

PAGET'S ASSOCIATION RESEARCH STRATEGY (2019-2024)

CONTEXT

The Paget's Association, also known as the National Association for the Relief of Paget's Disease, is the only UK charity to focus solely on Paget's Disease of Bone in adults. The Association acts as a resource for patients, carers and health professionals, offering high-quality information and support services. Founded in 1973, the Association relies on voluntary contributions, gifts, legacies and fundraising activities to continue and develop its work.

The aims of the charity are to:

- Offer support and information to those with Paget's disease
- Raise awareness of the disease amongst health professionals and the general public
- Support and fund research into all aspects of Paget's disease

RESEARCH PRIORITIES

The Association will consider funding research into any aspect of Paget's disease where there is clear patient benefit. This includes: basic scientific research; clinical research; translational research; curiosity-driven research; educational research, awareness and outreach programs. Applications from exceptional researchers outside of the field will be considered in order to develop new interest in the area, although such applicants are advised to contact the chair of the Research Sub-Committee (RSC) *via* email (research@paget.org.uk) to discuss strategic fit. Applicants should be based in the UK.

Specific priorities have been informed by survey of members and from the *Clinical Guideline on the Diagnosis and Management of Paget's Disease of Bone in Adults [Ralston et al. J Bone Miner Res. 2019 Apr;34(4):579-604]*. (Available from our website, www.paget.org.uk)

Indicative areas include, but are not limited to:

- pain in Paget's disease (e.g. mechanisms, clinical/lifestyle management)
- diagnosis, identification, risk assessment and improving the care pathway of Paget's disease
- epidemiology of Paget's disease
- pathogenic mechanisms (genetic, environmental) of Paget's disease and its complications
- defining therapeutic targets in Paget's disease
- early-stage / 'pump-priming' studies, including as a precursor to clinical trials
- educational programmes to raise awareness of Paget's disease, in patients and health professionals

Applications involving investigators from multiple PACE (Paget's Association Centres of Excellence) sites are particularly encouraged.

MAXIMISING THE POTENTIAL OF OUR RESEARCH AND ENSURING SCIENTIFIC QUALITY

With limited resources and uncertain income streams we aim to maximise our outcomes by offering a flexible range of different funding schemes, including up to:

(2021 Funding)

- **Two Research Project Grants** – to a maximum value of £60,000 each (in exceptional cases larger awards may be considered).
- **Two Flexible Funding Scheme Awards** – of up to £15,000 each:
 - (i) Paget's Recovery Award
 - (ii) COVID-Specific Research Award
- **Two Student Research Bursaries** - of £6,000 each.
- **One Educational Award** – to a maximum value of £6,000.

This research strategy document is a 'living document' and along with our research budget will be reviewed annually by the Research Sub-Committee (RSC) and Trustees, on behalf of patients, carers and members. The Association reserves the right to flexibly direct its annual research budget between the different funding schemes, based on the applications received. The overall research budget will be determined each year by the Board of Trustees.

Open calls for applications will be made (usually annually). Further details about our current funding opportunities and deadlines for submission of applications are published on our website, external websites, sent in emails to researchers (members) on our database, and publicised using our social media channels. Application forms, guidelines and conditions for the award of grants can be downloaded from our website, www.paget.org.uk

Applications will be subject to a rigorous peer review process, including external peer-review (research project grants). Since the costs of many projects are beyond our current resources we will always consider funding partnerships with appropriate partners, including industry.

We are keen that our research reaches the broadest possible audience and researchers funded by the Paget's Association are encouraged to publish in open access journals, to present their work at national/international conferences, to contribute to the Association's quarterly magazine, and to interact with patients and media.

We will monitor research projects and their outputs in terms of new knowledge (e.g. publications, presentations, patents) and outcomes (e.g. improvements in patient care) through annual reports, and report outcomes *via* the RSC to Trustees and members on a regular basis.