Skin 'n' Bones connection

ISSUE 12 1999 incorporating the PAA news price£3.00

Marathon

In this issue

As most of you probably read in the previous issue, Roger Dale, my uncle, was running the London Marathon last April in aid of the PAA. We are very proud to say that, despite knee trouble which gave him significant pain during the 26 miles (and, indeed, for several days afterwards), he managed to complete it in 4.5 hours, raising a magnificent £1650.

The day was fairly eventful for us too, as my family and I went down to London from Yorkshire to support Roger. Knowing that it would be a long day with lots of standing, I took my wheelchair which proved to be a big mistake. The train journey down to Euston was fine, but it was here that we encountered problems. Having not been to London since I have had PA, perhaps we were being naive, but there was absolutely no provision on the Underground for wheelchair users. We understood that there would not be lifts in all the stations, but we thought (obviously stupidly) that there would be some alternative arrangements made. Eventually, we were informed (by an extremely unhelpful information desk worker) that we could get a bus to Victoria. However, this was going to cost us more as we would not be able to use our travel cards. Also, these buses only ran every hour (and it was typical that we had just missed one) and appeared to go via Scotland as they took over an hour to go the short distance from Euston to Victoria!

In the end, as time was running short and tempers were beginning to fray, we decided to get a taxi. This was a different world. The taxi driver immediately jumped out to help and the taxi was equipped to take wheelchairs. We told this kind, friendly man our sorry tale and as we arrived at our destination, he wouldn't let us pay our £10 fare and gave us another £5 towards our charity (I have to confess, that Mum and I actually cried at this point!). It is really nice to know that there are some lovely people in the world, and then seeing my uncle hobbling to the finish line just confirmed it.

Kelly Forrester. PAA Action Group Member

A big thankyou to Roger - it really is appreciated.

We have since written to the Transport Authority and they have provided us with a booklet regarding travelling around London. David and Julie Chandler will hold this centrally, so if anyone wishes to access it, please contact them.

Congratulations

David Whitelaw successfully completed the London Marathon on behalf of the PAA - raising £920

David pictured with his wife Julie and the kids

PAA
PSORIATIC ARTHROPATHY ALLIANCE
Registered number: 1051169
Internet: www.paalliance.org

The PAA Team

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.

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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.

Psoriatic Arthropathy Alliance is a Registered Company Limited by Guarantee No: 3055414. Registered office: Faulkner House, Victoria Street, St.Albans, Herts. AL1 3SE

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EDITORIAL

Welcome to the new look *Skin 'n' Bones Connection* as you will see it is now bigger and we feel better than ever.

You may also have noticed that there hasn't been a PAA publication for a few months, this has been entirely due to re-designing and reassessment process - which has taken longer than expected. We at PAA feel that instead of 2 magazines (*PAA News* and *Skin 'n' Bones Connection*) it would be much more efficient to produce a combined publication.

We hope that you will find this edition of interest and maybe in the future you might wish to contribute an article, editorial or case history.

The next issue will be due out in late spring 2000, so please send your articles etc to the editor by the end of February 2000.

Finally, the PAA would like to thank you for continued support and wish you a happy, healthy and prosperous 2000.

Checks of Prescription Charge Exemption - Point of Dispensing Checks

Point of Dispensing (POD) checks start from 1 April 1999 for most exemption categories. They involve pharmacists, dispensing doctors and their staff asking patients, who claim exemption from the NHS prescription charge, for evidence of their exemption, except for any cases where the pharmacists or doctors may already be in possession of the evidence.

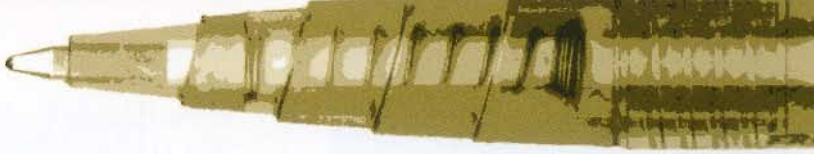
Patients who do not show evidence of their exemption will still receive their medication free of charge, but the pharmacist or doctor will mark their prescription for a subsequent check.

GPs' prescribing software is being amended so that computer generated prescriptions will include a patient's date of birth and age, but this will not be in place for all computer generated prescriptions before July 1999. Where the age and date of birth are included on the prescription form the dispensing doctor or pharmacist will not need to request any other evidence. POD checks for age exemptions (under 16s, those 16-18 in full time education and over 60s) will start in July 1999.

We have tried to ensure that POD checks are simple, but effective. And we believe that they are an important preventative measure, which should better help us to detect and deter fraud better. We also believe that it is important that patients who are genuinely exempt from the prescription charge should be confident that they can claim this.

We have a Free Prescriptions Advice Line, which will answer queries about exemptions and evidence. The calls are free and patients and practitioners can use the line. The number for the advice line is 0800 91 77 71 1. We are also producing an information leaflet on POD checks for practitioners and patients. The leaflets can be ordered from Two Ten Communications, Department of Health, PO Box 410, WETHERBY LS23 7LN. NHS Executive Directorate of Counter Fraud Services March 1999

Pen Pals Wanted !!!



Dear PAA

I have suffered from psoriasis for some time now and find it very distressing as it is all over my body and visible to everyone.

My condition causes me to be most self-conscious and this can be very depressing. I am receiving treatment for my condition but feel it would help me greatly if I could talk to someone who understands how I feel; perhaps a fellow sufferer?

I hope that my address does not act as a barrier to someone contacting me.

Here's my case history - here goes!!

I was diagnosed as having psoriasis seven years ago. It started to appear after I'd finished working for a security firm. I'd gone into a house which had just been found broken into and on entry was welcomed with a bucket of bleach and sugar, which temporarily blinded me. That year I felt horrible. About a month after I had finished working there, I started to notice tiny spots which were very itchy on my knee caps and feet.

As the weeks passed I was covered in spots which were scaly and irritable.

I was in and out to see my GP until he finally got a dermatologist to see me.

I was soon diagnosed as having chronic psoriasis - I felt so unclean and ashamed of my body.

I'd been in a good and strong relationship for three years and was engaged, but it was not very long before my fiancee started pulling away from me and making all kinds of excuses for not being seen with me and we separated. I had never felt so alone in all of my life even my mother and family thought first and kept a slight distance.

I was now under a specialist and he asked me if I'd go into hospital for a course of treatment. I was admitted to Broadgreen in Liverpool - it would be for only three weeks. When I finally left I'd been in for seven months. It was like being treated as a guinea pig - I had loads upon loads of creams and tar. I felt awful.

After I got released I could only go swimming at the baths at a certain time, if I'd go out for a meal, as once happened to me, I was told I was upsetting the customers in the restaurant and moved to a corner seat where no one could see me. I left in disgust.

I still have the same feelings now of being a social outcast and I find it very hard to get on with women, especially as I feel very shy and wary of them looking at me, I wear a lot of long sleeved tops and never wear shorts.

The last time I spoke to anybody about how I feel with psoriasis was when I was last in hospital. I now suffer with severe arthritis in my shoulder, arm and ankles.

I'd encourage more people to get in touch with the PAA.

At the moment my skin is rough and I'm still shy with people. I don't really know, but I'm slowly getting there. One of the worst things about my skin is the result of using steroid cream which I no longer apply.

The stretch marks I have on my leg muscles and thighs, also stomach look terrible and I do my best to hide them.

Thanks for giving me the opportunity to express how I feel.

David.

Please contact: Mr David Brown, Valentine Green Unit, CL 5897, H.M.P. Altcourse, Higher Lane, Fazakerley, Liverpool, L9 7LH.

Editors note:
Since David wrote to us he is now starting methotrexate as his treatment - I know he would really welcome a pen pal or two, so please write to him. Good luck with the treatment, David.

Education issues

Dear PAA

We spoke briefly at the PAA conference about how to pass on information to schools. I hope the following may be of use to you and to those amongst us in the PAA.

SENCO (Special Educational Needs Co-Ordinator): Every state run school must have one. His, though more usually her, role is to maintain records on all children with special needs within the school. "Special Needs" includes learning difficulties, sensory and physical impairments. The SENCO must ensure that every child on her Special Needs Register (Levels 2 to 5) has an Individual Education Plan (IEP) and that this is reviewed on a termly basis.

Code of Practice For Special Educational Needs: All state schools have to abide by this. It clearly sets out the method for assessing and monitoring children with Special Needs and establishes levels of 1 to 5, with 5 being the children who need the most help.

Statement Of Special Educational Needs: A child who is going to need more help than the school can normally be expected to provide is usually assessed for a Statement. A child with a physical problem like PA will require a Statement if he/she needs a lap-top computer or help in getting round the school, either in the form of someone to carry equipment or perhaps for a stairmate if in a wheelchair. Once a child has a Statement, targets are set on a termly basis via the IEP and a Review must be called at least annually and the parents or carers invited in to school to discuss whether there should be any change to the provision as set out in the Statement.

Policy on Behaviour: Every school must have a written policy on how to tackle bad behaviour including bullying. If a child is being bullied then a parent should ask to see the school policy on this.

cont. over

Advisory Teacher/Peripatetic Teacher: Most education authorities will have a teacher who advises the schools in the authority on how to deal with specific disabilities including those of physically disabled children. A school or a parent can ask the authority to provide specialist advice from such a person.

I have tried to keep to essentials. Attached is a draft letter that could be adapted and be sent to a school by a consultant or GP.

Alternatively, with a bit more thought, a PAA leaflet could be produced to be given to all parents to take into school when their child has been diagnosed as a PA sufferer.

Yours sincerely,
Alison Shuttleworth

Alison's draft letter . . .

To The Headteacher for the attention of the SENCO Whatever School

Re Joe Bloggs
DOB
Address

The above named child has recently been seen in this clinic and is suffering from Psoriatic Arthritis. This is a condition that affects Joe and is currently being treated with . . . . Include any of the following that are applicable and add any other points depending on the severity of the case.

Recommendations

1) Children with this condition very often suffer from teasing in school and Joe needs to know what he should do if this happens.
2) He will be very unhappy about changing clothes in public and may need to be excused from swimming.
3) He should be allowed to wear a track suit for PE if he prefers.
4) It will take him longer to get dressed and undressed than his peers and he should be given extra time to do this.
5) Joe should not be expected to take communal showers.
6) There will be times when he will need to be excused from PE or when a gentler activity should be provided.
7) Joe finds it difficult to hold a pen or pencil for any length of time and he should be given regular breaks from written work.
8) He may find it easier to use a computer keyboard.
9) Joe needs to be seated comfortably and may need to walk around the classroom periodically to avoid becoming too stiff. An occupational therapist would advise on suitable chair and desk heights.
10) The condition causes Joe to become very tired and he may need to be given extra time to complete some tasks and to be excused from others.
11) He should be allowed extra time to complete any exams, intemal and external.

Please do not hesitate to contact me should you require any further information.

Signed Dr . . . . . .

Editor's note: Thanks, Alison. The enclosed information is really useful and, yes, your idea of a leaflet has been taken on board at the PAA. Cheers.

TASTE THE NEW 'MARTINI METHOD' OF COMPUTER TRAINING IDEAL FOR HOUSE BOUND CARERS AND DISABLED PEOPLE

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Human back-up is provided through a Personal Tutor who can 'read' the screen whilst a trainee is learning and even offer on-line help, answering questions and giving 'real-time' guidance whilst you watch and practice.

Because there are no travelling or accommodation expenses, learning through PTAT can be a lot cheaper than conventional training methods.

"These days many people want to learn about computers or keep up-to-date with the latest programs but they often don't have the time or can't find the course that fits their needs. Be they working mums, house-husbands, house-bound people or students, using PTAT gives customers the option to learn when and where they want to. They can even sit exams and get internationally recognised qualifications after finishing their particular courses," says Dylan Gray, sales and marketing manager, CSC.

For more information about the PTAT courses, contact CSC on 0171 404 3636 or visit the web site: www.computerskillscentres.co.uk.

Computer Skills Centres is a Microsoft Certified Technical Education Centre offering the full range of training courses, both full - and part-time, leading to Microsoft certification.

Its full-time courses are designed for both complete beginners without experience in the IT industry and practising professionals looking to improve or widen their skills base. The group has been providing IT training in London for nearly 20 years. CSC tutors are chosen for their technical knowledge, real-life experience and ability to impart their knowledge to others. All CSC training staff are Microsoft Certified Trainers. As a Microsoft Certified Technical Education Centre, CSC works with Microsoft to deliver comprehensive training on the latest versions of all software. For more information about CSC, visit the web site: ~.computerskillscentres.com

Coming out of the Tunnel

Nigel Martin

case history

The Devastating Diagnosis

It was about four years ago now when I was first hit with the devastating news that I had psoriasis. "Psoriasis - what's that?" was the first question that I asked only to discover later how common the condition was. Finding out what I had, in one sense, was a relief because it meant that there actually was a reason for the pain in my joints (mainly elbows, knees and feet at that time), the constant feeling of tiredness and the strange patches on my knees which weren't going away. It was also interesting to note that a friend of mine who runs a chiropractic clinic in Lymington was the first to make an accurate diagnosis during the first consultation with her. This incidentally was after several visits to my GP regarding both my skin and joint complaints and a trip to Casualty for an x-ray on my foot. This was later confirmed when I was referred to a rheumatologist by my GP.

The Painful Process

After getting over the initial shock I didn't realise at the time that my life would never be the same again. Both the joint and skin condition gradually got worse. This incidentally coincided with the stress of the job that I was doing at the time, being a pastor in a growing church of approximately 200 adults and children. The next few months were like a dark tunnel when I went into a depressed state and was a misery to my family and those around me. I felt as if my life was gradually being stripped away. I had to give up two of the main joys in my life - firstly playing guitar because the pain in my fingers and wrists was too much and secondly I sold my motorbike because I no longer had the strength in my arms and wrists needed to handle it. Added to this I could no longer do simple everyday things like run or walk without severe pain. It was hard to watch other parents playing with their children in the park and having a three year-old son who couldn't understand why he couldn't jump on and be rough with his dad like the other kids. There were many occasions that I felt suicidal. I had not only lost my mobility but my self-confidence, my physical strength, my will to live and I was worried that I would lose my job.

Some Hopeful Insights

That was some time ago now and I'm pleased to say that I came through the tunnel. Since then I have moved to London from Somerset, started a new job, and my wife gave birth to our second child in July. The arthritis has dramatically improved and I am at present leading a normal life. I am once again able to play guitar. I've bought a new bike. I can walk and even run comfortably and my son Jonathan, who is now five, regularly takes advantage of me by jumping on me. All this has been without any treatment of drugs except for anti-inflammatory tablets that I took in the earlier stages. My skin condition also worsened along with the arthritis and remained severe but at present my GP has recommended the tar treatment combined with ultra-violet. So far this has dramatically improved my skin condition.

Reasons for Remission

I cannot give any evidence as to why my condition has improved so dramatically but I can point to several factors that have helped. Firstly, I have had many people praying that I would get better and as a committed Christian I do personally believe that God has the power to heal. Secondly, my new job as a community worker is a lot less stressful. Thirdly, my new doctor has been quick to respond to my needs and so far I have been impressed with the speed and efficiency of the local health authority. I have also been watching my diet and cut down on red wine, caffeine and cheese, and I tend to watch my diet closely. It is also common for sufferers to have periods of remission without any particular reason. The simple truth is that there are still only a few facts about psoriatic arthritis and therefore there is much need for more research so that doctors, specialists, carers, and even the general public, can have a greater knowledge of the illness and its effects on sufferers. Perhaps one of the biggest factors was the support and help I received from my family and close friends, and coming into contact with PAA who have all proved to invaluable and to whom I will be eternally grateful.

The Privilege of Helping Others

There is hope for the psoriasis sufferer and it is not all doom and gloom. There can be periods of remission. I am realistic enough to realise that things could get worse again, but for now I am enjoying life and trying to live it to the full, realising that I can never take my good health for granted. I have also gained a great sense of comfort, purpose and satisfaction in knowing that I am in a much stronger and privileged position to help other sufferers who are going through similar difficulties.

'PRODIGY'

INTRODUCTION

'PRODIGY', a computerised decision support system for GPs, has now been launched. The Department of Health claims the system will 'improve the effectiveness of GP prescribing', but evidence from pilot-testing gives limited support for this view. In fact, **PRODIGY** is raising concern among patients' organisations, the pharmaceutical industry and medical experts that some of the information it contains is outdated, misleading and, in some cases, entirely inappropriate.

PRODIGY (Prescribing RatiOnally with Decision support In General practice study), according to the Department of Health, 'delivers, at the touch of a button, the latest practical clinical guidance', yet the majority of the suggested medicines are more than 20 years old.

Following diagnosis, the doctor can type the name of a condition into a computer and be given medical advice and specific recommendations about which medicines to prescribe. The Department of Health says the system will also include 'information about non-drug treatment and patient information leaflets'.

A GOOD CONCEPT

Doctors need to take in a huge amount of information to keep abreast of medical developments. Patients increasingly want more information and expect to work with their doctor in choosing the treatment that meets their needs. A user-friendly system , able to be used with the patient during a consultation, could bring real benefit providing it is:

- driven by quality rather than cost,
- accurate and
- covers the range of up-to-date treatment options.

Unfortunately, judging from the first sets of **PRODIGY** guidelines to be released, these necessary conditions are not being met. Instead, the guidelines:

- favour older medicines (which are generally cheaper than newer medicines but which may be less effective or have potentially more troublesome side effects),
- give only a limited number of choices,
- are in some cases supported by inadequate evidence, and
- contain information which is misleading or open to question.

It is a basic tenet that scientific research should be open to peer review. Key facts not included in the launch of **PRODIGY** include:

- how, and by whom, new information will be included speedily on the system so that patients can benefit from the latest advances in treatments,
- how decisions about which medicines and treatment included on the system are made,
- how the patient information leaflets, available under the system, have been drawn up and whether expert advice from patient groups has been sought, and
- whether cost is the driving factor behind the decisions, rather than the quality of health care for the individual.

THE TRIALS

PRODIGY is being introduced on the basis of two phases of trials using 183 GP practices chosen for their ability to evaluate computer software. The Department of Health is claiming a very successful outcome for the Phase Two trial. Yet the responses in the pilot report read somewhat differently from the Department of Health's public statement on **PRODIGY's** release.

For instance, the DOH says that '94% of the **PRODIGY** GPs believe the clinical guidance is useful'. But the report shows that this percentage refers only to 'link' GPs (the volunteer **PRODIGY** contact in each participating practice). Of all the eligible GPs who filled out the **PRODIGY** questionnaire, only about 56% used the system. The pilot report treated this user sub-group as the total number of GPs involved. But even of this selective sample, 67% said the clinical guidance was only of 'some use' while 25% said it was of 'little or no use'.

This may help to explain why, of all the times GPs used **PRODIGY**, only 13% were followed through to conclusion - meaning that the GP either issued a prescription from **PRODIGY** or used the 'own choice' option. Three out of four times when the GP could have used **PRODIGY** (where guidelines were available for the condition) the system was bypassed altogether.

While almost all of the GPs rightly supported the concept of computer-based prescribing assistance and therefore looked favourably on the project itself, the Department of Health has overstated the nature of support for the specifics of **PRODIGY**. The decision to roll out the **PRODIGY** system in its present form to all GPs is premature.

SPECIFIC PROBLEMS IN THE FIRST SETS OF GUIDELINES

Judging by some of the advice in the first sets of guidelines, there is much that GPs ought to question but may not have the specialised knowledge needed to do so. Some of the recommendations give rise to major concern for patient well-being. For instance:

- The view that tricyclic antidepressants should be the routine first choice for the treatment of depression is a matter of debate. Tricyclics have their place in treatment but, for many people, are less well tolerated than the newer 'SSRIs', so compliance can be a problem. In addition, most tricyclics are sedating. Attempted suicide, a major risk in depression which can be difficult to predict, very often succeeds when tricyclics are used.
- The guideline on migraine recommends only one of a range of medicines known as 5HT1 antagonists. Yet each has different characteristics and patients frequently need to try more than one of these medicines to find the one that works best for them. Indeed, **PRODIGY's** description of the alternatives actively discourages GPs from using
- In COPD (chronic obstructive pulmonary disease), the excellent guidelines from the British Thoracic Society (1997) are ignored in favour of 1995 American guidelines. Different measurement methods are used in Europe and, given that relatively few Americans are treated in a GP setting, these US guidelines are not appropriate.

CONCLUSION

If doctors and the public are to have confidence that a prescribing decision support system provides accurate up-to-date information and genuinely serves patients' needs, rather than be a form of rationing in disguise, then its

objectives should be clearly stated from the outset and:

- the evidence base for the selection of individual medicines, including the specifics of who was consulted and what are their credentials in the specific therapeutic area, should be comprehensive and transparent,
- the process for continuous review should be effective and fully explained,
- the time delay involved in recommending new medicines should be clearly stated, and
- there must be a process of appeal for stakeholders who do not agree with any particular recommendation.

The Department of Health has claimed that doctors are free to prescribe other treatments as they think necessary. However, they also say that the guidelines will be used as the basis of audit, which many would regard as a means of curtailing GP prescribing. Given the time and budget pressures doctors are under, **PRODIGY** could rapidly become a barrier, rather than a boon, to the high quality of care patients have been promised by the Government's NHS reforms.

Delays in **PRODIGY's** take-up of new medicines would also have a major impact on UK research-based pharmaceutical companies in their current ability to offer the NHS the early benefit of new and better medicines. The likely uptake of new medicines has a direct bearing on the location of research including the clinical trials, without which it takes much longer for a country to develop a solid base of clinical expertise able to determine when and how to use a particular new medicine.

The pharmaceutical industry appreciates the need to use health care resources wisely. But the basic cost of a medicine is only one factor in assessing the implications of a treatment. Unless the DOH seeks wider views before introducing treatment guidelines and consults more widely on those in development, **PRODIGY** is likely to encourage doctors to provide a second-rate service for both individual patients and the NHS in the long run.

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DOCTORS WARN OF 'SEVERE' LIMITS IN SKIN CARE

Doctors have warned that dermatology could be severely rationed in the new NHS. The warning comes in an article written for the doctors' own magazine, the "General Practitioner".
The threat comes because the computerised prescribing aid for GPs, called PRODIGY, has been described as a Government tool to limit prescribing of medicines. Unfortunately, skin treatments are often seen by Government as a 'soft target' for primary care groups forced to cut costs, the report says.

Some years ago the government tried to introduce a 'Limited List' for skin treatments which limited treatments available to GPs to a small choice of treatments for each skin condition. A major campaign in which various skin care patient support groups were very active forced a change of policy. That battle was won but the war seems to go on. PRODIGY was then devised to inform doctors on which medicines they should choose in a range of conditions. Consultation with various groups, including patient representatives, led to some of the planned constraints being relaxed and this included skin treatments.

HOWEVER under the NEW NHS Bill currently being debated in Parliament, PRODIGY is to be implemented without further consultation and with the feared restrictions seemingly back in place. This latest version is woefully inadequate as far as dermatology is concerned, according to Dr Tim Mitchell, who is Secretary of the Primary Care Dermatology Society as well as being a GP in Bristol. According to Dr Mitchell only two moisturisers are listed in PRODIGY: soft paraffin and aqueous cream. In contrast he believes that doctors should have a wide range of skin treatments available.

We, in the PAA, know that each person with a skin condition is different from the next and needs to have treatments changed from time to time. PRODIGY, in its present form, will limit the options available to patients and doctors.

Although the government has denied that PRODIGY is being introduced as a tool to cut costs, it has admitted that it will be part of its clinical governance programme whereby doctors become accountable for the cost efficacy of their work. This, allied to the decision that funding of the well deserved salary increases for nurses has to be funded from within current budgets, including that for prescribing medicines, is an ominous sign for patients with long term medical conditions. It may be time for the PAA to go into action again!

REGIONAL HELP

At a meeting at the Hilton National Hotel on the May 15 1999 a strategy was devised to bring greater autonomy to the regions. Since the early days of the PAA it has been obvious that if the organisation was to provide the kind of service that founders David and Julie Chandler envisaged, there would have to be greater regional representation.

David and Julie have worked tirelessly to help those of us who suffer from the debilitating and often depressing disease of PA. I know from my own experience how helpful and reassuring it was to speak to a fellow sufferer who understood the symptoms, when I knew I was not getting through to my GP.

With the formation of regional action groups it is hoped that members will feel closer to a local representative and would even be prepared to offer to make a third layer of assistance at ground level by forming sub-groups.

The aims of the newly formed regional action groups are to bring the disease and all its manifestations to a greater awareness, not just among those with the disease, but also the medical profession and the public.

It is vital that we all play as large a part as possible. There are many ways of doing this. Case histories may show parallels with others which could help the professionals to assess problems. You may be aware of how much you depend on others for normal everyday tasks, you may be embarrassed to take part in social occasions when your psoriasis is particularly bad, or you may even see your own future by looking at a fellow sufferer in a worse condition than yourself. You may have some good ideas on how to raise money to help the PAA continue its ground breaking service in a climate where other charities are furiously fighting for every penny. We want to know your feelings on all kinds of issues and welcome your views for publication in the PAA newsletters.

All this is important information and the type of feedback we as regional action groups will need to know in order to provide the type of service that David and Julie have striven to provide. It is interesting to note that David gave up his regular work because of the restrictive nature of the disease, and now finds himself putting in more hours on behalf of the PAA than he did when he was being paid to earn a living.

In essence what I'm saying is that we can all contribute towards helping ourselves and those who wish to help us, by getting involved. So, those of us who have undertaken to do just a small part of what David and Julie have been doing since the PAA started will be pleased to hear from members within our regional area on any subject which they think needs to be addressed. One of these is membership, which needs to be increased, because not only does a larger membership bring in much needed funds but it gives us a bigger voice on important issues.

The following regional managers will be contacting members within their regions and in return look forward to hearing from them.

Other regional representatives are required for parts of the UK and Ireland which are not as yet represented. If you can help please contact David or Julie Chandler, as we need all the help we can get to fight this insidious disease.

John Bevan

IS ON THE WAY

– Herts and Essex –

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Cheque presentation

What's up Doc!

NEW PCG PILOT TO EXAMINE BENEFITS OF NURSE LED PSORIASIS CARE PACKAGE

A new initiative to examine the benefits of a 'satellite' nurse-led dermatology service, providing 'added-value' care to psoriasis patients, is being piloted through the Wellingborough Primary Care Group (PCG), in Northamptonshire. Psoriasis, a chronic skin disease, affects two per cent of the population.

The pilot - believed to be the first of its kind to be undertaken by a PCG - forms part of a pan-European initiative being implemented in the UK and six other countries by LEO Pharmaceuticals. LEO, a Danish pharmaceutical research foundation, is the leading dermatology company in Europe. "We believe that providing patients with a total care package will result in significantly improved quality of life for psoriasis patients as well as reducing the long-term costs to the healthcare provider," explains Dr Stephen Kownacki,GP, PCG board member for Wellingborough, hospital practitioner in dermatology and membership secretary for the Primary Care Dermatology Society (PCDS).

"This is a collaboration between practices in the Wellingborough PCG to deliver a service that, individually, each might not otherwise be able to provide."

"There are currently no guidelines for quality care in psoriasis. We aim to demonstrate that investing in the patient optimises outcomes and meets clinical governance recommendations; in brief, that investing in the short term, results in a better long-term outcome for all."

A specialist nurse will be employed for six months from the start of the pilot in October 1999 and all members of the primary healthcare teams will be allowed to refer patients to the nurse, who will be based at a town-centre location.

Patients will be seen by appointment and will have an extended, structured consultation with the nurse, during which their individual needs will be established and an appropriate care package delivered, including general education about psoriasis and its management, detailed instruction regarding their prescribed treatment and compliance advice. Prescribing will be undertaken by the patient's GP, based on an agreed protocol, but the nurse may make recommendations. Following the initial consultation a letter will be sent to the patient's GP who retains all clinical responsibility for the patient.

Further appointments will be offered and assessments of clinical status, patient satisfaction and quality of life will be made. Prescribing costs during the study period will be compared against a similar time period in 1998, as will referral rates to dermatologists. The intention is to fully document the costs and outcomes of delivering a defined psoriasis care package, thus enabling other sites to make an informed decision on its value.

"The focus is on establishing the patient profile and ensuring that they fully understand their condition and treatment. Additionally, the patients will be provided with psychological support - an opportunity to unburden themselves - and practical advice tailored to suit their individual needs," continues Dr Kownacki.

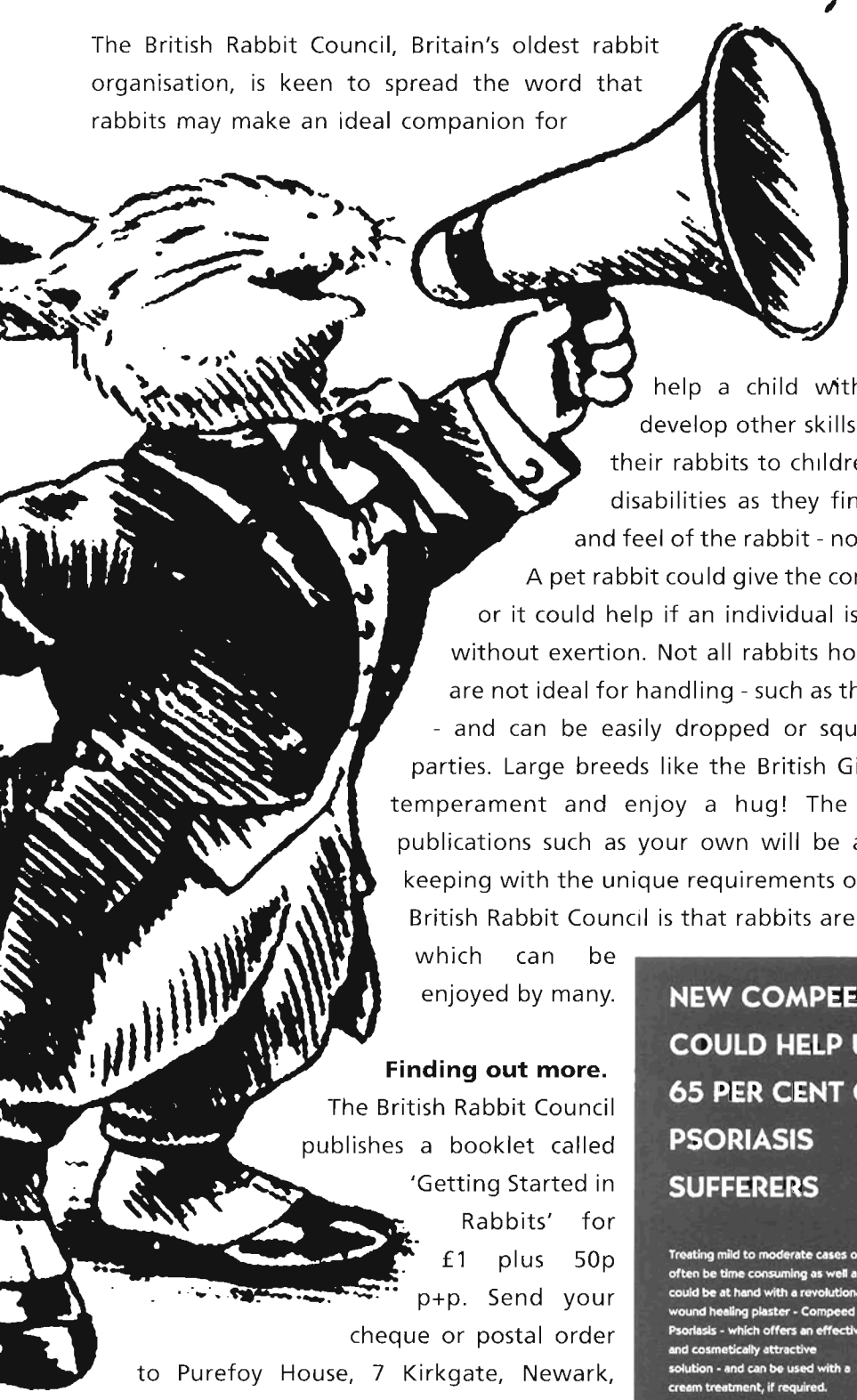
"Our aim is to provide proper evidence of the efficacy of nurse-led education and improved patient support, in the hope that we may be able to set up a permanent 'satellite' dermatology service in the future, leaving specialist services for diagnosis and the rare and difficult conditions."

The proposal for the pilot study, presented by Dr Kownacki, was accepted by the Wellingborough PCG at its second formal meeting in May 1999.

There is likely to be an increasing need for PCGs to demonstrate their commitment to the principles of clinical governance, and dermatology may be a therapeutic area that benefits.

The Primary Care Dermatology Society (PCDS) is the first national society for GPs with a special interest in dermatology and reflects the growing importance that GPs are attaching to the speciality. Affiliated to the British Association of Dermatologists (BAD), the PCDS was formed in July 1994 by a group of GP skin specialists who recognised the need for a forum where GPs could exchange views on primary care dermatology, develop skills and progress clinical research in this developing field of medicine.

Rabbit



The British Rabbit Council, Britain's oldest rabbit organisation, is keen to spread the word that rabbits may make an ideal companion for those with disabilities. The organisation feels that as rabbits are naturally friendly and good-natured - as well as inexpensive - they are likely to make an ideal companion to an older person, or will help a child with learning difficulties or a need to develop other skills. In fact some Members currently take their rabbits to children and adults with serious illnesses or disabilities as they find that the individual likes the touch and feel of the rabbit - not to mention the chance of a cosy hug! A pet rabbit could give the comfort of a regular routine or structure, or it could help if an individual is advised to keep as active as possible without exertion. Not all rabbits however are ideal! Some smaller breeds are not ideal for handling - such as the tiny Polish which has quite a temper - and can be easily dropped or squeezed, resulting in distress for both parties. Large breeds like the British Giant weighs about 20lb, have a good temperament and enjoy a hug! The British Rabbit Council hopes that publications such as your own will be able to match the benefits of rabbit keeping with the unique requirements of the readership. The emphasis by The British Rabbit Council is that rabbits are a rewarding and pleasurable pastime which can be enjoyed by many.

Finding out more.

The British Rabbit Council publishes a booklet called 'Getting Started in Rabbits' for £1 plus 50p p+p. Send your cheque or postal order to Purefoy House, 7 Kirkgate, Newark, Notts. NG24 1AD. They will also send some free leaflets if readers request them. Pet Plan Limited publish a booklet called The Rabbit List, which can be obtained from: Pet Plan Ltd, Computer House, Great West Road, Brentford, Middlesex TW8 9DX. but always get advice on which breed is suitable.

Rabbit 2000.

Don't forget Rabbit 2000 - the largest rabbit show of next year - to be held in July 2000! Everyone welcome. Readers can ring 01636 676042 for more information.

RESEARCH ROUND UP

DR ANTHONY WHITE

Medical research into psoriatic arthropathy currently resembles a patchwork quilt with many areas yet to be filled in and the exact place where particular patches should be sewn into a whole has yet to be worked out.

A relatively small number of papers on Psoriatic arthropathy were presented at the November 1998 meeting of the American College of Rheumatology and similarly at the June 1999 meeting in Glasgow of the Fourteenth European League Against Rheumatism Congress.

IS IT PSORIATIC ARTHRITIS OR IS IT GOUT?

Dr Daphna Gladman and her group at the Toronto hospital have probably the largest single collection of carefully studied patients with this condition and information from a number of studies, some of them conducted over a period of twenty years or more, is now coming into print. Patients with psoriatic arthritis sometimes have a raised serum urate level and this gives rise to confusion sometimes leading to an incorrect diagnosis of gout, particularly where the condition first affects the great toe, with redness, swelling and pain which is the characteristic first presentation of gout itself. This group has shown in their study that a raised serum urate occurs in 20% of patients with psoriatic arthritis. It was at one time thought that this might relate to the extent of skin, involvement because of the high cell turnover in the skin but their studies show this not to be the case, rather the raised urate level appears to reflect impairment of kidney function and raised blood pressure. There is an association with a raised serum Cholesterol, found in 62% of cases compared with 35% of controls, impaired kidney function in 15% versus 0.6% and raised blood pressure in 25% versus 10%. These studies were based on 265 patients and 165 controls with normal serum rate.

"I ALWAYS SAID YOU TOOK AFTER YOUR FATHER"

The Toronto group have also shown that the transmission of psoriatic arthritis from parent to child depends on whether it is inherited from father or mother to the extent that of 95 of those with an affected parent 62 had a history of the same condition in the father compared with, 33 with an affected mother, This is considered most likely to he due to a mechanism called genomic imprinting which makes the transmission of a gene more or less likely to happen depending on the sex of the transmitting parent.

EXPLORING THE CHEMISTRY OF INFLAMMATION

There are a number of studies on a fascinating group of substances called cytokines which are chemical substances involved in the process of inflammation and which switch on the activity of successive groups of cells, such as lymphocytes and monocytes, as the inflammatory process develops. Studies from the National Institutes of Health, Bethesda, USA, have compared different cytokines in rheumatoid arthritis and psoriatic arthritis. The cytokines TNFα, IL1α, and IL1β were all lower in psoriatic arthritis than rheumatoid arthritis whereas studies with cell activation markers showed that CD28 and CD69 were high and CD25 lower in psoriatic joint tissues obtained from needle biopsies. These studies may be helpful in deciding which of the new biological agents, such as TNFα, blocking injections, eg, Embral may be useful in psoriatic arthritis.

IS JOINT DAMAGE DIFFERENT IN PSORIATIC AND RHEUMATOID JOINTS?

Research from Lund University, Sweden, looked at the proteins from the matrix of articular cartilage and a component of joint fluid called aggrecan and compared 23 patients with psoriatic arthritis of the knee with 43 patients with rheumatoid arthritis affecting the knee. The aggrecan figures were highest in the rheumatoid group whose joints were becoming damaged and lower in the less affected rheumatoid subjects and those with psoriatic arthritis, whereas the matrix protein concentrations were highest in the psoriatic arthritis group so that clearly there is a difference in the processes which lead to destructive changes in the joints of those with psoriasis. The study also confirmed the impression that serious destructive changes are less common in psoriatic arthritis.

CHARTING THE SKIN AND BONES CONNECTION

Drs Jones and McHugh are well-known for their participation in the activities of PAA have looked at the time relationships between the joint, the skin and nail involvement in psoriatic arthritis prospectively over two years, and have confirmed that simultaneous flares and remissions of joint, skin and nail disease occur in a minority of psoriatic arthritis patients. Because the study looked forward rather than back, and charted patients' progress over the two years, it was possible to show that simultaneous flares and remissions were actually less common than the subjects themselves had thought. Only 5 of the 24 patients studied showed such features during the period of study so far as joint and skin activity were concerned, but simultaneous

exacerbation of joint and nail disease occurred in 9 of the patients, with nail and skin disease occurring simultaneously in 10. These linked changes were found to be independent of the timing of onset of joint disease or the development of psoriasis itself.

WHY PSORIATIC CELLS DIVIDE TOO OFTEN

Researchers at LSU Medical Centre, New Orleans, investigated the expression of P53, a gene affecting cell replication, often studied in tumour tissue, in the skin and joint tissue and joint in psoriasis. They concluded that P53 was over-expressed both in psoriatic skin and in the nuclei of lining cells of the joints in people with psoriasis but not in those with Osteoarthritis or in normal skin. It is thought that this finding relates to the.increased rate of cell division found in psoriasis and it is interesting that they found this in the joints as well as the skin. 'They do not mention whether the psoriatic patients also had psoriatic arthropathy and the numbers studied were small

VALUE OF COMBINATION DRUG TREATMENT

In another study from New Orleans by the same group, combination therapy using methotrexate and cyclosporin simultaneously was studied in patients whose psoriatic arthritis had proved difficult to treat with other measures and had failed to doses of methotrexate up to 50mg per week. The dose of methotrexate was dropped to 20mg per week and cyclosporin 2-3mg per kg of body weight was given for an average duration of 15 months, maximum 2 years. 'There was an improvement in the number of painful and swollen joints and in measures of inflammation, the ESR and C-reactive protein, which were highly significant and patients also improved on pain scores and general well being although there was still deterioration on x-rays comparing the start and finish of the study.

RELATING SPONDYLITIS TO PSORIASIS

Papers on psoriatic arthritis in the European meeting were much fewer in number. Drs Brophy and Calin of The Royal National Hospital for Rheumatic Diseases, Bath presented an interesting study on the time relationships between the onset of psoriasis and ankylosing spondylitis using their database of 4400 patients with ankylosing spondylitis, 16% of whom have psoriasis. They sent randomly a postal questionnaire to 150 of the patients with both conditions and with the co-operation of their GPs complete records were found in 45 patients and these were analysed as to the age of onset of psoriasis, of inflammatory bowel disease where it occurred, also iritis, and the onset of the ankylosing spondylitis itself They concluded that most usually the ankylosing spondylitis occurs first. They concluded from this that it is unlikely that the inflamed skin or inflamed gut is responsible for the release of infective agents which induce ankylosing spondyhtis but rather that the genes conferring this susceptibility to the skin, eye and bowel disorders may overlap with those for inflammatory joint disease.

THE LATER YOU GET PSORIASIS THE BETTER FOR YOUR JOINTS

Brocklebank and Keohane of the Dermatology Department of the Royal Hallamshire Hospital, Sheffield, studied the association between patients having the pattern of involvement which resembled rheumatoid arthritis in affecting many joints with those with few joints in respect of when the psoriasis itself began. They found that early onset of the skin disease predisposed to a pattern of arthritis more resembling rheumatoid, whereas a later onset made it more likely the patient would have a smaller number of joints involved.

PSA PATIENTS STAND OUT FROM THE REST IN IRISH STUDY

Stafford, Kane, Hickey, Bresnihan and Fitzgerald, St Vincent's Hospital, Dublin, compared psotiatic and non-psoriatic sero-negative arthritis in their Early Arthritis Clinic and found that they presented differently. 85 patients with psoriatic arthritis, 14 with reactive arthritis, 2 with ankylosing spondylitis, 2 with inflammatory bowel disease and 67 non-specific seronegative cases were studied. The number of tender and swollen joints correlated with the inflammatory markers ESR, C-reactive protein and Ritchie index in the psoriatic arthritis patients, but this was not well seen in the remainder of the group, Interestingly, 70% of the psoriatic arthritis patients needed disease-modifying drugs to control their arthritis compared with 37% for the others.

WHO DOES WELL AND WHO DOES NOT

Barton, Soran, Nelson and Sanders, from University of South Manchester, examined what characteristics were associated with a poor functional outcome in psoriatic arthritis 38 male and 42 female patients were studied. Patients over the age of 60 years, female and with patterns of joint involvement other than those with few joints, were found to have a poorer functional outcome. No relationship was found between the timing of onset of the psoriasis relative to the arthritis and functional outcome.

Access Denied

Anyone who has any sort of mobility problem will immediately identify with the title of this article. If it isn't enough that we have to put up with the disease itself, we also have to battle constantly when out and about in order to make our lives as normal as possible.

A couple of months ago when I was going through a 'bad' patch (no further explanation required, I'm sure), a trip to my local town centre left me even more despondent. Out of the seven establishments that I tried to get into, only two were remotely possible (one of which did involve my poor mum wrestling with an extremely heavy door only to find that once through it, it led us right into the middle of a long queue which we then had to fight our way down with several apologies for the bruised ankles we had just inflicted on the unsuspecting customers - but then I suppose they could have tried to get out of the way rather than just standing staring at us as if we were the entertainment kindly put on by the show). However, the final blow came when I approached an establishment which had three steps leading up to it. Not unusual, I know, but posted on the door at the top of the steps was a very kind notice informing me that a ramp was available. How very thoughtful, I thought, until I read the instructions underneath. . ."Please ask at counter"! What an insult. Are we really worth so little thinking time that a place like that will provide a ramp (probably because their big chiefs have told them to), but I gave no time to considering how we will call for that ramp? When I recounted this tale to the members of the Yorkshire Regional PAA, someone suggested I get a megaphone so that I could summon the staff from the bottom of the steps. ..very tempting!

However, taking the less embarrassing option, I wrote a letter to the manager and received a very apologetic letter by return of post and the matter was resolved within a couple of weeks. (It turns out there is a bell which is hidden round the side of the building and the notice on the door now very helpfully informs you of its existence.)

I used to think that because I had a mobility problem, I was unable to access these buildings, but after reading several articles produced by the Young Arthritis Care, I realised that that wasn't the case - it is not my fault but the fault of the environment. I cannot access these places because they do not allow me to. It is easy to roll over and just say "I can't go there" and "I can't do this", but we have to try. It does take a lot of effort and energy - energy I know which is very valuable to us - but every little helps. If every person who suffered with a mobility problem managed to get just one thoughtless notice changed, then that would be at least one step towards an accessible environment. ***Kelly Forrester***

A letter from: Amanda Rutland

Let me introduce myself, my name is Amanda Rutland and have been involved indirectly with the PAA since my mother, Hilary, 'found' David and Julie a couple of years ago. She suffers rather badly from psoriatic arthropathy, mainly the arthritis side, and being the loving daughter (!) I want to do all I can to help her. I was invited to join as a carer because the carers are often forgotten and as you know we suffer too!

I am currently looking at alternative therapies to help the condition since I qualified as a masseuse in June. I am also a Reiki practitioner and will be studying aromatherapy in September, although I also have a business selling essential oils and bath fizzez and soaps.

There are so many ways we can all help to heal ourselves. Each issue I shall be talking about different methods and therapies I have found that may benefit, although please note that no current medication should be stopped unless at the advice of your GP.

Traditional Chinese Medicine (TCM) is renowned for its success in treating skin conditions. Psoriasis is seen, in Chinese terms, as a 'heat-damp' condition, which can result from stress, dietary problems or climatic conditions, together with poor circulation as another possible cause. Herb infusions in teas and topical herbal creams may help but results can take up from three to six months to resolve. Try to avoid the heat - and damp-forming foods such as chocolate, seafood, citrus fruit and alcohol, although easier said than done, I feel! There are many Chinese herbalists around the country and they can usually be found in the Yellow Pages or through Talking Pages.

In the hot days of summer these are a few natural remedies that may prove helpful:

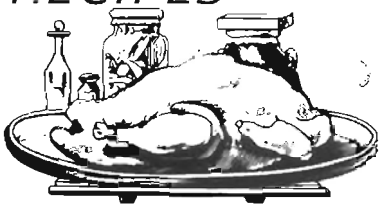
Zinc - an essential mineral that helps to strengthen the immune system and control inflammation. Try a multi-vitamin with 15mg of added zinc, and get plenty of brown rice, sunflower seeds and brewer's yeast.

Relax - stress can trigger extreme psoriasis, so add five drops of lavender oil to your bath. Lavender oil is a great stress reliever and a few drops on the pillow at night aids sleep.

Consult a naturopath - they will look at a number of factors, including diet and lifestyle, and try to bring the condition under control.

If you have any specific therapies you would like me to cover, any remedies that work for you and you would like to share, or more information on a personal level, write to me at: 36 Langdale Drive, Highwoods, Colchester, CO4 4TU. Telephone 07957 625 683, Email Amandar@cybergal.com

RECIPES



With painful joints and little energy, cooking can be a real chore for those suffering with psoriatic arthritis, and it can be very difficult to make meals simple but interesting. Hopefully, you will find these couple of recipes relatively quick and easy to prepare, but producing a tasty result.

Devilled Chicken (Serves 4)
Ingredients:
4 chicken legs
2 tbsp olive oil
3 tbsp white wine vinegar
3 tbsp white wine
2 tbsp Worcestershire sauce
3 tbsp tomato ketchup
3 tbsp soft, dark brown sugar
2 tbsp garlic (see tip)
few drops Tabasco sauce, to taste

Method:
1. Place the chicken legs into a casserole dish
2. Mix the remaining ingredients together in a bowl and pour over the chicken
3. Cover and cook in oven (200C/400F/Gas 6) for 45 minutes or until tender
4. Serve with jacket potatoes and vegetable of your choice (see tip).

Chicken Korma (Serves 4)
Ingredients:
350ml/12fl oz natural yogurt
200ml/7 fl oz double cream
25g/1 oz butter or margarine
1 tbsp ground turmeric
2 tbsp chilli powder
3 tbsp garlic
3 tbsp ground almonds
4 x 100g/4 oz boneless, skinless chicken breasts, diced (see tip)

Method:
1. Pre-heat the oven to 200C/400F/Gas 6. 2. Place diced chicken into a casserole dish. 3. Mix together remaining ingredients and pour it over the chicken. 4. Cover and cook in the oven for 35 minutes or until chicken is cooked through.

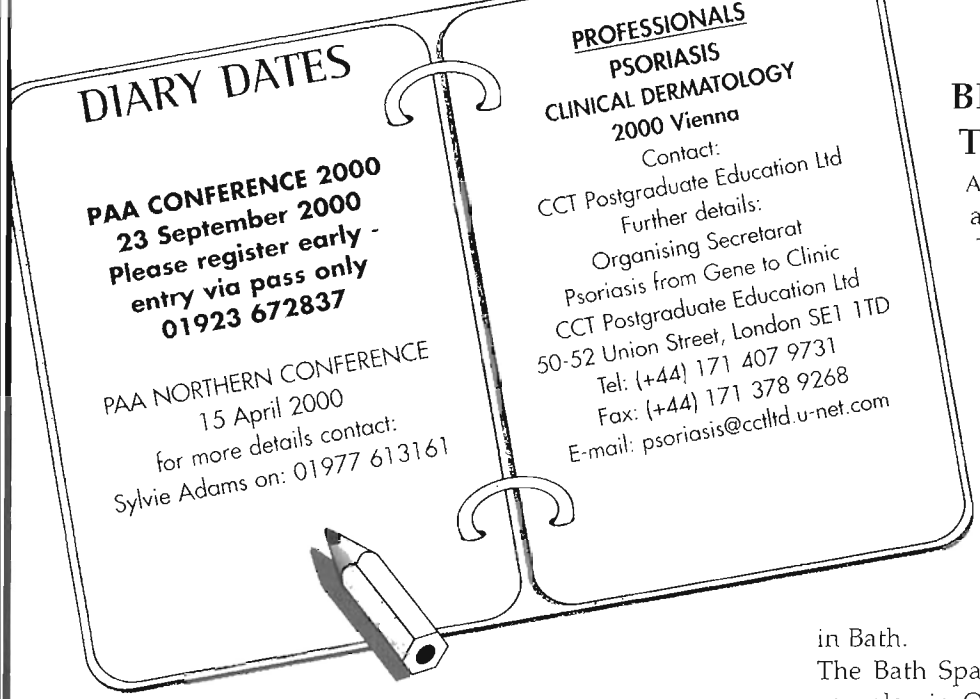
TIPS

➪ You can now buy ready minced garlic (and ginger) in a jar from most supermarkets and it is almost as good as fresh. Alternatively, use garlic salt or, if you like, it can be omitted from this recipe completely without too much difference to the end result.

➪ If you find it difficult cutting the chicken with a knife, try using sharp scissors instead. You can now get some scissors which are on a spring (a bit like secateurs) and have a handle big enough to put all your fingers through. I think I got mine from Woolworths, but I'm sure any good kitchen shop should be able to get hold of them for you (I think they are from the 'Good Grips' range). If you are unable to get these, then at least make sure you have a very sharp knife which makes cutting that bit easier. Also, look in the 'aids' catalogues for knives which have a special handle.

➪ If you find straining vegetables difficult, put a wire chip pan basket into the saucepan and then ,once cooked, they can be lifted out of the water in the basket and the heavy saucepan of water can be dealt with separately.

If you have any useful tips or easy recipes, then please send them in to the PAA and we will publish them in the next magazine.



Keep on Moving with Radian B

High impact, low impact, boxercise and cardio funk - they sound like phrases you might hear at a boxing match but these are the names of the new breed of fitness classes. Most people attend an aerobics class to improve their general fitness, tone up their muscles and enjoy the fun of a choreographed workout. However, the demanding levels of exercise required can leave you feeling like you have done ten rounds in the ring with Lennox Lewis.

There are more than 400 muscles in the body - the back alone contains 149 joints - each with their own group of tendons and ligaments. This means that even the smallest movement can involve a huge number of body parts. For example, you use around 80 muscles to lift a cup of coffee or tie a shoelace.

It is therefore not surprising that damage to muscles, ligaments, tendons and other soft tissues are common. Around 7% of people visiting GPs want help with symptoms arising from soft tissue damage. In fact, one in 30 of the adult population consults a doctor every year about back pain.

For most muscular aches and pains, rest, relaxation and effective pain relief will speed up recovery. For fast relief from minor injuries and back pain during or after an activity, use a topical analgesic such as a muscle rub or anti-inflammatory ibuprofen gel. The Radian-B range offers a variety of products to choose from for all the family. The Heat Spray, Muscle Lotion and Anti-inflammatory Ibuprofen Gel are easily absorbed by your skin to quickly relieve muscular aches and pains.

The Radian-B range consists of: Pain Relief Spray Anti-inflammatory Ibuprofen Gel, Muscle Lotion, Muscle Rub, Aromatherapy Bath and Mineral Bath.

BRITAIN'S FIRST GENUINE SPA TO PEOPLE

A planning application for the revival of the Spa at Bath was registered in June.

The Bath Spa Project - a Millennium Commission funded initiative to revive Bath's historic Spa - will be considered for Planning & Listed Building Consent during June.

If the application is successful, the Bath Spa will become Britain's only spa on the traditional model of natural spring water.

A stunning new Spa building in the form of a Bath stone cube in a translucent glass enclosure, by Nicholas Grimshaw & Partners, will mingle with the listed historic buildings of the World Heritage Site in Bath.

The Bath Spa Project hopes to start building the new Spa complex in October. Firstly the new building, but also the refurbishment of five listed buildings - the Cross Bath, the Hot Bath, 7 and 8 Bath Street and the Hetling Pump Room, bringing back to life a small quarter of the City less than 100 meters from the Roman Baths Museum.

Project leaders are expecting a wave of national interest for a number of reasons. Firstly you need a good memory to actually have any experience of a British spa. Bath was the last of the traditional British spas to close, in 1978. Since then, it's been a case of tap water jacuzzis, or off to Europe for British spa enthusiasts. Visuals of the open-air rooftop pool, fed by naturally hot spring water overlooking the Georgian streets and green skyline of Bath should be enough to get anyone scrabbling for their weekend bag in anticipation of Summer 2001.

Then, there is the opportunity to dip into the tiny, sacred Cross Bath, which is still fed by spring water passing through an underground cistern installed by the Romans in the 1st Century A.D. Plus, of course, the new Bath Spa, part-funded by the nation - or everyone who plays the Lottery, that is - in the form of a Millennium Commission grant.

The project could transform the local economy in Bath and North East Somerset. With a population of just 83,000, Bath pulls in over three million visitors a year - many of them from overseas. Yet most of them travel to the City for a day, or perhaps a weekend. With the added attraction of recovering the facility that was the City's heartbeat for over 2,000 years - the natural spa - the Project team has estimated that up to £8 million per annum will find its way into the local economy from 2001 onwards.

With five virtually derelict historic buildings restored to former glories, an example of contemporary architecture to set alongside its famous crescents and squares, and a unique urban sanctuary set to establish itself as a centre of wellbeing, the future of Bath looks to be positively glowing with health.

The Bath Spa Trust and Thermae Development Company B.V, supported by the Millennium Commission with funds from the National Lottery. Internet: www.bathspa.co.uk

For information on the revival of spa culture in the UK, please contact:
The British Spas Federation, Abbey Chambers, Abbey Churchyard, Bath BA1 1LE
Tel. 01225 477710. Email: susan-burt@ba~7nesgov.uk