

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales · Charity number 266071

Details

Other names NARPD, PAGETS ASSOCIATION

Status Registered

Legal form Other

Registered 1973-08-14

Register [View on the Charity Commission register](#)

Contact

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Jactin House
24 Hood St
Ancoats
Manchester
M4 6WX

Phone 01617994646

Email diana.wilkinson@paget.org.uk

Website www.paget.org.uk

Activities

Objects: TO PRESERVE AND PROTECT THE HEALTH OF PERSONS SUFFERING FROM PAGET'S DISEASE OF BONE AND THEIR FAMILIES BY A) PROVIDING INFORMATION AND SUPPORT, B) RAISING AWARENESS ABOUT PAGET'S DISEASE OF BONE BOTH WITHIN THE MEDICAL AND ALLIED HEALTH PROFESSIONS, AND AMONGST THE GENERAL PUBLIC, C) SUPPORTING AND FUNDING RESEARCH PROJECTS IN THE FIELD OF PAGET'S DISEASE OF BONE OR ITS TREATMENT.

Activities: The Paget's Association provides information and support to people whose lives are affected by all aspects of Paget's Disease of Bone and to educate health professionals. It works to raise the profile of the condition, and to raise awareness, both amongst members of the public and health professionals. It also supports and funds research into all aspects of Paget's Disease of Bone.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Elderly/old People, People With Disabilities, Other Defined Groups, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£67,302	£130,284	-	-
2023-12-31	£108,259	£228,400	-	-
2022-12-31	£125,227	£329,464	-	-
2021-12-31	£205,188	£257,302	-	-
2020-12-31	£88,273	£392,126	-	-

Trustees

Name	Role	Appointed
Professor Stuart Hamilton Ralston	Chair	2018-09-20
Alan Martin		2023-10-26
Amanda Sherwood		2020-10-16
Dr Faizanur Rahman		2022-09-30
Dr R Layfield		2016-09-29
Dr Sheelagh Farrow		2019-10-04
Dr Stephen Paul Tuck		2025-09-25
Eve Marcia Berry		2022-09-30
Kely Burman		2020-10-16
Mohamed El Erian		2023-10-27
Professor Graham G Russell		
Professor Jeremy Mark Wilkinson		2021-10-08

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales - Charity number 266071

Accounts

Charity registration number: 266071

National Association for the Relief of Pagets Disease

Annual Report and Financial Statements

for the Year Ended 31 December 2024

National Association for the Relief of Pagets Disease

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National Association for the Relief of Pagets Disease

Reference and Administrative Details

Charity Registration Number	266071
Principal Office	Jactin House 24 Hood Street Ancoats Manchester M4 6WX
Trustees	Professor Stuart Ralston, Chair Professor Robert Layfield, Vice Chair Professor Graham Russell, Honorary President Dr Sheelagh Farrow Ms Amanda Sherwood Ms Kely Burman Professor Jeremy Mark Wilkinson Ms Eve Berry Dr Faizanur Rahman Mr Mohamed El Erian Mr Alan Martin
Independent Examiner	Helen Binns FCA Beever and Struthers One Express 1 George Leigh Street Manchester M4 5DL
Bankers	Barclays Bank plc 1 Market Street Bolton BL1 3NJ
Investment Managers	Evelyn Partners Royal Liver Building Pier Head Liverpool L3 1NY

National Association for the Relief of Pagets Disease

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 December 2024.

Objectives and activities

Objects and aims

The Paget's Association is the only charity in the UK whose remit is solely concerned with people with Paget's Disease of Bone. The broad aims of the Association are to provide information and support for people with this condition and their families; to raise awareness about the condition amongst the general public and within the medical and allied health professions; and to support and fund research projects in the field of Paget's Disease of Bone.

Public benefit

The Paget's Association is an inclusive organisation which promotes the well-being of all people diagnosed with Paget's disease of bone, their families and carers. We provide information to people affected by the condition and also provide information and advice to healthcare professionals responsible for delivering their care. There is no charge for this service. We work to end the isolation of people with Paget's disease and encourage them to take control of their condition and treatment. We offer educational and social opportunities via our Paget's Information meetings which are free of charge and open to anyone with an interest in Paget's disease.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Membership

Membership of the Association is open to anyone who has an interest in Paget's disease. This includes those affected, their relatives and carers, as well as scientists and healthcare professionals. The current subscription for membership of the Association to receive the quarterly newsletter is £20 per annum for UK members and £30 for overseas members. Professional membership is free of charge. Information Meetings are generally free of charge to encourage maximum participation but occasionally a small fee may be charged to help defray costs of catering and venue hire.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Achievements and performance

Events

Two face-to-face information events for those with Paget's and their families were held in 2024: one in Cambridge and one in Middlesbrough, both hosted by local experts from the Paget's Association (NHS) Centres of Excellence.

Our Focus Group of members held virtual meetings to discuss various aspects related to Paget's disease and the Association.

Infrastructure

The website of the Association was completely redesigned and updated during 2023. This provides a greatly improved user journey and easier public access to all our information booklets and magazines, enabling those in need to find the information easily.

Support

Support continued through our Specialist Nurse and Director of Educational Resources (SNDER), who manages the Paget's Nurse Helpline, responding to queries via email, telephone, and social media. Our Paget's Buddy scheme also remained available, offering one-to-one support. The SNDER also facilitates regular Virtual Paget's Support Groups at different times to accommodate people worldwide. Additionally, many individuals found support through our international Facebook Support Group.

On Paget's Awareness Day, 11 January 2024, we hosted a virtual Question and Answer session with our Chair, Prof Stuart Ralston. Open to anyone with questions or concerns about Paget's disease, the event drew the highest number of attendees since its inception.

Information

All new members receive an information pack containing our booklets, leaflets, and the Association's magazine, Paget's News, which is sent to members and serves as a valuable source of information and support.

Raising awareness

On the 6th International Paget's Awareness Day, held on 11 January 2024, we launched a video series showcasing Paget's research-a journey through time and innovation. These videos were made available on the Association's website and YouTube channel and actively promoted on social media, which remains a key tool for raising awareness of Paget's disease to the widest possible audience. We have also enhanced our use of Google Ads to extend our reach to more people.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Research

The Association has a long history of funding high quality research projects that advance understanding of the causes of Paget's disease and/or provide new insights into management of the disease and the prevention of complications. In 2024, the Association continued to support research into Paget's through grant awards and has a portfolio of research grants already in progress with ongoing commitments of £124,374 at the end of 2024, although the Trustees decided that no new commitments for research should be made as of January 2024 due to a decrease in legacy income.

When the Association invites applications for grant funding, it does so through advertisements on its website. Each application is assessed by the Trustees, an external Research Grants Committee (RGC) and external peer reviewers and graded against the specific criteria and research objectives set out by the Research sub-committee (RSC, formed from Trustees). Some Trustees undertake research, related to their employment, within research facilities and/or hospitals and may receive funding from the Association, via their institution, to carry out research. Any decisions made regarding funding for these applications are made independently from the Trustee who is not permitted to take any part in the decision-making process. The same principles apply to funding of grants involving scientists from the same institution as a Trustee. An important part of this process is the role of lay people in the decision making, regarding the relevance of the applications to the Association's objectives. Each successful applicant is required to provide regular reports on the progress of the project for the RSC and for the Association's members via the Paget's News magazine.

Procedures for awarding research grants

The Research sub-committee (RSC) is responsible for overall strategy regarding setting an annual budget for research and upon deciding upon the range and types of awards that the Association should support and makes direct recommendations to the Board related to funding of smaller awards (less than £10,000). However, decisions on which larger project grants (typically more than £10,000) should be awarded has been delegated to an external RGC which was established in 2019. To minimise the risk of conflicts of interest, Trustees decided that the RGC should be Chaired by an individual without a specific interest in Paget's disease and have a membership of scientists and clinicians who do not have a direct research interest in Paget's disease. All larger grant applications are sent for external peer review and funding decisions made based on the reviewer's reports and the RGCs assessment of these reports. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are ratified by the board. Through these mechanisms, the Association has a robust and transparent system for awarding grants.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Financial review

Policy on reserves

In determining an appropriate level of reserves, the Board has continued to consider both operating costs which have historically been relatively stable and the wide variation in annual income which has predominantly arisen from legacies. The Board has agreed that reserves should be in place to cover at least 24 months operating expenditure.

Income in the year was £67,302 (2023: £108,259). The annual operating expenditure in 2024 was £170,037 (2023: £228,400). Expenditure comprised £130,284 (2023: £154,650) for charitable activities and £39,753 (2023: £73,750) for activities related to raising funds. A credit sum of £7,685 was allocated to Research costs due to reduction in research activities that were previously planned. Assets under investment saw a gain in the year of £25,585 (2023: 13,414).

The Board continues to review operating costs to identify and implement potential savings which will enable the Association to meet its policy on reserves.

Net assets amounted to £583,289 at 31 December 2024 (2023: £660,439). The balance of funds held will be invested to generate income to help cover operating costs and to mitigate the uncertainties of reliance on voluntary income and legacies

Investment policy and objectives

The purpose of the investments is both to provide an income return and capital appreciation. The Association's investment policy involves a balance of portfolios.

The Trustees meet our investment managers at least once a year and more often if necessary to discuss management of the Association's investment income. At the present time, about 70% is in a Cash and Cautious Bond portfolio that is low risk while still offering good returns and reasonable management fees. The remaining 30% of the Association's investment income is in a portfolio that is medium risk. The financial reports are reviewed at each Board meeting to ensure that the investments are performing favourably in terms of the UK Consumer Price Index (CPI) and income generation. The Trustees have an ethical policy not to invest in certain types of companies in view of the nature of the Charity's activities.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Plans for future periods

Activities planned to achieve aims

Patient information events will be held in person in April 2025 in Leicester and in September 2025 in Bath. This supplements the ongoing work to provide content and contact points remotely by phone or on-line methods as well as newsletters through the year. It is our intention to change the status of the Charity to a Charitable Incorporated Organisation (CIO) during 2025 or 2026. A motion to change to CIO status was approved by the membership of the Association at its AGM in 2023 and arrangements are being made to submit our proposal for CIO status to the Charity Commission. The Trustees have noted with concern that legacy income which has traditionally underpinned running of the charity has diminished over the past two years. The charity has already started to focus on fundraising during 2024 to ensure the long-term sustainability of the organisation without the need to charge for services provided. We plan a fundraising campaign called PagetAlert to promote earlier diagnosis and ensure treatment is given in a timely manner. The need for this was highlighted by a survey by the Association that revealed 45% of people with bone pain had waited more than 3 years to be diagnosed since symptom onset. The target is to raise £75,000.

To reach our goal, we will encourage supporters to donate to the charity either directly or by holding events and supporting runners in the London Marathon with a promise of runners each raising at least £1,500 in sponsorship. We also aim to seek new supporters through other channels.

During 2025 we expect to hold three face-to-face board meetings. Two of these will be combined with patient information events to reduce costs. It is our intention to pause new research funding for another year. The Association has also implemented a programme of grant applications from external sources to help fund information events as well as specific activities already undertaken by the charity such as enhancing our use of GoogleAds to reach a wider audience in need of support and/or as sources of donations.

The Trustees plan to review operating costs in relation to income and investments at the end of 2025 to ensure the financial sustainability of the charity is assured in the longer term.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Structure, governance and management

Nature of governing document

The National Association for the relief of Paget's Disease was founded in 1973. It is an unincorporated association governed by a Constitution and registered with the Charity Commission. During 2009, the charity adopted the working name of The Paget's Association and this is the name to be used in this report.

Structure of the Association

The Board of Trustees is responsible for setting the strategy and policies of the Paget's Association. The Board has up to twelve members and has three sub-committees. The role of these is to conduct a detailed analysis and review of the areas for which they are responsible, and to give strategic advice to the Board to facilitate delivery of the objectives of the organisation. Recommendations of the sub-committees are reported to and ratified by the Board of Trustees.

Throughout the period, the Finance Sub-Committee was chaired by Eve Berry, the Technology Sub-Committee was chaired by Dr Sheelagh Farrow and the Research Sub-Committee was chaired by Professor Rob Layfield.

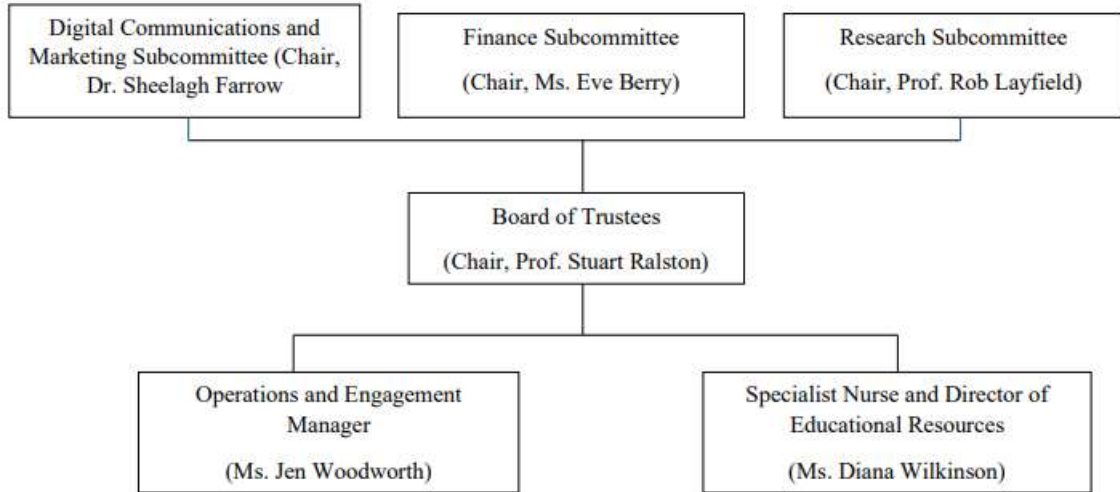
Day to day running of the Association

The day to day running of the Charity is undertaken by staff, working remotely to save on operating costs and in recognition of the change in working practices in recent years. Currently, the Association employs two full-time members of staff. These are an Operations and Engagement Manager and a Specialist Nurse and Director of Educational Resources. Employees of the Association are line-managed by the Chairman of the Association who conducts annual staff appraisals to review performance against objectives for the previous year and to set objectives for the coming year. The organisational structure of the charity as of 31st December 2024 is shown in Figure 1.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Figure 1. Organisational Structure of the Paget’s Association



Recruitment and appointment of trustees

Advertisements for trustees are posted on the website of the Association when a position becomes available. Prospective trustees may apply by contacting the Chairman of Association by letter or email. Their suitability for appointment is then discussed by the Board of trustees. If the prospective candidate is thought to be eligible to act as a trustee and is thought to offer expertise that would benefit the charity, an informal interview is set up with the Chair and other representatives of the Board. If the prospective candidate is felt to be suitable for appointment following this procedure their name is put forward to members of the Association for election at an upcoming Annual General Meeting of the Association. The prospective trustee may then be appointed based on votes cast by members of the Association.

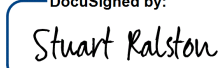
Induction and training of trustees

New trustees are provided with a one-to-one training session by the Chairman of the Board of Trustees who provides an overview of the duties of a trustee, the aims of the charity, the charity’s structure and practical aspects relevant to its day-to-day operation. Additional training sessions are organised with the chairs of the Finance Sub-committee, the Research Sub-committee and the Technology Sub-committee. New trustees also have the option of attending training courses on the responsibilities of charity trustees.

Major risks and management of those risks

The Trustees have examined the major strategic, business and operational risks that the Association faces and confirm that policies have been established to ensure regular monitoring and reporting. This will allow for timely intervention when necessary to lessen these risks.

The annual report was approved by the trustees of the charity on 30 May 2025 and signed on its behalf by:

DocuSigned by:

E5681B4200E04CE.....
 Professor Stuart Ralston
 Trustee

National Association for the Relief of Pagets Disease

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.


The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by the trustees of the charity on 30 May 2025 and signed on its behalf by:

DocuSigned by:

E5681B4200E04CB.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Independent Examiner's Report to the trustees of National Association for the Relief of Pagets Disease

I report to the trustees on my examination of the accounts of National Association for the Relief of Pagets Disease for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity trustees of National Association for the Relief of Pagets Disease you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').


I report in respect of my examination of the National Association for the Relief of Pagets Disease's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of National Association for the Relief of Pagets Disease as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed by:

F0FE206079D34EF.....
 Helen Binns FCA

Beever and Struthers
 One Express
 1 George Leigh Street
 Manchester
 M4 5DL

04-Jun-2025
 Date:.....

National Association for the Relief of Pagets Disease

Statement of Financial Activities for the Year Ended 31 December 2024

	Note	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Income and Endowments from:			
Donations and legacies	2	40,517	50,751
Other trading activities	3	20,392	39,272
Investment income	4	6,393	18,236
Total income		67,302	108,259
Expenditure on:			
Raising funds	5	39,753	73,750
Charitable activities	6	130,284	154,650
Total expenditure		170,037	228,400
Losses/(gains) on investment assets		(25,585)	(13,414)
Net expenditure		(77,150)	(106,727)
Net movement in funds		(77,150)	(106,727)
Reconciliation of funds			
Total funds brought forward		660,439	767,166
Total funds carried forward	18	583,289	660,439

All of the charity's activities derive from continuing operations during the above two periods.


