January 1994

THE PSORIATIC ARTHROPATHY SUPPORT GROUP

136,High Street,Bushey,Herts,WD2 3DJ.
0923-672837

NEWSLETTER: 2

A VERY HAPPY 1994 TO ALL OUR PA MEMBERS.

Both Julie and myself would like to take the opportunity of thanking all those of you who kindly sent us Seasonal wishes,it was nice to be remembered,and to wish you all a very happy and hopefully painfree as possible New Year!

NEW YEARS RESOLUTIONS?

~~To consider and not to be broken in a hurry!!~~

1. To take more care of myself and not get too depressed when the going gets tough;
2. To see my G.P. for a referral letter to a Rheumatologist and Dermatologist to get assessed (if not already done so) and to keep up-to-date with new medical treatments for both the arthritis and skin psoriasis.
3. To go regularly for check-ups.
4. To keep as mobile as possible.
5. Not to give my wife/husband and families a hard time when things are getting to me. It's easy to bite the heads off the ones you love!!
6. To ask questions about my illness,my medication,my treatments/options, because at the end of the day it is me who has to live and manage the condition,and my quality of life is what is important. I can only achieve this by having my questions and worries answered,so I will be tactful but assertive too when attending appointments.It is my right to be treated with respect as a human being,and to receive correct and appropriate treatment.
7. Acceptance of my illness is half the battle fought and the start of a more positive attitude to life.
8. Channel your energies,why not get more motivated in the Group.You might be surprised at what you can do and achieve!

APOLOGIES:

With regard to our recent News Journal,it was clearly pointed out to us that on the back page in the "Special Acknowledgements" section we had made a mistake. We printed "The British Society of Dermatologists". They are in fact known as "The British Association of Dermatologists". We apologise for the mistake and trust no inconvenience was caused.

Membership Packs

Some of you have experienced longish delays in receiving your membership packs,and these were caused because we were waiting for stocks of certain items.Hopefully you should have all received these by now. Sorry it took us so long.

MEMBERSHIP RENEWALS

For some of you membership renewals will be coming up again in a few months or so. We would just like to say it has been nice having you as part of the Group,and very much hope you will decide to join us for a further year,in which we hope to be able offer you more services .

MISSING PERSONS ALERT!!

Can you believe this I have actually misplaced a member!! Anyone who has been in touch with Ricky Ahmed lately could you please tell him when you next get in touch,to let me have his new address otherwise I cannot send him anything!!

Thanks.

CHANGE OF ADDRESS:

Please don't forget if you move to inform us of your change of address and telephone number. Thank you.

MEETING

We would like to start thinking about arranging a meeting with guest speakers on PA and Psoriasis for sometime next year. This can only be done if there are enough of you willing and interested in attending a central location.

Firstly, is there anyone willing to take the task of arranging such an event with ourselves?
Secondly, would you be prepared if we can arrange a venue to pay a reasonable cost for tickets as unfortunately Group funds cannot carry the whole burden of the costs at this stage in time.
Thirdly,we would like to hear from you all as to possible locations for such an event to take place.
Lastly,would you be interested in overnight accommodation if reasonable rates can be negotiated?Would it make it easier for you to attend if the location is not central for you.

We would like to have your imput please on these points,because if there is not interest shown in this idea then there will not be much point at this stage in arranging such an event. It'S UP TO YOU TO TELL US WHAT YOU WANT.

STOP PRESS!!

In February we hope to be bringing you news of a very important launch that is being planned,which concerns all of us who suffer with skin problems of all descriptions in a special news bulletin.Important things are taking place.

MEMBERS PAGE.....LETTERS,LETTERS!!

Dear PA Support Group,

I have had Psoriatic Arthritis for 9 years,and for the past 3 years have had a particular problem with my hips for which,as yet,no-one has been able to give me a diagnosis.

I have had my hips X-rayed and have been told that there is no deterioration of the hip joints. My G.P. thinks that it could be a problem with the connective tissue ie. the tendons,ligaments around the joints,becoming inflamed and shortened. This condition results in my walking being severely impaired by my hips being pulled off to one side. This puts great stress on my back,knees and feet.

It seems to have the medical professionals that I have had consultations with baffled. I would therefore,be interested to know if anyone else has this same problem and has had it diagnosed.

Mark Robson,
6,The Close,Prudhoe,Northumberland,NE42 5HY. (aged 25).

PREGNANCY & PA a members own account.

Dear David & Julie,

I developed scalp psoriasis aged 13,although it was diagnosed then as sebhorrhoeic dermatitis (1961),my mum was given some awful sulphur type ointment to rub in. I coped with my scaly scalp quite well through my teens and managed to hide it from most people,even friends. I remember using Lenium shampoo,but never had much help.

At around 23/24,I noticed small reddish circular areas under my nails,I didn't know that it was also psoriasis at first,until a Consultant finally confirmed this.

At age 25 I was pregnant,and after several months my scalp cleared completely! The only time it has been clear,so I think in my view there must be a hormonal link,and that high levels of hormones (oestrogen?) in women would possibly help in this way.

After my daughter's birth in 1974 I began to develop pains in my fingers and toes. I had been breast feeding and was abit run down. My G.P. suspected PA and this was confirmed by a Rheumatologist.

I am now 45 and have PA in my fingers,knees,toes and ankles and tend to have little flare-ups and remissions. I have found Rheumatolgists quite dismissive of PA,and as I cannot tolerate N.S.A.I.D.'s I get pretty fed-up.

I definitely think that pregnancy,or the natural fall in hormone levels afterwards,caused the PA to begin in my case.

One thing I have found is that strong hot sun can help my nails and fingers quite abit,but unfortunately my doctors will not let me have any ultra violet treatment and for the time being are proving alittle unco-operative on this course of action.

Janice Johnson,member,Scotland.

PREGNANCY.....

Another member has wrote in to say that whilst during pregnancy she was virtually clear of her psoriasis which she has suffered with for several years,but as soon as her child was born the psoriasis came back in full force. Even whilst taking the contraceptive pill she was clear. Later in life she was unfortunate enough to have a major operation,and it all flared up again.

Again our member feels like Janice that there could be a hormone connection to this,and how much does stress play a part in this puzzle?

THE LAST WORD:

From what we can gather talking with professionals and members comments, pregnancy and PA is unfortunately a gamble as to how the individual will fare,because PA is complex and no two people are exactly the same with PA,doctors are unable to say for sure if the PA will get worse or better during pregnancy. Not much help I'm afraid.

We leave this subject for now but we will be looking in to it more hopefully from the professionals point of view in the future.

YOUNG,FREE & SINGLE and living with PA!

Dear PA,

I am 29 years old,single and love sports and feel robbed of my youth sometimes,just when I get alittle down. I was diagnosed as having skin psoriasis in 1985 and PA in 1990. Last year I started using Dovonex ointment,which this I have found to work really well for my skin and controls the psoraisis to the extent that I almost forget I have it.

In 1990,one of my toes on my left foot became swollen and since then has become arthritic. More recently the toe on my right foot has also become swollen and looks like going the same way as the other,which makes it quite painful to walk and play sports.

I have considered having my feet operated on to try and reduce the pain and inflammation and have tried Surgam,which helped to reduce the pain and stiffness,although I am now on another drug.I am also trying a special diet with no refined foods and plenty of Cod Liver Oil (YUK!),Evening Primrose Oil,Selenium & Vitamin supplements and plenty of Wholemeal foods.

My outlook on life has changed,and I am not as spontaneous as I was but my philosohpy is Life Goes On,it's no good moaning and groaning,I can't put my life on hold just because I've got PA. I used to play a variety of sports,but now I have taken up less demanding ones.
I am not bitter about PA just annoyed,unlike skin psoriasis,I can't forget I've got PA because of the constant pain.

Ricky Ahmed,member,whereabouts unknown at the moment!!
If you would like to reply to his letter please send them to the office and once I track him down the letters will be passed on. Thanks.

Please keep your letters and contributions for this page coming in,we would all like to hear of your experiences and accounts.Even if you want a moan and a groan this is the page to do it!!

CASE HISTORY:

MY STORY OF PA

I first visited the doctor in October 1990,when two toes on my right foot became very painful and began to swell up to the extent that I was having difficulty walking. The doctor was about to prescribe painkillers when he asked if I was pregnant. I told him that my husband and I had been trying for about a month but I wasn't sure.So to be on the safe side the doctor arranged for a blood test which confirmed that I was pregnant. Obviously this meant that I could not be prescribed any drugs and the doctor advised me to take paracetomol if the pain got any worse.

The pain did get alot worse and over the next few weeks spread to my knees,back,elbows and fingers. It was a very difficult time as I already had my young son Ben to look after. The general lack of energy I felt was incredible,it was total fatigue. I would go to bed at 8.30pm and when I awoke next morning it would be as though I had never been to sleep. Every time I moved when I was asleep the pain would wake me up. My body seemed to sieze up overnight and I would soak in a hot bath in the morning to try and get my joints moving before going downstairs,usually on my bottom.

Initially I lost my appetite. I tried various diets which didn't help much but made me very constipated. I went back to the doctors,desperate and tearful. Although I had alot of support from my husband and family I just felt that I could not cope. The doctor made an appointment for me to see a Specialist.

The Specialist advised me that my condition was Psoriatic Arthritis and recommended drugs. Being pregnant I refused to take any as I did not want to harm my baby. No other treatment was offered. In desperation I turned to alternative medicine and was treated by an ortho-bionomist and this did offer some relief,although it had to stop when I was 5 months pregnant as I could not lay on my stomach.

I gave birth to my daughter Amy on 6.7.91. The arthritis seemed to improve. I went back to the doctors to ask about taking drugs to help me and was prescribed Naproxen,which I took for several months,although there seemed no improvement. I was still in alot of pain,even my jaw began clicking and my knees were very swollen and full of fluid. To walk my son to play group would exhaust me for the rest of the day.

I returned to see the Specialist in February 1992,to see if there was any other treatment I could have. He suggested more drugs and that I exercised more and lost weight. (I was still 2 stone overweight from carrying Amy).

I put myself on a low fat diet. Someone recommended a high dose of Evening Oil of Primrose so I began to take 3000 mls a day and two teaspoonfuls of Cod Liver Oil. I began to have a feeling of determination to beat this. I tried to go swimming 2 or 3 times a week doing 10-15 lengths each time. At this time I also started to use T-Gel for the Psoriasis on my scalp.

In March 1992 I went to the Ideal Home Exhibition with my mum. Although I could not walk around for more than half an hour I was determined to go. One stall was demonstrating an electric massage machine used to restore painful joints etc. The man demonstrated on my right leg,which was the worst. (I was now walking with a limp). After the treatment I felt that I could bend my leg a lot easier and was able to walk around the exhibition for two hours with ease. I was considering buying the machine even though uit cost £200.

From then on each day my condition began to improve and by the end of May 1992 I was about 90 per cent clear.

Today I am totally clear of PA and I try to stick to a healthy diet,eating plenty of fruit and vegetables and few sweets and I am now able to participate in a steps class each week.

The doctors don't know if the condition was connected with my pregnancy,i.e. a hormone imbalance,and I will never know what actually cured it,but if there are women who are pregnant and have developed this condition do not despair. It is not inevitable that you will have it forever. DON'T GIVE UP HOPE.

Julie Whitelaw,member,Bushey,Herts.
Many thanks to Julie for telling us about her story.

We would like to print some more case histories so please like Julie pluck up the courage and write to us. If you wish to remain anonymous that's fine.

HAIRDRESSERS

Many of you suffer from scalp psoriasis like myself and are only too aware of how embarrassing it is when you visit the hairdressers or the barbers. It takes me weeks to pluck up the courage to go and is such a relief when I have been.For me it's worse than a trip to the Dentist and that says something!
We thought it may be a good idea to try and build up a record of hairdressers and barbers around the Country that you find understanding and comfortable with. If you think this is a good idea please send us your canidates,their addresses and telephone numbers . Thanks. (David).

PLEASE NOTE:

In April,we are expecting the arrival of our first baby,so the day to day running of the group will regretfully be alittle disrupted until Julie gets back on her feet again to deal with all the correspondence etc. All correspondence will be answered but we apologise as it may take alittle longer than normal. With regard to telephone enquiries,again these will be dealt with in rotation as and when we can,but if you have an urgent query these will be handled as quickly as possible,but please state if they are urgent. Both Julie and myself apologise for any inconvenience that may be caused,but hopefully it will only be for a short period of time,and the work of the Group will not cease because of our personal circumstances,we are as determined as ever!

Julie & David Chandler
Co-Founders.

THE PSORIATIC ARTHROPATHY ALLIANCE

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Tele/Fax: 0923-672837

Sept 1994 **NEWSLETTER: 3**

NEWS UPDATE!!!!

What have we been up to,well quite alot. 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 it's 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,aggrevated by my reluctance to see a GP and my persistant 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 womans refuge. Within weeks the psoriasis disappeared but the arthritis esculated 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 abit 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 psoraisis 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 01%.

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. Predominent involvement of the distal interphalangeal joints. The disease often starts in the toes. Other joints may become pregressively 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 psoraisis 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 rhematoid arthritis. Eye lesions are common; conjuctivitis 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 steriod 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 not withstanding 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 deterioation.

Doreen Miles,Member,

Doreen's comment: I wonder how many PA sufferers would agree with the last statement,though everyone has there own "pain threshold". I took early retirement as I could not stand and work all day due to the arthritis in the scaro-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.

PSORIATIC ARTHROPATHY
ALLIANCE
136,High Street,Bushey,Herts,WD2 3DJ.
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 imput 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 disucss 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 Athropathy 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 Thaiiland 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 hisotry 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,kness,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

Individial 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 suoerficial 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,nopnsteroidal 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-efffect 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 accidently 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: There 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,oiley creames 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 fo the Guide dogs, they were very much appreciated.Please keep them coming.

Thank you to everyone that has sent in alittle 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

Alot 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 him if he would kindly add it to your prescription. These items can work out cheaper this way,although ask you 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:		BLUE LINE - Sensitive/Normal Skins	
Emulave Fluid (liquid soap)	£ 7.50	Regular bath additives	£9.96
Emulave Cleansing bar	£ 2.47	Aveenocream (moisturiser)	£4.92
Oilated bath additives	£ 9.69	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

This Newsletter has been kindly copied by Bioglan Laboratories Limited, Hitchin

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 benefical 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 phyiscal 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 imput 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 alittle 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 Discrimation 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. Alot 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 mammouth 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,it's 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 aquaintances. 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 Arthrits 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 suphasalzine...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 on going 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 suphasalzine and right inguinal hernia identified.

JULY 27: stopped taking suphasalzine (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.

CCTOBER 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 piller 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 Suphasalzine. 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.

others understand that theres 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 jumbling 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 its 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.