

Supporting those affected by Paget's Disease of Bone, funding research and raising awareness



Personal stories of treatment

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for the
Association**



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our raffle**

Chair's message

Dear Member,

Welcome to the May 2023 edition of *Paget's News*, which marks the midpoint of the Association's 50th Anniversary celebrations.

It has been a very busy year for the charity so far. We have been working flat out on the 50th Anniversary Symposium and have also moved headquarters to Jactin House in the Ancoats area of central Manchester. So, if you want to get in touch with us by letter, please take a note of our new address on page 5. Please note that Jactin House is a "virtual" office so you are unable to just drop in if you want to speak to a member of the team! You can make contact by telephone using the same number as before or by email. If you want to meet us face to face, why don't you consider attending one of our Paget's information events? The next one is being held near Stafford, hosted by Dr Zoe Paskins on 27 October this year. Full details are on pages 16-17.

The major event of the year was our 50th Anniversary Scientific Symposium and patient information session at The Lowry arts centre, Salford. The meeting, held on 19-20 April, was a great success. It was attended by many clinicians and scientists from around the world who submitted 42 presentations about the research they have been carrying out on Paget's disease. We also had 12 invited speakers who delivered lectures on all aspects of the disease, ranging from what we can learn from the cellular abnormalities that underlie the disease, to the outcomes of treatment with medicines and orthopaedic surgery. We plan to publish a



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 ”

summary of the presentations on our new website which is going to be launched later in the year. Watch this space! Other highlights of the meeting were the patient information event chaired by Diana Wilkinson and the Gala evening and networking session, attended by Patron Sir Henry Paget who outlined plans that the charity has for the years ahead; and Mr Recardo Patrick who entertained us with a live performance that was hugely appreciated by all present. It was also a pleasure for the Association to announce the award of four new PACE centres: one in Leicester, led by Trustee Dr Faiz Rahman; one in Keele, led by Dr Zoe Paskins; one in Cambridge, led by Dr Gavin Clunie; and one at Imperial College in London, led by

Dr Alexander Comminos. We will publish more detail about the Anniversary events in the August edition of *Paget's News* which will be a special 50th Anniversary edition.

Our regular feature on the latest research relevant to Paget's disease focused on two publications. The first from researchers in Greece which compared outcomes following treatment of Paget's disease with a course of risedronate tablets or an infusion of zoledronic acid. Although both treatments were effective, zoledronic acid was found to be superior, in keeping with the recommendation made in the 2019 guideline on Paget's disease which was led by the Association. The second highlighted paper is from Philippa Hulley and Helen Knowles from Oxford who describe a new way of culturing osteoclasts – bone-resorbing cells that are markedly increased in number and activity in Paget's disease. This research, which is supported in part by the Paget's Association, will help to improve understanding of the causes of Paget's disease and other bone diseases where osteoclast activity is increased.

I always like to read the personal stories of patients who have been diagnosed and treated for Paget's disease. Those highlighted in the present edition of the magazine illustrate that the reach of the Association now extends well beyond the UK. Currently we support 815 people with Paget's disease from more than 25 countries around the world through our Facebook support group. Accordingly, in addition to Linda Fenlon's interview on page 13, we have an interesting contribution from Emanuela Mazzoleni from Italy who had pain associated with

Paget's disease of the humerus, which responded well to zoledronic acid. Also the experience of Jim McKenney from the USA whose Paget's disease was diagnosed incidentally while undergoing tests for another condition and then successfully treated with the same medicine. I am sure you will join me in wishing all three contributors good health in the years to come and especially wish Emanuela good luck for her walk of the Camino de Santiago de Compostela in Spain next year.

Regular readers may recall that in the May 2022 edition of the magazine I mentioned that we had launched a fundraising campaign to mark the Association's 50th Anniversary with a target of £50,000. As you can see on page 22, we are now very close to this target having raised a magnificent £44,345! Special thanks are due to Janet and Graham Dixon who have raised more than £3,000 for the charity since 2018, but my thanks go out to everyone else who has contributed to fundraising over recent years. Let's keep these fundraising efforts going!

In closing I wanted to highlight that Sue Clegg, Office Manager has decided to retire at the end of April after 25 years with the Association. Sue will be greatly missed by her colleagues and all of the Trustees for the Paget's Association, but I am sure you will join me in wishing her a long and happy retirement.

Keep safe and stay well.

Best wishes,

Stuart Ralston
Chair, Paget's Association

The Paget's Association

Charity registration number: 266071

The Paget's Association is a charity in the United Kingdom, which focuses solely on Paget's Disease of Bone. Also known as The National Association for the Relief of Paget's Disease (NARPD), the charity was founded in 1973 by the late Mrs Ann Stansfield MBE.

In addition to providing information, support and guidance to all who require it, the Paget's Association raises awareness, and funds quality research.

Membership

Membership of the Paget's Association provides support and information in several ways. All members receive a Paget's Information Pack on joining, as well as our quarterly Paget's News magazine.

What is Paget's Disease of Bone?

Throughout life, normal bone is renewed and repaired through a process called bone remodelling. In Paget's disease, bone remodelling is accelerated and disorganised, leading to the formation of bone that has an abnormal structure.

Paget's disease may affect only one bone or several, and the affected bone is often enlarged and misshapen. It can be painful, and complications, such as fractures, can occur.

A more detailed explanation can be found on the Association's website and in our booklet '*Paget's Disease – The Facts*'.

Our website

There is a wealth of information regarding Paget's disease on our website.

www.paget.org.uk

Paget's Awareness Day

International Paget's Disease Awareness Day takes place annually on 11 January.

Contact us

The team at the Paget's Association would be more than happy to hear from you. Please get in touch!

Telephone

For all enquiries telephone:
0161 799 4646

Email

All general and membership enquiries:
membership@paget.org.uk

Postal address

You can write to us at the following address:

The Paget's Association,
 Jactin House, 24 Hood Street,
 Ancoats, Manchester, M4 6WX

Paget's Helpline

Our Paget's Helpline is available to anyone who requires support or has questions regarding Paget's disease. You can contact the Helpline by email, telephone (during office hours) or by writing to us at the address above.

