

Supporting those affected by Paiget's Disease of Bone, funding research and raising awareness

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Our Chair, Professor Stuart Ralston, receives prestigious award

Chair's message

Dear Friends and Supporters,

Welcome to the Spring issue of Paget's News. As always, the magazine is packed with useful information about Paget's disease, what we are doing to raise awareness, promote research and ensure that people who are affected are provided with accurate information and support.

Our cover highlights the issue of pain which is the most common reason that people with Paget's disease consult their GP. Because of the importance of this symptom, Paget's Awareness Day 2026 focused on the issue of pain with four video interviews. The first was with Anne Lambley, who took part in the ZiPP research study, which investigated the effects of zoledronic acid or placebo (a dummy treatment) in people who had a family history of Paget's. When Anne started the study, she didn't have any pain but by the time she finished the study, she had started to develop pain in her elbow. She initially put this down to her dog pulling on the lead, but tests revealed she had Paget's disease of the humerus bone at her elbow. Fortunately, this symptom responded very well to treatment with zoledronic acid, and she hasn't looked back since (except that her dog still pulls on the lead!). A curious thing that Anne noticed was that when she got a tattoo close to the area affected by Paget's disease, the pain was excruciating – much worse than she had ever experienced before with a tattoo. An insight into the reason for this was provided by the research carried out by Kathryn Berg and Dervil Dockrell, who conducted the Pain in Paget's Disease study (PiP). They explained that in the PiP study, they found heightened sensation in the skin overlying affected bones in people with Paget's disease.

They concluded that this was probably responsible for Anne's tattoo experience and might partly explain why pain in Paget's doesn't always respond to bisphosphonate drugs. Prof Rob Layfield, Vice Chair of the charity, interviewed Professor Chantal Chenu, from the Royal Veterinary College, who had also investigated mechanisms of pain in a disease model of Paget's. It was fascinating to learn that Professor Chenu and her team had also uncovered abnormalities in pain processing, aligning with those found in people with Paget's disease who took part in the PiP study. Professor Chenu speculated that these abnormalities could also go some way to explaining the frequent occurrence of pain in people with Paget's. The final interview was with Professor Lesley Colvin, an internationally recognised expert on the mechanisms of pain and its treatment and Chair of the SIGN guideline on pain. Professor Colvin gave a fascinating account of how the pain system works, explaining that damage to, or changes in shape of the bones in Paget's disease could not only trigger local pain but pain at other sites. If you haven't yet had a chance to view these interviews, I highly recommend it.

We also have an article featuring our Patron, Recardo Patrick, on page 6 of the magazine. Recardo was diagnosed with Paget's disease relatively early in his late 40's but was treated promptly and has provided unwavering support to the charity ever since. As an orphan, he moved between one foster home to another but in his early teens he discovered music, joining the group "Sweet Sensation" who earned international acclaim. The rest, as they say, is history. Recardo is now a successful entrepreneur, having founded nightclubs in Ibiza and Mallorca,

as well as being a successful restaurateur and businessman. Please take some time to read his profile in Rolling Stone magazine by scanning the QR code on page 6.

Although I haven't yet reached the dizzy heights of making Rolling Stone, Diana Wilkinson has put together two pieces dedicated to me on pages 12 and 13 of the magazine. The first focused on a meeting where I hosted friends, family and colleagues on 29 January in a series of lectures to mark my retirement from Edinburgh University. It's not a complete retirement though, as I'll continue to see patients with Paget's and other bone diseases in NHS Lothian, as well as continuing my work with the Charity, while having more time to spend with family and watching Partick Thistle F.C., my favourite football team. I was also honoured to receive the Sir James Black Medal from the Royal Society of Edinburgh towards the end of last year, as featured on page 13. The medal was awarded for my work on research into causes and treatment of bone disease, medical education and my work for the MHRA, where I held the position of Chair of the Commission for Human Medicines between 2013 and 2021, during which time the Commission advised the MHRA on licensing of COVID-19 vaccines.

Turning back to the Charity, I want to draw your attention to the fact that we will soon be transferring the assets of the National Association for Relief of Paget's disease to the Paget's Disease of Bone Association, which is a Charitable Incorporated Organisation (CIO). The Trustees decided to make this change for several reasons and we hope that the new charity will be fully up and running by the start of 2027.

continued overleaf

Please be assured that our mission to support people with Paget's will remain the same as it has always been for over 50 years.

As many of our readers know, deformity or bending of the bones can occur in Paget's disease, particularly when a weight bearing bone like the tibia (shin bone) is involved. That's exactly what happened to Alan Kidney whose experience is documented on page 21. Luckily, the deformed bone was picked up by Allan's GP who felt it might be Paget's disease, and he was successfully treated with risedronate. Although this didn't reverse the deformity, it helped the pain, allowing him to return to his hobby of ballroom dancing.

As you all know, our work is critically dependent on fundraising activities so I hope you'll explore ways to support us, whether by backing Diana and Brian's gliding adventure featured on pages 22-23, setting up a monthly donation, sponsoring Darcie, Ben and Abigail, who are some of our Marathon runners (page 30) or by hosting a coffee morning (hints and materials are provided on pages 14 to 18). On the subject of fundraising, I would like to acknowledge the tremendous support the Charity has had from Professor Grayson Ditchfield in memory of his late mother, Winifred, who had Paget's disease.

In closing, I hope that some of you will be able to join me at one of the upcoming information events this year. The first, hosted by Dr Judith Bubbear, will be held at the Village Hotel near Watford on 11 June and the second, hosted by Drs Nishanthi Thalayasingam and Nadia Tripp, will be held in Newcastle on 17 September.

With very best wishes to all.

Stuart Ralston
Chair, Paget's Association



Our charity and purpose

The Paget's Association is more formally known as The National Association for the Relief of Paget's Disease (NARPD). We are a UK charity, founded in 1973 by Ann Stansfield. We are currently in the process of converting to a Charitable Incorporated Organisation (CIO), which is a more modern structure. During this transition, you may notice two entries on the Charity Commission's register: our long-standing charity, The National Association for the Relief of Paget's Disease, and our newly created CIO, The Paget's Disease of Bone Association. Both will operate side by side for a period to ensure a smooth transition.

We are committed to preserving and protecting the health of people affected by Paget's Disease of Bone by providing information and support, raising awareness, supporting and funding research, collaborating with relevant organisations and taking any other actions that benefit those with the condition, their families, and carers.

Paget's Nurse Helpline

Our Helpline is available to offer support and answer any questions you may have about Paget's disease.

Email helpline@paget.org.uk

Telephone 0161 799 4646 (office)
 07713 568197 (mobile)

Post please use the address below



Website and social media

Our website provides a wealth of information and resources.

www.paget.org.uk

Why not connect with us on social media for updates and support?



Contact us

Email for all enquiries:
membership@paget.org.uk

Chair of the Association, Professor Stuart Ralston: chair@paget.org.uk

Telephone for all enquiries: **0161 799 4646**

Postal address

Write to us at The Paget's Association,
 Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX



Come along to a Paget's information day

Our popular, free Paget's Information Days offer a warm, reassuring space for anyone affected by Paget's disease, whether you're living with the condition yourself or supporting a family member. Health professionals are also very welcome to attend. These events are designed to help those with Paget's disease feel informed, supported and part of a community. The feedback we receive from these events is consistently excellent.

What you can expect

- **Expert speakers** sharing up-to-date insights on Paget's disease
- **Clear talks** covering a range of topics
- **Plenty of time for questions** in a relaxed atmosphere
- **Opportunities to connect** with others who may share similar experiences
- **Complimentary lunch** and refreshments

Whether you're newly diagnosed or simply looking to deepen your understanding, we will give you a warm welcome.

Booking essential

Places must be reserved in advance. You're very welcome to bring someone with you, just remember to book a place for them too.

