

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



Survey results

Key challenges in Paquet's disease

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Groundbreaking
research paves the
way for major study

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*Join us in
Leicester or Bath*

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PaquetAlert
– Shortening the
pain journey

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Anne blamed her dog for her elbow pain



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We'd love you to join us in Leicester or Bath for a Paget's information event



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Thank you to everyone who participated in our survey – the results are in!

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Chair's message

Dear members and supporters

Welcome to the Summer 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 about the condition, promote research and ensure that people who are affected are provided with accurate information and support.

Our cover features the results of a survey we conducted in October 2024 to find out more about symptoms, quality of life and mental health of people before they were diagnosed with Paget's disease. The full results are summarised on page 21 but the take-home message is that 45% waited more than three years and 20% waited more than 5 years for a diagnosis. During that time more than 90% experienced pain that adversely affected quality of life and two-thirds of individuals reported that the pain had affected their mental health. These findings illustrate that we still have a lot to do to ensure that people with Paget's disease are diagnosed in a timely manner and their symptoms treated. Based on these findings the charity has launched the **PagetAlert** campaign to promote earlier diagnosis of Paget's disease, particularly in those who have experienced bone pain. The aim of **PagetAlert** is to raise awareness, promoting early diagnosis and improving quality of life for people affected by Paget's disease. We will work with the NHS to try and make genetic testing for susceptibility to Paget disease available, since we know that this can identify people at high risk of developing the disease. We have so far raised £2,211 and



Approaching the finish line at the Etape Caledonia



Scan the QR code

I'll be looking for sponsorship one again for my second attempt at the 85-mile Caledonian Etape this May. Please scan the QR code to support me. Details of how you can support the campaign are shown on page 24. You also may wish to host a coffee morning on 10th May 2025 to raise funds. Details are provided on pages 14-18.

Paget's Awareness Day 2025 also focused on early diagnosis of Paget's disease. Thanks to Geraldine Hilson, Anne Lambley and Dr Cat Nairn who I interviewed on video and Dr Stephen Tuck from Middlesborough who did an audio podcast with me. All of these are still available to view and listen to on the Paget's Association website and also on YouTube.

We have a special feature on Anne's story on pages 7 and 8 of the magazine. I met Anne when she attended for a visit regarding the ZiPP-Long term extension study. She mentioned that she was getting pain in her left elbow and reckoned it might be due to her dog Lottie, pulling on the lead. As it turned out she had developed Paget's of the left elbow, and we were able to treat her with a zoledronic acid infusion which helped the pain considerably. Another thing that Anne noticed was that when she had a tattoo of the left arm recently, she found it extremely painful – much more than she had ever experienced before with any of her other tattoos. I was interested in that since in the Pain in Paget's disease (PiP) study we had noticed heightened perception of pain and vibration in the skin over affected areas which probably explains why this had occurred. Very interesting indeed!

One of the key aims of the Charity is to support research into the disease and it was a real delight to read the article by Associate Professor Philippa Hulley and Dr Helen Knowles on the 3D "mini-bone" cultures they established with funding from the Charity. I was also very pleased to see that they established a collaboration with Dr Dan Scott from the Paget's Association Centre of Excellence (PACE) at the University of Nottingham, to evaluate how the Paget disease susceptibility gene *SQSTM1* influences these cultures. It was also great to see that Philippa and Helen had received a grant from the Medical Research Council to continue this important work.

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continued from page 3

On the topic of research, Dr Rob Layfield and Diana Wilkinson have summarised the results of a research paper by Araújo and colleagues, in our Journal News feature on page 5. The researchers analysed the skeleton of a new world monkey from North-East Brazil dating back to the last ice age approximately 12,000 years ago and found evidence of a bone disorder with similarities to Paget's disease. If you have Paget's disease and are interested in research, please have a look at the feature on page 19 which concerns the Probiotics in Paget's Disease (PRiP) study. In this trial we are allocating people with Paget's to receive probiotics (good bacteria), dummy probiotics or calcium and vitamin D supplements. The aim is to determine if these interventions can help pain or reduce the metabolic activity of Paget's. If you are interested, please email Kathryn Berg. The study is running in several PACE across the UK.

In closing, I hope that some of our readers will be able to join me at one of the upcoming information events this year. The first, hosted by Dr Faizanur Rahman will be in St Martin's Conference Centre in Leicester, on May 29th 2025 and the second, hosted by Dr Sarah Hardcastle on 25th September 2025 will be at Bailbrook House near Bath.

I hope you have enjoyed reading the edition of the magazine as much as we have enjoyed compiling it.

With very best wishes to all

Stuart Ralston
Chair, Paget's Association

The Paget's Association



The Paget's Association, also known as The National Association for the Relief of Paget's Disease (NARPD), is a UK charity (registration no. 266071) founded in 1973 by Ann Stansfield. The Association extends support worldwide to those impacted by Paget's Disease of Bone, drives quality research and raises awareness of the condition.

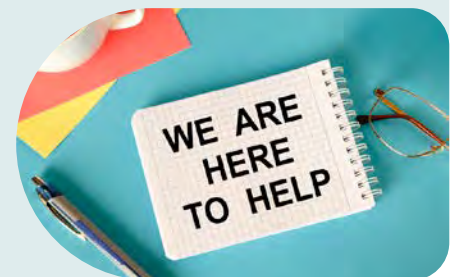
Paget's Nurse Helpline

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.

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

www.paget.org.uk



Contact us

Email All general and membership 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



Journal news



In this edition of Journal News, we delve into a paper highlighted by Professor Rob Layfield, Chair of the Association's Research Subcommittee. Our Specialist Nurse, Diana Wilkinson, offers a concise summary.

Paget's disease in an extinct monkey?

In 1992, the discovery of a nearly complete skeleton of a large platyrrhine (New World monkey) in the Toca da Boa Vista cave, Northeastern Brazil, led to researchers exploring the potential presence of metabolic bone disease. Although a precise age of the skeletal elements is unknown, the Late Pleistocene (Ice Age) is suggested. This species, weighing around 25 kg, is the largest known platyrrhine. The specimen appears to be the only case of metabolic bone disease in an extinct New World monkey.

The researchers documented various pathological changes found using radiographic and CT images of the affected bones. The lesions noted include cortical thickening, sclerosis and coarse trabeculae in the skull and long bones. The features observed support the diagnosis of metabolic bone

disease with lesions comparable to those seen in Paget's disease.

In their paper, the authors considered other diagnoses but concluded that this represents the closest relative of humans in the fossil record to be diagnosed with a disease closely resembling Paget's disease. They noted that the absence of other skeletal materials for comparison from the same species and period makes differential diagnosis challenging and conclusions must be drawn with caution. They stress the need for further studies using broader comparative samples of extinct and extant platyrrhines to refine the diagnosis and assess the evolutionary implications of such diseases in primates. Despite these limitations, the findings represent a significant contribution to understanding the paleobiology and health conditions of extinct New World monkeys.

This work adds to the ongoing debate about the natural history of Paget's disease, an area of research that the Paget's Association has promoted and supported. You can find out more by scanning this QR code.



Reference

Araújo AV, Dantas MAT, Liparini A, Cozzuol MA, Halenar-Price LB, Ribeiro RM, Barbosa FHS, Bandeira F, Araújo Júnior HI. Metabolic bone disease in an extinct neotropical primate. *Int J Paleopathol.* 2024 Nov 19;48:1-12. doi: 10.1016/j.ijpp.2024.11.003. Epub ahead of print. PMID: 39566418.

International Paget's Awareness Day

The Paget's Association is committed to driving earlier diagnosis to reduce the pain and anxiety caused by Paget's disease. On International Paget's Awareness Day (11 January), the focus, as highlighted by Professor Stuart Ralston in new video interviews and a podcast, was on identifying the condition early and providing appropriate treatment to prevent irreversible bone damage. All underscore the vital importance of early diagnosis and timely management of Paget's disease. They highlight the challenges of delayed diagnosis, stress the critical need for greater awareness in general practice, and offer valuable insights from research. Summaries of the recordings are provided below, and on page 8, Anne shares more about her personal experience.