■ Email: **helpline@paget.org.uk**

■ Telephone: **0161 799 4646**

■ Mobile: **07713 568197**

Chair of the Association

Professor Stuart Ralston
 Email: **chair@paget.org.uk**

Connect with us on



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Moving with the times



We've moved

Perhaps the biggest change for many charity workers during the Covid-19 pandemic was the switch to full-time remote working from home. The employees of the Paget's Association were no exception and the trend for many organisations has continued. Our two members of staff, Diana Wilkinson and



Diana (left) and Jen (right) outside Jactin House

Jen Woodworth, are now working largely remotely which has enabled the charity to reduce costs by moving its base to Jactin House, in the heart of Ancoats, Manchester.

Once the beating heart of industry, Ancoats has been described as one of the coolest neighbourhoods in Manchester. Jactin House was built in 1881 to house mill workers during the industrial revolution. Now it blends old with new to provide a modern, flexible co-working space and around it the local independent shops and eateries are thriving.

Please make a note of our new address (above). This is a postal address only therefore you are not able to visit us in person. If you would like to meet the team, you may want to consider attending one of our Information Events. Pre-paid envelopes with our old address should no longer be used and mail sent to our old address will be redirected for a limited time.

Please note our new address

The Paget's Association
Jactin House
24 Hood Street
Ancoats
Manchester
M4 6WX

No change to our telephone number
0161 799 4646



Our telephone number has not changed as the technology we use enables calls to be answered wherever the staff are working.



Some of the co-working space inside Jactin House

Service evaluation in Sheffield

The team at the Paget's Association Centre of Excellence in Sheffield has recently evaluated the service they provide to those who have Paget's disease. This was presented in a poster for delegates to view at the International Paget's Symposium in Manchester last month. The following is a summary by Diana Wilkinson.



The Metabolic Bone Centre in Sheffield hold a register of people whose Paget's disease is inactive so that they can be regularly followed up with annual blood tests and questionnaires, rather than asking them to attend clinic each year. The blood tests can either be carried out by the phlebotomist service at the hospital or at their local GP surgery. The results are evaluated by doctors with people only being recalled to clinic if their symptoms and/or blood test results suggest increased activity of their condition that may require further evaluation and intervention.

To evaluate this service, the team looked back at all those added to the Paget's register since 2015.

They determined how many people with Paget's associated abnormalities in their blood tests were recalled to clinic. In addition, satisfaction questionnaires were sent to all. In total 53 patients were included in the evaluation.

They found that 20 patients had had a significant increase in the level of alkaline phosphatase (ALP) in their blood; of these, six were recalled to clinic as they had symptoms such as pain. All six were offered bisphosphonate treatment and three accepted it. Only one had a significant decrease in ALP after taking the bisphosphonate. A further six patients were recalled as they reported pain at a site affected by their Paget's disease.

Overall responses to the questionnaire were positive towards being in the register system compared to having to attend the Metabolic Bone Centre clinic. Only three of the 29 who responded to the questionnaire were dissatisfied with the service.

It was concluded that most people with increased ALP were not recalled to clinic which may reflect a lack of a clear threshold for recall. The authors made recommendations for changes to allow the register to be a more effective and acceptable form of management for the people on it. These recommendations included:

- The addition of another blood test (P1NP) to investigate for biochemical abnormality caused by active Paget's disease. This test has been found to be comparable to serum ALP and is less affected by other conditions such as liver disease
- Adding a date to the patient questionnaires and scanning it with the outcome sheet into their system to make follow-up and future service evaluations more straightforward
- Production of a handover letter by the doctor when patients are placed on the register

Giving members a voice

Through the Paget's Association's Focus Group, those affected by Paget's disease and their families are able to give their opinions on various aspects of the charity's work. This helps ensure the Association's activities are meaningful to those who need help. The Association's Specialist Paget's Nurse, Diana Wilkinson, facilitates and supports the group as they explore opinions and generate ideas relevant to those with Paget's disease and the Paget's Association.

Currently seven members of the Association, who either have personal experience of Paget's disease themselves or have a family member with the condition, have joined the Focus Group. This is a voluntary role and the team at the Paget's Association would like to express their sincere thanks to Janet, Alan, Nigel, Lisa, Graham, Keith and Dorinda, who meet virtually a few times each year. At the invitation of the group, Trustee Kely Burman whose mother had Paget's disease, has recently joined the group. This provides the group with a direct link to the Board of Trustees.

Making a difference

Last year the group discussed all aspects of the Association's work concluding that the charity's information and support services are the most important and, of those, the website should be given priority so that people can easily find the support they need. Whilst other support services such as the Helpline, Paget's News



magazine, Support Groups, Paget's Network, Buddy scheme etc, were secondary, the group felt that all were still extremely important and that having a diverse range of activities meant that many individuals could be helped in a way that was best for them. Having listened to the group's opinion, the Board of Trustees decided that the Association's website was no longer the best it could be and commissioned a new website which will be available soon. Through this, it is anticipated that more people will be helped to find the support and information when they need it most.

Additional members needed

The Focus Group would like to add additional members to the team and welcome contact from any member of the Association who is interested. Please email Diana or telephone the office to express your interest. You do not require any special skills, just the willingness to share your opinions and the ability to use Zoom (we are happy to help if you are unfamiliar with it). Group member Alan Martin said, 'Building relationships, sharing experiences, and collectively exploring opportunities for improvement from the comfort of my home has been both fulfilling and enjoyable. I believe that all those involved in the life of the Association get a boost from the feedback and exchange of information that the Focus Group facilitates. It's good to make a small contribution to an organisation that has helped me so much in living with Paget's. I would urge other members to join the group.'

Ask a question

If you have a non-medical question that you would like the Focus Group to discuss and potentially pass to the Board of Trustees, you can get in touch through Diana in the first instance using the contact details above. You can also write to the address on page 3. Alternatively, questions about the running of the Association can be put to the Chair at the Annual General Meeting in Stafford (see page 15). All personal medical queries should go through the Paget's Helpline (see page 21).

