

PAA

PSORIATIC ARTHROPATHY ALLIANCE

NEWS JOURNAL

ISSUE NO.6 JUNE 1996



(Left Liz Lynne MP,
Centre David Chandler -
Director of the PAA,
Right John Marshall MP)

Official PAA Charity Launch

18th April 1996

Jubilee Room, Palace of Westminster • Sponsored by David Congdon
MP for Croydon North East

"The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with Psoriatic Arthritis and its associated skin disorder psoriasis".

Psoriatic Arthropathy Alliance is a registered Company limited by guarantee No: 3055414

Psoriatic Arthropathy Alliance, P.O.Box 111, St Albans,

Herts, AL2 3JO

Charity No: 1051169

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PSORIATIC ARTHRITIS CLINIC NEWS FROM LEEDS

Recruits needed!

Dear PAA

I am writing to you with a proposed new Psoriatic Arthritis Clinic which we have established in the Leeds General Infirmary for the North Yorkshire Region. We would be glad to see any patients with psoriatic arthritis in this area. Many of the original studies defining this condition were carried out and published from LGI by Professor V Wright and colleagues. We are hoping not only to continue this tradition but also develop it. In parallel with the clinical commitment to the management of patients with this condition, we are dedicated to develop research in this area.

We are considering a number of research proposals including clinical studies, novel techniques of investigation, treatment and also studies of the genetics of psoriatic arthritis. I do know that in the 1970's there was an extensive survey of family members of patients suffering from psoriatic arthritis undertaken in the Leeds area. Whilst we have many of the case notes, the family members are not easily identifiable from these files and I was hoping to avail of your help in this respect. If you know any persons or indeed any large families with a number of members suffering from psoriatic arthritis in the Yorkshire area, I would be very grateful if the PAA could put them in touch with us. If so, you could contact them directly, by highlighting our clinic in your newsletter or by identifying them and allowing us to contact them locally.

We held a symposium on psoriatic arthritis for the Northern and Yorkshire Region in January which was very successful and we see this has an area to which we are committed to develop not only regionally but nationally and indeed internationally.

There is a long tradition of clinical and research interest in psoriatic arthritis (PA) at Leeds. Indeed, the original descriptions of the different forms of arthritis in the UK came from Professor Wright and Dr Moll in this unit in the early 1970's. In order to maintain and develop this interest we have recently started a psoriatic arthritis initiative in the region. The first step in this is to provide a specialised clinic for patients with psoriatic arthritis in the Leeds area, which is now underway. Some may be aware that there appears to be a genetic link in PA and to study this more closely, we need to identify families in which more than one member has psoriatic arthritis, it may be a brother, sister, cousin, aunt, uncle or indeed grandparent! The relationship is not so important, if there are several members in one family with PA then this may be even more interesting.

Thank you for your anticipated co-operation.

Yours sincerely
Dr Douglas Veale
Consultant
Rheumatologist

THIS IS EXCITING NEWS.

*So please take part as well
as getting well looked after!*

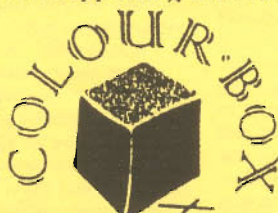
Dr Veale can be contacted on 0113 292 3956

Department of Rheumatology, Old Home
Leeds General Infirmary, Great George Street
Leeds LS1 3EX

Skin N' Bones Connection

NOW FOR SOMETHING COMPLETELY DIFFERENT!!!

**SONNY the bear and
SANDWICH CAT
are supporting the PAA!**



Many of you have already heard of COLOUR BOX MINIATURES, one of Britain's major giftware companies, based in Lauder, in the Scottish Borders, that produce Peter Fagan's collectable ranges for cat lovers "Home Sweet Home", the "Teddies", the dog lovers' "Personality Pups", the tiny "Hopscotch Minis" and "Good Golly". Perhaps you, like me, belong to the strong band of 51,000 members of the Collectors Club!

The "Eggbert" collection, "Bear & Me" and the newly acquired "Teviotdale Wildlife" range, are also other ranges marketed by Colour Box.

I have been a member of the "Collectors Club" since its early days and have seen Colour Box grow and thrive and the one thing I can whole heartedly say is that in all these years and its huge growth, Peter and Frances Fagan, the Managing Directors of the Company, have never lost touch with their members, making sure to attend as many roadshows, events and functions around the country and overseas that they possibly can. They truly care about their members and the products they produce and supply. Colour Box, as they grow, do enormous good work in the Charity sector, supporting as many good causes as they can.

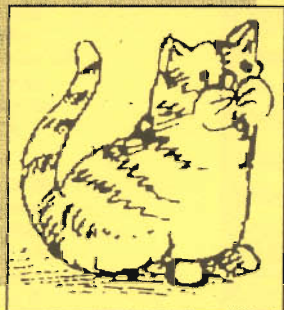
David one day said "Why don't we ask Colour Box if they would like to know more about PAA's work and like to get involved in some way".

I must confess it was with some trepidation that I approached Frances and Peter initially, as I thought the PAA might be too small for them to support, but after some thought and a push up the behind from David I took the plunge. Too small, rubbish. After mugging Peter Fagan at a roadshow, we all agreed to try and meet up to discuss things further, which we did on Monday, April 29th 1996.

We had an extensive discussion about the PAA's work, the condition and the PAA's plans for the future and how we could all work together to further the PAA's cause.

For all those not keen on teddies, cat lovers were catered for too, as also adopted was SANDWICH CAT. We hope if these prove popular to create a range of collectables that you will enjoy and hopefully start collecting through the PAA.

Our trip to Lauder, although business orientated was a sheer pleasure, Frances, together with all those we met at Colour Box, made our visit very special, and we really do hope we can work more closely on projects for the benefit of the PAA in the not too distant future, especially with the help of our PAA members and supporters. These two special pieces will be decorated in the PAA's colours, yellow, and black, and are available for all of you



to purchase at approximately £9.99 +p/p each. (At time of going to print, price to be confirmed).

This will help us raise funds BUT importantly, for you, they will once retired, become collectors pieces in the years to come, as Peter's retired work is fetching premium rates with his growing number of collectors. So they really are worth the purchase



HELP US WITH OUR FUNDRAISING

And get something special into the bargain. To purchase either or both of these pieces and get something special please complete the slip enclosed in this news journal.

**GO ON
GIVE A BEAR
OR SANDWICH CAT
A HOME
AND START
COLLECTING!!**

!!DIET!!

A question that is very commonly asked is whether diet may have a particular effect on arthritis. The answer is maybe - but unfortunately probably not a lot! Whereupon you will immediately want to inform me that the cider vinegar or olive oil capsules you take regularly work wonderfully for you. And I would not take issue with you for one moment as every individual is different and medical science does not have all the answers by any means. However I would add that most of the dietary remedies that you may have been recommended by reading the press or by listening to a well meaning colleague have not stood up to test in properly controlled trials. Also remember that there are often commercial reasons behind promoting products in chronic conditions in which the efficacy of such products may be difficult to assess, and indeed no different from "placebo". It may be worth for a moment explaining what we mean by "placebo".

A placebo effect is that effect that may be gained from simply intervening in treatment of a condition, regardless of whether that intervention works or not. A common placebo effect is seen in drug trials where a dummy tablet is given rather than an active tablet to some individuals who are unaware of the difference (in all such trials the individuals should be told that they have a chance of receiving inactive placebos). It is not uncommon for individuals to improve just with the dummy treatment - the so-called placebo effect. The more dramatic the dummy treatment e.g. an injection rather than a tablet - the greater the placebo effect. Doctors rely on placebo effects all the time - the more they insist or appear confident that a certain treatment will work the more likely such a treatment will work - despite the fact that it may have no effect at all on the

underlying disease process. Placebos are by no means a bad thing if the end result is that the patient feels better. Therefore by all means continue to take whatever remedy you believe is helping you feel better - so long as it is not doing your body any harm.

