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PAA

PSORIATIC ARTHROPATHY ALLIANCE

NEWSLETTER No 6. MARCH 1996

Registered Charity No: 1051169

IT'S OFFICIAL . . .

The P.A.A. has some good news that it would like to share with you all. *YES IT'S OFFICIAL* the P.A.A is now a fully REGISTERED CHARITY. Formal notice was received a week before Christmas 1995. So now the hard work begins for all of us!

HELLO.

We now have some new friends in Sweden, the Swedish Psoriasis Association that we have been corresponding with. *Hello Sweden*. One of their objectives like ourselves is to try and bridge the gap between rheumatology and dermatology to encourage better patient care for those of us with both aspects of the condition, which will also in turn stimulate early diagnosis hopefully. They are currently running a project around the Country to encourage more co-operation between departments/professionals. We wish them much luck with their efforts in this project.

GETTING INVOLVED :

We will shortly try and arrange a meeting those of you wanting to get more involved in the workload. An accessible venue will be sought so we can meet up to discuss the best ways to tackle the jobs that need doing. Have we got any good language translators in German, Dutch, French?

If so we've got some work for you!!!

DIARY DATE FOR 1996

Saturday, 21st September 1996

P.A.A. 2nd Annual Conference.

More details to follow in due course. We would like to see you all if you can make it. Arrangements for the children will be made so they can enjoy themselves too.

PLEASE IF YOU ARE INTERESTED AND HAVEN'T ALREADY DONE SO,

GET IN TOUCH WITH US!

1996 will be very much a developmental year and its a great opportunity to become involved with a friendly team,find your feet,gain confidence in new skills along the way in a fresh innovative new charity.

A PROBLEM PAGE?
How about it?

After last year's conference the subject improving contact lists to encourage more use of these came to the forefront. The following has been put forward.

"My experience with penpals would suggest. That just providing a list of names does not make people very compatible. I got a letter from one lady. I replied but it became obvious that we had very little in common and that it would not work out. I would like to be linked up with someone who shares the same sort of problems that my husband has - or the partner of that person, because I would like to know how they cope. Sometimes I get so down and would love to just know that other people do too and likewise to be there when they feel very down. I would like to see some sort of questionnaire as to age, severity of problems, what side of it concerns them most, what sort of age, type of person they would like to communicate with, what they would expect to get out of the correspondence.
For example, a recent problem my husband had was going to the dentist to have a minor operation. The operation meant having a general anaesthetic. Because his neck is locked rigid he could not be given one as they needed the headed bent backwards. In this case they were able to knock him out with a jab and do it very quickly but what if he needs a longer spell out now? Does any one else have this problem? How did they cope? The dentist is a problem because my husband cannot lie on his back. This means that while he can sit in the chair, the dentist is unable to lower the chair to work on his mouth and as his neck is locked rigid he cannot bend his head back for treatment. Do other people have that problem? How do they cope?
Another problem we have is bathing. Because of the severity of his psoriasis he has to soak in a bath of coal tar. He has great difficulty getting in and out of the bath. Up until now I have been hauling him but he is no light weight. We have investigated various bath aids but as he is 6ft 4in tall he takes up alot of bath and a seat in the bath is no good as his knees do not bend properly and therefore he can't fit in. We have at last found one which appears ideal but it costs £2-3,000 to fit What do other people do? How do they cope?
Perhaps a problem page in the newsletter would serve a better purpose than a penpal list, because then if you had a similar problem you could write to the person involved on that particular thing. This could mean you were writing at different times to different people on issues which actually concerned both. It would then be relevant and purposeful.

. . . . Member.

If you would like to correspond with this member we will gladly pass your letters on to her.

WHAT DO YOU THINK ?

We think a problem page is a good idea and could work, but it will solely rely on your contributions for a continued slot, as do the Case Histories! CONTRIBUTIONS,VIEWS PLEASE.

SKIN INFORMATION DAY ROADSHOWS.

These will be held at various locations around the Country, covering a number of skin conditions. The P.A.A along with other Patient Groups and Exhibitors will be there, so please come along if you can. It will be a good opportunity to meet up for a chat.

Edinburgh *Saturday 27th April 1996*
Plymouth *Saturday 8th June 1996*
Manchester *Saturday 5th November 1996*
Reading Saturday 5th October 1996
Inverness Saturday 28th September'96

More will be arranged in 1997. For further information and details of locations please contact David at the Skin Care Office on 0171-388-5655. The PAA will try to cover most of these events but it is advisable to check with us if you specifically want to come along to a particular location just in case we can't make it to save inconvenience and disappointment.

Psoriasis is on both sides of my family and affected me at the age of 16.

September 1991:
I woke up one morning with severe pain in my leg. After three weeks with the pain coming and going I went to the doctors and was told the pain was in my hip and it was probably Viral Arthritis. I was prescribed Naproxan and was told it would go away.
November 1991:

The pain no better and one week before we were due to have a once in a lifetime holiday to Florida with my two small children I was back at the doctors' because my back was giving me as much pain as my hip, I was told it was because I was walking so bad and he would send me for X rays and blood tests and to cancel my holiday.

February 1992:
X rays and blood tests showed nothing and given more Naproxan.

August 1992:
Back to the doctors, I couldn't stand the pain any longer and he told me he would refer me to a Rheumatologist. (I didn't get there).

Two days later:
The pain so severe my leg went into spasms. I was admitted to hospital. The Consultant hinted at P.A. but put my leg into traction for a week, pain not alot better and they were still not sure what the problem was, they decided to do a biopsy and it was confirmed I had Psoriatic Arthropathy. The tissue and bone damage was so bad they could do nothing but I would need a hip replacement in the near future. I was prescribed Voltarol and told to rest as much as possible.

September 1993:
After one year of a lot of bed rest and intense pain I had a hip replacement, it was a great success but pain had started up in my left shoulder and left foot. X-rays taken showing arthritis but nothing done

August 1995:
Pain has now also started in my right hip and left hand. I am now beginning to get frightened again, so back to the doctors to be told he knows nothing and he would refer to a Rheumatologist.
This is the first time I have been referred to someone who can perhaps help slow down the disease, that's when I get there, I have to wait three months, at least when I do get there I can ask the right questions thanks to the P.A.A. Meeting.

Mrs Lesley Sayers aged 39.

Case Histories

I was diagnosed to be suffering from PA in 1992, in my early thirties. In the January I experienced pain and stiffness in my knees, especially the right, with the symptoms hinting of arthritis but because all the blood tests showed no abnormality it was not till after an arthroscopy on the right knee later that year that the Consultant diagnosed PA. Looking back however I suspect that I had been suffering with PA the previous year, but in my jaw. Worsening symptoms were helped by cortisone injection, but later that year I started on going problems with pain and stiffness in my back and neck, and consulted an osteopath. Since then I have developed problems in various parts of my body, including a bad case of tendonitis in my left shoulder, pain and stiffness in my ankles, suspected PA in my large right toe plus pain and stiffness in my left hand centering around by thumb joints and more recently the elbow as well. Being left-handed and working daily with a VDU as a registered Insurance Broker I do worry about the future, particularly as it is possible that the hand problems are caused by osteoarthritis. My shoulder problem has been helped somewhat by a cortisone injection.

I have tried to control my symptoms with NSAIDs, currently Diclofenac Sodium but have to be careful as I am very small and they cause irritable bowel syndrome type symptoms, also with regular visits to an osteopath, hot and cold treatments, aromatherapy bubble baths, and when possible spa and hydro treatments.

I have also made changes to by diet as certain foods do aggravate my symptoms. But be careful, this can cause severe weight loss. I landed up like a skeleton until I got the diet right. Most important however, is trying to be kind to myself and remembering I am only human and sometimes cannot do what I used to.

My Psoriasis which is quite mild and in my scalp was diagnosed first about 1987, when I had psoriasis on my elbows, and in 1990, when the scalp problems began, although I had suffered with scalp problems from the age of 15, maybe it was psoriasis, who knows? I must admit to being lazy with the psoriasis, not liking the smelly and messy treatments.

The PA seems to be inherited, the psoriasis from my mother's family and arthritis paternally. I am not aware however of anyone else having PA. I seem to have suffered the normal course of eczema, hay fever,and then psoriasis and then PA.

Mrs Carol Noble,Herts.

RED CROSS SERVICE

Dear....

Prior to receiving your news journal No.5, I had asked my G.P. for a referral to the Red Cross for advice on the camouflage service.

I saw my G.P. in November, and saw Mrs Glennie of the Red Cross last week, although my GP wrote to them immediately. Perhaps Christmas coming caused the delay.

However I feel I wanted to write to you, to encourage other people to apply for this service. I have the psoriasis on my hands and elbows, and a little on my arms, and I have been buying and wearing long sleeved clothes, (even in the Summer). At times it has been very bad on my hands and with my arthritic fingers I have felt very very conscious indeed, (as it is difficult to cover ones hands).

As soon as the cream was applied there was an immediate difference, and I felt so different about the appearance of my elbows. I cannot express my thoughts clearly enough.

I now feel quite differently about buying new clothes - and wearing all the clothes in my wardrobe, some of which have not been worn for about two years.

I have had arthritis - originally called "Stills Disease" in my case as this was when I was a teenager in the late 1940's. From then on although I always had a slot of "Dandruff" it wasn't until about five years ago, that the psoriasis showed, after going to the Far East and taking Chloroquine. Now on reflection I have possibly been a P.A. sufferer all the time, but it was only in my scalp and was not associated with the arthritis.

Thank you P.A.A. for all your hard work that you are doing.

Anita.

SKIN CARE CAMPAIGN UP-DATE: CALLING ALL THOSE OF YOU IN SCOTLAND

The Skin Care Campaign is running an information campaign project regarding psoriasis,which it aims will raise the profile of the condition in Scotland. The P.A.A. has also been approached on the initiative for our input which we gladly welcomed. So again please look out for this campaign. It is anticipated that there will be quite extensive media coverage etc.

NEW TREATMENT

JUST LAUNCHED a new prescription only ointment is now available to the psoriasis patient called Curatoderm, produced by Merck Pharmaceuticals. It is a non staining, odourless, vitamin D preparation, which is applied once a day, and is, according to the makers, gentle enough to be used on the face and flexures, but your doctor will be the best person to advise you as to its suitability for you and the areas that should be treated.

FEEDBACK !

Not much response has yet been made regarding a weekend away as mentioned in Journal 5. I'll leave this open for the time being, but if there is no further response in the near future we will shelve the idea for the time being.

DIARIES: Again not much response!

THANK YOU.

I cannot let this issue of the newsletter go by without saying a very big thank you to all of you that wrote in with words of support regarding the "right to reply"article in Journal 5. Your comments were very much appreciated and bucked up my spirits as I was feeling rather low and tired. So ***THANK YOU*** and also for letting me let off steam!

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