Geraldine's struggle

Video watch time: 7 minutes

In this video interview, Geraldine Hilson speaks openly to Professor Ralston about her prolonged and challenging journey to being correctly diagnosed with Paget's disease and eventually receiving treatment. She recounts her frustration with the numerous delays and missteps, including not being referred to the appropriate specialist from the outset. In pain, she went to her GP several times and was referred to a urologist, followed by a physiotherapist. They both told her she had Paget's disease and there was nothing they could do other than recommend to her GP that she



Geraldine (left), Prof Stuart Ralston (centre) and Anne (right)

was referred to someone who knew about Paget's disease. When she returned to her GP, she was referred to DynamicHealth (DynamicHealth provides specialised services for those experiencing problems from muscles, nerves and joints), where she met a nurse who she felt really listened to her. However, it wasn't until Geraldine attended an information event organised by the Paget's Association in Cambridge, that she finally gained the critical insight she needed. Empowered and armed with information regarding exactly who she needed to see, she spoke to the nurse at Dynamic Health who wouldn't normally have made the referral but, understanding Geraldine's struggle, she offered to do it. An appointment with a rheumatologist was swiftly arranged and, at long last, Geraldine received the proper treatment she needed. Geraldine's experience highlights the need for timely, accurate information to guide people toward the care they need.

Paget's in the family

Video watch time: 5 minutes

Anne Lambley shared with Professor Ralston how participating in Paget's

research led to her diagnosis of Paget's disease. What started as a simple decision to contribute to a research study, turned into a pivotal moment that confirmed Paget's was part of her genetic heritage. This journey not only gave Anne a deeper understanding of the condition but also inspired her to encourage family members to take part in the research. She has since become a passionate advocate for the vital role research plays in identifying and managing hereditary conditions. Through the video interview and her detailed account on page 8, Anne hopes to inspire others to engage in medical studies and seek answers about their health, especially when a condition may be hereditary.

A GP's perspective

Video watch time: 4 minutes

In this interview, Professor Ralston was joined by Dr Cat Nairn, a GP in Edinburgh and former Trustee of the Paget's Association. Dr Nairn explained that while Paget's disease is relatively rare, GPs should consider it in older patients with musculoskeletal pain. She highlighted three common ways

Paget's is identified. Firstly, it may be an incidental finding during imaging for other conditions. Secondly, routine blood tests may show elevated alkaline phosphatase (ALP) levels and thirdly, when older patients present with bone pain, particularly in the lower back or hips. Dr Nairn referred to an article* she published a couple of years ago. She recommended requesting x-rays and ALP tests for those with unexplained musculoskeletal pain and advised that patients should be referred to the correct specialist if imaging or blood tests indicate Paget's disease. She noted that awareness and proactive consideration of Paget's are key to a timely diagnosis.

*Paget's disease of bone: when and why to refer to specialist care; C Nairn, S H Ralston, BJMP 2020; 70 (700): 561-562. DOI: 10.3399/bjgp20X713369

Dr Stephen Tuck and Prof Stuart Ralston

Podcast listening time: 6 minutes
In a podcast, Dr Tuck discusses with Professor Ralston research carried out in Middlesbrough, where they conducted an analysis of around 68,000 x-rays carried out at the hospital between 2015-2016. They identified 43 individuals who had signs of Paget's disease on the x-ray images but around three-quarters had not been referred to a specialist for advice.

How to watch the videos and listen to the podcast

To find the videos and podcast, simply click the link in the PDF version of this magazine.

Alternatively, scan the QR code or visit our website.



Dr Cat Nairn (left), Prof Stuart Ralston (centre) and Dr Stephen Tuck (right)

Awareness Daze

On 1 January 2022, Dan Brotzel set out on an ambitious and quirky challenge: to observe a different awareness day every day for an entire year. Along the way, he discovered Paget's Awareness Day, and after speaking with the team at the Paget's Association he was moved so deeply

that he ran the London Marathon in support of the Association. Dan's year-long journey was a whirlwind of contrasts, from very meaningful awareness days to delightfully absurd ones like Bubble Wrap Appreciation Day! He celebrated them all, meeting a fascinating array of people along the way. Some of them bravely facing life-changing challenges and others championing the strange, such as Goth Day. Dan found himself reflecting on the meaning of it all, in a world where poignant events like World Lymphoma Awareness Day shares the calendar with the light-heartedness of National Double Cheeseburger Day. The result of all this was his audiobook 'Awareness Daze' and we were pleased that Dan was able to feature Paget's Awareness Day too.



A heartfelt thank you for your support

Also celebrated on 11 January as well as Paget's Awareness Day, is Thank You Day but we didn't need a reminder to extend our heartfelt thanks to everyone who supported Paget's Awareness Day. From those who shared vital information in interviews to those who posted on social media, every contribution has brought much-needed attention to this important cause. Thank you all for your support – it means a great deal to us.

PagetAlert

Shortening the pain journey in Paget's Disease

As part of this year's Paget's Awareness Day, an ambitious new campaign, **PagetAlert**, was officially launched with the aim of raising £75,000 to address delays in diagnosis and improve patient outcomes. Full details can be found on page 24.

Donate to PagetAlert on our website
www.paget.org.uk

Anne's story

Hello. My name is Anne. I am 53 years of age and I live in the East Midlands in the heart of what was the mining industry. My brothers, father, grandfather and uncles all worked in the coal mines, which is interesting as links are being made with coal mining and Paget's. I am married but have not been blessed with children.

Working life

I left school at 17, when the local coal mine closed and my father was made redundant, as the family had no other means of income. I initially worked in a warehouse for 10 years and then went on to work for the police service, where I've been for the last 27 years. I have a love of animals and devote all my spare energy towards my two dogs who are my surrogate children.



Lottie – who was blamed for Anne's elbow pain

First encounter with Paget's

In 2011, my maternal uncle (also a miner) attended his GP's surgery complaining of bad headaches. He had tried all the usual pain

medication to no avail and was convinced he had something serious and terminal. Upon attending his appointment, the clinician noted immediately that his skull had some deformities and was convinced that this was in fact Paget's disease. He had some tests and this was confirmed. The researchers carrying out the 'Zoledronate in the Prevention of Paget's' (ZiPP) study advised him to inform his family and encourage them to be tested for Paget's. As a result of this, my mother (his sister) was tested and she was also found to have Paget's in her spine. I received a call from my mum advising of the diagnosis and asking that I contact the ZiPP study because of the familial link. I did this and blood tests were completed which showed that I also had the

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...people with Paget's disease had increased perception of pain and vibration over affected areas
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sequestosome 1 (SQSTM1) gene. One of my brothers had the blood test but was found not to have the gene so his journey with the study ended there. I then visited the ZiPP team in Edinburgh, in May 2012, for the initial scans and infusion of either zoledronic acid or a placebo.

Paget's diagnosis

I participated in the ZiPP study for the seven years as agreed which takes us to 2019. It was in April 2019 that I noticed that I was having some dull pain in my left elbow. I brushed it off but the pain just wasn't going



Anne and Lola

away. I consulted my GP who marked it off as tennis elbow and advised me to give it time. I was then considering why. Why had I got tennis elbow? There was nothing to have caused it... Unless it was due to the amount of time spent crocheting or maybe... It was at this point that I surmised that the cause had to be the dog. A new puppy, pulling on the lead, changing direction at random – 'ooh a leaf' or 'ooh a crisp packet' – it had to be the dog's fault. But two months later I made the trip to see the team in Edinburgh for the end of study tests and it was here at this point that I was given the news – you've got Paget's in your left elbow and a little bit on your skull. It wasn't the dog after all! Poor Lottie dog.

I did agree at this point to do the extended five years of the study which brings us to 2024. I am a lady who likes her ink and have several tattoos. During one tattoo session I was having work on my left arm, when the artist was doing the area near my elbow, I noted that the pain was far worse than normal and hurt more than anywhere else ever had – even the same location on the other arm was nowhere near as painful. Hot and cold sweats. Feeling nauseous. Lightheaded. All very strange.

