PAA PSORIATIC ARTHROPATHY ALLIANCE

SKIN & BONES CONNECTION

NEWS JOURNAL

ISSUE NUMBER 5: DECEMBER 1995

PAA

The Psoriatic Arthropathy Alliance

requests the pleasure of your company on
Saturday, 23rd September 1995
at
The Meeting Rooms
Zoological Society of London, Regent's Park, London, NW1 4RY
9.30am - 3.00pm
for their

INAUGURAL MEETING

Light buffet lunch will be provided
Partners and children welcome

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

Company limited by Guarantee
Reg No: 3055414

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

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INTEREST IN P.A.A.

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We also believe that at the time of printing all information to be correct but cannot be held responsible for any inaccuracies that may occur,nor do we endorse any products that may appear in this Journal. All opinions expressed herein are of the contributors and not necessarily those of the PAA. Always consult your own doctors for advice.

A NOTE FROM A MEMBER!

Dear David & Julie,

I would like through your newsjournal,to thank you both for your invaluable help in the last 2 years. After suffering 18 years of mental and physical pain,my new G.P. (my old one retired) agreed to send me to the Rheumatologist,Dr.Oliver Fitzgerald in Dublin,where after a 5 day stay in hospital in Dublin,and 3 weeks in a rehabilitation unit,I have won my 18 year fight in proving I have got PA and anklosing spondilitis which has caused some fusion in the Sacro joints.

There were times in the past I felt like giving up,but I carried on fighting the verdict of some doctors who thought my symptoms were in my mind.

So other members it does pay to fight your corner,no one else knows better than you if you are in pain.

David and Julie,thank you again and good luck in your new careers and carry on the good work with the P.A.A.

Yours gratefully,
Mrs Jacqueline Ward.

KEEP UP THE FIGHT FOR WHAT YOU BELIEVE

TO BE RIGHT!

PAA

PSORIATIC ARTHROPATHY ALLIANCE INAUGURAL MEETING

MEETING ROOMS ZOOLOGICAL SOCIETY Regent's Park London NW1 4RY

Saturday 23rd Sept 1995 9.30am-3.0pm

Programme

9.30-10.00am	Tea and coffee
10.30am	Introduction by David Chandler,Co-Founder/Director of PAA
10.40am	Mr Chris Friend, Government/Public Affairs Consultant & Director to PAA Talk: Patients in Partnership.
11.00-11.45am	"Speak Easy" opening by David Chandler. We would like to hear from you with your views,suggestions on the way forward for the continued work to be done by the PAA. Open debate.
11.30am	Coffee
11.45am	Dr.Anthony White,Royal Free Hospital,London.
	Followed by research up-dates from; Dr.Sharon Jones,Royal National Hospital for Rheumatic Diseases,Bath Ms.Elizabeth Ross,St.Bartholomews Hospital,London.
12.30pm	QUESTIONS & ANSWERS SESSION This session is open to all in the audience. Please feel free to ask any questions you may have to medical advisory team;
	Chaired by Mr Patrick Parker,Public Relations Consultant and Director to PAA.
	Rheumatology:Dr.Virginia Camp,Dr.D.Golding,Dr.A.White,Dr.Neil McHugh,Dr.Sharon Jones.
	Immunology: Ms.Elizabeth Ross.
	Specialist Dermatology Sister: Ms.Sherry Ross
1.30pm	Closing talk by David Chandler
	RAFFLE DRAW
1.45pm	Lunch: Light finger buffet
	END. Thank you for attending.

REPORT:

Psoriatic Arthropathy Alliance
Inaugural General Meeting 23rd September 1995.

Over 90 people came from many parts of the U.K. to take part in the PAA's first general meeting,held at the Conference Centre of the Royal Zoological Society in Regent's Park,London on Saturday,23rd September 1995.

Those with psoriatic arthritis,their families and health care professionals met to hear how the organisation has been progressing and its plans for the year ahead. Other objectives of the event were to provide an opportunity to discuss the Alliance and express "likes and dislikes" about its activities and services. Most of the medical and professional advisers of the PAA attended and gave valuable advice both formally and informally. The meeting was well supported by the medicines manufacturers and research based companies working in this field.

However one of the most important aims of the meeting was to provide an opportunity for those with the condition,their families,partners and carers to meet each other and exchange information and ideas on how to cope with PA.Because of the relative rareness of this condition such opportunities do not occur often.

Information was provided on how the organisation is proceeding towards charity status and how it is working with other organisations with similar goals and interests both at home and abroad. Not least in the Skin Care Campaign itself. The importance and value of the PAA,alone and in alliance,in representing the needs people with PA as an advocacy body working with politicians,civil servants,administrators and commerce,was stressed.

Formal medical and scientific imput was provided by some of our Advisors namely,Dr.Anthony

White,Consultant Rheumatologist,Royal Free Hospital,London,Dr.Sharon Jones,Registrar in Rheumatology, Royal National Hospital for Rheuamtic Diseases,Bath,Ms Elizabeth Ross,Clinical Research Assistant, St.Bartholomews Hospital,London.

