Skin 'n' Bones Connection

ISSUE 11 1999

Inside this issue:

Bone & Joint Decade • Diary • NHS Direct • Book Review

For the treatment of itching and dry skin conditions seen with eczema, dermatitis and scaling skin conditions.

Crookes Healthcare, Nottingham NG2 3AA.

Always read the label.

PAA
PO Box 111
St Albans, Herts
AL2 3JQ.
Tel/Fax: 01923 672837

The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

Designed by:
K. A. Sedlacek
Graphic Design
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PSORIATIC ARTHROPATHY ALLIANCE

Internet address: www.paalliance.org
Registered Charity No: 1051169

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This publication was provided with the aid of an Educational Grant from Pharmax Healthcare Ltd.

Skin 'n' bones CONNECTION

The Bone and Joint Decade 2000-2010

The goal of the Bone and Joint Decade is to improve the health-related quality of life for people with musculo-skeletal disorders throughout the world.

INTRODUCTION

Musculo-skeletal disorders are the most common causes of severe long-term pain and physical disability, affecting hundreds of millions of people across the world. The extent of the problem and its burden on patients and society can be understood from some examples:

1. Joint diseases account for half of all chronic conditions in persons aged 65 and over.
2. Back pain is the second leading cause of sick leave.
3. Fractures related to osteoporosis have almost doubled in number in the last decade; it is estimated that 40% of all women over 50 years in age will suffer from an osteoporotic fracture.
4. The severe injuries caused by traffic accidents and war produce a tremendous demand for preventive and restorative help. It is anticipated that 25% of health expenditure of developing countries will be spent on trauma-related care by the year 2010.
5. Crippling diseases and deformities continue to deprive many children of their normal development.

The impact from such bone and joint disorders on the individual, on society, and healthcare and social systems led to an initiative beginning with an inaugural Consensus Meeting held in Lund, Sweden, in April 1998 and culminated in a proposal for the Decade of the Bone and Joint from 2000-2010. The Decade of the Bone and Joint will raise awareness of the suffering and cost to society associated with musculo-skeletal disorders such as joint diseases, osteoporosis, spinal disorders, severe trauma to the extremities and crippling diseases and deformities in children; of presently available means to reduce this and the need to advance this through research.

No one single organisation alone can accomplish the desired benefits for the patient. The Bone and Joint Decade is a multi-disciplinary initiative involving everyone concerned with care including communities, patients, healthcare providers and researchers.

GOALS OF THE DECADE

The goals of the Decade will be achieved by:

1. Raising awareness of the growing burden of musculoskeletal disorders on society.
2. Empowering patients to participate in their own care.
3. Promoting cost-effective prevention and treatment.
4. advancing understanding of musculoskeletal disorders through research to improve prevention and treatment.

The campaign will promote initiatives in all parts of the world, with particular support for activities in developing countries. This will be in partnership with appropriate patient, professional and scientific organisations; research bodies; scientific journals; healthcare providers; governments and non-governmental organisations.

ACTION PROGRAMME

This initiative began with the inaugural consensus meeting in Lund, Sweden, in April 1998 and it will be launched at an international forum in 1999, with co-ordinated announcements made globally.

A series of consensus documents was prepared at this inaugural consensus meeting by selected non-expert groups, based on papers by experts in each of four chosen topics - joint diseases, back pain, osteoporosis and severe trauma of the extremities. The agreed and edited versions are published (Acta Orthop Scand (Suppl 281) 1998; 69). They provide valuable outlines for the four clinical fields that have been selected, and an indication of the potential for advance in other musculo-skeletal conditions. The common features in all four reports are what can be presently achieved, the need for research and advance, the conviction that this would probably be cost-effective in the future, and an awareness of the very wide differences in standards and needs throughout the world.

The aims and objectives of the Bone and Joint Decade were agreed at the end of the inaugural consensus meeting. Endorsement has been sought from a wide variety of stakeholders. An administrative structure has been established. There is a Steering Group which is representative of different geographical regions and disciplines. Its role is to direct and co-ordinate the endorsement, launch and activities of the Decade. One of the initial activities will be a health needs assessment for musculo-skeletal disorders. There will be national co-ordinators and co-ordinating groups representing the various stakeholders at a national level who will be responsible for national activities. All the organisations joining the initiative will be represented on its Board.

GUIDING PRINCIPLES OF THE DECADE

The Decade will be a global campaign to establish priorities and provide information and support to national and international organisations representing patients with musculo-skeletal disorders and healthcare professionals. This will enable them to achieve the goals of the campaign at both national and regional levels.

The campaign will set a framework to promote co-operation within the decade 2000-2010 rather than establish a new organisation.

The campaign will promote initiatives around all musculo-skeletal health.

The campaign will include initiatives in any geographical location and will try to support activities in developing countries.

The campaign programme will be developed in partnership with patient, professional and scientific organisations; research bodies; scientific journals; healthcare providers; governments and non-governmental organisations in consultation with all other stakeholders from all countries and regions.

The campaign will identify the size of the burden of musculo-skeletal disorders now and in the future by undertaking a review and compilation of existing data.

The campaign will support strategies that encourage the application of cost-effective prevention and treatment.

Research needs will be identified and investment in research will be encouraged.

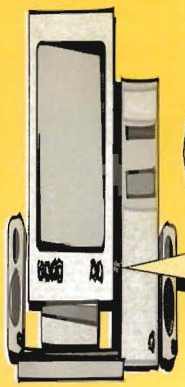
The strength of the campaign will depend on a co-ordinated approach. Any activities undertaken in co-operation with the campaign should be identified by using the trademark campaign logo.

All organisations joining the campaign will have a representative on its Board. A Steering Group has been elected to direct the project.

The campaign will act independently of sponsors and will not be linked to any one specific organisation.

Philanthropic donations will be sought from member organisations of the Board and other non-commercial organisations to fund the campaign initially.

PAA E-mail Discussion Group



Psoriatic Arthropathy Alliance
E-mail discussion group.
Would you like to 'talk' with other psoriatics via the Internet?
Chat? Exchange information and ideas? Find out what's new? Mutual support? Make friends?
To become a member of this E-Group contact the group moderator and PAA member
Mike Ainsworth <MAinswo884@aol.com>
Who will be happy to explain how it all works.

NHS Direct

I think something's wrong. Perhaps I should talk to Mum, rest or go to bed. Should I call out the doctor, go down to Casualty or get an ambulance to come out?

What is NHS Direct?

Staffed by nurses and trained operators, NHS Direct will give people immediate information and friendly advice on what to do and what not to do, at any time of the day or night. Of course, where NHS Direct staff think that there is serious cause for concern, they will advise people on what to do or connect the caller directly to 999 if they need an ambulance. Details of other relevant health information services, local late night pharmacists and out of hours dentists will also be provided as needed.

Why is NHS Direct needed?

Worrying health problems and questions can crop up at any time. Minor cuts or burns, a distressed baby where there is no obvious cause, a headache that won't go away..in many of these circumstances, people probably don't need to call out a doctor, or go to the accident and emergency department, or make a 999 emergency call, but people may still feel the need for advice from someone who is qualified and experienced. That's why the NHS has set up a 24 hour confidential Helpline - NHS Direct.

When will NHS Direct be available?

At the present time this service is being piloted in three locations:

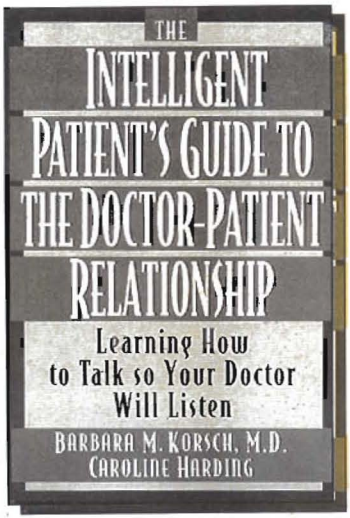
- in Preston, Chorley and South Ribble (service provided by the Lancashire Ambulance Service NHS Trust);
- in Newcastle, North Tyneside and Northumberland (service provided by the Northumbria Ambulance Service NHS Trust);
- in Milton Keynes (service provided by the Two Shires Ambulance Service).

NHS Direct services are not currently available in other areas of the country.

Early indications from the three NHS Direct pilot schemes have been very positive. It has now been agreed to expand the service to up to 15 million people through a second wave of pilots in all health regions, leading to cover for the whole country by 2000.

NHS Health Information Service:
Freephone 0800 66 55 44

Book Review

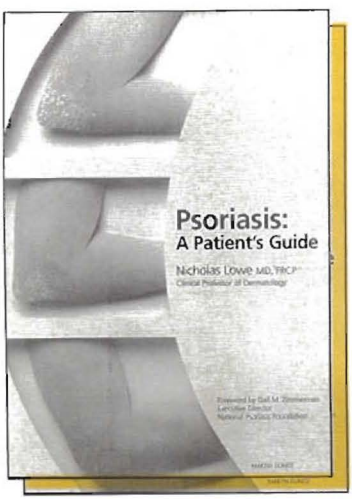


The Intelligent Patient's Guide to the Doctor-Patient Relationship.

Learning How to Talk so Your Doctor Will Listen.

Barbara M. Korsch, M.D,
Caroline Harding

ISBN: 0-19-510264-9
Oxford University Press



Psoriasis:
A Patient's Guide

Nicholas Lowe M.D. FRCP
Clinical Professor of
Dermatology

Foreword by Gail M.
Zimmerman
Executive Director
National Psoriasis Foundation

Martin Dunitz Ltd
ISBN: 1-85317-599-4

IT'S 'ALL GO!' FOR EVERYONE - LAUNCH OF FIRST DISABILITY-FRIENDLY HOTEL DIRECTORY COMPILED BY PERSONAL RESEARCH

With the disabled community comprising 50 million people within the EU - 36 million of whom are able to travel - MasterCard is launching 'All Go!', the first region-by-region guide to UK hotel access for everyone. 'All Go!' has been compiled using the 'mystery shopper' technique of telephone conversations with personnel from every hotel in the country. The directory only profiles hotels and hotel restaurants (not B&Bs, inns, etc.) which can provide rooms for those with disabilities, even at short notice. It is the only directory of its kind to be compiled by a wheelchair user - disability consultant, Jonathan Kaye - who has spent the last two years devising and developing the project.

The 1995 Disability Discrimination Act requires all companies providing goods and services - regardless of their turnover or number of employees - to have reached a certain standard for customers with disabilities, by October 1999. All Go! is invaluable in enabling the hotel industry to meet and develop these standards.

Mr Kaye commented:

"All Go! is not just a directory, it is a concept that I hope in time will embrace the whole of society. All Go! is innovative in its approach - listing only hotels that can provide both accommodation and restaurant facilities which are accessible to anyone.

97% of the potential disabled market wants the ability to travel independently or with family and friends utilising mainstream means, whilst only 3% wish to use specialised disability organisations. The EU travel and tourism industry is currently estimated to be losing £25-27bn per annum due to the lack of proper facilities for the disabled, most likely because they are unaware of the needs. I created All Go! for these commercial reasons as well as my personal dissatisfaction with some of the directories currently on offer."

Regional director of marketing for MasterCard, Rita Broe, commented: *"MasterCard is both aware of the Disability Discrimination Act and the need to promote disability awareness within the hotel industry. All Go! will be a valuable resource for this as well as encouraging travel agents and facilitators of hotel services to provide people with disabilities with the resources to create their own travel arrangements like anyone else. MasterCard is delighted to support this unique project."*

All Go! comprises hotel brands such as the Alton Towers hotel, Travel Inns, Thistle Hotels from Lands End to John O'Groats. It does **not** profile those hotels owned by charities that cater exclusively for guests with disabilities. Where applicable, it highlights those hotels and restaurants that have achieved the 'Tourism for All' status.

Supporters of the All Go! directory include the Association of British Travel Agents (ABTA) which is distributing 2000 copies to its members. The foreword is written by Jill Dando, founder member of the Society of Stars - a charity run by celebrities to both raise money for, and awareness of, people with cerebral palsy and other disabilities.

Allan Slater, operations director with special responsibility for guests with disabilities at Thistle Hotels commented, *"There are a number of Thistle Hotels throughout the country which offer facilities for guests with disabilities. The All Go! directory is a great way to promote hotels which can offer accessible accommodation and help those with disabilities to travel independently."*

All Go! is endorsed by a number of other charity partners including: Scope, Age Concern and The Stroke Association. Costing £4.95, it is available in bookshops from 28 October or from the publishers - BIG Group - on tel: 0171 383 2335 or email: allgo@biggroup.demon.co.uk.

For further press information, contact Lucy Bernard at NGA, tel: 0181 742 0200, email:mail@ngapr.com, website: http//www.ngapr.com

Extract: Opening Address Candy Atherton MP.
Event: PAA Conference

1

IT'S GOOD TO BE HERE. AS YOU KNOW I HAVE PSORIASIS AND THE ASSOCIATED ARTHRITIS. SOME OF YOU MAY HAVE READ THE ARTICLE IN THE DAILY MAIL WHICH, SOMEWHAT INACCURATELY, AND IN CONJUNCTION WITH AN APPALLING PICTURE, DESCRIBED SOME OF THE DIFFICULTIES I HAVE HAD.

THIS THOUGH IS MY CHANCE TO SPEAK TO THOSE WHO BOTH TREAT THE CONDITION OR ARE FELLOW SUFFERERS. I CAN REMEMBER MANY OCCASIONS, AS I HAVE LAIN ATTACHED TO A BED, OFTEN A HOSPITAL BED, WRAPPED IN BANDAGES AND OR SOME DISGUSTING BROWN GUNGE, WHEN I HAVE PLOTTED MY REVENGE ON THOSE WHO WOULD HAVE ME SUFFER THIS INDIGNITY.

THIS IS MY CHANCE. AND I WANT TO SAY PLEASE, PLEASE, TRY AND FIND A CLEANER WAY TO TREAT PSORIASIS, A TREATMENT THAT DOESN'T LEAVE BURN MARKS ON HOTEL SHEETS, OR GREASE THAT REFUSES TO COME OFF NEIGHBOURS' WALLS.

3

EARLIER THIS YEAR I WAS BEING SEEN BY A DERMATOLOGIST IN CORNWALL, AND AN EMERGENCY CONSULTANT IN LONDON, THE SAME SITUATION EXISTED FOR MY ARTHRITIS AND IN CORNWALL FOR MY STOMACH REACTIONS TO THE DRUGS THE DERMATOLOGIST PRESCRIBED FOR THE CONDITION. ALL THIS INVOLVED ENDLESS VISITS TO DIFFERENT DEPARTMENTS WHERE, USUALLY, AT LEAST ONE OF THE DRUGS WOULD BE CHANGED AND THAT WOULD IMPACT ON OTHER TREATMENTS. THE COST TO THE NHS WAS HORRENDOUS AS WERE THE RESULTS TO MY HEALTH.

IRONICALLY, WHEN THE INTERVIEW APPEARED IN THE DAILY MAIL I WAS EXPERIENCING THE WORST HEALTH I HAD EVER KNOWN. I HAD TO BE WHEELED AROUND THE HOUSE OF COMMONS IN A WHEELCHAIR - MY OFFICE HAS STAIRS AT BOTH ENDS OF THE CORRIDOR AND NO LIFT SO IT WAS TOUGH, AND I WAS IN DREADFUL PAIN.

2

I DON'T KNOW WHAT YOU THINK BUT I OFTEN FEEL THAT MOST OF THE TREATMENTS THAT HAVE BEEN DONE UNTO ME HAVE BEEN QUITE REVOLTING AND SOME OF THE DRUGS FOR THE ARTHRITIS I WOULD NOT WANT EVEN MY WORSE POLITICAL ENEMY TO ENDURE.

QUESTION. WHY DOES EVEN THE SHAMPOO HAVE TO COME IN A BOTTLE THAT RESEMBLES CATTLE SLURRY. WHY CAN'T IT LOOK LIKE A NORMAL SHAMPOO BOTTLE? IT MARKS US OUT AND IS, IN MY VIEW, UNNECESSARY.
THE SAME GOES FOR THE STUFF THAT WE ADD TO BATH WATER. IT MAKES MY BATHROOM RESEMBLE A VETS' PHARMACY.

NOW I DO NOT WANT TO GIVE THE WRONG IMPRESSION. I AM INORDINATELY GRATEFUL TO MANY OF THE CLINICIANS, CONSULTANTS, NURSES, PHYSIOS AND OCCUPATIONAL THERAPISTS WHO HAVE ATTEMPTED BATTLE WITH MY DISEASE. I JUST WISH THEY HAD ALWAYS TALKED TO ONE ANOTHER.

4

MY EVER PATIENT AND SAINTED GP AND DERMATOLOGIST IN CORNWALL DECIDED THAT, TO COIN A PHRASE, ENOUGH WAS ENOUGH, AND IN FUTURE ALL TREATMENTS WOULD GO THROUGH THE DERMATOLOGIST. IN THIS WAY THE NHS WOULD SAVE MONEY AND I MIGHT GET OFF THE MERRY-GO-ROUND OF DECLINING HEALTH. I WAS LUCKY THESE TWO DOCTORS DECIDED TO TAKE THIS ACTION. IT HAS MADE A DIFFERENCE.

I WISH OUR HEALTH SERVICE DID NOT THOUGH HAVE TO WAIT UNTIL A CRISIS OCCURS TO BE ABLE TO TREAT THE WHOLE PERSON RATHER THAN SHOVING ONE OFF FROM PILLAR TO POST SEEING DIFFERENT SPECIALISTS. I KNOW WE HAVE CONSULTANTS AND CLINICIANS HERE TODAY WHO AGREE. OUR CONDITION IS NOT THE PROVENANCE OF ONE SPECIALISM WITHIN HEALTHCARE, BUT OF A NUMBER.

5

AS A RESULT OF THE FACT FILE LAUNCH AT THE HOUSE OF COMMONS A NUMBER OF MPS WHO ATTENDED CONTACTED THEIR LOCAL HEALTH AUTHORITIES TO ASK WHAT SERVICES WERE PROVIDED AND WERE SURPRISED AT THE RANGE OF ANSWERS. I BELIEVE THOUGH WE SHOULD ALL HAVE A STANDARD OF CARE THAT WE CAN EXPECT AND THIS IS SOMETHING I HAVE RAISED WITH FRANK DOBSON.

I AM VERY PLEASED TO HAVE BEEN ASKED TO SPEAK TODAY AT THE START OF THE CONFERENCE AND TO BE ABLE TO HELP PROMOTE THE CONDITION AND HOW WE CAN OVERCOME THE PROBLEMS. I WAS OVERWHELMED BY THE RESPONSE TO THE DAILY MAIL ARTICLE. I AM STILL GETTING LETTERS AND PRODUCTS SENT THROUGH THE POST. I AM NOT IN A POSITION TO ENDORSE ANY OF THEM. TO DATE NONE HAVE RESULTED IN AN IMMEDIATE CLEARING OF MY HANDS - WHICH IS MY LITMUS TEST.

Candy Atherton MP

6

I HAVE TO GO LATER TODAY TO BLACKPOOL FOR THE LABOUR PARTY CONFERENCE SO I CANNOT STAY FOR THE ENTIRE DAY. BUT I THANK YOU FOR THE OPPORTUNITY TO MAKE MY PLEA. CONSULTANTS AND CLINICIANS - GET THE MANUFACTURERS TO IMPROVE THE PACKAGING, AT LEAST ALLOW US TO FEEL WE HAVE A NORMAL BATHROOM, AND CLINICIANS PLEASE, TREAT THE WHOLE PERSON.

Coal Tar Revisited

Tar has been used to treat skin disease for many centuries,[1] but the use of coal tar for psoriasis was popularised only around 60 or 70 years ago.[2] This came largely as a result of the research conducted by a doctor called Goeckerman, from the world renowned Mayo Clinic in the USA,[2] who studied the effects of ultraviolet (UV) light exposure on skin to which various different substances had been applied.

He gave his name to the Goeckerman regimen of coal tar ointment and tar baths together with UV light therapy. This regimen has since become a standard treatment for psoriasis around the world, although some doubts have been cast on the benefits obtained by adding the UV to coal tar treatment.[2]

Since its more widespread use in psoriasis, coal tar has been shown to be a well-established, effective topical treatment[5] with a good safety record.[3] In fact, most people with psoriasis will be familiar with tar-based preparations. Despite extensive use over the years, however, we still know very little about coal tar, for example about which of its many constituents is the most effective or how exactly it works in skin diseases like psoriasis.[4]

How crude can you get

Crude coal tar, despite the simple sounding name, is an extremely complex mixture which may contain as many as 10,000 different substances.[2] Of these around 400 have been identified as comprising 55 per cent of the tar by weight.[2] The most common substances in tar, however, may not necessarily be the most active ingredients.[2] In fact, only around half of the substances contained in tar have ever been identified, and nobody knows for certain what the most important anti-psoriatic substance in tar is.[1,4]

Efforts to gain a better understanding and a more comprehensive analysis of these different substances have been hampered by the sheer complexity of the crude coal tar itself.[2] What we do know is that it seems the cruder the coal tar preparation, the more effective it is.[2] This may not necessarily be an attractive prospect to those people with psoriasis who may dislike the mess and smell involved with cruder forms of coal tar. Recently there has been some new formulations of coal tar which appear to be effective at treating psoriasis, and that are not as messy and are more cosmetically acceptable for people to use than some of the old-fashioned preparations.

Safety in psoriasis

Researchers in the past have worried that coal tar could be carcinogenic, but in many years of clinical studies there has been no causal link shown between the use of coal tar for psoriasis and the subsequent development of skin and other types of cancers.[1,2,6] Nowadays, coal tar preparations are considered so safe that they can be bought over the counter in chemists and pharmacies.

A range of medical uses

Coal tar has been used to treat many different skin complaints, and has been used in dermatology since the last century.[2] Certain substances in coal tar give it an anti-itching effect, and its antiseptic properties mean that it has been used to treat various types and stages of eczema.[2] Coal tar has proved

very useful in subacute and chronic types of eczema, particularly as an alternative to topical corticosteroids which can cause skin thinning and other side effects.[2]

TAR: SOME FASCINATING FACTS
Did you know...

- Tar is one of the most ancient skin treatments still in use; it has been used to treat skin problems for an amazing 2,000 years.[1]
- Crude coal tar is thought to contain around 10,000 different substances; only half of these have been properly identified.[1]
- A bituminous medical tar can be obtained from rock formations containing the fossilised remains of fish![1]
- Coal tar is made by heating coal in the absence of air at temperatures of up to an immense 1200°C[2] - that's around five times hotter than the average kitchen oven.
- Coal tar can itself be heated to produce different types of oil; a residual by-product of this is pitch - the substance used in roadmaking.[1]

REFERENCES:

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4. Walter JF, Stoughton RB, DeQuoy PR. Suppression of epidermal proliferation by ultraviolet light, coal tar and anthralin. *Brit Jnl Derm* 1978;99:89-96

5. Williams et al. Re-examining crude coal tar treatment for psoriasis *Brit Jnl Derm* 1992;126:608-610

6. Jones et al. Further evidence of the safety of tar in the management of psoriasis. *Brit Jnl Derm* 1985;113:97-101

This article has been supplied by Holmes & Marchant Counsellor on behalf Pharmax Healthcare Ltd.

Good Vibrations Put Wheelchair Out Of Action

Niagara®, a little-known medical therapy, will shortly be celebrating 50 years of quietly bringing a better quality of life to hundreds of thousands of sufferers of chronic ailments world-wide.

The Niagara® Therapy, accidentally derived from the "good vibrations" of a coal sorting machine, is exclusive to the medical therapy products manufactured by the Niagara® Group and Adjustamatic.

It is a massage therapy that releases tension in the muscles, improving circulation. The therapy relies on a motor which generates a three-dimensional vibration, resulting in a deep, penetrating but gentle massage, providing a multitude of benefits with no harmful side effects. Niagara® Group and Adjustamatic products include therapy pads and hand units, adjustable beds and chairs.

In the case of a lady from Monmouth, Niagara® has brought continued relief from osteoarthritis since she was introduced to the therapy in 1986. After only 30 days of using her vibrating therapy pad she was able to put her wheelchair away in the shed.

Independent medical research has confirmed the beneficial properties of Niagara® products for a range of musculo-skeletal, circulatory, nervous and chest conditions, including diseases such as arthritis, rheumatism and back pain, which afflict millions of people in the UK.

"Although our therapy is relatively unknown among medical professionals, we feel the time has now come to tell our 'untold story' to UK medical and healthcare media so that more and more people can learn how to access a better quality of life. In my view there are few households who wouldn't benefit from a Niagara® product," said Niagara® Group managing director, Rob Wilkinson.

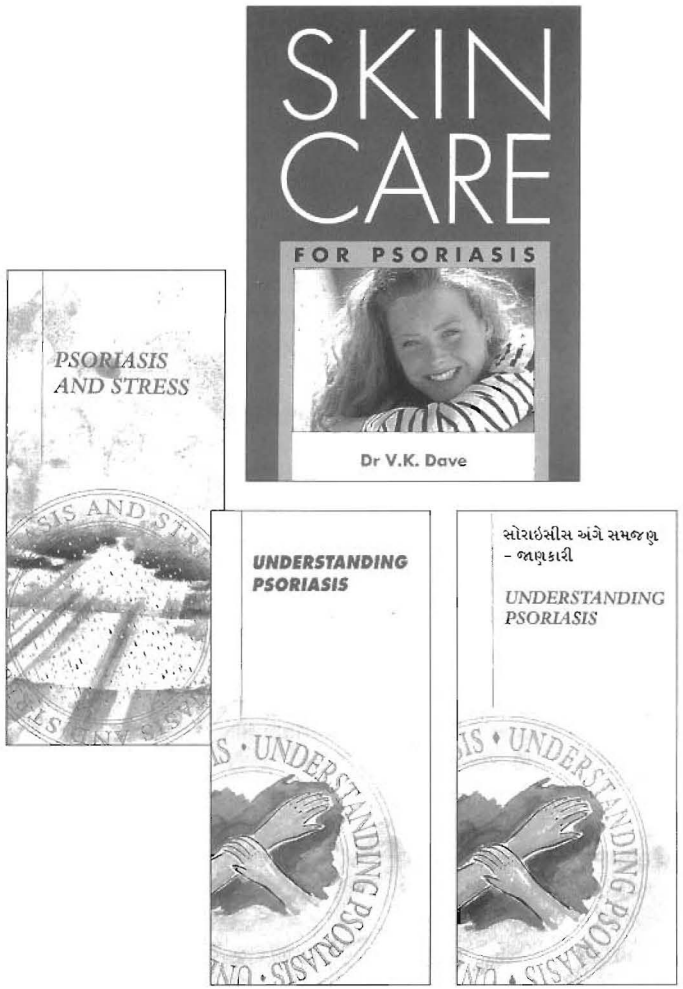
New clinical research into the action of the Niagara® Therapy on osteoarthritis of the knee, conducted by Niagara® Group medical advisers, GPs Martin Strudley and John Fraser, is currently ongoing, with results due towards the end of this year. "In my opinion the therapy is definitely under-recognised and we believe that the results of this current research for which we received ethical approval in spring 1998 will really make medical professionals sit up and take notice," said Martin Strudley.

With around 115 million working days lost each year because of back problems at an estimated cost to industry in lost production of more than £5 billion, back pain is the third most frequently experienced symptom of ill health in the UK. Arthritis and rheumatism pose a similar burden to society with six to eight million people in the UK suffering from rheumatic diseases, representing around 88 million lost working days annually. Given its proven role in reducing the suffering caused by these and other medical conditions, Niagara® Therapy has the potential to considerably reduce the estimated annual NHS bill of £100 million for back pain, arthritis and rheumatism. Niagara® should be recognised as a valuable complement to conventional medical treatment.

For further information or to speak to a user of Niagara® products, contact:

Deborah Lewis or
Jo Sensini
Tel: 0171 287 7477
Fax: 0171 287 7577
E-mail: deborah@republic-2.prestel.co.uk

WE ARE PLEASED TO SUPPORT THESE LEAFLETS

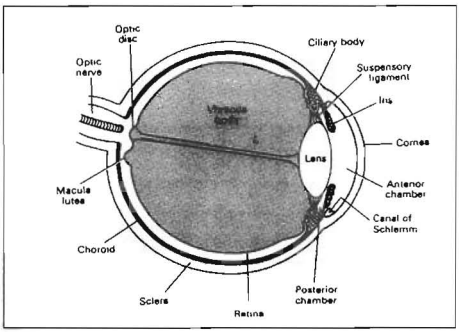


LEO

A PRIDE IN DERMATOLOGY

LEO Pharmaceuticals, Longwick Road, Princes Risborough, Buckinghamshire HP27 9RR
January 1998 1772

Psoriatic Arthritis and the Eyes



Fewer than 1 in 10 people with psoriatic arthritis develop a problem with the eyes called uveitis.

Uveitis

Uveitis means inflammation of the uvea. This can affect the iris (iritis), ciliary body (cyclitis) or the choroid (choroiditis). Symptoms depend on whether all or just part of the uvea is affected, but may include:

- dull, aching pain in the eye
- redness
- blurred or misty vision
- a muddy appearance to the coloured iris in the affected eye
- a pupil that may be smaller than that of the other eye and irregular in outline.

Symptoms can affect one or both eyes. Inflammation is thought to result from the immune system attacking the cells of the uvea. Treatment of uveitis is urgent to stop the inflamed iris from sticking to the lens behind. This would cause permanent damage to the eye and can also trigger glaucoma (rise in fluid pressure in the eye due to blocked drainage channels). Uveitis often returns from time to time.

Note: Children with psoriatic arthritis should have regular screening tests for uveitis as they may not develop symptoms until their eyesight has been damaged and irreversible visual impairment takes place.

Treatment

Inflammation is damped down with eye drops containing corticosteroid drugs. In severe cases, you may also need to take steroid tablets by mouth to boost the effect of the drops. Eye drops that relax the iris and ciliary body are also used. These make the pupil dilate and ensure that an inflamed iris does not stick to the eye lens (posterior synechia). The inflammation is monitored by regular examination of the eye using a slit-lamp. If steroid eye drops are used for prolonged periods, the fluid pressure in the eye will also need to be checked regularly. This is because long-term use of steroid drops can cause a form of glaucoma.

Useful address:
The Royal College of Ophthalmologists (eye specialists): Tel: 0171-935 0702. 17 Cornwall Terrace, London NW1 can provide a list of practising ophthalmologists.

EULAR Congress
6-11 June 1999
Glasgow, Scotland.
5-day health professionals conference
Eular 99 will include a 5-day programme aimed at meeting the needs of health professionals working in the field of Rheumatology, covering such topics as current practices, clinical updates, shared care. It will also entail a full scientific programme of six main themes.
Further details contact:
EULAR 99 Congress Secretariat,
41 Eagle Street, London, WC1R 4AR.
Tele: 44 (0) 171 242 3313
Fax: 44 (0) 171 242 3277
E-Mail:
eular99@rheumatology.org.uk

THE GENETICS REVOLUTION and the Future for Health & Social Care
23-24 June 1999
University of Glamorgan,
Pontypridd, nr Cardiff, Wales.
Further details:
Mala Pisavadia,
Welsh Institute for Health & Social Care,
University of Glamorgan,
Pontypridd, nr Cardiff, South Wales CF37 1DL.
Tel: +44-1443-483070
Fax: +44-1443-483079
E-mail:
mpisavad@glamorgan.ac.uk

PSORIATIC ARTHROPATHY ALLIANCE CONFERENCE
Saturday 25 September 1999
Woburn Safari Park
Bedfordshire
Early registration booking advisable.
Further details and registration form:
PAA, PO Box 111, St. Albans, Hertfordshire, AL2 3JQ.
Tel: 01923 672837
Fax: 01923 - 672837

PSORIASIS FROM GENE TO CLINIC
2-4 December 1999
Venue: Queen Elizabeth II Conference Centre, London, UK.
Main topics: Genes and genomics, epithelial mesenchyman interaction, immunology, psychosocial aspects - physical therapy, receptor - targeted therapy.
Further details and costings contact:
Ms Sherryll Eady,
Project Manager,
CCT Healthcare Communications Ltd,
50-52 Union Street,
London SE1 1TD.
Tel: +44 (0) 171 407 9731
Fax: +44 (0) 171 378 9268
E-mail: CCT Healthcare@compuserve.com

THE BONE AND JOINT DECADE 2000-2010
For Prevention and Treatment of Musculoskeletal Disorders.
Further contact details to be advised.

marathon 1999

"At 24 years of age the diagnosis of a crippling disease called Psoriatic Arthritis came with many mixed feelings: relief that I finally had a label to attach to all this pain I had been experiencing; shock; and most of all disbelief - surely there was some mistake?

The relief quickly faded though and it has been a long continuous battle to come to terms with it all. It started with just a pain in my heel, but has rapidly spread to include elbows, knees, toes, fingers, wrists, ankles, chest bone and spine. Apart from the obvious pain and the frustration and embarrassment of, at times, not being able to even wash or dress yourself, I find the symptom of Chronic Fatigue one of the worst to cope with. The feeling of complete exhaustion after carrying out the most menial of tasks is not only horribly frustrating but incredibly disabling. Even on a 'good day' when my joints are relatively pain free, a trip out to the shops, for example, will always require the use of my wheelchair.

This lifestyle is not exactly what I planned and hoped for myself and I certainly did not think I would be retired at this age - but after two years of several ups and many, many downs I am gradually learning to live side by side with this monstrous disease. The support I have had physically and emotionally from my friends and family alike has been - and continues to be - completely invaluable. Without them I really do not know how I would manage. I am constantly touched by the kind words and actions of those around me: my husband's life has also been turned upside down by this disease but I never hear a word of complaint or self pity; my parents are moving from Kent to Yorkshire in order to be near me and help out more; and now my uncle, advancing in years (!) and experiencing significant knee trouble, is going to endure pain and possible knee damage by running the London Marathon in order to raise money for the Psoriatic Arthropathy Alliance so that support and hope can continue to be given to sufferers like me.

All that I can say is a big thank you to you all.

Kelly Forrester

Here's the profile of our runner. He
Kelly's uncle - please support him to
help us. Sponsorship forms are
available from the office

Name:	Roger Dale
DoB:	4/9/49
Age:	49
Status:	Married with two teenage daughters.
Work:	Data Security Officer with the Police Information Technology Organisation.
Other:	Magistrate with Croydon Bench. Reflexologist and Masseur (Complementary Therapies). Amateur Dramatics. Scottish Country Dancing.
Sport:	Keen sportsman - football, cricket, badminton, squash, running. Knee ligament problems since early twenties (my twenties, not 1920s!) from football. Parachute jump in 1990 despite great fear of heights (for charity). Ran the London Marathon in 1983 (4 hours 6 minutes) - had to walk the last 9 miles due to painful knees.
Marathon 1999:	Wanted to push Kelly in her wheelchair but the organisers would not allow it. Now feel somewhat vulnerable by myself. Concerned about being rather older and heavier than 1983 with very suspect knees. Will not be able to train because I fear the knees will not take the strain. Relying on natural fitness and stamina.
Quote:	I am anticipating 26 miles of hard work and pain. However, my agony will last just a few hours. Kelly and others affected by PA are facing a lifetime of suffering. At the end of the 1983 Marathon, I said I would never do it again because I feared the consequences. My problems are nothing compared to the effects of PA and I am determined to complete the Marathon and raise a huge sum of money for the PAA.