Did Beethoven have Paget’s?

The Sheffield team receive their Centre of Excellence award

Paget’s Research Grants

An invitation to Norwich

Bill’s noisy bones – an interesting case
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Chairman’s message

Dear Member,

The last three months has proved to be a busy but exciting time for the Paget’s Association. As I highlighted in the last newsletter, we received three applications for the Allan Reid Student Research Bursary, which were reviewed by the Trustees at the April Board Meeting. These were all considered to be of high quality and worthy of support. We already had funding for one bursary, as a result of the fundraising efforts of the relatives, friends and colleagues of Allan Reid, who died of osteosarcoma, a rare complication of Paget’s disease. The Trustees were therefore delighted to receive additional funding for a further two Student Research Bursaries from the Michael Davie Research Foundation. This is a charity chaired by Dr Michael Davie, who many of you will remember was previously a Trustee of the Paget’s Association. We have decided to name the two additional bursaries the Ann Stansfield Student Research Bursary and the Michael Davie Student Research Bursary, in recognition of Mrs Stansfield’s role in establishing the Paget’s Association and Dr Davie’s generous support of the charity’s work. The names of the recipients of the Student Research Bursaries will be announced at the Patient Information Day and AGM in Norwich on 29th September, when all three will give a brief talk about their work on Paget’s disease.

In early June, I visited the Metabolic Bone Centre at the Northern General Hospital, Sheffield, to attend a Patient Information Meeting associated with the presentation of their Paget’s Association Centre of Excellence (PACE) award. The audience of patients, medical and nursing staff heard excellent lectures on Paget’s disease, the development of bisphosphonate treatment for the condition and the work of the Paget’s Association. Sheffield has a longstanding reputation for basic and clinical research into bone disease and its treatment, initiated by Professor Graham Russell, Professor John Kanis and colleagues, which has been continued by Professor Richard Eastell, Professor Eugene McCloskey and their team. This research has underpinned and informed the development of an excellent clinical service for patients with Paget’s disease and other bone disorders, headed by Dr Nicky Peel and supported by a multidisciplinary team of colleagues. I was therefore delighted to present the Centre of Excellence plaque to Nicky Peel, and expressed the hope that the Centre’s work will continue to benefit patients with Paget’s disease, not only in South Yorkshire, but also across the UK.

Following Dr Lynne Hocking’s departure as a Trustee in January, we advertised for another scientist to join the Board. I am delighted that Dr Robert Layfield, Associate Professor of Biochemistry at the University of Nottingham and Co-Director of the Nottingham PACE, expressed a willingness to serve as a Trustee. He has therefore been co-opted on to the Board, pending his formal appointment as a Trustee at the AGM in September. Rob is an active supporter of the Association and has spoken at several of our Patient Information Days. He is a welcome addition to the Board and will undoubtedly contribute a great deal to the work of the charity.

As you will have read elsewhere in this issue, plans are now well advanced for the Patient Information Day and AGM in Norwich. In addition to a number of excellent lectures and talks from the three recipients of our Student Research Bursaries, I will be presenting the Paget’s Association Centre of Excellence award to Professor Bill Fraser, Director of the Norwich PACE. I hope that as many of you as possible will be able to join us in what I’m sure will be an exciting meeting.

Roger
Professor Roger Francis, Chairman of the Paget’s Association

Details of Centre of Excellence award ceremonies and any Paget’s information events, which are organised alongside them, are published on our website as they become available www.paget.org.uk
The Lyke Wake Walk Challenge

It was back in February that my walking pal Pat announced that he would like to celebrate his 65th birthday by doing the Lyke Wake Walk and without hesitation, well perhaps a little, I agreed to accompany him. It’s not a decision to be taken lightly as the Lyke Wake Walk is not just a stroll down to the local pub (although we made sure there was a pub at the end), but it’s a walk of some 40 miles across the North York Moors, between Osmotherly, North Yorkshire and Ravenscar on the Yorkshire coast. The challenge is to complete the walk within 24 hours. This would not be our first time at attempting the walk, as Pat has completed the walk on 9 previous occasions and I have accompanied him on 4 of those, so we were well aware of the challenge we faced.

Having decided to undertake the challenge, I thought it would be appropriate, as my wife, Janet, has Paget’s disease, to try to raise some money for the Paget’s Association, and through sponsorship from family and friends, I raised £150.

We started the walk at Osmotherly at 4.20 am on 22 May 2016, Pat’s actual birthday, having stayed overnight at a local hotel. Our wives, Janet and Barbara, provided the back-up catering service by meeting us at various points where the path crosses the roads (they got to ride in the car!) to give us coffee, sandwiches and slices of Pat’s birthday cake.

The first section of the route follows the Cleveland Way for several miles. The path then heads along an old disused railway line towards the Red Lion Inn at Blakey Ridge, a convenient stopping point for anyone wishing to break the journey. This is roughly the halfway point of the walk. From there the path takes a route across the moors, which can be very boggy in places, passes near to Goathland and Fylingdales, and then eventually to Ravenscar.

The radio mast at Ravenscar is situated at the end of the walk and can be seen for several miles and this was certainly a welcome site as we got nearer to the end. With aching feet and limbs, and thoroughly fatigued after 40 miles, we reached the finishing point at 6.10 pm, just under 14 hours since leaving Osmotherly, which included four short breaks for refreshments. The actual walking time was about twelve and a half hours, not bad for a couple of oldies with a combined age of 134 years!

Having completed the challenge, we then stayed overnight at the Hayburn Wyke Inn, which is a short drive from the end of the walk, to continue our celebration of Pat’s birthday.

Graham Dixon, Louth

Will you take up the Lyke Wake Walk challenge for Paget’s?

Is there any better way to experience the North York Moors than heading out for a walk? Why not get a group of family and friends together to take on the Lyke Wake Walk challenge? If you aren’t physically able, then perhaps as Janet did, you can support the walkers with sandwiches and drinks along the way.

The Lyke Wake Walk is a complete crossing of the North Yorkshire Moors along their main east-west watershed between the Stone at grid reference 470994 and the Trig point at 971012. Every person who completes a crossing of the Lyke Wake Walk on foot within a period of 24 hours, and who reports it to The Lyke Wake Club, is eligible for membership of the club.

The walk is detailed on the website: www.lykewake.org

We would like to thank Graham for writing about his challenge and fundraising for the Paget’s Association.

Of course, there are many other beautiful walks in the UK so no matter how long or short, if you have a favourite walk, why not stride out for Paget’s. If you would like sponsorship forms please contact the Paget’s Association’s office.
Bill’s 90th Birthday Party

Bill Hart recently celebrated his 90th birthday, and requested that family and friends give consideration to supporting two of his favourite charities rather than giving gifts. The Paget’s Association was very happy to have been one of the chosen charities and we thank Bill and his family and friends for their support.

