

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



Join us in Cambridge for a Paget's Information Event

Pages 8 & 9

Plus

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Chair's message

Dear Member,

Welcome to the November 2023 edition of Paget's News. As always, the magazine is packed with useful information about Paget's disease and updates on our various events, as well as fundraising opportunities.

We had a highly successful day at the Moat House Hotel in Stafford where we held the Annual General Meeting (AGM), followed by an information event for those affected by Paget's disease and their families. As is mentioned on page 5 of the magazine, Mr Allan Martin and Mr Mohammed El Erian were elected as new members of the Board of Trustees of the Association. Allan brings to the charity a wealth of experience in matters relating to business and project management whereas Mohamed provides legal expertise and has already been assisting the Association in its wish to transition to a Charitable Incorporated Organisation. I look forward to working with both trustees in the years to come. The information event was hosted by Dr Zoe Paskins who is a Reader at the University of Keele and Honorary Consultant in Rheumatology at the Haywood Metabolic Bone Centre in Stoke-on-Trent. The attendees were treated to presentations on what happens to the skeleton when Paget's disease occurs, how it is diagnosed, and how it is treated. We also had an update on the causes of pain in Paget's, and also the role of physiotherapy and joint replacement in dealing with complications of the disease.

There is an update on some of the research the Charity funded this year on pages 6 and 7. The first project led by Adrian Heal



from Salford looks at the impact of Paget's disease on becoming unwell with Covid. The second, led by Dr Daniel Scott, a research fellow at Nottingham University, looks to establish a library of stem-cells which can be used to study disease mechanisms in Paget's disease. If successful, this project will represent a valuable resource for future generations of researchers who are working on the condition. The third project, which was the winner of the Winifred Ditchfield Educational Award, will allow the team at Norton Priory to update information about the disease within the Priory Museum. I am sure you will join me in wishing all three research teams success with their projects.

Looking forward to next year, we have a feature on our upcoming information event planned for June 2024 at the wonderful venue of Madingley Hall near Cambridge. This really is a fantastic venue. So if you are based in the Cambridge or East Anglia areas, I urge you to sign up to attend the meeting by completing the registration form on page 9 and returning it to our new office at Jactin House. Alternatively, please send an email to membership@paget.org.uk with your contact details and the names of those who are interested in attending.

The Association is dependent on fundraising to keep our work going and it was fantastic to see that 33 members of the Mearns Bowling Club in Glasgow raised £650 in support of our work, at their annual Allan Reid Trophy Day. If you are a runner or know anyone who is, please consider entering the London Marathon to support the work of the Association. The charity has a limited number of places available for this iconic event. Full details are on page 13.

Our regular feature highlighting research into Paget's disease focuses on the identification of antibodies in the teeth of ancient skeletons affected by Paget's at Norton Priory. The research team, led by Prof Rob Layfield, were able to isolate antibodies that still recognised viruses from teeth that were 800 years old! The researchers highlighted that this approach could provide new insights into human disease across a historic time course as well as help to reconstruct ancient diets and lifestyles.

I always like to hear the stories of people who have been affected by Paget's disease and it was interesting to read about the experience of Don Bastock from New South Wales, Australia, who was diagnosed with Paget's disease of the tibia. I was happy to hear that his pain was improved by risedronate treatment but sorry that he had to give up his hobby of golf. If you have a story to tell, please complete the "Share your story form" on page 11 and 12 and send it to Jactin House, or email Specialist Nurse Diana Wilkinson with details of your experience. Diana deals with many queries from people who are newly diagnosed with Paget's disease through our Helpline.

Many who are new to the disease don't know exactly what to expect and with so much misinformation around we thought it would be helpful to provide some quick facts about the disease on page 15 and a summary of myths and facts about the disease on page 16. If you are affected by Paget's disease, we hope that you will find this information useful.

One of the major initiatives that the charity has focused on over the past year is to build a new website and optimise our representation on social media channels. This work, led by Trustee Dr Sheelagh Farrow and other members of the Digital Communications and Marketing Committee (DCMC), is progressing very well and we hope to launch the new website before the end of the year. Watch this space!

In closing I thought I should mention how saddened I was to hear about the death of Marilyn McCallum who passed away suddenly recently. Marilyn worked with the charity for 16 years in various roles, starting as a part-time administrator, before being appointed as Chief Executive between 2007 and 2013. I am sure you will join me, and everyone involved with the charity, in extending our deepest condolences to Marilyn's family.

Finally on behalf of all at the Association, I would like to extend my best wishes for Christmas and the New Year and I hope that you will watch our new videos that will be released to celebrate Paget's Awareness Day on 11 January 2024.

Stay safe and keep well!

Stuart Ralston

Chair, Paget's Association

The Paget's Association

Charity registration number: 266071

The Paget's Association is a charity in the United Kingdom, which focuses solely on Paget's Disease of Bone. Also known as The National Association for the Relief of Paget's Disease (NARPD), the charity was founded in 1973 by the late Mrs Ann Stansfield MBE.

In addition to providing information, support and guidance to all who require it, the Paget's Association raises awareness, and funds quality research.

Membership

Membership of the Paget's Association provides support and information in several ways. All members receive a Paget's Information Pack on joining, as well as our Paget's News magazine.

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, bone remodelling 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.

A more detailed explanation can be found on the Association's website and in our booklet *'Paget's Disease – The Facts'*.

Our website

There is a wealth of information regarding Paget's disease on our website.

www.paget.org.uk

Paget's Awareness Day

International Paget's Disease Awareness Day takes place annually on 11 January.

Contact us

The team at the Paget's Association would be more than happy to hear from you. Please get in touch!

Telephone

For all enquiries telephone:
0161 799 4646

Email

All general and membership enquiries:
membership@paget.org.uk

Postal address

You can write to us at the following address:

The Paget's Association,
Jactin House, 24 Hood Street,
Ancoats, Manchester, M4 6WX

Paget's Helpline

Our Paget's Helpline is available to anyone who requires support or has questions regarding Paget's disease. You can contact the Helpline by email, telephone (during office hours) or by writing to us at the address above.

