

Supporting those affected by Paquet's Disease of Bone, funding research and raising awareness of the condition



The 50th Anniversary Fundraising Challenge

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Chair's Message

Dear Member,

As you can see, this edition of the magazine highlights the upcoming 50th Anniversary of the Association, which is now only four months away! On page 6 Diana Wilkinson concludes her three-part review of the history of the Association. Even though we have been through challenging times, the Association is still in good shape and is still the only charitable organisation that focuses solely on funding Paget's research, promoting awareness and providing support to people who have been diagnosed with Paget's Disease of Bone. We could not do this without your help, and it is amazing that, so far, we have raised £18,308 towards our target of £50,000, which we are aiming to reach by the end of 2023. So, many thanks to the Midnight Ramblers for their kind donation of £50, Peter Bardsley for his 31,000 steps, our London Marathon runners and everyone else who has been raising funds for the 50th Celebrations. Undoubtedly, the most daring was Diana Wilkinson's Wing Walk, featured on pages 10-11. I am sure you will agree that the pictures looked amazing, and Diana raised a magnificent £1,513 for her death-defying effort. If you want to look at a video of the event, please scan the QR code at the end of Diana's article on page 11.

The next few pages of the magazine give details of the Paget's information event and gala dinner, which will be held on 19th April 2023, and will coincide with the International Symposium on Paget's disease hosted by the Association at The Lowry, Salford Quays. It is a fantastic venue so please join us if you can, to celebrate 50 years of the Paget's Association!



One of the aims of the charity is to support research to advance knowledge about the causes, diagnosis and treatment of Paget's disease and I am delighted to report that we were able to fund two research grants this year. The first award is for research led by Professor Chantal Chenu at the Royal Veterinary College, London, and aims to find out more about the mechanisms of pain in Paget's disease. It is known that the activity of bone resorbing cells, called osteoclasts, are increased in Paget's disease and these cells resorb bone by secreting hydrochloric acid to dissolve bone mineral. Professor Chenu and her colleagues are investigating whether this causes activation of acid sensing receptors on nerve cells to cause pain. A second project, led by Radiologist, Dr Deepak Subedi, aims to develop a new technique using what's called Artificial Intelligence (AI), to screen for evidence of Paget's on x-rays performed for other reasons. If successful, this project offers the prospect of diagnosing the condition at a much earlier stage than is possible at present. I am sure you will join me in wishing both researchers success in their projects.

We are always keen to meet with people who have Paget's disease,

to provide information, and answer any questions they may have about the condition. We held two very successful information events this year. The first of these in Oxford, hosted by Dr Kassim Javaid, which was a great success, as was the event hosted by Dr Mike Stone and Dr Jane Turton in Cardiff. The feedback from both meetings was very positive and my special thanks go to orthopaedic surgeons Mr Anthony Palmer and Mr Sanjeev Agarwal, who both gave excellent lectures on the incredible technical advances in orthopaedic surgery that have taken place in recent years.

We are also looking forward to hosting Paget's Awareness Day on 11th January 2023. As in previous years, this will take the form of a series of video presentations in which I will interview Sheila, Allan and Mickey, who have Paget's disease, to ask how this has affected them personally. I will also be speaking to Dr Claire Clarkin, from the University of Southampton, about the research she has been conducting on Paget's, Diana Wilkinson who will explain about the support we offer, and Sue Clegg, who will discuss the history of the Association and give her insights into how things have changed over the 25 years in which she has been employed with us.

I would also like to highlight the informative article, written by our Specialist Nurse, Diana Wilkinson, and Professor Rob Layfield, on bisphosphonate-induced Osteonecrosis of the Jaw (ONJ). The article was prompted by a few queries we have had on the Helpline about this subject. Thankfully, this is a very rare adverse effect of bisphosphonate treatment in people with Paget's disease,

probably because bisphosphonate treatment is so effective in Paget's that treatment is required much less frequently than in other bone diseases.

In closing, I also wanted to welcome two new Trustees to the Association's Board. These are Dr Faiz Rahman, a Consultant in metabolic bone disease and chemical pathology at the University Hospitals of Leicester and Ms Eve Berry, a Chartered Accountant working in the drug discovery business. I am confident that our new Trustees will help to ensure the charity continues to work in a sustainable manner for many years to come.

On behalf of all at the Association, I would like to extend my best wishes for Christmas and the New Year, when it comes, and I very much hope to meet with many of you at our 50th Anniversary Celebrations in April 2023.

Stay safe and keep well!

Stuart Ralston

Chair, Paget's Association

Important Information for Professional Members

We are making changes to the way professional members receive the Paget's News magazine and from 2023 we will be sending the magazine by email instead of post to our professional members. If you are currently registered as a professional member of the Paget's Association and would like to continue to receive copies of the Paget's News magazine by email, please email membership@paget.org.uk and we will ensure you are added to our email magazine mailing list.

The Paget's Association

Charity registration number: 266071

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

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

Membership

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

What is Paget's Disease of Bone?

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

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

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

Our Website

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

www.paget.org.uk

Paget's Awareness Day

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

Contact us

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

Telephone

For all enquiries telephone:
0161 799 4646

Email

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

Postal Address

You can write to us at the following address:

The Paget's Association, Suite 5,
Moorfield House, Moorside Road,
Swinton, Manchester, M27 0EW

Paget's Helpline

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

■ Email: helpline@paget.org.uk

■ Telephone: **0161 799 4646**

■ Mobile: **07713 568197**

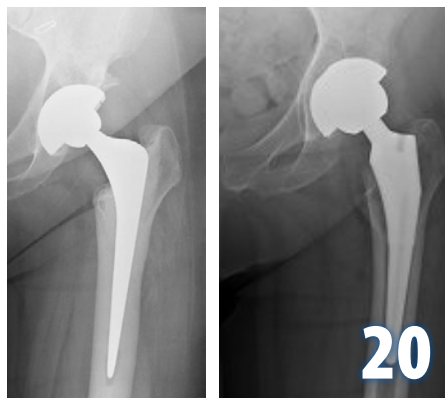
Chair of the Association

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

Connect with us on



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Welcome to the world Rudy

Trustee of the
Paget's Association,
Dr Cat Nairn, and
her husband are
delighted to share
news of the birth of
their baby boy, Rudy.

The team at the Paget's Association send our
congratulations to all the family.

New Trustees Elected at the AGM

We would like to welcome two new Trustees, Dr Faiz Rahman and Ms Eve Berry, who were elected at the Annual General Meeting, held in Cardiff, on 30th September.



Dr Faiz Rahman

Dr Rahman is a Consultant in Metabolic Medicine and Chemical Pathology at the University Hospitals of Leicester. He has supported Paget's research and been involved in looking after those with Paget's disease since 2009, in the Metabolic Bone Clinic at Leicester General Hospital.



Mrs Eve Berry

A Chartered Accountant, working in the drug discovery industry, Ms Eve Berry has been involved for many years in the healthcare sector. Her skills will assist the Paget's Association in its financial planning and help ensure the charity can run in a sustainable manner.

Minutes

The minutes from this meeting will be published in the February issue of Paget's News. Members can also request a copy from the Paget's Association's office.

London Marathon

We would like to thank all our runners who ran the TCS London Marathon in October and raised vital funds for the Association. Jo was one of them, completing it in 4 hours 47 mins. She also raised a fantastic £1,761. Jo said, "I really enjoyed it up until 20 miles, it was so difficult after that, but a wonderful experience. Thank you so much for allowing me to run for you."



Countdown to the Association's 50th Anniversary **Part 3**

The Paget's Association's 50th anniversary is now only a few months away. In the last two articles in this series, our Specialist Paget's Nurse, Diana Wilkinson, looked back at the origins of the Association. Here she continues the journey reflecting on some of the highlights and challenges that the charity has experienced.

Dedicated to Support Those in Need

The Paget's Association has been providing support for those with Paget's disease since its inception in 1973, when founder, the late Ann Stansfield MBE, supported many people affected by Paget's disease. It was in 2008 that a dedicated Nurse Helpline was set up to direct clinical queries to an experienced Registered Nurse. I took over this role in 2012, when the Association was preparing for its 40th anniversary in 2013.

40th Anniversary Events

The Association's 40th anniversary events took place in Manchester, in 2013. A Gala dinner and fundraising event was held at The Lowry, Salford Quays, and the following day, an informative Paget's Information Event was held at the Copthorne Hotel, Manchester.



A Challenging Period

Running a charity can be challenging, and towards the end of 2013, the Trustees had to make some difficult decisions, which saw a restructuring of the Association. The number of employees was halved, from four to two, project grant funding ceased, in favour of smaller research bursaries, and the offices owned by the Association were sold. Whilst it was an extremely difficult time for everyone involved, the sacrifices that were made meant that the Association was able to continue to offer information and support to those in need.

Building Back

Thanks to generous legacies and the measures that had been taken, the Association began to build back. In 2015, links with hospitals and researchers were made to form the Paget's Association's Centres of Excellence and in 2016, the Association was able, once again, to offer full research grant funding.

Responding to the Pandemic

Throughout the Covid-19 pandemic, like most charities, the Paget's Association faced various challenges. Several events were cancelled or postponed in 2020, research projects funded by the Association were delayed, and internal working arrangements changed. Despite this, our Helpline and office phone lines remained available as normal. We also offered to fund new research and gave further support to studies affected by the pandemic.

In June 2020, each member of the Paget's Association was given a complimentary face-covering, just

at the right time to coincide with government advice to wear them. New avenues of support were set up, including virtual Question and Answer sessions with our Chair, Professor Stuart Ralston, a Facebook Support Group and Virtual Paget's Support Groups. These gave people new platforms to share their experiences and discuss their concerns.

Once our Information Events were able to recommence, we ensured necessary measures were in place to comply with COVID-19 regulations and how wonderful it was to meet members and their families face-to-face once again.

New Financial Challenges

Like many other charities, the Paget's Association is not alone in facing new financial challenges. It saw its income decrease, as fundraising events were cancelled because of the pandemic. The return

on investments has fallen because of the current economic crisis, and, in addition, income from legacies fluctuates, and is never guaranteed. The Association has always risen to the challenges it has faced, and I know, that whilst we go through this difficult period, it will continue to adapt in whatever way is necessary, to help those affected by Paget's disease and support research into the condition.

A World Leader

We are not aware of any other charitable organisation in the world, which focuses solely on Paget's disease, and has the breadth of information and support services that the Paget's Association offers.

Individuals from several countries take part in our Virtual Paget's Support Groups and join in discussions in our Facebook Support Group.

Our Paget's Awareness Days in 2021 and 2022 included recorded

interviews with experts from around the world. This year especially, had an international theme as we considered Paget's disease from a global perspective. For Paget's Day 2023, on the 11th of January, we will release a series of video interviews that include personal experiences of people affected by Paget's disease in the UK and Canada. See page 22 for details.

The Paget's Association is truly leading the world in the fight against Paget's disease.

Join the Celebrations

Perhaps you would like to join us, in April next year, at one of our special 50th anniversary events? We are returning to The Lowry, in Salford Quays, Greater Manchester, for educational events and a Gala evening. Please see pages 12-14 for everything you need to know.

Diana

Paget's Association 50 YEARS ANNIVERSARY



Mrs Ann Stanfield MBE
Founder

“
I started by selling goods at Oldham market, 3 days a week, until the charity was registered in July 1973
”

50th Anniversary Campaign



As we look forward to the 50th Anniversary of the Paget's Association next year, our fundraising campaign to raise £50,000 by December 2023, has reached £18,308.

The Association relies upon individual donations and fundraising to ensure the continued provision of information and support, and to fund research. We not only need to ensure sufficient funds are available to secure the Association's future, but we also want to develop our services further.

Can You Help?

Could you donate, raise money, take part in the Paget's Fitness Challenge (details on page 9), or even make a regular commitment to donate a set amount each month?

No matter the size, every contribution helps the charity continue to be here for you and others.

How to Make a Donation or Pay-in Funds Raised

The Association's Website

Scan the QR code, with a smartphone camera, to be taken straight to the Paget's Association's donation page. Alternatively, visit www.paget.org.uk and click on the yellow 'donate' button at the top right. Then follow the simple instructions.



JustGiving's Website

You can also donate on our JustGiving 50th Anniversary Campaign page using the QR code here or use the details below. You can even link your own JustGiving fundraising page to this campaign.

<https://justgiving.com/campaign/Pagets50th>



Card: Call 0161 799 4646 to donate by debit/credit card.

Post: Post a cheque payable to 'Paget's Association' to: The Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.

BACS: To make a payment directly into the Association's bank account, please telephone the number above to request the Association's bank details.

Standing Order: To give a regular amount by standing order, request a form by emailing membership@paget.org.uk or calling 0161 799 4646.

Thank You for Making a Difference!

Thank you to all those who have already donated, sponsored a challenge, or raised funds!

Request a Fundraising Pack

Would you like to raise funds for the Paget's Association, but don't know where to start? Why not request our new fundraising pack, which contains ideas, tips and information to help get you started? The pack includes our fundraising booklet, full of ideas to inspire you, leaflets, a banner with the Association's logo printed on it to put up at your event and leaflets to help raise awareness.

Thank You for Making a Difference!

We'd like to say a huge thank you to everyone who has raised funds or donated to the Paget's Association. Your gifts help us to change the lives of those with Paget's disease and fund important research.

In the last edition of Paget's News, we featured members, Janet and Graham Dixon, who had held a car boot sale, and Chair of the Association, Prof Stuart Ralston, who completed the Etape Caledonia 2022 cycle race. Over the following pages, we feature other fundraisers who have contributed to the 50th Anniversary Fundraising Campaign. Thank you all for your efforts.

The Midnight Ramblers Raise Funds

We would like to thank the Midnight Ramblers, a band from Louth, Lincolnshire who kindly donated £50 from an event they performed at.



Peter's Fitness Challenge

In the May edition of this magazine, we challenged you to feel fitter and healthier by taking part in our Fitness Challenge. Mr Peter Bardsley from Birmingham took up the challenge for his 85th birthday. He walked 31,000 steps by the side of the canal near where he lives, which is roughly the equivalent of a half marathon (13.1 miles) and raised an amazing £250 in sponsorship.

Peter earned one of our silver medals for his achievement, thank you Peter and very well done!



Earn a Medal with our Fitness Challenge!

Support Those with Paget's Disease & Earn a Medal with our Fitness Challenge!

50 YEARS
ANNIVERSARY



If Peter's achievement has inspired you, why not challenge yourself and earn a Paget's Association medal?

All funds raised help us to reach our fundraising target of £50,000 for the 50th Anniversary of the Association.

Getting Started

■ This is your challenge. You choose the distance, the place, and the time you will take to do it.

■ You can walk, hike, run, swim, cycle or, if you use a wheelchair, wheel your way towards your goal

■ It does not matter whether it is half a mile, five miles or a marathon. What matters is that you push yourself safely towards a goal that is a challenge for you and will improve your level of fitness.

Make it Worthwhile

■ Ask your friends and family to sponsor you to raise funds for the Paget's Association (they may even join you!)

■ It does not matter if you have one sponsor or fifty, as long as you are improving your fitness and raising funds at the same time.

■ Once you have decided on your challenge, we can help you if you need it, whether you are using sponsorship forms or an online sponsorship platform, such as JustGiving.

■ Raising £25 will secure a bronze medal. You can also aim for silver or gold.

Bronze Fitness Medal

£25 minimum

Silver Fitness Medal

£100 minimum

Gold Fitness Medal

£500 minimum

Share your Achievement

To enable us to send you your Fitness Medal, you will need to let us know:

- details of the challenge you set
- what you achieved
- the amount of money you raised

In addition, if you have photographs of your challenge, we would love to see them.

You can contact us by telephone on 0161 799 4646 or email membership@paget.org.uk

Good Luck!

Diana's Fundraising Wing Walk

Thank you to all those who sponsored, Diana, our Specialist Paget's Nurse, to complete a Wing Walk fundraising challenge. A fantastic £1,513 was raised towards our 50th anniversary target of £50,000. Here's Diana's summary of the event.



A Special Challenge

It is so hard to raise funds for a condition that, let's face it, many people have never heard of, so when I decided I was going to take on a challenge, it had to be special.

On a beautiful summer's day, I arrived at Leeds East Airport in Church Fenton, North Yorkshire. Several people were awaiting their turn to take to the skies and raise funds for good causes. I watched a lady who was already up in the air on the top wing of a biplane and, watching from the safety of the tarmac, I think my main concern was the take-off. Still, I told myself, it was all for a good cause and I was ready to take on the challenge!

Safety Briefing

In the training room, a safety briefing took place, beginning with an introduction to the aircraft, a Boeing Stearman biplane. In the early 1930s, the Stearman Company designed

and built these sophisticated training planes for the US Air Force and Navy. When the company was taken over by Boeing, the biplane became known as the Boeing Stearman, which was produced in large numbers in Kansas. When they were no longer required by the military, they were sold for various uses such as crop dusting, aerial photography, and air shows where they were used for displays by professional wing walkers.

The professionals who wing walk today are tethered to the rig (basically a pole attached to the wing) so they can actually walk on the wing. The 'wing walk' offered to the inexperienced was not technically a walk because I would be strapped to the rig with a harness. Well, that was a relief!

I was briefed on how to climb up to the top wing and what to expect. The speed would be up to 130 mph, and the g-force would be an

experience! Most importantly, I was taught hand signals that could be used to communicate with the pilot.

Whilst I was reassured that, despite its age, the Boeing Stearman is a safe and reliable aircraft, the last thing I was told was that in case of engine failure, the aircraft could land on rocky ground (unlikely given the very flat farmland surrounding the airfield), and it could land upside down, therefore, the wing walker's head could hit the ground first (I hadn't planned for that!). I looked around for a crash helmet, but only goggles were provided. Reassurance was given that I could change my mind and have a refund, but this was quickly followed by paperwork that had to be signed to say that I understood the risks and with significant funds raised in sponsorship, backing out didn't feel like much of an option. So, with forms signed, I returned to the airfield to watch another wing walker experience a wonderfully safe landing.

My Turn

Looking up at the top of the two wings I began to wonder how I was even going to get up there, however, step-by-step instructions were given so that I did not stand



on any delicate areas of the aircraft. Once in place, one of the team members fitted me securely with the harness that would keep me upright and attached to the rig. It was at this point that I was told that the hand signals I was to use to communicate with the pilot differed slightly from those I had watched in the training video. This created my first moment of panic as I thought I'd learnt those pretty well. For reassurance, I asked him to repeat the new instructions, which, to be fair, were quite simple.

The pilot, Andy, came and stood where I could see him and asked if I was feeling adventurous. When I asked why, he said he could carry out some roller coaster manoeuvres. Well, it would have been a shame not to have tried the full experience, so I accepted and made sure I had remembered the signal for 'get me on the ground as soon as possible'. Off he went to take up his position below and whilst I could not see him, he could see me and those all-important hand signals.

Take Off



The moment I had been most worried about, the take-off, came after a very bumpy ride across the hard grass. Attached to the rig I felt myself wobble about within the straps, but once on the tarmac, it was a much smoother ride.



Diana (front centre) with some of her support team

It felt like a long way to the runway but finally, we were off and as we left the ground, I was pleasantly surprised that the take-off was quite smooth, and the momentary relief spurred me on for what was to come.

Manoeuvres

Once high above the ground, the aircraft turned on one side and then the other. Thanks to the goggles, my eyes didn't water but the g-force caused my cheeks to flap so much that I felt I had no control over my face.

The view was amazing. Looking down on the Yorkshire countryside, a farmer was ploughing a field and I could vaguely make out my support team in the distance.

The professionals make wing walking look poised and relaxed but when you are not used to the g-force, just moving your arms is challenging, however, I managed to signal to the pilot that I was okay. He must have got the message as we climbed steeply before dropping down in the first roller coaster manoeuvre. It was an experience that is hard to describe as it wasn't anything like a roller coaster at the fun fair! After a few of these, I did start to think I'd had enough. Up to that point I had been able to hold my legs in position on the rig, however, they decided to develop a will of their own and became harder to keep in place.

Soon after this, I was relieved to see we were heading for the runway, however, as the ground came nearer, I became concerned about how bumpy the landing would be. I needn't have been, it was very slick, and I was extremely grateful to Andy for his fantastic flying skills.

As we taxied along, I waved like crazy to let my family and friends know that I was okay. As I climbed down from the wing, I found that my legs were momentarily a little wobbly, but they soon recovered. The verdict? It was a once-in-a-lifetime challenge, which was as exhilarating as it was scary and a wonderful experience that I'll treasure forever.

All for a Good Cause

Like any other charity, the Paget's Association can only survive through the kindness of those who donate their time and/or money. I would like to thank everyone who so generously sponsored and supported me in this challenge. 'We' did it! Thank you!

Captured on Video

The event was captured on video, which you can watch on the Association's YouTube channel.

Scan the QR code or contact us and we will email you a link.



Diana

Show Your Support

If you would like to donate to Diana's challenge, it's not too late, you can either telephone the Association on 0161 799 4646 or scan the QR code with a smartphone to be taken to her JustGiving sponsorship page.

You are invited to a

Free Paget's Information Event

The Lowry, Salford Quays, Manchester
on **19th April 2023**

at 15:15 hrs until 17:15 hrs

Join us for refreshments from 14:30 hrs



International Speakers

Expert speakers from Canada, New Zealand, and the UK will guide the audience through various aspects of Paget's disease in this two-hour event. There will also be opportunities for discussion and to ask the speakers questions. Please see the programme on the next page.

Refreshments

The event is free to attend, and refreshments will be provided from 14:30 hrs.

The Venue

The Hexagon Room at The Lowry, Pier 8, The Quays, Salford, Greater Manchester, M50 3AZ.

Book Your Place

It is essential that you book your place. You are welcome to bring someone with you. You can register on our website or complete the booking form on page 16 and return it to the office.

www.paget.org.uk

Queries?

For further information or if you have a query please contact us.

Telephone: 0161 799 4646

Email: membership@paget.org.uk



thelowry.com

Patient/Family Information Event Programme

Wednesday 19th April 2023

15:15 hrs-17:15 hrs Salford Quays, Manchester

Welcome & Introduction

Mrs Diana Wilkinson

Specialist Paget's Nurse, Paget's Association, Manchester

Genetics & Environment

Dr Laëtitia Michou

Rheumatologist & Researcher, Quebec, Canada

Diagnosis – Past, Present & Future

Prof Stuart Ralston

Rheumatologist & Researcher, Edinburgh

Round Table with Dr Michou & Prof Ralston

Time to join in the discussion and ask the experts questions

Orthopaedic Surgery & Paget's

Mr Nav Makaram

Orthopaedic Surgeon & Researcher, Edinburgh

Benefits & Risks of Medical Treatment

Prof Ian Reid

Endocrinologist & Researcher, Auckland, New Zealand

Round Table with Mr Makaram & Prof Reid

Time to join in the discussion and ask the experts questions

Why not Stay for the Gala Evening?

At 19:00 hrs a Gala Evening with dinner will take place so why not join us for both events? See page 14 for details.

Join us for a **Gala Evening of Dining & Entertainment**

in celebration of 50 years of the Paget's Association
to be held in the **Compass Room of
The Lowry, Salford Quays, Manchester**
on **19th April 2023**, commencing at **19:00 hrs**



Join us at this special evening event.

Enjoy a welcome drink, a 3-course meal with wine, and entertainment
with your Master of Ceremonies, Mr Phil Colbert.

Tickets: £50 per person

To secure your place/s, you can register on the Association's website www.paget.org.uk
Alternatively, complete the form on page 16 and return it to the office.



Free Paget's Information Event

You may also wish to come along to the
free Paget's Information Event in the
afternoon (details on pages 12-13).

The Venue for our 50th Events



Salford Quays is Greater Manchester's unique waterfront destination, with good tram and bus links from Manchester City Centre. It is the home of MediaCityUK, which houses the BBC and ITV. Close by, you will find the Blue Peter Garden, the Coronation Street production centre, the Imperial War Museum, Manchester United Football Ground, and Lancashire Cricket Ground.

The Paget's 50th Anniversary events are taking place at The Lowry, which is opposite the Quayside Shopping Centre, with its shops, restaurants, and cinema.

The Lowry

Situated right on the waterfront in Salford Quays, The Lowry is a magnificent building, where visitors will find theatres, galleries, cafes, a bar, a restaurant, and, significantly, one of the largest L S Lowry art collections in the world.

Whilst several rooms have been set aside for our events, the Compass Room has been reserved for the Gala Evening (page 14). This beautiful room has an almost 360-degree view of Salford Quays.



Why not take some time to explore the area before joining us for the Paget's Information Event in the afternoon of the 19th April?



Then meet us in the Compass Room for the Gala Celebrations, where you will be able to enjoy the evening with other members, Trustees and staff.

The Lowry is a registered charity. The building is fully accessible with lifts to all floors and accessible toilets throughout.

Staying Overnight?

There are several hotels close by, including a Holiday Inn, Holiday Inn Express and a Premier Inn. We have negotiated a special rate with the Holiday Inn Manchester, Salford Quays, which is the closest of the hotels to The Lowry. If you would like information on how to access the special rate or on other hotels in the locality, please get in touch by telephone 0161 799 4646 or email membership@paget.org.uk



Booking Form for Patient/Family Information Event and Gala Evening

Cut out or photocopy this form or simply book on our website.

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

Free Patient/Family Information Event

This meeting is free of charge and includes refreshments on arrival.

I/we wish to attend the free Paget's Information Event at The Lowry on 19th April 2023

Names of those attending the Information Event

Gala Evening

I/we wish to attend the Gala Evening on 19th April 2023

How many tickets would you like to purchase for the Gala Evening? (£50 each)

Total cost £ Please make your cheque payable to 'Paget's Association'

If you would like to pay by debit or credit card please tick this box and someone from the Association will contact you to take your payment

Please state any special dietary requirements

Please note that you will be given a choice of menu prior to the event

Names of those attending the Gala Evening

For all of the above events, please complete the following

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

Please state any special requirements

Name & address for correspondence

Postcode

Telephone

Email address

Please return this form by post to: **The Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW** or email the above information to: membership@paget.org.uk

International Symposium on Paget's Disease

for Researchers, Clinicians, Allied Health Professionals and Students
at **The Lowry, Pier 8, The Quays, Salford, Greater Manchester, M50 3AZ**
on **19th and 20th April 2023**

Topics and speakers include:

Paget's Disease from a Patient's Perspective.....	Mr Simon Leigh (Dorset)
Clinical Outcomes with Medical Management of Paget's Disease	Prof Ian Reid (Auckland)
Understanding Bone Biology Through Research in Paget's Disease	Prof Chantal Chenu (London)
Genetic Determinants of Paget's Disease	Prof Wim Van Hul (Antwerp)
Insights from the Study of Ancient Skeletons	Prof Silvia Gonzalez (Liverpool)
Epigenetics and Paget's Disease	Prof Omar Albagha (Qatar)
A Global Perspective on Paget's Disease	Prof Terry O'Neill (Manchester)
Environmental Interactions and Paget's Disease	Dr Laëtitia Michou (Quebec)
Diagnosis – Past, Present and Future.....	Dr Elaine Dennison (Southampton)
Paget's Disease & Multisystem Proteinopathies.....	Dr Virginia Kimonis (California)
Clinical Outcomes with Orthopaedic Management of Paget's Disease.....	Miss Chloe Scott (Edinburgh)
Inherited Forms of Paget's Disease and Tumorigenesis	Dr Fernando Gianfrancesco (Naples)
Prospects for Preventing Paget's Disease	Prof Stuart Ralston (Edinburgh)

Register

Please register online: visit our website for details
Early bird registration: £225 (non-student) / £175 (student)

50 YEARS
ANNIVERSARY

Call for Abstracts

Guidelines for the submission of abstracts are available online.
Abstract submission deadline: 11th January 2023



In association with ECTS/BRS
in Liverpool, April 2023



New Research Funding

The Paget's Association continues to encourage and fund quality research projects, as well as investing in individuals to build research capacity. We are pleased to share details of two new research projects funded by the Association.



Chronic Pain Research

Pain is the symptom that most often takes those affected by Paget's disease to see their doctor. The Association is delighted to announce the funding of a new research study into chronic pain associated with Paget's disease.

Professor Chantal Chenu, a Professor of Skeletal Biology at the Royal Veterinary College, London, and Dr Shafaq Sikandar, a Senior Lecturer at the William Harvey Research Institute, London, are focusing their research on acidosis in relation to pain in Paget's disease. The following is a brief summary of their study.

Contribution of Acidosis to Chronic Pain in Paget's Disease

Paget's Disease of Bone is a common metabolic bone disorder. It is characterised by increased bone turnover and giant cells (osteoclasts) responsible for the destruction of the bone. The most frequent complication of Paget's disease is bone pain, which

considerably reduces quality of life. There are few analgesics that specifically target this pain and so patients continue to suffer.

Osteoclasts normally produce a large amount of acid to dissolve bone, but acid is also the most fundamental pain-inducing agent in the body. This research will investigate the idea that increased acidification of bone tissue, due to osteoclast action or inflammation, may contribute to the pain experienced by patients with Paget's disease.

The research will examine whether blocking proteins that sense the acidity (acid-sensing ion channels, ASICs) on the membrane of specialised nerve cells (sensory nerves) can reduce the transmission of the pain signals to the spine and brain. ASICs are suspected to mediate inflammatory pain in many tissues. They will test whether ASICs contribute to bone pain in Paget's disease. This will improve our understanding of the mechanisms of pain in the condition, and may guide the selection of new therapies for treating pain in those with Paget's disease.

Research to Aid Diagnosis

A Master of Research (MRes) degree is an internationally recognised advanced postgraduate research degree, designed to develop high-level research skills. The Paget's Association is pleased to be funding an MRes for Dr Deepak Subedi, a Consultant Radiologist at the Western General Hospital, Edinburgh. His supervisors will be Professor Stuart Ralston at the University of Edinburgh and Dr Sasan Mahmoodi at the University of Southampton.

Dr Subedi's degree will focus on the application of artificial intelligence (AI) to assist the radiological diagnosis of Paget's disease. This is something which was discussed with members at our Information Day in Southampton last year and could aid earlier diagnosis of Paget's.

Application of Artificial Intelligence to the Radiological Diagnosis of Paget's Disease

Dr Subedi will receive training in the use of AI and machine learning applied to image analysis, to devise novel techniques and algorithms, for the diagnosis of Paget's disease. In addition, he will acquire skills in experimental design, statistical analysis, data processing/management, data presentation, scientific writing, and public communication.

It is well recognised that only a small fraction of people with Paget's disease (perhaps 8-15%) come to medical attention. Previous studies of x-ray images of the abdomen taken from patients referred to hospital, for a variety of reasons, other than suspected Paget's disease, have shown that x-ray evidence of the disease may be present. In many of these patients, the diagnosis of Paget's is overlooked by the reporting radiologist or not mentioned as the referral has been for another reason.

This project will explore whether it is possible to use AI to diagnose the condition automatically from x-rays and other images taken for another reason. This will involve selecting images from a series of patients known to have Paget's disease and comparing them with "control" images, then developing AI algorithms to differentiate between the two. Once the algorithms have been developed, they will be tested in a replication set of x-rays to evaluate the sensitivity and specificity of the new method.

If successful this technique could, in the longer term, be applied across the NHS to diagnose Paget's disease automatically and flag this diagnosis to the referrer, who would then be able to evaluate whether further investigations and treatment are required.

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

Feedback from our Oxford Information Day

The Paget's Information Day in Oxford was an excellent opportunity to learn from the experts, discuss individual experiences, and have questions answered. We asked those attending what they found most beneficial about the event. Here are some of their responses.

Your next opportunity to join a similar event is in Manchester. For details see page 12.



"Meeting other people with Paget's disease"

"The sharing of information is very good"

"Explained some more of what I already knew"

"Better understanding of research projects and funding"

"Talking to and meeting other people with Paget's"

"Interaction with others"

"Patients' experiences"

"Learning more about what the Paget's Association does. Hearing about others' experiences"


"Meeting the people who have Paget's, the updates on research findings"

Hip Replacement Surgery


Mr Antony Palmer, Consultant Hip Surgeon at the Nuffield Orthopaedic Centre, Oxford and Senior Clinical Research Fellow at the University of Oxford, agreed to share the presentation he gave at our Oxford Information Day. We have shown an example below.

Request the Slides

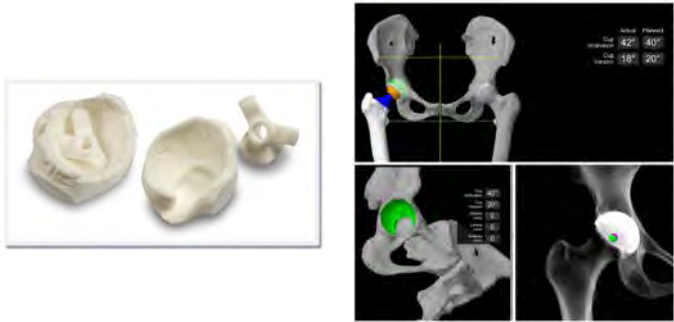
If you would like to view all the slides, you will find them in the members' area of our website. You can also email helpline@paget.org.uk and we will email them to you. Alternatively, if you would prefer them to be printed and posted to you, please telephone 0161 799 4646.




Advances in Hip Surgery



- Enhanced recovery
- Surgical approaches
- Robots and patient-specific guides
- Augmented reality





★★★★★ **200 Club Raffle** ★★★★★

If you are over 18 and would like to join the 200 Club raffle, please get in touch by telephoning 0161 799 4646 or by emailing membership@paget.org.uk

	July 2022	August 2022	September 2022
★★★★★ Congratulations ★★★★★	1st Prize £100 Ticket No. 182 <i>Sir Henry Paget</i> Banffshire	1st Prize £100 Ticket No. 44 <i>Sarah Lane</i> Essex	1st Prize £100 Ticket No. 183 <i>Sir Henry Paget</i> Banffshire
	2nd Prize £50 Ticket No. 144 <i>Kathleen Ford</i> Hertfordshire	2nd Prize £50 Ticket No. 11 <i>John Ferguson</i> Nottingham	2nd Prize £50 Ticket No. 18 <i>Carolyn Re</i> New South Wales

Volunteers Wanted for the Genetic Analysis to Predict the Development of Paget's Disease Study

Researchers at the University of Edinburgh are looking for people, across the UK, with a family history of Paget's Disease of Bone, to take part in a research study known as the Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD) study. This aims to offer people, with a family history of Paget's disease, a genetic test to determine how likely they are to develop the condition themselves. The team would like to hear both from people with Paget's disease who have a relative aged 45 years and over who may be interested in taking part, and also people over 45 who have a family member with the disease. Volunteers who take part in the study will undergo a bone scan to detect any early signs of Paget's, as well as blood tests and questionnaires.

Why are they doing the study?

