

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



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Plus, a chance to put your queries to our Professor Ralston on 10 January 2025



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Chair's message

Dear members and supporters

Welcome to the November 2024 edition of *Paget's News*. As always, the magazine is packed with features about Paget's disease and its diagnosis, research that is being performed into the disease from across the world, and our fundraising efforts. We are particularly excited to announce the launch of our new campaign – **PagetAlert** – as featured on page 14. The focus of this campaign is to drive earlier diagnosis of Paget's disease. We know that too many people are suffering symptoms, particularly bone pain, for too long before being diagnosed and given treatment to alleviate those symptoms. Of course, detection of the condition at an early stage can also reduce or even prevent development of complications. Earlier diagnosis will be the theme of Paget's Awareness Day on 11 January 2025. The Association is also running a Q&A session which I will be hosting on Friday 10 January between 5 pm and 6 pm UK time. If you have any questions about Paget's disease you want answered, whether they are to do with early diagnosis or other aspects of the disease, please register for the session through our website.

For **PagetAlert**, we have set ourselves an ambitious target of raising £75,000 and we hope you will support this campaign. My thanks to those of you who have already contributed by completing our survey around bone pain and diagnosis. The results of the survey were very interesting and will be highlighted in the next magazine.

Part of **PagetAlert** will be to provide updated guidelines to



clinicians to improve diagnosis and management of Paget's disease. In addition, we want to promote the availability of free genetic testing for susceptibility to Paget's disease on the NHS. Also, as regards early diagnosis, we want to continue to develop genetic markers that can be used to predict development of the condition through the GAPDPD study. If you have Paget's disease and you think that any family members would like to participate in the study, please visit gapdpd.co.uk. The study is running throughout 2025 in several hospitals across the UK and is open to anyone aged 45 and above who has a relative with Paget's.

Visit the GAPDPD website



Turning to the other features in the magazine, I really liked the community engagement event held at Nottingham University aimed at primary school-aged children. The event looked at the importance of bone health in general and explained what goes wrong with

the skeleton in people affected with Paget's disease as well as other bone diseases. Well done to all involved at the *IntoUniversity* team! This is followed by a very informative article on pages 5-7 on the resources that are available within the UK for people with disabilities. Details of the Priority Services Register, the Vulnerability Registration Service (VRS) and Community Equipment loans are all provided along with a link to the VRS website. Although these resources are not specifically for people with Paget's disease, we know that many people affected by the condition can experience reduced mobility and pain that can impact on their ability to perform daily tasks. Please check to see if any of these resources would be valuable to you.

We then have a nice feature about the Middlesbrough information event held in September of this year. Congratulations to Dr Stephen Tuck and his team and thanks to all those who attended. We also have minutes of the AGM which was held in Middlesbrough at the back of the magazine. We were very pleased with the number of delegates and the positive feedback from Middlesbrough. We are looking forward to holding similar events in the East Midlands in May 2025 and Bath in September 2025. I hope you can join us! More details will follow in future editions of the magazine.

We always like to keep our readers informed about developments in research into Paget's disease. One of the puzzling things about the condition is that it has become less common and less severe over recent decades. Many reasons

continued overleaf

have been suggested but we still don't really know why this has occurred. On pages 10-12 we feature a paper by Professor Tim Cundy, a Paget's researcher from New Zealand. He has put forward the idea that it might be because coal-burning fires are much less common now compared with previous decades. There was some evidence to support this from studies in Quebec, Canada where an association was found between wood-burning stoves and Paget's disease. At present it is speculative but interesting, nonetheless. As Professor Cundy says the hypothesis could stimulate research into the biology of the disease. Also on the research front, we feature case reports from Pakistan and Morocco on pages 16-17. Paget's disease is rare in both countries so well done to the researchers for picking these patients up and giving them treatment.

We also highlight the availability of a booklet on orthopaedic surgery in Paget's disease which we hope will be informative to those who might require an operation to replace an affected joint or fix a broken bone. The booklet can be downloaded free from the Association's website.

On behalf of all at the Association, I would like to extend my best wishes for Christmas and the New Year when it comes, and I very much hope to meet with many of you at our information events in May and September 2025.

Stay safe and keep well!

Stuart Ralston
Chair, Paget's Association

The Paget's Association



What is Paget's Disease of Bone?

Throughout life, normal bone is renewed and repaired through a process called bone remodelling. In Paget's disease, this is accelerated and disorganised, leading to the formation of bone that has an abnormal structure.

Paget's disease may affect only one bone or several, and the affected bone is often enlarged and misshapen. It can be painful and complications, such as fractures, can occur.

Paget's Nurse Helpline

The Helpline is available to anyone who requires information, support or has questions regarding Paget's disease.

Email
helpline@paget.org.uk

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

Post
Please use the address in the next column.

International Paget's Awareness Day

Annually on **11 January** we mark International Paget's Disease Awareness Day!



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.

Membership

Members of the Paget's Association receive a comprehensive Paget's Information Pack and regular editions of this Paget's News magazine.

Contact us

Feel free to reach out; the team at the Paget's Association would be delighted to hear from you!

