Paget's Association news
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Supporting those affected by Paget's Disease of Bone, encouraging research and raising awareness



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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), 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, encouraging research, collaborating with relevant organisations and taking any other actions that benefit those with the condition, their families and carers.

What is Paget's Disease of Bone?



Paget's disease affects the way bone renews itself. Old bone is broken down too quickly, while replacement bone forms at an accelerated rate and in a disorganised way. This results in bone with an abnormal structure.

The condition may affect one bone or several. Any bone can be affected but it is most commonly found in the pelvis, spine, skull or legs. Affected bones may become enlarged, weakened or misshapen.

The most common symptom is pain, although some people have no symptoms. Complications, such as fractures, can sometimes occur. Appropriate treatment can help control the disease and relieve symptoms.

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 7994646 (office)
07713568197 (mobile)

Post please use the address below

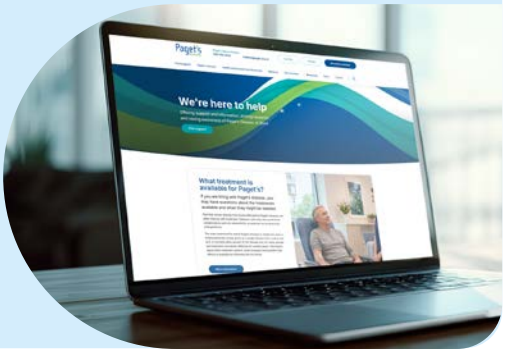


Website and social media

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 7994646

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

Chair's message

Dear Friends and Supporters,

Welcome to the Autumn 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.

We recently completed analysis of the shared experiences survey which yielded some very interesting results as summarised on pages 14-16. Thanks are due to the 133 people with Paget's disease who completed the survey and Diana who led the analysis. The survey had a truly international reach. Although 40% of respondents were from the UK, the remainder were from countries across the world, including the USA, Canada, Australia and New Zealand. A striking feature for me was the fact that 41% had misshapen or deformed bones which indicates that even today, people with Paget's experience this as a complication of the disease. A further 20% reported a positive family history of the disease, emphasising the importance of genetic or inherited factors in causing the disease. About half had been previously diagnosed as having vitamin D deficiency but more than 80% were taking vitamin or calcium supplements. There was nothing very remarkable about the environment people had grown up in or environmental patterns. There were very few smokers and most did not take alcohol regularly, indicating that people with Paget's disease generally have a healthy lifestyle. A major concern among respondents was delayed diagnosis and limited awareness of Paget's disease among healthcare professionals. Some people reported that blood



tests had shown raised alkaline phosphatase (ALP) levels for several years before Paget's disease was considered, while others described difficulties accessing appropriate tests, referrals or follow-up. These are all things that the Paget's Disease of Bone Association (PDBA) is looking to change through the PagetAlert campaign highlighted on page 19. As you can see, we are making progress with £50,640 raised against our target of £75,000, so progress is being made. As a charity funded entirely through donations, fundraising and legacies, we depend on the generosity of people like you to help us reach our target.

On the topic of fundraising, if you are making or updating your will and would like to leave a gift to the Association, please make sure that the will uses our new registered charity name, The Paget's Disease of Bone Association, registration number 1213575. The Paget's Disease of Bone Association is what's called a charitable incorporated organisation or CIO. This is a more modern legal structure designed specifically for charities, but the aims of the charity are the same as the National Association for Relief of Paget's Disease (NARPD) which was founded in 1973. If you are paying membership fees to the Association by Standing Order and wish to continue to contribute, can you please cancel your current Standing Order and set up a regular membership payment through our website at **www.paget.org.uk**. If you're not sure how to do this, please email us on **membership@paget.org.uk** or phone us on **0161 7994646** for advice.

On the topic of fundraising, I had the pleasure of taking part in a charity golf event, Pars for Paget's Disease, hosted by Kevin Duckworth in Livingston, as featured on page 18. Kevin is already one of our runners for the London Marathon in 2027 but he decided to organise this event as a fundraising starter! Kevin raised more than £1,900 for the Association. Although I didn't get any pars and was not one of the trophy winners, it was a great day, and it was a true pleasure to meet Kevin and other members of the golfing team.

The topic of Paget's Awareness Day 2027 is how the condition affects people from different backgrounds and ethnic groups. I was therefore very interested in the article on Paget's disease in Portugal on page 12. We thank Dr Roberto Pereira da Costa and Dr José Carlos Romeu for authoring the article which describes their experience in treating patients with the disease between 1974 and 2021.

On 8 January I will be answering your questions about Paget's disease live online (details on page 5) so do join me if you can!

We had a very successful information event hosted by Dr Nishanthi Thalayasingam and Dr Nadia Tripp, consultant rheumatologists from Newcastle. Details of the meeting are featured on pages 20-21 but suffice

continued on page 5

to say that feedback from delegates was excellent and it was great to hear the event helped people feel better informed about Paget's disease and more confident about discussing the condition with healthcare professionals. If you are interested in finding information about Paget's disease, it's important that you source information you can trust, as highlighted by the feature on page 13. Our Facebook support group provides an opportunity to connect with others affected by Paget's disease from around the world and of course The Paget's Association shares reliable information about Paget's disease, along with news and updates, through our own social media channels. If you turn to pages 8-9 you'll find a helpful article on pacing, a practical approach to managing activity levels and avoiding the cycle of overdoing things and paying the price later.

It is with great sadness that we learned of the passing of Dr Roger Smith in June 2026. Roger was a legendary figure in the field of bone disease in general and Paget's disease in particular and a former Chair of the Paget's Association. I have very fond memories of Roger and had the pleasure of interviewing him for Paget's Disease Awareness Day in 2021 on his early work with the use of bisphosphonates in the disease. He will be sorely missed.

On a happier note, please join me in congratulating our Patron Joyce Cupitt who celebrates her 100th birthday this year. I first met Joyce when she was a Trustee of the Association in 2000 and she has supported the charity ever since.

In closing, I should mention that, as part of the measures we are taking to manage the Paget's Association's finances carefully, we have made the difficult decision to reduce the number of issues of the Paget's News magazine from three to two during 2027. We will also be moving from a paper format to a fully digital format to reduce costs. We understand that receiving the magazine digitally may not be suitable or possible for everyone. If you are one of these people, please let us know by phoning us on **0161 7994646** or emailing us at: **membership@paget.org.uk** and we will work with you to try to find a solution as we don't want anyone to miss out.

I hope you enjoy reading the magazine as much as we have enjoyed putting it together and I hope to meet some of you at a forthcoming information event which is planned for September 2027. Watch this space!

With very best wishes to all.

Stuart Ralston

Chair, Paget's Association

Your chance to ask an expert – live Q&A

Join Professor Stuart Ralston for our next live Q&A session

Friday 8 January 2027

5.00 pm to 6.00 pm (GMT)



Do you have a question about Paget's disease? This is your opportunity to ask our Chair, Professor Stuart Ralston, your Paget's-related questions in a friendly and informal setting.

Whether you have recently been diagnosed, have been living with Paget's disease for many years, or simply want to learn more, everyone is welcome. You can ask a question live or just listen and learn from the discussion.

