



Research Confirms New Paquet's Gene

Page 20

Plus

Page 10
**Recardo's
Active
Lifestyle**

Page 13
**Countdown to our
50th Anniversary**

Page 21
**A Plausible Solution
to Beethoven's
Deafness?**

Page 22
**The Pain of
Paquet's Disease**

Chair's Message

Dear Member,

Welcome to the May 2022 edition of *Paget's News*. As always, the magazine is packed with news about the work we have been doing to support research and raise awareness about Paget's disease.

Our front-page story concerns the work of Dr Sachin Wani and colleagues from the Edinburgh and Liverpool Paget's Association Centres of Excellence who have found that genetic variations in the *PML* gene predispose to Paget's disease. The first clue that *PML* may be involved in Paget's disease came from research that was published by Omar Albagha and colleagues about 10 years ago. This highlighted that people who carry a specific genetic variant within the *PML* gene, in a region on chromosome 15, had an increased risk of developing Paget's disease. Their risk increased by about 30% compared with people who did not have the variant. The new research has shown that people with Paget's have lower levels of *PML* compared with those unaffected by the disease and has also demonstrated that low levels of *PML* increase the activity of bone resorbing cells (osteoclasts) and bone forming cells (osteoblasts), explaining why variants in this gene predispose to Paget's disease.

On the topic of research, it is heartening to see that the Pain in Paget's disease study (PiP) has started to recruit patients once again across the UK after a long spell of inactivity as a result of Covid. The researchers have recruited 117 patients to date and are hoping to reach their target of 200 by the end of the year. Pain is



“
*To support the
 50th Campaign,
 I have decided to
 pedal for Paget's by
 entering the Etape
 Caledonia cycle race*
 ”

the most common reason people with Paget's disease attend their doctor and we have an article on the topic of pain summarising key points from our recently updated booklet, 'Paget's Disease and Pain'.

Our support group meetings continue as normal, both virtually and face-to-face, supporting people with Paget's disease both in the UK and across the world. In addition, we have two face-to-face patient information events planned this year, where people with Paget's disease and their carers will be provided with the latest updates on the disease and will have the opportunity to ask our invited experts any questions they may have. The first will be

held at Jury's Inn, in Oxford, on June 24th (page 8) and the second in Cardiff on September 30th along with the Annual General Meeting of the Association.

As the 50th Anniversary of the Paget's Association approaches, the Trustees are keen to ensure that the work that we are doing is still as relevant to people with Paget's disease as it was when the Charity was founded in 1973. To help us do this, we have formed a focus group involving seven members of the Association who have personal experience of Paget's disease or have a family member with the condition. The group have already given important feedback on the structure of the 50th Anniversary Celebrations, in April 2023, and we are looking forward to receiving more ideas and feedback to help shape the strategy of the Association over the next 50 years! If you are interested in contributing to this work, please contact Diana Wilkinson who co-ordinates and facilitates meetings of the focus group.

Starting on page 13, there is a feature on our plans for the Paget's Association's 50th Anniversary celebrations next year. For health professionals, researchers and students, we will be hosting an International Symposium on Paget's disease at the Lowry Centre, in Manchester, on April 19-20th 2023. There will also be a special information event, on the afternoon of April 19th, at which those affected by Paget's will be able to interact with scientists from around the world, who are researching the condition. In addition, all are welcome to come along to our gala dinner on the evening of April 19th.

To mark the 50th Anniversary, we have launched a fundraising campaign, with a target of £50,000. Reaching this will allow us to continue our vital work supporting patients, funding research and help us continue to raise awareness of Paget's disease. If you would like to help us meet this challenge, please turn to pages 17-19 for ideas on what you can do.

To support the 50th Campaign, I have decided to pedal for Paget's by entering the Etape Caledonia cycle race, in May of this year. I am delighted to say that I have already raised £640, exceeding my original target of £500. As you can see from the photo I have already started training, even though the weather could have been better!



Here's hoping more donations are forthcoming. If you want to support me, please scan the QR code below. Alternatively, see page 19 for details of how to make a postal or card donation.



We continue to receive enthusiastic feedback from the 2022 Paget's Awareness Day video series, which focused on a global perspective on Paget's disease. The interview with one of the Patrons of the Association, Mr Recardo Patrick, was particularly well received and is still available on our YouTube channel. However, if you prefer reading to using the internet, a transcript of the interview can be found on pages 10 and 11. It makes interesting reading. Recardo was fortunate that the diagnosis of Paget's was made quickly, soon after he first developed symptoms and he was promptly treated, allowing him to maintain the very dynamic and active lifestyle that he enjoys to this day. I wish I had his energy!

In closing I wanted to highlight that, in common with all members of staff and Trustees of the Association, I was very saddened to hear of James Bell's passing earlier this year. James was a larger-than-life character who was an ardent supporter and fundraiser for the Paget's Association. As Diana Wilkinson has mentioned in our tribute to James on page 28, we will continue to remember him fondly and Diana in particular will miss his colourful correspondence.

Keep safe and stay well.

Best wishes,

Stuart Ralston

Chair, Paget's Association

The Paget's Association

Charity registration number: 266071

The Paget's Association is a national UK charity, focusing solely on Paget's Disease of Bone. Also known as The National Association for the Relief of Paget's Disease (NARPD).

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, including the Paget's Nurse Helpline, telephone: **0161 799 4646**

Email

To ensure that your email reaches the correct person, please choose from the following:

General and membership enquiries: **membership@paget.org.uk**

Paget's Nurse Helpline: **helpline@paget.org.uk**

Chair of the Paget's Association, Prof Stuart Ralston: **chair@paget.org.uk**

Our Address

You can write to us at:
**The Paget's Association
Suite 5, Moorfield House
Moorside Road, Swinton
Manchester, M27 0EW**

Our Website

www.paget.org.uk



Contents



Features

- 6 New Focus Group
- 10 Recardo's Active Life
- 12 News from the 2022 Awareness Day
- 13 Countdown to our 50th Anniversary
- 17 Earn a Medal with our Fitness Challenge
- 20 New Paget's Gene
- 21 A Plausible Solution to Beethoven's Deafness?
- 22 The Pain of Paget's Disease
- 25 Pain Research
- 28 A Tribute to James Bell

Events

- 5 Meet Experts in Cardiff
- 8 Oxford Paget's Information Day
- 14 An Invitation to Join us in Manchester
- 15 Gala Evening
- 16 International Symposium
- 32 Calendar of Events

Fundraising

- 7 Recycle for Paget's
- 18 £50,000 Target for the Association's 50th Year
- 29 26.2 Miles for Paget's
- 30 200 Club Raffle

Regulars

- 2 Chair's Message
- 27 Support
- 30 You are Amazing
- 30 In Memoriam
- 31 Meet the Team

Other

- 21 Publications News Feed
- 28 Bone Research Society Meeting
- 29 Connect with us Online
- 32 Contact us

Meet Experts in Cardiff

Join us in Cardiff, on the 30th September, to learn more about Paget's disease, chat with other members and ask the experts questions.

Local experts, from the Paget's Association's Centre of Excellence in Cardiff and Llandulas will join the Chair of the Paget's Association, Professor Stuart Ralston, Trustees, members and staff at this Paget's Information Event, which will cover many aspects of Paget's disease.

If you are affected by Paget's disease, or have a family member who is affected, then this event is for you. Researchers and Health Professionals are also very welcome to attend.

Attendance is Free

There is no charge to attend this event. Refreshments and lunch are also provided free of charge.

The Venue

Venue information will be available soon – please contact us for details.

Questions?

If you have any questions regarding this event, please email membership@paget.org.uk or telephone 0161 799 4646.

Booking Essential

It is essential to book for the event if you are planning to attend. Detailed information will be sent to you approximately two weeks prior to the event. You can book via our website or complete the form below. Alternatively, type the details into an email and send to membership@paget.org.uk

Annual General Meeting

The Association's Annual General Meeting will also take place on the 30th September. Details will accompany the August issue of this magazine.

BOOK ONLINE • www.paget.org.uk • **BOOK ONLINE** • www.paget.org.uk

**BOOKING
ESSENTIAL**

Booking Form for the Paget's Information Day in CARDIFF

Photocopy or cut out and post this form or simply book on our website.

This meeting is provided by the Paget's Association, free of charge, and includes a light lunch.

I/we wish to attend the Paget's Information Day

Name of 1st attendee
Name of 2nd attendee
Name of 3rd attendee
Name & address for correspondence
Postcode
Telephone
Email address

Number in party attending

Do you have any special dietary requirements?

Do you have any other special requirements?

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

Further details and a programme will be sent to you approximately two weeks prior to the event.

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

New Focus Group

A new focus group aims to make a difference to those affected by Paget's disease and influence the future of the Paget's Association.



Alan



Nigel



Janet



Graham



Lisa



Keith



Dorinda

The Paget's Association has given those affected by Paget's disease and their families the opportunity to shape the future through a new focus group. It can be easy to assume that we know what people need from the charity, however, working alongside this new group will ensure that the Association's work is meaningful to those who need our help.

Seven members of the Association, who have personal experience of Paget's disease themselves, or have a family member with the condition, have joined the focus group, which meets virtually using Zoom. This is a voluntary role and the team at the Paget's Association would like to express their sincere thanks to Janet, Alan, Nigel, Lisa, Graham, Keith and Dorinda, who are looking forward to making a positive difference in the fight against Paget's disease!

The Association's Specialist Paget's Nurse, Diana Wilkinson, moderates and supports the focus group, which has already begun to explore opinions and generate ideas related to specific issues relevant to those with Paget's disease and the Paget's Association. This assists the Association to fulfil its aims and align future plans with the wishes of those living with Paget's disease and their families. Discussions, so far, have included the strengths and weaknesses of the Association, support for those with the condition, and the plans for the Association's 50th Anniversary events. Some of their ideas are set out here, together with information on how you can contribute to the good work of the Association, by supporting others affected by Paget's disease or by suggesting topics for discussion at our events.

Offer Your Support to Someone in Need

Whilst we have our Paget's Support Network for members to contact each other, the focus group suggested putting together a separate list of members, who may not be part of the Network, but who are willing to offer support to people who are struggling with Paget's disease. This would be to speak with them on the telephone or communicate in other ways as agreed with the individuals concerned. If sufficient members come forward, we may be able to offer this support on a regional basis.

If you would like to assist with this, please contact Diana Wilkinson by telephone 0161 799 4646 or email diana.wilkinson@paget.org.uk

Suggest a Topic for Discussion at our Events

The focus group felt it important that members of the Association are given the opportunity to put suggestions forward for topics to be included at the Association's events. The following are the upcoming events that you may like to comment on.

Event for Researchers, Clinicians, Allied Health Professionals and Students

The Paget's Association is arranging an International Paget's Symposium, which will take place next April, for professionals to focus on Paget's disease. The Association has put together a committee to choose the speakers and topics for the event.

What should professionals discuss that is important to you? As someone affected by Paget's disease himself, Keith Simpson is part of the committee and would love to hear what you would like to see on the programme? You can get in touch with Keith by email keith43.simpson@outlook.com or telephone the Association on 0161 799 4646 and we will pass on your ideas. Keith will then take your suggestions forward to the committee.

Information Events for Those Affected by Paget's

If there is a topic you would like to see on the agenda for any of our patient and family events, please contact the Association, using any of the contact details on page 3, and we will do our best to accommodate as many suggestions as we can.



Recycle for Paget's

Jewellery

Through Recycling for Good Causes, we can recycle the following:

- **Watches**
- **Unwanted gold, silver, or costume jewellery, including damaged items**
- **Foreign or UK banknotes of any age**

This recycling project is a very easy way for you to raise money for the Paget's Association, whilst encouraging social responsibility through recycling and protecting the environment.

What do I need to do?

If you have any of the items above that you are willing to donate to the Paget's Association, go to their website to download a freepost address label or contact the Paget's Office to request a label.

Fill an envelope with your items, affix the freepost label and post in a Royal Mail post box.

Once your goods have been sorted and valued, the Association will receive a donation for your items from Recycling for Good Causes.

For further information visit www.recyclingforgoodcauses.org

Printer Ink Cartridges

Although we can no longer provide envelopes to post your used printer cartridges, you can continue to recycle them on behalf of the Paget's Association, by following the instructions on the Recycle4Charity website.

Because of changes implemented by the company, the minimum value of a cartridge package posted to them, must exceed £2.00.

What do I need to do?

The value of cartridges and all instructions how to recycle your cartridges on behalf of your chosen charity are listed on their website.

If your cartridges are not listed or do not amount to £2.00, please find a charity or school local to you which may take used cartridges, enabling you to continue to recycle responsibly and help protect the environment.

For further information visit www.recycle4charity.co.uk

Oxford Paget's Information Day

Members are invited to meet experts in Oxford, on the 24th June, at a Paget's Information Day.

Friday 24th June 2022

09:30 hrs – 15:30 hrs

The Jurys Inn

Godstow Road

Oxford

OX2 8AL

Local experts, including Dr Kassim Javaid, will join the Chair of the Paget's Association, Professor Stuart Ralston, Trustees, members, and staff to discuss various topics around Paget's disease, including research, treatment, and orthopaedic surgery.

This is an excellent opportunity, not only to learn more about the condition, but to meet other members, and ask the experts questions.

The event is aimed at those affected by Paget's disease, their families and carers, however, health professionals and researchers are all very welcome.

Lunch and Refreshments

There is no charge to attend this event. Refreshments and lunch are also provided free of charge.

The Venue

The Jurys Inn Oxford has accessible conference facilities for our meeting and accessible toilets. It is approximately three miles from Oxford city centre and is a 15-minute drive from the nearest train station. There is a bus stop close to the hotel, from where the bus into the city centre leaves. If you are travelling by car, the hotel is accessible from the A34, A44 and M40. There are 250 parking spaces available within the hotel grounds, including six accessible spaces.

CONFIRMED SPEAKERS

- Prof Stuart Ralston • Prof Phillipa Hulley
- Prof Rob Layfield • Dr Kasim Javaid

INVITED SPEAKERS

- a local Orthopaedic Consultant to discuss surgery
- a patient to share their experience



Staying Overnight?

For those staying overnight, there are leisure facilities including a heated indoor pool.

Further details can be found on the hotel's website www.jurysinns.com/hotels/oxford You can also contact the Paget's Association's office for more information.

Visit the City

As the Jurys Inn is a short drive from the centre of Oxford, you may like to take the opportunity to spend a few days in this fabulous city.

The University of Oxford dominates about a quarter of the city. It's made up of 38 colleges and many of the grand old buildings are attractions in their own right, giving Oxford its nickname of 'The City of Dreaming Spires'. You can also see familiar sights that are often used as the backdrop to many TV programmes and films, from Inspector Morse to Harry Potter. In addition, numerous tourist attractions include the Bodleian Library, Carfax Tower, with its panoramic views over the city, and the historic Covered Market.

For those who have booked to attend, detailed information will be sent approximately two weeks prior to the event.



Questions?

If you have any questions regarding this event, please email membership@paget.org.uk or telephone 0161 799 4646.

Booking Essential

It is essential to book for the event if you are planning to attend. You can do this online via our website or complete the form below. Alternatively, type your details into an email and send to membership@paget.org.uk



BOOK ONLINE • www.paget.org.uk • **BOOK ONLINE** • www.paget.org.uk

**BOOKING
ESSENTIAL**

Booking Form for the Paget's Information Day in OXFORD

Photocopy or cut out and post this form or simply book on our website.

This meeting is provided by the Paget's Association, free of charge, and includes a light lunch.

I/we wish to attend the Paget's Information Day

Name of 1st attendee

Name of 2nd attendee

Name of 3rd attendee

Name & address for correspondence

Postcode

Telephone

Email address

Number in party attending

Do you have any special dietary requirements?

Do you have any other special requirements?

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

Further details and a programme will be sent to you approximately two weeks prior to the event.

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

Recardo's Active Life, Despite Paget's Disease

In a video interview for Paget's Awareness Day this year, Patron of the Paget's Association, Mr Recardo Patrick, was interviewed by Professor Ralston, to explain his personal experience of Paget's disease. For those of you who haven't seen the video, we have transcribed the interview here.

Prof Stuart Ralston

Well, welcome to Paget's Awareness Day 2022, which coincides with the 208th Anniversary of Sir James Paget's birth. I am Professor Stuart Ralston. I'm Chair of the Paget's Association, and the theme of the Awareness Day this year is the global perspective of Paget's disease.

It's my pleasure to introduce Mr Recardo Patrick, who has kindly agreed to be interviewed today. Now, Recardo, among many things, is a well-known singer and recording artist and also, we're very lucky to have him as a Patron of the Paget's Association. So, welcome Recardo, thank you for joining us today.

Mr Recardo Patrick

My pleasure. Good afternoon, Professor.

Prof Stuart Ralston

Now we've spoken before, Recardo, and I know you were born and raised in Manchester, but perhaps you could say a few words about your heritage, your family, where you come from, so to speak.

Mr Recardo Patrick

Well, I was born in Manchester. My father was from Barbados and my mother was from Saint Kitts in the US Virgin Islands. They both came to the UK before I was born. So, I've been living around Manchester for most of my life. I actually live



Mr Recardo Patrick

It started when I'd picked up a new car and I drove from Ingolstadt in Germany, across to Zeebrugge, in Holland. I was driving for probably about two or three hours and I had to keep stopping because I had a twitch in my right thigh. I thought, 'that's really strange' and when I stopped and stood up, the twitch went. When I got back into the car, it got more severe. It was like an electric shock. It was really extremely painful. So, I took some painkillers, continued driving, and the painkillers seemed to numb the pain for about nine hours, until I got back to the UK. I didn't think anything else of it. I just thought I had sciatica or something, so I went to see a chiropractor.

I had all the heat treatment, the massages and whatever, and that seemed to have settled the nerve thing down, which I thought it was at the time. Anyway, the pain kept reoccurring and getting worse, but sporadic-like. I could only describe it as a very sharp electric shock type pain and I thought, there is something strange going on here.

I went to my doctor at Altrincham Medical Practice. Her name is Mary. She's a lovely doctor and was involved years ago in sickle cell research for Caribbean people in Manchester. When I said, "I've got sciatica", she said, "Well, that doesn't

between the UK, the Austrian Alps and Ibiza, which I have done for the last 30 years or so. I actually come back here for the cold because I like it, which is a bit strange, I know. At the weekend I was hiking up in the Lakes, in Loughrigg Fell, which is about a 14-mile hike because I like that kind of thing. I just love the winter here, which is a bit strange.

Prof Stuart Ralston

Amazing! Most people go south for the winter, but you're opposite. Anyway, very good to hear that. Now we know actually in the UK, the Manchester area, where you were born and brought up, is a hotspot for Paget's and you were diagnosed with Paget's. Maybe you can recollect what your symptoms were at the very start and what happened, how you were diagnosed?

sound like sciatica to me. I would like to send you for a blood test". So, I said, "What's a blood test got to do with the pain in my leg?" She said, "I'll tell you once I get the conclusion back."

So, I had the blood test and the doctor called me and said I needed to go and have scans, which got me worried – a CT scan and an MRI. After doing both of those, she told me that I had Paget's disease!

I was shocked. I said to her, "Why were you even looking for something called that?" I'd never heard of it myself and she said she'd been reading quite a lot about it in the last few years, and it sounded very similar to my symptoms. She'd never diagnosed anybody with Paget's disease before. I was shocked and quite upset.

Prof Stuart Ralston

OK, thank you. Well, it's great to hear that your GP was informed about Paget's disease. So, you had the scans and then what happened next? Were you referred to a specialist?

Mr Recardo Patrick

Well, then I went into the sadness mode of tears, shock, and horror, thinking I'm going to die and all the rest of it and then I got a referral letter through from Professor Selby who's at the MRI (Manchester Royal Infirmary). I went to see him, and he told me not to worry. They got it at a very early stage, judging from what they'd seen, and I was then recommended to take a course of zoledronic acid through an infusion, I'd read up on the zoledronic acid. I was quite afraid because apparently, your body can react against it in the first 24 hours. You can get horrific flu-like symptoms and then you're reborn! So, I reluctantly went and saw one of the nurses and I was ringing

“
*For me, the
 check-ups are
 extremely important
 and not being afraid
 of the results*
 ”

everybody that I knew under the sun about this zoledronic acid and all the rest of it. In the end I went for it, at the MRI, and sure enough, I had a flu-like attack for about 18 hours. It was like the worst flu I'd ever had and then literally, I felt reborn when it ended. I have never had a pain or a twitch or anything ever since.

Prof Stuart Ralston

Wow, that's amazing! How long ago Recardo was this treatment?

Mr Recardo Patrick

I think it must be about nine or ten years ago or maybe a little bit more?

Prof Stuart Ralston

Wow.

Mr Recardo Patrick

The thing is, every year I've been having an alkaline phosphatase (ALP) level blood check and the level is actually lower than normal, which is good. I also had an isotope bone scan last year and they said there was no sign of Paget's disease. It had gone into complete remission.

Prof Stuart Ralston

Wow, that's amazing and as you said at the start of our interview, you go hill walking etc. You're obviously quite an active guy.

Mr Recardo Patrick

I am extremely active. I'm a long-distance walker, speed walker,

long-distance swimmer, runner, cyclist, swimmer and hiker, and I go snowboarding. I do it all you know, every week. Obviously, I don't go snowboarding every week, but the rest, yes, and apparently the impact makes the bones stronger.

Prof Stuart Ralston

OK, well, it's very interesting to hear and I was going to ask if you were getting check-ups, but obviously, you are. You get your blood tested every so often, and your latest bone scan was OK.

Well, Recardo, it's been fantastic to talk to you today and thank you for sharing your story. I think it illustrates that you were picked up early. You were treated and have remained well ever since. So, I think your story will give hope to people with Paget's disease to get it diagnosed and get it treated.

Mr Recardo Patrick

Absolutely. I mean, one of the things I've learned, after being initially shocked by it, was, don't give up on your body basically. I train hard. I have not had any impingements whatsoever, but for me, the check-ups are extremely important and not being afraid of the results. You know, we only have one body and we have to deal with things as they come along. But it's not hindered my life for a moment in any way whatsoever, and I'm really grateful to people like yourself who are doing research, and Diana and everybody who's helping people with a situation like this.

Prof Stuart Ralston

Thanks, Recardo. Well, thanks for sharing your experience. You're an inspiration!

Mr Recardo Patrick

Thank you.

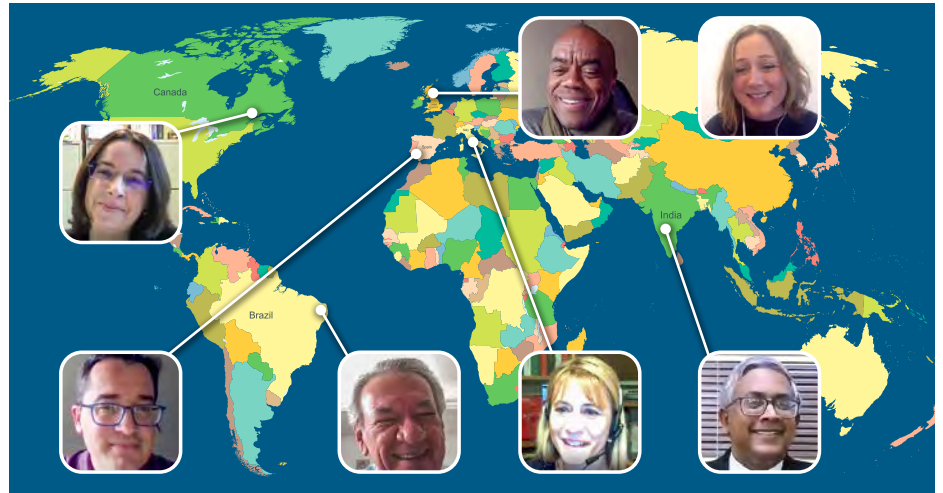
News from the 2022 Paget's Awareness Day

Watch all the Interviews

We have had enthusiastic feedback from those who watched all the fascinating videos produced to mark the fourth International Paget's Awareness Day.

The series of video interviews took us around the world, as Dr Tori Herridge interviewed experts from Italy, Spain, Canada, Brazil and India.

To find the videos, simply visit the home page of our website paget.org.uk and follow the link to 'A Global Perspective'. Alternatively, scan the QR code to the right.



We are also happy to provide a link to the videos in an email. To request this, simply email membership@paget.org.uk

Paget's News Magazine Multiple Choice Competition

Question 1

What is the name of the gentleman after whom Paget's disease is named?

Answer: Sir James Paget

Question 2

Which group of drugs is generally used to treat Paget's disease?

Answer: Bisphosphonates

Question 3

What is the most common reason for those with Paget's disease to visit their doctor?

Answer: Pain

Question 4

In which area of the world is Paget's disease most commonly found?

Answer: UK

Question 5

What is the medical term for the thigh bone?

Answer: Femur

The winner was Sheila Nursey from Norwich. Congratulations Sheila!

Online Multiple Choice Competition

The online competition was related to the videos released for Paget's Awareness Day.

Question 1

What did Dr Merlotti discuss in relation to Paget's disease and the Campania region of Italy?

Answer: Volcanoes

Question 2

A high incidence of Paget's disease is found in Quebec, in Canada. In her video interview, Dr Michou explained the link to the King's Daughters, who arrived in Quebec from France, between 1663 and 1673. Which King sent them?

Answer: Louis XIV

Question 3

Dr Corral-Gudino discussed a big increase in Paget's disease during the period between the nineties and the early two thousands. Which of the following areas was he speaking about?

Answer: Salamanca

Congratulations to Elaine McColl, from Edinburgh, who won the online competition.

Countdown to our 50th Anniversary **Part 1**

50 YEARS

ANNIVERSARY

It is less than twelve months before we celebrate the Paget's Association's 50th Anniversary, in April 2023. In this, and the following three issues of Paget's News, our Specialist Paget's Nurse, Diana Wilkinson, is looking back at the Association's history, before turning her attention to the charity's future.



Mrs Ann Stansfield MBE

Humble Beginnings

What can you recall about 1973? If it helps, it was the year Princess Royal married Captain Mark Phillips at Westminster Abbey. Many will remember the power cuts, the oil crisis, and a miners' strike. It was also the year the National Association for the Relief of Paget's Disease, otherwise known as The Paget's Association, was founded by Ann Stansfield MBE. When I was employed by the Association, in 2012, I was fascinated to discover its history. It began with Ann's husband, Alf...

Ann experienced considerable difficulty obtaining information and support for her husband, Alf, when he was diagnosed with Paget's disease. She spent many hours writing to hospitals, specialists, and universities worldwide, to collect information about the disease, and any appropriate treatment. Most of her letters were handwritten, although eventually, she obtained a manual typewriter. It was from

these humble beginnings that the charity was formed.

Through sheer determination and persistence, Ann not only made progress but also began to support many other people affected by Paget's disease. She built up and maintained a register of others affected by the condition, with whom she corresponded regularly. Even when visiting family in Australia, Ann took the opportunity to go on local radio to publicise the need for worldwide awareness of Paget's disease. Her achievements were acknowledged with an MBE in 1983, but more about that in the next issue of this magazine!

Establishing the Charity

Ann attracted the attention of specialists with a particular interest in Paget's disease, and in 1973, with the support of Dr Allan St. John Dixon and the Rehabilitation and Medical Research Trust, Ann established the National Association for the Relief of Paget's Disease, which remains the official title of the charity, however, it has since



*Professor Allan St. John Dixon
OBE MD FRCP*

adopted the the working title of the Paget's Association.

Dr Dixon, later Professor Dixon, was the first Chairman of the charity and subsequently served as Honorary President until 2011. In addition to his involvement with the Paget's Association, he helped to establish several other charities and was a Consultant Rheumatologist at the Royal National Hospital for Rheumatic Diseases from 1966 to 1986. He was honoured with an OBE in 1990. Professor Dixon passed away in 2014, aged 92.

Leading the Way

So, from humble beginnings, the Paget's Association was formed. Since then, countless individuals and families have been supported, and the Association has led the way in funding Paget's research. We know so much more about the disease now, than we did forty-nine years ago. All because a man, named Alf, not only suffered from Paget's disease, but had a wife who was prepared to do everything she could to help him and others.

Be Part of Something Special

I hope you will consider joining us at our special 50th Anniversary events, in Manchester, next year. You will find details on pages 14-16.

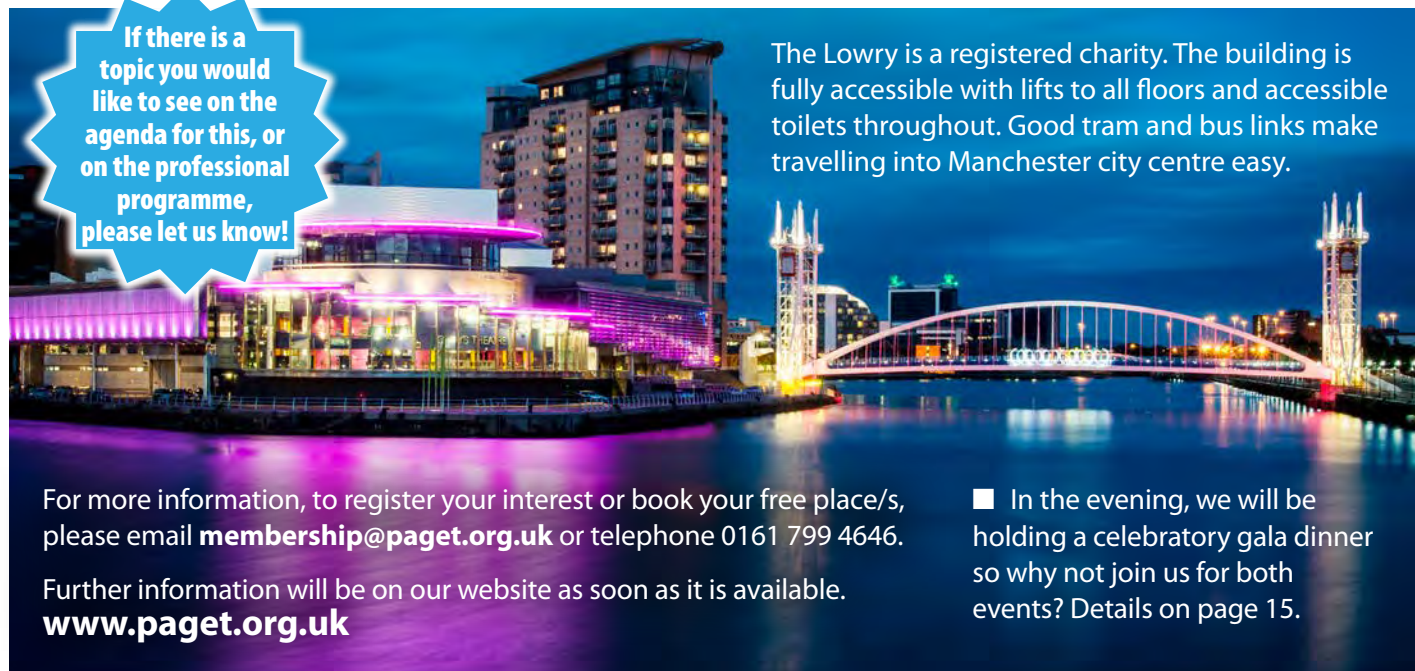
Diana

You are invited to a

Free Paget's Information Event

50 YEARS
ANNIVERSARY

to be held at **The Lowry, Salford Quays, Manchester, in Celebration of 50 Years of the Paget's Association on 19th April 2023**



If there is a topic you would like to see on the agenda for this, or on the professional programme, please let us know!

The Lowry is a registered charity. The building is fully accessible with lifts to all floors and accessible toilets throughout. Good tram and bus links make travelling into Manchester city centre easy.

For more information, to register your interest or book your free place/s, please email membership@paget.org.uk or telephone 0161 799 4646.

Further information will be on our website as soon as it is available. www.paget.org.uk

■ In the evening, we will be holding a celebratory gala dinner so why not join us for both events? Details on page 15.

The Paget's Information Event is expected to follow lunch and be one and a half hours of exciting new information about Paget's disease, delivered by expert speakers who will also answer your questions.

The Venue

Salford Quays is Greater Manchester's unique waterfront destination, just 15 minutes by tram from Manchester city centre.

The Quays is the home of MediaCityUK, which houses the BBC and ITV, and was officially opened in 2012 by The Queen. 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 (see page 15 for full details). This beautiful room has an almost 360-degree view of Salford Quays. Why not come along to the

Paget's Information Event in the afternoon of the 19th April and take some time out to explore the area before joining us in the Compass Room for the Gala celebrations, where you will be able to enjoy the evening with other members, Trustees and staff.

Staying Overnight?

There are several hotels close by, including a Holiday Inn, Holiday Inn Express and a Premier Inn. We are currently negotiating a special rate with the Holiday Inn, 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

Gala Evening

in Celebration of the 50th Anniversary of The Paget's Association

to be held in the Compass Room of
The Lowry, Salford Quays, Manchester

on

19th April 2023

★★★★

Welcome drink

★★★★

Three-course dinner

★★★★

Music, dancing and more with Master of Ceremonies, Mr Phil Colbert

★★★★

Ticket price – will be confirmed at a later date



■ For further information or to register your interest, email membership@paget.org.uk or telephone 0161 799 4646.

■ You may also wish to come along to the free Paget's Information Event taking place on the same day (details on page 14).

Paget's
Association

50 YEARS
ANNIVERSARY



2023 Manchester UK

International Symposium on Paget's Disease

in celebration of the 50th Anniversary of

The Paget's Association

Venue: The Lowry, Salford Quays

Save the date

19th – 20th April 2023

Abstract deadline

11th January 2023

www.paget.org.uk



In association with
ECTS/BRS in Liverpool, UK
15th – 18th April 2023

Earn a Medal with our Fitness Challenge!



We are challenging you to feel fitter and healthier by taking part in our Fitness Challenge. Donations raised by achieving your challenge target will earn a Paget's Fitness Medal and all money raised helps to support us in reaching our fundraising target for the 50th Anniversary of the Association.

Walk, Hike, Run, Swim, Cycle, or Wheel

We have achievement medals for people of any age or ability who can challenge themselves to go a little further than they normally would. You can walk, hike, run, swim, cycle or, if you use a wheelchair, wheel your way towards your goal.

How to get Involved

1. Set your Fitness Challenge

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

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.

2. Choose your Sponsorship Method and Contact us

Once you have decided on your challenge, we can help you get started, whether you are using sponsorship forms or an online sponsorship platform,

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

50 YEARS ANNIVERSARY



such as JustGiving. Contact us via telephone, email us at membership@paget.org.uk or write to us, to request a sponsorship pack containing everything you need to start collecting donations.

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.

3. Make it Worthwhile

Ask your friends and family to sponsor you to raise funds for the Paget's Association. They may even join you! All funds raised will go towards our 50th Anniversary target and your fitness will have improved.

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

■ **Bronze Fitness Medal:**
£25 minimum

■ **Silver Fitness Medal:**
£100 minimum

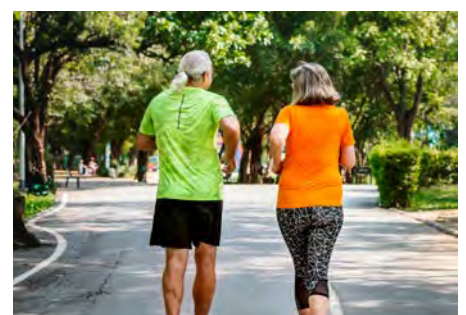
■ **Gold Fitness Medal:**
£500 minimum

4. Share your Achievement and Claim your Fitness Medal

To enable us to send you your Fitness Medal, you will need to let us know the details of the challenge you set, what you achieved, and the amount of money raised. In addition, if you have photos, we would love to see them.

Some of you may wish to track your challenge, with a smart device, using an app, such as Fitbit or Strava. If you do this, do send us a screenshot of your achievement from your app.

Good Luck!



£50,000 Target for the Association's 50th Year

As the team here at the Paget's Association look forward to its 50th anniversary year in 2023, we have launched a fundraising campaign to raise £50,000 by December 2023.

As a charity, the Association relies upon donations from individuals to ensure the continued provision of information and support, and to fund research. In this magazine, and earlier issues, you will see how the money we receive is put to good use. 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 funds for the Association, take part in the Paget's Fitness Challenge (details on page 17), 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.

Trustees Get Involved

Some of our Trustees are organising their own fundraising activities. Professor Stuart Ralston is pedaling for Paget's (see page 3) and Amanda Sherwood is climbing Paget Peak, in Canada, but more of that in the next issue!



Request a Fundraising Pack

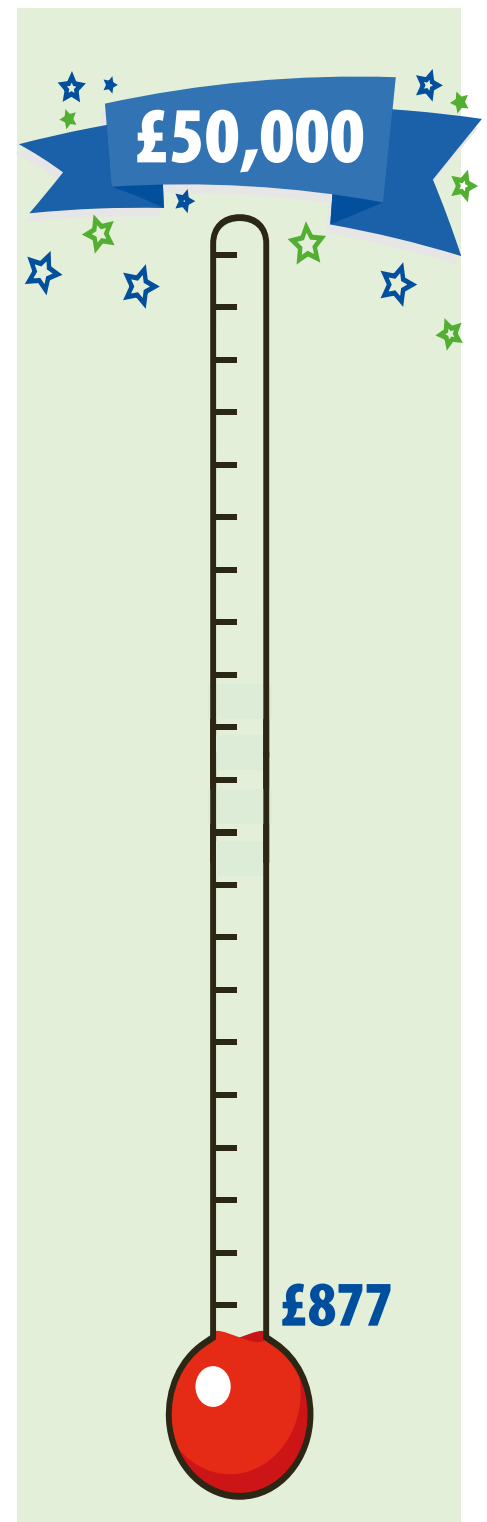
Would you like to raise funds for the Paget's Association, but don't know where to start? Why not request our new fundraising pack, which contains ideas, tips and information to help get you started? Also included are leaflets, a banner with the Association's logo printed on it and items to help raise awareness.

From a chocoholic's tombola and/or coffee morning to a sponsored silence or book exchange, there are also lots of fundraising ideas on our website <https://paget.org.uk/help-raise-funds>

You can set up your own online fundraising page on the JustGiving website or we can set one up for you. You can also link your page to our campaign.

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

Alternatively, sponsorship forms are available from our office.



Awards for Outstanding Fundraising Achievements

Awards will be available for outstanding fundraising achievements so request your pack and see what you can accomplish.

We can Help

If you need support or something special for your event, whether it is posters or t-shirts, have a chat with us and we will do our best to help. For further information, or to request your fundraising pack, please email membership@paget.org.uk or telephone 0161 799 4646.

IF YOU CAN, PLEASE HELP US REACH OUR TARGET!

Every donation counts, no matter how large or small, and could really make a difference for someone going through a very difficult time.

Help us Meet our Aims

The aims of the Paget's Association are to preserve and protect the health of those affected by Paget's Disease of Bone, and their families, by:

- ✓ **providing information and support**
- ✓ **raising awareness about Paget's disease, both within the medical and allied health professionals, and amongst the general public**
- ✓ **by supporting and funding research projects in the field of Paget's disease or its treatment**

YOU CAN DONATE TO THE CAMPAIGN OR PAY IN FUNDS RAISED IN ANY OF THE FOLLOWING WAYS

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 simply follow the 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 also link your own JustGiving fundraising page to this campaign. <https://justgiving.com/campaign/Pagets50th>



Telephone:

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.

Standing Order

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

News from Recently Published Research

In this regular feature in *Paget's News*, we briefly summarise papers discussing *Paget's* disease, from scientific and/or medical journals. These have been selected by the Chair of the Association's Research Subcommittee, Professor Rob Layfield, and our Specialist *Paget's* Nurse, Diana Wilkinson, to highlight areas of interest and provide a glimpse into some of the fascinating work taking place around the world.

Featured Paper

Funding from the Association Contributes to the Confirmation of a New *Paget's* Gene

A recent study, which was led by Dr Omar Albagha at the *Paget's* Association Centre of Excellence, in Edinburgh, was partly funded by the *Paget's* Association and has confirmed that a new *Paget's* gene called '*PML*' controls the biology of osteoclasts and osteoblasts, bone cells that are central to *Paget's* disease.

We have known for some time that genetics play an important role in susceptibility to *Paget's*, for example, with the *SQSTM1* gene playing a central role, but the precise genes involved have alluded researchers. In their research, Wani and co-workers have pinned down one such new gene, termed *PML*.



New *Paget's* Gene

By analysing blood samples from those living with *Paget's* disease, the team found that an alteration in the *PML* gene causes less of the *PML* protein to be made. This alteration is found in people with *Paget's* but not in individuals without signs of *Paget's*.

Further experiments showed that reducing levels of the *PML* protein is associated with increased bone turnover, a feature of *Paget's*, consistent with the genetic alteration being important in the

disease. Improved knowledge of *Paget's* genetics may help direct future clinical management.

Reference

Wani S., Daroszevska A., Salter D.M., van 't Hof, R., Ralston, S.H. and Albagha, O.M.E. (2022). *Reduced expression of PML predisposes to Paget's disease of bone by increasing osteoclast differentiation and bone resorption. Disease Models & Mechanisms. Mar 1. Epub ahead of print.*

Beethoven: A 195-year-old Controversy



Over the years, various papers have been written about Beethoven's numerous medical problems and the possible cause/s of his deafness. We know that Beethoven's skull was twice as thick as normal, and a photograph of his skull, taken at the first disinterment in 1863, showed prominent cheekbones and forehead, producing a lion-like appearance, which is known to occur in Paget's disease. Regular readers of this magazine may remember that this was discussed in an article, in 2016, by Assistant Professor of Pathology, Stanley Oiseth, who had concluded that "Paget's disease and its associated problems, complicated by the use of alcohol and, possibly, other drugs to relieve the symptoms, can explain most or all of Beethoven's medical problems".

This year, an article in the *Annals of Diagnostic Pathology*, by Dr P.W. Allen (Australia), considered

Beethoven's multiple symptoms, and in the summary below we outline what Dr Allen believes is the best explanation to date.

A Plausible Solution

Beethoven suffered from episodes of severe diarrhoea and increasing deafness. Born in 1770, he died in 1827, from cirrhosis of the liver. The nature of his diseases has been controversial ever since.

Without the assistance of biopsy or autopsy histology that would have permitted some certainty, it is impossible to prove the nature of the triad of diarrhoea, deafness and cirrhosis.

Until recently, no one has invoked a single disease that would explain the chronic afflictions of his bowel, ears and liver. Suggested diagnoses have included lead poisoning, alcoholic cirrhosis, viral hepatitis, inflammatory eye disease, rheumatism, inflammatory bowel disease, Paget's disease of bone, Cogan's syndrome, systemic lupus erythematosus, otosclerosis,

chronic pancreatitis, tuberculosis, sarcoidosis, Whipple's disease, renal papillary necrosis and syphilis.

In 2005, Collin Karmody, from the Department of Otolaryngology, Tufts-New England Medical Center, Boston, USA and Edgar Bachor, from the Department of Otolaryngology, Academic Hospital of the University of Jena, Germany, suggested that Beethoven suffered from chronic ulcerative colitis and its sequels. They based their conclusion on a review of a large body of material sourced from Germany and translated into English from the original documents. It is known that ulcerative colitis may be complicated by sensorineural deafness and sclerosing cholangitis, which progresses to cirrhosis, liver failure and death. These apparently diverse diseases are now believed to share an autoimmune pathogenesis. This explanation joins together Beethoven's triad of diarrhoea, deafness and cirrhosis.

Reference

Allen, P.W. (2022). Beethoven's triad: Diarrhoea, deafness and cirrhosis. A plausible solution to the 195-year-old controversy. Annals of Diagnostic Pathology, Volume 58, 151904.

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.



The Pain of Paget's Disease



Fortunately, not everyone who has Paget's disease will experience pain. It is, however, the commonest reason for those with the condition to visit their GP.

The following is an extract from our newly updated booklet, 'Paget's Disease and Pain'. The information contained in the booklet can help you to discuss pain with your medical team and it also details drug-free methods to help with pain management. You can download a PDF of the booklet from the members' section of our website, request a digital or hard copy by emailing membership@paget.org.uk or telephone the office on 0161 799 4646 to request a booklet by post.

What is Pain?

Pain can be described as an unpleasant sensory and emotional experience. It can be a warning that something is wrong, especially when it is severe and increasing. It is therefore important to have pain assessed by your doctor.

Pain in the muscles, joints, and bones, is common and can be acute or chronic. Acute pain usually comes on suddenly and is caused by something specific, such as an injury or a break in the bone (fracture). Acute pain usually settles down when the fracture has healed or when you have recovered from an injury. Chronic pain is ongoing and persistent. Some people with Paget's disease can experience chronic pain, either as the result of

What can influence chronic pain?



Figure 1. Many factors can influence pain, which can lead to being locked in a cycle of pain and distress

the disease being active or because of complications like osteoarthritis.

Several things can influence the development and intensity of chronic pain (Figure 1). It can have a considerable impact on quality of life, affecting relationships, activity levels, sleep, and the ability to work.

In addition, many factors, such as anxiety and fatigue, determine how your body will react to pain and whether your nerves will transmit or block a potentially painful message. Some people can become locked in a cycle of pain, depression, and stress.

Paget's Disease and Pain

Not all people who have Paget's disease experience pain. It is, however, the commonest presenting symptom of Paget's disease. It is important to define the cause of pain so that the correct treatment can be given.

In many people, Paget's disease affects a single bone, whereas in others, several bones may be affected. In general, pain caused by Paget's disease is localised to the affected site. For example, if you have Paget's disease in your skull, it might result in the occurrence of headaches.

Pain in Paget's disease may be related to what is known as "increased metabolic activity" of the disease. The reason why this pain occurs isn't entirely clear, but it is thought to be a consequence of increased bone cell activity. Such pain can respond well to treatment with a bisphosphonate, such as zoledronic acid. Many people, however, who have Paget's disease, experience pain related to other causes, and if that is the case, it is unlikely to be helped by bisphosphonate therapy. For detailed information on treatment see our booklet, *'Paget's Disease – The Facts'*.

Pain can also occur because of damage to the joints next to affected bones (osteoarthritis), a break in the bone (fracture), pressure on the nerves from enlargement of the bone or as the result of deformity of the bones, which can put stress on joints and soft tissues.

What is Bone Pain?

Bone pain at a specific site is detected by specialised transmitters located on the bone's surface, which

then pass messages through the nervous system to the brain where signals are recognised as pain. Pain in Paget's disease may be caused by increased metabolic activity. This can occur at rest or at night but can also be provoked by weight bearing on an affected bone.

Other Causes of Pain

Other causes of pain related to Paget's disease include:

Deformity of the bone – This is thought to be due to abnormal stresses on the surrounding tissues and stretching of the membrane surrounding the bone.

Stress fractures – These are small cracks in the bone that tend to occur in deformed weight-bearing bones, such as the thigh bone (femur) and shin bone (tibia).

Fractures – These usually occur as the result of a fall, causing the bone to break.

Osteosarcoma – This is a very rare type of bone cancer that can occur in people with Paget's disease.

Pain from Paget's in the Skull

Paget's disease of the skull can be associated with several symptoms, including headaches and a band-like tightness around the head, resulting in an unpleasant sensation. If the pain is the result of increased metabolic activity of Paget's disease, then treatment with a bisphosphonate, such as zoledronic acid or risedronate may help the pain.

People with Paget's disease can also get headaches as the result of other causes like a migraine. If you have Paget's disease and you experience

headaches, it is important that you speak with your GP or specialist to seek advice on whether they are likely to be due to Paget's disease or another cause.

Osteoarthritis and Paget's

Osteoarthritis is a common condition, even in people without Paget's disease. There is evidence that people with Paget's disease are more prone to develop osteoarthritis in joints adjacent to bones that are affected by Paget's and the most commonly affected sites are the hip and knee.

Paget's disease is thought to predispose to osteoarthritis for two main reasons. The first is whether there is deformity of the bone. This can place abnormal stresses on the joints nearby. An example would be if a tibia becomes bowed, this can cause shortening of the leg, which can predispose to arthritis of the knee or ankle. The second reason is that the bone in Paget's disease is denser than normal. If there is increased density of the bone next to a joint, it results in abnormal strain being put on the cartilage (lining of the joint), causing the surface of the joint to become worn. When osteoarthritis is advanced, the joint surface becomes damaged, and the underlying bone becomes even denser, eventually resulting in loss of all cartilage so that the bone surfaces rub against each other. This leads to increased stiffness and pain, which is usually worse on moving the affected joint or on weight-bearing.

The hips and knees are the most common joints to be affected by osteoarthritis in people with Paget's disease, but osteoarthritis may also affect the back (see page 24).

continued overleaf

What can Help Pain from Osteoarthritis?

- Make sure you are not carrying too much weight. If you are overweight, losing weight can help reduce the pain of osteoarthritis a great deal, especially when the knees and hips are affected.
- Muscle strengthening exercises can help reduce pain associated with osteoarthritis of the knees.
- Anti-inflammatory creams and gels, which are rubbed into the affected area can help ease the pain of osteoarthritis.
- When required, painkillers such as paracetamol may help, or, if this doesn't work, anti-inflammatory tablets, like ibuprofen, can be tried.
- If osteoarthritis becomes severe, particularly in your knees and hips, joint replacement surgery may be required. The most common reason for having a joint replacement is if the joint pain has not responded adequately to the measures listed above and it is having a negative impact on your quality of life. The results of joint replacement surgery for osteoarthritis in Paget's disease are excellent.

Back Pain

Back pain is very common. There are many causes, but in older people, it is often due to osteoarthritis affecting the joints of the spine. If osteoarthritis is the cause of the pain, it can be treated by medication. You may also find physiotherapy, acupuncture or TENS helpful.

Paget's disease can also cause back pain as the result of increased metabolic activity of the disease.

“
Pain, related specifically to active Paget's, often responds well to bisphosphonates within a few months
 ”

If this is the case, it may be helped by therapy with a bisphosphonate such as risedronate or zoledronic acid.

Back pain can also occur as the result of what is called spinal stenosis. This can affect people with Paget's disease of the spine because the affected bone enlarges, and this can cause pressure on the nerves that emerge from the spinal canal. The main symptom of spinal stenosis is pain, often radiating

to the buttocks or down the legs, but there may also be numbness, weakness, and a tingling sensation in the legs. Patients with severe spinal stenosis may experience difficulty walking.

The diagnosis of spinal stenosis is usually made by an MRI scan. If symptoms are severe or worsening, surgical treatment may be offered to release the pressure (decompression) and give the nerves more room. Surgical treatment can sometimes involve removing sections of the bone or the bones may be fused together.

What Other Types of Medication may be Required?

Analgesics

Some people with Paget's disease require painkillers (analgesics) as well as bisphosphonates to control pain, especially if the disease has led to damage to the bones and/or joints.

Medication to Treat Pain Associated with Paget's Disease

Bisphosphonates

When necessary, a group of drugs known as bisphosphonates are used to treat active Paget's disease because they effectively reduce bone cell activity.

In a small number of people, bisphosphonates may initially cause a slight increase in bone and muscle pain, but this usually subsides after a few days.

Whilst individual responses may vary, pain, related specifically to active Paget's

disease, often responds well to bisphosphonates within a few months.

The bisphosphonates commonly used in the UK are:

- Zoledronic acid 5mgs – Given intravenously (directly into the bloodstream), in a clinic setting.

- Risedronate 30mgs – Taken orally for two months.

- For further information regarding bisphosphonates, see our booklet 'Paget's Disease – The Facts'.

Individual responses to analgesia vary considerably, both in terms of efficacy and side effects. Always start with small doses of weak drugs that can be gradually increased or changed to stronger drugs until you have the best possible pain relief.

A variety of analgesics are used in the treatment of pain (request our Paget's Disease and Pain booklet for full details). Each type works in a different way to relieve pain and

some products contain more than one kind of analgesic.

Medication for Nerve Pain

Pain in Paget's disease may also be associated with nerve damage. This is sometimes referred to as neuropathic pain. Drugs that were originally created to treat other illnesses, such as depression (e.g., amitriptyline) or epilepsy (e.g., gabapentin), are commonly used to treat neuropathic pain.

These treatments may take several weeks before they begin to have an effect.

Calcitonin

In the past, calcitonin was used to treat Paget's disease. It is sometimes recommended for pain relief.

Further Information

To read more, please request your free booklet '*Paget's Disease and Pain*'.

Pain Research



The Paget's Association, in conjunction with the Michael Davie Research Foundation, awarded Kathryn Berg, a Research Assistant within the University of Edinburgh, a Student Research Bursary, which is enabling her to use her involvement with pain research, the Pain in Paget's (PiP) study, to work towards a master's degree (MSc).

Here Kathryn provides an update on the study and an opportunity to take part.

An Update from The Pain in Paget's Research Study Team

The Paget's Association currently funds the Pain in Paget's (PiP) Study, which aims to look at the differences between patients who experience pain associated with Paget's disease, and those who experience no pain. By comparing the two groups (those with pain and those without), the study team hope to identify characteristics

associated with pain in Paget's disease. To do this, they are looking at genetic and microbiome profiles and undertaking sensory testing, which involves a series of non-invasive tests designed to assess participant responses to various stimuli.

The central PiP research team is based at the University of

Edinburgh, under Professor Stuart Ralston's leadership, and has been working in hospitals up and down the country with many excellent local research teams. So far, 117 participants have come into clinic to take part in the study. The team has a new recruitment target of 200 patients nationwide, and hope to hit this target by autumn this year.



From bottom-left clockwise, Kathryn Berg and Dervil Dockrell (Edinburgh) with Dr Jane Turton, Lucy Knibbs and Alison McQueen at the Paget's Centre of Excellence in Cardiff after a successful recruitment week!

continued overleaf

Of the 117 participants who have come into the research clinics, 78 (67%) have reported that they currently suffer from musculoskeletal pain, which highlights the importance of this research. However, of the 78 participants reporting pain, just 27 (35%) appeared to have pain that was directly attributable to Paget's disease. This may be down to the effectiveness of previous treatment. Of the 75 participants who had previously had anti-Paget treatment (bisphosphonates), 73% reported that previous bone pain had either disappeared completely (19%), gotten a lot better (31%), or gotten a little better (22%). No participant who had been given anti-Paget treatment reported any worsening of pain after their treatment. The most common source of current pain appeared to be osteoarthritis, which affects 46% of those who reported musculoskeletal pain.

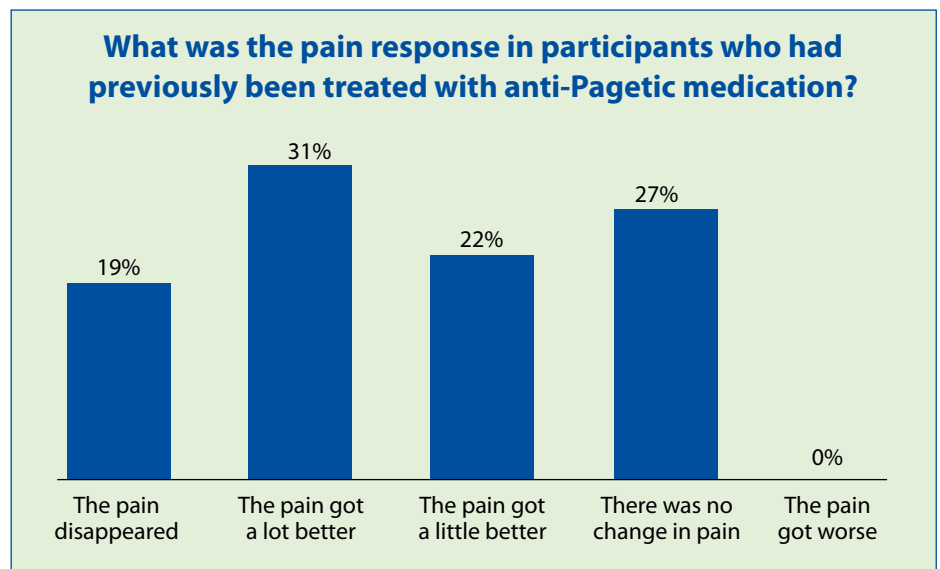
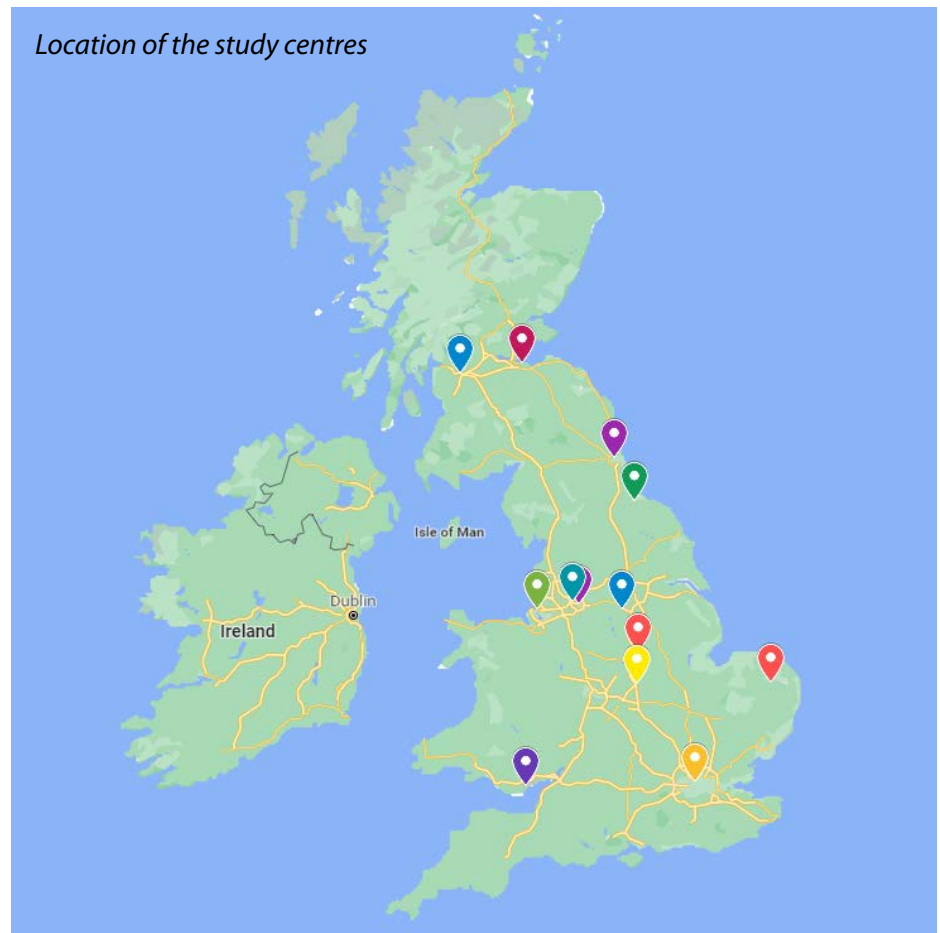
The study also captures data from a process called Quantitative Sensory Testing (QST). QST involves doing a series of sensory tests on the skin overlying a bone with Paget's disease and comparing this to a 'control' site on the skin overlying an unaffected bone, to assess if the body processes sensation differently in affected areas. As well as this, there are some questionnaires, which aim to collect information about the quality of life and the impact on/of physical activity in patients who experience pain with Paget's disease.

The study is currently open for recruitment in Stanmore, Liverpool, Nottingham, Edinburgh, Glasgow and Middlesbrough, and the team hope to open centres in Sheffield and Newcastle very shortly. The centres in Cardiff, Salford and Leicester have all completed

recruitment, thanks to the hard work of the teams in these hospitals running intensive clinic weeks!

If you would like to take part in the Pain in Paget's study or would like to be posted an information leaflet, please email Kathryn Berg (kathryn.berg@ed.ac.uk) or ring

the trial office on 0131 651 8741 to speak to a member of the team who can put you in touch with your local centre. The study visit lasts for approximately an hour and a half and involves completing questionnaires, giving blood and saliva samples and doing some sensory testing with the study team.



Support

Here are just some of the ways the Paget's Association can support you. New ideas are always welcome – just get in touch!

Worldwide Virtual Paget's Support Groups

We invite anyone affected by Paget's disease, including partners and family, to join us online at one of the Association's Virtual Paget's Support Groups. Each is a small, friendly group, that meets online (using Zoom) every two months. Those taking part have the opportunity to speak with others affected by Paget's disease, receive information regarding different aspects of the condition and make new friends. Our Specialist Paget's Nurse, Diana Wilkinson, facilitates the groups. There is no obligation to join every meeting and if you require assistance to use Zoom, we will do our best to support you – just let us know.

How it Works

- To take part, please email membership@paget.org.uk to tell us which group suits you best. Alternatively, you can register on our website.
- A link, to join via Zoom, will be sent to you via email a few days before your chosen meeting.
- Future meeting dates will be available on our website in due course.
- If you have any questions, please do not hesitate to get in touch.