Telephone For all enquiries
telephone: 0161 799 4646

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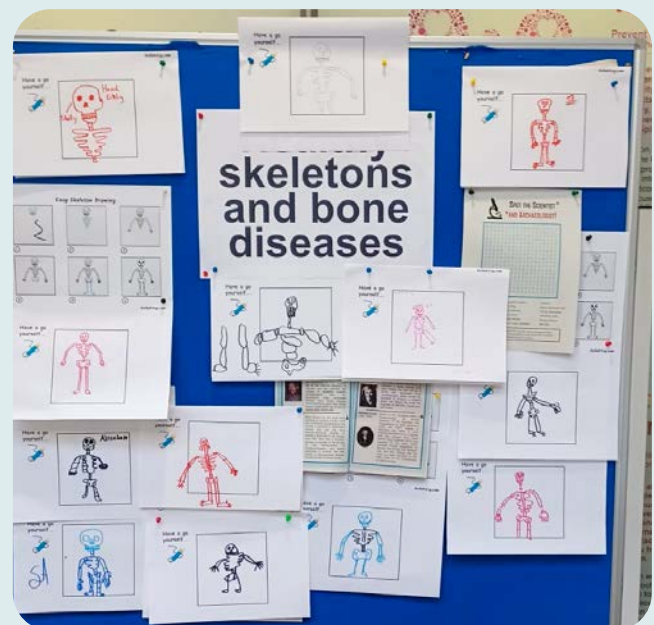


Family event teaches children about bone diseases



Educational resources developed with support from the Paget's Association featured in a family community engagement outreach event at the University of Nottingham on 3 July 2024. In collaboration with the University's charity partner, **IntoUniversity**, the event was part of a wider programme aimed at primary-aged children and their families who attend **IntoUniversity** learning centres in inner-city Nottingham. More than 120 children and their families attended the event and took part in hands-on activities related to healthy bones and bone diseases, including Paget's disease.

IntoUniversity 



Support when times are challenging

During challenging times when you may be vulnerable, whether due to health, age or sudden changes in circumstances, access to the right support is crucial. In some, Paget's disease can significantly affect daily activities by reducing mobility, causing pain and inducing fatigue, all of which can make tasks like walking, dressing or bathing difficult. Community Equipment Loans offer essential aids to help individuals maintain their independence at home and enhance quality of life during difficult times. In addition, services like the Priority Services Register (PSR) and the Vulnerability Registration Service (VRS) provide vital assistance when it's needed most. We have summarised these services below. For those outside the UK, it may be helpful to seek similar services in your area.

Priority Services Register

The Priority Services Register (PSR) is a free service provided by energy suppliers to support vulnerable individuals, such as the elderly, disabled, and those with specific health conditions. Initiated by Ofgem to ensure vulnerable people receive extra help, the PSR is not widely known, and registering can be challenging as many energy providers do not make the process clear.

Each energy supplier maintains its own PSR, so customers need to register separately with each provider and re-register if they switch. Benefits of registering include advance notice of power cuts, and priority support in emergencies.



Vulnerability Registration Service

Any of us at any time in our lives can have periods when, for whatever reason, we may be vulnerable because of an unexpected event such as an illness or change in circumstances. The Vulnerability Registration Service (VRS) supports individuals facing financial challenges or life events that make them vulnerable.

The VRS allows users to register their financial situation, enabling them to avoid repeatedly explaining their circumstances to multiple companies by simply sharing their VRS reference number. This helps them receive tailored support from companies that can adjust their communication and debt collection

practices to ensure fair treatment. Additionally, users can access specialist resources, such as charities and debt advice agencies that cater specifically to their needs. Strict checks are in place to ensure that companies using the service do so responsibly and in the best interest of those registered.

Providing a single reference point for companies to be aware of and consider someone's situation, the VRS helps ensure people are treated with sensitivity during vulnerable times. The service is free and allows users to record their circumstances at a given point in time when they are looking to protect themselves against further debt or where their well-being may not allow them to make reasonable decisions. The VRS also allows people to register on behalf of others if they have legal authority such as a Power of Attorney.

To join the VRS, users can sign up on the website and registration ensures that those in vulnerable situations receive the appropriate support and protection they need.

VRS website details



www.vulnerabilityregistration.service.co.uk

Community equipment loans

If you are finding tasks around the home difficult, Community Equipment Loans can help manage everyday tasks such as bathing, dressing, and cooking. A range of equipment can often be provided, free of charge, to help you live independently and reduce the need to go into hospital or a care home. It can also be provided when you return home after a stay in hospital. You may need equipment for a short while or long term. Either way, don't be afraid to find out if there is equipment available to you that could make life easier!

Local authorities have a duty under the Care Act 2014 to provide community equipment (aids and minor adaptations costing less than £1,000) free of charge to those who cannot complete two or more daily living activities, which are basic tasks that people do every day to maintain independence and care for themselves. This is not means tested. In addition, local authorities also have a duty to meet the needs



of people living with disabilities, through a means-tested Disabled Facilities Grant (DFG). Those who need an adaptation over the value of £1,000 such as ramps or wet rooms, can apply for a DFG. Despite strong evidence of the positive impact of equipment and adaptations, in 2019 a survey carried out by Versus Arthritis found that many people who need support did not access it. Only 16% of those surveyed were getting equipment and adaptations from their local authority. They found that 52% of those with eligible care needs had purchased items themselves despite being eligible for free equipment.

Access to community equipment typically begins with a free assessment carried out by a healthcare professional, such as an occupational therapist or a social worker. They will evaluate your specific needs and recommend appropriate equipment. Once identified, the equipment is loaned to you free of charge, for as long as it's needed. To access this support, contact your local council's adult social care team, GP or a local community equipment service. They will guide you through the assessment process and ensure that you receive the necessary equipment tailored to your needs.

Examples of community equipment loans

General

- Walking frame
- Grab rail

Kitchen

- Bottle, jar and tin openers
- Utensils with long, weighted or curved grips

Bedroom

- Button hookers and zip pullers
- Aids to help you put on socks
- Long-handled shoehorns

Bathroom

- Bath seat or bath lift
- Shower seat
- Raised toilet seat
- Rails
- Taps that are easy to turn

Thank you for joining us



Thank you to all those who came to our Paget's Information Events in Cambridge and Middlesbrough. We know from your feedback that those who attended feel better informed about Paget's disease and better prepared to discuss the condition with their healthcare professionals.

The dates of next year's events are below. Further details will be in the next edition of Paget's News and on our website as soon as the information is available.

Save the date!

Paget's information events 2025

East Midlands
Thursday
29 May 2025

.....
Bailbrook House
Bath BA1 7JD
Thursday
25 September 2025

A Paget's information event tailored for patients and families is scheduled to take place in the East Midlands, likely in the Leicester area. Additionally, another event is planned in Somerset, potentially near Bath.



Chair of the Association, Professor Stuart Ralston discussing pain in Paget's disease at our Paget's information event in Cambridge



Rheumatologist Dr Stephen Tuck introduced Pathologist Dr Harish Datta who discussed diagnosis and monitoring at the Middlesbrough event



Happy Birthday Bill

Specialist Nurse Diana Wilkinson with member Mr Bill Local who was celebrating his 90th birthday shortly after the Middlesbrough meeting. We hope you had a fabulous birthday, Bill!

Feedback from this year's events

We asked attendees what they found most beneficial about our Paget's information events and here are some of the responses.

- There was enough time between the sessions to meet and talk with both those affected by Paget's and specialists
- I now have a better understanding of the condition
- The genetic information
- Different aspects of Paget's: causes, genetics, good effects of treatments used, diagnosis in good time
- The relaxed nature and humour in which the information was put across helped me to absorb the information better
- Thank you very much. It has been a very interesting and informative day. Excellent!
- It's not often with an illness/condition you are able to understand the complexities presented by the experts
- Lots of new and interesting information
- Helpful information into the condition of Paget's disease, complications, treatment and especially pain
- I feel more confident when returning to my doctor to discuss things
- Finding out more about the disease and the different tests and treatments available
- It reduced the shock of diagnosis through the good explanations of treatment options.



Journal news



Professor Rob Layfield, Chair of the Association's Research Subcommittee, recently highlighted a scientific article titled 'The Mysterious Decline of Paget's Disease: A Link to Coal?', written by Tim Cundy, Professor of Medicine at the University of Auckland, New Zealand. Here, Specialist Paget's Nurse Diana Wilkinson summarises it for you. The article explores potential factors behind the unexplained reduction in cases of Paget's disease in the past few decades.

The mysterious decline of Paget's disease: a link to coal?

Paget's disease is more prevalent in certain geographical regions, such as Western Europe, Australia, and New Zealand. Surveys in the 1970s showed that the UK had a substantially higher number of people affected (prevalence) by Paget's disease than any other country. In the late twentieth and early twenty-first centuries, studies documented a rapid and unexplained change, with a greatly reduced prevalence and less severe disease.

There have been many theories into the causes of Paget's disease and research (including work supported by the Paget's Association) has identified clear links with mutations in several genes, notably SQSTM1. Genetic predisposition alone, however, does not account for the overall



decrease in Paget's disease cases or the less severe presentations observed in recent times. It is thought that environmental factors, such as diet, toxins, chemicals or infectious agents, might play a role.

There have been many scientific papers published that discuss these potential factors. In 1974, a paper tentatively suggested that improved vitamin D nutrition in childhood might be relevant, but Professor



Cundy thought that unlikely and given that vitamin D deficiency is seen all over the world, it would not explain the distribution. Viruses have been long explored as a possible trigger, including canine distemper and measles but these infections occur worldwide. Immunisation (of dogs) against distemper began in the late 1950s and immunisation (of humans) against measles began around 1969, which was too late to explain the recent decline in the prevalence of Paget's disease. Professor Cundy wondered if the environmental factor might be a pollutant. It was suggested in 2002 that calcium arsenate toxicity related to the cotton mills in Lancashire might be significant. Calcium arsenate was used on cotton plants as an insecticide between 1923 and 1945. The thought was that this could have contributed to the decline in prevalence between surveys carried out in the 1970s and 1990s but it didn't explain the decline in prevalence in other parts of Britain or other countries. In Quebec, Paget's disease has been associated with mining and wood-burning fires (Quebec has mines producing niobium, copper, titanium, gold, zinc,

copper, silver and graphite but not coal). Its prevalence in Quebec is also declining.

Professor Cundy proposed that there could be a link between the decline of Paget's disease and the reduction in domestic coal use. Using data on coal production, population size, and approximations of domestic use, the estimated exposure to domestic coal burning rose threefold in Britain during the nineteenth century and began to fall after 1900 following the industrial revolution and subsequent period of great change. Rapid industrialisation was driven by the use of coal for energy and, in the home, bituminous coal was customarily burnt on an open hearth for heating. The pattern of coal use fits with the decline in Paget's disease documented by death certification and prevalence surveys.

