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.