PAA

PSORIATIC ARTHROPATHY ALLIANCE

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Internet site: http://www.paalliance.org

Registered Charity No: 1051169

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NEWSLETTER 8.
MARCH 1997

AWARENESS CAMPAIGN

IT'S TIME TO LET EVERYONE KNOW THE PAA IS OUT THERE – THERE IS NO NEED TO STAND ALONE ANYMORE – IF YOU HAVE PSORIATIC ARTHRITIS – WE'RE HERE!!

Anyone interested in getting involved with our WEEK (21st April-25th April) who has not already indicated so, please get in touch with either ourselves at the office or our PR Company dealing with its arrangements who are:

Ms Bonnie Green,
HENDERSON GROUP ONE
Ryde House, Ripley, Surrey, GU23 6AT
Tel: 01483 225398. Fax: 01483 211043.
PRESS PACKS AVAILABLE
direct from Henderson Group One.

PRESCRIPTIONS

Are you having difficulty getting prescriptions from your GP?

Have you ever been refused any medication?

We are currently reviewing the latest proposals on prescribing and would be interested in hearing your experiences.

Behind the scenes peek
There's more to the PAA than meets the eye

The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

Case History:

ONE MAN'S PSORIASIS

Most people do not seem to be conscious of the need for a healthy skin until they have a problem, possibly because most people seem to be able to get away with it; but for a few of us it is not so easy.

People with skin conditions such as psoriasis can invariably benefit greatly from regular doses of controlled sunlight; the trick is not to over-do it in the first instance, then find the minimum and safe number of repeat doses to maintain a healthy skin.

I have suffered from psoriasis for a number of years and for a long time it was not too serious. It spread from my scalp to a leg, then across my back at waist level, which was a nuisance, but by-and-large I ignored it. Then all of a sudden it spread to parts of my body that other beers cannot reach, including my face with bits of skin, like grit, getting into my eyes.

At this stage in the proceedings I started to panic; I did not have enough hands to scratch all the itches at once. Over a period of years I had been taking a number of medicines (highly refined mono-chemicals) for two arthritic knees.

If you take a high enough dose to effect some improvement in your condition it is usual to suffer side effects, everything from constant bad headaches, where you cannot think or see straight, to a bout of internal bleeding (not recommended).

Having worked my way through the normal list of prescribed medicines and side effects. I tried Chinese ointment for the psoriasis which cleared my skin in three weeks but returned in a further six and attended the Homoeopathic Hospital in London for a year without any noticeable improvement, in either the psoriasis or the pain in my knees.

Some sources of information link arthritis and psoriasis with the retention of toxins in the body and stress. So as part of my programme of self help, I use the "Hay System" of "Food Combining" for health, which is not a diet; you can eat as much as you like. The idea is that you "Don't Mix Foods That Fight" simply by not eating starch and protein foods together at the same meal. Eaten separately foods can be digested and evacuated more easily and your general health improved as a result.

A common and effective method of applying medication in Spain is the use of suppositories. The last few inches of your bowel is able to absorb medicine!! If it can do that; it can also absorb toxins from body waste which is held in the intestines for too long (as in constipation)!! and the "Hay method of eating" solves these problems at a stroke.

Unrelieved stress does not help digestion, arthritis or psoriasis so in addition to "Food Combining" I have taken up Yoga, because with practice it produces a feeling of peace, both in the body and mind. It consists of relaxed gentle exercise, controlled breathing, control of the mind and meditation.

Yoga represents balanced moderation; it has become apparent that there is far more to it than just performing a number of exercises slowly. I am still very much a novice, so I have some way to go before I can expect to see any tangible results, but I do believe that "You are what you eat and what you think".

I have yet to investigate and set up a vitamin routine.

At the time of my psoriasis flare-up, I was under a rheumatologist who prescribed a fairly low dose of Azathioprine (body weight 75kg; daily dose 175mg Azathioprine, ie 2 x 50 and 1 x 75mg) with regular tests to check the white blood cell count.

Having investigated the purchase of Ultraviolet "A and B" sunray lamps versus the cost of a medicinal holiday to the Dead Sea, I found the cheapest option (which was immediately available) was to go to a Health Club and use their sun bed.

I have information about UV tubes and skin sensitivity, my score being below 12 (Type 1 skin) and of Celtic origin; so I needed to exercise some care.

The sun bed has 35 100 Watt Philips R-UVA tubes (total 3.5kW/Hr) and a timer that was fixed for 20 minutes with an ON/OFF switch; the sun bed has 14 tubes in the lid with a special UV face panel and 21 tubes in the base unit. The unit also has a two speed fan to keep you cool during the session.