Wherever you are in the world, we'd be delighted for you to join us. Please note that all timings are GMT (London).

To register, please email **membership@paget.org.uk**

A Zoom link will be emailed to you a few days before the event.



Important changes to your Paget's News magazine

As part of the measures we are taking to manage the Paget's Association's finances carefully, we have made the difficult decision to reduce the number of issues of the Paget's News magazine from three to two during 2027.

We know how much the magazine is valued by our members and supporters. Although the frequency of publication and the way we deliver it are changing, our commitment remains the same. We will continue to bring you reliable information, updates, research news and stories from across the Paget's community on a regular basis.

Digital format only

We will also be moving to provide Paget's News as a fully digital format. Making this change will help us significantly reduce printing and postage costs, while also cutting paper use and lowering the environmental impact associated with producing and distributing the magazine.

If we already have your email address and you have opted to receive emails from us, you should have been receiving the digital version of Paget's News alongside your printed copy for some time and so there will be a smooth transition for many of our community.

Please check

To make sure you continue to receive the magazine, please check that we have your current email address. If you think we already have your email address but you have not been receiving our emails, please contact us so that we can check your details. It is also worth checking your junk or spam folder, as our emails can occasionally be filtered there by mistake.

What to do if you cannot receive the magazine electronically

We understand that receiving the magazine digitally may not be suitable or possible for everyone. If you are one of these people, please let us know. We do not want anyone to miss out. Contact us on **0161 7994646** or email **membership@paget.org.uk** and we will work with you to try to find a solution.

A lifetime dedicated to medicine and research

Dr Roger Smith, 1930 – 2026

We were deeply saddened to learn of the death of Dr Roger Smith, who passed away at home on 5 June 2026. A highly respected physician, researcher and former Chair of the Paget's Association, Roger played a major part in advancing both knowledge and treatment of Paget's disease.

Born in Newcastle-under-Lyme, Roger grew up alongside his identical twin brother, Sydney. Their father helped to inspire Roger's early interest in science by teaching them chemistry. After completing National Service, Roger studied at Trinity College, Cambridge, achieving a First-Class degree in Biochemistry. He subsequently trained in medicine at University College Hospital, London.

His early research career took him to Jamaica, where he investigated severe childhood malnutrition. Later he undertook research in Los Angeles examining the physical effects of starvation in people with extreme obesity. These experiences helped establish the strong scientific foundation that he would later bring to the study of metabolic bone disease.

A pioneer in the treatment of Paget's disease

After holding several hospital and research posts in London, Roger moved to Oxford in 1969. It was not long afterwards, in 1971, that, together with our Honorary President, Professor Graham Russell, he published a landmark paper



in The Lancet, reporting the first active treatment for Paget's disease using bisphosphonates. This was a major breakthrough. Their work opened the way to the bisphosphonate treatments that have since transformed the care of people with Paget's disease.

That same year, Roger received his PhD for research into hydroxyproline excretion in bone disease. He combined his specialist work in metabolic bone disorders with a continuing commitment to general medicine, serving as an NHS consultant at the John Radcliffe Hospital while maintaining close links with the Nuffield Orthopaedic Centre.

Roger's work was wide-ranging and influential. Over the course of his career, he published more than 200 original papers, wrote four books and contributed specialist chapters to leading medical publications, including the Oxford Textbook of Medicine. His research interests also included osteogenesis imperfecta and other rare disorders affecting bone.

He held several senior professional positions, serving as Chair of both the Paget's Association and the Osteogenesis Imperfecta Society. Through these roles, he supported not only scientific progress but also the needs of patients and families living with bone conditions.

Roger valued academic life in Oxford. He was a Fellow of Nuffield College and later a Fellow and Emeritus Fellow of Green Templeton College.

In retirement, Roger continued to enjoy tennis, gardening and travelling, particularly to places where he could paint. He became an accomplished artist, working mainly in watercolours and acrylics, exhibiting his work during Oxfordshire Artweeks.

Reflecting on Roger's contribution

In 2021, our current Chair, Professor Stuart Ralston, interviewed Roger for Paget's Awareness Day. Their conversation provided a fascinating insight into the early development of bisphosphonate treatment and Roger's determination to find better ways of relieving the pain and complications caused by Paget's disease.

The Paget's Association will remember Roger with enormous gratitude and affection. His pioneering work changed the outlook for people with Paget's disease and helped establish the foundations of modern treatment. His contribution will remain an important part of the Association's history, and his legacy will continue through the many people who benefit from the advances he helped to make possible.

Pace yourself and stay active

Our Specialist Nurse, Diana, looks at pacing as a way to manage activity, avoid overdoing things and help people with Paget's disease stay as active as possible.



Finding your pace

Does doing too much at once leave you struggling later that day or the next? Does fear of increasing pain lead you to do less? Pacing is a way of finding a more sustainable middle ground. It involves planning and spreading activities rather than repeatedly switching between doing too much and doing very little.

For people affected by Paget's disease, pacing may be particularly useful if pain or reduced mobility makes everyday activities more difficult. It is important, however, to understand what pacing can and cannot do.

People sometimes think pacing means slowing down, resting frequently or stopping whenever pain increases. Research suggests that it is more helpful to think of pacing as organising activity so that you can do things more consistently and remain as active as possible.

What does the research tell us?

Researcher Dr Deborah Antcliff and colleagues have studied activity pacing extensively in people living with persistent pain and fatigue. Their work describes pacing as a combination of strategies which may include planning ahead, breaking larger jobs into smaller parts, alternating activities, using planned rest periods and gradually increasing activity when appropriate. Their message was clear that 'pacing should enable increases in meaningful activities, as opposed to attempting to avoid symptoms'.

Pacing is widely used in chronic pain management but the scientific evidence is more complicated than might be expected. A 2019 systematic review of randomised studies found that pacing did not appear to reduce pain intensity itself, although there was evidence that pacing strategies could reduce the impact of fatigue, lessen joint stiffness and make patterns of physical activity more consistent.

More recently, a systematic review published in 2026 examined pacing approaches for adults with chronic pain. Nine studies involving 873 people were included. Common elements were planning activities in advance, alternating activity and rest and changing activities or positions. Overall, results tended to show improved physical function, although results for pain and fatigue were mixed and the researchers rated confidence in the evidence as very low.

What the evidence does suggest is that pacing can provide a practical framework for organising activity and maintaining participation in everyday life.

Breaking the cycle

Imagine that you normally manage ten minutes of gardening before becoming uncomfortable. One morning you feel particularly well and decide to spend an hour tackling the garden. You may get a great deal done but afterwards your pain increases and you spend much of the following day resting. When you eventually feel better, you try to catch up again. Pacing tries to smooth out these extremes. Instead of asking, "How much can I possibly do today?", the question becomes, "How much can I do comfortably and consistently?" That might mean doing a smaller amount of gardening, taking a planned break or changing to another task before returning to it later.

Importantly, pacing should not mean automatically doing less. Too much rest can lead to loss of muscle strength and fitness, which may make everyday activity more difficult in the long term. Regular exercise is good because it helps maintain joint movement, muscle tone and general health. Strength and balance exercises are particularly useful in helping to reduce the risk of falls. Extreme or high-impact forms of exercise should, however, be discussed with your doctor if there is concern about placing excessive stress on Pagetic bone.