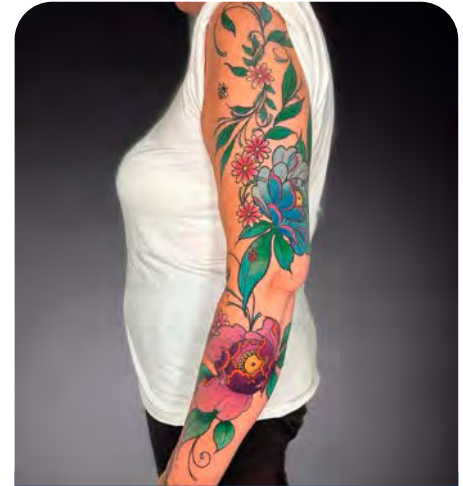
I mentioned this to the team and was advised the 'Pain in Paget's' study found that people with Paget's disease had increased perception of pain and vibration over affected areas. So, this experience, in hindsight, is almost certainly attributed to Paget's disease in my elbow.

In July 2024, I again met with the team in Edinburgh for the final tests and it was revealed that way back in 2012, when I started on her journey with the ZiPP study, I had been given the placebo and not the zoledronic acid. So, based on the results of the trial, it was suggested that an infusion of this would hopefully help, so this is what happened. The lovely nurse, Jo, accompanied me to all the tests and treatments which all went very smoothly. The day after the

infusion I did feel a little unwell but that was expected, and since then have made good progress and now have no pain in my elbow at all and only occasional head pain.

Engaging with the team from the ZiPP study has been enlightening and an honest pleasure. There was never a single second that I questioned participating in the trial. Why would I? It's a win-win situation. If people don't engage with research, then we will never learn anything. Be selfless. Do something for humanity. The people I have met on the trial are all without exception some of the loveliest people I have met. Ever.

My message – if something is hurting that isn't normal – get it checked. It's very easy to dismiss



Anne's tattoo. The edge of the blue flower was incredibly painful

the occasional twinge, and unless we know what the cause is, it is very easy to mistake it for something else. Oh and don't blame the dog!

Featured service

Meet others online



Meet others online at one of our Virtual Paget's Support Groups. Meetings take place every two months using Zoom. To support as many people as possible, meetings take place on different days and at different times.

These are small friendly groups connecting people from all over the world so, wherever you are, you can share your experiences with others living with Paget's. We are grateful to those who have been in touch to tell us how much you appreciate these meetings.

View the latest support group dates online



If you are not in the UK, please check what time each meeting is for you or contact us for assistance.

For more information or to take part, please email membership@paget.org.uk or register on our website.

You will receive a link to join by email a few days before the meeting. Should you not receive it, please check your junk folder, or get in touch.

Groundbreaking research paves the way for major study relevant to Paget's disease

Associate Professor Philippa Hulley and Dr Helen Knowles

In this article we highlight how previous research, supported by the Paget's Association, has paved the way for a significant and extended new study to begin, funded by the Medical Research Council (MRC). To fully appreciate the research, it is important to first understand Paget's disease at the cellular level and the function of healthy bone.

Understanding Paget's disease

Bone is living tissue, which is renewed and replaced throughout life. This process is known as bone remodelling and is important in maintaining a healthy skeleton by ensuring that old or damaged bone is removed from the skeleton and replaced with new healthy bone tissue. This balance of the breakdown of bone (resorption) and the production of new bone (formation) is carefully regulated.

There are three main types of bone cell involved in the remodelling process, osteoclasts, osteoblasts and osteocytes. The osteoclasts break down (resorb) old or damaged bone. The osteoblasts then lay down new bone. Some osteoblasts become buried in the newly formed bone and become osteocytes. Osteocytes play a key role in regulating the activity of osteoclasts and osteoblasts. Under normal circumstances, the amount of bone resorbed is exactly balanced by the amount of new bone that is formed. Over time, this bone is mineralised, forming a rigid and strong skeleton.

In Paget's disease, the processes of bone resorption and bone formation are markedly increased. The osteoclasts are larger than

normal and break down bone faster than unaffected cells. The osteoblasts respond to this by depositing new bone at an increased rate. This dysregulation of bone turnover in Paget's disease results in abnormalities of the bone structure, weakening of the bone and enlargement or deformity of the affected bones. Pagetic bone often appears misshapen and enlarged. It is this increase in bone turnover that can lead to elevated levels of ALP (alkaline phosphatase), a protein that is often seen in the blood of people affected with Paget's disease.

Insights into Paget's disease and bone ageing using a human 3D 'minibone' model

Associate Professor Philippa Hulley and Dr Helen Knowles, outline the next steps in their research.

Osteocytes are long-lived cells that respond to mechanical stimulation and maintain bone health by regulating the activity of bone-forming osteoblasts and bone-removing osteoclasts. It has recently been suggested that osteocytes might be the cells that initiate the loss of control that

results in the focal bone lesions that are characteristic of Paget's disease. This has been hard to test experimentally as human osteocytes are difficult to grow in the lab and, since Paget's is a human disease, mouse models are limited in predicting mechanisms and responses to treatment.

As the direct result of a previous Paget's Association project grant awarded to Associate Professor Philippa Hulley and Dr Helen Knowles, from the University of Oxford, in 2021, our team developed and published data on a human 3D 'minibone' system that replicates the formation of mature osteocytes in bone in a laboratory setting. The project grant also allowed us to develop methods of converting human stem cells into osteoblasts and osteocytes in the minibones. By introducing a common Paget's mutation in the *sequestosome 1* (*SQSTM1*) gene into these stem cells, we have been able to start to interrogate the specific role of human osteocytes in Paget's disease for the first time. Crucially, this system is a co-culture of osteoblasts and osteocytes (to which we can flexibly add normal or stem cell-derived osteoclasts), replicating some key osteocyte functions. Typically osteocytes release a protein, sclerostin, that switches off new

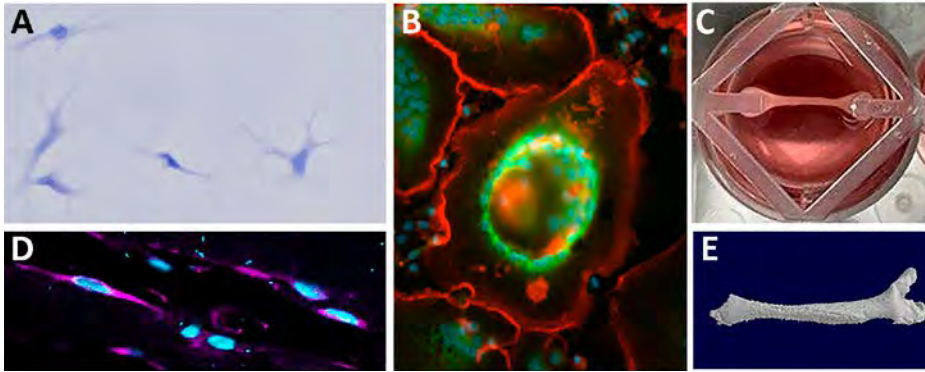


Figure shows (A) purple osteocytes with typical branching arms; (B) iPSC stem cell-derived osteoclasts (red) with multiple green/blue nuclei; (C) Minibone growing on its hanger; (D) Pink staining for sclerostin, a key mechanosensitive protein made by osteocytes; (E) micro CT imaging showing mineralisation of a minibone.

bone formation when the skeleton is strong enough. When the skeleton gets weaker or we do more physical work, osteocytes sense this and switch sclerostin off, thus allowing bones to get stronger. This can be mimicked using a therapeutic antibody to sclerostin or a short section of parathyroid hormone called Teriparatide. Our minibones drop sclerostin secretion when mechanically loaded or when given Teriparatide and recover once the treatment is stopped. This gives us a unique opportunity to look at the responses to mechanical loading in Pagetic minibones.

