PAA news

PSORIATIC ARTHROPATHY ALLIANCE

ISSUE 10 SPRING '98

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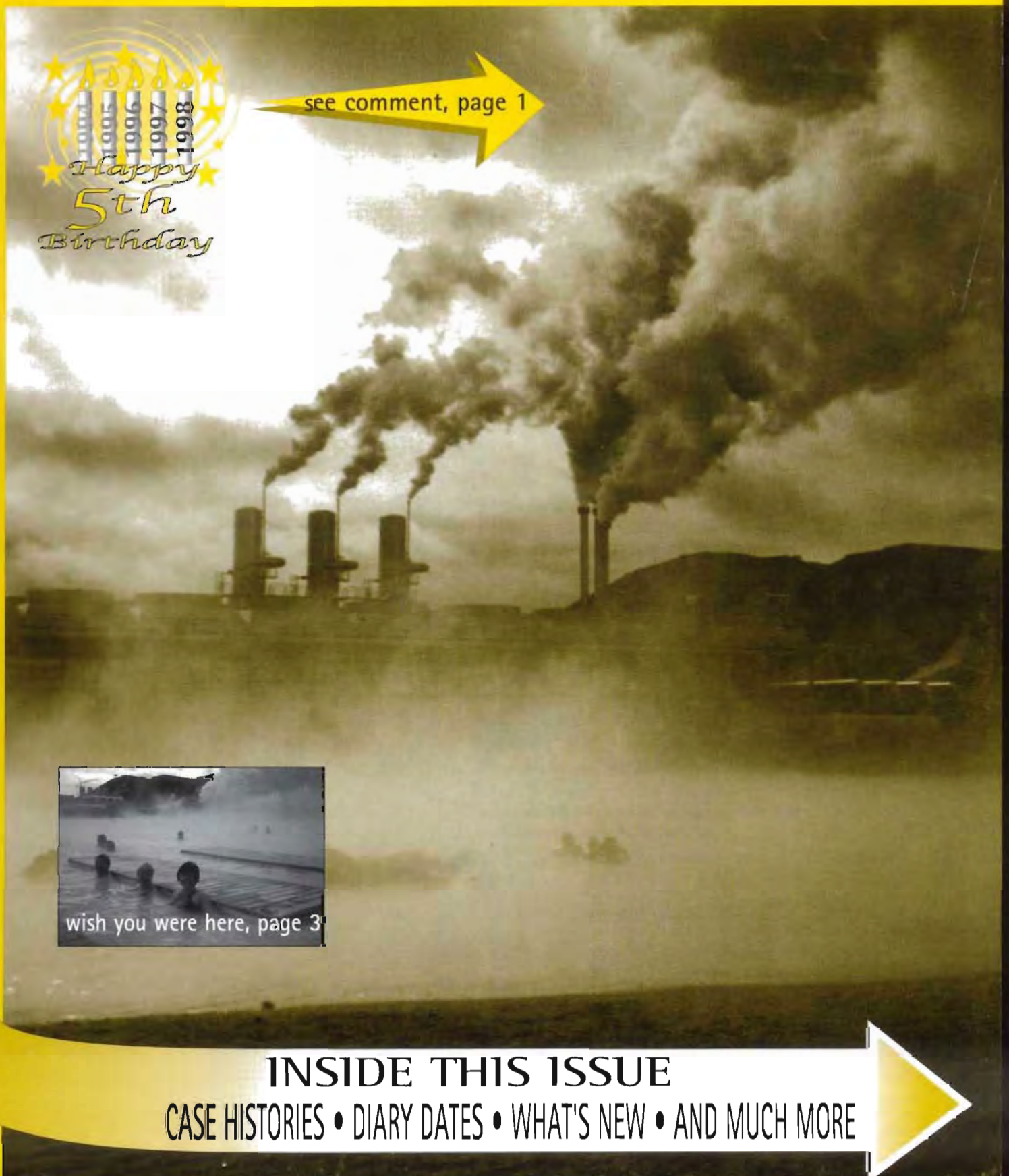

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The PAA Team

This Skin 'n' Bones Connection is produced by the Psoriatic Arthropathy Alliance and reviewed and approved by an editorial panel drawn from the board, medical and non-medical advisers.