Putting pacing into practice

Identify patterns

Record the activity, how long you spent doing it and how you felt later that day and the following day. The aim is not to analyse every ache and pain but to identify a level of activity that feels reasonably manageable and repeatable.

Break larger jobs into smaller ones

Rather than cleaning the whole house in one morning, for example, clean one room and do something different before continuing. Gardening could be divided into several shorter sessions. Shopping can be split between different days or combined with online shopping. Meals can sometimes be prepared in stages rather than standing for a prolonged period.



Change position and activity

If standing aggravates your symptoms, alternate standing tasks with something you can do sitting down. Similarly, rather than spending a long period on one physically demanding activity, alternate heavier and lighter tasks. Changing activity does not necessarily mean stopping altogether.

Plan breaks

It can be more helpful to take a short, planned break than to continue until pain or exhaustion forces you to stop. The key word, however, is planned. If activity only stops when pain becomes severe, symptoms remain in control of how much you do.

Build up gradually

Once an activity becomes manageable and consistent, you may be able to increase it gradually. For example, someone walking for ten minutes regularly might eventually add a little extra time or distance. Progress should be realistic and individual.

Perhaps the most useful message is that pacing is about using your energy and abilities more effectively so that you can continue doing the things that matter to you.

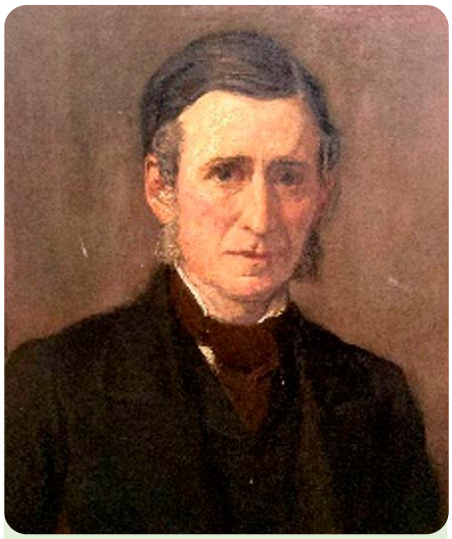
There will still be better days and more difficult ones. Life cannot always be divided neatly into timed activities and planned breaks. Pacing simply provides another tool to help you recognise your limits, avoid repeatedly overdoing things and gradually build confidence in what you can do. Sometimes, doing a little less today means being able to do much more over the course of the week.

References for further reading

Antcliff D, Burns L, English E, MacKenzie R, Geraghty AWA, Marriott-Smith J, Stansfield R, Storms K, Jinks C, Holden MA. *Operant Approach Activity Pacing Interventions for the Management of Chronic Pain: A Systematic Review.* Clin J Pain. 2026 Sep 1;42(9):e1393. doi: 10.1097/AJP.0000000000001393. PMID: 42085181.

Guy L, McKinstry C, Bruce C. *Effectiveness of Pacing as a Learned Strategy for People With Chronic Pain: A Systematic Review.* Am J Occup Ther. 2019 May/Jun;73(3):7303205060p1-7303205060p10. doi: 10.5014/ajot.2019.028555. PMID: 31120836.

Sir James Paget



Sir James Paget
11 Jan 1814 – 30 Dec 1899

Sir James Paget was one of the leading figures in 19th century British medicine. A highly respected surgeon and pathologist, he described in detail, in 1877, the bone disorder that would later bear his name, Paget's Disease of Bone.

In recognition of his distinguished contribution to medicine, Sir James Paget was made a Baronet by Queen Victoria in 1871. His family motto was 'Labor ipse voluptas', meaning 'Work itself is a pleasure', a fitting phrase for a man known for his extraordinary dedication to his work.

His contribution to medicine went far beyond this one condition and his name became associated with several other conditions. More than a century after his death, Sir James Paget's influence can still be felt. His powers of observation, meticulous approach and determination to improve medical understanding helped shape modern medicine and continue to inspire healthcare professionals today.

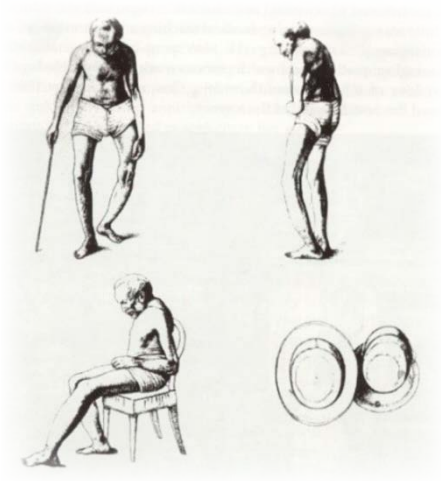
Did you know…?

- Sir James Paget warned young doctors about burnout and championed work-life balance – in the 1800s!
- He was close friends with Charles Darwin.
- He publicly supported women entering medicine.
- Paget's vivid case presentations blended narrative, observation and wit. His lectures were so popular, students arrived hours early – a Victorian version of going viral.
- He served as surgeon to Queen Victoria and was later made a Baronet.
- He loved his work and his personal motto was: 'Work itself is a pleasure.'

Paget's Disease of Bone

Did you know…?

- In 1877, Sir James Paget published a detailed account of the condition, which he called osteitis deformans. Aware that understanding of the disease was still developing, he wrote: 'A better name may be given when more is known of it.'
- By 1888, the condition had become closely associated with Paget himself. Sir Jonathan Hutchinson referred to it as Paget's Disease of Bone in the British Medical Journal, helping to establish the name by which we know it today.



Illustrations depicting his most renowned case, a 46-year-old coachman, originally published in his 1877 paper

Paget's Awareness Day



Paget's Awareness Day was launched by the Paget's Association in 2019 in Great Yarmouth, the birthplace of Sir James Paget. It continues to be marked each year on 11 January, the anniversary of his birth.

Looking ahead to 2027

In 2027, our focus will be on ethnicity and Paget's disease. We will explore what is known about how the condition affects different populations and whether its prevalence and presentation vary between ethnic groups.

New video recordings will be released as part of the Awareness Day programme, so keep an eye on our website for further information.

Action needed:

Standing Orders

Do you pay for your membership, raffle or regular donation by Standing Order?

As part of our transition to a Charitable Incorporated Organisation, we are changing our bank account. Unfortunately, this means we will no longer be able to receive payments through existing Standing Orders.

If your Standing Order is for membership

Please cancel your current Standing Order and set up a regular membership payment through our website at **www.paget.org.uk**

If you would prefer to continue paying by Standing Order, please contact us and we will provide the new details.

If your Standing Order is for raffle tickets

Please cancel your existing Standing Order and contact us so that we can advise you how to continue your payments.

If your Standing Order is for a regular donation

Please cancel your existing Standing Order and contact us so that we can provide the new payment details.

Questions

Your ongoing support makes a real difference to our work and we are extremely grateful for your continued commitment to the Association. If you have any questions or would like help setting up a new payment, please do not hesitate to contact us.

What's your story?

We are grateful to those who have shared their experience of Paget's disease in this magazine as we know it helps others. If you would like to share your story to help support others, please get in touch by emailing **diana.wilkinson@paget.org.uk** or by telephoning **0161 7994646**.

You will be given as much support as needed to put it together.



Paget's disease in Portugal

The Rheumatology Department of Unidade Local de Saúde Santa Maria (ULSSM) in Lisbon has roots dating back to 1977 and has long had a particular focus on metabolic bone diseases. In this study, the Metabolic Bone Diseases clinical team of this Department reviewed more than 40 years of experience caring for people with Paget's Disease of Bone (PDB). The team analysed 80 patients diagnosed between 1974 and 2021, focusing on where they were born and lived, possible environmental exposures, the pattern of bone involvement, symptoms, complications and response to treatment.

The majority of patients were female and the age at diagnosis was around 63 years. Of note, many patients came from rural backgrounds, with a particularly high proportion born in Alentejo, a region in southern Portugal where PDB has previously been reported as more frequent. However, only a small proportion of patients had a family history of PDB. Many had also had long-term contact with domestic animals or livestock. These findings do not prove that rural living or animal contact causes the disease, but they support the idea that geography, environment and genetic susceptibility may interact in its development.

The most common symptom was bone pain. Around half of the patients had disease affecting more than one bone, known as polyostotic disease. This form was associated with greater bone turnover activity on blood tests and with involvement of particular skeletal sites, including the pelvis, spine, femur, sacrum and skull.

Most patients were treated with zoledronate, a bisphosphonate given by infusion. Treatment was followed by an improvement in bone remodelling markers in the blood and



the majority of patients did not need retreatment. Notably, patients initially treated with zoledronate tended to remain well controlled for longer than those treated with other medicines.

This Portuguese cohort highlights the importance of geographic patterns in PDB and reinforces the role of zoledronate as an effective treatment associated with long periods of remission. In the future, we intend to perform genetic studies of this group of patients, which may help to clarify why some people are more susceptible to the condition, why it appears to cluster in particular regions and why bone involvement differs between patients.

- Roberto Pereira da Costa and José Carlos Romeu on behalf of the authors.

Reference

Lopes, A.R., Matos, C.O., da Costa, R.P., Travessa, A., Dias, P., Martins, P., Tenazinha, C., Fernandes, S., Barros, R., Cruz-Machado, A.R. and Romeu, J.C., 2026. Paget's disease of bone: Clinical and epidemiological characterisation of the population of a Portuguese tertiary centre. Bone, 208, p.117857.

Social media – finding health information you can trust

Social media can be a useful place to find health information, connect with others and discover new sources of support. Unfortunately, not everything we see online is accurate. Misleading information can spread quickly, particularly when posts are widely shared or attract large numbers of likes and followers.

The Patient Information Forum (PIF) has revealed the significant reach of misinformation. Four in ten UK adults have been affected by misinformation in the past three months, and seven in ten have seen misleading information on social media platforms.

Don't be influenced by likes and followers

A large following does not necessarily mean that the information being shared is reliable. Popular posts can still contain inaccurate or misleading claims, so look beyond the number of views, likes or followers before deciding whether to trust something.

Look at where the information comes from

Choose information from organisations you recognise and trust, such as the NHS, established health charities and professional healthcare organisations. You can check whether a charity is registered by searching the Charity Commission's website.

Check whether claims are challenged

Consider how the social media platform or account deals with false or misleading information. Does it identify suspicious content, provide fact-checking information or correct claims that have been shown to be inaccurate?

Think about who shared it

Information can feel more trustworthy when it has been shared by someone we know but a recommendation from a friend or family member does not make a health claim accurate. Consider where the information originally came from and whether the person or organisation sharing it may have a particular viewpoint or bias.

Think before you share

Before forwarding or reposting health information, ask yourself a few simple questions:

- Where did it come from?
- Is there evidence that it is true?
- Is someone trying to sell me something?
- Why am I sharing it?
- How does the information make me feel?

A quick fact-check can go a long way in stopping the spread of inaccurate health information. Social media offers valuable opportunities to connect, learn and find support, but health-related advice should always be verified against information from trusted sources.

Connect with us

The Paget's Association shares reliable information about Paget's disease, along with news and updates, through its own social media channels. You can follow us on Facebook and Instagram. Our YouTube channel includes a wide range of videos covering different aspects of Paget's disease, from personal experiences to interviews with leading experts. Our Facebook Support Group also provides an opportunity to connect with others affected by Paget's disease from around the world.

Facebook:
facebook.com/PagetsAssociation

Facebook Support Group:
facebook.com/groups/pagetsdiseaseofbone/

Instagram:
instagram.com/pagetsassociation/

YouTube:
youtube.com/c/PagetOrgUk

Shared Experiences Survey



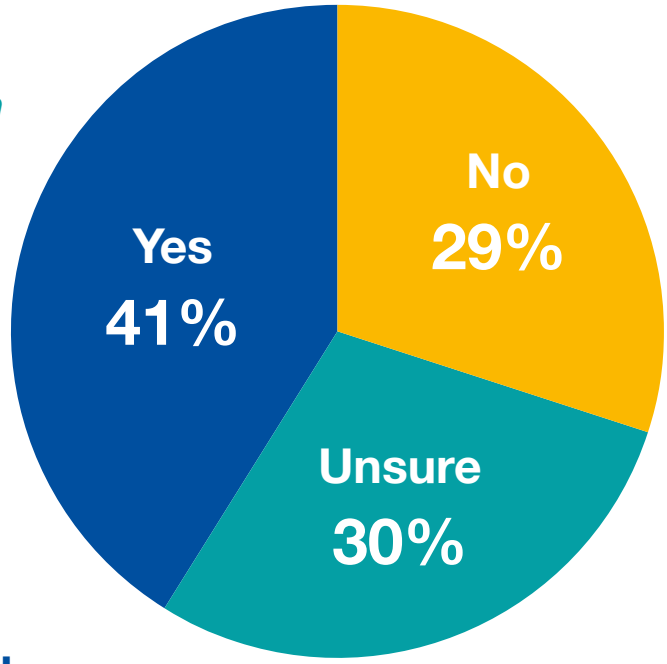
A huge thank you to everyone who took the time to complete our Shared Experiences Survey. We know many of you have been keen to see what the survey revealed, so we're pleased to share the results with you.

The survey was designed to help us build a broader picture of the experiences of people with Paget's disease and explore patterns and themes that may be of interest. Artificial intelligence (AI) was responsibly used as a tool to assist with the analysis of the results. This helped to bring together the large amount of information shared.

The 133 people who took part were all diagnosed with Paget's disease. Some had an existing connection with the Association, while others found the survey independently through our website. For some questions, respondents could select more than one answer or mention several factors, so percentages may total more than 100%.

While the survey explored a range of lifestyle, environmental and health factors, it cannot tell us whether any of these contribute to the development of Paget's disease. Instead, the findings provide an interesting snapshot of the experiences of the people who took part and highlight some of the questions that remain important to those living with the condition. We will continue to analyse the results, explore areas of interest and identify ways we can further improve the support we provide.

Have any bones been misshapen by Paget's disease?



