



Pot of Tea for Paget's

Tea with friends – what a lovely way to spend an afternoon.
Will you share a Pot of Tea for Paget's?

**Student
Research
Bursary**

**Peterborough
Information
Day**

**Bone Cancer
– A rare
complication of
Paget's Disease**

**Individual
experiences
of Paget's
Disease**

**Paget's
Association
Centres of
Excellence**

Paget's Association

Patrons

The Lord Stamp MA FRCP
Lt Col Sir Julian Paget Bt CVO MA
Mr Henry Paget
Mr Recardo Patrick

Honorary Patrons

Mrs Joyce Cupitt
Mr Ron Taft

Founder

The Late Mrs Ann Stansfield MBE

Honorary President

Prof Graham Russell

Trustees

Chair

Prof Roger Francis

Vice-chair

Dr Stephen Tuck
Mr Nigel Copeland
Prof William Fraser
Dr Lynne Hocking
Mr Peter Jones
Mr Michael Missett
Mrs Ingrid Pryor
Dr Michael Stone
Mrs Janet Strang

Staff

Specialist Paget's Nurse

Diana Wilkinson

Office Manager

Sue Clegg

Contact

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

Telephone: **0161 799 4646**

Website: **www.paget.org.uk**

Helpline email: **helpline@paget.org.uk**

Membership email: **sue@paget.org.uk**

Reg. Charity Number 266071



10

REMEMBERING
ALLAN



14

POT OF TEA
FOR PAGET'S



19

JOIN US IN
PETERBOROUGH
FOR OUR
INFORMATION
DAY & AGM



22

EXPERIENCES OF
PAGET'S DISEASE

CONTENTS



25

**DOREEN BECK
STUDENT
RESEARCH
BURSARY**



29

**PRIZE WORD
SEARCH
COMPETITION
– WIN A PAGET'S
GOODY BAG
WORTH OVER £20**

- | | |
|-----------|--|
| 4 | Chairman's message – Professor Roger Francis |
| 4 | Researchers ride again for Paget's |
| 5 | Paget's Association Centres of Excellence |
| 6 | Bone Cancer – A rare complication of Paget's Disease |
| 10 | Remembering Allan |
| 13 | Paget's Research Fund Donation Form |
| 14 | Pot of Tea for Paget's |
| 15 | Pot of Tea for Paget's – Invitation tickets |
| 19 | Peterborough Paget's Information Day & AGM |
| 20 | Recycle for Paget's |
| 21 | Paget's Nurse Helpline |
| 22 | Experiences of Paget's Disease |
| 23 | Support |
| 24 | New National Research Centre to tackle
Musculoskeletal Disorders in the workplace |
| 25 | The Virgin London Marathon 2015 |
| 25 | Doreen Beck Student Research Bursary 2015 |
| 26 | Time to tell my story by John Pryor |
| 26 | Give your support to future generations of Paget's sufferers |
| 27 | Member's Private Raffle |
| 28 | Changing lives just one donation at a time |
| 28 | Charity Flowers |
| 29 | Prize word search |
| 30 | Prize word search – Competition entry form |
| 31 | Remember Someone |
| 31 | In Memoriam – the gift that keeps on giving |
| 32 | Supporting the Paget's Association |

Chairman's message

The Board of Trustees made a number of important decisions at their last meeting in April, which will hopefully increase awareness of Paget's disease among health care professionals, improve clinical services for people with the condition and stimulate research into the underlying causes and treatment. The first of these decisions was to launch the Paget's Association Centres of Excellence initiative. Applications are invited from hospitals and universities around the UK, who will be expected to provide evidence of expertise in the investigation, diagnosis and treatment of Paget's disease and/or research into the condition. The Trustees hope that the award of Centre of Excellence status will provide applicants with the necessary local and national recognition that will facilitate their negotiation with health care providers, enabling them to offer the highest standard of care to patients. We hope that this initiative will also lead to productive interactions between the Paget's Association and the Centres of Excellence, such as in fundraising, participation in research projects and hosting meetings for members and other patients with Paget's disease. It is

anticipated that we will identify 10 to 20 Centres of Excellence geographically spread across the UK. In order to improve access to clinical services, the Trustees are keen to encourage 'hub and spoke' arrangements, whereby patients with Paget's disease might undergo investigation and treatment in a local hospital, rather than always having to travel longer distances to a major Centre. The deadline for the current round of applications is 30th May 2015 and we hope to announce details of the successful Centres of Excellence in July this year.

The Trustees also decided to offer the first of hopefully a number of Student Research Bursaries, to encourage a promising medical or science student to pursue research into Paget's Disease of Bone. This will enable the successful student to work towards an MRes, MSc, BSc or equivalent higher degree, under the supervision of a Professional Member of the Paget's Association. The first of these awards has been named the Doreen Beck Student Research Bursary, in recognition of her major fundraising achievements for the Paget's Association over many years. The application should be jointly prepared by the



student and supervisor, providing a summary of the proposed research and the student's role in the research. The deadline for submission of applications is 12th June 2015 and it is anticipated that the recipient will be invited to attend the Paget's Association's Annual General Meeting in September to formally receive the award. The Trustees also plan to advertise a second bursary next year, which will be named the Allan Reid Student Research Bursary. As you will read elsewhere in this Newsletter, Allan Reid tragically died last August from osteosarcoma, a rare complication of Paget's disease. Allan's friend Norman Kerr has spearheaded fundraising to support much needed research into Paget's disease. Along with family, friends and colleagues he has already raised £4,200, which together with the associated gift aid gives a total of almost £5,000. We are most grateful to everyone who has supported Norman's fundraising in memory of Allan Reid.

Roger

Researchers ride again for Paget's

Dr Lynne Hocking, a Trustee of the Paget's Association and a researcher at the University of Aberdeen cycled with a colleague, **Julie Crockett**, in last year's Prudential RideLondon-Surrey 100 cycle event.



Well they've bravely taken up the 100 mile challenge again to raise funds for the Paget's Association. If you'd like to sponsor them please contact Sue Clegg on **0161 799 4646**.



Centres of Excellence

The Trustees of the Paget's Association are inviting applications from clinicians and scientists to create Centres of Excellence in Paget's Disease within the UK.

This initiative will help raise awareness of Paget's disease and ensure optimal management of patients with Paget's and provision of services to patients and their carers. It will also continue to meet the mission of the charity by encouraging education and research in Paget's disease.

The Centres of Excellence in Paget's Disease will be geographically based within the UK.

The application for designation of Centre status should provide evidence of expertise in the management of Paget's Disease and / or research into the condition

Full details and application form can be found on our website: www.paget.org.uk

Applications should be submitted by email by 30th May 2015

Bone Cancer – A rare complication of Paget's Disease

The following pages contain discussion regarding a type of bone cancer (osteosarcoma) that is a very rare complication of Paget's disease. We look at this firstly from a medical point of view and then from the very personal experience of Mrs Norma Reid who lost her husband to this devastating condition.

Paget's Disease of Bone-associated Osteosarcoma: Molecular Basis, Signs & Symptoms, Treatment and Research

Darrell Green is a Big C-funded molecular biologist at the University of East Anglia, performing research towards a PhD. He works with Professor Tamas Dalmay, Head of Biological Sciences and Chair of RNA Biology at the University of East Anglia and Professor Bill Fraser who is a Trustee of The Paget's Association, Director of The Norfolk Bone and Joint Centre, the Bioanalytical Facility and Head of Department of Medicine at Norwich Medical School and Consultant Metabolic Physician at the Norfolk and Norwich University Hospital. Here they discuss the molecular basis of Paget's associated osteosarcoma, identification of patients at risk, signs and symptoms, treatment and current research.



Big C-funded molecular biologist, Darrell Green, at the University of East Anglia.

INTRODUCTION

Paget's associated osteosarcoma is a type of bone cancer that is a very rare complication of Paget's Disease of Bone. In less than 1:1,000 patients, Paget's disease can trigger a change in one of the main types of bone cell known as an osteoblast, turning the cell abnormal and becoming cancer-like (malignant). Bone cancer resulting from these changes in osteoblasts is called 'osteosarcoma'. This type of cancer is most often found in children and young adults. While Paget's patients are at risk of developing osteosarcoma, it is important to realise it is extremely rare. Modern treatments for Paget's disease are

believed to inhibit the development of Paget's associated osteosarcoma.

In this article, we explain the molecular basis of osteosarcoma, discuss identification of patients at risk, describe the signs and symptoms to look out for, then outline possible treatments for osteosarcoma. We also explore the current direction of research into the causes and diagnosis of this rare complication.

MOLECULAR BASIS

At an individual level, 'cancer' is rare. It is a genetic event where a cell has typically undergone alterations within its DNA, causing a downward spiral of uncontrolled growth. To put it into perspective, our DNA naturally changes every eight seconds. That equates to almost eleven thousand alterations every day. For 66% of the UK population, cancer will never happen. The human body has remarkable systems in place to ensure DNA damage is successfully repaired. There are many different types of cancer and bone cancer is considered a rare cancer. Therefore Paget's associated osteosarcoma is a rare complication of the second commonest metabolic bone disease in the UK.

The increased speed of bone remodelling in Paget's disease can increase the number of alterations to the DNA of osteoblasts, the bone cells responsible for making new bone. Even in a disorder such as Paget's disease, our bodies have mechanisms in place to withstand the increased damage to our DNA. It is only in less than 1:1,000 cases where a cancerous osteoblast can slip through the net and evade our defences. Drugs used to treat Paget's disease, such as Zoledronate, work by slowing down the rate of bone remodelling. This also has the effect of reducing the number of alterations that occur in osteoblasts compared to that of untreated Paget's disease.

One of the major goals in cancer research today is to identify the alterations that cause different types of cancer. That way, doctors and scientists can predict how and when

a cancer might occur. At present, the exact alterations that cause Paget's associated osteosarcoma are unknown. It is therefore vital to identify the individuals most at risk of developing osteosarcoma and make sure all patients are aware of the early signs of possible changes in the bone.

PATIENTS AT RISK

Paget's Disease of Bone can arise due to alterations in one or more genes. Some of these genes have a different impact on the severity of the disease. Alterations to the SQSTM1 gene have been linked to an earlier onset of Paget's disease, an increase in disease severity and an increase in chronic bone pain. It has been noted that patients carrying the SQSTM1 gene are most at risk of developing Paget's associated osteosarcoma. However, this does not mean to say that

other patients with a different set of genes cannot develop bone cancer. It also doesn't mean that all SQSTM1 positive patients will develop bone cancer. All patients should be regularly monitored and made aware of the early signs of Paget's associated osteosarcoma. As with all cases of cancer, early diagnosis is key to a good outcome.

SIGNS & SYMPTOMS

Bone cancers such as osteosarcoma are typically hard to spot because their signs are usually attributed to other factors, such as an accidental bump or knock. A key contrast between a slight knock and Paget's associated osteosarcoma is that bone cancer pain will progressively get worse. Some patients can experience trouble sleeping because of the increased pain. This is readily noticeable in comparison to any 'normal bone pain' patients suffer due to Paget's disease. It is imperative that any new pain or significant change in pain is reported to a doctor. Other symptoms can include a significant change in bone shape with swelling in the bone usually close to the area where the pain is increasing.

The blood test, serum alkaline phosphatase, which can be elevated in Paget's disease, may increase further and quite rapidly with the onset of Paget's associated osteosarcoma. X ray images may reveal a change in bone structure, a vague tumour mass extending beyond the bone, destruction to the surrounding bone and fracture (Figure 1b). A Computerised Tomography Scan (CT), Magnetic Resonance Imaging (MRI) or Positron Emission Tomography scan (PET) may sometimes be helpful in identifying the presence of osteosarcoma.

continued overleaf



Figure 1a
X-ray showing Paget's disease of bone in the head of femur. The bone is sparse and almost see-through in some parts.



Figure 1b
X-ray from the same patient showing osteosarcoma development in the femur. The bone appears thickened with structural changes. Evidence of a vague tumour mass blurs the outline of the bone.

Further confirmation that Paget's disease has resulted in osteosarcoma can be made by obtaining a sample (biopsy) of the affected bone. A small needle is used to extract some of the abnormal tissue and a specialist pathologist will look at the cells under a microscope to confirm whether the osteoblasts have become cancerous. The tell-tale signs at this stage are cells that are much larger than normal, containing 'messy' looking DNA that are secreting an immature form of bone (Figure 2b).

If it is found that osteosarcoma is present, it is important to undergo a medical examination called 'staging'. This is to determine if the cancer has spread, or 'metastasised', elsewhere around the body. The tests commonly used are chest X rays, lung tomograms, CT and bone scans. There are four possible outcomes in staging:

TREATMENT

There are less treatments available for Paget's associated osteosarcoma than there are for childhood osteosarcoma. Long-standing Paget's disease results in the bone developing an increased network of blood vessels. This makes localised surgical removal of the tumour much more difficult, as there is an increased risk of cancer cells leaking into the bloodstream and then spreading around the body. This would result in the tumour growing in other tissues (metastatic disease). To avoid this, surgeons may have to perform a limb-sparing procedure. This is when a surgeon removes the tumour as well as surrounding healthy tissue and bone to ensure there is no cancer left behind. The affected limb is reconstructed using prosthetic devices and bone grafts. In some cases it may be required to perform more extensive surgery,

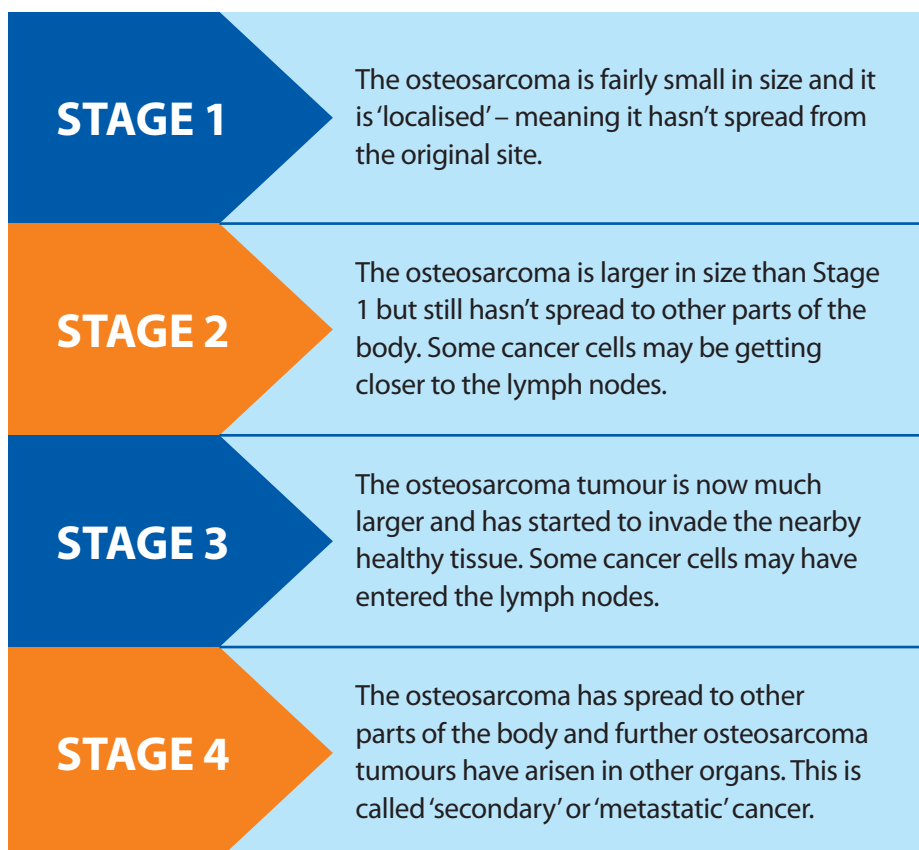
which could mean limb amputation as a life-saving procedure.

Surgery is often followed by further treatment using one or more anti-cancer drugs as 'chemotherapy'. This is to ensure that any cancer cells left behind are destroyed as well as preventing relapse of the disease. If the osteosarcoma is detected early on, it is possible to avoid drastic surgery and start with chemotherapy. In all cases, chemotherapy is delivered in 'cycles' – a couple of days spent in hospital receiving treatment followed by a few weeks of rest. Two drugs may be given called cisplatin and doxorubicin, which work by damaging the DNA of cancer cells so they cannot function and as a result the cells die. Just before the end of one treatment cycle, a drug called methotrexate may be prescribed which works by blocking the cancer cells from multiplying.

Common side effects of treating Paget's associated osteosarcoma with chemotherapy are similar to that of many cancer treatments; which can include nausea, sickness, diarrhoea, tiredness and hair loss. Each patient responds differently to chemotherapy, some patients will experience the side effects whereas others may not. Due to the age of a typical Paget's associated osteosarcoma patient, the decision may be taken to give palliative radiation therapy. The purpose of radiation here is to try to slow the growth of the tumour rather than completely removing the cancer.

FUTURE RESEARCH

A recurring theme of this article is that Paget's associated osteosarcoma is incredibly rare. As a result, there has been a limited amount of research performed and



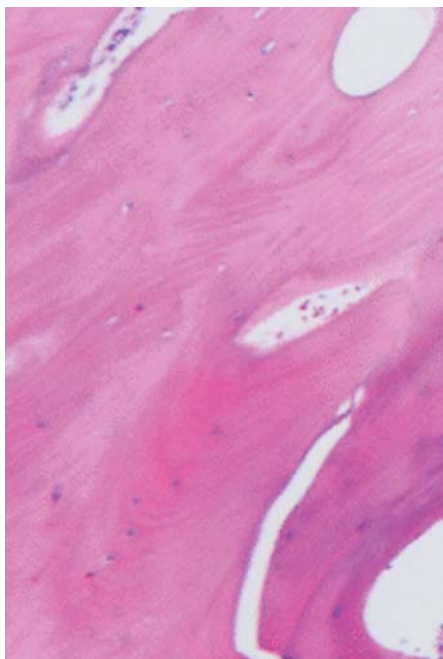


Figure 2a
Photomicrograph of normal bone. The cells (purple dots) are small in size and number, with surrounding healthy bone (in pink).

only a small number of research projects currently taking place. A key question for researchers is how the *SQSTM1* gene may play a role in the development of osteosarcoma. Out of the several genes involved in Paget's Disease of Bone, why is this one in particular an increased risk factor? Perhaps it is not the gene itself, but the regulation of the gene by external mechanisms. Genetic studies on tumour samples or cells in a laboratory may provide clues as to how this happens.

Another line of research that is of particular interest to our laboratory, is the identification of simple biomarkers that can be used to accurately identify when a patient has or is developing osteosarcoma. As with other bone cancers, it can take some time for the cancer to develop and cause symptoms. That can make osteosarcoma very difficult and expensive to

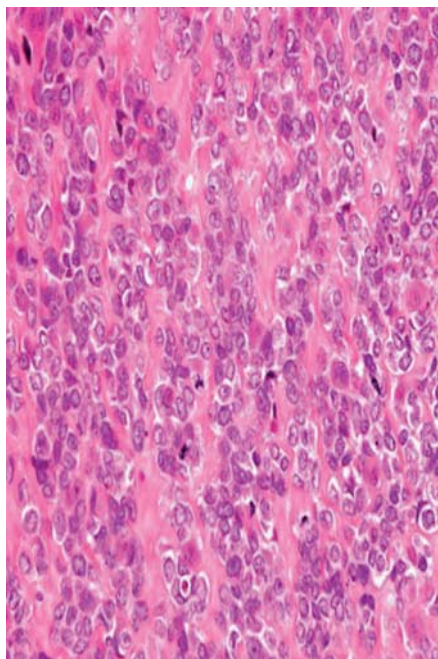


Figure 2b
Photomicrograph of a biopsy sample. The DNA of the cells (dark purple) is messy and irregular in shape, instead of being in neat circles. There are many oval shaped cells compared to the amount of bone (light pink staining). This is a clear example of where osteosarcoma has arisen in Paget's bone.

diagnose. Our laboratory has been studying molecules found in the bloodstream that may be detected by a simple fingerstick blood spot test that could be taken by the patient in their own home. The sample can then be sent to the laboratory to allow regular monitoring and possible earlier diagnosis. If this method turns out to be readily reproducible, reliable, cheap and easy to automate it could well be introduced in the future to help early diagnosis of osteosarcoma. There is also the possibility of introducing treatment at a time when it would have a greater efficacy.

SUMMARY

- Paget's associated osteosarcoma is a bone cancer that occurs in less than 1:1,000 of patients with Paget's Disease of Bone.
- Drugs used to treat Paget's disease, such as Zoledronate, may reduce the risk of bone cancer development.
- Symptoms of bone cancer include progressive pain that increases at night and sudden swelling around the affected bone.
- Chemotherapy is used to treat most bone cancer.
- Radical surgery may also be required.
- Research into Paget's-associated osteosarcoma is trying to answer how the *SQSTM1* gene may be involved and if molecules in the bloodstream may act as a quicker and cheaper route to diagnosis.

Figures 1a, 1b, 2b - Images reproduced from: Osteosarcoma arising on a background of Paget's disease report of an unusual case, A Qureshi, KF Zahid, SI Ibrahim, I Burney, 2013, with permission from BMJ Publishing Group Ltd.

Figure 2a – Taken by Professor Richard Ball at the Norfolk and Norwich University Hospital.

Remembering Allan

Allan Reid was born in Glasgow in 1957. At the age of 49, he was diagnosed with Paget's disease. Last year Allan died, aged 57, from Paget's – associated osteosarcoma, a type of bone cancer that is a very rare complication of Paget's disease. His wife, Norma shares below their traumatic experience and explains how his family and friends are fundraising to ensure something positive comes out of Allan's death.

For most of our married life Allan and I lived in Newton Mearns, a suburb in southern Glasgow. We had been married almost 35 years when Allan died. Our two daughters live close by: Jill with her fiancé Steven; and Pam with her husband Iain, and their daughter Sophie who was born last April. Allan was so proud to become a Granpa and his 80 year old mother, Margaret, a Great Grandma. Sophie was only 3 months and 3 weeks old when her Granpa died but she will always be hearing about him.

A little about Allan

Whilst Allan's working life began as a draughtsman in the shipyards, at 23 he went into food sales where he worked his way up to sales director. In 1999, together with his business partner, Graham, they set up their own food marketing company, "RSS", employing 100 people.

Allan loved watching St Mirren Football team, but his two main hobbies were golf and bowls which he was very good at. I shared his love of bowls, and two months before he died we entered and won a mixed pairs competition, receiving



Allan playing golf in Cyprus October 2012

a cup engraved with our names, and with which I am delighted. He was such a good sport.

Diagnosed with Paget's Disease

Allan had a sore leg when he went for a medical in 2007. Blood tests showed that his Alkaline Phosphatase (ALP) level was quite high. From this, Paget's disease in his pelvis, was diagnosed. Little did we know then that he would die from a very rare complication of the condition just 7 years later.

He was initially prescribed treatment, which was a 2 month course of Risedronate tablets. Each time he received the treatment, which was about every eighteen months, his ALP levels went down. Throughout that time he was never in pain and life continued as normal.

Something Changed

It was in January 2013 that something changed. Allan's leg, below his knee, became painful. He

said it felt like it was in a vice. He had the Paget's treatment again but this time the tablets didn't work. He went back to the consultant quite a few times and had many scans which threw up nothing abnormal. By this time he was walking with a noticeable limp.

We went on a cruise through the Panama Canal in April 2013 and, although Allan never complained, he was in absolute agony. When we came home he contacted his consultant who carried out blood tests. His ALP level was over 2000. We were extremely worried, although all his other tests were clear. Allan was taking all kinds of painkillers but nothing was working. The consultant suggested giving him different Paget's medication via a drip (Zoledronic Acid). Despite this he was still in agony. It was the end of May and we were distraught because this wasn't normal.

Allan was sent for scans and a radiologist spotted an abnormality which he didn't think was Paget's

disease. On 4th June we were told that he had a cancerous tumour in his pelvic bone. I knew this was coming. Allan didn't. He was always so positive.

Allan had developed Paget's-associated osteosarcoma, a rare bone cancer that occurs in less than 1:1,000 of patients with Paget's disease. He was in a private health scheme, however, because of the cancer he was transferred back to the NHS. It was over two months before he could start chemotherapy treatment. Each day seemed like an eternity. Life was torture. Allan continued to golf and bowl. He would never give up.

On August 16th 2013, he started a 3 weekly cycle of chemotherapy. Around that time a lump appeared on his skull. This was bone cancer as well but was successfully removed in March 2014. He had 6 ½ weeks of radiotherapy with an operation before and after to insert a "spacer" device into his pelvic area which would aid the treatment. By this time it was June. He still golfed



Best friends: (left to right) Norman, Tricia, Norma and Allan, in Jan 2013 before he became ill

and bowled. Alan was positive that the treatment would be successful. He said it was a blip.

On the 22nd of June 2014 he played golf at the Turnberry resort on the Ayrshire coast. He looked so well.

Apart from a limp you would never know. The following day he coughed up a spot of blood. The cancer had spread to his lungs. This was the start of a rapid decline. Within three weeks he couldn't breathe without oxygen, was in a wheelchair and he died at home on 1st August 2014.

Everybody loved Allan. He made a wonderful life for his family by creating a successful business and being a super husband, father and grandfather. The first we knew his condition was terminal had been the 10th of July last year. How I wish we'd never been told. The last few weeks were horrendous. Allan was so brave, so positive. He never gave up. He always made me laugh.

The medical team who were dealing with Allan's cancer appeared to know very little about Paget's disease. I wish more professionals and people generally were more aware of it. It took such a long time to diagnose

continued overleaf



"Allan lived for his family" (Left to right) Iain, Pam, Allan, Norma, Cousin Kenneth, Jill and Steven, March 2014



Allan after his chemo in May, with Norma and granddaughter, Sophie

his cancer because it is so rare for someone with Paget's disease to develop associated cancer.

We have all been deeply affected by this and it has certainly raised awareness of Paget's disease and Paget's-associated osteosarcoma. Allan's business was UK wide and he took part in many events, he touched many people's lives and many are now aware of the devastating illness that took him from us.

I didn't contact the Paget's Association until March 2014 because I hadn't known they existed. It was only when we started to panic that we looked on the internet to see if we could get advice and found the Association's website.

Raising funds to support research

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, 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 Just Giving Page which has so far raised over £4,200. So many people have donated including all of Allan's work colleagues. Norman worked for Allan too and he is planning a sponsored cycle across Scotland, on Allan's birthday.

Here are some of the events that have taken place to raise funds for the Paget's Association in memory of Allan:

- **The son of my best friend Toty plays in a band called Vasa and they had a door collection which raised £150.**
- **Toty's daughter, Lynsey, was sponsored to run 10K.**
- **A coffee morning was held in a special needs school.**
- **My daughter's friends did a Muddy Assault Course.**

This year, our bowling club, Mearns Bowling Club are having a competition. I am providing a cup in memory of Allan and Paget's. We will make it a yearly event.

When Allan was diagnosed with Paget's disease we just didn't realise

the seriousness of it. We never thought for a moment that it could turn into cancer. I know it's rare and don't want to worry people that this could happen but it was very distressing for us all to see Allan in so much pain, and despite tests nothing was found initially because it is so hard to detect. If anyone finds themselves in a similar situation and would like to talk about it I am more than willing to help. Please just contact me through The Paget's Association. We'd love the money raised to be used for research.

Norma



Sophie, Allan's granddaughter, age 6 months, taking part in the Millport Cycle. Oct 2014.

Norman's fund raising page can be found on the Just Giving website:

<https://www.justgiving.com/AllanReid>

Supporting Research in Memory of Allan

The Paget's Association want to ensure that the funds raised are used to support research into the condition. We are pleased to announce that Alan's family and friends have agreed that the money collected in memory of Allan, should be used for a bursary in Allan Reid's name, to help to support a young researcher working on Paget's disease. It will be a fitting and lasting memory of Allan.

Paget's Research Fund

The Paget's Association supports research into all aspects of Paget's disease. Without such research we wouldn't have the treatments that are in use today. We hope a cure for Paget's disease can one day be found so that tragic events such as Allan's no longer happen. Will you donate to our research fund?

To obtain a Paget's Research Collection Box or donate to our Paget's Research Fund please complete and return the form below or call our office on **0161 799 4646**.



Name

Address

Post code

Telephone number:

Complete for card payments only:

Card No.

Amount £

SWITCH / VISA / MASTERCARD (circle as appropriate)

Expiry Date:

Valid From Date:

Issue No. (Switch only)

Security No. (on back of card)

Signature:

Please tick as appropriate:

Please send me a Paget's Research Collection Box to the above address

I would like to contribute to the Paget's Association's Research Fund by donating

(circle as appropriate) £3 / £5 / £10 / £20 / £50 /

other amount £

Delete as appropriate:

I enclose a cheque payable to the Paget's Association

I wish to pay by debit/credit card - complete card payment details above or alternatively telephone **0161 799 4646** to provide your details.

I would like to Gift Aid my donation. I confirm I am a UK taxpayer and I agree to the Paget's Association claiming tax on all past, present and future donations I make to the charity.

Please treat my donations as Gift Aid donations. By ticking this box I confirm that I am paying, or will pay an amount of Income Tax and/or Capital Gains Tax to cover the amount the Paget's Association and any other charities or Community Amateur Sports Clubs (CASCs) will reclaim for the tax year (6 April one year to 5 April the next year). Council Tax and VAT do not qualify towards Gift Aid. The Paget's Association will reclaim 25p of tax for every £1 that has been given.

Signed

Date

Please return to: **The Paget's Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.**

Pot of Tea for Paget's



Tea with friends – what a lovely way to spend an afternoon. Will you share a Pot of Tea for Paget's? We're asking you to hold a charity tea & cake morning/afternoon with your family, friends and neighbours to raise funds which will help us provide information and support for those with Paget's disease.

To get you started we've provided some invitations on the following pages. Your guests are asked to make a donation to support the work of the Paget's Association. If you would like a box to use for your donations please let us know. You can photocopy the invitations or download more from the "Events" section of our website: www.paget.org.uk

All you need are a few key ingredients to make your event a success and join the fight to beat Paget's disease:

- A venue – which could be your home
- Some willing volunteers – cake bakers and tea / coffee makers
- The invitations to send to your family, friends and neighbours

How we can help

If you can arrange a larger event for your village, for instance in your local Community Centre or Church Hall, we can supply the following:

- Posters and more invitations
- Paget's leaflets to explain what your event is about and help raise awareness of Paget's disease

If you'd like to chat your event through or would like a collection box and leaflets please call us on **0161 799 4646**.

When you have concluded your tea party, send the money you have raised to us at: The Paget's Association, Suite 5, Moorfield House, Moorside Rd, Swinton, Manchester, M27 0EW. If you are willing to share details of your event in this newsletter please do tell us about it and send us your photos.

Please join our fight to help raise both awareness and funds - let's make a difference to those with Paget's disease.

Parkin for Paget's

- 8 oz /220g butter
- 4 oz /110g soft, dark brown sugar
- 2oz /55g black treacle
- 7oz /200g golden syrup
- 5oz /120g rolled oats
- 7 oz /200g self-raising flour
- 1 tsp baking powder
- 4 tsp ground ginger
- 1 tsp mixed spice
- 2 tsp nutmeg
- 2 large eggs, beaten
- 2 tbs milk

- Heat the oven to 275°F / 140°C / gas 1
- Grease and line a 20cm (8 inch) square cake tin.
- Use a heavy-based saucepan to melt together the butter, sugar, treacle and golden syrup over a gentle heat. Do not allow the mixture to boil.
- Sieve the flour and stir all the dry ingredients together.
- Gradually add the treacle mixture to the dry ingredients and mix thoroughly.
- Gradually, beat in the eggs.
- Add the milk and mix well.
- Pour the mixture into the tin and cook for up to 1½ hours until firm and set.
- When cooked allow to cool in the tin before removing and storing in an airtight tin. Serve after 3-4 days when the parkin will have become characteristically sticky.



If you have a favourite recipe which you would like to share in our newsletter please send it to The Paget's Association at the usual address.

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Pot of Tea for Paget's



You are invited to join

for **tea & cake**

on

Time.....

at

Guests are asked to make a donation to the work of the Paget's Association.

Suggested donation: £

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Fundraising for Paget's



Paget's disease is a bone disorder in which the normal repair and renewal process within bone is disrupted. Symptoms may include pain, deformity & fracture.

The Paget's Association is a registered UK charity whose aims are to:

- Offer support and information to those with Paget's Disease, their families and carers
- Raise awareness of the condition among health professionals and the general public
- Encourage and sponsor research into the causes, treatment and prevention of Paget's Disease

Peterborough Paget's Information Day & AGM



Thursday 17th September 2015

Venue: Park Inn by Radisson, Telephone House,
Wentworth Street, Peterborough, PE1 1DH.

Time: 09:30 – 15:30

Everything you ever wanted to know about Paget's disease in one place!

Dr Gavin Clunie Consultant Rheumatologist and Metabolic Bone Physician for Cambridge University Hospitals will join us at our Paget's Information Day, in Peterborough, on the 17th September. Our Honorary

President, Professor Graham Russell, our Chairman, Professor Roger Francis, our Vice-chair Dr Stephen Tuck, Trustee, Professor Bill Fraser and our Specialist Paget's Nurse, Diana Wilkinson will join Dr Clunie to discuss various aspects of Paget's disease as well as answer your questions. The topics which will be discussed will include diagnosis and treatment, research and who should be referred for surgery.

Whilst these events are aimed at those with Paget's disease, their families and carers, health professionals are also encouraged

to attend. The event is free and lunch will be provided. If you would like to attend please either complete and return the booking form below or email the information to sue@paget.org.uk. If you require further information please call us on **0161 799 4646**.

The Paget's Association's AGM

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



Booking Form for Peterborough Paget's Information Day

All meetings are provided by the Paget's Association free of charge and include a light lunch.

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

Number in party attending

Name of 1st attendee

Name of 2nd attendee

Name of 3rd attendee

Name & address for correspondence

Postcode

Tel

Email address

Do you have any special dietary requirements?

Do you have any other special requirements?

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

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

Please return the above form either by post to:
The Paget's Association, Suite 5, Moorfield House,
Moorside Road, Swinton, Manchester, M27 0EW or
email the above information to sue@paget.org.uk

Recycle for Paget's

Recycling is one way in which we can help lessen our use of resources and raise funds to help support those with Paget's disease.



Jewellery

Do you have any unwanted jewellery you could recycle for Paget's? This could be gold, silver, costume jewellery, watches (working or not). Even damaged, broken and incomplete items can be recycled. Encourage your family and friends to get involved as well by spring cleaning their jewellery box. Place them in a pre-paid envelope (available from the Paget's office) and pop it in the post.

Mobile Phones and Printer Cartridges

Our thanks go to all of you who send your mobile phones and printer cartridges to be recycled. Mr Hurcombe, from Wotton-under-Edge had saved over 25 cartridges and so we were able to arrange delivery of a box for these and collection from his home. If you work in an office we can do the same for you. Please contact Sue on the number below.

On receipt of your cartridges Reclaim-it will make a donation to the Paget's Association, at no cost to you. The amount of the donation will depend on the value of your donated cartridge.

STOP PRESS

Due to Royal Mail's policy change mobile phones can no longer be sent in the post. This means that we are no longer able to accept mobile phones for recycling through the post.

Stamps

The Paget's Association is now recycling postage stamps. Many of you have already sent your stamps to us – thank you all. We would especially like to thank Paget's sufferer and member, Mr John Ferguson from Nottingham who, during his teenage years was an avid stamp collector. On reading in the last newsletter we were recycling stamps, he got in touch with us offering two albums. Following his approval of the valuation the Association was delighted to receive £80.

Maybe you have an old stamp album at the back of a cupboard you would be willing to donate?

Save your stamps.

We accept the following:

- Any stamps collected from your post
- Everyday 1st and 2nd class
- GB or foreign
- Used or mint
- Special issue commemoratives



Please also ask friends and family, schools, local companies etc., to save their stamps for Paget's.

Leave no more than 1cm of envelope around each stamp but don't trim too close so that the perforations are damaged. Please send them into the Paget's Association's office. If you have a large number, we can send you a prepaid envelope in which to post them.

www.fundraisingstamps.com

Recycling Criteria

Recycle your empty **inkjet** cartridges. **Inkjets** fit in the palm of your hand and have a circuit board and jet plate on the bottom. It's cartridges that have circuit boards that have a recycling value when empty.

Makes you can recycle include HP, Dell, Lexmark, Canon, Samsung, Neopost.

Please don't send Epson or Kodak cartridges as they are actually ink tanks, not inkjets and unfortunately, are not on our wanted list.

Only cartridges which have not been refilled before and carry only the original equipment manufacturers

branding can be recycled. Cartridges don't have a donation value if:

- Damaged
- They have been previously refilled
- They have been labelled for another brand like Tesco, PC World or Office Depo
- They have labels removed or extra holes. (Signs that refilling has been attempted)

Envelopes to recycle printer cartridges, jewellery and stamps are available from the office. Please call Sue on 0161 799 4646 or email sue@paget.org.uk

Paget's Nurse Helpline:



Diana Wilkinson, our Specialist Paget's Nurse, answers your calls and emails on our Paget's Nurse Helpline. Here she shares some of the queries for the benefit of those of you who have similar questions.

Question 1

I am going for an infusion of Zoledronate. How much pain relief will I get?

Answer 1

Zoledronate is a bisphosphonate which is a type of drug that makes the bone cells behave in a more normal way. Such treatment often provides very effective pain relief which can, in some people, be effective for many years. Pain relief does however vary between individuals as does the length of time for the treatment to take effect. It is also important to realise that from the point of view of pain relief the treatment will only help if the pain is caused by active Paget's disease rather than complicating factors such as wear and tear of the joints (osteoarthritis), muscle pain or misshapen bone which can sometimes constrict a nerve.

Question 2

I have Paget's disease in my spine and my GP has given me Gabapentin for pain. How will this help and will I experience side-effects?

Answer 2

Paget's disease can cause bone to become enlarged and misshapen. Enlarged vertebrae may press on nearby nerves which can cause a variety of symptoms such as pain that may be described as shooting, burning or tingling. Known as peripheral neuropathic pain, this type of discomfort is often not relieved by normal analgesics and

is different to the more common bone pain of Paget's disease. Gabapentin is a drug that is suitable for this type of pain and may reduce discomfort by changing the way in which nerves send messages to your brain. Whilst some people feel improvement straight away, in others it can take some weeks. Gabapentin or similar drugs can be used in combination with other analgesics to improve pain relief. All drugs can have side effects in some people and the most common side effects of Gabapentin are drowsiness, dizziness and tiredness. If you have any concerns about side effects of the drug or you experience any new symptoms do return to your GP for advice.

Booklets

Our information booklets can be obtained from our office (contact details are on the inside front cover of this newsletter).

Whilst booklets are free of charge, stamps or donations towards postage are always appreciated.

All our booklets are available to members on our website, therefore whenever possible, electronic members are asked to download them from the members' area of the website: www.paget.org.uk

If your health centre or clinic would like some of our booklets or leaflets please let us know or ask them to contact us directly.

Booklets available:

Paget's Disease – The Facts
(revised April 2013)

Paget's Disease and Pain
(revised August 2013)

Paget's Disease – Investigations Explained
(revised Sept 2014)



Paget's Helpline

Telephone Diana on:
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

Information within this newsletter does not replace any individual medical advice provided by your doctor or healthcare provider. Always discuss your individual needs with those involved in your care.

Our Experiences of Paget's Disease

Aiming to help others who are newly diagnosed or struggling to cope with Paget's disease, members of the North Manchester Support Group shared their experiences of the condition for our new website. We thought those of you who don't use the website would appreciate reading them here.



"I have Paget's disease in my pelvis. I had successful treatment with bisphosphonate infusions which eased my pain and I didn't have any side-effects. I have not needed any treatment for the last ten years."

John

"As a member of the Paget's Association I find it helpful to know there are other people in the same situation and I can keep up with the treatments available. I started Risedronate but they didn't agree with me so I had to stop taking them. I am going to discuss having an infusion instead."

Margaret



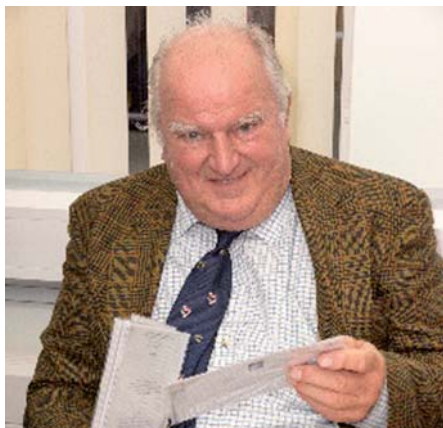
"I have Paget's disease in the femur which I've been aware of since 2000. I took a course of Risedronate tablets some time ago but I am not aware that it made any significant difference. I didn't have any side-effects. My leg is bent and I hope that the treatment slowed down the bending of the bone and relieved any pain that I might otherwise have had. I have my blood checked regularly by the practice nurse at my local health centre. To help with walking I have adapted shoes and an elbow crutch, provided by the hospital".

Eric



"I have known about the Paget's in my skull, spine and right femur since 1993. I was very lucky in being referred to Manchester Royal Infirmary. The consultant was excellent. I did have side-effects from a Pamidronate infusion but I was fine with the Zoledronic acid infusion which I had 3 years ago. It worked well and I am still pain free. Being a member of the Paget's Association is absolutely brilliant. I needed help when I was diagnosed and luckily found the Association. The rest is history. They are so supportive and helpful."

Linda



"My mother had Paget's disease. It took the hospital a long time to diagnose me but I know much more about it now that I have joined the Paget's Association."

Mike



"Now 66 and retired, I previously worked as part-time lecturer at local colleges teaching typing and shorthand for over 20 years. I also did some secretarial work at

The Paget's Association for a few months before taking up a part time post at the local university teaching shorthand on a degree course.

I was diagnosed with Paget's disease in my vertebrae (L1) at the age of 47, after having X-rays for excruciating back pain. The pain made walking, sitting and everyday activities difficult.

I am happy with the way the diagnosis was given. The results of an x-ray were given by my GP who was very good, and I was referred to a specialist at Salford Royal, where I have always been given information and facts about Paget's in a sensitive manner. Following further tests, I had bisphosphonate infusions which alleviated the pain and put the Paget's in remission. The side effects of my first infusion were as I expected, as it was explained to me that I may have flu like symptoms. The side-effects lasted an hour or two. When I needed an infusion again I didn't experience any side-effects but I had a complication at the site of the infusion.

Over the years I had further treatments but found I was suited to Risedronate oral treatment rather than infusions. Most of my bone problems now are due to osteoarthritis. I also have type 2 diabetes, bronchiectasis and asthma.

I find being a member of the Paget's Association helpful for information about Paget's and to be able to contact people in a similar situation. My advice is don't worry, as most people seem to live to a good age with it. There are much worse complaints to have. Consider yourself lucky to have treatment for it!"

Mary

Would you be willing to share your experience? Contact us using the contact details on the inside cover of this newsletter.

Photos: Lyndsey Colbert, Blackburn.
www.pcroadshows.com

SUPPORT

North Manchester Support Group Meeting

You don't have to live in Manchester – all are welcome to attend.

Venue: The meeting room, Worsley Road United Reformed Church, Swinton, Manchester, M27 0AG

Next Meeting Date: Tuesday 9th June 2015

Time: 13:45 – 15:15hrs

Organiser: Our Specialist Paget's Nurse, Diana Wilkinson

For further information contact: Diana on **07713568197 / 0161 799 4646**

Email: diana.wilkinson@paget.org.uk

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 can be arranged if there is sufficient interest.

South Manchester:

Contact Mr Ron Taft on 0161 485 7468

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

Truro: Contact Mr Robert Lewis on 01209 843678

The Paget's Support Network

If you'd like support from others with Paget's disease, the Paget's Support Network may be able to help.

It is a free network to enable members to talk to others who either have Paget's disease or who care for someone with 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.

New National Research Centre to tackle Musculoskeletal Disorders in the workplace

A major new research centre to tackle the impact of musculoskeletal disorders on people's ability to work has been announced by two leading medical research bodies. Researchers at the £1.4m Arthritis Research UK / Medical Research Council (MRC) Centre for Musculoskeletal Health and Work, led by the University of Southampton, aim to find cost-effective ways of reducing the impact of conditions that affect the muscles, joints and bones on people's employment and productivity, with benefits for patients, employers and society as a whole.

Director of the new centre, Professor David Coggon, said: "Musculoskeletal conditions are a major cause of sickness absence and job loss. We're enormously excited about our new centre which we hope will lead to new ways of preventing their occurrence, and helping employees who are affected to stay in productive work."

The centre will focus its research on the three main musculoskeletal causes of work disability – back, neck and arm pain, osteoarthritis and inflammatory arthritis. A special theme will be the impact of these conditions on older people who are approaching normal retirement age. Planned research projects include:

- Investigating whether a social media and internet campaign to spread positive messages about how best to manage back pain, can improve outcomes for patients.
- Working with GPs and employers to improve the effectiveness of the new GP 'fit note' which has replaced the sick note.



Photo (from left to right): Dr. Jim Smith - Deputy Chief Executive & Chief of Strategy, Medical Research Council, & Director of the MRC National Institute for Medical Research. Prof David Coggon - Director, Arthritis Research UK/MRC Centre for Musculoskeletal Health & Work. Dr. Karen Walker-Bone - Deputy Director, Arthritis Research UK/MRC Centre for Musculoskeletal Health & Work. Prof Cyrus Cooper - Director MRC Lifecourse Epidemiology Unit & Vice Dean Faculty of Medicine, University of Southampton. Dr. Liam O'Toole - Chief Executive Officer - Arthritis Research UK.

- Developing guidelines for patients undergoing surgery for conditions such as knee osteoarthritis and carpal tunnel syndrome on when they should return to work, and what their subsequent levels of activity in the workplace should be.
- Finding out whether working to an older age is good or bad for health, and in what circumstances.

According to the Office for National Statistics (ONS) almost 31 million days of work were lost last year due to back, neck and muscle problems, and they accounted for more prolonged absences than any other ailment. Musculoskeletal disorders have been the primary cause of absenteeism for the past five years, with the UK having one of the highest rates in Europe. However, more scientific evidence is needed on the best approaches to their management, and the interventions that could most effectively reduce

their impact in the workplace. The new centre aims to fill that gap.

The centre will be co-located with the MRC Lifecourse Epidemiology Unit at the University of Southampton, with collaborating 'spokes' at the Universities of Aberdeen, Oxford, Lancaster, Liverpool, Manchester and Salford, Guy's and St Thomas's Trust and Imperial College.

Professor Sir John Savill, Chief Executive of the Medical Research Council said: "The health and wellbeing of the UK workforce is vital to our economy. As demographic changes mean more people are working later in their lives, we must further our understanding of how to maintain healthy work environments to minimise the impact of ill health on our productivity. This new multi-disciplinary centre capitalises on decades of MRC investment in occupational research, and aims to help employees, employers and

policy makers face the challenges arising from the need to extend working lives, whilst reducing employee turnover and absenteeism. Our continued partnership with Arthritis Research UK demonstrates the MRC's commitment to working closely with research charities where our aims are aligned, to maximise the impact of funding for health research in the UK."

The Virgin London Marathon 2015

By the time you read this newsletter the 2015 London Marathon will have taken place. Thank you to all those who sponsored our runners and thank you runners for the fantastic effort you have all made, not only to complete the marathon and raise funds for the Association but also for helping to raise Awareness of Paget's Disease. Do send us your photos and we will publish them in our next newsletter along with details of the amount raised.



Paget's T-shirts and Vests

We are able to order Paget's t-shirts and vests for events. Please contact Sue Clegg on **0161 799 4646** for more information.

The Paget's Association Doreen Beck Student Research Bursary 2015

For many years Mrs Doreen Beck MBE, from Northern Ireland, has been a prolific fundraiser for the Paget's Association. Since 1988 she has raised over £230,000. This is an amazing achievement and Doreen was awarded the MBE in 1997 for her fundraising efforts.

In recognition of Doreen's tremendous support The Paget's Association is pleased to offer the **Doreen Beck Student Research Bursary** (£6,000) to encourage a promising UK medical or science student to pursue research into any aspect of Paget's Disease of Bone. The bursary will enable the recipient to participate in research and allow the student to study towards an MRes, MSc, BSc or equivalent higher degree in the 2015 to 2016 academic calendar.

The closing date for receipt of applications is 12th June 2015



Doreen Beck

Full details are available on our website: **www.paget.org.uk**

Alternatively email: **applications@paget.org.uk**

Telephone: **0161 799 4646**.

RAISING AWARENESS via Social Media

Find us on facebook
Paget's Association

Follow us on twitter
@PagetsDisease

See our boards
on Pinterest

Find us on
Google+

Time to tell my story

I have been meaning to put my experience as a Paget's sufferer on paper, for a long time. Recently my wife, Ingrid, joined the Board of Trustees of the Paget's Association so I thought it was about time to tell my story.

I was first diagnosed with Paget's Disease in April 1991, at the age of 57. I had been suffering pain in the appendix area for some time so my GP sent me for various tests. All these failed to show the cause of the pain. I was then sent for a barium meal and an alert Radiologist spotted what he thought was Paget's disease in my pelvic bone. When my doctor read the report he knew nothing about the disease, so had to refer to his medical books.

A subsequent full Isotope Bone Scan confirmed I had Paget's Disease in various places including the right side of my pelvis,

right upper femur, spine, right upper humerus and scapula.

On the advice of my daughter-in-law, who was a nurse in the Intensive Care Unit at Addenbrook's Hospital, I consulted a specialist there. The consultant put me on a Pamidronate infusion. On the way home from the hospital, a 25 mile journey, I was in such pain as my whole body went into muscular spasm. We had to turn around and go straight back to the hospital. It transpired I was allergic to something in the drug I had been given.

In view of the allergy, the consultant prescribed Risedronate which I take orally for a month, have a month's break and then take for a further month. I do this each year. This has been a success for me in that it appears that my Paget's has not deteriorated. Unfortunately, I am unable to have the latest

Zoledronate drug as it is my understanding that this contains something to which I am allergic.

I am able to tolerate the occasional pain but have suffered two serious problems from the disease. I had suffered with pain in my spine since my 30's and it is now thought to have been early Paget's, but as a result I had to give up golf and other sports. The other problem was in my upper right arm. The Paget's caused the bone to enlarge which resulted in the muscle pulling away from the joint. I had an operation to remedy this problem and although it took over a year for the nerves and muscle to heal, it is now fully functional again.

It was interesting to learn last year, when I offered my blood to be tested for research, that I have the Paget's SQSTM1 gene mutation.

Regards, John Pryor, Cambridge.

Give your support to future generations of Paget's sufferers

It's a fact that one of the reasons The Paget's Association has struggled financially over recent years is due to a fall in legacy giving. We believe people are still giving in this way but there are so many charities fighting for attention, how do you choose which one to give to? Well you can of course choose more than one but we ask you to consider remembering the small charities like The Paget's Association. A small charity like ours simply doesn't have the funds to employ

a fund raiser. We prefer to spend vital funds on the information and support services that we provide. In fact, we have recently reduced our overheads considerably enabling us to direct even more funds to the front line, supporting those with Paget's disease and raising awareness amongst the medical profession. You, our members, really can make a difference to our efforts by leaving a gift in your Will. If your estate is liable to Inheritance Tax, you could reduce the amount due by choosing to give money to

charity. Your Will really is one of the most important documents you will ever write. We also want to support those with Paget's disease and fund research into the condition, far into the future. Your gift however large or small can help us put an end to suffering for future generations. If you need further information, copies of the booklet, 'Leaving an Amazing Gift', are available from the Association's office and on our website. Information can also be found online at www.hmrc.gov.uk

MEMBER'S PRIVATE RAFFLE

What will You win?
£200 £100 £50

Have you joined yet? You could be a winner!

200 CLUB

Our 200 CLUB is a private raffle and unique to Paget's members so you really do stand a good chance of winning. By entering you are also boosting our research fund.

Well done to all our Paget's 200 Club winners

JANUARY 2015	£100 – 1st Prize: Ticket No 126 Mr R Bend, Cheshire	£50 – 2nd Prize: Ticket No 133 Mrs E M Davies, Surrey
FEBRUARY 2015	£100 – 1st Prize: Ticket No 88 Mrs J Gorham, Glasgow	£50 – 2nd Prize: Ticket No 142 Mr P Bardsley, Birmingham
MARCH 2015	£100 – 1st Prize: Ticket No 85 Mrs T Couch, Fife	£50 – 2nd Prize: Ticket No 90 Mrs E Wallace, Warrington

To enter the draw the cost is £5 each month. If you opt to pay monthly we ask that you pay by standing order, otherwise you can pay quarterly, half yearly or annually by standing order or cheque.

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. Please contact Sue Clegg our office manager for further information on 0161 799 4646.

GOOD LUCK!

If you would like to join the 200 Club or you require more information, please contact Sue Clegg: telephone: **0161 799 4646**, email: sue@paget.org.uk or complete the slip below.

I would like more information about joining the monthly 200 Club draw.

Name

Address

Postcode

Please send to: **Sue Clegg, The Paget's Association, Suite 5, Moorfield House, Moorside Rd, Swinton, Manchester, M27 0EW.**

Changing lives just one donation at a time

One donation of just £5 can provide vital information and advice to those struggling to get a proper assessment, and where needed, the correct treatment for Paget's disease. Would you help us to do this?

Ways to donate

- ✓ 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**

Why not Gift Aid your donation?

Taxpayers can easily boost their donation by completing a Gift Aid form which enables the Paget's Association to claim an additional 25p for each £1 donated. It costs you nothing. To request a form or for further advice please call Sue, our Office Manager, on **0161 799 4646** or download the gift aid form from our website: **www.paget.org.uk**

Acknowledgements

We would love to be able to acknowledge every donation personally however, because of



the cost of postage, this has become prohibitive. Whilst all donations from non-members will be acknowledged, a decision was made at the AGM in 2010 that donations under £25, given by members, would not be acknowledged by post. All donations of £25 or over however, will be acknowledged unless we are advised that this is not required. If you would like all of your donation to be put to good use, rather than some on postage, please consider putting a note in saying 'no receipt required', or alternatively send us your email address, so that we can personally thank you without incurring additional expense.

Send chocolates, flowers or even a herb garden

Use Charity Flowers for more than just flowers. When you use the *Charity Flowers* service the Paget's Association will receive 15 % for every order received when you quote The Paget's Association (TPA).

Call: **0870 5300 600** or visit **www.charityflowers.com** and find **The Paget's Association** under "T" in the list of charities.



Thank You

If you have used Charity Flowers, donated or given your time to raise funds for The Paget's Association, we want to say a massive thank you. Our thanks come not only from the Charity but also from the individuals you have helped us support and the researchers who strive every day to find a cure for Paget's disease. **Thank You.**



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, horizontally or diagonally, 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 answer to the February word search competition was: **result.**

Thank you to those who entered and for your feedback regarding the newsletter – we appreciate your comments. We also thank those who sent donations with their entries. The winner was randomly chosen out of the correct entries.



Congratulations to our winner **Mrs Elaine Wakefield from Sale, Cheshire** who has received a Paget's Goody Bag.

Treating Paget's Disease

If you have received a diagnosis of Paget's disease, it is important that you are assessed by a consultant with appropriate specialist knowledge. If **treatment** is required, **bisphosphonates**

are a class of drugs **effective** for Paget's disease, as they **calm** down the over **activity** within the **bone**. Whilst treatment is not a cure, it makes the bone **behave** in a more **normal** way and can **relieve** pain **caused** by **active** Paget's disease.

Treatment may be **recommended**, particularly if the **affected** bones are **painful**. Sometimes treatment is given if Paget's disease affects a **site** that might be **expected** to cause **complications** such as the skull or a **weight** bearing bone.

U D E E S R C E R F R T C R S
 A D E N V S E D E N V O R E B
 C E X D O I R L O N M L T L E
 T T P E N B T N I P V A L A H
 I C E V S E D C L E N L E M A
 V E C I W C M I E O V U A R V
 I F T T T E C M H F P E T O E
 T F E C M A I P O O F M B N R
 Y A D A T N S G H C T E A C I
 L G I I Y O A T H D E S U A C
 T E O O H C A L M T V R T N P
 S N T P S I T E E P R N R T E
 S N S S P R Y R T I I A H E N
 H I Y H T N E M T A E R T E R
 B O M P H P V Y C S P S O H M



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 25th June 2015

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 25th June 2015

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:

Remember Someone

Giving in memory of a loved one or friend is a very personal way of remembering them. 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).

You can create your own lasting tribute to someone special and you can even add their photo. They don't have to have had Paget's disease. Please note that if your memorial has been transferred from our old website and you would like to add a photo please contact us on **0161 799 4646** or send the image to diana.wilkinson@paget.org.uk

A section from our online Remembrance Garden

Dr Allan St John Dixon

Together with Ann Stansfield, Dr Allan St. John Dixon helped to establish the National Association for the Relief of Paget's Disease (NARPD) in 1973. He was the first Chairman of the charity and subsequently served as Honorary President until 2011. In addition to his role with the NARPD, now known as the Paget's Association, Allan helped to establish the National Osteoporosis Society, National Ankylosing Spondylitis Society and Remedi, a charity that supports research into rehabilitation. Allan sadly passed away in 2014. We are indebted to Allan for his contribution to the Paget's Association.



Lady Diana Frances Paget

Lady Diana Frances Paget, wife of Patron, Sir Julian Paget sadly passed away in 2014. She was always supportive of the Paget's Association and attended many of our events with her husband. Those of you who met her may perhaps remember her great love of gardening.



In Memoriam – the gift that keeps on giving

We remember and celebrate the lives of those named and thank the family and friends for their thoughtfulness in giving donations to the Paget's Association. Every donation is a lasting tribute to your loved one and the benefits live on. Your gifts enable us to fund research into Paget's disease, alongside supporting to those with the condition.

Michael Sharpe
Christine Richards
John Sharples
Lilian Sharples
Enid Davis



Supporting the Paget's Association

We are grateful for the many ways you find to support us. Thanks to the support of people like you, we are actively working towards building a better future for those whose lives have been or will be affected by Paget's disease. Please share your fundraising events and photos with us. We'll publish as many as we can here.

A day out with the YANCS

Our Specialist Paget's Nurse, Diana, is hoping for another sunny day as she has volunteered to have a tombola stall again at The YANCS (Yorkshire American Cars Club) show which takes place alongside Sewerby Gala.

Sewerby is near Bridlington on the east coast and the event takes place on Sunday 26th July on Sewerby Cricket Club's magnificent cliff top ground. There is a charge to enter the Gala field where there is usually a fun dog show, majorettes, helicopter rides, bands, displays, funfair, food stalls, tea rooms and much more. You will find our Paget's stall within the American car rally area.

Last year a number of people came along for information because either they or their families had been affected by Paget's disease. It was a very enjoyable day and Diana is hoping for another successful



event. If you can donate or fund any tombola prizes please send your contributions to the Paget's Association at the usual address and if you want an enjoyable day out by the sea why not come along?

Viking and Medieval Sale



Member, James Bell, has been an enthusiastic member of re-enactment societies for many years. Unfortunately, he can no longer take part in re-enactment events therefore James decided he wanted to sell some of his clothing and equipment to raise funds for The Paget's Association. The sale of these items has so far raised over £200. We would like to thank James and all those who purchased items for the benefit of the Association.



Sports Auction



Our thanks go to all our London Marathon runners who have been busy raising funds. Martin Avis did this by selling signed footballer photographs on Ebay. Do you have items you could sell to raise funds? Why not tidy out the loft and have a car boot sale or use one of the online selling sites?

Are you raising funds for Paget's?



Our thanks go to all our members who raise funds to support the work of the Paget's Association. Don't forget to tell us about how you are fundraising. From craft making to supermarket bag packing, we will be happy to support you as much as possible. If you are organising an event we can publicise it on our website and provide Paget's information for you to display.