Levering the pilot data supported by this Paget's Association project grant we have recently been awarded a £1 million, 3-year MRC project grant called 'Functional aging in human osteocytic networks' to extend this research. The mutations in *SQSTM1* that cause 50% of cases of sporadic Paget's disease of bone are also relevant in the broader context of bone aging. The amount of *SQSTM1* protein in bone cells reduces with age and defects in *SQSTM1* are linked to various age-related diseases, including metabolic bone disease (e.g. Paget's disease, osteoporosis). We will use our minibone model to answer fundamental biological questions about how osteocytes

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Perhaps most exciting will be tissue donations from Paget's patients undergoing routine joint replacement operations

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influence the aging process in human bones and age-related metabolic bone conditions.

This is a wide-ranging research study which calls on the expertise of a large and diverse team. Dr Dan Scott (University of Nottingham) is an expert in human stem cells and will introduce different Paget's-relevant *SQSTM1* mutations into these cells. This will allow the central bone biology team (Associate Professor Philippa Hulley, Dr Helen Knowles) to model different severities of disease in the minibone system and determine how variations in the function of *SQSTM1* protein affect osteocyte function, interaction with other bone cell types and bone biology. Our pilot data suggests that some of these effects include perturbations in the bone matrix and mechanical response; Prof Eleanor Stride and Associate Professor Dario Carugo

will lead a team of bioengineers in investigating quantitative effects on bone mechanics, tissue strain and response to mechanical loading in the mutant minibones.

Perhaps most exciting will be tissue donations from Paget's patients undergoing routine joint replacement operations under expert guidance from our surgeons, Mr Antony Palmer and Dr Mat Baldwin, Prof Kassim Javaid (physician and lead on a rare diseases network study), and Dr Jennie Brown, our pathologist. These bone cells and small tissue pieces are left as surgical waste and will be used as source of "real" Paget's cells to grow into minibones, as well as allowing us to apply state-of-the-art transcriptomics (gene expression) methods to map different cell types and states in the tissue. This will be backed up using an existing larger pathology archive of Pagetic tissue. Assoc Prof Sarah Snelling, Dr Carla Cohen and the versatile Dr Mat Baldwin are internationally recognised specialists in transcriptomic profiling and will help us to confirm real-world relevance of our minibones in comparison to actual tissue. This multidisciplinary approach is likely to yield insight into multiple aspects of Paget's disease and aging bone function and we look forward to feeding our progress back to the Paget's Association.

Research papers that Paget's Association funding contributed to

Hulley PA, Knowles HJ. A New Method to Sort Differentiating Osteoclasts into Defined Homogeneous Subgroups. *Cells*. 2022; 11(24):3973.

Knowles HJ, Chanalaris A, Koutsikouni A, Cribbs AP, Grover LM, Hulley PA. Mature primary human osteocytes in mini organotypic cultures secrete FGF23 and PTH1-34-regulated sclerostin. *Front Endocrinol (Lausanne)*. 2023; 14:1167734.

Join us at a Paget's information event



Leicester

Thursday 29 May 2025

Paget's
Information Event

St Martin's
Conference Centre

10:00 am – 3:30 pm

Bath

Thursday
25 September 2025

Paget's
Information Event

Bailbrook House

10:45 am – 3:30 pm

What is a Paget's information event?

Our free Paget's information events provide a welcoming and informative space for individuals with Paget's disease and their families to learn more about the condition. Health professionals are also welcome to come along.

What to expect

Expert speakers will cover a variety of topics related to Paget's disease. There will also be plenty of opportunities to ask questions. The atmosphere is relaxed and inclusive, making it an ideal setting for learning about the condition and connecting with others who may have similar experiences.

Complimentary lunch and refreshments

Lunch and refreshments are provided free of charge.

Booking essential

Your place must be booked in advance. You are welcome to bring someone with you but please ensure you reserve a place for them as well. You can book by visiting our website, emailing membership@paget.org.uk or by calling **0161 799 4646**. When booking, please let us know how many places you need and if you have any food allergies or dietary requirements.

Upcoming events

Leicester

A Paget's information event will be hosted by Dr Faiz Rahman from Leicester General Hospital, a Paget's Centre of Excellence. It will be held at St Martins Conference Centre, Leicester LE1 5PZ, on Thursday 29 May 2025. The full agenda is provided on the next page.

Bath

Dr Sarah Hardcastle from The Royal National Hospital for Rheumatic Diseases, a Paget's Centre of Excellence, is hosting a Paget's information event, on Thursday 25 September 2025 at Bailbrook House, Bath, BA1 7JD.

Questions?

Bailbrook House

If you have any questions about our events, please get in touch. Please see the contact details under the 'Booking' section to the left. We look forward to welcoming you and providing the support and information you need.



Paget's Information Event

Thursday 29 May 2025

St Martins House Conference Centre, 7 Peacock Lane, Leicester, LE1 5PZ

10:30 am – approx. 3:30 pm

Registration and refreshments will be available from 10:00 am

Welcome	Prof Stuart Ralston Chair, Paget's Association Rheumatologist & Researcher, Edinburgh
Understanding the Role of the Paget's Association	Mrs Diana Wilkinson Specialist Nurse & Director of Educational Resources, Paget's Association
What is Paget's disease?	Dr Mohamed Saeed Consultant Chemical Pathologist & Metabolic Physician, Leicester
Diagnosis and monitoring	Dr Peter Prinsloo Consultant Chemical Pathologist, Nottingham
Break	
Treatment	Dr Faiz Rahman Trustee & Consultant Metabolic Medicine & Chemical Pathology, Leicester
Update on research funded by the Paget's	Prof Rob Layfield Trustee & Professor of Protein Biochemistry, Nottingham
Lunch	
Genetic testing and early diagnosis	Prof Stuart Ralston
Orthopaedic surgery in Paget's disease	Prof Robert Ashford Consultant Orthopaedic Surgeon, Leicester
A final opportunity for questions	Prof Stuart Ralston

The Big Spring Coffee Morning for Paget's



Coffee and treats set to make a difference!

We invite you to host a fundraising coffee morning to support the Paget's Association. Help raise vital funds to support those living with Paget's disease while enjoying great company, coffee and delicious treats.

Official date: Saturday 10 May 2025

The official date is 10 May 2025 when we'd like as many members and supporters as possible to take part in the Big Spring Coffee Morning for Paget's. As well as raising funds, it's an opportunity to raise awareness. Can't make 10 May? You can choose a date and time that suits you and your guests.

Here's how you can get involved

Pick your venue

Whether it's your home, garden, or a community hall, any space that brings people together is perfect for a coffee morning.

Plan the treats

Bake or buy, it doesn't matter! Offer a selection of coffee, tea, cakes and biscuits.

Spread the word

It can be a small or large gathering. Think about inviting family, friends and neighbours. Let everyone know they're contributing to a great cause by attending! You can use the invitations on the next page, then photocopy or print more from our website. The invitations explain that guests are invited to donate to the Paget's Association.

Paws for coffee



If you have a big garden, you could even invite your friends to bring their four-legged friends and provide treats for them.

Fundraising made easy

Set up a donation jar at your event or use an online platform (get in touch if you need help with this). Let guests know that their donations will go to The Paget's Association, helping those affected by Paget's disease and contributing to our campaign for earlier diagnosis. Following your event, you can easily pay in the funds raised through our website or by posting a cheque.

Need support? We'll help!

To help make your coffee morning a success, if you would like banners, posters or leaflets explaining Paget's disease, simply email membership@paget.org.uk or call **0161 7994646**. You can also download leaflets from our website.

Start planning your coffee morning today!

Every coffee poured and every slice of cake shared brings us closer to making a big difference!





Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. The condition is often painful and complications such as fractures can occur.

The Paget's Association is a registered UK charity that

- provides support and information to those with Paget's Disease and their families
- raises awareness of the condition among health professionals and the public
- encourages and funds research into the causes, treatment and prevention of Paget's disease

Help us make a difference

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Big Coffee Morning invitations FRONT – please cut along dotted line



Paget's
Association

You are invited to join



for coffee/tea & cake
as part of the

Big Spring Coffee Morning for Paget's

on

time

at

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



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Big Coffee Morning invitations REVERSE – please cut along dotted line



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Thank you!





CALL FOR VOLUNTEERS WITH PAGET'S DISEASE OF BONE TO TAKE PART IN A NEW PROBIOTIC STUDY

If you are:

- ✓ Someone who has been diagnosed with Paget's disease of bone (PDB),
- ✓ Willing and able to give informed consent and commit to three study visits over six months,



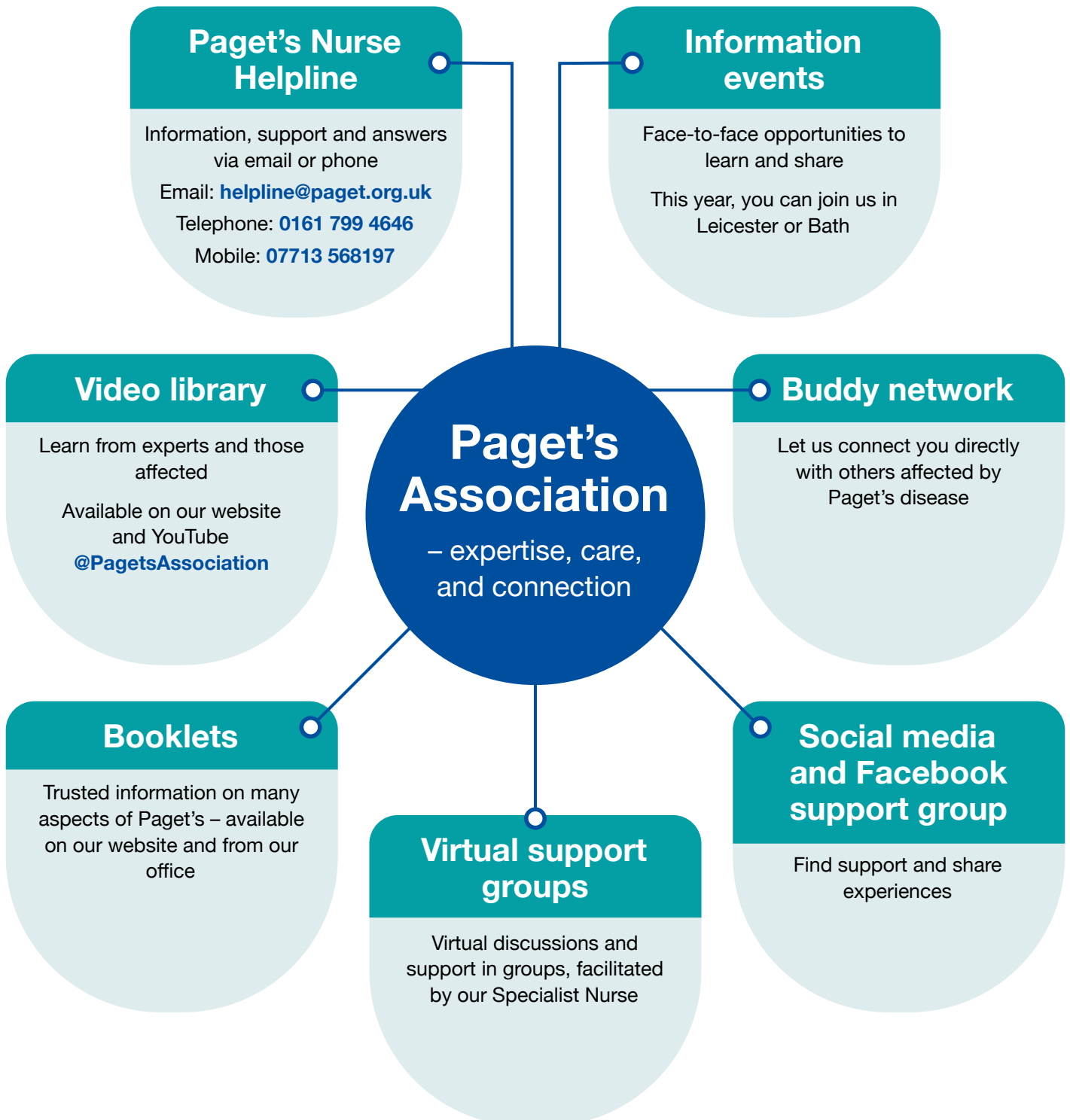
...then we invite you to join the Probiotics in Paget's Disease (PRiP) study, where we will be looking at the effect of probiotic use on PDB-related symptoms and signs.

Please email kathryn.berg@ed.ac.uk with your contact details and the name of your local hospital to take part in this exciting new research, or for more information about the PRiP Study.



Paget's circle of support

It's important to the team here at the Paget's Association to prevent individuals with Paget's disease from feeling isolated. We provide a supportive network that includes personalised help through the Nurse Helpline, virtual support groups, one-on-one connections, face-to-face events, social media, and educational resources. Through these layers of support, we strive to ensure that individuals feel connected, empowered, and never alone in their journey. If you need support, reach out today!



Survey results: pain and diagnosis

Thank you to everyone who participated in our recent (Oct 2024) survey* exploring pain, quality of life (QoL) and mental health prior to a Paget's disease diagnosis.

PagetAlert

*Shortening the pain journey
in Paget's Disease*

The survey has helped direct our **PagetAlert** fundraising campaign, which aims to encourage earlier diagnosis. The campaign is pivotal in raising awareness and encouraging early diagnosis. Early intervention has a profound impact, significantly improving outcomes and transforming lives. You can learn more about the **PagetAlert** campaign on page 24. Here we share the findings of our survey.

~45%

reported
>3 years to
diagnosis

~20%

waited
>5 years for a
diagnosis

>90%

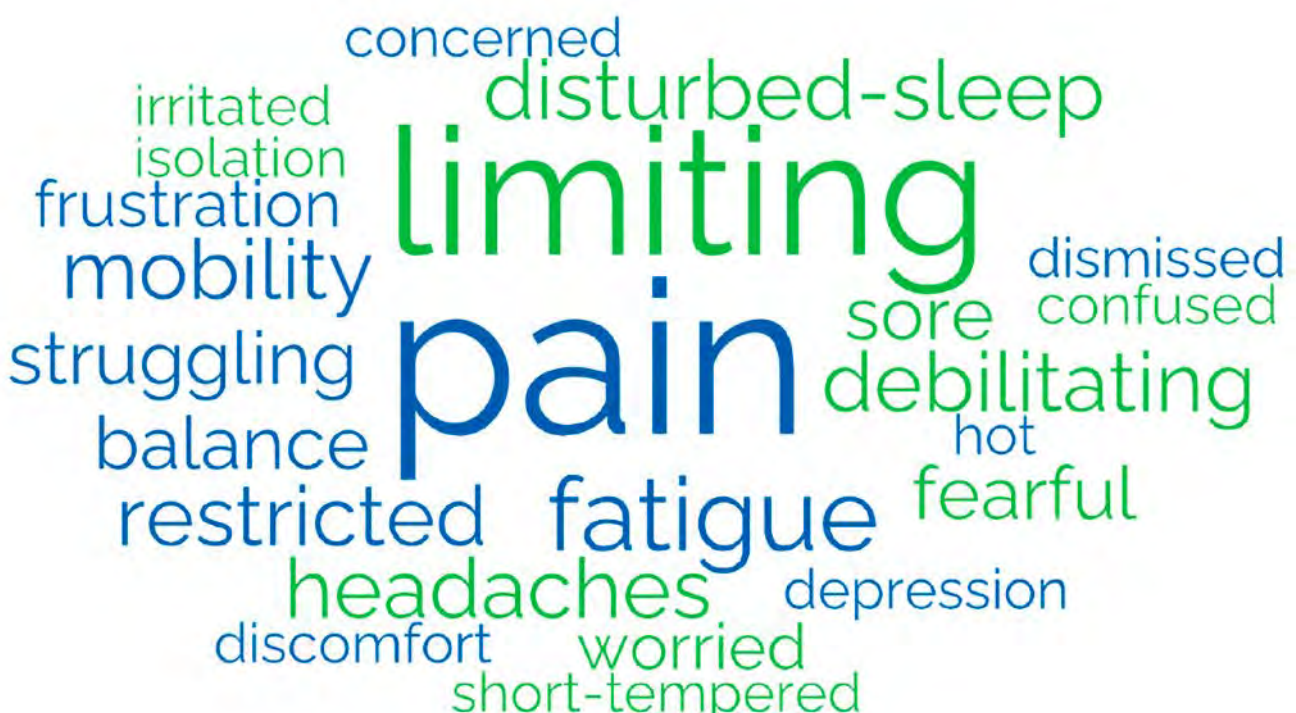
reported that
bone pain
impacted QoL**

2 in 3

stated that bone
pain affected
mental health

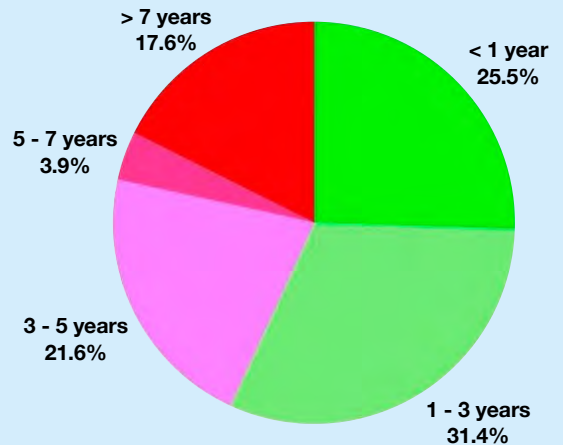
Pain before diagnosis

Participants in the survey were asked to describe their pain prior to receiving a diagnosis. This word cloud vividly captures their responses, reflecting the depth and range of their suffering.



Time from onset of bone pain to diagnosis

When asked how long it was from noticing bone pain to receiving a diagnosis of Paget's disease, we found that around 45% reported that it was over three years, with around 20% waiting over 5 years for a diagnosis.

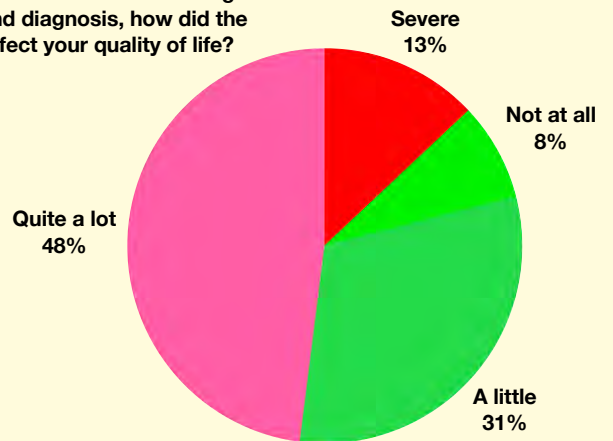


Quality of life and mental health

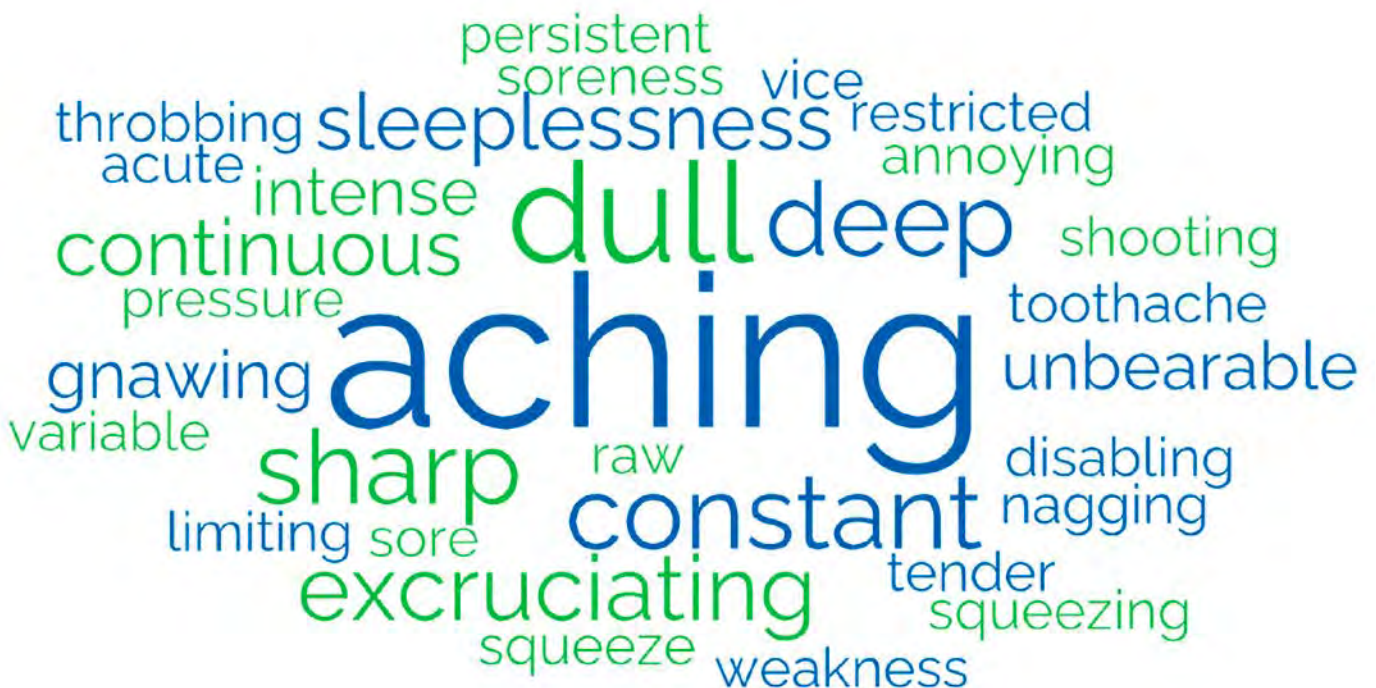
We asked participants to share how their symptoms affected their quality of life** prior to diagnosis:

During the period between noticing symptoms and diagnosis, over 90% reported that bone pain affected their quality of life. This is illustrated in the pie chart to the right and the word cloud below highlights the profound ways their lives were impacted before diagnosis. The final pie chart on the next page shows that bone pain affected the mental health of two in three people.

During the period between noticing symptoms and diagnosis, how did the condition affect your quality of life?



The words that best describe how Paget's disease affected people in the period before diagnosis.



Key challenges revealed

Finally, we asked those who experienced pain before diagnosis, if there was anything they wished to share about their journey to diagnosis. Their responses revealed recurring themes of frustration, delays and a general lack of awareness about the condition, as well as the emotional toll of living with uncertainty while suffering from unresolved pain.

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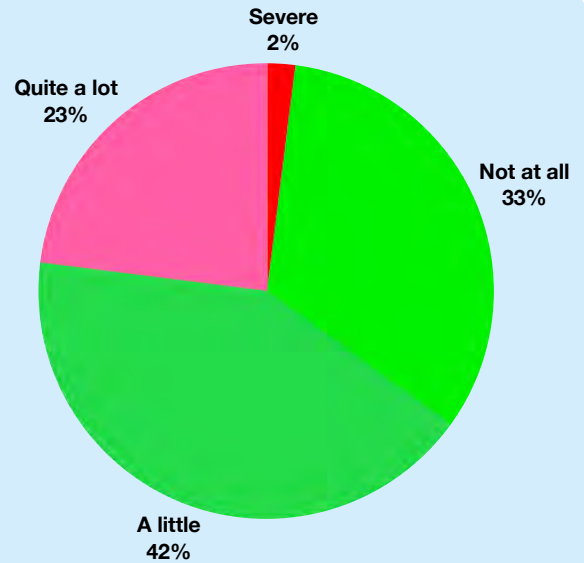
My alkaline phosphatase (ALP) was high for many years

”

A minority of participants were diagnosed quickly and experienced timely intervention. However, many people reported experiencing significant delays before receiving a diagnosis. Symptoms were often initially attributed to other conditions. Several encountered doctors who were unfamiliar with Paget's disease, leading to delays and misdiagnoses. As one person explained, “My alkaline phosphatase (ALP) was high for many years... I wish they could have treated it before the pain and permanent bone damage.”