■ Email: **helpline@paget.org.uk**

■ Telephone: **0161 799 4646**

■ Mobile: **07713 568197**

Chair of the Association

Professor Stuart Ralston
Email: **chair@paget.org.uk**

Connect with us on



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New Trustees Elected at the AGM

The Annual General Meeting (AGM) of the Paget's Association took place on 27 October at The Moat House, Stafford. We welcomed two new Trustees, Mr Alan Martin and Mr Mohamed El Erian.



Mr Alan Martin

Alan Martin is a retired company director who has spent most of his working life involved in healthcare-related projects. Here Alan explains his background and why he wanted to be involved with the Board of Trustees.

"I graduated with an honours degree in environmental engineering and worked for a Regional Health Authority, designing building services and overseeing their installation for new hospital projects. I then worked on projects in the UK and overseas before being appointed as the General Manager of the Healthcare

Division of a major UK company. The division undertook a wide range of operational, technical and aid-funded projects, some of which were carried out on behalf of the British Government. On the sale of the parent company, I purchased the consultancy part of the business and focussed our activities on assisting clients to manage large complex projects in the UK and Europe.

After retiring I was diagnosed with Paget's Disease and consequently joined the Paget's Association. I have attended Paget's Information Events and understand the relief and comfort they provide, especially to those newly diagnosed. I am a member of the Association's Focus Group. I strongly believe that interaction between patients and clinicians brings mutual benefits. Membership of the Association gave me an understanding of my condition and a means of gaining relief from the pain. I would like to give something back and therefore am delighted to have been elected as a Trustee."



Mr Mohamed El Erian

Mohamed El Erian is a solicitor at Jones Day, London, and qualified as an associate in the Corporate team in August 2023. Prior to being elected as a Trustee, he has been assisting the Paget's Association with legal matters as he explains here.

"I have had the pleasure of assisting the Paget's Association with legal aspects of transitioning to a Charitable Incorporated Organisation (CIO) and believe that joining the Association as a Trustee would help me learn more about the charity and help me better advise on its future direction.

I have a bachelor's degree from Queen Mary University of London and a master's degree in international law from the London School of Economics and Political Science. Previously, I worked in the political affairs team at the United Nations Security Council."

Minutes

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

New educational and research projects funded by the Paget's Association

We are pleased to share details of two new research projects and an educational award funded by the Association, in celebration of the charity's 50th Anniversary. The Paget's Association continues to encourage and fund quality research projects.

Paget's disease and COVID-19: what really happened in the Pandemic?

NEW RESEARCH

Principal Researcher: Dr Adrian Heald, Consultant Endocrinologist

Institution: Department of Endocrinology, Northern Care Alliance NHS Foundation Trust, Salford

During the COVID-19 pandemic, we saw that people with multiple health conditions and frailty were more likely to become seriously unwell after a COVID-19 infection. Are people with Paget's disease more likely to have other health conditions and frailty in older age compared to those without Paget's disease? This is the question researchers in Salford, a Paget's Association Centre of Excellence, want to answer using anonymised health records which cover the whole population of Greater Manchester (approximately 2.8 million).



With funding from the Paget's Association, they will consider whether people with Paget's disease are more likely to have other health conditions and frailty in older age because we know that these factors

have an impact on health outcomes. A key part of this research will look at the impact of Paget's disease on the likelihood of becoming unwell with COVID-19, taking into account levels of frailty and co-morbidity.

“
They will consider whether people with Paget's disease are more likely to have other health conditions and frailty in older age because we know that these factors have an impact on health outcomes
 ”

Engineering a Paget's disease stem cell bank

NEW RESEARCH

Principal Researcher: Dr Daniel Scott, Nottingham Research Fellow

Institution: University of Nottingham, School of Life Sciences

The recent advent of techniques to generate human induced pluripotent stem cells (iPSCs) – derived from patients – and to differentiate them into theoretically any cell type of the human body has presented a novel means to probe human disease-in-a-dish. Concurrently, advances in gene-editing approaches, for example using CRISPR editing,



means that researchers can precisely manipulate patient-derived iPSCs to introduce or 'correct' disease-associated gene 'mutations' to model how, in isolation, these genetic variants may underlie disease. Collectively, these approaches have revolutionised biomedical research.

With funding from the Paget's Association and the University of Nottingham, researchers propose to exploit in-house expertise at the Nottingham Paget's Centre of Excellence, with iPSC culture and

CRISPR gene editing, to engineer the first iteration of a Paget's disease stem cell bank. Specifically, they will introduce disease-associated mutations into different genes that predispose individuals to Paget's disease. The generated library of cell lines will act as a resource and be held in a collection for the broader Paget's research community, to incorporate into advanced patient-relevant cell models of Paget's disease, representing a platform to understand and ultimately better target the condition.

Winifred Ditchfield Award

Paget's at the Priory

Principal Researcher: Lynn Smith, Senior Keeper

Institution: University of Priory Museum & Gardens

A new educational project has been awarded funding by the Paget's Association, in collaboration with the **Michael Davie Foundation**. The Winifred Ditchfield Award has been granted to the team at Norton Priory Museum, Runcorn, Cheshire, to update the information on Paget's disease within the museum.

Part of the interpretation within the main gallery of the museum is an area devoted to the explanation of the usually high prevalence of

an ancient form of Paget's disease within the medieval human skeletal collection. Since 2016, thanks to the Paget's Association and other funders, the research team have carried out a substantial amount of further research which sheds light on the collection. The new funding will enable videos and gallery interpretations to be updated with the very latest scientific results and will include explanations of what they tell us about the history of the

disease and how this informs what we know of Paget's disease today. In addition, another medieval skeleton affected by Paget's disease will join the other two already on display to have their stories told as evidenced by the research.

