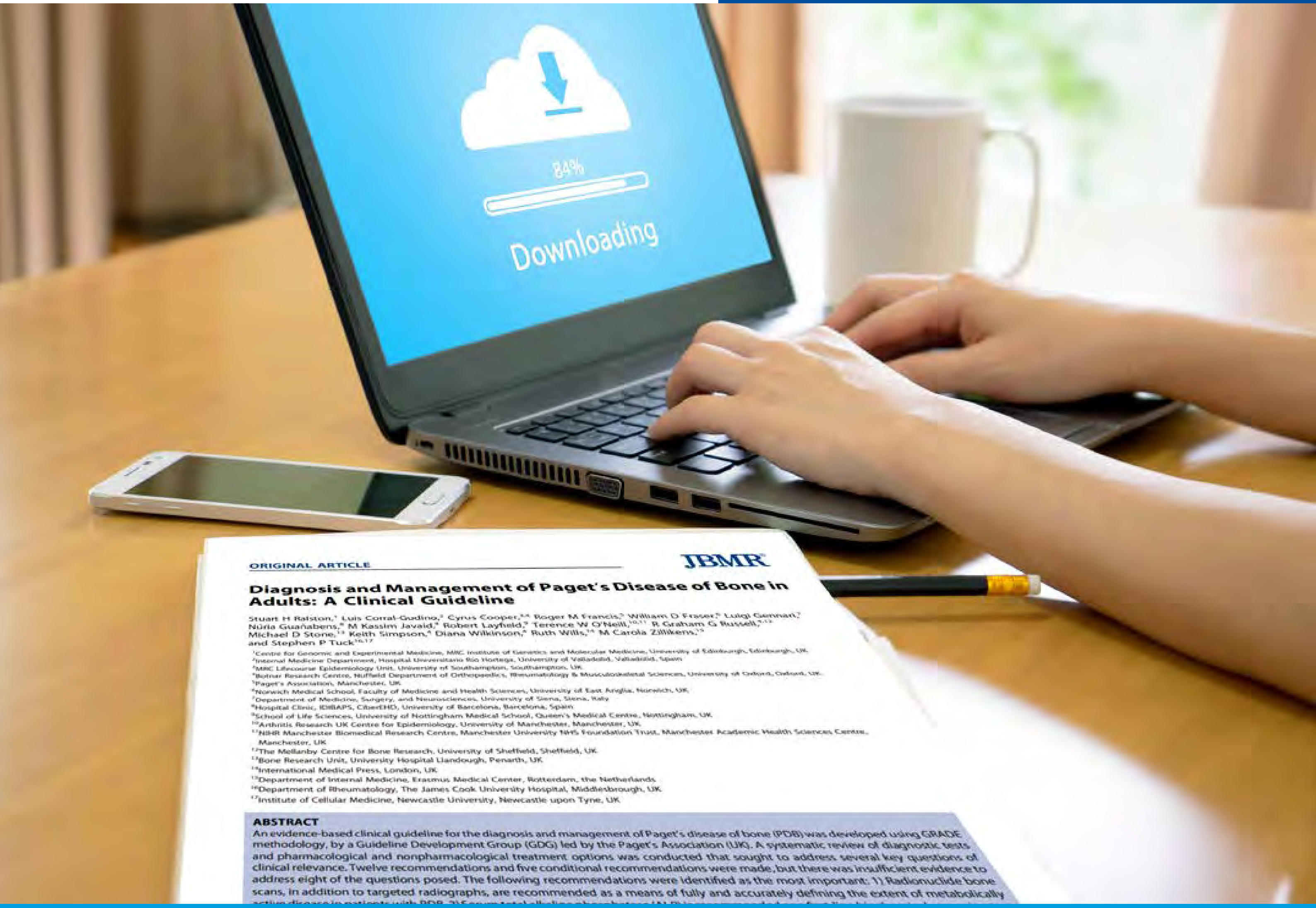
Paget's Association
Paget's news
AUGUST 2020



ORIGINAL ARTICLE

JBMR

Diagnosis and Management of Paget's Disease of Bone in Adults: A Clinical Guideline

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ABSTRACT

An evidence-based clinical guideline for the diagnosis and management of Paget's disease of bone (PDB) was developed using GRADE methodology, by a Guideline Development Group (GDG) led by the Paget's Association (UK). A systematic review of diagnostic tests and pharmacological and nonpharmacological treatment options was conducted that sought to address several key questions of clinical relevance. Twelve recommendations and five conditional recommendations were made, but there was insufficient evidence to address eight of the questions posed. The following recommendations were identified as the most important: 1) Radionuclide bone scans, in addition to targeted radiographs, are recommended as a means of fully and accurately defining the extent of metabolically

Paget's Guideline Success!
– one of the most downloaded papers

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Chairman's Message

Dear Member,

Welcome to the August 2020 edition of *Paget's Association News!*

We have been working hard to support our members during these troubled times and will continue to do so as we emerge from the coronavirus pandemic. This has involved a change in working practices for all at the Association as Diana, Sue and Jen moved from office-based to remote working, as described in the "Life in Lockdown" piece on page 24 of the magazine. Thanks to the wonders of modern technology, however, we have been able to keep everything going as close to normal as is possible.

We have reluctantly decided to postpone the Paget's Information Day, which we had scheduled for Southampton this October. Instead, we will carry the event over, at the same venue, in Autumn of 2021, by which time we hope the pandemic will truly be behind us. Many of us in the academic and clinical sector have got used to holding virtual meetings using web-based tools such as Zoom and Teams. Although this isn't quite the same as face-to-face meetings, we are interested in your view on whether you would find this type of event useful. If so, please complete the short questionnaire on page 12 to let us know.

> *If you wish to attend the AGM, please reserve a place as soon as possible*

Since our constitution stipulates that we need to hold the AGM this year with at least 10 people present in person, we have decided to move the event to a venue much closer to our headquarters in Manchester. The AGM will be held on Friday 16th October at the Novotel Manchester West, with a start time of 1.00pm. Members are welcome to come along, but please note that places are strictly limited due to social distancing rules. If you wish to attend please reserve a place as soon as possible by contacting the office by post, telephone or email. Even if you can't make it in person, you can vote on the items we will be discussing by completing the reply slip enclosed with the AGM papers.

One concern for many charities has been the negative financial impact of COVID-19 on investments, but I am happy to report that the charity's finances remain in pretty good shape, all things considered. While the value of our investments dropped quite a bit at the peak of the pandemic, things have recovered considerably, due in no small part to the skills and expertise of the staff at Tilney, who oversee our investments. As you can imagine the usual efforts of supporters who organise coffee mornings, raffles and those that take part in events such as the London Marathon have been hampered over recent months, but I am hoping that this will gradually return to normal by the end of the year.

Now that the number of patients with coronavirus needing hospital care is steadily dropping, it looks like it will soon be possible to reactivate research projects into Paget's disease. The Pain in Paget's (PiP) study, which was featured in the May issue of this magazine, has been on hold since early March but we expect to get this up and running once again in September or October. The Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD) project is a new research study led by the Edinburgh Paget's Association Centre of Excellence and is featured on page 10. This study is now open to recruitment and members of the study team would be interested to hear from you if you think this research project might be of interest to you or a family member.

As lockdown restrictions have eased across the UK, I hope that some of you are starting to go out and about and take some well-deserved holidays. I am certainly looking forward to that after several months of very hard work, which involved additional duties on the general medical wards, in addition to my usual duties taking care of patients with bone disease and various forms of arthritis. If you are going out, please be careful to observe social distancing rules and of course wear your Paget's Association face mask! I am very proud that the Association was able to provide these masks as a small token of appreciation for our members. I use mine every time I go to the supermarket. If I can also say a personal thanks to members who took the time to contact us with the very many messages of appreciation and donations that we received in response to this initiative. Additional masks can be purchased for friends and family as described on page 22 of the magazine.

In closing, I wanted to mention that sadly, Janet Strang and Peter Jones have decided to step down as Trustees following the next AGM. I would like to take this opportunity of thanking Janet and Peter for the huge contribution they have both made to the Association over recent years. On this note, I am also delighted to say that, in response to my previous Chairman's message in the May magazine we have applications from four individuals who wish to serve the Association as Trustees and these applications will be considered and voted upon at the upcoming AGM in October.

Wishing you all the best,

Stuart Ralston

Chairman, Paget's Association

The Paget's Association

Charity registration number: 266071

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

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

Connect with us on

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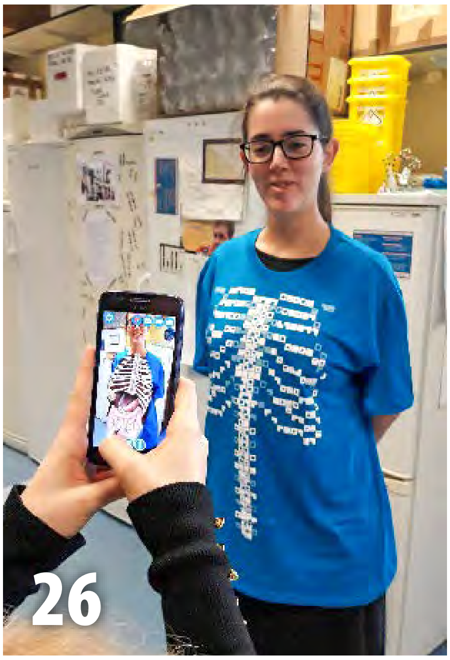

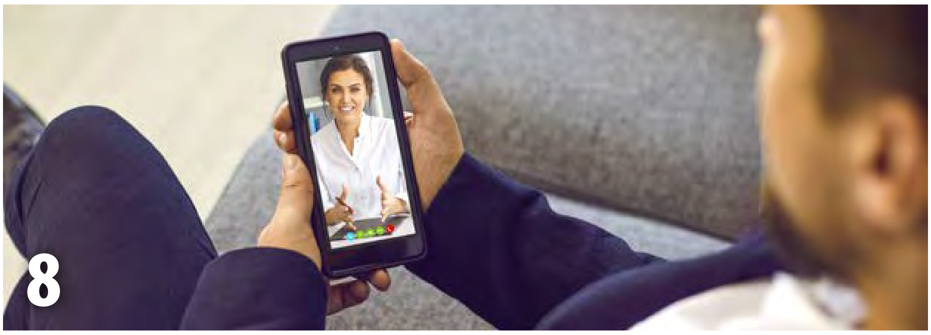

Features

Events

Fundraising

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Other

Paget's Guideline Success!

The Paget's Association is pleased to announce that the 'Guideline for the Diagnosis and Management of Paget's Disease of Bone in Adults', was in the top 10% of downloaded papers published during 2018-2019.

Published in the Journal of Bone and Mineral Research, the Guideline provides evidence-based recommendations for the diagnosis and management of Paget's disease. It allows health professionals to consider the available evidence and discuss options with the patient. It also highlights the areas where more research is needed.

The Guideline was commissioned by the Paget's Association, with the support of the European Calcified Tissue Society and the International Osteoporosis Society. We are grateful to all those who supported the production of the document and the Guideline Development Team who made it possible.

Visit our website to read details and download the full Guideline – paget.org.uk

Guideline Reference

Ralston, S. H., Corral-Gudino, L., Cooper, C., Francis, R. M., Fraser, W. D., Gennari, L., Guañabens, N., Javaid, M. K., Layfield, R., O'Neill, T. W., Russell, R. G., Stone, M. D., Simpson, K., Wilkinson, D., Wills, R., Zillikens, M. C. and Tuck, S. P. (2019), **Diagnosis and Management of Paget's Disease of Bone in Adults: Journal of Bone Mineral Research.** Vol. 34, p 579-604.

The Annual General Meeting of The Paget's Association

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

Friday 16th October 2020

Please see the separate information enclosed and use your vote!

Support Through Recent Months

We would like to reassure you that in recent months, despite the problems of COVID-19, the Paget's Association has continued to offer information and support to our members and to anyone affected by Paget's Disease of Bone. Here is a snapshot of some of the things the Association has been doing.

- **In March,** we made changes to support our Trustees and employees by changing working practices, supplying necessary equipment, to aid remote working and using video conferencing for meetings. These changes enabled our team to continue to provide our usual membership and information and support services.

- Our Nurse Helpline answered your questions regarding COVID-19 and those who have Paget's disease. We compiled the Helpline's frequently asked questions, emailed them to members and placed them on our website, together with activities to do at home during the lockdown.

- We reviewed the risk of holding face-to-face meetings, resulting in the cancellation of support group meetings, and the offer of remote support as an alternative.

▼ *One of our team meetings using Zoom*

- **In April,** we set up a Facebook Support Group to give people a new online platform to share their experiences and discuss their concerns. This group now has over 90 members and is still growing. One of the posts placed in the group was from member, Brian Gray, whose wife, Pam, wrote her first poem about COVID-19. We thank them for allowing us to share it (see page 7).

- We continued to review our activities and took the difficult decision to postpone our Members' Day in York.

- **In May,** our Paget's News magazine contained COVID-19 questions and answers, and a special pull-out of activities and competitions for readers to do at home. Due to closures, an alternative printing company had to be found to produce the magazine.

- We contacted the researchers whose projects we fund, to support and assist them with any difficulties and delays they might experience due to the ongoing situation.

- To help kickstart future projects, we produced a new leaflet explaining our funding opportunities for both research and education.

- We shared a video on our website of Sir Michael Rawlins, interviewing our Chairman, Professor Stuart Ralston, who is also Chair of the Commission on Human Medicines, regarding potential treatment options for the COVID-19 virus. This was part of a series of discussions for professionals, provided by the Royal Society of Medicine.

- **In June,** we sent each member a face-covering for their personal use, with our compliments. The UK Government's advice is clear that face-coverings and masks are not a substitute for social distancing. They advise, however, that face-coverings are worn in enclosed places where social distancing may be more difficult to achieve, and when you are likely to come into contact with people you do not normally meet. This is most relevant in more crowded areas, such as on public transport. There is evidence that face-coverings can protect others from getting infected if you have coronavirus but have not developed symptoms. Emerging evidence suggests that they may also afford some personal protection.

It is important to remember that face-coverings are not a substitute for social distancing and handwashing, which are the most effective ways of avoiding coronavirus. Remember, if you have symptoms of coronavirus, for example, a cough and/or high temperature, or loss of taste or smell, you and your household should isolate at home. Wearing a face-covering does not change this advice.

- **In July,** we continued to review our activities and update our website with appropriate information and advice.

The decision was taken to continue the working arrangements for staff, which were put in place in March.

We took the difficult decision to postpone our Information Day in Southampton until next year.

As the UK began to return to some form of normality, we started to look at new ways in which we could support our members in the months ahead. For up-to-date information, please visit our website or see the email updates that we send.

COVID-19

Coronavirus has arrived from out of the blue.
A nasty virus, much worse than the flu.

The effect that makes you cough and splatt.
It lays you flat out, no doubt about that.

The whole wide world is affected by this,
It seems to have appeared,
straight from the abyss.

Life has changed so very much,
No more contact, and no more touch.

We try to survive from day to day,
we've had to push friends and family away.

Our schooling and jobs are now done from home,
by simply using PCs and phones.

Hospitals built for our NHS,
Our key workers, simply the best.

With patients increasing day by day,
it's hard to keep the virus at bay.

No visitors, no PPE,
just another figure on TV.

So wear your masks and wash your hands.
Keep a two-metre distance,
as per government plans.

For your mental health, think of sunnier days,
when this nasty virus has gone away.

Pam Gray: May 2020

Remote Consultations and Help Online

Our Specialist Paget's Nurse, Diana Wilkinson, has been looking at the NHS services that are available online; how patients are increasingly interacting remotely, and she provides guidance on remote consultations.

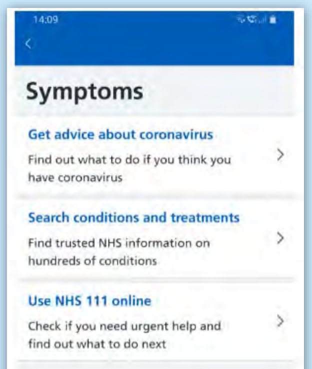
NHS Help Online

It is important to remember that NHS help is still available, and you should not avoid seeking it.

From the start of the COVID-19 pandemic, we were all asked to use online services as much as possible to help the NHS cope with demand. It can be easy to get NHS help using your smartphone, tablet or computer if you have one.

The NHS website includes advice on how to:

- **order repeat prescriptions**
- **contact your GP**
- **find out about urgent dental treatment**
- **manage long-term conditions**
- **maintain your mental and physical wellbeing**
- **get the most out of a remote consultation**



Get advice about coronavirus
Find out what to do if you think you have coronavirus

Search conditions and treatments
Find trusted NHS information on hundreds of conditions

Use NHS 111 online
Check if you need urgent help and find out what to do next

The NHS App

NHS App

The services available via the NHS app are growing. The app may be used for many things including to search trusted NHS information, make appointments and order repeat prescriptions.

Visit **www.nhs.uk**

Contacting Your GP

To contact your GP, you can use your GP surgery's website, the NHS app or telephone them.

Urgent Help ▶

- For urgent medical help, use the **NHS 111** online service, or telephone 111 if you are unable to obtain help online.
- In an emergency telephone **999**.

Remote Consultations – Guidance for Patients

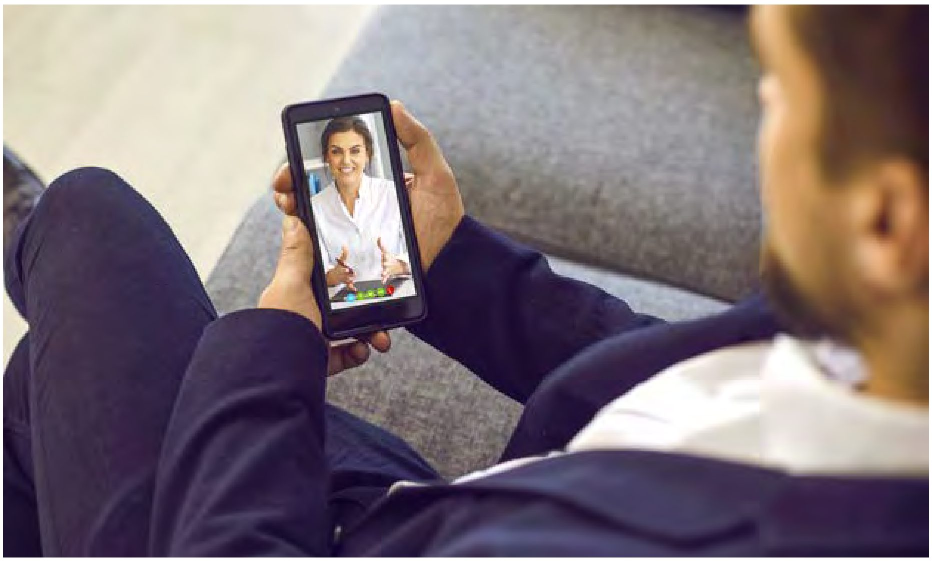
The COVID-19 pandemic meant that many healthcare professionals, such as consultants, GPs and specialist nurses, had to change the way they interact with patients. Remote telephone and video consultations, instead of face-to-face appointments, have been in use for some years, however, their use has greatly increased since the pandemic was declared. Not all healthcare professionals or patients have access to the same technology, so experiences are likely to vary.

The advantages of consultations by telephone or video are that they:

- prevent the transmission of the disease
- allow healthcare professionals to speak to patients who are unable to travel (e.g. due to self-isolation)
- support providers to meet increased demand in a particular locality
- allow healthcare professionals to work from home (e.g. due to self-isolation)

Can Anyone Have a Remote Consultation?

Remote consultations are not for everyone, however, they can be used for a wide range of patients and appointment types. In general, they are suitable for people who do not need a physical examination or test and who can communicate



via telephone or video. If there is a benefit to seeing the patient, then a video rather than a telephone consultation is preferred when possible. Depending on the outcome of your remote appointment, you may need to go to your health centre or hospital for a face-to-face appointment.

Your Remote Consultation

Before the appointment

- Your healthcare provider will decide which type of appointment (phone, video or face-to-face) to offer you.

- They should contact you to confirm the appointment and ensure you have the required technology. Do not worry if you do not have this, a telephone call will always be available.

- If you are offered a video appointment, you will receive a link with instructions on how to join the appointment, there will also be details on how to check in advance that your device is set up correctly.

- If you do not want to use video, you have a right to say no. Ensure you know how to turn the video off.

- Work out what questions you want to ask and make a note of them.

- Prepare a list of your recent medication, any changes to medication and dosages, as well as any over-the-counter medicines you are taking.

- Ask a family member to be with you if you would like this.

- Make sure the device you are using is fully charged.

- Try and be somewhere with stable internet or mobile connection.

- The appointment may not take place at the exact time so ensure you are available either side of your appointment time.

- Find somewhere quiet where you can talk freely and hear clearly.

During the appointment

- Make sure you will not be disturbed.

- Remember that technology may fail. Make sure you know how to reconnect if you get cut off.

- Ask any questions that you need to.

- If you are being prescribed medication, find out how to collect your prescription.

- Ask if you need a follow-up appointment.

- You can also ask about support for your condition and access to psychological support if required.

Face-to-Face Appointments

If you have been given a face-to-face appointment, you should attend, unless informed otherwise. Please follow any instructions given concerning wearing a face-covering and maintaining social distance.

(Some of the guidance regarding remote consultations has been adapted from guidance issued by the British Association of Dermatologists).

Support and Information Regarding Paget's Disease

Our website is full of information, news and magazines. There is a simple to use search facility, so you can easily find the information you need. Use the 'contact us' page on our website to get in touch with the Paget's Nurse Helpline or use any of the methods below.

Contact the Paget's Nurse Helpline

- Email: **helpline@paget.org.uk**
- Call: **0161 799 4646** and ask to speak to the Nurse
- Mobile: **07713568197**
- Twitter: **@PagetsDisease**
- Facebook: **www.facebook.com/PagetsAssociation**

Facebook Support Group

We have a Facebook Support Group, where members can share their experiences. To join, please visit **www.facebook.com/groups/pagetsdiseaseofbone**

New Research Study into the Genetics of Paget's Disease

Researchers at the Edinburgh Paget's Association Centre of Excellence (PACE) are leading a new research study, funded by the European Research Council, into the role of genetic factors in Paget's disease.

The Genetic Analysis to Predict the Development of Paget's Disease (GAPDPD) study is now open to recruitment and aims to determine, by genetic testing, if it is possible to predict the risk of Paget's disease developing in people who have a family history of the condition.

Our Specialist Paget's Nurse, Diana Wilkinson, spoke to the lead investigator, Professor Stuart Ralston, about the study and asked him to explain what this new research involves.

Diana

Why are you performing the GAPDPD study?

Prof Ralston

It has been known for many years that Paget's disease can run in families and there have been huge advances over the past ten years in identifying the genes that predispose to Paget's. The aim of this study is to see whether it is possible to develop a simple blood test, which can be offered to people with a family history of Paget's, to give them an idea if they are likely to develop Paget's disease later in life.

Diana

How does this differ from the ZiPP study in which genetic testing was also performed?

Prof Ralston

Good question Diana! When we set up the ZiPP study in 2009, we were only able to conduct testing for one gene *(SQSTM1)* that predisposed to Paget's disease. Since then about thirteen new genes have been identified and in GAPDPD we will be able to test for all these genes, which should give a much more accurate test than was previously possible.

Diana

Why would it be helpful for someone to know if they were at increased risk of Paget's using this test?

Prof Ralston

We know that Paget's disease can go undetected for many years and that it often doesn't cause symptoms in the early stages. However, as time goes on, complications may develop as the disease progresses. The advantage of having a genetic test that can predict individuals who are at increased risk is that they could be kept under close surveillance for signs or symptom of the disease and offered treatment at an early stage.

Diana

Who would be eligible to take part in the study?

Prof Ralston

We are looking for volunteers above the age of forty-five with a family history of Paget's disease, affecting a parent or sibling, as long as they have not been diagnosed with Paget's themselves.

Diana

What does the study involve?

Prof Ralston

People who take part in the study will be offered a bone scan, to determine if they have any evidence of Paget's disease, and will have a blood sample taken for genetic and biochemical testing. We will also ask volunteers to complete some questionnaires on diet, exercise, and lifestyle factors. Samples will be taken to analyse the microbiome, which is the name given to the microorganisms which normally live on our skin and in our gut. The microbiome is important for our health and is influenced by diet.

Diana

Does the study involve having any treatment?

Prof Ralston

No, not necessarily. If we find evidence of Paget's disease on the bone scan, and any symptoms develop that we think might be due to Paget's, then, of course, treatment would be offered as part of normal clinical care.

Diana

Will there be any follow up?

Prof Ralston

Yes, we want to keep in touch with participants for a period of up to five years. This will mostly be done by telephone, but at the end of the study, we will repeat the bone scan and other tests to determine if anything has changed. This follow up is important, since we know that the likelihood of developing Paget's increases with age.

Diana

Do you need to live close to Edinburgh to take part in GAPDPD?

Prof Ralston

No, the study is open to anyone who lives in the UK or the Republic of Ireland. We have identified several collaborating centres across the UK where participants can be seen.

Diana

Are there any advantages in taking part?

Prof Ralston

Yes, potentially. The study provides an opportunity to be screened for the presence of Paget's disease and of being kept under close surveillance for any signs or symptoms that may develop.

Diana

Are there any risks?

Prof Ralston

The bone scans involve exposure to small amounts of radiation. The chance of this causing health problems, that might not have otherwise occurred, is very small.

Diana

What should members of the Paget's Association do if they are interested in taking part, or would like further information?

Prof Ralston

Members can contact the study team, using one of the options below.

Contact one of the team members:

Judy Coyle, lead Research Nurse:
judy.coyle@ed.ac.uk

Jonathan Philips, Study Manager:
jonathan.phillips@igmm.ed.ac.uk

Stuart Ralston, Principal Investigator:
stuart.ralston@ed.ac.uk

Rosa-Lee Schafer, Study Administrator
Rosa-lee.schafer@igmm.ed.ac.uk

Telephone: 0131 651 8741

Write to:
GAPDPD Co-ordinating Centre, Centre for Genomic and
Experimental Medicine, University of Edinburgh,
Western General Hospital, Edinburgh, EH4 2XU.

Alternatively, register an interest in any Paget's research by using the 'contact us' form on the Paget's Association's website.

Judy (top left), Prof Ralston (top right) Jonathan (bottom left) and Rosa (bottom right)

Would an Online Event or Support Meeting Help You?

Would you join us online for any of the following?

- **Paget's Information Meeting**
- **Questions and Answers with a Paget's Expert**
- **Support Group**

As we continue to look at ways to support those with Paget's disease, it is important for us to consider the views of our members. We would like to know how many people would be interested in joining us online, using technology, such as Zoom on your laptop, iPad, tablet, smartphone or computer (with a microphone and webcam). Perhaps you have used this with your family and friends during the lockdown?

If you would be interested in any of the above, please either email **membership@paget.org.uk** or complete and return the form below.

We are also interested to hear from you if you would not want to join this type of online meeting. Perhaps you would like to suggest other ways in which we could support you.

Tell us your views

Would you join us online for any of the following?

Paget's Information Meeting **Yes** ☐ **No** ☐

Questions and Answers with a Paget's Expert **Yes** ☐ **No** ☐

Support Group **Yes** ☐ **No** ☐

Have you used Zoom before? **Yes** ☐ **No** ☐

Do you have any comments? ....

....

If an online meeting does not interest you, is there any other way we could support you?

....

....

....

Full Name
Address

Postcode
Telephone
Email
Date

Please post this form to:

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

Alternatively, email the information to:
membership@paget.org.uk

Bursary Research Helps Scientists Make an Important Discovery

In 2017, Jasmine Sanghera, a biomedicine student at the University of East Anglia (UEA) in Norwich, was awarded the Sir Julian Paget Student Research Bursary by the Paget's Association, to undertake research into a very rare complication of Paget's disease – bone cancer (osteosarcoma). We are delighted to announce that the Sir Julian Paget Student Research Bursary contributed to a paper published on the 13th July.

This work was part of a larger study, which discovered how and why primary bone cancer, which is mostly a childhood cancer, spreads to the lungs. This finding is extremely important as new drugs are now in the pipeline to prevent this spread. One of the adult patient donors in the study had osteosarcoma associated with Paget's disease and the research proved extremely insightful into comparisons between the childhood form and the Paget's form of osteosarcoma.

Jasmine will graduate as a Physician Associate in 2021 and said, "This bursary was instrumental in expanding my medical training portfolio, to actually experience scientific research and to take the latest findings with me as I embark on my upcoming medical career. I am so grateful to the Paget's Association and its supporters for giving me this opportunity".

Sir Henry Paget presented the Student Research Bursary Award to Jasmine in November 2017

Dr Darrell Green, who led the study and who once received a Student Research Bursary from the Paget's Association himself said, "It was fascinating to see the similarities and differences between childhood and Paget's osteosarcoma. We now have a far greater understanding of both disease states and that means we can intervene at the clinical level. This discovery would not have happened without funding from the Association, so thank you so much. Jasmine was a fantastic student and I wish her all the best with her medical career. That's another student entering medicine with the backing of the Paget's Association, which will also help raise awareness of the condition".

A Centre of Excellence

The University of East Anglia, together with the Norfolk and Norwich University Hospital NHS Foundation Trust, make up the Norwich Paget's Association Centre of Excellence. Under the leadership of Professor Bill Fraser, the hospital has a well-established metabolic bone disease service. Patients are seen at specialist bone clinics and the centre also hosts a service which provides specialist tests and advice on the interpretation of molecules involved in bone and calcium metabolism to units throughout the UK and for several in Europe (The Supra Regional Assay and Advisory Service).

You can read the university's press release on our website **paget.org.uk**

Paget's Disease and the Orthopaedic Surgeon

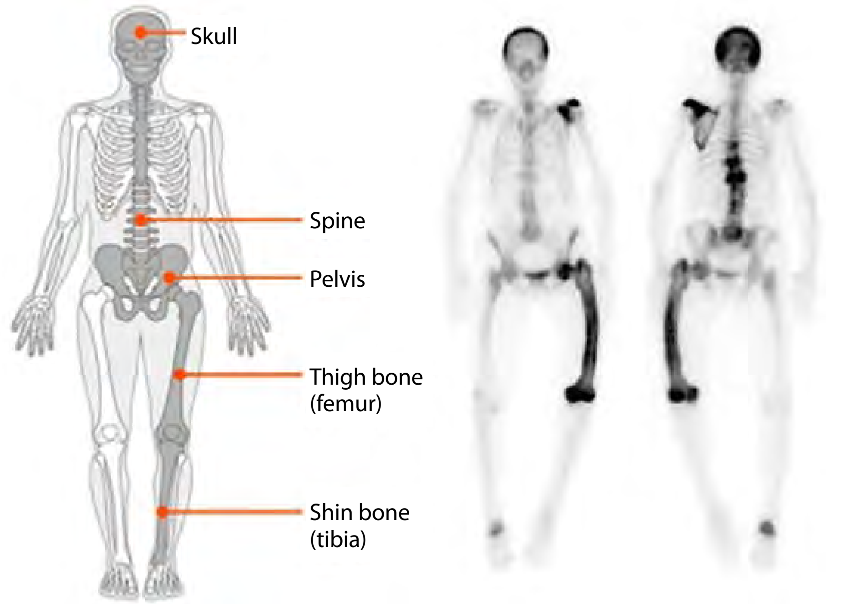
Mark Wilkinson is a Professor of Orthopaedics at the University of Sheffield and Honorary Consultant Orthopaedic Surgeon at Sheffield Teaching Hospitals NHS Foundation Trust. He gave a very interesting presentation at our Paget's Information Day, in Nottingham last year, and has kindly provided the following update for those interested in the role of the orthopaedic surgeon in relation to Paget's disease. A video of his presentation can be found on our website paget.org.uk/information-support/information-videos

Overview

In this article, I will describe the kind of problems a patient with Paget's disease might see an orthopaedic surgeon for, what the typical symptoms are, and how an orthopaedic surgeon might be able to help.

What Causes Paget's Disease?

Throughout our lives, bone is constantly being broken down and rebuilt in a process that doctors call remodelling. This is entirely normal and is part of how our bones adapt to changes, such as strenuous exercise or a break in the bone. Usually, remodelling is controlled by our body's chemicals and hormones. In Paget's disease, the control process does not work properly and becomes accelerated, like playing a record too fast (for those who remember those days!). We do not understand exactly what starts this process off, but we think that some of the answer might lie in our DNA. Whatever the reason, this change in the rate of bone remodelling can lead to changes in the shape, size, and strength of the bones. This is where an orthopaedic surgeon may be able to help.



Picture 1

What Bone Problems can Paget's Cause?

Paget's disease can be seen on the x-rays of one or two in 100 people over the age of 55 years, in the United Kingdom, the most commonplace in the world to find Paget's disease. In the majority of people, the disease causes no symptoms at all, but for others this is not the case. Problems include:

- Pain within the bone or adjacent joints.
- Deformity of the skull can cause headaches.
- When the enlarged bone with Paget's disease causes strain on a joint, this can lead to wear and tear arthritis.
- Because bone in Paget's disease is being remodelled more quickly than is usual, the bone can become softer than normal, causing it to develop a bend or cause a break.
- If the size of the bone increases, this can put pressure on the nerves that run through gaps in the bone.

For example, when the skull is affected, this can result in deafness and can also cause numbness in the face or other parts of the body.

- You might also have heard that Paget's disease can cause bone cancer. This is true, but is very, very rare, affecting less than 1 in 1,000 people.

Bent Bones and Breaks

Paget's disease might affect only one bone (monostotic), but most commonly it affects several bones (polyostotic). The most commonly affected bones are the pelvis, thigh, spine, skull, and shin.

Picture 1 (page 14), on the left, shows a drawing of the skeleton and names the bones. The images on the right show a patient's bone scan, seen from the front and back. The patient has polyostotic disease affecting the skull, left shoulder, spine, and left thigh bone. Some bending of the long bones that take the weight of the body, such as the thigh or shin bone, occurs in around one in ten people with symptomatic disease, and can make the bone more likely to break. When a break occurs, it may not happen suddenly, but can feel like an increase in bone pain that is already there and causes increased difficulty walking. These are known as fissure fractures. When these fractures occur, they can be treated by an orthopaedic surgeon. If there is a bend in the bone, the surgeon will aim to correct the bend by an operation called an osteotomy, at the same time as fixing the break.

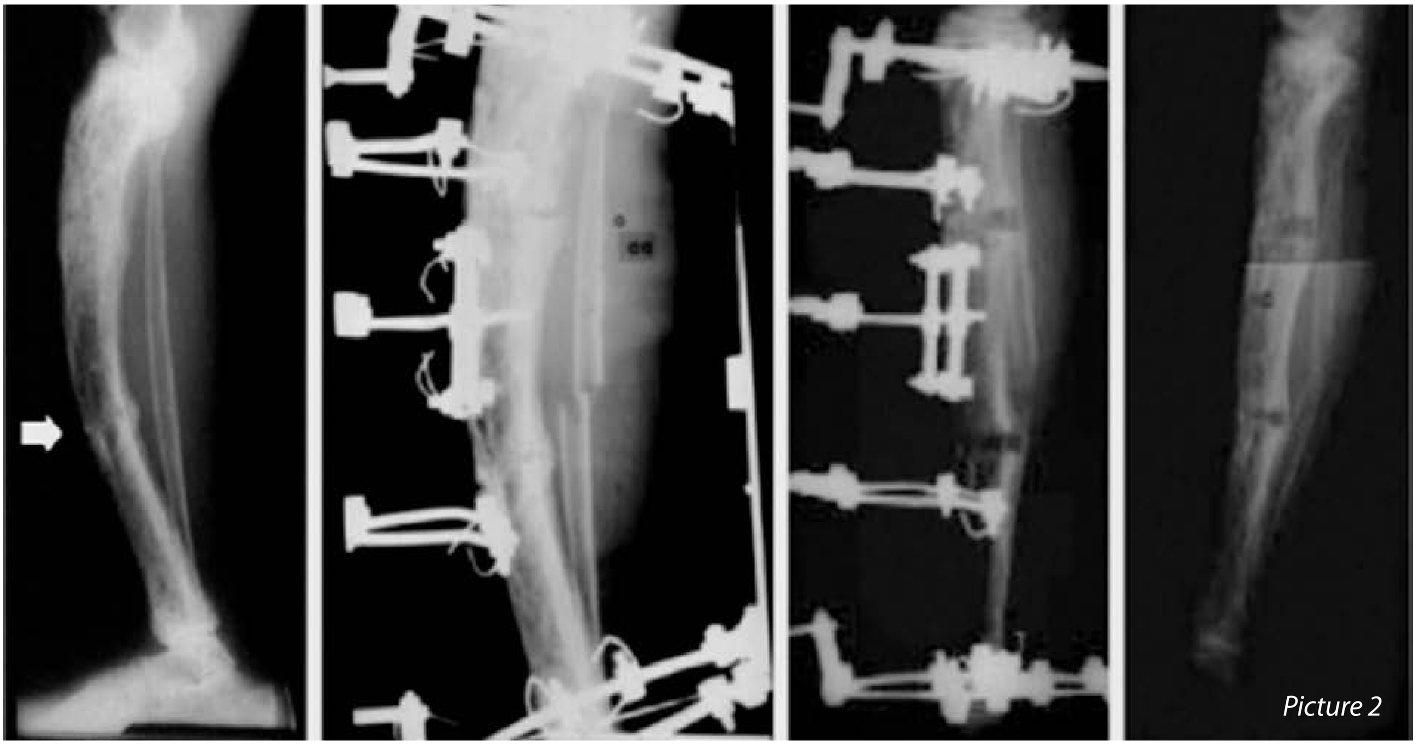
Picture 2 (below) shows a bowing deformity of the shin bone, with the arrow showing where a fissure fracture has occurred. The surgeon has made other breaks (osteotomies) and uses a frame to gradually correct the deformity and, at the same time, fix the fracture. This type of treatment is very successful but can take many months of wearing the frame until the treatment is complete.

An interesting fact about treatment of fractures in Paget's disease is that when the bone heals, it usually occurs with normal-looking bone at the site of the fracture, rather than appearing as bone affected by Paget's disease (pagetic bone).

Joint Pain and Arthritis

The changes of Paget's disease usually affect only one side of a joint and is not present in both bones that make up the joint. Paget's disease at one side of the joint does put it at higher risk of developing arthritis. *Picture 3* (page 16) is an x-ray of the pelvis that shows Paget's disease affecting the pelvic bone on the right side of the image. This can be seen as coarse texture of the bone, and is bigger than the same bone on the other side of the pelvis. The hip joint has arthritis due to the Paget's disease. This can be seen, as narrowing of the gap, between the bones at the hip joint, on the right of the image, compared to the hip joint on the other side. Use of the joint, such as walking, makes arthritis joint pain worse. The pain is also often worse at night and can affect the ability to work and engage in social activities.

(continued on page 16)



Picture 2

(continued from page 15)

Picture 3

Picture 4

Even daily activities such as dressing can cause problems.

Arthritis in Paget's disease is a problem, and this is where an orthopaedic surgeon can help. Usually, we ask that doctors treating patients with Paget's, control the disease activity before we treat the arthritis. Usually, active Paget's is a problem that can be dealt with fairly easily using bisphosphonates, and we then see a fall in the blood markers of the disease. This treatment is thought to reduce the amount of bleeding at the time of surgery.

Provided that the bone is not bent, we use the same joint replacement implants in patients with Paget's disease as we do in those with regular arthritis. *Picture 4* shows the same patient as in *picture 3*. The patient's arthritic hip has now been replaced.

When the bone is bent as well as having arthritis, then the operation might need to correct the deformity as well, but we have ways of doing that too!

Patients with Paget's disease experience a similar amount of pain relief and improved function as patients having the operation for regular arthritis, and the joint replacement does not wear out more quickly. Nor does it seem to matter which method is used to fix the implant into the bone (used with or without bone glue), as both types seem to last equally well.

Back Pain and Spinal Canal Narrowing

Back pain in Paget's disease can be due to bone pain from the disease itself, or because of wear and tear changes in the small joints of the back. In most cases, this can be treated with simple measures, such as maintaining a healthy weight, back strengthening exercises and regular activity. Sometimes the disease can cause narrowing of the spinal canal and nip the spinal cord, or cause narrowing at the point where the nerve leaves the spine. Where the spinal canal is narrowed it can cause symptoms of an aching in the buttocks and legs that can be accompanied by weakness in the legs on walking, and occasionally numbness in the legs.

Where the symptoms are severe or worsening, they can often be treated by spinal surgery. This sort of surgery can involve opening up the tightness, at the site where the nerve leaves the spinal canal (called a decompression) or can involve removing parts of the bone and fusing some of the spinal bones.

Paget's Disease and Bone Cancer

Very rarely a cancer can grow in pagetic bone. This happens in about one in a thousand people with the disease and is more common in older patients and men. Treatment for this problem depends on the bone involved, and the stage of the disease. The possible treatments include surgery, radiotherapy and chemotherapy.

Summary

The most common reason that a patient with Paget's disease sees an orthopaedic surgeon is when they come with arthritis and are seeking advice about joint replacement. Usually, Paget's disease is an incidental finding on their joint x-ray. Occasionally, we see patients who have a problem which is directly related to their disease. In these cases, the surgeon will liaise with their medical doctor about the best way to treat the problem. Orthopaedic surgeons have a wide range of possible treatments for these problems and most treatments are just as successful in the patient with Paget's disease as in those without the disease, although the operating itself can sometimes be more challenging.

J Mark Wilkinson, PhD, FRCS.

Professor Wilkinson speaking at our event in Nottingham

Southampton Paget's Information Day

It is with regret, that due to the health concerns relating to the coronavirus (COVID-19), the Paget's Association has taken the difficult decision to postpone the Southampton Paget's Information Day, which had been due to take place on 16th October this year. It will now be rescheduled for next autumn.

We hope as many of you as possible will join us in Southampton next year. We will provide more details as soon as we have them.

International Paget's Awareness Day

11th JANUARY 2021

Raising Awareness of Paget's Disease of Bone

Don't Forget

International Paget's Awareness Day is

We need your help to raise awareness.
Find further details in the next issue of Paget's News

Share Your Experience of Paget's Disease to Help Others

We would love to hear your views and experiences of Paget's disease and how it has affected you. Whether you want to tell us about how you were diagnosed, how treatment worked for you, or just how you cope day to day, we want to hear from you.

Offer Valuable Support to Others

We know that those who have Paget's disease really value hearing other people's experiences. Whether your story is good or bad, it might just be the support someone else needs, so we invite you to share your experience by completing the form below. This may then be featured in a future Paget's News magazine, for the benefit of all members.

If you like, you can include a photo, but it is not essential.

We are grateful to the members, who have previously shared their experiences

Complete the Form

If you prefer not to remove this form from your magazine, you can photocopy it or type the information into an email and send it to the email address at the bottom of the form.

You do not have to complete all the information and any edits we may suggest will be agreed with you, before publication in the Paget's News magazine.

Name ....

What county do you live in? .... **Are you retired?** ....

What is your current occupation, or if retired, before your retirement? ....

What are your hobbies/interests? ....

Is there anything you would like to share regarding how you were diagnosed with Paget's disease? e.g. Did it take a long time to get a diagnosis?

....

....

What symptoms have you experienced?

....

Have you suffered any complications of Paget's disease? e.g. broken bone, osteoarthritis in the joint adjacent to bone affected by Paget's.

Yes ☐ **No** ☐ **If yes, could you explain briefly?**

…………………………………………………………………………………………

…………………………………………………………………………………………

Have you needed any treatment for Paget's disease or for complications associated with it? Yes ☐ **No** ☐

If yes, briefly describe your experience of treatment.

…………………………………………………………………………………………

…………………………………………………………………………………………

Is there anything you have had to give up or change due to Paget's disease (e.g. driving, hobbies, work)?

…………………………………………………………………………………………

Any other comments

…………………………………………………………………………………………

…………………………………………………………………………………………

What would you say to anyone newly diagnosed with Paget's?

…………………………………………………………………………………………

…………………………………………………………………………………………

Please answer the following questions and note that the main purpose of this is for publication in this magazine. You may only wish to answer yes to the first question, however, if you are willing to permit the Association to use the above information in other ways, then please indicate this by answering the remaining questions accordingly.

Allowing us to use your story in several ways will help us to raise awareness of Paget's disease. You can, of course, withdraw your permission at any time.

Do you give the Paget's Association permission to use the details given on this form and any enclosed or attached photograph of yourself, now, and in the future, in the following ways? *(please tick the box Yes or No)*

1. Paget's magazine, which is also published in the members' area of our website? **Yes** ☐ **No** ☐

2. Other publications (printed or online) that the Paget's Association may produce to help support other members? **Yes** ☐ **No** ☐

3. The public website of the Paget's Association? **Yes** ☐ **No** ☐

4. Presentations/talks at meetings such as Paget's Information Days? **Yes** ☐ **No** ☐

5. Social Media i.e. Twitter, Facebook? **Yes** ☐ **No** ☐

Please give your full details below which are for office use only and not for publication.

Full Name

Address

Postcode

Telephone

Email

Signature

Date

Please post this form to **Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW**

Alternatively, email the information to **diana.wilkinson@paget.org.uk**

Thank you

Discover the Paget's Nurse Helpline

Administrative Assistant, Jen Woodworth, discusses the Paget's Nurse Helpline with Specialist Paget's Nurse, Diana Wilkinson.

Since working in the Paget's office, I have come to understand the vital role the Paget's Nurse Helpline plays in the work of the Association.

The Helpline, managed by a Specialist Nurse, was launched in 2008 and is a listening ear, offering information, support and reassurance for anyone who has questions about Paget's disease. Commonly, people contact the Helpline with queries regarding treatment or symptoms and they are able to discuss their worries or concerns in their own time.

Having previously worked in a busy GP practice, I can see how valuable it is, being able to pick up the phone (without waiting for an appointment!) and speak directly to a medical professional. The help and the reassurance it gives to callers is so important.

We are often asked about the Helpline and so I put the following questions to our Specialist Nurse, Diana Wilkinson. We hope you find them informative.

Jen

When is the Helpline open?

Diana

The Helpline is open during normal office hours. Outside of these hours, messages can be left. I aim to answer all queries within one working day whenever possible. Rest assured that each query received is important and will be answered.

Jen

How can people contact the Helpline?

Diana

Most people contact the Helpline by email or telephone. People can also contact the Helpline by sending a private message through Facebook, Twitter or WhatsApp.

The contact details for the Helpline can be found on the next page.

Jen

Who will callers speak to?

Diana

If you contact the Nurse Helpline, I will usually be the one to deal with your query. Since 2012, I have provided our information and support services.

As a nurse for the Paget's Association, my role is very different to any of my previous positions. When you work for a charity, with just three members of staff, you need to be able to turn your hand to various things in the course of a working week. I may have my nurses' hat on one minute and my technology hat on the next.

Jen

What do you think the best thing about the Helpline is?

Diana

The Helpline has many great attributes. It has a vital role to play in both educating patients about their condition and providing support. Sometimes it is possible to prevent patients being admitted to hospital and to reduce the number of people who decline or stop necessary treatment. If I had to choose one thing, it would be that the Helpline provides a lifeline in the weeks or months that people have to wait to be seen by a specialist. A lot of fear and concern can be eliminated, simply by providing information and dispelling myths during this time. Having the correct information, when you need it most, can make a big difference.

Jen

If someone has been to see their doctor, but the appointment has left them with unanswered questions about Paget's disease, can they contact the Helpline?

Diana

Of course, doctors have limited time to see their patients, once the patient has left the appointment and had time to process what has been said, they may have many questions.

I can spend more time answering queries and explain terms which may not have been fully understood.

Jen

Is the Helpline only for those who are recently diagnosed with Paget's?

Diana

The Helpline is for anyone who has queries about Paget's disease, whether they are newly diagnosed, or have had the condition for many years. I also answer queries from professionals working with patients, researchers studying the condition and the general public.

Jen

Has the coronavirus (COVID-19) pandemic affected the Helpline?

Diana

With the NHS currently under significant pressure due to COVID-19, it is more important than ever that those concerned about Paget's disease have their questions answered and obtain the support they need. When the UK went into lockdown in March, many people were anxious and contacted me with questions about how COVID-19 could affect someone with Paget's disease. Some of these questions were answered in our last magazine. They are also on our website. I want to reassure everyone that the Paget's Association has continued to offer support to anyone affected by Paget's disease and the ways in which people can contact the Helpline have not changed.

Jen

Do people contact you regarding side-effects of treatment for Paget's disease?

Diana

Yes. The potential for treatment to produce side-effects is a common concern. Often people just want to talk through the treatment they have been advised to have, to enable them to balance the benefits against any potential side-effects. Generally, the benefits of treating symptomatic Paget's disease usually outweigh the risks.

Jen

Are there common questions that you are asked a lot?

Diana

When someone is diagnosed with Paget's disease, they often search the internet and may see extreme cases of the condition, perhaps observing severe deformity in several bones. Aside from treatment, one of the commonest questions at this early stage is "Will I end up in a wheelchair?" Sadly, I still speak to people who have had Paget's disease for many years and are so severely affected that they do need to use a wheelchair. Nowadays, however, the likelihood of those recently diagnosed ever needing to use a wheelchair, because of Paget's, is extremely small because Paget's has generally become less severe.

For those who have had Paget's for many years, the most common question is regarding pain. I am often asked, "Do I need treatment for Paget's as I've developed pain again?" This is a question that only a good assessment can answer. Investigations such as blood tests and x-rays may help to differentiate between the pain of active Paget's disease and other causes, such as osteoarthritis, which can occur at the joint adjacent to pagetic bone.

Jen

If someone has concerns they would like to discuss with you, but are concerned about confidentiality, what would you advise?

Diana

All contacts to the Paget's Association and the Helpline are treated in confidence and in line with our written policies. Those who make contact do not need to be a member and many people contact the Helpline anonymously. If contact details are provided, purely so that I can send information to them, this information is not stored on our database.

Medical information is only shared on a 'need to know basis', for example, if I cannot answer someone's query, I may suggest that I share information with one of our trustees, who may be able to assist.

Jen

Do you have a final message for our members?

Diana

Please, don't ever think that I may be too busy to answer your query. I always want to help and will do so to the best of my ability. If you do not have a specific query, that is fine as I am happy simply to provide a listening ear.

I do want to thank all those who donate, or freely give their time to support the Paget's Association. Without you, I would not be able to provide the information and support that is vital to so many.

Contact the Nurse Helpline

@ helpline@paget.org.uk

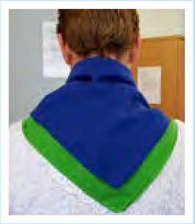
☎ **0161 799 4646**
and ask to speak to
the Nurse

07713568197

@PagetsDisease

www.facebook.com/PagetsAssociation

Shop to Support the Paget's Association

Item	Price	Number required	Total price
Face Mask This single blue and white face-covering (limited stock) has the Paget's Association's logo in the bottom corner and comes with one filter.  Please see our website shop for full details **https://paget.org.uk/shop**	£5.00		
Bobble Hat Embroidered with our logo 	£9.50		
Scarves/Bandanas  	£4.00 per set of 2 (one blue and one green)		
Paget's Tie Blue and green striped tie 	£10.00		
Paget's Badge 	£3.00		
Free Postage and Packing (UK only) Overseas members – please contact us for postage details	**Total Order Value**		£
	Donation		£
	Grand Total		£

Delivery and Payment
Send this completed order form to the address below:
The Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW
Alternatively, telephone the office on 0161 799 4646 or order via the shop on our website: **paget.org.uk/shop**
Please make your cheque payable to 'Paget's Association'. If you would like to pay by debit or credit card please tick this box ☐ and someone from the Association will contact you when your order has been received.

Thank You for Your Support

Name	Postcode
Address	Email
	Tel. No.

Referral for Assessment of Paget's Disease

When you need an initial diagnosis or an assessment of symptoms, it is important that there is a detailed assessment process, ideally carried out by a hospital consultant who understands Paget's disease.

Many rheumatologists and endocrinologists have the expertise to treat patients with Paget's disease and it is likely that most hospitals in the UK have a specialist who has experience of the condition. If there is no specialist locally, then referral to one of the Paget's Association Centres of Excellence might be beneficial.

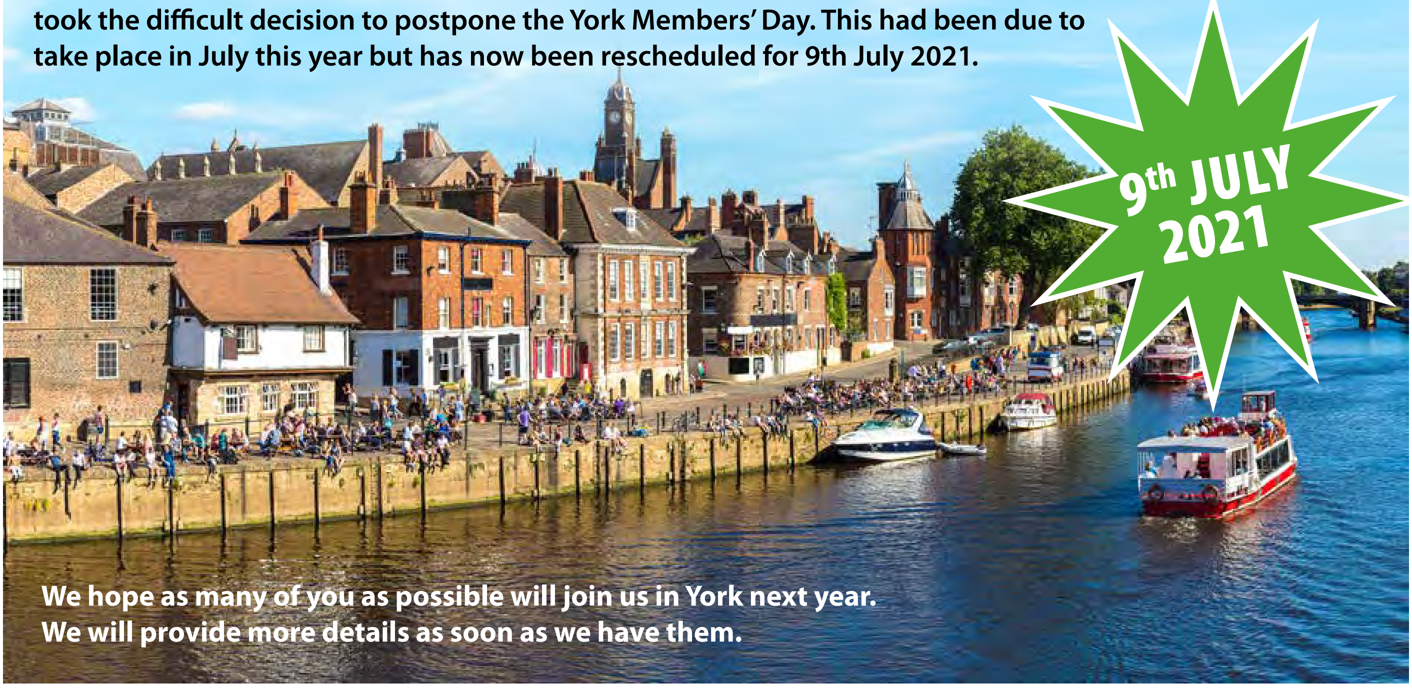
Paget's Association's Centres of Excellence

There are currently twelve Paget's Association Centres of Excellence. Each centre consists of specialists within NHS hospitals caring for patients, and researchers studying Paget's disease. For full details, please visit our website or contact the Paget's Association's office.

- **Edinburgh**
- **Newcastle upon Tyne**
- **Middlesbrough**
- **Liverpool**
- **Manchester**
- **Salford**
- **Sheffield**
- **Nottingham**
- **Norwich**
- **Stanmore**
- **Llandough/Cardiff**
- **Southampton**

York Members' Day 2021

Due to the health concerns relating to the coronavirus, (COVID-19) the Paget's Association took the difficult decision to postpone the York Members' Day. This had been due to take place in July this year but has now been rescheduled for 9th July 2021.



**We hope as many of you as possible will join us in York next year.
We will provide more details as soon as we have them.**

Paget's Office Update – Life in Lockdown

Virtual meetings helped our team to stay in touch

At the end of March, our working and personal lives changed in a way we never could have predicted. The new normal, of spending our days at home, and only leaving the house when necessary, affected us all. Here, the Paget's Association's employees explain how the coronavirus lockdown affected their work, our support services, communications, and the Association's finances.

Jen – *Administrative Assistant*

Staying in Touch with Members

Since going into lockdown, Diana, Sue and I have been finding new ways to run all the daily aspects of the office, with as little disruption to our members as possible. We have been lucky to be able to work from home, which has been different, with lunch breaks in the garden, and a more relaxed dress code!

Despite the challenges lockdown has created, we have continued to respond to all phone calls and postal correspondence, and have kept the Association running as smoothly as possible. Being in this new situation has inspired us to evolve some of the services we offer, including launching a new online support group within Facebook. This has generated many requests for information on Paget's disease, which we have been able to email to those requesting it. Members have been encouraged to renew their membership online where possible, and membership packs have still been posted out to new members who have joined since the lockdown started.

Although this has been a worrying and at times, quite surreal experience, it has taught me to value things I had previously taken for granted. Some of these things include being able to visit my family who live nearby, meeting up with friends, and being able to eat out at restaurants (a favourite hobby of mine!). When things do return to 'normal' I will appreciate the little things in life which I had previously taken for granted, that are actually so important. In this situation, I have seen a great amount of kindness and unity between people, which I hope remains long after this virus has gone.

Diana – *Specialist Paget's Nurse*

Maintaining Support and Information Services

In a rapidly changing situation, it was important that, firstly, I maintained the Nurse Helpline, which fluctuated from periods of quiet to flurries of concerns related to the pandemic, such as delayed treatment and appointments. I also pursued new ways to provide support and information, increased communication with those in need, updated our website and interacted with members of our new Facebook Support Group.

As employees, we each adapted in different ways and I would like to say a huge thank you to our Chairman and Trustees for the support they gave and continue to give us, allowing us to modify our working lives, as necessary. Whilst, due to the nature of my role, I've always been equipped to work remotely, my colleagues, Sue and Jen, also required that facility and as a result, we found new ways to connect and virtual meetings became the new norm. As things begin to return to normal, we will continue to use these to enhance our communications.

The cancellation of some events and meetings was sad but necessary, and I do miss these important face-to-face connections. Consequently, I have spent additional time providing information and have been busy producing a leaflet aimed at researchers and educators, alongside an information booklet for health professionals. I have also introduced a new pain section on our website.

From a personal perspective, not being able to visit family and friends, especially those who were ill, has been one of the worst things about the pandemic. I have appreciated the sanctuary of my garden, which has definitely benefitted from extra attention. Finally, as I write this, our spaniel is sitting at my feet, so I should say, she has also enjoyed extra attention and in return, we have benefitted from her heartening companionship.

Sue – *Office Manager*

Continuity and Financial Stability

Understandably, during a global pandemic, it is not just health that is affected, but also the economy. In March the Association's investments fell rapidly by 14%. Having responsibility for the finances of the Association, my priority was to liaise with our Finance Committee and together we ensured there was sufficient money accessible to us, to allow the Association to continue its day-to-day running, without having to draw on investments. I am pleased to say that there has been some recovery within the markets, which has meant our investments are now down by only 5%.

Many charities over the last few months have struggled because of costly overheads, and reliance on income from charity shops and fundraising activities, both of which have been massively curtailed, with the closing of non-essential shops and the lockdown. The Paget's Association, as a small charity, has been used to working with limited resources for many years. Our members, however, are supportive and appreciative of the help they receive from the Association. There are those who show their gratitude by donating on a regular basis, giving the Association some financial security in its planning, and there are those who remember the Association in their Will. It is from such money given recently, that the Association has been able to weather the storm of COVID-19, allowing it to adapt its working practices during this unprecedented time. I would like to take this opportunity to thank all our members for their loyal and continued support, and for the many donations we have received recently, to enable our work in supporting you to continue.

A Public Education Programme

Last year, Elizabeth Radley was presented with the Winifred Ditchfield Educational Award, in memory of Winifred, who had Paget's disease. Elizabeth is a PhD student at the University of Nottingham, who explains below how she used the Award to produce public education kits designed to raise awareness and understanding of Paget's disease.

Regular readers of Paget's News will remember the collaborative research project coordinated by the University of Nottingham. This work was supported by the Paget's Association and identified an ancient and unusual form of Paget's Disease of Bone within a collection of 130 medieval skeletons unearthed at Norton Priory in Runcorn, Cheshire.

Representing one of the first 'molecular' diagnoses of an ancient bone disease, the research expanded our understanding of the natural history of Paget's disease. This attracted a lot of media attention, with news articles published around the world and even a short section on BBC News!

Winifred Ditchfield Educational Award

Clearly, the public was interested in the molecular mechanisms of Paget's disease, both modern and ancient (as well they might be, it is very interesting!). To build on this and raise public awareness of Paget's disease, I was awarded the Winifred Ditchfield Educational Award.

I would like to express my sincere thanks to the Michael Davie Research Foundation who supported the Paget's Association in creating this new educational award, and Professor Ditchfield who supported the award in memory of his mother, Winifred Ditchfield.

Designing Educational Kits

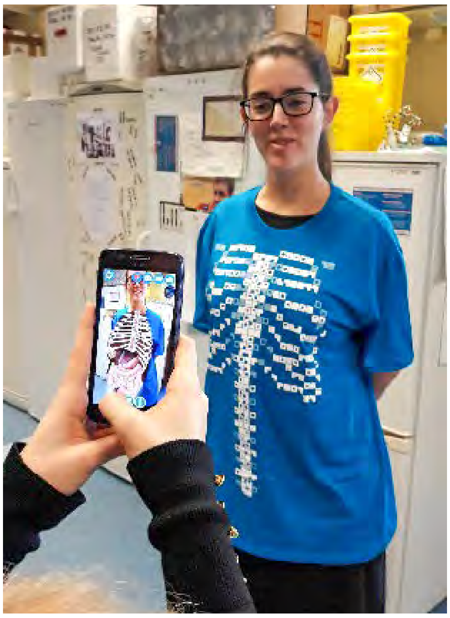
Over several months I worked with researchers, public engagement experts and members of our 'target audience', to find out how we could engage the public with Paget's disease research. As a result, I designed awareness kits which can be used at different events, such as Paget's Information Days, science festivals, and community events.

These portable and reusable kits use simple hands-on activities to explain complex ideas around the biochemistry, medicine, and archaeology of Paget's research. In total, three kits were produced, each focusing on one of these subjects. The image (left) shows some of the activities which are included in the kits.

What Do the Kits Contain?

Each kit contains 15 to 20 different activities around the specific topic. Given the diversity of the target audience, I kept the activities simple, with a flexible amount of medical, scientific and historical background information provided. These make the kits highly re-usable and sustainable; they need little adjustment to transition, from use with an audience of patients, to an audience of children visiting an archaeology museum, for example. I hope that a wide range of people will enjoy the activities. There is something for everyone and the audience chooses the level of medical biochemistry they explore.

New to Paget's and want to find out what it is all about? Or just want to play with virtual reality? Grab one of the Curiscope t-shirts (shown on page 27) and use a phone or tablet to take a virtual reality tour *of your own skeleton.* You can even sync it to your own heart rate! Compare this to the 3D printed pagetic



Lizzie demonstrates the Curiscope t-shirt

bone (pictured, below) and follow it up with the posters and information boards for an overview of the condition and to see how it affects your skeleton.

- **Already know about Paget's disease and want to learn how it actually works? Explore protein networks by trying to beat the Protein Jenga Tower, which mimics how proteins build up and interlock to form networks in healthy cells. But beware, one protein block out of place and the whole thing comes tumbling down! For more of a challenge include the wobbly protein blocks, such as Sequestosome 1 in Paget's disease, which make it harder to build your protein tower.**

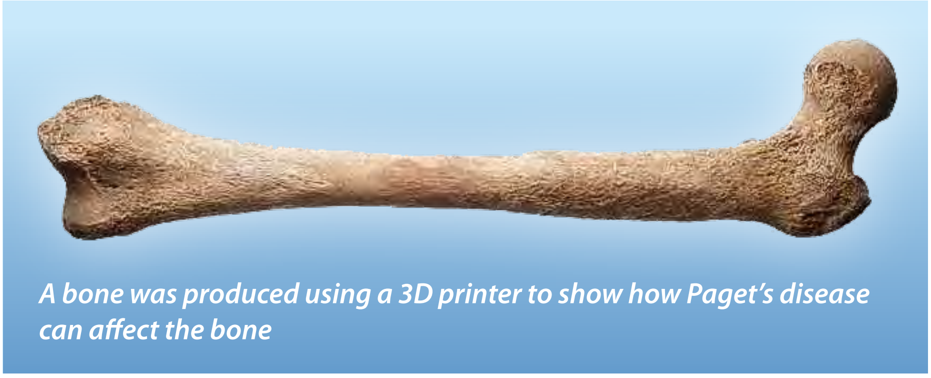
- **Feeling crafty? Make a movable skeleton hand, or get creative with some playdough to make a model of the Sequestosome 1 protein, which is linked to Paget's.**

- **Of course, there is the obligatory activity with pipe cleaners – you can use them to get an in-depth look at how scientists are understanding protein shape and how it relates to disease.**

- **Inspired by all the (really cool) science? Play the Spot the Scientist wordsearch or the Find Your Scientist Name game and learn about some key scientists and archaeologists.**

- **There are also jigsaws to identify proteins from ancient skeletons, pin the tail on the donkey inspired games (okay, pin the biochemistry on the archaeology), take-home activities to turn your own kitchen into a science lab, colouring books, origami proteins, bendy skeletons, and computer-aided designer proteins.**

Each kit comes complete with instructions, an information display board and everything you need to get stuck in with the cutting edge biochemical science that researchers, like those at the University of Nottingham, are conducting, to understand what Paget's disease is, how it has developed throughout history, how it affects individuals and how we can help manage it.



A bone was produced using a 3D printer to show how Paget's disease can affect the bone

Using the Kits

This project was perfectly timed to coincide with the media attention surrounding the research into ancient Paget's disease, establishing a legacy of long-term public awareness of Paget's disease and the Paget's Association. Exhibition of the kits at Paget's Information Days, community events, institution open days and science festivals will raise awareness of Paget's, the Paget's Association and the vital research it funds. It could also encourage uptake of science, technology, engineering and maths subjects into Higher Education and will hopefully encourage further cross-disciplinary collaborations between biochemists, archaeologists and medical charities.

Long Term Results

Making these kits available to a wide variety of events will help increase visibility and awareness of Paget's in the general public. This will raise understanding with those who have never heard of the condition. I hope increasing awareness of Paget's disease in this way can have longer term effects, such as helping patients understand and feel comfortable with the management of their condition. Medical diagnoses and treatment plans can be daunting and feel detached from the patient's day-to-day life and experience, and I hope that by trying some of these interactive activities, people can understand the processes behind their symptoms and can connect with their treatment.

Overall, I hope that using these kits will be just as fun and educational for the public as designing them was for me. The Winifred Ditchfield Educational Award was a great opportunity and I look forward to seeing the kits in use!

New Cards Spread Awareness of Paget's and Help Protect the Environment

DontSendMeACard.com

If you want to help reduce paper waste and make sending a card easier, you may wish to consider sending an electronic card (e-card), which supports the Paget's Association at the same time.

By donating the cost of a traditional card and postage, you can support our vital work without being out of pocket.

There is a wide range of card designs to choose from, including special designs created by the Paget's Association to help raise awareness of Paget's disease.

Full details and all designs can be found at **www.dontsendmeacard.com**

How it works

If you want to send multiple cards, you can send them all at once or tailor each message and send them individually. You could, for example, send a thank you card to a group of friends or wish someone a Happy Birthday! Why not take a look? The minimum donation is just £1.

1. Visit **www.dontsendmeacard.com**
2. Click on **'e-cards'** and then **'Find a Charity'**
3. Type **'Paget's'** into the search facility
4. Click on **'Paget's Association'**
5. Choose a card design (you can send cards to 100 different recipients for one donation)
6. Type your message to the recipient
7. Decide how much you would like to donate
8. Read the terms of use
9. Pay online

Thank You

We want to pass on our thanks to those of you who have already used this service to send cards to your loved ones, helping to support the work of the Paget's Association.

DontSendMeACard.com

Bright and Cheerful Photographic Competition

There is still time to enter our Bright and Cheerful Photographic Competition, to win a £25 shopping voucher plus a Paget's Goody Bag.

We have enjoyed seeing the entries so far! You can enter up to three photographs and the theme to these images should be *'Bright and Cheerful'.* This could be anything, from a photograph of the flowers in your garden which make you feel cheerful, to a pet who brings you happiness. The possibilities are endless, and we would love to see your ideas.

Closing date: **Friday 4th September 2020**

Just send your photographs to us by email or post using the details below.

Email your entry to **diana.wilkinson@paget.org.uk**

Alternatively, post to **Paget's Day Competition, Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.**

Wordsearch Competition

There is still time to enter the Wordsearch competition, which was published in the May edition of this magazine. The closing date is the **4th September 2020.**

Competition Rules

These competitions are for members of the Paget's Association only. Prizes are non-negotiable, non-transferable and there are no cash alternatives. Only one entry per member for each competition. The competition is only open to UK residents. These competitions are not open to employees, patrons and trustees, or their immediate family. The Paget's Association cannot accept responsibility if emails or hard copies are not received. Entries received after the specified closing date will not be accepted. When you enter the competition, you agree to these rules.

Asda Donates Raffle Prizes

We were delighted when Asda's Pendlebury Supermarket contacted the Paget's Association in June, with the good news that the Association had been selected as the store's charity of the month, to receive goods to the value of £50.

Sue, our Office Manager, went along to Asda to collect the items from Store Assistant, David. In return, Sue took the opportunity to pass on literature about the Association's work. Asda had very kindly selected a variety of chocolates and biscuits, which will be raffled to raise additional funds to aid our work.

Our thanks go to Lisa, the Deputy Manager, and her colleagues at Asda for nominating the Paget's Association.

Tell Your Friends!

The Paget's 200 Club is a monthly draw, open to anyone over the age of 18, so why not encourage your family and friends to join? Participants are in with a chance of winning one of two monthly prizes, £100 and £50. As a bonus, in June and December, the prizes are doubled.

For just £5 a month, it is a great way to support the work of the Association and there will never be more than 200 members in the draw. To join, please email **membership@paget.org.uk** or telephone **0161 799 4646**.

★ ★ ★ ★ ★ ★ Winners ★ ★ ★ ★ ★ ★

April 2020

1st Prize £100	2nd Prize £50
Ticket No. 90	Ticket No. 12
E A Wallace	*J Bell*
Warrington	*Northallerton*

May 2020

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

June DOUBLE PRIZE DRAW

1st Prize £200	2nd Prize £100
Ticket No. 151	Ticket No. 187
M Kelley	*B Leverton*
Stockport	*Wigan*

Gifts in Lieu of Flowers

We are grateful to those who choose to donate to the Paget's Association in memory of their loved one. Such donations help fund and improve services, such as our Helpline, for the benefit of others.

In Memoriam

Barbara Berry

Mabel Saul

Stanley Eager

Shelagh Arthur

Violet Stanton

Alan Keep

Bill Hart

Every Penny Counts

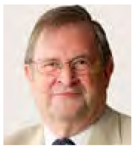
Like many charities, we rely heavily on gifts and legacies. Past legacies are supporting our work now, and gifts pledged today will ensure that we will be here for future generations.

Every penny really does count and will help make a difference to those whose lives have been affected by Paget's disease.

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

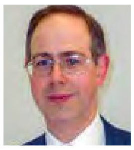


Prof Graham Russell
Emeritus Professor of Musculoskeletal Pharmacology within the Botnar Research Centre, Oxford and the Mellanby Centre for Bone Research, Sheffield, Graham Russell played a key role in the discovery and development of bisphosphonates for the treatment of bone disorders.

Chair of the Board

Prof Stuart Ralston
Chair of the Paget's Association, Professor Stuart Ralston 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 disease.

Vice-Chair



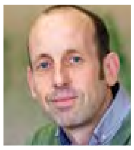
Dr Stephen Tuck
Dr Stephen Tuck is a Consultant Rheumatologist at the James Cook University Hospital, Middlesbrough and Honorary Lecturer at the Institute of Cellular Medicine, within Newcastle University.

Board of Trustees

Dr Anna Daroszewska
Dr Anna Daroszewska is Senior Lecturer and Honorary Consultant in Clinical Biochemistry and Metabolic Medicine, and in Rheumatology, at the University of Liverpool and Liverpool University Hospitals.

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

Mr Peter Jones
A carer for his mother, who has Paget's disease, Mr Peter Jones lives in Gloucestershire and runs his own management consultancy business.



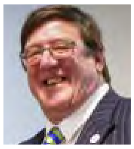
Prof Rob Layfield
Professor Rob Layfield, from the University of Nottingham, researches the protein that was found to carry mutations in some cases of Paget's disease.

Mr Michael Missett
Mr Mike Missett from Derbyshire, retired from working with the Trade Union, Unison.

Mr Michael Patnick
Now retired, Mr Mike Patnick lives in Sheffield and previously worked for Arthritis Research UK, where he was responsible for medical research grants.

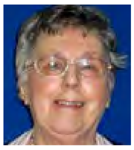
Mrs Janet Strang
From Weston-Super-Mare, Mrs Janet Strang is now retired. She previously worked with various charities including the Royal Osteoporosis Society.

Patrons

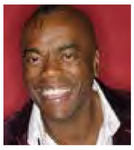


Sir Henry Paget
Sir Henry Paget is the great-great grandson of Sir James Paget, whose name was given to Paget's disease.

The Lord Trevor Stamp
An hereditary peer, Lord Trevor Stamp, before retirement, was a Consultant Physician at the Royal National Orthopaedic Hospital in Stanmore.



Mrs Joyce Cupitt
For many years Honorary Patron, Mrs Joyce Cupitt, served as a Trustee. Her late husband had Paget's disease.



Mr Recardo Patrick
Entertainer and businessman, Recardo Patrick, has Paget's disease. He rose to fame as lead singer with the band, Sweet Sensation.

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.

Get in Touch

Telephone: 0161 799 4646
Email: helpline@paget.org.uk
membership@paget.org.uk

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

Your Gifts Help Change Lives

Your gifts help change the lives of those with Paget's disease and every donation, no matter how small, is appreciated. If you would like to support our work, there are several ways in which you can donate.

HOW CAN I DONATE TO SUPPORT THE WORK OF THE PAGET'S ASSOCIATION?

ONLINE

Visit paget.org.uk
Click on the yellow 'donate' button at the top right and follow the instructions

TELEPHONE

Call **0161 799 4646**
to donate by
debit/credit card

STANDING ORDER

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

POST

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

Face-coverings

Many of you contacted us to express your gratitude for the complimentary face-covering we sent you and we wanted to say how much we appreciated your feedback. Thank you all.

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Thank you to all those who Gift Aid your donations to allow us to reclaim tax.