My information is that these R-UVA tubes have high efficiency reflectors with a small UVB output and are best suited to skin types "3" and "4"; people with skin type "2" should use them with caution!

As I am skin type "1" I decided to reduce the initial exposures to 3 x 10 minutes for the first week, 3 x 15 minutes for the second week and if there was no problem I would do the full 20 minutes thereafter. I arranged treatment on alternate days: Monday, Wednesday and Friday. Any sunburn symptoms would show within 24 hours of treatment and the sessions could be adjusted to suit. I used a cooking timer for the first six sessions and a friend to check my skin for sunburn.

After 9 treatments, ie 3 x 10, 3 x 15 and 3 x 20 = 135 minutes of 3.5kW/hr = a total of nearly 8kW over the three week period, my skin was completely clear and I have found by experiment that I need to top-up with a 20-minute session once every four weeks at the moment. Apart from a nice sun tan I am also aware that I now feel very well, better than I have felt for a long time.

The maximum number of sun bed sessions recommended by the Health Club is 20 per year! I would expect this to be safe for the fairest skin. If you ignore the initial burst of treatment to get the psoriasis under control, my subsequent maintenance dose of once every four weeks is well within the arbitrary safe recommendation.

Sun bed statistics:–

20 minutes on a powerful high-pressure sun bed is the equivalent of up to one hour on a Mediterranean beach.

As a general guide, no one should have more than 20 sun bed sessions a year.

Almost 40,000 people get skin cancer every year in Britain; 1,600 of them die.

Sun beds can cause eye infections such as conjunctivitis and even cataracts. It is essential to always wear goggles.

If you are under 40 you should be especially careful. Fifty per cent of all malignant melanomas begin as moles. Consult your GP if you notice any of the following signs: asymmetry, changes in colour, border irregularities, and diameter change.

I did enquire about prescribed UV treatment, but typical hospital methods involve taking drugs to make your body (and eyes) more sensitive to the Ultraviolet light and then, after treatment, you must wear dark glasses and keep all your skin covered and away from daylight for 24 hours. It seems to make hard work out of what is essentially a simple procedure.

John Byfield
'Moonrakers', The Rutts, Bushey Heath, Herts WD2 1LH.

EDITORIAL NOTE

PUVA is not the only UV treatment available in hospital. There is also UVB and the more recently introduced narrow-band UVB AT 311nm for which one does not need to take tablets or wear dark glasses after treatment.

Caution

Please always consult your doctor before embarking on any course of home treatments – they could be dangerous for you – everyone's different.

Letters

Dear Julie and David,

I have had psoriasis since I was in my early teens (I am 53 now) but my suffering has always been primarily mental. The psoriasis itself takes the form of red spots – no scales, no bleeding, no itch, just hundreds and hundreds of spots. Moreover, since the rash is usually confined to my back and thighs it is only in summer and on winter sun holidays that it is exposed. Even then my skin's rapid and positive response to the sun usually reduces it to white spots before disappearing altogether within a few days. But how I hate it: I HATE IT. I cannot deal with not being able to control it. Only the sun (or hospital-administered ultra-violet light treatment, when I can get it) seems to clear it. I smother myself in lotions and potions, buy Dead Sea products and E45 body lotion, all to no avail. My only way of dealing with it to this day is to pretend it does not exist. I shower, apply lotions and ointments with my eyes closed by feeling for the spots!

I have had a life-time of hospital out-patient clinics and I cannot count the times I have left in tears after being told by yet another doctor that mine is a very mild case. (I even had a 2-week spell as an in-patient: I found out later that I was admitted because the consultant thought I was suicidal). My doctor urged me to join the Psoriatic Association 'for support' but to do so required me to stop pretending it was not there, so I did not.

All of this was before the psoriatic arthritis. It began, slowly, 10 years ago in my knees and was diagnosed as cartilage problems. For a year I spent periods in bed, on crutches or walking with sticks before the pain and stiffness went as suddenly as it had appeared. Two years later I had treatment for 'tennis elbow'. Both of these diagnoses made sense to me at the time as I had been active in sport since childhood. Then 5 years ago my fingers swelled and became painful, then my wrists and the palms of my hands followed shortly afterwards by swelling and pain in my feet. This changed things; now my livelihood and my lifestyle were being threatened. The diagnosis of psoriatic arthritis sent my spirits into a downwards spiral. It meant I could not control this either. I scurried to join the PAA. This has been very helpful to me – I have tried new treatments and read about new research findings but it has not changed my attitude: I still survive through pretence.