To reserve your place, contact us by email membership@paget.org.uk or phone **0161 799 4646**. When booking, please let us know how many places you need and any food allergies or specific dietary requirements.

- If you have any questions, we're here to help. Please get in touch using the contact details above.

We look forward to welcoming you and offering the information and support you need.



Elstree – 11 June 2026

Venue: Village Hotel (Watford), Centennial Park, Centennial Avenue, Elstree, Borehamwood WD6 3SB

Host: Dr Judith Bubbear, Consultant in Metabolic Bone Disease at the Royal National Orthopaedic Hospital, Stanmore

Chair: Professor Stuart Ralston, Chair of the Paget's Association, renowned rheumatologist and researcher in Edinburgh.

Newcastle – 17 September 2026

Venue: The County Hotel, Neville Street, Newcastle upon Tyne NE1 5DF

Hosts: Rheumatologists, Dr Nishanthi Thalayasingam and Dr Nadia Tripp, from the Freeman Hospital.

Chair: Professor Stuart Ralston, Chair of the Paget's Association, renowned rheumatologist and researcher in Edinburgh.

The Recardo Patrick story

As a Patron of the Paget's Association, Recardo Patrick is a voice for those navigating the pain and concerns that come with having Paget's disease. But long before he was diagnosed, he was a child in England who spoke only to trees. The story of his career was profiled in Rolling Stone (France) in October. From disco fame with Sweet Sensation to reshaping the global nightlife scene, here's a glimpse into the man behind the music, the deals and the determination.

Silence to spotlight

Recardo Patrick's story begins in silence. As a child in England, he spent two years speaking only to trees, he was shuffled between foster homes, and was unaware of Christmas until he was twelve. Music became his first language. At 14, he joined the disco group Sweet Sensation, dazzling audiences and earning praise from legends like Diana Ross and Johnny Wilder.



Ibiza

As the pop wave faded, a call from Brasilio de Oliveira, founder of Ku, the world's largest club (later Privilege), changed everything. Recardo was invited to Ibiza, where he shared stages with George Michael and Freddie Mercury. It was the start of a new chapter.

The broker

In London, Granada Television was preparing to sell off its club holdings. He arrived at the shareholders' meeting without notes, yet effortlessly recited figures, profit margins and rental rates entirely from memory. He became the man for seemingly impossible deals.

AMØK

During the COVID-19 pandemic, he co-founded AMØK with Oscar Ruiz del Río and Alberto Dubois. AMØK is a club housed in a former theatre in Palma, where partying becomes a full cultural experience. Recardo commented, "AMØK isn't just a nightclub. It's a sensory laboratory. We can evoke the same sensations as with alcohol or drugs, simply through sound frequencies and smells." AMØK hosts fashion shows, art exhibitions, gastronomic evenings and charity events, all with a commitment to inclusivity.

You can find the original article on Rolling Stone France's website by scanning the QR code below.



Patron and patient

Beyond the stage and boardroom, Recardo is also passionate about health, maintaining a rigorous fitness routine. After being diagnosed with Paget's disease at age 48, he went on to become a Patron of the Paget's Association.

His journey with Paget's began with pain radiating down his thigh, which led to a diagnosis of Paget's disease in his right pelvis. He received an infusion of zoledronate, a treatment that caused brief flu-like symptoms but ultimately eliminated his pain. Years later, he remains symptom-free and undergoes annual monitoring. Paget's disease doesn't stop him from doing anything but he's deeply aware of how debilitating Paget's disease can be for others and hopes for a cure.



Scan the QR code to watch Recardo's interview with our Chair, Professor Stuart Ralston, on our website.

A new chapter for our charity

We want to share some important news. In April 2023, we held an Extraordinary General Meeting (EGM), where our members voted in favour of beginning the process to convert our charity into a Charitable Incorporated Organisation (CIO). Since then, we've been working carefully to ensure that this transition is as smooth as possible. This change marks an important step in strengthening our structure and securing a resilient future.

What is a CIO?

A CIO is a legal structure designed specifically for charities that wish to operate as a corporate body. It offers company-like benefits with simpler regulation. We are registered with the Charity Commission rather than Companies House. Our Trustees have limited liability and we can enter into contracts and hold property in our own name.

Two charities

If you visit the Charity Commission's website, you may notice that two charities are currently listed:

- **The National Association for the Relief of Paget's Disease (The Paget's Association)**

Founded by Ann Stansfield in 1973, she laid the foundation for our enduring mission to support those affected by Paget's Disease. Officially registered as **The National Association for the Relief of Paget's Disease**, we operate day to day as **The Paget's Association** (registered charity no. 266071). We've been providing information and support, funding and encouraging research, and raising awareness ever since.

- **The Paget's Disease of Bone Association**

This is our newly registered CIO, which has an improved name for clarity, as several other conditions also bear the Paget name. We officially registered **The Paget's Disease of Bone Association** on 9 June 2025 (registered charity no. 1213575).

As we move forward with the transition, we want to reassure you that we're handling it with continuity in mind. For a period, both our old and new charities will operate side by side. This overlap allows us to complete the legal and administrative steps smoothly.



The logo features the word 'Paget's' in a large, blue, sans-serif font. Below it, the words 'Disease of Bone Association' are written in a smaller, green, sans-serif font. The entire logo is enclosed in a rounded rectangular border.

New logo

During our transition to the Paget's Disease of Bone Association, our updated logo will begin to appear on our publications and digital platforms.

Here's what you can expect

- **Operational continuity:** our services, Paget's Helpline and research commitments continue as normal.
- **Contact details:** our registered office and contact details remain unchanged.
- **The same Trustees and staff:** the people you know and trust will continue their work.
- **Transfer of assets:** all funds, assets and resources will transfer to the new CIO, ensuring our work on behalf of those affected by Paget's disease continues seamlessly.
- **Membership:** if you are currently a member of the Paget's Association (NARPD), we will contact you in due course regarding the transfer of your membership to the Paget's Disease of Bone Association. Meanwhile, you will continue to be a member of the NARPD.

We're grateful for your ongoing support and look forward to continuing this journey together as we enter this exciting new chapter. We also extend our sincere thanks to Trustee Mohamed El Erian and Jones Day, London, for their generous *pro bono* support on this important transition.

International Paget's Awareness Day

Paget's Awareness Day 2026 focuses on pain

The Paget's Association is committed to promoting earlier diagnosis to reduce the pain, anxiety and distress caused by Paget's disease. For International Paget's Awareness Day on 11 January 2026, we placed a spotlight on one of the most significant aspects of the condition: pain. To mark the day, we released four new video interviews exploring the latest research and lived experiences that help us understand pain in Paget's disease. The videos are summarised below.

How to watch the videos

To view the videos, visit our website:

<https://paget.org.uk/pagets-awareness-day-2026/>

or scan the QR code.



Beyond ordinary pain: Anne's experience

Chair of the Paget's Association, Professor Stuart Ralston, spoke with Anne Lambley, who lives with Paget's disease and took part in a Paget's research study (ZiPP) for several years. Anne first noticed a dull ache in her left elbow in 2019, which she initially put down to her dog pulling on the lead. During final assessments, in Edinburgh, for the research, she learned that she had developed Paget's disease in her elbow and, to a lesser extent, in her skull.

Anne described her most severe episode of Paget's-related pain, which occurred in 2024 while she was getting a tattoo on her left arm. With several tattoos already, she expected the usual level of discomfort, but as the artist worked near the Pagetic area, the pain became excruciating. She became sweaty, alternately hot and cold, nauseous and light-headed, a reaction far beyond anything she had ever experienced.

Anne's experience reflects findings from the Pain in Paget's research study, funded by the Paget's Association. This study showed that the skin covering Pagetic bone is significantly more sensitive than normal. Anne now believes this heightened sensitivity explains the extreme discomfort she experienced.