Another individual shared how their persistent pain from a femur fracture was initially misdiagnosed as a muscular issue. After months of consultations with various specialists, they were finally diagnosed with Paget's disease. Similarly, a patient whose doctor initially linked their headaches to sinus problems or allergies described the severe discomfort they faced when chewing and wearing glasses,

During the period between noticing symptoms and diagnosis, how did the condition affect your mental health?



even wearing hats became painful. It took persistence on their part to have their concerns properly addressed.

Several emphasised the importance of self-advocacy. One remarked, “You should keep pushing if you're not getting answers quickly enough, even if you think you're being a pest.” This sentiment was widely echoed by others who felt they had to insist on further testing and referrals to specialists to get the right diagnosis.

“

I was told I had cancer... it was extremely traumatising

”

The emotional toll of these delays and misdiagnoses was also significant. One individual recounted their terror after being mistakenly told they had cancer following a CT scan, only to later learn it was Paget's disease: “I was told I had cancer... it was extremely traumatising.” Unfortunately, this is a concern frequently addressed on our Helpline.

One person noted how eventual treatment had dramatically improved their quality of life, “I had an X-ray which showed Paget's in the hip, however, because no red flags were showing it was active in blood tests, I was told the pain didn't relate to Paget's... Eventually, I had a bone scan which showed the Paget's was active and an infusion (zoledronic acid) was recommended. The infusion has been a lifesaver, I am now exercising daily and am nearly pain-free.”

These personal accounts underscore the challenges that individuals with Paget's disease face and highlight the urgent need for greater awareness among healthcare professionals. More timely and thorough investigations could significantly reduce the burden on patients, improving both their physical and emotional well-being.

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The infusion has been a lifesaver

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*An e-survey was conducted in October 2024 by the Paget's Association to gain deeper insights into the journey of individuals with bone pain before diagnosis. The response rate was 10.4% and data from 51-52 people was reviewed.

**QoL is a measure of a person's well-being that considers both positive and negative aspects.

PagetAlert

Shortening the pain journey in Paget's Disease

TARGET
£75,000

The Paget's Association has launched a campaign '**PagetAlert**' to encourage earlier diagnosis of Paget's disease, particularly in those who have experienced bone pain before diagnosis. The campaign is essential for raising awareness, promoting early diagnosis and improving the quality of life for people affected by Paget's disease. We will also continue to encourage new research to evaluate potential genetic testing to identify those most at risk and provide accurate and up-to-date clinical guidelines, resources and quality support for you, your families and future generations for years to come.

**RAISED
SO FAR
£2,211**



Ambitious target

Our ambitious target of £75,000 will help address the delays in diagnosing Paget's disease, which can lead to unnecessary complications such as pain, bone deformities and fractures. As all our funding comes from donations and legacies, your support is crucial in helping us reduce diagnosis time and ensure effective and timely pain management.

Do you know someone who could support us?

We're reaching out for help! Do you know a corporate business, company, or individual who might be interested in supporting our fundraising campaign? Whether it's through sponsorship, donations, or offering resources, every bit of help can have a huge impact. If someone comes to mind, please send us their details or encourage them to get in touch with us directly. Together, we can achieve so much more!

Thank you

Thank you to everyone who has already donated to our campaign. Your generosity will make a real difference in the fight against Paget's disease and we are deeply grateful for your support.

Raise funds

If you are planning a fundraising event, you can request a free fundraising pack!

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**.



Have you entered our raffle yet?

Prizes!

1st prize **£100**

2nd prize **£50**

Double Prize
Draw in June and
December

1st prize **£200**

2nd prize **£100**



We're excited to continue our mission to sell 200 tickets for the Paget's Association's Raffle and we need your support! This is not your average lottery. With only 200 tickets available, your chances of winning are good. Plus, by getting your friends and family involved, they will also be helping us raise much-needed funds.

Tickets are just £5 per month, and the draw takes place every month with two fantastic cash prizes: £100 for first place and £50 for second. But there's more! In June and December, the prizes are doubled, with £200 for first place and £100 for second.

Anyone over the age of 18 can take part, and you don't need to be a member of the Paget's Association. Whether you buy one ticket or two, your contribution goes directly towards supporting our charity and our mission. Together, we can make this raffle a success!

Winners ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

NOVEMBER 2024

1st Prize £100

Ticket no. 169
Janet Dixon
Louth

2nd Prize £50

Ticket no. 176
Vickie Reeves
Birmingham

DECEMBER DOUBLE PRIZE DRAW 2024

1st Prize £200

Ticket no. 4
Thomas Trevor
Oswestry

2nd Prize £100

Ticket no. 198
Anita Priestley
Leeds

JANUARY 2025

1st Prize £100

Ticket no. 99
Judith Moatt
South Wales

2nd Prize £50

Ticket no. 144
Kathleen Ford
Hertfordshire



Anyone over 18 can take part

It's easy to join

Joining is easy! Simply email membership@paget.org.uk or call **0161 799 4646** to let us know you'd like to join. Thank you for your support.



Understanding pain in Paget's disease

The Paget's Association, in partnership with the Michael Davie Research Foundation, awarded a Student Research Bursary to Kathryn Berg, a Research Assistant at the University of Edinburgh. This bursary supported her role in the Pain in Paget's (PiP) study as part of her journey toward earning a Master's degree (MSc). Here, Kathryn shares the findings of the PiP study.

What is Paget's disease?

Paget's disease is a condition that affects how our bones are renewed and repaired. While the renewal and repair process in bone is normally well organised, this process becomes abnormal in Paget's. There is excessive removal of bone coupled with increased formation which causes affected bones to enlarge, become weak, and in some cases become painful. Affected bones are more easily broken than normal bones and may become bent. Although some people with the condition experience symptoms like bone pain and bone deformity, many are unaware they have the disease until it's found during tests for other conditions.

Why does Paget's cause pain?

Bone pain is one of the most common symptoms reported by people living with Paget's disease but the cause of this pain isn't always clear. Sometimes pain occurs because of the abnormal renewal and repair process. If this is the case, medication that slows the process – which includes bisphosphonates like pamidronate, risedronate and zoledronic acid - can help the pain, or even make it disappear. Many people with Paget's disease have pain as the result of complications, like bending of the bones and

arthritis of the joints close to affected bones. Others might experience pain as the result of conditions unrelated to Paget's. The Pain in Paget's (PiP) Study was designed to help us understand the causes of pain in people with the condition.

“
Many people with Paget's disease have pain as the result of complications
 ”

The Pain in Paget's (PiP) Study

The PiP study, which was funded by the Paget's Association, has shed some light on why pain occurs in people living with Paget's disease. The study looked at 168 people with the condition across the UK, with the aim of understanding the causes of their pain. The research team found that the single most common cause of pain, occurring in two-thirds of people, was wear and tear of the joints or osteoarthritis. In about 27% of people, the osteoarthritis-affected joints were next to bones affected by Paget's but, in the majority, the joints affected by osteoarthritis were distant from the affected bones. It is known that Paget's can predispose to osteoarthritis in neighbouring joints, as the result

of the abnormal renewal and repair process. What is not clear is whether having Paget's disease can make osteoarthritis more likely to develop at sites unaffected by the disease.

There were many other causes of pain including bone deformities caused by Paget's, nerve pain, and conditions like fibromyalgia, tendonitis, and recent injuries. In a small number of people, the exact cause of pain was unclear.

