

The National Association for the Relief of Paget's Disease

Registered with the Charity Commission no. 266071

Constitution

Rules adopted 5th July 1973, as amended 21st March 1974, and 10th August 1989. As amended 10th September 2004, as amended 17th September 2010, and 7th September 2012. As amended 4th October 2019, as, amended 16th Oct 2020, 8th Oct 2021 and 19th April 2023.

Interpretation

Unless otherwise specified, words importing the singular include the plural and words importing any gender include every gender.

"clear day" means 24 hours from midnight following the triggering event.

Reference to an Act of Parliament are references to The Charities Act 1993 and The Charities Act 2006 or as amended or re-enacted from time to time and to any subordinate legislation made under it.

1. Name

The formal name of the charitable association hereby constituted shall be The National Association for the Relief of Paget's Disease ("the Association"). The working style of the Association shall be "The Paget's Association".

2. The objects of the Association are as follows:

To preserve and protect the health of persons suffering from Paget's Disease of Bone, and their families by:

2.1 Providing information and support

2.2 Raising awareness about Paget's Disease of Bone, both within the medical and allied health professions and amongst the general public

2.3 By supporting and funding research projects in the field of Paget's Disease of Bone or its treatment

3. The Management of the Association

3.1 The general management of the Association shall be vested in a Management Committee of trustees (hereinafter referred to as "the Board") which shall consist of the Chair, the Vice-Chair, the Chairs of the Finance, Technology and Research Sub-Committees (all of whom shall be elected by members of the Board) so that the total number of members of the Board at any one time shall be at least 5. An honorary president may also be co-opted onto the Board at the discretion of Board members. The honorary president will be an individual who has made an exceptional contribution to research into Paget's disease or its treatment. There shall be a maximum number of 12 members of the Board and every member of the Association.

3.2 Board members shall serve a three-year term of office but shall be eligible for re-election at the end of each term of office, subject to a vote by a majority decision of

members of the Association at the AGM. Board members who had served three consecutive three-year terms will be eligible to be re-elected for a further one year subject to a vote of members at the AGM.

3.3 Following 10 years of service, Board members will be obliged to step down but may apply for re-election after a minimum interval of one year.

3.4 The Chair of the Board shall hold office for a period of five years, unless until he shall die, retire or resign sooner. The Chair shall be nominated by Board members and the appointment ratified by vote by the members of the Association at an AGM. The Vice-Chair shall be appointed by the Chair .

3.5 In the event that a member of the Board is unable to continue prior to the expiration of his term of office for whatever reason, the Board may at its discretion, appoint a replacement.

3.6 The Board shall have the power to co-opt.

3.7 A co-opted member of the Board shall hold office only until the next AGM. A co-opted member may be re-elected or re-appointed by a majority decision of the members at the AGM.

3.8 The Association in may from time to time increase or reduce the number of members of the Board.

3.9 Subject to the minimum number of members referred to in Clause 3.1, the proceedings of the Board shall not be invalidated by any vacancy among their number or by any failure to appoint or any defect in the appointment or qualification of a member.

3.10 Nobody shall be appointed as a member of the Board who is aged under 18 or who would if appointed be disqualified under the provisions of Clause 8.

3.11 The Board shall have the responsibility of appointing Patrons of the Association. The Patrons will have a non-executive role and will act as ambassadors for the society on a wider stage. Individuals shall remain as Patrons so long as they are able to attend an AGM at least once every two years or in the event of being unable to attend, to register their apologies.

4. Determination of Membership of the Board

4.1 A member of the Board shall cease to hold office if they:

4.1.1 are disqualified from acting as a member of the Board by virtue of Section 72 of the Charities Act 1993 (or any statutory re-enactment or modification of that provision);

4.1.2 becomes incapable by reason of mental disorder, illness or injury of managing and administering his or her own affairs;

4.1.3 are absent without the permission of the Board from all their meetings held within a period of six months and the Board resolves that his office be vacated; or

4.1.4 notifies to the Board a wish to resign (but only if at least three members of the Board will remain in office when the notice of resignation is to take effect).

4.2 The Board may for good reason remove any member of the Board PROVIDED THAT the individual concerned shall have the right to be heard by the Board accompanied by a representative, before a final majority decision is made.

