

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



Your genes and Paget's disease

Pages 20 to 23

Plus

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**Mickey, Sheila
and Allan share
their stories**

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**Join us in
Manchester or
Stafford**

Chair's message

Dear Member,

Welcome to the February 2023 edition of Paget's News. As always the magazine is packed with information about the work we have been doing to support research and raise awareness about Paget's disease, as well as providing information on upcoming events and fundraising opportunities. This is an important year for the Association as it marks our 50th Anniversary.

We kicked off the year with our 5th Paget's Awareness Day on 11 January. We decided that an appropriate theme for the Awareness Day this year would be to highlight the perspective of people who had been diagnosed with the disease and how the charity has helped them. I interviewed three members of the Association who gave their personal stories of diagnosis and the support they had received throughout their journey with the condition. Many thanks to Mickey, Sheila and Allan for agreeing to tell their story. It was fantastic to hear how appreciative they were of the support the Association had given them, and how well they were doing. I also had the pleasure to interview Dr Claire Clarkin from Southampton who described the fascinating research she had been doing on blood supply of the bones, in an experimental model of Paget's disease, not least because Claire's research project was funded by the Association. We are looking forward to the results of these studies being published in the not-too-distant future. I also had the pleasure to interview Office Manager, Sue Clegg, who has been an employee of the Charity for 25 years. Sue gave



a detailed account of the history of the charity and reflected on the changes that she has seen over the years. She felt that the most notable change was our ability to reach out to people across the world due to the wonders of modern communication. Finally Diana Wilkinson our Specialist Nurse, explained about the many ways the Association offers information and support for those that require it. The Awareness Day feature is followed by a graphic on pages 10 and 11 which nicely illustrates milestones in the history of the charity. This leads on very nicely to details of our upcoming 50th Anniversary Celebration meeting in April at The Lowry, Salford Quays, Manchester. I very much hope many of you will be able to join us at this special event which includes an information session for people with Paget's disease and their families. There will also be a Gala Evening featuring a live performance by Recardo Patrick – a patron of the Association.

As many of you know, we have been running a fundraising campaign to raise £50,000 by the end of 2023. We have already raised £24,406 which means we are nearly halfway there! Many thanks to everyone who has contributed including Trustee

Amanda Sherwood who scaled Paget Peak in Canada (page 18) and Dan Brotzel who writes about his experience running the London Marathon for the Association last year (page 24).

Our regular feature on research into Paget's disease focuses on a review article about the disease by Dr Luigi Gennari and colleagues from the University of Siena. The authors outline the role that genetic factors play in the disease while highlighting the potential role of various environmental triggers that have been implicated in the disease. On the topic of genetics, we have a feature on the Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD) study on page 22. The purpose of the study is to try and figure out why some people with a family history of Paget's disease develop the disease and others do not. I was very pleased that Dorinda Blackley, from Lancashire, agreed to write about her experience of participating in the study. As you can see from her photograph with Edinburgh Castle in the background, she picked a beautiful day for the study visit!

In closing, I would like to draw your attention to our Information Event we have scheduled in Stafford on 27 October hosted by Dr Zoe Paskins. You can book online or by completing the form on page 5. More details to follow in the May edition of the magazine.

With best wishes to all.

Stuart Ralston
Chair, Paget's Association

Extraordinary General Meeting

Notice is hereby given that an **Extraordinary General Meeting (EGM)**

of the Paget's Association (also known as The National Association for the Relief of Paget's Disease)

will take place on

Wednesday 19 April 2023 at 5:20 pm

The EGM will be held in the **Hexagon room The Lowry, Pier 8 The Quays, Salford Greater Manchester M50 3AZ**

Further information is enclosed with this magazine

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 11 January.

Contact us

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

Telephone

For all enquiries telephone: **0161 799 4646**

Email

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

Postal address

You can write to us at the following address:

The Paget's Association, 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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Join us in Stafford

27 October 2023

10:30 am to 3:00 pm

Bring your questions regarding Paget's disease to a free Paget's Information Event on 27 October 2023, at The Moat House Hotel, Stafford. Set in the Staffordshire countryside, the venue has easy access from the M6 and is just 4 miles from Stafford train station (around 12 minutes in a taxi).

Local consultant Dr Zoe Paskins will be among the speakers who will discuss hot topics and answer any queries you have. Further details will be in our May magazine. Refreshments and lunch will be provided free of charge.



Reserve your place

You are welcome to bring someone with you, but please reserve your place/s. You can book via our website or complete and return the form below.

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

**BOOKING
ESSENTIAL**

Stafford Paget's Information Event booking form

Cut out or photocopy this form. Alternatively, book via our website.

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

FREE

I/we wish to attend the free Paget's Information Event at The Moat House, Stafford, on **27 October 2023**. (Please tick box)

Names of those attending

Please state any special dietary requirements

--

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

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

--

Name & address for correspondence

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

Telephone

--

Email

--

Please return this form by post to:

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

Personal experiences help raise awareness



Released for Paget's Awareness Day this year, a series of interviews were recorded by the Chair of the Paget's Association, Professor Stuart Ralston. He spoke with people living with Paget's disease about their experiences, a bone biologist from Southampton, Dr Clarkin, explained why the blood supply to bone affected by Paget's is an important area of research, and staff from the Association provided information about our support services and the history of the charity.

Professor Ralston spoke to 3 members of the Association, Mickey, Sheila and Allan about their experience of the condition. Their interviews are summarised below. You can watch the full interviews on our website (www.paget.org.uk), and our YouTube channel (@PagetsAssociation).

Mickey's back on the tennis courts

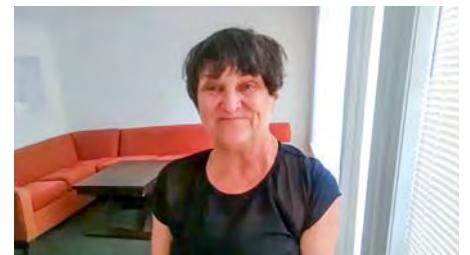
Mickey Cloutier is from Toronto, Canada. In her interview, she explained how she noticed symptoms about fifteen years ago. She commented, 'I was having to wear bigger hats and my balance was off. I did yoga, but I always had to hold on to the wall!'. Despite this, Mickey didn't become too concerned until about eighteen months ago when she started to experience pain and swelling around her knees. She went to see her GP who carried out scans and blood tests. One blood test showed a raised level of alkaline phosphatase (ALP). Mickey recalls the reading was 2200, and she was astonished to be told this was more than ten times the normal level.

