



## A Global Perspective on Paquet's Disease

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# Chair's Message

Dear Member,

Welcome to the February 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, as well as news of upcoming events and fundraising opportunities.

We have a six-page feature on Paget's Awareness Day 2022, which provided a global perspective on Paget's disease. Although the condition occurs most commonly in people from the UK, and in British people who have emigrated to other countries like Australia and New Zealand, it also occurs in other countries. To learn more about this, our friend and supporter, Dr Tori Herridge, interviewed clinicians from across the world to hear about their experience with Paget's disease. This provided a valuable insight into the origins of the condition in their countries, how it presents and how it is treated. Many of you may have already watched the videos, but if you haven't, I urge you to set aside a little time to have a look. The interviews are truly fascinating in providing a global perspective on Paget's disease. I was also very pleased to be able to interview one of our Patrons, Mr Recardo Patrick, about his experience with Paget's disease, from the time he first experienced symptoms, to his diagnosis and his highly successful treatment. I think Recardo's story will offer hope for anyone who is newly diagnosed in demonstrating how effective treatment can be, when given early enough.

Another reason for focusing on how Paget's disease affects people globally is because of the



“  
*The interviews are truly fascinating in providing a global perspective on Paget's disease*  
 ”

tremendous success of our Virtual Support Groups (held using Zoom), and our Facebook Support Group, which now has 515 members worldwide, from many countries such as Canada, USA, Italy, UK and Australia. The use of this technology has been incredibly effective in helping to support people with Paget's disease across the globe, in a way that we never could have dreamt of in previous years. Please turn to pages 14 and 15 for more details.

I am also happy to say that for the first time, we have developed goody bags (or more officially, Paget's Support Gift Bags) for people newly diagnosed with Paget's. Please turn to the article by Diana Wilkinson on pages 16 and 17 for more details.

We also have a report from the Paget's Information Day held in Southampton last October, on pages 21-23, where attendees were treated to a variety of presentations on Paget's disease, as well as research updates regarding projects based at the Southampton Paget's Association's Centre of Excellence.

Fundraising is vital to allow us to continue to support people with Paget's disease and I was delighted to hear that my friend and former Trustee, Keith Simpson, has been elected President of Sleaford Golf Club and has nominated the Paget's Association as his named charity. Please turn to page 19 if you are interested in making a donation. On the same note, I would like to thank our runners in the London Marathon who raised a magnificent £8,701.53 for the Association last year. Well done to all!

In closing, I would like to draw your attention to the various events the charity has in the pipeline. These include an Information Day in Oxford, in June 2022, the AGM and Information Day in Cardiff, in the autumn of 2022 and importantly, the meeting we are holding in Manchester in April 2023 to mark the 50th Anniversary of the Association.

I very much hope you enjoy reading the articles I have highlighted in this edition of the magazine, as well as all the other features.

Best wishes,

*Stuart Ralston*

**Chair, Paget's Association**

## To read previous issues of the Paget's News magazine:

Scan the QR code with a smartphone camera.



SCAN ME

Alternatively, type the following into your browser  
<https://paget.org.uk/members-area/newsletters>

You will need your login details for the Members' Area of the website. If you have not logged in previously, please email [membership@paget.org.uk](mailto:membership@paget.org.uk) to request a link to set your password – this will be sent during working hours only. If you do not receive an email, please check your junk mail folder. Should you experience any difficulty, please do get in touch with us, we will be happy to assist you.

# 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), the charity was founded in 1973, by the late Mrs Ann Stansfield MBE.

The Association raises awareness of the condition and provides high-quality information and support for patients, carers and health professionals. In addition, the Association funds quality research into Paget's disease.

### Chair of the Paget's Association

Professor Stuart Ralston  
 Email: [chair@paget.org.uk](mailto:chair@paget.org.uk)

### 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. This causes the affected bone to enlarge and, in many cases, to become painful. A more detailed explanation of this process can be found on our website and in our booklet 'Paget's Disease – The Facts.'

### Membership

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

### Website

There is a wealth of information regarding Paget's disease on our website, [www.paget.org.uk](http://www.paget.org.uk)

### Paget's Day

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

### Contact us

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

### Telephone

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

### Email

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

■ Membership enquiries:  
[membership@paget.org.uk](mailto:membership@paget.org.uk)

■ General enquiries:  
[sue@paget.org.uk](mailto:sue@paget.org.uk)

### Nurse Helpline

Our Nurse 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 below.

■ Email: [helpline@paget.org.uk](mailto:helpline@paget.org.uk)

■ Telephone: **0161 799 4646** and ask to speak to the nurse.

■ Mobile: **07713 568197**

### Our Address

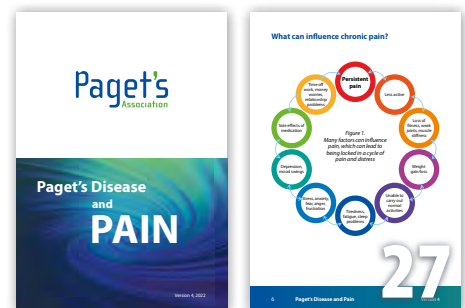
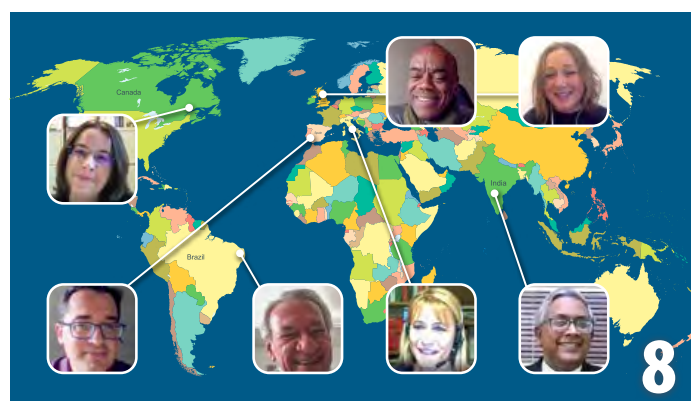
You can write to us at the following address:

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

### Connect with us on



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# Join us at an Event

The Paget's Association is planning several educational events in 2022 and 2023. Full details of each will be on our website as soon as the information is available and will also be in future editions of this magazine. You can book your place and find out more by emailing [membership@paget.org.uk](mailto:membership@paget.org.uk) or by telephoning 0161 799 4646.

## OXFORD

### Friday 24<sup>th</sup> June 2022 Paget's Information Event

A Paget's Information Event will take place in Oxford on the 24th June this year. Expert speakers will be providing information on various aspects of Paget's disease and will be available to answer your questions.

## CARDIFF

### Friday 30<sup>th</sup> September 2022 Paget's Information Day

In September, a Paget's Information Day will take place in Cardiff.

#### AGM

The Association's Annual General Meeting will take place alongside this event.

# Manchester 2023

## 19<sup>th</sup> and 20<sup>th</sup> April 2023

50 YEARS  
ANNIVERSARY

Next year, the Paget's Association will be celebrating its 50th Anniversary. We hope as many of you as possible will celebrate with us at our events.

## Save the Dates for Next Year!

### FOR PATIENTS

Educational Event  
Professionals welcome

### A CELEBRATION FOR ALL

Gala Dinner

### FOR PROFESSIONALS

International Symposium  
on Paget's Disease  
Patients welcome

# 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 to provide a glimpse into some of the fascinating work taking place around the world.



## Featured Paper

### Paget's Disease in Tunisia

This paper concerned a study of *Paget's disease* in sixty-nine patients who had been in hospital, in two rheumatology centres, in Tunisia, between 1994 to 2019.

