an English camping company. Our new found active outdoor life was supplemented by,yes,cod liver oil. Vitamin B too.

And,would you believe,we ate mussels,barbecued mackerel,and barbecued sardines until they came out of our ears and enjoyed an extremely good generally balanced Mediteranean diet. It also has to be said that we were at our fittest at that time too. At least,much fitter than I'd been as a teacher,with our lithe and tanned bodies at a time mighty close to our sixties!! (I now have the pleasure of being in my 61st year).

It was only after diagnosis that I realised that I actually had psoriasis. In my case,it was only evident in the winter...the summer sun and abundant UV definitely keeps me clear.Well,in the exposed areas at least!

Mike Elliott. His diary follows next.....

CASE HISTORY: MIKE'S DIARY

JUNE 1992: Tennis elbow, to which the experts have since said I was probably "predisposed" I was working in France at this time, doing fairly physically demanding work. By July I had to see a local doctor.

AUGUST 3: Referred to local rheumatologist for corticosteroid injection.

AUGUST 10: 2nd injection and by this time in full season, found it impossible to continue work and returned home to U.K.

SEPT/OCT: with continuing physio on the elbow, the increasing pain levels in my fingers were being monitored, as well as the general spread of pain in my joints. By mid October polyarthralgia was the given name, and blood tests began.

1993

JANUARY 14: local hospital rheumatologist diagnoses PA by symptoms and presence of psoriasis. In any event already prescribed NSAID's. ALSO 3rd injection in elbow.

JAN 28: return visit.

Treatment continued (physio, drugs etc, under direction of GP) Pain levels in both hands and right shoulder ever worsening. Right knee giving more bother.

APRIL 20: same elbow bursa swelling drained after no response to support.

MAY 27: right knee extremely swollen.

JULY: by mid July, both feet were giving great pain and walking was therefore very limited. By the end of month referral by GP to Southampton General Hospital Rheumatology Department.

AUGUST 23: Visit to Dr: Soton General.

OCT 8: to S.G.H. as patient for 12 days. Blood tests, hydrotherapy, physio, "education" programme re-nature of disease, plan for living, exercise routine established, x-rays, chiropody ("Bars" fitted for shoes) and two injections in right shoulder. Follow on-hydro and change from Voltarol to Indomethacin.

1994

JANUARY: by now general pain across shoulders as well as increasing pain generally on left side of body, (emphasis swing from right to left). Found even more frequent need to retire to bed, a situation gradually worsening over time. In any case, fatigue has been an ongoing problem.

JANUARY 24: S.G.Hosp.

FEBRUARY 21: S.G.Hosp. left shoulder now very painful and becoming "limited" as is the right.

JUNE 13: S.G.Hosp. on to suphasalazine and right inguinal hernia identified.

JULY 27: stopped taking suphasalazine (bad headaches, nausea) and on to auranofin.

SEPTEMBER 5: S.G.Hosp. Not possible to be given injections due to infection in big toe.

OCTOBER 6: local chiropody begins.

OCTOBER 18: routine visit to optician reveals my eye "flashes" at night due to pressure on nerves in the neck - relates to pre existing and worsening cervical spondylosis.

(occasional use of soft neck support) Especially in view of discomfort with shoulders in bed. It is difficult to know how to lie.

OCTOBER 27: recommended from last visit S.G.Hosp.increase gold tablets by 1/day. Left hip also now painful.

NOVEMBER 14: GP gave corticosteroid injection in left shoulder (via SGH).

DECEMBER 9: SGH - off auranofin (excess diarrhoea,abdominal pain and flatulence!). Now having gold by intramuscular injection at my GP's surgery. Weekly urine tests - monthly blood tests-- so far so good!

1995.

I still suffer with neck pain in both shoulders "frozen",mildly painful elbows,both hands have swollen,stiff fingers,with swollen "nodules"? in the palms,left wrist stiff with pain,left hip pain,left ankle pain,both feet with "met" pain (special insoles worn) all toes on both feet are very painful.

The Psoriasis is mild in my scalp with small plaques on my chest,currently large plaque in groin/scrotern area,with cracks and splits between and under toes (occasionally similar under right ear lobe!)plaque type on soles and nail deformation on toenails, finger nails show slight signs of "pitting".

Next visit to S.G.H. - April

Mike Elliott.

Thank's Mike,if only people realised just how much time we spend backwards and forwards,from pillar to post,from Dermatologist to Rheumatologist,to GP and various other clinics,not to mention the Chemist,I think they would have a shock!

LETTERS LETTERS LETTERS!!!!

Dear David,

I am now on Methotrexate and Suphasalazine. I wish it was one or the other. The Methotrexate is clearing my Psoriasis but not fully,so I try to pretend that the Psoriasis doesn't exist!

16 years of arthritis is trying at times. People think your o.k. because you had a hip replacement in 1991 and a knee in 1994,but the disease just progresses elsewhere with the spine,neck and hands causing frustration,sleepless nights and days unfulfilled,because your too tired to go out,unable sometimes to concentrate on conversations or to write a letter.