Mickey's doctor spoke to an endocrinologist and more tests were requested to check her liver, which were normal so the next step was a nuclear bone scan. When Mickey was told she had Paget's disease she said, 'To be honest, I was relieved to hear that there was a diagnosis because I went through years of thinking there's something really wrong but not knowing what it was. So even though it wasn't the best thing to hear, it was positive because then I could move forward'.

Her endocrinologist recommended an infusion of zoledronic acid. She explained the effect it had on her, 'You know, I want to start on a positive note because I am thrilled that we have something that really super affected me in a positive way. So, if we're looking at the big picture, I am thrilled that I was able to have the treatment. It was a little scary at first, but I got it. The first four days were scary. I had the flu-like side effects and didn't feel comfortable even standing, never mind walking, and I didn't know how long it would last'. Mickey found the Paget's Association's Facebook Support Group, where she found support from others in a similar situation. After around five months, it was obvious that there was a big and positive difference, her friend commented, 'I haven't seen you walk that easily for five years!'.

Mickey recalls how she thought she was going to have to stop playing tennis, 'I told everybody that was a major possibility but I'm back on the courts now and my ALP went down to 89 so that's fantastic'.

When asked if she thought there was any family history of Paget's disease, Mickey said she had watched one of the Association's videos, with Dr Michou, about hotspots in eastern Quebec, where both of Mickey's parents are from.



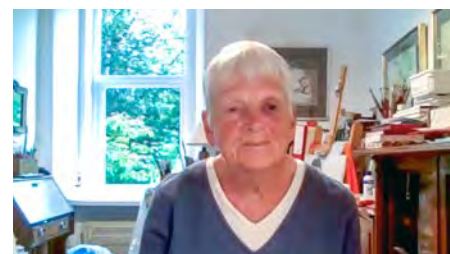
Mickey

Mickey said, 'I'm 95% French, with a heavy French background on both sides of my family'. Dr Michou will be speaking at our event in Manchester in April (see page 14).

Mickey went on to join one of the Association's Virtual Paget's Support Groups, which take place online using Zoom. She explained to Professor Ralston why the group helps her, 'I like it for two reasons, of course, the information aspect is fantastic. I've learned a lot about Paget's, how it affects other people, and what to expect. If I have any personal questions, I have a venue where I can ask a Paget's Nurse, which is amazing. On the other hand, I find it really useful because of the people that show up. I feel almost a camaraderie with them. I don't feel like such an outcast. It's great to be in a group of people where you don't have to explain this disease and spend the first ten or fifteen minutes talking about how you're not feeling well or how you got diagnosed. It's already there. So it's the camaraderie and I've laughed an awful lot. I know Paget's is not something to laugh at, but we're human and you form relationships, I feel I know the people in my group quite well and look forward to seeing them'.

Sheila took part in research

Sheila Murray, from the Isle of Bute in Scotland, was diagnosed several years ago when she was in her late forties/early fifties. She noticed her winter boot wouldn't go on properly on her left leg and made an appointment to see her GP. With a family history of Paget's disease, she wasn't surprised when an x-ray confirmed she had the condition and was asked by her GP whether she had any pain. She did not and the GP said 'That's fine. Just go away and forget it'.



Sheila

At the time her daughter's friend was doing a nursing course and told Sheila about the Paget's Association. She got in touch and found out about Paget's research being done by Professor Ralston in Scotland. She didn't hesitate to get involved and more recently says that one of her daughters decided to take part in a study into the genetics of Paget's disease, the GAPDPD study as described on page 23.

Now a patient of Professor Ralston's, Sheila recalled that despite being warned of potential side effects of treatment, she was fortunate to have no ill effects whatsoever. As her leg was bowed, she was also offered corrective surgery but decided against this as she had no pain. Sheila continues to live well with Paget's disease on the beautiful Isle of Bute, Scotland.

Paget's prevented Allan from dancing

A keen ballroom dancer Allan Kidney, from Hertfordshire, described how Paget's disease prevented him from dancing.

With a painful lower leg, Allan was diagnosed with cellulitis, an infection of the deeper layers of skin and the underlying tissue. Antibiotics made no difference and he was referred for an x-ray that revealed Paget's disease.

While waiting to see a specialist, Allan did some research and found the Paget's Association's website. When asked if the charity had helped him, he said, 'The Association helped me a lot. I was most appreciative of it. In fact, I became a life member as a thank you for the support I'd been given'.

Allan's rheumatologist treated him with two courses of an oral bisphosphonate, risedronate that helped but he continued to have some discomfort and one day his leg gave way. When a further x-ray was taken, it became apparent that he had a pseudofracture (not a true fracture) in the bone affected by Paget's disease. This healed without any further intervention and, eventually, Allan was pain-free.

Allan has not required any further treatment and he was pleased to say that he is back on the dance floor and dancing regularly.



Allan

Research looking at blood supply

Warmth can sometimes be felt around an area of Paget's disease as there is often increased blood supply to the affected area. In her interview for Paget's Awareness Day, bone biologist, Dr Claire Clarkin, explained to Professor Ralston how research in Southampton is studying the relationship between blood supply and Paget's.

Dr Clarkin has been working with engineers to improve imaging techniques to allow them to visualise and measure the network of blood vessels (vasculature). Funding from the Paget's Association has helped this work and allowed them to construct blood vessels in 3D.

Researchers measured bone strength and saw differences between male and female bone affected by Paget's disease (Pagetic bone) with bone in males much weaker than in females. Blood vessels in the areas of Pagetic bone in males were much larger and there were many more of them than in females. This suggests that differences in blood supply may be responsible for the increased fractures found in males.

In this fascinating interview, Dr Clarkin continued to discuss the potential for the development of drugs to treat Paget's disease by targeting blood vessels.



Dr Claire Clarkin

50 years of the Paget's Association

As the Paget's Association celebrates its 50th Anniversary, Professor Ralston interviewed Office Manager, Sue Clegg, regarding the history of the charity, and Diana Wilkinson, Specialist Paget's Nurse, to discuss the many ways in which the Association offers information and support to those who require it.

How to watch the videos

You can watch the videos on our website, and our YouTube channel (@PagetsAssociation). Alternatively, email membership@paget.org.uk to request a link.



Thank you for joining us on Paget's Day

Members from the UK, USA, Australia and New Zealand joined Professor Stuart Ralston for 2 virtual question and answer sessions held for Paget's Awareness Day. Thank you to all who attended. We hope you found the event beneficial.

