



A new strategy

For the Paget's Association's 50th Anniversary year, we have launched a new dynamic strategy for the next 5 years. The charity has a proud history of supporting those affected by Paget's disease, funding and encouraging research into the condition and raising awareness. We will build on this with a modern approach and with flexibility built in, enabling us to progress and adapt.

The Trustees and employees here at the Paget's Association are optimistic for the future and determined to make a positive difference to those who need our help. Are you ready to take this journey with us?



Chair of the Board of Trustees, Professor Stuart Ralston





The Paget's Association's Strategy 2023-2028

1

Continue to increase our reach to support more people affected by Paget's disease, their families, and carers

2

Increase awareness and understanding of Paget's disease among health professionals and the public

3

Promote early diagnosis and holistic care

4

Support Research into Paget's disease

5

Ensure continued good governance

STRATEGY

Objective

1

Continue to increase our reach to support more people affected by Paget's disease, their families, and carers

Rationale

For 50 years the Paget's Association's support services have been a lifeline for those affected by Paget's disease, their families and those who care for them. Acknowledging that people seek information through different channels, we will further enhance our digital presence. In this way, we will be able to support more people to obtain the professional care that they need, as well as a good quality of life.

How we will increase our reach

- As we continue to be the trusted source of information on Paget's disease, we will lead the narrative and challenge myths around the condition.
- Through new investments in external partnerships, we will optimise our use of digital platforms, such as Facebook, to engage with more people who need our help – this will be enhanced by the launch of a new, dynamic and accessible website.
- We will increase our reach both in the UK and internationally through support services, which bring people together to share experiences, learn from each other and find support, i.e. Virtual Paget's Support Groups and face-to-face Paget's Information Events.
- We will continue to provide easily accessible support through

our Paget's Nurse Helpline and by providing evidence-based information in different formats.

- Through initiatives, such as our Focus Group, we will ensure the views of those affected by Paget's disease and their families are heard and considered.
- Review of membership options.

Objective

2

Increase awareness and understanding of Paget's disease among health professionals and the public

Rationale

Lack of awareness must be overcome to prevent unnecessary pain and suffering in those affected by Paget's disease. The Association must significantly increase awareness and address the apparent lack of understanding among health professionals. To ensure individuals seek help early there also needs to be an increased awareness among the general public.

How we will increase awareness and understanding

- We will continue to work with healthcare professionals to ensure our resources are accessible, relevant and helpful to them.
- We will develop new initiatives including digital campaigns and target information where it is most needed.
- The Association will highlight Paget's disease and the Paget's Association within relevant disciplines including orthopaedics and radiology.

- We will seek Paget's Ambassadors, who will raise awareness among healthcare professionals and researchers.
- We will continue discussions with the Association's Focus Group, which consists of those affected by Paget's and also relatives of those with the condition.
- International initiatives and partnerships will increase awareness and understanding overseas.
- International Paget's Awareness Day will intensify our awareness message globally.

Objective

3

Promote early diagnosis and holistic care

Rationale

Paget's disease is underdiagnosed. When a diagnosis is made, it can often be after several years of symptoms. In addition, it is often misdiagnosed, sometimes as cancer. We want to ensure that those affected by Paget's disease are diagnosed early and have access to appropriate specialist care.

How early diagnosis and holistic care will be promoted

- To facilitate access to specialist care across the UK, we will extend the Paget's Association Centre of Excellence scheme, identifying further hospitals where excellence in the care of those with Paget's disease is being achieved.

STRATEGY

- We will seek to lessen missed opportunities for earlier diagnosis and intervention through education, guidance and support for healthcare professionals.
- We will continue to provide evidence-based resources on our website and incorporate feedback on content or additional needs.
- Information for GPs to give to people living with Paget's and their families/carers will continue to be available, with an enhanced priority in this area to foster best practices and raise standards.

Objective

4 Support Research into Paget's disease

Rationale

Better understanding, treatment, prevention, improved quality of life and, one day, a cure, requires high-quality research. The Paget's Association leads the way in supporting pioneering research that improves outcomes for people with Paget's disease.

How we will support research

■ In recognition of the Paget's disease research community in supporting the Association's goals throughout the past 50 years, for 2023 we launched our 50th Anniversary Research Awards, a new flexible funding scheme covering three areas and encouraging collaborative (multi-centre) research.

1. Pump-priming research e.g., pilot studies and/or defined pieces of experimental work that lead to clear opportunities to lever additional external funding
2. Educational activities and programmes that raise awareness about Paget's disease to health professionals and/or the broader public (the Winifred Ditchfield Award)
3. Capacity building in Paget's research, through flexible support for current or new postgraduate projects, or through undergraduate-led research projects e.g. student bursaries

Objective

5 Ensure continued good governance

Rationale

As a registered charity, the Paget's Association has always met its legal and moral obligations.

As legislation and the financial situation change it is important for the Association to be adaptable and flexible in ensuring we continue to demonstrate good governance.

How we will ensure continuing good governance

- We will focus on robust financial management on a daily basis, ensuring sufficient reserves are held while targeting expenditure to areas with maximum benefit for people with Paget's disease.
- We intend to create new income streams and continue to inspire legacies, particularly with the increased use of social media to encourage donations.
- As a charity, we will consider establishing the Paget's Association as a Charitable Incorporated Organisation (CIO) to align with current practice and provide additional benefits.
- Ongoing review and refinement of our policies across all areas will take place to ensure they are fit for purpose.
- We will continue to demonstrate accountability through regular correspondence/meetings with all stakeholders.

Contact us

Contact us if you would like to discuss this strategy

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