Between them they provided a comprehensive,valuable clincial and physiological background to the condition of PA,the difficulty of diagnosis,its current and future treatments and its immunological background and links.

They were joined by a further impressive array of our expert advisers,Dr.Doulgas Golding,Consultant Rheumatologist,Princess Alexandra Hospital,Harlow,Dr.Virginia Camp,Consultant in Rheumatology and Disability Medicine (S.Buckinghamshire NHS Trust);Dr.Neil McHugh,Consultant and Senior Lecturer,Royal National Hospital for Rheumatic Diseases,Bath,and Ms Sherry Ross,who is a Specialist Dermatology Sister,Newham Health Care Trust for a Question and Answer session chaired by Mr Patrick Parker,of Medical & Media Communications,director to the PAA. Between them this group dealt with a wide range of issues including diet,exercise,new treatments,alternative treatments,over the counter medicines and physiotherapy.

Chris Friend
Government & Public Affairs & Director to the PAA.

BOOKLET

"WHO'S WHO IN THE P.A.A"

The above booklet was produced especially for the Meeting,giving brief backgrounds on all those involved in the P.A.A. including pictures of most of us. Copies are still available for anyone wishing to have a copy. A5 S.A.E appreciated. Thanks.

FEEDBACK FEEDBACK!!!!

Here are the findings from the questionnaires all of you who attended kindly completed and sent back to us after the meeting. The feedback from these was extremely encouraging,positive and supportive,as you will see from some of the quotes from members,for all of us working within the PAA,with some very good suggestions coming through to base future meetings and work on. The PAA has alot of ground to cover!!

Here's what you said - FUTURE MEETINGS:

You would like to see more of the following covered at future meetings:-

* To hear more Case Histories from members willing to participate.
  To hear how members cope with the illness from day to day.

* Presentations on topics relating to psoriasis.

* Camouflage demonstrations.

* Presentations from drug manufacturers on the making of medicines.
  Success rates and side effects of various drugs.
  Progress of drug research.

* Would like to see more comparisons of treatments (topical applications available) and patient compliance.

* Talks and demonstrations from Physiotherapists on exercise and how they can help PA.

* Exhibitors concerning household aids for day to day living.
Footwear specialists offering advice.

* Alternative work opportunities: How to go about finding out whats available,to include course training etc.

* Exhibitors: Alternative therapies ie acupuncture,healing,tens machines massage,aromatherapy.

* How to cope with stress and pain management.

* Disability Living Allowance explained.
Other benefits explained.

* Presentation by Psychologist on the effects of Psoriasis and Pa.

* Discussion between members on adapting to PA once diagnosed.

* Workshops devoted to specific topics of PA.

* Presentation on Ankylosing spondylitis and PA.

* Hormones: the part they play in PA,Psoriasis

What you want the PAA to work on:-

* More public awareness of the condition
Highlighting the link between the skin and joints.
More media promotion

* Early diagnosis.

* Job discrimination : more investigation into how widespread this is and highlighted where possible.

* Tackle issues that make life difficult for those with PA such as ticket dispensers,public telephones,non-user friendly counters ie.Post offices (coinage difficult to pick up),etc.

* To inform bodies such as Social Services of the illness and difficulties faced by the person and their families/partners living with the illness.

YOUR SUGGESTIONS

Suggestions which have been put forward. Please could we have your views on these proposals!!

HOLIDAY - it has been suggested that perhaps we could arrange a short break in this Country,at a holiday village,Centre Parcs or other suitable location, would give members and their families a chance to meet up more socially and relax. YOUR COMMENTS PLEASE,if there is enough interest we will look into arranging this.

DIARIES - Again it was suggested that anyone interested,start a diary,detailing from day to day how they feel both phyiscally and mentally,what symptoms they experience reactions to foods eaten etc. These would then be sent in,the information compiled to see how many of you suffer from the same things,to what extent the illness affects your lives. This would be although time consuming,an interesting project which could produce alot of productive information. VIEWS PLEASE. This could be a study initiated by the P.A.A. and members on an in-house basis.

GET-TOGETHERS:

Anyone interested in forming a regional group covering Herts,Beds,Cambs and Essex? Or any other area please get in touch.

TALKBACK TALKBACK TALKBACK

It was our first Meeting,so there were bound to be a few teething problems which we will be able to learn from and make sure do not happen at future events.

Some of the problems were:-

Presentations made by our medical team and those taking part were supposed to be audio taped,so that they could be made available to all members and professionals after the event along with transcipts.Unfortunately the technician at London Zoo did not carry out this task which is a great pity. Thus material that can be supplied is very limited at this moment in time.

Lack of directions: This is something the P.A.A. inadequately failed to do sufficiently near to the event.This will be remedied in future.

More should have be done to take into account those travelling to the Meeting alone to be introduced to other members. It can be difficult when you are on your own to mingle.

Disabled toilet: Again through no fault of our own,when we arrived the disabled toiled was closed due to a blockage! Apologies to those who found it difficult to get upstairs.