5. Personal Interests of members of the Board

5.1 Subject to the provisions of Clause 5.2 no member of the Board shall receive remuneration or be interested (otherwise than as a member of the Board) in any contract entered into by the Board. Whenever a member of the Board has a personal interest in a matter to be discussed at a Board meeting, the member must:-

5.1.1 declare his interest before discussion begins on the matter;

5.1.2 withdraw from that part of the meeting unless expressly invited to remain in order to provide information;

5.1.3 not be counted in the quorum for that part of the meeting; and

5.1.4 withdraw during the vote and have no vote on the matter.

5.2 Any member of the Board for the time being who is engaged in a profession may charge and be paid a fee for the professional services done by him when instructed by the other members of the Board to act on behalf of the Association PROVIDED THAT he shall withdraw from any meeting at which his own instruction or fee, is under discussion.

6. Appointment of employees

The Board shall be responsible for appointment of employees of the Association. The duties and responsibilities of each employee will be agreed in a job description Employees will normally attend Board meeting but will not have voting rights

7. Meetings and Proceedings of the Board

7.1 The Board shall hold at least two ordinary meetings each year. The Chair, two members of the Board or the Office Manager at the request of two members of the Board, may call a meeting of the Board at any time upon not less than one calendar month being given to the other members of the Board of the matters to be discussed.

7.2 The Board shall meet annually to receive audited accounts and shall appoint an independent Auditor in accordance with Clause 13.1, alternatively an Independent Examination can be opted for by the Trustees.

7.3 The Chair shall preside at all meetings but if the Chair is absent the Vice-Chair will deputise. In the event that both the Chair and Vice Chair are absent members of the Board present shall choose one of their number to be Chair for the meeting before making any enquiry or supervising or performing any function or duty which in the opinion of the Board would be more conveniently undertaken or carried out by a sub-committee PROVIDED THAT all acts and proceedings of any such sub-committees shall be fully and promptly reported to the Board and shall not be inconsistent with this constitution.

7.4 There shall be a quorum when three members of the Board are present before any business can transacted.

7.5 Strategic decisions of the Association shall be determined by the Board, either by consensus, or by a majority of votes of the members of the Board present. In the event that

votes are equal on an issue the Chair shall have the casting vote. A resolution which is in writing and signed by all members of the Board will be considered equally valid as a resolution passed at a Board meeting and for this purpose the resolution may be contained in more than one document and may be treated as passed on the date of the last signature.

7.6 The Board may appoint one or more sub-committees consisting of three or more members of the Board for the purpose of making any enquiry or supervising or performing any function or duty which in the opinion of the Board would be more conveniently undertaken or carried out by a sub-committee PROVIDED THAT all acts and proceedings of any such sub-committees shall be fully and promptly reported to the Board.

7.7 Meetings of the Board will be usually be conducted on a face-to-face basis but in exceptional circumstances one or more members of the Board will be permitted to take part by video conferencing or by teleconference call.

7.8 Sub-Committee meetings will be generally conducted by teleconference or videoconference, but the resulting minutes and recommendations will be presented at the next Main Board Meeting.

8. Membership

8.1 Membership of the Association shall be granted to any individual over the age of 18 years who wishes to subscribe to the Association at whatever fees as decided by the Board and whether at an annual amount or not as the Board shall from time to time in its absolute discretion consider fit.

8.2 Each member shall be entitled to receive any pamphlets, bulletins or other information and in such format which the Association may from time to time produce and determine.

8.3 Each member shall have one vote.

8.4 The Board may by unanimous decision and for good reason terminate the membership of any individual PROVIDED THAT the individual concerned shall have the right to be heard by the Board, accompanied by a friend, before a final majority decision is made.

8.5 If the Association determines at an AGM that members shall pay an annual subscription then a member who fails to pay their subscription within six months of the due date shall cease to be a member automatically but may be re-admitted on payment of the amount owing.

8.6 A member may resign by written notice to the Association.

8.7 Membership of the Association is not transferable.

9. Powers

For the purposes aforesaid, the Association shall have the following powers which shall however, in no way derogate from the generality of the foregoing objects:-

9.1 Power to receive and collect donations, legacies and subscriptions.

9.2 Power to raise funds and to invite and receive contributions from all sources.

9.3 Power to publish and publicise the results of research and other activities and generally to provide to the public information and advice on the purposes of the Association.

