

The Psoriatic Arthropathy Support Group News Journal.

ISSUE NUMBER TWO MAY 1994



*Skin
Care
Campaign*

*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.

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BOOK REVIEWS:

NEW: THE PSORIASIS HANDBOOK

By Bill Habets £9.95 including P&P (Book No.203)

Published by :

Carnell Limited, Alresford, Nr Colchester, Essex, CO7 8AP.

(Cheques payable to Carnell Limited)

ISBN 1 85779 169 X

This is probably one of the better books I have seen on Psoriasis recently, covering all aspects of the condition, from what causes it, what it is, types, psoriasis and arthritis, medical treatments, hospital treatments, the new Vitamin D cream, Dead Sea therapies, psychological aspects of the condition, stress and the food factor.

BEAT PSORIASIS

The Natural Way

By Sandra Gibbons

£7.99 published by Thornsons ISBN 0 7225-2586-9

Sandra Gibbons herself a sufferer for many years has managed to overcome her skin condition, and has gone on to help many other sufferers of psoriasis and other skin conditions with her holistic approach. She is the Co-Founder of The Alternative Centre in London, a health consultant and lecturer in this field. Author of Living with Psoriasis.

Her book takes you through the holistic approach, treatments, alternative therapies, food, stress factors, children, pregnancy and patient stories.

Publications also available from : Alternative Centre Publications:
The Alternative Centre,
The White House,
Roxby Place.,
Fulham, London, SW6 1RS

Psoriatic Arthritis: what's new in Bath?

What is the link between skin and joint disease in Psoriasis? We are attempting to find out with our research here at the Royal National Hospital for Rheumatic Diseases in Bath and will keep you up to date. Psoriatic Arthritis has always been a special interest of our hospital which has been treating arthritis for over 250 years. A well known oil painting by William Hoare hangs in our hospital hallway depicting the first combined clinic. One young child is covered by a scaly rash very likely to be psoriasis and the reason for a trip to Bath to "take the waters". These days tap water alone is used in our hydrotherapy pool, but to good effect especially for those with chronic spinal and peripheral joint arthritis. A special clinic for psoriatic arthritis has been running for the last 5 years which reflects how seriously we take this condition. We are currently completing a follow up of the first 100 patients to attend the clinic which should give us some idea of the outcome. For example already we have found out that the group of patients with backbone involvement have a higher frequency of arthritis of the neck than expected. We are also looking at the different forms of joint involvement in psoriatic arthritis to see whether the outcomes may be any different, which is important to know of course when planning long-term treatment.

We find that there is a lot of interest in the role of diet and arthritis. A lot of our patients already take some form of dietary supplementation, although it is very difficult to prove that any diet is beneficial. There is some evidence that fish oils may help, at least the psoriasis. We are keen to look at the effect on arthritis as well, although it is likely that diet will only have a mild effect on arthritis. Nonetheless anything which allows a reduction in medication has to be of benefit.

We have just completed a study of blood fats in over 50 patients with psoriatic arthritis. The results show that these may be altered when the disease is active in a

similar way to rheumatoid arthritis. This is likely to to a non-specific consequence of inflammation although the mechanism is uncertain.

Adjacent to our hospital we have our research laboratories where scientists are working on many of the mechanisms that cause inflammation in the skin and joints. Of interest to us at the moment are certain proteins called addressins that stick to immune cells and allow them to gain entry to the skin and joint. One possibility we are exploring is that there may be a common protein lining both the skin and the joint that may be out of control, and so explain the common link between skin and joint disease. Stay tuned!!

Dr.Sharon Jones, MRCP, Research Registrar
Dr.Neil McHugh., MD FRACP, Consultant Senior
Lecturer in Rheumatology.

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TENS

(Transcutaneous Electrical Nerve Stimulation)

TENS is a simple, non-invasive technique, in which electrical currents, generated by a portable stimulating unit, powered by a small 9 volt battery, are passed through the surface of the skin to activate underlying nerves via two or four electrodes. Conductive gel or pre-gelled electrodes are used to decrease resistance across the skin-electrode interface, and the electrodes can be concealed under clothing if necessary.