The prior year Statement of Financial Activities is shown on page 23.

National Association for the Relief of Pagets Disease

(Registration number: 266071) Balance Sheet as at 31 December 2024

	Note	2024 £	2023 £
Fixed assets			
Intangible assets	12	29,170	41,526
Tangible assets	13	1,203	1,416
Investments	14	<u>602,517</u>	<u>674,921</u>
		<u>632,890</u>	<u>717,863</u>
Current assets			
Debtors	15	23,628	80,403
Cash at bank and in hand	16	<u>56,216</u>	<u>48,273</u>
		79,844	128,676
Creditors: Amounts falling due within one year	17	<u>(129,445)</u>	<u>(186,100)</u>
Net current liabilities		<u>(49,601)</u>	<u>(57,424)</u>
Net assets		<u>583,289</u>	<u>660,439</u>
Funds of the charity:			
Unrestricted income funds			
Unrestricted funds		<u>583,289</u>	<u>660,439</u>
Total funds	18	<u>583,289</u>	<u>660,439</u>

The financial statements on pages 11 to 24 were approved by the trustees, and authorised for issue on 30 May 2025 and signed on their behalf by:

DocuSigned by:

E5681B4200E04CB:.....
 Professor Stuart Ralston
 Trustee

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

National Association for the Relief of Pagets Disease meets the definition of a public benefit entity under FRS 102. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Grant expenditure

Grants payable are payments made to third parties in furtherance of the Charities' objects. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant awarded. This notification gives the recipient a reasonable expectation that they will receive the grant.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is exempt from tax on income and gains falling within section 5050 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight line basis over their estimated useful lives.

Amortisation

Amortisation is provided on intangible fixed assets so as to write off the cost, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Amortisation method and rate
Website/CRM Database	5 year straight line

Tangible fixed assets

Individual fixed assets costing £100.00 or more are initially recorded at cost.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixed and fittings	15% reducing balance

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of investments which are recognised at market value.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

2 Income from donations and legacies

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Donations and legacies;		
Donations from individuals	8,438	16,981
Legacies	33,083	17,040
Gift aid reclaimed	1,933	13,793
Grants, including capital grants;		
Grants from other charities	(2,937)	2,937
	40,517	50,751

3 Income from other trading activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Trading income;		
200 Club	4,525	4,640
Membership subscriptions	4,435	4,165
Sundry Merchandise	27	38
Sundry Fundraising	11,405	30,429
	20,392	39,272

4 Investment income

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable and similar income;		
Interest receivable on bank deposits	1,264	2,856
Other income from fixed asset investments	5,129	15,380
	6,393	18,236

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

5 Expenditure on raising funds

	Direct costs £	Allocated support costs £	Unrestricted funds 2024 £
Costs of trading activities	5,021	31,319	36,340
Investment management costs	3,413	-	3,413
	<u>8,434</u>	<u>31,319</u>	<u>39,753</u>

	Direct costs £	Allocated support costs £	Unrestricted funds 2023 £
Costs of trading activities	29,154	38,570	67,724
Investment management costs	6,026	-	6,026
	<u>35,180</u>	<u>38,570</u>	<u>73,750</u>

6 Expenditure on charitable activities

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2024 £
Support and raising awareness	51,186	-	86,783	137,969
Research	-	(21,495)	13,810	(7,685)
	<u>51,186</u>	<u>(21,495)</u>	<u>100,593</u>	<u>130,284</u>

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2023 £
Support and raising awareness	42,205	-	96,817	139,022
Research	-	4,060	11,568	15,628
	<u>42,205</u>	<u>4,060</u>	<u>108,385</u>	<u>154,650</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

7 Analysis of governance and support costs

Support costs allocated to charitable activities

		Governance costs £	Support costs £	Unrestricted funds 2024 £
Staff costs	Staff time	13,047	81,126	94,173
Office costs	Staff time	-	7,560	7,560
Staff training	Staff time	-	95	95
IT costs	Staff time	-	2,449	2,449
Depreciation	Staff time	-	12,568	12,568
Bank charges	Staff time	-	64	64
Insurance	Staff time	-	2,352	2,352
Cost of trustee meetings	Staff time	5,969	-	5,969
Accountancy fees	Staff time	3,307	-	3,307
Book-keeping costs	Staff time	-	3,375	3,375
		<u>22,323</u>	<u>109,589</u>	<u>131,912</u>

		Governance costs £	Support costs £	Unrestricted funds 2023 £
Staff costs	Staff time	4,236	97,816	102,052
Office costs	Staff time	-	13,428	13,428
Staff training	Staff time	-	143	143
IT costs	Staff time	-	2,960	2,960
Depreciation	Staff time	-	12,606	12,606
Bank charges	Staff time	-	325	325
Insurance	Staff time	-	2,165	2,165
Cost of trustee meetings	Staff time	6,572	-	6,572
Accountancy fees	Staff time	3,059	-	3,059
Book-keeping costs	Staff time	-	3,645	3,645
		<u>13,867</u>	<u>133,088</u>	<u>146,955</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year travel and subsistence expenses totalling £4,625 (2022: £4,873) were reimbursed or paid directly to six trustees (2023: ten trustees).

9 Staff costs

The aggregate payroll costs were as follows:

	2024 £	2023 £
Staff costs during the year were:		
Wages and salaries	83,551	90,601
Social security costs	3,968	4,203
Pension costs	6,654	7,248
	94,173	102,052
	94,173	102,052

The monthly average number of persons (including senior management / leadership team) employed by the charity during the year expressed as full time equivalents was as follows:

	2024 No	2023 No
Charitable activities	2	2
	2	2

No employee received emoluments of more than £60,000 during the year.

10 Independent examiner's remuneration

	2024 £	2023 £
Examination of the financial statements	1,300	1,260
Other fees to examiners		
All other services	2,007	1,799
	2,007	1,799

11 Taxation

The income and gains of the charity are exempt from taxation to the extent that they are applied to its charitable objectives.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

12 Intangible fixed assets

	Website/CRM Database £	Total £
Cost		
At 1 January 2024	61,781	61,781
At 31 December 2024	<u>61,781</u>	<u>61,781</u>
Amortisation		
At 1 January 2024	20,255	20,255
Charge for the year	<u>12,356</u>	<u>12,356</u>
At 31 December 2024	<u>32,611</u>	<u>32,611</u>
Net book value		
At 31 December 2024	<u>29,170</u>	<u>29,170</u>
At 31 December 2023	<u>41,526</u>	<u>41,526</u>

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 January 2024	3,776	3,776
At 31 December 2024	<u>3,776</u>	<u>3,776</u>
Depreciation		
At 1 January 2024	2,360	2,360
Charge for the year	<u>213</u>	<u>213</u>
At 31 December 2024	<u>2,573</u>	<u>2,573</u>
Net book value		
At 31 December 2024	<u>1,203</u>	<u>1,203</u>
At 31 December 2023	<u>1,416</u>	<u>1,416</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

14 Fixed asset investments

	Listed investments £	Cash held with investors £	Total £
Cost or Valuation			
At 1 January 2024	646,606	28,315	674,921
Revaluation	25,585	79,249	104,834
Additions	31,914	-	31,914
Disposals	(109,152)	(100,000)	(209,152)
At 31 December 2024	594,953	7,564	602,517
Net book value			
At 31 December 2024	594,953	7,564	602,517
At 31 December 2023	646,606	28,315	674,921

15 Debtors

	2024 £	2023 £
Prepayments	628	782
Accrued income	23,000	79,621
	23,628	80,403

16 Cash and cash equivalents

	2024 £	2023 £
Cash at bank	56,216	48,273

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

17 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	128	5,332
Other taxation and social security	2,206	1,868
Grants payable	124,374	176,485
Accruals	2,737	2,415
	129,445	186,100

18 Funds

	Balance at 1 January 2024 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2024 £
Unrestricted funds					
General	660,439	67,302	(170,037)	25,585	583,289

	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2023 £
Unrestricted funds					
General	767,166	108,259	(228,400)	13,414	660,439

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

19 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2024 £
Intangible fixed assets	29,170	29,170
Tangible fixed assets	1,203	1,203
Fixed asset investments	602,517	602,517
Current assets	79,844	79,844
Current liabilities	(129,445)	(129,445)
	<u>583,289</u>	<u>583,289</u>
Total net assets	<u>583,289</u>	<u>583,289</u>
	Unrestricted funds General £	Total funds at 31 December 2023 £
Intangible fixed assets	41,526	41,526
Tangible fixed assets	1,416	1,416
Fixed asset investments	674,921	674,921
Current assets	128,676	128,676
Current liabilities	(186,100)	(186,100)
	<u>660,439</u>	<u>660,439</u>
Total net assets	<u>660,439</u>	<u>660,439</u>

20 Related party transactions

There were no related party transactions in the year.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2024 (continued)

21 Prior year Statement of Financial Activities

	Unrestricted funds 2023 £
Income and Endowments from:	
Donations and legacies	50,751
Other trading activities	39,272
Investment income	18,236
	108,259
Expenditure on:	
Raising funds	73,750
Charitable activities	154,650
	228,400
Total expenditure	228,400
Losses/(gains) on investment assets	(13,414)
	(106,727)
Net expenditure	(106,727)
Net movement in funds	(106,727)
Reconciliation of funds	
Total funds brought forward	767,166
Total funds carried forward	660,439

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales - Charity number 266071

Accounts

Charity registration number: 266071

National Association for the Relief of Pagets Disease

Annual Report and Financial Statements

for the Year Ended 31 December 2023

National Association for the Relief of Pagets Disease

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National Association for the Relief of Pagets Disease

Reference and Administrative Details

Charity Registration Number	266071
Principal Office	Jactin House 24 Hood Street Ancoats Manchester M4 6WX
Trustees	Professor Stuart Ralston, Chair Professor Robert Layfield, Vice Chair Professor Graham Russell, Honorary President Dr Sheelagh Farrow Ms Amanda Sherwood Ms Kely Burman Professor Jeremy Mark Wilkinson Ms Eve Berry Dr Faizanur Rahman Mr Mohamed El Erian, appointed 27 October 2023 Mr Alan Martin, appointed 27 October 2023 Mr Alan Janes, resigned 27 October 2023 Dr Catherine Nairn, resigned 3 November 2023
Independent Examiner	Helen Binns FCA Beever and Struthers One Express 1 George Leigh Street Manchester M4 5DL
Bankers	Barclays Bank plc 1 Market Street Bolton BL1 3NJ
Investment Managers	Evelyn Partners Royal Liver Building Pier Head Liverpool L3 1NY

National Association for the Relief of Pagets Disease

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 December 2023.

Objectives and activities

Objects and aims

The Paget's Association is the only charity in the UK whose remit is solely concerned with people with Paget's Disease of Bone. The broad aims of the Association are to provide information and support for people with this condition and their families; to raise awareness about the condition amongst the general public and within the medical and allied health professions; and to support and fund research projects in the field of Paget's Disease of Bone.

Public benefit

The Paget's Association is an inclusive organisation which promotes the well-being of all people diagnosed with Paget's disease of bone, their families and carers. We provide information to people affected by the condition and also provide information and advice to healthcare professionals responsible for delivering their care. There is no charge for this service. We work to end the isolation of people with Paget's disease and encourage them to take control of their condition and treatment. We offer educational and social opportunities via our Paget's Information meetings which are free of charge and open to anyone with an interest in Paget's disease.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Membership

Membership of the Association is open to anyone who has an interest in Paget's disease. This includes those affected, their relatives and carers, as well as scientists and healthcare professionals. The current subscription for membership of the Association to receive the quarterly newsletter is £15 per annum for UK members and £25 for overseas members. Professional membership is free of charge. Information Meetings are generally free of charge to encourage maximum participation but occasionally a small fee may be charged to help defray costs of catering and venue hire.

National Association for the Relief of Paget's Disease

Trustees' Report (continued)

Achievements and performance

Events

An international medical symposium on Paget's disease was held in Manchester on 19th and 20th April 2023 to celebrate the 50th Anniversary of the Association. This was attended by delegates from around the world who are involved in research or clinical care of people with Paget's Disease of Bone. This was followed by a gala dinner attended by delegates, members of the Association and our patrons, Sir Henry Paget and Mr Recardo Patrick.

Two face-to-face information events for those with Paget's and their families were held in 2023: one in Salford on April 19th as part of the 2023 50th Anniversary events and one in Stafford in October, hosted by Dr Zoe Paskins from the Paget's Association Centre of Excellence in Stoke-on-Trent. This is one of four newly appointed Centres of Excellence. The others are in Leicester, Cambridge and London.

Our Focus Group of members held virtual meetings to discuss various aspects related to Paget's disease and the Association, reporting back to the Board of Trustees regularly.

Infrastructure

The website of the Association was completely redesigned and updated during 2023. This provides a greatly improved user journey and easier public access to all our information booklets and magazines, enabling those in need to find the information easily. The new website has allowed us to streamline the process for individuals who wish to join the Association as well as making it easier for existing members to renew.

Support

Support continued to be provided by our Specialist Nurse and Director of Educational Resources (SN DER) who manages the Paget's Nurse Helpline, responding to queries by email, telephone and social media. The SN DER facilitated several Virtual Paget's Support Groups which are available at different times of day to support people globally. In addition, many are also supported through our international Facebook Support Group, which continues to grow in membership. Support has also continued through our Paget's Support Network, Paget's Buddy scheme, and Support Gift Bags scheme for those newly diagnosed. These bags contain items to help support those having treatment.

Information

Our fact sheet 'Paget's Disease and Osteosarcoma' was updated.

The Association's magazine, Paget's News continued to be sent to members quarterly and remains an excellent source of information and support.

Raising awareness

On the 5th International Paget's Awareness Day, 11 January 2023 we produced and shared a video series highlighting personal experiences of those affected by Paget's disease, details of research being carried out on Paget's disease and a historical perspective on 50 years of the Paget's Association. These were made available online via the Association's website and YouTube channel, and promoted on social media, which continued to be used to raise awareness of Paget's disease to the widest possible audience. Our objective of raising awareness has been further facilitated by the increased and extensive use of social media including Facebook, LinkedIn and GoogleAds (facilitated by a charitable grant from Google); we have ascertained that our current policy of placing advertisements on Facebook has extended our reach to approximately 57,000 individuals, 7.5% of whom have accessed the Association's website through this route.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Raising awareness (continued)

For Paget's Awareness Day 2023, an online Paget's 'question and answer' session was held virtually with our Chair, Prof Stuart Ralston. The event was open to anyone who had queries or concerns about Paget's disease.

Research

In 2023, two small research grants and one educational grant were made. One research award was made to Dr Adrian Heald, Consultant Endocrinologist at the Northern Care Alliance NHS Foundation Trust, Salford to investigate the impact of COVID-19 on the care of people with Paget's disease. A second research award went to Daniel Scott at the University of Nottingham to establish a Paget's disease of bone stem cell bank. The Winifred Ditchfield Educational award was made to Lynn Smith, Senior Keeper at Norton Priory Museum and Gardens.

The Association continues to support research into Paget's through grant awards and has a portfolio of research grants already in progress with ongoing commitments of £111,051 at the end of 2023, although the Trustees decided that no new commitments for research should be made as of January 2024 due to a decrease in legacy income.

The Association has a long history of funding high quality research projects that advance understanding of the causes of Paget's disease and/or provide new insights into management of the disease and the prevention of complications. The Association invites applications for grant funding through advertisements on its website. Each application is assessed by the Trustees, an external Research Grants Committee (RGC) and external peer reviewers and graded against the specific criteria and research objectives set out by the Research sub-committee (RSC, formed from Trustees). Some Trustees undertake research, related to their employment, within research facilities and/or hospitals and may receive funding from the Association, via their institution, to carry out research. Any decisions made regarding funding for these applications are made independently from the Trustee who is not permitted to take any part in the decision-making process. The same principles apply to funding of grants involving scientists from the same institution as a Trustee.

An important part of this process is the role of lay people in the decision making, regarding the relevance of the applications to the Association's objectives. Each successful applicant is required to provide regular reports on the progress of the project for the RSC and for the Association's members via the magazine.

Procedures for awarding research grants

The Research sub-committee (RSC) is responsible for overall strategy regarding setting an annual budget for research and upon deciding upon the range and types of awards that the Association should support and makes direct recommendations to the board related to funding of smaller awards (less than £10,000). However, decisions on which larger project grants (typically more than £10,000) should be awarded has been delegated to an external RGC which was established in 2019. To minimise the risk of conflicts of interest, Trustees decided that the RGC should be Chaired by an individual without a specific interest in Paget's disease and have a membership of scientists and clinicians who do not have a direct research interest in Paget's disease. At the present time, the RGC is chaired by Professor Tim Arnett, from University College London and Prof Emma Duncan (King's College London) as professional members and Mrs Elizabeth Green as a lay member. All larger grant applications are sent for external peer review and funding decisions made based on the reviewer's reports and the RGCs assessment of these reports. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are ratified by the board. Through these mechanisms, the Association has a robust and transparent system for awarding grants.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Financial review

Policy on reserves

In determining an appropriate level of reserves, the board has continued to consider both operating costs which have historically been relatively stable and the wide variation in annual income which has predominantly arisen from legacies. The Board has agreed that reserves should be in place to cover at least 24 months operating expenditure.

