

Registered Charity No. 266071

# **Annual General Meeting**

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 19 September 2024 at 10.00 am

and will be held at

**Leonardo Hotel, Fry Street, Middlesbrough, TS1 1JH** 

### A message from our Chair

We hope as many members as possible will join us at the Annual General Meeting (AGM) of the Paget's Association on 19 September at the Leonardo Hotel, Middlesbrough. This will be followed by the Paget's Information Event.

Please book your place in advance if you would like to attend either or both of these events.

To book please email membership@paget.org.uk or telephone 0161 799 4646.

Professor Stuart Ralston Chair, Paget's Association

#### Use your vote

Members of the Paget's
Association are entitled to vote
at the AGM. If you are unable
to attend in person, you can
attend virtually using Zoom
(contact us for the link) or vote
on the resolutions on our website or by using
the form on page 8. If you have any queries,
please don't hesitate to contact us.

Unless you are attending in person or virtually, your online or postal form must be received by 12 noon (BST) on 5 September 2024

## **Annual General Meeting 2024**

## Agenda

- 1. Minutes of the AGM held in Stafford on 27 October 2023
- 2. Approval of the Accounts, year ending 31st Dec 2023
- 3. Reappointment of Beever & Struthers as independent financial auditors
- 4. Vote on new constitution
- 5. Forward planning for 2025 and beyond
- 6. Election of Trustees
- 7. Overview of activities in 2023 and 2024
- 8. Questions and any other business

## **New Constitution**

As you may be aware, the Paget's Association is in the process of becoming a Charitable Incorporated Organization (CIO). With this transition comes the need for a new constitution. The proposed constitution is now ready for your review. You can access the document on our website by scanning the QR code below or by following this link: <a href="https://paget.org.uk/get-involved/agm-voting-form-2024/">https://paget.org.uk/get-involved/agm-voting-form-2024/</a>



We encourage all members to carefully review the constitution before our AGM, where it will be officially considered for approval. Should you require any further information, please don't hesitate to contact us

# Statements of those standing to be re-elected as a Trustee

#### Mr Mark Wilkinson

"I have enjoyed being part of the Paget's Association family of trustees over the last 3 years. I hope that I have brought some insights from my surgical specialisation as an orthopaedic surgeon to the Board, as well as contributing to the finance committee and sharing my experience of charitable organisation incorporation from my previous charitable trustee post. I hope that the Association has found these experiences valuable and will re-appoint me for a second term as a trustee of the Paget's Association"



## **Make Your Membership Count**

As a member of the Paget's Association you are entitled to vote at the AGM.

If you are unable to attend in person, you can vote on the resolutions on our website or by using the form on the next page.

If you have any queries, please do not hesitate to contact us.



## Vote in person

You can vote in person by attending the AGM. To book your place, please contact us.

## Attend virtually to vote

If you are unable to attend in person but would like to attend virtually, please email **membership@paget.org.uk** to request a virtual meeting link (Zoom will be used for this).

# Vote on the Paget's Association's website



You can vote online via the Paget's Association's website. Please vote by 12 noon (BST) on 5 September 2024.

www.paget.org.uk

## Vote by post

To vote by post please use the form on page 8 and post it to the address at the bottom of the form.

Please post your voting form in good time. We must receive it by 12 noon (BST) on 5 September 2024.

Alternatively, scan and email your form to membership@paget.org.uk

## **Minutes of the Annual General Meeting (AGM)**

## of The Paget's Association held at The Moat House, Lower Penkridge Road, Acton Trussell, Stafford, ST17 0RJ

#### on Friday 27 October 2023 at 10.00 am

**Attendees in person:** 8 Trustees, 5 members, 2 employees

Attendees virtual: 1 Trustee,

1 member

**Apologies:** 2 Trustees

Professor Stuart Ralston, Chair of the Paget's Association (also known as the National Association for the Relief of Paget's Disease), welcomed everyone to the Annual General Meeting (AGM). He reminded the audience that only members can vote and if anyone had already voted postally or electronically that they could not vote again.

## Item 1: Annual General Meeting 2022

**Resolution:** That the minutes of the Annual General Meeting held on 30 September 2022 at the Holiday Inn, Cardiff, be approved.

 Professor Ralston proposed that the resolution be accepted and this was seconded by Miss Kathryn Berg.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

## Item 2: Extraordinary General Meeting 2023

**Resolution:** That the minutes of the Extraordinary General Meeting held on 19 April 2023 at The Lowry, The Quays, Salford, be approved.

 Professor Ralston proposed that the resolution be accepted and this was seconded by Mr Alan Janes.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

Item 3: Presentation of the Report and Accounts\* from the last financial year: 2022

Professor Ralston gave an overview of the Association's accounts for the year ending December 2022. He highlighted that compared to 2021 investments were down by around £50K and reserves down by approximately £300K.