TENS produces a "strong and comfortable" tingling sensation (electrical paraesthesia) within the painful area and the intensity and quality of electrical paraesthesia (i.e. pulse intensity, pulse frequency and pulse pattern) can be varied and controlled by the patient according to his/her requirements. TENS has been shown to produce useful analgesic effects in all types of patients suffering from acute or chronic pain and has gained worldwide attention and use.

TENS has many advantages over conventional treatment for pain. It does not require surgical intervention and, unlike analgesic drugs, has no serious adverse effects. It can be used long term and can if necessary be used in conjunction with other analgesics, such as drugs. Not every person responds to TENS treatment, the efficacy is approximately 60%. The reason for non-response to TENS by the other 40% is unknown at this point in time.

TENS works in two ways:-

PAIN GATE CONTROL: high frequency stimulus (15-150Hz) causes the central nervous system to transmit via the large diameter nerve signals that causes "gates" cells in the pain pathways to "switch off" pain transmission.

ENDORPHINE RELEASE: low frequency stimulation 2-9Hz encourages the release of morphine-like substances which block pain at receptor sites in the nerve pathways. Studies have shown that endomorphin related pain relief can often last for periods which extend considerably beyond the time stimulus.

SOME COMMONLY ASKED QUESTIONS AND ANSWERS:

Q. Does TENS work for all pain conditions, and on all patients?

A. No, there is a significant variation between patients with similar pain conditions. However, it is known that TENS does work in 6-70% of cases.

Q. How can I have a better chance of success?

A. Professional diagnosis and recommendation are vital in selecting the correct stimulator and placement of electrodes.

Q. Are there circumstances in which TENS should not be used?

Yes, for an un-diagnosed pain, when using a cardiac pacemaker, during the first three months of pregnancy, and other instances listed in our detailed literature.

Q. Can there be any permanent side effects caused by using TENS stimulator?

A. No, there is no known permanent side effects caused by using a TENS stimulator.

Q. How long will I have to use a TENS stimulator?

A. Some long term chronic pain sufferers may need to use a stimulator for long periods of time, maybe years. Other conditions may only need a short period of treatment.

For further details and free three week trial of their TENS machines please contact:-

N.H.EASTWOOD & SON LTD.,
118, East Barnet Road,
Barnet, Herts,
EN4 8RE.
Tele: 081- 441- 9641

PSORIATIC ARTHRITIS

Definition:

Psoriasis is a chronic skin condition which may affect 1-3% of the population. It presents with a scaly, itchy rash, often on the elbows, knees and scalp, as well as changes in the nails, including pitting and lifting of the nails.

Description of the arthritis:

About a third of the patients with psoriasis may develop a form of arthritis called Psoriatic Arthritis. The arthritis presents with joint pain and swelling, involving either few or many joints, and it may occur in a symmetric (both sides of the body at the same time) or asymmetric distribution (not the same joints on each side). The joint pain is often associated with stiffness, particularly in the morning, and gets better with activity. About a third of patients also have neck and/or back pain and stiffness, which may be associated with limitation of movements. In about a third of patients, there is a relationship between the severity of the skin disease and the activity of the arthritis.

Cause of psoriatic arthritis:

The cause of psoriasis and its associated arthritis is unknown. However it is thought that hereditary factors are important because the disease tends to run in families. There are some genetic markers which are more common in patients with psoriasis than in the general population, and others are more common in patients with psoriasis who developed arthritis. In addition, some abnormalities in the immune system in patients with psoriasis and psoriatic arthritis have been found. Some investigators believe that certain infections may be responsible for the disease, and others suggest that trauma may play a role in some cases.

Diagnosis of psoriatic arthritis:

Not all instances of pain in patients with psoriasis constitute arthritis. The specific pattern of joint involvement and its distribution helps the physician make the diagnosis. The diagnosis of psoriatic arthritis requires a careful history and physical

examination by a physician, as well as some laboratory tests to rule out other causes of arthritis, and x-rays, to identify the extent and the pattern of the disease. At times joint fluid aspiration and evaluation under the microscope is necessary to rule out other forms of arthritis such as gout.

Course of psoriatic arthritis:

The course of psoriatic arthritis is variable. The majority of patients do reasonably well and are able to continue with a relatively normal life style. However, in about 20% of the patients the arthritis may become deforming and destructive. It is thought that this damage results from persistent inflammation and the result of this process within the affected joints.

