

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



Bath's Royal National Hospital for Rheumatic Diseases is recognised as a Centre of Excellence

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Alan's struggle to obtain a diagnosis

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Urgent appeal as the Association faces unprecedented challenges

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Meet experts in Middlesbrough

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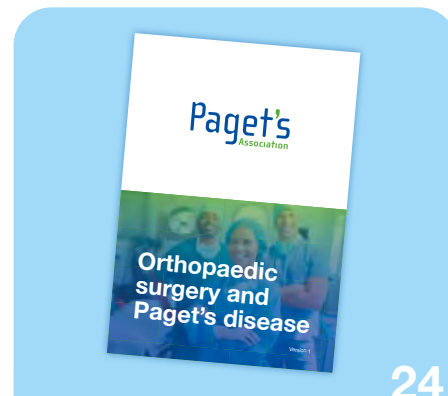
Alan's struggle

Alan has a simple message for anyone struggling with bone pain.



Urgent appeal!

The Paget's Association is currently facing unprecedented financial challenges.



New booklet

Our new booklet 'Orthopaedic surgery and Paget's disease' is now available.

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Please consider attending the Association's Annual General Meeting, virtually or in person, on
19 September 2024

(see separate AGM papers sent with this magazine)

Meet the team at the Paget's Association

Honorary President



Professor Graham Russell

Involved in research at both the Botnar Research Centre, Oxford and the Mellanby Centre for Bone Research, Sheffield, Graham played a key role in the discovery and development of bisphosphonates for the treatment of bone disorders.

Patrons



Sir Henry Paget

Sir Henry is the great-great grandson of Sir James Paget, whose name was given to Paget's disease.



Mrs Joyce Cupitt

Joyce served as a Trustee for many years. Her late husband had Paget's disease.



Mr Recardo Patrick

Recardo is an entertainer and businessman who rose to fame as lead singer with the band, Sweet Sensation. He has Paget's disease.

Employees



Mrs Diana Wilkinson

Specialist Nurse & Director of Educational Resources



Miss Jen Woodworth

Operations & Engagement Manager

Board of Trustees



Chair of the Board – Professor Stuart Ralston

Chair of the Paget's Association, Stuart is a Rheumatologist, based at the Western General Hospital, Edinburgh. He has researched widely on the role of both genetic and environmental factors in Paget's disease and has led several large clinical trials investigating the best methods of treatment for Paget's.



Vice-Chair – Professor Rob Layfield

Rob is a Professor at the University of Nottingham. He researches the protein that was found to carry mutations in some cases of Paget's disease.



Mrs Eve Berry

With many years of experience in the healthcare sector, Eve lives in London and is a Chartered Accountant, currently working in the drug discovery industry.



Mrs Kely Burman

A retired nurse and midwife living in Orsett, Kely has not only cared for those with Paget's disease, but her mother also had the condition.



Mr Mohamed El Erian

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



Dr Sheelagh Farrow

Sheelagh lives in Surrey and, prior to retirement, was Managing Director of International Medical Press, a provider of independent medical education.



Mr Alan Martin

A retired company director, Alan lives in Wokingham. He has Paget's disease and believes the interaction between patients and clinicians brings mutual benefits.



Dr Faiz Rahman

Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the University Hospitals of Leicester, where he is involved in caring for those with Paget's disease.



Mrs Amanda Sherwood

Amanda lives in Bristol and is now retired. She has experience in working for societies and teaching organisations which specialise in the field of bone and related topics.



Professor Mark Wilkinson

An Orthopaedic Surgeon in the Metabolic Bone Unit of the University of Sheffield, Mark has both an academic and clinical interest in Paget's disease.

Chair's message

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

Our cover feature highlights the fact that the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath has been recognised as a Paget's Disease Centre of Excellence (PACE). The RNHRD is an established specialist referral centre for rheumatic diseases, and it is fitting that they have been awarded PACE status. Congratulations to Dr Sarah Hardcastle and other members of the team in Bath! I will very much look forward to working with them in the years to come.

I was interested to read Allan Martin's story about the long struggle he had to receive a diagnosis of Paget's disease. This unfortunately is a recurring theme which I hear again and again at our patient information events across the country. There is actually no excuse for the delay in Alan's diagnosis since he had a raised alkaline phosphatase value which is typical of Paget's disease, but this was wrongly attributed to alcohol even though he drank very little. Eventually, the correct diagnosis was made, and he was treated with a good response by colleagues at the PACE centre in Stanmore. I thought that Alan's message was simple – if you have bone pain, please seek advice from your GP and mention Paget's disease as a possible cause.

Regular readers of the magazine will be aware that finances of the Association are not as healthy as we would like. We featured this in



the March issue of the Magazine and appealed to you for assistance in fund-raising to support the Association. The response has been fantastic! The London Marathon runners have raised more than £6,000 already. Their stories are featured on pages 19-21. Well done Jaime, Zack, Chris and Stephanie! Janet and Graham Dixon have also stepped up to the mark, raising £700 already this year. Janet and Graham have done a remarkable job in raising funds for the Association over the years and continue to do so. A bonus is the fact that as a former employee of Barclay's Bank, Janet can double the amount raised through Barclays match funding programme. I even managed to

raise over £2,700 myself through my sponsored cycle of the Etape Caledonia – so thanks to all my friends, family and colleagues who supported me in this effort. It was a fantastic day with good weather and managed to return a time of 6hrs 27mins which I was very happy about. Our very own Diana Wilkinson, pictured with her son Ben on page 19 raised a magnificent £191 at her recent birthday party.