The annual operating expenditure in 2023 was £228,400 (2022: £329,464) which comprised £154,650 (2022: £283,523) for charitable activities and £73,750 (2022: £45,941) for activities related to raising funds. A sum of £15,628 (2022: £124,480) was allocated to Research. The Board continues to review operating costs to identify and implement potential savings which will enable the Association to meet its policy on reserves. Notable savings implemented during 2023 included closure of our office in April and electing not to replace our office manager who retired in 2023, with a combined annual saving of about £44,000.

Net assets amounted to £660,439 at 31 December 2023 (2022: £767,166). The balance of funds held will be invested to generate income to cover operating costs, support new future research grants where funds permit, and to mitigate the uncertainties of reliance on voluntary income and legacies.

Investment policy and objectives

The purpose of the investments is both to provide an income return and capital appreciation. The Association's investment policy involves a balance of portfolios. The Trustees instructed our investment managers to move about 75% of the Association's investment income into a Cash and Cautious Bond portfolio that is low risk while still offering good returns and reduced management fees, after seeing underperformance in the portfolio. The remaining 25% of the Association's investment income is in a portfolio that is medium risk. The financial reports are reviewed at each board meeting to ensure that the investments are performing favourably in terms of the UK Consumer Price Index (CPI) and income generation. The Trustees have an ethical policy not to invest in certain types of companies in view of the nature of the Charity's activities.

Plans for future periods

Aims and key objectives for future periods

Patient information events will be held in person in June 2024 in Cambridge and September 2024 in Middlesbrough. This supplements the ongoing work to provide content and contact points remotely by phone or on-line methods as well as newsletters through the year. It is our intention to change the status of the Charity to a Charitable Incorporated Organisation (CIO) during 2024 or 2025. A motion to change to CIO status was approved by the membership of the Association at its AGM in 2023 and we are in the process of finalising our submission to the Charity Commission to incorporate as a CIO. The Trustees have noted with concern that legacy income which has traditionally underpinned running of the charity has diminished over the past two years. The charity has already started to focus on fundraising during 2024 to ensure the long-term sustainability of the organisation without the need to charge for services provided. This includes encouraging supporters to donate to the charity either directly or by holding events and supporting runners in the London Marathon with a promise of runners each raising at least £1,500 in sponsorship. In order to reduce costs, the Trustees have reduced the number of face-to-face board meetings from four annually to two annually and reverted to a virtual board meeting for two of these. The trustees have also decided to pause new research funding for the time being. The Association has also implemented a programme of grant applications to help fund information events as well as specific activities already undertaken by the charity such as enhancing our use of GoogleAds to reach a wider audience in need of support. Finally, it is our intention to increase membership fees by £5 annually both for UK members and international members and to offer existing members the option of receiving our magazine by email instead of by post, to reduce printing costs and postage costs.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Structure, governance and management

Nature of governing document

The National Association for the relief of Paget's Disease was founded in 1973. It is an unincorporated association governed by a Constitution and registered with the Charity Commission. During 2009, the charity adopted the working name of The Paget's Association and this is the name to be used in this report.

Structure of the Association

The Board of Trustees is responsible for setting the strategy and policies of the Paget's Association. The Board has up to twelve members and has three sub-committees. The role of these is to conduct a detailed analysis and review of the areas for which they are responsible, and to give strategic advice to the Board to facilitate delivery of the objectives of the organisation. Recommendations of the sub-committees are reported to and ratified by the Board of Trustees.

Throughout the period, the Finance Sub-Committee was chaired by Eve Berry, the Technology Sub-Committee was chaired by Dr Sheelagh Farrow and the Research Sub-Committee was chaired by Professor Rob Layfield.

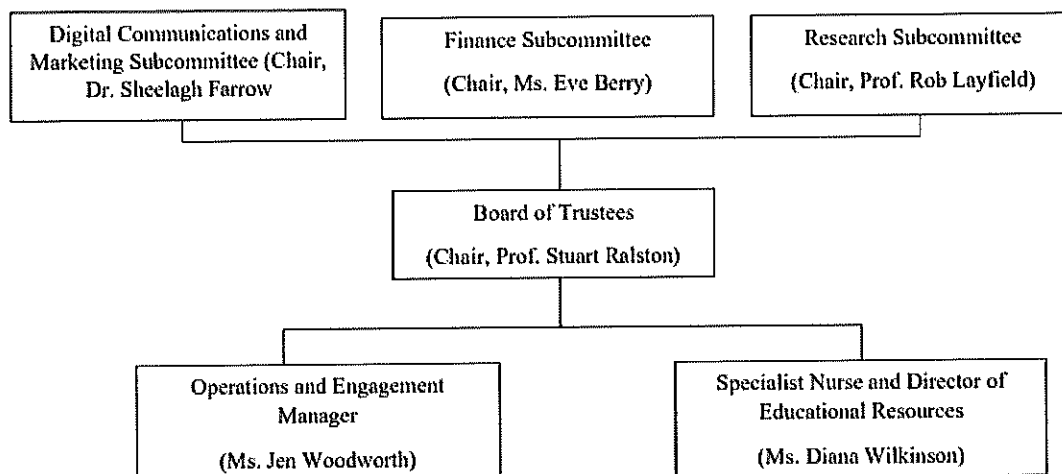
Day to day running of the Association

The day to day running of the Charity is undertaken by staff, working remotely to save on operating costs and in recognition of the change in working practices in recent years. Currently the Association employs two full time members of staff as at 31 December 2023, a reduction of one after the office manager retired in April 2023 which is also when the Charity relinquished the office space. These are an Operations and Engagement Manager and a Specialist Nurse and Director of Educational Resources. Employees of the Association are line managed by the Chairman of the Association who conducts annual staff appraisals to review performance against objectives for the previous year and to set objectives for the coming year. The organisational structure of the charity as of 31st December 2023 is shown in Figure 1.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Figure 1. Organisational Structure of the Paget's Association



Recruitment and appointment of trustees

Advertisements for trustees are posted on the website of the Association when a position becomes available. Prospective trustees may apply by contacting the Chairman of Association by letter or email. Their suitability for appointment is then discussed by the Board of trustees. If the prospective candidate is thought to be eligible to act as a trustee and is thought to offer expertise that would benefit the charity, an informal interview is set up with the Chair and other representatives of the Board. If the prospective candidate is felt to be suitable for appointment following this procedure their name is put forward to members of the Association for election at an upcoming Annual General Meeting of the Association. The prospective trustee may then be appointed based on votes cast by members of the Association.

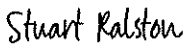
Induction and training of trustees

New trustees are provided with a one-to-one training session by the Chairman of the Board of Trustees who provides an overview of the duties of a trustee, the aims of the charity, the charity's structure and practical aspects relevant to its day-to-day operation. Additional training sessions are organised with the chairs of the Finance Sub-committee, the Research Sub-committee and the Technology Sub-committee. New trustees also have the option of attending training courses on the responsibilities of charity trustees.

Major risks and management of those risks

The Trustees have examined the major strategic, business and operational risks that the Association faces and confirm that policies have been established to ensure regular monitoring and reporting. This will allow for timely intervention when necessary to lessen these risks.

The annual report was approved by the trustees of the charity on 28/6/24 and signed on its behalf by:

DocuSigned by:

E6861B4200E04CB.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.


The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by the trustees of the charity on 28/6/24 and signed on its behalf by:

DocuSigned by:

E5681B4200E04CB
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Independent Examiner's Report to the trustees of National Association for the Relief of Pagets Disease

I report to the trustees on my examination of the accounts of National Association for the Relief of Pagets Disease for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity trustees of National Association for the Relief of Pagets Disease you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the National Association for the Relief of Pagets Disease's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of National Association for the Relief of Pagets Disease as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

H. E. Binns
Helen Binns FCA

Beever and Struthers
One Express
1 George Leigh Street
Manchester
M4 5DL

Date: 28.12.2023

National Association for the Relief of Pagets Disease

Statement of Financial Activities for the Year Ended 31 December 2023

	Note	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Income and Endowments from:			
Donations and legacies	2	50,751	88,924
Other trading activities	3	39,272	23,143
Investment income	4	18,236	13,160
Total income		<u>108,259</u>	<u>125,227</u>
Expenditure on:			
Raising funds	5	73,750	45,941
Charitable activities	6	154,650	283,523
Total expenditure		228,400	329,464
Losses/(gains) on investment assets		<u>(13,414)</u>	<u>59,132</u>
Net expenditure		<u>(106,727)</u>	<u>(263,369)</u>
Net movement in funds		(106,727)	(263,369)
Reconciliation of funds			
Total funds brought forward		<u>767,166</u>	<u>1,030,535</u>
Total funds carried forward	18	<u><u>660,439</u></u>	<u><u>767,166</u></u>

All of the charity's activities derive from continuing operations during the above two periods.

The prior year Statement of Financial Activities is shown on page 23.

National Association for the Relief of Pagets Disease

(Registration number: 266071)
Balance Sheet as at 31 December 2023

	Note	2023 £	2022 £
Fixed assets			
Intangible assets	12	41,526	3,661
Tangible assets	13	1,416	1,666
Investments	14	<u>674,921</u>	<u>702,453</u>
		<u>717,863</u>	<u>707,780</u>
Current assets			
Debtors	15	80,403	81,739
Cash at bank and in hand	16	<u>48,273</u>	<u>209,949</u>
		128,676	291,688
Creditors: Amounts falling due within one year	17	<u>(186,100)</u>	<u>(232,302)</u>
Net current (liabilities)/assets		<u>(57,424)</u>	<u>59,386</u>
Net assets		<u>660,439</u>	<u>767,166</u>
Funds of the charity:			
Unrestricted income funds			
Unrestricted funds		<u>660,439</u>	<u>767,166</u>
Total funds	18	<u>660,439</u>	<u>767,166</u>

The financial statements on pages 10 to 23 were approved by the trustees, and authorised for issue on 28/6/24... and signed on their behalf by:

DocuSigned by:

Stuart Ralston

.....
 5881B4200E04C8.....
 Professor Stuart Ralston
 Trustee

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

National Association for the Relief of Pagets Disease meets the definition of a public benefit entity under FRS 102. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Grant expenditure

Grants payable are payments made to third parties in furtherance of the Charities' objects. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant awarded. This notification gives the recipient a reasonable expectation that they will receive the grant.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is exempt from tax on income and gains falling within section 5050 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight line basis over their estimated useful lives.

Amortisation

Amortisation is provided on intangible fixed assets so as to write off the cost, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Amortisation method and rate
Website/CRM Database	5 year straight line

Tangible fixed assets

Individual fixed assets costing £100.00 or more are initially recorded at cost.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixed and fittings	15% reducing balance

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of investments which are recognised at market value.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

2 Income from donations and legacies

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Donations and legacies;		
Donations from individuals	16,981	80,420
Legacies	17,040	5,733
Gift aid reclaimed	13,793	2,771
Grants, including capital grants;		
Grants from other charities	2,937	-
	50,751	88,924

3 Income from other trading activities

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Trading income;		
200 Club	4,640	5,315
Membership subscriptions	4,165	4,490
Sundry Merchandise	38	42
Sundry Fundraising	30,429	13,296
	39,272	23,143

4 Investment income

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Interest receivable and similar income;		
Interest receivable on bank deposits	2,856	1,453
Other income from fixed asset investments	15,380	11,707
	18,236	13,160

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

5 Expenditure on raising funds

	Direct costs £	Allocated support costs £	Unrestricted funds 2023 £
Costs of trading activities	29,154	38,570	67,724
Investment management costs	6,026	-	6,026
	<u>35,180</u>	<u>38,570</u>	<u>73,750</u>

	Direct costs £	Allocated support costs £	Unrestricted funds 2022 £
Costs of trading activities	7,661	32,229	39,890
Investment management costs	6,051	-	6,051
	<u>13,712</u>	<u>32,229</u>	<u>45,941</u>

6 Expenditure on charitable activities

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2023 £
Support and raising awareness	42,205	-	96,817	139,022
Research	-	4,060	11,568	15,628
	<u>42,205</u>	<u>4,060</u>	<u>108,385</u>	<u>154,650</u>

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2022 £
Support and raising awareness	46,585	-	112,458	159,043
Research	470	111,051	12,959	124,480
	<u>47,055</u>	<u>111,051</u>	<u>125,417</u>	<u>283,523</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

7 Analysis of governance and support costs

Support costs allocated to charitable activities

		Governance costs £	Support costs £	Unrestricted funds 2023 £
Staff costs	Staff time	4,236	97,816	102,052
Office costs	Staff time	-	13,428	13,428
Staff training	Staff time	-	143	143
IT costs	Staff time	-	2,960	2,960
Depreciation	Staff time	-	12,606	12,606
Bank charges	Staff time	-	325	325
Insurance	Staff time	-	2,165	2,165
Cost of trustee meetings	Staff time	6,572	-	6,572
Accountancy fees	Staff time	3,059	-	3,059
Book-keeping costs	Staff time	-	3,645	3,645
		<u>13,867</u>	<u>133,088</u>	<u>146,955</u>

		Governance costs £	Support costs £	Unrestricted funds 2022 £
Staff costs	Staff time	11,950	107,172	119,122
Office costs	Staff time	-	16,076	16,076
Staff training	Staff time	-	95	95
IT costs	Staff time	-	4,550	4,550
Depreciation	Staff time	-	2,813	2,813
Bank charges	Staff time	-	543	543
Insurance	Staff time	-	2,422	2,422
Legal and professional costs	Staff time	20	-	20
Cost of trustee meetings	Staff time	8,759	-	8,759
Accountancy fees	Staff time	3,246	-	3,246
		<u>23,975</u>	<u>133,671</u>	<u>157,646</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year travel and subsistence expenses totalling £4,873 (2022: £3,357) were reimbursed or paid directly to ten trustees (2022: eight trustees).

9 Staff costs

The aggregate payroll costs were as follows:

	2023 £	2022 £
Staff costs during the year were:		
Wages and salaries	90,601	104,507
Social security costs	4,203	6,254
Pension costs	7,248	8,361
	102,052	119,122
	102,052	119,122

The monthly average number of persons (including senior management / leadership team) employed by the charity during the year expressed as full time equivalents was as follows:

	2023 No	2022 No
Charitable activities	2	3
	2	3

No employee received emoluments of more than £60,000 during the year.