THE WORK OF THE P.A.A.

Again from the feedback on questionnaires received all of you were very happy with us and our efforts. Although alittle more work has to be done to improve the PEN PAL lists in some way. A point was raised that a member had written to most on the list and had only received one reply. Julie has since written to the member concerned to find out more details and is awaiting her reply. There is little we can do ourselves as it is left up to those of you on the lists to contact each other,but please although it is difficult sometimes to write back promptly,if you have had a letter,no matter how long it takes,please give the courtesy of a reply to the person who has taken the time to write to you,even if it is a short one reply back.

NEWS JOURNALS: You all seem happy with these for the present.

RIGHT TO REPLY:

NEWS LETTERS: Out of all the returned questionnaires there was one unhappy person with a complaint. "A minor quibble (to some) but irritating to others,is the spelling and grammatical errors in the newsletters."

This comment I must confess saddened me greatly. As most of you are aware I produce the newsletters/journals with your help and your contributions, for which I am really grateful.

In reply to this statement I apologise if you find my work irritating to some severe degree,but would like to point out that my education may not be quite up to scratch,nor do I have any formal training in writing or running a Voluntary Organisation. Fate has played a part in this! I'm sorry to say,I am totally human with alot of faults,doing all the things that everyone has

to do,such as bringing up a young daughter,doing household chores,looking after a sick husband that needs his fair share of love and care,and generally keeping things on an even keel.

My time is divided between doing the above and running the P.A.A,with very little time for myself. Maybe alittle appreciation could be given for all the huge amounts of voluntary man hours that go into producing these publications,not to mention trying to encourage medical/non medical persons to contribute the articles, which is not easy by far,running the P.A.A., dealing with memberships,attending meetings,meeting deadlines, etc,making sure that people know that there is an illness called "Psoriatic Arthritis".

I am a total novice to all this, carrying out the work the only way I know how,but I obviously need to improve on the things that are more important,my spelling,and grammar to name but a few things. Up until 2½ years ago there were no newsletters or journals to read,so perhaps its better to read these with their imperfections rather than nothing at all.

It gets lonely sometimes doing this job.Is there any compassionate out there? Can't we be judged for our accomplishments and not our failings? I am just grateful that I can read and write and my heart goes out to those who can't and have to deal with the attached stigma,some living in fear in case people do find out.

Thank you all for letting me have a say.

Julie

SOME OF YOUR QUOTES

"As a dermatology nurse I found this session informative from a professional point of view and invaluable in hearing patients problems. It has stimulated some very simple ideas for me to take back to my department. It was well worth me attending this event on my day off. Thank you for a well organised informative meeting. It was nice to see so many people attend and actively participate in this

meeting."

"It was beneficial meeting other people with the same illness"

"Psoriasis and arthritis explained in a way that was informative and easy to understand".

"It was extremely beneficial to learn more about the disease and encouraging to hear about research."

"I learnt such alot on PA."
"I'm so glad I came to the Meeting,it was very helpful to me".

" We found the PAA unlike many groups eg.Disability Groups. Alot of them are apathetic you are not! keep up the good work".

"My husband and I thought the meeting was very informative and well organised,and the visit to the zoo finished the day off".

"Informative and thought provoking".

"It was very beneficial. Gave me impetus to stand up for my rights. Good to talk to other people about problem. Did my husband good too."

"We really enjoyed it. It added greatly to our knowledge. It was a treat to be talked to as though we could understand."

" I enjoyed the first meeting and the people I met. Thank you for inviting me."
"I think you are doing a terrific job,just keep it up".

"The venue was excellent,the talks especially Elizabeth Ross were informative - the atmosphere was friendly."

VIDEO NEWS!

To raise more awareness about Psoriatic Arthritis and the work of the P.A.A. it was decided in the planning stages of the Meeting that we would try to raise some sponsorship so as to enable us to have the proceedings videoed,which would also be made available on loan to members and medical/non-medical professionals.

Unfortunately the funding could not be raised and we thought all was lost until John Bevan,a member with psoriasis and PA, saved the day. He is himself a script writer,and his brother David, a full-time professional camera man,between them arranged access to equipment,film and a crew. All this and the crews' time was donated free to the day.

They mingled with visitors,took names and addresses of those who wanted to participate more in depth with interviews at a later date and filmed the presentations and general proceedings.

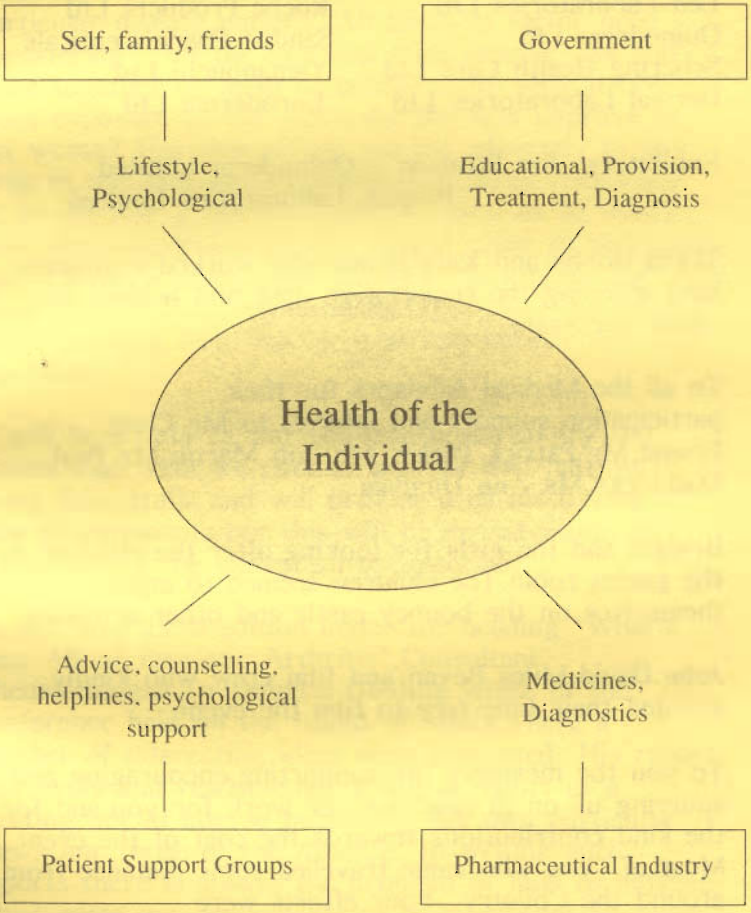
The aim now is to try and raise the necessary sponsorship so that we can edit the film,interview the advisors,and those of you willing who have varying degrees of PA,and hopefully make it into an informative short documentary,which will, if luck is with us,be taken up by Television and other media sources. But at this moment in time alot depends on funding as to how far we get with it.

Any of you who did not attend the meeting but would like to participate in the video in some way please let us know and we will let John know.

Will keep you all posted on further developments.

PATIENTS IN PARTNERSHIP

Where does the patient fit in to the overall plan!
A slide used in the presentation given by Chris Friend to illustrate what's involved in our health care.



THANK YOU

The P.A.A. wishes to thank the following for their help and sponsorship, in connection with the preparation of our first Meeting and donation of raffle prizes for the draw that was held:-

Bioglan Laboratories Ltd
Leo Laboratories Ltd
Quinoderm Ltd
Schering Health Care Ltd
Dermal Laboratories Ltd
Crookes Healthcare Ltd
Roche Products Ltd
Sandoz Pharmaceuticals
Yamanouchi Ltd
Euroderma Ltd

Exhibitors: Jon Stratton - Quinoderm Limited
Bioglan Laboratories Limited

Tricia Hobbs and Kate Heath who worked extremely hard manning the registration desk and helping out where necessary.

To all the Medical Advisors for their participation,support and interest,to Mr Chris Friend,Mr Patrick Parker,Mr Bob Martin,Mr Paul Maddocks,Ms Ann Dugdale.

Bridget and the girls for looking after the children in the games room.The children seemed to enjoy themselves on the bouncy castle and other activities.

John,David,Miles Bevan and film crew who kindly donated their time free to film the event.

To you the members for supporting,encouraging and spurring us on to continue our work for you,and for the kind contributions towards the cost of the event. Most of you who came travelled some distance from around the Country. Your efforts were appreciated,and it was lovely to see you all. See you next year.

Julie & David

CROSSFIRE COLUMN!!

Dr.Anthony White: Medical Adviser

WHAT DOES IT ALL MEAN?

Whatever we read in the press nationally,locally or in our own publication there is still no real substitute for tailoring the treatment to the whole patient and their particular disease pattern. All kinds of factor need considering - do the skin and joint trouble wax and wane together or seem to behave quite separately? Does exposure to the sun make the skin improve or get worse? Has this patient reacted adversely to any drug in the past and how does this relate chemically or in the way it works to the one now to be tried? How much alcohol does this patient claim to be taking and is this an estimate or a gross under-estimate? All these things need expert assessment along with others when planning how best to treat any patient with this condition.

It will be a duty of our editorial board to try and ensure that what we publish will not lead patients along false trails and will provide a balanced view of new developments,but this will be no substitute for the advice of the patient's own specialist.

In our May 1995 edition under the heading "What's New About Psoriatic Arthritis",Consultant Rheumatologist,Dr.Douglas Golding wrote of the conference held on the Island of Malta,where a number of interesting ideas were presented. His report was lively and readable,but it was a report of a meeting not of course presenting his own particular views nor those of the Alliance. In writing such reports there is always the problem of how to indicate which ideas are really likely to be significant advances in treatment and which merely speculative or sometimes just plain wrong.

So it was with some concern that rheumatologists up and down the Country have started to receive requests from patients via their doctors to have their treatment

changed from Sulphasalazine to Methotrexate on the grounds that this report in our Journal says the former is outdated and the latter is better. It shows at one and the same time the potential power of patients' organisations and the risk of unintended disinformation.