We look forward to seeing how Paget's disease will be further highlighted and explained to the many visitors, community groups and school children who spend time in the museum.

NEW EDUCATIONAL PROJECT

Cambridge Paget's Information Event

**Thursday
27 June 2024**

**Madingley Hall
Madingley
Cambridge
CB23 8AQ**

**10.00 am to 3.00 pm
(to be confirmed)**



Bring your questions to this free event on Thursday 27 June 2024 at Madingley Hall, Cambridge, a stunning venue about 20 minutes by taxi from Cambridge train station. Lunch and refreshments are included and you are welcome to bring someone with you but places must be booked in advance.

Reserve your place/s

You can reserve your place/s either on our website, by telephoning **0161 799 4646**, by sending an email to membership@paget.org.uk or by completing and returning the form on the next page.

Madingley Hall

Boasting seven acres of spectacular gardens and grounds designed in the 18th century by 'Capability' Brown, Madingley Hall is approximately four miles from the centre of Cambridge.

Steeped in history the building of Madingley Hall began in 1543 when the 'Shire Manor of Madingley'



was granted to John Hynde by an Act of Parliament. The Hall passed to his son, Sir Francis Hynde, who extended it in 1591 creating a larger family home. When Sir John Hynde Cotton inherited it in 1712 he transformed it from a panelled Tudor house into a Baroque building.

In 1861 Edward, Prince of Wales, arrived at Madingley Hall. His mother, Queen Victoria rented it for her son whilst he studied at university. His stay was brief and his departure sudden due to Prince Albert's death.

In 1871 the Hall was sold to a Mr Hurrell, and then in 1905 to Colonel Walter Harding, whose portrait hangs in the Gallery on the first floor. He completely renovated the Hall and in due course, his heirs sold it along with the land, to the University of Cambridge in 1948 for the sum of £50,000.



Reserve your place now

Today, Madingley Hall has 16 meeting rooms, 62 ensuite bedrooms and ample car parking. It is a popular wedding venue and is home to the University of Cambridge’s Institute of Continuing Education, which provides courses, conferences and summer programmes.

Visitors can walk around the garden from 10 am to 3 pm most days. Please see their website for more information.

www.madingleyhall.co.uk



BOOKING ESSENTIAL

Cambridge Paget’s Information Event booking form

Cut out or photocopy this form. Alternatively, call 0161 799 4646.

Please complete each section as appropriate. Full details will be sent to you approximately two weeks before the event.



I/we wish to attend the free Paget’s Information Event at Madingley Hall, Cambridge on 27 June 2024. (Please tick box)

Names of those attending

Name & address for correspondence

 Postcode

Please state any special dietary requirements

Telephone

Email

I am likely to be travelling by **car/bus/train/taxi**
(delete as appropriate)

Please state any special requirements
i.e. space for a wheelchair

Please return this form by post to:
The Paget’s Association, Jactin House, 24 Hood Street,
Ancoats, Manchester, M4 6WX
or email the above information to:
[**membership@paget.org.uk**](mailto:membership@paget.org.uk)

Allan Reid Trophy Day

A fundraising day at Mearns Bowling Club, Glasgow, raised a magnificent £650 to support the Paget's Association's vital work.

The weather was kind and thirty-three members participated in the Allan Reid Trophy Day. Member of the Paget's Association, Norma Reid said, 'Everyone thoroughly enjoyed it'. The trophy was presented in memory of Norma's husband, Allan, who passed away in 2014, from osteosarcoma, a type of bone cancer that is a very rare complication of Paget's disease.

Well done to all who organised the event and helped raise not only funds but also awareness of Paget's disease.



The winning team (left to right): Alan McAlister, Maureen Newbon and Barry Kavanagh

Don had fractures

Don Bastock is a retired Civil Engineer from New South Wales, Australia. To help others diagnosed with Paget's disease, Don completed our 'Share Your Story' form. We then liaised with him to approve any edits and check everything prior to publication in this magazine. This is Don's story.

What are your hobbies/interests?

- o Investigating the meaning of life and the universe
- o Choral singing (tenor)
- o Golf (pre-Paget's)
- o Scrabble
- o Languages

Is there anything you would like to share regarding how you were diagnosed with Paget's disease?

About 12 years ago I was referred to a local surgeon with pain in my right knee area. An x-ray indicated Paget's in the top of my right tibia.

Which bones are affected and what symptoms have you experienced?

Paget's is in the right tibia only. I had substantial swelling of the knee area and a year ago I experienced severe pain from the tibia, knee and ankle. I was diagnosed with insufficiency fractures* caused by Paget's. Physiotherapy and exercise improved the pain considerably.

* insufficiency fractures are a type of stress fracture sometimes caused by normal stress upon weakened bone.

Have you needed any treatment?

Yes, medication (risedronate tablets) quickly stopped the pain.

Is there anything you have had to give up or change due to Paget's disease?

Golf.

What would you say to anyone newly diagnosed with Paget's?

Exercise as much as you can.

Share your story

If you would like to share your experiences of Paget’s disease to help support others, please complete any or all of the sections below. You can email or post the responses to us. If you have any questions, please don’t hesitate to contact us.

Name

What county and country do you live in?

.....

What is your current occupation?

.....

If you are retired what was your occupation before your retirement?

.....

If you would like to tell us something about yourself e.g. your hobbies/interests, please do so here

.....

.....

.....

.....

Is there anything you would like to share regarding how you were diagnosed with Paget’s disease? e.g. Did it take a long time to get a diagnosis?

.....

.....

.....

.....

.....

.....

.....

Which bones are affected and what symptoms have you experienced?

.....

.....

.....

.....

Tell us about any treatment you have had for Paget's disease e.g. did it help?

.....
.....
.....

Have you suffered any complications of Paget's disease?

e.g. broken bone, osteoarthritis in the joint adjacent to bone affected by Paget's. Yes No

If yes, could you explain briefly?

