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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NHS National Institute for Health and Clinical Excellence

On 1 April 2005 NICE joined with the Health Development Agency to become the new National Institute for Health and Clinical Excellence (also to be known as NICE). NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE guidance is developed using the expertise of the NHS and the wider healthcare community including NHS staff, healthcare professionals, patients and carers, industry and the academic world.

Clinical guidelines are recommendations by NICE on the appropriate treatment and care of people with specific diseases and conditions within the NHS. They are based on the best available evidence. Guidelines help health professionals in their work, but they do not replace their knowledge and skills.

What NICE calls technology appraisals are recommendations on the use of new and existing medicines and treatments within the NHS, such as:

- medicines
- medical devices (for example, hearing aids or inhalers)
- diagnostic techniques (tests used to identify diseases)
- surgical procedures (such as repairing hernias)
- health promotion activities (for example, ways of helping people with diabetes manage their condition).

NICE bases recommendations on a review of clinical and economic evidence. Clinical evidence measures how well the medicine or treatment works. NICE also takes account of economic evidence, which is how well the medicine or treatment works in relation to how much it costs the NHS – does it represent value for money? NICE acknowledges that something can be both expensive and value for money.

The NICE Research and Development (R&D) programme promotes and commissions research, with the aim of raising healthcare standards to the highest possible levels within the NHS. The programme focuses on:

- working with research organisations, patients and other partners to explain NICE's research needs
- using research to improve the methods that NICE uses to develop guidance
- using research to find out how NICE can help the NHS implement and apply NICE guidance better.

NICE guidance is produced to improve the quality of care provided to patients.

NICE is committed to producing guidance for the NHS that:

- Meets the needs of patients, carers and the public.
- Involves patients, carers and the public in its development.

Patient and carer involvement

Opportunities for patient and carer involvement exist at a number of levels:

- National patient/carer organisations are consulted at all stages of guidance development.
- All NICE committees and working groups include at least two lay members with an interest in patient and carer issues.
- All NICE guidance is provided in formats written for patients, carers and the public.
- From time to time, the Institute commissions additional work on patient and carer views to inform the development of its guidance.

The NICE Patient Involvement Unit provides information, support and training to patients and carers (both organisations and individuals) that have an interest in NICE guidance.

Public involvement

Although NICE decisions are based on evidence provided by clinicians, researchers and patient experts, they are set against a background of social values and judgements. It is therefore important to take into account what the public thinks about key issues that inform the development of guidance NICE issues on the use of treatments and the care that people can expect in the NHS.

For this reason the Institute set up a Citizens Council, with 30 members drawn from all sections of the population, to have their say on wider issues. Council members reflect a cross section of age groups, social circumstances, ethnic backgrounds, regional differences and abilities. Their views and opinions provide a backdrop against which NICE and the independent Committees that advise it can develop their recommendations.

The Citizen's Council brings the views of the public to NICE decision-making. The Council meets twice a year in 3-day sessions, and members deliberate on questions put to them by the Board of NICE. Meetings are open to the public.

NICE will play an important role in the future of all patients, particularly those with a chronic long-term illness. There are currently three psoriatic therapies being appraised by NICE, etanercept and infliximab for psoriatic arthritis and etanercept and eflazimab for psoriasis, these drugs are classed as anti-TNF therapies and will play a major role in the treatment of the severe disease in the future. Both appraisals are expected to be published in January 2006. Further details about NICE can be found at www.nice.org.uk

Cover picture: Goonhilly Satellite Earth Station - David Chandler

Experts and MPs call for improved access to treatment.

MPs gathered at the House of Commons in April as experts and patient groups urged members of parliament to lobby for improved access to treatment for patients with psoriatic arthritis.

The Rt. Hon Bruce George MP, Chairman of the All Party Parliamentary Group on Skin and Baroness Masham of Ilton, Chair of the Psoriasis Association were among those speaking at the event, which is hoped will help raise the profile of the disease, its impact on patients' quality of life and the importance of improved access to anti-TNF agents for those that are eligible for treatment.

Psoriatic arthritis is a disease of younger adults and affects approximately 23% of those with psoriasis[1] putting estimates as high as 276,000 people in the UK with the disease.[2] A serious condition which causes severe morbidity, with impairments in quality of life similar to those of ischaemic heart disease, asthma or diabetes, psoriatic arthritis is also associated with increased mortality.[3]

The Rt Hon. Bruce George commented, "Psoriatic arthritis can have a profound impact on peoples' lives, they are essentially living with the burden of two conditions; with arthritis they have to cope with issues of physical disability and with psoriasis the issues of having a serious skin condition." David Chandler of the Psoriatic Arthropathy Alliance who has psoriatic arthritis gave an insight into living with the disease at the briefing and commented, "It took me ten years from the onset of my symptoms before I was given an accurate diagnosis. Although things are better now than they were, there is still a long way to go in terms of raising peoples' awareness of this disease, and ensuring that quality of patient care isn't lost between what are two distinct specialities - Rheumatology and Dermatology."

Giving the clinician's perspective, Bruce Kirkham, Consultant Rheumatologist at Guy's and St Thomas' Hospital, London shared his clinical experience of treating patients. He comments, "Until now we have only been able to offer patients with psoriatic arthritis treatments such as non-steroidal anti-inflammatory drugs (NSAIDs) or methotrexate. For patients who fail to respond to these treatments due to their limitations from lack of efficacy or side effects we are now, after many years of waiting for effective treatments, able to offer anti-TNF drugs which can make a real difference and help them live a normal life. This emphasizes the importance of patient access to specialist services and treatments."

References

1. http://www.psoriasis.org/facts/psa/ (accessed on 04.04.05)
2. Report on the Enquiry into the Impact of Skin Diseases on People's Lives. All Parliamentary Group on Skin. July 2003
3. Wong K, Gladman DD, Husted J, Long JA, Farewell VT. Arthritis Rheum. 1997 Oct; 40 (10): 1868-72

David Chandler, Dr. Bruce Kirkham, Baroness Masham of Ilton, Rt Hon. Bruce George

International Alliance of Patients' Organizations
A global voice for patients

Trust us - we're patients!