Among the sixty-nine patients, thirty-six were female (52.2%). The age at diagnosis ranged from thirty-five to eighty-seven years.

One patient reported a family history of *Paget's disease*.

Seven patients had no symptoms and of those who had symptoms, bone pain was the most frequent.

In half of the cases, *Paget's disease* was seen in just one bone (monostotic). The most commonly involved bones were the pelvis (43.5%), femur (21.7%), spine (21.7%) and skull (20.2%).

Forty-seven patients (68.1%) received bisphosphonate treatment and two received salmon calcitonin (2.8%). When patients were followed-up (between 2 to 240 months) bone pain had improved in 43.1% of patients. The alkaline phosphate level had returned to normal in twenty-two patients (43.1%), stabilised in twenty patients (39.2%), and worsened in nine patients (17.6%).

We were particularly interested in reading about complications in this paper, which occurred in fifty-one patients (73.19%) and were present at diagnosis. Forty patients had one complication. Nine patients had two complications, and two patients had three complications.

The most common complications were hearing loss (26%) and secondary osteoarthritis (23.1%). Twelve cases of osteoarthritis were in the hip and four in the knee. Fractures occurred in 15.9% and affected the femur, spine, humerus, and tibia.

The presence of complications was significantly associated with those who had *Paget's disease* in more than one bone (polyostotic), *Paget's* in the skull, and increased levels of alkaline phosphatase (ALP) in their blood. ALP levels at the time of diagnosis were between 68 and 8380 U/L.

#### Reference

Maatallah, K., Rahmouni, S., Miladi, S., Rouached, L., Ferjeni, H., Faza, A., Laatar, A., Kaffel, D., & Hamdi, W. (2020). *Paget's Disease of Bone in Tunisia: A Study of 69 Patients*. *Indian journal of endocrinology and metabolism*, 24(5), 422–427.

# An Italian Study looks at Medicinal Cannabis in Relation to Paget's Disease of Bone

A recently published study broadly considered whether cannabinoids (medicinal cannabis) and related compounds might be useful for targeting osteoclasts, the bone cells which are over-active in Paget's disease.

The authors took an indirect approach, first looking at the molecular machinery in osteoclasts that cannabinoids exploit to exert their effects, so-called 'receptors'. It has long been realised that cannabinoid receptors have effects

on osteoclasts, and also osteoblasts, another type of bone cell relevant to Paget's. The authors found evidence that osteoclasts from Paget's patients have more of these receptors than osteoclasts from healthy controls.

Further, they reported that a drug that targets these receptors can reduce the activity of osteoclasts, suggesting that, at least theoretically, the receptors might be new therapeutic targets in the future.

The work is based on a very small number of patients, so more work would be needed to determine whether this would really be a target for Paget's disease.

## Reference

*Paoletta M, Moretti A, Liguori S, Di Paola A, Tortora C, Argenziano M, Rossi F, Iolascon G. (2021) Role of the Endocannabinoid/Endovanilloid System in the Modulation of Osteoclast Activity in Paget's Disease of Bone. International Journal of Molecular Sciences. Sep 21;22(18):10158.*

## Publications News Feed

Professionals interested in Paget's disease may find the Professional Resources section of the Paget's Association's website useful. Among the resources, you will find an automatic news feed from [pubmed.ncbi.nlm.nih.gov](https://pubmed.ncbi.nlm.nih.gov). PubMed is a database of more than 32 million references to biomedical literature, such as scientific journals, and online books. Many include links to abstracts or full-text content.

When PubMed displays a new piece of content containing the terms 'Paget' and 'bone', details will appear on the 'Recent Publications News Feed', which can be accessed through the 'Professional Resources' page of our website or by scanning the QR code with a smartphone camera.

Please note that as the publications listed on the web page are from an automatic (RSS) feed, from an external website, not all content may be directly relevant to Paget's Disease of Bone. Please apply your discretion when reading the associated articles.



# A Global Perspective on Paget's Disease



**For the fourth International Paget's Awareness Day, on 11th January 2022, we produced a series of fascinating videos to look at Paget's disease around the world.**



Dr Tori Herridge interviewed experts from Italy, Spain, Canada, Brazil and India to hear their unique perspectives on Paget's disease. Dr Herridge, an evolutionary biologist and a presenter on Channel 4's Bone Detectives series, recorded the interviews, which were released for

Paget's Awareness Day. They can now be watched on our website or on our YouTube channel.

Patron of the Paget's Association, Mr Recardo Patrick, was interviewed by Professor Ralston to explain his personal experience of Paget's disease.

The day marked the 208th anniversary of the birth of Sir James Paget, whose name was given to Paget's disease.

## Dr Tori Herridge

As well as an evolutionary biologist and a presenter, Dr Herridge is also a Daphne Jackson Research Fellow at the Natural History Museum, Editor-in-Chief at Open Quaternary and Co-Founder of TrowelBlazers, an organisation dedicated to telling the stories of pioneering women in palaeontology, geology and archaeology.



## CANADA



**Dr Laëticia Michou, is a Rheumatologist, a Researcher and Associate Professor at**

**the University Laval in Québec, Canada.**

Paget's disease is Dr Michou's main area of research and Quebec has the highest number of cases of Paget's in Canada. In their video interview, Dr Herridge discusses the very important role that genetic factors play in the Quebec population with Dr Michou, as well as the potential environmental triggers for the disease in the French-Canadian population.

Dr Michou explained how Paget's disease affects the French-Canadian population. A mutation within a particular gene (SQSTM1) is involved in 46% of familial forms of Paget's disease in the French-Canadian population. Around six million people, are descended from approximately 1,500 ancestors who came from France about 400 years ago. Soldiers from Carignan-Salières, in France, arrived first, and then priests and also people who worked with fur. Almost all were men. Their religion was such that they were encouraged to have very large families, about 15 to 18 children, per family. They all spoke French and did not marry with the British population in New France. King Louis XIV of France sent hundreds of ladies in boats to marry with the people in New France. They were known as the King's Daughters. Almost all French Canadians currently have at least one ancestor who was a King's Daughter, so it's very specific and may influence the incidence and distribution of Paget's disease in Quebec.



Using a questionnaire, Dr Michou investigated environmental factors in one hundred and six patients who had Paget's disease, including eighty-six patients with the familial form. Many different potential environmental possibilities were considered, and wood-fired heating was something that came out as statistically important. Her research found that exposure to the smoke from wood-fired heating during childhood, as part of the Nordic way of life, may have contributed

with the occurrence of Paget's disease later in life. She speculated that maybe a component of smoke, heavy metals for example, may be a determinant of Paget's disease in the future. There may then be interaction of environmental and genetic factors. Dr Michou concluded that Paget's disease was associated with wood-fired heating in childhood and/or adolescence, regardless of the form of Paget's, familial or not.

Dr Michou pointed out that when a case of Paget's disease is found in Quebec, they often find a family history and frequently find brothers and sisters with undiagnosed Paget's disease.

As in the UK, the incidence and severity of Paget's disease in Quebec has declined over recent years.

“

*Almost all French Canadians currently have at least one ancestor who was a King's Daughter*

”



Frontenac Castle in Old Quebec City, Canada

## INDIA



**Professor Thomas Paul is Head of the Department of Endocrinology at the Christian**

**Medical College, in Vellore, India, which is a university teaching hospital. He has over twenty-five years of expertise and has a great enthusiasm for teaching students.**

Professor Paul became interested in metabolic bone disease early in his career. He was particularly fascinated with Paget's disease and the remarkable improvement in symptoms, such as pain, which can follow medical treatment. He explained that the true number of people affected by Paget's disease



was not known, but blood testing for alkaline phosphatase (ALP), in general practice, has become more popular and so they are seeing

more and more cases. This indicates that it is probably under-reported. A high ALP is just one indicator that someone may have Paget's disease. The experience in Vellore shows that once clinicians are aware of Paget's disease, they can recognise it and diagnose it.