Journal news



Scan the QR code to read the paper in full



This regular feature provides a glimpse into some of the research taking place around the world. In this issue, the Chair of the Association's Research Subcommittee, Professor Rob Layfield, and our Specialist Paget's Nurse, Diana Wilkinson, review a study that took place in Greece. This compared the two main treatments for Paget's disease used in the UK. The paper is summarised below. The full text is available online by scanning the QR code with a smartphone or searching for the above reference below.

Secondly, research at the University of Oxford funded by the Paget's Association, regarding a new method to investigate bone cells in Paget's disease is highlighted. Professor Layfield then discusses on page 10 what goes wrong inside bone cells when someone has Paget's disease.

Greek study evaluates treatment for Paget's

A retrospective study of data over 16 years (Dec 2005 to Nov 2021) at a hospital in northern Greece, assessed the therapeutic effect of a single intravenous infusion of zoledronic acid (5mg) or oral risedronate (30mg per day for 60 days) for Paget's disease. Both drugs are from a group known as bisphosphonates.

The study looked at patients over 55 years who had active Paget's disease and were treated with either a single intravenous infusion of 5mg zoledronic acid (46 patients) or a tablet of risedronate 30mg per day for 60 days (43 patients). All patients also received 1000mg of calcium and 400-800IU of calciferol daily.

The researchers measured the control of symptoms and normalisation of specific blood

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The authors of this paper concluded that their study showed zoledronic acid to be superior to risedronate in patients with active Paget's disease
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tests (serum ALP, serum P1NP, and serum CTX). The secondary outcome measures included the patient's quality of life.

Of those who had pain, a significant degree of clinical improvement was seen in 40 patients from the zoledronic acid group and 38 patients from the risedronate group. In the zoledronic acid group, mean scores for each of the eight components of a quality of life questionnaire had an upward trend at both 6 and 36 months indicating improvements whereas in the risedronate group the responses were more varied. A significantly greater improvement was found

in the zoledronic acid group compared to the risedronate group in terms of physical functioning at 6 months and general health and bodily pain at 6 and 36 months. In addition, the zoledronic acid group had a significant improvement from baseline scores in their physical and mental scores at both 6 and 24 months.

The authors of this paper concluded that their study showed zoledronic acid to be superior to risedronate in patients with active Paget's disease. This is in line with the clinical guideline published in 2019 commissioned by the Paget's Association. The guideline recommends bisphosphonates for the treatment of bone pain associated with Paget's disease and zoledronic acid as the first-line treatment.

REFERENCE

Zidrou C, Rizou S, Beletsiotis A. *The Superiority of Zoledronic Acid Over Risedronate for Paget's Disease: A 16-Year Experience at a Single Institution. Cureus.* 2022 Dec 25;14(12):e32923.

Paget's Association funds new method to investigate bone cells

Osteoclasts are large cells that remove bone in areas of the skeleton affected by Paget's disease and are the primary target of bisphosphonate drugs used to treat patients. We don't really know why they get so out of hand in Paget's disease but investigating this dysregulation more closely has been limited by the fact that they are difficult to culture.

Mature osteoclasts develop from fusion of multiple immature precursors under the influence of specific growth factors, but only some of them in any given plate of cells undergo the transformation, which results in a jumbled mix of cells to work with. They don't like being detached from surfaces or moved around, so it has been impossible to separate pure populations of the different stages

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They are now able to purify the different life stages of an osteoclast to 85% purity, allowing a big step forward in osteoclast experiments
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or to combine them with other bone cells to see how they interact with each other.

A new method has been published by Dr Helen Knowles and Prof Philippa Hulley, in Oxford, which for the first time creates tough osteoclasts from a patient's blood, which can be moved around, purified into age and stage groups,

and still carry on growing and resorbing bone afterwards.

The trick, discovered in this work funded by the Paget's Association, has been to generate them in a 3D collagen jelly, rather than a flat dish. They are now able to purify the different life stages of an osteoclast to 85% purity, allowing a big step forward in osteoclast experiments.

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

REFERENCE

Hulley PA, Knowles HJ. A New Method to Sort Differentiating Osteoclasts into Defined Homogeneous Subgroups. Cells. 2022; 11(24):3973.



Continued overleaf

What goes wrong inside bone cells in Paget's disease?

Prof Rob Layfield is a biochemist based at the University of Nottingham, who has researched Paget's disease since 2002, and is Chair of our Research Subcommittee. Here he gives an update on the valuable role that organisations such as the Paget's Association play in supporting research.

I started this piece by looking back at something I wrote for the magazine, under the same title, almost 10 years ago, after attending my first Paget's Association Information Day in Manchester on 13 September 2013. As nearly a decade has passed, I thought it a good time to reflect and update not only on what we have learned in that time, but also to highlight the ongoing contribution of the Association in driving research into Paget's disease.

The Paget's Association is the only UK charity with sole focus on Paget's disease. The Association continues to not only support those living with or affected by Paget's disease, but also to promote awareness and high-quality scientific research. Answering the question "what goes wrong" is one of the first steps in developing rational management approaches and treatments, and this is one critical aspect of the Association's research focus. What we have learned in the last decade is much more about the genetics of Paget's – several new genes that control susceptibility to Paget's have been identified. This is really important as it helps us not only understand "why" Paget's can develop, but it might also help us in the future to identify those most



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Identifying these environmental factors that interact with our genetics remains a priority
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at risk. Related to this, clinical trials are just starting to reveal whether using existing therapies is beneficial in people at the highest risk of developing Paget's before symptoms present i.e. can we 'prevent' Paget's disease. This 'people facing' research is vital, for example in understanding the real-life experiences of living with Paget's disease, such as the impact and causes of pain. In addition, so called 'epidemiological' research confirms that as we have suspected for some time, the incidence of Paget's is definitely falling in the UK. Whilst clearly this is good news, we still don't understand why, but this observation points to unknown environmental factors. Again, identifying these environmental factors that interact with our genetics remains a priority, as avoiding them clearly offers simple opportunities to manage and modulate progression of Paget's without the dependence on drug treatments.

