Paget's Association

news

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

Pedalling for Paget's

Professor Stuart Ralston completes 85-mile challenge

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Dear members 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.

Our cover feature concerns my successful attempt at the 85 mile Caledonian Etape cycle run in May of this year. Thanks to my many supporters, I managed to raise £1695. Although it was hard going, especially on the hill up to Schiehallion, the weather was beautiful, the views stunning and I think it's fair to say that all the cyclists who competed on that day had a fantastic time. When you add my £1695 to the magnificent fundraising from those featured in the summer magazine, Kely Burnham, Belinda Ratnayake and Janet and Graham Dixon, along with our runners in the London Marathon and Prof Terry O'Neill, who completed the Manchester Half-Marathon, the total has grown well. With many kind donations, including heartfelt donations in memory of loved ones, and Gift Aid, we have now raised £27,328 against our target of £75,000 for the ***PagetAlert*** Campaign. That means we are just over a third of the way to our goal! So, please keep your incredible fundraising efforts going and keep those generous donations coming in!

An important mission of the Association is to support research into Paget's disease and Prof Rob Layfield has authored a very interesting article on pages 6 to 8

> **"The Association is campaigning to promote the availability of genetic testing for *SQSTM1* within the NHS"**

which highlights some of the research that the Association has supported into the role of genetic and environmental factors in the disease and a project which has just been completed looking at a disease model to better understand the causes of pain in Paget's disease. I was also pleased that Rob highlighted the outcome of the Zoledronate in the Prevention of Paget's Disease study (ZiPP) which showed that genetic testing for SQTM1 variants coupled with treatment with the bisphosphonate zoledronic acid could reverse early changes of Paget's disease on bone scan, which were found in about 9% of people, and prevent the disease developing. This offers hope to people who have a family history of the disease and the Association is campaigning to promote the availability of genetic testing for *SQSTM1* within the NHS.

Diana Wilkinson has a very interesting feature about tinnitus on page 6. This can rarely affect people with Paget's disease if the skull is affected but I was interested to talk to a lady at one of our information days in Leicester who suffered from musical tinnitus, most probably as a result of the disease. Various treatments are available, depending on the underlying cause. It's a condition that Diana has experienced personally and it was reassuring to see that hearing aids had helped her manage the condition.

The 150th Anniversary of Paget's original description of the disease occurs in 2026. Paget described the disease in a presentation to the Royal Medico-Chirurgical Society of London in 1876 and his paper was published in 1877. There is a wonderful account of the life and times of Sir James Paget on pages 20-22. On a related note, I was very pleased to be one of the speakers at the 150th Anniversary Celebration of Sir James Paget which was held at the Royal Society of Medicine (RSM) on 5 November. The symposium was entitled "Sir James Paget and His Eponymous Diseases". In addition to Paget's Disease of Bone, which is arguably his most important contribution to medicine, the symposium covered Paget's disease of the breast, extra-mammary Paget's disease, and hearing loss in Paget's disease. Hugh Sturzaker, Retired Consultant Surgeon, at the James Paget University Hospital, in Great Yarmouth, gave an account of Sir James Paget's life and Jonnie Dingwall, son-in-law of one of our Patrons, Sir Henry Paget, talked about the wider Paget family.

Most people with Paget's disease will be familiar with getting their blood checked for alkaline phosphatase (ALP). Diana Wilkinson gives a very useful guide about what ALP values mean, what they can tell us about activity of the disease and what the limitations of the test are. The summary on page 17 is spot on as it emphasises that ALP is not the be-all and end-all but part of a jigsaw which helps doctors understand the condition, monitor how well treatment is working and plan the next steps for patient care.

continued overleaf

In closing, I want to thank Dr Sarah Harcastle from the Royal United Hospitals, Bath, who hosted a highly informative information day on Paget's at Bailbrook House on the outskirts of Bath. It was very well attended with a range of interesting talks on various aspects of Paget's disease including a very informative presentation on orthopaedic surgery and Paget's disease by Mr Nav Makaram from the orthopaedic service in Edinburgh.

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 forthcoming information events which are planned for June and September 2026. Watch this space!

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

Key dates and events

8 January 2026
Virtual question and answer event with Professor Ralston

11 January 2026
International Paget's Awareness Day

19 April 2026
Adidas Manchester Marathon

26 April 2026
TCS London Marathon

16 May 2026
Big Spring Coffee Morning for Paget's

June / September 2026
Paget's information events – dates and venues to be confirmed

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 for all enquiries:
membership@paget.org.uk

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

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

Postal address
Write to us at The Paget's Association,

Jactin House, 24 Hood Street,
Ancoats, Manchester, M4 6WX

Live online – Professor Ralston answers your questions

Thursday 8 January 2026
5.00 pm – 6.00 pm (GMT, via Zoom)

Join us online at 5.00 pm (GMT) on Thursday 8 January 2026, for an informative and interactive hour dedicated to Paget's disease. We are delighted to invite you to this virtual question and answer event hosted by our Chair Professor Stuart Ralston. Stuart, a renowned rheumatologist and researcher at the Paget's Association's Centre of Excellence in Edinburgh, is happy to answer any Paget's-related questions. Join us from anywhere in the world. Everyone is welcome to participate, whether you have specific queries or you would simply like to listen in and learn more.

How to take part

To register and receive the Zoom link, please email **membership@paget.org.uk**

If you're new to Zoom and would like some guidance, we're happy to help you get set up but please contact us before the day of the event, as we won't be able to provide technical assistance during the session.

International Paget's Awareness Day: 11 January 2026

The 2026 Paget's Awareness Day will focus on three important areas: Pain, Research and Lived Experience. We will be sharing a new series of videos featuring expert insights and real stories from those affected by Paget's disease. These will be available on our website and YouTube channel, so look out for them in the new year.

Help raise awareness

If you are affected by Paget's disease, your voice can make a real difference. By talking about your experiences with family and friends, sharing your story on social media or even contributing to this magazine, you can help others better understand the impact of the condition. Together, we can bring greater attention and care to Paget's disease, and support everyone living with its challenges.

The impact of research supported by the Paget's Association

Professor Rob Layfield summarises how wide-ranging and impactful some of the research funded by the Paget's Association has been in recent years. This article is based on his presentation delivered at our information event in Leicester in May.

Empowering patients and doctors

For decades, people living with Paget's disease often left their GPs or clinic with outdated advice. Some were told to expect inevitable deterioration. Others were prescribed treatments that didn't address their main symptoms. Sometimes doctors weren't always confident in how to manage the condition and patients struggled to find reliable information.

Hopefully, that's now changing, thanks in part to the first comprehensive clinical Guideline for Paget's Disease in Adults, published in 2019. The Guideline, shaped by scientific evidence and patient feedback, lays out clear recommendations for diagnosis and management. It was developed with support from the Paget's Association, alongside international partners. The result? Doctors now have an authoritative reference that helps them decide when to investigate further, when to prescribe medication and when to reassure.

Patients, meanwhile, gain access to resources that strip away the myths and empower them to have more confident conversations in the consulting room. If patients and doctors are both equipped with the right information, decisions become better and outcomes improve. This links to our current ***PagetAlert*** campaign which includes the ambition to reduce the time taken to obtain a diagnosis. Plans to update the Guideline, in particular in light of outcomes of clinical trials that considered the importance of genetic testing (see next page), will hopefully continue this positive change.

> ***"Unlocking the environmental and social factors at play could be the key to prevention in future generations"***

Listening to patients: pain in Paget's

One of the most striking insights from recent research is that pain in Paget's disease isn't always caused by Paget's itself. In a large study of people living with the condition, led by the University of Edinburgh and supported in part by the Paget's Association, nearly three-quarters of participants reported persistent pain. But when researchers looked more closely, they found that much of the pain came not from overactive Paget's bone lesions but from other causes, particularly osteoarthritis.

This matters enormously. For years, the assumption was that controlling Paget's disease activity with drugs like bisphosphonates would also relieve pain. For many, however, that approach failed, supporting the notion that patients need holistic care, not just bone scans and drugs, but proper pain assessment and support for related conditions.

By highlighting this issue, the research has shifted the focus of treatment. Doctors are increasingly alert to investigating other causes of discomfort, ensuring patients don't slip through the cracks. For some of those living with daily pain, that shift can hopefully mean the difference between years of frustration and finally getting relief.

Again, central to our current ***PagetAlert*** campaign is the goal of ensuring pain is properly managed.

Searching for causes

Despite its long history, Paget's disease was first described by Sir James Paget in 1877 (see page 20 for more details) but the exact causes remain a puzzle. Why do some people develop it and not others? Why are cases more common in some parts of the UK than others and why has its incidence fallen so dramatically over the past two to three decades?

Large-scale epidemiological studies are helping to piece together the answers. Work in Salford and Manchester, supported by the Paget's Association, found that the number of new diagnoses has plummeted, from around 0.75 per 10,000 people in 1999 to just 0.20 per 10,000 in 2015. The sharp decline hints that environmental factors, perhaps something in the diet, exposure to infection or some other environmental toxins may play a role.

Other work shows intriguing geographic patterns. The North-West of England has consistently recorded higher rates of Paget's than other regions. Within Greater Manchester, the researchers also found that prevalence was higher among people living in more deprived areas and that diagnosis varied by ethnicity. They found it was more common in Black or Black British populations and less common in Asian or Asian British groups. The reasons for these variations are still unclear, but the findings underscore a vital point: diagnosis is uneven. Some communities may be underdiagnosed, while others face higher risks without knowing why.

Unlocking the environmental and social factors at play could be the key to prevention in future generations. This ties in with research funded by the Paget's Association into ancient Paget's disease at Liverpool John Moores University, building on previous work from Nottingham, which aims to identify potential environmental triggers for an unusual form of medieval Paget's disease discovered at Norton Priory in Runcorn.

> ***"While environment matters, there's also a clear genetic dimension to Paget's disease"***

Families and genes

While environment matters, there's also a clear genetic dimension to Paget's disease. Around one in five patients has a family history of the condition and variants in a gene called *Sequestosome-1* are strongly linked to its development. Recent clinical trials led by The University of Edinburgh (in which former Trustee of the Paget's Association Professor Bill Fraser, Diana Wilkinson from the Association, and member Keith Charnock served on the trial steering committee) have shown how this knowledge can translate into practical benefits. Relatives of Paget's patients who carried *Sequestosome-1* variants were offered genetic testing. Those who tested positive were then given early monitoring and some received preventative treatment with zoledronic acid. The results were encouraging – genetic testing combined with proactive treatment reduced the chances of Paget's developing or progressing. For families, this approach offers reassurance and a sense of control. Instead of waiting for symptoms to strike, they can take steps in advance.

This finding is a real milestone, showing it's not just about treating the disease once it appears, but rather giving families peace of mind and potentially stopping Paget's before it causes damage. A priority of the Association is to encourage debate and new research to evaluate potential genetic testing, to identify those at most risk.

Building better models

For researchers trying to study Paget's disease in the lab, there has always been a frustrating problem: you can't easily replicate it in simple cell culture models, as bone cells are so highly specialised. Without accurate models, testing new treatments or probing the underlying biology has been slow and uncertain. That may now be changing. With support from the Paget's Association, now picked up by the Medical Research Council, researchers at the University of Oxford are developing fully human 3D bone models. These lab-grown structures mimic the complexity of real bone tissue, providing a controlled environment where Paget's mechanisms can be observed and potential drugs trialled.

This is like moving from a sketch to a working model, a system that behaves much more like human bone. It opens the door to experiments we simply couldn't do before. Over time, these models could accelerate the development of targeted therapies, replacing 'trial-and-error' with precise, personalised treatment.

continued overleaf

Why it matters

All this research, from guidelines and genetics to pain management and bone models, has one common thread: it starts with patients. The Paget's Association has made sure its priorities reflect the voices of those living with the condition. Surveys of members helped shape the research agenda. Patient representatives sit alongside scientists on trial committees.

Also, the findings are shared, not just in scientific journals but directly with the community, through our website and this magazine.

That patient-centred approach is paying off. For those diagnosed today, the landscape looks very different from just a decade ago. There's clearer advice, greater awareness of pain management, new insights into risk factors, and real hope that families might one day avoid the disease altogether. Still, challenges remain. Many cases are missed, especially in underserved groups. The environmental triggers remain elusive and while treatments can control the disease, there's no cure. That's why continuing investment in research is vital.

What we've learned from research supported by the Paget's Association

Diagnosis

Clearer guidelines mean doctors and patients can finally speak the same language about Paget's.

Causes

Paget's is declining rapidly, hinting at environmental triggers we don't yet understand.

Models

Lab-grown 3D bone opens the door to studying Paget's in ways we never could before.

Pain

Pain isn't always caused by Paget's itself – osteoarthritis and other conditions are often to blame.

Families

Genetic testing offers the potential for peace of mind for families and the chance to stop Paget's before it starts.

Patients first

When patients' voices guide research, the results change real lives.

We welcome Dr Stephen Tuck to the Board of Trustees

Following successful election at the Annual General Meeting (AGM), Dr Stephen Tuck has joined the Paget's Association's Board of Trustees. Consultant Rheumatologist Dr Tuck is Director of the Centre of Excellence at the Metabolic Bone Unit at the James Cook University Hospital, Middlesbrough. His involvement with the Paget's Association began in 2011 as a Trustee. He later became Vice-Chair until he retired from the Board in 2021, having completed a decade with the charity, the maximum continuous period allowed under the constitution. Returning to the Board, Dr Tuck said, "I am actively involved in research into Paget's, including the national 'Pain in Paget's Study', my work on patterns of referral of Paget's patients and also the effects of Paget's disease on the immune system. The latter is providing some useful and unexpected findings, which may provide insights into why Paget's is becoming less common. I always enjoy working with the Paget's Association and believe passionately in its importance in supporting patients, raising awareness of the condition and research".

Minutes of the AGM

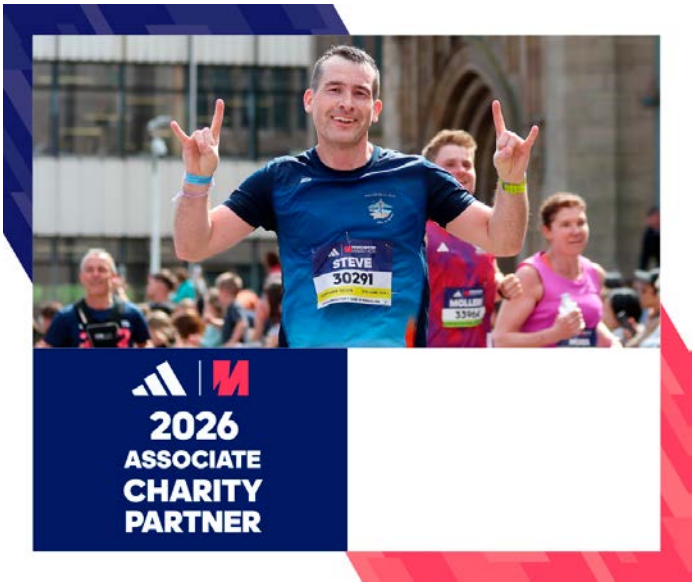
The minutes from the AGM will be published in the next issue of Paget's News. Members can also request a copy from the Association's office.

Manchester Marathon places!

Do you know someone ready for the challenge or are you a runner yourself? The Paget's Association has places available in the Adidas Manchester Marathon. Whether you're an experienced runner or tackling your very first marathon, this is a fantastic opportunity. By joining Team Paget's, you'll be helping to raise awareness as well as vital funds. To find out more or apply for a place, visit **www.paget.org.uk** or if you would prefer to speak to someone, call our office on 0161 766 4646.

London Marathon 2026 update

We're delighted to share that all our charity places for the 2026 TCS London Marathon have now been allocated. A huge thank you to everyone who applied and the very best of luck to our amazing runners as they train for this iconic event. If you would like to run on our behalf in the future, applications for our 2027 charity places will be available through our website.



Living with tinnitus

As some of you will know, when Paget's disease affects the skull, it can sometimes cause tinnitus. In the general population, tinnitus is a common condition. According to Tinnitus UK, a charity that supports people with the condition, around one in three people experience tinnitus at some point in their lives, and about one in seven live with it regularly or all the time. Although it is often linked with older adults, tinnitus can affect people of any age.

What is tinnitus?

Tinnitus is the perception of sound without an external source, so it cannot be heard by others. The sound may be constant or occasional, loud or quiet, and can be heard in one ear, both ears or in the middle of the head. Some people look for what's making the sound before realising it comes from within. Each person's experience is different. For some, tinnitus can significantly affect quality of life.

Types of tinnitus

Non-pulsatile tinnitus

Non-pulsatile tinnitus is the most common form of tinnitus. It's the perception of noises, such as ringing, buzzing, hissing, whistling or other noises. The sensation can present all the time or come and go. The volume of the noises heard can vary from one episode to the next.

Pulsatile tinnitus

In contrast, pulsatile tinnitus is a rhythmical noise that usually has the same beat as the heart. It can be identified by feeling the pulse at the same time as listening to the tinnitus. When doctors investigate cases of tinnitus, it is rare for them to find a single identifiable cause for the problem. However, with pulsatile tinnitus, the chances of finding a specific cause are more likely but still difficult. Pulsatile tinnitus is caused by a change in blood flow in the vessels near the ear or to a change in awareness of that blood flow. These vessels are located in the large arteries and veins in the neck and base of the skull, or the smaller ones in the ear itself. The change in blood flow can be caused by a variety of factors.

Musical tinnitus

Musical tinnitus, also known as musical hallucination, is the experience of hearing music when none is being played, but it tends to be longer lasting and doesn't mirror any external music you may have heard recently. In most people with musical hallucination, there is no underlying cause. There is not thought to be a connection to mental health conditions.

Although anyone can experience musical hallucination, there are some groups of people where it is more common. This includes people who live alone and people with hearing loss. It is also more common in women than men and in people over 60 years of age. In most people, there is no underlying cause found. Very rarely, it can be caused by serious conditions, for example by problems with the blood vessels in the brain or by brain tumours. In these conditions, there are likely to be other symptoms, but your doctor might choose to perform some investigations to rule them out. Musical hallucination is also more common in individuals who have epilepsy or Alzheimer's disease.

Is musical hallucination a psychiatric problem?

The majority of individuals with musical hallucination do not have any psychiatric problems. Musical hallucination is quite common in people who have obsessive compulsive disorder (OCD), in which they experience repetitive, intrusive and distressing thoughts and feel strong urges to repeatedly perform actions. It is estimated

that around four in ten individuals with OCD will experience musical hallucination at some time. The majority of individuals with musical hallucination do not have OCD.

Can musical hallucination be treated?

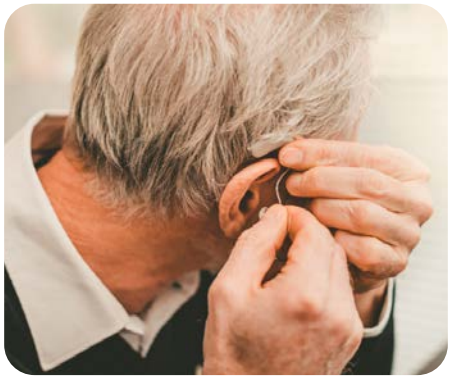
If musical hallucination has an underlying cause, addressing the cause will often relieve the hallucination. The most common cause is hearing loss. Many people find that musical hallucination becomes less intrusive once the condition has been explained and they are reassured that there is no serious underlying cause. If it continues to be troublesome despite this, it can be managed with the techniques used to treat other forms of tinnitus.

Causes of tinnitus

The causes of tinnitus are varied. A change in the ear, such as an ear infection, a cold or wax blocking the ear, might start tinnitus. Loud noise over a long time, such as power tools, live music concerts, or noisy machinery, can cause it. It can also be started by a stressful life event. When the event is over, the tinnitus may stop.

Otosclerosis is another cause and happens when a tiny bone inside your ear, called the stapes, fuses with other parts of the ear and stops you being able to hear properly. It's not known why otosclerosis happens, but you are more likely to get otosclerosis if a close relative has it.

Sometimes, but uncommonly, tinnitus can be linked to other medical conditions: head or neck injuries, cardiovascular disorders, such as high blood pressure, underactive thyroid (hypothyroidism) and diabetes. Some of you will be aware from experience that having Paget's disease in the skull can also cause tinnitus.



What can be done?

Managing tinnitus can be easier if help is given early. You can have an audiological assessment. Speak with your GP, who may refer you to see an Ear, Nose and Throat (ENT) specialist or a special tinnitus clinic. You may be offered an MRI scan. Doctors will help you understand and manage your tinnitus, but they will not usually be able to stop persistent tinnitus from happening.

The most important thing is to keep doing the things you enjoy. You may do things differently, such as having background music on when you are reading. When it first starts, tinnitus can be frightening but with time, you usually notice it less.

Information and resources are available, such as the Tinnitus UK Helpline (call 0800 018 0527 or chat online) and their website has tools for self-management. Visit **www.tinnitus.org.uk**

The National Institute for Health and Care Excellence (NICE) recommends offering hearing aids to those with tinnitus who also have some hearing loss. Hearing aids work by making the sounds around you louder. They can help you hear more easily, but they will not stop your hearing from getting worse. NICE also recommend psychological intervention such as Cognitive Behavioural Therapy (CBT) which is a type of counselling therapy to help you change how you think and act. It can change your relationship with tinnitus.

Self-help to manage tinnitus

Sound therapy

Playing background music or sounds such as gentle waves or rainfall can help.

Tinnitus apps

There are tinnitus apps that you can place on your phone. Some apps offer a variety of white noise and nature sounds, some enable you to personalise the sounds and some include relaxation and mindfulness tools.

Reduce stress

A regular relaxation routine can help to reduce stress levels. As you become more relaxed, you may find it easier to manage your tinnitus and not notice it as much.

Protect your ears

Avoid exposure to loud noise which can worsen tinnitus. Wear ear protectors in noisy places.

Sleep well

Tinnitus can cause difficulty sleeping. It can help to keep a regular sleep routine, avoid caffeine and excess alcohol, wind down before bed and use relaxation or gentle music to help. Using an app at night for soothing sounds, such as nature or rainfall, helps some people. You can even get sound pillows so that the sound is directed closer to your ear.

continued overleaf

Personal experience of tinnitus

I'm Diana, the nurse for the Paget's Association. I speak with many people whose Paget's disease in the skull has led to tinnitus. I also know several people without Paget's who live with tinnitus every day. I've seen firsthand the profound effect it can have, sometimes triggering panic attacks, especially at night.

I've lived with tinnitus myself for a number of years. Alongside it, what began as mild hearing loss has gradually worsened, particularly in one ear, where my tinnitus is also more severe. The sounds I hear vary but most often it's a whistling tone that can shift dramatically in pitch.

When my tinnitus first developed, I visited my GP and was referred to an ENT consultant. An MRI was carried out, which thankfully showed nothing abnormal. The consultant

suggested hearing aids, and I decided to give them a try. At the clinic, the staff were very supportive and set them up to connect via Bluetooth to an app on my phone. This allows me to control the volume and let other sounds from my phone come through the hearing aids.

I remember putting my hearing aids in for the first time - my immediate thought was how noisy my hair was! They do take some adjusting to and you have to get past any worries about how they look. Fortunately, it didn't take me long to adapt. I have good and bad days with tinnitus but the hearing aids have certainly helped. I find that amplifying external sounds makes the internal noise easier to ignore. Of course, they've improved my hearing as well, although I still struggle sometimes. Both hearing loss and tinnitus can be exhausting and, at times, embarrassing. There are only so many times you can apologise for asking someone to repeat themselves.

One of my worst experiences with tinnitus happened about 12 months ago. I went to a concert with several artists, and it was great until the final act which was extremely loud. We left early, but my ears were ringing loudly afterwards, as happens for many people after a loud concert. Unfortunately, after this had subsided, it left me with a new strange sound layered over my usual tinnitus, which lasted for around six months. Thankfully, it eventually went but it was a frightening reminder of my consultant's advice, *"Look after your hearing – stay away from loud noises!"*

Research

Research continues to explore treatments and understand the mechanisms behind tinnitus. In a recent study by Fouad et al. (2025), they looked at treating tinnitus associated with otosclerosis with a bisphosphonate. They considered non-pulsatile tinnitus, which usually has no structural cause, and pulsatile tinnitus, which is more likely to have an identifiable cause. They treated individuals with the bisphosphonate risedronate, which is an oral treatment often used for Paget's disease. They demonstrated significant improvement in those treated with the bisphosphonate compared to the control group.

Ref

Fouad, A., Mandour, M., Tomoum, M.O. et al. Effectiveness of bisphosphonate for alleviating tinnitus associated with otosclerosis: a prospective case–control study. *European Archives of Oto-Rhino-Laryngology;* 282, 647–658 (2025). Visit **https://doi.org/10.1007/s00405-024-08935-z**

Support

Tinnitus UK

https://tinnitus.org.uk/

Royal National Institute for the Deaf (RNID)

https://rnid.org.uk/information-and-support/tinnitus/tinnitus-causes/

Paget's Nurse Helpline

helpline@paget.org.uk

Support

Here are just some of the ways the Paget's Association can support you. New ideas are always welcome – just get in touch!

Worldwide virtual groups

We invite anyone affected by Paget's disease, including partners and family, to join us online at one of the Association's Virtual Paget's Support Groups. Each is a small, friendly group that meets online (using Zoom) every two months. Those taking part can speak with others affected by Paget's disease, receive information regarding different aspects of the condition and make new friends. Our Specialist Nurse, Diana Wilkinson, facilitates the groups. There is no obligation to join every meeting and if you require assistance to use Zoom, we will do our best to support you – just let us know in advance.

How it works

To take part, please email **helpline@paget.org.uk** to tell us which group suits you best.

Alternatively, you can register on our website.

A link to join via Zoom, will be sent to you by email a few days before your chosen meeting. **Should you not receive it, please check your spam email folder** or email **helpline@paget.org.uk**

Meeting dates are posted on our website as soon as they become available. If you have any questions, please don't hesitate to get in touch.

Meetings of the Virtual Paget's Support Groups

GROUP 1
Monday
15:00 hrs (GMT)
Please see our website for details of the next meeting

GROUP 2
Tuesday
09:00 hrs (GMT)
Please see our website for details of the next meeting

GROUP 3
Wednesday
18:00 hrs (GMT)
Please see our website for details of the next meeting

Facebook Support Group

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

Paget's Nurse Helpline

✔ Information ✔ Support ✔ Guidance

Thank you to everyone who has shared feedback regarding our Nurse Helpline. We are delighted to hear how much the service is valued, with users telling us they feel reassured knowing their concerns are listened to and their questions answered quickly.

Contact the Helpline

- Email: **helpline@paget.org.uk**
- Main number: **0161 799 4646** • Mobile: **07713568197**
- Complete the form on our website

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

Professor Ralston pedals for Paget's

£1,695 raised!

A heartfelt thank you to everyone who rallied behind our Chair Professor Stuart Ralston as he once again conquered the gruelling 85-mile course of the Etape Caledonia cycle event.

The picturesque town of Pitlochry, nestled in the heart of Scotland, served as both the starting point and the triumphant finish line.

The challenge was formidable from the start; Professor Ralston and his fellow cyclists braved a bitter May morning, shivering before they even set off.

Riders faced relentless hills, a sharp downhill hairpin bend, and a fast, twisting descent at Trinafour.

The course passed the stunning shores of Loch Rannoch and Loch Tummel (above), offering moments of spectacular beauty amid the gruelling effort.

One of the greatest challenges was the demanding climb up Mount Schiehallion (1,083m), a mountain of both natural majesty and scientific history. Chosen in the 18th century by Astronomer Royal Neville Maskelyne for the first measurement of the Earth's mass, Mt Schiehallion, known as the "fairy hill of the Caledonians" and nicknamed the "Matterhorn of Perthshire", is famous for its iconic silhouette.

Professor Ralston's determination paid off, not only in crossing the finish line on this formidable course but also in raising vital funds to support people affected by Paget's disease. His incredible effort brought in an amazing £1,695. Thank you to everyone who donated, cheered, and supported him on this remarkable journey.

You can still show your support and appreciation for Professor Ralston's incredible effort by donating through our website to thank him for going the extra mile!

What does my blood test mean?

Sometimes callers to our Paget's Nurse Helpline ask about the blood test most commonly used to diagnose and monitor Paget's disease: the alkaline phosphatase (ALP) test. In this article, our Specialist Nurse, Diana Wilkinson, explains what it is and addresses some of the most frequently asked questions.

Understanding Alkaline Phosphatase (ALP)

Alkaline Phosphatase (ALP) is an enzyme found throughout the body. It is mostly made in the liver and bones but it is also found in the kidneys, intestines and placenta. A blood test can measure ALP levels and abnormal results may suggest an underlying health issue. ALP is usually measured as part of a wider set of blood tests, such as liver function tests (LFTs) or a bone profile blood test. Not all changes in ALP are a cause for concern. Levels can naturally be higher, such as during pregnancy or while children's bones are developing.

Doctors may request an ALP test if someone shows signs of a liver or bone problem, or simply as part of routine blood tests. Elevated ALP levels can indicate potential problems which may require further investigation. For people with Paget's disease, ALP is the most commonly used blood test to help with diagnosis and monitoring.

Why can ALP reference ranges vary?

Every blood test result is reported with a reference range, which shows what is considered typical. The usual adult reference range for ALP is around 30 to 130 IU/L. However, this can vary slightly because different laboratories may use different methods to measure ALP. Although there has been work across the UK to make blood test reporting more consistent, small differences between laboratories are still possible.

> ***"Not everyone with active Paget's disease will show raised ALP levels"***

Misdiagnosis

Timely diagnosis of Paget's disease matters. Many people who contact our Helpline have been told they have a liver problem and advised to stop drinking alcohol, when in fact they have Paget's disease. This happens because blood tests show a raised ALP level, which can indicate a problem with the liver. If ALP is high but other tests are normal, and the person has bone pain or deformity, it may point to Paget's rather than liver disease.

Can ALP levels be normal despite active Paget's disease?

Yes. Not everyone with active Paget's disease will show raised ALP levels. Sometimes, ALP results fall within the normal range because of natural variation in enzyme levels. For example, if someone usually has very low ALP, a result that looks normal on paper may actually be higher than is typical for them.

People who are later diagnosed with Paget's disease often notice, when looking back at earlier tests, that their ALP was gradually rising but still recorded as being within the reference range. In other cases, results may appear normal if the area of bone affected by Paget's disease is relatively small and does not cause a large enough change in ALP to be detected. A normal result may, of course, mean that Paget's disease is not active at the time of the blood test.

Monitoring following treatment

The primary treatments for Paget's disease come from a group of drugs known as bisphosphonates. Monitoring ALP levels post-treatment serves as a gauge for treatment efficacy. A decrease in ALP can indicate reduced activity of Paget's disease, suggesting a positive response to therapy.

Does symptom improvement always correlate with ALP reduction?

When given for Paget's disease, bisphosphonates generally reduce the ALP. For many people, a fall in ALP following bisphosphonate treatment is accompanied by an improvement in symptoms such as pain. This is not always the case, however, because sometimes pain is related to the consequences of Paget's disease rather than the condition itself, e.g. osteoarthritis in an adjacent joint. It is therefore best to prevent or minimise these consequences through early intervention, helping to reduce pain and maintain quality of life. This highlights the importance of early diagnosis and treatment.

Summary

An ALP result within the normal range does not always rule out Paget's disease and a result outside the reference range does not always mean Paget's disease is active. ALP is not a specific test for Paget's disease. Instead, it provides one piece of the overall picture. Doctors interpret ALP alongside your symptoms, medical history, other blood tests and imaging such as x-rays and a nuclear bone scan. Taken together, these results help doctors understand the condition, monitor how well treatment is working and plan the next steps for your care.

Help ensure we are here for others

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 the Paget's Association and want to help ensure we are here for others in the future, leaving a gift in your will is a wonderful way to say thank you.

The Association does not receive any government funding and as a charity, we know we make a difference but we can only do so with the continued support of the public. Large or small, every gift helps.

> ***"One in five charity supporters over 40 have already decided to leave a charitable gift in their will"***

Join our monthly raffle!

Our raffle is limited to just 200 tickets and by inviting your friends, family and colleagues to take part, you'll not only help raise vital funds for the Paget's Association but will also spread much-needed awareness of Paget's disease.

Each ticket costs £5 per month and, if you like, you can buy two tickets to increase your chance of winning. The draw takes place every month with two cash prizes:

£100 first prize
£50 second prize

Plus, in **June** and **December**, the prize amounts are doubled!

Every ticket purchased supports the Paget's Association. Anyone aged 18 or over can join in and you do not need to be a member of the Association to take part.

To join and secure your chance to win, please email your request to **membership@paget.org.uk**

Winners

Anyone over 18 can take part

JUNE 2025

Double prize draw!
1st Prize £200 / Ticket no. 90
Eileen Wallace, Cheshire

2nd Prize £100 / Ticket no. 115
Iris Scriven, Newark

JULY 2025

1st Prize £100 / Ticket no. 22
Terence Holder, Leicester

2nd Prize £50 / Ticket no. 120
Ian Davis, West Sussex

AUGUST 2025

1st Prize £100 / Ticket no. 62
Ingrid Pryor, Cambridge

2nd Prize £50 / Ticket no. 172
Peter Bardsley Birmingham

SEPTEMBER 2025

1st Prize £100 / Ticket no. 26
Marie Turner, York

2nd Prize £50 / Ticket no. 22
Terence Holder, Leicester

OCTOBER 2025

1st Prize £100 / Ticket no. 99
J Moatt, Pothcawl

2nd Prize £50 / Ticket no. 55
Marilyn Milne, Essex

Looking for a thoughtful gift with real impact?

NEW

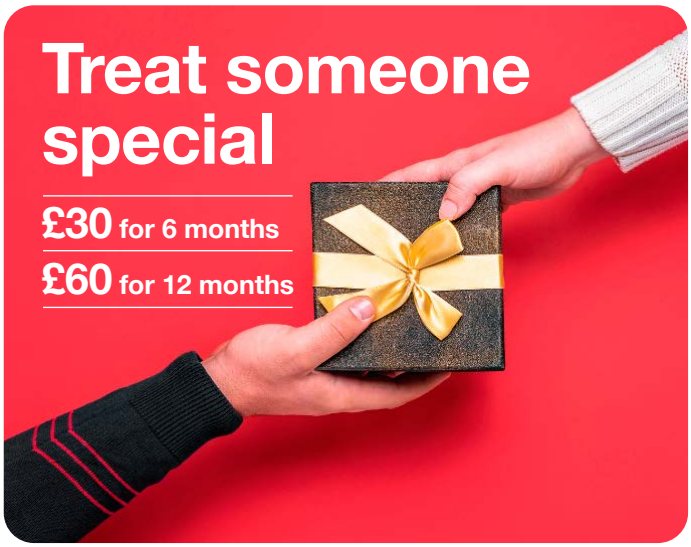
If you're looking for gift ideas for loved ones, why not give them the chance to win up to £200, while supporting a vital cause?

By gifting 6 or 12 months' entry into the Paget's Association's Raffle, you're not only giving your family or friends a monthly opportunity to win, you're also contributing directly to helping those affected by Paget's disease.

With a maximum of only 200 members, the odds of winning are genuinely in their favour.

You'll receive a personalised gift certificate to present to your friend or family member, the perfect feel-good gift for birthdays, Christmas or just because.

To find out more, visit **www.paget.org.uk/raffle-gift**
Alternatively, call us on 0161 799 4646.




Paget's Association

Gift CERTIFICATE

12 MONTHS RAFFLE ENTRY

This certificate entitles its recipient to twelve months' entry into the Paget's Association monthly raffle, with the chance to win up to £200 in cash prizes!

Each month, two lucky winners are drawn:
- 1st Prize - £100
- 2nd Prize - £50

With double prizes in June and December of £200 and £100

TICKET TICKET

Gifted to: Matthew Jones
From: Katie Smith
Valid from: 11th November 2025
Raffle ticket number: 112

The Paget's Association Raffle is limited to just 200 members, giving you excellent odds of winning. Every entry helps support the Paget's Association's vital work in raising awareness and supporting those affected by Paget's Disease of Bone.

Your gift includes:
- One raffle entry into 12 consecutive monthly draws
- The chance to win generous cash prizes
- The satisfaction of supporting a meaningful cause

All proceeds, after prize money, go directly towards our charitable work.
Winners will be notified by email.
Thank you for your support.

For more information or to continue your entry after the gift period, please visit: **www.paget.org.uk**

The man whose name was given to Paget's disease

Each year on 11 January, we mark Paget's Awareness Day, honouring one of the most influential figures in medical history, Sir James Paget. Born on 11 January in 1814, James was a pioneering surgeon, pathologist and teacher, whose legacy has shaped modern medicine in lasting ways. His name lives on through Paget's Disease of Bone, as well as other conditions that were named after him. Let's look at the man behind the name.

A passion for botany and natural history

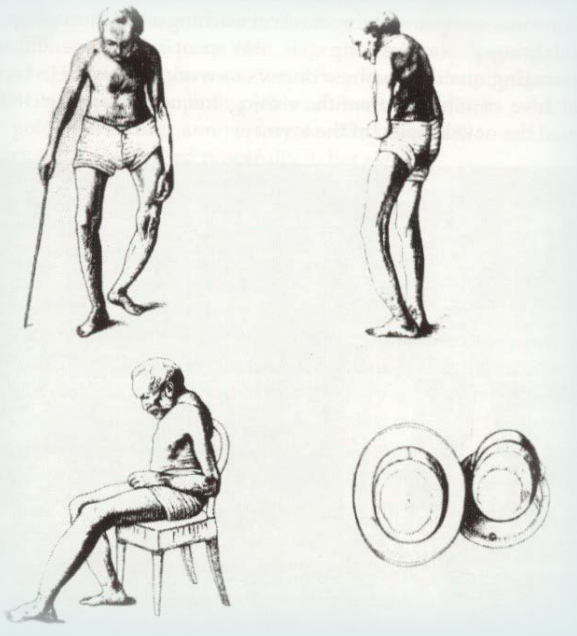
James Paget was born in the bustling port town of Great Yarmouth in Norfolk. He attended a modest local school and nurtured a passion for botany and natural history, a hobby that would later shape his scientific mind.

His early ambition was to join the Navy, but his mother persuaded him to reconsider. In 1834, he enrolled as a medical student at St Bartholomew's Hospital (St Bart's) in London. Winning many prizes, he quickly stood out for his diligence and exceptional observational skills. Financial constraints prevented him from immediately pursuing surgical training. Instead, he turned his talents to pathology and physiology, teaching and cataloguing specimens at both St Bartholomew's Museum and the Royal College of Surgeons, while also serving as the first warden of the medical college. In time, he was appointed assistant surgeon at St Bartholomew's, ultimately rising to become the leading surgeon of his generation.

While still a student, he made his first major scientific discovery: identifying the parasitic worm 'Trichinella spiralis' in human muscle tissue. The Trichina organism is a minute worm. Humans acquire the infestation by eating raw or improperly cooked pork. Driven by an unrelenting curiosity, James believed in the importance of observation. "All the men in the dissecting-rooms, teachers included, 'saw' the little specks in the muscles," he wrote, "but I believed that I alone 'looked at' them and 'observed' them – no one trained in natural history could have failed to do so". This deep attention to detail became a hallmark of his work. He authored more than 200 books and scientific papers and was the first to describe ten previously unrecognised medical conditions.

Paget's disease

In 1877, his paper 'On a Form of Chronic Inflammation of Bones' was published in the journal Medical Chirurgical Transactions. The paper described five cases of a condition he called 'osteitis deformans', later renamed 'Paget's Disease of Bone' in his honour. James initially believed the condition to be inflammatory, hence the name osteitis deformans. At the time, James said, "A better name may be given when more is known of it."



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

Today, we know it is not inflammatory but his extensive work remains highly regarded. In 1888, Sir Jonathan Hutchinson, writing in the British Medical Journal, referred to osteitis deformans as Paget's Disease of Bone, a chronic disorder caused by abnormal bone remodelling, in which bone is broken down and rebuilt in a disorganised manner.

James's most famous case involved a 46-year-old coachman who came to St Bart's in 1854 with pain in his legs. James followed the man's case for over 20 years, observing the progressive enlargement, deformity and bowing of his leg bones. His skull also enlarged to the point that he had to keep buying larger hats. His posture changed dramatically, and he eventually lost over four inches in height. After the patient died of bone cancer, a post-mortem revealed a dramatic disturbance in bone formation and structure, far beyond anything previously described.

What makes James's achievement remarkable is that he made this discovery decades before the invention of x-rays, relying solely on observation, clinical notes and post-mortem examinations. His original description was so precise that little has been added to it since and his work laid the foundation for future research and understanding of the condition.

A life of legacy and influence

James was Surgeon Extraordinary to Queen Victoria, and also President of the Royal Society of Medicine and the Royal College of Surgeons of England. He was a powerful advocate for medical education and public health. He was instrumental in improving standards of clinical training, supporting the careers of young doctors and advocating for women in medicine.

The plaque marking Sir James Paget's birthplace in Great Yarmouth

His dedication to patient care, coupled with a commitment to advancing medical knowledge, continues to inspire generations of healthcare professionals worldwide. The recognition of Paget's disease and other conditions bearing his name serves as a testament to his enduring impact on the medical community.

When he was 57, James contracted a serious illness, a form of 'blood poisoning' which he acquired whilst performing a post-mortem. As a result of this illness, he resigned as a surgeon and began to lighten his workload, but he continued with his private practice. Not long after, Queen Victoria conferred on him a baronetcy, which he accepted with pride. He chose as the motto for his coat of arms "Labor Ipse Voluptas" or "Work itself is a pleasure", which was very appropriate given his remarkable capacity for hard work and long hours. He continued to write, teach and influence medicine until his death on 30 December 1899, just shy of his 86th birthday. He was buried in Westminster Abbey.

Despite his success, James remained modest and grounded. He found his 'elevation' very amusing and on one occasion, when he had to delay the start of a family holiday, he wrote in a letter to his wife, Lydia North "Tomorrow I have to see a Baron, a Viscount, a Countess, and a Marquis! Cock-a-doodle Doo".

In conclusion, Sir James Paget's pioneering spirit, dedication and intellectual curiosity enriched our understanding of many diseases, including Paget's Disease of Bone. His legacy continues to inspire clinicians and researchers worldwide.

Paget's disease today

Today, Paget's disease remains a subject of ongoing research and clinical interest. Medical advancements, including imaging technologies and pharmacological therapies, have improved diagnosis, treatment and outcomes for patients. The condition can affect any bone but commonly affects the pelvis, spine, skull and long bones, such as the thigh (femur). Thankfully, we have seen a decline in incidence and severity, and modern bisphosphonate treatments help regulate bone turnover and manage symptoms.

A special celebration at the Royal Society of Medicine

A special event, the Sir James Paget and His Eponymous Diseases: 150th Anniversary Celebration, took place on 5 November, at the Royal Society of Medicine (RSM) to honour the enduring legacy of Sir James Paget, who in 1875 became President of the RSM and the Royal College of Surgeons of England. The event provided a rich overview of his influence on modern medicine and surgery, showcasing the high standards he set in his professional life. Jonnie Dingwall, son-in-law of Sir Henry Paget, who is a Patron of the Paget's Association and direct descendant of Sir James Paget, discussed the wider Paget family. The event also covered emerging therapies, diagnostic best practices, aesthetic medicine and complication management.

continued overleaf

Paget's Awareness Day

Awareness is vital, as Paget's disease often goes undiagnosed until symptoms become severe. That is why Paget's Awareness Day, held each year on 11 January, the anniversary of Sir James Paget's birth, plays such an important role. It not only raises understanding of the disease but also honours the man behind the name – a physician whose tireless dedication, scientific curiosity and quiet compassion helped shape modern evidence-based medicine.

The first Paget's Awareness Day took place in 2019 at the James Paget University Hospital in Great Yarmouth. Led by Professor Roger Francis, who was at that time Chair of the Paget's Association, the event combined an in-person information event with a live webinar that attracted 60 international participants. Among the speakers was Mr Hugh Sturzaker MBE, author of 'Sir James Paget: Surgeon Extraordinary and His Legacies', a book which is available to purchase online for those who wish to explore his life and work further.

We are honoured to have a descendant of Sir James Paget as a Patron of the Charity. Sir Henry Paget is the great-great-grandson of Sir James Paget.

St Bartholomew's Hospital

St Bartholomew's Hospital, founded in 1123, has provided continuous patient care on the same site for longer than any other hospital in England. The hospital celebrated its 900th anniversary in 2023.

The only medieval building now remaining at St Bartholomew's is the tower of the Church of St Bartholomew the Less. Formerly a chapel of the Priory, the church is now part of the parish of Great St Bartholomew. All the medieval hospital buildings were demolished during an eighteenth-century rebuilding programme. In 1994, the hospital joined with The Royal London Hospital and London Chest Hospital (which has since closed). In 1995, the medical college merged with the London Hospital Medical College and became what is today the Faculty of Medicine and Dentistry, Queen Mary University of London. In 1999, the Royal Hospitals NHS Trust was renamed Barts and The London NHS Trust. In 2012, when Whipps Cross and Newham University Hospitals joined the group, the new trust became known as Barts Health NHS Trust.

Supported by general medicine and community services provided by its sister hospitals, St Bartholomew's Hospital today is a specialist cardiac and cancer care centre.

Bust of Sir James Paget in the James Paget University Hospital, Great Yarmouth

Paget's Awareness Day 2026

In 2026, Paget's Awareness Day will explore pain, research and the lived experience of those affected by Paget's disease. More information about Paget's Awareness Day will be on our website in the new year. As in previous years, our Chair, Professor Stuart Ralston is holding a question and answer event live online on Thursday 8 January (see page 5 for full details and how to join).

No one should live with years of pain

Absolutely no one should live with years of pain before diagnosis. That's the driving force behind our ***PagetAlert*** Campaign, now well underway. By raising funds, we aim to address delays that, in some cases, cause unnecessary suffering despite help being available.

Early diagnosis means: ✔ **Less pain** ✔ **Faster treatment** ✔ **Better quality of life, now and for future generations**

Every pound matters

We're aiming high with a fundraising target of £75,000 and we need your help to get there. As a charity that relies entirely on donations, fundraising and legacies, every contribution counts. Truly, whether it's £5, £50 or £500, it brings us closer to the target and closer to easing the pain journey for many.

We are pleased to say that we are 36% towards our goal, please help us get even closer so we can continue to provide support for people with Paget's disease.

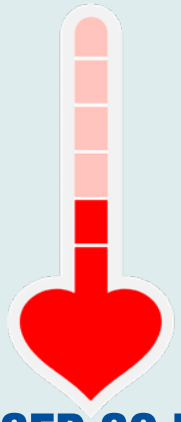
Could you open a door for us?

Do you know a business, company or individual who might want to get involved? From sponsorship to one-off donations to in-kind support, every act of generosity helps push us further forward.

Planning a fundraiser?

Big or small, every event makes a difference. Request your free fundraising pack today and we'll give you all the support you need. Together we can shorten the pain journey and change lives.

TARGET £75,000



RAISED SO FAR

£27,328

A huge thank you

A huge thank you to everyone who's already supported the ***PagetAlert*** Campaign. Your generosity offers hope to those affected by Paget's disease.

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

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**

Thank you for joining us in Bath

We extend our sincere thanks to everyone who attended our recent Paget's information event at Bailbrook House in Bath. The event was hosted by Dr Sarah Hardcastle, Consultant Rheumatologist at the Royal United Hospitals, Bath - a Paget's Association Centre of Excellence. It was a privilege to welcome so many of you to such a beautiful venue and we were delighted by the high level of interest and engagement throughout the day.

A wide range of topics were explored, including diagnosis, imaging, medication, monitoring, surgery, genetics and strategies for living well with a long-term condition. The event would not have been possible without our expert speakers who generously shared their time, knowledge and insights. Their contributions sparked meaningful conversations and gave attendees the chance to deepen their understanding of Paget's disease and have their questions answered.

We're already looking ahead to next year and are excited to plan further opportunities to connect, learn and share. Watch this space for details of future events which are expected to take place in June and September next year. We'd love you to join us!

Prof Stuart Ralston (right), Chair of the Paget's Association, discussing research with attendees

Diana Wilkinson, Specialist Nurse and Director of Education Resources at the Paget's Association, pictured with John Flay, a member of the Association

Mr Nav Makaram, Orthopaedic Registrar in Edinburgh, and Orthopaedics & Clinical Research Fellow at the University of Edinburgh, delivered a very interesting talk on joint replacement, offering valuable insights into current practices and advancements in the field

Jen Woodworth (left), Operations and Engagement Manager at the Paget's Association, with Belinda Ratnayake, a member of the Association

Some of the team from the Royal United Hospitals, Bath: (Left to right) Steve Windebank and Terrie Stocker, Osteoporosis & Metabolic Bone Specialist Nurses; Sarah Legg, Senior Rheumatology Physiotherapist; Dr Sarah Hardcastle, Consultant Rheumatologist and Director of the Centre of Excellence

Meet the team at the Paget's Association

Honorary President

Professor Graham Russell
Involved in research at both the Botnar Research Centre, Oxford and the Mellanby Centre for Bone Research, Sheffield, Graham played a key role in the discovery and development of bisphosphonates for the treatment of bone disorders.

Patrons

Sir Henry Paget
Sir Henry is the great-great grandson of Sir James Paget, whose name was given to Paget's disease.

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

Mr Recardo Patrick
Recardo is an entertainer and businessman who rose to fame as lead singer with the band, Sweet Sensation. He has Paget's disease.

Employees

Mrs Diana Wilkinson
Specialist Nurse & Director of Educational Resources

Miss Jen Woodworth
Operations & Engagement Manager

Board of Trustees

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

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

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

Mrs Kely Burman
A retired nurse and midwife living in Orsett, Kely has not only cared for those with Paget's disease, but her mother also had the condition.

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

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

Mr Alan Martin
A retired company director, Alan lives in Wokingham. He has Paget's disease and believes the interaction between patients and clinicians brings mutual benefits.

Dr Faiz Rahman
Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the University Hospitals of Leicester, where he is involved in caring for those with Paget's disease.

Mrs Amanda Sherwood
Amanda lives in Bristol and is now retired. She has experience in working for societies and teaching organisations which specialise in the field of bone and related topics.

Dr Stephen Tuck
Stephen is a Consultant Rheumatologist at the James Cook University Hospital, Middlesbrough and Honorary Lecturer at the Institute of Cellular Medicine, within Newcastle University.

Professor Mark Wilkinson
An Orthopaedic Surgeon in the Metabolic Bone Unit of the University of Sheffield, Mark has both an academic and clinical interest in Paget's disease.

Key dates and events

8 January 2026	Virtual question and answer event with Professor Ralston
11 January 2026	International Paget's Awareness Day
19 April 2026	Adidas Manchester Marathon
26 April 2026	TCS London Marathon
16 May 2026	Big Spring Coffee Morning for Paget's
June 2026	Paget's information event – date and venue to be confirmed
September 2026	Paget's information event – date and venue to be confirmed
Throughout the year	Virtual Paget's Support Groups

Do one thing for us

Together, we can achieve so much. Every small action matters and, when combined, they create something very powerful. By taking just one simple step from the options below, you'll be helping to keep our work thriving and our community strong.

Choose the action that feels right for you and know that your support truly helps us make a difference in someone's life.

1. **Take part in our raffle**
2. **Help raise vital funds**
3. **Make a donation**
4. **Become a member (if you haven't already)**
5. **Leave us a Google review**

(To leave a review scan the QR code, click the link, or search Google for 'Paget's Association')
https://g.page/r/CfNVc9N-FVCPEAE/review