Raising awareness in India

Our Chair, Professor Stuart Ralston, discussed rheumatology and bone disease with students and staff at Jaipur National University Institute for Medical Sciences Research Centre, India, when he conducted a lecture tour to celebrate the publication of the 24th edition of Davidson's Principles and Practice of Medicine, of which he is an editor and chapter author.



The Association's newsletters through the years



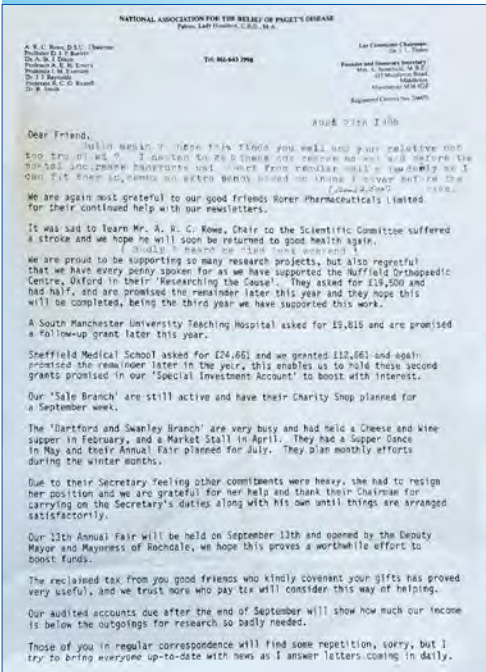
Mrs Ann Stansfield MBE
Founder

This year the Paget's Association celebrates its 50th Anniversary and it is more than 50 years since the Founder of the charity, Ann Stansfield, began regularly corresponding with those who needed help, and also with hospitals and universities around the world in search of more information about the condition. She progressed from handwritten letters to using a typewriter and then, with external assistance, was able to produce regular newsletters.

Some of our past newsletters are shown below. Whilst the design and logos may have changed over the years, the content has continued to be centred around the aims of the Association, that is, to support those affected by Paget's disease, to raise awareness, and to fund research.

1986

Funding for research and fundraising featured in this newsletter

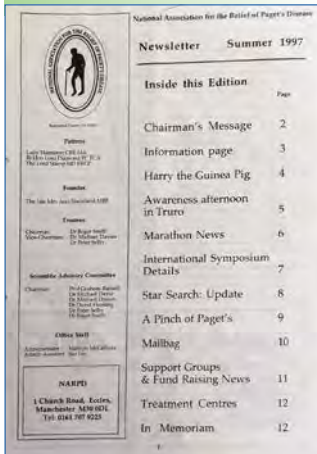


Tell us what you think

We hope you find our current newsletters interesting and would love to hear your feedback. You can contact us using the information on page 3.

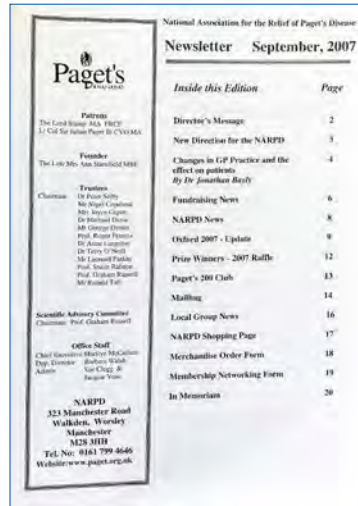
1997

Here the focus was on support groups, treatment centres and raising awareness



2007

This issue highlighted changes in GP practice and its effect on patients, and it had a shopping page to help raise funds



2022

Genetics, pain and personal experience of Paget's disease were included in this edition from last May



2011

Dr David Hosking reviewed how treatment with zoledronic acid was delivering prolonged remissions



50 years of the Paget's Association

1973



With assistance from Dr Allan St John Dixon, Mrs Ann Stansfield founded the National Association for the Relief of Paget's Disease, now more commonly known as the Paget's Association

In the Association's 10th year, the Founder, Ann Stansfield, received an MBE. Her husband, Alf was by her side and it was he who had kickstarted her journey as he suffered for many years with pain. This was because, to Ann's dismay, he was incorrectly diagnosed with other things before eventually discovering he had Paget's disease

1983



The Association's first conference took place in 1989, at Withington Hospital, Manchester

1989



Allan St John Dixon, the first Chair of the Association, received an OBE and the first organised support group began in Manchester.

1990



1992



Professionals from all over the world came to Manchester for the first international Symposium on Paget's disease

The Paget's Association in the 21st Century

For the first time, the Association employed a Registered Nurse to manage clinical queries on the Paget's Helpline



2008



2013



Events to mark the Association's 40th Anniversary took place at The Lowry, Salford Quays, Greater Manchester: Information Event and Gala Evening

The First International Paget's Awareness Day occurred on the 205th anniversary of Sir James Paget's birth, 11 January 2019. As he was born in Great Yarmouth, a Paget's Information Event with a live webinar was broadcast from James Paget University Hospital



2019

2020



The Association responded to the COVID-19 pandemic by making additional support available to those affected by Paget's disease, through its Helpline and social media channels, and by developing international virtual support groups

In celebration of 50 years of the Paget's Association, we return to The Lowry in Salford Quays, Greater Manchester. Activities include our international Paget's Symposium, Information Event and Gala Evening.



50 YEARS
ANNIVERSARY
2023

Join us at Salford Quays for our 50th Anniversary events: 19 to 20 April 2023



Events marking the Paget's Association's 50th Anniversary are detailed on the following pages. They are taking place at The Lowry, Salford Quays, Manchester. This is a unique waterfront destination with its shops, restaurants, and cinema.

Whether you are joining us for the Information Event (page 13), the Gala Evening (page 15) or the international Symposium (page 17), you will also find that there is plenty to explore in the surrounding area.

Salford Quays

There are good tram and bus links from Manchester City Centre to Salford Quays, that you may have seen on television, as the BBC and ITV have studios there. You can visit the nearby Imperial War Museum or the Coronation Street production centre. Football and cricket fans will find that they are not far from Manchester United Football Ground and Lancashire Cricket Ground.

Why not take some time to explore the local area before joining us for the Paget's Information Event at The Lowry, on the afternoon of 19 April? Later on you may wish to attend the Gala Evening and stay overnight in one of the many nearby hotels.

Discounted overnight stay

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 'MediaCity' Manchester, 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 call us on 0161 799 4646 or email membership@paget.org.uk

The Lowry

Our events are taking place at The Lowry, a fully accessible building, where visitors will find one of the largest L S Lowry art collections in the world as well as theatres, galleries, cafes, and a bar.

Whilst several rooms have been set aside for our events, the Compass Room has been reserved for the Gala Evening (page 15). This beautiful room has an almost 360-degree view of Salford Quays.



The Imperial War Museum, Salford Quays



The entrance to The Lowry



The Lowry with the Compass Room at the top, overlooking the water

Reserve your place

Read on for full details of all our 50th Anniversary events. You can reserve your place/s on our website or use the form on page 16.

You are invited to a

Free Paget's Information Event

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

at 3:15 pm to 5:15 pm

Join us for refreshments from 2:30 pm



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 2:30 pm.

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



Patient/family Information Event programme

Wednesday 19 April 2023

3:15 pm to 5:15 pm, 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 7:00 pm a Gala Evening with dinner will take place so why not join us for both events? See page 15 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 **19 April 2023**, commencing at **7:00 pm**

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.



Live performance

During the evening, there will be a live performance from Patron of the Association, Recardo Patrick. A worldwide entertainer and businessman Recardo first rose to fame as lead singer with the band Sweet Sensation who had a worldwide hit with 'Sad Sweet Dreamer'. He has worked alongside many other famous names including Michael Jackson, Whitney Houston, Elton John and Prince.



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 13 to 14).

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 19 April 2023

Names of those attending the Information Event

Gala Evening

I/we wish to attend the Gala Evening on 19 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 **19 to 20 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 www.paget.org.uk



In association with ECTS/BRS
in Liverpool, April 2023



Amanda reaches the summit of Paget Peak

As part of fundraising efforts for the 50th Anniversary of the Paget's Association, Amanda Sherwood, a Trustee of the Association, was challenged to reach the summit of Paget Peak, in Yoho National Park, Canada.

Paget Peak is a 9.5 kilometre hiking trail with those who reach the top rewarded with spectacular views. With an elevation of 2,560 metres (8,400 ft), the peak is named after Dean Paget, the first to record reaching the summit, and one of the founders of the Alpine Club of Canada. He reached the top with a group of club members in 1886.



Thank you so much for giving your support to me as I climbed Paget Peak. I am pleased to say that the mission was accomplished with a bit of moaning on the scree and boulder slope at the top (hence my sitting in the photograph). It was a bit longer than we anticipated as we had to climb uphill for three miles before the start of the trail. It took us six hours in total, but we did a little detour on the way down to a lake.

We were lucky with the weather, and although there were lots of warnings about bears and needing to have our bear spray at the ready, we didn't actually see any! Maybe next time....

Best wishes

Amanda



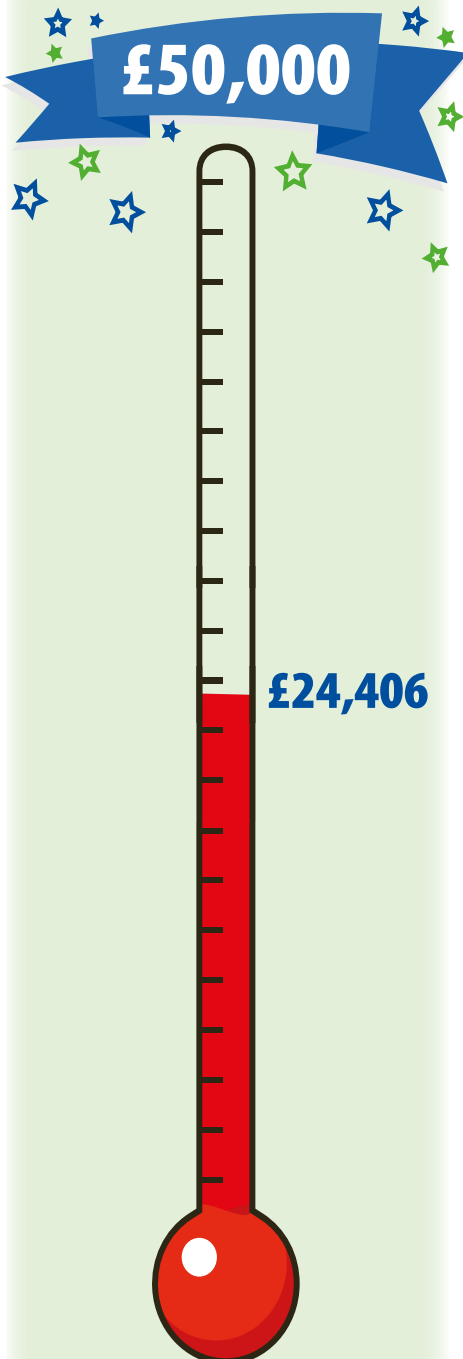
Support Amanda

So far, Amanda has raised a fantastic £650. You can sponsor her by telephoning the Association on 0161 799 4646 or scanning the QR code for her JustGiving sponsorship page www.justgiving.com/fundraising/pagetpeak



50th Anniversary campaign

The Paget's Association's 50th Anniversary fundraising campaign to raise £50,000 by December 2023, has reached a fantastic £24,406.



Seasonal fundraising

Janet and Graham Dixon, from Lincolnshire, crafted and sold these beautiful Christmas trees, raising £100, towards the campaign. This was kindly matched by Barclays Bank, making a grand total of £200. Thank you!



Thank you!

As we rely upon individual donations and fundraising to ensure the continuation of the charity, every single contribution really does help. We'd like to say a huge thank you to everyone who has raised funds or donated to the Anniversary campaign so far. Your kindness and generosity make a huge difference.

How to contribute

There are a number of ways you can donate or pay in funds you have raised.

JustGiving's website

You can also donate on our JustGiving 50th Anniversary Campaign page using the QR code here or the link 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

Bank transfer:

To make a payment directly into the Association's bank account, please telephone 0161 799 4646 to request bank details.

Standing order: To make a regular donation, email membership@paget.org.uk or call 0161 799 4646 to request a form.

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

If you would like to raise funds for the Paget's Association, but don't know where to start, why not request our fundraising pack? This contains information and ideas to help get you started with our fundraising booklet, a banner for your event, and leaflets to help raise awareness of Paget's disease.



Journal news



Scan the QR code to read the paper in full

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 recent review paper from the scientific journal *Frontiers in Cell and Developmental Biology*. It provides an update on how Paget's disease develops (pathogenesis) and the genetics involved. They summarise the paper below. The full text is available online.

The pathogenesis and genetics of Paget's disease

Paget's disease appears to be more common in males but it is difficult to quantify just how many people have it because many do not have symptoms, especially in the first few years after onset. It can affect one (monostotic form) or more bones (polyostotic form), which are typically enlarged and deformed. The affected skeletal sites are generally asymmetric and most frequently include bones in the leg (femur, tibia), pelvis, spine, and skull (one or more of these bones are affected in up to 90% of cases). In terms of natural history, the authors of this paper note that the first pagetic femur dates back to about three thousand years ago, and lesions suggestive of the condition have even been reported in vertebral bodies of dinosaurs from the late Palaeozoic to the mid-Mesozoic eras.

The cause of the condition remains in part unknown. Two main hypotheses have been proposed, a genetic one and one linked to the presence of environmental

“
Genetic susceptibility might not actually be sufficient for the clinical development of Paget's without the addition of environmental factors
 ”

triggers. Many countries have seen a progressive decline in the prevalence and severity of Paget's disease in recent years, which has made it a less frequently diagnosed disease. The reason for this is unknown, although the rapidity of change observed in areas such as the UK, where Paget's is more prevalent, points to an alteration in one or more environmental factors.

Over the past two decades, advances have been made in the cellular and molecular biology of Paget's, and some genetic mutations have been identified as a possible cause of the disorder in up to 20%–30% of cases. Around thirty different germline mutations of the Sequestosome 1 gene (*SQSTM1*) have been described in a significant proportion of familial and sporadic cases of Paget's disease. The authors

note that to date it has been shown that patients who possess *SQSTM1* gene mutations or other mutations (e.g., *ZNF687* or *PFN1*) have a more severe form of Paget's disease than those without mutations and may require more aggressive treatment. The extension of genetic analysis to the relatives of these patients could also allow the identification of new cases of recent onset, before deformities and other complications have developed, or even allow preventive treatment. This will become clearer when the results are published of an international clinical trial (the ZiPP study) in asymptomatic *SQSTM1* mutation carriers.

The authors explain that a significant number of genes involved in the pathogenesis of Paget's disease (namely *SQSTM1*, *VCP*, *PFN1*, and *OPTN*) have also been associated with neurodegenerative disorders in patients without Paget's, suggesting shared pathophysiological mechanisms. It is unclear however why some people with mutations in these genes develop Paget's disease while others develop neurological or muscle disorders.

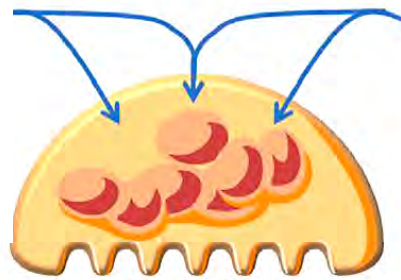
Both clinical and experimental observations indicate that genetic susceptibility might not actually be

ENVIRONMENTAL TRIGGERS

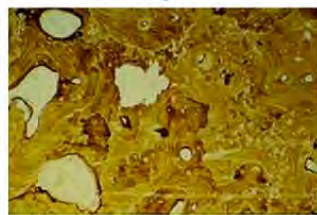
- **Viral infections** (*Paramyxovirus*)
- **Toxins** (*arsenic, pesticides, dioxins*)
- **Metal exposure** (*lead, cadmium,...*)
- **Dietary factors** (*Ca and/or vitamin D deficiency*)
- **Lifestyle factors** (*tobacco, wood fired heating*)

LOCAL FACTORS

Biomechanical stress
(increased blood flow)
others...



**PAGETIC
OSTEOCLAST**



PAGETIC LESIONS

PREDISPOSING GENES

- Germline mutations
SQSTM1
ZNF687
PFN1
(*TNFRSF11A, FKBP5*)

- Susceptibility variants
OPTN
TNFRSF11A
CSF1
RIN3
PML
TM7SF4

EPIGENETICS

- DNA methylation pattern
- MicroRNA expression profile

MODIFYING GENES

(e.g. *DOCK6*)

FIGURE 1

Updated pathogenetic model of Paget's Disease of Bone. This underlines the different genetic, environmental lifestyle and epigenetic factors and their potential reciprocal interactions in the pathogenesis of pagetic lesions

- Image reproduced with kind permission from the authors of the paper under the CC-BY licence

sufficient for the clinical development of Paget's without the addition of environmental factors, at least in a subset of cases. An update on the pathogenetic mechanisms of Paget's disease at the level of bone-resorbing osteoclast cells and their potential interactions is given in Figure 1.

Unknown mechanisms

Unfortunately, the molecular and cellular mechanisms leading to the development of Paget's disease remain largely unknown. The authors speculated that with further advances in technology, and more detailed studies and research, more will be discovered about the disease mechanism over the coming years.

REFERENCE

Gennari L, Rendina D, Merlotti D, Cavati G, Mingiano C, Cosso R, Materozzi M, Pirrotta F, Abate V, Calabrese M, Falchetti A. Update on the pathogenesis and genetics of Paget's disease of bone. *Frontiers in Cell and Developmental Biology*, 2022 Aug 12;10:932065.

Learn more

You can learn more and have an opportunity to ask questions about the genetics and the environmental causes of Paget's disease at our 50th Anniversary Information Event and international Symposium in Manchester this April (see pages 12 to 17).

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.



Your genes and risk of developing Paget's disease

We know that Paget's disease can run in families and that close relatives of people with the condition have a 7 times greater risk of developing the disease in later life compared to the general population. It is also known that it may go undetected for many years with presentation at a late stage, often with complications that are difficult to reverse.

Researchers at the University of Edinburgh are studying why some people with a family history of Paget's disease develop the disease and others do not, with the aim of predicting those at risk and enabling earlier diagnosis. In the November edition of this magazine, we highlighted that volunteers with a family history of Paget's are needed for the study known as Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD). The study offers people with a family history of Paget's disease, a genetic test to determine how likely they are to develop the condition themselves.

Concerned about her family history of Paget's disease, one of our members, Dorinda Blackley from Lancashire, decided to take part in the study and writes about her experience below.

My experience of taking part in Paget's research

At the Paget's meeting in Oxford last year I spoke with the Chair of the Paget's Association, Professor Stuart Ralston, and offered to take part in GAPDPD. This research is looking at people who do not have Paget's disease but have the disease in their family. My father, Syd, and coincidentally, my father-in-law, Colin, both had Paget's disease, although Syd suffered far more from its effects. If my father had been



alive, he would have wanted me to participate in the study. This, as well as a concern for my two children who have Paget's on both sides of their family.

Prof Ralston told me that apart from a couple of places in London, Edinburgh was the only other place offering tests at that time so I chose to go there. A member of Prof Ralston's team got in touch. She was extremely approachable, knowledgeable, warm and friendly and I found it very easy to work with her and I was told that the university would pay our costs.

I had a Covid 19 test which was negative and travelled up by train, in the hot weather of August 2022. The next day was lovely, so I decided to walk to the hospital. This was a big

mistake as I took a wrong turn and in the end got a taxi, arriving a little late for my appointment.

On arrival, team members greeted me and spent the next hour or so with me. I had height and weight recorded, BMI calculated and blood pressure measured. Then came a detailed questionnaire on health and lifestyle. I didn't find that a problem, except for the question regarding the length of time I spend awake but resting, moving, standing etc. I think I got the length of time I spend sitting to be longer than it is because I realise that I spend more time in the kitchen working than I had thought!

After lunch, I was taken for a bone scan with a radioactive tracer injected directly into the bloodstream. I was told that the risk of the low dose of radiation was small. I was then free to move around for the next couple of hours but was asked to drink as much water as possible as this improves the images. On such a hot day, this wasn't difficult. Before the scan, I changed into a gown and the scan itself lasted about 15 minutes. I was given kits to use at home for faecal and saliva samples, and packages in which to safely return them to the university.

In the early afternoon, I was all finished and walked back to the accommodation, and then on into

Edinburgh where I enjoyed the glorious weather and sat outside pavement cafes. I was saddened to see Jenner's had closed – a department store I had enjoyed visiting many times. That evening I took the bus into Edinburgh to Waverley station and arrived home in good time.

As it is a research study taking place over a long period of time, I won't know the results of the faecal tests and the genetic sequencing for another 5 years. I have to have a

health check around February 2025, and a repeat bone scan five years later. I will be very interested to read the findings of the study. Happily, I found out that I do not have Paget's disease!

The team carrying out the research was very supportive and couldn't have been more helpful. It was painless, and Edinburgh was a pleasure to visit.

If you were wondering about joining the study, I hope this has been

useful. For those of you who were not thinking of joining the study, then I hope you will give it your consideration.

I understand that further test centres are being set up and I hope that, as Paget's affects more people in the North West of England than anywhere else in the UK, a centre will be set up in that region by an interested medic.

Dorinda

Information about the GAPDPD study

Who can take part in the GAPDPD study

If you have either a parent or a sibling who has been diagnosed with Paget's disease, you are 45 or older, and have not been diagnosed with Paget's yourself, you can take part in the research.

Where is the study taking place?

The investigators are planning to perform the study in several sites across the UK and Ireland. You will be given a choice of the site that is most convenient for you. The study team will be very happy to reimburse any travel and accommodation costs that you might incur as a result of taking part in the study.

Since Dorinda took part in the study sites have opened in Edinburgh, Cardiff and London, with Keele, Liverpool and Cambridge due to start soon. Other sites are in the process of being set up in Bristol, Dublin, Leicester, Liverpool, Middlesbrough and Newcastle.

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

What is a radionuclide bone scan?

As part of the GAPDPD research, Dorinda had a radionuclide bone scan, which is also known as a scintigram, isotope bone scan or nuclear medicine bone scan. This is often carried out to determine which bones have Paget's disease and how active the disease is. This type of scan is also used to detect osteoarthritis, fractures, and bone tumours. It is different to a bone density scan (DEXA), which is used to diagnose osteoporosis.

The radionuclide scan involves an injection into a vein of a very small and safe amount of a mildly radioactive chemical called an isotope. There is then a waiting period of a couple of hours to allow the tracer to be absorbed by the bones. Then the scan is carried out with a camera that moves slowly to take images of the entire skeleton. Abnormal bone absorbs more radioactivity than normal bone, so these areas are highlighted and picked up by the scanner. There is usually no need to repeat the bone scan unless your specialist recommends it.

The London Marathon

Thank you and well done to our runners in the October TCS London Marathon, who raised a total of £5,535.

With the event returning to the Spring, there are just a few short months before a new group of runners take on the challenge for the Paget's Association on Sunday 23 April 2023. If you are interested in joining them, contact us membership@paget.org.uk

Good luck to all!

**26.2
MILES FOR
PAGET'S**

Dan's diary

Dan Brotzel, from London, was one of the runners for the Paget's Association last year. Here is his diary of his experience.

The big day

I'm up early to wolf down a giant bowl of granola and bananas. On the London Underground, I bump into a lean-looking man who says this will probably be his last marathon. He is a week shy of 70. 'What sort of time are you hoping for?' I ask. 'Well, I'm slow now,' he smiles ruefully. 'But I'd like to get in under 4 hours 30.' Goodness, I'd kill to finish in 4 hours 30.

Slowly, as I walk towards Charing Cross, more fellow runners appear clutching their tell-tale see-through bags full of sliders and cereal bars (both things I never thought to bring). The train to Blackheath is quickly full of runners, and we wait a long time between stops. The driver makes a lovely announcement wishing everyone luck, which warmed us all. Soon we are out among the throng streaming towards Greenwich Park.

A quick call to my wife, Eve, now joined at ours by Mum and my brother Adam and his wife, Helen. Then I start to worry that I haven't stretched enough but don't really know how to. I start on the glucose sachets early as someone advised me. We hear the elite runners set off over the sound system.

I wander around the Blue Zone and take in some of the costumes. There's a man with an ironing board strapped to his back and holding a fully-extended clothes drier, bearing T-shirts over his head promoting different charities. I see a man from the Samaritans dressed as a giant telephone, a clutch of life-size rhinos and a firefighter in full protective clothing with a gas cylinder on his back. These people are mad!

Soon enough I am in a pen and we are funnelling along a corridor of railings and then through the gate that marks the start. Our feet hit London road and even as I trot along

it's hard to realise that I am actually doing the Marathon instead of thinking about it or just boring other people with my training updates.

The support begins from the first metre of the course and it never lets up. I had imagined there would be pockets of people at key points like Tower Bridge and others had warned me of 'dead patches' where there's no one watching. In fact, the support was endless and persistent. Kids holding out sweets or palms for high fives (I stopped doing this quite early on for reasons of energy conservation). Sound systems on doorsteps. People waving from bedrooms and balconies. Endless posters, banners and inspiring messages.

Good causes

From cats to cancer, dyslexia to dementia, hospices to heart disease, every possible charitable cause seems to be represented. Several

pairs of runners joined by a cord connecting the sighted with the sightless. I realise I am among my people – a vast human soup of fundraisers and awareness boosters. I am proud to be representing the Paget's Association and I'm pleased my efforts will do good.

Steady progress

At 15 miles, past the Cutty Sark and just over Tower Bridge I am still going strong. I chug along at between 10.5 and 11 minutes per mile and my family can see steady progress on the app that allows your supporters to track you (a brilliant idea.) Then, alas, you don't turn left/west towards Big Ben and the finish; it's right/East and off to Docklands again. At this point the runners run both ways, and across the road I can see a vast stream of smug racers who have already completed the Docklands leg and are now heading for home. But here at least is the first sight of my family and I am very touched to see them all.

Misgivings

At about 17 miles, my legs go. At first I find that my shoes feel too tight and I keep stopping to adjust them (only later will I realise that a new pair of too-tight socks were the culprits.) I begin to have misgivings. Lots of people around me are walking now. Some are stopping. I had fanciful ideas of finishing times but really my goal has always been: not to walk. Stopping is OK; you have to go to the loo, stretch legs out, tie laces etc. But not walking is the non-negotiable I have set myself. But now with nine miles to go, I am wondering if that will be possible.

The noise is getting louder and louder. There are samba bands and drumming collectives; live singers and DJs. I start to feel sick, faint, tearful. My people are waiting



for me on the other side of the road, around the 22-mile mark. An attendant asks if I'm OK; tells me to walk for a bit. There is no shame in walking, of course; only I will know I walked when I so much wanted not to. The cacophony of shouts and beats is overwhelming; at times you feel as though you are running through a nightclub. It's almost oppressive and yet it is hard to give up when so many are willing you on. I tell myself I will keep going till I see my family. It takes an age for them to appear. I start to wonder if they have gone home. Later, I discover the tracker froze for a time, and they wondered if their man was down. I am running 12.5 minute miles now, slower than some walkers.

I'm in intense discomfort. It's certainly the hardest physical thing I've ever done. The muscles twang with every step, I can feel a knee going, and I wonder how much damage I'm doing to my joints by carrying on.

It takes an age for my people to appear again but when they do, it's like an oasis of hope in the desert. This time I stop and hug everyone, whisper 'Never again' repeatedly, and then try and crank my legs back into some kind of locomotion.

Those last nine miles are a battle of will with myself and the tunnel of

noise. I am quite a stubborn person on the quiet, and at a certain point the logic of completion kicks in: having run 22 miles, 22.5, 23, are you really going to give up now? Even if every bit of you is yelling to stop? Of course not. On we go. For the fourth or fifth time, a very tall, thin man in a chic bridal gown glides past me. At 25 miles, a runner stops to join in with a steel drum band. Where does his energy come from? I don't even have the energy to move a yard over and pat the cardboard energy booster signs anymore; I just mime from a distance.

The finish

Now the cheers are deafening. I am vaguely aware of fountains and monuments and a pinkish tinge to the roads. I cross the finishing line without realising I have finished. My sister manages to record the moment, which is very low-key; everyone around me is cheering gesticulating; I have my head down and am just soldiering on. I am so mashed I don't even realise I have finished.

There's a medal and a goodie bag. I don a foil cape and am surprised how warm it is when I remove it later. Under the trees at the edge of St James' Park, I chat with other runners. My brother messages to see if we can meet up, and a few minutes later, I am with my family; it means so much that they are here.

Dan

**Would you like a
place in the 2023
London Marathon?**

Contact us
membership@paget.org.uk

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

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

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

"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 group

Our Paget's Facebook 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 group

Our Sheffield group meets for a chat, support and refreshments, around three times a year, in Darnall, Sheffield, from 1:30 pm until 3:00 pm.



Information

Should you require our latest information booklets or back issues of this magazine, simply 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

★ ★ ★ 200 Club raffle ★ ★ ★

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



October 2022

1st Prize £100

Ticket No. 133

Ena Davies

Surrey

2nd Prize £50

Ticket No. 156

Veronica Ashton

Merseyside

November 2022

1st Prize £100

Ticket No. 185

Christine Cratchley

London

2nd Prize £50

Ticket No. 23

Kathleen Hanlon

Huddersfield

Double prize draw

December 2022

1st Prize £200

Ticket No. 135

Maureen Jones

Liverpool

2nd Prize £50

Ticket No. 62

Ingrid Pryor

Cambridge

The Minutes of the Paget's Association's Annual General Meeting

Held at the Holiday Inn, Cardiff – Friday 30 September 2022

Attendees: 5 Trustees, 4 members, 3 employees

Apologies: 1 Patron, 5 Trustees

Professor Ralston welcomed everyone to the Cardiff meeting. He highlighted that 19 votes had been returned by members and he reminded attendees that if they had already voted postally or electronically, not to vote a second time.

1. Minutes of the Annual General Meeting held on Friday 8 October 2021, at the Double Tree by Hilton Hotel, Southampton

The minutes of the 2021 AGM were presented to members and agreed as a true and accurate record. Professor Ralston proposed that the minutes be accepted as a true record of the meeting and was seconded by Mr Alan Janes.

For: 18 proxies 3 present

Against: 0

Abstentions: 1

2. Presentation of the Report and Accounts from the last financial year (2021)

Professor Ralston presented the Association's Report and Accounts for the previous financial year. He reported that income for 2021 had been £205,188, up from £88,273 in 2020. He highlighted that income from legacies was three times higher in 2021 than 2020. He displayed a graph showing the fluctuation of legacy income over recent years highlighting the substantial variations in legacy income from year to year. He reported that at the end of the financial year, the

fund balance was £1,030,535 up nearly £8,000 on the previous year. He added that if anyone wished to receive a copy of the full Report and Accounts, they should contact the Office Manager.

Professor Ralston proposed that the accounts and annual financial report be accepted, and this was seconded by Mr Alan Janes.

For: 18 proxies 3 present

Against: 0

Abstentions: 1

3. Appointment of the Association's independent financial examiner

Professor Ralston reported that the Association was pleased with the appointment of Beever and Struthers as the Association's financial examiners and proposed their re-appointment.

For: 18 proxies 3 present

Against: 0

Abstentions: 1

4. Election of Trustees and Officers

Professor Ralston informed members, that both Professor Rob Layfield's, and Dr Sheelagh Farrow's, 3-year terms of office, had been completed, but both were willing to stand for re-election. He further highlighted that there had been two additional trustee nominations for the Board, Mrs Eve Berry who had financial experience, and who was present at the AGM and Dr Faizanur Rahman, a consultant, specialising in Paget's disease, who was unable to be present, owing to work commitments.

