

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



# We need your help!

Page 6

Plus

Page 24

Groundbreaking results  
give hope on International  
Paget's Awareness Day

Pages 14 and 20

Meet experts in  
Cambridge or  
Middlesbrough

Pages 10 and 18

Diane, Hope, Susan  
and William all  
share their stories

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## Diane's experience

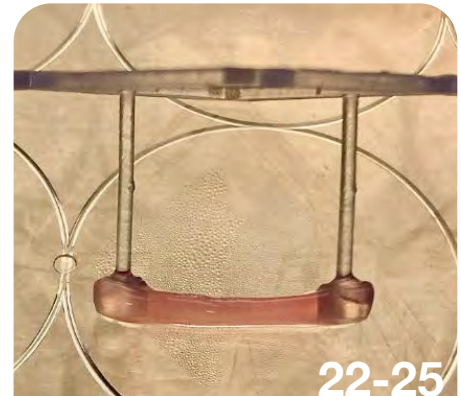
Diane was forced to retire early due to chronic pain. She shares her challenging journey.



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## Ask the experts at our Middlesbrough event

We look forward to welcoming you to the heart of Middlesbrough.



22-25

## International Paget's Awareness day 2024

Researchers, clinicians and our supporters collaborated to highlight Paget's research.

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# Meet the team at the Paget's Association

## Honorary President



**Professor Graham Russell**

Involvement 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.

# Chair's message

Dear Member

Welcome to the latest edition of Paget's News. As always, the magazine is packed with information about the work we have been doing to support research and raise awareness about Paget's disease, as well as providing information on upcoming events and fundraising opportunities.

Fundraising is a key theme of this edition. As you all know, 2023 was an important milestone for all of us involved in the charity, marking the 50th Anniversary of the Association. We held a highly successful international symposium on Paget's Disease of Bone at Salford Quays in April 2023 and exceeded our fundraising target of £50,000 to help support the meeting.

Unfortunately, our finances are not as healthy as we would like at the present time due to ongoing commitments to support research, raise awareness, and provide support for people with Paget's disease. Although we have made all efforts to reduce expenditure we have experienced a substantial decline in income due to a decrease in legacies over the past five years. I know from speaking to those involved in other charities that this is unfortunately a common theme.

We are hopeful that this may improve but, in the meantime, there is a lot that members of the Association can do to raise funds and allow us to continue our important work to support people with Paget's disease and their families. We have put a comprehensive guide to the various ways of raising funds on pages 6-9 of the magazine. Please have a look and consider what you might be able to do to support us. On a personal level, I was very interested in the *Easyfundraising* pathway which



allows you to raise funds for your preferred charity when shopping online with a variety of retailers. I have already signed up, downloaded the App onto my smartphone and am looking forward to trying it out!

In addition, I've decided to do a sponsored fundraising event by entering the Etape Caledonia in May. This is my third time; I completed 40 miles on my first attempt, 55 miles on my second and this year I'm going for the 85-mile challenge. So, it's a matter of death or glory! Please consider sponsoring me by scanning the QR code.

The third thing to highlight on the fundraising front is to consider registering for our monthly Raffle!

This is a great way to support us as well as a chance to win a prize of up to £200 in the monthly draw. Please email or call us if you want a form to register. If you have the last magazine, you'll also find one there.

Turning to our other features I was very interested to read Diane's story on pages 10-11. Like many people Diane was diagnosed at a late stage when Paget's disease had already resulted in bone deformity and a fracture of her thigh as well as osteoarthritis. She was treated with zoledronic acid but was unlucky to experience side effects the second time she received it. This is unusual but it looks as though things have now settled down. It was great to see the lovely picture of Diane with her grandchildren in sunny Western Australia on page 11.

Diane's experience shows how important it is that the condition is diagnosed early. The Zoledronate in the Prevention of Paget's disease (ZiPP) trial demonstrated this quite clearly and some of you may have looked at the video that Susan McKinnon agreed to do for Paget's Awareness Day in January, recounting



**Scan to sponsor my 85-mile cycle challenge!**



her experience as a trial participant. When Susan entered the trial, she had no symptoms, even though some signs of early disease were present on her bone scan at that time. She successfully completed the trial without having any problems but started to develop hip pain during the extension study. Luckily, we were able to offer treatment with zoledronic acid which helped her symptoms a great deal. The research group at the Edinburgh Centre of Excellence are continuing research aimed at diagnosing Paget's disease at an early stage in people with a family history of the condition. An outline of the study is provided on pages 16-17. We are looking for people aged 45 years or above with a family member who has been diagnosed with Paget's. Volunteers will undergo genetic testing to assess susceptibility to Paget's, as well as a bone scan to detect any signs of early disease. We have many centres open across the UK – so if you have a relative who may be interested, please get in touch with the GAPDPD team using the contact details on page 16.

In closing, I would like to draw your attention to two information events we have scheduled for this year. Details of the Cambridge event hosted by Dr Gavin Clunie on 27 June are on pages 14 and 15, and details of the Middlesbrough event hosted by Dr Stephen Tuck on 19 September are on pages 20 and 21. You can book by completing and returning the relevant form.

With best wishes to all for a successful year ahead!

*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

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

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

**Postal address**  
You can write to us at  
The Paget's Association,  
Jactin House, 24 Hood Street,  
Ancoats, Manchester, M4 6WX

**Website**  
**www.paget.org.uk**



# We need your help

## 50<sup>th</sup> Fundraising Campaign target smashed

We would like to thank everyone who donated, raised funds or took part in our 50th Fundraising Campaign. We are pleased to say that the £50,000 target was smashed, raising over £62,000. Well done everyone!

### A critical juncture

The 50th Fundraising Campaign played a pivotal role in supporting the Association; however, those who participated in the Annual General Meeting (AGM) will be aware that our most recent financial report, covering the year ending December 2022, showed that our outgoings exceeded our income necessitating us to draw on our reserves. A major part of our expenditure is directed towards research projects that we have committed to funding over several years and of course, there are also significant outgoings related to providing support for people who have or may have Paget's and raising awareness of the condition in general. Despite these financial challenges, our dedication to those with Paget's disease and ongoing research is unwavering.

The decline in income is largely attributed to a decrease in legacy contributions and we have already implemented cost-saving measures including a transition to virtual working and closure of the physical office.



The Paget's Association has been a beacon of hope for over fifty years but we find ourselves at a critical juncture, desperately in need of your support. The harsh reality is that, like many charities, we face an uphill struggle to continue our vital work.

### Everyone can help

The Paget's Association does not receive any government funding and its continuation depends solely on donations, fundraising, and legacies. Now more than ever we rely on those who can, to support us and be the lifeline that sustains our charity for those who depend on us.

With your help we can continue to provide our Nurse Helpline, information resources and support networks. We know how important these resources are to you and want to be able to continue to offer them to anyone who needs our support. Alongside this, donations help us continue to strive for earlier diagnosis and additional Centres of Excellence for the care and treatment of those with Paget's disease. Centres that also get involved in research. We know that funding quality research is key to discovering new treatments and exploring new developments such as the potential of genetic testing for those at risk of developing Paget's disease.

