Skin 'n' Bones connection

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

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Editorial:

The PAA has long been an advocate of access to information on all aspects of psoriatic arthritis and psoriasis, particularly at the point of delivery of care with instant access to relevant material. The growth of the Internet over the last few years has seen an explosion of information on all manners of subjects. Health related issues are particularly well represented. Whether it is an official website for an organisation, personal home pages or commercial promotion, the amount of information is often overwhelming.

The nature of a condition such as psoriatic arthritis and psoriasis means that the desperate search for the right information or resource can be very frustrating. The mixture of all singing all dancing sites full of whistles and bells and basic no nonsense plain text presentations often bears little indication of how useful or accurate the information really is.

Disclaimers are obligatory and mean that the information may be of no use at all or purely the authors own opinion. We must have all experienced the situation when talking to friends or relatives about our condition the answer that "My Aunt/Granny etc. has that and swears by x treatment, you should try it"

Every new drug or treatment is greeted with the term 'breakthrough' and various websites will be offering conflicting information about the efficacy and safety. It could be argued that only approved sites should be trusted, but who should approve the site and contents.

Ultimately, the source of new information should be referenced and where possible the original author or researcher credited. With this last thought in mind the PAA always endeavors to provide information that has been rigorously scrutinised by our Medical Advisory Panel (MAP) for accuracy and relevence. Members of our MAP are all respected professionals and are experts in their field.

International Federation of Psoriasis Associations (IFPA)

The International Federation of Psoriasis Associations (IFPA) is an international organization whose membership comprises the respective lay psoriasis groups in countries around the world. The PAA is the UK representative. The members of IFPA meet regularly to collaborate on ways to help people who have psoriasis and to discuss important issues affecting the world's psoriasis community. The last meeting was in San Francisco in June 2001 at which 17 member countries were represented (see picture); the next meeting is tentatively set for July 2002 in Paris.

Meetings such as the one held in San Francisco allows the exchange of information and gives a greater voice and awareness for those with both psoriatic arthritis and psoriasis. It is also interesting to learn that although there are different healthcare systems around the world, people with psoriasis and psoriatic arthritis face similar problems with treatments, employment, relationships and stigma.

Cover photo: David Chandler, Golden Gate Bridge, San Francisco

Pain Management - A Psychological Approach?

by Damian Gardner

SOME OPENING COMMENTS

It is not easy to summarise a 27 hour multi-disciplinary course into a short article. Nevertheless, I will do my best in the following paragraphs to give you an overview of some of the key principals of managing pain. Although not an academic article, all the principals described here are based on sound outcome research which indicates that effectively implementing pain management principals can make a major impact on the quality of life for people suffering chronic pain. The title of this article has a question mark at the end because I do not believe the psychological issues of chronic pain can be separated from the physical sensations and the behavioural activity that are linked to pain.

SOME UNDERLYING PRINCIPALS

- *Pain is real and is a mind and body phenomenon.* People without chronic pain may doubt that the sufferers pain is real and sometimes people with chronic pain begin to wonder themselves whether their pain is real. In part this arises from a common confusion over the difference between chronic pain and acute pain. A useful way of approaching the whole issue of the reality of pain, which is a very complex philosophical question, is to assume that when people have pain it is both a bodily phenomenon and affects their "mind".
- *Chronic pain is very different from acute pain.* We all learn about acute pain as children, we fall on gravel and hurt our knee, it bleeds and as we recover physically the pain gets less. This is our model of our word pain. Chronic pain is very different. Firstly, it goes on for a much longer period, often a three month cut-off is used. Second, the pain can continue irrespective of the damage that is causing the pain. Unlike acute pain there is not a neat relationship between the amount of damage and the level of pain, - rather pain fluctuates across days, weeks and sometimes over months and years. Chronic pain can continue for people long after the original damage has disappeared. An example of this is people who continue to have pain in, say, part of their foot after they have had a below the knee amputation. This principal is central because it brings home the idea that it may be useful to manage the pain in addition to or instead of addressing the medically underlying cause of the pain.
- *Management not cure. This principal follows from the above points.* Pain management means pain management, - it is not an attempt to cure pain. Instead it is a way of trying to control and regulate the experience of pain and minimise some of the secondary effects that arise from it.
- *Pain fluctuates with thoughts, feelings and biological factors.* This principal indicates that pain is a complex phenomenon determined by many different factors which interact in a variety of ways.
- *Relationships and society attitudes are relevant.* Because our thoughts and feelings play a role in our experience of pain it follows that the relationships we are in can also influence and be influenced by the experience of chronic pain. We may also react in a variety of ways to the attitudes of society to people with a disability, with a pain problem and so on.
- *Chronic pain syndrome is maintained by a series of vicious circles.* These vicious circles affect physical health, mood, activity and our self-concept and core beliefs about ourselves, the future and the world. More of this later.
- *It is useful to concentrate on what keeps chronic pain syndrome going.* This involves identifying and modifying the "maintenance factors". The emphasis is very different from delving into the past using the kind of psychological interpretation typical in specialist forms of psychotherapy. Nevertheless, it is also important to acknowledge that the beliefs and experiences which influence the personality may be important in the way we respond to our pain.
- Everyone is an individual but common patterns can be found. This principal is self-evident as anyone who has discussed their chronic pain with other people in pain will know.

SOME OF THE KEY VICIOUS CIRCLES

I am just going to summarise here some of the various vicious circles which can turn a pain problem into a pain "syndrome". In practice these vicious circles overlap and interact and it is difficult to separate them. It is useful, however to take them one by one because they highlight areas where changing your behaviour or the way you approach your life may be useful.

1 *Chronic pain affects posture and the patterns of pressure on the joints.* Changes in posture will in turn lead to an exacerbation of pain with the development of new pain problems. Of course, this

vicious circle is strongly affected by the direct impact of psoriatic arthritis.

2 *Increased disability leads to a reduction in activity levels.* Reduced activity levels however, will then in turn lead to possibly a greater degree of disability. Again this is self-evident to people with severe arthritic conditions.

3 *Increased chronic pain leads to a reduction of mood.* Following this, a reduction in mood often then leads to a level of pain being experienced as either more intense or more distressing/ or overwhelming. Needless to say mood may be affected by many other factors influenced by psoriatic arthritis or possibly by other influences in life that can affect the mood of anybody.

4 *Reductions in mood lead to reductions in activity.* Then, in turn, reduced activity seems to lead to a depressed mood. This vicious circle operates very powerfully in depressive conditions.

5 *Some of the above vicious circles can now be combined:* increased pain leads to a reduction in mood; a reduction in mood leads to reduced activity; reduced activity leads to a reduction in health status; and the reduced health status may in various ways exacerbate pain.

6 *Chronic pain affects relationships.* So far all the vicious circles have applied to people on their own. However, if you take any of the above vicious circles and summarise these in terms of increased personal stress or distress this often leads to conflict and/or withdrawal from people in your life. These changes in relationships can often lead to an exacerbation of the sense of personal stress and/or distress. Of course these relationship patterns are very individual and complex. They are made more complex if a person is a dependent on other people for aspect of care or needs to negotiate their ability to tolerate work demands, in the home or work place.

THE ROLE OF THOUGHTS AND BELIEFS

Up until now the factors considered have been either physical or behavioural. However "thoughts", "our minds", "the way we see the world" make a huge impact on everything that has been described so far. To take one simple example, changes in mood lead to changes in our thoughts and changes in thoughts then affect our mood. A common example of this is that when people are low in mood they tend to have negative automatic thoughts about themselves, the world and the future. These often quickly pass through one's mind, occasionally doing so in the form of images. Typically people may have thoughts like: "I am useless", (a negative thought about the self), "nobody cares", (a negative thought about the world), or "there's no point", (a negative thought about the future). Not surprisingly, these negative thoughts lead to reduction in mood and the more low you are in mood the more of these thoughts you get. The whole process is compounded by the role of memory since when people are low in mood they spontaneously recall more aversive memories. Typically the cycle of mood and thoughts then impacts on activity, relationships and choices.

OVER TIME DAY-TO-DAY THOUGHTS CAN LEAD TO CHANGES IN OUR LONG TERM BELIEFS ABOUT OURSELVES AND THE WORLD AND OTHERS

Unhelpful beliefs may become consolidated and reinforced and these then underpin the availability of even more aversive thoughts on a day to day basis. One example of this would be the very powerful thought of feeling helpless and unable to influence ones life "nothing I do can make a difference". Over repeated months and years the "habit" of thinking "what's the point" and "nothing helps" may become entrenched with the overriding belief that one is helpless to change one's situation.

The kinds of thoughts and the affects they have on our mood vary. Some key typical patterns of thoughts of people with chronic pain are as follows:

Hopeless thoughts, eg "there is no point" leads to depressed mood and potentially to despair.

Self-attack thoughts, including the idea of not being socially acceptable, lead to the emotion of shame.

"Should" thoughts often lead to making unnecessary choices or judgements about ones own behaviour or others and thoughts about **anticipated adversity** lead to increased anxiety and avoidance situations.

SOME INTERVENTIONS WHICH HELP

Up until now this series of mutely reinforcing factors may leave readers somewhat helpless and depressed! How can one break though these patterns? Well here are some suggestions. As you will see they are by no means all psychological in the narrow sense of the word nor are they "high tec". They are, however, very hard to implement in practice.

- *Exercise/activity.* This is extremely important but be sensible and follow the advice of physiotherapists and doctors. Generally though staying active over the years and decades will probably be the single most important approach to reducing your long term pain and disability.

- Pacing activity. Pacing goes with the above. The rules of pacing are very simple but putting it into practice can be extremely difficult. The major issue here is that people on a "good day" tend to do too much with the result that they suffer on the following day, and are more inactive. Not surprisingly, on the next good day they again tend to do too much. It is extremely difficult to reduce activity when one feels able to do more. However, reducing the activity on days when one if feeling good means that the overall activity level may gradually increase.

There are more complex ways of implementing pacing which involves timing ones "activity level tolerances" for key activities like standing, walking and sitting. To do this effectively one needs to take the average of three or four timings across the day or across a couple of days. This average tolerance level time then needs to be divided by half and the result of that is the "activity tolerance level" (this is also sometimes called a "baseline"). This final halved average time should then be the guide for managing all your activities of daily life. It is extremely frustrating to do this, but in the long term can lead to greater activity level and a reduction in cycling between periods of over activity and periods of under activity.

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PLANNING OF ACTIVITY
Planning is vastly underrated. By planning ahead one can find ways of breaking down over demanding activities or getting around situations which may seem insurmountable.

PRIORITISING
Because of reduced activity levels people tend to drop some of the fun/rewarding activities of life and end up with an overbalance of demands which are not very rewarding. It is very useful to prioritise, "namely do I really need to do this?" "do I need to do all of it?", "can I get someone else to do it?" etc, etc.

RELAXATION TECHNIQUES
Relaxation techniques are very useful for reducing muscle tension which arises from chronic pain and for resting the body after exercise. There is a range on the market and it is important to find a relaxation technique that suits you. It is important to say that relaxation is a skill which takes time to learn and it is worth sticking at relaxation for a least two weeks, daily., before deciding whether or not it is helpful. In order to maintain relaxation techniques it is very good to work them in as a daily routine when they soon seem to get squeezed out with the demands of busy lives.

EDUCATION KNOWLEDGE
Understanding chronic pain helps sufferers to feel less out of control and helpless.

SELF-MONITORING OF THOUGHTS, MOOD AND PAIN
Draw up a chart, monitor whatever is the problem, and the moment you start recording you will start to change what you are doing and become more aware of it. This is true for behaviours from eating chocolate bars, smoking cigarettes, doing too much activity or using your creams regularly. This is a low tech intervention which is extremely powerful and the only reason why people do not it is because it is quite hard to be disciplined to keep it up. However it does bring results. It also shows patterns and gives ideas for changing other aspects of your daily life.

SET GOALS FOR LEISURE AND PLEASURE
This notion goes with the idea of prioritising or if you have listed. If you have dropped leisure activities try and think of ways of getting them back, or think of new ones which you have never done before. Avoid saying "yes but.": it is very easy to talk oneself out of solving a problem because of the obstacles in the way. To get round such obstacles it is useful to plan with someone else who is supportive. If you have not got any ideas get a list of adult eduction classes and then you might find something you can do on a regular basis.

TEST OUT YOUR THOUGHTS
If you know what the negative thoughts are that tend to affect your mood and behaviour then you can start trying to test out whether they are accurate. For example, if you feel that there is no point in doing something why not test out and try it; if you feel you wouldn't achieve something why not test out and see if you can; if you feel something would be too painful to endure you may want to test that out. Of course, plan these "behavioural experiments" carefully in line with other medical advice. After you have completed them spend some time on what you may have learnt: even if they have not gone right it may be that there is some lesson there which can be useful for next time you try and implement a change.

CONVERT SHAME TO SELF-SUPPORT
This is easier said than done: shame is very powerful and people with chronic low back pain feel ashamed of their disability. Skin symptoms can exacerbate these feelings. These feelings may not be absolutely conscious but more linked to an underlying sense of low self-esteem, anxiety about "taking ones place in the world" and so on. Often linked to these emotions and sensations is a degree of self-criticism. Try and replace self-criticism with reassuring and encouraging self-talk. It really can make a difference. Think to yourself what would you say to somebody else who was feeling as awkward, embarrassed, critical of themselves; how would you encourage them, how would you encourage a child who felt like that? These are the ways you need to talk to yourself if you want to start to liberate yourself from shame and embarrassment.

GROWTH ACTIVITIES
Anything that is creative whether it is growing plants, making ceramics, doing cross-stitch - you name it - this is likely to be beneficial. These activities not only help people to feel a sense of achievement, but also to be absorbed in something other than their own physical ill health. Some people get the same experience simply from reading a good novel or listening to music. The idea is to find something that absorbes you emotionally, possibly spiritually and "takes you out of yourself" for a period.

FINAL COMMENTS
This is, as I said, a bit of a lightening summary. I hope that there are at least some points here that may be useful to you. If you want to pursue some of the suggestions around your thoughts and feelings I recommend the book "Mind Over Mood" by Padesky and Greenberg which is a self-help book on what is known as "cognitive therapy". A book called "Manage your Mind" by Butler and Hope is also useful and covers a range of other aspects of mental health. Some of the books on managing chronic pain listed below may also be useful, though do remember that most of these apply more to chronic back pain than to arthritic conditions. The major adjustment you may need to make is to really emphasise the importance of gradual changes in fitness and activity levels.

A final comment, all of the above should be put on hold if you are in a flair up of your condition in which case you need to slow right down, rest for a brief period, possibly increase medication use and take advise from professionals.

FURTHER READING

The Pain Relief Handbook
– *Dr Chris Wells & Graham Nown*
– Vermillion, ISBN 0-09-181371-9

Living With Your Pain
– *Annabel Broome & Helen Jellicoe*
– The BPS, ISBN 0-901715-77-8

Sex and Back Pain
– *Lauren Herbert*
– IMPACC USA
Tel No: 1-800-762-88-7720

Damian Gardner

NEW MEDICINES
REAL HOPE OR MERE HYPE?

DR ANTHONY WHITE

There has been an unprecedented series of apparent breakthroughs in the treatment of rheumatic diseases in the past three years without parallel since the introduction of cortisone into the treatment of rheumatoid arthritis more than half a century ago. Because psoriatic arthropathy is much less common than rheumatoid arthritis it has been difficult so far to organise trials of new medicines for this disease because the manufacturers for the most part have not felt it worthwhile to conduct trials for what it to them a small market. However happily this is beginning to change. Also the British Society for Rheumatology has put psoriatic arthritis very high up its list for new research resources.

Many of the medicines which are used to treat rheumatoid arthritis have been found to be of value in psoriatic arthritis too. Indeed one went in the opposite direction, methotrexate, starting off much earlier as a treatment for psoriasis and for the arthritis associated with it and later being adopted for use in rheumatoid arthritis.

NOVEL ANTI-INFLAMMATORY DRUGS

There are three main categories of new remedies. The well-established non-steroid anti-inflammatory drugs have all suffered from some problems, the ill-effects on the stomach and sometimes the small intestine, a tendency to precipitate asthma in sufferers from that condition and a tendency to cause fluid retention which worsens heart failure and high blood pressure. We now have additional agents referred to as Cox-2 inhibitors. The older drugs inhibit the enzymes, cyclo-oxygenase 1 and 2, whereas progressively newer remedies have sought to inhibit Cox-2 only, hence their name. Of these the two drugs which make the separation most completely are rofecoxib(Vioxx) and celecoxib (Celebrex). How well do these shape up in the heat of the day in ordinary clinical rheumatology practice outside the rareified atmosphere of the double-blind clinical trial? For trials patients are very carefully selected and must not have some of the risk factors which are encountered in everyday practice and for which, of course, these drugs are designed to be better than the older ones.

ORIGINAL AND BEST?

In this country Vioxx appeared first with a licence for osteoarthritis only, but as predicted rapidly became used for other kinds of arthritis too. In osteoarthritis of moderate severity, patients were fairly pleased with the results and very few complained of indigestion. However a number of patients complained that, although the drug did not upset them, it did not work in relieving their pain and this was the more obvious when it began to be used for inflammatory arthritis including that of psoriasis. Gradually it became apparent that there were some patients in whom this drug tended to cause at least as much fluid retention as some of the older ones and withdrawal of the drug has been necesssary in such cases. Trials compared it with quite high doses of ibuprofen (Nurofen) so that, not surprisingly, it came out better in terms of indigestion and gastric bleeding but this does not mean it is devoid of a tendency to cause such symptoms and certainly we do see them in everyday use. Celebrex was licensed later but for a much larger range of types of arthritis. It seems to be at least as good as Vioxx from the point of view of not causing indigestion and there is some evidence that it may be less likely to cause fluid retention. There is shortly to be a trial directly comparing these two drugs head to head, with particular respect to fluid retention and elevated blood pressure, so eventually we will know the answer to this.

BATTLE IN THE MARKET PLACE

There is obviously bound to be intense rivalry between the manufacturers of such similar products and a good deal of propaganda is put out on all sides. For instance, someone went through the figures very carefully with one of the Vioxx trials and put out the message that there was an increased number of heart attacks in those treated with it, compared with other drugs. What no-one seemed to point out at the time was that if you reduced the tendency for patients to have gastric bleeds, one of the ways you do this is by reducing the effect on platelet stickiness. The purpose of platelets is to block up little punctures in the walls of blood vessels. Aspirin-like drugs, which inhibit Cox-1 as well as Cox-2, protect against heart attacks by making the platelets less likely to stick and

therefore the blood less likely to clot. As they say, there is no free lunch, and you probably cannot have the advantage of reduced gastric bleeding and reduced incidence of heart attack at the same time with the same drug, or at least not with the ones available at the moment, although this may be eventually possible. At the same time, unfortunately, it is the case that neither of these new products are an improvement on the older ones from the point of view of induction of asthma, although no-one seems actually to have been mentioning this, and people have been given the feeling that the drugs are better all round. There is no evidence that either of them are more effective than previous ones from the point of subduing pain and swelling and they are only better from the point of view of not upsetting the stomach.

A UNIQUE MOLECULE

The second category of important medications is occupied by only one drug, Leflunomide, which has been little tried in psoriatic arthritis but the subject of a number of successful trials in rheumatoid arthritis. This is a very novel drug chemically, and this carries inherently the disadvantage that, although the trials have shown up very few major problems so far, we have no knowledge at all of what the long-term rare side-effects may turn out to be because it is insufficiently similar to other drugs for us to know what to look out for. Experience with this drug in this country is still not extensive and we do not know whether using it for psoriatic arthritis will be more or less successful than with rheumatoid arthritis. My own personal experience is very limited with it so far but the first patient with psoriatic arthritis to whom I have given it and who was not responding to a mixture of other powerful drugs, does seem to be responding better to this new one, so there is clearly a very strong case for a properly conducted trial of it in this disorder.

ANTI-TNF ALPHA

The third and major group of drugs which are the focus of most interest at the moment are those which act on tumour necrosis factor alpha, which could be described as the conductor of the cytokine orchestra. Cytokines are chemical messengers between certain types of cells which keep the inflammatory process going and as a result of a great deal of research, much of it done in the UK, under the direction of Professor Maini at the Kennedy Institute of Rheumatology, an antibody to this agent has been developed for clinical practice. There has recently been published a study of its effectiveness in psoriasis and it is very impressive in clearing even stubborn plaques of psoriasis within a surprisingly reasonable period of time. There are a number of trials of rheumatoid arthritis which show it to be effective even at a level of 70% improvement, according to the American College of Rheumatology criteria, if a sufficient dose is given. The problem is the cost and the fact that it has to be given by intravenous infusion. The NHS estimates the cost at £10,000 per year, so that we have the same problems in obtaining it as we have in trying to treat patients with gamma-interferon for their multiple sclerosis and postcode prescribing is the order of the day at the present time.

FORTHCOMING TRIAL IN PA

There is to be a proper double-blind controlled study of this biological agent, known as infliximab (Remicade) set up by the manufacturers very soon and we hope to be able to recruit patients for this, but they will initally be only those with very severe psoriatic arthropathy who are not responding to methotrexate. When this drug is used it is used in combination with low-dose methotrexate, so that those who cannot take that drug will obviously be unable to participate in the trial.

There are obviously side-effects with this treatment and the elimination of patients who have had tuberculosis or who may have any deep-seated chronic infection, does seem to be an important move in selecting those who should be treated with it. A wide range of minor side-effects have been reported, the most common being a flu-like feeling which follows the infusion and sometimes allergic reactions and this is the reason why it is given by infusion only under hospital supervision, usually as a day-case.

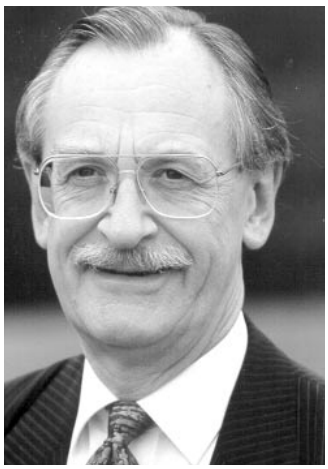
TRIALS AND TRIBULATIONS

The alternative to Remicade is etanercept (Embrel), already shown effective in trials for psoriatic arthritis, this works in a similar manner to Remicade although it structure and precise mechanisms of action are somewhat different. This is given by subcutaneous injection in the same way that diabetics give insulin to themselves, which obviates the need for hospital attendance and needs to be given much more frequently and patients have to adapt to self-injection. The range of side-effects is slightly different and since I talked about these medicines in the conference last year, there have been rather more problems with blood count abnormalities and particularly there has been reported a clinical picture resembling multiple sclerosis, which is rather worrying. The American authorities believe that what one is seeing with such patients developing

neurological abnormalities, is the unmasking of unsuspected mild multiple sclerosis which the treatment worsens. This would argue for careful scrutiny of patients for such an underlying problem before commencing the treatment. We are not sure whether this is really the whole explanation and demyelination, the process involved in mutiple sclerosis, has just been listed as an additional complication of the treatment itself in the etanercept literature, which would make one feel rather more cautious than before about prescribing this agent, the cost of which is very little different from that of Remicade. In addition there have been recurrent supply problems so that there is uncertaintly about how many patients can be supported long term with its use.

There remains the problem of how we are to persuade the Department of Health of the importance of giving such treatments to severely affected patients and surely the strongest argument must be the huge saving in cost if severe disability can be avoided, bearing in mind the huge expense incurring on carers, housing adaptations and other less effective medications used to try to fight the disease. The British Society of Rheumatology is collecting information about the policy of every health district as to which are providing treatments of this type and will be lobbying for changes in the priorities given to different types of treatment in favour of these medicines. Our support in this matter, as individuals and as an association, is vitally important.

If we can succeed there is real hope.



DR ANTHONY WHITE

NEW FORUM ENABLES PSORIASIS PATIENTS TO TELL THE PHARMACEUTICAL INDUSTRY WHAT THEY WANT OUT OF THEIR TREATMENTS

Psoriasis patients from associations in different countries meet to discuss their needs and opinions about psoriasis treatments in an exciting new forum, InterPSO.

InterPSO: The International Network of People with Psoriasis is a new psoriasis patient forum. It's aim is "to provide a forum for mutual and collective decision-making out of which can come a stronger voice for patients with psoriasis" says David Chandler, chairman of InterPSO, psoriatic patient and co-founder of the Psoriatic Arthropathy Alliance (PAA). **InterPSO** is a joint, international initiative between the PAA and Galderma Laboratories.

The presence of Galderma as an impartial observer creates a unique opportunity for patients to convey their needs directly to the pharmaceutical industry. The participants shared their experiences with regard to psoriasis and psoriatic arthritis with the patients from the other countries and also expressed their opinions concerning present and future treatments.

The first InterPSO meeting took place in Nice, earlier this year. Bringing together psoriasis association representatives and patients from the UK (PAA - Psoriatic Arthropathy Alliance), the Netherlands (PVN - Psoriasis Vereniging Nederland) and Germany (Deutscher Psoriasis Bund). Professor Ulrich Amon of the Psorisol centre in Hersbruck was also present.

Psoriasis is a chronic disease which cannot be cured at present. As a result, it can safely be said that for those who suffer from it and who need to follow life-long treatments, quality of life becomes of the utmost importance. The InterPSO meeting helped to raise the issue that current psoriasis treatments are often impractical, time-consuming and can be expensive, which results in a poor quality of life for the patients. It is widely felt among psoriasis patients that pharmaceutical companies and healthcare professionals do not understand nor take into account the importance and impact of treatments on quality of life and that there is a need to better educate healthcare professionals about the disease and its therapies. One of the aims of InterPSO is, therefore, *"to enable patients' views to be heard at an early stage in treatment development and so will lead, it is hoped, to new treatments based on patients' needs"*, says David Chandler.

The InterPSO meeting allowed patients to learn about and compare each other's experiences of living with psoriasis, both on a personal and cultural level. All agreed that there is much misunderstanding and misinformation about the disease resulting in stigma and discrimination, highlighting the need to raise awareness about the disease internationally. There was extensive discussion on treatments, both existing and future, topical and systemic and packaging and application.

Overall consensus:-
The attributes most looked for in a topical treatment:

- ✦ good efficacy
- ✦ low irritation
- ✦ low number of applications

Patients would like to see these attributes taken into account in the development of new therapies. This could help to improve their quality of life.

Galderma, who is supporting the InterPSO meetings with an educational grant, was keen to find out from the patients precisely how they feel the pharmaceutical industry can help them. As Thierry Rollin, strategic marketing manager at Galderma, explains *"I think it is key that we, who are responsible for the research and development of products, take patients' views into account as this can only help to lead to better adapted therapies".*
Apart from finding a cure, it was agreed that the industry can help :-

- ✦ By listening to and understanding the end user of their products, in order to develop more realistic treatment regimens.
- ✦ By helping patients' associations to produce more information for patients.

Perhaps most importantly in the short-term, however, patients would like the pharmaceutical industry to ensure that the information in patient leaflets is accessible to all:-

- ✦ Easy to understand
- ✦ Explaining all possible side effects
- ✦ To include details of further sources of information

"In working together on the development of InterPSO, the PAA and Galderma see their key role as working with patients for patients in partnership with industry", explains David Chandler. The next InterPSO meeting is due to be held next year when representatives of other associations will be invited to attend.

St Thomas' Hospital *Research*

At the St. John's Institute of Dermatology within St. Thomas' Hospital, London, research has been undertaken into the possible genetic causes of a range of skin diseases for over five years. At present we are concentrating on 'late onset' psoriasis, and we need to find individuals whose psoriasis did not appear until after the age of forty. The point of this work is to try and identify any inherited material (genes) that might possibly lead to this condition, hopefully increasing our understanding of psoriasis in general.

We preferably need people who have been seen by a dermatologist, and who live in the South East of England. The research involves completing a questionnaire about your psoriasis and taking a blood sample. This once off 10 ml. (about 2 tablespoons) blood sample can be taken at Lewisham Hospital or at St. Thomas', at the same time as filling in the questionnaire. The whole visit would take approximately thirty minutes. Are you in a position to help us? We are able to offer travel expenses for those in the South East of England.

For more information please contact:

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The Blue Lagoon and Psoriasis

The Blue Lagoon

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BIOLOGIC TREATMENTS
New Advances for Psoriasis

WHAT ARE BIOLOGIC TREATMENTS?

New 'biologic' treatments that offer a new direction for treating a diverse range of diseases are currently being researched and developed through the use of recombinant DNA technology. Each cell in our body contains DNA - a substance containing the blueprint (or genetic code) for the structure and function of each organism. The genetic code is made up of genes, unique sequences of DNA, each one coding for a different protein in the body. Using new DNA technology, researchers can identify elements that are important in a disease and use a copy of the relevant gene or genes to produce specific protein molecules that could be used as treatment. These treatments are made up from proteins that are naturally found in the body which is beneficial for the safety of the treatment. Although biologic treatments use copies of genes to produce the therapeutic molecule, they do not involve modifying the patient's genes.

The term 'biologies' describes a diverse range of therapeutic products. These include proteins such as monoclonal antibodies, cytokines (interferon, interleukin), and tissue growth factors.' These cutting-edge therapies may be able to provide substantial improvements on the current "chemical" treatments available, offering improved levels of efficacy and safety.

THE HISTORY OF BIOLOGIC TREATMENTS

In the mid-1970s Herbert Boyer at the University of California in San Francisco used knowledge of the sequence of amino acids in insulin to synthesise a copy of the gene which produces insulin. He inserted the gene into some E. coli bacteria. The E. coli then proceeded to produce the exact same insulin as would be produced normally in the human body. This was the first use of recombinant DNA technology to produce a therapeutic molecule. After becoming commercially available in the early 1980s recombinant human insulin revolutionised diabetes treatment. Since the 1980s, similar technologies have been used by companies to discover and mass produce exact copies of many other human proteins.

This technology has already been used to manufacture hormones for metabolic disorders, to treat conditions such as anaemia, as well as to produce numerous vaccines. Future applications of this technology include treatments aimed at tackling a variety of diseases, including skin conditions, such as psoriasis. Psoriasis involves a series of reactions associated with the immune system, this means that a biologic therapy could be developed which targets one of the reactions involved. Such a therapy would modify the series of reactions that cause the disease itself, rather than simply treating or reducing the symptoms and could therefore provide patients with long term disease-free and treatment free periods.

The recent completion of the mapping of the human genome will enhance current research into the proteins that can cause or inhibit certain diseases, which indicates the vast potential of biologic treatments.

THE FUTURE OF PSORIASIS TREATMENT

Treatments which are both fully effective and safe are not yet available for moderate to severe psoriasis. The treatments currently offered were not specifically developed for psoriasis and have serious safety issues with disabling or even life threatening side effects. The risk of such side effects may mean that patients are unwilling or unable to use the medication. For example, among the systemic therapy options, cyclosporine is an immunosuppressant with renal toxicity, which can cause hyperlipidemia and hypertension. Methotrexate is an antimetabolite which is often used in oncology treatment, and it has toxic effects on the liver and bone marrow. Acitretine acts on cell regulation, but has teratogenic properties and can cause hyperlipidemia, skeletal abnormalities, and hair loss.

Future treatments that are currently being developed include those that can selectively target the underlying cause of psoriasis. One area of current research is that into biologic treatments - therapeutic proteins manufactured using genetic engineering. In psoriasis, it is hoped to develop biologies that can target a specific agent or mechanism implicated in the cause of the disease, such as the subset of T cells of the immune system which are involved in the development of psoriatic symptoms. Such a treatment would modify the series of reactions that cause the disease itself, rather than simply treating or reducing the symptoms. The use of more selective targeting should result in a more effective treatment without the side effects of current therapies.

References

1. SkinCare Campaign - http://www.skincarecampaign.org/directory of skin disease/psoriasis
2. Psoriasis Association Factsheet: What Is It? April 2000
3. National Psoriasis Foundation - http://www.psoriasis.org:about psoriasis:types and severity
4. Feldman et a],. Advances in Psoriasis Treatment: Dermatology Online Journal: 6(1); page 1
5. Durbertret, L., Strategy for Treatment of Psoriasis: Systemic Treatments. The Journal of Dermatology: 25;788-792 (1998)
6. Sterling,S. Methotrexate Hepatotoxicity. Rheumatic Disease Clinics of North America: 23(4):883-915 (1997)
7. Warwick et al, Consensus Workshop on the Toxic Effects of Long-Tenn PUVA Therapy. Arch Dermatology: 134:595-598 (1998)
8. Centre for Biologics Evaluation and Research - http://www.fda.govlcber/index.htmi
9. National Psoriasis Foundation - http:l/www.psoriasis.org:about psoriasis:types and severity
10. National Psoriasis Association Press Release: September 1998
11. Biogen Inc. October 2001

KANGAL FISH SPRINGS: HISTORY

The springs were a kind of reed-bed until 1917. By chance a shepherd who was wounded on his foot saw his wound healed by the water of the spring.

This fact got the attention of the public and primitive pools were built in the late 1950s. In the 1960s the springs were taken over, by the local administration of Sivas and several lodging facilities were built.

The Kangal Springs are now famous around. The world and known for their ability to cure psoriasis, which up to now can only be treated medically. Their springs were generally used as a resort place and are at the disposal of patients suffering from this condition.

The springs were put to tender in 1996 by the local administration for a long-term operation contract. The area has now been turned into-a modern therapy centre for psoriasis patients.

The pools have concrete walls and floors paved with pebbles and drain into a stream which runs between buildings. The water itself remains at a constant temperature of approx 35˚C throughout the year. It has features which make it drinkable too.

HOW IT WORKS

There are three types of fish that are used in the process. A school of fish surround the body and lick it. The initial sensation is a pleasant one, the feeling of micro- massage, is then replaced by a tingling sensation over the skin. Massaging techniques are used by younger fish.

ACCESS:

There are flights to Sivas from Istanbul and Ankara- The springs are located about 98km from the city centre of Sivas.

RULES TO BE OBSERVED BY THE PATIENTS

1. Drink at least 3 glasses of healing water before breakfast.
2. Enter in the pool after breakfast.
3. Therapy starts through healing water rich in minerals and healing fishes.
4. The healing fish, unique in the world, live at a, water temperature of 37˚C (scientifically no fish can live in water with temperature exceeding 28˚C). There are 3 different types of this fish.
5. Along with the healing water containing-the selenium (known to be most elective in curing dermatological diseases) the healing fish start the healing process.
6. Enter the pool twice a day, staying in the water for eight hours in total.
7. No alcohol should be taken during the therapy.
8. No medicine for curing psoriasis should be taken during the cure.
9. The therapy must continue for 21 days; a stay of 8 hours per day in the pool must be observed.
10. Psoriasis affected patients observing these rules-leave the springs with total healing.

Note: The concentration of selenium, the friendliest element for the skin, is 1g per litre.

LODGING FACILITIES:

The springs contain hotel facilities-in 4 buildings, 5 pools, one, being in half-Olympic size, 16 private baths, a restaurant, a market, a coffee shop and a playground for children. Parking lots are available for caravans and picnickers.

Information kindly supplied by:
Blue Moon Travel Services
Blue Moon House
13 Sutton Parade, Church Road, London, NW4 I RR

Tel 020 8202 2028 Fax 020 8202 2661
www.bluemoontravel.co.uk
Email: enquiries@bluemoontavel.co.uk

Sources: Blue Moon Travel
Abridged version of an article taken from
www.tuvpo.com/fish/dfishe.html
by Dr Levent Undar

The Hydromols - two helping hands to reduce moisture loss

Hydromol Emollient

(light liquid paraffin, isopropyl myristate)

- always used with water - in the bath, infant bath, shower or as a sponge-down
- easily dispersed in the water
- cosmetically acceptable
- easy-to-clean the bath or shower-base after use
- free from fragrances, preservatives and lanolin

Hydromol Cream

(sodium pyrrolidone carboxylate)

- always apply after bathing, having patted the skin dry
- double-action, hydrating cream
- cosmetically acceptable
- free from fragrances and lanolin

Further information available from: Quinoderm Limited Manchester Road Oldham Lancashire OL8 4PB

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Copies of current and back issues of PAA publications are available at the costs set out below. PLEASE indicate which publication(s) you require, and return this form with your remittance. **Postage** is free on chargeable items but a suggested donation of **£1.00** would be gratefully accepted (**for free publications enclose a 6" x 9" SAE**) to:

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All payments should be made payable to the
PSORIATIC ARTHROPATHY ALLIANCE

Publication title	Issue no.	Publication Date	Unit Cost	Qty. Required	Sub total
Newsletter	7	September 1996	£3.00		
Skin 'n' Bones Connection	7	December 1996	£3.00		
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Clinical Trials booklet	-	2001	Free		
Nails Psoriasis leaflet	-	2001	Free		
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Psoriatic Care Fact File- 26 fact sheets	1st edition	1998	£7.50		
Psoriasis - A Guide To Emollients	-	1999	Free		
PAA -The Birth of a Charity A4 pamphlet	1st edition	1996	50p		

The follow non-PAA publications are also available by sending a 6"X 9" SAE.

Key facts about psoriasis booklet	-	-	£1.50		
So You've Got Psoriasis booklet	-	-	£3.50		

+ suggested postage donation	**£ 1.00**
TOTAL COST £	

Name _____ Title _____ Telephone _____

Address _____

Postcode _____ Country _____

Please allow 28 days for delivery. Thank you.

This information is supplied by the Psoriatic Arthropathy Alliance. A national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder, psoriasis. Registered charity no 1051169.
Further information can be obtained by contacting:
PAA PO Box 111 St Albans Herts AL2 3JQ . Tel: 0870 7703212 Fax: 0870 7703213. E-mail info@paalliance.org
A Company limited by guarantee registered in England no: 3055414.
Registered office: Faulkner House Victoria Street St. Albans Herts AL1 3SE.

Skin'n'Bones Connection

TO REGISTER OR SUBSCRIBE TO SKIN 'N' BONES CONNECTION

PLEASE FILL IN AND RETUREN TO PAA

SUBSCRIPTION FORM

Please complete the following clearly:-

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First Name(s) .....

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I would like to subscribe to Skin 'n' Bones Connection ☐

UK - £12.50 (including postage and packing) ☐

Overseas: £20.00 (including Air postage and packing) ☐

I enclosed my annual subscription fee of: £ .....

I would like to make a donation of: £ .....

PLEASE MAKE CHEQUES PAYABLE TO:
"PSORIATIC ARTHROPATHY ALLIANCE" Thank you.

Signed: .....

Date .....

QUESTIONNAIRE

(Completion optional and confidential)

SECTION 2

Where did you hear about the PAA? .....

.....

Occasionally we are supplied with product information and samples, as a would you like to receive these in the future? YES/NO

Would you be willing to enter into confidential surveys relating to psoriatic arthritis and/or psoriasis? YES/NO

How long have you had PA? .....

How long have you had Psoriasis? .....

Areas/joints affected? .....

Medication tried (please list) .....

.....

Current Medication taken? (please list) .....

.....

Any family history of PA or psoriasis in your family? .....

Other information:
Are there any websites or publications you think would be of interest to our readers? (please list)

.....

.....

.....

Signed .....

Date .....

All information given on this questionnaire is treated with the strictest confidence and will not be given out without the prior permission of yourself.

Thank you for your time and co-operation in the completion of this form.

What do I get if I Register?

- Opportunity to take part in patient focus group meetings
- Receive relevant mailings via PAA (such as surveys, new product information etc.)

What do I get if I subscribe?

Benefits of becoming a subscriber to Skin 'n' Bones Connection are:

- Two issues per year (two back issues immediately)
- Other mailings during the year about PAA activities and events.
- Free new information leaflets when produced
- Publications list
- Automatic inclusion to the PAA Register

PLEASE RETURN TO:
Subscriptions
Psoriatic Arthropathy Alliance
PO Box 111
St Albans Hertfordshire
AL2 3JQ UK

Letters

Dear PAA
May we take this opportunity to introduce our company Wings on Wheels. We operate group holidays for disabled people, their carers, friends and relatives both in the UK and worldwide.

Wings on Wheels' management escort our groups and we welcome people with physical disabilities. Wherever possible we use adapted hotel rooms and transportation, all air flights are by scheduled services to ensure the maximum comfort and assistance to the traveller. We operate interesting itineraries with a mixture of tours and plenty of free time included. We also include most meals, some of which are taken at outside venues obviously,with return transfers.

We can tailor make group holidays for your members according to their specific needs.

Further details:
www.wingsonwheels.co.uk

Ray Swart

5 LECHFORD ROAD
HORLEY
SURREY
RH6 7NB
Tele no 01293 437881
FAX 01293 437883

DEAD SEA MIRACLE ONE YEAR ON

Dear PAA
Twelve months ago I produced my first article on the benefits of the Dead Sea on my psoriasis. I produced it somewhat prematurely in that I have stated that I had received a skin clearance of 95% which of course is great.

However, what I hadn't realised at the time of writing my article was that my lesions would continue clearing over the next few weeks. Within two months of being home I cleared 100% and remained clear for seven months. Small lesions started to reappear mid December 2000.

By May this year I had a few minor patches on my elbows, knees, ankles and buttocks but nothing as severe as the previous year. I had already been told about the accumulative benefit of the Dead Sea and now I have experienced it first hand in that my total lesions were approximately a quarter of those I had the previous year when I first visited the Dead Sea.

I'm sure the cost can look a little daunting. For three weeks half board in a top hotel with flights and transfers cost me this year £1,699. This could have been reduced to £1,239 if I had shared. However, to be totally free if lesions and not have to use damaging steroids, probably ever again, then it's worth every penny to me and, like my Danish friend, I'll be back year after year as I never want to be a victim of this wretched condition again.

Ron Allsop

GERMAN MEDICINE NET

Dear PAA,

Re: A New Option for the Patients You Advise: Diagnosis, Screening and Treatment in Germany

We know that regrettably the British health system is currently not able to help all patients in Great Britain at short notice. German Medicine Net would like to offer its help with bridging the gap in medical treatment that currently seems to exist in Britain.

German Medicine Net is a coalition of German hospitals, consultants and outpatient surgeries aiming to offer foreign patients very good state of the art treatment as well as screening and diagnosis at a fair price. For most common operations as well as screening and diagnosis facilities there is virtually no waiting time.

We offer not only inpatient treatment, but also rehabilitation and a wide range of other services including outpatient operations. Thanks to modern minimum-invasive methods the costs for the latter often compare very favourably to traditional operating methods requiring extensive hospital stays.

Please note that we will also be able to find highly specialized doctors and hospitals for you who may be able to offer advice and help with difficult cases or rare complaints.

The recent decisions of the European Court and your Secretary of Health, Alan Milburn, opening the way for the treatment of British patients abroad are an expression of a general humane vision of mutual solidarity and help amongst close neighbours.

It is along these lines that we are offering help to you and the men, women and children you represent and advise. We would be very happy to be able to open up new perspectives and options to them so that they may be able find help and healing. We will do everything to make the whole procedure of seeking medical advice and treatment abroad (contacting specialists, travel arrangements, translations etc.) a pleasant, positive and above all health-promoting experience for them.

Please do not hesitate to contact us to discuss for further details.

Best regards

Yours sincerely
Hans Finck (Managing Director)

GERMAN MEDICINE NET CMBH
Email: HYPERLINK
mailto:contact@germanmedicine.net
contact@germanmedicine.net
HYPERLINK http://www.germanmedicine.net www.germanmedicine.net
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Skin'n'Bones Connection

Educational News

UNIVERSITY OF WALES
L A M P E T E R
Centre for Educational Development
Incorporating
Personal Development Unit and
Unit for Voluntary Sector Studies

1·8·2·2

PRIFYSCOL CYMRU
L A M P E T E R
LLANBEDR PONT STEFFAN
Canolfan Datblygiad Addysgol
Yn Cynnwys
Uned Datblygu Personol a'r
Uned am Astudiaethau Sector Wirfoddol

Re. The Certificate in Interpersonal Skills for Volunteers by distance learning

If you or your organisation is looking to accredit its volunteers' skills, you might be interested to know about the Certificate in Interpersonal Skills for Volunteers by distance learning. The Certificate in Interpersonal Skills for Volunteers was awarded a Queen's Anniversary Prize for Higher and Further Education in 1998.

Launched in February 1996 as a direct response to requests from the voluntary sector for a course to value and accredit the skills of volunteers, the Certificate in Interpersonal Skills draws on volunteers' experience of working with people. By having its basis in experiential learning, no formal academic qualifications are required for entry onto the course. Entry is based on having a minimum of 6 months' experience, working with people in a caring / supportive environment. Please note that due to either fee waivers or bursaries, the course is free to all prospective students resident in the UK and EU.
Areas covered by the Certificate in Interpersonal Skills include confidentiality, working with groups, communication skills, listening skills, stress management, negotiation, dealing with aggression, problem solving, working with professionals. Aspects of personal development and equal opportunities are also explored.

The course helps to raise volunteers' confidence as well as develop a greater awareness and level of their interpersonal skills. It also provides a comprehensive introduction to distance learning and study skills. Assessment is by assignment only and tutor support for students is available Monday - Friday, 9 am to 5 pm. At the end of each module, students submit an assignment reflecting the course material and drawing on their experience. On successful completion, students are awarded 40 credits at University level 1 and many students choose to continue their studies with us following on from this course.

In addition to the Certificate in Interpersonal Skills for Volunteers, there is an exciting programme of courses available, relating to the voluntary sector, including Managing Volunteers, Research Methods, Introduction to Psychology, Structures in Organisations and Experiencing Disability.

Please do not hesitate to contact either Deryn Wilcox or Clare Fisher by telephoning 0 1 570 424785 if you would like to receive a handbook or discuss the course(s) in more detail.

DIARY DATES
PAA Conference
2002
14th September
Woburn Safari Park
Bedfordshire
9.00am 4.30pm