The facts are rather different. Methotrexate has been used to treat Psoriasis of the skin for over twenty years and its benefits for the patient with both skin and joint involvment are well known and long established.The side effects and risks of this treatment too are well documentated and have been extensively studied. The risk of fibrosis or cirrhosis of the liver particularly in those with a history of heavy alcohol use was established in studies by the dermatologist and the Liver Unit at the Royal Free Hospital many years ago. The role of liver biopsy was established and the limitations of liver function tests done on blood samples,although still essential,were clearly demonstrated. There is also the potentially serious fibrosis of the lungs necessitating annual chest x-rays all through the period of treatment.As a recent case in my unit showed this can be surprisingly rapid in onset and require steroid and oxygen therapy as an inpatient in the severely affected case. Useful as it is this drug has sufficient toxicity to cause all those who use it to do so with due caution and to seek other forms of treatment as alternatives. There are also whole groups of patient for whom it is essentially unsuited owing to its particular risk to the foetus.

By contrast there is a quite large group of patients whose skin is very little affected and who have quite major joint involvment.Many of these patients are sent to rheumatologists as puzzles in diagnosis as the psoriasis has not been noted,confirmed as it so often is to tiny areas well hidden. It may be just a 1cm patch of scaly scalp or it may be hiding in the umbilicus for instance. Such patients need effective

treatment for their arthritis but the risks from Methotrexate treatment may be quite unacceptable. For these patients Sulphasalazine may prove of great value.

The early work on its use was done in Paris and hence most of the papers about it were not published in the English medical literature. Its use in continental Europe thus pre-dated its use here. From the viewpoint of many in the Malta meeting it could seem a well established treatment, particularly as much of the work on Methotrexate was done and written about in the American and British medical press. Actually Sulphasalazine is not yet even in the manufacturer's own literature advocated for psoriatic arthritis, although long used and originally synthesised for the treatment rheumatoid arthritis.

Since Dr. Golding's report from Malta there has appeared a further paper on the efficacy of Suphasalazine in the peripheral arthritis of psoriasis based on research at the University of Michigan, Ann Arbor (J. Rheumatol. 1995;22.5.894-898) and hence its usefulness is being more appreciated rather than less. At the same time a recent study indicates that Methotrexate may be of value in the spinal as well as the peripheral joint aspects of ankylosing spondylitis so that those people with psoriatic arthritis having a pattern resembling that disease could have a new avenue of treatment opening up for them.

Dr. Anthony White - Medical Advisor to the PAA
Psoriatic Arthritis Clinic, The Royal Free Hospital
London.

NEW PRODUCT INFO!!!!

An emollient in a spray

There is now a totally new type of emollient available to help counteract skin dryness,its name DERMAMIST.

It's a lanolin-free emollient spray,the first of its kind,which is clean,quick,easy to use and convenient,and best of all does not leave your skin feeling greasy.

Simply spray Dermamist onto the affected area of skin,preferably after a bath or shower. This will help to soften and soothe the skin by trapping in moisture and preventing it from drying out,bringing welcome relief to itchiness.

Dermamist is suitable for all ages and sensitive skins. It contains only naturally occurring oils and no lanolin or parabens. The ozone-friendly 250ml aerosol is handy to carry around and ideal for people leading an active lifestyle. Dermamist is now available direct from retail chemists or on prescription.

DERMAMIST is produced by Yamanouchi Pharma Limited,Yamanouchi House,Pyrford Road,West Byfleet, Surrey,KT14 6RA.

Happy Jill Hayes with her raffle prize, kindly donated by Euroderma Limited. Jill has been with us since the formation of the Alliance in 1993.

Sue Johnson, again one of our original members, with her bottle of Fortnum & Mason Veuve Clicquot Ponsardin 1988 (one of four kindly donated by Schering Health Care Limited).

Our Advisory team hard at work. Pictured left to right: Ms Sherry Ross, Ms Elizabeth Ross, Dr Sharron Jones, Dr Virginia Camp, Dr Anthony White, Dr Douglas Golding, Chair of session; Mr Patrick Parker. Dr. Neil McHugh out of camera range was sitting next to Sherry.

Mr Patrick Parker, Director to the P.A.A. chairing the Questions & Answers Session.

Mr Chris Friend. Director to the P.A.A. showing how things are done. "just like that"!! Presentation: Patients in partnership.

David Bevan and crew conducting an interview with willing participants.

REPORT:

PATIENT PACK LAUNCH SEMINAR:14th June 1995
Royal Pharmaceutical Society of Great Britain.

The Seminar was opened by Mr Gerald Malone,MP and Minister for Health,who reinforced the Government's backing to the Joint Working Group on Patient Packs and the importance of these new patients packs and their launch.

WHAT IS A PATIENT PACK?

These will consist of a course of medication together with a patient information leaflet in a ready-to-dispense pack. Most packs will contain enough medication for one months treatment.There will be special packs available to comply with shorter or longer courses that may be necessary along with starter packs where a patient needs to be started on a lower dose treatment.

The Patients Pack and its format will bring us in line with a recent EC Directive (1st Jan'94 92/27/EEC) which outlines new requirements for labelling and content of user information leaflet be provided with each medicine. Since that date all new medicines are produced in the correct format and all licences for existing medicines will only be renewed if they comply to these regulations. By January 1999 all medicines will have to contain the new style leaflets in the appropriate packaging.

The Pharmaceutical Industry will be considerably hit as they will have to change their production systems,as well as Pharmacists having to adjust to the new dispensing styles. To the patient it will mean clearer information on the drug and how to use it,possible side The medication will be packaged in user friendly packaging etc. Hopefully the needs of those with arthritis will be taken into account by the manufactuers.

PLEASE REMEMBER your Pharmacist will be only too happy to discuss any worries you may have about your medicines so please don't feel apprehensive about talking to him/her. There are

only too happy to help,and if they are not then they are not doing their job properly. The GP and the Pharmacist have key roles to play where the patient is concerned.

At the present time the only countries in Europe which still dispense medication from bulk supplies are Ireland,Holland and ourselves.

Phasing in of these packs will be gradual as from 1st December 1995,thereafter infour phases per year; March June,September and December for the next 3 years. At the beginning of each phase a designated group of medicines will transfer to the new patient packs.

A number of bodies have joined together to make up the "Patient Pack Joint Working Group" and consists of:-Royal Pharmaceutical Society of Great Britain,General Medical Services Committee of the British Medical Association,Pharmaceutical Services Negotiating Committee,Department of Health,Medicines Control Agency,British Generic Manufacturers Association and Association of the British Pharmaceutical Industry.

As a working Group they all realise there are going to be certain important criteria that have to be met. Adequate information to be added to leaflets as to side affects,clear instruction as to how to use the medication,the role of GPs and Pharmacists to back-up information in the patient packs,language barriers to be crossed. In-depth consultations have been and will continue to be made with patient groups and professionals to try to ensure better services for the patient. There is still an enormous amount of work to do to get things right.

The was an exceptionally good turnout of delegates ranging from patient groups such as ourselves,Pharmacists,Industry,Area Health Authorities.

PA and Pregnancy

The ratio of the number of women and men with PA varies between studies and between the different subgroups of disease.However in most studies,PA,like rheumatoid arthritis,has been found to affect women more often than men. This female preponderance has lead to an interest on the effect of pregnancy on PA.

EFFECT OF PREGNANCY ON ARTHRITIS

Less than 20% of female patients develop arthritis before their first pregnancy. Like rheumatoid arthritis,there is evidence of a hormonal influence on the occurrence of PA. For most,the time after having a baby and the time furing the menopause are two common times for developing arthritis and it is possible that hormonal factors at these times may trigger the onset of arthritis. Although the activity of arthritis and psoriasis can be variable during pregnancy,research has shown that in general it seems to improve during pregnancy and flare after the birth (post-partum flare) in a similar way to rheumatoid arthritis.

There is no significant increase in miscarriages in women with PA and no other unusual effects on the baby. Breast feeding is encouraged as in any normal pregnancy.

MEDICATION

Many patients are concerned about the effects of their medications on conception and pregnancy. There are no universal guidelines and medication needs to be tailored to individual needs. The general advice is that most medications used for arthritis during pregnanacy are safe,although it is sensible to keep medications to a minimum. Patients should be reassured that if a particular medication does need to be stopped for any

reason,there are alternatives.

Both female and male patients with PA should discuss a planned pregnancy with their rheumatologist,dermatologist or GP so that the best advice about their particular medication is given. This is particularly important for patients on disease-modifying therapy. Men with PA taking sulphasalzine should be aware that the drug may reduce the sperm count,but this is fully reversible on stopping the drug.

ONGOING RESEARCH

We are further examining the influence of hormonal factors such as pregnancy and the menopause on the onset and activity of PA. If you are female with PA and would be willing to complete a questionnaire about your arthritis,please contact:-

Dr.S.M.Jones,
Senior Registrar in Rheumatology,
Royal National Hospital for Rheumatic Diseases,
Upper Borough Walls,
BATH,BA1 1RL. Tele: 01225-465941.

RESEARCH PROJECT:

Recruits are still needed to participate in the research project currently being undertaken at St.Bartholomews Hospital into the cause of PA. It is very important to identify which cells are responsible for destruction in the skin and joints so that in the future we will be able to focus the treatment for controlling these cells.

Anyone interested in taking part in this study that has not already done so or you would like further details please contact:

Ms Elizabeth Ross,Clinical Research Assistant,
Immunology Department,The Medical College of Saint Bartholomew's Hospital,51-53,Bartholomews Close,West Smithfield,
London, EC1A 7BE. Tele: 0171-601-8428.

Elizabeth is particularly keen to speak to any of you who have larger joints,such as the knees that are swollen.

ALTERNATIVE HEALTH SLOT:

THE HEALING POWER OF CLAY

In Europe clay is in widespread use and forms a branch of alternative medicine known as ARGILOTHERAPY (Clay Therapy).

The definitive book on clay,its power and uses is "L'ARGILE QUI GUERIT" - "THE HEALING POWER OF CLAY" by Raymond Dextreit. Originally printed in 1954,it is available from Aquarian Publication. He is referred to by Leslie Kenton,the wellknown authoress of "Raw Energy",Ultrahealth and many more books.

Although,clays come in different forms and colours,ech with specific properties suitable for particular uses,they all share in a range of minerals and trace elements including silica,iron,magnesium,calcium,potassium,manganese,titanium and chromium.

The Clay Company only use air-dried clays. This is the original drying process which captures the clays in their natural state,as opposed to oven-dried clays.

The power of clay to help and heal various ailments is outlined by Mr Dextreit and is based on empirical knowledge that goes back centuries,if not thousands of years, and is still in practice in different cultures all over the world.

In Britain,white clay is found in many produts especially for the stomach. Equestrians know of the amazing help clay bandages and poultices are to horses' ankles and bones. Indeed the animal kingdom know to eat or wallow in clay.

The Clay Company produce a range of easy to use masks,bath soaks and bandages which are used and

recommended for all manner of ailments.

For a free brochure please send a S.A.E. to
The Clay Company,Penny Lane,Liverpool,L18 1DG.

Their range includes bath soaks for arthritic/rheumatic conditions,sensitive skin conditions,tired aching muscles,and detoxifying soaks as well as body wraps,and scrubs.

BOOKLIST

Betrayal of Trust by Vernon Coleman

£9.95 p&p free from:
Published by the European Medical Journal.

Available from Healthbooks,
Sales Office DT5,Publishing House,Trinity Place,
Barnstaple,Devon,EX32 9HJ.

Do doctors do more harm than good?Dr.Coleman is a medical doctor with something to say.

Restore Your Health the Dead Sea Way.

Sandra Gibbons published by The Green Library
The Alternative Centre.
£6.99.

BRITISH RED CROSS COSMETIC CAMOUFLAGE SERVICE "COVER UP & FEEL BETTER"

For two decades the British Red Cross Society's Cosmetic Camouflage Service has helped people cope with disfiguring marks and skin blemishes. It was set up in response to a Department of Health Survey of Dermatologists which identified the need for advice on the concealment of marks.Often these are the cause of embarrassement and distress.

British Red Cross members were already involved in the delivery of a unique hand and beauty care service to patients in hospitals. It seemed a natural progression to extend their knowledge and practice into the area of cosmetic camouflage. The Department of Health gave grant aid to the cost of training the first 50 members in the new skills. There are now over 160 members practising cosmetic camouflage throughout the UK in over 120 "clinics" held fortnightly or monthly - usually in the out-patient departments of District General Hospitals.

The advice is available to men,women and children. There is only one qualifying criterium and that is a medical referral from a consultant or G.P.

The majority of the 5000 or more referrals each yar present with dematological conditions. Initially those with birthmarks (port wine stains) were most numerous and those with vitiligo,but increasingly in recent years practitioners have received received referrals from those with other conditions - rosacea,acne and psoriasis. Referrals also come for those with scarring,caused surgically and accidentally,and from occasionally those with tattoos.

When a referral is received,an appointment will be arranged at a convenient "clinic". In the course of a consultation which may last between 45 and 60 minutes,the cosmetic camouflage practitioner will

colour match the special creams to the client's skin colour. The aim is a satisfactory match,either to the client's single colour or a simple mix of two or three colours. The client will be involved throughout and shown how to match the creams him/herself,before being instructed in how to apply and set the creams. Properly applied the creams can be made waterproof.Before concluding the consultation,the client will be given a "recipe" or a note will be passed to the doctor as the creams used by British Red Cross practitioners are available on prescription.

Clients may find the matching and application of creams difficult at first but in time and with practice will become very competent if not expert in camouflaging their own mark.If difficulties are experienced,a second appointment is always possible.

Many people have found that cosmetic camouflage has helped them to cope with a disfiguring mark,but it is not a miracle cure-all. It is a disguise which enables a client to go out and move among other people without feeling that everyone is looking at the mark on their skin; it allows the user to choose whether or when to reveal their "secret" to new friends or colleagues. It is more successful on some conditions than others: creams adhere more easily if the skin is smooth - but the appearance of many blemishes may be improved.

All the creams used by British Red Cross Cosemetic Camouflage practitioners may be prescribed - and all contain sun screens but the SPF is not quoted as often additional protection is required.

Anyone wishing to know more about the service and where it is available in their area should contact the Therapeutic Beauty Care Officer at their count branch HQ. The address and phone number will be listed in the phone book under British Red Cross Society.

Sian Scott
Development Officer
Therapeutic Beauty Care.

REPORT.....

PHARMACY WEEK:

19th June 1995:
Reception held at the National Westminster Hall,Bishopsgate,London.

Mrs Virginia Bottomley MP,then Secretary of State for Health duly attended this short function in the evening. She gave a brief speech endorsing the great work of our British Pharmacists,the role they play now and their part in the future,and wished them every success with Pharmacy Week.

Like everything in the Health Service the changes taking place will also affect the work of pharmacists.

During the course of my work with the PAA I'm always learning. By attending this function I am pleased to say I have gained quite abit more insight into the work of the Pharmacist. They are not there just to sell hairspray or dish out the haemorroid creams,under that coat lurks a very knowledgeable person. I am sure that sometimes we see our local Pharmacist as someone who works behind a counter all day serving customers,well I was wrong. They provide other back up services to the community,like delivering prescriptions to the elderly,disabled,visiting residential homes to bring staff up to date with the dispensation of drugs,training programmes.

Because of the amount of drugs coming through on the market,they are constantly reading,attending seminars to keep on top of things.They provide essential back-up for GPs and health professionals. Pharmacists are smartening themselves up and realise

their role is a bigger one for the future. They now run courses for sales assistants who dispense drug preparations within their stores and are realise the importance of polite service and appearance.

When you next go to your Pharmacist for your prescriptions you will probably find them taking more interest and asking you more questions about your medication don't worry they are trying to do their job more efficiently for you,so please be co-operative back,getting the balance right sometimes can be difficult,and many of us sometimes I feel sure think they are just being nosey or it's an inconvenience when you are in a rush and just need a packet of headache pills,but they have our best interests at heart.

Did you know that Pharmacists around the Country see on average 6 million people a day!!

They are there and willing to help you. If you have any worries about drugs prescribed or other preparations please ask their advice which is extensive.

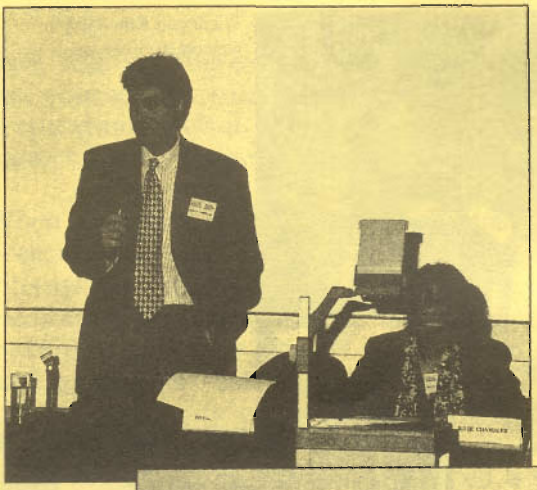
Whilst on this topic PLEASE REMEMBER if you are like most of us on long term drugs or use the topcial applications when you need to buy other preparations ie. headache pills,cough remedies, please check they are ok to take with your other other drug therapy because some do not go together!

Again many of us probably do not give this a second thought but we should from now on!

Tricia and Kate busy welcoming everyone.

Visitors starting to arrive.

Mr Tim Stephens, Arthritis Care, with his winning duck donated by Dermal Laboratories Ltd.



David Chandler (Julie sitting down) opening the Meeting.

Dr. Neil McHugh & Ms Sherry Ross taking part in the Questions & Answers Session.

David Chandler introducing the founding members of the Alliance, Julie Chandler, Tricia Hobbs, and Kate Heath.

SNIPPET

Whilst attending a recent seminar we came across an Organisation which we thought some of you may find interesting to read about.

The Steroid Aid Group

Formed in 1979 by Lilian Wilding after an appeal on Thames Television's programme "HELP". It was felt by the demand that it generated that there was a need for a self help group to exchange information and advice between people experiencing side affects from Steroid treatment.

Unfortunately Lilian Wilding died in 1985 but the work that she started still carries on and the Group is going strong.

The aims of the Organisation are to seek information about Steroids,stimulate research into their side affects,raise awareness and campaign for more information to be made available through companies,doctors to patients about the side affects of these drugs.They encourage exchange of information between their members.

There is a membership fee of £5.00.Members receive a current newsletter,full membership list,and some information on Steroids and their side effects.

For more information please write to (enclosing S.A.E)

Steroid Aid Group,P.O.Box 220,London,E17 3JR.

Special Acknowledgements

The Canadian Arthritis Society
Patricia Normandeau, The Canadian Psoriasis Foundation
The National Psoriasis Foundation,America
Arthritis & Rheumatism Council
British League Against Rheumatism
British Society for Rheumatology

The teams at Arthritis Care and Young Arthritis Care

All those involved in the Skin Care Campaign
LMCA (Long Term Medical Alliance)
Dermal Laboratories Limited
Quinoderm Ltd
Galderma (UK) Ltd
E. Merck Dermatology
Roche Products Ltd
Bioglan Laboratories Ltd
Stiefel Laboratories Ltd
Schering Health Care Ltd.
Leo Laboratories Ltd.
Crookes Healthcare Ltd.
Euroderma Limited.
Contact-a-Family.
Stafford-Miller Ltd.

Special thanks to all those in the medical & non-medical professions that have taken an interest and supported the group since its formation in April 1993 - it is your help along with our members who have made the Organisation possible.Thank you.

We would like to thank ROCHE Products Limited for their help in the copying of this issue of the Journal.