

PAA

PSORIATIC ARTHROPATHY ALLIANCE

P.O.Box 111, St Albans, Herts, AL2 3JQ. Tel/Fax: 01923 - 672837

Registered Charity No: 1051169

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NEWSLETTER 7.
SEPTEMBER 1996

NEW ! FUNDRAISING NEWS



PROMOTIONAL PIECES FOR THE PSORIATIC ARTHROPATHY ALLIANCE



"SANDWICH CAT"



"SONNY THE BEAR"

Both available from the PAA now
both priced at £6.95 each plus £1.50 p/p.

Cheques made payable to
"Psoriatic Arthropathy Alliance" please.

JUST LOOK AT THIS ...



COLOUR BOX MINIATURES have kindly
donated this breathtaking, very fragile
Limited Edition piece of 750 called
"Leopard" from their Teviotdale range for
the PAA Conference at Woburn in
September.

We hope you will be supportive and enter the
raffle.

We would also like to take this opportunity
of thanking Colour Box Miniatures for their
very generous support in donating this
spectacular piece to help further the PAA's
work.

CONGRATULATIONS . .

David earlier this year was nominated for the
John Doyle Achievement Award.

I'm very proud to announce that his
nomination was successful and he will be
presented with this award in October. On
behalf of all of us at the PAA, well done.

The Psoriatic Arthropathy Alliance is a registered national Charity
dedicated to raising awareness and helping people with Psoriatic Arthritis
and it's associated skin disorder known as Psoriasis.

"THE EFFUSION"

by Gillian Rowe, Ireland.

I never know if I have a mechanical problem or a medical problem, both seem to arrive together.

Apart from the back pain, general exhaustion, I have now developed a small effusion on my right knee.

This diagnosis coincided with the failure of my car engine to stay alive. Each gear change produced various warning indicators, to blaze on the instrument panel.

Approaching traffic lights the engine died, while the "Blackpool Illuminations" emerged. Eventually I pulled over and flicked the bonnet catch. Peering into the gloom, the engine, air filter, battery, and spare wheel were in their usual positions. Closing the bonnet I started to ponder, as the sodden squalls arrived. Perhaps this problem was not mechanical, but medical? With my right knee giving severe pain, I may not be assertive enough on the accelerator, so that was

my next line of investigation. Restarting the car I pounded the pedal. Slipping the clutch as if in a Grand Prix, the car bolted to life, and for the first time I knew the meaning of 0-60mph in 60 seconds!!

As the speedometer exceeded the speed limit, the dealers garage came into view. Drawing into the garage, I stationed the car outside the ashen roller shutters of the service bay. The Blackpool Illumination did not engage, and the engine resumed its natural tempo?

Weaving my way into the service area, I acknowledged a sensation of familiarity. The bays were occupied by cars, each surrounded by black panel padding, in case a mechanic dropped a spanner or scratch the paint work. The place was spotless. Not a drop of oil or knob of grease, stained the sapphire sterile floor. Each bay had its own tiered vermilion tool box, shimmering under fluorescent tubes. The mechanics wore cobalt boiler suits, crisp, clean and sharp. They manoeuvred around the cars, with

various clipboards, spare parts, and lint free cloths, as if in a customary waltz. I am not medically minded but I am mechanically minded, and found myself drawing a parallel. If I was a car, I would be suffering from an oil leak!

The service engineer approached while I was still thinking. Turning to him I said "I think I have an oil leak?" Stepping to the VDU, he inputted the year of the car, and the screen displayed various charts. Turning he shouted "Exactly where is the oil leak?", throwing my head in his direction I replied "My right knee!".

Oh how I wished I was a car! They could have laid me on the ramp, covered me over, except for the offending part, disconnected my swivel ball joint, replaced my worn seal, topped me off with lubricant, and I would be rejuvenated, even pain free.

Looking at Danny contorted under the dashboard with a swarm of wires, I wondered if he ever considered becoming a neurosurgeon?

PAA

CONFERENCE



**Being held this year at WOBURN
WOBURN SAFARI PARK
BEDFORDSHIRE**

Saturday 21st September 1996

Come along, it's going to be a good day, let's see you all there.

Kick-off time 10.30am

**Your chance to talk to the experts, they're friendly,
and they don't
bite!**



Speakers:

Dr. Douglas Golding, Dr. Neil McHugh, Dr. D Veale, Dr. Tony White

Exhibitors & Dermatology demonstrations

ADMISSION FREE

A wife's view

With hindsight, the origins of John's PA go back many years.

He tells me that he had psoriasis as a child, but I wasn't around then, and it had long cleared when I met him. Both his father and his paternal grand-father suffered from arthritis, the latter's starting in his mid-40s. I don't know what type of arthritis they had.