.....
.....
.....
.....

Is there anything you have had to give up or change due to Paget's disease?

.....
.....
.....

What would you say to anyone newly diagnosed with Paget's?

.....
.....
.....

Any other comments

.....
.....
.....

I am happy to share my story in the Paget's News magazine and am aware this is also available online.

Do you give your permission for us to share your story on social media? Yes No

Signed Date

As you will need to approve the final copy, please complete the following so we can contact you regarding your story. We would love you to include a photo if you would like to send one to us.

Email address (if you have one) Telephone number

You can type your responses into an email or scan the form and email it to **diana.wilkinson@paget.org.uk**
Alternatively, post the form to The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX.

Thank you

Do you know any marathon or long-distance runners?



With the excitement of this year's London Marathon behind us, it's time to turn our attention to the upcoming challenge on 21 April 2024. We're on the lookout for those in your circle of family and friends who might be eager to seize the opportunity to take part.

The Paget's Association holds a limited number of charity places and we're actively seeking passionate runners who are ready to embrace this incredible experience.

Upon acceptance, successful applicants are expected to contribute a non-refundable registration fee of £50 and to gain sponsorship of at least £1,500. If you or anyone within your family and friends would like to participate, an application form is available on our website. Alternatively, email membership@paget.org.uk or call us on **0161 799 4646**.

■ Please help us to raise funds by distributing this information as widely as possible.



Journal news



Antibodies hundreds of years old found in teeth may give new insights into triggers for ancient Paget's

A new research study that purified antibodies from a medieval person with Paget's disease, found that teeth could be capable of preserving antibodies for hundreds of years, allowing scientists to investigate the history of human exposure to environmental pathogens.

Antibodies are proteins produced by the immune system as a natural response to infectious organisms like viruses and bacteria. Their job is to recognise these microbes so that the immune system can attack them and clear them from the body. In the new paper, first presented at the International Symposium in April 2023 and now published in the journal *iScience*, antibodies extracted from 800-year-old medieval human teeth were found to be stable and still able to recognise viral proteins.

The study was led by Professor Robert Layfield, Vice-Chair of the Paget's Association, with research technician Barry Shaw



from the School of Life Sciences, University of Nottingham, in collaboration with Professor Anisur Rahman and Dr Thomas McDonnell from the Department of Medicine at University College London. It expands the study of ancient proteins, referred to as palaeoproteomics, potentially allowing experts to analyse how human antibody responses developed through history.

Palaeoproteomics can reach back into deep time with ancient proteins already successfully recovered and identified after preservation in 1.7 million year old dental enamel from an ancient rhinoceros and

an ostrich eggshell more than 6.5 million years old. In this new study, the authors also found preliminary evidence that, like the medieval human teeth, mammoth bones nearly 40,000 years old appear to preserve stable antibodies.

This science has previously been applied by the Nottingham team to the analysis of other disease-associated proteins recovered from archaeological human bones and teeth to allow identification of an unusual ancient form of Paget's disease at Norton Priory in Runcorn, Cheshire. Research funded by the Paget's Association enabled one of the authors Silvia Gonzalez, Professor in Quaternary Geology and Geoarchaeology at the School of Biological and Environmental Sciences, at Liverpool John Moores University, to investigate Paget's disease at Norton during Medieval times (AD 1020-1479). By studying their teeth (stable isotope studies) it was identified that these individuals had a mainly marine-based diet and

were born and lived locally in the North West of England, a recognised hotspot of modern Paget's disease.

Professor Layfield explained the new research: "In discovery science we come to expect the unexpected, but the realisation that intact, functional antibodies can be purified from skeletal remains in the archaeological record was quite astonishing. Some ancient proteins were known to be stable, but these tend to be 'structural' proteins such as collagens and keratins, that are pretty inert."

Professor Rahman added: "Antibodies are different because we are able to test whether they can still do their job of recognising viruses or bacteria even after hundreds of years. In this case we found that antibodies from medieval teeth were able to recognise Epstein-Barr virus, which causes glandular fever. In future it could be possible to look at how antibodies from ancient specimens react to diseases present during those periods, such as the Black Death."

Further functional analyses of ancient antibodies offer the potential to study if past exposure to candidate viral pathogens may have been an environmental trigger for medieval Paget's disease.

REFERENCE

Shaw, B., McDonnell, T., Radley, E., Thomas, B., Smith, L., Davenport, C., Gonzalez, S., Rahman, A., Layfield, R., *Preservation of whole antibodies within ancient teeth*, *ISCIENCE* (2023), doi: <https://doi.org/10.1016/j.isci.2023.107575>.

Visit the Paget's Association's website for details of the research and educational funding available
www.paget.org.uk

Quick facts

Paget's disease is often diagnosed incidentally through blood tests, x-rays or other imaging tests carried out for unrelated reasons. Blood tests that measure specific markers of bone turnover, such as alkaline phosphatase (ALP), may be above normal in active Paget's disease.

The most common symptom is pain.