Colonists moving from the UK to North America, Australia and New Zealand established coal mines and also used coal for domestic heating. Paget's disease was found in these settler populations but was largely absent from people indigenous to these lands. All over the world, the prevalence of the condition has

fallen, as the burning of coal in open hearths for domestic heating has fallen. The exact substance in coal that might have triggered the disease is unknown. Possible candidates include both organic and inorganic constituents of bituminous coal.

The coal hypothesis does not exclude the possibility that other factors could be important. While environmental factors may trigger Paget's disease, genetic factors play a significant role, particularly as sporadic cases become rarer. There is also the possibility that Paget's could emerge without a trigger, particularly when there is a strong genetic driver.

So, could changes in energy use, particularly coal, be a key factor in the mysterious decline in Paget's disease? It is plausible but the evidence remains circumstantial. Professor Cundy concludes his article by saying, "The coal hypothesis raises as yet unanswerable questions and the hypothesis outlined in the paper, suggesting a link to rapid industrialisation and implicating domestic coal use, is probably untestable at the population level, given the worldwide change in coal usage. However, this hypothesis could stimulate further research into the biology of the disease."

Reference

Cundy, T. (2024) The Decline of Paget's Disease of Bone and Domestic Coal Use — A Hypothesis. *Calcified Tissue International*, 115, 117–123.



*Scan the QR code
to read the paper in full.*

Your questions answered

We believe that sharing some of the common questions about Paget's disease submitted to our Paget's Nurse Helpline, along with their answers, may be helpful to others. Here, we focus specifically on questions regarding bone.



Do you have a question?

Contact the Paget's Nurse Helpline
Email: helpline@paget.org.uk
Telephone: 0161 799 4646

Q Can you explain what Paget's disease is?

A Paget's disease disrupts normal bone renewal. Adult bones are in a constant state of renewal through a process called bone remodelling. Cells known as osteoclasts break down old bone and cells called osteoblasts form new bone. This balance is critical for maintaining strong bones. In Paget's disease, this process goes awry. The osteoclasts become overly active, breaking down bone faster than normal. The osteoblasts then overcompensate by forming new bone too quickly. This results in new bone that is structurally abnormal. The affected bone may be larger, weaker and misshapen.

Q I've been told I have Paget's disease in my pelvis, that was discovered through an x-ray. How can I determine if I have Paget's in other bones as well?

A Radionuclide bone scans, also known as scintigrams, isotope bone scans or nuclear medicine bone scans, can determine which bones have Paget's disease and how active the disease is. The scan involves the use of a small amount of a radioactive tracer, which is injected into a vein in the arm. The tracer is given time to circulate then images are taken with a scanner (gamma camera). Note that this type of scan is not the same scan as a Dual-Energy X-ray Absorptiometry (DEXA) scan, which is used in the diagnosis of osteoporosis.

Q I had a bone scan that revealed three bones affected by Paget's disease. I assumed all my bones would be involved. Is that not the case?

A In someone with Paget's disease, not all bones will be affected. The disease may involve several bones (polyostotic Paget's disease) or just a single bone (monostotic). It can occur in any bone, however, it is more common in the pelvis, spine, thigh bone (femur), shin (tibia) and skull. The reason why only specific bones are affected remains unclear.

Q Does Paget's disease spread from one bone to another?

A No, although Paget's disease can progress within the bones it affects, it does not spread from one bone to another.

Q&A

Virtual Paget's question and answer event with Professor Stuart Ralston

Friday 10 January 2025, 5.00 pm – 6.00 pm

Professor Stuart Ralston will hold a virtual Paget's question and answer session, using Zoom, at 5 pm on Friday 10 January 2025. He will answer any questions you have regarding Paget's disease. You can also join in if you just want to listen to the discussion.

If you have not used Zoom before and would like us to help you, we will be happy to help but please get in touch before the day as we will not be able to assist on 10 January.

How to take part

To join the event, please email membership@paget.org.uk



Paget's Awareness Day focuses on early diagnosis

11 January 2025

We know that many people face challenges in getting a diagnosis of Paget's disease and ultimately, relief from their pain. On International Paget's Awareness Day 2025, our focus will be on early diagnosis. We will be sharing new videos that will help raise awareness of the signs and symptoms of the condition. Look out for these on our website and our YouTube channel.



Help bring attention to Paget's

If you are affected by Paget's disease you can raise awareness of its impact by sharing your experiences through conversations with family and friends, community forums, social media and this magazine.

Don't Forget



International
Paget's Awareness Day

**Raising Awareness of
Paget's Disease of Bone**

**Join the fight and help
raise awareness**

PagetAlert

Shortening the pain journey in Paget's Disease

The Paget's Association is launching a new campaign **PagetAlert** to drive our mission for earlier diagnosis and to reduce the pain and anxiety for those living with the condition. For those at risk of Paget's disease or with a family history, early intervention can control symptoms and reduce progression.

An ambitious target of £75,000 will help us to address the delays in diagnosis of Paget's disease that can lead to unnecessary complications, including pain, bone deformities and fractures.

All of our funding comes from donations and legacies so please support us by contributing to:

- reduce diagnosis time
- ensure pain is properly managed.

The Paget's Association will also continue to:

- encourage new research to evaluate potential genetic testing to identify those at most risk
- provide accurate and up-to-date clinical guidelines, resources and quality support
- still be here for you, your families, and future generations in years to come.

Raise funds

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



How to donate to PagetAlert

- > Visit our website where you can securely donate.
- > Contact our office for details on how to make a direct bank transfer.
- > Send a cheque payable to the Paget's Association to **The Paget's Association, Jactin House, 24 Hood Street, Ancoats, M4 6WX.**
- > Set up a monthly, standing order: please reach out to our office by emailing membership@paget.org.uk or calling **0161 799 4646.**



In the next issue of Paget's News:

Kathryn Berg presents the results of the *Pain in Paget's* study

The Big Spring Coffee Morning for Paget's

Coffee and treats set to make a difference!

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

● Official date: Saturday 10 May 2025

The official date is 10 May 2025 when we'd like as many members and supporters as possible to take part in the Big Spring Coffee Morning for Paget's. As well as raising funds, it's an opportunity to raise awareness as well.

Can't make 10 May? No worries! You can choose a date and time that suits you and your guests.

The Big Spring Coffee Morning for Paget's 10 May 2025

Here's how you can get involved:

● Pick your venue

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



Join members and supporters on 10th May or choose a date that works for you. Your efforts can make a big difference!

● Plan the treats

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

● Spread the word

It can be a small or large gathering – whatever suits you. Think about inviting family, friends and neighbours. Let everyone know they're contributing to a great cause by attending! In the next issue of this magazine, we'll give you some invitations and you'll be able to print more from our website.

The invitations will explain that guests are invited to donate to the Paget's Association.

● Fundraising made easy

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

● Need support? We'll help!

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

● Start planning your event today!

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



Case studies of Paget's disease: asymptomatic discovery and rare neurological complications



Published case studies featuring individuals affected by Paget's disease offer valuable insights into the condition. Our Specialist Nurse, Diana Wilkinson, has summarised two such cases: one from Pakistan and another from Morocco.

A case of Paget's of the skull

A recent case study was published in the Journal of Clinical and Translational Research where the authors presented a case of a 60-year-old female in Pakistan, whose Paget's disease was found when she was undergoing evaluation for gallbladder surgery. A blood test showed an alkaline phosphatase (ALP) of 1537 IU/L (normal range is between 30-130 although reference ranges may vary between laboratories). Her high ALP prompted further investigation and a bone scan revealed Paget's disease in the skull, although she was asymptomatic at diagnosis. Clinical symptoms differ with the disease location; skull involvement usually causes the skull to enlarge, along with headaches and/or deafness. When the base of the skull is affected, it can lead to rare complications such as hydrocephalus.



The lady had a bisphosphonate infusion of 5 mg zoledronic acid. She was followed-up after three months at the rheumatology outpatient department, when a repeat ALP test showed markedly reduced levels down to 250 IU/L.

Early detection and management of Paget's is important. While it might not initially present with symptoms, left unchecked, it can lead to severe complications. Therefore, it's crucial for healthcare professionals to thoroughly investigate any unusual blood test results, even in asymptomatic individuals. Staying vigilant and taking timely action can make a substantial difference in managing Paget's disease and ensuring better outcomes for those affected. A key goal of the Paget's Association is to push for early diagnosis.

The authors point out the rarity of this disease in Southeast Asia. In conclusion, they remarked that isolated raised ALP levels should always be investigated to rule out asymptomatic individuals.

Reference

Ali M, Farooq O, Rafique Z, Farooq H, Iftikhar F, Malik M. A rare case of asymptomatic Paget's disease of the skull in a 60-year-old Asian female. Journal of Clinical and Translational

Research. 2023 Jul 26;9(4):261-264. PMID: 37593243; PMCID: PMC10431192.



Read the full text

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10431192/>

Epilepsy, a rare complication of Paget's disease

This case study from authors in Morocco underscores a critical but rare aspect of Paget's disease – its ability to occasionally manifest alongside unusual neurological symptoms, such as epileptic seizures. While the connection between Paget's and headaches is more established, the occurrence of seizures, as illustrated in this case, is far less common and often poses a diagnostic challenge, particularly in older adults. The 75-year-old woman in this study presented with a history of chronic headaches that did not prompt a thorough investigation for Paget's disease until she experienced tonic-clonic seizures (the type of seizure most people picture when they think about seizures). These had begun three weeks before admission at a rate of one every other day. An examination showed bulging of temporal veins, head enlargement and protruding forehead. The authors provide compelling evidence suggesting the patient's seizures were directly related to Paget's affecting her skull. The epileptic activity seen on an EEG (a measure of electrical activity of the brain), was localised to the right frontal region of her brain – the same area where an MRI scan revealed the most significant bone thickening and compression. Despite being on anti-seizure medication, she experienced non-convulsive status epilepticus, suggesting an underlying, untreated cause. A bone scan showed Paget's disease restricted to her skull and face. An x-ray of her skull showed a characteristic 'cotton wool' appearance and her ALP levels were high (536 IU/L).

Her seizures completely resolved after she received zoledronic acid, a potent bisphosphonate used to treat



Paget's disease. Her anti-seizure medication was subsequently tapered off without any recurrence of seizures. Comprehensive diagnostic tests ruled out other possible causes including infections, metabolic disorders, inflammation or tumours, further strengthening the link between seizures and Paget's in this case.

While this case study sheds light on the potential for Paget's to cause epileptic seizures, the exact mechanisms responsible for this association remain unclear. The authors propose that the same processes involved in Paget's-related headaches might also play a role in seizure development. One such process is regional vascular steal syndrome where the increased blood flow to the Pagetic bone essentially "steals" blood from the surrounding tissues including the brain, potentially leading to ischaemia (reduced blood flow).

This case study serves as a crucial reminder to clinicians to consider Paget's as a potential diagnosis

in older patients presenting with neurological symptoms, even seemingly common complaints like chronic headaches. The delay in this case highlights a crucial point: the condition often mimics other conditions leading to delayed diagnosis and potential complications. Early recognition and prompt treatment with a bisphosphonate is needed to prevent rare debilitating complications like epileptic seizures, ultimately improving outcomes and quality of life.

Reference

Ouhabi D, Tibar H, Benomar A, Jiddane M, Regragui W. Headache and Status Epilepticus Reveal Paget's Disease of the Bone. *Cureus*.

2024 May
19;16(5):e60588.
doi: 10.7759/
cureus.60588.
PMID: 38894759;
PMCID:
PMC11184908.



Read the full text

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10431192/>

Win up to £200 in our monthly raffle!

We would love to hit our target of selling 200 raffle tickets in the Paget's Association's Raffle so please encourage your family and friends to join. The strict limit of 200 tickets for sale means that, unlike many lotteries, our raffle has remarkably favourable chances of winning. Moreover, when you encourage your friends, family and colleagues to join, you not only boost the funds raised but also raise awareness of Paget's disease.

By purchasing a ticket or even two you are contributing directly to our charity. Tickets are £5 per month. The draw takes place every month with two opportunities to win. The first prize is £100, and the second is £50 with prizes doubling in June and December. Anyone over 18 can take part (they do not need to be a member of the Paget's Association).

Easy to join

To join the raffle and secure your chance to win, please email your request to

membership@paget.org.uk

or call 0161 799 4646.

Prizes!

1st prize £100

2nd prize £50

Double Prize Draw in June and December

1st prize £200

2nd prize £100

Encourage your friends and family to join

Easy to join



Winners ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

JULY 2024

1st Prize £100

Ticket no. 103
Euan Allen
Suffolk

2nd Prize £50

Ticket no. 156
Veronica Ashton
Merseyside

AUGUST 2024

1st Prize £100

Ticket no. 8
Lucille Kay
Bedfordshire

2nd Prize £50

Ticket no. 97
Anne Chequer
Devon

SEPTEMBER 2024

1st Prize £100

Ticket no. 141
Terence Holder
Leicester

2nd Prize £50

Ticket no. 155
Eileen Rivers
Norfolk

OCTOBER 2024

1st Prize £100

Ticket no. 90
Eileen Wallace
Cheshire

2nd Prize £50

Ticket no. 171
John Dyer
Suffolk

☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

Anyone over 18 can take part

What's your story?

We are grateful to those who have shared their experience of Paget's disease in this magazine as we know it helps others. If you would like to share your story to help support others, please get in touch by emailing diana.wilkinson@paget.org.uk or by telephoning **0161 799 4646**.

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



PAGET'S DISEASE PODCAST

New patient information podcast from BIRD with Dr Sarah Hardcastle, Consultant Rheumatologist. Royal National Hospital for Rheumatic Diseases (RNHRD).

Listen now via the BIRD website:
www.birdbath.org.uk/podcasts
or on your usual platform.

The RNHRD was recently awarded a 'Centre of Excellence' Award by the Paget's Association
www.paget.org.uk



Bath Institute for
Rheumatic Diseases



New displays at Norton Priory



Items from the Paget's educational kit

In collaboration with the Michael Davie Foundation, an educational project at Norton Priory Museum and Gardens in Runcorn, Cheshire, received funding from the Paget's Association through the Winifred Ditchfield Award. This funding was provided to update information on Paget's disease within the museum.

One of the museum's main exhibits in the gallery includes an area dedicated to explaining the historically high prevalence of an ancient form of Paget's disease in the medieval human skeletal collection. Since 2016, with support from the Paget's Association and other funders, the research team

has conducted extensive research, shedding new light on this collection. The ground floor gallery now features six new videos discussing Paget's disease and the latest research results.

Additionally, six further short films, featuring Professor Rob Layfield, Chair of the Paget's Association's Research Committee, describe and demonstrate the Paget's educational kit, which explores bone biology and Paget's disease through engaging activities and puzzles. This kit was produced by Elizabeth Radley, a PhD student at the University of Nottingham, whose work was made possible through an educational

bursary from the Paget's Association. Norton Priory premiered these films during their Festival of Archaeology celebration in August. Visitors of all ages have been engaging with the new videos and the gallery alone is expected to reach approximately 30,000 visitors annually.

The new videos

- Science partners from The Crick Institute explain aDNA research
- Colleagues from the University of Nottingham discuss proteomics
- Collaborators from Liverpool John Moores University explain the stable isotope results
- Dr Carla Burrell provides an update on the osteoarchaeological work on the collection
- Former Trustee of the Paget's Association and patient, Keith Simpson, shares his experience of living with Paget's disease
- Trustee of the Association Dr Faiz Rahman explains the condition from a modern-day clinical perspective

The videos can be seen in the ground floor gallery



Now available: Orthopaedic surgery and Paget's disease

In certain instances, individuals affected by Paget's disease may find it necessary to see an orthopaedic surgeon. Successful surgical management of complications of Paget's disease can reduce pain and improve quality of life. The Paget's Association has produced a booklet '*Orthopaedic surgery and Paget's disease*' to help you understand the process. You can download it from the resources section of our website or contact us to request a copy.