Watch Professor Paul's video to learn more about Paget's disease in India and his very positive experience of treating patients.

“  
*The true number of people affected by Paget's disease is unknown*  
 ”



*The Venkataramana Temple of Gingee or Senji in Tamil Nadu, India*

## ITALY

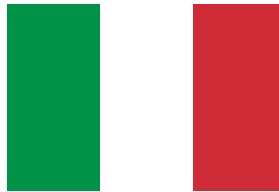


**Dr Daniela Merlotti is a clinician based at the University of Siena in Italy. She has**

**researched the genetics of different skeletal disorders, including Paget's disease.**

During the interview, Dr Merlotti discussed treatment, stressing the importance of treating patients with the right drug at the right time.

In her video interview she also informed Dr Herridge of the very high occurrence of Paget's disease in the Campania area of Italy. She discusses how both genetic and environmental factors may play a role in this. If you want to discover the role Mount Vesuvius might play in the development of Paget's disease, watch the video on our website.



“  
*Could Mount Vesuvius play a role in the development of Paget's disease?*

”



*Naples and Mount Vesuvius, Italy*

## SPAIN



**Dr Luis Corral-Gudino, is a Consultant at the University Hospital of Rio Hortega,**

**in Valladolid, Spain and an Associate Professor at Valladolid University. He has researched the epidemiology and management of Paget's disease.**

In his video interview with Dr Herridge, Dr Corral-Gudino discussed hot spots in specific areas of Spain.

Are there any special characteristics about this area, to explain the incidence of Paget's disease? What about cattle farming? To find the answers to these questions, visit our website to watch the interview.



“  
*What about cattle farming?*

”



*Plaza Mayor in Valladolid, Spain*

## BRAZIL



**Recife, in Brazil, is unusual because it has a much higher prevalence of Paget's**

**disease, even with the colonial history of the area and its multiple layers of European input. Dr Luiz Griz, Professor of Endocrinology at University of Pernambuco Medical School and an Endocrinologist in Recife, explains his experience of Paget's disease.**

“ I'm an Endocrinologist in Recife, capital of the state of Pernambuco in Brazil. I became involved with people with Paget's disease in 1993, when I spent six months in the Metabolic Bone Unit at the City Hospital in Nottingham. There I met a lot of people with Paget's disease.



When I came back to Recife, Dr Francisco Bandeira and I set up the Endocrinology and Bone Metabolism Unit at Agamenon Magalhães Hospital, where I started to treat my first patients with Paget's disease.

In South America, the incidence of Paget's disease is low. In Brazil, most cases reported are from Recife. Unlike other cities in Brazil, Recife had mixed colonisation, from European descendants, for approximately four centuries, starting with the Portuguese, followed by the Dutch and Jews. This mixture of races may have played a role in the high frequency

of Paget's disease in Recife. Over 90% of our patients with Paget's disease were of European descent. Only the state of Pernambuco has reported the numbers of people affected (prevalence) in Brazil, which is about 0.8% of the adult population. There are cases reported from Santa Catarina, a state in the south of Brazil, but not the prevalence.

When we published a paper about our patients with Paget's disease, in 2010, most had symptoms but currently, most do not have symptoms and of those who do, bone pain and deformity are the most common.

For treatment, zoledronic acid is my first choice. For those people who don't want to have an infusion, I give oral bisphosphonates.

Thank you so much to the Paget's Association, especially Professor Stuart Ralston. It was a great pleasure and privilege to take part in the interview. ”



*Marco Zero Square, Ancient Recife district, Brazil*

## MANCHESTER



**Patron of the Paget's Association, Mr Recardo Patrick, was interviewed by Chair of the Association, Professor Stuart Ralston.**

Recardo's experience is a personal one and his message full of hope and reassurance. He spoke of the devastation he felt when he was diagnosed, the treatment he had, side effects he experienced, and the very positive outcome. He was keen to point out that he has checks every year and continues to live a very active life, walking long distances, hiking, swimming, and snowboarding. He expressed his gratitude to the Paget's Association for the help and support he has been given and to the researchers who strive to learn more about the condition.



*Manchester skyline*

### How to Find the Videos

To find the videos, simply visit the home page of our website ([paget.org.uk](http://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](mailto:membership@paget.org.uk)



### Question and Answer Event

On Paget's Awareness Day, we also held a virtual Paget's Question and Answer event. Professor Ralston answered questions from the audience, which consisted of people affected by Paget's disease in several countries.

### Paget's Day Competitions

Thank you to all those who entered our Paget's Day competitions. The winners will be revealed in the May edition of this magazine.



**THANK YOU**  
TO ALL WHO TOOK PART IN  
**INTERNATIONAL PAGET'S AWARENESS DAY 2022**

# How We Can Support You

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



## Worldwide Virtual Paget's Support Groups

Following our first Virtual Paget's Support Group in October, we extended the initiative to create three small support groups. These groups now meet online (using Zoom) every two months. Each group meets on a different day and at a different time, enabling us to support people in different time zones. So far, we have supported people in the UK, the USA, Canada and Australia.

Those who attend the Virtual Paget's Support Group Meetings have the opportunity to speak with others affected by Paget's disease, receive information, and watch videos regarding different aspects of Paget's. The meetings are a chance to make new friends, and gain support from each other, as well as from our Specialist Paget's Nurse, Diana Wilkinson, who facilitates the groups.

We invite anyone affected by Paget's disease, including partners and family, to join us online. The groups are small and friendly. 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.



## Upcoming Virtual Paget's Support Group Meetings

### Group 1

Monday  
15:00 hours  
21<sup>st</sup> March  
2022

### Group 2

Tuesday  
09:00 hours  
22<sup>nd</sup> March  
2022

### Group 3

Wednesday  
18:00 hours  
23<sup>rd</sup> March  
2022

If you would like to take part in one of the Virtual Paget's Support Group Meetings, please tell us which one suits you best and a link will be sent to you via email a few days before your chosen meeting. If you have any questions, please do not hesitate to get in touch.

You can also register to join on our website, where future meeting dates will be available in due course.

## Local Support Groups

If you would like to attend one of our local group meetings, in Manchester or Sheffield, please contact Diana Wilkinson by email at [diana.wilkinson@paget.org.uk](mailto:diana.wilkinson@paget.org.uk) or by telephone on 0161 799 4646.

## Facebook Support Group

Our Facebook Support Group is a place where people from around the world are sharing their experiences and providing each other with support.

To join the Facebook group, please visit - <https://www.facebook.com/groups/pagetsdiseaseofbone/>

## Support Network

Members of the Paget's Association can join our Paget's Support Network. The Network enables members to connect by phone, letter, email or however you would like to communicate with others who have Paget's disease, or care for someone with the condition. Wherever you live, you are welcome to be part of this mutually supportive network.

To join, please contact the office to request a form by telephone on 0161 799 4646 or email at [membership@paget.org.uk](mailto:membership@paget.org.uk)

## What does the Paget's Association do?

### We provide information

We work with experts in Paget's disease to provide the latest evidence-based information for patients and families, as well as information and guidelines for health professionals

### We collaborate with hospitals and universities

We award Centre of Excellence status to hospital and university departments which demonstrate excellence in the care of people with Paget's and Paget's research

### We fund research

We encourage and fund quality research into various aspects of Paget's disease

### We hold educational events

We hold educational events for those with Paget's disease, and their families, to interact with clinicians and researchers

### We offer support

We are here to provide support for individuals and families, as well as health professionals and researchers, this includes the provision of a nurse-led Helpline service

### We raise awareness

Every day, in many ways, we raise awareness of Paget's disease

- Support us on Paget's Awareness Day, 11th of January, each year

### We connect you with others

We provide opportunities for those with Paget's disease to share experiences and connect with each other

### We care

We care about all those affected by Paget's disease and strive to make a positive difference to their lives

## Paget's Nurse Helpline

Information – Support – Guidance

Our confidential Nurse Helpline is available for anyone affected by Paget's Disease of Bone.

### Contact the Paget's Nurse Helpline

Email: [helpline@paget.org.uk](mailto:helpline@paget.org.uk)

Call: **0161 799 4646** and ask to speak to Diana

Mobile: **07713568197**

### Helpline Users Appreciate the Service

Thank you to those who have provided feedback regarding our Nurse Helpline.

Users have told us that they are grateful for the service, that concerns are appropriately addressed, and that queries are answered in a timely manner.



# Support for those Newly Diagnosed



Our new Support Gift Bags are designed to bring comfort to those who are newly diagnosed with Paget's disease. Our Specialist Paget's Nurse, Diana Wilkinson, explains.

## Paget's Support Gift Bag

"Do you remember when you were diagnosed with Paget's disease? Perhaps you had to search for information, answers, and support?"

When those who are newly diagnosed with Paget's disease, contact me via the Paget's Nurse Helpline, it is not unusual for them to be quite distressed by the diagnosis and worried about the future. Some may be waiting to see a consultant, and some may have been told they have Paget's disease, but there is no treatment (yes, I still hear that!). One of the most common questions

“*It's a little bag of kindness during a difficult time*”

I am asked is, "Will I end up in a wheelchair?" People are just so frightened of a disease they have often never heard of before.

Whilst I can provide information, answer questions, and offer support, there are many times I feel that something additional is required and if I could reach down

the telephone line to give someone in need a hug, I would!

Our new Paget's Support Gift Bag scheme is designed to provide support when it is needed most and brighten the day of those suffering emotionally and/or physically.

When someone who is newly diagnosed contacts the Association, we always provide written information, but now we have something extra to offer. Our free Paget's Support Gift Bags are full of products to help in those early days. It is a little bag of kindness during a difficult time."

*Diana*  
Specialist Paget's Nurse

## What's in the Bag?

Currently, the following items are included in each Support Gift Bag.

### Heat/Cold Pack

We include a reusable heat/cold pack. If the individual receiving the pack has pain, we hope this will bring some relief.

### Water Bottle

If their consultant recommends an infusion of zoledronic acid to treat Paget's disease, the water bottle included in the bag is intended to remind the patient to ensure they are well hydrated beforehand.



### Stress Ball

Anxiety and stress create tension. The benefit of repeatedly squeezing the stress ball we provide, is that it can release energy and alleviate tension. The repeated pattern of grip and release can also relieve arthritis and strengthen muscles in the wrists and hands.

### Information

Everyone who contacts the Association receives our booklet 'Paget's Disease – The Facts', the current issue of Paget's News magazine and information regarding the Paget's Association. If not already sent, these will be included in the package.





## Who might Receive a Support Gift Bag?

Currently, to receive a free Support Gift Bag, individuals must be recently diagnosed with Paget's

disease, live in the UK and must not have received one before. Providing sufficient supplies are available, at our discretion, we may also provide one to individuals who may not be newly diagnosed, but who are having an especially tough time and need extra support.

## Can You Help Someone Feel Supported?

If the pandemic has taught us one thing, it is that we need each other during tough times. Could you help someone who is struggling by donating a Support Gift Bag? If you would like to do this, you

could make it even more special, by adding a simple message of support, which we may include with the Bag.

## Our Promise to You

When you show you care, by donating to this scheme, we promise that for every £15 donated, we will send a Support Gift Bag to someone in need.

To donate, please select one of the payment methods below and return the completed form in the post. Alternatively, donate via our website, or contact us by email [membership@paget.org.uk](mailto:membership@paget.org.uk) or telephone 0161 799 4646.

# HELP SOMEONE BY DONATING A SUPPORT GIFT BAG TODAY

## Donate a Paget's Support Gift Bag



I would like to donate towards the Paget's Support Gift Bag scheme.

Please tick the amount you want to donate:

£15 (one bag)     £30 (two bags)

Other amount £

Please choose a payment method

- I enclose a cheque
- I wish to pay by card – if you tick this box, please provide a telephone number for us to call you
- I wish to pay by bank transfer – we will contact you with our bank account details

Alternatively, you can donate via our website.

Visit [paget.org.uk/donate](http://paget.org.uk/donate)

### Gift Aid

If you would like to Gift Aid your donation and have not already completed a Gift Aid form, you can use the one on the next page (page 18).

Name

Address

Postcode

Telephone no (if you are paying by card or BACS)

**A personal message (optional):** If you would like to include a short message of support to the individual/s who receive the bag, please write it below.

First name (optional)



## Charity Gift Aid Declaration

My details

Title	
First name	
Surname	
Full home address	
Postcode	
Signature	Date

Please notify the Paget's Association if you:

- Want to cancel this declaration
- Change your name or home address
- No longer pay sufficient tax on your income and/or capital gains

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-assessment tax return, or ask HM Revenue & Customs to adjust your tax code.

### Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

- I want to Gift Aid my donation and any donations I make in the future or have made in the past 4 years to the Paget's Association.**

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference.

*Please return this form to:*

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



# A New Role for Professor Layfield

**At the Association's Annual General Meeting in October, Chairman, Professor Stuart Ralston, announced that Professor Rob Layfield would be the new Vice-Chair of the charity. We asked him how he felt about his new role.**



"Having worked with the Association for some years now, I'm delighted to take up the position of Vice-Chair. It has been really exciting to see the Association go from strength to strength in recent years, providing support for our members and leading on supporting high-quality research. I'd encourage everybody to consider getting involved, perhaps even as a trustee. And please don't think you need to be an expert in some aspect of Paget's disease, everybody is supported and valued, and encouraged to continue their relevant experience in areas where it is most effective".

# Golf Club President's Charity

Each President of Sleaford Golf Club chooses a charity to raise funds for. The current President and former Trustee of the Paget's Association, Keith Simpson, has chosen the Association because of the support it gave him through difficult times.



## Keith's Story

Keith struggled with Paget's disease and its complications for several years. He had surgery on his femur (thigh bone) to repair a fracture and endured several months when he could not put weight on his right leg. He also has osteoarthritis and the effects of this and Paget's disease, meant some years ago he had to give up playing the sport he loves – golf.

A decade on, in 2018, following several operations, including two hip replacements, Keith finally felt able

to return to the golf course. Since then, he has not only been enjoying the sport, but he was delighted to become President of the club.

Keith said, *"Never give up, there is always help somewhere and the Paget's Association was certainly a very good source of support for me. Their advice and knowledge base are the best. I found that many of the charity's members, had similar problems, which helped me progress away from pain and to a better quality of life."*

Do take a look at Keith's fundraising page and support him if you can.

Donations can also be sent directly to the Paget's Association's office.

To find his fundraising page, either scan the QR code with a smartphone or visit <https://www.justgiving.com/Keith-Simpson12>

SCAN ME



# Southampton Information Day



Our autumn Paget's Information Day was arranged with the Paget's Association's Centre of Excellence in Southampton. Welcoming the audience to the event was Professor Cyrus Cooper OBE, who is the Director of the MRC Lifecourse Epidemiology Unit and Vice-Dean of Medicine at the University of Southampton.

## Paget's Disease – What's New?

Professor of Musculoskeletal Epidemiology and a Consultant in Rheumatology, Elaine Dennison, gave an overview of Paget's disease and a very informative update of recent studies, one of which looked at patterns of referral to secondary care, when Paget's disease is found on an x-ray. A total of 68,873 x-rays were screened and 43 cases of Paget's were found, however, 74% had not been referred to secondary care. To ensure patients received a referral when needed, Professor Dennison stressed the importance of education for radiologists and primary care physicians.

“  
*Paget's disease is still a hot research topic*  
”

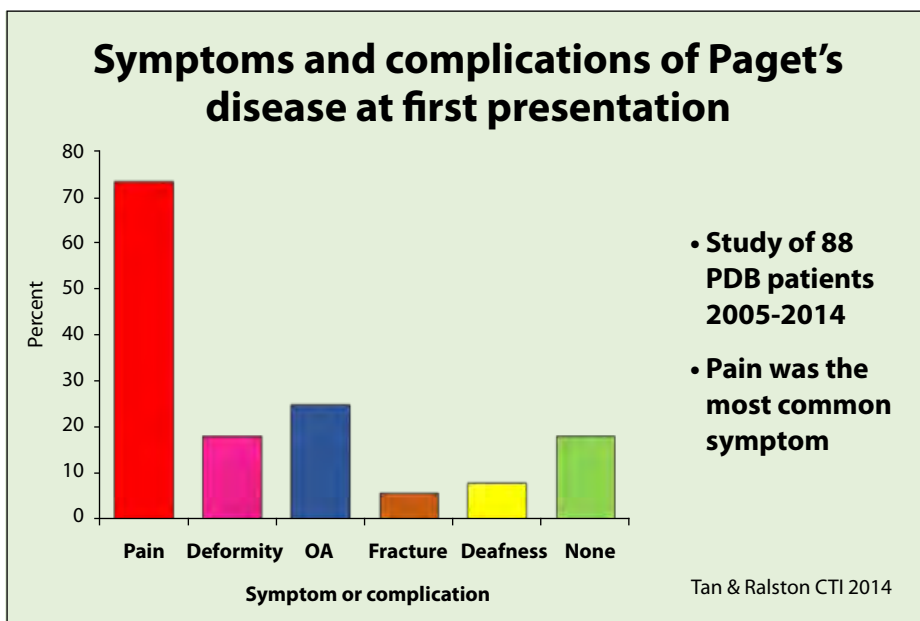
Discussing hip replacement in those with Paget's disease, Professor Dennison assured the audience that it is safe, and outcomes are generally good.

She concluded her talk by explaining that Paget's disease is still a hot research topic and future studies might include more work around joint replacement in patients with the condition.

## Symptoms, Complications and Treatment

Chairman of the Paget's Association, Professor Stuart Ralston, from Edinburgh, is also a Researcher and Consultant Rheumatologist. He explained the long-term outcomes and effects of treatment with zoledronic acid and risedronate, which are both from a group of drugs known as bisphosphonates. He questioned whether treatment should start earlier than it currently does and explained that the Zoledronate in the Prevention of Paget's (ZiPP) study, led by researchers in Edinburgh, aims to find out. We await the results, to discover if early intervention in those who are genetically at an increased risk of developing Paget's, may hold the key to preventing complications.

Professor Ralston also presented information from a study carried out between 2005 and 2014, which considered the symptoms and complications of Paget's disease that were present in 88 individuals when they were diagnosed. The chart to the right shows that pain was the most common symptom. Osteoarthritis (OA) was present in some of those assessed, as was deformity. A smaller number had



deafness or a fracture. The green bar on the chart shows that several people had no symptoms or complications at all.

Professor Ralston stressed that when pain occurs, it is important to define the cause so that the correct treatment can be given. Pain can be due to the activity of Paget's disease itself, or other causes, such as ligament strains or osteoarthritis. Pain due to increased activity of Paget's disease responds to bisphosphonate treatment, other causes, however, do not. He gave examples of acute and chronic pain, which can be seen in the image to the right. He discussed how drug treatments can help with pain. These include bisphosphonates, analgesics and nerve blockers.

There is more information regarding pain on our website ([paget.org.uk](http://paget.org.uk)) and in our newly updated booklet, 'Paget's Disease and Pain', which can be downloaded from the members' area of our website, or a hardcopy can be requested from our office.

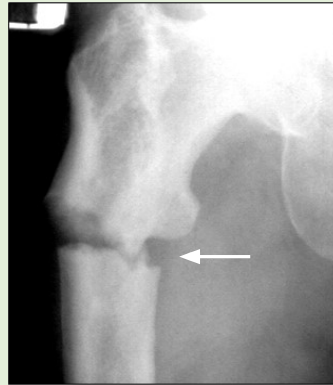
Professor Ralston also mentioned the Pain in Paget's (PiP) study, funded by the Paget's Association, which is ongoing and aims to answer many questions about pain.

## Understanding the Patient's Perspective on Paget's Disease

To understand the patients' perspective, Professor Dennison split the audience into two groups, led by two members of her team, Dr Jean Zhang and Dr Nicholas Fuggle, to discuss their experiences of Paget's disease and the care they received. It was noted that individuals taking part in the discussions were from many

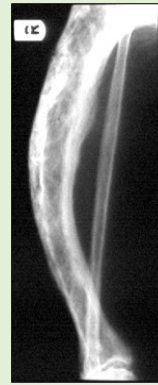
### Examples of acute and chronic pain in Paget's

Acute



Fracture through bone affected by Paget's

Chronic



Severely deformed bone as the result of Paget's



Severe OA secondary to Paget's

different areas of the UK. These discussions aimed to understand the patient's viewpoint and find ways of improving care.

Following the group discussions, Dr Zhang and Dr Fuggle brought the audience back together to highlight the main points raised within the groups. These included:

- **Pain, including pain in areas other than the bones affected by Paget's disease.**

Patients wanted to know if pain felt in areas of their body, that were unaffected by Paget's, could be related to the condition. This can sometimes be the case, for example, if the enlargement of bone affected by Paget's in the lower (lumbar) spine is causing pressure on a nerve that runs down the leg. Pain may be felt anywhere along the nerve pathway. More information regarding pain and Paget's disease can be found in the Paget's Association's newly updated booklet, which is available from our office (our contact details can be found on page 3).

- **Other conditions, which are related to Paget's disease, such as osteoarthritis (OA).**

Those who have Paget's are more prone to develop osteoarthritis in joints adjacent to affected bones. The most commonly affected sites are the hip and knee.

- **Paget's disease as an incidental finding was discussed.** This is when Paget's is found during investigations for something else.

- **Artificial intelligence (AI).**

One group wondered if AI could be used to identify Paget's on x-rays and automatically notify the patient's GP.

- **More training for junior doctors** may help improve awareness and understanding of Paget's disease.

- **The importance of ongoing support.**

When diagnosed with Paget's disease, some felt there was little discussion about it with the health professionals caring for them, nor guidance given as to what should happen next.

*continued overleaf*

■ **Communication** was a hot topic. Many felt that dialogue between patients and all health professionals involved in their care could be improved.

■ **Ongoing monitoring.** There was a variation in how often individuals were monitored and who by (consultant or GP). Some had yearly blood tests, whereas others were not monitored regularly, but could return to their GP if they felt there was a problem.

■ **Complications**, such as fracture and deafness, were discussed. The potential for complications to occur depends on which bones are affected. Thankfully, many people never develop complications. Further information regarding complications can be found in the Association's booklet, *'Paget's Disease- The Facts'*.

Through these discussions, the team in Southampton learned what most concerned patients, and discovered how care can differ throughout the UK. This knowledge enabled them to reflect and evaluate their own practice and will assist them to develop and improve the services and care they provide.

## Three Things

Specialist Paget's Nurse, Diana Wilkinson, highlighted three aspects of the Paget's Association's work that are making a positive difference to those who have Paget's disease. These are:

- ✓ Support
- ✓ Research
- ✓ Raising awareness

Diana shared examples of how the Association achieves these. She also explained that, as well as supporting people in the UK, the Association also supports many people who live overseas, as can be seen in the pie chart to the right.

## An Audit of Patient Records

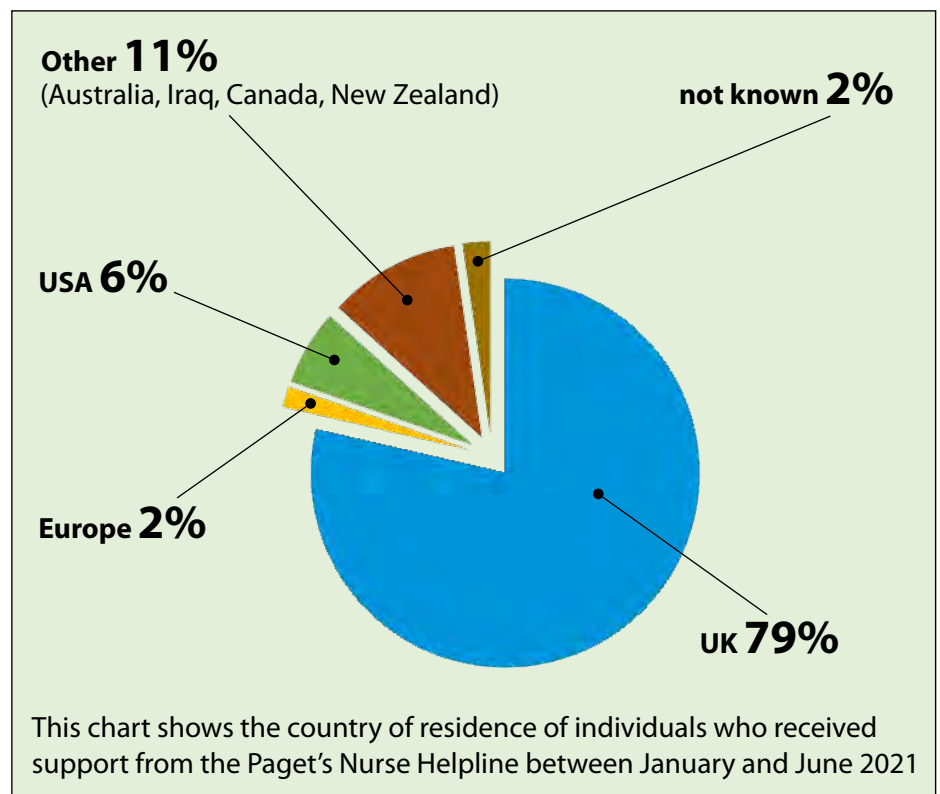
Dr Nicholas Fuggle is a Clinical Research Fellow and Specialist Registrar in Rheumatology, in Southampton. He discussed the results of their latest audit of electronic health records and clinic letters (2018-2020). Included in the audit was the site of Paget's disease in each individual, symptoms, treatment and follow-up. Dr Fuggle noted that recent consultations had not been face to face, due to COVID-19.

An earlier audit had been carried out from 2012-2018 and had been discussed at an event in 2018, when the team in Southampton received their Paget's Association Centre of Excellence award. The audit had led to the Paget's Passports, produced by the Paget's Association, for those attending clinic in Southampton and for all members of the Association.

The audits allowed for a better understanding of those with Paget's disease, who were seen at Southampton General Hospital and identification of how improvements in communicating clinical information might be made.

Presenting the results of the audit, Dr Fuggle explained that the frequency of reporting of the site of Paget's disease, the recording of a recent alkaline phosphatase (ALP) blood test and inclusion of the history of past treatment were generally good. Of the individuals that had received bisphosphonate therapy since their last appointment, not all had a pre and post ALP recorded, but the treatment plan and next follow-up appointment were generally well documented.

Dr Fuggle gave recommendations for improving clinic letters in the future, and acknowledged that encouragingly, the Paget's Passports seem to improve engagement and understanding of the condition.



## The Paget's Passport



The Paget's Passport is your record of your health in relation to Paget's disease. This one document provides useful information for you and all those involved in your care.

The Passport is useful for any appointments with health professionals, including dentists and pharmacists, and allied health care professionals such as audiologists, radiographers, occupational therapists, dietitians, and physiotherapists. The document can also help raise awareness of Paget's disease and can aid communication across many departments and specialities.

If you are a member of the Paget's Association, you should have received a Passport. New ones are available from our office if required. (contact details on page 3).

## Can Bone Shape and Vascular Changes Indicate Paget's?

We were pleased to see Dr Alisha Sharma at the meeting. She was the recipient of a Student Research Bursary from the Paget's Association in 2019, to carry out research into Paget's disease at the University of Southampton.

Her research considered if diagnosis of Paget's disease could be improved by assessing the bone's



microstructure. Could fracture sites be predicted and are there differences in male and female bone affected by Paget's disease? Whilst Dr Sharma was able to share some of her results at the Information Day, we are currently unable to provide further details here, as her study is awaiting publication.

## An Archaeological Perspective on Paget's

Palaeopathology is the study of diseases in ancient skeletons. Associate Professor of Archaeology at the University of Southampton, Sonia Zakrzewski, discussed how bone is examined and how the findings can help us learn about present-day disease. She provided information regarding archaeological examples of Paget's disease at Norton Priory, an Augustinian monastery (1115-1536),



Hulton Abbey, a Cistercian monastery (1219-1538), and St Peter's Church, Barton (950-1855).



Some of our members enjoying the Information Day

## What was Most Beneficial about the Event?

We asked those attending, what they found most beneficial about the event. Responses included:

- "Meeting others who have Paget's disease".
- "The presentations on treatment, research, and support".
- "The opportunity to have questions answered and to speak with experts".

# The 2021 Virgin London Marathon



**We would like to congratulate and thank our amazing runners who took part in the 2021 Virgin Money London Marathon, on Sunday 3rd October, for their hard work and excellent fundraising achievements. A fantastic total of £8,701.53 was raised.**

**Sarah, Deborah and Caroline were amongst the runners taking up the London Marathon challenge, in support of the Paget's Association. Here, they tell the story of their training, preparation, fundraising and the events of the big day.**

## Sarah's Unforgettable Experience



"Unlike most of the London Marathon runners this year, I didn't have the long wait due to COVID. Instead, my running took off over the pandemic, as a great way to de-stress in these challenging times. By the summer, I found myself completing longer distances and I was so chuffed

that the Paget's Association could offer me a charity place for 2021.

Over the remaining seven weeks I was so pleased to have raised over £1,200 for the charity. It has also been my 50th birthday year and I will remember the marathon experience for the rest of my life.

The support along the route was an incredible experience that I'll never forget. I hope anyone reading this will be inspired to take up running. You may also find you're on your way to a marathon!"

## Deborah and Caroline's Fun-filled Day!

"On 3rd October, we had a crazy and fun-filled day completing the 26.2 miles in the London Marathon. We knew it would be a HUGE challenge for two middle-aged, Saturday morning, chatty Park Runners, but we'd been offered the opportunity to take part by the Paget's Association.

Even though a marathon had never been on the agenda for either of us, we bought a book on training for a marathon and took up the challenge. Training consisted of 5k runs on Tuesday, Thursday and Saturday and longer runs, of increasing length,

on a Sunday. The plan was to start at 4 miles, increasing the distance by 2 miles a week to 22 miles, however, we actually only achieved 17 miles during our training.

We had made the decision at the start that we wanted to enjoy the whole process, and we trained together with the support of friends for most of our training runs. We trained in some beautiful places always chatting and stopping to take in the views and photos. We signed up for a couple of half marathons to get used to running with a large amount of people. We did the reasonably flat Milton Keynes half marathon and an extremely hilly, off-road mountain run in Cornwall, where reassuringly, Search and Rescue and Mountain Rescue were in the car park at the start!!!





Both of us struggled with the 17 mile training run and wondered how on earth we were going to do the extra 9.6 miles on the day, as the 17 miles pretty much finished us off. Two weeks after the 17 mile training run, however, we were at the start of the marathon in Greenwich, looking like proper athletes.

The weather and the atmosphere were amazing, and we set off, smiling and waving like the Queen, to the crowds of supporters lined up on the streets of London, some of whom were our own families and friends.

We not only enjoyed, but embraced the day, and chatted to anyone and everyone who spoke to us. We also sang and danced along the way to the bands along the route.

At 13 miles, we were well on target and amazed at how well we were doing, but soon after hit a wall. We actually struggled at different times but supported and encouraged each other. Luckily, our families were spread out along the route and were an amazing boost to us both, with supplies of much needed crisps and marmite sandwiches. Even when we were struggling, we were still able to acknowledge our "fans" and we danced, sang, clapped, and thanked the bands who had come to support everyone.

Around 17 miles in, the sun disappeared, and for about a mile (which seemed like 15 miles!) it was replaced with gale force winds, hail and rain. We actually ran on the pavement to take some protection from the trees. Thankfully, this "mini hurricane" was short-lived, and the sun came back out for the rest of the run.

We stopped for photos and hugs every time we saw our family and friends, but on the final stretch, when we saw them on Bird Cage Walk, we just had to say "Sorry, we can't stop

now!" We were so close and knew if we stopped, it would have been extremely hard to start again.

We finally crossed the finish line holding hands. Both of us were crying and we couldn't believe we had done it. We had actually just run 26.2 miles through London, the capital of England, past so many historical sights: The Cutty Sark, Tower Bridge, The Tower of London, Greenwich Observatory, Trafalgar Square, The Old Kent Road,

Docklands, Old Father Thames, Buckingham Palace, Spitalfields Market, The Shard, St Paul's, Big Ben and Westminster Abbey, to name but a few. Most importantly, we had raised a significant amount of money for the Paget's Association.

We are so grateful for all the support that our friends and family gave us. We are also extremely proud to have raised £5,246.60 for the Association and are grateful for all that they do to help and support people with Paget's."



Some of you may remember Mr Navnit Makaram speaking about surgery at our York Paget's information event. He also completed the London marathon for the Association and proudly displayed our banner after crossing the finish line.

## The 2022 TCS London Marathon

The 2022 TCS London Marathon will take place on Sunday 2nd October. It will be the third successive year that the London Marathon has been held in October rather than its traditional April date. It is expected to return to being a Spring event in 2023.

To apply for a Marathon place, please visit [paget.org.uk](https://www.paget.org.uk)



# Could you be a Trustee?



**If you have an interest in Paget's disease and would be interested in becoming a Trustee for the Paget's Association, we want to hear from you.**

**Those interested in trusteeship will be put forward for election at the Annual General Meeting, in the Autumn.**

## What does Trusteeship involve?

Trustees are expected to attend meetings of the Board of Trustees, which are held approximately three or four times a year. Meetings are often held in Manchester but can be held in the area where our Annual General Meeting, or an Information Day, is taking place. Between meetings, the Chairman may ask your opinion on issues concerning the charity and you may be given small tasks to carry out in line with your experience.

## Do Trustees require any special qualifications?

Anyone may apply. You do not need to have any special qualifications and the single most important thing is a desire to help the charity to support those affected by Paget's disease.

## Are expenses paid?

It is a voluntary role, so there is no payment. Expenses, however, are reimbursed and knowing that you are helping those with Paget's disease is very rewarding.

## How do I apply to become a Trustee?

If you would like to be considered for a place on the Board of Trustees, please write to us using the email address below, stating why you feel that you could fulfil this role.

## Apply now

You can apply now or any time before the closing date of the 5th May 2022. Alternatively, just start a conversation with us.

**Email:** [applications@paget.org.uk](mailto:applications@paget.org.uk)

**Closing date:** 17:00 hours, 5th May 2022

# UPDATED Pain Booklet Available



Not everyone who has Paget's disease experiences pain. It is, however, the commonest presenting symptom. Our newly updated booklet, 'Paget's Disease and Pain', will help you understand pain in relation to the condition and how it might be dealt with. No two people experience or deal with pain in the same way, which can make it difficult to treat. It is important to define the cause of pain so that the correct treatment can be given. Understanding your pain is the first step to achieving pain control.

This free booklet provides information that can help you to discuss pain with your medical team and details drug free methods to help with pain management.

You can download a PDF version from the members' section of our website, request a digital or hard copy by emailing [membership@paget.org.uk](mailto:membership@paget.org.uk) or telephone the office on 0161 799 4646 to request a booklet by post.

## Connect with us on Social Media

Join the conversation about Paget's disease online by following the Association's social media accounts, where we keep you up to date with the latest news from the Association, answer any questions you might have and where you can connect with others with Paget's disease for support and sharing experiences. Connect with us and say hello, we would love to hear from you!

 **Facebook Page**  
Like our Facebook page to see updates and news from us at  
<https://www.facebook.com/PagetsAssociation>

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

 **Twitter**  
Find us on Twitter  
<https://twitter.com/PagetsDisease>



 **Instagram**  
Follow our Instagram account  
<https://www.instagram.com/pagetsassociation/>

 **LinkedIn**  
Connect with us on LinkedIn  
<https://www.linkedin.com/company/the-paget-s-association/>

 **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>



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

Held at the DoubleTree by Hilton Hotel, Chilworth, Southampton, on Friday 8th October 2021

**Attendees:** 2 Trustees, 11 members, 3 employees

**Apologies:** 1 Patron, 10 Trustees, 1 member

Professor Ralston welcomed everyone to the Southampton meeting. He highlighted that twenty-five proxy 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 16th October 2020 by Zoom

The minutes of the 2020 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.

**For:** 25 proxies

**Against:** 0

**Abstentions:** 0

## 2. Presentation of the Report and Accounts from the Last Financial Year 2020

Professor Ralston presented the Association's Report and Accounts for the previous financial year. He reported that income for 2020 had been £88,273, down from £543,184 in 2019. He highlighted that income from legacies was considerably lower in 2020 than 2019 and displayed a graph showing the fluctuation of legacy income over the last fourteen years, pointing out that there were substantial

variations in legacy income from year to year. He reported that at the end of the financial year, the fund balance was £1,022,600, down £301,403 on the previous year, which was largely due to the stock market downturn as the result of the COVID-19 pandemic. He also mentioned that if anyone wished to receive a copy of the full accounts, they should contact the Office Manager.

Professor Ralston proposed that the accounts and annual financial report be accepted.

**For:** 25 proxies

**Against:** 0

**Abstentions:** 0

## 3. Appointment of the Association's Independent Financial Examiner

Professor Ralston reported that the Association had been very happy with the appointment of Beever and Struthers as the Association's financial examiners and proposed their re-appointment.

**For:** 25 proxies

**Against:** 0

**Abstentions:** 0

## 4. Revisions to the Association's Constitution

Professor Ralston outlined that the current objectives of the Paget's Association's Constitution be amended to the proposed objectives as given:

### Current Objectives

- To encourage, promote and assist research into the diagnosis, treatment, education and prevention of Paget's disease and related disorders.
- The relief of persons suffering from Paget's disease, and related disorders and to engage in individual, or joint activities, on their behalf.

### Proposed Objectives

To preserve and protect the health of persons suffering from Paget's Disease of Bone and their families by:

- a) providing information and support
- b) raising awareness about Paget's Disease of Bone, both within the medical and allied health professions, and amongst the general public
- c) by supporting and funding research projects in the field of Paget's Disease of Bone or its treatment

Professor Ralston proposed that the amendment be accepted.

**For:** 24 proxies

**Against:** 0

**Abstentions:** 1

## 5. Review of the Last Year's Activities (2020)

Professor Ralston invited Specialist Paget's Nurse, Diana Wilkinson, to give an update on activities undertaken by the Association during 2020, in which she highlighted the challenges faced by the charity, owing to the pandemic, which saw:

- Face to face events cancelled or postponed

- Paget's research delayed

- Home working implemented

- Fundraising events cancelled

As a result of the above, the Association increased support by:

- increasing contacts from the Nurse Helpline

- providing information on the Association's website and in the members' magazine, which included a question and answer section relating to COVID-19

- starting of a Facebook Support Group – of which membership had grown from 50 in June 2020 to 450 by September 2021

- providing all members with a complimentary face mask

Two new research projects had been funded and two new booklets produced, one to help promote research and educational funding and a second to provide information for healthcare professionals.

The Association had funded open access to journal articles on Paget's disease aimed at GPs.

Trustee Board Meetings had been held virtually, as was the 2020 Paget's Association AGM.

The 2nd Paget's Awareness Day, which highlighted Paget's Disease in Medieval skeletons at Norton Priory, had taken place on 11th January 2020. Research related to this had been partly funded by the Association. Display packs had been distributed to GP surgeries and community venues as part of the Awareness Day campaign.

Paget's research undertaken at Norton Priory was featured on Channel 4's Bone Detectives series.

One runner took part in the Virtual London Marathon 2020 on behalf of the Paget's Association.

## 6. Report of Activities During 2021

With COVID-19 restrictions being lifted during 2021, planned events were able to take place with additional COVID-19 measures implemented. These included the Information Day, held in York in July, and the Information Day and AGM in Southampton in October.

Although home working was still being undertaken, Board Meetings had become hybrid events.

A new Virtual Support Group had been set up and the Investigations Booklet revised.

Two new research projects were funded, and crisis funding, supporting current research grant holders affected by the pandemic, was offered.

The 3rd Paget's Awareness Day took place on 11th January 2021, as a virtual event with pre-recorded interviews with experts from around the world, highlighting the development of bisphosphonates and their role in the treatment of Paget's disease.

Professor Ralston was joined on Zoom, by members from all over the world, when he held a live virtual question and answer session.

A GP campaign was launched, which included booklets being sent to healthcare professionals. An advert was placed on a GP eLearning platform and Paget's articles were published in journals aimed at GPs.

Enquiries were received following the publishing of articles in the Northern Echo and People's Friend magazine.

Professor Ralston thanked the Specialist Paget's Nurse for her presentation.

## 7. Election of Trustees and Officers

Professor Ralston informed members that the terms of office, for both Dr Stephen Tuck and

Mr Michael Missett, had come to an end, following ten years of trusteeship, and Dr Anna Daroszevska was retiring from the Board, owing to a re-location to mainland Europe. Mr Mike Patnick's three-year term of office had been completed, but he was seeking re-election to the Board. There had been an additional two nominations to the Board, from Dr Mark Wilkinson and Dr Catherine Nairn.

Professor Ralston proposed the re-appointment of Mr Mike Patnick to the Board.

**For:** 25 proxies

**Against:** 0

**Abstentions:** 0

Professor Ralston proposed the appointment of Dr Mark Wilkinson to the Board.

**For:** 24 proxies

**Against:** 0

**Abstentions:** 1

Professor Ralston proposed the appointment of Dr Catherine Nairn to the Board.

**For:** 24 proxies

**Against:** 0

**Abstentions:** 1

Professor Ralston welcomed the new Trustees to the Board.

## 8. Any Other Business

Professor Ralston thanked Dr Stephen Tuck, Mr Michael Missett and Dr Anna Daroszevska for their service to the Association. Professor Ralston informed members that Professor Rob Layfield had accepted his invitation to replace Dr Tuck as Vice-Chair of the Association.

No questions were forthcoming from members.

Professor Ralston concluded the meeting by thanking all those present for attending.

# Your Amazing Gifts



*We want to say a massive thank you to all those who have decided to leave a gift to the Paget's Association in their will.*

*Without legacies, it simply would not be possible for the Association to continue to provide as much information, support and research funding as we do.*

*Making a will is one of the most important things you can do to ensure your wishes are carried out and there can be tax advantages as well. Large or small, your contribution will always make a difference.*

## In Memoriam

*Coralie Ross*

*Margaret Johnson*

*Frederick Yallop*

*Brian Ross*

## Six Reasons to Make a Will

1. *To make sure that your estate (your money and possessions) is managed and distributed exactly how you want it to be.*
2. *Reduce the chances of dispute.*
3. *Protect your partner if you are unmarried.*
4. *Decide who would look after your children.*
5. *Protect your pet's future.*
6. *Leave a legacy – a gift to a charity that means something to you.*

## Thank You

*We are indebted to all those who have chosen to remember their loved ones, by donating to the Paget's Association – you are all amazing!*

# 200 Club Winners ★★ ★

### October 2021

**1st Prize £100**   **2nd Prize £50**  
**Ticket No. 172**   **Ticket No. 67**  
 Peter Bardsley   Valerie Smith  
 Birmingham   Belgium

### November 2021

**1st Prize £100**   **2nd Prize £50**  
**Ticket No. 33**   **Ticket No. 52**  
 Harold Williams,   Jim Robinson,  
 Plymouth   Leicestershire

### December 2021

**1st Prize £200**   **2nd Prize £100**  
**Ticket No. 5**   **Ticket No. 195**  
 Shelagh Fletcher,   Norma Reid,  
 Merseyside   Glasgow



# 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.

# GET INVOLVED



**SHARE YOUR EXPERIENCE**



**DONATE TO THE PAGET'S ASSOCIATION**



**FUNDRAISE TO HELP OTHERS**



**CONNECT WITH US**

## DATES FOR YOUR DIARY

INFORMATION EVENTS	WHERE	DATE	DETAILS
<b>Paget's Information Event</b>	Oxford	24th June 2022	Page 5
<b>Paget's Information Day</b>	Cardiff	To be decided	Page 5
<b>Annual General Meeting</b>	Cardiff	To be decided	Page 5
<b>Virtual Paget's Support Groups</b>			
<b>Group 1</b>	Online – using Zoom	21st March 2022, 15:00 hrs	Page 14
<b>Group 2</b>	Online – using Zoom	22nd March 2022, 09:00 hrs	Page 14
<b>Group 3</b>	Online – using Zoom	23rd March 2022, 18:00 hrs	Page 14
<b>Local Support Groups</b>			
<b>Manchester Support Group Meeting</b>	Swinton, Salford	Contact us for details	Page 14
<b>Sheffield Support Group Meeting</b>	Handsworth, Sheffield	Contact us for details	Page 14
<b>Marathon</b>			
<b>TCS London Marathon</b>	London	2nd October 2022	Page 25

## 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**