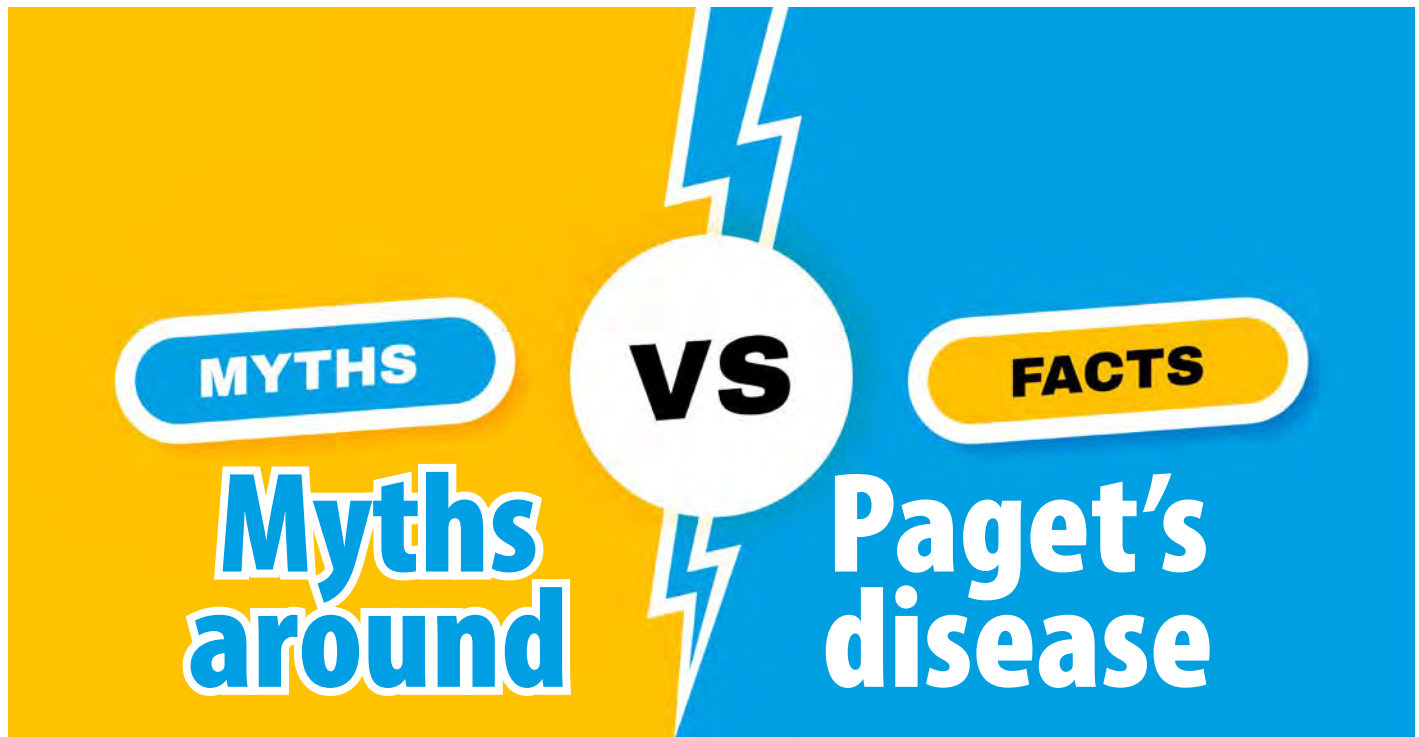
Treatment: Bisphosphonates (e.g. a zoledronic acid infusions or risedronate tablets) are the group of drugs most commonly used to slow bone turnover.

Paget's disease can affect any bone in the body but most commonly involves the pelvis, spine, skull, and long bones of the legs (such as the femur and tibia).

Some people will have the condition in just one bone (monostotic) whereas others will have it in several bones (polyostotic).

As to the cause of Paget's disease, genetic factors play a role and unknown environmental factors may also contribute to its development.

With appropriate treatment and management, the outlook for individuals with Paget's disease is generally favourable. Most people can lead a normal life with few limitations.



Based on the queries received by the Association's Nurse Helpline, it is evident that there are several misconceptions regarding Paget's Disease of Bone. Here, our Specialist Nurse Diana Wilkinson dispels some of these myths.

Myth Paget's affects every bone

Fact Paget's disease can affect one (monostotic) or several (polyostotic) bones but it does not affect them all.

Myth It is the same as osteoporosis

Fact Although both Paget's disease and osteoporosis involve abnormal bone metabolism, they are separate diseases. Osteoporosis is characterised by a decrease in bone density, making bones fragile. In contrast, Paget's disease results in excessive bone remodelling, leading to the formation of bone that has an abnormal structure. This can result in enlarged, weakened and misshapen bone.

Myth Those with Paget's will eventually require a wheelchair

Fact This is a question that is asked a great deal but thankfully it is very rare for people to become so immobile due to Paget's disease that they require a wheelchair.

Myth It always causes pain

Fact Not everyone affected by the disease experiences pain. In some instances, there may not be any symptoms at all.

Myth Paget's is linked to breast cancer

Fact Due to his extensive work, Sir James Paget's name was given to several diseases including Paget's Disease of the Breast, a type of breast cancer. These conditions have no other connection to Paget's Disease of Bone.

Myth It only affects older people

Fact While Paget's disease is more common in individuals over 50, it does affect many people under 50.

Myth Paget's disease is contagious

Fact Paget's disease is not contagious; you cannot catch it from someone who has the condition.

Myth It will always lead to deformities

Fact The intensity of Paget's disease varies among individuals and not everyone affected by the condition will experience visible bone deformities.

Myth Paget's disease inevitably leads to bone cancer

Fact An unusual and very rare complication of Paget's disease is a type of bone cancer called osteosarcoma. This is very rare, occurring in less than 1:1,000 people with the disease. Anyone who is concerned about this can contact our Paget's Nurse Helpline (page 22).

Myth Paget's can spread from bone to bone

Fact Paget's seldom spreads from one bone to another. However if it is not treated, it often progresses within the bone/s that it affects.

Myth Treatment cures it

Fact Treatment with a group of drugs known as bisphosphonates does not cure Paget's disease but it does make the bone cells behave more normally. This leads to better quality bone. Treatment can also greatly help pain arising directly from the condition. One treatment with a bisphosphonate, such as zoledronic acid, can be sufficient to quieten the disease for many years.

Myth Treatment is so good that further research is not needed

Fact Whilst it's true the treatment available for Paget's disease is, for many, very effective, we know that others still suffer from pain and complications. This is why it is vital that the Paget's Association continues to fund and encourage quality research.

Focus on Paget's research

Paget's Awareness Day 11 January 2024

On International Paget's Awareness Day 2024 the focus will be on research in the area of Paget's disease. We will be sharing videos from laboratories across the UK that will showcase some of the studies currently underway. Look out for these on our website and our YouTube channel.

Join Professor Stuart Ralston, Trustees and staff for a **Virtual** (via Zoom) **Paget's Question and Answer session** on **11 January 2024 at 4.00 pm.**

If you are not in the UK, please check the local time for you or get in touch.



Productive meeting of members in Stafford

We would like to extend our heartfelt gratitude to all those who attended the free information event on Paget's disease at the beautiful Moat House in Stafford. We know that many of you travelled quite a distance to join us so thank you for your enthusiasm and willingness to learn.

Throughout the event we had the privilege of hearing from experts whose presentations and insights were invaluable. We believe that the information shared will empower those with Paget's disease to make informed decisions about their health.



The Moat House, Stafford

For those who missed the event, we will be sharing some of the key highlights in the next edition of Paget's News. Next year we are holding similar events in Cambridge (page 8) and in the Middlesbrough area and we hope to see some of you there.

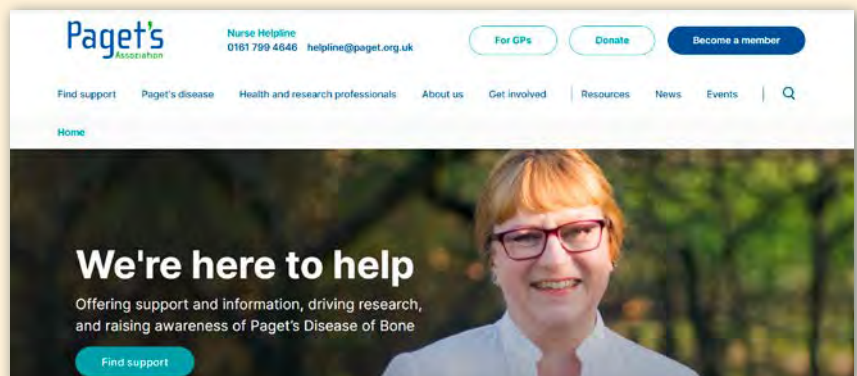
New website coming soon

Our new website will soon be live!

Establishing a robust online presence is pivotal for the Paget's Association, allowing us to extend our reach and assist more individuals. Our new website will continue to serve as a hub of information as well as supporting our ongoing mission to raise awareness about Paget's disease. This investment not only ensures our alignment with the ever-evolving

digital landscape but also underscores our commitment to environmental sustainability. With faster page loading, enhanced accessibility, an improved user experience, and heightened visibility, our website will stand out. It will boast robust security, accessibility, scalability and will be hosted by a provider running exclusively on renewable energy sources.

The website was designed with you in mind. We invite you to explore the wealth of information, stories, and more that it offers. Your feedback is welcome and we would be delighted to hear from you.



Enter the monthly draw and help make a difference!

By purchasing a ticket or even two in the Paget's Association's Raffle you can directly contribute to our charity and mission to help those in need. Together we can make a positive difference!

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.

Don't miss out on your chance to secure a cash prize. Unlike many lotteries our raffle has remarkably favourable chances of winning, thanks to our strict limit of 200 tickets for sale. 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.



Joining the raffle is simple; anyone over 18 can take part. To become a part of this initiative and secure your chance to win, request a form by emailing membership@paget.org.uk or by telephoning **0161 766 4646**.



★★★★★ Recent winners! ★★★★★

July

1st Prize £100
Ticket no. 185
Christine Cratchley
London

2nd Prize £50
Ticket no. 83
Thelma Couch
Fife

August

1st Prize £100
Ticket no. 184
Christine Cratchley
London

2nd Prize £50
Ticket no. 97
Anne Chequer
Devon

September

1st Prize £100
Ticket no. 90
Eileen Wallace
Warrington

2nd Prize £50
Ticket no. 200
Josephine Croft
Oxford

The Paget's Association's Raffle application form



Please accept my application for membership of the Paget's Association's Raffle. I have read and understand the rules.

Name

Address

Postcode

Email Telephone

Signature Date

Number of tickets per month required: 1 or 2 (please delete as required)

The cost of raffle entry is £5 per ticket per month. If you opt to pay monthly, we ask that you pay by standing order, otherwise you can pay half-yearly or annually by standing order, bank transfer (using the bank details below) or cheque. Cheques must accompany the completed form to be acceptable. To pay by standing order, please complete the standing order mandate below and return to the Paget's Association. Paying by standing order is the preferred method of payment as this eliminates the need for reminders and the risk of not being entered into the draw because of late payment.

Payment method

(please circle as appropriate)

I will be paying by -

Standing Order

Bank transfer

Cheque

Payment options for 1 number/month	Tick preferred option
Annually £60	
Half-yearly £30	
Monthly £5	

Payment options for 2 numbers/month	Tick preferred option
Annually £120	
Half-yearly £60	
Monthly £10	



Standing Order mandate – Paget's Association's Raffle (also known as the 200 Club)

To Bank plc

Bank address

Postcode

Pay to the credit of National Association for the Relief of Paget's Disease at:

Barclays Bank, 1 Market Street, Bolton, BL1 1BU. Account number 30660078 Sort code 20 10 71

The sum of £ **monthly/half yearly/annually** (delete as appropriate)

Commencing on / / **until further notice**

From: My / our account (name)

Account no Sort code

Home address

Postcode

Signed Date

Please return this form by post to:

The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester M4 6WX.

Paget's Association's Raffle rules

The rules for the Paget's Association's Raffle are simple and are as follows:

1. The Paget's Association's Raffle (also known as the 200 Club) is open to anyone over the age of 18 and is limited to two numbers per person, with a maximum of 200 numbers. Should there be more applicants than numbers, awaiting list will be drawn up, and when numbers become available, they will be allocated to the person at the top of the waiting list.