During the early years of our marriage John appeared to be perfectly healthy, except for one thing - about three or four times a year he would have violent bilious attacks, usually during the night. It was clearly not caused by food poisoning, as more often than not he had eaten nothing that I hadn't during the preceding day. A barium meal and X-rays revealed nothing amiss, so we just had to put up with it.

About 15 years ago, I began to visit an Acupuncturist with the aim of alleviating my severe tinnitus. The treatment eased the tinnitus to a very great extent, and also perked me up amazingly - I hadn't felt so well for years, and the resulting energetic approach to life highlighted the fact that John, too, was perhaps a little lethargic.

As a result, he consulted the Acupuncturist, who achieved similar results. We both continued to have treatment at regular intervals (roughly every six to eight weeks) for the next 14 years. One benefit of the treatment for John was that his bilious attacks ceased, and he suffered far less from indigestion than before.

We were, during that period, playing squash to an amateurish standard once a week. The first sign of John's arthritis came seven years ago when he was forty-one, and he complained that his right wrist was painful. This wrist was injured at the age of 8, when he was participating in a sack race at school. The pain persisted, he was forced to give up playing squash, and after six weeks he visited his G.P. who told him to go away.

We weren't satisfied with this; in view of the fact that John had visited the G.P. only once in ten years we thought it was obvious that he was not given to fussing, and that the problem was serious. He therefore consulted another Doctor in the practice, who was much more sympathetic (he also played squash!) and was sent for an X-ray. This revealed nothing amiss, so John was sent to have physiotherapy, was

given a wrist support and told to see how things went for a few months.

Six months later the wrist was no better. John revisited the sympathetic Doctor (by this time we had both transferred to his list) and he was referred to a specialist in physical medicine. Diagnosis was then very swift; the specialist asked John if he had scaly patches on knees or elbows, to which he replied no, but he had an itchy patch on his head which had been there about a year. Thus, we found out the problem, and were told that all he could be offered were anti-inflammatory drugs.

So things went for four years or so, the acupuncture continued, John's psoriasis spread further over his scalp and the arthritis spread to most other joints. A year ago he couldn't get his shoes on without a shoe-horn and, on a bad day, could barely walk. His shoulders deteriorated to the extent that he could not drive a manual car and he changed to one with power-assisted steering, automatic gears and electric windows.

The Acupuncturist was deeply concerned; he consulted colleagues, some of whom were using Chinese herbal medicine in conjunction with acupuncture. John tried two separate medicines in succession; both made the arthritis very much worse at once, and John took some while to recover from each.

We then wondered; if something ingested could worsen his condition, was it perhaps caused by something he was eating or drinking; i.e. a food allergy. (We were already aware that hot dairy products such as cream or cheese would make John faint and shivery; the last time he inadvertently ate some soup containing cream, he collapsed and had to be laid out on our friends' settee!)

The sympathetic G.P. came to the rescue again; he is the sort of person who always "knows a man who can"! He referred John to a Doctor in Salisbury who, although being a conventionally qualified G.P., specialises in allergy testing and homoeopathy. The testing was interesting; it is done electronically by skin electrical activity, incidentally utilising acupuncture points!

John was given a list of foods to avoid: all cow-dairy products (goats' milk and

cheese are fine for him, so we changed to those), red meats, citrus fruits, tomatoes and some other vegetables. In the main, this reads very like the Margaret Hills diet, doesn't it, except that John isn't allowed to have lamb. We wonder if these allergies caused John's earlier digestive problems. Fortunately, he is not allergic to tea, coffee or alcohol!

Homoeopathic medicine was also prescribed for John to take daily. This we feel is more acceptable than using conventional drugs over a long period.

This was in March 1995 and we set to to follow the diet strictly. John has had three subsequent visits to the homoeopath. The medicine has been changed in response to John's progress report, and the Doctor's manner has always been very reassuring as he is confident of success with just the right treatment. Although his services are not available on the N.H.S., he is registered with various Health Insurance Companies and so his moderate fees are recoverable.

Well, John has had his ups and downs, but after nine months of the diet and treatment his psoriasis was still just as wide-spread but very much milder - I have cut his hair for twenty-two years, so I know exactly how it's doing. The arthritis, too, is less vicious; over Christmas he was walking in his old, easy way and I quite forgot he had a problem on our weekend afternoon walks. Despite the recent cold, damp weather which has affected him adversely, we hope that the improvement will continue.

Over the last year John has embarked on learning to play the Organ - we have one at home that I play. John has never learned the piano so he had to start from scratch, but I am sure it has done him a world of good in keeping his hands and wrists moving and in exercising his feet and ankles. Not only that, but John has had to curtail other hobbies besides squash - we had an old Land Rover which we had to sell as John could no longer drive it, let alone tinker with it and take the engine etc. out as he used to! - so it has been good for him mentally to have a stiff challenge in the form of an enjoyable hobby.