Everyone can do something to help. Within the following pages, you will find numerous ideas of how you can help us continue our essential activities.

If you are in a position to donate, your one-off donation can make a meaningful difference in supporting individuals and families affected by Paget's disease.

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*The harsh reality is that, like many charities, we face an uphill struggle to continue our vital work*

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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 5.

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.



**£15**  
could pay for a support pack for someone who is newly diagnosed

**£20**  
could pay for our Specialist Nurse to answer a call from someone who is distressed about their diagnosis and for information to be posted

**£30**  
could pay for someone's place at one of our information events, which are free for those with Paget's disease to attend

**£100**  
could help our fight for earlier diagnosis through research

## Easyfundraising

With easyfundraising when you shop online brands donate to us. It won't cost you a penny!

Brands pay easyfundraising a commission when you start your shop from the easyfundraising website or app.

We know from those of you who have used this already that the donations can really mount up. It's completely FREE so we'd really appreciate it if you could take a moment to sign up and support us.

You can find our easyfundraising page at <https://www.easyfundraising.org.uk/causes/paget/>



## How it works

Over 7,000 brands partner with easyfundraising and each one will donate part of what you spend online to a cause of your choice. So you can choose to donate to the Paget's Association and the best bit is it won't cost you any extra. The cost is covered by the brand.

The brands include Argos, John Lewis, Tesco, Marks and Spencer, Asda, Iceland, Currys, Very, Comparethemarket and many more.



## PayPal Giving Fund



Another way you can help is to add a donation when you shop online and pay through PayPal.

1. Look for the option to add a donation during checkout.
2. Choose the charity you want to support.
3. Choose the amount you want to give.
4. Complete your purchase as usual.
5. Receive a donation receipt from PayPal Giving Fund.

## Send an ecard



Use [DontSendMeACard.com](https://www.dontsendmeacard.com) to send birthday, thank you or other cards and they will give the Paget's Association a small donation. You could also visit our website to donate the cost of cards and stamps.

Use the QR code or place the following in your browser [www.dontsendmeacard.com/ecards/charities/pagets-association](https://www.dontsendmeacard.com/ecards/charities/pagets-association)

If you sell something on eBay their system allows you to choose to donate between 10% and 100% of the item's sale price directly to the Paget's Association.

**We would like to thank those who have supported us in this way.**



## Support us when you sell an unwanted item

## Fundraising ideas from our Focus Group

The Association's Focus Group have been sharing ideas of how individuals and groups might fundraise. Here are some ideas.

- Sell or auction unwanted items on eBay or Facebook.
- Bring and buy stall at a local community event.
- Craft projects could be turned into items to sell e.g. knitting, crocheting, sewing, woodwork, art etc.
- Sell unwanted items or plants you've grown at a car boot or jumble sale.
- Organising a sponsored dog walk or swim.
- Give something up, such as smoking or drinking and donate the money saved.
- Puzzle or quiz night, making a charge to enter.
- Raffle or tombola: a chocolate tombola works well for children and a bottle tombola for adults.
- Complete a sponsored challenge.
- Invite friends to a coffee morning or soup lunch in return for a donation.
- Entertainment event. We have supported charity events at a local social club where a band has played for free and ticket sales have been donated to charity.
- If you have a special birthday or anniversary coming up, consider donating to the Association in place of gifts.
- Set up a birthday fundraiser for the Paget's Association on Facebook.



# FUNDRAISING

## Don't know where to start?

For help with fundraising request a Fundraising Pack from us. Included is a booklet, banner with the Association's logo, leaflets and, if available, promotional items to help raise awareness of Paget's disease and the work of the Association. For further information, or to request your pack please contact us.



Win with our monthly raffle!

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.

By purchasing a ticket or even two in the Paget's Association's Raffle you are contributing directly to our charity and our mission to help those in need. 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). To become a part of this initiative and secure a chance to win, request a form by emailing [membership@paget.org.uk](mailto:membership@paget.org.uk) or by telephoning **0161 766 4646**.

## Recent winners

**October 2023**  
**1st Prize £100**  
Ticket no. 45  
*Roger Francis*  
**2nd Prize £50**  
Ticket no. 4  
*Thomas Trevor*

**November 2023**  
**1st Prize £100**  
Ticket no. 194  
*Norma Reid*  
**2nd Prize £50**  
Ticket no. 169  
*Janet Dixon*

**December 2023**  
**– double prize draw!**  
**1st Prize £200**    **2nd Prize £100**  
Ticket no. 132    Ticket no. 190  
*Ena Davies*        *Margaret Read*

**January 2024**  
**1st Prize £100**  
Ticket no. 134  
*June Errington*  
**2nd Prize £50**  
Ticket no. 2  
*Gaynor Denton*

**February 2024**  
**1st Prize £100**  
Ticket no. 90  
*Eileen Wallace*  
**2nd Prize £50**  
Ticket no. 7  
*Terry Carter*

Help us get to **200** members  
Please tell your family and friends about the raffle

# Diane was forced to retire early due to chronic pain

**Diana Wilkinson, Specialist Nurse at the Paget's Association, summarises Diane Atkinson's experience of Paget's disease.**

Diane's home is in the picturesque landscapes of Western Australia. A former Associate Principal at a high school, she was forced to retire prematurely due to chronic pain. Beyond her career, Diane finds enjoyment in gardening, knitting, documenting her family history, and passionately supporting the West Coast Eagles in the Australian Football League.

When asked about her diagnosis of Paget's disease, Diane shared a challenging journey that included a total knee replacement seven years ago. During the procedure, her thigh bone (femur) was found to have a fracture and a bone in her lower leg (tibia) was found to be very 'chalky', necessitating the use of surgical glue to secure the new knee in place. The recovery from this initial surgery was lengthy, requiring six months away from work and a full year on crutches. After a year of intensive physiotherapy and hydrotherapy, her knee wasn't healing well, prompting her surgeon to request scans that ultimately led to a diagnosis of Paget's disease in her tibia and pelvis, despite no known family history of the condition.

Diane revealed that Paget's disease has significantly impacted her tibia, resulting in the bone bowing and showing signs of stress, yet thankfully avoiding fracture. The chronic pain has been a constant companion and the disease has also triggered complications, particularly osteoarthritis in the knee and hip adjacent to the affected bone. This exacerbated the overall impact of



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***The chronic pain has been a constant companion and the disease has also triggered complications, particularly osteoarthritis in the knee and hip adjacent to the affected bone***

”

Paget's disease on her daily life and added complexity to her ongoing battle with chronic pain.

Two years after her total knee replacement, Diane had to undergo a hip replacement and now, six years after her knee replacement, she faces the prospect of a revision due to signs of it loosening. Diane is taking vitamin D and calcium

supplements, as well as painkillers. She commented, “Hopefully the revision of the knee will give me some pain relief. Fingers crossed”.