It is not yet known what factors lead to the development of the destructive rather than the mild form of the arthritis. For that reason, it is better to make the diagnosis early and to treat the inflammation, in order to avoid further damage.

Treatment of psoriatic arthritis:

The treatment of psoriatic arthritis includes treatment of both the skin condition and the arthritis. The treatment begins with education, it may require modification of daily life to reduce stress, to provide more rest, exercise programme, and to allow time for the treatment modalities. Specific treatment includes specific programmes for both skin and joint components.

For the skin: Initially, topical medications including lubricants, baby oil, and topical corticosteroid creams may be used. Recently, a new cream which contains vitamin D (Calcipotriol) has been proven to be effective in the treatment of psoriasis. Sun exposure is often helpful, and the use of light treatment is beneficial. There are two types of light treatments, one called UVB light is available through most facilities, the other UVA light is often combined with a psoralen medication given either by mouth or through bath, is only available in specialized facilities. The use of PUVA (Psoralen with UVA light) has been useful for arthritis as well. There are several other medications that are effective for the skin and the joints and they will be discussed later.

For the arthritis: Non-steroidal anti-inflammatory medications (NSAIDs) may be used as initial treatment for the arthritis. These medications control both pain and inflammation, and are so often all that is required to control the disease. In addition, energy conservation and exercise programme is important. Since most patients find that the arthritis is worse when they are inactive, the proper compromise between activity and rest is important. Injections of steroid medications into the affected joints are often very helpful, and to avoid the use of other medications by mouth. When the NSAIDs are not effective, other medications may need to be considered. If the arthritis is particularly bad, but the skin is not too involved, medications such as gold injections, or antimalarials such as hydroxychloroquine are used. Pencillamine may also be used for the arthritis.

For both skin and joints: When the skin disease and the arthritis are active, it is better to use medications which may work for both. Methotrexate is the drug of choice, since it has been proven to work for both the arthritis and the skin psoriasis. Other medications include tegison, Imuran, salazopyrin and in resistant cases, cyclosporin A. The use of steroid medications by mouth is not recommended since there are many long term side effects, and high doses are required to control the psoriasis.

Surgery is sometimes required to correct the deformities and the damage which may result from uncontrolled inflammation. It is generally recommended that the arthritis be treated early, so that the damage, and the need for surgery, be avoided.

It is recommended that patients with psoriasis and arthritis be seen by a rheumatologist (a specialist in arthritis) in addition to their family doctor and dermatologist (skin specialist). It is important that the diagnosis is made early, and that appropriate therapy is instituted before damage has occurred.

Article kindly supplied by Dr. Dafna D. Gladman MD, FRCPC.,
Director of Psoriatic Arthritis Clinic, University of Toronto, The
Wellesley Hospital, Toronto, Canada.

S T A R T

(Skin Treatment and Research Trust)

Skin for life

Psoriasis

What it can mean to the sufferer:

When you've got psoriasis it's not only the disease you have to cope with....

Imagine being in a public place and finding people staring at your skin and backing away.

It's not the sort of attention many of us would welcome. Psoriasis sufferers may have to put up with this kind of reaction just as they have to live with often unsatisfactory and uncomfortable medical treatments. For some sufferers it can become too much. They become isolated and depressed. Distressed not only by the disease but also by the rejection they suffer.

Psoriasis is a common disease of the skin. It is estimated that 2-4 million people in the UK suffer from it. The cause is still unknown but the results are only too obvious - unsightly flaking red patches of skin. A disease such as this with a high level of visibility can cause much distress to sufferers as they have to learn to cope with the incorrect assumptions of other people that they might be suffering from a contagious disease. Activities such as swimming, dancing and playing sport where large areas of skin are exposed to view can become miserable experiences. There is no cure and treatments can be messy, inconvenient and time consuming.

What it means to the Scientist:

In normal skin there is a regular renewal of cells on the upper 5 layer (the epidermis). The whole cycle of regeneration of the epidermis takes about three weeks. In psoriasis this process happens at an astoundingly accelerated rate – the psoriasis sufferer's top layer can regrow in as little as three days – this is seven times as fast as normal. The result is the characteristic build up of flaking patches on the skin surface. The redness is caused by the increased blood supply from a lower layer of skin (the dermis) to the psoriatic patches.

What START did:

It is clear that something alters the normal speed and process of epidermal cell renewal. –The theory has been put forward that factors (naturally occurring substances) in the dermis influence the growth rate of the epidermis. To find out START scientists decided to investigate the by-products secreted by skin cells when they are cultured in a growing medium in the lab.

How we did it:

Psoriatic patients gave samples from areas with and without psoriasis. Normal skin from donors without psoriasis was used to act as a control. Cultures of skin cells from all these samples were grown in the lab and the medium containing the secreted substances was painstakingly analysed. We found that psoriatic skin produced more of one particular factor during its growth than normal skin.

The next step:

As so often happens in research each answer activates another question. Does this factor stimulate cell growth in some way? Or is it a by-product of a more complex process?

Researchers have found one more piece to add to the

jigsaw puzzle of skin disease. Next they will have to put this piece in its correct place in the puzzle.

Tips on Psoriasis:

Unfortunately, since psoriasis is still poorly understood we cannot suggest any particular line of treatment. Our hope is that the information we get from our research will help in the development of more effective treatments.

At the moment it is clear that different people find relief from a variety of approaches. If you have not yet seen a specialist (Dermatologist) and would like to do so, ask your GP to give you a letter of referral.

Useful reading:

"Psoriasis: A common guide to one of the Commoner Skin Diseases" by Professor Ronald Marks. Published by MacDonald Optima in the Positive Health Series.

Recent research by the Dermatology Department here at Westminster Hospital shows that a diet high in oily fish may be beneficial to the condition in some cases. Oily fish easily available to purchase are: Salmon, Herring, Mackerel, Pilchards, and Sardines.

A new ointment for Psoriasis:

Dovonox Ointment is a recently developed treatment for psoriasis which has just become available in the UK. The active ingredient is calcipotriol, which is a Vitamin D derivative.

Trials on over 3000 sufferers have shown promising results so far in the management of psoriasis in some patients.

Kindly supplied by START, Chelsea and Westminster Hospital, London.

SULPHASALAZINE

VALUE OF OLD DRUG CONFIRMED IN NEW ROLE FOR PSORIATIC ARTHRITIS

Sulphasalazine(Salazopyrin-EN) was first invented in Stockholm for the treatment of rheumatoid arthritis; it was little used in Britain for this purpose until 1985,when new studies showed that,contrary to previous opinion here,it is effective. It was used here for the treatment of ulcerative colitis meanwhile so fortunately had remained in production.

It was tried in Paris for psoriatic arthritis in the early 1980's but mention of this appeared only in the French literature on arthritis where I happened to see it and then began to use it for occasional patients with gratifying results in most cases,although I did note that it took a long time to work,usually at least three months. In 1988, a group of rheumatologists in the Birmingham area reported favourable results but otherwise very little was written about its use,other than in rheumatoid arthritis and some cases of ankylosing spondylitis.

Now a report has just appeared from a combined study in Glasgow and Leeds comparing active tablets with dummy tablets and confirming that at the end of three months the group on the active tablets was still improving compared with the others particularly in the number of tender painful joints,early morning stiffness and in the ESR,the blood test most usually done to see how well the inflammation is being kept under control. It is a pity the study did not continue for six months or a year as then its value would I feel sure have been shown more securely. It is a relatively easy drug for doctors in general practice to handle from the point of view of long term safety monitoring,compared with the alternatives available for those with severe psoriatic arthritis,so it is likely to become a more widely used treatment.

Dr.Anthony White,Consultant Rheumatologist,
Royal Free Hospital,London, Psoriatic Arthritis Clinic

BOOKLIST

We will be compiling a booklist to cover psoriasis and PA, together with other connected reading that may be of interest to you all, so if any of you have read a good book lately on psoriasis etc., please let us know and we can add it to the booklist. As the list grows in each successive issue of the journal we will compile from it a detailed list which will be available to members by post on application (SAE)

BOOKS BOOKS BOOKS

Arthritis Rheumatism & Psoriasis

Jan De Vries

Mainstream Publishing

ISBN 1-85158-028-x

£4.99

Beat Psoriasis

The Natural Way

Sandra Gibbons

(Co-Founder of The Alternative Centre, London).

Thorsons ISBN 0-7225-2586-9

£7.99

Psoriatic Arthritis

Edited by Lynn H. Gerber M.D.

