PAA Kids

Occasional Publication No. 1

Calling all kids with psoriasis and psoriatic arthritis - this is for you!!!

COME ON LET US KNOW YOU'RE OUT THERE!!

GET MOTIVATED - this is your chance to have your say!!
ARTICLES • PICTURES • PUZZLES • POEMS

PAA KIDS is run by kids for kids and will operate in future issues of Skin'N'Bones Connection if we all make it work by getting motivated, contributing and growing!! so come on GET WRITING!

Let's introduce ourselves to you - my name's Hannah, I am 10, with a sister, Amy whose 5. We haven't got psoriasis, but our dad has, so we know what its like. Besides living with it, we have grown up with the PAA and its work too, so we have met many people with it.
Next on the team is Aiden, he's 10, and Camilla, who is 11. They do not have the condition, but support all the efforts of the PAA, and help out each year at the PAA conference at Woburn Safari Park. Last year we all did a Tombola and guess the Woburn reindeer game - all without adults help - it was great fun.

Hope we will all get to meet you at future conferences and make some new friends.

DO YOU WANT A PEN PAL?

Here's your chance to get in touch with others. Just write in to us with a few details about yourself, then we will print it in future editions of Skin'N' Bones. Don't forget to give us your name, address, and please don't forget to get permission from your parents that it's OK to seek a pen pal.

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FIND THE WORDS!!

ARTHRITIS
ARTHROPATHY
BONES
CREAMS
COMPLIANCE
CONFERENCE
CURE
DEAD SEA
DISCRIMINATION
DRUGS
ESR
FEET
FINGER
FLARE
GENES
CLINICAL TRIALS
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HIPS
INTERPSO
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LOTION
NAILS
TREATMENTS
NICE
NHS
PAIN
PATCHES
PSORIATIC
PSORIASIS
PUSTULAR
PUVA
RESEARCH
SKIN
STRESS
TABLETS
TOE
TRIGGERS
REDDISH
RHEUMATOLOGIST

PAA Kids

YONGER PERSPECTIVE - kids need help too.

DID YOU KNOW?

FIRST THINGS FIRST - Psoriasis is not catching!!

Don't give up with your doctor or hospital – Psoriasis and treatments need to be found that suit you – this may take a little bit of time, and experimentation – so hang in there.

If you are lucky enough to see a specialist nurse dealing with your skin problem, don't be afraid to ask her questions – she will gladly explain or allay your fears. Sometimes your parents don't always have the answers, especially as to why things don't work with your treatments, so your doctor or nurse is the best person to get to know and talk to, especially to prescribe the treatments suited to you and your lifestyle!!

WHAT TRIGGERS YOUR PSORIASIS OR SOMETIMES MAKES IT WORSE?

Nobody really knows for sure, however if you are under pressure and stressed with exams, schoolwork, relationships, anything that really worries you, stress can make things worse, and you feel ten times worse – so get chilled out.

DON'T GET STRESSED OUT!

You can and probably will feel angry at times – "why me". Don't worry this is normal. You are bound to feel like this sometimes, fed-up with your treatments, doing them, not seeing any results from all that effort – going backwards and forwards to the doctors, wondering and worrying if the condition is getting worse or better – this is normal, you are normal for thinking like this. All these emotions will help you to cope better with your condition, throughout your life – so chill.

You will feel sometimes that the condition is "larger than life", a bit like a boil/spot on the end of your nose, that hurts and festers, and you think it stands out bigger than you are, when actually, nobody really notices that small redish mark on the end of your nose!! Then there will be other times when you totally forget you have a skin problem to treat, either its being good, cleared up, or there are other good things going in you life to take your mind off all your negative feelings. THIS IS NORMAL!!

HOW DO I DEAL WITH WHAT I'VE GOT?

Coming to terms with your skin and/or arthritis is the first step to managing your problem, then to deal with it and look after yourself – so little by little, accept that you have a problem but that's not your fault. Lots of other people have problems too, sometimes you just can't see them. Then get to know and feel comfortable with your medical condition.

SUMMER TIME

Be careful of the sun – don't get sunburnt and always use a good sun protection cream, especially if you are fair skinned.

SWIMMING:

Swimming is great and fun too, so don't get hung up about going – once you get a grip of yourself and go, you'll love it. However, your skin may become irritated by the chlorine in the water which varies in level from pool to pool. To combat this try to protect your skin by good moisturising, and if you can get a barrier cream to apply before you go into the water, this may help too.

MOISTURISING:

Don't forget this is really important to learn early on, and to make part of your daily skin routine.

WHY MOISTURISE?

Moisturising keeps skin hydrated, flexible and healthy and best of all it prevents worsening of the psoriasis, and can reduce irritation and itching. It helps in the winter months, when our skin does not get the opportunity to breath, being covered up in all our heavy, warm clothing.

HOW DO I DO THIS?

You can moisturise without too much trouble at all, for instance, in the bath. There are emollient products that you can add to the bath that do the job well, without you making any efforts at all, apart from enjoying your bath time!!

Then there are products that you can apply after your bath, or during the course of the day.

So, go on, give it a try.

MAKE YOUR TREATMENT TIMES FUN!

(Now you won't take us seriously, but honestly we are not MAD!!)

Invent games with your nurse, doctors and parents to make applying your treatments fun.

Example: Creaming speed record

Reward system: each time you go to the doctors/nurse or hospital, give yourself a treat, or ask your parents to give you one.

Give yourself a treat for each completed month of treatment, again ask your parents to let you have something special, so that it gives you an incentive to work for.

Give yourself targets to meet with your treatments goals.

Come on use your imagination, invent some games – Don't forget to tell us if they work too!!

PAA Kids

CHILDREN AND PSORIASIS
Did you know

- Psoriasis affects more girls than boys as youngsters but strangely it becomes equal when both sexes reach adulthood.
- It is estimated that approximately 80 million people world-wide suffer from psoriasis, with 25% having moderate to severe psoriasis.
- It is estimated that out of the total affected patients, 10-15% of these will be children under 10 years of age.
- It is estimated that 5 million people a year will seek help for their condition, with 15% being in the Paediatric (childrens') age group.
- Psoriasis is commonly compared to a snake, always shredding its skin to reveal a new one.
- The most common form of psoriasis in kids is "guttate" which is usually triggered off by a chest infection or the bugs called streptococcal, which cause sore throats.
- Scalp psoriasis is more common in kids, as is, seborrhoecic psoriasis
- Babies can get a form of psoriasis too called "nappy" or "napkin" psoriasis.
- Strange but true, in some cases, psoriasis has been known to completely disappear, never to return!! Spooky. Nobody knows why.
- A lot of the medical textbooks on psoriasis maintain it does not itch – but hey, we all know it does!
- You can use cover-up, concealing, camouflage creams to help make your skin look better.
- If you have to have an immunisation, don't worry or be surprised if a small patch of psoriasis develops around the jab site – it's common.
- If you go into hospital for any operation, you may develop patches around your incision/injury/scar site – don't worry – its common. TIP: Try not to go to hospital too often for other such treatments!!
- *Why do I get Psoriasis?*

Well, the chances are it may run within the generations of your family. Maybe someone unknown to you back in the history of your family had it, or one or both of your parents, brother, sister, aunt, uncles may have had or have it. So the chances are you may be prone to it yourself, keeping up the family tradition – there's nothing wrong with that!!

- *Why couldn't my doctor tell the difference between eczema and psoriasis?*

This happens because they both do look similar in appearance, both conditions being caused by the body's immune system function not working as well as it should. Saying this though, both eczema and psoriasis do have differing characteristics in their appearance, and it may mean that your doctor is not as well informed as he should be. GP's have to have a lot of knowledge about almost everything medical and sometimes they can get alittle confused in their findings.

Don't be too hard on him, if you are not sure of his diagnosis, always ask him nicely to refer you onto a dermatologist at your local hospital for a second opinion. You are entitled to be referred on if you are not happy.

PAA Kids just remember, be positive, be active, and be part of your treatment options – ask questions, SAY NO if you feel a treatment is not right for you – get your doctor working and talking with you about you, what you want and how you want to achieve good result in your treatment outcomes.

One day you will be an adult taking on these decisions yourself, so you might as well get into practise now for life!! Get the medical team around you that you want, you need, to help you achieve good outcomes and management of your condition.

OLD MR KELLY
HAD A PIMPLE ON HIS BELLY
HIS WIFE CUT IT OFF
AND IT TASTED LIKE
JELLY!!!!!!!!

@@@@@@@@@@@@@@

What's the time
Ten to Nine
Hang your knickers on the line
When the're dry
Bring them in
Put them in the biscuit tin
Eat a biscuit
Eat a cake
Eat your knickers by mistake
@@@@@@@@@@@@@@@@

If you have got any good limericks or rhymes, go on send them in.....please

REMEMBER
We want you input, case histories, puzzles, jokes, fundraising ideas, help us to help you get motivated, lets get PAA Kids rolling in 2004 and beyond.

PAA Kids PSORIATIC ARTHRITIS in Children

Arthritis in children

As many as 12,000 children in the UK suffer from juvenile chronic arthritis (JCA). There are three main types:

- ***Still's disease,*** (accounts for 20% of cases). Starts with a high fever, patchy red rash, enlarged lymph nodes, abdominal pain and weight loss.
- ***Polyarticular juvenile chronic arthritis***, in which many joints are affected. Pain, swelling and stiffness affect large and small joints symmetrically (for example both hips rather than one).
- ***Pauciarticular onset juvenile chronic arthritis***, in which only a few joints are affected.

Juvenile psoriatic arthritis is sometimes thought of as part of the spectrum of juvenile chronic arthritis summarised above but others regard it as a separate disease to be distinguished from these, having more in common with reactive arthritis and juvenile ankylosing spondylitis.

The Vancouver criteria for diagnosis of psoriatic arthritis in childhood are a useful guide:

Definite psoriatic arthritis

Arthritis with typical psoriatic rash
Arthritis with 3 of the 4 following minor criteria
Dactylitis (pink swollen "sausage" finger or toe)
Nail pitting or onycholysis (splitting and breaking up of nail)
Psoriasis-like rash
Family history of psoriasis in first or second degree relatives

Probable psoriatic arthritis

Arthritis with 2 of the 4 criteria listed above

There is a tendency for girls to be more likely to be to be affected than boys. Simultaneous onset of rash and arthritis is rather uncommon. As in the adult variety the end joints of the fingers are commonly involved. Generally, in juvenile chronic arthritis this does not happen but tendons are often inflamed. Of the joints involved the knee seems commonest in children. Chronic iridocyclitis, the eye inflammation more usually seen in the form of juvenile chronic arthritis with few joints involved, occurs in 8-17% of cases of psoriatic arthritis of childhood. In terms of severity, the condition lies somewhere between the forms of juvenile chronic arthritis with few and with many joints involved. No more than 10% of affected children have seriously disabling forms of the disorder.
Using strict criteria, researchers estimate that psoriatic arthritis accounts for up to 8% of cases of childhood arthritis. Using less strict criteria, including a period of five years follow-up during which the psoriasis may appear, they think the real figure may be 20%.

(source: Oxford Textbook of Rheumatology, Madison, Isenberg, Woo & Glass, Vol.2 1993, 677-679 and 714-715, Oxford Medical Publications)

Early diagnosis is important

If your child develops painful joints and there is a family history of psoriasis - even if the child shows no psoriasis at the time - it is worth mentioning the possibility to your doctor and the more so if any family member has psoriatic arthritis. If doubt remains, you should ask for referral to a specialist - ideally a paediatric rheumatologist, but as these are few a paediatrician or adult rheumatologist with an interest in the condition.

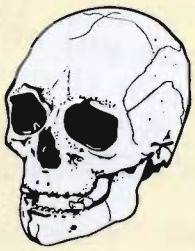
Treatment

The main aims of treating juvenile psoriatic arthritis are to reduce joint inflammation, maintain mobility and prevent deformity. Physiotherapy is as important as drug treatment. Daily exercises, hydrotherapy (supervised exercise in a warm pool), and day and night splints are all important for long-term joint mobility.
The aim of treatment is for your child to have as normal and active a childhood as possible.

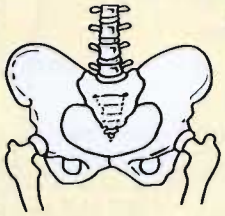
Useful address

The Disability Living Allowance has a Benefit Enquiry Line on 0800 88 22 00. See leaflet **DS706 for children under 16.**

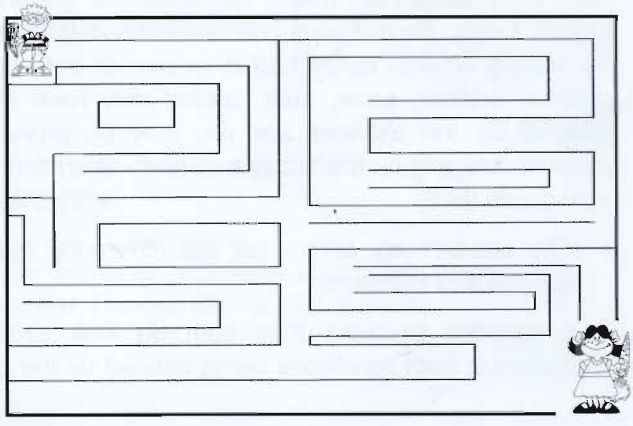
STICKS MAY BONES BUT STONES WORDS HURT



BREAK ME WILL AND HURT NEVER MY

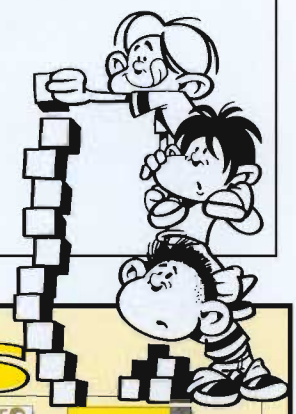


CAN YOU REARRANGE THE WORDS TO MAKE A WELL-KNOWN PROVERB? *(Answer on the back page)*



PAA Kids Drugs used in the treatment of childhood psoriatic arthropathy

Drug	What it does	Possible side-effects	Comments
Non-steroidal anti-inflammatories such as ibuprofen, naproxen) - by mouth - 1 to 4 times a day	Blocks an enzyme to reduce pain and inflammation	Rashes, indigestion, nausea, diarrhoea, increased bleeding	Should not be used in those with asthma or peptic ulcers. May make skin psoriasis worse
Corticosteroid injections into joint or tendons	Reduces joint or tendon inflammation	Allergy, introduction of infection into joint, flushing, small risk of muscle or tendon wasting	Only limited number of injections should be given to any one joint per year
Methotrexate - by mouth once a week with folic acid supplementation	Reduces cell division so fewer cells are made in the skin, gut and immune system	Bone marrow suppression, nausea, liver problems; increased risk of infection; rash	Used in severe cases under close medical supervision
Sulphasalazine - by mouth in tablet coated to protect the stomach; liquid form available - widely differing doses will suit different people due to rate of processing in the body calculated to body weight	A disease modifying agent also used in rheumatoid arthritis and colitis acts on the chemistry of inflammation to reduce swelling and pain	Headache, nausea, loss of appetite, rash, fever, reduced white blood cell count, mouth ulcers, reduced sperm count in male juveniles of fertile age (reversible), bruising	Regular blood count necessary



Free leaflets

All of these leaflets are available free. Please tick the leaflet(s) you require and send the form back with a self stamped addressed envelope

Send to: PAA Leaflets, PO Box 111, St Albans, Herts. AL2 3JQ UK

Name: _____

Address: _____

_____

Postcode: _____

My Child has Psoriasis

Psoriasis usually appears between the ages of 10 and 30, but it can occur at any age - even in babies and children. Many people inherit a tendency towards psoriasis, yet they do not all go on to suffer from it. However:

- A child has a 1 in 4 chance of developing psoriasis if one parent has it
- If both parents suffer from psoriasis, the risk increases to 3 in 5
- In identical twins there is a high probability of them both being affected. In non-identical twins the risk is about 1 in 5 if one already has psoriasis
- Two in three people with psoriasis are not aware of any previous family history of the condition but it does tend to run in families.

Symptoms only develop if they are triggered by a certain event. In children, psoriasis is often triggered by a bacterial sore throat due to a streptococcal infection. This is known as guttate psoriasis.

What is guttate psoriasis?

Guttate psoriasis mainly affects children aged 8 to 16 years. Symptoms usually appear within 10-14 days of a sore throat. Lots of small, red, scaly patches appear and quickly cover a wide area of the body. Symptoms usually get better within 2-4 months, but sometimes the patches enlarge to form plaque psoriasis. It is essential that in families with a history of psoriasis, any child developing a sore throat is seen quickly by the family doctor, who can begin treatment to reduce the risk of the child going on to develop chronic plaque psoriasis.

What can I do?

You can help your child to cope with psoriasis by explaining that:

- it's not catching
- it is a common skin problem and they are not alone
- you love them just as much with psoriasis as you did before - it is their personality that is important, not their physical appearance
- it is not anyone's fault: it is not due to lack of cleanliness and is certainly not catching
- topical skin treatments can help keep symptoms at bay **(See Factsheet 3)**
- if possible, let them talk or write to another child who also has psoriasis

Visit the school with your child and make sure their teacher knows the essential facts about psoriasis. Take leaflets and factsheets with you to leave behind. Make sure your child feels comfortable talking about psoriasis with you and the teacher, so they will bring any problems to your attention.

The **Anti-Bullying Campaign:** Tel: 0207 378 1446 - can send you a factsheet explaining what you can do if your child is bullied, and what you should expect from the school: 185 Tower Bridge Road, London SE1 2UF E-mail: info@changingfaces.co.uk www.changingfaces.co.uk

Changing Faces: Tel: 0207 706 4232 - Facial psoriasis is rare, but if your child is affected, Changing Faces can help them become more confident: 1-2 Junction Mews, London W2 1PN.

British Red Cross Camouflage Service: 0207 235 5454 - Call for details of your local Therapeutic Beauty Care Officer or write to the National Headquarters at 9 Grosvenor Crescent, London SW1X 7EJ. E-mail; information@redcross.org.uk www.redcross.org.uk

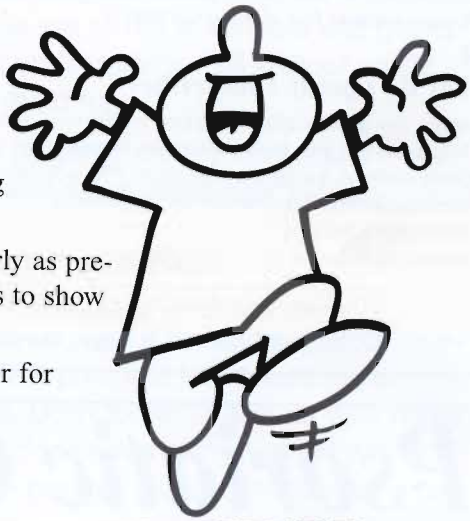
Psoriasis and the Young Adult

The changes that occur in your body during teenage life are stressful enough. When you have psoriasis, they can seem many times worse. Any form of skin disease can cause distress. It is only natural to feel embarrassed if you have visible symptoms.

Loss of confidence and self-esteem can make you feel unattractive and have a negative effect on your life. Unfortunately, the more you worry about your skin, the worse you will feel. Although stress does not cause psoriasis, it can trigger a flare-up.

Looking after your skin

- Regularly use emollient (softening) creams and bath additives. These help to keep moisture in your skin so it stays smooth and supple
- Use your treatment creams regularly as prescribed - these will usually show a good result within 3 to 6 weeks but may be tried for up to 3 months before you notice a response. Feel the treated area with your fingers and continue the treatment that is applied to the skin until the skin feels entirely smooth and normal. Any staining (such as from using dithranol) will clear within two weeks of stopping treatment
- If you have been given tablets to treat severe psoriasis, use these regularly as prescribed. But disease-modifying drugs may take several weeks or months to show a good result.



If you feel your treatment is not working, don't be afraid to see your doctor for advice. Don't just stop your treatments because you feel they are useless.

Tips to help you cope

Remember that 1 in 50 people have psoriasis, so you are not alone;

- Don't stop doing the things you enjoy, like sport. Be positive
- Reach out to people and life - don't withdraw and try to hide
- Aim to keep learning new skills and broadening your horizons
- Try not to take rejections personally. If others discriminate against you, it is through their lack of knowledge - and fear
- Use your experience to understand other people's problems and help them through difficult times
- Camouflage cream can help to damp down the redness of psoriasis so it is less noticeable. Many creams are available on prescription. For information and help, contact the Cosmetic Camouflage volunteer of your local British Red Cross - their number is in the phonebook. This service is available for men and women
- Learn more about your condition.

Organisations that can help

Careline: 0208 220 2290 (10am-4pm and 7-10pm) provides an opportunity to talk through worries, problems and fears with a trained counsellor. Cardinal Heenan Centre 326 Ilford High Road, Ilford, Essex IG1 1QP. Fax: 0208 220 3355

Changing Faces: Tel: 0207 706 4232 - can help with facial disfigurement and camouflage: 1-2 Junction Mews, London W2 1PN. info@changingfaces.co.uk www.changingfaces.co.uk

The British Red Cross: 0207 235 5454 - has a cosmetic camouflage service. Call for the number of your local Therapeutic Beauty Care Officer or write to the National Headquarters at 9 Grosvenor Crescent, London SW1X 7EJ. www.redcross.org.uk

Don't miss out
Get your copy today!
Skin 'N' Bone Connection
20 pages of news and info

Keep in touch with the PAA. Register free

- Opportunity to take part in patient focus group meetings
- Receive relevant free mailings via PAA

OR

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Benefits for 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

SUBSCRIPTION FORM

PLEASE COMPLETE THE FOLLOWING CLEARLY

SECTION 1 & SECTION 2 (optional)

SECTION 1

First Name(s) .....
Last Name .....
Title (Miss, Ms, Mrs., Other) .....
D.o.B .....
Address .....
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..... Postcode.....
Country .....
Telephone .....
Fax .....
E-mail .....
Mobile .....

SECTION 2

I would like to be added to the PAA Register (Free) ☐

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: £ .....

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

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

Signed: .....

Date .....

Psoriatic Care FACT FILE 2nd Edition

A UNIQUE RESOURCE FOR PSORIATIC PATIENTS IS HERE

A completely updated and extended second edition of this popular fact file. It provides instant access to 32 information sheets and additional material written in a simple easy to read style.

This is a book which can act as an essential and practical guide for those with psoriasis, by offering comprehensive useful advice along with contact information for other useful organisations.

Topics include:

PSORIASIS

- *What is Psoriasis?*
- *Psoriasis & the Young Adult*
- *Genital Psoriasis*
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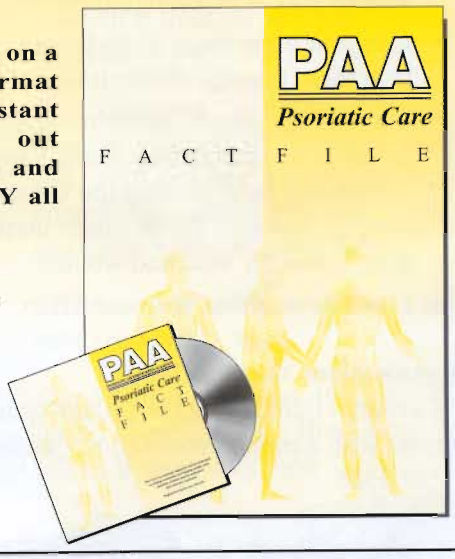

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