Bill was diagnosed with Paget’s disease about 5 years ago, and at the time was told there was little that could be done. Three years later his daughter was at a hospital appointment and happened to read an article in a magazine about Paget’s disease, at a clinic at The James Cook University Hospital, Middlesbrough. After requesting a referral, Bill was investigated further and was informed that he had extensive and widespread Paget’s disease. In fact, the consultant said he had never seen a patient with such extensive active Paget’s disease - hardly something for Bill to be famous for!

Shortly after assessment, Bill was given treatment and even though he suffered a severe reaction to it (yet another first for the consultant), he was determined to continue making the most of life. There was no way Paget’s disease was going to beat him. Not even 2 severely deformed legs were going to stop him gardening. He has however, modified his ways, and now travels up and down his very large vegetable garden with an old kitchen chair. Where there’s a will there’s a way!! Paget’s disease has less effect on his other hobby of watercolour painting, as you can see from the picture.

Recently, Bill reached the age of 90 and his daughter arranged a party, for around 70 family members and friends, to celebrate the occasion with him. At 90 you don’t need lots of presents, so Bill suggested donations in lieu of presents, which could be shared between various charities, one of which being the Paget’s Association. This also provided an opportunity to raise awareness of Paget’s disease and the support provided by the Association. Bill’s bone deformities provided a visual prompt to people, and his daughter was able to instil some humour by stating that she has been known to open the door after hearing what she thought was knocking at the door, only to find out it wasn’t visitors but Bill’s noisy bones!

The Paget’s Association would like to thank Bill, together with his family and friends for their kind donation of £100, and for allowing the charity to turn his paintings into notecards.
PAGET’S ASSOCIATION NEWSLETTER: AUGUST 2016

Bill has kindly given the Paget’s Association permission to turn his paintings into notecards. These are now available at a cost of £4.75 (including postage) for a pack of four. The cards are blank inside and on the reverse, each card shows a picture of Bill painting. Each card measures approximately 5 ¾ x 4 ¼ inches. All profits from the sale of the cards will go to the Paget’s Association. To order, please complete the order form on page 7, telephone the office on 0161 799 4646, or order via the shop on our website: http://www.paget.org.uk/shop/

Continued from page 5

Paget’s disease is not a nice condition to have, but Bill, even at 90, continues to enjoy life and even though the condition is very painful (not that he complains about that), he makes the most of every day - even mixing his own birthday cake, which as you can see from the photo turned out okay!! His birthday party was a great success and enjoyed by all his family and friends. It also provided an opportunity to donate some money to help others through The Paget’s Association.

An Interesting Case

Dr Stephen Tuck is Vice-Chairman of the Paget’s Association and Consultant Rheumatologist at the James Cook University Hospital, Middlesbrough. Here he comments on Bill’s experience.

Mr Hart’s case is a very interesting one. It is also sad in that his Paget’s disease had been present many years and it was thought that it could not be treated. I was very pleased to meet him and felt that I would be able to help him. He had very extensive Paget’s disease affecting his spine, pelvis, hips and sternum. He also had heart failure, which can be a complication of extensive Paget’s disease, albeit rare. I have only one other case that is more extensive. I did not expect to improve his heart failure, but thought I could get his Paget’s under control.

Prior to treatment, his ALP was 1387 (normal is about 130) and the bone specific marker was 2674 (beta-crosslaps). These results are some of the highest I have seen. After treatment with an infusion of zoledronate, the ALP fell to 128 and beta-crosslaps to 270. To my great pleasure, when he returned to see me he felt much better. Unfortunately, he did get a very rare complication of low calcium levels in his blood. This can happen if the individual does not have enough vitamin D or calcium prior to the infusion. This had been carefully checked before giving zoledronate. I can only assume that the sudden switching off of bone breakdown meant no calcium was being released from his bone into his blood and this caused the fall. I have heard of this happening, but had not witnessed it before.

Stephen

Bill’s paintings are now available in notecards to support the Paget’s Association

Bill has kindly given the Paget’s Association permission to turn his paintings into notecards. These are now available at a cost of £4.75 (including postage) for a pack of four. The cards are blank inside and on the reverse, each card shows a picture of Bill painting. Each card measures approximately 5 ¾ x 4 ¼ inches. All profits from the sale of the cards will go to the Paget’s Association. To order, please complete the order form on page 7, telephone the office on 0161 799 4646, or order via the shop on our website: http://www.paget.org.uk/shop/
# Notecard Order Form

<table>
<thead>
<tr>
<th>Item</th>
<th>Price per pack</th>
<th>Number of packs required</th>
<th>Total price</th>
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<td><strong>Shire horses</strong></td>
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<td><strong>Owl</strong></td>
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<td><strong>Ponies and dog</strong></td>
<td>£4.75</td>
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<td><strong>Long-tailed tit</strong></td>
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<td><strong>Poppies</strong></td>
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- The reverse of each card shows Bill painting
- Each card measures approximately 5 ¾ x 4 ¼ inches
- All prices include postage and packing
- Please make cheques payable to Paget’s Association

<table>
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<th>Total Order Value</th>
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Complete for card payments only:

- **Card No.**
- **Switch / Visa / Mastercard** (circle as appropriate)
- **Expiry Date:**
- **Valid From Date:**
- **Issue No. (Switch only)**
- **Security No. (on back of card)**
- **Signature**

Send the completed order form to the address below, allowing 28 days for delivery:
**The Paget’s Association, Suite 5, Moorfield Rd, Swinton, Manchester, M27 0EW**
Alternatively, telephone the office on 0161 799 4646 or order via the shop on our website: http://www.paget.org.uk/shop/
Sheffield Centre of Excellence

The Metabolic Bone Centre within Sheffield Teaching Hospitals NHS Foundation Trust has been awarded Paget’s Association Centre of Excellence status.

Based in a purpose-designed unit at the Northern General Hospital the centre is a fantastic example of a forward thinking team using the latest technology to care for their patients.

Professor Roger Francis, Chairman of the Paget’s Association, presented Dr Nicola Peel with the award at a Paget’s educational event, which took place in June. Clinicians, scientists and patients attended the event in the Medical Education Centre of the Northern General Hospital. Professors Richard Eastell and Eugene McCloskey, together with our Honorary President, Professor Graham Russell and our Specialist Paget’s Nurse, Diana Wilkinson, all gave enthusiastic presentations at the event.

Accepting the award Dr Nicola Peel, Clinical Lead and Consultant in Metabolic Bone Medicine at the centre said, “We are delighted to have been awarded Centre of Excellence status by the Paget’s Association. Not only does this reflect the high standard of care provided to patients in Sheffield with Pagets’ disease but it also recognises the role played by researchers in the city who were instrumental in developing the treatments now used worldwide to manage this condition.”

Patients with Paget’s disease are managed through consultant-led clinics and by the specialist nurse team, who also provide a telephone helpline and patient education. A recent development at the centre has been the introduction of a follow-up register for patients with stable Paget’s disease. The initiative involves offering an annual “virtual” review, allowing regular monitoring but minimizing the number of patient visits to the hospital. Dr Nicola Peel, Consultant and Clinical Lead, explains...

Streamlining care of patients with Paget’s disease

The Metabolic Bone Centre in Sheffield looks after more than 150 patients with Paget’s disease. We are fortunate to work in a purpose-designed unit, which houses both the outpatient clinics and a treatment room where intravenous therapy is administered by our specialist nurses. The department is close to the hospital’s medical imaging department and to the orthopaedic clinics, enabling easy access for patients who need onward referral.

Many of our patients travel a long distance to the clinic, and may need to rely on hospital transport or family and friends to bring them to their appointments. In common with many hospitals, parking spaces can be difficult to find nearby and as some of you may know, Sheffield is built on seven hills making access challenging for anyone but the fittest. When we surveyed our patients a few years ago, the most common message we heard was that although patients were very happy with the service once they arrived in the department, they found the journey difficult and wanted to keep the number of
Eugene McCloskey, Professor in Adult Bone disease at the Mellanby Centre for Bone Research, spoke about the Management of Paget’s disease. He is part of the team who are, together with the Paget’s Association, developing new guidelines for Paget’s disease. The collaboration includes the European Calcified Tissue Society (ECTS) and the International osteoporosis Foundation, (IOF) who have both contributed funds, together with representatives from the Bone Research Society. The guidelines will help to improve knowledge about the investigation, diagnosis and treatment of Paget’s disease, among GPs and hospital medical staff, outside the Paget’s Association Centres of Excellence.

appointments to a minimum. In the past, it was our routine practice to arrange for patients to have blood tests a week or two before their clinic appointment so the results were available when they saw the doctor. In response to the survey, we began to arrange the pre-clinic tests through the patients’ GP surgery or, when this was not possible, to undertake tests at the clinic appointment, and write to the patient and their GP with the results instead of arranging a further clinic visit.

When we looked at the results of this approach, we realised that in many cases, especially those with Paget’s disease affecting just one or two bones, or those who have had an infusion of zoledronic acid, that the disease remains quiescent (inactive), and that treatment may not be needed for years at a time. This led us to introduce a new model of care almost 2 years ago now, using a follow-up register, which we established with the agreement of our local commissioners.

In this model, patients with stable disease are offered the option of transferring to “remote” follow up. We utilise our departmental database to coordinate the register and patients are routinely contacted on an annual basis. They receive a short questionnaire to complete and return to us in a pre-paid envelope. This provides us with an update on their symptoms and medication. They also receive lab forms for blood tests and information so they can have the tests taken at the most convenient location for them. This may be their GP surgery, their nearest hospital, or they may choose to attend one of the drop-in sessions in our department when they can call in at their convenience without making an appointment.

Once the results of the lab tests are available and we have looked at the information from the questionnaire, one of the doctors will write to the patient and their GP with the results. If everything is stable, we...
simply arrange to reassess through the register in another 12 months. If the assessment suggests that the Paget's disease has become more active, we recall the patient back to clinic and will often arrange to administer treatment at the same appointment. Occasionally, the tests suggest an unrelated problem, which we ask the GP to follow up locally.

Feedback from our patients so far has been very positive. The approach particularly suits those people who find the journey to the clinic arduous, but also those who are still working, who no longer need to take time off work to attend a hospital visit. Patients also tell us that they appreciate still being under the oversight of the clinic and maintaining easy access to the metabolic bone team, through the nurse-led helpline, if they need to get in touch during the year. Many GP colleagues prefer the follow-up register to having patients discharged fully back to their care because they do not see enough patients with Paget's disease to feel confident about interpreting their tests and assessing their symptoms. Importantly, in these times of austerity, the follow-up register allows us to deliver quality care in an economical way, targeting use of clinic appointments and use of hospital transport at the right time for each individual patient.

Over the next year or two, we plan to evaluate the follow-up register more systematically. This will allow us to identify the strengths and weaknesses and refine the process as required. We anticipate that over time we will roll out the model to follow up patients with other chronic conditions, allowing more people to receive specialist care closer to home.

Dr Nicola Peel
Consultant and Clinical Lead

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.

Telephone: 07713 568197 or 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.

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.

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.

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

Booklets available from The Paget's Association

Booklets and leaflets containing information about Paget's disease and the support available, can be obtained from our office (contact details are on the inside front cover of this newsletter). All our booklets are also available to members on our website.
My Paget’s Experience by Sheila Nursey, Norwich

“My story really begins after I became a member of the Paget’s Association and the Paget’s Support Network”

Several years after being diagnosed with arthritis in my hip, I reluctantly went to my GP because the pain had become much worse. I was given painkillers, and unable to walk very far, I took to using a walking stick...

Much later, I was referred to a consultant at the Norwich and Norfolk University Hospital and after two years of appointments, it was suggested that I should have a total hip replacement. During the long wait for my operation however, I fell several times which resulted in my having a scan. Things changed when I was told the scan showed arthritis and Paget’s disease. “What’s Paget’s disease”, I enquired? I’d never heard of it. No one seemed to want to explain – but perhaps it was because they couldn’t!

I spent fifteen days in hospital following my hip replacement, after which I was taken home. No aftercare was offered and I felt abandoned. My son and daughter live miles away but I had to make quite a few phone calls to them. Eventually after several months, with the aid of a four-wheeled walker that my son and daughter bought me, I was able to walk down the path. Although I was still in great pain, with my walker for support, I was determined to attend a meeting in Norwich on Paget’s disease, which I had seen advertised in a local paper.

The meeting in 2012, was one of the Paget’s Association’s Information Days. It was very interesting and opened my eyes to the number of people suffering silently with Paget’s disease. My story really begins after I became a member of the Paget’s Association and the Paget’s Support Network. I was put in touch with people from all over the world who also have Paget’s and who wanted to connect with others in the same position. I was amazed, as I had felt so alone. The Paget’s Association helped me connect with Rhoda, who also lives in Norfolk. Unbelievably, after a long chat she told me she was seeing her consultant the next morning. She would ask him if he could see me.

It wasn’t long before all the appropriate arrangements had been made and I received an appointment. As soon as I saw the consultant at his desk, I knew here was somebody who would understand my pain and explain it all to me. He immediately ordered a bone scan, which revealed Paget’s in my pelvis, left tibia, coccyx and both feet, and there was a hairline fracture in my pelvis! No wonder I was in a lot of pain. After assessment of my medical history, he prescribed appropriate treatment. I felt so much better - like a 25 year old! I will always be eternally grateful to Rhoda and to the Professor for his explanation and medical help. At 90 years old, I have resigned myself to make the best of everything.

Online donations to The Paget’s Association

Online donations can be made via the yellow donate button which is present on every page of our website. The Paget’s Association accepts secure donations through PayPal. You do not need to have a PayPal account as a credit or debit card can be used. If you would like the Paget’s Association to reclaim tax on the donations you make, you can use the link ‘Can we claim Gift Aid on your donation?’ which will appear at the end of the PayPal payment process. You can also donate online by using any of the following:

£5 could provide vital information for someone struggling with a new diagnosis
£10 can provide a Paget’s information pack to someone newly diagnosed with Paget’s

Whilst we cannot promise to print them all, we welcome your comments, experiences, videos and photos by email to: helpline@paget.org.uk or post to: Diana Wilkinson, The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.
Dear Paget’s Association,

As somebody who has had Paget’s disease for over 25 years, I found the article, which appeared in the May newsletter, by Dr Rob Layfield, very useful and informative.

Although he has been involved with research into the disease at Nottingham for many years, he realises the importance of how this information might actually help those affected by the disease.

As well as publishing papers and literature on the findings, it is important that ultimately the patient will benefit.

The Paget’s Association Centres of Excellence will raise awareness across the country to help fund research for the future.

John Pryor, Cambridge

The Paget’s Association has invited applications for Paget’s research grants. Our grants are available for all areas of research into Paget’s Disease of Bone. Applications from collaborating centres, and research into aspects of pain in Paget’s disease are being encouraged. The application process is a two-stage process and submissions for the first stage have now closed. All successful applicants from the first stage will be required to submit full details of the research project to go forward to the second stage. These will then be assessed by external experts before a final decision is made regarding which projects to support.

Paget’s Association research grants are only available to investigators in the United Kingdom.
More than Meets the Eye

Last year Carla Burrell, a PhD student from Liverpool John Moores University was awarded the Doreen Beck Student Research Bursary. In April, Carla presented her work on Paget’s Disease of Bone at the American Association of Physical Anthropologists conference in Atlanta. 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. Carla presented her project ‘More than meets the eye: Paget’s disease within archaeological remains’ 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 presented her work within the poster session ‘Skeletal Biology.’ A poster presentation is the presentation of research information in a clear visual format. Posters are a wonderful component of communicating a project, and forms an important element of a researcher’s career. Carla’s poster brought much attention at the conference, highlighting her research concerning the prevalence of Paget’s Disease of Bone within archaeological collections. Her poster focuses on the radiographic analysis of 6 individuals from Norton Priory and 2 from Poulton Chapel, showing the full distribution pattern of Paget’s Disease, which is seen to affect over 75% of their skeletons. Carla has now received results from the radiocarbon analysis, funded by the Doreen Beck Student Research Bursary, identifying that these individuals are indeed medieval in origin (12th-14th Century). Alongside this, Carla has begun to review the rest of the collections and has since identified more individuals with Paget’s Disease of Bone. These new individuals are now subject of full radiographic analysis to identify the distribution, development, and progression of this Disease.

Answers to the crossword in the May edition of Paget’s News

Across
2. Largest bone in the body (5). Answer: femur
7. The femur is not a short bone (4). Answer: long
9. Column protecting nerves (6). Answer: spinal
10. Where bones meet (5). Answer: joint

Down
1. A bony helmet (5). Answer: skull
3. This can have a positive effect on bone health (8). Answer: exercise
4. Knee cap (7). Answer: patella
5. Protected by the rib cage (5). Answer: lungs
8. Found in bones not the garden (6). Answer: marrow

Congratulations to our winner Mary Curliss from Tyldesley who has received a £25 gift voucher to be spent at Boots.

Can you help?

Is there anybody out there willing to sponsor our competition?

This would cost approximately £100 per year. Perhaps you have a business which could donate national gift vouchers? Please contact us if you think you can help on 0161 799 4646.
Was Paget’s the cause of Beethoven’s deafness?

Hearing loss was recognised as a complication in Sir James Paget’s original description of Paget’s disease. Partial or total hearing loss can occur because the physical sound waves are blocked (“conductive” type of loss) before they reach the nerves that convert them to electrical signals and/or because the nerves carrying the electrical signals themselves are blocked (“sensorineural” type of loss). Although the exact mechanisms which underlie hearing loss in Paget’s disease are still debated, both conductive and sensorineural hearing loss can be seen if the skull is involved by the disease, even if total deafness is unusual.

It is a well-known fact that German composer, Ludwig van Beethoven, became completely deaf. Born in 1770, in Bonn, Germany, Beethoven gradually lost his hearing and by the time he was in his mid-thirties, he was completely deaf. Amazingly, some of his most important works were composed during this time, when he was unable to hear.

Beethoven’s medical problems were many and he died in 1827, at the age of 56. Over the years, various papers have been written about his health and possible cause/s of his deafness. The most recent was written by Dr Stanley Oiseth, who is an Assistant Professor of Pathology at New York Medical College and Director of Pathology at Phelps Memorial Hospital in Sleepy Hollow, New York, USA. The article titled, ‘Beethoven’s autopsy revisited: A pathologist sounds a final note’, was published last year in the Journal of Medical Biography and it gives a detailed and knowledgeable review of the original autopsy report.

Dr Oiseth considered each aspect of the report in detail, correlating each observation to documented signs and symptoms. Dr Oiseth has kindly provided the following summary of his paper.

Beethoven’s autopsy: A final note

The general problem with medical histories of historical figures is that they are speculative to a certain degree, and this analysis of Beethoven’s autopsy is no different. This type of analysis places significant importance on the accuracy of the facts used for speculation, and one should always be able to recognise speculation from fact. In the case of Beethoven the original autopsy provides the best source of information which can be correlated with documented clinical signs and symptoms.

Beethoven’s autopsy was undertaken the day after his death by Dr Johann Wagner of the Vienna Pathological Museum with his assistant, Dr Karl von Rokitansky. Beethoven’s skull was twice as thick as normal, and a photograph of his skull taken at the first disinterment in 1863 shows prominent frontal bossing (protuberance of the frontal areas of the skull), prominent cheekbones and forehead producing a lion-like appearance (leonine facies), which is known to occur in Paget’s disease.

Additional evidence of Paget’s disease was found by Dr Wagner when he noted that the facial (“seventh”) nerves were enlarged.
while the auditory ("eighth") nerves were shrunken (i.e. atrophied), despite their sharing a common pathway through the skull, the internal auditory meatus (IAM). Until this report, the significance of this discrepancy has never been realised, but it is a key observation that secures the diagnosis of Paget's disease. The seventh and eighth nerves, unlike the other nerves which exit from the spinal cord, exit directly through openings in the skull. The 7th nerve controls the facial muscles and is a well-formed nerve bundle or cord when it exits through the IAM. The 8th nerve however, is still in a "pre bundled" state and exists as numerous tiny nerve filaments which must pass through as many minute holes or foramina in the IAM before it comes together as another nerve bundle, as it enters the cranium to provide the electrical signals of hearing to the brain. If the bone of the IAM is thickened by Paget's disease, these foramina can be easily obstructed and the small filaments which pass through them are then easily damaged, causing atrophy and death. The facial nerve was also affected by external compression which blocked its lymphatic drainage leading to gross enlargement of the nerve, as seen in Beethoven's case.

The kidneys were filled with calcium deposits within all the calyces, or collecting chambers for urine within the kidney, secondary to hypercalcemia (high levels of calcium in blood) which is known to occur with Paget's disease, particularly when the patient is at bedrest, a common treatment for many ailments at the time. Beethoven was known for his bouts of depression, erratic behavior, and lethargy, all of which are known to be associated with hypercalcemia.

His final months were marked by the complications of cirrhosis of the liver – most likely caused by excessive intake of alcohol – associated with pancreatitis and kidney infections. His immediate cause of death was widespread bacterial infection with organ compromise (septic shock), with kidney abscesses caused by infection introduced by his physicians as they repeatedly drained the abundant intra-abdominal fluid caused by cirrhosis. There was no evidence of tuberculosis, syphilis, Crohn's disease or ulcerative colitis, as proposed at various times and by various authors. Paget's disease and its associated problems, complicated by the use of alcohol and possibly other drugs to relieve the symptoms, can explain most or all of Beethoven's medical problems.

Any illness with sufficient severity will always have both psychological and physical dimensions. Beethoven suffered much during the last half of his life, and had actually pleaded with his brothers to have his doctor find and make public a medical explanation for his 'disease' after his death, since he thought the world would judge him differently if the underlying physical reasons for his behaviour could be explained. This paper fulfils his wish.

Stanley J. Oiseth, MD
Director of Pathology
Phelps Memorial Hospital
Sleepy Hollow, New York.

Reference
Send your photographs for our 2017 calendar

Do you have any photographs which you would like to see in our 2017 calendar? It can be anything at all. Please ensure any individuals in the photo are happy for us to publish it.

Here are some ideas:
- a scene from a holiday
- a local photo of your area
- your garden
- your pets
- yourself
- family and friends
- a winter scene
- a local carnival
- crafts for Paget’s
- an event you held for Paget’s

Send your photographs by email to diana.wilkinson@paget.org.uk

or by post to: The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.

If your photo is chosen, we will let you know as soon as we can. All photos sent by post will be returned, unless you state that you do not require them back.

Joining forces in Liverpool

Liverpool was the venue for our latest Paget’s Information Event, organised jointly with the Bone Research Society (BRS). The Association would like to thank the BRS and in particular Dr Anna Daroszewska, from the University of Liverpool, for her assistance in organising the event.

Exceptionally well attended, the afternoon was both a great educational event and a wonderful networking experience. Attendees with Paget’s disease, who were not familiar with the Paget’s Association, were able to chat to others with the condition, and learn more of the support which is available to members of the Association. We were also pleased to see Health professionals, researchers, and scientists in the audience.

Joining Dr Anna Daroszewska, from the Paget’s Association, to speak about Paget’s disease, were Honorary President of The Paget’s Association, Professor Graham Russell; Vice-chair, Dr Stephen Tuck; Trustees, Professor Bill Fraser and Dr Rob Layfield; and our Specialist Paget’s Nurse, Diana Wilkinson. Lynn Smith from Norton Priory Museum, Runcorn, and Carla Burrell from Liverpool John Moores University looked at Paget’s disease from a local historical perspective.

Raising the profile of Paget’s

Over the two days following the Paget’s information event, Diana was invited by the Bone Research Society (BRS), to promote the work of the Paget’s Association at their annual conference. BRS meetings are renowned for their friendly atmosphere as well as high quality and exciting science. It was an opportunity for Diana to talk to the delegates, many of whom were young scientists and clinicians.

Not only did this raise the profile of Paget’s disease but it also raised awareness of the Paget’s Association and our current initiatives such as our research programme.
Manchester Paget’s Support Group

Our Specialist Paget’s Nurse, Diana Wilkinson, facilitates a support group in the Manchester area. At the June meeting the support group raised £32 by holding a raffle. In addition, they prepared a hoopla game and prizes for a fundraising stall at the summer fair of Worsley Road United Reformed Church.

Manchester Paget’s Support Group

Next Meeting:
Tuesday 13th September 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 mobile: 07713 568197
Office: 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 by contacting the office for further details: 0161 799 4646.

I would like to say a massive thank you to all members of the Manchester support group for their generous donations of prizes and for all their help with preparations for our stall at the summer fair, as well as support on the day. The total raised was £115.60. In addition, we were able to raise awareness of the Paget’s Association in the local community and support the church where our meetings are held.

Thank you everyone.

Diana
Specialist Paget’s Nurse

Philip Kempster preparing his Hoopla game for the fair

Linda Fenlon looking after the main stall and above her husband, Alan, shows children how to use the Hoopla
Norwich Paget’s Information Day & AGM

Date: Thursday 29th September 2016  Time: 9:30am – 3:30pm
Venue: The Music Room, The Assembly House, Theatre Street, Norwich, Norfolk, NR2 1RQ

Our information day in Norwich is particularly for those with Paget’s disease, their carers and family members. Health professionals, researchers and scientists are also encouraged to attend. Experts will discuss topics relevant to those with Paget’s disease and a light lunch will be provided. There will be the opportunity to ask questions and to meet others who have Paget’s disease.

The programme will include:

Presentation of the Norwich Paget’s Association Centre of Excellence Award

Management of Paget’s disease: Bill Fraser, Professor of Medicine, Consultant and Chemical Pathologist.

Joint replacement / history: Mr Keith Tucker, Consultant orthopaedic surgeon

Sir James Paget: Mr Hugh Sturzaker, Retired Consultant Surgeon and author of “Sir James Paget: Surgeon Extraordinary and His Legacies”

Your perspective on the Paget’s Association: Diana Wilkinson, Specialist Paget’s Nurse

My experience of Paget’s: Mr Keith Simpson, Member of the Paget’s Association

Question & Answer session

Presentation of Student Research Bursary Awards

Student research presentations

Closing remarks: Mr Henry Paget, Great, great grandson of Sir James Paget

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 to ask questions.

The Venue

A Grade I-listed building, The Assembly House dates back to 1248 when John Le Brun founded a hospital on the site dedicated to the Blessed Virgin Mary. The building is a fine example of Georgian architecture. The building we see today was designed in 1754 by Sir Thomas Ivory. It has a rich history and free guided tours of the building can be provided by arrangement. Today, The Assembly House is a registered Arts charity that supports a varied programme of visual and performing arts, including exhibitions, concerts, lectures and suites. Further information about the venue is available on their website: www.assemblyhousenorwich.co.uk

Booking

This event is free to attend however, booking is essential. If you would like to come along please complete the form on the next page. Further details and a programme will be sent to you approximately two weeks prior to the event.
### Booking form for **Norwich Information Day**

I / we wish to attend the Paget's Information Event in Norwich

<table>
<thead>
<tr>
<th>Number in party attending</th>
<th></th>
<th>I am likely to be travelling by car/bus/train/taxi (please delete as appropriate)</th>
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<tbody>
<tr>
<td>Name of 1st attendee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of 2nd attendee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of 3rd attendee</td>
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<tr>
<td>Name &amp; address for correspondence</td>
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<td>Postcode</td>
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<td>Tel no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Email address</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please return the above form by post:
The Paget’s Association, Suite 5, Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW.

or email **sue@paget.org.uk**

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### Follow these three easy steps...

1. **Join**
   - Head to easyfundraising and search for us to start raising.

2. **Book**
   - There are nearly 300 travel retailers on board, pick the one you want and get booking.

3. **Raise**
   - After you’ve made your booking, the retailer will make a donation to us at no extra cost whatsoever!

---

**All aboard for FREE donations!**

Help us by collecting FREE donations when you book holidays and travel. Follow these three easy steps...

- **easyfundraising.org.uk**
  - is not limited to groceries, clothes and gifts. You can also book your holidays, train travel and much more.

Find out more and join here: easyfundraising.org.uk/ /causes/paget/
Can you help us reach 200 members?

Our 200 Club was set up with the hope of attracting 200 members. It is a private raffle unique to Paget’s members and a great way to support the Paget’s Association whilst giving you the chance to win a prize.

Thanks to the generosity of our supporters, we raised £5,820 last year and of this, gave out £2,100 in prize money. Every ticket makes a difference.

Prizes

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.

Congratulations to all our prize-winners:

**APRIL 2016**

**1st Prize: £100**  
Ticket No. 57  
Mr A Keep, Derby

**2nd Prize: £50**  
Ticket No. 141  
Mr E Woodruffe, Chesterfield

**MAY 2016**

**1st Prize: £100**  
Ticket No. 140  
Mr N Copeland, Cheshire

**2nd Prize: £50**  
Ticket No. 13  
Mrs M Sabberton, Suffolk

**JUNE 2016 - DOUBLE PRIZE DRAW**

**1st Prize: £200**  
Ticket No. 24  
Mrs Kathleen Hanlon, Huddersfield

**2nd Prize: £100**  
Ticket No. 5  
Mrs Shelagh Fletcher, Maghull

Your ticket

To purchase a ticket you must be a member of the Paget’s Association. Tickets cost £5 each month and each member can have a maximum of two tickets. If you would like to take part in the draw please contact Sue Clegg, our Office Manager, for further information on 0161 799 4646.

The rules for the Paget’s 200 Club are simple and are as follows:

1. The Paget’s 200 Club is only open to members of the Paget’s Association and is limited to 2 tickets per member, with a maximum of 200 tickets. Should there be more applicants than tickets a waiting list will be drawn up and if tickets become available they will be allocated to the person at the top of the waiting list.
2. The membership fee is £5 per month, per ticket paid in advance. This may be paid quarterly, half yearly or annually by cheque or standing order, or monthly by standing order only.
3. Should membership drop below 50 at a future date, monthly draws will be suspended until this minimum figure is reached. If this situation should occur all members will be advised in writing.
4. The winning tickets will be drawn by staff at the Paget’s Association office on the last Wednesday of each month, winners will be advised by post and a list of prize winners for the preceding period will be included in each Newsletter.
5. Prizes will be a £100 first prize and a £50 second. Twice a year, in June and December, the prize money will be doubled ie £200 and £100 respectively.
6. Before each monthly draw takes place, a check will be made to ensure that the relevant monthly fee has been received in the office. If not, the ticket/s will be removed from that month’s draw, at which point we will contact the member to ascertain whether he/she wishes to continue with membership of the Paget’s 200 Club.
7. Should payment not be made for two consecutive months we will treat this as a termination of membership and offer the ticket to the person at the top of the waiting list.
8. All proceeds from activities relating to the Paget’s 200 Club will, with the exception of prize monies, be used for the furtherance of the work of the Association.
The Paget’s Association
200 Club Application Form

Please accept my application for membership of the Paget’s 200 Club.

Name
Address
Postcode
Tel:

Number of tickets required:
1 or 2
(please delete as required)

Cost of membership is £5 per ticket per 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. Payments by cheque must accompany this completed form. To pay by standing order, please complete the standing order mandate below and return to the Paget’s Office.

<table>
<thead>
<tr>
<th>Payment option</th>
<th>For 1 Ticket</th>
<th>Tick preferred option</th>
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<tr>
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<tr>
<td>Half Yearly</td>
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<tr>
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<td>£15</td>
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<tr>
<td>Monthly</td>
<td>£5</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Payment option</th>
<th>For 2 Tickets</th>
<th>Tick preferred option</th>
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</thead>
<tbody>
<tr>
<td>Annual</td>
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<tr>
<td>Half Yearly</td>
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<tr>
<td>Quarterly</td>
<td>£30</td>
<td></td>
</tr>
<tr>
<td>Monthly</td>
<td>£10</td>
<td></td>
</tr>
</tbody>
</table>

Standing Order Mandate – Paget’s 200 Club

To: (name of bank and branch)
Address
Postcode
Sort code

Pay to the credit of The National Association for the Relief of Paget's Disease at Barclays Bank, 1 Market Street, Bolton, BL1 1BU. Account Number 30660078. Sort Code 20-10-71

The sum of £

Monthly / Quarterly / Half Yearly / Annually
(Delete as appropriate)
Commencing on / / until further notice

From: My / Our Account (Name)
Account No.
Address
Postcode
Signed (Date)

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

For office use only:
P2C/
On Sunday 24 April 2016, history was made...

As the one millionth London Marathon finisher, Shannon Foudy, crossed the world famous Finish Line on The Mall. Shannon was running her first marathon to raise money for the Luton & Dunstable Neonatal Intensive Care Unit. A #oneinamillion social media campaign celebrated every finisher since the race began in 1981.

**The London Marathon Experience**

**Phil Beadle from Dagenham**

“This year was my 2nd London Marathon for the Paget’s Association, which seemed to make it easier. I knew in October that I would be running again, so I didn’t really stop training. On the day, my sons Luke and Ben and I had got to Greenwich Park early. The atmosphere was brilliant, the weather had been kind again this year, no rain and not too hot. As always the crowds were amazing, cheering the runners on every step of the 26.2 miles. I finished in 4 hours 34 mins, beating my time from last year, and raised over £1600, again beating last year. I wasn’t the one-millionth finisher, but I’m very proud to be one in a million. Thank you all for your help and support.”

*Phil*

**Neil Kirby and Simon Brown from Eastbourne**

“It was a fantastic event, great organisation, and amazing support throughout. We are delighted to have raised awareness for the Paget’s Association surpassing our £3k sponsorship target, raising £3,775. It was also Neil’s 30th marathon, which he ran in 4 hours 35 minutes, and it was my second, which I ran in 4 hours and 5 minutes. Thank you to Paget’s for the opportunity of this great event.”

*Simon*
Thomas Ager-Lowden from Leigh on Sea

Thomas believes that his secret to completing the marathon was his state of mind. This was 18-year-old Thomas’s first marathon and he ran on behalf of his Grandad, Keith Charnock, who has suffered with Paget’s for over 35 years.

Thomas with his Grandfather, Keith Charnock

Thomas’s training had been hindered due to an injury however, with the help of a friend who is a qualified sports physiotherapist, Thomas was given the go-ahead to complete the challenge.

He set himself a target to achieve the marathon in under 4 hours and he was very pleased to complete it in 3 hours, 58 minutes! Since his acceptance for the marathon, he has repeatedly said, “It’s only a state of mind”. Thomas is in the process of collecting in his sponsorship money and believes it will exceed his original target of £1,500.

“It’s only a state of mind”
Thomas

Disappointment over Fundraising Cycle Event

Well we know there are cyclists out there but unfortunately, we have not been able to fill any of our places in this year’s Prudential RideLondon – Surrey 100 cycle event.

Challenge – Find the Cyclist!

If you know someone who cycles, please tell him or her about the Prudential RideLondon – Surrey 100 cycle event. We are now accepting applications for 2017. Applicants do not need to have any connection with Paget’s disease however, they need to be willing to raise a minimum of £500 for the Paget’s Association.

The Event

Amateur cyclists participate in this 100-mile challenge on the same closed roads as the professionals, with the added incentive of raising money for good causes. The best of the action is broadcast live on TV both in the UK and internationally.

The Prudential RideLondon-Surrey 100 starts in Queen Elizabeth Olympic Park, then follows a 100-mile route on closed roads through the capital and into Surrey’s stunning countryside. With leg-testing climbs and a route made famous by the world’s best at the London 2012 Olympics, it’s a spectacular event. The event finishes on The Mall in central London.

How to Apply

Download the application form from our website: www.paget.org.uk, or call 0161 799 4646, to request an application form for 2017.

Photograph courtesy of Prudential RideLondon

Thomas with his Grandfather, Keith Charnock

Thomas Ager-Lowden from Leigh on Sea

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“It’s only a state of mind”
Thomas
You are invited to attend...

The Paget’s Association AGM

to be held on
Thursday 29th September 2016
1:30pm – 2:30pm
at
The Assembly House, Theatre Street, Norwich, NR2 1RQ

Notice is hereby given that the Annual General Meeting (AGM) of The Paget’s Association (also known as The National Association for the Relief of Paget’s Disease) will take place on Thursday 29th September 2016 at 1:30pm. This will be held at The Assembly House, Theatre Street, Norwich, NR2 1RQ.

The following pages include information required for the AGM:

- The proposed agenda for the AGM
- The minutes of the last AGM held at the Park Inn Peterborough, on 17th September 2015
- A brief summary of the Statement of Accounts and the Balance Sheet from the Report and Accounts

Full copies of the Report and Accounts can be obtained either at the AGM or from the office on request.

**Agenda**

1. Minutes of the Annual General Meeting held on Thursday 17th September 2015, at the Park Inn Peterborough
2. Presentation of the Report and Accounts from the last financial year
3. Re-appointment of Champion as the Association’s independent examiners
4. A review of the last year’s activities
5. Election of Trustees and officers
6. Any other business
The Minutes of the Paget’s Association Annual General Meeting held on Thursday 17th September 2015, at the Park Inn, Wentworth Street, Peterborough, PE1 1BA

1. Minutes of the Annual General Meeting held on Thursday 25th September 2014 at the Copthorne Hotel, Bramall Lane, Sheffield, S2 4SU

The AGM was opened by the Chairman, Professor Roger Francis. He commenced the meeting by introducing the Trustees of the Association. He outlined the minutes from the 2014 AGM which were agreed by those members present.

2. Presentation of the report and accounts from the financial year ending 2014

Professor Francis presented the Association’s Report and Accounts for the previous financial year. He explained that expenditure had now exceeded income for three consecutive years. In 2013, the trustees had begun restructuring the Association by halving the workforce, and temporarily suspending new research funding. In May 2014, the Walkden property had been sold and the proceeds invested. Suitable office accommodation had then been rented at Moorfield House, Swinton.

Professor Francis went on to review the financial activity of the Association. Although there was a deficit of £82,363 for the year ending 2014, expenditure was substantially lower than in the previous year. The Trustees were confident that the measures which had been put in place to improve the financial position of the charity were working. No questions were forthcoming.

3. Re-appointment of Champion as the Association’s independent examiners

Mr John Pryor proposed that Champion be re-appointed as the Association’s auditor. Mr Roy Doggett seconded the proposal, and all present agreed. Mr Allan Kidney questioned whether the accounts were audited or independently examined, as charities with income under £500,000 only needed their accounts to be independently examined. The Office Manager confirmed that the accounts are independently examined.

4. A review of the activities in 2014

Professor Francis presented information about the Association’s activities during 2014. The Association continued to meet its charitable aims by supplying information and support to all enquirers through booklets, newsletters, meetings, the Helpline, the website and social media. Three Paget’s Information Days were held in Bristol, Middlesbrough and Sheffield. The move to new office premises, had been a success. The number of Helpline enquiries had increased during the year.

Professor Francis was positive about the coming year for the Association. Ten Centres of Excellence had been identified in Cardiff, Stanmore, Norwich, Nottingham, Salford, Manchester, Sheffield, Middlesbrough, Newcastle and a joint centre in Edinburgh and Aberdeen. It is hoped that these centres will help improve the management of patients with Paget’s disease and research into the condition, but more information will be released in due course. The Trustees are also planning to re-introduce the research programme in 2016 thanks to a legacy, given with the specific request for research. During 2014, it had been decided to recognise the hard work of Mrs Doreen Beck, who had, in the past, been a prolific fundraiser for the Association. The Association had therefore, this year, introduced the Doreen Beck Research Student Bursary Award. Professor Francis paid tribute to Mrs Beck for her tireless efforts on behalf of the Association and congratulated Carla Burrell, a PhD student from Liverpool John Moores University, on being awarded the bursary.

5. Election of Trustee and Officers

Professor Francis informed those present that Mrs Janet Strang and Mr Nigel Copeland had completed their terms of office as trustees. Mr Copeland had served as a trustee for many years, but now felt it time to step down. Mrs Strang was willing to be re-elected. Professor Francis thanked Mr Copeland for all the work he had done on behalf of the Association during his term of office. Mrs Strang was nominated for re-election by Mrs Elizabeth Wood, and seconded by Mr John Pryor. Professor Francis reported that Mr Michael Patnick had been co-opted onto the Trustee Board in April. His former employment with Arthritis Research UK meant he had considerable charity experience to offer the Association, and therefore Professor Francis recommended that his appointment be formally agreed by those present. Mrs Liz Wood proposed the appointment and it was seconded by Mr John Dyer. Both appointments were agreed by those members present.

Professor Francis concluded the meeting by thanking all those present for attending.
# The Paget’s Association for the Relief of Paget’s Disease

## Statement of Financial Activities
(Incorporating the Income and Expenditure Account)

**Year Ended 31 December 2015**

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<th></th>
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<th>Total Funds 2014</th>
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<td>Investment income</td>
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<tr>
<td>Other incoming resources</td>
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<td>£5,510</td>
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<td><strong>Total Incoming Resources</strong></td>
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<td>£81,563</td>
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<td><strong>Resources Expended</strong></td>
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<tr>
<td>Fundraising trading: cost of goods sold and other costs</td>
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<td>(£7,048)</td>
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<tr>
<td>Charitable activities</td>
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<td>(£97,144)</td>
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<tr>
<td>Governance costs</td>
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<td>(£59,734)</td>
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<td><strong>Total Resources Expended</strong></td>
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<td><strong>Net Incoming/(Outgoing)</strong></td>
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<tr>
<td>Resources Before Other Recognised Gains and Losses</td>
<td>£74,476</td>
<td>(£82,363)</td>
</tr>
<tr>
<td><strong>Other Recognised Gains and Losses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gains on investment assets</td>
<td>£539</td>
<td>£5,259</td>
</tr>
<tr>
<td>Profit on disposal of tangible fixed assets for charity’s own use</td>
<td>–</td>
<td>£43,241</td>
</tr>
<tr>
<td><strong>Net Movement in Funds</strong></td>
<td>£75,015</td>
<td>(£33,863)</td>
</tr>
</tbody>
</table>

## Reconciliation of Funds

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total funds brought forward</td>
<td>£493,575</td>
<td>£527,438</td>
</tr>
<tr>
<td><strong>Total Funds Carried Forward</strong></td>
<td>£568,590</td>
<td>£493,575</td>
</tr>
</tbody>
</table>

## Balance Sheet

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>£1,999</td>
<td>£2,284</td>
</tr>
<tr>
<td>Investments</td>
<td>£434,356</td>
<td>£371,611</td>
</tr>
<tr>
<td><strong>Total Fixed Assets</strong></td>
<td>£436,355</td>
<td>£373,895</td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors</td>
<td>£5,421</td>
<td>£3,646</td>
</tr>
<tr>
<td>Cash at bank and in hand</td>
<td>£153,603</td>
<td>£149,009</td>
</tr>
<tr>
<td><strong>Creditors: Amounts Falling due Within One Year</strong></td>
<td>£159,024</td>
<td>£152,655</td>
</tr>
<tr>
<td><strong>Net Current Assets</strong></td>
<td>£132,235</td>
<td>£119,680</td>
</tr>
<tr>
<td><strong>Total Assets Less Current Liabilities</strong></td>
<td>£568,590</td>
<td>£493,575</td>
</tr>
<tr>
<td><strong>Net Assets</strong></td>
<td>£568,590</td>
<td>£493,575</td>
</tr>
<tr>
<td><strong>Funds</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restricted income funds</td>
<td>£124,425</td>
<td>£145,891</td>
</tr>
<tr>
<td>Unrestricted income funds</td>
<td>£444,165</td>
<td>£347,684</td>
</tr>
<tr>
<td><strong>Total Funds</strong></td>
<td>£568,590</td>
<td>£493,575</td>
</tr>
</tbody>
</table>
Committed Now and for Future Generations

With your help, we will still be here to support those affected by Paget's disease for generations to come. Every day those with Paget's disease and their families come to us for information, advice and support. We are committed to being here for future generations and want to continue to fund quality research for as long as it is needed. Much of our work is paid for by gifts people leave to us in their wills. Large or small, your gift really does make a difference.

If you have already chosen to remember the Paget's Association in your will, thank you. If not, would you consider putting your mark on the future by leaving a legacy to the Paget's Association?

Your will tells everyone what should happen to your money, possessions and property after you die. If you don't leave a will, the law decides how these are passed on and this may not be in line with your wishes. It's easy to make a will and it will save your family unnecessary distress at a difficult time. If you have already made a will and would like to add a gift to The Paget's Association, you can update your will with a codicil. This is a supplement to your will that can enable you to make simple changes or additions to it. Your Solicitor can tell you more about whether this is a suitable option for the changes you would like to make, and explain how to go about it.

Margaret Bean
Vera Downing
Brian Barron
John Micallef

Thank you to all 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.

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

Recycle Stamps, Jewellery and Printer Cartridges for Paget's

Please send your stamps to the Paget’s Association’s office: Moorfield House, Moorside Road, Swinton, Manchester, M27 0EW. If you have a large number, we can send you a prepaid envelope in which to post them.

Envelopes to recycle printer cartridges and jewellery are also available from the office. If you have any queries please call Sue on 0161 799 4646 or e-mail sue@paget.org.uk
Every Penny Matters

We want to say a special thank you to those who returned the donation form in the last newsletter. Your generosity is appreciated.

What can you do to help?

■ Are you a member of an interest group such as a craft group, choir or dance club who could hold a raffle or a sponsored event?

■ Are you a member of an organisation such as the inner wheel or rotary club who may be willing to fundraise for Paget’s?

■ Employees - can you get together with colleagues to hold a “Bring a pound to work for Paget’s day”?

■ Will the company you or a family member work for, consider the Paget’s Association as their charity of the year?

■ Do you run a business, which could sponsor our Nurse Helpline, a web page or Paget’s information event?

■ Perhaps you know a shop where you can place a “Pennies for Paget’s” collecting box on the counter?

We would love to hear your ideas and see your fundraising photos. We will publish as many as we can.

Climbing Ben Lomond for Allan

When Allan Reid, from Glasgow, died in 2014, from Paget’s-associated osteosarcoma, a type of bone cancer that is a very rare complication of Paget’s disease, his friend Norman Kerr set up a Just Giving Page to raise funds for Paget’s disease. Thanks to family and friends, they have now raised over £5700. This fantastic achievement enabled the Association to offer a Student Research Bursary in Allan’s name. The winner of this bursary will be announced in September at the Information Day and AGM in Norwich.

Norman’s latest fundraising challenge was to climb Ben Lomond, a distinctive mountain in the Scottish Highlands. Rising from the east shore of Loch Lomond to a height of 3,193ft, Ben Lomond rewards those who make it to the top with fantastic views of Loch Lomond and the Trossachs. Sixteen took on the challenge, on what would have been Allan’s 59th birthday. Norma, Allan’s widow said, “I’ve never climbed before, and we all agree it was the toughest thing we’ve ever done. We are so pleased we made it. Allan would have been so proud of us, as he would never have put us down for such an activity. I’m still in a state of shock from the experience!”

Thank you to everyone who has donated so far. The fundraising page can be found on the Just Giving website: www.justgiving.com/fundraising/AllanReid