Can you imagine my joy when my last order from Yoni International contained a leaflet about the Psoriatic Arthropathy Alliance.

This rambling letter is my way of saying thank you. I was overwhelmed by the box of 'goodies', which was as unexpected as it was welcome. But, more particularly, thank you for identifying the need for a separate group and for being prepared to give the time and the energy both to establish and to maintain it. What a commitment. Mere words cannot express my thanks. I have found all the literature both informative and enjoyable but I am awe-struck by the work you have done and are doing to raise public awareness of the disease: I do appreciate it.

I can now barely write, driving is a painful process which I undertake from necessity and not for pleasure, cutlery is difficult to manage and I drink only from half-filled (and so lightweight) cups and glasses. As for dropping things – I could write a book! But I feel much more positive since making contact with you. I cannot explain it, I just do. My 'pretence' strategy extended to the psoriatic arthritis once it was diagnosed and so I did not treat it or indeed even attend the doctor. I have changed that! I have made an appointment with my doctor and – an all time first – I will do what he tells me to do.

Thank you very much indeed.

Best wishes

Nancy Taylor, Member, Strathclyde.

Snippets

HAIRDRESSING CIRCLES!

Andrew Collinge, well known hairdresser and personality, is backing a new awareness campaign designed to boost hairdressers' understanding of psoriasis, and has recently launched along with the Hairdressing Council a new SCALP PSORIASIS Helpline.

On the Helpline (0171-734 3808), hairdressers can request information which can be given to clients.

Andrew Collinge stated "People with scalp psoriasis can often feel very embarrassed about their condition. With the right help and support from their hairdresser they can leave the salon with a greater feeling of self-esteem."

DON'T forget we're still trying to compile a DIRECTORY OF UNDER-STANDING HAIRDRESSERS nationwide, so please keep sending in your recommendations!!!

Dear David and Julie,

After many years feeling like an alien on this planet, I eventually found the support group called PAA. Better still was the fact that they had a pen-pal list of PA sufferers. Now at this stage I was extremely depressed, suicidal and in great despair. With a lot of effort I managed to write a couple of letters and sent them off. When the postman delivered several letters I was ecstatic. This was the beginning of making new friends who suffered from PA like myself. Many of my new friends sent me photographs and telephone numbers, which really meant a lot to me at the time. I now had an important life-line for when things were at their blackest. It must be said that not everyone I wrote to replied, which was sad, but I would urge anyone to write just one letter to someone on the list, and they will be rewarded in so many ways.

The PAA would like everyone's input and ideas on how best to improve the service. If you find writing the first letter hard, please tell us. If you have had a good/bad experience with the pen-pal list, then let us know. Or if you have any ideas at all, please put pen to paper and get writing now.

If anyone would like to write or telephone me regarding the pen-pal list, please feel free to do so.

Hoping you will keep me informed.

Yours sincerely,

Linda C. Barton

39 Fistral Crescent
STALYBRIDGE
Cheshire
SK15 3HN
Tel: 0161-303 8382

Please get writing to Linda soon!

DATES FOR THE DIARY:

SKIN INFORMATION DAYS:

Birmingham	**SATURDAY 1st MARCH 1997**
Cardiff	**SATURDAY 17th MAY 1997**
Middlesbrough	**SATURDAY 4th OCTOBER 1997**
Medway Towns	**SATURDAY 15th NOVEMBER 1997**

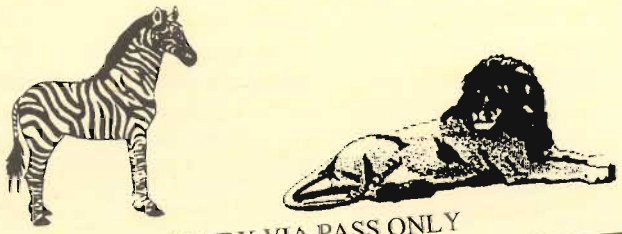
For further details of programmes/venues please ring Stephanie Witts, National Eczema Society: 0171-388 5651.

The PAA will try to have a presence at some of these days.

21st-25th APRIL 1997
PAA AWARENESS CAMPAIGN

SATURDAY 27th SEPTEMBER 1997
PAA ANNUAL CONFERENCE

WOBURN **Safari Park, Woburn, Bedfordshire.**
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.