Diane detailed her treatment journey. Initially she was prescribed risedronate, a daily tablet that proved to be ineffective, prompting a referral to a rheumatologist. The specialist suggested a zoledronic

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***Diane advocates exercise and finds hydrotherapy effective***

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acid infusion, which she had, and this was followed by a further infusion 12 months later. Unfortunately, the infusions brought their own challenges. Following the first, Diane experienced side effects including nausea, flu-like symptoms and widespread body pain. Unusually, Diane described the second infusion as being worse than the first. Severe vomiting necessitated a visit to the Emergency Department. This is unusual because those who have had side effects the first time often don't on the second occasion.

There is no doubt that Paget's disease has had a significant impact on Diane's life, as not only did it lead to early retirement but it also placed severe limitations on her everyday activities. Her spirit, however, prevails as she continues to do what she can to enjoy life within the constraints of her condition.

In her advice to those newly diagnosed with Paget's disease, Diane emphasises the importance of research and seeking support through groups like the Paget's Association. Despite the charity being based in the UK while Diane lives in Australia, she has found the support and resources provided invaluable. The Association has connected her with a community that understands her struggles, offering much-needed guidance and encouragement.



*Diane lives in Western Australia and is pictured here with her grandchildren*

Diane advocates exercise and finds hydrotherapy effective. She has incorporated these into a daily routine that includes a 1.5 km walk, 10 km on an exercise bike every second day and hydrotherapy on alternating days. These activities have become an integral part of her efforts to maintain her physical well-being.

Her journey is a testament to resilience in the face of adversity. Despite the challenges, Diane has found ways to adapt and incorporate activities that bring some relief. Her story serves as an encouraging guide for those grappling with the complexities of Paget's disease, offering insights into managing the condition.

**Get in touch to share your story**  
**membership@paget.org.uk**  
**0161 799 4646**

# Answering questions in Stafford

New members joined us at our Paget's information event in Stafford. Experts delved into the intricacies of Paget's disease and answered many questions.

## Detailed explanations

Dr Faiz Rahman is a Trustee of the Paget's Association and a Consultant in metabolic medicine and chemical pathology, in Leicester. He explained in detail what Paget's disease is and how it affects bone. He discussed known genetic factors and possible environmental triggers that may contribute to someone developing the condition, however, we don't yet know what these triggers are nor how they interact with the genetic factors.

Dr Rahman stressed that there is consistent evidence that over the last century, in many parts of the world including the UK, there has been a decline in the frequency and severity of Paget's disease.

## Hope for future generations

Chair of the Paget's Association Professor Stuart Ralston discussed how Paget's is diagnosed and expressed great hope for future generations in light of recent exciting research. Turn to page 24 to read more on this.

## A holistic approach

Dr Zoe Paskins, a local researcher from Keele University and a Consultant Rheumatologist in Stoke-on-Trent, explained the treatment of Paget's with a group of drugs known as bisphosphonates. She suggested a holistic approach to pain management because pain in your joints, limbs and back could



Mr Will Gregory discussed the importance of keeping active

be from lots of possible causes e.g. muscles, tendons, osteoarthritis, soft tissues. She explained that sometimes medical treatment may be a test to see if the pain is caused by Paget's disease.

## Active living with Paget's

Consultant Physiotherapist Mr Will Gregory, from Salford Royal Hospital, discussed the importance of keeping active to help maintain healthy bones, control weight, and keep joints moving.

## A sense of community

Specialist Nurse at the Paget's Association, Diana Wilkinson, explained how the charity provides support, resources, and a sense of community to help individuals and their families navigate the challenges and uncertainties that they may come across. She also highlighted the Association's five-year strategy.

## What to do if you have a fall

Mr Gregory examined the many ways falls can be prevented, but if a fall does happen he felt it was important to know how to get up safely.

- Stay calm and check that you are not badly injured
- Decide if you will be able to get up by yourself and, if you can, here's how:
  1. Roll onto one side.
  2. Ease yourself up onto your hands and knees.
  3. Crawl to the nearest firm surface such as a sturdy chair or piece of furniture.
  4. From a kneeling position, if possible put your arms onto the furniture e.g. the seat of a chair.
  5. Bring your strongest knee forward and put that foot on the floor.
  6. Push up with your arms and legs, pivoting around to sit on the surface.
  7. Rest before trying to get up.
  8. Call a friend/relative or your doctor.

## Pain in Paget's

Miss Kathryn Berg presented a comprehensive update on the Pain in Paget's (PiP) research. The study aimed to assess the frequency of musculoskeletal pain in individuals with Paget's disease, identify underlying causes, and investigate potential alterations in pain sensation. She shared insights into the diverse causes of pain discovered during the study, outlined the research methodology, and provided an overview of key findings, including patient responses to treatment. Once the research has been published we eagerly anticipate sharing the results in a future magazine. The research team are grateful to the 168 patients who participated in this invaluable study.

## Orthopaedic surgery

In an insightful session Mr Geraint Thomas, a Consultant Surgeon from Oswestry and Senior Lecturer in Population Orthopaedics at Keele University, delved into the scenarios where individuals with Paget's may require surgery, including procedures like hip replacement and corrective surgery for deformities. He highlighted potential complications and answered questions from the audience.



Several new members joined us for the event

## Feedback

Before concluding the event Dr Paskins opened the floor for any final questions and asked attendees to complete a feedback form. Here are some of the comments about the meeting and topics of interest that those attending found most beneficial.

- Updates on treatment.
- Networking and encouraging research.
- New information.
- It was very reassuring.
- Up-to-date information.
- In-depth knowledge of Paget's.
- A lot of questions that I had were answered.
- Meeting other patients.
- New information on treatment and support.
- The variety and expertise of speakers.
- Treatment and research.
- All presentations and interactions with others.
- Social interaction!
- The variety of topics.
- Learning about the disease and meeting others with Paget's.
- Joint replacement (hip and knee).
- Everything was first class.
- It is good to talk to other people with problems.
- Clear explanations from experts.
- It was all excellent.
- Good range of topics.
- Information on treatment.
- All very informative and covered all aspects.

## Join us in Cambridge or Middlesbrough

We will be holding similar events in Cambridge in June (see page 14) and Middlesbrough in September (details on page 20). Join us if you can.

# Cambridge Paget's information event

**Thursday  
27 June 2024**

**Madingley Hall  
Madingley  
Cambridge  
CB23 8AQ**

**10.00 am to  
approx. 3.30 pm**



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](mailto: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.



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](http://www.madingleyhall.co.uk)

**Reserve  
your  
place now**

**RESERVE**



**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.**

Names of those attending


Please state any food allergies or special dietary requirements

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*

Name & address for correspondence

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

Postcode

Telephone

Email

*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)

# Decoding the risk of Paget's disease in people with a family history of the condition

It has been known for many years, that people who have a relative affected by Paget's Disease of Bone are at increased risk of developing the condition as they get older; this risk starts to kick in from the age of about 45 years onward.

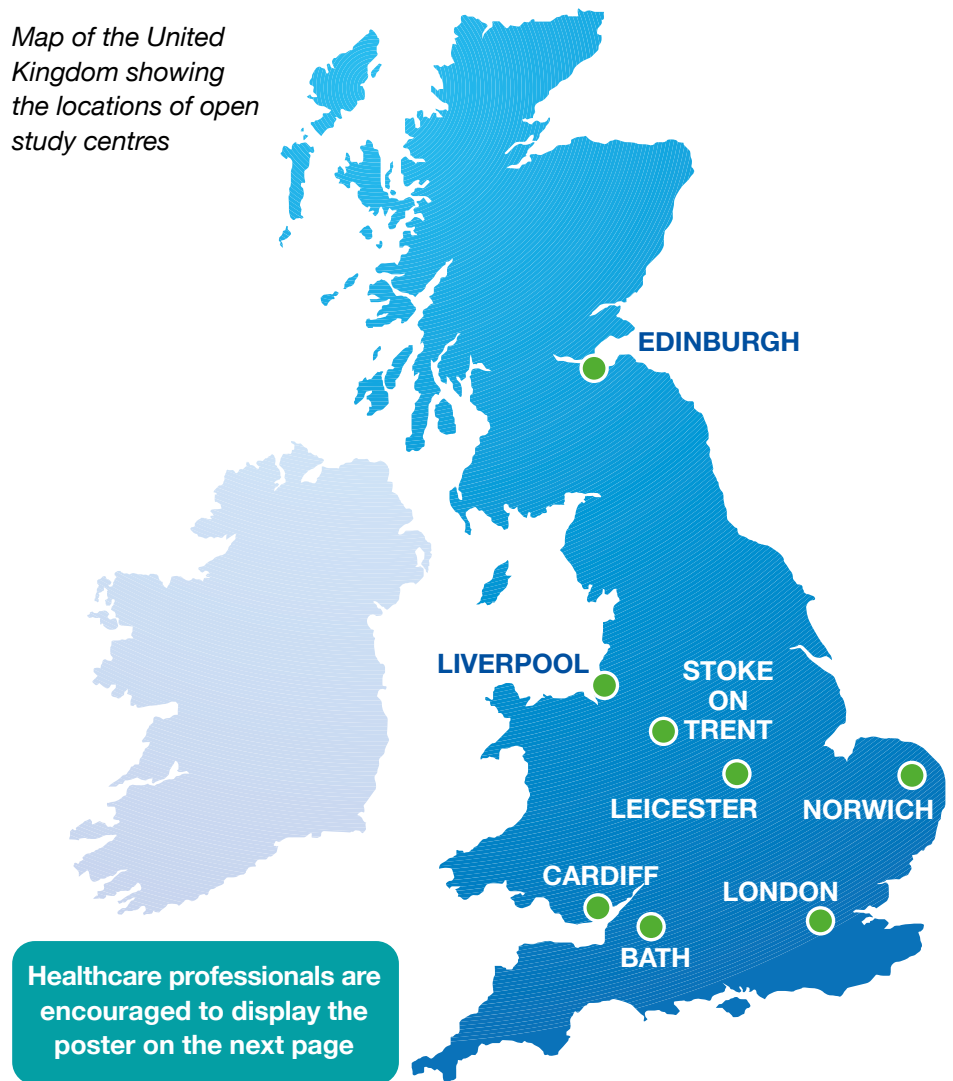
The research team at Edinburgh University, led by Chair of the Board of Trustees, Professor Stuart Ralston, is conducting a new research study in which they are offering people aged 45 years and above who have a family history of Paget's disease a genetic test and radionuclide bone scan to check for early signs of the disease.

The study, called the Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD), is now up and running in several study centres across the UK.

Dr Jonathan Philips, study manager, explained, "We know that having a relative with Paget's markedly increases your risk of developing it later in life – approximately seven-fold compared with people in the general population. The GAPDPD study will offer a genetic test and other tests to screen for evidence of the disease, as well as a radionuclide scan which is a very highly sensitive way of picking up early signs of the disease."

Professor Ralston added, "The problem with Paget's disease is that people may not know they have it until it has reached an advanced stage, by which point there may already have been damage to the bones. The benefit of picking up the disease early, as we hope to do in GAPDPD, is to allow us to identify the condition at an early stage when there is a good chance it can be reversed by treatment."

Map of the United Kingdom showing the locations of open study centres



## Who is eligible to take part?

If you have a parent or sibling diagnosed with Paget's and you are 45 years and older you are eligible. If you have Paget's and have children or siblings not diagnosed with the disease, please draw the study to their attention since they would probably be eligible.

If you are interested in hearing more, please get in touch with the GAPDPD team by phone on **0131 651 8741**, email at [GAPDPD@exseed.ed.ac.uk](mailto:GAPDPD@exseed.ed.ac.uk) or visit [www.GAPDPD.co.uk](http://www.GAPDPD.co.uk).



# GAPDPD study

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

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

### Study aims

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



### Who can take part?

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

### What will your relative need to do?

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

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



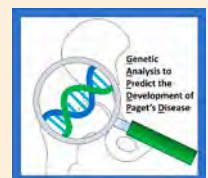
### Benefits

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



### What to do next?

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



# Hope's been lucky



**C. Hope Clark, from Chapin, South Carolina, USA, is both an author and a retired administration director. Hope commented, "I am an avid writer, and have published 18 novels, all mysteries. I also garden and raise chickens! I'm in love with strength training and I work out 5 days a week."**

Hope's GP told her for ten years to forget about her high ALP until an x-ray for something else showed Paget's disease in her pelvis. Hope explains, "He had little experience with it. I now see an endocrinologist annually. She had me on alendronate until I showed her information from the Paget's Association about infusions.

After an infusion of zoledronic acid, my ALP dropped and has remained normal for 6 years. I really like her because she listens. I've been lucky not to have had any complications. I get the occasional ache but have not had much of a problem since the treatment, and my bloods are checked at least annually."

Hope told us that she has given up snow skiing but continues to

be very active. She said her advice to anyone diagnosed with Paget's would be, "Do strength training. Keep moving. You can make your body stronger. Eat a low carbohydrate and higher protein diet and eat healthily. You don't have to decide to be fearful or give in. Fight to stay active. Fight to be fit. Fight to stay healthy. Paget's doesn't have to take over."

# William's reaction to the infusion was rare

William Foulkes, from South Glamorgan, Wales, is a retired hygienic installation engineer who has been married to his wife Christine for a fabulous 60 years. William's Paget's disease affects his hips, arms, ribs, legs and head. He said, "When I was diagnosed I had no idea what Paget's disease was. Professor Stone at Llandough Hospital explained it perfectly. I had the zoledronic acid infusion in March 2023 but was acutely ill for two months afterwards. It was a bad experience. Professor Stone said my reaction to the infusion was extremely rare."

Embracing his retirement, William has a diverse set of interests, from watching football and baking sourdough bread to the incredible joy he finds in tending his allotment.

He has found however that he can no longer enjoy walks as his hips are too painful.

When asked what he would say to anyone newly diagnosed William said, "Don't be afraid – help is there."



*William (left) on his 60th wedding anniversary in October 2023*

## Good to know

- Paget's disease affects the normal repair and renewal process of bone (remodelling).
- Pain is the most common symptom although the clinical presentation and severity vary widely.
- Many people who have Paget's disease do not have symptoms and will never develop complications.
- It is common in the UK, although the frequency and severity of the disease has declined.
- Causes: genetic factors play an important role in predisposing to Paget's disease and environmental triggers probably play a role, but the identity of these triggers is unclear.

# Insights, awareness and a shared commitment

On a snowy winter's day, Lumley Castle, Chester-le-Street, Durham, played host to the regular gathering of the Northeast's regular Regional Bone Meeting, chaired by Dr Stephen Tuck from the Paget's Association's Centre of Excellence in Middlesbrough. Attendees came from the Northeast of England including North and West Yorkshire, Northumberland and also Cumbria.

Dr Tuck said, "It is a meeting of all those who have an interest in metabolic bone disorders including Paget's disease. It comprises, doctors, specialist nurses, Fracture Liaison Service teams, radiographers, physiotherapists, pharmacists and occupational therapists. Its purpose is to discuss services, latest research and guidance, difficult cases and spread best practices. For example, when the Paget's guidelines were completed they were presented to this group. Over 100 people are invited."

During the meeting Dr Tuck emphasised the importance of delivering excellent care and ensuring optimal treatment outcomes. Our Specialist Nurse, Diana Wilkinson, was there to raise awareness of Paget's disease and gave a talk on 50 years of the Paget's Association, shedding light on the charity's invaluable contributions to those affected by Paget's disease and research into the condition.

The event not only provided a platform for the exchange of knowledge but also fostered a sense of community among bone health professionals. Lumley Castle blanketed in snow, became the backdrop for a day filled with insights, awareness and a shared commitment to advancing standards.



*Diana Wilkinson with Dr Stephen Tuck*

## Updating the clinical guideline

At the Paget's Association, our relentless commitment is to facilitate swift diagnosis for those in pain and provide optimal care for individuals diagnosed with Paget's disease. With this objective in mind, we commissioned the development of a clinical guideline for the diagnosis and management of adult Paget's disease, which was successfully published in 2019. We are aware of its positive impact on numerous patients. One of our goals for this year involves commissioning an updated guideline, supported by new research. Dedicated international experts and individuals affected by Paget's disease will generously contribute their time to ensure its timeliness and relevance.



# Ask the experts at our Middlesbrough information event

Reserve your place now

RESERVE

Join us at our Paget's information event in Middlesbrough to connect with experts, gain valuable information, and find support within the Paget's community. Dr Stephen Tuck from the Middlesbrough Centre of Excellence will be hosting the event. Lunch and refreshments are included.

## The venue

We look forward to welcoming you to the heart of Middlesbrough. The Leonardo Hotel is half a mile from Middlesbrough train station.

Middlesbrough has a rich industrial history, with notable connections to steel production and chemical manufacturing. It is the birthplace of the renowned explorer Captain James Cook and visitors will find a museum dedicated to his life and journeys situated in Stewart Park. An iconic landmark of Middlesbrough is the old Transporter Bridge which used to offer a unique means of crossing the River Tees.



## Book your place/s

Whether you're interested in treatment, diagnosis, surgery or you just want to ask questions, come along with your family or a friend and reserve your place/s by email, telephone or post.

**Thursday  
19 September  
2024**

**Leonardo Hotel  
Fry Street  
Middlesbrough  
TS1 1JH**

**10.45 am – 3.30 pm**



# 16<sup>th</sup> Scientific Symposium of Bone and Joint Disease

In January, the 16th Scientific Symposium of Bone and Joint Disease was held in Edinburgh. This was hosted by our Chair, Professor Stuart Ralston, and was followed by Burns Night when our Specialist Nurse, Diana Wilkinson gave a traditional speech in remembrance of Robert Burns.



**BOOKING  
ESSENTIAL**

## Middlesbrough 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 Leonardo Hotel, Fry Street, Middlesbrough on 19 September 2024.

Names of those attending


Please state any food allergies or special dietary requirements

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*

Name & address for correspondence

  
 .....  
  
 .....  
  
 .....  
 Postcode

Telephone

Email

*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)

# International Paget's Awareness Day 2024

On 11 January, researchers, clinicians and our supporters collaborated to highlight Paget's research on International Paget's Awareness Day 2024.

“ Research highlighted for Paget's Awareness Day revealed that the northwest of England still has one of the highest rates of Paget's disease in the world. ”

**Professor Rob Layfield, Chair, Research Subcommittee, Paget's Association**



## The UK's substantial contribution to Paget's research

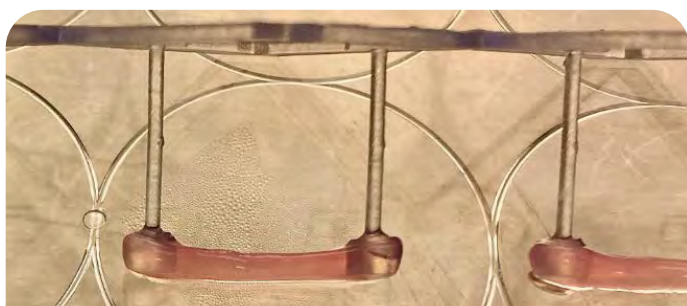
This image shows scientific publications on Paget's disease by country. In his video discussing research funded by the Paget's Association, Professor Layfield, Chair of the Association's Research Subcommittee, highlighted the number of scientific papers published globally, underscoring the substantial contribution made by the UK.



## A journey through time and innovation

Through videos released for International Paget's Awareness Day, you can discover new research and hope for the future. Embark on a visual journey with us through our videos which can be found on our website and YouTube channel. They encapsulate the essence of current Paget's research, not only bringing science to life but also providing a window into the dedication of those striving to unravel the mysteries of Paget's disease.

From laboratories to clinics, the Paget's Awareness Day videos highlight the collaborative efforts driving progress and the hope for a healthier future as groundbreaking results of research, Zoledronate in the Prevention of Paget's (ZiPP) are revealed (page 24). Read on for this and more exciting research.



## Bones in a dish unlock new possibilities

In her video Dr Philippa Hulley from the University of Oxford discussed research to develop a fully human 3 dimensional (3D) bone model of Paget's disease with Professor Rob Layfield. The 3D model of bone formed in a dish from stem cells revealed unexpected results.

The mini bone can be used to find and test new treatments for Paget's disease. Dr Philippa Hulley explains that it will be a powerful tool towards achieving personalised medicine with customisable use of an individual's cells.

**Video watch time: 10 minutes**

## The 210<sup>th</sup> anniversary of Sir James Paget's birth

This year marked the 6<sup>th</sup> Annual Awareness Day and the 210<sup>th</sup> anniversary of Sir James Paget's birth in Great Yarmouth, Norfolk. Renowned as one of the era's most respected surgeons, his legacy extends beyond his surgical skills. Having treated notable figures such as Queen Victoria and The Prince of Wales, he described as many as ten different clinical conditions and earned the distinguished title of the 'Father of British Pathology'.

Sir James Paget's influence was widespread, reflected in numerous honours bestowed upon him by various universities and institutions. His contributions to medicine and science were unparalleled and several medical conditions, including Paget's Disease of Bone, bear his name, a testament to his lasting impact.



## Research funded by the Association

Professor Rob Layfield clarifies in this video the Association's strategic approach to funding and encouraging research, and underlines the ongoing commitment to advancing our understanding of Paget's disease.

Visit our website to watch the video, read details of individual research studies and discover what research has taught us.

**Video watch time: 7 minutes**



## Historical Paget's disease: a hotspot and ancient teeth

The northwest of England has long been a hotspot for Paget's disease. Professor Layfield explained that this and research undertaken on medieval skeletal remains at Norton Priory, Cheshire, help to shape our understanding of the condition and the potential causes. Could ancient teeth hold the answer? Watch the video to learn more.

**Video watch time: 9 minutes**

*continued on page 24*

# Research results could change clinical practice

## Groundbreaking results pave the way for genetic testing



The results of research, Zoledronate in the Prevention of Paget's (ZiPP), will have major significance for those who develop Paget's disease.

In his video interview, Chair of the Paget's Association, Professor Stuart Ralston said, "The results of the ZiPP study will change clinical practice and pave the way for genetic testing to be offered to people with a family history of Paget's so that the condition can be picked up and treated at an early stage."

**Video watch time: 8 minutes**

## Susan contributed to research



Motivated by her brother's battle with Paget's disease, Susan McKinnon took part in research that could change the future for those who may develop Paget's.

She shares her experience of the ZiPP study in an insightful interview with Professor Stuart Ralston. She explains how she was diagnosed with Paget's disease and how she went on to have successful treatment.

**Video watch time: 7 minutes**

● You'll find a transcript of this video on the next page

“ The results of the ZiPP study will change clinical practice. ”  
**Professor Stuart Ralston, Chair, Paget's Association**



## Watch the videos

To watch the videos either scan the QR code or visit [www.paget.org.uk/pagets-awareness-day-2024/](http://www.paget.org.uk/pagets-awareness-day-2024/)



## Thank you for joining us

Members from far and wide joined our Chair Professor Stuart Ralston for a virtual question and answer session held on Paget's Awareness Day. Thank you to all who attended. We hope you found the event beneficial.





# Susan took part in research that could change the future



In a video for Paget's Awareness Day, Susan McKinnon was interviewed by Professor Stuart Ralston. She recalled how she took part in research and also discovered she had Paget's disease. The results of the research, Zoledronate in the Prevention of Paget's (ZiPP), have just been published and are expected to have major significance for those who develop the condition. In this outline of the interview Susan shares her experience of the ZiPP study, explains how she was diagnosed with Paget's and how she went on to have successful treatment.

**Stuart** My name is Stuart Ralston. I'm the Chair of the Paget's Association and it's my pleasure to welcome you to this short video presentation which is one of a series we've produced for Paget's Awareness Day 2024. It marks the 51st anniversary of the Paget's Association. Our theme this year is to look at new developments in research into Paget's. It's my great pleasure to introduce Mrs Susan McKinnon who is a participant in the ZiPP study, which stands for Zoledronate in the Prevention of Paget's and which has just been published.

Susan, I understand you enrolled in the ZiPP study because your brother had been diagnosed with Paget's and so maybe you could start by telling us a little about how the disease affected him and when he was diagnosed.

**Susan** He was in the Western General Hospital in Edinburgh with lung cancer and they became aware that he had a problem with his left hand and wrist prior to having lung cancer. He and his wife and children were tested for presence of the Paget's gene. I'm one of eight and was the one that had Paget's gene. The rest are all free of it.

**Stuart** Okay, that's interesting. So it was his wrist and it was kind of a bit bent I think, which can happen. You mentioned your other siblings. What about going back, like parents or grandparents, anyone else in the family?

**Susan** With us all talking about it we all realised that my mum's father, who was elderly, was quite stooped and had all the symptoms that you read about with Paget's. Also my mum always had problems with her hips and her back.

**Stuart** Okay. Yes, it's a common theme.

**Susan** So we were thinking it through.

**Stuart** Excellent. So back to you. You enrolled in the study and we're very grateful for that. At that time although you carried the gene, did you have any symptoms that you were aware of?

**Susan** No.

**Stuart** So you were completely fine and then you were in the study for about 5 years.

**Susan** It really came to a head when I broke my wrist and it didn't heal. They put a titanium plate in but I was still getting a lot of pain with it so they took the plate out and then it just ached. I've not got the same power in my left wrist at all. That was the first indication and then I met you. I got an appointment with you and we realised that I did have some symptoms.

**Stuart** I remember that. In fact you finished the ZiPP study and then went into what we call the extension study. I remember that you'd started to develop pain in your hip and that was giving you a lot of problems too.

**Susan** Yes. It was during the COVID lockdown. If I was lying on my side I was getting soreness that was waking me up. It wasn't until I came back to you and realised that Paget's was in the pelvis and hips too.

**Stuart** As you know the study was what's called blind. So we didn't know who had got what treatment but when you started to get pain, I had a look at your records. It turned out that you had been given the placebo. I looked at your scans and there was obviously quite active Paget's disease. Tell us what happened then. Did things improve?

**Susan** Well, you recommended the zoledronate infusion and it has made a big difference to me. I'm not so uncomfortable in bed and I feel I can get out from a sitting position much easier, without the discomfort which I was having before I had treatment.

**Stuart** Well that's really good to hear and of course the treatment you had was zoledronate and it is a pretty effective treatment. Would you recommend taking the test to someone else in the same position?

**Susan** Definitely. I would recommend it to anyone. I have children and I might have to say to them to get the test, to check that they've not got the gene from their mum.

**Stuart** Susan, thank you so much for sharing your story with us and for participating in this very important trial.

# Support our London Marathon runners

Get ready to witness an extraordinary feat of determination and resilience at this year's London Marathon on 21 April 2024. We are thrilled that our runners are gearing up to hit the streets of London. These dedicated individuals are not just running for personal goals; they are running to raise awareness and funds for the Paget's Association.

If you would like to support a runner you can do so on the individual's online fundraising page (just scan the QR code to find their page) or simply get in touch with us here at the Association. By supporting our charity runners you can turn their every step into a beacon of hope for those affected by Paget's disease.



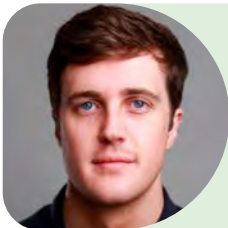
## Jaime Howard

Jaime said, "I feel very fortunate to be able to run for the charity, as I think it needs to be more in the public eye."



## Stephanie Bird

Having run for us before, Stephanie is very keen to do her best to support us again.



## Zack Zornitta

Zack aims to enhance the visibility of the Association as well as raise as much as he can to support those with Paget's.



## Chris Ford

A regular supporter of the Association, Chris is taking on this challenge once again for us.



## Rick Lim

Rick is travelling from the United States to run the marathon for us. He said he really wanted to support a small yet highly regarded organisation like ours.



**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](mailto:helpline@paget.org.uk)  
Telephone: **0161 799 4646**  
Mobile: **07713568197**

**Paget's information videos**

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

Search **YouTube** for **@PagetsAssociation** or visit [www.paget.org.uk](http://www.paget.org.uk)

**Information**

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

If you are able to, consider attending a **Paget's information event**.

**Paget's Network**

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

*Request a Support Network form*

**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](mailto: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>



# Thank you for remembering family and friends

We would like to express our heartfelt gratitude to all those who commemorate the memory of a loved one by donating to the Association on birthdays or anniversaries. Your generosity is appreciated.



If you've already included a bequest to the Association in your will, please know that we deeply appreciate your generosity. Legacies have for many years been a crucial source of funding for our quality research programs. By including the Paget's Association in your will, your generosity will endure, leaving a lasting impact on lives for generations to come.

# Minutes of the Annual General Meeting (AGM)

of The Paget's Association held at The Moat House, Lower Penkridge Road, Acton Trussell, Stafford, ST17 0RJ

on Friday 27 October 2023 at 10.00 am

**Attendees in person:** 8 Trustees, 5 members, 2 employees

**Attendees virtual:** 1 Trustee, 1 member

**Apologies:** 2 Trustees

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 can vote and if anyone had already voted postally or electronically that they could not vote again.

## Item 1: Annual General Meeting 2022

**Resolution:** That the minutes of the Annual General Meeting held on 30 September 2022 at the Holiday Inn, Cardiff, be approved.

● Professor Ralston proposed that the resolution be accepted and this was seconded by Miss Kathryn Berg.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

## Item 2: Extraordinary General Meeting 2023

**Resolution:** That the minutes of the Extraordinary General Meeting held on 19 April 2023 at The Lowry, The Quays, Salford, be approved.

● Professor Ralston proposed that the resolution be accepted and this was seconded by Mr Alan Janes.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

## Item 3: Presentation of the Report and Accounts\* from the last financial year: 2022

Professor Ralston gave an overview of the Association's accounts for the year ending December 2022. He highlighted that compared to 2021 investments were down by around £50K and reserves down by approximately £300K.

**Resolution:** That the Annual Report and Accounts for the year ended 31 December 2022 be accepted.

● Mrs Eve Berry proposed that the accounts be accepted and this was seconded by Mr Alan Janes.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 8   | 0       | 1       |

## Item 4: 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 and this was seconded by Professor Rob Layfield.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

## Item 5: Trustee appointments

Professor Ralston informed members that two Trustees, Mrs Kelly Burman and Mrs Amanda Sherwood, had completed their three-year terms of office and were standing for re-election. In addition, there were two new Trustee nominations, Mr Alan Martin, who has Paget's disease and was present at the AGM and Mr Mohamed El Erian, who was unable to attend. Mr El Erian is a solicitor and has been advising on converting the charity to a Charitable Incorporated Organisation.

**Resolution:** Re-appointment of Mrs Amanda Sherwood as a Trustee for a further 3 years.

● Professor Ralston proposed that the resolution be accepted and this was seconded by Dr Sheelagh Farrow.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

continued on page 30

**Resolution:** Re-appointment of Mrs Kely Burman as a Trustee for a further 3 years

● Professor Ralston proposed that the resolution be accepted and this was seconded by Dr Sheelagh Farrow.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

**Resolution:** Appointment of Mr Mohamed El Erian as a Trustee for 3 years

● Stuart Ralston proposed that the resolution be accepted and this was seconded by Kely Burman

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

**Resolution:** Appointment of Mr Alan Martin as a Trustee for 3 years

● Professor Ralston proposed that the resolution be accepted and this was seconded by Mrs Kely Burman.

| Member votes                       | For | Against | Abstain |
|------------------------------------|-----|---------|---------|
| Present (in person or virtually)   | 11  | 0       | 0       |
| Proxy (postal or electronic votes) | 9   | 0       | 0       |

**Item 6: Forward planning for 2024 and beyond**

Professor Ralston explained the following:

- Fixed costs had been reduced by moving from a rented office to a virtual office.
- Staffing had been reduced from three to two full-time members of staff, as the Office Manager, Mrs Sue Clegg, had retired from her full-time position and was now working part-time on a sessional basis to provide support with bookkeeping.
- Publication costs would be reduced from 2024 by publishing three magazines annually instead of four.
- There would continue to be a careful review of income and expenditure and a closer control of grant expenditure.
- The Association will further enhance its online and social media presence to connect with an expanding international audience as well as those within the UK.
- The most important aim for 2024 is to ensure that people with Paget's disease are supported and informed.

**Item 7: Questions and any other business**

No questions were raised.

The Vice-Chair of the Association, Professor Layfield, explained that Professor Ralston had served as the Chair of the Paget's Association for a five-year term, which commenced in September 2018 and had now concluded. Professor Layfield had contacted the Trustees to propose the re-election of Professor Ralston for an additional five-year term, which was subsequently approved through a majority vote.

**Item 8: A review of the last year's (2022) activities**

Specialist Nurse and Director of Educational Resources, Mrs Diana Wilkinson, gave a review of activities undertaken by the Association in 2022. These included:

**The 4th Annual Paget's Awareness Day, 11 January 2022**

Dr Herridge conducted video interviews with international experts in Paget's disease to gain a global perspective on the condition. A virtual Question and Answer session with Professor Ralston was held and there had been a significant emphasis placed on social media to help raise awareness.

**New Focus Group**

A new Focus Group had been formed to incorporate the opinions of people with Paget's disease and their families into the Association's decision-making.

**Face-to-face information events**

Two face-to-face Paget's information events were held in 2022, one in Oxford hosted by Dr Kassim Javaid and one in Cardiff hosted by Professor Mike Stone.

**Paget's information**

An updated 'Paget's & Pain' booklet had been produced and a 'Jargon Buster' had been created (both available online and in hardcopy).

**New research**

Two new funding awards had been made:

1. Research on the Contribution of Acidosis to Chronic Pain in Paget's led by Professor Chantal Chenu at the Royal Veterinary College, London.
2. Master of Research (MRes) degree – Application of Artificial Intelligence to the Radiological Diagnosis of Paget's by Dr Deepak Subedi at the University of Edinburgh & University of Southampton.

## Support

The introduction of 'Paget's Buddies' aimed to offer one-to-one support and support gift bags continued to be available to individuals recently diagnosed. Regular virtual support group meetings conducted via Zoom continued to provide assistance to individuals in various countries. The Nurse Helpline, Support Network, local groups and a dedicated Facebook group also continued to provide support.