London, United Kingdom, 29 February 2005 – "Trust us – we're patients" was the overwhelming theme of the International Alliance of Patients' Organizations (IAPO) first ever Global Patients Congress, held in London from 25-27 February 2005. Bringing together IAPO's member patients' organizations from around the world, over 70 patient leaders from a diverse range of therapeutic backgrounds exchanged valuable skills and experiences and worked together developing strategies to bring patients to the centre of healthcare systems.

The Congress was opened by Harry Cayton, Director for Patients and the Public at the Department of Health. He shared a personal message from The Rt. Hon. Dr. John Reid M.P. Secretary of State for Health, UK, "The Secretary of State has asked me to welcome you to this first Global Patients Congress and to England. The Government in the UK is strongly committed to the involvement of patients and the public in decisions about their personal health and health care and as citizens in the planning and improvement of health services. Active patient organisations are vital partners for governments, heath professionals and health care providers in improving health and increasing choice for all. The Secretary of State hopes you have a productive and stimulating conference."

Harry Cayton introduced the ideas, "Trust me, I'm a patient!" and "Nothing about us without us", which resonated with the delegates and were central to the themes of the Congress - patient involvement and partnerships. Patient delegates at the Congress quickly established a strong and mutually supportive community and, equally, they were keen to develop understanding and collaborative partnerships with healthcare policy-makers, professionals, providers and companies. The Congress brought together 28 representatives of these groups helping to build networks and foster collaborations for the future.

On the Saturday, the EU Commissioner for Health and Consumer Protection, Markos Kyprianou, headed a high-level international panel of policy-makers, patient representatives, providers and industry representatives that considered the benefits and challenges of patient involvement in healthcare policy, systems and delivery. Following the session, Albert van der Zeijden, Chair of IAPO, expressed his appreciation of the panellists' commitment to patient involvement and emphasized that "Patient involvement is often dependent on the goodwill of a few individuals. I know that with support and commitment from others we can make it the rule, rather than the exception".

On Sunday, IAPO's valued partners, the International Council of Nurses (ICN), the International Pharmaceutical Federation (FIP), the World Medical Association (WMA) as well as the International Federation of Medical Students Associations (IFMSA), shared their perspectives on the challenges health professionals experience and the need for collaboration to promote understanding between professionals and patients. Contributing to this issue, the World Health Organization (WHO) launched their new publication "Preparing a Healthcare Workforce for the 21st Century: The Challenge of Chronic Conditions". The report outlines five core competencies of patient-centred healthcare, partnering, quality improvement, information and communication technology and public health perspective. Dr JoAnne Epping-Jordan, Coordinator, Health Care for Chronic Conditions, WHO, commented, "These competencies do not replicate or preclude established core competencies (evidence-based care, ethical care), nor profession-specific competencies. Rather, they augment existing knowledge and skills to provide better outcomes for chronic conditions". Dr Epping-Jordan added, "It is entirely fitting to launch this publication at IAPO's first Global Patients Congress in the presence of contributors to the publication, IAPO, the European Respiratory Society (ERS), ICN, FIP and WMA".

The ideas and actions generated at the Congress are being fed into written guidelines to encourage meaningful patient involvement in healthcare policy, systems and delivery. IAPO will also launch a Manifesto for Patient-Centred Healthcare later this year, communicating the principles of patient-centred healthcare reflected in the meeting and by patients' organizations globally.

Delegates talk at the meeting

Commenting on the success of the Congress, Enrique Silver, IAPO Board Member and President of the Uruguayan Cystic Fibrosis Association commented, "This Congress has shown how much can be achieved when patients' organizations from around the world come together. I have experienced an amazing sense of community and shared values between patient leaders from Africa, the Americas, Asia and Europe." John Walsh, President and Chief Executive of the Alpha-1 Foundation in the United States added, "We worked hard together this weekend to identify the importance of the close collaboration of all stakeholders. The Congress provided a forum for all of us to identify the most important challenges we face to improve healthcare and structure the dialog for collaboration of all stakeholders moving forward. The open exchange and synergy generated helped each of our organizations by providing the framework to create initiatives to support our common goals. I think it is critical that we continue to foster global communications and look forward to making additional progress at the Congress next year".

PATIENT HEAL THY SELF

Clinical psychologists are to be trained by patients in a groundbreaking new strategy at the University of Manchester.

Dr Rory Allott is recruiting people from throughout the community to review Clinical Psychology training at the School of Psychological Science.

This follows a move towards 'user centrality' in the NHS that is, putting the patient at centre of everything the NHS does. The University is trying to match this new approach by involving the community in all aspects of professional training. Three years ago, Rory founded a small, highly successful network of clinical psychology trainees, lecturers and patient representatives. The group now want to extend this work into the heart of the community.

He explained: "In the first week of training there's a lecture called Collaborating with Consumers, meaning 'collaboration' as opposed to 'treatment'. Two past users of mental health services from the group, Graham Stierl and Carol Lovett, deliver a lecture to trainees on the experience of receiving a mental health service. It helps the trainees experience what it's like when someone has their first consultation with a mental health professional.

"There are no introductions. I just start reading from the Canterbury Tales in Middle English. Being polite students sit attentively for a while and try to understand what's going on. Then they fade in and out, get irritable and after five minutes can get quite angry. This has huge parallels with the actual experience of sitting in front of a Doctor."

Graham Stierl knows exactly how that feels. As a young man, he labelled the mentally ill 'nutters'. Ten years ago, having been made redundant and lost his father, mother, 36-year-old sister and 17-year-old son, he suffered a breakdown.

"I went to bed on the Friday night and on the Saturday morning I had just gone, I couldn't take anymore," he said. "I didn't see it coming. I didn't know what to do."

Graham, 59, from Clayton, found that joining self help groups added immensely to his treatment. He has been involved in 20 different groups over the decade, such as Crisis Point and Having A Voice, in Oldham, Wigan and Liverpool, in a variety of roles including vice president. He found his involvement in these groups extremely rewarding.

"People would come to Having a Voice with their heads down and we'd help them," he explained.

"We'd organise everything from trips to part time jobs. At Having A Voice there have been four marriages and two engagements so far, and only three people have returned to hospital in 14 years.