10 Independent examiner's remuneration

	2023 £	2022 £
Examination of the financial statements	1,260	1,200
Other fees to examiners		
All other services	1,799	2,046
	1,799	2,046

11 Taxation

The income and gains of the charity are exempt from taxation to the extent that they are applied to its charitable objectives.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

12 Intangible fixed assets

	Website/CRM Database £	Total £
Cost		
At 1 January 2023	11,560	11,560
Additions	<u>50,221</u>	<u>50,221</u>
At 31 December 2023	<u>61,781</u>	<u>61,781</u>
Amortisation		
At 1 January 2023	7,899	7,899
Charge for the year	<u>12,356</u>	<u>12,356</u>
At 31 December 2023	<u>20,255</u>	<u>20,255</u>
Net book value		
At 31 December 2023	<u>41,526</u>	<u>41,526</u>
At 31 December 2022	<u>3,661</u>	<u>3,661</u>

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 January 2023	<u>3,776</u>	<u>3,776</u>
At 31 December 2023	<u>3,776</u>	<u>3,776</u>
Depreciation		
At 1 January 2023	2,110	2,110
Charge for the year	<u>250</u>	<u>250</u>
At 31 December 2023	<u>2,360</u>	<u>2,360</u>
Net book value		
At 31 December 2023	<u>1,416</u>	<u>1,416</u>
At 31 December 2022	<u>1,666</u>	<u>1,666</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

14 Fixed asset investments

	Listed investments £	Cash held with investors £	Total £
Cost or Valuation			
At 1 January 2023	679,764	22,689	702,453
Revaluation	13,414	-	13,414
Additions	526,540	-	526,540
Disposals	(573,112)	-	(573,112)
Movement in cash held by investors	-	5,626	5,626
At 31 December 2023	<u>646,606</u>	<u>28,315</u>	<u>674,921</u>
Net book value			
At 31 December 2023	<u>646,606</u>	<u>28,315</u>	<u>674,921</u>
At 31 December 2022	<u>679,764</u>	<u>22,689</u>	<u>702,453</u>

15 Debtors

	2023 £	2022 £
Prepayments	782	16,531
Accrued income	<u>79,621</u>	<u>65,208</u>
	<u>80,403</u>	<u>81,739</u>

16 Cash and cash equivalents

	2023 £	2022 £
Cash on hand	-	103
Cash at bank	<u>48,273</u>	<u>209,846</u>
	<u>48,273</u>	<u>209,949</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

17 Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	5,332	169
Other taxation and social security	1,868	2,751
Grants payable	176,485	227,144
Accruals	2,415	2,238
	<u>186,100</u>	<u>232,302</u>

18 Funds

	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2023 £
Unrestricted funds					
General	<u>767,166</u>	<u>108,259</u>	<u>(228,400)</u>	<u>13,414</u>	<u>660,439</u>
	Balance at 1 January 2022 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2022 £
Unrestricted funds					
General	<u>1,030,535</u>	<u>125,227</u>	<u>(329,464)</u>	<u>(59,132)</u>	<u>767,166</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

19 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2023 £
Intangible fixed assets	41,526	41,526
Tangible fixed assets	1,416	1,416
Fixed asset investments	674,921	674,921
Current assets	128,676	128,676
Current liabilities	(186,100)	(186,100)
Total net assets	660,439	660,439
	Unrestricted funds General £	Total funds at 31 December 2022 £
Intangible fixed assets	3,661	3,661
Tangible fixed assets	1,666	1,666
Fixed asset investments	702,453	702,453
Current assets	291,688	291,688
Current liabilities	(232,302)	(232,302)
Total net assets	767,166	767,166

20 Related party transactions

There were no related party transactions in the year.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2023 (continued)

21 Prior year Statement of Financial Activities

	Unrestricted funds 2022 £
Income and Endowments from:	
Donations and legacies	88,924
Other trading activities	23,143
Investment income	13,160
Total income	<u>125,227</u>
Expenditure on:	
Raising funds	45,941
Charitable activities	283,523
Total expenditure	329,464
Losses/(gains) on investment assets	<u>59,132</u>
Net expenditure	<u>(263,369)</u>
Net movement in funds	(263,369)
Reconciliation of funds	
Total funds brought forward	<u>1,030,535</u>
Total funds carried forward	<u><u>767,166</u></u>

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales - Charity number 266071

Accounts

Charity registration number: 266071

National Association for the Relief of Pagets Disease

Annual Report and Financial Statements
for the Year Ended 31 December 2022

National Association for the Relief of Pagets Disease

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National Association for the Relief of Pagets Disease

Reference and Administrative Details

Charity Registration Number	266071
Principal Office	Jactin House 24 Hood Street Ancoats Manchester M4 6WX
Trustees	Professor Stuart Ralston, Chair Professor Robert Layfield, Vice Chair Professor Graham Russell, Honorary President Dr Sheelagh Farrow Ms Amanda Sherwood Mr Alan Janes Ms Kely Burman Professor Jeremy Mark Wilkinson Dr Catherine Nairn Ms Eve Berry, appointed 30 September 2022 Dr Faizanur Rahman, appointed 30 September 2022
Independent Examiner	Sue Hutchinson FCCA Beever and Struthers One Express 1 George Leigh Street Manchester M4 5DL
Bankers	Barclays Bank plc 1 Market Street Bolton BL1 3NJ
Investment Managers	Tilney Royal Liver Building Pier Head Liverpool L3 1NY

National Association for the Relief of Pagets Disease

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 December 2022.

Objectives and activities

Objects and aims

The Paget's Association is the only charity in the UK whose remit is solely concerned with people with Paget's Disease of Bone. The broad aims of the Association are to provide information and support for people with this condition and their families; to raise awareness about the condition amongst the general public and within the medical and allied health professions; and to support and fund research projects in the field of Paget's Disease of Bone.

Public benefit

The Paget's Association is an inclusive organisation which promotes the well-being of all people diagnosed with Paget's disease of bone, their families and carers. We provide information to people affected by the condition and also provide information and advice to healthcare professionals responsible for delivering their care. There is no charge for this service. We work to end the isolation of people with Paget's disease and encourage them to take control of their condition and treatment. We offer educational and social opportunities via our Paget's Information meetings which are free of charge and open to anyone with an interest in Paget's disease.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Membership

Membership of the Association is open to anyone who has an interest in Paget's disease. This includes those affected, their relatives and carers, as well as scientists and healthcare professionals. The current subscription for membership of the Association to receive the quarterly newsletter is £15 per annum for UK members and £20 for overseas members. Professional membership is free of charge. Information Meetings are generally free of charge to encourage maximum participation but occasionally a small fee may be charged to help defray costs of catering and venue hire.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Achievements and performance

The achievements and performance during 2022 were broadly in line with the plans for future periods outlined in the annual report for the year ending 31st December 2021 as discussed in more detail below.

Support

Our Virtual Paget's Support Groups continue to support people globally with regular online meetings, at differing times to cater for different time zones. Many are also supported through our international Facebook Support Group, which continues to grow in membership. The Paget's Nurse Helpline continues to be managed by our Specialist Paget's Nurse who responds to queries by email, telephone and social media.

Support has also continued through our Paget's Support Network, Paget's Buddy scheme, Sheffield Support Group and Support Gift Bags scheme for those newly diagnosed, which contain items to help with pain and support those having treatment. A Focus Group was established to explore opinions of those affected by Paget's disease and their families, and to generate ideas related to specific issues relevant to those with Paget's disease and/or the Paget's Association. The group meet virtually.

Increased use was made of social media to support those with Paget's disease and raise awareness of the condition. The Facebook Support Group, which was set up during 2020, has continued to grow in popularity and now has 815 members from the UK and other countries across the world including Australia, New Zealand, USA and Canada.

A Paget's question and answer session was held online, using Zoom, as part of the Paget's Awareness Day events on 11th January 2022.

The Association's website and database continued to be developed, to offer more information and online membership options.

Information

The Association's information booklet regarding Paget's and Pain was updated and a new Paget's Jargon Buster booklet produced. The Association's quarterly magazine, Paget's News continued to be an excellent source of information and support.

The Association commissioned a new website and database which will be launched in 2023. This will provide easier public access to all our information and will provide a better user experience, enabling individuals to find the information they require quickly and easily.

Raising awareness

To gain a global perspective, for the 4th International Paget's Awareness Day on 11th January 2022 we showcased a series of video interviews with experts from around the world including Spain, Italy, Brazil, India, and Canada. These were made available online via the Association's website and YouTube channel.

Social media continues to be used to raise awareness of Paget's disease and has proved to be an excellent vehicle for raising awareness not only in the UK but also globally.

To raise awareness amongst professionals in the field, the Association had an exhibition stand at the Bone Research Society's annual conference in Manchester and a virtual exhibition stand at the World Congress on Osteoporosis, Osteoarthritis and Musculoskeletal Diseases. In addition, slides were provided for digital displays in NHS waiting rooms.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Research

The Association has a long history of funding high quality research projects that advance understanding of the causes of Paget's disease and/or provide new insights into management of the disease and the prevention of complications. The Association invites applications for grant funding through advertisements on its website. Each application is assessed by the Trustees, an external Research Grants Committee (RGC) and external peer reviewers and graded against the specific criteria and research objectives set out by the Research sub-committee (RSC, formed from Trustees). Some Trustees undertake research, related to their employment, within research facilities and/or hospitals and may receive funding from the Association, via their institution, to carry out research. Any decisions made with regard to funding for these applications are made independently from the Trustee who is not permitted to take any part in the decision-making process. The same principles apply to funding of grants involving scientists from the same institution as a Trustee.

An important part of this process is the role of lay people in the decision making, regarding the relevance of the applications to the Association's objectives. Each successful applicant is required to provide regular reports on the progress of the project for the RSC and for the Association's members via the quarterly Newsletter.

Procedures for awarding research grants

The Research sub-committee (RSC) is responsible for overall strategy with regard to setting an annual budget for research and upon deciding upon the range and types of awards that the Association should support, and makes direct recommendations to the board related to funding of smaller awards (less than £10,000). However, decisions on which larger project grants (typically in excess of £10,000) should be awarded has been delegated to an external RGC which was established in 2019. To minimise the risk of conflicts of interest, Trustees decided that the RGC should be Chaired by an individual without a specific interest in Paget's disease and have a membership of scientists and clinicians who do not have a direct research interest in Paget's disease. At the present time, the RGC is chaired by Professor Tim Arnett, from University College London. Prof Emma Duncan (King's College London) and Dr Celia Gregson (Bristol University) as professional members and Mrs Elizabeth Green as a lay member. All larger grant applications are sent for external peer review and funding decisions made based on the reviewer's reports and the RGCs assessment of these reports. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are ratified by the board. Through these mechanisms, the Association has a robust and transparent system for awarding grants.

Financial review

Policy on reserves

In determining an appropriate level of reserves, the Board has considered both operating costs which are relatively stable and the wide variation in annual income which is heavily reliant on legacies. The Board has agreed that reserves should be in place to cover at least 24 months operating expenditure. The annual operating expenditure in 2022 was £329,464 which comprised £157,646 for operating costs and £159,043 for activities related to raising awareness of Paget's disease. A sum of £124,480 was allocated to Research. Investments were valued at £702,453 at the 31 December 2022. The Board continues to review operating costs to identify and implement potential savings which will enable the Association to meet its policy on reserves. This compares with a sum of £1,030,535 at the year-end in 2021. The balance of funds held will be invested to generate income for future research grants, to cover operating costs and to mitigate the uncertainties of reliance on voluntary income and legacies.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Investment policy and objectives

The purpose of the investments is both to provide an income return and capital appreciation. The Association's investment policy involves a balance of portfolios. The trustees have instructed our investment managers to maintain about 75% of the Associations investment income in a portfolio that is low risk and another comprising about 25% of the Associations investment income in a portfolio that is medium risk. The financial reports are reviewed at each board meeting to ensure that the investments are performing favourably in terms of the UK Consumer Prices Index (CPI) and income generation. The Trustees have an ethical policy not to invest in certain types of companies in view of the nature of the Charity's activities.

Plans for future periods

Aims and key objectives for future periods

During the next financial year, the Association will continue to review its income base and to control expenditure through judicious monitoring of outgoings and carefully prepared budgets. Priorities for the next financial year include:

- 1.To hold a Paget's Awareness Day in 2023 coinciding with the birthdate of Sir James Paget (11th January). As in recent years this will include new information videos and a digital awareness campaign with prominent use of social media channels.
- 2.To hold two face-to-face patient information events during 2023, one in Manchester on 19th April 2023 to coincide with the 50th Anniversary Scientific Symposium on Paget's disease and another on 27th October 2023, in Stafford to coincide with the AGM of the Association.
- 3.To continue to expand the charity's international reach through promotion of our Facebook group.
- 4.To continue with virtual and local patient support groups, where there is need.
- 5.To increase expenditure on social media activity and establish a new website with a budget of approximately £40,000 publicise the Association's charitable objectives and activities.
- 6.To advertise a Research Grants Round in January 2023 with an indicative total budget of £20,000.
- 7.To prepare for the Association's 50th Anniversary celebrations in April 2023. This will involve several activities, including a fundraising campaign with a target of raising £50,000 by the end of 2023.
- 8.To expand the network of Paget's Disease Centres of Excellence
- 9.To reduce operating costs by closing the Association's registered office with a move to a virtual office.
- 10.To review staffing needs of the Association with the intended retirement of Mrs Sue Clegg in 2023.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Structure, governance and management

Nature of governing document

The National Association for the relief of Paget's Disease was founded in 1973. It is an unincorporated association governed by a Constitution and registered with the Charity Commission. During 2009, the charity adopted the working name of The Paget's Association and this is the name to be used in this report.

Structure of the Association

The Board of Trustees is responsible for setting the strategy and policies of the Paget's Association. The Board has up to twelve members and has three sub-committees. The role of these is to conduct a detailed analysis and review of the areas for which they are responsible, and to give strategic advice to the Board to facilitate delivery of the objectives of the organisation. Recommendations of the sub-committees are reported to and ratified by the Board of Trustees.

Throughout 2022, the Finance Sub-Committee was chaired by Professor Stuart Ralston, the Technology Sub-Committee was chaired by Dr Sheelagh Farrow and the Research Sub-Committee was chaired by Professor Rob Layfield.

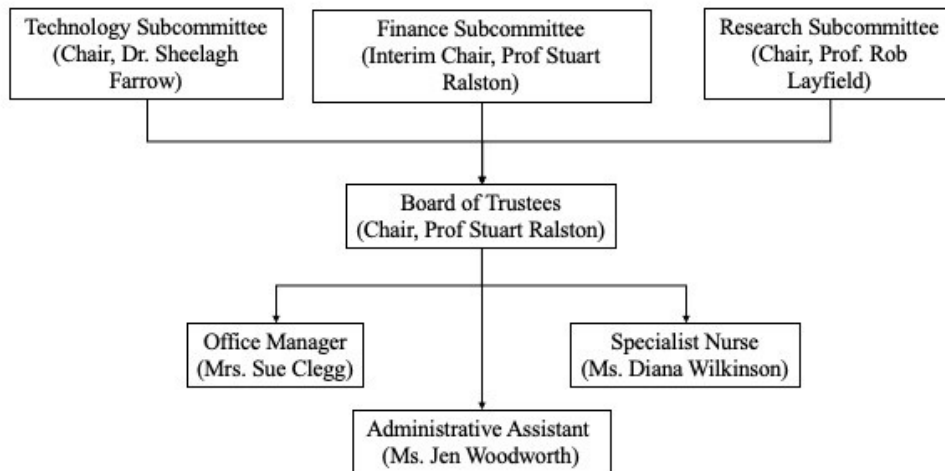
Day to day running of the Association

Day to day running of the Charity is undertaken by the staff based at the charity's registered office in Swinton. Currently the Association employs three full time members of staff. These are an office manager, an administrative assistant, and a specialist nurse. Employees of the Association are line managed by the Chairman of the Association who conducts annual staff appraisals to review performance against objectives for the previous year and to set objectives for the coming year. The organisational structure of the charity as of 31st December 2022 is shown in Figure 1.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Figure 1. Organisational Structure of the Paget's Association



Recruitment and appointment of trustees

Advertisements for trustees are posted on the website of the Association when a position becomes available. Prospective Trustees may apply by contacting the Chairman of Association by letter or email. Their suitability for appointment is then discussed by the Board of Trustees. If the prospective candidate is thought to be eligible to act as a trustee and is thought to offer expertise that would benefit the charity, an informal interview is set up with the Chair and other representatives of the Board. If the prospective candidate is felt to be suitable for appointment following this procedure their name is put forward to members of the Association for election at an upcoming Annual General Meeting of the Association. The prospective trustee may then be appointed based on votes cast by members of the Association.

Induction and training of trustees

New trustees are provided with a one-to-one training session by the Chairman of the Board of Trustees who provides an overview of the duties of a trustee, the aims of the charity, the charity's structure and practical aspects relevant to its day-to-day operation. Additional training sessions are organised with the chairs of the Finance Sub-committee, the Research Sub-committee and the Technology Sub-committee. New trustees also have the option of attending training courses on the responsibilities of Charity Trustees.

National Association for the Relief of Pagets Disease

Trustees' Report (continued)

Major risks and management of those risks

The Trustees have examined the major strategic, business and operational risks that the Association faces and confirm that policies have been established to ensure regular monitoring and reporting. This will allow for timely intervention when necessary to lessen these risks.

The annual report was approved by the trustees of the charity on^{03-Oct-2023} and signed on its behalf by:

DocuSigned by:

Prof Stuart Ralston

.....
E5681B4200E04CB.....

Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:


- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

03-Oct-2023

Approved by the trustees of the charity on and signed on its behalf by:

DocuSigned by:

E5681B4200E04CB:.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Independent Examiner's Report to the trustees of National Association for the Relief of Pagets Disease

I report to the trustees on my examination of the accounts of National Association for the Relief of Pagets Disease for the year ended 31 December 2022.

Responsibilities and basis of report

As the charity trustees of National Association for the Relief of Pagets Disease you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the National Association for the Relief of Pagets Disease's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of National Association for the Relief of Pagets Disease as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

DocuSigned by:

.....D927DD9C2502484.....
Sue Hutchinson FCCA

Beever and Struthers
One Express
1 George Leigh Street
Manchester
M4 5DL

12-Oct-2023
Date:.....

National Association for the Relief of Pagets Disease

Statement of Financial Activities for the Year Ended 31 December 2022

	Note	Unrestricted funds 2022 £	Unrestricted funds 2021 £
Income and Endowments from:			
Donations and legacies	2	88,924	170,474
Other trading activities	3	23,143	23,112
Investment income	4	13,160	11,602
Total income		<u>125,227</u>	<u>205,188</u>
Expenditure on:			
Raising funds	5	45,941	42,262
Charitable activities	6	283,523	215,040
Total expenditure		329,464	257,302
Losses/(gains) on investment assets		59,132	(60,049)
Net (expenditure)/income		<u>(263,369)</u>	<u>7,935</u>
Net movement in funds		(263,369)	7,935
Reconciliation of funds			
Total funds brought forward		<u>1,030,535</u>	<u>1,022,600</u>
Total funds carried forward	18	<u><u>767,166</u></u>	<u><u>1,030,535</u></u>

All of the charity's activities derive from continuing operations during the above two periods.

The prior year Statement of Financial Activities is shown on page 24.

National Association for the Relief of Pagets Disease

(Registration number: 266071) Balance Sheet as at 31 December 2022

	Note	2022 £	2021 £
Fixed assets			
Intangible assets	12	3,661	5,973
Tangible assets	13	1,666	2,166
Investments	14	<u>702,453</u>	<u>755,930</u>
		<u>707,780</u>	<u>764,069</u>
Current assets			
Debtors	15	81,739	220,714
Cash at bank and in hand	16	<u>209,949</u>	<u>216,066</u>
		291,688	436,780
Creditors: Amounts falling due within one year	17	<u>(232,302)</u>	<u>(170,314)</u>
Net current assets		<u>59,386</u>	<u>266,466</u>
Net assets		<u>767,166</u>	<u>1,030,535</u>
Funds of the charity:			
Unrestricted income funds			
Unrestricted funds		<u>767,166</u>	<u>1,030,535</u>
Total funds	18	<u>767,166</u>	<u>1,030,535</u>

The financial statements on pages 11 to 24 were approved by the trustees, and authorised for issue on 12-Oct-2023... and signed on their behalf by:

DocuSigned by:

 Professor Stuart Ralston
 Trustee
 12-Oct-2023

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

National Association for the Relief of Pagets Disease meets the definition of a public benefit entity under FRS 102. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

Grant expenditure

Grants payable are payments made to third parties in furtherance of the Charities' objects. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant awarded. This notification gives the recipient a reasonable expectation that they will receive the grant.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is exempt from tax on income and gains falling within section 5050 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight line basis over their estimated useful lives.

Amortisation

Amortisation is provided on intangible fixed assets so as to write off the cost, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Amortisation method and rate
Website/CRM Database	5 year straight line

Tangible fixed assets

Individual fixed assets costing £100.00 or more are initially recorded at cost.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixed and fittings	15% reducing balance

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of investments which are recognised at market value.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

2 Income from donations and legacies

	Unrestricted funds 2022 £	Unrestricted funds 2021 £
Donations and legacies;		
Donations from individuals	80,420	6,660
Legacies	5,733	160,430
Gift aid reclaimed	2,771	3,384
	88,924	170,474

3 Income from other trading activities

	Unrestricted funds 2021 £	Unrestricted funds 2021 £
Trading income;		
200 Club	5,315	5,680
Membership subscriptions	4,490	4,925
Sundry Merchandise	42	59
Sundry Fundraising	13,296	12,448
	23,143	23,112

4 Investment income

	Unrestricted funds 2022 £	Unrestricted funds 2021 £
Interest receivable and similar income;		
Interest receivable on bank deposits	1,453	1,950
Other income from fixed asset investments	11,707	9,652
	13,160	11,602

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

5 Expenditure on raising funds

	Direct costs £	Allocated support costs £	Unrestricted funds 2022 £
Costs of trading activities	7,661	32,229	39,890
Investment management costs	6,051	-	6,051
	<u>13,712</u>	<u>32,229</u>	<u>45,941</u>

	Direct costs £	Allocated support costs £	Unrestricted funds 2021 £
Costs of trading activities	5,419	30,717	36,136
Investment management costs	6,126	-	6,126
	<u>11,545</u>	<u>30,717</u>	<u>42,262</u>

6 Expenditure on charitable activities

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2022 £
Support and raising awareness	46,585	-	112,458	159,043
Research	470	111,051	12,959	124,480
	<u>47,055</u>	<u>111,051</u>	<u>125,417</u>	<u>283,523</u>

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2021 £
Support and raising awareness	27,116	-	107,180	134,296
Research	470	67,927	12,347	80,744
	<u>27,586</u>	<u>67,927</u>	<u>119,527</u>	<u>215,040</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

7 Analysis of governance and support costs

Support costs allocated to charitable activities

		Governance costs £	Support costs £	Unrestricted funds 2022 £
Staff costs	Staff time	11,950	107,172	119,122
Office costs	Staff time	-	16,076	16,076
Staff training	Staff time	-	95	95
IT costs	Staff time	-	4,550	4,550
Depreciation	Staff time	-	2,813	2,813
Bank charges	Staff time	-	543	543
Insurance	Staff time	-	2,422	2,422
Legal and professional costs	Staff time	20	-	20
Cost of trustee meetings	Staff time	8,759	-	8,759
Accountancy fees	Staff time	3,246	-	3,246
		23,975	133,671	157,646

		Governance costs £	Support costs £	Unrestricted funds 2021 £
Staff costs	Staff time	11,525	103,274	114,799
Office costs	Staff time	-	17,892	17,892
Staff training	Staff time	-	125	125
IT costs	Staff time	-	5,334	5,334
Depreciation	Staff time	-	2,817	2,817
Bank charges	Staff time	-	485	485
Legal and professional costs	Staff time	20	-	20
Cost of trustee meetings	Staff time	4,887	-	4,887
Accountancy fees	Staff time	3,885	-	3,885
		20,317	129,927	150,244

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year travel and subsistence expenses totalling £3,357 (2021: £4,157) were reimbursed or paid directly to eight trustees (2021: seven trustees).

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

9 Staff costs

The aggregate payroll costs were as follows:

	2022 £	2021 £
Staff costs during the year were:		
Wages and salaries	104,507	100,346
Social security costs	6,254	6,193
Pension costs	8,361	8,028
	119,122	114,567

The monthly average number of persons (including senior management / leadership team) employed by the charity during the year expressed as full time equivalents was as follows:

	2022 No	2021 No
Charitable activities	3	3

No employee received emoluments of more than £60,000 during the year.

10 Independent examiner's remuneration

	2022 £	2021 £
Examination of the financial statements	2,035	2,035
Other fees to examiners		
All other services	1,211	1,850

11 Taxation

The income and gains of the charity are exempt from taxation to the extent that they are applied to its charitable objectives.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

12 Intangible fixed assets

	Website/CRM Database £	Total £
Cost		
At 1 January 2022	11,560	11,560
At 31 December 2022	<u>11,560</u>	<u>11,560</u>
Amortisation		
At 1 January 2022	5,587	5,587
Charge for the year	<u>2,312</u>	<u>2,312</u>
At 31 December 2022	<u>7,899</u>	<u>7,899</u>
Net book value		
At 31 December 2022	<u>3,661</u>	<u>3,661</u>
At 31 December 2021	<u>5,973</u>	<u>5,973</u>

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 January 2022	3,776	3,776
At 31 December 2022	<u>3,776</u>	<u>3,776</u>
Depreciation		
At 1 January 2022	1,610	1,610
Charge for the year	<u>500</u>	<u>500</u>
At 31 December 2022	<u>2,110</u>	<u>2,110</u>
Net book value		
At 31 December 2022	<u>1,666</u>	<u>1,666</u>
At 31 December 2021	<u>2,166</u>	<u>2,166</u>

14 Fixed asset investments

	2022 £	2021 £
Other investments	<u>702,453</u>	<u>755,930</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

14. Fixed Asset Investments (continued)

	Listed investments £	Cash held with investors £	Total £
Cost or Valuation			
At 1 January 2022	674,000	81,930	755,930
Revaluation	(59,133)	(59,241)	(118,374)
Additions	247,207	-	247,207
Disposals	(182,310)	-	(182,310)
At 31 December 2022	<u>679,764</u>	<u>22,689</u>	<u>702,453</u>
Net book value			
At 31 December 2022	<u>679,764</u>	<u>22,689</u>	<u>702,453</u>
At 31 December 2021	<u>674,000</u>	<u>81,930</u>	<u>755,930</u>

15 Debtors

	2022 £	2021 £
Prepayments	16,531	-
Accrued income	65,208	220,714
	<u>81,739</u>	<u>220,714</u>

16 Cash and cash equivalents

	2022 £	2021 £
Cash on hand	103	103
Cash at bank	209,846	215,963
	<u>209,949</u>	<u>216,066</u>

17 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	169	96
Other taxation and social security	2,751	2,668
Grants payable	227,144	165,513
Accruals	2,238	2,037
	<u>232,302</u>	<u>170,314</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

18 Funds

	Balance at 1 January 2022 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2022 £
Unrestricted funds					
General	<u>1,030,535</u>	<u>125,227</u>	<u>(329,464)</u>	<u>(59,132)</u>	<u>767,166</u>
	Balance at 1 January 2021 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2021 £
Unrestricted funds					
General	<u>1,022,600</u>	<u>205,188</u>	<u>(257,302)</u>	<u>60,049</u>	<u>1,030,535</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

19 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2022 £
Intangible fixed assets	3,661	3,661
Tangible fixed assets	1,666	1,666
Fixed asset investments	702,453	702,453
Current assets	291,688	291,688
Current liabilities	<u>(232,302)</u>	<u>(232,302)</u>
Total net assets	<u>767,166</u>	<u>767,166</u>
	Unrestricted funds General £	Total funds at 31 December 2021 £
Intangible fixed assets	5,973	5,973
Tangible fixed assets	2,166	2,166
Fixed asset investments	755,930	755,930
Current assets	436,780	436,780
Current liabilities	<u>(170,314)</u>	<u>(170,314)</u>
Total net assets	<u>1,030,535</u>	<u>1,030,535</u>

20 Related party transactions

During the year grants have been allocated to research projects in which one of the trustees is connected. Professor Stuart Ralston is the director of the Edinburgh Paget's Disease Centre of Excellence. During the year grants totalling £25,712 were allocated to this research group. Professor Ralston has no involvement in the grant decision process.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2022 (continued)

21 Prior year Statement of Financial Activities

	Unrestricted funds 2021 £
Income and Endowments from:	
Donations and legacies	170,474
Other trading activities	23,112
Investment income	11,602
	205,188
Total income	205,188
Expenditure on:	
Raising funds	42,262
Charitable activities	215,040
	257,302
Total expenditure	257,302
Losses/(gains) on investment assets	(60,049)
	(60,049)
Net income	7,935
Net movement in funds	7,935
Reconciliation of funds	
Total funds brought forward	1,022,600
Total funds carried forward	1,030,535

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales - Charity number 266071

Accounts

Charity registration number: 266071

National Association for the Relief of Pagets Disease

Annual Report and Financial Statements

for the Year Ended 31 December 2021

National Association for the Relief of Pagets Disease

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**National Association for the Relief of Pagets Disease
Reference and Administrative Details**

Other Name Used	The Paget's Association
Charity Registration Number	266071
Principal Office	Suite 5 Moorfield House Moorside Road Swinton Manchester
Patrons	Sir Henry Paget Mr Ricardo Patrick The Lord Stamp MD FRCP
Honorary Patron	Mrs Joyce Cupitt
Trustees	Professor Stuart Ralston, Chair Dr Stephen Tuck, Vice Chair, resigned 8 October 2021 Professor Robert Layfield, Vice Chair Professor Graham Russell, Honorary President Mr Michael Patnick Dr Sheelagh Farrow Ms Amanda Sherwood Mr Alan Janes Ms Kely Burman Mr Niall Middleton, resigned 8 October 2021 Professor Jeremy Mark Wilkinson, appointed 8 October 2021 Dr Catherine Nairn, appointed 8 October 2021 Mr Michael Missett, resigned 8 October 2021 Dr Anna Daroszevska, resigned 8 October 2021
Independent Examiner	Sue Hutchinson FCCA Beever and Struthers St. George's House 215 - 219 Chester Road Manchester M15 4JE
Bankers	Barclays Bank plc 1 Market Street Bolton BL1 3NJ
Investment Managers	Tilney Royal Liver Building Pier Head Liverpool L3 1NY

National Association for the Relief of Pagets Disease Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 December 2021.

Objectives and activities

Objects and aims

The Paget's Association is the only charity in the UK whose remit is solely concerned with people with Paget's Disease of Bone. The broad aims of the Association are to provide information and support for people with this condition and their families; to raise awareness about the condition amongst the general public and within the medical and allied health professions; and to support and fund research projects in the field of Paget's Disease of Bone.

Public benefit

The Paget's Association is an inclusive organisation which promotes the well-being of all people diagnosed with Paget's disease of bone, their families and carers. We provide information to people affected by the condition and also provide information and advice to healthcare professionals responsible for delivering their care. There is no charge for this service. We work to end the isolation of people with Paget's disease and encourage them to take control of their condition and treatment. We offer educational and social opportunities via our Paget's Information meetings which are free of charge and open to anyone with an interest in Paget's disease.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Membership

Membership of the Association is open to anyone who has an interest in Paget's disease. This includes those affected, their relatives and carers, as well as scientists and healthcare professionals. The current subscription for membership of the Association to receive the quarterly newsletter is £15 per annum for UK members and £20 for overseas members. Professional membership is free of charge. Information Meetings are generally free of charge to encourage maximum participation but occasionally a small fee may be charged to help defray costs of catering and venue hire.

National Association for the Relief of Paget's Disease

Trustees' Report

Achievements and performance

The achievements and performance during 2021 were broadly in line with the plans for future periods outlined in the annual report for the year ending 31st December 2020 as discussed below.

Soon after the start of 2021, the Association hosted the third annual Paget's Awareness Day on 11th January. Once again this took the form of a series of video interviews with several experts and a patient. These were available to view online using the Association's website and YouTube channel. The series focused on the use of bisphosphonates for the treatment of Paget's disease with presentations on their initial development, their mode of action and their use in patients with Paget's disease.

Information events and support groups were reinstated during 2021. A face-to-face event was held in York in July 2021 and the 2021 AGM was held in combination with an information event in Southampton in October 2021.

Support

The Association continued to support people affected by Paget's disease in 2021 through the Paget's Nurse Telephone and email Helpline. In addition, regular contact was made from the Specialist Paget's Nurse to those normally attending face-to-face support groups and they were also encouraged to contact each other. Additional support was offered to those known to be experiencing difficulties. Further digital initiatives which were put in place as the result of the pandemic were as follows:

- New Virtual Paget's Support Groups were set up to hold regular online meetings for those affected by Paget's disease and their families.
- Increased use was made of social media to support those with Paget's disease and raise awareness of the condition.
- The Facebook Support Group, which was set up during 2020, has continued to grow in popularity throughout 2021 and now has 585 members from the UK and other countries across the world including Australia, New Zealand, USA and Canada.
- Support to patients with the disease was also continued to be offered via the Paget's Support Network.
- In addition to our regular members' email, a 'Paget's Friends' mailing list was offered and set up for non-members to keep in touch with our news and events.
- A Paget's question and answer session was held online, using Zoom, as part of the Paget's Awareness Day events on 11th January 2021. A similar event answered questions regarding COVID-19 and Paget's disease.
- The Association's website and database continued to be developed, to offer more information and online membership options.
- Free Support Gift Bags were introduced for those who are newly diagnosed and contain items to help with pain and support those having treatment.

Publications

Information booklets for those affected by Paget's disease were updated by Diana Wilkinson, the Paget's Specialist Nurse, with input from clinicians and patients serving on the Board of Trustees. This included revision of the booklet 'Paget's Disease - Investigations Explained', a new Paget's Jargon Buster, and the continuation of the Association's quarterly magazine, Paget's News. In addition, our booklet for health professionals was circulated as part of the Awareness Day GP Campaign.

National Association for the Relief of Pagets Disease Trustees' Report

Raising Awareness

A series of videos were released for Paget's Awareness Day focusing on developments in the treatment of Paget's disease. The awareness day was also used to promote the Association's support services via social media, to interact with supporters, and to begin a campaign to raise awareness amongst GPs by offering practices a professional information booklet, publishing articles in journals aimed at GPs, and through digital advertising on websites used by GPs. During the Autumn of 2021, preparations began for the Awareness Day in 2022 which will focus on a global perspective on Paget's disease. With the assistance of an external provider, we were successful in obtaining a Google Grant to give our website more prominence and increase awareness of our information, research and support services. In late 2021, an external social media provider was employed to co-ordinate and enhance social media channels. In the annual report for the year ending 31st December 2020 the board of trustees felt that a useful strategy to raise awareness amongst health care professionals would be to developing a medical education programme using the Association's website. However, during 2021 it became apparent that the Association's website would need essential maintenance and upgrading and it was felt that the medical education programme should be deferred for the time being until this work had been completed.

Centres of Excellence

The Paget's Association Centres of Excellence (PACE) continue to operate to promote awareness, high standards of clinical care and research into Paget's Disease. The Association currently supports twelve Centres of Excellence across the UK. The Trustees reviewed activities carried out by the PACE centres during 2021 and were generally pleased with the PACE programme but noted that communication with some centres was suboptimal. The trustees were undecided as to whether the PACE initiative should be extended or otherwise altered but felt that this should be reviewed in future years.

RESEARCH

The Association has a long history of funding high quality research projects that advance understanding of the causes of Paget's disease and/or provide new insights into management of the disease and the prevention of complications. The Association invites applications for grant funding through advertisements on its website. Each application is assessed by the Trustees, an external Research Grants Committee and external peer reviewers, and graded against the specific criteria and research objectives set out by the Research sub-committee. Some Trustees undertake research, related to their employment, within research facilities and/or hospitals and may receive funding from the Association, via their institution, to carry out research. Any decisions made with regard to funding for these applications are made independently from the Trustee who is not permitted to take any part in the decision-making process. The same principles apply to funding of grants involving scientists from the same institution as a Trustee.