To come back to the original question of "what goes wrong", despite some of the advances outlined above, in

truth we don't know a great deal more about the fundamental molecular mechanisms that underlie bone cell changes in Paget's. In fact one of the reasons for this slow progress is that unlike many other diseases, Paget's is incredibly difficult to study in the laboratory. This is in part because the bone cells affected – osteoclasts – are so highly specialised that growing them in a lab in order to establish 'cell models' is really challenging. Highlighted in this issue of the magazine, the Paget's Association-funded research of Prof Philippa Hulley and Dr Helen Knowles (Oxford) takes steps towards solving this problem, with development of new methods to grow human osteoclasts in controlled lab conditions. It is breakthroughs such as this which will ultimately allow us to understand and to beat Paget's disease.

I will end where I started my piece 10 years ago, with the family motto of Sir James Paget, the physician who first described the condition. *Labor ipse voluptas* – "work itself is a pleasure". Although we are acutely aware that Paget's does still cause concern and impacts the quality of life for many of our members, it is certainly a privilege to be part of the research community that the Association supports, and the greatest pleasure will be in the future to improve the lives of those who are touched by Paget's.

Rob

Thank you

We are grateful to all those who donate to help us drive quality research forward

They smashed it!

On behalf of the Paget's Association we want to thank all our runners who took part in the TCS London Marathon in April. Their fantastic efforts raised awareness and funds to support the Paget's Association so that we can continue to help and support anyone affected by the disease. We will update you with the total raised in the next magazine.

Enter the TCS London Marathon 2024

With the excitement of this year's event over, it's time to ask who might be interested in taking on this world-famous marathon in April 2024.

Many people apply for a place in the TCS London Marathon by means of the public ballot. This is an entry for a place along with thousands of others and then winners are chosen at random in a draw. For the many who are unsuccessful in this, an application can be made for a charity place.

The Paget's Association has a limited number of charity (Golden Bond) places. All successful applicants are required to pay a £50 non-refundable registration fee and raise a minimum of £1,500 in sponsorship.

Register your interest now!

If you, or someone you know, is interested in taking part please contact the Paget's office to register your interest by emailing membership@paget.org.uk or telephoning **0161 799 4646**.



New website coming soon

We are excited about launching our new website which will help us build the Association's digital presence. This is crucial for the Paget's Association to be able to reach and help more people. It will remain an excellent source of information and aid our continued mission to raise awareness of Paget's disease and to provide support for all who need it.

SOMETHING NEW IS COMING!

Personal stories of treatment



Linda recently required further treatment

Linda Fenlon from Irlam, Manchester is a member of the Paget's Association and has recently had treatment for Paget's disease. Here she shares her experience in an interview with Diana Wilkinson, our Specialist Nurse.

Q

Hello Linda. I understand you have had Paget's disease for some years?

A

Yes, I was 45 when I was diagnosed with Paget's in my skull, lower back and hip. It's now 30 years on and during that time I have had several bisphosphonate infusions. When I was treated with pamidronate, I had side-effects (flu-like symptoms) but it worked. I was a nurse at Withington hospital and had 6 months off but was eventually pain-free and went back full-time. The work was very hard though so I decided to retrain as a counsellor and started working at a GP surgery in Sale where I worked until I retired at 60.

The treatment (pamidronate) lasted about 5 years and then my pain returned. I was given an infusion of zoledronic acid that was a new drug at the time and was fortunate not to have any side effects. I have had it a few times now and whilst it takes a while to work, in the end I become pain-free.

Q

I understand you have recently required further treatment. Could you explain a little about that please?

A

Recently my pain has returned and I was offered and accepted another infusion of zoledronic acid. It's 5 years since the last one.

Q

Did you attend hospital as an outpatient for the infusion?

A

Yes. Salford Royal Hospital is only about 5 miles away from us so it was not a problem to get there. My husband always comes with me especially as I had a knee replacement in July and driving is still difficult for me. The hospital has a small ward specifically for those having infusions. Some people were there to have zoledronic acid for osteoporosis and some for Paget's disease.

The ward doesn't have beds but comfy armchairs and curtains to pull around if you want privacy.

Q

Can you describe your experience of having the infusion?

A

Having had previous infusions, I knew to keep myself hydrated and as soon as I sat down one of the staff nurses offered me a drink, brilliant service! A senior nurse admitted me, checked they had the correct medical history and told me that I would have my blood pressure and temperature taken during the infusion. The nurse inserted a cannula into a vein on the back of my hand. It went in easily and I didn't feel anything. The drip stands were at the side of the chairs and once the infusion started there was time to read or people-watch. The staff went from patient to patient checking everyone constantly.

I wasn't worried about the infusion as it is not my first but I do think about the bone cells and the effect the treatment has on them. I was a nurse so that's how my mind works. I guess those newly diagnosed can become concerned about potential side-effects but after 30 years and many infusions, I have only had problems with pamidronate.

Q

How long were you on the ward?

A

The infusion itself took about 15 minutes but I was on the ward for about three-quarters of an hour as the nurse advised me to stay to check I was feeling okay before I went home. I walked back to the car wondering how soon the treatment would work. I know it takes a while for the pain to reduce and I have always had good results with no side-effects from zoledronic acid.

Q

How are you feeling now?

A

At the moment I still have pain in my hip at night when I lie on my right side and in my lower back when I stand cooking. However, I am still able to cook and clean (a little bit!!), go out with friends and family (for lunch of course!), and live a normal life for a 74-year-old. I know it's because of the treatment I've had over the years that I am able to keep active.

I had an infusion just over a month ago and I do feel the pain is less, especially in my lower back, but that could be wishful thinking as it usually takes a few months to work for me!

I am sure I will have relief eventually as I always have before, so I'm looking forward to the spring when I will be feeling better and can get out and about thanks to the treatment. There is life with Paget's!

What is an infusion of zoledronic acid?

Paget's disease affects the normal bone remodelling process which occurs throughout life. In Paget's disease, bone remodelling is accelerated and disorganised, leading to the formation of bone that has an abnormal structure. Zoledronic acid is a 'bisphosphonate'. These are a group of drugs that work by slowing down the osteoclast cells that break down bone too rapidly in Paget's disease, thereby restoring a more normal remodelling process.

For those who require treatment, the current first-line bisphosphonate, due to its potency and prolonged duration of action, is zoledronic acid. It is the bisphosphonate most likely to relieve pain from active Paget's disease. A single dose of 5mg is given through an infusion (a drip) directly into the bloodstream (intravenous), over 15 minutes.

It can take several months for bisphosphonates to have their full effect and for the individual to feel the maximum benefit. This treatment often normalises the abnormal bone remodelling and one dose can be effective for many years.



Emanuela adapts to life with Paget's

Emanuela Mazzoleni is a 57-year-old nurse who lives in Italy. She wanted to share her experience of Paget's disease to help others.



“ When I had blood tests my alkaline phosphatase (ALP) was often high but progressive pain in my left shoulder began to restrict my movement. This led to investigations such as Magnetic Resonance Image (MRI) and x-rays. These highlighted the presence of Paget's disease in my left arm (humerus). From there a series of examinations began and I went to San Raffaele Hospital, Milan where there is expertise in Paget's. I had an infusion of zoledronic acid. After a couple of days of fever and nausea I was fine and it practically took all my pain away, especially at night, and my ALP is now in the normal range.

The treatment gave me a better quality of life although I'm more serene than I was! I had to change jobs as I worked in the operating room. Driving for long distances is a little painful but I take rests. I take care not to strain my arm but I try to do everything I want to, just with more care and attention. For example, I try not to fall! I have a cat and also a dog, Sky, but she is very quiet. She is my happiness but sometimes she pulls too much on the leash and I have to hold her with two hands so as not to strain my Pagetic arm. I enjoy reading, cooking and mountain walks, and this year I am planning on walking the Camino de Santiago de Compostela in Spain (without Sky though)... 100 km on foot!

The best advice I can give to anyone newly diagnosed is to find a hospital where the specialists have experience of Paget's disease. ”

Jim was shocked by his diagnosis

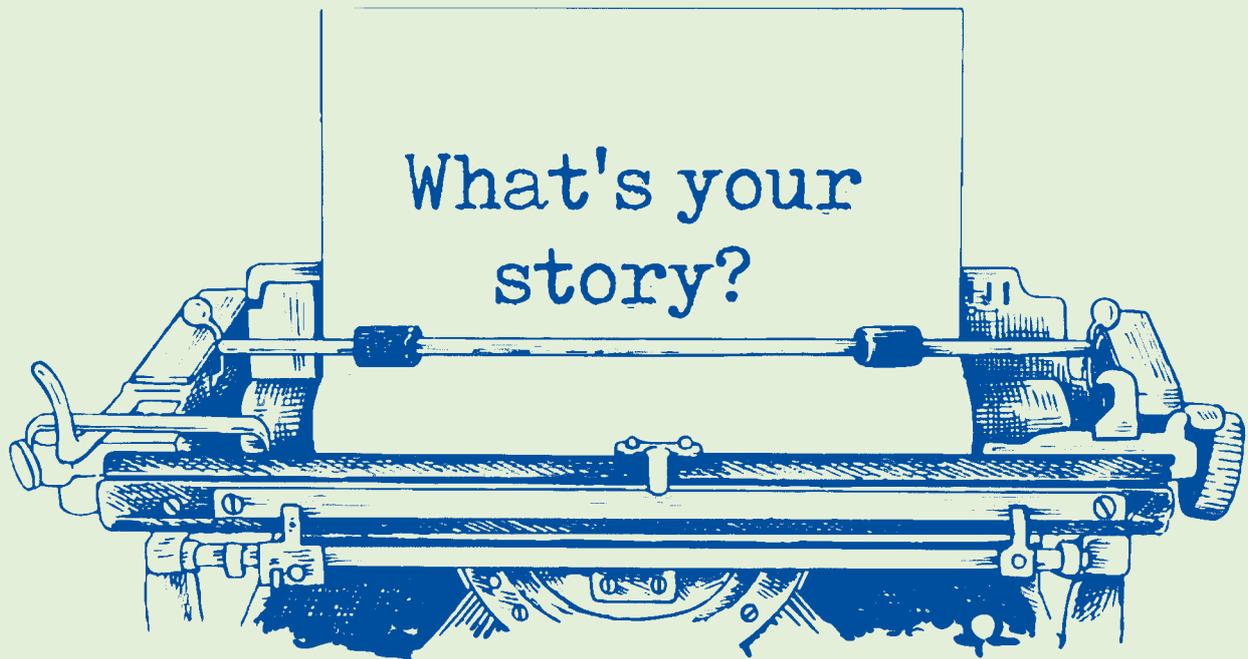
Jim McKenney is 71 and from Virginia, USA. Here he shares his experience of diagnosis and treatment.



“ My diagnosis was a complete shock. Paget's was discovered by chance in my pelvis, sacrum and spine (L5), when I had a bone scan for another reason. I was fortunate not to have experienced pain. My endocrinologist didn't think of Paget's, even with elevated blood levels of alkaline phosphatase (ALP) for 12 years, so I was lucky to learn of the condition before pain presented. In researching the condition, I found few local resources. The [paget.org.uk](https://www.paget.org.uk) website and all the information it provided is by far the best. I joined the Paget's Association and received yet more information. A wonderful resource was/is email correspondence with Specialist Paget's Nurse Diana Wilkinson who quickly answered all my questions. I also joined the Zoom sessions with a wonderful Paget's Support Group.

My decision to have treatment with the zoledronic acid infusion centred around two things. One, could the infusion be beneficial to me? Secondly, I was planning a tooth implant involving jaw bone. My decision was to wait for the infusion until my implant was well beyond successfully completed. Although information regarding the infusion to prevent future problems is scarce, I felt resources leaned towards it having a beneficial effect on the affected bones with few negatives. The infusion was simple with the only side effect being fatigue for a day.

Six weeks after my infusion my ALP test came back at 87, well within normal. ”



Share your story

Thank you to Linda, Emanuela and Jim who shared their stories on the previous pages. If you would like to share your experience of Paget's disease, to help support others, please get in touch by emailing diana.wilkinson@paget.org.uk or by telephoning **0161 799 4646**.

You will be given as much support as you need to put it together.

Extraordinary General Meeting

The minutes of the Extraordinary General Meeting (EGM) of the Paget's Association held at The Lowry, Salford, 19 April 2023 will be in a future edition of this magazine. Meanwhile, if you have any queries about the EGM, please get in touch with the Association's office using the details on page 3.

Annual General Meeting

The Annual General Meeting of the Paget's Association will take place on 27 October 2023, at 10:00 am, at The Moat House Stafford.



Stafford Information Event

27 October 2023

10:30 am to 3:00 pm

Our next Paget's Information Event is taking place at The Moat House, Stafford, a beautiful Grade II listed manor house hotel in the Staffordshire countryside. The venue has easy access from the M6 and is just 4 miles from Stafford train station (around 12 minutes in a taxi).

Bring your questions to this free event on 27 October 2023. Refreshments will be available at 10:30 am and the talks will commence at 11:15 am. Both refreshments and lunch will be provided free of charge.

Please see the full programme below.



The Moat House

Reserve your place

You are welcome to bring someone with you but places must be booked in advance. You can book by completing and returning the form on the next page, by telephoning **0161 799 4646**, or by sending an email to membership@paget.org.uk

Paget's Information Event

Friday 27 October 2023

10:30 am – 3:00 pm

Acton Suite, The Moat House

Lower Penkrige Road, Acton Trussell, Stafford, ST17 0RJ

Refreshments and registration

Welcome

Chair: **Prof Stuart Ralston**

What is Paget's disease?

Dr Faiz Rahman

Trustee, Paget's Association & Consultant, Leicester

Diagnosis, present and future

Prof Stuart Ralston

Chair, Paget's Association, Consultant & Researcher,
Edinburgh

Treatment

Dr Zoe Paskins

Consultant, Stoke-on-Trent, & Researcher,
Keele University

Support for all

Mrs Diana Wilkinson

Specialist Paget's Nurse, Paget's Association

Physiotherapy

Mr Will Gregor

Consultant Physiotherapist, Salford

Pain in Paget's

Miss Kathryn Berg

Data Manager, Edinburgh

Pros and cons of joint replacement for people with Paget's

Mr Geraint Thomas

Consultant Surgeon, Oswestry & Senior Lecturer, Keele
University

A final opportunity for questions

Prof Stuart Ralston



Local consultant, Dr Zoe Paskins, will be among the speakers who will discuss hot topics and answer any queries you have.

Honorary Consultant Rheumatologist and Clinical Lead at the Haywood Metabolic Bone Centre in Stoke-on-Trent, and Reader in rheumatology at Keele University, Dr Paskins' research interests include how to optimise management and identification of musculoskeletal disorders, as well as optimising patient-clinician communication.



Our Chair, Prof Stuart Ralston, speaking at a similar event in Cardiff

Reserve your free place now



BOOKING ESSENTIAL

Stafford Paget's Information Event booking form

Cut out or photocopy this form. Alternatively, call 0161 799 4646.

Please complete each section as appropriate. Full details will be sent to you approximately two weeks before the event.

FREE

I/we wish to attend the free Paget's Information Event at The Moat House, Stafford, on 27 October 2023. (Please tick box)

Names of those attending

Please state any special dietary requirements

--

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

Please state any special requirements *i.e. space for a wheelchair*

--

Name & address for correspondence

.....
.....
.....
Postcode

Telephone

--

Email

--

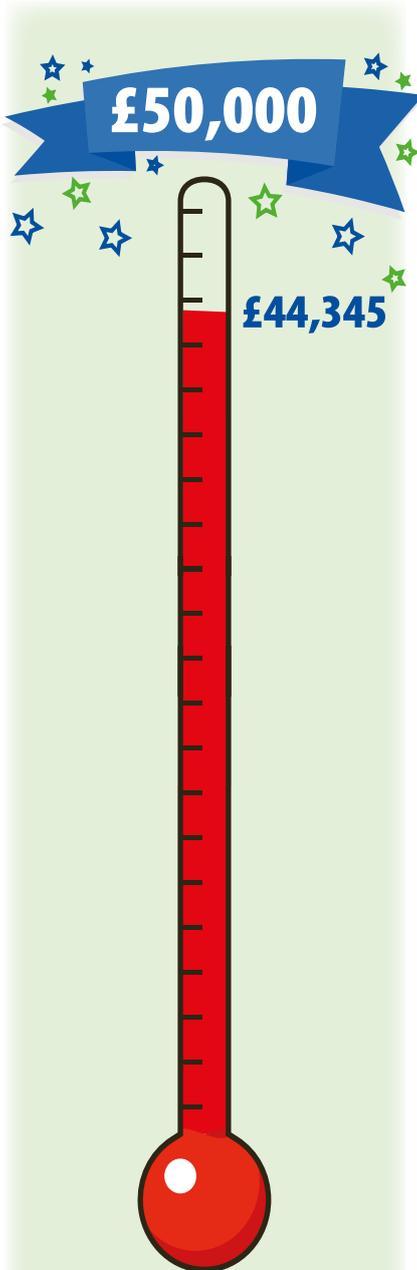
Please return this form by post to:

The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX

or email the above information to:

membership@paget.org.uk

50th Anniversary fundraising campaign



Thank you for making a difference!

Thank you to all those who have already donated, sponsored a challenge, or raised funds!

Thank you to everyone who has raised funds or donated to our 50th Anniversary fundraising campaign to raise £50,000 by December. Your generosity is sincerely appreciated. The total has now reached a fantastic £44,345.

How to contribute

There are a number of ways you can donate or pay in funds you have raised. Simply get in touch for details or use the 'Donate' facility on our website.

Call **0161 799 4646**

Email **membership@paget.org.uk**

www.paget.org.uk

At the 50th Anniversary Gala Evening, members Janet and Graham Dixon were presented with medals and a small gift for their fundraising efforts during the 50th Anniversary Campaign. They received their medals from Patron Sir Henry Paget. He congratulated them on being the members who have raised the most so far, by holding a car boot sale, making and selling wooden Christmas trees and selling items on Ebay, given to them by family, friends and neighbours. They raised a total of £930 towards the campaign, which includes £421 matched funding from Barclays Bank. Since 2018 they have raised in excess of £3,000 in support of the Association's work. Thank you Janet and Graham!



50th Anniversary Challenge update

Thank you to all those who kindly sponsored members of the Paget's Association's team who completed challenges to raise funds towards the 50th Anniversary Campaign. You will see below the final totals raised. Thank you to everyone who supported them!

40-mile cycle race

Professor Stuart Ralston
Chair, Paget's Association

Amount raised: **£2,613**



Hike to summit of Paget Peak

Mrs Amanda Sherwood
Trustee, Paget's Association

Amount raised: **£660**



Wing walk

Mrs Diana Wilkinson
Specialist Paget's Nurse

Amount raised: **£1,544**



Sue retires after 25 years

After 25 years of employment with the Paget's Association, Office Manager, Sue Clegg, retired last month. Chair of the Association, Professor Stuart Ralston, presented her with flowers and a gift at the 50th Anniversary Gala Evening. He expressed his sincere thanks for all her hard work over the years and wished her a long and happy retirement.



Legacies have allowed the Association to reach its 50th year

We are so grateful for every gift left to the Association in a will. Certainly, without such legacies the Paget's Association would not have been able to reach its 50th year this year.

Thank you

Thank you to all those who have chosen to remember someone by donating to the Association in memory of a loved one on birthdays or anniversaries.

In Memoriam

We celebrate the lives of

Clifford Fleetwood

John Burge

We are grateful to their families and friends for their thoughtfulness and lasting gifts



Paget's information and support services

Paget's Helpline

You can contact the team here at the Paget's Association for support, information, advice or simply a listening ear. Perhaps you are wondering what tests you may need, worried about potential side-effects of treatment or are unsure if your pain could be from Paget's. Our Registered Nurse, Diana, is usually available on the Helpline during office hours, to discuss any aspect of Paget's disease.



Contact the Paget's Helpline

Email: helpline@paget.org.uk

Call: 0161 799 4646

Featured service

Meet others online

Meet others online at one of our Virtual Paget's Support Groups. Meetings take place every two months using Zoom. To support as many people as possible, meetings take place on different days and at different times.

These are small friendly groups connecting people from all over the world so, wherever you are, you can share your experiences with others living with Paget's. We are grateful to those who have been in touch to tell us how much you appreciate these meetings.

If you are not in the UK, please check what time each meeting is for you or contact us for assistance.

For more information or to take part, please email membership@paget.org.uk or register on our website.

You will receive a link to join by email a few days before the meeting. Should you not receive it, please check your junk folder, or get in touch.



Meeting dates/UK local times

Group 1: Monday 12 June and 14 August 2023 at 3:00 pm

Group 2: Tuesday 13 June and 15 August 2023 at 9:00 am

Group 3: Wednesday 14 June and 16 August 2023 at 6:00 pm

Paget's Buddies

Would you simply like to talk to someone else who has Paget's disease? Our Paget's Buddy scheme provides one-to-one support between members of the Paget's Association.



- If you feel you would like to receive support, please get in touch and we will find you a support Buddy.
- Perhaps you would like to offer support to another member who is struggling with Paget's disease? Simply get in touch with us. It is purely a supportive role so no medical knowledge is required.



Paget's Network

Members of the Paget's Association can join our Paget's Support Network, which enables you to connect with other members by phone, letter, email or however you would like to communicate. If you would like to join please contact us to request a Support Network form.



Sheffield group

Around three times a year our small, informal, Support Group meet for a chat and refreshments in the Darnall area of Sheffield from 1:30 pm until 3:00 pm. If you would like to come along, please use the contact details below to get in touch.

Facebook support group

Our Paget's Facebook support group has many members from around the world who share their experiences and support one another.



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



Information

Our latest information booklets can be sent to you by email or post. Donations to cover postage are always welcome.

For those affected by Paget's disease and their family

Paget's Disease – the Facts
 Paget's Disease – Investigations Explained
 Paget's Disease and Pain
 Paget's Jargon Buster

For healthcare professionals

Paget's Disease of Bone – Information for Healthcare Professionals
 Paget's Disease of Bone – Clinical Guideline Summary

For information displays and fundraising

Paget's Disease of Bone – the Essential Facts
 Putting the fun into Fundraising

Paget's Passport

A place to record your health in relation to Paget's disease



Further Information

For further details about any of our information or services please get in touch using the details below.

Email: helpline@paget.org.uk

Telephone: **0161 799 4646**

Insights into the struggles of those with Paget's

Released for Paget's Awareness Day this year, a series of interviews were recorded by the Chair of the Paget's Association, Professor Stuart Ralston. These provide important information into the problems that can be experienced by those affected by Paget's disease. He spoke with Mickey, Sheila and Allan about their personal experiences of living with the condition. Professor Ralston also spoke with Dr Clarkin, a bone biologist from Southampton, who explained why the blood supply to affected bone is an important area of research, and staff from the Association who gave information about our support services and the history of the charity.



You can watch the full interviews on our website (www.paget.org.uk), or our YouTube channel (@PagetsAssociation), using your smartphone, tablet, laptop or PC. Summaries of the interviews were also published in the February edition of Paget's News.

SUPPORT THE PAGET'S ASSOCIATION by Joining the 200 Club Raffle

A winning opportunity!

Don't miss out on your chance of winning a prize in our raffle. Taking part in our monthly raffle is a fantastic way to help the Association raise funds and support the work we do. Of course, it also gives members a good chance of winning the first prize of £100, or the second prize of £50. In June and December, prizes are doubled to £200 and £100.

At just £5 a month, you could help us reach our target of 200 people taking part. Currently, we are not maximising the potential income from the scheme, so why not ask friends and family if they would be interested in joining?

If you are over 18 and would like to join the 200 Club raffle, please complete the form on page 25.

- The Paget's 200 Club is a raffle run by the Paget's Association** (Yellow circle)
- It is open to both members and non-members, over the age of 18** (Blue circle)
- £5 per month** (Red circle)
- Monthly draw** (Green circle)
- Two monthly prizes of £100 and £50. Double prize draw in June December** (Orange circle)
- Why not ask family and friends to join?** (Purple circle)



★ ★ ★ ★ ★ ★ ★ ★ ★ ★ Congratulations! ★ ★ ★ ★ ★ ★ ★ ★ ★ ★

January 2023

1st Prize £100
Ticket no. 178
Vickie Reeves
Birmingham

2nd Prize £50
Ticket no. 167
Eva Jackson
Manchester

February 2023

1st Prize £100
Ticket no. 164
Violet Donnelly
Co Tyrone

2nd Prize £50
Ticket no. 195
Norma Reid
Glasgow

March 2023

1st Prize £100
Ticket no. 171
John Dyer
Suffolk

2nd Prize £50
Ticket no. 48
Thomas Trevor
Oswestry

200 Club Raffle Application Form

Before completing this form, please read the rules of the 200 Club on page 26

Name

Address

..... Postcode

Telephone Email

Payment Option: 1 NUMBER		Tick preferred option
Annually	£60	
Half yearly	£30	
Quarterly	£15	
Monthly	£5	

Payment Option: 2 NUMBERS		Tick preferred option
Annually	£120	
Half yearly	£60	
Quarterly	£30	
Monthly	£10	

Standing order mandate – Paget's 200 Club raffle

To Bank plc

Branch

Bank address Postcode

Pay to the credit of 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 Sort code

Home address

..... Postcode

Signed Date

Please return this form by post to:

The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester M4 6WX.

200 Club raffle rules



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

1. The Paget's 200 Club is open to anyone over the age of 18 and is limited to two numbers per person, with a maximum of 200 numbers. Should there be more applicants than numbers, a waiting list will be drawn up, and when numbers 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 number, paid in advance. 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. Paying by standing order is the preferred method of payment, as this eliminates the need for reminders, and the risk of not being entered into a draw because of late payment. Payment by cheque must accompany the completed

application form. To pay by standing order, please complete the standing order mandate and return to the Paget's Association's office.

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 numbers 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 Paget's News magazine.

5. Prizes will be a £100 first prize and a £50 second prize. Twice a year, in June and December, the prize money will be doubled to £200 and £100 respectively.

6. Before each monthly draw takes place, a check will be made to ensure that all monthly fees have been received in the office. If not, the relevant numbers will be removed from that month's draw, at which point the member will be contacted to ascertain whether they wish 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 number 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.



Meet the team at the Paget's Association

Honorary President



Prof Graham Russell

Involved in research at both the Botnar

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

Patrons



Sir Henry Paget

Sir Henry is the great-great grandson of Sir James

Paget, whose name was given to Paget's disease.



Mrs Joyce Cupitt

Joyce served as a Trustee for many years. Her late

husband had Paget's disease.



Mr Recardo Patrick

Recardo is an entertainer and businessman

who rose to fame as lead singer with the band, Sweet Sensation. He has Paget's disease.

Employees



Mrs Diana Wilkinson



Miss Jen Woodworth

Board of Trustees

Chair of the Board



Prof Stuart Ralston

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

Vice-Chair



Prof Rob Layfield

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



Mrs Eve Berry

With many years of experience in the healthcare sector, Eve lives in London

and is a Chartered Accountant, currently working in the drug discovery industry.



Mrs Kely Burman

A retired nurse and midwife living in Orsett, Kely has not only cared for

those with Paget's disease, but her mother also had the condition.



Dr Sheelagh Farrow

Sheelagh lives in Surrey and, prior to retirement, was Managing Director

of International Medical Press, a provider of independent medical education.



Mr Alan Janes

Alan is a retired Company Director who has Paget's disease, and is

a volunteer within his local community in Oxford.



Dr Catherine Nairn

A General Practitioner, Catherine developed an interest in Paget's disease while working

at the Western General Hospital, in Edinburgh.



Dr Faiz Rahman

Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the University Hospitals

of Leicester, where he is involved in caring for those with Paget's disease.



Mrs Amanda Sherwood

Amanda lives in Bristol and is now retired.

She has experience in working for societies

and teaching organisations which specialise in the field of bone and related topics.



Prof Mark Wilkinson

An Orthopaedic Surgeon in the Metabolic Bone Unit of the University of Sheffield, Mark has both

an academic and clinical interest in Paget's disease.

Join us in 2023

Paget's **50** YEARS Association ANNIVERSARY

Join from home

Virtual Paget's Support Groups

Group 1

3:00 pm

Monday 12 June 2023

Monday 14 Aug 2023

Group 2

9:00 am

Tuesday 13 June 2023

Tuesday 15 Aug 2023

Group 3

6:00 pm

Wednesday 14 June 2023

Wednesday 16 Aug 2023

See page 21

Sheffield

Sheffield Support Group

22 June 2023

Darnall, Sheffield

1:30 pm – 3:00 pm

See page 22

Stafford

Paget's Information Event

27 October 2023

The Moat House, Stafford

10:30 am to 3:00 pm

A fabulous opportunity to meet others
and have your questions answered

See page 16

Stafford

The Paget's Association's Annual General Meeting

27 October 2023

The Moat House, Stafford

10:00 am

See page 15

Contact us

0161 799 4646

helpline@paget.org.uk | membership@paget.org.uk

Paget's
Association

www.paget.org.uk

The Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX