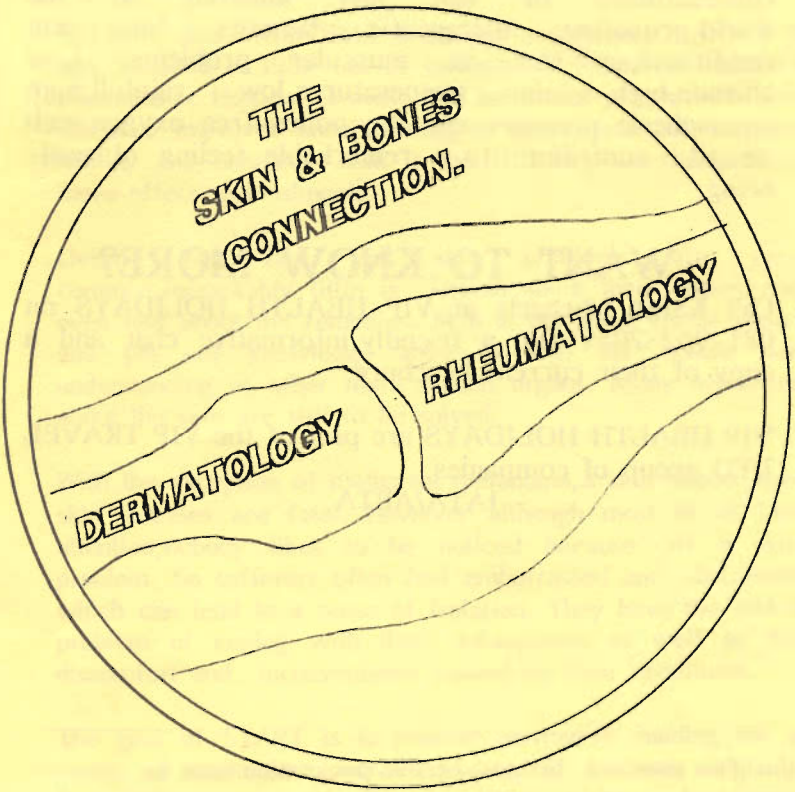
# The Psoriatic Arthropathy Support Group News Journal.

ISSUE NUMBER ONE OCTOBER 1993

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# S T A R T
# (Skin Treatment and Research Trust)
# Skin for life

Skin Problems affect everyone,old & young people,women and men alike. Sometimes they are deadly
like skin cancer,sometimes they are chronic,embarrassing & inconvenient like psoriasis.

START are determined to find a more effective way of treating these and other disorders.

## Who or what is START?

"START" stands for "Skin Treatment and Research Trust". It was founded in 1987 out of concern of doctors at London's Westminster Hospital,to make life better for people with skin diseases. Improved understanding of the differences between healthy and unhealthy skin is the first step on the path to more effective treatments.

Despite the fact that skin problems are very common,remarkably little is known about their causes and even less about the remedies. Skin is our most visible organ and yet our knowledge about it lags far behind our understanding of other more hidden organs. Many mysteries about the skin are still to be solved.

With the exception of malignant melanoma,a skin cancer,few skin diseases are fatal. However although most of us like attention,nobody likes to be noticed because of a skin problem. So sufferers often feel embarrassed and distressed which can lead to a sense of isolation. They have the added problem of coping with their unhappiness as well as the discomfort and inconvenience caused by their conditions.

The goal of START is to provide permanent funding for a centre of academic research dedicated to patients suffering from skin diseases – such as psoriasis,skin cancer,and other

disorders of the skin.

Projects supported by START are looking at the mechanisms of skin function – particularly growth and repair – comparing normal activity with various disease states. If we can learn more about the biochemical and immunological systems of the skin,researchers can hope to be able to point they way to better treatments.

START's researchers have a close association with their colleagues in the Dermatology clinic at Westminster Hospital. This interaction between doctors and researchers means that findings in the laboratory can be rapidly used to help patients.

High tech research is expensive – but rewards could be high for many people here and abroad.

Above kindly supplied by START.