2. The cost of raffle entry is £5 per ticket per month. If you opt to pay monthly, we ask that you pay by standing order, otherwise you can pay half-yearly or annually by standing order, bank transfer (using the bank details below) or cheque. Cheques must accompany the completed form to be acceptable. To pay by standing order, please complete the standing order mandate below and return to the Paget's Association. Paying by standing order is the preferred method of payment as this eliminates the need for reminders

and the risk of not being entered into the draw because of late payment. To pay by standing order, please complete the standing order mandate and return to the Paget's Association's office.

3. Should membership drop below 50 at a future date, monthly draws will be suspended until this minimum figure is reached. If this situation should occur all members will be advised in writing.

4. The winning numbers will be drawn by staff at the Paget's Association on the last Wednesday of each month. Winners will be advised by post, and a list of prize winners for the preceding period will be included in each Paget's News magazine.

5. Prizes will be a £100 first prize and a £50 second prize. Twice a year, in June and December, the prize money will be doubled to £200 and £100 respectively.

6. If payment is not received by the day of the draw, the relevant numbers will be withdrawn.

7. Should payment not be made for two consecutive months we will treat this as a termination of raffle membership and offer the number to the person at the top of the waiting list.


8. All proceeds from activities relating to the Paget's Association's Raffle will, with the exception of prize monies, be used for the furtherance of the work of the Association.

■ If you wish to participate in the Paget's Association's Raffle, please complete the application form overleaf and return it to the Paget's Association.

■ If you have any queries please contact us at membership@paget.org.uk or by telephoning **0161 799 4646**.

www.paget.org.uk





Information and support services provided by the Paget's Association

Paget's Buddies

If you would like to talk to someone else who has Paget's disease, simply contact our Helpline and we will arrange this for you.

Paget's Nurse Helpline

Contact us for support, information, or simply a listening ear.

Email: helpline@paget.org.uk

Telephone: **0161 799 4646**

Mobile: **07713568197**

Paget's information videos

View on YouTube a collection of videos discussing personal experiences, diagnosis, treatment methods, and research.

Search
YouTube for @PagetsAssociation

Paget's Network

Connect with several other members by phone, letter, email or however you would like to communicate.

Request a Support Network form

Information

Our latest information booklets can be downloaded from our website or sent to you by email or post.

Virtual Paget's Support Groups

Meet others affected by Paget's disease at one of our virtual support groups. For more information or to take part, please email membership@paget.org.uk or register on our website.

Facebook support group

To join, please scan the QR code with a smartphone or visit

<https://www.facebook.com/groups/pagetsdiseaseofbone>





We would like to wish
all our members a

*Happy
Christmas*

&
best wishes for a happy
and healthy 2024

Send an e-card
To support the Paget's Association
and help the environment why
not send an e-card?



Find us on
DontSendMeACard.com

Help us do more

We understand that everyone's circumstances are different and we are grateful for every donation regardless of size to help us fund advancements in research, provide vital resources and create a stronger support network for those affected by Paget's disease. We have accomplished so much together already but we want to do more.

Here's how you can contribute:

One-off donation

Your one-off donation can make a meaningful difference in supporting individuals and families affected by Paget's disease. You can donate on our

website, by bank transfer (call us for details) or send your cheque, made payable to the Paget's Association, to the address on page 3.

Monthly giving

Consider donating monthly by standing order. Your consistent support provides us with a stable foundation to plan and execute long-term projects. Simply request a standing order form from our office.

Raffle

By purchasing a number in the Paget's Association's Raffle you directly contribute to our charity and our mission to help those in need. Please see the details on page 19.

**50th
Anniversary
Fundraising
Campaign total
£61,041**

Fundraising

Get involved by organising a fundraising event that raises funds and awareness of Paget's disease.

Legacy giving

Leave a lasting legacy by including Paget's Association in your will and your generosity will continue to impact lives for generations to come.

Fortifying our online presence



Trustee Dr Sheelagh Farrow leads the Digital Communications and Marketing Committee (DCMC) of the Association, with a primary focus on overseeing and optimising the charity's digital marketing initiatives. The committee plays an indispensable role in ensuring the maintenance of a robust online presence and the effective utilisation of digital tools and platforms to achieve our objectives.

The DCMC has been actively supervising the commissioning of our new website and database. This is crucial for the Paget's Association to be able to reach and help more people. It will remain an excellent source of information and aid our continued mission to raise awareness of Paget's disease and to provide support for all who need it.

Another responsibility of the DCMC is to oversee our representation on social media platforms, including the management of digital advertising campaigns. This effort is vital in establishing and sustaining a favourable online reputation and ensuring effective engagement with the public.



The monitoring and analysis of our digital footprint are also carried out to enable the DCMC to make effective decisions to achieve the best results within the available resources.

The DCMC's diligent efforts are indispensable for fortifying our online presence, effectively engaging with those in need of our services, and raising awareness about Paget's disease.



Marilyn McCallum

In September we heard the sad news that former Chief Executive of the Paget's Association Marilyn McCallum had passed away suddenly. Marilyn was initially appointed as a part-time administrator in 1997 before becoming Director in 1999 and Chief Executive in 2007. She continued her dedicated service in this role until a reorganisation of the charity in 2013.

Over her sixteen years Marilyn oversaw many positive changes, firstly at the Association's office in Eccles and then at Walkden. These included the introduction of information technology within the administration of the charity.

Throughout her time with the Association, she always had the interests of the members at heart, which was exemplified in the innovations which she instigated and oversaw.

Everyone at the Paget's Association would like to extend their sincere condolences to her husband, Frank, children and grandchildren at this sad time.

An investment in the future

Whilst some of those living with Paget's disease have few problems from it and find treatment very successful, we know that for many others the condition can present a range of challenges and complications. In addition, the emotional impact of living with Paget's disease should not be overlooked. Coping with pain, limited mobility, and the uncertainty of disease progression may lead to feelings of frustration, isolation, and depression.

