Paget's Association

news

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

Paget's coffee morning a success!

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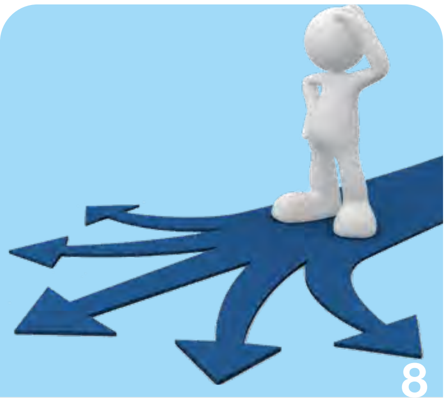

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Please consider attending the Association's

Annual General Meeting

virtually or in person, on

25 September 2025

(see separate AGM papers sent with this magazine)

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, and 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 the coffee morning that Trustee Kely Burnham held in May to support the ***PagetAlert*** fundraising campaign. Kely raised the magnificent sum of £510 which isn't a surprise when you turn to page 11 and look at the fabulous cakes that were provided. Thanks also to Belinda Ratnayake from Cornwall who raised £275 with her coffee morning in Cornwall. Well done both! Thanks also to the efforts of our runners in the London Marathon who raised over £8,400, and Professor Terry O'Neill from Salford Royal who raised £300 by completing the Manchester Half-Marathon. I repeated the 85-mile Caledonian Etape again but more details about that in the next issue of the magazine. So far, we have raised £21,404 against our target of £75,000 so please keep these fundraising efforts going!

Diana Wilkinson has a very interesting feature on page 6 about misdiagnosis of Paget's disease as a bone cancer. This is not an unusual occurrence which arises because many radiologists are not familiar with what Paget's disease looks like on things like MRI and CT scans. The Paget's Disease Clinical Guideline, which was published in 2019, emphasised the importance of radionuclide bone scans in diagnosis, and my experience is that this can usually point to the correct diagnosis and provide reassurance for everyone involved. Marion Burtenshaw's story on page 7 is typical but it's great to hear that the correct diagnosis was eventually reached and now her Paget's disease is under control.

The other feature on how to explain what Paget's disease is to a child on page 9 makes great reading. At the last information day in Leicester featured on pages 14-15, we were discussing how best to explain what Paget's involves to our grandchildren and Professor Rob Layfield came up with the idea of using artificial intelligence to come up with a poem. The Trustees all thought the results were impressive so we thought we would share it with you!

Our Leicester event was a great success and very well attended by people from across the West Midlands. Our next information event is going to be held in Bath on Thursday 25th September – so mark the date in your diary and come along if you can. As always, we have a great line-up of speakers and topics.

On the research front, we are highlighting two studies in progress which are being led by the Edinburgh PACE. One is on researching the effects of probiotics (healthy bacteria) in Paget's disease, the PRiP study (page 18), and the other is on detecting Paget's disease at an early stage in people who have a family history of the disease - the GAPDPD study (page 23). The PRiP study is for people with Paget's, whereas GAPDPD is for the grown-up children of people with the disease. Please make contact with the Edinburgh research team if you are interested in either. The Edinburgh team have set up study centres across the UK.

In closing, I wanted to draw your attention to our tribute to Bill Fraser on page 5. Bill was a friend and colleague for more than 40 years. He will be greatly missed by all of us at the Paget's Association, as well as the wider community in the field of bone disease.

With very best wishes to all.

Stuart Ralston

Chair, Paget's Association

Key dates and events

25 September 2025
Paget's information event in Bath

25 September 2025
AGM in Bath

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

The Paget's Association

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

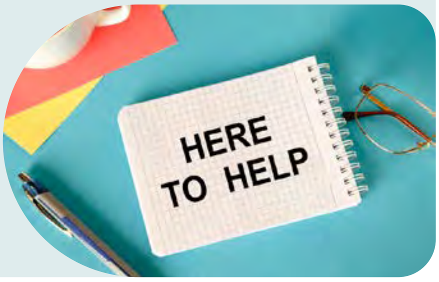
Paget's Nurse Helpline

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

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

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

Post please use the address below



Website and social media

Our website provides a wealth of information and resources.

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

www.paget.org.uk

Contact us

Email 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

A tribute to Professor William (Bill) Fraser

It is with deep sadness that we learned of the passing of Professor William (Bill) Fraser, a distinguished figure in the field of medicine and a cherished member of the Paget's community. He leaves behind a legacy of groundbreaking research and dedicated service.

Recently retired, Bill was a pioneering scientist, clinician and mentor to many. His contributions have left a lasting impact on the field and on all who had the privilege to work with him. He was known for his expertise in metabolic bone diseases, particularly Paget's disease and osteoporosis. He also co-founded Parathyroid UK.

Born and educated in Glasgow, Bill graduated from Glasgow University and trained in the city's teaching hospitals. His career took flight in Liverpool with his appointment in 1991 as Senior Lecturer in Chemical Pathology and Head of the Metabolic Bone Disease Unit at the Royal Liverpool University Hospital. He rose through the ranks to become Professor in 2001, and in 2008, he became head of the Unit of Clinical Chemistry and was then appointed Director of Masters in Research for Clinical Science. In 2010, he became Head of Musculoskeletal Biology.

