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skin 'n' bones connection



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Dear Reader

You may be interested to read about our newly launched website (pages 10-11), we need user feedback and would welcome any comments or contributions from readers and professionals alike.

I would also like to thank those of you who have sent in letters and suggestions for inclusion in **Skin 'n' Bones Connection**; these are always welcomed by us and other readers.

Finally, if you know or have any issues that affect you on a regional or local basis and which you think would be of interest to other readers then please let us know. We will do our best to be inclusive of all those affected by psoriasis and or psoriatic arthritis.

This is your chance to have your say through this magazine; it is your contributions that make its contents interesting to read.

Managing Editor

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Disclaimer

The contents of the journal are aimed at providing information that may be of interest to people with psoriasis and/or psoriatic arthritis or those who have a specialist interest, whether in a personal or professional capacity. Some articles which will be included are of general interest and may or may not relate directly to either psoriasis or psoriatic arthritis. This material may include aspects related to health, services or products that are available.

We believe that at the time of printing all information is correct and cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal.

All opinions are of the contributors and not necessarily those of the Psoriasis and Psoriatic Arthritis Alliance.

Always consult your own doctor or medical healthcare provider.

The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) is the new single identity of the Psoriatic Arthropathy Alliance and Psoriasis Support Trust. The organisation is independently funded and aims to be a definitive source of information and educational material for people with psoriasis and psoriatic arthritis in the UK. To be a support to both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas. We will be looking to provide positive advice that enables people to be involved as they move through their healthcare journey in an informed way, which is appropriate for their needs and any changing circumstances.

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There are a number of reasons why patient organisations exist. These can include single campaign issues that need to raise awareness or to increase funding for services of treatments. Probably the most common will be to help people most in need. This is the type of 'charity' that may not be what the Victorian philanthropists had in mind, by the provision of handouts, but that of a social and moral desire to offer a helping hand.

Whatever the reasons behind the origins of such organisations, there are real people that have a daily battle to live with their own chronic illness, the reality of this is shown in the letters and articles submitted to publications such as this journal, often in an e-mail but in the past usually via a handwritten letter.

There is something inspiring about such material and makes for the richness and soul of a charity. Cold facts and figures about chronic illness and cost of treatments, whether for political or campaigning issues, don't do justice to the real plight of real people.

For the most part charities are enveloped in an air of doom, gloom and hopelessness that their cause promotes; sometimes this is overplayed and turns off the awareness. It can also appear that there is no good news, as often those helped move on, which is exactly what a charity's role should be.

The day when a charity can say "job done" and closes its doors, is when a charity has fulfilled its aims and objectives successfully. For most this is only directional aspiration and although in many cases a charity does this by successfully helping people, unfortunately there are usually more people who are waiting to start the process.

In the past 15 years of this publication's life, there have been many published letters and case histories, which provide the answer to age-old human condition question of "you're not alone". This identification of how others are coping successfully against the odds is what makes a charity gauge its successes and failures. Given that many organisations are born out of a failure of some part of our society, whether ignorance, awareness or lack of resource, charities pick up the pieces and glue the broken lives back together, and sometimes you can hardly see the cracks. But the cracks are there and fragile, with sometimes a melancholy that haunts the individual as though something has died, the mourning period fades and although the light is there again, it is never as bright or seldom sparkles as before. The release of writing about conditions appears to be useful and possibly puts some meaning to the situation.

"...I think the one major setback 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 homing in on my hands..."

For those who live with either psoriasis or psoriatic arthritis these comments are very familiar. The point here is that nothing is said, which in the end speaks volumes.

There is another question that is often raised which is "why me?" as though there has been some finger that has picked us out of the crowd to suffer. The reverse of that is "I'm glad it's not me". In each case we shoulder guilt, the thought that perhaps we've done something wrong to get this condition or that we should salve our conscience in some way because we have been 'spared'. The latter is a major tool in the fundraiser's armoury and the 'insurance' that people 'buy' just in case.

Although, this may be a cynical viewpoint, we are like a moth to a flame when faced with such issues. The media campaigns that sell chronic illness in order to sell a cure are almost impossible to distinguish from real news and breakthroughs. The cynical use of photogenic successful individuals, who don't deserve such fates, is so stereotyped these days that it bares little or no relevance to real life. Why should it be so much worse for someone successful? Is there a sliding scale of suffering? It has to be remembered that we should all have an equal claim and that regardless of severity and the old adage "it could always be worse" or "there's always someone worse off than you" doesn't reduce the individual suffering. This also applies to the comment of "it's quite rare to have this". It is no consolation as having a chronic illness makes it 1 in 1 or 100% of your life.

"...I was only 13 years old when my family moved house to another part of the country, it was a very distressing time for me as all my friends were left behind. I began to notice dry scaly patches all over my body, under my nails and on my head, behind my ears and all over my limbs, although my face was not affected. I covered up but felt dirty scratching my body all the time. People would stare and I could hear nasty comments – you feel isolated being a teenager with something wrong with ..."

The case for history

... my doctor would give me a cream, but that didn't work; it just made the patches look red-raw and unacceptable for others to look at. The medical profession would ask if I had a history of this complaint in my family and I would whisper that I was adopted and feel even more of an outcast. Slowly, as the years went by, it became less noticeable. I even tried to be less self-conscious as I got older..."

If we go back to failure that charities try to counteract, you get a real sense of anger from individuals whose fate may have been more bearable if it hadn't been for various mistakes.

"...I get extremely tired, irritable and endure great pain. I try very hard to cope with daily living by myself but it is hard at times. It is especially hard to ask for help, both for people to do the practical things I can no longer do and also to ask for medical help when it all gets too much. I get so exhausted that some days it is an effort even to talk. I live in hope that my rheumatologist can at least make the rest of my life 'bearable' - I'm not looking for a miracle any more. I am sure that an early diagnosis of PsA is vital to prevent or delay permanent bone

damage and maintain mobility for as long as possible, In my case I nearly lost a leg through the wrong diagnosis being made!..."

The implications of such statements do make one wonder what is happening to those unable to voice their opinions, which brings us full circle to the idea that we have a certain moral duty to warn people about the oncoming train that is about to hit them and not just say "I'm glad I crossed the track in time" or "you know, it makes a terrible mess"; equally there is no excuse for shouting "fire" in a packed cinema.

We all have a certain responsibility to try and provide positive solutions, whether this is just tolerance or understanding in a non-patronising way, or a proactive voice that demands equity.

PAPAA exists to meet the demands of patients, carers, families and professionals involved in living or dealing with chronic diseases.

We need you to help us carry on with what is right for the patient. Your views and input count and also help others to come to terms with their condition and therefore create a more positive future.

NHS Information Centre

Latest NHS Information Centre figures highlight the changes in family doctors' pay

The NHS Information Centre has published figures that look at the changes in family doctors' pay over time as well as how pay varies according to factors such as age of GP and the number of partners in a practice.

The 2005/06 GP Earnings and Expenses Enquiry presented an analysis of tax returns for contracted GPs – the large majority of GPs in the UK.

The report's findings have been agreed by the Technical Steering Committee which included representatives from the four UK health departments, NHS Employers and the British Medical Association.

Findings include:

- As reported in October 2007, contracted GPs in the UK earned on average £110,004 in 2005/06.
- As also reported in October 2007, GPs working under a general medical services contract (the majority of contracted GPs) earned on average £106,312. In 1985/86, the most comparable group of GPs earned on average £25,254 (or, taking inflation into account,

£51,512 in today's terms). Of course, contractual arrangements and work done have also changed over this period.

- Average earnings rise with increasing age of contracted GPs up to the 50-59 age group when they earned an average £117,820 in 2005/06.
- Contracted GPs in rural practices earned on average £116,967, while contracted GPs in urban practices had average earnings of £108,455.
- Contracted GPs working alone in single-handed practices had the highest average earnings at £132,010, and contracted GPs working with six or more partners had the lowest average earnings at £105,769.

Because the report reflects earnings reported on tax returns, it includes private as well as NHS work and covers both full and part-time GPs.

Preliminary findings from the report were published last October, and those findings remain unchanged and once again exclude employers' superannuation contributions. The full report is at: www.ic.nhs.uk/pubs/gpearne



People with long-term chronic illnesses may be seen by a pharmacist instead of a GP in years to come.

People wanting help with lifestyle changes including giving up smoking, or who suffer from long-term health conditions, or who want health advice could find themselves being seen by a pharmacist trained to prescribe medicines.

The idea is being piloted in parts of Hampshire but pharmacists are aware they have to win the hearts and minds of both GPs and patients if they are to develop a bigger role.

University of Portsmouth lecturer and pharmacist Stephen Inns is currently one of just two doctor-funded pharmacists in Hampshire trained to prescribe drugs. He is among the UK's first cohort of independent prescribing pharmacists. He works alongside GPs in a cardiovascular clinic for two sessions a week and the other two days teaches tomorrow's pharmacists.

He said: "We are building bridges with primary care trusts – and GPs in particular – to open up the way pharmacists can take on a greater role in health care.

"If you say 'pharmacist' to most people they think of the chemist shop on the high street. What most people don't know is pharmacists are extremely knowledgeable about medicines and many GPs ask pharmacists for advice about new medicines or the ways medicines interact with each other.

"We also have training in patient care and many of our students studying pharmacy want to be able to fully use their extensive knowledge about medicines to help patients."

At the moment about 60 percent of a GP's time is spent reviewing patients with long-term chronic illnesses, according to Mr Inns. But with additional training pharmacists could take on the management of patient-care for such people, freeing GPs to spend more time diagnosing illnesses and treating more complex cases.

Training to provide this greater clinical role for pharmacists is currently being provided for postgraduate students at the University of Portsmouth by Dr Jane Portlock, principal lecturer in pharmacy practice.

One of Mr Inns's students, Shahik Mulla, is conducting a study which will give GPs, primary care trusts and the university a greater insight into what the future holds for patients and for those working in or for the NHS.

Shahik is in his fourth year studying pharmacy and is researching GPs' understanding of the skills of pharmacists and what they think about working more closely with pharmacists in the future.



He is shadowing pharmacists to get a better understanding of their current responsibilities – some are already responsible for medication and repeat prescription reviews in GP surgeries and for medicine management in nursing homes and training health care staff on medication updates.

The results of Shahik's study could have direct influence over hundreds of GP surgeries.

Shahik said: "If GPs can be persuaded to hand over some patient care to pharmacists this will reduce GPs' workload substantially. Pharmacists are not just for checking prescriptions; we can do a lot more – we have both clinical and patient contact skills."

The study is Shahik's final year project and includes sending an in-depth questionnaire to 250 GPs as well as those who 'buy' healthcare for primary care trusts and GP surgery practice managers. The report on the results will be available by June.

Survey reveals major discrepancies in care of patients with psoriasis

Psoriasis patients across the UK are experiencing differing and sometimes sub-standard levels of care, according to a recent survey by the British Association of Dermatologists.

The effect of the psychological, social and physical burden borne by patients with psoriasis is considerable. Indeed the emotional impact of psoriasis is such that as many as one in ten patients contemplate suicide, especially those of younger age; many more are dissatisfied with their treatment and seek more aggressive therapies.

Dr David Eedy, dermatologist in County Armagh and one of the study's authors, said: "Until recently most chronic skin disease has been managed either by GPs or in secondary care by specialist dermatologists with access to day-care and in-patient services. However, the government's initiative to provide 'Care Closer to Home' is changing the way such services are delivered. The care for patients with psoriasis is also changing with the advent of more effective treatments such as the biologics.

"The British Association of Dermatologists therefore conducted an audit of a hundred dermatology departments (units) in the UK to assess their staffing and facilities, with a focus on the provision of care for patients with psoriasis. It is hoped the results, which exposed major discrepancies and a 'postcode lottery' in the care of patients, will allow us to identify and tackle variations in standards, and to monitor the impact of healthcare reforms. We will be making the government aware of our findings."



KEY FINDINGS

1. Staffing

Whole Time Equivalent (WTE) for consultants is made up of 10 four-hour units, i.e. a 40 hour week, basically a full-time post. The BAD recommends that there should be one Whole Time Equivalent (WTE) dermatology consultant post per 100,000 of the population and that no consultant should work in isolation.

While these standards are being achieved in many parts of the UK (on average one dermatologist covers a population of 107,000), more than one in ten units (11 percent) have consultants who work in relative isolation.

Furthermore, specialist dermatological nurses greatly enhance patient care, but one in five departments had no specialist nurses.

Dr Colin Holden, President of the British Association of Dermatologists, said: "Our audit shows that some dermatologists still work alone, but we would like to see clinical networks developed so that all consultants work within teams and have the support of colleagues. Also worrying is that 20 percent of units do not have dermatology specialist nurses to support and educate patients with chronic inflammatory skin diseases, which enhances patients self-managing their treatment. This shortfall should be addressed."

On-call

A consultant dermatologist should be available to advise on the emergency care of patients with acute dermatological problems, but a third of units did not provide formal on-call, and of those who did, over a quarter did not provide 24-hour on-call advice. Less than half of units overall (47 percent) provided 24-hour on-call advice.

Furthermore, only 55 percent of the 42 hospitals with specialist registrars provided 24-hour on-call. Trainees must learn how to manage acute dermatological problems and on-call experience is an important part of the curriculum.

Dr Holden said: "Only 50 percent of units provide 24 hour on-call. This has implications not only for urgent dermatological problems but for the training of specialist registrars in emergency dermatology."

However, one positive finding of the audit is that patients with inflammatory skin diseases were waiting a median of 10 weeks for routine appointments – below the maximum 12 week wait.

2. Infrastructure and resources

Some patients do not respond to short contact therapy, or their psoriasis may be too extensive for them to undertake this treatment at home. In such circumstances the patient may be treated in a dermatology outpatient unit, or may be admitted to a dermatology ward.

In-patients

According to the audit, a third of units did not have adequate bathing and showering facilities for adult in-patients.

Furthermore, in 41 percent of units, topical treatments were applied by nurses who had no dermatology training, or by the patients themselves.

Dr Holden said: "Patients must have access to baths or showers - it is disappointing that such basic facilities were perceived to be inadequate in a third of units. It is also worrying that more than 40 percent of nurses caring for dermatology in-patients have had no dermatological training. Nor is it good practice to expect in-patients to apply their own treatments."

Out-patients

In 12 percent of units, dermatologists did not have access to dermatology nurses in their outpatient clinic, and in 20 percent there were no dermatology nurse specialists. Furthermore only 74 percent of units offered clinic rooms in which to apply topical treatments.

Clinical psychology services were available for adults and children in only around 40 percent of units.

"A minority of dermatologists do not have the support of dermatology nurses in out-patient clinics," said Dr Holden. "Nurses need space in which to educate and treat patients but a quarter of units do not have access to adequate out-patient facilities for treatment.

"The cumulative effect of the psychological, social and physical burden borne by patients with chronic skin diseases, such as psoriasis, is considerable and clinical psychology services should be much more widely available for dermatology patients."

3. Treatments

Conventional treatments for psoriasis include phototherapy (treatment with ultraviolet light), tar preparations and dithranol, which are both applied to the skin.

As an out-patient, the patient may be given a tar bath, and applications of dithranol in a stiffer paste than is used for short contact treatment. When dithranol is used under hospital supervision it is left on the skin for up to several hours under a tube-gauze dressing suit.

According to the survey, 38 percent of units stated they would consider using more crude coal tar and 46 more dithranol if facilities were staffed by trained nurses.

Scalp treatments were not provided in a quarter of units. Over one third of pharmacies could not readily provide coal tar or dithranol preparations.

In 95 percent of units, a medical physicist monitored the

UV output of the phototherapy equipment. It is mandatory that the UV output of phototherapy machines is monitored by a medical physicist - the safety of patients is compromised in those units (5%) without such arrangements.

According to Dr Holden: "Old fashioned treatments such as dithranol or tar are safe, effective and relatively cheap, albeit messy. Coal tar and dithranol still have a place in the management of some patients with psoriasis - both out-patients and in-patients - but units should invest in trained nurses and pharmacies to apply and supply the treatments respectively. Scalp psoriasis is particularly problematic for some patients, but a quarter of units denied patients the opportunity of out-patient scalp treatment."

Advances in our understanding of psoriasis in the last two decades have emphasised the importance of the immune system in the development and maintenance of plaques of psoriasis.

This knowledge, together with the biotechnological revolution, has led to the development of a range of new immunomodulatory agents, known as the biologics, examples of which include etanercept, efalizumab and infliximab. In addition to significantly reducing the physical severity of psoriasis, evidence from large randomised, controlled trials demonstrates that biologic therapies also improve multiple facets of quality of life.

Biologic therapies seem likely to play an increasingly important part in the treatment of chronic inflammatory skin diseases such as psoriasis.

Thirty-nine percent of units stated that prescribing of biologics for psoriasis was restricted for financial reasons.

Dr Holden said: "This somewhat exposes the myth of one NHS for all. Patients are experiencing a 'postcode lottery' for biologics in the treatment of psoriasis, where there are wide differences in availability of the drugs. This is similar to the differing prescription charges across the borders."

"Apart from feeding back to the individual hospital trusts we plan to feed key findings from this audit to parliamentary bodies. We will work with patient support groups to bring organisational deficiencies to the doorstep of the government."

Further information can be obtained from:
www.bad.org.uk



Patient-centred healthcare a reality for patients worldwide

The 3rd Global Patients Congress of the International Alliance of Patients' Organizations (IAPO), held in Budapest, Hungary, brought together over 180

all other healthcare stakeholders.

The Congress' key theme was further complemented by a focus on access to healthcare, patient safety, patient information and patient involvement. More and more patients are working with healthcare providers to make patient-centred healthcare a reality, and patient groups increasingly achieve recognition for the

holders and constituencies in a holistic manner''.

Sir Liam Donaldson highlighted the growing recognition given to patients as experts or teachers, helping to ensure that consumers receive the care they need in an appropriate and safe way. Sir Liam said that in the event of medical error we must always see the opportunity to forgive the error, "but we should not forgive an unwillingness to learn from it". He went on to say that the patient should be seen as our conscience for safe care, a catalyst for change, a witness of the quality of care, a compass, giving direction to our efforts and as teachers in how we learn from unsafe care. The work of the WHO Patients for Patients Safety programme, led by Susan Sheridan for the WHO World Alliance for Patients Safety, exemplifies this approach through its

representatives from around the world, which included patients and stakeholders in health, the European Commission, The World Health Organisation (WHO), global health associations, with the aim of learning from each other's experiences in developing patient-centred healthcare.

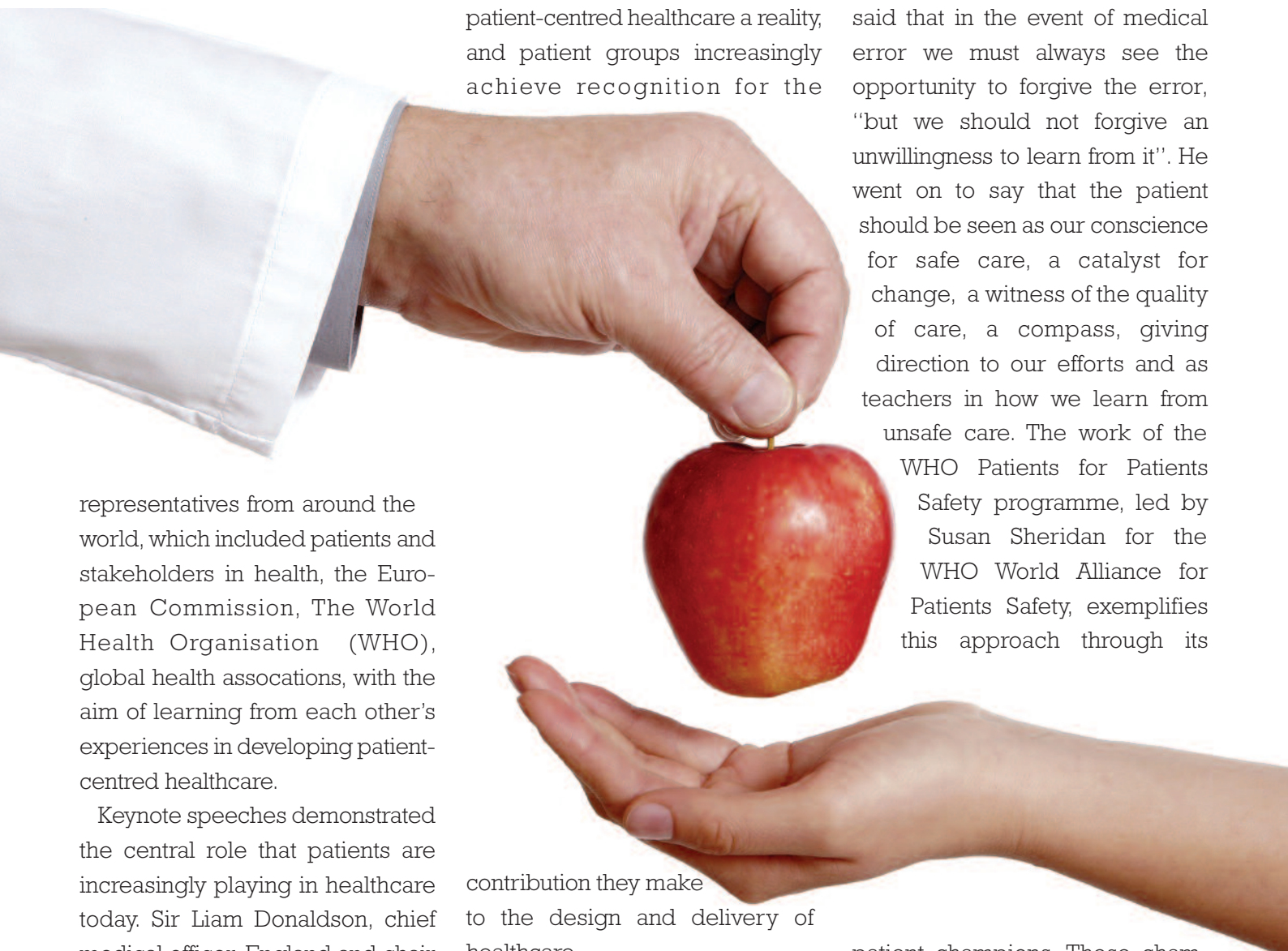
Keynote speeches demonstrated the central role that patients are increasingly playing in healthcare today. Sir Liam Donaldson, chief medical officer, England and chair of the WHO World Alliance for Patients' Safety, Ms Katalin Rapi, Secretary of State for Health Policy at the Ministry of Health, Hungary and Mr. Andrzej Rys, director, public health and risk assessment at the European Commission, DG SANCO, all highlighted the importance of developing collaboration between patients and

contribution they make to the design and delivery of healthcare.

Dr Linda Milan explained the progress of the 'People at the Centre of Health Care' project of the World Health Organisation (WHO), Western Pacific Regional Office (WPRO). This project draws on the IAPO Declaration on Patient-Centred Healthcare to support its work to "better respond to the needs of all healthcare stake

patient champions. These champions play a key role in improving patient safety both on a personal level in interactions with the healthcare system, but also by working in partnership with healthcare professionals, policy-makers and other stakeholders involved in healthcare.

Patient-centred healthcare and the valuable role of patients'



organisations was also the focus of the closing speech, given by Ms Katalin Rapi, secretary of state for health policy at the Ministry of Health in Hungary. Ms Rapi described the Hungarian government's efforts to provide meaningful support to civil society and patients' organisations as a key part of its aim to modernise healthcare delivery in the country, and stressed that the Hungarian

Ministry of Health shared the mission of IAPO in recognising that "patient-centred healthcare can only be realised by all players working together."

IAPO calls on all stakeholders in healthcare to include patients in a meaningful and sustainable way in all levels of their work and at all points of decision-making, and to build on existing models of involvement in collaboration with

patients around the world. "To meet patients' needs, decisions that affect a patients' healthcare, should not be taken without the full involvement of the patient at all levels of care, whether that be in the choosing of treatment options, developing healthcare policy or designing healthcare systems", said Myrl Weinberg, IAPO chair and president of the National Health Council (USA).



Guidance from the Medicines and Healthcare Products Regulatory Agency – steroids found in body lotion

The Medicines and Healthcare products Regulatory Agency (MHRA) has found steroids in an intensive body lotion, with Aloe Vera called OSAS, which claimed to contain natural ingredients. The lotion which is an unlicensed product, illegally claimed to treat eczema and psoriasis and has been found to be sold in a variety of Asian and African beauty shops in London and the West Midlands and over the internet.

The lotion was brought to the attention of the MHRA by a paediatric dermatologist who became concerned when the parent of a baby he was treating for eczema started to use this product on the baby. The lotion tested positive for variable amounts of betamethasone dipropionate – a type of medicine called a corticosteroid. The product also contains clotrimazole which is used in anti-fungal medications.

Strong corticosteroids (such as betamethasone) are only available on prescription and are used in the treatment of a variety of skin conditions such as eczema and psoriasis. Careful medical supervision of these treatments is important and inappropriate long-term use of corticosteroid medicines can cause skin thinning and other skin complications. The Agency would strongly advise that anyone using this

product, particularly on young children and babies, should stop immediately. Discontinuation of the product may cause a rebound effect (worsening of the condition) and you should therefore consult your doctor or healthcare provider about suitable treatments.

Anyone selling this product should stop doing so immediately, and remove it from their stock. If retailers are found still selling this product then the MHRA will take appropriate action.

The MHRA continues to seize, or receive from other agencies, for analysis a significant quantity of suspect herbal products. In recent months products being sold as herbal, natural and safe have tested positive for aristolochia, sildenafil, tadalafil, finasteride, clotrimazole, mebhydrolin, nonivamide and hydroquinone.

The MHRA Herbal Safety News pages highlight safety concerns associated with herbal medicines and are regularly updated to ensure that the most relevant information is made available to as wide an audience as possible.

There is also an e-mail alerting facility to which users can subscribe and receive an e-mail notification when the herbals section of the website is updated.

www.mhra.gov.uk

Is the web easy to navigate?

Is the web easy to navigate? Can be, unless you're a fly that is.

"'Will you walk into my parlour?' said the Spider to the Fly." This is the first line of the poem 'The Spider and the Fly' by Mary Howitt, published in 1829. When entering the world wide web, should the invitation be seen just as suspiciously?

For many people these days, the internet has become the first port of call. In many cases it is the only place where you can access information easily at the touch of a button.

So why has the world wide web become so integral to our daily lives? Possibly because of its ease of access and anonymity it provides. Most certainly the introduction of broadband and the proliferation of personal computers (PC), although perceived to be free, there is a cost of connection and equipment and a certain level of knowledge is needed to get the most out of using the web.

There are still many people who do not have the funds, access or desire to use the internet, and this is possibly causing a digital divide. The digital divide is a phrase often only used in the context of less economically developed countries (LEDCs) such as in Africa, where access to power, telephone lines or indeed a PC make connection impossible, but mostly the lack of access to funds to purchase these items is the barrier.

So in the UK, we are all starting to expect that there will be an instant answer on the web and if not, why not? At PAPAA a telephone call to us is often prefaced with "I've looked at your website, but...". The 'but' is so important because it proves that the web doesn't hold all the answers, and sometimes what is so obvious to web designers and those inputting information fails to work in reality.

Unfortunately, many websites do not have anyway of answering the 'but' question. It's a virtual world of virtual answers, flat statements and frequently asked questions (FAQs), which sometimes makes one wonder "who would ever ask that question frequently".

Also, do you really know who runs/owns a website? In some cases it's fairly obvious; I think we understand sites such as the British Broadcasting Corporation (BBC) and know what its purpose is.

So how do we know what the true motive of the website is and who's funding a website, particularly those

with healthcare advice? Well the simple answer is to ask, if the answer is not forthcoming look for some form of policy statement on funding, if it's not that obvious then maybe this could be for a reason. Look for sponsors logos, these can sometimes be the manufacturer of a treatment or product that relates to the content of the site. This is perfectly legitimate as long as it's clear. Sometimes sites will be quite innocuous and be very even-handed about a particular subject, but the sponsor's link will provide the real information about products. This happens



sometimes in 'awareness campaigns' which essentially are disease marketing activities with the aim of increasing awareness about a particular disease area that the sponsoring company has a product to treat; increased awareness leading to increased sales.

All of these issues are reasonable as long as we are told clearly (let's face it we're all grown-ups and shouldn't need a nanny to hold our hand). It is fairly obvious why certain companies sponsor activities for brand awareness and if there is a 'fit' by which the product directly relates to

Is the Web easy to navigate?

sponsored activity then it becomes mutually beneficial. Providing there isn't any overt pressure put on the recipients to provide endorsement.

So can you trust a non-sponsored site? Of course you should look for all the details set out previously, consider who has approved the site content; are there options to challenge the content? Can you contact the site owner? Is the site secure particularly when making payments?

So does the new PAPAA website answer the questions posed above?

- The site is owned and run by PAPAA

- There are no hidden links
- It's free to use
- You can browse anonymously
- You can contact PAPAA by telephone and e-mail
- You can comment and challenge content

And below is the funding policy as it appears on the site:

PAPAA is continually reviewing its activities and consulting with other organisations in order to provide services and activities that will be appropriate for the changing needs of patients in the 21st century.

The needs of people with psoriasis and psoriatic arthritis, are and will continue to be the thrust of all future activities the organisation delivers. These activities will be delivered in an appropriate way that is based on good evidence and input from patients, carers and healthcare professionals.

The PAPAA does not currently receive funds from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions or charitable grants. We believe that this allows us to act in a non-biased way and free from any influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe that it is beneficial to our constituent group.

We do not endorse products or make recommendations, we provide information that has been approved by healthcare professionals or has published evidence. We provide a signposting service to help people with psoriasis and psoriatic arthritis to make an informed choice and understand how to deal with their condition.

So feel reassured that with our best endeavours, we will continue to try to provide what people want and if it's not there, tells us and we'll try and deliver it when possible.

We want people to feel confident about content and feel that it can be trusted; we also want your input, as the world is full of differing opinions. It is our desire to share these in a fair and accurate manner in order to give the broadest view possible.

David Chandler

and psoriatic arthritis

ibe

Find

e to the PAPAA website

a joint venture between the Psoriatic Arthropathy Alliance, and the Psoriasis Support Trust, original charities into a single entity, becoming a principal resource of information and help for psoriatic arthritis in the UK.

day-to-day struggles of living with a long-term medical condition and problems that are psoriasis and psoriatic arthritis, and as an organisation is working to keep the patient centred voice

needed in order to provide a service that patients in the 21st Century will need, namely, PAPAA will aim to provide traditional patient support as well as new innovative

PSIASIS?
g-term (chronic) scaling disease of the skin, which affects 2% - 3% of the UK population. It raised scaly patches known as plaques...

ATIC ARTHRITIS?
f people with psoriasis may develop an associated arthritis called psoriatic arthropathy, n and swelling in the joints and connective tissue, accompanied by stiffness, particularly in

download includes easy to-print PDF files.

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and Psoriatic Arthritis Alliance is a registered charity No 1118192
tee registered in England and Wales No.6074887
ouse, 11-15 William Street, London, NW1 3ER

- It's funded by PAPAA
- Designed by an independent IT company paid by PAPAA
- Content is written or approved by doctors
- There is a Medical Advisory Board to oversee and update content
- The site carries no adverts or sponsorship

Holistic Neuro-Muscular Therapy

Neuro-Muscular Therapy (NMT) is an evolving therapy, for physical and emotional problems. The therapy aims to help restore the mind and body.

NMT is a simple technique using gentle touch or no direct contact. Connections are made between muscles, nerves and the brain, using manipulation of soft tissue, making use of the body's communication system. In this way the mind-body system can resolve problems of a musculo-skeletal or emotional/psychological nature. The whole process helps to reprogramme bringing about fundamental changes on physical, emotional and psychological levels.

Physical level

If a muscle goes into spasm it becomes tense causing a lot of pain and when we are in pain, we move to a 'position of ease'. But over time the muscles in that area start to remain tense and in doing so the muscle adjacent to these tense muscles also start to become tense. This in turn causes distortion and altered positions in posture. As a result, this original 'position of ease' changes as the surrounding muscle begins to ache and cause more pain. If this situation continues over time results in greater pain and restricted movement.

During a treatment you remain fully clothed and you may be required either to be lying down or sitting. In treatments for re-aligning the muscles, the therapist will place both hands on your body which will then begin the process of movement to reposition the muscles.

Where there is an acute muscle spasm, the therapy works well in relieving associated symptoms quickly. Most clients have found this therapy very relaxing and pleasant. Sessions vary but usually last about 1 hour.

Using touch in a specific way, the sensory nerves relay information to the brain. The brain assesses the problem in relation to its original blueprint. Neurotransmitters in the muscle respond, initiating this process of reprogramming, releasing tensions and restrictions with excellent long-term results. The therapist will continue with the process of positional release, which will assist the process of reversal to resolve the problem. This is a natural process whereby the brain registers this and releases the tensions from the corresponding muscles. The treatment uses gentle manipulation and will vary depending upon which muscle or muscles have become tense or distorted. It involves a mixture of firm and gentle pressure to be applied, but there is usually little discomfort. The treatment can be applied where there is an acute spasm or if the muscles have been tense for sometime. It helps relieve the acute pain brought on by a spasm, trigger points (often known as knots), pulled or twisted muscles. It is not uncommon for a therapist to start with giving treatment in a different area than where the pain is. This is due to the pain being a result from tense muscle elsewhere. Once the spasms are eased and the muscles return to their normal alignment and position, then mobility and movement becomes easier and less restrictive.

NMT is said to be effective for musculo-skeletal problems, back pain, restricted movement, injuries, general aches and pains as well as used at an emotional level to help with acute and chronic conditions such as depression, bereavement, fear, stress, anxiety, anger, behavioural problems and past emotional or traumatic experiences. It may also help with physical complaints i.e. irritable bowel syndrome, headaches and other symptoms often associated with emotional problems and stress.

Emotional level

For emotional and psychological problems, the therapist focuses on both the head and the body, which results in information being relayed through the nervous system, until it reaches the limbic system, an area of the brain that is associated with emotions and memories. The treatments release energy patterns of disturbed emotions from the mind-body system, allowing you to be yourself again, calm and relaxed. The therapist works directly with the energies, bypassing the need for you to re-experience any difficult and unwanted emotions. Sometimes these memories go back to childhood and are thought to be forgotten or thought of as minor. These memories however can have a detrimental effect on the way we feel in adult life. The therapist will place hands on your head and with gentle movements allow the mind-body system to restore itself to its natural state of being. The other energy centres (chakras) are then re-balanced.



How many sessions are needed?

The treatment may include the whole body or specific areas. No two treatments are the same. If required, treatments are usually 7 days apart initially, becoming less frequent once the basic problem has been resolved. The number of treatments required will be determined by the length of time the problem has been there and lifestyle.

The process has three different stages:

1. Resolution of a problem: acute or chronic
2. Support through a transitional period while the body adjusts to the changes that have taken place
3. Maintenance if the problem is aggravated by work or repetitive activity.

MEET THE PRACTITIONER

Gaynor Hughes, an experienced registered nurse, for over 20 years, specialising in orthopaedic nursing involving the musculo-skeletal system. Gaynor has a thorough understanding and knowledge of anatomy and physiology, and pain, also having worked in pain management.

Having gone through some challenging and difficult times in her life, Gaynor underwent a lot of self-personal development and growth, wherein she began to discover different ways to help people in both a complementary or alternative way to traditional conventional medicine or alongside it, obtaining qualifications in many therapies.

Qualifications include: Reiki Masters, Diploma in NMT, Diploma in Light Work Practitioner Therapy, VTCT for Indian Head Massage and Certificates in Crystal Healing, Past Life Healing, Hopi Ear Candle Therapies, Angel Attunement and foundation in Acupuncture.

To contact Gaynor Hughes telephone: 07866 438120 or e-mail: positivehealing@hotmail.co.uk

Gaynor works in Devon and Hertfordshire or on a mobile basis if mobility is difficult. Gift vouchers are available, payable on request.

The Royal National Hospital for Rheumatic Diseases in Bath – current research into psoriatic arthritis

The Royal National Hospital for Rheumatic Diseases in Bath (RNHRD) has been holding clinics dedicated to the care of patients with psoriatic arthritis (PsA) for over 15 years. RNHRD is one of only a few centres in the UK to offer this specialised service. RNHRD has been able to collect a lot of information over the years that has helped its active research programme. This has of course only been possible with the kind help of patients.

At the RNHRD there are over 400 patients who have consented to be part of the ongoing research programme in PsA. This makes RNHRD one of the largest centres for PsA in the country, Europe and indeed the world! Over the past few years, the hospital has been a major contributor to the international field of the genetics of PsA. RNHRD researchers have discovered novel genes which will help us understand more about both what makes a person susceptible to the disease and the ability to predict how severe this may be for individuals. Many patients have completed background and family history questionnaires, the results of which

have increased the knowledge of the strong inheritance pattern that has emerged in this disease.

Alongside collection of this demographic information, RNHRD is constantly collecting data relating to the changes in patient clinical status: how joints and skin have changed, and how this has affected a patient's ability to function on a day-to-day basis. This wealth of information puts RNHRD in a unique position of helping doctors understand what has happened to their patients over a long period of time. This will help to develop tools to identify predictors of how doctors think a patient's disease may progress in the future. Without patients' continuing help and support this research could not be carried out.

Dr Korendowych and Professor McHugh are the two consultants who run the PsA clinics at the RNHRD and currently see approximately 100 patients with PsA each month. There is also a registrar in clinic most weeks who rotates to other clinics every 6 months, so that they can gain experience in looking after patients with PsA.

Specialist nurse in PsA Nicola Waldron helps collect data for RNHRD research and offers support and advice to patients. Dr Korendowych and Nicola also hold a monthly biological therapy clinic for those patients who are on, or being assessed for, anti-TNF therapy. At clinic patients will hopefully have the opportunity to meet the different members of the team. Some will be regularly involved with individual patients care and others will be on an occasional basis, such as physiotherapists, occupational therapists, the podiatrist and the orthotist.



*Prof. Neil McHugh
Consultant Rheumatologist*

Methotrexate nail study

RNHRD is currently recruiting for a study of a topical methotrexate cream to evaluate its effectiveness in treating nail involvement with psoriasis (thickened, ridged, pitted nails) over the next few months. If you are not on methotrexate and have involvement of the nails on your hands and would like some more information then please contact the clinical trials team (01225 465941 ext 358).

The MIPA trial

RNHRD is currently one of the major centres participating in the MIPA trial (Methotrexate in Psoriatic Arthritis). This is a multi-centre trial which has recruited patients with PsA from around the country. Although we have been using methotrexate successfully for patients with PsA for many years, there has never been an independent study that examines in detail how the medication works on the joints and skin. The results of this important study should be available by the end of 2008.



*Dr Ellie Korendowych
Consultant Rheumatologist*

When developing a condition such as psoriasis or psoriatic arthritis patients face a dilemma, often abdicating any responsibility for treatment by placing themselves under the care of a general practitioner, and many say “I’ve got this problem, can you fix it?”. This might be a simplistic generalisation but pretty much a hope and desire.

Mostly patients are then treated with what is called conventional medicine. In the UK conventional treatments are rigorously tested in clinical trials in order to prove the treatment works. The product gains a licence and can be prescribed; a further step is undertaken by the National Institute of Health and Clinical Excellence (NICE) in England and Wales and in Scotland by the Scottish Medicines Consortium (SMC); these bodies review evidence and decide a treatments' place within the NHS, by producing guidance for doctors.

As with many treatments often the desired effect isn't always forthcoming; the treatment may have an unwanted side-effect or the patient is just uncomfortable with the treatment for various reasons, which may appear to be trivial to the prescriber but will be a real issue for the patient.

So the idea of complementing a conventional treatment or seeking an alternative therapy becomes in some cases an attractive solution. This particularly is the case when the hope of conventional medicine has left the patient less than satisfied.

So how can you judge if the claims made by complementary and alternative therapists are genuine and stand up to scrutiny, particularly as many practitioners have no formally recognised qualifications? Well, essentially it is an unregulated industry and as long as specific claims aren't made, then therapists are free to set up and provide a 'service'.

One in five of people in the UK now use complementary and alternative medicine (CAM), it is estimated that there are 50,000 non-medical complementary practitioners, with an enormous number of accreditation schemes and registration bodies to support them.

Popular therapies such as acupuncture and herbal medicine were recommended to be regulated by law by a House of Lords report in 2000¹.

The increasing integration of mainstream and complementary medicine is primarily driven by patient demand, as people choose complementary treatments. The annual turnover of complementary

healthcare is estimated to be £1.6 billion.

The British Medical Association (BMA)² has found that 80 percent of doctors would like to see acupuncture available on the NHS, and an estimated 25 percent of Scottish GPs have had some homoeopathic training.

It is reported that CAM is being used in GP practices for a range of patients, including those with cancer, mental health problems and coronary heart disease. Some hospitals are also using therapies such as massage and aromatherapy in cancer care and pain relief.

The main treatments are osteopathy, chiropractic, acupuncture, homoeopathy and herbal medicine and are those to which doctors most frequently refer their patients.

Other therapies, such as aromatherapy, reflexology, massage and hypnotherapy, make up a smaller percentage of referrals, with a very small number made for treatments such as reiki and shiatsu.

But this popularity doesn't necessarily correlate with scientific credibility. There is strong evidence, for example, that acupuncture is effective for a number of conditions, but the clinical evidence for the efficacy of homoeopathy is more controversial.

Many NHS practices offer some form of access to complementary medicine, either within the practice or via referral to an outside practitioner, with 42 percent of treatments having to be paid for by patients themselves. Overall, 90 percent of complementary therapies are purchased privately.

There are five homoeopathic NHS hospitals in the UK, and the British Medical Association says GPs have a duty to refer patients for homoeopathic treatments within the NHS.

The Department of Health recommends that only those therapies that are statutorily regulated or have robust self-regulation should be made available through public funding.

If you are contemplating the use of CAM, always do as much research as possible about the therapy and the practitioner, talk to your GP to see if you can access it via the NHS. If you know someone who has tried a particular therapy, ask their views and see if there were any benefits or problems that weren't obvious or considered.

References:

1. House of Lords Science and Technology - Sixth Report. Complementary and alternative medicine (2000) London: House of Lords, HMSO.
2. British Medical Association. London www.bma.org.uk. Accessed online May 2008.

NICE should assess drugs faster

A recent inquiry by the House of Commons Health Committee on National Institute for Health and Clinical Excellence (NICE), recommended that all medicines should be assessed at launch. A shorter, less in-depth evaluation should be made between licensing authorisation and marketing; this would enable clinicians to prescribe useful cost-effective drugs as soon as they are launched.

During the inquiry, there was evidence that NICE was carrying out many of its functions effectively, although some patient organisations, professional groups and the pharmaceutical industry criticised NICE for slow release of guidance and perceived unfairness of NICE recommendations, which are often appealed.

Problems that were identified included:

- Low number of medical technologies chosen for assessment
- NICE did not look at the wider benefits of treatments, this might include carers
- NICE doesn't always have access to all information needed to make full assessment
- Experts are not sufficiently used
- Guidance publication is slow

To improve guidance implementation NICE was recommended to:

- Give more help to primary care trusts (PCTs) to implement guidance
- PCTs should be more involved in the development of guidance
- There should be a better use of experts
- Change terminology for patients, so they know what they can expect by right from their local NHS.

In conclusion the committee report recognised that NICE does a vital job in difficult circumstances. The development of more and more health technologies and procedures, alongside rising patients' expectations and the aging population, is going to make it even more difficult in the future.

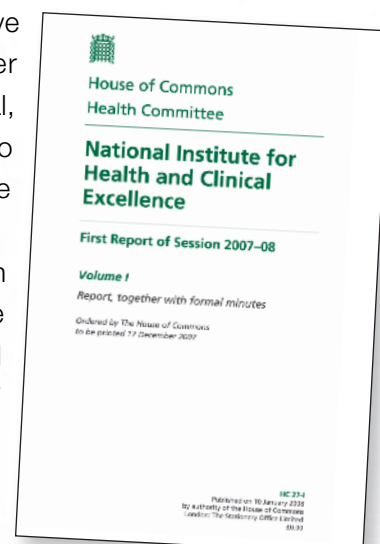
The report also said healthcare budgets in England, as in other countries, are limited, and patients cannot expect to receive every possible treatment. Demand outstrips

resources and priorities have to be determined. In other words rationing is essential, and NICE has a key role to play. No doubt the debate will continue.

House of Commons Health Committee National Institute for Health and Clinical Excellence First Report of Session 2007–08 Volume 1

Code HC 27-1 –

Published on 10 January 2008.



The full report is available to download from www.parliament.the-stationery-office.co.uk or to purchase from The Stationery Office as hard copy.

Ustekinumab shows promise in trial for psoriasis

The first reported findings from an international Phase 3 study showed that more than two-thirds of patients with moderate to severe plaque psoriasis receiving two doses of ustekinumab (CNTO 1275) achieved at least a 75 percent reduction in psoriasis at week 12, the primary endpoint of the study, as measured by the Psoriasis Area and Severity Index (PASI 75), a standard measure to demonstrate treatment efficacy.

Importantly, findings also showed that following one additional dose at week 16, a substantial proportion of patients receiving ustekinumab maintained a PASI 75 response through week 28. Data from the study, presented at the World Congress of Dermatology last year, involved more than 1,200 subjects and showed that within four weeks of initiating treatment with ustekinumab, patients experienced significant and clinically meaningful improvements in quality of life measures compared with patients receiving placebo.

Ustekinumab is a new, fully-human monoclonal antibody for the treatment of moderate to severe plaque psoriasis, and is being investigated as an infrequently-administered subcutaneous injection.

As with all studies these data will only have significance if they translate in to the real population.

Currently there are a number of these newer biological therapies available in the UK for the treatment of psoriasis and psoriatic arthritis. With more research being carried out there will no doubt be more treatments such as ustekinumab becoming available and therefore increase the choice and options patients will have.

Dear PAPAA,

Thank you for your recent letter and Heart leaflet. As you were asking for case histories etc. I thought you might be interested to hear about the successful treatment of my scalp psoriasis.

I was diagnosed with psoriatic arthritis (PsA) over 10 years ago. The psoriasis particularly affected my scalp and was uncomfortable, itchy and unsightly. I used steroid scalp lotions prescribed by a dermatologist on and off but although they seemed to damp down the condition, they never got rid of the problem, and it seemed to flare up when I stopped using them. Eventually I spoke to my GP and she explained that the build-up of scales on the scalp actually prevents scalp lotions working properly. She prescribed Coccois ointment to be applied every night and washed off in the morning for one week. It was a messy, smelly business but did the trick! She then prescribed Dovonex scalp lotion and after 4-6 weeks my scalp was completely clear! I now no longer use the treatment and 4 months later all is still OK. I can now wear dark coloured tops without looking like I've been out in a blizzard!

Also I would like to say to other readers that my arthritis has improved over the last year or so. My rheumatologist said that the disease may burn itself out, and aside from a bit of joint stiffness and the odd twinge this seems to be the case. I am sure that losing excess weight and eating a diet high in fruit, veg and oily fish, and low in animal fats has helped. Therefore a diagnosis of PsA does not necessarily mean a life sentence!

I hope this information is useful

Regards

S B



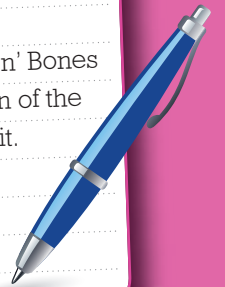
Dear PAPAA,

Just to let you know I feel better (in my mind) that I have finally joined a group where the people suffer similar distress as myself. I have not got the confidence to join coffee mornings etc. I have always felt unclean either because of my scalp, face, nails, it doesn't matter what, this is how serious this disease can affect people whether it's my nasty looking joints, or scaly face it makes one's self-confidence take a huge blow. I've got that off my chest but I had to say it as I have only just subscribed and I can say it is one of the bravest things I have done in a while.

Your name for your news journal – Skin 'n' Bones seems perfect and it covers the combination of the disease. I am looking forward to receiving it.

Yours

J



Dear PAPAA,

I was diagnosed as having psoriatic arthritis in September, after years of isolated aches and pains! I have suffered from psoriasis for 26 years also. The condition came to the fore last year when I had more pains than usual, developing from a very stiff ankle and foot to developing into a "flare-up", when my hands also became very painful and life seemed very grim.

It took my GP 3 months to refer me to a specialist and I am now well into a course of treatment. The relief on getting a diagnosis was the greatest step forward.

I am most interested to raise awareness in this condition. Statistically there must be a lot of us about but I currently only seem to encounter elderly "rheumatoids".

Being 40, I would be more interested in seeing how others of my age cope with this problem and how it can develop.

Yours

SA



Q Dear PAPAA,

Thank you for the recent issue of Skin 'n' Bones Connection, I've received the magazine for many years and have always enjoyed the content.

I would like to make a plea for us 'technophobes', although I'm not that old (45 years young) I do not have a computer and have never used the internet. Will you continue to have a printed version of the magazine or like so many other organisations only have it available electronically? It would be a shame to lose such a worthwhile product.

Yours

TB

A Dear TB,

We have no plans to only supply material on the internet, we fully recognise the need for printed material, Skin'n' Bones Connection will continue to be printed as long as people still want it in this media.

Note from editor: Back issues of Skin 'n' Bones Connection are still available, please contact us for a complete list.

Dear PAPAA,

I have just read a recent article in the magazine about a fellow psoriasis sufferer and your details were given to receive further information.

I have suffered from psoriasis on my scalp for a number of years and whilst I have visited my doctor about this condition all I received was a tar based shampoo and very little information about what actually caused the condition.

I should be grateful if you could forward some information on the illness and details of any known remedies whether medical or alternative medicine.

I am very grateful to you for running such an organisation and would like to keep in touch with any updates about the condition.

Yours

EF

Dear PAPAA,

I was pleased to come across PAPAA, we know no one else who has psoriasis except remembering the late playwright Dennis Potter. My husband is pretty smothered in psoriasis and has no movement left in most of his joints. Although he still gets about walking is painful and we have just got a wheelchair so that we can go out. Mostly we just sit inside and hide. He is very withdrawn. I am very ashamed of us as we leave such a mess behind us. We have just had our first holiday for years, complete with vacuum cleaner. I could never do it again. I am pretty fed up with it.

The constant creaming to no effect – it never gets better. I have to do everything as he can't even wash up properly and I have to bath him and sometimes dress him. I even have to comb and cut his hair. There is no hope that things will ever improve, just getting steadily worse and I am filled with despair. I am also the breadwinner. This sounds a very moaning letter. It's not really meant to be I just want to explain where I am at. My husband feels no need for support. He is resigned to it. I would welcome any information, advice or support, particularly on how others cope.

Yours

YW



Dear PAPAA,

I have recently read an article in a magazine about psoriasis – the link with arthritis. My poor mum has had psoriasis for almost 30 years and she does suffer quite badly with it, she has recently been suffering from pain in her back, shoulders and legs, and unfortunately has been diagnosed as having arthritis. On reading this article I feel I must write to you and ask for information and advice to be posted to me at the above address.

Thank you for the wonderful article.

Yours

JH



New shampoo available on prescription for adult scalp psoriasis

Etrivex shampoo contains the active substance called clobetasol propionate; it belongs to a group of medicines called topical corticosteroids (or steroids).

Topical corticosteroids are further classified into groups depending on their strength; clobetasol propionate is a very strong corticosteroid. 'Topical' means that it should only be applied to the surface of the skin.

Topical steroids reduce the redness, itchiness and inflammation associated with skin conditions.

Scalp psoriasis is caused by the skin cells of your scalp being produced too quickly. Etrivex shampoo is used to treat scalp psoriasis of moderate intensity in adults.

Not everyone will be suitable to use this type of shampoo and there will be certain conditions where your doctor will advise you not to consider this treatment, particularly if you are allergic to any of the ingredients.

Your doctor will tell you how long you need to use the shampoo to control your scalp psoriasis. Treatment should not normally continue for more than 4 weeks. However, if your scalp psoriasis is significantly improved before the end of

treatment, your doctor will advise you on how to proceed.

Application is directly to a dry scalp once a day, massaged into the affected areas. Left on for 15 minutes and washed out, then conventional shampoo can be used if further shampooing is required.

There are a number of other products for the treatment of scalp psoriasis, these include topical lotions, gels and creams, there are also tar based shampoos, some of which can be bought without prescription at a pharmacy.

Etrivex shampoo is marketed by Galderma (UK) Ltd. and is only available on prescription.



A scalp information leaflet about scalp psoriasis and treatments is available from PAPAA, or downloaded from our website www.papaa.org

Hard copy available free of charge please e-mail info@papaa.org or telephone 0870 7703212

Adalimumab licensed to treat moderate-to-severe psoriasis

A licence has been given for adalimumab as a treatment for moderate-to-severe chronic plaque psoriasis in the UK. Adalimumab is the first fully human anti-TNF (tumour necrosis factor) monoclonal antibody approved for the treatment of plaque psoriasis.

"Psoriasis is a disease that causes great distress physically and emotionally to patients," said Professor Christopher Griffiths, of the University of Manchester. "Anti-TNF treatments are a promising development for those with moderate-to-severe disease and the availability of a new treatment option is a big step forward. The licensing of adalimumab is a welcome announcement and provides an

additional tool for physicians to treat those who are seriously affected by the disease."

Clinical trials have evaluated the efficacy and safety of adalimumab in a range of moderate-to-severe plaque psoriasis patients, measuring and evaluating response using the standard Psoriasis Area and Severity

Index (PASI) among other measures.

Adalimumab is a fully human monoclonal antibody that works by specifically blocking the activity of TNF. Fully human monoclonal antibodies (antibodies derived from a single cell) are essentially indistinguishable from antibodies found in the body and represent the latest advance in the evolution of monoclonal antibodies. Adalimumab binds specifically to TNF and neutralises the biological function of TNF by blocking its interaction with cell surface TNF receptors.

Adalimumab is classed as a biological treatment and is only available on prescription following referral to secondary care and then only if other treatments or agents have failed to provide adequate response.

Your doctor will be in the best position to assess your suitability for this treatment and there may be many reasons that are related to your individual circumstance, that may not make you a suitable candidate for adalimumab. There are other biologics already licensed for psoriasis including etanercept, infliximab and efalizumab. More biologic treatments are currently in research trials, and we will report these as news emerges.

Adalimumab is marketed as HUMIRA® by Abbott and is only available on prescription.





A “no frills, down-to-earth” spa where you can unwind at your leisure, feeling comfortable and uninhibited, with nobody bothering you unnecessarily unless you need help!!

Nirvana Spa is based in Wokingham, Berkshire – fairly easy to get to, with plenty of parking, which takes the stress out of things before you get started!!

From the outside, Nirvana looks unassuming, but don't let that put you off. When you enter the small reception area, you are greeted by helpful, informative staff who will do all the initial signing-in formalities, give you your soft bath robe and towel and then point you off in the right direction to start your enjoyable, relaxing day, leaving you to explore in your own time the following treats:-

Surf Room: A 53 jet hydrotherapy pool heated to 35°C – a real experience in itself – its many powerful jets massaging and invigorating tired, over-used bodies bringing them back to life.

Ocean Room (small pool): Now this will be your first introduction to the delights of total relaxation floating unaided, with just the warm water to support you. Here is where you receive your induction on the main Celestial pool before entering it. For example what the water consists of to make you float, how to stand up and lay down without hurting yourself, and just getting you used to its sensations of floating.

The Celestial Pool is next: 40 minutes spent in darkness just floating, relaxing in this bigger pool, looking up at the painted stars twinkling on its ceiling.

The Roman Pool: Here you can relax on loungers, have a sleep or just unwind, read if you want to, or just have another dip in the warm water pool. Pool depth is 4'3.

The Garden Café: Here you can purchase food and drinks all day. Depending on the package you have booked, this is where your lunch, dinner or supper will also be served by friendly staff. If you have any questions, they are happy to help.

The Nirvana Room – Tepidarium: This room has 33 heated ceramic loungers. The room is very quiet and relaxing. No hassles, and no chaos!! Just there for you to relax.

The Fitness Pool: A full size 25m swimming pool, divided into two lanes, allowing you to swim at your own pace. It is 4ft in depth and much cooler than the other pools. Floats, woggles etc. are also permitted in this pool.

Jacuzzi: this is located by the fitness pool, also you can find a sauna and steam facility for men-only use. There is also this facility for women too.

Aromatherapy steam room and Monsoon Showers are for unisex use.

Nirvana Gym – Nirvana has good gym facilities too; open for guests to enjoy and use – there are qualified staff on hand to help you.

Treatment rooms: for those of you wanting to get the most out of your day, you can also choose from a variety of relaxing treatments and book these in advance of your visit.

Nirvana Spa shop: Here you can buy a variety of Nirvana Spa products. You can also purchase some of their products online from the webshop.

There is also a members only section for those who wish to join and become a regular visitor to Nirvana.

To enjoy what Nirvana has to offer there are various packages and options to suit most pockets and for more details of these, you can find them on the website:

www.nirvanaspa.co.uk

e-mail: info@nirvanaspa.co.uk

Tel: 0118 989 7575,

**Nirvana Spa, Mole Road,
Wokingham, Berkshire
RG41 5DJ.**

If you want no hassles, feel comfortable in a spa environment without the “snob” touch!! love water, friendly staff, good range of priced packages, then Nirvana is worth a try, certainly to feel your feet in getting used to a spa environment, which can put a lot off trying because of preconceived ideas.

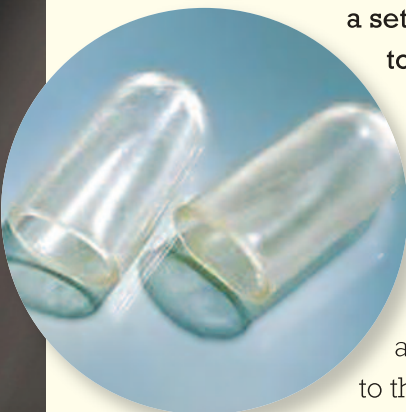


Here are a few items that have been brought to our attention by our readers. These are for your interest and in no way are we endorsing or recommending these products.



Firstly an interesting item from **Temps L** for protecting sensitive toes. These thermo-plastic gel tube (ref. 3937) can be cut to size to prevent shoes rubbing – a set of 2 costs £3.90 plus postage and packing.

Also available from **Temps L** are a set of flexible silicone gel toe and finger protectors (Ref: 8518) in packs of 2 priced £2.99 plus postage and packing.



Lakeland Plastics have a product which, according to the catalogue, aims to solve the problem of popping pills out of blister pack dispensers. **The**

Poppet Pill Dispenser (Ref: 21568) is priced at £2.99 plus postage and packing and is designed to make life easy by popping the pills out of the pack and then holding them until you've popped all you need.



Contact details for the above products:
Temps L, PO Box 38, St Peter Port, Guernsey, GY1 3BA. Telephone 0870 404 5678
www.tempsl.com

Lakeland Plastics, Windermere store
Tel: 015394 88100 www.lakeland.co.uk

The Evoluent Vertical Mouse £82.19. An ergonomically-shaped mouse designed to support your hand. Helps to both treat and prevent RSI. Call 0845 345 0010, or go to **www.posturite.co.uk**



Thermoskin Arthritic Gloves £19.99. Provide heat therapy and mild compression, supporting the joint and easing arthritis pain. Material retains body heat. At pharmacies nationwide or call 01455 639750 for stockists or go to **www.thermoskin.co.uk**



Hands First® Invisible Gloves Dry Feel Barrier Cream, 125ml, £7.99. Helps prevent dirt, grease and detergents from penetrating the skin. Forms a non-sticky film on the hands. Call 0845 803 9033, or go to **www.handsfirst.co.uk**



If you come across products or items that you have found useful or you think others will find of interest please let us know. There may be similar products on the market made by other manufacturers that are as useful so keep your eyes open as this page is designed to offer some useful gadgets.