Having said all that, there is a little bit of evidence that certain dietary interventions may offer more than just placebo. Certain fish oils taken in large quantities may have an anti-inflammatory effect - even if you do run the risk of smelling like a sardine! One estimate has it that at least six fish meals per week are required in order to gain a potentially useful anti-inflammatory effect. Fish oils contain a large proportion of certain polyunsaturated fats which are the building blocks of molecules called prostanoids (eg prostaglandin). Evening primrose oil contains high quantities of another polyunsaturated fat called gammalinoleic acid or GLA. The prostanoids derived from marine oils and evening primrose oil may help block certain pathways leading to inflammation. However one does need to take large quantities of these particular substances, and even then the effect may be no more than mild.

Several studies in rheumatoid arthritis have shown some benefits of diets containing fish oils or GLA, such as a reduced need for non-steroidal anti-inflammatory drugs. Of more relevance to us, it has been shown that skin psoriasis improved in some patients taking large quantities of fish oils compared to a placebo. To date there has not been a study which has shown a beneficial effect of fish oil or GLA on the joints in psoriatic arthritis, but more studies are obviously needed in this area.



Dr Neil McHugh

Consultant Senior Lecturer in Rheumatology
Royal National Hospital for Rheumatic Diseases, Bath

Skin N' Bones Connection

REPORT:

"PUTTING PATIENTS FIRST"

Meeting held at the Dorchester Hotel - December 1995

Arranged in conjunction with the Association of the British Pharmaceutical Industry (ABPI) and Long-Term Medical Conditions Alliance.

HEALTHCARE RATIONING - "PUTTING PATIENTS FIRST"

Patients must have an equal say in the debate on any rationing of health resources - according to the ABPI's 1996 edition of "AGENDA FOR HEALTH", entitled

"PUTTING PATIENTS FIRST" - which was launched at a special seminar held in London in December last year.

The publication examines the progress made in giving patients an effective voice in the treatment of their illness.

The growing necessity of seeking patients' views is supported in the document by the ABPI's Director General **Dr Trevor Jones** who points out that patients' views..



"...will be increasingly important in coming to terms with the vital issues of health funding and the choice and availability of medical care".

Doctors and pharmacists are adapting to a new more open relationship with patients, Dr Jones writes. And he adds:

"The Pharmaceutical Industry is devoting considerable effort into providing patients with more and better information about their medicines and the research that goes into discovering and developing them".

Dr Jones points to "...huge progress" made by the Pharmaceutical Industry to ensure that patients receive comprehensive information about their medicines, including the recent introduction of patient packs.

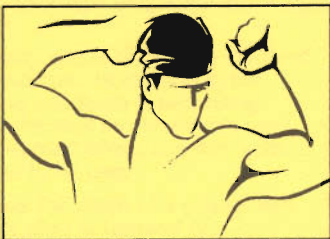
**Report by, Chris Friend,
Government Affairs Consultant,
Director/Advisor to the PAA**

Copies of the book "Putting Patients First" is available free from :

**The Association of the British
Pharmaceutical Industry
12 Whitehall, London.
SW1A 2DY**

or alternatively write to us at the PAA and we will send you a copy.

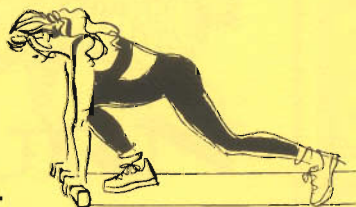
COMING SOON.....



PSORIATIC ARTHRITIS & EXERCISE

This year the PAA, due to ever-increasing demand, felt that a booklet on Psoriatic Arthritis and Exercise needed to be compiled. Well, our medical team have been beaver away, the drafts are nearly done and we hope to launch this new booklet at the Annual Conference in September in Woburn Safari Park. All that needs to be done is to find the funding or a kind sponsor to print the booklets up and distribute them into hospitals for us.