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START is a registered charity,trying desparately to raise £1 million to ensure the financial security of its research for the future. It is hoped that a secure endowment fund will enable the Trust to establish a coherent academic framework ensuring quality and continuity of research.

More on the work of START in future Journals.

Donations no matter how small are greatly appreciated by them and can be sent to :–

START,
Skin Treatment and Research Trust,
Chelsea and Westminster Hospital,
Fulham Road,
London,
SW10 9NH.

Further details please tele: 081 746 8174

Registered Charity No: 298474

ALTERNATIVE THERAPIES: A Member's Experience

## THE ALEXANDER TECHNIQUE

I have been having lessons in the Alexander Technique for several weeks now and have found them a tremendous help in relieving the muscular tension in my back caused by the pain of the arthritis.

What prompted me to seek a local teacher of the technique was noticing that I was getting more "lopsided" and leaning down to the right. I have now been taught how to stand truly upright with a straight spine. Also by using the correct muscles I can pull in my left hip (which on a bad day juts out to the left) and lift the right side of my rib-cage. With this gradual straightening up the pain goes and the back becomes free. When the pain is severe my back goes into spasm causing more pain. I have learned how to release this tension. The lessons involve learning how to do simple things, for example as getting up from a chair without putting undue stress on my back. Whether the arthritis led to the bad posture and subsequent pain or years of standing badly caused the arthritis to start, I do not know, but at least, now I can get some relief.

I quote from Richard Brennan's book on the Alexander Technique : "Arthritis sufferers can experience relief once they begin to become aware of and release the muscular tension they have unconsciously been holding".

I have gone into a lesson only able to walk with some difficulty and come out 40 minutes later walking freely - using what I have been taught is certainly helping me. Also, perhaps because I am more free from the stress of arthritic pain, the psoriasis is in remission except for my scalp and small areas...an added bonus!

Doreen Miles, Essex, Member.
Further information from: The Society of Teachers of the Alexander Technique (STAT), 10 London House, 266 Fulham Road, London SW10 9EL.

# BITS 'N' BOBS

## Reviews and Snippets

A recent study was conducted by Gallup on behalf of the Psoriasis Association from which these facts emerged:

10% believed their condition was infectious.

21% were unsure if the condition was or was not infectious.

75% were unaware of current advances and research in the condition.

57% wanted more information.

It was also evident that more people suffer with psoriasis than was first thought.

From "Here's Health", September 1993

What a pity the Psoriasis Association do not include a survey to their members to see how many of them actually have psoriatic arthritis – they may have a surprise.

### INFORMATION FREEBIE!!

As part of the Psoriasis Association's campaign for more awareness they have produced an audio cassette regarding psoriasis. We believe it is available free from the following address:

Understanding Psoriasis Tape,
The Stables, The Green,
Stadhampton, Oxford,
OX44 7UW.

# ACUPUNCTURE

The ancient Chinese explain acupuncture on the basis of their philosophy.
Qi(Chi), which is the vital flow of energy over the body,blood and body fluid are important substances and structures of the body. They sustain the vital activities and they nourish the body,thereby keeping the functions of the tissues,organs and channels in good order. The channels are the representation of the organs. They are a functional system in their own right and are responsible for conducting the flow of qi and blood through the body. The flow of qi can be disrupted by direct damage to the channels,such as trauma or by an internal imbalance of yin and yang within the body.

Yin and yang are opposites and at the same time interdependent.

The ancient Chinese used water and fire to symbolise yin and yang; anything hot,bright and overactive is yang, and anything cold,dim and underactive is yin.

The central principle of traditional Chinese medicine is to diagnose the cause of internal disease by using the relevant acupuncture points,to correct the flow of qi in the channels and correct the internal disease. In ancient China a physician was only paid while his patient was healthy,not while his patient was ill!

Arthritis falls into the group of diseases of the superficial channels of the body. The flow of qi and blood through the channels is disrupted. This usually gives rise to pain – if the flow of qi and blood is restored the pain will go. This can be achieved by insertion of needles along the channels.These needles are very fine and differ in length according to the area of the body,to which they are applied and are usually left in for 15–20 minutes.

The best method of knowing that you have stimulated an

acupuncture point is to obtain dequ (der-chi) over that point. Deqi means needling sensation and the sensation is usually quite strong,but not painful. Electrical stimulation can also be used as well as the manual stimulation technique.

A course of treatment usually comprises 6-8 sessions and there are no real contraindications for its use,but if the patient has a phobia of needles etc. Then maybe an alternative treatment should be sought.

The improvement from acupuncture may be permanent,but for such conditions as arthritis,acupuncture may have to be repeated at intervals to keep the affected area pain free.

Rosemary Jones,MCSP SRP.
Physiotherapist,BUPA Bushey Herts.

Further information:

The British Acupuncture Association,
34 Alderney Street,
London SW1V 4EU.
Tele: 071-834-1012 or 834-6229.

Further reading:
Acupuncture: From Ancient Art to Modern Medicine
by Alexander MacDonald
Published by: Allen & Unwin, 1982.
Introduction to the subject.

Acupuncture is sometimes available on the NHS or privately,and some doctors do actually use it in their NHS clinics to treat certain conditions.

# Psoriatic Arthritis - When to Treat

The importance with which rheumatologists regard psoriatic arthritis was shown at the recent international conference organised by the International League against Rheumatism in Barcelona, Spain. One entire morning was devoted to discussion on the causes,classification and treatment of this complex disorder. There has been much recent work carried out on the genetic predisposition to the condition although nothing is as yet fully clarified. A new classification of the disorder dividing it into 4 types is proposed and will probably be accepted. There are now a number of different drug treatments for this disorder and in the last few years trials of these drugs have been published in international and national journals showing their efficacy to suppress the disease.

Why then do many sufferers from psoriatic arthritis not receive these drug treatments and continue to be told by general practitioners and rheumatologists that there is nothing that can be done for them at the present? This seemingly negative attitude causes much frustration and distress to the sufferers and their relations. The answer to this question lies both in the nature of psoriatic arthritis and the types of drugs that are available.

Except in its very severest form which occurs in less than 5% of sufferers,psoriatic arthritis is a very much milder disease than the other common forms of arthritis such as rheumatoid arthritis or ankylosing spondylitis. Indeed it does not cause as much crippling when attacking the lower limbs as osteo-arthritis can do to elderly patients. Psoriatic arthritis tends to be

confined to a few joints and damage to these joints is slow and less
destructive than that caused by rheumatoid arthritis. In addition flare ups from psoriatic
arthritis tend to settle down and may be followed by some years of remission during which time no drugs or treatment are required and the sufferer can lead a completely normal life. The dilemma for the rheumatologist in treating patients with psoriatic arthritis is to try and identify those patients who belong to a group who will become severely disabled. Except in a few cases this is not usually obvious in the first year or two of the disease and since the majority of patients with psoriatic arthritis will be only mildly affected,clearly simple local treatment and advice and the use of the safest drugs possible are all that will be recommended.

Drugs used to treat any disease necessarily carry side effects,many of them dangerous,others uncomfortable for patients. The treatments used for the rheumatic diseases are no exception to this. Even the mildest of drugs available across the counter,such as paracetamol,aspirin or Ibuprofen (Nurofen) can cause indigestion or damage to the liver or kidneys if used long term and in the case of the latter two gastro-intestinal bleeding. The more powerful anti-inflammatory drugs,which are only available on prescription,also have a heavy burden of side effects particularly on the gastro-intestinal tract and may have to be given alongside other drugs so as to try and prevent these side effects. These newer drugs certainly have revolutionised the treatment of the rheumatic diseases and enable many patients to lead a normal and relatively pain free life but need to be prescribed with circumspection and after discussion between patient and doctor so that all the risks and benefits are

understood.

The more powerful drugs available for the treatment of psoriatic arthritis are not curative but may suppress the disease to a significant effect,cut short an acute attack and prevent
or delay long term damage to the joints. Their side effects are however far more severe and include damage to the bone marrow,kidneys,liver and skin,many of them very dangerous. Although these side effects can be prevented in some instances or minimised in others and most of them are reversible provided that the patient is regularly monitored,they nevertheless occur in a large number of patients and to many patients,their relatives and doctors are unacceptable. A balance therefore has to be struck in deciding the treatment required for a patient,by putting on the scales one side the risks of the disease to the patient and the likely benefits of the drug and on the other side,the risks of the side effects. In very many patients with psoriatic arthritis the balance will come down on the side of drug risk. Nevertheless any patient should have a chance of discussion with their doctor,the types of treatment available for psoriatic arthritis,the risks of the drug and the reasons why these drugs might or might not be used in their particular case. The right for these discussions and the chance to give informed consent for the use of the drugs is now enshrined in the patients charter. Sufferers from psoriatic arthritis should be prepared to ask questions of their doctors during consultations and should equally be prepared to take decisions for themselves as to whether they will or will not accept modern drug treatment for their condition.

Dr.A.V.Camp Rheumatologist Amersham Hospital,Bucks.

## ARTHRITIS:

It is difficult to know just how prevalent arthritis (inflammation of the joints) is among people with psoriasis. Most surveys indicate that about 1 person in 20 with psoriasis has some form of arthritis and that about 1 person in 20 with arthritis has had some form of psoriasis! However, these figures may be biased by the ways that the surveys have been conducted and the populations examined. It is certainly not most dermatologists' experience that 1 in 20 of their patients has severe arthritis. It may be that 1 in 20 has had some type of arthritis at some time. Luckily only a small proportion of patients have a severe problem with their joints.

One sort of arthritis, psoriatic arthropathy, only affects those with psoriasis. This disease most often attacks the joints at the ends of the fingers, which become swollen and painful. The jaw and some of the smaller joints of the back are sometimes also afflicted. In a small number of cases this disease can be very distressing. If it is allowed to progress unchecked it can eventually damage or even destroy the bone surface of the joints involved and, for example, make the fingers shorter. Fortunately this is extremely uncommon and can be greatly helped if the disease is properly treated in the early stages.

Another joint disease that psoriasis patients are more liable to get than most people is a kind of rheumatoid arthritis. It attacks the middle joints of the fingers (but not the end ones as in psoriatic arthropathy), and some larger joints, such as the wrists and ankles. Very rarely it may also affect the hips. Laboratory tests can distinguish this disease from ordinary rheumatoid arthritis, but from the patient's point of view the symptoms are very much the same. The joints become swollen and tender and do not work well as they used to. The disease tends to flare up and then die down again in an unpredictable way and may, with luck, eventually burn itself out. There are no magic cures, but it can be helped with drugs and physiotherapy following the advice of your doctor.

Reproduced by kind permission of Professor R. Marks
Head of Dermatology, Cardiff University.
Extract from:" Psoriasis, A Guide to One of the Commoner Skin Diseases".

# 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 journalwe will compile from it a detailed list which will be available to members by post on application (SAE appreciated).

## BOOKS BOOKS BOOKS

Rheumatism & Arthritis
Malcolm Jayson and Allan Dixon
Pan Books ISBN 0-330-31842-X £4.99

Psoriasis
A Guide to One of the Commoner Skin Diseases
Professor Ronald Marks
Optima ISBN 0-356-14501-8 £5.99

Psoriasis: A Practical Guide to Coping
Dr. Caroline Wilson
Crowood Health Guides
ISBN 1-85223-212-9 £3.50

Diets to Help Psoriasis
Harry Clements ND.DO.
ISBN 0-7225-1758-0 £2.99

# READERS TIPS:

You must all have some tips you use to make life easier,why not share them with us,no matter how small,they could help some of us,so it doesn't matter how silly the ideas seem,if they work that's the main thing,so tell us!!

**DAVID'S TIP:** Trouble writing,I do. Why not get a rubber band and wrap it around the pen or pencil you are using,it makes gripping and writing alittle easier. It's worth a try.