Video watch time is approximately 6 minutes.



Research uncovers surprising skin sensitivity

Researchers Kathryn Berg and Dervil Dockrell spoke with Professor Ralston about the Pain in Paget's Disease study. Using Quantitative Sensory Testing (QST), they assessed sensory responses, touch, temperature and pinprick, in people living with Paget's disease. QST can identify sensory changes in individuals who are not currently experiencing pain. Notably, the research

revealed heightened sensitivity to pain and vibration over affected bones, offering valuable new insight into why some people with Paget's disease experience particularly intense or unusual pain sensations.



Video watch time is approximately 4 minutes.



Understanding pain mechanisms

Professor Rob Layfield, Chair of the Association's Research Sub-Committee, interviewed Professor Chantal Chenu. Her Paget's Association-funded study, Contribution of Acidosis to Chronic Pain in Paget's Disease, helps build a clearer picture of the underlying molecular mechanisms driving pain in Paget's. She emphasised that bone is a highly active tissue, rich in nerves and blood vessels. Reflecting on the study's findings, she noted that the results align with the QST research from Edinburgh, supporting the idea that people with Paget's

disease may experience altered sensory processing and also lower pain thresholds. These factors could help explain aspects of chronic pain. The team also observed notable differences in bone architecture between sexes.



Video watch time is approximately 8 minutes.



Why pain doesn't always respond to treatment

Professor Lesley Colvin, Chair of Pain Medicine and Honorary Consultant in Anaesthesia and Pain Medicine, at the University of Dundee, joined Professor Stuart Ralston to discuss recent findings and management. Professor Colvin is a co-author of the new SIGN (Scottish Intercollegiate Guidelines Network) guideline (details on page 10) on the management of chronic pain (part 1). Professor Colvin explored pain mechanisms and possible reasons why pain in some people with Paget's disease does not respond to bisphosphonate treatment.

Professor Colvin explained that the pain system is constantly adapting, so damage from Paget's disease can trigger changes not only at the site of the affected bone but anywhere along the pain system, from the bone to the spinal cord and the brain. So, she accepted that it can be a challenge when treating the pain. Bisphosphonates for Paget's disease work well in some people and not so well in others. QST might be able to help understand the mechanisms in the individual so that doctors can direct treatment to improve treatment outcomes.

Is medicinal cannabis an option?

Professor Colvin mentioned medicinal cannabis, as patients often ask about it. The scientific evidence supporting medicinal cannabis remains weak, while the potential for harm is significant. The recommendation in the new SIGN guideline is that medicinal cannabis should not be used outside the context of a clinical trial.

What about diet and exercise?

The forthcoming part 2 of the SIGN guideline will include guidance on diet and exercise in relation to pain. Professor Colvin briefly commented that dietary supplements may have short-term benefits but the long-term impact is unclear. She was keen to stress that increasing physical activity shows the most consistent benefit with minimal harm for managing chronic pain.



Video watch time is approximately 13 minutes.

New pain guidelines

New guidelines relating to pain were published by the Scottish Intercollegiate Guidelines Network (SIGN) in December 2025. They focus on the management of chronic, non-malignant pain in adults (defined as pain lasting longer than 12 weeks). They were developed using standard methodology informed by a systematic review of the available evidence and are intended for healthcare professionals in both primary and secondary care who support people living with chronic pain. The guidelines do not cover pain caused by cancer or migraine.

Part 1

The first part of the guideline explains different options that might help with managing pain. It covers medicines such as opioids, naloxone, medicinal cannabis and antidepressants, as well as programmes that support people to live well with pain. These include pain management courses, psychological therapies, self-help approaches and activities that focus on managing pain in everyday life, both at home and at work.



You can read the SIGN guideline (Part 1) by scanning the QR code or by visiting <https://www.sign.ac.uk/guidelines/management-of-chronic-pain/>

Part 2

The second part of the guideline, which will be published this year, will look at a wide range of treatments that may help people manage pain. It will include information on medicines such as muscle relaxants, simple painkillers, topical treatments and antiepileptic drugs, as well as combinations of different medicines. It will also explore non-drug options, including hands-on and hands-off physical therapies, electrotherapy, alternative interventions and dietary approaches.

Booklet for patients, families and carers

The team are also producing a booklet for patients, families and carers that explains pain, outlines available support, offers self-management strategies and describes the care they can expect.

People's Friend magazine helps raise awareness

The health and wellbeing pages of The People's Friend magazine featured a section on Paget's disease in its 10 January edition. The article outlined how the condition can have a significant impact on those living with it and helped raise awareness among a wider audience who may not otherwise encounter information about the disease. Following its publication, readers contacted our Helpline to seek further advice and support, demonstrating the value of this kind of publicity.



Starting the year with insight

Thank you to everyone who joined us online on 8 January for our live question and answer session with Professor Stuart Ralston. We were delighted to welcome participants from across the UK and around the world for an engaging hour focused on Paget's disease. Our sincere thanks go to Professor Ralston for sharing his expertise and answering questions, and to all who took part. Your involvement helped make the session a success.

Your perspective matters!

Have you completed our shared experiences survey?

If you're living with Paget's Disease of Bone, we'd love to hear from you. Our anonymous survey explores shared experiences - things like occupation, environment and diet. It is purely for interest to see if we can spot common themes. In due course, we intend to publish a brief summary, with responses anonymised, in this magazine.

You may have received the survey by email. Please only complete it once.

Visit <https://forms.office.com/e/p48fJmRzfm> or scan the QR code. You will also find it in the news section of our website.



A simple and free way to turn your shopping into donations

Did you know you can support the Paget's Association when you shop online and there's no cost to you? Through easyfundraising, over 8,000 retailers will donate a percentage of what you spend. The donation comes from the brand, not you! These donations really add up and make a meaningful difference to our work. If you haven't joined yet, it only takes a few minutes.

1. Sign up for free online

Create your easyfundraising account and choose the Paget's Association as your cause.

Visit www.easyfundraising.org.uk

If you're shopping on a phone, you can download the easyfundraising app from the Apple store for iPhone or from the Play Store for Android.



2. Enable the Donation Reminder

The Donation Reminder is a handy reminder that tells you when a donation is available while you're visiting your favourite brands. If you enable this, there's no need to visit easyfundraising each time you shop.

3. Shop as normal

When you buy something, the retailer sends a donation to us. It's simple and free.

4. Track your impact

You can see the total raised and the Paget's Association will receive regular payments from easyfundraising.

easyfundraising turns your online shopping into everyday magic



easyfundraising

You shop, brands donate to us

Festschrift celebrates the career of Professor Stuart Ralston

Professor Stuart Ralston, Chair of the Paget's Association and Professor of Rheumatology at the University of Edinburgh, was celebrated in January at a Festschrift, a special event honouring the career and lasting influence of a leading figure in their field. Held in the Institute of Genetics and Cancer Lecture Theatre at the Western General Hospital in Edinburgh, the occasion combined cutting-edge science with genuine warmth and humour. Collaborators and former mentees from across the years came together to recognise Professor Ralston's remarkable contributions to the understanding of different aspects of bone disease, alongside heartfelt reflections from former students whose careers and confidence he helped to shape.



Professor Ralston (front right) with some of those who attended the event

Over an extraordinary career, Professor Ralston's research has shaped clinical practice, informed national policy and improved outcomes for countless patients. His contributions to medical education are also significant; as an editor of the textbook Davidson's Principles and Practice of Medicine, he fondly recalled being described by colleagues in India as a "living legend". He has also played a pivotal role in national leadership on medicines regulation, including overseeing the emergency approval of COVID-19 vaccines as Chair of the Commission on Human Medicines.



Professor Ralston (left) is congratulated by Professor Rob Layfield (right)

Most recently, his achievements were recognised with the Royal Society of Edinburgh's Sir James Black Medal, awarded in December 2025.