Misshapen bones

When asked whether Paget's disease had caused any bones to become misshapen, 41% said yes, 29% said no and 30% were unsure. Bone changes varied considerably in both where they occurred and how they appeared.

The pelvis and hips, legs, skull and spine were most frequently mentioned. People described bone enlargement or thickening, bowing of the legs, lumps or ridges, vertebral distortion, changes in the shape of the pelvis and spinal deformity. Skull changes included enlargement, bumps, indentations and prominent facial or brow bones.

Some people also reported differences in leg length, reduced movement, problems with joint alignment and the need for hip or knee replacement or spinal surgery. Others were unsure whether changes they had noticed were caused by Paget's disease.



This word cloud shows which bones people reported as being affected by Paget's disease, with the larger text indicating a more common response

Family history

Overall, 20% reported a known family history of Paget's disease, 56% reported no family history of Paget's disease that they were aware of and 24% were unsure or did not know. Among those who reported a family history, 55% mentioned a parent, 21% a grandparent, 9% a sibling and 15% another relative.

Geography and background

The survey had a strong international reach. Around 40% lived in the UK, 32% in the USA, 10% in Australia and 6% in Canada. People also took part from New Zealand, Ireland, Sweden, Norway, South Africa, Switzerland, Belgium, the UAE, the Netherlands, France and Poland.

When we asked where people spent most of their childhood, the pattern was similar, with 41% growing up in the UK, 29% in the USA, 11% in Australia and 5% in Canada. Ireland, South Africa, New Zealand, Sweden, Poland, Romania, the Netherlands and other countries were also reported.

Most people had not lived for more than ten years in another country. Among those who had, the UK was the most frequently mentioned, followed by the USA.

Among people who had grown up outside the UK, around one-third described UK family roots or close family connections. These included parents, grandparents and more distant ancestors from the UK.

Exploring work and environmental factors

The survey explored the different environments people had spent time in, as well as possible long-term exposures through work, hobbies and everyday life.

The type of environment people grew up in also varied. Just over half (53%) had grown up mainly in an urban environment, while 35% had grown up in a rural environment, 8% in an industrial environment and 4% in a coastal environment. Most people (86%) had not lived or worked for a long period on a farm, while around 14% had some farming background, most commonly mixed farming. Working lives were also varied, with desk-based work the most common, reported by 50%, followed by healthcare (16%) and teaching (14%).

We also asked about exposure to particular materials through work or hobbies. Most people (80%) had not worked extensively with wood, metals, chemicals, fabric or dust. Among those who had, dust was the most common, reported by 8%, followed by metals and chemicals at around 7% each, and wood and fabric at around 5% each. Exposure to traditional fires or stoves was much more common, with 53% reporting exposure to wood-burning fires and 46% to coal.

Looking at exposures lasting 10 years or more, almost half (49%) reported none of those listed. Among those who did, repetitive movements were most common (29%), followed by heavy lifting (25%) and repetitive physical strain (17%). Chemicals or pesticides were reported by 13%, industrial dust by 8% and vibrating machinery by 5%.

In the future, it would be interesting to know how common exposure to some of these factors is in the general population.

Diet and deficiencies

We asked people how they would describe their long-term adult diet. A balanced or mixed diet was by far the most common, reported by 77%.

Half of those taking part (50%) reported having been diagnosed with vitamin D deficiency, while 16% reported calcium deficiency.

We also asked whether people currently take dietary supplements. Vitamin D was the most common, taken by 78%, followed by calcium, taken by 37%. A multivitamin was taken by 17%; other supplements were mentioned by 23% and 13% said they did not currently take any supplements.

Physical activity

We asked whether people had regularly participated for five years or more in certain types of physical activity. Most (61%) selected none. Among those who had, long-distance walking or hiking was the most common (19%), followed by running (14%). High-impact sports were reported by 11%, while weightlifting and contact sports were each reported by 8%.

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Injury

We asked whether people had experienced an injury to an area later affected by Paget's disease. Most (56%) said no, while 21% said yes and 23% were unsure. Some provided descriptions including falls, fractures, road traffic accidents, horse-riding and sporting injuries.

Smoking and alcohol

The majority (61%) had never smoked, 36% were former smokers and just 3% were current smokers.

Regarding long-term alcohol consumption, 38% reported drinking no alcohol, while 49% reported low consumption of up to 14 units per week. A further 12% were in the moderate category (15–35 units per week for women and 15–50 units for men), while 1% reported high consumption.

Childhood illness

Almost two-thirds (65%) recalled having a significant viral illness during childhood. Many respondents recalled more than one childhood illness. Of those who provided further details, measles was the most common, mentioned by 71%, followed by chickenpox, 60%, and mumps, 52%. German measles was reported by 11%. Other viral illnesses mentioned included influenza, glandular fever, smallpox, hepatitis A and shingles.

Other health factors

Only 7% reported having had or been exposed to tuberculosis (TB). When we asked about arthritis, osteoarthritis was by far the most commonly reported type of arthritis, mentioned by around 43% of those taking part. A much smaller number mentioned rheumatoid or psoriatic arthritis.

Among the 89% of respondents who answered the question about other health conditions, high blood pressure and thyroid disorders were particularly common, followed by asthma, high cholesterol and diabetes. People also reported osteoporosis, osteopenia, cardiovascular conditions, neuropathy, gastrointestinal problems and a wide range of other health conditions.

The reality of living with Paget's disease

When we asked what people wished others understood about living with Paget's disease, pain was by far the strongest theme, mentioned by around 40% of those who answered. People described pain as chronic, severe, unpredictable and at times disabling. Several stressed that Paget's can be an invisible condition, meaning someone may look well while experiencing considerable pain, fatigue or difficulty with everyday activities.

The impact on mobility and independence was also frequently highlighted. People described difficulties with walking, standing, carrying weight, sleeping and remaining active. Some referred to bone deformity, poor balance, fractures and the lasting effects of bone and joint damage.

Experiences varied considerably, however, with some people reporting few or no symptoms while others described significant daily pain and loss of independence, with some commenting that they had to retire early.

Given the opportunity to add further comments, a major concern was delayed diagnosis and limited awareness of Paget's disease, particularly among healthcare professionals. Some people reported that blood tests had shown raised alkaline phosphatase (ALP) levels for several years before Paget's disease was considered, while others described difficulties accessing appropriate tests, referrals or follow-up. Several felt that earlier recognition and treatment might have prevented pain or permanent bone and joint damage. Concerns were also raised about fragmented care, with symptoms sometimes considered separately rather than as part of a person's overall health.

People wanted others to understand that Paget's disease affects everyone differently. Although treatment can control disease activity, it does not relieve pain caused by complications such as osteoarthritis in adjacent joints. This was reflected in comments about zoledronic acid treatment. Some people reported that treatment had successfully controlled their symptoms and normalised their ALP, while others were concerned about side effects or unsure whether treatment would improve their pain. Obtaining follow-up after treatment was raised as a concern.

There was considerable interest in why Paget's disease develops and what future research may uncover, reinforcing the importance of continued research, alongside greater awareness, earlier diagnosis and access to appropriate care and support.

A clear message was that Paget's disease should be recognised as more than simply a bone condition. Its effects can be physical, emotional and practical and, for some, can have a significant impact on their everyday life.

