

Paget's Association

Registered Charity No: 266071



Putting the
Fun
into Fundraising

Your Support Means so Much



The Paget's Association is a national charity, ensuring that anyone affected by Paget's Disease of Bone has somewhere to turn for advice and support. The dedication of our supporters is invaluable and there are lots of ways you can help.

People who have Paget's disease can sometimes have no symptoms. At the other end of the scale, however, it can be a very painful and disabling condition.



Simon's Story



At the age of 55, Simon was diagnosed with Paget's disease of the right tibia (shin bone). He had 3 intravenous bisphosphonate infusions, with good results, but was left with the classic sabre-shaped bowing of the tibia, both forward and outwards. This was gradually damaging his knee and ankle joints, causing pain when walking, which necessitated the use of a stick.

In 2016 Simon underwent limb reconstruction. His orthopaedic surgeon broke his right tibia and fibula (a double osteotomy) and he was fitted with a Taylor Spatial Frame which had bolts screwed into his tibia, as well as wires going right through the bones and out via the other side of his leg. To bring the knee and ankle into the correct alignment, daily adjustments to the frame were made, using a spanner to move six struts, by 1mm per day. This progressively straightened his leg. The adjustment program took five months, during which time Simon walked with crutches. To help stimulate bone growth he tried to bear his weight through his leg, as much as comfort would allow. According to Simon, caring for the pin sites and walking in the frame were not easy, but he now has a straight leg, and can walk unaided without pain.

Whilst in his frame Simon attended a Paget's Information Event to get the latest update from the experts on the cause, diagnosis and treatment of Paget's disease. He said, 'It was an important and rare opportunity to meet other people with Paget's, and to hear their stories and experiences. I had never met anyone with Paget's disease until the Information Event, which was a great environment in which to share our very different journeys.'

What Difference will my Donation Make?

As a small charity, we rely on donations to continue our valuable work. We keep costs and overheads low, ensuring that every penny makes a difference to those we support.



Provides information and support for someone newly diagnosed with Paget's disease



Funds maintenance of our Support Network for a year



Pays for the printing of 100 copies of our Paget's – The Facts booklet



Will sponsor one of our Information Events where those affected by Paget's disease can listen to presentations by health professionals, giving them up-to-date information on the condition

Get Involved

There are lots of ways that you can get involved to raise funds for the Paget's Association.

London Marathon



Each year we have places in the London Marathon. If you would like to run in this event, please visit our website for full details, www.paget.org.uk or get in touch with our office on 0161 799 4646.

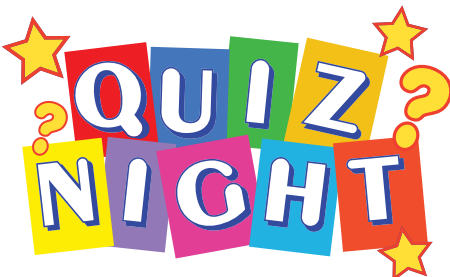
You don't have to run a marathon to raise money for the Paget's Association. Here are a few less challenging ideas.

Cupcake Challenge



Who can resist homemade cakes? Why not invite friends round for cake and coffee, or afternoon tea, and ask for a donation to the Paget's Association. Perhaps you could have a cake sale at work and donate the proceeds.

Quiz Night



Could you be quiz master for the evening? Invite your friends to your home, or hire a venue, and make a charge for admission, snacks and drinks. You could even hold a raffle, on the night, to raise some extra funds.

Declutter



Do you want to clear your home of clutter? Why not sell items which you no longer need, at a car boot sale, or on eBay for Charity.

Give in Celebration



Instead of a gift for your birthday or anniversary, have you considered asking family and friends for a donation to the Paget's Association?

Dress Down Day



Dress down days, or casual days, have become very popular, allowing workers to wear more casual attire. Why not ask your work colleagues to swap their suits for jeans and t-shirts for a day, in exchange for a donation.

Crafts



Are you creative? Why not knit, sew, or make greeting cards to sell at craft events on behalf of the Association.

Sponsored Events



Why not arrange a sponsored event? This could be a really big challenge, like a sky dive or parachute jump. If you are happy to forgo the adrenaline rush, why not take part in a sponsored swim or sponsored silence?

Match Funding

Some organisations offer 'match-funding' to employees, which means they match the amount of money you raise. Potentially, you could double your fundraising total! You could also ask whether the organisation you work for would be willing to make the Paget's Association their Charity of the Year.

Collection boxes are available from the office on request. Put them in your reception area or canteen at work, and let your colleagues know that they are there.

Our Thanks to You

Meet some of the wonderful people who have raised funds for us.



Zoe Ager, cycled from London to Paris in 24 hours, raising an incredible £1,500 for our funds. Zoe chose to cycle for Paget's because her grandfather, Keith, has lived with Paget's for many years and she wanted to support him and others with the disease.



Janet and Graham Dixon, have been fundraising on our behalf, since Janet was diagnosed with Paget's in 2013. Not only have they decluttered their home, they have been helping friends and neighbours with theirs, by holding car boot sales and selling items on eBay, with all the proceeds coming to the Association.



When Rebecca's cousin was diagnosed with Paget's disease in 2018 she put on her trainers and ran in the Boston, Lincolnshire Marathon for us. Never having run before, and after just eleven months of training, Rebecca raised £600 from sponsorship and a further £500 was match funded by her employer.



Having been offered one of the Paget's Association's Golden Bond places to run in the Virgin London Marathon, Matt Deller spent a day at his local brewery, brewing what was to become 'Running Man Beer'. Six weeks later he returned to the brewery

to help bottle and label 300 bottles. The whole process took just 2 months and during this time he was pre-selling Running Man Beer to friends and colleagues, all of which helped to boost his sponsorship total. Matt said, "I had a great day brewing this beer and it was even better when I finally sampled a bottle after the gruelling 26.2 miles."

Legal Information

Now that you have decided to fundraise for the Paget's Association, here are a few tips to make sure that your fundraising event is safe and legal. By law you will be a trustee of the funds you raise. You must ensure that all donations and sponsorship money, from your event, is paid to us. Please understand that if you do something that threatens or damages the name or reputation of the Paget's Association, we may have to ask you to stop fundraising.



Organising an Event

Useful information on organising an event can be found on the government website **www.gov.uk** Search on the site for 'Organising a voluntary event.'

Health and Safety

If you are organising an event, it is important that you consider the health and safety of yourself and the people who will be attending your event. You should conduct your own Risk Assessment to identify any possible risks at your event. You should assess any hazards, as either high or low risk, and have an idea of how serious the harm to you, and others involved in the event, could be. If you assess your event as high risk, please contact the Association for advice.

It is important to ensure that you have adequate first aid cover. Advice on this is available from St John Ambulance.

Organising a Raffle

www.gamblingcommission.gov.uk is the website to go to for advice on the legalities of holding a raffle.

Sponsorship

Sponsorship is a great way to raise funds and awareness of Paget's disease. You can involve your family, friends and work colleagues in what you are doing, both on and off-line.

If any of your sponsors are UK taxpayers, they can Gift Aid their donation. This enables us to claim an extra 25p for every £1 donated.

giftaid it

Shout about what you are doing!



Let everyone know what you are doing and why. If you would like some banners, leaflets, and information on the work of the Paget's Association, please contact the office by email **membership@paget.org.uk** or telephone 0161 799 4646.

If you have Paget's disease, please consider sharing your story with others. People are often supportive and generous, once they know how your condition affects you.

Don't forget to let the Paget's Association know about your event so that we can publicise it on our social media pages, website and in our newsletter.

Put up posters about your event. You could also let your local press or radio station know, by sending a simple account to them, and don't forget to include donation details. If you would like any help with this, please let us know.

Sending in the Funds Raised

You can donate the funds you have raised in any of the following ways:



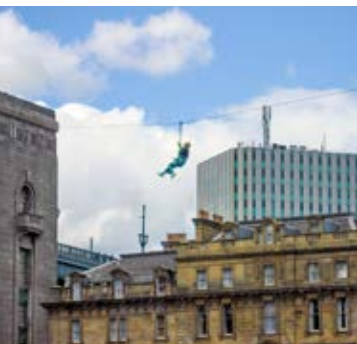
- Via an online fundraising page
- Via our website **www.paget.org.uk**
- By cheque or postal order
- Paying over the telephone by debit or credit card

It is quick and easy to set up an online personal fundraising page. Once you have done so, don't forget to share the link on your social media pages so that family, friends and colleagues can see what you are doing.

If you would like to do this, we are registered with 'Virgin Money Giving', 'BT MyDonate' and 'Justgiving'. Charges to the Association are lower with Virgin Money Giving and BT MyDonate. All are easy to use, and a convenient way to collect donations, which are automatically transferred to the charity's bank account.

We accept cheques and postal orders made payable to the Paget's Association. Please send to the address on the back of this booklet.

Donations can also be made via our Facebook page.



Get in touch

The Paget's Association

Tel: 0161 799 4646

Email: membership@paget.org.uk

www.paget.org.uk

Registered Charity No: 266071