Luis R. Espinoza M.D.

ISBN 0-8089-1709-9 7915-44

£37.00

Direct from: Harcourt Brace & Co., Ltd.

Foots Cray High Street,

Sidcup, Kent, DA14 5HP.

NB. This is a collection of medical papers written on subject and can be somewhat technical in format.

Arthritis at your age?

Jill Holroyd - The Grindle Press

ISBN 0-9518816-0-4 £11.95

Good read covers all aspects of arthritis etc.

THE SKIN CARE CAMPAIGN

All of the Groups involved in the Skin Campaign duly attended the launch of the Parliamentary Group on Skin Care at the House of Commons on April 18th 1994, and it was a great success and generated a good turn out of MPs from the Commons and persons from the House of Lords.

The setting up of this Parliamentary Group will be invaluable and beneficial to skin sufferers everywhere given time to establish itself.

It's now up to you our members, professional people reading this Journal and other interested parties to write to us with things you would like to see changed, questioned, pursued in regard to the care and quality of treatment of skin sufferers. So there's no excuses now you can have your say through us, who will put your needs to this Parliamentary Group.

Watch out for the main launch of the Skin Care Campaign to the public in July. Should be mega!!!

OUR THANKS TO:

Anita MacAulay, who kindly held a coffee morning and donated the proceeds of same to the Support Group. Well done and thank you Anita.

Congratulations and a thank you go to Kate Heath, who wrote to N.H. Eastwood & Son Ltd, on behalf of the Support Group, who manufacture TENS. Her efforts were kindly repaid by the generous donation of a TENS machine by N.H. Eastwood & Son Ltd, for use by our members on a trial loan basis.

Thank you to Doreen Miles for her continued efforts in the Group.

Robert Cooper for his help in spreading the word.

To all of you who have renewed your membership, thank you for sticking with us.

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SNIPPETS

The Fifth International Symposium on the treatment of Psoriasis and Psoriasis-Arthritis was held in Jerusalem in March of this year.

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Monday-Friday 10.00 am - 5.00 pm

(Info on Patient's Charter, health services; operation waiting times, complaints procedures, common diseases.)

BIRTH ANNOUNCEMENT:

Thought you might all like to know we had a baby girl, called Hannah Elizabeth, three weeks early!! on Monday, March 28th 1994 at 10.18 am, who weighed in at 5lb 12ozs, and yes she has a great pair of lungs!!!

Julie & David.

SNIPPET

Dr. N. McHugh, from The Royal National Hospital for Rheumatic Diseases in Bath, one of our much valued advisers will be giving a lecture on The Skin and Joints in Psoriatic Arthropathy in September at the British Society of Rheumatology Conference in Bath, where we too will be having a stand to promote the illness and our Group.

We will let you know what went on.

USEFUL ADDRESSES/TELE No'S:

Arthritis Care,
18-20, Stephenson Way,
London,
NW1 2HD.

Tele: 071-916-1500
Wyeth Helpline: Freephone 0800 289 170

Young Arthritis Care,
Address as above.

Benefits Enquiry Line (BEL)
Freephone 0800 882200

PLEASE DON'T FORGET

We need case histories and contributions for the forthcoming news letters. Your efforts help others, please spare a few moments to jot some things down on paper and send them in. Without contributions it's pointless having newsletters!! so again it's all up to you the members.

Special Acknowledgements

The Canadian Arthritis Society
Patricia Normandeau, The Canadian Psoriasis
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Sheri Decker, The National Psoriasis
Foundation, America
Arthritis & Rheumatism Council
Kate Baillie, British League Against Rheumatism
Anne Mansfield, British Society for Rheumatology
The teams at Arthritis Care and Young Arthritis Care
All those involved in the Skin Care Campaign
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Jon Stratton, Quinoderm Ltd
Dr. R.N. Wild, Kabi Pharmacia
Galderma (UK) Ltd
Merck Dermatology
Nigel Davies & Jennie Fletcher: Roche Products Ltd
Ann Dugdale, Bioglan Laboratories Ltd
Colin Trinder, Stiefel Laboratories Ltd
Schering Health Care Ltd.
Schering-Plough Ltd.
Leo Laboratories Ltd.
Crookes Healthcare Ltd.
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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 Group possible. Thank you.