**Resolution:** That the Annual Report and Accounts for the year ended 31 December 2022 be accepted.

• Mrs Eve Berry proposed that the accounts be accepted and this was seconded by Mr Alan Janes.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	8	0	1

Item 4: Re-appointment of Beever and Struthers as the Association's Financial Independent Examiners

**Resolution:** That Beever and Struthers be re-appointed as external Financial Examiners of the Association.

 Professor Ralston proposed that the resolution be accepted and this was seconded by Professor Rob Layfield.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

**Item 5: Trustee appointments** 

Professor Ralston informed members that two Trustees, Mrs Kelly Burman and Mrs Amanda Sherwood, had completed their three-year terms of office and were standing for re-election. In addition, there were two new Trustee nominations, Mr Alan Martin, who has Paget's disease and was present at the AGM and Mr Mohamed El Erian, who was unable to attend. Mr El Erian is a solicitor and has been advising on converting the charity to a Charitable Incorporated Organisation.

**Resolution:** Re-appointment of Mrs Amanda Sherwood as a Trustee for a further 3 years.

 Professor Ralston proposed that the resolution be accepted and this was seconded by Dr Sheelagh Farrow.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

**Resolution:** Re-appointment of Mrs Kely Burman as a Trustee for a further 3 years

 Professor Ralston proposed that the resolution be accepted and this was seconded by Dr Sheelagh Farrow.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

**Resolution:** Appointment of Mr Mohamed El Erian as a Trustee for 3 years

 Stuart Ralston proposed that the resolution be accepted and this was seconded by Kely Burman

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

**Resolution:** Appointment of Mr Alan Martin as a Trustee for 3 years

 Professor Ralston proposed that the resolution be accepted and this was seconded by Mrs Kely Burman.

Member votes	For	Against	Abstain
Present (in person or virtually)	11	0	0
Proxy (postal or electronic votes)	9	0	0

## Item 6: Forward planning for 2024 and beyond

Professor Ralston explained the following:

- Fixed costs had been reduced by moving from a rented office to a virtual office.
- Staffing had been reduced from three to two full-time members of staff, as the Office Manager, Mrs Sue Clegg, had retired from her full-time position and was now working part-time on a sessional basis to provide support with bookkeeping.
- Publication costs would be reduced from 2024 by publishing three magazines annually instead of four.
- There would continue to be a careful review of income and expenditure and a closer control of grant expenditure.
- The Association will further enhance its online and social media presence to connect with an expanding international audience as well as those within the UK.
- The most important aim for 2024 is to ensure that people with Paget's disease are supported and informed.

## Item 7: Questions and any other business

No questions were raised.

The Vice-Chair of the Association, Professor Layfield, explained that Professor Ralston had served as the Chair of the Paget's Association for a five-year term, which commenced in September 2018 and had now concluded. Professor Layfield had contacted the Trustees to propose the re-election of Professor Ralston for an additional five-year term, which was subsequently approved through a majority vote.

## Item 8: A review of the last year's (2022) activities

Specialist Nurse and Director of Educational Resources, Mrs Diana Wilkinson, gave a review of activities undertaken by the Association in 2022. These included:

#### The 4th Annual Paget's Awareness Day, 11 January 2022

Dr Herridge conducted video interviews with international experts in Paget's disease to gain a global perspective on the condition. A virtual Question and Answer session with Professor Ralston was held and there had been a significant emphasis placed on social media to help raise awareness.

#### **New Focus Group**

A new Focus Group had been formed to incorporate the opinions of people with Paget's disease and their families into the Association's decision-making.

#### **Face-to-face information events**

Two face-to-face Paget's information events were held in 2022, one in Oxford hosted by Dr Kassim Javaid and one in Cardiff hosted by Professor Mike Stone.

#### **Paget's information**

An updated 'Paget's & Pain' booklet had been produced and a 'Jargon Buster' had been created (both available online and in hardcopy).

#### **New research**

Two new funding awards had been made:

1. Research on the Contribution of Acidosis to Chronic Pain in Paget's led by Professor Chantal Chenu at the Royal Veterinary College, London.

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2. Master of Research (MRes) degree – Application of Artificial Intelligence to the Radiological Diagnosis of Paget's by Dr Deepak Subedi at the University of Edinburgh & University of Southampton.

#### **Support**

The introduction of 'Paget's Buddies' aimed to offer one-to-one support and support gift bags continued to be available to individuals recently diagnosed. Regular virtual support group meetings conducted via Zoom continued to provide assistance to individuals in various countries. The Nurse Helpline, Support Network, local groups and a dedicated Facebook group also continued to provide support.