After twenty successful years in Liverpool, Bill took up the role of Professor of Medicine at the University of East Anglia, later becoming Dean of Norwich Medical School. Bill earned international recognition for his pioneering work as a clinical biochemist. A highly active researcher, he championed pioneering studies into metabolic bone diseases, including Paget's disease. He also served as an Honorary Consultant at Norfolk and Norwich University Hospitals NHS Foundation Trust. His commitment to both advancing medical science and to patient care was evident to all who knew him.

The Norfolk and Norwich University Hospital NHS Foundation Trust, together with the University of East Anglia were, in 2015, awarded the Paget's Association Centre of Excellence, recognising their outstanding contributions to both research into Paget's disease and patient care. Bill was the Director of the centre and together with Co-director Professor Jeremy Turner, they took up the challenge to cycle for the Paget's Association in the RideLondon – Surrey 100-mile cycle event, raising funds and awareness of Paget's disease.

Bill was a Trustee of the Paget's Association from 2009 to 2018 and many members of the Association will remember him from the talks he gave at our patient information days. They were always interesting and his lecturing style made complex topics simple.

The team here at the Association remember him fondly. He was a fountain of knowledge and a great character who always had an amusing story and an insightful perspective. His passing leaves a profound void, yet his influence will continue to shape and inspire future generations. We extend our heartfelt condolences to his family and to all who had the privilege of knowing him. He will be deeply missed and fondly remembered.

Paget's disease and bone cancer: understanding misdiagnosis

I'm Diana Wilkinson, and you might speak with me if you call the Paget's Association's Nurse Helpline. I often talk to people who are first told they have bone cancer, only to learn later they have Paget's disease. Here I shed light on why this misdiagnosis can happen.

To be clear, while Paget's disease is not cancer, in rare cases, Paget's can develop into a type of primary bone cancer called osteosarcoma. However in this piece, I'm referring only to cases where individuals previously undiagnosed with Paget's disease, undergo imaging and are initially told they have bone cancer, only for further tests to reveal that they actually have Paget's disease instead.

Why do these misdiagnoses occur?

Bone pain and deformity in the affected bone are common symptoms of both Paget's disease and bone cancer. Making the correct diagnosis can be challenging when imaging, such as x-rays and scans sometimes show changes that resemble bone cancer or bone metastasis. Metastasis is the spread of cancer cells from the place where they first formed to another part of the body. Certain cancers are more likely to spread to the bones, including breast and prostate cancers.

The coexistence of Paget's disease and a malignancy can make it difficult to distinguish between the two conditions, especially when imaging studies show confusing findings. It's not surprising then, that if someone with breast cancer develops bone pain, a clinician's first thought might be bone metastasis. It should be a priority to confirm or rule this out. The key is to avoid being blindsided by this and to consider other possible diagnoses such as Paget's disease. A thorough clinical evaluation is crucial for accurate diagnosis. Careful evaluation using multiple imaging techniques and sometimes a bone biopsy may be necessary to rule out cancer and make an accurate diagnosis.

> *"The key is to avoid being blindsided... and to consider other possible disgnoses such as Paget's"*

In medical literature worldwide, there are documented cases of Paget's disease presenting in ways that mimic primary bone cancer or bone metastasis. Below and on the following page are brief summaries of two examples, accompanied by a personal account generously shared by a member of the Paget's Association.

Paget's of the humerus mimicking metastatic disease

In the journal Clinical Nuclear Medicine, a team from the Department of Radiology at the Memorial Sloan-Kettering Cancer Centre in New York reported the following case.

A 71-year-old man had been diagnosed with malignant mesothelioma, a rare and aggressive cancer that develops in the lining that covers the outer surface of some of the body's organs. It is most commonly linked to asbestos exposure. He was referred for Positron Emission Tomography (PET) and Computed Tomography (CT) scans to determine how far the disease had spread. The findings of the PET scan corresponded to mesothelioma. In addition, activity was detected in the upper bone of his left arm (humerus) raising suspicion of metastasis. The CT scan, however, showed thickening of the bone and a "Swiss cheese" appearance consistent with Paget's disease.

When evaluating skeletal lesions, especially for distinguishing benign Paget's disease from other bone conditions in cancer patients, the authors highlight the significance of fusion imaging. This combines data from multiple imaging modalities to enhance diagnostic precision. Each technique offers distinct advantages tailored to visualise specific tissues, organs or conditions effectively.

Paget's mistaken for metastasis in someone with cancer of the endometrium

The Acta Endocrinologica (Buc) is a medical journal from Bucharest, Romania. It focuses on the study of hormones and related disorders. A case was published of a 77-year-old woman with cancer in the lining of her uterus (endometrium). She was experiencing severe pelvic pain. An x-ray and CT scan showed abnormalities in her lower back bone (L5 vertebra), the base of her spine (sacrum), and part of her pelvis (ischium and pubis). Doctors initially diagnosed metastatic bone cancer.

