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

Taking fundraising to new heights

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Chair's message

Dear Friends and Supporters,

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

Our cover feature highlights Diana Wilkinson's sponsored glider challenge which raised an incredible £1,291 in support of the PagetAlert campaign, which seeks to shorten the time between people experiencing symptoms of Paget's Disease and receiving a diagnosis. We aim to do this by raising awareness of the symptoms of the disease among patients and healthcare professionals and ensuring that those with symptoms get referred quickly for a specialist opinion and treatment. You can read about the heights Diana went to in her glider challenge on pages 14 and 15. The charity had four runners in the London Marathon earlier this year: Abigail Fletcher, Ben Dockrell, Darcie Alabaster and Alexander Trubov. So far, the London Marathon team have raised over £8000 with further donations still coming in. We now also have places in the first ever Saturday London Marathon – see page 8 for details. Additionally, Professor Terence O'Neill, lead of the Salford Royal Paget's Centre of Excellence also did his bit by running in the Manchester Marathon, raising an impressive £500 and winning a gold Paget's Fitness medal in addition to the Marathon medal. Well done to all our athletes who are featured on pages 8 and 23. On a less strenuous note, well done to

> ***"There are lots of ways that you can help to support the Association – please have a look on page 9 for some ideas"***

Trustee Kely Burman who raised £530 in a coffee morning this spring as featured on page 18, following on from a similarly successful event she hosted in 2025. Hopefully Kely will go for three in a row and host another one in 2027! As a result of these and other fundraising efforts, we have raised £37,799 towards our target of £75,000 for PagetAlert so we are more than halfway there. There are lots of ways that you can help to support the Association – please have a look on page 9 for some ideas. Anything you can do to support the charity is much appreciated so that we can continue to support people with Paget's disease and their families.

An important aim of the charity is to inform people about Paget's disease and go over things like diagnosis, monitoring and treatment options. It was a pleasure to join the team from the Royal National Orthopaedic Hospital at Stanmore who hosted an information day in Elstree. We covered a range of topics and feedback from participants was very positive. We also managed to raise £127 from our raffle and I'm delighted to say that one of our hosts, Dr Judith Bubbear, won a raffle prize! More details of the event are on pages 10 and 11. Many of the questions we had at this event focused on treatment options and our Specialist Nurse Diana has written a brief guide to bisphosphonates on pages 6 and 7. These are the most widely used treatments for Paget's disease, and as Diana points out, the effect of a single dose of zoledronic acid, the most popular treatment, can last for many years. On the research front, Professor Rob Layfield, Chair of the Association's Research Committee, focused on two topics; one is the use of cochlear implants for the treatment of hearing loss in Paget's. There isn't any good evidence that bisphosphonates can help hearing loss but the paper Rob highlighted from researchers in Arkansas showed that these implants can really make a difference. The second item reports the possible presence of a Paget's-like disorder in a boa constrictor. More details are discussed on page 17. I was interested in the fact that there was evidence of bacterial infection, which made me think back to the original description of Sir James Paget who named the condition "osteitis deformans" thinking that infection may also cause the human disease. There hasn't been confirmation that Paget's disease in humans is caused by infection but maybe this was an underlying cause of the abnormal bone remodelling in the snake. Fascinating stuff!

continued overleaf

Looking forward, I would like to draw your attention to the fact that we will soon be transferring assets of the Paget's Association to the Paget's Disease of Bone Association, which has been established as a charitable incorporated organisation (CIO), which has various advantages as summarised on page 26. The CIO has a new logo and has been separately registered with the Charity Commission but its mission is exactly the same as the Paget's Association and will continue to raise awareness about the disease, support research and provide information and support to those affected by Paget's and their families.

Our ability to support people with Paget's disease from all over the world has been revolutionised by virtual support groups and the feature on Jill Donahue, from Florida is a very good demonstration of this. Jill's story is featured on page 5. She's hoping to link up with other people with Paget's. If you would like to be put in touch with Jill, please contact our Paget's Helpline.

In closing, I wanted to draw your attention to our upcoming information event and AGM which is scheduled to be held in Newcastle on 17th September 2026, hosted by Dr Nishanthi Thalayasingam and Dr Nadia Tripp who run the metabolic bone service at the Freeman Hospital. I very much hope readers in the Northeast will be able to join us for what promises to be an enjoyable and informative event.

With very best wishes to all.

Stuart Ralston

Chair, Paget's Association

Our charity and purpose

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

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

Paget's Nurse Helpline

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

Email **helpline@paget.org.uk**

Telephone **0161 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

Jill wants to connect with others

Jill Donahue lives in the south of Florida. She is a retired registered nurse who enjoys concerts, plays, social groups, volunteering on her condominium board, knitting, walking her dog and enjoying life with her loving husband.

Jill was diagnosed with Paget's disease in 2008, aged 58, after experiencing persistent left hip pain and while still working in a hospital in New Hampshire. She saw an orthopaedic consultant who requested a bone scan. This showed activity in several bones, including her spine (T3, T7, T11), pelvis and both hips. Initially, doctors feared that it was secondary cancer that had spread, so they searched for a primary site. After seeing an oncologist and almost beginning radiation treatment, a bone biopsy confirmed Paget's disease. She consulted a Paget's specialist at Massachusetts General Hospital to confirm her diagnosis and treatment plan. She went on to receive an infusion of zoledronic acid which eased her pain.

Jill experiences hip pain and increasing thoracic pain as the day progresses and has also experienced complications, including a pathological fracture of a rib and osteoarthritis in several areas. Over the years, her hip pain was managed with ultrasound-guided steroid injections. However, these had to stop because of the risk of joint damage. She occasionally takes a nonsteroidal anti-inflammatory drug (NSAID) and manages symptoms by planning activities earlier in the day to reduce pain.

When her pain increased again, Jill received a second infusion in 2025 and underwent a platelet-rich plasma (PRP) injection into her right hip. The combined treatment led to complete relief of her hip pain. PRP injections use a concentrated sample of your own blood platelets injected into an affected joint or tendon. Platelets release growth factors that may reduce inflammation and improve pain and function. Some studies show benefit but responses vary widely person to person.