9.4 Power to support research teams working in furtherance of the objects of the Association.

9.5 Power to appoint a full or part time Paget's Specialist Nurse.

9.6 Power to appoint such advisory Sub-Committees as the Board may from time to time think fit.

9.7 Power to do all such other things as shall in the opinion of the Board be necessary for the achievement and furtherance of the objects of the Association.

PROVIDED ALWAYS that under no circumstances shall funds of the Association be applied in a manner which is not exclusively charitable save where employment of persons and day-to-day running expenses are necessary for the proper administration of the Association.

10. General Meetings

10.1 There shall be an annual general meeting ("AGM") of the Association which shall usually be held in the autumn of each year. The date of the AGM shall be agreed by the Board. The Association shall give at least one calendar month's notice of the AGM to all members and the notice will state the business to be transacted.

10.2 All the members of the Association shall be entitled to attend and vote at any general meeting. Each member at a general meeting shall be entitled to one vote in person. Or in the case of a member being unable to attend through disability, ill health or for some other reason the member is entitled to vote via written proxy through the Chair.

10.3 There shall be a quorum at a general meeting when at least ten members are present in person or are present remotely by means of videoconferencing or similar technology or have voted on motions to be discussed at the meeting in advance, either through the Association's website or by post. The Chair shall preside at any meeting at which they are present. If the Chair is absent from any meeting, the Vice-Chair shall preside or if they are absent, some other member elected by those present shall preside.

10.4 Save where expressly stated otherwise in these Clauses, every issue to be transacted at a general meeting is to be determined by a simple majority of the votes cast by the members present in person. The Chair at the general meeting shall be entitled to a second or casting vote.

10.5 The Board shall present to each AGM the report and accounts of the Association for the preceding year.

10.6 Nominations for election to the Board must be made in writing by members of the Association and must be submitted to the Association at least one calendar month before the AGM. In the event nominations exceed vacancies, the election shall be decided by ballot the result of which shall be announced by the Chair at the AGM.

10.7 The Board may call a special general meeting of the Association at any time PROVIDED THAT at least one calendar months' notice is given to the members. If at least ten members request such a meeting in writing stating the business to be considered the Office Manager shall call such a meeting upon at least one calendar months' notice stating the business to be transacted.

11. Property

11.1 The Association may acquire by purchase or otherwise and may (subject to the consents for the time being by law required) exchange, sell, lease, charge (as permitted by the Charities Act 2006) or dispose of all or any part of freehold and leasehold land for occupation for the purposes of achieving the objects of the Association.

11.2 The property of the Association must be held by not less than two or more than four persons who for this purpose shall be designated "the Property Trustees" and whose office shall be ratified at the AGM following their appointment.

11.3 In the event that a Property Trustee shall die, resign or retire the remaining Property Trustees shall by deed appoint another person as a Property Trustee in his or her stead and such deed together with a required form of transfer executed by all parties shall be registered with the Land Registry for the District within which the property is situated, accompanied by the required fee. A person is disqualified from holding the office of a Property Trustee where such person is under the age of eighteen years or who would be disqualified under Clause 4 hereof.

11.4 The Property Trustees shall act at all times as directed by the Board and their position shall be purely honorary.

12. Receipts and Expenditure

12.1 The funds of the Association including all donations, contributions and bequests shall be paid into an account (or accounts) operated by the Board in the name of the Association at such bank as the Board shall from time to time decide. All cheques drawn on the account(s) shall be signed by two authorised signatories and in accordance with the following:-

- (a) Transactions up to and including £500: any two authorised signatories; And for the purpose of this Clause the "authorised signatories" means any Honorary Officer (being the Chair, the Vice-Chair and any Trustee) and the Office Manager and a nominated employee.
- (b) Transactions exceeding £500: any nominated Trustee and the Office Manager or a nominated employee.

12.2 The funds belonging to the Association shall be applied and invested by the Board only for the purpose of furthering the objects of the Association.