Professor Ralston proposed the re-appointment of Professor Layfield to the Board.

For: 19 proxies 3 present

Against: 0

Abstentions: 0

Professor Ralston proposed the re-appointment of Dr Sheelagh Farrow to the Board.

For: 19 proxies 3 present

Against: 0

Abstentions: 0

Professor Ralston proposed the appointment of Mrs Eve Berry to the Board.

For: 18 proxies 3 present

Against: 0

Abstentions: 1

Professor Ralston proposed the appointment of Dr Faizanur Rahman to the Board.

For: 18 proxies 3 present

Against: 0

Abstentions: 1

Professor Ralston welcomed the new Trustees to the Board and congratulated the existing Trustees on their re-election.

5. Review of the last year's activities (2021)

Professor Ralston invited Specialist Paget's Nurse, Diana Wilkinson, to give an update on activities undertaken by the Association during 2021, which included:

3rd Annual Paget's Awareness Day - 11 January 2021

The Paget's Awareness Day featured a series of videos based on the 'Treatment Story', with a live online

question and answer session, on the day, led by Professor Stuart Ralston.

A campaign had been undertaken to highlight Paget's disease, amongst GPs and Healthcare Professionals through adverts, booklets, and articles in journals.

Social Media had played a significant role in raising awareness of the work of the charity.

Research and educational funding
Oxford and Edinburgh Universities had been awarded funding from the Association for two new research projects.

Support services
The Association had continued to provide support through its Helpline and Networking Scheme.

Social media
The use of social media had increased globally, with the Paget's Facebook Group providing peer-to-peer support for those with Paget's disease.

Virtual Paget's Support Groups
The introduction of bi-monthly Virtual Paget's Support Groups, via Zoom, supporting people in several countries, had proved to be very popular.

Updated information
The Paget's disease booklet, 'Investigations' had been revised, and a 'Jargon Buster' had been developed for the Association's website, which was also printed in the quarterly magazine.

Support Gift Bags
Support Gift Bags had been introduced for those newly diagnosed with Paget's disease

Paget's Friends
A mailing list had been set up for non-members of the Association to keep up-to-date with current Paget's news and events.

Face-to-Face Information Events
The resumption of face-to-face meetings, following the pandemic, had seen two Information Events

take place, the first in York in July, with a second meeting in Southampton in October which incorporated the annual AGM.

Post pandemic
Local support groups had once again been able to meet in person. Board Meetings had transferred from online to hybrid. Staff had continued to work mostly from home.

6. Review of this year's activities (2022)

Activities for 2022 had included the following:

4th Annual Paget's Awareness Day
11 January 2022

Dr Herridge from Channel 4's Bone Detectives, had recorded a series of interviews on 'A Global Perspective on Paget's Disease', with experts on the condition, from around the world.

A live online question and answer session had taken place on the day, with Professor Stuart Ralston.

Social media had featured heavily once again, in helping to raise awareness of Paget's disease.

Research funding
Two new funding awards had been made:

1. Contribution of Acidosis to Chronic Pain in Paget's
2. Master of Research (MRes) Degree – Application of Artificial Intelligence to the Radiological Diagnoses of Paget's Disease.

New Focus Group
Consisting of members of the Paget's Association, the Focus Group ensures that opinions of people with Paget's disease, and their families, are kept at the forefront of all decisions.

Information Events
In June a face-to-face Information Event had been held in Oxford, with a second, held in Cardiff, in September, which also incorporated the annual AGM.

Information

The *Paget's & Pain* booklet had been updated and a new booklet – '*Jargon Buster*', had been made available for all new members.

Digital information had been provided for the clinic waiting room at the hospital in Portsmouth.

Support

A new Paget's Buddies Scheme had been set up

Support Groups had continued throughout the year, both virtually and via facebook, in addition to local support groups.

Support Gift Bags continued to be given to those newly diagnosed with Paget's disease.

The Helpline continued to provide information and support.

Raising awareness

There has been increased working with external agencies for the purpose of social media and digital marketing.

The Specialist Paget's Nurse concluded her presentation with an update on preparations to mark the 50th Anniversary of the Paget's Association. The Lowry, at Salford Quays has been chosen to hold the following three events in April 2023, to be held over two days.

- Professional international Symposium
- Patient Information Event
- A Gala Evening

Professor Ralston thanked the Specialist Paget's Nurse for the update on activities during 2021 and 2022 and concluded the meeting by thanking all those present for attending.

At this point Professor Graham Russell, Honorary President of the Paget's Association, took the opportunity to thank the Chairman, Trustees and staff for their commitment and hard work during the past twelve months.

Strengthening our online presence

To improve the experience of those who find the Paget's Association online and to strengthen our presence in the digital world, the charity is investing in a new website. Built with security, accessibility and scalability in mind, the site will also be hosted by a supplier whose data centre exclusively uses renewable energy.

We asked our Trustees and members of our Focus Group to each provide three words that would represent their ideal website. Their replies are shown in the word cloud opposite and these, together with detailed discussions, are currently taking place with our new supplier. We look forward to sharing the finished product with you soon.



Legacies have allowed the Association to reach its 50th year

We are so grateful for every gift left to the Association in a will. Certainly, without such legacies the Paget's Association would not have been able to reach its fiftieth year this year.

Thank you

Thank you to all those who have chosen to remember someone by donating to the Association in memory of a loved one on birthdays or anniversaries.

In Memoriam

We celebrate the life of

Sarah Platt

We are grateful to their families and friends for their thoughtfulness and lasting gifts

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



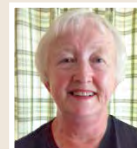
Prof Stuart Ralston

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 London, 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

Mrs 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.

Join us in 2023

Paget's **50** YEARS Association ANNIVERSARY

Paget's Information Events



Free events for patients and their families to learn and ask questions about Paget's disease

19 April 2023 / Salford, Greater Manchester / details on page 12

27 October 2023 / Stafford, Staffordshire / details on page 5

Gala Evening



An evening in celebration of the 50th Anniversary of the Paget's Association

19 April 2023

Salford, Greater Manchester

See page 15

International Paget's Symposium



A conference for researchers, clinicians, nurses, allied health professionals and students

19 to 20 April 2023

Salford, Greater Manchester

See page 17

Contact us

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Paget's
Association

www.paget.org.uk

Information, support and research