## Item 9: Report of activities during 2023

Mrs Wilkinson provided a summary of the activities undertaken in 2023, encompassing the following points:

## The 5th Paget's Awareness Day, 11 January 2023

The Awareness Day showcased personal experiences in a video series that marked the Association's 50th anniversary. Professor Ralston led a virtual Question and Answer session and an expanded social media campaign took place.

#### New research funded

- 1. Paget's Disease and COVID-19: what really happened in the Pandemic? led by Dr Adrian Heald, NHS Foundation Trust, Salford.
- 2. Engineering a Paget's Disease of Bone stem cell bank led by Dr. Daniel Scott, University of Nottingham.

#### New educational award

The Winifred Ditchfield Educational Award was funded by the Paget's Association, in collaboration with the Michael Davie Foundation. It was awarded to Norton Priory Museum and Gardens to update information on Paget's disease within the museum and enhance their educational programme.

## Paget's Association Centres of Excellence

Four new Centres of Excellence were added in Stoke on Trent, London, Cambridge, and Leicester.

#### **International Paget's Symposium**

For the Paget's Association's 50th anniversary, a two-day international Paget's symposium was held at The Lowry, The Quays, Salford. A successful £50,000 Anniversary fundraising campaign had surpassed its target by over £12,000.

## Face-to-face Paget's information events

An information event for those affected by Paget's disease and their families had taken place in Salford, hosted by the Paget's Association and another would take place in Stafford, hosted by Dr Zoe Paskins.

#### Information and support

Mrs Wilkinson highlighted the following:

- A new website and database is being built and is due to launch later this year.
- The Association's fact sheet regarding osteosarcoma and Paget's was reviewed and updated.
- Support gift bags for the newly diagnosed had continued to be available.
- Services such as the Paget's
   Helpline, Virtual Support Groups,
   Paget's Buddies, Support Network
   and Facebook group continued to
   provide support and expand the
   charity's international reach.

#### Strategy 2023 - 2028

A strategy for 2023 to 2028 was developed and was published in the August edition of the Paget's News magazine. It is also available on the charity's website.

The meeting ended at 10.30 am

# National Association for the Relief of Paget's Disease

#### Statement of Financial Activities for the Year Ended 31 December 2023

	Unrestricted	Unrestricted
	Funds	Funds
	2023	2022
	£	£
Income and Endowments from		
Donations and legacies	50,751	88,924
Other trading activities	39,272	23,143
Investment income	18,236	13,160
Total income	108,259	125,227
Expenditure on		
Raising funds	73,750	45,941
Charitable activities	154,650	283,523
Total expenditure	228,400	329,464
Losses/(gains) on investment assets	(13,414)	59,132
Net (expenditure)/income	(106,727)	(263,369)
Net movement in funds	(106,727)	(263,369)
Reconciliation of funds		
Total funds brought forward	767,166	1,030,535
Total funds carried forward	660,439	767,166
Balance Sheet as at 31 December 2023		
	2023	2022
	£	£
Fixed Assets		
Intangible assets	41,526	3,661
Tangible assets	1,416	1,666
Investments	674,921	702,453
	717,863	707,780
Current Assets		
Debtors	80,403	81,739
Cash at bank and in hand	48,273	209,949
	128,676	291,688
Creditors: Amounts falling due within one year	(186,100)	(232,302)
Net current (liabilities)/assets		59,386
	(57,424)	39,300
Net Assets	(57,424) 660,439	767,166
Net Assets Funds of the charity		
Funds of the charity		

The full Report and Accounts document is available from the Paget's Association's office and on our website.

## **AGM** proxy voting form

If you are unable to attend in person or virtually, you can vote on the resolutions on our website or by using this proxy voting form.

Please cast your vote for the resolutions and initial any alterations.

### Paget's Association's member details

I am unable to attend the AGM in person and therefore appoint the Chair of the meeting as my proxy to enter my vote on the resolutions as indicated below.

	Posto	ode		
Telephone	no Email address			
Number	Resolution	For	Against	Abstair
1	Annual General Meeting 2023 That the minutes of the Annual General Meeting held in Stafford on 27 October 2023 be approved			
2	Annual Report and Accounts 2023 That the Annual Report and Accounts for the year ended 31 December 2023 be accepted			
3	Independent Financial Examiners That Beever & Struthers be re-appointed as external Financial Examiners of the Association			
4	New constitution of the Paget's Association That the new constitution be accepted			
	Trustee Appointments			
5	Mr Mark Wilkinson Re-appointment for a further 3 years			

## **Returning your voting form**

Your voting form must be received by 12 noon (BST) on 5 September 2024

Please ensure the form is signed and dated, then return either by post to: Paget's Association, Jactin House, 24 Hood Street, Ancoats, Manchester, M4 6WX, or scan and email to <a href="mailto:membership@paget.org.uk">membership@paget.org.uk</a>

Signature ...... Date ......