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.

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COMMENT

David, Julie and Hannah

April 7, 1993,was a significant date for both Julie and myself. It was the day when Julie made a live radio broadcast on BBC Three Counties announcing the launch of the then called Psoriatic Arthropathy Support Group. After a name change and a few ups and downs the PAA are now celebrating its 5th birthday.

We owe a lot of thanks to those who have supported and believed in us since that day and of course a huge thank you to the continued support of the membership.

Although April 7 was the launch date it followed a lot of heart searching and planning by Julie, who had seen my decline from a fully active person to one who was extremely low and depressed. The pain was visible on her face as she watched me struggle to carry out simple day-to-day tasks with my swollen fingers and painful toes.

Her desire and passion to try and help others from sinking into the same lifestyle we had experienced over the previous three years since my own diagnosis in 1990, directly led to that fateful day in 1993.

Since then I can count myself fortunate to have a wife as dedicated and loving as Julie and, since the birth of our daughter Hannah in 1994, a future to look forward to. I still have problems with both skin and joints and some days this wretched condition really infuriates me, but I feel that I am luckier than most and at least this organisation now exists to benefit others.

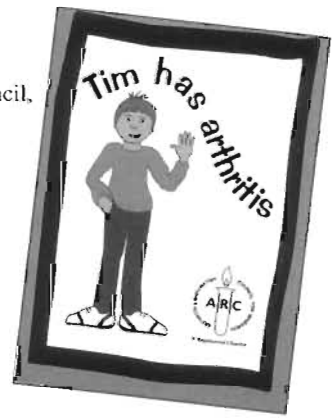
NEW BOOKLET

DRIVING AND ARTHRITIS
A new booklet for drivers with arthritis has been published by the Forum of Mobility Centres and covers all aspects of driving.

For a free copy please send an SAE to:
Banstead Mobility Centre,
Damson Way,
Fountain Drive,
Carshalton,
Surrey,
SM5 4NR.

TIM HAS ARTHRITIS.
General booklet on arthritis written in story form aimed at the young child.

More details from:
Publications Department,
Arthritis & Rheumatism Council,
Copeman House,
St Mary's Court,
Chesterfield,
Derbyshire,
S41 7TD.



case history

HILARY RUTLAND
Location: Suffolk
Age now: 54
Age at onset of PA: 32
Years before diagnosis: 7

I was only 13 years old when my family moved to Suffolk from Essex, it was a very distressing time for me as all my friends were left behind. I began to notice dry scaly patches all over my body, under my nails and on my head, behind my ears and all over my limbs, although my face was not affected. I covered up but felt dirty scratching my body all the time. People would stare and I could hear nasty comments - you feel isolated being a teenager with something wrong with you.

My doctor would give me a cream, but that didn't work it just made the patches look red raw and unacceptable for others to look at. The medical profession would ask if I had a history of this complaint in my family and I would whisper that I was adopted and feel even more of an outcast. Slowly, as the years went by, it became less noticeable. I even tried to be less self-conscious as I got older. The sun helped but you cannot rely on that in this country.

About a year after having my last child and approaching middle-age, I began to get a searing pain in the balls of my feet. My doctor said I had gout, which is quite an eye-opener for someone who is teetotal. I was given pain killers and left to get on with it. The pain was unbearable, and I could hardly walk. Again the doctor dismissed the complaint as gout, but my toes started to swell and deform and I was sent for X-rays and to see a consultant. He gave me anti-inflammatory drugs which made me very sick, and the gout was now given the name 'rheumatoid arthritis'. I read books on the subject but two plus two didn't make four with me. After many courses of wax baths and physio by the bucketful I was told I would have to put up with it. My fingers started to deform, swell and throb and the pain was something you cannot describe, so you keep taking pain killers and watch that you do not overdose, which is not easy when you do not know what to do with yourself. People ask how you are, but they don't really want to know and you are sick and tired of telling people, because they don't understand what you are going through.

The consultant at my local hospital decided to refer me to a rheumatologist to try and stabilise my condition. The rheumatologist thought my condition was due to my psoriasis, but was not sure. I was put on a course of different tablets, which I am still taking. Over the years I have tried many types of pills and am now on quite an assortment.

My faith in my consultant hit an all-time low after he said to me: "There is nothing more we can do, you will have to put up with it". I often came away from the hospital, got into my car, which I found difficult to drive, and cried my eyes out. As time went on, my back, neck, hands, wrists and ankles were all affected.

Then one day I was listening to my car radio and I heard Woman's Hour, with Dennis Potter talking about his condition called psoriatic arthritis, and what he described was what I had. Tears flowed down my face and I sobbed my heart out. At last someone knew what I was going through, but what impressed me most was what he said about the pain: "No one is interested in your pain. It is your pain to get on with in your life and learn to live with it". I have tried to live with that theory ever since, but sometimes it is a hard task.

I now have an excellent consultant who is interested in my complaint and has helped me enormously, as has my GP. My condition is deteriorating, although steroids have helped and so have anti depressants. Emotionally you hit rock bottom trying to cope with walking and everyday life. In 1996 my husband noticed a very small article in the Daily Mail about the Psoriatic Arthropahy Alliance and I wrote to them straight away. It is such a relief to be in touch with others who are also having to cope with this little-known crippling disease.

TRAVEL

TRAVELLERS' EXPERIENCE !

With regard to the references to Iceland in earlier PAA News, I have been fortunate enough to visit both the Dead Sea in Israel and the Blue Lagoon in Iceland.

I went to Iceland at a time when I needed some quiet relaxation, and this beautiful peaceful country was able to provide plenty of this. I stayed in Reykjavik, a very pretty city with its backdrop of snow-capped mountains, and what other capital city can boast a salmon river flowing through its centre? The food is interesting too, consisting of sea birds (Puffin featured on many menus), fish of all kinds and the tasty Icelandic lamb.

On my first day there I looked at the tourist brochures, and spent some time afterwards exploring the delights of the waterfalls and geysers. Undoubtedly though the item that had caught my eye was the Blue Lagoon, described as "hot, healthy and exotic". What tired old tourist could resist such an offer, so I decided to find out for myself. From a long way off steam from the lagoon could be seen rising into the sky, the deep blue hot water being collected in a pool beside the Svartsengi Geotherma power station, after its heat had been exchanged for domestic supplies. I do not have psoriasis or eczema (my husband does, though), but my own skin is dry and sensitive, and after only one hour in the pool I felt really good. The effects were long lasting too. Indeed, all of Iceland's water either for bathing or in a swimming pool is very soft and soothing. Temperatures in the pools are maintained at a steady 25°-30° centigrade all the year round. Talking to the staff at the lagoon they told me that after the curative powers for skin disorders was discovered in the 1980s, the pool now attracts thousands of people with psoriasis, eczema and other skin ailments, and many bathers soon notice improvement after just a few dips. Scientists are still studying the mineral-rich geothermal water to discover exactly what it contains to be of such benefit.

To sum up I would say that the Dead Sea and the Blue Lagoon are both very good. The advantages of Iceland are that it is close enough to go for a long weekend as I did, summer months are warm with almost constant daylight, and even in winter the outdoor pools are hot enough to bathe in. It is a lovely country where peace and relaxation are guaranteed.

Tricia Hobbs
PAA Membership Renewals Secretary.

TRAVEL CONSULTANTS

specialising in spa/health holidays:-

Erna Low Consultants Limited
9 Reece Mews
London
SW7 3HE
Tel: 24 hr brochure line: 0171 584 7820
Tel: 0171 584 2842 Fax: 0171 589 9531

Superstar Holidays
Tel: 01345 125847 (Dead Sea holidays)

Peltours
Tel: 0181 343 0590

Classic Tours
148 Curtain Road
London
EC2A 3AR
Tel: 0171 613 4441

VIP Health Holidays
42 North Audley Street
London
W1S 4PY

Thermalia Travel Limited
12 New College Parade
Finchley Road
Swiss Cottage
London
NW3 5EP
Holidays specialising in fish therapy.

TRAVELLING IN 1998
USEFUL INFORMATION

ROGER CHANT Associates

47-49 College Road
Bromley
Kent
BR1 3PU
Tel: 0800 28 17 13
Fax: 0800 21 49 86

Roger Chant
Associates

CONTACT: Laura Beesley - Travel Insurance Adviser

Roger Chant Associates are a small company specialising in travel insurance for individuals with medical problems and physical disabilities. Their policies can help those who want to travel anywhere in the world, providing you are fit to travel!
Give them a ring first.

HOLIDAY CARE SERVICE

The UK's Central resource for the disabled or physically unfit traveller. Their database covers all aspects of tourism and holidays in this country and elsewhere, such as Greece, Majorca, Israel and USA, together with information on equipment, care hire, etc.

Contact: Mr Derek Moore, Manager.

HOLIDAY CARE SERVICE
a charity

HOLIDAY NEWS JUST IN . . . .

FIRST INTERNATIONAL YOUTH CAMP FOR PSORIASIS TREATMENT, DEAD SEA, ISRAEL.

Two Periods: 5-26/7/1998 and 26/7 - 16/8/1998.

Oranim Travel in association with the Israel Psoriasis Association have arranged the FIRST INTERNATIONAL YOUTH CAMP FOR PSORIASIS TREATMENT for 9-17 year olds. Youngsters in this age group are encouraged from all over the world.

The youth camp will be held on the northern side of the Dead Sea, 30 minutes from Jerusalem at the Dead Sea Medical Centre. All guests will be housed in kibbutz guest houses in the area. Numerous activities are planned, including tours of Israel, dinners, disco nights and much more.

The solarium is located on a private beach with full medical treatment on hand 24 hours a day.

Guests will be met personally at the airport and transferred to the camp.

For further information please contact:
Ms Sharron Malka
Sales & Marketing Manager
Oranim Travel Limited
4 Hakikar Street,
P.O.Box 858
Kfar-Saba 44108
Israel.

Tel: 972 9 767 4477
Fax: 972 9 767 4481
e-mail :
Oranim@netvision.net.il

CALVERT TRUST

Kielder holidays

Holidays based in Northumberland at the Calvert Trust Complex on the shores of Europe's biggest man-made lake. The resort is designed for guests with special needs and is built at ground level, giving full access for wheelchair users,and those guests with mobility problems. There are activities such as sailing, riding, lake activities, archery, or simply just having a well earned rest!

Further details from:
Calvert Trust Kielder
Kielder Water
Hexham
Northumberland

Tel: 01434 250232
Fax: 01434 250015.

HELP HELP HELP HELP HELP HEL

The PAA - Will it be here for you in the year 2000?

FUNDRAISER URGENTLY NEEDED - YOUR CHARITY IS NOW UNDER THREAT.

ARE YOU * CREATIVE * OUTGOING * IMAGINATIVE * ABOVE ALL RELIABLE * LIKE A CHALLENGE? If so the PAA needs you to take up the GAUNTLET to become a FUNDRAISER for the PAA to ensure that the work of the Psoriatic Arthropathy Alliance continues.

The PAA has come a long way in five years but now all that sheer hard work may be lost forever if we cannot secure a constant, regular flow of funding within the next eight months.

DO YOU THINK YOU CAN HELP?
The post is a challenging one, working closely with and alongside the PAA Management Team. Initially the post will be unpaid but could lead to full/part-time paid employment.

You must be willing to tackle all aspects of fundraising:
Tackle local and national business *Create sponsorship *Create interest in the PAA's work *Work on and develop projects

Generate media and PR, thus creating funding *Generate advertising space for the PAA publications to secure their regular productions *Research and apply to grant making trusts on a regular basis *Help motivate the PAA membership - and aid those who want to get started fundraising *Develop a fundraising committee

These are to name but a few tasks - interested?

YOU must be able to work on your own initiative, keep to guidelines set by the Charity's constitution and legal requirements, work to deadlines and have a solid commitment to the work of the PAA, its aims and objectives.

Hours to suit, but must be reliable and can work from home if desired. Telephone/fax, business line will be provided.

Please telephone David Chandler on 01923 672837 or drop us a line at the office.

THIS POST IS VITAL IF THE PAA IS TO SURVIVE FROM 1999 ONWARDS - WE ARE AT A CRITICAL STAGE.

A CUT ABOVE THE REST

You may recall we are still trying to compile a directory of sympathetic hairdressers around the country who are familiar with scalp psoriasis. So far there has not been much response from you all - please have a think and drop us a line!

Hairdressers

Mr D J Hales
Donald of Lewes
24 Fisher Street
Lewes
Sussex
BN7 2DG

Ms Sara Colburt
7 Penfold Close
Sapcote
Leicestershire
LE9 4FL
Tel: 01455 273013

Ms Christine Breaxell
20 Sandyhurst Close
Poole
Dorset
BH17 9JS
Tel: 01202 242246

Sally Ann Hair Flair
25 East Hill
Colchester
Essex

Hair & Sirs
65 Liverpool Road
Burscough
Lancs
Tel: Burscough 896075
Contacts: Lynn and Sharon

Helen Noble
A Certain Flair
63 High Street
Buntingford
Herts
SG9 9AD
Tel: 01763 272131

Filino Hairdressing
49B, Museum Street
London
WC1A 1LY
Tel: 0171 405 1081
Unisex Salon

Nu Look
Hair & Beauty
Unisex Salon
2A , Thompson Road
Denton Village
Newhaven
Sussex

The Green Room
51 Ber Street
Norwich
Norfolk
Contact: Ms Nikki Paul

Dawn Dawdry
(She has Psoriasis herself)
Salon Tel no:
011473 631437

CONGRATULATIONS to

AMANDA RUTLAND who successfully completed her 2,000ft parachute jump on 25 October 1997, after having one postponed attempt due to severe weather conditions. Amanda is partially sighted too, so it took a lot of courage for her. At her first attempt Amanda was geared up, but after waiting in vain for the weather to improve, she was forced to wait a few more weeks for her successful parachute jump.

WELL DONE AMANDA, you did the PAA proud and raised more than £700.

A supporters' award is winging its way to you.

Again WELL DONE to CHARLES HARVIE, whose account of his walk you read about in Newsjournal 9.

He along with Amanda enters our Scroll of Achievements record.

A WORD FROM AUSTRALIA !

Dear PAA,

I am writing in the hope that you will be able to help me in my search for a better understanding, more information, and perhaps some moral support of PA.

It is 11 years since my search began and it has taken 11 years to confirm PA. The specialist said that had the (numerous) doctors taken the time to check my pitted nails they could have confirmed PA - simple things are often overlooked.

Perhaps it is because I live in the country (on a farm) that I am more isolated from support groups and know no other person with a less condition such as mine does seem to become more severe with each inflammatory flare-up, as this year saw the need for a walking frame, crutches and walking stick, although I'm now improving. I was unable to move for one to two weeks, even couldn't hold a cup of tea, which required two hands, comb my hair or cut my food as my hands and sausage fingers became clawed. Further, I could not write or hold a pen a few weeks ago, and cannot even now.

I still can't close my fingers into a fist. This last bout has taken 14 weeks to recover to some degree of acceptance. All my joints are affected, my left leg and foot are numb and I have bursitis.

How much worse can it get, I think. Are there any precautions I can take? Diets? Do hormones play a role? Are bonny growths on the spine par for the course? Is it PA? Or a two-in-one condition?

The long wait for blood test results before pain-relieving medication is given has confirmed my resolve that there's some room for improvement between doctor/patient and general information.

While I like my GP, she admits that she knows nothing about PA (I'm her first patient) and so it's with her encouragement that I now write to you. Her husband is a psychologist and has taken a small role in helping me to put some pieces together as I also have a post -traumatic stress disorder history..

My specialist has had me on Methotrexate for five months at 25mg each Sunday, and numerous other drugs have been tried, e.g. Prednisone, Salazoyrin, etc. I refuse to take these last two again, and as for Methotrexate - hm, well, I've never been so sick as when on it and four other drugs. Frankly, good old aspirin gets my vote of confidence.

The Psoriasis Association in our capital city also suggested that I write to you and ask to be kept informed.

Please don't think I expect each and every question answered. Basically, I'm wondering if there is someone out there that understands and would like to help. It is so close to my heart - I hope I may be able to help others one day somehow.