Reading this booklet is essential for those affected by Paget's disease, as it provides valuable insights into when orthopaedic surgery may be necessary and how surgical interventions can significantly improve pain management and mobility, enhancing overall quality of life.

The following is an excerpt from the booklet.

Back pain and spinal canal narrowing in Paget's disease

Back pain in Paget's disease can be due to bone pain from the disease itself or because of changes in the small joints of the back. In most cases, this can be treated with simple measures such as maintaining a healthy weight, back strengthening exercises and regular activity.

Sometimes the disease can cause narrowing of the spinal canal and nip the spinal cord or cause narrowing at the point where the nerve leaves the spine. Where the spinal canal is narrowed it can cause symptoms of an aching in the buttocks and legs that can be accompanied by weakness in the legs on walking, and occasionally numbness in the legs.

Where the symptoms are severe or worsening and medical treatment is unsuccessful, spinal surgery may be required and would usually be performed by a spinal surgeon. This sort of surgery can involve opening up the tightness at the site where the nerve leaves the spinal canal (known as decompression), or can involve removing parts of the bone and fusing some of the spinal bones.



SCAN ME



Pain UK engages GPs on chronic pain management



Antony Chuter, a volunteer with Pain UK, recently represented the organisation at the Royal College of GPs (RCGP) conference in Liverpool in October. The conference attracted a diverse mix of GPs, with a significant presence of GP Registrars (GPs in their final five years of training post-medical school).

One notable activity at the Pain UK stand was a mini survey that engaged attendees with the question: "How do you feel when someone living with pain comes into your consulting room?" Responses varied widely, reflecting the complex challenges faced by GPs due to limited treatment options and complex side effects associated with pain management. The discussions highlighted a recurring issue among patients: feeling unheard, disbelieved, misunderstood, and uncared for. Participants explored strategies to address these concerns, emphasising the importance of GPs



Antony manning the Pain UK stand at the RCGP conference

acknowledging patients' experiences and expressing empathy. While acknowledging the limitations in pain management, GPs expressed their commitment to providing ongoing support to patients despite the persistence of pain for many.

We extend our gratitude to Pain UK for offering the Paget's Association the opportunity to provide informative leaflets at their stand,

tailored specifically for healthcare professionals. The demand for these resources was evident, as all the leaflets were taken by the close of the conference. Antony's involvement underscored Pain UK's mission to raise awareness and foster dialogue on improving the patient experience within healthcare settings, particularly concerning chronic pain management.

Cheering on the 2025 London Marathon Runners



As the excitement builds for the April 2025 London Marathon, we want to extend our thanks to all the incredible runners who

are dedicating their time, energy, and miles to support the Paget's Association. Their commitment to training, raising awareness, and fundraising is not only inspiring but also has a positive impact on our charity. We can't wait to see them cross the finish line and celebrate their achievements!

To learn more about our runners and find out how you can sponsor them, please email membership@paget.org.uk or call 0161 799 4646.



Information and support services provided by the Paget's Association

Paget's Nurse Helpline

Managed by an experienced Registered Nurse, we invite you to contact our Nurse Helpline for support, information, or simply a listening ear.

Email: helpline@paget.org.uk Telephone: **0161 799 4646** Mobile: **07713568197**

Virtual Paget's Support Groups, Buddies and Support Network

Facilitated by our Specialist Paget's Nurse, Diana Wilkinson, you can meet others affected by Paget's disease at one of our Virtual Support Groups. The groups use Zoom to connect. For more information or to take part, please email membership@paget.org.uk or register on our website.

If you would simply like to talk to someone else who has Paget's disease, please contact our Nurse Helpline (see above) and we will do our best to arrange this for you through either our Buddies or Network scheme.

Paget's information events

If you are able to, consider attending a free Paget's Information event, where you can connect with experts, gain valuable information, ask questions and find support within the Paget's community. Lunch and refreshments are included and you are welcome to bring someone with you but places must be booked in advance.

Information booklets

Our information booklets cover various aspects of Paget's disease, such as general information about Paget's disease, pain, investigations and orthopaedic surgery. They can be downloaded from our website or sent to you by email or post.

Visit the 'Resources' section of our website www.paget.org.uk/resources/



Paget's information videos

A collection of videos discussing personal experiences, diagnosis, treatment and research are available to view on YouTube or our website. Search YouTube for [@PagetsAssociation](https://www.youtube.com/PagetsAssociation) or visit www.paget.org.uk (see the resources section).

Facebook support group

The Facebook Paget's support group is a private group for those affected by Paget's disease and their families. To join please scan the QR code with a smartphone or visit <https://www.facebook.com/groups/pagetsdiseaseofbone>



Your legacy can make amazing things happen

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

Heartfelt thanks

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.



Inspire others

Perhaps you could inspire others by sharing your story with us and our readers. Simply get in touch by email membership@paget.org.uk or phone 0161 799 4646.

Publications news feed

Professionals interested in Paget's disease may find the Professional Resources section of the Paget's Association's website useful. Included is an automatic (RSS) news feed from pubmed.ncbi.nlm.nih.gov. PubMed is a database of references to biomedical literature, such as scientific journals, and online books. When PubMed displays new content containing specific terms, details will appear on our website.

Please note that not all content may be directly relevant to Paget's Disease of Bone.

View the publications

<https://paget.org.uk/health-and-research-professionals/professional-resources/recent-publications-news-feed/>



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.

Minutes of the Annual General Meeting (AGM)

of The Paget's Association held at The Leonardo Hotel, Fry Street, Middlesbrough on 19 September 2024, at 10:00 am

Attendees in person: 6 Trustees/ members; 5 Members; 2 Employees

Attendees virtual: 1 Trustee

Apologies: 4 Trustees

Minutes taken by: Diana Wilkinson

Welcome

Professor Stuart Ralston, Chair of the Paget's Association (also known as the National Association for the Relief of Paget's Disease), welcomed everyone to the Annual General Meeting (AGM). He reminded the audience that only members could vote and if anyone had already voted postally or electronically, they should not vote again.

Item 1: Annual General Meeting 2023

Resolution: That the minutes of the Annual General Meeting held at The Moat House, Stafford, on 27 October 2023 be approved.

- Professor Ralston proposed that the resolution be accepted.

Member votes	For	Against	Abstain
Present (in person or virtually)	10	0	0
Proxy (postal or electronic votes)	8	0	0

Item 2: Presentation of the Report and Accounts from the last financial year: 2023

Professor Ralston provided an overview of the Association's accounts for the year ending

December 2023 and compared the annual with that of 2022. He noted a decline in income from donations and legacies in 2023 and reflected on the fluctuations in legacy income over the past 17 years. He explained that the Association had been actively working to reduce costs, resulting in overall expenditure being lower in 2023 compared to 2022. Professor Ralston reported that the charity's remaining funds at the end of 2023 were lower than the previous year, expressing concern over the challenging financial outlook. He reassured members that the Trustees were proactively taking steps to address this.

Resolution: That the annual Report and Accounts for the year ended 31 December 2023 be accepted.

- Professor Ralston proposed that the Report and Accounts be accepted.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	8	0	0

Item 3: Re-appointment of Beever and Struthers as the Association's financial independent examiners

Resolution: That Beever and Struthers be re-appointed as external Financial Examiners of the Association.

- Professor Ralston proposed that the resolution be accepted.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	8	0	0

Item 4: New constitution

Professor Ralston explained that the Paget's Association was in the process of becoming a Charitable Incorporated Organisation (CIO), therefore, a new constitution had been written. He explained that becoming a CIO had advantages both for the Association and the Trustees.

Resolution: That the new constitution of The Paget's Association be accepted.

- Professor Ralston proposed that the resolution be accepted.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	8	0	0

Item 5: Trustee appointments

Professor Ralston informed members that Trustee Mr Mark Wilkinson, had completed his three-year term of office and was standing for re-election.



Resolution: Re-appointment of Mr Mark Wilkinson as a Trustee for a further 3 years.

- Professor Ralston proposed that the resolution be accepted.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	8	0	0

Item 6: A review of the activities in 2023 and 2024

Specialist Nurse and Director of Educational Resources, Mrs Diana Wilkinson, gave a review of activities undertaken by the Association in 2023. These included:

- activities for the annual Paget's Awareness Day (11 January 2023), which focused on personal stories and celebrated fifty years of the Paget's Association

- two in-person Paget's information events, held in Salford and Stafford, for those affected by Paget's disease and their families
- an international Paget's symposium in Salford, bringing together researchers, clinicians, and students
- award of four new Centres of Excellence
- funding of two new research projects and an educational award
- closure of the Association's Salford office, with staff transitioning to working from home
- launch of a new website in December 2023
- continuation of the Association's information and support services
- steps were taken toward converting the charity into a Charitable Incorporated Organisation (CIO).

Mrs Wilkinson provided a summary of the activities undertaken so far in 2024. These included:

- activities for the 2024 Paget's Awareness Day, which focused on Paget's research
- two Paget's information events, held in Cambridge and Middlesbrough, for individuals affected by Paget's disease and their families
- designation of a new Centre of Excellence in Bath
- continued progress towards converting the charity to a Charitable Incorporated Organisation (CIO)
- ongoing provision of a wide range of information and support services.

Item 7: Forward planning for 2025 and beyond

Professor Ralston explained that the 2025 Paget's Awareness Day would focus on early diagnosis, the Association's magazine would continue to be produced, and he anticipated there being Paget's information events in the Leicester and Bath areas.

Item 8: Questions and any other business

No questions were raised and no other business was discussed.

Send e-cards, donate postage savings and help protect the environment

Spread awareness of Paget's, help protect the environment, save time and raise funds by sending an electronic card (e-card) and support the Paget's Association at the same time. You will find cards for every occasion on the DontSendMeACard.com website, including special designs created by the Paget's Association to help raise awareness of Paget's disease. If you need to send cards to a large group, you can send all of your e-cards in one hit or tailor each message and send them individually.



Find us on
DontSendMeACard.com

How it works

- 1 Choose a charity
- 2 Select an e-card image
- 3 Write a personal message
- 4 Donate the cost of the card via PayPal or credit card.

Your e-card recipients will see that you gave in lieu of a card and can do the same.



**As this is our last
magazine of the year
we want to wish you a
joyous Christmas
&
send our very best
wishes for 2025**