The Festschrift featured five bone-themed sessions, with speakers from the UK and overseas reflecting the breadth of Professor Ralston's influence across genetics, clinical care and translational science. A dedicated session on Paget's disease included presentations from Professors Omar Albagha (Qatar) and Rob Layfield (Nottingham), Chair of the Paget's Association's Research Subcommittee and Vice-Chair of the charity. They spoke of Stuart's guidance, collaborative spirit and lasting impact on both scientific understanding and patient care. Professor Layfield reflected on a 25-year collaboration that began when Stuart invited him to Aberdeen, an invitation that saw him bitten by the Paget's research bug. He described their work together as fun, productive and genuinely collaborative, highlighting how their research significantly advanced knowledge of the disease.

Professor Ralston described himself as a clinician who strayed into research. His career took him from Glasgow to Aberdeen and then to Edinburgh. Many people with Paget's disease, including members of the Paget's Association, took part in his clinical studies. The PRISM study, the largest clinical trial ever conducted in Paget's disease, was followed by

the ZiPP study, which demonstrated that targeted genetic testing and early treatment with zoledronic acid (a bisphosphonate) can have a profound impact on early Paget's disease. These findings are expected to shape future NHS practice. His most recent research focused on understanding pain in Paget's disease – the symptom most commonly experienced by those living with the condition.

Throughout the day, affectionate tributes punctuated the science.

Professor David Reid recalled the encouragement he received early in his academic career, while Professor Struan Grant joked that, as Professor Ralston's first PhD student, he had saved him from a career in accountancy.

Sir Gordon Duff captured the feeling in the room, describing Professor Ralston as a true giant in his field. To close the day, a message arrived from Tony Watt, striker for Partick Thistle F.C., offering heartfelt congratulations

on his retirement and acknowledging his many achievements. As a devoted fan, this was a particularly special moment for Professor Ralston.

As he enters flexible retirement, Professor Ralston looks forward to spending more time with his family and travelling widely. He is continuing in his role as Chair of the Paget's Association. We congratulate him on a remarkable career and celebrate the invaluable work he continues to carry out for those affected by Paget's disease.

Professor Stuart Ralston receives prestigious award

Our Chair, Stuart Ralston, Professor of Rheumatology at the University of Edinburgh, was one of ten distinguished individuals from across a range of disciplines, including medicine, disease research, marine biology, law, astrophysics and machine learning, who attended a reception at the Royal Society of Edinburgh (RSE) to receive the Sir James Black Medal. Sir James Whyte Black (1924 -2010) was awarded a Knighthood in 1981, the Nobel Prize for Medicine in 1988, the Order of Merit in 2000 and the RSE Royal Medal in 2001.

The Sir James Black Medal celebrates individuals whose exceptional contributions have advanced Scotland's research landscape. Their work not only elevates Scotland's global reputation but also improves lives around the world. The 2025 awards were presented by Professor Anne Anderson, RSE Vice-President of Research, who warmly congratulated all recipients on their achievements.

Transformative contributions to medicine and public health

Professor Ralston is internationally renowned for his pioneering research into bone and joint disease, work that has revolutionised patient care and informed national guidelines. His commitment to medical education has influenced and inspired generations of students and professionals across the globe.



Throughout his career, Professor Ralston has demonstrated exceptional insight, innovation and leadership, having a profound impact both in the UK and internationally. As Chair of the Medicines and Healthcare products Regulatory Agency (MHRA), he played a national role in overseeing the safety of medicines. The MHRA advised on the emergency approval of the COVID-19 vaccines which saved countless lives.

Professor Ralston said, "I am honoured to accept this award on behalf of my current research team at the University of Edinburgh and other collaborators that I've worked with over the past four decades. I would like to acknowledge the funding I've received from Versus Arthritis, the NIHR, the European Research Council and the Royal Osteoporosis Society, which has supported the programmes of research that I have been involved with to gain a greater understanding of the causes of bone disease and to optimise treatment strategies. I've also been fortunate to contribute to medical education worldwide as an author and editor of Davidson's Principles and Practice of Medicine and to have played a role in Medicines Regulation in the UK as Chair of the Commission for Human Medicines between 2013 and 2021, during which time the Commission provided advice to the MHRA on the licensing of COVID vaccines."

The 2026 Big Spring Coffee Morning for Paget's

Mark your calendars for the 2026 Big Spring Coffee Morning! We have brewed up another opportunity to raise vital funds and awareness for those living with Paget's disease.

Saturday 30 May 2026 or choose a date to suit you!

We'd love for as many members and supporters as possible to take part on 30 May, but you are welcome to host your coffee morning on any date that suits you. Whether it's a small catch-up with a few friends or a larger gathering with colleagues, every event makes a difference. Bring people together, enjoy delicious treats and support a cause that truly matters to you.



How to get involved

1. Pick your venue

Decide where you'd like to host your coffee morning, whether it's in your kitchen, your garden, or any welcoming space where people can comfortably come together.

2. Spread the word

Decide who you'd like to invite – friends, family, neighbours and/or colleagues. Let your guests know that by simply coming along and making a small donation, they'll be helping the Paget's Association continue its vital work.

You're welcome to use the invitations on the next page, download additional printable invites from our website, or get in touch and we'll happily send some by post. Alternatively, a simple email explaining what you're doing and why is just as effective.

3. Plan the treats

Bake your favourite cakes or pick up a tempting selection from your local shop - whatever works best for you. You might also like to include a fruit platter or lighter options for guests who prefer them.

4. Hold your event

Make sure a donation jar is clearly visible (just use an empty jar tied with ribbon). Add a sign displaying a QR code linking to the Paget's Association donation page (we can help with this!). You may wish to say a few words about why you're hosting the event and how their support makes a difference. Most importantly, enjoy the occasion and celebrate the impact you're making together.

5. Submit the funds raised

Pay in the money you've raised quickly and securely via our website or send a cheque (payable to the Paget's Association) to the address on page 4. Every contribution helps us support people affected by Paget's disease. Thank you for your support and for making a real difference.

Need support? We'll help!

To help make your coffee morning a success, if you would like banners, a QR code, posters or leaflets, simply email membership@paget.org.uk or call **0161 7994646**. You can also download digital leaflets from our website to email to your guests or simply send them a link to the site so they can learn more and donate directly.



Paget's
Association



You're Invited!

**Join me for the 2026 Big Spring
Coffee Morning for Paget's**

Enjoy coffee and cake while helping raise
awareness and vital funds for those
affected by Paget's disease

Date

time

at

.....



*Guests are asked to make a donation to
support the work of the Paget's Association*



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Big Spring Coffee Morning invitations REVERSE – please cut along dotted line



Paget's disease is a bone disorder in which the normal cycle of bone renewal and repair is disrupted. This can lead to pain, deformity and complications such as fractures.

The Paget's Association is a registered UK charity dedicated to improving the lives of those affected by the condition by:

- ✔ **Providing expert support and reliable information**
- ✔ **Raising awareness to promote understanding and early diagnosis**
- ✔ **Encouraging and funding vital research**

Together, we can bring help to those who need it most.

Thank you!



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Thank you!



Remembering Winifred

The Paget's Association is deeply grateful for the ongoing support of families affected by Paget's disease. Among them is Professor Grayson Ditchfield, whose late mother, Winifred, lived with the condition.

Mrs Winifred Ditchfield was diagnosed with Paget's disease of the spine and neck in 1989. When she joined the Paget's Association the following year, she received a personal letter of welcome from the Founder, Mrs Ann Stansfield MBE. This was a gesture that left a lasting impression.

Through her work as medical secretary to the distinguished orthopaedic surgeon Sir Harry Platt (1886-1986) at Manchester Royal Infirmary, Mrs Ditchfield had a strong understanding of bone conditions. This knowledge, combined with the support and reassurance provided by the Association, helped her to navigate her own diagnosis and to empathise with others.