Professor Rob Layfield, Vice Chair of the Association and Chair of the research committee, has highlighted some recent research articles which we thought you might find of interest on pages 16 and 17. I was particularly interested in the article published by Urquiaga and colleagues who looked at the frequency with which Paget's occurs in former servicemen in Birmingham, Alabama in the USA. It's known that Paget's does occur in the USA, albeit less commonly than in the UK. The interesting thing about this survey was that African-American individuals had an earlier age at diagnosis than white patients. It was not possible to figure out what this



Approaching the finish line at the Etape Caledonia

might be from design of the study, but it does raise some interesting questions which deserve further research. The second paper published by the Italian Society of Osteoporosis, Mineral Metabolism and Skeletal Disease (SIOMMS) released a paper on best practice for the diagnosis and treatment of Paget's disease. It is nice to see that the recommendations were similar to those of the 2019 guideline on Paget's which was supported by the Association. As new research into Paget's has emerged, the Association will be supporting an update of the 2019 clinical guideline, particularly taking account of the role of genetic testing in diagnosis and the ZiPP study which was published towards the end of 2023. Watch this space!

In closing I would like to draw your attention to the fact that we have produced a new information booklet on the role of orthopaedic surgery in Paget's disease. It has been estimated that between 10-15% of people with Paget's disease might need orthopaedic surgery to replace worn out joints or repair fractures. As orthopaedic surgery is one of the most popular topics in our information events across the country we felt that this booklet would be a useful resource for people who had had surgery or are due to have it.

I hope you enjoy reading the magazine and continue to help raise funds for the Association so that we can continue our important work!

Keep well and stay safe!

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



Alan's struggle to obtain a diagnosis

Now living in Wokingham, Alan, aged 81, comes originally from the northwest of England – a known hotspot for Paget's disease. With no known family history of the condition, he was diagnosed with Paget's disease a few years ago. Alan said, "I have a twin brother, but he did not have Paget's. My Dad died when he was 61 so perhaps he didn't live long enough to know if he would develop it or not." Alan married his wife Margaret at 25, and together they purchased a plot of land and over a four-year period built their home. They have two daughters. Living close to the Lake District and the Yorkshire Dales they enjoyed walking in their spare time.

Working life

Alan left school at 16 and went into his father's engineering business. On completing his apprenticeship, he went on to become a technician as part of a team designing and building research equipment in the physics department at Lancaster University. He later moved to Berkshire to join the NHS as an engineer. He was sponsored by his region on a four-year honour's engineering degree course. On completing his degree, he continued to work in London at the regional offices designing and project managing the installation of services within newly-built hospitals. The degree course and the cost of commuting to London had depleted their savings and financial struggles led him to seek alternative work. He became a Chief Engineer at a new university teaching hospital in Saudi Arabia.



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In 2017, Alan began experiencing hip pain, attributing it to wear and tear associated with ageing

”



Alan went on to become the General Manager of the medical services division of a large international company. He later purchased and ran the consultancy part of the business until his retirement aged 63.

Leisure activities keep Alan active

Having to travel overseas at short notice made it difficult for Alan to join any group leisure activities. This combined with the enjoyment he got from designing, making and building things led to him spending his leisure time on "projects" including renovating a house and, together with a friend, building a 38-foot boat. In his retirement, he now spends much of his spare time in his workshop making and repairing things for family and friends. He also enjoys woodcarving and leatherwork. Examples of his craft, including a carved kingfisher and the carved and painted tree creeper are shown in the photo. He said, "Carving, making and repairing things keeps my brain and hands active".

Obtaining a diagnosis

In 2017, Alan began experiencing hip pain, attributing it to wear and tear associated with ageing. His GP agreed with this. Alan had annual blood tests and was told that everything seemed okay but the GP indicated that the liver function tests were showing that he needed to control his lifestyle and drink less alcohol. Alan never drank very much

so he was confused by this and explained that to his GP, however, the annual advice didn't change. He knows now that it was his alkaline phosphatase (ALP) that was raised and that this can be raised if Paget's disease is active. We know from our Paget's Nurse Helpline that Alan is not alone in his experience of being asked to cut back on alcohol when in fact he drank very little.

Alan's pain increased and in October 2018 he recalled coming home from holiday feeling worse than when he had set off. A few days later he discovered that he had a urinary infection and was prescribed antibiotics. These didn't help so he was referred to a consultant. The consultation uncovered a slight abnormality with his prostate so he had an MRI scan. When he returned for the result, his consultant asked if he knew he had Paget's disease. He didn't and so his consultant explained that it was a problem with his bones but there was no cure. He went home happy that they hadn't found prostate cancer but feeling resigned to a life of pain and increasing immobility.

Discovering the Association helped Alan obtain treatment

It was Margaret who decided to do some research on Paget's disease and found the Paget's Association. Alan remembers, "I became a member as soon as I could and went to a Paget's Information Event in York". Empowered by all this new information, Alan achieved a referral to a consultant at the Paget's Centre of Excellence in Stanmore. The pandemic delayed him being seen, have tests and receive treatment. However, a bone scan eventually showed Paget's disease



Alan refines his beautiful carving of a tree creeper

“ Alan’s message is simple. If you know anyone struggling with bone pain, encourage them to be persistent until it is investigated properly rather than assuming it is an inevitable product of advancing years! ”

in his left pelvic bone. In 2022 he had successful treatment, an infusion of zoledronic acid. Following this

he was delighted that his pain had largely disappeared apart from an occasional ache. A follow-up blood test in December 2023 showed that his ALP had gone down from 193 to 54 (normal range around 30-130 although due to a variety of measuring techniques, reference ranges may vary slightly between different laboratories. You can ask what your level of ALP is and what the normal range is).

Alan decided to help others by taking part in the Pain in Paget's study and by becoming a Trustee of the Paget's Association. In June, Alan spoke at our Paget's Information Event in Cambridge. He reflected on how he should have been alerted to the problem earlier, not only by his GP but perhaps also by the fact that he had one leg shorter than the other. This was discovered because he had visited a particularly excellent clothes shop whenever they returned to north Lancashire where Margaret liked to stock up on trousers. Alan decided he would have a pair from the men's section. Measuring his legs the salesperson declared that Alan had one leg three-quarters of an inch shorter than the other. Was this the first indicator that something was amiss?

A simple message

Alan's message is simple. If you know anyone struggling with bone pain, encourage them to be persistent until it is investigated properly rather than assuming it is an inevitable product of advancing years! Or the result of inaccurate assumptions regarding one's lifestyle.



Scan the QR code to watch a short video of Alan as he explains how he went from being told there was no hope, to finding help through the Paget's Association.

Urgent appeal

In our last magazine, we outlined the unprecedented financial challenge the Paget's Association is currently facing to be able to continue its vital work. We now stand at a critical juncture and the coming months will be a testing time, as the Trustees look for ways to preserve our services for you.

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The Paget's Association is currently facing unprecedented financial challenges

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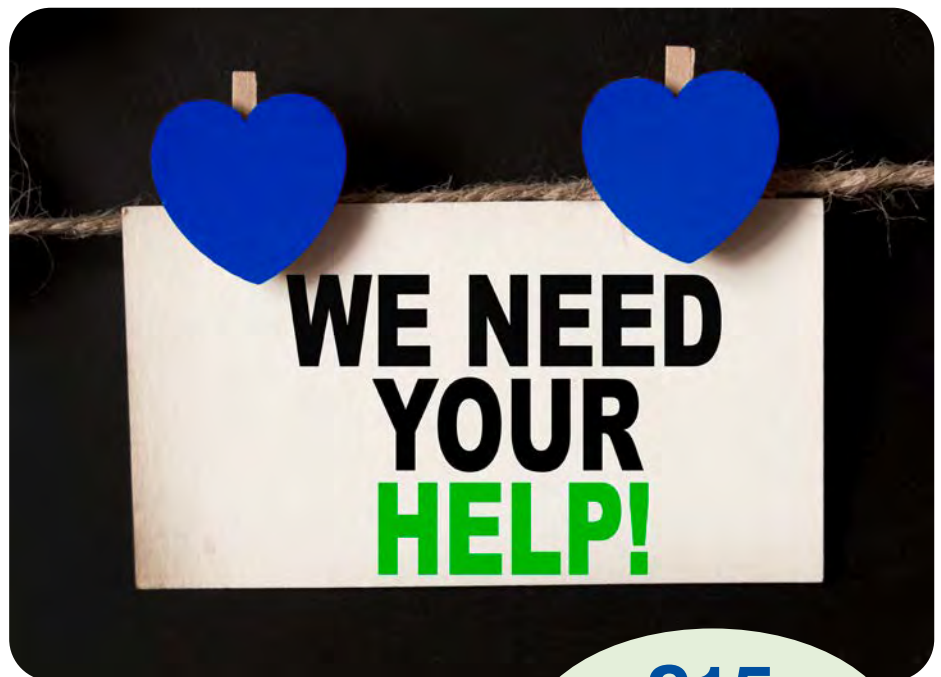
Will you be part of the lifeline that sustains our charity for those who depend on us? Your support is urgently needed. Now more than ever, we rely on those who can, to support us.

If you are in a position to donate, your one-off or monthly donation can make a meaningful difference to how long we can continue to support

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Will you be part of the lifeline that sustains our charity for those who depend on us?

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individuals and families affected by Paget's disease. You can donate on our website, by bank transfer (call us for details) or send a cheque payable to the Paget's Association to the address on page 5.

If you would like to donate monthly your consistent support provides us with a stable foundation to plan ahead. Simply get in touch with our office.

We depend on donations, fundraising and legacies

We do not receive any government funding; our survival depends solely on donations, fundraising and legacies. If you are in a position to donate, your contribution can make a meaningful difference in supporting individuals and families affected by Paget's disease.

£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

£40

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



Scan the QR code to go to the donate page of our website

Encourage others to leave a legacy

If you have already included a gift to the Paget's Association in your will, we extend our heartfelt thanks. Your generosity plays a crucial role in ensuring the long-term sustainability of our charity. Perhaps you could inspire others by sharing your story with us and our readers.

Everyone can do something

In the last edition of Paget's News, we published numerous ideas of how you can help us raise funds. One of them is our monthly raffle. We would love to hit our target of 200 members so please encourage your family and friends to join. Read on for details.

“

We now stand at a critical juncture and the coming months will be a testing time, as the Trustees look for ways to preserve our services for you

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Thank you

To those who have already generously contributed to our cause, we extend our grateful thanks.

Every donation, no matter the size, impacts our ability to continue to provide essential support and information to those in need.

Join our monthly raffle!

Thanks to our strict limit of 200 tickets for sale and unlike many lotteries, our raffle has remarkably favourable chances of winning. Moreover, when you encourage your friends, family and colleagues to join, you not only boost the funds raised but also raise awareness of Paget's disease.

By purchasing a ticket or even two 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 join the raffle and secure a chance to win, please email your request to

membership@paget.org.uk

If you are unable to email us, please complete the form on page 10.



Double prize draw!

Winners ☆ ☆ ☆ ☆ ☆ ☆ ☆

January 2024

1st Prize £100

Ticket no. 134
June Errington
Bournemouth

2nd Prize £50

Ticket no. 2
Gaynor Denton
Liverpool

February 2024

1st Prize £100

Ticket no. 90
Eileen Wallace
Cheshire

2nd Prize £50

Ticket no. 7
Terry Carter
Sussex

March 2024

1st Prize £100

Ticket no. 64
Kenneth Speare
Cornwall

2nd Prize £50

Ticket no. 67
Valerie Smith
Belgium

April 2024

1st Prize £100

Ticket no. 142
Peter Bardsley
Birmingham

2nd Prize £50

Ticket no. 1
Sylvia Conyers
Essex

May 2024

1st Prize £100

Ticket no. 171
John Dyer
Suffolk

2nd Prize £50

Ticket no. 4
Thomas Trevor
Oswestry

June 2024 Double prize draw

1st Prize £200

Ticket no. 135
Maureen Jones
Liverpool

2nd Prize £100

Ticket no. 190
Margaret Read
Leeds



Anyone over 18 can take part

Please tell your family and friends about the raffle

The easiest way to join is to send your request to membership@paget.org.uk
If you are unable to email us, please complete this form

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 (see next page).

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, a waiting 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 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



A new Centre of Excellence in Bath



Bath's Royal National Hospital for Rheumatic Diseases (RNHRD) has been recognised as a Paget's Association Centre of Excellence. The award recognises the RNHRD's diagnostic and treatment facilities, the clinical expertise of its staff, the number of patients cared for and its involvement in Paget's disease research.

At the RNHRD, people with suspected Paget's disease, and those with a known diagnosis, are seen in a monthly metabolic bone disease clinic supervised by specialist consultants. Scans, x-rays and other necessary investigations such as blood tests can all be done on site, and those who need treatment receive it in the centre's dedicated infusion unit. The team also includes a nurse specialist and physiotherapy and occupational therapy teams, all of whom help to provide support to patients.

Dr Sarah Hardcastle, Consultant Rheumatologist at the RNHRD, part of the Royal United Hospitals Bath NHS Foundation Trust, said: "We are extremely pleased to be receiving this award in recognition of the care we provide to our patients with Paget's disease, and our involvement in Paget's disease research. Our recent research efforts have been supported thanks to a generous legacy donation that was left to the department in 2020. This has been used to fund staff research time and is one of the key reasons we have received this Centre of Excellence accolade. We look forward to working with the Paget's Association to continue to improve the outlook for patients with this condition in the future." Dr Hardcastle and fellow RNHRD consultant Dr Tehseen Ahmed are co-directors of the Centre of Excellence.



Trustee of the Paget's Association Mrs Amanda Sherwood presents the award to Dr Sarah Hardcastle

From left to right: Dr Tehseen Ahmed, Consultant Rheumatologist; Helen Rayner, Rheumatology Research Practitioner; Amanda Sherwood, Trustee, Paget's Association; Dr Sarah Hardcastle, Consultant Rheumatologist; and Terrie Stocker, Osteoporosis Nurse Specialist

“

We look forward to working with the Paget's Association to continue to improve the outlook for patients with this condition in the future

”

Dr Sarah Hardcastle

Paget's Association Centres of Excellence

As the only UK charity dedicated to Paget's Disease of Bone, the Paget's Association is keen to improve patient access to appropriate specialist care. The Paget's Association Centre of Excellence Award Scheme recognises hospital and university departments that demonstrate expertise in both the clinical management of Paget's disease and research into the condition. The award is increasing awareness of the condition and improving access to services.

Further Information about each centre is available on our website: www.paget.org.uk



Scan me



Ask the experts at our Middlesbrough information event



Join us at our Paget's information event in Middlesbrough on Thursday 19 September, to connect with experts, gain valuable information, and find support within the Paget's community. We look forward to welcoming you to the heart of Middlesbrough. The Leonardo Hotel is half a mile from Middlesbrough train station. Dr Stephen Tuck from the local Centre of Excellence will be hosting the event. Lunch and refreshments are included.

Book your place/s

You will find the draft agenda below so 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.

Paget's Information Event

Leonardo Hotel, Middlesbrough / 10.45 am - 3.30 pm

Registration & Refreshments	
What is Paget's disease?	Prof Stuart Ralston Chair, Paget's Association Rheumatologist and researcher, Edinburgh
Diagnosis and monitoring	Dr Harish Datta Pathologist James Cook Hospital, Middlesbrough
Treatment	Dr Stephen Tuck Rheumatologist, James Cook Hospital, Middlesbrough Director, Paget's Centre of Excellence
Lunch	
Genetic testing and preventative treatment	Prof Stuart Ralston
Behind the scenes (at the Association)	Mrs Diana Wilkinson Specialist Nurse, Paget's Association
Research and complications	Dr Julie Walker Pathologist and Researcher James Cook Hospital, Middlesbrough
Joint replacement in Paget's	Mr Ian Wallace Orthopaedic surgeon James Cook Hospital, Middlesbrough
A final opportunity for questions	Prof Stuart Ralston

**Thursday
19 September
2024**

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

10.45 am – 3.30 pm

**Thursday
19 September
2024**

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

10.45 am – 3.30 pm

**Thursday
19 September
2024**

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

10.45 am – 3.30 pm



**The easiest way to book your place/s is to email membership@paget.org.uk
If you are unable to email us, please call 0161 799 4646 or complete this form.**

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.

FREE

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

Journal news from around the world



Many articles are regularly published in medical and scientific journals regarding different aspects of Paget's disease. Here we take a glance at some of the publications from around the world. In this issue, Chair of the Association's Research Subcommittee, Professor Rob Layfield, has chosen two papers. The first considers Paget's disease in a US Southeastern Veteran population and the second looks at recommendations from an Italian group. The papers have been summarised by our Specialist Nurse, Diana Wilkinson. More information is available from the Association or by using the QR codes provided.

Paget's disease in the US: A veteran population

Paget's disease has long been associated with individuals of European descent. However, recent clinical observations sparked debate: could this pattern differ within the US Southeastern Military Veteran population, particularly among African Americans?

To explore this, researchers conducted a cross-sectional study using the Veterans Affairs' Clinical Data Warehouse (CDW) and a review of electronic medical records. Using the CDW, they identified people from the Birmingham VA Medical Centre (BVAMC) with an International Classification of Diseases code for Paget's disease (between January 2000 and December 2020). They extracted their self-reported race and determined the proportion of African Americans, which they compared to the proportion of white patients. As a secondary goal, they extracted

relevant clinical characteristics from electronic medical records.

They identified 285 individuals from the BVAMC with Paget's disease. African Americans comprised a significantly higher proportion compared to white patients. Moreover, African American patients tended to present with the condition at a younger age (64.6 vs 70.1 years) than their counterparts. However, no significant disparities were found in clinical characteristics like alkaline phosphatase levels or disease severity.

These findings shed light on an intriguing demographic pattern within the BVAMC population, suggesting a higher prevalence of Paget's disease among African Americans. Moreover, this study aligns with emerging evidence hinting at a potential cluster of Paget's disease among African Americans in the US Southeast. Further research is warranted to delve deeper into the underlying factors (genetic or environmental) contributing to these demographic

variations in Paget's disease prevalence.

Reference

Urquiaga M, Gaffo A. Paget disease of bone in a southeastern Veteran population. American Journal of the Medical Sciences. 2024 Feb 15:S0002-9629(24)01064-4. doi: 10.1016/j.amjms.2024.02.005. Epub ahead of print. PMID: 38364993.



Scan the QR code for more information.

Italian position paper on best practices

The Italian Society of Osteoporosis, Mineral Metabolism and Skeletal Diseases (SIOMMMS) recently released a position paper regarding best practices for diagnosis and treatment of Paget's disease.

The article reminds the reader that Paget's disease is often overlooked in clinical practice, so that diagnosis is made at a later stage and progression of the disease can lead to complications that compromise the quality of life. Based on these considerations, the somewhat contrasting outcomes from previous guidelines (those commissioned by the Paget's Association, published 2019 and the Endocrine Society's, 2014) and the results of more recent studies, the SIOMMMS found it necessary to provide up-to-date indications for the diagnosis and treatment of the disease. Due to the lack of good evidence from Randomised Controlled Trials (RCT) to support clear recommendations, available information from the literature together with expert opinion of the panel was used to provide suggestions for the clinical practice.

They stated that the diagnosis of Paget's disease should be mainly

based on symptoms together with biochemical and radiological features. A bone scan is also recommended to assess disease extension or detect early Pagetic lesions e.g. in those with a family history of Paget's.

The authors said that while they had no doubts about recommending bisphosphonate treatment to symptomatic patients at diagnosis, some debate arose concerning the necessity of treatment in patients without symptoms. Similar concerns were raised about previously-treated patients in the presence of biochemical recurrence e.g. an increase in blood levels of alkaline phosphatase (ALP) or other bone turnover markers. They concluded that given the safety and long-term efficacy of potent intravenous bisphosphonates such as zoledronate, treatment of most if not all cases at the time of diagnosis was recommended.

Reference

Rendina D, Falchetti A, Diacinti D, Bertoldo F, Merlotti D, Giannini S, Cianferotti L, Girasole G, Di Monaco M, Gonnelli S, Malavolta N, Minisola S, Vescini F, Rossini M, Frediani B, Chiodini I, Asciutti F, Gennari L. Diagnosis and treatment of Paget's disease of bone: position paper from the Italian Society of Osteoporosis, Mineral Metabolism and Skeletal Diseases (SIOMMMS). J Endocrinol Invest. 2024 Mar 15. doi: 10.1007/s40618-024-02318-1. Epub ahead of print. PMID: 38488978.



Scan the QR code
to read the paper in full.

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.



Reference

Ralston, S. H. et al, (2019), Diagnosis and Management of Paget's Disease of Bone in Adults: A Clinical Guideline. Journal of Bone Mineral Research. Vol. 34, p 579-604.

Scan the QR code to read more about the guideline on our website.



**THANK
YOU!**

We extend our heartfelt gratitude to everyone who has contributed to fundraising efforts for the Paget's Association so far this year. From a gruelling 85-mile cycle event and the challenging London Marathon to smaller events, every effort is greatly appreciated.

Conquering the Etape Caledonia 85-mile cycle event

Our Chair Professor Stuart Ralston achieved an impressive feat by conquering the challenging 85-mile course of the Etape Caledonia cycle event on 12 May in 6 hours 27 minutes. His determination not only led him through the rolling hills and scenic forest-lined roads surrounding Loch Rannoch and Loch Tummel but also propelled him up the demanding and twisting ascent of Mt Schiehallion. Rising to 3,547, this majestic peak known as the 'fairy hill of the Caledonians,' boasts an iconic conical silhouette when viewed from the west and is affectionately known as the 'Matterhorn of Perthshire.' Professor Ralston's efforts raised over £2,700 for the Paget's Association.



Birthday raffle

Our Specialist Nurse, Diana Wilkinson, organised a raffle during her birthday celebrations. Thanks to the generous contributions of the partygoers, the raffle raised £171 and a further donation took the total to £191 to support the work of the Paget's Association.



Diana and her son, Ben, drawing the raffle

London Marathon Success

We would like to thank all our runners who completed the TCS London Marathon in April raising vital funds for the Association. The team raised over £6,000.

We are grateful to everyone who supported the runners in any way. Three of our five runners share their thoughts on the next page.



London Marathon 27 April 2025

We have places in next year's London Marathon.

Please get in touch if you or someone you know would like to take part.



“
**Well done
Jaime, Zack,
Chris and
Stephanie!**
”



Jaime's marathon experience

"Hi, I am Jaime. I feel so proud to have run the London Marathon this year in aid of the Paget's Association, after applying for a place with them back in December 2023. Thank you so much for the opportunity. What an absolutely amazing experience. This was my first Marathon and to run at such a prestigious event was mind-blowing.

As a youngster I was never into running or any type of athletics for that matter, usually coming last or close to it in the cross country at my old middle school. I put this down to being the shortest in the year, my little legs were going nowhere fast. I was more of a sit-down sportsman, enjoying things like fishing and sailing. As I got into my early twenties, I met my wife-to-be Sophia and she tried to get me into running, but to no avail. I found myself getting into martial arts after suffering a serious injury from a robbery in a local supermarket. I enjoyed this type of fitness until our second child came along. I found being with the family more important, so fitness took a bit of a fall. Again, after a couple of

years, Sophia tried to get me out of the house and on to the pavements but it just wasn't my thing.

Then, in October 2018 my eldest decided to do the Duke Of Edinburgh Award, which meant she had to do some sort of monitored sport. She chose to do Parkrun which is a community event where you can walk, jog or run in various parks at the weekend. Great, loads of people, no need for me to join in 'the fun' or so I thought. The morning of the first run she came into my bedroom in the early hours saying she didn't want to go alone, I turned to my wife to say 'off you go then', only to be presented with my 'very own' already printed Parkrun barcode. Planned in advance? I think so! Still, I trudged off, I'm sure saying a few choice words under my breath, but within 10 minutes of getting there, I enjoyed the atmosphere and have never really looked back.

“

It was one of the best experiences I've ever had and I really appreciate the Paget's Association for giving me the opportunity

”

I have now got 3 half marathons and a couple of local 5-mile Fun Runs under my belt. I also trained for the virtual London Marathon back in 2022. Unfortunately, after picking up a heel injury 3 weeks before the big day, I had to pull out. I do most of my running with just a few friends, one of whom (Will) applied last year in the ballot (he might have had a slight push from me). I felt bad as he was the only one of our group to get in, so I looked for a charity place and luckily for me, The Paget's Association was looking for someone. After chatting

with Diana over email, I was so glad to be accepted.

I am so pleased that while putting in the miles in training I was also able to spread the word and raise money for the Association. I must be honest, before this I had never heard of Paget's disease, but whilst applying I did a fair bit of research and decided I would really like to put my name to it and not just raise money but awareness too. Having started a window cleaning business back in 1988, I had a lot of customers to chat to over lots of cups of tea and Will worked in a local school as a PE teacher, which it was suggested would help raise money too. Unfortunately, before any sort of organising could be arranged, one of the pupils fell very ill so the next charitable event was to raise money for him. But with the help of my family, customers, Will and Parkrun goers, we have at the moment raised over £2,877.

I must say it has been a GREAT journey from day one. I have been astonished at how many of my customers knew about the disease and had very close dealings with it. It has been a real eye-opener as I have spread the word and I'm sure Yorkshire, Tetley and the other tea makers have had their profits soar.

For the marathon itself, I wanted to try to do it in just under 4 hours, but with Sophia, my youngest, other members of the family, friends and the crowd behind me, I managed the official time of 3 hours 50 minutes. I'm not going to lie, after feeling great for the first 25 miles, that last one wasn't the most enjoyable out of the 26. But it was one of the best experiences I've ever had and I really appreciate the Paget's Association for giving me the opportunity. I am so pleased that while putting in the miles in training I was also able to spread the word and raise money for the Association. Many thanks!"

Jaime



A first for Zack

"I was incredibly lucky to run the marathon in support of the Association's good work for those suffering from Paget's. My first ever marathon felt great for the first half, and exceptionally difficult for the second! The crowds and music and support from everyone on the day really helps push you further than you think you could go."

Zack

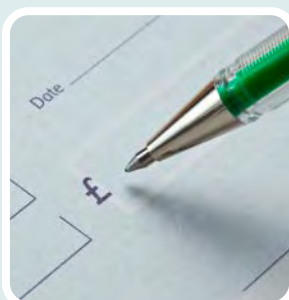
Stephanie's tremendous pride

"Running the 2024 London Marathon for Paget's was the best experience. It gave me tremendous pride both in my own abilities as I age and that I'm helping people who suffer the effects with Paget's Disease both now and in the future."

Stephanie



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.



Janet and Graham want to give a little back

Janet and Graham Dixon have been raising funds for the Association for several years. From sponsored walks and car boot sales to eBay and Facebook, their efforts and enthusiasm to help the charity is infectious. They said, "The reason we are passionate about raising funds for the Paget's Association is because we want to give a little back, for all the help and support that the charity has provided. If it was not for the Association, Janet may not have had access to the excellent care she has received through one of the Centres of Excellence".

Janet and Graham have demonstrated remarkable dedication in their efforts. Their diverse and engaging strategies reflect their commitment to making a difference. Graham undertook the challenging Yorkshire Three Peaks, covering a challenging 25-mile route within the demanding timeframe of 12 hours. Additionally, he tackled The Lyke Wake Walk, a gruelling 40-mile route completed within a stringent 24-hour timeframe.



In addition, Janet and Graham have used their creative talents by handcrafting wooden Christmas trees, bird nesting boxes and garden planters, offering practical and charming items they could sell to their supporters.

Their annual presence at a Car Boot sale has consistently yielded impressive results. They have even hosted a coffee morning on Paget's Awareness Day, raising money and providing a platform for education and discussion.

They have embraced digital fundraising, using platforms such as eBay and Facebook to sell items. Their approach not only generated revenue but also fostered community involvement, with many of the items being generously donated by neighbours, friends, and family. Their efforts underscore the strength of their network and the collective desire to contribute to the Paget's Association's vital work.

So far this year they have raised £700 and as a retired employee of Barclays Bank, Janet also has an annual opportunity to double the amount they raise through Barclays' match funding programme.

Janet and Graham's approach to fundraising reflects their dedication to supporting the Paget's Association and we are very grateful for all they do.

If you would like to fundraise for us, get in touch and we will assist in any way we can.

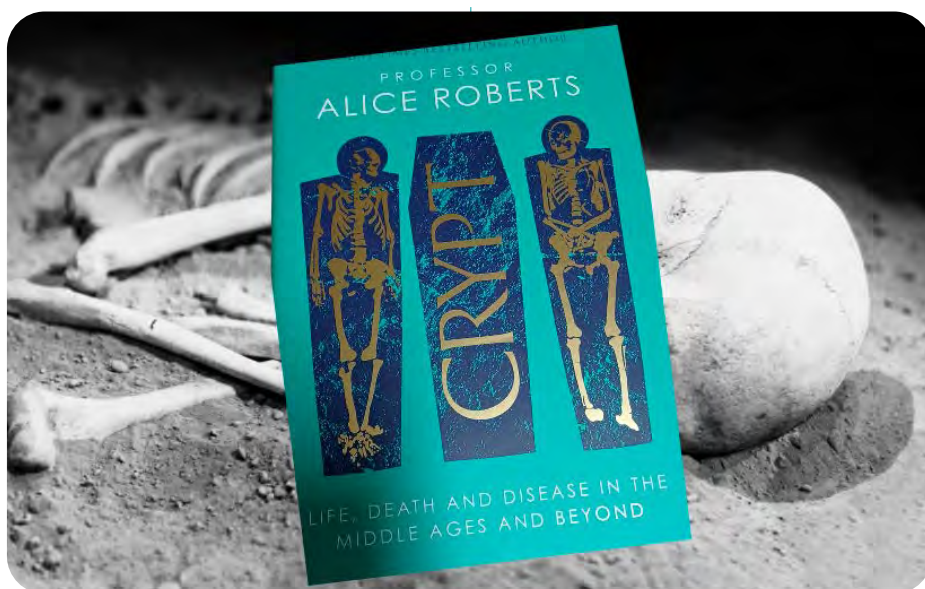


So far this year, they have raised £700 and have received match funding through Barclays Bank

New book highlights Paget's disease

Best-selling Sunday Times author, Professor Alice Roberts, known for her role in 'Digging for Britain', recently published a book entitled "Crypt." This final instalment of her highly acclaimed trilogy explores the experience of life, death and disease in the Middle Ages and beyond. Alice explores the impact of incurable epidemics, looks at how modern science is unlocking secrets of the Mary Rose shipwreck and reveals how archaeogenetic research is shedding new light on diseases such as leprosy, syphilis and the plague.

We are delighted that Alice also highlights medieval skeletons from Norton Priory in Cheshire, where multidisciplinary research found a high percentage were affected by an ancient form of Paget's disease. The research at Norton Priory was



made possible with funding from the Wellcome Trust, the Paget's Association and the Michael Davie Research Foundation. Coordinated by researchers at the University of Nottingham, the study involved

analysing proteins and genetic material preserved in bones and teeth that are more than 800 years old. Alice's book and her tour of the UK to promote it will help raise awareness of Paget's disease.

Clinical Trials Day

The Research Innovation Centre of the Royal National Orthopaedic Hospital (RNOH) in London, held a Clinical Trials Day on 7 June 2024, to raise the profile of their research. The event coincided with #Red4Research Day which aimed to get as many people as possible wearing red to demonstrate their support and appreciation for all those participating, undertaking and supporting research. Research at the RNOH is focused on musculoskeletal as well as

neuro-musculoskeletal conditions, rehabilitation, peripheral nerve injury repair and more, offering hope to patients worldwide.

The Paget's Association supported the day by providing a display of information and resources from our Paget's educational kit tailored to shed light on bone biology and Paget's disease through engaging activities and puzzles. With links to medicine, archaeology and history, the kit was produced by Elizabeth Radley who was a PhD student at the University of Nottingham.



The kit that was produced by Elizabeth Radley

Elizabeth's work was made possible through an educational bursary from the Paget's Association established in memory of the late Winifred Ditchfield, who had Paget's disease.

New booklet: Orthopaedic surgery and Paget's disease

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

When might surgery be required?

Surgery may be required under the following circumstances.

- If an affected bone breaks (fractures), an operation may be required to fix the fracture.
- When Paget's disease puts strain on joints it can lead to damage (osteoarthritis) and if pain and disability from this become severe, joint replacement may be required.
- When there is marked bone deformity, usually seen in the lower leg, a controlled fracture called an osteotomy can be carried out. This involves breaking the bone and realigning it to correct the shape.
- If nerve compression occurs, surgery may be necessary, e.g. Paget's disease in the spine can cause deformed bone to press on the spinal cord. This can cause narrowing that occasionally needs to be corrected surgically, if medical treatment is unsuccessful.
- Paget's disease can cause bone cancer but is very rare. When it does occur, surgery may be used to remove the tumour.

The new booklet discusses how an orthopaedic surgeon can help with these issues. The most common reason that someone with Paget's disease sees an orthopaedic surgeon is when they have osteoarthritis and are seeking advice about joint replacement.

To download this booklet and others, scan the QR code or visit <https://paget.org.uk/resources/>



Information from the Faculty of Pain Medicine

The Faculty of Pain Medicine (FPM) is an academic institution and part of the Royal College of Anaesthetists. The FPM is the professional body responsible for the training, assessment, practice and continuing professional development of specialist medical practitioners in the management of pain in the UK. They have a multi-disciplinary approach to pain management informed by evidence-based practice and research.

Whilst not specifically for Paget's disease, the FPM have materials available relating to pain and its management for people and their relatives. Five medication leaflets provide information on amitriptyline, nortriptyline, pregabalin, gabapentin and duloxetine. Several intervention leaflets offer information relating to commonly undertaken injections in pain medicine and aim to answer some questions that people may have.

The information can be downloaded from the FPM website

<https://fpm.ac.uk/patients>.

Paget's and pain

The Paget's Association has a leaflet regarding Paget's disease and pain which all new members receive and can be downloaded from our website www.paget.org.uk.

Scan the QR
code to go
straight to the
FPM website



GAPDPD study

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

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

Study aims

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



Who can take part?

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

What will your relative need to do?

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

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



Benefits

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



What to do next?

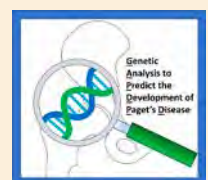
If you have a relative who may be interested in this research opportunity, please ask the doctor you see for an informational leaflet to pass on to them. Additional information can be found on the study website at GAPDPD.co.uk or via the QR code below



GAPDPD Study website



CANCER
RESEARCH
UK



Have you left the Paget's Association a legacy?

A BIG
thank
you
♥

Leaving a legacy to any charity can make a big impact on future generations. Legacies have for many years been a crucial source of funding for the Paget's Association. If you've already included a bequest to the Association in your will, please know that we deeply appreciate your generosity.

Donations on birthdays and anniversaries

We wish to convey our sincere appreciation to everyone who honours the memory of a loved one through donations to the Association on birthdays or anniversaries.

Your kindness is appreciated.



Remembering Alex

We remember with fondness Alex Smethurst, a member of the Manchester Support Group until he moved to be closer to his beloved family in Cambridge. It was with heavy hearts that we learned of his passing following a brief illness in March, at the age of 91. Our Specialist Nurse Diana reflected, "Alex was a respected member of the Support Group. Our heartfelt condolences go out to his family".



Information and support services provided by the Paget's Association

Paget's Nurse Helpline

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

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

Virtual Paget's Support Groups, Buddies and Support Network

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

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

Paget's information events

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

Information booklets

Our information booklets cover various aspects of Paget's disease, such as general information about Paget's disease, pain, investigations and orthopaedic surgery.

They can be downloaded from our website or sent to you by email or post.

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



Paget's information videos

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

Facebook support group

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