The role of the Paget's Association

We also asked whether the Paget's Association had helped people in any way. Of the 133 respondents, 74% gave a positive response, either saying directly that the Association had helped them or describing information or support they had found useful. Around 19% said that the Association had not helped them, although this does not necessarily mean they had a poor experience. Some respondents indicated that they had not needed support, had not yet contacted the Association, were newly diagnosed or had only recently become aware of it, so they may simply not have had an opportunity to use its services. The remaining responses could not be clearly classified.

Among those who described how the Association had helped them, 20% mentioned the Paget's News magazine and 16% our website. Virtual support groups, including Zoom sessions, were mentioned by 8%, while 8% mentioned the Helpline or direct contact with the Association. Facebook was mentioned by 5%. Other sources of support included videos, webinars, conferences or meetings, information packs and involvement in research.

Several respondents also said the Association had helped them better understand Paget's disease, feel reassured and less alone and access reliable information. In one case, the Association helped a respondent to access appropriate specialist care and treatment.

Several people expressed gratitude for the information and support provided by the Paget's Association. Some described the reassurance of discovering the Association after diagnosis, particularly where local knowledge or specialist support was limited.

We are extremely grateful to everyone who shared their experiences. Your contributions help us better understand what matters to people affected by Paget's disease and will help shape our future work.

Happy 100th birthday, Joyce!



We have a very special reason to celebrate this December, as our Honorary Patron, Joyce Cupitt, turns 100!

Joyce is a remarkable lady who has given so much to the Paget's Association over many years. Serving as a Trustee for an incredible 14 years, she gave her time, support and commitment generously to the Association and to those affected by Paget's disease.

When she retired from the Board in 2014, we were delighted that she accepted the role of Honorary Patron, allowing her long and valued association with our charity to continue. At the time, Joyce wrote movingly about how much the Association had meant to both her and her husband, Thomas. She described her time as a Trustee as a "joy and pleasure" and said that her life had been enriched by the kindness and friendship she had received. We feel very much the same about Joyce. Her warmth, loyalty and dedication have meant a great deal to Trustees, staff and members alike.

Joyce, thank you for everything you have given to the Paget's Association over the years. We hope your very special birthday is filled with much happiness and happy memories.

Happy 100th birthday, Joyce, with love from everyone at the Paget's Association.

Pars for Paget's

In October, Kevin Duckworth organised a Pars for Paget's Charity Golf Day at Deer Park Golf Club in Livingston, raising over £1,900 for the Paget's Association. The event was part of Kevin's fundraising efforts ahead of taking part in the 2027 London Marathon. Our Chair, Professor Stuart Ralston, also took part in the event.

We are grateful to Kevin for organising the event and to everyone who supported it, helping to raise such a fantastic amount. Well done Kevin and good luck with your training.

If you would like to support any of our nine London Marathon runners, please donate on our website or get in touch.



Pars for Paget's Charity Golf Day



Prof Stuart Ralston (left) with Kevin Duckworth (right)



The proud winners

No one should have to wait years for a diagnosis

Too many people live with pain for years before discovering that Paget's disease is the cause. During that time, their health, independence and quality of life may suffer. That is why our *PagetAlert* Campaign encourages earlier diagnosis to help prevent unnecessary suffering.

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

TARGET £75,000

RAISED SO FAR £50,640



Help us raise £75,000

Our target is ambitious but the need is urgent

As a charity funded entirely through donations, fundraising and legacies, we depend on the generosity of people like you to help us reach our target. Every gift matters. Whether you donate £5, £50 or £500, you will help bring us closer to a future where fewer people endure years of unexplained pain.



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 7994646.**

Together, we can make a difference

A heartfelt thank you to everyone who has already supported the ***PagetAlert*** Campaign.

Scan to learn more about ***PagetAlert***

Learning and connecting

Paget's Association
CENTRE OF EXCELLENCE

Our Newcastle information event brought together people affected by Paget's disease, healthcare professionals and researchers for a day of expert talks, practical information and shared discussion.



Attendees take their seats for the event

On 17 September, the Paget's Association held a free information event at The County Hotel in Newcastle upon Tyne, in collaboration with the Newcastle Bone Clinic, a Paget's Association Centre of Excellence. The event was chaired by Professor Stuart Ralston and hosted by Newcastle rheumatologists Dr Nishanthi Thalayasingam and Dr Nadia Tripp.

The programme was designed to give people living with Paget's disease, their families and carers the chance to hear directly from specialists, ask questions and learn more about the condition. Health professionals and researchers were also welcomed.

From history to future treatment

The morning began with the history of Paget's disease, followed by sessions on diagnosis and management and a case presentation. Attendees also learned more about the role of the Paget's Association.

After lunch, the focus turned to interpreting radiology, genetic testing and preventative treatment, referral pathways including orthopaedic care and a final question-and-answer session. Together, the talks provided a broad overview of the condition, from diagnosis and treatment to current research and access to specialist care.

What attendees told us

Feedback from the day was very positive. Attendees told us that the event helped them feel better informed about Paget's disease and more confident about discussing the condition with healthcare professionals. When asked what they found most beneficial, people highlighted learning about the history, symptoms, diagnosis, radiology, testing, referral pathways and treatment of Paget's disease. Others valued meeting clinicians and hearing a clear overview of the work of the Association.



Dr Nishanthi Thalayasingam



Dr Nadia Tripp

Dr Nishanthi Thalayasingam and Dr Nadia Tripp explored the history of Paget's disease, placing it in context from Sir James Paget and Victorian medicine through to the present day. They will be summarising their talk for a future edition of Paget's News.

Feedback included: "Really interesting to see Paget's in context, thank you!" and "Great presentation. Definitely improved my awareness."



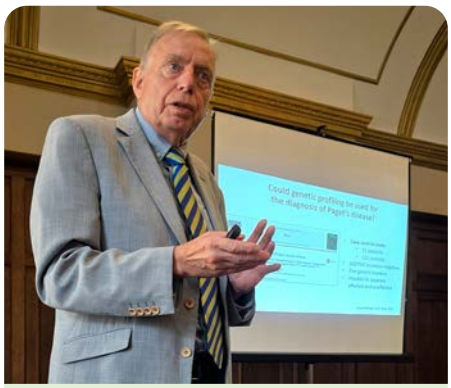
Dr Krishna Dasigan reflected on how far treatment for Paget's disease has come. He highlighted that biochemical control can last for many years after effective treatment, that returning symptoms do not always mean Paget's disease has become active again and that sometimes stepping back from further treatment can be part of good clinical management.

Feedback from the session included, "Thank you. It's intriguing to think it's been so widespread and, while we can diagnose it, we can't yet understand it fully…"



Dr John Tuckett gave a fascinating and very well-received talk, using X-rays to explain the different phases of Paget's disease and the various scanning techniques used.

A member of the audience said, "Great to see X-ray evidence and explanations of different phases and techniques of scanning. Thank you!"



Professor Stuart Ralston gave a very engaging and informative presentation, including an overview of genetic testing.

A participant said, "Useful to get insight into genetic testing as I had no idea. Great presenter."