Jill hopes to connect with others who have Paget's

Although her activity is modified, Jill remains positive and proactive. She hopes to connect with others living with Paget's disease to learn how best to manage her condition and will be joining one of our Paget's Virtual Support Groups. If you would like to be put in touch with her, please contact our Helpline by email **helpline@paget.org.uk** and we will let her know.

Jill's advice to anyone newly diagnosed is to seek knowledgeable medical professionals, as she felt some clinicians did not manage her condition appropriately, and one didn't believe the level of pain she was experiencing. She encourages people to advocate for proper care and to trust their own experience of pain and symptoms.

Treatment with bisphosphonates

Bisphosphonates are the most commonly used medicines to treat Paget's disease. Should you need treatment, your doctor will assess whether they're suitable for you, based on your overall health. For Paget's disease, bisphosphonates are given as a one-off treatment, the benefits of which can last several years.

Our Specialist Nurse, Diana, takes a closer look.

How do they work?

When people reach out to our Helpline, they often tell me that they're unsure about treatment. I understand how important clear information is, so I often begin by explaining the fundamentals.

Our bones are made of living tissue, constantly being broken down and rebuilt by specialist bone cells. This process is known as bone remodelling. When this process is in balance, bones stay healthy and strong. In Paget's disease, however, this remodelling becomes accelerated and disorganised, which leads to bone being formed with an abnormal structure.

Bisphosphonates are drugs which work by restoring a more normal bone remodelling process. These drugs can also relieve or reduce bone pain, although it's important to know that they can take several months to have their full effect.

The two bisphosphonate treatments most commonly used for Paget's disease in the UK are zoledronic acid and risedronate.

Dental care

Dental work is usually carried out before bisphosphonate treatment because these medicines can, in a small number of cases, affect the way bone heals in the jaw (osteonecrosis of the jaw). Having any necessary dental treatment completed beforehand reduces this risk and helps ensure your mouth is in the best possible condition before treatment begins.

Once you have a bisphosphonate in your system, it's important that your dentist knows. This allows them to plan any dental procedures safely and to discuss any precautions that may be needed.

Zoledronic acid infusion

Zoledronic acid is considered the first-line treatment for Paget's disease due to its potency and prolonged duration of action. It is also the bisphosphonate most likely to relieve pain from active Paget's disease. It is usually given in hospital, as an outpatient, although I have known some GP surgeries to occasionally give it. A single dose of 5mg is given through a drip (infusion) directly into a vein in your arm (intravenous) and usually takes around 15 to 30 minutes. Over the following months, this treatment often normalises the abnormal bone remodelling and, for Paget's disease, one single dose can be effective for many years.

Risedronate tablets

The most commonly used oral bisphosphonate is 30mg of risedronate sodium, taken daily, as a two-month course.

How to take the tablet safely

Tablets like risedronate can sometimes irritate the tube (oesophagus) that carries food to your stomach. To help prevent this, it's important to take them in a way that lets the tablet move quickly into your stomach and stay there until it dissolves.

- Either sit upright or stand to take the tablet and for at least 30 minutes after taking it. This helps the tablet travel straight down into your stomach and reduces the chance of it getting stuck or causing irritation on the way down.
- Swallow the tablet whole; do not crush or chew it.
- Wait at least 30 minutes before eating or drinking anything other than water and before taking any other medicines or supplements. This gives your body time to absorb the tablet properly. If taken at the same time as any of the following medicines, they lessen the effect: calcium, magnesium, aluminium (e.g. some indigestion mixtures) or iron.
- Avoid bending over or lying down until after you've had your breakfast. This helps prevent the medication from washing back up into your oesophagus, which can cause irritation.

> ***"For Paget's disease, one single dose of zoledronic acid can be effective for many years"***

What about side effects?

Serious side effects are rare. Most people who need bisphosphonates find them helpful. Of course, side effects can happen, but your doctor will discuss these with you and help you consider the pros and cons.

When treatment is recommended, the benefits of protecting your bones often outweigh the risks of potential side effects. Regarding the zoledronic acid infusion, some people worry about possible flu-like side effects, though these don't affect everyone. Ensuring adequate hydration before and after the infusion, along with taking paracetamol, may help minimise any associated discomfort. For the complete and most up-to-date information regarding side effects, you can visit the British National Formulary at **www.bnf.nice.org.uk**

Follow up

An assessment of your response to treatment is usually carried out between three and six months after the treatment has finished. This typically includes a blood test and a follow-up appointment to evaluate whether your symptoms have improved.

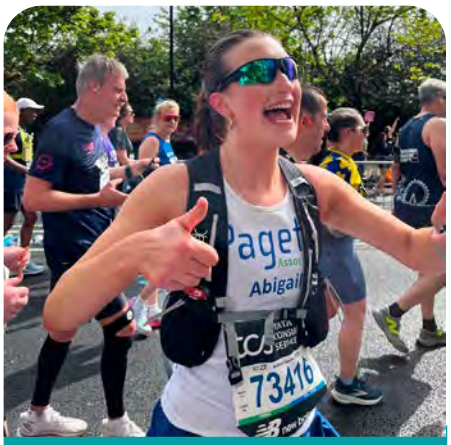
Paget's Nurse Helpline

If you would like to discuss treatment further, you are welcome to contact us:

Email helpline@paget.org.uk

Telephone 0161 7994646

Our 2026 marathon heroes



Running for Paget's: Abigail Fletcher

A heartfelt thank you to all our incredible 2026 runners in both the Manchester and London Marathons. Completing 26.2 miles is an extraordinary achievement, but they went even further, raising over £8,000, with additional support through Gift Aid, and helping to shine a much-needed light on Paget's disease along the way. A huge thank-you also to their amazing supporters who donated and cheered them on.