Paget's disease can run in families. Close relatives of people with Paget's have a seven times greater risk of developing the disease in later life, than someone in the general population. It is known that it may go undetected for many years and then present at a late stage with complications that are difficult to reverse. The researchers want to be able to avoid that happening in the future.

What's the aim of the study?

The researchers want to be able to predict why some people with a family history of Paget's disease develop the disease and others do not. People who enrol in the study will also be kept under close surveillance for any signs or symptoms of the disease should they occur.

Who can take part?

Anyone who is aged 45 years or older with a parent or sibling who has been diagnosed with Paget's



disease can take part. The only exclusion would be if your relative had already been diagnosed with the condition.

Where is the study taking place?

The investigators are planning to perform the study in several sites across the UK and Ireland. One site has already been set up in Edinburgh, but other sites are in the process of being set up in Bristol, Cambridge, Cardiff, Dublin, Keele, Leicester, London, Liverpool, Middlesbrough and Newcastle. They will give you a choice of the site that is most convenient for you.

What about travel costs?

The study team will be very happy to reimburse any travel and accommodation costs that your relative might incur as a result of taking part in the study.

How do I find out more?

If you think you may be interested or would like to find out more, please contact the study team by emailing gapdpd@ed.ac.uk or the Chief Investigator, Professor Stuart Ralston, by emailing stuart.ralston@ed.ac.uk

Paget's Awareness Day 11th January 2023

Professor Ralston to Answer Questions Live on Paget's Day

Professor Stuart Ralston will hold a virtual Paget's question and answer session, using Zoom, at 17:00 hrs on Wednesday 11th January.

He will answer any questions you have regarding Paget's disease. You can also join in if you just want to listen to the discussion.

If you have not used Zoom before and would like us to test the connection etc with you, please get in touch.



Live Q & A
Wednesday
11th January
17:00 hrs

To take part, from wherever you are in the world, please email membership@paget.org.uk and we will send you a link to join. Should you not receive the link, please check your junk folder or get in touch.

Paget's Day Video Campaign

For International Paget's Awareness Day 2023, we will be raising awareness by sharing videos of personal experiences of Paget's disease, as well as information about our support services and the history of the Paget's Association. In addition, our Chair, Professor Stuart Ralston will be interviewing a researcher in Southampton.

How to Watch

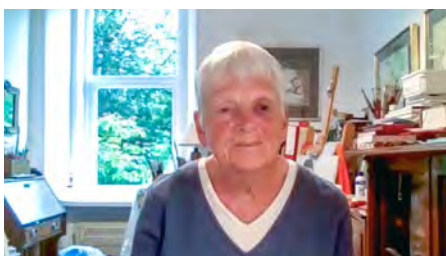
From January, you can watch the videos on our website, and our YouTube channel (search YouTube for 'Paget's Association').

Help Raise Awareness

Join in the fight against Paget's disease by inviting your family and friends to watch the videos or by sharing them on social media.

Personal Stories

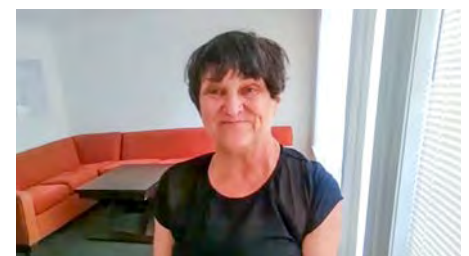
In their videos, Sheila and Allan in the UK and Mickey in Canada will explain how Paget's disease has affected them and what their experience of treatment is.



Sheila



Allan



Mickey

Paget's Research

In her video, Dr Claire Clarkin will talk to Professor Stuart Ralston about Paget's research in Southampton.



Dr Claire Clarkin

The Association and the Support it Provides

The series will also feature an interview with Sue Clegg, our Office Manager, who will talk about the history of the Paget's Association, and Diana Wilkinson, our Specialist Nurse, who will explain the support offered by the charity.



Diana



Sue



*We would like to wish
all our members a
Happy Christmas &
Best Wishes for a
Happy and Healthy
2023*

Send an E-card

**to Support the Paget's Association
and Help the Environment**

Find us on

DontSendMeACard.com



Journal News



Many articles are published in medical and research journals regarding different aspects of Paget's disease. This regular feature highlights areas of interest and provides a glimpse into some of the fascinating research taking place around the world. In this issue, the Chair of the Association's Research Subcommittee, Professor Rob Layfield, and our Specialist Paget's Nurse, Diana Wilkinson, have chosen a review paper from the *Journal of Clinical Endocrinology and Metabolism*, which focuses on Medication-Related Osteonecrosis of the Jaw (MRONJ). Diana introduces the subject and summarises the review below.

Osteonecrosis of the Jaw

Throughout life, normal bone is renewed and repaired through a process called bone remodelling. In Paget's disease, bone remodelling is accelerated and disorganised, leading to the formation of bone that has an abnormal structure. Drugs that target particular bone cells (osteoclasts) involved in this process are used to treat Paget's disease and other conditions, such as osteoporosis and bone cancer. In Paget's disease osteoclasts remove (resorb) too much bone, therefore, targeting these cells with particular drugs is a good treatment and known as antiresorptive therapy. A group of drugs known as bisphosphonates, such as zoledronate and risedronate, fall into this category and are used to treat Paget's disease.

Rarely Seen in Paget's Disease

On rare occasions, bisphosphonates are associated with osteonecrosis of the jaw (ONJ). This is a condition which may present after dental surgery when exposed bone fails to heal. ONJ has been linked to the use of potent antiresorptive agents, termed Medication-Related ONJ (MRONJ). This is rarely seen in those with Paget's disease and,

“
The benefits of antiresorptive therapy far outweigh the risk for MRONJ development
 ”

if bisphosphonate treatment is required, the benefits often outweigh the risk of any potential side effects. We know, however, from the number of queries regarding ONJ that the Paget's Association's Helpline receives, that those affected by Paget's disease have questions about it.

The following is a summary of a review organised by the European Calcified Tissue Society (ECTS) into ONJ and the use of antiresorptive medication. The full review is freely available online (see page 25).

A Critical Review

A working group of the European Calcified Tissue Society (ECTS) and two experts aimed to identify the differences in various aspects of MRONJ among distinct patient categories and provide recommendations on how to mitigate the risk and optimally manage MRONJ. They carried out a detailed review of existing literature on MRONJ incidence, characteristics, and treatment applied in bone disease.

Introduction

Antiresorptive therapy significantly reduces fracture risk in patients with benign bone disease and skeletal-related events in people with secondary bone cancer (bone metastases).

Osteonecrosis of the jaw (ONJ) is a rare but severe condition manifested as one or more areas of dead bone tissue (known as necrotic bone lesions) that are exposed or can be probed through an abnormal passageway (fistula) in the jaw and persist for at least 8 weeks without response to appropriate therapy. ONJ is more commonly located in the mandible but can be detected in both bones of the jaw. It may be accompanied by pain, inflammation, redness, pus, and loose teeth.

Although ONJ may occur spontaneously, in most cases it is the result of a dental procedure, for example, tooth extraction or oral surgery.

The occurrence of ONJ was initially associated with bisphosphonates. Later, it was also attributed to denosumab, antiangiogenic medications and tyrosine kinase inhibitors. To date, several other medications, mostly used in the oncology setting, have also been linked to the risk what is known as Medication-Related ONJ (MRONJ).

An imbalance of bone turnover, with increased osteoclast resorption rate, characterises a broad spectrum of bone diseases, ranging from osteoporosis and other benign bone diseases, to cancer treatment-induced bone loss and bone metastases in advanced malignancies. In all these conditions, targeting the osteoclast with antiresorptive agents is currently the cornerstone of treatment. Among them, bisphosphonates, and denosumab are the more potent and more frequently used agents in everyday clinical practice.

The Review

The ECTS suggested that there is confusion among clinicians and dentists regarding the occurrence and optimal prevention/management of ONJ, possibly owing to discrepancy regarding definition, incidence, characteristics, and treatment. This may in part relate to the underlying bone disease and consequent regimen (doses and frequency) of the antiresorptives administered. They wanted to clarify various aspects of ONJ and provide recommendations on how to mitigate risk and optimally manage ONJ in each of these patient categories.

Conclusions

Risks for MRONJ – The risk for MRONJ largely depends on the underlying bone disease and the relevant antiresorptive treatment. The risk for MRONJ is much higher in patients with advanced malignancies compared to those with benign bone diseases because of the higher doses and more frequent administration of antiresorptive agents in individuals with compromised general health, along with coadministration of other medications that predispose to MRONJ.

Prevention – Preventive measures, including maintenance of good oral health, completion of any required dental treatment before commencing antiresorptive therapy, at least in patients with metastatic bone disease, and the use of antibiotics before and after a surgical procedure substantially reduce the risk of MRONJ.

Management – When MRONJ occurs, it is usually conservative management (e.g. good oral hygiene, antibacterial mouth washes, antibiotics if required) should be applied to the majority of cases. In cases of MRONJ that do not respond to conservative treatment, surgery may be recommended.

Benefits of Treatment – The authors concluded that the benefits of antiresorptive therapy include major reductions in skeletal-related events in oncology patients and fracture risk reduction in those with osteoporosis. However, ONJ can severely affect a person's quality of life, therefore,

a personalised treatment plan with careful consideration of all aspects is very important. The authors recommended that physicians and dentists should be mindful that the benefits of antiresorptive therapy far outweigh the risk for MRONJ development.

Reference

Anastasilakis AD, Pepe J, Napoli N, Palermo A, Magopoulos C, Khan AA, Zillikens MC, Body JJ. Osteonecrosis of the Jaw and Antiresorptive Agents in Benign and Malignant Diseases: A Critical Review Organized by the ECTS. *Journal of Clinical Endocrinology Metabolism*. 2022 Apr 19;107(5):1441-1460.



Find the article online by going to the page below or by scanning the QR code

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9016445/>

Publications News Feed

Professionals interested in Paget's disease may find the Professional Resources section of the Paget's Association's website useful. Included is an automatic (RSS) news feed from pubmed.ncbi.nlm.nih.gov. PubMed is a database of references to biomedical literature, such as scientific journals, and online books. When PubMed displays new content containing specific terms, details will appear on our website. Please note that not all content may be directly relevant to Paget's Disease of Bone.



Making a Difference in Cardiff



Our Information Days are a tremendous opportunity to network, learn about Paget's disease from the experts and have your questions answered. Our latest event took place in September at the Holiday Inn, Cardiff, and the feedback from the event was excellent. These events allow time for discussion with various specialists all in one place - something that is not often available to those with Paget's disease in a clinical setting. On behalf of the Paget's Association, thank you to all those who contributed to a very successful day. With special thanks to Professor Mike Stone and Dr Jane Turton.

Physiotherapy

Local Physiotherapist, Ms Zoe Oram-Jones, discussed how physiotherapy can help those with Paget's disease, and explained that the following resources are available in the Cardiff area.

- **Dewiscymru:** seated/ supported yoga sessions
- **AgeCymru:** Nordic Walking, LIFT, Tai Chi, Walking Befrienders
- **Healthwise:** discounted membership at leisure centres to use the gym, pool, and access all classes (referral from clinic required)

Pain

Dr Jane Turton, Associate Specialist Physician in Cardiff, gave an excellent talk on pain management, including how to relieve acute and persistent pain through:

- **local heat and cold**
- **pain relieving medication**
- **TENS**
- **acupuncture**
- **locally invasive injections**

Joint Replacement

Mr Sanjeev Agarwal, a Consultant Orthopaedic Surgeon in Cardiff, expertly reviewed joint replacement surgery. He explained that figures from the National Joint Registry show that 75,000 hip joints and 85,000 knee joints are replaced each year.

Treatment

Prof Mike Stone, Consultant Physician at the University Hospital Llandough and Director of Bone Research in Cardiff discussed the treatment and monitoring of Paget's disease.

He mentioned that, out of all the treatments, zoledronic acid is the one most likely to improve quality of life (including pain and general wellbeing) and return blood tests to normal. In addition, research has shown that, following zoledronic acid, few patients "relapse", even after six and a half years.

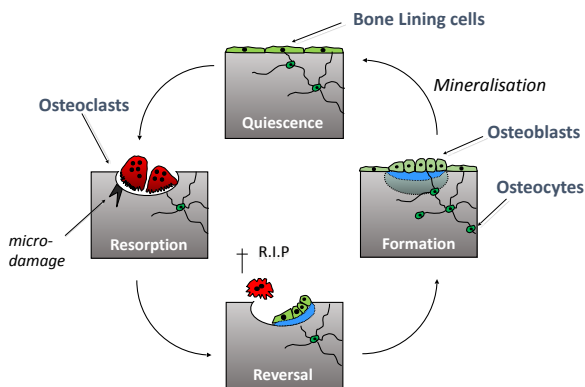


Prof Stone with some of his team, who joined us for the day

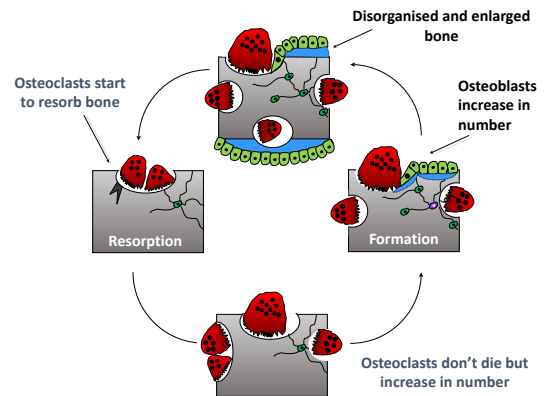
What is Paget's Disease?

Prof Stuart Ralston explained how 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. You will find snapshots below from his presentation. He also discussed the clinical features, potential complications and causes of the condition.

Bone turnover and the normal bone remodelling cycle



Bone turnover and the abnormal bone remodelling cycle in Paget's disease



Prof Ralston summarised his talk with the following key points:

- Paget's disease is caused by abnormally increased bone remodelling targeting specific bones
- There is increased osteoclast and osteoblast activity
- Variation in genes that regulate osteoclast function are an important cause
- Environmental triggers also contribute, but we are not clear what these factors are
- The increase in bone remodelling can be treated and this can improve symptoms
- Outstanding questions:
 - Why are some bones targeted whereas others are not?
 - What are the environmental triggers? Diet? The microbiome? Factors related to social deprivation? Previous skeletal injury?
 - How do these triggers interact with genetic factors?



Trustees and staff of the Paget's Association joined members in the audience



Paget's Information and Support Services

Paget's Helpline



- ✓ Information
- ✓ Support
- ✓ Guidance

The Paget's Helpline is a service provided by the team here at the Paget's Association. A Registered Nurse is usually available during office hours, to discuss any aspect of Paget's disease.



Contact the Paget's Helpline
 Email: helpline@paget.org.uk
 Call: **0161 799 4646**
 Call or text mobile: **07713568197**

Virtual Support Groups



Meet others online at one of our Virtual Paget's Support Groups. Meetings take place every two months, using Zoom. To support as many people as possible, meetings take place on different days and at different times.

For more information or to take part, please email membership@paget.org.uk or register on our website. A link, to join, will be emailed

to you a few days before the meeting. Should you not receive it, please check your junk folder, or get in touch.

Feedback

"I am so glad I found this group and look forward to seeing the members again"

"It was wonderful sharing and learning from others with Paget's Disease"

"Today's meeting made me feel included and not so alone"

Thank you to those who have been in touch to let us know how much you appreciate these online meetings.



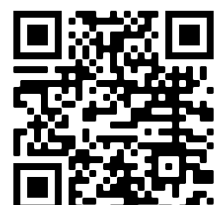
Paget's Support Network

Members of the Paget's Association can join our Paget's Support Network, which enables you to connect with other Network members by phone, letter, email or however you would like to communicate.

Facebook Support Group

Our Paget's Facebook Support Group continues to grow, as people from around the world share their experiences and support each other.

To join the Facebook group, please scan the QR code with a smartphone or visit <https://www.facebook.com/groups/pagetsdiseaseofbone>





Sheffield Support Group

The Sheffield Support Group meets around three times a year, in Darnall, Sheffield, from 13:30 hrs until 15:00 hrs.



Information

Should you require our latest information booklets or back issues of this magazine, get in touch with our office. We can send them to you by email or post.



Support for the Newly Diagnosed

When someone who has just been diagnosed with Paget's disease, contacts the Paget's Association, they may receive a free Paget's Support Gift Bag, containing useful items to help them through what we know can be a difficult time. We want to say thank you to all those who have donated to help us provide these. Your support is very much appreciated!



Paget's Buddies

Would you simply like to talk to someone else who has Paget's disease? Our Paget's Buddy scheme provides one-to-one support between members of the Paget's Association.

If you feel you would like to receive support, please get in touch and we will find you a support buddy. If you would like to offer support to another member who is struggling with Paget's disease, please let us know. It is purely a supportive role, so no medical knowledge is required.

Further Information

For further details about any of our information or services, please get in touch using the details below
Email: helpline@paget.org.uk Telephone: 0161 799 4646

Raising Awareness Among Clinicians, Researchers and Students

Professionals working in the field of bone disease came from both the UK and overseas to attend the Bone Research Society's 2022 conference, in Manchester. They were able to receive information regarding Paget's disease, research, and Paget's educational events from the Paget's Association's exhibition stand.



Lord Trevor Stamp, Patron of the Paget's Association

Following a short illness, Patron of the Paget's Association, Trevor Stamp, passed away peacefully on 20th October 2022, aged 87 years at the Royal Surrey County Hospital. We would like to express our heartfelt condolences to his family at this difficult time.

Trevor Charles Bosworth Stamp, was born on 18 September 1935. He was a hereditary peer, who graduated from Cambridge University, in 1956, with a Bachelor of Arts degree. He then went to the US, where he obtained a Master of Science degree from Yale University, Connecticut. He continued his clinical studies at Saint Mary's Hospital, London, qualifying in medicine in 1960.



Trevor Stamp (1935-2022) pictured during the 25th Anniversary of the Association in 1998, at St Catherine's College, Oxford

He was awarded a Doctor of Medicine degree in 1972, and became a Fellow of the Royal College of Physicians of London in 1978.

Trevor Stamp was an eminent physician who during a long and successful career, helped to advance understanding of metabolic bone disease and vitamin D metabolism. He spent twenty-five years as a Consultant Physician and Director of the Department of Bone and Mineral Metabolism at the Royal National Orthopaedic Hospital (RNOH), Stanmore between 1974 and 1999.

Saddened to hear the news of his passing, Honorary President of the Paget's Association, Professor Graham Russell, said, "Trevor was an excellent physician who was held in very high regard by his colleagues and his many friends".

You Really can Make a Difference

You can make a real difference to the Paget's Association by leaving a gift in your will. The reality is that without such legacies left by people like you, the Paget's Association would have difficulty continuing to support people with Paget's disease and fund research into the condition.

Thank You

Donating to the Paget's Association in memory of a loved one on birthdays or anniversaries is a wonderful way to celebrate their life and everything that made them special.

Thank you to all those who have chosen to remember someone in this way.

In Memoriam

We celebrate the lives of those named and thank their families and friends for their thoughtfulness and lasting gifts.

Raymond Powdrill

Edna Lee

Meet the Team at the Paget's Association

Honorary President



Prof 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.

Board of Trustees

Chair of the Board



Prof 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.



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.



Dr Sheelagh Farrow

Sheelagh lives in Surrey and is Managing Director of International Medical Press, a provider of independent medical education.



Mr Alan Janes

Alan is a retired Company Director who has Paget's disease, and is a volunteer within his local community in Oxford.

Vice-Chair



Prof 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.



Dr Catherine Nairn

A General Practitioner, Catherine developed an interest in Paget's disease while working at the Western General Hospital, in Edinburgh.



Dr Faiz Rahman

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



Mr Michael Patnick

Retired and living in Sheffield, Mike has previously worked for Arthritis Research UK, where he was responsible for overseeing medical research grants.



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.



Prof 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.



Employees

Sister Diana Wilkinson

Specialist Paget's Nurse, Diana Wilkinson, provides our information and support services.

Mrs Sue Clegg

Office Manager, Sue Clegg, manages the Association's finances.

Miss Jen Woodworth

Administrative Assistant, Jen Woodworth, is responsible for membership administration, and various communications including social media.

Paget's Question & Answer Event

with **Professor Stuart Ralston**

Live – Online – Via Zoom

Wednesday 11th January, 17:00 hrs

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Virtual Paget's Support Groups

See page 28

Paget's Information Event

A free event for patients & families

The Lowry, Pier 8, The Quays,
Manchester, M50 3AZ

Wednesday 19th April 2023

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International Paget's Symposium

**An event for Researchers, Clinicians,
Allied Health Professionals, & Students**

The Lowry, Pier 8, The Quays,
Manchester, M50 3AZ

**Wednesday 19th &
Thursday 20th April 2023**

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GALA EVENING

**In Celebration of the Association's
50th Anniversary**



The Lowry, Pier 8, The Quays,
Manchester, M50 3AZ

Wednesday 19th April 2023

Tickets: £50 – includes a welcome
drink, three-course meal with wine, and
entertainment

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CONTACT US

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Paget's
Association

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Information, Support and Research