Psoriatic Arthropathy Alliance News Journal.

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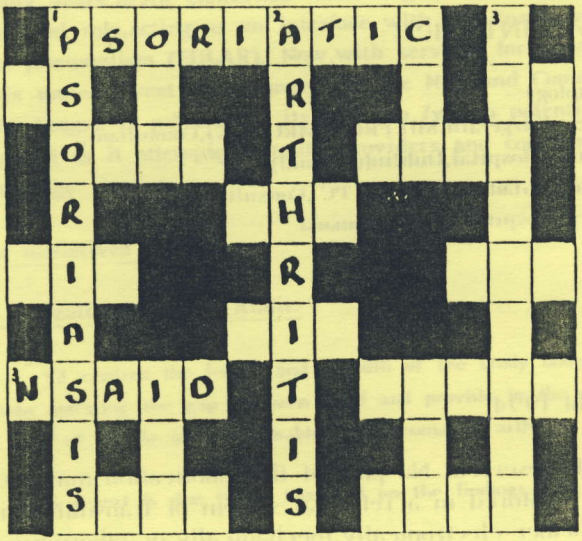

CLUES

ACROSS

1. Someone who has Psoriasis (9)
3. A treatment for P.A.(5)

DOWN

1. A skin condition (9)
2. Form of joint disease (9)
3. Cure Psoriatic Arthropathy (7)

THE SKIN & BONES CONNECTION

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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

THE BRITISH LEAGUE AGAINST RHEUMATISM - (BLAR)

The British League Against Rheumatism was founded on 13th June 1972. Two decades later,20 organisations concerned in one way or another with the care of people with arthritis,both professional bodies,such as the British Society for Rhematology and support groups,such as The Psoriatic Arthropathy Alliance come together under the umbrella of the League.

For many years,BLAR concerned itself largely with its international role,acting as an interface with the European League Against Rheumatism (EULAR). Now,with services for people with arthritis under threat from changes in the NHS and Community Care,the League is galvanising its strength (which potentially is very great) as it attempts to unite providers and consumers of rheumatology services.

Recent initiatives include:

1. Health Provision Audit:

12 centres the length and breadth of the study undertook a pilot into assessing the gap between need and provisio in the medical and social care of people severely disabled by rheumatoid arthritis.

A report is due to be launched on the findings later this year.

The Regional Groups set up under this project have in several cases continued to meet,with representatives from BLAR constituent organisations liaising at local level in attempts to influence the purchasers' plans.

2. Exhibitions at National Meetings:

BLAR provides the opportunity for member associations to publicise their activities and events through the BLAR Diary of Events and through complimentary exhibition space at certain major national and international

scientific meetings.
The Psoriatic Arthropathy Alliance produced literature for display to delegates at the BSR's AGM in Brighton where up to 800 rheumatologists and allied health professionals attended.

Literature was also taken to the EULAR meeting in Istanbul,so news of the Group will be available to international audiences.

1 Quality Issues:

The BIAR recently wrote round to Purchasers of rheumatology services asking for copies of the quality specifications used when purchasing a rheumatology service. Although all specifications received included general points of interest when considering rheumatology services such as:-

- Access
- Equity
- Implementation of Patients' Charter in Out Patient Departments.

Few had information relating directly to rheumatology services.

To this end,the League is planning to collate information that its member organisations would like to be distributed to purchasers,and hopefully the Psoriatic Arthropathy Alliance will be able to contribute to this discussion,to ensure that the specific needs of people with Psoriatic Arthritis are taken into account when services are planned.

Ms.Kate Baillie
Executive Secretary,
BIAR.

BUDDING ARTISTS????

We need your flare and imagination at the office.
If you feel you would like to design a front cover for future journal issues please have a go and send in your ideas for publication

GO ON HAVE A GO!!!

COMPETITION: EDGAR STENE PRIZE 1995

EULAR (European League Against Rheumatism are running the above competition The prize,the value of which is Swiss Francs 1,000,and will be presented at the Opening Ceremony of the EULAR Congress 1995 in Amsterdam,(18-23 June) and will be published in the EULAR Journal "Rheumatology in Europe". BLAR will meet the successful applicants travelling expenses to Amsterdam and EULAR will pay for two nights hotel accommodation.

Theme of the prize is as follows:-

The Everyday life of a young person with arthritis from childhood to adolescence.

Describe your experiences from childhood to adolescence,for instance,the treatment you have received,your home life,the impact on your education;friends and if applicable your working life,the hardships you have faced because of your illness.

What sort of support have your received from Society?

Competition entrants should submit an essay on the above topic,not exceeding three typewritten pages to Ms.Kate Baillie,Executive Secretary,British League Against Rheumatism,(BLAR),3,St.Andrew's Place,Regents Park,London,NW1 4LB,by no later than 1st December 1994.

The essays will then be judged by a panel of BLAR General Section members,and the best three entries from the UK will then be sent to EULAR by 15th February 1995 - the EULAR jury will announce the

winner in mid April 1995.

Please have a go,and if you would like to also send a copy of any entries to us we will print these in the Journals with your permission.

If anyone would like a copy of the Rules please let us know and we will forward these to you. GET WRITING and GOOD LUCK!!

DRUGS DRUGS DRUGS!!!

The ABPI (The Association of the British Pharmaceutical Industry)
has taken note of the need for more patient information about medication and has now produced and made available to the General Public the following:-

The Compendium of Patient Information Leaflets.

Priced at £7.50 (inc postage and packing) direct from
Datapharm Publications,
12,Whitehall,
London,
SW1A 2DY.

It is a book made up of patient information leaflets on a range of medications from creams,lotions to pills. It is a very useful guide explaining side affects,how to take your medication etc. Hopefully the publication will be up dated and added to regularly,making it more comprehensive in time.

A much needed book.

REPORT:
SOUTH EAST PHARMACEUTICAL INDUSTRY GROUP (SEPIG)

What is SEPIG?

Seven Companies in Kent and Sussex discover,develop,make and distribute medicines. They represent the most successful high technology in the South East.

Together they form the South East Pharmaceutical Industry Group (SEPIG). SEPIG's aims to inform industry in the region of what it is,what it does,how it does it and to maintain an active link between industry and everyone concerned with health care locally,whetehr they are providers or a user of services. It has an programme of contact with professionals within the region,health authority management,pharmacists and GPs,together with local MPs and MEPs, and contact is maintained with schools,and local community or patient groups.

In September we were invited to attend a meeting along with other Patient Groups with representatives from some of the Pharmaceutical Industry based in the South East,namely,Schering Health Care Ltd,Upjohn Limited,Pfizer Ltd;together with Government Affairs advisers and Dr.Leonard Brooks,who concluded the meeting with an overview of what had been said that afternoon.

It was a most informative afternoon with topics such as MS,Thrush,Incontinence we touched upon. But more importantly we were given an insight into what was happening with budgets for medicines,how these budgets were to be assessed,who was to hold the purse strings,and the various processes involved in making monetary decisions.

Mr Chris Friend and Mr Bob Martin,both Government Affairs advisors,took us through how a drug is conceived through to the end product,marketing,,licensing procedures and beyond,which were very interesting and informative talks. I think we all left the meeting with a better understanding of the whole process of what the drug industry is about.

The Drug Industry,which was once a closed shop, is slowly beginning to see the need to work with Patient Groups,to see what we are all about and what we are trying to do,and to access our needs,and to see how they can help us and work together. We were all given a chance to voice our opinions and concerns for patients and their medications. One of the main concerns that came out from us all was the lack of information given to the patient on side affects. Already this problem is being addressed and more information will be included in medication packs by law with all new medicines coming onto the market from January of this year. However,saying this your doctor should still take responsibility to explain any side affects to you before prescribing any drugs,and if you are not sure of his decisions,question him to satisfy yourself before taking them. Even ask your pharmacist,who can be of great help.

These type of meetings we hope will become more regular and widespread amongst other Pharmaceutical Groups),will be a big and positive step forward to be viewed with great optimism.

DID YOU READ?

Whilst stabilising the foundations of a 15th century church,thousand year old skeletons were uncovered,nearly 3,000 of them.Scientists are studying these at the rheumatology dept.Bristol University,to define why certain forms of arthritis are more common today than in the past. Psoriatic arthritis and Gout has been found to be present in some of the remains.

Fifth International Symposium on the Treatment of Psoriasis and Psoriatic Arthritis, Israel 6-11th March 1994

The conference was initially disappointing because two of the main speakers did not attend, apparently due to the Hebron massacre the previous week. (In fact, we encountered no signs of trouble at all). However it was a truly international event with delegates from the USA, Russia, the Ukraine, Bulgaria, Germany, Holland, Sweden, Turkey, India, Belgium, South Africa, Norway, as well as UK and Israel. The focus was significantly more on psoriasis than arthritis, with considerably more dermatologists and rheumatologists, which was educational for me. The papers were all delivered in English, which unfortunately made some of the papers from Russia totally incomprehensible due to a lack of familiarity with the language.

The conference commenced with an overview of the pathogenesis and therapy of psoriasis, which was a useful introduction. The various topical therapies, systemic therapy and phototherapy were discussed. Three papers on the aetiology of psoriatic arthritis followed. Professor Lipkin (New York) presented a study of ä1-antitrypsin deficiency in psoriatic patients, finding that 5 of 45 patients had the abnormal phenotype, although only 2 of these had marked reductions in ä1-antitryspin content and function. He concluded that this may identify patients at greater risk from methotrexate of cyclosporine therapy. A large population study of psoriasis provided evidence that a recessive mode of inheritance should not be excluded. An immunohistochemical study of lysozyme in the skin showed this to be more strongly expressed in psoriatic plaque than normal skin, concluding that this may have some role in the aetiology.

The following two sessions had papers on the mechanism of action and efficacy of some of the newer therapies for psoriasis. A study of Interferon φ showed minimal benefit and psoriasis was induced

at the site of subcutaneous injection. Topical short contact anthralin therapy has been used for Psoriasis for many years,but the side-effects of inflammation of normal skin and staining may be reduced by inactivation of the drug by triethanolomine application. Another study showed that it can be readily applied to plaques using a washable stick. A study of a UV comb (Psoracomb) concluded that it was no more beneficial than conventional topical methods of treatment. A prospective study of 82 Indian patients with psoriasis treated with oral methotrexate was presented. Only one patient was refractory to treatment and the drug was successfully used without serious side-effects in all patients. Professor Zacchariae (Denmark) presented data on his extensive experience in the use of Methotrexate and Cyclosporin A in psoriasis. He found that both drugs give an improvement of more than 75% in 90% of psoriatics,but that methotrexate should remain the first-line systemic therapy for severe psoriasis. He suggested that cyclosporine A should be changed to other therapies after two to three years due to doubts about long-term nephrotoxicity. I presented a study of 101 patients with psoriatic arthritis,showing that just over a quarter required systemic oral (disease-modifying) therapy and charting the change in the specific drugs used. I found that methotrexate has replaced intramuscular gold as the most commonly used disease modifying therapy of the past four years. The controversy over the need for liver biopsies was discussed. The dermatologists maintain that they are necessary after 1.5g treatment and yearly thereafter whereas rheumatologists consider this unnecessary.

The results of a trial of a new derivative of Cyclosporine,SDZ IMM 125,were presented,concluding that it was beneficial but side effects may limit its use. Retinoids are also used systemically in the treatment of psoriasis and a dose of 1mg/kg/day has been suggested. A study from Bulgaria showed beneficial effects with low dose tigason (0.25-0.3mg/kg/day,but this was heavily criticised by the audience because the work was

uncontrolled. Treatments specifically for psoriatic arthritis included joint injections of rifamycin SV and,most extraordinarily,ozone therapy,with unconvincing results for both. An open study of cyclosporine in psoriatic arthritis showed it to be effective,with renal dysfunction the major side effect. The mechanism of action of Retinoids and Vitamin D3 was examined by Professor Jablonska from Poland,who found that they synergisitically inhibit proliferation and angiogenic capability of various human keratinocyte lines.

Israeli dermatologists are keen to promote the Dead Sea as an international treatment for severe psoriasis and Scandinavians,Russians and Americans are apparently sent there for treatment. One of the plenary sessions was set at the Dead Sea and a number of papers by the Israeli doctors focussed on on the treatment there over the last 20 years. The Dead Sea treatment consists of climotherapy,ie the sun with UV radiation which provides most of the benefit,and bathing in the mineral-rich Dead Sea,which provides the remaining benefit. No prospective clinical trials have been done comparing Dead Sea treatment to hospital methods,but a retrospective study showed there was no difference in remission times between Dead Sea and hospital treatment. An attempt has been made to quantify UV radiation so that patients can be appropriately dosed in a similar way to conventional UVB and PUVA therapy,but I doubt the usefulness of this in practice. Another paper showed that blood pressure falls on going down the 1200ft to the Dead Sea in both hypertensive and normal patients,concluding that hypertension is not a contraindication for sending patients there. Papers on the mechanisms of phototherapy,whether by PUVA,UVB,or climotherapy revealed very little new information. Serum Vitamin D3 increases after Dead Sea treatment and CD4+lymphocytes decrease following phototherapy. The microvilli on psoriatic keratinocytes reduce after Dead Sea treatment,and a similar but lesser effect is seen with Dead Sea bath salts. Themost important beneficial mineral in the Dead Sea may be magnesium

bromide which inhibits dermal proliferation. The benefits of other spa mineral,sun,and mud treatments in Bulgaria,Russia and Turkey were also presented,the latter involving the use of swarms of fish!!

To conclude,Spa therapy is an alternative to conventional treatments for psoriasis for the wealthy. Methotrexate remains the best systemic therapy for both psoriasis and psoriatic arthritis.

Dr.Sharon Jones,MRCP,Research Registrar,
Royal National Hospital for Rheumatic Diseases,Bath.

REPORT

British Society for Rheumatology (BSR)

Heberden Round - 22/23rd September 1994 BATH.

BSR kindly allowed us to have a display stand for one day at this meeting,whereby both Julie and myself attended.
It was a good day wherein we met some very interesting and helpful professionals who took an active interest in the work we were doing. We also had the rare opportunity of meeting most of our medical advisors in the same place at the same time!! which was nice,and comforting to see them getting more clued up on the subject!!

Dr Neil McHugh gave an interesting and thorough talk on Psoriatic Arthritis and kindly gave the Group a plug at the end. If any of you would like a copy of the talk by him please let us know. (SAE appreciated thanks.)
We also had a good enquiry response for more Group information from Rheumatologists for display in their clinics that attended which were promptly followed up.

David.

GENETICS OF PSORIATIC ARTHRITIS

- Although PA is not strictly a hereditary condition, genetic factors are important and both psoriasis and psoriatic arthritis may cluster in families.
- It is very likely that children of parents with psoriatic arthritis will not be similarly affected.
- Certain related conditions may occur in relatives, such as inflammatory disease of the bowel and iritis (an eye disease).
- There is some evidence that psoriasis is more likely to be handed down to successive generations by the male side of the family.
- Certain markers on genes that regulate immunity to infections may be associated with different types and severity of psoriatic arthritis.
- It is not likely that there is one single genetic cause for psoriatic arthritis.
- Psoriatic arthritis is likely to occur when a genetically susceptible individual is exposed to some sort of environmental trigger (e.g. a "Virus", trauma, toxin, hormones etc).

RESEARCH PROJECT read on.....

As someone who sufferers from psoriatic arthritis you are aware of the discomfort and inconvenience caused by the disease. At present,very little is known about what causes psoriatic arthritis or how it will progress. It is important,therefore, for research to be carried out which examines this disease specifically. At St.Bartholomew's hospital the immunology and rheumatology departments have undertaken a joint project which we hope will define some important aspects of psoriatic arthritis.

We and others feel that it is significant thatboth the skin and joints are affected in psoriatic arthritis. Among other things,we would like to examine the role played by certain cells,called T lymphocytes,which we think contribute to the tissue destruction at both these sites. in order to make these investigations,however,we are wholly dependent on the participation of people sufferering from psoriatic arthritis.

If you would like to find out more about this project please contact me directly in the immunology department at St.Bartholomew's hospital or through the psoriatic arthropathy alliance. The involvement of people sufferering from this disease is essential for productive research which will eventually aid in more effective management of psoriatic arthritis. Your participation would be greatly appreciated.

Elizabeth Ross
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Tele: 071-601-8104/8199: Fax: 071-606-0845

A SPECIAL THANK YOU:

We think Sally Dale,member from Leicester deserves a special thank you because her efforts of fundraising for the Group was quite an achievement and we are very proud of her.

She climbed a mountain!! here's her account...

At 4.15am on the 2nd June 1994,my waking thought was "what have I let myself in for?",but it was too late - I'd collected lists of sponsors,booked into a guest house and made arrangements to meet up with relatives in Wales. The reason? to climb Mount Snowdon!!

Armed with sandwiches and drinks to last through every eventuality,we set off at 8.30 am along the "rnyddl"path. The first part of the path is a gentle slope and the scenery quickly becomes breathtakingly beautiful.As you near the top part of the mountain it plunges into a mist even on the hottest of days and is a transformation into another world. As the path becomes steeper,it feels like walking into a "no mans" land and the relief is enormous when at last out of the fog, a cafe looms up and the summit becomes within sight.It feels like standing on top of the world and after 5½ hours of hard work,you've attained your goal (and raised some money in the process of course!).

Sally raised £271.00 from her efforts for the Group,and sore feet as you can all imagine.

Thanks Sally,you're a true inspiration

Earlier this year Sandra MacPherson,of GP News, decided to take up our cause and produced a good clear concise article in that publication. Included in the article was a picture of arthropathic psoriasis of the finger joints. Thought you may be interested in the below extract of that article.

GP.NEWS February 1994

Psoriatic Arthropathy is easy to miss

By Sandra MacPherson

A new patient support group has been set up to highlight psoriatic arthropathy.

Their campaign will claim that doctors miss the diagnosis.

The group's co-founder,also a sufferer of psoriatic arthropathy,David Chandler says people are sometimes mislabelled as hypochondriacs.

Consultant rheumatologist at the Royal Free and Whittington Hospitals in London,Dr.Anthony White agrees.

"It is the sort of condition that you could miss if you do not happen to think of it. There are not a great number of leads.

"It can occur in patients with only very minimal psoriasis-people you would not think of as having psoriasis".

he explained that pains can occur in different joints at different times. They may be quite severe,but have disappeared by the time the patient gets to see the doctor.

The clinical picture of psoriatic arthropathy is highly variable (see box).

Psoriatic arthropathy

* Is seronegative
* Is highly variable
* May or may not be progressive
* Can be mild affecting peripheral joints.
* Can be widespread resembling rheumatoid arthritis
* Can affect the spine resembling ankylosing spondylitis

Treatment:

* Non steroidal anti-inflammatory drugs (though these can make Psoriasis worse in some patients).
* Steroid injection in individual joints.
* Sulphasalazine.
* Methotrexate or azathioprine (under strict hospital supervision)for more widespread severe disease.

Dr.White estimates that up to 20 per cent of psoriasis patients have psoriatic arthropathy.

There is no specific confirmatory test. A past or present history of nail involvement is highly suggestive.

The pits in the surface of the nails which are considered a classic sign of psoriatic arthropathy may not always be present. They come and go as does the joint pain.

If there are no signs of psoriasis it is worth asking about family history. Some patients may have inherited the arthritis with out obvious psoriasis.

Dr.White added that seasonal variation in joint pain may also point to the diagnosis.

Joint involvment is often less severe in summer when the skin is less affected.
For more information contact.....

AROUND THE WORLD NEWS:

The First National Psoriasis Tissue Bank.

In April 1992,the National Psoriasis Foundation awarded a Grant to Dr.Alan Menter,from Baylor University in Texas to set up a national gene bank (later referred to in this article as "Tissue bank") located at the University of Texas,Southwestern Medical College in Dallas,Texas,which is to be a

repository of blood samples taken from three generation families with psoriasis. The cells taken can be stored infinitely and used by researchers anywhere who will then be able to analyze their genetic structure. The Bank was to initially store cell lines from families with psoriasis,but they hope to store other biological material such as samples from lesions and skin,bone and cartilage,which can then be used by researchers doing other types of psoriasis and psoriatic arthritis research.

The Bank is owned by The National Psoriasis Foundation,who closely monitor it's progress,and have extensively publized it's existance to the Medical profession as well as to sufferers,and is managed by Dr.Menter in conjunction with others,and is financially maintained by the sale of these cells to those interested researchers,and the monies put back into the Centre.

WHY GENETICS?

The discovery of the gene or genes associated with causing psoriasis and psoriatic arthritis could lead to much improved therapies and hopefully a cure.

Each gene in our body carries the blueprint for a protein that the body needs. The genes recently identified as linked to cystic fibrosis and Duchenne's muscular dystrophy produce certain proteins and researchers hope to design a therapy targeted to correct the specific proteinmalfunctions that are found in these disorders. The same,theoretically,could be done for psoriasis. Currently we do not know why conventional psoriasis therapies work and new ones are very difficult to develop as we do not understand much about what cause psoriasis.

Although many regulatory pathways have been found to be abnormal in psoriasis, the central regulatory pathway has eluded researchers. As a result, therapeutic advances have come by "serendipity". The identification of a specific gene may reveal the biochemical pathway or process responsible for psoriasis.

Though psoriasis seems to have multiple causes or triggers, the genetic trigger seems to be key in those people whose psoriasis first appeared when they were young.

In patients with psoriasis, one-third report having a relative with psoriasis. If psoriasis appears before the age of 30, the number of patients having arelative with psoriasis goes up to 50-70 percent. In contrast people whose psoriasis began at 60-70 rarely have close family members with psoriasis, indicating other possible factors coming into play.

It is believed that psoriasis will be found to have several genes linked to its cause rather than one, which is commonly the case for the rare, life-threatening disorders which have been the focus to date of most genetic research. Chronic disorders such as psoriasis are believed to be linked to several genes which could complicate the search.

Chromosome 6 (there are 24 chromosomes in the body) was commonly believed to be the site of the gene but now researchers believe the gene(s) may be elsewhere, though it is not known where.

Article taken with kind permission from National Psoriasis Foundation "Bulletin" May/June 1991 issue, and has been slightly anglicised in some parts.

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