An important part of this process is the role of lay people in the decision making, regarding the relevance of the applications to the Association's objectives. Each successful applicant is required to provide regular reports on the progress of the project for the Research sub-committee and also for the Association's members via the quarterly Newsletter.

Procedures for awarding research grants

The Research sub-committee (RSC) is responsible for overall strategy with regard to setting an annual budget for research and upon deciding upon the range and types of awards that the Association should support. However, decisions on which grants should be awarded has been delegated to a research grants committee (RGC) which was established in 2019. In order to minimise the risk of conflicts of interest, Trustees made a decision that the RGC should be Chaired by an individual without a specific interest in Paget's disease and also has a membership of the RGC should comprise scientists and clinicians who do not have a direct research interest in Paget's disease themselves. At the present time, the RGC is chaired by Professor Tim Arnett, from University College London. Prof Emma Duncan (King's College London) and Dr Celia Gregson (Bristol University) as professional members and Mrs Elizabeth Green as a lay member. All grant applications are sent for external peer review and funding decisions made on the basis of the reviewer's reports and the RGCs assessment of these report. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are ratified by the board. Through these mechanisms, the Association has a robust and transparent system for awarding grants.

The trustees of the Association set aside a budget of up to £168,000 during 2021 for new grant funding to be awarded during 2022 and this is expected to generate expenditure during 2023 to 2024.

National Association for the Relief of Pagets Disease Trustees' Report

Financial review

Policy on reserves

In determining an appropriate level of reserves, the Board has taken into account both operating costs which are relatively stable and the wide variation in annual income which is heavily reliant on legacies. The Board has agreed that reserves should be in place to cover at least 24 months operating expenditure. The annual operating expenditure in 2021 was estimated to be in the region of £410,000 which comprised £136,023 for wages and operating costs and £134,296 for activities related to raising awareness of Paget's disease. A sum of £168,000 was allocated to the Research Committee for grant funding. Investments were valued at £755,930 at the 31st December 2021 taking into consideration other assets and liabilities, the total available funds at the end of 2021 were £1,030,535 which is sufficient to cover twenty-four months expenditure. The board noted that during 2021 only one endowment of £16,000 had been received but that an additional endowment of £154,474 had been received early in 2022 and this had been included in the financial summary.

The balance of funds held will be invested to generate income for future research grants, to cover operating costs and to mitigate the uncertainties of reliance on voluntary income and legacies.

At the year end the charity held total reserves of £1,030,535 (2020: £1,022,600) of which £8,139 (2020: £10,957) are held in fixed assets and £Nil (2020: £Nil) held in restricted funds. This leaves £1,022,396 (2020: £1,011,643) in free reserves.

Investment policy and objectives

Tilney Bestinvest in Liverpool manages long-term investments on behalf of the Trustees. The purpose of the investments is both to provide an income return and capital appreciation. The Association's investment policy involves balanced portfolios incorporating a medium to low level of risk. The Trustees have not issued specific instructions to the investment managers, but the financial reports are reviewed at each board meeting to ensure that the investments are performing favourably in terms of the UK Consumer Prices Index (CPI) and the ARC sterling balanced asset PCI. The Trustees have an ethical policy not to invest in certain types of companies in view of the nature of the Charity's activities.

Plans for future periods

During the next financial year, the Association will continue to review its income base and to control expenditure through judicious monitoring of outgoings and carefully prepared budgets. Priorities for the next financial year include:

1. To hold a Paget's Awareness Day in 2022 coinciding with the birthdate of Sir James Paget (11th January). Recognising the fact that the Association was able to considerably extend the reach of the Awareness Day event in 2021 through a digital approach, a similar strategy will be used for 2022 with prominent use of social media channels. As alluded to earlier, preparations for the 2022 Awareness Day were conducted towards the end of 2021, as were the video recordings which formed the basis of the event that would focus on a global perspective on Paget's disease.
2. To hold two face-to-face patient information events during 2022, one in Oxford, on 24th June 2022 and another on 30th September 2022, in Cardiff, to coincide with the AGM of the Association.
3. To continue with virtual and local patient support groups, where there is need and considering any UK Government restrictions that may be in force due to COVID-19.
4. To allocate expenditure on social media activity with a budget of approximately £10,000 during the coming year to publicise the Association's charitable objectives and activities. It is anticipated that the increase in social media activity might provide a new channel by which donations to the Association can be made.
5. To advertise a Research Grants Round in January 2022 with an indicative budget of £168,000.
6. To prepare for the Association's 50th Anniversary celebrations in 2023. This will involve several activities, including a fundraising campaign with a target of raising £50,000 by the end of 2023; establishing a focus group to help shape the strategy of the charity over future years and to host an international scientific symposium on Paget's disease coupled to an information session aimed at patients in the spring of 2023 in Manchester, the Association's birthplace.

National Association for the Relief of Pagets Disease Trustees' Report

7. The board of Trustees felt that while development of a medical education programme in Paget's disease and a review of the PACE centre programme remained important objectives, this work might need to be deferred until 2023 given the many other activities planned for 2022.

Structure, governance and management

Nature of governing document

The National Association for the relief of Paget's Disease was founded in 1973. It is an unincorporated association governed by a Constitution and registered with the Charity Commission. During 2009, the charity adopted the working name of The Paget's Association, and this is the name to be used in this report.

Structure of the Association

The Board of Trustees is responsible for setting the strategy and policies of the Paget's Association. The Board has up to twelve members and has three sub-committees. The role of these is to conduct a detailed analysis and review of the areas for which they are responsible, and to give strategic advice to the Board to facilitate delivery of the objectives of the organisation. Recommendations of the sub-committees are reported to and ratified by the Board of Trustees.

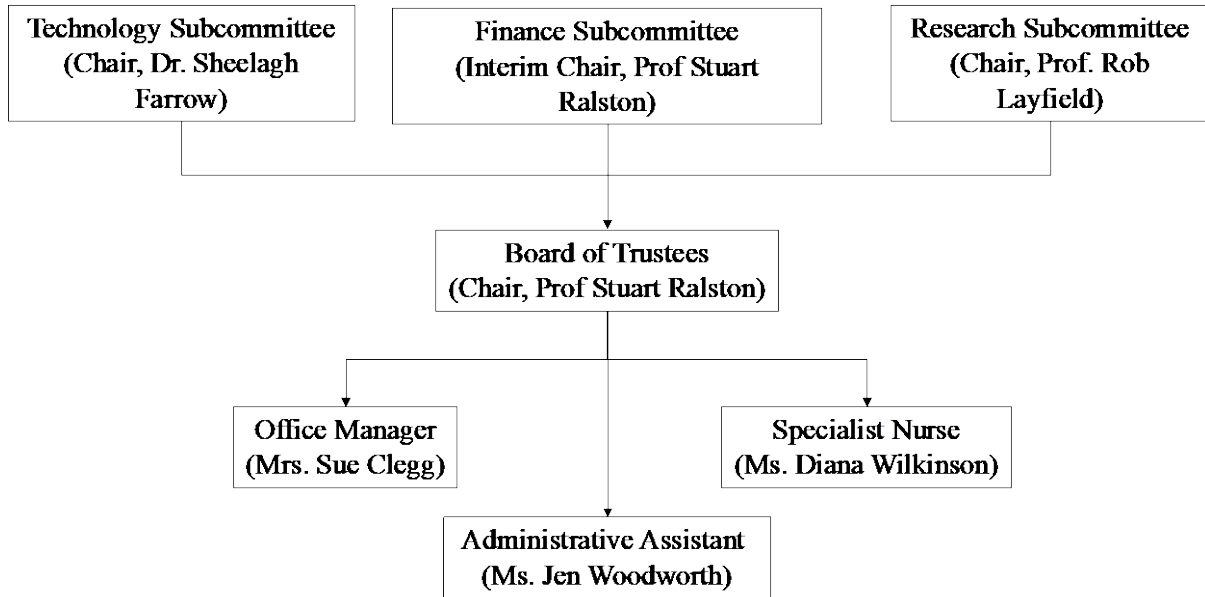
Throughout 2021, the Finance Sub-Committee was chaired by Professor Stuart Ralston, the Technology Sub-Committee was chaired by Dr Sheelagh Farrow and the Research Sub-Committee was chaired by Professor Rob Layfield.

Day to day running of the Association

Day to day running of the Charity is undertaken by the staff based at the charity's registered office in Swinton. Currently the Association employs three full time members of staff. These are an office manager, an administrative assistant, and a specialist nurse. Employees of the Association are line managed by the Chairman of the Association who conducts annual staff appraisals to review performance against objectives for the previous year and to set objectives for the coming year. The organisational structure of the charity as of 31st December 2021 is shown in Figure 1.

National Association for the Relief of Pagets Disease Trustees' Report

Figure 1. Organisational Structure of the Paget's Association



National Association for the Relief of Pagets Disease Trustees' Report

Recruitment and appointment of trustees

Advertisements for trustees are posted on the website of the Association when a position becomes available. Prospective Trustees may apply by contacting the Chairman of Association by letter or email. Their suitability for appointment is then discussed by the Board of Trustees. If the prospective candidate is thought to be eligible to act as a trustee and is thought to offer expertise that would benefit the charity, an informal interview is set up with the Chair and other representatives of the Board. If the prospective candidate is felt to be suitable for appointment following this procedure their name is put forward to members of the Association for election at an upcoming Annual General Meeting of the Association. The prospective trustee may then be appointed based on votes cast by members of the Association.

Induction and training of trustees

New trustees are provided with a one-to-one training session by the Chairman of the Board of Trustees who provides an overview of the duties of a trustee, the aims of the charity, the charity's structure and practical aspects relevant to its day-to-day operation. Additional training sessions are organised with the chairs of the Finance Sub-committee, the Research Sub-committee and the Technology Sub-committee. New trustees also have the option of attending training courses on the responsibilities of Charity Trustees.

Major risks and management of those risks

The Trustees have examined the major strategic, business and operational risks that the Association faces and confirm that policies have been established to ensure regular monitoring and reporting. This will allow for timely intervention when necessary to lessen these risks.

The annual report was approved by the trustees of the charity on 28th April 2022 and signed on its behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees of the charity on 28th April 2022 and signed on its behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease
Independent Examiner's Report to the trustees of National Association for the Relief of
Pagets Disease

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 December 2021 which are set out on pages 11 to 24.

Respective responsibilities of trustees and examiner

As the charity's trustees of National Association for the Relief of Pagets Disease you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the National Association for the Relief of Pagets Disease's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of National Association for the Relief of Pagets Disease as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

.....
Sue Hutchinson FCCA

Beever and Struthers
St. George's House
215 - 219 Chester Road
Manchester
M15 4JE

Date:.....

National Association for the Relief of Pagets Disease
Statement of Financial Activities for the Year Ended 31 December 2021

	Note	Unrestricted funds £	Total 2021 £
Income and Endowments from:			
Donations and legacies	2	170,474	170,474
Other trading activities	3	23,112	23,112
Investment income	4	11,602	11,602
Total income		205,188	205,188
Expenditure on:			
Raising funds	5	(42,262)	(42,262)
Charitable activities	6	(215,040)	(215,040)
Total expenditure		(257,302)	(257,302)
Gains/losses on investment assets		60,049	60,049
Net expenditure		(197,253)	(197,253)
Net movement in funds		7,935	7,935
Reconciliation of funds			
Total funds brought forward		1,022,600	1,022,600
Total funds carried forward	18	1,030,535	1,030,535

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2021 is shown in note 18.

The prior year Statement of Financial Activities is shown on page 24.

National Association for the Relief of Pagets Disease
(Registration number: 266071)
Balance Sheet as at 31 December 2021

	Note	2021 £	2020 £
Fixed assets			
Intangible assets	12	5,973	8,285
Tangible assets	13	2,166	2,672
Investments	14	755,930	692,354
		<u>764,069</u>	<u>703,311</u>
Current assets			
Debtors	15	220,714	172,214
Cash at bank and in hand	16	216,066	309,514
		<u>436,780</u>	<u>481,728</u>
Creditors: Amounts falling due within one year	17	<u>(170,314)</u>	<u>(162,439)</u>
Net current assets		<u>266,466</u>	<u>319,289</u>
Net assets		<u>1,030,535</u>	<u>1,022,600</u>
Funds of the charity:			
Unrestricted income funds			
Unrestricted funds		<u>1,030,535</u>	<u>1,022,600</u>
Total funds	18	<u>1,030,535</u>	<u>1,022,600</u>

The financial statements on pages 11 to 24 were approved by the trustees, and authorised for issue on 28th April 2022 and signed on their behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

National Association for the Relief of Pagets Disease meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

Grant expenditure

Grants payable are payments made to third parties in furtherance of the Charities' objects. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant awarded. This notification gives the recipient a reasonable expectation that they will receive the grant.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees's meetings and reimbursed expenses.

Taxation

The charity is exempt from tax on income and gains falling within section 5050 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight-line basis over their estimated useful lives.

Amortisation

Amortisation is provided on intangible fixed assets so as to write off the cost, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Amortisation method and rate
Website/CRM Database	5 year straight line

Tangible fixed assets

Individual fixed assets costing £100.00 or more are initially recorded at cost.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixed and fittings	15% reducing balance

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of investments which are recognised at market value.

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

2 Income from donations and legacies

	Unrestricted funds General £	Total 2021 £	Total 2020 £
Donations and legacies;			
Donations from individuals	6,660	6,660	9,962
Legacies	160,430	160,430	43,065
Gift aid reclaimed	3,384	3,384	2,302
	170,474	170,474	55,329

3 Income from other trading activities

	Unrestricted funds General £	Total 2021 £	Total 2020 £
Trading income;			
200 Club	5,680	5,680	6,195
Events income;			
Pennies for Paget's Boxes	-	-	27
Membership subscriptions	4,925	4,925	5,065
Sundry Merchandise	59	59	101
Sundry Fundraising	12,448	12,448	5,415
	23,112	23,112	16,803

4 Investment income

	Unrestricted funds General £	Total 2021 £	Total 2020 £
Interest receivable and similar income;			
Interest receivable on bank deposits	1,950	1,950	2,950
Other income from fixed asset investments	9,652	9,652	13,191
	11,602	11,602	16,141

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

5 Expenditure on raising funds

	Direct costs £	Allocated support costs £	Total 2021 £
Costs of trading activities	5,419	30,717	36,136
Investment management costs	6,126	-	6,126
	11,545	30,717	42,262

	Direct costs £	Allocated support costs £	Total 2020 £
Costs of trading activities	10,118	30,185	40,303
Investment management costs	5,491	-	5,491
	15,609	30,185	45,794

6 Expenditure on charitable activities

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2021 £
Support and raising awareness	27,116	-	107,180	134,296
Research	470	67,927	12,347	80,744
	27,586	67,927	119,527	215,040

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2020 £
Support and raising awareness	19,247	-	104,139	123,386
Research	470	210,566	11,910	222,946
	19,717	210,566	116,049	346,332

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

7 Analysis of governance and support costs

Support costs allocated to charitable activities

	Basis of allocation	Governance costs £	Support costs £	Total 2021 £
Staff costs	Staff time	11,525	88,821	100,346
Office costs	Staff time	-	18,124	18,124
Staff training	Staff time	-	125	125
IT costs	Staff time	-	5,334	5,334
Depreciation	Staff time	-	2,817	2,817
Bank charges	Staff time	-	485	485
Legal and professional costs	Staff time	20	-	20
Cost of trustee meetings	Staff time	4,887	-	4,887
Accountancy fees	Staff time	3,885	-	3,885
		<u>20,317</u>	<u>115,706</u>	<u>136,023</u>
	Basis of allocation	Governance costs £	Support costs £	Total 2020 £
Staff costs	Staff time	11,293	99,168	110,461
Office costs	Staff time	-	16,420	16,420
Staff training	Staff time	-	433	433
IT costs	Staff time	-	7,862	7,862
Depreciation	Staff time	-	2,823	2,823
Bank charges	Staff time	-	481	481
Insurance	Staff time	-	2,220	2,220
Legal and professional costs	Staff time	1,060	-	1,060
Cost of trustee meetings	Staff time	985	-	985
Accountancy fees	Staff time	3,489	-	3,489
		<u>16,827</u>	<u>129,407</u>	<u>146,234</u>

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year travel and subsistence expenses totalling £4,157 (2020: £749) were reimbursed or paid directly to seven trustees (2020: six trustees).

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

9 Staff costs

The aggregate payroll costs were as follows:

	2021	2020
	£	£
Staff costs during the year were:		
Wages and salaries	100,346	96,947
Social security costs	6,193	5,758
Pension costs	8,028	7,756
	114,567	110,461

The monthly average number of persons (including senior management team) employed by the charity during the year expressed as full-time equivalents was as follows:

	2021	2020
	No	No
Charitable activities	3	3

No employee received emoluments of more than £60,000 during the year

10 Independent examiner's remuneration

	2021	2020
	£	£
Examination of the financial statements	2,035	1,968
Other fees to examiners		
All other services	1,850	1,521

11 Taxation

The income and gains of the charity are exempt from taxation to the extent they are applied to its charitable objectives.