"It has given me confidence, helped me feel even better about myself. Not only have I come back, I am able to help others. Now I can say I'm the expert here, I know what it's like, I've been there."

Carol Lovett agrees: "Setting up the group at the University of Manchester has been genuinely inclusive. We established the agenda for the work together, which allowed me and Graham to contribute fully, exactly like everyone else around the table - we were made to feel like equals. It has been a great experience."

Carol, 50, from Higher Openshaw, suffered a breakdown in 1998 as she completed her degree course with a 2:1 and came to the end of a messy divorce, while still caring for her two children, then aged 10 and 15.

"I had managed to get through so much but, as my course and the divorce came to an end, I lost it," she recalled. "I didn't want to leave my bedroom. I wouldn't eat or drink too much so I didn't have to go to the toilet. I never went downstairs or answered the phone.

"Luckily I was helped by my friends and family and received very supportive treatment without having to go to hospital.

"Getting better at home was very important. In the same way, working with service user groups has empowered me, plus it's harder to argue with someone who has been there, who knows exactly what it's like. We have a lot to offer the trainees."

Rory said: "We are moving away from the Ivory Tower and putting out some rope ladders into the community. People who have experience of using health services generate ideas that I could never come up with - for example, only someone who has spent long periods in hospital could possibly know what that is like. This expertise can bring an extra dimension to the training of Clinical Psychologists.

"The people we recruit to help guide training will provide a long needed bridge to others around them. This will ensure that the Clinical Psychologists of the future provide services that meet the wants of their patients."

Rory hopes to recruit people from throughout the North West representing all the groups of people who might use Clincial Psychology services: adults, older adults, children and young people and people with learning difficulties. He hopes they will get involved in all aspects of training: curriculum development, extending the database of interested community groups, training the lecturers or attending meetings with organisers of training.

Freedom of Information Act

For many years' pressure groups have been campaigning for access to information held by government departments and public bodies, which, as we as we all know, tend by nature to be secretive. Bit-by-bit pressure groups, individual members of parliament and others have overcome the intrinsic barriers to letting us know what is going on.

In 1994 the then Government moved some way to giving us better access to information about government departments creating a Code of Practice for Open Government, which led to the creation of the Patients' Charter by the Department of Health which was at least a step in the right direction. But it took until the end of 2000 for actual law to be passed directing public bodies to meet the information needs of the public. The Freedom of Information Act was passed in that year but not implemented. It gave general right of access to all types of information held by all public authorities but its full implementation date did not come into effect until January this year, hence the current flourish if interest and activity.

However it isn't just us who can benefit from this new opportunity. In reality the Act gives access to anyone including journalists, political parties lobby groups, commercial organisations and UK citizens overseas and even non-UK citizens.

So, since the New Year's Day all public authorities must answer ALL requests for information held on file. The NHS is covered by the new legislation and must provide all types of recorded information it holds when requested to do so. Compliance with Act is compulsory and there are penalties for non-compliance, which apply to the organisation itself, and to individual members of staff involved. Indeed continued failure to comply could result in a prison sentence.

What type of information can be requested? The answer to this is any type of information that the authorities believe will not cause significant harm. Mainly, this means harm to the State, of course, and refers to national security and law enforcement. It also applies to harm to an individual such as one suffering from a mental illness where, in the opinion of the information holder, disclosure could cause them damage.

Within this context public employees including those in the NHS have been advised to be as open as possible and to supply any information that is requested.

What does this all mean for us? From now on we can no longer be fobbed off from obtaining information by the public body merely invoking vague reference to data protection, client confidentiality or commercial confidence. For instance within the NHS we can obtain the following types of data: -

- Waiting lists
- Hospital episode statistics - including individual doctors success rates
- Accident and emergency waiting times
- Ambulance response times
- Information regarding complaints from health regulatory bodies such as the General Medical Council for medical practitioners, the Nursing and Midwifery Council, The Healthcare Commission covering information about other healthcare professionals) and the Healthcare Ombudsman
- Inspection reports - (via the Healthcare Commission)
- Financial information - available in the annual report of the relevant organisation
- Medicines safety and clinical trial data - via the Medicines and Healthcare products Regulatory Agency (MRHA)

The new Freedom of Information Act is, as you would imagine, intrinsically bound up with the Data Protection Act and with the Human Rights Act, both of which give partial protection from disclosure of personal information about us. An Information Commission has been established to oversee the working of all three pieces of legislation. The role of the Information Commissioner will not only concern general data held by public bodies but also, it is hoped, act as an adjudicator where information about oneself is denied for example on grounds of perceived risk to physical or mental health of the subject.

If individuals or groups use the Act in a 'vexatious' way access to information can be denied. This would apply if repeated requests are made for data already provided. Also there is a cash limit. If the provision of the retrieval of information costs a government department more than £600 or another public organisation more than £450 it may be refused. There are other grounds for refusing to provide information, 23 in all, but these are discretionary which means they can be overruled if it is thought the information sought is in the public interest.

In practice, all that you have to do, as a member of the public, is to make an application in writing. The targeted public body must reply within twenty days.

Should your request be refused an appeal can be made to the organisation in question. If this does not produce the required result you can appeal to the Information Commissioner, thence to an information tribunal and, if all else fails, an appeal can be made to the High Court. While all this seems daunting it should be remembered that the public body which fails to meet its duty to disclose information could be charged with contempt of court resulting in a possible fine or even jail for responsible individuals, not to mention bad press coverage. From guidance that the NHS has provided for its staff it is clear that the new law is being taken seriously and that

healthcare professionals will be expected to comply in full. This seems to be true of Social Services also.

Will it make a difference to our lives? While the intention is no doubt to help individuals and groups with a genuine need or grievance there is a potential for abuse by the media and by those wanting to obtain information for political gain.

On the positive side it should be easier for us as individuals or as a patient support group like the PAA to obtain information on local as well as national services and to build comparisons with those elsewhere in order to enhance campaigns for improved care.