A bone scan (scintigraphy) was performed, revealing the same areas suggestive of metastatic bone involvement. However, blood tests showed elevated levels of bone turnover markers prompting further investigation, as these findings could also be indicative of Paget's disease. It was important to be certain, therefore, a bone biopsy was performed. Microscopic examination of the bone tissue confirmed Paget's disease in her pelvis as it revealed a distinctive mosaic pattern of bone. In Paget's disease, this abnormal pattern replaces the normal parallel structure. Importantly, there were no signs indicating that endometrial cancer had spread to the bone.

References

Mahmood S, Martinez de Llano SR. (2008) Paget disease of the humerus mimicking metastatic disease in a patient with metastatic malignant mesothelioma on whole body F-18 FDG PET/CT. Clin Nucl Med. Jul;33(7):510-2. doi: 10.1097/RLU.0b013e318177928a.

Yalin GY, Dogansen SC, Canbaz B, Gul N, Bilgic B, Uzum AK. (2017) Incidental paget's disease disguised as bone metastasis in a patient with endometrium carcinoma. Acta Endocrinol (Buc). Jan-Mar;13(1):111-114. doi: 10.4183/aeb.2017.111.

> “I was so happy to finally get a diagnosis of Paget's disease in my spine”

Marion's bone cancer scare

Here, Marion Burtenshaw shares her relief after a cancer scare turned out to be Paget's Disease.

In 2019, I had a routine x-ray to identify the cause of chronic back pain. I was getting on in years and thought it was quite normal to have aches and pains, especially in the spine. You can imagine my shock when the radiology report stated that the degeneration in my T7 vertebrae could be lymphoma or cancer that had spread from another part of my body (metastasis)! I was sent for further CT imaging which also showed metastasis, possibly Paget's Disease, and was recommended further imaging plus a bone scan.

It wasn't until 2022, after two cancer diagnoses quite unrelated to my spine, that the imaging in my T7 vertebrae was finally identified as Paget's. I was very happy to finally get this diagnosis as I didn't have to go through a spinal biopsy! Since then, I have had three zoledronic acid infusions, which also treated my osteoporosis. So far, I am happy to report that my Paget's disease is in remission.

I am so grateful to the Paget's Association for being there for me during this very stressful time in my life. I live in Canada and my family doctor had never had a patient diagnosed with Paget's, but I have been able to access ongoing support through Zoom meetings and emails with the Association, for which I am very grateful!

Sincerely,

Marion Burtenshaw

The role of the Patient Advice and Liaison Service (PALS)

In the complex healthcare landscape, where questions and concerns often arise, some people find it helpful to talk to someone who understands the complaints process and get some guidance and support. The Patient Advice and Liaison Service (PALS) is a free, confidential and independent service found in many NHS hospitals. PALS provide a point of contact for patients, their families and their carers, offering advice, support and information on health-related matters, resolving concerns, and imparting crucial information about healthcare services.

Before you go to PALS, remember that many issues can be resolved quickly by speaking directly to the staff at the place where you received care.

How can PALS help?

PALS offers comprehensive support by answering health-related questions including those relating to NHS services and helping you take a more active role in your healthcare. Acting as a mediator, PALS assists in resolving issues, provides guidance on the NHS complaints procedure, and contributes to improving NHS services by listening to patient concerns and suggestions.

When you call your local PALS, you can speak with a PALS staff member, who'll try to help you resolve issues informally with the hospital without the need to make a complaint. They can be particularly helpful if your issue is urgent and you need action immediately.

Finding your nearest PALS

In England and Wales, to locate your nearest PALS, visit the NHS website and enter your town: **https://www.nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals**

Once you have located your nearest PALS website page you will have the option of telephoning them or completing a contact form. The 111 telephone service can also provide contact details for your nearest PALS office.

In Scotland, it is known as the Patient Advice and Support Service (PASS) and is delivered by the Citizens Advice network. You can call the PASS helpline on 0800 917 2127 or complete the contact form on their website: **https://pass-scotland.org.uk/**

In Northern Ireland, the equivalent of PALS is the Patient and Client Council (PCC). Telephone 0800 917 0222 or complete the contact form on their website: **https://pcc-ni.net/**

Explaining Paget's disease to a child

This gentle, child-friendly poem is written for grandparents, parents or caregivers who want to help a child understand Paget's disease. It uses characters Blast (the builder) and Clast (the clearer) as nicknames for the bone cells, osteoblasts and osteoclasts. It turns a complex medical condition into a simple explanation of how our bones normally stay strong and healthy, and then what happens when things get a little mixed up.

Busy bones

Deep inside your body, under your skin,
Lives a busy town where bones begin.
A town of tunnels, strong and bright
Where two bone builders work day and night.

Meet Clast, the chiseller, strong and loud,
He chips old bone away, feeling proud.
"I clear the way!" Clast likes to boast,
"I crunch up bone when it's needed most!"

Then there's Blast, so careful and neat,
She builds up bone from head to feet.
"I patch and paint," she says with cheer,
"To keep our skeleton strong all year!"

Clast and Blast make quite the pair,
Fixing bones with love and care.
Old bone out, new bone in
That's how healthy bones begin!

But one day, Clast got far too keen.
He started chomping like a bone machine!
"I'm helping!" he cried, not seeing the mess
The bone town now was under stress!