Dr Stephen Tuck gave an informative and reassuring talk, including discussion of when surgery may be needed for people with Paget's disease.

Feedback included this remark, "Really enjoyed Dr Tuck's talk and felt reassured by his comments on surgery needed when diagnosed with Paget's of the pelvis/hip."

Bringing people together

Information events are about more than presentations. They also give people the opportunity to meet others affected by Paget's disease, talk informally with specialists and share experiences in a friendly setting.



Dr Matt Grove gave a clear and informative talk, explaining the complexities of Paget's disease and giving practical examples of how it can be managed.

One delegate commented, "It's more complex than we realise. Thank you for the explanations and examples of management. Thank you."

The Newcastle event created time for questions throughout the day, as well as networking over refreshments and lunch. Feedback suggested that this combination of expert information and personal contact was particularly valuable.

Thank you

We are grateful to everyone who attended and contributed to the day, and to all the speakers who gave their time and expertise. We also extend our sincere thanks to the Barbour Foundation for their generosity in supporting the event. Particular thanks go to our hosts, Dr Nishanthi Thalayasingam and Dr Nadia Tripp, and to the Newcastle Bone Clinic for working with us to make the event possible.

Join us next time

If you missed Newcastle, we hope you will be able to join us at our next Paget's information event. Details of this will be announced next year.

An important update regarding leaving a gift in your will

If you are making or updating your will and would like to leave a gift to the Paget's Association, please make sure that your will uses our new registered charity name, The Paget's Disease of Bone Association, registered charity number 1213575. Using the full name and charity registration number will help ensure that your gift reaches our charity exactly as you intend.

For a period, you may see two Paget's charities listed on the Charity Commission register. Our original charity, The National Association for the Relief of Paget's Disease (NARPD), also known as the Paget's Association, charity number 266071, will remain in place while the transition is completed. The new charity, The Paget's Disease of Bone Association, charity number 1213575, is the charity we are moving forward with.



Why has the charity name and registration number changed?

You may be wondering why the name and charity number have changed. In April 2023, our members voted at an Extraordinary General Meeting to begin the process of converting the Association into a Charitable Incorporated Organisation (CIO). Following a careful period of preparation, The Paget's Disease of Bone Association was registered on 9 June 2025, with charity number 1213575.

Our new name

The Paget's Disease of Bone Association

Registered charity number 1213575

What is a CIO?

The NARPD was formed in 1973. A CIO is a more modern legal structure designed specifically for charities. It allows the charity to operate more effectively, while giving Trustees limited liability. Importantly, it remains a charity regulated by the Charity Commission.

Here's what you can expect

- Operational continuity: our services, Paget's Helpline and research commitments will 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.

Your gift

A gift in your will, whatever its size, can help ensure that future generations affected by Paget's disease continue to have access to reliable information, support and research. Thank you.



The Paget's Disease of Bone Association's charitable aims

To preserve and protect the health of persons suffering from Paget's Disease of Bone and their families by:

a) providing information and support

b) raising awareness about Paget's disease both within the medical and allied health professions, and amongst the general public

c) supporting and funding research projects in the field of Paget's disease or its treatment

d) working and coordinating with other organisations (charitable, voluntary, governmental or otherwise) to support those affected by rare bone disorders

e) undertaking any other actions and/or objects in support of persons suffering from Paget's disease or who may be at risk of suffering from Paget's disease, their families and carers.

Remembering family and friends

To all who remember a loved one through donations to the Association on special dates or in place of funeral flowers, please accept our heartfelt thanks. Your kindness not only pays tribute to those you cherish but also helps sustain the work we do.



Win up to £200!

Our monthly raffle is limited to just 200 tickets, giving you a great chance of winning while helping to support our vital work.

- **£5 per ticket, per month**
- **Two prizes every month:** £100 and £50, plus prizes double in June and December, giving you a chance to win up to £200
- **Open to anyone aged 18+** (membership of the Association is not required)

To buy a ticket and enter the next draw, simply email **membership@paget.org.uk** or call **0161 7994646**.

Do you pay for your ticket by Standing Order?

As we have changed our bank account, if you currently pay for your raffle tickets by Standing Order, please cancel your existing Standing Order and contact us. We will provide the new bank details and explain how to set up your new payment.

Winners

July 2026

1st prize £100 / ticket no. 99

2nd prize £50 / ticket no. 170

August 2026

1st prize £100 / ticket no. 187

2nd prize £50 / ticket no. 29

September 2026

1st prize £100 / ticket no. 14

2nd prize £50 / ticket no. 145

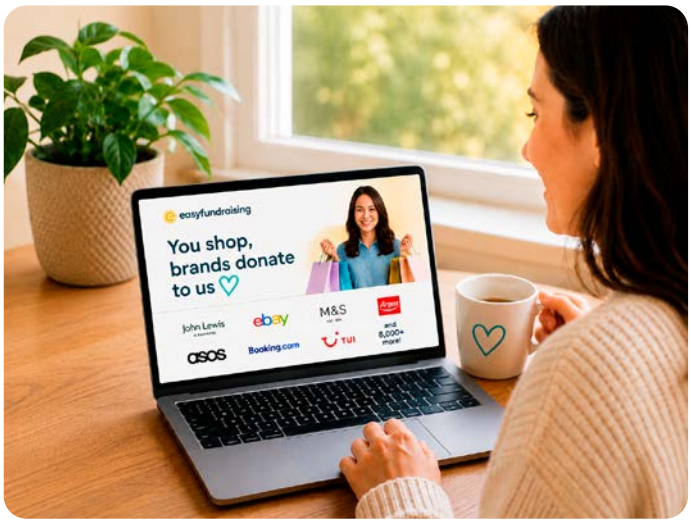
Turning unwanted items into vital funds



Members Janet and Graham Dixon from Lincolnshire have once again been busy raising funds for the Paget's Association. They sold unwanted items, many kindly donated by family, friends and neighbours, raising a fantastic £525. As a former Barclays Bank employee, Janet was also able to take advantage of the bank's generous Match Funding scheme, adding a further £525 and bringing the total raised to an amazing £1,050.

A huge thank you to Janet and Graham for their continued support and to everyone who donated items to help make this fantastic result possible.

Could you sell your unwanted items to support us?



Turn your everyday shopping into donations, at no cost to you

Did you know you can support the Paget's Association every time you shop online? Through easyfundraising, many online retailers will donate a small percentage of what you spend to us and it won't cost you a penny.

Sign up for free

Create an account at **easyfundraising.org.uk** and choose the Paget's Association as your cause.

1 Activate easyfundraising

Use the app or Donation Reminder so you don't miss a donation when you shop.

2 Shop as normal

Buy from participating retailers as usual. The retailer makes the donation, not you!

3 Give it a go

It only takes a few minutes to get started and every time you shop, the retailer supports our work. You can even keep track of how much your shopping has raised for us.

Paget's Association

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 The County Hotel, Neville Street, Newcastle upon Tyne NE1 5DF on Thursday 17 September 2026, at 10.00 am

Item 1: Welcome
Professor Stuart Ralston, Chair of the National Association for the Relief of Paget's Disease (NARPD), welcomed everyone to the Annual General Meeting.

Item 2: Minutes of the Annual General Meeting 2025
The minutes of the 2025 AGM were presented for approval.

- **Resolution:** That the minutes of the Annual General Meeting held in Bath on 25 September 2025 be approved.

Professor Ralston proposed the resolution. Following a formal vote, the resolution was carried unanimously.

Member votes	For	Against	Abstain
Present (in person or virtually)	6	0	0
Proxy (postal or electronic votes)	23	0	0

Item 3: Accounts 2025
Professor Ralston presented a summary of the Association's accounts for the year ended 31 December 2025.

- **Resolution:** That the accounts for the year ended 31 December 2025 be accepted.

Professor Ralston proposed the resolution. Following a formal vote, the resolution was carried unanimously.

Member votes	For	Against	Abstain
Present (in person or virtually)	6	0	0
Proxy (postal or electronic votes)	23	0	0

Item 4: Independent examiners
The meeting considered the reappointment of the Association's independent financial examiners.

- **Resolution:** That Menzies (formerly known as Beever and Struthers) be reappointed as the Association's independent financial examiners.

Professor Ralston proposed the resolution. Following a formal vote, the resolution was carried unanimously.

Member votes	For	Against	Abstain
Present (in person or virtually)	6	0	0
Proxy (postal or electronic votes)	23	0	0

Item 5: Review of activities in 2025 and 2026
Diana Wilkinson, Specialist Nurse and Director of Educational Resources, gave an overview of the Association's activities during 2025 and the work undertaken so far in 2026.

During 2025, the Association held its 7th annual Paget's Awareness Day on 11 January. The theme was early diagnosis of Paget's disease. Activities included a series of video interviews, a live online Q&A session with Professor Stuart Ralston and an extensive social media campaign.

Two in-person information events were held in Leicester and Bath, providing information and support for people affected by Paget's disease and their families. The Association continued to fund Paget's research and provide a range of support and information services. A review of the 2019 Clinical Guideline for the Diagnosis and Management of Paget's Disease in Adults was initiated.

The 8th annual Paget's Awareness Day took place on 11 January 2026, with a focus on pain in Paget's disease. Activities included a new video series, a live online Q&A session with Professor Ralston and a social media campaign. An in-person information event was held in Elstree, with a further event in Newcastle taking place after the AGM. The Association continued to provide its information and support services and to support Paget's research. Work on the updated clinical guideline progressed, with an advanced draft completed in September 2026.

Item 6: Forward planning
Professor Ralston provided an update on the Association's transition to a Charitable Incorporated Organisation (CIO). The Paget's Disease of Bone Association, charity number 1213575, was established as a CIO in June 2025. The transfer of NARPD's assets to the new charity was underway and was expected to be completed before the end of 2026. As part of the transition, the charity will operate under the name The Paget's Disease of Bone Association.

Plans for Paget's Awareness Day 2027 will focus on Paget's disease in people from different geographical and ethnic backgrounds. The programme will include interviews with patients and clinicians, with contributions from the UK, India and Italy.

Looking further ahead, Professor Ralston explained that the Association would continue supporting people affected by Paget's disease, redouble efforts to increase fundraising and reduce costs wherever possible. A planning workshop could also be established to consider the charity's future financial health and sustainability.

Attendees were invited to ask questions or make comments. None were raised. The meeting closed at 10.15 am.

Paget's Disease of Bone Association

Reg. charity no. 1213575

Minutes of the Annual General Meeting (AGM)

of the Paget's Disease of Bone Association held at The County Hotel, Neville Street, Newcastle upon Tyne NE1 5DF on Friday 18 September 2026, at 10.30 am

Item 1: Welcome
Professor Stuart Ralston, Chair, welcomed everyone to the Annual General Meeting (AGM) of the Paget's Disease of Bone Association (PDBA).

Item 2: Accounts 2025
The accounts of the Paget's Disease of Bone Association for the year ended 31 December 2025 were presented for approval. The PDBA had no financial assets in terms of income or expenditure for the financial year ending 31 December 2025.

- **Resolution:** That the accounts for the year ended 31 December 2025 be accepted.

Following a formal vote, the resolution was carried unanimously. All votes cast were in favour.

Member votes	For	Against	Abstain
Present (in person or virtually)	9	0	0
Proxy (postal or electronic votes)	2	0	0

Item 3: Independent financial examiners
The meeting considered the appointment of Menzies as the Association's external financial examiners.

- **Resolution:** That Menzies be appointed as the external financial examiners of the PDBA.

Following a formal vote, the resolution was carried unanimously. All votes cast were in favour.

Member votes	For	Against	Abstain
Present (in person or virtually)	9	0	0
Proxy (postal or electronic votes)	2	0	0

Item 4: Trustee appointment
The meeting considered the appointment of Dr Stephen Tuck as a Trustee of the PDBA for a three-year term.

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

Following a formal vote, the resolution was carried unanimously. All votes cast were in favour.

Member votes	For	Against	Abstain
Present (in person or virtually)	9	0	0
Proxy (postal or electronic votes)	2	0	0

Item 5: Forward planning
An update was provided on the next stages of the transition from the National Association for the Relief of Paget's Disease (NARPD) to the Paget's Disease of Bone Association (PDBA). The transfer of NARPD's assets to PDBA is intended to be completed by the end of 2026. It is also planned for staff payroll to transfer to PDBA before the end of the year. The NARPD will continue to operate during the transition before being wound down. Trustees were asked to consider how legacies left to the NARPD might be transferred to the PDBA.

Attendees were invited to ask questions or offer comments. It was suggested that the minimum number be 6 rather than 10. This would be looked into.

The meeting closed at 10.40 am.



Meet the team

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.



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.



Mr Mohamed El Erian
A solicitor at Jones Day, London, Mohamed brings his legal expertise to the Board of Trustees.



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 Sheelagh Farrow
Sheelagh lives in Surrey and, prior to retirement, was Managing Director of International Medical Press, a provider of independent medical education.



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.



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.



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.

Information • Support • Guidance

Friendly support groups



Our friendly online support groups are open to anyone affected by Paget's disease. They offer a chance to meet others who understand, share experiences and receive reliable information in a small, welcoming group.

Meetings are held online using Zoom every two months and are facilitated by our Specialist Nurse, Diana Wilkinson. If you are unsure about using Zoom, Diana will be happy to help.

What people say

"Thanks so much for your work with the group. It truly has made a difference to my experience with Paget's"

"Thanks to you and the Association, I feel more able to cope with this condition"

How to join

To join a group, email **helpline@paget.org.uk** or register through our website. We will send you a Zoom link a few days before the meeting. If you do not receive it, please check your spam folder or get in touch with us.

Paget's Nurse Helpline

Our Nurse Helpline provides confidential support and reliable information for anyone affected by Paget's disease. We are very grateful to everyone who has shared feedback about the service. People tell us how reassuring it is to have someone who understands Paget's disease, listens to their concerns and responds to their questions.

Contact the Helpline

You can contact the Helpline in any of the following ways:

- **Email:** helpline@paget.org.uk
- **Telephone:** 0161 7994646
- **Mobile:** 07713568197
- **Web form:** Complete the form on our website

https://paget.org.uk/find-support/pagets-nurse-helpline/

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