

Psoriasis & Psoriatic Arthritis Alliance

About Us



A positive approach

to psoriasis and

psoriatic arthritis



What is PAPAA?

PAPAA is a principal source of advice, support and information on psoriasis and psoriatic arthritis in the United Kingdom.

PAPAA provides support to people with psoriasis and psoriatic arthritis, their families and carers. We also support healthcare professionals and assist the wider community to understand the needs of people affected by both conditions.

About PAPAA

PAPAA was formed because we felt there was a shortage of good information about psoriasis and psoriatic arthritis. You can find out the history of PAPAA on page 6 of this leaflet.

We know only too well the day-to-day struggles of living with a long-term medical condition and the problems that are faced by those with psoriasis and psoriatic arthritis.

We believe that by involving people who are actively affected by psoriasis and psoriatic arthritis, the charity will have the focus and insight needed to provide services that patients in the 21st century really want, whether it's information, a listening ear or a disease management programme. PAPAA aims to provide traditional patient support as well as new innovative approaches that a changing healthcare environment requires. As an organisation, we're dedicated to keeping the patient-centred voice alive.

PAPAA's philosophy

The needs of people with psoriasis and psoriatic arthritis drive everything that we do. All of our activities are delivered in an appropriate way and based on good evidence and input from patients, carers and healthcare professionals.



- PAPAA provides a service to help people with psoriasis and psoriatic arthritis to make an informed choice and understand how to deal with their condition in a constructive and confident way.
- PAPAA provides information that has been approved by healthcare professionals or has been proven beneficial by published evidence.
- PAPAA is a certified member of The Information Standard Scheme, a mark that ensures material is accurate, impartial, balanced, evidence-based and well-written.
- PAPAA does not receive funds from the pharmaceutical industry or commercial sector.
- PAPAA does not link its activities to commercial marketing or public relations campaigns and will only link its name or logo to an activity it believes is beneficial to its constituent group.
- PAPAA does not endorse products or make recommendations.

What does PAPAA offer?

As much or as little as you need, with no obligation. All of our support services are FREE and confidential.

The PAPAA website

We offer access to an extensive range of specialist information on all aspects of psoriasis and psoriatic arthritis, via our website and as printed material.

Our website contains more than 1,000 interesting, informative and well-presented items including:

- insights
- real life stories
- image galleries
- news
- surveys
- quizzes



Accessing information

The website also provides access to free interactive multimedia electronic targeted intervention for psoriasis (eTIPs). eTIPs is a programme that uses cognitive behavioural therapy (CBT) to help the way you think and react to certain situations that may affect your thinking and moods associated with psoriasis.

The website also provides links to PAPAA TV, a YouTube channel which hosts a range of educational short films containing real people's stories about their psoriasis and psoriatic arthritis.

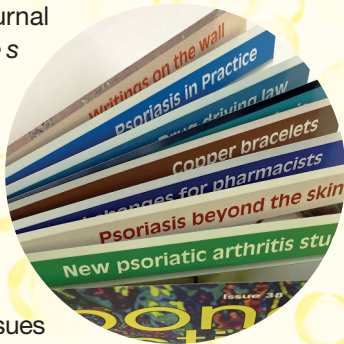
We also have a lively social media presence, with Facebook and Twitter pages. You can find the links to both pages directly from the PAPAA website.



You can order printed information by contacting PAPAA directly by post, telephone, email or by placing an order on our secure ecommerce site: www.psoriasis-shop.org.

Skin 'n' Bones Connection

For those of you who prefer a more traditional way of keeping up to date with the news, we produce a printed bi-annual news journal called *Skin 'n' Bones Connection*, which is available on subscription. Each journal contains a range of articles of interest to people with psoriasis and psoriatic arthritis. Included in the annual subscription is:



- the most recent two issues of the journal
- the next two issues, sent to you when published
- other mailings, such as new leaflets and surveys
- automatic inclusion in the PAPAA register.

The PAPAA register

Although PAPAA does not have a formal membership scheme, you can register free as a supporter via the PAPAA register. The register is a secure database of friends,

supporters and people with or interested in psoriasis, psoriatic arthritis and other related conditions. Only we at PAPAA have access to the register, which we use to carry out surveys, promotional activities and mailings as part of our regular distribution process. The more people we have on the register, the better our research and ongoing activities will be. But it's entirely optional, so even if you opt in, you can opt out at a later date.



What else does PAPAA do?

PAPAA spends a lot of time working on behalf of people with psoriasis and psoriatic arthritis.

- We support medical research via a small grant scheme
- We supply healthcare professionals with information material for patients
- We represent and advocate on behalf of patients
- We raise awareness and respond to the media on relevant issues.

As a charity, PAPAA actively engages with suitable media and responds enthusiastically to requests and invitations to provide the perspective and views of people with psoriasis and psoriatic arthritis. The wide-ranging issues on which we are asked to comment include disease management, guidelines, access to care, drug and treatment evaluation, regulatory and safety concerns.

We also monitor and engage with government agencies such as the National Institute for Health and Care Excellence (NICE), the Scottish Medicine Consortium (SMC), the All Wales Medicines Strategy Group (AWMSG), The Department of Health, Social Services and Public Safety (HPSS) in Northern Ireland and the Medicines and Healthcare Products Regulatory Agency (MHRA). Many healthcare professional groups and medical charities also come to us for advice and input.

Can you get involved with PAPAA?

Yes, we openly encourage your support and involvement, whether you'd like to become a lay reviewer of our material, a fundraiser, a distributor of leaflets or just support us by spreading the word about what PAPAA has to offer. For more ideas, see our website or **Get Involved** leaflet.

How is PAPAA funded?

We believe that in order to retain our independence, we need to be clear about the motivations of our funders/supporters and the potential impact that these may have on PAPAA's reputation.

The majority of PAPAA activities are funded via:

- donations
- subscriptions
- charitable grants



History of PAPAA

PAPAA was founded in 2007 as a joint venture between the Psoriatic Arthropathy Alliance (PAA) (Reg Charity No: 1051169), and the Psoriasis Support Trust (PST) (Reg Charity No: 1088359). The aim was to merge these two charities into a single entity, to establish a single, coherent, principal resource of information and help for people with psoriasis and psoriatic arthritis in the UK.

The PAA was founded by David and Julie Chandler in 1993, as an organisation specifically for people with psoriatic arthritis. David, who has both psoriasis and psoriatic arthritis, was forced to retire from commercial business at the age of 36 through ill-health caused by the conditions.

David and Julie soon discovered that the amount of information and knowledge about the disease was minimal. It was Julie, David's wife, who decided that she could best help David by forming an active group of fellow sufferers to

provide much-needed help and support to her husband as well as others in a similar situation.

The PAA, although set up for psoriatic arthritis, began to cover psoriasis too, because of demand from members and supporters. It quickly became respected among the medical profession and people affected by psoriasis and psoriatic arthritis.

The PAA was supported by a team of unpaid volunteers, including clinical specialists from the fields of dermatology, rheumatology, immunology, physiotherapy, nursing, scientific and pharmaceutical experts, together with input from the worlds of business and public relations.

Its main activity was an education and information programme, which included the *Skin 'n' Bones Connection* journal, the *Psoriatic Care Fact File* and various information leaflets and booklets.

The PST was set up in March 2001 by Charles Peel to help people with psoriasis. With the assistance of medical advice, the trustees reviewed the various treatments available to people with psoriasis. The trustees decided to concentrate on the effects of stress on psoriasis and how people could deal with the psychological effects the condition has. The PST supported, via a grant, the development work of a team at the Department of Medicine (Dermatology) at Hope Hospital, University of Manchester, headed by Prof Christopher Griffiths. This work led to the development of a programme that assists people with psoriasis to deal with their condition in a more effective and positive manner. The PST also provided the PAA with some financial assistance to consolidate its work with patients.

The motivation to merge the original charities was to maximise the combined essence, thrust and strengths into an effective, modern and dynamic organisation, which would continue to put people with psoriasis and psoriatic arthritis first.



The charity for people with psoriasis and psoriatic arthritis

**PAPAA, the single identity of the
Psoriatic Arthropathy Alliance and the
Psoriasis Support Trust.**

**The organisation is independently funded and is a
principal source of information and educational
material for people with psoriasis and psoriatic
arthritis in the UK.**

**PAPAA supports both patients and professionals by
providing material that can be trusted (evidence-
based), which has been approved and contains no
bias or agendas.**

**PAPAA provides positive advice that enables
people to be involved, as they move through
their healthcare journey, in an informed way
which is appropriate for their needs and any
changing circumstances.**

Contact:

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registered in England and Wales No. 6074887**

Registered Charity No. 1118192

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