Upcoming Virtual Paget's Support Group Meetings

Group 1
Monday
15:00 hrs BST
30th May 2022

Group 2
Tuesday
09:00 hrs BST
31st May 2022

Group 3
Wednesday
18:00 hrs BST
1st June 2022

Facebook Support Group

Our 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 visit – <https://www.facebook.com/groups/pagetsdiseaseofbone/>

Local Support

Sheffield Group

The Sheffield Support Group met in March, at a new venue: the Green Meeting Room, at the Church of Christ, Station Rd, Darnall, Sheffield, which has parking and disabled access.

- Meetings take place around three times a year, from 13:30hrs until 15:00hrs.
- The next meeting will be on Thursday 14th July.

If you would like to join this small, informal group, facilitated by our Specialist Nurse, for refreshments,

to make new friends, and obtain information and support regarding Paget's disease, please contact Diana Wilkinson by email diana.wilkinson@paget.org.uk or by telephone 0161 799 4646.

Manchester Group Closure

The Manchester Support Group will hold their final meeting this year, following which the group will officially close. Should sufficient interest in the group arise in the future, however, we are happy to consider reinstating it.

Paget's Helpline

- ✓ Information
- ✓ Support
- ✓ Guidance

Contact the Paget's Helpline
Email: helpline@paget.org.uk
Call: 0161 799 4646
Mobile: 07713568197

A Tribute to James Bell

James Bell, known to his friends as Dinger, became a member and supporter of the Paget's Association when he discovered he had Paget's disease in his pelvis, in 2013.

In October 2021, his wife, Rose, sadly passed away and it was a few short months later when we were saddened to learn that James had followed Rose, passing away on the 11th January. This is a tribute to James.

Since the 1970s, James had been troubled with hip and back pain. In 2016, he had recalled his experience in an article in this magazine, saying, "I am fortunate to have a first-class consultant who looks after my Paget's disease. It certainly hasn't stopped me from leading an active life. I have enjoyed cycling for many years and used to be able to manage 70 miles a day. Each year, I take my grandchildren to Brompton Carnival where, in various guises, I enter the fancy dress competition. I've also been an active member of re-enactment societies for many years; however, I retired from battle. I do though, remain an enthusiastic observer!"

James became an avid supporter of the Paget's Association and attended one of our Paget's Information Days, in Middlesbrough. A keen cyclist, he would take the Association's leaflets to libraries and community venues wherever his travels took him. Regular postcards and photographs would drop through the Association's letterbox as he kept us up to date with his latest activities. He not only endeavoured to raise awareness of Paget's disease but also raised vital funds to support those affected by it.



James at Brompton Carnival in 2014

Former Vice-Chair of the Paget's Association, Dr Stephen Tuck commented, "I was very sorry to hear of Mr Bell's passing. He had been a patient of mine for some years. I was pleased to be able to help with his Paget's and its complications. He was a fascinating character. He would tell me tales of his re-enactment events and always

greeted me with a Roman salute. I was always deeply impressed with his enthusiasm for fundraising, and he never failed to present me with money he had raised for the Paget's Association. He was a great character and a consultation with him brightened up even the most difficult of days. I hope that he rests in peace."

Having spoken with James on a number of occasions, the Association's Specialist Paget's Nurse, Diana Wilkinson, said, "When I last spoke to James he was looking forward to moving to Richmond to be near his daughter. He also asked for some of the Association's leaflets so that he could put a display outside his home on Paget's Awareness Day, the 11th January. He was very much looking forward to supporting the cause. Sadly, Paget's Day was also the day of his passing. I'm not sure what he would have made of that! We will remember him fondly and will miss his colourful correspondence".

Bone Research Society

ANNUAL MEETING 2020

6-8 JULY 2020 • MANCHESTER, UK



Bone Research Society's Annual Meeting

Researchers, clinicians and students attending the Bone Research Society's annual meeting in Manchester, in July, will be able to collect information regarding Paget's disease from the Paget's Association's exhibition stand.

26.2 Miles for Paget's

Over the last few months, runners have been applying to the Paget's Association for places in the 2022 TCS London Marathon, taking place on Sunday 2nd October. It is expected to return to being a spring event in 2023.

The successful applicants are not only training for the marathon but are all committed to raising at least £1,500 to support the Association's work. If you would like to sponsor a runner to complete the 26.2 miles, on this iconic course, please get in touch with the Paget's Association's office (details on page 3).



We still have places available. If you would like to run for the Paget's Association please contact us for further information about the TCS London Marathon, or visit [paget.org.uk](https://www.paget.org.uk)

CONNECT with us Online



Visit our website for information on Paget's disease, individual experiences, videos, events and more
www.paget.org.uk



YouTube

Our YouTube channel contains a range of videos covering all aspects of Paget's disease, from people's individual experiences of Paget's, to presentations from leading experts, find them all here
<https://www.youtube.com/c/PagetOrgUk>

Facebook Support Group

Join our online Facebook support group to meet people from around the world
<https://www.facebook.com/groups/pagetsdiseaseofbone/>

 Paget's Association

facebook

Being diagnosed with any condition can be daunting, especially one that is often overlooked.

Paget's disease affects many thousands, both diagnosed and undiagnosed, but few have heard of it.

The Paget's Association is here to help support patients and their families, and also to fund research into this bone condition.

Find out more about The Paget's Association: <https://zcu.io/HYGt>



PROVIDING INFORMATION AND SUPPORT TO ALL THOSE AFFECTED BY PAGET'S DISEASE OF BONE.

Paget's
Association

You are Amazing!



The Paget's Association does not receive any government funding and is completely reliant on donations, fundraising and legacies.

We want to say a massive thank you to all those who have donated or raised funds for the Paget's Association.

We are also indebted to those of you who have decided to leave a gift to the Paget's Association in your will, as well as those who have chosen to remember their loved ones, by donating.

Look what our supporters have helped us achieve so far!

- Support Gift Bags
- Educational Awards
- Valuable Paget's Research
- Paget's Information Packs
- Increased Helpline Support
- Student Research Bursaries
- Informative Patient Booklets
- Educational Information Events
- Distribution of Clinical Guidelines
- Professional Information Brochures
- Open Access to Professional Journal Articles
- Increased use of Social Media to Raise Awareness
- Advertisements to Raise Awareness in GP Journals and on Websites

 *In Memoriam*

Royston Gay

Winifred Ditchfield

James Bell

Patricia Penwarne



David Couch

WE APPRECIATE YOUR SUPPORT, THANK YOU

★★★★★ 200 Club Winners ★★★★★

January 2022

1st Prize £100 **2nd Prize £50**
Ticket No. 103 **Ticket No. 6**
 Euan Allen Shelagh Fletcher
 Bury St Edmonds Maghull

February 2022

1st Prize £100 **2nd Prize £50**
Ticket No. 120 **Ticket No. 16**
 Ian Davis Sheila Murray
 Haywards Heath Isle of Bute

March 2022

1st Prize £100 **2nd Prize £50**
Ticket No. 12 **Ticket No. 11**
 Patricia Wood John Ferguson
 Stirlingshire Nottingham

Join the Club

If you are over 18 and would like to join the 200 Club raffle, please get in touch using the contact details on page 3.

Meet the Team

With the exception of three members of staff, the team at the Paget's Association consists of volunteers who give their time freely to ensure the continued success of the charity.

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.



The Lord Trevor Stamp

Before retirement, hereditary peer, Lord Stamp, was a Consultant Physician at the Royal National Orthopaedic Hospital in Stanmore.



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 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.



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 Association Events

2022

EVENT	WHERE	DATE	DETAILS
VIRTUAL PAGET'S SUPPORT GROUPS			
These groups meet every two months. For more dates, visit our website or get in touch.			
Group 1 – Monday meetings at 15:00 hrs	Online using Zoom	30th May 2022	Page 27
Group 2 – Tuesday meetings at 09:00 hrs	Online using Zoom	31st May 2022	Page 27
Group 3 – Wednesday meetings at 18:00 hrs	Online using Zoom	1st June 2022	Page 27
LOCAL SUPPORT GROUP			
Sheffield Support Group Meeting	Darnall, Sheffield	14th July 2022 Contact us for details	Page 27
INFORMATION EVENTS			
Paget's Information Day	Oxford	24th June 2022	Page 8
Paget's Information Day	Cardiff	30th September 2022	Page 5
ANNUAL GENERAL MEETING			
AGM	Cardiff	30th September 2022	Page 5
TCS LONDON MARATHON			
TCS London Marathon	London	2nd October 2022	Page 29

2023

EVENT	WHERE	DATE	DETAILS
50th ANNIVERSARY EVENTS			
Paget's Information Event for patients & families	The Lowry Pier 8 The Quays Manchester M50 3AZ	19th April 2023	Page 14
Gala Evening for all		19th April 2023	Page 15
International Paget's Symposium – for Clinicians, Allied Health Professionals, Researchers & Students		19th & 20th April 2023	Page 16

CONTACT US

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

Paget's
Association

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

paget.org.uk

Information, Support and Research