### Item 9: Report of activities during 2023

Mrs Wilkinson provided a summary of the activities undertaken in 2023, encompassing the following points:

#### The 5th Paget's Awareness Day, 11 January 2023

The Awareness Day showcased personal experiences in a video series that marked the Association's 50th anniversary. Professor Ralston led a virtual Question and Answer session and an expanded social media campaign took place.

## New research funded

1. Paget's Disease and COVID-19: what really happened in the Pandemic? – led by Dr Adrian Heald, NHS Foundation Trust, Salford.
2. Engineering a Paget's Disease of Bone stem cell bank – led by Dr. Daniel Scott, University of Nottingham.

## New educational award

The Winifred Ditchfield Educational Award was funded by the Paget's Association, in collaboration with the Michael Davie Foundation. It was awarded to Norton Priory Museum and Gardens to update information on Paget's disease within the museum and enhance their educational programme.

## Paget's Association Centres of Excellence

Four new Centres of Excellence were added in Stoke on Trent, London, Cambridge, and Leicester.

## International Paget's Symposium

For the Paget's Association's 50th anniversary, a two-day international Paget's symposium was held at The Lowry, The Quays, Salford. A successful £50,000 Anniversary fundraising campaign had surpassed its target by over £12,000.

## Face-to-face Paget's information events

An information event for those affected by Paget's disease and their families had taken place in Salford, hosted by the Paget's Association and another would take place in Stafford, hosted by Dr Zoe Paskins.

## Information and support

Mrs Wilkinson highlighted the following:

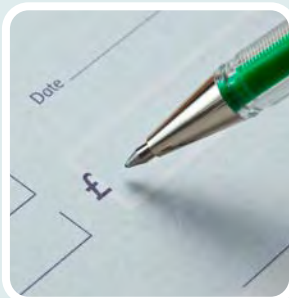
- A new website and database is being built and is due to launch later this year.
- The Association's fact sheet regarding osteosarcoma and Paget's was reviewed and updated.
- Support gift bags for the newly diagnosed had continued to be available.
- Services such as the Paget's Helpline, Virtual Support Groups, Paget's Buddies, Support Network and Facebook group continued to provide support and expand the charity's international reach.

## Strategy 2023 – 2028

A strategy for 2023 to 2028 was developed and was published in the August edition of the Paget's News magazine. It is also available on the charity's website.

- The meeting ended at 10.30 am

## Overseas cheques



Our bank has informed us that they will no longer process overseas cheques. If you are from outside the UK and wish to pay your membership fee or donate, please consider doing so online via our website. Thank you for your understanding.



# Paget's information events 2024

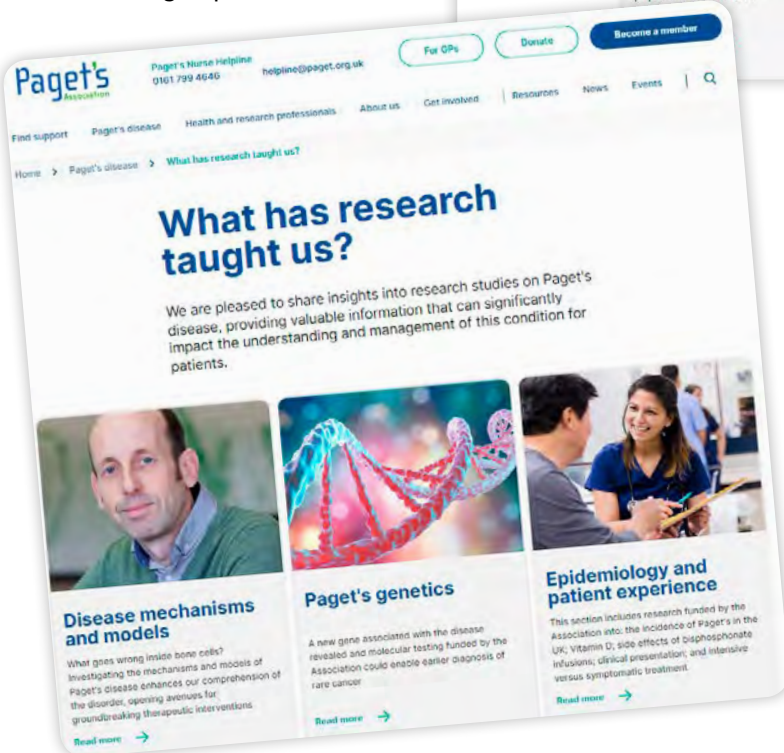
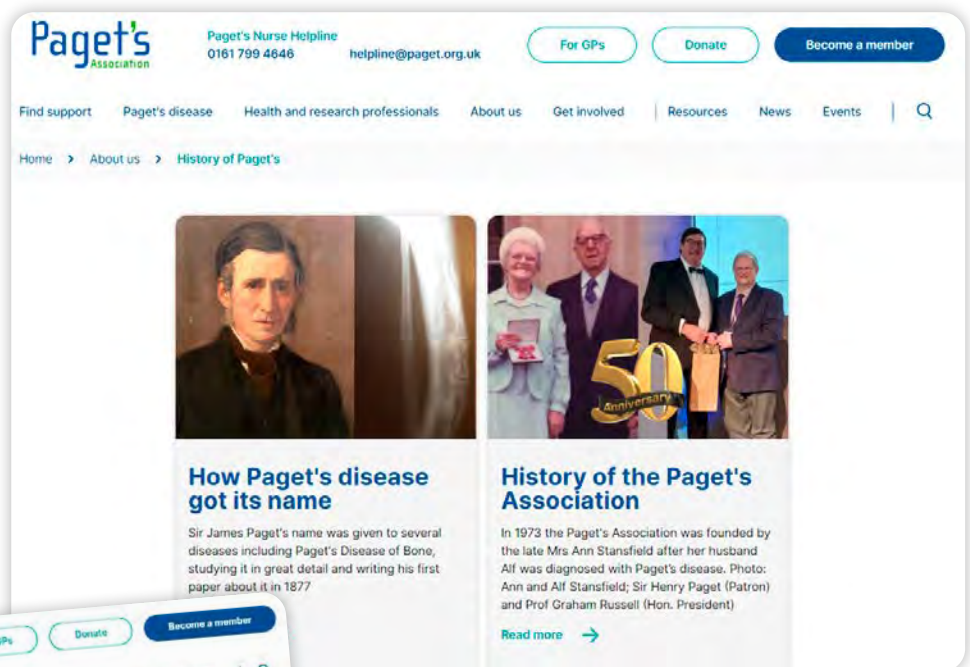
Thursday 27 June  
Madingley Hall  
Cambridge

Thursday 19 September  
Leonardo Hotel  
Middlesbrough

## Our new website is live!

### Exciting news!

Our newly launched website is a significant step in fortifying the Paget's Association's online presence. This dynamic platform not only prioritises and broadens our reach but also has robust security and is hosted by a provider exclusively using renewable energy sources. With faster loading times, enhanced accessibility, and an improved user experience, our website is set to not only provide information and raise awareness but also make a lasting impression.



### Try it now!

Delve into a wealth of information, personal stories, and more. Your feedback is invaluable so take a look around and join us on this digital journey!