The degree of psychological-social morbidity that accompanies Psoriasis (and for that matter PA) is commonly underestimated - "yeah I agree".(BMJ Vol.303 Oct.1991).

Consultants see you,evaluate your needs in their eyes,then shake hands and give you an appointment in 6 months. Meanwhile you cope with the ups and downs. Luckily for me the Rheumatologist has just opened up a day clinic with a resident rheumatology nurse. I should be able to phone her for an appointment and be seen hopefully within days. I just hope that money keeps coming in to keep the idea going.

I suppose that at the moment I am a pessimist about the NHS. Reading the Guardian,watching TV and listening to Radio 4 does nothing to alleviate my worries.

If you publish this short letter then it might help Rheumatologists/Dermatologists and

I know that this form of arthritis is difficult to recognise but perhaps GP's should be made more aware of this painful and disabling arthritis. Perhaps the good work that the PAA is doing will achieve this. I also look forward to making new pen pals,so get writing!!

Yours faithfully,
Patricia Court
45,Abbotsford Road Attleborough,Nuneaton,Warwickshire,CV11 4RG.

Dear both,

Have any trials been done on the benefit of massage with sesame seed oil? My back and legs are much better and the psoriasis,it hasn't gone but it's not as inflamed.

Could you organise double blind tests? Also I believe comfrey oil is very good – but more expensive.

Barbara Mason,Scotland.

Dear Julie,

.....

I am returning some of the samples as they are things I would not use:-

1. All oily bath additives:

I tried some of these last year. They make the bath slippery! I have osteoporosis and do not wish to risk a fall in the bath. Also they left thebath very dirty and difficult to clean.

2. Meted Shampoo:

Tried it last year. Very bad! Left my hair dry and brittle and difficult to curl.

3. Hydromol: Tried it,did not like it.

4. Wash E45 : Tried it – horribly oily.

I use Alphosyl cream and Alphosyl lotion,which I get on prescription – but are probably available without one.

They are the best remedy I have ever used for psoriasis and I wish you would recommend them to other people even if you have not got samples.

Also for ordinary hand care I find Weleda Iris Handgel by far the best.

Best wishes,
.....Member,Kent.

The views and opinions expressed in this newsletter are those of the members and authors. They do not necessarily represent the views or policies of the Psoriatic Arthropathy Alliance. The "Letters Section" is included for information,debate and free speech and the Psoriatic Arthropathy Alliance remains totally neutral in all respects.

others understand that there's more to the person than their joints and skin. The whole person, their families and any other illnesses along with underlying political confusion should be taken into account.

Barbara Bone.

Dear Both and everybody in the Alliance,

Let me change the subject from blotchy skin and aching bones to greet you all and perhaps give you a bit of hope from Aberdeen. There is life with PA.

I love life and there's so much to do. My only draw back is I've not enough energy to do all I want to. Today the sky is blue and clear and with two pairs of trousers and a very thick jumper - I'm going jumblin' this afternoon. I've got a rucksack with a seat attached so I can sit down in the queue. This aside, when you see grey skies they depress you, think of it not as grey but a beautiful mix of blue, yellow and crimson. This does help.

Light is so beautiful and it's free and we all have windows and doors.

IT'S A BEGINNING

Love is not love
which alters when it alteration finds,
Or bends with the remover to remove.
Oh no, it is an ever-fixed mark
That looks on tempests and
is never shaken.

Barbara Mason

Dear David & Julie,

I would just like to say thank you for all the information and samples that you sent me, they were very useful.

I am now in my forties and have suffered with psoriasis since the age of 12. It is now after years of treatment in a mild state. I have also suffered with a very stiff and painful neck for a number of years. After various visits to my GP I was told it was rheumatics, given pain killers and sent away.

However last October, after suffering from a chronic back strain injury I was made redundant from my employment. One month later my index finger started to swell and then both of my knees followed suit. I was in a great deal of pain and was taken to my GP. I hobbled into the surgery (I resembled the tin man from the "Wizard of Oz"). I was told I could have rheumatoid arthritis and sent for blood tests. I went home to rest and took Naprosyn I had been prescribed. Whilst at home I picked up a magazine and started to read various letters. One which took my eye was from a lady who had heard that arthritis and psoriasis were linked. I was amazed for I was quite ignorant of this condition.

I returned to my GP to be told that there was no rheumatoid factor in my blood. I then mentioned psoriatic arthritis to my GP and she confirmed the link. I was eventually sent to see a rheumatologist and my own diagnosis was confirmed.

Six months on I have been given indomethacin, and now votarol but I find it hard to tolerate these drugs. I am now still in a great deal of pain and I have to use a wheelchair for shopping and other outings.

I was told by my rheumatologist that my stiff neck was perhaps the onset of psoriatic arthritis, but had been overlooked. The onset of my severe arthritis I think could have been due to the stress of my redundancy.