Blast tried hard to fix each crack,
But Clast was zooming forth and back.
He worked too fast, she couldn't keep pace
The new bone looked a little out of place.

"Clast, slow down!" said Blast with care,
"This isn't how we should repair.
The bone is bumpy, thick and odd
We need to tell the Brain in charge!"

The Brain sent help to lend a hand,
To understand and make a plan.
"This looks like Paget's disease," they said,
"A bone disorder in the legs or head."

"Don't worry," said the doctor kind,
"With care and checks, solutions we'll find.
Medicines can help slow Clast down,
So bone stays strong from toe to crown."

Now Clast still chips, and Blast still builds,
But they've learned to work with greater skills.
Together they keep the bones just right
Strong and sturdy, day and night.

This poem was created in whole or in part using GenAI. It is for entertainment purposes only. It may contain errors or inaccuracies and please note that AI-generated content may not always reflect the most current standards or accurate information.

The Big Spring Coffee Morning

We want to say a big thank you to those who supported our Big Spring Coffee Morning on 10 May. From hosting an event to baking cakes and making donations, your wonderful efforts brought people together and raised awareness of Paget's disease whilst raising vital funds for the Association.

Every coffee shared and every penny raised helps us continue offering support, information, and hope to those who need it most. Thank you for making a real difference — we couldn't do it without you!

£275

A special shout-out to member *Belinda Ratnayake* who raised a fabulous £275 with her coffee morning in Cornwall. *Well done!*

Kely's Coffee Morning

Trustee Kely Burman's coffee morning in Essex was a great success. She welcomed 31 ladies, all eager to learn more about Paget's disease. Guests asked thoughtful questions about the condition and Kely was able to offer insight and support. As Kely said, "If the coffee morning helped one person, it was worth it!" and we couldn't agree more. We're delighted to share that Kely's event raised an incredible £510, with even more to come through via Gift Aid!

Kely's coffee morning was a wonderful opportunity to raise awareness about Paget's disease, while enjoying the sunshine, delicious treats, and great company.

Connect with experts in Bath

Thursday
25 September 2025

Paget's
Information Event

Bailbrook House

10:45 am – 3:30 pm

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

Join us

Our next event takes place on **Thursday 25 September 2025**, at Bailbrook House, Bath BA1 7JD. Dr Sarah Hardcastle from The Royal National Hospital for Rheumatic Diseases, a Paget's Association Centre of Excellence, is hosting the event. Please see the next page for details of the planned speakers.

What to expect

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

Complimentary lunch and refreshments

Lunch and refreshments are provided free of charge.

Booking essential

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

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

Bath Paget's Information Event

Thursday 25 September 2025

11:15 am – 3:30 pm

Registration and refreshments will be available from 10:45 am

at Bailbrook House (Newbridge Room), Eveleigh Avenue, London Road W, Bath, BA1 7JD

In collaboration with The Royal National Hospital for Rheumatic Diseases (RNHRD), a Paget's Association Centre of Excellence

Welcome	**Chair: Prof Stuart Ralston** Chair, Paget's Association Rheumatologist & Researcher, Edinburgh
What is Paget's disease?	**Dr Sarah Hardcastle** Consultant Rheumatologist, RNHRD
Diagnosis and monitoring	**Dr Tehseen Ahmed** Consultant Rheumatologist, RNHRD
Imaging in Paget's disease	**Dr Sian Davies** Consultant Musculoskeletal Radiologist, Royal United Hospital, Bath
The role of the Paget's Association & *PagetAlert*	**Mrs Diana Wilkinson** Specialist Nurse & Director of Educational Resources, Paget's Association
Lunch	
Genetic testing and research	**Prof Stuart Ralston**
Medications for Paget's disease	**Dr Sarah Hardcastle**
Surgical treatment / joint replacement	**Mr Nav Makaram** Orthopaedic Registrar, Edinburgh Orthopaedics & Clinical Research Fellow, University of Edinburgh
Living well with a long-term condition	**Ms Sarah Legg** Senior Rheumatology Physiotherapist, RNHRD
A final opportunity for questions	**Prof Stuart Ralston**

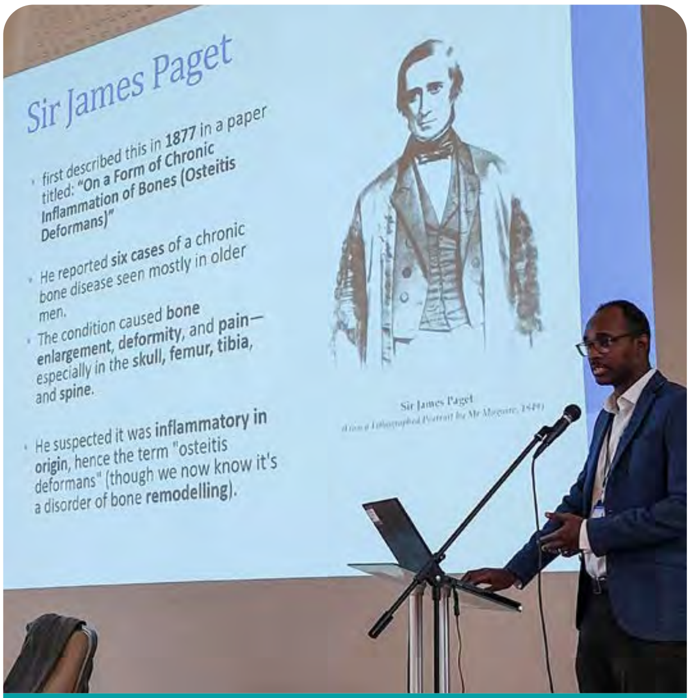
Whilst this agenda has been confirmed, timings and speakers may be subject to change.