Saturday places available in the 2027 Double TCS London Marathon

For the first time ever, the London Marathon will take place over two days. As well as the traditional Sunday race, a special Saturday event on 24 April 2027 has been introduced.

Our Sunday Marathon places have already been filled but we now have places available for the Saturday so this is your chance to be part of London Marathon history. If you are interested, please complete the application form on our website or share this opportunity with anyone you think would love the challenge.
https://paget.org.uk/get-involved/london-marathon/

Darcie Alabaster taking on the challenge

Smiles all round as Ben Dockrell and Abigail Fletcher celebrate and display their medals

Fun ways to support the Paget's Association

You don't have to run a marathon to make a difference!

Someone with Paget's disease needs your support. Please help us be here for them. Whether you have an hour to spare or are planning a special celebration, there are plenty of simple and enjoyable ways to raise funds. Whatever you choose to do, every pound raised helps us support people affected by Paget's disease and those facing the often long journey to diagnosis. Together, we can do more.

Celebrate a special occasion

If you're celebrating a birthday, anniversary, wedding or other special occasion, why not ask friends and family to make a donation to the Paget's Association instead of buying gifts?

Run a chocolate tombola

A tombola is always a favourite at local fairs and community events and many organisers are happy to offer charity stalls at a reduced rate or even free of charge. You could have a chocolate tombola by collecting chocolates over time, then display them attractively and sell tickets for a chance to win. If you need help regarding how to organise the tickets, just get in touch. It's inexpensive to organise and appeals to all ages.

More ideas

- Hold a garden party or afternoon tea event.
- Have a car boot sale with items you no longer need.
- Do a sponsored walk, swim or cycle.
- Ask grandchildren to complete a sponsored challenge.
- Sell homemade cakes, crafts or knitted items.
- Sell homegrown flowers or vegetables.
- Hold a book sale or book swap.
- Organise a dress-down day at work.
- Arrange a concert, quiz night or dance.

If you'd like help planning a fundraising event or wish to pay in the funds you've raised, please get in touch using the contact details on page 4.

Informed, inspired and empowered

Thank you to everyone who joined us at our recent Paget's information event in Elstree. The day brought together people affected by Paget's disease, healthcare professionals and researchers for a packed programme of information, learning and discussion.

The event opened with an introduction from Diana Wilkinson, Specialist Nurse at the Paget's Association, who introduced attendees to the work of our charity, the services we provide, and the fundraising efforts that help make our support, education and research activities possible.

We were delighted to welcome an outstanding panel of expert speakers, including our Chair, Professor Stuart Ralston from Edinburgh; Professor Richard Keen and Dr Judith Bubbear, Consultants in Metabolic Bone Disease at the Royal National Orthopaedic Hospital (RNOH); Martyn Dudley, Clinical Nurse Specialist; Sophie Barlow, Physiotherapist; and Mr John Stammers, Orthopaedic Surgeon, all from the RNOH. The day concluded with a fascinating presentation from Professor Rob Layfield, Professor of Protein Biochemistry at the University of Nottingham, who shared insights into the history of Paget's disease. Together, they shared their expertise on a wide range of topics, including the diagnosis and monitoring of Paget's disease, treatment options, self-management strategies for pain, joint replacement surgery, genetic testing, prevention and the fascinating history of Paget's disease.

Mr John Stammers, Orthopaedic Surgeon at the RNOH, outlined how joint replacement can help people affected by Paget's disease and osteoarthritis

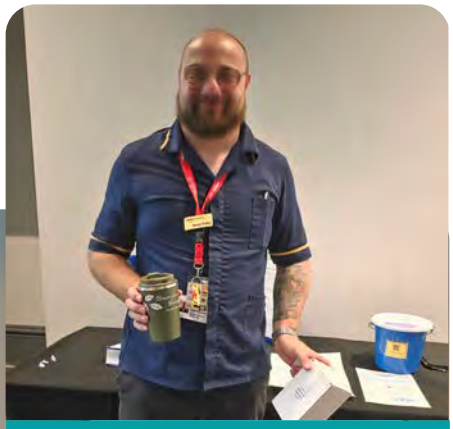
We were delighted to receive feedback that attendees left feeling better informed about Paget's disease and more confident in discussing the condition with their healthcare professionals. Events like these provide a valuable opportunity to learn from experts, ask questions, and connect with others affected by the condition.

A special thank you to everyone who supported our raffle, which raised an impressive £127 for the charity. With 12 fantastic prizes on offer, there was plenty of excitement on the day. The star prize was a signed copy of *'Crypt'* by Alice Roberts, well known for presenting Digging for Britain and a Sunday Times bestselling author. Among its many fascinating stories,

The day proved hugely informative for attendees, who responded with excellent feedback

the book highlights medieval skeletons discovered at Norton Priory in Cheshire, where multidisciplinary research identified a remarkably high prevalence of an ancient form of Paget's disease.

You will find details of our next Paget's information event on the following page. We hope to see some of you there.



Clinical Nurse Specialist Martyn Dudley from the RNOH delivered an informative session on treatment and later won a raffle prize

Dr Judith Bubbear from the RNOH provided a valuable overview of diagnosis and monitoring. Her day ended on a high note when she won a raffle prize

Professor Richard Keen from the RNOH delivered a precise explanation of Paget's disease

The proud winner of a signed copy of Crypt by Alice Roberts

More raffle winners!

Come along to our Paget's information event in Newcastle

Our free Paget's Information event at The County Hotel, Newcastle, offers a supportive, friendly environment for anyone affected by Paget's disease, including family members and carers. Health professionals are very welcome too. Each event is designed to inform, empower and build community. The feedback we receive is consistently outstanding.

What you can expect

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

Speakers

A full agenda will be available on our website as soon as it is available. Confirmed speakers include:

- Prof Stuart Ralston: Genetic testing and preventative treatment
- Dr Nishanthi Thalayasingam and Dr Nadia Tripp: History of Paget's
- Dr Matt Grove: Diagnosis and management
- Dr Dasigan: Case presentation
- Dr John Tuckett: Radiology review
- Diana Wilkinson: The role of the Paget's Association
- Other speakers will be confirmed nearer the time

17 September 2026

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

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

Chair: Professor Stuart Ralston, Chair of the Paget's Association

Places must be booked in advance

Places must be reserved. You're very welcome to bring someone with you, just remember to book a place for them too. To reserve your place, contact us by email **membership@paget.org.uk** or phone 0161 7994646. When booking, please let us know how many places you need and any food allergies or specific dietary requirements.

If you have any questions, we're happy to help. Simply get in touch.

Shared experiences survey

A survey has been emailed to everyone on our mailing list. It is for anyone who has a confirmed diagnosis of Paget's disease. Its purpose is to explore shared experiences among people living with the condition and is purely for interest. If we receive enough responses, the findings may help us identify common themes or patterns in areas such as occupation, diet or environment.

Once we have gathered a sufficient number of responses, we plan to publish a summary in this magazine. All information will be anonymised. If you have not received the survey and would like to take part, please get in touch.

To take part, please email **helpline@paget.org.uk**

Monthly raffle: great odds, real impact

With only 200 tickets available each month, the chances of winning our raffle are impressive and each ticket supports our vital work. Simply email **membership@paget.org.uk** or call **0161 7994646** to secure your ticket and be entered into the next draw.

Ticket details

- **£5 per ticket, per month**
- **Two prizes every month**
  - 1st prize: £100
  - 2nd prize: £50
- **Prizes double in June and December**
  - 1st prize: £200
  - 2nd prize: £100
- **Open to anyone aged 18+ (membership not required)**

Winners

MARCH 2026

1st Prize £100 / Ticket no. 49
2nd Prize £50 / Ticket no. 97

MAY 2026

1st Prize £100 / Ticket no. 36
2nd Prize £50 / Ticket no. 84

APRIL 2026

1st Prize £100 / Ticket no. 62
2nd Prize £50 / Ticket no. 1

JUNE 2026

DOUBLE PRIZE DRAW
1st Prize £200 / Ticket no. 97
2nd Prize £100 / Ticket no. 124

Taking fundraising to new heights

"Thanks to the amazing support of everyone who sponsored us, we raised a fantastic £1,291 and contributions are still being made, which means so much"

How far would you go to support a cause you care about? For our Specialist Nurse Diana, the answer was high above the Lincolnshire countryside. Together with her husband, she took on a gliding challenge that pushed her out of her comfort zone, tested her nerves and created a memory that will last a lifetime. Diana reflects on her experience below.

Why did I take on this challenge?

After 14 years with the Paget's Association, I know just how urgently we need support simply to survive the next couple of years and to keep driving forward our PagetAlert campaign. Every day, I speak to people living with Paget's disease who are struggling for answers, support and reassurance. For many, we are the first place they feel heard. We provide trusted information, practical guidance and emotional support, and we receive no government funding to do it. Our income has fallen sharply, and without increased donations, the future of the charity is at real risk. If we were no longer here, people affected by Paget's disease would lose a vital lifeline. That's why I stepped out of my comfort zone and took on this challenge for the Paget's Association.

I never imagined I'd find myself flying in a glider, let alone taking the controls, instead of just being a passenger. The challenge was something my husband, Brian, and I decided to do as part of our fundraising efforts. Thanks to the amazing support of everyone who sponsored us, we raised a fantastic £1,291 and contributions are still being made, which means so much.

Flying for Paget's

We arrived early with our support team, Janet and Graham Dixon.


Pat and Diana with her parachute!

As Janet lives with Paget's disease, they understand why fundraising matters and they've been supported by the Paget's Association themselves, attending our events and being connected with a rheumatologist and surgeon who provided the help when they needed it most. They're tireless fundraisers themselves, regularly raising money through eBay sales and car boot events.

Arriving early meant we were able to watch the gliders closely and chat with gliding instructor Pat Fowler. I admit, I was worried about the launch, as I was not entirely sure how a winch-launched ascent would work. With no hills in the area, a winch is the only way to get the glider into the air. After watching a few take-offs, it was clear just how efficient the process is. After the launch, the glider is on its own. With no engine to rely on, the pilot must read the sky, searching for thermals, invisible columns of warm air that lift the glider and keep it soaring. Unfortunately, on that day, thermals were in short supply and so we would not be able to get anywhere near Pat's recent achievement of five hours in the sky! Watching them come in to land was incredibly peaceful, with a real sense of calm as they silently returned to the runway.

Brian – ready to go

Ready to fly – Diana and Pat

As our turn approached, we discovered we were required to wear a parachute – oh, I had a lot of questions! Why do I need one? How does it work? How do you get out of the cockpit? Had Pat ever had to use one? The answers were reassuring. The parachute is simply a precaution and we were given clear instructions on how it works. If a quick exit is needed, there is a jettison switch and an easy-release seatbelt. Thankfully, Pat said he had never had to use his parachute, which was a huge relief, as jumping out of any aircraft is definitely not on my bucket list!

Time to fly

When my turn came, Pat was brilliant from start to finish, reassuring me every step of the way. I sat in the front, as Pat took the seat behind me. During the launch, I was concentrating on taking a video but I did feel the sudden lift as I was pushed back in my seat. When he invited me to take the controls, I agreed, although I must admit it was with some trepidation. I followed his instructions carefully and soon found myself looking out to Mablethorpe and the sea beyond as I steered the glider over the countryside. At one point, Pat was actually clapping his hands in the back to prove that I was flying it myself. Wow!

It was an incredible feeling, both exhilarating and peaceful. Gliding silently through the sky, with only the rush of air around us, was so different to being in a plane with engines. When it came to landing, I was more than happy to hand the controls back to Pat. His expertise brought us safely back to the ground, completing an unforgettable experience.

It was fabulous to share such a unique experience with my husband Brian, who also successfully completed the challenge. We're both immensely grateful for all the support we've received. A heartfelt thank you to everyone who sponsored us and helped us raise such a fantastic amount. Your encouragement made all the difference.

Left to right:
Support team – Graham and Janet Dixon
Instructor – Pat Fowler
Fundraisers – Brian and Diana Wilkinson

Thank you

My sincere thanks to everyone who supported us in any way, to Pat, my instructor, for his patience, reassurance and expertise, and everyone at the Lincolnshire Gliding Club for their very warm welcome. If anyone's tempted to try it, I'd say go for it. The club organise times when anyone can go and try it and there are other clubs around the country. Stepping out of my comfort zone and into the cockpit to fly the glider myself is not something I ever imagined I would do. It is an experience I will never forget.

You can visit our website to watch the video and see it for yourself.

Diana

The glider used is currently being loaned by the Trent Valley Gliding Club to the Lincolnshire Gliding Club.

Visit the page to watch the video, see more photos and/or donate

https://paget.org.uk/news/Keep-our-lifeline-alive/

Visit the website of the Lincolnshire Gliding Club

http://www.lincsgliding.org.uk/

Research round-up

Professor Rob Layfield, Chair of the Association's Research Subcommittee, highlighted two recent articles of interest to the Paget's community. The first looks at how cochlear implants may help people with hearing loss due to Paget's disease. The second considers a report of rare Paget-like bone changes in a snake, broadening our understanding of how abnormal bone remodelling can appear across different species. Here, our Specialist Paget's Nurse, Diana Wilkinson, takes you through the key points.

Systematic review finds cochlear implants may help hearing loss in those with Paget's

We know that when Paget's disease affects the skull, it can sometimes cause hearing loss. The exact mechanism for hearing loss in Paget's is unclear; however, it is likely to be multifactorial. A systematic review published in the Journal of Otology & Neurotology suggests that cochlear implants can improve hearing in people with Paget's disease.

Researchers from the University of Arkansas for Medical Sciences reviewed published medical reports to see how people with Paget's disease responded to cochlear implants. They searched major medical databases for studies written in English up to January 2024. They found 8 articles describing 9 people who had received implants. Two people had juvenile or early-onset Paget's disease, which is a rare and very severe genetic form of the condition. The other seven were older adults, aged 59 to 86 at the time they received their implants.

Scans showed that 8 of the 9 individuals had abnormal bone thickening or overgrowth in areas around the ear and skull base prior to surgery. These changes can make implant surgery more technically difficult. Despite this, all showed early improvement in hearing and speech understanding after surgery. Long-term results, tracked over 3 to 6 years in most cases, were also encouraging, with 7 patients maintaining improved hearing over time, one patient experiencing a gradual decline after 3 years. No surgical complications were reported.

While bisphosphonates are the main treatment for patients with Paget's disease, the studies reviewed did not consistently report their use. As a result, it could not be assessed whether disease stage or medical management influenced the outcomes.

A beneficial treatment option

The authors conclude that a cochlear implant may be 'both feasible and beneficial for selected patients' who have severe hearing loss caused by Paget's disease. However, detailed pre-operative imaging is likely to be important, as bone changes associated with the condition can alter normal anatomy and make surgical planning more complex. Although the abnormal bone can make implantation more technically demanding, existing evidence shows that many patients can still experience meaningful hearing restoration and improved quality of life. The researchers noted that larger studies are needed to quantify the risks associated with cochlear implantation for individuals with Paget's disease, as well as a consideration of any use of bisphosphonates (not reported in this study).

Reference

Burnett AK, Nguyen K, Doran A, Hudefi A, Eckard P, Vibhute M, Blake L, Dornhoffer J, Saadi R. Cochlear Implantation Outcomes in Paget's Disease of the Bone: A Systematic Review. Otology & Neurotology, March 2026; 47(3):434-440. DOI: 10.1097/MAO.0000000000004819.

Rare Paget-like bone disease reported in a boa constrictor

Veterinary researchers in South Korea reported an unusual case of a Paget-like bone remodelling disorder in a snake, highlighting that diseases resembling Paget's disease may also occur in animals.

Boa constrictors are widely recognised snakes that typically grow to around two to three metres in length and because their active ground movement depends heavily on spinal flexibility, good vertebral health is essential to their mobility and overall wellbeing. The case, reported in the Journal of Veterinary Science, described a 23-year-old male red-tailed boa constrictor (relatively old for such a snake) that developed severe skeletal abnormalities and showed a marked decline in its overall health.

The snake was taken for veterinary care after showing several concerning symptoms, including loss of appetite, difficulty shedding its skin properly, stiffness of the spine and reduced movement. X-rays and CT scans, similar to those that would be performed in humans, revealed widespread deformities in the spine. Blood tests showed very high levels of alkaline phosphatase (ALP 1,512 U/L) which exceeded previously reported reference values (96 to 116 U/L) for snakes. ALP is an enzyme often linked to increased bone activity in Paget's disease. In addition, blood cultures detected Escherichia coli, suggesting a bacterial infection was also present.

The snake was treated with antibiotics (enrofloxacin) and steroids (dexamethasone) which led to some temporary improvement, with appetite partially returning, ALP levels falling and general comfort improving. The snake's living conditions were changed by moving it to an enclosure twice as large as its previous habitat. Within the new enclosure, the temperature gradient was maintained with a hot zone at 30°C and a cool zone at 25°C. The enclosure was adapted to meet the snake's reduced mobility: there were no climbing structures due to severe spinal rigidity and the floor was lined with soft, moisture-retaining materials to improve comfort and support shedding. The 2-metre-long space allowed the snake to stretch fully and move with less strain.

> ***"While rare, Paget-like bone disease may occur in reptiles and other animals"***

With continued treatment, food intake gradually resumed, reaching 30% of baseline and subsequently improving to 50%–60%. The snake's mobility and quality of life appeared to improve for a time. After two months, the snake's ALP level had more than halved, falling to 473 U/L and no further bacterial growth was detected. However, the vertebral deformities remained and the snake was unable to bend, maintaining an increasingly extended posture.

Symptoms later returned, including loss of appetite and shedding problems. Due to the snake's ongoing decline in health and wellbeing and following a zoo-based quality-of-life assessment, the decision was made to proceed with humane euthanasia. Examination after death found extensive spinal deformities, while microscopic analysis revealed thickened trabeculae, mosaic lamellar bone and osteoclast proliferation, consistent with a Paget-like bone remodelling disorder.

Of course, Paget's disease is best known as a human condition, where bone is broken down and rebuilt in a disorganised way, leading to enlarged and weakened bones. It is rarely described in animals but this report in an old snake adds to occasional past mentions of Paget-like changes in non-human species, such as dogs, rodents and reptiles, though confirmed cases remain extremely uncommon. As so few animal cases have been documented, vets still know little about the causes, progression or best treatment options.

Conclusion

The researchers say this case highlights the importance of imaging, blood tests, microscopic tissue examination (histopathology) and welfare-centred care. Although no cure was possible, changes to the snake's environment appeared to provide temporary comfort and improved mobility.

While rare, Paget-like bone disease may occur in reptiles and other animals, and this unusual boa constrictor case may help veterinarians recognise similar disorders earlier and improve care for affected animals.

The authors noted that 'Animal care and clinical management were conducted under the oversight of the zoo's animal care and welfare committee'.

Reference

Youn SH, Lee NY, Shin KY, Shin HJ, Yang JY, Kim DY. Paget-like bone remodelling disorder in a red-tailed boa (Boa constrictor constrictor): diagnosis and management. J Vet Sci. 2026 Mar;27(2):e22. https://doi.org/10.4142/jvs.25281.

Kely's Coffee morning raises £530

Kely (right) enjoying refreshments with her friends

For the second year running, Trustee Kely Burman hosted a spring coffee morning. Once again, it proved to be a tremendous success. Her guests enjoyed refreshments while taking the opportunity to learn more about Paget's disease. We are pleased to report that the morning raised £530, with additional funds coming through Gift Aid. Well done, Kely!

Shortening the pain journey

Absolutely no one should live with years of pain before diagnosis. That's the driving force behind our PagetAlert Campaign. 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**

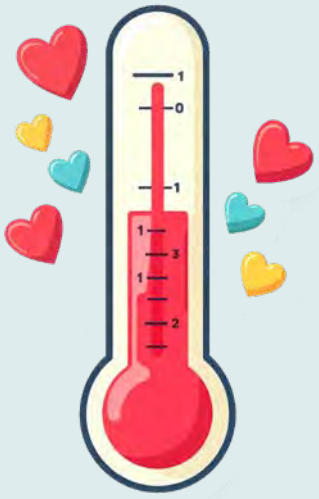
We're aiming high with a fundraising target of £75,000 and we need your help to get there. As a charity that relies entirely on donations, fundraising and legacies, every contribution counts. Whether it's £5, £50 or £500, it brings us closer to the target and closer to easing the pain journey for many.

Thank you

A massive thank you to everyone who's already supported the ***PagetAlert*** Campaign. Your support is driving real change for people affected by Paget's disease. We've now passed the halfway mark and we couldn't have reached this point without you. Thank you for standing with us.

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

TARGET
£75,000
RAISED SO FAR
£37,799



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.**

Living well with a long-term condition

Physiotherapist Sarah Legg, from the Royal United Hospital in Bath, spoke at our Paget's information day in Bath last year. Here, she shares an overview of the key themes from her talk.

Managing a long-term condition such as Paget's disease often involves more than medical treatment or surgical options. While medication can play a vital role, lifestyle strategies can also make a meaningful difference in day-to-day wellbeing. Although research specific to Paget's is limited, there is good evidence that many self-management approaches are effective for other long-term painful conditions, including arthritis.

Findings from a survey conducted by the Paget's Association highlighted the main challenges faced by people living with Paget's: pain, disturbed sleep and fatigue. Meanwhile, a 2024 research paper, *Causes of Musculoskeletal Pain in Paget's Disease of Bone* (Berg et al.), shows that the most common cause of pain in Paget's is actually arthritis in nearby joints, rather than Paget's activity itself.

Understanding pain: more than a physical symptom

Pain is complex. It can certainly stem from physical changes such as inflammation, nerve irritation or mechanical strain. But that's only part of the story. For many years, clinicians have understood pain through a biopsychosocial model – one that recognises the influence of psychological factors, such as mood and stress, and social factors, such as support networks and daily routines. These elements can interact with physical symptoms, sometimes amplifying the overall experience of pain.

The sleep–pain cycle

Sleep is not simply "switching off"; it's an active, restorative process vital to the body's functioning. Unfortunately, when sleep is disrupted, pain can feel worse and become harder to manage. Likewise, pain can interfere with falling or staying asleep, creating a frustrating cycle. There's no single treatment that guarantees better sleep but sleep hygiene, habits and environmental changes that support sleep can make a real difference. This might involve routine, light exposure, reducing caffeine or adjusting your sleep environment. Both pain and poor sleep can activate the sympathetic

nervous system, our “fight or flight” stress response, which in turn may heighten pain sensitivity and make rest more difficult.

So what can help?

1. Relaxation techniques

Relaxation isn’t the same as simply resting. True relaxation activates the parasympathetic nervous system, known as the “rest and digest” response, helping counterbalance stress. Even simple techniques can help. A good starting point is breathwork, for example, gently lengthening the out-breath for 10 breaths. This signals to the body that it is safe, reducing tension and calming the nervous system.

2. Pacing your activities

Pacing means working with your body, not against it. Instead of pushing hard and then needing long recovery periods, pacing helps smooth out activity levels, making daily tasks more manageable. It often involves breaking tasks into smaller steps, building in regular breaks and focusing on “how can I do this?” rather than “I can’t do this”. Rather than being restrictive,

> *“Pacing means working with your body, not against it”*

pacing can open up new ways of staying active and engaged.

3. Physical activity that works for you

Starting exercise when you live with pain can feel daunting but the evidence is clear: regular physical activity can reduce pain, especially in conditions like osteoarthritis. Movement also supports sleep, improves mood and boosts overall quality of life. The key is choosing something enjoyable or sustainable, such as walking, swimming, tai chi, gentle strength work or anything else that feels right for you.

4. Values-based goal setting

Meaningful goals are easier to stick with when they align with what truly matters to you. Consider what you want to be able to do and why it matters. For example:

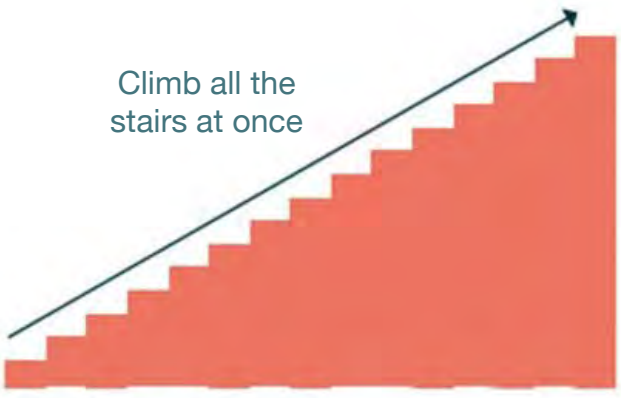
- I want to improve my walking distance so I can spend more time in nature.
- I want to build strength so I can comfortably hold my grandchild.
- I want to pace myself so I can enjoy full days out with friends.

Once you identify your “why,” you can break the goal into small, realistic steps, helping you get started and stay motivated.

Living well, one step at a time

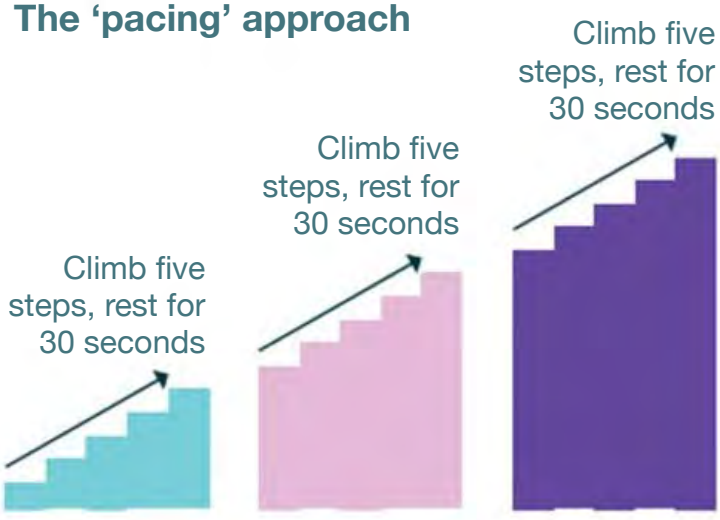
Managing a long-term condition like Paget’s can feel overwhelming but small lifestyle changes can create a meaningful shift in how you feel day to day. Whether it’s improving sleep, gently increasing activity or learning effective pacing, each strategy can strengthen your ability to live well.

The ‘big push’ approach



Result: You have to rest for 10 minutes at the top and feel achy and tired the next day.

The ‘pacing’ approach



Result: You don’t need a long rest at the top and don’t feel tired the next day.

Step up and earn a fitness medal

Our Fitness Challenge is back and your medal is waiting!

By committing to a personal fitness goal, you'll be working towards improved health and wellbeing while raising funds for the Paget's Association. Participants who complete their challenge will receive a Paget's Fitness Medal in recognition of their achievement. All donations support our vital work for those affected by Paget's disease.

How does it work?

The challenge is simple: go a little further than you normally would and make it count. We have achievement medals for people of any age or ability who can challenge themselves to go a little further than they normally would. You can walk, hike, run, swim, cycle, or, if you use a wheelchair, wheel your way towards your goal.

1. Set your fitness challenge

This is your challenge. You can choose the distance, the place and the time you will take to do it. It does not matter whether it is half a mile, five miles or a marathon. What matters is that you push yourself safely towards a goal that is a challenge for you and will improve your level of fitness.

2. Get sponsors

Once you have decided on your challenge, you need to find sponsors. The easiest way is to set up and share a fundraising page on an online sponsorship platform, such as JustGiving, where we are currently listed as The National Association for the Relief of Paget's Disease (use the link below or scan the QR code). Alternatively, contact us for a sponsorship form, collect cash and contact us for details of how to pay it in.

https://www.justgiving.com/narpd/donate

SCAN ME

3. Make it count

Ask your friends and family to sponsor your challenge to raise funds for the Paget's Association. They may even join you.

It doesn't matter if you have four sponsors or thirty, as long as you are improving your fitness and raising funds at the same time.

4. Celebrate and claim your medal

To enable us to send you your Paget's Fitness Medal, you will need to let us know the details of the challenge that you set, what you achieved and the amount of money raised (please see the amounts required for each medal detailed on the next page.). In addition, if you have photos, we would love to share them. Those of you who use an app to track your progress may wish to send us a screenshot of your achievement.

Get in touch to tell us what you've achieved:

Email membership@paget.org.uk

Telephone 0161 7994646

The Medals

Paying in the money you've raised

If you've used an online fundraising platform, the funds will be sent automatically to the charity. If you have cash to pay in, you can send it to us in one of the following ways:

- Use the donate section of our website and send us an email to let us know the funds are for your challenge.
- Arrange a bank transfer with us – contact us for details on 0161 7994646.
- Post a cheque made payable to 'The Paget's Association' to The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX.

A champion for patients

Professor Terence O'Neill, Director of the Salford Royal Paget's Association Centre of Excellence, has long been a champion for those living with Paget's disease. He took that commitment a step further by completing the Manchester Marathon and raising an impressive £500 for the Paget's Association.

First gold Fitness Medal of 2026

His fitness journey earned him not only the coveted Marathon Medal but also the first gold Paget's Fitness Medal of 2026, recognising the positive steps he has taken for his own wellbeing. We are immensely grateful for his commitment to patient care and for the support he provides to our charity.

A simple and free way to turn your shopping into donations

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

1. Sign up for free online

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

Visit **www.easyfundraising.org.uk**

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

2. Enable the Donation Reminder

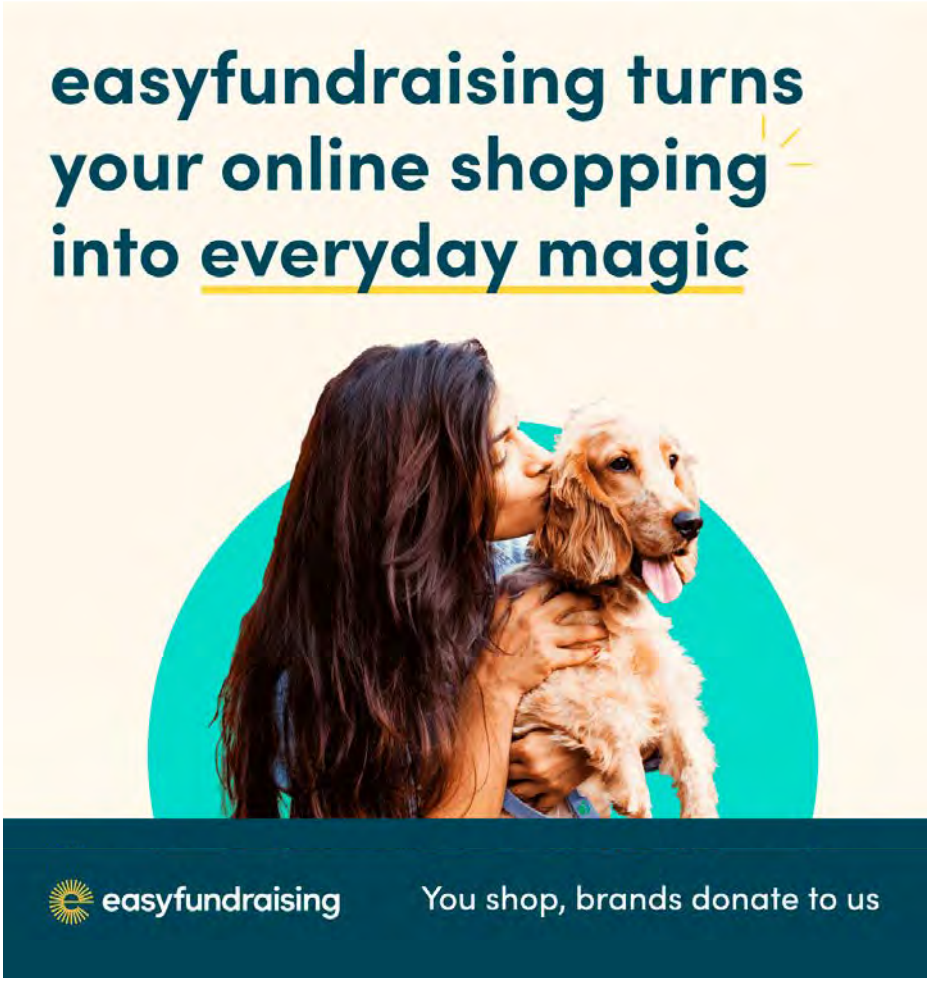
The Donation Reminder is a handy reminder that tells you when a donation is available while you're visiting your favourite brands. If you enable this, there's no need to visit easyfundraising each time you shop.

3. Shop as normal

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

4. Track your impact

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



Plan for the future

Talking about death is never easy, but planning ahead is one of the kindest gifts you can give to those you love. By sharing your wishes now, whether you would prefer burial or cremation, a traditional funeral or something simpler, or donations to a chosen charity instead of flowers, you can ease the burden on your family and friends at a difficult time. It is also sensible to think about costs, as even with a prepaid funeral plan, there may still be additional expenses, such as certificates.

Making a will is very important. It ensures your money, property and possessions are passed on exactly as you intend. Without a will, the law decides how your estate is distributed, which may not reflect your wishes. In some circumstances, if there are no surviving relatives, your estate could pass to the Crown.

Once you have provided for your loved ones, you may wish to consider leaving a gift in your will to a cause close to your heart. Legacies have been a valued source of support for the Paget's Association for many years. If you have already chosen to include a gift to the Association in your will, please accept our sincere thanks. By remembering the Paget's Association, you are doing more than leaving a donation; you are helping to create a brighter future for those affected by Paget's disease for generations to come. One day, it may even help us find a cure. Imagine a future where the challenges of Paget's disease no longer exist. Your generosity could help make that possible.

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.

Remember a charity in your will

A new chapter for our charity

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

What is a CIO?

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

Two charities

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

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

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

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

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

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

Paget's
Disease of Bone Association

New logo

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

Here's what you can expect

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

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

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.

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.

Newcastle Paget's information event

17 September 2026

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

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

Chair: Professor Stuart Ralston, Chair of the Paget's Association

Annual General Meeting

The National Association for the Relief of Paget's Disease

The Annual General Meeting (AGM) of The National Association for the Relief of Paget's Disease (also known as The Paget's Association) will take place on 17 September 2026 at 10.00 am, at The County Hotel, Neville Street, Newcastle upon Tyne, NE1 5DF. Please see the separate AGM papers sent with this magazine.

Use your vote

We encourage all members to take part, either in person or remotely via Zoom. To request the Zoom link, please email **membership@paget.org.uk**

If you are unable to attend, please remember to cast your vote. Full details can be found in the AGM information that has been sent to you. Non-members are welcome to attend but are not eligible to vote. Please contact our office if you have any queries.

We would like to thank all our contributors for their time, creativity and dedication in bringing this magazine to life, with special thanks to Mark & Anne Garforth (magazine design and proofreading).