I'm 48 years old and a mother of three who have left the nest. My husband and I live on a small farm (40 cows) - he also works at the local high school. I am known as a creative artist, paint (oils), love crafts and make small button dolls and pin cushions (wool) etc, and love gardening especially herbs and books.

I am not neat and nice, more like rough and ready.

Hope I'm not a nuisance.

Sincerely
Clare Richter (Mrs)

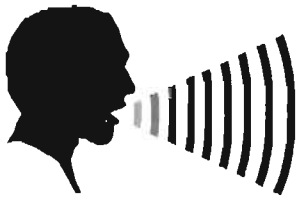
PS from the EDITOR:
Come on, all our PAA members, please get writing. I know Clare would dearly love to hear from you, so let her know she's among friends who understand!! Please....

DIARY DATES

PUBLICATION	COPY DATE
Summer (June) 1998 Journal	30 April 1998
Autumn (September) 1998 News	31 July 1998
Winter (December) 1998 Journal	31 October 1998
Spring (March) 1999 News	31 January 1999
Summer (June) 1999 Journal	30 April 1999

PAA WOBURN CONFERENCE
'Seeking out Solutions'
26th Sept 1998
Please register early- entry via pass only
01923 672837

Free Tickets
To the 1998 Independent Living Show
To order your free tickets call today
01275 836465
Wembley Exhibition Centre
9th - 10th September



CALLING ALL PAA MEMBERS

Dear PAA

CAN YOU HELP ME? PLEASE CAN YOU TELL ME IF THERE ARE ANY PSORIATIC ARTHRITIS CLINICS OR RESEARCH PROGRAMMES?

These are frequently asked questions so we thought it about time that we complied a listing of all interested professionals in psoriatic arthritis, all known research projects and all known psoriatic arthritis clinics operating around the country for YOUR USE.

So if every member wrote to us and let us know if they were being treated in a special clinic, were involved in a special research project or indeed were being treated by sympathetic dermatology/rheumatology or other health professionals for their condition, we could COMPILE THAT LIST which would be an invaluable aid to our work.

If however there is no interest from you then this will mean our list will take longer to compile and will undoubtedly have gaps. So please enter into the spirit of this project - it really is a useful project to undertake and requires little effort from yourselves.

PAA

What's new

Roche Consumer Health has recently launched a new range of skin care products. The new Bepanthol range includes Moisturising Shower Cream, Rich Moisturising Lotion and a Rich Emollient Cream. The range is available from independent pharmacies and leading retail outlets nationwide.

SNIPPET

THE CENTRE FOR MOTHERS WITH RHEUMATIC DISEASE

This centre is located in the city of Trondheim, Norway, and works closely with the Rheumatology Department at Trondheim University Hospital.

If you are a woman with rheumatic disease who is planning a pregnancy or caring for small children, you can contact the centre for information.

Health professionals are also encouraged to contact them for information.

The centre has produced a book entitled "Being a Rheumatic Mother", which offers practical advice for both partners and medical professionals, along with a section on the most frequently asked questions.

For further details please write to :
Centre for Mothers with Rheumatic Disease
Department of Rheumatology
University of Trondheim
N-7006 Trondheim
Norway.

E-mail address: revma@forum.no<mail to:revma@forum.no>Tel:+ 47 73 99 79 90
Fax : + 47 73 99 76 98
Discussion Groups: <http://WWW.FORUM.NO/cgi-shl/dbml.exe?template=/cfpro/modresenteret/rheuma/temaer.dbm>

PAA

Dovonex - change of use

Leo Pharmaceuticals, makers of the Dovenex range of topical treatments, has announced new prescribing details for its products for 1998.
Dovonex ointment and cream can now be used once or twice daily. However, Leo say that for the best response Dovonex (ointment and cream) should always be used twice daily.

PAA

Stop Press

Phillip Evans son of PAA member Colin Evans will be taking part in a sponsored cycle ride from London to Brighton on June 21 on behalf of the PAA. Anyone who would like to sponsor Phillip please contact us at the office and we will pass on your details.

This publication was provided with an Educational Grant from:
Unfortunately we were unable to gain sponsorship for this publication. For details of how to support any PAA publication please call:
01923 672837