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

12 Intangible fixed assets

	Website/CRM Database £	Total £
Cost		
At 1 January 2021	11,560	11,560
At 31 December 2021	11,560	11,560
Amortisation		
At 1 January 2021	3,275	3,275
Charge for the year	2,312	2,312
At 31 December 2021	5,587	5,587
Net book value		
At 31 December 2021	5,973	5,973
At 31 December 2020	8,285	8,285

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 January 2021	3,776	3,776
At 31 December 2021	3,776	3,776
Depreciation		
At 1 January 2021	1,104	1,104
Charge for the year	506	506
At 31 December 2021	1,610	1,610
Net book value		
At 31 December 2021	2,166	2,166
At 31 December 2020	2,672	2,672

14 Fixed asset investments

	2021 £	2020 £
Other investments	755,930	692,354

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

14. Fixed Asset Investments (continued)

	Listed investments £	Cash held with investors £	Total £
Cost or Valuation			
At 1 January 2021	664,371	27,983	692,354
Revaluation	60,049	53,947	113,996
Additions	62,259	-	62,259
Disposals	(112,679)	-	(112,679)
At 31 December 2021	<u>674,000</u>	<u>81,930</u>	<u>755,930</u>
Net book value			
At 31 December 2021	<u>674,000</u>	<u>81,930</u>	<u>755,930</u>
At 31 December 2020	<u>664,371</u>	<u>27,983</u>	<u>692,354</u>

15 Debtors

	2021 £	2020 £
Accrued income	<u>220,714</u>	<u>172,214</u>

16 Cash and cash equivalents

	2021 £	2020 £
Cash on hand	103	68
Cash at bank	<u>215,963</u>	<u>309,446</u>
	<u>216,066</u>	<u>309,514</u>

17 Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	96	76
Other taxation and social security	2,668	2,568
Grants payable	165,513	157,557
Accruals	<u>2,037</u>	<u>2,238</u>
	<u>170,314</u>	<u>162,439</u>

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

18 Funds

	Balance at 1 January 2021 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2021 £
Unrestricted funds					
General	1,022,600	205,188	(257,302)	60,049	1,030,535
Unrestricted funds					
	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2020 £
General	1,140,551	85,831	(201,142)	(2,640)	1,022,600
Restricted funds	183,452	2,442	(190,984)	5,090	-
Total funds	1,324,003	88,273	(392,126)	2,450	1,022,600

The specific purposes for which the funds are to be applied are as follows:

Restricted funds are specific monies held by the charity for the purpose of contributing towards research and education.

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

19 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2021 £
Intangible fixed assets	5,973	5,973
Tangible fixed assets	2,166	2,166
Fixed asset investments	755,930	755,930
Current assets	436,780	436,780
Current liabilities	(170,314)	(170,314)
	<hr/>	<hr/>
Total net assets	1,030,535	1,030,535
	<hr/>	<hr/>
	Unrestricted funds General £	Total funds at 31 December 2020 £
Intangible fixed assets	8,285	8,285
Tangible fixed assets	2,672	2,672
Fixed asset investments	692,354	692,354
Current assets	481,728	481,728
Current liabilities	(162,439)	(162,439)
	<hr/>	<hr/>
Total net assets	1,022,600	1,022,600
	<hr/>	<hr/>

20 Related party transactions

There were no related party transactions in the current year or in the previous year.

National Association for the Relief of Pagets Disease
Notes to the Financial Statements for the Year Ended 31 December 2021

21 Prior year Statement of Financial Activities

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £
Income and Endowments from:				
Donations and legacies	2	55,329	-	55,329
Other trading activities	3	16,776	27	16,803
Investment income	4	13,726	2,415	16,141
Total income		<u>85,831</u>	<u>2,442</u>	<u>88,273</u>
Expenditure on:				
Raising funds	5	(44,634)	(1,160)	(45,794)
Charitable activities	6	(156,508)	(189,824)	(346,332)
Total expenditure		<u>(201,142)</u>	<u>(190,984)</u>	<u>(392,126)</u>
Gains/losses on investment assets		<u>(2,640)</u>	<u>5,090</u>	<u>2,450</u>
Net expenditure		<u>(117,951)</u>	<u>(183,452)</u>	<u>(301,403)</u>
Net movement in funds		<u>(117,951)</u>	<u>(183,452)</u>	<u>(301,403)</u>
Reconciliation of funds				
Total funds brought forward		<u>1,140,551</u>	<u>183,452</u>	<u>1,324,003</u>
Total funds carried forward	18	<u>1,022,600</u>	-	<u>1,022,600</u>

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

England & Wales - Charity number 266071

Accounts

Charity registration number: 266071

National Association for the Relief of Pagets Disease

Annual Report and Financial Statements

for the Year Ended 31 December 2020

National Association for the Relief of Pagets Disease

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National Association for the Relief of Pagets Disease

Reference and Administrative Details

Other Name Used	The Paget's Association
Charity Registration Number	266071
Principal Office	Suite 5 Moorfield House Moorside Road Swinton Manchester
Patrons	Sir Henry Paget Mr Ricardo Patrick The Lord Stamp MD FRCP
Honorary Patron	Mrs Joyce Cupitt
Trustees	Professor Stuart Ralston, Chair Dr Stephen Tuck, Vice Chair, re-appointed 16 October 2020 Ms Kely Burman, appointed 16 October 2020 Dr Anna Daroszezwska Dr Sheelagh Farrow Mr Alan Janes, appointed 16 October 2020 Professor Robert Layfield Mr Niall Middleton, appointed 16 October 2020 Mr Michael Missett Mr Michael Patnick Professor Graham Russell, Honorary President Ms Amanda Sherwood, appointed 16 October 2020 Mr Peter Jones, resigned 16 October 2020 Mr Keith Simpson, resigned 16 February 2020 Ms Janet Strang, resigned 16 October 2020
Independent Examiner	Sue Hutchinson FCCA Beever and Struthers St. George's House 215 - 219 Chester Road Manchester M15 4JE

National Association for the Relief of Pagets Disease

Reference and Administrative Details

Bankers

Barclays Bank plc
1 Market Street
Bolton
BL1 3NJ

Investment Managers

Tilney
Royal Liver Building
Pier Head
Liverpool
L3 1NY

National Association for the Relief of Pagets Disease

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 December 2020.

Objectives and activities

Objects and aims

The Paget's Association is the only charity in the UK whose remit is solely concerned with people with Paget's Disease of Bone. The broad aims of the Association are to provide information and support for people with this condition and their families; to raise awareness about the condition amongst the general public and within the medical and allied health professions; and to support and fund research projects in the field of Paget's Disease of Bone.

Public benefit

The Paget's Association is an inclusive organisation which promotes the well-being of all people diagnosed with Paget's disease of bone, their families and carers. We provide information to people affected by the condition and also provide information and advice to healthcare professionals responsible for delivering their care. There is no charge for this service. We work to end the isolation of people with Paget's disease and encourage them to take control of their condition and treatment. We offer educational and social opportunities via our Paget's Information meetings which are free of charge and open to anyone with an interest in Paget's disease.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Membership

Membership of the Association is open to anyone who has an interest in Paget's disease. This includes those affected, their relatives and carers, as well as scientists and healthcare professionals. The current subscription for membership of the Association to receive the quarterly newsletter is £15 per annum for UK members and £20 for overseas members. Professional membership is free of charge. Information Meetings are generally free of charge to encourage maximum participation but occasionally a small fee may be charged to help defray costs of catering and venue hire.

Achievements and performance

Events

Soon after the start of 2020, the Association hosted the second annual Paget's Awareness Day on 11th January. In contrast to the previous year when a face-to-face event was held, the event in 2020 took the form of a documentary which was available to view online using the Associations YouTube channel and website. The documentary focused on research concerning a medieval form of Paget's disease, affecting skeletal remains at Norton Priory, Cheshire. This research had been supported and partly funded by the Association and involved researchers from PACE centres in Nottingham, Norwich and Liverpool. The Awareness Day was also used to promote the Association's support services via social media, to interact with supporters, and to offer a Paget's Information Display Pack to those affected by Paget's disease to take to their local GP surgeries and community venues. During 2020 preparations began for the subsequent years Awareness Day and several video interviews were filmed, which would form the basis of the event which has been scheduled for 11th January 2021

Information events and support groups that had been planned as face-to-face meetings were cancelled, due to the COVID-19 pandemic as were many fundraising events. The 2020 AGM was held on 20th October 2020 as a virtual event.

National Association for the Relief of Paget's Disease

Trustees' Report

Support

The Association continued to support people affected by Paget's disease in 2020 through the Paget's Nurse Telephone and email Helpline. In addition, regular contact was made from the Specialist Paget's Nurse to those normally attending face-to-face support groups and they were also encouraged to contact each other. Additional support was offered to those known to be experiencing difficulties. Further digital initiatives which were put in place as the result of the pandemic were as follows:

- Increased use was made of social media to support those with Paget's disease and raise awareness of the condition.
- A Facebook Support Group was set up.
- COVID-19 questions and answers were placed on our website and in our Paget's News magazine.
- Ideas for activities to do at home, during lockdown, were developed for our website and magazine.
- Support was offered via the Paget's Support Network.
- In addition to our regular members' email, a 'Paget's Friends' mailing list was offered and set up for non-members to keep in touch with our news and events.
- A new booklet regarding Paget's disease, containing clinical information and case studies was made available to health professionals both online and as a hard copy
- A virtual support group, using zoom, was offered and a Paget's question and answer session offered, and was scheduled to take place early 2021.
- The website and database continued to be developed, to offer more information and online membership options.

Shortly after the national lockdown was imposed by the UK Government in March 2020 and mask wearing was made compulsory in shops, the Trustees unanimously decided that a face covering bearing the logo of the Association should be supplied to all members of the Association free of charge. This gesture was received very positively by members many of whom sent messages to the Association's office by post and email thanking the Association for this gesture and its support during the pandemic.

Publications

The Guideline on management of Paget's disease which was published in April 2019 in the Journal of Bone and Mineral Research has continued to influence clinical practice internationally having been cited 40 times since its original publication.

An important aim of the Association is to raise awareness and disseminate knowledge about Paget's disease in General Practitioners. To achieve this aim, the Association gave financial support for two open access publications on the topic of Paget's disease which were specifically aimed at General Practitioners. One was published in the November 2020 issue of the British Journal of General Practice focussing on clues to the diagnosis of Paget's and on when and why to a referral to specialist care should be made; a second published in November issue of The Practitioner, covered similar ground but with more detail on the disease. In addition, Dr Stephen Tuck, Vice Chair of the Board of Trustees published a review on Paget's disease in the November 2020 issue of Clinical Medicine and Prof Stuart Ralston published a review on the role of bisphosphonates in the treatment of Paget's disease in the September 2020 issue of Bone.

Centres of Excellence

The Paget's Association Centres of Excellence (PACE) continue to operate to promote awareness, high standards of clinical care and research into Paget's Disease. The Association currently supports twelve Centres of Excellence across the UK. The Trustees decided to review activities carried out by the PACE centres since they were established and to decide on whether the PACE initiative should be extended or otherwise altered during 2021.

National Association for the Relief of Pagets Disease

Trustees' Report

Research

The Association has a long history of funding high quality research projects that advance understanding of the causes of Paget's disease and/or provide new insights into management of the disease and the prevention of complications. The Association invites applications for grant funding through advertisements on its website. Each application is assessed by the Trustees, an external Research Grants Committee and external peer reviewers, and graded against the specific criteria and research objectives set out by the Research Sub-committee. Although Trustees may receive funding from the association to carry out research, any decisions made with regard to these applications are made independently from the Trustee who is not permitted to take any part in the decision-making process. The same principles apply to funding of grants involving scientists from the same institution as a Trustee.

An important part of this process is the role of lay people in the decision making, regarding the relevance of the applications to the Association's objectives. Each successful applicant is required to provide regular reports on the progress of the project for the Research sub-committee and also for the Association's members via the quarterly Newsletter.

Procedures for awarding research grants

The Research Sub-committee (RSC) is responsible for overall strategy with regard to setting an annual budget for research and upon deciding the range and types of awards that the Association should support. However, decisions on which grants should be awarded has been delegated to a Research Grants Committee (RGC) which was established in 2019. In order to minimise the risk of conflicts of interest, Trustees made a decision that the RGC should be chaired by an individual without a specific interest in Paget's disease and also the membership of the RGC should comprise scientists and clinicians who do not have a direct research interest in Paget's disease themselves. From 2019 to date, the RGC has been chaired by Professor Tim Arnett, from University College London. During 2020, the other members of the RGC were Frances Williams (King's College London) and Dr Celia Gregson (Bristol University), as professional members, and Prof George Smith as a lay member. All grant applications are sent for external peer review and funding decisions made on the basis of the reviewer's reports and the RGC's assessment of these. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are ratified by the Board. Through these mechanisms, the Association has a robust and transparent system for awarding grants.

The Association set aside a budget of approximately £151,000 to cover commitments for existing research grants active during 2020 although in fact, only £86,000 was awarded. It is important to note that expenditure on these awards is not thought to be required until 2022 or 2023 since research capacity in the NHS and Universities has been markedly reduced as the result of the pandemic.

Financial review

In the financial period which ended on 31st December 2020, the total income was £88,273 compared with the previous year of £543,184. The reduction in income was because in 2019, legacy income was exceptionally high at £403,700 as compared with £43,065 in 2020. Investment income was relatively stable at £16,141 in 2020 as compared with £18,611 in 2019. The Association's support costs related to charitable activities for 2020 was £146,234 as compared with £130,016, during 2019.

Our investment portfolio was valued at £692,304 at the end of 2020 compared with £682,204 at the end of the previous year. Total assets on 31st Dec 2020 were £1,022,600 as compared with £1,324,003 in 2019.

The Trustees can confirm that there are adequate assets to meet the Association's future expenditure plans. All ongoing and proposed expenditure can be met from existing funds.

National Association for the Relief of Pagets Disease

Trustees' Report

Policy on reserves

In determining an appropriate level of reserves, the Board has taken into account both operating costs which are relatively stable and the wide variation in annual income which is heavily reliant on legacies. The Board has agreed that reserves should be in place to cover at least 24 months operating expenditure. The annual operating expenditure in 2020 was estimated to be in the region of £410,000 which comprised £146,000 for wages and operating costs and £124,000 for activities related to raising awareness of Paget's disease. A sum of approximately £140,000 was allocated to the Research. Investments were valued at £692,354 at the 31st December 2020 taking into consideration other assets and liabilities, the total available funds at the end of 2020 were £1,022,600 which is sufficient to cover twenty-four months expenditure. The balance of funds held will be invested to generate income for future research grants, to cover operating costs and to mitigate the uncertainties of reliance on voluntary income and legacies.

At the year end the charity held total reserves of £1,022,600 (2019: £1,324,003) of which £703,311 (2019: £695,982) are held in fixed assets and £Nil (2019: £183,542) held in restricted funds. This leaves £319,289 (2019: £445,569) in free reserves.

Investment policy and objectives

Tilney Bestinvest In Liverpool manages long-term investments on behalf of the Trustees. The Association's investment policy involves balanced portfolios incorporating a medium to low level of risk. The Trustees have an ethical policy not to invest in certain types of companies in view of the nature of the Charity's activities.

Plans for future periods

During the next financial year, the Association will continue to review its income base and to control expenditure through judicious monitoring of outgoings and carefully prepared budgets. Priorities for the next financial year include:

1. To continue to encourage collaborative working between the twelve Paget's Association Centres of Excellence and to conduct a formal review of activities conducted by PACE with a view to adapting and possibly extending the number of PACE centres. The budget allocated to the PACE centres will also be reviewed.
2. To hold a Paget's Awareness Day in 2021 coinciding with the birthdate of Sir James Paget (11th January). Recognising the fact that the Association was able to considerably extend the reach of the Awareness Day event in 2020 through a digital approach a similar strategy will be used for 2021 with prominent use of social media channels. As alluded to earlier, planning of the 2021 Awareness Day was conducted during 2020 as were the video recordings which formed the basis of the event.
3. To hold two patient information events during 2021. It is anticipated that it should be possible to run these events on a face-to-face basis, but this will be subject to any UK Government restrictions that may be in force at the time of the planned events.
4. To explore the possibility of restarting local patient support groups, subject to any UK Government restrictions that may be in force.
5. To develop a medical education programme using the Association's website to promote awareness and education about Paget's disease for General Practitioners and other healthcare professionals.
6. To increase expenditure on social media activity and other digital initiatives with a budget of approximately £10,000 during the coming year to publicise the Associations charitable objectives and activities.
7. To advertise a Research Grants Round in January 2021 with an indicative budget of £168,000.

National Association for the Relief of Pagets Disease

Trustees' Report

Structure, governance and management

Nature of governing document

The National Association for the relief of Paget's Disease was founded in 1973. It is an unincorporated association governed by a Constitution and registered with the Charity Commission. During 2009, the charity adopted the working name of The Paget's Association and this is the name to be used in this report.

