Charity No: 1118192

About Us

This information is produced by the
Psoriasis and Psoriatic Arthritis Alliance

www.papaa.org

Background

The origins of PAPAA (the Psoriasis and Psoriatic Arthritis Alliance) trace back to 1993 when David and Julie Chandler founded a charity to provide essential support and understanding for those living with psoriatic disease. In 2007, this group merged with another charity established by Charles Peel in 2001, creating the modern and dynamic organisation that the charity is today. Our mission is to highlight the needs of individuals affected by all aspects of psoriatic disease in the UK.

We are a vital resource for individuals affected by the collective conditions. We provide essential advice, support, and information for patients, their families, and caregivers. In addition to our patient-focused initiatives, we equip healthcare professionals with valuable resources to enhance patient care and deepen their understanding.

We recognise the daily challenges of living with long-term medical issues and understand the unique struggles faced by those with psoriatic disease. By actively involving individuals directly impacted by these conditions, we ensure that our services are relevant and responsive to current and future needs—whether through providing information, offering a listening ear, or implementing disease management programmes.

We align with the evolving healthcare landscape and are dedicated to delivering both traditional support and innovative solutions. Our mission is to amplify the psoriatic voice, ensuring it remains at the forefront of our efforts.

Priorities

The needs of the individuals affected are at the heart of everything we do. Our activities are guided by evidence and informed by the insights of real people's lived experiences, caregivers, and healthcare professionals.

- **Empowering choices:** We provide resources that enable people to make informed decisions and manage their conditions confidently and constructively.
- **Evidence-based information:** Our materials have approval from healthcare professionals or are supported by published evidence or collective knowledge, ensuring they are accurate, impartial, balanced, and well-written.
- **Transparency:** To uphold our independence and provide unbiased support, we primarily rely on donations, subscriptions, grants, and other

sources of not-for-profit income generations. When we collaborate with for-profit organisations, we follow strict guidelines to protect our integrity. If the organisation is a pharmaceutical company, we also comply with ABPI standards. All partnerships are evaluated transparently to ensure they align with our mission and benefit our constituents.

- **Neutral stance:** The charity does not endorse specific products or make recommendations, focusing instead on providing unbiased support and information.
- **Confidentiality:** Whether you subscribe, join, visit our website, or request information, you can communicate with us in confidence or even anonymously.

Our commitment to these principles ensures that we remain a trusted source for those navigating psoriatic disease.

Activities

We offer a wide range of information and resources to support individuals affected by psoriatic disease and those who provide their healthcare. Our primary goal is to deliver free, reliable, and accessible information that empowers individuals to effectively manage their conditions.

By offering these resources, we aim to empower and motivate both patients and healthcare professionals with knowledge to improve health outcomes and quality of life.

This includes

- **Useful information:** Clear and concise details on various aspects of psoriatic disease.
- **Real-life stories:** Personal experiences shared by others living with these conditions, including videos, offering insight and inspiration.
- **News and updates:** The latest developments in research, treatments, and our initiatives.
- **Extensive further reading:** In our knowledge bank we provide curated articles and studies for those looking to deepen their understanding.
- **Interactive self-help programmes:** Tools and resources designed to help you manage your condition actively.
- **Image galleries:** Visual resources to better understand the conditions and their effects.
- **Surveys:** Opportunities to share your experiences and contribute to ongoing research and advocacy efforts.
- **Digital news:** A newsletter to keep you updated.
- **Skin 'n' Bones Connection:** A bi-annual news journal, print version or download.

We also actively advocate for people by:

Supporting medical research: Through a small grant scheme to further studies and initiatives.

Providing training for healthcare professionals: Offering programs and materials to enhance patient care.

Advocating for patients: Representing the interests and needs of patients in various forums.

Raising awareness: Engaging with the media on relevant issues related to psoriatic disease.

Socials: Via an active social media presence.

We also monitor and engage with government agencies and healthcare professional groups to ensure that the voices of patients are heard.

Participation

We encourage your support and involvement in various ways, whether you want to become a lay reviewer, a regular donor, a fundraiser, or simply help spread the word about PAPAA.

Funding

To maintain our independence, we clearly outline the motivations of our funders. Our activities are primarily funded through:

- Donations
- Subscriptions
- Charitable grants
- Other income generation

Summary

Get ready to dive into what we do! This brief introduction offers just a glimpse of our work. To unlock the full picture and explore everything we have to offer, head over to our website. For all the details, see the back of this leaflet.