13. Accounts

13.1 The financial year of the Association shall end on the 31st day of December in each year and the accounts of the Association shall be presented by the Office Manager to the Board within six months thereafter. The accounts shall be audited by an independent auditor appointed by the Board for the purpose in accordance with Part 8, Section 144 of the Charities Act 2011.

In accordance with the option made available to Trustees by Part 8 and sections 145 of the Charities Act 2011, the Trustees are entitled to opt for an independent examination provided the charity's gross income threshold is £500,000 or less and where the charity's gross income exceeds £250,000 its gross assets are £3.36 million or less.

13.2 All the proper costs, charges and expenses of and incidental to the management of the Association shall first be defrayed out of the income of the Association.

13.3 Subject to the payments aforesaid the Board shall as and when it thinks fit (but subject to any special trusts attached to any part of the funds of the Association) apply or cause to be applied the whole or any part of the income of the Association and may apply capital of the Association in furtherance of the objects of the Association referred to in Clause 2.

14. Annual Report and Annual Return

The Board shall comply with their obligations under The Charities Act 2006 (or any statutory re-enactment or modification of that Act) with regard to the preparation of an Annual Report and an Annual Return and their transmission to the Charities Commission and in particular shall file an annual return within 10 months of the end of the financial year end of the Association.

15. Alterations to the Constitution

These Clauses other than Clauses 1,2,9,18 and this Clause (which may only be altered with the prior written consent of The Charity Commissioners) may be altered or revoked and new Clauses not inconsistent with Clause 1,2,9,18 and this Clause may be altered and revoked by a two thirds majority decision of members present at a general meeting but any proposal to alter the Clauses for the time being in force, must be communicated to the Chair in writing at least 28 clear days' before the meeting at which the proposal is to be moved.

16. Amalgamation

If at any time the Board shall decide unanimously that the purposes of the Association could be more beneficially and conveniently attained in conjunction with some other charity or charities it may apply the cash investments and other property held on account of the Association accordingly and may amalgamate or cause to be amalgamated the fund with such other charity or charities if and so far as amalgamation shall be legally possible provided that such a decision is approved at a general meeting of the Association.

17. Dissolution

If the Board decides that it is necessary or desirable to dissolve the Association it shall call a meeting of all members of the Association, of which not less than one calendar month's notice (stating the terms of the resolution to be proposed) shall be given. If the proposal is confirmed by a two-thirds majority of those present and voting at the general meeting the Board shall have power to realise any assets held by or on behalf of the Association. Any assets remaining after the satisfaction of any debts and liabilities shall be given or transferred to such other charitable institution or institutions having objects similar to the objects of the Association as the members of the Association shall determine or failing that shall be applied for some other charitable purpose. A copy of the statement of accounts for the final accounting period of the Association must be sent to The Charities Commission as soon as reasonably practicable.

18. Insurance

The Association may purchase Trustee Indemnity Insurance and any other forms of insurance cover the Board shall from time to time in its absolute discretion consider necessary for the protection of the Association and its assets and including the position of

the Property Trustees and public liability and shall observe the provisions of the Charities Act 2006 in this respect.

19. Notices

19.1 Any notice to be served under these Clauses may be sent by hand, or by post, or by electronic means or (where applicable to members generally) may be published in any suitable journal or newspaper or in any newspaper distributed by the Association.

19.2 The address at which a member is entitled to receive notices is their last known address registered with the Association. Any notice given in accordance with these Clauses is to be treated for all purposes as having been received:-

- (a) 24 hours after being delivered by hand to the relevant address;
- (b) 2 clear days after being sent by first class post to that address;
- (c) 7 clear days after being sent by overseas post to that address;
- (d) on the date of the publication of a journal or newspaper or newsletter containing the notice;
- (e) on being handed to the member personally or, if earlier, as soon as a member acknowledges actual receipt.

19.3 A technical defect in the giving of a notice of which the members or the Board are unaware at the time does not invalidate decisions taken at a meeting.

ADOPTED AT A MEETING HELD AT

The Lowry, Pier 8, Salford Quays, Greater Manchester

ON

19th April 2023

Signed by

Professor Stuart Ralston

Chair

Witness

Name: Professor Rob Layfield

Address:

Occupation: Researcher, University of Nottingham