

An Amazing Venue for the Association's 50th Anniversary Events

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Chair's Message

Dear Member,

Welcome to the August 2022 edition of *Paget's News*. As always, the magazine is packed with useful information about Paget's disease and what we are doing to raise awareness of the condition, promote research, and ensure that people who have the disease are provided with accurate information and support.

On page 10 you can read about the very successful Paget's Information Day that we held in Oxford on 24th July. Oxford has a special place in the history of treating Paget's disease, in that it was here that the use of bisphosphonate drugs was pioneered by Dr Roger Smith, a former Chairman of the Association, and Professor Graham Russell, our Honorary President. In view of that, it was my great pleasure to have a chat with Roger during one of the coffee breaks. The audience was treated to a series of presentations on the causes of Paget's disease, and the medical and surgical approaches to treatment. Professor Rob Layfield gave a highly informative presentation on the impact that UK-based clinicians and scientists made whilst researching into Paget's disease, and we were also given an update on the cutting-edge research that Professor Phillipa Hulley and her colleagues are carrying out in Paget's disease, using a novel cell culture-based model system. We also had a most informative round-table session where patients with Paget's shared their personal stories. A common theme that emerged was delayed diagnosis, which strikes a chord with Michael Share's account of



his experience with the disease on page 12. The event closed with our Specialist Nurse, Diana Wilkinson's, presentation on what we are planning for the Association's 50th Anniversary in 2023.

On that topic, we have an extensive feature on the 50th Anniversary Celebrations between pages 13 and 18, including some of the fundraising efforts that are being held to mark this important milestone in the history of the charity. Diana Wilkinson starts this feature off with part two of an account of the history of the Association on page 13 (part 1 having been published in the April 2022 edition of the magazine). This is followed on pages 14-16 with information about Salford Quays and The Lowry, where the 50th Anniversary Celebrations will take place. We then highlight some of the fundraising efforts that are being undertaken, from Janet and Graham Dixon's car boot sale to my "Pedal for Paget's" in the Caledonian Etape cycle run, Amanda Sherwood's ascent of Paget's Peak in Canada this coming September and Diana Wilkinson's wing walk! So far, we have raised a magnificent £6,946, with more to come as we aim to reach our £50,000 target. If you think you would like to help,

please turn to page 17 for more information and details of how to request a fundraising pack.

The Association puts a lot of value into supporting research into Paget's disease and it was delightful to see an update on the Norton Priory research project featured on pages 10 and 11. The new project, seeks to further investigate the genetic makeup of individuals affected by this form of Paget's disease in medieval times and to investigate whether environmental toxins, such as lead, might have played a role in causation of the disease. I was also interested to read the research paper on Paget's disease in China, featured in the article by Professor Rob Layfield and Diana Wilkinson. Although Paget's is uncommon in China, the symptoms experienced by affected patients were very similar to those in the UK and interestingly, about one-third of patients had been misdiagnosed as having other conditions.

In closing, I would like to highlight the upcoming Paget's Information Day and Annual General Meeting (AGM) of the Association to be hosted in Cardiff, this September, by former Trustee, Dr Mike Stone and his colleague Dr Jane Turton. Details are provided on pages 6 and 7. The papers for the AGM are enclosed with your copy of the magazine and I urge you to have a look at them and make your membership count by voting on the resolutions and Trustee appointments and re-appointments.

Keep safe and stay well.

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 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

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

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

■ General enquiries:
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

■ 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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Journal News



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, summarise a Chinese paper from the journal, *Frontiers in Endocrinology*.

Paget's Disease in China

Paget's disease is rare in China, and most clinicians are not familiar with it. To gain better insight into the clinical characteristics of the disease, and reduce the rate of misdiagnosis among Chinese patients, researchers analysed fifty Chinese individuals (thirty-one male and nineteen female) with the condition.

The patients were aged from 29-85 years and the mean age of diagnosis of Paget's disease was 48 years. In these patients, the most frequently involved bones were the pelvis (52%), femur (42%), tibia (28%), skull (28%) and spine (18%). Thirty-two (64%) of the patients had more than one bone affected (polyostotic Paget's disease).

The majority (94%) had symptoms, of which bone pain (86%) was the most common. Other symptoms included an increase in skin temperature (26%), and bone deformity (22%). The level of alkaline phosphatase in their blood tests was significantly increased and the most common complications in this study were osteoarthritis (40%) and fracture (14%). Ten fractures occurred in seven of the fifty patients (54%), and all the fractures were in bones affected by Paget's disease.

Notably, in this group of patients, 36% had initially been misdiagnosed with other conditions, such as bone cancer, fibrous dysplasia, benign tumour, and rheumatism. In one patient, the incorrect diagnosis had led to unnecessary treatment.

“
36% had initially
been misdiagnosed
with other conditions
”

Forty-one patients were treated with an intravenous bisphosphonate (zoledronic acid). Two patients, who had mild symptoms, received an oral bisphosphonate (alendronate) and two refused any treatment. The remaining three cases were treated with pamidronate, calcitonin and denosumab, respectively.

Follow-up results showed that patients responded well to bisphosphonates and, of those who had zoledronic acid, most only required it once in their lifetime to avoid clinical relapse (defined by the recurrence of bone pain).

Sporadic Paget's disease (no known history of other family members with the condition), is more common in China than familial Paget's

disease (more than one family member affected), whereas Western countries have a higher proportion of familial Paget's disease. In this research, only 4% of the patients had a mutation in the SQSTM1 gene, which is more common in the UK. The authors acknowledged that the prevalence of the disease is likely to be underestimated in China due to the lack of understanding of the condition by clinicians.

Overall, the researchers concluded that, in contrast to Western patients, Chinese patients develop Paget's disease earlier, experience more severe symptoms with bone pain being very common, and have a higher proportion of sporadic Paget's disease.

Reference

Tao X, Liu L, Yang X, Wei Z, Chen Z, Zhang G, Zhang Z, Yue H. (2022). *Clinical Characteristics and Pathogenic Gene Identification in Chinese Patients with Paget's Disease of Bone*. *Frontiers in Endocrinology*, vol. 13, 850462, 9 March, doi:10.3389/fendo.2022.850462.

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.



Join us in Cardiff for a Paget's Information Event

Why not join us in Cardiff, on Friday 30th September, to learn about Paget's disease, chat with other members, and ask the experts questions?

This Paget's Information Day will cover many aspects of Paget's disease so, if you are affected by the condition, or have a family member who is affected, then this event is for you. Researchers and Health Professionals are also very welcome to attend.

Local experts, from the Paget's Association's Centre of Excellence in Cardiff and Llandulas, will join the Chair of the Paget's Association, Professor Stuart Ralston, Trustees, members, and staff.

Visit Cardiff

If you are coming to our Paget's Information Day, why not take some time to explore Cardiff? The venue is the Holiday Inn on Castle Street, which is approximately a ten-minute walk from Cardiff Central Station. Sports fans are a five-minute walk from the Principality Stadium, the home of Welsh rugby, and fifteen minutes from the Swalec Stadium. The shops of central Cardiff are right outside the hotel door and Cardiff Castle is just a two-minute walk away.

Wales has more castles per square mile than any other country in Europe and there are fifteen castles within around an hour's drive of Cardiff. The most famous is Cardiff Castle, which has stood for nearly 2,000 years at the heart of the city.



Paget's Information Day

Friday 30th September 2022

10:00 hrs – 15:30 hrs



Behind Cardiff Castle, and a short walk from the city's high street is Bute Park. This is a beautiful green space in heart of the city. Bute Park's arboretum contains over 3,000 individually catalogued trees, some of which are rare and ornamental. There is also a visitor centre, three cafes, and a wealth of horticulture and wildlife.

Another popular attraction is the National Museum of Cardiff, which has a range of art and science displays.



The Venue

The event will take place at the Holiday Inn Cardiff City, Castle Street, Cardiff, CF10 1XD.

Booking Essential

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

Detailed information will be sent to those who have booked approximately two weeks prior to the event.

Annual General Meeting

The Association's Annual General Meeting will also take place on the 30th September and will take up approximately 45 minutes of the day. If you would like to attend, you will have the opportunity to discover what has been happening at the Association in the last twelve months.

Please see the separate information enclosed and don't forget to use your vote!

Attendance is Free

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

Questions?

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



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

**BOOKING
ESSENTIAL**

Booking Form for the Paget's Information Day in CARDIFF

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

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

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

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

Number in party attending

Do you have any special dietary requirements?

Do you have any other special requirements?

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

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

Please return this form by post to:

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

or email the above information to: membership@paget.org.uk

Learning and Sharing in Oxford

Thank you to all those who attended our Paget's Information Day at the Jurys Inn, Oxford. It was an excellent opportunity, not only to learn more about Paget's disease, but also ask the experts questions.



From the feedback given, we know that those attending really appreciated meeting others with Paget's disease and discovering how the condition affected them.

We hope to see many of you at a similar event in Cardiff, in September (for details see page 6).



Chair, Prof Stuart Ralston (left) with Dr Roger Smith (right), who chaired the Paget's Association in the 1990s. Together with Prof Graham Russell, Dr Smith carried out the first human research trials of a bisphosphonate to treat Paget's disease.



Staff from the Paget's Association. From left to right: Diana Wilkinson, Jen Woodworth, Sue Clegg.



Trustee, Alan Janes, spoke of his personal experience of Paget's disease.



Those in attendance took the opportunity to speak with the Association's Chair, and Specialist Paget's Nurse, to ask questions and learn from each other's experiences.



Members chat with staff from the Association.



Prof Rob Layfield, Chair of the Association's Research Subcommittee, explained that whilst the charity may be small, it has a big impact on Paget's research, and that, in his opinion, capacity building, including encouraging new researchers into the Paget's field and supporting them, is critical.



Prof Philippa Hulley explained how research being carried out in Oxford, funded by the Paget's Association, is developing a fully human 3D bone model of Paget's disease.

The research will provide a uniquely human drug discovery tool for testing novel therapeutics and achieving personalised medicine with customisable use of individual patient's cells or mutations.



Prof Stuart Ralston explained how Paget's disease becomes more common as people get older. He also spoke about genetics in Paget's, potential environmental triggers, and treatment.



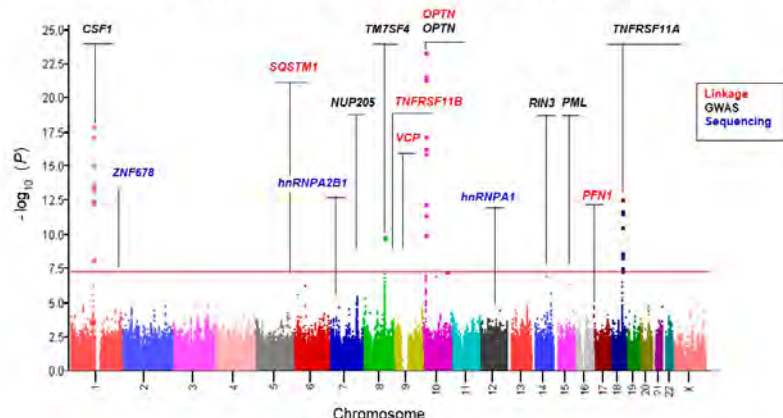
He concluded by acknowledging that there were questions that remained unanswered:

- Why are some bones targeted whereas others are not?
- What are the environmental triggers?
- How do these triggers interact with genetic factors?
- Why do genes that predispose to Paget's in some people cause muscle and nerve problems in other people?



Consultant Orthopaedic Surgeon, Mr Antony Palmer, discussed hip replacement, including how robots are sometimes used to assist the operation.

Genes that predispose to Paget's disease of bone and related syndromes



Diana Wilkinson closed the event by looking back over the last 49 years and looking forward to the 50th Anniversary Celebrations next year.

An Update of Paget's Research at Norton Priory, Cheshire

A research project, supported by a grant from the Paget's Association, is focused on obtaining ancient DNA, protein and isotopic analysis (paleodiet analyses) from skeletons from the Medieval Norton Priory Human Skeletal Collection. Fourteen of these individuals that exhibit skeletal changes indicative of Paget's disease, and one individual without the disease, have been selected for further detailed study. In the May 2020 edition of Paget's News, we informed readers of this research, however, it was unfortunately delayed due to the Covid-19 pandemic. We are pleased to announce that it is back on track and making excellent progress.

The research team includes: Professor Silvia Gonzalez, from Liverpool John Moores University, Dr Carla Burrell and Dr Sam Rennie, both at Bournemouth University, Dr Pontus Skogland, from the Crick Institute, London, and Lynn Smith, Senior Keeper at the Norton Museum and Gardens. Professor Gonzalez provides an update below.

Norton Priory in the northwest of England is Europe's largest monastic excavation with 130 human skeletons dating between the 12th-15th century. These were excavated during the 1970s-1980s. The skeletons are believed to be Augustinian Canons and important benefactors to the Priory.

Since 2015, research exploring Paget's disease at Norton Priory has provided new insights into its ancient form. Originally, only six skeletons were thought to present with skeletal lesions indicative of Paget's (approximately 5%). However, after a multidisciplinary research initiative, which took place over the last six years, many more individuals with the condition have since been identified (46 out of 130 skeletons; approximately 35%). This is a remarkable increase and a very high rate of prevalence recorded in an archaeological collection, indeed the highest in the world.

The research at Norton Priory has, so far, been a fascinating journey,

providing new information related to Paget's in the past. Researchers reported results in 2019 (Shaw et al.) on eighteen individuals (around 14%) from Norton Priory, who presented with skeletal changes of Paget's disease, with up to 75% of their skeleton affected. The results



A view of the Medieval Norton Priory grounds, showing some stone coffin burials



From left to right: Lynn Smith, Prof Silvia Gonzalez, Dr Sam Rennie and Dr Carla Burrell

also show that they were born and lived locally in the northwest of England and had a diet consisting mostly of fish. It has been noted, however, that how the disease presented in these individuals is somewhat different in comparison to contemporary cases. In 2019, researchers applied new proteomic (ancient proteins) research methods to these skeletons and identified an ancient sequence of p62 Paget's disease protein associated with the presence of the condition in modern individuals. These results support the notion that individuals with Paget's disease at Norton Priory had a precursory form, that differs from contemporary Paget's, and it is worthy of further exploration, using archaeological samples to understand how it has changed through time.

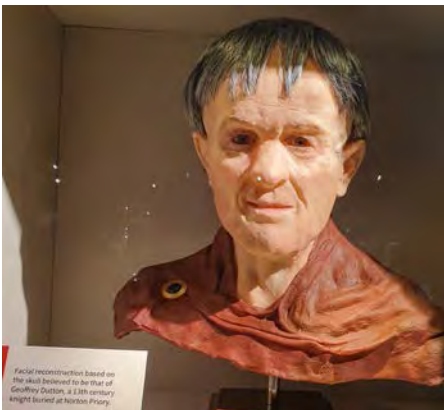
Due to the success of the previous multidisciplinary research study in 2019, this new investigation extends the molecular analysis to study an additional fourteen individuals

with Paget's disease from Norton, with a healthy individual as a reference sample. The idea is to characterise in detail these fifteen individuals, to obtain detailed information about their Medieval paleodiet, their geographical origin, together with the study of ancient proteins preserved in their teeth (proteomics), and to establish potential genetic familial links between the individuals through obtaining their full genome DNA information.

One of the individuals selected to be studied in this project is a skeleton currently on display at the Norton Museum. It is of a male, aged over 46 years of age, with evidence of the effects of Paget's disease. The skeleton is believed to be that of Geoffrey Dutton, who was born around 1200. He became a knight, and from 1218-1220 went to a Crusade. On his death in 1248 he was buried in a prominent place within the Church at Norton.

The objectives for the 2022 project

1. To obtain the age of the new skeletons through radiocarbon dating of their teeth.
2. To reconstruct their Medieval paleodiet using carbon and nitrogen isotope studies.



A facial reconstruction of Geoffrey Dutton, who was buried in Norton Priory Church



A skeleton and stone lid on display at Norton Priory Museum. There is evidence that this is Geoffrey Dutton, a 13th Century knight, who went to a Crusade and died in 1248. The skeleton has strong evidence of Paget's disease and it is part of the skeletons studied in this research

3. To identify the geographical point of origin of these individuals using strontium and oxygen stable isotopes studies.
4. To explore whether lead isotopes in the environment may have contributed to the high rate of observed bone pathology.
5. To obtain full genome DNA data which will identify whether any of the individuals are related.
6. To obtain ancient protein strands which will be used to identify the presence of the ancient p62 Paget's disease protein, as reported in the comprehensive molecular research study, in 2019 (see the reference opposite).

Building on previous research, the results are expected to be ready by the end of this year and they will continue to extend our knowledge and interpretation of this ancient form of Paget's disease at Norton Priory. The data will contribute to the overall chronology, diet and geographic point of origin of the burials from Norton Priory, and also in our understanding of the past prevalence and causes of Paget's

disease. This detailed insight will help us to understand why so many of these individuals were affected by the condition. It will also allow exploration of the changes of the disease through time, providing new, valuable information that will contribute to the understanding of modern Paget's disease.

The key to understanding the history of Paget's disease through time and the bridge between archaeological and modern clinical research has been made possible by the generous economic support of the Paget's Association.

Reference for the 2019 Research

Shaw, B., Burrell, C.L., Green, D., Navarro-Martinez, A., Scott, D., Daroszewska, A., van 't Hof, R., Smith, L., Hargrave, F., Mistry, S., Bottrill, A., Kessler, B., Fisher, R., Singh, A., Dalmy, T., Fraser, W.D., Henneberger, K., King, T., Gonzalez, S., Layfield, R. (2019).

Molecular insights into an ancient form of Paget's Disease of Bone. Proceedings of the National Academy of Sciences, 116, 10463-10472.

Michael's Experience

Michael Share recently became a member of the Paget's Association and wanted to share his experience of Paget's disease. Michael works as a part-time security officer in London and is also studying full-time for a Health Sciences with Foundation Degree. His spare time is taken up with activities including exercising, walking, reading and computers. Here is Michael's experience in his own words.

My Story

"I felt that it took a long time for me to be diagnosed with Paget's disease. I am 65 now, and although it was diagnosed only recently, looking back I think I may have had it for a number of years.

“

The after-effects were similar to having flu

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I experienced pain in several areas, and Paget's disease was suspected last year when I had an abnormal blood test and was referred to a specialist. Scans and x-rays revealed that I have Paget's in my pelvis, left shoulder, and right arm.

I was prescribed an infusion of zoledronic acid, which I had in March. The after-effects were similar to having flu, such as shivering and shaking, however, I'm so glad that I had the infusion, as the pain has improved. Should I require further treatment, I won't hesitate to agree to it.

“

I'm so glad that I had the infusion, as the pain has improved

”

I have to say that there isn't anything I have had to change or give up due to Paget's disease, and to anyone who suspects they may have Paget's, I would advise you to go to your GP and get it assessed straight away."

Michael

Paget's Disease Around the World

Watch our videos to learn about Paget's disease in other countries as Dr Tori Herridge interviews experts from Italy, Spain, Canada, Brazil and India.

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



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

Countdown to the Association's 50th Anniversary **Part 2**

As we look forward to celebrating the Paget's Association's 50th Anniversary, in April 2023, our Specialist Paget's Nurse, Diana Wilkinson, continues to reflect on the Association's history.

In the last edition, she looked at how the charity was founded in 1973 by Ann Stansfield MBE. In this edition, she begins with Ann's visit to London to receive her MBE.

An MBE for the Association's Founder

A Member of the Order of the British Empire (MBE) medal is awarded to those who positively and significantly impact their community. In 1983, ten years after founding the Paget's Association, Ann Stansfield was awarded the MBE, in recognition of her dedication and tremendous achievements in supporting those affected by Paget's disease.

It was a wonderful occasion when Ann, accompanied by her husband, Alf, went to London to receive her award. Alf, affected by Paget's disease himself, must have been very proud to know that Ann's endeavours to help him and others had led to this honour.

When, just a year later, Alf passed away, aged 77, he had suffered for at least 27 years with Paget's disease. In the Association's newsletter, Ann wrote, "It was his wish for 'No flowers but if desired, donations to our cause'. I hope to continue this work in his memory." Ann was certainly unstinting in her dedication to the cause and so her fight to help those with Paget's disease continued.

Ann's efforts drew the attention of several consultants who developed



Ann and Alf Stansfield

a special interest in Paget's disease. In the late 1980s, Professor David Anderson, a consultant at Hope Hospital in Salford (now Salford Royal), asked his secretary to assist Ann with the various tasks involved in administering the charity. The Association's office then moved from Ann's front room to the hospital.

The charity continued to develop activities, including conferences, regular newsletters, and, in 1990, the first organised local support group, began in Manchester.

Ann's Final Letter

During the summer of 1991, Ann wrote her final letter to members which read, "I would ask you all to continue giving your support whenever and wherever possible so that together we can overcome the problems facing sufferers and ultimately reach the goal towards

50 YEARS
ANNIVERSARY

which we are all working". Since then, there has been considerable improvement in the treatment of Paget's disease, however, Ann's message still applies, as the Association still needs the support of its members to be able to continue its work.

In 1995, at the age of 85, Ann passed away. The headline in the local newspaper read, 'Farewell to Mrs Charity'. She was a local hero who shone a light nationally on Paget's disease.

As Ann would have wished, the Association carried on. Over the years, the Trustees and employees have changed, the charity has moved offices several times, and various challenges have been overcome, to ensure that the work Ann began, from her front room forty-nine years ago, continues.

When I came to work for the Paget's Association, one of the first things I noticed was that there was no complacency, but a constant desire to move forward, to do more. There is always more to learn, more to discover, and more to do in the fight against this disease. Everything we do is done with the knowledge that it has to help make a difference, not only to those living with Paget's disease today, but also to future generations.

As the 50th Anniversary of the founding of the Paget's Association draws closer, I hope you will join us, if you can, at one of our special events, in April, next year.

Diana



A Special Paget's Information Event

50 YEARS
ANNIVERSARY

You are invited to a free Paget's Information Event to be held at:
The Lowry, Salford Quays, Manchester, on 19th April 2023, in Celebration of 50 Years of the Paget's Association.

Paget's Information Event
19th April 2023

What's New in Paget's Disease?

Looking especially at what is new and interesting, the speakers will be presenting the latest information on Paget's disease. There will also be the opportunity to ask questions.

The Paget's Information Event is for patients and their families. It is expected to commence around 15:00 hrs (to be confirmed) and be approximately two hours of exciting new information about Paget's disease, delivered by expert speakers who will also answer your questions.

Stay for the Celebrations

In the evening, we will be holding a celebratory Gala Dinner (page 15) so why not join us for both events?

Reserve your Place

To reserve your place/s at the event, please register on our website, email membership@paget.org.uk or telephone 0161 799 4646.



thelowry.com

Gala Dinner

In celebration of the 50th Anniversary of the Paget's Association, a Gala Dinner will be held in the Compass Room of The Lowry, Salford Quays, Manchester on 19th April 2023. You are invited to book your place/s and join other members, professionals, Trustees, and staff for this special evening.

A welcome drink will await you, followed by a three-course dinner including drinks. The evening will include music, dancing and more with Master of Ceremonies, Mr Phil Colbert.

Book your place/s

Tickets are priced at £50 each. To book your place/s for the Gala Dinner, please either register on our website, email membership@paget.org.uk or telephone 0161 799 4646.



Gala Dinner
19th April 2023



MC: Mr Phil Colbert

The Venue for our 50th Events

Salford Quays is Greater Manchester's unique waterfront destination, with good tram and bus links from Manchester City Centre. It is the home of MediaCityUK, which houses the BBC and ITV, and was officially opened in 2012 by the Queen. Close by, you will find the Blue Peter Garden, the Coronation Street production centre, the Imperial War Museum, Manchester United Football Ground, and Lancashire Cricket Ground.

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

The Lowry

Situated right on the waterfront in Salford Quays, The Lowry is a



magnificent building, where visitors will find theatres, galleries, cafes, a bar, a restaurant, and, significantly, one of the largest L S Lowry art collections in the world.

Whilst several rooms have been set aside for our events, the Compass Room has been reserved for the Gala Evening (details above). This beautiful room has an almost 360-degree view of Salford Quays. Why not take some time to explore the area before joining us for the

Paget's Information Event in the afternoon of the 19th April. Then meet us in the Compass Room for the Gala Celebrations, where you will be able to enjoy the evening with other members, Trustees and staff.

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

Staying Overnight?

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

An International Symposium on Paget's Disease

19th and 20th April 2023

for

Researchers, Clinicians, Allied Health
Professionals and Students

at

The Lowry, Salford Quays, Manchester

Abstract deadline: 11th January 2023

REGISTER

Please email membership@paget.org.uk
to register your interest in this event.
We will send full registration details as
soon as they are available.

In association with ECTS/BRS,
Liverpool, April 2023



50th Fundraising Activities

The Paget's Association's 50th Anniversary Campaign to raise £50,000 by December 2023 is well underway.

Trustees and Staff take up the Challenge

In May, our Chair, Professor Stuart Ralston, took on the forty-mile Etape Caledonia cycle race. The Association's Nurse, Diana Wilkinson, will soon be flying on the wing of a biplane, and in September, one of our Trustees, Amanda Sherwood, is going to climb Paget Peak, in Canada. Details of all these challenges and how you can support them can be found on pages 19-20.



Can You Help?

Could you donate, raise funds for the Association or even make a regular commitment to donate a set amount each month? No matter the size, every contribution helps the charity continue to be here for you and others.



For ideas and information, to help you raise funds for the Paget's Association, please request a fundraising pack. We can include Paget's Association banners, together with promotional items to help raise awareness of Paget's disease. For further information, or to request your pack, please email membership@paget.org.uk or telephone 0161 799 4646.

You can set up your own online fundraising page on the JustGiving website or we can set one up for you. You can also link your page to our campaign. <https://justgiving.com/campaign/Pagets50th>

Alternatively, sponsorship forms are available from our office.

If you need support or something special for your event, have a chat with us and we will do our best to help. Awards will be available for outstanding fundraising achievements!

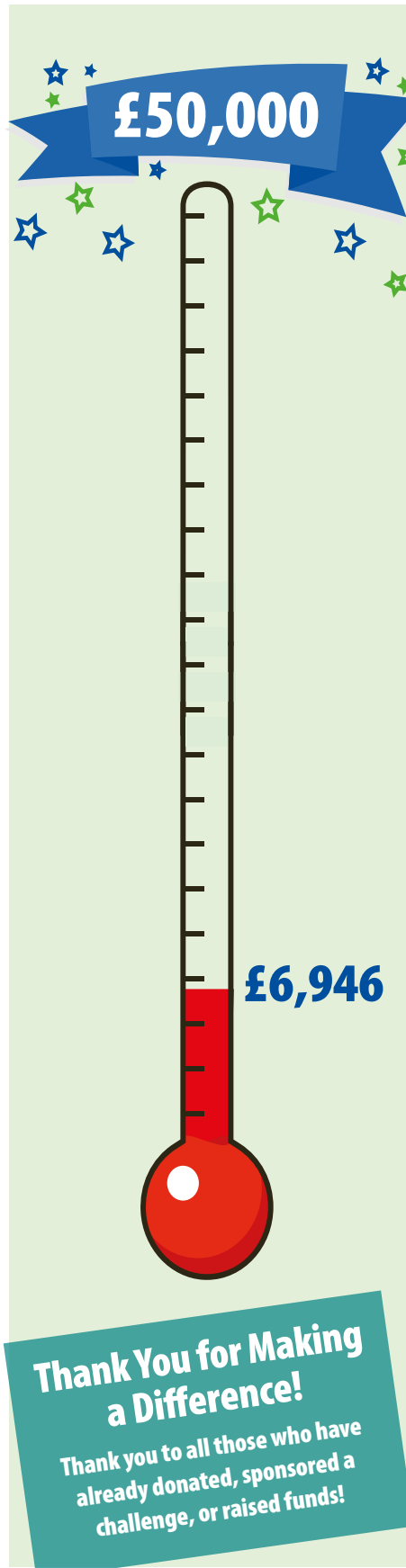
Janet and Graham Acquire Match-Funding

In May, members, Janet and Graham Dixon, had a stall at Saltfleet Car Boot Sale, supported by family, friends and neighbours, who kindly donated their unwanted items. They raised a terrific £321, which was kindly matched by Barclays Bank, making a grand total of £642 to add to the 50th Anniversary Fundraising Campaign. Thank you to all who made the event a success.



continued overleaf

Donate to the 50th Anniversary Campaign



You can help us meet our aim to preserve and protect the health of those affected by Paget's disease, by either making a donation, or by paying in funds you have raised, in any of the following ways. Every donation counts, no matter how large or small, and could really make a difference for someone affected by Paget's disease, going through a very difficult time.

The Association's Website

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



JustGiving's Website

You can also donate on our JustGiving 50th Anniversary Campaign page using the QR code here or use the details below. You can even link your own JustGiving fundraising page to this campaign. <https://justgiving.com/campaign/Pagets50th>



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

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

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

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

The Aims of the Paget's Association

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

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

Trustees and Staff take on Challenges for the 50th Anniversary Campaign

Three of the team here at the Paget's Association have taken up challenges to help raise funds towards the ambitious target of £50,000 for the 50th Anniversary Campaign.

Professor Ralston Pedals for Paget's

Chair of the Paget's Association, Professor Stuart Ralston, a Rheumatologist and Researcher in Edinburgh, completed the Etape Caledonia 2022 cycle race, in May, to raise funds towards the 50th Anniversary Campaign.



This forty-mile event took place through the spectacular Scottish Highlands. Beginning in Pitlochry, Professor Ralston made his way through rolling hills and forest-lined roads around Loch Rannoch and Loch Tummel.

Thank you so much to all who have sponsored him. So far, he has raised a fantastic £2,394.

You can still sponsor him by completing the form on page 20, by telephoning the Association on 0161 799 4646 or by scanning the QR code with a smartphone to be taken to his JustGiving sponsorship page.

Trustee, Amanda, Takes on Paget Peak

Paget Peak is a 9.5 kilometre hiking trail in Yoho National Park, British Columbia, Canada. With an elevation of 2,560 metres (8,400 ft), the peak is named after Dean Paget, the first to record ascending the peak and one of the founders of the Alpine Club of Canada. He reached the top with a group of club members in 1886.

In September, Trustee of the Paget's Association, Amanda Sherwood, is taking on the challenge of reaching the summit, where hikers are rewarded with spectacular views. She will begin from the dense subalpine forest and continue to climb steadily through the forested lower slopes of Paget Peak, where glimpses can be seen of Lake O'Hara and Lake Louise.

Amanda is also raising funds for the Paget's Association. She said, "I am delighted to climb Paget Peak on behalf of the Paget's Association. As a relatively new Trustee, I'm so impressed by the outstanding support and various resources that the Association provides to patients, carers, and researchers. As part of a collective fundraising effort for the 50th Anniversary of the Association, I have volunteered to climb Paget Peak in British Columbia, Canada.



View towards Kicking Horse Valley at the summit of Paget Peak at Yoho National Park

Although not too long a walk, it is a difficult climb – made all the more exciting by the presence of many bears in the area! It's going to be quite a challenge for me..."

You can sponsor Amanda by either completing the form on page 20, by telephoning the Association on 0161 799 4646 or by scanning the QR code to be taken to her JustGiving sponsorship page.

Diana's Wing Walk for Paget's



Standing on the wing of a biplane, flying through the air at speeds of up to 130 mph and reaching heights of

up to 700 ft, is the challenge Diana Wilkinson, our Specialist Paget's Nurse, has set herself.

As part of the Association's 50th Fundraising Campaign, Diana hopes to raise as much as possible to help



keep the services provided by the Paget's Association going.

Diana said, "Strapped (firmly, I hope), to the wing of a Boeing Stearman, it will be like nothing I've ever done before. There will be ground training to do, and hand signals to learn before I'm allowed to climb on the



wing. Apparently, my cheeks may flap and my eyes stream, but it'll be fun, right? Either

way, I know how much the charity needs funds, so I hope to raise as much as possible and I'll just have to summon up plenty of courage on the day!"

If you would like to sponsor Diana, you can either complete the form below, telephone the Association on 0161 799 4646 or scan the QR code with a smartphone to be taken to her JustGiving sponsorship page.

Wing Walking History

Wing walking initially arose out of practicality. Pilots would venture onto the wings of their planes to carry out repairs. Ormer Locklear is generally considered to be the first person to wing walk and recognise its commercial appeal. In 1917, he joined the U.S. Army Air Service and began climbing onto his biplane's wing, while in

mid-air, to resolve problems with the plane. These 'stunts' boosted his colleagues' morale, and other pilots started developing their own stunts. Ormer is reported as having said, "I don't do these things because I want to run the risk of being killed. I do it to demonstrate what can be done".

During the infancy of wing walking, eight wing walkers died

in a relatively short period. Ormer Locklear perished in 1920 while performing a stunt for a film.

In 1936 such stunts were banned by the American government as too dangerous, but in the 1950s wing walking started again, mostly on Boeing Stearman bi-planes, which were considered safer and stronger than those used previously.

Sponsor a Challenge *I would like to sponsor (choose just one or as many as you like)*

Prof Ralston's Bike Race Amanda's Paget Peak Hike Diana's Wing Walk

Please state the **total sponsorship amount** or circle as appropriate: £3 / £5 / £10 / £20 / £50 / £100 / other amount £ _____

I enclose a cheque / I wish to pay by card (delete as appropriate)

Name
Address
Postcode
Telephone

- 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 the Paget's Association will contact you, on receipt of this form. Alternatively, telephone the office on 0161 799 4646 with your card details.

Gift Aid Declaration

If you are a taxpayer, donating through Gift Aid means the charity can claim an extra 25p for every £1 you give. It will not cost you any extra. If you would like to Gift Aid your donation, you must tick one of the boxes below:

- I want to Gift Aid my donation of £ _____
- 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.

Signature	Date
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Paget's Helpline

The Association's Helpline often receives questions regarding diet, supplements, and bone health. Our Specialist Paget's Nurse, Diana Wilkinson, answers the most common queries below.

Is there a special diet or particular food that can improve Paget's disease?

Those with Paget's disease do not need a special diet and there is no evidence of any specific food having a beneficial effect on the condition. Overall, a well-balanced diet is important, for your bones and for your general health. Maintaining a healthy weight is also important because if you are underweight or overweight, your risk of breaking a bone increases.

A guide to healthy eating, the Eatwell Guide, can be found on the government's website www.gov.uk

What role do calcium and vitamin D play in bone health?

To keep bones strong, calcium and vitamin D are essential for everyone, not just those with Paget's disease, however, these alone cannot keep them healthy. That is why a well-balanced diet is important.

Calcium helps maintain bone strength, but it can only do this if your body has sufficient vitamin D, which helps your body effectively absorb and use calcium. You should be able to get all the calcium you need by eating a varied and balanced diet. Calcium is in foods such as milk, cheese, curly kale, tofu and bread made with fortified flour.

It has been estimated that around one in six adults, in the UK, have low levels of vitamin D, which can lead to bone pain and muscle weakness. Some people, such as those who are housebound, are more likely to

have lower levels of vitamin D, which is mostly obtained by the action of sunlight on the skin. It is also in foods such as oily fish and fortified cereal.

In the UK, obtaining vitamin D from sunlight exposure can be achieved without risking sun damage. This means short periods of around ten minutes in the sun, with the hands and face uncovered, without sunscreen, from around early April to the end of September. In the UK, winter sunlight does not make vitamin D, therefore, some people might not have enough to last through the winter and may need a supplement to boost their diet.

In 2016, advice given by Public Health England, following a report by the Scientific Advisory Committee on Nutrition (SCAN) was for everyone to have a daily supplement of 10 micrograms (which is equal to 400 International Units) of vitamin D. This was a general recommendation for everyone, as it is difficult to know who receives enough sunlight exposure to produce vitamin D, and also to cover those at risk of deficiency. Most vitamin D supplements contain vitamin D3 (cholecalciferol) which may be slightly more effective than vitamin D2 (ergocalciferol).

In April this year, a review was launched by the Office for Health Improvement and Disparities, to promote the importance of vitamin D and identify ways to improve intake across the population, including through dietary supplements and fortified food and drink.



Scan the QR code with a smartphone to be taken to the Eatwell Guide

Why am I being asked to take calcium and vitamin D supplements prior to treatment for Paget's?

Treatment for Paget's disease, such as an infusion of zoledronic acid, may cause a decrease in calcium levels. The risk of this is reduced in people who have a good dietary calcium intake and those with normal levels of vitamin D. Sometimes vitamin D levels (25-hydroxy vitamin D) are measured before treatment to determine if supplements are required. Depending on the results, calcium and vitamin D supplements may be given prior to treatment as a preventative measure.

Can exercise help keep my bones healthy?

Bone is living tissue and, throughout life, exercise and being generally physically active help to keep bones strong and healthy. Regular exercise is also essential for maintaining joint mobility.

Paget's Helpline

- ✓ Information
- ✓ Support
- ✓ Guidance

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

Information and Support Services

Information

For our latest booklets and back issues of this magazine, or to request a new Paget's Passport, get in touch with our office or visit our website.

www.paget.org.uk



Paget's Helpline

- ✓ Information
- ✓ Support
- ✓ Guidance

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



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



Facebook Support Group

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

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



Sheffield Support Group

The Sheffield Support Group met in July, in Darnall, Sheffield. The group gets together around three times a year, from 13:30 hrs until 15:00 hrs. The next meeting is expected to be in October or November.

For more information or to join this informal group, please get in touch by emailing helpline@paget.org.uk or by telephoning 0161 799 4646.



Virtual Support Groups

Meet others online at one of our Virtual Paget's Support Groups. Meetings take place every two months, using Zoom.

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.



NEW

Paget's Buddies

In the May edition of this magazine, we asked if anyone would like to offer support to another member who is struggling with Paget's disease. This is a new initiative, which we are calling Paget's Buddies. It was set in motion by our recently formed Focus Group, and it provides one to one support between members of the Paget's Association.



Diana, our Specialist Paget's Nurse, commented, "I want to thank those who have agreed to support someone in need. We do require more people to come forward to help with this. No medical knowledge is required as it is purely a supportive role. If you feel you can support someone, or would like to find a buddy for support, please get in touch and I will do my best to find you a Buddy!"

You can contact Diana Wilkinson by telephone 0161 799 4646 or email diana.wilkinson@paget.org.uk and let her know if you would like to offer your support or if you are looking for a support buddy.

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

Support for those Newly Diagnosed



Our Support Gift Bags are designed to bring comfort to those who are newly diagnosed with Paget's disease.

Paget's Support Gift Bag

When someone who has just been diagnosed with Paget's disease, contacts the Paget's Association, they may be distressed by the diagnosis and worried about the future, as they search for information and/or wait to see a consultant. Whilst we always provide written information, we now have something extra to offer. Our free Paget's Support Gift Bags are designed to help those newly diagnosed.

We hope our Paget's Support Gift Bags are an act of kindness when it is needed most, and something to brighten the day of those suffering emotionally and/or physically.

Thank You

If you have donated to help us provide those who are struggling with a Support Gift Bag, thank you so much! Your generosity is appreciated.



“
If you have already donated to help us provide those who are struggling with a Support Gift Bag, thank you so much!
”

Donate a Bag to Help Someone

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 complete the form on the next page and return the completed form in the post. Alternatively, donate via our website, or contact us by email, membership@paget.org.uk or telephone 0161 799 4646.

If you like, you can even add a simple message of support, which we may include with the Bag.

What's in the Bag?

The following items are included:

■ 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 recipient 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.

Connect with us Online

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

YouTube

Our YouTube channel contains a range of videos covering all aspects of Paget's disease, from people's individual experiences of Paget's, to presentations from leading experts, find them all here

<https://www.youtube.com/c/PagetOrgUk>

Facebook 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/>

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 payable to 'Paget's Association'

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

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)

★★★★★ 200 Club Winners ★★★★★

April 2022

1st Prize £100 **2nd Prize £50**
Ticket No. 100 **Ticket No. 87**
Judith Moatt *Annette Allan*
 Porthcawl Aryshire

May 2022

1st Prize £100 **2nd Prize £50**
Ticket No. 153 **Ticket No. 6**
Terry Holder *Shelagh Fletcher*
 Leicester Liverpool

June 2022 Double Prize Draw

1st Prize £200 **2nd Prize £100**
Ticket No. 5 **Ticket No. 19**
Shelagh Fletcher *Anthony Manders*
 Liverpool Shrewsbury

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.

Do Something Exceptional

Writing your will does not have to be a solemn matter. In fact, it can be an opportunity for you to do something exceptional. A gift in your will to the Paget's Association will continue to benefit and transform lives by funding quality research and support services.

The Association does not receive any government funding and is completely reliant on donations, fundraising and legacies. We are grateful to those of you who have kindly chosen to remember the Paget's Association in your will, and if you are considering this type of gift, thank you. Every gift, large or small, really does make a difference.



Our supporters have helped us achieve so much!

- Support gift bags
- Educational awards
- Quality Paget's research
- Paget's information packs
- Increased helpline support
- Student research bursaries
- Informative patient booklets
- Educational information events
- Distribution of clinical guidelines
- Professional information brochures
- Open access to professional journal articles
- Increased use of social media to raise awareness
- Advertisements to raise awareness in GP journals and on websites



In Memoriam

Johanna Lyons

Margaret Taylor



We would like to thank those who remember their loved one by sending donations to the Paget's Association. We celebrate the lives of those named, and thank their families and friends for their thoughtfulness and lasting gifts.

WE APPRECIATE YOUR SUPPORT, THANK YOU

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

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

Patrons



Sir Henry Paget

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



The Lord Trevor Stamp

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



Mrs Joyce Cupitt

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



Mr Recardo Patrick

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

Board of Trustees

Chair of the Board



Prof Stuart Ralston

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



Mrs Kely Burman

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



Dr Sheelagh Farrow

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



Mr Alan Janes

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

Vice-Chair



Prof Rob Layfield

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



Dr Catherine Nairn

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



Mr Michael Patnick

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



Mrs Amanda Sherwood

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



Prof Mark Wilkinson

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

Employees



Sister Diana Wilkinson

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

Mrs Sue Clegg

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

Miss Jen Woodworth

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

Paget's Association Events

2022

EVENT	WHERE	DATE	DETAILS
VIRTUAL PAGET'S SUPPORT GROUPS			
These groups meet every two months. For more dates, visit our website or get in touch.			
Group 1 – Monday meetings at 15:00 hrs	Online using Zoom	10th October 2022	Page 22
Group 2 – Tuesday meetings at 09:00 hrs	Online using Zoom	11th October 2022	Page 22
Group 3 – Wednesday meetings at 18:00 hrs	Online using Zoom	12th October 2022	Page 22
LOCAL SUPPORT GROUP			
Sheffield Support Group Meeting	Darnall, Sheffield	Contact us for details	Page 6
INFORMATION EVENTS			
Paget's Information Day	Cardiff	30th September 2022	Page 6
ANNUAL GENERAL MEETING			
AGM	Cardiff	30th September 2022	Page 7
TCS LONDON MARATHON			
TCS London Marathon	London	2nd October 2022	

2023

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

CONTACT US

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

Paget's
Association

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

paget.org.uk

Information, Support and Research