Wish us luck



REPORT:

ALL PARTY PARLIAMENTARY GROUP ON SKIN

February 15th 1996

Dr Anthony White, Rheumatology and Professor Chris Griffiths, Dermatology, both gave excellent presentations to those present, which I am pleased to report was a full room consisting of Dermatologists, MPs, members of the Lords, Patient Groups and members from the Industry.

The P.A.A. was kindly allotted a 1/2 slot, in which to briefly educate those attending on aspects of P.A.

Together both Professor Griffiths and Dr White covered this complex subject quite extensively. A brief history of the illness was given involving the connection with gout and its social acceptability in older times, and how psoriasis was also confused with leprosy, but thankfully times have changed since then. Difficulties in diagnosis on the rheumatology side were explained, and it was emphasized that more care should be taken to ascertain any skin involvement, nail activity, or family history when making a diagnosis, and it was vital that students be taught to look for these.

Professor Griffiths covered psoriasis from treatments, social difficulties involved with the illness and the genetic aspects of the condition. In relation to the genetic side of things, research into this area of the condition is becoming quite active. He passed round the room some of the coal tar treatments used in psoriasis treatments which prompted a few up-turned noses, together with looks of surprise that these types of treatments had to be used.

One sad alarming issue that was raised by him was the death of a young man due to over exposure to a sun bed. He eventually died in hospital of hypothermia, caused by the skin's inability to cope with sudden temperature changes due to the nature of how psoriasis operates shedding and renewing skin cells.

Everyone needs to be careful of incorrect use of sunbeds at the best of times but if you have psoriasis you should be extra careful and aware of the potential dangers involved.

I can safely say that by the time our speakers had finished people were certainly more educated than before they entered the room! *Julie.*

DIARY NOTE

P.A.A.

ANNUAL CONFERENCE

Saturday 21st September 1996

WOBURN SAFARI PARK

Bedfordshire



WOBURN

Further details will follow in due course.

Skin N' Bones Connection



BOOK REVIEWS

ARTHRITIS:

What exercises really work.?

This book grew out of the first ever in-depth survey in America of over 1000 patients with osteo and rheumatoid arthritis. The results from this indicated that a combination of exercise, diet and life-style is the most effective treatment against arthritis.

This book examines what exercises really work. It provides a complete set of exercises, carefully explained and illustrated.

Written by Dava Sobel and Arthur C Klein who are both Medical Journalists and live in the USA and is a sequel to "Arthritis what really works", published last year.

Published by

Robinson Publishing

7 Kensington Church Court,
London W8 4SP

Price: £5.99*



HANDBOOK REVIEW *by the Disability Alliance*

DISABILITY RIGHTS HANDBOOK
21st EDITION; 1996-97

Since 1977, the Disability Rights Handbook has proved an essential, authoritative guide to disabled people on their entitlement to social security benefits and other services. Widely acclaimed for its accessibility, detail and accuracy, the Handbook has attracted an extensive readership of disabled people and those who live and work with them. It now has a print run of 30,000. The number of changes to benefits and services in the last year makes the new 21st edition indispensable.

The book includes:

- a complete new section on Jobseekers Allowance - a new benefit to be introduced during 1996 which replaces unemployment benefit.
- full details of the new criminal injuries compensation scheme for victims of crime.
- details of changes to Income Support
- information on major changes to Housing Benefit for private tenants.

All sections of the book are fully up-dated to take account of legal changes and it is further backed up with an extensive directory - providing the addresses and telephone numbers of disability organisations and advice agencies throughout Great Britain and Northern Ireland.

The DISABILITY RIGHTS HANDBOOK: 21st Edition, by Judith Paterson, will be published in May priced £9.95 (£5.95 for those claiming benefit). For further information, please contact the Sales Dept. on 0171 247 8776

Company limited by guarantee without share capital Number 2056801. Registered Office: Universal House, 88-94 Wentworth St., London E1 7SA.

**Please note before commencing any form of exercise, please check with your doctor or physiotherapies that these are safe and beneficial for you. Each person is an individual and what may suit one will not be suitable for another.*



New Product



NEWS!!