## Prescription Charges!

If you have alot of prescriptions during the course of the year,have you ever thought of buying a season ticket for them,although the outlay may seem costly it can sometimes work out cheaper during the course of the year. Why not ask your doctor or at your local chemist,post office,Family Health Services Authority,or obtain form FP95 (EC95 for Scotland)from the DHSS.

It will save you money if ie.you have more than 5 items in 4 months or more than 14 items in 12 months.

### THE WEATHER??

**Julie:** I always know when we are going to have some bad weather,David's joints start to play up,and he gets right down in the dumps for a good few days before we get some rain or a bad storm,or a cold spell,he works better than the barometer. We mentioned this to our Rheumatologist,
who thought we had cracked! BUT we wonder how many of you actually feel the same way when the weather is on the change? Like to have your views on this theory,or maybe we are mad!

# MANAGEMENT OF PSORIASIS & ARTHROPATHY

A Holistic Review:

1. EAT SENSIBLY: A prepoderance of alkaline foods (ie) fruit and vegetables should be eaten. In arthritis acid foods should not constitute more than 10% of one's diet. Fish oils have been found to be of no proven benefit.
2. ALCOHOL: Can precipitate and exacerbate psoriasis - it should be cut out or taken in minimal amounts only.
3. SMOKING: Has been linked to the onset of certain forms of psoriasis.
4. REDUCE STRESS: Either by change in lifestyle or counselling. Exercise is a great stress reducer.
5. HAVE PLENTY OF SUN: Sunlight improves more than 90% of patients and a relaxing seaside holiday for two weeks often works wonders. In severe cases a month's treatment at the Dead Sea in Israel can produce a remission which can last for a year. This is thought to be due to the special mineral mud packs in conjunction with the high salt level in the sea and surrounding air, which means one can sit for longer in the sun without burning.
6. HOMOEOPATHY & ACUPUNCTURE: These may help by boosting the body's immune system. Acupuncture is particularly useful in relieving stress and for arthritis.
7. TOPICAL TREATMENTS: These can vary from a moisturising agent to a potent drug. If possible a steroid cream should not be used. Short term ditheranol or calcipotriol are useful for mild to moderate conditions.

Dr.R.E.Alexander
MB.Ch.B.M.R.C.P. Dip.Ac.
Qualified acupuncturist and regional representative (North London area) for British Holistic Medical Association.

# THE DEAD SEA SALT CO.LTD.,

We have arranged with the kind co=operation of the Dead Sea Salt Co.,Ltd a 20% discount on all orders placed by our members. As you may or may not know they produce many products for the treatment of Psoriasis and arthritis.If you would like more information on their products we have details at the office we can send you or write direct to them at: Dead Sea Salt Co.Ltd.,P.O.Box 11,2a,Golden Manor,Hanwell,London,W7 3HQ.

Please also send your orders to the above address so as to obtain your discount on products. Thank you.

We hope to do a feature on the Dead Sea Salt Co.Ltd and their products in forthcoming journals,along with information on the International Treatment Centre in Israel.

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## PA & Psoriasis: Mark Dunn,London.Member, How he manages his condition could help you!

Management Tips:-

1. Keep warm in cold weather. In cold weather your liver works harder converting stored body fat and sugar into energy with increased production of inflammatory chemicals as a by-product.

2. Exercise makes the liver convert fats and sugars with the same effect but you have to exercise to keep from rusting up! Gentle swimming in a warm pool is the best exercise as the liver doesn't get too stressed and the joints are supported. If you are lucky enough lolling about in a jacuzzi or spa bath is also excellent for both body and mind.

3. Sex is a good all round exercise; keeps your morale up in the face of disability.

4. A good mattress is essential,it keeps joints from getting worse at night. A bad or sagging mattress will restrict natural movement when asleep,leading to immobile joints which cause unnaturally stressful positions for the limbs. Don't pay less than £300 for a standard double mattress or £400 for a whole bed. Go for a mattress that has a soft surface but strong interior springs. A good enough mattress should almost be too heavy for two people to lift.

5. Stress: Keep it to a minimum. Having PA is enough stress for one person/family. My pain gets much worse if life stresses get worse. Stress probably decreases one's ability to manage or ignore pain.

6. A walking stick: My pride kept me from using one for too long. It helps when things are bad.

7. A combative attitude to PA. It is necessary to fight a disease. Giving in to it,grinning and bearing it is the same as losing and defeat. Winning the fight requires all sorts of strategies - like I use above.

8. Finally CARE,ATTENTION,HOPE are the best medicine. It does not matter where you get these essential ingredients from,whether it be from you consultant,GP,homeopath,osteopath,psychotherapist,preist,faith healer,neighbour etc.,just as long as you avail yourself of them on a regular basis. This means for at least a half hour per week,preferably for

an hour, someone is focussing on you and your pain and trying to do something about it. You will feel better.

9. Don't stay with a GP or Consultant who will only give you five minutes, who doesn't want to talk or explain; it is too demoralising and will make you feel worse. Care, attention and hope won't cure PA (but you never know) but they will make you feel a whole lot better.

## DIETARY SELF-HELP TREATMENT:

1. Cut out all animal fats including eggs and dairy produce; chicken, fish, very low fat margarine and cheese and skimmed milk are allowed. Beef, bacon, pork, lamb, ice cream, French cheeses, cream desserts etc. are not allowed.

2. Cut out all processed foods and refined sugar products. No cakes, biscuits, jam, fizzy pop, sweets, chocolate, canned fruit etc. Instead eat fresh fruit, fresh bread, fresh salad, fresh vegetables, honey, low sugar jam and drinks.

3. Increase consumption of fish and fish oil and olive and nut oils. Consume 10ml fish oil per day (5ml whizzed up in fresh orange juice morning and night).

4. Avoid vegetables of the nightshade family, mainly of South America in origin - peppers, chillies, tomatoes, potatoes, aubergines and also curry spices. These contain the chemical that the human liver secretes that inflames the joint linings.

5. Cut back alcohol consumption to a minimum. Alcohol stresses the liver which produces more inflammatory chemicals.

6. Things may improve by cutting back on tea and coffee to two cups of either per day (no sugar).

**N.B. Before contemplating any dietary self-help programme it is always best to check with your doctor first to see if this is the best course of action to take in case of adverse affects.**

# SPECIAL THANKS
# to the following members.

Barbara Bone,Newcastle-upon-Tyne.
Barbara recently had a piece in TV Quick about her psoriasis and arthritis and was kind enough to get the group mentioned. It was a really good article,and if anyone wishes to have a copy of the article, would they please let us know.

Janice Johnson,Scotland.
Thanks for all your hard work in Scotland, Janice, trying to get the group known and for getting a small piece in the local paper.

Jill Hayes, Surrey.
Thanks for spreading the word, Jill.

Doreen Miles,Essex.
Thanks for all your contributions and practical help and research.

Ricky Ahmed,Middlesbrough.
Thanks for all your support and practical help,and well done for getting a piece in the local paper.

Thanks to Geoff and Tricia Hobbs for taking on the task of looking after the membership and helping out in other important ways.

Thanks to Kate Heath, Essex, for your practical and supportive help.

# Special Acknowledgements

The Canadian Arthritis Society
Patricia Normandeau, The Canadian Psoriasis Foundation
Sheri Decker,The National Psoriasis Foundation,America
The British Society of Dermatology
Kate Baillie,British Society of Rheumatologists

The teams at Arthritis Care and Young Arthritis Care

Ian Mitchelson,Dermal Laboratories Limited
John Hannan,Dead Sea Salt Co.Ltd
Karen Michaels,V.I.P. Health Travel Ltd
Rami Ruhig,Ein Bokek,International Centre for the Treatment of Psoriasis
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-Plough Ltd.
Crookes Healthcare Ltd.
G.Cooper, Leo Laboratories Ltd

We would like to take this opportunity to express our special thanks to Mrs Patricia Normandeau,of The Canadian Psoriasis Foundation,for all her invaluable help in the supply of valuable information for our use,and for ker kind support.
Again 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 - it is your help along with our members who have made the group possible. Thank you.