Annual General Meeting (AGM)

All are welcome to attend the Paget's Association's AGM which precedes this event at 10:00 am. However, only members are eligible to vote.

Our event in Leicester

Thank you to everyone who attended our Paget's information event in Leicester. We were delighted to welcome such an engaged audience. Many important questions were asked and answered, sparking valuable conversations. Your participation made the event a real success and we look forward to welcoming you to future events.



Sir James Paget

- first described this in **1877** in a paper titled: **"On a Form of Chronic Inflammation of Bones (Osteitis Deformans)"**
- He reported **six cases** of a chronic bone disease seen mostly in older men.
- The condition caused **bone enlargement, deformity,** and **pain**—especially in the **skull, femur, tibia,** and **spine.**
- He suspected it was **inflammatory in origin,** hence the term "osteitis deformans" (though we now know it's a disorder of bone **remodelling**).

Sir James Paget

Dr Mohamed Saeed explained Paget's disease and how it got its name

Causes of pain in Paget's disease

Related to Paget's
- Increased 'Metabolic Activity'
  - Raised ALP
  - Responds to Bisphosphonate
- Deformed bones
- Osteoarthritis
- Fractures
- Spinal Stenosis
- Nerve Compression

Dr Faiz Rahman looked at the causes of pain and the treatment of Paget's

Bone formation
P1NP
Increase
Measure of osteoblast bone formation

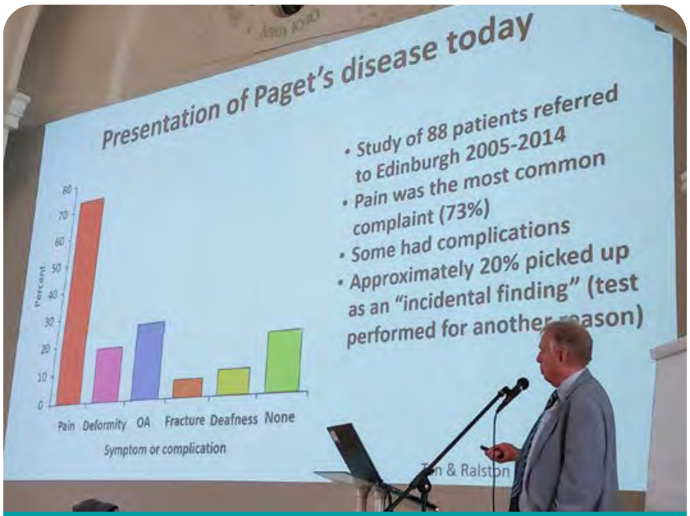
BONE ANATOMY

Bone resorption
Serum CTx
Measure of osteoclast bone resorption
Increase

Dr Peter Prinsloo discussed how the condition is diagnosed and monitored

> *"The knowledge of the professionals gave me a fantastic and interesting insight into Paget's"*

(Left to right) Speakers: Dr Peter Prinsloo, Dr Faiz Rahman, Dr Mohamed Saeed, Prof Rob Layfield and Prof Stuart Ralston



Presentation of Paget's disease today

- Study of 88 patients referred to Edinburgh 2005-2014
- Pain was the most common complaint (73%)
- Some had complications
- Approximately 20% picked up as an "incidental finding" (test performed for another reason)

Prof Stuart Ralston chaired the event and considered how Paget's presents itself today, how research is making a difference and the potential for genetic testing

3. Understanding Causes of Paget's Disease

Website: www.paget.org.uk

Research into historical Paget's disease suggests what some of the **environmental triggers** might be …as well as help raise public awareness

Research funded into ancient Paget's

BONE DETECTIVES COMES TO NORTON PRIORY MUSEUM & GARDENS

Prof Rob Layfield gave an update on research supported by the Paget's Association

Attendees with Diana Wilkinson, Specialist Nurse, (centre) Paget's Association

> *"The event highlighted the support available for Paget's patients"*

Feedback

Thank you to everyone who took the time to provide feedback. Here's a snapshot of what was shared.

> *"Really appreciate the day and the benefit of being a member. Very informative. Thank you"*

> *"Very well organised and informative. Only slight negative is not much reference to Paget's of the skull"*

> *"Able to ask direct questions and put mind at rest"*

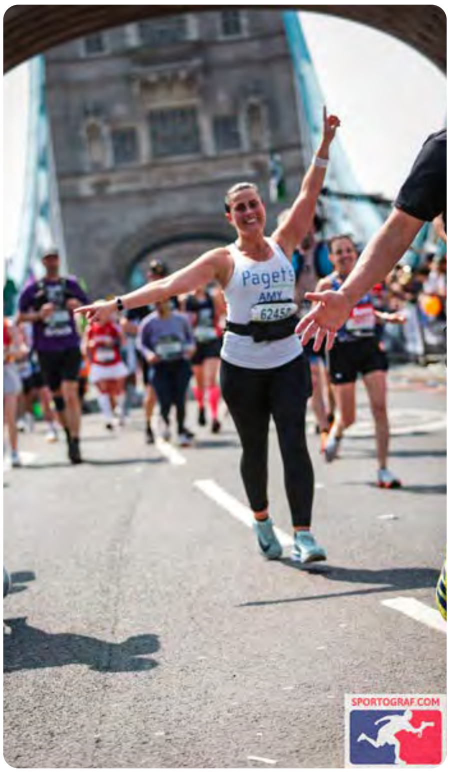
> *"Very enjoyable day. Catering was very good and plentiful"*

> *"Thank you to the Association for holding this amazing conference. I was previously unaware of many aspects of the disease that have now been wonderfully explained"*

London Marathon breaks the Guinness World Record

The 2025 TCS London Marathon made history by breaking the Guinness World Record for the most finishers in a marathon! With an incredible 56,640 participants crossing the iconic Finish Line on The Mall, each of our runners contributed to this remarkable achievement.

We extend our deepest gratitude to Holly, Matt, Chris, Ben and Amy, who not only completed the 26.2 miles but also raised over £8,400 (plus Gift Aid) and raised awareness of Paget's disease. Your dedication, commitment, and resilience are truly inspiring!



How to apply

As we celebrate this milestone, we invite you to visit our website to learn more about future marathons and apply for a place.

> *It was an honour to run for your charity. I thank everyone for the kind words of encouragement and support!*
>
> **Amy Hackett**

NEW! Run for us in the Manchester Marathon!

We're thrilled to announce that the Paget's Association has places in the Manchester Marathon! Know someone up for the challenge? Fancy running yourself? Every step and every pound raised makes a real difference. 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.

£300 raised!

Professor Terence O'Neill, from Salford Royal, a Paget's Association Centre of Excellence, successfully completed the Manchester Half Marathon on 18 May, raising £300 to support the work of the Association.

Cycling for Paget's

Thank you to everyone who supported our Chair, Stuart Ralston, in the 85-mile Caledonian Etape. Stay tuned – we'll share photos and full details in our next magazine!

Photo: Professor Ralston approaching the finish line after 85 miles. Time on the clock 6 hours 24 minutes, with 1463 meters of ascent!

PRiP

Probiotics in Paget's Disease

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

If you are:

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

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

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

V1 12/01/2024

igc INSTITUTE OF GENETICS & CANCER

UKRI Medical Research Council

THE UNIVERSITY of EDINBURGH

CANCER RESEARCH UK

Remembering Mary

I'm your little worry
worm. Keep me near
and squeeze me tight
Tell me your worries
and everything will be
alright.

We were very sorry to hear of the passing of Mary Curliss, a warm and creative lady who lived with Paget's disease and was a valued member of the Manchester Paget's Support Group. She also worked with the Association for a short time, during which her excellent shorthand skills came in very useful. She will be remembered with affection by all who knew her. Diana our Specialist Nurse said, "Mary was lovely and following the closure of the support group, I enjoyed exchanging emails with her and hearing about her latest craft projects. I especially remember her crocheting little worry worms after she met a lady in hospital who made them for people with autism, such a thoughtful gesture."

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1. Either scan the QR code on this page or visit **www.easyfundraising.org.uk**
2. Sign up and search for Paget's Association
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Your questions answered

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

Q What exactly is Paget's Disease of Bone?

A Paget's disease is a chronic disorder that disrupts the normal process of bone remodelling. In healthy bones, old bone tissue is broken down and replaced by new tissue at a balanced rate. In Paget's disease, this cycle goes awry, resulting in bones that are enlarged, misshapen, and more prone to fractures.

Q What problems can arise from enlarged and misshapen bone in Paget's?

A Enlarged and misshapen bones can alter physical appearance, such as a visibly enlarged thigh or weight-bearing bones may become bowed. This structural change may place added stress on joints and muscles, potentially leading to discomfort and mobility issues. Additionally, bone expansion can compress nearby nerves, causing pain, tingling or numbness. This is particularly concerning when the spine or skull is affected, as nerve compression in these areas can result in more serious complications.

Q Does Paget's disease affect blood vessels?

A In areas of Paget's disease, newly formed bone often has an increased number of blood vessels compared to normal bone. These blood vessels play a crucial role in supplying nutrients and supporting the heightened activity of bone cells observed in the disease. Those with Paget's may notice warmth coming from the area, particularly in bones such as the shin. Research continues to explore the dynamic relationship between bone formation and vascular development in Paget's disease.

Do you have a question?

Contact the Paget's Nurse Helpline

Email: helpline@paget.org.uk

Telephone: 0161 799 4646

Thanks for joining our virtual Q&A

Thank you to everyone who attended the virtual Q&A with Professor Ralston in June. These sessions can be announced at short notice, so keep an eye on our website or sign up for email updates to make sure you don't miss the next one!

Paget’s circle of support

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

Paget’s Association

– expertise, care, and connection

Paget’s Nurse Helpline

Information, support and answers via email or phone

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

Telephone: **0161 799 4646**

Mobile: **07713 568197**

Information events

Face-to-face opportunities to learn and share

Join us in Bath in September

Video library

Learn from experts and those affected

Available on our website and YouTube **@PagetsAssociation**

Buddy network

Let us connect you directly with others affected by Paget’s disease

Booklets

Trusted information on many aspects of Paget’s – available on our website and from our office

Virtual support groups

Virtual discussions and support in groups, facilitated by our Specialist Nurse

Social media and Facebook support group

Find support and share experiences

Declutter and donate

Members Janet and Graham Dixon from Lincolnshire sold unwanted items, most of which were kindly donated by family, friends and neighbours, and generously donated the proceeds of £580 to the Paget’s Association. Janet, as a former employee of Barclays Bank, utilised their generous Match Funding scheme to double the impact of their donation, resulting in a total contribution of an amazing £1,160! Thank you both so much for your efforts.

Thanks, Janet and Graham!

£580 raised and doubled to £1,160 with Match Funding!

Could your clutter help our cause? Have a clear-out, sell your unwanted items, and donate the proceeds to help change lives.

The Annual General Meeting (AGM) of the Paget’s Association (also known as The National Association for the Relief of Paget’s Disease) will take place on Thursday 25 September 2025, at 10:00 am and will be held at Bailbrook House, Eveleigh Avenue, London Road W, Bath, BA1 7JD.

We encourage all members to participate either in person or remotely via Zoom (please email membership@paget.org.uk to request the link). If you are unable to attend, don’t forget to use your vote! Please refer to the enclosed AGM information included with this magazine for further details. If you are not a member, you can still attend but cannot vote.

Thank you for your continued support.

GAPDPD study

Do you have Paget's Disease of Bone? We need your relative's help!

Paget's Disease of Bone (PDB) can run in families. For those who don't have the condition but have a relative who does, there is an opportunity to participate in an innovative 5-year research study to screen for their likelihood of developing PDB in the future.

Study aims

- Develop genetic and epigenetic markers to predict PDB risk in people with family history of PDB
- Screen for early Paget's disease using radionuclide bone scans
- Analyse samples for biomarkers of PDB

Who can take part?

- Anyone who has a parent, offspring or sibling who has been diagnosed with PDB
- Not already been diagnosed with PDB themselves
- Be over 45 years old currently

What will your relative need to do?

Attend three in-person clinic visits over 5 years. Each visit takes about 1-3 hours that will include:

- Getting a special bone scan called a "radionuclide bone scan" at the first and last visits
- Filling out questionnaires about their health, diet, and quality of life
- Providing blood samples, as well as stool and saliva samples to analyse your genes and gut bacteria

Benefits

- Monitoring for Paget's disease signs and symptoms
- Contribute to developing Paget's disease research goals

What to do next?

If you have a relative who may be interested in this research opportunity, please ask the doctor you see for an informational leaflet to pass on to them. Additional information can be found on the study website at GAPDPD.co.uk or via the QR code below

GAPDPD Study website

igc
INSTITUTE OF GENETICS & CANCER

UKRI Medical Research Council

THE UNIVERSITY of EDINBURGH

CANCER RESEARCH UK

Genetic Analysis to Predict the Development of Paget's Disease

Your legacy can make amazing things happen

When you include the Paget's Association in your will, you're not just donating – you're believing in a brighter future. Your gift, big or small, will help us get closer to better treatments, more answers and maybe even a cure for Paget's disease. Imagine a world free from the challenges it brings. Your legacy could make it happen!

Thank you

Legacies have for many years been a crucial source of funding for the Paget's Association. If you have already included a gift to the Paget's Association in your will, we extend our heartfelt thanks. Your generosity plays a crucial role in ensuring the long-term sustainability of our charity.

How to leave a gift in your will

Select individuals, organisations, and/or charities you wish to include in your will. Typically, beneficiaries include family members, friends and charities that you wish to benefit from your legacy.

Estimate the potential value of your estate

Estimate the potential value of your estate by accounting for all your assets, including property, cash, bank and savings accounts, and personal belongings.

Inheritance Tax

Bear in mind that, in some cases, inheritance tax may apply. The standard Inheritance Tax rate is 40%; however, if you leave at least 10% of your net estate to charity, you may qualify to pay inheritance tax at a reduced rate of 36%. For detailed guidance, please refer to the Government website: **www.gov.uk/inheritance-tax**

Decide on the types of gifts you wish to leave

There are several options available. A residuary gift is the portion of your estate that remains after all debts, taxes and other bequests have been settled. A pecuniary gift refers to a precise sum of money, while a specific gift involves a particular item or collection of items you wish to leave.

Select your executors

It is important to select your executors carefully, as they are responsible for carrying out the instructions in your will. Many people appoint loved ones as executors and it is good practice to appoint more than one executor (up to a maximum of four) to ensure timely responses. Alternatively, you can choose a professional executor, such as a solicitor. If desired, your loved ones can also appoint a professional executor at a later stage.

Consult a professional

When drafting a will it's advisable to consult a professional who will ensure it is valid and properly signed and witnessed.

Let us know

Gifts left in wills make up most of the Paget's Association's income. If you have left a gift to the Paget's Association, we would love to thank you so do let us know. It's down to your generosity that we can continue our vital work.

Keep your will safe

Professional executors may offer to store your will. You should retain a copy in a place that is easy to find. You may wish to give a copy to the named executors or make them aware of where the will is kept.

Ensure your will is kept up to date

If you need to update your will, simple changes can be carried out by the addition of a codicil. More complex changes will require a new will. If you make a new will, ensure your old will is destroyed.

Sally was thrilled to win £100

Sally Roberts from Stratford-Upon-Avon recently won £100 in the Paget's Association's Raffle. She said, "I was absolutely thrilled to win £100 in the raffle. It was such a surprise. It really lifted my spirits as I was convalescing from a hip replacement".

Help us reach our goal

We're on a mission to sell 200 tickets for this monthly Raffle and we need your help to make it happen!

This isn't your typical lottery. With only 200 tickets sold, your odds of winning are better than a lot of other raffles and lotteries. The best bit is that every ticket sold helps raise vital funds for our work. You can get your friends and family involved too. The more support we have, the greater the impact we can make together.

How it works

Tickets are just £5 per month with monthly cash prizes: £100 for 1st place, £50 for 2nd. There are bonus draws in June and December when prizes are doubled (£200 for 1st, £100 for 2nd).

Anyone aged 18 or over can enter and you do not need to be a member of the Paget's Association. Whether you choose one ticket or two, every entry brings us closer to our fundraising target and supports those affected by Paget's disease.

Joining is easy!

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

☆☆☆☆☆☆☆ Winners ☆☆☆☆☆☆☆

☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

FEBRUARY 2025	MARCH 2025	APRIL 2025	MAY 2025
1st Prize £100 Ticket no. 15 *M Sabberton* *Suffolk*	**1st Prize £100** Ticket no. 32 *S Roberts* *West Midlands*	**1st Prize £100** Ticket no. 12 *P Wood* *Stirlingshire*	**1st Prize £100** Ticket no. 171 *J Dyer* *Suffolk*
2nd Prize £50 Ticket no. 100 *J Moatt* *South Wales*	**2nd Prize £50** Ticket no. 152 *H Pick* *East Yorkshire*	**2nd Prize £50** Ticket no. 35 *B Ratnayake* *Cornwall*	**2nd Prize £50** Ticket no. 141 *T Holder* *Leicester*

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Anyone over 18 can take part

Marking special days

A heartfelt thank you to everyone who has chosen to honour the memory of a loved one by donating to the Paget's Association on birthdays, anniversaries or other special occasions. Your thoughtful generosity makes a real difference. We are truly grateful for your support.

International Paget's Awareness Day

Each year, on 11 January, we mark Paget's Awareness Day to raise awareness of the condition, increase understanding, and highlight the support available to those affected. Visit our website to learn more about Paget's Awareness Day and to watch video interviews from previous events, featuring experts and individuals affected by Paget's.

Membership of the Paget's Association

Not a member yet? Join the Paget's Association today and gain access to a supportive community committed to helping you navigate Paget's disease. With your membership, you'll receive a comprehensive Paget's Information Pack filled with essential resources to guide you every step of the way. Join easily online on our website.

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.

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.

Shortening the pain journey

Paget*Alert*

Shortening the pain journey
in Paget's Disease

Our ***'PagetAlert'*** Campaign is well underway to raise funds that will help us to promote earlier diagnosis of Paget's disease, especially for those who experience bone pain before being diagnosed. This vital initiative is about shortening the pain journey and improving lives. Tackling delays in diagnosis can avoid years of pain. By encouraging early detection and sharing the latest clinical guidance and resources, we're working to ensure a brighter future for those affected by Paget's disease, for now, and for generations to come.

With your help, we can reach our target

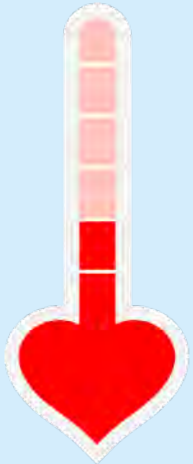
Every pound you donate will go directly towards our ambitious fundraising target of £75,000. As a charity that relies entirely on donations, fundraising and legacies, we truly can't do this without you. Every donation, big or small, brings us closer to our target.

Thank you

We extend our heartfelt thanks to everyone who has donated to our ***PagetAlert*** Campaign so far. Your kindness and support mean the world to us and to the many people who will benefit from our vital work.

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

TARGET £75,000



RAISED SO FAR
£21,404

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**.

Could you connect us with a business that could help?

Perhaps you could introduce us to a business, company or individual who might be interested in supporting our work? Whether it's sponsorship, a one-off donation or offering resources, every act of generosity helps move us closer to our goal.

Planning a fundraiser?

If you're organising a fundraising event, you can request a free fundraising pack and we will help in any way we can.