Referral for Surgery in Paget’s Disease

Dr Tuck discusses the reasons why surgery is occasionally required

New Research Bursary | Members Share Experiences | Spinal Stenosis | Cyclists Wanted
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Office Manager
Sue Clegg

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Helpline email: helpline@paget.org.uk
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REFERRAL FOR ORTHOPAEDIC SURGERY IN PAGET’S DISEASE OF BONE BY DR. STEPHEN TUCK

SPOTLIGHT ON MIDDLESBROUGH

ALLAN REID STUDENT RESEARCH BURSARY 2016

ASK AN EXPERT!

PAGET’S INFORMATION EVENTS 2016 – LIVERPOOL & NORWICH
CONTENTS

4 Chairman’s message – Professor Roger Francis
5 Referral for orthopaedic surgery in Paget’s Disease of Bone by Dr. Stephen Tuck
10 The Paget’s Association Centre of Excellence Award
11 Spotlight on Middlesbrough
12 Allan Reid Student Research Bursary 2016
14 Paget’s Information Events 2016 – Liverpool & Norwich
16 Members share their experience of Paget’s Disease
17 Together we can make a difference
18 Support and Information
19 Prize word search
21 Paget’s Research at Norton Priory
22 Spinal stenosis
23 A member shares his experience of surgery
24 Health Professional Meetings
25 Paget’s disease within archaeological remains – a presentation by Carla Burrell
26 Reduce your inheritance tax bill
27 Shop Online
28 Thank You for Your Support

SPINAL STENOSIS – A MEMBER’S EXPERIENCE

PAGET’S DISEASE WITHIN ARCHAEOLOGICAL REMAINS – A PRESENTATION BY CARLA BURRELL
Chairman’s message

Dear Member,

As you will be aware, the Paget’s Association has identified ten Centres of Excellence around the UK. We are now arranging visits to each Centre, to present a plaque commemorating the award and highlighting their important contribution to the provision of services to patients with Paget’s disease and research into the condition. The first of these visits was to Middlesbrough in November, when I was delighted to present a Centre of Excellence plaque to the Rheumatology Department at James Cook University Hospital. A Clinic for the management of patients with bone disease was set up in Middlesbrough a number of years ago by Dr. John Fordham. The excellent work of the Metabolic Bone Clinic has continued under the leadership of Dr. Stephen Tuck, providing treatment for patients with Paget’s disease and other bone disorders, as well as pursuing important research into bone disease. The presentation was followed by an educational meeting, attended by a number of our members.

The second visit was to Nottingham in January, where the University of Nottingham and Nottingham University Hospitals NHS Trust were jointly recognised as a Centre of Excellence. The presentation was followed by an educational meeting, attended by local hospital doctors, GPs and patients.

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and research into Paget’s disease.

The Paget’s Association is keen to
foster close collaboration between
clinicians treating the disorder and
scientists investigating the causes
and potential new treatments.

In order to improve knowledge
about the investigation, diagnosis
and treatment of Paget’s disease
among GPs and hospital medical staff
outside the Centres of Excellence, we
are continuing to work on new UK
Guidelines, as the previous document
was published in 2002 and does not
include information on the newer
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from the European Calcified Tissue
Society and International Osteoporosis
Foundation, we have commissioned a
comprehensive systematic literature
review, to ensure that we identify
all the relevant research papers. The
results will be used to make sure that
the new UK Guidelines are evidence
based wherever possible and will
be helpful when Guidelines are
developed in other countries with
different health care systems and
licensed drug treatments. Depending
how long the systematic literature
review takes to complete, we may
develop a UK care pathway, to provide
guidance on the management of
Paget’s disease until the new Guideline
is available.

As we have recently received a
substantial legacy to support research
into Paget’s disease, the Trustees have
decided to re-launch our Research
Grants Programme. As many of our
members have highlighted the
problem of pain, we are particularly
interested in supporting projects
which address the causes and
management of pain in patients with
Paget’s disease. Full details will be
available on our website.

Following the successful award of
the Doreen Beck Student Research
Bursary to Carla Burrell last year, we
are also now inviting applications for a
Student Research Bursary in memory
of Allan Reid (details on page 13).

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Nottingham is a good example of
such collaboration, with the excellent
clinical service and clinical research
programme developed by Professor
David Hosking, now run by Dr.
Peter Prinsloo, and the pioneering

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Research Grants Programme

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Roger
Referral for orthopaedic surgery in Paget’s Disease of Bone

by Dr. Stephen Tuck

Dr Stephen Tuck is Vice-chair of the Paget’s Association, Honorary Senior Lecturer at the Institute of Cellular Medicine, Newcastle University, and Consultant Rheumatologist at the James Cook University Hospital.

Despite the very good treatments we have for controlling the activity of Pagetic bone there is still occasionally the need for involvement of orthopaedic surgeons. This is usually because of complications arising as a result of the changes the condition causes in bone size, structure and deformity. There are a number of possible reasons to refer to orthopaedic surgery in Paget’s disease of bone. These include:

1. The necessity to correct for deformity, e.g. of the lower limb
2. Joint replacement because of secondary osteoarthritis
3. Neurological complications, e.g. spinal canal stenosis
4. Fracture of bone weakened by Paget’s disease
5. Prophylactic insertion of rods to prevent complete fracture of areas of micro-fracture especially in weight bearing areas.
6. The very rare development of bone tumours, e.g. osteosarcoma.

There are many factors to consider when it comes to surgery on Pagetic bone. First of all, untreated Pagetic bone is highly metabolically active.

As a consequence of which it has an increased blood flow, which could result in excessive loss at the time of surgery. It is therefore considered advisable that the Paget’s disease is brought under control prior to any bone surgery, for example with intravenous zoledronic acid. This may well require careful co-ordination between the physician treating the Paget’s disease and the surgeon who is to operate. The activity of the Paget’s should be checked prior to surgery and if necessary treated to bring bone cell activity under control. It is believed that doing so will minimise blood loss.

The increased and uncoordinated bone cell activity results in both bone expansion and deformity. Despite this the resultant bone is brittle and more likely to break. So one reason why Paget’s patients come to the attention of trauma surgeons is because of fractures. The altered shape and bone enlargement also puts extra stress on neighbouring joints, which are predisposed to increased wear and hence more likely to degenerate and require replacement. The altered shape and size also needs to be carefully considered when planning surgery as this will need correcting and influence choice of metalwork. The surgeon needs to be aware that the bone is more brittle when operating and take care.

Figure 1 illustrates some of the problems. The x-ray and isotope bone scan show the bony expansion and resultant deformity with the tibia having become bowed. Looking closely at the isotope bone scan one can see that the gentleman in question is actually standing on tip toe on the left leg. This is because the bowing has led to leg shortening causing problems with walking and bone. The knee is also showing signs of loss of cartilage with reduction in joint space and secondary osteoarthritis. One way to have helped this man would have been to ask an orthopaedic surgeon to consider operating to remove a wedge of bone in order to straighten the leg (an osteotomy) and/or joint replacement. This particular patient, however, had too many co-morbidities (other illnesses) for surgery to be considered. He was therefore treated with zoledronic acid to control the activity of his Paget’s and also received pain killers (analgesics), physiotherapy and sent to orthotics. The orthotics department provided him with insoles to build up the height of Continued over
his shoes and help with the leg length discrepancy. All of these things improved his symptoms and made him much more comfortable. Walking aides such as walking sticks and frames should also be considered. Such approaches, as well as occupational therapy, should really be considered prior to any surgical referral as it is possible that they may delay or even render surgery unnecessary.

Nevertheless, despite the physicians best efforts surgery may be necessary. The neighbouring joint may become so worn so as to require joint replacement. Before sending a patient to the surgeon it should first be established if the joint is sufficiently damaged and is having a significant impact on their lives so that the benefits of surgery will outweigh the risks. An x-ray will show the degree of damage, but this doesn’t always correlate with symptoms. There are a number of standard questions that can be used to assess the severity of impact on day to day life. These include:

- rest pain
- pain on standing
- how far the patient can walk without pain or having to stop?
- does it disturb sleep and if so how often?
- ability to use stairs
- if the patient drives, how far can they drive without pain/having to stop?
- can they get into and out of cars and how difficult is this?
- can they cut their toe nails?
- can they put their shoes and socks on?
- difficulty dressing
These questions are equally applicable to knee and hip replacements. Once the surgeon sees the patient they need to consider: the bone cell activity which may result in increased blood flow as mentioned above, altered shape of the bone, altered architecture and fragility, and also the possibility of involvement of neighbouring bone e.g. pelvis or femur. Blood loss can be reduced by the use of pre-treatment with bisphosphonates, e.g. zoledronate and the use of a cell saver. Although, with knee replacement, blood loss can be reduced by use of a tourniquet. Most knee and hip replacements are performed under spinal anaesthetic, but the spine can sometimes also be involved with Paget’s disease, making it difficult to undertake spinal anaesthesia necessitating a switch to full anaesthesia. The nature of the bone quality and its shape can influence the planning of the procedure and the implant design that will be used. In a hip replacement the integrity of the pelvis, which is a common site to be involved, must be considered. In the situation of total knee replacement, there may well be knee instability, fixed flexion deformity and altered alignment to be considered and corrected during the procedure.

**Figure 2** shows an x-ray of a 70 year old man who was complaining of right hip pain and was found on routine blood tests, to have an isolated raised alkaline phosphatase. This was investigated by his GP and no explanation was found. He was referred to secondary care and an x-ray confirmed the presence of Paget’s disease. A subsequent isotope bone scan demonstrated the extent of the disease. His Paget’s activity was brought under control with zoledronic acid, but he continued to suffer severe problems with his hip which were solved after a total hip replacement.

*Continued over*
Figure 3 illustrates another case of a 68 year old man who presented with a hip fracture to the trauma surgeons who noted at the time of fixation that the bone quality was rather odd and x-rays confirmed that the fracture had occurred because of Pagetic involvement of his femur. The gentleman was referred to the bone clinic and he was found to have extensive Paget’s disease on isotope bone scan. There was also uptake in the spine, which x-rays confirmed to be due to Paget’s in the spine (figure 4). He was also noted to have bilateral hearing aids possibly because of skull involvement. Blood tests revealed very high levels of bone cell activity with an alkaline phosphatase of 868 u/L and a beta crosslaps of 1051 ng/L. These came down rapidly in response to intravenous zoledronic acid to 90 u/L and 200ng/L respectively. The importance of knowing the extent of Pagetic involvement became apparent a few years later when, despite good biochemical control, he presented with back pain and symptoms of spinal canal stenosis. The spinal canal stenosis was confirmed with MRI. A further infusion of zoledronic acid was given in part to ensure that there was no residual activity prior to surgery, but also because occasionally treatment of the Paget’s can result in resolution in spinal canal stenosis symptoms preventing surgery. In this particular case zoledronic did not work, but he did very well with surgical intervention and has remained well ever since.

Pagetic bone doesn’t always fracture completely, but can develop partial fractures. These can be very small, so called micro-fractures. Figure 5 shows an x-ray of a person with Paget’s disease in the humerus of their upper arm with micro-fractures. These can subsequently progress to full fractures and can be a cause of pain when the
Paget’s disease is otherwise well treated. They sometimes respond to intravenous bisphosphonates such as pamidronate, which worked well for this patient. In a weight bearing bone, prophylactic insertion of metal rods by an orthopaedic surgeon should be considered in order to prevent complete fracture.

The final reason to require referral for surgery is the development of malignant transformation of the Pagetic bone, for example to osteosarcoma. An example is shown in figures 6 and 7. This affected a man in his 90’s who had had Paget’s disease of his left tibia for at least thirty years. Despite good treatment of his condition he went on to develop further pain in his femur and x-rays sadly confirmed the presence of osteosarcoma. This requires referral to a centre that specialises in bone tumours. It should be emphasised that this is an extremely rare complication of Paget’s disease of bone.
The Paget’s Association Centre of Excellence Award

Care, Treatment & Research for those with Paget’s Disease of Bone

As the only charity in the UK dedicated to Paget’s Disease of Bone, The Paget’s Association is keen to improve patient access to appropriate specialist care and address the apparent lack of understanding of the condition.

The Paget’s Association Centre of Excellence Award recognises hospital and university departments which demonstrate excellence in both the treatment of Paget’s disease and research into the condition. In November last year, ten award winning centres were announced. It is anticipated that further centres will be identified in due course, to allow easier access to specialist care right across the UK.

Paget’s Association Centres of Excellence

The award winning centres and their directors from north to south of the UK are:

- **Professor Stuart Ralston** at the Western General Hospital and University of Edinburgh
- **Dr Terry Aspray** at the Freeman Hospital in Newcastle upon Tyne
- **Dr Stephen Tuck** at The James Cook University Hospital, Middlesbrough
- **Professor Terry O’Neill** at Salford Royal NHS Foundation Trust, Salford
- **Professor Peter Selby** at Manchester Royal Infirmary
- **Dr Nicky Peel** at the Metabolic Bone Centre, Northern General Hospital, Sheffield
- **Dr Peter Prinsloo** at Nottingham City Hospital, in collaboration with Dr Rob Layfield’s research programme at the University of Nottingham
- **Professor Bill Fraser** at the Norfolk and Norwich University Hospital and the University of East Anglia
- **Dr Richard Keen** at the Metabolic Bone Unit, Royal National Orthopaedic Hospital, Stanmore
- **Dr Mike Stone** at the University Hospital Llandough and Cardiff Royal Infirmary
The first Centre of Excellence award ceremony took place in November at The James Cook University Hospital, Middlesbrough. Professor Roger Francis, Chairman of the Paget’s Association, presented Dr Stephen Tuck, director of the Paget’s Association Centre of Excellence at the hospital, with a plaque which will be displayed in the Rheumatology Department.

Professor Francis, said, “James Cook University Hospital has been awarded centre of excellence status in recognition of the comprehensive range of services developed for the management and support of patients with Paget’s disease of bone, together with plans for research into the treatment of the condition.”

Dr Stephen Tuck, accepted the award expressing his thanks to all those involved, saying, “I am very honoured that the department of rheumatology has been given this award from the Paget’s Association. We have an excellent team and patients being referred to James Cook should be reassured that they will be receiving quality care.”

Following the presentation an educational event, to which all local GP’s were invited, was held in the lecture theatre. Speakers included Professor Francis, Dr Tuck, Dr Rob Layfield from Nottingham and our Specialist Nurse, Diana Wilkinson who commented, “It was good to see health professionals coming together to extend their knowledge. I would like to thank all concerned for making the event a success, including the patients who came to show their support. It’s fantastic to be able to shout about the good work taking place in our Centres of Excellence and raise awareness of Paget’s disease”.

The Middlesbrough Centre is based at James Cook University Hospital within the Department of Rheumatology. The Bone Clinic, with specialist treatment of metabolic bone disorders, has existed at The James Cook hospital since 1992 and was founded by Dr Tuck’s predecessor Dr John Fordham. Since taking over Dr Tuck has expanded the bone unit, which now includes a fracture liaison service and clinic for those with Paget’s Disease of Bone, as well as other rare bone disorders. The input of clinical biochemist, Dr Pattman, has been invaluable for the care of metabolic bone disorders. The unit has combined clinics with orthopaedics which allows the careful planning of the control of Paget’s disease prior to undertaking orthopaedic procedures. The dedicated day case unit allows the administration of intravenous zoledronic acid, by nurses familiar with the condition, and the medications used to treat it. The unit provides a tertiary referral centre for complex cases from surrounding hospitals. The rheumatology department has outreach services to Northallerton, Whitby, Redcar, Guisborough and Broughton. The unit remains involved in research, having taken part in the recent ZIPP study. Dr Tuck is currently chairing the committee responsible for the production of UK Guidelines for the Management of Paget’s Disease. It is hoped that the unit can be an integral part of further research and in linking with the other centres of excellence.

Full details of all the award ceremonies and events taking place will be in the news section of our website: www.paget.org.uk Alternatively, telephone the office for details on 0161 799 4646.
Applications are invited for the Allan Reid Student Research Bursary 2016

The Paget’s Association is pleased to announce the Allan Reid Student Research Bursary 2016

Allan Reid

Allan Reid, from Glasgow, died, aged just 57, from Paget’s – associated osteosarcoma, a type of bone cancer that is a very rare complication of Paget’s disease. Allan discovered that he had Paget’s disease when he went for a medical in 2007. Blood tests showed that his Alkaline Phosphatase (ALP) level was high. Further tests revealed Paget’s disease in his pelvis. Little did he know then that he would die from such a very rare complication of the condition just 7 years later, in August 2014.

Fundraising in Memory of Allan

Following Allan’s death, his wife, Norma, his family, and friends set about fundraising to ensure something positive came out of Allan’s passing. So far, over £4250 has been raised. Norma explains, “Everybody loved Allan. He made a wonderful life for his family by creating a successful business and being a super husband, father and grandfather. There has got to be more research into Paget’s disease and Paget’s-associated osteosarcoma. With this in mind we set about fundraising and on what would have been our 35th Wedding Anniversary, in October 2014, fifteen of us cycled around Millport on the Isle of Cumbrae which is over 10 miles. Our little granddaughter, Sophie, came too. Allan only got to know her for a short while but she was his pride and joy. Allan’s best friend, Norman Kerr, set up a JustGiving Page and so many people have donated including all of Allan’s work colleagues”.

Norman’s fund raising page can be found on the JustGiving website: www.justgiving.com/AllanReid

Paget’s Associated Osteosarcoma

Whilst people with Paget’s disease have a very small risk of developing osteosarcoma, it is important to realise that it is extremely rare, occurring in less than 1:1,000. It arises when a change is triggered in one of the main types of bone cell (osteoblast), turning the cell abnormal and becoming cancer-like (malignant). Symptoms can include a significant change in bone shape with swelling in the bone and pain which progressively becomes worse. It is imperative that any new pain or significant change in pain is reported to a doctor. One of the tests the doctor would then carry out is the blood test for alkaline phosphatase, which can be elevated in Paget’s disease and can increase rapidly with the onset of osteosarcoma. It is believed that modern treatments for Paget’s disease may inhibit the development of Paget’s associated osteosarcoma.

The Paget’s Association Allan Reid Student Research Bursary 2016

Family and friends of Allan have agreed that the money collected in his memory should be used for a student research bursary in his name. The Paget’s Association is therefore pleased to offer the Allan Reid Student Research Bursary of £6000, to encourage a promising UK medical or science student to pursue research into Paget’s Disease of Bone.

The closing date for receipt of applications is 31st March 2016. Full details are given on the following page and also on our website: www.paget.org.uk Alternatively email: applications@paget.org.uk or telephone: 0161 799 4646

osteoarcoma.
The Paget’s Association of the United Kingdom is pleased to offer a Student Research Bursary of £6000 to encourage a promising UK medical or science student to pursue research into any aspect of Paget’s Disease of Bone. The Association will provide a stipend to the recipient of the student award to participate in research, under the guidance of an Association Member, to allow the student to study towards an MRes, MSc, BSc or equivalent higher degree in the 2016 to 2017 academic calendar. The recipient is invited to attend the Association’s Annual General Meeting to formally receive the award.

APPLICATION REQUIREMENTS:

› Summary of the research project, jointly prepared by Mentor and Student including student’s role in the research project (1000 words maximum)

› Mentor statement which includes Mentor’s role in the research project including his/her plans for research training

› Student’s CV (mailing address and contact details must be included)

APPLICATIONS:

Applications should be sent by email to The Paget’s Association: applications@paget.org.uk

INTERVIEW

Following shortlisting of the projects, candidates will be invited to an interview to determine the award recipient.

The closing date for receipt of applications is 31st March 2016.
The Paget’s Association & The Bone Research Society

Invite you to Liverpool Paget’s Information Meeting

Date: Wednesday 29th June 2016  
Time: 1pm – 4:30pm  
Venue: The Foresight Centre, University of Liverpool, Liverpool

This meeting will be slightly different to our usual educational events as it is being organised jointly with the Bone Research Society (BRS). The event is for people with Paget’s disease however, health professionals are also encouraged to attend. Tea and coffee will be available.

Topics to be discussed include an introduction to Paget’s disease, treatment, case studies, research, local history of Paget’s and archaeology of Paget’s.

Chair: Dr Anna Daroszewska

Speakers:

Professor Bill Fraser – Trustee of The Paget’s Association & Head of the Department of Medicine, Norwich Medical School

Dr Rob Layfield – Associate Professor in Biochemistry, Nottingham

Dr Anna Daroszewska – Senior Lecturer in Musculoskeletal Biology & Consultant in Rheumatology and Clinical Chemistry, Liverpool

Dr Stephen Tuck – Vice-chair, Paget’s Association & Consultant Rheumatologist, Middlesbrough

Lynn Smith – Curator of Norton Priory Museum, Runcorn

Carla Burrell – Winner of the Doreen Beck Paget’s Student Research Award 2015, Liverpool

Diana Wilkinson – Specialist Paget’s Nurse, The Paget’s Association

If you would like to come along please complete the booking form and return it to the office as soon as possible. If you require further information regarding the agenda please call us on 0161 799 4646.

Booking form for Liverpool Paget’s Information Meeting

I/we wish to attend the Liverpool Paget’s Information Meeting  Number in party attending

Name of 1st attendee

Name of 2nd attendee

Name of 3rd attendee

Name & address for correspondence

Do you have any 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 the above form by post or email to: The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW. sue@paget.org.uk
Our information day in Norwich is particularly for those with Paget’s disease, their families and carers. Health professionals are also welcome. Experts will discuss topics relevant to those with Paget’s disease and a light lunch will be provided.

A small section of the day will be given to the Annual General Meeting of the Paget’s Association. This is your opportunity to find out all that has been happening at the Association in the last twelve months and also to ask questions.

If you are interested in attending the Norwich Information Day please complete the form below and we will send details to you when they become available. Further details will also be in the May edition of Paget’s News.

I /we would like information regarding the Paget’s Information Day in Norwich

Name & address for correspondence

Tel no

Email address

Postcode

Details will be sent to you when they become available.

Centre of Excellence award ceremonies and any Paget’s information events, that are organised alongside them, will be published on our website as they become available

www.paget.org.uk

Please return the above form by post or email to:
The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.
sue@paget.org.uk
Members share their experience of Paget’s Disease

Someone finally took an interest in me

I first noticed a change in the shape of my left leg when I was in my thirties (I am now 80). I visited my GP and she said she thought it was muscular. After a few years the leg was noticeably bowed. My GP then sent me for an x-ray. The doctor at the hospital said it might be Paget’s disease but it was in the early stages and he could not be sure.

I had no more appointments or x-rays for the next ten years and my leg was badly deformed by then. I asked my GP to make an appointment at the hospital again where I was seen by a very nice doctor. My leg was x-rayed and he said it was a nasty looking leg which he found interesting. He told me he would need to consult his associates but I should make an appointment for 6 months’ time. I did this and when I turned up for my appointment the doctor was very rude and asked me why I was there. I told him I was there about my leg and he asked me if I knew I had Paget’s disease. I said yes and his answer was “Well there will be no more appointments”. I was very upset when I left and decided to write a letter of complaint. I visited my GP to tell her what I intended doing and on looking up my records she informed me that she had been sent a letter to inform her that I didn’t need any more appointments. As I had not consulted my GP since my last hospital appointment I did not know this.

Sometime later a friend looked up Paget’s disease on his computer and this resulted in me joining the Paget’s Association. In one of the magazines there was a list of doctors who were interested in Paget’s disease, one of them was a consultant in a hospital near me. My GP arranged an appointment for me to visit this doctor. He was very nice and was amazed that I had never had any treatment for my leg. He wrote to my GP suggesting I had a blood test every two months to check my alkaline phosphatase level. That was about 12 years ago and I am now given a course of Risedronate tablets when necessary. I have not had any medication for some months now so I hope that perhaps the Paget’s is slowing down.

I am lucky to have never had any pain in my leg and can still drive my automatic car. I am very grateful to my friend for putting me in touch with the Paget’s Association, for the Association for printing the doctors’ names, and also to the doctor who finally took an interest in me.

Sarah Miller, Ayrshire

Dear Members,

I am 94 and feel fortunate (after reading the experiences of others in the Paget’s newsletter) that Paget’s has had little effect on me so far. I was diagnosed with Paget’s disease more than 10 years ago but I had no physical problems until a couple of years back, when I started having pain in my thighs. I was given tablets which had little effect. Later, an infusion of Zoledronate proved helpful almost immediately in removing the pain. Since then, I have not had any pain and am not aware of my Paget’s disease at all now.

Regards,
Jack Pitt
Bingley, West Yorkshire
Together we can make a difference

We know that members want to hear from others who have experience of Paget’s disease. Thank you to all those who completed the form in the November edition of Paget’s News which gave you the opportunity to share your experiences, good or bad, for the benefit of others, via this newsletter.

Can you summarise your feelings about the condition in just one sentence? If so, please place your comments here and we will print them in an edition of Paget’s News. Your comments may just help someone who is struggling with the effects of Paget’s disease.

Thank you

Diana

Share your experience

Summarise your feelings about Paget’s disease in one sentence:

Please complete the following – ticking the boxes as appropriate:

I am happy for my name and the town where I live to be printed in the Paget’s newsletter – tick as appropriate:

☐ Yes  ☐ No – I would like my comments to be shown as “anonymous”

Signed

Date

Print Name

Address

Post code

Please post the above information to Diana Wilkinson, The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW or send the above by email to diana.wilkinson@paget.org.uk
Support and Information

Paget’s Nurse Helpline

Your calls and emails to our Nurse Helpline are answered by an experienced Registered Nurse. You can contact Diana Wilkinson, our Specialist Paget’s Nurse by telephone, email or letter.

Paget’s Support Network

The Paget’s Support Network is a free network to enable members to talk to others who either have Paget’s disease or who care for someone who has the condition. Communication can be by telephone, letter or email. It is a free, mutually supportive network and is open to any Paget’s Association member wherever you live in the UK or abroad.

To join the Support Network and speak to others who understand the impact that Paget’s disease can have on your life, please request a form from the office:

0161 799 4646
or email: helpline@paget.org.uk

On receipt of the form, we will send you a list of contacts. Please note that to save postage costs, if we hold an email address for you, we will send the list via email. If you prefer however, to have this sent in the post please let us know.

Volunteers who offer local support

For information regarding local support in the following areas, please contact the number given below. All those named below are members who have kindly volunteered to be a contact for support in their area. Local group meetings may be arranged if there is sufficient interest.

Cambridgeshire: Contact Mrs Ingrid Pryor on 01223 277550
Cumbria: Contact Mrs Doreen Scott on 01946 811366
Northern Ireland: Contact Mrs Deirdre Fleming on 028 3832 8562
South Manchester: Contact Mr Ron Taft on 0161 485 7468
Truro: Contact Mr Robert Lewis on 01209 843678

North Manchester Paget’s Support Group

The Chairman, Professor Francis joined the December meeting of the support group to discuss Guidelines for Paget’s disease. A raffle was held which raised £32.

Next Meeting:
Date: Tuesday 8th March 2016
Venue: The meeting room, Worsley Road United Reformed Church, Swinton, Manchester, M27 0AG
Time: 13:45 – 15:15hrs
Organiser: Our Specialist Paget’s Nurse, Diana Wilkinson

For further information contact:
Diana on 07713 568197 / 0161 799 4646
Email: diana.wilkinson@paget.org.uk

We always welcome discussion about new groups so if you are interested in starting a group or being a named person for support in your area, please get in touch.

Dear Members,

I have recently been told I have Paget’s disease. I am a 37 year old female and am looking for other sufferers within my age group. I am struggling with the diagnosis but am also relieved because at times I thought I was going ‘mad’ as no cause could be found for my pain. I’m sure people thought I was making it up or it was all in my head. I wondered if someone within my age range who has suffered or is suffering with the effects of Paget’s might be willing to talk about their experience.

Simone, Lincolnshire

If you would like to contact Simone please call the Paget’s Association on 0161 799 4646 or email helpline@paget.org.uk
Prize word search

Enter our word search competition for a chance to win a Paget’s Goody Bag worth over £20

With the exception of one, each word written in blue within the paragraphs below, can be found separately in the grid. Words may run forwards, backwards, or horizontally, in a straight unbroken line. One word however, does not appear in the grid - which one? This is your prize answer.

To enter please follow the instructions overleaf.

The Paget’s Association

Founded in 1973, The Paget's Association, also known as the National Association for the Relief of Paget’s Disease, is the only national UK charity wholly dedicated to supporting those with Paget’s Disease of Bone. The Association acts as a resource for patients, carers and health professionals, offering high quality information and support services including our nurse helpline, support network and information days. The Paget’s Association relies on voluntary contributions, gifts, legacies and fundraising activities to continue and to develop its work. We believe that together with our supporters we can build a better future for those whose lives have been or will be affected by Paget’s disease. The aims of the charity are to:

– Offer support and information to those with Paget’s disease
– Raise awareness of the disease among health professionals and the general public
– Support research into all aspects of Paget’s disease

The answer to the November word search was: femur. Congratulations to our winner Mrs Betty Young from London who has received a Paget’s Goody Bag.

The answer to the November word search was:

femur.
Competition entry form
– Prize word search

Post your completed entry to:
The Paget’s Association
Suite 5, Moorfield House
Moorside Road, Swinton
Manchester, M27 0EW

Alternatively, you can enter by emailing the answer with your name and address to:
diana.wilkinson@paget.org.uk
Your entry must be received by
4th April 2016

Competition rules

■ The competition is for members of the Paget’s Association only.
■ The winner will be selected at random from the correct entries.
■ The Paget’s Association’s decision is final.
■ Winners will be notified within one month after the competition closing date.
■ The prize is non-negotiable, non-transferable and there is no cash alternative.
■ Only one entry per household.
■ The competition is only open to UK residents.
■ The competition is not open to employees or their immediate family.
■ The competition is not open to trustees of the Paget’s Association or their immediate family.
■ The Paget’s Association cannot accept responsibility if emails or hard copies are not received.
■ Incorrectly completed entries will be disqualified.
■ Entries received after the specified closing date will not be accepted.

I would like to enter the word search competition and agree to the rules.
The word missing from the grid is

Name

Address

Post code

Your entry must be received by 4th April 2016

The competition is free to enter. Donations are of course, always welcome. We are always keen to hear your views about this newsletter. If you have any comments please tell us here:

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________
Paget’s Research at Norton Priory

Unique to Paget’s members, our 200 Club is a private raffle and by entering you are also boosting our research fund. To enter the draw the cost is £5 each month. You must be a member of the Paget’s Association to take part and each member can have a maximum of two tickets. **The first prize each month is £100 and the second prize is £50.** In June and December however, the prize money is doubled to £200 and £100 respectively. No administration charges are taken out so all money given in this way goes towards research projects, funded by the Association, once prize money has been taken out.

If you would like to take part in the raffle please contact Sue Clegg our Office Manager for further information on 0161 799 4646.

**WELL DONE TO ALL OUR WINNERS**

**WANT TO JOIN OUR MEMBER’S PRIVATE RAFFLE?**

Win Win Win

You may have read in previous editions of Paget’s News that there is a great deal of interest in Paget’s disease at Norton Priory Museum, Runcorn. The museum will reopen in the summer when displays will include information regarding Paget’s disease. Last month a meeting was held to discuss the ongoing Paget’s research. We will update you as the work progresses.

Photo left to right- back row: Lynn Smith, Prof Bill Fraser, Prof Rob Van ’T Hof, Dr Rob Layfield. Front row: Darrell Green, Carla Burrell, Diana Wilkinson, Dr Anna Daroszewska, Prof Silvia Gonzalez, David McIntosh.

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**PRIZE WINNERS NOVEMBER 2015**

**1st Prize: £100**
Ticket No. 52
Mr J Robinson, Leicester

**2nd Prize: £50**
Ticket No. 82
Mr R Powdroll, Leicester

**PRIZE WINNERS DECEMBER 2015**

**DOUBLE PRIZE DRAW**

**1st Prize: £200**
Ticket No. 159
Mr Roy Hobson, Sheffield

**2nd Prize: £100**
Ticket No. 92
Mrs Elsie Woodman, Worthing

**PRIZE WINNERS JANUARY 2016**

**1st Prize: £100**
Ticket No. 156
Veronica Ashton, Maghull

**2nd Prize: £50**
Ticket No. 5
Shelagh Fletcher, Maghull
Paget’s Nurse Helpline

Spinal Stenosis

Our Specialist Paget’s Nurse, Diana, is often asked about spinal stenosis. Here she explains a little about it.

The normal spinal column has a central passage (canal) through which the spinal cord passes down. To each side of the canal, spinal nerve roots branch out at every level. The spinal cord stops at the top of the lumbar spine (lower back) and below that tiny nerve rootlets splay out like a horse’s tail (cauda equina). The normal vertebral canal provides adequate room for the spinal cord. In spinal stenosis, the spinal nerve roots and/or cauda equina become trapped or compressed because the space around the spinal cord is narrowed.

The main symptoms include pain, numbness, weakness and a tingling sensation in one or both legs. This can make walking difficult and painful. Most cases of spinal stenosis result from a gradual, degenerative aging process but there can be other causes. Misshapen and enlarged vertebrae due to Paget’s disease can result in spinal stenosis.

Non-surgical treatments can include physiotherapy, injections or medication. Surgery to relieve the problem is known as decompression surgery and is usually only considered in severe cases, if non-surgical treatments have not helped and symptoms are having a significant impact on quality of life. The objective of surgery is to give the spinal nerves more room. There is good evidence that such surgery can be an effective treatment.

Contact the NURSE HELPLINE

If you require information, support or have a specific query about Paget’s disease you can call, email or write to the Helpline:

Telephone: 07713 568197
0161 799 4646
Email: helpline@paget.org.uk
Write to: Diana Wilkinson, Specialist Paget’s Nurse
The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW

The Yellow Card Scheme

The Yellow Card Scheme is used alongside other scientific safety information to monitor the safety of UK medicines and act as an early warning system to identify potential side-effects and adverse reactions. Anyone can report a suspected side effect or adverse drug reaction. The scheme is run by the Medicines and Healthcare products Regulatory Agency (MHRA) who make changes, if necessary, to the warnings given to people taking a medicine, or to the way medicines are used, to minimise potential risks. Whilst traditionally the scheme used yellow cards sent in the post, reports are now sent via the Yellow Card website: yellowcard.mhra.gov.uk

Last year a free Yellow Card smartphone app was introduced to supplement the website. The app allows patients, carers and healthcare professionals to report problems directly to the Yellow Card Scheme. The information reported assists MHRA to ensure that medicines and healthcare products are safe. Users can search for a specific medicine to report a problem or view a graph illustrating reported side-effects. Users can also track the medicine and receive alerts about it. Reports can also be made for herbal medicines and homeopathic remedies available on the UK market.

The app requires iOS 8.2 or later and is also available on Android.
A member shares his experience of surgery

James Bell has been a member and supporter of the Paget’s Association since discovering he had Paget’s disease in his pelvis, in 2013. He has been troubled with both hip and back pain since the 1970s. Whilst James is not aware of any Paget’s disease in his spine, he has suffered from spinal stenosis and wanted to share his experience of surgery in the hope that it will help others who have a similar problem.

When I left the army (Green Howards Regiment) I was only able to do certain work (lifting was sometimes difficult) so I took any job I could cope with. My back and hip pain started in the 1970s and I didn’t find out that I had Paget’s disease until 2013. I am fortunate to have a first class consultant who looks after my Paget’s disease and this seems stable. It certainly hasn’t stopped me leading an active life. I have enjoyed cycling for many years and used to be able to manage 70 miles a day. Each year I take my grandchildren to Brompton carnival where I enter the fancy dress competition in various guises and sometimes with a bike included (see photos). I’ve also been an active member of re-enactment societies for many years, however, at 79 I’ve now retired from battle. I do though, remain an enthusiastic observer!

My recent need for surgery was as a result of back pain and also pain down my left leg. I was told that a trapped nerve on the left side of my spine was the cause. I was offered surgery to release the nerve and had the opportunity to discuss it fully with the surgeon, but I was quite anxious about it and so refused the operation at first. The pain continued and I gave surgery further thought. I felt I had far too many questions but

I discussed them with the surgeon, my GP, my Paget’s consultant and the nurse from the Paget’s Association. I was always given straight answers, in words I understood, and I eventually decided that whilst surgery wasn’t without risks, the potential benefits outweighed them. Decision made!

I was in hospital overnight and returning home I was told only to lift a teapot and kettle for 6 weeks which is not easy for a busy bee like me! I must report now that I managed my convalescence, the wound healed quickly and what’s more I feel ten years younger! Bending is not easy and getting dressed takes longer. Occasionally, I do need a walking stick and sometimes have painful cramp but am nearly 80 and still fitter than some in their twenties!

I am now back on my bike, affectionately known as “Bertha” and can often be found cycling around the Whitby area. As it happens it’s not unusual for me to take some Paget’s leaflets with me to distribute here and there – libraries and such like. The ladies in the Paget’s office keep me supplied with Paget’s literature and tell me I’m doing a good thing passing it on. I’m glad to help as there are so many folk who have never heard of it. I also encourage friends to fill the Pennies for Paget’s research boxes and am trying to dispel the myth that Yorkshire men have short arms and deep pockets!

James
Health Professional Meetings

Paget’s disease will be on the agenda at the following meetings for health professionals:

**Bone Research Society (BRS) Annual Meeting**
- **Date:** 29th June – 1st July, 2016
- **Venue:** University of Liverpool, Liverpool
- [www.boneresearchsociety.org](http://www.boneresearchsociety.org)

**7th International Workshop on the Molecular Pharmacology and Therapeutics of Bone and other Musculoskeletal Diseases**
- **Date:** 2nd – 5th July, 2016
- **Venue:** St Catherine’s College, Oxford
- [www.molpharmworkshop.org](http://www.molpharmworkshop.org)

Neil Kirby and Simon Brown on the London Marathon

Neil Kirby owner of The Langham Hotel, Eastbourne, along with his manager Simon Brown, have taken on the London Marathon challenge for the Paget’s Association. We asked Simon about their training and fundraising plans.

We started our training early and by November we were training enthusiastically (see image on right)! In total we each run 3-4 times a week with at least one of these runs being an intensive 2-3 hour killer! Nutrition is equally as important so we have both been cutting back on the good stuff which is in itself another challenge especially with the temptations that come with Christmas!

We are involved in many different events at the Langham Hotel from Pudding and Wine Clubs to Special Themed Events and a Ladies and Gentlemen’s Lunch Club which has over 600 members. These guys and gals have been superb supporters of our chosen charities over the years and we are very confident in their support for this challenging event. It will be Neil’s 30th full marathon! We look forward to sharing our journey and keeping people updated through Facebook, Twitter, our website [www.langhamhotel.co.uk](http://www.langhamhotel.co.uk) and our 1000+ email subscribers.

Simon (left) and Neil (right) ready for a run
More than meets the eye: **Paget’s disease within archaeological remains**

You may have read in the last newsletter that Carla Burrell, a PhD student from Liverpool John Moores University was awarded the Doreen Beck Student Research Bursary.

Carla will be presenting her work on Paget’s Disease of Bone at the American Association of Physical Anthropologists conference, which will be held in Atlanta in April 2016. This is an annual event with an attendance of over a thousand scientists and students from all over the world, and forms one of the world’s leading professional organisations for anthropologists. This conference features over 60 sessions with many corresponding workshops and events. Here, Carla will be presenting her project ‘More than meets the eye: Paget’s disease within archaeological remains’, within the Poster Session called ‘Skeletal Biology’. She will be supported by her supervisors and co-authors, Professor Joel. D. Irish and Professor Silvia Gonzalez, in addition to Lynn Smith, Senior Keeper at Norton Priory Museum and Gardens, and Michael Emery, Site Director of the Poulton Research Project.

Carla will present an update on her research surrounding the prevalence of Paget’s disease within the skeletal collections from Norton Priory and Poulton Chapel (both in Cheshire). Previously just 6 individuals from Norton Priory and 2 from Poulton Chapel had been identified to have Paget’s disease. Over the last year however, Carla has reviewed a further 250 individuals for this initial phase of work and the results are suggesting a much higher frequency than that previously recorded. Further updates will be provided after attendance at the conference.

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**Cyclists are invited to apply for the 2016 PRUDENTIAL RIDE LONDON – SURREY 100**

If you know someone who cycles please tell them about this event. Applicants are required to raise a minimum of £500.

Download the application form from our website [www.paget.org.uk](http://www.paget.org.uk), or call [0161 799 4646](tel:01617994646) or email [sue@paget.org.uk](mailto:sue@paget.org.uk) to request an application form.
Reduce Your Inheritance Tax Bill

Benjamin Franklin said, the only things that are certain in life, are death and taxes, and inheritance tax touches on both of them. Did you know that if you leave something to charity in your will it doesn’t count towards the value of your estate and can eliminate or reduce Inheritance Tax? Your estate is everything you leave behind, minus any debts.

Approximately £150 of every £1000 received by charities in the UK comes from legacy donations. There are two ways this can be done:

● a fixed amount of money, known as a ‘pecuniary legacy’
● a share of what’s left when all costs and other legacies have been paid, known as a ‘residuary legacy’

If you are keen to support a charity such as the Paget’s Association, then leaving a gift in your will is something to consider. Your gift will assist us to help others suffering the pain and disability of Paget’s disease.

Free Independent Advice

The Money Advice Service is an independent service, set up by the government to help people manage their money. They have a free and impartial advice service. You can telephone them on 0300 500 5000 or visit www.moneyadviseservice.org.uk

Further information is also available on the government website: www.gov.uk

Collection Envelopes

If someone you love has passed away and you would like to celebrate their life by having a collection in lieu of sending flowers to the funeral, you can request collection envelopes from the Paget’s Association.

The benefit of using these envelopes is that there is the opportunity to Gift Aid the donations, meaning that they could be worth 25% more. To order collection envelopes please call Sue on 0161 799 4646.

Online Remembrance Garden

Our Online Remembrance Garden is a special way to remember a loved one. This free service is available on our website: www.paget.org.uk

In Memoriam

Winifred Ditchfield
Stanley Warwick
Tegwen Owen

We thank the family and friends of those named for their thoughtfulness in giving donations in memory of their loved ones. Every donation is a wonderful tribute to your loved one and enables the Paget’s Association to continue to support those who need our help.
Envelopes to recycle printer cartridges, jewellery and stamps are available from the office. Please call Sue on 0161 799 4646 or e-mail sue@paget.org.uk

Recycle for Paget’s
Here’s what you raised during 2015

- **STAMPS**: £321.29
- **INK CARTRIDGES & MOBILE PHONES**: £45
- **JEWELLERY**: £43

SHOP ONLINE
AT ANY OF 3,000 RETAILERS AND THE PAGET’S ASSOCIATION CAN BENEFIT

How does it work?
Visit easyfundraising.org.uk
Register and select Paget’s Association as your chosen charity. Go to the retailer’s website by using the search facility.

Start shopping
There will be no additional cost to you but you will be raising funds for The Paget’s Association.
Thank You for Your Support

The Paget’s Association greatly appreciates the support and loyalty of members. Thank you each one of you who support the Paget’s Association in any way. We are unable to mention everyone individually on this page but hope that you will continue to find new ways to support us. If you have any fundraising suggestions you are welcome to contact us to discuss how we can help. If you do something to raise funds, we encourage you to share the details and photos with us. We will publish as many as we can here. Thank you!

Fundraising ideas

You will find fundraising ideas on our website. Here are just a few:

- Hold a coffee morning or garden party
- If you are a member of a group, would they hold a raffle for Paget’s?
- Make cards, cakes or other items to sell at a local event
- Ask your children / grandchildren/ friends to do a sponsored walk / swim / silence / dog walk
- Have a table top / car boot sale – clear out your clutter and raise money for the Association – we both benefit
- Hold a book sale or book exchange
- Sell flowers or surplus vegetables you have grown in your garden
- Sell your handmade crafts, cards, knitting etc
- Contact a local supermarket and ask if you can go along with a friend to do a bag pack
- Organise a dance, formal ball or a concert
- Do your online shopping with any of 3000 popular retailers via easyfundraising.org.uk

Are you a member of an interest group who could raise funds for Paget’s?

Our thanks go to St Marks Ladies group, Lowestoft who donated £100.

Celebrating a Special Occasion?

Some of our members use special occasions to support the Association. If you have a special birthday or anniversary, a wedding or party please consider making a donation to the Association in lieu of gifts.

We are grateful to Mrs Pullen from Chesterfield who thought about the Paget’s Association when it was her 80th Birthday. Thank you to all those who donated. A total of £200 was raised.

Neighbours get together

Mrs Handley encouraged the residents of Kingfisher Court, in Isleworth, Middlesex to donate, raising a total of £62. Thank you all.

Ways to Donate

One donation of just £5 can provide vital information and advice to those struggling with Paget’s disease. Will you help us to do this?

- Telephone with debit or credit card details: 0161 799 4646
- Send a cheque made payable to Paget’s Association
- Pay directly into the Association’s account: 30660078, sort code: 20-10-71, giving your name as the reference
- Donate via our website www.paget.org.uk
- Make a regular gift by setting up a standing order. Call for a form: 0161 799 4646
- Donate via your mobile phone. Text PPAO22 (note: the 4th character is the letter O) to 70070. Then type a space followed by the amount you wish to donate (with or without a pound sign - up to £10). You will receive a text acknowledgement of your donation

eBay for charity

Support a good cause when you sell

Did you know you can sell unwanted items while raising valuable funds through the online auction site, eBay? When you list your item use the advanced selling option where you can choose to support the Paget’s Association. Decide exactly what percentage of your final selling price you’d like to give. Your listing can be seen by everyone who searches through eBay.co.uk. It will also get extra visibility through the eBay for Charity pages. It’s a great way to make a difference. You can also contribute while buying items from other sellers. For more information visit: http://pages.ebay.co.uk/ebayforcharity/sell.html