In contrast to the opportunities afforded by the Freedom of Information Act there is a growing issue concerning data held about us by public and private organisations and how third parties can gain access to it. Much of this is to our benefit in terms of disease management and possible cures but the gain is not without some risk to privacy. The debate will continue…

Chris Friend
PAA Trustee

PAA Kids

FREQUENTLY ASKED QUESTIONS ABOUT Juvenile Psoriatic Arthritis (JPsA)

What does Juvenile Psoriatic Arthritis actually mean?

Juvenile – means that it begins before the age of 16 years of age.

Psoriatic – means that it is in some way linked to the skin disease, Psoriasis, even if that only means another family member has it- you don't have to have skin psoriasis to have juvenile psoriatic arthritis!

Arthritis – means painful swelling of a joint causing loss of mobility of the joint.
Juvenile Psoriatic Arthritis (JPsA) is one of 7 types of juvenile idiopathic arthritis (JIA). The term idiopathic means that we do not know the causes.

How common is JPsA?
Not very! JPsA represents approximately 10% of all patients with JIA i.e. 1 in 10 000 children/young people in the UK. When all patients with JIA are considered, JIA affects 1 in 1000 children/young people in the UK i.e. it is more common than cystic fibrosis, but less common than diabetes in this age group. JPsA is much less common than adult psoriatic arthritis.

What causes JPsA?
No one knows – yet! Hopefully research will one day tell us.

How is JPsA diagnosed?
There are no blood tests that diagnose arthritis – only ones that tell you and your doctors how much inflammation there is anywhere in your body.

JPsA is diagnosed by someone familiar with childhood arthritis, listening to your story and then examining all your joints, looking for pain, swelling and loss of the normal range of movement. In addition, the skin is examined looking for even the slightest sign of psoriasis whether on the skin or in the nails (pits). Sometimes psoriasis can be as mild as mild dandruff! Sometimes psoriasis can just be one small scaly patch behind the ear or in the belly-button! But sometimes you can have JPsA and NOT have skin psoriasis! The skin psoriasis may just be in your family. Part of the diagnosis includes finding out if your parents or any brothers or sisters has psoriasis i.e. a family history.

When does JPsA start?
JPsA can start at any age but usually begins when you are quite young ie. in early childhood. It affects as many boys as girls.

How is JPsA different from psoriatic arthritis in adults?
The most important difference is that children and young people are still growing and developing unlike adults. Arthritis in children and young people can affect growth. Growth not only means how tall you are but also the shape of your bones and joints, the length of your bones as well as all the changes that happen at puberty, how you feel about yourself, your self-confidence, how you get on at school and at home etc.

Another important difference is that you may not have any inflammation or active arthritis when you are an adult. This is the case for approximately two thirds of young people with JIA.

As in adults, psoriatic arthritis may affect a few or several joints in children but arthritis in the spine is unusual in JPsA.

There difference in eye inflammation which is mentioned below.

HOW DOES JPsA affect your body?
JPsA can affect a few OR lots of joints, causing them to look swollen. It can also cause inflammation of the tendons – tendonitis. Sometimes this tendonitis causes the fingers or toes to swell and look like sausages!! – referred to by doctors as dactylitis. This is a very characteristic finding of JPsA.

JPsA can also affect other parts of the body. Psoriasis can affect the skin and nails. In JPsA the eyes can also become inflamed. In children and young people this is usually painless and the eye may look perfectly normal from the outside. It is only with a special light – a slit lamp – can the inflammation be seen ie chronic anterior uveitis. This is different from the painful red eye (acute anterior uveitis) seen in adult psoriatic arthritis.

If many joints are affected in JPsA, with a lot of inflammation, children can go off their food and even become anaemic due to the arthritis. This anaemia however is not due to being short of iron or other vitamins. It is due to the inflammation and only when the inflammation is controlled will their appetite and anaemia start improving.

If arthritis is very active around the time of puberty, the body may not develop as quickly as other young people. In girls, periods may start later. Once the arthritis is controlled, puberty then takes place normally.

Why do you have to go to hospital?
JPsA is an uncommon condition in children and it is therefore important for children to be looked after by paediatric specialists who are familiar with the condition.

Why do I need blood tests?
There are several reasons for having blood tests. Blood tests like the ESR and CRP can tell how much inflammation there is in your body. The main reasons for blood tests after diagnosis however are usually to look for side effects of drugs like Methotrexate.

Are there any activities I should not do? Why?
It is difficult to generalize. Specialist teams would prefer to look first at all the activities that you CAN do before considering what you cannot do. The majority of young people with arthritis should enjoy unrestricted activity.

Why do I have to be seen at hospital so much?
After JPsA has been diagnosed it is important to be seen by your specialists to make sure that the arthritis is controlled as soon as possible, and that you learn about the condition and

the therapies offered. Once the disease is controlled you will need to be seen less often. It is still important to check that you and your bones and your joints grow and develop normally and that your drug therapy causes no side effects.

Who am I likely to see with my condition?
Hopefully over the course of your treatment you will build up a friendly, professional team around you that will help you to manage and become confident living with your condition. These professionals may well be:- physiotherapists, occupational therapists, podiatrists, paediatricians, GP, specialist nurses, counsellors (if appropriate), dieticians (if appropriate), who will all be there to help you when you need them most.

Why do I have to go and see an eye specialist?
For some unknown reason, young people with JPsA are at risk of developing inflammation in the eye, This is called chronic anterior uveitis (see above). It is different to adult psoriatic arthritis. Since the inflammation doesn't cause pain or redness or anything obvious – it is very important for ALL children and young people with JIA/JPsA (even if only suspected) to have a special examination by an eye specialist. This is known as a "slit lamp examination".

How is JPsA treated?
First of all, the aim of treating JPsA is to control any pain and swelling, control the inflammation, prevent any damage or deformity, and make sure you continue to grow and develop like your friends without arthritis. Treatment also involves keeping the muscles around your joints strong and minimizing any side effects of therapy. Most important of all is for the rheumatology team to help you and your family learn more about the arthritis and what can be done to keep you independent, active and living a full life.

Treatment therefore involves lots of things and lots of people working together as well as working with you and your family to keep you well.

Drug treatments:
The first drug treatment used for arthritis is a non-steroidal anti-inflammatory drugs(NSAID) such as ibuprofen, piroxicam (Feldene) or Naproxen. These drugs will help pain, stiffness and swelling. They will not prevent inflammation however. There are many treatment options that may be available to you, in agreement with your doctor, so there is much that can be done to make you more comfortable.

Will it ever go away?
When all children with JIA are considered, approximately two thirds (2 out of every 3) young people will NOT have active inflammation in adulthood. However, one third will and it is difficult to predict which young people will have on-going inflammation. It is often those with more severe inflammation and more joints involved.

When I am an adult will JPsA become adult psoriatic arthritis like in adults?
You will always have or have had JPsA – the name doesn't change, whatever your age. By keeping this name, adult rheumatologists will then remember the differences between JPsA and adult psoriatic arthritis as mentioned above. An adult who has had arthritis as a child had has a very different experience with arthritis than an adult who has had a healthy childhood and then developed arthritis as an adult.

Can I pass on JPsA to any children I might have in the future?
Very unlikely. The arthritis part of JPsA is not passed on to your children although, the skin condition, Psoriasis can be. Having JPsA also does not affect your ability to have children but drugs like methotrexate can affect the unborn baby and it is therefore very important when young people taking this drug become sexually active, they use effective contraception.

Lastly, don't forget your doctor, GP practice, and rheumatology nurses are there to help you. If you have any doubts, concerns, questions, just ask them!!!

Useful sources of information:-

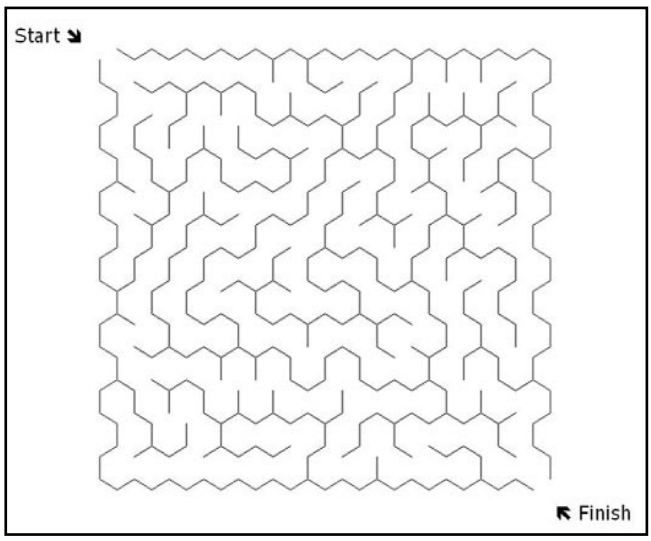
THE SOURCE HELPLINE:
"The Source" helpline is for young people under 25.
Tel: 080 8808 2000

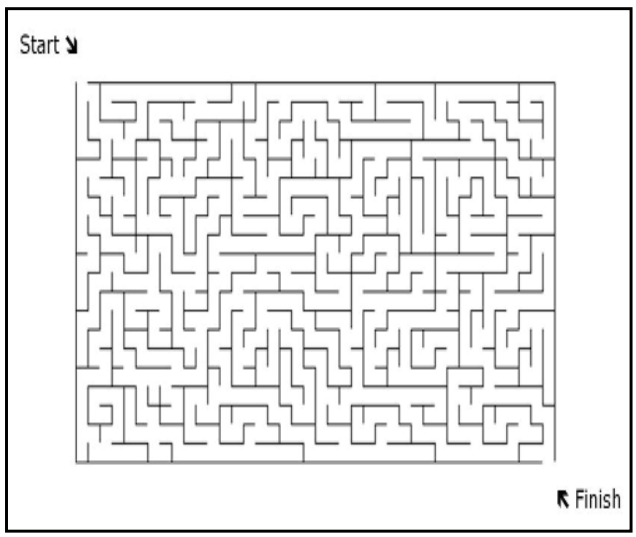
Arthritis in Teenagers – ARC booklet:
www.arc.org.uk

University of Birmingham paediatric interactive site for children with arthritis.
http://reheumb.bham.ac.uk/kidzone/k1intro.html

Psoriatic Arthropathy Alliance,
PO Box 111, St Albans, Herts, AL2 3JQ
www.ThePaa.org

MAZE CRAZE





REMEMBER
We want your input, case histories, puzzles, jokes, fundraising ideas, help us to help you get motivated, lets get PAA Kids rolling in 2005 and beyond.

Researchers Discover Key Protein in Psoriasis

Researchers at The University of Texas M. D. Anderson Cancer Center simultaneously have resolved a controversy over the cause of psoriasis and developed the first mouse model that fully mimics the human disorder. What's more, the scientists have demonstrated they can block the signals that lead to psoriasis in their mouse model with a topical skin treatment that can prevent new outbreaks as well as treat existing psoriatic plaques.

"We have developed a mouse model that exhibits all the major features of human psoriatic lesions and shown we can reverse those steps," said John DiGiovanni, Ph.D., the study's principal investigator and director of M. D. Anderson's Department of Carcinogenesis. "We may have found an entirely new treatment option for psoriasis."

The study, which appeared in the January 2005 issue of the journal Nature Medicine, shows a protein called STAT3 is a crucial initiator of psoriasis and must be present and activated for psoriasis to develop in their mouse model.

Psoriasis is a chronic condition in which patches of skin become inflamed and develop itchy red, flaky scales. Areas of the body most affected include the scalp, elbows, knees, and lower back. Psoriasis affects about two percent of people worldwide, with men and women equally susceptible. Current treatment for psoriasis focuses on reducing inflammation and slowing down the rapid growth and shedding of skin cells called keratinocytes. There is no effective curative treatment for the underlying condition, according to DiGiovanni.

"There has been an ongoing controversy about whether the primary defect in psoriasis is in the immune system or in the keratinocytes," says DiGiovanni. "We may have found the link – the change in keratinocytes that cooperates with the immune system cells necessary for development of human psoriasis."

The researchers became interested in STAT3 when they learned it was associated with wound healing, a process that shares many of the same molecular features with psoriasis and with cancer.

DiGiovanni's research team has recently shown that STAT3 is involved in the development of skin cancer and began investigating its role in psoriasis, another disease in which skin cells grow inappropriately.

They belong to a class of proteins called transcription factors, potent proteins that can set off a cascade of events by simultaneously activating many genes. In the case of STAT3, activation leads to the production of growth-promoting and cell survival proteins. Activated STAT3 is essential in normal skin to promote wound healing. When the healing process is complete, normal STAT3 returns to its inactive form. But when it fails to turn off, the wound healing process continues and skin cells proliferate.

The researchers first looked for activated STAT3 in the skin of psoriasis patients and found high levels of activated STAT3 in psoriasis lesions in 19 of 21 patients. Based on this observation, the researchers decided to develop a mouse model in which the gene that encodes STAT3 is always turned on in the keratinocyte skin cells. When the genetically altered mice were born they looked relatively normal, but by the time they were two weeks old, they began to develop scaly patches on their tails that sometimes spread to their lower back. When the scientists examined skin samples from the scaly patches they discovered that the patches mimicked human psoriasis very closely.

"This mouse model recapitulated all of the major epidermal and immunological features of human psoriasis, something that other animal models fail to do," said DiGiovanni.

The researchers also noticed that if the animals suffered an abrasion, such as when they scratch themselves, they frequently developed a scaly lesion in the irritated area, just as many people develop psoriasis lesions after a mild injury, a characteristic called the Koebner phenomenon. DiGiovanni said this pattern is consistent with the idea that psoriasis is a form of over-active wound healing response.

In another experiment, the scientists transplanted skin from their STAT3 mice to a mouse that produces no T cells, a key component of the immune system that is believed to be necessary for development of psoriasis. The transplanted skin did not initially develop psoriasis lesions.

However, when the scientists injected activated T cells into the skin grafts on T cell-free mice, the mice then developed psoriasis following mild injury.

"This experiment showed it is necessary to have both activated STAT3 in keratinocytes and infiltrating, activated T cells to develop psoriasis," said DiGiovanni. "Neither is sufficient alone."

The scientists then tested whether blocking STAT3 could reverse the development of psoriasis. They applied a solution to the skin of their STAT3 mouse that contained a small piece of DNA called an oligonucleotide designed to bind STAT3 and prevent it from activating genes. The STAT3-blocking agent significantly halted the progress of the lesions and reversed symptoms such as slowing cell growth, shrinking dilated blood capillaries and reducing inflammation.

"This study opens the door to a whole new kind of therapy for psoriasis," said DiGiovanni. "This is

a brand new target for treatment."

He also noted that certain aspects of psoriasis and early stages of cancer development in skin share similarities. However, psoriasis never progresses to cancer, he noted. "We still have much to learn about psoriasis, and this mouse model will help us learn much more about the molecular events that happen during the disease process," he said. In addition, it may help us learn more about early stages of cancer and why certain changes favour one disease versus the other."

DiGiovanni's collaborators included Shigetoshi Sano, M.D., Keith Syson Chan, Ph.D., Steve Carbajal, Mary Peavey, and Kaoru Kiguchi, M.D., Ph.D., of M. D. Anderson; John Clifford, Ph.D., Feist-Weiller Cancer Center and Louisiana State University, Shreveport, La.; Brian Nickoloff, M.D., Ph.D., Loyola University of Chicago; and Satoshi Itami, M.D., Ph.D., Osaka University Graduate School of Medicine, Osaka, Japan.

The study was funded by grants from the National Institutes of Health, a National Institute of Environmental Health Sciences Center grant and an M. D. Anderson Cancer Center Support Grant.

Wound healers cause skin disease

Dutch researcher Manon Franssen has shown that cells which heal the skin following an injury play an important role in the development of the skin disease psoriasis. In people with psoriasis, the skin peels much faster than normal so that it flakes and becomes inflamed.

Franssen investigated the transit amplifying cells in the uppermost layer of the skin. These cells develop from stem cells (general unspecialised cells) and specialise into skin cells when new skin cells are needed. The transit amplifying cells are involved in the healing of the skin following an injury and in the regular renewing of the skin.

Normally these cells wait until they receive a signal to develop into skin cells. Franssen discovered that in people with psoriasis, some of the transit amplifying cells divide without waiting for a signal. As a result of this, too many skin cells develop and the skin is renewed more quickly than normal. However, when Franssen cultured the transit amplifying cells from the skin of psoriasis patients, these cells grew less quickly. Exactly how the cell division of transit amplifying cells and stem cells is regulated, is not yet clear.

In the case of psoriasis, not only is there a more rapid renewal of the skin, but the number of cell layers on the surface also increases. The skin condition causes red marks that are rich in blood and often inflamed. These red marks are covered with shiny white flakes of skin and sometimes itch. Psoriasis is not infectious.

A cure for the disease is still not available and at present only the symptoms can be controlled. According to the Dutch Psoriasis Society about 300,000 people in the Netherlands suffer from a form of this disease. Stem cell therapy might be able to provide a cure for them in the future.

Stem cells currently form an important research area in medicine. Stem cell therapy – the replacement of defective or absent stem cells, tissues or organs in patients – should be able to cure many diseases in the future.

Stem cells from the uppermost layer of the skin have never been isolated. The isolation of their descendants, the transit amplifying cells, is an important step in the right direction. By culturing these cells from patients, complete pieces of skin can be reproduced. These are extremely useful in the treatment of burns, bedsores or skin cancer. The culturing of 'diseased' skin offers the possibility of thoroughly studying diseases and testing new treatments.

The research was funded by the Netherlands Organisation for Scientific Research

Move for 'spin-out' aids treatments for skin disease

NEW treatments for eczema and psoriasis have come a step closer, thanks to a deal which allows some of the UK's leading skin disease specialists to work together.

York Pharma has bought University of Sheffield spin-out Molecular SkinCare, creating a business which aims to become a major force in the dermatology markets in Europe, the US and Japan.

Michael Garrison, Molecular SkinCare's chief executive, said the agreement would turn academic discoveries into skin disease products.

The deal means that York Pharma, an AIM-listed strategic acquirer, will have the use of Molecular SkinCare's laboratory and dermatology experts.

Terry Sadler, chief executive of York Pharma, which is based in Hitchin, Hertfordshire, said: "This is a business transforming transaction, which both parties recognised as a perfect fit. The quality of the combined portfolio and enlarged team creates a business that will make a significant impact on the dermatology market in the coming years, both scientifically and commercially."

He said a tie-up between academics and hard-nosed commercial companies was in keeping with Government policy.

Molecular SkinCare emerged from the University of Sheffield in 2001, and its nine-strong staff includes experts in molecular biology and clinical dermatology.

Mr Garrison and his team have been working on projects to find cream and drug-based treatments for eczema and psoriasis which will reach critical phases over the next two years.

The Sheffield researchers think they can improve on current psoriasis treatments, which have annual sales of around £266m.

Molecular SkinCare is also studying ways of repairing skin.

York Pharma operates in half of the world's dermatology markets. Sales of dermatology products in the developed world totalled £5bn last year.

By Catherine Smith, Jonathan Barker and Alan Menter
ISBN 1-899541-98-5
www.fastfactsbooks.com
64 pages

"Correct diagnosis and treatment of psoriasis can be problematic – this book provides a thorough, practical account of the clinical presentations, differential diagnosis and range of modern therapies. It can be an essential resource for anyone who manages psoriasis patients in the primary care setting"
Authors

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Clinical presentation
Differential Diagnosis
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Phototherapy
Systemic Therapy
Future Trends

Please note this book was designed originally for clinicians and health professionals.

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Check Publications List page 17

PSORIASIS & PSORIATIC ARTHRITIS CONFERENCE

Saturday 17th September 2005

WOBURN SAFARI PARK

BEDFORDSHIRE 9.00am - 3.30pm

All the Whys or Wiser the better

PROGRAMME

9.00	Registration
10.30	**Welcome - The Role of the PAA** - David Chandler - Co-Founder PAA
	Session 1 - Chair Dr Virginia Camp Consultant Rheumatologist Kettering General Hospital
10.45	**Why not ask? Questions sent to the PAA**- Dr Anthony White Consultant Rheumatologist Royal Free Hospital London
11.30	**Why phototherapy?** - Rosemary Moakes Phototherapy Nurse Dermatology Department - Kettering General Hospital
	Why all the blood tests? - Kathy Italiano Dermatology Specialist Nurse Kettering General Hospital
12.00	**Why Patient Choice 1** - Catherine Buckley Chartered Physiotherapist West Herts Therapy Service
	Why Patient Choice 2 - Patrick Parker Non Executive Director Bromley Hospitals NHS Trust
	Session 1 Q & As
12.30	Lunch
	Session 2 - Chair Dr Anthony White
1.30	**Why Research? - new biological therapies.** - Dr Bruce Kirkham Consultant Rheumatologist Guys Hospital London
2.00	**Why Clinical Trials?** - Dr Anthony Chu Consultant Dermatologist Hammersmith Hospital London
	Session 2 Q & As
	Session 3 – Chair –Patrick Parker
2.30	**Questions and Answers**
3.30	Close

This conference is organised by the 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 number: 1051169

Further information can be obtained by contacting:

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Conference 2005

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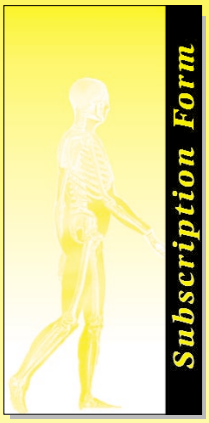

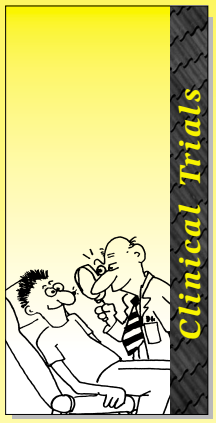

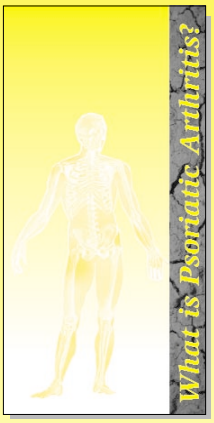

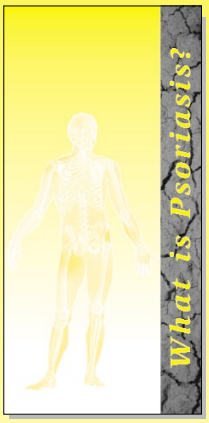

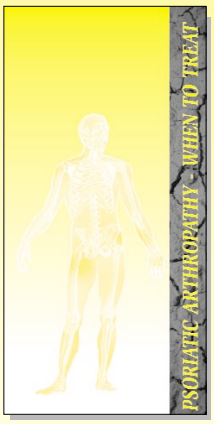

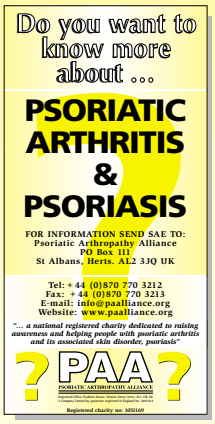

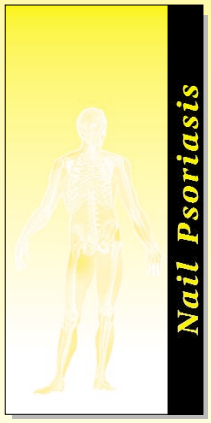

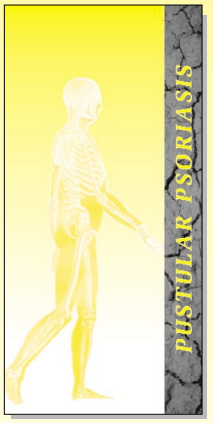

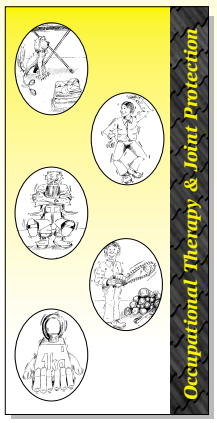

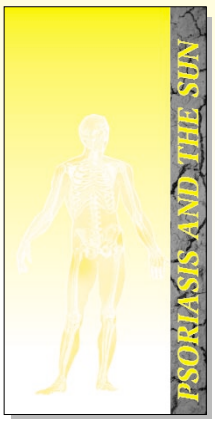

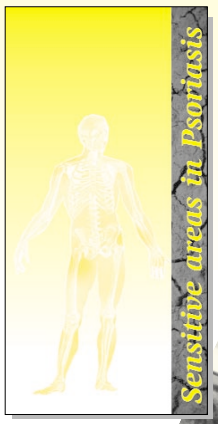

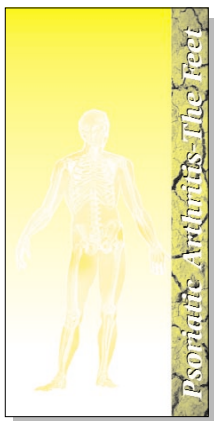

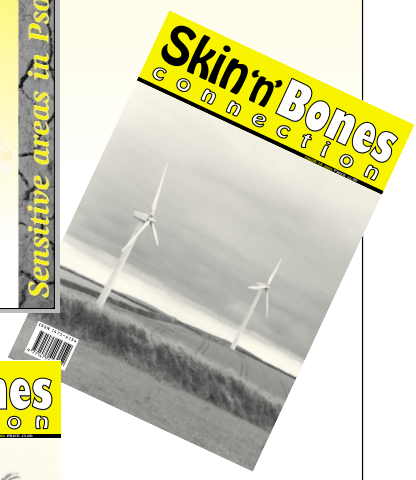

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.....

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New WHO study asks,

"How happy are you with your lot in life?"

Researchers at the University of Bath are asking people throughout Britain to describe how happy they are with their lot in life to help improve the effect of the healthcare they receive.

The researchers have set up an online survey to collect information on the factors that contribute to the quality of life of people in Britain. (The survey is at: http://www.bath.ac.uk/whoqol/questionnaires).

The results will be used to create a survey that doctors can use to assess a patient's perception of their quality of life and work out the potential impact of medical intervention on their everyday lives.

This is important because a person's perception of their quality of life can, for example, influence how quickly they recover from an operation or make a difference to the psychological impact they experience when they become ill.

The on-line survey, which is sponsored by the World Health Organisation (WHO) and the European Commission, asks people questions about their experiences over a two-week period, their ability to do activities and their satisfaction with various important aspects of their life.

Respondents will then be able to print out a quality of life profile that includes a graphical analysis of their physical health, psychological well-being, social relationships, environment and overall quality of life.

"Surgeons tell us that they can do exactly the same procedure on two similar people, but whilst one is back at work within a week, the other can become depressed and disabled by their situation. It is the patient's perception of how the operation affects them that is the greatest influence on the difference," said Professor Suzanne Skevington, who heads the WHO Field Centre for the Study of Quality of Life at the University of Bath.

"In a nutshell, quality of life is about people's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".

"This survey is also a useful tool for people to take stock of how they perceive their own quality of life and look for areas where they can redress any unbalance that may exist."

The survey questionnaire – the WHOQOL - has been developed over the last decade through a collaboration of researchers and clinicians with focus groups of users throughout the world, to take into account nuances in people's perception of life quality evident in different cultures, religions and other belief systems.

This has helped to highlight the differences in perceptions of quality of life in different cultures and countries. For example, skin colour can affect a person's quality of life in India, feeling secure is important to Israeli's, while in the UK simply feeling 'fed up' can have a detrimental effect on life quality.

"From global studies we have already found that in Britain, a person's perception of a high quality life is closely linked to their feelings of happiness and contentment. However, in other cultures happiness comes out as low as 17th, among the 25 aspects of quality of life that we measure. In the US for example, the availability of accessible health and social care is one of the most important influences on quality of life" said Professor Skevington.

"It is not so much a country's standard of living that has an affect on quality of life, but more the meaning that these resources have for your life. For example, extensive living space is important in the US but is less important in Japan, an equally developed country."

Made-to-measure Skin And Bones

Scientists at The University of Manchester have developed the breakthrough technology which will allow tailor-made tissues and bones to be grown, simply by inputting their dimensions into a computer.

Professor Brian Derby, Head of the Ink-Jet Printing of Human Cells Project research team, said: "It is difficult for a surgeon to reconstruct any complex disfiguring of the face using CT scans, but with this technology we are able to build a fragment which will fit exactly. We can place cells in any designed position in order to grow tissue or bone."

This breakthrough overcomes problems currently faced by scientists who are unable to grow large tissues and have limited control over the shape or size the tissue will grow to. It also allows more than one type of cell to be printed at once, which opens up the possibility of being able to create bone grafts.

"Using conventional methods, you are only able to grow tissues which are a few millimetres thick, which is fine for growing artificial skin, but if you wanted to grow cartilage, for instance, it would be impossible," Professor Derby says.

The key to the advance which Professor Derby and his team have made is the innovative way in which they are able to pre-determine the size and shape of the tissue or bone grown.

Using the printers, they are able create 3-dimensional structures, known as 'tissue scaffolds'. The shape of the scaffold determines the shape of the tissue as it grows. The structures are created by printing very thin layers of a material repeatedly on top of each other until the structure is built. Each layer is just 10 microns thick (1,000 layers equals 1cm in thickness).

This method allows larger tissues to be grown than previously possible. The reason for this is the way in which the cells are inserted into the structures.

Before being fed into the printer, the cells are suspended in a nutrient rich liquid not dissimilar to ink, which ensures their survival. The cells are then fed into the printer and seeded directly into the structure as it is built. This avoids any 'sticking to the surface' which is a major disadvantage of current methods that infuse the cells into the structure after it has been built.

"The problem is getting cells into the interior of these constructions as they naturally stick to the sides of whatever they are being inserted into. If they stick to the sides then this limits the number of cells which can grow into tissues, and the lack of penetration also limits their size. By using inkjet printing we are able to seed the cells into the construction as we build it, which means 'sticking' isn't a problem," says Professor Derby.

Professor Derby believes the potential for this technology is huge: "You could print the scaffolding to create an organ in a day," he says.

DIARY DATES

PAA Conference 2005

17th September
Woburn Safari Park, Beds
9.00am 3.30pm

The Allergy Show
17-19 June 2005
Olympia, London

for people with asthma, eczema, hayfever & allergies