As you know, the Paget's Association provides invaluable resources for those living with the condition and funds research to improve our understanding of the disease, develop better treatments, and work towards a cure. Running a charity however, requires significant financial resources, and that's where legacies are crucial.

A gift left in a will is an investment in the future and a powerful way to make a lasting impact on the Paget's Association and the individuals we serve. Leaving a legacy to a charity in the UK also offers advantages for the individual. In the UK, donations made to charities through a will can be exempt from inheritance tax. Your donation will either be taken off the value of your estate before inheritance tax is calculated or reduce your inheritance tax rate if 10% or more of your estate is left to charity. You can donate a fixed amount or what's left after other gifts have been given out.

The government website has more information www.gov.uk/donating-to-charity/leaving-gifts-to-charity-in-your-will

Will you help us ensure that the Paget's Association has the necessary resources to continue our important work, support those living with Paget's disease, and ultimately find a cure? Please consider leaving a gift in your will to the Paget's Association. If you have already done this, thank you, your support means so much.

Remembering family and friends on birthdays and anniversaries

We would like to extend our sincere thanks to all those who chose to honour the memory of a loved one by donating to the Association on birthdays or anniversaries. Your kindness is appreciated.



**Have you
made a
note of
our new
address?**

Paget's
Association

**The Paget's Association
Jactin House
24 Hood Street
Ancoats
Manchester
M4 6WX**

**Our telephone number
remains the same
0161 799 4646**



Changes to your Paget's News magazine

We would like to bring to your attention an important update regarding our Paget's News magazine. After careful consideration, the Trustees have decided to make a change to our current magazine schedule. Starting next year, the number of magazines published annually will be reduced from four to three.



This decision was made based on several factors including the need to optimise our resources, market trends and operational considerations. While we understand that some of you may have grown accustomed to receiving four magazines each year, we believe this adjustment will ultimately benefit the charity and our members. We will continue to produce content that is relevant, informative, and engaging. By focusing on fewer issues, we aim to deliver a more enriching and impactful reading experience.

We encourage you to share any concerns or suggestions you may have regarding this decision. We are committed to continuously improving and adapting to meet the evolving needs of our members and the wider community. Please feel free to reach out to us with any questions or comments you may have. We appreciate your understanding and ongoing support as we strive to provide the best possible experience for you all.

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.



Dr Catherine Nairn

A General Practitioner, Catherine developed an interest in Paget's disease while working

at the Western General Hospital, in Edinburgh.



Mrs Kely Burman

A retired nurse and midwife living in Orsett, Kely has not only cared for those with Paget's

disease, but her mother also had the condition.



Dr Faiz Rahman

Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the

University Hospitals of Leicester, where he is involved in caring for those with Paget's disease.



Mr Mohamed El Erian

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



Mrs Amanda Sherwood

Amanda lives in Bristol and is now retired. She has experience in working for societies

and teaching organisations which specialise in the field of bone and related topics.



Dr Sheelagh Farrow

Sheelagh lives in Surrey and, prior to retirement, was Managing Director of International Medical

Press, a provider of independent medical education.



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.

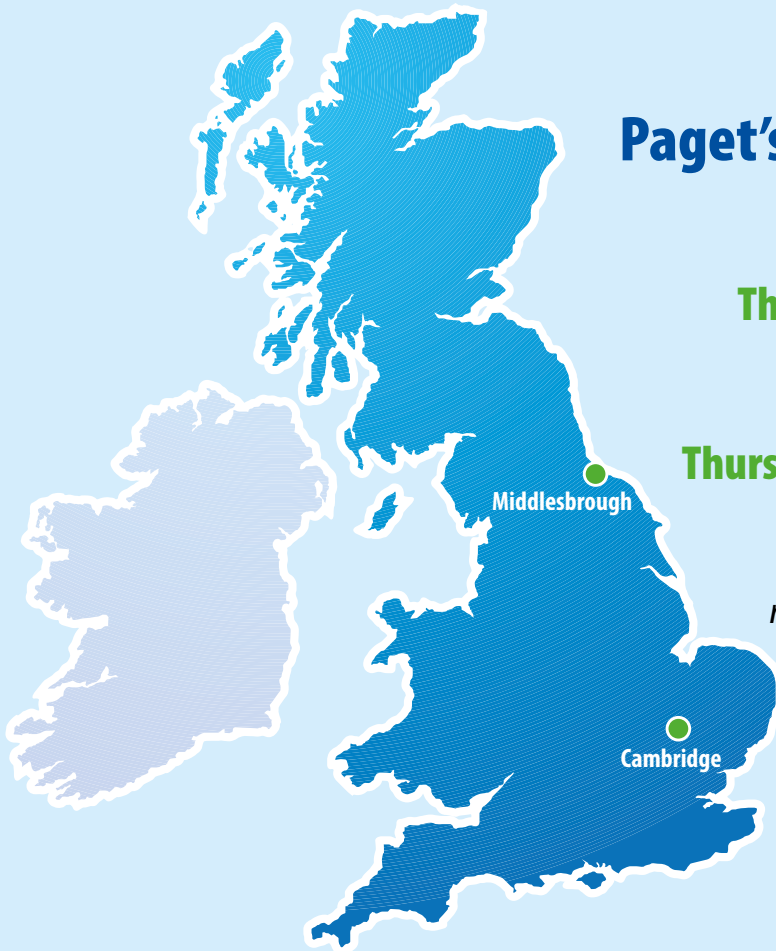


Mr Alan Martin

A retired company director, Alan lives in Wokingham. He has Paget's disease and

believes the interaction between patients and clinicians brings mutual benefits.

Join us in 2024



FREE

Paget's Information Events

Cambridge

Thursday 27 June 2024

Middlesbrough

Thursday 19 September 2024

*Lunch and
refreshments included*

Virtual Paget's Support Groups

Please see our website for dates and times

Contact us

0161 799 4646
helpline@paget.org.uk | membership@paget.org.uk

Paget's
Association

www.paget.org.uk

The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX