PAA news

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Pharmacy Plus

DRUGS DIRECT REVOLUTIONISES HEALTHCARE IN THE COMMUNITY. *see page 5*

Who says you can't do it? Disability need not be a restriction. *see page 5*

Andrew Tarbard continues to use technology thanks to a left-handed keyboard, which he discovered through AbilityNet

INSIDE THIS ISSUE

CASE HISTORIES • DIARY DATES • WHAT'S NEW • AND MUCH MORE

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.

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

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K. A. Sedlacek
Graphic Design
01932 356438

PAA CONFERENCE 1999 WOBURN

Register now!

Saturday 25th September
Woburn Safari Park
Bedfordshire
9.00am - 4.30pm

To register your interest and to receive further details about attending Conference '99, please write to:
PAA, PO BOX 111,
St. ALBANS, HERTS AL2 3JQ

PAA

DEAD SEA - DEAD CHEAP

Inexpensive Remission for Psoriasis Sufferers

More than one million people in Britain alone suffer from the seriously debilitating skin condition, psoriasis And, though a cure is not known, extended remission can be achieved particularly from exposure in the Dead Sea

A new 32-page A5 booklet, Dead Sea - Dead Cheap, from PDSDC, Eastgate House, Humberstone Road, Leicester LE5 3GJ, price £5 inc p&p (cheques to PDSDC) explains how inexpensive this need be.

Written by a therapist, Susan Fletcher, and her patient, Andrew Gamble, two weeks, exposure in the Dead Sea, all travel, including sightseeing in Jordan, accommodation and meals was achieved for under £500 each

The booklet details the authors' experience at the Jordanian Dead Sea, its geography and climate, how to get there, where to stay, visas, currency, health, diet, what to take, how to prepare and much more. Importantly it shows how two weeks' healing for psoriasis sufferers can be achieved for less than a third of the cost of what might be expected

And if you can't make the Dead Sea, there is useful advice in the booklet on dietary changes and supplements to improve psoriasis

Further information from Susan Fletcher tel/fax 01263 587517 or
Andrew Gamble tel 0116 2511647 fax 0116 2514775

CASE HISTORY

Vivien Cage

Name: Vivien Cave. Age: 46

I was diagnosed as having psoriatic arthritis in 1979, after having suffered for several months from what my unsympathetic doctor called 'chilblains' in my blue sausage-shaped toes, apart from the fact that I could only walk with difficulty and had a large patch of psoriasis on one of my legs.

At the time I was teaching in a school with very long corridors and several flights of stairs. I had to allow several minutes of my precious breaktime to beat the rush and get to my classroom and not all staff were sympathetic.

I was eventually diagnosed by the wonderful Dr Woolf at Wanstead Hospital and started a course of hydrotherapy and wax treatments to my hands - which, incidentally, did nothing to alleviate the symptoms of the disease, but made me feel so *pampered* !

I was by that time Head of Music at a tough boys' school in the East End of London and had to cope with travelling to Wanstead every Friday for a blood and urine test. Colleagues here were totally unsympathetic and, in the end, I decided to stop going, which meant that I had to stop the medication.

Luckily, I seemed to be in 'recession' at the time and went to a Chinese acupuncturist and herbalist in Coptic Street (opposite the British Museum) for several treatments, which were wonderfully relaxing.

In 1984 I applied for, and got, the Head of Music post at the Forces Secondary School in Episkopi, Cyprus. Initially, living in the Officers' Mess was interesting (rather, I imagine like being at a boarding school) but the chefs' idea of what constituted a vegetarian diet was not mine.

Eventually I was able to move out into a flat in a local Greek Cypriot village. There was no flare-up of the arthritis or psoriasis at all until June of 1985, when I was producing the all-Island Shakespeare play at the Curium Amphitheatre. I woke up one morning stiff and in acute pain. It was difficult to balance on the steep steps of the amphitheatre and I was asked - nay, ordered - to be admitted to the Base hospital after the production was over.

I spent ten days there whilst they got my ESR rate down from over 70 and from then on I was carefully monitored and regularly saw an RAF consultant rheumatologist.

I 'followed' him to my next post as Head of Music at another big school in the north of Germany and tended to see him every six months or so. All this time I had been on a combination of NSAIDs, which seemed to be working.

I left Germany in December 1992 and was Head of Music at a school in the East End of London when I had the first of a series of operations to my right wrist.

There need not, of course, have been a series of operations: the first one, to remove the ulna-head and fuse the wrist actually worked, but whilst my arm was in plaster the ulna went 'walkies' and tore through my extensor tendons. This necessitated a major repair operation, my retirement from full-time teaching and most of 1996 spent in plaster and attending physiotherapy.

The hand and wrist had healed well, we thought, but I woke up one Saturday in September of last year to find that the extensor tendon of my right thumb had ruptured. So in I went again. My surgeon transferred the wrist tendon I wasn't using to my thumb and, dare I say it, did a jolly good job!

I'm due to go in next week for the operation to remove the ulna-head and fuse the bones of my left wrist, but this time I'm going to ask him to pin them so we don't have a repeat of the disaster of three years ago.

Not all has been gloom and doom.

I still teach - though not music - on a supply basis at two local schools; I am the Vice-Chair of Governors of my local infant school; I am Chair and co-founder of the Patient Participation Group at my local surgery and am involved in voluntary work at my local hospital, and I have a range of interests which I pursue.

All this came out of despair and sickness and I would never have had the time had I still been teaching full-time.

CASE HISTORY

Monica Mottram

I contracted psoriasis at the age of 6 and have had it ever since (I am now 58). I remember it very clearly. I just woke up one morning and looked at my hands and feet and they were encrusted in this horrible scaly stuff. I screamed my head off. My parents were very distressed as well since they did not know what was wrong.

From that time on while I was young I was taken from one specialist to another in the hope of a 'cure'. But of course all that anyone could come up with was the old fashioned smelly coal tar and sun lamps. I can't remember whether the treatment helped really. All I do remember is having to learn at a very early age how to spread the 'gunge' on my body (the psoriasis had spread by then) and then put the dressings over followed by bandages. So I was a dab hand at doing arm and leg bandages, especially the joints. However, as children are very resilient, I just got on with things and didn't worry too much.

I did get a shock when I was about 11 and went with the rest of my school class to the local pool for my first swimming lesson. I had my costume and towel and was very excited. However that's as far as it went. As I was walking past the pool attendant he looked at my skin and said, "You can't go in that pool." I explained to him it was called psoriasis and was not contagious but he was adamant that I could not go into the pool "I don't want to risk it" were his words. So no swimming lessons for me. However there were compensations. I was given extra English lessons instead and ever since have had a great love for the English language.

The rest of my body I was able to cover with stockings and jumpers etc. but I could not hide my hands and as I grew up I just became hardened to any comments that were made when anyone saw my hands and asked questions. However, there were (and still are) often very well-meaning people who knew someone who had 'used such and such and was cured'. It became a way of life with me to trot out some answer such as "Well, I'll try it sometime."

Psoriasis had an effect on my life when it came to boyfriends. Most of the boys I met took one look at my hands and turned the other way. In my teens when I was going to dances it was a nightmare for me because I knew that after I accepted a dance I would then be led back to my chair and left very quickly. That is not to say that every boy was like that, as I did meet some very nice ones. However, because my father was in the forces, as a family we moved about a lot and sometimes I would have to leave a nice boyfriend behind.

I think the one major set-back to me when I was younger was not being allowed to train to become a nurse. I had always wanted to be a nurse for as long as I could remember. However, I could quite understand that patients would not want to be treated by someone with 'sores' all over their hands. On top of which my feet often cracked and bled and sometimes I had trouble standing or walking. Well, nurses have to do most things at a run! So I set about taking a business training course and became a secretary. I really enjoyed doing shorthand and typing and was very good at it. However, here again, psoriasis reared its ugly head. When trying for promotion, comments would be made about my hands and I would not get the job. Although it was not stated, I knew it was because the job involved greeting clients and when shaking hands with anyone their eyes were like magnets honing in on my hands.

When I was 27 I was hospitalised for a period to try to clear up my psoriasis. I spent three weeks in St Bartholomew's Hospital as a 'skinny' patient. It really was an education. I thought I was bad until I saw some of the other skinny patients. They literally did not have any normal skin on their bodies at all. I felt so grateful that I was not like that and from then on I have always thought to myself that I am lucky only to have psoriasis mildly. When I left Barts my skin was almost clear apart from scalp and feet and I made the decision to work abroad in the sunshine. So I chose North Africa and spent some good times out there. And of course, the sunshine also kept my psoriasis at bay. I was almost like a 'normal' person.

I returned to England after five years and I was lucky that my psoriasis did not come back to my hands. I eventually learned to swim and took sailing lessons and enjoyed my life very much. But in my forties I went through some traumatic times both at home and at work and it showed up by the "return of the psoriasis". However it was never as bad as it had been when I was younger, for which I was very grateful.

During all these years I was never told that a certain type of arthritis often manifested itself with the psoriasis. So really I consider myself extremely fortunate that only in the past four years have I been stricken with the dreaded psoriatic arthropathy. It seems to have made up for lost time and has galloped along though - much to my indignation, I might add. I had plans to go camel trekking across the Sahara and back-packing through India as well as lots of other ideas once I retired in two years' time. However, the nearest I will come to camel trekking is driving a scooter along the beach at Southport; and back-packing will be a basket containing a tin cup and primus stove attached to the front of the scooter.

All in all, I feel I have been extremely fortunate, because when I read articles where people have developed psoriasis late in life I know it must be extremely hard to deal with. I grew up with my skin condition and have become inured to it. However, when you have had a lovely clear skin for years and suddenly develop what to other people must be horrible scaly sores, I really do feel for that person. The only hope is that eventually the person can live with the condition. If not then they will become very unhappy indeed. There are at present no cures for the condition, but who knows, with modern medicine, some time in the not too distant future there may be. So don't lose heart. Life is for living in spite of this horrid thing we have. And, although it is not really a consolation, if you look far enough you can always find someone in a much worse situation than yourself.

Monica Mottram (Miss)

PRIME TIME HELPS PEOPLE WITH DISABILITIES FIND WORK

PrimeTime
RECRUITMENT

Prime Time Recruitment is making significant progress placing people with disabilities in suitable employment.

Gill Pearce, Disability Employment Adviser at the Grimsby Job Centre, takes referrals from agencies for disabled people who are finding it particularly difficult to find employment. Gill approached local recruitment agencies to see if they were handling any suitable vacancies.

Less than a year later, with the aid of Prime Time, three men have found short or long term employment. Gill credits the good working relationship with Lyn Young, branch manager of Prime Time Recruitment Grimsby, and the efforts the branch has made to understand some of the problems faced by people with disabilities.

Simon Fletcher suffers from arthritis and psoriasis. He is a very willing and capable worker who has found difficulty getting employment because employers worry that his illnesses might impede his work. This is not the case and it is Prime Time's negotiations with the local authority that has enabled Simon to work as a street cleaner since last August.

Paul, in his late forties, has a learning disability and mental health problem. Gill spent time building Paul's self-confidence, which had taken a knock during several years of unemployment. Prime Time put Paul forward for a job vacancy at the local authority and he was snapped up and now works there on a permanent basis.

John, in his late twenties, has a learning disability. He has tremendous application to his work, a feature which was being overlooked by other employers he had approached. Since Gill Pearce and Prime Time have offered help, John has completed three temporary assignments for North East Lincolnshire Council.

Lyn Young, branch manager, says, "I alert Gill about appropriate new vacancies, to give her the opportunity to put forward anyone she thinks would be suitable. This works well because we are not building up peoples' hopes unnecessarily. Sadly, people with disabilities tell us how often they are turned away from work with other agencies, so it is very satisfying to know that Prime Time has been able to help."

For further information please contact Caroline Harrison at Hyde Public Relations on telephone: 0171 554 4200 or facsimile: 0171 753 8696 or e-mail: hpr@zoo.co.uk

Welcome to our service...

DRUGS DIRECT REVOLUTIONISES HEALTHCARE IN THE COMMUNITY

PharmacyPlus Direct
0800 389 0044

Thousands of people are set to benefit from the launch of a free 'prescription management' service which will see prescribed drugs delivered direct to their door, advice on medicines via a telephone hot-line, one to one pharmaceutical counselling, plus an automatic drug reminder programme and home visits by pharmacists for patients who require them.

Pharmacy Plus Direct, which was launched on Monday 1st February, will mean the sick or infirm need no longer struggle to get to a chemist or find a friend or relative to do it for them - instead they can receive first class pharmaceutical care from their armchair at home.

The new service is being offered by the West-based pioneering pharmacy group, Pharmacy Plus, and is designed to build a closer link between patients and healthcare professionals such as GPs, district nurses and midwives, and meet the changing medical needs of the population.

While some pharmacy groups already offer 'informal' delivery services for prescriptions, this is the first openly promoted free 'prescription management' service to offer the same kind of benefits that patients can receive in chemists - one to one contact with a trained pharmacist, ongoing guidance and support, advice on medicines and possible side effects and sound health advice which takes into account patients' individual medical histories.

Under the new service, prescriptions will be collected from doctors' surgeries on request by a patient, processed by the pharmacist at the dispensary and then delivered to the patient's home by specially trained staff within 24 hours.

The Pharmacy Plus chain, which now has twelve retail outlets across the West, was first established in January 1995 by managing director Tariq Muhammad, a pharmacist who was keen to buck the trend followed by other pharmacies by adopting a more community-led approach to pharmaceutical care and advice, with the emphasis firmly on customer care.

The Pharmacy Plus Direct service was developed in conjunction with Business Link West, who have earmarked Pharmacy Plus as a growing company and have supported its development with a grant contribution and professional advice.

PAA

AbilityNet

Microsoft

NEW ABILITYNET CENTRE FOR SOUTH EAST PUTS THE DISABLED IN TOUCH WITH TECHNOLOGY

ACCESS to adaptive technology has been made easier for people in the South East, after the recent opening of the South East AbilityNet Centre by Jane Griffiths, Member of Parliament for Reading East.

The new centre is based at the Microsoft Campus in Reading and forms part of AbilityNet's expanding regional network aimed at maximising the benefits of adaptive technology to the disabled. It is available to employers and employees and offers a range of services to assist people with special needs.

Disabled people can contact the Centre to make an appointment and receive a free assessment to determine their needs. Adaptive technology based at the centre includes voice-activated software, synthesisers and enlarged keypads.

Microsoft's involvement is part of the company's on-going commitment to using technology as an enabler and includes financial and product support as well as hosting the Centre. With more regional centres planned, AbilityNet hopes other companies around the UK will follow the blueprint partnership with Microsoft.

Opening AbilityNet's new centre, Jane Griffiths MP, said: "I am pleased to be present at the launch of the first AbilityNet centre that has come about through the partnership between Microsoft and the AbilityNet organisation. The Government is keen to see people getting back to work wherever possible for their own social as well as financial well-being. I look forward to other organisations providing the same support to AbilityNet as Microsoft, so that other centres can open in other parts of the country".

David Svendsen, Chairman of Microsoft Ltd, said: "Employers have a responsibility to accommodate the special needs of staff with disabilities and AbilityNet is an important part of Microsoft's accessibility strategy. Through the Centre's services, we can help employers to support disabled people in the workplace. The partnership between Microsoft and AbilityNet is a great example of how we have been able to support a vital service through the utilisation of our facilities here in Reading."

AbilityNet is one of the UK's leading disability advice organisations and has national offices in Warwick, West Byfleet and Malvern. Its other regional office is based in Liverpool, and there are plans to expand the network across the UK. Details about the offices are available on Freephone 0800 269545.

Your Letters.

I have been reading your newsletter for two or three years and have attended one of your Woburn conferences. You are doing most worthwhile work and I have been extremely grateful for the insights I have received as a result.

I felt that my recent experience of herbal treatment might be of some interest to your readers. Now aged 37, I have been suffering from psoriasis and associated psoriatic arthropathy for more than 12 years. I am fortunate - so far the P.A. has been confined to a huge knee and painful joints in the hands and feet.

A decade ago, less-than-helpful advice from a leading London hospital skin specialist was: "Your skin seems to be getting better, so you can ignore your swollen knee."

Subsequently, I was referred to an extremely good local rheumatologist and we tried a wide variety of accepted medical treatments. Some were quite powerful and others involved stays in hospital. While some offered short term respite, none gave long-term alleviation.

Having virtually exhausted the catalogue of (safe) medical treatments, I felt I had nothing to lose from seeking alternative help - and my enlightened consultant encouraged me.

I tried a controlled arthritis diet and was treated by two homeopaths - all without any noticeable impact on my psoriasis or P.A. The homeopaths both said that P.A. was an extremely difficult condition to treat - and one admitted after a short time that there was little she could do to help me.

Eventually, I consulted a herbalist. He prescribed a number of herbs for my skin and joints - I'm sure that I can obtain details of his prescription, if this would be of interest.

He was unable to make any progress with the skin, but the impact on my PA was dramatic. It went into total remission within four months.

He began by prescribing herbal preparations intended to treat the liver and kidney and slowly adjusted the prescription to herbs that would have a more direct effect on the joints. The treatment ended a year ago - and my condition is still (touch wood) in complete remission. I even survived last winter without the usual aches and pains.

I don't know how long this relief will last. When the treatment started the herbalist was not confident that he would succeed - and he made no promises about the long-term benefits. I do not know whether herbal treatment will benefit other readers - but feel that those who have tried all the avenues offered by conventional medicine might wish to investigate this option.

Yours sincerely
Brian Johnson

For contributions to the PAA news or Skin 'n' Bones please send your articles to:
Contributions, PAA, PO Box 111,
St. Albans, Herts, AL2 3JQ

I have in the past suffered with mild psoriasis on my scalp and also with a form of scalp dermatitis. I have found since using Pantene shampoo for normal hair that I have had little or no problems with my scalp. I had thought this just coincidence until a friend having her hair done, who also suffers with an itchy scalp and has found Pantene to be very helpful, was told by her hairdresser not to use it because it stops the scalp from producing new scales in the way it should.

Surely for someone with psoriasis or scalp dermatitis this is good news.

Is there someone who can comment on this?

Could someone write to me or reply to me in the Skin 'n' Bones Connection?

Carol Noble (Member)
p.s A relation of mine who suffers with psoriasis has been diagnosed with suffering from Crohn's disease. Is there any known connection?

My name is David Lawrence and I am 59 years old, married with two teenage children.

We decided to move to Portugal 11 years ago, mainly because the sunshine helps most psoriatics like myself.

The sun does help but not a fraction of the help I get from Methotrexate!!! I only tried it a for few months ago and though I have to have regular blood and urine tests, so far, so good. This drug has changed my life and I would urge anyone with P.A. to see a rheumatologist who might want to try this drug on them.

I wish anyone with P.A. 'good luck' and you are welcome to write to me if you want to. I tried just about everything for 36 years with very little success.

Lastly, in my case I have no side effects, so why not have a serious think about it.

David Lawrence
p.s. All my end finger joints were red and sore with thick nails, but now they are just about perfect.

COPY DATES

Publication	Copy Date
Summer Journal	30 April 99
Autumn News	31 July 99
Winter Journal	31 Aug 99

DATES
PAA Conference '99
Saturday 25th
September 1999
Woburn Safari Park
"REGISTER NOW"

Professional Dates

European League Against Rheumatism Congress
SECC Glasgow, UK
11th June
Tel 0171 242 3313

National Learning Disability Nursing Conference 1999
12th and 13th July 1999
Cambridge
Tel 0171 391 6285

PAA

Back issues of PAA NEWS (Newsletter) and Skin 'n' Bones Connection (Journal) are available to purchase.
For publication list and order form please send an SAE to:
PAA Publications
PO Box 111, St. Albans, Herts AL2 3JQ
or visit our Website: www.paalliance.org

PAA

Get in the Driving Seat at 1999 Mobility Roadshow

The Mobility Roadshow, Europe's premier outdoor mobility event for disabled and elderly people, will take place at the Transport Research Laboratory, Crowthorne, Berkshire, from 25-27 June 1999. **A registered Charity established in February 1998, Mobility Choice also promotes all aspects of independent mobility for disabled and elderly people through a variety of projects.**

With the focus on choice and opportunity, the Roadshow provides a hands-on showcase for a wide range of vehicles and equipment in a 'no pressure' environment.

Visitors will be able to test-drive adapted vehicles by all the major motor manufacturers on the Transport Research Laboratory's test track. Around 200 exhibitors will present mobility products for disabled and elderly people, ranging from scooters and wheelchairs to rear view mirrors and accessible public transport.

the Mobility Roadshow
the future of mobility

Other attractions include the opportunity to ride in 4 x 4 vehicles, specially adapted skid cars and go-karts with hand controls.

More than 60,000 visitors, the majority of them disabled people and their carers, are expected at this annual event. Visitors can obtain impartial advice on a range of mobility issues at the Information Village, while families are also well catered for with a fully staffed crèche and entertainment available on site.

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CROOKES HEALTHCARE