“
Mrs Ditchfield greatly valued the clear information and sense of community offered through the Association's regular newsletters
”

Sir Harry Platt, President of the Royal College of Surgeons from 1954 to 1957, was a prominent figure in the development of orthopaedic surgery and also played an active role in the creation of the National Health Service.

A generous supporter of the charity until her death in February 1996, Mrs Ditchfield greatly valued the clear information and sense of community offered through the Association's regular newsletters. Thirty years later, Professor Ditchfield remains an avid supporter of our cause, continuing his mother's legacy. We thank him sincerely for his enduring commitment to the Paget's Association and the families we support.

Be one of the 200

We would love to sell all 200 tickets for the Paget's Association Raffle. Will you help us get there? With only 200 tickets in the draw, your chances of winning are great. Even better, every ticket directly supports our vital work. For just £5 a month, you can be entered into our monthly draw to win £100 or £50 and in June and December, those prizes are doubled! Anyone aged 18 or over can take part. Whether you buy one ticket or two, you will be helping our cause.

Joining is easy!

Simply email membership@paget.org.uk or call 0161 799 4646 to let us know you'd like to join.

Winners

NOVEMBER 2025

1st Prize £100 / Ticket no. 198
Anita Priestley, Leeds

2nd Prize £50 / Ticket no. 115
Iris Scriven, Newark

DECEMBER 2025

Double prize draw
1st Prize £200 / Ticket no. 36
Alan Howison, Hinckley
2nd Prize £100 / Ticket no. 49
Alan Howison, Hinckley

JANUARY 2026

1st Prize £100 / Ticket no. 67
Valerie Smith, Belgium

2nd Prize £50 / Ticket no. 4
Thomas Trevor, Oswestry

FEBRUARY 2026

1st Prize £100 / Ticket no. 185
Christine Cratchley, London
2nd Prize £50 / Ticket no. 135
Maureen Jones, Liverpool

Changes in bone shape

Paget's disease disrupts the delicate balance of bone renewal, which may lead to structural changes that can affect quality of life. When Paget's disease was first described by Sir James Paget in 1877, one of the presenting features of his original patient was that he had bowed limbs and an expanding skull, leading to him requiring progressively larger hats. It is encouraging news that Paget's disease has become less common and less severe.

What causes bone to become misshapen?

Understanding how Paget's disease affects the bone starts with knowing how healthy bone naturally renews itself. Bone is a living tissue that is constantly renewed and repaired through a process called bone remodelling. In healthy bone this process is well-regulated, producing new bone in an organised, structured way. When examining normal bone under a microscope, a uniform pattern can be seen. In Paget's disease, the rate of bone remodelling becomes markedly accelerated. The new bone, known as Pagetic bone, forms in a disorganised way and an irregular pattern is apparent when viewed under a microscope. This abnormal bone is structurally weaker than healthy bone and often becomes enlarged and misshapen. These changes develop gradually over several years and may be noticeable or they may only be detected when an x-ray is taken. These gradual changes can alter the shape of the affected bone and sometimes lead to visible differences in appearance, such as enlargement, bending or changes in symmetry.

Symptoms caused by changes in bone shape

Symptoms will depend on which bones are affected by Paget's disease. If, for example, the bones of the leg are affected, they may bend under the stress of carrying body weight. As the bone bends, it changes how it carries weight. With the thigh bone (femur), the inner



Paget's disease affecting the skull can cause the head to enlarge over time, sometimes meaning that progressively larger hat sizes are needed

side tends to become thicker, and in contrast, the outer side becomes thinner and weaker. This weaker area is more likely to develop small cracks, known as stress fractures, which can cause pain and may develop into a complete fracture. A bowed leg can also make the leg shorter than the other. This may affect walking and cause pain.

An enlarged bone can put extra strain on nearby joints, leading to joint pain or osteoarthritis. This is common in the hip joint when the pelvis is affected. When the skull is affected, there may be a visible increase in the size of the skull and a high forehead may be noticed.

In some cases, an enlarged bone may press on a nerve, causing symptoms such as pain, tingling, numbness or weakness.

Can changes in bone shape be prevented or treated?

While existing changes in bone shape cannot be reversed with medication, treatment with bisphosphonates can help slow or sometimes prevent further changes. Bisphosphonates are commonly used to calm the overactive bone-remodelling process, helping to reduce pain, prevent or slow further changes and lower the risk of fractures. Depending on which bones are affected, supportive aids, including walking aids or shoe inserts, may be beneficial. In more severe cases, surgery may be required to repair fractures, realign significantly bowed bones or replace damaged joints, such as the hip joint.

Straightening a bent bone

In Paget's disease bending of the long bones that take the weight of the body, such as the femur or shin (tibia) bone can make the bone more likely to fracture. The bend in the bone may put abnormal stresses on the surrounding tissues and cause pain. An orthopaedic surgeon may recommend straightening the bone by an osteotomy operation. Osteotomy means 'cutting of the bone'. It may also be carried out to shorten or lengthen a bone.

Have you experienced changes in bone shape?

Get in touch by email: diana.wilkison@paget.org.uk or by post to The Paget's Association, Jactin House, 24 Hood Street, Ancoats, M4 6WX.



This gentleman's upper arm has bent due to Paget's disease in his humerus



Paget's disease has caused enlargement of the lower arm



Paget's disease has affected this lady's leg, causing it to bow

Allan's experience

Allan Kidney's experience offers a personal look at how changes in the shape of a bone can be easily missed, ignored or mistaken for something else. His story is a reminder that one of the subtle clues of Paget's disease can be a bone that simply doesn't look quite as it should; in Allan's case, it is particularly noticeable when compared with his other leg.

"In October 2014, I developed pain in my right leg. At first, the urgent care doctor diagnosed it as cellulitis. When I later visited my GP, he remarked that I had a bandy right leg. He didn't mention that Paget's was a possibility. It was the first time anyone had ever suggested such a thing and I had been completely oblivious to the fact that anything was wrong. It wasn't until a month later, after an x-ray, that the real cause became clear. It was Paget's disease and my GP suggested I 'look it up'. I was referred to an endocrinologist, who advised that Paget's disease affected the upper two-thirds of my right shinbone (tibia), along with a hairline (pseudo) fracture. Plenty of people had seen my legs, yet no one had said anything; I still don't know whether they were being polite or, like me, genuinely hadn't noticed.

About nine months after that, I faced another setback. Soft-tissue damage left me unable to use the leg. I initially tried an elastic knee support, then went to a local chemist for something more substantial. Unfortunately, the



brace they provided was ineffective. It relied on the bones above and below the knee being aligned, but Paget's had already reshaped both, leaving them out of line and making the device unusable.

Looking back, I can see the likely trigger for the crack in my bone. Before my diagnosis, I had been enthusiastically dancing the ballroom tango. The stress on my tibia,

already weakened by undetected Paget's disease, may have caused the pseudo-fracture that set everything in motion. Happily, in due course and after treatment with oral tablets (risedronate), I was able to return to dancing, this time taking a little more care but, thankfully, without any further trouble."

Allan

Taking flight for Paget's

Diana Wilkinson, our Specialist Nurse, is taking to the skies to raise funds for the Paget's Association. If you remember Diana's brave wing-walk or her daring zip-wire across the Tyne to raise funds, you'll know she doesn't shy away from a challenge. Her next adventure will take her back into the skies but this time in a glider. Diana explains...



Pat taking his granddaughter for a flight

Taking the controls

With no engine and under the calm, expert supervision of Pat Fowler, an experienced gliding instructor, I will be winch-launched into the air, and once airborne, I will be taking on the extra challenge of flying the glider myself. It's something I initially said I didn't want to do, but in the end, I decided to embrace the experience and give it a go!

Sharing this adventure with me is my husband Brian, who will be taking to the skies separately. He will also have the opportunity to pilot the glider himself. We'll be flying from the Lincolnshire Gliding Club, based since 1978 at the former RAF Strubby airfield, three miles from Mablethorpe and the Lincolnshire coast. The club operates both two-seater and single-seater gliders. Due to the flat Lincolnshire landscape, they are all launched using a steel cable, wound in by a winch and powered by a large diesel engine at the far end of the runway. The launch is dramatic – the glider leaves the ground quickly and climbs steeply at an angle of

around 40 to 45 degrees. At the top of the launch, the cable is released and suddenly you're free in almost silent flight. At that point, we'll be at a height of around 1,200 to 1,500 feet, before gradually descending unless we find thermals, columns of warm air rising from the ground. I am told that catching a thermal can lift a glider as high as 5,000 to 6,000 feet, right up to the base of the clouds. On a good gliding day, it's even possible to move from one cumulus cloud to another and fly cross-country. As Pat told us, "The longest I've stayed up is over five hours and my furthest cross-country flight was well over 60 miles – although sadly, most days aren't thermic!"



The views over the Lincolnshire coast can be spectacular

During the flight, Pat will encourage me to take control of the glider, letting me experience what it really feels like to fly and just how sensitive the controls are. I'll be in the front seat, which is scary in itself. I may have the best views but I think I'll just concentrate on not crashing!

If there are no thermals, we'll descend back to the airfield. If we're lucky enough to catch rising air, we could stay aloft for up to half an hour and then, thankfully, it will be Pat who will safely and gently land the glider.

A lifeline under threat

This flight is the latest in a little run of fundraising adventures. Whether you cheered me on from the Tyne during my zip-wire challenge or supported me as I stood on the wing of a plane for a wing-walk, you'll know I only take on these things because the Paget's Association truly matters to me. I care about the people we support. After almost 14 years with the charity, I know that, now more than ever, we urgently need funds simply to survive beyond the next couple of years, as well as to drive forward our **PagetAlert** campaign (see page 27). That's why I'm taking on this challenge and why your support means so much.

Every day, I speak to people living with Paget's disease. Many are struggling to get a diagnosis, often after years of unanswered questions. Others are living with constant pain, uncertainty and the emotional toll of not knowing where to turn next. For so many, the Paget's Association is the first place they feel heard and supported.

We provide trusted information, practical advice, emotional reassurance and vital signposting to specialist care. This is support that simply isn't available anywhere else.

The charity receives no government funding, and in recent years our income has fallen dramatically. Fewer donations and a sharp decline in legacies mean we are now facing a very real and serious threat to our future. Without an increase in financial support, our survival as a charity is at risk. If the Paget's Association were no longer here, there would be no trusted website for people to turn to, no reliable information to guide them and no knowledgeable support when they need it most.



Everything we provide, from our resources to our Helpline, exists only because of the generosity of those who believe in our work. That is why I'm stepping outside my comfort zone again. Please support this fundraising adventure if you can. Every donation, no matter how small, will help the Paget's Association continue its essential work, ensuring that people affected by Paget's disease are not left to cope alone.

How to sponsor us

Diana and Brian are inviting you to sponsor them on this challenge. Your support would mean the world. To sponsor them:

- Visit www.justgiving.com/page/diana-wilkinson-glider-flight



Scan the QR code

- Get in touch for the details to make a bank transfer:
- Contact us by email membership@paget.org.uk or call **0161 799 4646**.

A grand day of winners

In November, a Christmas Craft Fair took place at The Grand Hotel, Scarborough, where our Specialist Nurse, Diana Wilkinson ran a fundraising tombola. There was an array of prizes, from a large teddy bear, a hamper and festive treats to seaside buckets and spades. Throughout the day, leaflets about Paget's disease were handed out, giving Diana the chance to explain the condition and raise awareness among the visitors. Thanks to the generosity of those who took part, £101 was raised. We are grateful to everyone who supported the stall.

With community events and summer fairs being planned for the coming months, now is a great time to think about hosting a stall of your own. It's a simple, enjoyable way to get involved and raise valuable funds.



Frequently asked questions



Being diagnosed with Paget's disease can raise many questions. From understanding what the condition means for you to knowing how to manage symptoms and explore treatment options, the journey can feel overwhelming at times. That's why the Paget's Association is here - to support you with clear information every step of the way.

Our Helpline is available to anyone affected by Paget's disease, whether you have been newly diagnosed, have been living with the condition for some time or are caring for someone who has it. We offer a listening ear and trusted advice, helping you make informed decisions about your health. To highlight some of the most frequently asked questions, we sat down with Diana Wilkenson, our Specialist Nurse who manages our Helpline. Every day, Diana connects with people seeking answers and reassurance. Here, she shares some of the most common questions.

What is Paget's disease?

Throughout life, normal bone is renewed and repaired through a process called bone remodelling. Paget's disease is characterised by abnormalities in this process. The affected bone is renewed and repaired at an increased rate, causing abnormalities in the bone's structure. Pagetic bone can appear enlarged and misshapen.

How do you pronounce Paget's disease?

The pronunciation of Paget's disease is PAH-jets. The first part is pronounced 'Pah' - the "a" being like the "a" in "hat" or "pat".

Is Paget's disease serious?

Whilst Paget's disease can be a serious condition, its severity depends on the extent of bone involvement and any complications that arise. Many people with Paget's disease don't experience significant symptoms and the condition is often found incidentally during imaging or blood tests for other issues. When it is detected early and managed with appropriate treatment, it can often be well controlled.

Most people with Paget's disease have a normal life expectancy. In very rare cases, however, a complication called osteosarcoma, a type of bone cancer, can occur. This happens in less than 1% of people with Paget's disease. If you have questions about this or any other aspect of Paget's disease, please contact our Paget's Nurse Helpline.

What bones are affected by Paget's disease?

Paget's disease can affect any bone but the bones most commonly affected are the pelvis, spine, skull, femur and tibia. It can affect one bone (monostotic) or multiple bones (polyostotic). It is unclear why only certain bones are affected.

Does Paget's disease spread?

Although Paget's disease can affect multiple bones, it does not spread from one bone to another.

What causes Paget's disease?

The exact cause of Paget's disease remains unclear but it's believed to result from a combination of genetic and environmental factors. Genetic predisposition does play a key role, especially variations in the SQSTM1 gene. Mutations in this gene are found in 40–50% of people with a family history and 5–10% of those without. The children of people with Paget's disease are about seven times more likely to develop Paget's disease than people who don't have a family history. Environmental factors are also suspected.

Is Paget's disease painful?

Paget's disease can be painful but not everyone experiences pain. When it does occur, it is typically dull, aching and persistent, and may worsen at night. Bone pain is certainly the most common reason for people with Paget's disease to see their GP. Pain can occur in any affected bone. Fortunately, appropriate treatment can relieve or significantly reduce the pain for most people when it is directly due to Paget's. Pain, however, can be due to several other factors, including damage to adjacent joints due to the strain that bone expansion puts on them (osteoarthritis) or pressure that expanded bone can place on nerves. Further insight into the pain experienced in Paget's disease is provided by experts in the videos produced for Paget's Awareness Day (see page 8).

Who treats Paget's disease?

Paget's disease is typically treated by specialists working in a Metabolic Bone Clinic. These may be rheumatologists, endocrinologists, pathologists or other consultants with expertise in bone metabolism disorders.

How is Paget's disease treated?

The main treatment is with a group of drugs known as bisphosphonates. These are medications that help regulate the overactive bone remodelling process seen in Paget's disease. Commonly used bisphosphonates include zoledronic acid, given as a single intravenous dose, as well as oral options such as risedronate. Zoledronic acid is often preferred due to its long-lasting effects. Paget's disease is treated to reduce symptoms, slow excessive bone turnover and, when possible, prevent complications. Treatment is often very effective in eliminating or reducing bone pain.

Why is it called Paget's disease?

Paget's Disease of Bone is named after Sir James Paget, a British surgeon and pathologist who eloquently described the condition in 1877. He observed abnormal bone growth and changes in the structure of bones in some of his patients. His work led to a greater understanding of the condition. Sir James Paget made significant contributions to the study of Paget's disease and also to several other diseases. As a result, several diseases bear his name. Despite the shared name, they are, however, entirely unrelated conditions. Thankfully, the incidence and severity of Paget's Disease of Bone have declined considerably since Sir James Paget's time.

Paget's Nurse Helpline – here to help and reassure

Contact the Helpline

- Email: helpline@paget.org.uk
- Main number: **0161 799 4646**
- Mobile/WhatsApp: **07713568197**



- Complete the form on our website:
[https://paget.org.uk/
find-support/
pagets-nurse-helpline/](https://paget.org.uk/find-support/pagets-nurse-helpline/)

Friendly support groups

Our friendly online groups are for anyone affected by Paget's disease. Meet others who understand, share experiences and receive reliable information, all in small virtual sessions (using Zoom) held every two months. Our Specialist Nurse, Diana Wilkinson, facilitates each group and we're happy to help if you need support using Zoom.

How to join

To join a group email helpline@paget.org.uk or register on our website. You'll receive your Zoom link a few days before the meeting. If it doesn't arrive, please check your spam folder and contact us if you don't see it.



Tax benefits of donating

Donating to charity isn't just an act of kindness; it can be a financially smart choice. Supporting a charitable cause, such as the Paget's Association, is one of the most meaningful ways to make a difference and many people don't realise that their generosity can also bring financial benefits to themselves. Whether you give regularly or are considering your first donation, we want you to understand the available tax advantages can help you.



Gift Aid: the simple way to boost your donation

In the UK, Gift Aid is one of the easiest and most effective ways to increase the value of your donation at no extra cost to you. If you're a UK taxpayer, every £1 you donate can become £1.25 for our charity. All you need to do is complete a simple Gift Aid declaration, either a paper form or by saying yes to Gift Aid on our online donation form. We can then claim 25% from the government.



Additional tax relief for higher-rate taxpayers

If you pay higher or additional rate tax (or intermediate, higher, advanced or top rates in Scotland), you can claim extra tax relief on Gift Aid donations. This is in addition to the 25% the charity already claims. You can reclaim the difference between the basic rate of tax (20%) and the highest rate you pay. For example, if

you pay income tax at 40% or 45%, you can claim back the extra relief through your Self-Assessment tax return or by asking HMRC to adjust your tax code, allowing you to benefit from the tax saving.

Donating through Payroll Giving

Payroll Giving is a tax-efficient way to give directly from your salary. Donations are taken before income tax is applied. This means each donation costs you less while the charity receives the full amount. For example, a £20 monthly gift only costs a basic-rate taxpayer £16, or a higher-rate taxpayer even less. Payroll Giving is especially beneficial for higher-rate taxpayers, who receive the relief immediately without needing to claim it back later.

Your employer must set up and run the Payroll Giving scheme. Donations are taken from your pay before tax (but after National Insurance) and sent to a Payroll Giving agency, which then passes them on to your chosen charities. Agencies may charge an administration fee, which employers can choose to cover. Any costs of running the scheme can be deducted from business profits before tax.



Tax relief on gifts of assets and shares

For donors able to give more than cash, the UK offers generous tax relief on gifts to charity of certain shares, securities and other investments, land and buildings. This relief is available in addition to the relief from Capital Gains Tax for gifts to charity from individuals and the relief from Corporation Tax on gains for gifts to charity by companies.

Leaving a gift to charity in your will

Your will says what will happen to your money, property and possessions after you die. If you leave a gift to a charity, your donation will be taken off the value of your estate before inheritance tax is calculated. If 10% or more of your estate is left to charity, your inheritance tax rate may also be reduced. You can donate a fixed amount, an item or what's left after other gifts have been given out.

Win-win

Your generosity helps charities like the Paget's Association deliver vital support services and create lasting positive change. Thanks to the UK's tax-relief system, giving back can give something back to you as well.

Where to find information

You can find reliable, up-to-date information on the UK Government website at www.gov.uk

PagetAlert – because no one deserves years of pain

Too many people wait, in pain, for far too long before Paget's disease is diagnosed. Our *PagetAlert* Campaign is tackling these delays so people can get the help they need sooner.

Early diagnosis means: ✓ Less pain ✓ Faster treatment ✓ Better quality of life

We are aiming to raise £75,000 and as a charity funded entirely by donations, every pound genuinely matters.

Thank you

We are pleased that we have already raised £31,730. Thank you to everyone who's helped us get this far.

Could you give a monthly donation?

Choosing to give a fixed sum each month is a powerful thing. Even a small monthly donation grows into something extraordinary over time. For the Paget's Association, regular donations provide a reliable income that we can count on. Month by month, they become the steady force that keeps our Helpline open, our information flowing and our community supported. Contact us if you would be willing to support us in this way. You can email membership@paget.org.uk or telephone **0161 799 4646**.



Scan to learn more about
PagetAlert

TARGET
£75,000
RAISED SO FAR
£31,730



How to donate to *PagetAlert*

- Visit our website where you can securely donate.
- Contact our office for details on how to make a direct bank transfer.
- Send a cheque payable to the Paget's Association to The Paget's Association, Jactin House, 24 Hood Street, Ancoats, M4 6WX.
- Set up a monthly standing order: please reach out to our office by emailing membership@paget.org.uk or calling **0161 799 4646**





Reg. charity no. 266071

Minutes of the Annual General Meeting (AGM) of the National Association for the Relief of Paget's Disease (The Paget's Association) held at Bailbrook House, Eveleigh Avenue, Bath, BA1 7JD on Thursday 25 September 2025, at 10.00 am

Item 1: Welcome

Professor Stuart Ralston, Chair of the Paget's Association (also known as the National Association for the Relief of Paget's Disease), welcomed everyone to the Annual General Meeting (AGM).

Item 2: Minutes of the Annual General Meeting 2024

- **Resolution:** That the minutes of the Annual General Meeting held in Middlesbrough on Thursday 19 September 2024 be approved.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 2 | 0 | 2 |
| Proxy (postal or electronic votes) | 16 | 0 | 0 |

Item 3: Presentation of the Report and Accounts from the last financial year: 2024

Professor Ralston presented a summary of the Association's accounts for the year ending December 2024. He mentioned that investments are managed by Evelyn Partners. Reference was made to the full financial report and Charity Commission submission, which are available online.

- **Resolution:** That the Annual Report and Accounts for the year ended 31 December 2024 be accepted.

Professor Ralston proposed that the Report and Accounts be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 2 | 0 | 1 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

Item 4: Re-appointment of Beever and Struthers as the Association's financial independent examiners

- **Resolution:** That Beever & Struthers be re-appointed as external Financial Examiners of the Association

Professor Ralston proposed that Beever & Struthers be re-appointed.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 2 | 0 | 1 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

Item 5: Trustee appointments

Professor Ralston informed members that Dr Stephen Tuck, a rheumatologist based in Middlesbrough and a recognised expert in Paget's disease, has contributed to the development of national clinical guidelines. Dr Tuck previously served as a Trustee for ten years, stepping down in 2021 upon completing a decade of service with the charity. He has now re-applied.

- **Resolution:** That Dr Stephen Tuck be appointed as a Trustee for 3 years.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 4 | 0 | 0 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

Professor Ralston informed members that Trustee Professor Rob Layfield was standing for re-election for a year, marking a full decade of service, the maximum term permitted under the Association's constitution. Additionally, Mrs Eve Berry, Dr Sheelagh Farrow and Dr Faiz Rahman were each seeking to extend their trusteeship by a further three years.

- **Resolution:** To re-appoint Professor Rob Layfield for a further year.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 4 | 0 | 0 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

- **Resolution:** To re-appoint Mrs Eve Berry for a further three years.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 4 | 0 | 0 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

- **Resolution:** To re-appoint Dr Sheelagh Farrow for a further three years.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 4 | 0 | 0 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

- **Resolution:** To re-appoint Dr Faiz Rahman for a further three years.

Professor Ralston proposed that the resolution be accepted.

| Member votes | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually) | 4 | 0 | 0 |
| Proxy (postal or electronic votes) | 17 | 0 | 0 |

Item 6: A review of the activities in 2024 and 2025

Specialist Nurse and Director of Educational Resources Mrs Diana Wilkinson presented a summary of the Association’s activities throughout 2024. Highlights included initiatives for the annual Paget’s Awareness Day held on 11 January, which focused on Paget’s Research - A Journey Through Time and Innovation. Paget’s information events were held in Cambridge and Middlesbrough for individuals affected by Paget’s disease and their families. The year also saw the designation of a new Centre of Excellence in Bath, the continued funding of Paget’s research projects, and the sustained delivery of the Association’s information and support services. In addition, steps were taken toward transitioning the charity into a Charitable Incorporated Organisation (CIO).

Mrs Wilkinson also provided an overview of the activities undertaken so far in 2025. These included the 2025 Paget’s Awareness Day, which focused on the importance of diagnosing Paget’s disease early. Paget’s information events were held in Leicester and Bath. Progress continued toward converting the charity to a CIO and Mrs Wilkinson explained that the CIO would have a revised name, becoming the Paget’s Disease of Bone Association. The Association maintained its range of information and support services and instigated a review of the 2019 Guideline for the Diagnosis and Management of Paget’s Disease in Adults. Attendees were invited to ask questions. None were raised.

Item 7: Forward planning

Professor Ralston provided further detail regarding establishing the Charity as a Charitable Incorporated Organisation (CIO), noting that all assets of the existing charity

would be transferred during 2026. He thanked Trustee Mr Mohamed El-Erian for his valuable contributions to the CIO. Mr El-Erian, a lawyer at Jones Day, is generously providing pro bono support.

Professor Ralston shared an update on the progress of the clinical guideline, reporting that a literature review had been completed by Dr Luis Corral Gudino, relevant publications had been identified, and existing sections had been updated. A draft guideline is expected in the first quarter of 2026 and it will be submitted for publication later in the year.

Planning is underway for events in 2026, including Paget’s Awareness Day on 11 January, which is expected to include discussions on pain. A Paget’s information event in the London area is anticipated for June or July 2026 and a similar event plus the Annual General Meeting is expected to take place in Newcastle in September 2026.

Professor Ralston addressed the financial challenges posed by a sustained decline in legacy income over the past 18 years, explaining that this has led to a reduction in the Association’s unrestricted funds. He emphasised the importance of continuing to minimise costs wherever possible, without compromising the Association’s mission. He explained that the Association no longer has premises and that staff numbers were reduced in 2023 as part of cost-saving measures. He reaffirmed the commitment to ongoing fundraising efforts.

Attendees were invited to ask questions or offer comments. None were raised.

The meeting closed at 10.25 am.

Our incredible runners

Get ready to cheer on an extraordinary display of determination and resilience at this year's Manchester (19 April) and London (26 April) Marathons. We're delighted that our incredible runners are preparing to take to the streets, not only in pursuit of personal achievement but to raise vital awareness and funds for the Paget's Association.

Here are some of the fantastic runners taking part. You can visit their individual online fundraising page by scanning their QR code, following the link in their name or by contacting us directly at the Association. Your support can turn every mile they run into a beacon of hope for those affected by Paget's disease. Good luck, everyone.



**Sponsor
Darcie**



**Sponsor
Ben**



**Sponsor
Abigail**



“

Training for the London Marathon is going well so far, even with the cold, rainy mornings. I'm enjoying the journey, embracing the challenges, and feeling so excited to run the marathon for a cause that means a lot to me.

Darcie

”

Ben and Abigail

Ben Dockrell from Leeds and Abigail Fletcher from Edinburgh have teamed up to run the London Marathon together. Abigail said, "I'm running the London Marathon for the Paget's Association to help raise awareness and funds. They do incredible work supporting those affected and funding vital research and I'm proud to run for them".



Facebook Support Group

Our Facebook Support Group continues to grow as people from around the world share their experiences and support each other. To join the Facebook group, please scan the QR code or visit <https://www.facebook.com/groups/pagetsdiseaseofbone/>

Meet the team at the Paget's Association

Honorary President



Professor Graham Russell

Involved in research at both the Botnar Research Centre,

Oxford and the Mellanby Centre for Bone Research, Sheffield, Graham played a key role in the discovery and development of bisphosphonates for the treatment of bone disorders.

Patrons



Sir Henry Paget

Sir Henry is the great-great grandson of Sir James Paget,

whose name was given to Paget's disease.



Mrs Joyce Cupitt

Joyce served as a Trustee for many years. Her late husband had Paget's disease.



Mr Recardo Patrick

Recardo is an entertainer and businessman who rose to fame as

lead singer with the band, Sweet Sensation. He has Paget's disease.

Employees



Mrs Diana Wilkinson

Specialist Nurse & Director of Educational Resources



Miss Jen Woodworth

Operations & Engagement Manager

Board of Trustees



Chair of the Board – Professor Stuart Ralston

Chair of the Paget's Association, Stuart is a Rheumatologist, based at the Western General Hospital, Edinburgh. He has researched widely on the role of both genetic and environmental factors in Paget's disease and has led several large clinical trials investigating the best methods of treatment for Paget's.



Vice-Chair – Professor Rob Layfield

Rob is a Professor at the University of Nottingham. He researches the protein that was found to carry mutations in some cases of Paget's disease.



Mrs Eve Berry

With many years of experience in the healthcare sector, Eve lives in London and is a Chartered Accountant, currently working in the drug discovery industry.



Mrs Kely Burman

A retired nurse and midwife living in Orsett, Kely has not only

cared for those with Paget's disease, but her mother also had the condition.



Mr Mohamed El Erian

A solicitor at Jones Day, London, Mohamed

brings his legal expertise to the Board of Trustees.



Dr Sheelagh Farrow

Sheelagh lives in Surrey and, prior to retirement, was Managing Director

of International Medical Press, a provider of independent medical education.



Mr Alan Martin

A retired company director, Alan lives in Wokingham. He has Paget's disease and

believes the interaction between patients and clinicians brings mutual benefits.



Dr Faiz Rahman

Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the

University Hospitals of Leicester, where he is involved in caring for those with Paget's disease.



Mrs Amanda Sherwood

Amanda lives in Bristol and is now retired.

She has experience in working for societies and teaching organisations which specialise in the field of bone and related topics.



Dr Stephen Tuck

Stephen is a Consultant Rheumatologist at the James Cook University Hospital,

Middlesbrough and Honorary Lecturer at the Institute of Cellular Medicine, within Newcastle University.



Professor Mark Wilkinson

An Orthopaedic Surgeon in the Metabolic Bone Unit

of the University of Sheffield, Mark has both an academic and clinical interest in Paget's disease.

Key dates and events



19 April 2026

**Adidas
Manchester
Marathon**

11 June 2026

**Paget's
Information Day
Village Hotel
(Watford), Elstree**

26 April 2026

**TCS
London
Marathon**

17 September 2026

**Paget's
Information Day
The County Hotel,
Newcastle upon Tyne**

30 May 2026

**Big Spring
Coffee Morning
for Paget's**

Throughout the year

**Virtual Paget's
Support Groups**
See our website for details
www.paget.org.uk