Prescription Only

You may recall in the last Newsletter we told you about a new ointment call "Curatoderm" produced by Merck, well its all go as there is yet another new product just released on the market, this time for **SCALP PSORIASIS**. Its name is "BETAMOUSSE". The makers Evans Medical claim that "it is a new convenient foam mousse formulation of tried and trusted topical corticosteroid, offering a novel approach to treating scalp psoriasis".

The corticosteroid used is Betamethasone Valerate. Applications is a small amount applied twice a day.

They also claim that it has added benefits of no lingering odours, pleasant and clean to use and will not stain clothes or linen.

PLEASE NOTE IT SHOULD NOT BE USED FOR PROLONGED PERIODS.

Note from P.A.A. Like any medication, if you at anytime experience or THINK YOU ARE experiencing adverse effects from any prescribed medication go and check with you doctor that the product used is suitable for you. Best to be sure and not in doubt.

Skin 'N' Bones Connection

NEWS FROM SWEDEN

DID YOU KNOW? About 200,000 Swedish people have psoriasis.

The Swedish Psoriasis Association like the PAA realise the great extent of ignorance together with negative attitudes associated with a skin condition, which for some can be more of an emotional strain than the condition itself. They like ourselves believe it is important that the general public together with the medical profession are educated on what it is like living with a skin disease, and in our case the associated arthritis that may accompany psoriasis.

The Organisation was founded in 1963 and now has over 24,000 members who are organised in 24 country sections and a 100 local sections across Sweden.

It is a non-profit making, non-sectarian, non-political interest body, providing information, moulding public opinion about the skin disease. It also supports research into psoriasis through contributions via its two research funds.

Treatment centres are run Councils, which are very similar to "drop-in" centres, where the patient can come along and treat themselves, with expert trained staff on hand to assist where necessary. Treatments offered range from topical applications, various kinds of baths, sauna, light treatments,

and many centres now offer foot care and soft X-ray treatment (Bucky Treatment). Normal procedure is to usually obtain a doctor's referral letter for a first visit, after that you can go as little or as often as you like. Treatment Centres are designed to be very informal and relaxed, and for most people it is also a social meeting place as well.

Who knows, perhaps the PAA if you, the membership wanted to, could start a National Fundraising Appeal over a period of time so that we could open a centre like this here in England. If that worked we could go on from there - now there's a good idea!!

PSO - Youth, is the youth organisation of the Swedish Psoriasis Association, which was founded in 1983, and now has representatives and sections all over Sweden. It arranges courses and camps and actively spreads information about what it is like to be young and living with psoriasis.

THE PAA WELCOMED KRISTINA SODERLIND *Director from the Swedish Psoriasis Association*



Kristina was holidaying here in May. David myself and Jon Bastow (Leo Laboratories, an invited guest) were lucky enough to meet up with her while she was visiting.

It was great to have the chance of chatting in depth

about the work of her Association and the PAA, the same problems the Organisation faces in raising awareness, the projects they are working on, research, our ideas for future plans, and most importantly how the Organisations could work together in the future.



In such a short space of time we covered many interesting things and felt that we had known Kristina for many years, she felt like a good friend. It was a very positive meeting for all of us and we very much look forward to seeing her again soon.

AND YES, the PAA and the Swedish Psoriasis Association will be working together hopefully for many years to come. Kristina kindly also gave us permission to circulate information that they had produced on various topics and any other future information and news. As soon as we can get some translating done we will let you know. The same goes for the PAA's information. Kristina's Organisation is willing to use this. **HELPING EACH OTHER** that's what it is all about.

The Swedish Psoriasis Association is an impressive Organisation, one to be congratulated, and if the PAA in time can do as well, it will be a quality service psoriasis patients will gladly benefit from.

As soon as Kristina visits again we will all get together, but in the meantime hopefully we will be hearing from her in the forthcoming news journal.

Skin 'N' Bones Connection

Skin Information Day

Popular TV Presenter,
Mairi McHaffie taking
an interest in the PAA



Edinburgh - 27th April 1996

The first Skin Care Campaign Roadshow was held in Scotland recently alongside the launch of a Scottish Psoriasis Campaign aimed at raising awareness and the profile of Psoriasis in Scotland.

In this respect there was extensive coverage on the radio and in the media attracting a huge response in enquiries from those wanting to know more about psoriasis and the Skin Care Campaign.

If when this limited Campaign is over and the results gathered, it deemed a success the Campaign may be undertaken in various regions around the Country.



The Skin Information Day itself proved to also be a success with a good attendance and a lot of interest in the PAA stand, which is good news.

There were various talks throughout the day, including "Psoriasis and Treatments" by Dr Danny Kemmett, "Everyday Living with Psoriasis" by Dr Jean Cooper, a talk by Mr Jonathan Bastow, Leo Laboratories, who produce a well known treatment

for Psoriasis, entitled "The Long and Winding Road", and talk about the problems and time needed before a drug comes to the market place. There was also a question and answer session with a panel drawn from the days speakers, including Ms Penelope Fraser, Psychologist. Ms Mairi McHaffie, a young well known television presenter attended the event, she herself has suffered with psoriasis since the age of 3, so fully appreciates the frustrations caused, and also gave a talk on her personal experiences of living with the condition. Videos were also running throughout the day on



various topics including psoriasis, and there were numerous exhibitors on hand to offer expert advice and samples to take home and try.

It was nice to see a couple of our long standing members too, making themselves known to us. Hello Barbara and Janice thanks for coming to see us.

Further details:

Skin Care Campaign Office:

Tel: 0171 388 5655

Next Roadshow:

Plymouth

Sat. 8th June '96

Inverness

Sat. 28th September '96

Reading

Sat. 5th October '96

Manchester

Sat. 5th November '96

Questions & Answers

Q. I have been told that although the arthritis is connected to psoriasis, if you can get rid of the psoriasis it does not follow the arthritis will go. Is this the case?

A. Whether the arthritis gets better following improvement in the skin depends on whether you are one of those patients in whom the skin and joints wax and wane together. If so, treatment of the skin condition, or the avoidance of factors which make it worse, or the effects of sunshine on the skin may all be followed by improvements in the joints. In patients who have this sequence of events it is usually consistent over time and improvements can be expected in the joints each time the skin improves. In other patients arthritis can be troublesome with the most minimal area of the skin involved, the treatment of the skin has no noticeable effect on the joints.

Q. I recently went to hospital for an arthroscopy on my left knee. Three weeks later I went to see the orthopaedic surgeon for the results. He informed me that although as yet there was no joint inflammation, I asked him that if there was no joint damage WHY were my knees so painful? His answer was "good question" and left the room. Please could you enlighten me more?

A. When a joint is examined by arthroscopy, the degree of magnification of the tissues is quite small and fine detail, as would be seen down a microscope, is not obtained, so that it is entirely possible for inflammation to be present in a degree to cause pain which would not be visible by this method. Also in psoriatic arthritis the inflammation can be intense over a short period of time and then subside, leaving no visible trace by the time arthroscopy is performed.

Q. How do doctors treat patients with Ankylosing Spondylitis and Psoriasis?

A. Ankylosing Spondylitis, or a condition very similar to it, does indeed occur in a proportion of people with psoriasis, and in particular in those who have B27 tissue type. The treatment of the spondylitis element is essentially similar to that for ordinary Ankylosing Spondylitis in people who have no psoriasis, and consists of the prescription of anti-inflammatory medicines and a programme of hydrotherapy and physiotherapy to maintain spinal mobility.

In some patients, individual joints as well as the spine are involved, and it may well be that psoriasis and the infective agents which trigger the arthritis in an individual, also trigger the Spondylitis, joint involvement in either condition will respond to the same medication, e.g. sulphasalazine which has slower, but more fundamental effect on the condition than non-steroidal anti-inflammatory drugs.