Mr & Mrs Gopsill

DATES FOR THE DIARY:

24th-26th SEPTEMBER 1996

NAIDEX (National Aids for the Disabled Exhibition)
WEMBLEY CONFERENCE & EXHIBITION CENTRE
Empire Way, Wembley, Middx, HA9 0DW

The exhibition provides an opportunity for professionals and those who have some form of physical disability, to see and try out new aids and equipment.
Free Seminars on various topics run throughout the show, including "Care of the Arthritic Hand" (Tuesday 24th September 10.30am - 11.30am)
Further details/advance details: Reed Exhibitions Tele: 0181-910-7873 or 01844-262728

10 o'clock start

2nd NOVEMBER 1996, SATURDAY

GENETIC INTEREST GROUP
St.Alban's Centre, Baldwins Gardens, London EC1

Lunch, tea and coffee provided.
Voluntary charge of £5.00 to help cover costs of catering, hall etc.

Talking to your children about inherited genetic conditions can be difficult, with seemingly no correct or good way of doing it. The aim of this event is to give parents the chance to get together to discuss and explore this issues, as well as sharing ideas and proposing solutions.

Should be an interesting day. All are welcome.

Further details/booking forms can be obtained from Ms Jennifer Wiggins,
Children's Project Officer,

Genetic Interest Group, tel: 0171-430-0090 or enclose S.A.E to her at
GIG, Farringdon Point, 29-35, Farringdon Road, London EC1M 3JB

Alternatively, S.A.E. to the PAA office who will also be happy supply you with details.

Parents workshop

5th-7th DECEMBER 1996

PSORIASIS From Gene to clinic
London

An International Congress for medical professionals organised by Prof. Christopher E. M. Griffiths, Hope Hospital, Manchester and Jonathan N.W.N. Barker, St. John's Institute of Dermatology, London.

DECEMBER 1996

PAA News Journal.

What's New ?

NEW PRODUCT LAUNCH . . .

Bioglan Laboratories, the makers of the well known Aveeno range and Cocois scalp application, have now launched a new emulsifying ointment called "EPADERM".

It is indicated for general use as an emollient to moisturise and soften dry skin. Active ingredients being yellow soft paraffin BP and emulsifying wax BP, and does not contain any colourants, preservatives or fragrance.

Epaderm is easily applied, less tacky than some formulations and is easily washed off, and dissolves readily in hot water. Some conventional soaps can be alkaline, causing irritation to sensitive skins, thus Epaderm could be a useful substitute.

ELECTRICAL PRODUCT INFO PIFCO Model 7701 HEALTH WAX BATH

Suitable for home treatment to aid in the relief of osteoarthritis, rheumatoid conditions etc, and can be used on the hands and feet.

Comes complete with wax, thermal pouch, spatula and a comprehensive booklet.

*Available from Argos Superstores
priced £99.00*

Manufacturers do recommend though that this product should not be used on open sores, cuts, hot and swollen joints or during a Raynauds attack if you suffer from this condition.

If in doubt about any product you fancy trying, please consult your doctor or physiotherapist before purchasing this product, just to make sure it is suitable for your needs and will not cause further unnecessary damage.

News in Brief

IMPROVING DECISION MAKING AND APPEALS IN SOCIAL SECURITY

Earlier this year the Secretary of State for Social Security announced plans for radical reforms in its business procedures, which included a review as to decision making and appeals arrangements, and a consultation document outlining such proposals was published in July of this year.

The PAA has been sent copies of the Summary document for the Consultation paper for any comments we would like to put forward.

Any member wishing to receive a copy of the Summary paper please send a large SAE to us. Any comments, suggestions, proposals will be noted with a view to a formal response to the Department of Social Security before October 1996.

HELP . . . The PAA needs you . . .

Our plea still stands for TRANSLATORS please. We need information translated from Swedish, Dutch, German, French into English on a regular basis, and to write reviews from information sent on what's happening around the World, so anyone willing to help out with this or some part of it would be hugely welcomed, besides it's a really interesting challenge!!

Lottery Round Applications

As you may be aware we are eligible to apply for a Grant from the National Lottery Board, as this round covers disabilities and research.

The PAA has lodged an application outlining in detail its plans to develop regional contacts around the Country, which will be overseen by a full-time national Co-Ordinator, which in turn will enable the

PAA to radically develop the Organisation and further its work quite substantially. So fingers crossed that we are successful. Failing, this it is the PAA intention, to implement this project as soon as funding and resources become available, it may just take more time to carry out. It's an ambitious plan but the PAA can do it with your support and encouragement behind us.
We'll keep you posted.

THE WORLD: JUST A BUTTON AWAY !

The PAA will soon have its own Web Site with a home page of its own. The Internet beckons !!

This newsletter is sponsored by:

 EVANS MEDICAL