Structure of the Association

The Board of Trustees is responsible for setting the strategy and policies of the Paget's Association. The Board has up to twelve members and has three sub-committees. The role of these is to conduct a detailed analysis and review of the areas for which they are responsible, and to give strategic advice to the Board to facilitate delivery of the objectives of the organisation. Recommendations of the sub-committees are reported to and ratified by the Board of Trustees.

The Finance sub-committee was chaired by Mr. Keith Simpson until January 2020 when he resigned from the Board of Trustees and since then, Professor Stuart H Ralston has been acting as interim chair. The Technology sub-committee was chaired by Mr Peter Jones until October 2020 when he resigned from the Board of Trustees and since then, the Technology sub-committee has been chaired by Dr Sheelagh Farrow. Professor Rob Layfield has served as Chair of the Research sub-committee throughout 2020.

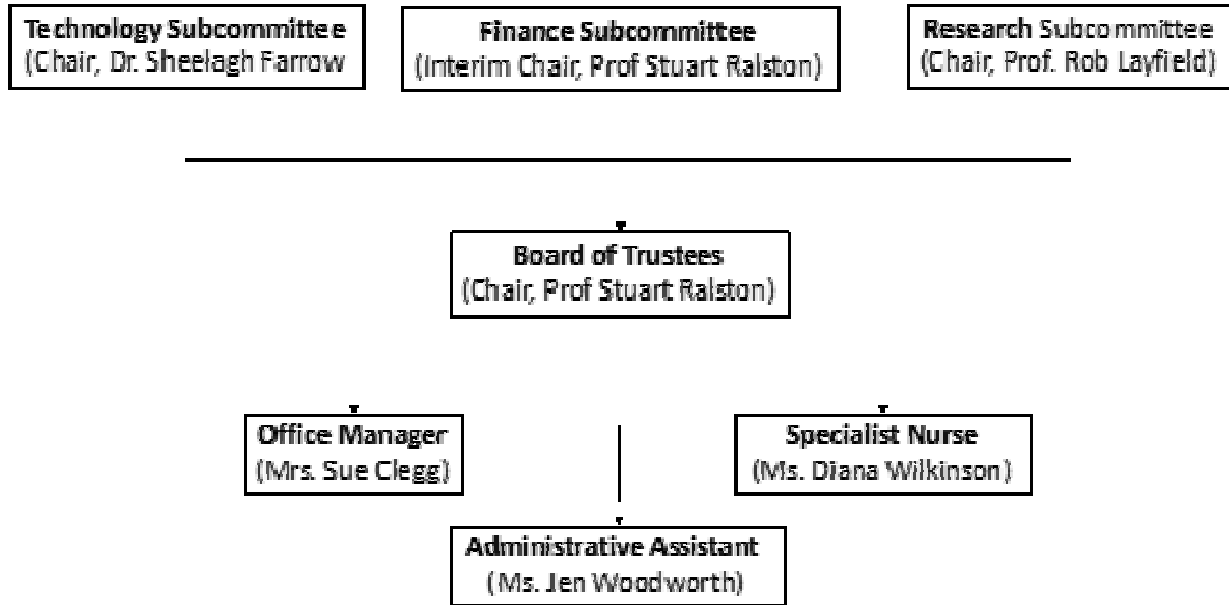
Day to day running of the Association

Day to day running of the Charity is undertaken by the staff based at the charity's registered office in Swinton. Currently the Association employs three full time members of staff. These are an office manager, an administrative assistant, and a specialist nurse. Employees of the Association are line managed by the Chairman of the Association who conducts annual staff appraisals to review performance against objectives for the previous year and to set objectives for the coming year. The organisational structure of the charity as of 31st December 2020 is shown in Figure 1.

National Association for the Relief of Pagets Disease

Trustees' Report

Figure 1. Organisational Structure of the Paget's Association



National Association for the Relief of Pagets Disease

Trustees' Report

Recruitment and appointment of trustees

Advertisements for trustees are posted on the website of the Association when a position becomes available. Prospective Trustees may apply by contacting the Chairman of Association by letter or email. Their suitability for appointment is then discussed by the Board of Trustees. If the prospective candidate is thought to be eligible to act as a trustee and is thought to offer expertise that would benefit the charity, an informal interview is set up with the Chair and other representatives of the Board. If the prospective candidate is felt to be suitable for appointment following this procedure their name is put forward to members of the Association for election at an upcoming Annual General Meeting of the Association. The prospective trustee may then be appointed based on votes cast by members of the Association.

Induction and training of trustees

New trustees are provided with a one-to-one training session by the Chairman of the Board of Trustees who provides an overview of the duties of a trustee, the aims of the charity, the charity's structure and practical aspects relevant to its day-to-day operation. Additional training sessions are organised with the chairs of the Finance Sub-committee, the Research Sub-committee and the Technology Sub-committee. New trustees also have the option of attending training courses on the responsibilities of Charity Trustees.

Major risks and management of those risks

The Trustees have examined the major strategic, business and operational risks that the Association faces and confirm that policies have been established to ensure regular monitoring and reporting. This will allow for timely intervention when necessary to lessen these risks.

The annual report was approved by the trustees of the charity on 8 July 2021 and signed on its behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees of the charity on 8 July 2021 and signed on its behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Independent Examiner's Report to the trustees of National Association for the Relief of Pagets Disease

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 December 2020 which are set out on pages 12 to 25.

Respective responsibilities of trustees and examiner

As the charity's trustees of National Association for the Relief of Pagets Disease you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the National Association for the Relief of Pagets Disease's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of National Association for the Relief of Pagets Disease as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

.....
Sue Hutchinson FCCA

Beever and Struthers
St. George's House
215 - 219 Chester Road
Manchester
M15 4JE

Date:.....

National Association for the Relief of Pagets Disease

Statement of Financial Activities for the Year Ended 31 December 2020

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £
Income and Endowments from:				
Donations and legacies	2	55,329	-	55,329
Other trading activities	3	16,776	27	16,803
Investment income	4	13,726	2,415	16,141
Total income		<u>85,831</u>	<u>2,442</u>	<u>88,273</u>
Expenditure on:				
Raising funds	5	(44,634)	(1,160)	(45,794)
Charitable activities	6	(156,508)	(189,824)	(346,332)
Total expenditure		(201,142)	(190,984)	(392,126)
Gains/losses on investment assets		(2,640)	5,090	2,450
Net expenditure		<u>(117,951)</u>	<u>(183,452)</u>	<u>(301,403)</u>
Net movement in funds		(117,951)	(183,452)	(301,403)
Reconciliation of funds				
Total funds brought forward		<u>1,140,551</u>	<u>183,452</u>	<u>1,324,003</u>
Total funds carried forward	18	<u>1,022,600</u>	<u>-</u>	<u>1,022,600</u>

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2019 is shown in note 18.

The prior year Statement of Financial Activities is shown on page 26.

National Association for the Relief of Pagets Disease

**(Registration number: 266071)
Balance Sheet as at 31 December 2020**

	Note	2020 £	2019 £
Fixed assets			
Intangible assets	12	8,285	10,596
Tangible assets	13	2,672	3,182
Investments	14	<u>692,354</u>	<u>682,204</u>
		<u>703,311</u>	<u>695,982</u>
Current assets			
Debtors	15	172,214	399,714
Cash at bank and in hand	16	<u>309,514</u>	<u>240,836</u>
		481,728	640,550
Creditors: Amounts falling due within one year	17	<u>(162,439)</u>	<u>(12,529)</u>
Net current assets		<u>319,289</u>	<u>628,021</u>
Net assets		<u>1,022,600</u>	<u>1,324,003</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		-	183,452
Unrestricted income funds			
Unrestricted funds		<u>1,022,600</u>	<u>1,140,551</u>
Total funds	18	<u>1,022,600</u>	<u>1,324,003</u>

The financial statements on pages 12 to 25 were approved by the trustees, and authorised for issue on 8 July 2021 and signed on their behalf by:

.....
Professor Stuart Ralston
Trustee

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

National Association for the Relief of Pagets Disease meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

Grant expenditure

Grants payable are payments made to third parties in furtherance of the Charities' objects. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant awarded. This notification gives the recipient a reasonable expectation that they will receive the grant.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees's meetings and reimbursed expenses.

Taxation

The charity is exempt from tax on income and gains falling within section 5050 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight line basis over their estimated useful lives.

Amortisation

Amortisation is provided on intangible fixed assets so as to write off the cost, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Amortisation method and rate
Website/CRM Database	5 year straight line

Tangible fixed assets

Individual fixed assets costing £100.00 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixed and fittings	15% reducing balance

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of investments which are recognised at market value.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

2 Income from donations and legacies

	Unrestricted funds General £	Total 2020 £	Total 2019 £
Donations and legacies;			
Donations from individuals	9,962	9,962	80,273
Legacies	43,065	43,065	403,700
Gift aid reclaimed	2,302	2,302	7,753
	55,329	55,329	491,726

3 Income from other trading activities

	Unrestricted funds General £	Restricted funds £	Total funds £	Total 2019 £
Trading income;				
200 Club	6,195	-	6,195	6,255
Events income;				
Pennies for Paget's Boxes	-	27	27	12,570
London Marathon	-	-	-	5,638
Sponsorship income	-	-	-	1,065
Membership subscriptions	5,065	-	5,065	6,375
Sundry Merchandise	101	-	101	481
Sundry Fundraising	5,415	-	5,415	463
	16,776	27	16,803	32,847

4 Investment income

	Unrestricted funds General £	Restricted funds £	Total 2020 £	Total 2019 £
Interest receivable and similar income;				
Interest receivable on bank deposits	2,950	-	2,950	4,088
Other income from fixed asset investments	10,776	2,415	13,191	14,523
	13,726	2,415	16,141	18,611

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

5 Expenditure on raising funds

	Direct costs £	Allocated support costs £	Total 2020 £
Costs of trading activities	10,118	30,185	40,303
Investment management costs	5,491	-	5,491
	15,609	30,185	45,794
	Direct costs £	Allocated support costs £	Total 2019 £
Costs of trading activities	10,658	22,255	32,913
Investment management costs	5,449	-	5,449
	16,107	22,255	38,362

6 Expenditure on charitable activities

	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2020 £
Support and raising awareness	19,247	-	104,139	123,386
Research	470	210,566	11,910	222,946
	19,717	210,566	116,049	346,332
	Activity undertaken directly £	Grant funding of activity £	Activity support costs £	2019 £
Support and raising awareness	27,577	-	95,904	123,481
Research	516	14,079	11,857	26,452
	28,093	14,079	107,761	149,933

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

7 Analysis of governance and support costs

Support costs allocated to charitable activities

		Governance costs £	Support costs £	Total 2020 £
Staff costs	Staff time	11,293	99,168	110,461
Office costs	Staff time	-	16,420	16,420
Staff training	Staff time	-	433	433
IT costs	Staff time	-	7,862	7,862
Depreciation	Staff time	-	2,823	2,823
Bank charges	Staff time	-	481	481
Insurance	Staff time	-	2,220	2,220
Legal and professional costs	Staff time	1,060	-	1,060
Cost of trustee meetings	Staff time	985	-	985
Accountancy fees	Staff time	3,489	-	3,489
		16,827	129,407	146,234
		Governance costs £	Support costs £	Total 2019 £
Staff costs	Staff time	11,192	87,870	99,062
Office costs	Staff time	-	16,301	16,301
IT costs	Staff time	-	2,086	2,086
Depreciation	Staff time	-	1,230	1,230
Loss on disposal of fixed assets	Staff time	-	937	937
Bank charges	Staff time	-	672	672
Insurance	Staff time	-	1,845	1,845
Legal and professional costs	Staff time	20	-	20
Cost of trustee meetings	Staff time	4,988	-	4,988
Accountancy fees	Staff time	2,875	-	2,875
		19,075	110,941	130,016

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

9 Staff costs

The aggregate payroll costs were as follows:

	2020 £	2019 £
Staff costs during the year were:		
Wages and salaries	96,947	86,609
Social security costs	5,758	5,695
Pension costs	7,756	6,758
	<u>110,461</u>	<u>99,062</u>

The monthly average number of persons (including senior management team) employed by the charity during the year expressed as full time equivalents was as follows:

	2020 No	2019 No
Charitable activities	<u>3</u>	<u>3</u>

No employee received emoluments of more than £60,000 during the year

10 Independent examiner's remuneration

	2020 £	2019 £
Examination of the financial statements	<u>1,968</u>	<u>1,950</u>
Other fees to examiners		
All other services	<u>1,521</u>	<u>925</u>

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

11 Taxation

The charity is a registered charity and is therefore exempt from taxation.

12 Intangible fixed assets

	Website/CRM Database £	Total £
Cost		
At 1 January 2020	11,560	11,560
At 31 December 2020	11,560	11,560
Amortisation		
At 1 January 2020	963	963
Charge for the year	2,312	2,312
At 31 December 2020	3,275	3,275
Net book value		
At 31 December 2020	8,285	8,285
At 31 December 2019	10,597	10,597

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 January 2020	3,776	3,776
At 31 December 2020	3,776	3,776
Depreciation		
At 1 January 2020	594	594
Charge for the year	510	510
At 31 December 2020	1,104	1,104
Net book value		
At 31 December 2020	2,672	2,672
At 31 December 2019	3,182	3,182

14 Fixed asset investments

	2020 £	2019 £
Other investments	692,354	682,204

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

14. Fixed Asset Investments (continued)

	Listed investments £	Cash held with investors £	Total £
Cost or Valuation			
At 1 January 2020	612,762	69,442	682,204
Revaluation	2,451	(41,459)	(39,008)
Additions	284,938	-	284,938
Disposals	(235,780)	-	(235,780)
At 31 December 2020	664,371	27,983	692,354
Net book value			
At 31 December 2020	664,371	27,983	692,354
At 31 December 2019	612,762	69,442	682,204

15 Debtors

	2020 £	2019 £
Accrued income	172,214	399,714

16 Cash and cash equivalents

	2020 £	2019 £
Cash on hand	68	199
Cash at bank	309,446	240,637
	309,514	240,836

17 Creditors: amounts falling due within one year

	2020 £	2019 £
Trade creditors	76	7,799
Other taxation and social security	2,568	2,390
Grants payable	157,557	-
Accruals	2,238	2,340
	162,439	12,529

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

18 Funds

	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2020 £
Unrestricted funds					
General	1,140,551	85,831	(201,142)	(2,640)	1,022,600
Restricted funds	<u>183,452</u>	<u>2,442</u>	<u>(190,984)</u>	<u>5,090</u>	<u>-</u>
Total funds	<u><u>1,324,003</u></u>	<u><u>88,273</u></u>	<u><u>(392,126)</u></u>	<u><u>2,450</u></u>	<u><u>1,022,600</u></u>
	Balance at 1 January 2019 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 December 2019 £
Unrestricted funds					
General	739,480	527,841	(173,070)	46,300	1,140,551
Restricted funds	<u>164,773</u>	<u>15,343</u>	<u>(15,225)</u>	<u>18,561</u>	<u>183,452</u>
Total funds	<u><u>904,253</u></u>	<u><u>543,184</u></u>	<u><u>(188,295)</u></u>	<u><u>64,861</u></u>	<u><u>1,324,003</u></u>

The specific purposes for which the funds are to be applied are as follows:

Restricted funds are specific monies held by the charity for the purpose of contributing towards research and education.

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

19 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2020 £
Intangible fixed assets	8,285	8,285
Tangible fixed assets	2,672	2,672
Fixed asset investments	692,354	692,354
Current assets	481,728	481,728
Current liabilities	(162,439)	(162,439)
Total net assets	1,022,600	1,022,600

	Unrestricted funds General £	Restricted funds £	Total funds at 31 December 2019 £
Intangible fixed assets	10,596	-	10,596
Tangible fixed assets	3,182	-	3,182
Fixed asset investments	537,368	144,836	682,204
Current assets	601,934	38,616	640,550
Current liabilities	(12,529)	-	(12,529)
Total net assets	1,140,551	183,452	1,324,003

National Association for the Relief of Pagets Disease

Notes to the Financial Statements for the Year Ended 31 December 2020

20 Prior year Statement of Financial Activities

	Note	Unrestricted funds £	Restricted funds £	Total 2019 £
Income and Endowments from:				
Donations and legacies	2	491,726	-	491,726
Other trading activities	3	20,277	12,570	32,847
Investment income	4	15,838	2,773	18,611
Total income		<u>527,841</u>	<u>15,343</u>	<u>543,184</u>
Expenditure on:				
Raising funds	5	(37,216)	(1,146)	(38,362)
Charitable activities	6	(135,854)	(14,079)	(149,933)
Total expenditure		(173,070)	(15,225)	(188,295)
Gains/losses on investment assets		46,300	18,561	64,861
Net income		<u>401,071</u>	<u>18,679</u>	<u>419,750</u>
Net movement in funds		401,071	18,679	419,750
Reconciliation of funds				
Total funds brought forward		<u>739,480</u>	<u>164,773</u>	<u>904,253</u>
Total funds carried forward	18	<u><u>1,140,551</u></u>	<u><u>183,452</u></u>	<u><u>1,324,003</u></u>