Recently there has been evidence that ordinary Ankylosing Spondylitis in which the spinal condition does not respond to sulphasalazine may respond favourably in that respect to methotrexate which of course is already widely used for patients both with psoriasis and psoriatic arthritis.

Q. Could you tell me why I feel so tired with PA?

A. Tiredness is a feature common to all the forms of inflammatory arthritis, and for a long time it was put down to psychological causes and to the effects of chronic pain. There is now evidence that chemical substances that the body produces during inflammation, known as interleukins may be directly responsible for this effect and so when the disease comes under better control, particularly with medicines

which suppress these substances the tiredness begins to improve.

Q. I would like to know why my left knee swelled up with blood and after 7 aspirations, six weeks rest and an arthroscopy (which didn't reveal why) it is still swollen, although I am now using it and back at work. The treatment I am on is Methotrexate - intra-muscular injection once weekly and one Indomethacin 75mg nightly?

A. When a knee is very intensely inflamed, as can be the case in psoriatic arthropathy, there is a great increase in the bloodflow in the lining of the joint, and it becomes congested and bleeds very easily with the most minimal trauma and this is probably what happened in your case. Because there are other serious cases of bleeding into a joint, which requires careful investigation, arthroscopy was a reasonable thing to do. If the case was simply the intensity of the inflammation, this would tend to have subsided after rest and aspiration, so that by the time an arthroscopy was done, it probably would not show anything. You do not say whether anything was injected into your joint, such as steroid, in any of the seven aspirations performed. It is very unusual to have to do as many aspirations as seven and it may be that the reason the fluid kept returning was that the inflammation continued, although not as intensely as when the bleeding occurred, and was not brought under control, either by steroid injection or with the dose of Methotrexate which you were receiving at that time. Methotrexate takes a considerable time to achieve its maximum effect and different patients need widely differing doses.

Dr Anthony White
Consultant
Rheumatologist

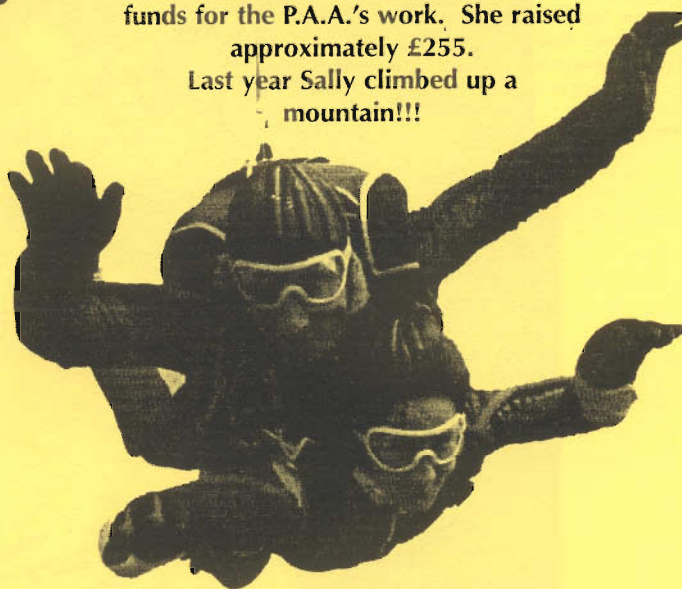
*Royal Free Hospital
London*

CONGRATULATIONS

Sally's Leap for Charity

Sally Dale on 4th May 1996 completed her first tandem skydive to help raise funds for the P.A.A.'s work. She raised approximately £255.

Last year Sally climbed up a mountain!!!



THE HINKLEY TIMES • THURSDAY 18 APRIL 1996

Sufferer set to make charity parachute jump

A PARACHUTE jump is the next step for a Burbage woman who wants to raise awareness about a potentially debilitating disease.

Miss Sally Dale of Lucas Road is finalising plans to make the jump in Banbury this month to publicise the Psoriatic Arthropathy Alliance.

The brave descent ironically comes at a time when the little-known charity is getting off the ground by officially becoming a registered charity today.

The British Parachute Association will be supervising the jump to promote the disease, which may be affecting a staggering 7,500 people in this country.

Despite these figures and the fact that the official launch is taking place in the Jubilee Room at the House of Commons later this month, local businesses have not been keen to help.

Anyone wishing to help Miss Dale, who is still looking for about £140 to cover the cost of the jump, can contact her on Hinkley 614842.

As the proposed date of the jump comes nearer she has managed to enlist the company of a friend, Julie Charnell, through a "bit of smooth talking" and she hopes to attract sponsorship too.

The 26-year-old, who has suffered with the disease for almost

10 years, became aware of the PAA three years ago and her aim is to help as many other sufferers as she can.

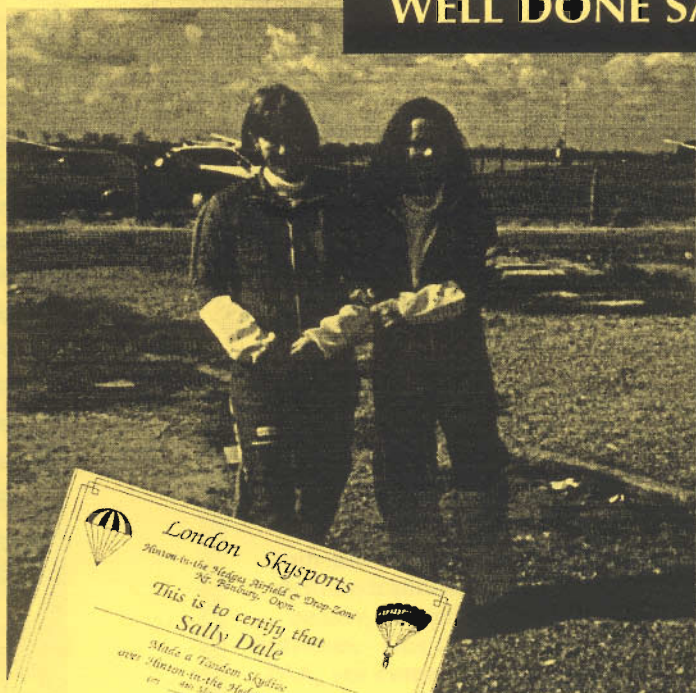
The PAA exists to encourage early diagnosis, provide information and campaign for better treatments through furthering research.

There are no meetings in Hinkley at the moment but it is hoped there will be in the future, when more people become aware of the charity and its support network.

The charity has recently distributed its sixth newsletter to its 400 members.

WELL DONE SALLY!!

Sally Dale with her friend Julie Charnell, who both completed the jump in May this year



Taking the plunge for new charity

A BURBAGE woman is planning a parachute jump to help publicise a new charity being launched to help people who suffer with a little known disease. Sally Dale (26), of Lucas Road, Burbage, is one of an estimated 750,000 people in Britain who have psoriatic arthropathy, a combination of the painful skin condition

psoriasis and arthritis. On April 18, Sally will be attending the launch of the new Psoriatic Arthropathy Alliance, which was recently given charitable status.

Its aims are to: Promote self-help and encourage early diagnosis; Campaign for better treatments and illness management;

Provide information and initiate educational projects;

Work with medical and non-medical professionals to benefit people with the condition;

Encourage working relations with like-minded organisations overseas.

Sally, a wages clerk, has had the condition since she was 17,

although it was not diagnosed until four years later.

"It is pretty painful, but obviously there are varying degrees of it," she said.

"There are some people who are crippled with it."

"When I first got it I didn't know anybody else who had got it, and I felt really cut off."

Treatments includ-

ing creams, anti-inflammatories, steroids help keep the condition controlled. There are now about 400 members in the PAA.

Sally will be making her parachute jump to raise funds - she hopes to top £500 - and she will be happy to hear from sponsors, or fellow PAA sufferers, on 01455 614842.

Sally has kindly asked if all of you who pledged monies for her jump could send these direct to the P.A.A. office please, and thanks to you all for your support.

Skin N' Bones Connection

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