ENTRY VIA PASS ONLY

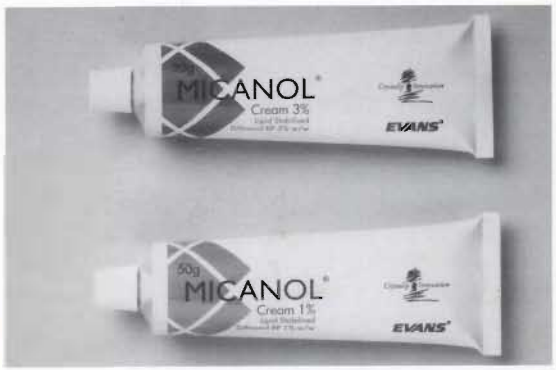
What's New?

NEW PRODUCT LAUNCHES...

MICANOL
A new formulation of a tried and tested drug, Dithranol, which has been used in the treatment of psoriasis for more than 70 years, is now available in the UK from Evans Medical, pharmaceutical company. The new cream is supposed to be easier to use than traditional formulations and reduces staining and irritation when used correctly.

Micanol is applied to the skin once a day where it forms a dry non-sticky surface. The cream does not spread beyond the area treated, nor does it contain preservatives and is intended to be user-friendly, with the aim of better patient compliance.

1% cream is available over the counter at pharmacies or on prescription, and 3% cream on prescription for the treatment of psoriasis on the body or scalp for adults and the elderly.

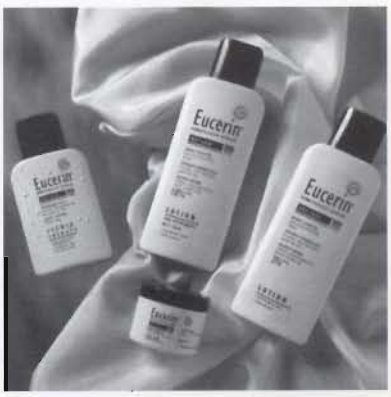


EUCERIN
Beiersdorf UK has recently launched the Eucerin Dry Skin Range, consisting of Eucerin lotion, shower therapy and cream, which is already established in many countries around the world, with Eucerin being the number one product recommended by dermatologists in the USA.

The active ingredient is urea, a highly effective moisturiser, which is naturally found in healthy skin. In contrast to other emollients urea actually binds moisture into the skin effectively improving skin hydration.

Eucerin lotion is available in two strengths, 3% (250ml £6.89) or 10% (250ml £7.89), and the cream at 5% (75ml £5.99). The lower concentrations of 3% and 5% are indicated for dry skins whereas the higher concentration is recommended for moisturising extremely dry skin.

The shower therapy (150ml £6.69) provides a cleansing action to soothe, soften and protect against dry and itchy skin. The manufacturers claim it will improve skin hydration, smooth rough skin and relieve itching and discomfort.



News in Brief

LOTTERY UPDATE:

As reported in our last newsletter we applied to the Lotteries Board in the summer for part funding so that we could commence work on setting up a Regional Co-ordinators project across the country. After the enormous time, effort and thought that went into the application we were extremely LUCKY to get an assessment of the project, which took 2½ hours carried out by a personal visit from an assessor – needless to say it was a GRUELLING task.

We are bitterly sorry to report our application was unsuccessful, not because it wasn't good enough and didn't come up to scratch, but purely because this Lottery Round was terribly over subscribed, with the bigger charities benefitting before us little ones.

BUT the GOOD NEWS IS – after dusting and picking ourselves up from the gloom and doom, the PROJECT will go ahead, albeit slower than anticipated, and has already begun in earnest. The PAA has been busy pinpointing those of you ready to get stuck in and start work. WE WILL KEEP YOU POSTED!!

NSAID
MOBIC (meloxicam)
Indications: Rheumatoid arthritis, Osteoarthritis, Polyarthritis

Boehringer Ingelheim have recently launched the first preferential COX-2 Inhibitor, Mobic (meloxicam), with the efficacy of standard NSAIDs such as diclofenac, piroxicam and naproxen, but is supposed to have fewer gastrointestinal side effects.

NSAIDs work by inhibiting the enzyme cyclo-oxygenase (COX), which is responsible for the production of prostaglandins from arachidonic acid. Recently, it has been found that there are two isoforms of cyclo-oxygenase: COX-1, which has a housekeeping or protective function, particularly on the gastrointestinal tract, and COX-2, which produces prostaglandins at sites of tissue inflammation. Therefore, the blanket inhibition of prostaglandin production by NSAIDs results in a therapeutic anti-inflammatory action, but also in unwanted side-effects such as peptic ulceration and renal toxicity.

Mobic is the first of the NSAID class of drugs which has been shown to inhibit preferentially COX-2 and to exert a potent anti-inflammatory effect while reducing the risk of gastric and renal prostaglandin depletion.

This newsletter is sponsored by:

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