How does treatment help?

The PiP study found that bisphosphonate treatments – especially intravenous zoledronic acid – were effective at helping pain, but not everyone responded to these treatments. Overall, 16% of people reported that their pain completely disappeared after treatment with bisphosphonates and about one third said it improved a lot. However, pain was not improved or changed only marginally in the remainder. This suggests that in these people other factors, such as osteoarthritis, might be driving the pain rather than the bone changes seen in Paget's.

Quality of life and the importance of understanding pain

Pain can have a significant impact on quality of life, and this was evident in the PiP study. People who experienced pain had lower scores

across all areas of a questionnaire called the 36-Item Short Form Survey (SF36), a questionnaire that measures health-related quality of life, compared to those without pain. This highlights the importance of identifying the root causes of pain in people with Paget's so that they can receive appropriate treatment. For example, if osteoarthritis is the primary cause of pain, treatments like physiotherapy, weight management, and painkillers are likely to be more beneficial than bisphosphonate therapy. Recognising the different sources of pain also helps prevent unnecessary treatments and ensures that people with Paget's can manage their condition more effectively.

What's next for Paget's disease research?

The PiP study also looked at whether specific markers in the blood could help predict pain in people with Paget's. Researchers measured

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”

various markers of bone turnover and inflammation, but interestingly, none of these were strongly linked to pain. While this finding was unexpected, it reinforces the idea that pain in Paget's is often due to a combination of factors rather than just bone disease itself.

One area that researchers are continuing to explore is the role of what are called cytokines in PDB-related pain. In the PiP study, there was an association between serum levels of a cytokine called M-CSF and pain. This is of interest because M-CSF is known to stimulate activity of bone resorbing

cells and we know that these cells are hyperactive in PDB. The PiP team are continuing research on the relationship between M-CSF and pain.

Final thoughts

Paget's disease can be a source of pain and discomfort but it's clear from the latest research that the causes of pain in Paget's are complex and varied. For many people, osteoarthritis and other age-related conditions may be the main source of their discomfort, rather than the disease itself. This highlights the importance of thorough medical evaluation and tailored treatment plans to address the full range of issues that people with the condition may face.

If you or someone you know is living with Paget's disease and experiencing pain, it's essential to speak with a healthcare professional who can help identify the most effective treatments, to tackle the root cause of pain. With the right approach, it's possible to manage symptoms and maintain a good quality of life.

London Marathon 2025



With the April 2025 London Marathon approaching, we want to thank all our incredible runners. Their dedication to training, raising awareness of Paget's disease and fundraising is truly inspiring and really makes a difference. We can't wait to cheer them across the finish line and celebrate their achievements!

To learn more about our runners and how to sponsor them, please email membership@paget.org.uk or simply donate through our website.



2026 Contact us to find out more about running the London Marathon in 2026.

Myths about gifts in wills explained

Remembering a charity in your will is a wonderfully kind gesture. It allows your values and passions to live on, supporting causes that mattered to you in life. This form of giving is simpler and more impactful than most people think, raising a remarkable £4 billion for UK charities annually. In fact, without such gifts, the Paget's Association would not be here today. There are, however, still myths surrounding this form of generosity that need to be cleared up. Here, we bust some of the common ones and shine a light on how you can make a lasting difference.



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The Paget's Association does not receive any government funding at all
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Myth Your loved ones will miss out if you give to charity

You can absolutely provide for your loved ones first. Even leaving a small percentage of your estate can help

charities while still ensuring your loved ones benefit from the bulk of your estate. 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, making your generosity a win for everyone. Given the genetic elements of Paget's disease, a gift in your will left to the Paget's Association could mean that future generations of your family benefit from the work of the charity in the future.



“
We're all richer when charities thrive
”

Myth Only wealthy people leave gifts to charity

You don't have to be wealthy to make a difference. You can leave a charitable gift of any size, from a set sum to a percentage of your estate, known as a "residuary gift." You could also donate an asset or item of value, such as property. There's no minimum amount, and every contribution makes an impact.

Myth You can only leave gifts to big charities

You don't need to leave a gift to a well-known organisation. Each year, over 10,000 UK charities, large and small, are named in wills. You can choose to leave a gift to any registered charity, regardless of size.

Myth You must choose only one charity

You do not have to choose just one charity. You can spread your gift across multiple organisations if you wish.

Myth My gift won't make a difference

This couldn't be further from the truth. Many charities, such as the Paget's Association, which does not receive any government funding at all, rely heavily on these donations to fund vital support services.



We're all richer when charities thrive

Has a charity helped you or someone you love? Chances are that a charity has or will touch your life and it may be when you least expect it. Charities are there for all of us in times of need. They make a difference but they can only do so with the continued support of the public.

Take the next step

According to the UK charity consortium *Remember a Charity*, one in five charity supporters over 40 have already decided to leave a charitable gift in their will. If you've been touched by a charity and want to help ensure they're there for others in the future, leaving a gift in your will is a beautiful way to say thank you. Whether you choose to support a large charity or a smaller one close to your heart, every gift helps.

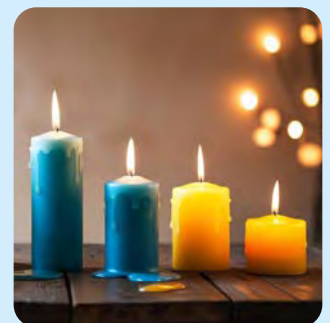
If you are thinking of leaving a gift in your will. You can visit the government website for information and seek advice from a solicitor or professional will writer to make sure your legacy reflects your wishes.



**Scan me for advice from
the Government website**

Donations on birthdays and anniversaries

Thank you to anyone who has honoured the memory of a loved one through donations to the Paget's Association on birthdays or anniversaries. Your kindness is appreciated.



Your questions answered

Here are some of the most common questions about Paget's disease submitted to the Paget's Nurse Helpline, along with their answers. We hope sharing these insights will be helpful to others.



Do you have a question?
 Contact the Paget's Nurse Helpline
 Email: helpline@paget.org.uk
 Telephone: 0161 799 4646

Q Is Paget's disease the same as osteoporosis?

A Some people have both Paget's and osteoporosis. Although both affect bone metabolism, they are different conditions. Osteoporosis causes bones to become brittle and weak due to loss of bone density. Paget's disease is abnormal bone remodelling, where old bone is removed and replaced too quickly, leading to bone that is weak due to its abnormal structure. The affected bone/s may be enlarged, misshapen and appear thicker on an x-ray.

Q Can Paget's disease be cured with treatment?

A Whilst treatment cannot cure Paget's disease, medication (e.g. bisphosphonates) can effectively manage the symptoms and slow disease progression. Treatment can help control abnormal bone remodelling and reduce pain but it cannot reverse structural changes in the bones that have already occurred.

Q Is surgery necessary to treat Paget's disease?

A Many people do not have complications from Paget's disease but for others, this is not the case. In certain instances, individuals affected by Paget's disease may find it necessary to see an orthopaedic surgeon. Surgery is typically only considered in cases where a severe complication has arisen, like a fracture, severe osteoarthritis or a bone deformity that impairs mobility. Successful surgical management of complications can reduce pain and improve quality of life. Whilst the operation itself can sometimes be more challenging, most surgical treatments are just as successful in those who have Paget's disease as in those who do not. The most common reason that someone with Paget's disease sees an orthopaedic surgeon is when they have osteoarthritis and are seeking advice about joint replacement.

Meet the team at the Paget's Association

Honorary President



Professor Graham Russell

Involvement 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.



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.

The Big Spring Coffee Morning for Paget's

Saturday 10 May 2025
or choose your own date!

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Paget's information event

Bailbrook House,
Bath, BA1 7JD

Thursday 25 September 2025

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Paget's information event

St Martins Conference Centre,
Leicester LE1 5PZ

Thursday 29 May 2025

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Virtual Support Groups

Meet others affected by Pagets online (using Zoom). Check our website for dates and to register or get in touch.

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